How can European policy recommendations inform use of standardized terminologies in clinical information systems in Sweden and Denmark?

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Introduction

Semantic interoperability in health requires the use of standardized clinical terminologies and classifications. However, many such standards exist, and deciding on which terminologies to implement, and how to implement them has proven difficult [1-3]. These difficulties have been acknowledged on the European level. Consequently, the Horizon2020 research project AS-SESS CT aims to investigate the fitness of the international clinical terminology SNOMED CT as a potential standard for large scale eHealth deployments in the EU. The investigation includes comparison of SNOMED CT to other standardized clinical terminologies and local terminologies. This comparison is done to be able to make fair recommendations to the European Commission about standardized terminology adoption in Europe. Representatives from both Sweden and Denmark participate in ASSESS CT, and data have been collected from Danish and Swedish stakeholders to represent current terminology experiences, opinions and expectations. One of these data collection methods have been two focus group interviews (one Swedish and one Danish) [4] plus a common follow-up session conducted in April 2015. The aim of the focus groups was to gather expert opinions, beliefs, and attitudes regarding the European views on current and future terminology use in the health care sector, with a special focus on the role of SNOMED CT.

The focus groups have been formed using inclusion criteria's that aimed to provide a broad range of perspectives from policy makers, vendors and implementers of clinical terminologies in Denmark and Sweden. In addition, participants were selected so that there would be a balanced view of the benefits and shortcomings of using SNOMED CT compared to other terminologies. Consequently, people involved in health terminology related work, but without using SNOMED CT, was selected as well as those working with SNOMED CT.

The results showed that Denmark and Sweden is in the same situation when it comes to terminology adoption. Both countries have extensive current use of international classifications, have translated SNOMED CT, and face the challenges associated with coordinating the first large implementations of SNOMED CT. Consequently, it makes sense in a future perspective to share experiences, discuss possible solutions and maybe even do cross-border projects.

One way of initiating such knowledge sharing is to keep the discussion alive among Danish and Swedish stakeholders, and continue to learn from the best European experiences.

Focus of the workshop

In this section, we present the focus of the workshop. First we present the preliminary finding from the Danish and Swedish focus groups conducted as a part of the ASSESS CT project, to give insight into health terminology challenges as perceived by Danish and Swedish stakeholders. Next, we present how these findings have helped form European policy recommendations.

In the workshop session, the aim is to evaluate whether the policy recommendations could actually help resolve terminological challenges as perceived by the focus group and the attending audience.

Key findings from Danish and Swedish focus groups

The focus group discussions showed that many of the perceived benefits and shortcomings of implementing and using standardised classifications and terminologies were true for all terminologies. For example, many terminologies aid in exchanging healthcare data, which have its meaning unambiguously defined. In other aspects, the discussed terminologies differed, in purpose, granulation level, coverage, perceived quality etc., making them fit for different purposes. The availability of many different terminologies with different characteristics makes it difficult to choose one terminology over another.

Even if there are perceived benefits of choosing one terminology over the other, shifting terminologies is a challenge. The existing classifications are in wide-spread use but there are gaps which are not easily filled while keeping to the existing terminology workflows.

Findings of the focus group also suggested that many of the perceived barriers relates to the gap between an international complex terminology and local needs. For example, focus group members mentioned: Stakeholders' preference for their own terms, lack of sufficient stakeholder involvement in terminology related projects and lack of synonyms in SNOMED CT are barriers of SNOMED CT adoption.

Focus group results showed that stakeholders are concerned about what human- and IT-resources are available and important when it comes to supporting terminology implementation. It was highlighted that such problem is more significant in

small countries compared to larger ones, because it is not feasible to have large terminology competence centres in small countries. In addition, they pointed out that efficient tooling e.g. with focus on getting different overviews of terminology in use, could improve implementation processes. In addition, they emphasised that when we decide to use SNOMED CT for a specific purpose, we should be aware of evaluating whether intended benefits are reached. This will help form realistic business cases, which are most important if stakeholders are to invest in both technical and organisational terminology implementation.

In conclusion, the challenges ranged from adoption related, to implementation and business related:

- **Adoption:** The challenge of choosing one terminology over another and migration challenges given the existing terminological workflow in the health sector

- **Implementation:** The challenge of using an international terminology in local settings and the challenge of lacking education and tooling, which is enlarged in smaller countries

- **Business:** The challenge of setting up positive business cases for terminology implementation

From European findings to policy recommendations

The results from the Danish and Swedish focus groups have been key findings in the ASSESS CT project as a whole because Denmark and Sweden are some of the first non-English speaking countries that have started adopting SNOMED CT. Together with other European implementation experiences and studies performed as a part of the ASSESS CT project, they will inform the policy recommendations which are the final deliverable of the ASSESS CT project. The final deliverable will not just be a list of recommendations, but some guidance on how those recommendations may be taken forward across Europe, including recommended actions for different stakeholders. At the time of the workshop, a first draft of this final deliverable will be finished.

Organization of workshop

The workshop will have two parts: First a summary of the focus group results will be presented, and we will facilitate a short discussion session with the audience to establish whether their views on terminology related challenges are in accordance with the findings of the focus group.

In the second part a selected subset of ASSESS CT policy recommendations will be presented one by one. For each recommendation, the audience will discuss and rate the importance in a Scandinavian context.

Intended audience

Stakeholders from national e-health bodies, health IT implementation organizations, vendors, and universities with interest in the use of classifications and terminologies in health IT.

Expected outcome

We intend to create an open dialog about terminology implementation, to build the ground for more collaboration between the Scandinavian countries. In addition, we will track the main points of the discussion and feed them back to the European ASSESS CT project, to ensure that a broad range of Scandinavian perspectives will continue to inform the project.

Acknowledgments

References

1. Rector AL. Clinical terminology: why is it so hard? Methods Inf Med. 1999 Dec;38(4-5):239-52.
2. Lee D, Cornet R, Lau F, de Keizer N. A survey of SNOMED CT implementations. J Biomed Inform. 2013 Feb;46(1):87-96.
3. Wing TL. ICD-10 Medical Coding: The Role of Perioperative Services in Addressing Implementation Challenges. AORN J. 2016 Feb;103(2):177-88.
4. ASSESS CT project consortium. Deliverable 1.2 Report from the Focus Groups and Delphi study Available from: http://assess-ct.eu/fileadmin/assess_ct/typo3tut/assess_ct_d1_2_report_from_focus_groups_and_questionnaires.pdf

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