Management and Administration of SNOMED CT as a part of an Interdisciplinary Terminology for Health and Social Care

Socialstyrelsen

Foreword

This report details the National Board of Health and Welfare's proposal for administration of SNOMED CT as a part of the interdisciplinary terminology for health and social care. The report emphasizes the importance of further administration, development, responsibility and commission to fulfil the objectives of the National Strategy for eHealth. The report also discusses issues related to broadened administration, expertise and training needs which the National Board of Health and Welfare believes the Government should consider.

The commission An Interdisciplinary Terminology for Health and Social Care has been reported back to the Government via a final report and three factual reports, this being one of the latter. A list of terms used can be found at the end of the report.

The National Board of Health and Welfare's proposals for administration cover planning and decision-making organization, management of expertise-related issues, licensing, administration model and releases.

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Content

Introduction

The goal of the National Board of Health and Welfare is to create and provide a national regulatory framework that contributes to knowledge-based health information systems, good health and good health and social care services. The field of terminology and informatics is one of the National Board of Health and Welfare's working areas.

Background

The National Strategy for eHealth, which was decided in 2006 [1], and revised in 2010, formulates a vision for IT development in health and social care services. The strategy aims for effective information provision in health and social care services. This means both that the right person has access to relevant information in the right situation in the care process, and that it is possible to find, understand and compile information for follow-up at local and national levels.

Six action areas were originally identified as being important for the national efforts:

- Bringing laws and regulations into line with extended use of ICT
- Creating a common information structure
- Creating a common technical infrastructure
- Facilitating interoperable, supportive ICT systems.
- Facilitating access to information across organizational boundaries
- Making information and services easily accessible to citizens.

The Interdisciplinary terminology for health and social care is part of the action area of information structure.

Commission

In May 2007, the Government decreed that [2]:

"The National Board of Health and Welfare shall take overall national and strategic responsibility for ensuring that individual patient and user-specific information shall become less ambiguous, easier to follow-up and more accessible in accordance with the objectives and principles laid down in the Government's written communication entitled National IT Strategy for Health and Social Care. The initiatives include the development of a national information structure and the establishing, provision and administration of a national terminology and classification resource."

The Government had previously that spring determined that Sweden should be a member of the international association IHTSDO[1] for the administration and development of the international clinical terminology SNOMED CT[2]. This terminology is a part of the interdisciplinary terminology for health and social care. The commission has been carried out under the project name An Interdisciplinary Terminology for Health and Social Care. The results of the project are known as the interdisciplinary terminology for health and social care.

The decision on SNOMED CT

In connection with the commission to translate SNOMED CT, the National Board of Health and Welfare was given the responsibility for Sweden's operational cooperation and participation in IHTSDO. This means that the National Board of Health and Welfare is the Swedish national release centre for both the international and the Swedish version of SNOMED CT.

Since 2007, the National Board of Health and Welfare participates in IHTSDO's internal work and in quality assurance and development activities around SNOMED CT. Participation in IHTSDO is generally assessed to be of importance for the National Board of Health and Welfare's future work and development in Sweden in the future.

The administrative organization's objectives, goals and restrictions

The overall aim of the administration is to provide uniform and unambiguous concepts and terms for health and social care services documentation, monitoring, research and knowledge development, and to promote a coherent interdisciplinary terminology for health and social care services on a national level.

The goal of the administration is for the National Board of Health and Welfare to regularly provide controlled and updated releases of SNOMED CT which facilitate its use in health and social care services.

SNOMED CT can be used in different ways within the field of health and social care, as evidenced by the final report of the Interdisciplinary terminology [3]. The National Board of Health and Welfare's administrative obligations are restricted to providing SNOMED CT in a standardized format. The National Board of Health and Welfare is not responsible for the adaptation of the standardized format for different user needs and systems.

Administration groups

The administrative organization's primary target groups are the terminology and informatics managers in county councils and municipalities, IT suppliers, health and social care service professionals with special interest in or responsibility for documentation issues, professional organizations, actors

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[1] IHTSDO International Health Terminology Standards Development Organization
[2] Systematized Nomenclature of Medicine – Clinical Terms

in the National Strategy for eHealth, researchers, private health care providers, decision makers in municipalities and county councils, IT directors, the National Board of Health and Welfare, and other agencies active in the health and social care sector.

The concept of administration of SNOMED CT

The realization of the ambitions and objectives expressed in the National Strategy for eHealth poses a long-term commitment for the administration of national sources and knowledge resources, as well as continued investments to support development, introduction and use of e.g., EHR systems, individualized communication between information systems and decision support systems.

An administration organization for the interdisciplinary terminology requires a clear assignment and commission, the necessary resources in terms of expertise and funding, and proper coordination between the National Board of Health and Welfare and local and regional users of SNOMED CT. A further assignment is required; one which aims to support and coordinate development work on the applications that are regulated on a national level and which includes the interdisciplinary terminology.

The administration of SNOMED CT includes responsibility for ensuring that:

- there is proper handling of licenses and contracts
- the Swedish version of SNOMED CT (SNOMED CT SE) is updated, translated and available
- the Swedish version of SNOMED CT is expanded when necessary,
- the reference sets from SNOMED CT created by the National Board of Health and Welfare for national use are available and quality assured
- other reference sets from SNOMED CT created for national use are available
- mapping results created for national use are available
- methodologies and training materials are available
- qualified knowledge of methods is maintained
- the administrative organization is operational and quality assured
- technical and content-related user support is provided
- information initiatives are undertaken to impart knowledge on the use and administration of SNOMED CT.

Administrative cooperation on a national level

The administration report focuses on SNOMED CT, as procedures already exist for administration of the terminology database and the nationally used health-related classifications. Special development work will, however, be required in this area.

The terminology database needs to be developed in order to be integrated with the publication of other sources such as quality indicators and modelling concepts from the national information structure. The terminology database must also be developed technically in order to be linked with the service for the provision of the interdisciplinary terminology. A requirement specification was developed in 2011.

The National Board of Health and Welfare must also develop more effective tools for management of the nationally used health-related classifications, which, for example, shall be used by organizations to report to health data registers. Administration and distribution of the classifications should be carried out in accordance with the same principles that apply to SNOMED CT, with compatible technical solutions for tools and uniform distribution formats. It is also important that continuous communication and contact with users who are responsible for the introduction of classifications in IT systems can be implemented in a controlled manner, as with SNOMED CT, in order to ensure proper usage. The administration model for classifications is not described in detail here; it is dealt with separately.

For related matters such as statistical coding systems (variables, indicators, etc.) and framework, which are directly or indirectly related to the interdisciplinary terminology, it is necessary to guarantee coordination processes on a national level. There is currently no clear ownership for many of the small coding systems which are used both nationally and locally. Even matters relating to the national application of various information standards in health and social care services could ultimately be included in these preparatory processes on a national level. It is still unclear as to whether and how the National Board of Health and Welfare can be responsible for such national processes, and if so, in what form. The question needs to be investigated and further clarified.

International administrative cooperation

Denmark's decision to translate SNOMED CT came two years ahead of Sweden. For the translation work, the National Board of Health and Welfare has made use of the experience, methods and IT tools developed by Denmark's National Board of Health. The experience gained by the Danish organization provided support when the Swedish project organization was established in 2007.

In the process of developing an administration model for SNOMED CT, the expertise and knowledge from other countries has played an important role as it has provided the opportunity to study active administration on location. The National Board of Health and Welfare has also taken stock of the documentation, tools and recommendations from the IHTSDO countries which are already administrating SNOMED CT. Examples of organizations which the National Board of Health and Welfare has regular contact with are NHS Connecting for Health in the UK, Canada Health Infoway, and Australia's National E-Health Transition Authority (NEHTA).

Several countries have employed initiatives similar to those run under the Swedish strategy for eHealth. Despite differences in commission and organization or other elements, these initiatives have a common

denominator, namely the ambition to realize coherent governance and administration of information management. This largely corresponds to the objectives of the strategy for eHealth. When the opportunity arises, the National Board of Health and Welfare also cooperates with other countries and organizations to promote common procedures on an international level.

The demand for national coordination on regulatory framework and standards in the information sector is also linked to equivalent international developments. Not least in the EU, measures are being pushed that will lead to secure information exchange, both internationally and nationally.

In order for the national initiative and expertise building in the Swedish strategy for eHealth to be effective, it is necessary that the national commitment is long-term and stable, and that international cooperation is built up in this area.

Risks surrounding the administration

The National Board of Health and Welfare has made a risk assessment in face of the establishment of the administrative organization; shown below.

The administration requires the existence of specific knowledge and expertise in the field of informatics, both at the National Board of Health and Welfare and on a local level. There is a risk that the National Board of Health and Welfare will be unable to recruit enough individuals with qualified expertise to run operations in the short term as the sphere of activity is relatively new in Sweden. Skills development and training should therefore be a prioritized area.

Another prerequisite is that the administrative organization for SNOMED CT has access to the necessary IT support on all levels; international, national and local. An example of this is tools for the creation and management of reference sets from SNOMED CT. There is a risk that the development of the necessary tools will be delayed or lack sufficient funding. This would then mean that the development of the Swedish products would be hampered or that transitional solutions must be financed and run in parallel.

In order for the strategy for national eHealth to reach its goals, the common information structure must be implemented and used. This calls for national cooperation and governance. The National Board of Health and Welfare has identified two areas in which national cooperation and governance is particularly important, one of which is administrative responsibilities and administrative coordination. If the responsibility and coordination are not clear, there is a risk that this will create difficulties for users, which hampers both introduction and usage. The National Board of Health and Welfare believes there is a need for clarification of the overall liability issues surrounding the continued development and administration of the various components of the common information structure.

The second risk area is the non-usage of nationally developed methods, processes and products, e.g., when translating SNOMED CT or mapping, which are relevant for national and international usage. If the national actors do not follow proven methods, there is a risk that quality is compromised, which would undermine confidence in the investment in national eHealth.

Dissemination of information and knowledge of the methods should therefore be a prioritized work area.

It is a strategic choice to develop and administrate SNOMED CT together with other countries as there is mutual interest in exchanging information, building knowledge and sharing development costs and expertise. The restrictions in terms of available expertise are common to most countries involved in the development of the area, making cooperation even more important. At the same time, this creates a dependency which affects both the National Board of Health and Welfare's development and administration on a national level. International development must be continuously monitored, and active participation in contexts which affect national efforts must be prioritized.

The field of administration

The field of administration is divided into administrative objectives and regulatory framework. The administrative objectives are the products that will be made available to users. The regulatory framework governs usage and availability.

Representatives for the interdisciplinary terminology's target groups have identified an effective administration structure as the most important factor in principals and suppliers taking on the work of introducing SNOMED CT within health and social care services documentation. Efforts to establish an administrative organization are therefore a priority.

Administrative objects

The Swedish version of SNOMED CT

The National Board of Health and Welfare is responsible for the Swedish version of SNOMED CT. The fundamental translation work was carried out during the period 2007–2010. There are a total of around 280,000 SNOMED CT concepts in Swedish, and it is these which will be administrated and made available.

Administration of the Swedish version includes:

- translation of newly added concepts from English which then supplement the Swedish version
- checking the contents of the various releases so that changes are traceable over time
- identification of Swedish concepts not found in SNOMED CT, as well as modelling of these and translation into English. Where required, these can be introduced in the international version of SNOMED CT.

Many new concepts which need to be added are specific to Swedish health and social care services and shall therefore be represented solely in the Swedish extension of SNOMED CT.

The National Board of Health and Welfare has developed a method for translation which includes linguistic guidelines. The method also includes editing of previously translated concepts and terms [4].

Methods

Among the methods to be used in the administration of the interdisciplinary terminology, there are a number of methods which have been previously cleared for use by the National Board of Health and Welfare. Others are developed during the project period. Two methods have been tried and tested over a number of years in terminology work:

- terminology science

- method for terminology work.

Three methods have been completed and tested:
- method for translation of SNOMED CT
- method for mapping within health and social care services
- method for management of synonyms in the Swedish version of SNOMED CT.

Three additional methods have been defined and will be tested when the interdisciplinary terminology is in use:
- method for identification and analysis of information content
- method for modelling in SNOMED CT
- method for managing SNOMED CT reference sets.

The methods are detailed in the factual report Methods for the Interdisciplinary Terminology for Health and Social Care[5].

Reference sets

The term 'reference set' refers to a set of identified concepts which are a subset of SNOMED CT's total content. The reference set can be large or small and a single concept or term can be included in several different reference sets which have different purposes. A reference set in this context signifies a set of identified concepts which is suitable for use in a particular speciality, organization or area of application and which is distributed in accordance with IHTSDO's data format standards[3] [6]. The fact that a concept in SNOMED CT belongs to a particular reference set provides information about the context in which the concept can be used.

The reference sets are created using a special method [7] provided by the National Board of Health and Welfare and are presented in a standardized format. The method describes how reference sets can be used to group concepts to be presented in the user interface in EHR systems, templates, search lists, program menus, etc.

Each reference set requires ownership from a responsible party and administrator, responsible for ensuring that the content is accurate and up-to-date. The owner creates the reference set in collaboration with the relevant parties/stakeholders in order to achieve the highest possible quality and coverage and will then assume responsibility for it. If content is missing in the reference set, the owner of the reference set is to be contacted for updates.

The National Board of Health and Welfare has chosen to focus on reference sets on two levels: those created to be used nationally; *national reference sets,* and those created and used locally or for a specific area of application, for example, by IT suppliers; *local reference sets.*

The *national reference sets* are designed to be useful for a larger target group and in several different contexts and are thus governed by the contract signed by the National Board of Health and Welfare and the owner of the reference set. The primary criterion for national reference sets is that they

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[3] Within IHTSDO these are also known as RefSets

are to be used in national resources within health and social care services, such as IT support, guidance and national registries, e.g., national guidelines and health data registers. It can also be developed for use in the documentation within a specific clinical speciality, and has therefore been established on a national level.

Reference set owners may be different organizational groups who see a need for a reference set on a national level, e.g., specialist associations, professional organizations, regions, Government agencies or specific projects. The National Board of Health and Welfare can also be a reference set owner and therefore assume responsibility for the quality of these reference sets. The reference sets should be made in collaboration with relevant parties in order to achieve the highest possible quality. The reference sets will then, along with a description of the content, be reported back to the National Board of Health and Welfare which in accordance with the contract with the reference set owner provides them as part of SNOMED CT SE.

The national reference sets shall be named in accordance with the National Board of Health and Welfare's standards for naming, so that the name clearly describes the area of application of each reference set and for which activity or purpose it has been developed. One example of naming in accordance with the standard is a reference set for the National Board of Health and Welfare's national guidelines for stroke:

SCTSE2011:1_ID0001_SOSNR_Stroke.

The name includes the version and release of SNOMED CT which the reference set is based on, the owner's ID number and activity and the area of application of the reference set. A description of the content of each national reference set will be made available on the National Board of Health and Welfare's website.

The local reference sets are created and used according to local needs, e.g., concepts and terms used for a specific documentation system. These reference sets need not be reported back to the National Board of Health and Welfare. It is the user and the administrator of the reference set who are responsible for how it should be used, as a whole or in part. The reference sets do not necessarily exclude each other; the content of different reference sets can overlap in that the same concepts may be included in several samples. Reference sets created for national use can be used to create local reference sets. Local reference sets should, however, not be used if national reference sets for the same activity and purpose exist.

More information on the principles for and ownership and control of the reference sets will appear in the National Board of Health and Welfare's reference set policy which is published in connection with the planned Swedish release of SNOMED CT in autumn 2011.

Mapping results

'Mapping' refers to the comparison of concepts from two different systems to establish whether or not one system's concepts correspond to the concepts of the other. Mapping must be undertaken if concepts are to be identified by

SNOMED CT IDs. Mapping shall be carried out in accordance with the method defined in the method document, under Method for mapping in the health and social care sector [8]. The mapping results will be documented in a coherent manner so that they are available for testing and reuse.

The National Board of Health and Welfare will conduct fundamental mapping to sources which it is currently responsible for. Mapping of classifications and other coding systems with international publishers which are actively administrated by organizations such as the WHO should firstly be carried out through agreements between IHTSDO and these organizations, and secondly through national projects. The National Board of Health and Welfare is also responsible for ensuring availability of the mapping results. The National Board of Health and Welfare is not responsible for the mapping results produced by other organizations, unless the work was commissioned by the National Board of Health and Welfare and formulated according to the developed method. The National Board of Health and Welfare can, however, distribute these results provided that they have a standardized format and are considered to be of national interest.

As with the reference sets, the owner of the mapping results is responsible for ensuring that administration in the form of updates is performed, both continuously and where required.

Rules for access and use

User licenses

SNOMED CT is an international, copyrighted product that requires users to have a licence which is regulated by different types of agreement. There are different types of licenses, as shown in the diagram below. To gain access to the official national Swedish extension of SNOMED CT, Swedish and international licences are required, both of which are provided by the National Board of Health and Welfare following application[4]. The agreement on reference sets is regulated separately but is also governed by the license agreement. If there is also a need to develop a local Swedish extension of SNOMED CT, an additional license is required. This license can be applied for directly via IHTSDO[5]. A description of what is meant by the 'local extension' is available below.

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[4] http://www.socialstyrelsen.se/halsoinformatik/nationelltfacksprak/snomedct-licens
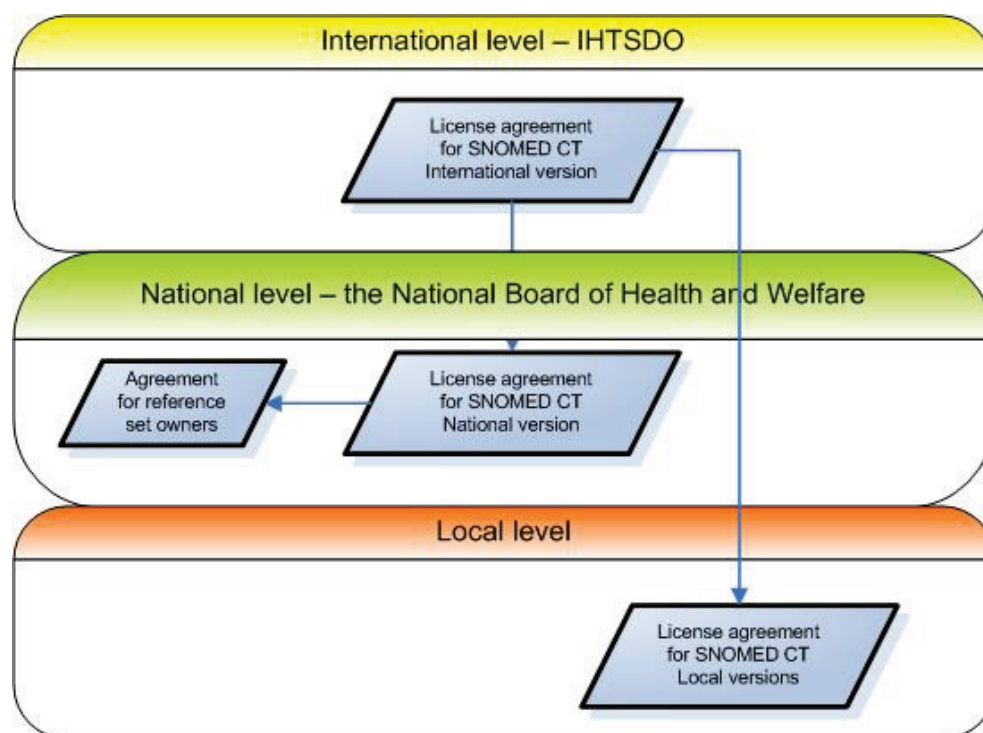[5] http://www.ihtsdo.org/snomed-ct/namespaces/

Figure 1 Types of agreements and contracting parties

License agreement

SNOMED CT is provided through Sweden's membership in IHTSDO at no cost to users in Sweden. For access to and use of SNOMED CT a license must first be obtained which is endorsed by the National Board of Health and Welfare, which is responsible for IHTSDO regarding any Swedish licenses. Licenses can be applied for by companies, individuals, universities, other Government agencies, representatives from the health and social care services, etc. The license includes eligibility for two new releases each year, for both the Swedish and international versions, and the ability to manipulate the content.

In a broad outline, the license includes the following commitments:

- The licensee is required to use a current release of SNOMED CT.
- If SNOMED CT is used in a country that is not a member of IHTSDO, the licensee incurs a fee. The sum depends on the country in which this usage occurs. This fee is controlled via feedback that every licensee is required to perform.

The license agreement is legally binding and the licensee agrees to comply with the rules established by IHTSDO for the use of SNOMED CT. The agreement also includes additional national stipulations which govern national application of SNOMED CT SE. One condition is that the licensee performs active feedback twice a year, to report if SNOMED CT has been used outside Sweden or in another IHTSDO-member country (see above). In the future there will be an additional agreement between the National Board of Health and Welfare and the reference set owners (more information in the section on reference sets).

During the project period, it was possible for organizations, IT companies and individuals to gain access to SNOMED CT under a special license agreement, albeit with restricted functionality. The agreement in this form has been extended until 31 December 2011 and shall in the second half of 2011 be supplemented by a new license agreement. The release scheduled for October 2011 will be provided in the standardized IHTSDO format (see appendix 1) facilitating its usage in EHR systems. Other usage will be governed by the new agreement.

National and local versions of SNOMED CT

To promote the development of SNOMED CT, all licensees, in accordance with IHTSDO's regulations, [9] will have the ability to manipulate and develop SNOMED CT. Anyone who has a license is also permitted to create their own local version ('extension') of SNOMED CT. In order to create a local extension, a 'namespace identifier'[6] is required in addition to a SNOMED CT license, which the licensee may apply for via IHTSDO. An assigned 'namespace identifier' implies that a local extension of SNOMED CT has been created and is used to identify the creator of a new concept. The possibility for this development of SNOMED CT is governed by IHTSDO's regulations and the rules of the member state where the user is active.

The license agreement for the Swedish version of SNOMED CT (see above) governs the use of these local extensions. The licensee agrees under the agreement to update their systems and their local extension to a current national SNOMED CT release distributed by the National Board of Health and Welfare. SNOMED CT SE has the namespace identifier 1000052. This ID number is also linked to the OID number (see below) for SNOMED CT SE.

The concepts, terms, synonyms and definitions missing from SNOMED CT SE and which are needed in local operations are handled in accordance with IHTSDO's principles. The content changes which are modelled in local extensions and which are considered to be of national importance are to be reported to the National Board of Health and Welfare, which then decides whether or not to refer these to IHTSDO for inclusion in the international version. Principles for what should be considered of national importance will be developed by the National Board of Health and Welfare. The owner of a local extension can make additions and amendments using their own namespace identifier, but these may not then be directly transferred to SNOMED CT SE. The recommendation is that these amendments and additions are reported to the National Board of Health and Welfare as proposals before they are used. If the amendments and additions are urgent and are implemented before being processed by the National Board of Health and Welfare, this means extensive local maintenance work must be carried out once the concept has been reported to the national extension, as even local extensions must be updated to the current release of SNOMED CT SE. When the amendments or additions are transferred to SNOMED CT

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[6] http://www.ihtsdo.org/snomed-ct/namespaces/

SE, a revision must be conducted, and the local amendments or additions made inactive. This procedure will prevent the arising of a situation in which there are several active duplicates with different identifiers. When a concept is approved for SNOMED CT SE, the local identifier will change to a national identifier. More information about the reporting of new concepts in SNOMED CT is found in the section on reporting and handling of proposed amendments.

OID numbers

The Object Identifier (OID) is intended as a standard for identification of objects. The standard has characteristics that make it possible to identify who is responsible for and administrates, for example, a coding system or terminology used in information systems. More information is available on the National Board of Health and Welfare's website.

The National Board of Health and Welfare has decided to assign an OID number to the Swedish version of SNOMED CT. The OID for SNOMED CT SE is 1.2.752.116.2.1.1, and it shows that the National Board of Health and Welfare owns and manages the object. This number will not change.

The release number of SNOMED CT SE shows how up-to-date the release used is. At present, the fundamental principle is that a current release of SNOMED CT should be used.

Methods for managing the use of the interdisciplinary terminology

The transfer of information between electronic systems requires uniform terminology and structured information to ensure information security, which is of significance for the safety of individuals within the care process. The positive effects of the use of an interdisciplinary terminology are, among other things, increased information quality and new opportunities for training and development. The EU Directive on cross-border health care together with the Swedish national efforts for improved utilization of information technology within health and social care, require cross-border consistency and an unambiguous management of concepts and terms.

The National Board of Health and Welfare makes the preliminary assessment that the Board has the necessary authorization to standardize the use of concepts and terms, as well as classifications within the health and social care services. This will be further investigated in the review of the National Board of Health and Welfare's regulations on information management and record keeping in health care (SOSFS 2008:14) starting in 2011. In the current situation the regulations are deemed to be the method that can best ensure widespread implementation.

Planning and decision-making organization

Today, the National Board of Health and Welfare is responsible for the process for the preparation and establishing of terminology-related tasks for the terminology database, as well as maintenance and provision of certain national health-related statistical classifications. The corresponding preparation and decision-making processes which are clear and transparent must be established for the interdisciplinary terminology as a whole. It is also important that there are forms of coordination with the administration of the national information structure and with the actors for the application of the common information structure.

The proposal for the processing and decision-making organization for the interdisciplinary terminology includes links to all parts of the interdisciplinary terminology and the separate preparation processes. The proposal aims to clarify how the processes shall be coordinated in the administration of the interdisciplinary terminology.

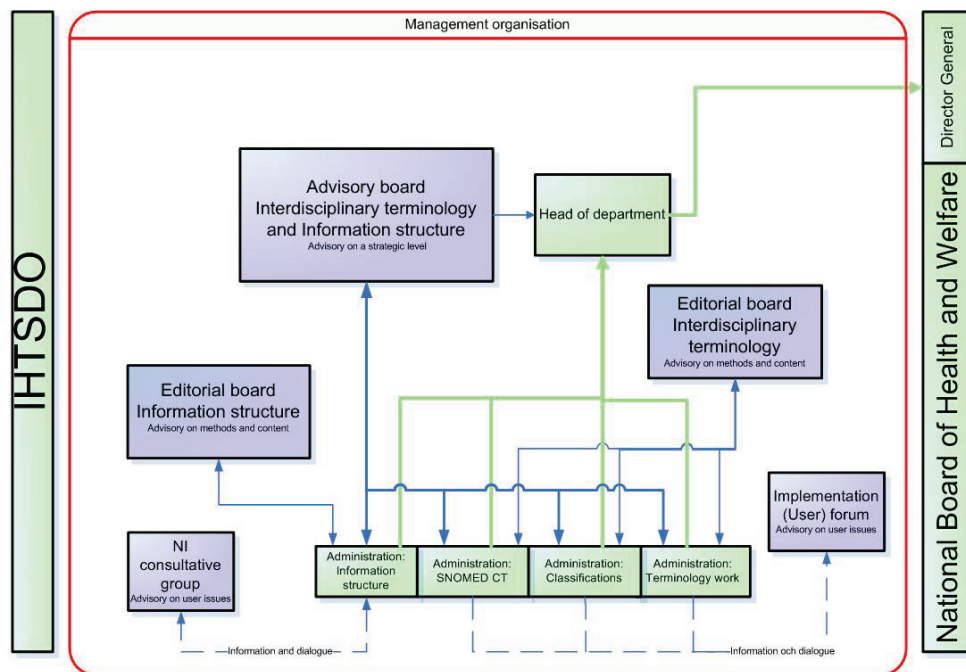*Diagram 2. Proposal for the processing and decision-making organization for the interdisciplinary terminology*

Diagram 2 depicts how the proposed preparation and decision-making organization is composed. Three groups have been proposed: a council for the interdisciplinary terminology, an editorial board and a user forum. Decisions relating to the interdisciplinary terminology are proposed to be

made by the National Board of Health and Welfare's line organization, following preparation and, when required, broad external establishment.

The Council for the interdisciplinary terminology

The purpose of the Council for the interdisciplinary terminology is to deal with issues of a strategic nature. The Council includes individuals, who from their different perspectives and roles can contribute to stable administration and the development of the interdisciplinary terminology. The Chair of the Council is the Director of the department at the National Board of Health and Welfare, where the administration of the interdisciplinary terminology is organized. The secretary is the Head of the unit at the National Board of Health and Welfare, where the administration of the interdisciplinary terminology is organized.

Other participants are:

- Swedish official representatives of the IHTSDO cooperation
- Representatives of the National Board of Health and Welfare's departments and IT unit as well as the National Information structure
- Representative for CeHis
- Representative for SALAR
- Representative for the Medical Products Agency
- Representatives of private health care providers
- User forum Chair.

Editorial board

The role of the editorial board is to assist in quality control and problem resolution. The editorial board handles issues within the areas of terminology, classifications, coding systems and SNOMED CT. Questions that may be relevant to discuss in the editorial board are the methods for mapping, modelling, translation, synonym management, reference set management, classifications, coding systems and the terminology database. The editorial board has the opportunity to collaborate with internal and external experts in each area. These experts are appointed by their respective organizations at the request of the National Board of Health and Welfare. Which experts are called to the editorial board meetings, depends on the issue that is up for discussion. The Chair is the person at the National Board of Health and Welfare who is responsible for the administration of the interdisciplinary terminology.

User forum

The user forum has the task of providing, through dialogue and clear communication channels, users' views on the administration and the need for development of the interdisciplinary terminology. Representatives of all stakeholder groups are welcome to the user forum. Initially, the National Board of Health and Welfare intends to organize two meetings per year. The Chair is a representative who is also one of the participants in IHTSDO's

Affiliate Forum. The secretary is appointed by the group. Other participants include:

- patient organizations
- licence holders of SNOMED CT
- users of the interdisciplinary terminology
- IT suppliers
- health and social care service providers
- professional organizations
- universities and colleges
- other education providers
- The National Board of Health and Welfare
- etc.

Implementation of the administration
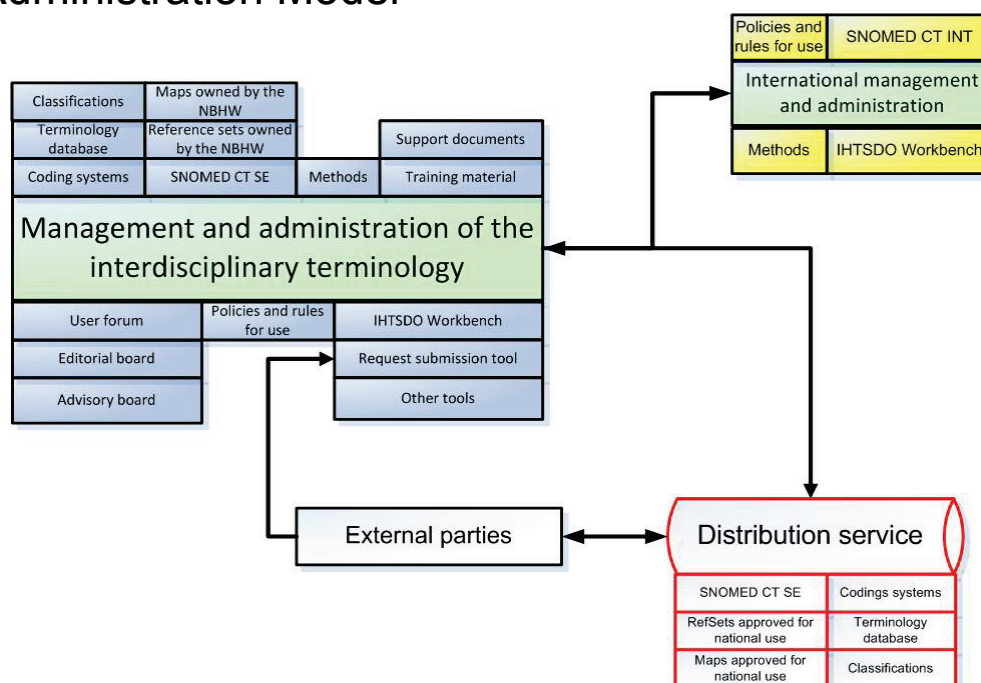
Administration Model

Diagram 3. Components of the National Board of Health and Welfare's administration and relationship to the international administration and the external interested parties

The above diagram describes the content of the administration which the National Board of Health and Welfare has proposed. The administration of the interdisciplinary terminology is initially focused on SNOMED CT as it involves a new commitment which places new demands on the organization. In the long-term, the entire interdisciplinary terminology will likely be jointly administrated with similar processes and provided through one and the same distribution service.

The core activity of the administration is to translate SNOMED CT and to ensure that the content of the Swedish version of SNOMED CT is quality assured and developed through various applications. The National Board of Health and Welfare has developed processes for dealing with users' need for additions in SNOMED CT. It is also through users' ability to report the errors and required additions identified in SNOMED CT that the quality of the content can be improved and developed. The National Board of Health and Welfare is responsible for making decisions on which amendments and additions are to be made in SNOMED CT.

To further ensure the quality of the content that is used for documentation, reference sets should be created and used. These reference

sets should include only those concepts and terms which are considered to be clear, accurate and of sufficiently high quality.

The National Board of Health and Welfare will initially provide SNOMED CT and all reference sets and mapping results approved for national use through a dedicated web service. In the long-term, even the Board's terminology database, classifications and coding systems and other materials such as training will be provided via this web service.

There are processes and rules for administration and development of the international version of SNOMED CT, including quality assurance methods. Sweden participates in the work to establish and clarify the processes, methods and framework which are to be used. All international management is performed at IHTSDO's office in Denmark.

Administration requires different skills and functions

When the National Board of Health and Welfare was commissioned to prepare the interdisciplinary terminology for health and social care, it was decided to base the project staffing on persons whose skills would also prove useful for future administration. The project work is therefore part of the skills development within the Board. The National Board of Health and Welfare has previously established knowledge of and routines for terminology and classification work, and now the knowledge of SNOMED CT and informatics has increased and deepened. There is a need within several areas for further development of expertise in order for the administration to be implemented with sufficiently high quality and to a reasonable extent.

The National Board of Health and Welfare believes that focus on the interdisciplinary terminology also implies an increased national responsibility in this new field of knowledge, a responsibility which the administrative organization must take on. This means that during a transitional period, more resources will be required to support and encourage e.g., principals, professional organizations and IT suppliers who wish to adopt and use the interdisciplinary terminology.

Internal skills development

Several roles within the administration require special expertise and involve a great responsibility for quality assurance and effective cooperation in the administration process. It is important that the organization ensures that there are clear job descriptions with sound skills development plans for all positions. There must also be resources for continuous training of existing and new staff to ensure the availability of relevant methodology, not only within the administrative organization but also in other parts of the National Board of Health and Welfare which participate in the Board's common internal processes.

Below is a description of functions and roles in the administrative organization. Resource requirements for staff and operations 2011–2014 are presented in the project's final report [3].

Administration responsibility

The administration responsibilities include coordinating the National Board of Health and Welfare's management of SNOMED CT, the quality assurance process and the development of support routines. There should also be a person designated to be in charge of the administration and a team that takes collective responsibility for planning, collaboration, work with and within IHTSDO, managing licences and agreements, communication, contacts with local administrative organizations and inquiries. The group is also responsible for developing policy documentation and procedures for coordination with other parts of the National Board of Health and Welfare and with other agencies and organizations whenever quality assurance of the interdisciplinary terminology is required. Responsibility for the coordination and implementation of internal and external training may also at a later stage be placed with the group.

Translation of SNOMED CT

The administration task includes performing translations between English and Swedish, to prepare matters for the editorial board and to interact within the National Board of Health and Welfare and with the professional organizations. The area of responsibility includes the translation, linguistic guidelines, editorial board decisions and documentation of medical terminology in writing.

Mapping of terminologies and classifications to SNOMED CT

The administration task includes the provision of methods and routines for mapping that ensure the quality of the interdisciplinary terminology and providing knowledge support for the mapping process at both regional and local levels. The National Board of Health and Welfare is responsible for providing the approved mapping results. The collaboration takes place with specialists from various fields and operational areas of health and social care services. The area of responsibility is the method for mapping and the published mapping results.

Modelling concepts in SNOMED CT

The administration task includes modelling the Swedish concepts in SNOMED CT SE as well as participation in and contribution to the modelling work for the international version. The collaboration takes place with experts from specialist areas and operational areas within health and social care services. The area of responsibility is the method for modelling and documentation of the methodology and modelling results which are added to SNOMED CT SE and SNOMED CT INT.

Reference sets

The administration task includes working with experts within a speciality or an operational area to create defined reference sets from SNOMED CT for use within a speciality or a field of activity. The collaboration takes place with specialists and experts within specialist areas and subject and operational areas within health and social care services. The area of responsibility is the method for managing reference sets and documentation of reference sets.

Terminology binding

The administration task includes applying and further developing the methodology for terminology binding, i.e., the linking of concepts to the information models. Collaboration takes place within the National Board of Health and Welfare, with persons responsible for the information models at CeHis and international experts. Responsibilities are methods and decisions of principle for terminology binding.

Content administration and support for the Swedish version of SNOMED CT

The administration task includes receiving and handling incoming requests for the content of the Swedish version of SNOMED CT (SNOMED CT SE) and other distributed products such as reference sets, mapping tables, technical documentation and user manuals and information about the supply process related to each release.

   It also includes responsibility for handling the process of updating content in Sweden, as well as towards the IHTSDO for the international version of SNOMED CT. The collaboration takes place with users and licensees in Sweden. The area of responsibility is the release updates of SNOMED CT SE.

Support for tools and distribution services

The administrative work involves ongoing technical support for the National Board of Health and Welfare's tools and distribution services. Collaboration takes place with the IT department of the National Board of Health and Welfare. The area of responsibility is the continuous running of the National Board of Health and Welfare's tools and distribution services for SNOMED CT and other products.

Development of tools and distribution services

The administrative work includes responsibility for technical maintenance and further development of the National Board of Health and Welfare's tools and distribution services based on the organization's requirements. This includes the use of IHTSDO Workbench or other tools, technical specifications for user interfaces and functions and adaptation of the distribution service for the needs of the National Board of Health and

Welfare. Collaboration takes place primarily with the IT department of the National Board of Health and Welfare, but also with IHTSDO and other suppliers of tools and services. The area of responsibility is the technical maintenance and functionality of the National Board of Health and Welfare's tools and distribution services for SNOMED CT and other related products.

External expertise

The possibility for internal development efforts and participation in activities initiated by other actors is affected by the limited availability of specific expertise. The administrative organization must be able to ensure access to external experts in specialist areas which the administration comprises. In some areas, external resources are constantly required, such as quality reviews and assistance with editing of mapping and translation, while in other areas more extensive efforts - from e.g. informaticians - are required. Key development projects must, however, be budgeted and staffed separately.

Tools for SNOMED CT

Together with other member countries of IHTSDO, Sweden is participating in the development of a common technological platform with tools for development, maintenance and distribution of SNOMED CT and its applications. This "toolbox" has been named IHTSDO Workbench and is financed by member countries in order to facilitate sound cooperation and exchange of knowledge and use of products in a common technological environment. It also reduces the total need of investment among the members of essentially similar functions. In order for the development of IHTSDO Workbench to be carried out in accordance with the best interests of all member countries, an advisory group (Workbench Advisory Group) has been appointed. All member countries have the opportunity to participate in this group to discuss priorities and respond to new common and national developments needs.

The ambition is that the tool will contain all the parts relevant for member countries' internal administration. The National Board of Health and Welfare plans primarily to use IHTSDO Workbench in the continued management of the interdisciplinary terminology and thus contribute both with resources and with work efforts to test various features as they become available. The tool will then gradually be taken into operation internationally during 2010–2012. In Sweden there are plans to begin testing in 2011. The source code for IHTSDO Workbench is open and therefore available for further development externally.

As the IHTSDO Workbench has been developed during the project period for the interdisciplinary terminology and is not yet available in a finished version, use and evaluation has so far been limited. Until all parts of IHTSDO Workbench are in place, it may be of interest for the National Board of Health and Welfare to use other tools where necessary or

desirable. The opportunity to use tools developed by IHTSDO does not therefore exclude alternative solutions, should these prove more effective.

Resources and expertise from the National Board of Health and Welfare will be required in order for IHTSDO Workbench to be established, tested and implemented in the IT environment chosen by the National Board of Health and Welfare.

Details of existing and planned functionality can be found in Annex 2.

Continued development of SNOMED CT

Since the IHTSDO was formed and took over administration of SNOMED CT in 2007, the organization has grown, both in the number of member countries, users and areas of responsibility. This has meant many quick changes during the period. The demand for increased user-friendliness and quick change of the content of SNOMED CT has influenced the organization's strategic direction. A strategic plan aimed for 2015 was decided in 2010 [10]. The organization oversees, among other things, the processes for additions and other amendments in SNOMED CT with the aim of achieving the highest possible quality and level of usability.

In its present form the organization is relatively young and Sweden took an early strategic decision to work on its creation and influence its direction. One consequence of being part of a development process is that certain national processes and methods detailed in this document may be subject to change, depending on international decisions. The decisions taken affect different aspects of the administration of SNOMED CT, such as content, tools, relationships to other standards, and resource needs.

IHTSDO's decision to invest in a new administration platform for SNOMED CT is an example of a strategic choice which affects the work in Sweden. In the long-term, this means that Sweden will have access to an advanced tool which has been jointly developed by several countries in which there is expertise in a field which is at present relatively new in Sweden. Another consequence is that many of the modules required to completely fulfil the needs of the National Board of Health and Welfare and other users in Sweden are still under development. The order of development is jointly prioritized and is primarily based on the international version of SNOMED CT, not the individual member countries' needs. The National Board of Health and Welfare welcomes the opportunity to be involved in and develop SNOMED CT, and the amendments brought about by the cooperation within IHTSDO are deemed to benefit the National Board of Health and Welfare's work and therefore Swedish users as well.

Provision of the interdisciplinary terminology

From October 2011 the National Board of Health and Welfare is to provide SNOMED CT in a standard format. At this point there will be a new license agreement and a new website for provision. The future method of provision may change depending on usage and technological development. The National Board of Health and Welfare must abide by the rules of provision which are provided by IHTSDO and it must also cater for the Swedish users' needs. Below is an outline of the different steps in the plan for the Swedish provision.

Handling of SNOMED CT SE releases
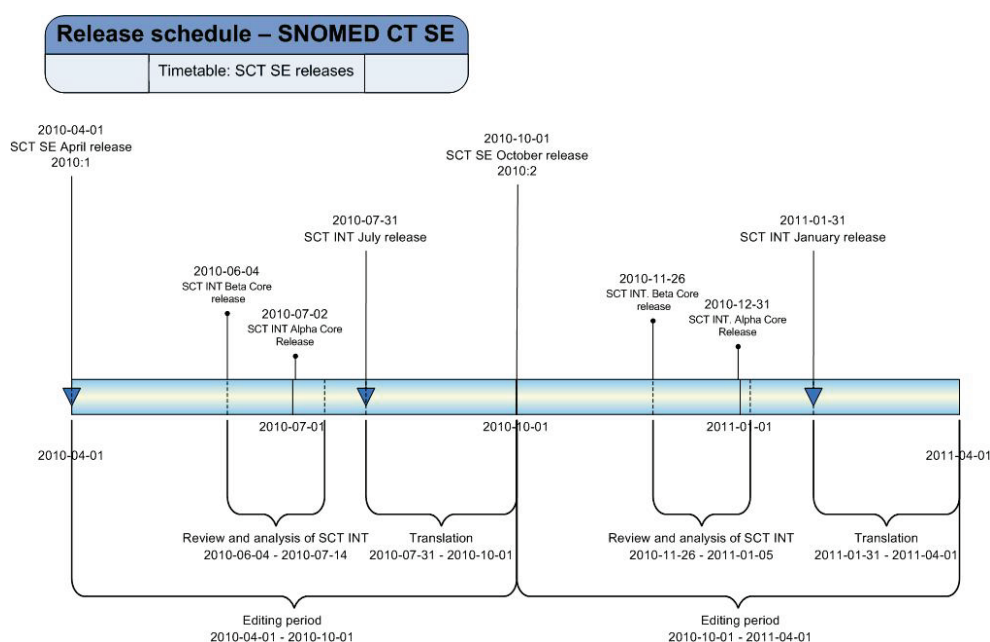
Diagram 4. Timetable for releases of SNOMED CT INT and SNOMED CT SE with focus on the National Board of Health and Welfare's handling of the translation process.

SNOMED CT is internationally distributed twice a year, on January 31 and July 31. Each new release includes the international version of SNOMED CT (concepts, terms and relationships) along with instructions for implementation and use. This material is made available to all Swedish licensees.

Under the plan, SNOMED CT SE will be updated and distributed twice a year, in April and October. The new release includes the translation of new concepts and amendments in SNOMED CT INT, Swedish additions of

concepts, terms and relationships, and instructions in the form of release documentation and a user guide, in Swedish. New releases do not imply the loss of previously used information; in fact, all concepts that have at some point been added to SNOMED CT are saved. If a concept is considered to be outdated, it is marked with the "retired" status, but it will always be searchable.

The licensee agrees under the license agreement to use a current release of SNOMED CT SE. "Current" refers to the latest release or the previous one. More information on licensing and user commitment is found on the National Board of Health and Welfare's website[7].
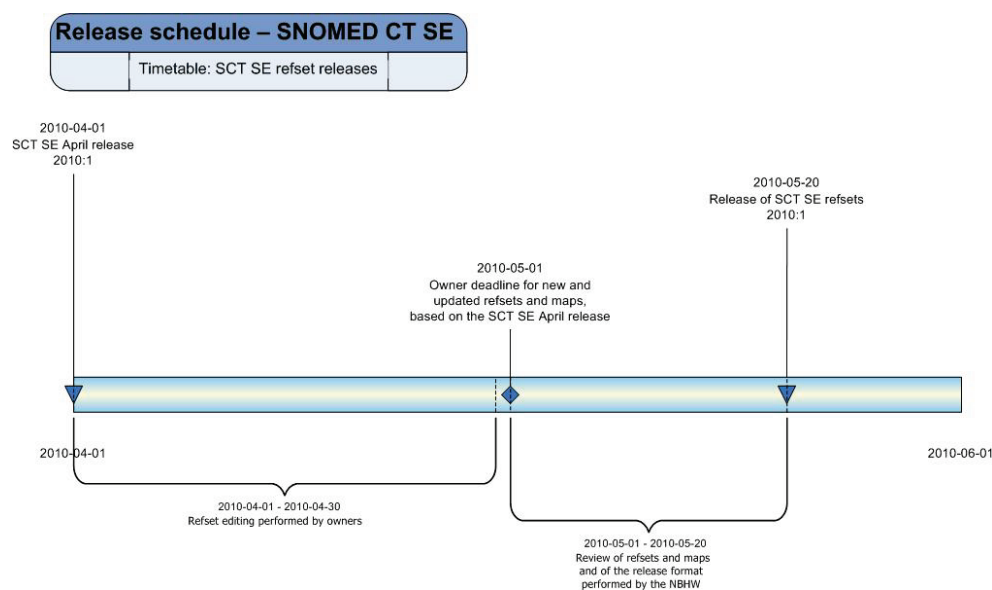

Figure 5. Timetable for the process surrounding the release of reference sets and mapping results for SNOMED CT SE.

In addition to the distribution of the Swedish version of SNOMED CT every six months, the reference sets and mapping results will be distributed twice a year, in May and November.

The new releases of SNOMED CT SE include amendments to the concepts, terms and relationships, and new content that may affect the existing reference sets and mapping results. Keeping the reference sets and maps up-to-date in accordance with the latest release greatly impacts the quality, and it is the respective owner who is responsible for this updating. Updating reference sets and mapping tables is required in both national and local versions of SNOMED CT, but only the national version is regulated by the agreement.

The reference sets and mapping tables are published six weeks following the provision of a new release of SNOMED CT SE. The National Board of Health and Welfare is responsible for verifying that the owners have made all updates in accordance with the agreement. If this is not the case, the reference sets and/or mapping tables will be marked as inactive, and use of inactive reference sets or mapping tables may compromise quality. More information on the principles for and ownership of reference sets will be

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[7] www.socialstyrelsen.se/facksprak

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made available in the National Board of Health and Welfare's reference set policy which will be published in autumn 2011.

Release documentation for SNOMED CT

Each release, both the international and the national versions, comes with release documentation that details the amendments that have been made since the previous release. The purpose of this is to enable users to easily monitor and identify amendments and additions in SNOMED CT. The number of amendments varies from release to release, but these have so far not concerned a large portion of the material.

The two latest releases of the international version of SNOMED CT contained amendments (new concepts, amended terms and relationships, and inactivation of certain concepts) corresponding to an average of about 0.65%, which is around 2,200 amendments. In addition to the amendments originating from the international version, there will be a number of Swedish amendments and additions. At present it is difficult to estimate the volume of these.

Release format of SNOMED CT

Since 2010, SNOMED CT has been provided in a well-defined release format called Release Format 2 (RF2). The sole intention of the release format is for its use in the provision of SNOMED CT and not, for example, to control which database format SNOMED CT is stored in when it is used in EHR systems. A detailed description can be found in appendix 1 and in the IHTSDO documentation "Technical reference guide" [11].

Distribution service

The interdisciplinary terminology includes a number of resources, products, user guides, policies and guidelines, training materials, etc. From autumn 2011, all of this shall be provided through the website www.facksprak.socialstyrelsen.se.

The National Board of Health and Welfare's distribution service requires active registration of the subsets which the user desires, and all future changes in the registered subsets will then be conveyed to the user. Depending on which subset package the user desires, a license may be required for the user to gain access to the material. This applies to SNOMED CT, for example. The license is applied for in connection with registration of each subset package. A user account can be updated by adding or removing subset packages. The website provides possibilities for communication between the National Board of Health and Welfare and users. It is important to note that the website is intended to provide materials of various types and that it therefore does not have a content search engine or any similar function. At each visit, the user must log on. In accordance with the National Board of Health and Welfare's plan, the website shall function in parallel with what will be a more dynamic provision service, both in terms of access and interaction.

Future provision

The National Board of Health and Welfare has conducted three workshops to identify the requirements for a service that is primarily designed to provide SNOMED CT. Participants in the workshops included representatives of CeHis, national projects such as the Infection Tool and quality registries as well as the supplier organization Swedish Medtech and their client groups. In total between 10 and 15 persons participated in each workshop. The results of the workshops form the basis for further investigative work and procurement.

What is so far apparent is the need for coordination with other national services. The need of a future solution will be clarified through application projects, dissemination of knowledge and through expertise building amongst users. Within the framework of international cooperation, discussions are ongoing to plan for future provision, both nationally and internationally. These are discussions which the National Board of Health and Welfare monitors and is involved in.

Support for the use of SNOMED CT

Reporting and handling amendments

SNOMED CT is continuously updated and the content is amended. Updates are often made following proposals for amendments, additions, and other user-submitted comments, and it is therefore important that there is a tool for questions and comments concerning the content.

Within IHTSDO, the web-based portal *Request Submission System* is used for questions and comments concerning the content of SNOMED CT. Authorized users of this portal are usually the organization in charge in each member country, which reports well-prepared amendment or addition proposals via an online form. IHTSDO modellers audit the proposals and approve or reject them based on the criteria for the content of SNOMED CT. The current status of submitted amendment proposals can be monitored via the web portal. This tool handles both individual amendments and more extensive changes. It is possible to search the reported addition and amendment proposals, both those of the logged-in user and of others, which are not yet included in any release.

In Sweden, a similar flow and regulatory framework for amendments and additions in the existing content will be created and a similar web-based tool will be used. Users who have comments on the content of SNOMED CT will be able to specify the change they believe needs to be made, justify the proposal and then send this to the National Board of Health and Welfare. The National Board of Health and Welfare decides whether the proposal can be approved or rejected based on the criteria provided for SNOMED CT. In the long-term, it will be possible for comments and proposed amendments linked to the terminology database and the classifications provided by the National Board of Health and Welfare to be made through this tool.

Approved proposals are handled in one of the following ways:

- Proposed linguistic amendments (concerning e.g., translation, spelling or linguistic inconsistency) are dealt with directly by the National Board of Health and Welfare, without reporting to IHTSDO. Approved amendments to the Swedish terms are then included in SNOMED CT SE, and the party that made the proposal will be notified of which release the amendment will be included in. Any proposals for linguistic changes in the international version of SNOMED CT are also to be reported.

- Proposals for structural amendments (wrongly allocated concepts, incorrect relationships, etc.) result in modelling work. The results are then reported to IHTSDO by the National Board of Health and Welfare. If a proposal concerns concepts that are found only in the Swedish extension, the amendment may be implemented immediately, without reporting to IHTSDO, and included in

SNOMED CT SE. The party that made the proposal will be notified of which release the amendment will be included in.

- Proposals for additional concepts are modelled in the Swedish extension of SNOMED CT. If the new concepts are considered to be of such significance that they should also be included in the international version, another process is followed. At present, IHTSDO is working on the development of guidelines for whether a concept is relevant on a national level and/or international level.

- Proposals for additional synonyms are prepared and sent, where necessary, for referral. Approved synonyms are then included in SNOMED CT SE. The party that made the proposal will be notified of which release the amendment will be included in.

The user who submitted the proposal will receive an e-mail with information on the outcome, irrespective of whether the proposal is approved or rejected.

The National Board of Health and Welfare's work with proposed amendments and additions will in certain cases involve the editorial board serving as support for the decision, where persons with knowledge of terminology science, translation, mapping and modelling, and expertise from different professions and specialities within the field of health and social care services are involved.

The National Board of Health and Welfare provides SNOMED CT in a standardized international file format. The user, in collaboration with the IT supplier, can create a suitable technical environment for practical application.

Request submission tool
SNOMED CT SE

Editor

Additional synonyms

Structural amendments

Linguistic amendments

Additional concepts

Decision — YES — Modeling

Decision YES

NO

NO

Editorial board

Decision YES NO

Editorial board

Feedback to submitter

YES

Decision

Feedback to submitter

Decision

Editorial board

Feedback to submitter

YES

Modeling

Modeling Translation Se→En

NO

Editorial board

Feedback to submitter

Feedback to submitter

Editorial board

Decision

Advisory board Decision

Decision

YES/NO

SCT SE release documentation

YES/NO

SCT SE

RSS IHTSDO

Requests affecting SCT INT

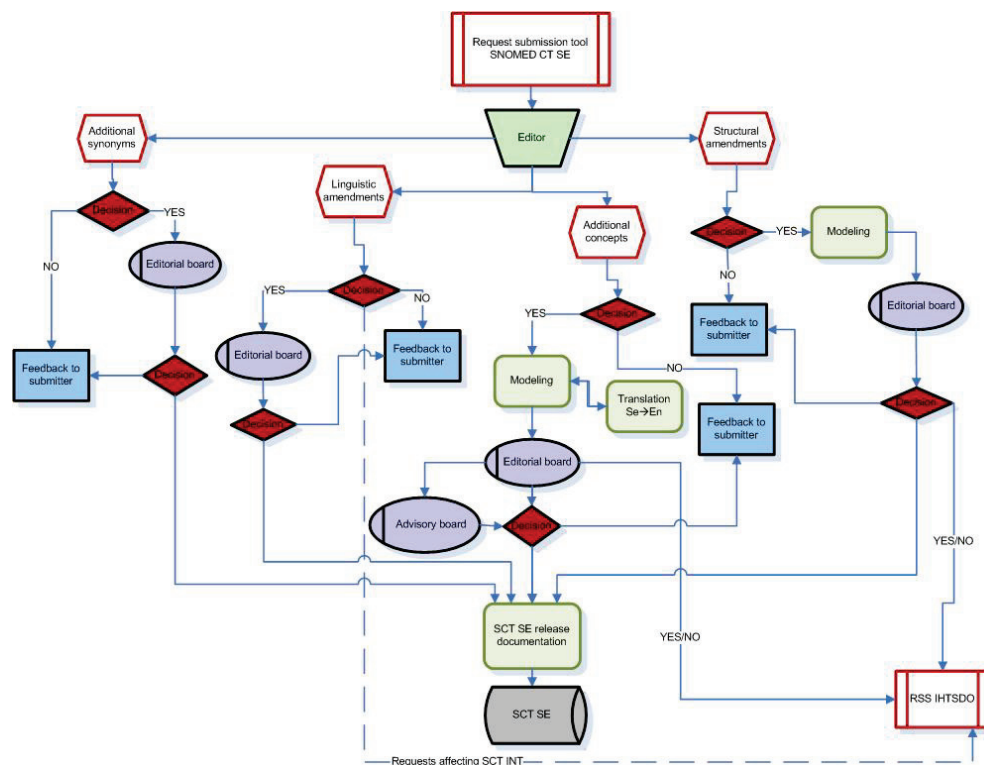*Diagram 6. Internal handling of received amendment proposals.*

The National Board of Health and Welfare is responsible for ensuring that relevant training material exists for the interdisciplinary terminology's content and methods, and that this is administrated and provided. In the framework of the IHTSDO activities, skill requirements and training materials are developed to support the training planning in each member country. The skill requirements detail what should be required from persons who are to develop, maintain, administer and implement SNOMED CT.

Support

During a transitional period, the National Board of Health and Welfare will provide some form of technical support in connection with the downloading of new releases of SNOMED CT SE. Support will be available during office hours and all questions are to be sent via e-mail to snomedct@socialstyrelsen.se.

Support for application projects, for example for issues that arise in connection with mappings, will initially be provided following arrangement with the respective project managers. In the long-term, the tools which can be used for mapping and managing of reference sets will be adapted for use in application projects.

It is suggested that the National Board of Health and Welfare is given the task of building expertise among principals and other interested parties through specific development of knowledge on SNOMED CT and training in the related methods amongst a smaller number of users. These persons will in turn educate others.

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Technical description of SNOMED CT

Release Format 2

Since 2010, SNOMED CT has been provided in a well-defined release format called Release Format 2 (RF2). The sole intention of the release format is for its use in the provision of SNOMED CT, and not for example to control which database format SNOMED CT is stored in when it is used in documentation systems. RF2 consists of several text files with the character encoding UTF-8. Each text file contains a table with rows and tab-separated columns. The three most important tables are the concepts, descriptions and relationships tables[8].

The concepts table contains one concept per row. For each concept a unique ID number is stored, together with information regarding whether the concept is fully defined or primitive.

The descriptions table contains one concept per row. For each description, a unique ID number is stored, together with information regarding which concept the description refers to and the textual term from which the description is composed. In previous release formats, terms have been limited to consisting of ordinary text (plain text) with a maximum of 255 characters, but RF2 allows for these to be supplemented with terms that are, for example, written in limited HTML, XHTML and DITA, and have a size of up to 32 kilobytes. There is also information on which language, e.g., Swedish or English, the term is written in, if the term is fully defined or a synonym, and whether or not the term is case-sensitive.

The relationships table contains one relationship per row. For each relationship a unique ID number is stored, together with information regarding which concept the relationship originates from, which concept the relationship links to and the relationship type, e.g., "is a" or "finding site". It also states whether the relationship is grouped with other relationships, and the relationship's characteristic type is denoted.

The three tables above, as well as most other tables that are part of RF2, also contain columns for information on module and release. The division into modules is, for example, used to indicate that one concept belongs to the international version of SNOMED CT and that another belongs to e.g., the Swedish version. The release handling column is used so that all changes to SNOMED CT are traceable. Concepts, descriptions, relationships and other components of SNOMED CT cannot therefore be removed completely; it is only possible to mark them as inactive/retired.

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[8] The word *description* is translated to *beskrivning* in the Swedish version. A description is an item of information that contains seven information fields. One of these information fields is entitled *term* and contains the textual name of the concept.

The release handling columns are used to store information on when amendments and deactivations have been made.

Release Format 2 - technical description

RF2 consists of several text files with the character encoding UTF-8. Each text file contains a table with rows and tab-separated columns. The three most important tables are the concepts, descriptions and relationships tables. In these tables, the following data types are used:

Data type	Description
SCTID	Positive integer between 6 and 18 digits long.
Integer	32-bit positive or negative integer.
String	Text field in the character encoding UTF-8.
Boolean	Boolean value, where "0" represents false and "1" true.
Time	Date stored with numbers in the format YYYYMMDD.

The concepts table is as follows:

Column	Data type	Description
ID	SCTID	Concept's unique ID number.
effectiveTime	Time	Date when this version of the concept takes effect.
active	Boolean	If this version of the concept is *active* or *inactive*.
moduleId	SCTID	The module to which the concept belongs.
definitionStatusId	SCTID	Concept's definition status. Currently either *fully defined* or *primitive*.

The descriptions table is as follows:

Column	Data type	Description
ID	SCTID	Description's unique ID number.
effectiveTime	Time	The date when this version of the description takes effect.
active	Boolean	If this version of the description is *active* or *inactive.*
moduleId	SCTID	The module to which the description belongs.
conceptId	SCTID	ID number of the concept to which the described belongs.
languageCode	String	The description's language is coded in accordance with ISO-639-1.
typeId	SCTID	Description type. Currently either *fully specified name* or *synonym.*
term	String	Description text.
caseSignificanceId	SCTID	Whether or not the description is case-sensitive. Currently, whether or not the first character is case-sensitive.

The relationships table is as follows:

Column	Data type	Description
ID	SCTID	Description's unique ID number.
effectiveTime	Time	Date when this version of the description takes effect.
active	Boolean	If this version of the relationship is *active* or *inactive.*
moduleId	SCTID	The module to which the relationship belongs.
sourceId	SCTID	ID number of the relationship's source concept.
destinationId	SCTID	ID number of the relationship's target concept.
relationshipGroup	Integer	The logical association group that the relationship belongs to.
typeId	SCTID	Relationship type.
characteristicTypeId	SCTID	Relationship's characteristic type. Currently either *defining, qualifying* or *additional.*
modifierId	SCTID	Relationship's description logic restriction. Currently *exists.*

Below are examples of content in the concepts table. The first two rows contain information on the concept with the ID number 258606004. The columns *effectiveTime* and *active* in the first row show that the concept was put into effect on 31-01-2002, the date of the first release of SNOMED CT. In the column *definitionStatusId* we can see that the concept was at that time *primitive.* In the second row we see in the columns *effectiveTime* and *active* that the concept was updated on 31-07-2008, and in the column *definitionStatusId* we see that the amendment meant changing the concept's definition status to *fully defined.*

The final two rows contain information on the concept with the ID number 23294000. This concepts also came into effect on 31-01-2002 and were *primitive.* The concept was updated on 31-01-2010, being made inactive, as shown in the column *active.*

ID	effectiveTime	active	moduleId	definitionStatusId
258606004	20020131	1	900000000000380005	900000000000130009
258606004	20080731	1	900000000000380005	900000000000128007
23294000	20020131	1	900000000000380005	900000000000130009
23294000	20100131	0	900000000000380005	900000000000130009

Below are examples of content in the descriptions table. The first two rows contain descriptions for the concept with the ID number 258606004, as shown in the column *conceptId*. The first description has the ID number 650042015. In the column *language code* we see that the description is written in the language *en*, i.e., English, and in the column *typeId* we see that the description is of the type *fully specified name.* The column *term* contains the text itself, in this case *Lower respiratory sample (specimen),* and in the column *caseSignificanceId* we see that the first letter of the text is not case sensitive. The second description is quite similar to the first. The differences are that it has a different ID number, 384803012, that the column *typeId* shows that it is of the type *synonym* and that the actual text is *Lower respiratory sample.*

In the same way, the next two rows contain one description that is fully specified name and one that is a synonym of the concept with the ID number 23294000.

The final row contains a description of the concept with the ID number 180290000. The column *caseSignificanceId* shows that the first letter of the description is case-sensitive and in the description text, *COP - Change of plaster,* we see that the text begins with an abbreviation in capital letters, which is the likely reason for the description being case-sensitive.

ID	effective Time	Active	moduleId	conceptId	langua geCode	typeId	term	caseSignificanceId
650042015	20020131	1	900000000000380005	258606004	en	900000000000003001	Lower respiratory sample (specimen)	900000000000448009
384803012	20020131	1	900000000000380005	258606004	en	900000000000187000	Lower respiratory sample	900000000000448009
752797013	20020131	1	900000000000380005	23294000	en	900000000000003001	Sports injury (morphologic abnormality)	900000000000448009
39097017	20020131	1	900000000000380005	23294000	en	900000000000187000	Sports injury	900000000000448009
278863010	20020131	1	900000000000380005	180290000	en	900000000000187000	COP - Change of plaster	900000000000022005

Below are examples of content in the relationships table and two diagrams which represent the examples graphically. The first two rows contain relationships from the concept with the ID number 258606004, as shown in the column *sourceId*. The concept is, as we have already seen, *Lower respiratory sample.* The relationship with the ID number 79907027 is, according to the column *typeId*, of the type *Is a.* The column *destinationId* shows that the relationship leads to the concept *Respiratory sample.* This relationship means that the term *Lower respiratory sample* is subordinate to the concept *Respiratory sample.* The relationship with the ID number 1956685021, added on 31-07-2008, is of the type *Specimen source topography* and leads to the concept *Lower respiratory tract structure.* The addition of this relationship was what made the concept status change, on 31-07-2008, from *primitive* to *fully defined.*

The final three rows contain relationships from the concept with the ID number 23294000. The relationship with the ID number 185995026 is of the type *Is a,* and leads to the concept *Traumatic abnormality.* The column *effectiveTime* shows that the relationship was valid from 31-01-2002 to the day before 31-01-2010. On 31-01-2010 a new relationship was added, and the reason for these changes is, as

shown in the concept table, that the concept went from being active to inactive. The relationship with the ID number 3639451022 is of the type *Is a* and leads to the concept *Ambiguous concept,* which explains why the concept was made inactive.

ID	effective Time	active	moduleId	sourceId	destinationId	Relationship Group	typeId	characteristicTypeId	modifierId
79907027	20020131	1	900000000000380005	258606004	258603007	0	116680003	900000000000006009	900000000000451002
1956685021	20080731	1	900000000000380005	258606004	82094008	0	118169006	900000000000006009	900000000000451002
185995026	20020131	1	900000000000380005	23294000	19130008	0	116680003	900000000000006009	900000000000451002
185995026	20100131	0	900000000000380005	23294000	19130008	0	116680003	900000000000006009	900000000000451002
3639451022	20100131	1	900000000000380005	23294000	363660007	0	116680003	900000000000006009	900000000000451002
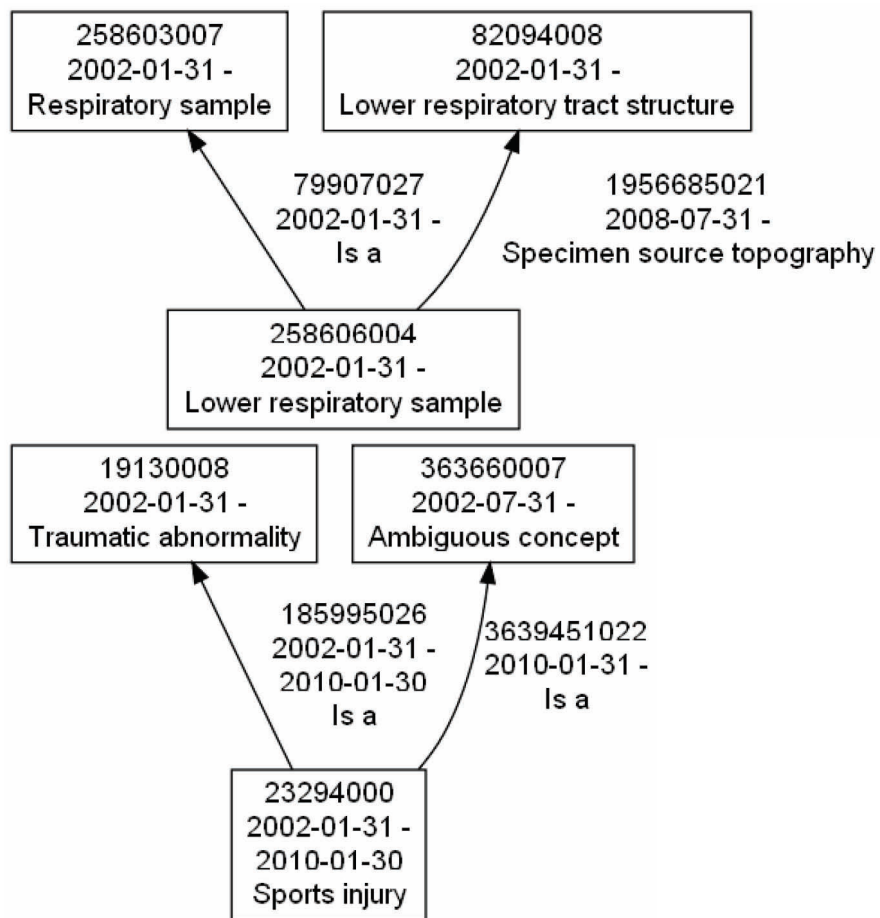
IHTSDO Workbench

IHTSDO Workbench is a software application which makes it possible to work with SNOMED CT in different ways. The application consists of a base platform and a number of modules. The development of IHTSDO Workbench grew out of the need for a new environment for modelling additions to and updating SNOMED CT. The first parts that were created were therefore the actual platform and a module for modelling and classification of the content of SNOMED CT. The next step was to develop a module for the translation of SNOMED CT, and at present there is ongoing work on a module for mapping SNOMED CT to other terminologies and classifications. More modules will certainly be added in the future. As IHTSDO Workbench has been developed during the project period for the interdisciplinary terminology and is not yet available in a finished version, use and evaluation has so far been limited. This means that the National Board of Health and Welfare may need to implement alternative solutions until all of the modules are fully developed.

The following describes the present, and the future as it looks today.

Current version

The latest public version of IHTSDO Workbench is "IHTSDO Standalone Editor Release Version 1.3.2-IHTSDO-gr" which was released on 21 June 2010. A new version is expected in summer 2011. The current version contains the following fundamental modules:

Browser (search module)

One of the modules is a browser for searching the SNOMED CT content. The browser is primarily intended to support other functions in IHTSDO Workbench but can also be used as it is. For searches only in SNOMED CT, there are other stand-alone browsers which require less processing performance. A list of these is available on the National Board of Health and Welfare's website.

SNOMED CT Editor (editing module)

IHTSDO Workbench also includes a module with basic functionality for making amendments to SNOMED CT's existing content and for adding new content. There is also a classifier which can classify concepts in SNOMED CT once amendments and additions to the content have been made.

Reference Set module

Another feature is a module for creating SNOMED CT reference sets, also called RefSet. A RefSet is a subset of SNOMED CT content which can be

transferred between different computer programs in a standardized way. A RefSet may, for example, contain concepts which represent procedures that are relevant for Swedish primary care or all descriptions which in a given month will be translated from English to Swedish. The managing of reference sets is detailed in the section on reference sets and in the method for managing these.

System requirements

The recommended hardware configuration for running the latest version of IHTSDO Workbench is:

- monitor with a minimum resolution of 1,400 * 1,050 pixels
- computer with at least 3 GB of RAM
- hard drive with at least 40 GB of free space and with a minimum speed of 7,400 RPM
- Dual Core processor with a minimum frequency of 2.6 GHz.

This means that a fairly high-spec computer is required in order to run IHTSDO Workbench.

Ongoing development

At present, development of the new modules and features of IHTSDO Workbench detailed below is under way.

Migration of modelling for the international version

In order to move the development work with the international version of SNOMED CT from previously used tools to IHTSDO Workbench, more functions in addition to the basic modelling functions are required. A development project is therefore under way to supplement IHTSDO Workbench with functions in different areas, e.g., by adding functions which facilitate better quality assurance of the SNOMED CT content. The user interface is being improved and possibilities of automation and report generation will be added. Features for workflow and conflict resolution between different versions of the SNOMED CT content are under development. Features are also being added to create the files included in distributions of SNOMED CT. The project has a deadline of 1 March 2011, after which acceptance testing will commence and will last until 1 June. From the end of July all development and maintenance of the international version of SNOMED CT will be carried out in IHTSDO Workbench.

Translation

To facilitate an effective and concept-based approach to the translation of SNOMED CT descriptions from one language to another, a translation module for IHTSDO Workbench is under development. The translation module is important for Sweden, as it enables translation from English into

Swedish of the additions in the international version of SNOMED CT. Another possibility is for translations of proposed Swedish additions (from Swedish to English) to be included in the international version. Representatives from the Interdisciplinary Terminology project have therefore acted as requirement specifiers and evaluators during the development of the translation module. The translation module will be available for testing in spring 2011 and some member countries, of which Sweden is one of the first, will then begin to test it. The testing also includes the RefSet module and the editing module.

Mapping

To be able to use SNOMED CT with other classification and terminology systems, mappings between SNOMED CT and the other systems are required. A module for creating mappings is under development in IHTSDO Workbench. The mapping module is primarily developed for a project that aims to map from SNOMED CT to ICD-10, but it will also be possible to use the mapping module for mapping to other terminologies and classifications. At present, it is unclear if in its first version it will also be possible to use it to map *from* another system to SNOMED CT, a feature which is in demand in Sweden. Due to international prioritization, it will not be possible to make the mapping module available before December 2011. A consequence of this is that the National Board of Health and Welfare will need to consider alternative solutions for the mapping work.

Documentation

The current documentation for IHTSDO Workbench is written primarily from a technical perspective, but work is under way internationally to produce documentation with a less technical perspective. The documentation will be made available in spring 2011.

Future development

Additional modules will certainly be added to the IHTSDO Workbench in the future, and discussions are already under way regarding such modules.

When SNOMED CT is used to represent information, it is possible to use both pre- and post-coordinated concepts from SNOMED CT [12]. Creating post-coordinated concepts is however complicated, and those less experienced may need assistance to create such concepts. A possible future module in IHTSDO Workbench under discussion is therefore an editing module which facilitates the creation of post-coordinated concepts.

To structure the content in SNOMED CT, there is a concept model which specifies what types of relationships different concepts may have, depending on the hierarchy the concepts belong to. The concept model is available in a machine-readable format, which allows it to be used automatically to check that the content of SNOMED CT is consistent with the concept model, thus ensuring the quality of SNOMED CT. The work to maintain the machine-readable concept model is however complex, and

discussions are therefore ongoing regarding the possibility of expanding IHTSDO Workbench with a new module that contains an editing function for the concept model.

In order to simplify the development of IHTSDO Workbench, a survey and possible updating of the tool's architecture are under discussion.

The National Board of Health and Welfare's need for IHTSDO Workbench

Much of the National Board of Health and Welfare's need for development and maintenance of SNOMED CT will in the future likely be covered by the modules in IHTSDO Workbench described above.

One area where IHTSDO Workbench does not yet cover the needs of the National Board of Health and Welfare is the updating and quality assurance of the mapping tables and RefSets which are already in use when, for example, concepts and structure are altered in subsequent releases of SNOMED CT. For each new release of SNOMED CT, a great deal of manual auditing of all RefSets and mapping tables is required. Certain functionality for automated support in the audit process is included in IHTSDO Workbench, but additional support may be required in order to further simplify the audit process. Separate tools for automated control outside of IHTSDO Workbench do however exist. This is not only of interest to the National Board of Health and Welfare but also for the reference set owners who are responsible for carrying out this auditing in order to publish an updated reference set.

The National Board of Health and Welfare has like many other users a need to be able to map *from* other classification and terminology systems to SNOMED CT. Internationally, however, the focus is primarily the opposite, namely to be able to map from SNOMED CT to other classification systems. It is therefore uncertain at present as to whether or not the mapping module currently under development will be able to fulfil the National Board of Health and Welfare's need for mapping from other sources to SNOMED CT. In all likelihood, special development work will be required for this.