Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Catalogue of National Health and Social Care Data Collections

March 2014

Version 2.0

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive high quality and safe care for people using our health and social care services. HIQA's role is to promote sustainable improvements, safeguard people using health and social care services, support informed decisions on how services are delivered, and promote person-centred care for the benefit of the public.

The Authority's mandate to date extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, the Health Information and Quality Authority has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for those health and social care services in Ireland that by law are required to be regulated by the Authority.
- **Supporting Improvement** – Supporting health and social care services to implement standards by providing education in quality improvement tools and methodologies.
- **Social Services Inspectorate** – Registering and inspecting residential centres for dependent people and inspecting children detention schools, foster care services and child protection services.
- **Monitoring Healthcare Quality and Safety** – Monitoring the quality and safety of health and personal social care services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** – Ensuring the best outcome for people who use our health services and best use of resources by evaluating the clinical and cost effectiveness of drugs, equipment, diagnostic techniques and health promotion activities.
- **Health Information** – Advising on the efficient and secure collection and sharing of health information, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of 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 imperative 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 a key 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, the Health Information and Quality Authority (the Authority) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), the Authority is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving the 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 drive 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 (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and silos of information which prevents the safe, effective, transfer of information. This results in service users being asked to provide the same information on multiple occasions.

Information can be lost, documentation is poor, and there is over-reliance 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, based on standards and international best practice. A robust health information environment will allow all stakeholders – the general public, patients and service users, health professionals and policy makers – to make choices or decisions based on the best available information. This is a fundamental requirement for a high reliability healthcare system.

Through its health information function, the Authority 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. The publication of this Catalogue of National Health and Social Care Data Collections will benefit all stakeholders by informing and increasing awareness on the existence, purpose and content of data collections and how data can be accessed. By outlining all of the national health and social care data collections it also assists in identifying gaps or inconsistencies in health information in Ireland.

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Acknowledgements

The Health Information and Quality Authority would like to thank all of those who participated in compiling the Catalogue through completion of templates to describe their data collections along with providing their data elements.

Part 1

Introduction

1

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/concepts that are found in a healthcare record. This allows comparison of events within and between records.

Data: are numbers, symbols, words, images, graphics that have yet to be organised or analysed.

Data catalogue: can be defined as a comprehensive list of datasets outlined in a systematic fashion. Data catalogues and data inventories are important resources in informing and increasing awareness among stakeholders on the existence, purpose and access to currently available information collections.

Data dictionary: describes the rules for the data to be recorded in a data collection. These can include the meaning of the data, dealing with missing data, relationships to other data, source of the data, usage, and format.

Data providers: are those that are responsible for the data collection, for example, the Central Statistics Office (CSO) is responsible for Vital Statistics – Deaths Registration.

Dataset: 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.

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

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

National health and social care data collections: are defined for the purpose of this project as national repositories of routinely collected health and social care data (including administrative collections, censuses, national surveys, and patient registries) in the Republic of Ireland.

Public Health Language (PHL) terms: these terms refer to a controlled language to describe terms used in health in a standardised way to enable them to be used as search terms.(1)

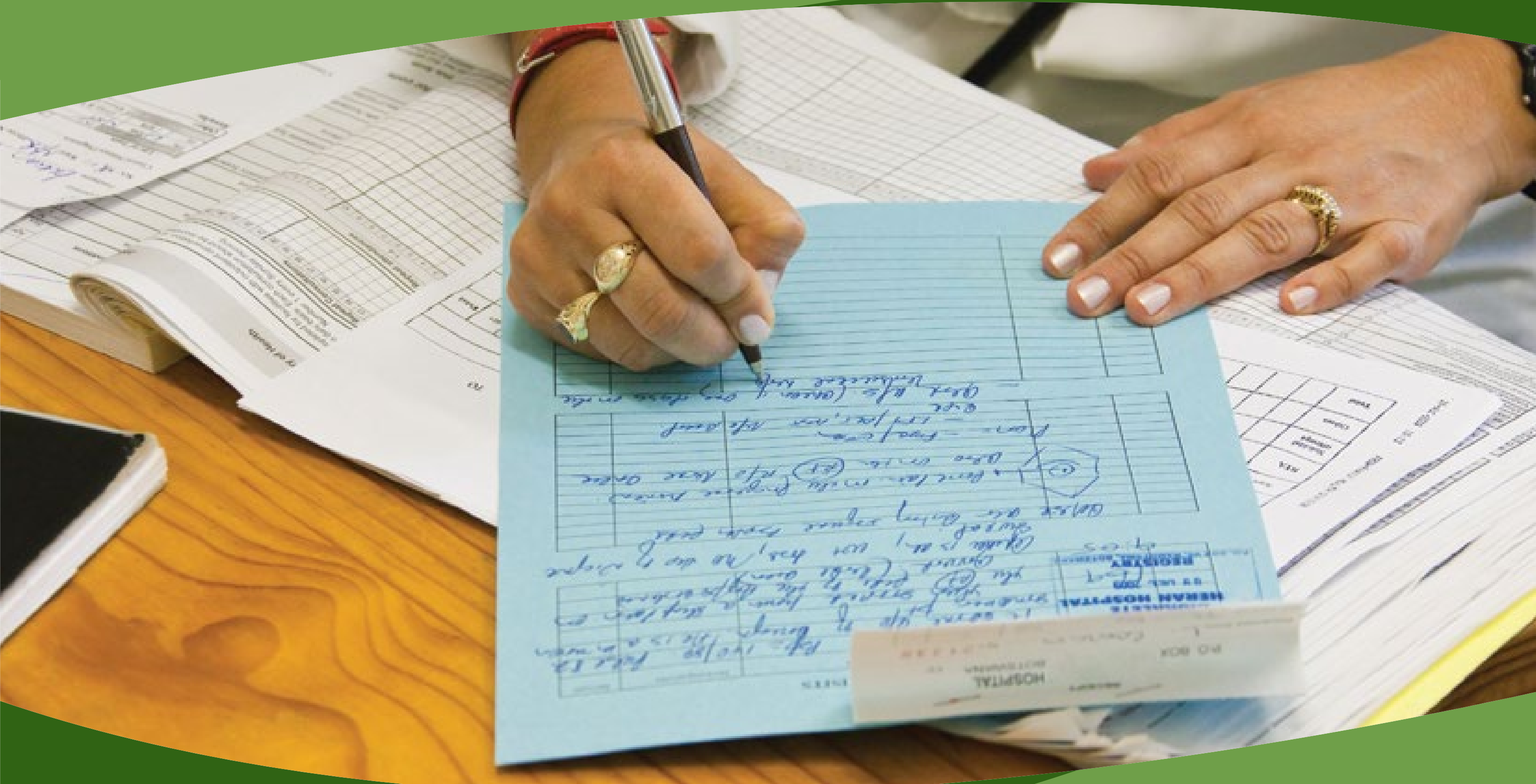
Secondary collection of data: relates to information collected in the course of providing care, being used for purposes other than direct service user care such as audit, performance reporting, service planning and research.

Statement of Purpose: a statement of purpose for a data collection succinctly captures why the data collection exists and what it does.(2)

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.

2

Background



A considerable amount of data is collected on a regular basis about our health and social care services in Ireland. This data is used for many important purposes such as informed decision making, monitoring of diseases, planning of services, policy making, improving population health and for international reporting purposes.

Safe, reliable health and social care depends on access to and use of good quality information. Information is essential to achieve a high quality, value for money healthcare system.(3) In addition, information has a key role to play in planning and managing services, where to locate a new service, whether or not to introduce a new national screening programme, and in evaluating performance.

All stakeholders (the general public, patients and service users, health professionals and policy makers) need access to complete, valid and up-to-date information in order to make choices and decisions. Ultimately, the primary purpose of collecting this data should be to improve the quality and safety of health and social care services. It is vital that there is confidence in all aspects of the quality of this information as the delivery of safe and effective healthcare depends on access to, and use of information that is accurate, relevant, valid, reliable, timely and complete.

National health and social care data collections* are defined as national repositories of routinely collected health and social care data, including administrative collections, censuses, surveys, and national patient registries in the Republic of Ireland. They collect a considerable amount of data on a regular basis to provide us with a wealth of information about our health and social care services.

The importance and need for high quality health information in improving the safety and quality of patient care has been outlined in a number of key national strategy documents from the Department of Health, including *Quality and Fairness – A Health System for You,*(4) the *National Health Information Strategy,*(5) and in the *Report of the Commission on Patient Safety and Quality Assurance – Building a Culture of Patient Safety.*(6) Most recently, the new *eHealth Strategy for Ireland* published in December 2013(7) highlights the importance of access to quality health data sources to drive improvements in the quality and safety of care.

A detailed catalogue of all national health and social care data collections in Ireland was published in 2010.(8) In total, 97 data collections were included in the 2010 Catalogue as follows:

- national data collections of health and social care information in Ireland (n=57)
- national censuses (n=6)

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* In keeping with international practice, the term 'National Health Information Source' has been replaced by 'National Health and Social Care Data Collection' since the publication of the Authority's previous documents, *Catalogue of National Health Information Sources in Ireland (2010)*, the *International Review of Health Information Sources, Identification of Themes for National Health Information Sources* and *Draft Standards for National Health Information Resources.*

- data collections without national coverage/regional data collections (n=7)
- systems that collated data from a number of different sources (n=18)
- national surveys (n=9).

An online version of the Catalogue was developed in 2010 as an interactive searchable version to make the data easier to access.

The publication of this revised Version 2.0, also available online, provides a national overview of data relating to a particular health or social care service and will benefit all stakeholders by informing them about, and increasing their awareness of, the existence, purpose and content of these collections and how data can be accessed.

3

Standards for National Data Collections

The Health Information and Quality Authority was established under the Health Act 2007(9) with the primary objective to promote safety and quality in the provision of health and personal social services for the benefit of the health and welfare of the public. The functions of the Authority as outlined in the Health Act, 2007 include:

> 8 (1)(i) to evaluate available information respecting the services and the health and welfare of the population;
>
> 8 (1)(j) to provide advice and make recommendations to the Minister and the Executive about deficiencies identified by the Authority in respect of the information referred to in *paragraph (i)*;
>
> 8 (1)(k) to set standards as the Authority considers appropriate for the Executive and service providers respecting data and information in their possession in relation to services and the health and welfare of the population;

In 2010 a survey was conducted by the Authority of a representative sample of 10 national data collections using a semi-structured interview format in order to understand in more detail the availability of data, uses of data, access to data and the high level information flows.(10) The overall aim of the survey was to identify and extract specific themes to inform the development of standards. An international review(11) of the approaches taken by other countries was conducted, which covered six countries in detail. A multi-disciplinary advisory group was convened in May 2011 which worked with the Authority on the development of draft standards. The *Draft Standards for National Health Information Resources*(12) underwent an eight-week public consultation.

The Authority will submit these standards to the Minister for Health for approval when the Health Information Bill(13) gives the Authority the legal remit to set standards for designated national health and social care data collections in Ireland and monitor compliance against these new standards. Currently the Authority's remit, outlined in the Health Act 2007, only extends to systems owned and operated by the HSE. These new statutory functions will enable the Authority to publish high level quality standards for national health and social care data collections in Ireland. Pending the publication of the Health Information Bill, the Authority has developed Guiding Principles based on the standards for national data collections.(2)

In addition, the *National Standards for Safer Better Healthcare*(14) and other standards in the area of social care developed by the Authority devote a whole section to the use of information to monitor and drive improvements in health and social care quality and safety. Promotion of local use of the data is critical to ensuring that providers take responsibility for the quality of the data they provide to the national collection.

The following is a list of publications produced by the Authority that relate to health and social care data collections:

- *Catalogue of National Health and Information Sources in Ireland (2010)*(8)
- *An International Review of Health Information Sources*(11)
- *Identification of Themes for Standards for National Health Information Sources in Ireland*(10)
- *Draft Standards for National Health Information Resources*(12)
- *What you should know about Data Quality – A guide for health and social care staff*(15)
- *What you should know about Information Governance – A guide for health and social care staff*(16)
- *Guiding Principles for National Health and Social Care Data Collections.*(2)

3.1 Aim and target audience

This document aims to enable all stakeholders (including the general public, patients and service users, clinicians, researchers, and healthcare providers) to readily access information about health and social care data collections in Ireland. By providing this information, this Catalogue should help to increase both the awareness and use of existing national health data collections in order to drive improvements in the quality and safety of our health and social care services in Ireland.

4

Methodology

All of the agencies responsible for national data collections (data providers) were contacted and requested to update the summary metadata template as outlined in Table 1 to describe their particular data collection. In addition, the full list of data elements and accompanying data dictionaries/definitions were also requested from all the relevant data providers. All of this information was reviewed and validated by the data providers.

National data collections included in this Catalogue are those that have completed and returned the summary metadata template (this includes the regional data collections and censuses). Every effort was made to contact all of the data providers that were included in the 2010 Catalogue. However, a small number of providers did not respond (n=4) and therefore the templates describing these collections have not been validated since the 2010 publication.

4.1 Metadata template

Metadata is a structured way of describing any resource such as a book, a report, or in this case, a dataset. It is sometimes referred to as 'data to describe data'. It was decided to base our template to describe the data collections on the metadata standard used in the All-Ireland Health Data Inventory.(17, 18) The use of a standardised approach meant that the information collated on the collections could be easily compared and could also potentially link in with other data inventories and information catalogues. Additional information relating to the content of each data collection was also captured (for example, the method of data collection for each data collection).

The following metadata template (see Table 1) providing a description of the field names to assist with completion of the template was sent to all data providers.

Table 1: Summary template for description of health and social care data collections

Table No.	Description
Title	Official name of the data collection/registry.
Managing Organisation	The organisation, agency, the responsible managing unit, institution or group with overall responsibility for the national data collection.
Contributor	Organisations/individuals responsible for contributing to the content of the data collection.
Subject	PHL terms and/or keywords to describe what the data collection is about.
Description/ Summary	General description of the content of the data collection.
Statement of Purpose	Purpose and objective of the data collection.
Coverage	Geographical coverage of the data collection.
Method of data collection	Describe how the data is provided to the national collection.
Data content	Summary of the type of information collected.
Data dictionary	Has a dictionary of the data items collected for the data collection been developed?
Clinical coding scheme	What clinical coding/disease classification scheme is in operation (if any)?
Accessing data	How to access data.
Date collection commenced	Date data collection was established.
Published information /update frequency	How often is the data published/updated?
Web address	Website address (URL) for the data collection.
Generic email contact	Please provide a contact email for the data collection/register.
Other comments	Please add any additional comments in relation to dataset.

4.2 Data elements and data dictionaries

The Authority requested that each of the national data collections provide either a copy of their data dictionary or a list of data elements along with their description. This data will be available from the Authority's website (www.hiqa.ie). This will increase awareness of the national data collections and will also enable better use of data by providing all stakeholders with the relevant information associated with each data collection.

A data dictionary describes the rules for the data to be recorded in a data collection. The following components are usually included: data variable name, definition of data variable, list of values for data variables, field length, source of the data, format, and instructions for completion.

A small number of data collections have published a full data dictionary for their data collection, a number of systems have one in development and many others have their data variables defined. A well-established data dictionary underpins data quality.

4.3 Identification of data collections

To identify new national collections for potential inclusion in this updated Catalogue a thorough desktop research was undertaken. This was further supported by input from key stakeholders in order to prepare an up-to-date list of the national health and social care data collections in Ireland.

National health and social care data collections were defined for the purpose of this project as national repositories of routinely collected health and social care data (including administrative data, censuses, national surveys, and patient registries) in the Republic of Ireland. An example of a national health data collection is the Hospital In-Patient Enquiry Scheme (HIPE), which collects information on discharges from acute hospitals nationally. These data collections are outlined in Section 5 of this Catalogue.

While identifying collections for potential inclusion in this Catalogue, it became evident that not all collections had national coverage. However, owing to the importance of some regional data collections of national importance, it was decided to include them in a separate section, e.g. cardiac surgery registers. These collections are outlined in Section 7 of this Catalogue.

Within this Catalogue, the Authority also categorised national censuses (e.g. Census of Population and other Population Data) and national routinely collected health surveys (e.g. The Irish Longitudinal study on Ageing – TILDA). These collections are outlined in Sections 6 and 9 of this Catalogue.

There were also a number of systems that collate data from a number of different data collections, e.g. the Public Health Information System (PHIS) managed by the Department of Health, collates data from the Hospital In-Patient Enquiry Scheme and the National Cancer Registry. These collections are outlined in Section 8 of this Catalogue.The Authority also decided to include some of the major European and international data collections to which Ireland contributes national data.

In total, 108 data collections are included in this Catalogue, sub-divided as follows:

- national data collections of health and social care in Ireland (n=74)
- national censuses (n=3)
- data collections without national coverage/regional collections (n=7)
- systems that collate data from a number of different sources (n=15)
- national surveys (n=9).

4.4 Other health and social care data collections identified

4.4.1 New data collections

Since the publication of the 2010 Catalogue there have been a number of new data collections developed, for example, the National Office of Clinical Audit (NOCA) will have five national data collections when fully established. Some national data collections have replaced older data collections in the 2010 publication, for example the Health Service Executive, Planning Performance and Business Information Unit has expanded how and what they collect to support performance reporting. The following is a list of the new data collections that were not included in the 2010 publication:

Health Protection Surveillance Centre
- Alcohol Hand Rub Consumption Monitoring
- Hand Hygiene Compliance Monitoring

Health Service Executive, Business Information Unit
- Child Protection and Welfare Services
- Disability Services
- Health and Wellbeing and Governance
- Mental Health Services
- Older People Services
- Primary Care and Social Inclusion and Palliative Care

Mater Misericordiae University Hospital
- Irish Heart Valve Bank Register
- National Spinal Injuries Unit

National Cancer Control Programme
- National Cancer Control Programme (NCCP)
- National Cancer Drug Management Programme

National Office of Clinical Audit

- Irish Audit of Surgical Mortality (IASM)*
- Irish Hip Fracture Database
- Irish National Orthopaedic Register (INOR)†
- Major Trauma Audit
- National Intensive Care Audit (ICU Audit)

National Perinatal Epidemiology Centre

- National Perinatal Epidemiology databases: Perinatal Mortality, Severe Maternal Morbidity and Homebirth Databases

4.5.2 Data collections in development

A number of national health and social care collections were identified but not included in this Catalogue either because they are still in a development stage or because it was not possible to obtain detailed information on the data collection in time for publication of this document, as follows. Data collections identified as currently in development include:

Health Protection Surveillance Centre

- Surveillance of healthcare-associated infections in Ireland

Health Service Executive

- National Stroke Register

4.5.3 Data collections no longer in operation

Since the publication of the Catalogue in 2010 a number of data collections are no longer in operation:

Enable Ireland

- South of Ireland Cerebral Palsy Register

Health Information and Quality Authority

- Census of Children's Residential Centres

Health Service Executive

- WISDOM
- Diabetes Register for Diabetic Retinopathy Screening – Mid-West, Limerick, Clare and North Tipperary

Health Protection Surveillance Centre

- MRSA in Intensive Care Units (ICU) Surveillance

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[*] Data collection has been postponed for the Irish Audit of Surgical Mortality (IASM) pending the forthcoming Health Information Bill.

[†] The National Office of Clinical Audit has indicated that the date of first data collection for the Irish National Orthopaedic Register (INOR) will be early 2014.

4.5 Document Outline

To assist in categorising the health and social care data collections in Ireland, they have been grouped into the following sub-categories in the document:

- National collections of health and social care data collections in Ireland.
- National censuses.
- Collections without national coverage/regional collections.
- Systems that collated data from a number of different data collections.
- National surveys.

The collections are listed alphabetically within each category and there is also a look-up index at the back of the document for ease of use.

The Authority has attempted to provide a comprehensive listing of the national health data collections in Ireland. However, it is possible that not all national collections were identified.

Every effort has been made to ensure that the information relating to the data collections presented here is accurate and up-to-date at time of publication.

Systems have been described as they existed in 2013.

As data collections invariably change over time, it is hoped to keep this Catalogue updated.

Part 2

Catalogue of National Health and Social Care Data Collections in Ireland

5

National Data Collections of Health and Social Care in Ireland

5.1 Alcohol Hand Rub Consumption Monitoring
5.2 Alpha One Patient Registry
5.3 Blood Donor Database
5.4 BreastCheck (The National Breast Screening Programme)
5.5 Central Treatment List (CTL)
5.6 CervicalCheck: Cervical Screening Register
5.7 Clostridium difficile enhanced surveillance
5.8 Computerised Infectious Disease Reporting (CIDR)
5.9 Cystic Fibrosis Registry of Ireland
5.10 Enhanced Bacteraemia (Bloodstream infections) Surveillance in Ireland
5.11 Fatalities and other Traffic Statistics
5.12 Hand Hygiene Compliance Monitoring
5.13 Heart Rhythm Ireland (Irish National Pacemaker Register)
5.14 HIV Antenatal Testing
5.15 Hospital In-Patient Enquiry
5.16 HSE Performance Reports – Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme
5.17 HSE Performance Reports – Child Protection and Welfare Services
5.18 HSE Performance Reports – Disability Services
5.19 HSE Performance Reports – Health and Wellbeing and Governance
5.20 HSE Performance Reports – Mental Health Services
5.21 HSE Performance Reports – Older People Services
5.22 HSE Performance Reports – Primary Care and Social Inclusion and Palliative Care
5.23 Immunisation Uptake Statistics
5.24 Irish Audit of Surgical Mortality (IASM)
5.25 Irish Biologic Therapies Register
5.26 Irish Childhood Diabetes National Register
5.27 Irish Epilepsy and Pregnancy Register
5.28 Irish Heart Valve Bank Register
5.29 Irish Hip Fracture Database
5.30 Irish Motor Neurone Disease Register
5.31 Irish National Orthopaedic Register (INOR)
5.32 Irish Unrelated Bone Marrow Registry (IUBMR)
5.33 Major Trauma Audit (MTA)
5.34 MHC – Admissions of Children to Approved Centres
5.35 MHC – Deaths relating to all residents in Approved Centres
5.36 MHC – Involuntary Admission Activity
5.37 MHC – Administration of Electro-convulsive Therapy (ECT) in approved centres

5.38 MHC – Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres
5.39 National Adverse Event Management System (NAEMS)
5.40 National Antimicrobial Resistance Surveillance
5.41 National Cancer Control Programme (NCCP)
5.42 National Cancer Drug Management Programme
5.43 National Cancer Registry Ireland
5.44 National Cleft Database
5.45 National Drug-Related Deaths Index (NDRDI)
5.46 National Drug Treatment Reporting System (NDTRS)
5.47 National Haemophilia Register
5.48 National Health Schemes Data (Primary Care Reimbursement Service)
5.49 National Hepatitis C Database
5.50 National Intellectual Disability Database (NIDD)
5.51 National Intensive Care Audit (ICU Audit)
5.52 National Organ Procurement Service Statistics
5.53 National Paediatric Haemopoietic Stem Cell Transplantation
5.54 National Paediatric Mortality Register
5.55 National Perinatal Epidemiology databases: Perinatal Mortality, Severe Maternal Morbidity and Homebirth Databases
5.56 National Perinatal Reporting System
5.57 National Physical and Sensory Disability Database (NPSDD)
5.58 National Poisons Information Centre Database
5.59 National Psychiatric Inpatient Reporting System (NPIRS)
5.60 National Registry of Deliberate Self Harm Ireland
5.61 National Renal Transplant Registry
5.62 National Spinal Injuries Unit
5.63 NHS Blood and Transplant Audit UK & Ireland
5.64 Out of Hospital Cardiac Arrest Register (OHCAR)
5.65 Patient Treatment Register (PTR)
5.66 PHECC – Cardiac First Response Report (CFRR)
5.67 PHECC – Patient Care Report (PCR)
5.68 PHECC – Patient Transport Report (PTR)
5.69 Sentinel Flu Surveillance
5.70 Surveillance of antimicrobial consumption in Ireland
5.71 Vital Statistics – Deaths Registration
5.72 Vital Statistics – Live Births Registration
5.73 Work Related Injuries Database
5.74 Workplace Fatalities Database

Table 5.1	**Alcohol Hand Rub Consumption Monitoring**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	All acute hospitals, infection prevention and control staff, pharmacists, stores managers
Subject	Keywords: alcohol hand rub, hand hygiene, infection control, surveillance
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 published quarterly.
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.
Coverage	38 acute facilities contributed to the data in quarter 1 2013
Method of data collection	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. HPSC provide rates in litres per 1000 bed-days used.
Data content	Completed MS Excel sheet of products used, quantity and any additional information.
Data dictionary	No
Clinical Coding Scheme	N/A
Accessing data	HPSC website
Date collection commenced	2006
Published information/ Update frequency	Standalone quarterly reports; annual reports
Wed address	http://www.hpsc.ie/hpsc/A-Z/Gastroenteric/Handwashing/HandHygieneAudit/
Generic email contact	hpsc@hse.ie
Other comments	Data can represent amount dispensed (pharmacy data) or amount purchased (stores data).

Table 5.2	**Alpha One Foundation Registry**
Managing Organisation	Alpha One Foundation
Contributor	Persons with Alpha-1 Antitrypsin Deficiency (AATD) attending the National Alpha-1 Clinic in Beaumont Hospital
Subject	PHL terms: DEMOGRAPHIC DATA, GENETIC DIAGNOSIS, CLINICAL DATA, CLINICAL TRIALS Keywords: Alpha 1 Antitrypsin (AAT), patient registry
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 trends, design clinical trials to test new therapies and improve the delivery of care for people with AATD.
Statement of Purpose	The purpose of the register is to: ■ 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.
Coverage	National – all Alpha-1 patients attending National Alpha-1 Clinic in Beaumont Hospital
Method of data collection	Data is collected in the National Alpha-1 Clinic 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.
Data content	Height, weight, gender, genotype, pulmonary function test results, liver function tests, hospitalisations, and complications related to lung and liver manifestations of AATD
Data dictionary	No

Clinical Coding Scheme	No coding system is used
Accessing data	Annual report and data request
Date collection commenced	Data collection commenced in 2005
Published information/ Update frequency	Data is published in the Alpha One Foundation annual report.
Web address	http://alpharegistry.alphaonefoundation.eu/
Generic email contact	alpha1@rcsi.ie
Other comments	

Table 5.3	Blood Donor Database
Managing Organisation	Irish Blood Transfusion Service (IBTS)
Contributor	Blood Donor Clinics in Ireland
Subject	PHL terms: BLOOD TRANSFUSION, DONOR
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 also used for analysis of the blood donor population. The IBTS also publishes information on the current blood supply available for donation in Ireland.
Statement of Purpose	To maintain a computerised donor database on individuals who donate blood.
Coverage	National – all who attend a blood donation clinic are required to register with the IBTS.
Method of data collection	All donors are required to register with the IBTS, when they present at a donation clinic, and fill out a health and lifestyle questionnaire.
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
Clinical Coding Scheme	Not applicable
Accessing data	Annual reports. Blood supply levels are available on the IBTS website.
Date collection commenced	Data collection commenced when the Blood Transfusion Service Board came into existence in 1965 and absorbed the Cork Blood Transfusion Service in 1975 and the Limerick Blood Transfusion Service in 1991. In 2000 the name of the organisation was changed to the Irish Blood Transfusion Service (IBTS).
Published information/ Update frequency	Annual reports
Web address	http://www.giveblood.ie
Generic email contact	clinics@ibts.ie info@ibts.ie
Other comments	

Table 5.4	**BreastCheck (The National Breast Screening Programme)**
Managing Organisation	National Cancer Screening Service
Contributor	In order to identify the target population for screening, data is supplied by the Department of Social Protection, General Medical Services, private health insurance providers and also self-registration by women. Clinical data is collected on individuals that receive a service, which is provided by clinicians and entered by data officers.
Subject	PHL terms: BREAST CANCER, SCREENING, WOMEN
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 (aged 50 to 64 years) 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, General Medical Services and private health insurance providers. BreastCheck is allowed to source this information under The Health (Provision of Information Act) 1997.
Statement of Purpose	BreastCheck is a Government-funded programme providing breast screening and invites women aged 50 to 64 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	National – women aged 50-64
Method of data collection	Monthly upload of files received from each of the providers. There is also a BreastCheck website facility for self-registration by women. External agency carries out a de-duplication process every month.

Data content	Client data information; 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	Yes
Clinical Coding Scheme	Not used
Accessing data	Programme report – hard-copy and published online
Date collection commenced	The programme was rolled out in 2000 in 3 health board regions (Eastern Regional Health Authority, North Eastern Health Board and Midland Health Board), in 2005 there was partial expansion, and by 2007 the programme was national.
Published information/ Update frequency	Annual
Web address	http://www.breastcheck.ie
Generic email contact	info@cancerscreening.ie
Other comments	Maintenance of the population register is by an external data management company.

Table 5.5	Central Treatment List (CTL)
Managing Organisation	HSE National Drug Treatment Centre
Contributor	Prescribing doctors
Subject	PHL terms: DRUGS MISUSE Keywords: methadone, opiate, treatment
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 problem 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.
Statement of Purpose	To regulate the dispensing of methadone treatment in Ireland.
Coverage	National – all Clients prescribed methadone within Ireland
Method of data collection	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.
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
Clinical Coding Scheme	Not applicable
Accessing data	Access to data only by staff operating the CTL
Date collection commenced	1st October 1998
Published information/ Update 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.

Web address	http://www.addictionireland.ie
Generic email contact	ctl@dtcb.ie
Other comments	The Central Treatment List 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.

Table 5.6	**CervicalCheck: Cervical Screening Register**
Managing Organisation	National Cancer Screening Service
Contributor	In order to identify the target population for screening, data is supplied by the Department of Social Protection and self referral. Laboratory data is provided by colposcopy clinics and cytology and histology laboratories. Clinical data is provided by general practitioners, practice nurses and clinicians in hospitals.
Subject	PHL terms: CERVICAL SCREENING, REGISTER
Description/ Summary	CervicalCheck maintains a population register containing demographic data of eligible women for the purposes of screening. The screening interval for women aged 25 to 44 is three years and for women aged 45 to 60 years is five years. It also contains clinical data so that women who have had smear tests can be contacted for follow-up treatments and clinical referral recommendations.
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 smear tests can be contacted for follow-up treatments and clinical referral recommendations.
Coverage	National – women aged 25-60 years
Method of data collection	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 (cytology, and colposcopy data – with histology data due to be online shortly) 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.

Data content	Date of birth; forename; surname at birth; mother's maiden name; PPS number; middle names; address; phone number. To maintain confidentiality, each woman has a unique identification number on the register, known as the Cervical Screening Programme ID (CSP ID). Cytology, colposcopy and histology clinical data in relation to a woman's smear test and any follow up treatment is also captured.
Data dictionary	Not available
Clinical Coding Scheme	SNOMED coding for histology results
Accessing data	Programme report
Date collection commenced	2000 - Phase 1 of ICSP (Irish Cervical Screening Programme) established in the Mid Western Health Board Region. National programme in September 2008.
Published information/ Update frequency	Annual report
Web address	http://www.cervicalcheck.ie
Generic email contact	info@cancerscreening.ie
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 captured for each event for a woman.

Table 5.7	**Clostridium difficile Enhanced Surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	Consultant microbiologists, infection prevention and control staff
Subject	Keywords: Clostridium difficile, infection control, surveillance
Description/ Summary	Clostridium difficile infection (CDI), also known as CDAD, has been a notifiable disease since May 2008. All new cases of CDI that meet the case definition are notifiable under 'acute infectious gastroenteritis (AIG)' and reported through CIDR (Computerised Infectious Disease Reporting). However since August 1st 2009 the 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.
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.
Coverage	Participation of hospitals is voluntary. Since the project has only begun since 2009 it is too early to estimate the number of participants.
Method of data collection	Participating ICUs email their data monthly using an Excel spreadsheet. Data is encrypted.
Data content	Age, sex, hospital admission, type of CDAD case (new/ recurrent), location of onset of infection (healthcare/community), origin of infection (healthcare-associated or community-associated), severity of illness
Data dictionary	Not available
Clinical Coding Scheme	Not in use
Accessing data	Quarterly feedback to participants; annual reports
Date collection commenced	2009
Published information/ Update frequency	Annual reports

Web address	http://www.hpsc.ie/hpsc/A-Z/Gastroenteric/Clostridiumdifficile/CdifficileEnhancedSurveillance/
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.8	**Computerised Infectious Disease Reporting (CIDR)**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	HSE, Health Protection Surveillance Centre, Food Safety Authority of Ireland, the Food Safety Promotion Board and the Department of Health
Subject	PHL terms: COMMUNICABLE DISEASE, MONITORING, INFORMATION SYSTEM
Description/ Summary	CIDR is an information system developed to manage the surveillance and control of infectious diseases in Ireland. It also monitors organisms' ability to resist antibiotic drugs (antimicrobial resistance). Infectious disease outbreak data is also collected in CIDR together with enhanced surveillance data for many infectious diseases. There are currently over 80 notifiable diseases, covering areas such as: ▪ vaccine-preventable diseases, ▪ respiratory and direct contact diseases, ▪ infectious intestinal diseases, ▪ vectorborne and zoonotic diseases, ▪ bloodborne and sexually transmitted infections and ▪ healthcare associated infections. The full list of notifiable diseases can be found at www.hpsc.ie. All notifiable diseases/pathogens with the exceptions of *S. aureus* (EARSS organism), *Enterococcus* species (EARSS organism), Ano-genital Warts and Non-specific urethritis are collected by CIDR. S.I. No. 452/2011 – Infectious Diseases (Amendment) Regulations 2011- http://www.irishstatutebook.ie/2011/en/si/0452.html
Statement of Purpose	HPSC uses CIDR together with other systems to provide the best possible information for the control and prevention of infectious diseases.
Coverage	National – Departments of Public Health, Microbiology Laboratories, Reference Laboratories, HPSC

Method of data collection	CIDR is a web-based system with all information held in a single shared national information repository. Information from laboratories is entered electronically or manually into CIDR by laboratory scientists/microbiologists. This information is then linked to clinical and epidemiological information provided by public health professionals.
Data content	Minimum core data sets: Patient: surname, disease, Health Board, County Clinical notification: date of notification, Health Board, County Laboratory report: lab name, lab specimen ID, reported date, organism, patient surname, patient health board, patient county, lab notifier Event: disease and interpreted overall lab result, Health Board, County Outbreak: disease, health board, County, outbreak type Additional core data items and enhanced data items varying by disease are collected as available, including lab test results and antibiotic sensitivity test results.
Data dictionary	No - core data elements were based on a National General Practice Information Technology (GPIT) demographic data set developed in 1999.
Clinical Coding Scheme	Predominantly based on ECDC case definitions. http://www.hpsc.ie/hpsc/NotifiableDiseases/CaseDefinitions/File,823,en.pdf http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2008:159:0046:01:EN:HTML
Accessing data	Users can access data according to role and location as laid out in the CIDR National Business Rules policy (v2). On-demand reports are provided for CIDR users. Weekly and annual reports for the public are published on the HPSC website.
Date collection commenced	Pilot phase – 2004; National implementation began in 2005
Published information/ Update frequency	Weekly and annual reports produced and published on HPSC public website at http://www.hpsc.ie/hpsc/NotifiableDiseases
Web address	http://www.hpsc.ie/hpsc/CIDR
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.9	**Cystic Fibrosis Registry of Ireland**
Managing Organisation	Cystic Fibrosis Registry of Ireland
Contributor	Irish hospitals that provide care to Cystic Fibrosis (CF) patients
Subject	Keywords: cystic fibrosis, patient register, demographic data, genotype data, diagnosis, pulmonary function, hospitalisations
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.
Statement of Purpose	The Cystic Fibrosis Registry of Ireland 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. Aims and Objectives Registry Process: ▪ 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.

	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. Planning and Management: ■ To assist in the planning and management of health services and essential resources for people with CF. 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, the Cystic Fibrosis Association of 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 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	Republic of Ireland – all hospitals/centres/clinics offering primary and shared care to CF patients. Voluntary participation.
Method of data collection	Participation is voluntary; enrolment is based on patient consent to have their medical record details added to the registry. Data is taken from patient medical charts by registry staff and input takes place on a secure internet based computer system.
Data content	Name and address, date of birth, HSE area, ethnicity, name of consultant and family doctor, diagnostic tests, genotype, symptoms/method of diagnosis, age at diagnosis, number of hospitalisations between annual assessments, complications, pulmonary function tests, chest X-ray reports, clinical chemistry, long term therapies, vaccinations/immunisations, infections, cultures and treatments, nutritional summary, physiotherapy summary, transplant status, social details such as number of days off work or school in previous 12 months.

Data dictionary	Yes
Clinical Coding Scheme	Not used
Accessing data	Annual report. CF consultant/team access to own patient data via secure internet access. Researcher access to anonymised data via a management approval process.
Date collection commenced	2001
Published information/ Update frequency	Annual reports
Web address	http://www.cfri.ie/index.php
Generic email contact	cfr@ucd.ie
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.

Table 5.10 Enhanced Bacteraemia (Bloodstream Infections) Surveillance in Ireland

Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	All acute hospitals
Subject	Keywords: health protection, communicable disease, infection control
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.
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.
Coverage	Voluntary participation (9 laboratories reported in 2012, accounting for 35% of EARS-Net isolates)
Method of data collection	In Ireland, the system was enhanced to gather additional information including patient risk factors, sources of infection and patient outcome.
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
Clinical Coding Scheme	Not applicable
Accessing data	Annual reports on website
Date collection commenced	2004
Published information/ Update frequency	Annual reports

Web address	http://www.hpsc.ie
Generic email contact	hpsc@hse.ie
Other comments	Dataset is currently being revised, to promote a higher level of participation. Revised dataset is due to be in place by quarter 1 2014.

Table 5.11	**Fatalities and other Traffic Statistics**
Managing Organisation	Garda National Traffic Bureau
Contributor	Garda National Traffic Bureau, Garda Síochána
Subject	Keywords: traffic fatalities, collisions, road, Garda
Description/ Summary	The number of road users killed on Irish roads, updated daily.
Statement of Purpose	To collect data on the number of road users killed on Irish roads.
Coverage	National – the number of road users killed in Ireland
Method of data collection	Electronic – CT68 forms are completed on the Garda PULSE computer system and paper copies of the forms are also generated and sent from the 108 Garda Districts to the Road Safety Authority (RSA). RSA also receives an annual data of all collision data from the PULSE system. These forms are validated individually and geo-referenced.
Data content	Collision location, details of vehicles involved, details of person involved, road surface, weather, injury severity, date and time of collision, driver information and other information such as possible collision causes.
Data dictionary	Yes
Clinical Coding Scheme	Not applicable
Accessing data	Report on "Daily Fatalities and other Traffic Statistics" can be accessed on Garda.ie website. Annual RSA Road Collision Facts Reports on RSA.ie website.
Date collection commenced	1959 (the electronic version commenced in 2001)
Published information/ Update frequency	On Garda.ie website – "Daily Fatalities and other Traffic Statistics" available Summary data for the year up to the current date. Monthly comparisons available from 2001 – 2008 On rsa.ie website Annual RSA Road Collision Facts Reports/Analysis of collision data

Web address	http://www.garda.ie and www.rsa.ie
Generic email contact	Not provided
Other comments	

Table 5.12	**Hand Hygiene Compliance Monitoring**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	All acute hospitals, infection prevention and control staff
Subject	Keywords: hand hygiene, infection control, surveillance, healthcare workers
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 and the results published.
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.
Coverage	43 public and nine private acute facilities contributed to the data in July 2013.
Method of data collection	Trained, infection and control staff conduct hospital-wide audits of hand hygiene compliance by the facility's own healthcare workers. Twice yearly national audits are conducted, of 7 wards per facility with 30 opportunities per each ward audited. Automated data upload, analysis, report generation and approval for publication facilitated via HPSC's online tool, MicroB.
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	No
Clinical Coding Scheme	N/A
Accessing data	HPSC website
Date collection commenced	2011
Published information/ Update frequency	Standalone twice yearly reports; Annual reports; Epi-Insight articles
Wed address	http://www.hpsc.ie/hpsc/A-Z/Gastroenteric/Handwashing/HandHygieneAudit/
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.13	**Heart Rhythm Ireland (Irish National Pacemaker Register)**
Managing Organisation	G-Pace Ltd
Contributor	All hospitals which manage and treat patients with pacemaker and Implantable Cardioverter Defibrillator (ICD) implants and follow-ups.
Subject	Keywords: pacemaker, ICD, national database, patient ID card
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.
Statement of Purpose	To provide a registry for implanted cardiac devices in Ireland.
Coverage	24 Hospitals, 25,000 Patients
Method of data collection	Data is collected electronically at the point of care and entered by clinical staff in the participating hospitals.
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	Yes for internal use – not publicly available
Clinical Coding Scheme	No
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.
Date collection commenced	The database was created in February 2008. The first patient record was logged in September 2008.
Published information/ Update frequency	Data not currently published. Data entered on a daily basis, as devices are implanted.
Web address	www.heartrhythmireland.com
Generic email contact	info@heartrhythmireland.com
Other comments	

Table 5.14	HIV Antenatal Testing
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	Maternity hospitals/units; Departments of Public Health
Subject	PHL terms: COMMUNICABLE DISEASES, HIV INFECTION, ANTENATAL
Description/ Summary	Antenatal HIV testing for pregnant women. In April 1999, the then 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.
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.
Coverage	Voluntary participation – 20 hospitals participating
Method of data collection	Data are collected on a quarterly 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.
Data content	Number of women seen, number offered testing, number accepted testing, number positive, number new positive.
Data dictionary	Not available
Clinical Coding Scheme	Not used
Accessing data	Annual reports available on HPSC website
Date collection commenced	2002
Published information/ Update frequency	Reports on the Antenatal HIV programme are published annually
Wed address	http://www.hpsc.ie/hpsc/A-Z/HepatitisHIVAIDSandSTIs/HIVandAIDS/AntenatalHIVTesting/Publications/
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.15	Hospital In-Patient Enquiry
Managing Organisation	With effect from January 1, 2014, the Healthcare Pricing Office (HPO) will have responsibility for the Hospital In-Patient Enquiry (HIPE) scheme. While the HPO will initially be established on an administrative basis, it is planned that this Office will ultimately be established on a statutory basis.
Contributor	Irish public hospitals
Subject	PHL terms: DEMOGRAPHIC DATA, HOSPITAL DISCHARGE, IN-PATIENT SERVICES
Description/ Summary	HIPE is the principal source of national data on discharges from acute hospitals in Ireland.
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.
Coverage	All acute public hospitals participate in HIPE.
Method of data collection	Data is taken from medical charts or records and coded by trained clinical coders before entering into HIPE system (HIPE Portal).
Data content	HIPE collects demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally.
Data dictionary	Yes – full data dictionary published on HPO website. www.hpo.ie
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), 6th Edition.
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.

Date collection commenced	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 Health Service Executive. From January 1, 2014 the scheme is managed by the HPO (www.hpo.ie).
Published information/ Update frequency	*Activity in Acute Public Hospitals in Ireland* annual reports are available on the HPO website, www.hpo.ie.
Web address	www.hpo.ie
Generic email contact	info@hpo.ie
Other comments	Data Quality is a central task critical to the work of HIPE departments in hospitals and also at the HPO. Coder training, data quality initiatives and the HPO designed and developed software (including the Checker, HIPE Portal inbuilt data entry edits and HIPE Coding Audit Toolkit - HCAT) ensure that data are being constantly reviewed.

Table 5.16	**HSE Performance Reports – Acute Hospitals including Clinical Programmes, National Ambulance Service and National Cancer Control Programme**
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	All acute hospitals
Subject	Keywords: acute, activity, inpatient discharges, day cases, emergency presentations, inpatient admissions, bed utilisation, births, beds
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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/corporate/performancereports/Acutemetadata13.pdf 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: ▪ percentage of all patients arriving by ambulance wait <20mins for handover to doctor/nurse, surgical patient (corrected) average length of stay; ▪ percentage of emergency re-admissions for acute medical conditions to the same hospital within 28 days of discharge.
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	All acute hospitals

Method of data collection	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 monthly basis via email. Data is input on an excel workbook. Data is also sourced from national data collections such as the National Stroke Register, Hospital In Patient Enquiry and PHECC.
Data content	Data on acute hospital activity
Data dictionary	See metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports/Acutemetadata13.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Information is published in performance reports each month
Date collection commenced	National collection of this data began in January 2006
Published information/ Update frequency	Information is published in Performance Assurance Reports and Management Data Reports each month, this is based on KPIs as set out in the National Service Plan.
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	acutebiu@hse.ie
Other comments	

Table 5.17	**HSE Performance Reports – Child Protection and Welfare Services**
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	All 32 Local Health Offices via Child Care Information Officers
Subject	Keywords: child protection, children in care, activity data
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 child protection and welfare services. The full list of these metrics/ indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Child%20Protection%20and%20Welfare%20Services.pdf. Items such as child abuse, child welfare, residential and foster care are included as indicators. Example of an indicator include: ▪ percentage of referrals of child welfare concerns received during the reporting period where a preliminary enquiry (National Intake Form) was completed within 24 hours of receipt of the referral; ▪ percentage of initial assessments which led to the child being listed on the Child Protection Notification System (CPNS).
Statement of Purpose	To monitor and measure children protection and welfare services and report on activity against National Service Plan.
Coverage	All 32 Local Health Offices

Method of data collection	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 monthly basis via email. For the majority of the data to support these indicators is submitted from the Local Health Office via Child Care Information Officers to the Business Information Unit and is reported on to the relevant personnel in the HSE. Some of the indicators are published in the Performance Report and/or in the Management Data Report. Data is also sourced from national data collections such as State of Nations Children.
Data content	Data on child abuse, child welfare, residential and foster care
Data dictionary	See Metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Child%20Protection%20and%20Welfare%20Services.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly Performance Assurance and Management Data reports, annual reports, data requests
Date collection commenced	1999
Published information/ Update frequency	Data appears in monthly Performance Assurance Report or Management Data Report
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.18	HSE Performance Reports – Disability Services
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	Disability services are delivered by both the HSE and HSE non statutory partners.
Subject	Keywords: disability, physical and sensory disability, intellectual disability, day care, respite, residential care, congregated settings, personal assistant, home support services, disability act.
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 disability services. The full list of these metrics/indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Disability.pdf. Items such as day services, respite services, home support are included as indicators. Examples of an indicator include: ■ total number of home support hours delivered to adults and children with an intellectual disability and/or Autism; ■ number of persons with an intellectual disability and/or autism benefiting from work/work-like activity services.
Statement of Purpose	To monitor activity against targets in relation to HSE funded service provision for persons with a physical and or sensory disability or an intellectual disability.
Coverage	All providers of HSE funded disability services.

Method of data collection	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 monthly basis via email. Data in relation to Rehab Training Places comes from the Occupational Guidance Database (OGS). 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 Intellectual Disability Database (NIDD) and the National Physical and Sensory Database (NPSD). These databases are managed by the Health Research Board.
Data content	Activity in relation to disability services provision.
Data dictionary	See Metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Disability.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly/Quarterly Performance Assurance and monthly data reports, annual reports, data requests
Date collection commenced	2013
Published information/ Update frequency	Rolled up data appears in monthly Performance Assurance Report and Management Data Report published on www.hse.ie
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.19	**HSE Performance Reports – Health and Wellbeing and Governance**
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	Local Health Officers, Health Service Executive, Public Health Doctors
Subject	Keywords: health, wellbeing, child health development screening, tobacco control, food safety, health inequalities, Immunisation and vaccines, healthcare associated infections.
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 Health and Wellbeing and Governance. The full list of these metrics/ indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Health%20and%20Wellbeing.pdf. Items such as child health development screening, tobacco control, food safety, health inequalities, Immunisation and vaccines and healthcare associated infections are included as indicators. Examples of an indicator include: ■ rate of MRSA bloodstream infections in acute hospitals per 1,000 bed days used; ■ percentage of children at 12 months of age who have received two doses of the Meningococcal group C vaccine (Men C2).
Statement of Purpose	To monitor and measure provision of service for health and wellbeing and governance and report on activity against National Service Plan.
Coverage	National

Method of data collection	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 monthly basis via email. Data is also sources from national data collections such as the Health Protection Surveillance Centre
Data content	Data on health, wellbeing, child health development screening, tobacco control, food safety, health inequalities, immunisation and vaccines, healthcare associated infections.
Data dictionary	See metadata: http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Health%20and%20Wellbeing.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly Performance Assurance and Management Data Reports, annual reports, data requests.
Date collection commenced	
Published information/ Update frequency	Data appears in monthly Performance Assurance and Management Data Reports.
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.20	HSE Performance Reports – Mental Health Services
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	Health Research Board, all mental health admissions
Subject	Keywords: mental health, general adult mental health, psychiatry of old age, community child and adolescent mental health, child and adolescent mental health
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 mental health services. The full list of these metrics/indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Mental%20Health.pdf. Items such general adult mental health, psychiatry of old age, community child and adolescent mental health, child and adolescent mental health are included as indicators. Examples of an indicator include: ▪ number of adult involuntary admissions; ▪ number of referrals (including re-referred) received by General Adult Mental Health Team
Statement of Purpose	To gain information on mental health activity to support the monitoring and evaluating of trends over time per area/region and across the service nationally.
Coverage	National

Method of data collection	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 monthly basis via email. Data is also sources from national data collections such as Mental Health Commission and National Psychiatric Inpatient Reporting System.
Data content	Data on mental health admissions.
Data dictionary	See Metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Mental%20Health.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly Performance Assurance and Management Data Reports, annual reports, data requests
Date collection commenced	2009
Published information/ Update frequency	Rolled up data appears in monthly Performance Assurance and Management Data Reports.
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.21	HSE Performance Reports – Older People Services
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	All 32 Local Health Offices
Subject	Keywords: older persons, activity data
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 older people. The full list of these metrics/indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports /KPI%202013%20Older%20 People.pdf. Items such as home care package activity; elder abuse; subvention activity are included as indicators. Examples of an indicator include: ▪ total number of Home Care Packages provided; ▪ total number of home help hours provided for all care groups, (excluding provision of hours from Home Care Packages). For the majority of the data to support these indicators is submitted from the Local Health Office to the Business Information Unit and is reported on to the relevant personnel in the HSE. Some of the indicators are published in the Performance Report and/or in the Management Data Report.
Statement of Purpose	To monitor and measure provision of service for older people and report on activity against National Service Plan.
Coverage	All 32 Local Health Offices

Method of data collection	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 monthly basis via email. For the majority of the data to support these indicators is submitted from the Local Health Office to the Business Information Unit and is reported on to the relevant personnel in the HSE. Some of the indicators are published in the Performance Report and/or in the Management Data Report.
Data content	Data on home help activity in the community; home care package activity in the Community; subvention and contract bed activity in the community.
Data dictionary	See Metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports /KPI%202013%20Older%20People.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly Performance Assurance and Management Data Reports, annual reports, data requests
Date collection commenced	2006
Published information/ Update frequency	Data appears in monthly Performance Assurance Report or Management Data Report
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.22	HSE Performance Reports – Primary Care and Social Inclusion and Palliative Care
Managing Organisation	HSE - Planning, Performance and Business Information Unit
Contributor	Physiotherapists and Occupational Therapists in each Local Health Office, Co-Ops in each of the four HSE Regions (Dublin Mid-Leinster, Dublin North East, West and South), Orthodontic services, Primary Care Division
Subject	Keywords: primary care, physiotherapists, occupational therapists
Description/ Summary	The Planning, Performance and Business Information 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 2013 and the HSE Operational Plan 2013. The performance report is used by the Performance Monitoring and Control committee (PMCC), the 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 Primary Care and Social Inclusion and Palliative Care. The full list of these metrics/indicators can be found on the HSE website: http://www.hse.ie/eng/services/Publications/corporate/performancereports/ KPI%202013%20Primary%20Care.pdf. Items such as primary care, GP out of hour's service, physiotherapy referral, occupational therapy, orthodontics, methadone treatment, substance misuse, homeless service and traveller health screening are included as indicators. Examples of an indicator include: ■ number of PCTs implementing the National Integrated Care Package for Diabetes (dependent on the appointment of the ICDNs); ■ number of patients for whom a primary care physiotherapy referral was received in the reporting month.
Statement of Purpose	To monitor and measure Primary Care and Social Inclusion and Palliative Care services and report on activity against National Service Plan.

Coverage	All 32 Local Health Offices and all 9 Co-Ops
Method of data collection	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 monthly basis via email.
Data content	Data on physiotherapy, occupational therapy, GP out of office hours, orthodontics, primary care.
Data dictionary	See Metadata; http://www.hse.ie/eng/services/Publications/corporate/performancereports/KPI%202013%20Primary%20Care.pdf
Clinical Coding Scheme	Not applicable
Accessing data	Monthly Performance Assurance and Management Data Reports, annual reports, data requests
Date collection commenced	2006
Published information/ Update frequency	Data appears in monthly Performance Assurance Report or Management Data Report
Web address	http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Generic email contact	nonacutebiu@hse.ie
Other comments	

Table 5.23	**Immunisation Uptake Statistics**
Managing Organisation	HSE – Health Protection Surveillance Centre (HPSC)
Contributor	Local Health Offices and HSE areas
Subject	PHL terms: IMMUNISATION
Description/ Summary	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 three doses of vaccines against diphtheria, pertussis, tetanus, *Haemophilus influenzae* type b, polio and meningococcal group C, one dose of BCG vaccine (BCG uptake at 12 months only), one booster dose of vaccine against *Haemophilus influenzae* type b after 12 months of age (Hib uptake at 24 months only) and one dose of vaccine against measles, mumps and rubella (MMR1 uptake at 24 months only). HPSC collates the national immunisation uptake data and produces quarterly and annual reports which are available on the HPSC website.
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.
Coverage	Children 12 months of age; children 24 months of age
Method of data collection	Immunisation uptake data are requested from 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.
Data content	Number eligible for immunisation with each vaccine/antigen; number immunised with each vaccine/antigen; % uptake for each vaccine/antigen.
Data dictionary	Not available
Clinical Coding Scheme	Not applicable
Accessing data	Summary figures are published on HPSC website
Date collection commenced	2000

Published information/ Update frequency	Quarterly reports published
Web address	http://www.hpsc.ie
Generic email contact	hpsc@hse.ie
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. It also provides up-to-date information leaflets for parents and health-care professionals. It hosts a website www.immunisation.ie and is developing a national IT register for immunisations. The 2008 Immunisation Guidelines are available at http://www.immunisation.ie and on HPSC website.

Table 5.24	Irish Audit of Surgical Mortality (IASM)
Managing Organisation	National Office of Clinical Audit (NOCA), under Service Legal Agreement (SLG) between Royal College of Surgeons in Ireland and the Quality and Patient Safety Directorate of the Health Service Executive
Contributor	Consultant surgeons and anaesthetists from both public and independent hospitals in Ireland.
Subject	Keywords: In-hospital surgical deaths; clinician data; surgical pathway; peer review audit; areas of concern or for consideration; quality of surgical care.
Description/ Summary	Irish Audit of Surgical Mortality (IASM) will provide confidential, independent, peer review of all reported deaths which occur following an episode of surgical care. Surgeons and anaesthetists practicing in both public and private hospitals in Ireland will be encouraged to report all deaths under their care through the IASM portal. Participation in IASM by clinicians is on a voluntary basis currently. Objectives of IASM: ■ to increase surgical patient safety in all Irish hospitals, public and independent; ■ to promote a culture of transparency around surgical and anaesthetic practice; ■ to increase public confidence in surgical service provision; ■ to ensure that systems failures in surgical care in Irish hospitals are proactively identified and resolved; ■ to identify potentially preventable factors associated with surgical deaths and ensure personal and organisational learning occurs through relevant peer review and support; ■ to reduce surgical mortality levels in Irish hospitals; ■ to provide feedback to clinicians and hospitals on all deaths reported; ■ to enable comparison of data with similar international audits associated with surgical mortality; ■ to publish an annual report which can contribute to surgical practice improvement nationally and internationally; ■ to provide valid and effective clinical audit pursuant of agreed Professional Competence Schemes of the Royal College of Surgeons in Ireland and the College of Anaesthetists in Ireland and their Members; ■ to contribute to international knowledge around surgical mortality audit, through discussion papers initially, in peer-reviewed healthcare journals to highlight the work IASM.

Statement of Purpose	Through systematic peer review of deaths associated with surgical care, IASM aims to reduce surgical mortality in Ireland, thereby ensuring that Irish patients receive surgical care of the highest possible standard.
Coverage	National audit with data collection from all public and independent hospitals.
Method of data collection	The IASM on-line reporting system will be hosted on a secure database managed and accessed by NOCA (www.iasm.ie), supported by the IT Department of the RCSI. ■ The site will be firewalled and will have no overlap with any other RCSI databases. ■ IASM will be open to all surgeons and anaesthetists nationally who practice in public and independent facilities and are registered with the Medical Council.
Data content	Clinician details; hospital details; admission details; care pathway details; comorbidities; other specialty involvement; diagnostic details; surgery details; clinical interventions; details of death; areas of concern or for consideration relating to care provision; peer review findings; hospital response to findings.
Data dictionary	User manual for participants and reviewers will be available on website. Data dictionary not applicable
Clinical Coding Scheme	Not applicable
Accessing data	IASM Annual reports as agreed by IASM Governance Committee and NOCA Governance Board and subsequently issued by NOCA
Date collection commenced	Data collection to commence in 2014
Published information/ Update frequency	Reports to be published annually once data collection has commenced
Web address	http://www.noca.ie
Generic email contact	Not provided
Other comments	The IASM online reporting system is ready for data collection at present. A Governance Committee comprised of all relevant stakeholders has been formed, and clinicians throughout Ireland are engaged in the process. However data collection has been postponed pending the forthcoming Health Information Bill which will offer protection to clinical audit activities and participants.

Table 5.25	**Irish Biologic Therapies Register***
Managing Organisation	Rheumatology Department, St. Vincent's University Hospital (SVUH)
Contributor	The medical team and nursing staff of the Rheumatology Department of St. Vincent's University Hospital.
Subject	Keywords: rheumatology
Description/ Summary	This register collects data on all patients attending the Rheumatology service who receive biologic therapies (predominantly anti-TNF therapies).
Statement of Purpose	To collect data on all patients attending the Rheumatology service who receive biologic therapies (predominantly anti-TNF therapies).
Coverage	Patients who attend the rheumatology department and receive biological therapies at St. Vincent's University Hospital.
Method of data collection	Data is entered in real time in the clinic by clinicians and afterwards from a questionnaire completed by patients who have attended the clinic.
Data content	Demographics, clinical data, treatment, outcome measures
Data dictionary	Yes
Clinical Coding Scheme	No
Accessing data	Data submitted to European League Against Rheumatism (EULAR) and Annals of Rheumatic Disease.
Date collection commenced	2004
Published information/ Update frequency	Annual
Web address	Not provided
Generic email contact	Not provided
Other comments	

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* Information relating to the Irish Biologic Therapies Register was last updated for the 2010 publication of the Catalogue.

Table 5.26	Irish Childhood Diabetes National Register (ICDNR)
Managing Organisation	Tallaght Hospital and Trinity College Dublin
Contributor	20 participating centres nationally
Subject	PHL terms: DIABETES MELLITUS, CHILD HEALTH Keywords: Type 1 diabetes, incidence, childhood
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 2003 database on the Tallaght Hospital server.
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	20 participating centres nationally
Method of data collection	Data is collected at the point of care by local paediatric consultants/endocrinologists and diabetes nurse specialists. Data entered on proforma data sheets and centrally entered onto the register.
Data content	Paper form only – name and address. Database – unique register ID; location (urban/rural); date of birth; gender; date of diagnosis; date of first Insulin Injection; hospital at which diagnosis was made; consultant responsible for care; symptoms (if any) and duration of symptoms (in days/weeks); blood results at diagnosis; height/weight at diagnosis (if available) and at first outpatient department appointment; number of brothers/sisters; birth order; birth history; (birth weight, gestation (in weeks) mode of delivery); infant feeding; (method of feeding from birth; breast/bottle including duration of either or both; 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/autoimmune disease; medical card (yes/no); long term illness card (yes/no); private health insurance(yes/no); parents' occupation; ethnic origin.
Data dictionary	No
Clinical Coding Scheme	No

Accessing data	The data will be published and accessed through annual reports to participants and on website
Date collection commenced	January 2008
Published information/ Update frequency	Ongoing data collection. Data awaiting publication.
Web address	Not web enabled at present
Generic email contact	diabetes.register@tcd.ie
Other comments	

Table 5.27	**Irish Epilepsy and Pregnancy Register**
Managing Organisation	Beaumont Hospital Epilepsy Research Group; Royal College of Surgeons in Ireland (RCSI)
Contributor	Pregnant women with epilepsy; GPs of pregnant women with epilepsy; Health care professionals of pregnant women with epilepsy
Subject	PHL terms: EPILEPSY, PREGNANCY, DRUG Keywords: epilepsy, pregnancy, anti-epileptic drugs, folic acid, risk of malformations
Description/ Summary	The Irish epilepsy and pregnancy register was set up to register all women with epilepsy who are currently pregnant in Ireland. The register was set up to determine the safest strategies for the treatment of women with epilepsy who are currently pregnant or planning a pregnancy.
Statement of Purpose	*Primary objectives* ▪ To establish an ongoing nationwide prospective registry of epilepsy and pregnancy in the Republic of Ireland, which will have close links with the United Kingdom registry based in Belfast. ▪ To establish the relative safety of the individual antiepileptic drugs with reference to major malformations in the offspring of women with epilepsy. *Secondary objectives* ▪ To establish whether seizure frequency is related to adverse outcome in pregnancy. ▪ To establish the rate of preconceptual folic acid administration in women with epilepsy and whether this beneficially affects outcome. ▪ To educate people about epilepsy and pregnancy by giving pre-conceptual, pregnancy and post-pregnancy advice (related to epilepsy).
Coverage	National voluntary participation (currently 860+ patients)

Method of data collection	Pregnant women can either self register or a referral is sent from the GP or other health professionals. The forms are available from the following website (www.epilepsypregnancyregister.ie). Written consent is required from all women when registering. Neurologist or other health professional will do a follow-up telephone registration with pregnant woman. Data is collected over the telephone or face to face at clinics. Data is collected and stored electronically with a paper trail. Three months after the estimated date of delivery the patient's GP is sent a further questionnaire asking for obstetric history, present and previous, and details of the outcome of this pregnancy. If there is any abnormal outcome, specific details will be requested. Future neurodevelopment of the child may be assessed, if appropriate.
Data content	Includes: mother details include: name; address; contact number; nationality; date of birth; gestation (weeks) at registration; expected date of delivery; previous past pregnancies. Epilepsy details of mother include: date of onset of epilepsy; seizure type; aetiology if known; seizure during pregnancy? If yes what type; antiepileptic drug (AED) history (current and 3 months prior to conception). Folic acid details include: was it prescribed; was it taken pre-conceptually; dose of folic acid; duration of folic acid. Other details include: GP details; smoking status; where heard about register; who registered woman with epilepsy to register; whether currently attending a specialist for their epilepsy. Baby details include: date of birth; gestational age at birth; gender; birth weight; method of delivery; outcome of pregnancy; birth defect present? nature of defect if present.
Data dictionary	No
Clinical Coding Scheme	Coding of pregnancy outcome malformations only in line with UK epilepsy and pregnancy register malformation grading Grading of malformations: 1 = Major Malformation; 2 = Minor malformation; 3 = Pregnancy Loss; 4 = Gene/Chromosomal abnormality; 0 = Not a malformation - normal variation
Accessing data	Data presented at national and international conferences. Results are currently combined with UK epilepsy and pregnancy register and published. There is a future plan to report total numbers registered to date on the website. No formal data requests procedure at present.

Date collection commenced	May 2001 Amalgamated with UK epilepsy and pregnancy register in May 2007
Published information/ Update frequency	Data published via conferences – national and international.
Web address	http://www.epilepsypregnancyregister.ie/
Generic email contact	Not provided
Other comments	Freephone number 1800 320 820

Table 5.28	Irish Heart Valve Bank Register
Managing Organisation	Mater Misericordiae University Hospital (MMUH)
Contributor	All acute public hospitals and all private hospitals that perform open cardiac surgery
Subject	Keywords: donors, homografts, processing, storage, release
Description/ Summary	The data is currently collected in a paper based system. The data includes demographics, medical and social history of donors and demographics and medical history of recipients. The data allows tracking of tissue from donation to transplantation.
Statement of Purpose	Data allows tracking of all relevant information concerning homograft tissue in accordance with EU and Irish Tissue legislation.
Coverage	National – all acute public hospitals and all private hospitals that perform open cardiac surgery.
Method of data collection	Manual collection of data from donors/donor chart and/or family. Data is collected by the National Donor Coordinators based in Beaumont hospital, Heart Lung Transplant Coordinators based in the Mater Misericordiae University Hospital (MMUH), transplant registrars based in the MMUH, cardiac theatre nurses based in MMUH, Irish Blood Transfusion Service, implanting surgeon and nurses. The data is organised and recorded in the designated chart by the heart valve bank administrator and quality manager.
Data content	Includes details of donor demographics, medical and social history of donors and demographics and medical history of recipients.
Data dictionary	No
Clinical Coding Scheme	Not used
Accessing data	Restricted to donor access to donor information and recipient access to recipient information.
Date collection commenced	10th August 1993
Published information/ Update frequency	Not published
Web address	www.mater.ie/services/depts/c/cardio-thoracic
Generic email contact	mmh@mater.ie
Other comments	

Table 5.29	**Irish Hip Fracture Database (IHFD)**
Managing Organisation	National Office of Clinical Audit (NOCA)
Contributor	Irish public hospitals
Subject	Keywords: hip fracture
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.
Statement of Purpose	Develop a prospective audit of care standards and outcomes for hip fracture care and use synergy of standards, data and feedback 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.
Coverage	National - all acute hospitals that operate on hip fracture patients, 16 in total
Method of data collection	Data is taken from the medical record by clinical staff with permitted access and inputted into the HIPE portal.
Data content	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, secondary prevention, physiotherapy/occupational therapy initiation and multidisciplinary rehabilitation.
Data dictionary	Yes
Clinical Coding Scheme	No
Accessing data	Each site has a designated clinical lead and data collector who can access their own data at any point during the data collection. There may be more than one data collector in each site.
Date collection commenced	2012
Published information/ Update frequency	Annual reports commencing 2014

Web address	www.noca.ie
Generic email contact	Not provided
Other comments	Anyone over the age of 30 with a proximal femur fracture (i.e. upper third of the femur) should be included. A patient unique identifier is used and no patient is identified in the data. it is a cumulative report of overall performance for each care standard.

Table 5.30	**Irish Motor Neurone Disease Register**
Managing Organisation	National Motor Neurone Disease (MND) Clinic at Beaumont Hospital
Contributor	Consultant neurologists, neurophysiologists, geriatricians, community based clinical professionals
Subject	Keywords: motor neurone disease incidence
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 1,800 patients. On average 80 new cases per annum, with 250 people affected at any one time. A DNA bank was added in 1998. This bank contains samples from over 300 patients.
Statement of Purpose	The purpose of the Register is to track the incidence, prevalence and clinical features of MND in the Irish population.
Coverage	All known patients diagnosed with MND each year in the Republic of Ireland.
Method of data collection	The register is based on direct nationwide chart review/ confirmation by the diagnosing physician. 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.
Data content	Age, the date of onset, type of MND, clinical features, progression, survival, presence of associated features including cognitive decline.
Data dictionary	No
Clinical Coding Scheme	ICD-9: Amyotrophic lateral sclerosis (ALS), MND, Progressive Bulbar palsy
Accessing data	Password protected restricted access. Standard operational procedures are in place with signed confidentiality agreements in use. Actual access to the database is limited to 1-2 personnel. Information yielded from the database is via a coded system to maintain confidentiality.
Date collection commenced	1994 – full capture since 1995
Published information/ Update frequency	Scientific peer-reviewed publications listed on MND website (www.mnd.ie).

Web address	http://www.mnd.ie
Generic email contact	mndregister@gmail.com
Other comments	

Table 5.31	Irish National Orthopaedic Register (INOR)*
Managing Organisation	The Royal College of Surgeons in Ireland (RCSI) and the Health Service Executive (HSE), under a jointly developed service level agreement have undertaken the establishment, administration and management of the National Office of Clinical Audit (NOCA) through the NOCA Governance Board. The Irish National Orthopaedic Register (INOR) will be set up by NOCA supported clinically by the Irish Institute of Trauma and Orthopaedic Surgery (IITOS).
Contributor	Irish Elective Orthopaedic Hospitals Public and Independent
Subject	Keywords: orthopaedic, arthroplasty, clinical audit
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 hospitals nationally. The objectives of INOR are to: ■ Increase patient safety, confidence and overall experience. ■ Enable early detection of failing devices, procedures, institutions or surgeons or any combination (device, implanted materials, procedures, institutions and/or surgeons) to limit the impact for future patients. ■ Enable better identification and management of individuals in at-risk groups to improve patient experience and outcomes. ■ Reduce surgical revision rates and improve both costs and patient outcomes. ■ Optimise the pre-operative, peri-operative and post operative process to improve quality of service. ■ Provide orthopaedic surgeons the opportunity to participate and contribute to measurable clinical audit. ■ To monitor implant performance against the group norms for Ireland and within the wider international community. ■ To monitor patient outcome and to use patient self scoring as part of the indicator for device failure (and not just revision surgery).

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* The National Office of Clinical Audit has indicated that the date of first data collection for the Irish National Orthopaedic Register (INOR) will be early 2014.

Statement of Purpose	To provide an electronic point of care system to record and monitor all elective orthopaedic surgical procedures performed in participating hospitals. INOR will rely on patient scoring systems; adverse incident recording system and surgical revision rates to monitor implant performance and patient outcomes. This will provide continuous feedback to patients, participating centres and surgeons. Through the monitoring of joint replacement surgery and implant devices, INOR aims to reduce the cost of revision surgery in Ireland, to identify risk associated with joint replacement and thereby ensure that Irish patients receive the highest possible standard of orthopaedic care within our hospitals.
Coverage	All Elective Orthopaedic Centres and Independent Hospitals in Ireland
Method of data collection	Data is extracted from patient administration systems, ORMIS (Operating Room Management Information System) and INOR (Functionality designed programme) and collated for reporting through NOCA.
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, GP details.
Data dictionary	User manual for participants and reviewers will be available on website. Data Dictionary not applicable at this time.
Clinical Coding Scheme	ICD-10-AM for coding diagnoses and ACHI for procedures.
Accessing data	NOCA Office – INOR Annual reports (National reports, Surgeon reports, Hospital reports)
Date collection commenced	Data collection will commence in early 2014
Published information/ Update frequency	Annual reports – once data collection commenced
Web address	http://www.noca.ie
Generic email contact	Not provided
Other comments	

Table 5.32	Irish Unrelated Bone Marrow Registry (IUBMR)
Managing Organisation	Irish Blood Transfusion Service (IBTS)
Contributor	Volunteer bone marrow/stem cell donors in Ireland
Subject	PHL terms: DONOR, TRANSPLANTATION Keywords: bone marrow, register, and haemopoietic stem cells
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 a patient needing a bone marrow transplant. The IUBMR is part of a worldwide network of unrelated donor registries.
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 a patient needing a bone marrow transplant.
Coverage	Voluntary Participation.
Method of data collection	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.
Data content	Details include: name; sex; date of birth; address; phone number; blood group; tissue type; consent. There are also links to IBTS Progesa (blood donor) system which provides virology blood group/ blood donation history.
Data dictionary	No
Clinical Coding Scheme	No
Accessing data	IBTS annual reports
Date collection commenced	The IUBMR was established in 1989
Published information/ Update frequency	Annual reports
Web address	http://www.giveblood.ie/Become_a_Donor/Bone_Marrow_Registry/Bone_Marrow_Registry.html
Generic email contact	bonemarrow@ibts.ie
Other comments	

Table 5.33	Major Trauma Audit (MTA)
Managing Organisation	National Office of Clinical Audit (NOCA)
Contributor	Irish public and voluntary hospitals
Subject	Keywords: trauma, injury severity
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 its base in Manchester, UK. Objectives of Major Trauma Audit: ▪ To provide a national baseline of current patient demands in trauma care, clinical practice and performance. ▪ To identify current practice in the process of care of trauma patients, to map trends in this process of care and to develop improved care pathways for the seriously injured population. ▪ To identify variance in patient process and the impact of such variance on patient care. ▪ To promote reflective clinical practice and to encourage peer performance review at local and national level. ▪ To capture the impact of complex patients on hospital length of stay and predict local and national resource implications. ▪ To provide high quality data to enable peer reviewed research and to drive clinical change.
Statement of Purpose	MTA will provide a framework for hospitals to collect standardised data on patient injury, care processes and patient outcomes.
Coverage	All trauma receiving public emergency departments participate in this audit.
Method of data collection	Hospital-level MTA co-ordinators submit data on a web-based data collection and reporting system.
Data content	This data includes: pre-hospital times, mechanism of injury, patient’s hospital journey, injury severity, times to treatment, length of stay, and outcomes based on mortality.

Data dictionary	Available via TARN site: http://www.eurotrauma.net/site2/images/revised_utstein_template_-_data_dictionary_v1.1.1-25.pdf
Clinical Coding Scheme	ICD–10 injury codes (S and T) are used to identify reports for inclusion in MTA
Accessing data	NOCA annual reports
Date collection commenced	2013
Published information/ Update frequency	Ad-hoc reports from TARN, Hospital and tri-annual reports from TARN, NOCA annual report.
Web address	www.noca.ie
Generic email contact	Not provided
Other comments	

Table 5.34	MHC – Admissions of Children to Approved Centres
Managing Organisation	Mental Health Commission (MHC) Standards and Quality Assurance Division
Contributor	Approved centres. The definition of an approved centre is as follows: As per Part 5 Section 62 of the Mental Health Act 2001: A 'centre' means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An 'approved centre' is a centre that is registered pursuant to the Act. The Mental Health Commission establishes and maintains the Register of Approved Centres pursuant to the Act. http://www.mhcirl.ie/Registration/ACRegister
Subject	Keywords: child demographic data, approved centre admissions, mental health in-patient services.
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.
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 (Amendment) Act, 2003 ▪ Data Protection Act, 1988 ▪ Freedom of Information (Amendment) Act, 2003 ▪ Freedom of Information Act, 1997
Coverage	National – all approved centres that admit children.

Method of data collection	Data are taken from medical charts or records and returned to the Mental Health Commission. Admissions to Adult Units are notified to MHC, within 72 of the admission, using a specified clinical practice form. Notification of discharge is sent to the MHC, within 72 hours of discharge, using a specified clinical practice form.MHC enters data on receipt into an Access Database. Admissions to Child Units are reported to MHC on a monthly basis using a specified electronic template. MHC imports data on receipt into an Access Database.
Data content	Child ID; date of birth; gender; date of admission; legal status on admission; date of discharge; legal status at discharge
Data dictionary	Available internally – not published
Clinical Coding Scheme	Not applicable
Accessing data	MHC annual reports and data requests
Date collection commenced	01/11/2006 (Full commencement of the Mental health Act 2001)
Published information/ Update frequency	Annual reports since 2006
Web address	http://www.mhcirl.ie/Publications/Annual_Reports/
Generic email contact	info@mhcirl.ie
Other comments	

Table 5.35	**MHC – Deaths of residents in Approved Centres and sudden, unexplained deaths of individuals attending a day hospital, day centre or residing in a 24 hour staffed community residence**
Managing Organisation	Mental Health Commission (MHC) Standards and Quality Assurance Division
Contributor	Approved Centres, Day Hospitals, Day Centres and 24 Hour Staffed Residences. The definition of an approved centre is as follows: As per Part 5 Section 62 of the Mental Health Act 2001: A 'centre' means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An 'approved centre' is a centre that is registered pursuant to the Act. The Mental Health Commission establishes and maintains the Register of Approved Centres pursuant to the Act. See http://www.mhcirl.ie/Registration/ACRegister
Subject	Keywords: demographic data, deaths, sudden unexplained deaths, approved centres, day hospitals, day centres and 24 hour staffed residences
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.
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 (Amendment) Act, 2003 ▪ Data Protection Act, 1988 ▪ Freedom of Information (Amendment) Act, 2003 ▪ Freedom of Information Act, 1997
Coverage	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.
Method of data collection	Deaths are notified to MHC using the prescribed Death Notification form. Approved centre deaths are required to be notified within 48 hours of the death. Day hospitals, day centres or 24 hour staffed residences are required to notify sudden, unexplained deaths, within 7 days of the death. MHC enters data on receipt into an Access database.
Data content	Initials; date of birth; legal status; marital status; diagnosis; date of death; circumstances surrounding death.
Data dictionary	Available internally – not published
Clinical Coding Scheme	ICD-10
Accessing data	MHC annual report and data requests
Date collection commenced	01/02/2008
Published information/ Update frequency	MHC annual reports since 2008.
Web address	http://www.mhcirl.ie/Publications/Annual_Reports/
Generic email contact	info@mhcirl.ie
Other comments	

Table 5.36	**MHC – Involuntary Admission Activity (Adults)**
Managing Organisation	Mental Health Commission (MHC) Tribunals Division
Contributor	All approved centres. The definition of an approved centre is as follows: As per Part 5 Section 62 of the Mental Health Act 2001: A 'centre' means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An 'approved centre' is a centre that is registered pursuant to the Act. The Mental Health Commission establishes and maintains the Register of Approved Centres pursuant to the Act. http://www.mhcirl.ie/Registration/ACRegister
Subject	Keywords: adult demographic data, involuntary admissions, approved centres, mental health in-patient services
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.
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	National – all involuntary admissions to approved centres.

Method of data collection	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).
Data content	Name; address; date of birth; gender; date of involuntary admission and approved centre
Data dictionary	Available internally– not published
Clinical Coding Scheme	ICD-10
Accessing data	Quarterly reports on MHC website, MHC annual report and data requests
Date collection commenced	01/11/2006
Published information/ Update frequency	Quarterly reports and MHC annual reports since 2006
Web address	http://www.mhcirl.ie/Mental_Health_Tribunals/Involuntary_Admission_Activity/
Generic email contact	info@mhcirl.ie
Other comments	

Table 5.37	**MHC – Administration of Electro-convulsive Therapy (ECT) in approved centres**
Managing Organisation	Mental Health Commission (MHC) Standards and Quality Assurance Division
Contributor	All approved centres. The definition of an approved centre is as follows: As per Part 5 Section 62 of the Mental Health Act 2001. A 'centre' means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An 'approved centre' is a centre that is registered pursuant to the Act. The Mental Health Commission establishes and maintains the Register of Approved Centres pursuant to the Act. http://www.mhcirl.ie/Registration/ACRegister.
Subject	Keywords: demographic data, approved centres, mental health in-patient services, Electro-Convulsive Therapy (ECT)
Description/ Summary	MHC collects demographic and clinical data in relation to the administration of ECT in approved centres nationally.
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 (Amendment) Act 2003 ■ Data Protection Act, 1988 ■ Freedom of Information (Amendment) Act 2003 ■ Freedom of Information Act, 1997

Coverage	National: All approved centres that administer ECT or refer a person to another approved centre for ECT treatment.
Method of data collection	Data are extracted from registers in approved centres and returned on prescribed electronic data collection templates to the MHC on a quarterly basis. Data on administration of ECT without consent are returned in a statutory form at the time when the treatment without consent has been prescribed and approved. MHC enters data on receipt into an Access database.
Data content	Service user initials; gender; date of birth; legal status; information regarding the programme of ECT.
Data dictionary	Available internally – not published
Clinical Coding Scheme	ICD-10
Accessing data	Annual reports – Administration of ECT in approved centres activity report and data requests
Date collection commenced	01/01/2008
Published information/ Update frequency	Annual activity reports published on MHC website
Web address	http://www.mhcirl.ie/Publications
Generic email contact	info@mhcirl.ie
Other comments	

Table 5.38	**MHC – Use of Seclusion, Mechanical Restraint and Physical Restraint in approved centres**
Managing Organisation	Mental Health Commission (MHC) Standards and Quality Assurance Division
Contributor	All approved centres. The definition of an approved centre is as follows: As per Part 5 Section 62 of the Mental Health Act 2001. A 'centre' means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An 'approved centre' is a centre that is registered pursuant to the Act. The Mental Health Commission establishes and maintains the Register of Approved Centres pursuant to the Act. http://www.mhcirl.ie/Registration/ACRegister.
Subject	Keywords: demographic data, use of seclusion, mechanical means of bodily restraint, physical restraint, approved centres, mental health in-patient services
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.
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 (Amendment) Act 2003 ■ Data Protection Act, 1988 ■ Freedom of Information (Amendment) Act 2003 ■ Freedom of Information Act, 1997
Coverage	National - all approved centres that use seclusion or restraint.
Method of data collection	Data are extracted from registers and clinical practice forms in approved centres and returned on prescribed data collection templates to the MHC on a quarterly basis. MHC enters data on receipt into an Access database.
Data content	Service user initials; gender; date of birth; details regarding the use of seclusion; mechanical and physical restraint
Data dictionary	Available internally – not published
Clinical Coding Scheme	No
Accessing data	Annual reports – Seclusion and Restraint in approved centres activity report and data requests
Date collection commenced	01/01/2008
Published information/ Update frequency	Annual activity reports published on MHC website
Web address	http://www.mhcirl.ie/Publications
Generic email contact	info@mhcirl.ie
Other comments	

Table 5.39	**National Adverse Event Management System (NAEMS) (formally known as STARSweb)**
Managing Organisation	Clinical Indemnity Scheme (CIS), State Claims Agency on behalf of the Department of Health
Contributor	Hospitals and other healthcare enterprises
Subject	Keywords: clinical negligence claims, indemnity, risk management
Description/ Summary	National Adverse Event Management System (NAEMS) is a national web-based database for the reporting of adverse clinical incidents and 'near misses'. The Clinical Indemnity Scheme (CIS) was established in 2002, in order to rationalise pre-existing medical indemnity arrangements by transferring to the State, via the Health Service Executive (HSE), hospitals and other health agencies, responsibility for managing clinical negligence claims and associated risks. Under the scheme, which is managed by the State Claims Agency (SCA), the name used by the National Treasury Management Agency (NTMA) when carrying out its claims' and risk management functions, the State assumes full responsibility for the indemnification and management of all clinical negligence claims, including those which are birth-related. Although the system has a primary Claims Management functionality, the clinical incident reporting feature is designed to support sharing of learning from "near misses" and in the aftermath of serious adverse clinical events, at local and national levels.
Statement of Purpose	Support for effective claims and risk management in all enterprises indentified by the Clinical Indemnity Scheme.
Coverage	All adverse clinical events and near-misses
Method of data collection	A confidential, highly secure web-based IT system (known as NAEMS) links hospitals and other healthcare enterprises to the CIS core database. Information is entered to the system locally. Paper based incident form usually completed by healthcare professional. Submitted to Risk Management department, where clerical officer inputs data on the system. Some hospitals have electronic entry facilities.
Data content	Includes demographic details, event/near miss, full event details, sub-speciality, outcome, risk rating, contributory factors, actions taken/planned
Data dictionary	No
Clinical Coding Scheme	Not available

Accessing data	Each enterprise has access to its own data and is entered on site, but the SCA has access to all data in order to identify emerging trends. Although the data entry at enterprise level includes identifying patient details, personnel at CIS are unable to see such data, as per Data Protection legislation. The CIS publishes aggregate annual data in its newsletter and on its website. Aggregate data are used in presentations to relevant professional bodies, enterprises, media queries.
Date collection commenced	November 2003
Published information/ Update frequency	Annual aggregated data published by the CIS publishes in its newsletter and on its website. Aggregate data are used in presentations to relevant professionals bodies, enterprises, media queries etc.
Web address	http://www.stateclaims.ie/ClinicalIndemnityScheme/introduction.html
Generic email contact	info@stateclaims.ie
Other comments	

Table 5.40	**National Antimicrobial Resistance Surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	44 microbiology laboratories representing all acute public and private hospitals, plus other healthcare institutions.
Subject	Keywords: antimicrobial resistance, surveillance
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 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 comprises a network of over 800 microbiological laboratories serving some 1200 hospitals in 30 countries that collects routinely-generated antimicrobial susceptibility testing data on invasive infections caused by seven important bacterial pathogens: *Staphylococcus aureus (S. aureus), Streptococcus pneumoniae (S. pneumoniae), Escherichia coli (E. coli), Enterococcus faecalis (E. faecalis), Enterococcus faecium (E.faecium), Klebsiella pneumoniae (K. pneumoniae) and Pseudomonas aeruginosa (P. aeruginosa).* As of Quarter 1 2009, 44 Irish laboratories serving 62 acute hospitals (public and private) participate in EARS-Net, representing approximately 100% coverage of the Irish population.
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.
Coverage	As of Quarter 1 2009, all 44 microbiology laboratories in Ireland were participating in EARS-Net representing 100% coverage of the Irish population.
Method of data collection	EARS-Net collects data on the first invasive isolate (from blood or cerebrospinal fluid) of each pathogen per patient per quarter. 85% of the records are received electronically (usually file downloads from the Laboratory Information Management System or WHONET files, a free software used to manage antimicrobial resistance data) containing data on the following: *S. pneumoniae, S. aureus, E. coli, K. pneumoniae, E. faecium/ faecalis* and *P. aeruginosa.* For the remaining 15%, isolate record forms are submitted.

Data content	Laboratory data: current date dd/mm/yyyy; laboratory code; isolate data; isolate sample number (lab) max. 12 characters; isolate source tick box; date of sample collection. Patient data: patient ID/code; sex; date of birth; hospital data; name/code of hospital; origin of patient; date of admission; hospital department; antibiotic susceptibility testing.
Data dictionary	Not available
Clinical Coding Scheme	Not applicable
Accessing data	Reports published on HPSC website
Date collection commenced	*S. aureus/S. pneumoniae* - 1999; *E. coli/Enterococci* - 2002; *K. pneumoniae/P. aeruginosa* – 2006
Published information/ Update frequency	Quarterly and annual reports published on HPSC website
Web address	www.hpsc.ie
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.41	National Cancer Control Programme (NCCP)
Managing Organisation	National Cancer Control Programme (NCCP) which is a Directorate of the Health Service Executive
Contributor	Irish public hospitals
Subject	PHL terms: CANCER, CONTROL Keywords; cancer service activity
Description/ Summary	NCCP collects data on cancer service activity, waiting times and areas relating to quality and patient safety. These are primarily collected through the use of key performance indicators (KPI) and through national audits of the quality and safety of particular services or tumour treatments. The data are used to inform cancer service planning and evaluation.
Statement of Purpose	To collect data on cancer service activity, waiting times and areas relating to quality and patient safety. The full statement of purpose can found at the following link: http://www.hse.ie/eng/services/list/5/nccp/profs/NCCP%20Statement%20of%20Intent%20for%20Collection%20of%20Data.pdf
Coverage	National – all acute public hospitals that provide cancer services participate in the collection of data.
Method of data collection	Data is taken from hospital computer systems (e.g. waiting times, referrals etc.), from patient files where required (e.g. finalisation of patient treatment plan) and other sources within the hospital (e.g. records of MDT meetings). The information is inputted into spreadsheets or pro-forma documents by hospital staff. No personal information is provided. The information is transmitted by e-mail to a dedicated e-mail address.
Data content	The data collected varies depending on the nature of information being sought. Different treatment programmes and tumour types have different types and levels of information collected. For example, for the collection of information regarding breast cancer treatment, one KPI relates to “all new patients deemed urgent following a consultant surgery assessment shall have imaging done within one week of the first visit”. The data collected for this KPI would be: the specialist clinical surgical assessment of all patients following their first visit to the clinic; the date of the clinic visit; the type of imaging procedure carried out; the date that the imaging procedures were carried out. There are numerous KPIs in different tumour groups and treatment programmes.
Data dictionary	Yes

Clinical Coding Scheme	Not used
Accessing data	KPI data is published in the HSE's monthly Performance Report, which are available at: http://www.hse.ie/eng/services/Publications/corporate/performancereports/2013pr.html
Date collection commenced	2009
Published information/ Update frequency	Monthly
Web address	http://www.hse.ie/eng/services/list/5/nccp/
Generic email contact	info@cancercontrol.ie
Other comments	

Table 5.42	**National Cancer Drug Management Programme**
Managing Organisation	National Cancer Control Programme (NCCP), Health Service Executive
Contributor	Irish public hospitals
Subject	PHL terms: CANCER, DRUG, Keywords; demographic data, drug use data, financial data
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.
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: http://www.hse.ie/eng/services/list/5/nccp/profs/NCCP%20Statement%20of%20Intent%20for%20Collection%20of%20Data.pdf
Coverage	National – there are 26 acute public hospitals nationally that provide cancer drug services and participate in the National Cancer Drug Management Programme.
Method of data collection	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 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
Clinical Coding Scheme	ICD-10
Accessing data	Monthly HSE Performance Report, NCCP annual report, data requests.
Date collection commenced	Data collection commenced September 2012. Reporting process commenced April 2013.
Published information/ Update frequency	Hospitals update data on an ongoing basis, as cancer drugs are dispensed. Monthly reports received by NCCP from PCRS.

Web address	http://www.hse.ie/eng/services/list/5/nccp/
Generic email contact	oncologydrugs@cancercontrol.ie
Other comments	

Table 5.43	National Cancer Registry Ireland
Managing Organisation	National Cancer Registry Ireland (NCRI) in conjunction with the Department of Health
Contributor	21 Tumour Registration Officers employed by NCRI working in hospitals around the country. Death Certificates collected from CSO (Central Statistics Office); Information on hospital episodes contributed by ESRI (HIPE data)
Subject	PHL terms: CANCER, MORBIDITY
Description/ Summary	The National Cancer Registry has been collecting comprehensive cancer information for the whole 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.
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.
Coverage	Reporting to the Registry is national since 1994 and is voluntary. Estimated coverage is 96-97% of all diagnosed cancers.
Method of data collection	The National Cancer Registry collects cancer data itself: Actively - by employing workers to go to hospitals and other healthcare centres regularly to look through records for new cases of cancer. Passively - by waiting to be notified of new cancer cases by doctors, nurses, laboratories and so on, and by processing death certificates. In recent times, the Registry has also begun to put the necessary technologies in place to receive data electronically. It is hoped that this will speed up registration in the future.

Data content	Includes: type of cancer; site; staging; age and sex; treatments and selected procedures; patient demographics; date and cause of death
Data dictionary	Yes
Clinical Coding Scheme	ICD 10; ICD O (International Classification of Diseases for Oncology) - 3rd Edition ; ICD10 AM (ACHI) for procedures; TNM 5 staging system
Accessing data	On-line cancer rates; data-set download; data requests; annual reports
Date collection commenced	The Irish National Cancer Registry was set up in 1991 and began registering cancers nationwide in January 1994.
Published information/ Update frequency	Data is collected daily and reported on annually. Research projects also publish its findings when complete. As the data on the website is updated regularly, the online cancer rates and data download may differ from the Registry’s published report.
Web address	http://www.ncri.ie
Generic email contact	info@ncri.ie
Other comments	

Table 5.44	National Cleft Database
Managing Organisation	Dublin Cleft Centre (DCC) encompasses members of the multidisciplinary cleft teams from Temple Street Children's University Hospital, Our Lady's Hospital Crumlin, St James Hospital and the Mater Misericordiae Hospital
Contributor	Multidisciplinary team in cleft care – (Plastic Surgery, Speech and Language Therapy, Orthodontics, Dental, Maxilla Facial, Prostodontics, ENT, Audiology, Cleft Nurse Specialist, Clinical Photography, Cleft Co-ordinator/Manager)
Subject	Keywords: cleft palate, cleft lip palate
Description/ Summary	The National Cleft Database enables the stakeholders to monitor the frequency and incidence of clefting in Ireland. It facilitates audit, research and reporting on the quality of cleft care. It supports planning and development of appropriate services and enables coordination of these 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.
Statement of Purpose	The purpose is to provide information on children or adults who present with Cleft Lip and/or palate.
Coverage	National - participation is voluntary.
Method of data collection	The data is compiled from several sources i.e. the cleft database registration proforma, healthcare records, hospital patient registrations system (IPMS) and audit records from each discipline of the multi-disciplinary cleft care team.
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; integrity/ growth records photographs); objective assessment of velopharyngeal function; instrumental assessment of resonance; cleft coordinator contact; clinic details; cleft CNS contact; genetics patient status
Data dictionary	On-going work in progress for completion of data dictionary.
Clinical Coding Scheme	Not applicable

Accessing data	Data requests by team members (DCC) to Cleft coordinator/ manager. Annual audit of annual returns to Craniofacial Society of Great Britain and Ireland (CFSGBI). Annual report generated for Congenital Anomalies Registry.
Date collection commenced	January 2002
Published information/ Update frequency	Data submitted annually to Craniofacial Society of Great Britain and Ireland (CFSGBI), and to the HSE Congenital Anomalies Registry.
Web address	http://www.craniofacialsociety.org.uk/; http://www.eurocran.org
Generic email contact	Not provided
Other comments	Data set design is produced by the multi-disciplinary team in Cleft Care under the auspices of DCC.

Table 5.45	National Drug-Related Deaths Index (NDRDI)
Managing Organisation	The National Health Information Systems Unit in the Health Research Board in conjunction with the Department of Health and the Department of Justice and Equality.
Contributor	The Coroner Service, The General Mortality Register, The Central Treatment List and HIPE.
Subject	PHL terms: DRUGS MISUSE, ALCOHOL MISUSE, MORTALITY
Description/ Summary	The National Drug-Related Deaths Index is an epidemiological database which records cases of drug- and alcohol-related deaths, and deaths among drug users and among alcoholics in Ireland.
Statement of Purpose	Epidemiological monitoring of cases of drug- and alcohol-related deaths, and deaths among drug users and among alcoholics in Ireland.
Coverage	All drug and alcohol related deaths in Ireland are covered.
Method of data collection	Staff from the HRB collects data from Coroner Service files relating to all deaths where a history of drug use was recorded or where drug or alcohol misuse was implicated in the death. Data from the other agencies is submitted in electronic format.
Data content	Administrative details; demographic details; socio-economic information; problem drug use at time of death; risk behaviours; drug treatment history; details of death itself; medical diagnosis.
Data dictionary	Yes as part of information manual
Clinical Coding Scheme	HIPE data - ICD-10- AM Cause of death for the General Mortality Register - ICD
Accessing data	Reports/publications and requests for information
Date collection commenced	September 2005
Published information/ Update frequency	Data are collected on an annual basis
Web address	http://www.hrb.ie/health-information-in-house-research/alcohol-drugs/ndrdi/
Generic email contact	ndrdi@hrb.ie
Other comments	

Table 5.46	**National Drug Treatment Reporting System (NDTRS)**
Managing Organisation	The National Health Information Systems Unit in the Health Research Board on behalf of the Department of Health
Contributor	Drug treatment centres throughout Ireland.
Subject	PHL terms: DRUGS MISUSE, ALCOHOL MISUSE, EPIDEMIOLOGY, TREATMENT
Description/ Summary	The National Drug Treatment Reporting System (NDTRS) is an epidemiological database on treated drug and alcohol misuse in Ireland. Since 2004, clients reporting alcohol as their main problem drug have been recorded by the system.
Statement of Purpose	The NDTRS was established as an epidemiological database on treated drug and alcohol misuse in Ireland. It records incidence of drug and alcohol treatment.
Coverage	Drug treatment centres in Ireland. Participation in NDTRS is not mandatory.
Method of data collection	Service providers at drug treatment centres throughout Ireland complete a form on each individual who attends for the first treatment or returns for alcohol use in a calendar year and forwards them to the Drugs and Alcohol Research Unit in the HRB for data entry.
Data content	Includes details of substance use; risk behaviour; treatment status; admission and treatment exit details. Demographic details include: gender; age; date of birth; area of residence; nationality; ethnic background; employment status; and educational level.
Data dictionary	Yes – as part of information manual
Clinical Coding Scheme	N/A
Accessing data	Data requests can be made to the HRB. Annual reports/Publications on HRB website Online access to data at http://www.drugsandalcohol.ie/
Date collection commenced	It was established in 1990 in the Greater Dublin area and was extended in 1995 to cover all areas of the country.
Published information/ Update frequency	Data collected on an annual basis

Web address	http://www.hrb.ie/health-information-in-house-research/alcohol-drugs/ndtrs/
Generic email address	ndtrs@hrb.ie
Other comments	

Table 5.47	National Haemophilia Register (Clintech)
Managing Organisation	National Centre for Hereditary Coagulation Disorders (NCHCD)
Contributor	Medical, nursing, administration, haemovigilance, physiotherapy, dental, social work and psychology Staff
Subject	Keywords: haemophilia, electronic patient record
Description/ Summary	Complete national electronic record for all patients with haemophilia and other related bleeding and clotting disorders. Interfaced to St James's Hospital Patient Administration System/EPR (St James's Hospitals electronic patient record). Networked to Our Lady's Hospital, Crumlin, Cork University Hospital and Galway University Hospital via Citrix Virtual Private Network. Clintech is the name of the national database collecting a full patient record which can be utilised by all relevant staff providing care to patients with haemophilia and other related bleeding and clotting disorders.
Statement of Purpose	To maintain a full national electronic record for all patients with haemophilia and other related bleeding and clotting disorders in Ireland.
Coverage	Central database (housed in St James's Hospital), access from other centres via Citrix Virtual Private Network. This is a National Register, all patients with haemophilia and related bleeding and clotting disorders are on this register.
Method of data collection	Data is collected at the point of care and retrospectively. The system was developed so that data can be entered at the point of care in the clinic however individual clinicians operate differently and some enter the data retrospectively. Generally all nurses enter data at the point of care.
Data content	Includes the following: demographics; diagnosis; allergies; test results; medical and nursing notes; prescriptions and care providers.
Data dictionary	Not published
Clinical Coding Scheme	ICD-10
Accessing data	Networked, via Citrix and remote access via Citrix/VPN. Role based access password controlled. There is no facility for public access.
Date collection commenced	May 2005

Published information/ Update frequency	No data is published
Web address	http://www.stjames.ie/Departments/DepartmentsA-Z/N/NationalCentreforHereditaryCoagulationDisorders
Generic email contact	Not provided
Other comments	FDA CRF21, 11 compliant (Title 21 CFR Part II of the Code of Federal Regulations deals with the FDA guidelines on electronic records and electronic signatures (ERES). "Part II", as it is commonly called, defines the criteria under which electronic records and electronic signatures are considered to be trustworthy, reliable and equivalent to paper records. GAMP complaint (Good Automated Manufacturing Practice Guide for Validation of Automated Systems in Pharmaceutical Manufacture).

Table 5.48	National Health Schemes Data (Primary Care Reimbursement Service)
Managing Organisation	Health Service Executive
Contributor	General Practitioners, Community Pharmacies, Dentists and Optometrists/Ophthalmologists, Health Service Executive - Regions
Subject	Keywords: client, prescribing data, prescription, products, reference data, special type consultation, records, electronic health record, unique health identifier
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.
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	The data covers the main national health schemes throughout the entire country.
Method of data collection	Data is processed under the following Schemes/Payment Arrangements: ■ General Medical Services (GMS) ■ Drugs Payment Scheme (DPS) ■ Long Term Illness Scheme (LTI) ■ Dental Treatment Services Scheme (DTSS) ■ 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.
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 publicly available
Clinical Coding Scheme	Not applicable
Accessing data	The Primary Care Reimbursement Service compiles statistics and trend analyses which are provided to other areas within the HSE, the Government, customers, stakeholders and to members of the public. Portions of data are made visible to registered users, e.g. GPs. The data is transactional in nature.
Date collection commenced	The HSE has been a collector of this type of data since 1970. Online records on its current system range periods up to 17 years, i.e. first records visible online dated in 1993.
Published information/ Update frequency	Data is published annually in reports, available on the HSE website. Data is also published in the Key Trends report and the Health Statistics reports issued by the Information Unit. The CSO also publish summary data on their website.
Web address	http://www.hse.ie/eng/staff/pcrs/
Generic email contact	pcrs@hse.ie
Other comments	

Table 5.49	National Hepatitis C Database
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	Patients with Hepatitis C contracted through contaminated blood and blood products, Hepatology units
Subject	Keywords: Hepatitis C, blood, infected, anti-D immunoglobulin, blood transfusion, haemophilia, renal disease
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.
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.
Coverage	Consenting patients, and patients who have died, approx 70% of eligible patients
Method of data collection	Data collected from medical records in Specialist Hepatology units across the country by a HPSC Research Nurse. Consent required for all living patients.
Data content	Age; sex; how patient became infected; medical condition; results of tests; treatments received
Data dictionary	No
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.

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
Date collection commenced	Development began in 2004; data collection commenced in 2005.
Published information/ Update frequency	Annual data collection; reports published on website, see www.hcvdatabase.ie
Web address	http://www.hpsc.ie/hpsc/A-Z/HepatitisHIVAIDSandSTIs/HepatitisC/
Generic email contact	hpsc@hse.ie
Other comments	The second year of annual follow-up data collection in 2009 will include data up to the end of 2008.

Table 5.50	**National Intellectual Disability Database (NIDD)**
Managing Organisation	National Health Information Systems Unit in the Health Research Board (HRB) in conjunction with the Department of Health
Contributor	Intellectual disability service providers (HSE local health offices and non-statutory bodies), school principals.
Subject	PHL terms: LEARNING DISABILITY, DISABILITY CARE
Description/ Summary	The National Intellectual Disability Database (NIDD) is a set of information that outlines the specialised health services currently used or needed by people with intellectual disability. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need.
Statement of Purpose	The NIDD is a service planning tool designed to capture date on the usage of and need for specialist disability services among people with intellectual disability.
Coverage	At present, in excess of 27,000 registrations. Participation is voluntary.
Method of data collection	The Health Service Executive (HSE) areas within the Republic of Ireland administer the NIDD. Responsibility for providing the information to the HSE areas lies primarily with the service providers, HSE personnel and school principals, who complete a database form for each individual.
Data content	Includes details on current service provision (type of services; agency providing service; frequency) and future service requirements (type of services; year when required; frequency). Personal details include: date of birth; gender; area of residence and level of intellectual disability. Administrative details include: date; HSE area with responsibility for returning data and agency responsible for returning data.
Data dictionary	Yes – as part of information manual
Clinical Coding Scheme	For the purposes of the NIDD, intellectual disability is defined using the criteria set out in the International Statistical Classification of Diseases, 10th Revision, (ICD-10), which categorises degrees of disability on a scale ranging from mild to moderate to severe to profound
Accessing data	Data requests, Reports/publications, Reports modules available to HSE and service providers; access is based on role and level of responsibility.
Date collection commenced	1995

Published information/ Update frequency	The HRB extracts information annually (excluding personal information such as name and address) from the NIDD. An annual report is published and bulletins with Local Health Office area data are circulated to the HSE. In addition, trend data from the NIDD are published periodically.
Web address	http://www.hrb.ie/health-information-in-house-research/disability/nidd/
Generic email contact	disability@hrb.ie
Other comments	Two national audits of the NIDD have taken place to date; one in 1999 and one in 2007. Bi-monthly validations are undertaken on the data.

Table 5.51	**National Intensive Care Audit (ICU Audit)***
Managing Organisation	National Office of Clinical Audit (NOCA), under Service Legal Assessment (SLA) between Royal College of Surgeons in Ireland and the Quality and Patient Safety Directorate of the Health Service Executive
Contributor	Irish public and voluntary hospitals
Subject	Keywords: intensive care units, activity analysis, patient pathway, outcomes, benchmarking quality in intensive care
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 acute hospitals nationally.
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 ICNARC Casemix Programme (Intensive Care National Audit and Research Centre – 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. ■ Improve the quality of data for HIPE by providing data on procedures and diagnoses arising while the patient is in ICU. ■ Provide data on cost efficiency of each Unit by measuring cost per bed day and linking this to complexity of care. ■ Support Irish and international research to enhance patient care.
Coverage	National audit with data collection from public hospitals with Intensive Care Units.
Method of data collection	Data is collected by ICU audit nurses in every hospital. Data is downloaded from hospital systems, taken from medical charts or records and entering onto the ICU Audit system.
Data content	Demographic details; admission details; clinical details; comorbidities; diagnostic details; surgery details; clinical interventions; details of organs supported and level of care delivered; ICU and hospital outcome; details of organ donation; unit acquired infection; HIPE support data

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* It is proposed that data collection for the National Intensive Care Audit (ICU Audit) will commence in early 2014.

Data dictionary	User definition manual will be available for the ICNARC data set. Full list of data set points will be available once project begins from the ICU Audit Coordinator on request.
Clinical Coding Scheme	ICNARC coding method and definitions used for one aspect of the data set. www.icnarc.org
Accessing data	Annual reports as agreed by ICU Audit Governance Committee and NOCA Governance Board and subsequently issued by NOCA.
Date collection commenced	Data collection will commence in early 2014
Published information/ Update frequency	Annual reports – once data collection commenced
Web address	http://www.noca.ie
Generic email contact	Not provided
Other comments	

Table 5.52	National Organ Procurement Service Statistics
Managing Organisation	National Organ Procurement Office at Beaumont Hospital
Contributor	Participating hospitals
Subject	PHL terms: TRANSPLANTATION, DONOR Keywords: organ donation, transplants, transplantation
Description/ Summary	All organ donations in the Republic of Ireland are coordinated through the Irish Organ Procurement Office at Beaumont Hospital. Strict ethical guidelines protect the interests of organ donors, their families, and transplant recipients.
Statement of Purpose	The purpose of this data collection is to have accurate national data on organs donated in the Republic of Ireland.
Coverage	All organs donated/transplanted in the Republic of Ireland.
Method of data collection	Data collated by the National Organ Procurement Office at Beaumont Hospital.
Data content	Number of referrals; donors (adult/paediatric; multi-organ/ kidney only); numbers of each organ retrieved; exported and transplanted. Donor details (age; blood type; cause of death; nationality). Participating hospitals; number of transplants and waiting list by centre. Live donors: number of live potential donors assessed; number of live transplants; relationship to transplantee; number of donors where transplant carried out abroad; number of live donor work up in process; number of donations not carried out and reason; live donors attending for annual follow up. Transplanted PT: dialysis stats; length of time on pool; number of first grafts.
Data dictionary	No
Clinical Coding Scheme	Not applicable
Accessing data	Annual report
Date collection commenced	The National Organ Procurement Service was created in 1986
Published information/ Update frequency	Annual reports published on Beaumont Hospital website and HSE website.

Web address	http://www.beaumont.ie/depts/support/transplant/organ_procurement.html http://hse.ie/eng/about/Who/qualityandpatientsafety/New_QPS/QPS_Programmes/National_Organ_Donation_and_Transplantation_Office.html
Generic email contact	nodto@hse.ie
Other comments	The National Organ Donation and Transplantation Office has been established in the HSE and is conducting a review of activity reporting requirements.

Table 5.53	National Paediatric Haemopoietic Stem Cell Transplantation Register
Managing Organisation	National Paediatric Haemopoietic, Stem Cell Transplant (HSCT) unit, Our Lady's Children's Hospital, Crumlin
Contributor	Haematology/Oncology Unit, Our Lady's Children's Hospital
Subject	Keywords: stem cell, donor, transplant
Description/ Summary	National data collection for patients who receive stem cell transplantation in Our Lady's Children's Hospital. This data is submitted to the European Group for Blood and Marrow Transplantation (EBMT) on an ongoing basis.
Statement of Purpose	The purpose of the European Group for Blood and Marrow Transplantation (EBMT) Registry is to provide a pool of data to perform retrospective studies, assess epidemiological trends, or prepare prospective trials.
Coverage	National data collection for patients who receive stem cell transplantation in Our Lady's Children's Hospital.
Method of data collection	Data taken from patients' healthcare records and laboratory systems.
Data content	Demographics, stem cells details and treatment, donor details, follow up
Data dictionary	No
Clinical Coding Scheme	Not applicable
Accessing data	Access restricted to relevant data management staff
Date collection commenced	1980s
Published information/ Update frequency	Ongoing updates. Peer-reviewed publications.
Web address	http://www.ebmt.org/
Generic email contact	registryhelpdesk@ebmt.org (EBMT Central Registry Office, UK)
Other comments	

Table 5.54	National Paediatric Mortality Register*
Managing Organisation	Irish Sudden Infant Death Association
Contributor	GP, coroner, pathologist, parents
Subject	Keywords: Sudden Infant Death Syndrome (SIDS), infant mortality, research, epidemiology, risk factors
Description/ Summary	The Paediatric Mortality Register obtains information on all sudden, unexpected/unexplained deaths in infants and young children in Ireland and conducts research into the identification of causes and prevention of sudden infant death as well as formulating childcare guidelines for parents on how best to reduce an infant's risk of SIDS. The register also provides and publishes accurate data on the incidence and categories of all paediatric deaths under 15 years on an annual basis (2010 onwards).
Statement of Purpose	To provide accurate up to date information on Sudden Infant Death Syndrome (SIDS) in Ireland.
Coverage	All Sudden Infant Deaths. Voluntary reporting to the register.
Method of data collection	If consent is obtained, cases are notified to the register by Emergency Department staff. Families are then contacted by the register and asked to participate in completing a questionnaire (via face to face interview with register personnel) relating to details of the mother's pregnancy and birth, infant health and wellbeing, parenting practices, socio-demographics and the circumstances surrounding the death of the infant. Post mortem results and medical records are also requested and obtained with the families' signed consent. Participation is voluntary. 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 register personnel only. The register's strength lies in the size and continuity of the dataset now comprising 500 SIDS cases and 1700 controls allowing trends in variables such as smoking rates, breastfeeding rates and use of medical services to be tracked on an annual basis.

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* Information relating to the National Paediatric Mortality Register was last updated for the 2010 publication of the Catalogue.

	Ongoing annual surveillance means that effects and changes in sudden infant death are monitored as they occur, with social and demographic factors documented alongside, enabling us to identify significant issues and needs as they occur. In relation to all paediatric deaths <15yrs, information on cause of death received form the CSO on a quarterly basis.
Data content	Content includes infant age; sex; infant birth weight; place of death; circumstances surrounding the infant's death; mother's pregnancy history; maternal and paternal smoking status; alcohol consumption; infant medications taken; sleeping arrangements.
Data dictionary	No
Clinical Coding Scheme	ICD-10 codes assigned by the CSO (Central Statistics Office)
Accessing data	Annual reports. Access to original paper version of questionnaires is restricted to register personnel only (locked filing cabinets). Access to the electronic database is further restricted to the register's two researchers (password protected files).
Date collection commenced	1992
Published information/ Update frequency	Annual reports published since 1993
Web address	www.sidsireland.ie
Generic email contact	Not provided
Other comments	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.

Table 5.55	National Perinatal Epidemiology databases: Perinatal Mortality Surveillance System, Severe Maternal Morbidity Audit and Surveillance of Homebirths Databases
Managing Organisation	The National Perinatal Epidemiology Centre (NPEC)
Contributor	Consultant Obstetricians and Midwives from the 20 Irish maternity hospitals/units and 15 self employed community Midwives
Subject	PHL terms: PERINATAL, MORTALITY, MATERNAL Keywords: perinatal mortality data, severe maternal morbidity data, major obstetric haemorrhage data, data relating to homebirths
Description/ Summary	NPEC Database is a computer based form designed to collect clinical information relating to perinatal mortality, severe maternal morbidity and homebirths in Ireland.
Statement of Purpose	The National Perinatal Epidemiology Centre is based in the University College Cork (UCC) Anu Research Centre in Cork University Maternity Hospital (CUMH). The overall objective of the Centre is to collaborate with Irish maternity hospitals to translate clinical audit data and epidemiological evidence into improved maternity services for families in Ireland. Achievement of their mission is carried out using a range of research methodologies, including prospective surveillance, Hospital In-Patient Enquiry (HIPE) data analysis, and systematic reviews. The specific roles of the Centre are: ■ to collaborate with government agencies to collate outcome data from maternity hospitals in Ireland; ■ to evaluate and publish nationally representative perinatal mortality and severe maternal morbidity data on an annual basis; ■ to contribute to the development of clinical protocols and guidelines based on analysis of data.
Coverage	National – all 20 Maternity Hospitals and self employed Community Midwives
Method of data collection	Data are submitted online or via paper based form to the NPEC database.

Data content	Includes details of admission; diagnosis; and procedures. Patient details include: age; gender; height; BMI; ethnicity; record of previous medical history; gestation; parity; date of delivery; mode of delivery; neonatal outcomes; date and time of birth; date and time of death; cause of death and associated factors.
Data dictionary	In progress – data dictionaries for all databases will be completed shortly
Clinical Coding Scheme	Coding classification developed by the NPEC
Accessing data	Annual reports, data requests
Date collection commenced	Data collection commenced in 2009
Published information/ Update frequency	Annual reports and peer reviewed journals
Web address	http://www.ucc.ie/en/npec/
Generic email contact	npec@ucc.ie
Other comments	

Table 5.56	National Perinatal Reporting System
Managing Organisation	With effect from January 1, 2014, the Healthcare Pricing Office (HPO) will have responsibility for the National Perinatal Reporting System (NPRS). While the HPO will initially be established on an administrative basis, it is planned that this Office will ultimately be established on a statutory basis.
Contributor	Irish maternity hospitals/departments and independent midwives
Subject	PHL terms: CHILDBIRTH, PREGNANCY, PERINATAL DEATH
Description/ Summary	The National Perinatal Reporting System (NPRS) has as its principal aim, the provision of national statistics on perinatal events.
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	All maternity hospitals/departments and independent midwives report to NPRS covering 100% of births in Ireland.
Method of data collection	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 validation. Approximately 40% of hospitals submit data electronically to the NPRS system.
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	Currently in development
Clinical Coding Scheme	ICD-10 for the coding of morbidity and mortality data
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 using the online data request form, available at www.hpo.ie. In addition annual reports on Perinatal Statistics are available at www.hpo.ie

Date collection commenced	NPRS was established in the 1980's and managed in the Department of Health. Between 1999 and 2013 the Economic and Social Research Institute managed the system on behalf of the Department of Health and the Health Service Executive. From January 1, 2014 the system is managed by the Healthcare Pricing Office (www.hpo.ie).
Published information/ Update frequency	*Perinatal Statistics Report* annual reports published on HPO website. www.hpo.ie
Web address	www.hpo.ie or www.nprs.ie
Generic email contact	nprs@hpo.ie
Other comments	

Table 5.57	National Physical and Sensory Disability Database (NPSDD)
Managing Organisation	National Health Information Systems Unit in the Health Research Board (HRB) in conjunction with the Department of Health
Contributor	Service providers (HSE and non-statutory)
Subject	PHL terms: PHYSICAL DISABILITY, SENSORY FUNCTIONS, DISABILITY CARE
Description/ Summary	The National Physical and Sensory Disability Database (NPSDD) is a set of information that outlines the specialised health services currently used or needed by people with physical/ sensory disability.
Statement of Purpose	The NPSDD is a service planning tool designed to capture data on the usage of and need for specialist disability services among people with physical and sensory disability.
Coverage	Registration is voluntary, there are more than 27,000 people registered on the database. (Registration is limited to individuals aged less than 66 years with a physical/sensory disability who are availing of, or who require, a specialised health or personal social service and who consent to register on the database).
Method of data collection	The Health Service Executive (HSE) areas administer the NPSDD but some service providers are responsible for the registration and review of their service users. Individuals wishing to participate are interviewed by their key worker or a data collector. A database form is completed and the data is recorded in the database by the service provider or HSE Local Health Officer personnel.
Data content	Personal and demographic details include date of birth, gender, primary carer details and living accommodation/arrangements. Service use information includes details of current services use and future service needs, technical aids and appliances, barriers and challenges, measure of participation restriction and WHODAS II.*
Data dictionary	Yes
Clinical Coding Scheme	Proprietary system based on ICD-10 for diagnostic information (Primary and secondary diagnosis); ICF for Measure of Activity and Participation (MAP) data.

Accessing data	Access to NPSDD data is guided by a strict protocol agreed and monitored by the NPSDD national committee. This governs access by researchers, HSE and service providers. A reporting module is available to authorised NPSDD users; access is based on role and level of responsibility. Annual reports and Local Health Office bulletins are produced. The HRB also publishes annual bulletins on the 'Measure of Activity and Participation' (MAP) data.
Date collection commenced	2002
Published information/ Update frequency	Data are collected on an ongoing basis and extracted each year to produce an annual report. Annual bulletins are published based on the 'Measure of Activity and Participation' (MAP) data.
Web address	http://www.hrb.ie/health-information-in-house-research/disability/npsdd/
Generic email contact	disability@hrb.ie
Other comments	*The WHODAS II (World Health Organisation's Disability Assessment Schedule) is a measure of the difficulty the individual has had with performing particular daily activities over a period of 30 days (from date of data form completion). The extent to which these difficulties have interfered with his/her life is also captured. An evaluation of the NPSDD was undertaken in 2003 (HRB, 2005); data validations are undertaken prior to, and after taking the national extract.

Table 5.58	National Poisons Information Centre Database
Managing Organisation	National Poisons Information Centre (NPIC)
Contributor	Hospitals, GPs, GP co-ops, community pharmacists, members of the public
Subject	PHL terms: POISONOUS SUBSTANCES Keywords: poisoning, human
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 reports. This is a database of enquiries to the National Poisons Information Centre from 2004 to date. Enquires from 1998 to 2003 inclusive are held on separate, older databases. For earlier years only annual reports (paper based) are available.
Statement of Purpose	To provide information to healthcare professionals, to assist them in the management of acute poisonings, give advice to members of the public on accidental poisoning in children and to collect and analyse epidemiological data on acute poisonings in Ireland.
Coverage	National data on enquiries received by the National Poisons Information Centre.
Method of data collection	The data are collected on paper at the time of the enquiry and later inputted into the database (UKPID). Selected enquiries are followed up by telephone to determine the outcome of the case.
Data content	Responder; enquirer; nature of enquiry; patient information; agent information; severity; response; outcome (in selected cases).
Data dictionary	No
Clinical Coding Scheme	WHO Adverse Reaction Terminology (ART) codes for features of poisoning. Poisoning Severity Score (PSS) for grading severity of poisoning.

Accessing data	Recent annual reports are available on the website. We can provide detailed data to regulatory authorities on request.
Date collection commenced	The current database was created in 2004. There are earlier computer databases for enquiries from 1999 to 2003 inclusive, and 1993 to 1998 inclusive. Only paper based annual reports are available for the years prior to 1993.
Published information/ Update frequency	Annual reports published
Web address	http://www.poisons.ie/index.asp
Generic email contact	npicdublin@beaumont.ie
Other comments	

Table 5.59	**National Psychiatric Inpatient Reporting System (NPIRS)**
Managing Organisation	NPIRS Team in the National Health Information Systems (NHIS) at the Health Research Board
Contributor	All approved centres under the Mental Health Act 2001.
Subject	PHL terms: PSYCHIATRIC CARE, IN-PATIENT SERVICES, HOSPITAL DISCHARGE/ADMISSION, MENTAL HEALTH
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.
Statement of Purpose	The NPIRS is a psychiatric database which provides detailed information on all admissions and discharges to in-patient psychiatric services in Ireland.
Coverage	All centres approved under the Mental Health Act 2001 including private psychiatric hospitals and child and adolescent units.
Method of data collection	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 or manually (paper-based).
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 admissions and discharge primary and secondary diagnosis. Other information includes: legal status on admission and reason for discharge; date of admission and discharge are also collected.
Data dictionary	Yes

Clinical Coding Scheme	The Clinical coding scheme is the WHO International Classification of Diseases (ICD 10).
Accessing data	Annual reports plus HSE area bulletins and a national bulletin are published. In addition, quarterly Performance Indicator (PI) reports are produced for the HSE on selected mental health indicators on the database. Excel tables are available on the HRB website; data is available on request. Data is also available on the Public Health Information System.
Date collection commenced	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.
Published information/ Update frequency	Data are returned on a quarterly basis to the HRB either electronically or manually (paper-based). A number of approved centres such as those not included in Performance Indicator reports (e.g., private hospitals and child and adolescent units) return data on annual basis.
Web address	http://www.hrb.ie/health-information-in-house-research/mental-health/information-systems/npirs-national-psychiatric-in-patient-reporting-system
Generic email contact	hrb@hrb.ie
Other comments	

Table 5.60	**National Registry of Deliberate Self Harm Ireland**
Managing Organisation	National Suicide Research Foundation (NSRF) on behalf of Department of Health. The Registry is funded by the HSE's National Office for Suicide Prevention.
Contributor	Irish hospital emergency departments
Subject	PHL terms: INJURY, POISONING, SELF-HARM
Description/ Summary	The National Registry of Deliberate Self Harm is a national system of population monitoring for the occurrence of deliberate self-harm in Ireland.
Statement of Purpose	The aims of the National Registry of Deliberate Self Harm are: ■ to establish the extent and nature of hospital-treated deliberate 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.
Coverage	National – all hospital-treated episodes of deliberate self-harm
Method of data collection	Since 2006, all data for deliberate self-harm presentations are recorded at the presenting hospital by registry data registration officers. Data is transferred electronically to the offices of the NSRF.
Data content	Includes detail of the presentation including: date and hour of attendance at hospital; brought to hospital by ambulance; method(s) of self harm; drugs taken; medical card status; recommended next care. Patient details including area of residence, gender and age.
Data dictionary	Yes
Clinical Coding Scheme	Method(s) of self harm WHO ICD-10
Accessing data	Annual and quarterly reports, data requests
Date collection commenced	1995
Published Information/ Update Frequency	Annual reports from the NSRF website. Quarterly reports are also available.

Web address	http://www.nsrf.ie/cms/
Generic email contact	info@nsrf.ie
Other comments	

Table 5.61	**National Renal Transplant Registry**
Managing Organisation	Beaumont Hospital
Contributor	Medical and nurse specialists in renal units throughout the Republic of Ireland.
Subject	PHL terms: TRANSPLANTATION, KIDNEY DISEASE, SURVIVAL RATE Keywords: renal transplant, outcome
Description/ Summary	This database is a renal database collecting data since 1964. It is used to assess graft and patient survival, monitor factors affecting outcome and monitor performance.
Statement of Purpose	The national registry is maintained for the recipients of renal and pancreas transplants and this aids the annual follow-up of patients which is essential for the long term survival of the allograft. The upkeep of a national registry is also 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 must also at all times comply 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	All consecutive renal transplants from 1964 to date
Method of data collection	Data is collated in the renal unit from healthcare records and laboratory reports.
Data content	Includes details on parameters at time of transplant, renal disease and source of transplant. Patient details include: gender; area of residence and date of birth.
Data dictionary	No
Clinical Coding Scheme	EDTA renal disease code
Accessing data	Beaumont Hospital Transplant Nephrology and Urology
Date collection commenced	2002

Published information/ Update frequency	On-going, continual update
Web address	http://www.beaumont.ie/
Generic email contact	Not provided
Other comments	

Table 5.62	**National Spinal Injuries Unit**
Managing Organisation	National Spinal Injuries Unit
Contributor	All Irish public hospitals
Subject	Keywords: spinal referrals; spinal injury
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.
Statement of Purpose	To capture all spinal injury referrals for the Mater Hospital.
Coverage	National
Method of data collection	Referral forms are faxed from referring hospital, then if the patient is admitted to the Mater Hospital, data from the medical inpatient chart is inputted by a Data Manager.
Data content	Demographics, mechanism, type and location of injury, American Spinal Injury Association Score, advice given, if inpatient – procedure information
Data dictionary	None at present
Clinical Coding Scheme	ICD-10
Accessing data	Contact the Data Manager in the Mater Hospital
Date collection commenced	In MS Excel database from June 2008, then using Patient Advocate Tracking System (P.A.T.S.) from Jan 2012.
Published information/ Update frequency	Six monthly and annual reports for audit and research purposes.
Web address	None at present
Generic email contact	None at present
Other comments	

Table 5.63	**NHS Blood and Transplant Audit UK & Ireland**
Managing Organisation	NHS Blood and Transplant Audit UK & Ireland (NHSBT) in conjunction with the Royal College of Surgeons Clinical Effectiveness Unit
Contributor	St. Vincent's University Hospital – SVUH (for Ireland) and all UK hospitals involved in liver transplantations.
Subject	Keywords: transplant; liver transplant; organ
Description/ Summary	NHS Blood and Transplant (NHSBT) is a special health authority of the NHS. As well as being responsible for providing a reliable, efficient supply of blood, organs and other services, NHSBT collects information about patients for use in analysis. SVUH submits data on all liver transplants in the Republic of Ireland to the National Transplant Database of NHSBT. The NHSBT provides database facilities where an electronic record is submitted at key times of transplantation.
Statement of Purpose	The purpose of this data collection is to have accurate national data on liver transplantation in Ireland.
Coverage	SVUH in Ireland only; all hospitals participating in liver transplants in UK
Method of data collection	Data is taken from healthcare record and entered via network to UK Transplant (UKT).
Data content	Data inputted to complete medical indices at specific times in transplant history.
Data dictionary	Data dictionary provided by NHSBT
Clinical Coding Scheme	Yes – disease codes based on NHSBT data set
Accessing data	Activity reports for Ireland available on organdonation.nhs.uk website
Date collection commenced	March 1st 1994
Published information/ Update frequency	See NHSBT for regularly released reports re Transplant Activity in the Republic of Ireland; Irish Transplant Activity Report 2006-2007
Web address	http://organdonation.nhs.uk
Generic email contact	Not provided
Other comments	

Table 5.64	Out of Hospital Cardiac Arrest Register (OHCAR)
Managing Organisation	OHCAR is based in the HSE North West Department of Public Health and is carried out in collaboration with the National Ambulance Service, National University Institute Galway and the Pre-Hospital Emergency Care Council (PHECC). The OHCAR Steering Group is responsible for directing the project and includes representatives from each organisation.
Contributor	OHCAR data is collected from existing sources including ambulance Patient Care Reports, ambulance call logs, hospital, and GP records.
Subject	Keywords: pre-hospital resuscitation, cardiac arrest, out-of-hospital cardiac arrest, OHCAR, Utstein Register
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.
Statement of Purpose	The purpose of the OHCAR register is to facilitate improvements in survival from OHCA in Ireland by fulfilling the following objectives: ■ establish the current OHCA survival rate; ■ identify factors that contribute to survival; ■ identify what could be done differently to improve survival; ■ provide regular feedback to service providers.
Coverage	National
Method of data collection	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. Currently trialling an electronic data collection tool in the Midlands with a view to extending OHCAR nationally. 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 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, Circulation* 110:3385-3397
Data dictionary	Yes – devised by the OHCAR Steering Group
Clinical Coding Scheme	Clinical coding scheme not used but drop down options based on Utstein dataset
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
Date collection commenced	Established in the North West since November 2007 and nationwide since 2012.
Published information/ Update 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. Two 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 and printed in-house in paper copy
Web address	www.nuigalway.ie/ohcar
Generic email contact	Not provided
Other comments	

Table 5.65	**Patient Treatment Register (PTR)**
Managing Organisation	The National Treatment Purchase Fund (NTPF) in conjunction with the Department of Health
Contributor	Irish public hospitals
Subject	PHL terms: WAITING TIMES, HOSPITALS
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.
Statement of Purpose	To measure waiting times for both in-patient/day-case and outpatient patients.
Coverage	44 Irish public hospitals report to PTR.
Method of data collection	When a patient is placed on an in-patient/day-case or outpatient public hospital waiting list their details are submitted by the hospital to the NTPF and placed on the PTR.
Data content	Waiting times for in-patient/day-case treatments and outpatient appointments in public hospitals.
Data dictionary	Not available
Clinical Coding Scheme	ICD 10–AM for in-patient/day-case. Not yet in place for outpatient data.
Accessing data	There is on-line access available to waiting times in information by hospital. Monthly reports are produced. Hospitals receive weekly reports.
Date collection commenced	The PTR began in 2005 and was rolled out nationally in 2006. In-patient/day-case (IPDC) completed nationally December 2007. Outpatient (OP) data collection started in October 2012.
Published information/ Update frequency	Reports published monthly on website
Web address	http://www.ntpf.ie
Generic email contact	Not provided
Other comments	

Table 5.66	**PHECC – Cardiac First Response Report (CFR Report)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC)
Contributor	Trained Responders; Ambulance control centres; Coronary Heart Attack Ireland Register (CHAIR); Out of Hospital Cardiac Arrest Register (OHCAR), PHECC Medical Advisory Group (MAG)
Subject	PHL terms: EMERGENCY CARE, AMBULANCE, PATIENT, PRE-HOSPITAL, CARDIAC, RESPONSE
Description/ Summary	The Cardiac First Response (CFR) report is a two-part patient record which collects data according to the international utstein-style template which ultimately summarises outcomes and survival rates following out of hospital cardiac arrests. When a trained responder attends an incident the patient information is recorded on a CFR report
Statement of Purpose	To collect data in order to summarises outcomes and survival rates following out of hospital cardiac arrests.
Coverage	All incidents where a trained responder is in attendance, national coverage
Method of data collection	Data on pre-hospital cardiac arrest is collected on the CFR Report each time a trained responder attends an incident. Out of hospital cardiac arrest data is collected from the following sources: CFR Report, Patient Care Report (PCR) Ambulance Service Control Centre Systems, destination hospital emergency departments(ED's), GP systems. It is collated, verified and entered in to the national out-of-hospital cardiac arrest register (OHCAR).
Data content	Patient details: name; age; gender; date of incident; time data; incident address/location type; history of coronary disease. Event details: collapse details; chest compression details; defibrillation details; return of spontaneous circulation (ROSC) details; medication and care management details; FAST assessment details; CFR Report handover details.
Data dictionary	No. Cardiac first response report completion guide published.
Clinical Coding Scheme	ICD-10 AM for incident location data.

Accessing data	CFR report is a two part report and access to the bottom carbon copy of the completed record is through the national ambulance service. Part 1 of the CFR report is handed over to the Emergency Department/ destination facility to which the patient is transported. Currently no annual report produced based on the CFR report only.
Date collection commenced	October 2008
Published information/ Update frequency	No annual report produced for cardiac first response
Web address	http://www.phecit.ie
Generic email contact	info@phecc.ie
Other comments	

Table 5.67	**PHECC – Patient Care Report (PCR)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC)
Contributor	Pre-hospital emergency care providers/ national ambulance service practitioners
Subject	PHL terms: EMERGENCY CARE, AMBULANCE, PATIENT, PRE-HOSPITAL, PRACTITIONER
Description/ Summary	The Patient Care Report (PCR) facilitates the collection of patient pre-hospital data by the practitioner from time of call to handover of patient to destination facility. The information is collected by statutory ambulance services, auxiliary and voluntary services and private ambulance service providers. Paper-based collection of patient data using the national PCR was commenced in the HSE ambulance service in July 2005 and was further rolled out nationally over a six month period. A pilot of electronic data capture commenced in October 2007 in HSE North East ambulance region; in 2008 in Belmullet ambulance station and further national since 2010 The data is collected real time at point of care whether paper or electronic system. Currently the paper-based data is accessed only by the ambulance service or by them on behalf of a third party. This data is used for strategic planning of the ambulance service, informs research into new skill, services/equipment. It can also assist in development of both service and individual training plans for the practitioners. The data is also used for clinical audit. The objective of the PCR is to facilitate a national framework to record accurate, robust and timely pre-hospital patient data which will provide a vital link in the continuum of patient care in the hospital/destination facility. The PCR provides vital clinical audit information for research into new skills, services, equipment and other resources required in the future.
Statement of Purpose	To facilitate a national framework to record accurate, robust and timely pre-hospital patient data which will provide a vital link in the continuum of patient care in the hospital/destination facility.
Coverage	National from mid 2010

Method of data collection	Patient information is entered on the paper PCR in real time. PCRs must be completed in all circumstances listed: - All emergency calls - All urgent calls - All calls where an 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: During handover at the Emergency Department (ED) in the hospital the top copy of the form is stored with the patient's hospital record/chart. The bottom copy is returned to the ambulance station where stored. Electronic process (piloted in a number of areas – see description above): The ambulance control centre collects patient data in response to calls from the public and the information is integrated with the electronic PCR system on tablet PCs in the ambulance. The auxiliary, voluntary and some private ambulance service providers also collect pre-hospital patient data. Shortly these providers will enter the information into a desktop version of the electronic PCR. This desk top version will be located in ten individual organisations headquarters only.
Data content	Includes the following: patient care report number; demographic data; ambulance region communications centre code; call data; incident information; patient's chief complaint; clinical impression; allergies; medications; past medical history; event details; vital observations; care management data; journey data; patient assessment; clinical status
Data dictionary	Guidebook for PCR and dataset definitions published on PHECC website
Clinical Coding Scheme	ICD 10-AM in the background for all fields possible.

Accessing data	Paper: The PCR data is accessed by retrieving the relevant paper records from storage in the individual ambulance headquarters of which there are 9 nationally including Dublin Fire Brigade. HSE Midlands scan all of their PCRs and they are stored on an electronic system in HSE Midlands ambulance headquarters. Electronic data: ■ via electronic viewing module called e-Triage ED at destination EDs to which the patient is being transported, ■ via electronic viewing module called e-Triage Station where practitioners/ambulance service managers have access to view the patient data, ■ via Reporting Module for access to aggregated data by ambulance service management and PHECC (Pre-Hospital Emergency Care Council). Access to identifiable data as follows: Assistant National Director of the Ambulance Service, Chief Ambulance Officers in the various HSE regions, Deputy Chief Ambulance Officers and Training Officers and Dublin Fire Brigade Management. Access to de-identified data: all practitioners have access to the patient de-identified record of the patient they administered care to and transported. The Auxiliary and Voluntary organisations access PCR data by retrieving their paper records from storage in their individual organisations headquarters.
Date collection commenced	Paper collection of patient data using the national Patient Care Report was commenced in the HSE ambulance service in July 2005 and was further rolled out nationally over a six month period. A pilot of electronic data capture commenced in October 2007 in HSE North East ambulance region/2008 in Belmullet ambulance station and national since 2010.
Published information/ Update frequency	Data collected each time a patient is treated and transported by the ambulance service. Data not published.
Web address	http://www.phecit.ie
Generic email contact	info@phecc.ie
Other comments	

Table 5.68	**PHECC – Patient Transport Report (PTR)**
Managing Organisation	Pre-Hospital Emergency Care Council (PHECC)
Contributor	Ambulance service practitioners
Subject	PHL terms: EMERGENCY CARE, AMBULANCE, PATIENT, PRE-HOSPITAL, TRANSPORT
Description/ Summary	The Patient Transport Report (PTR) records patient data on pre-planned patient ambulance transports for our patients and other scheduled journeys where the patient requires special vehicle or special care but limited to administration of oxygen or stretcher requirements.
Statement of Purpose	To record patient data on pre-planned patient ambulance transports for outpatients and other scheduled journeys where the patient requires special vehicle or special care but limited to administration of oxygen or stretcher requirements.
Coverage	Only used by a select number of services as some of the services prefer to capture all patient data, regardless of the care provided, on the PHECC Patient Care Report.
Method of data collection	Data collected at point of contact (i.e. each time a patient is transported by the ambulance service) on a paper report by the ambulance service practitioners.
Data content	Patient data: name; date of birth; age; gender. Patient status: walking/carrying chair/stretcher/other; medication; accompanied by. Transport details: date of call; incident number; from; to; reason for transportation; start time; finish time; station pin; vehicle call sign. Data elements: surname, first name, age, date of birth, gender, walking carrying chair, stretcher, other, patient medication, patient accompanied, date of call, incident number, transported from address, transported to address, Reason, start time, finish time, station PIN, vehicle call sign, practitioner PIN, Practitioner PIN.
Data dictionary	Not available
Clinical Coding Scheme	Not available
Accessing data	Access to records via ambulance service chief ambulance officer for that region
Date collection commenced	01/09/2007

Published information/ Update frequency	There are no formal annual reports published. Currently any published patient transport data is done so by the HSE Ambulance Centre Headquarters Control Centres from the data collected by them on their Control Centre Systems.
Web address	http://www.phecit.ie/DesktopDefault.aspx?tabId=982
Generic email contact	info@phecc.ie
Other comments	In the event of a patient who is transported in a taxi which is contracted to do specific journeys on behalf of the HSE ambulance service, the patient information is collected by the relevant HSE ambulance service communication centres.

Table 5.69	**Sentinel Flu Surveillance**
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	Sixty sentinel general practices through the ICGP; National Virus Reference Laboratory (NVRL); Departments of Public Health; Hospital ICUs; GP Out Of Hours Services; General Register Office; PCRS
Subject	Keywords: sentinel, influenza
Description/ Summary	It is a collaborative sentinel surveillance project involving the Irish College of General Practitioners (ICGP), the National Virus Reference Laboratory (NVRL) and the Departments of Public Health (HSE areas). Reports on the number of patients with influenza-like illness (ILI) on a weekly basis. Sentinel GPs send a combined nasal and throat swab to the NVRL, on at least five patients per week where a clinical diagnosis of ILI is made during the influenza season. Also operated in sentinel hospitals and schools.
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.
Coverage	5.7% of the national population (60 sentinel GP practices)
Method of data collection	Participating sentinel GPs email clinical returns to the ICGP coordinator each week and it is then collated in an Excel file which is emailed to HPSC. Virological data are received by HPSC in an Excel File from NVRL each week. At HPSC, clinical and virological data are imported into an MS Access database. HSE area Departments of Public Health send the sentinel school and hospital data to HPSC by email each week.
Data content	Patient demographics including: date of birth; gender and diagnosis. Epidemiological data including: vaccination status and laboratory test results.
Data dictionary	No
Clinical Coding Scheme	Not used
Accessing data	Weekly reports on website; annual report
Date collection commenced	2000

Published information/ Update frequency	Weekly and annual reports
Web address	http://www.hpsc.ie/hpsc/A-Z/Respiratory/Influenza/
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.70	Surveillance of Antimicrobial Consumption in Ireland
Managing Organisation	Health Protection Surveillance Centre (HPSC)
Contributor	The European Surveillance of Antimicrobial Consumption Network (ESAC-Net) is an international network aiming to collect information on the use of antibiotics and other anti-infective drugs, coordinated by the European Centre for Disease Prevention and Control (ECDC). HPSC provides the data from primary care and hospital care areas in Ireland to ESAC-Net.
Subject	Keywords: antimicrobial consumption
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.
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.
Coverage	42 acute hospitals participating; coverage of primary care is over 95%
Method of data collection	Hospitals pharmacies send data directly to HPSC by quarters. Primary care data are received on a monthly basis from IMS Health.
Data content	Hospitals provide data (ward/quantities/cost) on the antimicrobials (by product and pack) dispensed in each quarter. Primary care data are by quantity of antimicrobials (by product and pack) sold by retail pharmacy aggregated to sub-county level in each month.
Data dictionary	No
Clinical Coding Scheme	N/A
Accessing data	HPSC website
Date collection commenced	Community antimicrobial consumption: 2003 Hospital antimicrobial consumption: 2004
Published information/ Update frequency	Standalone twice yearly reports; annual reports; Epi-Insight articles

Web address	http://www.hpsc.ie/hpsc/A-Z/MicrobiologyAntimicrobialResistance/EuropeanSurveillanceofAntimicrobialConsumptionESAC/
Generic email contact	hpsc@hse.ie
Other comments	

Table 5.71	**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).
Contributor	Department of Social Protection, Central Statistics Office and General Register Office
Subject	PHL term: DEATHS
Description/ Summary	The data is collected under the Vital Statistics Act 1952 and Section 73 of the Civil Registration Act 2004.
Statement of Purpose	To collect vital statistics on all deaths in Ireland.
Coverage	All deaths in Ireland
Method of data collection	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 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	No
Clinical Coding Scheme	ICD-10
Accessing data	On-line from CSO website or in hard copy
Date collection commenced	Civil registration for deaths commenced in 1864
Published information/ Update frequency	Quarterly and annually
Web address	http://www.cso.ie/statistics/BirthsDeathsandMarriages.htm
Generic email contact	information@cso.ie
Other comments	

Table 5.72	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.
Contributor	Department of Social Protection, Central Statistics Office and General Register Office
Subject	PHL term: CHILDBIRTH
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.
Statement of Purpose	To collect vital statistics on live births in Ireland.
Coverage	All live births in Ireland
Method of data collection	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 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
Data dictionary	No
Clinical Coding Scheme	Not applicable
Accessing data	On-line from CSO website
Date collection commenced	Civil registration of births commenced in 1864
Published information/ Update frequency	Quarterly and annually
Web address	http://www.cso.ie/statistics/BirthsDeathsandMarriages.htm
Generic email contact	information@cso.ie
Other comments	

Table 5.73	Work Related Injuries Database
Managing Organisation	The Health and Safety Authority (HSA)
Contributor	Employers/self employed people
Subject	PHL terms: ACCIDENTS, OCCUPATIONAL HEALTH AND SAFETY
Description/ Summary	The systematic collection and analysis of data to monitor health and safety performance and identify major risks is vital for the effective functioning of the HSA. The HSA currently maintains in-house databases of reported injuries, complaints received, inspections and investigations and enforcement actions taken.
Statement of Purpose	■ To provide national statistics and trends on work-related accidents. ■ To inform the HSA on the effectiveness of its interventions. ■ To inform decision making regarding the optimal targeting of the Authority's resources.
Coverage	All workplace accidents that meet certain definitions are legally required to be reported to the HSA. Comparison of the HSA's database of work-related injuries with Central Statistics Office (CSO) estimates suggests that under-reporting remains a problem in some sectors.
Method of data collection	Employers are legally required to report incidents to the Authority when injuries cause four or more days' absence from work. Injuries are reported by filing in an incident report form (IR1) either online (through HSA website) or as a hard copy.
Data content	The data items include: incident details (date, time, location); injured party details (name, personal details); injury details.
Data dictionary	Not available
Clinical Coding Scheme	Not used
Accessing data	The following reports can be downloaded from www.hsa.ie: ■ Annual report ■ Annual Summary of Workplace Injury, Illness and Fatality Statistics ■ Website
Date collection commenced	The HSA has been gathering data since its inception in 1989.

Published information/ Update frequency	Annual reports. Lag of 2 years to calculate the rates due to use of CSO (Central Statistics Office) occupational numbers.
Web address	http://www.hsa.ie/eng/Statistics/
Generic email contact	Not provided
Other comments	

Table 5.74	**Workplace Fatalities Database**
Managing Organisation	The Health and Safety Authority (HSA)
Contributor	Employers/next of kin for self employed people
Subject	PHL terms: ACCIDENTS, MORTALITY, OCCUPATIONAL HEALTH AND SAFETY
Description/ Summary	The HSA has responsibility for maintaining the official database of workplace fatalities.
Statement of Purpose	■ To provide national statistics and trends on work-related accidents. ■ To inform the HSA on the effectiveness of its interventions. ■ To inform decision making regarding the optimal targeting of the Authority's resources.
Coverage	All workplace fatalities are legally required to be reported to the HSA.
Method of data collection	Employers (or next of kin for self-employed persons) are required to notify the HSA in writing upon the occurrence of a fatal accident in the workplace by filing in an incident report form (IR1) either online (through HSA website) or as a hard copy.
Data content	Name of deceased, location of accident, brief particulars of the accident
Data dictionary	No
Clinical Coding Scheme	Not used
Accessing data	The following reports can be downloaded from www.hsa.ie: ■ Annual report ■ Annual Summary of Workplace Injury, Illness and Fatality Statistics ■ Website
Date collection commenced	The HSA has been gathering data since its inception in 1989
Published information/ Update frequency	Annual reports

Web address	http://www.hsa.ie/eng/Statistics/
Generic email contact	Not provided
Other comments	

6

National Censuses

Table 6.1	Census of Population and other Population Data
Managing Organisation	Central Statistics Office (CSO)
Contributor	Population of Republic of Ireland
Subject	PHL terms: CENSUS, POPULATION
Description/ Summary	The Census of Population is a collection of information relating to persons and households in the Republic of Ireland. The Census of Population statistics are disseminated through a range of specialised publications, releases and other media.
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	De facto population
Method of data collection	Census - householder completion of census form
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	Yes
Clinical Coding Scheme	N/A
Accessing data	Interactive tables for the 1996, 2002, 2006 and 2011 censuses are available on the CSO website.
Date collection commenced	Historical census data since 1926 (and links to data pre-1926) available on the CSO website.
Published information/ Update frequency	Every 5 years
Web address	http://www.cso.ie/census
Generic email contact	Information@cso.ie
Other comments	Further information see: http://www.cso.ie/surveysandmethodologies/standard_reports_methods_quality.htm. Ethnic or Cultural Background data: The 8th volume of the Census 2002, the 5th Volume of the Census 2006 and Profile 7, Census 2011 (Ethnic and cultural background in Ireland) contain results relating to the Irish Traveller community, covering the main demographic and socio-economic topics distinguished in the census.

Table 6.2	**Health Service Personnel Census**
Managing Organisation	HR Management Information, Health Service Executive
Contributor	Each health service payroll covered by employment monitoring/ ceilings as set by the Department of Health
Subject	PHL terms: MEDICAL STAFF, HEALTH SERVICES, HUMAN RESOURCES MANAGEMENT
Description/ Summary	Health Service employment is measured through the Health Service Personnel Census which collates employment data in respect of the Health Service Executive, voluntary hospitals and certain Disability Services which are covered by the employment ceiling as set by the Department of Health in conjunction with the Department of Public Expenditure and Reform. The Health Service Personnel Census gathers data on staff employed in the public health service (Health Service Executive (HSE), the voluntary hospitals and certain agencies in the disability sector). The purpose of the census is to monitor the number of persons in whole-time equivalence (WTE) terms who are employed in the public health service by grade, gender, functional area and location on a monthly basis. The main propose of the Personnel Census is to measure health service employment, pay costs and project future pension commitments.
Statement of Purpose	To measure health service employment, pay costs and project future pension commitments.
Coverage	All agencies encompassed by Health Services Employment Control Framework.
Method of data collection	Monthly
Data content	Staff category; grade grouping; grade; type of administration (HSE, S38 Hospital, S38 other service; directorate; hospital group; ISA; agency; number (WTE and headcount); employment contract type and gender. Individual's personal data are not returned.
Data dictionary	Not available
Clinical Coding Scheme	Not applicable
Accessing data	HSE website "Fact Files". Information is widely circulated within the Health Service and to other official sources on a monthly basis and on request.
Date collection commenced	HR Management Information has been responsible for collecting and reporting data for the Health Service Personnel Census since 2006.

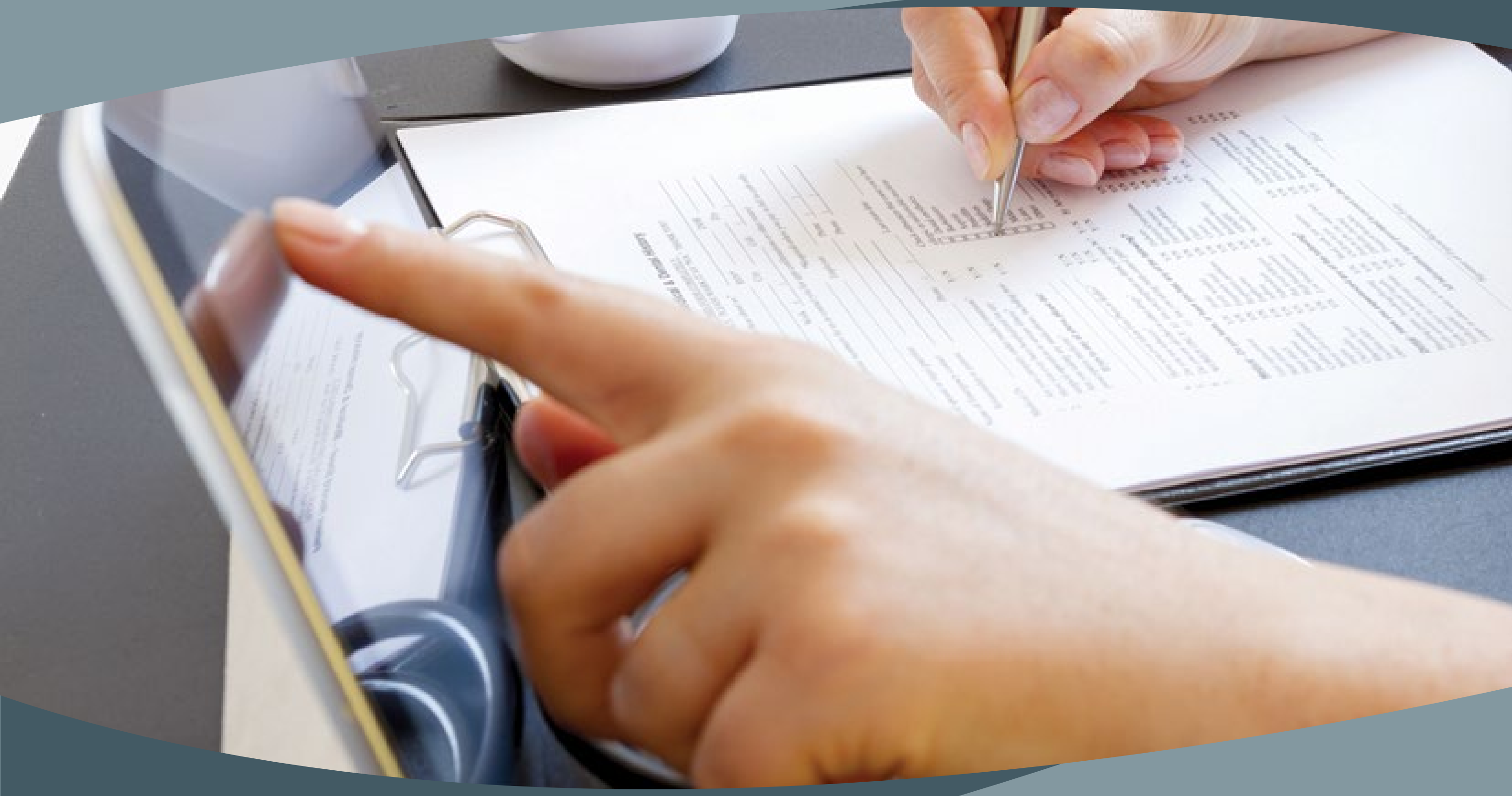
Published information/ Update frequency	Data is collected on a monthly basis
Web address	http://www.hse.ie/eng/staff/Resources/Employment_Reports/
Generic email contact	nemu@hse.ie
Other comments	

Table 6.3	**Irish Psychiatric Units and Hospitals Census**
Managing Organisation	National Psychiatric Inpatient Reporting System Team in the National Health Information Systems (NHIS) at the Health Research Board (HRB).
Contributor	All approved centres under the Mental Health Act 2001.
Subject	PHL terms: PSYCHIATRIC CARE, IN-PATIENT SERVICES, PSYCHIATRIC RESIDENTS/INPATIENTS, MENTAL HEALTH
Description/ Summary	The database records data on all residents (on 31st March of the census year in question) of psychiatric inpatient facilities on the register of approved centres under the Mental Health Act 2001.
Statement of Purpose	The census database is a psychiatric inpatient database which captures the number of patient's resident on a certain date. The census data are invaluable for the planning and future development of mental health services and they allow us to predict possible future bed and hospital requirements at both national and local levels.
Coverage	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.
Method of data collection	Data for the census are collected by each hospital/centre for each inpatient resident on 31st March and returned to the HRB either manually (paper-based) or electronically.
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 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	Yes
Clinical Coding Scheme	The clinical coding scheme is the WHO International Classification of Diseases (ICD-10).
Accessing data	Census report for each census year and a census bulletin. Data is available on request. Data is also available on the PHIS (Department of Health).

Date collection commenced	On advice from the Commission of Enquiry on Mental Illness (Department of Health, 1966), the Department of Health carried out a census of patients resident on 31st March 1963 in Irish psychiatric hospitals and information on all admissions, discharges and deaths thereafter was collected locally and returned to the Department of Health. On the establishment of the Medico-Social Research Board (MSRB), the census and admission data were transferred to that organisation for analysis and publication. The MSRB published the results of the 1963 psychiatric in-patient census (Walsh 1971), along with a composite publication of data for 1965–1969 (O'Hare and Walsh 1972). In 1971 the MSRB revised and improved this reporting from in-patient psychiatric facilities, commencing with a census on 31 March of that year. Subsequently, the MSRB, and later its successor, the Health Research Board (HRB), continued the series of annual activities reports on admissions, discharges and deaths and continued decennial censuses which became quinquennial in 2006. The most recent publicly available census was conducted in 2010.
Published information/ Update frequency	Census data are returned by all hospitals/units operating under the provisions of the Mental Health Act 2001 to the HRB either electronically or manually. 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 will take place every three years resources permitting.
Web address	http://www.hrb.ie/health-information-in-house-research/mental-health/information-systems/irish-psychiatric-units-and-hospitals-census
Generic email contact	hrb@hrb.ie
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 imported into the database it is validated by the database programme and errors are identified. Once data is corrected and imported, 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

Data collections without national coverage/ regional data collections



Cardiac surgery registers

The Irish Cardiac Surgery Register (ICSR) was set up in 1983 and contained information on cardiac surgery on adults in Ireland. The ICSR has fully ceased operation since 2007.

Currently data for cardiac surgery are collected in four centres in Ireland: Cork University Hospital, Galway University Hospital, Mater Misericordiae University Hospital and St. James's Hospital. Anonymised data from these registers are submitted on an annual basis to a database of the Society of Cardiothoracic Surgeons of Great Britain and Ireland and a report is published annually.

Information submitted by two of the centres, Cork University Hospital and Galway University Hospital is provided on the following page.

Table 7.1	Cardiac surgery register for patients attending Cork University Hospital
Managing Organisation	Cardiac Service Division, Cork University Hospital
Contributor	Cardiologists and Cardiothoracic Surgeons from the Cardiac Services Division, Cork University Hospital.
Subject	Keywords: cardiac surgery, cardio-thoracic surgery
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.
Statement of Purpose	To measure the quality of care of adult cardiac surgery and provide information for quality improvement and research.
Coverage	HSE South region
Method of data collection	Data is collected from the healthcare record and other systems in use in the hospital i.e. cardiac catheterisation laboratory, laboratory, clerical/secretarial.
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
Clinical Coding Scheme	N/A
Accessing data	Anonymous data is provided in the National Adult Cardiac Surgical Database Report, Society for Cardiothoracic Surgery in Great Britain and Ireland.
Date collection commenced	July 2002
Published information/ Update frequency	Data published in National Adult Cardiac Surgical Database Annual Report, Society for Cardiothoracic Surgery in Great Britain and Ireland.
Web address	http://www.scts.org/ http://www.eacts.org
Generic email contact	Not provided
Other comments	

Table 7.2	Cardiac Surgery Register for patients who attend Galway University Hospital*
Managing Organisation	Society for Cardio-Thoracic Surgery in Great Britain and Ireland (SCTS). The European Association for Cardio-Thoracic Surgery (EACTS)
Contributor	The cardiac surgery team in Galway University Hospital
Subject	Keywords: cardiac surgery; cardio-thoracic surgery
Description/ Summary	This is a register for all patients who attend the Galway University Hospital and undergo cardiac surgery.
Statement of Purpose	To measure the quality of care of adult cardiac surgery and provide information for quality improvement and research.
Coverage	All patients who attend Galway University Hospital for cardiac surgery.
Method of data collection	Data is entered directly into the electronic register with clinical validation.
Data content	Demographic; clinical; mortality dataset for patients undergoing cardiac surgery.
Data dictionary	Yes – see EACTS website
Clinical Coding Scheme	Not applicable
Accessing data	Published in an anonymised international report in the Society for Cardio Thoracic Surgery in Great Britain and Ireland (SCTS) and then uploaded onto EACTS.
Date collection commenced	May 2007
Published information/ Update frequency	Annual published in an anonymised international report.
Web address	http://www.scts.org; http://www.eacts.org
Generic email contact	Not provided
Other comments	

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* Information relating to the Cardiac Surgery Register – Galway University Hospital was last updated for the 2010 publication of the Catalogue.

Table 7.3	Eastern Area Cerebral Palsy Register
Managing Organisation	Central Remedial Clinic (CRC)
Contributor	Service providers for children with cerebral palsy (data collected by CRC epidemiologist).
Subject	Keywords: cerebral palsy; register
Description/ Summary	This is a confidential cerebral palsy (CP) Register for the Eastern area of Ireland (covering Greater Dublin, Kildare, Wicklow and Meath). Perinatal and paediatric descriptors are collected.
Statement of Purpose	To monitor trends in occurrence and severity of children with CP and to identify high risk categories with a view to informing prevention.
Coverage	Children born from 1976 onwards with a diagnosis of CP resident in the study area of Greater Dublin, Kildare, Wicklow and Meath.
Method of data collection	Data taken from medical charts all coded to numeric form.
Data content	Perinatal descriptors: place of birth; area of residence. Paediatric descriptors: type and severity of CP; additional disabilities; congenital anomalies; brain imaging results. Other: referral and treatment history nationality of parents.
Data dictionary	No
Clinical Coding Scheme	Single diagnosis study. Congenital anomalies ICD-10 for the European network, SCPE (Surveillance of Cerebral Palsy in Europe).
Accessing data	Summaries provided on requests from professionals and health services. Raw data not released except to the SCPE network (Surveillance of Cerebral Palsy in Europe). SCPE receives selected data excluding date of birth and area of residence.
Date collection commenced	1984
Published information/ Update frequency	Periodic. Bi-annual report to funding body – CRC Research Committee. Occasional presentations and publications.
Web address	Not available
Generic email contact	Not provided
Other comments	Data are anonymous - identified by code number. The epidemiological study can inform planning and monitoring of services.

Table 7.4	**Coronary Heart Attack Ireland Register (CHAIR)**
Managing Organisation	HSE
Contributor	Eight hospitals (HSE-S region, voluntary and private), with acute coronary care facilities, in Cork and Kerry.
Subject	Keywords: demographics, cardiac history, risk factors, medication, working diagnosis, investigations
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.
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.
Coverage	Pilot in HSE – South (Cork and Kerry) region. Voluntary participation.

Method of data collection	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 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 software provider) and the use of web-enabled access with data protected within the HSE firewall.
Data content	CHAIR information covers nine distinct areas: patient demographics; admission Details; thrombolysis details; risk factors; clinical details (procedures)+B3; investigations; medications at discharge; discharge details; follow up details CHAIR/CARDS 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	A user manual and data dictionary exist for CHAIR and CHAIR-CARDS.
Clinical Coding Scheme	Not applicable
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. The data has also been made available to certain researchers initially in UCC and more recently in TCD.
Date collection commenced	Between July 2002 and May 2003 (for all eight hospitals)
Published information/ Update frequency	Summary progress reports have been published 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. Past CHAIR data in process of analysis for eventual journal publication.

Web address	http://www.irishheart.ie/iopen24/chair-t-13_46.html
Generic email contact	Not provided
Other comments	CHAIR was a Department of Health initiative facilitated by the Southern Health Board. It was handed over to the HSE (on formation of HSE).

Table 7.5	e-Heartbeat
Managing Organisation	Health Services Executive (HSE)
Contributor	Prior to 2012, 21 acute hospitals were collecting data for Heartbeat. In 2012 there were significant changes and currently 6 out of 9 acute hospitals that perform Percutaneous Coronary Intervention (PCI) contribute data to e-Heartbeat. The following 6 centres are currently collecting data; Cork University Hospital, University Hospital Galway, St Vincent's Hospital Dublin, Mid Western Regional Hospital Limerick, AMNCH Tallaght and Beaumont Hospital. The plan is to recruit the remaining 3 centres in the near future: St James Hospital, Mater Misericordiae University hospital and Waterford Regional Hospital.
Subject	Keywords: demographic data, admission medications, discharge medications, reperfusion data, date and time of reperfusion, smoking cessation data, mortality data
Description/ Summary	The vision of the e-Heartbeat programme is to save lives in Ireland through implementing and assuring best practice in the care of acute myocardial infarction (AMI) patients using the American Institute for Healthcare Improvement (IHI) methodology to achieve sustainable improvement.
Statement of Purpose	The purpose of Heartbeat is to monitor, observe and improve the implementation of the Optimal Reperfusion Service (ORS) and evidence based discharge therapies for ST Elevation Myocardial Infarction patients.
Coverage	e-Heartbeat collects information on STEMI patients in 6 out of the 9 primary PCI centres.
Method of data collection	Data is collected and recorded by hospital staff on patients that are admitted with ST Elevation Myocardial Infarction (STEMI). Data forwarded to researcher at Trinity/St James's and entered on MS Access database. Researcher performs analysis on the data of all participating hospitals. Data is reported back to the hospitals each quarter. This includes their own data as compared to data across all hospitals.

Data content	Arrival time and date; gender; age at admission; early administration of aspirin; aspirin at discharge; Early administration of Beta- Blocker; Beta-blocker at discharge; ACE inhibitor or angiotensin receptor blockers (ARB) at discharge for patients with left ventricular systolic dysfunction; timely initiation of reperfusion (thrombolysis or percutaneous coronary intervention via recording of time and date); smoking cessation counselling; lipid lowering medication on discharge; in hospital mortality.
Data dictionary	A 'How to' Manual produced explaining all terms and including a datasheet.
Clinical Coding Scheme	Not used. STEMIs recognised via clinician diagnosis rather than a coding scheme.
Accessing data	Data presented at various events and distributed widely with HSE (Network Managers etc). Quarterly reporting of data to individual hospitals and others. Summary data can be publicly accessed via HSE website. Data can be accessed by individual PCI centres (for that centre's data). Reporting is still being developed.
Date collection commenced	Data collection commenced in Oct 2006. However changes were made to the data set and the number of centres contributing in early 2012. e-Heartbeat collects 54 data items using the ESRI HIPE portal system in 6 hospitals.
Published information/ Update frequency	Summary progress reports published on HSE website.
Web address	http://www.hse.ie/eng/staff/FactFile/HSE_Approach/Population_Health/Cardiovascular_Care_/Heart_Beat/
Generic email contact	Not provided
Other comments	

Table 7.6	**Heartwatch**
Managing Organisation	Irish College of General Practitioners (ICGP)
Contributor	Participant Heartwatch GP Practices
Subject	Keywords: cardiovascular disease, continuing care, interventions
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.
Statement of Purpose	The aim of Heartwatch is to reduce the morbidity and mortality of patients with cardiovascular disease (secondary prevention).
Coverage	20% of GPs nationwide
Method of data collection	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 content	Up to four patient visits annually; measures include current status of patient; risk factors; diet and exercise; medications and referrals.
Data dictionary	Yes
Clinical Coding Scheme	No
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.
Date collection commenced	2003
Published information/ Update frequency	Publications using Heartwatch data are available on the ICGP website at this address http://www.icgp.ie/go/research/heartwatch/reports
Web address	http://www.icgp.ie/heartwatch
Generic email contact	heartwatch@icgp.ie
Other comments	

Table 7.7	**EUROCAT South, East and South-East (Congenital Anomaly Registers)**
Managing Organisation	Departments of Public Health in association with EUROCAT central registry http://www.eurocat-network.eu/
Contributor	Cork and Kerry Teaching Hospitals, St Luke's Hospital Kilkenny, Waterford Regional Hospital, South Tipperary General Hospital, Wexford General Hospital; HSE community disability services, Irish Paediatric Hospitals and Central Statistics Office (CSO)
Subject	PHL terms: CONGENITAL ANOMALY, MALFORMATION, BIRTH DEFECTS, ABNORMALITY, PUBLIC HEALTH, POPULATION BASED REGISTRY, SURVEILLANCE
Description/ Summary	There are three active regional congenital anomaly registers in the Republic of Ireland. 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.
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 congenital anomalies.
Coverage	EUROCAT South covers the counties of Cork and Kerry in the South West of Ireland (population-based, all mothers resident in this geographic area). EUROCAT South-East covers the counties of Carlow, Kilkenny, Wexford, Waterford and South Tipperary. EUROCAT East covers Dublin and the Eastern region.

Method of data collection	A HSE registry nurse collects data from medical charts/records and codes data before entering it electronically on the EUROCAT local register. The registry is based on active case finding. Data for the registry includes hospital records from obstetric and neonatal departments, paediatric cardiology and orthopedics outpatient letters, Hospital In-patient Enquiry Data (HIPE), birth notifications, stillbirth certificates, Central Statistics Office (CSO) data on deaths in children up to the age of 2 years, post mortem examinations, and social allowance records. The national cytogenetic laboratory and the national centre for paediatric cardiology and cardiac surgery database are additional sources of confirmatory data.
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, smoking and alcohol status, illness during pregnancy and outcome of previous pregnancies is gathered.
Data dictionary	Yes – full data dictionary published on EUROCAT website http://www.eurocat-network.eu/content/EUROCAT-Guide-1.3.pdf http://www.eurocat-network.eu/aboutus/datacollection/guidelinesforregistration/previouscodingguides/instructionmanuals
Clinical Coding Scheme	ICD-10-AM McKusick/OMIM Code International Standard Classification of Education International Standard Classification of Occupations ATC Code Drug Description
Accessing data	Open access to anonymous data via the EUROCAT website. Researcher access to local anonymised data via a management approval process.
Date collection commenced	EUROCAT East data collection commenced in 1979 EUROCAT South data collection commenced in 1996 EUROCAT South-East data collection commenced in 1997
Published information/ Update 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.
Web address	http://www.eurocat-network.eu/ www.hse.ie/congenitalanomalyregistersireland
Generic email contact	
Other comments	

8

Systems that collate data from a number of different sources

National

European/International

National

Table 8.1	Ageing in Ireland
Managing Organisation	Central Statistics Office (CSO)
Description/ summary	The social partnership agreement 2003-2005 requested the CSO to support a move towards more evidence-based policy making. The National Statistics Board further requested that the CSO provide a comprehensive set of social indicators with emphasis on disaggregation by key characteristics such as age. Ageing in Ireland is published by the CSO, it examines the lives of people aged 65 and over in Ireland.
Data sources used to compile report	The following sources are used to compile this report: ▪ Census of Population 2002, 2006, ▪ Vital Statistics, ▪ EU Survey on Income and Living Conditions, ▪ Quarterly National Household Survey, ▪ Eurostat, ▪ Department of Social Protection, ▪ Hospital-In-Patient Enquiry, ▪ Annual Survey of Long Stay Units, ▪ Department of Health, ▪ Department of Environment, Heritage and Local Government.
Statement of Purpose	To provide a set of social indicators to examine the lives of people aged 65 and over in Ireland.
Coverage	Persons aged 65 and over in Ireland. Ireland is also compared to other EU countries and where available five additional countries (Turkey, Croatia, TFYR of Macedonia, Iceland, Norway and Sweden).
Methods of Collection	The CSO gathers the data from all sources and compiles the report.
Data content	The indicators included in this report cover the domains of: population; health and care; accommodation; economic situation and lifestyles. Under Health and Care it reports on life expectancy; hospital activity; health status; smoking death rates; prevalence of disability; carers.

Published Information/ Update frequency	Annual, first published in 2007
Web address	http://www.cso.ie/newsevents/pr_ageinginireland2007.htm
Generic email contact	information@cso.ie
Other comments	

Table 8.2	**Community Profiles Tool**
Managing Organisation	Institute of Public Health in Ireland (IPH)
Description/ Summary	The Community Profiles Tool can be used to develop local health and wellbeing profiles from over 200 health-related indicators compiled from a range of data sources. Users can create tables, maps and charts of health-related indicators, and integrate this with key public health documents from the Health Well website such as relevant interventions, policies, and evidence related to each indicator.
Data Sources used to compile the report	■ An Garda Síochána, Republic of Ireland ■ Central Statistics Office, Republic of Ireland ■ Central Services Agency, Northern Ireland ■ Central Survey Unit, Northern Ireland ■ Communicable Disease Surveillance Centre, Northern Ireland ■ Department for Social Development, Northern Ireland ■ Department of Education, Northern Ireland ■ Department of Education and Skills, Republic of Ireland ■ Department of Enterprise, Trade and Investment, Northern Ireland ■ Department of Environment, Heritage and Local Government, Republic of Ireland ■ Department of Finance and Personnel, Northern Ireland ■ Department of Health, Republic of Ireland ■ Department of Health and Social Services and Public Safety, Northern Ireland ■ Department of Social Protection, Republic of Ireland ■ Environmental Protection Agency, Republic of Ireland ■ Economic and Social Research Institute, Republic of Ireland ■ Health Protection Surveillance Centre, Republic of Ireland ■ Health Research Board, Republic of Ireland ■ Health Service Executive, Republic of Ireland ■ Irish Social Science Data Archive, University College Dublin, Republic of Ireland ■ Local Government Services Management Board, Republic of Ireland

	■ National Cancer Registry Ireland ■ Northern Ireland Cancer Registry ■ Northern Ireland Fire and Rescue Service ■ Northern Ireland Housing Executive ■ Northern Ireland Neighbourhood Information Service ■ Northern Ireland Statistics and Research Agency ■ Police Service of Northern Ireland ■ Primary Care Reimbursement Service, Republic of Ireland.
Statement of Purpose	To develop local health and wellbeing profiles from over 200 health-related indicators compiled from a range of data sources.
Coverage	Local Authority area (county councils and city councils) in the Republic of Ireland and every Local Government District in Northern Ireland.
Method of data collection	Data is coordinated by the Institute of Public Health in Ireland.
Data content	The indicators cover a wide range of public health issues and are grouped into themes such as obesity; diabetes; mental health; hypertension; living conditions; working conditions
Published information/ Update frequency	Quarterly reviews and updates depending on the availability of updated indicator data.
Wed address	http://www.thehealthwell.info/community-profiles/
Generic email contact	data-manager@thehealthwell.info
Other comments	With the Community Profiles, users can: ■ Build customised data tables of health-related indicators by selecting individual indicators or all the indicators in a specific theme for up to four geographical areas. ■ Create a map of any indicator to see how it varies across the island. ■ Browse details of key public health documents from the Health Well related to any indicator or theme. ■ Carry out more complex analyses using The Health Well's online data tools which includes mapping and graphing features. ■ Download data tables, charts and maps to your computer or save other relevant materials in your (free) online user MyWell account.

Table 8.3	**CompStat**
Managing Organisation	Planning, Performance and Business Information Unit of the Chief Operating Officer and Deputy Director General of the Health Service Executive (HSE)
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 Mid-Leinster, Dublin North East, South and West) 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 in-patient, out-patient and day-case perspective and on community services metrics from a Local Health Office (LHO) which is representative of all care groups.
Data Sources used to compile the report	Data from 29 Irish public hospitals and 32 LHO, the National Hospitals Office, Casemix/HIPE, Finance, Human Resources
Statement of Purpose	The purpose of Compstat is to enable monthly management of hospital and Local Health Office performance using a scorecard performance report on a suite of relevant metrics.
Coverage	50 public hospitals and 32 Local Health Offices
Method of data collection	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 and community services.
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. Access measures the waiting times that people experience for different services. Resources assesses whether a hospital or Local Health Office (LHO) is making best use of its human and financial resources.
Published information/ Update frequency	Monthly

Web address	http://www.hse.ie/eng/about/Who/corpoperf/
Generic email contact	compstat@hse.ie
Other comments	

Table 8.4	Drug Situation Ireland
Managing Organisation	National Health Information Systems Unit, Health Research Board (HRB)
Description/ Summary	Each year, the National Health Information Systems Unit of the HRB presents a report on the drugs situation in Ireland to the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA). The Report - Ireland Drugs Situation – is integrated into the EMCDDA's annual report on the state of Drugs Problem in the European Union and Norway.
Data Sources used to compile this report	The following sources are used to compile this report: ■ Drug treatment figures (source: National Drug Treatment Reporting System, HRB); ■ Drug use in the general population (source: general population survey, National Advisory Committee in Drugs; ■ Problematic opiate use (source: capture-recapture study, NACD); ■ Drug-related deaths (source: General Mortality Register, CSO); ■ Drug-related infectious diseases (source: Health Protection Surveillance Centre, HSE); ■ Drug-related crime figures (source: An Garda Síochána and Revenue Commissioners); ■ Drug-related prevention information (source: Health Promotion Unit and Department of Education and Science); ■ Demand reduction interventions (source: Local and Regional Drug Task Forces). Also reported is any new research that has been carried out in the drugs area in Ireland. In addition, any new developments in policy or strategy, legislative measures in the drugs area, public opinion on drugs, etc.
Statement of Purpose	Annual reporting on the drug situation in Ireland for comparative purposes.
Coverage	Member states of the European Union
Method of data collection	Data collated by the HRB and submitted to the EMCDDA

Data content	The annual 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; drugs markets; demand/reduction; interventions; key issues arising.
Published information/ Update frequency	Annual report published by the EMCDDA; annual reports specific to Ireland 2002-2012.
Web address	http://www.emcdda.europa.eu/publications/country-overviews/ie; http://www.drugsandalcohol.ie/php/annual_report.php
Generic email contact	ndc@hrb.ie
Other comments	

Table 8.5	**Health Atlas Ireland**
Managing Organisation	Health Intelligence Unit, Health and Wellbeing Directorate, Health Service Executive
Description/ summary	Health Atlas Ireland supports 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. 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 Health Intelligence HSE. It evolved in collaboration with many agencies including: ▪ Health Protection Surveillance Centre, ▪ Health Service Executive, ▪ Information and Communication Technology - Health Service Executive, ▪ Department of Health, ▪ Royal College of Physicians Ireland, ▪ Royal College of Surgeons Ireland, ▪ Central Statistics Office, ▪ Ordnance Survey Ireland , ▪ GeoDirectory, ▪ University College Dublin, ▪ National University Ireland Maynooth, ▪ Dublin City University, ▪ Primary Care Reimbursement Service - Health Service Executive, ▪ 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 sources used to compile report	Health Atlas Ireland enables controlled access to a suite of datasets collected by other parties.

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	Republic of Ireland
Methods of Collection	Data is made available to Health Atlas Ireland, Health and Wellbeing Directorate, HSE from the primary data collections.
Data content	Health Atlas Ireland provides an analytical and display "window" to a range of datasets including: demography; hospital activity; prescribing; mortality; financial; human resource; service location; range of mapping functions.
Published Information/ Update 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 find patient addresses, 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.
Web address	https://www.healthatlasireland.ie
Generic email contact	healthintelligenceireland@hse.ie
Other comments	Health Atlas Ireland is a multi-level enabler that promotes easy access, analysis and display of data that is relevant to all health domains.

Table 8.6	Health in Ireland – Key Trends
Managing Organisation	Information Unit, Department of Health
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 Sources used to compile this report	Department of Health and other public agencies financial records, European Social Fund, National Lottery and DSP (Department of Social Protection) Treatment Benefit financial records, Health Insurance schemes estimates and CSO (Central Statistics Office) estimates of household expenditure on medical goods and services.
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.
Coverage	National
Method of data collection	Compiled from various sources.
Data content	Population and life expectancy; health of the population; hospital care; primary care and community services; health service employment; health service expenditure.
Published information/ Update frequency	Annually
Web address	http://www.dohc.ie/statistics/
Generic email contact	http://www.dohc.ie/about_us/contact/custserv.html
Other comments	

Table 8.7	**Irish Casemix Programme***
Managing Organisation	Casemix/HIPE unit within the Health Service Executive
Description/ Summary	Casemix is an internationally accepted system which allows for the monitoring and evaluation of health services. It is simply the comparison of activity and costs between hospitals (for management purposes) by classifying hospital data into a manageable number of discrete groups called DRGs (Diagnosis Related Groups), which are clinically similar and consume similar resources (e.g. appendectomy, hip replacement). Casemix allows for the collection, categorisation and interpretation of hospital patient data related to the types of cases treated, in order to assist hospitals define their products, measure their productivity and assess quality. In an era of evidence based medicine, Casemix contributes towards evidence based management. Casemix is an international system, with the same basic principles of data collection, classification, funding 'like-with-like' and taking high cost and unique issues into account. One of the key features of Casemix that has helped it spread around the world in just twenty years is that the data is freely shared and there is a strong focus on Peer Group review. Casemix provides a common language that supports a unique collaboration between clinicians, statisticians, accountants, managers, funders and policy makers. A national Casemix Project was established in 1991 and the first financial allocations were applied in 1993.
Data Sources used to compile the report	■ HIPE (Hospital In-Patient Enquiry) ■ Annual accounts of the hospitals
Statement of Purpose	To collect, and compare Irish hospitals' activity and costs data.
Coverage	38 public hospitals
Method of data collection	Activity data comes from HIPE (Hospital In-Patient Enquiry) and cost data comes from the annual accounts of the hospital via a standardised costing returns form which contains a detailed breakdown of the hospitals' finances.

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* A new Healthcare Pricing Office (HPO) was established on an administrative basis on 01.01.2014. This new structure was established through the merging of the National Casemix Programme in the HSE and the Health Research and Information Division in the ESRI. As a result the details in relation to the National Casemix Programme as outlined here are currently changing and this information will be updated in due course.

Data content	HIPE Data: age; gender; diagnoses; procedures; type of admission; mode of emergency admission; source of admission; date of admission; date of discharge; discharge destination, infant admission weight; marital status; medical card indicator; GMS (General Medical Services) patient number; area of residence; patient status on discharge; day case identifier; day ward indicator; day ward ID; ITU/ICU days; consultant identifiers; consultant types, days in private/ semiprivate bed; days in public bed; procedure dates; ward ID; temporary leave days. Costing Data: in general the data are collected under the following broad categories: OPD clinics; ED and non-Casemix specialties; externs; overheads; radiology; medical services; theatres; wards; labs; HIPE data.
Published information/ Update frequency	HIPE data is collected on an ongoing basis. Costing data is collected annually. General public, bodies/groups external to HSE and non-casemix participants - data requests. Casemix Hospitals - Casemix Annual Circular, Casemix Annual Report, Casemix Peer Group Package, Casemix KPIs, Shared Information System
Wed address	http://www.casemix.ie
Generic email contact	Not provided
Other comments	The Irish Casemix Programme places high importance on good quality data. Audit is therefore an integral part of all data collection programmes, specifically the HIPE and the Specialty Costing Systems. The HIPE Coding Audit Toolkit is integrated with the W-HIPE software to facilitate efficient and consistent auditing both nationally and locally. The principal aim of the software is to assist the hospital personnel in the auditing process, which in turn raises the overall quality of the data both within the hospital and nationally. On an annual basis a full reconciliation of activity data and financial data is undertaken by the Casemix Specialty Costing team in order to ensure accuracy of costing returns. As part of this process, queries are sent out to the Casemix hospitals requesting clarification on any changes in activity levels which are beyond what could be normally expected. The results of both of these processes are taken into account in the final budget adjustments each year.

Table 8.8	**Public Health Information System (PHIS)**
Managing Organisation	Information Unit, Department of Health
Description/ Summary	The Public Health Information System (PHIS) is a collection of tables of health-related data produced by the Department of Health.
Data Sources used to compile this report	Data sources include the Central Statistics Office; Economic and Social Research Institute; Health Research Board; and the National Cancer Registry of Ireland.
Statement of Purpose	To collate and summarise health-related data.
Coverage	National - data on hospital discharges refer to public acute hospitals only
Method of data collection	Data are requested from a wide range of sources including the Central Statistics Office, Economic and Social Research Institute, Health Research Board and National Cancer Registry. The data are formatted and categorised by the Information Unit and loaded onto the PHIS database.
Data content	PHIS contains tables on cancer; demography; fertility; hospital discharges; mortality and psychiatric admissions.
Published information/ Update frequency	PHIS tables are updated as and when new data becomes available from the individual data sources.
Web address	http://www.thehealthwell.info/phis-tables?source=hometabs
Generic email contact	Not provided
Other comments	

Table 8.9	**State of the Nation's Children**
Managing Organisation	Research Division, Department of Children and Youth Affairs.
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 Department of Children and Youth Affairs (DCYA) in association with Central Statistics Office and the Health Promotion Research Centre of the National University of Ireland, Galway prepares this publication.
Data sources used to compile report	The following sources are used to compile this report: ▪ Census of the Population; ▪ Child Care Interim Dataset; ▪ Education Welfare Board Database; ▪ European Health for All Database; ▪ European School Project on Alcohol and Drugs (ESPAD) Survey; ▪ European Union Survey of Income and Living conditions (EU-SILC); ▪ Garda Annual Report; ▪ Health Behaviour of School-Aged Children (HBSC) Survey; ▪ Hospital In-Patient Enquiry (HIPE); ▪ Immunisation Uptake Statistics; ▪ Kidscreen; ▪ National Health Services Performance Indicators; ▪ National Intellectual Disability Database (NIDD); ▪ National Perinatal Reporting System (NPRS); ▪ National Physical and Sensory Disability Database (NPSDD); ▪ National Psychiatric In-Patient Reporting System (NPIRS); ▪ Patient Treatment Register (PTR); ▪ Population Estimates; ▪ Post-Primary Pupil Database; ▪ Programme for International Student Assessment (PISA) Survey;

	■ Quarterly National Household Survey (QNHS); ■ Triennial Assessment of Housing Need published in the Quarterly Bulletin on Housing Statistics; ■ Tuarascáil Staitistiúil; ■ Vital Statistics.
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.
Coverage	National - children aged 0-17 years
Methods of Collection	The State of the Nations Children reports use data drawn for the most recent and most reliable administration, survey and census sources including those sources listed above.
Data content	Socio-demographics; children’s outcomes health; children’s outcomes social; emotional and behavioural; formal and informal supports
Published Information/ Update frequency	Biennial
Web address	http://www.dcya.gov.ie
Generic email contact	dcyaresearch@dcya.gov.ie
Other comments	The State of the Nations Children series will be continued as part of the implementation of the National Strategy for Research and Data on Children’s Lives, 2011-2016.

Table 8.10	**Statistical Information on Social Welfare Services**
Managing Organisation	The Department of Social Protection
Description/ Summary	Comprehensive data relating to the recipients and beneficiaries of services provided by the Department of Social Protection.
Data Sources used to compile this report	Information is provided from the following sources: ■ Department of Social Protection ■ Department of Finance ■ Department of Enterprise, Trade and Innovation ■ Office of the Revenue Commissioners ■ Health Service Executive
Statement of Purpose	To provide a source of reliable statistical data for the development and implementation of policies to protect those dependent on social welfare.
Coverage	All recipients and beneficiaries of services provided by the Department of Social Protection in Ireland.
Method of data collection	Data is generated by various scheme owners throughout the Department of Social Protection who forward their information to the Statistics Unit to be collated into the Annual Statistical Report.
Data content	Information includes details of expenditure on, and recipients and beneficiaries of: jobseeker's benefit and allowance; illness benefit; invalidity pension; disability allowance; blind pension; carer's allowance; carer's benefit; injury benefit and occupational injury benefits and other social protection schemes.
Published information/ Update frequency	Annual reports published around July of each year and made available on the Department website.
Web address	http://www.welfare.ie/EN/Policy/ResearchSurveysAndStatistics/Pages/StatInfoReportsIndex.aspx
Generic email contact	Not provided
Other comments	

Table 8.11	Women and Men in Ireland
Managing Organisation	Central Statistics Office (CSO)
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 Sources used to compile this report	The following sources are used to compile this report: ■ Central Statistics Office ■ Eurostat ■ Department of Social and Family Affairs ■ Revenue commissioners ■ Inter-Parliamentary Union Database ■ Department of Finance ■ Irish Sports Council ■ Arts Council ■ Department of Education and Science ■ Health Service Executive ■ Hospital Inpatient Enquiry ■ Information Unit, Department of Health ■ Health Research Board ■ National Intellectual Disability Database ■ Irish Prison Service ■ Road Safety Authority ■ National Roads Authority ■ Department of the Environment, Heritage and Local Government ■ United Nations Economic Commission for Europe
Statement of Purpose	To conduct a social indicator report to identify important gender differences in the activities of men and women.
Coverage	National. Ireland is compared to other EU countries and where available five additional countries (Turkey, Croatia, Macedonia, Iceland, Norway and Switzerland).

Method of data collection	The CSO gathers the data from all sources and compiles the report.
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.
Published information/ Update frequency	Annual from 2004 to 2012 and bi-annual from 2012 onwards, so the most recent publication was in February 2012 (with a reference year of 2011) and the next report will be published in 2014 (with a reference year of 2013).
Web address	http://www.cso.ie/en/releasesandpublications/womenandmeninireland/womenandmeninireland2011/
Generic email contact	information@cso.ie
Other comments	

European/International

Table 8.12	**European Health for all Database (HFA-DB)**
Managing Organisation	World Health Organization (WHO) European Office, Copenhagen, Denmark
Description/ summary	HFA-DB 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 sources used to compile report	The data comes from: ■ an extensive network of country experts working in statistical, monitoring and surveillance units in ministries; ■ WHO/Europe's technical programmes; and ■ partner organizations such as the Organisation for Economic Co-operation and Development (OECD).
Statement of Purpose	To collate independent, comparable and up to date health statistics for all WHO Member States in the European region.
Coverage	The database includes data for all 53 WHO Member States in the European Region, although data availability and comparability may be limited for some countries. The database covers the period from 1970 to the present.
Methods of Collection	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 twice a year for an update of the 600 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.
Data content	HFA-DB is updated biannually and contains about 600 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).

Published Information/ Update frequency	Bi-annually
Web address	http://www.euro.who.int/hfadb
Generic email contact	Not provided
Other comments	

Table 8.13	**Eurostat Health Statistics**
Managing Organisation	Eurostat
Description/ summary	Eurostat is the Statistical Office of the European Commission. It collects and collates data on a wide range of themes including health statistics. The data navigation tree contains a number of folders under the two main headings of public health and health and safety at work. Under public health, some of the sub-headings include: healthy life years at birth, causes of death, healthcare expenditure (i.e. hospitals and GPs), healthcare resources and patients (non-expenditure data), healthcare indicators from Survey of Income and Living Conditions (EU-SILC). Under health and safety at work, some of the sub-headings include: Accidents at work, Work-related accidents and Health problems.
Data sources used to compile report	Member States submit data from a number of sources including National Statistical Offices, Social Security institutes, Ministries of Health and Ministries responsible for Labour Affairs.
Statement of Purpose	To collect and collate data on a wide range of themes including health statistics.
Coverage	European Union, the former Yugoslav Republic of Macedonia, Albania, Iceland, Norway and Switzerland
Methods of Collection	Eurostat sends out a request for data annually. Each Member States submits data on an excel spreadsheet. Eurostat validates and collates the data for publication on its website and for inclusion in its publications. In addition to above, data is transmitted annually to Eurostat, OECD and the WHO by means of the joint data collection on non-monetary healthcare statistics. This joint data collection is a harmonised approach developed by Eurostat, OECD and World Health Organisation in order to reduce the data collection burden on countries.
Data content	Public health data; health and safety at work data
Published Information/ Update frequency	Annually
Web address	http://epp.eurostat.ec.europa.eu/portal/page/portal/health/introduction
Generic email contact	Not provided
Other comments	

Table 8.14	Organisation for Economic Co-Operation and Development (OECD) Health Data
Managing Organisation	The Health Division, within the Directorate for Employment, Labour and Social Affairs 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 thirty three member states. Much of the information pertains to health expenditure and financial data.
Data sources used to compile report	Production of the OECD health data is by contribution from the national data correspondents and international organisations. The national source in Ireland is the Department of Health and the Central Statistics Office.
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 advisors in governments, the private sector and the academic community, to carry out comparative analyses and draw lessons from international comparisons of diverse healthcare systems.
Coverage	Thirty-three member states of the OECD. Data goes back to 1960 where available.
Methods of Collection	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 Central Statistics Office) 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.
Data content	Health status; healthcare resources and utilisation; long term care resources and utilisation; health expenditure; pharmaceutical consumption and non medical determinants of health.
Published Information/ Update frequency	Annual
Web address	http://www.oecd.org/els/health-systems/
Generic email contact	Not provided
Other comments	

Table 8.15	World Health Organization Global Health Observatory
Managing Organisation	World Health Organization
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. The WHO Statistical Information System (WHOSIS) has recently been upgraded and incorporated into the GHO.
Data sources used to compile report	Data sources are civil registration authorities, population censuses, household surveys, administration reporting systems, surveillance systems and facility reporting systems of Member States.
Statement of Purpose	To provide easy access to country data and statistics with a focus on comparable estimates and to WHO’s analyses to monitor global, regional and country situation and trends.
Coverage	The 194 members of the World Health Organization
Methods of Collection	Annual compilation of data from the Member States.
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 World Health Organization’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.
Published Information/ Update frequency	Annual
Web address	http://www.who.int/gho/en/
Generic email address	gho_info@who.int.
Other comments	

9

National Surveys

Table 9.1	European Social Survey
Description/ Summary	The European Social Survey (ESS) is an academically-driven social survey designed to chart and explain the interaction between Europe's changing institutions and the attitudes, beliefs and behaviour patterns of its diverse populations. The project is directed by the Centre for Comparative Social Surveys, City University, UK.
Managing Organisation	Centre for Comparative Social Surveys, City University, UK
Contributors	36 European countries including Ireland participating
Data content	The questionnaire includes two main sections, each consisting of approximately 120 items; a 'core' module which remains relatively constant from round to round, plus two or more 'rotating' modules, repeated at intervals. The core module aims to monitor change and continuity in a wide range of social variables, including media use; social and public trust; political interest and participation; socio-political orientations; governance and efficacy; moral; political and social values; social exclusion, national, ethnic and religious allegiances; well-being; health and security; human values; demographics and socio-economics. Examples of health questions - 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?
Coverage	36 European countries including Ireland
Methods of Collection	Face to face interviews across Europe
Published Information/ Update frequency	Biennial, 2002 - 2012. The data are available free of charge and without restrictions, for not-for-profit purposes. To access data files, you have to register as an ESS data user.
Web address	http://www.europeansocialsurvey.org/
Generic email contact	ess@city.ac.uk
Other comments	

Table 9.2	**Growing Up in Ireland**
Description/ Summary	The main aim of this national longitudinal study of children is to paint a full picture of children in Ireland and how they are developing in the current social, economic and cultural environment. This information will be used to assist in policy formation and in the provision of services which will ensure all children have the best possible start in life. The study will take place over seven years and follow the progress of two groups of children (at age of selection - nine-year old children and nine-month old infants).
Managing Organisation	The Department of Children and Youth Affairs
Contributors	A consortium of researchers led by the Economic and Social Research Institute (ESRI) and Trinity College Dublin.
Data content	The main health topics covered are summarised below. The dataset includes a wide range of topics in addition to health information. Child Cohort – birth weight, gestational age at birth, mode of delivery; time spent in neonatal intensive care unit (NICU), breastfeeding; any on-going chronic physical or mental health problems; accidents or injuries requiring hospitalisation, child’s use of health services, hospital in-patient, A&E; dental care; physical, emotional or mental health; speech and hearing; diet and exercise; current height and weight (measured by interviewer for parents and child); medical card and private health insurance coverage. Also some information on parent health (general health rating, chronic conditions, depression, cigarette and alcohol use). At 13 years, additional information on pubertal development and young person’s cigarette and alcohol use is collected. Infant Cohort – similar health topics as child cohort at Wave 1 but with additional information on head circumference, breastfeeding, developmental status, and viral infections at 9 months. Infant cohort at 3 years has information on antibiotic use, and at 5 years there is more detailed information collected about accidents and injuries.

Coverage	Child Cohort – the child cohort is made up of just over 8,500 children who were selected randomly through the national school system. A nationally representative sample of 900 schools was selected from all over Ireland including mainstream national schools, private schools and special schools. Wave one of the child cohort ran from September 2007 to June 2008. Wave two of the child cohort (when the child was 13 years of age) was completed from August 2011 to March 2012. Infant Cohort – the infant cohort is made up of just over 11,000 nine month old infants selected randomly from the Child Benefit Register. Recruitment of these families began in September 2008 and ran until April 2009. Wave two of the infant cohort (when the child was 3 years of age) was completed from December 2010 to June 2011. Data collection for the home phase of Wave Three (when the child was 5 years of age) began in February 2013 and was ongoing until September 2013; collection of information from schools took place in Winter 2013.
Methods of Collection	Child Cohort: in both waves, information was collected from the child and their parent(s)/guardian(s), as well as the relevant school principal. In Wave one the child's school teacher was also asked to complete two paper questionnaires. Infant Cohort: at all waves a specially trained study researcher arranged a visit to the home of the infant at a time convenient for the family. The infant's parent(s) /guardian(s) were then asked to fill out separate questionnaires covering areas that included the child's health and development, daily routines and childcare arrangements.
Published Information/ Update frequency	Reports using the data are published on a regular basis once data collection has taken place. Child Cohort – follow up with same group of 8,500 children when they are 13 years old. Infant Cohort – follow up with same group of 11,000 children when they are three years and five years of age.
Web address	http://www.growingup.ie/
Generic email contact	growingup@esri.ie
Other comments	Archived data are available to researchers via the Irish Social Sciences Data Archive at http://www.ucd.ie/issda. Workshops on using the data are hosted in the ESRI on an occasional basis – see www.growingup.ie for details. As of Autumn 2013, data from Wave 1 of the child cohort, and Waves 1 and 2 of the infant cohort have been archived.

Table 9.3	Health Behaviour in School Aged Children (HBSC)
Description/ Summary	Health Behaviour in School-aged Children (HBSC) is a cross-national 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 (2010) involved more than 300,000 children from 40 countries and regions across Europe and North America.
Managing Organisation	The Health Promotion Research Centre, National University of Ireland, Galway
Contributors	These data are collected by teachers in school classrooms, by administering standardised questionnaires to pupils. Completed questionnaires were received from 16, 060 pupils across 256 schools in the Republic of Ireland.
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; Body Mass Index (BMI).
Coverage	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.
Methods of Collection	Survey, self-completion questionnaire administered in school classrooms.
Published Information/ Update frequency	Every four years. Reports, papers and factsheets available on HBSC Ireland website www.nuigalway.ie/hbsc
Web address	http://www.nuigalway.ie/hbsc/index.html
Generic email contact	hbsc@nuigalway.ie
Other comments	

Table 9.4	Lifeways
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.
Managing Organisation	University College Dublin School of Public Health, Physiotherapy and Population Science
Contributors	Coombe Women's Hospital and University College Galway, General Practitioners, HSE- Eastern and Western regions
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 five and ten years.
Coverage	As of September 2013, 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.
Methods of Collection	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.
Published Information/ Update Frequency	Findings from the study are published on an on-going basis. A list of publications to date is available at http://www.ucd.ie/phpps/lifeways/ourresearch/#pp
Web Address	http://www.ucd.ie/phpps/lifeways/
Generic Email Contact	lifeways@ucd.ie
Other Comments	The Lifeways Study is overseen by a steering committee. Access to the study data is via application to that committee.

Table 9.5	**SHARE* – Survey of Health, Ageing and Retirement in Europe**
Description/ Summary	The Survey of Health, Ageing and Retirement in Europe (SHARE) is a longitudinal, multidisciplinary and cross-national panel database of micro data on health, socio-economic status and social and family networks of more than 30,000 individuals aged 50 or over, coordinated centrally at the Munich Research Institute for the Economics of Aging (MEA), Germany.
Managing Organisation	Geary Institute, UCD
Contributors	Ireland and 11 other Western European countries. Poland, Czech Republic and Israel have also joined the survey. The core modules are also comparable to the main ageing survey in Britain (The English Longitudinal Study of Ageing - ELSA) and the US (Health and Retirement Study - HRS).
Data content	Health variables (e.g. self-reported health; health conditions; physical and cognitive functioning; health behaviour; use of healthcare facilities). Bio-markers (e.g. grip strength; body-mass index; peak flow). Psychological variables (e.g. psychological health; well-being; life satisfaction). Economic variables (current work activity; job characteristics; opportunities to work past retirement age, sources and composition of current income; wealth and consumption; housing, education). Social support variables (e.g. assistance within families; transfers of income and assets; social networks; volunteer activities).
Coverage	From 2004 – Austria, Belgium, Denmark, France, Germany, Greece, Italy, The Netherlands, Spain, Sweden. From 2005-2006 Israel, from 2006- 2007 Czech Republic, Poland and Ireland for individuals aged over 50 years of age.
Methods of Collection	Share data collection is based on a computer-assisted personal interview (CAPI) and a self-completion paper and pencil questionnaire.

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* This information in relation to the 'SHARE' survey was not updated since the 2010 publication of the Catalogue

Published Information/ Update frequency	Wave 1: 2004; Wave 2, 2008
Web address	http://www.share-project.org SHARE Ireland accessible at: http://geary.ucd.ie/share/index.php
Generic email contact	SHAREIreland@ucd.ie
Other comments	

Table 9.6	**SILC – Survey on Income and Living Conditions**
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.
Managing Organisation	Central Statistics Office (CSO)
Contributors	Random sample of households surveyed by CSO.
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.
Coverage	Information is collected continuously throughout the year, with up to 130 households surveyed each week to give a total sample of 5,000 to 6,000 households in each year.
Methods of Collection	A representative random sample of households throughout the country is approached to provide the required information. The survey 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. The questionnaire can be found at the following site: http://www.cso.ie/en/media/csoie/eusilc/documents/SILCmanual2010.pdf
Published Information/ Update 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 http://www.ucd.ie/issda/dataset-info/silc.htm
Web address	http://www.cso.ie/eusilc/default.htm
Generic email contact	Income&modules@cso.ie
Other comments	

Table 9.7	**SLÁN – Survey of Lifestyle, Attitudes, and Nutrition**
Description/ Summary	SLÁN is a national survey of the lifestyle, attitudes and nutrition of people living in Ireland. To date surveys have been carried out in 1998, 2002 and 2007.
Managing Organisation	Department of Health (DoH)
Contributors	Royal College of Surgeons of Ireland (RCSI), Economic and Social Research Institute (ESRI), University College Cork (UCC), and National University of Ireland, Galway (NUIG)
Data content	The survey covers general health, behaviours relating to health (e.g. exercise; nutrition) and the use of certain health services.
Coverage	SLÁN 2007 is the largest survey to date. A scientifically representative random sample of over 10,000 people aged 18+ were interviewed in their own homes.
Methods of Collection	SLÁN (1998, 2002) - self administered postal questionnaire. SLÁN 2007 - A scientifically representative random sample of over 10,000 people aged 18+ were interviewed in their own homes, by experienced researchers from the Economic and Social Research Institute (ESRI). In addition, over 1,200 people who participated in the survey also participated in a detailed medical examination.
Published Information/ Update frequency	SLÁN 2007 is the most recent national survey. Plans for future survey frequency and formats are the remit of the Department of Health are not currently available. The full SLÁN 2007 dataset has been made available from The Irish Social Science Data Archive (ISSDA) since October 2009.
Web address	http://www.slan06.ie/
Generic email contact	Not provided
Other comments	

Table 9.8	Quarterly National Household Survey (QNHS) – Health Module
Description/ Summary	The Quarterly National Household Survey (QNHS) is a large-scale, nationwide survey of households in Ireland, carried out by the Central Statistics Office (CSO). It is designed to produce quarterly labour force estimates that include the official measure of employment and unemployment in the state. The survey began in September 1997, replacing the annual April Labour Force Survey (LFS). A module on health was added to the QNHS for Q3 2001, Q3 2007 and Q3 2010.
Managing Organisation	Central Statistics Office (CSO)
Contributors	Nationwide sample of households in Ireland conducted by the CSO
Data content	Health module – includes questions on GP visits; pharmacy visits; nurse visits; day surgery; in-patient hospital stay; A&E attendance; outpatient attendance; private hospital attendance; waiting list for procedure; length of time on waiting list; private health insurance; medical card holder; health status; disability; time off work due to illness.
Coverage	Nationwide sample of households in Ireland – 39,000 households. The survey results are weighted to reflect the national population.
Methods of Collection	12 field coordinators and 152 field interviewers conduct interviews with 39,000 households each quarter. The survey meets the requirements of Council Regulation (EC) No. 577/98 (March 1998), which requires the introduction of quarterly labour force surveys in EU member states
Published Information/ Update frequency	Quarterly – on CSO website
Web address	http://www.cso.ie/qnhs/default.htm
Generic email contact	information@cso.ie
Other comments	

Table 9.9	TILDA – The Irish Longitudinal Study on Ageing
Description/ Summary	The Irish Longitudinal Study on Ageing (TILDA) was launched in November 2006. It explores the health, lifestyles and financial situation of over 8,000 people as they grow older, and observes how their circumstances change over a 10 year period. TILDA provides a comprehensive and accurate picture of the characteristics, needs and contributions of older persons in Ireland that will be invaluable for policy-makers and public sector service planners, voluntary sector actors engaged in activities that seek to enhance the social integration of older citizens and many private sector companies in the insurance and services industries. Furthermore, the study delivers quality cutting edge research consistent with the emerging national initiative towards a "knowledge society" built on innovations in science and technology. TILDA is necessary to act as the foundation on which we can plan appropriate health, medical, social and economic policies for our older people.
Managing Organisation	Trinity College Dublin (TCD)
Contributors	The Irish Longitudinal Study on Ageing is being carried out by Trinity College Dublin, in collaboration with an inter-disciplinary panel of scientific researchers, with expertise in various fields of ageing, from the following institutions: ■ Dundalk Institute of Technology ■ Economic and Social Research Institute ■ National University of Ireland, Galway ■ Queen's University Belfast ■ The Royal College of Surgeons in Ireland ■ University College Cork ■ University College Dublin ■ Waterford Institute of Technology

Data content	Interviews and Health Assessments: Fieldwork for TILDA involves interviews using computer-aided personal interviewing (CAPI) techniques and either a visit by the respondent to a TILDA Health Assessment Centre, where appropriate medical measurement facilities are available, or a visit to the respondents' home by a qualified research nurse to take physical measurements and bio-medical samples. All respondents are also requested to fill out a self-completion questionnaire. 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 measurements taken include: height, weight and waist circumference; blood pressure lying and standing; walking speed and tests of balance; eyesight and hearing; bone and muscle strength; assessment of memory and thinking; assessment of lung function; in addition, blood samples are collected for the analysis of various biomarkers.
Coverage	A nationally representative sample of at least 8,000 adults aged 50 and over, resident in Ireland, was selected using a population sift. The selected addresses were visited by an interviewer from Ipsos Market and Opinion Research International and all persons aged 50 or over (and their spouses/partners of any age) were canvassed to participate in the survey. Over 8,500 people have taken part to date. The method used to select participants for the TILDA study was designed to ensure that the sample would be representative of the Irish population aged 50 and over. 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 Geodirectory, a comprehensive listing/mapping of residential addresses in Ireland compiled by the Ordinance Survey Office. Each address in the country has an equal probability of selection from the sample list of addresses.
Methods of Collection	Participants are invited to attend a dedicated centre in TCD for the TILDA health assessments.
Published Information/ Update frequency	Full reports published after each wave of data collection. Supplementary reports published periodically. Wave 1 report published 2011. Wave 2 report due 2013.

Web address	http://www.tcd.ie/tilda/
Generic email contact	tilda@tcd.ie
Other comments	Wave 3 data collection for TILDA due to commence in 2014

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Glossary of abbreviations

AAT: Alpha-1 Antitrypsin

AATD: Alpha-1 Antitrypsin Deficiency

A & E: Accident and Emergency

ACHI: Australian Classifications of Health Interventions

ARDRG: Australian-Refined Diagnosis Related Group

AED: Anti-epileptic Drug

AIG: Acute Infectious Gastroenteritis

ALS: Amyotrophic Lateral Sclerosis

AMI: Acute Myocardial Infraction

AMNCH: Adelaide and Meath Hospital, incorporating the National Children's Hospital, Dublin

ART: Adverse Reaction Terminology

BIU: Business Intelligence Unit

BMI: Body mass index

CAO: Chief ambulance officer

CAPI: Computer-assisted personal interview

CDAD: *Clostridium difficile*-associated disease

CDI: *Clostridium difficile* infection

CF: Cystic Fibrosis

CFRR: Cardiac First Response Report

CFSGBI: Craniofacial Society of Great Britain and Ireland

CHAIR: Coronary Heart Attack Ireland Register

CIDR: Computerised Infectious Disease Reporting

CIS: Clinical Indemnity Scheme

CPNMT: Child Protection Notification Management Team

CPNS: Child Protection Notification Service

CSP: Cervical Screening Programme

CSO: Central Statistics Office

CTL: Central Treatment List

DED: District Electoral Division

DCC: Dublin Cleft Centre

DOH: Department of Health

DOHC: Department of Health and Children

DkIT: Dundalk Institute of Technology

DPS: Drug Payment Scheme

DRG: Diagnosis Related Groups

DSFA: Department of Social and Family Affairs

DSP: Department of Social Protection

DTCB: Drug Treatment Centre Board

DTSS: Dental Treatment Services Scheme

EACTS: European Association for Cardio-Thoracic Surgery

EARSS: European Antimicrobial Resistance Surveillance System

EBMT: The European Group for Blood and Marrow Transplantation

EC: European Commission

ECDC: European Centre for Disease Prevention and Control

ECG: Electrocardiogram

ECT: Electro-Convulsive Therapy

EDD: Expected Date of Delivery

ED: Emergency Department

ED: Electoral Division

EDTA: European Dialysis and Transplant Association

EEA: European Economic Area

ELSA: English Longitudinal Study of Ageing

EMCDDA: European Monitoring Centre for Drugs and Drug Addiction

EPR: Electronic Patient Record

ERHA: Eastern Regional Health Authority

ESAC: European Surveillance of Antimicrobial Consumption

ESPAD: European School Project on Alcohol and Drugs

ESRI: Economic and Social Research Institute

ESS: European Social Survey

EU: European Union

EUROCAT: European Surveillance of Congenital Anomalies

EULAR: European Union League Against Rheumatism

EU-SILC: European Union – Survey on Income and Living Conditions

FDA: Food and Drug Administration

GAMP: Good Automated Manufacturing Practice

GDP: Gross Domestic Product

GHO: Global Health Observatory

GMS: General Medical Services

GNI: Gross National Income

GP: General Practitioner

GPIT: General Practice Information Technology

GPVC: General Practitioner Visit Card

GRO: General Register Office

GUM: Genito-Urinary Medicine

HBSC: Health Behaviour in School-Aged Children

HFA-DB: European Health for All DataBase

HIPE: Hospital In-Patient Enquiry

HIQA: Health Information and Quality Authority

HPO: Healthcare Pricing Office

HPSC: Health Protection Surveillance Centre

HRB: Health Research Board

HRIM: Health Research and Information Division

HRS: Health and Retirement Study

HSA: Health and Safety Authority

HSCT: Haemopoietic Stem Cell Transplant

HSE: Health Service Executive

HSE-COS: Health Service Executive - Community Ophthalmic Services Scheme

HSE-E: Health Service Executive - East

HTD: High Tech Drugs

IASM: Irish Audit of Surgical Mortality

IBTS: Irish Blood Transfusion Service

ICD: Implantable Cardioverter Defibrillator

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

ICD-O: International Classification of Diseases for Oncology

ICF: International Classification of Functioning, Disability and Health

ICGP: Irish College of General Practitioners

ICSP: Irish Cervical Screening Programme

ICU: Intensive Care Unit

IHFD: Irish Hip Fracture Database

IITOS: Irish Institute of Trauma and Orthopaedic Surgery

ILI: Influenza-like illness

ILO: International Labour Organization

INOR: Irish National Orthopaedic Register

INCD: Independent National Data Centre

IPH: Institute of Public Health in Ireland

ISSDA: Irish Social Science Data Archive

ITU: Intensive Therapy unit

IUBMR: Irish Unrelated Bone Marrow Registry

KPI: Key Performance Indicator

LFS: Labour Force Survey

LHO: Local Health Office

LTI: Long Term Illness Scheme

MAP: Measure of Activity and Participation

MDCs: Major Diagnostic Categories

MHB: Midlands Health Board

MHC: Mental Health Commission

MHRU: Mental Health Research Unit

MND: Motor Neurone Disease

MRSA: Meticillin-resistant *Staphylococcus aureus*

MSRB: Medico-Social Research Board

MTA: Major Trauma Audit

NAEMS: National Adverse Events Management System

NASC: National AIDS Strategy Committee

NCCP: National Cancer Control Programme

NCHCD: National Centre for Hereditary Coagulation Disorders

NDRDI: National Drug-Related Deaths Index

NDTRS: National Drug Treatment Reporting System

NHSBT: National Health Service (NHS) Blood and Transplant

NICU: Neonatal Intensive Care Unit

NIDD: National Disability Database

NIO: National Immunisation Office

NISRA: Northern Ireland Statistics and Research Agency

NEHB: North Eastern Health Board

NOCA: National Office of Clinical Audit

NPEC: National Perinatal Epidemiology Centre

NPIC: National Poisons Information Centre

NPIRS: National Psychiatric In-Patient Reporting System

NPRS: National Perinatal Reporting System

NPSDD: National Physical and Sensory Disability Database

NSB: National Statistics Board

NTBSS: National Tuberculosis Surveillance System

NTMA: National Treasury Management Agency

NTPF: National Treatment Purchase Fund

NUIG: National University of Ireland Galway

NVRL: National Virus Reference Laboratory

OECD: Organisation for Economic Cooperation and Development

OHCAR: Out of Hospital Cardiac Arrest Register

ORMIS: Office of the Minister for Children and Youth Affairs

ORMYS: Operating Room Management Information Systems

ORS: Optimal Reperfusion Service

PATS: Patient Advocate Tracking System

PCR: Patient Care Report

PCRS: Primary Care Reimbursement Service

PHECC: Pre-Hospital Emergency Care Council

PHL: Public Health Language

PHIS: Public Health Information System

PI: Performance Indicator

PISA: Programme for International Student Assessment

PMCC: Performance Monitoring and Control Conmmittee

POWCAR: Place of Work Census of Anonymised Records

PROMS: Patient Reported Outcome Measures

PSS: Poisoning Severity Score

PTR: Patient Treatment Register

PTR: Patient Transport Report

QNHS: Quarterly National Household Survey

RCSI: Royal College of Surgeons

RSA: Road Safety Authority

SARI: Strategy for the Control of Antimicrobial Resistance in Ireland

SARS: Sample of Anonymised Records

SCA: State Claims Agency

SCPE: Surveillance of Cerebral Palsy in Europe

SCTS: Society for Cardio-Thoracic Surgery in Great Britain and Ireland

SHARE: Survey of Health, Ageing and Retirement in Europe

SIAT: System for Involuntary Admission and Tribunals

SICPR: Southern Ireland Cerebral Palsy Register

SIDS: Sudden Infant Death Syndrome

SILC: Survey on Income and Living Conditions

SLÁN: Survey of Lifestyles, Attitudes and Nutrition

SSI: Social Services Inspectorate

STI: Sexually Transmitted Infection

TARN: Trauma Audit and Research Network

TCD: Trinity College Dublin

TFYR: The Former Yugoslav Republic of Macedonia

TILDA: The Irish Longitudinal Study on Ageing

UCC: University College Cork

UCD: University College Dublin

UKT: United Kingdom Transplant

WHO: World Health Organization

WHODAS: World Health Organization's Disability Assessment Schedule

WHOSIS: WHO Statistical Information System

WIT: Waterford Institute of Technology

WTE: Whole Time Equivalent

YTD: Year-to-date

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For further information please contact:

Health Information and Quality Authority
Dublin Regional Office
George’s Court
George’s Lane
Smithfield
Dublin 7

Phone: +353 (0) 1 814 7400
URL: www.hiqa.ie