



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# Guidance on Terminology Standards for Ireland

July 2017

***Safer Better Care***

## Version Control

Date	Version	Change
<b>December 2013</b>	1.0	Published as <i>Guidance on Classification and Terminology Standards for Ireland</i> .
<b>July 2017</b>	2.0	Updated to reflect revisions to international standards and other relevant changes.

## 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's ultimate aim is to safeguard people using services 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 the Health Information function of HIQA

Healthcare 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 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 and hospitals.

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

In Ireland, information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions.

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

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

One of the areas addressed through this work programme is the need to set standards to enable information to be shared electronically, commonly referred to as interoperability standards. This Guidance document revises the previous guidance published in 2013\*

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\*The Guidance document published in 2013 has been superseded by this document and the previous versions have been removed from HIQA website. The previous version is available on request from HIQA.

<sup>(1)</sup> reflecting changes to international terminology standards and a significant change at national level — specifically, the purchase of a national Systematized Nomenclature of Medicine — Clinical Terms<sup>®</sup> (SNOMED CT<sup>®</sup>) licence for Ireland.<sup>(2)</sup> It also includes specific guidance on the approach to be adopted to support the correct implementation of the SNOMED CT licence in Ireland, in accordance with national standards and international best practice. Furthermore, it used new naming conventions that reflect recent EU research.<sup>(3)</sup>

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# 1 Introduction

Safe, reliable healthcare depends on access to and use of information that is accurate, valid, reliable, timely, relevant, legible and complete.<sup>(4)</sup> Ensuring that information can be shared efficiently and effectively and in a manner which protects the privacy and confidentiality of patients is critical. EHealth can enhance the quality, accessibility and efficiency of all healthcare services through the secure, timely, accurate and comprehensive exchange of clinical and administrative data. Its benefits include:

- better and safer patient care
- improved integration and sharing of health information to enable patient-centred integrated care
- more cost-effective delivery of healthcare
- more efficient national planning
- improved research through the provision of more timely and higher quality information
- reduced in medication errors through ePrescribing
- more timely access by health professionals to the right medical information at the right time
- improved support for patient self-management.<sup>(5)</sup>

In the Irish context, many reports and strategies have highlighted the need for a national Electronic Health Record including the Commission for Patient Safety and Quality Assurance and the eHealth Strategy for Ireland.<sup>(6)</sup> The Health Service Executive (HSE) has established the Office of the Chief Information Officer, which is responsible for implementing Ireland's eHealth Strategy. The Office of the Chief Information Officer is responsible for the delivery of technology to support healthcare across Ireland and have published the Knowledge and Information Strategy in this regard.<sup>(7)</sup> One of the key building blocks central to any eHealth programme is a set of eHealth interoperability standards including messaging and terminology standards based on widely available and implemented international standards.

## 1.1 Background

This document is a revision of the original *Guidance on Classification and Terminology Standards*, published by HIQA in 2013.<sup>(1)</sup> Guidance is developed as per HIQA's legislative remit under the Health Act 2007 and subsequent amendments to the Act.

Under the Health Act 2007, HIQA has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information.

The responsibilities of HIQA are outlined in the following sections of the Act:

- Section 8(1)(i): to evaluate available information respecting the services and the health and welfare of the population
- Section 8(1)(j): to provide advice and make recommendations to the Minister for Health and the HSE about deficiencies identified by HIQA in respect of the information referred to in paragraph (i)
- Section 8(1)(k): to set standards as HIQA considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population.
- Section 8(1) (l): to advise the Minister for Health and the HSE as to the level of compliance by the HSE and service providers with the standards referred to in paragraph (k).

Under Section 8(1) (k) of the Health Act 2007, HIQA is charged with setting standards for health information. This includes standards for the communication of health information between healthcare providers. Some of the most recent standards that HIQA has published in this regard include:

- *National Standard for a Dispensing Note including a Clinical Document Architecture specification*<sup>(8)</sup>
- *National Standard for a Procedure Dataset including a Clinical Document Architecture specification*<sup>(9)</sup>
- *National standard diagnosis dataset and clinical document architecture (CDA) template*<sup>(10)</sup>
- *National standard adverse reaction dataset and clinical document architecture (CDA) template*<sup>(11)</sup>
- *ePrescription dataset and clinical document architecture standard*<sup>(12)</sup>
- *General Practice Messaging Standard Version 3.0*<sup>(13)</sup>

Under Section 8(1) (j) of the Act, HIQA has the responsibility to provide advice and make recommendations to the Minister for Health and the HSE about deficiencies identified by HIQA in respect of the information referred to in paragraph (i). HIQA is charged with undertaking guidance in relation to gaps in the health information community.

This guidance document is part of a suite of guidance documents that HIQA has previously published including:

- *Overview of Healthcare Interoperability Standards*<sup>(14)</sup>
- *Guidance on Messaging Standards for Ireland*.<sup>(15)</sup>

## 1.2 Purpose

The purpose of this guidance is to provide direction on terminology standards in Ireland for the short to medium term. HIQA has developed this guidance to provide the eHealth community in Ireland with direction on standards development and to support better decision making and consistency around future eHealth investments.

This document is a revision of the *Guidance on Classification and Terminology Standards for Ireland*, published in 2013, and has been updated to reflect changes to the international terminology standards reviewed.<sup>(1)</sup>

These changes include the Fifth Edition of the World Health Organization (WHO) International Classification of Disease, Tenth Revision, (ICD-10), published a ICD-10:2016.<sup>(16)</sup> The eleventh revision (ICD-11) is being trialled extensively ahead of scheduled formal adoption by the WHO in May 2018.<sup>(17)</sup> In addition, Logical Observation Identifiers Names and Codes<sup>®</sup> (LOINC<sup>®</sup>) version 2.59 was released in February 2017.<sup>(18)</sup>

Since 2015, the mandatory terminology standard for clinical content in the UK is Systematized Nomenclature of Medicine — Clinical Terms<sup>®</sup> (SNOMED CT<sup>®</sup>). The final maintenance release and retirement dates for Read Codes were announced by the National Health Service (NHS).<sup>(19,20)</sup> The International Classification of Primary Care<sup>®</sup>, Second Edition (ICPC-2<sup>®</sup>) and Office of Population Census and Surveys Classification of Surgical Operations and Procedures, Fourth Edition (OPCS-4) continue to be used. OPCS-4 was removed from

the Irish Hospital In-patient Enquiry (HIPE) system in 1990 and is no longer used in Ireland.<sup>(21)</sup>

The adoption of SNOMED CT in the UK mirrors its wider international adoption, with 30 countries are now listed as members of SNOMED International<sup>®</sup>, the new trading name of the International Health Terminology Standards Development Organization (IHTSDO).<sup>(22)</sup> In a significant national development, Ireland was accepted as a member of SNOMED International in 2016. Recent EU research provides a revised model of terminology standards and naming conventions, which are used in this document.<sup>(3)</sup>

This guidance is being developed to inform key stakeholders such as public and private service users, vendors, purchasers and implementers of health information systems, healthcare providers, the wider health informatics community and any other interested parties, about the proposed future direction of terminology standards in Ireland, and to encourage wider participation in standards development. The guidance is targeted principally at those involved in specifying the requirements for, and the development and implementation of, new health information systems and eHealth applications, both locally and nationally.

### 1.3 Methodology

In order to consult with stakeholders on the development of eHealth standards, HIQA produced the consultation document *Developing National eHealth Interoperability Standards for Ireland: A Consultation Document*<sup>(23)</sup>. This consultation identified the need for guidance documents in three areas — general interoperability standards, terminology standards and messaging standards — to ensure that information can be exchanged electronically in a safe and efficient way.

In December 2013, HIQA published its original *Guidance on Classification and Terminology Standards for Ireland*<sup>(1)</sup> This document is a revision of the Guidance published in 2013. During the development of this Guidance document, a review of international and national best practice was undertaken which identified recent

changes to international terminology standards and a significant change at national level — specifically, the purchase of a national Systematized Nomenclature of Medicine — Clinical Terms<sup>®</sup> (SNOMED CT<sup>®</sup>) licence for Ireland.<sup>(2)</sup> It also includes specific guidance on the approach to be adopted to support the correct implementation of the SNOMED CT licence in Ireland, in accordance with national standards and international best practice. Furthermore, it used new naming conventions that reflect recent EU research.<sup>(3)</sup> A draft Guidance document for consultation was developed and a targeted consultation was undertaken. The Guidance document was updated following the targeted consultation.

The document provides an overview of classification and terminology standards and in Section 2 of the document. Section 3 identifies and provides details on four candidate standards which have been developed by international standards development organisations. An overview of international and national implementation is provided for each. Following this, a detail optional analysis assessment of each of the standards and their relevance to Ireland is provided in Section 4 of the document. Section 5 provides HIQA's conclusions and updated Guidance on classification and terminology standards for Ireland.

## 2 Terminology Standards

Terminology standards support the strategy of collecting data once and then using it multiple times, where possible. They can ensure that higher quality data is recorded during the patient visit and that this high quality data is available for epidemiological research and statistical reporting after the visit.<sup>(3)</sup>

Terminology standards are a fundamental part of any eHealth ecosystem.<sup>(3,14)</sup> They ensure semantic interoperability — that is, that healthcare systems understand and use data in the same way, as defined by the terminology standard.<sup>(14,24)</sup> Systems using different terminology standards can communicate using one of the mappings developed between the standards. This multiplicity of standards and mappings has given rise to the idea of a terminology ecosystem, within an eHealth ecosystem.<sup>(3)</sup>

Real world complexity complicates the question of international terminology standards. ‘Comparable patient data’ has long been recognized as the key to more ‘efficient and effective’ patient care.<sup>(25)</sup> In spite of this shared goal, terminologies evolved in inconsistent and fragmented ways — often in competition with each other. Adaptations often diverged significantly, if not completely, from original meanings and purpose. Following sustained international effort, terminology standards have become more consistent. Reflecting this convergence, recent EU research classifies terminologies into three types<sup>(3)</sup>:

- **Reference terminology** — sometimes known as a nomenclature, a reference terminology defines the meaning of all terms in a clinical domain unambiguously and independent of any specific purpose.<sup>(3)</sup> Often known simply as terminologies, international reference terminologies such as SNOMED CT and LOINC are widely used in clinical coding.<sup>(3)</sup> Reference terminology-based coding at the point of care has been shown to significantly improve the overall quality of clinical data.<sup>(14)</sup> The original guidance document used the term clinical terminology.<sup>(1)</sup>
- **Aggregation terminology** — an aggregation terminology defines a set of ‘non-overlapping classes in single hierarchies’ according to aggregation terminology

rules.<sup>(3)</sup> Also known as classifications, international aggregation terminologies are more suited to the recording and analysis of secondary use data, such as for epidemiological research or to generate health statistics.<sup>(3,14)</sup> Aggregation terminologies provide the framework to generate administrative, public health and research information from routinely collected clinical data. Specific national level aggregation terminologies are sometimes used for reimbursement. The original guidance document used the term classification.<sup>(1)</sup>

- **User interface terminology** — also known as entry terms, a user interface terminology defines 'a collection of terms that are used in written and oral communication by a group of users'. Each term is described in terms of the natural language they belong to, as well as by dialect, time, clinical specialty and professional group.

Reference terminology and aggregation terminology standards are independent of spoken language.<sup>(3)</sup> A user interface terminology standard defines the set of spoken language terms that correspond to the reference terminology or aggregation terminology standard in question. For example, where a localized version of a reference terminology or aggregation terminology is not available, a user interface terminology can be useful for defining the set of local language terms that correspond to the reference terminology or aggregation terminology.

Designed to serve different purposes within clinical coding systems, reference terminologies and aggregation terminologies should be considered complementary.<sup>(3,25,26,27,28)</sup> Alone, neither a reference terminology nor an aggregation terminology can serve all purposes for which health information is currently used or likely to be used in the future. However, when each is used appropriately, they combine to provide a common medical language for epidemiology, for clinical trials, for bio surveillance, for reimbursement - and ultimately for an electronic health record.<sup>(25,27)</sup> They also significantly improve the quality of data collected. The following sections describe reference terminologies and aggregation terminologies, then compare and contrast the purposes of each.

## 2.1 Reference terminologies

A reference terminology is a structured collection of descriptive terms for use in clinical practice.<sup>(1)</sup> It is defined as 'standardized terms and their synonyms which record patient findings, circumstances, events, and interventions with sufficient detail to support clinical care, decision support, outcomes research, and quality improvement; and can be efficiently mapped to broader aggregation terminologies for administrative, regulatory, oversight, and fiscal requirements.'<sup>(25)</sup> This recognizes both the essential purpose of each reference terminology and the relationship to aggregation terminologies.

When implemented, reference terminologies can facilitate the coding of clinical information captured in an electronic health record or electronic patient record at the point of care.<sup>(3)</sup> Reference terminologies such as SNOMED CT are essential to support full semantic interoperability between systems. They ensure that the information shared is unambiguous and clearly understood.

Reference terminology-coded clinical data is used to filter electronic health record content by relevance, and to generate and navigate summaries of complex patient record communications. Combined with formal clinical guidelines, reference terminology-coded data supports safer decision making systems and the generation of accurate safety alerts in multi-actor care systems. Data analytics requires reference terminology-coded data for effective benchmarking, service planning, and commissioning. This data also underpins evidence-based strategic decision making and outcome optimisation.

Some key benefits of using reference terminologies in healthcare records are:

- more accurate and precise recording of clinical information
- more efficient searching of patient records
- improved retrieval of relevant clinical information
- sustained point of care decision support
- support for automatic identification of patient risk factors
- enabling clinical audit
- alerting of possible drug interactions
- monitoring of the responses of treatments
- identification and monitoring of long term population diseases or outcomes
- a large number of coded medical records potentially available for research

- enabling communication of patient information with other healthcare professionals.<sup>(1,29)</sup>

Commonly used reference terminologies include:

- LOINC, the most widely used laboratory reporting reference terminology worldwide.
- SNOMED CT, which is becoming known as the de facto reference terminology standard worldwide.<sup>(1)</sup>

## 2.2 Aggregation terminologies

An aggregation terminology is a method of grouping concepts in a systematic way (that is, into classes) within a particular domain for a specified purpose.<sup>(1)</sup> Concepts are categorized according to common attributes, qualities, or properties. Aggregation terminologies group similar diseases and procedures based on pre-determined categories such as the cause of a disease. They are by far the most widely used approach to coding healthcare data in existence today.<sup>(1,25,30)</sup>

Aggregation terminologies enable the effective secondary use of reference terminology-coded data. Examples of secondary use are reimbursement, statistical and public health reporting, and operational/strategic planning, as well as quality of care measurements and other administrative functions.<sup>(28)</sup> They facilitate public health researchers and decision makers to devise population screening and prevention actions.<sup>(3)</sup> The standardized cohorts and data sets they provide are also vital for clinical research, rare disease registries, and bio banking.

The benefits of using aggregation terminologies include:

- organisation of information into standard groupings of diseases, which allows for easy storage, retrieval and analysis of health information
- sharing and comparing health information between hospitals, regions and countries
- data comparisons in the same location across different time periods
- compilation of national mortality and morbidity statistics
- direct surveillance of epidemic or pandemic outbreaks.<sup>(1,29)</sup>

Some of the most recognised aggregation terminologies used in healthcare include the International Classification of Disease, Tenth Revision, (ICD-10) which is used internationally.<sup>(1)</sup> The Australian Modification of ICD-10 (ICD-10-AM) is widely used to code diagnosis data including in the Hospital In-patient Enquiry Scheme (HIPE) in Ireland. The Australian Classification for Health Interventions (ACHI) is used for interventions, together with another secondary classification, The Grouper. The Grouper groups discharges to Diagnosis Related Groups (DRGs) of cases expected to consume similar levels of resources for case-mix and reimbursement. In the UK, the International Classification of Primary Care, Second Edition, (ICPC-2) is used for coding primary care data and the Office of Population Census and Surveys Classification of Surgical Operations and Procedures (OPCS) is used to code surgical operations and procedures.

### **2.3 User interface terminologies**

A user interface terminology is a collection of terms that is used in written and oral communication by a group of users — for example, in a data entry form.<sup>(3)</sup> As natural language terms, user interface terms tend to be ambiguous. The definition of a user interface term includes the dialect, time, clinical specialty and professional group as well as the natural language. Though not limited to translation or localization purposes, a user interface terminology can bridge the gap between an end user language and an aggregation terminology or a reference terminology. As no translation or localization is required, user interface terminologies are not considered necessary at this time in the Irish context. The remainder of this guidance discusses reference terminologies and aggregation terminologies only.

### **2.4 Using reference terminologies and aggregation terminologies**

Compared to aggregation terminologies, reference terminologies are generally more comprehensive and precise, and offer a more accurate representation of the healthcare domain.<sup>(1)</sup> They have much greater flexibility than aggregation terminologies and are expressed in natural language. As such, they are considered input systems. However, used in isolation, reference terminologies are not suitable for all healthcare scenarios. They can also be difficult to implement because of their immense size, complex granularity, and complex hierarchies.

Aggregation terminologies make it easier to retrieve information from computer systems in the form of reports. They are therefore considered output rather than input (or data entry) systems. Aggregation terminologies are also used for reimbursement purposes. Aggregation terminologies fail to define all of the individual concepts within a given healthcare domain.<sup>(14)</sup> Though frequently used as such, they are not intended or designed to document clinical care.<sup>(28)</sup>

Reference terminologies can be mapped to broader aggregation terminologies for administrative, regulatory, oversight and fiscal requirements.<sup>(25)</sup> In fact, the full benefits of reference terminologies and aggregation terminologies are realised only when they are linked — that is, when the following two conditions are met:

- A reference terminology is used to collect clinical information as part of the clinical encounter at the point of care.
- an aggregation terminology, linked to the reference terminology, is used to generate data for secondary use for statistical and epidemiological analysis, reporting requirements, measuring quality of care and monitoring resource allocation.<sup>(28)</sup>

To illustrate the differences, Table 1<sup>(1)</sup> contrasts the situations where reference terminologies and aggregation terminologies are typically used.

**Table 1 — Use of reference terminology versus aggregation terminology**

	<b>Reference terminology</b>	<b>Aggregation terminology</b>
<b>Users</b>	Healthcare providers	Healthcare records departments personnel
<b>Information captured</b>	Whatever the provider can observe, test, or obtain otherwise during the visit	Healthcare record, as documented during the patient encounter
<b>Timing</b>	While the patient is present	After the patient has left
<b>Aim</b>	Document information about the patient and the encounter	Identify a single primary discharge diagnosis or procedure
<b>Purpose</b>	Record patient findings, circumstances, events, and interventions	Report morbidity and mortality statistics, or reimburse.

Similarly, Table 2 contrasts the differences in structure between reference terminologies and aggregation terminologies.<sup>(1)</sup>

**Table 2 — Structure of reference terminology versus aggregation terminology**

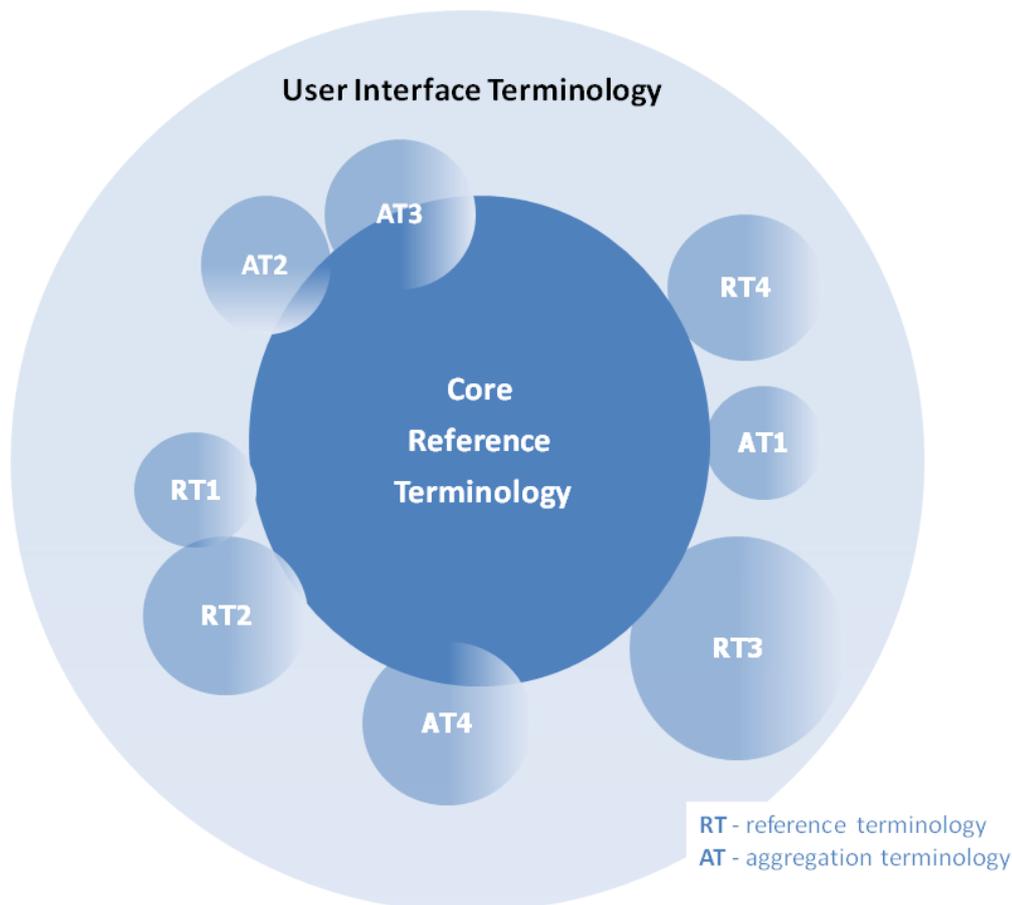
	Reference terminology	Aggregation terminology
<b>Hierarchy</b>	Multi-hierarchical	Mono-hierarchical, with inclusion and exclusion criteria to avoid overlap.
<b>Specificity</b>	Clinician may be as general or as specific as they want using: <ul style="list-style-type: none"> <li>• multiple codes,</li> <li>• a combination of codes, and (where necessary) uncoded free text</li> </ul>	Fewer codes
<b>NOS and NEC categories*</b>	Not included (generally)	Included

\***Not otherwise specified (NOS)** and **not elsewhere classified (NEC)** categories indicate a discrepancy between the clinical record and the coding system:

- **Not otherwise specified** indicates the clinical record lacks sufficient information to support a specific diagnosis, but supports a general diagnosis.
- **Not elsewhere classified** indicates the clinical record contains sufficient information to support a specific diagnosis, but that the coding system does not have a code for the diagnosis.<sup>(31)</sup>

## 2.5 Terminology ecosystem

As Figure 1 shows, reference terminologies, aggregation terminologies, and user interface terminologies play different roles in a terminology ecosystem.<sup>(3)</sup> In terminology ecosystems, overlapping reference terminologies require this clearly defined mapping. A **core reference terminology** can supplement more specialized reference terminologies for specific disciplines. The core reference terminology provides the most extensive conceptual coverage, linking to other more specialized terminologies. It is selected because it covers the greatest number, but not the totality, of concepts in multiple domains.

**Figure 1 — Role of different terminologies in a terminology ecosystem**

**Source:** Reproduced from [assess-ct.eu/fileadmin/assess\\_ct/final\\_brochure/assessct\\_final\\_brochure.pdf](https://assess-ct.eu/fileadmin/assess_ct/final_brochure/assessct_final_brochure.pdf)

Figure 1 shows how a national terminology ecosystem consists of a balanced combination of reference terminologies and aggregation terminologies.<sup>(3)</sup> In any given country, a number of reference terminology and aggregation terminology standards are usually already in use. There may be huge variations in how widely and how correctly each standard has been implemented — for example, the EU research project found that aggregation terminologies are sometimes used beyond their real scope.<sup>(30)</sup> The EU project also outlined that terminology ecosystem benefits from a coordinated approach to the development of standards. Such an approach is based on a shared understanding of appropriate use of the prevailing reference terminology, aggregation terminology, and user interface terminology standards. It also requires that candidate international standards be assessed and selected using transparent and objective processes.

Health terminologies can be furthermore described by their scope, e.g., clinical specialty (e.g. neurology, surgery, cardiology etc.), their domain (such as disorders, procedures), and

by the groups of users they are targeted to, which include health professionals (physicians, nurses) and laypersons. The latter especially matters for interface terminologies.

Finally, health terminologies are distinguished by their language and the jurisdiction where they are used. Multilingual terminologies are characterised by providing terms in more than one language. International terminologies are developed by supranational organisation for international use. It should be noted that political borders and linguistic boundaries do often not coincide.

In summary, within the terminology ecosystem terminologies may be classified into three types – reference terminologies, aggregation terminologies and user interface terminologies. Reference terminologies such as LOINC and SNOMED CT are generally more comprehensive in the domain they attempt to represent and are best used to collect clinical information at the point of care. Aggregation terminologies such as ICD-10 or ICPC-2 do not attempt to define all of the individual concepts within the domain they represent, rather they attempt to group concepts in a systematic way and are best regarded as output terminologies. They are best used to generate data for secondary usage such as statistical and epidemiological analysis. User interface terminologies tend to be represent a domain using a group of users' natural language. Each terminology type serves a specific purpose and the full benefits of terminologies is achieved when primarily used the specific purpose for which they it was designed with the full benefits of all the terminology systems realised through mappings between terminologies

## 3 Candidate standards

The original guidance document assessed six candidate international standards, identified through public consultation, that could be adopted as national standards for clinical coding in Ireland.<sup>(1)</sup> The standards were selected based on international uptake and on existing Irish standards.

Of the six original candidates, two standards are no longer eligible for assessment: Office of Population Census and Surveys Classification of Surgical Operations and Procedures, Fourth Edition (OPCS-4) and Read Codes. Following the NHS decision in 2014 to retire them, Read Codes are no longer considered a candidate national standard.<sup>(19)</sup> OPCS was used to code procedures in the Hospital In-Patient Enquiry (HIPE) system until 1990.<sup>(21)</sup> It is no longer in use in Ireland. Appendix A, Retired Candidate Standards, briefly describes these retired candidate standards.

This guidance document assesses the latest versions of the four remaining standards. Appendix B provides a summary of the assessment model. A detailed copy of the assessment for the four standards can be found in Appendix C through Appendix F.

### Reference Terminologies

- Systematized Nomenclature of Medicine — Clinical Terms (SNOMED CT)
- Logical Observation Identifiers Names and Codes (LOINC)

### Aggregation Terminologies

- International Classification of Diseases, Tenth Edition, Australian Modification, (ICD-10-AM)/ Australian Classification of Health Interventions (ACHI)
- International Classification of Primary Care, Second Edition (ICPC-2)

### 3.1 Reference terminology: SNOMED CT

A multilingual system, SNOMED CT is the 'most comprehensive and precise' reference terminology currently available internationally.<sup>(1,3,32)</sup> It covers many aspects of healthcare, including patient histories, details of procedures, and the spread of epidemic disease.<sup>(33)</sup> It does not attempt to standardise the whole of the medical language nor does it intend that

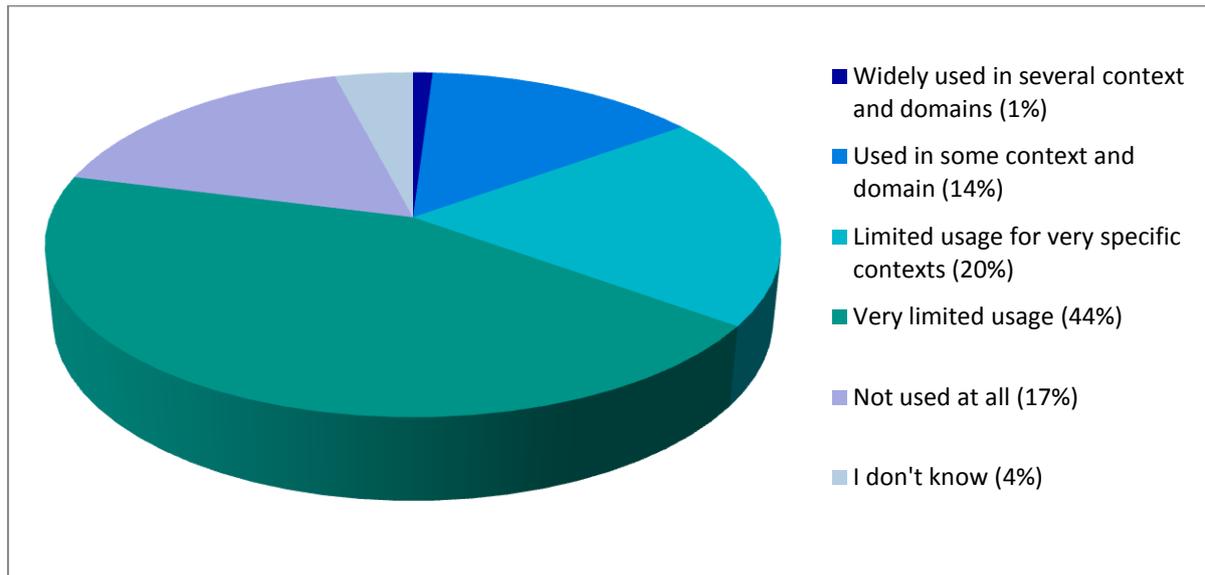
all clinicians should use the same terms.<sup>(34)</sup> Instead, SNOMED CT attempts to provide the language to adequately reflect the meaning and use of medical concepts. Since 2016, it has been maintained by SNOMED International, which is the new trading name of the International Health Terminology Standards Development Organization (IHTSDO).<sup>(35)</sup> SNOMED International is a not-for-profit organisation.

SNOMED CT is described as the lingua franca within electronic patient records and electronic health records.<sup>(1)</sup> It aims to improve the quality and safety of healthcare by improving the accuracy of storage and or recording of clinical data in patient records and by recording health care encounters.<sup>(36)</sup> It can also be used to integrate decision support systems within clinical information systems, supporting evidence-based care.

SNOMED CT consisted of more than 321,000 active concepts, over 1 million English-language descriptions and over 1 million logically-defining relationships linking concepts.<sup>(1)</sup> SNOMED CT is 'context less', which means it aims to be applicable and cover all medical scenarios.<sup>(37)</sup> In this way, it was designed for use in computerized systems — unlike aggregation terminologies such as ICD and ICPC. SNOMED CT also supports cross mapping to other reference terminologies and aggregation terminologies such as ICD-10, LOINC, and OPCS-4. The International Edition includes a mapping to the ICD-10 Classification. Mappings to other reference terminologies and aggregation terminologies are released separately.

A large-scale EU research project, *ASSESS CT: Assessing SNOMED CT for Large Scale Health Deployments in the EU*, reviewed SNOMED CT use worldwide, with particular emphasis on EU member states.<sup>(3)</sup> Over 350 stakeholders, from 34 countries — including 24 EU member states — contributed to the project.<sup>(30)</sup> Reporting in December 2016, the project strongly recommended SNOMED CT as a core reference technology for semantic interoperability in electronic health records throughout the EU.<sup>(30)</sup> It found that content coverage in SNOMED CT to be superior to that of any other terminology. It also outlined the long term, strategic benefits of adoption and it showed that SNOMED CT already functions as a core reference terminology in Denmark.<sup>(24)</sup>

The report placed these recommendations in the context of current use. According to SNOMED International, SNOMED CT is used in more than 50 countries.<sup>(22)</sup>

**Figure 2 - Actual use of SNOMED CT**

**Source:** Assess CT, from [assess-ct.eu/fileadmin/assess\\_ct/final\\_brochure/assesstct\\_final\\_brochure.pdf](https://assess-ct.eu/fileadmin/assess_ct/final_brochure/assesstct_final_brochure.pdf)

However, as Figure 2 shows, the ASSESS CT project found actual use was lower.<sup>(38)</sup> 60% of member states surveyed reported *very limited use* or *no use* of SNOMED CT in their country. The UK was the only member state found to have fully adopted SNOMED to date.

Finally, ASSESS CT organized joint workshops with US experts, to share knowledge, and developed recommendations to support adoption. The recommendations noted that SNOMED CT worked best as part of a coordinated terminology strategy, rather than as a standalone solution. The recommendations also highlighted the need for more best practices and evidence and they suggested a use-case based approach, engaging stakeholders and assessing the impact on business architecture as appropriate.<sup>(30,39)</sup>

### 3.1.1 Structure and versioning

The core components of SNOMED CT consist of concepts, descriptions, hierarchies and relationships.<sup>(36)</sup> The components are defined below as:

- **Concepts:** basic unit of meaning designated by a unique numeric code, unique name (Fully Specified Name), and descriptions, including preferred term and one or more synonyms
- **Descriptions:** terms or names (synonyms) assigned to a concept

- **Hierarchies:** 19 higher level hierarchies; each has sub-hierarchies
  - **Relationships:** link concepts either within a hierarchy or across hierarchies
- Relationships between concepts are pre-defined, which means that SNOMED CT defines concepts through meaningful (semantic) relationships with other concepts rather than a coding hierarchy as is the case with ICD. The codes used to represent concepts are designed specifically to facilitate computer processing.

The International Edition of SNOMED CT is released twice yearly, at the end of January and the end of July.<sup>(40)</sup> A translated Spanish language edition is published in the following March and October respectively. The July 2016 release comprised more than 321, 000 active concepts, to which over 5,000 new concepts were added in January 2017.<sup>(33)</sup> SNOMED International members typically receive a beta version for trial two months before the release date.<sup>(41)</sup> Their changes are incorporated in a pre-release version that affiliates also receive, a few days before the official full, international release.

## 3.2 Reference terminology: LOINC

A widely used reference terminology, LOINC was developed as a common terminology for laboratory and clinical observations in electronic reports.<sup>(42,43)</sup> One of the main goals of LOINC is to facilitate the communication and grouping of test results for clinical care, healthcare management, and research. It is maintained free of charge by the Regenstrief Institute, an international, not-for-profit organisation. The LOINC name is a registered trademark.

LOINC is used primarily to identify laboratory tests when test results are messaged electronically from laboratories to healthcare professionals.<sup>(44)</sup> When hospitals or other healthcare organisations receive messages using LOINC codes from multiple laboratories, they can automatically file the results in the correct location of their medical records and can use the data for clinical care and management purposes.<sup>(42)</sup>

LOINC codes are also used in the HL7 Clinical Document Architecture to defined clinical documents.<sup>(45)</sup> Using the LOINC Document Ontology (LOINC DO), hospitals and other healthcare facilities can group documents as needed. This, in turn, supports more consistent navigation in a document viewer and ensures the retrieval of all relevant documents when a

user requests them. Document templates based on the LOINC DO can make data entry simpler and more efficient.

### 3.2.1 Structure and versioning

LOINC is 'a set of universal names and ID codes for identifying laboratory and clinical test results in the context of ... observation report messages'.<sup>(46)</sup> The LOINC code identifies the test result or clinical observation. Other fields in the message can transmit the identity of the source laboratory and special details about the sample. The LOINC Getting Started Guide uses the example of the observations field in HL7 version 2 message.<sup>(47)</sup> In this field, the LOINC code can be thought of as representing the 'question' — that is, the test or measurement. Similarly, the SNOMED CT code represents the 'answer' — that is, the observation result.

LOINC comes with a mapping programme called Regenstrief LOINC Mapping Assistant (RELMA<sup>®</sup>) to assist the mapping of local test codes to LOINC codes and to facilitate browsing of the LOINC results.<sup>(48)</sup> RELMA is available as a Windows-based mapping utility. LOINC is available as a Microsoft Access database file and a tab-delimited text file.

Released in December 2016, LOINC 2.58 has 83,337 terms, with 2509 added in June 2016.<sup>(18)</sup> LOINC covers concepts in the laboratory domain and includes identifiers for haematology, biochemistry, microbiology, serology, toxicology and identifiers for drug and cell counts and antibiotic susceptibility.<sup>(1)</sup> The clinical section of the LOINC database includes entries for clinical findings and findings when undertaking procedures such as cardiac tests and ultrasounds. Over time the database has increased its scope to include other code names for clinical observations, nursing diagnosis, nursing interventions, outcomes classifications, and patient care data sets.

The Document Ontology (DO) in LOINC names and classifies the five attributes of clinical documents that ensure the documents can be understood across healthcare systems. The attributes are:

- the subject matter domain, such as cardiology or paediatrics
- the role, such physician or patient,
- the setting, such as hospital or outpatient department,
- the type of service, such as consultation or discharge summary,

- the kind of document, such as a clinical note or referral letter.

LOINC is used in 166 countries worldwide, and is provided in 21 separate language releases, including Belgian French and Canadian French.<sup>(18,49)</sup> New versions of LOINC and RELMA are released twice yearly, in June and December.<sup>(50,51)</sup> Similar to SNOMED CT, users receive a 'preview' ahead of the public release, to allow them to test and provide feedback.<sup>(51)</sup> The last significant releases, LOINC 2.58 and RELMA 6.17, were in December 2016.<sup>(18)</sup> In January 2017, LOINC 2.59 and RELMA 6.18 were made available, though were very limited in scope.<sup>(18)</sup> LOINC is in use in Ireland and was selected as the terminology to support the identification of laboratory orders for the Standardisation of Laboratory Test Codes project.<sup>(1)</sup>

### 3.3 Aggregation terminology: ICPC-2

The International Classification of Primary Care (ICPC) is an aggregation terminology designed for use in primary care or general practice.<sup>(52)</sup> Since 2003, ICPC-2 is the World Health Organization (WHO) approved aggregation terminology for the recording of data in primary care. ICPC is copyright property of the World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA).<sup>(53)</sup>

ICPC was designed as an epidemiological tool to enable healthcare providers to use a single aggregation terminology system to code information for three aspects of the health care encounter — that is, a patient's reasons for encounter, the healthcare practitioner's assessment of the diagnosis or problem, and process of care (decision, action, or plans).<sup>(52)</sup>

A key attraction of ICPC-2 is the ability to record the reason for encounter as distinct from the practitioner's observation.<sup>(1)</sup> It is also praised for its ease of use because of the small number of codes. However, it has also been criticised for its slow development and upgrade. ICPC-2 still does not include codes for some commonly-encountered conditions, forcing GPs to group these together in 'other, non-specific' categories.

#### 3.3.1 Structure and versioning

The ICPC-2 is unique as it enables the provider to classify the initial episode of care from the time the patient first presents with a specific problem until the final encounter for the same problem resulting in a more defined diagnosis.<sup>(1)</sup> ICPC-2 is designed for use in paper-based

statistical collections and in electronic information systems for both encounters and episodes of care. It has inclusion and exclusion criteria in addition to paper-based and electronic indexes to guide appropriate usage. Mappings are provided from other aggregation terminologies such as ICD-10.

Known as ICPC-1, the first version of ICPC was published in 1987 by WONCA.<sup>(54)</sup> The second version ICPC-2 was published in 1998, with ICPC-2-E released in 2000, which refers to an electronic version of the aggregation terminology. The stated revision cycle for ICPC-2 is 11 years.

In 2012, the WONCA International Classification Committee (WICC) Translations Group reported that ICPC-2 had been translated into 32 languages, with other language versions planned.<sup>(55)</sup> The WHO website reports WONCA as having 118 member organisations, representing family doctors in over 130 countries and territories around the world.<sup>(53)</sup> In 2016, researchers surveyed eligible participants from 109 countries, to understand ICPC use<sup>(56)</sup>. 52 countries responded. Though available in 34 countries, and used in primary care in 27, ICPC-2 was mandatory in only 6 countries. Where ICPC was used, it was typically non-mandatory.

### 3.4 Aggregation terminology: ICD

The World Health Organization (WHO) International Classification of Disease (ICD) is ‘...the foundation for the identification of health trends and statistics globally... allowing the world to compare and share health information using a common language’.<sup>(57)</sup> ICD provides a comprehensive definition of diseases, disorders, injuries, symptoms, and the reason for the encounter, together with social factors and external causes. Definitions are organized into standard groups, helping to improve the retrieval and analysis of health information for evidenced-based decision-making. Grouping also facilitates direct comparisons of health information in different locations, or from the same location at different times.

ICD is the international standard:

- for defining and reporting diseases and health conditions in all clinical and research purposes.
- for mortality and morbidity statistics.

Originally intended primarily for secondary data use, ICD is now used for health information purposes in public health, primary, secondary and tertiary care settings. In fact, the International Classification of Disease, Tenth Edition (ICD-10) was found to be the second most widely used standard, after ICPC, for *primary* care.<sup>(56)</sup> A wide variety of healthcare and related professions use ICD, including physicians, nurses, policy makers, and national health programme managers.

The most recent and widely used revision is ICD-10, which is in use since 1990.<sup>(57)</sup> Following the United States' long-delayed adoption of ICD-10 in 2015, few countries still use ICD-9.<sup>(58,59)</sup> The 11th revision is currently being developed and is due for release in 2018.<sup>(17)</sup>

### 3.4.1 Structure and versioning

ICD-10 organises medical concepts according to a relevant body system — for example, nervous system.<sup>(34)</sup> It also consists of 'special groups' chapters relating to epidemic diseases, constitutional and general diseases, developmental diseases and injuries. The special groups chapters have arranged concepts according to aetiology, in order to facilitate epidemiological research. Any healthcare condition can be assigned a unique category and given a code, up to five characters long in ICD-10-AM (diagnoses). ICD-10 chapters are arranged in categorical blocks and each block has a three-character code with the option of adding a character to increase clinical specificity — for example, H40 *Glaucoma*, H40.1 *Primary open-angle glaucoma*.

ICD contains:

- tabular lists containing cause-of-death titles and codes
- inclusion and exclusion terms for cause-of-death titles
- an alphabetical index of diseases and nature of injury, external causes of injury, table of drugs and chemicals
- descriptions, guidelines, and coding resources

ICD-10 is used to report morbidity data in 194 countries and to report mortality data in 117 countries.<sup>(37,57)</sup> It has been translated into 43 languages. About 70% of the world's health expenditures (USD \$ 3.5 billion per year) are allocated for reimbursement and resourcing using ICD.<sup>(57)</sup> In 2016, a study of ICPC-2 usage worldwide found that ICD was the second

most widely used standard *in primary care* even though ICD was originally intended for *secondary data use*.<sup>(56)</sup>

ICD-10 is has been updated, with new editions published since 1990. For example, the UK formally adopted the ICD-10, fifth edition, in April 2016.<sup>(60)</sup> Other country specific implementations have been developed and published. The International Classification of Disease, Tenth Revision, Australian Modification (ICD-10-AM) disease component is based on ICD-10.<sup>(21)</sup>

The Australian Classification of Health Interventions (ACHI) is used to record procedures. Together with the Australian Coding Standard (ACS), this combined code is known as ICD-10-AM/ACHI/ACS 8th Edition. Clinical coders use ICD-10-AM, 8<sup>th</sup> Edition, for coding diagnoses from the acute hospitals in Ireland.<sup>(21)</sup> This combination is considered to accurately reflect an episode of health care.

### 3.5 National Landscape

All acute hospitals in Ireland use the HIPE system to code data. The HIPE scheme was established in 1971 and is currently maintained by the Healthcare Pricing Office in association with the HSE. HIPE is a computer-based health information system, designed to collect national data on coded discharge summaries and morbidity information from acute hospitals in Ireland.

Clinical coders use the WHO International Classification of Disease, Tenth Revision, Eighth Edition, Australian Modification (ICD-10-AM, 8<sup>th</sup> Edition), to code diagnoses from the acute hospitals in Ireland since 1<sup>st</sup> January 2015.<sup>(21)</sup> The Australian Classification of Health Interventions (ACHI) is used to record procedures. Together with the Australian Coding Standard (ACS), this combined code is known as **ICD-10-AM/ACHI/ACS 8th Edition**. This combination is considered to accurately reflect an episode of health care. In 2016, 59 Irish hospitals, including all 48 acute hospitals, coded and reported on over 1.7 million discharges.<sup>(61)</sup>

The HIPE system collects the demographic, clinical, and administrative data coded using ICD-10-AM/ACHI/ACS 8<sup>th</sup> edition. HIPE data is used in research and planning — for example, in hospital activity statistics related to diseases or procedures and for quality assurance studies and drug trials. It is also used by the Department of Health and the HSE in the planning, provision and capacity of acute hospital services.

ICD and ICPC-2 are used in primary care in Ireland, together with ICPC-2. Used to code diseases, ICPC-2 is established in Irish general practice. For example, the General Practice Information Technology Group (GPIT) requires software systems for general practice management to support both ICD-10 and ICPC-2 coding.<sup>(62)</sup> Coordinators from the group work with GPs on the coding of clinical encounters using ICPC-2 and subsequent auditing of clinical practice. The Irish Primary Care Research Network extracts data coded with ICPC-2 and ICD-10-AM from GP practice management systems.<sup>(63)</sup>

LOINC is also in use in Ireland and was selected as the terminology to support the identification of laboratory orders for the Standardisation of Laboratory Test Codes project.<sup>(1)</sup>

As discussed earlier, Ireland has become a member of the IHTSDO and SNOMED CT licensing for Ireland is in set up mode. Each SNOMED International member has an obligation to support adoption through the establishment of a National Release Centre (NRC).<sup>(64)</sup> The NRC is the single point of contact between SNOMED International and affiliates in the member country. SNOMED International's NRC handbook provides comprehensive guidelines to members for establishing an NRC. It identifies the three phases of NRC organisation - establishment, rollout, and maintenance - and outlines crucial steps during each phase.

Based on these guidelines, and on international experience, the following steps are crucial during the establishment phase of the Irish NRC:

- **Set Up Governance** — identify the governance and operational model that will be used nationally. As a SNOMED licence holder, Ireland now has a responsibility to set up a National Release Centre and to allocate adequate financing, which will ensure that sufficient resources can be assigned and an appropriate portfolio of projects selected and undertaken.

- **Build Local Expertise** — understand how to implement SNOMED CT correctly in the Irish context. Existing knowledge of SNOMED CT in Ireland has not been audited. Any additional expertise must be built through the implementation of a carefully-selected portfolio of projects, comprising a representative set of real world challenges and scenarios. SNOMED CT is implemented using subsets of the overall coding system — for example, a pharmacy subset may be required. Domain expertise is necessary to develop subsets. Though no recent audit has been carried out, use of SNOMED CT in Ireland is understood to be limited.<sup>(1,34)</sup>
- **Engage Stakeholders** — involve key contacts whose championing of SNOMED CT will contribute to its successful adoption. It is crucial to deliver value 'early and often' to key project contacts. Soliciting the key contacts' feedback at regular intervals and acting on it appropriately also fosters their confidence in the adoption program. Involving key contacts early in the program can build a community of use and encourage these stakeholders to become advocates during the later stages of wider adoption.
- **Prioritize Projects** — select the tool to evaluate the contribution that each candidate project can make to the overall adoption strategy. It is vital to select an appropriate project prioritisation tool, which will identify and select projects that contribute strategically to stakeholder engagement and to local expertise, while giving due weight to the usual project feasibility considerations.

In summary, four standards are identified which would potentially bring benefits to eHealth initiatives in Ireland. A widely used reference terminology, LOINC was developed as a common terminology for laboratory and clinical observations in electronic reports and for identifying clinical document types in electronic messaging and is in use in Ireland. Use of Australian edition of ICD-10 known as ICD-10-AU is well established in Ireland through HIPE reporting. ICPC-2 is a well-established aggregation terminology with some reported use in Ireland. Ireland has recently taken up membership of SNOMED International, making SNOMED CT available to all stakeholders. With membership of SNOMED International there is a mandatory requirement to set up a National Release Centre to coordinate the implementation of SNOMED CT in Ireland.

## 4 Assessment

### 4.1 Approach

National standards to support eHealth, together with any technical materials, are developed based on Health Information and Quality Authority (HIQA) processes. These processes are broadly in line with the World Trade Organization (WTO) Code of Good Practice for the Preparation, Adoption and Applications of Standards.<sup>(1)</sup>

When developing national standards, HIQA processes broadly prefer the adoption of international standards that:

- are open and non-proprietary.
- have been fully implemented and validated.
- ensure value for money and minimize the cost of compliance.
- take into account industry developments and health service delivery opportunities.
- require minimal adaption to meet Irish requirements.

HIQA considers developing an entirely new standard for Ireland only as a last resort — that is, when no appropriate international standard is available.

During the development of national terminology standards, HIQA used a Canadian model to assess each of the candidate international standards<sup>(65)</sup> The Canadian model, which was used to select Canadian health information standards, consists of five principles, each with specific criteria. The principles are:

- The standard must be clinically relevant.
- The standard must meet a specific business need.
- The standard must be vendor neutral and backward compatible.
- The standard must be financially viable.
- The standard must have established governance and processes.

For more information about the tool, see Appendix B, Assessment model summary.

## 4.2 Results

Each candidate standard was assessed using the principles defined by the model. All four standards met the criteria for each of the principles outlined. This section explores how the candidate standards met each of the criteria for each assessment principle.

First, **the standard must be clinically relevant**. This means that the standard supports clinical practice, meets requirements across disciplines, support cross-healthcare delivery, and improves outcomes. All four standards were found to be clinically relevant. Clinical practice can be supported by using **reference terminologies** and **aggregation terminologies** in combination to satisfy coding requirements.<sup>(27)</sup> Equally, a combination of **reference terminologies** and **aggregation terminologies** provide support across healthcare disciplines and in cross-healthcare delivery settings. Finally, the combination of **reference terminology** standards for clinical coding input systems and **aggregation terminology** standards for reporting and other output systems was shown to result in improved clinical outcomes for patients.

Next, **the standard must meet Irish business needs**. The reference terminologies assessed **aid workflow** by assisting healthcare professionals and clinicians to capture clinical information at the point of care, improving clinical decision making and patient safety. The aggregation terminologies aid workflow for secondary data use, improving reporting and helping clinical and administrative staff to carry out their functions. All standards were shown to be **mature and stable** — for example, 30 countries have now acquired the right to a national SNOMED licence and ICD-10 has been in use since 1994. ICPC-2 is well established in general practice in Ireland. All aggregation terminologies and reference terminologies were **generally considered feasible to implement**. However, implementation is only feasible when the necessary experience and expertise is available, among other factors.

The third principle is that **the standard must be vendor neutral and backward compatible**. This allows the use of the most appropriate technology available. The standards assessed were all owned by either non-profit institutions or governments, and as such may be considered vendor neutral. Candidate standards should also be backward compatible, to eliminate the need to start over when upgrading to a new version of a

standard. However, it is sometimes necessary to sacrifice backward compatibility to take advantage of a new and improved standard with a completely different architecture. Backward compatibility varied among the standards assessed and each case must be considered. However, the impact of this variability was limited.

Fourth, **the standard must be financially viable**. Licensing costs vary across the different reference terminologies and aggregation terminologies. However, licensing is only a small part of the cost of implementing either a reference terminology or an aggregation terminology. Successful implementation also requires appropriate resourcing and financing. Other countries have invested heavily in implementing both. Implementing reference terminology or aggregation terminology, at regional or national level, will require an incremental approach.

Finally, **the standard must have established governance and process**.

There is strong governance by organisations that maintain each standard and all organisations are open to contribution from Irish stakeholders. All standards are actively maintained. Licensing is required for all terminological systems reviewed in this assessment. However, it is required at different levels — for example, for commercial, for non-commercial or for research. SNOMED CT issue different categories of licensing, including research, national and organisation-based licences.

In summary, the standards assessed broadly meet the assessment principles. However, as noted earlier, the Irish healthcare system has very specific needs, which, together with the attendant impact on feasibility, require more consideration.

## 5 Conclusions

Reference terminologies and aggregation terminologies are designed for distinctly different purposes and to satisfy diverse user requirements.<sup>(26)</sup> The full benefits of each are realized only when they are used in combination. Therefore, HIQA has developed this guidance to provide direction on national terminology standards and their correct use.

As part of the standard development process, candidate international standards for terminologies were identified. These candidate standards were then assessed in terms of their suitability for adoption as national standards for Ireland. Adapted from a Canadian model, the assessment model used consisted of five principles with defined criteria. The results were summarized in section 4.2 Results, with full results for each standard presented in the relevant appendix.

Across Ireland, the exchange of administrative and clinical information is managed using many different types of systems and computer software. The standards that are used to communicate information unambiguously between different systems vary and may include bespoke, proprietary, or commonly used international reference terminology standards such as LOINC, SNOMED CT, ICPC-2, or ICD-10 and its different international versions. To safely send and receive information, such as laboratory orders between different types of systems, a standard exchange format and semantics are required. The implementation of a standard would result in a range of project-specific implementation needs.

In Ireland, substantial aggregation terminology expertise and experience is available primarily in ICD-10-AM, in acute settings and in some primary care settings.<sup>(21,34)</sup> Clinical coders in the acute hospitals use ICD-10-AM for coding diagnoses. ACHI is used for procedures. There is some experience in using LOINC for laboratory coding and ICPC-2 in primary care. It is feasible to continue to use ICD and LOINC for the purposes that they were designed for.

The EU research on SNOMED CT illustrates some of the challenges that can arise when implementing a national reference terminology or aggregation terminology standard.<sup>(3,30)</sup> The same research makes some recommendations to support successful adoption of an aggregation terminology, or a reference terminology such as SNOMED CT, as a national

standard. The research findings recommend a step-wise, incremental approach when adopting any terminology standard, with pilot projects focused on specific use cases. They highlight the need for clear governance and direction on use. They also emphasise the need to allocate sufficient human and financial resources. This ensures the availability of necessary tools and professional training and that appropriate pilot projects can be undertaken. Programs to increase awareness of organisational benefits also require financing and resourcing. These recommendations align with the practices outlined in SNOMED International's guidelines for members.<sup>(36)</sup>

To assist the health IT community in optimizing the use of reference terminologies and aggregation terminology in their respective healthcare settings, HIQA provides the following guidance:

### Guidance

- 1) When used for the purpose for which they were designed **terminology systems** can improve the quality of data available in health and social care settings. The current use of terminologies across the health and social care settings in Ireland should be built upon and expanded.
- 2) As Ireland has recently been accepted as a member of SNOMED International key steps in the supporting the implementation of **SNOMED CT** in Ireland through a National Release Centre include:
  - a. Set Up Governance
  - b. Build Local Expertise
  - c. Engage Stakeholders
  - d. Prioritize ProjectsA review of the feasibility of continuing to support SNOMED CT should be considered at an appropriate time.
- 3) The **LOINC** terminology should continue to be developed and implemented in Ireland. (This includes developing a national catalogue of laboratory codes, which was identified by a subgroup of the national messaging body as necessary to support interoperability.)

- 4) The **ICD-10-AM** terminology should continue to be used in the systems used to code episodes of care in the Hospital Inpatient Patient Enquiry System.
- 5) The **ICPC-2** and **ICD-10** terminologies should continue to be supported in primary care.

HIQA will regularly review this guidance and will continue to engage and consult with stakeholders and keep abreast of developments in the standards landscape internationally.

## Appendix A Retired Candidate Standards

### OPCS-4

The UK Office of Population Census and Surveys Classification of Surgical Operations and Procedures (**OPCS**) is an aggregation terminology used for coding operations, procedures and interventions carried out on a patient during an episode of health care in a secondary care institution.<sup>(66,67)</sup> It is used to support operational and strategic planning, resource utilisation, performance management, reimbursement, research and epidemiology. OPCS-4 is one of the two aggregation terminologies mandated by the UK National Health Service (NHS); the other aggregation terminology is ICD-10.

OPCS was designed for use in the UK and the Standardisation Committee for Care Information is responsible for the development, authoring and annual review cycle.<sup>(68)</sup> OPCS-4 is covered by Crown Copyright and updated annually by NHS Digital. Implementation of the latest version is OPCS-4.8 began on 1 April 2017.

OCPS was used to code procedures in the HIPE system until 1990.<sup>(21)</sup> It is no longer in use in Ireland and is no longer considered a candidate national standard.

### Read Codes

Developed in the early 1980s by Dr James Read, a UK general practitioner (GP), Read Codes were intended to code any clinical data in a GP's practice management system.<sup>(69)</sup> They were sold to the Crown for £1.25 million and have been in use in the NHS since 1985. In 1999, they were adopted as a UK national standard for recording the clinical information in general practice.

In 2014, the UK Terminology Centre (UKTC) confirmed the decision to retire Read Codes versions 2 (v2) and 3 (v3 or CTV3) in favour of SNOMED CT.<sup>(19)</sup> Read Code v2 is no longer maintained, while any changes requested to v3 are also authored in SNOMED CT to facilitate the migration to that standard. Both standards will be withdrawn in April 2020 and are no longer considered candidate national standards for Ireland.

## Appendix B Assessment model summary

Principle 1. The standard must be clinically relevant		
1.1	<b>Clinical appropriateness</b>	The standard should <b>be supportive of clinical practice</b> (where relevant)
1.2	<b>Cross discipline</b>	The standard should <b>be provider independent</b> (where relevant) — that is, used across disciplines, such as by physicians, nurses, pharmacists, laboratory professionals, allied health professionals and so on.
1.3	<b>Cross healthcare delivery setting</b>	The standard should <b>be independent of healthcare-delivery-setting</b> — that is, appropriate for use across health sectors, such as acute care, community care, and long-term care.
1.4	<b>Clinical outcomes</b>	The standard should <b>be supportive of patient care</b> — message types should be defined across administrative, clinical, requesting and prescribing use cases, and support the carrying of clinical information and requests for results and services

Principle 2. The standard must meet specific business needs		
2.1	<b>Business need</b>	The standard should <b>be developed</b> based on a <b>defined business requirement</b> , against which it is <b>later validated</b> .
2.2	<b>Maturity/stability</b>	The standard should <b>be assessed</b> to determine: <ul style="list-style-type: none"> <li>▪ how widely it has been implemented and tested</li> <li>▪ whether further development is needed</li> </ul>
2.3	<b>Feasibility</b>	The standard should <b>be feasible to implement</b> — that is, capable of being implemented within a reasonable time, budget, and resource skill set. (Known critical dependencies impacting implementation must be identified — for example, other components or standards that are not yet developed.)
2.4	<b>Workflow</b>	The standard should <b>balance the impact on</b> the user's <b>workflow</b> with improvements to <b>patient care</b> , directly or indirectly.

<b>Principle 3. The standard must be vendor neutral and backward compatible</b>		
<b>3.1</b>	<b>Vendor neutral</b>	The standard should <b>be independent of any vendor</b> .
<b>3.2</b>	<b>Backward compatibility</b>	The standard should <b>be compatible and interoperable</b> with <b>previous versions</b> of the standard.

<b>Principle 4. The standard must be financially viable</b>		
<b>4.1</b>	<b>Affordability</b>	The standard should <b>be viable in terms of licensing and maintenance fees</b> , and have a feasible funding strategy.
<b>4.2</b>	<b>Implementation costs</b>	The standard should <b>be financially viable to implement</b> .

<b>Principle 5. The standard must have established governance and processes</b>		
<b>5.1</b>	<b>Intellectual property</b>	The standard should <b>be governed by clear, documented intellectual property ownership</b> and or licensing model.
<b>5.2</b>	<b>Governance structure</b>	The standard should <b>be developed using HIQA's standards development process</b> , in keeping with HIQA's standards decision-making process.
<b>5.3</b>	<b>Irish influence</b>	The standard should <b>be developed and maintained</b> using an <b>open and transparent process</b> , with opportunity for Irish stakeholders to be engaged.
<b>5.4</b>	<b>Sustainability</b>	The standard should <b>have sustainable maintenance processes and resourcing requirements</b> — that is, to monitor conformance and enhance the standard when necessary.

## Appendix C SNOMED CT assessment results

### Principle 1. The standard must be clinically relevant

**1.1 Clinical appropriateness** — Clinical practice can be supported by using reference terminologies and aggregation terminologies in combination to satisfy coding requirements.<sup>(27)</sup> The full benefits of each are realised when:

- reference terminologies are used to collect clinical information as part of the clinical encounter at the point of care.
- aggregation terminologies linked to reference terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation.

SNOMED CT gives the most comprehensive content coverage of any reference terminology, supporting clinical practice in a wide range of clinical scenarios.<sup>(3)</sup>

**1.2 Cross discipline** — SNOMED CT fully supports a wide range of healthcare professionals in their various roles as it is considered the most comprehensive clinical reference terminology currently available internationally.<sup>(1,3,70)</sup> SNOMED CT covers many aspects of healthcare including clinical findings, procedures, body structures, organisms, substances, and pharmaceutical and biological products. EU research recommends SNOMED CT as a core reference terminology for a national terminology ecosystem, reflecting its cross-disciplinary nature.

**1.3 Cross-healthcare delivery setting** — SNOMED CT is described as the lingua franca of electronic patient records and electronic health records.<sup>(1)</sup> Broad in scope, its concepts represent the wide range of information types that need to be recorded in clinical records.<sup>(1,3)</sup> SNOMED CT has a logical multi-axial subtype hierarchy, which allows it to express information with different levels of detail and precision. As a result, practitioners from different disciplines and specialties can record appropriate data at different stages in the delivery of patient care.

**1.4 Clinical outcomes** — As a reference terminology, SNOMED CT facilitates the coding of clinical information captured in an electronic health record or electronic patient record during the course of a patient’s encounter.<sup>(1)</sup> It is considered to give the most comprehensive content coverage of any reference terminology.<sup>(3)</sup> It is also expected to help improve the overall quality of clinical data and, in turn, clinical care and outcomes.

## **Principle 2. The standard must meet specific Irish business needs**

**2.1 Business need** — As a reference terminology, SNOMED CT aids workflow by assisting healthcare professionals and clinicians to capture clinical information at the point of care, improving clinical decision making and patient safety.

**2.2 Maturity and stability** — SNOMED CT has been adopted as a national terminology standard by 30 countries.<sup>(22)</sup> It has been adopted as the mandatory terminology in the UK and is widely implemented.<sup>(20)</sup> The ASSESS CT project has recommended that SNOMED CT be adopted as a core reference terminology in the EU.<sup>(3)</sup>

**2.3 Feasibility** — Adoption is feasible only if adequate resources and financing are allocated.<sup>(1)</sup> This will ensure that an appropriate portfolio of projects can be undertaken. As a member of SNOMED International, Ireland has a responsibility to set up a National Release Centre.<sup>(64)</sup> EU research also recommends that the following actions be taken to ensure successful adoption:

- **Set Up Governance** — identify the governance and operational model that will be used nationally.
- **Build Local Expertise** — understand how to implement SNOMED CT correctly in the Irish context.
- **Engage Stakeholders** — involve key contacts whose championing of SNOMED CT will contribute to its successful adoption.
- **Prioritize Projects** — select the tool to evaluate the contribution that each candidate project can make to the overall adoption strategy.<sup>(3)</sup>

These actions are discussed fully in Chapter 5, Conclusions.

**2.4 Workflow** — Reference terminologies complement clinical workflow, supporting clinicians and healthcare professionals in coding clinical information when the patient is

present.<sup>(1)</sup> A reference terminology also complements secondary data use when it is granular in structure and contains relationships between concepts. SNOMED CT is considered the most comprehensive reference terminologies to capture clinical information at the point of care, which improves clinical decision making and patient safety.<sup>(3)</sup> It also improves secondary data workflow, such as reporting, because it is granular in structure and because it contains relationships between concepts.<sup>(1)</sup>

### **Principle 3. The standard must be vendor neutral and backward compatible**

**3.1 Vendor neutral** — SNOMED CT is the registered trademark of the not-for-profit organisation, SNOMED International, which owns intellectual property rights.<sup>(70)</sup>

**3.2 Backward compatibility** — SNOMED CT is backward compatible between releases and SNOMED CT concept identifiers are never reused.<sup>(36)</sup> Concepts can be made inactive, but never deleted, from the terminology. If one concept supersedes another, both concepts are linked.

### **Principle 4. The standard must be financially viable**

**4.1 Affordability** and **4.2 Implementation costs** — Implementation costs for reference terminologies and aggregation terminologies alike are multi factorial. The SNOMED CT licence has been purchased.<sup>(2)</sup> Other costs are less obvious and require further analysis. These range from education and training of clinicians and clinical coders, to the costs of change to business practice and daily workflow, to the development costs associated with supporting reference terminologies and aggregation terminologies within ICT systems.<sup>(3)</sup>

### **Principle 5. The standard must have established governance and processes**

**5.1 Intellectual property** — SNOMED International owns the intellectual property rights of SNOMED CT and antecedent works since April 2007.<sup>(35)</sup> SNOMED International is responsible for ongoing maintenance, development, quality assurance, and distribution of SNOMED CT. Members own the intellectual property rights to additions and extensions they may make to the international release but SNOMED International reserves the rights to have

the changes and any associated intellectual property rights transferred back to the international edition of SNOMED CT.

**5.2 Governance structure** — Based in London, SNOMED International is responsible for the development, quality assurance, distribution, and administration of the rights to SNOMED CT.<sup>(35)</sup> SNOMED International is the new trading name of the not-for-profit International Health Terminology Standards Development Organisation (IHTSDO). IHTSDO was formed in 2007 with the aim of fostering the development and use of suitable standardised clinical terminologies, notably SNOMED CT, in order to support the safe, accurate, and effective exchange of health information.

The IHTSDO General Assembly (GA) is the highest authority of the organisation and is composed of representatives from all member countries with equal representation. The GA is collectively charged with assuring that the purpose, objects and principles of the Organisation are pursued and that the interests of the IHTSDO are safeguarded. Arrangements for governance of the IHTSDO and SNOMED CT are set out in the IHTSDO Articles of Association. The GA appoints the Management Board (MB), which has overall responsibility for the management and direction of the IHTSDO.

**5.3 Irish influence** — As a member of SNOMED International, Ireland has the right (and the responsibility) to provide input on behalf of all Irish affiliates to SNOMED International about necessary changes and revisions, and to collaborate with other members to achieve SNOMED International's other goals.<sup>(71)</sup> For example, members typically receive a beta version for trial two months before the release date.<sup>(41)</sup> Their changes are incorporated in a pre-release version that affiliates also receive, a few days before the official full, international release.

**5.4 Sustainability** — SNOMED International releases SNOMED CT twice annually, incorporating updates from charter members and working groups into the new releases.<sup>(40)</sup> The ASSESS CT project lists 'a transparent and robust maintenance project' as a strategic long-term benefit of SNOMED CT.<sup>(30)</sup>

## Appendix D LOINC assessment results

### Principle 1. The standard must be clinically relevant

**1.1 Clinical appropriateness** — Clinical practice can be supported by using reference terminologies and aggregation terminologies in combination to satisfy coding requirements.<sup>(27)</sup> The full benefits of each are realised when:

- reference terminologies are used to collect clinical information as part of the clinical encounter at the point of care.
- aggregation terminologies linked to reference terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation.

As a reference terminology, LOINC is appropriate for use in laboratory settings, to code observations in HL7 messages and, in clinical settings, to help manage clinical documents.<sup>(45,46)</sup> In Ireland, LOINC is the terminology used to identify laboratory orders in the Standardisation of Laboratory Test Codes project.<sup>(1)</sup> It is also used in Healthlink to identify message types.

**1.2 Cross Discipline** — LOINC is primarily used by laboratory staff and pathologists.<sup>(42,43)</sup> It covers the laboratory domain and includes codes for haematology, biochemistry, microbiology, serology, toxicology and identifiers for drug and cell counts and antibiotic susceptibility. The Document Ontology (DO) in LOINC includes entries for clinical observations, nursing diagnosis, nursing interventions, outcomes classification, and patient care data sets.<sup>(45)</sup>

**1.3 Cross-healthcare delivery setting** — LOINC was developed to support the electronic movement of clinical data from laboratories that produce the data to hospitals, physician's offices, and payers who use the data for clinical care and management purposes.<sup>(3)</sup> The LOINC document ontology also includes concepts to identify clinical assessments and findings.<sup>(45)</sup>

**1.4 Clinical outcomes** — Reference terminologies facilitating the coding of clinical information captured in an electronic health record or electronic patient record during the course of a patient’s encounter.<sup>(1)</sup> Expressed in natural language, they are considered input systems. Reference terminologies are generally more comprehensive and precise than aggregation terminologies. They have greater flexibility and offer a more accurate representation of the healthcare domain. However, their immense size, complex granularity and complex hierarchies make them unsuitable for use in isolation across the whole of the health sector for data collection and reporting.

## **Principle 2. The standard must meet specific Irish business needs**

**2.1 Business need** — Reference terminologies aid workflow by assisting healthcare professionals and clinicians to capture clinical information at the point of care, improving clinical decision making and patient safety. As discussed earlier, LOINC is used in laboratory settings, to code observations in HL7 messages, and in clinical settings, to help manage clinical documents.<sup>(45,46)</sup>

**2.2 Maturity and stability** — LOINC is used in 166 countries worldwide and is provided in 21 separate language releases, including Belgian French and Canadian French.<sup>(18,49)</sup> It is widely used in Canada, Germany, Switzerland, Australia, South Korea, Estonia, Brazil, New Zealand and the US.<sup>(42)</sup> LOINC is in use in Ireland and was selected as the terminology to support the identification of laboratory orders for the Standardisation of Laboratory Test Codes project.<sup>(1)</sup>

**2.3 Feasibility** — To implement LOINC at a national level would require resources and expertise from pathologists and other laboratory, clinical and technical experts.<sup>(1)</sup> Some experience in LOINC exists in Ireland.<sup>(34)</sup> For example, LOINC concepts are used for laboratory ordering, emergency department alerts and referrals to hospital outpatient services.

**2.4 Workflow** — Reference terminologies complement clinical workflow, supporting clinicians and healthcare professionals in coding clinical information when the patient is present.<sup>(34)</sup> LOINC supports clinicians and healthcare professionals through laboratory ordering, emergency department alerts and referrals to hospital outpatient services.

### Principle 3. The standard must be vendor neutral and backward compatible

**3.1 Vendor neutral** — All candidate terminologies are vendor neutral. LOINC is owned and maintained by the Regenstrief Institute, a not-for-profit organization.<sup>(43)</sup> Registration and use of LOINC is free.

**3.2 Backward compatibility** — LOINC is backward compatible with earlier releases.<sup>(72)</sup> Concepts are never deleted from the terminology and identifiers are never reused.<sup>(1)</sup> The LOINC coding system does not deprecate or reuse codes but does allow for duplication of concepts. As such, it may have multiple entries for very similar concepts.

### Principle 4. The standard must be financially viable.

**4.1 Affordability** — The LOINC database, together with associated documents and programs, are copyrighted; however, the copyright permits all commercial and non-commercial uses at no cost.<sup>(44)</sup>

**4.2 Implementation costs** — Implementation costs for reference terminologies and aggregation terminologies are multi factorial. Obvious costs include the purchasing of licences, but the other costs are less obvious. These range from education and training of clinicians and clinical coders, to the costs of change to business practice and daily workflow, to the development costs associated with supporting reference terminologies and aggregation terminologies within ICT systems.<sup>(3)</sup>

### Principle 5. The standard must have established governance and processes

**5.1 Intellectual property** — The Regenstrief Institute owns the copyright to LOINC and the supporting materials.<sup>(49)</sup> The LOINC database and associated documents and programmes are copyrighted; however, the copyright permits all commercial and non-commercial uses at no cost. If the LOINC database or its contents are distributed as a database, such distributions must include all parts of the formal LOINC term, the LOINC short name, the LOINC code, the deprecated flag, and the copyright. The copyright notice is

needed to prevent variants, which would defeat the purpose of this standard. No such notice is required when LOINC codes are used in messages to report test results.

**5.2 Governance structure** — The development and maintenance of LOINC is a voluntary effort, carried out by the not-for-profit medical research organisation, the Regenstrief Institute.<sup>(43)</sup> The Institute is endorsed by the American Clinical Laboratory Association and the College of American Pathologists.<sup>(1)</sup>

**5.3 Irish influence** — The Regenstrief Institute receives submissions for new content and requests from the user community.<sup>(73)</sup> Submissions are accepted electronically for new entries, which are incorporated into subsequent releases.

**5.4 Sustainability** — New versions of LOINC and RELMA are released twice yearly, in June and December.<sup>(50)</sup> The most recent version, LOINC 2.59, was released in February 2017.<sup>(18)</sup> Similar to SNOMED CT, LOINC users receive a 'preview' ahead of the public release, to allow them to test and provide feedback.<sup>(51)</sup>

## Appendix E ICD assessment results

### Principle 1. The standard must be clinically relevant

**1.1 Clinical appropriateness** — Clinical practice can be supported by using reference terminologies and aggregation terminologies in combination to satisfy coding requirements.<sup>(27)</sup> The full benefits of each are realised when:

- reference terminologies are used to collect clinical information as part of the clinical encounter at the point of care.
- aggregation terminologies linked to reference terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation.

ICD is the most widely used aggregation terminology, covering scenarios in public health, primary, secondary and tertiary care settings.<sup>(57)</sup>

**1.2 Cross Discipline** — ICD is used for health information purposes in public health, primary, secondary and tertiary care settings.<sup>(1)</sup> It enables the storage and retrieval of diagnostic information for epidemiological and health management purposes and for clinical use. It is also used for collating national mortality and morbidity statistics and for reimbursement.<sup>(57)</sup>

**1.3 Cross-healthcare delivery setting** — ICD is used for health information purposes in public health, primary, secondary and tertiary care settings.<sup>(1)</sup> In Ireland, ICD is used already in both primary and secondary care settings. All Irish acute hospitals code use ICD-10-AM/ACHI, 8<sup>th</sup> Edition, to code data. For general practices, the General Practice Information Technology Group (GPIT) requires all GP management software to support both ICD-10 and ICPC-2 coding.<sup>(62)</sup> The Irish Primary Care Research Network extracts data coded with ICPC-2 and ICD-10-AM from GP practice management systems.<sup>(63)</sup>

**1.4 Clinical outcomes** — Aggregation terminologies play a key role in supporting patient care and are regarded as the most widely used approach to coding data in healthcare today. In Ireland, the HIPE system collects demographic, clinical, and administrative data coded using ICD-10-AM/ACHI/ACS 8<sup>th</sup> Edition. As stated previously, the Irish Primary Care

Research Network (IPCRN) also extracts data coded using ICD-10-AM from GP practice management systems.<sup>(63)</sup> This data is used for research about diseases or procedures, for quality assurance studies, and for drug trials. In these ways, it contributes the improved clinical outcomes.

## Principle 2. The standard must meet specific Irish business needs

**2.1 Business need** — Aggregation terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation. The Irish Primary Care Research Network extracts data coded with ICPC-2 and ICD-10-AM.<sup>(63)</sup> The HIPE system collects demographic, clinical, and administrative data coded using ICD-10-AM/ACHI/ACS 8<sup>th</sup> edition. HIPE data is used in research and planning — for example, in hospital activity statistics related to diseases or procedures, for quality assurance studies and for drug trials. It is also used by the Department of Health and the HSE in the planning, provision and capacity of acute hospital services.

**2.2 Maturity and stability** — ICD-10 is used to report morbidity data in 194 countries and to report mortality data in 117 countries.<sup>(37,57)</sup> It has been translated into 43 languages. About 70% of the world's health expenditures (USD \$ 3.5 billion per year) are allocated for reimbursement and resourcing using ICD.<sup>(57)</sup> In 2016, a study of ICPC-2 usage worldwide found that ICD was the second most widely used standard *in primary care* — though ICD was originally intended for *secondary data use*.<sup>(56)</sup> Currently undergoing extensive testing, ICD-11 is scheduled to be adopted by the WHO in May 2018.

**2.3 Feasibility** — As discussed earlier, ICD is used already in both primary and secondary care settings in Ireland. It is used in all Irish acute hospitals and in general practice management systems.<sup>(62)</sup> The Irish Primary Care Research Network (IPCRN) extracts data coded with ICPC-2 and ICD-10-AM.<sup>(63)</sup> As such, skills, expertise, and resources may be available for wider adoption.

**2.4 Workflow** — Aggregation terminologies primarily facilitate healthcare records departments to code information that has been recorded during the patient's encounter, typically following the patient's visit. Considered output systems, they facilitate clinical and

administrative staff to carry out their functions, particularly concerning secondary data use. Aggregation terminologies support the retrospective data entry of clinical information and are appropriate for statistical and epidemiological reporting purposes. As discussed earlier, ICD supports clinical coding in Irish primary and secondary care.<sup>(34)</sup> It also supports secondary data use in research and planning.

### **Principle 3. The standard must be vendor neutral and backward compatible**

**3.1 Vendor neutral** — Similarly, all aggregation terminologies assessed are vendor neutral. ICD is owned by the World Health Organization (WHO).

**3.2 Backward compatibility** — ICD-10 is updated intermittently, as new editions, and the backward compatibility is maintained between these editions.<sup>(16)</sup> While new diseases are introduced as they emerge, outdated concepts of diseases, symptoms or syndromes are not deleted, but are inactivated instead. ICD-11 will support a change history, and maintains compatibility with previous editions.<sup>(1)</sup>

### **Principle 4. The standard must be financially viable**

**4.1 Affordability** and **4.2 Implementation costs** — Implementation costs for reference terminologies and aggregation terminologies are multi-factorial. Obvious costs include the purchasing of licences, but the other costs are less obvious. These range from education and training of clinicians and clinical coders, to the costs of change to business practice and daily workflow, to the development costs associated with supporting aggregation terminologies and terminologies within ICT systems.<sup>(3)</sup>

### **Principle 5. The standard must have established governance and processes**

**5.1 Intellectual property** — The WHO requires an ICD licence for commercial, research and organisational use.<sup>(1)</sup> Both electronic and bound versions of ICD-10 can be purchased from the WHO. The WHO issues:

- commercial licences to companies wishing to incorporate and distribute WHO classifications in their software products for sale to customers in certain countries

- internal licences to organisations wishing to incorporate WHO classifications into their internal information systems for use by employees for administrative purposes — for example, health records management
- non-commercial licences to organisations planning to use WHO classifications for non-commercial or research purposes, if they qualify.<sup>(74)</sup>

While ICD is licenced from WHO, ICD10AM/ACHI/Grouper is used under licence from the Australian government.

**5.2 Governance structure** — ICD-10 was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in World Health Organization (WHO) member states as from 1994.<sup>(57)</sup> The WHO is a specialized agency of the United Nations that is concerned with international public health. It was established on 7 April 1948, with its headquarters in Geneva, Switzerland. The WHO is a member of the United Nations Development Group. The World Health Assembly is the decision-making body of WHO. It is attended by delegations from all WHO Member States and focuses on a specific health agenda prepared by the Executive Board.

**5.3 Irish influence** — The WHO is supporting current work to develop ICD-11 and actively encourage all member states, such as Ireland, to get involved in the development process.<sup>(17)</sup> The HPO have representation on the WHO Update Reference Committee (WHO-URC). The HPO also feedback to Independent Hospital Pricing Authority, Australian (IHPA) who publish ICD-10-AM/ACHI/ACS on issues that could impact future editions.

The Irish Coding Standards provide guidance and have the basic objective of satisfying sound coding convention according to ICD-10-AM/ACHI/ACS 8th Edition. They also augment, clarify or replace the Australian Coding Standards as appropriate. Many of the issues addressed are as a direct result of input and feedback from the Irish clinical coding, healthcare and clinical community. IHPA are informed of all new or amended ICS.

**5.4 Sustainability** — ICD is maintained by the WHO. ICD-10 is updated periodically, as required.<sup>(16)</sup> ICD-11 is in development and is scheduled to be released in 2018.<sup>(17)</sup>

## Appendix F ICPC-2 assessment results

### Principle 1. The standard must be clinically relevant

**1.1 Clinical appropriateness** — Clinical practice can be supported by using reference terminologies and aggregation terminologies in combination to satisfy coding requirements.<sup>(27)</sup> The full benefits of each are realised when:

- reference terminologies are used to collect clinical information as part of the clinical encounter at the point of care.
- aggregation terminologies linked to reference terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation.

ICPC-2 is designed to support general practitioners in recording details of clinical encounters.<sup>(54)</sup> It can also be used to support practitioners in secondary care.

**1.2 Cross discipline** — ICPC-2 is designed primarily for use in general practice but can also support practitioners in secondary care.<sup>(54)</sup> It can be used by general practitioners in paper-based statistical collections and in electronic information systems to record the reason for the encounter, the healthcare practitioner's assessment of the diagnosis or problem and the process of care arising out of the encounter.

**1.3 Cross-healthcare delivery setting** — Used for disease coding, ICPC-2 is established in general practice in Ireland.<sup>(63)</sup> The General Practice Information Technology Group (GPIT) requires software systems for general practice management to support both ICD-10 and ICPC-2 coding.<sup>(62)</sup> Coordinators from the group work with GPs on the coding of clinical encounters using ICPC-2 and subsequent auditing of clinical practice. The Irish Primary Care Research Network extracts data coded with ICPC-2 and ICD-10-AM.<sup>(63)</sup>

**1.4 Clinical outcomes** — Aggregation terminologies play a key role in supporting patient care and are regarded as the most widely used approach to coding data in healthcare today. Aggregation terminologies group similar diseases and procedures based on pre-determined, broad categories — for example, for body systems or the cause of a disease. Unlike other aggregation terminologies, ICPC classifies a clinical encounter from the beginning, with a

reason for encounter (RFE), to a conclusion with a more defined problem, diagnosis, or disease.<sup>(69)</sup>

## Principle 2. The standard must meet specific Irish business needs

**2.1 Business need** — Aggregation terminologies are used to generate data for secondary use for statistical and epidemiological analysis, external reporting requirements, measuring quality of care and monitoring resource allocation. ICPC-2 is a required coding standard for general practice management systems in Ireland.<sup>(34)</sup> Coordinators from the certifying body, the GPIT, work with GPs on the coding of clinical encounters. The IPCRN also extracts ICPC-2 data for research into Irish primary care.

**2.2 Maturity and stability** — ICPC-2 is recognised as a suitable aggregation terminology for general practice,<sup>(34)</sup> having achieved recognition from the WHO. It is currently the most widely used in countries such as Australia, the Netherlands, Spain, Norway, Slovenia, Denmark, Finland and France.<sup>(34)</sup> ICPC-2 has been translated into 19 languages.

**2.3 Feasibility** — There is some experience with ICPC-2 coding in Ireland.<sup>(34)</sup> ICPC-2 is well established in general practice in Ireland and is used for disease coding. To achieve the Irish College of General Practitioners (ICGP) certification, general practice software management systems are required to support the coding of information using ICPC-2 and ICD-10.<sup>(62)</sup> The IPCRN also extracts data coded using ICPC-2.

**2.4 Workflow** — Aggregation terminologies primarily facilitate healthcare records departments to code information that has been recorded during the patient's encounter, typically following the patient's visit. Considered 'output' systems, they facilitate clinical and administrative staff to carry out their functions, particularly concerning secondary data use. Aggregation terminologies support the retrospective data entry of clinical information and are appropriate for statistical and epidemiological reporting purposes. ICPC-2 facilitates GPs in Ireland to record critical aspects of each patient encounter, which are later available to the IPCRN for research and planning purposes.

### Principle 3. The standard must be vendor neutral and backward compatible

**3.1 Vendor neutral** — All aggregation terminologies assessed are vendor neutral. ICPC-2 is owned and governed by the World Organization of Family Doctors (WONCA), a not-for-profit organization.<sup>(52)</sup>

**3.2 Backward compatibility** — Early indications are that ICPC-3 will be a significant change on ICPC-2 and may not be completely backward compatible<sup>(1)</sup>.

### Principle 4. The standard must be financially viable

**4.1 Affordability** — Commercial or national use of ICPC-2 requires a formal licence from WONCA.<sup>(52)</sup> In the first instance, the regional members of the WONCA International aggregation terminology committee should be contacted for advice regarding licences.

**4.2 Implementation costs** — Implementation costs for terminologies and aggregation terminologies are multi-factorial. Obvious costs include the purchasing of licences, but the other costs are less obvious. These range from education and training of clinicians and clinical coders, to the costs of change to business practice and daily workflow, to the development costs associated with supporting aggregation terminologies and terminologies within ICT systems.

### Principle 5. The standard must have established governance and processes

**5.1 Intellectual property** — WONCA owns the intellectual property rights to ICPC-2. WONCA is a global not-for-profit professional organisation in official collaborative relations with the World Health Organization (WHO), representing family doctors and family medicine from all regions of the world. The mission of WONCA is to maintain and improve the quality of life of the peoples of the world through defining and promoting its values, and by fostering and maintaining high standards of care in general practice/family medicine.<sup>(53)</sup> The ICGP is a member of WONCA.

**5.2 Governance structure** — ICPC-2 is part of the WHO Family of Classifications (FIC).<sup>(69)</sup> Commercial or national use requires a formal licence from WONCA. In the first instance the

regional members of the WONCA International aggregation terminology Committee should be contacted for advice regarding licences.

**5.3 Irish influence** — The Irish College of General Practitioners is a member of the WONCA organisation, which owns the intellectual copyright for ICPC-2.

**5.3 Sustainability** — Currently stable, ICPC-2 is supported by the WHO through WONCA and ICPC-3 is in active development.<sup>(52)</sup>

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