National standard demographic dataset and guidance for use in health and social care settings in Ireland

January 2016

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high quality and safe care for people using our health and social care services in Ireland. HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

HIQA aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA has statutory responsibility for:

- **Setting Standards for Health and Social Services –** Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland.

- **Regulation –** Registering and inspecting designated centres.

- **Monitoring Children's Services –** Monitoring and inspecting children's social services.

- **Monitoring Healthcare Safety and Quality –** Monitoring the safety and quality of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health Technology Assessment –** Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.

- **Health Information** – Advising on the efficient and secure collection and sharing of health information, setting standards, 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 (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care, 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.

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

Through its health information function, the Authority is addressing these issues and working to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of services. A key requirement is the ability to accurately and consistently identify service users. Hence, one of the areas currently being addressed through this work programme is the development of a national standard demographic dataset and guidance for use in health and social care settings in Ireland.

In December 2013, HIQA released the first version of the National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland. As a result of feedback we received on the first version of the Standard, and with the expected introduction of a national healthcare identifier in 2015, HIQA feels it is timely to review and revise the National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland.

Table of contents

1. Introduction

Safe and reliable health and social care depends on access to, and use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. A demographic dataset is essential to provide core information about patients and other service users. It comprises of identifying data elements about an individual, including, for example, the individual's date of birth, name and address as well as other items associated with an individual.

The purpose of the National Standard Demographic Dataset for health and social care services in Ireland is to remove the duplication and variation within and between service providers when collecting patients' and service users' demographic data. It assists all service providers, including primary care centres, general practitioners, hospitals, primary care services, health and social care professionals, children's residential centres and residential centres for older people or residential services for children and adults with disabilities to collect standard core data about patients and service users.

The development of a national standard demographic dataset helps to standardise how demographic data is recorded and facilitates easier sharing of information within and between health and social care services. This helps to reduce duplication in a number of areas, including, for example, fewer duplicate records, appointments, testing and prescribing, resulting in time, administration and cost savings. A national standard demographic dataset allows tracking and trending demographic data, hence enabling better planning of services and care provided.

The guidance accompanying the demographic dataset provides support and assistance to the health and social care sector to meet the requirements of the National Standard Demographic Dataset, and ensure consistency in the recording of the data.

1.1 Relationship with the individual health identifier and associated dataset

The ability to uniquely identify individuals is imperative to provide high-quality and safe care. The Health Information and Quality Authority has recognised the importance of being able to uniquely identify individuals and has recommended the introduction of an individual health identifier.[1] The implementation of the individual health identifier commenced in 2015. An individual health identifier comprises of three main components: the number

itself, the dataset associated with the number, and the system that supports the number and dataset. The purpose of the individual health identifier is to safely identify individuals accessing health and social care services in Ireland. The dataset associated with the individual health identifier will contain data elements such as name, date of birth and address.

The National Standard Demographic Dataset sets out how health and social care providers should record demographic data about individuals accessing their services. The National Standard Demographic Dataset includes all the data elements present in the individual health identifier dataset with the exception of the Personal Public Service (PPS) number. It is important to note that it is intended that the PPS number is included in the individual health identifier dataset purely for the purposes of searching for an individual health identifier and will not be downloadable or visible to users of the individual health identifier system. Therefore, including the PPS number in the National Standard Demographic Dataset would be inappropriate.

When the individual health identifier is implemented, service providers will be able to access the individual health identifier system. Access to the individual health identifier system could potentially be via the providers' information technology systems. Using the same format for demographic elements will allow for quicker and more accurate searching of the individual health identifier system. It could also potentially mean that service providers have the ability to download the appropriate data elements from the individual health identifier dataset to their local systems.

2. Background

The Health Information and Quality Authority (HIQA) was established under the Health Act 2007[2] with the primary aim to promote patient safety and quality throughout health and social care settings. HIQA has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information as outlined in the Health Act 2007. These statutory functions provide the basis for HIQA to have a central role in coordinating and facilitating the improved collection, use and dissemination of health information by all stakeholders.

In 2012, one key deficiency identified by both HIQA and a number of stakeholders was the absence of a national standard demographic dataset across the Irish health and social care sector. At that time there was no standardised or agreed guidance on the collection of demographic data. The lack of a national demographic dataset had resulted in each health and social

care provider designing their own rules for the data elements they wished to collect on each individual.

Consequently a variety of approaches have been used to collect and format data elements. This results in many permutations and combinations for each data element. Examples include how to collect name details; for instance the name McCarthy can be collected as 'McCarthy', 'Mc Carthy', 'MacCarthy' and so forth. Date of birth can be collected as dd/mm/yy, dd/mm/yyyy, mm/dd/yy or mm/dd/yyyy leading to a potential for duplication of records. It is therefore crucial to have a single national standard to ensure consistency at a national and local level of such important demographic data.

In 2013 HIQA published the *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland.* We are now undertaking a revision of that Standard.

3. Benefits of this work

Why standardise demographic data?

One of the key requirements to support the delivery, planning and monitoring of services, is the ability to have access to quality information about an individual. A national standard demographic dataset defines a set of demographic data elements that will be recorded for each service user. The same data elements should be recorded for each service user in all health and social care services throughout the country.

Standardisation of demographic data increases efficiency by providing a clear understanding of what each data element means. This enables greater accuracy in the recording and interpretation of data, allowing for safer communication of each service user's demographic details. Standardised demographic data also limits the way data can be collected, interpreted and exchanged between different groups resulting in time and cost savings.[3]

A wide range of stakeholders benefit from having a standardised demographic dataset in place, including people who use our health and social services, healthcare practitioners, healthcare organisations and service planners. Some examples of these benefits are listed below.

What the standard demographic dataset means for people who use our health and social care services:

- safer, better care for service users due to available, accurate and complete demographic data for each service user
- standardisation of the core demographic data enables more accurate analysis of current and future demands and needs of service users
- works towards removing the need for repeated provision of demographic data on each visit to the health or social care service provider
- assists in reducing administration and costs as demographic data need only be collected once.

What the standard demographic dataset means for general practitioners:

- enables the recording of more accurate and consistent data which improves the reliability of information to make informed decisions
- assists in service user identification, therefore preventing duplication or misidentification errors, and less duplication of testing and prescribing
- allows information to be exchanged and transferred between information systems, therefore reducing administrative tasks
- cost-saving and time-saving benefits.

What the standard demographic dataset means for hospitals:

- ensures more complete and accurate information on which to base potentially life-critical clinical decisions
- allows information to be exchanged and transferred between information systems
- accountability and improved communications
- reduction in significant levels of duplication of administrative effort, less wastage of time and resources, and hence greater efficiencies.

4. Scope of national standard demographic dataset

The National Standard Demographic Dataset presents health and social care service providers with a standard core set of data elements to support the consistent, complete, and accurate recording of information for each service user. A national standard works towards the removal of duplication and improving the safety and quality of care provided. The objectives of the National Standard Demographic Dataset are to:

- Establish a national standard demographic dataset that is collected by all health and social care service providers in Ireland (including primary care centres, general practitioners, hospitals, primary care services, health and social care professionals, children's residential centres, and residential centres for older people or residential services for children and adults with disabilities) based on international standards and best practice.

- Develop supporting guidance for demographic data entry.

This dataset does not aim to specify the requirements for electronic transfer of demographic data. In addition to the demographic dataset HIQA has developed a *General Practice Messaging Standard* [4], a *National Standard for Patient Referral Information* [5] and *Standardising Patient Discharge Summary Information,* [6] all of which can be found on http://www.hiqa.ie.

5. Methodology

The original standard published in 2013 was developed by conducting a review of national practice through examining the demographic data being collected by a number of national agencies both within and outside of health and social care services. Relevant international standards were reviewed and detailed discussions were conducted with a number of key stakeholders. Throughout the development of the original demographic dataset, HIQA consulted with members of the General Practice Information Technology Group and the Department of Social Protection, Client Identity Services. The following international standards were reviewed:

- ISO/TS 22220:2011. Technical Specification. Health Informatics – Identification of subjects of healthcare [7]
- ISO/TS 27527:2010. Technical Specification. Health Informatics –

Provider identification[8]

- ISO 3166-1:2006. Codes for the representation of names of countries and their subdivisions - Part 1: Country codes[9]
- AS 4846-2006. Australian Standard. Health Care Provider Identification.[10]
- AS 4590-2006. Interchange of client information standard[11]
- ASTM E1714-00. Guide for Properties of a Universal Health Care Identifier[12]
- ITU-T E.123. Notation for national and international telephone numbers, e-mail addresses and web addresses[13]
- European Convention on Nationality[14]

In addition, a review was conducted of demographic datasets associated with national patient identifiers in use in other countries, including the New Zealand National Health Index (NHI) number dataset,[15] the UK National Health Service (NHS) number dataset[16] and the proposed dataset associated with the Health Identifier Act 2014 in Ireland.[*]

An eight-week public consultation on the original *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland* took place from February 18, 2013 to April 12, 2013. All submissions to the consultation were reviewed and informed the development of the original version of the National Standard Demographic Dataset.

In order to develop this revision of the Standards HIQA revisited the standards listed above. The dataset in the Health Identifiers Act 2014 was also reviewed. During the development of the revised Standards HIQA undertook a targeted consultation with key stakeholders and a broader group of stakeholders via a public consultation. The draft revision of the standard for consultation was published in October 2015 for a five week period which ran until 13 November 2015. Following consideration of the feedback, the standards have been revised. A broad overview of the feedback received is contained in the Statement of Outcomes available on www.hiqa.ie

---

[*] The Health Identifiers Bill was signed in law in July 2014.

6. National standard demographic dataset

For ease of use the National standard demographic dataset is divided into six sections – name, address, healthcare identifiers, communication details, additional demographic details and communications. The data items in each section of the demographic dataset are described below, along with the optionality and brief note on the usage. Detail guidance on each data item is provided in section 7. Some data items can repeat. For example, surname and address can repeat to allow for a changes in surname and address.

Name	Description	Optionality	Usage
1. Name Details	This section aims to sub-divide the components of a service user's name to ensure that each service user is accurately and uniquely identified, and to work towards the removal of duplication or mis-identification, leading to an improvement in safety and care provided. In addition to recording the service user's current name, the dataset allows for the classification of names, which indicates if the name is a birth name, married name and so forth, allowing previous name(s) or different names to be recorded.		
1.1 Name title	The title relevant to a specific family name for this service user.	Optional	Name title options include Doctor (Dr) and Mister (Mr).
1.2 Given name	The service user's identifying name.	Mandatory	The first name by which the service user is identified.
1.3 Family name	The second part of the service user's name which denotes their family or marital name.	Mandatory	This is the family or marital name of the service user. For example, Smith.
1.4 Name suffix	Additional term used following a person's name to identify a service user.	Mandatory where applicable	Identifies the service user's name suffix, for instance Senior (Sr) or Junior (Jr).
1.5 Name usage classification	A classification that enables differentiation between the usage of names for a service user. An individual name may have many	Optional	The service user may use a married name and pre-married name for different purposes.

Name	Description	Optionality	Usage
	uses.		
1.6 Preferred name	Indicates the name by which the service user prefers to be identified. This is the name that will be displayed when the service user is referenced; it will be used on screens, reports, letters and data collections.	Optional	The field should be populated with a Y or an N to indicate this name is the service user's preferred name. Only one name record should be recorded as the preferred name.
2. Address	This section provides information relating to the address for the service user. It provides the facility to record various types of addresses, for example home, business or postal address. It also provides for recording the low-level details of the address including the street name and number into one composite field. Data items are included for higher level information including suburb, town, townland, locality, Dublin district and county. Country may be recorded but usually only for patients or services users whom are not resident in Ireland. Finally, it provides for the new Eircode to be populated.		
2.1 Address line(s)	This is a composite field consisting of some but not all of; Building complex sub-unit type abbreviation, Building complex sub-unit number, Address site name, House or property number, Street name and type.	Mandatory	This field allows for collection of address information regarding building, house or apartment number and street.
2.2 Suburb/ Town/Townland/ Locality	The full name of the locality describing the specific address of a service user.	Optional	The full name of the locality describing the specific address of a service user.
2.3 District/County	The full name of the county where the	Optional	For example, Dublin 7 or County

Name	Description	Optionality	Usage
	service user resides.		Cork.
2.4 Country	The full name of the country where the service user resides.	Optional	The full name of the country where the service user resides.
2.5 Postcode	A code representing the address of the service user.	Optional	A code as defined by the Department of Communications, Energy and Natural Resources.
2.6 Address type	Multiple addresses may be recorded. Each address should have an associated address type code. There should only be one current home address and one current postal address. It should be noted that the service user may indicate that c/o (in care of) needs to be included with the address. If this is the case, please put c/o in front of the postal address.	Optional	Indicates the type of address record that has been recorded, for example place of residence or postal address.
3. Health Identifiers	A Health Identifier can be defined as the designation permanently assigned to an individual for the purpose of identification to facilitate the provision of health and social care. This section allows for recording of a service user's identifiers. Multiple numbers may be collected. Identifiers may be issued at local or regional level. Initially all local numbers used should be provided but with the roll out of the individual health identifier, this should also be included. The type of the identifier and the value of the identifier should both be recorded.		
3.1 Health identifier	A number or code assigned to a service user by a health or social care provider. This may be assigned at a local, regional or	Mandatory where applicable	Multiple numbers may be collected. Initially local numbers should be provided but with the roll out of the

Name	Description	Optionality	Usage
	national level.		individual health identifier this should also be included.
3.2 Health identifier type	A code to identify the type of number recorded in 3.1.	Mandatory where applicable	Examples include medical record number or individual health identifier.
4. Additional demographic details	These are additional data elements that are necessary to identify the service user. This section is made up of data elements that qualify and ensure the accurate identification for the service user. Data items in this section include date of birth and gender.		
4.1 Date of birth	The date of birth of the service user.	Mandatory	The date of birth should follow the following format: dd/mm/yyyy.
4.2 Place of birth	Birthplace. If the service user was born in Ireland, the county in which they were born. If the service user was born outside of Ireland, the country in which they were born.	Optional	Examples of county include; Galway, Roscommon Examples of country include Poland and China.
4.3 Gender	The service user being male or female.	Mandatory	Examples are male and female.
4.4 Mother's birth family name	The original family name of the service user's mother.	Optional	For example, Smith.
4.5 Nationality	The legal bond between a person and a State.[17]	Optional	Polish Chinese Irish.
4.6 Date of death	The date that the service user died.	Mandatory where applicable	The format for date of death should be dd/mm/yyyy.
4.7 Source of death notification	The source of information about the service user's death.	Optional	For example, Relative, General Register Office.

Name	Description	Optionality	Usage
5. Communication Details	This section identifies the contact details for the service user and the preferred method of communication, for example, landline, mobile phone or email.		
5.1 Communication Details – Type	Landline Telephone, Mobile Phone, Email, URL, Other.	Optional	Indicates the communication type. For example, mobile phone.
5.2 Communication Details – Value		Optional	Provides the number for the given type; for example,+353 86 6234541.
5.3 Communication Details - Contact preference	An indication of the most appropriate time during the day or week to contact the service user. For example, daytime hours.	Optional	An indication of the most appropriate time during the day or week to contact the service user. For example, daytime hours.
6 Personal Characteristics	Personal characteristics are the individual features which can be used to identify a person. Traditional methods of identification centre on something one possesses, such as a token or driving licence, or something one knows, such as passwords, addresses or names. Biometric identifiers may be used in addition to conventional identification methods as they can be faster and more reliable. Unlike traditional methods, biometric identifiers are part of the person themselves and therefore cannot be forgotten or stolen.		
6.1 Personal Characteristics	Signature, photographic identification, voice recognition, iris scanning, retinal scanning, hand geometry, signature dynamics, keystroke dynamics, lip movement, thermal face image, thermal hand image, gait, blood type or DNA.	Optional	The coded text will list a range of identifiers including possible biometric identifiers, such as fingerprint and voice recognition.

7. Standard demographic dataset guidance

Guidance is now provided specific to each of the six data items in the demographic dataset.

7.1   Name details

The follow provides the specific guidance relevant to the recording of name details provided in section 6 above.

7.1.1 Name title (Dataset 1.1)

A prefix added to a service user's name in certain circumstances.

Data type	Coded text.
Data domain	The following is a non-exhaustive list of commonly used abbreviations. The full list of possible name titles can be found in ISO/TS 22220:2011.[7]

Name title	Abbreviation
Doctor	Dr
Miss	Ms
Mister	Mr
Missus	Mrs
Professor	Prof

Guide for use	If for instance the service user specifies that their name title is Doctor, use the abbreviation Dr.
Verification rules	Titles of Ms, Mrs, Bean Uí (a direct translation into Irish for Mrs) should only be accepted for females.
	Titles of Mr, Sir, and an tUasal (a direct translation into Irish for Mr) should only be accepted for males.
Source standards	ISO/TS 22220:2011.

7.1.2 Given name (Dataset 1.2)

The service user's given name, first name or forename.

Data type	Text.
Data domain	Not applicable.

Guide for use   Mixed case should be used.

Given name should preferably be recorded as per the birth certificate or passport. If the service user prefers to be called by a different name, a shortened version of their own name or perhaps a nickname, this should be recorded and marked as their preferred name.

Source standards   ISO/TS 22220:2011.

Registering an unnamed newborn baby
Assign gender using boy and girl after mother's forename. These are more distinct than male and female. Use the possessive S after mother's forename as it is only one character, is more parent friendly and flows better with boy and girl. For those rare cases where gender cannot be assigned use "baby" after mothers forename.
Examples: Celiasboy, Celiasgirl, Celiasbaby.

Registering unnamed newborn twins
Use the order number first followed by mother's first name, possessive S and gender boy/girl. For rarer multiple births use the follow prefixes where appropriate - Quad, Quin, Sext, Sept, Oct, Non

Examples: Twinone Celiasgirl, Twintwo celiasgirl.

Shortened or alternate first given name
If the service user uses a shortened or alternate version of their first given name record this as the given name and mark it as the preferred name.

Example: The service user's given name is Jennifer but she prefers to be called Amy. In this instance, record Amy as the given name and mark it as the preferred name and Jennifer as the given name and mark it as not the preferred name.

Punctuation
If special characters form part of the given name, they should be included, where possible.
Example: Ann-Marie, Grégoire, Seán, Áine.

Registering an un-identified service user
If the service user's given name is not known, record 'unknown', where possible, in the given name field.

Use of first initial
If the service user's given name is not known, but the first letter (initial) in the name is known, record the first letter in the given name field. A full stop shall not follow after the initial.

Service user with only one name

In extremely rare circumstances, a service user may not have a given name and a family name: they have only one name by which they are known. If the service user has only one name, record it in the family name and enter 'unknown' in the given name.

7.1.3 Family name (Dataset 1.3)

The second part of the service user's name which denotes their family, surname, last name or marital name.

Data type	Text.
Data domain	Not applicable.
Guide for use	Mixed case should be used.

The family name should be recorded in the format preferred by the service user. The format should be the same as that written by the service user on a registration form, or in the same format as that printed on an identification card, to ensure consistent collection of name data.

When a person uses two names for their family name, both names should be registered as a family name.

Some people use more than one name: for example formal name, birth name, married or pre-marriage name (section 7.1.5 outlines the different classifications). Each should be recorded but the given name the person wants to be referred to as should be identified using the preferred name field.

Verification rules	Not applicable.
Source standards	ISO/TS 22220:2011.

Registering an unidentified service user

The default for unknown family name should be 'unknown' in all instances and the name recorded as the other name. A fictitious family name such as Doe shall not be created, as this is an actual family name.

Registering a pseudonym

A pseudonym is a fictitious or partial name instead of the full or actual name used. This process might be mandatory in order to mask the identity of an individual, for example in the case of HIV testing where the person wants to remain anonymous. It is recommended that the service user be asked to record both the pseudonym in addition to a legally-known name. This requires

local systems to be able to identify which name is to be used as the preferred name for the purposes of the test. This might require the temporary change of a name to preferred name, which is changed to another name after the pseudonym use is over. It is important to recognise that this is not total anonymity as there is a link to the usual identifiers of the individual. In a case where a service user is allowed full anonymity, to register a pseudonym against a true identity would be to breach the anonymity. Where anonymity is mandatory or permitted, no link can be made.

Registering unnamed birth(s) – Single and multiple
An unnamed (newborn) baby should use their mother's family name and follow the guidance above for given name.

Punctuation
If special characters form part of the family name, they should be included, where possible. For example, hyphenated names should be entered with a hyphen. Other alphabetical characters to be aware of include:

Fada á	Eth ð
Tilde ñ	Grave ò
Acute ó	Circumflex ô
Umlaut ü	

Apostrophe
There should be no spaces before or after the apostrophe, such as in the example shown, between the O and the apostrophe or between the apostrophe and Brien.
Example: O'Brien.

Full stop
There should be no space before a full stop, such as in the example shown, between St and the full stop.

Example: St. John.

Space

If the service user has recorded their family name as more than one word, there should be a space between the words.

Example: Mc Donald, Ni Shuilleabháin, Le Brun, Mac Carthy.

If the service user has recorded their family name as one word, there should be no space.

Example: McGuirk, MacWilliam.

Misspelled family name
If the service user's family name has been misspelled in error, update the family name with the correct spelling and record the misspelled family name as another name in the name usage field as other. Recording misspelled names is important for filing and identifying documents that might be issued with previous versions of the person's name and for future identification of the service user, should they contact the health system again and have the same problem with spelling.

7.1.4 Name suffix (Dataset 1.4)

Additional term used following a person's name to identify a service user.

Data type	Coded text.
Data domain	Name suffix should be abbreviated. The following are some examples of commonly used abbreviations. The full list of examples can be found in ISO/TS 22220:2011.[7]

Name Suffix	Abbreviation
Junior	Jr
Senior	Sr

Guide for use	Mixed case should be used (rather than upper case only).
Validation rules	Not applicable.
Source standards	ISO/TS 22220:2011.

7.1.5 Name usage (Dataset 1.5)

Clearly identifying how each name is used, for example is the name on the birth certificate, or is it the pre-marriage (maiden) name.

Data type	Coded text. This code is obtained from ISO/TS 22220:2011.[7]
Data domain	The following are some examples of name uses. The listing from ISO/TS 22220:2011[7] has been adapted for the Irish context in that birth certificate name has been included.

Code	Description	Alternative Code
1	Maiden name	M
2	Newborn name	N
3	Birth certificate name	B
4	Other name	O

Guide for use More than one name can be recorded for a service user and each of these names may have more than one usage at any given point in time.

Validation rules Not applicable.

Collection method The following question format might assist with data collection:

Is this the name that you always use or would you like to categorise it, for instance as your maiden name, newborn name, registered name or under other name?

Example Marianne Smith M
Marianne Jones

Source standards ISO/TS 22220:2011.

Maiden name
Maiden name (Pre-marriage name [M]) is the name used by the service user prior to marriage.

Newborn name
Newborn name (N) type is reserved for the identification of unnamed newborn babies. It acts as a preferred name until an actual name is available, at which time it is no longer used.

Birth certificate name
The official name on the birth certificate. For example, the birth certificate (B) name could be Margaret, but the service user may actually be known as Sheila.

Other name
Other name (O) is any other name that a person is also known by, or has been known by in the past; that is, all other names. This includes misspelled names, or name variations that are to be retained as they have been used to identify this person. More than one other name may be recorded for a service user.

7.1.6 Preferred name (Dataset 1.6)

The preferred name or alias indicates the name by which the service user likes to be known.

Data type   Boolean.

Data domain

Code	Description
Y	This is the preferred name.
N	This is not the preferred name.

Guide for use   This is the name that will be displayed when the service user is referenced. It is to be used on screens, reports, letters and data collections. The service user should be able to provide documentation that verifies that their 'preferred name' is in fact used. It should be highlighted that this will be the name used in correspondence, healthcare records and so forth.

Verification rules Only one name for any individual person can be allocated as the preferred name at any point in time.

Example   The service user's given name is Jonathan, but Jack is his preferred name.

Source standards ISO/TS 22220:2011.

7.2 Address

The follow provides the specific guidance relevant to the recording of address details provided in section 6 above.

7.2.1 Address line (Dataset 2.1)

A composite of one or more standard address components that describe a low level of geographical or physical description of a location that, used in conjunction with the other high-level address components, such as "suburb/town/locality name", "postal code", "state/territory/province", and "country", forms a complete geographical or physical address.

Data type   Text.

Data domain   This item is a combination of the following standard address data elements that may be integrated in the address line in the following sequence:

Building complex sub-unit type
Building complex sub-unit number
Address site name
House or property number
Street name

Guide for use	One complete identification description of a location of an address can comprise one, or more than one, instance of address line. Instances of address lines are commonly identified in electronic information systems as address-line 1, address-line 2, and so on. Where address line is collected as a stand-alone item, software may be used to parse the address line details to separate the subcomponents.
	Multiple address lines may be recorded as required. Address line can include more than one physical line of text.
	All of the relevant "street" details, including building or property name, should be captured in this field. The field is free text, although some commonly used abbreviations are permitted.
	No unnecessary punctuation should be added to the address, for example no full stop following street type.
	Residential facilities Enter name of the residential facility (such as the nursing home, caravan park, prison or boarding school) before the street address.
	The full street address should be recorded. This may be a combination of the above components.
	EXAMPLE 1 Level 15 Room 2B 27 James Street
	EXAMPLE 2 Level 7 Room 15 Customs House Main Street
	EXAMPLE 3 Unit 2A Technology Park 4 Centre Road
Verification rule	Not applicable.
Collection method	The format of data collection is less important than consistent use of conventions in the recording of address data. Hence, the address may be collected in an

unstructured manner but should ideally be stored in a structured format.

Unknown address.
Enter "unknown" in the address line field.

No fixed address.
Enter "unknown" in lieu of street number and name in the address line field.

Example   APT, CTGE.

Source standards   ISO/TS 22220:2011.

7.2.1.1 Building and or complex sub-unit type (Dataset 2.1)

The specification of the type of a separately identifiable portion within a building or complex, to clearly distinguish it from another.

Data type   Coded text.

Data domain   The data domain is from ISO/TS 22220,[7] the list includes but is not restricted to the below. Please see ISO/TS 22220 for the full listing:

Description
Apartment
Duplex
Marine Berth
Room
Townhouse
Warehouse
Cottage
Flat
Penthouse
Studio
Unit

Guide for use   This data item identifies the type of building where the service user is contactable.

Verification rule   Not applicable.

Source standards   ISO/TS 22220:2011.

7.2.1.2 Building complex sub-unit number (Dataset 2.1)

The specification of the number of identifier of a building complex to clearly distinguish it from another.

Data type   Alphanumeric.

Data domain   Not applicable.

Guide for use   The building complex sub-unit should be recorded with its corresponding building complex sub-unit type abbreviation.

Verification rule   Not applicable.

Source standards   ISO/TS 22220:2011.

7.2.1.3 Address site name (Dataset 2.1)

The full name used to identify the physical building or property as part of its location.

Data type   Text.

Data domain   Not applicable.

Guide for use   This information is not usually abbreviated. It should include any reference to a wing or other components of a building complex. A comma is to be used to separate the wing reference from the rest of the building name.

Verification rule   Not applicable.

Example   Hazelwood apartment complex.

Source standards   ISO/TS 22220:2011.

7.2.1.4 Street number (Dataset 2.1)

The numeric or string reference number of a house or property that is unique within a street name, suburb.

Data type   Alphanumeric.

Data domain   Not applicable.

Guide for use	Generally only one street number is used. Occasionally it is alphanumerical.
Verification rule	Not applicable.
Source standards	ISO/TS 22220:2011.

7.2.1.5 Street name (Dataset 2.1)

The name that identifies a public thoroughfare and differentiates it from others in the same locality.

Data type	Text.
Data domain	Not applicable.
Guide for use	Street name should be written in full, where space permits, in order to avoid potential confusion in the case of an emergency and to improve the quality of street type information.
Verification rule	Not applicable.
Source standards	ISO/TS 22220:2011.

7.2.2 Suburb/town/townland/locality (Dataset 2.2)

The full name describing the suburb/town/townland/locality describing the specific address of a service user.

Data type	Text.
Data domain	Suburb, town, townland or locality.
Guide for use	This should identify the location that the service user currently resides in.
Verification rule	The townland or locality name must meet official names as per the Department of the Environment, Community and Local Government. It should also be confirmed that the townland or locality is located in the county specified by the service user as their area of residence.
Example	Blackrock, Drumshambo North, Frenchpark.

Source standards   ISO/TS 22220:2011 AS 4590-2006.

7.2.3 County area/county (Dataset 2.3)

The full name of the county where the service user resides.

Data type   Text.

Data domain   The list below is indicative and is not exhaustive of the
                       county areas and counties in Ireland:

                       Description
                       Cork
                       Kildare
                       Kilkenny
                       Dublin 7
                       Dublin

Guide for use   Record the county or county area as identified by the
                       service user.

Verification rules   The county or county area must be in Ireland.

7.2.4 Country identifier (Dataset 2.4)

A code representing the country component of a service user's address.
Where the service user does not reside in Ireland this field should be
recorded.

Data type   Text.

Data domain   The data domain includes, but is not restricted to the
                       below. The full listing can be obtained from ISO 3166-
                       1:2013[18].

                       Description
                       United States of America
                       France
                       Australia

Guide for use   This field identifies the country of location for each
address.

Verification rule   It must meet the criteria set out by International
                       Standards Organisation (ISO 3166-1:2013).

Source standards   ISO 3166-1:2006. ISO/TS 22220:2011

7.2.5 Postal code (Dataset 2.5)

A code representing the address of the service user, as defined by the postal service.

Data type   Alphanumeric.

Data domain   Post codes were introduced to Ireland in July 2015 and official post codes should be recorded in this data field.

Guide for use   This code identifies the location of each address.

Verification rule   It must meet the criteria set out by the Department of Communications, Energy and Natural Resources.

Source standards   ISO/TS 22220:2011.

7.2.6 Address type (Dataset 2.6)

The address of the service user.

Data type   Coded Text.

Data domain   The list below indicates the code options, the full listing can be found in ISO/TS 22220:2011:

Description	Code
Place of residence	R
Postal address	P

Guide for use   Multiple addresses may be recorded as required. Each address should have an associated address type code. There should only be one current home address and one current postal address. It should be noted that the service user may indicate that c/o (in care of) needs to be included with the address. If this is the case, please put c/o in front of the postal address.

Verification rules   Not applicable.

Collection method   The following question format might assist with data collection:

> *Is that address your place of residence and, or your postal address?*

Example   Place of residence: R

Source standards   ISO/TS 22220:2011.

7.3   Health identifiers

The following provides specific guidance relevant to the recording of health identifiers provided in section 6 above.

7.3.1 Health identifiers (type) (Dataset 3.1)

An Individual Health Identifier can be defined as the designation permanently assigned to an individual for the purpose of identification to facilitate the provision of health and social care in both public and private healthcare.

Data type	Coded Text.
Guide for use	The value in this field identifies the Health Identifier Type; for example, Medical Record Number, Individual Health Identifier.
Validation rules	Field may not be blank.
Collection method	The Authority responsible for issuing the specific health identifier will determine the most appropriate means for health and social care providers to allocate this health number.
Example	Individual Health Identifier.
Source standards	ISO/TS 22220:2011.

7.3.2 Health identifier (value) (Dataset 3.2)

An additional number or code assigned to a service user by a health or social care provider. In the event that this is recorded, it is mandatory.

Data type	Alphanumeric.
Data domain	Not applicable.
Guide for use	Individual agencies, establishments or collection authorities may use their own alphabetic, numeric or string coding systems when creating identifiers.

Validation rules	Dependent on the type of health identifier.
Collection Method	This will be dependent on the type of health identifier.
Example	Dependent on the format used by the issuer of the health identifier.
Source standards	ISO/TS 22220:2011, ASTM E1714-00, Guide for Properties of a Universal Health Care Identifier.

7.4   Additional demographic details

The follow provides the specific guidance relevant to the recording of additional demographic details provided in section 6 above.

7.4.1 Date of birth (Dataset 4.1)

The date of birth of the service user as per the birth certificate.

Data type	Date.
Data domain	Valid dates.
Guide for use	Date should be recorded in the day/month/year format. Dates may be written in a variety of formats that can be confusing if read by personnel with a different cultural background. In the context where different cultures interact, a date such as "07-05-10" can have numerous different meanings.
	Where date of birth is not accurately known, an approximate date should be used to derive age. For example, if the service user estimates that they are 30, then in 2015 date of birth should be recorded as 00/00/1985.
Verification rules	Birth date should be less than or equal to date of death.
Source standards	ISO/TS 22220:2011.

7.4.2 Place of birth (Dataset 4.2)

Definition	The county in which the service user was born, if born in Ireland. If born outside of Ireland the country in which the service user was born.

Data type	Coded text.
Data domain	The counties must be the same format as outlined in 2.3. The countries must be a similar format as outlined in 2.4.
Guide for use	Counties – please refer to 2.3. Countries – please refer to 2.4.
Verification rules	Birth date should be less than or equal to date of death.
Source standards	ISO/TS 22220:2011.

7.4.3 Gender (Dataset 4.3)

The service user being male or female. This describes the gender for administrative purposes only. Clinically the concept of gender may need to address not just genetic, but also expressed, anatomical and hormonal gender.

Data type	Coded text.		
Data domain	Code	Descriptor	Alternative code
	1	Male	M
	2	Female	F

Guide for use	This data element indicates the gender of the person based on legal documents for example, birth certificate.
Verification rules	Accept only allowed values. Field should not be blank.
Source standards	ISO/TS 22220:2011.

7.4.4 Mother's birth family name (maiden name) (Dataset 4.4)

Definition	The original family name of the service user's mother.

Data type	Text.
Data domain	Not applicable.
Guide for use	The mother's birth family name (maiden name) is her last name as it appears on her own birth certificate.
Verification rules	All letters of the alphabet and additional characters as identified in family name.
Source standards	ISO/TS 22220:2011.

7.4.5 Nationality (Dataset 4.5)

Definition	The legal bond between a person and a State[19].
Source standards	European Convention on Nationality.
Data type	Text.
Data domain	A valid nationality.
Guide for use	The passport that the service user holds is their valid nationality *(in the event that the service user holds two passports, it is the person's preference which one they choose to be recorded as their nationality)*.
Verification rules	The nationality should relate to a country.

7.4.6 Date of death (Dataset 4.6)

Definition	The date of death of the service user.
Data type	Date.
Data domain	Valid dates.
Guide for use	Date should be recorded in the day/month/year format. Dates may be written in a variety of formats that can be confusing if read by personnel with a different cultural background. In the context where different cultures interact, a date such as "07-05-10" can have numerous different meanings.

Validation rule	Where date of birth is collected, date of death should be equal to or greater than the date of birth of the same person.
Source standards	ISO/TS 22220:2011.

7.4.7 Source of death notification (Dataset 4.7)

Definition	This indicates the source of information about a service user's death. This field provides an indication of the certainty of the information.
Data type	Coded text. This code is obtained from ISO/TS 22220:2011.[7]

Data domain	Description	Code
	Registry	1
	Healthcare provider	2
	Relative	3
	Other	4
	Unknown	9

| Guide for use | Registry: Notification received from an official national registry office such as the General Registry Office or the coroner.

Healthcare provider: Death is notified directly by a healthcare provider, other than the person responsible for certification of death.

Relative: A relative of the service user.

Other: Death is identified through newspapers and other sources.

Unknown: Source of information about the service user's death is not known. |
| --- | --- |
| Validation rule | Valid codes or blank. |
| Collection method | This data element should always be used in conjunction with date of death. |
| Example | General Registry Office: 1 |
| Source standards | ISO/TS 22220:2011. |

7.5   Commmunication details

The follow provides the specific guidance relevant to communuication preferences provided in section 6 above.

7.5.1 Communication type (Dataset 5.1)

A code representing a type of communication device used by a service user.

Data type	Coded text. This can be found in ISO/TS 22220:2011[7]

Data domain	Code	Description	
Alternative			
	1	Landline Telephone T	
	2	Mobile phone	M
	3	Email	E
	4	URL/web address	U
	5	Other	O

Guide for use	Each instance should have the appropriate electronic communication medium and usage code assigned.

Verification rules	Not applicable.

Source standards	ISO/TS 22220:2011, AS 4846-2006.

7.5.2 Communications value (Dataset 5.2)

A unique combination of characters used as input to electronic telecommunication equipment for the purpose of contacting a service user.

Data type	Text.

Data domain	A text string valid for a specific communication medium including spaces where applicable.

Guide for use	Record the full contact details. It may include multiple electronic communication details or addresses, for example multiple phone numbers and email addresses.

Verification rules	The international prefix symbol should be + (plus) and should precede the country code in the international number. It serves to remind the subscriber to dial the international prefix, which differs from country to country, and also serves to identify the number as an international telephone number.[20]

The symbol ( ) (parentheses) should be used to indicate that the digits within the ( ) are not always dialled, for example (091) 524523.

Example   (091)520000, +22 609 123 4567,[12] <u>serviceuser@home.ie</u>

Source standards   ISO/TS 22220:2011, AS 4846-2006, ITU-T E.123.

7.5.3 Contact preference (Dataset 5.3)

An indication of the preferences for use of this contact type.

Data type   Coded text

Data domain | Description | Code |
|---|---|
| Business hours | B |
| Day time hours | D |
| Weekend hours | W |
| At all times | A |
| Evening/night hours | E |

Guide for use   Indication of the most appropriate times in the day to use that method of communication.

Verification rules   Not applicable. Example: At all times: A

Source standards   ISO/TS 22220:2011.

7.6 Personal characteristics

The follow provides the specific guidance relevant to the recording of personal characteristics provided in section 6 above.

7.6.1 Personal characteristics (Dataset 6.1)

Personal characteristics are the individual features which can be used to identify a person. Both traditional methods such as signature or photograph and biometric features such as retinal scanning or fingerprints are included in this data item.

Data type   Dependent on the type of personal characteristic used.

Data domain   Dependent on the type of personal characteristic used.

Guide for use   Dependent on the type of personal characteristic used.

Validation rules   Dependent on the type of personal characteristic used.

Collection method Dependent on the type of personal characteristic used.

Example   Signature, photograph, fingerprint, retinal scan.

Source standards   Dependent on the type of biometric identification used.

Glossary of terms

Term	Definition
Service user	Any person who uses or is a potential user of a health or social care service. For example a patient, client or resident.
Individual health identifier	An individual health identifier[†] comprises of three main components: the number itself, the dataset associated with the number, and the system that supports the number and dataset. The purpose of the individual health identifier is to safely identify individuals accessing health and social care services in Ireland. The dataset associated with the individual health identifier will contain data elements such as name, date of birth and address.
Biometric identification	Biometric identifiers are part of the person; they are measurable biological characteristics, such as a recording of a finger print or the shape of facial features.
Optionality	Refers to whether the data element is mandatory, mandatory where applicable or optional. *Mandatory* means that it is required. *Mandatory when applicable* means that if the data element applies to the service user it is required and must be completed. *Optional* means that it

[†] The Health Identifiers Act 2014 legislates for the implementation of identifiers for individual, healthcare practitioners and healthcare organisations.

Term	Definition
Page	needs to be completed when appropriate.
Mandatory	Mandatory data elements must be recorded for each service user.
Mandatory where applicable	Mandatory where applicable are data elements that should be populated if the data element is relevant and applicable to the service user.
Optional	The data elements may not be applicable to all service users, and therefore should be collected when appropriate.

References‡

Reference List

(1) Health Information and Quality Authority. *Recommendations for a Unique Health Identifier in Ireland for individuals*. 2009. Available online from: http://www.hiqa.ie/content/recommendations-unique-health-identifier-individuals-ireland.

(2) The Health Act 2007. Dublin: The Stationery Office; 2007. Available online from: http://www.irishstatutebook.ie/2007/en/act/pub/0023/index.html.

(3) Australian Institute of Health and Welfare. *A guide to data development*. Canberra: AIHW; Report No.: HWI 94. 2007. Available online from: http://www.aihw.gov.au/search/?q=a+guide+to+data+development.

(4) Health Information and Quality Authority. *General Practice Messaging Standard Version 2.0*. 2011. Available online from: http://www.hiqa.ie/publications/general-practice-messaging-standard-version-20.

(5) Health Information and Quality Authority. *Report and Recommendations on Patient Referrals from General Practice to Outpatient and Radiology Services, including the National Standard for Patient Referral Information*. 2011. Available online from: http://www.hiqa.ie/publications/report-and-recommendations-patient-referrals-general-practice-outpatient-and-radiology-.

(6) Health Information and Quality Authority. *National Standard for Patient Discharge Summary Information* [Online]. Available from: http://www.hiqa.ie/publications/national-standard-patient-discharge-summary-information. Accessed on: 12 August 2013.

(7) International Organization for Standardization (ISO). *ISO/TS 22220:2011. Technical Specification. Health Informatics – Identification of subjects of health care*. 2011.

(8) International Organization for Standardization (ISO). *ISO/TS 27527:2010. Technical Specification. Health Informatics - Provider identification*. 2010.

(9) International Standards Organisation. *ISO 3166-1:2006: Codes for the representation of names of countries and their subdivisions -- Part 1: Country codes*. 2006. Available online from:

---

‡ All references accessed during preparation of this report, unless otherwise stated.

http://www.iso.org/iso/home/store/catalogue_ics/catalogue_detail_ics.htm?csnumber=39719. Accessed on: 14 May 2013.

(10) Standards Australia. *Australian Standard AS 4846-2006. Health Care Provider Identification*. 2006.

(11) Australian Government. *AS 4590:2006. Interchange of client information standard*. 2006. Available online from: https://govshare.gov.au/xmlui/handle/10772/6391. Accessed on: 23 May 2013.

(12) The American Society for Testing Materials. *ASTM International: Standard Guide for Properties of a Universal Healthcare Identifier (UHID)*. 1995. Available online from: http://www.astm.org/Standards/E1714.htm. Accessed on: 23 May 2012.

(13) International Telecommunications Union. *ITU-T E.123. Notation for national and international telephone numbers, e-mail addresses and web addresses*. 2001. Available online from: http://www.itu.int/rec/T-REC-E.123-200102-I. Accessed on: 24 June 2013.

(14) European Convention on Nationality.1997. Available online from: http://conventions.coe.int/Treaty/EN/Reports/Html/166.htm. Accessed on:

(15) Ministry of Health NZ. *National Health Index number, New Zealand.* [Online]. Available from: http://www.health.govt.nz/our-work/health-identity/national-health-index.

(16) National Health Service UK. *NHS Number* [Online]. Available from: http://www.nhs.uk/NHSEngland/thenhs/records/Pages/thenhsnumber.aspx.

(17) European Convention on Nationality.1997. Available online from: http://conventions.coe.int/Treaty/EN/Reports/Html/166.htm. Accessed on:

(18) International Standards Organisation. *International Standards Organisation 3166-2:2007*. 2007. Available online from: http://www.iso.org/iso/country_codes. Accessed on: 17 July 2013.

(19) European Convention on Nationality.1997. Available online from: http://conventions.coe.int/Treaty/EN/Reports/Html/166.htm. Accessed on:

(20) International Telecommunications Union. *Notation for national and international telephone numbers, e-mail addresses and Web addresses*. 2001. Available online from: http://www.itu.int/rec/T-REC-E.123-200102-I/en. Accessed on: 17 July 2013.