

Governance Arrangements for the Scottish Longitudinal Study

1. Introduction

1.1 The Scottish Longitudinal Study (SLS) has been established as a resource for demographic, social and health related research which integrates data from a number of sources including Census, vital events registration and health records. As such, it should be managed, promoted and used so as to maximise public benefit. The rights and interests of the research participants must be protected whilst the long term value of the study is realised. This document specifies how the organisations involved in developing the study will carry out this responsibility via the governance arrangements established for the SLS.

1.2 The governance arrangements outlined in this document use various terms to define organisations and groups which share in this collective responsibility. These are as follows:

'The Scottish Longitudinal Study' ('The SLS' for short) refers to the entirety of information provided by or collected indirectly from those people who are selected for membership in the SLS.

'The Data Custodians' or **'Data Providers'** are the organisations which hold the responsibility for the original source data used in the study.

'The Longitudinal Studies Centre – Scotland (LSCS)' is the organisation which established the SLS.

'The SLS Director' is the senior social scientist responsible for the creation and development of the study and for the management of data access and data security procedures as determined by the Steering Committee.

'The SLS Project Manager' is responsible to the **'SLS Director'** and the **'SLS Steering Committee'** for the management and running of **the Study**.

'The SLS Unit' refers to the team of researchers and other staff supporting the SLS Director in carrying out his responsibilities. **'The SLS Unit'** is comprised of:

'The SLS Project Manager';
'SLS Database Administrators';
and **'SLS User Support Officers'.**

'The Steering Committee' is the body responsible to the Data Providers for ensuring maximum public benefit is achieved from the study and the interests of the study members are protected.

'The SLS Research Board' is the body established by the Steering Committee to oversee the access management system.

'The Research Institution' is the legal body that employs the SLS Project Director and his team.

'Access arrangements' refer to the methods and processes through which information from the study is made available to the research community for research purposes.

2. The governance arrangements

2.1. The study is set up and operates under a data sharing agreement between the data providers, on the one hand, and the beneficiary research institution, the University of St Andrews, on the other. In accordance with the National Statistics (NS) policy on data matching and confidentiality set out in the NS Code of Practice and the associated Protocols on Data Access and Confidentiality and Data Matching, the terms and conditions of this agreement are recorded in a set of **Data Access Agreement (DAA) and related documents**.

2.2. A **Steering Committee** representing the Data Providers was established to oversee all strategic aspects of the project on matters pertaining to the data matching, data holding and access to the SLS. The committee's role is to ensure that the confidentiality of personal data is maintained while recognising the need for legitimate access to the database for research. The detailed functions of the Steering Committee are set out in the Terms of Reference for the Committee (see section 3)

2.3 The Steering Committee comprises members from the Data Providers and the Research Institution as well as independent members who bring relevant expertise and the perspective of the study members to the work of the committee. The Steering Committee is chaired by the GROS main statistical contact under the terms of the DAA.

2.4. The DAA documents and the membership of the Steering Committee will be updated when and if new data sources are incorporated into the Study.

2.5. The Steering Committee is accountable to the Responsible Statisticians of the data providing organisations.

3. Terms of Reference for the Steering Committee

3.1 The role of the Steering Committee is to lay down the parameters within which the study must operate and monitor compliance with these.

In particular, to approve:

- broad criteria for selecting study members;
- arrangements for protecting confidentiality of the actual selection criteria;
- the scope of the linked data to be held initially;
- any extensions to study membership or to the scope of data held;

- arrangements for obtaining, linking and holding study data so that confidentiality is observed and identifiable data is held only where necessary to aid future linkage;
- arrangements for analyzing linked data and ensuring that any analysis released does not infringe legal or privacy constraints;
- and to ensure that the study complies with any future National Statistics Code of Practice on data sharing or linkage.

4. Access Management

4.1 Access principles are established by the Steering Committee. The management and development of these principles is the responsibility of the SLS Project Director and his/her team under the oversight of the **SLS Research Board** established by the Steering Committee.

4.2 The SLS Research Board is accountable to the Steering Committee and submits regular update reports to Committee meetings. It comprises representatives of the Data Providers, the Research Institution and external members representing the social and medical research community. The Research Board is chaired by the GROS main statistical contact for the SLS under the terms of the DAA.

4.3 The detailed functions of the Research Board are set out in the **Terms of Reference** for the Board (see section 5). Access arrangements are articulated in detail in procedural documentation which include the following:

- Criteria for the approval of applications to use SLS data;
- Data Access Protocol;
- Disclosure Control Protocol;
- Clearance Data Custodian: Role Specification
- User guidance on accessing the data given on the University of St Andrew's website at <http://www.lscs.ac.uk/sls/access.htm>

5. Terms of Reference for the Research Board

5.1 Roles

The Scottish Longitudinal Study Research Board (SLSRB) has been created by the Scottish Longitudinal Study Steering Committee (SLSSC) to approve applications to use the SLS, monitor access to the SLS and review publications produced as a result of access to the SLS.

The SLSSC recognise that access to the SLS involves a risk of disclosure of personal information. The SLSRB has been formed to ensure that all possible procedures to protect the data and minimise disclosure risk are in place.

SLSRB decisions will be communicated to applicants by the Board, with a statement of the conditions of access, or why any application was declined

5.2 Aim of the Board

To comply with the conditions laid down by the SLSSC under which research proposals to use the Scottish Longitudinal Study (SLS) must be submitted and approved. In particular:

- The Research Board will consider for approval all proposals to use SLS data. These will include all requests from both academic and non-academic researchers.
- The Research Board will oversee the management of the access system implemented by the SLS Director and his/her team.
- To assure the Registrar General and other Data Providers that the confidentiality of the SLS is guaranteed and that the risk of inadvertent disclosure is minimised.

5.3 Meetings

- The Research Board meetings will be held as required, but generally on a 12 week basis.
- Where issues require a panel decision or discussion, papers must be included on the SLSRB agenda and submitted a minimum of 7 working days prior to the meeting.

5.4 Reporting and Documentation

- A report of all projects approved and rejected will be provided to SLSSC meetings.
- Documentation of decisions, actions and minutes of SLSRB meetings will be kept
- Details of projects approved and subsequent papers resulting from the work will be published on the Longitudinal Studies Centre – Scotland (LSCS) Website (www.lscs.ac.uk).