Management of Reference Sets by Healthcare Professionals

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Audience
People that are interested in healthcare professionals developing and managing their own clinical terms of their specialty and how this is dealt with in the Netherlands. People who are interested in how can be dealt with the problems that come up when there is no translation to the nation native language available and how is dealt with jargon of different specialisms.

Objectives
Describing a tool for healthcare professionals for creating and managing terminology subsets. Describing a procedure for developing and managing terminology Reference Sets from different clinical specialties/domains with different jargon.

Abstract
In health information systems diagnoses sets and procedure sets are used to register medical data. These sets are based on SNOMED CT or another terminology system. Ideally the sets are created and managed by a group of healthcare professionals that are the owner of this content. Nictiz, as the National Release Center in the Netherlands, developed a reference set tool in which reference sets, for example based on SNOMED CT, are managed by care professionals. The reference set editor is a user friendly tool, where it is possible to search for (SNOMED CT) concepts and add or remove concepts to/from the set (by searching or by using the hierarchy). In this tool it also is possible to manage relations (mappings) to other terminology systems and to relate translations (descriptions) to concepts.

Our experience is that the workbench is not suited to be used by care professionals, so the workbench is used as release tool. The set defined by the care professionals (in the reference set tool) is loaded into the IHTSDO workbench, and from there the sets can be released together with the SNOMED CT international release. If there are descriptions that could not be related to a SNOMED CT concept, a new concept is created in the workbench, assigned a code and added to the national extension, which is released together with the international release. In the workbench it still is a challenge to use and integrate the reference sets together with the synonyms and different translations (including jargon per specialism) the correct way.

One of our most recent use case is the optometric terminology. It is a very small field (800 diagnoses and 4 system suppliers) and therefore very suitable as a first real implementation to learn from the experience. Besides that the optometry is not a standard domain with preselected diagnoses and procedures, so they have to select them their selves. They work in a shop (to sell lenses and spectators), so their system is different from the standard care organizations, but they do have to communicate with ophthalmologists and general practitioners, which have their own jargon and reference set.

The optometrists needed a proper diagnoses and procedures set for the client (patient) record, referral and in the near future for billing purposes. After consultation with Nictiz they decided that SNOMED CT would serve their needs. With the reference set tool the optometrists defined reference sets of diagnoses and procedures for use in their information systems and added (Dutch) translations where needed. No extension
to SNOMED CT was needed in this case. The reimbursement codes will be related to the SNOMED CT concepts in the reference set tool by the optometricians in a later stage. A link to ICD10 for statistical purposes will also be made available.

The example shows how SNOMED CT can be used in a real life environment and which steps and tools are necessary to support a group of healthcare professionals. The user group thus can feel and indeed are responsible of their own terminology lists. A good procedure and (national) terminology server is necessary to ensure that the descriptions the healthcare professionals are using are related to the correct SNOMED CT concepts. The example is just one of the many (sub)specialisms that will be dealt with in the future in the Netherlands.