



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Information Governance and Management Standards for the Health Identifiers Operator in Ireland

30 July 2015

About the Health Information and Quality Authority

The Health Information and Quality Authority (the Authority or HIQA) is the independent Authority established to drive high quality and safe care for people using our health and social care services. The Authority'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 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, or HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), the Authority is charged with evaluating the quality of the information available on health and social care, 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 archives of information which prevent the safe and 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, clear 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.

The Authority has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements.

This document presents information and governance standards for health identifiers operator[±] in Ireland with the aim of underpinning the introduction of health identifiers in Ireland with a robust governance framework for the health identifiers operator, which will inspire trust and acceptance of health identifiers in Ireland.

[±] For clarity, the singular 'health identifiers operator' will be used through this standards document to refer to each business unit within the Health Service Executive (HSE) that is responsible for setting up and maintaining the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers.

Table of contents

Part 1:	Introduction	11
	1.1. Introduction	12
	1.2. Benefits of individual health identifiers	13
	1.3. Benefits of health services provider identifiers	15
	1.4. Purpose of the document	16
	1.5. Legislative framework	16
	1.6. How the standards were developed	17
	1.7. Standard themes	17
	1.8. Monitoring of compliance with these standards	18
Part 2:	Information governance and management standards for the health identifiers operator in Ireland	20
Appendix 1	Prescribed dataset for the individual health identifier	37
Appendix 2	Prescribed dataset for the health services provider identifier	38
Appendix 3	Concepts and definitions	40
Appendix 4	Implementing these standards	44
Appendix 5	Standards development process	46
Appendix 6	Members of the Advisory Group	48

Glossary of terms used in these standards

Compliance framework: a tool which supports health service providers to comply with relevant European and Irish legislation and standards.

Data exchange agreements: a formal document between relevant parties that specifies the procedures to follow and the responsibilities of each party with respect to any personal information that is shared between them. The main aim of a data exchange agreement is to facilitate clear communication between relevant parties. Any data sharing agreement should include the following items: period of agreement, intended use of data, constraints on the use of data, data confidentiality and security, methods of sharing data and the financial cost of sharing data.⁽¹⁾ Data exchange agreements must be developed in line with legislation.

Data quality: data that is 'fit for purpose' or 'fit for use'.⁽²⁾ Data can be considered to be of good quality when the correct data is available in a timely manner to decision makers who can confidently rely on it. A more complete definition of data quality can be found in the Authority's *Guidance on information governance for health and social care services in Ireland*.⁽³⁾

The quality of data can be determined through assessment against a number of attributes or dimensions. These dimensions are defined as:

Data quality dimension	Description
Accurate	It describes or measures what it was designed to describe or measure.
Valid	It is collected in accordance with any rules or definitions applicable for that information. These rules check for correctness, meaningfulness, and security before the data is processed. This enables comparison and benchmarking over time.
Reliable	It is collected consistently over time, whether manually or electronically.
Timely	It is collected within a reasonable time period after the activity it measures and it is available when it is required and as often as it is required.
Relevant	It meets the needs of the information users.
Legible	It is readable and understandable for the intended users.
Complete	It has all those items required to describe or measure the intended activity or event.

Health identifier record: a service user's individual health identifier and their identifying particulars.

Health identifier record system: the system that contains both the service user's health identifier record and any actions – accessing, modifying or verifying – that have taken place with respect to either the identifier or the identifying particulars.

Health practitioner: is defined in the Health Identifiers Act 2014 as:

- a) a registered medical practitioner within the meaning of section 2 of the Medical Practitioners Act 2007 or a medical practitioner practising medicine pursuant to section 50 of that Act,
- b) a registered dentist within the meaning of section 2 of the Dentists Act 1985,
- c) a registered pharmacist or registered pharmaceutical assistant within the meaning of the Pharmacy Act 2007,
- d) a registered nurse or registered midwife within the meaning of section 2(1) of the Nurses and Midwives Act 2011,
- e) a registered optometrist or registered dispensing optician within the meaning of section 2 of the Opticians Act 1956,
- f) a registrant within the meaning of section 3(1) of the Health and Social Care Professionals Act 2005,
- g) a person whose name is entered in the register of pre-hospital emergency care practitioners established under the Pre-Hospital Emergency Care Council (Establishment) Order 2000 (S.I. No. 109 of 2000), or
- h) a person who falls within a class of persons, being a class of persons who provide a health service, prescribed for the purposes of this paragraph.

Health services provider: any person, organisation, part of an organisation and employees of persons or organisations that deliver health or social care services

Health services provider identifier: a unique number that is assigned to a health services provider.

Individual health identifier: a unique number that is assigned to a service user, such as a patient, when a health service is being, has been or may be provided for that service user.

National Register of Individual Health Identifiers: a register that contains a service users' individual health identifier and their identifying particulars, as mandated in the Health Identifiers Act 2014. The Health Identifiers Act 2014 prescribes what data can be collected and used in the National Register of Individual Health Identifiers and is documented in Appendix 1.

National Register of Health Services Provider Identifiers: a register that contains a health service providers' health identifier and their identifying particulars, as mandated in the Health Identifiers Act 2014. Part 3, Section 14, Subsection 1 of the Health Identifiers Act 2014 prescribes what data can be collected and used in the National Register of Health Services Provider Identifiers and is documented in Appendix 2.

National registers: a term used to refer to two national registers that contain health identifiers. It is mandated in the Health Identifiers Act 2014 that two registers are set up to store individual health identifiers, health services provider identifiers and associated identifying information. These two data collections are known as the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers.

Policy: a course of action adopted by an organisation which directs activities and which employees must follow.

Privacy: the right of individuals to keep information about themselves from being disclosed; that is, people are in control of others access to themselves or information about themselves. Individuals decide when, where and with whom to share their personal health information⁽⁴⁾

Privacy risk: the likelihood of a breach to an individual's privacy.

Privacy impact: the effect that a breach of privacy has on an individual

Privacy impact assessment: a common tool that assists in the detection of potential privacy risks around the collection and use of personal health information. Its main purpose is to protect the privacy rights of service users. More information can be found in the Authority's *Guidance on Privacy Impact Assessment Health and Social Care*.⁽⁵⁾

Procedure: the established or official way of implementing a defined policy.

Service user: people who use health and social care services, their parents, guardians, carers and family, their nominated advocates and potential users of health and social care services. Any reference to the term service user does not include service providers who use services on behalf of their patients, for example, family doctors using diagnostic laboratory services.

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

Statement of purpose: a document that describes the aims and objectives of the health identifiers operator including how resources are aligned to deliver these objectives. Anyone reading the statement of purpose should be able to understand easily and identify the range of activities that the health identifiers operator is involved in.

Trusted source: a term used to describe the data sources that are used to populate and update as required the national registers, since they are recognised as being highly reliable or accurate by the health identifiers operator.

Part 1: Introduction

1.1. Introduction

Being able to identify a service user uniquely is essential for patient safety in the provision and management of high quality healthcare. Being able to identify healthcare practitioners and healthcare services uniquely is essential for improving sharing healthcare information between healthcare practitioners.

An individual health identifier (IHI) is a number that uniquely and safely identifies each service user that has used, is using or may use a health or social care service in Ireland. The main benefit of using IHIs is improvements to patient safety.

A health services provider identifier (HSPI) is a unique number that is assigned to a health services provider, such as a hospital or a healthcare professional. Using HSPIs supports the secure and safe exchange of health information.

Previously the Authority has made *Recommendations for a Unique Health Identifier for Individuals in Ireland* (March 2009)⁽⁶⁾ and published an *International Review of Unique Health Identifiers for Individuals* (February 2010)⁽⁷⁾. The Authority also made *Recommendations for Unique Health Identifiers for Healthcare Practitioners and Organisations* (July 2011)⁽⁸⁾.

The Health Identifiers Act 2014 is the law that underpins the introduction of health identifiers in Ireland. It provides the legal basis for setting up two new national data stores or registers, the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers.

The National Register of Individual Health Identifiers will contain a unique number and associated demographic information for each service user who is being, has been or may be provided with a health or social care service in Ireland. This unique number is known as a service users' IHI. Its purpose is to uniquely identify each service user so that patient safety can be improved within the Irish health and social care service. Allocating an IHI to new born babies helps link their healthcare records for life.

The National Register of Health Services Provider Identifiers will contain a unique number for each provider that offers health services in Ireland. This identifier will be known as the HSPI. It is a unique, non-transferable number assigned to all health service providers. Health service providers include practitioners who provide health and social care services, for example, a general practitioner (GP) or a dentist, and the organisations where the health or social care service is provided, such as a laboratory or a hospital. The National Register of Health Services Provider Identifiers provides a single trusted source of data which will allow for more comprehensive, accurate, health service human resource planning and research to take place.⁽⁸⁾

While the Minister is responsible for overseeing its implementation, the Health Identifiers Act 2014 allows for delegation of certain tasks, such as setting up and maintaining the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers to the Health Service Executive (HSE). Different business units within the HSE may be responsible for these tasks. Each business unit is known as a health identifiers operator.

The Authority has developed these standards to support the health identifiers operator as it sets up and maintains these two new national registers. Implementing these standards will promote trust among the public that the registers are established in line with the law. In turn, this creates confidence that both health service providers and service users can be uniquely identified, which ultimately leads to improvements in patient safety.

The international experience of introducing health identifiers in other jurisdictions has been carefully considered when developing these standards. For example, a standard requiring that a privacy impact assessment is conducted has been included following lessons learnt in Australia which indicated that it is vital to identify and plan for privacy risks.⁽⁹⁾ Communication and engagement with stakeholders that builds trust in the proposed system of health identifiers has also been identified as a key requirement.⁽⁹⁾ Finally, it is critical that any proposed system protects the privacy and accuracy of health identifiers and associated details.

This document presents *Information Governance and Management Standards for the Health Identifiers Operator in Ireland*. These standards are aimed at the health identifiers operator in Ireland with the intention of underpinning the introduction of health identifiers in Ireland with a robust governance framework for the health identifiers operator, which will inspire trust and acceptance of health identifiers in Ireland.

1.2. Benefits of individual health identifiers

The main benefit of having an IHI is to ensure patient safety. Being able to uniquely identify each user will improve patient safety by reducing the number of adverse events that may occur, such as giving the patient incorrect medication or vaccinations, or admitting an incorrect patient for surgery. IHIs differ from an electronic health record, which is an electronic version of a service user's medical history. The IHI is one of the key enablers required to implement electronic health records and eHealth solutions such as ePrescribing. The IHI has the following benefits:

Benefits for service users:

- improved accuracy and speed in identifying service users and their health records, which will result in safer and better care
- health and social care records in different healthcare organisations may be accurately associated with the service user
- health information can be shared safely and seamlessly between public and private health service providers, for example referral letters sent from a public hospital to a private sector GP
- enables electronic transfer of the service user's health information, which results in faster care for service users
- improves quality of health and social care services by providing information that can be used to monitor, evaluate and report on performance, which in turn drives accountability
- supports a relationship of trust between service users and health service providers by providing good quality information.

Benefits for healthcare practitioners:

- accurately links service users to their record
- identifies service users in all communications with other health and social care providers
- enables safe transfer of service users' records electronically
- enables electronic referrals, discharge summaries and prescriptions to be sent, which results in more timely exchange of important information.

Benefits for healthcare organisations:

- helps create and maintain a complete record for each service user
- enables service user information to be shared safely within and across organisational boundaries
- improves efficiency in administrative tasks.

Benefits for social care providers:

- accurately and safely identifies people who use social care services
- helps create a complete record of a service users' care by its inclusion on records that may span different health and social care organisations
- safe and efficient coordination of social care with healthcare.

Benefits for service planners and researchers:

- improves the quality of health and social care services by providing information that can be used to plan services
- supports publication of data on health and social care use, which enables greater transparency about vital public services.

1.3. Benefits of health services provider identifiers

The HSPI is another one of the key enablers required to implement electronic health records (EHRs) and eHealth solutions, such as ePrescribing. The benefits of implementing EHRs include:

Benefits for service users:

- supports the secure and effective exchange of health information by uniquely identifying both healthcare professionals and organisations when information is being exchanged, which aids transparency, and may result in speedier referrals and shorter waiting times
- assists administrators of health information systems to manage who can access these systems
- acts as a building block or enabler to support the introduction of national electronic health systems, such as ePrescribing
- supports audit trails in national electronic health systems. For example, in England it is possible for service users to book and alter appointments themselves in outpatient clinics. This service would not be possible without having unique identifiers for health service providers.

Benefits for healthcare practitioners:

- facilitates secure transmission of service user information, such as laboratory results or discharge letters
- reduces administrative effort
- provides easier access to information held about health services providers in a national health information resource.

Benefits for healthcare organisations:

- supports the introduction of a statutory licensing system that applies to both publicly and privately funded healthcare services
- provides a single authoritative source of healthcare practitioners and organisations, which will remove the need for multiple computer systems to maintain their own copy of this data, in turn saving time, resources and administrative effort.

Benefits for service planners and researchers:

- reduces administrative effort, by having a single authoritative source rather than multiple systems containing similar data
- supports the ability to measure and analyse how resources, including the workforce are used to provide health and social care services
- enhances the ability of health agencies to plan services.

1.4. Purpose of the document

The purpose of this document is to set down the information governance and management standards for the health identifiers operator in Ireland. This document describes the standards that apply to the health identifiers operator with respect to how the national registers are set up and managed. These standards support and enable the efficient and effective establishment and management of both registers and will ensure that the personal information associated with each identifier is properly protected. The primary audience for this document is the health identifiers operator.

This document is presented in two parts:

- Part 1 describes how these standards were developed in line with the Authority's standards development process. It provides background information on what health identifiers are, and the purpose and role of the health identifiers operator. More detailed information on concepts associated with health identifiers is described in Appendix 3 and Appendix 4 discusses the roles to be undertaken by the major stakeholders in implementing health identifiers.
- Part 2 presents the standards and lists features that would likely be in place for a standard to be met.

1.5. Legislative framework

These standards have been developed in line with relevant legislation. Firstly, under Part 2, Section 8 of the Health Act 2007, as amended, the Authority is responsible for setting standards for all aspects of health information and monitoring compliance with those standards.⁽¹⁰⁾

Secondly, the Health Identifiers Act 2014 provides specific legislation for the creation and governance of health identifiers for individuals and health services providers.⁽¹¹⁾

Finally, under the Data Protection Acts 1988 and 2003,⁽¹²⁾ the health identifiers operator is a data controller and as such, the health identifiers operator is obliged to follow the eight rules of data protection:⁽¹³⁾

- obtain and process information fairly
- keep it only for one or more specified, explicit and lawful purposes
- use and disclose it only in ways compatible with these purposes
- keep it safe and secure
- keep it accurate, complete and up to date

- ensure that it is adequate, relevant and not excessive
- retain it for no longer than is necessary for the purpose or purposes
- give a copy of his and or her personal data to an individual, on request.

1.6. How the standards were developed

The standards were developed in line with the Authority's standards development process, which is described in detail in Appendix 5. A literature review was conducted of relevant published research, standards in other jurisdictions, government policy and reports by national and international governmental and non-governmental organisations. An Advisory Group was established with relevant experts.

Draft standards for consultation were developed, influenced by findings from the literature review and by consultation with our advisory group and other stakeholders. The list of members on this advisory group is listed in Appendix 6.

A public consultation was held from 12 March 2015 to 24 April 2015 where feedback was requested from interested parties. 70 responses in total were received during the consultation process. All feedback from the public consultation was analysed, considered and used to inform the final version of these standards. For more information on the consultation process please see the Statement of Outcomes document available at www.hiqa.ie.

Lastly, a standards approval process was followed once the final version of the standards was complete. Approval to publish these standards was sought from the Executive Management Team and from the Board of the Authority. Once approval was obtained, the standards were sent to the Minister for approval and published.

1.7. Standard themes

The Authority has selected appropriate themes for inclusion in these standards, adapted from the Authority's framework for standards development. These themes can apply equally to health or social care standards and aim to provide a road map for improving the quality, safety and reliability of health and social care in Ireland. The four themes selected and adapted to represent the *Information Governance and Management Standards for the Health Identifiers Operator in Ireland* are:

- Person-centred – a person-centred approach places the service user at the centre of what the health identifiers operator does.
- Leadership, governance and management – stipulates that appropriate management structures are in place which support clear accountability, good

decision-making and risk management. These structures allow the health identifiers operator meet its strategic, statutory and financial obligations.

- Use of information – the national registers contain a rich source of data in the form of health identifier records. The health identifiers operator is responsible for maintaining the quality and privacy of health identifier records as it sets up and manages the national registers.
- Workforce – the health identifiers operator’s workforce includes management, administration and information technology staff and others as deemed necessary. The health identifiers operator is obliged to deliver appropriate evidence-based training to its workforce that will allow the workforce establish and manage the national registers appropriately in line with relevant standards and legislation.

These four themes are designed to work together. Collectively, they describe how the health identifiers operator provides a high-quality, safe and reliable service to service users and health services providers. A number of standard statements are arranged under each theme – for example, the theme ‘leadership, governance and management’ has six standards. The standards are outcome-based. Therefore, each standard, as described in the ‘standard statement’, outlines the high-level outcome required to contribute to the safe, reliable provision of health identifiers.

The ‘features’ are examples of arrangements that the health identifiers operator is likely to have in place to meet the standard and achieve the required outcome. The list of features provided under each standard statement heading is not an exhaustive list and the requirements of the standards can be met in different ways.

1.8. Monitoring of compliance with these standards

The health identifiers operator will need to show it complies with the finalised information governance and management standards for the health identifiers operator in Ireland.

Additionally, the health identifiers operator will be expected to enter into formalised agreements with trusted source owners and health service providers that:

- protect service users and health service providers’ personal health information
- define how data can be shared
- explain how to effectively use the national registers in line with published standards and the law.

The health identifiers operator is expected to demonstrate implementation of, and adherence to, such agreements so they can illustrate compliance with published

standards and the law. As mandated in Part 7, Section 31 of the Health Identifiers Act 2014, these agreements should be developed in consultation with the Data Protection Commissioner.

The Authority will respond to information it receives and, in accordance with its regulatory remit, bring to the attention of the health identifiers operator any information that raises concerns about the use of the national registers. The Authority will also develop, publish and assess the health identifiers operator against an Assessment Framework. The Assessment Framework will detail what elements must be in place for the health identifiers operator to comply with each standard statement.

Part 2: Information governance and management standards for the health identifiers operator in Ireland

Theme 1 Person-centred

The health identifiers operator must place the service user at the centre of its operation.

A person-centred approach ensures that the health identifiers operator will establish and maintain the national registers in a safe and effective way. The health identifiers operator protects service users and health service providers' personal information.

Being person-centred requires that the health identifiers operator communicates with service users and health service providers in a manner that supports the development of a relationship built on trust. This includes:

- providing appropriate information that allows the public to understand the role and purpose of health identifiers in the Irish health and social care system
- proactively responding to queries, questions and complaints from those using the national registers.

Standard 1.1

The health identifiers operator conducts privacy impact assessments at critical points during the establishment and operation of the national registers.

Features meeting this standard are likely to include the following:

- 1.1.1 Arrangements are in place to conduct privacy impact assessments^{Y1}:
- prior to the establishment of the national registers
 - when significant system changes are planned to identify any new or potential privacy risks that may arise as a consequence of the proposed system change.
- 1.1.2 The procedure for conducting privacy impact assessments and findings identified are published and subject to independent review.
- 1.1.3 Where privacy risks are identified, measures are implemented to mitigate or avoid these risks. Identified risks and recommendations on how they will be mitigated or avoided are published.

^{Y1} Information on how privacy impact assessments are conducted can be found at <http://www.hiqa.ie/resource-centre/professionals/privacy-impact-assessments>

Standard 1.2

The health identifiers operator develops, implements and reviews a communication plan that effectively engages with health service providers and service users in relation to the use of the national registers.

Features meeting this standard are likely to include the following:

- 1.2.1 A communications plan is developed and implemented, using appropriate media, that engages and informs service users and health service providers about:
 - the role of the health identifiers operator and the national registers in the Irish healthcare system
 - how individual health identifiers, health service provider identifiers and health identifier records are used and shared
 - service users and health services providers' rights as data subjects.
- 1.2.2 A statement of information practices which communicates how the health identifiers operator collect, use, share and protect health identifier records is developed, reviewed and updated, where necessary.
- 1.2.3 Mechanisms are in place that allow for two-way communication between the health identifiers operator and health service providers and service users. This allows health service providers and service users submit complaints, queries and comments to the health identifiers operator.
- 1.2.4 Measures are in place to evaluate and, where necessary, improve the level and effectiveness of communication with service users and health service providers.

Theme 2 Leadership, governance and management

In an effective governance and management structure, there are clear lines of accountability, good decision-making and effective risk management. Effective leadership, governance and management systems are in place for the health identifiers operator to meet its strategic, statutory and financial obligations.

The health identifiers operator is tasked with establishing and managing the national registers. Under the Health Identifiers Act 2014 and the Data Protection Acts 1988 and 2003, the health identifiers operator is obliged to protect service users' personal data. This is an aim that will be achieved when effective governance arrangements are in place, reviewed regularly and updated if necessary.

In its role as data controller, the health identifiers operator is responsible for ensuring that health service providers access health identifier records in line with relevant Irish and European legislation and published standards.

Standard 2.1

The health identifiers operator has effective leadership, governance and management arrangements in place with clear lines of accountability.

Features meeting this standard are likely to include the following:

- 2.1.1 Governance and management arrangements which clearly define roles, accountabilities and responsibilities within the health identifiers operator are publicly available.
- 2.1.2 Identified individuals are appointed whose role(s) include:
- overall executive accountability, responsibility and authority for the delivery of an effective service by the health identifiers operator
 - leading a governance system that clearly specifies, delegates and integrates corporate governance
 - formally reporting on the progress of the health identifiers operator in meeting its objectives by way of a publicly available annual performance report
 - acting as a liaison point between the health identifiers operator and other interested parties, such as its own workforce, government departments, health service providers, service users and others.
- 2.1.3 An Oversight Committee is established to advise the health identifiers operator on the operation and management of the national registers.
- 2.1.4 Performance of the health identifiers operator's workforce is monitored, managed and developed. The performance management takes place at both individual and team level, and includes evaluating service users' feedback and taking action to address identified areas for improvement.
- 2.1.5 Strategic and operational plans for the health identifiers operator are developed, and set clear objectives and plans for the delivery of health identifiers.
- 2.1.6 Effective information governance framework is implemented to protect health identifier records of service users and health service providers.
- 2.1.7 An established risk management framework is in place within the health identifiers operator. Risks are reviewed at management and staff meetings and the risk register is regularly updated. These arrangements include having systems in place to effectively manage risk, including a designated

individual(s) to contact in an emergency. Should a significant risk occur, there is a full remediation, communication and learning cycle associated with it.

- 2.1.8 An established quality assurance framework is in place in the health identifiers operator. Quality metrics are defined and reviewed at management and staff meetings. Progress against quality metrics is measured and published at regular intervals.
- 2.1.9 Resources allocated to the health identifiers operator are planned and managed so that the objectives of the national registers are met.

Standard 2.2

The health identifiers operator maintains a publicly available statement of purpose.

Features meeting this standard are likely to include the following:

- 2.2.1 A statement of purpose for the health identifiers operator that accurately describes why the national registers exist.
- 2.2.2 A statement of purpose is publicly available and is shared with all stakeholders, including service users, in an accessible format.
- 2.2.3 The statement of purpose is regularly reviewed to ensure that it is sustainable, based on needs and on what can be delivered effectively and efficiently within available resources.
- 2.2.4 Governance arrangements are in place that can provide assurance that the health identifiers operator is meeting its aims and objectives within the scope of the statement of purpose.
- 2.2.5 Relevant parties are notified and consulted regarding any proposed significant changes to the statement of purpose.

Standard 2.3

The health identifiers operator complies with relevant Irish and European legislation and standards when establishing and managing the national registers.

Features meeting this standard are likely to include the following:

- 2.3.1 An identified individual is appointed whose role includes:
- conducting regular reviews of Irish and European legislation and published standards to determine what is relevant to the establishment and operation of the national registers
 - documenting risk assessment of any identified gap in compliance with legislation and taking appropriate, timely action to achieve compliance to ensure the quality and safety of the functions of the health identifiers operator.
- 2.3.2 Clearly documented and implemented arrangements are in place that allows the health identifiers operator to illustrate compliance with relevant, published standards and legislation.
- 2.3.3 Clear governance arrangements are in place that allows findings from audits to be reported, implemented and monitored effectively.

Standard 2.4

The health identifiers operator has formalised arrangements with health service providers for the safe and effective use of the national registers in line with relevant legislation and standards.

Features meeting this standard are likely to include the following:

- 2.4.1 A compliance framework is developed that allows health service providers to demonstrate self-compliance with published relevant standards and legislation.
- 2.4.2 The health service providers' use of the national registers is monitored and evaluated and improvements are implemented based on the findings.
- 2.4.3 Service level agreements with health service providers and third party vendors are developed. The service level agreement defines the obligations of all parties involved including:
- services offered to the health service providers by the health identifiers operator
 - who to contact in the event of a problem with the health identifiers record system
 - health identifiers record system's performance and availability.
- 2.4.4 Education and training resources are provided for health service providers that inform them how to use the national registers as part of the health services providers' day-to-day operation. For example, creating an information leaflet about how important it is to protect service users' health identifier records.

Standard 2.5

The health identifiers operator has formalised arrangements with trusted sources that protect personal information and define which data can be shared for the purpose of establishing and maintaining the national registers.

Features meeting this standard are likely to include the following:

- 2.5.1 Formalised agreements between trusted sources and the health identifiers operator on data sharing arrangements are in place in order to protect the privacy, quality and confidentiality of the data used to establish and maintain the national registers.
- 2.5.2 Arrangements are in place that ensures formalised data sharing agreements are followed in order to allow data sharing to occur in a safe, secure and timely manner for specific purposes so that the national registers are kept accurate and up to date.
- 2.5.3 Measures are in place that prevents the health identifier operator updating information on the trusted sources' information systems.
- 2.5.4 Measures are in place that allows modifications to data exchange agreements in conjunction with trusted sources and the Data Protection Commissioner in line with the Health Identifiers Act 2014.

Standard 2.6

The health identifier operator monitors, reviews, evaluates and improves the service it provides on an ongoing basis.

Features meeting this standard are likely to include the following:

- 2.6.1 An identified individual is appointed whose role includes responsibility for ensuring that the quality of the national registers is monitored, reviewed, evaluated and improved continually.
- 2.6.2 The performance of the functions of the health identifiers operator is monitored and improved based on evidence.
- 2.6.3 An established system is in place to ask for and use feedback from service users and health service providers to improve the service provided by the health identifiers operator.

Theme 3 Use of Information

The national registers hold a rich source of data in the form of health identifier records. The health identifiers operator is responsible for setting up and managing the two national registers that hold the health identifiers records. This responsibility includes:

- maintaining the data quality of the health identifier records stored in the national registers
- protecting service users and health service providers' health identifier records.

Information governance provides a means of bringing together all the relevant legislation, guidance and evidence-based practice that applies to the handling of information. It offers a consistent way for people working in health and social care to deal with the many different legal provisions, guidance, and professional codes of conduct that apply to handling personal health information.⁽³⁾ Effective information governance arrangements protect the health identifier records of service users and health service providers. It is vital that service users and health service providers trust that their health identifiers are created, stored and processed in a manner that is safe and protects service users' confidentiality.

Data quality refers to data that is 'fit for purpose' or 'fit for use'.⁽²⁾ Data can be considered to be of good quality when the correct data is available in a timely manner to decision-makers who can confidently rely on it. The quality of data can be determined through assessment against a number of attributes or dimensions. These dimensions are accurate, valid, reliable, timely, relevant, legible and complete and are further defined in the glossary of terms in this report.⁽³⁾

Standard 3.1**The health identifiers operator maintains and reviews the privacy of health identifier records contained in the national registers.****Features meeting this standard are likely to include the following:**

- 3.1.1 A nominated Data Protection Officer is appointed whose role includes maintaining, improving, and auditing systems and processes used to protect all data processed by the health identifiers operator.
- 3.1.2 Standard operating procedures are developed that detail how the health identifiers operator collect, store, share, use and protect health identifier records. These procedures are regularly monitored, reviewed and updated to ensure their consistent implementation, validity and appropriateness.
- 3.1.3 Policies and procedures are in place to protect service users and health service providers' health identifier records, in both paper and electronic format, from unauthorised access. These measures include using appropriate methods and technologies that protect and safeguard health identifier records.
- 3.1.4 Arrangements are in place to facilitate service users and health service providers to view and where necessary request modification to their health identifier record, in line with the Data Protection Acts 1988 and 2003 and the Freedom of Information Act 2014. Requests to view or request modification of health identifier records are conducted in a timely manner.
- 3.1.5 Measures are in place to prohibit modifying or transferring a service user's individual health identifier to another service user throughout a service user's lifetime or after their death, as mandated in the Health Identifiers Act 2014.
- 3.1.6 Measures are in place to prohibit transferring a health services provider identifier from one health services provider to another under any circumstances, as mandated in the Health Identifiers Act 2014.
- 3.1.7 Trusted sources are used to populate the national registers in accordance with data exchange agreements. Such data may need additional validation and verification prior to inclusion in the appropriate register.
- 3.1.8 Effective information technology links between the health identifiers operator and health service providers are in place to ensure information transfers occur in a safe, integrated way and in line with the Data Protection legislation.

Standard 3.2

The health identifiers operator maintains and reviews the quality of data contained in the national registers.

Features meeting this standard are likely to include the following:

- 3.2.1 The data set prescribed in the Health Identifiers Act 2014 is used to establish, assign and locate health identifiers in the National Register of Individual Health Identifiers.
- 3.2.2 The data set prescribed in the Health Identifiers Act 2014 is used to establish, assign and locate health identifiers in the National Register of Health Services Provider Identifiers.
- 3.2.3 Procedures are in place that validate and verify change requests, where such validation or verification is deemed necessary, which are presented for inclusion in the national registers. Procedures used to verify changes are applied consistently to any change request that relates to a service user's or health service provider's health identifier record, regardless of where the change request originated from.
- 3.2.4 Verified changes to health identifier records for both service users and health service providers are updated in the appropriate register in a timely manner and in line with the Health Identifiers Act 2014.
- 3.2.5 Business continuity and disaster recovery policies and procedures are developed, implemented and reviewed regularly. These policies and procedures ensure the national registers to be available for use in real time by those who are authorised to access them.
- 3.2.6 The quality of health identifier records is audited and programmes are developed and implemented to improve the quality of these records, as required.
- 3.2.7 Policies and procedures are developed, maintained, reviewed and updated (where necessary) by the health identifiers operator that define how health service providers can access and use the national registers, and against which the health identifiers operator can audit compliance.

Theme 4 Workforce

The health identifiers operator's workforce comprises professionals who have been tasked with establishing and managing the national registers. The workforce includes management, administration and information technology staff and others as deemed necessary. The Health Identifiers Act 2014 makes provision for the delegation of functions to the HSE. Accordingly, a business unit within the HSE will be responsible for implementing the provisions contained within the Health Identifiers Act 2014.

The health identifiers operator's workforce is the core of the national registers. Having an appropriately skilled and trained workforce in place to establish and manage the national registers is essential for the health identifiers operator to achieve its objectives. Therefore, the management of the health identifiers operator is obliged to deliver regular training programmes to ensure its workforce are trained to establish and manage the national registers in line with relevant Irish and European legislation, published standards and best practice.

Standard 4.1

The health identifiers operator delivers regular evidence-based training programmes to its own workforce in relation to establishing, maintaining and using the national registers.

Features meeting this standard are likely to include the following:

- 4.1.1 A formal mandatory induction programme is developed for its workforce that includes a focus on the privacy and confidentiality of service users and health service providers' personal information.
- 4.1.2 An evidence-based training, educational and development programme is developed with a specific focus on, but not limited to the following:
 - the Health Identifiers Act 2014, the Data Protection Acts 1988 and 2003 and the Freedom of Information Act 2014
 - the importance of privacy and confidentiality of service users and health service providers' personal information
 - policies and standard operating procedures for establishing, managing and using the national registers
 - information sharing arrangements in line with agreed data exchange agreements
 - escalation paths in the event of queries and change requests.
- 4.1.3 Arrangements are in place that supports the workforces' continuous professional development so that the functions of the health identifiers operator are delivered effectively and securely by appropriately trained staff.
- 4.1.4 Timely delivery of training, as per the training schedule. New members of the workforce are trained up on commencement of their duties and all members of the workforce have annual training and development plans in place.
- 4.1.5 Training materials are evaluated for effectiveness, and updated or modified if necessary.
- 4.1.6 Evaluation of training programmes are conducted and analysed, and where necessary, further training is delivered.
- 4.1.7 Work practices should reflect the training provided to the workforce.

Appendix 1 Prescribed dataset for the individual health identifier

The Health Identifiers Act 2014 prescribes what data can be collected and used in the National Register of Individual Health Identifiers. Only using this prescribed dataset is one of the features of Standard 3.2. The following table summarises what data can be collected and stored in the National Register of Individual Health Identifiers. However, not all data items must be collected. Initially, only a subset of the data items listed will be collected.

Data in your health identifier record

- Surname
- Forename
- Date of birth
- Place of birth
- Sex
- All former surnames
- Mother's surname and all her former surnames
- Address
- Nationality
- Personal public service number (if any)
- Date of death in case of a deceased individual
- Signature
- Photograph
- Other relevant identifying particulars in the opinion of the Minister

Appendix 2 Prescribed dataset for the health services provider identifier

Part 3, Section 14, Subsection 1 of the Health Identifiers Act 2014 prescribes what data can be collected and used in the National Register of Health Services Provider Identifiers. Only using this prescribed dataset is one of the features of Standard 3.2.

The National Register of Health Services Provider Identifiers consists of five parts. Not all parts of the register are mandatory. Different parts are populated depending on whether the health services provider is a healthcare practitioner or a healthcare organisation.

The five parts are:

Part A – Health practitioner

- Health services provider identifier
- Surname
- Forename
- Business address and if different, the place and name of employment
- Name of professional regulatory body that the health practitioner is registered with
- Registration number
- Other relevant particulars in the opinion of the Minister

Part B – Healthcare organisation

- Health services provider identifier
- Legal name and trading name if applicable
- Business address
- Locations at which it provides health services
- Description of health services it provides
- Other relevant particulars in the opinion of the Minister

Part C – Employees of health practitioners or healthcare organisations

- Health services provider identifier
- Surname
- Forename
- Capacity in which he or she is an employee
- Place of employment
- Name and HSPI of his or her employer
- Other relevant particulars in the opinion of the Minister

Part D – agent of a health practitioner

- Health services provider identifier
- Surname

- Forename
- Capacity in which he or she is an agent
- Place of employment
- Name and HSPI of his or her principal health practitioner
- Other relevant particulars in the opinion of the Minister

Part E – agent of a healthcare organisation

- Health services provider identifier
- Legal name and trading name if applicable
- Business address
- Capacity in which it is an agent
- Place and HSPI of where it is an agent
- Name and HSPI of the health services provider who is its principal
- Other relevant particulars in the opinion of the Minister

Appendix 3 Concepts and definitions

Individual health identifier

An individual health identifier or IHI is a number that uniquely and safely identifies each service user that has used, is using or may use a health or social care service in Ireland.

A service user shall be asked for their IHI when they attend a health or social care provider. If the service user does not know their IHI, the health or social care provider can search the National Register of Individual Health Identifiers to locate the service user's IHI, using specific demographic information such as name or date of birth. If an IHI is not found for that service user, the health or social care provider shall request and obtain one from the health identifiers operator in real-time.

A service user's IHI shall be stored on their health services provider's computer system or on paper if no electronic system exists. It shall be used in their medical record at the health service provider that they attend. It will also be included on communications a health services provider has about the service user.

Example 1

After you attend your general practitioner (GP), your IHI will be stored on their local system in your medical record, whether paper or electronic.

Any time your GP communicates with another health service provider on your behalf, your IHI will be included on that communication.

Should you require a blood test, for example, your GP will include your IHI with this request. The hospital will return both your IHI and the result of the blood test to your GP. This allows your GP to safely identify you when they receive the result.

Example 2

Your IHI will be recorded on your medical record in the hospital's computer system if you attend an emergency department. When the hospital sends a discharge letter to your GP, your IHI will be included in that communication to your GP. The discharge letter may be paper or electronic. This allows your GP to safely identify you when they receive the discharge letter.

The Health Identifiers Act 2014 stipulates that:

- an IHI is assigned to each living person and each person who has died following commencement of the Act.
- measures are put in place to prohibit modifying or transferring a service user's IHI to another service user throughout a service user's lifetime or after their death.

Health services provider identifier

A health services provider identifier or HSPI is a unique number that is assigned to a health services provider, such as a hospital, clinic or a registered healthcare professional.

A HSPI will be given to registered healthcare providers and people within health or social care providers who are required to access the National Register of Individual Health Identifiers.

The National Register of Health Services Provider Identifiers is the register that contains all HSPIs. It will be publicly available to search.

A HSPI shall be stored on a service user's record when the health services provider provides a service to that service user. It shall also be included on relevant communication about that service user.

The Health Identifiers Act 2014 stipulates that, a HSPI:

- be assigned to each health service provider who has, can or will provide health services to a service user
- remain assigned to the health service provider for the duration of time that the health service provider continues to provide health services to service users
- be non-transferable between health service providers.

National registers of health identifiers

The Health Identifiers Act 2014 mandates that two new national registers are set up to contain health identifiers and associated personal data used to identify service users and health service providers. These two registers are known as:

- National Register of Individual Health Identifiers
- National Register of Health Services Provider Identifiers.

The National Register of Individual Health Identifiers contains the IHI of service users and their associated identifying particulars. A health identifier record is a combination of your individual health identifier and other personal data that is used to safely identify you. The Health Identifier Act 2014 allows for the following data to be collected and stored in your health identifier record:

Data in your health identifier record

- Surname
- Forename
- Date of birth
- Place of birth
- Sex
- All former surnames
- Mother's surname and all her former surnames
- Address
- Nationality
- Personal public service number (if any)
- Date of death in case of a deceased individual
- Signature
- Photograph

An IHI and its associated dataset are considered 'personal data' under the terms of the Data Protection Acts 1988 and 2003. Health identifier records need to be kept safe and secure under legislation – both the Data Protection Acts and the Health Identifier Act 2014 apply. Penalties apply if it is discovered that your IHI is not adequately protected or used incorrectly.

The National Register of Health Services Provider Identifiers contains providers' HSPI and their associated identifying particulars. Each HSPI is associated with a set of identifying data that is mandated in the Health Identifiers Act 2014, and included in Appendix 2 of this HIQA document.

Health identifiers operator

The Health Identifier Act 2014 allows for delegation of specific functions under the Act to the Health Service Executive (HSE). A business unit within the Health Service Executive will be set up to manage the population's health identifier records, which consists of each service users IHI and other personal data. This business unit will be known as the 'health identifiers operator'.

Within the HSE, different business units may be responsible for setting up and managing each register. So, these standards apply to each business unit that is assigned duties contained in the Health Identifiers Act 2014. For clarity, the singular 'health identifiers operator' will be used to refer to each business unit that is assigned duties contained in the Health Identifiers Act 2014.

Setting up and overseeing the national registers is a complex task, involving a range of professionals with different skill sets who are required to conduct a number of tasks. These tasks may include but are not limited to:

- authorising access to the national registers
- assigning, updating and verifying health identifiers
- answering queries about health identifiers from service users, healthcare administrative staff, health and social care professionals and management
- escalating queries and change requests (for example, when a person wishes to update his or her record with a new address) appropriately
- ensuring access to the national registers is controlled appropriately
- engaging with stakeholders
- generating reports as required
- carrying out investigations into the operation of the Health Identifiers Act 2014 as mandated in Section 28 of the Act
- ensuring data agreements with professional regulatory bodies and others are agreed and adhered to
- ensuring compliance of the operator itself with the provisions contained in the Health Identifiers Act 2014.

The health identifiers operator is required to develop and implement an information governance framework. This is a formal way of ensuring that service users and health service providers' personal information is protected. Having an information governance framework in place protects personal information relating to service users and health service providers in line with relevant legislation and standards.

Health services provider

A health services provider is any person, organisation, part of an organisation and employees of persons or organisations that deliver health or social care services.

Trusted source

A trusted source is a data source that is considered highly reliable and is used to populate or update the national registers.

Example of trusted source	For which register?
Database of the Public Service Identity (PSI) dataset maintained by the Department of Social Protection	National Register of Individual Health Identifiers
Register of Medical Practitioners	National Register of Health Services Provider Identifiers

Appendix 4 Implementing these standards

What is needed to introduce health identifiers in Ireland?

Many organisations within the health and social care sector need to work together to successfully introduce health identifiers. The following illustrates what the role of each of these organisations is, as health identifiers are introduced in Ireland.

Department of Health

- Develop legislation: Health Identifiers Act 2014
- the Minister is responsible for delegating specific functions of the Health Identifiers Act 2014 to the HSE
- the Minister also has responsibility for other elements contained in the Health Identifiers Act 2014

Health Identifiers Operator

- Establish and manage the National Register of Individual Health Identifiers
- Establish and manage the National Register of Health Services Provider Identifiers

Health Information and Quality Authority

- Develop and monitor standards that support the introduction of health identifiers in Ireland

Health service providers

- Use health identifiers to uniquely identify service users and health service providers (both professionals and organisations)

Trusted sources

- Populate and update the National Register of Individual Health Identifiers
- Populate and update the National Register of Health Services Provider Identifiers

Implementing these standards

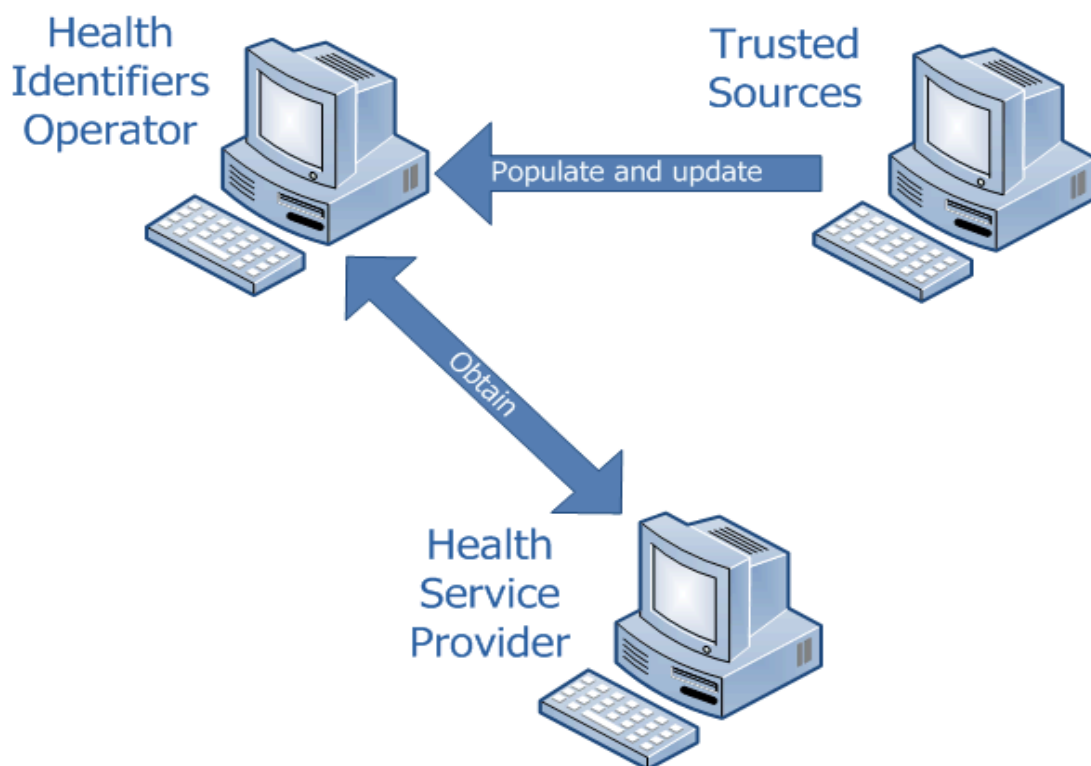
The plan is to initially populate the National Register of Individual Health Identifiers from existing reliable data sources – known as trusted sources.

Health service providers, as part of their day-to-day operation, are required to request an IHI from the National Register of Individual Health Identifiers on behalf

of service users when they present for care. The health identifier operator is required to provide an individual health identifier upon receipt of a request in real-time.

The health service provider is also required to send requests to update service users' demographic details if and when they become aware of such changes. The health identifiers operator is required to verify and validate such requests and update the register as necessary. This relationship is illustrated in Figure 1 below.

Figure 1: Relationship between key stakeholders with respect to establishing and maintaining the National Register of Individual Health Identifiers

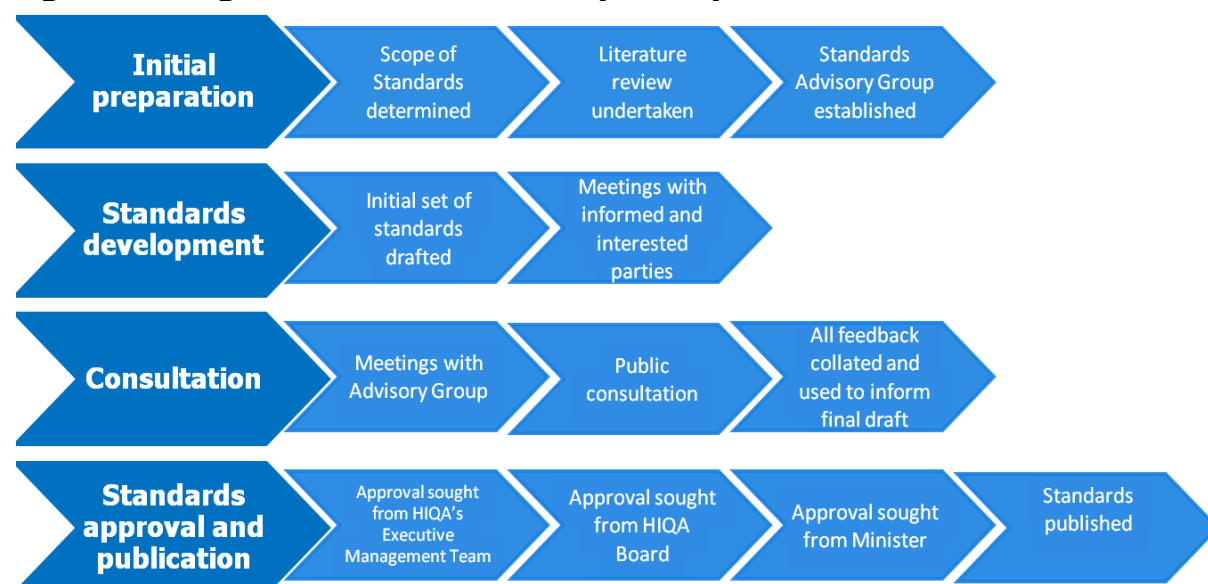


Similarly, interested parties are required to work together to support the introduction of health services provider identifier into the Irish healthcare system. The National Register of Health Services Provider Identifiers is populated and updated from trusted sources. Again, health service providers and trusted sources are required to send requests to update health service providers' information if and when they become aware of them. The health identifiers operator is required to verify and validate such requests and update the register as necessary.

Appendix 5 Standards development process

These standards have been developed in accordance with the Authority's standards development policy. Figure 1 highlights the four main stages within the Authority's standards development process.

Figure 1: Stages of standards development process



Stage	Description
Initial preparation	<p>The project's scope is agreed internally. In this case, the scope includes developing information governance and management standards for the health identifiers operator in Ireland.</p> <p>A literature review of relevant published research, standards in other jurisdictions, government policy and reports by national and international governmental and non-governmental organisations is undertaken. An early draft of the standards take account of the findings from this literature review.</p> <p>An advisory group is established with relevant experts.</p>
Standards development	<p>The standards development team prepare a set of draft standards, which are then reviewed by key personnel internally. Amendments are made to these draft standards based on internal feedback.</p>
Consultation	<p>Two forms of consultation are conducted as part of the development of these standards:</p> <ul style="list-style-type: none"> • An advisory group is established to seek guidance and feedback on the draft standards. The list of members on this advisory group is listed Appendix 6. • A public consultation is held, where the draft standards are published on the Authority's website so that comments and feedback can be received from the public in relation to them. A statement of outcomes document will be published following

analysis of the feedback received from the public consultation. All feedback received from the advisory group and the public consultation is analysed and considered. Feedback is used to inform the final version of these standards.

Standards approval and publication

A standards approval process is followed once the final version of the standards is complete. In this case, approval to publish these standards is sought from the Executive Management Team and from the Board of the Authority. Once approval is obtained, the standards are sent to the Minister for approval and published.

Appendix 6 Members of the Advisory Group

Name	Organisation
Rachel Flynn (Chairperson)	Health Information and Quality Authority (HIQA)
Damon Berry	National Standards Authority of Ireland
Patrick Burke	Health Service Executive (HSE)
Aidan Clancy	Department of Health
Kevin Conlon	Department of Health
Gerard Crotty	Irish Hospital Consultants Association
Ann Curran	Medical Council of Ireland
Peter Dennehy	Nursing and Midwifery Board of Ireland
Roisin Doherty	HSE
Jamie-Lee Ferguson	Dental Council of Ireland
Gemma Garvan	Healthlink
Damhnait Gaughan	Pharmaceutical Society of Ireland
Tessa Greally	HSE
Mairin Haran	Department of Social Protection
Sarah Jordan	HIQA
Sharon Hayden	Our Lady's Children's Hospital, Crumlin, Dublin
Chrissie Keane	National Standards Authority of Ireland
Ivan McConkey	HSE
Stephen McMahon	Irish Patients Association
Micheal O'Briain	Health Insurance Authority
Kevin O'Carroll	HIQA
Tracy O'Carroll	HIQA
Brian O'Mahony	Irish College of General Practitioners
Oliver Plunkett	HSE
Joe Ryan	HSE
Fran Thompson	HSE

Reference list

- (1) CapacityPlus. *HRIS Strengthening Implementation Guidebook: Creating a data-sharing agreement*. 2011. Available online from: <http://www.ihris.org/toolkit/tools/data-sharing.html>.
- (2) Wang RSDM. Beyond Accuracy: What Data Quality Means to Data Consumers. *National E-Health Transition Authority*. 1996; 12(4): pp.5-34.
- (3) Health Information and Quality Authority. *Guidance on Information Governance for health and social care services in Ireland*. 2012.
- (4) Erickson JaMS. Caring for Patients while Respecting their Privacy: Challenges of Maintaining Privacy and Confidentiality. *Online Journal of Issues in Nursing 2005*. 2005; 10(2): Available online from: <http://www.medscape.com/viewarticle/506840> 4. Accessed on: 19 May 2015.
- (5) Health Information and Quality Authority. *Guidance on Privacy Impact Assessment Health and Social Care*. 2010. Available online from: <http://www.hiqa.ie/resource-centre/professionals/privacy-impact-assessments>.
- (6) Health Information and Quality Authority (HIQA). *Recommendations for a Unique Health Identifier for Individuals in Ireland*. 2009. Available online from: http://www.hiqa.ie/system/files/Unique_Health_Identifier_Report.pdf. Accessed on: 12 September 2012.
- (7) Health Information and Quality Authority (HIQA). *International Review of Unique Health Identifiers for Individuals*. 2010. Available online from: <http://www.hiqa.ie/healthcare/health-information/health-identifiers>.
- (8) Health Information and Quality Authority (HIQA). *Recommendations for Unique Health Identifiers for Healthcare Practitioners and Organisations*. 2011. Available online from: <http://www.hiqa.ie/publications/recommendations-unique-health-identifiers-healthcare-practitioners-and-organisations>. Accessed on: 22 October 2012.
- (9) Health Information and Quality Authority. *Recommendations for a Unique Health Identifier for Individuals in Ireland*. 2009. Available online from: http://www.hiqa.ie/system/files/Unique_Health_Identifier_Report.pdf. Accessed on: 3 November 2014.
- (10) Health Act 2007. 2007.
- (11) Health Identifiers Act 2014. 2014. Available online from: <http://www.irishstatutebook.ie/2014/en/act/pub/0015/index.html>. Accessed on: 6 August 2014.

- (12) Data Protection (Amendment) Act 2003. 2002.
- (13) Data Protection Commissioners. *Data Protection Acts 1988 and 2003: A Guide for Data Controllers*. [Pamphlet]. 2004.

Published by the Health Information and Quality Authority.

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