Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Draft information governance and management standards for the health identifiers operator in Ireland

Public consultation document

March 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 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 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.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In accordance with the Health Act 2007, [sections 8(1)(j) and 8(2)(d)], one of the key functions of the Authority is to provide advice to the Minister for Health and the HSE about deficiencies identified regarding health information. It is on this basis that the Authority is undertaking this project.

This document presents draft information and governance standards for public consultation. These standards are aimed at the 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 identifier operator’ will be used through this standards document to refer to each business unit within the Health Service Executive (HSE) that may be assigned duties contained in the Health Identifiers Act 2014.

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Executive summary

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

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

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
- the National Register of Health Services Provider Identifiers.

The National Register of Individual Health Identifiers will contain an individual health identifier and associated demographic information for each person who is being, has been or may be provided with a health or social care service in Ireland. This identifier will be known as an individual health identifier. Its purpose is to uniquely identify each person so that patient safety can be improved within the Irish health and social care service. Benefits associated with introducing individual health identifiers include reducing the number of adverse events that may happen, such as giving the patient incorrect medication or vaccinations or admitting the wrong person for surgery. Allocating an individual health identifier to new born babies helps link their healthcare records for life.

The National Register of Health Services Provider Identifiers will contain a health services provider identifier for each provider that offers health services in Ireland. This identifier will be known as a health services provider identifier. 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. Benefits associated with introducing health services provider identifiers include reducing administrative overhead and cost while also providing clearer accountability by clearly identifying the person and organisation responsible at each stage of a service-user's care pathway.(1) 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.(1)

While the Minister is responsible for overseeing its implementation, the Health Identifiers Act 2014 allows the Minister to delegate 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.

This document presents information governance and management standards for the health identifiers operator for public consultation. These draft standards apply to the operator when health identifiers are introduced to the Irish health and social care sector.

The Health Information and Quality Authority (the Authority or HIQA) have developed these draft 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 draft standards. For example, a draft standard requiring that a privacy impact assessment is conducted has been included following lessons learnt in Australia which indicated that is it vital to identify and plan for privacy risks. Communication and engagement with stakeholders that builds trust in the proposed system of health identifiers has also been identified as a key requirement. Finally, it is critical that any proposed system protects the privacy and accuracy of health identifiers and associated details.

The Authority is inviting your comments on these draft standards. The Authority will consider and review all comments received during the consultation process. Following this process, the Authority will finalise the standards. The closing date for receipt of submissions is 24 April at 5 pm.

Part 1: Introduction

1.1. Introduction

Being able to identify an individual uniquely is critical to patient safety when providing and managing high-quality health and social care. Poor patient identification processes can be the cause of many common adverse events, such as dispensing incorrect medication to a patient, performing the wrong surgery on a patient or providing the incorrect vaccination to a patient. Introducing an individual health identifier to the Irish healthcare information infrastructure has many benefits, including improving patient safety(2) and reducing administrative costs.(3) Using individual health identifiers also facilitates key Government initiatives such as the Department of Health's *eHealth Strategy for Ireland*,(4) the Money-Follows-the-Patient model for funding public hospital care(5) and the introduction of a system of Universal Health Insurance.

An individual health identifier is a unique, non-transferable number assigned to all people using health and social care services in Ireland, which will last for their lifetime. Its purpose is to accurately identify the person, enabling health and social care to be delivered to the right patient, in the right place and at the right time. The individual health identifier is a unique number and does not contain any personal data.(6) No clinical information may be contained in the National Register of Individual Health Identifiers.(6)

Similarly, a health services provider identifier is a number that accurately identifies the practitioners who provide health and social care services, for example, the hospital, general practitioner (GP) and so on, and the locations where the health services are provided. In addition to reducing administrative overheads and costs, introducing a health services provider identifier to the Irish healthcare system also provides clearer accountability by clearly identifying the person and organisation responsible at each stage of a service-user's care pathway.(1) The National Register of Health Services Provider Identifiers provides a single trusted source of data.(1) Using the National Register of Health Services Provider Identifiers facilitates the ability to track linkages between practitioners, their location and the organisations they work for in the delivery of care.(1)

The Authority has documented the experience of other juristicitions when introducing health identifiers in its 2010 publication, *International Review of Unique Health Identifiers for Individuals*.(7) The international experience of introducing health identifiers has been considered when developing these draft information and management standards for the health identifiers in Ireland. For example, lessons learnt in Australia include conducting privacy impact assessments when planning and establishing the national register and at key points during the project. International experience found that communication and stakeholder engagement, which also includes public awareness campaigns, is critical to introducing health identifiers successfully. Finally, protecting the privacy and accuracy of health identifier records was also found to be critical to the successful introduction of health identifiers.

In 2013, the Department of Health published the Health Identifiers Bill, which progressed through the Houses of the Oireachtas and was enacted as the Health Identifiers Act 2014. The Health Identifiers Act 2014(8) provides the legal basis for setting up two national registers:

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

The National Register of Individual Health Identifiers will contain an individual health identifier and associated demographic information for each person who is being, has been or may be provided with a health or social care service in Ireland. The National Register of Health Services Provider Identifiers will contain a health services provider identifier for each provider that offers health services in Ireland.

The Minister for Health is responsible for overseeing the implementation of the relevant law. However, the Minister can delegate certain functions, such as establishing 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 setting up and managing the two registers. Each business unit is known as a health identifiers operator.

The Health Information and Quality Authority (the Authority) has developed these draft standards to support the introduction of health identifiers into the Irish healthcare system by providing information governance and management standards that the health identifiers operator must put into practice. Implementing these standards will promote trust among service users and health service providers that the national registers have been established in accordance with the law and in line with best practice. In turn, this creates confidence that health service providers can be uniquely identified and can uniquely identify the service users to whom they are providing services, which ultimately leads to improvements in patient safety.

1.2. Purpose of the document

The Health Identifiers Act 2014 provides the legal basis for setting up two national registers.(8) The National Register of Individual Health Identifiers will contain an individual health identifier and associated information for each person who is being, has been or may be provided with a health service in Ireland. The National Register of Health Service Providers Identifiers will contain a health services provider identifier for each provider that offers health services in Ireland. Additionally, the Health Identifiers Act 2014 sets out certain governance mechanisms that apply to setting up and managing the two registers.

The purpose of this document is to set out the draft information governance and management standards for establishing and managing the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers (the national registers) in line with national standards, relevant legislation[±] and best practice. These draft standards will be submitted to the Minister of Health for approval.

Part 5 of the Health Identifiers Act 2014 allows certain activities, such as setting up and managing the national registers, to be delegated to the Health Service Executive (HSE). 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.

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.

This document is aimed at the health identifiers operator.

[±] Applicable legislation includes the Health Identifiers Act 2014, the Data Protection Acts 1988 and 2003 and the Health Act 2007.

1.3. Layout of the document

This document is presented in two parts:

- Part 1 describes how these draft 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.
- Part 2 presents the draft standards and lists features that would likely be in place when the standard is being met.

1.4. Legislative framework

These draft standards have been developed in line with relevant legislation. Firstly, the Health Identifiers Act 2014 provides legislation for the creation and governance of health identifiers for individuals and health services providers.(8)

Secondly, 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.(9)

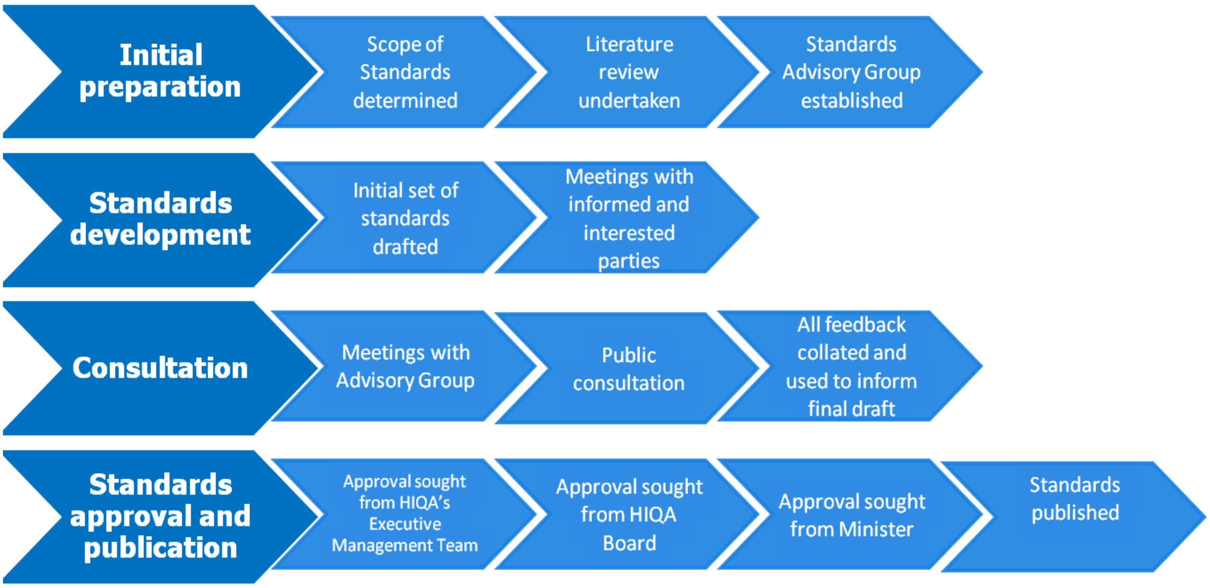
Finally, under the Data Protection Acts 1988 and 2003,(10) the health identifiers operator is a data controller and as such, the health identifiers operator is obliged to follow the eight rules of data protection:(11)

- 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.

1.5. How the standards were developed

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



First stage – initial preparation

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.

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. The draft standards take account of the findings from this literature review.

An advisory group is established with relevant experts.

Second stage – standards development

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.

Third stage – consultation

Two forms of consultation will be conducted as part of the development of these standards:

- An advisory group is established to seek guidance and feedback on the draft standards. The list of members on this advisory group is listed in Appendix 3.
- 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 will be analysed and considered. Feedback will be used to inform the final version of these draft standards.

Fourth and final stage – 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 Board of the Authority. Once approval is obtained, the standards are sent to the Minister for approval and published.

1.6. Standard themes

The Authority has selected appropriate themes for inclusion in these draft 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 five themes selected and adapted to represent the *Draft Information Governance and Management Standards for the Health Identifiers Operator in Ireland* are:

- Person-centred support – person-centred support promotes consideration and respect for service users' dignity, privacy and autonomy. Person-centred support places the service user at the centre of what all the health identifiers operator does.
- Leadership, governance and management – stipulates that appropriate management structures are in place which support clear accountability, 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 contains 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.
- Use of resources – resources includes human, physical and financial. The health identifiers operator is required to plan and effectively manage these resources in order to meet the objectives of 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 five 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.

1.7. 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 that they can illustrate that they are complying 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.

1.8. Review of these standards

The Authority will review these draft standards once the national registers have been established and are operational.

1.9. Public consultation

This document presents for public consultation the proposed *Draft information governance and management standards for the health identifiers operator in Ireland* for a period of six weeks. The Authority will consider and review all submissions received during the consultation process. Following this process, the Authority will finalise the standards.

The closing date for receipt of submissions is 24 April at 5 pm.

How to make a submission

A number of consultation questions have been prepared for your consideration when reviewing the standards. These questions are grouped together in the consultation feedback form. They are not intended, in any way, to limit feedback, and any other comments are welcome. There are three ways to tell us what you think:

- Complete the online consultation feedback form by clicking here. This will bring to you an online version of the consultation feedback form.
- Download the consultation feedback form from www.hiqa.ie and email your completed forms to standards@hiqa.ie.

- Print off a copy of the consultation feedback form from our website and post it to us at:

  Health Information and Quality Authority
  Draft Information Governance and Management Standards for the Health Identifiers Operator in Ireland
  George's Court
  George's Lane
  Smithfield
  Dublin 7

For further information or if you have any questions you can talk to the consultation team by calling (01) 828 6748. You can also find us on Facebook and Twitter.

How we will use your comments

Following the consultation, the Authority will analyse the submissions and as a result may make further amendments to the document. We will present the main amendments in a separate statement of outcomes document which we will publish.

This is your opportunity to participate in the development of standards. We wish to thank you in advance for taking the time to submit your comments.

1.10. Concepts and definitions

1.10.1 Individual health identifier

An individual health identifier is a unique number that is assigned to a person when a health service is being, has been or may be provided for that person. A service user shall be asked for their individual health identifier when they attend a health or social care service provider. If the service user has not been assigned an individual health identifier or does not know what it is, the health service provider may search for it on the National Register of Individual Health Identifiers using specific demographic information, such as name, date of birth, address or mother's maiden name. If an individual health identifier for a service user is not found on the National Register of Individual Health Identifiers, the health service provider can request and obtain one from the health identifiers operator at that time. The Health Identifiers Act 2014 mandates that the individual health identifier is recorded in the service user's record in the health service provider's system and used in relevant communication about the service user.

Following commencement of the Health Identifiers Act 2014, an individual health identifier will:

- be assigned to each living person and each person who has died on or after enactment
- be non-transferable between service users and remains assigned to the service user for the duration of their life and after their death.

1.10.2 Health services provider identifier

A health services provider identifier is a unique number that is assigned to a health service provider. A health service provider can be either a health professional or a healthcare organisation. The identifier for a health service provider can be obtained by searching the National Register of Health Services Provider Identifiers, which will be publicly available. The Health Identifiers Act 2014 mandates that the health services provider identifier is recorded on service user's records when the health service provider provides a service to that service user and on relevant communication about that service user.

Following commencement of the Health Identifiers Act 2014, a health services provider identifier will:

- 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.

1.10.3 National registers of health identifiers

The Health Identifiers Act 2014 mandates that two registers be set up to contain the health identifiers and their identifying particulars. These are the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers.

The National Register of Individual Health Identifiers contains the individual health identifier of people using services and their associated identifying particulars. Each individual health identifier is associated with a set of identifying particulars consisting of surname, forename, date of birth, place of birth, sex, all former surnames, mother's surname and all former surnames of his or her mother, address, nationality, personal public service number, data of death in the case of a deceased individual and photograph. This dataset is mandated in the Health Identifiers Act 2014 and included in Appendix 1. An individual health identifier and its associated dataset are considered 'personal data' under the terms of the Data Protection Acts 1988 and 2003. However, initially only a subset of what is legally allowed to be stored in your health identifier record will be stored.

The National Register of Health Services Provider Identifiers contains providers' health services provider identifiers and their associated identifying particulars. Each identifier is associated with a set of identifying particulars that is mandated in the Health Identifiers Act 2014, and included in Appendix 2.

Throughout this document, the two registers are referred to as the national registers.

1.10.4 Health identifiers operator

The term 'health identifiers operator' refers to the organisation or part of the organisation that will be responsible for setting up and maintaining the national registers. A provision in the Health Identifiers Act 2014 allows for delegation of functions contained in the Act to the Health Service Executive (HSE). 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. The framework will support the introduction and maintenance of health identifiers in Ireland. 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.

1.10.5 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.

1.10.6 Trusted source

As the *International Review of Unique Health Identifiers for Individuals* shows, this approach of using other data sources to initially populate a national register of health identifiers has been used in other countries with good results.(7) For example, the Department of Veteran Affairs is a trusted data source for the Australian IHI service.(12)

Other data sources are used to initially populate and update (as required) the national registers. Examples of potential sources include the Department of Social Protection and professional regulatory bodies such as the Irish Medical Council. The term 'trusted source' is used throughout this document to refer to such data sources since they are recognised as being highly reliable or accurate by the health identifiers operator.

1.11. What is needed to introduce health identifiers in Ireland?

Introducing health identifiers into the Irish health and social care system requires a number of key stakeholders to work together to achieve the objectives of the national registers. The main parties are:

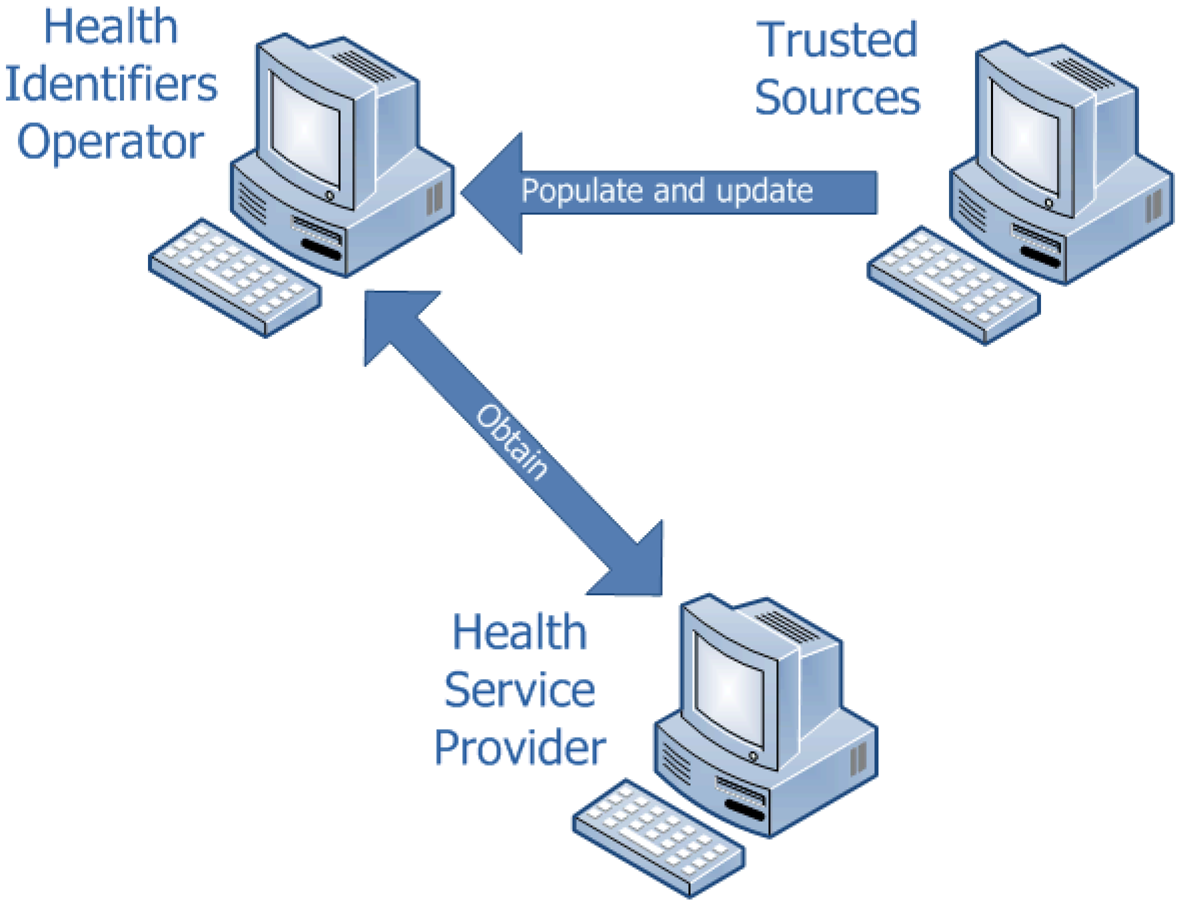
- Health identifiers operator – a business unit responsible for establishing and maintaining the national registers. More detail on the role and function of the health identifiers operator is provided in Section 1.10.4.
- Trusted source – a data source that is used to populate or update the national registers.
- Health service providers – those who will use the national registers as part of their day-to-day work to obtain an individual health identifier or health services provider identifier or to send a request to update information in the national registers.

These three participants are required to work together within defined relationships to support, establish and maintain the national registers. The National Register of Individual Health Identifiers is populated and updated from trusted sources. Health service providers, as part of their day-to-day operation, are required to request an individual health identifier from the National Register of Individual Health Identifiers on behalf of service users when they present for care. 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.

Similarly, interested parties are required to work jointly 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.

The relationship between the three interested parties is illustrated in Figure 2.

Figure 2: Relationship between key stakeholders with respect to establishing and maintaining the National Register of Individual Health Identifiers



1.12. Benefits of individual health identifiers

The main benefit of having an individual health identifier is an improvement to patient safety. Being able to uniquely identify each user will improve patient safety by reducing the number of adverse events that may happen, such as giving the patient incorrect medication or vaccinations or admitting the wrong person for surgery.

Your IHI is different from an electronic health record, which is an electronic version of your medical history. The IHI is one on the key enablers required to implement electronic health records. Also, once the IHI is implemented, other benefits arise for service users, general practice, healthcare providers and social care providers, as follows:

- Benefits for **service users**:
    - Improved accuracy in identifying you and your medical records will lead to safer and better care being provided to you
    - your records in different healthcare organisations may be accurately associated with you
    - your 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
    - health identifiers enable electronic transfer of your health information, which results in faster care for you
- Benefits for **general practices**:
    - Accurately links service users to their record
    - identifies patients in all communications with other health and social care providers
    - enables safe transfer of patient records electronically
    - enables electronic referrals, discharge summaries and electronic prescriptions to be sent, which results in more timely exchange of important information.
- Benefits for **hospitals**:
    - helps create and maintain a complete record for each patient
    - enables patient 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 person’s care by its inclusion on records that may span different health and social care organisations
    - safe and efficient coordination of social care with healthcare.

1.13. Benefits of health services provider identifiers

There are many benefits of having and using a health services provider identifer, for a wide variety of interested parties, including service users, healthcare practitioners, healthcare organiisations, professional regulatory bodies and service planners.

- Benefits for **service users**:
    - supports the secure exchange of health information by uniquely identifying both healthcare professionals and organisations when information is being exchanged
    - 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 to patients to book and alter appointments themselves in outpatient clinics. This service would not be possible without health service providers having unique identifiers.
- Benefits for **healthcare practitioners**:
    - facilitates secure transmission of patient information, such as laboratory results or discharge letters
    - reduces administrative effort.
- Benefits for **healthcare organisations**:
    - supports the introduction of a statutory licensing system that applies to both publicly and privately funded healthcare service
    - 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, which in turn will save time, resources and administrative effort.
- Benefits for **professional regulatory bodies**:
    - improves tracking of healthcare practitioners across regulatory authorities and internationally.

- Benefits for **service planners**:
    - 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.

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

Theme 1 Person-centred support

Person-centred support places service users at the centre of all that the health identifiers operator does. Person-centred support promotes consideration and respect for service users' dignity, privacy and autonomy.

Being person-centred means that the health identifiers operator communicates in a manner that supports the development of a relationship based on trust. Good communication and the provision of adequate, appropriate information ensures that people using services and health service providers understand the role and purpose of health identifiers in the Irish health and social care system.

Being person-centred also means that the health identifiers operator establishes and maintains the national registers in such as way as to protect service users and health service providers' personal information.

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:

- prior to the establishment of the national registers
- at appropriate intervals to identify any new or potential privacy risks that may arise during the operation of the national registers.

1.1.2 Where privacy risks are identified, measures are implemented to mitigate or avoid these risks.

1.1.3 Findings of identified risks and recommendations on how they will be mitigated or avoided are published and influence the next stage of implementation.

Standard 1.2
The health identifiers operator develops, implements and reviews a communications plan that effectively informs service users in relation to the use of the national registers.

Features meeting this standard are likely to include the following:

1.2.1 Developing and implementing a communications plan, using appropriate media, that informs service users and health service providers about:

- the role the health identifiers operator and the national registers in the Irish healthcare system
- how personal health identifier records are used and shared
- service users and health services providers' rights as data subjects.

1.2.2 Develop, review and update, where necessary, the statement of information practices which communicates how the health identifiers operator collect, use, share and protect health identifier records.

1.2.3 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

Effective leadership, governance and management stipulate that appropriate management structures are in place in order to ensure clear accountability, decision-making and risk management. The necessary arrangements are in place for the organisation 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 is achievable 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 An identified individual whose role includes:

- 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
- 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.

2.1.2 Governance arrangements which clearly define roles, accountabilities and responsibilities within the health identifiers operator. These governance arrangements are publicly available.

2.1.3 Monitor, manage and develop the performance of the health identifiers operator's workforce, at individual and team level, including the evaluation of service users' feedback and taking action to address identified areas for improvement.

2.1.4 Strategic and operational plans for the health identifiers operator set clear objectives and plans for the delivery of health identifiers. Strategic and operational plans are implemented.

2.1.5 Effective information governance arrangements protect health identifier records of service users and health service providers.

2.1.6 An established risk management framework is in place in the health identifiers operator. Risks are reviewed at management and staff meetings and the risk register is regularly updated. This includes systems being in place to effectively manage risk, including a designated person(s) to contact in an emergency.

2.1.7 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.

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 captures why the national registers exist and what they do.

2.2.2 A statement of purpose which is publicly available and communicated to all stakeholders, including service users, in an accessible format.

2.2.3 Regular review of the statement of purpose to ensure it is sustainable based on needs and on what can be delivered effectively and efficiently within available resources.

2.2.4 Governance arrangements 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 Notification of, and consultation with, relevant parties 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 person 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 health identifiers operator.

2.3.2 Clearly documented and implemented arrangements that allow the health identifiers operator to illustrate compliance with published standards and legislation.

2.3.3 Clear governance arrangements to allow 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 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 Develop a compliance framework that allows health service providers to demonstrate self-compliance with published relevant standards and legislation.

2.4.2 Monitor and evaluate performance on the use of the national registers by health service providers and implement improvements based on the findings.

2.4.3 Development of service level agreements between the health identifiers operator and health service providers. The service level agreement defines the obligations of both the health identifiers operator and health service providers, and may cover such topics as:

- 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 Providing education and training resources 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 data exchange agreements 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 data exchange agreements between trusted sources and the health identifiers operator on data sharing arrangements in order to protect the privacy, quality and confidentiality of the data used to establish and maintain the national registers.

2.5.2 Arrangements which ensure 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 that restrict health identifier records being transferred from the national registers back to any trusted source.

2.5.4 Measures that allow modifications to data exchange agreements in conjunction with trusted sources and the Data Protection Commissioner in line with the Health Identifiers Act 2014.

2.5.5 Development of, and adherence to, data exchange agreements with other EU member states 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 whose role includes responsibility for ensuring that the quality of the national registers is monitored, reviewed, evaluated and improved continually.

2.6.2 Develop, implement and continually evaluate the health identifiers operator to actively improve its quality. Decisions to modify or improve the health identifiers operator are evidence-based.

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.(13) 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'.(14) 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.(13)

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 Develop and implement standard operating procedures which detail how the health identifiers operator collect, store, share, use and protect health identifier records.

3.1.2 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.

3.1.3 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. Facilitating requests to view or request modification of health identifier records are conducted in a timely manner.

3.1.4 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.

3.1.5 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.

3.1.6 Using trusted sources – included in the Health Identifiers Act 2014 – to populate the national registers in accordance with agreed data exchange agreements.(15) Such data may need additional validation and verification prior to inclusion in the appropriate register.

3.1.7 Proactive monitoring, reviewing and updating of these policies and procedures to ensure their validity and appropriateness.

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 Using the data set prescribed in the Health Identifiers Act 2014 to establish, assign and locate health identifiers in the National Register of Individual Health Identifiers.

3.2.2 Using the data set prescribed in the Health Identifiers Act 2014 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 procedures allow the national registers be a high availability resource.

3.2.6 Formalised arrangements allow audits on the quality of health identifier records to be conducted, 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 Use of resources

The health identifiers operator is required to plan and effectively manage its resources in line with the objectives of the creation and ongoing existence of the national registers. It must make sure that its resources are adequate to ensure the sustainability, continuous relevance and maximum impact of the national registers. Resources include human, physical, financial and natural resources.

Since resources are finite, and budgets limited, the health identifiers operator is required to carefully manage its resources to ensure that they are used in the most efficient, useful and effective manner. The allocation of resources is a fundamental factor in the delivery of quality data as the deployment of resources significantly impacts on the quality of information provided and the future sustainability of the national registers.

Standard 4.1
The health identifiers operator plans and manages the allocation and uses of resources assigned to it to meet the objectives of the national registers.

Features meeting this standard are likely to include the following:

4.1.1 Clear plans that take account of the funding and resources required for the viability of the health identifiers operator.

4.1.2 Consultation with key stakeholders including service users, policy makers and their own workforce regarding the allocation of resources to achieve the best quality and safety outcomes for service users.

4.1.3 Transparent and effective decision-making arrangements when planning, procuring and managing the use of resources for the effective establishment and operation of the National Registers.

4.1.4 Resource decisions are informed by:

- explicit consideration of the quality, safety and ethical implications of such decisions
- risk assessment of the decisions
- best available evidence
- service users and health service providers' views.

4.1.5 Transparent reporting on financial performance in line with relevant legislation and national policy.

Theme 5 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 5.1
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:

5.1.1 A formal mandatory induction programme for its workforce that includes a focus on the privacy and confidentiality of service users and health service providers' personal information.

5.1.2 An evidence-based training, educational and development programme with a specific focus on, but not limited to the following:

- the Health Identifiers Act 2014
- the importance of privacy and confidentiality of service users and health service providers' personal information
- 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.

5.1.3 Developing and implementing a training schedule which is tailored to specific members of the workforce to develop competencies in order to ensure the delivery of an effective and secure health identifiers operator.

5.1.4 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 are required to attend annual refresher courses.

5.1.5 Training materials are evaluated for effectiveness, and updated or modified if necessary.

5.1.6 Evaluation of training programmes are conducted and analysed, and where necessary, further training is delivered.

5.1.7 Work practices reflect the training provided to the workforce.

Appendix 1 Prescribed dataset for the individual health identifer

The Health Identifiers Act 2014 prescribes what data can be collected and used in the National Registers. Only using this prescribed dataset is one of the features of Standard 3.2 of these draft standards. The prescribed data set for the National Register of Individual Health Identifiers is contained in the Health Identifiers Act 2014 under a definition for 'other identifying particulars' and is listed here.

> ..."other identifying particulars", in relation to an individual, means any one or more of the following particulars:
>
> (a) surname;
> (b) forename;
> (c) date of birth;
> (d) place of birth;
> (e) sex;
> (f) all former surnames;
> (g) mother's surname and all former surnames of his or her mother (including mother's surname at mother's birth);
> (h) address;
> (i) nationality;
> (j) personal public service number (if any) within the meaning of section 262 of the Social Welfare Consolidation Act 2005;
> (k) date of death in the case of a deceased individual;
> (l) signature (not being a signature which falls within a class of signatures prescribed as a class of signatures to which this paragraph does not apply);
> (m) photograph (not being a photograph which falls within a class of photographs prescribed as a class of photographs to which this paragraph does not apply);
> (n) subject to section 3(5), any other particulars (excluding clinical information relating to the individual) prescribed for the purpose of this paragraph that, in the opinion of the Minister, are relevant to identifying the individual;...

Appendix 2 Prescribed dataset for the health services provider identifier

The Health Identifiers Act 2014 prescribes what data can be collected and used in the national registers. Only using this prescribed dataset is one of the features of Standard 3.2 of these draft standards. The prescribed data set for the National Register of Health Services Provider Identifiers is contained in the Health Identifiers Act 2014 and listed here.

Part 3, Section 14, Subsection 1:

...(a) in Part A of the Register, in relation to each health practitioner referred to in paragraph (a) of the definition of "health services provider" in section 2(1) who has been assigned a health services provider identifier -

- (i) the health services provider identifier, and
- (ii) the following particulars to the extent that they are known:
  - (I) surname;
  - (II) forename;
  - (III) business address and, if different, the place of employment and name of employer;
  - (IV) the name of the professional regulatory body with which the practitioner is registered and the registration number assigned to the practitioner by that body;
  - (V) subject to subsection (2), any other particulars prescribed for the purposes of this clause that, in the opinion of the Minister, are relevant to identifying the practitioner,

(b) in Part B of the Register, in relation to each relevant body referred to in paragraph (b) of the definition of "health services provider" in section 2(1) which has been assigned a health services provider identifier -

- (i) the health services provider identifier, and
- (ii) the following particulars to the extent that they are known:
  - (I) its legal name and, where applicable, the name under which it trades;
  - (II) its business address;
  - (III) the locations at which it provides health services and a description of those services;
  - (IV) any other particulars prescribed for the purposes of this clause that, in the opinion of the Minister, are relevant to identifying the body and the health services it provides,

(c) in Part C of the Register, in relation to a relevant employee referred to in paragraph (c) of the definition of "health services provider" in section 2(1) who has been assigned a health services provider identifier -

- (i) the health services provider identifier, and
- (ii) the following particulars to the extent that they are known:

(I) surname;

(II) forename;

(III) the capacity in which he or she is a relevant employee, the place at which he or she is employed as a relevant employee and the name and health services provider identifier of the health services provider who is his or her employer;

(IV) subject to subsection (2), any other particulars prescribed for the purposes of this clause that, in the opinion of the Minister, are relevant to identifying the relevant employee,

(d) in Part D of the Register, in relation to each relevant agent referred to in paragraph (d) of the definition of "health services provider" in section 2(1) who has been assigned a health services provider identifier -

(i) the health services provider identifier, and

(ii) the following particulars to the extent that they are known:

(I) surname;

(II) forename;

(III) the capacity in which he or she is a relevant agent, the place at which he or she acts as a relevant agent and the name and health services provider identifier of the health services provider who is the relevant agent's principal;

(IV) subject to subsection (2), any other particulars prescribed for the purposes of this clause that, in the opinion of the Minister, are relevant to identifying the relevant agent,

and

(e) in Part E of the Register, in relation to a relevant agent referred to in paragraph (e) of the definition of "health services provider" in section 2(1) which has been assigned a health services provider identifier -

(i) the health services provider identifier, and

(ii) the following particulars to the extent that they are known:

(I) its legal name and, where applicable, the name under which it trades;

(II) its business address;

(III) the capacity in which it is a relevant agent, the place at which it acts as a relevant agent and the name and health services provider identifier of the health services provider who is the relevant agent's principal;

(IV) any other particulars prescribed for the purposes of this clause that, in the opinion of the Minister, are relevant to identifying the relevant agent.

Appendix 3 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

Glossary of terms used in these draft 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.(15) Data exchange agreements must be developed in line with legislation.

Data quality: data that is 'fit for purpose' or 'fit for use'.(14) 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.*(13)

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, as described in Part 1, Section 2 of the Health Identifiers Act 2014.

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.

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.

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 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.(16)

The process involves the evaluation of broad privacy implications of projects and relevant legislative compliance. Where potential privacy risks are identified, a search is undertaken, in consultation with stakeholders, for ways to avoid or reduce these risks. A privacy impact assessment should be conducted during the planning phase of a project. Identifying and evaluating any privacy concerns during this phase can genuinely influence the development of a project before any significant investment has been made. A privacy impact assessment should also be conducted at set times during the project's life cycle to identify new potential privacy concerns that may arise during the project's implementation.

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.

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