Public Health and Informatics
J. Mantas et al. (Eds.)

doi:10.3233/SHTI210161

Development of a Framework for Redesigning a Terminology Maintenance Process - Case Study in the Netherlands

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Abstract. Structuring clinical data in electronic health records supports reuse of data to improve quality of care, reduce costs and perform research. This requires terminologies to assign terms from language used in a specific domain to medical concepts. Given the developing character of medical knowledge, these terminologies need continuous maintenance. Nonetheless, little is known about terminology maintenance processes. To specify the (re)design of a terminology maintenance process, we first merged and adapted two static theoretical frameworks that consisted of criteria relating to using a terminology, divided among relevant stakeholders. Following, we applied the framework to the healthcare terminology maintenance process in the Netherlands. We held interviews with relevant stakeholders and used the framework as checklist to identify missing criteria and bottlenecks. Saturation in interviews and fulfilment of the criteria indicated that all bottlenecks were discovered, therefore the framework was considered useful for redesigning a terminology maintenance process. Other countries could benefit from this framework as well to discover and resolve any unfulfilled maintenance criteria.

Keywords. Terminology maintenance, semantic interoperability, Electronic Health Records, EHR.

1. Introduction

Implementation of Electronic Health Records (EHRs) has been accompanied by the promise of increased patient safety, reduced medical errors, improved efficiency, reuse of healthcare data and reduced costs [1-4]. However, in order to realize these benefits, EHR systems need to be interoperable implying that data is unambiguous [1, 2], while the often used free text, which is rich in details, can be ambiguous [3].

An approach to standardize the representation of clinical data and therewith improve interoperability is the use of (interface) terminologies [1, 5, 6]. Interface terminologies represent the language used in a particular domain and are used to describe lists of terms [7, 8]. Interface terminologies facilitate the display of computer-stored patient information to human-understandable text, and structure clinical "free-text" expressions to more structured, machine interpretable expressions [9].

Given the developing nature of clinical knowledge these terminologies should be revised and maintained regularly [1, 5]. Therefore, systematic terminology maintenance

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is required [10, 11]. While the need for an established design for maintenance processes has been acknowledged, few studies have been concerned with the actual organization of terminology maintenance processes [1, 12].

A framework by Raiez et al [10] highlights the importance of regularly updating terminologies by a maintenance organization. It should be possible to extend terminologies infinitely, using inactivation instead of removal of existing concepts. Available administrators should use an application or system for their maintenance process. Each new proposal should be documented and validated and performed in a standardized way. Another framework is the Dutch standard NEN 7522 "Maintenance of coding systems and other terminological systems" [13], which established seven activities relating to terminologies. These activities are assigned to a role: the user, authorizer, financer, distributor and three roles for maintaining the terminology, which are subdivided in a functional holder, a technical holder, and a general holder. The general holder surveys the other holders and distributors in their maintenance work. For instance, the functional holder focuses on the control of various versions of the terminology system and should propose changes for terminology terms based on demands from the user. A combination of NEN 7522 and the Raiez-framework could be a foundation for standardization of maintenance processes, but that has, to our knowledge, not been investigated.

In this study the goal was to (1) merge the frameworks into one, (2) apply the framework to an existing process to identify bottlenecks in the process and come up with solutions, and (3) check its validity by application.

2. Methods

First, we merged and adapted the two frameworks. The resulting framework concerned criteria relating to using a terminology, that were divided among the NEN 7522 roles. We did not include financers in examining the maintenance process, because they do not relate directly to the maintenance process, but to the provision of the maintenance system. Furthermore, only the Raiez-criteria specific for the maintenance process were assigned to the identified roles. The criteria that related to specific aspects of a terminology system itself (e.g. 'The codes that are assigned to concepts must be non-significant') were excluded.

Second, to test and validate the framework, we performed a case study. We applied the framework to the terminology maintenance process of two Dutch University Medical Centers. As in other countries, in the Netherlands a national organization, called Dutch Hospital Data (DHD), is responsible for the maintenance of the Diagnosis Thesaurus (DT), which is the terminology used in EHRs in most Dutch hospitals [14]. Healthcare providers make use of the DT to select the best-fitting diagnose (code) for their patients. We identified stakeholders and their roles in the process according to the framework. We recruited the stakeholders and asked them to recruit other stakeholders that were relevant according to the framework, i.e. snowball sampling. We held semi-structured interviews with the stakeholders until saturation was reached in finding bottlenecks (e.g., the time it takes to process change requests to the terminology is too long) in their terminology maintenance process, using the framework criteria as checklist. We discussed potential solutions for each missing item and we validated and translated these solutions into practical implications until no new implications arose in follow-up interviews (i.e. member checking [15]). In this way, we assessed the validity of the framework by

monitoring whether saturation in the answers about missing criteria was reached and lead to fulfillment of all criteria.

3. Results

Figure 1 shows the 67 criteria in the merged framework per NEN 7522 role. In *italic,* the Raiez-criteria are shown.
Thirteen interviews were held with stakeholders, including clinicians, an employee of DHD and medical administrators, who were all assigned a role. Of the 67 criteria, 44 (65.7%) were completely fulfilled, 16 (23.9%) were partly fulfilled and 7 (10.4%) were not fulfilled. Saturation was reached and in the second round of interviewing, all bottlenecks, solutions and practical implications were validated by relevant stakeholders. For instance, interviewees indicated that clinicians are currently not aware of the possibility of making change proposals or the way to do that (Figure 1, user 'j', functional holder 'l'), which is why the DT is perceived incomplete and change proposals take long (Figure 1, functional holder 'm', 'n'). An application to support the proposal process was not available, but was validated as solution to decrease response time and increase awareness (Figure 1, technical holder 'g', 'h', 'i', 'j').

4. Discussion and conclusion

To our knowledge, this study was the first to extend existing static theoretical frameworks that consisted of criteria relating to using a terminology, divided among stakeholders relevant in a terminology maintenance process, to an applicable framework checklist that can be used for the (re)design of a terminology maintenance process. We applied the framework and discovered that due to its "check listing" character, it was sufficiently easy to identify bottlenecks in the process, such as the need for increasing awareness and the use of applications for change proposals. Response time for change proposals could decrease and users will be aware of and perform more change proposals, leading to better maintained terminologies. This ultimately leads to improved user experience and data quality. Importance of creating awareness is also supported by Horsky [16] who mentioned that creating awareness results in better registration. The findings of this study also extend the need for a systematically arranged terminology maintenance process, as do [10], [11], and [17]. However, even if there is an established maintenance process to update terminologies in a way that they reach full coverage, studies show that other issues relating to terminology use should also be solved, e.g. a poor search-functionality could also be reason for perceived incompleteness [18, 19]. A strength of our study is that it involved all relevant stakeholders and interviews were performed until saturation was reached, allowing us to assume that we captured all bottlenecks. One weakness is that we only examined one organization using the EHR (Epic). Nonetheless, as there are more hospitals that use Epic, even internationally, they might benefit from the results presented. Future research could use our steps and use the criteria of our framework to assess similar terminology maintenance processes. We also suggest establishing key performance indicators so practical solutions can be prioritized and executed based on their feasibility. It should be determined whether the executed implications improved the terminology maintenance process and whether this eventually leads to better data quality and reuse.

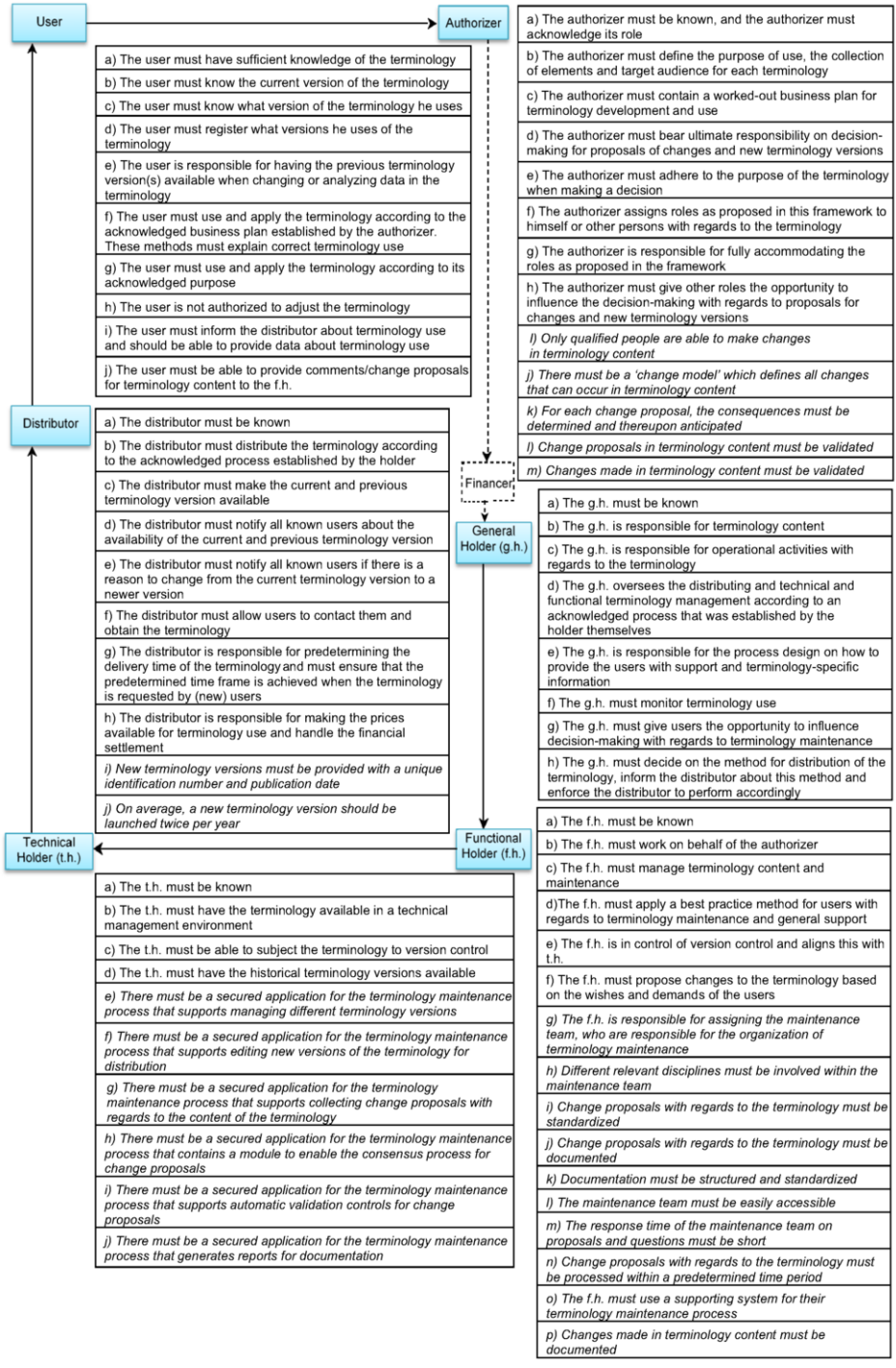

Figure 1. The merged framework. In *italic* the criteria from the Raiez-framework are shown, that were divided among the NEN 7522 roles.

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