Accessing data held within the Scottish Suicide Information Database (ScotSID)

What is ScotSID?

ScotSID is a national database that holds information on all individuals dying in Scotland from definite or probable suicide from January 2009 onwards. The database is constructed by linking together routine administrative data: no new data are collected. The database is held by the Information Services Division of NHS National Services Scotland (ISD).

Currently (April 2013), the database includes data from individuals’ National Records of Scotland (NRS) death records (e.g. date of death, age, sex, cause of death) linked to a range of routine health records held by ISD. The included health records provide information on any hospital admissions, outpatient and A&E attendances, prescriptions, and drug misuse services that the individuals received in defined periods prior to their death. In addition to these ISD records, information on whether an individual’s death was subject to an NHS Scotland suicide review, or review by the Mental Welfare Commission, is also provided by Healthcare Improvement Scotland to ISD for incorporation into the database. It is anticipated that the database will expand over time to incorporate a wider range of routine data.

ScotSID is funded by the Scottish Government. The detail of its development is overseen by a Steering Group which includes representatives of the Scottish Government, NHS Boards, Health Scotland, Healthcare Improvement Scotland, academia, relevant voluntary organisations, NRS, ISD, and others.

As ScotSID has been established, careful attention has been paid to privacy and confidentiality issues. As the individuals contained within the database are deceased, the included data are not subject to the Data Protection Act. Nevertheless, ISD is bound by a duty of confidentiality to all patients whether living or dead and NHS National Services Scotland holds a role analogous to that of Data Controller in relation to the database. ISD has followed established guidance on confidentiality (for example the Confidentiality and Security Advisory Group for Scotland’s 2002 report on Protecting Patient Confidentiality http://www.sehd.scot.nhs.uk/publications/ppcr/ppcr.pdf) when developing ScotSID.

NHS Board Caldicott Guardians have been kept informed of ScotSID’s development, a detailed information security protocol is in place, and Privacy Advisory Committee approval has been secured for the database. A data sharing agreement between NHS Healthcare Improvement Scotland and ISD covers the transfer and incorporation of information on suicide reviews.

ISD has published an annual ScotSID report from 2011 and these are available on http://www.isdscotland.org/Health-Topics/Mental-Health/Related-Publications/. These reports provide background information on ScotSID along with summary analyses of the information contained within the database.
How can I access ScotSID data for my project?

Individuals/organisations may wish to access ScotSID data for various purposes, for example:

- A voluntary organisation may wish ISD to undertake an ad hoc analysis of ScotSID data and provide aggregated results (i.e. tables showing overall numbers/proportions of individuals with particular characteristics of interest).
- An NHS Board may want ISD to provide them with an extract of individual level ScotSID data (i.e. a file containing one record per individual) relating to persons who had been living in their Board area. This could then be analysed by the Board to explore the characteristics of residents completing suicide.
- A group of researchers may want ISD to provide them with an extract of individual level ScotSID data covering the whole of Scotland as part of a national research project.

If applicants are looking for data items that are derived from NRS and ISD datasets only (i.e. death and health records), such requests will be treated similarly to any other requests for ISD data.

- Requests for aggregated information should be submitted to ISD’s Information Request Service - see [http://www.isdscotland.org/About-ISD/Information-Requests/](http://www.isdscotland.org/About-ISD/Information-Requests/). Applicants should note that all aggregated outputs will be reviewed by ISD prior to release to ensure that they do not inadvertently allow identification of individuals.
- ISD is in general able to supply individual level data to NHS Boards on persons living or treated in that particular Board area for legitimate purposes such as planning and monitoring the quality of services. Such requests should also be submitted to ISD’s Information Request Service.
- Requests for data to support research should be submitted to ISD’s electronic Data Research and Innovation Service (eDRIS) – see [http://www.isdscotland.org/Products-and-Services/eDRIS/](http://www.isdscotland.org/Products-and-Services/eDRIS/). Researchers looking for individual level data are likely to need approval from the Privacy Advisory Committee before data are released and only anonymised data (i.e. containing no obvious identifiers such as individuals’ names) would usually be provided. Other permissions such as ethical approval may also be required depending on the nature of the request.

If applicants are looking for data items that originally came from other organisations, such as data on suicide reviews from Healthcare Improvement Scotland, requests should be submitted in the same way as outlined above. In such cases, ISD will liaise with the supplying organisation and review the terms of the data sharing agreement with that organisation before releasing the data. Applicants should be aware that, as more data sources are incorporated into ScotSID, there may be multiple possible sources for certain data items.

Finally, as NHS National Services Scotland is a public authority, applicants may alternatively submit requests for information under the terms of the Freedom of Information (Scotland) Act 2002. Further information on submitting an FOI request can be found here [http://www.isdscotland.org/Freedom-of-Information.asp](http://www.isdscotland.org/Freedom-of-Information.asp).

ISD’s Caldicott Guardian has final responsibility for authorising the release from ISD of information that actually or potentially allows identification of individuals. Regardless of the type of data request, ISD may charge for the time involved in preparing data extracts and conducting analyses.

The ScotSID Steering Group has an interest in ensuring that all analyses involving ScotSID data are robust and appropriately interpreted and disseminated for the public good. ISD therefore notifies the Steering Group on a quarterly basis of data requests received that involve ScotSID. Depending on the nature of the requests, the Steering Group may subsequently invite applicants to discuss their request more fully with the Group and/or offer to review any draft publications before they are sent to a journal or otherwise made publicly available. ScotSID should always be acknowledged in any reports or publications based on ScotSID data.