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TERMINOLOGY SYSTEMS FOR HEALTH PROBLEMS AND PROCEDURES IN PRIMARY CARE

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ABSTRACT

Background and overall aim: Semantic interoperability addresses issues of how to best facilitate the coding, transmission and use of meaning across seamless health services, between providers, patients, citizens and authorities, and in research and training. One requirement for electronic patient record systems and their semantic interoperability is the consistent use of modern terminology systems. The overall aim is to explore semantic interoperability in primary care using terminology systems to code, map, enrich and reuse primary care data concerning diagnoses, health problems and procedures.

Method: The terminology systems KSH97-P/ICD-10 and SNOMED CT were used in a mapping trial (study I), resulting in a baseline mapping that was further developed to enrich KSH97-P with SNOMED CT by adding a multiple chapter division and attributes to KSH97-P's categories (study II). The mappings and the aggregation methods from study II were used to compare and describe diagnosis distribution between KSH97-P and SNOMED CT from diagnostic data collected in 2006 (study III). A sample of 200 anonymised record entries from Skaraborg were used with the intention of retrieving GP notes. Procedure concepts were identified and coded to KVÅ and SNOMED CT and comparisons were made (study IV).

Results: New mapping rules had a significant impact in the mapping trial, and intercoder reliability in our study reached 83% (study I). A new and poly-hierarchical chapter division of KSH97-P's categories was created using the category and chapter mappings and SNOMED CT's generic structure. KSH97-P's categories were also extended with attributes using the category mappings and SNOMED CT's defining attribute relationships (study II). The diagnosis distribution showed differences mainly in infectious and digestive system disorders when comparing KSH97-P/ICD-10 at the chapter level with SNOMED CT. The perspectives of 'Associated morphology', 'Causative agents' and 'Finding sites' regarding primary care disorders and health problems were added (III). In 417 procedures found in the record entries, 206 procedure-concept/category pairs were assessed as a complete match compared to 10 in KVÅ (study IV).

Conclusion: It is possible to use mappings from KSH97-P to SNOMED CT and SNOMED CT's structure to enrich KSH97-P's mono-hierarchical structure, adding new views of significance regarding clinical data that can be of use in describing and developing primary care. There are challenges involved in using SNOMED CT and supportive tools are needed.

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to by their Roman numerals.

I. Vikström A, Skånér Y, Strender L-E, Nilsson GH.
Mapping the categories of the Swedish primary health care version of ICD-10 to SNOMED CT concepts: Rule development and intercoder reliability in a mapping trial. *BMC Medical Informatics and Decision Making* 2007; 7:9.

II. Nyström M, Vikström A, Nilsson GH, Åhlfeldt H, Orman H.
Enriching a primary health care version of ICD-10 using SNOMED CT mapping. *Journal of Biomedical Semantics* 2010; 1:7.

III. Vikström A, Nyström M, Åhlfeldt H, Strender L-E, Nilsson GH.
Views of diagnosis distribution in primary care in 2.5 million encounters in Stockholm: a comparison between ICD-10 and SNOMED CT. *Informatics in Primary Care* 2010; 1:17-29.

IV. Vikström A, Hägglund M, Nyström M, Strender L-E, Koch S, Hjerpe P, Lindblad U, Nilsson GH. Coding of procedures documented by general practitioners in Swedish primary care – an explorative study using two procedure coding systems. Submitted manuscript.

CONTENTS

1 LIST OF ABBREVIATIONS

EHR	Electronic Health Record
EPR	Electronic Patient Record
GP	General practitioner
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th revision
ICD-10-SE	The Swedish version of ICD-10, earlier called KSH97
ICF	The International Classification of Functioning, Disability and Health
ICPC	International Codes in Primary Care
ISO	The International Organization for Standardization
KSH97-P	A Swedish primary care version of ICD-10. In Swedish: Klassifikation av sjukdomar och hälsoproblem, primärvård
KVÅ	The Classification of Health Interventions. In Swedish: Klassifikation av vårdåtgärder
MeSH	Medical Subject Headings
PC	Primary care
SNOMED CT	Systematized Nomenclature of Medicine, Clinical Terms
TS	Terminology system
WHO	World Health Organization

2 GLOSSARY

Term	**Description**
mono-hierarchy	hierarchy where concepts or categories are classified according to a single hierarchy
poly-hierarchy	hierarchy where concepts or categories are allowed to be classified with one or more than one hierarchy
terminology system	terminology resources such as terminologies, concept systems and classifications, which are used for different purposes in health care and have different structures and content. Synonym: terminological system

3 BACKGROUND

3.1 PRIMARY CARE

Primary care (PC) in Sweden, as part of community care, is mandated to respond to people's needs for such basic medical treatment, care, prevention and rehabilitation that does not require hospital-based medical and technical resources or other specialized expertise, irrespective of disease, age or patient group (1). PC, with general practice as the core medical specialty, provides ambulatory and home healthcare outside hospitals. It is regarded as a fundamental constituent of the Swedish healthcare system (2) and accounts for 17% of the net costs of health care in the country (3).

3.2 ELECTRONIC PATIENT RECORDS IN PRIMARY CARE

In this thesis, electronic patient record (EPR) and electronic health record (EHR) are used synonymously for the Medical Subject Headings (MeSH) term “computerized medical records system”. Use of EPRs by general practitioners (GP) is almost universal in Sweden, as is also the case in several other countries (4). In Norway, GPs were found to use EPRs to a greater extent than hospital-based MDs (5) as was also shown in a study of seven other industrialized nations (4). Nearly all EPRs have mechanisms for coding vital data and procedures (6). Different professionals such as general practitioners (GPs), district nurses, physiotherapists and occupational therapists work in PC and are required by Swedish law to carry out health care documentation, which is normally done in EPRs. Health care documentation in Swedish PC is difficult to use for secondary purposes such as research and follow-up (7). EPRs can support coding of health care problems, diagnoses and procedures in PC to enable reuse of data for different purposes However, the extent to which coding of diagnoses and procedures is done in PC is not well known, since such coding for collection on a national basis is not mandatory in Sweden. When this coding has been done in EPRs in PC, only classifications developed on a national level in Sweden have been available until recently. SNOMED CT, an international clinical terminology and coding system designed for all of health care has recently been introduced in Sweden and could possibly cover the large and diverse area of PC for coding and reuse of data.

3.2.1 Semantic interoperability

Interoperability of EHR-systems refers to the ability of two or more EHR systems to exchange both computer interpretable data and human interpretable information and knowledge. Semantic interoperability means that the precise meaning of exchanged information is understandable by any other system or application not initially developed for this purpose (8). Semantic interoperability addresses issues of how to best facilitate the coding, transmission and use of meaning across seamless health services, between providers, patients, citizens and authorities, and in research and training. The information transferred may be at the level of individual patients, but it can also be aggregated information for quality assurance, policy, remuneration or research (9). One requirement for EPR-systems and their semantic interoperability which is relevant for this thesis is the consistent use of modern terminology systems (TS). The primary goal of ontologies and terminologies for interoperability is to enable the faithful exchange of meaning between machines and between machines and people (9).

3.2.2 Coding of clinical information in EPRs

Coding is needed because there are so many ways that a clinical concept can be represented (6). A code is a simple representation (or label) given to a concept that allows it to be processed within an information system(6). Coding involves the structured use of clinician documentation and other clinical data contained in an individual EPR as the source for determining the appropriate code assignment within a terminology or classification (10). Coding is done with a wide range of TSs – from international classifications on a relatively high level of abstraction to additional, single-purpose terminologies (11). The quality of diagnostic coding has been thoroughly studied. Several steps are involved in the process of coding, and errors can occur (12, 13). Furthermore, both low reliability between coders and coding inaccuracy have been documented (14, 15). However, high reliability, correctness and completeness have also been reported (7, 16, 17). Coding in EPRs in connection with patient encounters is referred to as primary coding, in contrast to when coding is performed by coders other than the health care professionals responsible for the record entries, i.e. secondary coding. Different methods for automated coding have been developed (18). To some extent clinicians look upon encoding data in medical records as an administrative burden and extra workload. Coding by trained coders is common in hospital health care but not in PC. Coding of treatments, prescriptions and referrals by GPs in PC has also received some attention. The reason for introducing procedure coding can be perceived as unclear by health care personnel and can also result in additional work (19, 20).

3.2.3 Reuse of coded clinical information

Structuring and coding of information in EPRs in PC has been suggested to hold great potential. It may provide a source for research and statistical analysis (21), make an important contribution towards interoperability of health care information systems, and potentially provide a basis for reimbursement models (22). Routinely collected PC computer data, aggregated into large databases, is used for audit, quality improvement, health service planning, epidemiological studies and research (21). Health problems and managed morbidity in PC have been studied using different coding systems such as the International Statistical Classification of Diseases and Related Health Problems (ICD), Read Codes and International Codes in Primary Care (ICPC) (2, 23-26). The National Board of Health and Welfare has directed that patient data are to be documented as far as possible with the help of nationally defined concepts and terminology, classifications and other coding systems, and should also serve as a basis for monitoring the results and quality of health care (27). For the information recorded and managed in health care to constitute a long-term and useful resource, information structure and common terminology and standards are required (28). A coherent regulatory framework is needed to describe how information is organized in order to develop effective decision support for care, treatment and support decisions, and for control, care monitoring, open comparisons and research (28). Swedish public health research, for example, is strong in the areas of descriptive and etiological investigations due in part to the very good data infrastructure (29). Examples of national statistics using the International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10) include those concerning inpatient diseases in Sweden.

3.3 TERMINOLOGY SYSTEMS

3.3.1 Definitions

There has been no generally agreed upon way of naming and defining TS systems in this area. In previous studies and a standard from the International Organization for Standardization (ISO) attempts have been made to describe different types and characteristics of TSs using a uniform approach (6, 30-32). “Terminology system” in this thesis refers to terminology resources such as terminologies, concept systems and classifications, which are used for different purposes in health care and have different structures and content. A synonym is terminological system. Classifications are used mainly for statistical and reimbursement purposes. Terminologies are often used to describe clinical 'input' data within EHR-systems and are based on national or international terminology standards (6), or are developed locally or by vendors (33). A classification is described as an arrangement of objects or concepts (by the *is_member_of* relation), based on their essential characteristics, into groups of concepts called classes (31). A coding system has been described as a “combination of a set of concepts [coded concepts], a set of code values, and at least one coding scheme mapping code values to coded concepts” (32). Clinical coding systems have been said to play a key role in epidemiological studies and health service research, from the use of Medical Subject Headings (MeSH) terms for conducting literature searches for systematic reviews, to studies that use ICD codes to classify and compare diseases (34).

3.3.2 Medical terminology systems evolution and historical development

To satisfy more needs with TSs than those existing today, both Rossi Mori et al. (35) and Cimino (36) call for an evolution of the medical TSs towards more flexibility in order to achieve several aims (36). Rossi Mori et al. describe three generations of medical TSs (35). The first generation comprises traditional TSs. This generation includes controlled vocabularies, nomenclatures, taxonomies and coding systems that satisfy most needs in paper-based information systems. In this generation, systems typically consist of a list of phrases, a list of codes, a coding scheme and a hierarchy. The role of the coding scheme is to map between phrases and codes (35). Examples of systems in the first generation are ICD-10 (30), KSH97-P and the International Classification of Functioning, Disability and Health (ICF).

The second generation comprises compositional systems. These systems have a categorical structure, a cross-thesaurus, a structured list of phrases and a knowledge base of dissections (35). The categorical structure gives a high-level description of the content, i.e. what kinds of concepts are included and how they relate to each other. This can be seen as a framework of slots for which the cross-thesaurus provides a set of labels to be inserted when the content is modeled. By means of the cross-thesaurus, each element in the structured list of phrases is represented according to the categorical structure; these descriptions constitute the knowledge base of dissections. Examples of systems in the second generation are Nomenclature, Properties and Units (NPU), and Logical Observation Identifiers, Names and Codes (LOINC) (35).

The third generation consists of formal systems. In this generation the systems have a set of symbols and a set of formal rules to manipulate the symbols, and these sets can be seen as a set of concepts and a set of relations between the concepts (35). Examples of a third generation system is GALEN-IN-USE's surgical procedures (35)

One problem in the first generation is that reorganization of categories in the systems to satisfy different purposes is not supported (35). Reuse of data organized with first generation systems therefore needs human interpretation of the categories and the environment where the data were originally collected. This is a smaller problem in the second generation and it is even smaller in the third generation. In the second generation, categories can be reorganized according to the information in the knowledge base of dissection. In the third generation, formal rules can be used for reorganization (35).

Cimino enumerates twelve characteristics of the structure and content in medical TSs in "Desiderata for controlled medical vocabularies in the twenty-first century" and these characteristics emerge from earlier vocabulary research (36). Five of these characteristics are of interest in this thesis:

- *Content*. The importance of vocabulary content cannot be over stressed, and a formal methodology is needed for expanding content (36). Arts contends that coverage and correctness are quality aspects of content. Arts defines content coverage as “the extent to which the content (e.g. concepts or terms) within a subset, representative for the domain of interest, can be represented by the content of the terminological system”. Correctness is defined in relation to concepts as non-redundant, non-vague and non-ambiguous, but also that terms are free of textual errors and attached to the right concepts and that relations are consistent and in accordance with the factual relations between concepts(37).

- *Poly-hierarchy*. Systems need to shift from a strict mono-hierarchy to a poly-hierarchy (36). It is impossible to properly represent the real world in a strict mono-hierarchy where each category has only one parent. The categories in the real world can belong to more than one parent (33, 36, 38, 39) . A poly-hierarchical structure supports the representation and aggregation of healthcare data on the basis of specific medical aspects.

- *Formal definitions*. Systems need formal definitions expressed as collections of different kinds of relationships between the concepts (36). Formal definitions can be used by computers for formal manipulations of the categories, which is impossible with unstructured text definitions (36). One manipulation is to help a user locate a specific category in a TS (38).

- *Multiple granularity*. Systems need to have concepts of different granularity covering the same area (36). Different use cases need systems with different granularities depending on the required level of detail of the categories. A multipurpose system therefore needs multiple granularities. Different use cases represent sufficient detail of the information in health records in order to use the information in areas such as direct patient care, decision support and quality assurance (33). For example, different health care professionals performing procedures in a specific domain, such as PC, must be able to code them on a sufficient level of detail.

- *Multiple consistent views*. Systems need to be able to consistently present their content in different views (36). Some use cases require a simple structure of the system's categories and others need a richer structure. The kind of structure depends on the required level of detail and the categories' required type of information (36,38). To present equivalent information independent of the view used, the views need to be consistent (36).

Straub et al. (40) argue that the different kinds of medical TSs have different purposes and need to co-exist. Medical TSs with fewer categories and a semantic model with more restrictions, such as a hierarchical tree, provide useful information reduction or simplification for cases where a richer medical TS provides too much information.

As pointed out by Rossi Mori et al. (35), and demonstrated by Alecu et al. (41), second and third generation systems can augment first generation systems with easier re-organization and maintenance and with harmonization and cross-referencing of different first generation systems.

Today, all three generations of TSs are used internationally as well as in Sweden. Areas of interest in research include formal systems and the notion of ontology, which is sometimes used as a synonym for different types of terminological systems (31) in the debate and in a great deal of research (42). Ontology has been defined as a symbolic logical model of some part of the meaning of the notions used in a field, i.e. those things which are universally true or true by definition "sensu information system"(9). "Formal ontology" is also a term used in this area. Oliviera (43) observed that "with the increase of biomedical data more powerful methods were necessary, in order to organize and manage all the emergent entities and miscellaneous relationships ….for ontologies to be used in daily applications". There are several formal top level or "upper" ontologies that are used to describe general concepts that are shared across various knowledge domains, with the idea of supporting semantic interoperability between different ontologies at lower levels, for example the Basic Formal Ontology (BFO) (44).

The use of TSs in information systems is an area where knowledge is developing. Decisions are required on how the terminology should fit into the information structure, for example with information standards (45, 46). This process is often called terminology binding (47). This area of interest lies outside the main focus of this thesis.

3.3.3 ICD-10

The ICD-10 was endorsed by the 43d World Health Assembly in May 1990 and came into use in World Health Organization (WHO) Member States starting in 1994. The

ICD-classifications have become the international standard diagnostic classifications for all general epidemiological purposes and many health management purposes and are by far the most widely used TSs in EHRs (11, 49). ICD-10 is primarily intended for statistical reporting and administrative tasks such as disease monitoring and quality assurance (50). It is used to classify diseases and other health problems recorded in many types of health and vital records including death certificates and hospital records (48). ICD-10 is used in Sweden but is not considered entirely suitable for PC (51).

ICD has developed as a practical classification that includes a number of compromises based on etiology, anatomical site, circumstances of onset, etc.(50), and it has internal inconsistencies (12). The ICD classifications were neither based on nor intended as a model of health problems, but were pragmatically developed from the admittedly arbitrary structure proposed by William Farr in 1855 (52, 53) . Farr's structure, which is reflected in how diseases are divided into chapters in the ICD-10, groups diseases into five sets (52, 54):

- epidemic diseases
- constitutional or general diseases
- local diseases arranged by site
- developmental diseases
- injuries

The presentation of ICD-10 (52) focuses on the role of a member of a family of classifications rather than the internal structure. ICD-10 belongs to the first generation of TSs (35). ICD-10 has rules for classification; for example, the chapters have different priorities: chapters XV *Pregnancy, childbirth and the puerperium* and XVI *Certain conditions originating in the perinatal period*, have the highest priority; and chapters I *Certain infectious and parasitic diseases*, II *Neoplasms*, and XVII *Congenital malformations, deformations and chromosomal abnormalities* have higher priority than the chapters related to organ systems (55). The terms 'include' and 'exclude' are used to clarify what should and what should not be a part of a category. In ICD-10, a category can only be included in one chapter (54) . For those categories in which it would be possible to include more than one chapter, a decision has been made about the chapter in which the category should be included. This is demonstrated in ICD-10 by the excludes remarks on the chapter level. An excludes remark means that the categories in the remark could have been included in the chapter, but are instead included in other specified chapters (54). The categories including the word 'Other' in ICD-10 are residual categories for conditions that cannot be allocated to the more specific categories (50).

The method often used for statistics with ICD-10 is aggregation of diagnostic categories on the three-character category level, for example ‘Influenza/pneumonia categories J10–J18’, or on the chapter level. Attempts at restructuring the mono-hierarchical structure of ICD-10 have been proposed (56) . Diseases of interest to a user may be scattered throughout the ICD system, and manual selection of the relevant codes is prone to error (12). Epidemiological studies using ICD-10 demonstrate the possible shortcomings of the ICD-10 classification structure. With respect to its original purpose, ICD-10 has shortcomings when scaling up for reuse for multiple purposes, such as in health care record systems, whereas reference terminologies directly address these scaling and reuse issues (57).

3.3.4 KSH97-P – A primary care version of ICD-10

In Sweden, a PC version of ICD-10 has been developed that has the acronym KSH97-P (in Swedish, Klassifikation av sjukdomar och hälsoproblem 1997 Primärvård KSH97-P) (58). KSH97-P is a subset of ICD-10 categories which concern diseases and health-related problems common in PC. KSH97-P consists of a total of 972 categories in the version used in 2006, out of which 611 categories correspond to one single ICD-10 category, and 361 categories are constructed as a cluster of ICD-10 categories with a new code name (here: P-categories). Each category in KSH97-P has a connection to one of 21 chapters in ICD-10. KSH97-P has the same chapter division as ICD-10. The exceptions are that ICD-10 chapter XX *External causes of morbidity and mortality* is excluded in KSH97-P (58), and chapter XXII *Codes for special purposes* is excluded in both the Swedish version of ICD-10 (earlier called KSH97, now ICD-10-SE (59) and KSH97-P (58). As described above, ICD-10, and thus KSH97-P (58), use multiple principles for chapter division (54). The preface to KSH97-P states that these different kinds of chapter divisions may involve practical problems because it is not evident to which chapter a specific disease or condition belongs.

In KSH97-P categories, as in the Swedish version of ICD-10, 'and' should be interpreted as 'and/or', according to classification rules. Most categories in KSH97-P correspond to categories in the three- or four-character levels in ICD-10. Rubrics in KSH97-P are as close to the Swedish translation of ICD-10 as possible. KSH97-P, like ICD-10, belongs to the first generation of TSs. The recommendation from the National Board of Health and Welfare is for KSH97-P statistics to be aggregated on an ICD-10 chapter level or with special groups of manually customized grouped categories, based on statistical needs within PC (58). Other TSs of interest are ICPC (60) and the International Classification of Functioning, Disability and Health (ICF) (61). ICPC is in current use in PC in many countries (6) - however not in Sweden - and is also used for procedure coding.

3.3.5 Procedure coding systems and the Classification of Health Interventions (KVÅ)

Numerous national procedure coding systems are in use but international standards are generally lacking in the field of medical procedure coding (62). Procedure coding systems are often used in connection with reimbursement systems but can also be used for clinical, research and follow-up purposes (62-64). In 1998 a procedure coding system for PC was developed in Sweden based on International Codes in Primary Care (ICPC), but implementation was very limited (65). Since 2007 it has been mandatory in almost all of health care to report coded procedures to a National Patient Register. However, it is not mandatory to report procedures in PC, and GPs in Sweden do not normally code procedures (22). Procedure coding systems are not systematically used for reimbursement reasons in Swedish PC. By tradition, procedure coding has been performed to some extent with the ICD-10, as ICD-10 primarily includes procedures in chapter 21.

The “Classification of Health Interventions” or KVÅ is a relatively new classification, nationally developed and maintained by the National Board of Health and Welfare in Sweden for use by different health care professionals in all areas of health care (65), and it is a first generation TS. KVÅ is used in Swedish health care and has been proposed to be mandatory for reporting procedures in PC. The primary aim of KVÅ is that it should be used for monitoring performance at local, regional and national levels, primarily to allow for monitoring of health content and secondarily the burden of care and resource use (65). KVÅ should consist of procedures done by health professionals in direct contact with the patient, i.e. not all procedures done in health care (65).

3.3.6 SNOMED CT

3.3.6.1 Purpose

The Systematized Nomenclature of Medicine, Clinical Terms (SNOMED CT) is an international clinical terminology intended for clinical documentation and reporting (66). SNOMED CT is said to cover both abstraction and representation. The structure of SNOMED CT is assumed to be useful for aggregated analysis of outcomes, decision support, knowledge-based practice guidelines, etc., in a clinical setting. SNOMED CT is a terminology for the EPR, and was formed in 1999 by the convergence of SNOMED RT and the United Kingdom's Clinical Terms Version 3 (formerly known as the Read Codes), originally developed for PC (67, 68). It has been suggested that concept systems such as SNOMED CT have a large volume and a granularity that are unsuited to the administrative purposes for which a classification is designed (10).A comparison between KSH97-P, ICD-10, and SNOMED CT is shown in **Table 1.**

Table 1. A comparison between number of concepts, owner and publisher, and intended usage of the Swedish PC version of ICD-10, KSH97-P, KVÅ and SNOMED CT.

Coding system	**Owner and publisher**	**Number of concepts or categories**	**Intended usage**
ICD-10	WHO	Appr. 10 000	Statistical reporting and administrative tasks such as disease monitoring and quality assurance (ICD-10)
KSH97P- a PC version of the Swedish ICD-10	The Swedish National Board of Health and Welfare.	972 (2006)	Same as ICD-10
KVÅ- the Classification of Health Interventions	The Swedish National Board of Health and Welfare	9 329 (in July 2009)	Monitoring performance of health content, burden of care and resource use

SNOMED CT	The International Health Terminology Standards Development Organization (IHTSDO)	Appr. 300 000	Coding, retrieving, and analyzing clinical data, representing clinical information across the scope of health care, from structured, computerized clinical records

3.3.6.2 Structure: Concepts, descriptions, relationships and hierarchies

SNOMED CT consists of concepts, descriptions and relationships (69). Each concept in SNOMED CT is said to have a clinical meaning and is identified by a unique number (69). Associated with each concept are two or more descriptions, which are human readable terms, and information about the terms (69). Concepts in SNOMED CT can be retired from active to inactive concepts (69). Klein and Smith suggest that “concept” in SNOMED CT means a “concept system node” (70). Schultz and Cornet describe three different interpretations of what expressions in SNOMED CT represent: (1) Instantiated by objects that exist independently of a domain-specific perspective; (2) Instantiated by representational artifacts as contained in an EPR – called the ”EHR interpretation”; (3) Instantiated by patients or clinical situations (71).

Concepts are formally defined in terms of their relationships with other concept (69). There is also a concept model that controls which types of concepts can be related to which types of relations (69). *Is a* relationships and defining attribute relationships are known as the ‘defining characteristics’ of SNOMED CT concepts. In this thesis *Is a* refers to the defining hierarchical relationship. Every active SNOMED CT concept (except the SNOMED CT concept ‘Root concept’) has at least one *Is a* relationship to a supertype (‘parent’) concept. A concept in SNOMED CT can have more than one *Is a* relationship to ‘parent’ concepts, which creates a poly-hierarchical structure (69). The defining relationships logically represent a concept by establishing relationships between the concepts (66). According to an unsubstantiated report, defining attributes in SNOMED CT should be assigned to those hierarchies where retrieval of clinical data is most useful and relevant (e.g. procedures, findings and diseases) (72). Attributes are the bridges between SNOMED CT’s main hierarchies – e.g. Clinical finding and Procedure – and supporting hierarchies like Organism, Substance, and Body structure (72).

A concept is primitive when its modeling (roles and parents) does not fully express its meaning. 'Primitive' concepts do not have the unique relationships needed to distinguish them from their parent or sibling concepts (66). In a later version of the User Guide, the definition of primitive is somewhat changed to “when its logic definition does not sufficiently express its meaning so that its subtypes can be computably recognized. Primitive concept codes also do not have the defining relationships that would be needed to computably distinguish them from their parent or sibling concepts” (69). SNOMED CT is evolving towards a third generation system. Unlike classifications such as ICD-10, SNOMED CT hierarchies are formulated using a subset of first order logic known as ‘description logic’ that specifies their semantics (73). A study found several major types of problems in SNOMED CT hierarchies related to the description logic modeling and classification process, and the authors concluded that the SNOMED CT hierarchies cannot be relied upon in their present state (73).

3.3.6.3 Usage of SNOMED CT

In a review that included earlier versions of SNOMED over a 40-year period, it was reported that a majority of studies focused on the use of SNOMED in theory, and that studies of SNOMED in clinical practice were scarce (74). Very few studies gave any indication regarding the use of SNOMED to improve the care process or the outcome of care (74). In a recent survey it was indicated that concept search and clinical coding are the two most common direct uses and that 39% of the respondents using SNOMED CT currently use SNOMED CT in production systems (75). Most uses remain basic, and do not capitalize on the rich semantics of the terminology (75). Lee found a lack of adequate guidance and examples of how SNOMED CT can and should be implemented (76). A study described four significant challenges in implementing SNOMED CT into electronic clinical documentation: (1) designing the graphical user interface for selecting SNOMED CT values; (2) gathering and validating template specifications that use SNOMED CT subsets; (3) handling SNOMED CT subsets and extensions; and (4) creating algorithms and the technological infrastructure to generate fast, meaningful, non-redundant search results (77).

Another study described the creation of a local interface terminology in a hospital, with SNOMED CT as a reference terminology (78). An interface terminology is described as facilitating direct entry of clinical data into the EHR system (79). The clinical data extraction process from the EHRs in the same hospital, using rules based in SNOMED CT knowledge data, was very effective (80). The usage of SNOMED in PC/general practice has been the focus of little study. A small study indicated that SNOMED CT is a viable coding terminology in general practice and also found that GPs are not ready to do coding on a routine basis without an additional incentive – mostly in the form of improved care or care management (81). It has been suggested that migrating GP systems to SNOMED-CT could be considered a sensible recommendation to improve the classification of diabetes (82).

The International Health Terminology Standards Development Organisation (IHTSDO) is an international not-for-profit organization based in Denmark that develops and promotes the use of SNOMED CT. One vision of the IHTSDO is inclusion of all clinical and social care professions and covering both clinical and related health information in SNOMED CT (83). Studies have confirmed coverage for certain areas; for example, the International Classification of Nursing Practice (ICNP). SNOMED CT was found to represent most (92.5%) of the ICNP nursing diagnosis and intervention catalogue concepts (84). In addition, SNOMED CT provided relatively complete content coverage of terms to support clinical decision-making and quality of care oversight in nursing homes in three domain areas (85). SNOMED CT could be mapped fairly well to care-planning procedures in a multidisciplinary setting such as advanced home health care (86). SNOMED CT was also used for the creation of a vocabulary to improve communication among multidisciplinary clinicians, and an evaluation of the coverage of multidisciplinary health factors in SNOMED CT for multiple chemical sensitivity was performed and showed that SNOMED CT had a reasonable coverage (87).

Sweden is one of 15 members of IHTSDO. The international SNOMED CT has recently been translated to Swedish by the Swedish National Board of Health and Welfare but is not in common use. The National Board of Health and Welfare now considers SNOMED CT to be a national interdisciplinary terminology for use as a resource together with traditional classifications (88).

3.4 MAPPING TERMINOLOGY SYSTEMS

The concept 'mapping' is described as “linking terminology content between two schemes” (89). Mappings may allow organizations to use two or more TSs together; for example, to be able to compare statistics with different versions of TS, and achieve system interoperability and data standardization (90). Ingenerf and Giere explored the different roles of statistical classifications and formal concept representation systems, deducing the need for co-existence and the former being linked to the latter (91). Mapping can be done with entirely different methods comprising more or less automated procedures, lexical matching and concept matching and structural matching (90, 92-95). Research has been done on terminology mapping with the goal of developing effective automated methodologies for mapping (90). The importance of rules that are outlined in the mapping process has been described (92, 95). Mapping for reimbursement purposes, where several rule-based instructions for coding would need to be incorporated, is different from mapping for epidemiological purposes (96).

3.4.1 Mapping with SNOMED CT

It has been suggested that cross-mappings between SNOMED CT and classifications like ICD-10 should maximize the value of the clinical data and the benefits of an EHR system (10). SNOMED CT concepts are mapped to some classifications, for example ICD-9-CM in the US edition and ICD-10 in a UK-edition. SNOMED CT and ICD-10 are also mapped into the Unified Medical Library System (UMLS) (93) and a mapping with ICPC-2 has been performed (90). WHO and IHTSDO have worked on a collaborative arrangement to link the WHO Family of Classifications and the SNOMED CT in order to make it easier to summarize information from individual patient records into aggregated results needed for health policy, health services, management and research (97).

3.4.1.1 Post-coordination

Post-coordination is a representation of a clinical meaning using a combination of two or more concepts with SNOMED CT (69) and is suggested as a way to solve the content completeness problem among different terminologies (90). Post-coordination can be used in different settings such as coding, mapping between terminologies and research, for example when measuring content coverage in TSs. Post-coordination is also used in SNOMED CT to express context information that is not the default context of the concepts, for example family history disorders and procedures not performed on the patient (69). Three limitations of post-coordination in clinical terminologies have been described: (1) difficulty in restricting composition to medically meaningful concepts; (2) ability to create unrecognized duplicate concept representations; and (3) inefficiency with respect to composing complex concepts from simpler concepts (79). There are different types of post-coordination in SNOMED CT: qualification or refinement of concepts can be used to represent more detailed concepts and combinations of concepts which do not include any qualifier value (98). Qualification refers to appending a qualifying characteristic to a concept (98). Refinement is similar to qualification, but instead of appending a qualifying characteristic to a concept, a subtype of a defining characteristic associated with a concept is selected (98). In SNOMED CT the distinction between refinement and qualification is dependent on which attributes are regarded as defining (98). Certain post-coordination's demand advanced knowledge of the post-coordination rules, domain expertise, and an intimate understanding of the SNOMED CT terminology structure (99). The implementation of an automatic system of rules for concept post-coordination improves their representation by enabling the proper use of SNOMED CT relationships, as well as the adequate representation of medical concepts (100). The measurement of content coverage with SNOMED CT or any other TS can be influenced by using a method that includes post-coordination. Inconsistencies in coding have been found due to different post-coordination of concepts when coding clinical research questions to SNOMED CT (101).

3.5 RATIONALE - TERMINOLOGY SYSTEMS FOR HEALTH PROBLEMS AND PROCEDURES IN PRIMARY CARE

The extent to which different TSs cover the great diversity of health problems, diagnoses and procedures in PC has not been sufficiently described. Methods for coding and distribution of PC information from EPRs rely among other things on the inherent structure of the TS used. Mapping different TSs such as terminologies and classifications has been pointed out as a way to attain additional advantages in describing and documenting health care data. The enrichment thereby hypothetically provides useful multiple views of a disease panorama that is coded with a traditional disease classification. Also, it would be of interest to examine the level of intercoder reliability that can be reached using a manual mapping process when mapping KSH97-P to SNOMED CT, and to determine which mapping rules are necessary in the process. Another aim would be to obtain better knowledge of the characteristics of the systems that need to be addressed when creating and using a mapping from ICD-10/KSH97-P to SNOMED CT. Further, it would be of interest to explore whether mappings from KSH97-P to SNOMED CT and SNOMED CT's structure can be used to enrich KSH97-P's mono-hierarchical structure. There is also a lack of research describing which procedures are actually performed and how they are documented in PC EPRs by different groups of health care professionals. Therefore it is important to gain more knowledge about how procedure coding could be performed and its potential effect on clinical work. How TSs such as SNOMED CT can be used by GPs to code and describe procedures in PC is still unclear. More specifically, how diagnoses and health problems in PC are distributed with KSH97-P and ICD-10 compared to SNOMED CT is unknown. Further, it is not known how Swedish GPs document procedures in PC or to what extent the TSs KVÅ and SNOMED CT could be used to structure this procedure documentation.

4 AIMS

The overall aim were to explore semantic interoperability in primary care with the use of terminology systems to code, map, enrich and reuse primary care data concerning diagnoses, health problems and procedures.

4.1 SPECIFIC AIMS

Study I
To explore and develop rules to be used in a manual mapping process.
To evaluate intercoder reliability and the assessed degree of concordance when the Swedish PC version of ICD-10 is matched to SNOMED CT.
To describe characteristics in the coding systems that are related to obstacles to high quality mapping.

Study II
To explore whether SNOMED CT's poly-hierarchical generic structure can be used to add a multiple chapter division to KSH97-P's categories where each category may belong to more than one chapter.
To explore whether SNOMED CT's defining attribute relationships can be used to add attributes to KSH97-P's categories.

Study III
To describe and compare diagnoses and health problems in KSH97-P/ICD-10 and SNOMED CT using PC diagnostic data from EPRs.
To explore and exemplify complementary ways of aggregating diagnoses and health problems generated from a mapping to SNOMED CT.

Study IV
To describe procedures documented by GPs in Swedish EPRs.
To describe and compare how the content in the different TSs KVÅ and SNOMED CT covers the procedures’ content and also the degree of concordance between the documented procedures and the two TSs.

5 MATERIAL AND METHODS

5.1 ETHICAL ISSUES

Studies I and II do not have ethical approval, as they do not encompasses research involving living persons, research on the deceased, biological material from people, or research that involves dealing with sensitive information about people or personal information concerning offenses against the laws. Studies I and II concern research about two TSs in health care. The regional ethical review board in Stockholm approved study III (no. 2007 1102–31). The regional ethics review board in Gothenburg approved study IV (no. 2005 494-05).

5.2 COMPREHENSIVE VIEW OF THE STUDIES

Table 2 shows an overall view of the design, the data collection and methods used, the statistical analysis, the TSs used and what was studied in each of the four studies. The results from study I were further developed and used in study II. The mappings and aggregation methods from study II were used in study III. Study IV used the aggregation method from study III.

Table 2. Comprehensive view of the studies.

Study	Design	Data collection/method	Statistical Analysis	Terminology systems	What was studied?
I	Mapping trial	Manual mapping	Logistic regression Pearson's Chi-square test Cohen's Kappa (K)	KSH97-P/ICD-10 SNOMED CT	Mapping process, intercoder reliability
II	Observation and explorative	Manual and statistical mapping, multiple chapter division, additional attribute method	Descriptive	KSH97-P/ICD-10 SNOMED CT	Enrichment of KSH97-P/ICD 10 with SNOMED CT
III	Retrospective, cross-sectional	Register study, aggregation	Descriptive	KSH97-P/ICD-10 SNOMED CT	Diagnosis and health problems in PC in Stockholm
IV	Qualitative, retrospective, cross-sectional	Content analysis, coding, assessment, aggregation	Descriptive	KVÅ SNOMED CT	Procedures in PC in Skaraborg

5.3 VERSIONS OF SNOMED CT

The versions of SNOMED CT that were used in study I were from January and July 2006, UK Edition, and the results were updated in studies II and III according to the SNOMED CT release from January 2007, UK Edition. In study IV, the SNOMED CT version used was the international version from July 2009. Mappings with SNOMED CT in studies I and II were done only with an English version of SNOMED CT. In study IV we also had access to the proceeding results of the translations of SNOMED CT to Swedish.

5.4 STUDY I

5.4.1 Material

In study I mapping was done by two coders (YS, AV). One of the coders is a PC physician (YS) and the other is a health informatician (AV), and both have broad experience in the area of terminology. The Clue system (version, 5.5.0133) was used for browsing in SNOMED CT (102). The Clue system shows the concept, concept id, concept status (for example, 'current' or 'limited'), concept relations, and descriptions. Several sources were used for the KSH97-P. One source was a file with the master KSH97-P category code and text in Swedish, and suggested English translations (103). These categories matched the Swedish translation of ICD-10. Another source was an IT-system called 'Visaren', which showed the corresponding ICD-10 categories both on a chapter and a category level, as well as the 'exclude' rules and a 'recommended term' for each category that was a 'short term' (104). The English version of ICD-10 and the Swedish and English versions of Medical Subject Headings (MeSH) were used for general translation purposes (105).

5.4.2 Mapping and assessment

The 972 categories in KSH97-P were randomly divided into an allotment of three sets of categories with different content: A (n = 323), B (n = 326) and C (n = 323). Mapping was done independently by the coders in three sequences using the three different sets of categories. The manual mapping process comprised four activities:
1. Interpreting: which means that each coder analyzed the meaning of concepts and categories including, when applicable, translations of keywords and search terms from Swedish to English.
2. Matching: which means that each coder matched one KSH97-P category to one SNOMED CT concept. Categories with no match in SNOMED CT were marked as '0' (none found).
3. Assessing: which means that each coder assessed every matched concept-category pair on how well they matched. The assessment scale used was 'partly concordant' (1) for concepts that approximated the category meaning, and 'completely concordant' (2) if the concept completely captured the meaning of the category. A supplementary assessment of the 'partly concordant' concept-category pairs was done independently by the coders after the mapping of all three sequences, as they were assigned into three different groups: 'target (SNOMED CT) more specific than source (KSH97-P)' (a), 'target less specific than source' (b), and 'imprecise but neither more nor less specific'(c), using a categorization from the SNOMED cross-mapping method (106).

4. Rules development, which means that each coder saw the need for and suggested new rules and decided upon rules in consensus with the other coder.

5.4.3 The Intercoder reliability and analysis of obstacles

When the coders chose the same SNOMED CT concepts for one KSH97-P category, these were called 'equally chosen concepts'. This was measured as intercoder reliability by comparing the results after each of the three sequences, A, B and C. The structural and content factors as obstacles to high quality mapping were analyzed both statistically and qualitatively.

5.4.4 Statistics

The number and percentage share of matching results were calculated. Logistic regression was used, with the outcome variable indicating 'equally chosen concepts', to analyze if there were any significant differences between sequences A, B and C. Pearson's Chi-square test was used when analyzing results between the clustered ICD-10 categories (P-categories) and the non-P categories. Cohen's Kappa (K) and the percent agreement were used to measure the intercoder reliability of assessments. Suggested interpretations of K values are < 0.20 = poor, 0.21–0.40 = fair, 0.41–0.60 = moderate, 0.61–0.80 = good, and 0.81–1.00 = very good (107). The percentage share was calculated based on the rate of equally chosen categories in each chapter of ICD-10.

5.5 STUDY II

5.5.1 Baseline category mapping

A baseline category mapping from KSH97-P's categories to SNOMED CT's concepts was used. The first phase of the mapping process is described in study I. Mapping was completed through consensus decisions, following the mapping rules and striving to achieve a result with "completely concordant" mappings for each category. In summary, 14 (1%) of the 972 categories in KSH97-P did not have a matched concept in SNOMED CT, 888 (91%) were mapped to one concept, 64 (7%) were mapped to two concepts, and 6 (1%) were mapped to three concepts. Of the 958 mapped categories, 938 (98%) categories were mapped to clinical finding concepts and 20 (2%) categories were mapped to procedural concepts.

5.5.2 Further mappings

The methods build upon the baseline category mapping. The initial chapter mapping was manually done and the baseline category mapping was converted to the same SNOMED CT version as the initial chapter mapping. The category mapping and chapter mapping were put together and manually compared to each other and the mappings were updated. The category mapping was used to create the statistical chapter mapping. The statistical chapter mapping and the manually created chapter mapping were manually compared to each other and the manual chapter mapping was updated. The chapter mapping and category mapping were used for creating the multiple chapter division and the category mapping was used for creating the additional attributes.

5.5.2.1 Initial chapter mapping

The chapters were mapped to SNOMED CT's concepts based on the meaning of the chapter's rubric and a general assessment of both the chapter's content in ICD-10, using the international WHO-version of ICD-10 (54), and the subset of categories present in each chapter in KSH97-P. The same rules used for the category mapping and the excludes remarks in ICD-10 were considered as rules that do not exist in SNOMED CT.

Chapters XVIII *Symptoms, signs and abnormal clinical and laboratory findings*, not elsewhere classified, and XXI *Factors influencing health status and contact with health services*, were assessed as unable to map to SNOMED CT's concepts. The combination of different symptoms and abnormal clinical and laboratory findings in chapter XVIII's rubric were not considered to be a clinical concept, but a collection of different phenomena in a rubric that do not map to a concept or post-coordinated expression of manageable size in SNOMED CT. In summary, 2 (10%) of the 20 chapters in KSH97-P did not have a matched concept in SNOMED CT, 14 (70%) were mapped to one concept, 1 (5%) was mapped to two concepts, 2 (10%) were mapped to three concepts, and 1 (5%) was mapped to four concepts.

5.5.2.2 Mappings update

To improve the baseline category mapping and initial chapter mapping, the mappings were converted to the same SNOMED CT release, the category mappings and the chapter mappings were compared manually, and statistical chapter mappings were calculated and compared with the manual mappings. These steps are described below. To check that the category and chapter mappings were not unintentionally mapped to different hierarchies in SNOMED CT, the category and chapter mappings were compared manually. The category mapping was used to create the statistical chapter mapping. A statistical chapter mapping was created for comparison with the manual chapter mapping. The statistical chapter mapping preferred concepts where the descendants were targets of many categories in the same chapter but few categories from other chapters. The creation of the mapping is described below. The statistical chapter mapping was based on two quantities calculated for each combination of a chapter in KSH97-P and a concept in SNOMED CT (n times m possible instances, where n is the number of chapters and m is the number of concepts):

- categories current chapter (c): the number of categories in the current KSH97-P chapter that were mapped to the current SNOMED CT concept or any of its descendants.
- categories other chapters (o): the number of categories in chapters other than the current KSH97-P chapter that were mapped to the current SNOMED CT concept or any of its descendants.

For each combination of a chapter in KSH97-P and a concept in SNOMED CT where $c > 0$, the following score was calculated:

$$score = c * \frac{c}{c+o}$$

In other words, the calculations above determined the number of "correct" categories weighted with the compactness of "correct" categories in proportion to all categories. For each chapter in KSH97-P, all SNOMED CT concepts were then ranked. The concept with the highest score was ranked as the best statistical chapter mapping and the concept with the second highest score was ranked as the second best statistical chapter mapping, etc.

For each chapter, the manual chapter mapping was compared with the statistical chapter mappings. If a highly ranked statistical chapter mapping subsumed more of the concepts mapped from categories in the chapter than the manual mapping, and the statistical chapter mapping was in line with the mapping rules, then the manual mapping was updated. The final mappings, which are the results of the mapping updates described above, are used in the rest of this study.

5.5.3 Multiple chapter division

To examine whether the poly-hierarchical *Is a* relationships of SNOMED CT can be used to replace KSH97-P's mono-hierarchical chapter division with a poly-hierarchical chapter division, KSH97-P's categories were divided into a multiple chapter division using SNOMED CT's *Is a* relationships. The multiple chapter division was generated using the algorithm described and exemplified below. For each category, the mapped concepts were extracted together with their ancestors to a mapped set. This created one mapped set for each mapped KSH97-P concept. If one or more chapters were mapped to any of the concepts in the mapped set, the category related to the mapped set was assumed to belong to these chapter(s) - regardless of what chapter they originally belonged to. This means that each category might belong to zero, one or more new chapter(s).

5.5.4 Additional attributes

To examine whether the defining attribute relationships of SNOMED CT could extend KSH97-P categories with attributes, a list of additional attributes was created. The additional attributes were generated using the algorithm described and exemplified below. For each category the mapped concepts were extracted together with their ancestors to a mapped set. This created one mapped set for each mapped KSH97-P concept. The mapped sets were created in the same way as for the multiple chapter division. Then all defining attribute relationships from concepts in the mapped set were followed and the target concepts were included in a specific attribute value set for each relationship type. In each attribute value set, the concepts that were ancestors of another concept in the same attribute value set were removed. The remaining concepts in each attribute value set constituted attribute values of the respective attribute types for that category.

The additional attributes algorithm used the mapped set to follow each defining attribute relationship and included all the target concepts in different attribute value sets according to which attribute type they were related to.

We measured the distribution of the attribute values as the proportion of categories that related attributes of the same attribute type to the same attribute value.

5.5.5 Fully defined and primitive ancestors

The quality of the multiple chapter division and additional attributes is dependent on how completely modeled the concepts in SNOMED CT are that are mapped from KSH97-P's categories and these concepts' ancestors. (These concepts are the concepts in the mapped sets.) The mapped concepts and their ancestors were therefore extracted and the number of fully defined concepts and primitive concepts were counted. The numbers of outgoing defining relationships from fully defined and primitive concepts were also counted. The proportion of fully defined concepts in SNOMED CT in total were also counted.

5.6 STUDY III

5.6.1 Sample

The diagnostic data used in this study were coded by PC physicians (GPs) and automatically collected from the EPRs in Stockholm County throughout 2006. Diagnostic codes were reported in an average of 78% of the encounters. The encounters with registered diagnostic coding, for which it was possible to use up to 15 diagnostic codes for every care contact, had one code in 82% of all care contacts, two codes in 13% of all care contacts and 2% of the contacts had more than three diagnostic codes.

5.6.2 Description of and comparison between ICD-10 and SNOMED CT

We used a category mapping from KSH97-P to SNOMED CT that was based on study I. We applied an additional mapping on an ICD-10 chapter level, as described in study II. We used the mapping results of categories and chapters from study II to aggregate PC diagnostic data through SNOMED CT *Is a* relationships to describe the data and make comparisons between ICD-10 and SNOMED CT on the chapter level. For each chapter we extracted the mapped chapter concept(s) together with the mapped concepts' *Is a* descendants. All diagnoses belonging to a category that were mapped to any of the extracted concepts were assumed to belong to the specific chapter. This implies that a specific category could belong to zero chapters, or one or more than one chapter.

5.6.3 Exploring complementary ways of aggregating with SNOMED CT

To explore and exemplify complementary ways of aggregating diagnoses and health problems, we used the category mapping. We carried out aggregations through the defining *Is a* relationships and defining attribute relationships, as described above. For each category the mapped concept(s) was/were extracted together with its/their ancestors (all supertypes) to a mapped set. All defining attribute relationships from concepts in the mapped set were then followed, and the target concepts were included in a specific attribute value set for each relationship type. In each attribute value set the concepts that were ancestors of another concept in the same attribute value set were removed. The remaining concepts in each attribute value set were assumed to be attribute values of the respective attribute types in the category. Attribute relationships include the concept (object), attribute type and attribute value (another concept) (72). The attribute relationships related to 'acute upper respiratory infection of multiple sites' are specified in **Table 3**.

Table 3. **Attribute relationships to the concept "Acute upper respiratory infections of multiple and unspecified sites" in SNOMED CT.**

Attribute type	Attribute value
Causative agent	Infectious agent
Clinical course	Sudden onset AND/OR short duration
Finding site	Structure of multiple topographic sites
Finding site	Upper respiratory tract structure

As the attribute values are arranged in a poly-hierarchy, diagnoses can be included in more than one attribute value. In this study we chose to explore three attribute relationships from the KSH97-P to SNOMED CT mapping, which in relation to the 972 categories were found to be present as follows: associated morphology (47%), finding site (74%) and causative agent (13%) (study II).

5.7 STUDY IV

5.7.1 Sample

Two hundred anonymised record entries, documented during 2005, were randomly selected from a research database containing 11 000 000 record entries from EPRs collected from PC in the Skaraborg area in Sweden from 1991 to October 2006. The intention was to retrieve GP notes only. However, the profession title had been removed from all clinicians during the anonymisation step. During the randomized selection, record entries from GPs were identified in a probability based process using identification numbers of the clinicians and contact types for their record entries. No TS had been used to code procedures in the record entries.

5.7.2 KVÅ

The version of KVÅ that was used was available in July 2009 and had 9 329 coded categories. Every category belongs to one of eight chapters and also to one of 23 sections. Otherwise the 9 329 categories do not have a hierarchical structure with rubrics as in the International Statistical Classification of Diseases version 10 (ICD-10) (65).

5.7.3 Identifying concepts

Content analysis is a research method used to make inferences from textual data by grouping together similar types of utterances and ideas (108). A framework for using content analysis in identifying meaningful concepts in free text in medical records has been developed for linking qualitative texts to the International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY) (109). For the purpose of this study, we used a method influenced by content analysis to identify meaningful concepts that were explicitly documented as a procedure in the context of each record entry. We chose to analyze only the manifest content, i.e. the written context, not the content that was left out.

5.7.4 Definition of procedure

Health care activity has been defined as activity performed for a subject of care with the intention of directly or indirectly improving or maintaining the health of that subject of care (110). Our definition of a procedure was: an intentional procedure done by the responsible GP as a part of directly or indirectly improving or maintaining the health of the patient.

5.7.5 Coding process

The coders were two of the authors (AV and MH). A panel of experts was consulted for issues that needed clarification both regarding the identified procedures and the coding of procedures. Certain questions concerning KVÅ were addressed to an expert at the Swedish National Board of Health and Welfare. We browsed for concepts in SNOMED CT using the freeware browser CliniClue and the translation platform "Healthterm" used for translating SNOMED CT to Swedish, with the aim of finding health care procedures on the most detailed level possible (102,111). Two researchers (AV and MH) analyzed the record entries in eight sequences, with 20-40 record entries in each sequence. The researchers first examined the record entries of each sequence independently, and then together, in order to agree on identification and encoding of the procedures. If the researchers disagreed, the panel of experts was consulted to reach a decision on how to interpret and code a procedure. Coding rules were set up before and during the process. Examples of coding rules were to allow coding to more than one concept for a procedure, and not to code the exact time when a procedure should be done or was done. Procedure concepts in SNOMED CT normally mean that they have actually occurred (69). Representation of a clinical meaning using a combination of two or more concepts with SNOMED CT (post-coordination) was only used to specify the degree of completion, or states, of a procedure as well as its various future states prior to its being initiated or completed; for example, if the procedure was "planned" (69).

5.7.6 Assessment

An assessment of the concordance between each coded procedure and category/concept pair was performed. A pair is either a procedure coded with a category in KVÅ or a procedure coded with a concept in SNOMED CT. The assessment scale used is seen in **Table 4.**

Table 4. **Assessment scale**
Assessment scale used for assessing concordance between coded procedure-category/concept pairs. Source is procedure in record entry; target is category/concept in KVÅ or SNOMED CT.

Code	Text
1	complete match between source and target
2	source is more specific than target
3	source is more general than target
4	source and target are partly overlapping

5.7.1 Aggregation and abstraction

In order to describe how the procedures that were coded with SNOMED CT were presented at a detailed and at a more general level, we used the poly-hierarchic structure of SNOMED CT. We carried out aggregations for the chosen SNOMED CT concepts and the number of times they had been selected in the coding process by the defining *Is a* relationships in SNOMED CT. For each category the mapped concept(s) was/were extracted together with its/their ancestors (all generic concepts) to a mapped set. Procedure concepts in the record entries that could not be coded with KVÅ were grouped to more general procedure concepts using a method influenced by content analysis to describe what types of procedures were not adequately covered by KVÅ.

6 RESULTS

6.1 STUDY I

6.1.1 Rules

A general principle or rule for mapping that was outlined before the first sequence, A, was to have a concept oriented perspective. New rules were developed after sequences A and B:

- To give priority to concepts from the ‘disorder’ or ‘finding’ hierarchy in SNOMED CT over ‘morphological structure’, ‘body structure’ or ‘context depending category’/’situation concepts’.
- Not to use ‘navigational’ concepts. These concepts are not part of active clinical terminology.
- To thoroughly analyze if the Z-categories in chapter XXI of ICD-10 refer to procedures or states.
- To consider the ‘exclude’ rule in ICD-10 as a rule that does not exist in SNOMED.
- To adhere to strict rules of priority regarding master data information sources for the classification categories in KSH97-P.
- To give priority to order of terms in the original master category text in cases where the concepts were partly matched to SNOMED CT.

6.1.2 Intercoder reliability

The intercoder reliability (the percentage share of SNOMED CT concepts to KSH97-P-categories that were equally chosen by the coders) increased from 69% to 83% when adding mapping rules after sequences A and B (**Table 5**). New mapping rules had a statistical significant impact on the results between sequences A - B and A - C. Logistic regression showed a significant difference between sequences A - B ($p = 0.01$), and sequences A - C ($p = 0.001$), but not between B and C ($p = 0.055$). The intercoder reliability for the entire set (A, B and C) of KSH97-P categories and SNOMED CT concepts was 77%.

Table 5. Intercoder reliability between sequences A, B and C, and the number and percentage share of equally chosen SNOMED CT concepts matched to P-categories (clustered ICD-10 categories within KSH97-P).

	Sequence A (n=323)	**Sequence B (n=326)**	**Sequence C (n=323)**
Equally chosen SNOMED CT concepts matched to all KSH97-P categories	223 (69%)	254 (78%)	269 (83%)
Equally chosen SNOMED CT concepts matched to P-categories (clustered ICD-10 categories within KSH97-P)	76 (59%)	86 (70%)	83 (76%)

The P-categories, which were clustered ICD-categories, varied between sequences A, B and C (**Table 5**). The P-categories were randomly distributed in the allotment of three sets of categories as follows: sequence A; 130, sequence B; 122, and sequence C; 109. The percentage share of equally chosen P-categories differed significantly between A and B when Pearson's Chi square was used ($p = 0.047$), as well as between A and C ($p = 0.004$), but not between sequences B and C ($p = 0.334$). The rate of equally chosen P-categories for the entire set was 68% as compared to the rate for non-P-categories, which was 82%. The Z-categories from chapter XXI in ICD-10 had a 23% rate of equally chosen categories, which was lower compared to other chapters.

6.1.3 Assessment and errors

The subjective assessment by each coder of every matched concept-category pair and its concordance was 85.3% or 829 (Coder 1), and 87.9% or 854 (Coder 2), respectively, for (2) 'completely concordant', and for (1) 'partly concordant' it was 13% or 127 (coder 1), and 11.7% or 114 (coder 2), respectively. The intercoder reliability for the coders' assessments reached 89%, which was moderate (K = 0.49). The assignment of the 'partly concordant' concept-category pairs into three groups is shown in **Table 6.**

Table 6. Extent of matching in the concept-category pairs assessed by each coder (YS and AV) and non found concepts in SNOMED CT.

Concordance	**Coder 1(YS)**		**Coder 2 (AV)**	
0 (non found)	16 (1.7%)		4 (0.4%)	
1 (partly concordant)	127 (13%)		114 (11.7%)	
1a. target (SNOMED CT) more specific than source (KSH97-P)		77 (60%)		75 (65%)
1b. target less specific than source		25 (20%)		20 (18%)
1c. imprecise but neither more nor less specific’		25 (20%)		19 (17%)
2 (completely concordant)	829 (85.3%)		854 (87.9%)	
Total	972 (100%)	127 (100%)	972 (100%)	114 (100%)

Non equally chosen SNOMED CT concepts due to human factor errors and structural and content dependent factors in the coding systems are shown in **Table 7**. Examples of human errors were missing characteristics in a concept, such as 'acute' in 'acute otitits media', and not following the mapping rules.

Table 7. Number of non equally chosen SNOMED CT concepts and human dependent errors.

	Sequence A	Sequence B	Sequence C	Sequence A-C
Non equally chosen SNOMED CT concepts due to human dependent errors	14	11	3	28
Non equally chosen concepts due to structural and content dependent factors in SNOMED CT and ICD-10/KSH97-P	86	61	51	198

SNOMED CT contains more specialized concepts than ICD-10. This led to choices of different but related or similar concepts from SNOMED CT, considered as concepts in good agreement with a KSH97-P category.

6.2 STUDY II

6.2.1 Mappings update

To improve the baseline category mapping and initial chapter mapping, the mappings were converted to the same SNOMED CT release, the category mappings and the chapter mappings were compared manually, and statistical chapter mappings were calculated and compared with the manual mappings. The algorithm for creating statistical chapter mapping created mappings for all chapters.

6.2.1.1 Comparison of manual and statistical chapter mappings

The comparison of manual and statistical chapter mappings gave the following results. For chapters I, II, V, VI, IX, X, XI, XII, XV and XVII, the manual and the best statistical mappings were mapped to the same concept. For chapters XVIII and XXI, there was no manual mapping. The best statistical mapping for chapter XVIII was Clinical history and observation findings, and for chapter XXI it was Procedure. These concepts are very general and are therefore of no use. These 12 manual chapter mappings were therefore not updated.

For chapters VII, VIII and XIV, the best statistical mappings were mapped to a finding concept. Furthermore, the manual mappings and the second or the third best statistical mappings were mapped to the corresponding disorder concept. After inspection, the manual mappings for chapters VII and VIII were left without changes. This was because there were small differences between the numbers of covered categories for the different chapter mappings and the differences consisted mainly of non-disease categories. The manual mapping for chapter XIV was changed to the best statistical mapping to better cover its disease categories.

Each of chapters III, IV, XIII and XIX had manual mappings to more than one concept. For each chapter at least one mapping was equal to a highly ranked statistical mapping and at least one mapping was equal to a poorly ranked statistical mapping. A review showed that categories covered by poorly ranked manual mappings were KSH97-P categories that covered a broad area of relevant diseases and were equivalent to many categories in ICD-10. The manual mappings were therefore considered to be correct and were left without changes.

Chapter XVI had only one manual mapping and that mapping was equal to a poorly ranked statistical mapping. The mapping was to the concept “Perinatal finding”, which covers only one category from the chapter in KSH97-P. The highest ranked statistical mapping was to the concept Disorder of fetus or newborn, which covers the other 15 categories in the chapter.

6.2.2 Multiple chapter division

The multiple chapter division is summarized in **Table 8**, which shows the proportions of categories from each KSH97-P chapter that were divided into new chapters. Some categories were excluded from the multiple chapter division. One reason was the lack of mappings from categories and chapters to SNOMEDCT.

Table 8. Multiple chapter division summary.

Multiple chapter division chapter	**Original chapter**																				
	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV	XV	XVI	XVII	XVIII	XIX	XXI	All
I	**.94**									**.11**	.02	.05	.01	.03	.07	.19				.03	.10
II		**1.00**										.05			.03		.03				.09
III		.01	**.92**			.03			.02	.08		.03				.06	.03	.02			.02
IV		.06		**.87**			.03						.01		.03	.06		.01			.04
V					**.91**	.06						.02		.02							.05
VI	.04	.04		.03	.19	**.86**	.08	.05	.10				.01			.06	.13	.02	.02		.07
VII	.01	.03					**.97**						.01			.06	.03		.03		.04
VIII		.03						**.86**									.03		.03		.02
IX	.01				.02	.06	.03		**.86**		.02	.03	.01	.02	.03	.06	.05	.02			.06
X	.02	.06							.04	**1.00**						.06	.05	.03	.02		.06
XI	.13	.22		.17					.04	.16	**.86**	.02	.01	.02	.03		.20	.03	.02		.10
XII	.18	.04					.06					**.88**		.02			.10	.02			.09
XIII	.01	.04				.06		.05		.05	.06	.03	**.76**	.02	.07		.10		.55		.12
XIV	.04	.25		.10	.02				.04					**.83**	.10		.13	.09	.02		.10
XV					.02										**.90**						.03
XVI																**1.00**	.03				.02
XVII				.03						.03			.01		.03		**.90**				.04
XVIII																					

XIX	.01	.02	.02	.02	.02	.06	.03	.13	.01	**.73**	.06
XXI											

In **Table 8**, KSH97-P’s original chapters are represented in the columns to the left and the complete KSH97-P in the column furthest to the right. The rows then show the proportion of categories that appeared in each chapter after the multiple chapter division. For instance, 11% of categories in chapter X *Diseases of the respiratory system* were assigned to chapter I *Certain infectious and parasitic diseases*. Not all categories were included in the multiple chapter division. One reason is that some categories and chapters were not mapped to SNOMED CT. Another reason is that SNOMED CT’s structure does not include all categories in the division. The multiple chapter division does not intentionally care about the excludes remarks in ICD-10.

Table 9 shows some examples of how categories were divided in multiple chapters. The first three columns show the KSH97-P’s category's chapter number, code and term. The last column shows the category’s chapter number according to the multiple chapter division. These categories are only a small selection of examples from the complete multiple chapter division.

Table 9 - Examples of multiple chapter division.

Original chapter number	Category code	Category term	Mapped chapter number
V	F01-	Vascular dementia	V
V	F01-	Vascular dementia	VI
V	F01-	Vascular dementia	IX
V	F01-	Vascular dementia	XIX
IX	I84-	Hemorrhoids	IX
IX	I84-	Hemorrhoids	XI
X	J36-	Peritonsillar abscess	X
X	J36-	Peritonsillar abscess	XI

6.2.3 Additional attributes

Table 10 shows the proportion of categories in each KSH97-P chapter and the total that have additional attributes of different attribute types modelled according to the additional attribute method. **Table 11** shows the average number of categories that have the same attribute value for each attribute type. The corresponding median values were also calculated in the study and were in most cases close to the average values. **Table 12** demonstrates some examples of categories and their additional attributes.

ATTRIBUTE TYPE	CHAPTERS IN KSH97-P																				
	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV	XV	XVI	XVII	XVIII	XIX	XXI	All
After	.04			.03		.03			.02		.02	.02							.03		.01
Associated finding																				.03	.00
Associated morphology	.20	1.00	.15	.13	.02	.26	.61	.52	.44	.74	.45	.73	.57	.55	.17	.38	.93	.11	.81		.47
Associated with			.23	.07			.03			.03		.02						.01	.08		.01
Causative agent	.96			.03	.15	.03		.05		.16	.08	.16	.01	.03	.07	.19	.03		.09	.03	.13
Clinical course	.04				.04	.03	.03	.19	.06	.26	.04		.01	.02			.03	.01	.02		.03
Direct device																				.03	.00
Direct substance																				.03	.00
Due to			.23	.03			.03			.05		.13							.02		.02
Finding context																		.04		.03	.01
Finding informer																		.03			.00
Finding method																	.03	.09		.03	.01
Finding site	.46	.84	.23	.67	.21	.97	1.00	1.00	.94	1.00	.98	.95	.95	.92	.33	.44	.93	.65	.72		.74
Has definitional manifestation	.10		.92	.07	.19	.20		.10	.06	.03	.02	.06	.02	.03	.03	.06	.03	.03			.06
Has focus																				.11	.00
Has intent																				.03	.00
Has interpretation							.25							.03				.10			.02
Interprets					.04	.06	.25	.14				.02	.02	.08			.03	.35		.09	.06
Method																				.40	.01
Occurrence				.03	.02					.03			.04		.07	.63	.90				.06
Pathological process						.03						.02									.00
Procedure context																				.03	.00
Procedure device																				.03	.00
Procedure site																				.06	.00
Procedure site - Indirect																				.03	.00
Subject relationship context																		.04		.06	.01
Temporal context																		.04		.06	.01

Table 10. Attribute types in each chapter.

ATTRIBUTE TYPE	CHAPTERS IN KSH97-P																				
	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV	XV	XVI	XVII	XVIII	XIX	XXI	All
After	1.5			1.0		1.0			1.0		1.0	1.0							1.0		1.3
Associated finding																				1.0	1.0
Associated morphology	1.5	3.8	.7	1.3	.5	1.0	1.4	1.4	1.7	1.8	1.5	1.5	1.7	1.6	1.0	1.5	2.1	1.3	3.7		2.7
Associated with			3.0	1.0			1.0			1.0		1.0						1.0	1.7		1.4
Causative agent	1.1			1.0	1.8	.5		1.0		1.0	1.0	1.0	1.0	2.0	2.0	3.0	1.0		1.0	1.0	1.3
Clinical course	3.0				1.0	1.0	1.0	2.0	3.0	5.0	1.0		1.0	1.0			1.0	1.0	1.0		1.3
Direct device																				1.0	1.0
Direct substance																				1.0	1.0
Due to			1.0	1.0			1.0			.7		1.6							1.0		1.5
Finding context																		4.0		1.0	5.0
Finding informer																		3.0			3.0
Finding method																	1.0	4.0		1.0	3.3
Finding site	1.7	**1.3**	3.0	1.8	2.0	1.3	1.6	1.9	1.3	1.6	1.4	3.6	1.1	1.7	1.0	.9	1.0	1.4	.9		2.0
Has definitional manifestation	4.0		1.3	1.0	1.8	1.8		1.0	1.5	1.0	1.0	1.3	2.0	2.0	1.0	.3	1.0	.8			2.0
Has focus																				1.3	1.3
Has intent																				1.0	1.0
Has interpretation							4.5							2.0				1.8			4.0
Interprets					.5	.7	3.0	1.5				1.0	1.0	1.0			1.0	.9		1.0	1.2
Method																				2.0	2.0
Occurrence				1.0	1.0					1.0			1.0		1.0	3.3	36.0				9.0
Pathological process						1.0						1.0									2.0
Procedure context																				1.0	1.0
Procedure device																				1.0	1.0
Procedure site																				1.0	1.0
Procedure site - Indirect																				1.0	1.0
Subject relationship context																		4.0		1.0	3.0
Temporal context																		4.0		1.0	3.0

Table 11. Different attribute values in each chapter.

Table 11 shows the number of categories, in each chapter and in total, for which each attribute type was used, divided by the number of unique attribute values for each attribute type. This means that the table shows the average number of categories with the same attribute value for each attribute type. The corresponding median values were also calculated in the study and were in most cases close to the average values, but the median values were omitted from the study results to shorten the paper. For example, 66 of the 79 categories in chapter II *Neoplasms* have attributes of type *Finding site* with 49 different attribute values. This means that the corresponding value in the table is 66/49=1.3. If, hypothetically, all 79 categories in the chapter had had attributes of type *Finding site* with attribute value *Body structure*, the corresponding value would be 79/1=79. In the actual case the attribute information is informative, but in the hypothetical case the attribute information would be of limited use. If few categories have attributes of a specific attribute type in a specific chapter, these categories can easily have unique attribute values for these attributes. Therefore it is not useful to compare values in **Table 11** for attribute types and chapters where **Table 10** shows that only a few categories have attributes.

Table 12. Examples of additional attributes.
The first three columns show a category's chapter number, code and term. The last two columns show the attribute types and attribute values according to SNOMED CT's defining attribute relationships. These categories are only a small selection of examples from the complete additional attributes.

Chapter number	Category code	Category term	Attribute type	Attribute value
VIII	H669P	Otitis media, unspecified	Associated morphology	Inflammation
VIII	H669P	Otitis media, unspecified	Finding site	Middle ear structure
X	J06-P	Acute upper respiratory infections of multiple and unspecified sites	Causative agent	Infectious agent
X	J06-P	Acute upper respiratory infections of multiple and unspecified sites	Clinical course	Sudden onset AND/OR short duration
X	J06-P	Acute upper respiratory infections of multiple and unspecified sites	Finding site	Structure of multiple topographic sites
X	J06-P	Acute upper respiratory infections of multiple and unspecified sites	Finding site	Upper respiratory tract structure
XIII	M259P	Joint disorder	Finding site	Joint structure

Fully defined ancestors
Among the concepts that were mapped from KSH97-P's categories and these concepts' ancestors, 1,786 (63%) concepts were fully defined and 1,061 (37%) were primitive. There were a total of 10,010 outgoing defining relationships from the concepts and their ancestors. From all concepts in SNOMED CT, 13% were fully defined.

6.3 STUDY III

6.3.1 Diagnosis with KSH97-P

There were 2 563 031 office encounters with GPs in the PC units. In the encounters, 2 508 944 diagnoses were coded according to KSH97-P/ICD-10. Of these, 113 775 diagnoses were assigned to one of the 14 diagnostic categories that were not mapped to a SNOMED CT concept, of which 100 259 were coded Z54-P, 'Persons encountering health services for specific procedures and health care'. In all, 41 390 of the diagnoses were assigned to codes in ICD-10 instead of KSH97-P.

6.3.2 Chapter level comparison between ICD-10 and SNOMED CT

A chapter level comparison of diagnostic data between KSH97-P/ICD-10 and SNOMED CT is presented in **Table 13**.

Table 13. A comparison of diagnoses and health problems in KSH97-P/ICD-10 and SNOMED CT using PC diagnostic data from 2006 in Stockholm, aggregated on an ICD 10 chapter level. Chapters XX and XXII in ICD-10 are not a part of KSH97-P. Chapters XVIII *Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified* and XXI *Factors influencing health status and contact with health services* were assessed as unable to map to SNOMED CT's concepts.

Chapter in ICD 10	Chapter name in ICD-10	Diagnosis KSH97-P/ICD-10 number and percentage share (%) (N=2 508 944)	SNOMED CT concepts matching ICD-10 chapter level	Diagnosis SNOMED CT number and percentage share (%) (n= 2 210 540)
I	Certain infectious and parasitic diseases	108,893 (4.3)	Infectious disease	316,391 (14.3)
II	Neoplasms	29,553 (1.2)	Neoplasm and/or hamartoma	348,78 (1.6)
III	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	12,918 (0.5)	Disorder of cellular component of blood/ Disorder of immune structure/Disorder of immune function / Disorder of hemostatic system	67,378 (3.0)
IV	Endocrine, nutritional and metabolic diseases	124,899 (5.0)	Disorder of endocrine system Metabolic disease/ Nutritional disorder	105,988 (4.8)
V	Mental and behavioural disorders	135,440 (5.4)	Mental disorder	118,342 (5.4)
VI	Diseases of the nervous system	26,950 (1.0)	Disorder of nervous system	55,061 (2.5)
VII	Diseases of the eye and adnexa	39,631 (1.6)	Visual system disorder	40,818 (1.9)
VIII	Diseases of the ear and mastoid	123,306 (5.0)	Disorder of ear	120,980 (5.5)

	process			
IX	Diseases of the circulatory system	246,022 (9.8)	Disorder of cardio-vascular system	251,984 (11.4)
X	Diseases of the respiratory system	375,006 (15.0)	Disorder of respiratory system	377,837 (17.1)
XI	Diseases of the digestive system	56,583 (2.3)	Disorder of digestive system	194,904 (8.8)
XII	Diseases of the skin and subcutaneous tissue	138,890 (5.4)	Disorder of integument	160,319 (7.3)
XIII	Diseases of the musculoskeletal system and connective tissue	281,787 (11.2)	Disorder of musculoskeletal system/Disorder of connective tissue	168,815 (7.6)
XIV	Diseases of the genitourinary system	90,443 (3.6)	Urogenital finding	104,814 (4.7)
XV	Pregnancy, childbirth and the puerperium	1,303 (0.1)	Pregnancy, childbirth and puerperium finding	992 (0)
XVI	Certain conditions originating in the perinatal period	84 (0)	Perinatal finding (finding)/ Disorder of fetus or newborn	72 (0)
XVII	Congenital malformations, deformations and chromosomal abnormalities	24,76 (0.1)	Congenital disease	5,158 (0.2)
XVIII	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	303,700 (12.1)	- (no match)	
XIX	Injury, poisoning and certain other consequences of external causes	105,203 (4.2)	Traumatic AND/OR non-traumatic injury Accidental poisoning by drugs, medicines and biologicals	85,809 (3.9)
XXI	Factors influencing health status and contact with health services	299,443 (11.9)	- (no match)	

‘Diseases of the digestive system’ differed, with 194 904 (8.8%) in SNOMED CT and 56 583 (2.3%) in KSH97-P/ICD-10. There were 316 391 (14.3%) diagnoses classified as ‘Infectious disease’ in SNOMED CT, which is higher than in KSH97-P/ICD-10 Chapter I, ‘Certain infectious and parasitic diseases’, where the figures were 108 893 (4.3%). The frequency of ‘Diseases of the musculoskeletal system and connective tissue’ was 168 815 (7.6%) in SNOMED CT, which was lower than the frequency of 281 787 (11.2%) in KSH97-P/ICD-10. In the remaining chapters the differences in frequency were below 3%. A total of 298 404 (12%) of the diagnoses were assigned to categories in ICD-10 that were not taken care of in the mapping process.

The use of *Is a* relationships in SNOMED CT aggregated the diagnostic data to 2861 concepts, showing a new, multidimensional view of different specific medical aspects, where every view can be further explored. A subset of such concept views is shown in **Table 14**, with a diagnosis percentage share cut-off at 5.5 percent.

Table 14. A SNOMED CT concept aggregation of diagnoses and health problems using PC diagnostic data from 2006. The defining *Is a* relationships in SNOMED CT are used. This table shows concepts with a diagnosis percentage share cut-off at 5.5%. The root concept "SNOMED CT" is excluded.

SNOMED CT concept	**Number of concepts** (**N**= 2508944).	**Percentage share (%)**
Clinical finding	2,216,264	88.3
Disease	1,757,334	70.0
Finding by site	1,748,773	69.7
Disorder by body site	1,420,758	56.6
Disorder of body system	1,383,001	55.1
Finding of body region	1,316,074	52.5
Finding of head and neck region	548,981	21.9
Finding of trunk structure	475,429	18.9
Inflammatory disorder	449,050	17.9
Inflammation of specific body structures or tissue	444,690	17.7
Inflammation of specific body systems	438623	17.5
Respiratory finding	433563	17.3
Inflammation of specific body organs	390976	15.6
Ear, nose and throat finding	390342	15.6
Disorder of body cavity	390306	15.6
Ear, nose and throat disorder	385886	15.4
Disorder of respiratory system	377837	15.1
Disorder of trunk	373868	14.9
Head finding	357932	14.3
Disorder of head	339902	13.5
Infectious disease	316391	12.6
Viscous structure finding	276703	11.0
Upper respiratory tract finding	266681	10.6

Cardiovascular finding	266070	10.6
Disorder of upper respiratory system	264906	10.6
General finding of abdomen	258671	10.3
Disorder of cardiovascular system	251984	10.0
General finding of soft tissue	250908	10.0
Infection by site	244572	9.7
Acute disease	237530	9.5
Inflammatory disorder of head	236785	9.4
Musculoskeletal finding	226468	9.0
Disorder of soft tissue	213494	8.5
Digestive system finding	203010	8.1
Neurological finding	200411	8.0
Integumentary system finding	197507	7.9
Disorder of digestive system	194904	7.8
Finding of region of thorax	192661	7.7
Disorder of abdomen	186630	7.4
Respiratory tract infection	184909	7.4
Acute respiratory disease	184660	7.4
Acute infectious disease	183304	7.3
Acute respiratory infections	183056	7.3
Disorder of digestive organ	179425	7.2
Sensory nervous system finding	178008	7.1
Blood vessel finding	174821	7.0
Vascular disorder	174821	7.0
Disorder of thorax	169109	6.7
Soft tissue lesion	168694	6.7
Observation of sensation	166697	6.6
Pain/sensation finding	166697	6.6
Disorder of integument	160319	6.4
Finding of pain sense	159722	6.4
Pain	159722	6.4
Disorder of musculoskeletal system	158196	6.3
Skin finding	148951	5.9
Acute inflammatory disease	144570	5.8
Procedure	141870	5.7
Clinical history and observation findings	141224	5.6
Procedure by method	141009	5.6
Disorder of digestive tract	140376	5.6
Arterial finding	139866	5.6
Disorder of artery	139866	5.6
Acute upper respiratory infection	139155	5.5

The chosen attribute relationships in SNOMED CT were connected to the diagnostic categories inKSH97- P, as shown in **Table 15**.

Table 15. A SNOMED CT concept aggregation of diagnoses and health problems using PC diagnostic data from 2006. The clinically relevant defining attribute relationships Associated morphology, Causative agent and Finding site in SNOMED CT are presented in order, at different breaking points, showing number and percentage share.

Attribute type	Attribute value	Numerical order	Diagnosis (N=2508944) number (%)
Associated morphology	Inflammatory morphology	5	449050 (18.0)
	Inflammation	6	438912 (17.5)
	Acute inflammation	7	144570 (5.8)
	Acute inflammatory morphology	8	144570 (5.8)
	Mechanical abnormality	9	142897 (5.7)
	Damage	10	85703 (3.4)
	Traumatic abnormality	11	82573 (3.2)
	Mass	12	55680 (2.2)
	Growth alteration	13	44894 (1.8)
	Proliferation	14	40996 (1.6)
	Proliferative mass	15	40903 (1.6)
	Suppurative inflammation	16	40144 (1.6)
	Traumatic abnormality by morphology	17	39674 (1.6)
	Neoplasm and/or hamartoma	18	34878 (1.4)
	Eruption	19	30718 (1.2)
	Acute suppurative inflammation	20	26919 (1.0)
Causative agent			
	Organism	2	317358 (12.7)
	Infectious agent	3	316391(12.6)
	Microorganism	4	109574 (4.3)
	Virus	5	61926 (2.5)
	Bacteria	6	31130 (1.2)
	Superkingdom Bacteria	7	18216 (0.7)
	Prokaryote	8	18216 (0.7)
	DNA virus	9	17717 (0.7)
	Fungal microorganism	10	16387 (0.7)
	Fungus	11	16387 (0.7)
	Class Spirochaetes	12	11063 (0.4)
	Order Spirochaetales	13	11063 (0.4)
	Phylum Spirochaetes	14	11063 (0.4)
	Family Spirochaetaceae	15	11061 (0.4)
	Arthropod-borne organism	16	11058 (0.4)
	Pathogenic organism	17	11058 (0.4)
	Borrelia	18	11057 (0.54
	Borrelia burgdorferi	19	11057 (0.4)
	Enveloped dsDNA virus	20	10788 (0.4)

Finding site			
	Upper body part structure	8	766869 (30.6)
	Upper body structure	9	766869 (30.6)
	Head and neck structure	10	548981 (21.9)
	Structure of respiratory system and/or intrathoracic structure	11	520258 (20.7)
	Neck, chest, abdomen, and pelvis	12	517052 (20.6)
	Neck, chest and abdomen	13	491912 (19.6)
	Trunk structure	14	475429 (19.0)
	Chest, abdomen, and pelvis	15	472793 (18.8)
	Structure of subregion of trunk	16	472793 (18.8)
	Chest and abdomen	17	447653 (17.8)
	Structure of respiratory system	18	433563 (17.2)
	Body space structure	19	427541 (17.0)
	Body cavity structure	20	409525 (16.3)

Unlike the *Is a* relationship showing disorders and findings concepts in **Table 14**, **Table 15** presents the perspectives of 'Associated morphology', 'Causative agents' and 'Finding sites' for PC disorders and findings.

6.4 STUDY IV

6.4.1 Procedures documented by GPs

There were 417 procedures found in the 200 EPR record entries. The numbers of procedures identified in each record entry are shown in **Table 16**. Most commonly, only one procedure was present (43.5%) in each record entry. In 10.0% of the record entries no procedure was found. With a few exceptions, medical history taking and physical investigation procedures to assess health status were usually not documented as procedures in the record entries.

Table 16. Procedures in record entries
Procedures found in the 200 record entries.

Procedures (n)	Record entries with none or a certain number (%) of procedures
0	20 (10.0)
1	87 (43.5)
2	31 (15.5)
3	25 (12.5)
4	16 (8.0)
5	10 (5.0)
6	5 (2.5)
7	3 (1.5)
8	1 (0.5)
9	1 (0.5)
10	0 (0.0)
11	1(0.5)

Sixteen procedures (3.8%) could not be coded with any TS. Eighteen procedures (4.3%) could not be coded with SNOMED CT and 95 procedures (22.8%) could not be coded with KVÅ. Planned or booked future treatments or investigations, regardless of the type, could not be coded with KVÅ.

6.4.2 Description and comparison of content

The content coverage differed extensively between the two TSs. There were 399 (95.7%) procedures in the record entries that could be coded with SNOMED CT, compared to 322 (77.2%) that could be coded with KVÅ. The procedures were coded with 148 different SNOMED CT concepts and 36 different KVÅ categories. **Figure 1** shows the distribution of procedures from the top node concept “procedure” in SNOMED CT, and the most common procedure “Procedure by method” (n=305). The procedures coded with KVÅ-categories at a 1% cut-off level are shown in **Table 17**.

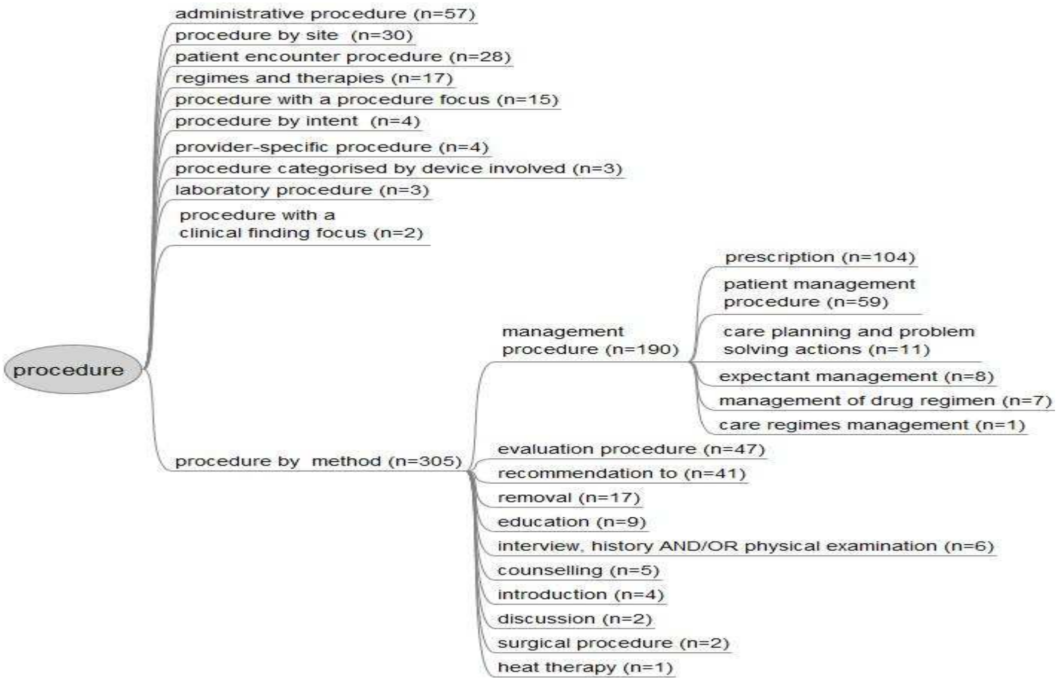

Figure 1. Procedures in SNOMED CT found in record entries.
This figure shows the distribution of procedures from the record entries from the top node "Procedure" to the nearest subtype or child-concepts, and the distribution in the "Management procedure" concept-tree. "Procedure by site", "Procedure by method" and "Administrative procedure" are all examples of the nearest subtype to the Procedure concept. "Prescription" is a subtype of "Management procedure".

Table 17. KVÅ categories used for coding at a 1% cut-off level, shown in number and % of procedures in the record entries.

KVÅ category	Number (%)
Prescription of drug	126 (30.2)
Referral NOS	55 (13.2)
Information/education about examinations and treatments	37 (8.9)
Certificate, simple	12 (2.9)
Information and counseling with the patient by post	13 (3.1)
Information/education about self-care program	14(3.4)
Specimen collection NOS	7 (1.7)
Information and counseling with the patient by phone	8 (1.9)
Other specified specimen collection	7 (1.7)
Certificate, extensive	5 (1.2)
Obtaining advice from other health care personnel NOS	4 (1.0)

With regard to the above, “Referrals” can serve as an example. “Referrals” in KVÅ were coded with “Referral NOS” (not otherwise specified), i.e. it was not possible to code the type of recipient in KVÅ. Referrals were described with almost the same frequency in KVÅ (n=55) as in SNOMED CT (n=58), whereas in SNOMED CT referrals were coded with 19 different types of recipients. Thirty-two (16.0%) of the encounters had one or more than one referral to another department, excluding radiology. Another example is procedures concerning drugs and medication. Procedures coded with KVÅ were all coded to the category “Prescription of drugs” (n=126) with the definition “Measures during the initiation, evaluation and release of drugs that include considerations together with the patient regarding prescriptions, written instructions, evaluation of efficacy and side effects”. Procedures concerning drugs and medication were coded with 21 different concepts in SNOMED CT: Prescription of drug (n=94), Recommendation regarding when to take drug (n=9), Prescription renewal (n=6), Drug treatment stopped - medical advice (n=6), Prescription dose change (n=4), Recommendation to continue with drug treatment (n=3), Recommendation to start drug treatment (n=3), Warfarin control test (n=2), Patient medication education (n=2), Warfarin dose unchanged (n=2). The following procedures were coded once (n=1): Injection of therapeutic agent, Administration of vaccine to produce active immunity, Follow-up thyroid assessment, Warfarin therapy started, Repeat prescription - follow-up assessment, Warfarin monitoring, Injection of steroid into knee joint, Evaluation of response to medications, Asthma medication review, Medication monitoring, and Beta adrenergic receptor blocking agent therapy.

6.4.3 Description and comparison of the degree of concordance

A comparison of the degree of concordance between the procedure- concept/category pairs coded with SNOMED CT and with KVÅ is shown in **Figure 2**. The procedures coded with KVÅ were assessed to be of a much lower concordance than those coded with SNOMED CT. In KVÅ, 10 procedure-concept/category pairs were a complete match compared to 206 to SNOMED CT. Almost all of the procedures identified in the text were regarded as more specific than the categories found in KVÅ; for example, “Specimen collection, NOS”. Of the procedures coded with SNOMED CT, 48.1% were considered as more specific than the concept found.

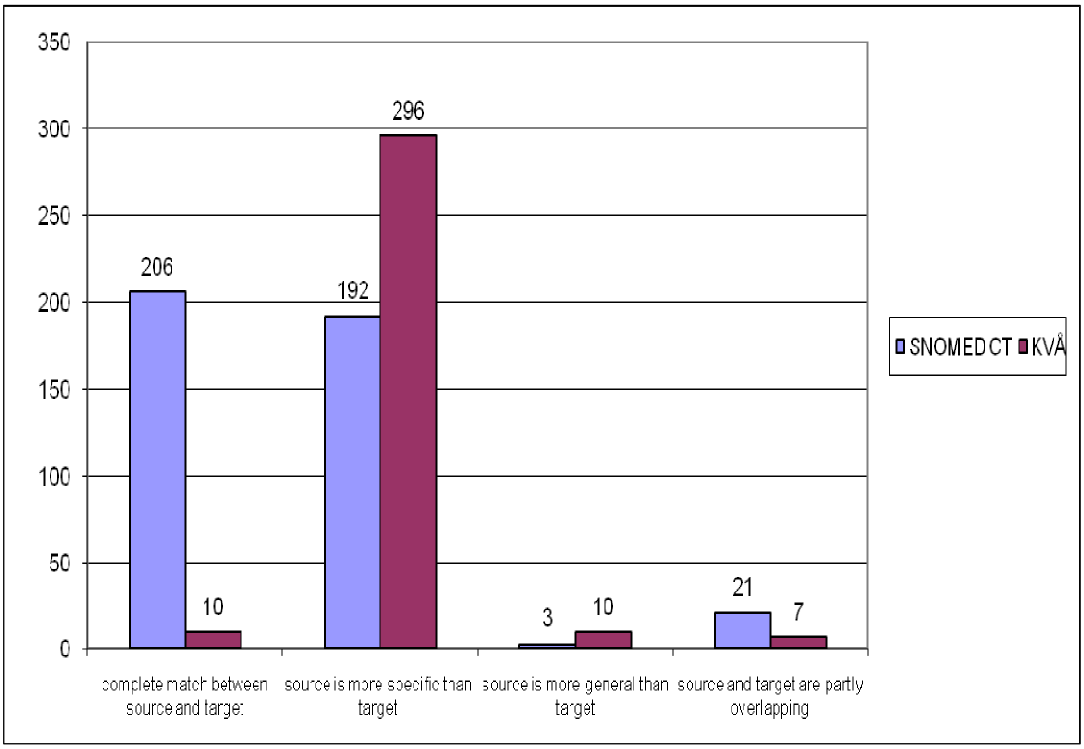

Figure 2. **A comparison of the degree of concordance between procedure-concept/category pairs with SNOMED CT and KVÅ. The figure shows the number of procedure- concept/category pairs coded to SNOMED CT and KVÅ assessed to a value in the assessment scale. "Source" is procedure in record entries and "target" is category/concept in KVÅ or SNOMED CT.**

Procedures that involved relatives, for example information or instructions to a relative, were difficult to find in SNOMED CT and were assessed at a lower level of concordance in SNOMED CT than in KVÅ. An example of assessment of a procedure that differed between the two TSs is shown in **Table 18**.

Table 18. Examples of different assessments of procedure-category/concept pairs coded with SNOMED CT and KVÅ.

Procedure	SNOMED CT concept	SNOMED CT assess-ment	KVÅ-category	KVÅ assess-ment
Referral to outpatient ophthalmology clinic	Referral to ophthalmology service	1	Referral NOS	2
Drug treatment stopped	Drug treatment stopped - medical advice	1	Prescription of drug	2
Calls the patient's mother and asks her to collect a new urine sample	Informing next of kin	4	Information and counseling with next-of-kin by telephone	2

Alter drug dosage	Prescription dose change	1	Prescription of drug	2

When the procedures were explicitly documented with dynamic characteristics or states, they were post-coordinated in SNOMED CT as follows: “carried out” (n=32), “planned” (n=31), “requested” (n=10), “needed” (n=5), “rescheduled” (n=1) and “not done” (n=1). Despite the post-coordinations, reasoning about further contacts or future plans and treatments related to possible changes in the patient’s health condition is not sufficiently captured in the coding by either TS.

7 DISCUSSION

7.1 PRINCIPAL FINDINGS

New mapping rules had a significant impact on the results between sequences A - B and A – C in study I. Mapping from ICD-10-categories to SNOMED CT needs clear and extensive rules. The intercoder reliability reached 83%. The obstacles to high quality mapping were mainly differences in agreement between coders due to both structural and content factors in SNOMED CT and ICD-10/KSH97-P.

A new and poly-hierarchical chapter division of KSH97-P's categories was created using the category and chapter mappings and SNOMED CT's generic structure in study II. In the new chapter division, most categories were included in their original chapters. A considerable number of concepts were included in other than their original chapters. KSH97-P's categories were also extended with attributes using the category mappings and SNOMED CT's defining attribute relationships.

Presentation of the diagnosis distribution showed differences mainly in infectious and digestive system disorders when comparing KSH97-P/ICD-10 at the chapter level to SNOMED CT in study III. The usage of *Is a* relationships in SNOMED CT aggregated the diagnostic data to 2861 concepts, showing a multidimensional view of different specific medical aspects. The perspectives of 'Associated morphology', 'Causative agents' and 'Finding sites' regarding PC disorders and health problems were shown through the chosen attribute relationships.

The 417 procedures found in the 200 EPR entries were coded with 36 different KVÅ categories and 148 different SNOMED CT concepts in study IV. Of the procedures, 22.8% could not be coded with any KVÅ category and 4.3% could not be coded with any SNOMED CT concept. In SNOMED CT, 206 procedure-concept/category pairs were assessed as a complete match compared to 10 in KVÅ.

7.2 CODED CLINICAL INFORMATION

Our results indicate that SNOMED CT covers diagnoses and procedures documented by GPs in PC. The mappings to SNOMED CT from the PC version of ICD-10, KSH97-P, showed that SNOMED CT covered 99% of the categories, and the coding of procedures in EPRs to SNOMED CT covered almost all of the procedures content in our sample. Content coverage is one of the most important aspects of a TS, since physicians need to be able to completely and accurately depict the patient's status or care process (30) as do other health care professionals. Furthermore, there is a need for adding content, which will need formal, explicit, reproducible methods for recognizing and filling gaps (36). We had reason to expect that SNOMED CT would cover the GPs' PC domain well, as SNOMED CT was created by the convergence of SNOMED RT and a terminology originally developed for PC (the United Kingdom's Clinical Terms Version 3, formerly known as the Read Codes) (67, 68) and this expectation was confirmed. Our results concerning coverage could not be confirmed by the literature due to the lack of studies regarding SNOMED CT and PC data.

The multiple chapter division in study II could be applied to diagnostic data in study III. The poly-hierarchical structure of SNOMED CT revealed a high percentage of digestive and infectious diseases that were hidden in the mono-hierarchical structure of KSH97-P. SNOMED CT allows a concept to have *Is a* relationships in several hierarchies; for example, to be both an infectious or a neoplastic disease and a disorder of the digestive system. This provides a way to view diagnostic data from complementary, clinical views of importance. It has been suggested that we will be better able to reuse data when we can employ terminologies that support clinically relevant levels of detail (11). The multiple granularity in SNOMED CT increased the various levels of clinical detail of the data, and the multiple consistent views in SNOMED CT increased the possibilities for multipurpose data aggregation compared to the existing classification structure in ICD-10. The latter is based on a number of well-known compromises (50) and has limitations when used for statistical purposes and multipurpose data aggregation due to the fact that its chapter structure has only a few consistent views (57). The present recommendation for obtaining statistics on certain diseases of interest is to use manual selection of KSH97-P categories, (58) which is a method that could lead to arbitrary, non-comparable groups and is prone to error (56). Further, defining attribute relationships in SNOMED CT provided additional information not possible to aggregate in ICD-10, for example information on inflammation that can improve data aggregation of the clinical content in EHRs.

Based on the results shown in this thesis, it is obvious that there are challenges involved in analyzing SNOMED CT data. This may be related to the finding that most uses of SNOMED CT remain basic and do not capitalize on the rich semantics of the terminology (75).

7.3 MEDICAL TERMINOLOGY SYSTEMS EVOLUTION

7.3.1 Enriching classifications

The mappings from KSH97-P to SNOMED CT enriched KSH97-P's mono-hierarchical structure. According to the meta classification by Rossi Mori et al. (35). KSH97-P is a first generation system, but after the addition of the multiple chapter division and additional attributes, it is possible to compare KSH97-P with a second generation system, at least with respect to structure. The categories in KSH97-P constitute a list of categories, and the additional attributes and their structure in SNOMED CT can be seen as a cross-thesaurus. The relationships between KSH97-P categories and their attributes correspond to a knowledge base of dissections. SNOMED CT's concept model together with information about how the mappings are done can be seen as a categorical structure. One major improvement in a second generation system in comparison with a first generation system is, according to Rossi Mori et al., the possibility of automatically rearranging categories to satisfy different purposes (35). Our results show that KSH97-P's categories can be rearranged using the multiple chapter division and prioritization to include concepts in chapters other than those they are normally in. For example, F01- Vascular dementia is mapped to four original chapters as shown in **Table 9**. It is also highly possible to rearrange the categories using the additional attributes according to Finding site and to a lesser extent according to Associated morphology. An even larger number of reorganizations would probably have been possible if a higher proportion of the used concepts in SNOMED CT were fully defined.

Cimino (36) advocates characteristics similar to those of Rossi Mori et al. (35). Five desired characteristics according to Cimino are content, poly-hierarchy, formal definitions, multiple granularity and multiple consistent views (36). SNOMED CT fulfills these criteria, but none of them is fulfilled by KSH97-P. KSH97-P's "hierarchy" of chapters and categories does not fulfill what Cimino (36) terms multiple granularity; this is because only categories are meant to be used for coding. In ICD-10, on the other hand, the possibility of coding on the three, four or in some parts five-character level would qualify as multiple granularity.

It is beneficial that 63% of the used concepts in SNOMED CT are fully defined when the fraction of fully defined concepts of the entire SNOMED CT is 13%. However, the used concepts are central for Swedish PC and probably in PC in many other countries as well.

7.3.2 Multiple chapter division

The multiple chapter division shows that the chapter division in KSH97-P, which only allows one category to be included in one chapter, hides information about the categories in KSH97-P. It also shows that it is possible to extend the chapter division to a multiple chapter division using SNOMED CT.

The largest inclusion of categories in a chapter other than the original is the inclusion of 55% of the categories of chapter XIX *Injury, poisoning and certain other consequences of external causes* in chapter XIII *Diseases of the musculoskeletal system and connective tissue*. Chapter XIX has priority over chapter XIII according to the excludes remarks in ICD-10, which implies that those categories from chapter XIX would probably also be fitting for chapter XIII. Chapter II *Neoplasms* has many inclusions of its categories in chapter XIV *Diseases of the genitourinary system* and chapter XI *Diseases of the digestive system*, and smaller inclusions in eight other chapters. The biggest exceptions where inclusions of categories in other chapters cannot be explained by the excludes remarks' priorities are the following: 19% of the categories in chapter V *Mental and behavioural disorders* are included in chapter VI *Diseases of the nervous system*; 19% of the categories in chapter XVI *Certain conditions originating in the perinatal period* are included in chapter I *Certain infectious and parasitic diseases*; 16% of the categories in chapter X *Diseases of the respiratory system* are included in chapter XI *Diseases of the digestive system*. Further analysis of these exceptions shows that these categories fit into the other chapters, although there are no excludes remarks' priorities that can explain the inclusions. Evidently, chapter division is a complex task that cannot be accomplished through a set of simple excludes remarks.

Not all categories are included in the multiple chapter division. One reason for this is that some categories and chapters are not mapped to SNOMED CT's concepts. Another reason is that SNOMED CT's structure does not include all categories in the division. However, the exclusion of categories in the multiple chapter division because of SNOMED CT's structure does not necessarily mean that its structure is incomplete.

7.3.3 Additional attributes

Additional attributes can be discussed from several perspectives. From a clinical point of view, attributes concerning Finding site, Associated morphology and Causative agent can be considered useful complements to the traditional classifications. The attribute type Finding site includes a number of clinically relevant attribute values such as Upper respiratory tract structure, Head and neck structure and Joint structure, which can be considered of great interest in health planning and epidemiology. Furthermore, the attribute type Associated morphology includes a long list of clinically relevant attribute values for data aggregation. Further, the attribute type Causative agent includes attribute values such as Infectious agent (in general), Bacteria, and Tobacco that are common and important causes of health problems that, given our mapping, can be analyzed in a broad and more reliable way than before. Except for Finding site and Associated morphology, there are no attribute types that are frequently used for all categories in KSH97-P. However, other attribute types are useful for analysis of specific chapters in KSH97-P.

Regarding Finding site, two organ system chapters stand out as particularly ill-defined: chapter III *Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism* and chapter V *Mental and behavioural disorders*, with 23% and 21% of categories, respectively. Due to the diversity of chapter XVIII *Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified*, it is not surprising that its categories are inconsistently described throughout the mapping. Exploring the soundness of these attributes is, however, beyond the scope of this thesis. In addition, this chapter and chapter XXI were excluded from chapter mapping. Based on the lack of an overall pattern in added attributes, the initial remark regarding the difficulty of chapter mapping - i.e. chapter rubrics referring to heterogeneous collections rather than clinical concepts - proved reasonable.

7.4 MAPPING

In the chapter/category mapping to SNOMED CT, most categories are included in their own original chapter in ICD-10, which reflects the structure of KSH97-P and SNOMED CT and the intention of the mappings. Besides relying on descriptions rather than definitions, mapping imposes an extra layer of uncertainty and source of error. Findings, for example, that some categories did not make their way to their original chapters and that not all categories received additional attributes as expected could be explained by: KSH97-P (source) issues such as counter-intuitive and overly pragmatic chapter inclusion, mapping problems (which are bound to occur when diverse contexts meet) and SNOMED CT (target) problems such as incomplete or even faulty relationships. There were several obstacles to achieving the high quality "baseline" mapping used in study II. Similarity or relatedness between concepts in SNOMED CT was found in our results to be one reason for different chosen concepts. Relatedness refers to human judgments regarding the relatedness of pairs of concepts (113).There were also several obstacles in ICD-10/KSH97-P to attaining high quality mapping. In the baseline mappings, 8% of the categories were mapped to more than one concept in SNOMED CT to obtain a high degree of content coverage. The use of compositional concepts (post-coordination) with SNOMED CT can provide a significant improvement in the content coverage (114). With the procedure coding, post-coordination could possibly be used to specify the reasons for examinations, the body-parts examined, and the drugs prescribed, if such information is wanted. Our experience of coding with post-coordination and reuse of post-coordinated concepts in SNOMED CT is that certain post-coordinations are complicated and require supportive tools or advanced knowledge of the post-coordination rules, domain expertise and an intimate understanding of the SNOMED CT terminology structure as described by Richesson (99). In addition, attention must be paid to the limitations of post-coordination described by Rosenbloom (79).

7.5 STRENGTHS

Our results show that it is possible to use SNOMED CT to generate new statistical information from PC data using diagnostic data coded by GPs according to KSH97-P/ICD-10. To our knowledge, there are no previous studies on statistics using ICD-10 diagnostic data and SNOMED CT. The data used in study III consist of a complete sample of diagnostic codes from all of Stockholm County collected during a one-year period. During this period, the vast majority of the encounters were coded (78%). The coding of the diagnostic data was done by the GPs at the time of the office encounters, and was judged to be unrelated to any reimbursement system, which is known to have an impact on diagnostic coding. Our studies are several of only a few investigations that have succeeded in creating an enriched second generation TS in three different ways: by mapping, multi-chapter division, and added attribute. In the procedure coding study, we used a random sample from a large database of patient records, gathered from everyday clinical practice in PC. The coding was done in a stepwise process by two coders, with the support of an expert group.

7.6 LIMITATIONS

The results in studies II and III are dependent on the quality of the mappings from KSH97-P to SNOMED CT and the quality of the modeling of the relationships in SNOMED CT. However, actions have been taken to use mappings of good quality. Another limitation is that the statistical chapter mapping's scoring formula was designed during this study and is not well established in this research area. The loss of diagnoses from the collected data in the mapping process influenced the results in study III in different ways. The impact of possible quality errors in the diagnostic coding process that have been shown in previous studies is unknown for the coded diagnoses (7, 14-17). Far from all concepts have attributes in SNOMED CT. Also, the SNOMED CT structure has not been checked by the authors, but has been accepted as is for the purpose of this studies. The number of record entries (200) in study IV was limited, but they were randomly selected from 11 000 000 record entries in the database and therefore constituted a representative sample.

7.7 IMPLICATIONS FOR HEALTH CARE

The results have several implications for PC. Hidden information about health problems and diagnoses, coded with categories in KSH97-P that is explored in this thesis consists of multiple views that are useful to clinicians for a range of purposes. PC in Sweden accounts for 17% of the net costs of health care, but diagnoses are not collected nationally and there is little knowledge about the procedures performed by different professions in PC. Aggregation and interpretation of epidemiological statistics could benefit from the use of SNOMED CT when diagnostic categories from patient records in PC are analyzed, as well as in follow-up of clinical data and quality assurance. Clinically relevant consistent views of a TS system can also be used, for example, to search for categories to use during coding of the diagnoses in EPRs. Multiple chapter division could support navigation in clinical information retrieval systems and decision support systems. Attribute values such as Traumatic abnormality and Inflammation should be of interest for health planning as well as quality improvement. Collection (and secondary use) of procedures as coded data could be used as information for other caregivers or professions about planned procedures, as a basis for reimbursement, or for studying certain areas of interest to evaluate procedures related to health problems.

It may not be necessary to change the coding system from KSH97-P/ICD-10 to SNOMED CT for the end user. The mappings permit several generations of TS to be used together. Our results show that it is possible to keep the mono-hierarchical medical TS KSH97-P as it is and use it as an aggregation terminology, but at the same time enriching it with a more complete model of health problems. This can be an integrated way for medical TSs with different purposes and characteristics to co-exist, which Straub et al. favor (40). However, our results also show that since mono-hierarchical medical TSs give a limited view of the real world, a better solution in the long run is to use TSs with richer structures, but with integrated aggregation structures for statistical calculations. A subset of SNOMED CT in clinical use would therefore probably be needed to reach the full potential of the system. Our results imply that SNOMED CT can be used for procedure coding in PC for the same, as well as for additional purposes, as KVÅ. However, when deciding to use a TS, the aim or aims of doing so should determine which TS to choose. In my opinion, the frequent usage of information systems in health care in Sweden could strongly benefit from the use of second generations of TSs developed for use in these environments.

The use of SNOMED CT in an information system such as EPRs involves a number of prerequisites such as standards and methods for terminology binding. Schulz suggests that for scheduled or cancelled procedures, the consistent use of an information model (e.g. HL7 or openEHR) is preferable to the use of logic-based formalism in a clinical terminology (71), and Richesson discusses solutions for diseases and time concepts in SNOMED CT (99). The challenge of coding with SNOMED CT or a terminology based on SNOMED CT reveals the need for shortlists of concepts and coding support tools. Methods and analytic tools for SNOMED CT data are needed to facilitate the reuse of data.

Because of the similarities in structure between KSH97-P and ICD-10, it is likely that extending the chapter division to a multiple chapter division using mappings to SNOMED CT is applicable to ICD-10 and other similarly structured medical TSs.

8 CONCLUSION

Mapping from ICD-10-categories to SNOMED CT needs clear and extensive rules. It is possible to reach high intercoder reliability in mapping from ICD-10-categories to SNOMED CT. However, several obstacles to high quality mapping remain due to structure and content characteristics in both TSs. A mapping from ICD-10 categories to SNOMED CT concepts would benefit from post-coordination.

It is possible to use mappings from KSH97-P to SNOMED CT and SNOMED CT's structure to enrich KSH97-P's mono-hierarchical structure. The enrichment makes it possible to group KSH97-P categories in different ways than KSH97-P's original chapter division. It is possible to use SNOMED CT to enrich KSH97-P in such a way that it fulfills Cimino's characteristics of content, poly-hierarchy, formal definitions, multiple granularity and multiple consistent views.

The chapter level comparison between diagnoses and health problems in KSH97-P/ICD-10 and SNOMED CT using PC diagnostic data showed minor differences except regarding infectious and digestive system disorders where there were marked differences. Aggregations of diagnoses and health problems generated from SNOMED CT *Is a* and attribute relationships enabled exploration of complementary and interesting clinical views of importance. SNOMED CT is useful, gives a different view on a chapter level and adds new views of significance regarding the clinical data that can be of use in describing and developing PC.

Procedures documented by GPs are present in nearly all EPR entries, and the spectrum of procedures documented by GPs in PC is wide. SNOMED CT covered almost all of the procedures' content. KVÅ covered the procedures to a lesser extent and with a much lower degree of concordance. SNOMED CT is a more flexible TS that can be used for different purposes for procedure coding in PC.

9 FUTURE RESEARCH

Numerous possibilities are open for further analysis of PC data in terms of detail, different parts or problem areas, sex, age, geographical location, health care consumption, etc. A spectrum of medical informatics research has emerged with the help of SNOMED CT – collecting, retrieving, analyzing and storing data – and there is a need for research in all of these areas, especially regarding methods and tools for the reuse of the rich semantics of SNOMED CT coded data. Health care information documented by different health care professionals in PC needs to be explored in relation to SNOMED CT, as it is important that TSs can be used in everyday multiprofessional environments.

An interesting extension would be to analyze the complete ICD-10 and not only a PC version. The results of a study analyzing ICD-10 using the methods in this thesis could be useful input in the work of revising ICD-10 to ICD-11. It would also be interesting to analyze other medical terminology systems using the same methods as in this study.

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11 SUMMARY IN SWEDISH

Bakgrund och övergripande syfte

”Semantisk interoperabilitet” behandlar frågor om hur man bäst kan underlätta kodning, överföring och utbyte av information i hälsotjänster mellan patienter, medborgare och myndigheter, forskning och utbildning. Förenklat kan man säja att det handlar om att utbyta information mellan människor och maskiner på ett säkert och begripligt sätt. I de elektroniska patientjournalsystem som används i hälso- och sjukvården finns viktig vårdinformation som kan återanvändas för olika syften, t ex forskning och statistisk analys, kommunikation mellan olika informationssystem i hälso- och sjukvården, för beslutsstöd och i ekonomiska ersättningssystem. I primärvårdens journalsystem finns också information om diagnoser och åtgärder, men sådan information samlas inte in på nationell nivå till patientregister, till skillnad från diagnoser och åtgärder från sjukhusvårdens och annan öppen specialistvård. För att få semantisk interoperabilitet krävs bland annat en konsekvent användning av moderna terminologisystem. Dessa används för att koda (märka upp) och bearbeta data, t ex diagnoser. Terminologisystemens inneboende struktur (t ex detaljeringsnivån och hierarkierna) och innehåll ser olika ut och det har betydelse för hur data kan kodas och återanvändas eller bearbetas för olika syften. Tre generationer av terminologisystem med vissa egenskaper beskrivs. Klassifikationer som tillhör den första generationen av terminologisystem används idag i Sverige, t ex ICD-10 för hälsoproblem och diagnoser och en svensk version för primärvården, KSH97-P. En svensk åtgärdsklassifikation, KVÅ, används i Sverige och tillhör också den första generationens terminologisystem. SNOMED CT som tillhör senare generations terminologisystem skulle med sin storlek och detaljrikedom kunna täcka det stora varierande fält som information i primärvården utgör, i syfte att återanvända av data från primärvården. I vilken utsträckning KSH97-P och KVÅ används i svensk primärvård är inte så väl känt och SNOMED CT är nyligen introducerat i Sverige. Att länka ihop eller ”mappa” terminologisystem som används för olika syften kan vara ett sätt att uppnå ytterligare fördelar i att beskriva och dokumentera vårdinformation. Genom mappningen kan ett terminologisystem berikas med egenskaper från ett annat terminologisystem. Det övergripande syftet med denna avhandling är att utforska semantisk interoperabilitet inom primärvården med användandet av terminologisystem för att koda, mappa, berika och återanvända primärvårdens data om diagnoser, hälsoproblem och åtgärder.

Metod

KSH97-P/ICD-10 och SNOMED CT användes i en mappningsstudie och reliabilitet mellan kodarna mättes efter att nya mappningsregler tillämpats (studie I) och mappningen utvecklades ytterligare för att berika KSH97-P med egenskaper från SNOMED CT (studie II). Mappningsresultat och metoder för aggregering från studie II användes för att jämföra och beskriva diagnoser med KSH97-P och SNOMED CT med hjälp av diagnosdata som samlats in 2006 från primärvården i Stockholms län (III). I ett slumpmässigt urval av 200 avidentifierade journalanteckningar från Skaraborg identifierades åtgärdsbegrepp i anteckningarna och kodades till KVÅ och SNOMED CT och jämförelser beskrevs (studie IV).

Resultat

KSH97-Ps kategorier och ICD-10s kapitel mappades till SNOMED CT i studie I och II. Reliabilitet mellan kodarna som mappade uppnådde 83%. En ny och poly-hierarkisk kapiteluppdelning av KSH97-P: s kategorier skapades och nya egenskaper tillfördes KSH97-Ps kategorier med hjälp av SNOMED CT (II). Jämförelsen mellan diagnoser i KSH97-Poch ICD-10 respektive SNOMED CT på kapitelnivå uppvisade skillnader främst för infektionssjukdomar och sjukdomar i magtarmsystemet. Med SNOMED CT tillkom perspektiven ”Associerad morfologi” (t ex inflammation), ”kausativt agens” (t ex virus), och ”fyndplats” (t ex bröstkorg) på primärvårdens sjukdomar och hälsoproblem (III). 417 åtgärder fanns i journalanteckningarna, varav 206 kunde kodas med en komplett matchning till SNOMED CT jämfört med 10 åtgärder i KVÅ (studie IV).

Slutsats

Det är möjligt att använda mappningar från KSH97-P till SNOMED CT och SNOMED CT struktur för att berika KSH97-P: s mono-hierarkiska struktur och addera nya vyer av betydelse när det gäller kliniskt data som kan vara till nytta för att beskriva och utveckla primärvården. Det finns flera utmaningar i att använda SNOMED CT kliniskt i framtiden och det behövs stödjande verktyg.

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13 ERRATA

Study I
Correct year in reference 11:

"Lussier YA, Li J: Terminological Mapping for High Throughput Comparative Biology of Phenotypes. Pacific Symposium on Biocomputing **2004**, 9:202-13."

Study III

Page 19:

"…67 (7%) were mapped to more than on concept"

Correct:
"..71 (8%) were mapped to more than on concept"

Correct reference nr 2:
Njalsson T. On Content of Practice. The advantage of computerized information systems in family practice. Scand J Prim Health Care 1995; 13 suppl. 1-102