







# A State-of-the Art Review of SNOMED CT **Terminology Binding and Recommendations for Practice and Research**

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# **Abstract**

Background Unambiguous sharing of data requires information models and terminology in combination, but there is a lack of knowledge as to how they should be combined, leading to impaired interoperability.

**Objectives** To facilitate creation of quidelines for SNOMED CT terminology binding we have performed a literature review to find existing recommendations and expose knowledge gaps. The primary audience is practitioners and researchers working with terminology binding.

**Methods** PubMed, Scopus, and Web of Science were searched for papers containing "terminology binding," "subset," "map," "information model" or "implement" and the term "SNOMED."

Results The search yielded 616 unique papers published from 2004 to 2020, from which 55 papers were selected and analyzed inductively. Topics described in the papers include problems related to input material, SNOMED CT, information models, and lack of appropriate tools as well as recommendations regarding competence.

Conclusion Recommendations are given for practitioners and researchers. Many of the stated problems can be solved by better co-operation between domain experts and informaticians and better knowledge of SNOMED CT. Settings where these competences either work together or where staff with knowledge of both act as brokers are well equipped for terminology binding. Tooling is not thoroughly researched and might

be a possible way to facilitate terminology binding.

## **Keywords**

- terminology binding
- SNOMED CT
- electronic health records
- information models

# Introduction

Data sharing within and between stakeholders in health care is low. Part of the problem is lack of semantic interoperability, in other words the data entered at one place and time cannot be reused in other places and over time unambiguously.

SNOMED CT has evolved over decades into what today is the most comprehensive terminology in the medical field. In 2016 it was judged "the best available core reference terminology for cross-border, national, and regional eHealth deployments in Europe." But neither SNOMED CT nor any other

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terminology is a stand-alone solution to the problem of semantic interoperability, a terminology must be used in harmonisation with one or many information models that can provide structure.

Establishing links between elements of a terminology and an information model is called terminology binding<sup>2</sup> and is also often referred to as mapping or subset development. Terminology binding is typically performed during configuration of health record systems, in response to data sharing efforts or during implementation of decision support systems. Providing relevant subsets for different parts of an information model terminology binding can also facilitate natural language processing (NLP) of narrative text.

There is, however, a lack of published guidelines on the process of terminology binding SNOMED CT. A paper from 2012 describes a method for mapping,<sup>3</sup> but a survey on SNOMED CT implementations in 2013 stated that there is a lack of "subset development methodologies,"<sup>4</sup> and a literature review in 2015 stated that these processes were rarely described.<sup>5</sup> In 2015, the TermInfo project<sup>6</sup> wrote guidelines for the binding of SNOMED CT to HL7 Reference Information Model, and in 2016 it was proposed that guidelines should be developed on the combination of information model elements and SNOMED CT hierarchy as well as granularity issues.<sup>1</sup>

Lack of guidelines makes performing terminology binding difficult and the result inconsistent, hindering reuse of data and impeding transformation to sharable data in health care.

# **Objectives**

This paper provides a state-of-the-art review<sup>7</sup> and analysis of research published about terminology binding processes concerning SNOMED CT. We aim to collate existing knowledge on difficulties and possible solutions and to point out relevant future research. The primary audience is practitioners and researchers working with terminology binding.

# **Definitions**

Ironically there is a lack of terminological clarity in this perisemantic area working toward unambiguity. This paper uses the following terms and definitions for *concept*, *description*, *subset*, *subset development*, *information model*, *terminology binding*, *value set binding*, and *mapping*.

SNOMED CT is made up of *concepts* representing things in the real world, for example disorders assumed to exist in real patients or procedures done or to be done on real patients. Others call these representational entities (or just entities). In SNOMED CT each concept has two or more *descriptions* linked to it, each containing one term. One description is the Fully Specified Name (FSN)<sup>9</sup> which includes a term that is always unique within SNOMED CT, while the other descriptions are synonyms that have terms for use in different languages and/or contexts. Synonyms are not always unique within SNOMED CT. For example, the concept with id 22298006 has FSN "myocardial infarction (disorder)." It also has the descriptions "Heart attack" and "MI" (in English) and "hjärtinfarkt" (in Swedish), among others.

A *subset* is a collection of components from a terminology. SNOMED CT subsets presented in RF2-format are simple reference sets, often called just "refsets." In some use cases subsets are called value sets. A SNOMED CT subset can include either SNOMED CT concepts, which in an interface can be represented by any of the descriptions linked to them, or specified descriptions.

Subset development is the process of choosing concepts or descriptions from a terminology relevant to a specific application. SNOMED CT subsets can be defined either by enumerating the included concepts (extensional subsets) or by using SNOMED CTs description logic (intentional subsets).

An (clinical) *information model* is defined by ISO/DIS 13972:2020 as "logical models designed to express one or more clinical concepts and their context in a standardized and reusable manner, specifying the requirements for health, clinical and care information as a discrete set of logical clinical data elements." <sup>10</sup>

According to Benson and Grieve "Terminology binding is the process of establishing links between elements of a terminology such as SNOMED and an information model." Value set binding is a type of terminology binding where a subset of a terminology is stated as the allowed values for a certain part of an information model, for example the allowed concepts in a section of Family History could be a subset of all concepts subsumed by 64572001 | Disease (disorder)|.

The difference between "value set binding" and "subset development" is that a value set binding will always refer to a specified part of an information model, whereas subsets can be developed for multiple use cases and, sometimes after adjustment, be used as value sets in different information models.

Mapping can mean at least two things. First, making an extensional subset by starting with an existing list of terms and selecting corresponding SNOMED CT concepts and then abandoning the initial list. This type of mapping produces a subset with one concept per entity.

Second, making a link between concepts in one terminology and concepts in SNOMED CT, intending to continue using both terminologies (for new and/or legacy data) and using the map to transfer data from one to the other. This type of mapping produces a map with concepts from two terminologies linked to each other.

## Methods

## **Choice of Databases and Primary Inclusion**

Two larger literature reviews on SNOMED CT use have been published, one in 2008 covering 1966 to 2006<sup>11</sup> and one in 2014 covering 2001 to 2012.<sup>12</sup> The 2008 review searched Medline, whereas the 2014 review also included Embase. Both of these databases are geared toward medical and biomedical science. To find publications also published in the informatics field we chose to perform searches in Scopus, Web of Science, and Medline.

For primary inclusion we searched for papers containing SNOMED in some form and some term that could relate to terminology binding, subset development, or mapping. We used the term "SNOMED" as this also includes similar

Table 1 Database search strings and hits

| Database       | Search string   | Hits |  |  |
|----------------|---|------|--|--|
| Scopus         | TITLE-ABS-KEY (SNOMED) AND TITLE-ABS-KEY ("terminology binding" OR subset* OR map* OR "information model" OR implement*) AND NOT TITLE-ABS-KEY ICD* |      |  |  |
| Web of Science | $TS = SNOMED \ AND \ TS = $ ("terminology binding" OR subset* OR map* OR "information model" OR implement*) NOT $TS = ICD^*$                        | 358  |  |  |
| Medline        | SNOMED AND ("terminology binding" OR subset* OR map* OR "information model" OR implement*) NOT ICD*   |      |  |  |

predecessors, such as SNOMED RT. We considered older versions not relevant since the structure of them are significantly different from SNOMED CT. Although UMLS includes SNOMED CT, for the same reasons, papers only describing UMLS were not considered relevant.

Since ICD is used for statistics, reporting and reimbursement, there are many papers on mappings between these two terminologies. We are interested in terminology binding done for implementation purposes. A search including ICD was found to severely decrease specificity with only a small gain in sensitivity and papers with "ICD" in title or tag were therefore excluded acknowledging that this would omit potential papers where both ICD and SNOMED CT were used in clinical practice.

Many findings in informatics are presented at conferences rather than published in journals, and therefore we have included both conference proceedings and journal papers. We had no limit timewise historically, and a complementary search was made on April 13, 2020 to include papers published during our work. See **Table 1** for search strings and total hits in the three databases.

The three resulting lists of papers were merged in Zotero reference management software.<sup>13</sup> Papers with the same title, author, and publication year were identified as duplicates and removed, see Fig. 1.

#### **Abstract Review and First Exclusion**

We imported the resulting 616 papers into Rayyan software. 14 Papers which described processes where medical information had been mapped to SNOMED CT resulting in a subset or a map for implementation and papers with recommendations of how such work should be performed were included. To refine and ensure consensus about the exclusion/inclusion criteria, the review was unblinded after the first 20 papers were analyzed, and the results discussed within the group. The remaining papers were then reviewed

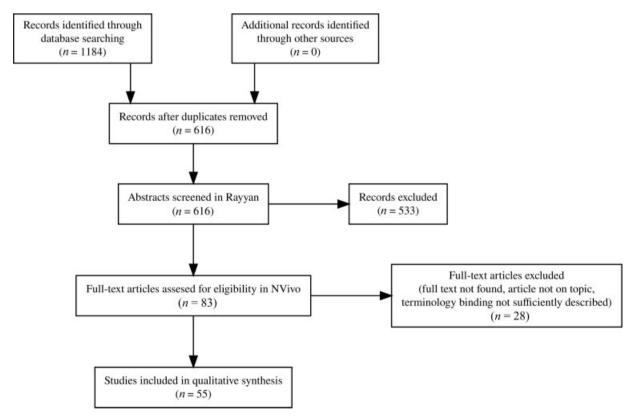


Fig. 1 PRISMA diagram.

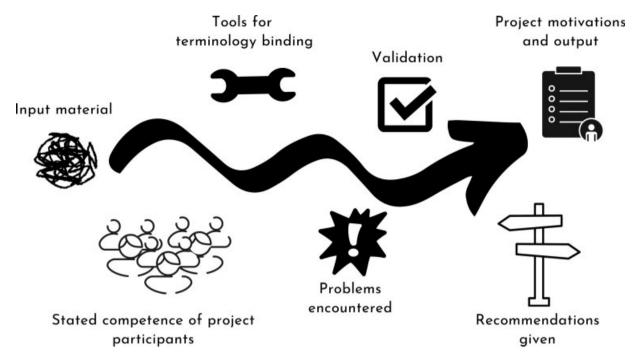


Fig. 2 Terminology binding topics.

in a blinded fashion where at least two reviewers categorised each paper. In cases of disagreement, a third reviewer made the final choice.

When there was both a journal paper and a conference proceeding published on the same material, both were read, and if the journal article was an improved version of the conference proceeding only the journal paper was included. If, however, they presented different ideas, albeit from the same material, both were included.

Papers in other languages than English, review papers and papers where full text was not accessible were excluded.

## Full-Text Review, Coding, and Secondary Exclusion

The resulting list of papers was then imported into nVivo. 15 Initially, the four authors thoroughly read 20 randomly selected papers. These were discussed and a consensus was reached on what topics to look for in all papers. The topics were chosen to capture important aspects of the context where the work was performed and different parts of the terminology binding process. The authors have different academic and practical backgrounds, ensuring width of scope. These topics correspond to what Webster and Watson refer to as "concepts," 16 but as this term has a specific meaning in SNOMED CT, we prefer the term "topic." Together they constitute a conceptual framework as described by Rowe.<sup>17</sup> The topics were represented as nodes in NVivo and sub-nodes were developed iteratively during the annotation process.

During this process, 28 articles were excluded because they were not on topic, the terminology binding process was not sufficiently described, or full text was not available. The included papers are listed in -Appendix A. During annotation, subtopics were developed iteratively with results as described under the respective topic below.

## **Synthesis of Results**

We have used both quantitative and qualitative methods, and the results of these will be intertwined. Calculations were performed in MS Excel and Chi-square method was used for quantitative analysis across topics.

#### Results

## The Following Topics Were Chosen

The content analysis of the papers described under methods above led to the formulation of seven key topics as shown in **► Fig. 2**.

#### **Input Material**

The majority of the described projects (n = 46, 84%) focused on information used for documentation. Of these, 33 used existing terminology such as EHR templates or local term lists as input. The projects starting with free text often had domain experts or focus groups who produced a list of terms as input, while two projects used both free text and listed terms as input.

A smaller proportion of the projects focused on information in guidelines or literature, and all of these started with free text, see Fig. 3. These projects were performed to support improved data-gathering in half of the cases (n=4)and as part of the development of clinical decision support systems (n = 5) in the other half.

Papers with different types of input data were evenly distributed over time.

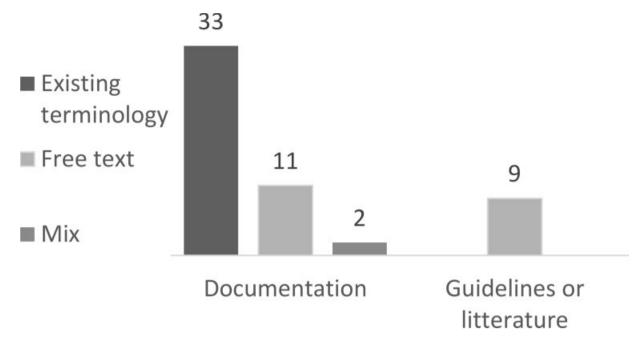


Fig. 3 Input material.

## **Stated Competence of Project Participants**

Of the papers, 40% (n=22) did not state the competence of those who performed the terminology binding. This includes the papers focused on development of tools where domain knowledge is less relevant. Of the papers mentioning competence, half reported both terminological and domain knowledge. This could be one person with double competences or separate people working together. The other half of the papers were evenly split between domain experts and terminologists doing the work, see **Fig. 4**. No statistically significant difference was found in the distribution of competence with regard to the aim of the project described. The co-operation between terminologist and domain experts was stressed in nine papers.

## **Tools for Terminology Binding**

Terminology browsers, sometimes multiple, were the most commonly mentioned tools, with *CliniClue Browser* and *SNOMED International's Browser* being most frequent. Others were: *Gephi, HealthTerm* (only used for browsing), *Nictiz Terminology Browser*, *UMLS Metathesaurus*, and a prototype visualization tool called *TermViz*. Five projects mentioned having used multiple browsers, which sometimes yielded different results during look-ups. <sup>18</sup>

In the included projects 11 different tools that used to support terminology binding were mentioned (**Table 2**). The tools range from one-off local projects to software that is still available in 2020.

Six papers stated the use of *Excel* for managing and storing subsets. One project used both *SNOMED International's developer toolkit* and an *SQL server*<sup>19</sup> to manage subsets. No paper mentioned a FHIR-based terminology server. One paper used a tool included in the EHR to develop templates,

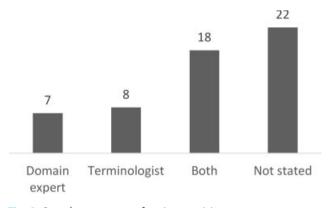


Fig. 4 Stated competence of project participants.

where the terminology bindings were thus documented,<sup>20</sup> albeit not in an easily sharable format.

Five papers mentioned lack of appropriate tooling as a specific problem.

#### **Problems Encountered**

We have identified four themes regarding the problems described in the included articles.

## **Problems Related to Input Material**

To correctly bind input material to SNOMED CT concepts the input material needs to be properly understood by either human, machines, or both in collaboration. Assumed information must somehow be considered and included in the input for terminology binding. An example is "Basically, all salpingectomy/oophorectomy cases have been done robotically in the practice since several years ago. This is not reflected in the documentation of surgical notes." <sup>21</sup> If this is not taken into

account during terminology binding, underspecified concepts might be selected.

Local terms or abbreviations can be difficult to interpret, for example "In orthopaedics, the term "SLAP tear" is a short form for describing a tear to the labrum"<sup>22</sup> and homonyms used in different contexts might lead to misinterpretation as demonstrated by "The term "left adnexa" used to describe the left uterine adnexa, but it could also refer to the left ocular adnexa."<sup>22</sup>

Some papers report problems where the input material has multiple terms perceived as synonyms, for example "the neurological finding of bilateral extensor plantar response was expressed in 13 different ways."

Projects which describe mapping of clinical guidelines or decision support systems report granularity issues, for example they "often encountered a guideline term too general to appear as a patient data item in electronic medical records."<sup>24</sup>

Where the input material is derived from statistical classifications, terms based on "not elsewhere classified" or "other specified" can cause problems because a corresponding concept is not allowed in SNOMED CT. For example, "concepts such as "other cardiovascular problems" are vague, as they depend on what has been specified in the context."<sup>24</sup>

#### Problems Related to SNOMED CT

The most common problem during mapping, mentioned in approximately 60% of papers, was failure to find an appropriate concept despite relevant searches. This was mostly in the order of a few percent of the entire subset or less and was

generally solved by requests for new concepts. It was never stated as a significant problem, but the delay caused by this made some use local extensions where they could add concepts more quickly.<sup>22</sup>

Lack of terms for existing concepts was also mentioned as in "the terminology used in the clinical area cannot always be found in SNOMED CT. In this case we tried to find a concept ID that represents the concept that lies behind the terminology used by the care professional."<sup>25</sup> Sometimes multiple very similar terms in SNOMED CT for different concepts made finding the right concept difficult.<sup>18</sup>

Some SNOMED CT terms were deemed incorrect in relation to FSN or other terms for the same concept, for example "we did not think that "depression (finding)" and "sadness" were semantically equal as defined by SNOMED CT," and some terms were formatted inconsistently for example "left popliteal artery structure (body structure) and structure of right popliteal artery (body structure)." Cultural differences sometimes make terms incorrect as in the "use of stimulants, like alcohol, marihuana, and cigarettes is defined as abuse of these stimulants although the use of stimulants is not always considered as abuse." 25

Half of the papers mentioned difficulties pertaining to the SNOMED CT concept model. For example, the model was perceived to be developed for surgical procedures, resulting in difficulties post-coordinating, and it was stated that "there is no proper way to post-coordinate nonoperative or nonsurgical concepts." One paper lacked the possibility of documenting patient preferences as in ""patient-prefers-bct,"

Table 2 Tools mentioned in included papers

| Name of tool  | References | Publication year | Stated use in project  |
|---|------------|------------------|--|
| BioPortal<br>Annotator  | 54         | 2013             | a tool that processes text submitted by a user, recognizes relevant biomedical terms in the text, and returns the annotations to the user. |
| eleMAP  | 55         | 2011             | semi-automatic mapping of research DEs [Data Elements] to standardized biomedical vocabularies and metadata registries.                    |
| LexValueSets  | 56         | 2008             | context-driven value sets extraction.  |
| Mayo Clinic Tools<br>SAVS/MCSV  | 57,58      | 2004, 2006       | The MCVS is a set of tools which facilitates health vocabulary indexing.   |
| Medical Text<br>Extraction,<br>Reasoning, and<br>Mapping System<br>(MTERMS) | 59         | 2016             | generic natural language processing (NLP) application to process and map local allergy entries to the standard terminologies.              |
| MoST  | 31         | 2008             | archetype authoring, semi-automatic SNOMED CT terminology binding assistance and terminology visualization                                 |
| SAMT/SSMT   | 60         | 2014             | discover mappings between clinical terms and SNOMED-CT concepts.   |
| Snapper   | 33,34      | 2010, 2011       | creating mappings from an existing terminology to SNOMED CT.   |
| Termworks by<br>Apelon  | 30,58      | 2004, 2008       | searched SNOMED for concept names matching the unresolved narratives using a multi-step algorithm.   |
| UMLS MetaMap  | 28         | 2010             | map biomedical text to the [UMLS] Metathesaurus.   |
| Unnamed tool  | 61         | 2012             | propose a hybrid approach relying on linguistics as well as structural information [for mapping].  |

describing the patients preference of breast conserving treatment over mastectomy."<sup>28</sup> Combinations made of existing concepts, for example "six-courses-anthracycline-chemotherapy" or the intention "elimination-distant-metastases"<sup>28</sup> were reported as absent, but others stated that post-coordination solved problems with lacking concepts, for example the concept "asthma education completed before the enrolment for the DMP"<sup>29</sup> was post-coordinated. Post-coordinating was deemed more complicated than requesting new precoordinated concepts because "these require a sophisticated knowledge of concept modelling and the evolution of SNOMED hierarchies over time"<sup>30</sup> and "post-coordination may be equivalent to an existing precoordination or another post-coordination. Logical contradictions also have to be checked for and avoided."<sup>31</sup>

Choice of hierarchies can be difficult, with similar concepts found in observable entities and findings.<sup>3,25,32</sup>.

Another problem with the concept model reported was the way subsumption includes concepts that can be correct in one setting but incorrect in another, for example "the specializations of the SNOMED CT concept "nose and throat examination" include the concept "rhinolaryngologic examination under general anesthesia" which is not a part of the preoperative airway examinations that is mentioned in the guideline."

Refsets used to document subsets are sometimes reported to lack functionality because the "format does not directly allow for specific concepts to be included merely for navigational grouping purposes and not selectable in the user interface."<sup>33</sup>

The choice between what to document with terminology and what to document with an information model is mentioned with, for example, finger extensors and laterality<sup>25</sup> and "patient younger than 1 year" versus date of birth.<sup>27</sup>

Some descriptions state solutions that use the SNOMED CT concept model incorrectly, revealing that there is a lack of knowledge among both authors and reviewers, for example "in the archetype Apgar, the ELEMENT term Colour referring to the skin was mapped to the SNOMED CT concept Colors (qualifier value) because a more specific concept in SNOMED CT has not been found"<sup>32</sup> and "when examining the family history of a stroke patient one wants to know if stroke at an early age runs in the family. For this concept we needed three SNOMED CT codes: one for stroke, one for age, and one for young."<sup>25</sup>

Lack of recommendations for modelling<sup>34</sup> and the need to further develop modelling guidelines<sup>3</sup> was raised as a problem.

## **Problems Related to Information Models**

Several papers point out the need for a stated information model to bind the terminology to, either at national or international level, and the agencies sharing information with one another need continued communication.<sup>3,24,30,35,36</sup> Arguments for this are both to share the burden of the work<sup>35</sup> and to obtain semantic interoperability.<sup>3</sup>

#### **Problems Related to Tools**

The necessity of tools to support mapping is stressed with, for example, "default context .... should be supported by tooling" and "continue the search for useful IT-tools for documentation of the structured clinical content." Some of the problems mentioned above, for example related to the choice of concepts from the wrong hierarchy, could be prevented with supported tooling.

Problems also occurred when tools were used, for instance when different parts of projects used different tools, thus producing different results for the same task. This occurred both with mapping tools<sup>30</sup> and browsers. In the browsers it was sometimes due to different settings regarding extension and version.<sup>18</sup>

In one paper a publicly available tool is suggested to support consistent post-coordination.<sup>37</sup>

#### **Validation**

Validation was described in 69% (n=38) of included papers, the most common type being independent reviewers working with the same material and then comparing results. Papers on tooling described automatic controls within the tools but also used human controls as in "all filtered SNOMED CT results are presented to the clinical modeler as candidate mappings."  $^{31}$ 

#### **Project Motivations and Output**

Four main types of motivation and corresponding outputs from the included projects were found. Evaluation of applicability (29%, n = 16) includes projects that evaluated SNOMED CT coverage solely or compared SNOMED CT coverage with other terminologies against a set of terms or local codes in a particular setting, often as a first step in an implementation or as part of preparation for such, but no implementation was described. The output was sometimes a subset or map, but more often a measurement of coverage of a domain. Papers included in descriptions of implementations (29%, n=16) describe single projects and their experiences. Examples include shifting to SNOMED CT in a clinical registry or template in an EHR, and the direct output of the work was, for example, a subset, a map between code systems, or a template populated with SNOMED CT. Recommendations (22%, n=12) group papers which provide general descriptions of or recommendations on how terminology binding can be done. Some include a case description as well, but the focus of the papers is generic recommendations. The output in these papers was the recommendation in itself.

The final group consists of papers on the *development of tools* (20%, n = 11) where either  $\beta$  software or evaluations of different approaches used in software development were described.

No patterns in the distribution of types of projects over the time-period were found. None of the papers described repeated work. Successive projects from the same research groups is not counted as repeated work.

#### **Recommendations Given**

We have identified three themes regarding the recommendations given in the included articles.

## **Ensure Domain Knowledge and Informatics Competence**

Among the papers stating recommendations more than half stress the need for knowledge of both domain and informatics within the project. Some examples are: "it is critical to have terminologists with considerable clinical background or domain expertise"26 and "requires considerable training before successful implementation"<sup>23</sup> When clinicians with no prior experience of informatics were engaged "substantial education was needed."35

Another argument for engaging clinicians in the work is to enable and make sure that good work practices guide the configuration of IT systems, and not the other way around, as in this example: "No decision support tool should disrupt the nurse's workflow, increase documentation burden, or decrease time with the patient; all these variables should be tested."38

## Follow a Process Including Validation

Papers describing a process start with domain analysis, sorting of the input material or making process flow diagrams as in "graphical representation of the clinical process, using symbols for start- and end-points, process, decision points, data, etc."35

Both manual projects and automated projects recommended using some type of validation, either as a single step or as a continuous process as in "there was ongoing collaboration-validation, discussion, and commentary for each group of maps. This was critical to achieving eventual consensus on the final maps."<sup>26</sup>

Some projects took note of the "quality of the relationship between source legacy interface terms and target SNOMED CT concepts"26 and others used Krippendorff's Alpha to mathematically measure discrepancies.<sup>36</sup>

We found detailed recommendations of how to choose concepts regarding, for example, hierarchies and granularity only in one paper.3

#### Plan for Maintenance

Since SNOMED CT is an evolving terminology there needs to be plans and systems for the maintenance of developed subsets<sup>39</sup> or maps, and this expense can be relatively substantial.30

#### **Article Statistics**

Publication year for the included articles was evenly distributed from 2004 to 2020. The included articles were found evenly in journals (n = 29) and in conference proceedings (n=26). The majority were published in Information System outlets: three papers were from medical journals, none from medical conferences. Fifty-three percent (n=29) of first authors were women. Papers came from all parts of the world with a majority from North America. Denmark and the Netherlands dominated in Europe.

Projects varied in size, with the smallest describing a method for post-coordination tested on 10 terms and the largest using both structured and narrative data as input starting with over 37,000 values.

#### Discussion

In the subsequent sections the findings in the previous sections are analyzed and discussed with respect to our research aim: to collate existing knowledge on difficulties and possible solutions and to point out relevant future research. We have organized the discussion primarily based on the findings reported under problems and recommendations found above. Recommendations are given for both practice and research.

#### **General Process**

We found no established process for terminology binding to SNOMED CT in the included papers; however, most processes described started with a review of what information would be relevant to document, proceeded to find relevant terms and concepts in SNOMED CT and then performed some type of validation with domain experts.

During the first step care must be taken to evaluate the quality of the input data before using it as a starting point for terminology binding. There might be a technical debt pertaining to previous or existing systems that preferably should not be brought into the new information structure. 40,41 It was stressed that the way clinicians work should take precedence over the system, rather than the other way around.

RECOMMENDATION FOR PRACTICE: Sort input data, select relevant concepts, validate.

RECOMMENDATION FOR RESEARCH: Test and refine the process described above. Evaluate balance between keeping legacy structures and resolving technical debt.

## Understanding the Meaning of Terms

The repeated problems described with understanding the meaning of terms in the input material stresses the necessity of domain knowledge. Insufficient knowledge of context and language used in the setting also obstructs understanding of the terms used in SNOMED CT. It is shown that domain knowledge is highly important when configuring templates or other types of data-collection material<sup>42</sup> and our finding that 75% of papers with stated competence had involved some sort of domain knowledge supports this being understood amongst the described projects.

Knowledge of the logical structure of SNOMED CT is also necessary to make qualified choices between concepts and judge when and what new terms or concepts are needed. Informaticians can provide this competence, but some knowledge of informatics is also needed by the domain experts and many papers stressed the cooperation between informaticians and domain experts. More supportive tools could perhaps alleviate the need for knowledge about SNOMED CT intricacies.

RECOMMENDATION FOR PRACTICE: Involve domain experts and invest time in educating them in informatics and SNOMED CT.

RECOMMENDATION FOR RESEARCH: Design supportive tooling geared to domain experts without in-depth knowledge about informatics or SNOMED CT.

## **Unspecified Terms**

The problems reported regarding explicitly unspecified terms in the input material cover two principally different types of entities, not otherwise specified (NOS) and not elsewhere classified (NEC).<sup>43</sup>

NOS terms can be terminology bound to SNOMED CT by using content at a higher level in the hierarchy, for example 233604007 | *Pneumonia* (*disorder*) | for unspecified pneumonia. This binding is a 1–1 map as both concepts mean the same thing.

NEC terms are defined by the other existing terms in the set and are therefore subject to semantic drift as the set evolves. Such concepts are not allowed in SNOMED CT, and it is thus not possible to bind an NEC term to a SNOMED CT concept. (It is, however, possible to bind from SNOMED CT to NEC terms). NEC terms also require in-depth knowledge of the rest of the set to be used accurately and should be used by skilled classifiers, or software, rather than by clinicians.

It must at times be possible to enter data even when none of the available concepts in the list are adequate. A possible solution in these situations is to allow free text entry. The entered text could be analyzed, and sequentially corresponding concepts could be added to the subset as, for example, described by Warren et al.<sup>44</sup> It is not possible, however, to automatically map all the free-text entries to the NEC term, as the free-text entry could have been chosen for numerous reasons.

Sometimes the free text would be used when there is actually a matching term in the subset. NLP could perhaps be used to suggest suitable terms from the subset and thus decrease the amount of unstructured data.

RECOMMENDATIONS FOR PRACTICE: Use general concepts for nonspecified terms. Enable free text entries for situations where the subset might be incomplete, and data must be entered.

RECOMMENDATIONS FOR RESEARCH: Find effective processes for analysing data entered as free text to either bind it to an existing concept in the subset or add the requested concept to the subset.

## **Incorrect Terms**

SNOMED CT includes many terms, and some are inevitably outdated or incorrect. SNOMED International provides a content request service for National Release Centres (NRC) to report errors. Some NRCs also offer a message function in the browser<sup>45</sup>

for all users to report issues, but these are not mentioned in any paper included and are perhaps not well known.

Sometimes the incorrect terms are related to context and setting, for instance drug abuse versus recreational use of drugs. To our knowledge there is no proposed solution to this apart from not using the conflicting concepts.<sup>25</sup> Context-specific concepts can be added per extension but are then not interoperable outside that extension. Discrepancies as these are hard to cater for when trying to use a single terminology on a global scale and the example where cultural influence impedes semantic interoperability.

RECOMMENDATION FOR PRACTICE: Report incorrect terms to National Release Centre (NRC) or SNOMED International. Develop local extensions when needed.

RECOMMENDATION FOR RESEARCH: Design processes for managing reported incorrect terms considering both promptness and quality.

## **Lack of Terms or Concepts**

Lack of terms or concepts introduces delay in implementation processes, as required terms are not immediately available for use. However, the fact that a concept or term does not exist in SNOMED CT does not imply it should not exist, merely that no one has yet made a request. Given access to a SNOMED CT module, new terms and concepts can technically be added as long as they follow SNOMED CT's principles of being understandable, reproducible, and useful and other editorial principles. Ho paper described a project with direct access to an authoring environment and possibility to edit or add SNOMED CT content, but that might perhaps be a way to speed up development of SNOMED CT and production of complete subsets.

Since content is added on a request basis the coverage of a domain is correlated to the use of SNOMED CT in that particular domain, and the problem with lack of concepts will probably decrease with increased usage of SNOMED CT. There are clinical reference groups (CRGs) administratively supported by SNOMED International working with segments of the terminology relevant to their domain, but these need clinicians who can allocate time without compensation.

For some lacking concepts it might be better to use another terminology, for example LOINC, UniProt or human phenotype ontology (HPO). We have not analyzed the demarcation between these terminologies and SNOMED CT in this review. Guidelines for when to use what terminology and maps to bridge between them could provide valuable support. Such work has been undertaken for LOINC and SNOMED CT, HPO, and SNOMED CT.<sup>47</sup>

RECOMMENDATION FOR PRACTICE: Engage in relevant CRGs. Request new content as needed.

RECOMMENDATION FOR RESEARCH: Design supportive software for authoring of content close to the implementation setting. Continue developing maps and demarcations between terminologies.

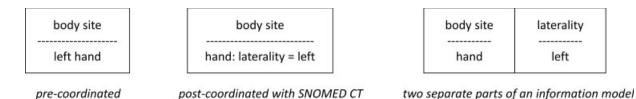


Fig. 5 Using precoordinated concepts or post-coordinating or using the information model.

## **Using Precoordinated Concepts or Post-coordinating** or Using the Information Model

The choice of post- or precoordination within SNOMED CT or using the information model to express compound meanings is a challenge. For example, laterality of a body site could be included in a precoordinated concept ({body site=left hand)), be post-coordinated with SNOMED CT ({body site = hand: laterality = left) or stored in two separate classes of an information model ({body site = hand}, {laterality = left}), see ►Fig. 5.

Legacy systems must sometimes catch all information in a single concept, and this generates expectations to find even rather complex notions, such as breast cancer (event) + before (time-relation) + distal venous thrombosis (event), precoordinated in SNOMED CT. Precoordinating such concepts has negative implications for information sharing and reusability and would also lead to combinatorial explosions.<sup>48</sup> What to precoordinate, what to post-coordinate with SNOMED CT, and what to document using an information model is, however sometimes a difficult choice and has implications for information sharing.

Information represented by using different classes from an information model are only understandable via normal form if the involved classes also are terminology bound to SNOMED CT, which they rarely are. On the other hand, if the classes in the communicating systems are the same, i.e., they share an information model or parts thereof, the information can be understood.

There is a difference regarding pre- and post-coordination within SNOMED CT depending on if the purpose is to refine concepts within the same hierarchy to different degrees (as, for example, adding laterality), or if the purpose is adding information that also alters the context (for instance negations). This discrepancy is not discussed in the papers, perhaps because it is not well known.

There is an abundance of precoordinated concepts in various domains within SNOMED CT today, but there is also ongoing work on delimiting what types of concepts should be precoordinated and what should best be managed with post-coordination or in an information model. This work is partly described in the Precoordination Pattern Project within SNOMED International, but this is not mentioned in any of the papers and perhaps not well-known outside SNOMED International internal work areas.

Post-coordination is perceived to be difficult, and none of the papers used tooling to support such work.

RECOMMENDATION FOR PRACTICE: Be consistent regarding what to store with terminology and what to store with an information model. Use the same demarcation as those with whom you will share information if possible.

RECOMMENDATION FOR RESEARCH: Develop tooling to facilitate post-coordination and comparison of pre- and post-coordinated SNOMED CT content. Compare different demarcation lines between terminology and information model in the search for an optimal compromise.

#### **Choice of Information Model**

There is an expressed wish to share the effort of terminology binding. Terminology binding is relative to the information model used, and thus it would be helpful if there was an agreement on what information model to use. There are, however, several information models in health care, and it is unlikely that any one of these will be chosen as the sole information model in the foreseeable future.

One solution could be to perform terminology binding based on how the information is documented or displayed, i.e., at the model-of-use-level, 49 and leaving conversion to different information models, i.e., level of meaning, to informaticians. This would be somewhat like detailed clinical models (DCMs)<sup>50</sup> or the clinical information model initiative (CIMI),<sup>51</sup> which are neutral to information models. The feasibility of these solutions has not been described in the included papers.

RECOMMENDATION FOR PRACTICE: It is beyond the scope of this paper to recommend an information model. Prioritise internal information structure.

RECOMMENDATION FOR RESEARCH: Evaluate feasibility of DCMs and similar solutions.

#### **Intentional Subsets Do Not Meet Expectations**

Intentional subsets can be developed using Expression Constraint Language (ECL). 52 ECL is a domain-specific language developed for SNOMED CT. The simplest form is to include all children of a concept, but limitations can also be made with attributes and text-strings. Some papers described the problem that all children under a concept were not always relevant for the use case at hand. Concepts not logically defined regarding all their characteristics, "primitive" in SNOMED CT, might not be included in intentional subsets and manual curation of intentionally developed subset will be necessary for some implementation work.

RECOMMENDATION FOR PRACTICE: Manually validate subsets developed with ECL.

RECOMMENDATION FOR RESEARCH: Participate in enhancing the SNOMED CT concept model to improve ECL searches. Develop methods to minimise primitive content.

## **Proficiency with SNOMED CT**

SNOMED CT is a complex terminology, more so than many of the alternatives. This complexity makes it possible to cater for diverse and advance needs but comes at the cost of greater knowledge requirements for correct implementation and use. Terminology binding to precoordinated content requires knowledge of the construction of SNOMED CT regarding hierarchies and inheritance of attributes, among other things. Complete terminology binding also often needs either post-coordination or modelling of new content, which requires even more knowledge of SNOMED CT.

Today SNOMED International offers courses and several different software use the Machine-Readable Concept Model (MRCM) to facilitate correct modelling. Some of the papers were written before this support was readily available, but some of the example problems provided in the papers nevertheless show symptoms of lack of knowledge rather than deficiencies in SNOMED CT, among both authors and reviewers.

RECOMMENDATION FOR PRACTICE: Participate in education and user for a develop targeted education toward different types of users.

RECOMMENDATION FOR RESEARCH: Design supportive tooling geared to domain experts without in-depth knowledge about informatics or SNOMED CT.

## Tools

Tools can be used for different parts of the terminology binding process; for gathering input data, for the actual mapping including iterative cooperative work, for storing or sharing the result. Software for managing developed maps or subsets are not covered in this literature review.

Different tools can support different parts of this process. The spreadsheet program MS Excel is the most commonly used software to manage and store subsets in the included projects. A possible explanation for this is widespread access. As several papers stated, Excel is not, however, a suitable tool for the actual mapping.

One explanation to low usage of mapping tools in the described projects could be the business model for the commercially available tools, especially for situations relating to evaluation of applicability or smaller terminology binding projects. Perhaps open-source tools, pay-by-use license or a shared license hosted by NRCs could facilitate usage of supportive tools.

Another explanation could be that local code systems still prevail. Demand for sharable data are now increasing and might put pressure on transferring from free text or local codes to using SNOMED CT or other terminologies, and thus encourage the development of facilitating software.

It is noteworthy that many of the described terminology binding tools are developed within a research setting, and as far as we know have not become widely used.

No paper described software support for publishing or sharing subsets or maps, something that is becoming increasingly common, for example, among FHIR and OpenEHR communities.

Informaticians are scarce and use of supportive tools could be a way of facilitating shared work with subject matter experts, improving quality and reducing administrative work. It would be interesting to read about tooling in gray information, <sup>53</sup> but to our knowledge there is no established journal or other media for that type of content.

RECOMMENDATION FOR PRACTICE: Use dedicated tooling where such exists.

RECOMMENDATION FOR RESEARCH: Design methods and tools suited for supporting terminology binding.

## **Conclusion**

In this state-of-the-art literature review we have described problems reported in the process of terminology binding to SNOMED CT and analyzed these against solutions suggested in the included papers, other published knowledge, and our own experiences. We have formulated recommendations for practitioners as well as future research for each problem described. These recommendations for terminology binding processes could facilitate semantic interoperability within health care and thus alleviate the problems described under Introduction.

Our focus has been on work geared to SNOMED CT, but some insights might be relevant for those working toward other terminologies.

Many of the stated problems can be solved by better cooperation between domain experts and informaticians and better knowledge of SNOMED CT. Settings where these competences either work together or where staff with double knowledge act as brokers are well equipped for terminology binding. Tooling is not thoroughly researched and might be a possible way to facilitate terminology binding and terminology curation.

## **Bias/Limitations**

This review is affected by the same publication bias as all academic work. Successful and/or well-funded groups publish their work, sometimes iteratively, whereas less successful attempts, which would be very interesting, might not be published and are thus not included. We have tried to minimise this by including all journals and conferences indexed in three different databases. The knowledge

developed within the user community (as opposed to the academic community) is also not fully captured in this review, and we can only claim to describe the academic knowledge of the area. Particularly, the practical experiences of most implementers will not be covered by the academic literature. This study could be further enhanced by a study of published outside the research grav information<sup>53</sup> community.

#### Note

This article does not contain research involving human or animal subjects.

#### **Authors' Contributions**

A.Ro., D.K., and L.L. were equally responsible for conducting the overall literature review, including designing the search strategy and drafting the manuscript. D.K. provided domain expertise for constructing the initial search terms and acted as a third reviewer in any case of disagreement when A.Ro. and L.L. performed study selection. A.Ro. performed data extraction assisted by D.K. and L.L. A.Ra. provided valuable advice on designing the methodological approach and revised the manuscript critically. All the authors read and approved the final manuscript.

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#### **Conflict of Interest**

None declared.

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