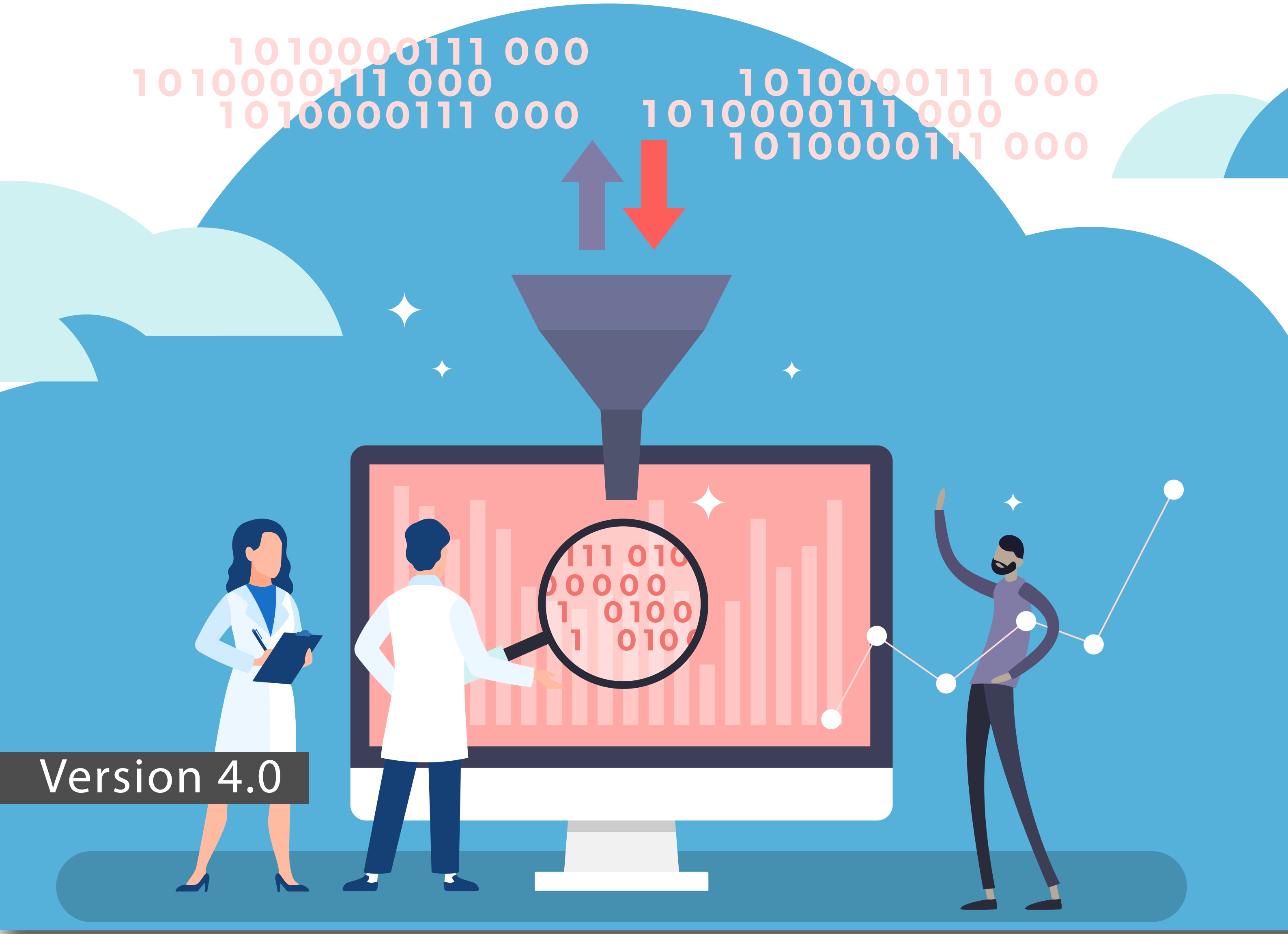
Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

CATALOGUE

NATIONAL DATA COLLECTIONS OF HEALTH AND SOCIAL CARE



Version 4.0

About the Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.

- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.

- **Regulating health services —** Regulating medical exposure to ionising radiation.

- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.

- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.

- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

Overview of the Health Information Function

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is, therefore, very important that information is managed in the most effective way possible in order to ensure a high-quality safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests — if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has an important role to play in healthcare planning decisions — where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under Section (8)(1)(k) of the Health Act 2007, (1) the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under Section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving its quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to promote quality and safety in health and social care settings is available when, and where, it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient’s general practitioner and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in health and social care services in Ireland is highly fragmented with major gaps and silos of information. This results in individuals being asked to provide the same information on multiple occasions.

In Ireland, information can be lost, documentation is poor, and there is an overreliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions.

Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions.

As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information in Ireland, based on standards and international best practice. A robust health information environment will allow all stakeholders — patients and service users, health professionals, policy-makers and the general public — to make choices or decisions based on the best available information. This is a fundamental requirement for a highly reliable healthcare system.

Through its health information function, HIQA is addressing these issues and working to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of services.

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Acknowledgments

The Health Information and Quality Authority would like to sincerely thank all organisations who assisted in compiling this fourth version of the *Catalogue of National Health and Social Care Data Collections* through completion of metadata templates to describe their national data collections.

Definitions

The following list provides an explanation of words and terms that have a particular meaning in the context of this document.

Census: a procedure of systematically acquiring and recording information about the members of a given population.

Clinical coding scheme: a comprehensive system which allows the recording, in a standardised manner, of all events or concepts that are found in a healthcare record. This allows comparison of events within and between records.

Data: the building blocks for information. It has been described as numbers, symbols, words, images and graphics that have been validated but yet to be organised or analysed.

Data dictionary: a descriptive list of names (also called representations or displays), definitions and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardise definitions and ensure consistency of use. It is a tool to aid in the standardisation of data definitions.

Data provider: any person, organisation, or part of an organisation contributing data to the national health or social care data collection, for example, a hospital, general practitioner (GP) or laboratory.

Data quality framework: a document which outlines the approaches to systematically assess, document and improve data quality and includes data quality policies and procedures; key performance indicators and metrics; audits; and improvement initiatives.

Data quality statement: a statement prepared to accompany all published outputs from the national health and social care data collection which highlights the dimensions of data quality, including strengths and weaknesses, so that potential data users can make informed judgments about fitness for use.

Data user: any stakeholder who uses data held by a health or social care organisation or any information outputs from the organisation.

Dataset: a dataset (or data set) is the data that is collected by the information collections. The data is usually presented in tabular form.

Disease classification system: a system for the standardised recording of different diseases. It allows for the translation of the words used for diagnoses, procedures and other medical problems into codes. This permits standardised recording, interpretation and comparison of data within and between healthcare organisations.

Equity stratifiers: Variables selected to reflect perceived inequalities in the population that is the subject of data collection, for example, place of residence, gender and religion.(1)

Health information: health information is defined as information, recorded in any form, which is created or communicated by an organisation or individual relating to the past, present or future physical or mental health or social care of an individual or group of individuals (also referred to as a cohort). Health information also includes information relating to the management of the health and social care system.

Information: information is data that has been processed or analysed to produce something useful.

Managing organisation: the organisation, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection. The term describes the variety of arrangements which are in place for a responsible body to govern, manage and organise national health and social care data collections in Ireland. This may not always be a formalised organisation or a body established on a statutory basis.

Metadata: metadata provides summary information in a structured way about the content of a resource such as a report, a book or a dataset. It can be defined as 'data to explain data'.

National health and social care data collections: national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries in Ireland.

Statement of information practices: a document made available to service users that sets out what information the service collects; how it is used; with whom it is shared and for what purpose; the safeguards that are in place to protect it; and how service users can access information held about them.

Statement of purpose: a publicly available document which succinctly captures why the national health and social care data collection exists and clearly outlines its overall function and stated objectives. It may also outline the name of the managing organisation and governance arrangements, the year of commencement, the target population, funding arrangements and legislation that it must adhere to.

Survey: is an investigation about the characteristics of a given population by means of collecting data from a sample of that population and estimating their characteristics through the systematic use of statistical methodology.

Part 1. Introduction

1 Background

1.1 National data collections

National data collections (NDCs) are national repositories of routinely collected health and social care data in Ireland. NDCs play a vital role by providing a national overview of a particular health or social care-related issue or service. The collection, use and sharing of health information is crucial to providing direct care to people using health and social care services; it is therefore essential that data is of a high quality and used to its full potential.(2) The secondary use of sharing health information, or uses beyond direct care, is also of great importance in driving improvements in health and social care systems. This relates to information collected for individual care being shared and used for other purposes. These other purposes may include the planning and management of health and social care services, the evaluation and improvement of services, and policy development and research.(2)

As evident from this catalogue, from a governance perspective, the management of NDCs in Ireland's health information landscape is currently complex. A number of managing organisations are responsible for the collection and storage of these datasets, including the HSE, Government departments, and independent organisations outside of the HSE, such as the National Office of Clinical Audit (NOCA), and the Health Research Board (HRB).(2)

The importance of high-quality health information has been outlined in recently published national strategy documents. In particular, the Sláintecare Implementation Strategy emphasises the importance of access to timely, relevant and high-quality data sources in ensuring the success of Ireland's Sláintecare programme.(3) Ultimately, the delivery of Ireland's health and social care services will be underpinned by a robust approach to data collection, analysis and management.(3)

1.2 Information management standards

HIQA's *Information management standards for national health and social care data collections*(4) are being revised and will be published in 2023. The standards aim to provide a roadmap for organisations to improve the quality of national health information and data, which will ultimately contribute to the delivery of safe and reliable healthcare. The primary objective of the standards is to improve information management practices at all levels within health and social care services including: service providers; national data collections; and at the level of the organisations with overarching responsibility for governance of information management, including the HSE and Tusla. In 2017, HIQA also commenced a review programme(5) to assess organisations against the standards.

1.3 Legislation

Recently enacted and forthcoming European-level legislation in relation to health information underlines the importance of data protection for individuals whose data is held and processed by organisations including those within the Irish health system. Such legislation includes the General Data Protection Regulation (GDPR), which forms the basis of Ireland's Data Protection Laws collectively recognised as the Data Protection Acts 1988-2018.(6) Forthcoming legislative change in Europe includes the enactment of the *Data Act* and *Data Governance Act*. These Acts will have a significant impact on the use and sharing of health data in Ireland, and are relevant to those organisations that access and use health data and information, including the organisations that manage the collections listed in this catalogue.

1.4 Current developments in health information in Ireland and Europe

Currently in Ireland, work is being undertaken to develop new Health Information Legislation following Cabinet approval to develop the general scheme of a Health Information Bill. The forthcoming Bill will inform a 'fit for purpose' health information system in Ireland, that strengthens the delivery of healthcare to patients and reinforces better planning and delivery of services.(7) The Bill will also support the development of a National Health Information Centre, with an overarching goal to strive for better outcomes for patients by setting out functions and governance rules regarding the collection and processing of health information for primary and secondary use purposes.(7)

In addition to the development of legislation, there are several initiatives currently underway in Ireland aimed at driving improvements in health information.(8) As part of Ireland's recent Public Service Data Strategy 2019-2023, the Government has developed the Public Service Data Catalogue, with an overall goal to promote more openness and greater transparency around the different data managed by the public service.(9) The expansion of the Integrated Information Service (IIS) in response to the COVID-19 pandemic is another recent development that highlights the importance of access to reliable health data and information.(10) In addition, the recently developed Health System Performance Assessment Framework underlines the importance of access to reliable data in order to ensure the effectiveness of this new approach to assessing the performance of Ireland's health system. There are also projects currently being developed and rolled out in the area of health information, such as: the HSE's health and social care data dictionary;(11) and a proof of concept for a technical infrastructure to support access, sharing, storage and linkage of health data known as DASSL (Data Access Storage Sharing and Linkage).(12)

At a European level, work is underway for the creation of an EU-wide data sharing platform known as the European Health Data Space (EHDS) which will encourage international data sharing to support healthcare delivery, as well as the use of data for secondary purposes, such as health research and policy-making.(13) In order to progress the development of this platform, the Towards a European Health Data Space (TEHDAS) project has been established. The TEHDAS project aims to help EU member states and the European Commission to develop principles for the secondary use of health data in order to improve public health and health research and innovation in Europe.(14) As part of its recommendations for ensuring data quality in the EHDS for the secondary use of data, the recent TEHDAS Joint Action report recommends that member states be obliged to publish their data preparation procedures, as well as metadata for their collections.(15)

Considerable time, effort and resources have been invested into establishing and running high-quality data collections in Ireland. Thus, the use of this data needs to be promoted to maximise its benefit for the population it serves. Furthermore, timely access to relevant and accurate data improves the quality of health and social care by informing decision-making, service planning, policy-making and high-quality research. It is therefore essential to drive, encourage and facilitate the use of this data.

1.5 Aim of catalogue

The aim of this fourth version of the catalogue is to enable all stakeholders (including the general public, people who use health and social care services, clinicians, researchers, and healthcare providers) to readily access information about health and social care data collections in Ireland. By providing this information, this catalogue aims to promote the maximum use of existing national data collections in order to drive improvements in the quality and safety of our health and social care services in Ireland. The COVID-19 pandemic has highlighted the important role that high-quality data plays in the delivery of care. In response to the public health emergency, several new national data collections have been established. These new collections are included in this revision of the catalogue along with a number of other newly identified collections.

2 Methodology

The following sections will outline the methodology used to update the catalogue.

2.1 Key definitions

The following definitions are used for this catalogue:

➢ **National health and social care data collections**

National collections of routine health and social care data (including administrative collections, censuses, national routine surveys, and patient registries) currently collected in Ireland. An example is the Hospital In-Patient Enquiry scheme (HIPE).

➢ **Managing organisation**

The organisation, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection. The term describes the variety of arrangements which are in place for a responsible body to govern, manage and organise national health and social care data collections in Ireland. This may not always be a formalised organisation or a body established on a statutory basis. An example is the Health Research Board (HRB) which is the managing organisation of the National Ability Supports System.

2.2 Update of metadata template

2.2.1 Desktop review

As part of this revision of the catalogue, the metadata template has been updated to include new fields, amend some and remove others. This update was based on the findings from a review of the Dublin Core Metadata Initiative’s Metadata Terms, and a review of metadata templates for health and social care data collections in use in other jurisdictions, carried out by HIQA.

Metadata templates in the following jurisdictions were selected for review based on the availability of information and evidence:

- Australia – Australian Institute of Health and Welfare (AIHW)
- Canada – Canadian Institute for Health Information (CIHI)
- New Zealand – New Zealand Ministry of Health
- Scotland – Public Health Scotland.

The findings of the review of the DCMI’s Metadata Terms and the review of metadata templates for data collections in other jurisdictions highlighted relevant elements or specifications that were considered in the update of HIQA's metadata template.

Based on the findings of the review, the metadata template was updated to capture the following information in additional or amended fields: scope; temporal coverage; data users; national-level identifier variables; and frequency of data collection. The previous template included the field 'data providers', which has now been replaced by 'data users'.

Three of the jurisdictions included in the review included a section on 'scope' and 'frequency of data collection' in their metadata, while all jurisdictions provided for 'temporal coverage'. However, temporal coverage was captured under a variety of headings, generally capturing a specific period of time or date range.

'Audience' and 'unique identifiers', were less common elements across the metadata reviewed in the four international jurisdictions, but were considered to be relevant for inclusion in HIQA's revised template. These elements were therefore included under 'data users' and 'national-level identifier variables'.

2.2.2 Addition of equity stratifiers

The previous version of the metadata template requested data collections to include their data dictionaries, if available. In addition to this field, data collections were also requested to list the equity stratifiers included in their dataset as part of the updated metadata template. Generally, health inequalities refer to differences in health outcomes between population groups.(1) In order to understand and tackle health inequalities, it is important to both recognise and measure them.(1)

Equity stratifiers may be defined as specific variables selected to reflect a perceived inequality, for example, place of residence, gender and religion. They are often used to measure and monitor inequalities through comparing aggregate data on groups of people.(1) PROGRESS-Plus(16) was included in the template as a guide to assist managing organisations in identifying those equity stratifiers present in their data collection. The tool summarises the equity stratifiers most frequently used when measuring health inequalities. It is important to note that PROGRESS-Plus does not provide a fully comprehensive list of equity stratifiers; equity stratifiers should be chosen dependent on the social and cultural context.(1)

Ninety-four data collections included one or more equity stratifiers in their dataset.

2.2.3 Updated template

HIQA's updated metadata template can be found in Table 1. New and amended fields are marked by an asterisk.

Table 1. Summary template for description of national data collections

Field name	Description
Title	Official name of the national data collection.
Managing Organisation	The organisation, agency, responsible managing unit, institution or group with overall responsibility for the national data collection.
Web address	Website address (URL) of the national data collection.
Year established	Year the national data collection was established.
Statement of Purpose	The overall purpose and objective of the data collection. *Please include 'in scope' and 'out of scope'.
Coverage ***(geographical and temporal)**	Geographical coverage of the national data collection, for example, national/regional. *Temporal coverage of the national data collection, for example, data collection start and finish dates.
Description/ Summary	General description of the national data collection.
***Data users**	Who are the key users of this data collection? Please include a list of these.
Data content	Summary of the categories of information collected (for example, patient demographics, diagnoses, treatments, procedures, laboratory investigations, hospital admissions, outcomes and so on).
Data dictionary	Is a data dictionary in place defining the data elements within this national data collection? If yes, please provide URL link to current data dictionary if it is available online.
***National-level identifier variables**[1]	Are national-level identifier variables (for example, PPSN, IHI) included in this national data collection?
***Equity stratifiers**	Are equity stratifiers included within the dataset (for example, Place of residence, Race, Occupation, Gender, Religion, Education, Socioeconomic status, Social capital)? If yes, please include a list of these.
Data collection methodology	Describe how the data is provided to the national collection. *Include frequency of data collection, for example, quarterly basis, annual basis.
Clinical coding scheme	What clinical coding/ disease classification scheme is in place (if any)?
Size of national collection	What is the average number of records created in the national collection annually?
Publication frequency	How often is data published?

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[1] This field does not apply to collated sources of health and social care information as outlined in section 8 and 9 of this Catalogue and hence excluded from templates in these sections.

Field name	Description
Accessing data	How can data from the national collection be accessed? If available online, please provide URL link to data request form.
Open Data portal access	Is data from the national collection available via Ireland's Open Data Portal (https://data.gov.ie/)?
Generic email contact	Please provide a generic contact email for the national collection.
Generic telephone contact	Please provide a generic contact telephone number for the national collection.
Other comments	Please add any additional comments in relation to the national collection.

*new or amended fields

2.3 Engagement with managing organisations

In order to update the catalogue, the managing organisations of all national data collections included in the previous version of the catalogue were contacted by HIQA and requested to update a summary metadata template to provide a standardised description of their national data collection. HIQA also identified and contacted new collections for potential inclusion in this updated version of the catalogue. To ensure the completeness and accuracy of the data provided, the data was reviewed and validated by the data providers.

2.4 Selection of data collections for inclusion

To meet the definition of national data collections for inclusion in this catalogue, the national data collection had to have national coverage and be currently collecting data. Data collections with regional coverage were also included where they were considered of national importance. These regional collections are grouped separately (see section 5). Some collections are no longer collecting data or in operation (please see section 2.5.3) and were therefore removed since the previous version of the catalogue. Others requested that they be removed in this update of the catalogue. In addition, E-health and other clinical management systems such as NIMIS (National Integrated Medical Imaging System) are out of scope. New data collections were also identified through engagement with managing organisations during the development of this version of the catalogue and have been included (please see section 2.5.1). Others are summarised as being in development (please see section 2.5.2).

2.4.1 Categorisation of data collections

Data collections and collated sources of information selected for inclusion were categorised as follows:

- **National data collections** such as the Hospital In-Patient Enquiry (HIPE) (section 4).
- **Data collections with regional coverage** such as the Coronary Heart Attack Ireland Register (CHAIR) (section 5).
- **Censuses**, for instance, the Census of Population and other population data (section 6).
- **Surveys**, for example, The Irish Longitudinal study on Ageing (TILDA) (section 7).
- **National performance and activity reports**[2] such as performance reports produced by the Health Service Executive (HSE) and Child and Family Agency (Tusla) (section 8).
- **Additional collated sources of health information (national and international)**[3] for example, State of the Nations Children collates data from a number of sources including the Census of Population and other population data and HIPE (section 9).

2.5 Updates since Version 3.0 of the Catalogue was published

2.5.1 New data collections

Since the last revision of the catalogue,(17) a number of new data collections have been identified (see Table 2). For example, the National Office of Clinical Audit (NOCA) has established three new clinical audits.

Some national data collections have replaced older collections; for example, The National Ability Supports System has replaced the National Physical and Sensory Disability Database and the National Intellectual Disability Database. The following is a list of data collections that are new to the catalogue.

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[2] 'National performance and activity reports' are systems that pool aggregate data, to produce datasets on key performance indicators (KPIs) to monitor and report on the performance and activity of services.

[3] 'Additional collated sources of health information' are defined as systems that pool aggregated data from a number of existing national data collections.

Additional data collections were identified, but are not included in this version of the catalogue (see Table 3).

Table 2. New data collections identified since Version 3.0 of the *Catalogue of national health and social care data collections*

Managing organisation	National data collection
Central Statistics Office (CSO)	COVID-19 Data Research Hub
Central Statistics Office (CSO)	Irish Health Survey
Health Information and Quality Authority (HIQA)	Irish Database of Statutory Notifications from Social Care
Health Information and Quality Authority (HIQA)/Health Service Executive (HSE)/ Department of Health	National Inpatient Experience Survey
Health Information and Quality Authority (HIQA)/ Health Service Executive (HSE)/ Department of Health	National Maternity Experience Survey
Health Protection Surveillance Centre (HPSC)	Surveilllance of Severe Acute Respiratory Infections (SARI)
Health Protection Surveillance Centre – Seroepidemiology Unit (SEU)	National Serosurveillance Programme (NSP)
Health Research Board (HRB) – Evidence Centre	2019–20 Irish National Drug and Alcohol Survey
Health Research Board (HRB) – National Health Information Systems Unit/HSE	National Ability Supports System (NASS)
Health Safety Authority (HSA)	Work Related Fatal and Non-Fatal Incident Database [4]
HSE – Health Identifiers Service	Health Directory
HSE – Health Identifiers Service	National Register of Individual Health Identifiers
HSE – Office of the Chief Clinical Officer	COVAX: National COVID-19 Immunisation System
HSE – Planning, Performance and Business Information Unit	HSE Performance Reports- National Screening Services [5]
HSE – Planning, Performance and Business Information Unit	HSE Performance Reports- Palliative Care [6]

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[4] Previously the 'Work-Related Injuries Database', this collection incorporates both work-related fatal and non-fatal incidents.
[5] Moved from Health and Wellbeing to new template.
[6] Moved from Primary Care to new template.

Managing organisation	National data collection
HSE – Planning, Performance and Business Information Unit	HSE Performance Reports- Primary Care Reimbursement Service [7]
Irish Prostate Cancer Outcomes (IPCOR)	Irish Prostate Cancer Outcomes Research (IPCOR)
National and International Skin Registry Solutions CLG (NISR)	Irish Epidermolysis Bullosa (EB) Registry
National Office of Clinical Audit (NOCA)	Irish Heart Attack Audit (IHAA) [8]
National Office of Clinical Audit (NOCA)	Irish National Audit of Stroke (INAS)
National Office of Clinical Audit (NOCA)	Irish Paediatric Critical Care Audit (IPCCA)
National Office of Clinical Audit (NOCA)	Intensive Care Unit - Bed Information System (ICU-BIS)
National Perinatal Epidemiology Centre (NPEC) UCC	Neonatal Therapeutic Hypothermia Audit
National Perinatal Epidemiology Centre (NPEC) UCC	National Maternity data- Robson Ten Groups Classification system (TGCS)

Table 3. Additional data collections identified but not included in this catalogue

Managing organisation	National data collection
HSE – Office of the Chief Information Officer	COVID Care-Tracker (CCT)
HSE – Office of the Chief Information Officer	COVID Tracker App
Central Statistics Office (CSO)	COVID-19 Information Hub

2.5.2 Data collections in development

A number of national health and social care collections were not included in this catalogue because they are either still in development or not fully operational (see Table 3). For example, the National Care Experience Programme currently has three further surveys in development. Data collections identified as being in development are outlined in Table 4.

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[7] Moved from Primary Care to new template.
[8] Previously Heartbeat Portal.

Table 4. Data collections currently in development and not included in this catalogue

Managing organisation	National data collection
Health Information and Quality Authority (HIQA)/Health Service Executive (HSE)/Department of Health	National End of Life Survey
Health Information and Quality Authority (HIQA)/Health Service Executive (HSE)/Department of Health	National Maternity Bereavement Experience Survey
Health Information and Quality Authority (HIQA)/Health Service Executive (HSE)/Department of Health	National Nursing Home Experience Survey
Institute of Public Health (IPH)	The Public Health Data Centre[9]
National and International Skin Registry Solutions CLG (NISRS)	The Irish Atopic Eczema Systemic Therapy Register
National and International Skin Registry Solutions CLG (NISRS)	Global Registry of Alopecia Areata Disease Severity and Treatment Safety- GRASS Ireland

2.5.3 Data collections removed from the catalogue

Some data collections have been removed from this version of the catalogue as they are either no longer operational, or are not currently collecting data. For example, SLÁN – Survey of Lifestyle, Attitudes, and Nutrition is no longer operational. The Eastern Area Cerebral Palsy Register is currently dormant, and therefore, not currently collecting data. Table 5 identifies those data collections that have been removed from this version of the catalogue and the reason why.

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[9] This is an expanded and renamed version of Community Profile Tools data collection.

Table 5. Data collections excluded from Version 4.0 of the Catalogue

Managing organisation	National data collection	Status
Central Remedial Clinic (CRC)	Eastern Area Cerebral Palsy Register	Not currently collecting data
Central Statistics Office (CSO)	Ageing in Ireland	Discontinued
Central Statistics Office (CSO)	QNHS — Quarterly National Household Survey — Health Module [10]	Replaced by Labour Force Survey (LFS)
Department of Health	SLÁN – Survey of Lifestyle, Attitudes, and Nutrition	Discontinued
Department of Social Protection	Statistical Information on Social Welfare Services	Out of scope for current catalogue
Epilepsy Ireland	Irish Epilepsy and Pregnancy Register	Not currently collecting data
Health Protection Surveillance Centre (HPSC)	Influenza Surveillance – Critical Care Units	Discontinued
Health Protection Surveillance Centre (HPSC)	National Ano-Genital Warts database	Discontinued
Health Research Board (HRB)/Department of Health	National Intellectual Disability Database (NIDD)	Replaced by the National Ability Supports System (NASS)
Health Research Board (HRB)/Department of Health	National Physical and Sensory Disability Database (NPSDD)	Replaced by the National Ability Supports System (NASS)
HSE- Health & Wellbeing Division, Health Intelligence Unit and EUROCAT	EUROCAT European Registries of Congenital Anomalies (EUROCAT East)	Not currently collecting data
Institute of Public Health (IPH)	Community Profile Tools	Currently being expanded and renamed as Public Health Data Centre

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[10] The Labour Force Survey (LFS) has replaced the Quarterly National Household Survey (QNHS) and does not include a health module.

Institute of Public Health (IPH)	The Health Well	Discontinued
Pre-Hospital Emergency Care Council (PHECC)	Patient Transport Report (PTR)	Discontinued

3 Summary analysis of national health and social care data collections within this catalogue

This version of the catalogue includes 128 data collections and collated sources of information, which are grouped into the following sub-categories:

Catalogue of national health and social care data collections in Ireland (Part 2)

- national data collections (n=84)
- data collections with regional coverage (n=7)
- national censuses (n=3)
- national surveys (n=11)

Collated sources of health and social care information (Part 3)

- national performance and activity reports (n=10)
- additional collated sources of health information – national (n=9)
- additional collated sources of health information – international (n=4)

The collections are listed in alphabetical order within each category and there is also an index at the end of the document for ease of use.

Efforts were made to contact all of the managing organisations included in the previous version of the catalogue, as well as the data providers of newly identified data collections. However, no response was received from three managing organisations. Where no response was received but the collection continues to collect data, it was decided to include templates previously submitted by the managing organisation in question. The templates describing these collections are clearly identified.

HIQA has attempted to provide a comprehensive list of all national health and social care data collections currently in existence in 2022. However, it is possible that not all data collections have been identified.

Please note that the data collated within these metadata templates have been provided by the managing organisations of the national data collections.

Part 2. National health and social care data collections in Ireland

4 National health and social care data collections in Ireland

- Acute Flaccid Paralysis (AFP) surveillance
- Administration of Electro-convulsive Therapy (ECT) in approved centres
- Admissions of Children to Approved Centres
- Alcohol Hand Rub Consumption Surveillance
- Alpha One Foundation Registry
- Ambulatory Care Report (ACR)
- Blood Donor Database
- BowelScreen (The National Bowel Screening Programme)
- BreastCheck (The National Breast Screening Programme)
- Cardiac First Response (CFR) Report
- Central Treatment List (CTL)
- CervicalCheck (The National Cervical Screening Programme)
- Cleft Database
- *Clostridioides difficile* infection enhanced surveillance
- Computerised Infectious Disease Reporting (CIDR) system
- COVAX: National COVID-19 Immunisation System
- Cystic Fibrosis Registry of Ireland
- Deaths relating to all residents in Approved Centres and Community Mental Health Centres
- Diabetic RetinaScreen (The National Diabetic Retinal Screening Programme)
- Enhanced Bacteraemia (bloodstream infections) Surveillance in Ireland
- Hand Hygiene Compliance Monitoring
- Health Directory
- Heart Rhythm Ireland (Irish National Pacemaker Register)
- HIV Antenatal Testing
- Hospital In-Patient Enquiry (HIPE)
- Immunisation uptake statistics at 12 and 24 months of age
- Influenza Immunization Uptake Statistics among health care workers
- Intensive Care Unit - Bed Information System (ICU-BIS)
- Involuntary Admission Activity (Adults)*
- Irish Biologic Therapies Register*
- Irish Childhood Diabetes National Register (ICDNR)
- Irish Database of Statutory Notifications from Social Care
- Irish Epidermolysis Bullosa (EB) Registry
- Irish Heart Attack Audit (IHAA)
- Irish Hip Fracture Database (IHFD)
- Irish Motor Neurone Disease Register
- Irish National Audit of Stroke (INAS)
- Irish National Intensive Care Unit (ICU) Audit

- Irish National Orthopaedic Register (INOR)
- Irish National Rare Kidney Disease Registry
- Irish Paediatric Critical Care Audit (IPCCA)
- Irish Prostate Cancer Outcomes Research (IPCOR)
- Irish Thoracic Society Interstitial Lung Disease Registry
- Irish Unrelated Bone Marrow Registry (IUBMR)
- Major Trauma Audit (MTA)
- National Ability Supports System (NASS)
- National Antimicrobial Resistance Surveillance (EARS-Net Ireland)
- National Audit of Hospital Mortality (NAHM)
- National Audit of Severe Maternal Morbidity
- National Cancer Registry Ireland (NCRI)
- National Drug Treatment Reporting System (NDTRS)
- National Drug-Related Deaths Index (NDRDI)
- National Haemophilia Register
- National Hepatitis C Database
- National Incident Management System (NIMS)
- National Maternity data- Robson Ten Groups Classification system (TGCS)
- National Oncology Drug Management System
- National Organ Procurement Service Data
- National Paediatric Mortality Register (NPMR)
- National Perinatal Reporting System (NPRS)
- National Poisons Information Centre Database (NPIC)
- National Psychiatric Inpatient Reporting System (NPIRS)
- National Register of Individual Health Identifiers
- National Renal Transplant Registry
- National School Immunisation System: SIS
- National Self-Harm Registry Ireland (NSHRI)
- National Serosurveillance Programme (NSP)
- National Spinal Injuries Unit
- Neonatal Therapeutic Hypothermia Audit
- Out of Hospital Cardiac Arrest Register (OHCAR)
- Patient Care Report (PCR)
- Patient Treatment Register (PTR)
- Perinatal Mortality National Clinical Audit
- Planned Home Births in Ireland Audit
- Primary Care Reimbursement Service (PCRS)
- Road Fatalities and Injury Collision Statistics
- Sentinel GP Respiratory Infections Surveillance
- Surveillance of antimicrobial consumption in Ireland
- Surveilllance of Severe Acute Respiratory Infections (SARI)

- Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres
- Very Low Birth Weight Infants in the Republic of Ireland
- Vital Statistics — Deaths Registration
- Vital Statistics — Live Births Registration
- Work Related Fatal and Non- Fatal Injuries Database.

4.1 Acute flaccid Paralysis (AFP) surveillance

Title	**Acute flaccid Paralysis (AFP) surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/vaccinepreventable/polio/acuteflaccidparalysisafp/
Year established	1998.
Statement of Purpose	In Scope: To provide information on children aged less than 15 years of age presenting to Irish hospitals with acute flaccid paralysis. This information is used to ensure that all AFP cases in children are adequately investigated and to out-rule polio as a cause of the paralysis – this is in line with WHO recommendations that all countries should heighten surveillance to ensure that no polio cases are undetected.
Coverage **(geographical and temporal)**	Children aged less than 15 years of age from all regions of the country. Case surveillance is monitored on on-going, annual basis.
Description/ Summary	HPSC communicates regularly with each paediatric hospital /unit to request and remind clinicians on the need to report all AFP cases in children aged less than 15 years of age. The completed forms are sent to HPSC. Anonymised copies are then subsequently forwarded to the NVRL. HPSC collates the data each year and usually reports to the National Polio elimination Committee. A report may also be provided on the HPSC website and in the Epi-Insight monthly newsletter issued by the HPSC. (Note in 2021, two cases of APF cases were reported with no final diagnosis and no enhanced surveillance forms completed).
Data users	WHO (https://eapr.euro.who.int/)
Data content	Case based data (anonymised) with clinical details of onset of paralysis, part of body affected, laboratory and radiological tests undertaken and results, polio vaccination history and outcome.

Title	**Acute flaccid Paralysis (AFP) surveillance**
Data dictionary	Not available.
National-level identifier variables	No (DOB and patient initials maybe collected initially when case is reported, but these details removed from the HPSC database after a period of time once an annual electronic report is submitted online to WHO at https://eapr.euro.who.int/)
Equity stratifiers	Among the equity stratifiers collected on each case are county of residence, gender and ethnicity.
Data collection methodology	Preliminary data is collected whenever a new case is reported and later, a surveillance form is completed by the relevant hospital which is then faxed or emailed to HPSC where the details are entered into an Access database.
Clinical coding scheme	Not in use.
Size of national collection	6 - 8 average number of records created annually. (Note: Much fewer cases have been reported in recent years (2020, 2021) on account of the COVID-19 pandemic with fewer enhanced surveillance forms completed).
Publication frequency	Annual summary figures are published on the HPSC website http://www.hpsc.ie/A-Z/VaccinePreventable/Polio/AcuteFlaccidParalysisAFP/
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300
Other comments	AFP data in children aged less than 15 years of age is voluntary. It is estimated that there should be about 10-11 cases of AFP occurring in children aged less than 15 years of age each year. Under-reporting is likely in view of the normal reporting rate of between 6-8 cases per year or less.

coimisiún meabhair - shláinte
mental health commission

4.2 Administration of Electro-convulsive Therapy (ECT) in Approved Centres

Title	**Administration of Electro-convulsive Therapy (ECT) in approved Centres**
Managing Organisation	Mental Health Commission (MHC) - Standards and Quality Assurance Division.
Web address	http://www.mhcirl.ie/
Year established	2008.
Statement of Purpose	The Commission was established in 2002. They are an independent body and their functions are set out by law in the Mental Health Act 2001. Their main functions are to promote, encourage and foster high standards and good practices in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted. The Mental Health Commission is responsible for regulating and monitoring mental health services. Data on the administration of ECT are collected in accordance with provisions in the following: ▪ Code of Practice on use of Electro-convulsive Therapy for Voluntary Patients (MHC, 2009) ▪ Mental Health Act 2001 ▪ Quality Framework for Mental Health Services in Ireland (MHC, 2009) ▪ Rules Governing the use of Electro-convulsive Therapy (MHC, 2009). Data are processed in adherence with the following legislation: ▪ Data Protection Act 2018 ▪ Data Protection (Amendment) Act 2003 ▪ Data Protection Act 1988 ▪ Freedom of Information (Amendment) Act 2003 ▪ Freedom of Information Act 1997. Data within scope is data relating to the carrying out of treatments nationally. Data that does not relate to this is out of scope.
Coverage **(geographical and temporal)**	National: All approved centres that administer ECT or refer a person to another approved centre for ECT treatment. Collection started 01/01/2008 and is ongoing.

Title	**Administration of Electro-convulsive Therapy (ECT) in approved Centres**
Description/ Summary	MHC collects demographic and clinical data in relation to the administration of ECT in approved centres nationally.
Data users	MHC Staff - Corporate Team Regulatory Team Inspectorate Team Tribunals Team.
Data content	Service user initials; gender; date of birth; legal status; information regarding the programme of ECT.
Data dictionary	Yes, not online.
National-level identifier variables	Services are requested to provide unique service identifiers.
Equity stratifiers	Yes - Gender.
Data collection methodology	Data are extracted from registers in approved centres and submitted on a secure online system by clinicians or administrative staff with an individual user account. The secure online system is operated by MHC staff who also have individual user accounts. Data collection occurs when information is submitted to MHC by clinicians or administrative staff in approved centres. Staff in approved centres are required to submit this data within 7 days of the completion of the ECT programme.
Clinical coding scheme	ICD-10.
Size of national collection	350 average records created annually.
Publication frequency	Annual activity reports published on MHC website.
Accessing data	Annual reports – Administration of ECT in approved centres activity report and data requests.
Open Data portal access	No.
Generic email contact	info@mhcirl.ie
Generic telephone contact	+353 1 6362400

4.3 Admissions of Children to Approved Centres

Title	**Admissions of Children to Approved Centres**
Managing Organisation	Mental Health Commission (MHC) - Standards and Quality Assurance Division.
Web address	http://www.mhcirl.ie/
Year established	2006.
Statement of Purpose	The Commission was established in 2002. They are an independent body and their functions are set out by law in the Mental Health Act 2001. Their main functions are to promote, encourage and foster high standards and good practices in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted. The Mental Health Commission is responsible for regulating and monitoring mental health services. Data on the admission of children to approved centres are collected in accordance with provisions in the following: ▪ Code of Practice on the Admission of Children to Approved Centres (MHC, 2006) and Addendum to the Code (MHC, 2009), ▪ Mental Health Act 2001 ▪ Quality Framework for Mental Health Services in Ireland (MHC, 2009). Data are processed in adherence with the following legislation: ▪ Data Protection Act 2018 ▪ Data Protection (Amendment) Act 2003 ▪ Data Protection Act 1988 ▪ Freedom of Information (Amendment) Act 2003 ▪ Freedom of Information Act 1997. Data within scope is data relating to the carrying out of treatments nationally. Data that does not relate to this is out of scope.
Coverage (geographical and temporal)	National – all approved centres that admit children. Collection started 01/11/2006 and is ongoing.

Title	**Admissions of Children to Approved Centres**
Description/ Summary	Admissions of children to Approved Centres are notified to the Mental Health Commission. "Child" means a person under the age of 18 years other than a person who is or has been married; Section 25 Mental Health Act 2001.
Data users	MHC Staff - Corporate Team Regulatory Team Inspectorate Team Tribunals Team.
Data content	Child ID; date of birth; gender; date of admission; legal status on admission; date of discharge; legal status at discharge.
Data dictionary	Yes, not online.
National-level identifier variables	Services are requested to provide unique service identifiers.
Equity stratifiers	Yes - Gender.
Data collection methodology	Data are extracted from medical charts or records in approved centres and submitted on a secure online system by clinicians or administrative with an individual user account. The secure online system is operated by MHC staff who also have individual user accounts. Data collection occurs when information is submitted to MHC by clinicians or administrative staff in approved centres. Staff in approved centres are required to submit this data within 7 days of admission to an approved centre and within 72 hours of discharge from an approved centre.
Clinical coding scheme	Not in use.
Size of national collection	450 average number of records created annually.
Publication frequency	Annual reports since 2006.
Accessing data	MHC annual reports and data requests.
Open Data portal access	No.
Generic email contact	info@mhcirl.ie
Generic telephone contact	+353 1 6362400

4.4 Alcohol Hand Rub Consumption Surveillance

Title	**Alcohol Hand Rub Consumption Surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/infectioncontrolandhai/handhygiene/alcoholhandrubconsumptionsurveillance/
Year established	2011.
Statement of Purpose	In scope: To support overall multi-faceted strategy for the control and prevention of infectious diseases by providing standardised measure of alcohol hand gel consumption for acute hospitals.
Coverage **(geographical and temporal)**	32 acute hospitals regularly contribute to the data.
Description/ Summary	Surveillance of consumption of alcohol-based hand washing gels in acute hospitals. Data from entire facility in litres per each quarter supplied to HPSC. Results as rates, expressed as litre per 1000 Bed-days used per hospital are published quarterly.
Data users	Infection control teams in acute hospitals.
Data content	Completed MS Excel sheet of products used, quantity and any additional information.
Data dictionary	Not available.
National-level identifier variables	Not applicable.
Equity stratifiers	Not applicable.
Data collection methodology	Infection prevention and control staff, pharmacists or stores managers provide data on a quarterly basis, of the total amount of alcohol had rub used in litres. An MS Excel template is used for data entry. HPSC provide rates in litres per 1000 bed-days used.

Title	**Alcohol Hand Rub Consumption Surveillance**
Clinical coding scheme	N/A.
Size of national collection	Approx 130 records created for the numerator data annually.
Publication frequency	Bi-annual and annual reports published and available on HPSC website, www.hpsc.ie .
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.5 Alpha One Foundation Registry

Title	**Alpha One Foundation Registry**
Managing Organisation	Alpha One Foundation.
Web address	https://www.alpha1.ie/irish-alpha-1-registry/
Year established	2005.
Statement of Purpose	The purpose of the register is to: In scope: ▪ to establish a database of patients and their clinical details, ▪ to promote basic and clinical research into AATD and coordinate this activity ▪ to collect, assess and disseminate information concerning all aspects of AATD ▪ to encourage and support awareness of AATD. Out of Scope: ▪ Mailing Lists.
Coverage **(geographical and temporal)**	Ireland - 32 counties– all Alpha-1 patients attending National Alpha-1 Outpatient Clinic in Beaumont Hospital. Start Date – 2005. No End Date.
Description/ Summary	The Alpha One Foundation was established in 2001 to promote research into Alpha-1, to improve diagnosis, treatment and to improve life expectancy and lifestyle of people with this condition. In 2004 the National Targeted Detection Programme for AATD, funded by the Department of Health, was launched by the Foundation in Beaumont Hospital, providing free testing to persons with chronic pulmonary conditions and also relatives of persons with AATD. The national Alpha-1 registry was launched in 2005 to track the health of people with Alpha-1 Antitrypsin Deficiency across Ireland. Information in the registry helps clinicians and researchers see new

Title	Alpha One Foundation Registry
	trends, design clinical trials to test new therapies and improve the delivery of care for people with AATD.
Data users	Medical and Research Teams.
Data content	Height, weight, gender, phenotype/genotype, pulmonary function test results, liver function tests, hospitalisations, and complications related to lung and liver manifestations of AATD.
Data dictionary	Not available.
National-level identifier variables	No.
Equity stratifiers	Place of residence, ethnicity, occupation, gender.
Data collection methodology	Data is collected weekly in the National Alpha-1 Outpatient Clinic in Beaumont Hospital from patients' medical charts and information provided by patients themselves. Annual assessment of all enrolees takes place. The registry is part of a research study and is confidential. Written consent is gained from patients as part of ethical approval to collect and analyse data. Participation is voluntary.
Clinical coding scheme	Not in use.
Size of national collection	50 records created on average annually.
Publication frequency	Data is published in the Alpha One Foundation annual report.
Accessing data	Annual report and data requests.
Open Data portal access	No.
Generic email contact	alpha1@rcsi.ie
Generic telephone contact	+353 1 8093749

4.6 Ambulatory Care Report (ACR)

Title	**Ambulatory Care Report (ACR)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC).
Web address	https://www.phecit.ie/
Year established	2014.
Statement of Purpose	To collect event data on the patient who primarily requires first-aid and capture of data if additional care is required. This will: 1. Facilitate strategic planning primarily for voluntary and auxiliary organisations. 2. Provide a link in the continuum of patient care across all voluntary and auxiliary organisations in the event of patient handover to another licensed CPG provider. 3. Provide a platform for clinical audit. 4. Inform research into new skill, services/equipment.
Coverage **(geographical and temporal)**	National coverage at all events which have medical cover provided by responders/practitioners, on contract or volunteering on behalf of a licensed CPG provider.
Description/ Summary	The ACR is the principal source for patient data captured at events.
Data users	Responders, practitioners, research.
Data content	The ACR collects patient demographic data, detailed patient assessment clinical data, medical interventions, medications administered, destination handover data, practitioner and administrative data.
Data variables/ data dictionary	Not available. Information Standard details ACR data set.
National-level identifier variables	PPSN and IHI are not included. There is a Unique Identifier on each form.
Equity stratifiers	Patient address is included.
Data collection methodology	Event data is collected on the ACR real time for every patient contact. Patient information is entered on the 2 part report in circumstances listed: All circumstances where a patient is treated.

Title	**Ambulatory Care Report (ACR)**
	All circumstances where a patient refuses treatment contrary to advice given by the responder/practitioner. In the event of the patient being transported to an ED/destination facility an ACR copy is included at handover and stored with the patient record/chart. The remaining copy remains with the licensed CPG provider organisation for storage. eACR used by CPG Providers.
Clinical coding scheme	Not in use.
Size of national collection	Information not available to PHECC as patient records processed and controlled by the licensed CPG provider.
Publication frequency	Currently no annual report published for ACR data collected. The individual auxiliary and voluntary CPG approved licensed providers may publish their own annual activity reports.
Accessing data	Access to data through the individual licensed CPG provider who utilises the ACR.
Open Data portal access	No.
Generic email contact	info@phecc.ie
Generic telephone contact	+353 45 882042
Other comments	Pre-Hospital Emergency Care Council (PHECC) is responsible for the development of the standard by which the data is collected. In addition PHECC develop the ACR which is primarily utilised by responders / practitioners on contract or volunteering on behalf of auxiliary and voluntary organisation at venues where Events are taking place nationally. All PHECC information standards and related patient report forms are reviewed at least every three years to facilitate capture of care delivered in the pre-hospital environment by practitioners and compliance with national data collection standards.

4.7 Blood Donor Database

Title	**Blood Donor Database**
Managing Organisation	Irish Blood Transfusion Service.
Web address	http://www.giveblood.ie/
Year established	1965 — Data collection commenced by Blood Transfusion Service Board. 1975 — Cork Blood Transfusion Service included. 1991 — Limerick Blood Transfusion Service included. 2000 — Name changed to the Irish Blood Transfusion Service (IBTS).
Statement of Purpose	To maintain a computerised donor database on individuals who donate blood.
Coverage **(geographical and temporal)**	National — all who attend a blood donation clinic are required to register with the IBTS. Data collection commenced in 1965 and is ongoing.
Description/ Summary	The IBTS maintains a computerised donor database on individuals who donate blood. This database (called Progesa) is used by the IBTS to communicate with donors, record their donation and test result details. This information is used for analysis of the blood donor population. The IBTS also publishes information on the current blood supply available for donation in Ireland.
Data users	IBTS.
Data content	Information includes donor details (gender, name, address, date of birth and telephone number), donation details and test result details.
Data dictionary	Not available.
National-level identifier variables	No.
Equity stratifiers	Place of residence & Gender.
Data collection methodology	All donors are required to register with the IBTS, when they present at a donation clinic, and fill out a health and lifestyle questionnaire. Ongoing data collection.
Clinical coding scheme	N/A.
Size of national collection	Average of 15,688 from 2016 to 2020.
Publication frequency	Annual reports.

Title	**Blood Donor Database**
Accessing data	Annual reports. Blood supply levels are available on the IBTS website.
Open Data portal access	No.
Generic email contact	contactus@ibts.ie
Generic telephone contact	+ 353 1 4322800

4.8 BowelScreen (The National Bowel Screening Programme)

Title	**BowelScreen (The National Bowel Screening Programme)**
Managing Organisation	National Screening Service.
Web address	http://www.bowelscreen.ie
Year established	2012.
Statement of Purpose	Bowel screening aims to find bowel cancer at an early stage in people who have no symptoms. If bowel cancer is found early, there is a much better chance of treating it successfully. Screening data collected allows for BowelScreen to maintain a record of key performance indicators pertaining to individual consultant's clinical performance in screening centres. Monitoring this information is essential to ensure quality assurance for the programme. Screening for adenomas, pre-cancer lesions and bowel cancer in people with no symptoms is in scope.
Coverage **(geographical and temporal)**	National - Men and Women aged between 60 and 69 years inclusive.
	Men & Women can be added to the register via two pathways: 1. Notification from the Dept. of Social Protection, 2. Self-register by calling freephone. Men & Women can verify that they are on the register online. Records will remain inactive until the Man or woman reaches 60 years.
Description/ Summary	BowelScreen maintains a population register containing demographic data of eligible men and women aged 60-69 for the purposes of screening. It also contains data so that men and women, who have completed the BowelScreen home test kit (FIT), can be contacted, if necessary, for follow up treatment. All eligible men and women aged between 60 and 69 years are invited every 2 years to complete a home test kit.
Data users	Internal stakeholders - NSS and Programme staff. External stakeholders - database software providers, FIT kit distributer, letter printing company, call management centre, FIT laboratory analysis staff (clinical and administrative), Hospital endoscopy (clinical and administrative), histopathology laboratories (clinical and administrative), radiology (clinical and administrative) and surgery (clinical and administrative), General Practitioners.

Title	**BowelScreen (The National Bowel Screening Programme)**
Data content	Client demographic data; clinical examination/results of screening; further assessments/data on cancers detected; outcome of treatments/follow-up data may be included after consideration; standardised data sheets completed by surgeons; standardised data forms completed by pathologists; biopsy reports/hospital pathology records. To Maintain client confidentiality, each client has a unique identification number on the register, known as a Colorectal ID or COR ID.
Data dictionary	Not available. Development of a data dictionary commenced.
National-level identifier variables	PPSN -incomplete coverage within the BowelScreen Register database. IHI- field to be added to BowelScreen register when IHI available.
Equity stratifiers	Gender Place of residence District Electoral Division.
Data collection methodology	Files imported monthly from Department of Social Protection and self-registration.
Clinical coding scheme	Not in use.
Size of national collection	Approximately 250,000 men and women aged 60-69 years invited annually. Approximately 500,000 active clients on register.
Publication frequency	Bi-Annually.
Accessing data	Programme Report and data requests.
Open Data portal access	No.
Generic email contact	info@bowelscreen.ie
Generic telephone contact	+353 1 8659300
Other comments	The Cancer Strategy 2017-2026 has recommended the extension of the programme to all men and women aged between 55 and 74 years.

BreastCheck
An Clár Náisiúnta Scagthástála Cíoch
The National Breast Screening Programme

4.9 BreastCheck (The National Breast Screening Programme)

Title	**BreastCheck (The National Breast Screening Programme)**
Managing Organisation	National Screening Service.
Web address	http://www.breastcheck.ie/
Year established	2000 (three health board regions). 2005 (partial expansion). 2007 (national).
Statement of Purpose	BreastCheck is a Government funded programme providing breast screening and invites women aged between 50 to 69 years for a free mammogram on an area-by-area basis every two years. The aim of BreastCheck is to reduce deaths from breast cancer by finding and treating the disease at an early stage. The purpose of the database is to provide a population register containing demographic data to identify eligible women for the purposes of screening. Clinical data is collected on individuals that receive a service, which is provided by clinicians and entered by data officers.
Coverage **(geographical and temporal)**	National – BreastCheck has completed an age extension project to include all women aged between 50 to 69 years to be invited for routine breast screening every two years.
	2000 - Dublin, Wicklow, Kildare, Laois, Offaly, Westmeath, Longford, Cavan, Monaghan, Louth and Meath. 2005 - Addition of Carlow, Kilkenny and Wexford. 2007 - Expansion to full national coverage including all 26 counties. 2000-2016 Data imported to include age range from 48 years up to 65 years old. 2016 - Age range extension to include up to 70 years old.
Description/ Summary	BreastCheck is a Government funded programme providing breast screening to women through a network of four static centres and a number of mobile units. Screening is offered to eligible women by personal invitation for a free mammogram on an area-by-area basis every two years. BreastCheck compiles a register (list) of women eligible for screening from information supplied by the Department of Social Protection (pre-2020 also included other sources of data). BreastCheck is allowed to source this information under The Health (Provision of Information) Act, 1997.
Data users	BreastCheck & National Screening Service Staff

Title	**BreastCheck (The National Breast Screening Programme)**
	Host Hospitals/Private Hospitals providing services or care to our service users NCRI General Practitioners (See note under Other comments re: service providers).
Data content	Client demographic data; clinical examination/results of screening; further assessments/data on cancers detected; outcome of treatments/follow-up data may be included after consideration; standardised data sheets completed by surgeons; surgical data on biopsy reports (in cases where women attend another hospital for pathology and/or surgery); standardised data forms completed by pathologists; biopsy reports/hospital pathology records (in cases where women attend another hospital for pathology and/or surgery).
Data dictionary	Not available. Data dictionary currently in final stages of review.
National-level identifier variables	PPSN - incomplete coverage within the data. IHI to be incorporated into new BreastCheck IT system (CRIS) which is under development.
Equity stratifiers	Place of residence. Gender-Data selected by default using gender by data providers.
Data collection methodology	Monthly upload of files received from the provider. There is also a BreastCheck website facility for self-registration by women. External agency carries out a de-duplication process every 6 weeks.
Clinical coding scheme	BreastCheck SNOMED dataset currently under development with the SNOMED CT Irish National Release Centre for implementation in the new BreastCheck IT system (Client Radiology Information System - new BreastCheck IT system under development)
Size of national collection	Approximately 280,000 eligible women to be invited for screening annually. The target uptake for the programme is >70%. Approximately 560,000 active clients on register.
Publication frequency	Annually.
Accessing data	Programme report and data requests.
Open Data portal access	No.
Generic email contact	info@breastcheck.ie

Title	**BreastCheck (The National Breast Screening Programme)**
Generic telephone contact	+353 1 8659300
Other comments	Maintenance of the population register is by an external data management company. Outsourced letters, Call management and Text Messaging providers have access to our data but are not data users. They provide services on behalf of BreastCheck utilising our data.

4.10 Cardiac First Response Report (CFR Report)

Title	**Cardiac First Response Report (CFR Report)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC) is responsible for the development of the standard by which the data is collected. In addition PHECC develop the CFR Report which is utilised community first responder scheme members dispatched by the national ambulance service.
Web address	https://www.phecit.ie/
Year established	2008.
Statement of Purpose	To collect out-of-hospital cardiac arrests data on the patient population who suffer an out-of-hospital cardiac arrest in order to collect information on pre-hospital treatments, summarise outcomes and survival rates.
Coverage **(geographical and temporal)**	National coverage. All incidents where a community first responder who has completed a recognised Cardiac First Response course is in attendance.
Description/ Summary	The Cardiac First Response (CFR) report is a two-part patient record which is completed for every patient contact by a trained community first responder who attends an incident. The data is collected in line with the international Utstein style template which ultimately summarises outcomes and survival rates.
Data users	Responders, research.
Data content	The CFR Report collects patient demographic data, detailed cardiac event related data such as: collapse, chest compressions, defibrillator, shock and return of spontaneous data. In addition medical interventions, medications administered and handover data.
Data dictionary	Not available. Information Standard details CFR data set.
National-level identifier variables	PPSN and IHI are not included. There is a Unique Identifier on each form.
Equity stratifiers	Patient address is included.
Data collection methodology	Out-of-hospital cardiac arrest data is collected on the CFR Report each time a trained responder attends an incident. In addition out-of-hospital cardiac arrest data is collected from the following sources: Patient Care Report (PCR) Ambulance Service National Emergency Operations Centre (NEOC) Systems, destination hospital/ emergency

Title	**Cardiac First Response Report (CFR Report)**
	department (ED), GP systems. It is collated, verified and entered in to the national out-of-hospital cardiac arrest register (OHCAR).
Clinical coding scheme	Not in use.
Size of national collection	Information not available to PHECC as patient records processed and controlled by the licensed CPG provider who operates an ambulance service.
Publication frequency	Currently no annual report published for CFR report data collected. The out-of-hospital cardiac arrest register (OHCAR) publishes an annual report based on data collected on Patient Care Report (PCR), which includes the CFR report data elements and other sources such as: National Emergency Operations Centre Systems, destination hospital/ emergency department (ED), GP systems.
Accessing data	Access to data through the individual licensed CPG provider who utilises the CFR report i.e. national ambulance service. A CFR report copy is included in handover at the Emergency Department (ED)/destination facility and stored with the hospital record/chart. The second copy is returned to the licenced CPG provider organisation for storage.
Open Data portal access	No.
Generic email contact	info@phecc.ie
Generic telephone contact	+353 45 882042
Other comments	All PHECC information standards and related patient report forms are reviewed at least every three years to facilitate capture of care delivered in the pre-hospital environment by practitioners and compliance with national data collection standards.

4.11 Central Treatment List (CTL)

Title	**Central Treatment List (CTL)**
Managing Organisation	HSE, National Drug Treatment Centre.
Web address	http://www.addictionireland.ie/
Year established	1998.
Statement of Purpose	To regulate the dispensing of methadone and buprenorphine/Naloxone treatment in Ireland.
Coverage (geographical and temporal)	National (Republic Ireland) — all clients prescribed methadone and buprenorphine/Naloxone treatment within Ireland.
Description/ Summary	Administrative database to regulate the dispensing of methadone treatment. The Central Treatment List (CTL) was established under Statutory Instrument No. 225 (Minister for Health and Children 1998) and is a complete register of all patients receiving methadone (as treatment for problems with opiate use) in Ireland. When a person is considered suitable for methadone detoxification, stabilisation or maintenance, a unique number is allocated to the client and a treatment card is issued for clients when dispensed in community pharmacies.
Data users	GPs, Pharmacists, Consultants, Medical Practitioners, Addiction Nurses.
Data content	Name, address, date of birth, gender, District Electoral Division (DED), HSE area, Local Health Office (LHO) area, task force area, date commenced on methadone, type of methadone treatment, prescribing doctor, dispensing clinic, date and reason for discontinuation of methadone, client photograph and client signature.
Data dictionary	No.
National-level identifier variables	No.
Equity stratifiers	Gender.

Title	**Central Treatment List (CTL)**
Data collection methodology	When a person is considered suitable for methadone detoxification, stabilisation or maintenance, in compliance with Regulations the prescribing doctor notifies the CTL with completion of an entry form and a unique number is allocated to the client. Information is updated on a daily basis. Monthly and yearly Stats are compiled.
Clinical coding scheme	Not applicable.
Size of national collection	As of 2021 there was 11,892 people in receipt of methadone and 765 in receipt of suboxone products (Buprenorphine/Naloxone and Buprenorphine (subutex).
Publication frequency	Numbers on the CTL are published annually by the Health Service Executive and Health Research Board. Monthly regional summary reports are circulated, as appropriate. Analysis reports can be requested.
Accessing data	Access to data only by staff operating the CTL.
Open Data portal access	N/A.
Generic email contact	ctl@dtcb.ie
Generic telephone contact	
Other comments	The CTL was established under S.I. No. 225/1998: Misuse of drugs (supervision of prescription and supply of methadone) regulations, 1998. The Department of Health established a Methadone Implementation Prescribing Committee which meets four times a year. The first external review of the Methadone Treatment Protocol in Ireland was published in 2010.

4.12 CervicalCheck (The National Cervical Screening Programme)

Title	**CervicalCheck (The National Cervical Screening Programme)**
Managing Organisation	National Screening Service.
Web address	http://www.hse.ie/cervicalcheck
Year established	2000 (phase 1) 2008 (national programme established).
Statement of Purpose	The overall aim of CervicalCheck is to reduce the incidence of cervical cancer by detecting changes in the cells of the cervix before they become cancerous. The purpose of the database is to provide a population register containing demographic data to identify eligible women for the purposes of screening. The database also contains clinical data so that women who have had screening tests can be contacted for follow-up treatments and clinical referral recommendations.
Coverage **(geographical and temporal)**	National – principally women aged between 25 and 65 years, additionally some women aged less than 25 years and over 65 years where there is a clinical requirement. Women and people with a cervix can be added to the register via three pathways: 1. Notification from the Dept. of Social Protection, 2. Self-register online or by calling freephone 3. Attend for a screening test in primary care/attendance at a programme Colposcopy clinic. Records will remain inactive until the women reaches 24 years and 6 months.
Description/ Summary	CervicalCheck maintains a population register containing demographic data of eligible women and people with a cervix aged 25 to 65 for the purposes of screening. The screening interval for women aged between 25 to 29 years is three years and for women aged 30 to 65 years is five years. It also contains clinical data so that women who have had cervical screening tests can be contacted for follow up treatments and clinical referral recommendations.
Data users	Internal stakeholders- NSS and Programme staff. External stakeholders- database software providers, letter printing company, document scanning company, call management centre, screening laboratory staff (clinical and administrative), histopathology laboratories- (clinical and administrative), hospital colposcopy staff (clinical and administrative) and General Practitioners and their staff (practice nurse and admin). Hospital MDT where cases are discussed NCRI use anonymised data for statistical purposes. CERVIVA use anonymised data for statistical purposes.

Title	**CervicalCheck (The National Cervical Screening Programme)**
Data content	Client demographic data - Date of birth; mother's maiden name; To maintain confidentiality, each woman has a unique identification number on the register, known as the Cervical Screening Programme ID (CSP ID). Cytology, HPV testing, colposcopy and histology clinical data in relation to a woman's screening test and any follow up treatment is also captured.
Data dictionary	Not available. Development of a data dictionary has commenced and will be available in 2022.
National-level identifier variables	PPSN – yes. IHI-a field to be added to CervicalCheck register when IHI available.
Equity stratifiers	Gender, place of residence.
Data collection methodology	The processes for data collection are: ▪ a monthly electronic feed in a standard format from Department of Social Protection which is imported into the Register (to update demographics only); ▪ daily electronic feeds from service providers (screening tests results and colposcopy data, web import) and monthly or quarterly softcopy feeds (histology data) which update clinical details but can also update demographic data (in a standard format agreed between CervicalCheck and the service providers) ▪ Updates from women and GP practices via telephone, letter, email or the website to register a woman's demographics for the programme or to update their existing demographic data.
Clinical coding scheme	SNOMED coding for histology results.
Size of national collection	Approximately 295,000 women are invited annually for a cervical screening test. The target coverage for the programme is >80%. Approximately 1.3 million active clients on register.
Publication frequency	Annually.
Accessing data	Programme report and data requests.
Open Data portal access	No.

Title	**CervicalCheck (The National Cervical Screening Programme)**
Generic email contact	info@cervicalcheck.ie
Generic telephone contact	+353 1 8659300
Other comments	A number of providers of General Practice management software products have developed electronic versions of the CervicalCheck cervical cytology and colposcopy referral forms. Not all of the fields listed are mandatory so there will be variance in the range of data, outside of minimum demographics, particularly clinical data, captured for each event for a woman.

4.13 Cleft Database

Title	**Cleft Database**
Managing Organisation	Dublin Cleft Centre.
Web address	www.cleftcareireland.ie – Team/Services website. The database is not web based.
Year established	2002.
Statement of Purpose	The purpose is to gather centralised information on children or adults who present with cleft lip and/or palate which aids delivery of follow-up care, audit and research.
Coverage **(geographical and temporal)**	National — participation is voluntary. Cleft is a lifelong condition and data collection starts from antenatal referral and is maintained throughout life with patient consent.
Description/ Summary	The National Cleft Database enables the stakeholders to monitor the frequency and incidence of cleft in Ireland. It facilitates audit, research and reporting on the quality of cleft care. It supports planning, development and coordination of multidisciplinary services across hospitals and community services. The cleft database incorporates the minimum records required to comply with the audit requirements as stipulated by Eurocran for Cleft Lip and Palate for children. Statistical information on an annual basis can be used for benchmarking purposes within the Craniofacial Society of Great Britain and Ireland.
Data users	The Multidisciplinary Cleft Team ▪ Cleft Service Coordinators ▪ Plastic Surgeons ▪ Maxillofacial Surgeons ▪ Cleft Nurse Specialists ▪ Speech & Language Therapists ▪ Audiologists ▪ Clinical Photographers ▪ Paediatric Dentistry ▪ Orthodontists ▪ Prosthodontists. These data users with the development and support of the cleft data collection and reporting software, training of coders, data quality, audit and reporting respond to requests for data in line with current GDPR, Hospital Ethical & Research Regulations.
Data content	Initial registry i.e. demographic data; referral source; cleft classification and medical history; feeding history; antenatal diagnosis; primary surgical care pathway. Follow-up registry i.e. surgical care pathway. Audit records i.e. hearing; speech; dental; palatal fistula records, growth records photographs); objective assessment of velopharyngeal

Title	**Cleft Database**
	function; Cleft Q quality of life measure, sleep study data for babies with Robin Sequence, instrumental assessment of resonance; cleft coordinator contact; clinic details; cleft Clinical Nurse Specialist (CNS) contact; genetics patient status.
Data dictionary	This is being developed at present.
National-level identifier variables	PPSN is included in the dataset.
Equity stratifiers	The following data is not collected at present: ▪ Address ▪ Gender ▪ Religion, if any ▪ Ethnicity.
Data collection methodology	The data is compiled from several sources i.e. the cleft database registration pro forma, healthcare records, hospital patient registrations system (IPMS) and audit records such as patients completed Cleft Q questionnaires and records from each discipline of the multidisciplinary cleft care team.
Clinical coding scheme	"RPL" Code for Cleft Classification.
Size of national collection	▪ 80 to 100 New-born Registrations ▪ Standardized Audit Records at age 5,10,15,18 years and final outcome: ▪ Plastics ▪ Nursing ▪ Speech & Language ▪ Audiology ▪ Dental ▪ Orthodontic ▪ Prosthodontic ▪ Maxillofacial ▪ Clinical Photography ▪ Patient Recorded Outcome measure from age 10 years.
Publication frequency	Data submitted annually to Craniofacial Society of Great Britain and Ireland (CFSGBI), and to the Health Service Executive Congenital Anomalies Registry (EUROCAT). Data will be submitted to the European Reference Network (ERN) from 2023.
Accessing data	Data requests received by team members at the DCC are forwarded to the Cleft Data Manager. Annual audit of annual returns to Craniofacial Society of Great Britain and Ireland (CFSGBI). Annual report generated for Congenital Anomalies Registry.
Open Data portal access	No.

Title	**Cleft Database**
Generic email contact	sandra.byrne@cuh.ie
Generic telephone contact	+353 1 8784702
Other comments	Dataset design is produced by the multidisciplinary team in cleft care under the auspices of DCC. Ongoing work in progress for completion of data dictionary. This template updated 31/05/2022.

4.14 *Clostridioides difficile* infection enhanced surveillance

Title	***Clostridioides difficile* infection enhanced surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/clostridioidesdifficile/
Year established	2009.
Statement of Purpose	To provide the best possible information for the control and prevention of infectious diseases, by providing timely information and independent advice, and by carrying out disease surveillance, epidemiological investigation and related research and training. In scope: Includes healthcare (public and private hospitals and long-term care facilities) and community associated cases. Out of scope: Infection in children under 2 years of age.
Coverage (geographical and temporal)	Participation of hospitals is voluntary. In Q1 2022, 60 acute public (n=48) and private (n=12) hospitals provided data. Data collection start date in August 2009.
Description/ Summary	*Clostridioides difficile* infection (CDI) became a notifiable disease in May 2008. In August 2009, HPSC began collecting enhanced surveillance data on all CDI cases from acute hospitals on a voluntary basis. The enhanced surveillance collects information on both new and recurrent cases and also on the onset and origin of cases. Data is reported back to participants on a quarterly basis to enable hospitals monitor trends over time.
Data users	Consultant Microbiologists; Hospital Infection Prevention & Control teams (nurses, surveillance scientists); AMRIC clinical lead; Directors of Public Health & public health medial and epidemiologist colleagues; HPSC medical & epidemiologist colleagues; Dept. of Health; HSE Communications office; National *C. difficile* Reference Laboratory; Hospital activity data providers.
Data content	Age, sex, hospital admission, type of CDI case (new/recurrent), location of onset of infection (healthcare/community), origin of infection (healthcare-associated or community-associated), origin

Title	***Clostridioides difficile* infection enhanced surveillance**
	facility (reporting hospital or long-term care facility; if ambulatory care provided for community-associated cases), severity of illness, treatment, ribotype & sequence type (provided by NRL) of isolate.
Data dictionary	Enhanced surveillance protocol provides definition of variables: https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/clostridioidesdifficile/enhancedsurveillance/File,13927,en.pdf
National-level identifier variables	No.
Equity stratifiers	Yes: Gender, Age.
Data collection methodology	Participating hospitals email their data quarterly using an Excel spread sheet. Transmission is encrypted.
Clinical coding scheme	Not in use.
Size of national collection	1,870 average number of records created annually.
Publication frequency	Quarterly and annual reports are available on the HPSC website, www.hpsc.ie.
Accessing data	Data requests can be submitted via info@hpsc.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	cdifficiledatahpsc@hpsc.ie
Generic telephone contact	+353 1 8765300

4.15 Computerised Infectious Disease Reporting (CIDR) system

Title	**Computerised Infectious Disease Reporting (CIDR) system**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	http://www.hpsc.ie/hpsc/CIDR
Year established	CIDR was established in 2004, however, historical data on the notifiable infectious diseases was also included in the system i.e. **1988-June 2000** (historical aggregate data on notifiable diseases collected by the Department of Health) **July 2000 onwards** (case-based information on notifiable diseases reported by Departments of Public Health to HPSC) **2004** (Outbreak data included) **2004 - 2010** (current format implemented in Departments of Public Health and Microbiology laboratories. While awaiting CIDR implementation, Departments of Public Health continued to report to HPSC using the system established in July 2000 and these data were imported to CIDR) **2013:** (Case-based reporting of STIs implemented on CIDR).
Statement of Purpose	CIDR is used for the statutory surveillance of notifiable infectious diseases in Ireland (including COVID-19) in order to provide the best possible information for the control and prevention of infectious diseases. The objectives of CIDR include: 1. To monitor trends 2. To detect changes in disease occurrence e.g. identify outbreaks and new pathogens 3. To describe the current burden and epidemiology of disease 4. To determine risk factors for the disease and populations at greatest risk 5. To guide public health actions and inform policy 6. To evaluate control measures / interventions 7. To generate hypotheses and stimulate research. **In scope:** Infectious Disease Notifications on 80 of 89 notifiable diseases. **Out of scope:** Nine notifiable diseases whereby data collected through separate surveillance systems. These include some of the pathogens (n=5) under antimicrobial resistance surveillance (AMR), namely Enterococcal bacteraemia, Escherichia coli infection (invasive),

Title	**Computerised Infectious Disease Reporting (CIDR) system**
	Klebsiella pneumoniae infection (invasive), mcr-positive Enterobacteriaceae infection or colonisation, Novel or Rare Antimicrobial-resistant Organism (NRAO), Pseudomonas aeruginosa infection (invasive), Staphylococcus aureus bacteraemia and two sexually transmitted infections i.e. Ano-genital warts and Non-specific urethritis.
Coverage **(geographical and temporal)**	National. **1988-present** (varies depending on when the disease became notifiable and case-base reporting implemented). **1988-July 2000** – aggregate data **July 2000 onwards** – case-based reporting implemented in Ireland **2004** - Outbreak data included **2004-2010** – CIDR pilot and go-live implementation (excluding STIs). Historical data and data from regions awaiting implementation on CIDR imported to the system. **2013** – Case-based reporting of STIs commenced and included on CIDR.
Description/ Summary	CIDR is the information system developed to manage the surveillance and control of notifiable infectious diseases in Ireland. Case-based data on laboratory and clinical notifications are collected on CIDR, which includes: ▪ Vaccine-preventable diseases, ▪ Respiratory (including COVID-19) and direct contact diseases, ▪ Infectious intestinal diseases, ▪ Vector borne and zoonotic diseases, ▪ Blood borne and sexually transmitted infections and ▪ Healthcare associated infections. Enhanced surveillance data (additional detailed data) are also collected on many of the infectious diseases. Summary data on infectious disease outbreaks are also collected in CIDR and individual cases notified on CIDR and associated with an outbreak are linked to the outbreak. The full list of notifiable diseases can be found at www.hpsc.ie. The current list is also specified in S.I. No. 258/2022 - Infectious Diseases (Amendment) Regulations 2022, available at https://www.irishstatutebook.ie/eli/2022/si/258/
Data users	Departments of Public Health, HPSC, HSE Senior Management and healthcare workers, Department of Health and other policy makers, researchers, European Centre for Disease Control (ECDC) and World Health Organisation (WHO).
Data content	▪ Patient demographics (name, address, age, gender, ethnicity, country of birth, occupation)

Title	**Computerised Infectious Disease Reporting (CIDR) system**
	▪ Positive laboratory results (organism, type, specimen and test details) ▪ Onset and diagnosis dates ▪ Hospitalisation status ▪ Outcome. Additional epidemiological information (enhanced surveillance) are collected on certain diseases and depending on the disease can include: ▪ Symptoms ▪ Underlying medical conditions ▪ Other risk factors ▪ Exposures ▪ Severity indicators including detailed information on o ICU admission o Outcomes ▪ Vaccination status ▪ Typing and whole genome sequencing (WGS) results. Information on outbreaks are also collected on CIDR (HSE area, disease, outbreak type, location and cases associated with it are linked.
Data dictionary	No (Core data elements were based on a National General Practice Information Technology (GPIT) demographic data set developed in 1999).
National-level identifier variables	No, IHI or PPSN are not included on CIDR.
Equity stratifiers	Some equity stratifiers are included i.e. ▪ Place of residence ▪ Ethnicity ▪ Country of birth ▪ Gender ▪ Occupation
Data collection methodology	CIDR is a web-based information system with the data collected held in a single shared national information repository. Data from laboratories are uploaded electronically or entered manually to CIDR by public and some private laboratories. Staff in Departments of Public Health (or in HPSC on behalf of Public Health) process laboratory notifications on CIDR and also input clinical notifications, outbreak data, data from private laboratories and enhanced /epidemiological data collected by Public Health professionals or other healthcare professionals. Thereby laboratory, clinical, epidemiological and outbreak data are linked on CIDR.

Title	**Computerised Infectious Disease Reporting (CIDR) system**
	During the COVID-19 pandemic, a Robotic Process Automation (RPA) solution was implemented on CIDR to assist with the processing of laboratory records and the entering of enhanced data. Once these data are processed on CIDR they are available through the CIDR SAP Business Objects Reporting repository to the relevant Department of Public Health and HPSC (national view) to review, analyse, interpret and report on. Data are collected and processed on CIDR on a daily basis (Monday-Friday) and during the COVID-19 pandemic, seven days per week (Sunday-Saturday).
Clinical coding scheme	No clinical coding or international classification of disease (ICD) system is in use. However, surveillance case definitions are applied (i.e. the set of clinical and microbiological criteria by which a case of infectious disease is defined. The case definitions used in Ireland are predominantly based on EC case definitions. For details see: http://www.hpsc.ie/NotifiableDiseases/CaseDefinitions/)
Size of national collection	On average 33,394 cases were reported annually between 2013-2019, range 25,814 – 46,065. As a result of the COVID-19 pandemic the annual number of notifications increased exponentially with 134,775 and 698,627 cases notified in 2020 and 2021, respectively and almost 900,000 to date in 2022 (as of 8th August). On average 550 outbreaks were reported annually between 2013-2019. As a result of the COVID-19 pandemic the annual number of outbreaks notified, increased exponentially to approx. 11,000 in both 2020 and 2021 and just over 3,000 to date in 2022 (as of 8th August).
Publication frequency	Weekly and annual reports are produced and published on HPSC public website at http://www.hpsc.ie/hpsc/NotifiableDiseases The HPSC hub on the Epidemiology of COVID-19 in Ireland is updated weekly and available at https://epi-covid-19-hpscireland.hub.arcgis.com/ Quarterly or biannual reports are also produced for some disease areas and published on the HPSC website at http://www.hpsc.ie
Accessing data	CIDR users can access data according to their role and location as laid out in the CIDR National Business Rules policy (v4). On-demand reports are provided to CIDR users through the CIDR SAS Business Objects Reporting repository. Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis. Depending on the level of detail requested, some requests undergo a formal review process, conducted by the CIDR National Peer Review Group.

Title	**Computerised Infectious Disease Reporting (CIDR) system**
	The CIDR National Peer Review Group is a sub-group of the National CIDR National Business Rules Committee and was established to facilitate the collaborative use of CIDR data for research and other purposes, whilst ensuring confidentiality and data protection issues are appropriately addressed. Enquiries from researchers to access CIDR data cam be submitted to cidrdatarequests@hpsc.ie
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.16 COVAX: National Covid-19 Immunisation System

Title	**COVAX: National Covid-19 Immunisation System**
Managing Organisation	HSE – Office of the Chief Clinical Officer.
Web address	https://www.hpsc.ie/
Year established	2021.
Statement of Purpose	The COVAX system is an electronic dataset which records all COVID-19 vaccinations for all residents[11] in the State. It also assists in the planning of vaccination clinics as well as being used for statistical and activity analysis. In-Scope: All COVID-19 vaccinations for all residents who receive a vaccination in Ireland leading to a Vaccination certificate for travel purposes. Out-of-Scope: Non-COVID-19 vaccinations (e.g. Schools Immunisation Programme).
Coverage (geographical and temporal)	National – all residents of the State who have registered for COVID-19 vaccination during 2021 and 2022 to date. The data collection start date was the 27th December 2020 and continues to this day.
Description/ summary	The data collection are made up of retrospective (from paper records) and real time data entry records detailing the the processing of each residents who received a vaccination (if consented) or not. The data includes the person-identifying information of the citizen. It also includes data on citizens who were not vaccinated by virtue of non-attendance.
Data users	▪ National Immunisation Office ▪ Staff in vaccination centres ▪ HPSC ▪ OoCIO COVAX team ▪ OoCIO IIS department ▪ Health Identifiers Department

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[11] In this template, the term 'Residents' means all people living in the Irish State, whether citizen or not but excludes those 'visiting' the country (i.e. tourists).

Title	**COVAX: National Covid-19 Immunisation System**
	▪ GPs via IIS COVAX lookup function.
Data content	▪ Client demographic records ▪ Client immunisation records ▪ Client eligibility records ▪ Relevant client clinical information ▪ Client consent documentation ▪ Adverse incidents ▪ Appointment messages.
Data dictionary	Available on request.
National-level identifier variables	IHI allocation is 95% for all records. COVAX is also a source system for IHI lookup, and will be an authentication system for client consented government authorisation of ID. PPSN is requested at registration to enable GP payments.
Equity stratifiers	Ethnicity Nationality Occupation (for healthcare professionals) Eligibility Cohorts.
Data collection methodology	The data are collected on an as-required basis. This, in practise, is a daily occurrence as residents can log onto a portal to provide their information. In addition to this, information is provided via electronic transmission from GPs and Pharmacies at the point of vaccination.
Clinical coding scheme	Snomed coding exists for the covid-19 vaccine and other fields such as Ethnicity.
Size of national collection	▪ 4 million registrations ▪ 11 million immunisations.
Publication frequency	Data is updated and published continuously. The national figures are published daily by the HPSC.
Accessing data	The data in Covax are accessed by staff in the NIO for the purpose of data curation and vaccination programme management. The data are also accessed by Vaccination Centre staff for the purpose of system maintenance, data quality and data entry. In addition to the national

Title	**COVAX: National Covid-19 Immunisation System**
	aggregate data published by the HPSC, individual Client immunisation records may be requested by individuals through their local immunisation office as a Subject Access Request and are provided automatically in the form of vaccination certificates for HSE vaccines. This is a function provided by OoCIO IIS (Integrated Information Systems) staff who automate release of quality checked immunisation records, and also provide a facility for GPs and Pharmacies to look up vaccine history.
Open Data portal access	No.
Generic email contact	COVID19-support@hse.ie
Generic telephone contact	None.
Other comments	Clients can find information on their immunisation schedule and what to expect during a vaccination at the national immunisation website at: www.immunisation.ie

4.17 Cystic Fibrosis Registry of Ireland

Title	**Cystic Fibrosis Registry of Ireland**
Managing Organisation	Cystic Fibrosis Registry of Ireland.
Web address	http://www.cfri.ie
Year established	2001.
Statement of Purpose	The Cystic Fibrosis Registry of Ireland (CFRI) was established to provide for the relief of sickness, suffering and distress and to advance education by collecting and analysing information relating to cystic fibrosis which can be used to facilitate research and provide accurate reports in order to monitor and improve treatments which will contribute to the quality of care of persons with CF. **In-scope & out of scope** - we collect and analyse information related to CF encounters from the following HSE-recognised CF centres only and not from any other hospital within Ireland. We collect data from: ▪ The HSE-designated CF specialist centres: Beaumont Hospital, St Vincent's University Hospital, CHI (Children's Health Ireland) group (including National Children's Hospital, Tallaght, Our Lady's Children's Hospital, Crumlin, Temple Street Children's University Hospital), University Hospital Galway, Cork University Hospital and University Hospital Limerick ▪ Five CF clinics (Cavan General Hospital, Mayo University Hospital, Our Lady of Lourdes Hospital, Drogheda, Sligo University Hospital, and University Hospital Waterford) ▪ The Irish National Lung Transplant Programme at the Mater Misericordiae University Hospital Dublin. Our aims and objectives relate to the following areas of work: **1. Registry Process**

Title	**Cystic Fibrosis Registry of Ireland**
	▪ To identify, record, analyse, and store information relating to the prevalence, incidence, and treatment of existing and newly diagnosed people with CF in the Republic of Ireland ▪ To register all persons with CF whose usual residence is in the Republic of Ireland ▪ To provide data on the long-term prognosis for people with CF in the Republic of Ireland and to compare this information with international data ▪ To compare CF management and treatment in Ireland with best international practices ▪ To ensure that all information is complete, accurate, timely and confidential in order to effectively use the data collected ▪ To develop and improve CF registry methodology. **2. Research**: ▪ To promote and facilitate the use of clinical data in approved research projects ▪ To initiate research into the causes, distribution, treatment and outcome of people with CF, and to participate in similar research initiated by others and to publish the findings ▪ To assist in the evaluation of novel treatments and screening programmes. **3. Healthcare Planning and Management:** ▪ To assist in the planning and management of health services and essential resources for people with CF. **4. Reporting:** ▪ To publish an annual report based upon the activities of the Registry ▪ To furnish information and assistance in relation to any aspect of CF to the HSE, CF Ireland, and other service providers, and people with CF ▪ To provide specially requested de-identified reports for clinicians, the HSE, and hospitals. To provide individual consultants with trends and updated information in respect of their patient population. Ethical approval has been

Title	**Cystic Fibrosis Registry of Ireland**
	received from all hospitals that participate in the Cystic Fibrosis Registry of Ireland. Written patient consent has been received by all patients participating in the registry.
Coverage (geographical and temporal)	**Geographic** - national coverage throughout Republic of Ireland - all hospitals/centres/clinics offering primary and shared care to CF patients are included (as noted above). Participation in the registry is voluntary. **Temporal** – CFRI commenced data collection in 2002 and data collection is ongoing
Description/ summary	The Cystic Fibrosis Registry of Ireland collects and analyses information relating to CF in order to improve the quality of care for all of the people with CF in the Republic of Ireland and to keep relevant medical records of each patient with CF in a central computer system.
Data users	Clinical teams, researchers, policy makers (e.g., EMA), and HSE.
Data content	Patient data is collected according to the following categories: 1. Patient demographics –name and address, date of birth, HSE area, ethnicity, date of consent. 2. Core medical care information – centres of care (including primary hospital), medical record number, IHI number, name of consultant, diagnostic data on when & how CF was diagnosed. 3. Encounter data on type & date of encounter e.g., annual review, CF clinic, study visit etc. 4. Clinical data relating to diagnostic tests, genotype, symptoms/method of diagnosis, age at diagnosis, CF history, number of hospitalisations between annual assessments, complications, pulmonary function tests, chest X-ray reports, clinical chemistry, long term therapies, infections, cultures and treatments, nutritional summary, physiotherapy summary and exercise/activity data, transplant status, and pregnancy status. 5. Data on clinical trial participation.
Data dictionary	Data dictionary available on request.
National-level identifier variables	There is no national unique identifier. CFRI collects hospital level medical record number (MRN) and provision has been made to collect a unique national health identifier when that is made available. CFRI allocates each consented CF patient with a unique registry ID. At a CF centre level CFRI collects day month and year of birth, full date of birth of CF patients that have given explicit consent.
Equity stratifiers	The CFRI data set collects data relating to sex, country of birth, ethnicity and address.

Title	**Cystic Fibrosis Registry of Ireland**
Data collection methodology	Enrolment in the registry is subject to a process of gaining informed consent from patients diagnosed with CF/their parents or carer (if under 18). Participation is voluntary. Data is collected from patient medical charts and input into a secure internet-based computer database. Data collection is undertaken by CFRI data collectors. Data is collected on a continual basis throughout the year and CFRI data collectors collect data on an encounter basis.
Clinical coding scheme	N/A.
Size of national collection	Covering approximately 1,560* records created for mostly living registry participants annually. *based on 2020 annual report data.
Publication frequency	Annually via our annual reports: https://cfri.ie/annual-reports/
Accessing data	Summary data is published in the Annual Report. CF consultant/team can request read only access to their centre's patient data. Researchers can request access to de-identified data by submitting a CFRI Data Application Form: https://cfri.ie/apply-for-data/ Each application is reviewed by the CFRI Scientific Committee and must be approved prior to the release of any data. Please direct any emails to: info@cfri.ie
Open Data portal access	No.
Generic email contact	info@cfri.ie
Generic telephone contact	+353 1 7163177
Other comments	The registry is accessible to permitted users only through secure internet access. Founded in 2001; database finalised and first patient entered onto system in 2002.

coimisiún meabhair - shláinte
mental health commission

4.18 Deaths relating to all residents in Approved Centres and Community Mental Health Centres

Title	**Deaths relating to all residents in Approved Centres and Community Mental Health Centres**
Managing Organisation	Mental Health Commission (MHC) - Standards and Quality Assurance Division.
Web address	http://www.mhcirl.ie/
Year established	2008.
Statement of Purpose	The Commission was established in 2002. They are an independent body and their functions are set out by law in the Mental Health Act 2001. Their main functions are to promote, encourage and foster high standards and good practices in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted. The Mental Health Commission is responsible for regulating and monitoring mental health services. Data on the deaths are collected in accordance with provisions in the following: ▪ Code of Practice for Mental Health Services on the Notification of Deaths and Incident Reporting (MHC, 2008) ▪ Mental Health Act 2001 (Approved Centre) Regulations 2006 ▪ Mental Health Act 2001 ▪ Quality Framework for Mental Health Services in Ireland (MHC, 2009). Data are processed in adherence with the following legislation: ▪ Data Protection Act 2018 ▪ Data Protection (Amendment) Act 2003 ▪ Data Protection Act 1988 ▪ Freedom of Information (Amendment) Act 2003 ▪ Freedom of Information Act 1997. Data within scope is data relating to the carrying out of treatments nationally. Data that does not relate to this is out of scope.
Coverage (geographical and temporal)	National coverage - all deaths relating to residents of approved centres and sudden unexplained deaths of service users attending a day hospital, day centre or 24 hour staffed residences.

Title	**Deaths relating to all residents in Approved Centres and Community Mental Health Centres**
	Collection started 01/02/2008 and is ongoing.
Description/ Summary	MHC collects demographic and clinical data in relation to the death of any resident in an approved centre and any sudden, unexplained death of a person attending a day hospital, day centre or 24 hour staffed residence.
Data users	MHC Staff - Corporate Team Regulatory Team Inspectorate Team Tribunals Team.
Data content	Initials; date of birth; legal status; marital status; diagnosis; date of death; circumstances surrounding death.
Data dictionary	Yes, not online.
National-level identifier variables	Services are requested to provide unique service identifiers.
Equity stratifiers	Yes - Gender.
Data collection methodology	Data are extracted from medical charts or records in approved centres and submitted on a secure online system by clinicians or administrative with an individual user account. The secure online system is operated by MHC staff who also have individual user accounts. Data collection occurs when information is submitted to MHC by clinicians or administrative staff in approved centres. Staff in approved centres are required to submit this data within 48 hours from the date that the death has occurred within an approved centre and within 7 days from the date of the death if the service is a community health service and if the circumstances of the death are sudden and unexplained.
Clinical coding scheme	ICD-10.
Size of national collection	450 average number of records created annually.
Publication frequency	MHC annual reports since 2008.
Accessing data	MHC annual report and data requests.
Open Data portal access	No.
Generic email contact	info@mhcirl.ie

Title	**Deaths relating to all residents in Approved Centres and Community Mental Health Centres**
Generic telephone contact	+353 1 6362400

Diabetic RetinaScreen
An Clár Náisiúnta Scagthástála Reitiní do Dhiaibéitigh
The National Diabetic Retinal Screening Programme

4.19 Diabetic RetinaScreen (The National Diabetic Retinal Screening Programme)

Title	**Diabetic RetinaScreen (The National Diabetic Retinal Screening Programme)**
Managing Organisation	National Screening Service.
Web address	http://www.diabeticretinascreen.ie/
Year established	2013 (national programme commenced) 2014 (annual screening).
Statement of Purpose	The primary goal of the Diabetic RetinaScreen Programme is to reduce the risk of sight loss among people with diabetes by the early detection and treatment of sight –threatening retinopathy. The purpose of the database is to provide a population register containing demographic to identify eligible people for the purpose of screening. The database also contains clinical data in order that those who require treatment can be contacted for follow-up treatment and clinical referral recommendations.
Coverage **(geographical and temporal)**	National - for people diagnosed with Type 1 or Type 2 diabetes aged 12 years and over.
	Children (aged 12 years and over) Women and Men who are diagnosed with Diabetes can be added to the register via two pathways: 1. Notification from their General Practitioner, Diabetologist, Ophthalmologist or Endocrinologist to the Programme. 2. Self register on-line, or by calling the Freephone line and forwarding to GP or Consultant for signature. Records will remain inactive a person has NPL in both eyes or until the person has deceased. (There is no age limit).
Description/ Summary	Diabetic RetinaScreen maintains a population register containing demographic data of the eligible people diagnosed with Type 1 or Type 2 Diabetes aged 12 years and over for the purposes of call/recall annual screening. It also contains clinical data in order that those who require treatment can be contacted for follow-up treatment and clinical referral recommendations.
Data users	Internal stakeholders - NSS and Programme staff. External stakeholders - Screening & Grading providers, database software providers, letter printing company, document scanning company, call management centre, DRS Ophthalmology clinics (clinical and administrative staff) and General Practitioners. Diabetes Ireland, Diabetes Programme HSE.
Data content	Client demographical data, Unique DRS ID Number, screening data grading outcome, clinical examination, further assessments/data on

Title	**Diabetic RetinaScreen (The National Diabetic Retinal Screening Programme)**
	retinopathy detected; outcome of treatments/follow-up data. Appointment schedules. Approved Consent.
Data dictionary	Not available.
National-level identifier variables	PPSN for some participants. Placeholder in place for IHI when available.
Equity stratifiers	Place of residence. Gender - data selected by default using gender by data providers.
Data collection methodology	Initially files were imported from PCRS. Data collection can be facilitated by self-registration and registration by health professionals, contacting the call centre.
Clinical coding scheme	Not in use.
Size of national collection	Approximately 200,000 people on the register, 170,000 of these have consented. Approximately 150,000 invited for screening.
Publication frequency	Bi-Annually.
Accessing data	Programme Statistical Report and data requests.
Open Data portal access	No.
Generic email contact	info@diabeticretinascreen.ie
Generic telephone contact	+353 1 8659300
Other comments	There are two providers contracted to invite screen and grade all consented participants including onward referral for treatment if needed. All screening outcomes are communicated back to participants GP or nominated Ophthalmologist/Endocrinologist. 8 Treatment clinics capture clinical information on those who have been referred for treatment.

4.20 Enhanced Bacteraemia (Bloodstream infections) Surveillance in Ireland

Title	**Enhanced Bacteraemia (Bloodstream infections) Surveillance in Ireland**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/europeanantimicrobialresistancesurveillancesystemearss/enhancedbacteraemiasurveillance/enhancedears-netsurveillancereports/
Year established	2004.
Statement of Purpose	To provide epidemiological insights into antimicrobial resistance data from key pathogens in order to inform infection prevention and control teams and other policy decision makers.
Coverage **(geographical and temporal)**	Voluntary participation (22 laboratories regularly participate accounting for 45% of EARS-Net isolates). Data are collected quarterly.
Description/ Summary	Data on bacteraemia caused by selected pathogens is currently collected as part of the European Antimicrobial Resistance Surveillance System (EARS-NET). EARS-NET was enhanced in Ireland to collect demographic, risk factor and clinical data for each EARS-NET isolate reported since 2004. The enhanced programme involves voluntary participation by hospitals that provide data on invasive pathogens causing bloodstream infections.
Data users	Infection control teams in participating acute hospitals.
Data content	Patient details: patient number/chart number, date of birth, age, sex, date of admission, date specimen taken, patient admitted from, patient outcome details, healthcare associated details, organism and laboratory info, risk factors, primary source of infection, clinical features.
Data dictionary	Not available.
National-level identifier variables	No national-level identifier is used.
Equity stratifiers	Equity stratifiers not included in the dataset.
Data collection methodology	In Ireland, the system was enhanced to gather additional information including patient risk factors, sources of infection and patient outcome.

Title	**Enhanced Bacteraemia (Bloodstream infections) Surveillance in Ireland**
	This is an enhancement of the existing EARS-Net data collection system. Data are collected on a quarterly basis.
Clinical coding scheme	Not in use.
Size of national collection	Enhanced data were collected on approx. 1,600 EARS-Net blood-culture isolates for 2018.
Publication frequency	Annual reports available on HPSC website.
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.21 Hand Hygiene Compliance Monitoring

Title	**Hand Hygiene Compliance Monitoring**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/infectioncontrolandhai/handhygiene/handhygieneaudit/
Year established	2011.
Statement of Purpose	In scope: To support overall multi-faceted strategy for the control and prevention of infectious diseases by providing standardised measure of observational hand hygiene compliance for acute hospitals.
Coverage **(geographical and temporal)**	42 public and nine private acute hospitals contributed to the data in Oct 2021. This represents an even geographical spread across Ireland. Data collected twice per year in May/June and Oct/Nov.
Description/ Summary	Compliance with World Health Organization (WHO) "Five Moments of Hand Hygiene" opportunities by healthcare workers in acute hospitals. Data from hand hygiene audit tools (MS Excel) are collated by HPSC via the MicroB online tool and the results published.
Data users	Infection control teams in acute hospitals.
Data content	MS Excel tools of wards audited, WHO moment, hand hygiene action taken, staff category, with date/time and (additional optional fields are also taken).
Data dictionary	Not available.
National-level identifier variables	Not applicable.
Equity stratifiers	Not applicable.
Data collection methodology	Trained infection and control staff conduct hospital-wide audits of hand hygiene compliance by the facility's own healthcare workers. Twice yearly (June & Oct) national audits are conducted, of 7 wards per facility with 30 hand hygiene opportunities per each ward audited. Automated data upload, analysis, report generation and approval for publication facilitated via HPSC's online tool, MicroB.
Clinical coding scheme	N/A.

Title	**Hand Hygiene Compliance Monitoring**
Size of national collection	N/A.
Publication frequency	Bi-annual and annual reports are available on HPSC website at www.hpsc.ie.
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.22 Health Directory

Title	**Health Directory**
Managing Organisation	HSE HIDS – Health Identifiers Service Health Identifiers Service (HIDS) within the National Operational Performance & Integration Unit, Chief Operations Office, HSE. The Health Identifier Service provides the HSE with an identity management service for Individuals and Health Services. The HIDS service is the designated authority, provided for under the Health Identifiers Act 2014, which establishes and operates all identifiers in systems across the HSE.
Web address	https://www.hse.ie/eng/about/who/national-services/individual-health-identifier/
Year established	The Health Directory project commenced in 2011 as the HSE identified the need to create a repository for standard codes and identifiers of service providers and service provider sites as an enabler of HSE systems' integration.
Statement of Purpose	The Health Directory is the basis for the provision of identifiers for Health Service Providers - Practitioners, Locations, People and Organisations. The technical infrastructure for the planned Health Directory is currently in development.
Coverage (geographical and temporal)	National. Data collection began in 2016 and is ongoing.
Description/ summary	The HSE Health Directory is a technical infrastructure which stores, maintains and publishes standard codes and identifiers for health-related entities such as sites/locations and practitioners, services and organisations.
Data users	Health Directory Data users to date: ➢ Health Care Practitioners *(GPs only – other Health Practitioners in development)*: circa 5540 GP practitioners offering their services in 8240 sites / locations. Systems: IBM/Salesforce, Health link, Swift Queue, IPMS, NIMIS, St. John's of God, MedLis etc. ➢ Facility IDs: approximately 21,010 line listings of unique IDs for both Health & Social Care and non-Health & Social Care site /

Title	**Health Directory**
	location. The directory information is used to support Covid–19 work and reporting by providing a unique 6-digit 'Facility ID' to each site / location at which testing is carried out and provide Eircode and geo-referencing to aid tracking and also assist testing and immunisation teams. Systems: COVAX, Covid Care Tracker (CCT) Swift Queue, Pharmavax, Health Protection Surveillance Centre etc.
Data content	The HSE Health Directory is a technical infrastructure which stores, maintains and publishes standard codes and identifiers for health-related entities such as sites/locations and practitioners, services and organisations. This data set is under development but includes location identifiers Service Directory Site id Healthlink id Gln Site name Address Phone1 Phone2 Phone3 Mobile Fax Email Mcn Mc status Gsrn First name Second name Family name Aka C-19 Health Directory FacilityID SettingType ServiceType EntityType CHO PublicHealthArea CentreName Address1 Address2 Address3 Address4 County Eircode

Title	**Health Directory**
	ItmEast ItmNorth Etrs89Lat Etrs89long GLN RegistrationID RegisteredProvider MaxOccupancy RegistrationAuthority CreatedDate UpdatedDate UpdatedAction FacilityStatus HealthlinkID Healthmail
Data dictionary	Upon delivery of the new HSE Health Directory data standardisation to follow 'future state' data model; GS1/SNOMED.
National-level identifier variables	There are national unique identifiers, Health Directory is the technical infrastructure which stores, maintains and publishes standard codes and identifiers for health-related entities such as Sites/Locations and Practitioners, Services & Organisations.
Equity stratifiers	The Health Directory captures only the occupation (data source: MCN) and business address of GP practitioners at the moment.
Data collection methodology	Daily demographic feeds from the Department of Social Protection.
Clinical coding scheme	N/A.
Size of national collection	▪ Facility IDs: approximately 21,010 line listings of unique IDs for both Health & Social Care and non-Health & Social Care site / location. The directory information is used to support Covid – 19 work and reporting ▪ Health Care Practitioners *(GPs only – other Health Practitioners in development)*: circa 5540 GP practitioners offering their services in 8240 sites / locations**.**
Publication frequency	Data accessible on request via web based portal and API (Doctors/Locations API & HD Covid Facilities API).
Accessing data	Data accessible on request via web based portal access and API.

Title	**Health Directory**
Open Data portal access	Not at the moment; early engagement with Open Data team to publish data is commencing.
Generic email contact	health.directory@hse.ie
Generic telephone contact	Due to current working from Home arrangements please refer to the email address above.
Other comments	Additional information is available on request.

4.23 Heart Rhythm Ireland (Irish National Pacemaker Register)

Title	**Heart Rhythm Ireland (Irish National Pacemaker Register)**
Managing Organisation	G-Pace Ltd.
Web address	http://www.heartrhythmireland.com/
Year established	2008.
Statement of Purpose	To provide a registry for implanted cardiac devices in Ireland. To both public and Private hospitals.
Coverage **(geographical and temporal)**	38 Hospitals, Approx 50,000 Patients. The Irish National Pacemaker Register commenced in 2008 and is ongoing.
Description/ Summary	A web based database which collects information regarding Pacemakers and ICDs. The initial goal for setting up the database was to produce accurate statistics for Irish implant rates for the first time.
Data users	The key users on the registry are physicians, cardiac technicians and administration staff of Heart Rhythm Ireland.
Data content	Patient demographics, physicians' report of implant procedure, device details – e.g. model number and serial number, lead details – e.g. model number, serial number, technicians follow up report.
Data dictionary	Not available.
National-level identifier variables	There is no PPSN or IHI identifier. HRI generate a unique ID number that the hospitals can identify the patient with when they enter the hospital.
Equity stratifiers	Place of residence for the purpose of sending out ID cards.
Data collection methodology	Data is collected electronically at the point of care and entered by clinical staff in the participating hospitals. The data is uploaded daily as staff enter the data of the device details.
Clinical coding scheme	Not in use.
Size of national collection	Approximately 4,000 records created on average annually.

Title	**Heart Rhythm Ireland (Irish National Pacemaker Register)**
Publication frequency	Data not currently published. Data entered on a daily basis, as devices are implanted.
Accessing data	Each hospital has full access to data regarding their own patients. They also have access to data of those patients who have consented to be available nationally. Anonymous statistical information is supplied to device manufacturers on a quarterly basis. Data not publicly available currently.
Open Data portal access	No.
Generic email contact	info@heartrhythmireland.com
Generic telephone contact	+353 41 6871457
Other comments	

4.24 HIV Antenatal Testing

Title	**HIV Antenatal Testing**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/hivandaids/antenatalhivtesting/reportsonantenatalhivtestinginireland/
Year established	2002.
Statement of Purpose	To provide the best possible information for the control and prevention of infectious diseases, by providing timely information and independent advice, and by carrying out disease surveillance, epidemiological investigation and related research and training. Data on some private patients attending public hospitals is not provided.
Coverage **(geographical and temporal)**	Voluntary participation - 19 maternity hospitals/units participating. Data collected since 2002.
Description/ Summary	Antenatal HIV testing for pregnant women. In April 1999, the Department of Health and Children, on the advice of the National AIDS Strategy Committee (NASC), introduced a policy of voluntary antenatal HIV testing in Ireland. As part of this programme, it is recommended that HIV testing be offered to all women who attend for antenatal services. HPSC were asked to set up a system to monitor the HIV antenatal testing programme.
Data users	Maternity Units/Hospitals; Royal College of Obstetricians and Gynaecologists (RCOG); Department of Health; Departments of Public Health; HPSC-HSE.
Data content	Aggregate data on number of women seen, number offered testing, number accepted testing, number positive, number new positive.
Data dictionary	Not available. No individual data are collected.
National-level identifier variables	
Equity stratifiers	
Data collection methodology	Data are collected on an annual basis by the HPSC from maternity hospitals and units. Surveillance forms are completed by staff in maternity hospitals/clinics on paper or electronically and returned to HPSC.

Title	**HIV Antenatal Testing**
Clinical coding scheme	Not required.
Size of national collection	19 Maternity Hospitals/Units provide data which contributes 19 records of data annually.
Publication frequency	Reports on the Antenatal HIV programme are published annually on the HPSC website.
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.25 Hospital In-Patient Enquiry (HIPE)

Title	**Hospital In-Patient Enquiry (HIPE)**
Managing Organisation	Healthcare Pricing Office (HPO) within the National Finance Division, HSE.
Web address	www.hpo.ie
Year established	Commenced as a pilot in 1969. Rolled out to all acute public hospitals in early 1970s. Between 1990 and 2013 the Economic and Social Research Institute (ESRI) managed the scheme on behalf of the Department of Health and the HSE. Since January 2014 the scheme has been managed by the Healthcare Pricing Office (HPO) in the HSE (www.hpo.ie).
Statement of Purpose	To maintain a timely accurate national database of hospital discharge activity that meets the needs of the data users (including policymakers, clinical teams and researchers), through the development and support of the data collection and reporting software, training of coders, data quality, audit, reporting, and responding to requests for data. All acute public hospitals participate in HIPE. Private hospitals are not included.
Coverage (geographical and temporal)	National- all acute public hospitals participate in HIPE. HIPE data collection commenced in 1971 and is ongoing.
Description/ summary	HIPE is the principal source of national data on discharges from acute hospitals in Ireland.
Data users	HSE, policy-makers, clinical teams and researchers.
Data content	HIPE collects demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally.
Data variables/ data dictionary	Yes – full data dictionary published on HPO website. www.hpo.ie
National-level identifier variables	There is no national unique identifier. HIPE collects Hospital level healthcare record number. At national level HIPE collects month and year of birth, full date of birth is collected at hospital level only.

Title	**Hospital In-Patient Enquiry (HIPE)**
Equity stratifiers	Sex, age, area of residence captured by HIPE and included in data dictionary. Equity stratifiers not specifically identified currently. HIPE data relies on information collected at hospital level.
Data collection methodology	Information is abstracted from medical charts or records and coded by trained clinical coders in line with national and international coding guidelines before entering into HIPE system (HIPE Portal). HIPE data is exported from acute hospitals to the HPO on a monthly basis with an expectation of a time lag of 28 days post patient discharge.
Clinical coding scheme	Discharges are coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), Australian Classification of Health interventions (ACHI), Australian Coding Standards (ACS), 10th Edition. 10th edition was introduced in January 2020. Irish Coding Standards (ICS) are published annually by the HPO to provide guidance on the use of the classification in Ireland. An updated clinical coding classification is adopted every 4-5 years to ensure currency and comparability internationally.
Size of national collection	Approximately 1.7 million HIPE records created annually.
Publication frequency	Activity in Acute Public Hospitals in Ireland annual reports are available on the HPO website, www.hpo.ie.
Accessing data	Data sets for HIPE discharges are provided to a number of state agencies in order to address specific data requirements. Data requests can be submitted using the online data request form, available at www.hpo.ie. The HPO also manages an online data reporting tool. HIPE annual reports, Activity in Acute Public Hospitals in Ireland are available at www.hpo.ie.
Open Data portal access	Yes.
Generic email contact	info@hpo.ie
Generic telephone contact	+353 87 2558124
Other comments	Additional information and documentation regarding HIPE is available at www.hpo.ie

4.26 Immunisation Uptake Statistics at 12 and 24 months of age

Title	**Immunisation Uptake Statistics at 12 and 24 months of age**
Managing Organisation	HSE-Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/vaccinepreventable/vaccination/immunisationuptakestatistics/immunisationuptakestatisticsat12and24monthsofage/
Year established	2000.
Statement of Purpose	To measure the national uptake of the vaccines recommended as part of the primary childhood immunisation schedule.
Coverage **(geographical and temporal)**	National coverage of children 12 months of age and children 24 months of age. Data also reported by Community Healthcare Organisation, (former) HSE Area and Local Health Office
Description/ Summary	Vaccines in the primary childhood immunisation schedule are given by General Practitioners; the returns (records of GP administered vaccinations to patients) are sent to the local HSE Area and recorded on the local database. Each HSE area maintains a childhood immunisation database and since 2000 provides HPSC with immunisation uptake data on a quarterly basis. These data relate to children on the HSE area databases who reached their first or second birthday (uptake at 12 and 24 months, respectively) in that quarter and who received the recommended number of doses of vaccines against diphtheria, pertussis, tetanus, *Haemophilus influenzae* type b, polio and meningococcal group C, meningococcal group B, pneumococcal conjugate vaccine, rotavirus vaccine, measles, mumps and rubella. HPSC collates the national immunisation uptake data and produces quarterly and annual reports which are available on the HPSC website.
Data users	Immunisation staff in the Community Healthcare Organisations (CHOs), HSE-National Immunisation Office (NIO), Departments of Public Health, HSE-HPSC.
Data content	Number eligible for immunisation with each vaccine/antigen; number immunised with each vaccine/antigen; % uptake for each vaccine/antigen. These data are collated by Local Health Office, and former HSE Areas.
Data dictionary	Yes. Not available online.

Title	**Immunisation Uptake Statistics at 12 and 24 months of age**
National-level identifier variables	No.
Equity stratifiers	No.
Data collection methodology	Immunisation uptake data are requested from the HSE areas by HPSC six weeks after quarter end. It is requested that the HSE areas extract the data from their databases within two weeks of this request. Data should be submitted to HPSC as soon as possible after this. The published data are data held on the database on the day of data extraction.
Clinical coding scheme	Not in use.
Size of national collection	Aggregate data on approx. 60,000 children in 2021 (equivalent to annual birth cohort).
Publication frequency	Quarterly reports published on HPSC website.
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300
Other comments	The National Immunisation Office (NIO) oversees day-to-day implementation of the national immunisation programme by the HSE and is responsible for the procurement and distribution of vaccines and related training activities (cold chain management, vaccination guidance). It also provides up-to-date information leaflets for parents and health-care professionals. It hosts a website http://www.hse.ie/eng/health/immunisation/ and is developing a national IT register for immunisations. The 2013, and updates to the Immunisation Guidelines are available on the HSE website and on HPSC website.

4.27 Influenza immunisation Uptake Statistics among health care workers

Title	**Influenza immunisation Uptake Statistics among health care workers**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzaandhealthcareworkers/
Year established	2011 (for the 2011-2012 influenza season).
Statement of Purpose	In scope: To provide data on influenza vaccine uptake among health care workers (HCWs) working in Irish hospitals and long-term care facilities (LTCFs).
Coverage **(geographical and temporal)**	National. Annual surveys to date have been conducted during the official flu season with a request issued for provisional data in early November for mid-December and again in late February for mid-March.
Description/ Summary	Each hospital or long term care facility reports on number of staff vaccinated with influenza vaccine for the current influenza season, the total number of staff employed during the period under review (influenza season) by staff category. Additional information is collected on the uptake of the vaccine among long term and respite residents of LTCFs. The data is currently provided twice during the influenza season (mid-season and end of season). HPSC collates the data and produces a mid-season/provisional and end of season reports which are available on the HPSC website.
Data users	Key Users: National Immunisation Office, World Health Organisation, Department of Health, Senior HSE Management and other stakeholders such as flu leads based in Hospital Groups and in Community Health Organisations.
Data content	Number of HCW staff, by professional category; number vaccinated with influenza vaccine; percentage uptake.
Data dictionary	Not available.
National-level identifier variables	No, the data collected is aggregate-based with only the reporting healthcare facility and the hospital group/CHO area to which it belongs/is located.
Equity stratifiers	No.
Data collection methodology	Each hospital or long term care facility has a contact point. This contact point is sent an email at midseason and end of season with a

Title	**Influenza immunisation Uptake Statistics among health care workers**
	link to a web-based survey is circulated via email. Healthcare facility managers or designated flu leads input data relating to the number of staff employed and number vaccinated with influenza vaccine by staff professional category, (of which there are six official HSE categories). Data are downloaded in HPSC via the Qualtrics platform, held on an excel database and analysed. Analyses are later published on the HPSC website.
Clinical coding scheme	Not in use.
Size of national collection	For each facility a record is created- approximately 50 to 65 hospitals, (including privates ones), and 292 more residential care facilities. Based on 2021-2022 season data returns, the number of eligible staff from reporting hospitals and LTCFs was 70,857 (hospital HCWs) and 21,648 (LTCF HCWs), respectively.
Publication frequency	Provisional figures are reported during mid-season with a complete annual report published on HPSC website (www.hpsc.ie).
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300
Other comments	A current protocol document and reports from the 2012-2013 season onwards are available on the HPSC website: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzaandhealthcareworkers/

ICU Bed Information System (ICU BIS)

4.28 Intensive Care Unit - Bed Information System (ICU-BIS)

Title	**Intensive Care Unit - Bed Information System (ICU-BIS)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	www.noca.ie
Year established	2020.
Statement of Purpose	To provide timely data for managing ICU capacity, bed availability and facilitation of inter-hospital transfers. During the pandemic, ICU-BIS scope expanded to provide information on COVID-19 specific data and trends for decision makers in the HSE and Department of Health to guide policy. In-scope: Intensive care units occupancy and capacity data. Out of scope: detailed patient level information, this is collected via the ICU audit.
Coverage (geographical and temporal)	National ; ▪ 26 adult public hospitals who have an ICU ▪ 2 paediatric ICUs at CHI ▪ 5 private hospitals who have an ICU. Temporal coverage: March 2020 to date.
Description/summary	Data collected by ICU-BIS falls into two categories; ICU occupancy data and COVID-19 specific patient data. ICU occupancy data; Total beds, Staffed /Open beds, occupied beds, reserved beds for new admission, patients cleared for discharge to a ward bed, available beds, number of patients invasively ventilated, number of patients receiving Dialysis (both Intermittent haemodialysis (IHD)& Continuous renal replacement therapy (CRRT). COVID-19 specific patient data; (i) numbers of COVID-19 patients in each Unit, (ii) numbers invasively ventilated, (iii) new admissions, (iv) discharges and (v) deaths in the last 24 hours. Patient level data on COVID-19 patients regarding age, sex, vaccination status, whether currently or recently pregnant (If female), primary reason for admission to ICU (COVID or Non-COVID), location in, source of infection (if known).
Data users	Data from ICU-BIS is issued daily to many stakeholders. This data is incorporated in internal hospital, hospital group, and HSE and DoH

Title	**Intensive Care Unit - Bed Information System (ICU-BIS)**
	dashboards. Data also used to inform the public, for modelling, research and open data. Groups; HPSC, IEMAG, DoH, NCAGL/CCO, SDU, ESRI, QID,CSO,RCSI HG, IEHG, SSWHG, DMHG, CCP, Critical care community (Clinicians, Doctors, Nurses), Critical care programme.
Data content	ICU occupancy data; Total beds, Staffed /Open beds, occupied beds, reserved beds for new admission, patients cleared for discharge to a ward bed, available beds, number of patients invasively ventilated, number of patients receiving Dialysis (both Intermittent haemodialysis (IHD)& Continuous renal replacement therapy (CRRT). COVID-19 specific patient data; (i) numbers of COVID-19 patients in each Unit, (ii) numbers invasively ventilated, (iii) new admissions, (iv) discharges and (v) deaths in the last 24 hours. Patient level data on COVID-19 patients regarding age, sex, vaccination status, whether currently or recently pregnant (If female), primary reason for admission to ICU (COVID or Non-COVID), location in, source of infection (if known).
Data variables/ data dictionary	Not publicly available but available on request from NOCA, see www.noca.ie for contact details.
National-level identifier variables	No national-level identifier variables collected.
Equity stratifiers	For Covid positive patients only: age and gender.
Data collection methodology	The ICU-BIS data are updated at least once a day on the ICU BIS website, providing up-to-date information on ICU bed occupancy and COVID specific data. A designated user (ICU Consultant/doctor, Clinical Nurse Manager, Nurse in charge, ICU clerical support, Bed management) in each of the participating hospitals enters or gives the data to the NOCA data collector. The data is validated daily by NOCA.
Clinical coding scheme	None.
Size of national collection	Varied dependent on COVID surge.
Publication frequency	Daily to COVID response.
Accessing data	Data request form available at https://www.noca.ie/about-noca/access-to-audit-data

Title	**Intensive Care Unit - Bed Information System (ICU-BIS)**
Open Data portal access	Yes HSE COVID-19 daily operations updates; https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/coronavirus-daily-operations-updates.html Ireland's COVID-19 Data Hub :ICU Section (Government of Ireland); https://covid19ireland-geohive.hub.arcgis.com/ Ireland's Open Data Portal : COVID-19 NOCA ICUBIS Historic Time Series (Government of Ireland); https://covid-19.geohive.ie/datasets/c8208a0a8ff04a45b2922ae69e9b2206_0 Weekly COVID-19 country overview (ECDC); https://covid19-country-overviews.ecdc.europa.eu/
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

coimisiún meabhair - shláinte
mental health commission

4.29 Involuntary Admission Activity (Adults) *

*This template has not been updated since version 3.0 of the Catalogue in 2017.

Title	**Involuntary Admission Activity (Adults)**
Managing Organisation	Mental Health Commission (MHC)-Tribunals Division.
Web address	http://www.mhcirl.ie/
Year established	2006.
Statement of Purpose	The Commission was established in 2002. They are an independent body and their functions are set out by law in the Mental Health Act 2001. Their main functions are to promote, encourage and foster high standards and good practices in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted. The Mental Health Commission is responsible for regulating and monitoring mental health services. Data on the involuntary admissions of adults to approved centres are collected in accordance with provisions in the following legislation: ▪ Mental Health Act, 2001 ▪ Mental Health Act, 2008. Data are processed in adherence with the following legislation: ▪ Data Protection (Amendment) Act 2003 ▪ Data Protection Act 1988 ▪ Freedom of Information (Amendment) Act 2003 ▪ Freedom of Information Act 1997.
Coverage **(geographical and temporal)**	National – all involuntary admissions to approved centres.
Description/ Summary	Under Section 33(3) of the Mental Health Act, 2001, the Mental Health Tribunals Division of the Mental Health Commission is responsible for establishing mental health tribunals for patients admitted on an involuntary basis. MHC collects demographic and clinical involuntary admission data, in relation to adults, in order to fulfil this statutory function.
Data users	

Title	**Involuntary Admission Activity (Adults)**
Data content	Name; address; date of birth; gender; date of involuntary admission and approved centre.
Data dictionary	No data dictionary available. Data requirements are outlined in the two Statutory forms: http://www.mhcirl.ie/File/Form_6_Revised_01_12_2011.pdf http://www.mhcirl.ie/File/Form_13_Revised_01_12_2011.pdf
National-level identifier variables	
Equity stratifiers	
Data collection methodology	A suite of statutory forms are used by centres approved under the Mental Health Act 2001 to notify the Commission of the required information relating to each involuntary patient. Information is held in their 'System for Involuntary Admission and Tribunals' (SIAT).
Clinical coding scheme	ICD-10.
Size of national collection	2,400 average number of records created annually.
Publication frequency	Quarterly reports and MHC annual reports since 2006.
Accessing data	Quarterly reports on MHC website, MHC annual report and data requests.
Open Data portal access	No.
Generic email contact	info@mhcirl.ie
Generic telephone contact	+353 1 6362400

4.30 Irish Biologic Therapies Register*

*This template has not been updated since version 2.0 of the Catalogue in 2014.

Title	**Irish Biologic Therapies Register**
Managing Organisation	Rheumatology Department St. Vincent's University Hospital.
Web address	
Year established	2004.
Statement of Purpose	To collect data on all patients attending the rheumatology service who receive biologic therapies, predominantly anti-tumour necrosis factor (anti-TNF therapies).
Coverage **(geographical and temporal)**	Patients who attend the Rheumatology Department and receive biological therapies at St. Vincent's University Hospital.
Description/ Summary	This register collects data on all patients attending the rheumatology service who receive biologic therapies (predominantly anti-TNF therapies).
Data users	
Data content	Demographics, clinical data, treatment, and outcome measures.
Data dictionary	
National-level identifier variables	
Equity stratifiers	
Data collection methodology	Data is entered in real time in the clinic by clinicians and afterwards from a questionnaire completed by patients who have attended the clinic.
Clinical coding scheme	No.
Size of national collection	
Publication frequency	Annual.
Accessing data	Data submitted to European League Against Rheumatism (EULAR) and Annals of Rheumatic Disease.
Open Data portal access	

Title	**Irish Biologic Therapies Register**
Generic email contact	
Generic telephone contact	
Other comments	This template has not been updated since Version 2.0 of the Catalogue in 2014.

4.31 Irish Childhood Diabetes National Register (ICDNR)

Title	**Irish Childhood Diabetes National Register (ICDNR)**
Managing Organisation	Children's Health Ireland (CHI) at Tallaght University Hospital and Trinity College Dublin.
Web address	Not web enabled. Information on the ICDNR is available at: https://www.tcd.ie/medicine/paediatrics/research/projects/ https://www.diabetes.ie/living-with-diabetes/child-diabetes/16867-2/
Year established	2008.
Statement of Purpose	To develop and maintain an epidemiological register, of children and young people under the age of fifteen years, developing type 1 diabetes, not secondary to any other condition, in the Republic of Ireland.
Coverage **(geographical and temporal)**	19 participating centres nationally. One smaller independent centre has merged with a tertiary centre in 2020. Data collection began in January 2008 and is ongoing to date.
Description/ Summary	The purpose of this collection is to develop and maintain an epidemiological register, of children and young people under the age of fifteen years, developing type 1 diabetes, not secondary to any other condition, in the Republic of Ireland. Data is collected in hard copy format from all participating centres. Input to Microsoft Access Database on the Tallaght University Hospital server.
Data users	The data collection is used by the key Research staff working with the ICDNR project.
Data content	Location (urban/rural); date of birth; country of birth (if overseas -date of arrival in Ireland); ethnic group/origin; gender; date of diagnosis; source of referral; date of first Insulin Injection; hospital at which diagnosis was made; consultant responsible for care; symptoms and duration of symptoms (in days/weeks); blood results at diagnosis; height/weight at first discharge; number of brothers/sisters; birth order; birth history; birth weight, gestation (in weeks) mode of delivery); infant feeding; (exclusive breast feeding? (yes/no); age at first solid feed (in months)); BCG vaccination (yes/no); history of type 1 or 2 diabetes in immediate family (mother, father, brother, sister, twin); associated conditions/autoimmune disease; medical card (yes/no); private health insurance (yes/no).

Title	**Irish Childhood Diabetes National Register (ICDNR)**
Data dictionary	Not available online.
National-level identifier variables	No.
Equity stratifiers	No.
Data collection methodology	Data is collected on an ongoing basis throughout the year at the point of care by local paediatric consultants/endocrinologists and diabetes nurse specialists. Cross-checks are carried out with centres frequently and at least quarterly. Data entered on proforma data sheets and centrally entered onto the register.
Clinical coding scheme	Not in use.
Size of national collection	300 records created on average nationally.
Publication frequency	Ongoing data collection. Publication of incidence data as years are closed, checked and verified.
Accessing data	Through relevant medical publications and presentations. Requests to Steering Group for anonymous data.
Open Data portal access	No.
Generic email contact	diabetes.register@tcd.ie
Generic telephone contact	+353 1 8963763
Other comments	The Register provides data to the HSE to support service planning and resource allocation decisions to optimise the care of children with diabetes in Ireland.

4.32 Irish Database of Statutory Notifications from Social Care

Title	**Irish Database of Statutory Notifications from Social Care**
Managing Organisation	Health Information and Quality Authority.
Web address	https://www.hiqa.ie/areas-we-work/Database-of-Statutory-Notifications (Open access version only)
Year established	2020.
Statement of Purpose	The LENS (**LE**arning from Statutory **N**otifications in **S**ocial Care) Project is a HIQA initiative to compile statutory notification data into an analysable database and to use these data to inform quality and safety improvements in social care services. The LENS Project is funded by Health Research Board's Secondary Data Analysis Project Grant [SDAP-2019-005] and co-funded by HIQA. The database includes notifications received from specified social care services, primarily residential centres for older persons and people with disabilities.
Coverage **(geographical and temporal)**	Republic of Ireland. Data from 2013 to 2020 is currently available and data is added on a yearly basis.
Description/ Summary	The Chief Inspector in HIQA is responsible for regulating nursing homes and residential services for people with disabilities (collectively referred to herein as designated centres). Among the regulatory requirements of designated centres is the reporting of incidents and adverse events that occur in their services, to the Chief Inspector. Some events are required to be reported within three days (for example, serious injury, outbreak of disease) and others are reported every three months (for example, pattern of theft or burglary, use of restrictive practices).
Data users	Residents of social care services; advocates; health researchers; regulatory agencies.
Data content	Any information relevant to the regulatory requirement to submit statutory notifications in accordance with regulations for the care and welfare of people living in nursing homes and residential disability services.

Title	**Irish Database of Statutory Notifications from Social Care**
Data dictionary	There is a data dictionary available for the open access version: https://www.hiqa.ie/sites/default/files/2021-02/Database-of-Statutory-Notifications-from-Social-Care-Open-Access_Data-Dictionary.pdf
National-level identifier variables	It is a requirement that there is no personally identifiable information submitted for the dataset.
Equity stratifiers	N/A.
Data collection methodology	Designated centres for older people and people with a disability are required to submit notifications to the Chief Inspector in HIQA under the Health Act 2007 and associated regulations.
Clinical coding scheme	N/A.
Size of national collection	80,000.
Publication frequency	Yearly.
Accessing data	Open access is available online here: https://www.hiqa.ie/areas-we-work/Database-of-Statutory-Notifications The full-version is only available to HIQA staff internally or by request to lens@hiqa.ie
Open Data portal access	No.
Generic email contact	lens@hiqa.ie
Generic telephone contact	+353 21 2409300

4.33 Irish Epidermolysis Bullosa (EB) Registry

Title	**Irish Epidermolysis Bullosa (EB) Registry**
Managing Organisation	National and International Skin Registry Solutions (NISR) CLG.
Web address	https://nisrsolutions.com
Year established	2021.
Statement of Purpose	The Irish Epidermolysis Bullosa (EB) Registry was established in 2020 as a subcommittee of the National and International Skin Registry Solutions CLG to identify, collect, record, store and analyse information relating to the prevalence and incidence of EB. This information could be used to examine how symptoms and treatments change over time and the impact that evolving therapies have on patient and physician reported outcomes. Information on EB could be provided to governmental agencies, health care providers and payers, and help improve planning and delivery of care and services for people with EB. It will also provide an important source of information for future research and advocacy. Key aspects of the registry: It incorporates best international practice in international registries It is a not-for-profit initiative The dataset is based on open source code and will be available to all, facilitating interoperability across platforms The data model is patient-centred and workflows are clinician-centred Registry experts, clinicians and patients guided the develop of the registry The registry has the potential to be expanded and further developed to support EB clinical care The registry is GDPR compliant and has been approved by the hospital ethics committees where data is collected from Through broadscale participation and collaboration, we will be able to answer pressing questions for our EB patients and their caregivers.
Coverage	Geographic: This registry is currently running from Crumlin Children's Hospital and St James Hospital.

Title	**Irish Epidermolysis Bullosa (EB) Registry**
(geographical and temporal)	Temporal: Data collection commenced March 2021 and is ongoing.
Description/ Summary	The Irish EB registry is an observational study of the EB patient population in Ireland recently launched by NISR. It is being run at Our Lady's Children's Hospital Crumlin and St James's Hospital, Dublin. By collecting and analysing information on people with EB in Ireland, we can better understand their health and wellbeing, and the benefits of treatments provided.
Data users	Key users of this data collection include; clinical teams, government agencies, health boards, hospitals, health care professionals, approved researchers, policy makers (e.g., EMA) and the HSE.
Data content	EB Registry collects data relating to demographics and diagnosis of patients at baseline and their health status at each hospital visit, (e.g. height, weight, blood test results, procedures, treatments, health complications, healthcare service use and information about how the condition and treatments impact patients' quality of life).
Data dictionary	A list of collected variables is available upon request.
National-level identifier variables	There is no national-level identifier however each patient enrolled is assigned their own unique registry I.D.
Equity stratifiers	The EB dataset collects data relating to sex, country of birth, educational level and ethnicity.
Data collection methodology	Enrolment in the registry is subject to a process of gaining informed explicit consent from patients diagnosed with EB/their parents or carer (if under 18). Participation is voluntary. The data is then collected from the patient's charts after their standard clinic visits and entered onto the registry platform. Data is collected from patient medical charts and inputted into a secure internet-based computer database. Data collection is undertaken by EB registry data collectors. Data is collected on a continual basis throughout the year and EB data collectors collect data on an encounter basis.
Clinical coding scheme	N/A, this system does not use coding.
Size of national collection	We do not yet have that data.
Publication frequency	This data will be published annually via annual reports.

Title	**Irish Epidermolysis Bullosa (EB) Registry**
Accessing data	Summary data is published in the Annual Report. EB consultant/team can request read only access to their centre's patient data. Researchers can request access to de-identified data by submitting an Irish EB Data Application Form. Each application is reviewed by the Irish EB Scientific Committee and must be approved prior to the release of any data. Please direct any emails to: ebregistry@nisrsolutions.com
Open Data portal access	No.
Generic email contact	ebregistry@nisrsolutions.com
Generic telephone contact	+353 1 7166320
Other comments	The registry is accessible to permitted users only through secure internet access.

IHAA Irish Heart Attack Audit

4.34 Irish Heart Attack Audit (IHAA)

Title	**Irish Heart Attack Audit (IHAA)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	2012 - under governance of the HSE National Acute Coronary Syndrome Programme, governance transferred to NOCA in 2019.
Statement of Purpose	Aim: To conduct audit of Acute Coronary Syndrome (ACS) care. IHAA objectives can be found at this link: https://www.noca.ie/acs-objectives In scope: ▪ Currently the IHAA collects data on all patients with an ST elevated Myocardial Infarction (STEMI), who are admitted to a percutaneous intervention (PCI) centre for Primary PCI ▪ Patients can be either admitted directly to a PCI centre or transferred from another hospital to the PCI centre ▪ Cases reported are 18 years or more. Out of scope: ▪ No data is collected on patients with a Non-ST elevated Myocardial Infarction (NSTEMI) or unstable angina at this time ▪ All cases less than 18 years of age.
Coverage (geographical and temporal)	National. All hospitals that provide a Primary PCI service, n=10. The degree of coverage of STEMI cases is based on the number of STEMI (ICD 10 AM codes i21.0, i21.1, i21.2, i21.3) cases discharged from the PCI centres against the number of cases submitted onto the Heartbeat portal via HIPE (Hospital In-patient Enquiry) system.
Description/ summary	The Irish Heart Attack Audit reports on data from the Heartbeat portal which is a web based system that uses the HIPE portal infrastructure. It audits against agreed standards and guidelines and reports on outcomes for patients with STEMI.

Title	**Irish Heart Attack Audit (IHAA)**
Data users	HSE Business Intelligence Unit, hospital groups, hospital managers/CEO's, clinical teams.
Data content	Demographics, past medical history/risk factors, reperfusion timeliness (e.g. door to balloon, first medical contact to balloon), secondary prevention and outcomes.
Data dictionary	Data dictionary not currently available online but available on request from NOCA please see www.noca.ie for contact details.
National-level identifier variables	No access to individual identifiers available Nationally.
Equity stratifiers	The IHAA data dictionary links to the HIPE data dictionary which includes: age and gender.
Data collection methodology	Data is taken from the medical record by audit coordinators (senior cardiology nursing staff) with permitted access and inputted into the HIPE Heartbeat portal. Data can be entered while the patient is an in-patient and completed on discharge. Data entry is requested to be complete within the quarter following discharge from hospital. If a patient is transferred to a local hospital for on-going acute STEMI care audit coordinators contact colleagues in the local hospital to access additional outcome data e.g. discharge destination. All data must be submitted by the close of the HIPE file, usually one quarter after end of calendar year.
Clinical coding scheme	ICD 10 AM.
Size of national collection	1500.
Publication frequency	Two National KPIs are reported quarterly to the HSE BIU and to the Hospital Groups – preliminary data until year end. National report published will be published annually. Dashboard reports due to be reported quarterly in 2022.
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.

Title	**Irish Heart Attack Audit (IHAA)**
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577
Other comments	

Irish Hip Fracture
Database IHFD

4.35 Irish Hip Fracture Database (IHFD)

Title	**Irish Hip Fracture Database (IHFD)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	2012.
Statement of Purpose	Develop a prospective audit of case-mix, care standards and outcomes for hip fracture care and use synergy of standards, data, feedback and quality improvement to focus attention on hip fracture care locally and nationally. It benchmarks care and uses data to create a drive for sustained improvements in clinical standards and cost-effectiveness. IHFD objectives can be found at this link: https://www.noca.ie/audits/ihfd-objectives In scope: ▪ All hospitals that provide acute hip fracture services, n=16 ▪ All patients with principle or secondary diagnosis ICD 10 AM codes either identified as a HIPE Injury Diagnosis Code S72.00 to S72.2 OR with a specified type of hip fracture (e.g. intracapsular – displaced, intracapsular – undisplaced, intertrochanteric, or subtrochanteric) are recorded in the IHFD ▪ All cases recorded are >18 years of age and the reference population for the national report are >60 years of age ▪ For hospital level reporting each hospital must have >80% of their hip fracture cases submitted to the IHFD. Out of scope: ▪ Hospitals who do not provide hip fracture services ▪ All cases <18 years of age.
Coverage **(geographical and temporal)**	National - all acute hospitals that operate on hip fracture patients (16 Hospitals in total). Coverage is based on discharges within the calendar year for example 1/1/22-31/12/22. The percentage of patients with HIPE episodes for

Title	**Irish Hip Fracture Database (IHFD)**
	hip fracture with data coded on the IHFD are included. The HIPE system closes the national HIPE file usually by 31/3/23).
Description/ Summary	The Irish Hip Fracture Database (IHFD) is a web based system that uses the HIPE (Hospital In-patient Enquiry) portal infrastructure. It audits care standards and outcomes for patients with hip fractures.
Data users	Hospital managers/ CEO's, hip fracture governance committees, hospital groups, Healthcare Pricing Office (HPO), Business Intelligence Unit (BIU), Clinical Programme for Trauma and Orthopaedics, National Office of Trauma Services.
Data content	Demographics, details of time/date of injury, type of injury, time to surgery, surgeon grade, anaesthetic grade, type of fracture, surgery, anaesthetic, input from geriatrician, falls assessment, bone health assessment, physiotherapy input. Outcomes- LOS, discharge destination, functional outcomes.
Data dictionary	Data dictionary and abbreviated data dictionary available at request from IHFD audit manager. Details on the http://www.noca.ie
National-level identifier variables	No national level identifiers are available.
[Equity stratifiers]()	The HIPE variables merged with the IHFD dataset includes: age, gender, marital status (not reported on).
Data collection methodology	Data is taken from the medical record by clinical staff with permitted access and inputted into the IHFD add-on screen on the HIPE portal. Data can be entered while the patient is an in-patient and completed on discharge. Data entry is requested to be complete within the quarter following discharge from hospital. All data must be submitted by the close of the HIPE file, usually one quarter after end of calendar year. A data collection/ reporting calendar with quarterly targets is used each year for the hospitals to align their data entry to.
Clinical coding scheme	ICD 10 AM.
Size of national collection	3700 records created on average nationally.
Publication frequency	Quarterly data on the seven Irish Hip Fracture Standards (IHFS) are reported to the hospitals and hospital groups, HPO and Clinical Programme for Trauma and Orthopaedics along with the Best Practice Tariff. Quarterly reports are sent to the BIU on IHFS 2. Quarterly BPT reports are shared with the HPO. Annual reports.
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data

Title	**Irish Hip Fracture Database (IHFD)**
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

4.36 Irish Motor Neurone Disease Register

Title	**Irish Motor Neurone Disease Register**
Managing Organisation	National Motor Neurone Disease (MND) Clinic.
Web address	http://mnd.ie/
Year established	1994 (Full roll-out 1995).
Statement of Purpose	The purpose of the Register is to track the incidence, prevalence and clinical features of MND in the Irish population. The Register aims to gather a relatively narrow capture of key variables on all MND patients which help us describe the population. More detailed information is gathered through cohort studies to which people identified through the Register are consented separately.
Coverage **(geographical and temporal)**	All known patients diagnosed with MND each year in the Republic of Ireland. Temporally data is collected from a person with MND as soon as they consent to be included which is generally shortly after they are diagnosed. Data collection is actively continued, mainly through the health record until the person dies. After a person is deceased, a limited form of data collection can continue if we receive further information on their family history, usually this occurs when another member of the same family is diagnosed with the condition.
Description/ Summary	The Irish MND register includes all known patients diagnosed with MND each year. It dates back to 1994 and it now has clinical information from over 2,300 patients. On average 110 new cases per annum, with 300 people affected at any one time. A DNA bank was added in 1998. This bank contains samples from over 1250 patients.
Data users	Members of Prof. Hardiman's ALS Research Team are the most common users. Additional users include European collaborators on jointly funded MND research projects. Patient Advocacy groups, e.g. Irish Motor Neurone Disease Association, avail of statistics generated by the collection for service planning. Allied health professionals with reason to need up-to-date Irish MND statistics for educational or service planning needs.
Data content	Age, the date of onset, type of MND, clinical features, progression, survival, presence of associated features including cognitive decline.
Data dictionary	Yes data dictionary is in place. Not available.
National-level identifier variables	No national level identifiers used.
Equity stratifiers	Place of residence, gender, education, occupation and occupational status are included in the dataset.
Data collection methodology	HIPE departments in all major hospitals are searched using ICD-9 to ascertain and confirm all MND diagnosis. The Central Statistics Office (CSO) Deaths Register is searched using ICD-9 primarily to capture MND cases where the subject passed away shortly after diagnosis. The

Title	**Irish Motor Neurone Disease Register**
	register is based on direct nationwide chart review/ confirmation by the diagnosing physician.
Clinical coding scheme	ICD-9: Amyotrophic lateral sclerosis (ALS), MND, Progressive Bulbar palsy.
Size of national collection	120 average number of new cases registered annually.
Publication frequency	Scientific peer-reviewed publications listed on the TCD website (Click here for publication list). Data continuously updated.
Accessing data	Requests for data or statistics from the register are considered on a case by case basis after contact has been made either via the email below or directly to Professor Hardiman.
Open Data portal access	No.
Generic email contact	mndregister@gmail.com
Generic telephone contact	See http://mnd.ie/research-resources/
Other comments	None.

4.37 Irish National Audit of Stroke (INAS)

Title	**Irish National Audit of Stroke (INAS)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	2012 - under governance of the HSE National Stroke Programme, governance transferred to NOCA in 2019.
Statement of Purpose	Aim: To conduct audit of stroke care including clinical care and service organisation. INAS objectives can be found at this link: https://www.noca.ie/audits/inas-objectives In scope: ▪ All hospitals that provide acute stroke services, n=24 ▪ All patients with principle diagnosis ICD 10 AM codes i61 (haemorrhagic stroke), i63 (Ischaemic stroke), i64 (stroke unspecified) or with a hospital acquired diagnosis (HADx) of ICD 10 AM codes i61, i63, i64 ▪ All cases reported are >16 years of age ▪ For inclusion in the INAS National report each hospital must have >80% of their stroke cases submitted to the stroke audit portal. Out of scope: ▪ Hospitals who do not provide acute stroke services ▪ All cases <16 years of age ▪ Cases coded as subarachnoid haemorrhage (ICD 10 AM i60) ▪ Cases coded as sub-dural haemorrhage (ICD 10 AM i62) ▪ Hospitals with <80% of their stroke cases submitted to the stroke audit portal within the HIPE (Hospital In-patient Enquiry) system.
Coverage (geographical and temporal)	National. All hospitals that provide acute stroke services, n=24. Coverage is based on discharges within the calendar year for example 1/1/22-31/12/22. The percentage of patients with ICD 10 AM codes i61, i63, i64 discharged from each of the 24 hospitals who have >80% of those cases with additional clinical audit data submitted to the

Title	**Irish National Audit of Stroke (INAS)**
	stroke audit portal within the HIPE system by the close of the HIPE file (normally closed by 31/3/23).
Description/ summary	The Irish National Audit of Stroke is a web based system that uses the HIPE portal infrastructure. It audits against agreed standards and guidelines and reports on outcomes for patients with stroke.
Data users	HSE Business Intelligence Unit, hospital groups, hospital managers/CEO's, clinical stroke teams.
Data content	Demographics, emergency care timeliness (e.g. Door to Imaging, Thrombolysis, Thrombectomy), stroke unit care, secondary preventions, outcomes, health and social care professional dataset.
Data variables/ data dictionary	Data dictionary not currently available online but available on request from NOCA< please see www.noca.ie for contact details.
National-level identifier variables	No access to individual identifiers available Nationally.
Equity stratifiers	The INAS data dictionary links to the HIPE data dictionary which includes age and gender.
Data collection methodology	Data is taken from the medical record by audit coordinators (senior nursing staff) with permitted access and inputted into the HIPE stroke audit portal. Data can be entered while the patient is an in-patient and completed on discharge. Data entry is requested to be complete within the quarter following discharge from hospital. All data must be submitted by the close of the HIPE file, usually one quarter after end of calendar year.
Clinical coding scheme	ICD 10 AM.
Size of national collection	6000.
Publication frequency	Three KPIs reported quarterly to the HSE BIU and to the Hospital Groups – preliminary data until year end. National report published annually. Dashboard reports due to be reported quarterly in 2022.
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data

Title	**Irish National Audit of Stroke (INAS)**
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

4.38 Irish National Intensive Care Unit (ICU) Audit

Title	**Irish National Intensive Care Unit Audit (ICU) Audit**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	2015 (January, data collection in first unit began). 2019 Phase1 and Phase 2 Units in 22 hospitals collecting data. Planned roll-out to remaining 4 acute hospitals by 2023 and Private hospitals engagement to follow.
Statement of Purpose	National ICU Audit aims to; ▪ Measure indicators of the quality of care in each ICU and benchmark these against other units in Ireland and the UK through the Intensive Care National Audit and Research Centre ICNARC – the UK body for ICU Audit ▪ Measure activity in each unit to aid the planning of critical care services locally and nationally ▪ Provide data on complexity of care provided for each patient with potential to link this to reimbursement in the future ▪ National Coverage to include all ICU's in Public and Private sector ▪ Improve the quality of data for HIPE by providing data on procedures and diagnoses arising while the patient is in ICU to link cost to complexity of care ▪ Support Irish and international research to enhance patient care.
Coverage **(geographical and temporal)**	National audit with data collection from public and private hospitals with Intensive Care Units. National Coverage to include all ICUs in Public and Private sector.
Description/ Summary	National Intensive Care Audit is a computer-based system designed to collect demographic, clinical and outcome details on admissions to ICU's, in hospitals nationally.
Data users	▪ HSE and DOH ▪ Hospital staff Clinical and non-Clinical ▪ General Public through public reporting.
Data content	Demographic details; admission details; clinical details; comorbidities; diagnostic details; clinical interventions; details of organs supported and level of care delivered, ICU and hospital outcome, details of organ donation, unit acquired infection and data to support HIPE coding.

Title	**Irish National Intensive Care Unit Audit (ICU) Audit**
Data dictionary	A data dictionary and data collection manuals for all data items are available. Updating these in 2022 for new dataset changes https://www.noca.ie/audits/irish-national-icu-audit
National-level identifier variables	There is a Facility to include IHI within database from 2022 once available from HSE.
Equity stratifiers	Included within the dataset are Ethnicity, Residence prior to admission, Gender, Country of birth from 2022.
Data collection methodology	All patients admitted to ICU/HDU in contributing hospital ICU's have data collected for the full stay up to discharge from the acute hospital Data is collected by ICU audit Coordinators (all nurses). Data is downloaded from hospital systems, taken from medical charts or records, and entering onto the ICU Audit system. Data collection and validation is continuous, with quarterly reporting.
Clinical coding scheme	ICNARC coding method and definitions used for one aspect of the data set. www.icnarc.org
Size of national collection	Records are the number of ICU Admissions which fluxes with requirement for ICU care. During 2020 (1 January 2020 to 31 December) there were 11,793 admissions to participating ICUs nationally. Full national figure yet to be determined as all sites not rolled out.
Publication frequency	Quarterly Quality Reports sent to hospitals and public reporting Annually from 2017
Accessing data	Annual reports as agreed by ICU Audit Governance Committee and NOCA Governance Board and subsequently issued by NOCA. Data request form available at https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

INOR Irish National Orthopaedic Register

4.39 Irish National Orthopaedic Register (INOR)

Title	**Irish National Orthopaedic Register (INOR)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	http://www.noca.ie/
Year established	2014 (December, collection commenced at the development site). The electronic system went live in May 2016.
Statement of Purpose	The main objective of INOR is to monitor the quality and safety of arthroplasty, ensure safe surgical practice for patients and to maintain a register of implants used. INOR will support hospitals should an implant recall occur. INOR's secondary objectives are to: ▪ define the epidemiology of joint replacement surgery in Ireland ▪ provide timely information on the outcomes of joint replacements ▪ identify risk factors for poor outcomes ▪ assist in the assessment and education of clinicians. INOR benefits can be found at this link: https://www.noca.ie/audits/inor-benefits In scope: ▪ INOR collects data on elective hip and knee joint replacement arthroplasties (surgeries), both primary and revision, that are carried out in participating hospitals. Out of scope: ▪ Elective hip or knee arthroplasty for trauma patients ▪ Elective hip or knee arthroplasty for bone tumours ▪ Other joints e.g. ankle, elbow and shoulders.
Coverage (geographical and temporal)	When INOR implementation is complete, all elective public and private Orthopaedic Centres in Ireland will be included. As of Dec 2021, INOR includes nine participating hospitals. Data collection on participating patients is for the lifetime of the implant or the patient.
Description/ Summary	INOR is an electronic point of care system, designed to collect demographic, clinical and implant component data on patients admitted to hospital for primary and revision arthroplasty surgery in

Title	**Irish National Orthopaedic Register (INOR)**
	hospitals nationally. Clinical and patient-reported outcome information is also collected at defined time points following patients' surgery.
Data users	Hospital managers/ CEO's,hospital clinical teams, hospital groups, clinical programme for trauma and orthopaedics.
Data content	Includes details of the following: pre-operative assessment (comorbidities/body mass index), peri operative clinical data (diagnosis/procedure/implant component details), post-operative assessment (complications/incidents), patient reported outcome measures (PROMs), demographic patient details include name and gender. Consent status (consent to participate in the Register) is also collected and for non-consenting patients, no demographic data is stored on INOR.
Data dictionary	Not currently publicly available but available on request, please see contact details at www.noca.ie
National-level identifier variables	No national level identifiers are available.
Equity stratifiers	Age and gender.
Data collection methodology	Data collection is in real time at time of procedure and ongoing. Data is entered directly onto INOR by the clinical team, at the point of care (Nurses, Surgeons and Patients). The INOR system collects data in real-time in: ▪ Pre- and Post-Operative assessment units to record Pre-Operative MDS information, Patient Consent, Post-Operative assessment MDS information and PROMs ▪ Orthopaedic Theatres to record Peri-operative MDS information, Components and to provide a Post-Operative note to consultants ▪ NOCA to monitor and manage the system, including the provision of register Reports.
Clinical coding scheme	ICD-10-AM for coding diagnoses and ACHI for procedures.
Size of national collection	Project currently in roll-out phase. There are almost 20,000 patients in the Register. The number of patients annually will continue in increase as hospital participation increases.
Publication frequency	First National report published in November 2021. Hospital reports sent to hospitals. From 2022 onwards Key Quality Indicators will be reported quarterly to the Hospitals and Hospital Groups.

Title	**Irish National Orthopaedic Register (INOR)**
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

4.40 Irish National Rare Kidney Disease Registry

Title	**Irish National Rare Kidney Disease Registry**
Managing Organisation	Trinity Health Kidney Centre, Tallaght Hospital.
Web address	https://www.tcd.ie/medicine/thkc/research/rare.php
Year established	2012.
Statement of Purpose	In scope: 1. Act as a contact registry for Irish patients with systemic vasculitis. 2. To provide key outcome data (death, end-stage kidney disease, relapse, complications) of patients with primary systemic vasculitis. 3. To link to discrete samples in the RKD biobank. Out of scope: 1. Private Hospitals.
Coverage (geographical and temporal)	National; the primary centres managing patients with ANCA vasculitis are included. The following sites collect data: 1. Tallaght University Hospital (lead site) 2. St James Hospital 3. St Vincents Hospital 4. Beaumont Hospital 5. Mater Hospital 6. University Hospital Galway 7. Cork University Hospital 8. University Hospital Limerick. Start: 1/7/12 Finish: Data collection ongoing.
Description/ summary	Established initially with support from Science Foundation Ireland and linked to the RKD biobank. It is a core element of the HSE-designated Vasculitis Ireland Network centre of expertise, which became a full member of the RITA European Reference Network in later Jan 2022. A key requirement of this membership is maintenance of a relevant rare disease registry.

Title	**Irish National Rare Kidney Disease Registry**
	The Vasculitis Ireland Awareness national patient organisation is intimately linked with the registry.
Data users	HSE, Policy makers, ERN-RITA, Clinical researchers, Clinical teams.
Data content	Demographics, vasculitis-focused clinical variables, diagnostic criteria, immunosuppressive medication, complications of therapy, mortality, biopsy details, longitudinal data concerning disease activity and lab results collected at clinical visits.
Data dictionary	Yes: https://www.tcd.ie/medicine/thkc/assets/EUVAS_data_dictionary_v1.xlsx
National-level identifier variables	Data are pseudonymised so national identifiers are not used.
Equity stratifiers	Equity stratifiers: 1. County of residence 2. Ethnicity 3. Gender 4. Education.
Data collection methodology	Data are generally entered by the primary medical team with support from research nurses in some centres. It is strongly reliant upon NCHD support for data entry. There is no linkage to hospital IT systems. A contracted data manager surveys data quality on each site on a rotating basis.
Clinical coding scheme	Chapel Hill Consensus vasculitis classification criteria. Orphacodes are used alongside diagnostic terms.
Size of national collection	Approximately 60 records created on average annually.
Publication frequency	Audited and summarised annually, published on website.
Accessing data	By submission of a data and sample access request form http://www.tcd.ie/medicine/thkc/research/downloads-collaborators.php
Open Data portal access	No.
Generic email contact	Rkdnurse@tcd.ie
Generic telephone contact	+353 1 8962105

IPCCA Irish Paediatric Critical Care Audit

4.41 Irish Paediatric Critical Care Audit (IPCCA)

Title	**Irish Paediatric Critical Care Audit (IPCCA)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	http://www.noca.ie/
Year established	2015.
Statement of Purpose	The overall purpose of the IPCCA is to improve critical care services provided to paediatric patients by measuring the quality of care and outcomes against predetermined standards, using data from the UK and the Republic of Ireland (ROI) as a whole as a benchmark. Objectives: ▪ Measure the quality of care in CHI at Crumlin and CHI at Temple Street, and benchmark this against other PCCUs across the UK ▪ Provide data on the epidemiology and complexity of care provided for each patient. This has the potential to link in with best practice tariffs reimbursement in the future ▪ Improve the quality of data for the Hospital In-Patient Enquiry (HIPE) scheme by providing data on diagnosis and procedures arising while the patient is in PCCU ▪ Support Irish and international research in order to enhance patient care ▪ Make recommendations based on validated data. In scope: ▪ All admissions of children to paediatric critical care units (PCCUs) in Ireland (CHI at Crumlin and CHI at Temple Street) ▪ Admissions of children to adult ICU in Ireland ▪ Paediatric critical care retrieval and transport of paediatric patients requiring critical care treatment. Out of scope: ▪ Data on children who are aged 16 years and over admitted to ICU.

Title	**Irish Paediatric Critical Care Audit (IPCCA)**
Coverage (geographical and temporal)	National audit with data collection from public hospitals with Paediatric critical care units, the regional Paediatric High Dependency Unit at University Hospital Limerick (UHL) and children aged < 16 treated in adult ICU. Under consideration: regional paediatric high dependency units and intensive care units. Coverage is based on patient's discharge date from ICU and must be within the calendar year for example 1/1/22-31/12/22.
Description/ summary	This audit provides a complete account of activity and outcomes in all paediatric intensive care units providing critical care to children in the ROI. In addition to data from specialised paediatric critical care units and from transfer and retrieval services that traditionally provide data to PICANet (based in the UK), this audit also includes data from adult ICUs and the regional Paediatric High Dependency Unit at UHL, giving a complete description of national activity.
Data users	Patients and their parents and carers, patient advocacy groups, healthcare professionals, hospital managers and hospital groups, multidisciplinary teams (MDTs) caring for patients in PCCUs or ICUs, policy-makers.
Data content	▪ Admission data: each child's demographic details, including their date of birth, ethnicity and sex. The PICANet database also collects details about where children are admitted from, their date of admission, their clinical diagnoses, and some physiological parameters on admission to PCCU, including arterial blood gas results, blood pressure, medical history and ventilation status. Data on outcome and discharge details are also included. The medical interventions that each child receives each day are also recorded as part of the audit ▪ Referral data: These include details of the referring hospital, demographic details about the child, the grade of the referring doctor or nurse, the transport team involved, and the destination PCCU ▪ Transport data: These include details about the transport team, journey times, any interventions carried out, and critical incidents.
Data dictionary	https://www.picanet.org.uk/data-collection/data-manuals-and-guidance/

Title	**Irish Paediatric Critical Care Audit (IPCCA)**
	Full list of data set points is available from NOCA at auditinfo@noca.ie
National-level identifier variables	No national identifiers are included.
Equity stratifiers	Yes, each child's demographic details, including their date of birth, ethnicity and sex.
Data collection methodology	Each hospital/ transport organisation submits data to PICANet via a secure web-based portal. Data submission can involve direct entry of patient data or monthly upload of a data file from an existing clinical information system. The dataset is frozen on 31 March annually. Data for children admitted to adult ICU's is provided by NOCA's INICUA ICNARC dataset.
Clinical coding scheme	SNOMED CT. CT3 The Read diagnostic codes.
Size of national collection	On average data on ~1500 admission records per annum.
Publication frequency	NOCA produces national reports at regular intervals. PICANet produces annual audit reports, which monitor activity, and makes comparisons over a 3-year reporting period for PCCUs across England, Scotland, Wales, Northern Ireland (NI) and the ROI.
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577
Other comments	

4.42 Irish Prostate Cancer Outcomes Research (IPCOR)

Title	**Irish Prostate Cancer Outcomes Research (IPCOR)**
Managing Organisation	IPCOR Steering Committee. UCD is the data controller.
Web address	https://www.ipcor.ie/
Year established	2016.
Statement of Purpose	To conduct a unique, prospective, national, longitudinal clinical study with patient reported outcomes on men diagnosed with and treated for prostate cancer in Ireland. The data is used to generate reports and scientific publications for the public, researchers, clinicians, hospitals and National Cancer Control Programme on prostate cancer care in Ireland.
Coverage **(geographical and temporal)**	National. The data was collected from 16 hospitals, 9 public and 7 private hospitals. The collection began in February 2016 and was completed in January 2020.
Description/ Summary	Clinical and patient reported data from men with prostate cancer from the time of diagnosis and throughout treatment.
Data users	Public, clinicians, researchers, NCCP.
Data content	Patient demographics, symptoms at diagnosis, pathology data, PSA data, imaging data, treatments, complications of treatments, procedures, follow-up: recurrence/relapse, further treatments, patient reported outcomes.
Data dictionary	The data dictionary is not currently available.
National-level identifier variables	No national level identifiers are included in this collection.
Equity stratifiers	The following equality stratifiers are included: ▪ Occupation ▪ Gender ▪ Marital status ▪ Deprivation Index.
Data collection methodology	Research officers employed by IPCOR through the National Cancer Registry Ireland register men in 16 hospitals across Ireland and collect

Title	**Irish Prostate Cancer Outcomes Research (IPCOR)**
	the IPCOR clinical dataset. Eligible men are then contacted by the National Cancer Registry Ireland on behalf of IPCOR and asked to complete quality of life questionnaires before their treatment begins. Clinical follow up data was collected annually. Up to three years follow up data was collected.
Clinical coding scheme	AJCC Prostate Staging 7th Edition Clavien-Dindo Classification: Surgical Complications CTCAE Version 4: Medical Complications
Size of national collection	Approx 2500.
Publication frequency	Ad hoc. A public report was published in November 2018.
Accessing data	Application to IPCOR Steering Committee. Information can be found at www.ipcor.ie
Open Data portal access	No.
Generic email contact	ipcor@ucd.ie
Generic telephone contact	

4.43 Irish Thoracic Society Interstitial Lung Disease Registry

Title	**Irish Thoracic Society Interstitial Lung Disease Registry**
Managing Organisation	The Irish Thoracic Society (ITS).
Web address	
Year established	2016 (Pilot in three centres).
Statement of Purpose	The main objective of the ILD Registry of Ireland is to provide for the relief of sickness, suffering, and distress, and to advance education by collecting and analysing information relating to interstitial lung disease in Ireland, which can be used to facilitate research and provide accurate reports in order to monitor and improve treatments which will contribute to the quality of care of persons with interstitial lung disease.
Coverage **(geographical and temporal)**	National. The Registry is currently not actively collecting data due to the impact of COVID-19 but plans to resume collection in 2022 are underway and it will be for a three year period.
Description/ Summary	Identify, record, analyse, and store information relating to the prevalence, incidence, and treatment of interstitial lung disease (ILD) in the Republic of Ireland. This will allow us to provide data on the long term prognosis of ILD in the Republic of Ireland, and to compare this information with international data. We will particularly focus on Idiopathic Pulmonary Fibrosis (IPF) in view of recent and international developments in this disease. Provide a framework on which to develop strategies in the evaluation of novel treatments in ILD and facilitate treatment of these patients in a fair and appropriate manner. Promote and facilitate the use of clinical data in approved research projects, relating to the causes, distribution, treatment, and outcome of ILD in the Republic of Ireland Enhance and develop important dialogue and information streams to the Health Service Executive in Ireland that will assist in the planning and management of health services and essential resources for ILD in Ireland.
Data users	Healthcare professionals, HSE, policymakers, patient representative charity, researchers.

Title	**Irish Thoracic Society Interstitial Lung Disease Registry**
Data content	Patient demographics, diagnostic procedures performed, treatment and outcomes.
Data dictionary	Not available.
National-level identifier variables	No.
Equity stratifiers	Gender, ethnicity, country of birth, country of residence.
Data collection methodology	Data is inputted to the registry via a standard web browser. Data is stored in a central system which can be accessed by the ITS only. Data is collected monthly.
Clinical coding scheme	Not applicable.
Size of national collection	It is expected that an average of 200 cases will be recorded annually.
Publication frequency	It is planned at a minimum to publish data in the form of an annual report.
Accessing data	By application to the Irish Thoracic Society ILD oversight committee which is composed of members of the ITS and lay members both medical and non medical.
Open Data portal access	No.
Generic email contact	info@irishthoracicsociety.com
Generic telephone contact	+353 1 5677201
Other comments	The Registry was developed in 2014/2015 and the first data was inputted on a pilot basis from 3 centres in 2016. This was subsequently extended to 5 centres. There was an Annual Report in 2018. https://irishthoracicsociety.com/wp-content/uploads/2018/11/ITS-ILD-Registry-Annual-Report-2018.pdf The Registry is currently not actively collecting data due to the impact of COVID-19 but plans to resume collection in 2022 are underway.

4.44 Irish Unrelated Bone Marrow Registry (IUBMR)

Title	**Irish Unrelated Bone Marrow Registry (IUBMR)**
Managing Organisation	Irish Blood Transfusion Service.
Web address	http://www.giveblood.ie/Become_a_Donor/Bone_Marrow_Registry/Bone_Marrow_Registry.html
Year established	1989.
Statement of Purpose	To provide a register of people who are willing to donate their bone marrow/stem cells if they are found to match an unrelated patient needing a bone marrow transplant. Irish Bone Marrow Transplant units which includes CHI, Crumlin and St. James's Hospital.
Coverage **(geographical and temporal)**	Voluntary participation. National. Data collection commenced in 1989 and is ongoing.
Description/ Summary	The Irish Unrelated Bone Marrow Registry (IUBMR) is a register of people who are willing to donate their bone marrow/stem cells if they are found to match an unrelated patient needing a stem cell transplant. The IUBMR is part of a worldwide network of unrelated donor registries.
Data users	IBTS.
Data content	Details include: name; sex; date of birth; address; phone number; blood group; Human leukocyte antigen (HLA) type; consent. There are also links to IBTS eProgesa (blood donor) system which provides virology blood group/blood donation history.
Data dictionary	Not available.
National-level identifier variables	No.
Equity stratifiers	Place of Residence & Gender.
Data collection methodology	Volunteers who are willing to be searched as potential bone marrow donors for patients can apply to be on the register via an online-form. On-going data collection.

Title	**Irish Unrelated Bone Marrow Registry (IUBMR)**
Clinical coding scheme	Not in use.
Size of national collection	Approximately 700–1,000 records created on average annually (donors recruited).
Publication frequency	Annual reports.
Accessing data	IBTS annual reports available publicly on www.giveblood.ie
Open Data portal access	No.
Generic email contact	bonemarrow@ibts.ie
Generic telephone contact	+353 1 4322898

MTA Major Trauma Audit

4.45 Major Trauma Audit (MTA)

Title	**Major Trauma Audit (MTA)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	http://www.noca.ie/
Year established	2013.
Statement of Purpose	Aim: The MTA will drive system-wide quality improvement to achieve the best outcomes for trauma patients in Ireland. MTA objectives can be found at this link: https://www.noca.ie/audits/mta-objectives Scope: 1. All trauma patients irrespective of age. 2. who fulfil one of the following length of stay criteria: a Direct admissions ▪ Trauma admissions whose length of stay is 3 days or more ▪ Trauma patients admitted to a High Dependency Area regardless of length of stay ▪ Deaths of trauma patients occurring in the hospital including the Emergency Department (even if the cause of death is medical) ▪ Trauma patients transferred to other hospital for specialist care or for an ICU/HDU bed. b Patients transferred in who ▪ Trauma patients transferred into your hospital for specialist care or ICU/HDU bed whose combined hospital stay at both sites is 3 days or more ▪ Trauma admissions to a ICU/HDU area regardless of length of stay ▪ Trauma patients who die from their injuries (even if the cause of death is medical). 3. and whose isolated injuries meet the TARN injury criteria.
Coverage **(geographical and temporal)**	National- all acute hospitals that receive major trauma (26 hospitals in total).

Title	**Major Trauma Audit (MTA)**
	Coverage is based on discharges within the calendar year for example 1/1/22-31/12/22. The percentage of patients with HIPE episodes with trauma codes (ICS 10-AM S and T codes) that fulfil the length of stay criteria for the MTA. The hospitals can select cases on HIPE from the lists generated for trauma cases and highlight if they are eligible or not eligible and why. Excluded cases are removed from the hospitals denominators at the end of each annual reporting cycle.
Description/ Summary	The Major Trauma Audit (MTA) will provide a framework for hospitals to collect standardised data on patient injury, care processes and patient outcomes. The National Office of Clinical Audit (NOCA) will provide the frameworks and operational support for the introduction of MTA in Ireland, through participation in the UK Trauma Audit and Research Network (TARN). TARN is based on web-enabled collection of a standardised dataset for patients who are admitted to hospital or die in the Emergency Department (ED) with centralised analysis and benchmarking of data undertaken at TARN based in the Manchester Academic Health Science Centre University of Manchester.
Data users	Hospital managers/ CEO's, hip fracture governance committees, hospital groups, Healthcare Pricing Office (HPO), National Office of Trauma Services.
Data content	This data includes: patient demographics, type and cause of injury, injury severity, pre-hospital data, and patient's hospital journey e.g. time to treatment, length of stay, and outcomes based on mortality.
Data dictionary	Yes, available via TARN: www.tarn.ac.uk
National-level identifier variables	No national level identifiers are available.
Equity stratifiers	Age and gender are included.
Data collection methodology	Hospital-level MTA audit co-ordinators submit data on a web-based data collection and reporting system. Data is taken from the medical record and electronic patient systems by clinical staff with permitted access and inputted into TARN. Data can be entered while the patient is an in-patient and completed on discharge. Data entry is requested to be complete within the quarter following discharge from hospital. A data collection/ reporting calendar with quarterly targets is used each year for the hospitals to align their data entry to.
Clinical coding scheme	ICD–10 injury codes (S and T) are used to identify reports for inclusion in MTA.
Size of national collection	6000 records expected per annum.
Publication frequency	NOCA annual report and quarterly hospital group reports. In 2022 MTA will also be distributing quarterly hospital level dashboard reports. TARN supply three clinical working reports each year and two dashboard reports.

Title	**Major Trauma Audit (MTA)**
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

4.46 National Ability Supports System (NASS)

Title	National Ability Supports System (NASS)
Managing Organisation	National Health Information Systems Unit of the Health Research Board (HRB). The HRB and Health Service (HSE) Executive are joint controllers of NASS data.
Web address	https://link.hrb.ie
Year established	In 2019 NASS replaced the National Intellectual Disability Database (NIDD, established 1995) and the National Physical and Sensory Disability Database (NPSDD, established 2002). NASS is one of four national health information systems managed by the HRB's National Health Information Systems Unit and hosted on the Unit's web-based platform, LINK.
Statement of Purpose	To collect data on the HSE-funded disability services that people use or require in a 5-year period. New services provided to service users aged over 65 years are out of scope as these are managed by HSE Older Persons' rather than Disability services.
Coverage (geographical and temporal)	National. NASS data collection is carried out on an annual basis.
Description/summary	NASS contains national data relating to HSE disability-funded services provided to service users. Data is recorded by service providers, both HSE and non-HSE.
Data users	HSE; Department of Health, Department of Children, Equality Disability, Integration, and Youth; policy-makers; and researchers.
Data content	NASS collects demographic, socioeconomic, diagnostic and outcome data on service users in addition to details about the assistive technology and services they receive and/or require.
Data dictionary	Yes. https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/how-data-is-collected/

Title	**National Ability Supports System (NASS)**
National-level identifier variables	PPSN is not captured. A field to capture the IHI is included in the dataset. Awaiting assistance from HSE's Access to Information & Health Identifiers programme to populate this field.
Equity stratifiers	Sex, age, employment status, ethic/cultural background, type of living accommodation are captured by NASS.
Data collection methodology	Trained users within HSE and non-HSE organisations who provide HSE disability-funded services record information about their service users and the services they receive or require in the web-based system. Each user record is reviewed annually. Data may be recorded manually or uploaded to the system in a file containing multiple records. The data collection period runs from January/February to end December each year.
Clinical coding scheme	No formal clinical coding/ disease classification scheme is used. Currently diagnoses are coded using a coding system based on ICD-10. A move to the SNOMED terminology is planned.
Size of national collection	Each annual dataset contains approximately 36,000 existing or newly registered records.
Publication frequency	Reports are published annually and are available on the HRB website, www.hrb.ie.
Accessing data	Requests for NASS data can be submitted using the data request form, NASS Data Requests.
Open Data portal access	No.
Generic email contact	nass@hrb.ie
Generic telephone contact	HRB reception: +353 1 2345000 Ask that the call be forwarded to a member of the NASS Team.
Other comments	Additional information and documentation regarding NASS is available in the Disability section of the HRB website.

4.47 National Antimicrobial Resistance Surveillance (EARS-Net Ireland)

Title	**National Antimicrobial Resistance Surveillance (EARS-Net Ireland)**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/microbiologyantimicrobialresistance/europeanantimicrobialresistancesurveillancesystemearss/
Year established	*1999 (Staphylococcus aureus*; *Streptococcus pneumonia*); *2002 (Escherichia coli*; *Enterococcus faecalis* and *Enterococcus faecium*); *2006 (Klebsiella pneumoniae*; *Pseudomonas aeruginosa*); *2014 (Acinetobacter* spp.).
Statement of Purpose	To monitor trends in antimicrobial resistance data from 8 key pathogens (listed above) in order to inform infection prevention and control teams and other policy decision makers. The data from EARS-Net are used to produce a national report on *S. aureus*/MRSA bacteraemia by acute hospital.
Coverage (geographical and temporal)	All microbiology laboratories are required to participate in EARS-Net surveillance. However, resource issues can result in labs suspending their participation. Between 2017 and 2020, coverage of the Irish population has exceeded 95%. Data are available from 1999-2021.
Description/ Summary	The European Antimicrobial Resistance Surveillance System (EARSS) was established in 1999 in response to the growing threat of antimicrobial resistance in Europe. In 2010 EARSS

Title	**National Antimicrobial Resistance Surveillance (EARS-Net Ireland)**
	coordination was transferred to the European Centre for Disease Prevention and Control (ECDC) and renamed the European Antimicrobial Resistance Surveillance Network (EARS-Net). EARS-Net Ireland comprises a network of 36 microbiological laboratories serving 60 acute hospitals (both public and private) in Ireland that collects routinely-generated antimicrobial susceptibility testing data on invasive infections caused by eight important bacterial pathogens: *S. aureus, S. pneumoniae, E. coli, E. faecalis, E. faecium, K. pneumoniae, P. aeruginosa and Acinetobacter spp.* Additionally, data are collected on invasive cases of: ▪ Group A and Group B streptococci ▪ *Candida* spp. to check for the presence of *C. auris*, an important emerging pathogen.
Data users	Clinical microbiologists; Surveillance Staff, Medical Scientists, Infection Prevention and Control Teams, Hospital Managers; National Policy Makers.
Data content	Laboratory data: laboratory code; isolate data; isolate sample number (lab); sample type (i.e. blood or CSF); date of sample collection; antibiotic susceptibility testing. Patient data: patient ID/MRN; sex; date of birth; hospital data; EARSS hospital code; date of admission; hospital department (if available).
Data dictionary	Not available.
National-level identifier variables	No.
Equity stratifiers	No.
Data collection methodology	EARS-Net collects data on the first invasive isolate (from blood or cerebrospinal fluid) of each pathogen per patient per year. The majority (95%) of the records are received electronically (usually as file downloads from the Laboratory Information Management System; Excel files; or WHONET files, a free software used to manage antimicrobial resistance data). For the

Title	**National Antimicrobial Resistance Surveillance (EARS-Net Ireland)**
	remaining 5%, isolate record forms are submitted (but these are being phased out in 2022). Data is currently collected on an annual basis (note: pre-pandemic, this was on a biannual basis).
Clinical coding scheme	Not in use.
Size of national collection	Approximately 6,200 records created in 2021.
Publication frequency	Annual reports published on HPSC website (www.hpsc.ie).
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hpsc.ie amr@hpsc.ie
Generic telephone contact	+353 1 8765300

4.48 National Audit of Hospital Mortality (NAHM)

Title	**National Audit of Hospital Mortality (NAHM)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	2015.
Statement of Purpose	The objectives of NAHM are to: 1. Understand and improve the quality of hospital based mortality data. 2. Identify areas for improvement – NQAIS NAHM Tool. 3. Promote reflection on the quality of overall patient care. 'In scope' are all patients admitted on HIPE for in-hospital treatment. 'Out of scope' are Maternity patients, Day case patients and Mental Health patients. Also excluded are deaths which occur in ED as they are not captured on HIPE.
Coverage **(geographical and temporal)**	National data. Temporal coverage starts at 2005 and is updated quarterly.
Description/ Summary	In-hospital mortality patterns have been used internationally as one indicator of the quality of care. While there are a number of similar ways of doing this, the standardised mortality ratio (SMR) is the most commonly used approach for looking at hospital mortality patterns within a country. The SMR is the ratio between the observed number of patients who die in hospital and the number that would be expected to die in hospital on the basis of the overall national rate. It is based on the primary reason a patient is admitted to hospital. Importantly this does not infer the cause of death. The information comes from the Hospital In-Patient Enquiry (HIPE) system, which contains clinical and administrative data on patients who have been admitted to hospital and is routinely collected by all publicly funded acute hospitals. Personal information i.e. information which could be used to identify a patient such as name, address and date of birth, is not taken from the hospital system and is not used in this audit. Patient confidentiality and privacy is fully protected in this manner. To ensure that "like is compared with like" across the diversity of hospitals, factors that potentially may directly influence the outcome are adjusted for in the analysis, for example, patient age and the

Title	**National Audit of Hospital Mortality (NAHM)**
	presence of other serious illnesses to calculate the number of expected deaths.
Data users	NAHM users are identified at hospital and hospital group level. These include CEO/General Managers, Clinical Directors, Quality & Risk Managers, Audit Managers, DON, HIPE, Business Managers etc. Hospital Groups / Acute Operations receive quarterly reports from NOCA which includes NAHM data.
Data content	This data includes information that is taken directly from HIPE including: some patient demographics, co-morbidities, admission source, admission type, principal diagnosis, secondary diagnoses.
Data dictionary	HIPE data dictionary available at www.hpo.ie NAHM data dictionary not currently available on line but available on request from NOCA, please see www.noca.ie for contact details.
National-level identifier variables	No national level identifiers are available.
Equity stratifiers	Data includes age and gender.
Data collection methodology	There is no dedicated data collection. Data for NQAIS NAHM is sourced from HIPE which is coded on discharge. HIPE data is sent from the HPO (Healthcare Pricing Office) to the NHIU (National Health Intelligence Unit) HSE then uploaded to the NQAIS NAHM Tool on a quarterly basis or more frequently as required.
Clinical coding scheme	ICD–10 AM V10. Further broken down to CCS (Clinical Classification System) Groupings.
Size of national collection	433,386 records created in 2021 nationally.
Publication frequency	Published annually, 1st report published December 2016. NQAIS NAHM tool is updated for hospitals own view on a quarterly basis.
Accessing data	Each hospital CEO/Manager has nominated staff within their hospital to access the NAHM tool. Each Hospital Group CEO has nominated staff within their group to access the NAHM tool.
Open Data portal access	No.
Generic email contact	auditinfo@noca.ie
Generic telephone contact	+353 1 4028577

4.49 National Audit of Severe Maternal Morbidity

Title	**National Audit of Severe Maternal Morbidity**
Managing Organisation	National Perinatal Epidemiology Centre, Dept. of Obstetrics and Gynaecology, 5th Floor, Cork University Maternity Hospital, Wilton, Cork
Web address	http://www.ucc.ie/en/npec/
Year established	2011.
Statement of Purpose	To investigate the incidence and cause of severe maternal morbidity (SMM) in Ireland. Further, to investigate the location of maternal care for women requiring higher levels of care. This will assist in informing clinical practice, public health interventions and counselling of prospective mothers. As major obstetric haemorrhage (MOH) continues to be the leading cause of SMM the NPEC commenced the MOH audit nationally in 2021.
Coverage (geographical and temporal)	National Audit all 19 maternity units are participating. Data collection commenced in 2011 and is ongoing.
Description/ Summary	Designated severe maternal morbidity coordinators within all maternity units collate and submit data on women experiencing specific severe maternal morbidities and /or who require a higher level of care to the NPEC using a specific, detailed notification form.
Data users	Maternity services staff, unit co-ordinators, hospital senior management, hospital risk management, policy makers in the HSE, DOH staff, service users.
Data content	Data including maternal details (demographics, past medical history, current pregnancy details including delivery and maternal outcomes); hospital details; Baby outcome details.
Data dictionary	Available on request from npec@ucc.ie
National-level identifier variables	No.
Equity stratifiers	Ethnic group, Gender.
Data collection methodology	SMM data is submitted either via the secure online NPEC database, or alternatively by paper format.
Clinical coding scheme	The NPEC adapted the validated methodology of the Scottish Confidential Audit Severe Maternal Morbidity (SCASMM) to evaluate

Title	**National Audit of Severe Maternal Morbidity**
	SMM in Ireland. This methodology utilises organ dysfunction, SMM morbidities and management criteria including Interventional Radiology (IR) and Intensive Care Unit (ICU) management.
Size of national collection	In 2019, similar to previous years, there were 375 cases.
Publication frequency	National NPEC Perinatal Mortality Reports and individual maternity hospital reports published 12-18 months within end of data collection year.
Accessing data	NPEC have a data access policy. Applicants must complete a data request form which is reviewed by a data access committee. https://www.ucc.ie/en/npec/dataaccesscommittee/dataaccesscommittee/
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205042
Other comments	This audit includes a supplementary audit major obstetric haemorrhage.

4.50 National Cancer Registry Ireland (NCRI)

Title	**National Cancer Registry Ireland (NCRI)**
Managing Organisation	National Cancer Registry Ireland (NCRI) in conjunction with the Department of Health.
Web address	http://www.ncri.ie/
Year established	1991 (set up). 1994 (began nationwide cancer registration). Data collected for years of incidence 1994 onwards.
Statement of Purpose	The purpose of the National Cancer Registry is; ▪ to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland ▪ to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs ▪ to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services ▪ to publish an annual report based on the activities of the Registry ▪ To furnish advice, information and assistance in relation to any aspect of such service to the Minister. In scope: 1. The date of incidence is after the 01/01/1994. 2. Resident in the Republic of Ireland - The residence is defined as the place the person has lived for the previous twelve months. The purpose of recording residence is that the rate of tumour incidence can be related to a specific population. 3. The list of registerable tumours are as follows: i. All tumours described as "malignant"(/3), "in situ"(/2), "of uncertain behaviour"(/1) or "borderline malignancy"(/1) listed in the World Health Organisation (WHO) ICD-O Manual. ii. All intracranial (inside the dome of the skull) and spinal cord tumours. This includes benign tumours of the Central Nervous

Title	**National Cancer Registry Ireland (NCRI)**
	System, meninges, cranial nerves (e.g. acoustic neuroma), pituitary gland and pineal gland. 4. In some cases, subsequent tumours may be diagnosed in someone who is already known to have cancer and these tumours are registered if they meet the NCRI's registration criteria. Out of scope: 1. Tumours diagnosed prior to 01/01/1994. 2. Non-residents of Ireland as per the definition above.
Coverage (geographical and temporal)	The National Cancer Registry of Ireland covers the Republic of Ireland. Collection of population-based incidence data for the entire country commenced in January 1994.
Description/ Summary	The National Cancer Registry has been collecting comprehensive information on cancer and related tumours for the resident population of the Republic of Ireland since 1994. The information collected is used in research into the causes of cancer, in education and information programmes, and in the planning of a national cancer strategy to deliver the best cancer care to the whole population.
Data users	Department of Health, Health Service Executive, hospitals, clinicians, researchers, International Agency for Research on Cancer (IARC), European Cancer Information System, cancer charities, media and patients.
Data content	Information collected includes name, address, sex and date of birth, PPSN, the type and location of the cancer, how advanced the cancer is and the primary treatment received by the patient. The Registry also follows up the numbers dying from their cancer or from other causes.
Data dictionary	The NCRI Data Dictionary was published in March 2022. https://www.ncri.ie/sites/ncri/files/documents/Data%20Dictionary%20Report%20-%20Final.pdf
National-level identifier variables	PPSN is recorded. IHI is not available.
Equity stratifiers	Biological sex (not Gender) Place of residence (not yet in core dataset but routinely used for analyses) Derived Electoral District (ED) of residence Derived Small Area of residence Derived quintiles of Pobal deprivation indices (by ED linkage).
Data collection methodology	The NCRI receives data electronically from the following sources ▪ Monthly or quarterly electronic feeds from histopathology labs

Title	**National Cancer Registry Ireland (NCRI)**
	▪ Quarterly, biannual or annual ▪ electronic feeds from radiotherapy units ▪ Quarterly electronic feed from the Hospital In Patient Enquiry (HIPE) system ▪ Quarterly electronic feed from the Central Statistics Office (CSO). Approximately 90% of tumours are created electronically and are followed up manually. The remainder of tumours are created from paper based sources. Cancer Data Registrars (CDRs), assigned to hospitals around the country, access a range of data sources to follow up all new cancers and register all relevant patient, tumour and primary treatment details on the NCRI Cancer Registration System (CRS). The NCRI is provided with all death certificates from the Central Statistics Office (CSO). Tumours initially notified by death certificate (DCI) are followed up with the hospital of death and most tumours are subsequently confirmed from other data sources. Only a small percentage of tumours (<1%) remain classified as notified by death certificate only (DCO), in keeping with international standards.
Clinical coding scheme	Tumours are coded using the World Health Organisation (WHO) International Classification of Diseases for Oncology (ICD-O) ▪ 1994 to 2004 ICD O Version 2 ▪ 2005 to 2011 ICD O Version 3 ▪ 2012 to 2019 ICD O Version 3.1 ▪ 2020 onwards ICD O Version 3.2. Tumours are staged using the Union for International Cancer Control (UICC) TNM* Classification of Malignant Tumours (**Tumour, Node, Metastases*) ▪ 1994 to 2001/2002 4th edition ▪ 2002/2003 to 2013 5th edition ▪ 2014 onwards 7th edition. For years of incidence 1994 to 2010 (part) treatments are coded using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). For years of incidence 2010 (part) onwards treatments are coded using

Title	**National Cancer Registry Ireland (NCRI)**
	Australian Classification of Health Intervention (ACHI) 6th edition. NCRI reports statistics in International Classification of Diseases 10th edition (ICD-10) modified to take account of the most recent ICD-O behaviour recommendations. Systematized Nomenclature of Medicine (SNOMED) coding is used by histopathology labs to code tissue specimens. The codes provided by the labs are converted to ICD-O by the NCRI.
Size of national collection	45,000 new tumour records per year are created of which 35k are invasive, or 25k invasive excluding non-melanoma skin cancers.
Publication frequency	Updated incidence statistics are reported on annually in NCRI's annual statistical report. Figures on the website have not always been updated annually, thus the online figures may differ from the Registry's published report.
Accessing data	Aggregated statistics through online PDFs of reports, online incidence and survival statistics pages or data requests. Individual-level data (generally pseudonymised) can be requested, and is subject to relevant review (in relation to Subject Access Request, Freedom of Information, GDPR and other considerations) before any such information is provided. https://www.ncri.ie/faqs/our-data-how-we-collect-it/how-can-information-be-accessed
Open Data portal access	No.
Generic email contact	ncr_info@ncri.ie
Generic telephone contact	+353 21 4318014

4.51 National Drug Treatment Reporting System (NDTRS)

Title	**National Drug Treatment Reporting System (NDTRS)**
Managing Organisation	Health Research Board (HRB)- National Health Information Systems Unit
Web address	www.hrb.ie
Year established	1995
Statement of Purpose	The NDTRS was established as an epidemiological database on drug and alcohol misuse treatment episodes in publically funded services.It records incidence of drug and alcohol treatment. **Treatment as defined in the NDTRS**: ▪ any activity that aims to improve the psychological, medical and social state of individuals ▪ one or more of the following: medication (detoxification, methadone reduction and substitution programmes), addiction counselling, group therapy, psychotherapy and/or life skills training ▪ treatment in residential and non-residential settings ▪ treatment in prison. Treatment episodes on functional addictions e.g. gambling, spending etc are submitted on voluntary basis. Treatment episodes on concerned persons i.e. people affected by the drug use of another person are submitted on a voluntary basis. **NDTRS does not include:** ▪ programme that provide needle exchange only ▪ interventions solely concerned with the physical complications of problem drug or alcohol use (for example, emergency response to

Title	**National Drug Treatment Reporting System (NDTRS)**
	overdoses, or treatment of blood-borne infections and sexually transmitted infections) ▪ contacts with services which involve requests for social assistance only ▪ interventions for non-addiction issues (e.g., mental health problems, social issues) without also providing interventions for an addiction issue ▪ requests for practical information only ▪ contacts by telephone, letter or internet only (unless a treatment activity is provided via teleworking).
Coverage **(geographical and temporal)**	National. Data is published annually (approximately 6 months in arrears) however the on-line portal can faciliate real time reporting.
Description/ Summary	The NDTRS is an epidemiological database on treated cases problem drug and alcohol use in Ireland. It records episodes of treatment during the calendar year. It also records incidence and prevalence of drug and alcohol treatment.
Data users	▪ Addiction services ▪ HSE ▪ Drug and alcohol Task Force ▪ Policy makers ▪ Academics ▪ Advocacy groups ▪ International agencies which monitor data on drug treatment.
Data content	Basic demographic information; reason for treatment, source of referral. If treated, up to 5 problem drugs including alcohol can be recorded; history of drug use; risk behaviour in relation to injecting; type of treatment; treatment outcomes.
Data dictionary	A comprehensive data collection protocol is available which outlines all the questions and responses: https://www.hrb.ie/data-collections-evidence/alcohol-and-drug-treatment/how-data-is-collected/
National-level identifier variables	PPSN is not collected. There is a facility to collect IHI built into the on-line portal.
Equity stratifiers	Geocodes for place of residence Sex (including transgender) Self defined sexual orientation Country of birth Lanuage spoken at home

Title	**National Drug Treatment Reporting System (NDTRS)**
	Ethnicity Occupation Employment status.
Data collection methodology	Service providers at drug treatment centres throughout Ireland compile a record of each episode of treatment who attends through the online data entry portal. Submission of data on paper forms can be facilitated if required. As there is currently no unique health identifier in Ireland, the NDTRS records episodes (or cases) of treatment, not individuals. Data is published annually (approximately 6 months in arrears) however the on-line portal can faciliate real time reporting.
Clinical coding scheme	N/A.
Size of national collection	Approximately 25,000 average number of records created annually.
Publication frequency	Annual bulletins.
Accessing data	Interactive tables available at http://www.drugsandalcohol.ie Data requests to the HRB. https://www.hrb.ie/data-collections-evidence/alcohol-and-drug-treatment/request-data/ Published data on www.hrb.ie
Open Data portal access	No.
Generic email contact	ndtrs@hrb.ie
Generic telephone contact	+353 1 2345000
Other comments	The NDTRS is compliant with current EU reporting requirements on drug treatment and as such provides annual treatment data to the EMCCDA on behalf of the Department of Health.

4.52 National Drug-Related Deaths Index (NDRDI)

Title	**National Drug-Related Deaths Index (NDRDI)**
Managing Organisation	Health Research Board- The National Health Information Systems Unit in conjunction with the Department of Health and the Department of Justice.
Web address	http://www.hrb.ie
Year established	2005. Subset of data were retrospectively collected from 1998.
Statement of Purpose	Epidemiological monitoring of drug- and alcohol-related deaths, and deaths among people who use drugs and among alcohol dependent persons in Ireland. The objective of the Index is to provide high quality data so that the State can respond in a timely manner with accurate data on drug-related mortality. Does not include deaths caused by the drug or alcohol use of another person if the deceased does not meet the NDRDI inclusion criteria above. Does not include deaths due to medical misadventure if the deceased does not the NDRDI inclusion criteria above.
Coverage **(geographical and temporal)**	National coverage. Data is collected annually. Example of temporal coverage: 2017 data was collected between September 2018 to May 2019 and published in December 2019.
Description/ Summary	The National Drug-Related Deaths Index is an epidemiological database which records drug- and alcohol-related deaths, and deaths among people who used drugs and among alcohol dependent persons in Ireland.
Data users	▪ Policy makers ▪ Service providers ▪ Academics ▪ Advocacy groups ▪ International agencies which monitor data on drug-related mortality.
Data content	Administrative details; demographic details; socio-economic information; drug use at time of death; other risk behaviours; drug treatment history; toxicology; manner and cause of death.

Title	**National Drug-Related Deaths Index (NDRDI)**
Data dictionary	Currently under revision as part of HRB LINK on-line data entry portal project.
National-level identifier variables	PPSN is not collected. There is a facility to collect IHI built into the new on-line portal.
Equity stratifiers	Place of residence Sex (including transgender) Self defined sexual orientation Country of birth Ethnicity Occupation Employment status.
Data collection methodology	NDRDI staff manually collect data on an annual basis from closed coronial files relating to all deaths where a history of drug use and or alcohol dependency was recorded or where drug or alcohol was implicated in the death. Data from the other agencies is submitted in electronic format on an annual basis.
Clinical coding scheme	Cause and manner of death as recorded on the Coroner's Certificate in the Coronial files, or the cause of death as recorded on the General Mortality Register through the Central Statistics Office are coded using WHO ICD10. From 2019 onwards the Anatomical Therapeutic Chemical (ATC) drug classification system is incorporated into the NDRDI.
Size of national collection	Approximately 1,400 average number of records created annually.
Publication frequency	Data is published annually.
Accessing data	For data requests: https://www.hrb.ie/data-collections-evidence/alcohol-and-drug-deaths/request-data/
Open Data portal access	No.
Generic email contact	ndrdi@hrb.ie
Generic telephone contact	+353 1 2345000
Other comments	A new on-line system will be completed for the NDRDI in 2022 as part of the HRB LINK project to improve data security.

4.53 National Haemophilia System

Title	**National Haemophilia System**
Managing Organisation	National Coagulation Centre (NCC), St. James's Hospital, James's Street, Dublin 8.
Web address	https://www.stjames.ie/services/hope/nationalcoagulationcentre/
Year established	2005 (May).
Statement of Purpose	To maintain a national electronic record for all people with haemophilia and other related bleeding disorders in Ireland.
Coverage (geographical and temporal)	This is a National Register and includes three Comprehensive Care Centres and one Haemophilia Treatment Centre. Data collections stats from 2005 but may include earlier dates if uploaded. There is no finish date as data collection is on-going.
Description/ Summary	Cloud based National electronic record for all people with haemophilia and other related bleeding disorders. Interfaced to St James's Hospital Patient Administration System/EPR (St James's Hospitals electronic patient record). Also accessed by Children's Health Ireland at Crumlin, Cork University Hospital and Galway University Hospital. The data collection operates as an individual electronic health record but is also searchable as a National Register for Haemophilia and related bleeding disorders.
Data users	Healthcare professionals and administrative staff in all three Comprehensive Care Centres and one Haemophilia Treatment Centre in Ireland.
Data content	Includes the following: demographics; diagnosis; allergies; test results; medical and nursing notes; prescriptions; Laboratory investigation; outcomes and care providers.
Data dictionary	Not available.
National-level identifier variables	Not at present.
Equity stratifiers	Yes, race, gender, religion.
Data collection methodology	Data is collected at the point of care in a continuous manner by designated health care staff.
Clinical coding scheme	SNOMED-CT.
Size of national collection	The average number of records created annually is not available at this time. There are approximately 20160 active and closed records on the system.

Title	**National Haemophilia System**
Publication frequency	Annual report to the World Federation of Haemophilia. Intermittent reports for research studies approved by the Research and Ethics Committee.
Accessing data	Cloud based system accessed via URL. https://nhl.indici.ie/Login/Login Role based access for healthcare staff which is password controlled along with full audit trail. There is no facility for public access. Access for researchers may be granted if approval given by St James's Ethics Committee and local approval as per Access Request Policy.
Open Data portal access	No.
Generic email contact	ncc@stjames.ie
Generic telephone contact	+353 1 4162141
Other comments	

4.54 National Hepatitis C Database

Title	**National Hepatitis C Database**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	www.hcvdatabase.ie
Year established	2005.
Statement of Purpose	In scope: To follow the natural and treated history of hepatitis C in people infected through blood and blood products administered in Ireland and to evaluate the impact of various host and virus factors on disease progression.
Coverage **(geographical and temporal)**	Consenting patients, and patients who have died, 77% of eligible patients. National data collection, initially carried out annually, subsequently moved to periodic rounds of data collection (once every 2-4 years). Most recent data collection was 2018.
Description/ Summary	Database of persons infected with hepatitis C through the administration of blood and blood products in Ireland. Objectives of database ▪ To follow the natural history of infection in this group of people ▪ To evaluate the impact of various host factors on the progression of the disease ▪ To evaluate the outcomes of treatment To monitor the uptake of services ▪ To provide information for the planning and evaluation of health services ▪ To serve as a resource for future research into hepatitis C.
Data users	People infected through blood and blood products in Ireland, consultant hepatologists & gastroenterologists, hospitals & other healthcare providers, general public.
Data content	Age; sex; how patient became infected; medical conditions; results of tests; treatments received and treatment outcomes.
Data dictionary	Data dictionary not available.

Title	**National Hepatitis C Database**
National-level identifier variables	PPSN, IHI, hospital number, names and addresses are not included in the dataset.
Equity stratifiers	Equity stratifiers are not included in the dataset.
Data collection methodology	Data collected from medical records in Specialist Hepatology units across the country by a HPSC Research Nurse. Consent is required for all living patients. Data were initially collected annually, but subsequently changed to periodically. The most recent period was for data from 2014 to the end of 2017 (covering a 4-year time period)
Clinical coding scheme	Cause of death and medical conditions coded using the World Health Organization (WHO) ICD-10 system. Medications coded using the Anatomical Therapeutic Chemical (ATC) coding system.
Size of national collection	Total number in database: 1,322, small numbers of additional patients added at each round of data collection.
Publication frequency	Every 1-4 years (latest report delayed due staff being reassigned to COVID-19 work). Reports published on website, see **www.hcvdatabase.ie**
Accessing data	Web-based database accessible only through the government virtual private network (VPN). Username and password required. Reports published on website, see **www.hcvdatabase.ie.** Data requests can be submitted by email to hcvdatabase@hpsc.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hcvdatabase@hpsc.ie
Generic telephone contact	+353 1 8765300

NIMS
Córas Náisiúnta um Bainistíocht Teagmhais
National Incident Management System

4.55 National Incident Management System (NIMS)

Title	**National Incident Management System (NIMS)**
Managing Organisation	The HSE is the 'owner' of the NIMS healthcare data with respect of patient safety/service user incidents. The SCA is the joint controller of incident data and 'owner' of data with respect to patient safety related claims. The HSE in conjunction with the SCA jointly manage NIMS. Note: other incident and claim types are also captured, managed, and analysed on NIMS. There is also an aligned but separate governance with Tusla for service user's incidents.
Web address	https://www.riskonnectclearsight.eu/Enterprise/login.cmdx??c=NIMS
Year established	2003.
Statement of Purpose	To maintain and provide the national database of patient safety incident data that meets the needs of data users in the health and social care sector (including quality and patient safety clinical teams, management, policy makers, risk/health and safety managers, facilities staff, and researchers) whilst also supporting effective claims and risk management by the HSE and the SCA. Note comment above re: Tusla.
Coverage **(geographical and temporal)**	NIMS is used by all the public health and social care service and is provided to certain private hospitals as part of SafetNet. The areas covered include: ▪ all Hospital Groups, acute hospitals ▪ the CHO's and Voluntary Community (S. 38's) healthcare sectors ▪ National Ambulance Service ▪ HSE Corporate. Note: TUSLA also The database was implemented across the Health Care sector from 2004 with rollout completion in 2006.
Description/ Summary	National Incident Management System (NIMS) is the principal source of national data on incident activity for the Irish health and social care service. It has been designated as the primary system for end to end risk management of all incidents (capture, investigations and reporting) both by the DoH and the HSE. It is an end to end risk management web-based system and its purpose is as follows: ▪ Capture of incidents (including Serious Reportable Events); involving patients including dangerous occurrences and complaints

Title	**National Incident Management System (NIMS)**
	▪ Management of incident reviews ▪ Recording of review conclusions ▪ Recording of review recommendations ▪ Tracking recommendations to closure ▪ Multiple reporting and analytical tools which could be pointed at all captured data ▪ Facilitates reporting and analysis of patient safety incident data captured ▪ Facilitates reporting and analysis of review conclusions and contributory factors ▪ Facilitates reporting and analysis of key performance indicators (KPIs) as set out in the HSE Service Plan ▪ Facilitates the analysis of safety performance to inform risk initiatives. Note: NIMS also captures incidents involving health care workers (HCW) and members of the public and property damage. It also is used to manage claims arising from all incident types.
Data users	Patient safety data collection used by HSE National Directorate Quality and Patient Safety, Quality and Patient Safety Professionals, medical researchers, HC managers, Department of Health NPSO, medical professional bodies, HC organisations, SCA.Data from NIMS is also provided to and used by Government, public representatives and media.
Data content	Includes demographic details, locations, incident type, division, specialties, procedures/medications, injuries, outcomes, severity ratings, contributory factors, actions taken/planned and values e.g. birth rates, bed days, employee headcount etc.
Data dictionary	Available to NIMS users via the systems 'News and Announcements' Page. This is available to registered and licensed users of NIMS.
National-level identifier variables	There are currently no national level identifiers where it was included main address and location are the individual identifiers.
Equity stratifiers	For incident data the following equity stratifiers and may be collected place of residence, occupation and gender. Note residence will apply to a smaller percentage of incidents as most incidents occur in a workplace or in a Health Care providers premises. For claims arising from incidents all investigation, medical, legal reports, actuarial reports, other expert reports etc may attach to the claim on the system may possibly include all the equity stratifiers however claims screen fields only require place of residence, occupation and gender.

Title	**National Incident Management System (NIMS)**
Data collection methodology	NIMS is a confidential, highly secure web-based IT system that links hospitals and other health social care enterprises to a core database. Information is entered to the system locally either via paper based National Incident Report Forms (NIRF) or electronic point of entry reporting (ePoE) and subsequently reviewed. Data relating to the reviews conclusions and outcomes can then be input to the system. Data is available to users depending on their role – hierarchical access model.
Clinical coding scheme	Anatomical Therapeutic Chemical Classification System (ATC) and aligned to the World Health Organisation (WHO) Conceptual Framework for the International Classification for Patient Safety.
Size of national collection	Approximately 170,000 patient safety related records created annually.
Publication frequency	Daily, Monthly, Quarterly, Annually and as per request. Real time access to dashboards and reports is available to all users.
Accessing data	Each health and social care enterprise has access to its own data in order to identify emerging trends for risk management purposes, media requests and parliamentary questions. External requests can be forwarded to either NIMS@hse.ie or the SCA Data Services Team at stateclaims@ntma.ie
Open Data portal access	No.
Generic email contact	stateclaims@ntma.ie
Generic telephone contact	+353 1 2384900
Other comments	Future development includes: ▪ work ongoing to implement HIQA report 'Review of information management practices for the National Incident Management System (NIMS) within the HSE' , May 2021 recommendations ▪ continued programme to convert method of incident capture from paper based to electronic using NIMS ePoE functionality ▪ addition of Risk Register module ▪ reconfiguration to allow for reporting as required by the Patient Safety Bill ▪ addition of Clinical Audit module.

NATIONAL PERINATAL
EPIDEMIOLOGY CENTRE

4.56 National Maternity data- Robson Ten Group Classification system (TGCS)

Title	**Robson Ten Group Classification System (TGCS)**
Managing Organisation	National Perinatal Epidemiology Centre, Dept. of Obstetrics and Gynaecology, 5th Floor, Cork University Maternity Hospital, Wilton, Cork.
Web address	http://www.ucc.ie/en/npec/
Year established	The Robson TGCS has been collected by units since 2009 however in 2015 it was decided it would be collected nationally by the NPEC and in 2020 all units collected data.
Statement of Purpose	The Robson Ten Group Classification System (TGCS) is a classification system by which all perinatal events and outcomes can be compared. The system classifies all pregnant women into one of ten groups, each of which are mutually exclusive and, as a set, comprehensive. This system has been used extensively internationally to analyse caesarean deliveries. In 2015, the World Health Organization (WHO) endorsed the Robson TGCS as the global standard for assessing, monitoring, and comparing CS rates within and between healthcare facilities over time.
Coverage **(geographical and temporal)**	All 19 units collected data in 2020 for Robson TGCS.
Description/ Summary	Designated data coordinators within all maternity units collate and submit data on Robson TGCS to the NPEC.
Data users	Maternity services staff, perinatal mortality data coordinators, hospital senior management, hospital risk management, policy developers in the HSE, DOH staff, service users.
Data content	Aggregate data on CS and number of maternities in each group.
Data dictionary	Available on request from npec@ucc.ie
National-level identifier variables	No.
Equity stratifiers	No.
Data collection methodology	Data is submitted on an excel template frequencies varies across units.

Title	**Robson Ten Group Classification System (TGCS)**
Clinical coding scheme	N/A.
Size of national collection	Data is collected on all maternities and caesarean sections in Ireland.
Publication frequency	Updates are available from the NPEC website, the Robson Data is used in the PM and SMM annual reports.
Accessing data	NPEC have a data access policy. Applicants must complete a data request form which is reviewed by a data access committee. https://www.ucc.ie/en/npec/dataaccesscommittee/dataaccesscommittee/
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205053
Other comments	

4.57 National Oncology Drugs Management System

Title	**National Oncology Drugs Management System**
Managing Organisation	National Cancer Control Programme (NCCP), Health Service Executive.
Web address	http://www.hse.ie/cancer
Year established	Data collection commenced September 2012. Reporting process commenced April 2013.
Statement of Purpose	To coordinate and manage the use of cancer drugs nationally. The full statement of purpose can be found at the following link: https://www.hse.ie/eng/services/list/5/cancer/pubs/nccp-statement-of-intent-for-collection-of-data.pdf [PDF].
Coverage **(geographical and temporal)**	National – there are 26 acute public hospitals nationally that provide cancer drug services and participate in the National Cancer Drug Management Programme. Data collection is on a continuous basis to enable a funding mechanism.
Description/ Summary	The National Cancer Drug Management Programme coordinates and manages the use of cancer drugs nationally. A key component of the programme is the Oncology Drugs Management System, which is operated by the Primary Care Reimbursement Service (PCRS) on behalf of NCCP. This online based system is designed to collect information from hospitals on an ongoing basis in relation to patient demographic data, cancer drug use and cancer drug spending.
Data users	National Cancer Control Programme, Primary Care Reimbursement Service, CPU.
Data content	Patient information includes: name; date of birth; gender; address; contact details (if available); PPS or medical card number or long term illness card number (if available).
Data dictionary	Yes, but not available online.
National-level identifier variables	PPSN.
Equity stratifiers	Place of residence.
Data collection methodology	Hospital staff input the required data into an online system. The system is managed and operated by PCRS. Anonymised aggregated reports from the system are provided by PCRS to NCCP. Data is collected monthly.

Title	**National Oncology Drugs Management System**
Clinical coding scheme	ICD-10.
Size of national collection	21,030 claims submitted – 2021 17,019 claims submitted – 2020 15,640 claims submitted – 2019
Publication frequency	Hospitals update data on an ongoing basis, as cancer drugs are dispensed. Ongoing reports provided to NCCP by PCRS.
Accessing data	Monthly HSE Performance Report, NCCP annual report, data requests.
Open Data portal access	No.
Generic email contact	oncologydrugs@cancercontrol.ie
Generic telephone contact	+ 353 1 8287150

4.58 National Organ Procurement Service Data

Title	**National Organ Procurement Service Data**
Managing Organisation	Organ Donation Transplant Ireland (ODTI)/ HSE- National Organ Procurement Office.
Web address	www.odti.ie
Year established	2016.
Statement of Purpose	The purpose of this data collection is to have accurate national data on organs procured, transplanted, exported and imported and sent for research.
Coverage (geographical and temporal)	All organs procured, transplanted, exported and imported in the Republic of Ireland. National data collection started in 2016 by the ODTI and is ongoing. Each year sets starts on the 1st of January and finishes on the 31st December.
Description/ summary	All organ donations in the Republic of Ireland are coordinated through the National Organ Procurement Service in the ODTI. Ethical guidelines protect the interests of deceased organ donors, their families, and transplant recipients.
Data users	HSE, DOH, Council of Europe, WHO, Clinical teams and researchers.
Data content	Number of referrals, number of donors, number of no consents, number of medically unsuitable referrals, number of single organ donors, number of multi organ donors, number of non utilised donors, number of heart donors, number of lung donors, number of liver donors, number of kidney donors, donor information & non conversion donor activity information.
Data dictionary	Not available.
National-level identifier variables	We document the IRD number, Irish Registered Donor number.
Equity stratifiers	Gender and age.

Title	**National Organ Procurement Service Data**
Data collection methodology	Data collated by reviewing the donor files and non conversion donor activity logbook and collating on the data base. Data is collected after each donor and non conversion referral.
Clinical coding scheme	N/A.
Size of national collection	6 year Average is 176 per annum.
Publication frequency	Annually.
Accessing data	Annual reports and specific data requests.
Open Data portal access	No.
Generic email contact	odti@hse.ie
Generic telephone contact	+353 1 8788388

NPMR National Paediatric Mortality Register

4.59 National Paediatric Mortality Register (NPMR)

Title	**National Paediatric Mortality Register (NPMR)**
Managing Organisation	National Office of Clinical Audit (NOCA).
Web address	https://www.noca.ie/
Year established	1992 under governance of SIDS Ireland, governance transferred to NOCA in 2020.
Statement of Purpose	To provide accurate up to date information on mortality in Ireland to include all deaths in children <16yrs but does not include deaths occurring in maternity hospitals. In scope: In-hospital deaths of children aged up to 15 completed years. Out of scope: children who die outside of hospital, children who die in maternity hospitals.
Coverage **(geographical and temporal)**	National data collected on children <2yrs from 1992. Scope of data collection extended to all children <16yrs, initiated in CHI at Temple St and CHI at Tallaght in 2019 and is ongoing with objective to extend to all units nationally.
Description/ Summary	The Paediatric Mortality Register collects and analyses data on all deaths in children <16yrs nationally. Reports provide accurate data on the incidence of all paediatric deaths (aged 28days - 15 completed years); ▪ Deaths by age and gender ▪ Deaths by place of death- hospital v elsewhere ▪ Death by cause of death category ▪ Annual trends in cod categories- highlight lack of decline in suicide rates, stabilisation of SIDS rates, high rates of injury deaths resulting from NAI in young children (parental mental health issue) ▪ Comparison with international data. An element of quantitative analysis relating to the narrative description provided at the end of autopsy reports.
Data users	CHI/other hospital groups, HSE, TUSLA, NPEC, paediatricians, Coroners, academia, Irish Hospice Foundation, patient organisations, Proposed NOCA Paediatric Audit Advisory Committee.
Data content	Content includes age; sex; infant birth weight; place of death; cause of deaths, hospital transferred from, pathologist, Coroner.

Title	**National Paediatric Mortality Register (NPMR)**
Data dictionary	Not currently publicly available.
National-level identifier variables	No.
Equity stratifiers	Age and gender.
Data collection methodology	Complete notification form forwarded directly to NOCA by hospital. CSO provides quarterly metadata files of deaths registered. Coroners provide post mortem results. All data is coded and entered in the register's database. A coding system is used in order to assist with transfer of data into the statistical software package used for analysis. All data entry, statistical analysis, database management and reporting of results is carried out by NOCA NPMR personnel only. Ongoing annual surveillance means that effects and changes in paediatric death are monitored as they occur, with demographic factors documented alongside.
Clinical coding scheme	ICD-10 codes assigned by the CSO (Central Statistics Office).
Size of national collection	Approximately 300 deaths registered by CSO annually. Autopsy reports on approximately one third of deaths. All deaths occurring in CHI at Temple St and CHI at Tallaght notified to NPMR = 28 records per year on average.
Publication frequency	Annual reports published since 1993.
Accessing data	https://www.noca.ie/about-noca/access-to-audit-data
Open Data portal access	No.
Generic email contact	npmr@cuh.ie
Generic telephone contact	+353 1 8788455
Other comments	The register is in the process of developing a strategy for extending its notification to all units nationally. This register was previously called the National Sudden Infant Death Register. Infant mortality data, issued on a quarterly basis by the CSO, refers to deaths registered during that period. Due to delays in registration, the figures in some cases relate to deaths that occurred in the previous year. This means that SIDS figure from the CSO may differ from those of the register since the register's figures are based on year of occurrence. The register also includes SIDS deaths in infants over one year of age whereas the CSO restricts its infant mortality figures to those deaths which occurred in infants under one year of age only.

4.60 National Perinatal Reporting System (NPRS)

Title	**National Perinatal Reporting System (NPRS)**
Managing Organisation	Healthcare Pricing Office (HPO) within the National Finance Division, HSE.
Web address	http://www.hpo.ie/
Year established	Commenced as a pilot in 1969. Rolled out to all maternity hospitals in early 1970s. Between 1990 and 2013 the Economic and Social Research Institute (ESRI) managed the scheme on behalf of the Department of Health and the HSE. Since January 2014 the scheme has been managed by the Healthcare Pricing Office (HPO) in the HSE (www.hpo.ie).
Statement of Purpose	To maintain a timely accurate national database of key perinatal indicators over time. Collection, processing, management and reporting of data on all births nationally that meets the needs of the data users (including policymakers, clinical teams and researchers), through the development and support of the system.
Coverage **(geographical and temporal)**	All maternity hospitals/departments and independent midwives report to NPRS covering 100% of births in Ireland. NPRS data collection commenced in 1970 and is ongoing.
Description/ Summary	The National Perinatal Reporting System (NPRS) has as its principal aim, the provision of national statistics on perinatal events.
Data users	HSE, Department of Health, policy-makers, clinical teams and researchers.
Data content	The information collected includes: data on pregnancy outcomes (with particular reference to perinatal mortality and important aspects of perinatal care); descriptive social and biological characteristics of mothers giving birth.
Data dictionary	Yes – full data dictionary published on HPO website. www.hpo.ie
National-level identifier variables	There is no national unique identifier. At national level NPRS collects date of birth.
Equity stratifiers	Gender, occupation age, area of residence captured by NPRS and included in data dictionary. Equity stratifiers not specifically identified currently. NPRS data relies on information collected at hospital level.
Data collection methodology	All births are registered and notified on a standard four part birth notification form which is completed where the birth takes place. Part 3 of this paper form is sent to the HPO office for data entry and

Title	**National Perinatal Reporting System (NPRS)**
	validation. Approximately 40% of hospitals submit data electronically to the NPRS system.
Clinical coding scheme	ICD-10 for the coding of morbidity and mortality data.
Size of national collection	Approximately 60,000 average number of records created annually.
Publication frequency	Perinatal Statistics Report. Annual reports published on HPO website. www.hpo.ie
Accessing data	NPRS data sets are provided to a number of state agencies in order to address specific data requirements. Data requests can be submitted to nprs@hpo.ie directly. In addition annual reports on Perinatal Statistics on the HPO website.
Open Data portal access	No.
Generic email contact	nprs@hpo.ie
Generic telephone contact	+353 87 3403672
Other comments	Additional information and documentation regarding HIPE is available at www.hpo.ie

4.61 National Poisons Information Centre Database (NPIC)

Title	**National Poisons Information Centre Database (NPIC)**
Managing Organisation	Beaumont Hospital.
Web address	http://www.poisons.ie/
Year established	Pre-1993 (Paper based) 1993-2003 Excel files 2004 onwards (Database, 3 versions, 2004 current version).
Statement of Purpose	To provide information to healthcare professionals, to assist them in the management of acute poisonings, to give advice to members of the public on accidental poisoning in children and to collect and analyse epidemiological data on acute poisonings in Ireland. Case records in the NPIC database are from self-reported calls. The NPIC is not contacted about every case of poisoning treated in hospital or by GPs. The records reflect only the information collected when the public or healthcare professionals report an actual or potential exposure to a substance or request information on the treatment of poisoning. Exposures do not necessarily represent a poisoning or overdose. The NPIC sometimes receives more than one call about the same patient so there may be multiple case records for one patient. The Poisoning Severity Score reflects symptoms reported at the time the NPIC was contacted. Follow-up data are not available in all cases to determine the outcome of the case after the initial call.
Coverage **(geographical and temporal)**	National data on enquiries received by the National Poisons Information Centre. Aggregate data (annual reports) available for 1966 to 1993. Full dataset for 1993 to 2021 inclusive.
Description/ Summary	The main function of the National Poisons Information Centre is to provide information to healthcare professionals, to assist them in the management of acute poisonings. The Centre also gives advice to members of the public on accidental poisoning in children. The National Poisons Information Centre Database collects and analyses epidemiological data on acute poisonings in Ireland. The Centre provides a 24 hour service, 365 days a year. Enquiries are answered by Poisons Information Officers between 8am and 10pm, while night-time calls are automatically diverted to the UK National Poisons Information Service (NPIS). Enquiries are logged on a computer database called UK Poisons Information Database (UKPID) which is used to generate

Title	**National Poisons Information Centre Database (NPIC)**
	reports. This is a database of enquiries to the National Poisons Information Centre from 2004 to date. Enquiry data from 1998 to 2003 inclusive have been exported from older databases into Excel files. For earlier years only annual reports (paper based) are available.
Data users	National Poisons Information Centre, Health and Safety Authority, Department of Agriculture, Pesticide Registration and Control Division, Clinical teams and researchers.
Data content	Responder; enquirer; nature of enquiry; patient demographics; agent information; poisoning severity score; response; outcome (in selected cases).
Data dictionary	Not available.
National-level identifier variables	National-level identifier variables are not included.
Equity stratifiers	Age and gender are included in the dataset.
Data collection methodology	The data are collected on paper at the time of the enquiry and later entered into the database (UKPID) (daily). Selected enquiries are followed up by telephone to determine the outcome of the case.
Clinical coding scheme	WHO Adverse Reaction Terminology (ART) codes for features of poisoning. Poisoning Severity Score (PSS) for grading severity of poisoning.
Size of national collection	10,000 average number of records created annually.
Publication frequency	Annual reports published. Data sub-sets may be published in meeting abstracts or articles in toxicology/medical journals.
Accessing data	Recent annual reports are available on the website www.poison.ie We can provide detailed anonymised data to regulatory authorities and researchers on request. This may be subject to ethics committee approval. Email npicdublin@beaumont.ie to request access.
Open Data portal access	No.
Generic email contact	npicdublin@beaumont.ie
Generic telephone contact	+353 1 8092566
Other comments	We will respond to data requests as quickly as possible but answering telephone enquiries takes priority for staff time.

4.62 National Psychiatric Inpatient Reporting System (NPIRS)

Title	**National Psychiatric Inpatient Reporting System (NPIRS)**
Managing Organisation	Health Research Board (HRB) - National Health Information Systems (NHIS).
Web address	http://www.hrb.ie
Year established	Established in 1963, arising from the recommendations of the report of the Commission of Enquiry on Mental Illness (Department of Health, 1966). It has been maintained by the Medico-Social Research Board (MSRB) and subsequently, the Health Research Board (HRB), since 1971.
Statement of Purpose	The NPIRS is a psychiatric inpatient database which provides detailed information on all admissions to and discharges from in-patient psychiatric services in Ireland for service planning and delivery, the Department of Health, the HSE, clinicians, service user advocacy groups and research/academics through the quarterly production of KPI reports, the annual report, regional bulletins and requests for data/research collaboration. Community mental health settings are not included in coverage.
Coverage **(geographical and temporal)**	All centres approved under the Mental Health Act 2001 including private psychiatric hospitals and child and adolescent units are included. Data collection commenced in 1963 with a census of all in-patients and annual data has been published since 1965 to the present.
Description/ Summary	The database records all admissions to, discharges from and deaths in Irish psychiatric units and hospitals on the register of approved centres under the Mental Health Act 2001. The annual reports produced from the database play a key role in the planning of service delivery. National and regional bulletins capturing data for the HSE areas, along with an in-patient census carried out every three years, are also produced from the database. The database also provides much of the data on Performance Indicators (PIs) for the mental health services which are used to monitor targets in certain keys areas of the services.
Data users	Department of Health, HSE, Mental Health Commission, service user advocacy groups, clinicians, academics/researchers.

Title	**National Psychiatric Inpatient Reporting System (NPIRS)**
Data content	Data collected includes demographic and clinical information relating to all admissions, discharges and deaths for Irish psychiatric units and hospitals. Demographic information includes gender; age; marital status; address and socio-economic group. Clinical information includes: ICD 10 admission and discharge diagnoses. Up to four admission and discharge diagnoses can be recorded from 2021. Other information includes: legal status on admission and reason for discharge; date of admission and discharge and where a patient is discharged to are also collected.
Data dictionary	A data dictionary is in place however this is not available online.
National-level identifier variables	Most hospitals use their own unique number/identifier for patients. IHI field is included on the system to facilitate the collection of this field but it is not currently collected. PPSN is not collected.
Equity stratifiers	Address from which admitted (not including first line address), gender, ethnicity, occupation, socio economic group and country of birth are all included in the database and are collected/completed by NPIRS contacts in each hospital/unit.
Data collection methodology	Data are collected by each hospital/approved centre upon admission/discharge of a patient and returned to the NPIRS team in the National Health Information Systems of the HRB. Data are returned electronically on a quarterly basis by acute psychiatric hospitals/units and yearly by non-acute psychiatric hospitals/units.
Clinical coding scheme	The Clinical coding scheme is the WHO International Classification of Diseases (ICD 10).
Size of national collection	Approximately 17,000 admissions and 17,000 discharges are recorded on average annually.
Publication frequency	Data are published annually in the report 'Activities of Irish Psychiatric Units and Hospitals' while the inpatient census report is published every three years. PI data are currently produced for the HSE every quarter.
Accessing data	Annual reports plus CHO bulletins are published and available to download on the HRB website. In addition, quarterly Performance Indicator (PI) reports for each CHO area are produced for the HSE on selected mental health indicators. These are only available to individuals within each CHO area. A Hospital Type and National PI report are also produced quarterly and are made available to HSE management teams, Department of Health teams and senior clinicians/ECDs. Annual data are available to download in pdf or excel format on the HRB website and further data are also available on request subject to certain terms and conditions. Data are also available on Public Health Information System and interactive tables are available at www.cso.ie.

Title	**National Psychiatric Inpatient Reporting System (NPIRS)**
Open Data portal access	Yes.
Generic email contact	npirs@hrb.ie
Generic telephone contact	+353 1 2345000
Other comments	Futher information on the NPIRS database is available at www.hrb.ie

4.63 National Register of Individual Health Identifiers

Title	**National Register of Individual Health Identifiers**
Managing Organisation	HSE HIDS – Health Identifiers Service Health Identifiers Service (HIDS) within the National Operational Performance & Integration Unit, Chief Operations Office, HSE. The Health Identifier Service provides the HSE with an identity management service for Individuals and Health Services. The HIDS service is the designated authority, provided for under the Health Identifiers Act 2014, which establishes and operates all identifiers in systems across the HSE.
Web address	https://www.hse.ie/eng/about/who/national-services/individual-health-identifier/
Year established	The Health Identifiers Act was enacted in July 2014 which gave a legal basis to establishing the technical department. The Health Identifiers Business Service (HIDS) commenced in October 2019.
Statement of Purpose	With the enactment of the Health Identifiers Act in 2014, residents and former residents in Ireland with a Personal Public Services Number (PPSN) were and are given an Individual Health Identifier (IHI) number. It is used to uniquely identify each person engaging with the Health Service Executive and relevant social care agencies. The main benefit of having an IHI is to ensure patient safety by correctly identifying a patient. Your IHI will help to improve the accuracy in associating your medical records held in different healthcare organisations so they are correctly attributed to you. Your IHI will provide the key to enabling your electronic healthcare record.
Coverage (geographical and temporal)	National. Data collection began in 2016 and is ongoing.
Description/ summary	An Individual Health Identifier or IHI is a number that uniquely and safely identifies each person that has used, is using or may use a health or social care service in Ireland. It will last for your lifetime and

Title	**National Register of Individual Health Identifiers**
	will never be re-issued to anyone else. The Health Identifiers Act enacted in July 2014 allows for the creation and operation of a unique health identifier for any person using a health or social care service in Ireland. The Minister for Health has delegated the authority to create and operate the IHI to the Health Service Executive (HSE). The purpose of the IHI is to accurately identify everyone so that health and social care can be delivered to the right person, in the right place and at the right time. The IHI can be used to identify an individual correctly and allow those who are delivering services to them to be assured that they have relevant information for the right person. The ultimate benefit of having an IHI for those who use health and social care services is safer and better quality care.
Data users	The Health Identifiers Service is still in development and the key users will continue to grow. The current key users of IHI data are Covid-related platforms that cover Covid-19 Testing and Vaccination programmes. This will extend to all technical systems, their users and reports associated with the IHI.
Data content	The Health Identifier Act 2014 provides the legal basis to collect, store and process the following data in your IHI record: Surname Forename Date of Birth Place of Birth Sex All former surnames Mother's surname and all her former surnames Address Nationality Personal public service number (if any) Date of death in the case of a deceased individual Signature Photograph Middle name(s) Address (es) Postcodes/Eircodes Mobile phone numbers Other phone numbers Email addresses Medical card numbers, other health scheme numbers Medical record numbers Unique system identifiers.
Data dictionary	https://www.hiqa.ie/sites/default/files/2017-01/Demographic-Dataset-and-Guidance.pdf

Title	**National Register of Individual Health Identifiers**
National-level identifier variables	Yes PPSN is noted as one of the Other Identifying Particulars (OIPs) on the Health Identifiers Act 2014.
Equity stratifiers	▪ Place of Residence ▪ Sex.
Data collection methodology	Daily demographic feeds from the Department of Social Protection.
Clinical coding scheme	The IHI does not hold any Clinical coding or classification information.
Size of national collection	With the enactment of the Health Identifiers Act in 2014, residents and former residents in Ireland with a Personal Public Services Number (PPSN) were given an Individual Health Identifier (IHI) number. It is used to uniquely identify each person engaging with the Health Service Executive and relevant social care agencies. 381,186 IHI numbers were assigned in the past year.
Publication frequency	N/A.
Accessing data	Queries can be directed to hids.info@hse.ie
Open Data portal access	No.
Generic email contact	Hids.info@hse.ie
Generic telephone contact	Due to current working from Home arrangements please refer to the email address above.

4.64 National Renal Transplant Registry

Title	**National Renal Transplant Registry**
Managing Organisation	Beaumont Hospital.
Web address	http://www.beaumont.ie/
Year established	2002.
Statement of Purpose	The purpose of the registry is to provide robust data capable of informing the outcomes of renal transplants/recipients in Ireland. The upkeep of a national registry is required by law (SI No325/2012) which came into effect in August 2012 in compliance with EU Directive 2010/53/EU on Standards of Quality and Safety of Human Organs intended for Transplantation. The upkeep of the National Registry complies with DIRECTIVE 95/46/EC of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
Coverage (geographical and temporal)	All consecutive renal transplants from 1964 performed in Ireland. Data collection starts at time of transplant and finishes at failure of allograft or death of recipient.
Description/ Summary	This database is a renal database collecting data since 1964. It is used to assess graft survival and patient survival, monitor factors affecting outcomes.
Data users	Data manager, renal statistician.
Data content	Includes details on date of transplant, time on dialysis prior to transplant, end stage kidney disease, length of stay. Patient details include: gender; area of residence and date of birth.
Data dictionary	Data dictionary is provided for data manager –not available online.
National-level identifier variables	No.
Equity stratifiers	Gender and area of residence.

Title	**National Renal Transplant Registry**
Data collection methodology	Data is collated in the renal unit from hospital based systems and laboratory reports. Collected at time of transplant and yearly afterwards.
Clinical coding scheme	European Dialysis and Transplant Association (EDTA) renal disease code.
Size of national collection	150.
Publication frequency	Annual report available on hospital web site.
Accessing data	National Kidney Transplant Service Director. CEO.
Open Data portal access	Not available.
Generic email contact	Not available.
Generic telephone contact	Not available.

4.65 National School Immunisation System: SIS

Title	**National School Immunisation System: SIS**
Managing Organisation	HSE – Office of the Chief Clinical Officer.
Web address	https://www.hpsc.ie/
Year established	2011.
Statement of Purpose	The SIS is an electronic dataset which records all childhood vaccinations for children of School-going age. It also assists in the preparation and planning of vaccination sessions in schools and mop-up clinics as well as being used for statistical and activity analysis. In-Scope: All vaccinations for children of school-going age. Out-of-Scope: Baby & Toddler immunisations and adult Community Immunisations (Flu, Covid-19 etc.)
Coverage (geographical and temporal)	National – all children of school age within the State. SIS has collected data on School Immunisations since the Academic Year of 2010-2011.
Description/ summary	The data collection are made up of retrospective data entry records from paper records detailing the processing of each school-going aged child who received a vaccination (if consented) or not. The data includes the person-identifying information of the child and one parent/guardian (or self if age appropriate) along with a record of the consent provided (or declined). It also includes data on children who were not vaccinated by virtue of non-attendance.
Data users	▪ National Immunisation Office ▪ CHO Data Quality Leads (data-input) ▪ CHO Management ▪ HPSC ▪ Designated HSE Medical Professionals

Title	**National School Immunisation System: SIS**
	▪ (*Future*) National Cancer Registry – Cervical Check Screening (HPV Vaccinations) ▪ (Future) IHI.
Data content	▪ Client demographic records ▪ Client immunisation records ▪ Client consent documentation.
Data dictionary	Available on request.
National-level identifier variables	IHI is 80% successful over each year of records collected, work is ongoing to improve this uptake. PPSN is requested from parents.
Equity stratifiers	None of these are included. SIS does have DEIS status for schools attended.
Data collection methodology	Dept Education provide schools. School immunisation staff provide details of school cohorts. Parents and guardians provide demographic information and vaccinators provide vaccine information on the medical record form. Data is entered on the system on a near-daily basis during each working day (Mon-Fri) of the academic year.
Clinical coding scheme	No clinical coding takes place.
Size of national collection	270,000 records created on average annually; ▪ Avg 90k Vaccinations per anum ▪ Avg 185k Vaccinations per anum ▪ Avg 1.7k Vaccinations in other settings.
Publication frequency	Data is updated continuously and national figures are published annually by the HPSC.
Accessing data	Programme report on the HPSC website. Client immunisation records are requested by individuals through their local immunisation office as a Subject Access Request.
Open Data portal access	No.
Generic email contact	immunisation@hse.ie

Title	**National School Immunisation System: SIS**
Generic telephone contact	+353 1 8676108
Other comments	Clients can find information on their immunisation schedule and what to expect during a vaccination at the national immunisation website at: www.immunisation.ie

National Suicide
Research Foundation

4.66 National Self-Harm Registry Ireland (NSHRI)

Title	**National Self-Harm Registry Ireland (NSHRI)**
Managing Organisation	National Suicide Research Foundation (NSRF) on behalf of Department of Health. The NSHRI is funded by the HSE's National Office for Suicide Prevention.
Web address	http://nsrf.ie/
Year established	1995 (at a regional level). 2006 (all hospital emergency departments included).
Statement of Purpose	The NSHRI is a national surveillance system which gathers information on hospital presenting self-harm at Emergency Departments in all hospitals across Ireland. The aims of the NSHRI are: ▪ to establish the extent and nature of hospital presenting self-harm in Ireland ▪ to monitor trends over time and by area ▪ to contribute to policy development in the area of suicidal behaviour ▪ to help the progress of research and prevention. All acute public hospitals, both general and paediatric, contribute data to the NSHRI. Private hospitals are not included.
Coverage (geographical and temporal)	National – all acute public hospitals, both general and paediatric, contribute data to the NSHRI. Data collection for the NSHRI commenced at a regional level in 1995 and expanded to full national coverage in 2006. Data collection is ongoing.
Description/ Summary	The NSHRI is a national system of population monitoring for the occurrence of self-harm in Ireland.
Data users	HSE, policymakers, clinical teams and researchers.
Data content	The NSHRI gathers information on hospital presentations of self-harm including: date and hour of attendance at hospital; mode of transport to hospital; method(s) of self-harm; type and quantity of drugs taken (if applicable); medical card status; recommended next care. Patient details include area of residence, sex and age.
Data dictionary	Yes, the full data dictionary is available on our website. http://nsrf.ie/
National-level identifier variables	National-level identifier variables (e.g. PPSN, IHI) are not included in the NSHRI.
Equity stratifiers	Sex, age and area of residence are gathered by the NSHRI. The NSHRI relies on information collected at hospital level.

Title	**National Self-Harm Registry Ireland (NSHRI)**
Data collection methodology	Data on self-harm presentations are extracted at the presenting hospital by NSHRI trained data registration officers. Data is transferred electronically to the offices of the NSRF. NSHRI data are collected on a weekly basis.
Clinical coding scheme	Method(s) of self-harm are recorded according to the World Health Organisation's International Classification of Disease (ICD-10).
Size of national collection	The NSHRI records approximately 12,500 presentations annually.
Publication frequency	The findings from the NSHRI are disseminated each year via an annual report. In addition to this, interim reports are published every six months. NSHRI data are also published in peer-reviewed publications. Periodic reports are prepared for relevant agencies (e.g. National Office for Suicide Prevention). A list of NSHRI-related publications is accessible via www.nsrf.ie
Accessing data	Data can be accessed via annual and interim reports. Aggregate data is also available, on request.
Open Data portal access	No.
Generic email contact	infonsrf@ucc.ie
Generic telephone contact	+353 21 420 5551
Other comments	In 2015, the NSHRI was recognised by the World Health Organisation as a template for self-harm surveillance for countries at global level. The NSHRI template was used to produce a Practice Manual for Establishing and Maintaining Surveillance Systems for Suicide Attempts and Self-Harm (WHO, 2016).

4.67 National Serosurveillance Programme (NSP)

Title	**National Serosurveillance Programme (NSP)**
Managing Organisation	Seroepidemiology Unit (SEU), Health Protection and Surveillance Centre (HPSC).
Web address	National Serosurveillance Programme - Health Protection Surveillance Centre (hpsc.ie)
Year established	The National Serosurveillance Programme commenced initially as a pilot in October 2021 with eight acute laboratories. The NSP formally launched in January 2022. Eight acute laboratories of national geographic spread, submit residual sera specimens to the Programme at collection cycles of 6 weekly intervals. In parallel, a collaborative study with the Irish Blood Transfusion service (IBTS) was initiated in October 2021 and has since been extended until December 2022.
Statement of Purpose	The initial objective of the National Serosurveillance Programme is to report on the seroprevalence of COVID-19 due to vaccination or infection in Ireland over time, by age and quantitative antibody levels. The programme, in time, will provide information on the prevalence of antibodies of other infectious diseases of public health importance.
Coverage (geographical and temporal)	National- currently 8 acute laboratories of geographic spread, submit residual sera specimens to the NSP. A schedule of collection cycles at 6-week intervals has been agreed until end 2022. The Irish Blood Transfusion Service (IBTS) contribute data from 500 blood donor specimens every two weeks from three fixed sites, two in Dublin and one in Cork.
Description/ summary	The National Serosurveillance Programme is the principal source of data on the seroprevalence of COVID-19 in Ireland.
Data users	HSE, Department of Health, policy-makers, clinical teams, analytic partners, researchers and members of the public.
Data content	The NSP collects anonymised data from residual sera specimens from a network of acute laboratories. Anonymised blood donor specimen data from the IBTS is also collected. The dataset includes date of birth,

Title	**National Serosurveillance Programme (NSP)**
	gender, date of sample collection and county of residence. Results of specimen testing (positive, negative or not tested) and level of quantitative antibodies are also collected.
Data dictionary	Development in progress.
National-level identifier variables	Gender, date of birth and county of residence are included in the National Serosurveillance Programme dataset.
Equity stratifiers	The following equity stratifiers are included in the dataset: 1. Gender 2. County of residence
Data collection methodology	Anonymised demographic data on residual sera specimens is collected at source in the acute laboratories. Laboratory partners update specimen details on the Laboratory Data Form before sending to the Seroepidemiology Unit (SEU). Specimens are sent to the National Virus Reference Laboratory (NVRL) for testing. Once testing is complete, specimen results data is sent to HPSC SEU. Specimen result data is then matched with the anonymised demographic data forms from our laboratory partners, using the SEU ID as the primary identifier. IBTS collect data on blood donor specimens. Specimens are tested on site in IBTS and in St James's Hospital
Clinical coding scheme	Not applicable.
Size of national collection	To date data on approximately 17,716 specimens have been submitted to the NSP. This total includes result data from IBTS and the network of acute laboratories.
Publication frequency	The National Serosurveillance Programme publishes reports at periodic intervals on www.hpsc.ie Reports - Health Protection Surveillance Centre (hpsc.ie) From 15.07.22 anonymised NSP programme is published in the **HPSC Seroepidemiology of COVID-19 Data Hub** This data will be updated at periodic intervals.
Accessing data	The National Serosurveillance Programme publishes reports at periodic intervals on www.hpsc.ie

Title	**National Serosurveillance Programme (NSP)**
	Reports - Health Protection Surveillance Centre (hpsc.ie) From 15.07.22 anonymised NSP programme data is published in the **HPSC Seroepidemiology of COVID-19 Data Hub**
Open Data portal access	No.
Generic email contact	seu.programme@hpsc.ie
Generic telephone contact	+ 353 1 8765300
Other comments	Additional information and documentation regarding the National Serosurveillance Programme is available by contacting seu.programme@hpsc.ie or National Serosurveillance Programme - Health Protection Surveillance Centre (hpsc.ie)

4.68 National Spinal Injuries Unit

Title	**National Spinal Injuries Unit**
Managing Organisation	National Spinal Injuries Unit, Mater Misericordiae University Hospital (MMUH).
Web address	Spinal injuries unit web address; http://www.mater.ie/services/spinal-injuries-unit/
Year established	2008 (June- Excel database) 2012 (January- ongoing - Patient Advocate Tracking System (P.A.T.S.).
Statement of Purpose	To capture all spinal injury consultations, referrals, OPD & admissions to the Mater Hospital (does not include details of treatment in other hospitals).
Coverage **(geographical and temporal)**	National. Commenced in June 2008 and is ongoing.
Description/ Summary	This is a register for all Spinal patients referred for consultation/ admission to the Mater Hospital. It uses Patient Advocate Tracking System (PATS) software.
Data users	HSE, policy makers, clinical teams and researchers.
Data content	Demographics, mechanism, type and location of injury, American Spinal Injury Association Score, advice given, if inpatient – procedure information.
Data dictionary	International Spinal Cord Injury Core Data Set (available on request).
National-level identifier variables	No.
Equity stratifiers	Sex, age, area of residence captured. Equity stratifies not specifically identified currently.
Data collection methodology	Referring hospitals use online Spinal Portal. Data draw down weekly, monthly, quarterly, annually, and as and when required.
Clinical coding scheme	ICD-10. (International Classification of Diseases)
Size of national collection	If it is just new cases, and not including referral only roughly 400 annually.
Publication frequency	Six monthly and annual reports for audit and research purposes.
Accessing data	Contact the Spinal Data Manager in the Orthopaedic Department, Mater Hospital.
Open Data portal access	No.

Title	**National Spinal Injuries Unit**
Generic email contact	rgunapala@mater.ie
Generic telephone contact	+353 1 809 7455

4.69 Neonatal Therapeutic Hypothermia Audit

Title	**Neonatal Therapeutic Hypothermia Audit**
Managing Organisation	The National Perinatal Epidemiology Centre (Dept. of Obstetrics and Gynaecology, 5th Floor, Cork University Maternity Hospital, Wilton, Cork) in collaboration with the National Clinical Programme for Paediatrics and Neonatology (NCPPN) and the National Women and Infant Health Programme (NWIHP).
Web address	https://www.ucc.ie/en/npec/
Year established	2016.
Statement of Purpose	The purpose of the Audit is to present an overview and national statistics of Neonatal Therapeutic Hypothermia. TH is now considered the standard treatment for term infants with moderate to severe HIE. It is a therapy during which the infant is cooled within six hours of birth to a targeted core body temperature of between 33°C to 34°C for a duration of 72 hours. Following the 72-hour period, the infant is rewarmed to normal body temperature over a 6-12 hour period. Encompassing data on all cases of TH will serve as a platform for identification of maternal, infant and clinical risks factors associated with the requirement for TH interventions; development of best practice guidelines; and identification of trends over time.
Coverage **(geographical and temporal)**	National coverage: involves every infant who underwent TH in Ireland. Data is collected on an annual basis starting on the 1st of January and finishing on the 31st of December.
Description/ Summary	For the national neonatal TH review, medical records are the primary source of information. Data were collected on site in the 19 maternity units/hospitals and neonatal intensive care units or special care baby units (NICU/SCBU) in the Republic of Ireland. The NCPPN, NPEC and NWIHP collected data on all cases of neonatal therapeutic hypothermia in 2019 by taking an active case ascertainment approach.
Data users	Maternity care staff, neonatal staff, unit co-ordinators, hospital senior management, hospital risk management, policy develops in the HSE, DOH staff, service users. Academics working in research institutions and employees undertaking research in national and international agencies.

Title	**Neonatal Therapeutic Hypothermia Audit**
Data content	Maternal details (demographics, past medical history, current pregnancy details including delivery and maternal outcomes); hospital details; Baby outcome detail.
Data dictionary	Available on request from npec@ucc.ie
National-level identifier variables	No.
Equity stratifiers	Ethnic group, Occupation, Social capital, Gender health coverage (i.e., public, and private).
Data collection methodology	Data is collected by the national neonatal TH co-ordinator on site in the 19 maternity units/hospitals and neonatal intensive care units from medical records. Data is uploaded to the electronic register hosted by the NPEC and the data is processed. Data is submitted on the secure online NPEC database on an annual basis.
Clinical coding scheme	Not in use.
Size of national collection	The 2016-2017 reported on 140 infants who were treated with TH. In 2018, 69 infants were treated with TH, and in 2019, 72 infants were treated with TH.
Publication frequency	In 2018, a report was published with data from 2016 and 2017. From then, reports are published annually.
Accessing data	It is the NPEC's policy that all requests for data for research purposes be considered by a committee, termed the Data Access Committee.
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205053

Out-of-Hospital Cardiac Arrest Register
OHCAR Ireland
At the heart of evidence

4.70 Out of Hospital Cardiac Arrest Register (OHCAR)

Title	**Out of Hospital Cardiac Arrest Register (OHCAR)**
Managing Organisation	OHCAR is based in the National Ambulance Service. The OHCAR Steering Group is responsible for directing the project.
Web address	http://www.nuigalway.ie/ohcar
Year established	2007 (November, North West) 2012 (National).
Statement of Purpose	The purpose of the OHCAR register is to facilitate improvements in survival from OHCA in Ireland by fulfilling the following objectives: ▪ establishing the current OHCA survival rate ▪ identifying factors that contribute to survival ▪ identifying what could be done differently to improve survival ▪ providing regular feedback to service providers.
Coverage **(geographical and temporal)**	National. OHCAR started collecting data on a regional basis from 2007 – 2012 and nationally thereafter to present day.
Description/ Summary	A project to set up an Irish Out-of-Hospital Cardiac Arrest Register (OHCAR) was established in November 2007 in accordance with the recommendations of the Report of the Task Force on Sudden Cardiac Death (2006). The purpose of the Register is to enable further understanding and research into OHCAR in Ireland. By quantifying and describing cardiac arrests that occur in the community the register will enable: ▪ Investigation of the determinations of survival/death from OHCAR ▪ Investigation of the effect of interventions on survival/death ▪ Monitoring of survival from OHCAR and subsequent quality of life.
Data users	Academics, researchers, HSE and other interested parties.

Title	**Out of Hospital Cardiac Arrest Register (OHCAR)**
Data content	A summary of data demographics; incident data; vital observations; ECG data; medical treatment; resuscitation data; discharge data from hospitals; first responder data. Based on international dataset ref: *Jacobs et al (2004) Update and Simplification of the Utstein Templates for Resuscitation Registries: A Statement for Healthcare Professionals, Circulation110:3385-3397* *http://www.sciencedirect.com/science/article/pii/S030095720400382X*
Data dictionary	Yes; https://www.nuigalway.ie/media/collegeofmedicinenursinghealthsciences/disciplines/generalpractice/5--OHCAR-Data-Dictionary.pdf
National-level identifier variables	No.
Equity stratifiers	Place of residence.
Data collection methodology	The OHCAR data collection continuum begins at receipt of the emergency call and ends at patient discharge from hospital. Summary findings from the data are reported back to ambulance management. In order that the data on OHCAR can be compared with other registries, data is collected using the internationally agreed Utstein template. Additional data items that are important in the Irish context are also collected. Data is collected daily.
Clinical coding scheme	Not in use, but drop down options based on Utstein dataset.
Size of national collection	3,500 records created on average nationally.
Publication frequency	Summary data are published on a quarterly and annual basis. Quarterly reports are available to the personnel who provide the original data on a regional basis but are not suitable for wider distribution due to risk of patient identification. Eleven annual reports have been published by OHCAR and circulated to a distribution list approved by the OHCAR Steering Group - reports are made available via the Project Manager and are presented in soft copy.
Accessing data	Access to identifiable data restricted to OHCAR Project Manager and OHCAR Administrator only. Anonymised aggregated data made available through annual reports and in form of quarterly reports which are sent to ambulance personnel in participating regions (i.e. original data providers). As regional data numbers are small, personnel are advised that data is for their use only and not to be discussed outside their regional service. This model of data dissemination has been discussed with the Office of the Data Protection Commissioner.
Open Data portal access	No.
Generic email contact	OHCAR@hse.ie

Title	**Out of Hospital Cardiac Arrest Register (OHCAR)**
Generic telephone contact	+353 87 7089807

4.71 Patient Care Report (PCR)

Title	**Patient Care Report (PCR)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC).
Web address	https://www.phecit.ie/
Year established	2005 commenced in the HSE national ambulance service and nationally over a six month period followed. Voluntary, Auxiliary and Private licensed CPG providers who operate an ambulance service commenced usage 2006 and completed 2008.
Statement of Purpose	To facilitate: 1) a national framework to record accurate, complete and timely pre-hospital patient data which will provide a vital link in the continuum of patient care in the hospital/destination facility 2) robust national clinical audit 3) strategic planning 4) informs research into new skill, services/equipment.
Coverage **(geographical and temporal)**	2005/2006 (national statutory ambulance services) 2008 (Private, Auxiliary and Voluntary licensed CPG providers with an ambulance service).
Description/ Summary	The Patient Care Report (PCR) is the principal source of patient data collection pre-hospital from time of call receipt by the pre-hospital practitioner to handover of patient at ED/destination facility. In the event of an ambulance service not utilising the PHECC PCR; the PHECC Information standard contains the data set on which any alternative PCR is designed.
Data users	Pre-Hospital Emergency Care Practitioners, medical professionals, research groups.
Data content	The PCR collects patient demographic data, detailed patient assessment clinical data, medical interventions, medications administered, destination handover data, practitioner and administrative data.
Data dictionary	Not available. Information Standard details PCR data set.
National-level identifier variables	IHI is included on a PCR.
Equity stratifiers	Patient address is included.
Data collection methodology	Patient information is entered on the 2-part PCR in real time for every patient contact.

Title	**Patient Care Report (PCR)**
	The PCR must be completed in all circumstances: ▪ All emergency calls ▪ All urgent calls ▪ All calls where a practitioner has to treat a patient ▪ All calls involving refusal of treatment and or transport contrary to the advice given by the practitioner ▪ All calls where patient is treated at scene and not transported. Paper-based system: A PCR copy is included in handover at the Emergency Department (ED)/destination facility and stored with the hospital record/chart. The remaining copy is returned to the licenced CPG provider organisation for storage. ePCR also used by CPG Providers.
Clinical coding scheme	Clinical impression, mechanism of injury and incident location terminology are all compliant with ICD 10-AM.
Size of national collection	Information not available to PHECC as patient records processed and controlled by the licensed CPG provider who operates an ambulance service.
Publication frequency	No data published by PHECC on this data as PHECC publishes the standard and related patient report form only. PHECC has no oversight on data collected other than review of clinical audits submitted as a requirement of the annual licensed provider approval process.
Accessing data	Access to data through the individual licensed CPG provider who use the PCR.
Open Data portal access	No.
Generic email contact	info@phecc.ie
Generic telephone contact	+353 45 882042
Other comments	All PHECC information standards and related patient report forms are reviewed at least every three years to facilitate capture of care delivered in the pre-hospital environment by practitioners and compliance with national data collection standards.

an ciste náisiúnta um cheannach cóireála
the national treatment purchase fund

4.72 Patient Treatment Register (PTR)

Title	**Patient Treatment Register (PTR)**
Managing Organisation	The National Treatment Purchase Fund (NTPF) in conjunction with the Department of Health.
Web address	http://www.ntpf.ie/home/home.htm
Year established	2005 (formed) 2006 (rolled out) 2007 (December, in-patient/day-case completed) 2012 (October, outpatient data collection began).
Statement of Purpose	To report on the waiting list for both in-patient/day-case and outpatient patients. Provide statistics and trends. Provide basis for treatment commissioned by NTPF. Data is received from a number of public hospitals. Private hospitals are not included.
Coverage **(geographical and temporal)**	46 Irish public hospitals report to PTR. Data Collection: Dec '07 – Present.
Description/ Summary	The Patient Treatment Register (PTR) is a register of surgical and medical patients on in-patient/day-case and outpatient waiting lists in Ireland. It provides up to date information on wait times for in-patient/day-case treatments and outpatient new appointments.
Data users	General Public, Department of Health, TD's and Ministers, HSE, Hospital Staff, Hospital Group Leads, Clinical Groups, Researchers.
Data content	Patient demographics, procedure codes, hospital, consultant and specialty details.
Data dictionary	Data dictionary available at: www.data.gov.ie
National-level identifier variables	There is no National Health Identifier available, nor do we collect PPSN.
Equity stratifiers	Gender, Date of Birth, Area of Residence are all collected at hospital level, though not published externally from NTPF.
Data collection methodology	When a patient is placed on an in-patient/day-case or outpatient public hospital waiting list their details are submitted by secure encryption by the hospital to the NTPF and placed on the PTR. Both Inpatient and Outpatient data is collected every week.
Clinical coding scheme	ICD 10–AM for in-patient/day-case. Not yet in place for outpatient data.

Title	**Patient Treatment Register (PTR)**
Size of national collection	26 million records.
Publication frequency	Reports published monthly on website.
Accessing data	There is on-line access available to waiting times in information by hospital. Monthly reports are produced. Hospitals receive weekly reports.
Open Data portal access	Yes – Monthly Publication Data.
Generic email contact	reports@ntpf.ie
Generic telephone contact	+353 1 6427101 (IT Dept)

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

4.73 Perinatal Mortality National Clinical Audit

Title	**Perinatal Mortality National Clinical Audit**
Managing Organisation	National Perinatal Epidemiology Centre, Dept. of Obstetrics and Gynaecology, 5th Floor, Cork University Maternity Hospital, Wilton, Cork.
Web address	http://www.ucc.ie/en/npec/
Year established	2008. 2011 (data collection tool).
Statement of Purpose	To address the investigation of perinatal mortality in Ireland from a clinical perspective. To identify modifiable risk factors impacting on adverse perinatal outcomes. This will enhance clinical interpretation of perinatal deaths which will further assist in informing clinical practice, public health interventions and counselling of prospective parents.
Coverage (geographical and temporal)	National. Data collection commenced in 2008 and is ongoing.
Description/ Summary	Designated perinatal mortality data coordinators within all maternity units collate and submit data on all perinatal deaths occurring in their unit to the NPEC using a specific, detailed notification form.
Data users	Maternity services staff, perinatal mortality data coordinators, hospital senior management, hospital risk management, policy developers in the HSE, DOH staff, service users.
Data content	Anonymised data including: maternal details (demographics, past medical history, current pregnancy details including delivery and maternal outcomes); hospital details; Baby details (including cause and timing of death).
Data dictionary	Available on request from npec@ucc.ie
National-level identifier variables	No.
Equity stratifiers	Ethnic group, Occupation, Social capital, Gender.
Data collection methodology	Data is submitted either via the secure online NPEC database, or alternatively by paper format.
Clinical coding scheme	NPEC maternal and fetal classification system on cause of death. This was based on the validated Centre for Maternal and Child Enquiries (CMACE) classification system.

Title	**Perinatal Mortality National Clinical Audit**
Size of national collection	In 2019, similar to previous years, there were 392 cases.
Publication frequency	National NPEC Perinatal Mortality Reports and individual maternity hospital reports published 12-18 months within end of data collection year.
Accessing data	NPEC have a data access policy. Applicants must complete a data request form which is reviewed by a data access committee. https://www.ucc.ie/en/npec/dataaccesscommittee/dataaccesscommittee/
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205042

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

4.74 Planned Home Births in Ireland Audit

Title	**Planned Home Births in Ireland Audit**
Managing Organisation	National Perinatal Epidemiology Centre, Dept. of Obstetrics and Gynaecology, 5th Floor, Cork University Maternity Hospital, Wilton, Cork.
Web address	https://www.ucc.ie/en/npec/
Year established	2012.
Statement of Purpose	The purpose of the audit is to examine both the maternal and fetal outcomes of planned home births, including outcomes whereby the care of the woman is transferred for hospital care in the antenatal period, during labour or the postnatal period.
Coverage **(geographical and temporal)**	National coverage: all planned births with the HSE home birth service are recorded. Data is collected on an annual basis starting on the 1st of January and finishing on the 31st of December.
Description/ Summary	Self Employed Community Midwives (SECMs) in Ireland provide a home birth service on behalf of the Health Service Executive (HSE). Maternity records of midwifery care provided are sent by the SECM to the Designated Midwifery Officer (DMO) in their respective HSE area. The DMO reviews the maternity records then collates the data using a standardised audit tool.
Data users	Maternity care staff, neonatal staff, unit co-ordinators, hospital senior management, hospital risk management, policy develops in the HSE, DOH staff, service users. Academics working in research institutions and employees undertaking research in national and international agencies.
Data content	Women's demographics; Previous medical and obstetric history Medical and obstetric details for the current pregnancy; Birth details, Delivery details, Maternal and infant outcomes.
Data dictionary	Available on request from npec@ucc.ie
National-level identifier variables	No.
Equity stratifiers	Ethnic group, occupation, social capital, gender.
Data collection methodology	Data is collected by the SECM and sent to the DMO in their respective HSE area. After reviewing the maternity records, the DMOs collates the data using a standardised audit tool and data is uploaded to the

Title	**Planned Home Births in Ireland Audit**
	electronic register hosted by the NPEC or is forwarded to the National Perinatal Epidemiology Centre (NPEC) for analysis. Data is submitted on the secure online NPEC database on an annual basis.
Clinical coding scheme	Not in use.
Size of national collection	250 records created on average nationally. In 2018, 231 women planned to give birth at home, in 2019, 272 infants and in 2020 345 women planned to give birth at home.
Publication frequency	Every 12-18 months.
Accessing data	NPEC have a data access policy. Applicants must complete a data request form which is reviewed by a data access committee. https://www.ucc.ie/en/npec/dataaccesscommittee/dataaccesscommittee/
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205053

4.75 Primary Care Reimbursement Service (PCRS)

Title	**Primary Care Reimbursement Service (PCRS)**
Managing Organisation	Health Service Executive- National Health Schemes Data.
Web address	http://www.hse.ie/eng/staff/pcrs/
Year established	1970 (data collection) 1993 (first records visible online).
Statement of Purpose	To support the delivery of primary healthcare by providing reimbursement services to primary care contractors for the provision of health services to members of the public in their own community.
Coverage **(geographical and temporal)**	The data covers the main national health schemes throughout the entire country. 1970-present.
Description/ Summary	The HSE supports the delivery of primary healthcare by operating contracts with primary care contractors for the provision of health services to members of the public in their own community.
Data users	Government, HSE, CSO, business interests, researchers, media, public.
Data content	The data contains information on the number of people in use of the services; details of health services provided and medicine products prescribed and dispensed.
Data dictionary	Not available.
National-level identifier variables	Patient identifiers are collected to record eligibility which include PPSN.
Equity stratifiers	Place of residence and gender are captured for medical card holders. Where means test apply, income is also captured.
Data collection methodology	Claim data is processed and payments are made by the Primary Care Reimbursement Service under the following Schemes/Payment Arrangements: ▪ General Medical Services (GMS) ▪ Drugs Payment Scheme (DPS) ▪ Long Term Illness Scheme (LTI) ▪ Dental Treatment Services Scheme (DTSS)

Title	**Primary Care Reimbursement Service (PCRS)**
	▪ European Economic Area (EEA) ▪ High Tech Drugs (HTD) ▪ Primary Childhood Immunisation Scheme ▪ Health (Amendment) Act 1996 ▪ Methadone Treatment Scheme ▪ Health Service Executive Community Ophthalmic Services Scheme (HSE-COS) ▪ Immunisations for certain GMS Eligible Persons ▪ General Practitioner Visit Card (GPVC) Data is collected via both electronic and manual data capture approaches. Data is captured record by record in real time as its generated and also in batches from various parts of the health system, e.g. HSE offices and Pharmacies etc.
Clinical coding scheme	N/A.
Size of national collection	In 2021, PCRS carried out between 80 and 90 million business transactions which corresponded to reimbursement for items of service. There are 12 community health schemes and the PCRS data model including core and supporting data structures comprises approximately 1,400 entities.
Publication frequency	Data is published annually in the PCRS statistical analysis report, available on the website, with monthly updates available on the Publications page. The CSO also publish summary data on their website.
Accessing data	Access via https://www.hse.ie/eng/staff/pcrs/pcrs-publications/
Open Data portal access	Yes.
Generic email contact	PCRS.ReportQueries@hse.ie
Generic telephone contact	+353 1 8647100
Other comments	Primary Care Contractors are the primary source of data within PCRS via their claims.

4.76 Road Fatalities and Injury Collision Statistics

Title	**Road Fatalities and Injury Collision Statistics**
Managing Organisation	Road Safety Authority (RSA) have overall responsibility for the national collection in conjunction with the Garda National Roads Policing Bureau. Under Section 8 of the Road Safety Authority Act 2006, the RSA has a statutory obligation to collect, compile, prepare, publish or distribute information and statistics relating to road safety.
Web address	http://www.garda.ie/ and http://www.rsa.ie/
Year established	Fatality figures are available since 1959 but a more complete version of the data has been kept since 1996. The collection was managed by, the then, National Roads Authority and in 2006 the collection transferred to the Road Safety Authority who were granted a statutory remit to manage it.
Statement of Purpose	To collect, collate, analyse and disseminate the road injury collision data, with the aim of creating and maintaining an accurate and timely dataset of road injury collisions. While data is collected and collated for all incident types, including material damage cases, only records relating to injury collisions (fatal, serious, and minor) are analysed and disseminated. From this perspective, injury incidents are 'in scope' and material damage incidents are 'out of scope'.
Coverage **(geographical and temporal)**	National - the number of road users killed and injured in Ireland and other summary statistics of these collisions. There is a **daily** transfer of data electronically to the RSA.
Description/ Summary	Principal source of data and information on fatal and injury collisions on Irish roads.
Data users	A range of national and international stakeholders, including (but not limited to): National: Department of Transport (DoT), Local Government Management Agency (LGMA), Local Authorities, Researchers, engineering companies.

Title	**Road Fatalities and Injury Collision Statistics**
	International: EC CARE Group, European Transport Safety Council (ETSC), International Traffic Safety Data and Analysis Group (IRTAD).
Data content	Data includes location with co-ordinates, date and time, road and weather conditions, vehicle and injury information in fatal and injury collisions.
Data dictionary	Internal documentation, including data dictionaries, is available, although this has not been published online. When disseminating raw data to stakeholders, a data dictionary, along with other supporting documentation (such as the terms and conditions of use), is provided for their reference.
National-level identifier variables	PPSN and IHI are not included in this dataset. The data variables cover three main elements of an incident: the **location** of the collision, the **persons** involved in the collision, and the **vehicles** involved in the collision.
Equity stratifiers	Gender.
Data collection methodology	There is a **daily** transfer of data electronically to the RSA; these records are individually assessed and validated. This system was introduced from 1st January 2014 and saw a move away from the paper based form (CT68) previously sent to the RSA by AGS.
Clinical coding scheme	Not available.
Size of national collection	Not in use.
Publication frequency	Data is published on an ongoing and regular basis throughout the year.
Accessing data	On RSA website – 1. Annual RSA Road Collision Facts Reports. 2. Provisional review of fatalities at the end of the each year. 3. Ad-hoc reports and analysis of collision data released on an on-going basis. On CSO website – 1. Annual updates available on Statbank through the Other Public Sector Databases page. 2. Annual Transport Omnibus Report. On Garda website – 1. “Traffic Statistics” available updated regularly. 2. Summary data for the year up to the current date. 3. Monthly comparisons available from 2008 - 2013.

Title	**Road Fatalities and Injury Collision Statistics**
	4. Archived Road Collision Statistics - 1961 to 2007.
Open Data portal access	No.
Generic email contact	researchdept@rsa.ie
Generic telephone contact	+353 96 25000
Other comments	Since the catalogue was last updated, internal validation processes have been further refined, leading to continuous improvements in data quality.

4.77 Sentinel GP respiratory surveillance

Title	**Sentinel GP respiratory surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/
Year established	2000.
Statement of Purpose	1. Monitor COVID-19/influenza-like illness (ILI) disease incidence in the community 2. Provide an early warning system for the circulation of influenza virus, SARS-CoV-2, respiratory syncytial virus (RSV) and other respiratory viruses (ORV) with epidemic/pandemic potential 3. Monitor the epidemiology of COVID-19, influenza, RSV and ORV in the community and to determine which age groups and risk groups are most affected, so that targeted public health interventions (vaccines and antivirals) can be implemented 4. Identify SARS-CoV-2 and influenza viruses circulating in the community for the timely detection of genotypic/phenotypic changes and to assess vaccine strain match and antiviral resistance 5. Monitor COVID-19 and influenza vaccine effectiveness in primary care.
Coverage **(geographical and temporal)**	Data collection commenced in 2000. Data collection is weekly (Monday-Sunday) and runs year-round. As of 8th August 2022, the Irish sentinel GP network comprised of 61 general practices (including 173 general practitioners) nationally and covered approximately 6.9% of the national population (2016 CSO census) and 5% of all Irish GPs.
Description/ Summary	The sentinel GP surveillance system is a collaborative surveillance project involving sentinel GPs, the Health Protection Surveillance Centre, the Irish College of General Practitioners (ICGP) and the National Virus Reference Laboratory (NVRL). Currently, the sentinel GP network monitors patients consulting with influenza-like illness (ILI)/COVID-19 symptomatic patients. The influenza and COVID-19 case definitions are published on the HPSC

Title	**Sentinel GP respiratory surveillance**
	website. A combined nasal and throat swab is taken from symptomatic patients and sent to the NVRL for PCR testing for influenza, SARS-CoV-2, RSV and ORVs. HPSC collate and analyse clinical, epidemiological and laboratory data and produce weekly/monthly surveillance reports.
Data users	HPSC, NVRL, ICGP, Departments of Public Health, HSE, Department of Health, the European Centre for Disease Control (ECDC), World Health Organisation (WHO) and other stakeholders.
Data content	Patient demographics include date of birth, gender and diagnosis. Epidemiological data includes vaccination status and laboratory test results.
Data dictionary	Data dictionary is not available online.
National-level identifier variables	No.
Equity stratifiers	Gender.
Data collection methodology	Participating sentinel GPs report a basic dataset on ILI clinical consultations each week to the sentinel GP coordinator. The sentinel GP coordinator collates the data and reports it to HPSC each week. These data are used for calculating sentinel GP ILI consultation rates. A more detailed epidemiological dataset is reported on Healthlink as part of the sentinel GP COVID-19 referral process, which at the time of publication was integrated into processes for COVID-19 community testing centres. HPSC access these referral data via the Healthlink reporting portal. Virological data from the sentinel GP network are reported to HPSC from the NVRL each week. Clinical, epidemiological and virological data are formatted and validated, analysed and reported by HPSC.
Clinical coding scheme	▪ Influenza-like illness/influenza case definition (as per the ECDC case definition) published on HPSC website. ▪ COVID-19 interim case definition published on HPSC website.
Size of national collection	The average number of annual clinical ILI consultations reported from the sentinel GP network (2016-2021*) is 2,526 and 1,318 sentinel GP ILI virological specimens tested. **Please note as of March 2020, the COVID-19 pandemic increased the number of ILI consultations reported and specimens tested.*
Publication frequency	Weekly/monthly and annual reports, published on HPSC website. https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/

Title	**Sentinel GP respiratory surveillance**
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300
Other comments	At the time of publication, sentinel GP surveillance was integrated into processes at COVID-19 community testing centres and was under review.

4.78 Surveillance of antimicrobial consumption in Ireland

Title	**Surveillance of antimicrobial consumption in Ireland**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	http://www.hpsc.ie/hpsc/A-Z/MicrobiologyAntimicrobialResistance/EuropeanSurveillanceofAntimicrobialConsumptionESAC/
Year established	2003 (data collection and reporting for primary care), 2004 (pilot), 2006 (full data collection).
Statement of Purpose	In scope: To support overall multi-faceted strategy for the control and prevention of infectious diseases by providing standardised measure of antimicrobial consumption for acute hospitals and community setting.
Coverage **(geographical and temporal)**	42 public acute hospitals participating; coverage of primary care is over 95%. Data collected on monthly basis where possible, else quarterly.
Description/ Summary	Data on antimicrobials dispensed by hospital pharmacies, and antimicrobials purchased by community pharmacies, are collected and converted into a standardised measure using the World Health Organization ATC/DDD classification.
Data users	Infection control teams. HSE KPI. ECDC.
Data content	Hospitals provide data (ward/quantities/cost) on the antimicrobial drugs (by product and pack) dispensed in each quarter. Primary care data are by quantity of antimicrobial drugs (by product and pack) sold by retail pharmacy aggregated to sub-county level in each month.
Data dictionary	Not available.
National-level identifier variables	Not applicable.
Equity stratifiers	Not applicable.
Data collection methodology	Hospitals pharmacies send data directly to HPSC by quarters or by months where possible; a secure online tool (MicroB) is available to

Title	**Surveillance of antimicrobial consumption in Ireland**
	assist remote uploading and analysis. Primary care data are received on a monthly basis from IMS Health.
Clinical coding scheme	World Health Organization ATC/DDD classification scheme.
Size of national collection	Hospital data: approximately 140,000 cumulative transactions (packages of each drug dispensed to each hospital ward within a quarter) per annum. Primary care: approximately 100,000 cumulative sales transactions (packages of each drug sold by wholesalers to sub-county level geographical segments in each month) per annum. Note these transactions are not the same as prescriptions.
Publication frequency	Bi-annual and annual reports are available on the HPSC website.
Accessing data	Reports are available from the HPSC website via the MicroB Open reports microsites: http://www.hpsc.ie/A-Z/MicrobiologyAntimicrobialResistance/EuropeanSurveillanceofAntimicrobialConsumptionESAC/PublicMicroBReports/ Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	The MicroB Open reports are interactive and detailed analysis for each hospital in can be easily accessed.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300

4.79 Surveillance of severe acute respiratory infections (SARI)

Title	**Surveillance of severe acute respiratory infections (SARI)**
Managing Organisation	Health Protection Surveillance Centre (HPSC).
Web address	Weekly publication on HPSC website to commence soon. www.hpsc.ie
Year established	Commenced in July 2021 in one SARI hospital site, St Vincent's University Hospital.
Statement of Purpose	1. Monitor SARI incidence trends 2. Describe intensity of activity and severity of SARI infections 3. To identify and monitor groups at risk of severe disease 4. To assess the SARI burden of disease 5. To assess and monitor vaccine effectiveness 6. To develop recommendations for SARI surveillance. In scope: SARI surveillance monitors SARI cases admitted through the Emergency Department, based on clinical symptoms. Only one SARI hospital site was included at the time of publication. Out of scope: Patients that develop SARI during their admission, or are admitted through alternate routes, are not included in the surveillance system. Patients under 14 years of age were not included in the current SARI hospital site.
Coverage (geographical and temporal)	Limited to one acute hospital – St Vincent's University Hospital, Dublin, which has a catchment population of 304,146 (those aged 14 years and older) according to 2021 population projection. Surveillance began in July 2021; data are analysed on a weekly ongoing basis.
Description/summary	SARI surveillance in Ireland is a syndromic sentinel hospital surveillance project, which is part of a wider European network of SARI hospitals, E-SARI-NET. There is currently only one SARI sentinel hospital site in Ireland, collecting case-based data. SARI cases are identified from new admissions through the Emergency Department, based on clinical symptoms. SARI patients are tested for SARS-CoV-2, influenza and respiratory syncytial virus (RSV). Epidemiological reports are produced by HPSC on a weekly basis on the incidence of persons hospitalised with SARI; epidemiological, clinical and virological data are

Title	**Surveillance of severe acute respiratory infections (SARI)**
	described, including influenza and COVID-19 vaccination status and outcome.
Data users	HPSC, NVRL, SVUH, HSE, Department of Health, Departments of Public Health, European Centre for Disease Control (ECDC), World Health Organisation (WHO) and other stakeholders.
Data content	▪ Patient demographics (age, gender, address, ethnicity, occupation) ▪ Symptoms ▪ Pre-existing conditions ▪ Laboratory investigations ▪ Antiviral usage ▪ Outcomes ▪ Vaccination status
Data dictionary	Data dictionary is not available online.
National-level identifier variables	IHI is recorded, where available.
Equity stratifiers	Sex, age, address, ethnicity, and occupation are collected.
Data collection methodology	Information is extracted from medical charts or records by research nurses, and from laboratory information systems by an epidemiologist. Data are extracted from the hospital SARI database to an excel file, and sent to HPSC on a weekly basis. Data are imported into the HPSC SARI database. The HSE Integrated Information Service (IIS) match SARI patients to COVID-19 vaccine data (from the National COVID-19 vaccination system) on a weekly basis. These data are imported into the HPSC SARI database.
Clinical coding scheme	Definition of SARI as per the ECDC case definition. ECDC SARI definition: A hospitalised (for at least 24 hours) person with acute respiratory infection, with at least one of the following symptoms: cough, fever, shortness of breath OR sudden onset of anosmia, ageusia or dysgeusia with onset of symptoms within 14 days prior to hospital admission. No coding is used.
Size of national collection	The average number of SARI cases reported each week is 11 (range 2 to 29).

Title	**Surveillance of severe acute respiratory infections (SARI)**
Publication frequency	SARI surveillance reports are distributed to stakeholders weekly. The report is not currently available online.
Accessing data	Data requests can be submitted via hpsc@hse.ie and will be assessed on a case-by-case basis.
Open Data portal access	No.
Generic email contact	hpsc@hse.ie
Generic telephone contact	+353 1 8765300
Other comments	

coimisiún meabhair - shláinte
mental health commission

4.80 Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres

Title	**Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres**
Managing Organisation	Mental Health Commission (MHC) - Standards and Quality Assurance Division.
Web address	http://www.mhcirl.ie/Publications
Year established	2008.
Statement of Purpose	The Commission was established in 2002. They are an independent body and their functions are set out by law in the Mental Health Act 2001. Their main functions are to promote, encourage and foster high standards and good practices in the delivery of mental health services and to protect the interests of patients who are involuntarily admitted. The Mental Health Commission is responsible for regulating and monitoring mental health services. Data on the use of seclusion, mechanical restraint and physical restraint in approved centres are collected in accordance with provisions in the following: ▪ Code of Practice on the use of Physical Restraint in Approved Centres (MHC, 2009) ▪ Mental Health Act, 2001 ▪ Quality Framework for Mental Health Services in Ireland (MHC, 2009) ▪ Rules Governing the use of Seclusion and Mechanical Means of Bodily Restraint (MHC, 2009). Data are processed in adherence with the following legislation: ▪ Data Protection Act 2018 ▪ Data Protection (Amendment) Act 2003 ▪ Data Protection Act 1988 ▪ Freedom of Information (Amendment) Act 2003, ▪ Freedom of Information Act 1997. Data within scope is data relating to the carrying out of treatments nationally. Data that does not relate to this is out of scope.

Title	**Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres**
Coverage **(geographical and temporal)**	National - all approved centres that use seclusion or restraint. Collection started 01/01/2008 and is ongoing.
Description/ Summary	MHC collects and reports on demographic and administrative data in relation to the use of seclusion, mechanical restraint and physical restraint in approved centres nationally.
Data users	MHC Staff - Corporate Team Regulatory Team Inspectorate Team Tribunals Team.
Data content	Service user initials; gender; date of birth; details regarding the use of seclusion; mechanical and physical restraint.
Data dictionary	Yes, not online.
National-level identifier variables	Services are requested to provide unique service identifiers.
Equity stratifiers	Yes - Gender.
Data collection methodology	Data are extracted from registers and clinical practice forms in approved centres and returned on prescribed data collection templates to the MHC on annual basis. MHC stores the information on its password protected information system or in a secure electronic file management facility. Data collection occurs when information is submitted to MHC by clinicians or administrative staff in approved centres. Staff in approved centres are required to submit this data within 7 days of the event.
Clinical coding scheme	Not in use.
Size of national collection	4,500 average number of records created annually.
Publication frequency	Annual activity reports published on MHC website.
Accessing data	Annual reports – Seclusion and Restraint in approved centres activity report and data requests.
Open Data portal access	No.
Generic email contact	info@mhcirl.ie

Title	**Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres**
Generic telephone contact	+353 1 6362400
Other comments	From later in 2022, data for recording seclusion is due to be stored on the existing online system by clinicians or administrative staff with an individual user account. The secure online system is operated by MHC staff who also have individual user accounts. Data collection will then occur when information is submitted to MHC by clinicians or administrative staff in approved centres.

4.81 Very Low Birth Weight Infants in the Republic of Ireland

Title	**Very Low Birth Weight Infants in the Republic of Ireland**
Managing Organisation	The National Perinatal Epidemiology Centre (NPEC) in collaboration with NICORE ROI (Neonatal Intensive Care Outcomes Research and Evaluation) and in conjunction with the Vermont Oxford Network (VON).
Web address	http://www.ucc.ie/en/npec/ https://public.vtoxford.org/
Year established	2014.
Statement of Purpose	The purpose of the audit is to improve the quality and safety of care for very low birth weight babies in Ireland. **Scope:** Any infant born with a weight from 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive) who is admitted to or dies in any location in any neonatal centre in ROI within 28 days of birth.
Coverage **(geographical and temporal)**	National coverage: 19 neonatal centres and two tertiary paediatric children's hospitals Data collection commenced in 2014 and is ongoing.
Description/ Summary	Hospitals submit their data to the Vermont Oxford Network. The VON returns the data on the infants born in the Republic of Ireland to NPEC and this centre subsequently analyses it and publishes an annual report. General data from all participant VON centres (the network data) is also available to the NPEC. The NPEC holds these data acting as a national repository for the yearly national data.
Data users	Maternity care staff, neonatal staff, unit co-ordinators, hospital senior management, hospital risk management, policy developers in the HSE, DOH staff, service users.
Data content	Inclusion criteria: infants born alive between 401 and 1500g or whose gestational age is between 22 weeks 0 days and 29 weeks 6 days. Infant Characteristics, Prenatal care, neonatal care, mortality and survival, infant morbidities and outcomes.
Data dictionary	https://vtoxford.zendesk.com/hc/en-us/articles/4405064008467-2022-Manual-of-Operations-Part-2-Release-26-1-PDF-

Title	**Very Low Birth Weight Infants in the Republic of Ireland**
National-level identifier variables	No.
Equity stratifiers	Ethnic group, gender.
Data collection methodology	Through the VON online data submission platform (eNICQ) or in exceptional circumstances, by submission of paper forms to the NPEC. Data is collected on an annual basis.
Clinical coding scheme	Not in use.
Size of national collection	In 2019, similar to previous years, there were 505 infants included.
Publication frequency	Annual reports published 12-18 months within end of data collection year.
Accessing data	NPEC have a data access policy. Applicants must complete a data request form which is reviewed by a data access committee. https://www.ucc.ie/en/npec/dataaccesscommittee/dataaccesscommittee/
Open Data portal access	No.
Generic email contact	npec@ucc.ie
Generic telephone contact	+353 21 4205054
Other comments	Audit coordinators and collaborators in each participating unit are responsible for submitting data on all eligible cases from their centre. This is done on a voluntary basis. Ireland is one of many few countries with full national representation in the VON audit. The NPEC, supports the national participation of Ireland in this VON audit by financing the annual membership fee on behalf of all 21 centres, providing administrative support and managing, analysing and publishing the annual reports.

4.82 Vital Statistics — Deaths Registration

Title	**Vital Statistics - Deaths Registration**
Managing Organisation	Department of Social Protection, prepared by the Central Statistics Office (CSO) for the Minister for Social Protection. Data received from the General Register Office (GRO).
Web address	https://www.cso.ie/en/statistics/birthsdeathsandmarriages/
Year established	1864.
Statement of Purpose	To collect vital statistics on all deaths in Ireland.
Coverage **(geographical and temporal)**	All deaths in Ireland. Data received on an ongoing basis from the GRO.
Description/ Summary	The data is collected under the Vital Statistics Act 1952 and Section 73 of the Civil Registration Act 2004.
Data users	Eurostat & General Public.
Data content	Date of death, address of residence of deceased, place of death, cause of death, occupation of deceased, age of deceased, sex of deceased, marital status of deceased.
Data dictionary	Not available.
National-level identifier variables	N/A.
Equity stratifiers	N/A.
Data collection methodology	All data is received electronically. Prior to Sept 2003, data was coded from death certificates. In September 2003, electronic transfer of data from the General Registry Office commenced on a phased basis. Data is received weekly from the GRO.
Clinical coding scheme	ICD-10.
Size of national collection	Approximately 30,000 records created on average nationally.
Publication frequency	Quarterly and annually.
Accessing data	On-line from CSO website or in hard copy **https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/**

Title	**Vital Statistics - Deaths Registration**
Open Data portal access	Yes
Generic email contact	information@cso.ie
Generic telephone contact	+353 21 4535000

4.83 Vital Statistics — Live Births Registration

Title	**Vital Statistics - Live Births Registration**
Managing Organisation	Department of Social Protection, prepared by the Central Statistics Office (CSO) for the Minister for Social Protection. Data received from the General Register Office.
Web address	https://www.cso.ie/en/statistics/birthsdeathsandmarriages/
Year established	1864.
Statement of Purpose	To collect vital statistics on live births in Ireland.
Coverage **(geographical and temporal)**	All live births in Ireland. Data received on an ongoing basis from the GRO.
Description/ Summary	The data is collected under the Vital Statistics Act 1952 and Section 73 of the Civil Registration Act 2004. Provides information on live births in Ireland, used in calculating natural increase which contributes to the population estimates and in fertility analysis.
Data users	Eurostat & general public.
Data content	Live births – birth weight; gestational age; date of birth of infant; date of birth of parents; marital status of mother; number of previous children; county of residence of mother; multiplicity; occupation of parents; baby's forename; nationality of mother and father, place of birth type.
Data dictionary	Not available.
National-level identifier variables	N/A.
Equity stratifiers	N/A.
Data collection methodology	Live births are registered with a local Registrar and General Register Office (GRO). Data are then forwarded electronically from the GRO to the CSO for Vital Statistics. Data is received weekly from the GRO.
Clinical coding scheme	N/A.
Size of national collection	Approximately 60,000 records created on average nationally.
Publication frequency	Quarterly and annually.

Title	**Vital Statistics - Live Births Registration**
Accessing data	On-line from CSO website.
Open Data portal access	Yes.
Generic email contact	information@cso.ie
Generic telephone contact	+353 21 4535000
Other comments	

An tÚdarás Sláinte agus Sábháilteachta
Health and Safety Authority

4.84 Work Related Fatal and Non-Fatal Incident Database

Title	**Work Related Fatal and Non-Fatal Incident Database**
Managing Organisation	The Health and Safety Authority (HSA).
Web address	www.hsa.ie
Year established	The HSA has been gathering data since its inception in 1989.
Statement of Purpose	The HSA collects data on accidents at work as part of its requirement to comply with the Framework Directive 89/391/EEC (1) on measures to encourage improvements in the safety and health of workers at work. The European Statistics on Accidents at Work (ESAW) methodology specifies the information that is to be collected by the HSA. In addition, Under the Safety, Health and Welfare at Work (General Application) Regulations 2016 all employers and self-employed persons are legally obliged to report the injury of an employee as a result of an accident while at work. This provides national statistics and trends on work-related accidents and informs the Authority's Programme of Work.
Coverage **(geographical and temporal)**	Under the Safety, Health and Welfare at Work (General Application) Regulations 2016, all employers and self-employed persons are legally obliged to report the injury of an employee as a result of an accident while at work. Injuries must be reported if the employee is unable to carry out their normal work for more than three consecutive days, excluding the day of the accident. Data collection is continuous and is reported on an annual basis.
Description/ Summary	Non-fatal incidents and dangerous occurrences are self-reported (i.e. reported by employers and self-employed persons). Fatal incidents can be reported by employers, self-employed persons, or An Garda Síochána. Notifications should be sent via a standard form available here and are submitted to the Authority's Contact Centre.
Data users	Key users are Authority Staff. Reports and key statistics based on the data are made available for a variety of users: -Board members -Industry Stakeholders

<table>
<tr><th>Title</th><th>Work Related Fatal and Non-Fatal Incident Database</th></tr>
<tr><td></td><td>-Executive Team
-Media
-Government Departments and Agencies
-General Public
-Academia
-The European Statistical Office, Eurostat, via the European Statistics on Accidents at Work Framework.</td></tr>
<tr><td>Data content</td><td>The data items include: incident details (date, time, location); injured party details (name, gender, employment status, age etc.); employer details (company, NACE code, location etc.), injury details (trigger, body part injured etc.)

ESAW methodology specifies the information to be collected.</td></tr>
<tr><td>Data dictionary</td><td>ESAW methodology provides definitions of all fields. We are currently developing a new core platform of which a data dictionary will be a part.</td></tr>
<tr><td>National-level identifier variables</td><td>Eircodes are included but not mandatory as of yet. Standard business identifiers may be included in future.</td></tr>
<tr><td>Equity stratifiers</td><td>Employment status, type of worker, age, gender, nationality, place of employment.</td></tr>
<tr><td>Data collection methodology</td><td>Notifications should be sent via a standard form available here and are submitted to the Authority’s Contact Centre.

Notifications are sent on a continuous basis (as incidents arise).</td></tr>
<tr><td>Clinical coding scheme</td><td>N/A.</td></tr>
<tr><td>Size of national collection</td><td><table><tr><th></th><th>Average 2017 - 2021</th></tr><tr><td>Fatal incidents</td><td>45.4</td></tr><tr><td>Non-fatal incidents</td><td>8792.4</td></tr><tr><td>Dangerous Occurrences</td><td>288.4</td></tr></table></td></tr>
<tr><td>Publication frequency</td><td>The Annual Review of Workplace Injuries, Illnesses and Fatalities is published annually.

Data is sent to Eurostat Annually (18 months in arrears).</td></tr>
<tr><td>Accessing data</td><td>The following reports can be downloaded from www.hsa.ie: Statistics - Health and Safety Authority (hsa.ie)

Annual Review of Workplace Injuries, Illnesses and Fatalities 2019–2020</td></tr>
</table>

Title	**Work Related Fatal and Non-Fatal Incident Database**
	Other sectoral reports recently published: Work-Related Deaths Involving Vehicles in Ireland 2010–2019 A Review of Work-Related Fatalities in Agriculture in Ireland 2011-2020
Open Data portal access	Non-Fatal Workplace Injuries - Datasets - data.gov.ie
Generic email contact	statistics@hsa.ie
Generic telephone contact	0818 289 389
Other comments	Underreporting in certain sectors is a European wide problem. Thus, our reports also refer to the CSO's Workplace Accidents and Illnesses module of the LFS for data on accidents at work.

5 Data collections with regional coverage

- Adult Cardiac Database — Galway
- Cardiac Surgery Register — Cork
- Coronary Heart Attack Ireland Register (CHAIR)
- Heartwatch
- Joint Research Centre (JRC) EUROCAT European Registries of Congenital Anomalies. Cork and Kerry Congenital Anomaly Register, JRC EUROCAT Registry 49
- National Thoracic Surgery Outcomes
- South East Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)

5.1 Adult Cardiac Database- Galway

Title	**Adult Cardiac Database- Galway**
Managing Organisation	European Association for Cardio-Thoracic Surgery.
Web address	http://www.eacts.org/quip/adult-cardiac-database/
Year established	N/A.
Statement of Purpose	To measure the quality of care of adult cardiac surgery and provide information for quality improvement and research. To encourage improvement of clinical outcomes for patients and to promote the importance of integrating quality improvement initiatives into daily clinical practice. All cardiac surgical procedures performed by the team at Galway University Hospital.
Coverage **(geographical and temporal)**	All patients who attend Galway University Hospital for cardiac surgery. Galway University Hospital is a tertiary referral hospital and part of the Saolta Hospital Group which covers a large geographical area in the West and North West of Ireland serving a population of over 700,000 people within its catchment area. **The electronic patient management system is currently being upgraded in line with the New EACTS Adult Cardiac Surgery data dictionary with planned submission of cardiac surgery outcome data to the European Association for Cardiothoracic Surgery moving forward. This project is in the final stages.
Description/ Summary	This is a register for all patients who attend Galway University Hospital and undergo cardiac surgery.
Data users	Clinical teams and researchers.
Data content	Below you will find a breakdown of the information collected for cardiac surgical patients; **Cardiac Surgery** Gender, age, cardiac history, previous interventions, pre-operative risk factors, pre-operative haemodynamics and catheterisation, Pre-operative status and support, operation, coronary surgery information, valve surgery information, perfusion and myocardial

Title	**Adult Cardiac Database- Galway**
	protection, post-operative course and discharge details (including mortality).
Data dictionary	https://www.eacts.org/wp-content/uploads/2019/08/EACTS-ACD-NEW-Data-Dictionary-Summary-of-Changes.pdf
National-level identifier variables	No.
Equity stratifiers	Gender.
Data collection methodology	Data is entered directly into the electronic register with clinical validation. Annual basis.
Clinical coding scheme	N/A.
Size of national collection	Cardiac- In excess of 100,000 procedures annually.
Publication frequency	Annual. Published in an anonymised report.
Accessing data	Annual Reports published by EACTS.
Open Data portal access	No.
Generic email contact	info@eacts.co.uk
Generic telephone contact	+44 (0)1753 832 166
Other comments	Morbidity and mortality cases are regularly presented at morbidity and mortality conferences with multi-disciplinary representation by departments including cardiothoracic surgery, cardiology, anaesthesia, nursing and perfusion.

5.2 Cardiac Surgery Register — Cork

Title	**Cardiac Surgery Register — Cork**
Managing Organisation	Cork University Hospital.
Web address	http://www.eacts.org/ http://scts.org/
Year established	1999. We started submitting since 1999.
Statement of Purpose	To measure the quality of care of adult cardiac surgery and provide information for quality improvement and research.
Coverage **(geographical and temporal)**	HSE South/ South West Region, and Mid West Region. Cardiac data collection commenced 1999 and is ongoing.
Description/ Summary	This register captures data on cardiac surgical stay in the hospital on a computer-based system. This includes demographic, clinical and administrative data.
Data users	Medical Personnel, Nursing Personnel, Medical Students and allied Medical Personnel.
Data content	Demographics, diagnosis, procedures including surgical procedures performed, admission and discharge data.
Data dictionary	Yes, see European Association for Cardio-Thoracic Surgery (EACTS) website. http://www.eacts.org/
National-level identifier variables	No. Health Card Record number and date of birth.
Equity stratifiers	Gender and age some of the other acquired on admission by hospital records.
Data collection methodology	Data is collected from the healthcare record and other systems in use in the hospital i.e. cardiac catheterisation laboratory, laboratory, clerical/secretarial.
Clinical coding scheme	N/A.
Size of national collection	500.

Title	**Cardiac Surgery Register — Cork**
Publication frequency	Data published in National Adult Cardiac Surgical Database Annual Report, Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS). European Database.
Accessing data	Anonymous data in the National Adult Cardiac Surgical Database Report, SCTS.
Open Data portal access	No.
Generic email contact	http://www.eacts.org/ http://scts.org/
Generic telephone contact	Above Association Numbers.
Other comments	http://scts.org/

5.3 Coronary Heart Attack Ireland Register (CHAIR)

Title	**Coronary Heart Attack Ireland Register (CHAIR)**
Managing Organisation	Health Service Executive (HSE) – South/South West Hospital Group.
Web address	N/A.
Year established	2002 (July, roll-out began) 2003 (May, roll-out complete for all eight hospitals in Cork and Kerry).
Statement of Purpose	The aim of CHAIR is to gather information on hospital patients admitted with suspected or confirmed acute coronary syndromes (ACS) in order to improve the delivery of healthcare and to improve patient outcomes. Its objectives are: ▪ to record, describe and analyse registered patient demographics, diagnostic and treatment details and hospital outcomes ▪ to facilitate the development of strategies to improve the quality of ACS patient care ▪ to contribute towards the development of a national plan for the in-patient and community management of patients with ACS ▪ To provide data for the Heartbeat portal to support NOCA IHAA.
Coverage (geographical and temporal)	Pilot in HSE - South (Cork and Kerry and South Tipperary) region. Private hospital participation. Data collection commenced in 2002 and is ongoing.
Description/ summary	CHAIR is a computer register that gathers information on hospital patients admitted with suspected or confirmed acute coronary syndromes in order to improve the delivery of healthcare and to improve patient outcomes on discharge from hospital. Acute coronary syndromes (ACS) include heart attack (myocardial infarction) and unstable angina. In mid-2007 CHAIR adopted the European Cardiology Audit and Registration Data Standards (CARDS) Acute Coronary Syndromes (ACS) dataset and became known as CHAIR/CARDS ACS.
Data users	CHAIR Programme Team, Consultant Cardiology teams across South/South West Hospital Group, hospital group business managers.

Title	**Coronary Heart Attack Ireland Register (CHAIR)**
Data content	CHAIR information covers nine distinct areas: patient demographics; admission Details; thrombolysis details; risk factors; clinical details (procedures); investigations; medications at discharge; discharge details; follow up details; CHAIR/CARDS ACS information covers ten distinct areas: demographics; history (relevant to CAD); risk factors (relevant to CAD); medication: pre hospital; working diagnosis; investigations and treatment (including thrombolysis); medication: during hospital stay; outcome; medication: at discharge; follow up.
Data dictionary	Data dictionary is in place but is not available online.
National-level identifier variables	No.
Equity stratifiers	Yes: ▪ Place of residence ▪ Gender.
Data collection methodology	A CHAIR Registration Officer collects the data at each hospital. CHAIR data (2002 to 2007) was essentially in two forms: ▪ personal data in the local database (within the hospital) ▪ 'anonymised' data (no MRN, no name and no address) in the central database (located in Dublin). The personal data in the hospital database is information from the patient medical record. In 2007 CHAIR adopted the European CARDS ACS dataset. This entailed new software (and a new software provider) and the use of web-enabled access with data protected within the HSE South firewall. Annonymised data is also entered onto the Heartbeat portal to form part of the NOCA National database.
Clinical coding scheme	N/A.
Size of national collection	Approximately 800 records created on average annually.
Publication frequency	Summary progress reports have been published in the past on the Irish Heart Foundation (IHF) website and CHAIR information presented at various events. CHAIR information has been used for journal publications. CHAIR/CARDS data is presented regularly within the CHAIR hospitals at STEMI meetings and Mortality and Morbidity meetings. Data is used regularly by junior doctors and researchers.

Title	**Coronary Heart Attack Ireland Register (CHAIR)**
Accessing data	This data is available to the CHAIR Registration Officer and to certain hospital and medical staff. It has protection from public use by way of unique user IDs, passwords and physical access to the system. Requests for access to the data should be made to the Office of the CEO South/South West Hospital Group.
Open Data portal access	No.
Generic email contact	N/A.
Generic telephone contact	N/A.
Other comments	CHAIR was a Department of Health initiative facilitated by the Southern Health Board beginning in 2001. It was handed over to the HSE (on formation of HSE) which is where it remains. A User Manual and Data Dictionary exist for CHAIR and CHAIR CARDS ACS which are available to Registration Officers.

5.4 Heartwatch

Title	**Heartwatch**
Managing Organisation	Irish College of General Practitioners (ICGP)
Web address	http://www.icgp.ie/go/research/heartwatch
Year established	2003.
Statement of Purpose	The aim of Heartwatch is to reduce the morbidity and mortality of patients with cardiovascular disease (secondary prevention).
Coverage **(geographical and temporal)**	20% of GPs nationwide. Data collection commenced in 2003; and is geographically diverse, representing all of the country.
Description/ Summary	The Heartwatch Programme has not advanced beyond Phase 1 which is a pilot demonstration programme. As such the purpose was to demonstrate the benefit of involvement in a structured care programme with care implemented according to defined clinical protocols.
Data users	ICGP, HSE, GP Cardiovasculare Clinical Lead, Academic Reserachers.
Data content	Up to four patient visits annually; measures include current status of patient; risk factors; diet and exercise; medications and referrals.
Data dictionary	Yes http://www.icgp.ie/go/research/heartwatch/heartwatch_faqs/B4BBE9AC-F8B7-5457-4810B4E031764F8D.html
National-level identifier variables	No.
Equity stratifiers	Yes Gender.
Data collection methodology	Data is collected at scheduled Heartwatch visits with patients who have agreed to participate in the programme. The GP practice completes the relevant data at each patient visit and enters the data on their GP software programme. Once data is completed they upload anonymised patient reports via the INDC website using an ID and password. Data is uploaded monthly by practices.
Clinical coding scheme	Not relevant for this activity.

Title	**Heartwatch**
Size of national collection	23,554 patients registered with 472,235 continuing care visits in total; approximately 25,000 new records annually.
Publication frequency	Annually.
Accessing data	Individual GPs have access to their own data. Automated aggregated reports are produced on request for the HSE by the Heartwatch administrator. There is no access to individual patient data. Access by application to aggregated anonymous data.
Open Data portal access	No.
Generic email contact	heartwatch@icgp.ie
Generic telephone contact	+353 1 6763705

5.5 Joint Research Centre (JRC) EUROCAT European Registries of Congenital Anomalies. Cork and Kerry Congenital Anomaly Register, JRC EUROCAT Registry 49

Title	**Joint Research Centre (JRC) EUROCAT European Registries of Congenital Anomalies. Cork and Kerry Congenital Anomaly Register, JRC EUROCAT Registry 49**
Managing Organisation	Department of Public Health, HSE-S in association with EUROCAT central registry https://eu-rd-platform.jrc.ec.europa.eu/eurocat_en
Web address	https://eu-rd-platform.jrc.ec.europa.eu/eurocat_en and www.hse.ie/congenitalanomalyregistersireland/
Year established	EUROCAT South data collection commenced in 1996.
Statement of Purpose	To improve the health of the Irish people through the provision of health intelligence on congenital anomalies. In addition to facilitating early warning of new teratogenic exposures, this data is used to inform and evaluate primary prevention of congenital anomalies and to enable the planning of health services for these conditions. They collect information to: ▪ learn more about congenital anomalies and help research into their causes, treatment and prevention ▪ provide early warning of potential harmful exposures that may contribute to anomalies during pregnancy ▪ examine the survival and health of babies born with anomalies, ▪ look at trends and the numbers of babies born with a congenital anomaly in our region ▪ participate and contribute to the European network of registries.
Coverage (geographical and temporal)	JRC EUROCAT South covers the counties of Cork and Kerry in the South West of Ireland (population-based, all mothers resident in this geographic area). Data collection commenced in 1996 and is ongoing.
Description/ Summary	There are three regional congenital anomaly registers in the Republic of Ireland. All are members of JRC EUROCAT, the European network of congenital anomaly registers; they provide an anonymised

Title	**Joint Research Centre (JRC) EUROCAT European Registries of Congenital Anomalies. Cork and Kerry Congenital Anomaly Register, JRC EUROCAT Registry 49**
	computerised register of cases of congenital anomaly born to mothers resident in Ireland. As of 2022, only two of the registries are active JRC EUROCAT South and JRC EUROCAT South-East. JRC EUROCAT East is not active currently.
Data content	Detailed description of the anomaly and baby malformations, demographics of parents and baby such as age, date of birth, weight, date of delivery, parental occupation, medications taken, chronic paternal illness, smoking and alcohol status, maternal illness before and during pregnancy and outcome of previous pregnancies is gathered.
Data users	The Irish congenital anomaly registries working with the EUROCAT central registry and the EUROCAT network of registries. EUROCAT aims to encourage the use of its data for epidemiological surveillance and research whilst ensuring the protection of complete confidentiality of the data and ensuring that existing knowledge is fully brought to bear on the interpretation of its data. Details available at EUROCAT | EU RD Platform (europa.eu)
Data collection methodology	A HSE registry nurse collects data from medical charts/records on an ongoing basis and codes data before entering it electronically on the JRC-EUROCAT local register. Data is uploaded to the JRC EUROCAT bi-annually. The registry is based on active case finding.
Data dictionary	Yes – full data dictionary published on JRC-EUROCAT website https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection/guidelines-for-data-registration_en
National-level identifier variables	N/A.
Equity stratifiers	Maternal education; Socioeconomic status of mother; Socioeconomic status of father; Migrant status; Maternal place of residence Mother's occupation at time of conception included as an exposure variable Father's occupation.
Clinical coding scheme	ICD-10-AM https://www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf McKusick/OMIM Code http://www.ncbi.nlm.nih.gov/omim

Title	**Joint Research Centre (JRC) EUROCAT European Registries of Congenital Anomalies. Cork and Kerry Congenital Anomaly Register, JRC EUROCAT Registry 49**
	International Standard Classification of Education http://uis.unesco.org/en/topic/international-standard-classification-education-isced International Standard Classification of Occupations https://www.ilo.org/public/english/bureau/stat/isco/ ATC Code Drug Description https://www.whocc.no/atc_ddd_index/ Orpha Codes http://www.rd-code.eu/introduction/
Size of national collection	HSE South average 220 cases per annum.
Publication frequency	Links to annual newsletters and published reports from the registry are available on the HSE registries website. All JRC-EUROCAT publications on congenital anomalies are publicly listed on the JRC-EUROCAT website.
Accessing data	Open access to anonymous data via the JRC EUROCAT website. Researcher access to local anonymised data via a management approval process.
Open Data portal access	No.
Generic email contact	dph@hse.ie
Generic telephone contact	+353 21 4927601

5.6 National Thoracic Surgery Outcomes

Title	**National Thoracic Surgery Outcomes**
Managing Organisation	Society of Cardiothoracic Surgery in Great Britain and Ireland.
Web address	https://scts.org/patients/lungs.aspx
Year established	N/A.
Statement of Purpose	To measure the quality of care of adult thoracic surgery and provide information for quality improvement and research. To encourage improvement of clinical outcomes for patients and to promote the importance of integrating quality improvement initiatives into daily clinical practice. All thoracic surgical procedures performed by the team at Galway University Hospital.
Coverage **(geographical and temporal)**	All patients who attend Galway University Hospital for thoracic surgery. Galway University Hospital is a tertiary referral hospital and part of the Saolta Hospital Group which covers a large geographical area in the West and North West of Ireland serving a population of over 700,000 people within its catchment area. 2020-2021 thoracic surgery mortality data has been submitted to SCTS for presentation at the thoracic forum in coming months.
Description/ Summary	This is a register for all patients who attend Galway University Hospital and undergo thoracic surgery.
Data users	Clinical teams and researchers.
Data content	**Thoracic Surgery** Data collected includes a breakdown of the procedure type and method of surgical incision as well as number of deaths associated with each procedure type.
Data dictionary	Thoracic SCTS template collects data pertaining to the number of open approach, endoscopic approach and robotic procedures as well as the number of mortalities under a number of sub-sections; lung resections-primary malignant, lung resections-all other pathologies, mesothelioma surgery (therapeutic), pleural procedures-other, chest wall-diaphragmatic procedures, mediastinal procedures, oesophageal/gastric procedures, tracheal surgery and ‘other’ surgery- major and minor.

Title	**National Thoracic Surgery Outcomes**
National-level identifier variables	No.
Equity stratifiers	No.
Data collection methodology	Data is submitted to the SCTS research team. Annual basis (financial year).
Clinical coding scheme	N/A.
Size of national collection	Thoracic-In excess of 25,000 procedures annually.
Publication frequency	Annual. Published in an anonymised report.
Accessing data	Annual Reports published by SCTS.
Open Data portal access	No.
Generic email contact	https://scts.org/about_scts/contact_options.aspx
Generic telephone contact	+44 (0)20 7869 6893
Other comments	Morbidity and mortality cases are regularly presented at morbidity and mortality conferences with multi-disciplinary representation by departments including cardiothoracic surgery, cardiology, anaesthesia, nursing and perfusion. Key Performance Indicators are also monitored for lung cancer patients by the National Cancer Centre Control Programme (NCCP).

5.7 South East Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)

Title	**South East Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)**
Managing Organisation	Department of Public Health, HSE South-East, in association with EUROCAT central registry http://www.eurocat-network.eu/
Web address	http://www.eurocat-network.eu/ and http://www.hse.ie/congenitalanomalyregistersireland
Year established	1997.
Statement of Purpose	To improve the health of the Irish people through the provision of health intelligence on congenital anomalies. In addition to facilitating early warning of new teratogenic exposures, this data is used to inform and evaluate primary prevention of congenital anomalies and to enable the planning of health services for these conditions. They collect information to: ▪ learn more about congenital anomalies and help research into their causes, treatment and prevention, ▪ provide early warning of potential harmful exposures that may contribute to anomalies during pregnancy, ▪ examine the survival and health of babies born with anomalies, ▪ look at trends and the numbers of babies born with a congenital anomaly in our region, ▪ participate in local and national research on specific anomalies ▪ participate and contribute to the European network of congenital anomalies.
Coverage **(geographical and temporal)**	The registry provides congenital anomalies surveillance for all births where the mother is resident in counties Carlow, Kilkenny, Wexford, Waterford and South Tipperary. The registry included data for births for years 1997 onwards. (There has been a delay with collection and uploading of data from year 2020 and 2021.)
Description/ Summary	There are three active regional congenital anomaly registers in the Republic of Ireland.

Title	**South East Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)**
	All three, EUROCAT South, EUROCAT South-East and EUROCAT East are members of EUROCAT, the European network of congenital anomaly registers, they provide an anonymised computerised register of cases of congenital anomaly born to mothers resident in Ireland. Together the registers cover 60% of all births in Ireland.
Data users	The Irish congenital anomaly registries working with the EUROCAT central registry and the EUROCAT network of registries. EUROCAT aims to encourage the use of its data for epidemiological surveillance and research whilst ensuring the protection of complete confidentiality of the data and ensuring that existing knowledge is fully brought to bear on the interpretation of its data. Details available at https://eu-rd-platform.jrc.ec.europa.eu/eurocat_en
Data content	Detailed description of the anomaly and baby malformations, demographics of parents and baby such as age, date of birth, weight, date of delivery, parental occupation, medications, smoking and alcohol status, illness during pregnancy and outcome of previous pregnancies.
Data dictionary	Yes, http://www.eurocat-network.eu/content/EUROCAT-Guide-1.3.pdf http://www.eurocat-network.eu/aboutus/datacollection/guidelinesforregistration/previouscodingguides/instructionmanuals
National-level identifier variables	No.
Equity stratifiers	Maternal education; Socioeconomic status of mother; Socioeconomic status of father; Migrant status Mother's occupation at time of conception included as an exposure variable.
Data collection methodology	A HSE registry nurse gathers and collates data from the data providers on an ongoing basis throughout the year. The registry is based on active case finding. The data is validated and coded data before entering it electronically on the EUROCAT data management Programme. The anonymised data is uploaded twice annually to the EUROCAT central registry.
Clinical coding scheme	ICD-10-AM McKusick/OMIM Code International Standard Classification of Education International Standard Classification of Occupations ATC Code Drug Description.
Size of national collection	Approximately 140 cases per annum from 7,500 births (South east Registry).
Publication frequency	Links to annual newsletters and published reports from the registry are available on the HSE registries website. All EUROCAT publications on congenital anomalies are publicly listed on the EUROCAT website at: https://eu-rd-platform.jrc.ec.europa.eu/eurocat_en
Accessing data	Open access to anonymised data via the EUROCAT website. Researcher access to local anonymised data via a management approval process.

Title	**South East Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)**
Open Data portal access	No.
Generic email contact	Not available.
Generic telephone contact	Not available.
Other comments	There is no national registry of congenital anomalies. The South East Registry is one of three which between them cover approximately 60% of births in Ireland. The individual registry contact details are at: https://www.hse.ie/congenitalanomalyregistersireland/

6 National censuses

- Census of Population and other population data
- Health Service Personnel Census [HSPC]
- Irish Psychiatric Units and Hospitals Census.

An Phríomh-Oifig Staidrimh
Central Statistics Office

6.1 Census of Population and other population data

Title	**Census of Population and other population data**
Managing Organisation	Central Statistics Office (CSO).
Web address	http://www.cso.ie/en/census/
Year established	1926 (and links to data pre-1926 available on the CSO website).
Statement of Purpose	To collect information relating to persons and households in the Republic of Ireland to help to plan for services to meet demand in healthcare and education, for example.
Coverage **(geographical and temporal)**	De facto population. The delivery and collections of Census forms span over a 10 week period. The Census 2016 Quality Report is available on the CSO website here: https://www.cso.ie/en/media/csoie/methods/censusofpopulation/Census_2016_Quality_Report_rev_0918.pdf
Description/ Summary	The Census of Population is a collection of information relating to persons and households in Ireland. The Census of Population statistics are disseminated through a range of specialised publications, releases and other media.
Data users	Census Data gives government, local authorities, agencies, service providers and the public, the complete suite of demographics of the State at various geographic levels. Health, Disabilities, Age Groups, Nationalities, Ethnicity, Housing, Families, Principal Economic Status, Social Class, Occupational and Industry data are some of the topics available.
Data content	Accommodation; demographics; education; employment; disability or long term illness; time and distance of travel to work; school or college; economic status; Irish language; ethnicity; nationality; migration and carers.
Data dictionary	Not available.
National-level identifier variables	Not applicable.
Equity stratifiers	The Census has a number of questions that pertain to Religion, Ethnicity, Education Level, Occupation and Health among others. Additionally the Census derive the Socio Economic Group (SEG) and the Social Class for persons. Further information on Social Class and SEG is available on the CSO website here: https://www.cso.ie/en/releasesandpublications/ep/p-cp11eoi/cp11eoi/bgn/

Title	**Census of Population and other population data**
Data collection methodology	Census - householder completion of census form. The Census is carried out in 5 years cycles. However due to Covid-19 the schedule Census in 2021 was postponed to 2022.
Clinical coding scheme	N/A.
Size of national collection	N/A.
Publication frequency	Every 5 years.
Accessing data	Interactive tables for the 1996, 2002, 2006, 2011 and 2016 censuses are available on the CSO website. https://data.cso.ie/#
Open Data portal access	No.
Generic email contact	census@cso.ie information@cso.ie
Generic telephone contact	1800 236 787
Other comments	Please see link to the Census 2016 results page where demographics are explained in each profile. https://www.cso.ie/en/census/census2016reports/ Also find all the small area demographics on 11 geographical boundaries available here https://www.cso.ie/en/census/census2016reports/census2016smallareapopulationstatistics/ and a link to our SAPMAP application here. https://cso.maps.arcgis.com/apps/webappviewer/index.html?id=4d19cf7b1251408c99ccde18859ff739 Following the Census 2022, detailed results will be available on the CSO website from April 2023.

6.2 Health Service Personnel Census [HSPC]

Title	**Health Service Personnel Census [HSPC]**
Managing Organisation	Heath Service Executive [HSE], Strategic Workforce Planning & Intelligence, Oak House Millennium Park, Naas, Co. Kildare.
Web address	https://www.hse.ie/eng/staff/resources/our-workforce/
Year established	1990-2006: Department of Health. 2006 onwards: Strategic Workforce Planning & Intelligence, HSE.
Statement of Purpose	Monthly reporting of directly employed public health service staffing by grade for resourcing and planning purposes.
Coverage **(geographical and temporal)**	National; configured based on service delivery structures (Hospital Groups, CHI, Community Healthcare Organisations (CHOs), HWB, HBS, & National Services.
Description/ Summary	Collation of monthly employment data from all public health service employers (HSE, Section 38 hospitals & voluntary agencies) in whole-time equivalence (WTE), headcount (HC), grade, gender, functional area and location terms monitoring, resourcing & workforce planning purposes. HSPC has a statutory basis.
Data users	Published information; HSE/ Wider Health Service; Government Departments (D/Health & DPER); WHO; Eurostat; service providers; Workforce Planners; State Claims etc.
Data content	Number (WTE & HC): Gender; contract type (ID, fixed-term, specified purpose; Full-Time, Part-Time; Career break); Grade level (individual level data is not recorded).
Data dictionary	https://www.hse.ie/eng/staff/resources/our-workforce/workforce-reporting/hspc-instructions-2022.pdf
National-level identifier variables	N/A.
Equity stratifiers	Gender and occupation.
Data collection methodology	SAP Bex, Excel or CSV files. Monthly data collection.

Title	**Health Service Personnel Census [HSPC]**
Clinical coding scheme	N/A.
Size of national collection	1.7M.
Publication frequency	Monthly.
Accessing data	HSE website (see above) & widely circulated within the Health Service/ Government Departments (Health & DPER) and to other official sources on a monthly/ annual basis. Specific reports generated on request.
Open Data portal access	http://databank.per.gov.ie/Public_Service_Numbers.aspx?rep=Health
Generic email contact	personnelcensus@hse.ie workforcedata@hse.ie
Generic telephone contact	+353 45 880407
Other comments	additional information available at: https://www.hse.ie/eng/staff/resources/our-workforce/workforce-reporting/

6.3 Irish Psychiatric Units and Hospitals Census

Title	**Irish Psychiatric Units and Hospitals Census**
Managing Organisation	National Health Information Systems Unit at the Health Research Board (HRB).
Web address	http://www.hrb.ie
Year established	1963.
Statement of Purpose	The census database is a psychiatric inpatient database which captures the number of psychiatric patient's resident on a certain date for the planning and future development of mental health services and to allow for the prediction of possible future bed and hospital requirements at both national and local levels by service planners, HSE management teams and clinicians. Coverage is limited to residents in MHC approved centres. Community provision is out of scope.
Coverage (geographical and temporal)	All psychiatric units and hospitals operating under the provisions of the Mental Health Act 2001 and on the register of approved centres under the Mental Health Act. Data has been collected at various census intervals since 1963.
Description/ Summary	The database records data on all residents (on 31 March of the census year in question) of psychiatric inpatient facilities on the register of approved centres under the Mental Health Act 2001.
Data users	The key users are service planners, Department of Health, HSE, Mental Health Commission, clinicians, academics/researchers.
Data content	Includes: socio-demographic; clinical and diagnostic information on all residents of psychiatric inpatient services on census night. Socio-demographic details include gender; age, marital status; address, occupation and socio-economic group. Clinical and diagnostic information include: legal status on census night; primary and secondary diagnosis. Date of present admission is also recorded.
Data dictionary	A data dictionary is available but is not available online.
National-level identifier variables	Most hospitals use unique patient identifiers but PPSN is not used. The IHI field is included but is currently not collected.

Title	**Irish Psychiatric Units and Hospitals Census**
Equity stratifiers	Address from which admitted (not including first line address), gender, ethnicity, occupation, socio economic group, country of birth are all included in the database and are collected/completed by NPIRS contacts in each hospital/unit.
Data collection methodology	Data for the census are collected by each hospital/centre for each inpatient resident on 31 March and returned electronically to the HRB. Data is currently collected every three years and this timeframe is reviewed according to demands for increased or decreased frequency for census data.
Clinical coding scheme	The Clinical coding scheme is the WHO International Classification of Diseases (ICD-10).
Size of national collection	In the last Census in 2019 there were 2,308 records.
Publication frequency	Census data are returned by all hospitals/units operating under the provisions of the Mental Health Act 2001 to the HRB. Frequency of publications depends on when the census was carried out; the first census report was 1963. The next census took place in 1971 and census data were published every 10 years thereafter until 2001. The next census in 2006 took place after a period of five years. From 2010 the census has taken place every three years resources permitting. The most recent census was 2019.
Accessing data	The census report for each census year and a census bulletin are available with recent reports available on the HRB website along with tables for download. Data is available on request. Data is also available on the PHIS (Department of Health).
Open Data portal access	No.
Generic email contact	npirs@hrb.ie
Generic telephone contact	+353 1 2345000
Other comments	Database administrators in the HRB manually clean and check each individual data file received from hospitals. Certain fields are coded manually, e.g. socio-economic group. Prior to the file being uploaded to the database it is validated by the database programme and errors are identified. Once data is corrected and uploaded, it is again validated prior to the forwarding of the census status report to each hospital. Data is again validated prior to the production of the census report. Sign offs are required from all units and hospitals.

7 National surveys

- European Social Survey (ESS)
- Growing Up in Ireland (GUI) – National Longitudinal Study of Children in Ireland
- Health Behaviour in School Aged Children (HBSC)
- Healthy Ireland Survey
- Irish Health Survey (IHS)
- 2019–20 Irish National Drug and Alcohol Survey
- Lifeways Cross-Generation Cohort Study
- National Inpatient Experience Survey
- National Maternity Experience Survey
- SILC- Survey on Income and Living Conditions
- TILDA- The Irish Longitudinal Study on Ageing.

7.1 European Social Survey (ESS)

Title	**European Social Survey (ESS)**
Managing Organisation	European Social Survey European Research Infrastructure Consortium (ESS ERIC), School of Arts and Social Sciences, City, University of London.
Web address	www.europeansocialsurvey.org
Year established	The ESS was established in 2001, with data collected for the first time in 2002/03.
Statement of Purpose	The overall purpose and objective of the data collection. ▪ to chart stability and change in social structure, conditions and attitudes in Europe and to interpret how Europe's social, political and moral fabric is changing ▪ to achieve and spread higher standards of rigour in cross-national research in the social sciences, including for example, questionnaire design and pre-testing, sampling, data collection, reduction of bias and the reliability of questions ▪ to introduce soundly-based indicators of national progress, based on citizens' perceptions and judgements of key aspects of their societies ▪ to undertake and facilitate the training of European social researchers in comparative quantitative measurement and analysis ▪ to improve the visibility and outreach of data on social change among academics, policy makers and the wider public.
Coverage **(geographical and temporal)**	38 European countries (including Ireland) have participated in at least one round since 2002/03; 32 countries (including Ireland) are participating in ESS Round 10 (2020-22).
Description/ Summary	The European Social Survey (ESS) is an academically driven cross-national survey that has been conducted across Europe every two years since 2002/03. It was developed to offer academics and researchers a reliable dataset that measures the attitudes and behaviours of the general population both across and within European countries.

Title	**European Social Survey (ESS)**
	The ESS was awarded European Research Infrastructure Consortium (ERIC) status in 2013. The ESS ERIC Headquarters are hosted by, City, University of London (UK).
Data users	The ESS has 192,929 registered users of its data. The vast majority of users are students (69.5%) and faculty and research (16.2%). Other types of users are Ph.D. thesis (6.2%); private individual (2.8%); organisation (NGO) (1.4%); other (1.3%); government (1.3%); private enterprise (1%) and journalist (0.3%).
Data content	Each iteration of the survey includes a core module composed of the same questions on crime and justice, democracy, discrimination, Europe, government, health and wellbeing, identity, immigration, media, political values and participation, religion and social trust. The main questionnaire also includes the 21-item Schwartz human values scale. The 21-item scale is a series of statements developed by Shalom H. Schwartz (The Hebrew University of Jerusalem) to better understand the moral values of respondents. Additionally, in each round of the ESS, two other topics are covered in more depth following an open call for proposals. This open call process means that the ESS has included rotating modules on ageism, citizen involvement, climate change and energy, crime and justice, democracy, economic morality, the relationship between family, work and wellbeing, the fairness of income and opportunities, health, immigration, social inequalities in health, timing of life, welfare and wellbeing. Examples of Health questions from the core module of the ESS questionnaire include: How is your health in general?; Are you hampered in your daily activities in any way by any longstanding illness, or disability, infirmity or mental health problem? Questions measuring wellbeing are also included. Round 2 (2004/05) included a rotating module on health and care seeking, and Round 7 (2014/15) included a rotating module on social inequalities in health. This social inequalities module will be repeated in Round 11 (2023/24). All data can be analysed by a wide range of socio demographics, collected from respondents, and weighted to be representative of the entire national population of each country.
Data dictionary	Survey documentation for ESS Round 9 (latest round with released data) is available at the following link: http://www.europeansocialsurvey.org/data/download.html?r=9

Title	**European Social Survey (ESS)**
National-level identifier variables	All data can be analysed at the regional level (NUTS).
Equity stratifiers	A wide range of sociodemographic measures are included in the dataset, including: marital status; place of residence; education; occupation; activity last seven days; ever been in employment; main source of income; partner's occupation and highest level of education; socioeconomic status; gender; religion; parents' highest level of education; parents' occupation when 14 years old; year of birth; household composition; children.
Data collection methodology	Primarily designed as a time series, the questionnaire is asked to a newly selected representative sample of adults aged 15+ in each country, chosen using strict probability methods. Up until Round 10, data collection took place during face-to-face interviews only every two years. Due to the pandemic affecting Round 10 data collection, self-completion data collection methods (online and postal questionnaires) have been completed in some countries.
Clinical coding scheme	N/A.
Size of national collection	The ESS Survey Specification states that the minimum 'effective achieved sample size' must be 1,500, or 800 in countries with ESS populations (aged 15+) of less than 2 million after discounting for design effects.
Publication frequency	Biennially since 2002.
Accessing data	The data is available free of charge and without restrictions for not-for-profit purposes. The data files can be accessed after registering as an ESS data user on www.europeansocialsurvey.org
Open Data portal access	N/A.
Generic email contact	ess@city.ac.uk
Generic telephone contact	+44 (0)207 0404901
Other comments	In the coming months, all data and documentation will be available via https://ess-search.nsd.no/en/all/query/ Data will still be available via www.europeansocialsurvey.org until January 2023.

7.2 Growing Up in Ireland (GUI) – National Longitudinal Study of Children in Ireland

Title	**Growing Up in Ireland (GUI) – National Longitudinal Study of Children in Ireland**
Managing Organisation	The Department of Children, Equality, Disability, Integration and Youth in association with the Central Statistics Office.
Web address	https://www.growingup.ie/
Year established	2006.
Statement of Purpose	The purpose of GUI is to study the factors that contribute to or undermine the well-being of children in contemporary Irish families; and through this, contribute to the setting of effective and responsive policies relating to children and the design of services for children and families. Cohort '98 (Child Cohort) is a representative sample of 9-year-olds in Ireland born between 1st November 1997 and 31st October 1998. Cohort '08 (Infant Cohort) is a representative sample of 9-month-olds in Ireland born between 1st December 2007 and 30th June 2008.
Coverage **(geographical and temporal)**	GUI is a national longitudinal study which tracks two cohorts of children: a child cohort of 8,500 who were 9 years old when data collection began in 2007/8; and an infant cohort of 11,000, who were nine months old when data collection began in 2008/9. The infant cohort sample was generated randomly through the child benefit register, and were interviewed when they were 9 months old (2008/2009), 3 years old (2010/2011), 5 years old (2013), 7/8 years old (2016), 9 years old (2017/2018) and 13 years old (2021/2022). The child cohort sample was generated from a nationally representative sample of 900 schools, and were interviewed when they were 9 years old (2007/2008), 13 years old (2011/2012), 17/18 years old (2015/2016) and 20 years old (2018/2019).
Description/ Summary	Growing Up in Ireland is the national longitudinal study of children in Ireland, mainly funded by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), and managed by DCEDIY in association with the Central Statistics Office.
Data users	The key users of GUI data are students, academics, researchers, policy makers.
Data content	GUI collects data across a number of domains and themes including:

Title	**Growing Up in Ireland (GUI) – National Longitudinal Study of Children in Ireland**
	▪ Cognitive/educational development (e.g. cognitive/academic achievement, early childhood home learning and childcare environments, attitudes and aspirations) ▪ Socio-emotional development (e.g. behaviour, self-esteem, mental health and relationships) ▪ Health (e.g. breastfeeding, child health and health care utilisation, illness and injury, disability and long term chronic conditions, diet, BMI, physical exercise, and health behaviours) ▪ Economic/civic participation (from 17 years) (e.g. household characteristics, family income/work/social welfare, neighbourhood and accommodation).
Data dictionary	Data dictionaries for each wave are available from: https://www.ucd.ie/issda/
National-level identifier	No national level identifier variables are included.
Equity stratifiers	Equity stratifiers are included in most waves: Place of residence, Race, Occupation, Gender, Religion, Education, Socioeconomic status, Social capital.
Data collection methodology	Anonymised GUI data are publicly available from two sources. An anonymised Microdata File available from https://www.ucd.ie/issda/ and a more detailed Research Microdata File available from https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/rmfregister/ There have been four waves of data collection from the child cohort; at 9 years of age in 2007/8; at 13 in 2011/12; at 17/18 years old in 2015/16; and at 20 years old in 2018/19. There have also been five waves of data collection from the infant cohort: at 9 months in 2008/9; at three years old in 2010/11; at five in 2013; at age 7/8 in 2016; and at nine in 2017/18. We are currently (2021/2022) in the field conducting age 13 interviews. For all waves information was collected from the child, and their parent(s)/guardian(s) and where relevant the child's school teacher and the school principal.
Clinical coding scheme	Chronic illness questions are coding using ICD-10 as a guide.
Size of national collection	The study is following almost 20,000 children. Data is not collected annually but as described above.
Publication frequency	Technical, descriptive and thematic reports using GUI data are published on a regular basis and available on the GUI website.

Title	**Growing Up in Ireland (GUI) – National Longitudinal Study of Children in Ireland**
	The data is made available through the Irish Social Science Data Archive and the Central Statistics Office after each wave of data collection.
Accessing data	- The Anonymised Microdata File (AMF) is a publicly available anonymised dataset. Researchers wishing to access the AMF should apply to the Irish Social Science Data Archive (ISSDA) at www.ucd.ie/issda - The Research Microdata File (RMF) is a more detailed dataset. Access to the RMF is project specific and subject to appointment of the researcher as an Officer of Statistics by the Central Statistics Office, meaning that the researcher is subject to the full rigour and penalties of the Statistics Act, 1993. Researchers wishing to access the RMF should apply to the Central Statistics Office. The form is available on the following link: https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/rmfregister/ - GUI qualitative data for the child cohort age 9 is also a publicly available as an anonymised dataset. Researchers wishing to access the qualitative data file should apply to the Irish Qualitative Data Archive (IQDA).
Open Data portal access	No.
Generic email contact	growingup@esri.ie
Generic telephone contact	1800 200 434 (ESRI contact number for GUI)

hbsc
HEALTH BEHAVIOUR IN
SCHOOL-AGED CHILDREN
ÉIREANN / IRELAND

7.3 Health Behaviour in School Aged Children (HBSC)

Title	**Health Behaviour in School Aged Children (HBSC)**
Managing Organisation	The HBSC Ireland Research Team, Health Promotion Research Centre, National University of Ireland, Galway.
Web address	www.nuigalway.ie/hbsc
Year established	1998.
Statement of Purpose	To increase understanding of young people's health and well-being and to use the findings to inform and influence health promotion policy and practice at national and international levels. The sample frame includes all schools in Ireland with pupils from 3-6th class in primary schools and 1st-pre-leaving certificate in post-primary schools. Schools with only junior classes or only leaving certificate classes are not sampled.
Coverage **(geographical and temporal)**	The target age groups for the HBSC study are 11, 13 and 15 year olds attending school. These age groups represent the onset of adolescence, the challenge of physical and emotional changes, and the middle years when important life and career decisions are beginning to be made. HBSC Ireland collects data from children from 3rd class to 5th year (pre-leaving certificate year), ages from 9-17 years. Data have been collected in the Spring terms of 1998, 2002, 2006, 2010, 2014, 2018 and forthcoming in 2022.
Description/ Summary	Health Behaviour in School-aged Children (HBSC) is a crossnational research study conducted in collaboration with the WHO Regional Office for Europe. The study aims to gain new insight into, and increase our understanding of young people's health and well-being, health behaviours and their social context. In addition, the findings from the HBSC surveys are used to inform and influence children's policy and practice at national and international levels. HBSC was initiated in 1982. HBSC 2022 involves more than 200,000 children from 51 countries and regions across Europe and North America.
Data users	Government Departments, NGOs, Academic Researchers, WHO/UNICEF/OECD/EU.

Title	**Health Behaviour in School Aged Children (HBSC)**
Data content	Health behaviours: physical activity; eating and dieting; smoking; alcohol use; cannabis use; sexual behaviour; violence and bullying; injuries. Health outcomes: symptoms; life satisfaction; self-reported health.
Data dictionary	Yes there is a data dictionary that can be shared with data users.
National-level identifier variables	No national level identifiers are included in this data.
Equity stratifiers	The equity stratifiers in the data include, age, gender, social class, migrant status, place of birth (self and parents), traveller status, disability status, carer status, local area perceptions and family affluence.
Data collection methodology	Survey, self-completion questionnaire administered in school classrooms. Data are collected every four years since 1998.
Clinical coding scheme	Not in use.
Size of national collection	13,000-16,000 every four years.
Publication frequency	Every four years. Reports, papers, factsheets and data visuals available at www.nuigalway.ie/hbsc
Accessing data	National data can be requested from the HBSC Ireland Helpdesk; hbsc@nuigalway.ie; Irish data is also available in the international data portal: http://hbsc-nesstar.nsd.no/webview/
Open Data portal access	No.
Generic email contact	hbsc@nuigalway.ie
Generic telephone contact	+353 91 493641
Other comments	International data, including Irish data, can also be accessed via the HBSC data portal at: http://hbsc-nesstar.nsd.no/webview/ or via http://www.uib.no/en/hbscdata/94226/access-other-hbsc-survey-data

7.4 Healthy Ireland Survey

Title	**Healthy Ireland Survey**
Managing Organisation	Department of Health.
Web address	https://www.gov.ie/en/collection/231c02-healthy-ireland-survey-wave/
Year established	2014.
Statement of Purpose	In scope: The purpose of the Healthy Ireland Survey is to provide data on the health of the nation across a range of health behaviours and attitudes, and to monitor progress against key national policy targets. The Survey collates data on a range of health behaviours including, but not limited to, smoking, alcohol use, diet and nutrition, health service utilisation, and physical activity. The Survey was conducted by personal interview (CAPI) from 2015-2019; as a result of infection control considerations in the context of the Covid-19 pandemic, it has switched to phone (CATI) for 2021. Out of scope: Matters unrelated to health, administrative healthcare records.
Coverage **(geographical and temporal)**	**National, annual.** CAPI (2015-2019): Data collection begins towards the end of September and continues until June/July of the following year. CATI (2021): Data collection commences in October and continues to March/April of the following year. *Note: the 2020 Survey was cancelled in March 2020 as a result of the Covid-19 pandemic and infection risks associated with personal interview.*
Description/ Summary	The Healthy Ireland Survey is an annual survey of a representative sample of the population (aged 15 and over) living in Ireland. Until 2020, the Survey involved in-home, face-to-face interviews (Computer Aided Personal Interview; CAPI) with a sample of approximately 7,400 individuals, representative of the Irish population aged 15 and over. However, in light of continuing Covid 19 restrictions and the infection risk posed by in-person visits to private homes, the Survey has moved to computer aided telephone interviewing (CATI), which does not incur infection risk. The Survey collates data on a range of health behaviours including, but not limited to, smoking, alcohol use, diet and nutrition, health service usage, mental health and physical activity.

Title	**Healthy Ireland Survey**
Data users	Survey data is used to inform current and future policy direction and programme development and implementation and is used by policy makers both in the Department of Health, other Government Departments and the wider health service. Results are also shared publicly for research purposes; the data from the Survey is deposited with the Irish Social Science Data Archive for use by researchers. Researchers in good standing can also contact the Department individually and enter into legal agreements for access to more detailed RMF files. The potential use of the data for research purposes is conveyed to respondents as part of the consent process. Finally, Survey data provides essential information regarding international data reporting requirements; relevant data are shared with the CSO, Eurostat and OECD as required. Link to HI Survey Reports: https://www.gov.ie/en/policy-information/706608-healthy-ireland-policies/#the-healthy-ireland-survey
Data content	The topics covered include general health, health service utilisation and key lifestyle factors, such as smoking, alcohol consumption, physical activity, diet, mental health and wellbeing, sexual health and, latterly, the impacts of the Covid-19 pandemic (HI Survey 2021) in order to monitor the key trends and policy impacts in those areas. It also offers flexibility for the substitution of further modules to meet particular policy needs, including cross-sectoral /health determinant 'health in all policies' issues and new international reporting requirements.
Data dictionary	Yes, https://www.ucd.ie/issda/data/healthyireland/
National-level identifier variables	Eircodes and addresses are requested on a voluntary basis (CATI) - if the preference of the respondent is not to share this information, or they are not aware of their Eircode, country level location information is sampled. Under previous CAPI methodology, addresses were sampled via Geodirectory (further details in the 2015-2019 Reports)
Equity stratifiers	Yes. These are: ▪ Place of residence (county at minimum) (address under CAPI) ▪ Age ▪ Gender ▪ Marital Status ▪ Medical/GP card ownership ▪ Use of Private Health Insurance Level of Education ▪ Employment Status ▪ Details of Employment ▪ Ethnic background/Race ▪ Country of Birth ▪ Details of children, if any

Title	**Healthy Ireland Survey**
	- Carer responsibilities, if any.
Data collection methodology	The Survey is conducted on an annual basis. Until 2020, the Survey involved in-home, face-to-face interviews (Computer Aided Personal Interview; CAPI) with a sample of approximately 7,400 individuals, representative of the Irish population aged 15 and over. However, in light of continuing Covid 19 restrictions and the infection risk posed by in-person visits to private homes, the Survey has moved to computer aided telephone interviewing (CATI), which does not incur infection risk. The recording of height, weight and waist circumference is an optional element of the survey. Respondents aged 17 and over have been asked to complete a self-completion questionnaire on issues relating to sexual health. In 2021, a voluntary module on suicide awareness was completed online by 31% of respondents.
Clinical coding scheme	Respondents are asked to identify any chronic conditions they have been diagnosed with. However, clinical coding schemes/methods are not applied.
Size of national collection	7,500 records created on average annually.
Publication frequency	Summary reports are published annually after each wave of data collection. The 2020 Survey, which was conducted by CAPI, could not be completed as a result of necessary Covid-19 restrictions.
Accessing data	An Anonymised Microdata File (AMF) for each wave is deposited in the Irish Social Science Data Archive (ISSDA) and is available for research and teaching purposes subject to the ISSDA End User Licence Agreement. https://www.ucd.ie/issda/#:~:text=3%20Simple%20Steps%20to%20Apply,signed%20consent%20form%20by%20email Information and forms for applications for access to the Researcher Microdata File (RMF), through DoH directly, can be found at: https://www.gov.ie/en/collection/231c02-healthy-ireland-survey-wave/
Open Data portal access	No.
Generic email contact	healthyireland@health.gov.ie
Generic telephone contact	+353 1 6354000

An Phríomh-Oifig Staidrimh Central Statistics Office

7.5 Irish Health Survey (IHS)

Field name	**Irish Health Survey (IHS)**
Managing Organisation	Central Statistics Office (CSO).
Web address	https://www.cso.ie/en/statistics/health/irishhealthsurvey/
Year established	2015.
Statement of Purpose	The "Main Results" publication provides data and insights on various aspects of health in Ireland. The other publications in the series present data on the health experience of persons with disabilities and carers.
Coverage (geographical and temporal)	National and NUTS 3 Regional level are available. IHS data collection commenced in 2015 and is collected every 3 – 4 years.
Description/ summary	IHS is the principal source of national data for self-reported perceptions of persons aged 15 years and over, and outlines their view of their health status – from how well they are feeling, to the extent to which they suffer from long-standing health conditions, as well as other factors
Data users	Eurostat, Government Departments, Research Centres and Universities, National Media, General Public
Data content	IHS collects health statistics for persons aged 15 years and over. The survey includes data on self-perceived health status, prevalence of long lasting conditions, limitations in everyday activities, mental health status, engagement with the health system, health determinants, carers and persons with disabilities.
Data dictionary	No – a full dictionary is not available but detailed explanation of terms is available in the background notes of the publications: https://www.cso.ie/en/releasesandpublications/ep/p-ihsmr/irishhealthsurvey2019-mainresults/backgroundnotes/ https://www.cso.ie/en/releasesandpublications/ep/p-ihsd/irishhealthsurvey2019-personswithdisabilities/backgroundnotes/ https://www.cso.ie/en/releasesandpublications/ep/p-ihsc/irishhealthsurvey2019-carersandsocialsupports/

Field name	**Irish Health Survey (IHS)**
National-level identifier variables	There is no national unique identifiers available in the IHS.
Equity stratifiers	YES - Sex, age, NUTS3 regional breakdown, Employment status, Nationality, and Deprivation Quintile.
Data collection methodology	The 2015 Health Survey was administered via a self-completion questionnaire. The survey data was collected via an interviewer administered interview where respondents were asked questions on their health status and health experiences. IHS data is collected every 3 – 4 years.
Clinical coding scheme	Not applicable to IHS.
Size of national collection	There were 7,600 responses to the 2019 survey.
Publication frequency	The Irish Health Survey will be published every 3 – 4 years.
Accessing data	Not applicable.
Open Data portal access	No.
Generic email contact	Health@cso.ie
Generic telephone contact	+353 21 4535485

7.6 2019-20 Irish National Drug and Alcohol Survey

Title	**2019–20 Irish National Drug and Alcohol Survey.**
Managing Organisation	Health Research Board (HRB) - Evidence Centre.
Web address	https://www.drugsandalcohol.ie/34287/ and https://www.hrb.ie/publications/publication/the-2019-20-irish-national-drug-and-alcohol-survey-main-findings/returnPage/1/
Year established	2002.
Statement of Purpose	The National Drug and Alcohol Survey (NDAS) collects information on alcohol and tobacco consumption and drug use among the general population in Ireland. It also surveys people's attitudes and perceptions relating to tobacco, alcohol, and other drug use and records the impact of drug use on people's communities. The 2019–20 NDAS collected information from 5,762 people aged 15 years and older across Ireland. Out of scope: health status, treatment interventions, prescribed medications apart from sedatives tranquillisers and pain relief.
Coverage **(geographical and temporal)**	Prevalence estimates are calculated at a national level and for the 10 Regional Drug and Alcohol Taskforce (RDATF) areas at a later stage. Data collection start February 2019. Data collection finish March 2020.
Description/ Summary	The survey used stratified and multistage area probability sampling methods to select a representative sample of the Irish population that was aged 15 years and older and was living in private households. The primary sampling frame was An Post/Ordnance Survey Ireland's GeoDirectory, a complete database of every building in the Republic of Ireland. Each of the 2.2 million addresses contained in GeoDirectory includes an accurate standardised postal address, usage details for each building (commercial or residential), a unique 8-digit identity number, Eircode, and geo-coordinates which accurately locate the centre point of each building to within one metre. The sample needed to sufficiently large and structured to provide national estimates of drug use prevalence and estimates for RDATF area. It was calculated that 650 completed interviews in each of the 10 RDATF areas would be required.

Title	**2019–20 Irish National Drug and Alcohol Survey.**
	A three-stage process was used to construct the sample for this survey. Stratification techniques were used to select primary sampling units (PSUs). In this survey, electoral divisions (EDs) were defined as PSUs. In this survey, EDs were defined as PSUs. In the first stage of stratification, the number of addresses for each RDATF was agreed at between 980 and 1,344. In the second stage of stratification, 421 PSUs were randomly selected. These PSUs were then ranked by sociodemographic indicators (degree of urban/rural respondents and proportion of owner occupiers) to ensure that a representative cross-section of areas was included. In this way, PSUs of all sizes and compositions would have an equal chance of selection. Twenty-eight addresses were chosen randomly selected from each of the randomly selected 421 PSUs. A household was defined as a person, or as a group of people who normally live at the same property and who share a living room or at least one meal a day. In properties with multiple households, one was randomly selected using a Kish grid. Individuals (aged 15 years and older) within each selected household were randomly selected to take part in the survey. This was done by listing all individuals' aged 15 years and older living in the household and then randomly selecting one using the CAPI device.
Data users	Policy makers; service providers in drug treatment, harm reduction and prevention; researchers; general public.
Data content	The data collected provide: A profile of tobacco use, including e-cigarettes, in Ireland A detailed description of drinking patterns (including hazardous drinking patterns) in Ireland, and the harms associated with alcohol use Prevalence estimates of lifetime, last year, and last month use of illegal and prescribable drugs A description of drug use according to sex, age, and area deprivation level An estimation of the prevalence of alcohol use disorder and cannabis use disorder Findings on the perceptions and attitudes of people in Ireland towards tobacco, alcohol, and drug use, and Information on the impact of drug use on local communities.
Data dictionary	No.
National-level identifier variables	No.
Equity stratifiers	Marital status, ethnicity, living situation, number of children, employment status, benefits/allowances in receipt of, occupation, employment type, social class, highest level of education completed.

Title	**2019–20 Irish National Drug and Alcohol Survey.**
Data collection methodology	The survey data were recorded face-to-face in respondents' homes using the Computer-Assisted Personal Interviewing (CAPI) technique. The HRB commissioned Ipsos MRBI to undertake data collection. The survey has been repeated every four years since 2002. The previous four surveys were carried out in 2002/03; 2006/07; 2010/11; 2014/15.
Clinical coding scheme	AUD: alcohol use disorder AUDIT-C: Alcohol Use Disorders Identification Test–Concise CUD: cannabis use disorder DSM-5 : Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition DSM-IV: Diagnostic and Statistical Manual of Psychiatric Disorders, Fourth Edition HED: heavy episodic drinking M-CIDI: Munich-Composite International Diagnostic Interview
Size of national collection	Survey undertaken every 4 years. Approximately 6,000 records created per survey.
Publication frequency	Every four years.
Accessing data	On www.drugsandalcohol.ie website.
Open Data portal access	N/A.
Generic email contact	GPS@hrb.ie
Generic telephone contact	+353 1 2345168

7.7 Lifeways Cross-Generation Cohort Study

Title	**Lifeways Cross-Generation Cohort Study**
Managing Organisation	University College Dublin School of Public Health, Physiotherapy and Sports Science.
Web address	www.ucd.ie/lifeways/
Year established	2001, mothers and infants recruited during 2002-3.
Statement of Purpose	The Lifeways Cross-Generation Cohort Study was established to assess the influence of socio-economic, lifestyle, cross-generational and health service factors associated with health and development, and contains data on mothers, fathers, children, and grandparents.
Coverage **(geographical and temporal)**	As of Mar 2022 1,133 families have been involved, recruited from the Dublin and Galway City catchment areas. Study data is available on 1,133 mothers, 1,114 children, 505 fathers and 1,604 grandparents. Data collection commenced in 2001 with gone through multiple rounds of collection and is currently ongoing.
Description/ Summary	Lifeways is a unique cohort study, designed to capture Irish longitudinal life-course data, by recruiting three generations of the same family. Participants, who are essentially well at baseline, are followed up over time. As outcomes or diseases slowly develop, baseline data are then analysed to identify lifestyle, socio-economic and health service factors, which are associated with these outcomes.
Data users	Researchers.
Data content	Self-reported baseline lifestyle and health status information; ante-natal and birth records; immunisation records; follow up data from GPs; measurements of BMI, blood pressure and collection of blood, hair and saliva samples; follow-up health and lifestyle questionnaires at six and ten years.
Data dictionary	There is a data dictionary in place that is not available online but can be requested.
National-level identifier variables	No national-level identifier variables in the cohort.

Title	**Lifeways Cross-Generation Cohort Study**
Equity stratifiers	Data is stored on place of residence, occupation, gender, education, socioeconomic status, age, health information, and parents' smoking/alcohol status.
Data collection methodology	Data is collected from a variety of sources including questionnaires, electronic ante-natal and birth records; immunisation records from HSE; child and adult health records; GP note searches; analysis of clinical samples. Follow-up rounds of data collection are performed at key developmental points: during pregnancy, Child aged 0, aged 3/year 4, aged 5/year 6, aged 9/10, with a year 20-21 follow-up planned. A scientific newsletter was sent to 777 families in January 2022.
Clinical coding scheme	N/A, internal codebook used.
Size of national collection	No annual data collection. Cohort contacted at distinct follow-up points: 3 years, 5 years, and 9 years after proband child birth.
Publication frequency	Findings from the study are published on an on-going basis. A list of publications to date is available at www.ucd.ie/lifeways/
Accessing data	Access to the data is only through direct collaboration with the PI and the project researchers.
Open Data portal access	No.
Generic email contact	lifeways@ucd.ie
Generic telephone contact	1890202502

7.8 National Inpatient Experience Survey

Title	**National Inpatient Experience Survey**
Managing Organisation	Partnership between HIQA, HSE and Department of Health with HIQA as lead partner.
Web address	https://yourexperience.ie/
Year established	2017.
Statement of Purpose	The National Care Experience Programme asks people about their experiences of care in order to improve the quality of health and social care services in Ireland. All acute public hospitals participate in the National Inpatient Experience Survey.
Coverage **(geographical and temporal)**	National. The National Inpatient Experience Survey commenced in 2017 and is ongoing on an annual basis (except in 2020).
Description/ Summary	The overall purpose and objective of the National Care Experience Programme is to engage with and understand the experience of patients and use this feedback to inform the future development, planning, design and delivery of patient-centred care. The target population for the National Inpatient Experience Survey includes all patients aged 16 and over, who have spent a minimum of 24 hours in a public acute hospital, have been discharged during a specific month and who hold a postal address in the Republic of Ireland.
Data users	HSE, Department of Health, HIQA, researchers and academia, and patient representative organisations.
Data content	The National Inpatient Experience Survey gathers information on experiences of care, as patient's progress through the hospital system. Information is gathered on the following themes: admission to hospital, the ward environment, care and treatment, interaction with staff, the discharge process, and care during COVID-19. Additional information is gathered on patient demographics (self-reported).

Title	**National Inpatient Experience Survey**
Data dictionary	https://yourexperience.ie/wp-content/uploads/2019/07/NPE_Survey_DataDictionary.pdf
National-level identifier variables	National-level identifier variables are not collected, however name, address and date of birth are collected.
Equity stratifiers	Sex, age, ethnicity, home address and medical card status are collected.
Data collection methodology	Information on patient experience is collected through a structured survey questionnaire. The survey asks 64 structured tick-box questions as well as three open-ended questions for comments. The survey can be completed online or by returning the questionnaire via freepost. The data is collected on an annual basis.
Clinical coding scheme	N/A.
Size of national collection	A total of 50,196 people have responded to the survey: 13,706 in 2017; 13,404 in 2018; 12,343 in 2019 and 10,743 in 2021.
Publication frequency	The National Inpatient Experience Survey is conducted annually.
Accessing data	1. Public reporting of data in an aggregate format: reports available on https://yourexperience.ie/ 2. Data request forms are available at: https://yourexperience.ie/about/contact-us/request-data-for-research/ and https://yourexperience.ie/about/contact-us/request-personal-data/ 3. Access to real time survey responses via a survey portal — national and hospital views of data in an aggregate format, available to service providers.
Open Data portal access	National Inpatient Experience Survey - https://yourexperience.ie/inpatient/interactive-charts/
Generic email contact	info@yourexperience.ie
Generic telephone contact	1800 314 093
Other comments	The National Inpatient Experience Survey is the largest national patient experience survey ever conducted in Ireland: over 10,000 people participate in the survey annually. The survey has been undertaken in 2017, 2018, 2019 and 2021. To date, the National Inpatient Experience Survey and the National Maternity Experience Survey have been conducted as part of the

Title	National Inpatient Experience Survey
	National Care Experience Programme. In 2022, three further surveys, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and National End of Life Survey are in development. See https://yourexperience.ie/

National Care Experience Programme

7.9 National Maternity Experience Survey

Title	**National Maternity Experience Survey**
Managing Organisation	Partnership between HIQA, HSE and Department of Health with HIQA as lead partner.
Web address	https://yourexperience.ie/
Year established	2019.
Statement of Purpose	The National Care Experience Programme asks people about their experiences of care in order to improve the quality of health and social care services in Ireland. All nineteen maternity units/hospitals and the HSE National Home Births Services participate in the National Maternity Experience Survey.
Coverage **(geographical and temporal)**	National. The National Maternity Experience Survey commenced in 2019 and will be conducted every two-three years and in alternate years to the National Maternity Bereavement Experience Survey.
Description/ Summary	The overall purpose and objective of the National Care Experience Programme is to engage with and understand the experience of patients and use this feedback to inform the future development, planning, design and delivery of patient-centred care. The target population for the National Maternity Experience Survey includes women aged 16 or over who have given birth in specific months and who hold a postal address in the Republic of Ireland. The National Care Experience Programme will undertake a dedicated survey for women who experience a negative maternity outcome such as a miscarriage, stillbirth or neonatal death in 2022 https://yourexperience.ie/maternity-bereavement/about-the-survey/
Data users	HSE, Department of Health, HIQA, researchers and academia, and patient representative organisations.
Data content	The National Maternity Experience Survey gathers information on women's experiences of maternity services from their antenatal care through to labour and birth and their care after birth, in hospital, the

Title	**National Maternity Experience Survey**
	community and at home. Additional information is gathered on demographics (self-reported).
Data dictionary	https://yourexperience.ie/wp-content/uploads/2019/07/NPE_Survey_DataDictionary.pdf
National-level identifier variables	National-level identifier variables are not collected, however name, address and date of birth are collected.
Equity stratifiers	Sex, age, ethnicity, home address and medical card status are collected.
Data collection methodology	The National Maternity Experience Survey includes 65 structured, tick-box questions and three open-ended (free-flow) questions. The survey can be completed online or by returning the questionnaire via freepost. The data is collected on an annual basis at two-three year intervals.
Clinical coding scheme	N/A.
Size of national collection	3,204 women responded to the National Maternity Experience Survey 2020.
Publication frequency	The National Maternity Experience Survey will be conducted every two-three years and in alternate years to the National Maternity Bereavement Experience Survey.
Accessing data	1. Public reporting of data in an aggregate format: reports available on https://yourexperience.ie/ 2. Data request forms are available at: https://yourexperience.ie/about/contact-us/request-data-for-research/ and https://yourexperience.ie/about/contact-us/request-personal-data/ 3. Access to real time survey responses via a survey portal — national and hospital views of data in an aggregate format, available to service providers.
Open Data portal access	National Maternity Experience Survey - https://yourexperience.ie/maternity/interactive-charts/
Generic email contact	info@yourexperience.ie
Generic telephone contact	1800 314 093
Other comments	To date, the National Inpatient Experience Survey and the National Maternity Experience Survey have been conducted as part of the National Care Experience Programme. In 2022, three further surveys, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and National End of Life Survey are in development. See https://yourexperience.ie/

An Phríomh-Oifig Staidrimh
Central Statistics Office

7.10 SILC- Survey on Income and Living Conditions

Title	**SILC- Survey on Income and Living Conditions**
Managing Organisation	Central Statistics Office (CSO).
Web address	https://www.cso.ie/en/statistics/socialconditions/surveyonincomeandlivingconditionssilc/
Year established	2003.
Statement of Purpose	The primary focus of the Survey on Income and Living Conditions (SILC) is the collection of information on the income and living conditions of different types of households in Ireland, in order to derive indicators on poverty, deprivation and social exclusion. It is a voluntary (for selected respondents) survey of private households. Individuals living in institutions or communal accommodation and persons of no fixed abode are out of scope for this survey. It is carried out under EU legislation (Council Regulation No 2019/1700) and commenced in Ireland in June 2003.
Coverage **(geographical and temporal)**	Information is collected annually in the first 6 months of the year. The sample population is all private households and their current members residing in the state at the time of data collection, excluding offshore island communities.
Description/ Summary	The (European Union – EU) Survey on Income and Living Conditions (EU-SILC) is an annual survey conducted by the Central Statistics Office (CSO) to obtain information on the income and living conditions of different types of households. The survey also collects information on poverty and social exclusion.
Data users	General public, researchers, Eurostat, government departments (e.g. DEASP, Finance, DCEDIY).
Data content	The core outputs from the EU-SILC each year will include: detailed income data on households and individuals; the number/proportion of persons at-risk-of-poverty; the number/proportion of persons living in 'consistent poverty'; information on enforced deprivation.
Data dictionary	Not available.
National-level identifier variables	PPSNs are collected for processing purposes only and are not retained on final disseminated datasets.
Equity stratifiers	SILC collects data on region of residence, occupation, sex, education. Possible analysis is dependent on sample size.
Data collection methodology	Information is collected annually in the first 6 months of the year. A representative random sample of private households throughout the country is approached to provide the required information. The survey

Title	**SILC- Survey on Income and Living Conditions**
	is voluntary from a respondent's perspective. Data is required in both cross-sectional (pertaining to a given time in a certain time period) and longitudinal (pertaining to individual-level changes over time) dimensions. Therefore certain households will be surveyed on an annual basis. Further details: https://www.cso.ie/en/methods/socialconditions/silc/
Clinical coding scheme	N/A.
Size of national collection	4,200 records created on average nationally.
Publication frequency	Annual. The CSO will make anonymised files relating to SILC data available free of charge to students and researchers for non-commercial purposes through the Irish Social Science Data Archive (ISSDA) which can be accessed at: https://www.ucd.ie/issda/data/eusurveyofincomeandlivingconditionseu-silc/
Accessing data	On PxStat: https://data.cso.ie/product/silc or via a research microdata file (RMF): https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/
Open Data portal access	No.
Generic email contact	icw@cso.ie
Generic telephone contact	+353 21 4535000

tilda
Staidéar Fadaimseartha na
hÉireann um Dhul in Aois

The Irish Longitudinal
Study on Ageing

7.11 TILDA – The Irish Longitudinal Study on Ageing

Title	**TILDA – The Irish Longitudinal Study on Ageing**
Managing Organisation	Trinity College Dublin (TCD).
Web address	http://tilda.tcd.ie/
Year established	2009.
Statement of Purpose	The Irish Longitudinal study on Ageing (TILDA) is an inter-institutional initiative led by Trinity College Dublin which aims to produce improvement in the quantity and quality of data, research and information relating to older people and ageing in Ireland. In scope: Eligible respondents for this study include individuals aged 50 and over and their spouses or partners of any age. The study will involve interviews on a two yearly basis with a sample cohort of 8,000+ people aged 50 and over (or their spouses/partners) and resident in Ireland, collecting detailed information on all aspects of their lives, including the economic (pensions, employment, living standards), health (physical, mental, service needs and usage) and social aspects (contact with friends and kin, formal and informal care, social participation). Both survey interviews and physical and biological measurements are utilised. Out of scope: TILDA is not a clinical study and does not provide diagnostic health outcomes for participants. (A full statement of purpose available at - https://tilda.tcd.ie/publications/reports/pdf/Report_DesignReport. pdf-TILDA Design Report, 2010)
Coverage **(geographical and temporal)**	A nationally representative sample of adults aged 50 and over, resident in Ireland, was selected. An initial multi-stage sample of addresses was chosen by means of the RANSAM sampling procedure, which was developed by the Economic and Social Research Institute (ESRI) based on the Irish GeodirectoryOver 8,500 people have taken part to date. Six waves of fieldwork have been completed so far. Wave 1 of TILDA took place from October 2009 to February 2011. Wave 2 took place from April 2012 to January 2013. Wave 3 took place from March 2014 to October 2015. Wave 4 took place from January 2016 to December 2016. Wave 5 took place from January 2018 to December 2018. Wave

Title	**TILDA – The Irish Longitudinal Study on Ageing**
	6 interviews took place from March 2021 to December 2021, with the health assessment component due to start in mid-2022.
Description/ Summary	TILDA collects information on all aspects of health, economic and social circumstances from people aged 50 and over in a series of data collection waves once every two years. TILDA provides a comprehensive and accurate picture of the characteristics, needs and contributions of older persons in Ireland to inform and support improvements in policy and practice; advancements in technology and innovation; tailored education and training through an enhanced ageing research infrastructure; harmonisation with leading international research to ensure adoption of best policy and practice and comparability of results.
Data users	TILDA is primarily used by academic researchers, masters and PhD students, policy makers, and health, social and economic researchers.
Data content	TILDA collects a wide range of data on the health, economic and social aspects of participants' lives through personal interviews, self-completion questionnaires and health assessment measures. Some of the main topics included in the data are demographics, social circumstances, income & assets and subjective & objective health measures.
Data dictionary	A data dictionary for all publicly available waves of TILDA is available on https://www.ucd.ie/issda/data/tilda/
National-level identifier variables	Medical card numbers of participants are collected during data collection.
Equity stratifiers	The dataset contains age, gender, location of residence, occupation, social class, education level, religion and income.
Data collection methodology	Each wave of data collection involves a structured Computer Aided Personal Interview (CAPI) with a trained interviewer in the participant's home. Each participant is also left a 'self-completion questionnaire' including potentially sensitive questions for them to fill in and return to TILDA by mail. At alternating waves of data collection, each participant is invited to undergo a health assessment, either a full health assessment at a specialised TILDA health centre or a modified partial assessment in their own home where travel to a centre was not practicable. If a participant is unable to complete an interview themselves due to physical or cognitive impairment, a proxy interview completed by a close family member or friend is sought. If a participant has passed away between waves, a family member or close friend will be asked to complete an End-of-Life (EOL) interview of their behalf. Data collection for each wave takes place every two years.
Clinical coding scheme	ICD-10 used in archived datasets.

Title	**TILDA – The Irish Longitudinal Study on Ageing**
Size of national collection	N/A.
Publication frequency	Data collection occurs in waves every two years. Full reports are published after each wave of data collection. Wave 1 report published 2011, Wave 2 report in 2014 and Wave 3 due in 2017. Wave 4 report published in 2018. Wave 5 report was published in 2020. The Wave 6 report will be published in 2022. Additional supplementary reports are published periodically. Academic papers and reports are published on an ongoing basis with over 400 journal articles and 50 reports published to date.
Accessing data	Archived datasets are available through the Irish Social Science Data Archive (ISSDA) at https://www.ucd.ie/issda/data/tilda/
Open Data portal access	No.
Generic email contact	tilda@tcd.ie
Generic telephone contact	+353 1 8962509
Other comments	Six waves of data collection have taken place to date, with the third health assessment due to take place in mid-2022.

Part 3. Collated sources of health and social care information

8 National performance and activity reports

- HSE Performance Reports — Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme
- HSE Performance Reports — Disability Services
- HSE Performance Reports — Mental Health Services
- HSE Performance Reports- National Screening Services
- HSE Performance Reports — Older People Services
- HSE Performance Reports- Palliative Care
- HSE Performance Reports — Population Health and Wellbeing
- HSE Performance Reports- Primary Care Reimbursement Service
- HSE Performance Reports — Primary Care and Social Inclusion
- Tusla — Performance and Activity Datasets.

8.1 HSE Performance Reports — Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme

Title	**HSE Performance Reports — Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme**
Managing Organisation	HSE – Operational Performance and Integration Unit.
Web address	https://www.hse.ie/eng/services/publications/performancereports/
Year established	2006.
Statement of Purpose	To monitor hospital activity. Collection of data assists in performance improvement and is an integral part of monitoring activity in the service planning process.
Coverage **(geographical and temporal)**	All acute hospitals. Data collection commenced in 2006 and is ongoing.
Description/ Summary	The Operational Performance and Integration Unit collates the HSE's Performance Reports (PR), which provide an overall analysis of key performance data from Finance, HR, Hospital and Primary and Community Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022. The performance report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operating Officer on behalf of Director General to monitor performance against planned activity, as outlined in the National Service Plan, and to highlight areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the metrics covered in the Performance Report. The HSE have agreed a number of metrics/indicators for acute hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme. The full list of these metrics/indicators can be found on the HSE website: http://www.hse.ie/eng/services/publications/KPIs/ Items such as acute care in medicine and surgery, average length of stay, inpatient and day case waiting time are included as indicators. Examples of an indicator include:

Title	**HSE Performance Reports — Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme**
	▪ % of adults waiting <12 months for an elective procedure (inpatient) ▪ Percentage of emergency re-admissions for acute medical conditions to the same hospital within 30 days of discharge.
Data users	Hospital Groups, Hospitals, Department of Health, HSE Management and HSE Board.
Data content	Data on acute hospital activity.
Data dictionary	See metadata; **http://www.hse.ie/eng/services/publications/KPIs/**
Equity stratifiers	
Data collection methodology	Data collected to support these indicators is a combination of collecting primary data and data from national data collections. Primary data is submitted from all hospitals to the Business Information Unit on a daily, weekly and monthly basis via email and data transfers. Data is also sourced from national data collections such as the Delayed Transfer of Care Web browser directly from hospitals, National Treatment Purchase Fund, NCCP, National Stroke Register, Hospital In Patient Enquiry and NAS.
Clinical coding scheme	N/A.
Size of national collection	N/A.
Publication frequency	Information is published in Performance Profile Reports and Management Data Reports each month. This is based on KPIs as set out in the National Service Plan.
Accessing data	Information is published in performance reports each month.
Open Data portal access	No.
Generic email contact	acutebiu@hse.ie
Generic telephone contact	+353 1 7785222

8.2 HSE Performance Reports — Disability Services

Title	**HSE Performance Reports — Disability Services**
Managing Organisation	HSE – Business Information Unit – Community Health Care.
Web address	http://www.hse.ie/eng/services/publications/performancereports/
Year established	2013.
Statement of Purpose	To monitor activity against targets set in the National Service Plan in relation to HSE funded service provision for persons with a physical and or sensory disability or an intellectual disability.
Coverage **(geographical and temporal)**	All providers of HSE funded disability services, LHOs, CHOs and National. Data collection commenced in 2013 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from Disability Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022 and the HSE Operational Plans 2022. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Examples of an indicator include: ▪ No. of Home Support Service Hours delivered to people with a disability (ID/Autism and Physical and Sensory Disability) ▪ No. of day only respite sessions accessed by people with a disability.

Title	**HSE Performance Reports — Disability Services**
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs.
Data content	Aggregate activity collected in relation to disability services provision. See Metadata; **http://www.hse.ie/eng/services/publications/KPIs/**
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Data collected to support these indicators is a combination of collecting primary data and data from national data collections. Primary data is submitted to the Business Information Unit on a monthly and quarterly basis via email. Data in relation to Rehab Training Places is received from the Day Services Database. Data in relation to Disability Act compliance comes from the Assessment of Need database. Both of these databases are internal to the HSE. Data is also sourced from the National Ability Support System (NASS). These databases are managed by the Health Research Board & HSE.
Clinical coding scheme	N/A.
Size of national collection	15,968 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports. The reporting frequency of the individual KPI's inform the scheduling of the publication of data.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website http://www.hse.ie/eng/services/publications/performancereports/ Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie

Title	**HSE Performance Reports — Disability Services**
	or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.3 HSE Performance Reports — Mental Health Services

Title	**HSE Performance Reports — Mental Health Services**
Managing Organisation	HSE – Business Information Unit - Community Health Care.
Web address	http://www.hse.ie/eng/services/Publications/corporate
Year established	2009.
Statement of Purpose	To monitor and measure provision of services within the Mental Health Services and report on activity against the National Service Plan.
Coverage **(geographical and temporal)**	National, CHO, LHO, Mental Health Team Level and Service Providers. Data collection commenced 2009 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports, which provide an overall analysis of key performance data from Mental Health Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan and the HSE Operational Plans. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Items such community adult mental health, psychiatry of later life, child and adolescent mental health (CAMHS). Examples of an indicator include: ▪ number of referrals (including re-referred) received by General Adult Community Mental Health Team ▪ %. of new (including re-referred) Psychiatry of Later Life Community Mental Health Team cases offered appointment and DNA in the current month

Title	**HSE Performance Reports — Mental Health Services**
	- % of urgent referrals to CAMHS teams responded to within three working days.
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs.
Data content	Data is collected in aggregate Age, geographical area determine teams. (DED – Populations based). Focus on length of time waiting to be seen. See Metadata; http://www.hse.ie/eng/services/publications/KPIs/
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Community Adult Mental Health KPIs collected monthly from 117 teams. Community CAMHS KPIs collected monthly from 73 Teams. Psychiatry of Later Life KPIs collected monthly from 32 Teams. Acute Adult admissions collected quarterly by HRB from 29 units. CAMHS Day Service from 4 teams. Monthly.
Clinical coding scheme	No.
Size of national collection	278,280 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/services/publications/performancereports/ Data is published in the HSE Annual Reports. Data request can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.

Title	**HSE Performance Reports — Mental Health Services**
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.4 HSE Performance Reports — National Screening Service

Title	**HSE Performance Reports — National Screening Service**
Managing Organisation	HSE – Business Information Unit - Community Health Care.
Web address	http://www.hse.ie/eng/services/publications/performancereports/
Year established	2015.
Statement of Purpose	To monitor and measure provision of services for National Screening Service and report on activity against National Service Plan.
Coverage **(geographical and temporal)**	National. Data collection commenced in June 2015 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from National Screening Service. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan and the HSE Operational Plans. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Items such as Breast Screening and Bowel Screening are included as indicators. Examples of an indicator include: ▪ No of women in the eligible population who have had a complete mammogram

Title	**HSE Performance Reports — National Screening Service**
	▪ No of clients who have completed a satisfactory BowelScreen FIT test.
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.
Data content	Data on BreastCheck, CervicalCheck, BowelScreen, Diabetic RetinaScreen. See metadata: **http://www.hse.ie/eng/services/publications/KPIs/**
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Data collected to support these indicators is a combination of collecting data from national data collectors who submit to the Business Information Unit on a monthly basis via excel. Example of National Data source is the National Screening Service.
Clinical coding scheme	N/A.
Size of national collection	266 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/servcies/publications/performancereports/ Data is published in the HSE Annual Reports. Data requests can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie

Title	**HSE Performance Reports — National Screening Service**
	or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.5 HSE Performance Reports — Services for Older People

Title	**HSE Performance Reports — Services for Older People**
Managing Organisation	HSE — Business Information Unit -Community Health Care.
Web address	http://www.hse.ie/eng/services/Publications/corporate/
Year established	2006.
Statement of Purpose	To monitor and measure provision of services for Older People and report on activity against the National Service Plan and HSE Operational Plan.
Coverage **(geographical and temporal)**	Dependent on specific KPI. For some, all 32 Local Health Offices. For others coverage is at a National or Community Health Care Organisation level. Data is collected on a monthly and quarterly basis and is ongoing.
Description/ Summary	The Business Information Unit Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from and Primary and Community Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022 and the Operational Plans 2022. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Business Information Unit collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data for Primary and Community Services.
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.
Data content	Data is collected in aggregate.

Title	**HSE Performance Reports — Services for Older People**
	KPIs pertaining to Specialist areas such as Home Support, Intensive Home Care Packages, Public Beds and NHSS activities. Examples of indicator include: ▪ No of home support hours provided (excluding provision of hours from intensive home support packages (IHCPs)) ▪ No of persons funded under NHSS in long term residential care during the reporting month. See Metadata; http://www.hse.ie/eng/services/publications/KPIs/
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Methods of data collection to support these Indicators comprise both National and Local Collection; ▪ National collection – National data is received from one source from the relevant Older Peoples' Specialist Office via Business Information Unit ▪ Local collection – data is provided by the 32 Local Health Offices to the Business Information Unit. All data is submitted on a Corporate Information Facility Template which is in excel format. Reporting frequency is KPI specific and can be either monthly or quarterly. This detail is specified in the relevant NSP.
Clinical coding scheme	N/A.
Size of national collection	26,136 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/services/publications/performancereports/

Title	**HSE Performance Reports — Services for Older People**
	Data is published in the HSE Annual Reports. Data request can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.6 HSE Performance Reports — Palliative Care

Title	**HSE Performance Reports — Palliative Care**
Managing Organisation	HSE – Business Information Unit - Community Health Care.
Web address	http://www.hse.ie/eng/services/Publications/performancereports/
Year established	2006.
Statement of Purpose	To monitor and measure Palliative Care services and report on activity against National Service Plan and HSE Operational Plans.
Coverage **(geographical and temporal)**	All 32 Local Health Offices and all 9 Community Health Care Organisations and Hospital Groups and Hospitals which provide Palliative Care Services. Data collection commenced in 2006 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports (PR), which provide an overall analysis of key performance data from Palliative Care. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022 and the HSE Operational Plans 2022. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Inpatient Palliative Care Services, Community Palliative Care Services are included as indicators. Examples of an indicator include: Access to specialist inpatient bed within seven days (during the reporting month).
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.

Title	**HSE Performance Reports — Palliative Care**
Data content	Data is collected in aggregate. Palliative care services aggregate data only, patients seen, ethnicity, age, gender, geographical area, cancer and non-cancer high level diagnosis categories. See Metadata http://www.hse.ie/eng/services/publications/KPIs/ 2021 due to be published and 2022 will follow.
Data dictionary	N/A.
Equity stratifiers	See data content above.
Data collection methodology	Data collected to support these indicators are a combination of collecting primary data and data from national data collectors in the LHOS/CHOs. Primary data is submitted from all CHOs and relevant Hospitals to the Business Information Unit on a monthly basis via excel.
Clinical coding scheme	Clinical data is not collected.
Size of national collection	132,924.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/services/publications/performancereports/ Data is published in the HSE Annual Reports. Data request can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie or

Title	**HSE Performance Reports — Palliative Care**
	CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.7 HSE Performance Reports – Population Health and Wellbeing

Title	**HSE Performance Reports – Population Health and Wellbeing**
Managing Organisation	HSE – Business Information Unit - Community Health Care.
Web address	http://www.hse.ie/eng/services/publications/performancereports/
Year established	2015.
Statement of Purpose	To monitor and measure provision of services for Population Health and Wellbeing and report on activity against National Service Plan.
Coverage **(geographical and temporal)**	Depending on the KPI, National, CHO & LHO and or Hospital Group/ Hospital. Data collection commenced in June 2015 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from Population Health and Wellbeing. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan and the HSE Operational Plans. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Items such Tobacco Control, Food Safety, Immunisation and Vaccines are included as indicators. Examples of an indicator include: ▪ % children aged 24 months who have received the measles, mumps, rubella (MMR) vaccine

Title	HSE Performance Reports – Population Health and Wellbeing
	▪ No of official food control planned, and planned surveillance inspections of food businesses.
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.
Data content	Data on Population Health and Wellbeing activity; Immunisations, Environmental Health, Tobacco, MECC and Public Health. See metadata: **http://www.hse.ie/eng/services/publications/KPIs/**
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Data collected to support these indicators is a combination of collecting primary data and data from national data collectors who submit to the Business Information Unit on a monthly basis via excel. Example of National Data source is the Health Protection Surveillance Centre.
Clinical coding scheme	N/A.
Size of national collection	9,402 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/servcies/publications/performancereports/ Data is published in the HSE Annual Reports. Data requests can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.

Title	**HSE Performance Reports – Population Health and Wellbeing**
Generic email contact	CommunityHealth.Data123@hse.ie or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.8 HSE Performance Reports — Primary Care and Social Inclusion

Title	**HSE Performance Reports — Primary Care and Social Inclusion**
Managing Organisation	HSE — Business Information Unit -Community Health Care.
Web address	http://www.hse.ie/eng/services/Publications/performancereports/
Year established	2006.
Statement of Purpose	To monitor and measure Primary Care and Social Inclusion and report on activity against National Service Plan and HSE Operational Plans.
Coverage **(geographical and temporal)**	All 32 Local Health Offices and all 9 Community Health Care Organisations and Service Providers. Data collection commenced in 2006 and is on-going. Data is collected on a monthly and quarterly basis.
Description/ Summary	The Business Information Unit Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from and Primary and Community Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022 and the HSE Operational Plan 2022. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Business Information Unit collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data Primary and Community Services. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan 2022 and the HSE Operational Plan 2022. Items such as primary care, GP out of hour's service, physiotherapy referral, occupational therapy referrals, no of therapy face to face, telephone and video and audio conferencing contacts, orthodontics,

Title	**HSE Performance Reports — Primary Care and Social Inclusion**
	substance misuse, homeless service and traveller health screening, Examples of an indicator include: number of patients for whom a primary care physiotherapy referral was received in the reporting month substitution treatment (outside prisons).
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.
Data content	Data is collected in aggregate. Geographical area, by therapy nos. on waiting lists for treatment and assessment. See Metadata; http://www.hse.ie/eng/services/publications/KPIs/
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Data collected to support these indicators is a combination of collecting primary data and data from national data collectors. Primary data is submitted from all CHOS and some Servicer Providers to the Business Information Unit on a monthly or quarterly basis via excel.
Clinical coding scheme	N/A.
Size of national collection	Primary Care 360,846. Social Inclusion 9,168.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/services/publications/performancereports/ Data is published in the HSE Annual Reports. Data request can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.

Title	**HSE Performance Reports — Primary Care and Social Inclusion**
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

8.9 HSE Performance Reports – Primary Care Reimbursement Service

Title	**HSE Performance Reports – Primary Care Reimbursement Service**
Managing Organisation	HSE – Business Information Unit - Community Health Care.
Web address	http://www.hse.ie/eng/services/publications/performancereports/
Year established	2006.
Statement of Purpose	To monitor and measure provision of services for Primary Care Reimbursement Service and report on activity against National Service Plan.
Coverage **(geographical and temporal)**	National. Data collection commenced in 2006 and is ongoing.
Description/ Summary	The Business Information Unit -Community Health Care - collates the HSE's Performance Reports (PP), which provide an overall analysis of key performance data from Primary Care Reimbursement Service. The activity data reported is based on Performance Activity and Key Performance Indicators outlined in the National Service Plan and the HSE Operational Plans. The Performance Report is overseen by the National Planning Oversight Group (NPOG), led by the Chief Operations Officer on behalf of the CEO. NPOG monitors performance against planned activity, as outlined in the National Service Plan, and highlights areas for improvement. A Management Data Report is also produced each month which provides more detailed data on the Metrics covered in the Performance Report. Items such as Medical Cards and Drug payment Scheme are included as indicators. Examples of an indicator include: ▪ No of persons covered by medical cards at the end of a reporting month

Title	**HSE Performance Reports – Primary Care Reimbursement Service**
	▪ No of high tech drugs scheme claims.
Data users	BIU – CHC, CHOs, EMT, HSE Board NPOG, DOH and Service Leads for CHOs and Hospital Groups.
Data content	Data on Medical Card, GP Visit Cards, GMS, LTI, DPS, Hi Tech Drugs, Ophthalmic and Dental Treatment Services. See metadata: **http://www.hse.ie/eng/services/publications/KPIs/**
Data dictionary	N/A.
Equity stratifiers	No.
Data collection methodology	Data collected to support these indicators is a combination of collecting primary data and data from national data collectors who submit to the Business Information Unit on a monthly basis via excel. Example of National Data source is the Primary Care Reimbursement Service.
Clinical coding scheme	N/A.
Size of national collection	3,360 lines of data annually.
Publication frequency	Performance Reports and Management Data Reports are published quarterly and data is presented in these reports.
Accessing data	Performance Reports and Management Data Reports are published and can be located on the HSE website: http://www.hse.ie/eng/servcies/publications/performancereports/ Data is published in the HSE Annual Reports. Data requests can also be made. Data requests are routed through the Care Group/ Service Area as they are the owners of data, the NBIU assist with data requests as required by the Care Group/Service Area.
Open Data portal access	No.
Generic email contact	CommunityHealth.Data123@hse.ie

Title	**HSE Performance Reports – Primary Care Reimbursement Service**
	or CommunityHealth.Data45@hse.ie or Communityhealth.Data678@hse.ie
Generic telephone contact	N/A.

TUSLA
An Ghníomhaireacht um Leanaí agus an Teaghlach
Child and Family Agency

8.10 Tusla — Performance and Activity Datasets

Title	**Tusla — Performance and Activity Datasets**
Managing Organisation	Tusla – Child and Family Agency.
Web address	Published data can be accessed from http://www.tusla.ie/data-figures
Year established	2014 (Tusla) Prior to the establishment of Tusla (2014), performance and activity data for HSE Children and Family Services was collected and published by the HSE.
Statement of Purpose	To comply with statutory reporting obligations; measure and monitor performance of the operational system; improve service delivery and outcomes for children and families engaging with services; inform policy and research and provide information (accountability) to the public.
Coverage (geographical and temporal)	National / Tusla Regional / Tusla Area level. Publication of the data in its current format commenced in 2014 when Tusla was established and is ongoing.
Description/ Summary	Datasets of key performance and activity metrics and indicators defined for Tusla services as follows: - Child Protection and Welfare Services; - Alternative Care Services (incl. foster care, residential care, aftercare, adoption); - Family Support Services; - Tusla Education Support Services; - Children's Services Regulation (Early Years Inspectorate, Alternative Education, Assessment & Registration Service; Alternative Care Inspection & Monitoring Service) - Human Resources - Finance.
Data users	Tusla; Department of Children, Equality, Disability, Integration & Youth; policy makers; researchers; media; members of the Oireachtas; public.

Title	**Tusla — Performance and Activity Datasets**
Data content	Datasets comprise a number of activity metrics and indicators (aggregate data) e.g., Referrals to services, assessments conducted, children in care and placement types, young people in receipt of aftercare services, approval and assessment of foster carers, waiting-lists (allocation to a social worker), applications for information and tracing (adoption), children referred for adoption; early years services inspected, children on register/assessments for home education, inspections of non-statutory alternative care services, staffing levels, variance from budget.
Data dictionary	Data definitions in place for datasets – not published online.
Equity stratifiers	Aftercare dataset: data on young people (18-22 years) in receipt of aftercare services engaged in education/accredited training disaggregated by type of education.
Data collection methodology	Data recorded on Tusla's National Child Care Information System (NCCIS) is extracted directly from the system for reporting / publication. Data not recorded on NCCIS is collected at an area / service level and submitted by e-mail to the Performance Reporting Function of the Quality & Regulation Directorate for collation, analysis and publication. Data is collated on a monthly / quarterly and annual basis (depending on the dataset).
Clinical coding scheme	N/A.
Size of national collection	>100,000 records.
Publication frequency	Monthly, Quarterly, Annually (depending on dataset).
Accessing data	Published data can be accessed from http://www.tusla.ie/data-figures Data access requests from researchers are considered.
Open Data portal access	A number of datasets are available via Ireland's Open Data https://data.tusla.ie/Home/OpenData
Generic email contact	info@tusla.ie

Title	**Tusla — Performance and Activity Datasets**
Generic telephone contact	+353 1 7718500

9 Additional collated sources of health information

National

- CompStat
- COVID-19 Data Research Hub
- Health Atlas Ireland
- Health in Ireland — Key Trends
- Health Statistics (PHIS)
- Institute of Public Health Repository
- 2021 National Report (2020 data) to the European Monitoring Centre for Drugs and Drug Addiction by the Reitox National Focal Point. Ireland: new developments, trends.
- State of the Nation's Children
- Women and Men in Ireland.

European/international

- European Health for All family of databases
- Eurostat Health Statistics
- Organisation for Economic Co-Operation and Development (OECD) Health Data
- World Health Organization Global Health Observatory.

National

9.1 Compstat

Title	**Compstat**
Managing Organisation	HSE – Operational Performance and Integration Unit.
Web address	http://www.healthatlasireland.ie
Year established	2012.
Statement of Purpose	The purpose of Compstat is to enable monthly management of hospital performance using a scorecard performance report on a suite of relevant metrics.
Coverage **(geographical and temporal)**	51 public hospitals. Data collection commenced in 2012 and is ongoing.
Description/ Summary	CompStat is a web-enabled performance management and reporting system which operates on a monthly cycle including a monthly performance forum process involving all stakeholders wherein the HSE Regions (Dublin Midlands, Ireland East Hospital Group, RCSI Hospital Group, UL Hospital Group, Children's Hospital Group, South/South West Hospital Group and Saolta) are the locus of performance control. The purpose of CompStat is to build around a balanced accountability framework of quality, access and resources and incorporates a scorecard performance report on a suite of relevant metrics. CompStat focuses on acute hospitals metrics from an inpatient, out-patient and day-case perspective, waiting list data, clinical programme data.
Data users	Hospital Groups, Hospitals, Department of Health, HSE Management and HSE Board.
Data content	CompStat measures are grouped into three areas – Quality, Access and Resources. Quality focuses on the quality and safety of care provided to the people who access our services.

Title	**Compstat**
	Access measures the waiting times that people experience for different services. Resources assesses whether a hospital is making best use of its human and financial resources.
Data dictionary	Not available.
Equity stratifiers	N/A.
Data collection methodology	Data is submitted on a monthly basis from the teaching, regional and general hospitals to the HSE CompStat office. This data collection is supplemented by other primary data sources covering hospital services.
Clinical coding scheme	N/A.
Size of national collection	N/A.
Publication frequency	Monthly.
Accessing data	Information is published in http://www.healthatlasireland.ie each month.
Open Data portal access	No.
Generic email contact	compstat@hse.ie
Generic telephone contact	+353 1 7785222

An Phríomh-Oifig Staidrimh
Central Statistics Office

9.2 COVID-19 Data Research Hub

Title	**COVID-19 Data Research Hub**
Managing Organisation	Central Statistics Office.
Web address	https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/covid-19dataresearchhub/
Year established	2021.
Statement of Purpose	The purpose of the CSO COVID-19 data research hub is to make individual level administrative COVID-19 datasets available to researchers via the CSO Researcher Microdata Files (RMF) process under Section 20(c) of The Statistics Act, 1993.
Coverage **(geographical and temporal)**	Data extracts provided by the HSE to CSO. 2020 onwards.
Description/ Summary	The COVID-19 Data Research Hub contains individual level administrative data sets obtained from the HSE. The datasets within the Research Hub contain pseudonymised individual level data on those who have been diagnosed with COVID-19, been referred for testing, been treated in hospital for COVID-19 or have been identified as being a close contact of a confirmed case.
Data users	Registered researchers from registered research organisations. https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/registerofresearchorganisations/
Data content	https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/covid-19dataresearchhub/covid-19rmfregister/
Data dictionary	
Equity stratifiers	
Data collection methodology	https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/covid-19dataresearchhub/faqs/
Clinical coding scheme	https://www.cso.ie/en/aboutus/lgdp/csodatapolicies/dataforresearchers/covid-19dataresearchhub/faqs/
Size of national collection	

Title	**COVID-19 Data Research Hub**
Publication frequency	
Accessing data	
Open Data portal access	
Generic email contact	
Generic telephone contact	
Other comments	

9.3 Health Atlas Ireland

Title	**Health Atlas Ireland**
Managing Organisation	National Health Intelligence Unit, Research & Evidence, Strategy and Research, Jervis House, Jervis St., Dublin 1. D01 W596.
Web address	https://www.healthatlasireland.ie
Year established	2006.
Statement of Purpose	To support the quest for better health for patients, their families and the population by exploiting the quality assurance, health mapping and research potential of available data.
Coverage **(geographical and temporal)**	Republic of Ireland. This data collection commenced in 2006 and is ongoing.
Description/ Summary	The open source application enables role-based web access to key health related datasets that enables ad-hoc queries, area profiling, quality of care, and geo-spatial analyses and displays to inform decision makers at all levels from clinical practice to policy. Health Atlas Ireland was developed by the National Health Intelligence Unit, HSE. It evolved in collaboration with many agencies including: ▪ Health Service Executive ▪ Health Protection Surveillance Centre - HSE ▪ OoCIO - HSE ▪ Sláintecare ▪ Department of Health ▪ Royal College of Physicians Ireland ▪ Royal College of Surgeons Ireland ▪ Central Statistics Office ▪ Ordnance Survey Ireland ▪ GeoDirectory ▪ University College Dublin

Title	**Health Atlas Ireland**
	▪ National University Ireland Maynooth ▪ Dublin City University ▪ Trinity College Dublin ▪ Primary Care Eligibility & Reimbursement Service - HSE ▪ Economic and Social Research Institute ▪ Road Safety Authority ▪ An Garda Siochana ▪ Irish Air Corps ▪ Irish Coast Guard. Seed funding was provided by the Health Research Board.
Data users	HSE, health policy-makers, acute & community clinical teams and researchers.
Data content	Health Atlas Ireland provides, via tiered access, an analytical and display route to a range of datasets gathered by others including: demography (census etc); hospital activity; prescribing; mortality; human resources; service location; along with a range of mapping functions.
Data dictionary	Each Health Atlas Ireland application has a 'User Guide' or equivalent defining key variables and methodologies, and refers back to the original data source(s) as appropriate.
Equity stratifiers	Per original data source(s) as appropriate.
Data collection methodology	Data is made available to Health Atlas Ireland, HSE from the various primary data collections at an agreed cadence.
Clinical coding scheme	Per original data source(s) as appropriate.
Size of national collection	Varies per original data source(s) – platform total 1.7M+
Publication frequency	Health Atlas Ireland is an analytical and display system that users can exploit in the context of their own missions. The frequency of data updates is determined by the primary data sources. The internal map centre allows HSE staff, and associated agencies, to use provided patient addresses to locate services, to create customised maps, and to review CSO demographic data for their areas. The 'Services near you' option on the HSE Website (http://www.hse.ie) allows the public to locate services on a map and to obtain key service contact information.

Title	**Health Atlas Ireland**
Accessing data	Access to most of the modules has to be sought and requested on a person by person basis through a controlled process – see www.healthatlasireland.ie All persons with access to the HSE internal network can access a part of the 'collection' e.g. to make use of a module to make use of census data, service location data and maps etc.
Open Data portal access	No.
Generic email contact	Via www.healthatlasireland.ie
Generic telephone contact	N/A.

An Roinn Sláinte
Department of Health

9.4 Health in Ireland — Key Trends

Title	**Health in Ireland — Key Trends**
Managing Organisation	Department of Health, Statistics & Analytics Unit.
Web address	https://www.gov.ie/en/publication/350b7-health-in-ireland-key-trends-2021/
Year established	2008.
Statement of Purpose	To provide summary statistics on health and healthcare. It also aims to highlight selected trends and topics of growing concern and to include new data where it becomes available. All aspects of the public health system in Ireland are in scope. Activity and employment in private hospitals is out of scope.
Coverage **(geographical and temporal)**	National. Each edition of Key Trends contains data from the previous five years.
Description/ Summary	Health in Ireland - Key Trends provides summary statistics on health and healthcare. Most data tables provide data for the previous 10 years. It also aims to highlight selected trends and topics of growing concern and to include new data where it becomes available. The booklet is divided into six chapters ranging from population, life expectancy and health status through to healthcare delivery, staffing and costs.
Data users	Persons and Institutions engaged in researching health in Ireland.
Data content	Population and life expectancy; health of the population; hospital care; primary care and community services; health service employment; health service expenditure.
Data dictionary	No.
Equity stratifiers	Data in Key Trends are high-level aggregations. Where possible, indicators are broken down by Age, Sex and Region.
Data collection methodology	Compiled from various sources - either manually retrieved from online public databases or published reports, or by requesting the information from the relevant organisation. Key Trends is published annually.
Clinical coding scheme	Not applicable.
Size of national collection	Key Trends contains c.100 tables/graphs

Title	**Health in Ireland — Key Trends**
Publication frequency	Annually.
Accessing data	From the Dept of Health website: https://www.gov.ie/en/publication/350b7-health-in-ireland-key-trends-2021/
Open Data portal access	No.
Generic email contact	john_heslin@health.gov.ie
Generic telephone contact	+353 1 6353108

An Roinn Sláinte
Department of Health

9.5 Health Statistics

Title	**Health Statistics (PHIS)**
Managing Organisation	Department of Health - Statistics and Analytics Unit.
Web address	https://data.cso.ie/product/DH
Year established	2020.
Statement of Purpose	Health statistics related to acute and maternity public hospital activity and mortality based on anonymised data sources are in scope. Private hospital activity is out of scope. Ancillary data on resourcing, financing, staff and facilities, and identifiable health data are out of scope. Primary care data is also out of scope.
Coverage **(geographical and temporal)**	National – 1980 – 2020.
Description/ Summary	Health Statistics is a collection of aggregated tables of health-related data produced by the Department of Health focused primarily on morbidity and mortality.
Data users	Persons and institutions engaged in researching health in Ireland.
Data content	Health Statistics tables on cancer; demography; fertility; hospital discharges; maternity; mortality; morbidity.
Data dictionary	No.
Equity stratifiers	Yes; Sex, County and Age group.
Data collection methodology	Data is provided annually to our Statistics and Analytics Unit.
Clinical coding scheme	Mortality data is classified using the Eurostat 65 Cause of Death Shortlist. Morbidity data is classified using the International Shortlist for Hospital Morbidity Tabulation (ISHMT) – Eurostat / OECD / WHO. (Version 2008-11-10) for diagnoses and the ICD-10-AM / ACHI Procedure Shortlist for procedures.
Size of national collection	On average, 1.1 million records are added to the collection annually.
Publication frequency	Health Statistics are updated quarterly on data.cso.ie.

Title	**Health Statistics (PHIS)**
Accessing data	https://data.cso.ie/product/DH
Open Data portal access	No.
Generic email contact	info@health.gov.ie
Generic telephone contact	+353 1 6354000

9.6 Institute of Public Health Repository

Title	**Institute of Public Health Repository**
Managing Organisation	Institute of Public Health in Ireland.
Web address	https://www.iphrepository.com
Year established	2021.
Statement of Purpose	To provide access to health information resources that are needed to develop systems-wide solutions to improve population health and wellbeing, tackle health inequalities and address the social determinants of health (SDH) across the island of Ireland. We focus on promoting health and wellbeing, improving health equity, and reducing health inequalities throughout the life course. The Institute has researchers and policy specialists from a range of disciplines based in offices in Dublin and Belfast and is jointly funded by the Departments of Health in Ireland and Northern Ireland.
Coverage (geographical and temporal)	Republic of Ireland, Northern Ireland, United Kingdom. 1998 to date.
Description/ Summary	The Repository contains public health resources from across the Island of Ireland, providing access to a broad range of health information resources from organisations including the IPH, Department of Health (Ireland), Department of Health (NI).
Data users	The Institute works with national and local government departments, and have established partnerships with public health schools, clinical and academic institutions, and community organisations on the island of Ireland, in the UK, EU and globally.
Data content	The resources cover a wide range of public health issues and are grouped in a number of ways including by publisher, region, type of report etc.
Data dictionary	N/A.
Equity stratifiers	N/A.
Data collection methodology	Resources are managed by the Institute of Public Health in Ireland.
Clinical coding scheme	N/A.
Size of national collection	N/A.
Publication frequency	The resources contained are updated continuously throughout the year.

Title	**Institute of Public Health Repository**
Accessing data	https://www.iphrepository.com
Open Data portal access	No.
Generic email contact	info@publichealth.ie
Generic telephone contact	+353 1 4786300
Other comments	The Institute of Public Health Repository is an affiliate of https://publichealth.ie/

9.7 2021 National Report (2020 data) to the European Monitoring Centre for Drugs and Drug Addiction by the Reitox National Focal Point. Ireland: new developments, trends.

Title	**2021 National Report (2020 data) to the EMCDDA by the Reitox National Focal Point. Ireland: new developments, trends.**
Managing Organisation	Health Research Board (HRB) - Evidence Centre, Reitox National Focal Point.
Web address	http://www.emcdda.europa.eu/countries/ireland; and http://www.drugsandalcohol.ie/php/annual_report.php
Year established	1997.
Statement of Purpose	The European Monitoring Centre for Drugs and Drug Addiction coordinates the work of 29 National Focal Points that act as monitoring centres gathering and analysing drug-related information in their own countries (27 EU member states, Norway and Turkey) and supplying data to the EMCDDA. The Irish Focal Point to the EMCDDA is based in the Health Research Board. Each year it provides a report on the drug situation in Ireland which is prepared according to common data-collection standards and tool. The national report comprises 10 separate workbooks, each dealing a separate topic. Out of scope: prescribed medications apart from sedative/tranquillisers and pain relief. Behavioural addictions (gambling etc.)
Coverage **(geographical and temporal)**	Member states of the European Union. Data collection commenced in 1997 and is updated annually.
Description/ Summary	Each year, the Irish Focal Point to the EMCDDA, based in the Health Research Board, presents a report on the drugs situation in Ireland to the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA). Data from this national report is aggregated with data from the other member states to prepare into the EMCDDA's annual European Drugs Report published in June each year.

Title	**2021 National Report (2020 data) to the EMCDDA by the Reitox National Focal Point. Ireland: new developments, trends.**
Data users	European Union Drugs Agency; European Commission; Researchers; Policymakers.
Data content	The national report includes issues such as main trends and developments; national strategy; institutional and legal framework; epidemiological situation (prevalence, patterns; health consequences); social and legal correlates and consequences; illicit drugs markets; demand/reduction; interventions; key issues arising.
Data dictionary	No.
Equity stratifiers	No.
Data collection methodology	Data collated annually from surveys, health surveillance systems, administrative data provided by health services, NGOs, law enforcement agencies and government departments.
Clinical coding scheme	No.
Size of national collection	No.
Publication frequency	Annual report published by the EMCDDA; annual reports specific to Ireland 2002-2021.
Accessing data	On www.drugsandalcohol.ie website.
Open Data portal access	N/A.
Generic email contact	druglibrary@hrb.ie
Generic telephone contact	+353 1 2345168
Other comments	Since 2015 the national report has been submitted via a series of workbooks dealing with the following general themes: Drug policy; Legal framework; Prevention; Drugs, Harms and harm reduction; Treatment; Prisons; Research; and, Best practice.

9.8 State of the Nation's Children

Title	**State of the Nation's Children**
Managing Organisation	Department of Children, Equality, Disability, Integration, and Youth, Research and Evaluation Unit.
Web address	https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/
Year established	2006.
Statement of Purpose	To chart the well-being of children in Ireland, track changes over time, benchmark progress in Ireland relative to other countries and highlight policy issues arising. Included are data relating to all children aged 0-17 years resident in Ireland, as well as various international comparisons of this cohort. A small number of indicators include young adults 18-24 years.
Coverage **(geographical and temporal)**	National - children aged 0-17 years. Data presented range from the year 2000, in the first version, to 2021, in the most recent version.
Description/ Summary	The State of the Nation's Children report provides a description of child well-being in Ireland. It brings together information from administrative, survey and census data. The report is arranged around four broad categories, these are socio-demographics, children's relationships, children's outcomes, formal and informal supports. The Research and Evaluation Unit within the Department of Children, Equality, Disability, Integration, and Youth (DCEDIY) prepares this publication, with input provided by a variety of data providers. The following sources are used to compile this report: ▪ Central Statistics Office: Census of the Population; ▪ Central Statistics Office: Vital Statistics; ▪ Central Statistics Office: European Union Survey of Income and Living conditions (EU-SILC); ▪ Department of Children and Youth Affairs: ECCE Database (Programmes Implementation Platform) ▪ Department of Housing, Planning, Community and Local Government: Summary of Social Housing Assessments ▪ Department of Justice and Equality: Annual Report of the Committee Appointed to Monitor the Effectiveness of the Diversion Programme (An Garda Síochána); ▪ Educational Research Centre: Programme for International Student Assessment (PISA) Survey;

Title	**State of the Nation's Children**
	▪ Healthcare Pricing Office: National Perinatal Reporting System (NPRS); ▪ Healthcare Pricing Office: Hospital In-Patient Enquiry System ▪ Health Promotion Research Centre, NUI Galway: Health Behaviour of School-Aged Children (HBSC) Survey; ▪ Health Protection Surveillance Centre: Immunisation Uptake Statistics; ▪ Health Research Board: National Intellectual Disability Database (NIDD); ▪ Health Research Board: National Physical and Sensory Disability Database (NPSDD); ▪ Health Service Executive Performance Indicators; ▪ Hospital In-Patient Enquiry (HIPE); ▪ National Psychiatric In-Patient Reporting System (NPIRS); ▪ National Suicide Research Foundation: National Self-Harm Registry; ▪ National Nutrition Surveillance Centre: European Childhood Obesity Surveillance Initiative ▪ National Treatment Purchase Fund: Patient Treatment Register (PTR); ▪ Population Estimates, CSO; ▪ Quarterly National Household Survey (QNHS); ▪ Summary of Social Housing Assessments, Department of Housing, Planning and Local Government; ▪ Tusla, the Child and Family Agency: Review of Adequacy Reports; ▪ Tusla, the Child and Family Agency: Primary and Post-Primary Pupil Annual School Attendance; ▪ Tusla, the Child and Family Agency: Outturn of Monthly Activity Data Returns and Quarterly Performance Indicator Returns.
Data users	Key data users include: ▪ Irish government departments ▪ Academic researchers

Title	**State of the Nation's Children**
	- Policy, Research, and Advocacy bodies for children - Interested members of public.
Data content	Socio-demographics; children's outcomes health; children's outcomes social, emotional and behavioural; formal and informal supports.
Data dictionary	No data dictionary.
Equity stratifiers	Equity stratifiers included: - County/Region - Gender - Educational attainment - Socioeconomic class - Traveller Status - Immigrant status - Disability and/or chronic illness status.
Data collection methodology	The Research and Evaluation Unit of the DCEDIY compile data from the most recent and reliable survey, census and administrative sources as listed above via direct contact with the sources and/or drawing on existing published data. These data sources publish at various frequencies, from quarterly to Quinquennially (every 5 years).
Clinical coding scheme	N/A.
Size of national collection	147 Tables & 30 Figures.
Publication frequency	Biennially.
Accessing data	Available on DCEDIY website (https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-). Hard copies available from Government Publications or DCEDIY on request.
Open Data portal access	Yes.
Generic email contact	Research_and_Evaluation_Unit_DCYA@dcya.gov.ie
Generic telephone contact	+353 1 6493000

An
Phríomh-Oifig
Staidrimh
Central
Statistics
Office

9.9 Women and Men in Ireland

Title	**Women and Men in Ireland**
Managing Organisation	Central Statistics Office (CSO).
Web address	http://www.cso.ie/en/statistics/womenandmeninireland/
Year established	2004.
Statement of Purpose	To conduct a social indicator report to identify important gender differences in the activities of men and women. The scope of the publication varies from year to year. All new released data that is available with gender breakdown is considered and may be included.
Coverage **(geographical and temporal)**	National. Ireland is compared to other EU countries and where available five additional countries (Turkey, Croatia, Macedonia, Iceland, Norway and Switzerland). The temporal coverage varies. As the publication is a collection of data already published elsewhere, the same time frames are not available everywhere. The report will collate the available data in Q1 of the year following the reference year (eg. For Women and Men in Ireland 2022, the data will be obtained in Q1 2023. In some cases, this will be data from 2022, but the most recently available data from each source will be used.)
Description/ Summary	Women and Men in Ireland is published by the Central Statistics Office (CSO). The social partnership agreement 2003-2005 requested the CSO to support a move towards more evidence based policy-making. Responding to this request, the National Statistics Board (NSB) asked the CSO to prepare a social indicator report covering all aspects of social statistics. The first gender report was published in 2004.
Data users	The report is available to all on the CSO website. It is not specifically provided to data users. Various organisations who have contacted us in relation to the report include: ▪ The Women’s Council of Ireland ▪ Department of Children, Equality, Disability, Integration and Youth (DECIDY) ▪ IHREC

Title	**Women and Men in Ireland**
	- Universities - The Citizen's Assembly - Media.
Data content	These indicators have been presented across eight domains for women and men in Ireland. These indicators are European Union Council policy indicators, population; employment; social cohesion and lifestyles; education; health; crime and transport. Under health the following is reported on death rates; medical cards; hospital; mental illness and disability; carers; health personnel. The indicators are reviewed each publication to ensure that any new indicators or data is captured.
Data dictionary	There is no data dictionary available. All data for this report is obtained from other published sources which may have their own data dictionary.
Equity stratifiers	Yes, gender is included in every table where applicable. Other equality dimensions will be considered in the upcoming update.
Data collection methodology	The CSO gathers the data from all sources and compiles the report. The report is published on a three yearly basis with the next publication due in 2023. The data included in the report comes from a wide variety of sources which are all collected at different frequencies.
Clinical coding scheme	N/A.
Size of national collection	N/A.
Publication frequency	Annual from 2004 to 2012 and bi-annual from 2012 to 2016. After 2016, the data was published in 2020 with 2019 data and is scheduled to be published next in 2023 with 2022 as the reference year for the data.
Accessing data	N/A.
Open Data portal access	No.
Generic email contact	sscu@cso.ie
Generic telephone contact	+353 21 4535000
Other comments	

European/International

9.10 European Health for All family of databases

Title	**European Health for All family of databases**
Managing Organisation	World Health Organization Regional Office for Europe (WHO- Europe), Copenhagen, Denmark.
Web address	https://gateway.euro.who.int/hfa-explorer and API at http://dw.euro.who.int/
Year established	Mid-1980s.
Statement of Purpose	To collate independent, comparable and up to date health statistics for all WHO Member States in the European region to support the monitoring of health trends.
Coverage **(geographical and temporal)**	The database includes data for all 53 WHO Member States in the WHO European Region, although data availability and comparability may be limited for some countries. The databases cover the period from 1970 to the present.
Description/ Summary	HFA is a central database of independent, comparable and up-to-date basic health statistics. It has been a key source of information on health in the European Region since WHO/ Europe launched it in the mid-1980s. It contains time series from 1970.
Data users	Public health professionals, policy makers, media professionals, health professionals and researchers.
Data content	HFA is updated annually and contains about 1450 indicators for the 53 member states in the region. The indicators cover: basic demographics; health status (mortality, morbidity, maternal health and child health); health determinants (such as lifestyle and environment) healthcare (resources and utilization).
Data dictionary	Yes, http://dw.euro.who.int/
Equity stratifiers	N/A.
Data collection methodology	There are various sources from which WHO/Europe regularly collects health data. Part of the data is annually collected directly from countries; a request for data is issued by the WHO every year for an update of around 200 indicators. Data is submitted on excel spreadsheets. Another part of data comes from those WHO technical units that collect appropriate statistical information within their own field. Mostly this relates to the incidence of infectious diseases, immunisation and mortality data by cause, age and sex. Secondary information sources, such as other international organisations and agencies, are also an important source of data for a number of indicators. In addition to above, data is transmitted annually to Eurostat, OECD and the WHO by means of the Joint Data Collection on non-Monetary Health Care Statistics. This joint data collection is a harmonised approach developed by Eurostat, OECD and WHO in order to reduce the data collection burden on countries.

Title	**European Health for All family of databases**
Clinical coding scheme	International Statistical Classification of Diseases (ICD).
Size of national collection	N/A.
Publication frequency	Annually.
Accessing data	The data is available to users through the HFA explorer at the internet address http://gateway.euro.who.int/en/hfa-explorer/, a tool that allows integrated access to indicators, enables dynamic comparisons and exploration. The Gateway is the main entry-point and interface for the data warehouse. The data warehouse is a unique repository that integrates WHO Europe databases The WHO Europe integrated Data Warehouse API lets programmatically access the indicators and query the data in several ways, using parameters to specify a request.
Open Data portal access	N/A.
Generic email contact	euhiudata@who.int
Generic telephone contact	+454 533 7000

9.11 Eurostat Health Statistics

Title	**Eurostat Health Statistics**
Managing Organisation	Eurostat.
Web address	http://ec.europa.eu/eurostat/web/health/overview
Year established	1953.
Statement of Purpose	Health statistics are used to monitor the EU Health strategy, the EU Strategy on health and safety at work and their contribution to the Europe 2020 strategy. They have a key role to support the elaboration of evidence-based policies both at national and European levels. Those statistics also serve for calculating indicators of the health portfolio used for the monitoring of the social protection and social inclusion and the set of indicators known as the European Core Health Indicators (ECHI) and are part of the Sustainable Development Goals (SDGs).
Coverage **(geographical and temporal)**	EU Data collection commenced in 1953 and is ongoing.
Description/ Summary	Eurostat is the Statistical Office of the EU. It collects and collates data on a wide range of themes including health statistics. The data is categorised under two main headings: public health and health and safety at work. Under public health, some of the sub-headings include: health status (e.g. self-reported health and morbidity), health determinants (e.g. overweight and obesity, tobacco and alcohol consumption), healthcare (e.g healthcare expenditure, healthcare resources), morbidity (e.g diagnosis-specific morbidity), disability (e.g. prevalence of disability, employment of disabled persons) and causes of death (e.g. national and regional mortality data by causes of death). Under health and safety at work, sub-headings include: Accidents at work, occupational diseases and other work- related health problems.
Data users	▪ Academic researchers ▪ Policy-makers ▪ Journalists.

Title	**Eurostat Health Statistics**
Data content	Public health data; health and safety at work data. http://ec.europa.eu/eurostat/estat-navtree-portlet-prod/BulkDownloadListing?sort=1&dir=dic
Data dictionary	https://ec.europa.eu/eurostat/web/health/data
Equity stratifiers	Sex, age, education, income quintile, place of residence, occupation, disability.
Data collection methodology	Eurostat sends out a request for data annually to statistical authorities within each member state, which is collated for publication. A collaborative data collection has been developed by Eurostat, the OECD and the WHO as a harmonised approach to data collection of non-monetary healthcare statistics in order to reduce the data collection burden on countries. Eurostat applies specific methodology to ensure that the data is comparable.
Clinical coding scheme	International statistical Classification of Diseases and related health problems - ICD-10 Volume 2
Size of national collection	N/A.
Publication frequency	Updated release calendars are available on the website. Data is updated on a daily basis.
Accessing data	ALL European statistics are available in the database on Eurostat website.
Open Data portal access	No.
Generic email contact	
Generic telephone contact	+353 151 33080
Other comments	Eurostat was established in 1953 and has broadened its remit since then to collate a range of data including health data.

9.12 Organisation for Economic Co-operation and Development (OECD) Health Data*

*This template has not been updated since version 3.0 of the catalogue in 2017.

Title	**Organisation for Economic Co-operation and Development (OECD) Health Data**
Managing Organisation	Organisation for Economic Co-operation and Development.
Web address	http://www.oecd.org/health/health-systems/
Year established	
Statement of Purpose	The purpose of this data collection is to provide a comprehensive source of comparable statistics on health and health systems across OECD countries. It is an essential tool for health researchers and policy-makers, the private sector and the academic community, to carry out comparative analyses and draw lessons from international comparisons of diverse healthcare systems.
Coverage **(geographical and temporal)**	Thirty-five member states of the OECD.
Description/ Summary	OECD Health Data, maintained by the OECD, enables analyses and lessons to be drawn from comparisons of the healthcare systems of the 35 member states.
Data users	
Data content	Health status; health risk factors; healthcare resources and utilisation of health services; long-term care resources and utilisation; quality of care; health expenditure and health financing; pharmaceutical markets and non-medical determinants of health.
Data dictionary	
Equity stratifiers	
Data collection methodology	Production of OECD health data is by contribution from national health data correspondents (i.e. for Ireland the Department of Health) and health accounts experts (for Ireland the CSO) in the OECD member states. In addition to above, data is transmitted annually to Eurostat, OECD and the WHO by means of the 'Joint Data Collection on non-Monetary Health Care Statistics'. This joint data collection is a harmonised approach developed by Eurostat, OECD and WHO in order to reduce the data collection burden on countries.

Title	**Organisation for Economic Co-operation and Development (OECD) Health Data**
Clinical coding scheme	
Size of national collection	
Publication frequency	On a continual basis.
Accessing data	Data is available on the website http://stats.oecd.org/index.aspx?DataSetCode=HEALTH_STAT
Open Data portal access	No.
Generic email contact	Questions regarding specific data can be directed to the named contact listed on each table.
Generic telephone contact	

9.13 World Health Organization Global Health Observatory

Title	**World Health Organization Global Health Observatory**
Managing Organisation	World Health Organization.
Web address	https://www.who.int/data/gho
Year established	2009 — however, historic data is available from the early 1930s for certain datasets.
Statement of Purpose	To provide easy access to country health data and statistics with a focus on comparable estimates and to WHO's analyses to monitor global, regional and country situation and trends.
Coverage **(geographical and temporal)**	The 194 members of the WHO. 2009 to present.
Description/ Summary	The Global Health Observatory (GHO) is WHO's portal providing access to data and analyses for monitoring the global health situation. It provides critical data and analyses for key health themes, as well as direct access to the full database. The GHO presents data from all WHO programmes and provides links to supporting information.
Data users	▪ Academic researchers ▪ Policy makers ▪ Students ▪ Journalists.
Data content	The GHO database contains an extensive list of indicators, which can be selected by theme or through multi-dimension query functionality. It is the WHO's main health statistics repository. Core statistical data include the following major categories: demographic and socioeconomic statistics; health service coverage; health systems resources; inequities in healthcare and health outcomes; mortality and burden of disease and risk factors.
Data dictionary	Yes. There is a data dictionary in place. https://www.who.int/data/gho/indicator-metadata-registry
Equity stratifiers	Yes, equity stratifiers are in place. Place of residence, Sex, Wealth Quintiles, Education of mother, age groups.
Data collection methodology	Annual compilation of data from the member states. Includes a hundred data sets with different modalities of collection (from topic-specific surveys sent to key informants, to household surveys and statistical reports).
Clinical coding scheme	International Classification of Diseases and Related Health Problems (ICD) and others.
Size of national collection	Thousands.
Publication frequency	Annual data across several areas, the observatory itself updates every one to two weeks.

Title	**World Health Organization Global Health Observatory**
Accessing data	Via a web browser at https://www.who.int/data/gho and via an Application Programming Interface (API) at https://www.who.int/data/gho/info/gho-odata-api
Open Data portal access	No.
Generic email contact	gho_info@who.int
Generic telephone contact	
Other comments	Please come back to us in a year or two, as the WHO digital ecosystem is being improved.

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11 Glossary of abbreviations

Abbreviation	Term
AAT	Alpha-1 antitrypsin
AATD	Alpha-1 antitrypsin deficiency
A&E	Accident and emergency
ACHI	Australian Classifications of Health Interventions
ACR	Ambulatory care report
ACS	Acute coronary syndromes
ACS	Australian Coding Standards
AFP	Acute flaccid paralysis
AGS	An Garda Síochána
AIHW	Australian Institute of Health and Welfare
ALS	Amyotrophic lateral sclerosis
AMF	Anonymised microdata file
AMI	Acute myocardial infraction
AMRIC	Antimicrobial resistance and infection
ANCA	Anti-neutrophil cytoplasmic autoantibodies
API	The Edwin Application Programming Interface
ART	Adverse reaction terminology
ATC	Anatomical therapeutic chemical
AUD	Alcohol use disorder
AUDIT-C	Alcohol Use Disorders Identification Test- Concise
BIU	Business information unit
BMI	Body mass index
BPT	Best practice tariff
CAD	Coronary artery disease
CAMHS	Community Adult Mental Health Service
CAO	Chief Ambulance Officer
CAPI	Computer-assisted personal interview
CARDS	European Cardiology Audit and Registration Data Standards
CATI	Computer aided telephone interviewing
CCP	Critical care programme
CCT	COVID-Care Tracker

Abbreviation	Term
CDI	*Clostridioides difficile* infection
CDRs	Cancer Data Registrars
CF	Cystic fibrosis
CFRR	Cardiac First Response Report
CFRI	Cystic Fibrosis Registry Ireland
CFSGBI	Craniofacial Society of Great Britain and Ireland
CHAIR	Coronary Heart Attack Ireland Register
CHI	Children’s Health Ireland
CHO	Community healthcare organisation
CIDR	Computerised Infectious Disease Reporting
CIHI	Canadian Institute for Health Information
CMACE	Centre for Maternal and Child Enquiries
CNS	Clinical Nurse Specialist
COR ID	Colorectal ID
CP	Cerebral palsy
CPG	Clinical practice guidelines
CPU	Corporate Pharmaceutical Unit
CRC	Central Remedial Clinic
CRS	Cancer Registration System
CSP	Cervical Screening Programme
CSO	Central Statistics Office
CSS	Clinical Classification System
CTL	Central Treatment List
CUD	Cannabis use disorder
CUH	Cork University Hospital
CUMH	Cork University Maternity Hospital
DASSL	Data Access Storage Sharing and Linkage
DED	District electoral division
DCC	Dublin Cleft Centre
DCMI	Dublin Core Metadata Initiative
DCEDIY	Department of Children, Equality, Disability, Integration and Youth
DCO	Death certificate only

Abbreviation	Term
DDD	Defined daily dose
DMO	Designated Midwifery Officer
DOB	Date of birth
DoH	Department of Health
DoT	Department of Transport
DPER	Department of Public Expenditure and Reform
	Department of Public Health
DPS	Drug Payment Scheme
DSA	Delegated State authorities
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
DSM- IV	Diagnostic and Statistical Manual of Psychiatric Disorders, Fourth Edition
DTSS	Dental Treatment Services Scheme
EACTS	European Association for Cardio-Thoracic Surgery
EARS-NET	European Antimicrobial Resistance Surveillance Network
EARSS	European Antimicrobial Resistance Surveillance System
EB	Epidermolysis Bullosa
EC	European Commission
ECCE	Early Childhood Care and Education
ECDC	European Centre for Disease Prevention and Control
ECG	Electrocardiogram
ECHI	European Core Health Indicators
ECT	Electroconvulsive therapy
ED	Emergency department
EDTA	European Dialysis and Transplant Association
EEA	European Economic Area
EHDS	European Health Data Space
ELAR	European League Against Rheumatism
EMA	European Medicines Agency
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EOL	End-of-life
e-PoE	Electronic point of entry

Abbreviation	**Term**
EPR	Electronic patient record
ERIC	European Research Infrastructure Consortium
ERN	European Reference Network
ERN-RITA	European Reference Network- Rare Immunodeficiency Auto inflammatory and Autoimmune Disease
E-SARI-NET	European network of SARI hospitals
ESAW	European Statistics on Accidents at Work
ESRI	Economic and Social Research Institute
ESS	European Social Survey
ETSC	European Transport Safety Council
EU	European Union
EU SILC	European Union Survey on Income and Living Conditions
EUROCAT	European Registry of Congenital Anomalies
EULAR	European League Against Rheumatism
EU-SILC	European Union – Survey on Income and Living Conditions
FDA	Food and Drug Administration
GAMP	Good automated manufacturing practice
GDPR	General Data Protection Regulation
GH	General hospital
GHO	Global Health Observatory
GIS	Geographic information system
GMS	General Medical Services
GP	General practitioner
GPIT	General Practice Information Technology
GPVC	General Practitioner Visit Card
GRO	General Register Office
GUI	Growing up in Ireland
HBS	Health Business Services
HBSC	Health Behaviour in School-Aged Children
HC	Headcount
HCPs	Healthcare professionals
HCWs	Healthcare workers
HDU	High dependency unit

Abbreviation	**Term**
HED	Heavy episode drinking
HFA	Housing Finance Agency
HFA-DB	European Health for All DataBase
HIDS	Health Identifiers Service
HIPE	Hospital In-Patient Enquiry
HIPS Bill	Health Information and Patient Safety Bill
HIQA	Health Information and Quality Authority
HIV	Human immunodeficiency virus
HLA	Human leukocyte antigen
HPO	Healthcare Pricing Office
HPSC	Health Protection Surveillance Centre
HRB	Health Research Board
HSA	Health and Safety Authority
HSE	Health Service Executive
HSE-COS	Health Service Executive Community Ophthalmic Services Scheme
HSPC	Health Service Personnel Census
HTD	High tech drugs
IBTS	Irish Blood Transfusion Service
ICD	Implantable cardioverter defibrillator
ICD-NR	Irish Childhood Diabetes National Register
ICD-9	International Statistical Classification of Diseases and Related Health Problems, Ninth Revision
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Classification of Disease and Related Health Problems, Tenth Revision, Australian Modification
ICF	International Classification of Functioning, Disability and Health
ICGP	Irish College of General Practitioners
ICS	Irish Coding Standards
ICT	Information and communications technology
ICU	Intensive care unit
ICU-BIS	Intensive Care Unit-Bed Information System

Abbreviation	Term
ICNARC	Intensive Care National Audit and Research Centre
IHAA	Irish Heart Attack Audit
IHF	Irish Heart Foundation
IHFD	Irish Hip Fracture Database
IHFS	Irish Hip Fracture Standards
IHI	Institute for Healthcare Improvement
IHI	Individual Health Identifier
IIS	Integrated Information Service
ILD	Interstitial Lung Disease Registry
ILI	Influenza-like illness
INAAS	Irish National Audit of Stroke
INDC	Independent National Data Centre
INICUA	Irish National Intensive Care Unit Audit
INOR	Irish National Orthopaedic Register
IPCA	Irish Paediatric Critical Care Audit
IPCOR	Irish Prostate Cancer Registry of Ireland
IPD	Invasive pneumococcal disease
IPF	Idiopathic pulmonary fibrosis
IPH	Institute of Public Health in Ireland
IPH-CPT	Institute of Public Health in Ireland Community Profile Tool
IPMS	Integrated Patient Management System
IQDA	Irish Qualitative Data Archive
IRTAD	International Traffic Safety Council
ISHMT	International Shortlists for Hospital Morbidity Tabulation
ISSDA	Irish Social Science Data Archive
ITS	Irish Thoracic Society
IUBMR	Irish Unrelated Bone Marrow Registry
JCR	Joint Research Centres
KPI	Key performance indicator
LENS	**LE**arning from Statutory **N**otifications in **S**ocial Care
LFS	Labour Force Survey
LGMA	Local Government Management Agency

Abbreviation	Term
LHO	Local health office
LTCF	Long-term care facilities
LTI	Long-Term Illness Scheme
MAP	Measure of activity and participation
M-CIDI	Munich-Composite International Diagnostic Interview
MDS	Minimum dataset
MHC	Mental Health Commission
MHIS	Mental Health Information Systems Unit
MMR	Measles, mumps, rubella
MMUH	Mater Misericordiae University Hospital
MND	Motor neurone disease
MRBI	Market Research Bureau Ireland
MRN	Medical record number
MSRB	Medico-Social Research Board
MTA	Major Trauma Audit
NACDA	National Advisory Committee on Drugs and Alcohol
NAEMS	National Adverse Events Management System
NAHM	National Audit of Hospital Mortality
NASC	National AIDS Strategy Committee
NASS	National Ability Support System
NCC	National Coagulation Centre
NCCP	National Cancer Control Programme
NCCIS	National Childcare Information System
NCHD	Non-consultant hospital doctor
NCHCD	National Centre for Hereditary Coagulation Disorders
NCPPN	National Clinical Programme for Paediatrics and Neonatology
NCRI	National Cancer Registry Ireland
NDAS	National Drug and Alcohol Survey
NDCs	National data collections
NDRDI	National Drug-Related Deaths Index
NDTC	National Drug Treatment Centre
NDTRS	National Drug Treatment Reporting System

Abbreviation	**Term**
NEOC	National Emergency Operations Centre
NGO	Non-governmental organisation
NHIS	National Health Information Systems
NHSS	Nursing Homes Support Scheme
NHIU	National Health Intelligence Unit
NICOR	Neonatal Intensive Care Outcomes Research and Evaluation
NICU	Neonatal intensive care units
NIDD	National Intellectual Disability Database
NIO	National Immunisation Office
NIMIS	National Integrated Medical Imaging System
NIMS	National Incident Management System
NIRF	National Incident Report Forms
NISR	National and International Skin Registry Solutions CLG
NOCA	National Office of Clinical Audit
NPEC	National Perinatal Epidemiology Centre
NPE Survey	National Patient Experience Survey
NPIC	National Poisons Information Centre
NPIRS	National Psychiatric In-Patient Reporting System
NPIS	National Poisons Information Service
NPMR	National Paediatric Mortality Register
NPOG	National Planning Oversight Group
NPRS	National Perinatal Reporting System
NPSDD	National Physical and Sensory Disability Database
NPSO	National Patient Safety Office
NQAIS	National Quality Assurance Improvement System
NRAO	Novel or Rare Antimicrobial-resistant Organism
NSB	National Statistics Board
NSHRI	National Self-Harm Registry Ireland
NSRF	National Suicide Research Foundation
NSP	National Serosurveillance Programme
NSS	National Screening Service
NSTEMI	Non-ST elevated myocardial infection

Abbreviation	Term
NTPF	National Treatment Purchase Fund
NUIG	National University of Ireland Galway
NVRL	National Virus Reference Laboratory
NWIHP	National Women and Infant Health Programme
ODTI	Organ Donation and Transplant Ireland
OECD	Organisation for Economic Co-operation and Development
OHCAR	Out of Hospital Cardiac Arrest Register
OPD	Outpatient department
ORV	Other respiratory viruses
PATS	Patient Advocate Tracking System
PCI	Percutaneous coronary intervention
PCR	Patient Care Report
PCR	Polymerase chain reaction
PCRS	Primary Care Reimbursement Service
PHECC	Pre-Hospital Emergency Care Council
PHIS	Public Health Information System
PI	Performance indicator
PICA	Paediatric Intensive Care Audit
PISA	Programme for International Student Assessment
PPSN	Personal Public Service number
PR	Performance report
PROMS	Patient reported outcome measures
PSS	Poisoning Severity Score
PSUs	Primary sampling units
PTR	Patient Treatment Register
PTR	Patient Transport Report
QNHS	Quarterly National Household Survey
RCOG	Royal College of Obstetricians and Gynaecologists
RCSI	Royal College of Surgeons in Ireland
RDAT	Regional Drug and Alcohol Taskforce
RITA	European Reference Network on immunodeficiency, auto-inflammatory and autoimmune diseases
RKD	Rare kidney disease

Abbreviation	**Term**
RMF	Researcher microdata file
RSA	Road Safety Authority
RSV	Respiratory syncytial virus
SARI	Surveillance of severe acute respiratory infections
SCA	State Claims Agency
SCASMM	Scottish Confidential Audit Severe Maternal Morbidity
SCBU	Special care baby units
SCPE	Surveillance of Cerebral Palsy in Europe
SCTS	Society for Cardiothoracic Surgery
SDG	Sustainable development goals
SDH	Social Determinants of Health
SECMs	Self-employed community midwives
SIAT	System for Involuntary Admission and Tribunals
SIDS	Sudden infant death syndrome
SILC	Survey on Income and Living Conditions
SIS	National School Immunisation System
SLÁN	Survey of Lifestyles, Attitudes and Nutrition
SMM	Severe maternal morbidity
SMR	Standardised mortality ratio
SNOMED	Systematized Nomenclature of Medicine
SRE	Serious reportable events
STEMI	ST-elevation myocardial infarction
SVUH	St Vincent’s University Hospital
TARN	UK Trauma Audit and Research Network
TCD	Trinity College Dublin
TGCS	Robson Ten Group Classification System
TILDA	The Irish Longitudinal Study on Ageing
TNM	The Classification of Malignant Tumors 5 staging system
TNF	Tumour necrosis factor
UCC	University College Cork
UHL	University Hospital Limerick
UICC	Union for International Cancer Control

Abbreviation	Term
UKPID	UK Poisons Information Database
UL	University of Limerick
UK	United Kingdom
VON	Vermont Oxford Network
VPN	Virtual private network
VTEC	Verotoxigenic *E. coli*
WGS	Whole genome sequencing
WHO	World Health Organization
WHONET	WHO Collaborating Centre for Surveillance of Antimicrobial Resistance
WTE	Whole-time equivalent

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