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eHealth Terminology Management in Austria

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Abstract. When it comes to establishing and operating a nationwide personal health record (PHR), effective and efficient terminology management including the development, administration, maintenance and publishing of terminologies is a precondition for semantic interoperability. In the Austrian national patient health record "ELGA" all relevant terminologies are provided and distributed by means of a CTS2-conformant terminology server. In the following article, issues and lessons learned from terminology management in a large-scale eHealth project are presented. Experience has proved the necessity of a national authority for medical terminology management in Austria.

Keywords. Terminology; Terminology Server; Semantics; Interoperability; Vocabulary, Controlled; Patient Health Record; Electronic Health Record

1. Introduction

Semantic interoperability within a nationwide electronic patient record, entailing the interconnection of highly diverse organizations with various IT systems, can only be achieved by providing standardized terminologies. In order to cover the needs of clinical documentation, a plethora of special terms, abbreviations and codes, organized in systems like nomenclatures and classifications is a prerequisite. The terminology server has proved to be a helpful tool to support efficient terminology management. Preliminary results and experiences from the Austrian national patient health record "ELGA" are reported.

1.1. ELGA and e-Health applications in Austria

ELGA was put into operation in December 2015. It allows a cross domain exchange of health data between all authorized Austrian Health Care Provider (HCP) and enables secure and reliable access to health data for any patient visiting a HCP. In the first phase, distinct clinical documents (physician and nurse discharge letters, laboratory and radiology reports) can be shared. Other data like medication will follow later. The format for the documents is restricted to CDA Rel.2 (HL7 Clinical Document Architecture, ISO/HL7 27932:2009). All documents are required by law to conform to the nationally harmonized HL7 CDA implementation guidelines. Specific coded health data (e.g. diagnoses or laboratory analyses) have to be included. [1]

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2. Terminology Management in Austria

2.1. Terminologies used in ELGA

In order to ensure semantic interoperability within ELGA approximately 150 terminologies, including code lists2 and value sets3 are used.

Most of them were chosen or developed in the course of the CDA implementation guide development by interdisciplinary working groups. Wherever possible, a German translation is provided to support understanding of the concepts and ease readability of the exchanged data. The terminologies range from micro-vocabularies, which were developed specifically for ELGA to well-known international medical terminologies, among others:

- LOINC for laboratory tests as well as for document and section encoding.[2] A value set of LOINC codes and preliminary ELGA-wide codes was developed for laboratory analyses and is constantly maintained and updated in coordination with the laboratory community. This value set defines a hierarchical and sequential order to enhance readability and comparability of laboratory reports throughout Austria.
- ICD-10⁴ for diagnoses encoding. In Austria, an adapted version of the international standard is in use.[3]
- ATC⁵ to qualify active ingredients. The complete set of medication data, used to identify and describe single products for the eMedication (e.g. ATC, product name, route of administration, substances) is aggregated in one extensive code list with the PZN⁶ as a unique identifier.
- APPC (Austrian PACS Procedure Code) to facilitate the retrieval of radiological documents. APPC, developed by the Radiologic Branch of the Austrian Medical Association, is a multiaxial system to encode modality, laterality, procedures and anatomy of radiological procedures.[4]

2.2. Terminology Server

A terminology server provides terminologies in a standardized format to users in a distributed environment with the objective of fostering semantic interoperability. It enables users to synchronize local vocabularies with centrally managed ones. Terminology developing organizations can develop new vocabularies while maintaining existing ones; end-users can easily access relevant terminologies. [5][6][7]

A terminology server was established in the Austrian eHealth infrastructure in order to make all the terminologies used for ELGA and other eHealth projects available from a central repository. As a starting point, the terminology server, developed by the University of Applied Sciences Dortmund was used. The open source product is based on the CTS2 standard (Common Terminology Services 2).[8] Adaption, customization and the development of additional features were carried out by the University of Applied

 $^{^{2}}$ Code list: a list of clinical concepts with their identifiers required to describe health conditions and healthcare activities, and to allow their subsequent retrieval or analysis

³ Value Set: a clearly identifiable and versioned view of one or more code lists for a special usage

⁴ 10th revision of the International Statistical Classification of Diseases and Related Health Problems

 $^{^{\}rm 5}$ Anatomical Therapeutical Chemical Classification System, developed by the World Health Organization (WHO)

⁶ Pharma-Zentral-Nummer (central pharmaceutical number) in Austria

Sciences Technikum Wien. Development and operation were accompanied by ELGA GmbH and funded by the Austrian ministry of health. The terminology server provides a large part of the CTS2 services by use of web services and a web-based graphical user interface. Exporting terminologies in different standards-based formats including IHE Sharing Value Sets (SVS) and Classification Markup Language (ClaML) is provided via both interfaces. Additionally, the web frontend offers a separate platform to collaboratively develop or modify terminologies, including features to table, discuss and ballot change proposals. [9]

2.3. Terminology Management in ELGA

The whole set of terminologies is managed at the central Austrian terminology server. Changes are published as new versions of value sets or code lists, old versions are kept available for research purposes. Searching for new versions is possible both manually and in an automatized way. Operators of ELGA-related IT systems are advised to perform weekly checks. As ELGA-related terminologies are provided and maintained by different organizations, responsibility for each terminology is assigned accordingly (i.e. to a responsible person/user). The terminology server offers special features designed to help these users meet their responsibility.

Different developing organizations as well as diverse characteristics and purposes of terminologies lead to varying release cycles of terminologies. Whereas value sets dealing with structural or administrative data stay broadly constant over time, very specific code lists including the extensive list of medications may change on a monthly basis. Nonetheless, change and maintenance work has to be performed as uniformly as possible. This process of continuing change, including the notification of users has yet to be established.

In order to facilitate the correct use of terminologies in the context of ELGA, manuals are provided. They comprise a handbook for the application of terminologies as well as an implementation guide for using LOINC, especially for mapping local codes to the centrally provided list of LOINC codes.

2.3.1. Terminologies in CDA

Wherever a selection of values is defined in ELGA CDA implementation guides, the value set is referenced with its unique name. Concepts in ELGA value sets always refer to a particular version of a code system, keeping the value sets independent from changes in the code system. Code systems and value sets are identified with an OID (Object Identifier, ISO/IEC 9834). Changing the OID from one version of a terminology to another is not compulsory, unless the meaning of a code is changed. According to Cimino's Desiderata [10], deleting codes from code systems is seen as bad practice and thus avoided.

Within a CDA document a concept is denoted with its code and the OID of the code system. The value set binding in ELGA CDA implementation guides is dynamic. Dynamic binding means that the allowed values for a coded item automatically change (expand or contract) as the value set is maintained over time. Hence, the currently valid version of the value set in the terminology server at a given point in time has to be used when creating a document (value sets also carry an effective date). As a consequence, the current value sets are integrated in the validation rule set based on Schematron (ISO/IEC 19757-3:2006).

3. Results

As ELGA is now in operation, highly structured CDA documents are produced by document sources, proving that the use of ELGA terminologies has already been well established. The terminology server is in productive use, the demand and interest for its services is rising steadily. The web frontend is mostly used for manual research and terminology maintenance. To automatically synchronize relevant terminologies the web services are regularly applied by organizations in charge of producing CDA documents as well as by central ELGA components or applications including eMedication and the ELGA web portal for citizens.

The challenge of integrating the services provided by the terminology server in one's own IT infrastructure, mapping local codes to ELGA codes and keeping up-to-date has been accepted by involved parties like the regional associations of hospitals. One of the early adopters, the Vienna association of hospitals has recently released a best practice guideline. Its findings prove the benefits of well-considered local terminology management interacting with the central terminology server.

Alongside ELGA GmbH a growing number of organizations and individuals are taking part in terminology development and maintenance. The Austrian Ministry of Health uses the terminology server to publish both the Austrian version of the ICD-10 as well as a catalogue to encode medical services. The Austrian Agency for Health and Food Safety (AGES) provides an extensive set of vocabularies related to medication as well as a monthly update directly on the terminology server. In the laboratory community there is an active contribution of key users to the laboratory parameter lists. Therefore, a process was originated enabling members of all user groups to hand in proposals, change requests and error reports in a structured way.

4. Discussion, Lessons Learned and Conclusion

A number of challenges arose during the process of putting IT-supported terminology management in practice in a large-scale eHealth project such as ELGA. A key issue is the handling of historical, possibly deprecated codes. Whereas deleting codes from a code system without changing the OID is not recommended but not utterly preventable, ELGA value sets were originally designed to exclusively carry currently valid codes. Hence, value sets do not support a status value for a single code. In addition, a code in a value set may be replaced by another. For document consumers this entails the need to store historic versions of terminologies. As the current version of the value sets is integrated in the CDA validation rule set, it is inevitable for document sources to use the most recent valid version of value sets. With different release cycles and possibly high effort to integrate the value set in the local environment, this turned out to be a high hurdle for implementers. For example, for the list of laboratory parameters, which is updated on a quarterly to semiannual basis with ELGA-specific codes being gradually replaced by LOINC codes, the laboratory community claims to keep those historical (deprecated) codes in the value set. One possible strategy to overcome this issue would be the introduction of a "status" to codes in a value set. However, this would have serious impact on terminology maintenance and distribution as well as on the authoring and validation of CDA documents. Deleting items from terminologies, even if a substitute is provided, presents an obstacle for users in applying terminologies. A suitable way to address this issue is currently being discussed.

The ELGA value set of laboratory parameters contains Austrian-German display names for LOINC codes. These display names conform to the accustomed naming conventions of the Austrian medical community and not to the naming conventions of LOINC translation. An official translation requires the translation of LOINC parts (A LOINC concept is defined by several parts/axes). The final translation is therefore an algorithmic composition of several terms, which reflects the multiaxial structure of LOINC but has the disadvantage of poor readability.

Regarding the provided data formats IHE SVS and ClaML, it has to be stated that both have weak points. The SVS-based format to import and export terminologies had to be extended as elements like hierarchical position, description or units for measurements are not defined in the specification. The very generic ClaML format, on the other hand, is rather complex and supports the concept of value sets insufficiently.

As more and more parties, terminology providers but most notably consumers are using the terminology server, efficient distribution of value sets becomes more and more important. Fetching new versions is designed as a pull-mechanism instead of pushing notifications to users. However, it has to be ensured that the right terminologies are in use at the right time.

4.1. Conclusion

When it comes to establishing and operating a nationwide PHR, effective and efficient terminology management including the development, maintenance and publishing of terminologies is of crucial importance. As illustrated above, the need to further advance the terminology management became visible in the course of operation. Organizational and technical processes have to be implemented and refined in accordance with the demands of all involved parties. Dealing with changes and historical values as well as reacting to the needs of users is a main challenge. The experiences gained so far clearly show the benefits of a terminology server and most notably the necessity of a national authority for medical terminology management in Austria.

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