**Public Benefit and Privacy Panel for Health and Social Care**

**Application Form**

|  |  |  |  |
| --- | --- | --- | --- |
| **Application Control**  *Applicants should not complete the “submitted date” field* | | | |
| Application Coordinator |  | | |
| Application Number |  | Submitted Date |  |
| Applicant Name |  | | |
| Proposal Name |  | | |
| Project End Date |  | | |

|  |  |
| --- | --- |
| **Pre-submission checklist**  *Applicants should not fill out this section –* ***to be completed by the eDRIS coordinator*** | |
| Approved Information Governance Training | Approved training complete and certificates received  Approved training complete and certificates pending |
| Use of recognised safe haven | Yes  No |
| NHSCR Involvement | Yes  Reference number:................  Email Confirmation of approval supplied:  No |
| Is project covered by National Safe Haven generic ethics approval? | Yes  No |

|  |
| --- |
| **Supporting Documents** |
| Please list *only* supporting documents which you have clearly referenced in your application – the name of each should clearly indicate what the document/file/reference is about.  Suggestions:   * SURE Training Certificates for xxxxxxxxxx * Institutional ethical approval letter (file name xxxxx) * SLS Application Form (file name: xxxxx) * SLS research board approval letter (file name:xxxxxxx) |

**Note to Applicants**

Prior to completing your application form you should:

* Contact the eDRIS Team, who will assist you - [phs.edris@nhs.net](mailto:phs.edris@nhs.net) or by phone on 0131 275 7333
* Read and understand the separate Guidance for Applicants

Your application should be typed, not handwritten. Your eDRIS application coordinator will inform you of how to submit your application form and any supporting evidence. Before submitting your completed application, you should ensure that:

* All relevant sections of the application are complete
* Relevant supporting evidence is attached
* Individuals named on the form have read and approved its submission

Please note that submitted applications may be circulated to panel members, administrative colleagues, NHSScotland information governance and information security colleagues, Caldicott Guardians, the CHI Advisory Group and, where appropriate, non-NHS Scotland colleagues from a variety of participating partner bodies, in the course of processing. You must make your eDRIS application coordinator aware of any confidential or sensitive information contained in your application which you would consider inappropriate for circulation in such a manner. Your application could be subject to disclosure or partial disclosure under the Freedom of Information (Scotland) Act, and will be retained in line with NHSScotland information policy.

## Section 1 – People

|  |  |  |  |
| --- | --- | --- | --- |
| **1.1** | **Applicant** *Please read section 1.1 of the guidance* | | |
| **1.1.01** | Full Name: | |  |
| **1.1.02** | Title: | |  |
| **1.1.03** | Position (if PhD researcher, please also complete section 1.2): | |  |
| **1.1.04** | Professional Registration No.: | |  |
| **1.1.05** | Organisation Name: | |  |
| **1.1.06** | Address (incl. postcode): | |  |
| **1.1.07** | Email: | |  |
| **1.1.08** | Do you have an NHS contract/honorary contract? | | Choose an item. |
| **1.1.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) training <https://adrn.ac.uk/understand-data/sure-training/> and passed the final examination  - Administrative Data Research Centre-Scotland | |
|  | Date completed: |  | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.2** | **PhD Supervisor** *Please read section 1.2 of the guidance* | | |
| **1.2.01** | Full Name: | |  |
| **1.2.02** | Title: | |  |
| **1.2.03** | Position: | |  |
| **1.2.04** | Professional Registration No.: | |  |
| **1.2.05** | Organisation Name: | |  |
| **1.2.06** | Address (incl. postcode): | |  |
| **1.2.07** | Email: | |  |
| **1.2.08** | Does this person have an NHS contract/honorary contract? | | Choose an item. |
| **1.2.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: |  | |
|  | Date completed: |  | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.3** | **Clinical Sponsor/Lead** *Please read section 1.3 of the guidance* | | |
| **1.3.01** | Full Name: | |  |
| **1.3.02** | Title: | |  |
| **1.3.03** | Position: | |  |
| **1.3.04** | Professional Registration No.: | |  |
| **1.3.05** | Organisation Name: | |  |
| **1.3.06** | Address (incl. postcode): | |  |
| **1.3.07** | Email: | |  |
| **1.3.08** | Does this person have an NHS contract/honorary contract? | | Choose an item. |
| **1.3.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) <https://adrn.ac.uk/understand-data/sure-training/>  and passed the final examination - Administrative Data Research Centre-Scotland | |
|  | Date completed: |  | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.4** | **Information/Data Custodian** *Please read section 1.4 of the guidance* | | |
| **1.4.01** | Full Name: | | Christopher Dibben |
| **1.4.02** | Title: | | Professor |
| **1.4.03** | Position: | | Chair in Geography |
| **1.4.04** | Professional Registration No.: | | N/A |
| **1.4.05** | Organisation Name: | | The University of Edinburgh |
| **1.4.06** | Address (incl. postcode): | | Geography Building, Drummond Street, Edinburgh EH8 9XP |
| **1.4.07** | Email: | | Chris.dibben@ed.ac.uk |
| **1.4.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.4.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended ONS Safe Researcher Training (SURE) Previously, developed the ADLS Safe Researcher course. | |
|  | Date completed: | 13/11/18 | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Joan Nolan |
| **1.5.02** | Title: | | Ms |
| **1.5.03** | Position: | | SLS Database Manager |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | joan.nolan@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) ADRN UK | |
|  | Date completed: | 18 May 2018 | |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Zengyi Huang |
| **1.5.02** | Title: | | Mr |
| **1.5.03** | Position: | | SLS Database Developer/Research Fellow |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | Zengyi.huang@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) ADRN UK | |
|  | Date completed: | 18 May 2018 | |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Greg Blackadder |
| **1.5.02** | Title: | | Mr |
| **1.5.03** | Position: | | NRS SLS Project Manager |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The National Records of Scotland |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | greg.blackadder@nrscotland.gov.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) ADRN UK | |
|  | Date completed: | 18 Sept 2018 | |

**SLS SUPPORT OFFICERS**

|  |  |  |  |
| --- | --- | --- | --- |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Dawn Everington |
| **1.5.02** | Title: | | Ms |
| **1.5.03** | Position: | | SLS Support Officer |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | d.everington@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe Researcher Training with SCADR  <https://www.scadr.ac.uk/> | |
|  | Date completed: | 6 March 2020 | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Lynne Forrest |
| **1.5.02** | Title: | | Dr |
| **1.5.03** | Position: | | SLS Support Officer |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | lynne.forrest@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) ADRN UK | |
|  | Date completed: | 18th May 2018 | |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Zhiqiang Feng |
| **1.5.02** | Title: | | Dr |
| **1.5.03** | Position: | | SLS Support Officer/Senior Lecturer |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | Geography Building, Drummond Street, Edinburgh EH8 9XP |
| **1.5.07** | Email: | | Zhiqiang.feng@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | Attended Safe User of Research data Environments (SURE) ADRN UK | |
|  | Date completed: | 18th September 2018 | |
| **1.5 Others with access to identifiable or potentially identifiable data** *Please read section 1.5 of the guidance* | | | |
| **1.5.01** | Full Name: | | Lee Williamson |
| **1.5.02** | Title: | | Dr |
| **1.5.03** | Position: | | SLS Support Officer/Research Fellow |
| **1.5.04** | Professional Registration No.: | | N/A |
| **1.5.05** | Organisation Name: | | The University of Edinburgh |
| **1.5.06** | Address (incl. postcode): | | LSCS, Ladywell House, Ladywell Road, Edinburgh EH12 7TF |
| **1.5.07** | Email: | | lee.williamson@ed.ac.uk |
| **1.5.08** | Does this person have an NHS contract/honorary contract? | | No |
| **1.5.09** | Provide details of the most recent information governance training undertaken - a list of training courses is included at Appendix A of guidance notes | | |
|  | Name and institution of course: | ONS Safe Researcher Training run by SCADR  <https://www.scadr.ac.uk/> | |
|  | Date completed: | 25/05/20 | |

|  |  |  |  |
| --- | --- | --- | --- |
| **1.6 Others** *Please read section 1.6 of the guidance* | | | |
| *Complete this section if applicable – for each additional person* | | | |
| Full Name: |  | Involvement in Proposal: |  |
| Organisation: |  | Position: |  |

**Section 2 – Organisations & Bodies**

|  |  |  |
| --- | --- | --- |
| **2.1** | **Organisation or Body Leading Proposal** *Please read section 2.1 of the guidance* | |
| **2.1.01** | Organisation or Body Name:  *If the organisation here is an NHSScotland board, note this and go directly to question 2.1.03* |  |
| **2.1.02** | Is this a commercial organisation or body? | Choose an item. |
| **2.1.02a** | If ‘Yes’, please provide a full explanation of the organisation or body’s activity and industry sector, including any previous experience of using NHSScotland data - append supporting documentation as appropriate |  |
| **2.1.03** | Is this organisation or body wholly funding or paying for the costs of conducting the proposal? | Choose an item. |

|  |  |  |
| --- | --- | --- |
| **2.2** | **Main Contact for Lead Organisation** *Please read section 2.2 of the guidance* | |
| **2.2.01** | Full Name: | Renate Gertz |
| **2.2.02** | Title: | Dr |
| **2.2.03** | Position: | Data Protection Officer |
| **2.2.04** | Email: | Rena.Gertz@ed.ac.uk |

|  |  |  |
| --- | --- | --- |
| **2.3** | **Organisation or Body Funding Proposal** *Please read section 2.3 of the guidance* | |
| *Complete the following section if you answered ‘No’ to question 2.1.03* | | |
| **2.3.01** | Organisation or Body Name:  *If the organisation here is an NHSScotland board note this and, go directly to section 2.4* | Economic and Social Research Council (ESRC) |
| **2.3.02** | Is this organisation or body a commercial organisation? | Choose an item. |
| **2.3.02a** | If ‘Yes’,please provide a full explanation of the organisation or body’s activity and industry sector, including any previous experience of using NHSScotland data - append supporting documentation as appropriate |  |

|  |  |  |
| --- | --- | --- |
| **2.4 Other Relevant Organisations or Bodies** *Please read section 2.3 of the guidance* | | |
| *Complete this section if applicable* | | |
| Organisation Name | Nature of Business/Sector | Nature of interest in proposal |
| Scottish Longitudinal Study Development and Support Unit (SLS-DSU) | Support unit for the use of the Scottish Longitudinal Study (SLS), a large-scale linkage study created using data from administrative and statistical sources. | Provider of the SLS data |

## Section 3 – Overview

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **3.1** | **Proposal Essentials** *Please read section 3.1 of the guidance* | | | |
| **3.1.01** | Please specify the proposal end date | |  | |
| **3.1.02** | Is this proposal:   * an extension * a renewal of an existing approval * related to a previous application (approved or not)   Please provide details, include the reference number of the original application, and summarise the changes requested | | |  |
| **3.1.03** | Does this proposal require updates of information or to be repeated at regular intervals? If yes please advise the frequency | | |  |
| **3.1.04** | What is the substantive purpose of the proposal? (please choose **one** option from below that best matches your proposal) | | | |
|  | Patient Care | Research | | |
|  | Audit | Performance Monitoring/Management | | |
|  | Service Planning/Improvement | Health/Social Care Administration | | |
|  | Systems Implementation/Testing | Training/Education | | |
|  | Other |  | | |
|  | If other clearly defined purpose, please give details: | | | |
| **3.1.05** | Access is being requested to data from which sources? (tick as many as are relevant) | | | |
|  | NHS National Services Scotland  Public Health Scotland (PHS)  A single NHS Scotland Board (excluding NSS/PHS) including any system/database  More than one NHS Scotland Board including any system/database  Community Health Index (CHI) database  NHS Central Registry  Other | | | |
|  | If other, please give details: | | | |
|  | | | |
| **3.1.06** | Provide a clear and concise ***lay*** outline of the proposal (max. 250 words). This may be published on the PBPP website. | | | |
|  | | | |
| **3.1.07** | Provide a description of the aims and objectives of the proposal. | | | |
|  | | | |
| **3.1.08** | Provide a description of the envisaged benefits to the public and/or patients. | | | |
|  | | | |
| **3.1.09** | Provide a concise description of: the research study design (sample size, inclusion/exclusion criteria, time period); data collection; data processing or other means required to achieve the aims of your proposal. | | | |
|  | | | |
| **3.1.10** | Provide a clear and concise outline of any statistical methods that will be used in the project (if applicable). | | | |
|  | | | |
| **3.1.11** | Provide a diagram/description to illustrate the data flow or data linkage process envisaged (if applicable). | | | |
|  | | | |
| **3.1.12** | Does the proposal have implications for, or target, vulnerable populations? Please give details. Definitions of vulnerable populations are given in section 5 of Appendix A of the guidance notes. | | | |
|  | | | |
| **3.1.13** | Does the proposal seek access to highly sensitive data? Please give details. Definitions of sensitive data are given in section 6 of Appendix A of the guidance notes. | | | |
|  | | | |
| **3.1.14** | Does the proposal seek to use information exclusively about deceased persons? Please give details. | | | |
|  | | | |
| **3.1.15** | Describe how you have included public input / lay representation in your proposal design. | | | |
|  | | | |
| **3.1.16** | Describe any peer review undertaken, with details (for example formal review by a peer organisation or funding body, informal internal review, and review by a third party). | | | |
|  | | | |
| **3.1.17** | Describe how the proposal has been designed to demonstrate that privacy risk has been adequately assessed, is appropriately managed, and has been reduced to acceptably low levels (e.g. has a data protection impact assessment (DPIA) been carried out, if appropriate). Please provide any relevant supporting documentation. | | | |
| All members of the research team attended and passed an exam on handling sensitive administrative data (see documentation attached). In addition, all the data will be analysed in the SLS Safe Setting room (i.e. a safe haven based at the National Record of Scotland). See next sections for more detailed information on how the project team will handle data processing and findings’ dissemination.  A data protection impact assessment (DPIA) has been filled in by the researchers in consultation with the e-DRIS officer, SLS team and the Data Protection Officer at the University of Edinburgh. The DPIA has been submitted together with this application. | | | |
| **3.1.18** | Is there *any* commercial aspect or dimension to the proposal or its outcomes? If yes, please give details. | | | |
|  | | | |

|  |  |
| --- | --- |
| **3.2** | **Statutory and Regulatory Context** *Please read section 3.2 of the guidance* |
| **3.2.01** | Does your proposal have a statutory or regulatory justification - is the proposal responding to a statutory or regulatory instruction, duty or order? Please give details. |
|  |
| **3.2.02** | If your organisation will be processing personal and/or special category data as part of this proposal then please cite the lawful basis for processing under current data protection law. |
| The General Data Protection Regulation (Regulation (EU) 2016/679 of European Parliament and of the Council) states under Article 6 on Lawfulness of processing, paragraph 1, that processing shall be lawful only if and to the extent that at least one of the conditions listed under subparagraphs a-f applies. Our project satisfies the condition stated under Art. 6 (1), subparagraph e: ‘*processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller’.*  Article 9 on Processing of special categories of personal datastates in paragraph (1): ‘Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited.’ However, paragraph 2 subsequently states that paragraph 1 shall not apply if one of the following (detailed in subparagraphs a-j) applies. The use of ethnicity in our project satisfies the condition listed under subparagraph j: *‘processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject’.* |
| **3.2.03** | Are there any existing information sharing agreements or contracts in place which support your proposal? Please give details and attach as supporting documentation. |
| *SLS Research Board Approval*  *SLS Approved Researcher*  *All members of the research team:*  *Safe researcher training* |
| **3.2.04** | Are regulatory approvals from outside Scotland pending or received? Please give details. |
|  |

|  |  |  |
| --- | --- | --- |
| **3.3** | **Research and Ethics Governance** *Please read section 3.3 of the guidance* | |
| **3.3.01** | Has your proposal sought NHS or university research ethics approval? | Choose an item. |
| **3.3.01a** | If yes, provide committee details, status of approval (i.e. pending, approved, etc) and reference number. Please attach as supporting documentation if available | |
|  | |
| **3.3.01b** | If no, explain why NHS or university research/ethics approval is not sought: | |
|  | |

|  |  |  |
| --- | --- | --- |
| **3.4** | **Safe Havens** *Please read section 3.4 of the guidance* | |
| **3.4.01** | Do you intend to access the data requested exclusively through a safe haven listed at Appendix A of guidance notes? Please provide details of which safe haven/s.  *If you have answered ‘Yes’ you do not need to complete sections 5.1 or 5.2* | |
| Yes access will be via:  [National Records Scotland (NRS) Safe Haven using the Scottish Longitudinal Study (SLS)](http://sls.lscs.ac.uk/) | |
| **3.4.02** | If you applying to use NHS NSS / PHS data and you do not intend to do this through the National Safe Haven, please explain why then proceed to Section 4. | |
|  | |
| **3.4.03** | Will you be accessing the safe haven remotely? | Choose an item. |
| **3.4.04** | How and at what location will you be accessing the safe haven? E.g. on a university-provided laptop from a university office. | |
| SLS-DSU based at the National Records of Scotland, Ladywell House, Edinburgh – data will be provided via a safe computer located in the safe-setting room with no internet access. | |

**Section 4 – Data & Data Subjects**

|  |  |
| --- | --- |
| **4.1 New Data yet to be collected** *Please read section 4.1 of the guidance* | |
| Dataset/source Name | Collection by (whom)? |
|  |  |
|  |  |
|  |  |

|  |  |  |
| --- | --- | --- |
| **4.2 All Other Existing Datasets / sources** *Please read section 4.2 of the guidance*  **Please note that contact should be established as early in the process as possible with NHS Scotland boards/Data providers to discuss data provisioning requirements for any of the applicable sources listed below.** | | |
| Dataset/source Name | Data Controller (Organisation)  **For existing dataset/sources for which the data controller is not an NHSScotland board, please append evidence of the data controllers permission to use the data** |
| Scottish Longitudinal Study (SLS) | National Records of Scotland (NRS)  This project has been developed with members of the SLS team and approved by the SLS Research Board (SLS RB) on XX/XX/XX (date of letter confirming the project was approved). Every proposed project is considered by the SLS RB to ensure that the proposed use of the data is appropriate and there are clear benefits which outweigh potential privacy risks. The SLS project number is: 201X\_XXX. Attached is the approval letter from the SLS RB. For more info on the SLS RB please see: <http://sls.lscs.ac.uk/about/people/>  The Scottish Longitudinal Study is designed as a resource available to approved researchers studying research questions that would benefit from the longitudinal approach (similar to the ONS Longitudinal Study). The SLS data are obtained from administrative sources (1991, 2001, 2011 censuses and NRS vital events).  <http://sls.lscs.ac.uk/guides-resources/what-data-are-included/> |
| Scottish Index of Multiple Deprivation (SIMD), overall & domain scores & ranks | SIMD is produced at regular time intervals by the Scottish Government.  *To note there is already some SIMD data within the SLS, but only for 2004 as it is freely available online. For example the 2016 SIMD data is available from:*[*http://www.gov.scot/Topics/Statistics/SIMD*](http://www.gov.scot/Topics/Statistics/SIMD)  It is available freely online for anyone to download. Thus, SLS researchers can link or request SLS staff to link in SIMD data for whatever time period is most appropriate to their sample, either overall or the SIMD domains, scores or ranks of relevance to the research topic. |

|  |  |
| --- | --- |
| **4.2.01** | How were individuals originally informed of the use of their data? You should ensure that you include an appropriate explanation for each of the data sources which you have listed above. |
| The general public are made aware of how their data may be used for research purposes in the NHS Scotland Information Leaflet, “**Confidentiality: how the NHS protects your personal health information**.”  This leaflet is publically available at  <http://www.nhsinform.co.uk/rights/publications/easyread/~/media/hrisdocuments/other%20formats/easy%20read/confideasyread.ashx/>  The information leaflet states that, “Sometimes we use information about your health to help improve NHS services and the health of the public. Such as:  - to find out how many people have an illness or disease  - to look at how safe and effective a treatment is  - to check that the NHS is providing a good service  - to plan how many beds, wards and staff are needed  - to train students and staff  - to check that the NHS spends money properly  - for research.  **SLS**  The census form informs respondents that the data will be used for statistical purposes. The SLS unit does not have contact details for the SLS members due to third party linkage.  The SLS database contains anonymised data for approximately 5.3% sample of the Scottish population. The data are linked using a third party (NHSCR) and at no time is any name or address data available to the SLS unit. Identification required by ISD to identify SLS members and perform linkages is supplied to ISD by NRS and NHSCR. The SLS unit supply an encrypted identifier for each of the cases which will be returned with the requested linked ISD data to allow matching back to the data held by the SLS unit.  **ScotXed**  Based on the Education Analytical Services data sharing process:  The Scottish Government – Education Analytical Services data sharing process is based on the [ICO Data Sharing Code of Practice](https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf) (<https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf>). They aim to facilitate the sharing of data and maximise the value of data for the benefit of the education and wider community. This aim, however, is carefully scrutinised against the need to protect the privacy of the individuals who provided us with the data.  Following extensive public consultation, the [Guiding Principles for Data Linkage](http://www.scotland.gov.uk/Publications/2012/11/9015) (<http://www.gov.scot/Resource/0040/00407739.pdf>) were published in 2012, demonstrating the Scottish Government’s commitment to improving the decision making process for data users and data controllers in-line with increasing technical capacity. The Guiding Principles were developed to ensure that statistical and administrative data can be securely and efficiently linked for research and statistical purposes in the public interest. They support the legal, ethical and efficient use of data for linkage purposes within a controlled and secure environment.  Some of the key aspects included in the Guiding Principles for Data Linkage are listed below.   * Consent of data subjects is an important consideration, although it is not a necessary requirement for data linkage under the Data Protection Act. The consent principles should be departed from only where there is a strong justification and approval has been granted by an appropriate oversight body. * There are degrees of data anonymisation and it may not be possible to completely remove the risk of re-identification. Nevertheless, data can be anonymised sufficiently (often referred to as 'pseudonymisation') for data controllers to make a reasonable risk-based judgement that data can be shared. The anonymisation principles may have less importance if consent for linkage of non-anonymised data has been given or if linkage has been approved by an appropriate oversight body. * Security of data transfer, storage and use is vital for the protection of privacy, especially where there is any risk of re-identification. * Anyone who applies to access or link data via one of Scotland's national safe havens (secure data access points) must have undergone appropriate training which is necessary to gain ‘approved researcher’ status. Further security measures can be taken to prevent any single person or organisation having unrestricted access to data, for example the establishment of an Access Control Policy or Data Access Agreement. |

|  |  |  |  |
| --- | --- | --- | --- |
| **4.3 Data Variables** *Please read section 4.3 of the guidance* | | | |
| Dataset/source Name | Variable | Time Period/Range | Please check to indicate if this item is used for processing only and will not be part of the output |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

|  |  |
| --- | --- |
| **‘**Data protection law requires that the use of either directly or indirectly identifiable data variables is minimised to those which are strictly necessary. This is known as the ‘data minimisation’ principle. In the table below please justify the need for all of the identifiable or potentially identifiable variables included in your proposal: | |
| Identifying or Potentially identifying Variable | Justification |
| N/A | All potentially identifying variables (e.g. date of birth) are not available for researchers’ use. Further information about strategies used to avoid identification are provided in section **5.4.01b.** |
|  |  |
|  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **4.4** | **Methodology** *Please read section 4.4 of the guidance* | | |
| **4.4.01** | Does the proposal require any of the following: | | |
| Data linking  Use of matched controls  Single anonymised data extract  Other (please specify):  The results of data linking the SLS sample to the CHI number are stored as a look-up which is to be used to extract the required data | | |
| **4.4.02** | If the proposal requires data linkage, who is undertaking the linkage e.g. eDRIS team, local analysts etc..?  Using SLS study spine originally created by the medical linkage team/eDRIS | | |
| **4.4.03** | What variables will be processed for linkage? | | |
| CHI Number | Forename | Surname |
| Date of Birth | Address | NHS Number |
| Postcode | Other Please Specify:  Using encrypted SLSno - an ID from the SLS study spine - originally created by the medical linkage team/eDRIS | |

|  |  |  |
| --- | --- | --- |
| **4.5** | **NRS/NHSCR Data Sources** *Please read section 4.5 of the guidance* | |
| *Complete this section if access to NHSCR is required, or if there is any National Records of Scotland involvement* | | |
| **4.5.01** | Does the proposal require access to NHS Central Registry as a sampling frame for cohorts? | No |
| **4.5.02** | Does the proposal involve flagging of individuals on the NHSCR for long term follow up? | No |
| **4.5.03** | If yes,is flagging necessary: | |
|  | To trace and contact individuals throughout the UK? | |
|  | To be informed of fact and cause of death? | |
|  | To be informed of the incidence of on-going anonymised cancers registrations? | |
|  | To be informed of emigrations prospectively and retrospectively? | |
| **4.5.04** | Is any other NRS/NHSCR involvement required? Please provide details  No | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **4.6** | **Making Contact with Individuals** *Please read section 4.6 of the guidance* | | | | |
| **4.6.01** | Is any direct contact with any group of individuals required? If Yes, please provide details below | | | | No |
|  | Contact Group and Method of contact | | | | Contact by (whom) |
|  | Hospital Consultants | Letter | Phone | Other (specify) : |  |
|  | Other NHSS Staff | Letter | Phone | Other (specify) : |  |
|  | General Practitioners | Letter | Phone | Other (specify) : |  |
|  | Patients/Public | Letter | Phone | Other (specify) : |  |
|  | Relatives of participants | Letter | Phone | Other (specify): |  |
|  | Others (please specify): | Letter | Phone | Other (specify) : |  |
| **4.6.02** | Please explain why contact is being made – append copies of relevant correspondence as supporting evidence | | | | |
|  |  | | | | |

|  |  |
| --- | --- |
| **4.7** | **Community Health Index (CHI) Database** *Please read section 4.7 of the guidance* |
| *Complete this section if access to CHI Database is required* | |
| **4.7.01** | What monitoring and audit of the use of CHI is planned? Please provide details |
|  |
| **4.7.02** | What technical method will be used to access CHI (online read-only, download, other extract, anonymised extract, etc)? Please provide details |
|  |
| **4.7.03** | Have any risks been identified in the proposal which relate specifically to CHI? |
|  |

**Section 5 – Data Processing**

|  |  |  |
| --- | --- | --- |
| **5.1** | **Access** *Please read section 5.1 of the guidance* | |
| *Complete the following section if you answered ‘No’ to question 3.4.1* | | |
| **5.1.01** | At what location is identifiable or potentially identifiable data being accessed? | |
|  | |
| **5.1.02** | Please provide details of security policies/procedures governing access to this physical and technical environment. Please append supporting documentation referencing appropriate sections. | |
|  | |
| **5.1.03** | Does this policy/procedure cover password policy in detail? Please provide details/ append supporting documentation referencing appropriate sections. | |
|  | |
| **5.1.04** | Does this policy/procedure cover user account management, including review or removal of access to sensitive/personal data, in detail? Please provide details/ append supporting documentation referencing appropriate sections. | |
|  | |
| **5.1.05** | Will individuals with access to data have individual or shared accounts? | |
|  | |
| **5.1.06** | Will the data be accessed by staff working off site e.g. staff working from home at any time during the duration of the proposal? | Choose an item. |
| **5.1.06a** | If yes, are policies/procedures in place to facilitate, monitor and audit this access? Please provide details/ append supporting documentation. | |
|  | |
| **5.1.07** | Provide any additional detail of how data is protected from unauthorised access | |
|  | |

|  |  |  |
| --- | --- | --- |
| **5.2** | **Storage & Use** *Please read section 5.2 of the guidance* | |
| *Complete the following section if you answered ‘No’ to question 3.4.1* | | |
| **5.2.01** | Where is data being stored and used? (location, organisation, address – refer to addresses in previous sections if appropriate) | |
|  | |
| **5.2.02** | ISO 27001 Cert. No. |  |
| **5.2.03** | Please provide details of security policy/procedure governing storage and use of data within this physical and technical environment – append supporting documentation referencing appropriate sections | |
|  | |
| **5.2.04** | Does this policy/procedure cover the implementation of up-to-date controls for the detection and prevention of malware? Please provide details/ append supporting documentation | |
|  | |
| **5.2.05** | Does this policy/procedure cover access control and auditing of system administrator activity? Please provide details/ append supporting documentation referencing appropriate sections | |
|  | |
| **5.2.06** | Does this policy/procedure cover the production of backups and the controls in place around these? Please provide details/ append supporting documentation | |
|  | |
| **5.2.07** | Does this policy/procedure describe the controls in place to prohibit unauthorised copying of data? Please provide details/ append supporting documentation referencing appropriate sections | |
|  | |
| **5.2.08** | Does this policy/procedure describe physical and site controls? Please provide details/ append supporting documentation referencing appropriate sections | |
| **5.2.09** | Does this policy/procedure cover hardware repair, replacement or disposal and protection of data from inappropriate access during such procedures? Please provide details/ append supporting documentation | |
|  | |
| **5.2.10** | Describe the systems, software and security used to store and use data - please provide details/ append supporting documentation | |
|  | |
| **5.2.11** | Is outsourced IT in use? If yes, please give details | |
|  | |
| ***Please repeat section 5.2 above for each relevant location in the proposal – see guidance*** | | |

|  |  |  |
| --- | --- | --- |
| **5.3** | **Transfer** *Please read section 5.3 of the guidance* | |
| **5.3.01** | Please provide details of security policy/procedure to ensure that data will be transferred in such a way that it is protected from inappropriate or unauthorised access (mention email encryption, secure file transfer protocols SFTP, device encryption, physical controls, etc, as appropriate) - append supporting documentation | |
| Globalscape SFTP – already approved by both eDRIS & NRS as a secure method for file transfer of past SLS linkages (can provide more details if need be). | |
| **5.3.02** | At what intervals/ trigger points will data transfer take place? E.g. one off transfer, monthly intervals | |
| Once, to transfer encrypted SLS identifiers to the eDRIS team, then once to retrieve the linked file(s) created by eDRIS. | |
| **5.3.03** | Will any identifiable or potentially identifiable data be transferred outside of the UK? | Choose an item. |
| **5.3.03a** | If yes,please provide details of the country of destination, the method of transfer, the proposed location and method of storage outside of the UK, and details of any further onward transfer | |
|  | |
| **5.3.04** | Other than initial transfers from source systems, is there any copying of data required within the proposal? If yes, please give details | |
| The encrypted extract of SLS identifiers is transferred from a SLS PC connected to the SLS network (with no internet connection) to a SLS PC with an internet connection within the same room using an internal use only encrypted password protected SLS pen drive. The data is then transferred using a secure eDRIS website which is accessed using a time limited username and password supplied by eDRIS. Only two SLS team members have the authority to transfer data from and on to the SLS network. The reverse procedure is followed to load data from eDRIS onto the SLS network. When data are extracted from the SLS database to provide a research dataset for a particular project it is stored in a project folder which is created at the beginning of the project. There will be 2 project folders for each project, one is a ‘public folder’ to which only the authorised researcher of that project and all SLS support staff can have access, and the other is a ‘private’ folder to which only some SLS support staff (the data administrators and the support person for the particular project) can have access. The private folder holds the raw data extract and code used to manipulate that data into a ‘safe’ form that can then be passed to the public folder. | |

|  |  |  |
| --- | --- | --- |
| **5.4** | **Dissemination** *Please read section 5.4 of the guidance* | |
| **5.4.01** | Will proposal findings be published or disseminated beyond those listed in Section 1? (*If you have answered ‘No’, go directly to section 5.5)* | Choose an item. |
| **5.4.01a** | If yes, how will proposal findings be published or disseminated, to what audience and in what format? Please give details | |
| Researcher cut and paste from SLS application form - Dissemination and Impact.  However please read the guidelines | |
| **5.4.01b** | If yes, what steps will be taken to ensure that persons cannot be identified in published Please give details and confirm what disclosure control policy will be applied | |
| Output is released to users under strict statistical disclosure controls (SDC) - tabulations or modelling results are checked to ensure that they are non-disclosive. Cleared outputs are encrypted before sending to users by SLS Support Officers. Final outputs, including papers and conference presentations must be cleared by the NRS SLS Project Manager as SLS Data Custodian before entering the public domain. To summarise the smallest cell size allowed is 10 (but when working with health data additional check are of course made for example so that these don’t relate to 1 person have multiple events). | |
| **5.4.01c** | If yes, are there any circumstances where a living or dead individual would be cited? (E.g. where a person consented to their data being used as a case study)? Please give details | |
| No | |
| **5.4.01d** | If yes, were any permissions to publish data required or sought (for example from data controllers)? Please provide details | |
| The NRS SLS project manager - an employee of NRS as Data Custodian - gives permission for all final outputs to enter the public domain. | |

|  |  |
| --- | --- |
| **5.5** | **Retain/Dispose** *Please read section 5.5 of the guidance* |
| **5.5.01** | Which information/data/records retention policy will you be applying to the proposal data (details of the policy and the organisation to which it belongs)? |
| SLS policy.  Linked data files from eDRIS are erased from the encrypted memory stick immediately after they have been successfully transferred to the private project folder on the LSCS/SLS network. |
| **5.5.02** | How long do you intend to retain identifiable or potentially identifiable data after the conclusion of the proposal (including archive/backup copies)? |
| The project folders should be held for 5 years on the SLS server and may then be archived off onto external media for safe storage. Archived material should be held permanently. |
| **5.5.03** | Who will retain the data and where? |
| LSCS, NRS, Ladywell House, Ladywell Road, Edinburgh, EH12 7TF. Encrypted backup data are also held in Thomas Thomson House, 99 Bankhead Crossway North, Sighthill Industrial Estate, Edinburgh, EH11 4DX |
| **5.5.04** | What is the purpose for retaining the data for the specified time? |
| The data is retained by the SLS in order that if a researcher produces an academic peer reviewed journal paper and the results published are in question the user can retrieve their data to either reproduce the research/analysis or to re-check results to respond to the claim |
| **5.5.05** | What method of disposal or destruction will be used when this period has expired (including archive/backup copies)? |
| Project data will be kept indefinitely.  However, old, obsolete or broken computer equipment (including backup tapes and hard disks) is safely destroyed in accordance with NRS policy. |
| **5.5.06** | What evidence will be obtained that destruction has occurred (eg IT supplier certificate of destruction, etc)? |
| Logs are maintained when LSCS/SLS equipment is passed to NRS for safe disposal.  NRS keep certificates of destruction. |

|  |  |
| --- | --- |
| **5.6** | **Review** *Please read section 5.6 of the guidance* |
| **5.6.01** | Describe how the mechanisms which safeguard data security will be audited and reviewed at regular intervals to ensure their continued efficacy |
| SLS staff regularly review the restricted level of variables which could be potentially identifiable. SLS Support Officers also check the data and variables received from ISD/eDRIS ahead of passing to the researchers to use. We would not allow researchers to request for their research project variables deemed restricted for SLS projects (for example, day dates). |
| **5.6.02** | Describe any resource implications to any of the proposed measures for the protection of physical or technical security of information which are unresolved at the time of this application? (for example encryption of devices is an intention not yet fulfilled, training is not yet undertaken, etc) |
| N/A |
| **5.6.03** | Describe the breach reporting mechanisms to be invoked in the event of any inappropriate access to data or other information security incident |
| Incidents such as attempts to use the USB port in the Safe Setting are automatically logged. These logs are reviewed during and after any visits to the Safe Setting.   NRS Security will be informed of any security incident. |

## 

## Section 6 – Declaration

* I DECLARE THAT this application is accurate, and that, should it be successful, any health data made accessible will be used for no other purpose, and in no other way, than as described above.
* I UNDERTAKE TO notify the Public Benefit and Privacy Panel (PBPP) of any future changes to the purpose or manner in which data is processed in accordance with this application.
* I UNDERSTAND THAT any future applications by me, or my employing or sponsoring organisation, may be refused should any health data made accessible be used for any other purpose or in any other way than that described above.
* I AGREE TO abide by any conditions attached to the application by the PBPP during the approval process. I understand that failure to comply with these conditions may result in any future applications by me, or my employing or sponsoring organisation, may be refused.
* I CERTIFY THAT all those who have access to health data in this proposal are aware of the requirements of confidentiality and understand that any breach (eg disclosure of confidential information to a person not authorised to receive it) will be reported to the data controller, and in the case of NHS Scotland originated data to Scottish Government eHealth division.
* I CERTIFY THAT that only the persons named in the PBPP form (1.1-1.6) as requiring access to the data will be given access and that the data will not be transferred to anyone else.
* I GUARANTEE THAT no publication will appear in any form in which an individual may be identified without the written permission of that individual, and that I will apply appropriate disclosure control when planning publications involving the data requested.
* I UNDERSTAND THAT the Data Controller, and agents acting on its behalf, reserves the right to inspect the data on the sites where it is being processed.

To be signified by the APPLICANT

|  |  |
| --- | --- |
| Name (in Capitals): | Date: |

To be signified by the PhD SUPERVISOR (if applicable)

|  |  |
| --- | --- |
| Name (in Capitals): | Date: |

* I DECLARE THAT (the applicant named above) is a *bona fide* worker engaged in a reputable project and that the data he/she asks for can be entrusted to him/her in the knowledge that he/she will conscientiously discharge his/her obligations, including in regard to confidentiality of the data, as stated in the declaration above.

To be signified by the INFORMATION CUSTODIAN named in Section 1.4 above (where the Information Custodian is not the applicant).

|  |  |
| --- | --- |
| Name (in Capitals): | Date: |

I ACCEPT the organisation’s obligations and roles with respect to the processing of data for the purposes outlined in this application.

To be signified by the Main Contact for the Lead Organisation named in Section 2.2 above

|  |  |
| --- | --- |
| Name (in Capitals): | Date: |