

Review of the National Self-Harm Registry Ireland: Summary



The National Self-Harm Registry Ireland (NSHRI) monitors the incidence of hospital presenting self-harm in the Republic of Ireland. Established in 2000 by the National Suicide Research Foundation (NSRF), the NSHRI has had full coverage of all adult and paediatric hospitals in Ireland since 2006. It is the only national self-harm registry in the world and formed the basis of recent WHO guidance on best practice in establishing and maintaining self-harm registries.

The HSE National Office for Suicide Prevention (NSOP) commissioned a review of the NSHRI in September 2017 as part of Connecting for Life (CfL) strategic objective “To improve access to timely and high quality data on suicide and self-harm (CfL 7.2)”

Key Points:

- The NSHRI data and reports are valued by practitioners and policy makers throughout Ireland. Registry data are key to monitoring aspects of Ireland’s National Strategy to Reduce Suicide (2015-2020) – Connecting for Life (CfL).
- NSHRI data have shone a light on the problem of hospital presenting self-harm in Ireland, leading to a number of national programmes, most notably the National Clinical Programme for the assessment and management of patients presenting to the Emergency Department following Self-Harm (NCP) and the National Dialectical Behaviour Therapy (DBT) service.
- Elements of the NSHRI data collection processes and IT are now somewhat dated and the NSHRI team are not closely linked in with the hospitals where data are collected. Variations in approaches to data collection and the quality of data between hospitals mean that some apparent differences between areas/hospitals in the incidence, management and risk factors for self-harm are likely to be biased.
- Procedures for data collection need reviewing and updating, and the data collection application needs replacing. The NSHRI team needs to work more closely with local clinicians to improve data quality, feedback findings from NSHRI and ensure appropriate governance / ethical approvals are in place.
- There has been a suggestion that data collected by the National Clinical Programme (NCP) for self-harm may render the NSHRI redundant. In our assessment, the completeness, depth and breadth of NSHRI data are stronger than the NCP data, but would be further strengthened by the inclusion of some core data on NCP referrals and aftercare.
- The costs of the NSHRI appear to be reasonable compared to those of two major UK-based registries.
- The NSHRI has produced 2-6 peer-reviewed research outputs per year since 2013; however NSHRI data are under-used for evaluating Ireland’s major suicide / self-harm prevention initiatives.

The researchers

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Background

Since its inception, the impact and value of the National Self-Harm Registry Ireland (NSHRI) has been reviewed from time to time by external experts, but no formal wide-ranging review has previously been carried out. In September 2017, the National Office for Suicide Prevention (NOSP) commissioned Professor David Gunnell and Jon Hallett from the University of Bristol to undertake a formal review of the NSHRI.

The NSHRI has been monitoring the incidence of hospital presenting self-harm to all adult and paediatric hospitals in the Republic of Ireland since 2006. The NSHRI began initially in Cork and Limerick in the 1990s, as part of the European Multicentre Study of Self Harm. From 2000 onwards, with funding from the Department of Health and Children, it gradually increased its coverage to the whole of the Republic of Ireland by 2006. In more recent years the team has helped establish a Registry in Northern Ireland, run by the Public Health Agency, leading to the coverage of all of Ireland. The NSHRI has been funded by the Health Service Executive's (HSE) National Office for Suicide Prevention (NOSP) since 2005. The NSHRI is operated by the National Suicide Research Foundation (NSRF).

The Purpose of the NSHRI

The aims of the NSHRI, as defined by the National Suicide Research Foundation's (NSRF)¹ are:

- To establish the extent and nature of hospital-treated self-harm in Ireland.
- To monitor trends over time and also by area.
- To contribute to policy and development in the area of suicidal behaviour.
- To help the progress of research and prevention.

These aims are expanded upon in the NSHRI's 2016 annual report (page 2) to include "to determine and monitor the incidence and repetition of self-harm presentations to hospital emergency departments in Ireland with the aim of identifying high-incidence groups and informing services, practitioners and policy makers

¹ (<http://www.nsrif.ie/our-research/our-systems/national-self-harm-registry-ireland>)

concerned with the prevention of suicidal behaviour."

The report goes on to say that "From a public health perspective, the NSHRI fulfils a major objective in providing real-time data on trends and high-risk groups for self-harm in Ireland". Additionally, the NSHRI provides key indicator data for *Connecting for Life (CfL)* Ireland's National Strategy to Reduce Suicide (2015-2020) Outcomes Framework [Department of Health 2015].

Operation of the NSHRI

Data collection is carried out by a team of 15 Data Registration Officers (DROs). The DROs collect data from all acute hospital emergency departments in Ireland (adult and paediatric). DROs identify and input all identified episodes of self-harm for the previous calendar year by the end of March the following year. Annual reports are usually published by August/September the following year. Data collection processes and approaches to coding variables are clearly outlined in the NSHRI's Standard Operating Procedures; these are reviewed at regular (held 2-3 times per year) meetings of DROs convened by the NSHRI leads. DROs use a variety of approaches to identify cases.

Purpose of the Review

The review had seven objectives:

1. Describe the purpose and operation of the NSHRI.
2. Provide an assessment of the NSHRI's attributes.
3. Describe levels of integration with other systems, including the National Clinical Care Programme (NCP) for the Assessment and

Management of Patients Presenting to Emergency Departments following Self-Harm.

4. Gather credible evidence regarding the performance of the Registry.
5. Review the impact of the NSHRI at an international level.
6. Assess the value for money of the NSHRI compared against similar surveillance systems.
7. Make recommendations for further development, improvement and sustainability of the Registry.

Methodology

The following approaches were used to carry out the review:

- Document review of Registry documents and publications.
- One-to-one discussions and/or focus groups with key stakeholders and informants identified by HSE and NSRF.
- On-line survey of 87 people identified as being key informants at each hospital in the Republic of Ireland – these largely consisted of Consultant Liaison Psychiatrists, Emergency Medicine consultants and Clinical Nurse Specialists delivering the NCP.
- On-line survey of 84 individuals identified as key to local or national suicide and self-harm prevention and treatment activities, including HSE Resource Officers for Suicide Prevention; Members of C/L Strategy Groups; Public Health Specialists; Department of Health staff.
- Review of ad-hoc analyses of The Registry data and documents requested from the Registry team.
- Hospital visit to review the process of case identification and data retrieval in action.
- An assessment of the costs of the Registry by obtaining costs from two other leading UK Registries – a) The Northern Ireland Self-harm Registry and b) the Multicentre Registry for Self-Harm (covering the cities of Derby, Oxford and Manchester in the UK).

The work as carried out between December 2017 and April 2018

Recommendations

Table 1 summarises the recommendations arising from the review, for future development, improvement and sustainability of the NSHRI.

The 23 recommendations are presented by review objective and thematically. In addition, the recommendations that require immediate or short-term action within the next 12-18 months are highlighted. Eight recommendations (9-15) explicitly focused on the NSHRI data base; including:

- an assessment of the impact of the GDPR on the NSHRI (recommendation 10)
- replacement of the current NSHRI data collection application (recommendation 14) and
- a number of recommendations focused on improving the quality of data collected (for example recommendation 1-8).

Two recommendations (22 and 23) are identified as requiring a longer-time frame. One of these is a broader recommendation that HSE reviews its overall provision of services to support people who have self-harmed or are at risk of self-harming (Recommendation 23).

The remaining recommendations require action within 18 months to 3 years. These include addressing the overlap between the NSHRI and the NCP data collection systems (Recommendation 16) and developing the potential of using the NSHRI data to inform local clinical practice (Recommendation 21).

The full technical Review Report is available upon request from:

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For future information on the National Self-Harm Registry Ireland see <https://www.nsrif.ie/national-self-harm-registry-ireland/> or contact

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Table 1: Recommendations arising from Review of the NSHRI

Operation of NSHRI (Study Objective 1)
<ul style="list-style-type: none"> • Recommendation 1 Data Extraction: Data retrieval, transcription & entry processes should be reviewed for each hospital contributing to the NSHRI to ensure practices are followed that reduce transcription errors. If paper records are used initially, a standard form should be produced for each patient.
<ul style="list-style-type: none"> • Recommendation 2: Support for DROs & Hospital Governance: DROs should have a named clinical and medical records lead at each hospital with whom they meet regularly & who has (in their job description) a responsibility for inducting them and facilitating data collection processes (including provision of space & access to records & IT systems). The clinical lead at each hospital should have responsibility for the oversight of the Governance arrangements/ethical approvals for each site.
<ul style="list-style-type: none"> • Recommendations 3 Case Ascertainment: An analysis of HIPE recorded self-harm vs. NSHRI recorded self-harm admissions to hospital beds should be carried out to determine the extent of mis-reporting across all sites; in those sites with extensive misreporting data collection processes should be made more robust.
<ul style="list-style-type: none"> • Recommendation 4: Case Ascertainment: Hospital administrative staff who enter data onto ED info systems should receive regular training on coding of SH to make data retrieval more robust.
<ul style="list-style-type: none"> • Recommendation 5: Case Ascertainment Clinicians should be asked to clearly record key items such as the presence or absence of alcohol misuse in their assessments.
<ul style="list-style-type: none"> • Recommendation 6: Engagement of hospital staff: The NSHRI Team should work more closely with each local centre to provide regular (e.g. annual) feedback on data, data collection, opportunities for collaboration on issues of specific local interest. This might include annual hospital specific reports comparing their position (e.g. in relation to levels of psychosocial assessment/self-discharge relative to other hospitals
<ul style="list-style-type: none"> • Recommendation 7 Extending data collection: Consideration should also be given to widening the scope of data collection to include new cases identified on HIPE records. It would be useful to contrast the cases recorded on the NCP system by the Clinical Nurse Specialists with those on the NSHRI to identify areas of particularly poor ascertainment, & seek to implement improvements in data capture.
<ul style="list-style-type: none"> • Recommendations 8 Data quality & missing data: Differences between centres in data completeness should be reviewed by NSRF team &, where possible, improvements in the consistency of data collection implemented. Outputs from the NSHRI should contain a note of caution about interpreting variations in some variables.
NSHRI Database Design (Study Objective 2)
<ul style="list-style-type: none"> • Recommendation 9 Computing/IT: The NSRF should give consideration to using public-key cryptography for encrypting patient identifiers. The identifiers could be encrypted on DRO laptops using the public key and decrypted by the central Registry team using the private key.
<ul style="list-style-type: none"> • Recommendation 10 Computing/IT: The NSRF should undertake an assessment of the impact of the GDPR on the NSHRI, particularly given that the NSHRI stores patients' details in recoverable & pseudonymised forms.
<ul style="list-style-type: none"> • Recommendation 11 Computing/IT: The NSRF should commission an audit of the information security of the NSHRI & its processes against best-practice standards such as the ISO/IEC 27000 series. The audit should encompass all NSHRI information and processes, not just the IT aspects.
<ul style="list-style-type: none"> • Recommendation 12 Computing/IT: The NSRF should sign the information technology access agreement with UCC as soon as possible.
<ul style="list-style-type: none"> • Recommendation 13 Computing/IT: The NSRF takes steps to ensure the unavailability of any single person cannot affect IT support for the NSHRI.
<ul style="list-style-type: none"> • Recommendation 14 Computing/IT: The NSRF should replace the data collection application. The new application should: <ul style="list-style-type: none"> • be implemented on a platform which can be maintained for the foreseeable future • use a dedicated server application so data are uploaded seamlessly from the client application • generate better error messages, particularly for bulk uploads from Excel spread sheets • be drivable entirely from the keyboard as far as possible, with a natural path for tabbing through the fields

<ul style="list-style-type: none"> • be informed by the Northern Ireland application, but not necessarily be based on it • use an alternative to the CSO website for finding addresses
<ul style="list-style-type: none"> • Recommendation 15 Computing/IT: The NSRF should ensure the laptops issued to DROs have adequate battery life to be used away from a power source during data collection.
Integration of the NSHRI with other systems e.g. NCP (Study Objective 3)
<ul style="list-style-type: none"> • Recommendation 16 Overlaps between NSHRI & NCP data collection systems: There should be a single shared data collection system across the NSHRI and the HSE. If lead by the NSHRI team, it would free up nurse time and generate a richer, single data source. A meeting should be arranged between a group of CNS and Data Registration Officers and the strategic leaders of both teams to develop a way forward that optimises data quality, timeliness and comprehensiveness.
<ul style="list-style-type: none"> • Recommendation 17 Extending data collection: It would be useful for the NSHRI to record episodes of SH occurring in the community and managed by SCAN nurses. If this was possible this would be a valuable addition to the scope and evaluative potential of NSHRI.
<ul style="list-style-type: none"> • Recommendation 18 The NSHRI's research programme: The NSHRI / DBT teams might consider comparing areas with and without the DBT service or a before/ after evaluation.
Impact of NSHRI at an international level (Study Objective 5)
<ul style="list-style-type: none"> • Recommendation 19 The NSHRI's research programme: The NSRF should focus more on research questions addressing the impact, effectiveness and cost-effectiveness of major HSE / NOSP investments such as the SCAN nurses and the Clinical Care Programme. There are opportunities to use natural experimental designs to assess the impact of these programmes
<ul style="list-style-type: none"> • Recommendation 20 The NSHRI's research programme: To improve relevance of NSHRI's research programme & connectedness with services a regular (e.g. annual) meet between NSHRI lead, National Clinical Programme Lead, NOSP lead, SCAN nurse lead & liaison psych lead might be helpful.
Other recommendations
<ul style="list-style-type: none"> • Recommendation 21 Supporting clinical practice: As well as performing a surveillance function, NSHRI data could potentially be used to inform local clinical practice e.g. by identifying frequent attenders (those presenting 5+ times comprise 2% of patients, yet 10% of attendances). Such patients are often not recognised at the point of clinical contact as they may see a different person at each attendance. Specific "frequent attender plans" / treatment programmes could be developed for these patients proactively. Likewise high risk patients (e.g. those surviving a suicide attempt by drowning or hanging) who do not appear to have received an assessment could be identified and followed up more assertively.
<ul style="list-style-type: none"> • Recommendations 22 Extending data collection to people with suicidal thoughts: The NSHRI team has considered extending data collection to include patients presenting to hospital with suicidal thoughts. Such data are collected by Northern Ireland's Registry. There would be some value in extending data collection however this would have important resource implications and there would be challenges in developing a clear case definition (as the extent to which suicidal thoughts are recognised will depend on the extent to which they are elicited in a clinical assessment). A small pilot project to assess feasibility or close working with Northern Ireland's Registry would determine the value of extending data collection. It is the review teams view that the value of the NSHRI would be enhanced more by collecting a richer (and more accurate) dataset on patients who present following self-harm.
<ul style="list-style-type: none"> • Recommendation 23 Overlaps in service provision: Given the range and number of interventions/investments aimed at caring for people with suicidal thoughts or who had attempted suicide (e.g. SCAN nurses, Clinical Nurse Specialists, the DBT programme) the HSE should review the tapestry of service provision in this area.

Recommendations to be prioritised in the next 12 to 18 months