Health Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Recommendations regarding the adoption of SNOMED Clinical Terms as the Clinical Terminology for Ireland

May 2014

Safer Better Care

About the Health Information and Quality Authority

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

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

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for those health and social care services in Ireland that by law are required to be regulated by the Authority.

- **Supporting Improvement –** Supporting health and social care services to implement standards by providing education in quality improvement tools and methodologies.

- **Social Services Inspectorate** – Registering and inspecting residential centres for dependent people and inspecting children detention schools, foster care services and child protection services.

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

- **Health Technology Assessment** – Ensuring the best outcome for people who use our health services and best use of resources by evaluating the clinical and cost effectiveness of drugs, equipment, diagnostic techniques and health promotion activities.

- **Health Information** – Advising on the efficient and secure collection and sharing of health information, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of Health Information function

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 (the Authority) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), the Authority is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

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

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

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

Through its health information function, the Authority is addressing these issues and working to ensure that high quality health and social care information is available to support the delivery, planning and monitoring of services. One of the areas currently being addressed through this work programme is the need to set standards to enable information to be shared electronically, commonly referred to as interoperability standards. A public consultation document on eHealth[1] was published by the Authority in 2011. The feedback from the consultation identified the need to provide a guidance document on terminology and classification systems, and this guidance was published by the Authority in 2013.[2] This report extends this work and will make recommendations on the adoption of Systemised Nomenclature of Medicine – Clinical Terms (SNOMED CT) as the clinical terminology for Ireland. SNOMED CT is an extensive clinical terminology – originally created by the NHS in England and College of American Pathologists – which is owned, maintained, and distributed by the International Health Terminology Standards Development Organisation (International Health Terminology Standards Development Organisation), a not-for-profit association based in Denmark.

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[1]

 eHealth is defined as – 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies…. the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication Technology'.[1]

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Executive Summary

The purpose of this report is to provide advice to the Minister for Health on adopting SNOMED CT as a national standard for Ireland, including the implications of such a decision. This includes the requirement to purchase a national license for SNOMED CT and to establish a national release centre in 2015. The cost and considerations of implementing SNOMED CT in Ireland are also included in this report. SNOMED CT is a terminology system that can be implemented in computer systems to represent clinically relevant information reliably and reproducibly.

Clinical coding is 'the translation of medical terminology as written by the clinician to describe a patient's complaint, problem, diagnosis, treatment or reason for seeking medical attention, into a coded format' which is nationally and internationally recognised.[3]

The collection and analysis of basic clinical facts multiple times is needed from different perspectives and for different purposes across the healthcare system. Currently the Irish health system principally uses a classification system called the International Classification of Diseases and related Health Problems, tenth revision Australian Modification (ICD-10-AM) to classify and report activity in respect of inpatient and day cases using the Hospital In-Patient Enquiry (HIPE) system.[4] It is important to be aware of the relationship between classifications and terminologies. Neither a classification system nor a clinical terminology such as SNOMED CT alone can serve all purposes for which health information is currently used or indeed will likely be used in the future.[5] Terminologies are used primarily to capture clinical information at the point of care, such as a patient visiting their general practitioner (GP). As such, they are usually highly detailed and fine grained. The granularity (level of detail in a set of data) that SNOMED CT provides allows for better representation of clinical events. SNOMED CT is considered complementary to other coding systems and classifications including ICD-10. [6]

Research shows that SNOMED CT is the most comprehensive clinical terminology currently available and covers many aspect of healthcare including diseases, symptoms, procedures and medical devices.[7] It was developed to improve the quality of clinical data in patient records in order to help improve the overall quality of care received by patients. SNOMED CT has the potential to deliver numerous benefits to patients and healthcare providers. Patients can benefit by receiving improved quality and safety of care. SNOMED CT allows healthcare providers to accurately code clinical records in a standard and meaningful way and at the level of

detail needed. The principal benefits of SNOMED CT for clinical administrators are the potential it offers to generate cost savings and to improve efficiency.

SNOMED CT is owned and governed by the International Health Terminology Standards Development Organisation which currently has 27 members. The purpose of a national release centre is to support the implementation of SNOMED CT within a jurisdiction. The national release centre acts as the interface between the International Health Terminology Standards Development Organisation, other national release centres and all organisations or individuals within a jurisdiction that have an interest in SNOMED CT.

SNOMED CT plays a key role in eHealth and facilitates the effective exchange of meaningful information between healthcare systems. SNOMED CT strongly aligns with various European Union (EU) and national initiatives on eHealth and healthcare policy. Over the past decade, the EU has demonstrated strong support for eHealth as outlined in various initiatives such as the eHealth Action Plan (2004),[8] Renewing Health (2008)[9] and its most recent publication, the e-Health Action Plan 2012-2020 – Innovative Healthcare for the 21st Century.[10] SNOMED CT supports the requirements put forward in Irish national health policy including the recent white paper on Universal Health Insurance (2014),[11] the policy paper on hospital financing 'Money follows the patient' (2013)[12] and the eHealth strategy for Ireland (2013).[13]

SNOMED CT is a complex terminology system to implement due to both its size and structure. Once the national release centre for Ireland has been established, SNOMED CT should be adopted gradually on a project-by-project basis.

The main costs involved in operating a national release centre include the purchase of the national licence and resourcing such a centre with personnel who can support the various stakeholders.

The current cost of a SNOMED CT annual licence for Ireland is $61,432. There is also a one-off payment required on joining the International Health Terminology Standards Development Organisation equivalent to the annual licence. The licensing model is designed to encourage the uptake of national licences. If a country acquires a national license it is not necessary for affiliates such as hospitals, vendors, academia or individuals to purchase a license in order to use SNOMED CT. If a country does not acquire a national licence, the cost of an affiliate licence from the International Health Terminology Standards Development Organisation is between $563 to $1,688 per organisation, depending on the size and nature and extent of use of SNOMED CT within the organisation. Each general practice in Ireland would be considered an organisation for licensing purposes.

In order to support the implementation of SNOMED CT a clinical terminologist would be required full time within the national release centre. Administrative support would also be required. Further costs for the national release centre would include hosting educational and training workshops and conferences and some international travel to other national release centres and to attend meetings of the International Health Terminology Standards Development Organisation.

Other costs include the implementation of SNOMED CT into clinical information and communications technology (ICT) applications. While the costs associated with incorporating SNOMED CT into existing clinical information systems would be significant, an approach which focuses primarily on phasing in the use of SNOMED CT with the introduction of new systems rather than trying to retrofit it within existing systems would be more practical and more cost-effective. In Ireland, for example, the national Clinical Care Programmes are developing their ICT and data requirements, the role of the national release centre would be to support them in defining their requirements. The subsequent costs of implementing of SNOMED CT into the resulting systems should be borne within the procurement of new systems.

The adoption of a standard terminology system is essential to the implementation of the eHealth strategy including implementation of Electronic Health records and ePrescribing and it is also essentially to the delivery of a health information infrastructure based on the principle 'create once use many times'. Long term there is agreement internationally that adoption of SNOMED CT at national level is the only viable option to realising the full benefits of eHealth. But the international review has shown that adoption is a slow and difficult process and clinician buy-in is challenging but critical – not surprisingly since the use of SNOMED CT impacts directly on the way clinicians capture data. Stakeholder engagement is seen as one of the critical and main early tasks.

Support from external organisations and in particular a national release centre in another jurisdiction will possibly be required until sufficient knowledge and experience is gained in the Irish setting, in order for the Irish national release centre to work independently.

The return on investment therefore should be considered a long-term goal. As a starting point, SNOMED CT is best suited to implementation where coded clinical information is already used in practice such as primary care or community care and/or where there is an opportunity to include SNOMED CT into the requirements for any new clinical information systems to be procured.

The Authority's recommendations for the adoption of SNOMED CT as the National Clinical Terminology are as follows:

> **SNOMED CT Recommendations**
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> **Recommendation 1:** SNOMED CT should be adopted as a national clinical terminology for Ireland immediately.
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> **Recommendation 2:** A SNOMED CT national license should be purchased and the resourcing and functioning of a national release centre for Ireland should commence in 2015.
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> **Recommendation 3:** The feasibility of entering into an agreement with a SNOMED CT national release centre in another jurisdiction should be investigated in order to provide support in the short-term (early stages of operation of SNOMED CT in Ireland).
>
> **Recommendation 4:** SNOMED CT should be introduced gradually on a project-by-project basis with the active support of the SNOMED CT National Release Centre.
>
> **Recommendation 5:** In order to future-proof information communication technology (ICT) investment, the requirement to support SNOMED CT should be included in all relevant software procurements from now on.
>
> **Recommendation 6:** A review should be undertaken to determine the most appropriate agency to establish and operate the SNOMED CT National Release Centre

1   Introduction

This report provides advice to the Minister for Health on adopting SNOMED CT as a national standard including the implications of such a decision. This includes the requirement to purchase a national license for SNOMED CT and to establish a national release centre. The cost of implementing the recommendations is also included in this report.

Clinical coding is 'the translation of medical terminology as written by the clinician to describe a patient's complaint, problem, diagnosis, treatment or reason for seeking medical attention, into a coded format' which is nationally and internationally recognised.[3] One of the principal benefits of coding is to improve the quality and safety of patient care. There is a constant drive to improve the quality and safety of medical practice and hospital services. The increasing expectations and costs of medical care and the varied and wide use of healthcare data mean the structure and content of data both in paper and electronic format is becoming ever more important.

Data and information are terms that are sometimes used interchangeably. However, data is the raw product that precedes information. Once data is collated, analysed and contextualised, it then becomes information. Good quality information is dependent on good quality data. Good quality data is data that meets the requirements of data users to support service delivery, quality improvement, performance reporting and planning. Data quality includes the accuracy of coding and data entry, the timeliness of data, the comprehensiveness of data collection and the degree to which all relevant records are captured.[14]

The principal purpose of medical record taking is to record and communicate information about patients and their care. The data collected as part of service provision is known as primary data. Primary data includes, for example, a service user's name, address, gender and occupation. This data is recorded by administration staff when a service user attends for their first appointment. Primary data also includes clinical data recorded in the healthcare record. Secondary datasets are created from primary data. For example, data is used from the primary source, usually the healthcare record, for national databases such as the National Cancer Registry Ireland[15] or Hospital In-Patient Enquiry (HIPE).[4]

The traditional single doctor-patient relationship is being replaced by an integrated care model under which the patient is cared for by a multidisciplinary team often located in different places. The ability to share clinical information between members of the team is vital to the safe delivery of integrated care. Basically information should accompany the patient along the care pathway.

Secondary use of information relates to information collected in the course of providing care which can then be used for purposes other than direct service-user care. Secondary uses of information include managing, delivering, auditing, evaluating existing or potential health services for planning purposes and research. Most national data collections are regarded as secondary rather than primary sources of information, although the data they contain is generally sourced from primary data.[16] Currently, secondary use of data often involves human translation from a medical record to secondary use datasets. Many of the causes of inaccurate clinical codling of secondary data are rooted in the quality of medical notes. The ideal situation is to record clinical data once as close to the clinical situation as possible and to reuse this data for secondary use purposes. This model has obvious potential to enhance data accuracy and generate financial savings. Information should be transformed through automatic processes where possible to support secondary use and reduce the potential for transcription errors.

In order to improve the quality of data available to the healthcare system the quality of information recorded during a patient's consultation needs to be improved. Improving the quality of data in medical records provides better quality data to support many outcomes including improving clinical care, rapid clinical responses, decision support and clinical audit. Other benefits include better support for payment on clinical outcomes, sharing records with patients, secondary use of clinical information, patient safety, interoperability and research and record retrieval.

1.1   Terminological Systems – Classifications and Terminologies

A guidance document on terminology and classification systems was published by the Authority in December 2013[2] and provided an assessment of existing terminological systems which includes both coding classifications such as the International Classification of Diseases and related Health Problems (ICD) and terminologies such as Logical Observation Identifiers Names and Codes (LOINC) and SNOMED CT. One of the key recommendations from the guidance was to assess the adoption of SNOMED CT as the national clinical terminology for Ireland.

Clinical documents, classifications and terminologies are different in origin, size and purpose[17] as illustrated in Figure 1 on the following page. Documents, clinical notes and free text entries sit at the bottom of the pyramid and are the largest in scale and size. Terminologies, such as SNOMED CT, attempt to define all concepts of medicine and sit between documents and classifications. Classifications generally consist of fewer concepts when compared to terminologies. Classifications attempt to group similar concepts to support epidemiological and management purposes. Diagnosis related groups (DRGs) sit at the top of the pyramid. The original objective

of DRGs was to develop a classification system that identified the 'products' that the patient received and were designed to be homogeneous units of hospital activity to which reimbursement could be attached.

Figure 1. Types, size and purpose of clinical coding systems
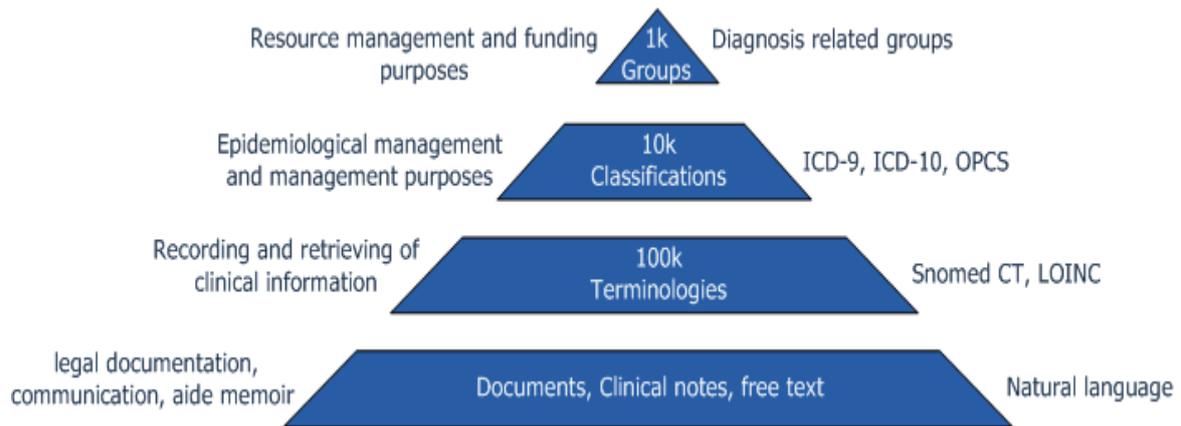
Neither a classification system nor a clinical terminology system alone can serve all purposes for which health information is currently used or indeed, will likely be used in the future.[5] Terminologies are used primarily to capture clinical information at the point of care. As such, they are usually highly detailed and fine grained. The granularity provided by SNOMED CT allows for better representation of clinical events. Classification systems are intended for use with secondary use data such as reimbursement, statistical and public health reporting, operational and strategic planning, quality of care measurements, and other administrative functions.[17] The main differences are illustrated in Figure 2 below.

Figure 2. Classifications and terminologies satisfy different business needs

| Criteria	Terminologies	Classifications
Actor	Healthcare practitioners	Healthcare records personnel
Source of Information	Whatever the provider can observe, test or obtain otherwise from the patient	The healthcare record as documented in the healthcare record during the patient encounter
Timing	Used for clinical data capture at the point-of-care	Used for clinical data capture after the patient encounter has finished
Goal	Document information about the patient and the encounter according to professional	Identify a single primary discharge diagnosis or procedure for the purposes of

Criteria	Terminologies	Classifications
	standards and to meet the information needs of the health system	morbidity and mortality statistics for reimbursement purposes
Code system	Multi-hierarchical terminology. Clinician may be as general or as specific as they want. Specificity is served by allowing multiple codes, a combination of codes and where necessary uncoded free text. NOS and NEC values are generally not included in the system. More robust data retrieval More clinically granular or detailed such as more clinical terms,	Single hierarchical, with inclusion and exclusion criteria to avoid overlap. Not Otherwise Specified (NOS) categories to code cases where the clinical record is not specific enough for the code system. Not elsewhere classified (NEC) categories to code cases where the clinical record is more specific than the code system Limitations to data retrieval Less granular, grouping of diseases (less clinical terms)
Examples	SNOMED CT, LOINC, Read Codes	ICPC-2, ICD-10, ICD-10-AM OPCS-4

1.2   Cross-mapping

Cross-mapping is the ability to link from one terminological system to another. SNOMED CT is considered complementary to other coding systems and classifications including ICD-10. Figure 3 illustrates the cross-mapping between SNOMED CT and the ICD-10-AM classification system. Several years ago work was carried out between the International Health Terminology Standards Development Organisation and the World Health Organization (WHO) to map 9,500 SNOMED CT concepts and their descendants to the appropriate ICD-10 code. The purpose of the SNOMED CT to ICD-10 mapping project was to support the epidemiological, statistical and administrative reporting needs of the International Health Terminology Standards Development Organisation member countries and the WHO. The priority list of SNOMED CT concepts to be mapped to ICD-10 codes was assembled based upon frequency of SNOMED CT concepts used in clinical data repositories in International Health Terminology Standards Development Organisation member

countries.[18] A baseline mapping between the two systems was included in the January 2013 SNOMED CT release. The expected release of the SNOMED CT to ICD-10 mapping will be in the fourth quarter of 2014.[6]

Figure 3. SNOMED CT and its dependents map to one ICD-10-AM code
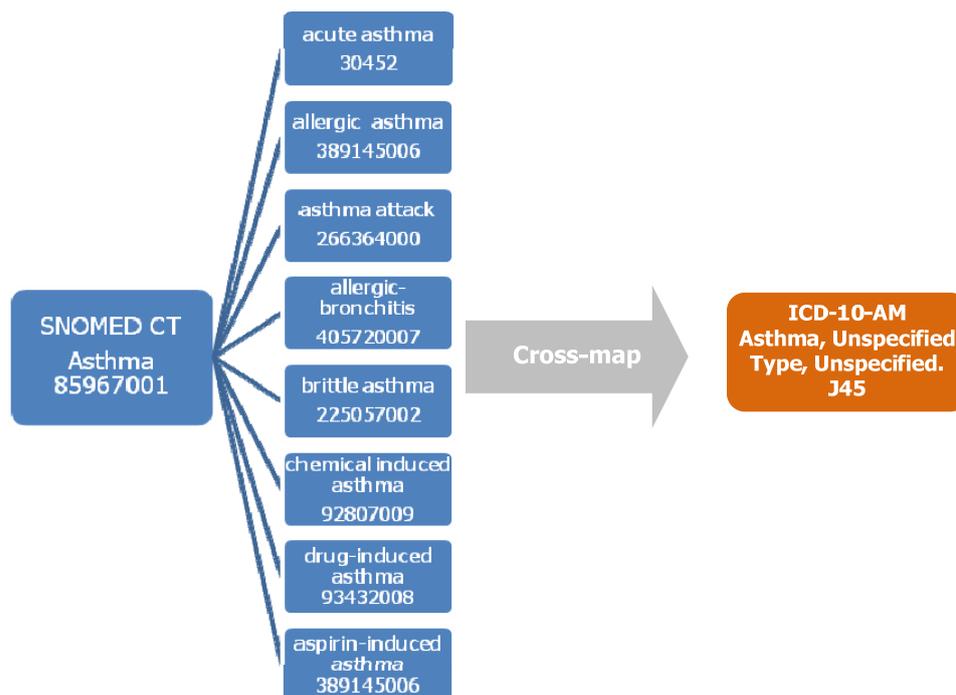
1.3   Rationale for the adoption of SNOMED CT

Over the past decade, the European Union (EU) has demonstrated strong support for eHealth as outlined in various initiatives such as the eHealth Action Plan (2004),[8] Renewing Health (2008)[19] and its most recent publication the *e-Health Action Plan 2012-2020 – Innovative Healthcare for the 21st Century*.[10] One of the prerequisites for eHealth are terminological systems including SNOMED CT as they are one of the key components needed to enable the semantic interoperability of health information.

A good example of an EU cross-border initiative is the epSOS project[20] which involves 23 countries who work together to produce patient summaries and ePrescribing solutions. ePrescribing is one of the priority areas outlined in the eHealth strategy for Ireland recently published by the Department of Health.[13] The epSOS project defines the data requirements for both discharge summaries and prescriptions when they are transferred across national boundaries. It also defines

all codes used within the framework and these codes originate from well-established code systems including SNOMED CT.

SNOMED CT aligns with national health policy including the recent white paper on Universal health insurance (UHI) (2014),[11] the policy paper on hospital financing 'Money follows the patient' (2013)[12] and the eHealth strategy for Ireland (2013),[13] which advocates semantic interoperability across healthcare systems.

Universal health insurance aims to develop a single-tier health service which promotes impartial access to high quality care on the basis of need. The delivery of UHI is dependent on a number of critical building blocks that need to be put in place to support the new system. The UHI white paper outlines the need for an information building block to help deliver the UHI system. This includes focusing on new information systems, their structures and governance requirements including standardised, high quality health information datasets, mandatory reporting requirements, central data repositories and effective interoperable IT systems. SNOMED CT can play a key role in supporting the requirements for the information and financial building blocks of the UHI. The policy paper on hospital financing 'Money follows the patient' (2013)[12] refers to a new funding model. This system aims for money to follow patients out of hospital settings and towards safe, timely care in primary and community settings.

Currently, the Irish health system demonstrates a strong capability to code and report activity in relation to inpatient and day case services using HIPE. The 'Money follows the patient policy' [12] suggests that it is appropriate that "the HIPE system would be maintained as the standard classification and coding system on which future universal prospective payment systems would be built". However, "the timeliness of coding must improve dramatically in order to support the safe and successful introduction of 'Money Follows the Patient' and the classification system will have to evolve to fully articulate policy intentions."

SNOMED CT can work together with current classification systems and can facilitate the recording and coding of high quality patient information by healthcare providers at the point of care. A key principle outlined in 'Money follows the patient' [12] is that data should be collected and exchanged once but then used for multiple purposes by different strategic stakeholders. The coding of clinical information using SNOMED CT can facilitate the exchange of high quality, consistent and meaningful information between healthcare practitioners.

There are risks associated with not adopting SNOMED CT and continuing with the status quo. Currently in Ireland data is fragmented and is located in unconnected silos. Different coding systems, often bespoke, have been developed in order to support the collection and sharing of information in a structured manner. Structured

information that is shared across health providers include laboratory results, referrals and discharge summaries. In the case of laboratory results, laboratories use different codes to identify similar tests. Practice management systems have to maintain mappings internally in order to identify similar tests from different sources. These mappings cost time and effort and can be prone to human error.

2   SNOMED CT

SNOMED CT is a 'comprehensive clinical terminology that provides clinical content and expressivity for clinical documentation and reporting. It can be used to code, retrieve, and analyse clinical data'.[7] It was developed to improve the quality of clinical data in patient records with the aim of improving the quality of care received by patients. It arose out of the merger of SNOMED Reference Terminology – a coding system used by pathologists in the United States – and the National Health Services (NHS) Clinical Terms Version 3, which was primarily used in the United Kingdom. Since 2007 the International Health Terminology Standards Development Organisation owns and is responsible for the development, quality assurance and distribution of SNOMED CT, which has been adopted by 27 countries as their national clinical terminology and is in use in many other countries in clinical information systems.[21]

SNOMED CT is the largest clinical terminology currently available and covers many aspect of healthcare including diseases, symptoms, procedures and medical devices. It attempts to be the 'periodic table' of healthcare concepts.

The core release is composed of terminology files and includes SNOMED CT concepts, descriptions and relationships.[22] It consists of more than 293,000 active concepts, 765,000 active English-language descriptions and more the 830,000 logically-defining relationships linking concepts. The International Health Terminology Standards Development Organisation issues a core release of SNOMED CT twice yearly.

2.1   Benefits of implementing SNOMED CT

A SNOMED CT enabled clinical information system allows healthcare practitioners to take advantage of advanced or robust clinical decision support as a result of having computable or codified data at a very granular level. SNOMED CT is critical to 'free the data' from the 'various silos of health information islands'. This means information can be easily shared in a timely and accurate manner between different healthcare practitioners and across organisational boundaries when appropriate.

SNOMED CT will provide numerous safety benefits for the patients including:

- reduce the number of multiple requests for the same information, by facilitating the meaningful sharing of information between healthcare providers and organisations,
- encoded clinical information in a patient's health record enables computers support clinical decision making by providing contextually relevant information at the point of care to automatically generate alarms, alerts and checks
- searching and retrieval of clinical information in a patient's record is dependent on using a terminology such as SNOMED CT. If clinical information is reliably coded then searches can also be used to determine whether a certain piece of information has not been documented in the patient's record
- patients who have a certain set of clinical features need to be identified for multiple reasons. This may include the need to identify patients eligible for a screening programme, or a clinical trial, or to detect patients who are at high risk of developing a disease, for example. influenza. To identify patients who automatically fall into a given category, the clinical information in the patient's health record must be recorded using a standard terminology
- potential reduction of adverse reactions due to treatment with pharmaceutical products, due to better quality data and reporting.

One of the main benefits of SNOMED CT for healthcare providers is its completeness. This facilitates accurate coding of clinical records in a standard way and at the required level of detail. Some of the many benefits of accurately coded clinical records include:

- key up-to-date data for each patient available at the time of care
- diagnosis and treatment based on more comprehensive and accurate patient data
- enables sharing of information between clinical information systems and allows different information systems to understand the information that is being shared
- tracking a patient's progress facilitated by integrated tools instead of following a paper trail
- efficient searching of patient records
- retrieval of relevant clinical information
- point of care decision support
- automatic identification of patient risk factors
- monitoring of response to treatment
- monitoring of adverse reactions to treatment
- long-term disease or outcome analysis
- large populations of consistent data for medical research.

The principal benefits of SNOMED CT for clinical administrators are the potential for cost savings and improved efficiency such as:

- savings can be generated due to a reduction in unnecessary duplication of laboratory tests or other investigations
- elimination of repeated data entry improves data quality and reduces transcription errors
- improved information allows resources to be managed more efficiently to deliver better quality care
- planning will be based on near real-time clinically accurate data
- standardised approach permits cost-effective sharing of information between clinical information systems
- secondary uses of the data, such as quality improvement, service planning, research, and epidemiology are supported.

SNOMED CT allows clinicians to communicate effectively across care settings and over the lifetime of a patient record. It aims to achieve better quality and safer care for patients through improved data quality. In order to achieve improved data quality it is not necessary to code every piece of a medical record, to concurrently use all medical terminologies, to document more about an encounter than what is known or to document findings with more certainly that they actually have to.[23]

2.2   SNOMED CT case study

The following case study is an example of how the implementation of SNOMED CT helped to improve data quality.

Figure 4. Case Study: the adoption of SNOMED CT to improve data quality

> **Case Study 1: SNOMED CT improves data quality**
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> The Leeds Teaching Hospitals Trust in the UK implemented SNOMED CT in their emergency department (ED) clinical information system as a way to improve data quality and to allow clinicians to record diagnoses in a clinically meaningful way. The project also aimed to support the completion of the UK Commissioning Data Set returns[2] which is a mandated code set required for EDs to report diagnoses centrally.
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> A set of SNOMED CT concepts for diagnoses in emergency medicine was identified and each concept was then mapped to the corresponding Commissioning Data Set

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[2] For more information on Commissioning Data Set returns please refer to the NHS Data Dictionary, at http://www.connectingforhealth.nhs.uk/systemsandservices/data/nhsdmds.

code. The SNOMED CT codes and descriptions were loaded into the existing clinical information system and users were able to choose from this list. Codes supported clinicians to record information in a clinically relevant way and the mappings to the Commissioning Data Set codes were used to meet the reporting requirements.

Prior to implementing the SNOMED CT subsets, the data quality of the Commissioning Data Set returns was considered to be sub-optimal with a high proportion of the mandatory field for diagnosis filled with 'other diagnosis' instead of a specific diagnosis. The existing clinical information system had a predefined list of 40 high level diagnoses codes that were created to fulfil the Commissioning Data Set requirements. However, they were deemed to be of little use clinically. An audit was carried out six months after the introduction of SNOMED CT which demonstrated a significant reduction in the lack of 'other diagnoses' cases recorded, reducing from 30% to 7%.

There were various reasons why the Leeds Teaching Hospitals decided to use SNOMED CT. Most notably it improved data quality by increasing the level of detail and accuracy of data recording by clinicians . The decision to use SNOMED CT aligned with the international direction on clinical terminologies recommending SNOMED CT as the terminology of choice. The deliverables consisted of a SNOMED CT subset of approximately 2,000 concepts and a mapping table of SNOMED CT to Commissioning Data Set return codes.[24]

In the Irish context, an example of where SNOMED CT could provide benefit is in relation to coding discharge summaries. Clinical information can be coded using SNOMED CT at the point of care by healthcare providers. This coded information can be automatically populated into a discharge summary which can then be automatically mapped to the current ICD-10-AM classification used in Ireland to report on discharge activity as collected by the HIPE system.

2.3   SNOMED CT misconceptions

SNOMED CT is not an attempt to standardise medical language and to get clinicians to use the same terms, rather it attempts to reflect the concepts of medicine accurately and to provide words and phrases which adequately reflect the meanings and use of medical concepts. It is a clinical reference terminology and not just a list of codes for symptoms or procedures.

SNOMED CT is not a clinical information system nor is it a decision support system but it can be used to integrate decision supports systems within clinical information systems. It is a dictionary of concepts with the relationships between concepts defined. It represents terminological knowledge only. For example, SNOMED CT holds within it the structure for the concepts 'Appendicitis', 'Anorexia', 'Nausea' and 'Abdominal pain'. SNOMED CT can be used within a clinical information system to record for a given patient that an episode of appendicitis was associated with anorexia, nausea or abdominal pain.

SNOMED CT is not complete. In research by Elhanan et al. (2011),[25] a survey of SNOMED CT users indicated the coverage was perceived to be at least 85% complete by 42% of responders but noticeably 60% were least satisfied with its quality. Various deficiencies were encountered at least 'somewhat often' by 28%–61% of responders. Incorrect data was identified as being more bothersome than missing data. Respondents indicated that significant resources should be allocated to ensure more consistent and complete conceptual representations and to further enhance content coverage. Enhanced synonym coverage and the introduction of textual definitions were important to respondents (54% and 63%, respectively). As a new version of SNOMED CT is released twice yearly with new additions to the terminology, there is an opportunity to remedy any deficiencies in a timely fashion.

SNOMED CT is large and its scale can be an issue when developing, using and maintaining it. If an individual spent one minute familiarising themselves with each description, and spent 40 hours per week looking at SNOMED CT, it would take over 6.5 years to examine all active descriptions. SNOMED CT has a structure which end users should not need to be familiar with as most users only need access to a limited set of all of the concepts contained within it. In order to implement SNOMED CT, datasets need to be defined for projects and SNOMED CT examined both for relevant concepts and for concepts which are missing.

3   The International Health Terminology Standards Development Organisation

The International Health Terminology Standards Development Organisation[21] is a not-for-profit organisation that develops and promotes the use of SNOMED CT. The International Health Terminology Standards Development Organisation is based in Denmark and was formed in 2007 to develop and maintain international health terminology systems, in particular SNOMED CT.

Members of the International Health Terminology Standards Development Organisation can be either an agency of a national government or other bodies (such as corporations or regional government agencies) endorsed by an

appropriate national government authority within the country it represents. Organisations that use SNOMED CT or develop software or services using SNOMED CT require an affiliate license. Affiliates can include vendors, hospital management, hospital departments (clinicians and healthcare professionals), universities, clinicians, academic researchers and government.

There were nine founder or charter members including Australia, Canada, Denmark, Lithuania, The Netherlands, New Zealand, Sweden, the United Kingdom and the United States. The International Health Terminology Standards Development Organisation now has 27 members and has issued affiliate licenses to more than 5,000 individuals and organisations. The governance structure of the International Health Terminology Standards Development Organisation includes a general assembly, a management board, standing committees, working groups including special interest groups and project groups, harmonisation bodies and member and affiliate forums.

Members are encouraged to attend general assembly meetings twice yearly where they can fully participate and vote on important issues and can also nominate candidates for appointment to the management board, committees and working groups of the organisation. There are 10 other meetings throughout the year usually conducted via teleconference or video conferencing between the member countries.

Member countries are encouraged to participate in the organisation's twice yearly working group meetings. They are also encouraged to participate in special interest groups and project groups which are focused on completing specific tasks within a defined period of time such as the mapping special interest project group. The organisation also provides forums and networks for members to share their experiences with using the terminology.

3.1   The Role of the SNOMED CT national release centre

The purpose of the national release centre is to support the implementation of SNOMED CT within a jurisdiction. The national release centre acts as the interface between the International Health Terminology Standards Development Organisation, other national release centres and all affiliates that have an interest in SNOMED CT. The International Health Terminology Standards Development Organisation states that where a national release centre exists there should be no direct contact between the International Health Terminology Standards Development Organisation and affiliates. All queries and communication in relation to SNOMED CT from affiliates must be passed through the national release centre to the International Health Terminology Standards Development Organisation and vice versa. The International Health Terminology Standards Development Organisation outlines well

defined requirements to operate a national release centre. The overall function of a national release centre is to manage the licensing, release, and distribution of SNOMED CT. The core activities that are required to fulfil this function include communication and stakeholder engagement, education and training on SNOMED CT, responsibilities around the administration of licensing and distribution of SNOMED CT content.

Significant investment is needed from an national release centre to engage with clinical stakeholders in order to promote the uptake of SNOMED CT. It is also crucial to raise political awareness by highlighting the costs, benefits and limitations of introducing SNOMED CT. Stakeholder's expectations need to be managed particularly in relation to the limitations that exist with the terminology (see section 2.3).

Different levels of education and training are required depending on the target audience, the demand and level of interest from stakeholders to receive training, the scale and number of implementations planned or ongoing. Education and training can be delivered at workshops usually covering an introductory level to SNOMED CT. In addition to workshops, the national release centre can provide ongoing initiatives to disseminate training and educational materials by developing their own training material such as online e-learning courses, webinars and presentations. More advanced end-user training about SNOMED CT may be provided by external consultants who could be contracted on a needs basis by the national release centre.

It is the responsibility of the national release centre to roll out and support SNOMED CT at national level. The International Health Terminology Standards Development Organisation is responsible for the international licensing and distribution of SNOMED CT. Once a national license is acquired, it is the responsibility of the national release centre to distribute affiliate licenses within its own jurisdiction. Members are required to survey their affiliates and submit information about licensing every six months regarding the number of affiliates operating under the national licence.

SNOMED CT is not implemented in its entirety as it is so vast. In order to manage the implementation of SNOMED CT, the development of subsets and the cross-mapping of SNOMED CT to other classifications and terminologies are needed. Subsets are a set of SNOMED CT concepts associated with a particular clinical area which guides a clinician in choosing appropriate SNOMED CT concepts for that area. (See Appendix 1 for a detailed example of subset development). Cross-mapping between SNOMED CT and other classifications and terminologies is important to facilitate the integration of subsets with existing coding systems.

Although the International Health Terminology Standards Development Organisation contend that SNOMED CT is a global terminology covering all healthcare domains, it recognises that it is not always possible to gain agreement on all requirements from the different member countries. Hence, there is often a need to adapt the terminology to meet specific local requirements. This is achieved by allowing each member country to develop and maintain a national extension. To create a national extension, the national release centre accepts requests for new concepts from affiliates within its jurisdiction and these local concepts need to synchronise with the international release distributed by the International Health Terminology Standards Development Organisation.

The International Health Terminology Standards Development Organisation provides a software tooling workbench which makes it easier for national release centres to manage activities such as the development of subsets and cross-maps and provides functionality to search and navigate the SNOMED CT content. The organisation also provides educational sessions on the workbench if required. It is not necessary to invest in building sophisticated software tools to manage releases or for developing subsets as in-house tooling can be expensive and take a long time to develop. Instead, a simple tool that can be used is an Excel spreadsheets for the distribution and release of SNOMED CT. Starting with a simple tool gives the national release centre the opportunity to refine processes before investing in more expensive tooling.

The number of personnel and the type of skills needed to operate a national release centre are dictated by the SNOMED CT projects undertaken. A clinical terminologist and an administrator are the minimum resources required to establish and operate a national release centre. A clinical terminologist would need a clinical background with experience in clinical terminologies. Depending on the projects undertaken, other expertise is required. For example, an ePrescribing project that requires coding would need domain experts in pharmacy to be involved. Larger and more complicated projects need more specialist resources.

3.2   SNOMED CT international review

The Authority undertook an international review of seven countries to understand the requirements for the establishment and operation of a national release centre. The countries included in the review are Denmark, Estonia, Singapore, United Kingdom, New Zealand, Malta and Poland. All countries reviewed are currently members of the International Health Terminology Standards Development Organisation. There were various reasons why each country was included in the review. Denmark, Singapore, New Zealand and the UK have made significant

investments in eHealth particularly in the context of a national electronic health record (EHR) that uses SNOMED CT. The United Kingdom Terminology Centre (UKTC) is the national release centre exemplar and is a pioneer in the software tooling and release processes for SNOMED CT. New Zealand is a founding member of the organisation and has a similar healthcare system to Ireland. Estonia became a member of the organisation in 2010. The decision to purchase a national license was because SNOMED CT was already in use in laboratory information systems and it made financial sense to purchase a national license rather than individual organisations paying separately for affiliate licenses. Malta joined the International Health Terminology Standards Development Organisation in 2012 and is of a similar demographic to Ireland. Malta's membership of the organisation was driven by its government's participation in the epSOS project[26] and the planned implementation of EHR systems that would include the use of SNOMED CT. Poland joined the International Health Terminology Standards Development Organisation in 2011 and has concentrated its efforts on translation. Work is underway there to set up administration of licensing for affiliates who want to use SNOMED CT.

Several reasons why each country purchased a national license include:

- the maturity and investment in eHealth initiatives
- the readiness to adopt a clinical terminology nationally
- existing experience with supporting other classifications and coding systems
- a legitimate business case for implementing a clinical terminology
- the funding and resources that were available to them.

The key lessons learned from the international review included:

- significant time is required to get clinical buy-in and to build relationships with clinical stakeholders
- the national release centre needs to promote political awareness and drive through the benefits of SNOMED CT
- it is important to start the implementation of SNOMED CT with a well defined use-case
- cross-mapping between proprietary terminological systems such as ICD and SNOMED CT is a significant work effort. Investment in expensive software tooling is not required when initially establishing a national release centre and effort would be better invested in setting up administrative processes instead
- SNOMED CT is complicated to use but is promising. SNOMED CT does not cover all concepts for all healthcare domains but is constantly revised and updated. It is important to manage user expectations and to be realistic about the potential use of SNOMED CT

- more established centres such as the UKTC are working towards national interoperability projects involving the use of SNOMED CT in electronic national patient summaries and referrals
- it could be advantageous for Ireland to align with another established national release centres and gain from their experiences, processes and tooling.

3.3   SNOMED CT in the Irish context

The core functions needed to operate a national release centre are outlined in section 3.1. In Ireland, a phased approach for the establishment and operation of a national release centre is needed over a short-, medium- to long-term period. The functions and time frames to establish and operate the national release centre are based on international experiences from other countries. The functions of a national release centre in the Irish context and a time frame for its implementation are illustrated in Figure 5 below. The aim of implementing SNOMED CT is to build enough capacity and expertise in Ireland to eventually support multiple health IT projects of varying complexity.

Figure 5: Functions and time frame for the establishment of a SNOMED CT national release centre

Implementation of a National Release Centre
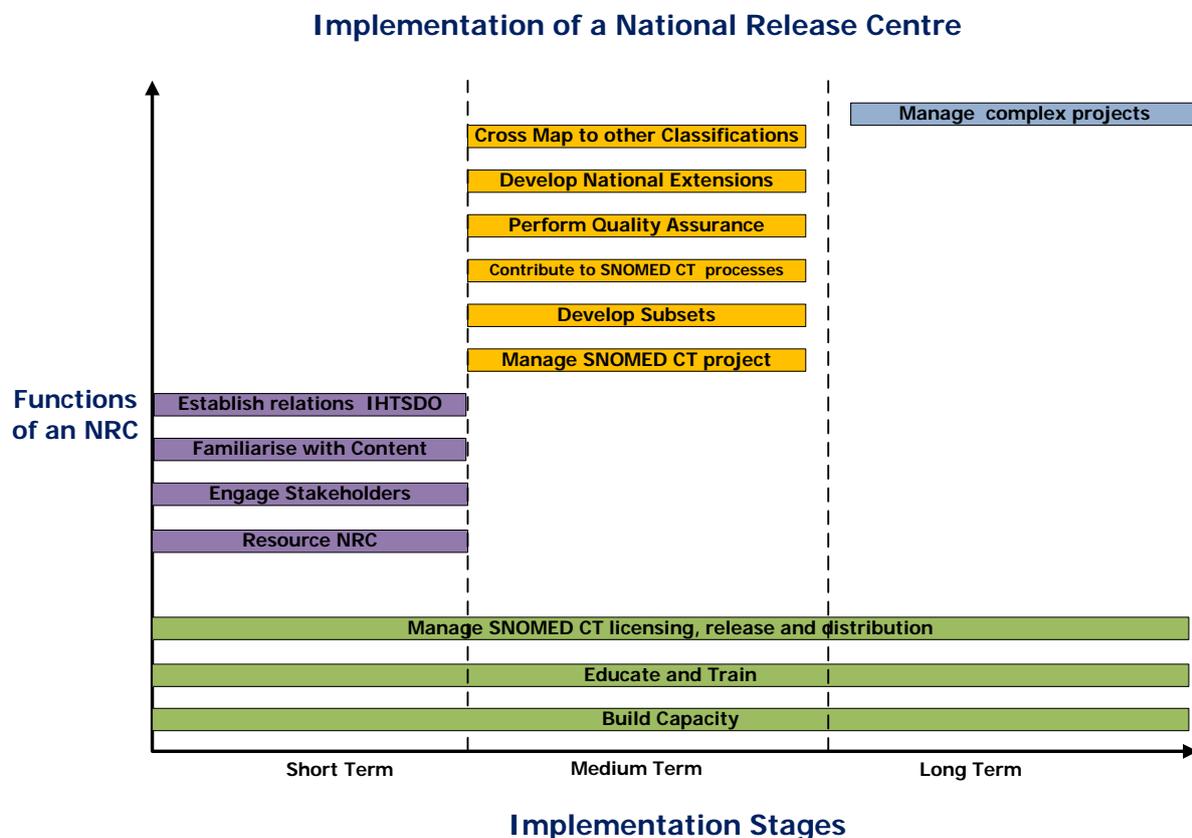
In the short term, the first step should be to employ a clinical terminologist to manage the national release centre and an administrator to provide support. The initial tasks that the clinical terminologist would complete is to familiarise themselves with SNOMED CT content, release management and distribution, subset development, tooling and cross-mapping functions. The clinical terminologist must also actively engage with key stakeholders such as government, relevant healthcare agencies and the healthcare community particularly clinicians in order to gain buy-in to promote the benefits and use of the terminology.

It is important to establish a relationship with the International Health Terminology Standards Development Organisation and other national release centres by attending forums and working group meetings where relevant. Tasks that should be initiated in the short term but are also considered ongoing functions include education and training, managing and distributing the release of SNOMED CT and the administration of licensing.

Once the foundations are in place and short-term goals are met, a SNOMED CT project should be initiated to gain experience in using SNOMED CT at a practical level. The activities undertaken in the medium term will be centred on the implementation of SNOMED CT and will present a significant learning curve but will strengthen knowledge and proficiency in the terminology. An example of a how a generic process could be used to implement SNOMED CT is illustrated in Appendix 1 and is useful to help understand the effort involved. As mentioned, SNOMED CT is not implemented in its entirety as it is so vast and is implemented using subsets.

Other activities that should be undertaken in the medium term would include further investment and improvements in the release process, software tooling, national extensions and cross-mapping functions. As the national release centre gains experience, processes and projects may become more sophisticated and the number of projects may increase. It will become necessary to advance how SNOMED CT core is released and maintained. Developing in-house tools to support SNOMED CT can be expensive and can take a lengthy time to develop.

The long-term vision for SNOMED CT in Ireland is to build enough capacity in terms of human resources, expertise, software tooling and education and development. This will facilitate the implementation of SNOMED CT projects whether they are small or large-scale, simple or complex. A long-term goal will be to maintain and support existing SNOMED CT projects that will be developed. Also it will be important to actively participant with the International Health Terminology Standards Development Organisation and feed into its decision making regarding SNOMED CT.

3.4   Considerations for SNOMED CT implementation in Ireland

SNOMED CT is a complex terminology system to implement due to both its size and structure and needs to be deployed over a long-term phased basis. The early stages of operating a national release centre are easily managed if appropriate resources are provided. These activities include establishing a relationship with the International Health Terminology Standards Development Organisation and other national affiliates, administration of licensing, education and training, managing distribution of the core release, engaging stakeholders and familiarising with content. It is possible that a clinical terminologist could undertake these roles with the support of an administrator. Managing expectations and prioritising projects would require a formal governance structure to be put in place.

In the intermediate term, activities would include supporting stakeholders in implementing SNOMED CT in their projects. In Ireland, the national Clinical Care Programmes are each developing their ICT and data requirements. Independent of these, major IT projects are also underway including the National Laboratory Project known as MedLis and the Health Service Executive's (HSE's) Integrated Services Framework. As shown from the case study in Figure 4, SNOMED CT could improve the data quality of information collected when the Clinical Care Programmes implement their systems. In order to support these stakeholders and their requirements, appropriate personnel are required who have both clinical and data modelling skills. SNOMED CT and the mapping of data requirements is a time-consuming process.

Striking a balance between resources required and the level of expectation of the national release centre to meet all the potential demands from major stakeholders need to be managed. The investment in SNOMED CT is a long-term investment. Support from external organisations and in particular a national release centre in another jurisdiction will probably be required until sufficient knowledge and experience is gained so that the national release centre can work independently.

3.5   Costing

The current cost of a SNOMED CT licence for Ireland is $61,432. There is also a one-off payment required on joining the International Health Terminology Standards Development Organisation equivalent to the annual licence. If a country does not acquire a national licence, the cost of an affiliate licence from the organisation is between $563 to $1688 per organisation, depending on the size and nature and extent of use of SNOMED CT within that organisation. Each general practice in Ireland would be considered an organisation for licensing purposes. This licensing model is designed to encourage the uptake of national licences.

The administration of licensing is straightforward and the most substantial cost of establishing a national release centre is the human resources required. For example, it would be necessary to employ a whole-time equivalent clinical terminologist to manage a national release centre to carry out its initial functions such as education and training, development of SNOMED CT clinical content, administration of licensing and to manage exemplar projects.

A clinical terminologist would need to have a clinical background, experience with clinical terminologies and project management skills. It would also be necessary to employ administrative support for the establishment and operation of the national release centre. Additional clinical terminologists and administrative personnel will be required when the national release centre is operating at a greater capacity and when more projects need to be managed.

Other cost associated with implementing SNOMED CT include the costs of delivering training and educational workshops and conferences should also be included. There will also be the costs of attending meeting held twice yearly of the International Health Terminology Standards Development Organisation

Further costs include the costs associated with implementing SNOMED CT in clinical information systems which have varying support from vendors. This should be financed in the context of ICT projects and not specifically by the national release centre.

A key role of the national release centre is to distribute affiliate licenses within its jurisdiction. Most member countries have chosen not to charge affiliate members within their jurisdiction. There is a provision in the articles of association[27] that affiliate members may be charged for their use of SNOMED CT but the national release centre may only do so on a cost recovery basis and that a profit may not be made from SNOMED CT on licensing within the territory. If an affiliate within a country engages in activities using SNOMED CT in non-member countries, they need to pay an additional fee through the International Health Terminology Standards Development Organisation.

The return on any investment in SNOMED CT will need to be measured in the longer term as opposed to the shorter term. The licensing model for SNOMED CT is designed so that it is more cost-effective to purchase a national license. The real benefit of SNOMED CT is in terms of data quality and its ability to enable two or more systems to communicate with each other in a meaningful way i.e. semantic interoperability. These benefits are harder to quantify. SNOMED CT is an investment in the future rather than a project which will save money and show cost savings in the short term.

4   Conclusion and recommendations

The purpose of this report is to make recommendations on whether now is an appropriate time to purchase a national SNOMED CT licence and as a consequence establish a national release centre. SNOMED CT is a clinical terminology developed to improve the quality of clinical data in patient records with the aim of improving the quality of care received by patients.

SNOMED CT is the largest clinical terminology currently available and covers many aspect of healthcare including diseases, symptoms, procedures and medical devices. It attempts to be the 'periodic table' of healthcare concepts. SNOMED CT can improve the quality of data recorded during a clinical encounter. Improving the quality of data leads to benefits for patients, clinicians and hospital and healthcare administrators as discussed in section 2.1 above. The use of a standardised terminology such as SNOMED CT is critical to facilitating the meaningful sharing of information between healthcare practitioners and providers. SNOMED CT is not an attempt to standardise medical language, it is a dictionary of medical concepts. Though vast it is not complete and continues to be expanded.

Owned and governed by the International Health Terminology Standards Development Organisation, it has been adopted in 27 countries internationally. Informed by an international review of seven of these countries it is clear adopting SNOMED CT as a national terminology is considered the long term approach but it presents challenges at a local level. A phased approach needs to be taken when implementing SNOMED CT.

The main expenses of establishing a national release centre to support the roll out SNOMED CT in Ireland include the purchase of the national licence, the costs of resourcing a national release centre with personnel who can support the stakeholders and the cost associated with operating education and training for stakeholders.

Other costs include the implementation of SNOMED CT into clinical applications but these costs should be excluded from the cost of the national release centre and included in the cost of implementing new systems. The focus should be on phasing in the use of SNOMED CT by supporting key stakeholders such as the clinical care programmes to define their information requirements so that these can be included in the procurements of new national systems. Focusing on implementing SNOMED CT in new systems rather than trying to retrofit SNOMED CT within existing systems would be more a practical and more cost-effective approach.

There is a significant need to improve the information we have on our health services and SNOMED CT can support the implementation of EU and Irish reports, including the EU's Health Action Plan 2012-2020 – Innovative Healthcare for the 21st Century. [10] SNOMED CT also supports the requirements put forward in Irish national health policy including the recent white paper on Universal Health Insurance (2014), [11] the policy paper on hospital financing 'Money follows the patient' (2013)[12] and the eHealth strategy for Ireland (2013). [13]

The return on investment should be seen as a long-term goal. It is important to start to build capacity and expertise so that over the long term the benefit from investing in SNOMED CT can be realised.

The Authority's recommendations on SNOMED CT are below.

> ## SNOMED CT Recommendations
>
> **Recommendation 1:** SNOMED CT should be adopted as a national clinical terminology for Ireland immediately.
>
> **Recommendation 2:** A SNOMED CT National license should be purchased and the resourcing and functioning of a national release centre for Ireland should commence in 2015.
>
> **Recommendation 3:** The feasibility of entering into an agreement with a SNOMED CT national release centre in another jurisdiction should be investigated in order to provide support in the short-term (early stages of operation of SNOMED CT in Ireland).
>
> **Recommendation 4:** SNOMED CT should be introduced gradually on a project-by-project basis with the active support of the SNOMED CT National Release Centre.
>
> **Recommendation 5:** In order to future proof information communication technology (ICT) investment, the requirement to support SNOMED CT should be included in all relevant software procurements from now on.
>
> **Recommendation 6:** A review should be undertaken to determine the most appropriate agency to establish and operate the SNOMED CT National Release Centre

Appendices

Appendix 1 – Subset development

Figure 6. Generic process for the development of subsets

Process to develop subsets for a SNOMED CT Project
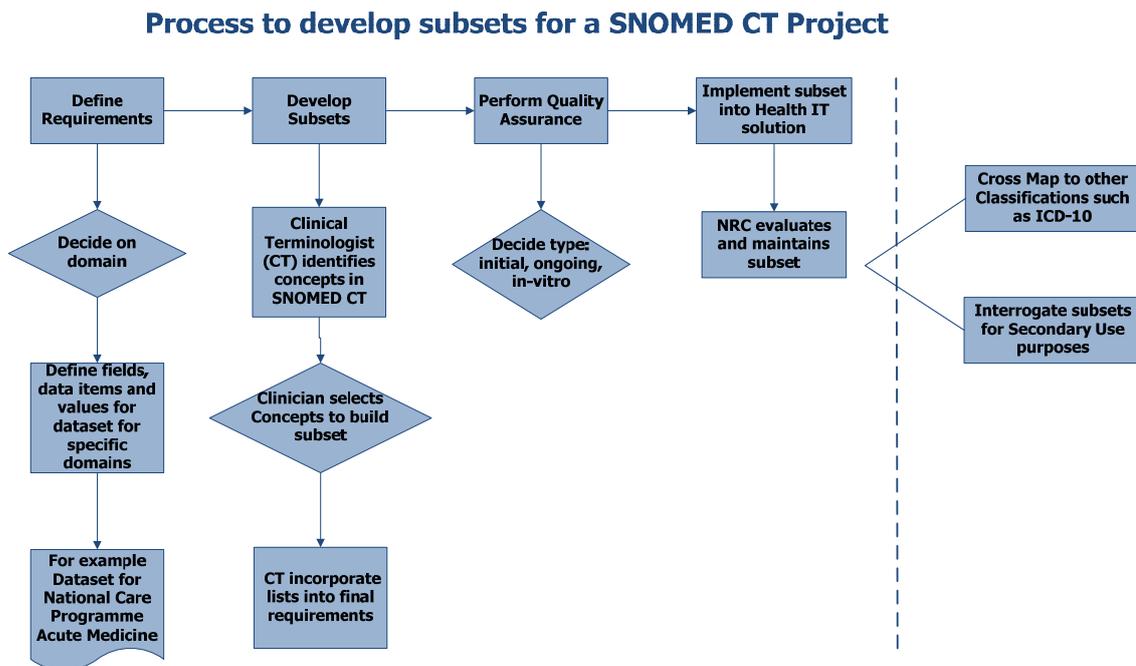
There are four key steps necessary to implement SNOMED CT subsets into a clinical information system. These are specifying dataset requirements, developing subsets, performing quality assurance and finally implementing subsets in the clinical information system. Each of the steps in this process is described below:

- Define Requirements: the first step in implementing a SNOMED CT project is to define the business case and data requirements for it. The clinical terminologist must work with domain experts throughout the entire process. Initially they will work together to develop a dataset and ensure the appropriate data fields, items and values are well defined and validated.

- Develop Subsets: Subsets can be large or small and the work effort required to develop and implement subsets into a clinical information system is dependent on scale of the subset. An example of a simple subset is for source of referral which may contain as few as 10 concepts. A more complex subset would by a complete diagnosis subset which could have thousands of concepts. The advantages of starting off developing simple subset is that it is easier identify all the relevant concepts in SNOMED CT and to subsequently

map these to proprietary terms currently in use. The clinical terminologist and domain experts will work closely together during this stage to identify the concepts in SNOMED CT and the domain expert decides what concepts constitute the appropriate subsets. The final list can then be incorporated into the requirements specification, tender document or implementation specifications. It is possible to acquire a subset from another international national release centre and modify it for local use. This may be appropriate for the initial stages of running a national release centre while capacity and expertise is built in this area.

- Quality Assure Subsets: Prior to a release, the SNOMED CT content undergoes a quality assurance process. This may be achieved external to the national release centre at another international centre or internally until enough expertise and experience has been developed.

- Implement subsets into clinical information systems: There should be a clear distinction between the role of the implementer and the national release centre. Typically, the national release centre acts as a facilitator of SNOMED CT initiatives and works with the vendors and implementers to get the projects off the ground, provide a high level of education and gives direction to projects. Also, consideration needs to be given to vendors and their role in the implementation of SNOMED CT. Vendors use the subset specifications to integrate the SNOMED CT subset into the clinical information system via checkboxes, radio buttons and pick lists. The subset lists are seamlessly integrated into clinical information systems. Subsets mean that clinicians do not need access to the whole of the SNOMED CT core nor do they need to know the codes in SNOMED CT, they simply interact with the user interface and the coding of the information is transparent and behind the scenes.

Appendix 2 – SNOMED CT international review

The overall aim for conducting an international review is to understand the activities and requirements to operate a national release centre. The countries included in the IR are Denmark, Estonia, Singapore, United Kingdom (including England and Scotland), New Zealand, Malta and Poland. Consultation with the International Health Terminology Standards Development Organisation, the organisation that develops and promotes the use of SNOMED CT internationally, was carried out to research the requirements needed for an agency to undertake the role of the SNOMED CT national release centre.

Methodology

All countries reviewed are currently members of the International Health Terminology Standards Development Organisation. Each country was chosen for particular reasons summarised as follows:

- Denmark have invested heavily in eHealth initiatives, are a founding member of IHTSO and are a similar geographical size to Ireland
- Singapore have in recent years invested heavily in eHealth initiatives,   in particular they are working towards a national EHR and
  have chosen to adopt SNOMED CT as their national clinical terminology
- United Kingdom Terminology Centre (UKTC) based in England is the exemplar of a national release centre, is a founding member of the International Health Terminology Standards Development Organisation and are pioneers in the tooling and processes for a SNOMED CT national release centre.
- Scotland are a similar geographical size to Ireland and have a similar approach to Ireland, taking an incremental step-by-step approach to procurement and implementation of eHealth initiatives
- Estonia can add some valuable lessons for Ireland as they are in the early stages of establishing and running a national release centre
- New Zealand are a founding member of the International Health Terminology Standards Development Organisation and have a similar healthcare system as Ireland
- Poland (2011) and Malta (2012) recently joined the International Health Terminology Standards Development Organisation Malta is of a similar demographic to Ireland.

The key topics that were discussed during consultation included an overview of their healthcare system, the background to the establishment of the national release centre, current business activities, operational activities such as licensing,

translation, release management, training and education, formal governance and key lessons learned.

Each topic was divided into a set of questions (See Appendix 3) and discussed via teleconference with an appropriate representative. Key notes were taken during the teleconference and written up accordingly. Additional information was elicited from literature provided by the International Health Terminology Standards Development Organisation website, follow up meetings or taken from online resources. The notes for each country were examined and grouped according to background, terminological systems and operational activities.

Summary of findings

The approach and reasons to introduce SNOMED CT varied among the countries. The context for purchasing a national license depended on the following factors:

- maturity and investment in eHealth initiatives
- readiness to adopt a clinical terminology nationally
- experience with supporting other classifications and coding systems
- requirements and a legitimate business case for implementing a clinical terminology
- funding and resources available.

In the case of Denmark, Singapore, New Zealand and the UK, significant investments have been made in eHealth particularly in the context of a national EHR. Estonia became a member of the International Health Terminology Standards Development Organisation in 2010. The decision to purchase a national license was based on the fact that SNOMED CT is in use, particularly in laboratory information systems, and it made financial sense to purchase a national license rather than individual organisations paying separately for affiliate licenses.

The responses from each country are detailed below:

1   Denmark

Standards are in widespread use in Denmark, mainly for message based communication. Responsibility for the development and deployment of these standards lies with the Danish healthcare organisation, MedCom, which sets standards for IT systems and coordinates various organisations including healthcare providers, laboratories, vendors and other relevant bodies in order to develop standards for interoperability.

The National Board of Health (NBH) is Denmark's representative to the International Health Terminology Standards Development Organisation. Denmark was a founding member of the International Health Terminology Standards Development Organisation, with the national release centre formally set up in 2008. The release centre is located in the Health Documentation Division of the NBH and is responsible for the distribution and management of SNOMED CT. Currently, the NBH, Digital Health and other third parties are working on a strategy for implementing SNOMED CT for widespread use with particular attention focused on usability, reliability and implementation.

There is currently no mandate to enforce the use of SNOMED CT. The main driver behind the adoption of SNOMED CT was to adopt a common terminology to cover all domains and use cases. This is because a classification system like ICD-10 were not considered granular enough to support the recording on clinical data and may not cover all local requirements e.g. it is necessary to create several local codes to be able to code into more detail. A formal assessment was conducted to evaluate the introduction of SNOMED CT but is written in Danish and is not translated to English.

Various clinical terminology systems are used in different areas of the Danish healthcare sector.

- World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF)
- ICD -10 is used in secondary care for payment returns to inform healthcare statistics
- ICPC is used throughout all GP facilitates
- Denmark has an informal agreement with other Nordic countries i.e.
- Norway and Sweden to maintain the NPU terminology which covers clinical laboratory sciences (used instead of LOINC) relevant standards for laboratory data and imaging (X-rays, etc.), for example the DICOM standard

A number of pilot projects have been implemented using SNOMED CT, however, currently there is no funding from the Ministry of Interior and Health for implementation projects. In this regard, political awareness and driving through the cost benefits of SNOMED CT are deemed essential.

There has been extensive investment in translation activities and significant contribution to the development of the "translation guidance documentation" as published on the International Health Terminology Standards Development Organisation website. Translation has been completed for approximately 300,000 concepts from the core (English US) into Danish and has taken up most of the effort and resources to date. The initiative to conduct the translation project was

undertaken by the national release centre without a formal request from vendors or end users.

The national release centre manages the licensing of SNOMED CT for 35 affiliates including consultants, universities, vendors and hospitals (pathology departments). The administration and management of licensing is not considered a significant effort for the national release centre. The licensing process involves dealing with requests from customers which are managed using a username and password. Activities and use of SNOMED CT is gathered from affiliates using a questionnaire.

Denmark maintains it own national extension of SNOMED CT and considerable work effort is required for the development and management of tooling and release management. Up to 800 or 1200 new concepts per release may be requested by affiliates and an in-house solution has been developed to manage releases which are accessible online to customers. The tooling is used in the creation of subsets and refsets, can facilitate mapping between different terminology systems. Releases are packaged and transmitted via ftp to the customer.

Training and education are key components to the successful adoption of SNOMED CT. A series of workshops were held over three years for different disciplines including; vendors, healthcare I.T. professionals, healthcare professionals, clinicians, administrators and universities, principally aimed to provide information about the basics of SNOMED CT, terminology, information modeling issues and clinical guidelines. They continue to organise workshops bi-annually for affiliates. The Danish national release centre hosted a conference (in collaboration with Sweden) on SNOMED CT aimed at a nursing audience. It was appropriate to employ a consultant for training purposes when required rather than employ a WTE. Also the five regions in Denmark are responsible for the training of SNOMED CT, making it possible to contract training activities to vendors.

The resource requirements to run the Danish national release centre for SNOMED CT are limited to 1.5 WTE. The skills they identified included a clinical terminologist who understands the release process and to contract out specific work to a consultant when necessary. A project manager with significant political awareness who can persuade government of the requirement and benefits of SNOMED CT is essential. A project manager for the implementation of pilots is valuable. I.T. support is required but only intermittingly. A high-level summary of the resource and costs involved include: licensing, translation efforts, support and maintenance of a tooling workbench, human resource to include two project managers, a clinical terminology specialist and an administrator. The main cost is in terms of human resources.

There is some cost associated with International Health Terminology Standards Development Organisation membership including attendance at an annual meeting

in Denmark, one other annual meeting abroad, ten monthly teleconferences or videoconference which requires approximately five-six hours per month. The cost accrued may also depend on the number of Special Interest Groups (SIG) that the national release centre participates in.

Some key experiences outlined by the Danish national release centre are to explain the benefits and barriers to SNOMED CT adoption to decision makers. This can be achieved by using good use case examples e.g. emphasise quality improvements. Also, there is a need to be aware of the benefits of adopting international terminology systems rather than developing national terminology systems.

2   Singapore

The Ministry of Health Holdings (MOHH) is closely aligned with Singapore's Ministry of Health to strategically drive initiatives for the public healthcare sector, including a national I.T. strategy for public hospitals. The overarching initiative is the design, development and deployment of a national EHR to facilitate the sharing of health information between authorised healthcare providers. The push for an EHR is partly driven by a sizeable research community and the need for secondary use and trend/statistical data. To achieve this, there is a need for common data structures and content between facilities to ensure data is exchanged and interpreted in a meaningful way. This is the main driver behind the adoption of SNOMED CT as the national clinical terminology. Singapore has been focusing on establishing a national standards programme and since joining the International Health Terminology Standards Development Organisation in 2008, the main focus has been on establishing the national release centre (national release centre). There was no formal assessment carried out for the adoption of SNOMED CT. There is a health information technical committee which oversee the development and implementation of all standards in Singapore.

SNOMED CT is not mandated for use in Singapore. However, there are some pockets of SNOMED CT implementations throughout the healthcare sector with half of the island committed to using the terminology for acute care services. Primary care services are usually provided to the local community via polyclinics to manage chronic disease and specialist services using out-patients clinics. In most cases, GPs are not computerised and predominantly serve the expatriate community.

Currently the main SNOMED CT developments are on the semantic interoperability of diagnosis and medication data across the different healthcare sectors, using the SNOMED CT international. A diagnosis subset for discharge summaries is maintained and attempts to implement this in electronic discharge summaries is in progress. A

significant amount of resources have been allocated to the development of a national drug dictionary based on SNOMED CT.

There is a high prevalence for electronic prescribing in Singapore. Learning from the Australian medication terminology model will inform the development of the drug dictionary but the front end model (prescriptions, dispensing and supply) will not be as complex as the English DM+D and Australian and New Zealand models. There is a project for laboratory orders and results utilised both LOINC and SNOMED CT in combination. SNOMED CT is used to get a higher level of abstraction for laboratory orders.

Other coding systems in use include ICD-9, used for the classification and diagnosis of disease and a migration project is underway to move from ICD-9 to ICD-10 AM to be completed by January 2012.

Translation projects are not conducted in Singapore. Licensing is considered a straightforward task with no major issues highlighted. There is a part-time resource (.5 WTE) working on the administration of licensing.

Singapore does not maintain its own national extension of SNOMED CT. The release process is also managed in an uncomplicated way. Vendors receive releases of the diagnosis subset in an excel spreadsheet which contains the SNOMED CT concept id and associated descriptions of concepts in the subset. Email request may be received from affiliates for inclusion of new concepts into the spreadsheet which may be added to the subset but they do not maintain a regular release cycle. The national release centre is investing in tooling and expect roll out in approximately 18 months but advises that building bespoke tools are expensive.

Education and training on SNOMED CT has been limited. It has been difficult to get personnel with appropriate skills to carry out training. An observation from end-user training concluded the user is generally not concerned with the clinical terminology they use but more so with the ease at which they can code at the front end e.g. how to select a description. The national release centre has been involved in educational sessions at standards conferences but usually for overall standards development and not just SNOMED CT.

Their involvement with International Health Terminology Standards Development Organisation at SIGs and working groups are dependent on the work they are concentrating on at a particular time e.g. currently the SNOMED implementation SIG, some pharmacy working groups and the information model taskforce. They are not on the International Health Terminology Standards Development Organisation management board and attend on average two meetings per month.

The resources for the current activities total 20 staff but that covers the development and maintenance of all standards including SNOMED CT. It also includes projects such as the drug dictionary and tasks such as messaging, coding, mapping, tooling and programme management. It is estimated that 4-6 resources are responsible for the development and support of tooling (customers use CliniClue® and Microsoft Excel). There are 3 pharmacists required for the drug dictionary project supported by an expert user in tooling and mapping.

A number of recommendations were stated for the establishment of a national release centre based on the lessons learned to date in Singapore. They include the following:

- recommendation to align with another national release centre
- keep it simple. For example, diagnosis has 8000 concepts. Start with a specific use case. This is also important as it makes it easier to map between terminology systems
- do not invest in expensive tooling (use excel), you can then refine your process, make your mistakes with an inexpensive tool
- significant time is spent with selling SNOMED CT to clinicians e.g. getting clinical buy-in
- workbench – estimate 2-3 years before ready for uptake

3   United Kingdom (including Scotland)

The UK Terminology Centre (UKTC) is the main agency with responsibility for clinical coding and classifications activity across the United Kingdom. The national release centre was formally set up between 2007 and 2008, just after the establishment of International Health Terminology Standards Development Organisation. However, the terminology centre dates back to the 1990's. A governance board has been established between the UKTC and members of the "Home Countries" (England, Scotland, Wales, and Northern Ireland). The UKTC have hosted workshops for International Health Terminology Standards Development Organisation members on the experiences and practicalities of managing a national release centre. The UKTC is located in Leeds, England.

Read v2 is used by nearly a 100% of general practitioners motivated by the quality and outcomes framework (QOF), a reimbursement scheme operating in England. Read v2 is a mature coding system but is not rich enough to be effective for coding other clinical areas outside primary care. Read v2 is also used in primary care in Scotland and Wales. In addition, nearly 100% of all GPs are engaged in ePrescribing. However, coding in secondary care is significantly more difficult to implement.

The overall NHS National Programme for IT (NPfIT) investment was the main driving force behind the adoption of SNOMED CT. The programme includes projects like a patient's summary care record, ePrescribing, payment by results and secondary use services which all require a common terminology. SNOMED CT has the capacity to cover all clinical care concepts. A simple business case for the adoption of SNOMED CT is the requirement for a common terminology across all domains.

The UKTC manages the licensing of SNOMED CT for 1400 affiliates across a range of disciplines including health providers (clinical and hospitals), industry and research. The management of licensing is considered a straightforward task and is completed for all terminology systems at the UKTC. To date, 5500 endpoint registrations with 1400 SNOMED registrations have been processed. The UKTC employ an in-house, online tool for the administration and distribution of licensing.

THE UKTC maintains a national extension of SNOMED CT and maintains the Read Code in sync with its national release of SNOMED CT. The read codes are linked or mapped to SNOMED CT concepts using cross-maps. For the SNOMED CT release process, following a 3-4 months period of requests for new concepts an authoring process is undertaken involving clinical terminologists and new concepts are added to the national extension. Following this a batch request is forwarded to the International Health Terminology Standards Development Organisation to add these new concepts to the international core release. Once they are added to the core release, the local code needs to be retired following an updated international core release. This is quite a costly exercise and potentially reconciliation would be easier if International Health Terminology Standards Development Organisation issued codes that the UK could use alongside a UK namespace. This would allow UKTC to author directly into an international release. There is a possibility for this new process to be implemented in the future. This change to the reconciliation process will directly help smaller NCRs with its releases and synchronisation process.

Substantial resources are required to operate the UKTC. The clinical terminologists division requires 8 WTE clinical terminologists and employs 2 or 3 additional consultants when required. This division needs people who have a clinical background in nursing, medics and other healthcare professionals. The pharmacy division employs 7 WTE with a pharmacy background. There are 16 WTE clinical coders who support all clinical coding including OPCS, ICD-10 etc. This division provides guidance, infrastructure, authoring and support cross mapping and electronic distribution for ICD-10. A helpdesk is available to provide guidance, development and support for classifications and they manage approximately 5000 helpdesk queries annually.

There are numerous pilot projects of SNOMED CT implementations and examples of SNOMED CT used by UKTC affiliates. The main lessons learned from the UKTC

experience to date include: there was 'lock in' with multinational suppliers tasked to implement NPfIT which brought about problems. Other smaller and local suppliers now have the opportunity to get involved with national health IT projects. The mapping between proprietary terminologies is a significant work effort.

Training and education on different terminology systems are conducted by the UKTC. Training is given (or funding is given) to trusts for ICD-10 and OPCS training. However, there is no real training need for Read in the GP community. There are two WTE resources working on SNOMED CT training and education. One qualified SNOMED CT trainer with technical expertise in SNOMED CT and a background in I.T. training and the second person has previous experience as a university lecturer in I.T. and as an I.T. trainer. It is very advantageous to have a qualified clinical terminologist liaise with the I.T. trainer (SNOMED CT) for questions and up skilling when needed. Private companies and consultants are also employed to provide end-user training in SNOMED CT. There is an initiative to pilot elearning training on SNOMED CT in the near future. There is an attempt to get SNOMED CT integrated on some University curriculums e.g. future nursing curriculum. SNOMED CT is not an approved standard, therefore, vendors are required to organise their own training. CFH will potentially set up some webinars and coordinate with vendors on this.

3.1   Scotland

As mentioned in 3.4.2, the UKTC is the main agency with responsibility for SNOMED CT and classifications activity across the United Kingdom including Scotland. The Scottish Information Services Division (ISD) terminology service provides support and guidance in the use of clinical classifications, coding and terminology to NHS Scotland using locally based training, an advisory service and the publication of National guidelines.

Coding systems supported by the service include ICD, OPCS, Read, SNOMED-CT and codes for clinical imaging procedures. It also coordinates new "code" requests for Read, clinical imaging procedures and SNOMED CT. Scotland ISD is not a terminology release centre but has representation on the UKTC governance group and they run a national standards steering committee on clinical terminologies. The current remit in ISD is to train clinical coders and there is a team of 6 WTE to do so.

Scotland does not have a mandate to enforce the use of SNOMED CT. To date, there has been little customer demand but recently some clinicians and or specialists in secondary care who use OPCS are interested in SNOMED CT as they are increasingly unsatisfied with this classification system which is not meeting their needs. In terms of primary care, Read v2 is the main terminology of choice in Scotland. However, a recent Scottish report suggests that SNOMED CT would be its long-term terminology

of choice and aligns with the recent announcement by the UKTC that 'SNOMED CT will be the sole supported terminology by 2015'.

The main limitations to adopting and using SNOMED CT were summarised to include: difference in scope of sub-sets and difficulty in linking them to a business case e.g. justifying the benefits and costs, integration and mapping to legacy systems, the lack of uptake from suppliers and although there are gaps and limitations in Read v2 it is being used successfully.

4   New Zealand

The current health I.T. plan for New Zealand has a vision for shared healthcare and shared health records by 2014 and recognises the need for standardised clinical information to achieve this. New Zealand is a small country with approximately 4 million people, divided into 20 district health boards. There is a large rural community in New Zealand; hence primary care and particularly GPs play a central role in the provision of care. Vendors play a significant role in advancing the health information plan but because New Zealand is a small market, vendors are not in a position to make sizeable modifications to their products. Therefore, New Zealand takes the approach of endorsing international standards and adapting them to the local context, such as for local needs.

The decision to adopt SNOMED CT was driven by the objectives of the the Information Strategy for New Zealand (HIS-NZ) (2005) [6] and the need for a clinical terminology for the transaction of clinical information e.g. not administrative/ financial/reimbursement functions.

Different types of classifications and coding systems are in use. ICD-10 is used for national collections. Read codes are used but there is an attempt to move away from these codes and introduce SNOMED CT. The ambulance services use Read codes on the accident insurance form and GPs use Read codes to report on accidents. There is a re-engineering project ongoing to changeover from using Read codes to SNOMED CT regarding lodgement codes for claims. LOINC is used for the order and results of lab tests and this is currently being incorporated into SNOMED CT. Pathologists are using SNOMED CT for diagnosis using specific reference sets. A classification called SNO dent is being used in dentistry. It was planned to adopt and adapt the Australian Medicines Terminology (The New Zealand Member has assisted with the use of SNOMED CT for AMT).

The purpose of the National Release Centre is to support the implementation of SNOMED CT within New Zealand and the main responsibilities include: consultation and communication, application review and processing, release management,

international reporting and the administration of the International Health Terminology Standards Development Organisation workbench application which is designed to support national extensions and subset (reference set) development (*taken directly from the International Health Terminology Standards Development Organisation website*).

The national release centre is located in the Ministry of Health. There are currently 46 affiliates including hospitals, GPs, vendors and Universities. The national release centre is tasked with sending on feedback reports every six months to the International Health Terminology Standards Development Organisation regarding who is using licences, how they are using them etc. They have had no issues to date in this regard. It is part of someone's role within the ministry of health to manage this task estimated to take a .5 WTE to carry out the licensing role. They do not have dedicated (WTE) resources for the national release centre. The work is managed within the Ministry for Health and a project team is established as required. They seed the funding to get the SNOMED CT projects up and running. Vendors also play a huge role in the implementations and are relied on for mapping and sometimes training purposes. They recognise the need for a diverse skill set to complement each other and run the national release centre and SNOMED CT projects and include; health informaticians, technical and clinical roles.

Training and Education is provided by volunteers. An initiative that has proven quite successful is for medical students who are I.T. savvy to give training sessions and workshops on SNOMED CT. There is a lot of SNOMED CT expertise to avail of in New Zealand; however, consultants who provide training in SNOMED CT are parachuted in if needed.

Translation activities are not being carried out. The release management process takes place every 6 months e.g. download the core release from the International Health Terminology Standards Development Organisation and distribute it to clients using a CD-ROM. This is deemed straightforward role. A resource would spend approximately 1 month on this e.g. 2 months annually. There has been no need to have a support role e.g. helpdesk. They have not invested in in-house tooling and recommend using the International Health Terminology Standards Development Organisation workbench when mature. They use Excel to manage releases.

In terms of governance arrangements, the Health Information Standards Organisation (HISO) is the standards-setting body in New Zealand. The national release centre is governed by this organisation and also uses the articles of association issued by the International Health Terminology Standards Development Organisation. They have one representative on the management board of the organisation. HISO endorse international standards. When that standard is endorsed

it has to be used for any projects that are initiated from that point onwards. SNOMED CT is mandated for use in NZ.

Some lessons learned from the New Zealand experience include:

- building relationships and clinical engagement is critical
- huge effort is spent with engagement and getting buy in from clinicians. This started with a small group who were interested in quality measures, and who were sold the benefits of SNOMED CT to them subsequently becoming the advocates for SNOMED CT.

5   Estonia

In Estonia, the eHealth Foundation and the EVS (Centre for Standardisation) are responsible for the use of health informatics standards. The EVS is a not-for-profit organisation and is the national standards body in Estonia, established in 2000. The eHealth Foundation promote and develop national eSolutions within the healthcare system. In January 2010, Estonia became an ordinary member of the International Health Terminology Standards Development Organisation with the aim of developing SNOMED CT for digital health records, health research and other applications. The national release centre is physically located in the eHealth Foundation.

One of the main drivers for joining the International Health Terminology Standards Development Organisation and adopting SNOMED CT in Estonia was to promote safe, accurate, and effective exchange of clinical and related health information. Also, SNOMED CT was already in development in different areas it was decided that it made more financial sense to take up a National license than to have individual organisations pay for SNOMED CT separately. Historically laboratories in Estonia have been using versions of SNOMED CT which has been used in some daycare, tertiary centers and hospitals. However, overall it is not in widespread use. The other terminology systems in use include ICD-10 within the department of Minister and Social Affairs, ATC which is used in its national drugs system and LOINC implemented in the laboratory domain and translated into Estonian. There are some codes used in its national ePrescribing project.

Currently, there are 12 affiliates availing of the National SNOMED CT license ranging from research, vendors and hospitals disciplines. The administration of licensing does not require much effort and involves sending reports to the International Health Terminology Standards Development Organisation twice a year regarding appropriate usage of SNOMED CT and issuing and maintaining license agreements with affiliates. They maintain and distribute the International Health Terminology Standards Development Organisation international release every six months and distribute it to affiliates via a central server where clients can download the

international/core release via ftp to the customer site. Estonia does not maintain a national extension of SNOMED CT and they do not receive internal requests to include new concepts in the international release. Some investigation into the International Health Terminology Standards Development Organisation workbench tool has been carried out but it is not appropriate for them to use at this time however they use the CliniClue® tool (for end-users) and Microsoft Excel for release management purposes.

There are no translation projects in progress but this is considered an important future objective and is high on its agenda. Training and education to date has been minimal and they have found it difficult to acquire external training (from a qualified consultant). In response, 5 to 6 resources attended international training conferences twice a year for training and up skilling and were proficient to develop in-house training material for lectures. In turn, the lectures were given to the vendor community. Recently, there has been increased interest from the GP community and family therapists to receive this education. They attend the International Health Terminology Standards Development Organisation general assembly and management board meeting if it is relevant to work they are conducting at that time. They do not attend the monthly teleconference meetings because of the language barrier e.g. all business in the organisation is conducted through English. They currently participate in two special interest groups (SIG) namely the technical and the quality and education meetings.

In terms of resources, they currently have no WTE dedicated to the SNOMED CT national release centre full-time. The work of the release centre is conducted through the Minister of Social Affairs, where all support for classification and coding is undertaken. There are typically three to four part-time resources that work on the support and development of SNOMED CT. Clinical terminologists who comprise nursing and medical specialists who work in the Minister of Social Affairs on coding and classifications could be deployed as part of a SNOMED CT project as required. There is also a part-time resource representing the vendor and healthcare professional's community. Having previously discussed the cost of adopting SNOMED CT during its initial evaluations with a Scandinavian country, it was estimated that the cost of the SNOMED CT license would equate to approximately 20% of the annual cost of supporting SNOMED CT, however, Estonia would estimate this to be closer 10%. It is not possible to give an exact figure on the annual cost of implementing SNOMED CT as they do not break down the cost of coding per terminology systems.

The main experiences and lessons learned from Estonia are that SNOMED CT is complicated to use but is promising. Following major debate and evaluation within Estonia, it was concluded that SNOMED CT does not have the capability to cover the

concepts for all healthcare domains. As a result, it is imperative to manage user expectations in this regard and be realistic about the potential of SNOMED CT use.

Future work: A subset project for clinical findings (40,000 concepts in SNOMED CT) will get underway in September 2011 and will cover all healthcare specialties in Estonia. This project will employ 5 to 6 people part-time and will be carried out over a year. Advisors for this work will consist of GPs, scientists, analysts and terminologists.

6   Malta

Health care in Malta is delivered through a mix of Government and private services. The statutory system is publicly financed and is free at the point of use. Secondary care is delivered mainly through Government hospitals, but also through small private hospitals, while primary care depends heavily on the service given by private family doctors, together with the services provided in Government health centres. Parliament is responsible for enacting health care legislation and for approving the Government's health care budget. Otherwise most decisions regarding health policy and are taken at the level of the Ministry for Health. The Ministry for Health is responsible for management and provision of Government-funded health care for all the population. It has several regulatory functions and nominates members on Government Commissions and Agencies related to health.

ICD-10 is in wise use for the classification of mortality and morbidity in Government hospitals. ICD-9-CM (PCS) is in wide use for the classification of surgical operations in Government hospitals. ICPC is in limited use for the classification of "reason for encounter" at the A&E Department at Mater Dei Hospital (the main Government hospital) and for activity in the primary care sector. ATC is in limited use for the classification of medication on discharge from Government hospitals. SNOMED-CT is being gradually introduced in the context of electronic clinical documentation, with mapping of SNOMED-CT concepts to classes in established classification systems Membership of the International Health Terminology Standards Development Organisation was driven mainly by Government's participation in the epSOS project and the planned implementation of electronic health record systems that would include the use of SNOMED CT. There is no strong end-user demand for SNOMED CT as yet. The gradual introduction of SNOMED CT was a strategic choice made in the context of the development of the national eHealth infrastructure. There is no strong clinical coding culture in Malta; initiatives such as the introduction of the use of SNOMED CT are typically driven by the Government and are generally accepted as long as they do not lead to an unreasonable increase in workload at the clinical interface.

Malta is still at an early stage of adoption of SNOMED CT. The national release centre in Malta was established at the beginning of 2012, shortly after Malta became a member of the International Health Terminology Standards Development Organisation. The national release centre is a function within the eHealth Office, which forms part of the Information Management Unit in the Ministry for Health. To date there is no formal board of management or TOR. The eHealth Office offer an online service using the Ministry of Health's website whereby the potential licence holders can make contact with the national release centre. The office receives and manages applications for affiliate licences. Data files are provided to licence holders on optical disc at request. To date Malta has been a passive user of the core release and therefore has not yet set up a process to manage "requests for change". There has been no formal education and training to date. Malta has participated by teleconference in General Assembly / Management Board meetings, and intends to participate in the Members' Forum.

During 2013 the eHealth Office continued mapping of health data concepts in local use to existing SNOMED CT (International) concepts, using a mix of controlled vocabularies and free text analysis. It also promoted the use of the ATC classification for the medicines prescribed on discharge from Government hospitals, with mapping to the corresponding SNOMED CT concepts, based on the "Virtual Medical Product" paradigm. The Ministry was active in the epSOS interoperability project, in which a subset of SNOMED CT concepts are used in a number of epSOS value sets.

In terms of human resources for operating the national release centre, the only specifically-defined role to date has been that of "Nominated Representative" (representing Malta in the International Health Terminology Standards Development Organisation). The work related to the implementation of SNOMED CT and functioning of the national release centre has been carried out by persons in the eHealth Office in the following roles: consultant public health physician, web content manager, ICT Applications Officer, manager and clinical coding. At present less than 0.2 WTE are allocated to working on SNOMED CT. The skills identified to operate the national release centre include expertise in clinical coding and semantics, web content management skills, database management skills and public health management skills and have been available in-house. Malta has only been a member of the International Health Terminology Standards Development Organisation for just over two years; over this period of time there has been no significant change in resource requirement.

7   Poland

Poland has recently joined the International Health Terminology Standards Development Organisation and the national release centre operates under the

National Centre for Health Information Systems (CSIOZ) which was established on 1 August 2000 by the ordinance of Minister of Health on 31 July 2000. Its first task is to translate SNOMED CT into Polish. CSIOZ received the organisation's documents (International Health Terminology Standards Development Organisation Management Guidelines Translation SCT, International Health Terminology Standards Development Organisation Translation Guidelines, TQA background, methodology and toolkit TQA) which will form the basis for the commencement of a tender for the translation of SNOMED CT. At the time of this report, the terminological systems used in all sectors of healthcare in Poland are ICD-10 and ICD-9. Work is underway to set up administration of licensing for affiliates who want to use SNOMED CT.

Appendix 3 – Consultation questions

1.0 Background
1.1 Give a background of the national healthcare set up in your country. 1.2 What terminological systems are in use and for what domain in primary care /secondary care, national systems etc? 1.3 What are the drivers behind the adoption of SNOMED CT? e.g. customers demand, political demand? 1.4 Was there a formal assessment of SNOMED CT undertaken before adoption? 1.5 Is there any report (in English) available on assessments, costs/benefits? 1.6 What SNOMED CT projects are being undertaken and what is your involvement?
2.0 Background to the national release centre
2.1 When was the national release centre formally set up? 2.2 Where is the centre located?
3.0 Current business case and activities
3.1 Licensing 3.1.1 How does the national release centre manage licensing? **3.2 Translation** 3.2.1 What effort has been required to translate SNOMED CT 3.3 What was the cost of translation e.g. duration, experience, maintenance? **3.4 Content Management** 3.4.1 What process is supported for local 'Requests for change'? 3.4.2 What effort is required to make submissions for the international release e.g. Core release? 3.4.3 What is the maintenance effort required to manage the national release with the international release?
4.0 Training
4.1 What has been organised for the general user community? 4.2 How many resources are required for training purposes? 4.3 Do you organise workshops 4.4 Have you developed your own online materials? 4.5 Did you develop materials in addition to the International Health Terminology Standards Development Organisation materials?
5.0 International Health Terminology Standards Development Organisation
5.1 What interactions/communications do you have with international colleagues and other national release centres? 5.2 What interactions do you have with the International Health Terminology Standards Development Organisation?
6.0 Release Management
6.1 Detail the SNOMED CT release process used. 6.2 What tools are used to manage the release process?
7.0 Operational /Organisational Structure

7.1 What roles are required to support SNOMED CT?
7.2 How many WTE are allocated to SNOMED CT?
7.3 What key skills sets are required?
7.4 What specific skills did the organisation have to up skill in?
7.5 How has the role of the national release centre evolved?
8.0 Annual funding allocation and Costs
8.1 How much does it cost to run the NRC (national release centre) in terms of resource, training, admin etc?
8.2 How has the resourcing requirements evolved (increased) over the years?
9.0 Formal Governance
9.1 What are the governance arrangements with the national release centre e.g. who sits on the board, how is it arranged, what are its terms of reference?
9.2 Where does it sit in relation to other committees? e.g. has it a national steering committee?
10.0 Lessons Learned
10.1 What are the barriers/issues in setting up and operation of a national release centre?
10.2 Is there clinical buy-in?

Glossary of Terms

Classification: a classification is a method of organizing and or grouping 'concepts' in a systematic way (e.g. into classes) within a particular domain for a specified purpose. They are arranged into categories according to common attributes, quality or property.

Concepts: concepts are used to describe the combination of a code (unique numeric or alphanumeric number) and a textual description assigned to the code, more formally known as a rubric.

Logical Observation Identifiers Names and Codes (LOINC): A universal terminology systems for tests, measurements, and observations.

Terminological system: umbrella term for the following: terminology, classification, vocabulary thesaurus, and so on.

Terminology: is a list of terms referring to concepts in a particular domain.

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