eHealth Governance Initiative eHGI

Information Paper

MAKING USE OF SNOMED CT: KEY QUESTIONS and STATUS as of SEPTEMBER 2013

1. Introduction

This document aims at explaining in a synthetic way why certain Member States (MS) have decided to use SNOMED CT (Clinical Terms) and what role that terminology plays in their overall strategy for semantic interoperability.
The MS which have contributed to this paper are those that are currently members of the IHTSDO (International health Terminology Standard Development Organization), the organization responsible for producing SNOMED CT.

2. Rationale for using SNOMED-CT

A number of European MS, 13 (including Belgium), have -to date- decided to join the IHTSDO. Joining the IHTSDO allows the MS to get direct access to the terminology and information about its use and IHTSDO terminology resources, as well as being able to influence the development of the terminology.
The rationale for deciding to join the organization and to make use of SNOMED CT is usually based on one or all of the following considerations:

- The ***Electronic Health Record (EHR)*** and clinical information must be as much as possible the ***starting point*** for any medical data sharing. Re-creating data for multiple purposes must be avoided as much as possible. This demands structured data to support care and EHRs.

  Narrative text is not adequate as a starting point; structured (including encoded) text is needed for cross-border interoperability, data re-use and "processability", decision support and portability of citizen's health data in an open eHealth environment.

- The role of standardized terminologies: the path to structured, encoded and interoperable health data needs support from a general-purpose terminology system with a specific set of fundamental features[1]

[1] *Should be concept-oriented and designed to be multilingual*
Should have a methodology to adapt to upcoming needs of healthcare
Should be fit for left-side and also right-side semantic standardization
Should have the potential to be used in knowledge-based systems
Should have a strong potential to be an international standard

Although currently imperfect, there is no real alternative to SNOMED CT at this time if one wants to provide a fine grained and multi-disciplinary care terminology which, despite primarily being meant for clinical records and communications, is enabled to cover the needs of all related sectors (administration, social care, research, secondary data use). SNOMED CT provides a very comprehensive set of clinical concepts together with an ontology which organizes these concepts. This set serves as a global conceptual resource for the SNOMED CT user community but can be adapted by each MS provided that a few key principles are respected.

- The increasing complexity of patient care requires content in the EHR to be unambiguous and understandable to multiple care providers, to be comprehensive and to provide relevant and rich detail; this has not always been the case in paper records. The use of a national/international set of structured terms for fast (and legible) selection in care record keeping supports this aim and clinical specialties that have adopted SNOMED CT are working towards structured records with comprehensive structured (i.e. machine processable) data content.

- The objective is to effectively integrate appropriate semantic resources formally used in a given territory to address a variety of information requirements (clinical, financial, epidemiological, research etc.). IHTSDO has as an objective to achieve collectively, within the limit of resources made available by its members , the integration (mapping) of key available international semantic resources such as LOINC, ICD, ICPC -only to name a few- with SNOMED CT. The mapping with national legacy systems remains the responsibility of individual MS. Special interest and projects groups have been setup to support specific needs and harmonization work. This work is needed for transition purposes but in the long run convergence is highly desirable because of the amount of resources needed to obtain the integration.

  The decision to use SNOMED CT does not thus exclude the use of other semantic resources but it supports the idea that the codification of data needs to start from clinical concepts usable at the point of care. It is then the role of national "terminology servers" (or translation engines) to allow automated conversions between coding systems. In some countries this will be done with decentralized terminology servers, which is a decision the terminology system allows.

- SNOMED CT is thus seen as an essential but partial element of a semantic interoperability strategy; this strategy ultimately aims at allowing clinicians to code data without ever seeing any code and preserving the quality and precision of the data. Physicians do not need to understand SNOMED CT, the EHR makes every day work more safe and efficient for staff. Professionals use SNOMED CT by recording their

preferred clinical terms or expressions, allowing the real-time encoding of information at the point of care.

3. Preparing SNOMED-CT for national use

3.1: Full set, sub-set, use case set: Translating what and by whom?

One of the very first questions an MS has to answer when entering IHTSDO is to decide if it will use SNOMED-CT ***as such*** or if it will decide to use only a part of it. In the latter case, the choice can be to work on a ***use case*** approach, like Lithuania, or on a **national refset** approach, like Canada or Belgium. One has then to first proceed with a ***selection*** of the SNOMED CT concepts which requires adoption of a selection methodology, competent and trained human resources and the elaboration of implementation or user guidelines. There is much availability of material, guidelines and selections of refsets already made within IHTSDO or in one or more of its member countries which can support this work through not having to start from scratch.

As English is not the official language of most EU MS, SNOMED CT needs to be translated in the official MS language(s) of each MS. For MS which have several official languages, this burden of translation is even more important although it can potentially be shared with other MS. An example is Spain accessing the IHTSDO Spanish translation being able to do adjustments and review of this into Spanish rather than translating all on its own.

Those choices have of course important implications.

- The decision to translate SNOMED CT ***as such*** is costly but guarantees a full international **linguistic** interoperability. A full translation provides a thorough quality review of the content but also allows for knowledge to be built within the country. The question of the "usability" of SNOMED CT "as such" remains however intact.

- The decision to build a ***broad national refset*** based on SNOMED CT which is translated in national language(s) is also costly as it requires important resources to deal with the selection of concepts. The arguments for such a decision are the following:
    - Not all SNOMED CT concepts are intended for use as data within the clinical record. Some concepts only have navigational purposes for browsing or locating related concepts in the terminology.
    - 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 costs of maintenance and translation are more limited.

- The data model of the electronic medical record makes some concepts superfluous. E.g. concepts with a time indication (old, first trimester,...) can be eliminated because the birth date, date encounter, start and stop date of clinical findings and procedures are already known and should not be covered by extra terms.
- A combination of primary concepts in one term is to be avoided because it leads to an explosion of concepts. Moreover, primary concept may need a separate registration because they have called for specific care paths and care takers.
- Cross-mapping between systems and International interoperability resources remains preserved as the whole SNOMED-CT concept set remains available. Imported SNOMED-CT codes not present in the national refset are however not (necessarily) available in national language.

After a review of SNOMED CT, certain concepts can be considered as obsolete, ambiguous, unspecific, unusable or not adapted to national context. Consequently the national refset is considered more efficient and responsive to use while preserving a high level of granularity. The result of the work should ideally be validated by other countries contributing to a new international SCT 'subset'.

- 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. It will not provide full semantic interoperability but the ability of identifying European refsets like in epSOS or "professional specialty refsets" provides selected interoperability.

Member States also have different strategies when addressing the question of how to proceed with translation: Using translators, using healthcare professionals or a mix of both. When a strategy of pre-selection of concepts is chosen, use of healthcare professionals is usually the rule. There is a recommended process of translation identified within IHTSDO which is clearly described in documentation.

3.2 Pre and Post-coordination of concepts:

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.

Pre-coordinated concepts are the de facto standard in most electronic health records. Therefore, recorded concepts tend to be very much pre-coordinated at present.
However, the combination of primary concepts and their attributes duplicate pre-coordinated terms. This duplication in encoded representation may cause

difficulties in interpreting content as equivalent in certain conditions.
Typical instances of combined concepts are all the axis modifiers, such as 'absence of' 'family history of', etc.
Encoding concepts with their causing agent (biological, chemical, physical) is another source of a never-ending number of combined concepts.
Furthermore, some attributes can be coded in an alternative coding system to SNOMED CT. E.g. when the medication is coded in ATC, post-coordination of adverse events should be post-coordinated with ATC to avoid redundant coding.

Such a choice of "post-coordinated concepts" however relies on the willingness of the software industry to implement a certain number of functional specifications and rules. A users' ability to post-coordinate clinical terms (i.e. construct multi-faceted encoded statements) in care records thus depends on support from IT developers. This is thus at best a mid-term strategy and in the short term it is usually accepted to keep more pre-coordinated concepts than ultimately needed.

4. Dealing with National Legacy Systems, Standards and International standards development organizations.

The development of a national reference terminology is critical in order to support the overall "one entry- multiple use"[2] policy. As mentioned above, using SNOMED CT as a cross-mapping reference terminology is one of the reasons for opting for it. The standardization work at national level has often been developed in an ad hoc, silo based and incremental way. The political decision to align standards and legacy systems is thus essential but is a time and resource consuming process.

For some legacy systems, the mapping exercise is pretty limited but even in this case, it requires a very close collaboration with all users in order to come to an agreement on a "convergence" calendar. It is however important to start at one point in time and to immediately align any new development.
One has in particular to revisit and map all the concepts embedded in standard messages and registries. Mapping with systems used for reimbursement is particularly challenging but needs to be considered as early as possible as it usually requires a lot of human input and is of critical importance for users and therefore critical for the successful introduction of SNOMED CT. This is all depending on how far along the implementation of EHR a country is, ie starting from "scratch" or making changes to an existing platform.

In order to map between systems and to allow an integrated maintenance of both concepts and rules, the investment in a ***TERMINOLOGY MANAGEMENT SYSTEM***[3] is a must. The market is today quickly evolving and available products are equipped with enriched functionalities such as fuzzy mapping which makes

[2] A single entry allows registration in multiple systems intended for different uses.
[3] IHTSDO has developed a system both for maintenance of the core (international) terminology and for use by MSs who want to translate, maintain and distribute the terminology. However available functionalities do not always match with MS needs.

possible (pre)automated conversion support. Although the added value of such a tool looks obvious, the decision to make the investment is not easy to take given its relatively high cost and the fact that it remains for now a "niche" market. It's a long term investment which is not always easy to make but one which will provide large benefits in the end.

5. User Interfaces (Run time components)

Investing in a national reference terminology and creating the conditions for its national maintenance is an absolute prerequisite but is far from sufficient to make it "usable" by final users.

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. In order to achieve this, state of the art code conversion, syntactic and semantic functionalities need to be embedded in the EHR. Given the high fragmentation of the EHR market, the level of investment required, and the language dependency, it is probably not realistic to expect that each EHR provider will be able to deliver those functionalities at an acceptable level of price and performance. Public authorities could leave the development and implementation of terminology interfaces entirely to the industry. However the Health Authorities could test key providers of semantic technology making results public (pre-procurement public assessment). They could eventually even negotiate conditions in case of a contract for a larger group of users.

In many instances, providers of terminology management systems do also provide run time components.
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 and, at the same time, to allow an interactive maintenance of the resources with the input of the final users. Observing end-user patterns of terminology use and identifying the most frequent combinations and trends of terminology search and selection is a source of potential economies of scale and usability enhancements.

6. Testing and validation

Before putting the SNOMED CT based national refset to life, preliminary tests in different environments are necessary in order to guarantee sufficient robustness and its usability. As mentioned above, this also requires specific agreements with the industry.

However the work and expertise present in the several MS implementing SNOMED CT can also be used to support validation work and/or diminish costs:

- Cross-comparison of methodologies used for selection of SNOMED CT between MS (provided that scope is identical)

- Cross-validation of translated set or sub-set in one specific language or reuse of those translations (provided that SNOMED translation rules have been applied). One example is epSOS.

Furthermore, exchange of information on quality, performance and price of existing tools (terminology management system, run time components) would also be highly beneficial. Common tender could also have a significant impact on costs.

7. Costs

Aside from the "entry" and license costs to IHTSDO (to cover joint priorities and work such as cross-mappings to other standards and maintenance and update of the international core of SNOMED CT) which is calculated according to national GDP, the development of a national terminology server requires substantial additional resources.
Here is a non-exhaustive list of those associated costs:

- Selection and validation of concepts: qualified healthcare professionals
- Translation of concepts: translators and/or qualified healthcare professionals
- Participation in IHSTDO Special Interest Groups and projects: Human resources
- Permanent coordination structure: "national terminology (release) center": Qualified Human resources
- Mapping with other (legacy) systems: terminologists
- Terminology management system: licence/usage costs
- Terminology server infrastructure costs
- Run time components: licence/usage costs
- Testing costs

8. Market Development

The adoption of an international terminology has a number of benefits both to the ability of EU healthcare vendors to compete in other markets, but also to improve the quality of healthcares systems in the EU as it reduces the burden of development through reducing the different country specific approaches. The adoption of a single international terminology will enable:

- Specialist niche suppliers to emerge that can lever the terminology and its modeling to improve current functionality
- Suppliers to deliver products across the EU and beyond as they can develop to a single terminology and coding system
- Reduced cost of healthcare systems in the long terms as maintenance of the terminology, subsets, query and report specifications, business rules for decision support and medical alerts etc is not hospital/country specific
- Improvement of vendor healthcare systems as development can focus on functionality and less on terminology and mapping maintenance

9. Annex:

- Description of choices and current status in each MS.