DELIVERABLE

Project Acronym: **ASSESS CT**

Grant Agreement number: **643818**

Project Title: **Assessing SNOMED CT for Large Scale eHealth Deployments in the EU**

D4.1 Portfolio of (best) practices

Authors:

Dipak Kalra	EuroRec
Veli Stroetmann	empirica
Kirstine Rosenbeck Goeeg	Aalborg University
Anne Randorff Højen	Aalborg University
Heike Dewenter	Univ. Applied Sciences Niederrhein
Reza Fathollah Nejad	Univ. Applied Sciences Niederrhein
Catherine Chronaki	HL7 Foundation
Stefan Schulz	Medical University Graz

Project co-funded by the European Commission within **H2020-PHC-2014-2015/H2020_PHC-2014-single-stage**		
Dissemination Level		
PU	Public	X
PP	Restricted to other programme participants (including the Commission Services	
RE	Restricted to a group specified by the consortium (including the Commission Services	
CO	Confidential, only for members of the consortium (including the Commission Services)	

Revision History, Status, Abstract, Keywords, Statement of Originality

Revision History

Revision	Date	Author	Organisation	Description
1	14/9/15	Dipak Kalra	EuroRec	Initial draft for WP4 interaction, via Google Docs
2	12/10/15	WP4 team		Version iteratively updated by WP4 partners leading up to the Berlin workshop
3	9/10/15	Robert Vander Stichele	RAMIT	Inclusion of table and literature review findings on the barriers to SNOMED CT adoption
4	17/10/15	Dipak Kalra	EuroRec	Most sections re-written, many turned into narrative, incorporating feedback from discussions at the Berlin workshop
5	24/10/15	Dipak Kalra	EuroRec	Updates following WP4 feedback on version 4, primarily from Catherine Chronaki, addition of the Executive Summary, formatting
6	25/10/2015	Stefan Schulz	MUG	Review comments throughout the document
7	30/10/2015	Dipak Kalra	EuroRec	Finalisation of the document for submission

Date of delivery	Contractual:	30.09.2015	Actual	30.10.2015
Status	final ☒ /draft ☐			

Abstract (for dissemination)	This deliverable consolidates the experience so far gained, in Europe and the US, in adopting SNOMED CT and other large scale clinical terminology systems. It serves as a guideline or check-list of issues to be considered and approaches to be defined when designing a coherent and holistic strategy for the advancement of semantic interoperability through large-scale terminology systems.
Keywords	Business driver, strategy, barrier, adoption, terminology, semantic interoperability

Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

Table of Content

1 Executive Summary

This deliverable consolidates the experience so far gained, in Europe and the US, in adopting SNOMED CT and other large scale clinical terminology systems, as part of a national and/or European strategy towards advancing the semantic interoperability of health data. Our experience has shown that most adoptions are at early stage, with little evaluation evidence on which to determine successful practices, let alone best practices. There is also sufficient variation in the approaches so far adopted that one cannot yet confirm what is consensus practice. We can therefore consider the international experience gained as "emergent practice", but this does not negate the value of the learning points already encountered across Europe, and internationally.

This deliverable consolidates these emergent practices and learning points as a kind of guideline or check-list of issues to be considered and approaches to be defined when designing a coherent and holistic strategy for the advancement of semantic interoperability through large-scale terminology systems.

It is important to consider the adoption of a new or alternative terminology system within the context of an overall semantic interoperability strategy, since there are many complementary elements of an adoption strategy that need to be taken forward at the same time in order to optimise the use of the terminology system and to maximise the benefits from it. This includes determining the priority drivers for advancing semantic interoperability, within the health and care ecosystem and including a range of secondary uses of the data. It is also important to consider whether the drivers are entirely within the border of a single national health system, or if there are particular areas of Member State co-operation (bilaterally, or at a European scale) that can influence and support the adoption strategy.

The adoption strategy needs to include some core decisions about the role the terminology will play, especially if it is intended to serve primarily as a reference terminology, to enable greater coherence in the maintenance and mapping of multiple existing national terminologies, or if it is also intended as a user interface terminology that become reflected in the words and phrases clinicians and others will see on data entry and review screens.

Budgets will need to be set, and often need to be ring-fenced, for activities, services and expertise that need to be funded and provided at a national level, such as the development of RefSets, the translations of terms, the development of clinical models and value lists, terminology distribution services, and expertise to support the ICT and health professional communities. Specific decisions will need to be taken, ideally at a national level rather than in a fragmentary way, about key areas of terminology use such as the extent to which post-coordination will be supported.

The adoption strategy also needs to determine the measures that will be provided for, and possibly centrally funded, to support wide-scale uptake of the terminology system, within products that capture and communicate and analyse health data, and within repositories and systems the process health data such as registries and reimbursement frameworks. Such measures may include financial incentive packages for the ICT marketplace and for health care provider organisations to invest in technologies and in training to increase the proportion of data that are well structured and coded, and to maximise benefits realisation.

Depending upon the priority scenarios for adoption, not all of the points in this document will be relevant to each country or region, at a particular point in time. Future work, to be reported in subsequent deliverables, will examine the kinds of decisions that need to be taken for different adoption scenarios, and the success strategies that might be of greatest importance for any given scenario.

2 Abbreviations

ATC	Anatomical Therapeutic Chemical (Classification System)
CDA	(Health Level 7) Clinical Document Architecture
CEF	Connecting Europe Facility
ECDC	European Center for Disease Prevention and Control
eHGI	eHealth Governance Initiative
EMA	European Medicines Agency
FHIR	(Health Level 7) Fast Health Interoperability Resources
HL7	Health Level 7
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
IHTSDO	International Health Terminology Standards Development Organisation
MS	Member State
NRC	National Release Center
NLP	Natural Language Processing
RefSet	Reference Set: a subset of terms from a terminology, for use within a given domain
SCT	SNOMED CT
SDO	Standard Development Organization
WP	Work Package

3 Introduction

This deliverable is the first report from work package 4 of ASSESS CT, which will eventually publish recommendations on the adoption of large-scale (international) clinical terminologies, such as SNOMED CT, as part of a national and/or European strategy towards advancing the semantic interoperability of health data. This work package in particular is charged with consolidating the key learning points from the empirical work of work packages 1, 2, and 3 of the project, and for interacting with multiple stakeholders to obtain feedback on those consolidated learning points.

This first deliverable has not yet reached the stage of recommendations, but primarily consolidates the experience so far gained, in Europe and the US, in adopting SNOMED CT and other large scale clinical terminology systems. It was originally intended to present best practices. However, our experience has shown that most such adoptions are at early stage, with almost no available evaluation evidence on which to determine successful practices, let alone best practices. There is also sufficient variation in the approaches so far adopted that one cannot yet confirm what is consensus practice. We can therefore best consider the observations made by the empirical work packages as "emergent practice", but this does not negate the value of the learning points already encountered across Europe, and internationally.

This deliverable consolidates these emergent practices and learning points (including where possible any learning from a lack of adoption success) as a kind of guideline or check-list of issues to be considered and approaches to be defined when designing a coherent and holistic strategy for the advancement of semantic interoperability through large-scale terminology systems. SNOMED CT inevitably features large within such experience and within the guideline, but is deliberately not positioned exclusively as the approach advocated. It should also be noted that much of the experience has been gained in pilot projects and at the largest scale in single countries, but consideration is also given in this work package to those points that might be taken forward at a European level through Member State cooperation and/or through European level policy decisions. The later deliverables of this work package will more strongly emphasise the European dimension, compared to this report.

This adoption guideline is organised in sections that seek to help answer the following questions.

1. What have proved to be the drivers (the most desired business benefits) across the EU Member States for the adoption of a large-scale terminology as part of an overall strategy for better semantic interoperability?

2. What have been the key features of that adoption strategy, in terms of the initial roles for the terminology, the areas within health care services that it has been applied, and any national level governance measures that have been needed?

3. What are the key features of the operational strategy for adoption, including what concrete choices have had to be made about the terminology itself, other standardization and interoperability decisions, the specific operational steps needed to put the terminology system into use, within national infrastructures and health system products?

4. Where have significant costs been incurred or where are they planned for (since in many cases they have not yet been incurred, but are anticipated)? If not yet incurred, what do experts advise to be the important areas of investment that Member States should budget for?

5. What have been the success strategies attempted thus far, or what strategies are recommended by experts, to be used to help ensure the smooth and effective scale up of terminology implementation, use and acceptance?

6. What have proved, so far, to be the major areas of challenge, and issues, that need to be tackled when adopting the terminology system and complementary semantic interoperability measures, in particular with SNOMED CT?

Having consulted with multiple experts and stakeholders on the content of this guideline, most recently at a multi stakeholder workshop held in early October, in Berlin, the next phase of work of this work package will be to identify the most important gaps in knowledge and in capability that should be addressed, ideally at a European level, in order to better position Europe and its member states to obtain maximum value from large-scale terminology systems. The final deliverable of this work package will be the definitive recommendations to eHealth Network and to Member States about large-scale clinical terminology systems adoption.

4 Drivers for national investments in semantic interoperability

This first section of the guideline deals with drivers for adoption. Whilst a clinical terminology system is usually considered to be of primary importance for the capture and representation of clinical information about individual patients, to be stored in electronic health records and used to support downstream quality of care, this is not the only potential business benefit of a terminology system within the health, care, public health and research ecosystem. It is arguably the most challenging part of the ecosystem into which to introduce a novel and substantial change to existing practices and to existing systems. It can therefore be a long time from the decision to use a new international terminology system for direct data entry at the clinical coalface, and the realisation of benefits, unless this is initially targeted at very focused adoption scenarios. We have therefore observed that countries and regions and pilot projects have sometimes considered other business benefits, and therefore adoption drivers, in addition to direct patient care, or as early win alternatives to help introduce the terminology system and to gain acceptance of it. The list below describes the spectrum of drivers for adoption that have been encountered through the projects and activities we have learned about, and from the literature, as candidates for any adopting community to weigh up and prioritise before making a final decision.

As with any large-scale investment, it is prudent to determine the highest priority drivers, and for these to be explicitly and transparently communicated to all involved stakeholders. These drivers will substantially dictate the adoption strategy and operational strategy, may influence financial and other incentives, and will undoubtedly determine the business benefits that need to be demonstrated downstream to justify that strategic choice and investment.

It should be noted that we cannot in this report project with any accuracy the timelines for the achievement of business benefits for each of these drivers. This has to be a locally determined matter, by evaluating the proposed level of investment, the current legacy situation, the pace of migration that is feasible, what level of improvement would be considered as a success, and precisely how it is proposed to measure benefits.

4.1 Better quality and safety of care to individual patients

More complete coded documentation. The increasing complexity of patient care requires the content in the EHR to be unambiguous and understandable to multiple care providers *and interpretable by computers*, to be comprehensive and to provide relevant and rich detail. Fine grained terminology can therefore support more complete and accurate coded clinical documentation, provided that the user interfaces for selecting relevant terms are friendly and avoid overloading the clinician with too many choices or a complex system of navigating term hierarchies. The ability for computers to interpret coded EHR data is an important driver, since clinicians have much experience of interpreting handwritten and typed information that is in free text, received from other care providers: terminology systems bring little, if any, benefit for human readability purposes. Computable uses of EHR data include filtering and navigation of a large or complex patient record, the generation of summary screens, and the decision support and care pathway drivers mentioned below. MS feedback has drawn attention to the lack of rich enough terminology support for nurse documentation, clinical processes, rare and genetic diseases.

Example quotes from WP1 focus group experts

Finland: "our existing terminology systems are weak in representing healthcare processes, roles, haematology, rare diseases, genetic disorders"

Finland: "ICD-10 is not granular enough for genetics"

Denmark:" there is as yet no agreed terminology for nurse documentation"

Sweden: "reasons for prescription, both generally and specifically for antibiotics, is now being collected in a structured (coded) and standardized manner"

Better overview of each patient's information. Well-structured and coded information can enable EHR systems to automatically generate patient summaries and disease monitoring dashboards. Without these tools it can be time consuming and error prone for a clinician unfamiliar with a patient to obtain the necessary overview. An EHR system could also highlight to a clinician any previous occurrence of an observation or finding they are just entering, or another finding of relevance - for example to query the EHR for previously recorded information about pain or the use of analgesics, and generate a purpose specific overview.

Example quotes from WP1 focus group experts

Denmark: "if you have a patient who complains about a pain, you could query the EHR for earlier recorded information about that pain, and get a much more purpose specific overview, instead of drowning in data"

Better records to enable decision support. This seems to be one of the strongest direct patient care drivers for enhancing the proportion of structured and coded information in EHRs. Decision support has a well-established evidence base for improving patient safety and optimising clinical outcomes, and this need will increase as medicine becomes more complex, the volume of clinical guidelines grows, and healthcare professionals come under increasing time and resource pressures. However its extent of use is somewhat limited by the limited domains of the EHR data over which algorithms can reason and provide accurate advice to clinicians. A focus on enhancing decision support not only acts as a potential driver for the adoption or enhanced use of terminology systems, it provides a basis for prioritisation, since the codes most important to adopt are those for which we currently have decision support needs and capabilities.

Example quotes from WP1 focus group experts

Croatia: "ICD-10 is not sufficient to encode data for decision support and analytics"

Netherlands: "this is an important benefit from adopting new international terminologies"

Denmark: "A representative for a vendor mentioned several times in the focus group that decision support would be the main driver for them to improve use of terminology in their electronic health record. Health professionals at the hospitals are under much pressure, and short stays at hospitals, as the main reasons why better decision making is important."

Denmark: "an example is where you can put in the patient's condition, and the system suggests interventions based on the condition. The driver is to limit intervention to the things that are actually possible and make documentation more efficient"

Support the adoption of point of care evidence based clinical guidelines, through care pathway systems that can interrogate the EHR content for a given patient in order to generate alerts, provide prompts, make recommendations on the nature and timing of future care activities and orchestrate multi-actor workflows. (Note that electronic care pathways often make use of decision support components, but may include additional functions and make richer use of the coded content of an EHR.)

Improved patient safety is an expected outcome from all of the above drivers, but relies primarily upon making computational use of the coded data. It is important to recognise that the patient safety value of scaling up the level of semantically interoperable health data relies upon the querying and retrieval of complete and relevant information about an individual patient, to present it directly to the clinician or indirectly via a computed alert or recommendation. The level of granularity of the terms and data structures used to capture, store and exchange the EHR data must be sufficient to support correct safety alerts, without too many false positives or false negatives: for example ATC codes seem not to be fine grained enough to support prescribing safety algorithms. Unless natural language processing (NLP) technologies are also used, information that has not been coded will be invisible to such computational processing, just as will information in an unconnected EHR in another care setting. Even with NLP one cannot rely upon all safety critical events to be detected, nor to avoid a certain rate of false positives. *The safety of patient safety alerts therefore hinges upon the completeness and accuracy of the structured and coded EHR they can access and analyse.*

Example quote from WP1 focus group experts

"Denmark and Finland: prescribing safety requires greater granularity than ATC"

4.2 Enriched EHR data exchange for continuity of care

Underpinning multi-professional collaboration. Patient care increasingly involves multiple professionals working in different care settings, forming a kind of "just in time" virtual team for each patient. Paper based communications between such actors are a well recognised point of failure leading to suboptimal and sometimes unsafe care. Electronic communications (such as electronic discharge summaries) can be transferred faster, but the bottleneck of staff time to compose such documentation remains. However, smart rules for the semi-automatic generation of summary communications can reduce that workload burden and improve the quality and timeliness of shared care communications.

Offering all relevant actors direct access to each other's records is another approach. However without the filtering and navigational support referred to above, can easily leader overload, missing key facts and therefore fail to improve continuity of care. Some health systems and initiatives employ care co-ordinators (case managers) to orchestrate care, but this is expensive. Computable and semantically interoperable EHR data can be leveraged to flag up critical facts relevant to a particular multi-actor care pathway, and can flag up issues in the management of one condition that has bearing on another. However, the realisation of

computable benefit from shared EHRs relies upon the existence of correspondingly computable care pathways, reminder systems, alerts etc. as discussed above.

Example quotes from WP1 focus group experts

Croatia: "this is the main driver for deciding to adopt SCT"

Germany: "this is important, given the high levels of electronic documentation in Germany, especially when professionals are sharing a care pathway"

Germany: "generated data can be used in different contexts for different purposes, preserving the defined semantics of that data"

Netherlands: "this is an important benefit from adopting new international terminologies"

Denmark: "multi-professional collaboration is one of the main drivers in a national project where SNOMED CT is used as reference terminology for documentation within the home care setting(nursing, rehabilitation, home-aid)"

Sharing EHRs with patients. Studies have shown that patients value access to structured and coded data within their EHRs, sometimes simply to read their records but increasingly wishing to take advantage of applications and tools that can re-present their data more usefully to aid understanding, generate charts and tables, highlight trends, support education about their health conditions, and enable patients to play active roles in self care.

At present few personal health record (PHR) systems use the same international terminology systems as might be used by healthcare professionals, and so the reverse flow of PHR data into EHRs will not easily permit that data to be co-processed alongside EHR data. Recognising, though, that health professionals are not all comfortable with including patient generated or provided data into their EHR, this reverse flow might not be a strong decision-influencing driver. However, a national semantic interoperability strategy may include incentives for the PHR marketplace to align with that strategy.

Example quote from WP1 focus group experts

Croatia: "using SCT may help communication with patients"

4.3 Cost reduction (in the healthcare system)

Reduce duplicate data capture through better interoperability. Healthcare activities are sometimes documented multiple times, for example in a health record, a clinic letter or discharge summary, a reimbursement claim, a disease registry entry etc. For some of these the documentation might initially be paper and later entered into a computer system, which is not only time consuming but misses out on any real time benefit that system could provide the author (such as validation checks, reminders, warnings).

Capture reporting and reimbursement codes at source, in a more efficient way. The use of codes for reimbursement is generally aimed at optimising reimbursement, not at cost reduction. The cost reduction element lies in reducing the duplicate effort to code for clinical care in the EHR and to code for reimbursement, quality monitoring and public health purposes, using different terminology systems. Reimbursement codes are generally more coarse-grained than clinical documentation codes, so reimbursement can be derived from clinical coding, but not the other direction. If such mappings are used, changes to a reimbursement framework can be introduced at lower cost and with little or no disruption to the majority of healthcare staff. However, it should be noted that reimbursement systems

usually contain rules that have historically been linked to terminology systems like ICD, and so these too would need to be redefined.

Consolidate from multiple existing terminologies. Most health systems presently use a mixture of terminology systems, for reimbursements, hospital activity monitoring, births and deaths, disease registries, screening programmes etc. Many of these systems are maintained by each country, including cross-mappings between them and to international terminology systems such as ICD. Several countries have expressed the interest in reducing this burden of developing and maintaining cross-mappings by using SNOMED CT as a core reference terminology (i.e. as a common mapping target or semantic broker), and this being one of the reasons for opting for it. It is also being considered as a terminology to replace some of the national terminology system, thereby reducing even further the cost of maintaining local terminologies.

Example quotes from WP1 focus group experts

Finland: "e.g. need to map SNOMED 3 used by pathologists and ICD-10 used by clinicians"

Denmark: "In the national "home care documentation" project, SNOMED CT functions as a reference terminology, allowing each profession to apply the coding systems already in use (such as ICF, ICD etc.). SNOMED CT therefore functions as a common reference enabling information comparison across professions."

Denmark: "the meaning of concepts is well defined at the international level, rather than having their roots in the local health system"

4.4 Optimising reimbursement

To use fine grained clinical data from the EHR as the basis for generating more accurate activity and outcomes data, to map into reimbursement claims. (This may, on the one side, reduce the likelihood of "up-coding", where a more expensive interpretation of a patient's care is claimed for than is actually the case. On the other side, it may improve the completeness of claims since the requirement for duplicate coding for claims as well as for clinical documentation can result in missed claims.)

4.5 Analysis (secondary) uses

Analytic uses of health data can be powerful drivers for adopting a coherent semantic interoperability approach, including focusing the uses of terminology. The list below gives examples of analytic uses that have been articulated by experts, used in pilot projects, and in most cases demonstrated to some extent. In some examples such as population health screening and disease registries, subject-level data needs to be incorporated. In others it is the analysis results that are needed, which might be derived through pooling data extracts for central analysis or by distributing the queries though a federated network. However, they all require data from multiple sources across the health ecosystem to be combined and co-processed, and therefore to be semantically interoperable.

- Benchmarking, service planning, commissioning
- Evidence based strategic decision making and planning
- Outcome optimisation, improving efficiency
- Public health, surveillance, screening, prevention

- Populating and maintaining registries
- Pharmacovigilance
- Comparative effectiveness and outcomes research
- Identifying eligible patients for clinical trials
- Enabling large scale epidemiological research

On the one hand, health data can only be combined if it is originally captured in a semantically consistent way, or can be mapped to a common representation for the analysis. In general, analysis use cases will not deliver benefits until a high degree of coding quality has been reached. This requires a significant preparatory effort, i.e. a revolution in documentation culture. This means that the capability to fulfil these purposes in a better way through a new or alternative terminology choice will depend upon the widespread use of that terminology in the source data. On the other hand, the data items needed for these purposes can serve as the focus for prioritising that terminology adoption and accompanying efforts to improve data quality in the capture of those data items.

Example quotes from WP1 focus group experts

Sweden: "the healthcare industry, including providers, pharmaceutical and biomedical technology industry, needs standards to enable benchmarking of results"

Croatia: "this is a second driver for deciding to adopt SCT"

Germany: "regarded as an important driver and potential benefit"

Sweden: "the use of antibiotics, and particularly the reason for antibiotic use, is being collected on a national scale"

Sweden: "the (about 100) national quality registries are being mapped to standardized terminologies and classifications"

Sweden: "healthcare quality registries are being mapped to standardized terminologies and classifications in order to facilitate the transfer from EHR systems to the registries."

4.6 Cross-border information and knowledge sharing

The principal driver for investments in semantic interoperability at a European level, supported by EC funding, has been the cross-border healthcare rights of citizens. This has triggered projects, specifications, standards and profiles that handle the cross-border communication of patient summaries and prescriptions, primarily to support unplanned care e.g. holidaymakers, business travellers, overseas postings, military personnel, refugees. These services are targeted for early adoption by the Connecting Europe Facility. (Our European surveys suggest SNOMED CT would be the best core clinical terminology for populating cross-border patient summaries.) There is now a momentum to extend these specifications and services to support cross-border planned care. Smaller scale clinical data sets might also be useful to exchange across countries, such as laboratory and radiology results, medical device readings. In all of these cases semantically interoperable data is required, and clearly requires consistent use of information models, clinical models and terminology value lists. At present some countries are planning to map locally captured and stored EHR data (in whatever structures and terms presently in use) to the European interchange specifications, which use SNOMED CT for the patient summary. This is clearly the lowest cost approach to conformance. Migrating the underlying EHR systems and repositories to natively capture, store and process patient summary data items in the formats of the European patient summary guidelines would not make sense if all other patient data

are handled in the existing ways. It has also been noted by many countries and experts that the volume of cross-border patient flows is too low to justify significant investment by most Member States, unless that strategy can be aligned with other within in-border needs for semantic interoperability.

However, information support for the cross-border flow of patients has overshadowed consideration of other benefits from Member State alignment of semantic interoperability strategies and approaches. Many of the analytics uses listed above do also have drivers for Member State collaborations and comparisons. These include gathering and sharing patient safety intelligence (e.g. adverse event reporting, pharmacovigilance, pharmaco-epidemiology, Infection outbreak control), and sharing and comparing various benchmarks and quality metrics. There are, therefore, many reasons why Member States might wish to collaborate and benefit from collaborating around common terminology choices, and more broadly around common approaches to advancing semantic interoperability.

Clinical research is usually undertaken across countries, and the ability to combine research data sets is therefore an important business driver. Indeed the European Research Networks are the next priority for CEF services. There is value not only in sharing research data, but also being able to pool analyses that have been computed on consistent data held in each country: there would be value in registries, bio-banks, rare disease communities adopting common semantic interoperability approaches, irrespective of how often subject level data might be shared between them.

On a short term and pragmatic level, Member State co-operation on semantic interoperability can enable sharing of costs (such as clinical model development, term translations, RefSet and value set development, sharing best practices and quality assurance processes, and all countries being able to take advantage of internationally agreed definitions of concepts. This is not in itself a driver for investing in semantic interoperability, but may influence decisions about what semantic interoperability approaches to select.

5 Adoption strategy

National adoption requires national governance. The adoption strategy, this section of the guideline, builds on the business drivers and determines where in the health ecosystem the terminology system will initially be embedded, and subsequently scaled up. This may be specified in terms of the kinds of organisation and ICT systems that will initially deploy the terminology, the kinds of specialty or care pathways within which it may be used, the kinds of reporting or analytics it will be used for, and/or the existing terminologies it is to replace. It is also important to determine at the outset whether it will primarily be used fully "behind-the-scenes" as a tool for mapping existing coded concepts and terms to improve their interoperability (e.g. for cross-mapping, as a pivot representation) without being obvious to the end users of those systems (i.e. as a reference terminology), somewhat “behind the scenes” by being mapped and storied within clinical applications from the (unchanged) terms presented to end-users, or if it will be visibly delivered through applications for direct data entry or review, as an end-user terminology (also known as an interface terminology).

Other elements of the adoption strategy will include policy instruments that may need to be enacted in order to permit or to encourage the evolution of systems, practices, reimbursements, procurements etc. to promote the adoption of the new terminology system. Policy instruments might also be required to remove barriers to change, such as to replace existing paper based statutory reporting systems with electronic ones.

Importantly, the adoption strategy should determine a high-level business model and financial model for change, in order to ensure that organisations are sufficiently resourced (or incentivised) to invest in the necessary change processes. This may include ring-fencing budgets for procurement of new or replacement ICT systems that conform to the new terminology and wider semantic interoperability strategy.

The adoption strategy should be clear about which support services and infrastructure is will be provided and funded centrally, perhaps on a national basis, such as terminology competence centres, terminology distribution networks, the development of tools, the development of value sets and clinical models, education and training resources and events, and of course the overall licensing arrangements including secondary uses of the terminology system such as educators, researchers and product developers.

Organisational changes will be needed in order to enable the adoption of a new terminology especially if it will be used in new documentation or analytics situations. Organisational changes may also be needed for benefits realisation: e.g. to take advantage of new sources of learning and new opportunities for collaboration.

At national and local levels, it will be essential for key stakeholders to be advised of, and consent to, responsibilities they will take in implementing the adoption strategy.

5.1 Developing the adoption strategy

Multi-stakeholder consultations and evidence gathering are vital, to determine the right adoption strategy. One of the very first questions a MS has to answer is whether it is intended to use the new terminology system in full, or to work on a subset of it (for example by developing a national RefSet like Belgium), or even more narrowly in particular use cases (like Lithuania), care settings or specialities (at least, initially).

Starting with pilot projects that offer a manageable scope, willing participants and high value use cases provides the opportunity for organisations and stakeholders to tackle real world clinical, business and technical needs. Projects which are based on a strong business case that targets concrete clinical benefits through the establishment of health IT solutions

which translate structured data and vocabulary into better care decisions, reduced errors and reduced duplication, are the most likely to succeed [5]. Project are also most likely to succeed if there are already agreed information flows, information structures and semantic content, whether already implemented or not.

Examples of focused areas that are candidates for initial adoption include:

- Within existing data exchange messages, e.g.:
  - laboratory and pathology requests and reports
  - medicines / prescriptions, possibly including allergy lists
  - referral and discharge communications, including operative procedures
  - diagnoses and problem lists
- For exchanging standardised patient health summaries, or for populating nationally-held summaries
- For reimbursement/commissioning
- For populating and analysing patient (quality, disease, procedure) registries e.g. cancer, rare diseases
- For epidemiological surveillance e.g. communicable diseases

Example quotes from WP1 focus group experts

Netherlands: "Mapping the (structure and) content of registries to SNOMED CT will provide a stimulus for using SNOMED CT in clinical practice"

Denmark: "Almost all focus group members mention a positive business case as a core part of starting SNOMED CT implementation projects"

Denmark: "Terminology implementation should be prioritized and work should be organized so that there is actually time for it."

For further information on governance issues that need to be addressed in a national adoption strategy please see: http://www.ncbi.nlm.nih.gov/pubmed/25160179

6 Operational strategy

The decision to adopt a particular large-scale terminology system is not simply a binary one. This section of the guideline lists the additional decisions that have to be made as part of an operational strategy for adoption. One group of such decisions relates to how the terminology itself is to be used. A large scale international terminology is too complex to simply use "out of the box". Decisions have to be made about how much of it to use, in what kinds of "chunk", in which settings and in particular the extent to which term coordination is to be used, or not used, at least in the initial stages of adoption.

A terminology system cannot be used as the only component of health informatics standardisation. Decisions therefore need to be made about the kinds of information model, clinical model, message and interface standard and other informatics representations that will be used alongside the new terminology, or are already in use and (may) need to be adapted to accommodate the new terminology choice. Decision support and guideline rules also need to be developed or converted so that they will leverage clinical data represented using that new terminology; such rules and algorithms are one of the most important ways in which the benefits of adopting the new terminology will be realised.

It is unusual to be able to conduct a radical rip-and-replace approach to terminology change. Existing terminology systems may need to be retained, others only gradually phased out. The operational strategy therefore needs to include approaches for the coexistence of multiple terminology systems within given domains, settings and countries, and also what migration strategy is considered feasible to achieve, in terms of time, cost and stakeholder impact.

All of the above decisions will impact on the systems that will be created or adapted to use the nominated semantic interoperability solutions. The operational strategy therefore needs to include a strategy for legacy system migration, and take into consideration the time needed for the development and testing of new systems by vendors, their deployment across the geographical domain, embedding the systems into each organisation and its workflows, and training users to use the new systems and the new terminology systems well.

Education is an important part of the successful adoption of a new terminology strategy: terminologists and informaticians will need to become significant experts in the development of new value sets, translation of terms, developing mappings. Others, especially software developers who will possibly require an equal range of skills, will need to develop or adapt queries, algorithms, rules, and the tools and applications that use those, so that equivalent and hopefully better intelligence can be derived from data represented using that new terminology. Others will need less intensive and deep knowledge, but nevertheless a reasonable understanding of the hierarchical, probably poly-hierarchical, organisation of the new terminology, so that they can build end user applications, Interface specifications, report generators and undertake various business intelligence activities within healthcare provider organisations, health ministries or public health organisations. If the terminology is being implemented to provide user interface terms, end users who will select the terms through the process of clinical documentation or in a secondary way such as clinical coding, will need other kinds of training that help them to make the most appropriate term choice, and to foster consistent term selection practices within and between specialist domains.

6.1 Role played by the terminology

The strategy that is developed should be to advance the extent of the semantic interoperability of health data, and to realise benefits from that. However, the inclusion of a

large-scale terminology as part of that strategy will need to distinguish two distinct roles that the terminology can play within the health ICT ecosystem.

1. As a reference terminology. In this case the terminology acts as an organised library of concepts to which other terminology systems are mapped and clinical models are bound.

The development of a reference terminology is considered essential in order to support an overall "one entry, multiple use" policy: end users should not need to enter the same information multiple times using different terminologies or coding schemes. The systems used by healthcare professionals and others to capture and to view health data may not visibly change. The terminology is primarily used to optimise and maintain mappings to and from other terminology systems, although the new terminology might also be used within downstream systems such as registries, as well as supporting analytics. The terminology in effect functions as the common reference terminology for all future national mappings.

Example citations and quotes

"Using SNOMED CT as a cross-mapping reference terminology is one of the reasons for opting for it." [4]

"When deciding a strategy, the link between the SNOMED CT thesaurus and other cross-mapped thesauri or databanks such as the drugs database and the possibility to associate/combine SNOMED concepts need also to be considered as it can lead to an important reduction of distinct concepts." [4]

Finland: "Mapping the SNOMED CT terms with the codes of the current Finnish health information infrastructure would be a useful way to start the adoption process without too much change for end users."

2. As a user interface terminology. In this case the end users such as health professionals will have updated applications that offer them terms from the new terminology during data entry, and new clinical data will therefore be encoded with that terminology. This introduces greater adoption challenges, including verification that the terms chosen for adoption genuinely meet the users' documentation needs. Mechanisms will be needed to ensure that terms are selected and used consistently. The interface terms should normally be stored in the EHR, for legal purposes. Direct use of a high quality international terminology, on the other hand, has the potential to deliver a wider range of benefits.

6.2 Approach to subsets and language translation

To date the main natural language translation decision that countries have made is whether to translate the full set of terms, or only some of them. This issue has primarily arisen for SNOMED CT. The selection of which parts to translate, if not the whole, may be dependent upon the intended uses of SNOMED CT. Countries may choose first to define a single national RefSet (like Belgium), or to define value lists related to the population of clinical models and information models that will be used for specific use cases (like Canada, Lithuania), or the terms corresponding to terms that need to be mapped if SNOMED CT is to act as a national reference terminology.

The decision to translate SNOMED CT in full is costly but guarantees a full international linguistic interoperability. Cross mapping between systems and International interoperability resources remains preserved as the whole SNOMED CT concept set remains available. On the other hand a smaller terminology with distinctive concepts is easier to use (more efficient

for supporting fast and preferred choices in electronic clinical record-keeping) than a vast terminology with many rarely used quasi-synonyms. The decision to select only the concepts needed to support a specific use case is of limited cost but is not compatible with a global "terminology sever" strategy aiming at integrating all semantic resources at national level. [4]

Subsets might be generated from part of the SNOMED CT hierarchy, through mappings from an existing terminology, or from a collection of frequently occurring terms within existing EHR systems [6]. If SNOMED CT is proposed as an end user interface terminology, then the starting point for the translation exercise may not be the terms in SNOMED CT, but the language (and existing terms) used by clinicians and other people who need to enter health data. This existing language will need to be mapped to SNOMED CT Fully Specified Names (which need not always be translated, if the mapping can be performed by terminologists proficient in English). If this approach is followed then the impact on users and on end user applications can be minimised.

When planning and undertaking the translation itself, a combination of terminologist expertise and healthcare professional expertise is usually required. This is especially the case for the development of value lists, which are often associated with (or "bound to") clinical models (see below).

6.3 Approach to post-co-ordination

Term coordination is especially a feature of SNOMED CT. This is a formal approach to combining terms, including the relationships between them, in order to express a complex concept. There are many advantages with adopting this approach within a terminology system, especially the ability to computably recognise parts of the complex expression, as well as the expression as a whole. When the terminology includes coordinated terms as part of its official release, these are generally known as pre-coordinated concepts. Because they are part of the standard release, there is a strong likelihood that they will be used consistently.

However, because the rules for how terms can be combined are standardised, terms can also be combined (coordinated) by an adopting community, by particular developers of ICT products, and potentially by end users "on demand" when entering clinical data. This is known as post-coordination. The attraction of this is the ability for users to express nearly anything they might conceivably wish to state as a combination of one or more terms, even catering for clinical situations that were not anticipated when the terminology system was developed. The adverse effect, though, is that it can introduce such a degree of flexibility in the selection and combination of terms that the end result is inconsistent use of the terminology, including many different ways of representing nearly identical concepts, at worst not much better than using ordinary words (in free text).

It is recognised that it is difficult to build easy to use applications and interfaces to support post-coordination. ICT product developers would need to cater for the ability to receive a much greater diversity of possible terminological expressions from other systems, and potentially have to query and analyse much more heterogeneous data within their own repositories. The safety implications of this have not yet been formally evaluated.

Implementing post-coordination continues to be a challenge both from a graphical user interface design and clinical terminology point of view (e.g., creating clinically nonsensical concepts, concept duplication and inefficiency of concept composition). In some cases there are some alternatives to post-coordination, such as using an information model (where post-coordination effectively occurs behind the scenes). For example, instead of including the subject relationship context in a single post-coordinated expression, the relationship is stored as a separate data element. [6]

Post-coordination might initially be limited to qualifying key terms, using small value lists and/or within clinical models i.e. in very constrained circumstances and with limited combinatorial options.

6.4 Clinical model development

Clinical models are information models that define the structural relationships between a small number of data items that together represent the clinical data "ingredients" that care professional would use when documenting a single observation, finding, can activity or a planned course of action. Examples of clinical models are openEHR archetypes, EN ISO 13606 archetypes, HL7 Templates, HL7 Detailed Clinical Models, CIMI models. More ad hoc representations of clinical models are used in some countries, by some EHR system vendors, and by other communities.

There is as yet a limited number of such models that have gained strong evidence of endorsement and adoption, internationally, and most countries scaling up the semantic interoperability of their health data ecosystem will need to develop new clinical models, although they may obtain some existing models from other sources, and review these locally for possible adoption.

Clinical models are relevant because they are gaining recognition as the most useful granularity of information model to contain and group value lists of terms, making it easy for care providers to select only the relevant terms when entering health data, aiming to provide enough flexibility to cater for realistic documentation needs, whilst to some extent constraining the flexibility to optimise the consistency of data entered by multiple actors in multiple situations, when seeking to represent the same concept.

A library of clinical models, developed to support the documentation of care for given use cases, provides a series of "hooks" and contexts for the development of terminology value lists, which in turn provides a scoping to the challenge of term selection and translation when adopting a large terminology system. In order for a terminology system like SNOMED CT to be used alongside clinical models, it needs to define its semantic interface to such models, which is complicated by the fact that SNOMED CT effectively includes its own kind of information model (the Situation hierarchy).

There is growing experience, some of it now becoming published, in good practices in the development and the quality assurance of clinical models and their terminology value lists.

> *Example quote from WP1 focus group experts*
>
> *Sweden: "it is not sufficient to only consider terminologies but the terminologies in their information structure context"*

6.5 Terminology version management and distribution

Terminology systems are regularly revised, and released as updates (for example, six monthly for SNOMED CT). Each new release may have implications at a country level for language translation of terms, updating RefSets and other subsets, mapping tables to other terminology systems, and user applications that will provide updated term choices, repositories, queries and reporting systems. Some of these issues will be handled nationally, because they affect aspects of the National terminology infrastructure, and others will need

to be cascaded as notifications of change to ICT developers, health care providers and other organisations.

The mechanisms provided by a country for access to the latest version of national terminology systems therefore needs to be robust, supporting both a *pull* (any registered user can access the latest version of the terminology from any reasonable location) and *push* (registered users are notified when an updated version is now available, and can easily access information about what has changed).

In a highly connected country, direct communication of the EHR with a national terminology server or a network of collaborative terminology services is probably the best solution to guarantee an optimal universal service [4]. However, most European MS host only a simple web portal for access to terminology updates, which are often Excel files. They do not host a national terminology server, nor do they have short term funded plans to establish one

Example quote from WP1 focus group experts

Sweden: "Having easy access to the terminologies, e.g. through web interfaces, download sites etc. are seen as a key facilitator"

7 Resourcing priorities and strategies

Enhancing the quality of semantic interoperability across a healthy ecosystem, including the adoption of a new large scale terminology system, has important resource implications. Some of these, at the lower-cost end, can be absorbed by existing organisations such as healthcare organisations and ICT vendors. However, there are often some substantial efforts that need to be made to configure a terminology system for use within a national health ecosystem, and these are usually incurred at a national level. This section of the guideline lists the most significant such national resource implications encountered through our investigations, and also includes a few areas where the cost implications may be distributed but might require "stimulus packages" from a national budget. It is not possible to quantify the resource and locations for each of these items in generic terms, since the cost and effort implications will be country specific, dependent partly upon the existence human, organisational and ICT infrastructure and partly upon the national ambition in using the terminology system including the anticipated pace of change.

Developing expertise. Training staff in key national and local organisations to be able to support the national adoption, including translations, RefSet development, clinical modelling, terminology cross-mappings, legacy system migration, user interface (re)design, data entry and data analysis.

Terminology licensing. At present IHTSDO advocates national adoption and therefore a nationally priced license for SNOMED CT. Entry-level licenses can be negotiated for companies or pilot projects that are looking to make only a small scale implementation, either using small parts of the terminology such as value lists, or a very small scale deployment.

Language translation and quality assurance. It has been estimated by experts that a budget of around €3 million is required for full SNOMED CT translation, per language[1]. However the extent of translation may be influenced by the proportion of the terminology to be adopted, the point below.

Developing extensions, subsets, RefSets, value sets and binding to clinical models. This normally requires the establishment of a (national) Terminology Competence Centre, with multi professional and multidisciplinary engagement from health and social care, plus public health and research includes. Terminologist expertise is invariably required to support these stakeholders.

Defining and maintaining cross-mappings to existing and legacy terminologies in use. The initial costs can be high, but may diminish substantially if the legacy terminology systems are gradually phased out.

Terminology version management and distribution. This usually requires the establishment of a (national) Terminology Release Centre, which may be the same as the Terminology Competence Centre.

[1] This figure has been reported by experts within a national focus group discussion, but has not been validated

EHR system adaptation. This has many elements requiring investment, with the most important ones listed here:

- Vendor specific (internal) terminology management and mappings
- Database and EHR repository changes
- UI and application adaptions
- Handling of post-coordination, if adopted
- Legacy data migration
- Software and interoperability testing
- End user acceptance, clinical and safety validation

Other legacy system adaptations, for example:

- Disease and procedure registries
- Central (e.g. national) health activity reporting and reimbursement systems, and international reporting
- Population health screening and surveillance systems (e.g. infection control, pharmacovigilance)

Clinical end user training, coding staff and data analyst training, primarily:

- Development of educational materials
- Delivery of education programmes and onsite training, including the cost of staff time during training
- Organisational change processes during terminology changeover

Research and evaluations. It is important that a national adoption program reserves some budget for national or local projects to investigate optimal ways of leveraging the new terminology and to establish the evidence of benefits.

8 Success strategies

Enhancing the quality of semantic interoperability across a healthy ecosystem, including the adoption of a new large scale terminology system, has important resource implications. Some of these, at the lower-cost end, can be absorbed by existing organisations such as healthcare organisations and ICT vendors. However, there are often some substantial efforts that need to be made to configure a terminology system for use within a national health ecosystem, and these are usually incurred at a national level. This section of the guideline lists the most significant such national resource implications encountered through our investigations, and also includes a few areas where the cost implications may be distributed but might require "stimulus packages" from a national budget. It is not possible to quantify the resource and locations for each of these items in generic terms, since the cost and effort implications will be country specific, dependent partly upon the existence human, organisational and ICT infrastructure and partly upon the national ambition in using the terminology system including the anticipated pace of change.

8.1.1 Strategy and governance is needed at a national level, including adoption guidance

Example quotes from WP1 focus group experts

Denmark: "a clear national strategy for adoption helps to justify ICT vendor investment"

Germany: "It is essential to establish national terminology competence centres, to work on national terminology extensions and translations, maintenance, international knowledge exchange, publication issues, training, promoting and positioning"

Sweden: "a national level quality assurance process and system is needed"

Spain: there is one national terminology release center and some regional ones striving for close cooperation."

8.1.2 Adequately staff a national terminology competence and resource centre

8.1.3 Ring-fenced budgets should be allocated to organisations adopting a new national terminology system

- For national components such as expert work and infrastructure procurements
- To procure updated ICT products at care provider sites, and at national centres such as the hosts of registries
- To train clinicians and coders
- To adapt care pathways and workflows

8.1.4 Promote the benefits of structured and coded data, and especially of the chosen terminologies

- Demonstrate the benefit to patient care
- Demonstrate the benefit for public health
- Demonstrate the benefit to cross-organisational communications

- Specifically show how the new terminology system will bring additional benefits over the general benefits of improved infrastructures, more coded data and other interoperability standards

8.1.5 Translations, value set development, adoption and user education need to be targeted at delivering appropriate use cases

Example quotes from WP1 focus group experts

Germany: "Harmonisation is needed for secondary use: definition of data elements, with a limited number of value sets for each data element[2]"

8.1.6 Accompanying measures such as nationally developed mappings to other terminologies must be funded as a priority

Example quotes from WP1 focus group experts

Croatia: "an incentive to use SCT would be if the present reimbursement system based on ICD-10 was mapped to SCT"

Denmark: "suggests mapping clinical documentation terms to reimbursement codes to avoid duplicate coding"

8.1.7 The updated user interfaces must increase the speed of clinical documentation

- The goal is to have healthcare professionals coding without having the feeling that they are forced to assign codes: in a clinical setting, the matching between a lexical expression in a given language and the concept in the national reference terminology needs thus to be as fast and intuitive as possible. [4]
- User interfaces must enable clinicians to encode data during documentation, not post-hoc
- User interfaces and other tools must hide the complexity of SNOMED CT from end users

8.1.8 Train clinicians to use SNOMED CT as their user interface terminology

- Training may be more effective if the terminology is learned in the context of their EHR system and applications, rather than as an abstraction
- Limited training may be required in a new terminology if an existing user interface terminology is being retained, or if the choice of terms is highly intuitive

8.1.9 Promote user acceptance

- Clinicians must perceive increased coding as being for quality assurance and research, not to regulate their practice

[2] The term "data element" has been used here to mean a fine grained data item comprising a name-value pair.

- Seeking endorsement and engagement from professional associations

8.1.10 Support and fund organisational change processes

- Change management processes, maintenance processes and stakeholder facing tools are essential components

8.1.11 Good quality EHR data is needed at a national level before it can serve cross-border purposes

- However, this does not negate the value of early co-operation around alignment of choices and strategies, and mutual or pan-European collaboration on tools, translations, RefSet and value set development etc.

9 Challenges and barriers to SNOMED CT adoption

Terminology systems are not perfect, and nor are the ecosystems into which a new terminology is to be assimilated. This final section of the guideline lists, in bullet point form, the most important issues and problems that have been identified by existing projects and systems, drawn especially from focus groups of national experts held in several European countries, and a formal review of the literature in which a number of early pilot implementations have been described, including the issues encountered. This section focuses specifically on issues that seem to have been identified when adopting SNOMED CT. However, some of them are not unique to SNOMED CT, and might be risks or challenges with the adoption of any new large-scale terminology system on a national scale.

Table 1 at the end of the section lists some of the issues encountered in the literature alongside proposed mitigations. These issues, and in particular the mitigation strategies that might be used to address them, will be explored in depth during a workshop planned for December 2015.

9.1 Issues with terminology system(s)

The need to continue use of multiple local and international terminologies

- Incongruence of the hierarchies of different terminology systems
- Limited alignment between SCT and ICD makes mapping / migration difficult
- Naive approaches to terminology mapping and indexing would critically affect the performance, success and results of such applications
- EMA (clinical trials) and ECDC (infection outbreaks) use other terminologies, not SCT
- Most countries use other terminology systems for billing and statistical purposes
- Older versions of terms and code sets usually have to be maintained
- Need to maintain usage of classifications, both for secondary and primary purposes, together with an increased use of SNOMED CT
- Clinicians and coders code differently – perhaps due to insufficient training or local cultures.

Lack of translations of international terminologies into many European languages

- No evidence of benefit to countries that have invested in a full translation
- No clear guidance on how much or little of SNOMED CT needs to be translated in order to realise some initial benefits
- Lack of synonyms (i.e. the terms most often used by clinicians for documentation and communication) is a barrier, and having a system for managing these terms seems to be a challenge

Content coverage might not be enough to fully document the health and care for common conditions

- The Netherlands found content coverage for stroke to be around half of the concepts needed
- Radiology procedures cannot today be represented adequately using SNOMED CT
- Needs terms and a concept model for social care and care services, which are deficient in SNOMED CT

- Need improved coverage over all care professional domains (e.g., allied health professionals, nursing, care and cure)

Size and complexity of SNOMED CT

- The lack of a user interface terminology
- The SNOMED CT hierarchy is missing concepts making some queries difficult to execute
- Representation of some complex compositional expressions require semantics not present in SNOMED CT (e.g. negation)
- The SNOMED CT hierarchy is frequently updated, effectively changing the results of analysis queries that use the hierarchy
- Perception of immaturity of SNOMED CT for large scale system implementation
- Errors exist in SNOMED CT, finding them is difficult
    - Inconsistent modelling of a significant portion of the concepts, affecting computability (e.g. “Amputation of the toe” is a kind of “Amputation of the leg”)
    - Inconsistency and redundant representations of identical information
    - No easy way for terminology users to report discovered errors
- May be too large and clumsy for usability
- Perceived complexity may be the issue rather than real complexity
- Lack of knowledge on SNOMED CT is an important barrier for SNOMED CT adoption. It is somewhat intuitive to grasp how a classification works. But understanding the meaning and purpose of an ontology-based terminology like SNOMED CT is a challenge, like understanding how to utilize this complex structure for the range of purposes, which SNOMED CT claims to be able to support.

Value set development needs to be carefully co-ordinated

- Need to ensure that value sets defined within different clinical models are consistent if their purpose is the same
- Terms can have different meanings in different contexts (which might be dictated by the clinical model(s) in which value sets are used)

Post-coordination requires some use of description logic (steep learning curve)

- There is the risk of a high error rate with post-coordination, which ideally should be undertaken using a description logic approach[3]
- SNOMED CT post-coordinated expressions need to be queried using description logic, not standard query languages like SQL

Terminology version management is complex and costly to manage

- Bi-annual revisions of SNOMED CT undermine large scale mapping efforts of extensive proprietary concepts systems
- The sheer volume of concepts could make auditing a large terminology, such as SNOMED CT, a daunting task

SCT licensing issues

- The high cost of a national licence might be mostly a perception issue, as the licence fee is not so high when taking into account the overall expenditures involved in the adoption of a new terminology system at a national scale

[3] However this would require a more expressive language for the upper level, together with high performance reasoners.

9.2 Issues with other interoperability standards

- Lack of nationally-agreed information models and clinical models to enable EHR interoperability is a barrier to SNOMED CT adoption[4]
- SNOMED CT tools for browsing and selecting terms are hard to use and that combined with, in case of some vendors limited support for SNOMED CT in EHRs, is another barrier to use
- Stakeholders across Europe including Estonia, Germany, and Austria, recognising the benefits of international standards and profiles, have worked with SNOMED CT in HL7 CDA and FHIR; they reported difficulties and complexity in mapping to/from other terminologies, and also in combining the declarative logic of SNOMED CT with CDA documents
- They also noted that a lack of consensus on structured EHR data forms i.e. clinical information structures or templates, is a barrier to SNOMED CT adoption and EHR interoperability
- In the context of health information exchange, extracting data from clinical applications or EHR systems to populate CDA documents by selecting the proper SCT codes is not straightforward. Incorporating the right SCT value sets requires at the moment, costly specialised expertise.

9.3 Issues with health ICT products and marketplace

Difficult to stimulate the market: vendor adoption is low (although national vendors may find it easier to enter a pan-European market place if EU MS have consistent terminology strategies)

Products that incorporate SNOMED CT tend to be more expensive

- SNOMED CT adoption might take vendor resources away from other product improvements and updates

Few products support post-coordination

- It is difficult to design a post-coordination interface that is intuitive and unobtrusive

Complexity of system redesign or adaptation is underestimated and not budgeted for by procurers

- Lack of common strategies for navigating and selecting concepts, especially given the rich variety of synonyms and spelling variants in use
- Complexity of SNOMED CT implementation in tertiary care where specialists collaborate across several disciplines

Lack of procurement expertise

- Lack of essential competencies, both on the side of the users of health information and, particularly, when procuring health information systems
- Procurements vary as to their required support of terminologies

[4] This situation is in practice worse, since most information models in use (e.g. in legacy EHR systems in use) are completely disconnected from information model standards

9.4 Other barriers to adoption

Lack of an adoption strategy/pathway and co-ordination, for newly-adopting countries

- Ill-prepared large scale introduction of SNOMED CT in nations, may disrupt existing longitudinal data collection, if no attention to legacy conversion is given

License costs

- The expensive national-scale licensing model inhibits smaller scale piloting and experimentation, to build up experience and locally-relevant evidence

Limited number of concrete national eHealth programmes and projects that could use SNOMED CT

Limited expertise to undertake translation

- Lack of experts, would take a long time using SNOMED CT to reach the current level of data quality using ICD
- Greater need for know-how for translations and mapping than may be currently available in some countries

Lack of good quality structured and coded data in EHR systems

- Need for best practice guidance on how to improve the level of structuring and coding within EHRs
- The existence of vague concepts in guidelines, difficult to link to any nomenclature or classification
- It is important that the adoption is clinically led, not IT led

End user acceptance

- Acceptance of a different unfamiliar terminology
- Acceptance of the expectations of greater levels of coding
- Perception that existing terminologies and classifications suffice for the required purpose
- In the pharmaceutical sector strong and widely used reference terminologies exist, without a perceived need for change

Overall cost of adoption

- The “cost” of the change management process: it is a long incremental process, with the need to manage the human resistance to change

Lack of published concrete evidence of benefits

- Low awareness about the actual return of investments (not limited to the economic aspects)
- The majority of published studies of SNOMED CT focus on 'theoretical' and 'pre-development/design'
- Systematic reviews of the effectiveness of decision support systems do not contain studies based on SNOMED CT codification
- Poor results of surveys of implementation projects
- Lack of examples of international cross-national comparative epidemiological research based on SNOMED CT
- Pilots / proofs of concept are needed to show implementability, usability, and quality and completeness of content

- Proof of concept is needed demonstrating the effectiveness and efficiency of capturing and using data with SNOMED CT as a reference terminology
- There is currently a lack of good examples which explain the benefit of standardised terminologies, at least on the national level
- Low awareness about the actual return of investments (not limited to the economic aspects)
- Too little empirical evidence of benefit
- Evidence is needed to which extent NLP approaches have the potential to automatically provide SNOMED CT encodings of reasonable quality

Some of the these SNOMED CT specific barriers have been derived from the literature, and are repeated below in Table 1, linked their specific citations, together with some suggested remediating interventions.

Table 1: Barriers to SNOMED CT implementation and remediating interventions

	Reference	Barrier to implementation	Suggested remediating interventions (where known)
1		Delineation of concepts by formal logic instead of human classical definition	Linguistic definitions of core concepts for human use
2	Cornet et al., 2013? Karlsson et al. , 2014	Complexity of the compositional terminology for post-coordination. A high error rate in post-coordinated terms.	More functional and capable reasoners for user guidance in post-coordination. The results of a preliminary study using proxy measures must be taken with caution. However, the high rate of misclassification indicates that, until -Better documentation of specifications for qualifiers. ---- Qualifiers more in line with common clinical usage. - automatic system of rules within the Terminology Server
3	Rodrigues et al., 2014 Schulz et al., 2014	Incongruences between concepts maps of SNOMED CT and conceptual hierarchies of other classifications	Common ontology for SNOMED CT and ICD
4	Højen et al., 2014 Randorff Højen et al., 2012	Inconsistency and redundant representations of identical information.	Logical repair of historical integration of several specialized terminologies on similar subjects. Systematic terminology binding checks with architypes in real-life EHR-systems and existing medical guidelines.
5	Højen et al., 2014	Perception that existing terminologies and classifications suffice for the required purpose	Demonstrate superior performance for specific purpose
6	Højen et al., 2014	Perception of immaturity of SNOMED CT for large scale system implementation	Demonstration of successful large scale large system implementation
7	Højen et al., 2014 (b)	Lack of common strategies for navigating and selecting concepts	an interactive web-based terminology visualization tool TermViz (provides an overview of concepts and their hierarchical relations).

8	Agrawal et al., 2014	Inconsistent modelling of a significant portion of the concepts (in the most semantically complex hierarchy of SNOMED CT, the Procedure hierarchy, and possibly in other sections of the hierarchy, e.g. problem list), affecting their computability.	-Group auditing techniques. -Construction of structural indicator to effectively ferret out potentially problematic concepts where those QA efforts should be focused.
9	Lee et al., 2014	The majority of published studies of SNOMED CT focus on 'theoretical' and 'pre-development/design'. Poor results of surveys of implementation projects	More implementation projects should be reported in the scientific literature. Searches for implementation research should go into “grey” literature
10	Brown et al., 2006	The lack of a linguistic interface terminology. SNOMED CT is promising as a terminology for knowledge representation underlying a large general medical evaluation. It performed less well as an interface terminology.	Address the very frequent term variation.
11	Kokkinakis, 2011	Naïve approaches to terminology mapping and indexing would critically affect the performance, success and results of such applications	Assess the validity, reliability and coverage of the comprehensive SNOMED CT translations (e.g. the Swedish translation).
12		Lack of graphical user interface	Innovative visualisation of hierarchies, formal logical relations,
13	Liu et al, 2010	Complexity of SNOMED CT implementation in tertiary care were specialists collaborate across several disciplines	Highly sophisticated visual interfaces of SNOMED CT values and subsets, in confrontation with template specifications
14	Ahmadian et al., 2010	The existence of vague concepts in guidelines, difficult to link to any nomenclature or classification	Formalisation of guidelines with SNOMED CT. Education of guideline producers.
15	Wade et al., 2009	Bi-annual revisions of SNOMED CT undermine large scale mapping efforts of extensive proprietary concepts systems.	Auditing the processes used in terminology development to include the impact that their revisions may have on real-world clinical implementation.
16	Wang et al., 2008	The sheer volume of concepts	

		make auditing a large terminology, such as SNOMED CT, a daunting task.	
17	Rosenbloom et al., 2009	Representation of some complex compositional expressions require semantics not present in SNOMED CT.	Enrich SNOMED CT semantics
18	Smith, 2008	Attempts to agree on meanings of terms are traditionally based on three concept-based approach in biomedical terminologies (Cimino, Wüster, and Campbell). Terminology construction should be motivated by the goal of alignment not on concepts but on the universals (kinds, types) in reality and thereby also on the corresponding instances (individuals, tokens).	Auditing reference terminologies with semantic web techniques.
19	Moja et al., 2014	Systematic reviews of the effectiveness of decision support systems do not contain studies based on SNOMED CT codification.	
20		No examples of international cross-national comparative epidemiological research based on SNOMED CT	
21		In the pharmaceutical sector strong and widely used reference terminologies exist, without a perceived need for change.	
22		Ill-prepared large scale introduction of SNOMED CT in nations, may disrupt existing longitudinal data collection, if no attention to legacy conversion is given.	
23	Mortenson et al., 2014	Errors exist in SNOMED CT, finding them is difficult	Applying a crowdsourcing methodology to identify errors in SNOMED CT
24	Andrews et al., 2007	Variation in the use of SNOMED CT	

Reference list for Table 1

- Agrawal A, Elhanan G. Contrasting lexical similarity and formal definitions in SNOMED CT: consistency and implications. J Biomed Inform. 2014 Feb;47:192-8.
- Ahmadian L, Cornet R, de Keizer NF. Facilitating pre-operative assessment guidelines representation using SNOMED CT. J Biomed Inform. 2010 Dec;43(6):883-90.
- Andrews JE, Richesson RL, Krischer J. Variation of SNOMED CT coding of clinical research concepts among coding experts. Journal of the American Medical Informatics Association. 2007. 14(4), 497-506.
- Bakhshi-Raiez F, de Keizer NF, Cornet R, Dorrepaal M, Dongelmans D, Jaspers MW. A usability evaluation of a SNOMED CT based compositional interface terminology for intensive care. Int J Med Inform. 2012 May;81(5):351-62.
- Brown SH, Elkin PL, Bauer BA, Wahner-Roedler D, Husser CS, Temesgen Z, Hardenbrook SP, Fielstein EM, Rosenbloom ST. SNOMED CT: utility for a general medical evaluation template. AMIA Annu Symp Proc. 2006:101-5.
- Højen AR, Elberg PB, Andersen SK. SNOMED CT adoption in Denmark--why is it so hard? Stud Health Technol Inform. 2014;205:226-30.
- Højen AR, Sundvall E, Gøeg KR. Methods and applications for visualization of SNOMED CT concept sets. Appl Clin Inform. 2014 Feb 19;5(1):127-52.
- Karlsson D, Nyström M, Cornet R. Does SNOMED CT post-coordination scale? Stud Health Technol Inform. 2014;205:1048-52.
- Kokkinakis D. What is the coverage of SNOMED CT®on scientific medical corpora? Stud Health Technol Inform. 2011;169:814-8.
- Lee D, Cornet R, Lau F, de Keizer N. A survey of SNOMED CT implementations. J Biomed Inform. 2013 Feb;46(1):87-96.
- Lee D, de Keizer N, Lau F, Cornet R. Literature review of SNOMED CT use. J Am Med Inform Assoc. 2014 Feb;21(e1):e11-9. doi: 10.1136/amiajnl-2013-001636. Epub 2013 Jul 4. Review.
- Liu J, Lane K, Lo E, Lam M, Truong T, Veillette C. Addressing SNOMED CT implementation challenges through multi-disciplinary collaboration. Stud Health Technol Inform. 2010;160(Pt 2):981-5.
- Moja L, Kwag KH, Lytras T, Bertizzolo L, Brandt L, Pecoraro V, Rigon G, Vaona A, Ruggiero F, Mangia M, Iorio A, Kunnamo I, Bonovas S. Effectiveness of computerized decision support systems linked to electronic health records: a systematic review and meta-analysis. Am J Public Health. 2014 Dec;104(12):e12-22.
- Mortensen JM, Minty EP, Januszyk M, Sweeney TE, Rector AL, Noy NF, Musen MA. Using the wisdom of the crowds to find critical errors in biomedical ontologies: a study of SNOMED CT. J Am Med Inform Assoc. 2014.
- Randorff Højen A, Sundvall E, Rosenbeck Gøeg K. Visualizing sets of SNOMED CT concepts to support consistent terminology implementation and reuse of clinical data. Stud Health Technol Inform. 2013;192:1160.
- Rector A, Iannone L. Lexically suggest, logically define: quality assurance of the use of qualifiers and expected results of post-coordination in SNOMED CT. J Biomed Inform. 2012 Apr;45(2):199-209.

- Rodrigues JM, Schulz S, Rector A, Spackman K, Millar J, Campbell J, Ustün B, Chute CG, Solbrig H, Della Mea V, Persson KB. ICD-11 and SNOMED CT Common Ontology: circulatory system. Stud Health Technol Inform. 2014;205:1043-7.
- Rosenbloom ST, Brown SH, Froehling D, Bauer BA, Wahner-Roedler DL, Gregg WM, Elkin PL. Using SNOMED CT to represent two interface terminologies. J Am Med Inform Assoc. 2009 Jan-Feb;16(1):81-8.
- Schulz S, Rodrigues JM, Rector A, Spackman K, Campbell J, Ustün B, Chute CG, Solbrig H, Della Mea V, Millar J, Brand Persson K. What's in a class? Lessons learnt from the ICD - SNOMED CT harmonisation. Stud Health Technol Inform. 2014;205:1038-42.
- Smith B. From concepts to clinical reality: an essay on the benchmarking of biomedical terminologies. J Biomed Inform. 2006 Jun;39(3):288-98.
- Wang Y, Wei D, Xu J, Elhanan G, Perl Y, Halper M, Chen Y, Spackman KA, Hripcsak G. Auditing complex concepts in overlapping subsets of SNOMED. AMIA Annu Symp Proc. 2008 Nov 6:273-7.

10 Reference sources

[1] ASSESS CT D1.1 questionnaire results

[2] ASSESS CT D1.2 focus group results

[3] ASSESS CT D3.1 Assessment Framework

[4] EHGI - Making use of SNOMED CT

[5] Building the Business Case for SNOMED CT, Buchanan and Koehn

[6] A survey of SNOMED CT implementations, Lee, Cornet et al (2012)