A Requirements-Driven Redesign of a Terminology Maintenance Process in the Netherlands

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ABSTRACT

In this study, we merged two frameworks that consisted of terminology maintenance process criteria divided among relevant stakeholders. We applied this framework to the current healthcare terminology maintenance process in the Netherlands to examine what could be improved, based on the criteria. Following, we aimed to redesign the terminology maintenance process. In the Netherlands, a Diagnose Thesaurus (DT) is used by healthcare providers to select a best-fitting diagnose (code), which then allows for structuring data from electronic health records (EHRs). Thirteen interviews were held with stakeholders to derive issues and suggestions in the current maintenance process and validate those. The outcomes indicated that a systematic terminology maintenance process in the Netherlands is essential to improve the (use of) DT. Change proposals can be performed by specialists, which will be authorized by scientific associations (SA's) and Dutch Hospital Data (DHD). The process is perceived valuable for the maintenance of DT but could be improved. For instance, by implementing a functionality for the change proposals in the EHR system, or by increasing awareness among requesting entities about the availability of doing a change request. Moreover, agreements between DHD and authorizing parties should be revised, and updates should be given about the status of the requests. In addition to that, supportive tools could enhance better communication and silent approval methods might fasten the authorization process. Medical administrators could fulfil an advising and filtering role to change proposals, potentially by gaining insights in free-text notes, search strings and diagnose codes. Future research should focus on the implementation of our suggestions to see if it indeed improves the process. Last, other studies could use our terminology maintenance criteria framework to investigate other (international) terminology maintenance processes and potentially create a set of generalizable criteria.

Keywords

Terminology; terminology maintenance process; healthcare; Diagnose Thesaurus; Dutch Hospital Data.

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 [1, 2] and data reusable [3, 5]. An obstacle to the global adoption of interoperable EHR systems is the challenge of capturing structured and standardized clinical data [6] as healthcare providers prefer to document healthcare findings in natural language [1, 3]. Natural language is very rich in details but can be ambiguous [3].

An approach to standardize the representation of clinical data and therefore improve interoperability is the use of terminologies or ontology-based models, such as SNOMED CT [1, 7, 8]. Terminologies in healthcare can be defined as the systematic collections of healthcare-related terms that support the standardized entry of patient data by clinicians [6, 9]. As a result of the need for structured and standardized data storage, many terminology systems have been developed [1, 10].

Given the varying nature of clinical knowledge, it is required that these terminologies should be revised and maintained regularly [1, 7]. Therefore, it is necessary that terminology maintenance is performed in a systematic way [10]. While the need for an established design for standardized maintenance processes has been acknowledged, few authors have been concerned with the actual organization of terminology maintenance processes [1, 11].

In the Netherlands, Dutch Hospital Data[1] is, among others, responsible for the maintenance of the Diagnose Thesaurus (DT), which is an interface terminology used in EHRs of a growing number of Dutch hospitals [12]. DHD collects, controls and adjusts the DT for all Dutch hospitals and provides a two-monthly update of the thesaurus. Healthcare providers make use of the DT to select the best-fitting diagnose (code) for their patients.

In this study, we aimed to gain insights in and redesign the current terminology maintenance process in the Netherlands. We applied existing terminology maintenance process frameworks to the maintenance process of the DT in two academic hospitals based in Amsterdam that both use the same EHR system (Epic[2]). The application of the framework allowed us to indicate issues in the current process, formulate and validate suggestions and therefore propose an improved new terminology maintenance process, which has, to our knowledge, not been investigated before.

2. THEORETICAL BACKGROUND

2.1 Terminology

In literature, 'terminology' is often used interchangeably with various terms, such as 'thesaurus', 'vocabulary', 'nomenclature' and 'classification'[13].

In this paper, we define the concept 'terminology' and corresponding concepts according to the definition(s) of Keizer & Abu-Hanna [13]. A terminology "consists of a collection of words or phrases ("terms") referring to concepts in a particular domain". A terminology is a thesaurus when terms are ordered and where terms can be defined by more than one (synonymous) term. If a thesaurus or terminology is accompanied with a definition, it is a vocabulary. If concepts are arranged based on their characteristics, we speak of 'classification'. Then, a 'nomenclature' is defined as a system of terms used in a particular area to compose new (complex) concepts. An 'ontology' is often used as a synonym for different types of terminology systems, which is a formal specification of concepts, relations and functions in a domain [13]. Examples of terminology systems used in medicine include the International Classification of Diseases (ICD)[3] and SNOMED CT[4] [14]. In this thesis, terminology or thesaurus are both used to indicate the DT.

2.2 Types of terminologies

Depending on the role of a terminology system we can distinguish three types: reference terminology, interface terminology and aggregation terminology. In figure 1, the three types of terminology are presented as established by Park et al [1].

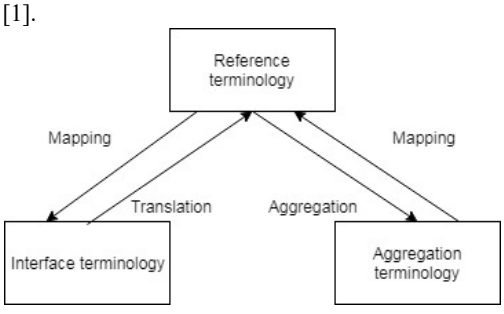

Figure 1. Types of terminology [15].

Interface terminologies, sometimes referred to as entry terminologies or clinical interface terminologies, represent the language used in a domain [9] and are used to describe lists of terms [6]. Interface terminologies facilitate the display of

[1] https://www.dhd.nl/Paginas/home.aspx

[2] https://www.epic.com/

[3] https://www.who.int/classifications/icd/en/

[4] http://www.snomed.org/

computer-stored patient information to human-understandable text, and structure natural language expressions to more structured, machine interpretable expressions [16]. The DT of DHD is an example of an interface terminology.

A reference terminology provides representational units (also "concepts" or "classes") that allow for complex organization and aggregation of clinical information [1, 9]. SNOMED CT is an example of a reference terminology.

Aggregation or administrative terminologies [5] concern the classification of information [1]. An example of an aggregation terminology is the ICD [17].

2.3 Terminology quality aspects

The design of current EHRs is often not user-friendly and may negatively affect the code selection process as clinicians might choose a less specific or less desirable code that does not fit the actual diagnosis [18]. The study by Horsky et al [18] examined diagnostic coding among ambulatory clinicians and found that there are significant differences in coding among the clinicians. This is due to the fact that current terminologies lack expressivity and accuracy and have inadequate domain coverage [4, 6, 7, 18]. It was therefore suggested that one should improve healthcare training programs where awareness can be created of the importance of structuring, registration and documentation [18]. Better syntactic consistency will help users, such as clinicians, find and select better suiting terms for their diagnoses or ideas [7]. Therefore, the design of EHR systems should be user-friendly, in accordance with the requirements of the end-users, as that may lower the rate of inappropriate and omitted codes [18]. Structuring clinical documentation in a user-friendly design and providing terminologies with enough term coverage could potentially also reduce the number of added notes ('free text') [19], which ultimately leads to improved data quality and better research opportunities as data can be retrieved more easily.

2.4 Terminology maintenance

Earlier research acknowledged that large terminologies like those mentioned before are replete with inconsistencies, redundancy or incompleteness [20]. Therefore, the methodology by which large terminologies are maintained could play an important role in these issues. Schulz [9] argued that good interface terminologies, e.g. DT, require continuous maintenance. Other literature states that terminologies should be regularly checked and updated, but a minimal amount of processes are formally designed for this [21]. SNOMED CT for example is updated twice a year. New, updated or changed terms are retrieved from, among others, submissions for additions and modifications. This method of open participation leads to more detailed and improved terminologies [21].

Another example in maintaining or adjusting terminologies is from the US Veteran's Administration [22]. In their research, whenever terms did not match the predefined terms in the lexicon, a note was sent to a central repository. This type of data management can help improve data quality as it helps maintaining the terminology [23]. The concept terminology maintenance used in this thesis is derived from the maintenance definition defined by the British Standard Institution (BSI) [24]. Terminology maintenance concerns "the combination of all technical, administrative and managerial actions during the life cycle of the terminology intended to retain it in the state for its required function".

A framework by Raiez et al [10] shows four aspects to terminology maintenance: process design, execution, support and change model. In short, this framework highlights importance of updating terminologies regularly, which should be performed by a maintenance team. It should be possible to extend terminologies infinitely, without the removal of existing concepts. In addition, the administrators should use an application or system for their maintenance process. Each new proposal should be documented and validated. Last, if new concepts are requested, this should be done in a standardized way. Although the need for standardization of terminologies is recognized in literature, the design of maintenance processes has not yet been explored well [10]. A study by Chute et al [17] highlights the need for a coordinating authority for vocabulary maintenance as that would simplify the updating process of terminologies.

ISO 26162:2012 also proposes requirements to the design and maintenance of terminology systems [25]. These requirements overlap most of the Raiez-framework [10]. For instance, both indicate that it should be possible to add an unlimited amount of terms to the system. Furthermore, ISO 26162:2012 requires that the system should help decide whether a term is redundant, and it should help decide whether a term should be added. Also, validation of data is needed to minimize errors in data entry. Organizing and managing terminology systems is a complex task [25]. The more stakeholders are involved in the systems, the more flow control and (structured) agreements are needed. Changing the content usually requires changing terms in an established order, and those modifications or changes should only be done when clearly justified, as argued by the ISO 26162:2012 standard. It may even be necessary to review each input, if data categories are changed (e.g., merged, split). The ISO 26162:2012 standard also highlights the importance of data protection. Further, the standard argues that using certain permissions and roles can help prevent improper data modification. The varying activities that are involved in terminology maintenance processes are previously established by the Dutch Standards Institute ('NEN') in 2010 [26]. NEN 7522 established seven activities relating to terminologies. These activities are assigned to a role, viz. 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. This last role surveys the other holders and distributors in their maintenance work. For instance, the functional holder focuses on the control of various versions and should propose changes to the terminology system based on the demands from the user. All these roles, in combination with the Raiez-framework [10] and the ISO 26162:2012 standard [25] can be a foundation for standardization of maintenance processes, but that has, to our knowledge, not been investigated.

3. METHODS

In order to standardize a terminology maintenance process, it is first important to investigate if existing frameworks can be applied to assess terminology maintenance processes. Therefore, we selected two Academic hospitals in Amsterdam and investigated their maintenance process based on the five steps described below. We derived issues in this Dutch process and based on (validated) suggestions we came up with the design of a new process for the Netherlands.

3.1 Framework development

The requirements for a maintenance process should be determined by the parties involved in such maintenance process. Therefore this study first aimed to map the stakeholders involved in maintenance of terminologies using the NEN 7522 standard and the maintenance criteria from the Raiez-framework [10]. We combined these two frameworks into one. This framework was used to identify what roles and criteria were missing or incomplete in the evaluated process for Amsterdam UMC, which created the foundation for the requirements. For our framework, 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.

3.2 Stakeholder identification

According to the NEN 7522, the following stakeholders should be taken into consideration: general holders, functional holders, technical holders, distributors, financers, users and authorizers. Given the aim of this study, we did not include the financers for this study, because they do not relate directly to maintenance, but to the provision of the maintenance system.

Given the setting of our study, we had to recruit people from the 'using' organization, Amsterdam UMC, and the 'holding' organization, DHD [12]. Therefore, we recruited the medical coders in hospitals who are responsible for the download and implementation of the DT and we aimed to include employees of DHD. We first contacted these stakeholders via email and performed several interviews in the period April – June 2019. The medical coders included in this study worked at Amsterdam UMC. We used snowball sampling to find all relevant stakeholders that fulfil the NEN 7522 roles. In order to include authorizing parties, we sent an email to all Scientific Associations (SA's)[5] in the Netherlands (32 secretariats) and held interviews with their members. We specifically excluded Nictiz and RIVM as they provide linking between the DT (interface terminology) and SNOMED (reference term) and DT and ICD (aggregate term) respectively, which we considered a derived product.

3.3 The current process: semi-structured interviews

The aim of the structured interviews was to get insight into the current process of DT maintenance and the areas for improvement. We created a separate interview guide for each of the parties involved. The questions were focused on the (issues in the) current process, how that could be improved and what the stakeholders wished to see in the new process. All interview guides were developed using the Raiez-framework [10], the NEN 7522 norm [26], a checklist for qualitative research [27], and conversations within the research team. The interview guides were used for conducting semi-structured interviews. All interviews were held in Dutch and quotes were translated into English for the purpose of this thesis. Follow-up questions were asked for more in-depth answers. At the start of the interviews, participants were informed about the purpose of the research, and they gave consent that their (anonymized) data will be used for scientific research and publication. All interviews were audio-recorded and transcribed for requirement analysis. To minimize recall bias, recordings were transcribed within 24 hours after the interview.

3.4 Data analysis: issues and suggestions

During interviews, issues in the current process were highlighted and suggestions were given on what could be improved. This led to the design of a new process, based on the requirements, with the suggestions intermingled. The interviews were transcribed and coded according to the ground theory open coding approach [28], starting with open coding to create an oversight of the collected data, by categorizing them in labels and codes. The codes were assigned using Atlas.ti 8 software[6]. Following open coding, clusters of codes were created (i.e. axial coding) to (re)place the codes in the framework. Codes and requirements were also discussed during meetings within the research team and changed accordingly. Codes were assigned to statements in the interview transcripts, forming the basis for the design of the improved process [29].

3.5 Validation

In order to validate the suggestions, this study uses a so-called V-model approach [30]. The V-model involves requirement analysis (interviews) and thereafter involves user acceptance testing or face validity. User acceptance testing or face validity in this study concerns acceptance of the process design with the suggestions intertwined, which is achieved when there are no new requirements proposed by the medical coders, DHD-employee(s) and other parties involved that were included in the study (saturation). Face validity is the extent to which the designed process is covering the purpose of being a helpful maintenance process as perceived by the parties involved [31]. This means that we validated the suggestions with the parties relevant to the suggestion, i.e. if a new process aspect, though proposed by a specialist, would affect the process of the medical administrators, we would validate the process with the medical administrators. Or, if a suggestion was given by a specialist that would affect the workflow of specialists, we would validate it with another specialist than the one who made the suggestion.

4. RESULTS

4.1 Framework

In table 1, the combined framework based on the Raiez-framework [10] and NEN 7522 [26] is shown including the roles and corresponding criteria needed for a maintenance process. The affected criteria will be explained in the following subchapters and are marked between brackets.

4.2 Stakeholder identification

A total of thirteen participants were included in this study, all assigned a role within the NEN 7522 norm. Two medical coders participated, from two different hospitals, fulfilling the role of user (after this referred to as M_1 and M_2). They are considered to be users because they are responsible for the download and integration of the DT in the hospital. One expert involved in this study maintained terminologies at DHD (D_1). DHD can act as authorizer, distributor and general, functional and technical holder.

DHD is not the only authorizing party. Other authorizing parties are the Scientific Associations (SA's), Nictiz[7] (for changes to the SNOMED CT codes), NZa[8] (for changes to the DBC codes) and RIVM[9] (for changes to the ICD-10 codes). We received 21 responses to our email invitation for SA's. From these respondents, ten interviews were planned with people who indicated to be involved in the authorization process. Nine out of ten participants were medical specialists (S_1-S_9) and one participant was a policy officer (B_1). The ten interviewees were working at eight different SA's (S_7, S_8 and B_1 work at the same SA). A 'policy officer' has expertise in the registration process but is not necessarily a healthcare provider. The authorizing group within SA's are either consisting of one, two or three people and are board member(s) of the Association for the Defense of Professional Interests or the Registration committee. Three interviews focused on the issues in the current process and suggestions for the new process. The following seven interviewees were also asked to validate aforementioned suggestions. If new issues or suggestions emerged, these were taken into consideration for the next interviews.

4.3 The current process

From the interviews, it became apparent that specialists struggle with the DT or see no purpose in it (S_4, S_5, S_9). B_1, S_4, S_5, S_7 and S_9 mentioned that it was difficult to decide if the list should be a very specific or a more general list. As argued by B_1: 'if you make it more specific, it also becomes more sensitive to mistakes' and S_7: 'you want to register a lot, but then it is either

[5] https://www.demedischspecialist.nl/federatie/leden-0

[6] https://atlasti.com/product/mac-os-edition/

[7] https://www.nictiz.nl/

[8] https://www.nza.nl

[9] https://www.rivm.nl/

too precise or too vague, which makes it lose its purpose'. The differences in demands for the DT relate to the fact that there are academic hospitals that require extended lists and smaller, general hospitals that need less terms. DHD therefore offers a basic and extended list, although this is implemented later in the process and not established for all terms, according to S_9. SA-participants S_5, S_9, B_1 and D_1 agreed that this functionality is lost because of the design of the EHR system. Some participants suggested revising the DT completely (S_9, B_1 S_5), or add mapping within the DT (S_5). Thereafter, the DT can be maintained efficiently, according to S_5, which is done with the change requests.

Figure 2 shows the flows that can remain the same (black), flows that need to be removed (red) and new flows to be added (green) in the evaluated process. As shown, the change requests are performed by medical specialists. If a specialist wants to make a request, he or she can write their question in free-text via the Epic-report button (figure 2, (1)), which is used for all EHR-related comments and complaints. The specialists can also send their request directly to the medical administrators via email. If the request is performed by the clinician using the Epic report button, this request is sent to the corresponding IT-desk in the hospital, which sends an alert to the account of the medical administration in TOPdesk[10] (figure 2, (2)), which is a management system used in the corresponding hospitals. The medical administration has to log on into TOPdesk to check if there are new notifications or alerts.

In order to provide some standardization in the change process, DHD uses a standardized Excel-sheet that medical administrators can download from the DHD-website[11]. DHD requires the name and function of the specialist who is requesting the change, the hospital and department, the corresponding ICD-10, thesaurus ID or SNOMED ID, the type of request and the reason why this request is needed (free text). If information is missing or ambiguous, DHD has email contact with the medical administration. The medical administration then requests that information from the doctor who filed the request.

The medical administration sends the complete Excel-sheet via email to DHD (figure 2, (3)). DHD checks the request in their technical validation (figure 2, (4)). If the request does not fulfil their guideline-criteria[12], the request is not followed through and administrators receive an email that the request is not valid and therefore the term will not be added, changed or updated (figure 2, (4.1)).

After technical validation, the proposals are sent to the external parties, as mentioned in *4.2. Stakeholder Identification,* to be authorized (figure 2, (5)). Requests that relate to the content of the terms, like synonym changes, addition or removal of terms are treated by the corresponding SA's. Per illustration, 'heart attack' is treated by both the SA for heart diseases and lung diseases. All SA-participants agreed that the proposed terms are usually accepted, sometimes with minor (textual) changes. If a term is rejected, DHD does not implement the change (table 1, 2d). In order to keep the requesting clinicians and medical administrators updated, DHD provides a status and reference number of their request online (table 1, 5j). If SA's do not respond, DHD sends reminders via email after a certain amount of time. Further issues around the authorization process are explained in the next subchapter.

After the corresponding SA's agreed with the change in their authorization, DHD changes the term in their newest version of the DT (figure 2, (6)). This happens in their technical environment and is done by authorized employees (table 1, 1i, 2i). Every two months, a new DT is uploaded to the DHD-website, that hospitals, or medical administrators, can download and import in their systems (figure 2, (7)). All relevant parties are informed about the newest versions and the changed terms via email, with comments attached to the changed terms (is/becomes'-list) (table 1, 6d, 6e). DHD does not, however, know what versions of the DT hospitals actually use (table 1, 1j).

4.4 Issues in the current process

Issue 1: The authorization process

Response time

As a result of multiple parties and SA's being involved in the authorization process, the time period in which a proposal is handled varies (table 1, 4n, 4m). D_1 explains: 'The response time of SA's varies, which forces us to wait with implementing the request until all SA's have responded. […] We have SA's that haven't responded for two years, but we contact them to remind them, but they forget' (table 1, 2c, 2j).

It is argued that the response times vary because the members of the SA rotate often or they consider it to be difficult (B_1), and the members do not feel urged to handle the requests, although they are given reminders (S_4, S_5). S_4 stated: 'There is no hurry to the change requests, I can be on vacation for three weeks and that's fine'. This was also supported by S_5, who also mentioned he was the only one doing the requests in his SA (table 1, 4i, 4m, 4n). Also, SA's have responsibilities other than approving these requests, S_1 mentioned. Further, smaller issues were mentioned that related to the lack of detailed explanation in the time status or feedback reports (table 1, 4m, 4n, 5j), the bad usability of the Excel-sheet and lack of standardization in the feedback provision of the SA's. S_1 stated: 'I added some colors, and here [in the format] you see that I added a comment.' (table 1, 4k).

Another issue related to the response time was given by several interviewees was the routing of the authorization process. M_2 stated: 'why would the doctors first go to Epic, then to us, if they can apply for changes directly to the SA?' (table 1, 4d, 4l). This is also mentioned by S_2, S_6 and S_8 who wondered why the specialists, who are often member of the SA's, first have to submit a request via the administrators, as the request needs to be verified by (the same) specialists from the SA as well. S_2: 'sometimes we even receive our own requests back' (table 1, 4d).

Different authorization roles

SA-employees act differently to their authorization role in the process (table 1, 2f, 2g, 2j). S_2 explained that they made a new agreement with DHD, in which it is established that DHD does not wait for all approvals about the content. If it were only small remarks, DHD should just implement the changes and wait for approval later. 'Otherwise, the requesting specialisms are just waiting for their proposal to be implemented', so S_2 mentioned (table 1, 2k). This is, however, in contrast with S_4 who indicated he did reject requests because 'otherwise, the database or list will be too long for the specialists that do not work in academic hospitals'.

Suggestions to improve the authorization process

Agreements

In order to deal with non-response, DHD sends email reminders to the SA's. However, S_4 and S_5 do not feel hurried at all as mentioned earlier. DHD could for instance implement the 'silent approval method' that S_2 argued for textual changes. We did not validate this with the SA's, as it requires single agreements with each of the authorizing SA-members (table 1, 2c, 2j).

Tool

D_1 thinks "implementing a collaborative tool will improve response time, where there is an overview page showing 'these requests are ready for you'" (table 1, 4d). As argued by D_1, one

[10] https://page.topdesk.com/nl/wat-is-topdesk

[11] https://www.dhd.nl/producten-diensten/diagnosethesaurus/wijzigingsverzoek-diagnosethesaurus/Paginas/default.aspx

[12] https://www.dhd.nl/producten-diensten/diagnosethesaurus/documents/Inhoudelijke%20richtlijnen%20Diagnosethesaurus%20versie%202.2.pdf

standardized tool in which both the SA's and the DHD-employees can log-on would help to speed up the process and improve contact between DHD and SA's (table 1, 4i-4o). However, S_1 and S_3 argued that the current process, in which the communication is based on email contact, is fine as well. S_1: 'logging in would be another obstacle to the process. If I see the request and the attached file in my email, I get reminded to handle those requests'. On the other hand, D_1 argued that 'doctors can easily log on and perform some requests between their consultations, instead of opening the Excel-sheet and working through each line separately'. This is in contradiction with S_5 who said he would bundle the requests anyway.

Based on the suggestions, it was considered useful to integrate the communication within the collaborative tool, for example in a chat box, as it might enhance reaching consensus faster (table 1, 4o, 5g-5j). Users should not have to change their workflow by logging-on to these tools, but should be alerted, making the effort as little as possible. The tool should therefore combine both email alerts and logging-in from both parties. This tool should be managed by the technical holder. This suggestion was validated by S_4-S_9 and B_1 and D_1. The suggestion did not occur in the conversation with S_2 and was therefore not validated by that participant.

Online format

There is no standardized supporting system in the maintenance process, except for the standardized Excel sheet format (table 1, 4i, 4o, 5g-5j). The format is, however, not forcing users to fill in all the fields, therefore the support is lacking 'automatic validation controls' and it does not provide the means to reach consensus (table 1, 5h, 5i). DHD uses one dashboard-like tool to collect the requests and monitor the status of each request (table 1, 5g). Excel-files that are sent to the SA's or other external parties are derived from this tool, which is found time-consuming by D_1. Both M_1 and M_2 suggested a 'more user-friendly format' or perhaps an 'online format' for the collection of proposals (table 1, 5g). This was validated by S_4 - S_6 and D_1. This suggestion did not occur in the conversation with S_7, S_8 and S_9 and was therefore not validated by them.

Feedback about updates

Both M_1 and M_2 agreed that they wished to receive more detailed status updates about the request. Also, M_1 mentioned that DHD should pinpoint what exactly would be the reason why a proposal is rejected in the emails, instead of referring to the complete guideline. When proposing this to D_1, it was agreed that this could be beneficial, although it would take more time.

As for improving the flow of the maintenance process, M_1 and M_2 further argue that they do not check TOPdesk regularly so 'it would be nice to receive a signal in our email from TOPdesk that would state there is a new proposal.' Whether this is technically possible, should still be checked with the Service Desk at Amsterdam UMC. D_1 further argued that it would be required to receive more feedback about the versions in use per hospital (table 1, 1j).

New routing

It was suggested by S_6 to re-evaluate the routing of the proposals, because the current flow seems inefficient. It was suggested that specialists should go directly to the SA's with their requests. S_3 stated, however, that the process is good as-is, because if all specialists would go directly to the SA, these would be overloaded with requests. S_2 further states: 'I don't think my colleagues will make the effort to do it themselves'. We did not further look into the new routing.

Issue 2: Performing requests

According to S_2, S_3, S_4, S_5, S_9, M_1 and M_2 specialists are not aware of the possibility of making request or they do not know how, and therefore there is a small amount of requests, which is why the DT remains incomplete. M_2: 'I don't even think doctors know where to find us' S_2 stated: "[…] because specialists are not aware, they pick any close-related term and think 'I have always done it like that'". This is in agreement with S_5 who said, 'I don't even know whom to turn to in my hospital [for a change request]' (table 1, 1k, 4l).

Suggestions for improving the execution of requests

Awareness

It was suggested by M_2 that clinicians should gain better insights into how to make proposals for changes, for example in providing better Epic training to them (table 1, 1k). It was also suggested by S_9 that DHD should send (yearly) emails explaining what change proposals are, and how specialists can make them (table 1, 1k, 3d, 3e, 3g). B_1 and S_7 mentioned that they (could) provide information about change proposals and DT revision projects via a newsletter within their SA. During the validation interview with D_1 it was stated that DHD is aware that it should invest in better publicity with regards to change proposals.

Functionality in EHR system

In order to improve the DT, S_5, M_1, M_2 argue that the design of the Epic system should be optimized. D_1 also stated: "you would rather have that whenever a doctor looks for a diagnosis or operation, there exists a button like 'I miss something' or 'This is something I would like to add'. In the hospital, this should alert the right party, and then the request is sent to us. But I can see that it is difficult as all those hospital systems are designed differently". S_2, S_3, S_4, S_5, S_7, S_9 validate a similar functionality in the EHR system, but they all stated that if that functionality in the EHR were to be implemented, the system might overflow in requests. S_6 and S_8 did not answer the validation question about this functionality. With regards to the concern of overflowing the system, the researcher suggested that some entity, like the medical administrators, should play a filtering role with the incoming requests, before finalizing it and sending it to DHD. The filtering would happen by sending the attempts together with the doctor's ID and the chosen term from the list to the medical administrators. In this way, medical administrators gain insight in what the clinician was struggling with. If they see that a synonym is indeed missing, they can suggest a change proposal and fill in the (Excel-)format. Both M_1 and M_2 liked the idea of reacting to search strings, but M_1 argued 'we should still discuss with the clinicians if they want to make the request'.

Advising role

M_1 and M_2 suggested that they could play an 'advising role' for proposing changes to the DT. M_1: 'I think if we would have insights in the terms available in the DT and the changes clinicians make in free-text fields, we could propose changes ourselves' (table 1, 4f). In order to fulfil such advising roles, the administrators would need to have insights in what the clinicians are coding (incorrectly), but also determine thresholds on when a request should be proposed. According to both administrators it is essential that the proposals are still discussed with the specialists.

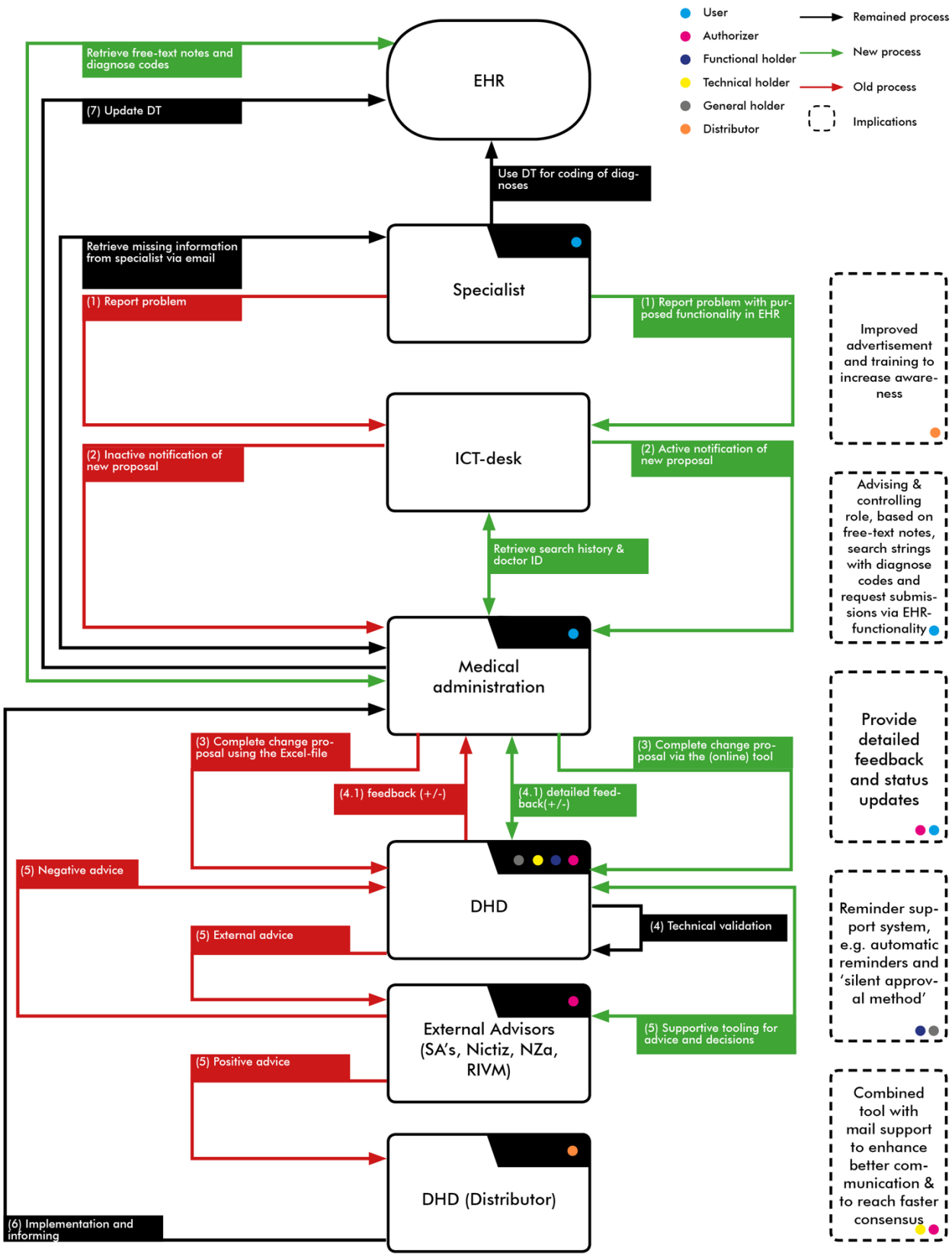

Figure 2. The current and future process. The old process that needs to be revised (red arrows), the new process (green arrows) and the process that remained the same (black arrows), derived from the interviews. The implications, based on the suggestions, that affect the stakeholders are shown in the dotted squares. The numbers indicate the phases.

Table 1: Terminology maintenance criteria framework. Criteria are either fulfilled (v), partly fulfilled (~) or not fulfilled (x) for the investigated process at Amsterdam UMC and DHD.

1. User: the retrieving organizations of the terminology system (hospitals, medical administrators)	
a) The user should have sufficient knowledge of the terminology system	V
b) The user should know what the current version is of the terminology system	V
c) The user should know what versions of the terminology system he uses	V
d) The user should register what versions are used to capture data	V
e) The user is responsible for having available the historical version of the terminology system when editing or analyzing data from previous versions	V
f) The user should apply the terminology system in the way it is approved by the authorizer	V
g) The user should apply the terminology system conform purpose	V
i) The user is not authorized to adjust the terminology	V
j) The user should let the distributor know in what way(s) the terminology system is used	X
k) The user should be able to provide comments/changes/proposals for changes to the functional holder of the terminology system	~
2. Authoriser: RIVM, Nictiz, NZa, Scientific Association (Association for the Defense of Professional Interests, Registration committee and policy officer(s))	
a) The authorizer must be known, and the authorizer must acknowledge its role	V
b) The authorizer must define the purpose of use, the collection of elements and target audience for each terminology system	V
c) The authorizer must contain a worked-out business plan for the development and the use of the terminology system	~
d) The authorizer must be (end-)responsible on decision-making	V
e) The authorizer must adhere to the purpose of the terminology system when making a decision	V
f) The authorizer assigns roles to himself or other natural legal persons with regards to the terminology system	~
g) The authorizer is responsible for fully accommodating the roles as proposed in the document	X
h) The authorizer must give other roles the opportunity to influence the decision-making	V
I) Only qualified people should be able to make changes in the terminology content	V
j) There must be a 'change model' which defines all changes that can occur in the content of a terminology system	~
k) For each proposal, the consequences must be determined and thereupon anticipated	~
l) Proposals for changes in the terminology content must be validated	V
m) Changes made in the terminology content must be validated	V
3. **Holder: DHD**	
a) The holder must be known	V
b) The holder is responsible for the content of the terminology system	V
c) The holder is responsible for operational activities around the terminology system	V
d) The holder must monitor the technical and functional holder and distributing of the terminology system on the base of the proposed process description by him/her	~
e) The holder must be responsible for the way information and support is offered	~
f) The holder must monitor the use of the terminology system	V
g) The holder must give users the opportunity to influence decision-making	~
h) The holder must decide on the way the terminology system is distributed, inform the distributor about this method and enforce the distributor to perform it in that way	V
4. Functional holder (f.h.): DHD	
a) The f.h. must be known	V
b) The f.h. must work on behalf of the authorizer	V

c) The f.h. must perform the content management and maintenance of the terminology system	V
d)The f.h. should handle a *best practice* method with regards to terminology maintenance and the delivering support for the keeping of the system	~
e) The f.h. should be in control of version control and align this with the technical holder	V
f) The f.h. must propose changes to the terminology system based on the wishes of the users of the terminology system	~
g) Assign a maintenance team, responsible for the organization of the maintenance	V
h) Different relevant disciplines should be involved within the maintenance team	V
i) Proposals for changes in terminology must be standardized	X
j) Proposals for changes must be documented	~
k) Documentation must be structured and standardized	~
l) The maintenance team must be easily accessible	~
m) The response time of the maintenance team on proposals and questions must be short	X
n) Proposals must be processed within a predetermined time period	X
o) The f.h. must use a supporting system for their maintenance process	~
p) The application must be secured with a login name and password	V
q) Changes made in the terminology content must be documented	V
5. Technical holder (t.h.): DHD	
a) The t.h. must be known	V
b) The t.h. must keep the terminology system in a technical management environment	V
c) The t.h. must be able to carry version control	V
d) The t.h. must have the historical versions of the terminology system	V
e) The application must support managing of different versions of the terminology system	V
f) The application must support editing of new versions for distribution	V
g) The application must support collecting proposals for changes	~
h) The application must contain a module to enable the consensus process	X
i) The application must support the automatic validation controls	X
j) The application must generate reports for documentation	~
6. Distributor: DHD	
a) The distributor must be known	V
b) The distributor must distribute the terminology system according to the acknowledged method established by the holder	V
c) The distributor must make the current and penultimate version of the terminology system available	V
d) The distributor must notify all known users about the availability of the availability of the current and penultimate version of the terminology system	V
e) The distributor must notify all known users if there is a reason to change from the penultimate version of the terminology to the newest version of the system	V
f) The distributor should allow users to contact them and obtain the terminology system	V
g) The distributor must determine a period in which the application for a terminology system is met and ensure that the terminology system indeed is delivered in the established period.	V
h) The distributor must announce the prices for the purchase, use and distribute of the terminology system and arrange a financial settlement	V
i) New versions of the terminology system must be provided with a unique id-number, including publication date	V
j) Depending on the type of terminology system, on average twice a year a new version of the system must be launched	V

5. DISCUSSION

5.1 Principal findings

In this thesis, we investigated a terminology maintenance process in two Amsterdam-based hospitals in order to come up with a new design of the maintenance process with suggestions on how to improve this process. We merged two frameworks of Raiez et al [10] and NEN 7522 [26] that helped us identify the missing criteria for the maintenance process. The findings of this study extend the need for an systematically arranged terminology maintenance process, as do [10] and [21]. This, because an established maintenance process leads to consistent and complete terminologies which could potentially lead to improved data quality. As studied, most specialists from SA's consider the current DT to be either incomplete or too long, albeit not performing the requests to improve its content. Consequently, specialists cannot choose the desired code and document in free-text fields instead. However, it is questionable if they do that because they consider the terms from the DT not descriptive enough or that the terms from the DT are not descriptive enough because the specialists are not concerned with making the change proposals in the first place. Or, that specialists actually do want to make a change request, but do not know how.

This study highlights the need to improve current authorization process (e.g. by using supportive applications that require minimal effort (table 1, 5g-5j)) in which agreements (relating to the response time) are established between the relevant parties. Also, it is essential that distributors of the terminology should create awareness among the users. Following, users will be aware of making change requests and perform requests to add, modify or remove terms. As a result, the value of DT increases as they can now choose a desired term, reducing potentially free-text notes and therefore improving data quality (table 1, 3g). Further, improving the quality of the content of the DT could also be established by giving administrators insights in specialists' coding and their free-text notes or search strings as then the administrators can suggest a proposal in agreement with the specialist. We checked with an Epic-employee whether sending search strings from specialists to the administrators is technically possible. It was argued that logging these search strings is not yet possible but could be implemented in the future. This process change does, however, increase the workload for the administrators, requires specific training and should therefore be further investigated.

It is also required that the EHR system offers some functionality that eases the change request process, increasing again the awareness of making a change request and eventually improving data quality. However, some SA-participants expressed their concerns about such functionality, as it might lead to irrelevant requests. Therefore, (Dutch) hospitals should have a 'filtering' entity like medical administrators who only forward meaningful requests.

Although some participants raised concerns about the many parties involved in the current process, we did not further investigate current routing. If specialists would send their request directly to their SA, the SA's might be overloaded with (irrelevant) requests. DHD currently performs a triaging role, ensuring only relevant proposals are forwarded to the concerned SA's. It is questionable if specialists would know for themselves to where to send their request and whether they find time to do so. Therefore, we consider the functionality in Epic most beneficial, along with creating awareness of improving the DT using change proposals.

5.2 Relation to other literature

Research by Wixom and Todd [32] stated that in order for Information Technology (IT) to be successful, user satisfaction and technology acceptance are key factors. We consider adding awareness to their proposed integrated research model. Importance of creating awareness is also supported by Horsky [18] who mentioned that creating awareness results in better registration. A study by Davis further adds that perceived usefulness is highly influential to technology acceptance [33]. Subsequently, because some specialists consider the current DT inefficient, it might be necessary to revise the DT completely in order to increase the perceived usefulness. With increased usefulness, user acceptance increases and eventually the actual use increases too [32]. Thereafter, the proposed maintenance process can be used to maintain this perceived value. But without perceived value in the first place, the maintenance process for improvement of the use of the DT alone will not suffice.

Wade et al [21] further stated that open participation leads to better terminology maintenance. Open participation is also supported by ISO16212 [26] and our framework, indicating that the user should be able to provide suggestions to improve the DT (table 1, 1k). In addition to that, we argue that open participation should be standardized in order to achieve optimal results in maintaining the terminology, in our case the DT. Standardization in the open participation process should be enhanced by the authorizer, who then also validates the suggestions in a standardized manner (table 1, 4j) [17]. Eagon [22] added that whenever a term is missing, a note should be sent to a central authority in order to deal with that. Chute et al [17] stated that this central authority can simplify the maintenance process. We support this finding and add that the EHR systems should provide some functionality in order to send the notification, so that administrators can fulfil their 'filtering' role.

Last, improving the use of DT by specialists and therefore improving (structured) data entry in EHR systems requires that the system, the EHR in which the DT is implemented, is built to the demands of the user [19]. If the functionality in the EHR is implemented, user testing would be needed to check if the functionality indeed improves the number of requests and to check what the design should look like, in order to increase user satisfaction and therefore technology acceptance [32].

5.3 Strengths and limitations

This study was the first to provide insights in and propose suggestions to a terminology maintenance process in the Netherlands. We combined two existing frameworks that can be used to further asses other terminology maintenance processes. Furthermore, this study concerned all relevant stakeholders; multiple SA's and interviews were performed until saturation was reached. In addition to that, most suggestions were validated with the V-model [30]. However, it would require an actual implementation effort to see if the process actually benefits from the suggestions, e.g. faster authorization or (perceived) improved content of DT. Although this research did provide some meaningful findings, it has its limitations. First, although a qualitative approach was considered the best method to achieve our objectives, such approach has drawbacks. For example, the answers of the participants in our study may have been socially desirable or prone to recollection bias. However, we are confident that we collected accurate results as we received varying answers among the participants about the process. Further, only one researcher did the coding and interviews, making the data collection and synthesis less robust than when this would have been in duplicate. In the study, we only examined one 'using organization', Amsterdam UMC, that uses one software system. Therefore, it remains uncertain if the results can be applied to other hospitals. Nonetheless, as there are more hospitals that use Epic, these might benefit from the results as presented. Moreover, we did include multiple SA's and DHD is the distributing and authorizing body for each hospital in the Netherlands, making the results about authorization applicable nationwide. Our suggestions might not, however, be valid for international terminology maintenance processes.

5.4 Implications for practice

In table 2, we present some practice implications for the design of terminology maintenance processes for the Netherlands that extend our framework, as indicated earlier in figure 2. The

implications are divided in two phases of the process: before the proposal and during the proposal, both enabling better use of DT and therefore potentially data quality.

Table 2: Practice implications for the (Dutch) terminology maintenance process. [1] Concerns the same required 'controlling entity'.

	Description/solution
Pre-proposal	
Increase awareness	Distributor should (frequently) inform relevant stakeholders about possibility of doing change proposals and the availability of the DT; implement change proposal request training for specialists
Implement functionality for requests in EHR	The functionality should help users in performing requests, it requires a controlling entity[1]
Controlling entity[1]	Have administrators control request submissions and data entry with, e.g., search strings or attempts
Active advice	Have administrators judge free-text fields of specialists in order to suggest new proposals
Revision of DT	Initiate projects to revise the complete DT per specialism if value of DT is not perceived and use mapping when possible
During proposal	
Tooling	Use supportive (online) tooling for change proposals, e.g. an online format for authorizer-user and collaborative tooling for authorizer-distributor, but minimize using effort
Feedback	Provide feedback to the users about the status of the request, with specific time indications for how long the request will take; provide feedback to the distributor about the use of the DT
Agreements	Establish agreements among all SA's for the response time and 'silent approval' method for smaller changes

5.5 Implications for research

This study yields three main implications for research. First, we encourage other researchers to implement the proposed suggestions to investigate if the maintenance process does indeed improve, for instance in the time it takes between the authorization and distribution of the newest version of DT. Second, it would be useful for researchers to investigate whether there is a potential for a core set of criteria or performance indicators that can be applied broadly across a wide range of terminology maintenance processes. Though our results might not be exactly applicable to other countries, studies could systematically apply our framework criteria to other processes, in order to come up with these generalizable criteria. Additionally, in relation to improving data quality in EHR systems, researchers should extend the findings by interviewing or surveying more healthcare providers on why they structure poorly with the DT, which could help in deciding how to increase awareness and help in deciding the design for the request-functionality in the EHR system.

6. CONCLUSION

This study was the first to provide insights in the terminology maintenance process in the Netherlands. It presents a framework for the implementation or assessment of similar terminology maintenance processes (in healthcare).

We developed a maintenance criteria framework and applied it to an Amsterdam-based maintenance process in order to gain insights in the current issues and to come up with recommendations on how to improve the process. Overall, a systematic terminology maintenance process is found valuable as it should ensure frequent updating and therefore improved content of the DT, which could then potentially lead to structured (clinical) data entry. Nonetheless, it is essential that the value of DT is recognized by the specialists in the first place, before implementing this terminology maintenance process. Following, complete revision of the (content of the) DT might be needed. Thereafter, the maintenance process can be assembled. In the proposed process, we highlighted the importance of creating more awareness about the possibility to do a change request, the implementation of supportive (online) tooling, revised agreements between authorizing parties, informing the users about status of the requests, and we suggested that administrators should play an advising and filtering role depending on the implementation of a request-functionality in the EHR system. Though these suggestions are validated, additional research is needed that examines the actual implementation of these suggestions so improvements can be measured in practice. The study included all relevant stakeholders involved in a maintenance process, making it applicable nationwide. We believe our merged maintenance criteria framework could be used to assess similar maintenance processes in healthcare and that it provides an important step on the path to providing generally applicable criteria for other terminology maintenance processes.

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