

National Self-Harm Registry Ireland

Data Protection Policy and Procedures

The National Suicide Research Foundation operates the National Self-Harm Registry Ireland, which records data on self-harm presentations to all hospital emergency departments in the Republic of Ireland. The Registry was established, at the request of the Department of Health and Children, in 2000 and is funded by the Health Service Executive's National Office for Suicide Prevention. Ethical approval was granted to the Registry by the National Research Ethics Committee of the Faculty of Public Health Medicine and from the management and ethics committees with responsibility for the individual hospitals and former health board areas.

The purpose of the Registry is to:

- Determine and monitor the incidence and repetition of hospital-treated self-harm;
- Identify high-incidence groups and areas;
- Inform services and practitioners concerned with the prevention of suicidal behaviour.

Individuals who engage in self-harm are at heightened risk for suicide, and so data on hospital-treated self-harm can inform activities to reduce the risk of suicide in this population. Data from the Registry provides real-time data on trends and high-risk groups for self-harm in Ireland, informing services and policy in the prevention of suicide. The Registry is a key component in the outcomes framework of the Irish National Strategy to Reduce Suicide in Ireland, Connecting for Life, 2015-2020.

Lawful basis for processing personal data

- Under EU General Data Protection Regulation (GDPR), the Registry processes personal data on the lawful basis of 'legitimate interests', as outlined in Article 6(1)(f).
- Article 9(2)(i) of the GDPR and Section 47 of the Irish Data Protection Bill 2018 allows for the processing of special categories of personal data for purposes of public interest in the area of public health, such as ensuring high standards of quality and safety of health care.
- Article 9(2)(j) and Section 48 of the Irish Data Protection Bill 2018 allows for the processing of a special category of personal data for or archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

Operation of the National Self-Harm Registry Ireland

The Registry endeavours to collect data on all self-harm presentations to hospital emergency departments. The principal source of data is the emergency department records system. Registry data are collected by appointed and trained data registration officers.

Processing of personal data as part of the Registry requires that suitable and specific measures be taken to safeguard the fundamental rights and freedoms of data subjects, which include those outlined in Section 32(1) of the Irish Data Protection Bill 2018.

The data registration officers enter the Registry data onto their laptop computer using a custom-designed Registry data entry system. The data is stored on a secure server in University College Cork. Access to this server is only permitted by the Registry Manager. Access to the core masterfile is highly restricted. It is used for data checking and linking of repeat self-harm presentations and for the linkage with mortality data but it is not used for general analysis purposes.

A second Registry masterfile is maintained in which the unique Registry code has been replaced by an arbitrary but equally unique patient number. This masterfile is used for analysis purposes. The file may be made available to Foundation staff and may also be provided to researchers from other institutions pending written agreement to abide by stipulated terms and conditions.

Release of data

Anonymised Registry data may also be released in an aggregate format which does not allow individuals to be identified directly or indirectly. Aggregate data releases take the form of annual and other periodic reports and research bulletins, articles and presentations. They may be made routinely or in response to a request from an agency or individual. Registry data may also be released at the level of individual hospital presentations, i.e. microdata. There is no potential for an individual patient to be identified directly or indirectly and an agreement stipulating the terms and conditions must be signed by the requester of the data.

Data confidentiality

Maintaining the security and confidentiality of the Registry data is of paramount importance and it is something that is emphasised in the induction of Registry staff and regularly at team meetings. Each staff member working with Registry data signs a confidentiality undertaking. Any breach of the security or confidentiality of the Registry data will be considered a serious disciplinary matter and may lead to dismissal. Data registration officers who collect Registry data from hospitals also adhere to the security and confidentiality arrangements in place in the hospitals.

Preservation of confidentiality, as well as being an obligation, is essential to maintain the trust of those who provide the Registry with information. Hospital staff must be assured that the welfare of

their patients will be respected and that the Registry staff will observe the same strict rules with regard to confidentiality that exist in the hospital. The Registry staff also have a legal and moral obligation to avoid acts that may cause suffering or distress to any individual.

In carrying out its functions, the Registry staff must adhere to the following guidelines:

- Permission for access to medical records must be sought from each individual hospital;
- An information leaflet describing the Registry must be made available in a suitable place within the emergency department of each participating hospital;
- No disadvantage, harm or distress may be caused to the patient by this access;
- Appropriate safeguards must be in place to preserve the confidentiality of the information in the Registry's custody;
- Reports of the Registry must not contain information which would disclose the identity of a patient.

Rights of data subjects

An individual who may have presented to hospital as a result of self-harm may contact the Foundation to enquire if the Registry recorded data relating to them. In line with the Data Protection Act, such an individual will be asked to put their request in writing giving the details needed to help locate their data within the Registry database. The individual will be advised that their case may not have been recorded by the Registry if it did not meet the Registry case-definition criteria and that their information may not be retrievable if there is any discrepancy between the information recorded in the hospital and the information they provide to the Registry in their request. They will be advised that a copy of all information recorded about them by the Registry will be provided to them, that this will be done free of charge, that any inaccurate information will be rectified or erased and if they wish all information in the Registry related to them will be erased.

For further information, please contact the NSRF offices | +353 21 420 5551 | info@nsrf.ie | 4th Floor, Western Gateway Building, University College Cork, Ireland.