

# SNOMED CT® National Release Center Guide June 2016 International Release (US English)

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## SNOMED CT National Release Center Guide



SNOMED CT National Release Center Guide

Welcome to the Editorial Guide
The SNOMED CT National Release Center Guide
provides an introduction to IHTSDO and SNOMED CT
for those working in or planning to development a
National Release Center. It is also applicable to
countries considering joining IHTSDO and Members.
The SNOMED CT National Release Center Guide

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#### 1. Introduction

#### Background

When a country joins IHTSDO it gains a number of rights and obligations related to IHTSDO products, including SNOMED Clinical Terms (SNOMED CT). All IHTSDO Member countries also play a key role within the governance and advisory bodies of IHTSDO. Therefore, joining IHTSDO brings with it a need to learn how IHTSDO works, the roles of IHTSDO Members and practical ways to maximize the benefits of membership.

An important first step is to designate an organization as a National Release Center (NRC) to fulfill the operational requirements of membership, including managing the national distribution of SNOMED CT. This guide is a high-level introductory document for National Release Centers.

#### Objective

The objective of the "IHTSDO National Release Center Guide" (NRC Guide) is to offer a practical and useful starting point for IHTSDO Member countries. It provides guidance on NRC responsibilities and the relationships between NRCs, IHTSDO, and implementers and users within a Member country.

This document is also intended to provide guidance on how NRCs can support an effective and efficient introduction of SNOMED CT in their countries. However, it does not provide a general introduction to SNOMED CT. Readers interested in learning more about IHTSDO's terminology should refer instead to the SNOMED CT Starter Guide.

The SNOMED CT Starter Guide can be found here: http://snomed.org/starterguide

#### Target Audience

The target audience of the NRC Guide is those people responsible for establishing, managing and working within a National Release Center. While primarily designed for new IHTSDO Members, this guide also provides a useful reference for NRC staff in existing Member countries

Readers of this guide should already have an understanding of what an IHTSDO Member is and what an Affiliate is. The IHTSDO Glossary can be used to clarify specific words and phrases used.

The SNOMED CT Glossary can be found here: http://snomed.org/glossary

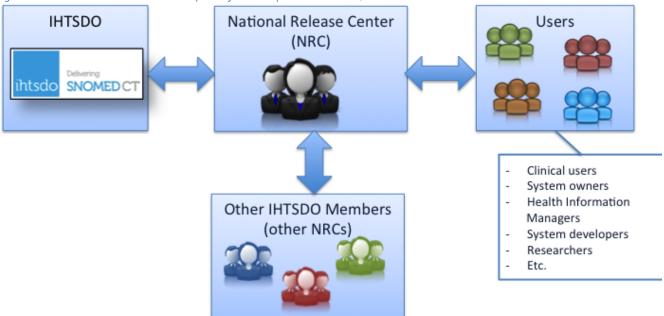
This document uses the term "Member country" as this is considered easier to understand than the more formal term "Member territory." In most cases Members are countries or states recognized by the United Nations, but in exceptional circumstances entities that are not strictly "countries" may be permitted to join IHTSDO as Members.



## 2. What Is a National Release Center?

A National Release Center (NRC) is an official point of contact within a Member's jurisdiction that has the responsibility to serve as the interface between IHTSDO, the national users and Affiliates, and other Members.

Figure 1 A National Release Center is the primary contact point for IHTSDO, users and other IHTSDO Members.



IHTSDO requires each Member to have a nominated organization that fulfills a small set of core NRC responsibilities. These responsibilities include receiving the International Release of SNOMED CT from IHTSDO, making it available to licensees in the Member country, and promoting and supporting adoption and deployment of SNOMED CT in the Member country. Some NRCs also provide additional products and services to support national use of SNOMED CT. Provided that the core responsibilities are fulfilled, each Member is free to decide whether or not their NRC should provide other related services or products.

For Members that choose only to distribute the International Release of SNOMED CT, the NRC can be limited to only one or two people to undertake the minimal required services. NRCs of other Members are larger organizations that have many other responsibilities related to SNOMED CT and also manage the use of other health informatics standards within that country. An NRC can be established as a new body or organization within the Member country, or it can be folded into an existing body or organization.

As the primary contact point for both national Affiliates and IHTSDO, the NRC plays a central role in effective and efficient collaboration with the various partners. The term "National Release Center" is used by IHTSDO, but a Member may give the organization that fulfills this role in their country a different name.

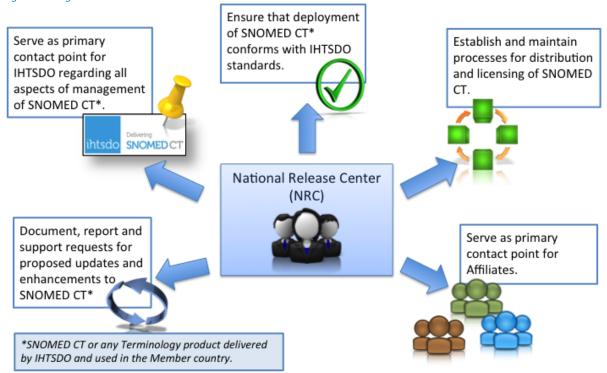


## 3. NRC responsibilities

The best way to organize an NRC depends on a wide range of factors, including the number of potential Affiliates, the vision and strategy for use of SNOMED CT in the country, the national eHealth infrastructure, the extent of customization, etc. But Members of IHTSDO are, at a minimum, required to fulfill a set of core responsibilities within the Member's territory, as shown in Figure 2 and specified in the Articles of Association. Typically, the NRC fulfills most of these obligations, however a Member may make other arrangements to fulfill some of the obligations.

The Articles of Association for IHTSDO can be found here: http://snomed.org/articles.

Figure 2 Obligations of IHTSDO Members.



- NRCs are required to serve as primary points of contact for IHTSDO with regards to all aspects of the management of the terminology products.
- NRCs are the primary points of contact for Affiliates within a Member country.
  - Affiliates should be able to contact the NRC for guidance and direction with respect to implementation and use of SNOMED CT within the Member country.
  - The NRCs should serve as intermediaries between the Affiliates and the SNOMED CT community, for example:
    - Encouraging experts and other appropriate persons to contribute to the work of IHTSDO;
    - Assisting IHTSDO to communicate with Affiliates and experts entitled to and wishing to be enrolled as IHTSDO
      Affiliates
- NRCs are required to establish and maintain processes necessary for distribution and licensing of SNOMED CT and the other ter minology products.
  - This includes developing the appropriate mechanisms for users to gain access to National (where applicable) and International Editions of SNOMED CT and related products, and mechanisms to retrieve and manage Affiliate licenses. (See section 9 on tooling for process support.)
  - This includes managing license reporting annually and reporting Affiliates' activities in non-Member countries to
- NRCs are required to ensure that any deployment of a terminology product owned by IHTSDO conforms to IHTSDO standards.
- NRCs must facilitate feedback from users on SNOMED CT, including managing change requests.

Besides these areas, there is a range of other responsibilities that NRC may decide to undertake. The table below lists a set of possible responsibility areas. The list is not exhaustive but includes the main areas that NRCs currently cover. Some of the areas are marked as "Required," as these are part of the core responsibility areas.



#### Table 1. NRC Responsibility areas

Responsibility area	Required	Optional
Manage licenses (manually or automatically)	•	
Distribute International Releases	•	
Manage Extensions (Authoring, release, distribution and maintenance)		•
Manage Reference sets (Authoring, release, distribution and maintenance)		•
Manage Mappings (Authoring, release, distribution and maintenance)		•
Manage Translations (Authoring, release, distribution and maintenance)		•
Offer Tooling		
As user service: To enable users to access and explore SNOMED CT		•
As NRC tool: Support SNOMED CT management		•
Manage change requests for organizations in the country	•	
Offer education, promotion and training		•
Engage stakeholders		•
Offer implementation consultancy		•

## NRC competencies

The competencies required for an NRC are dependent on what services the NRC chooses to deliver. However, most NRC staff should have a general understanding of SNOMED CT and IHTSDO.

If an NRC is unable to provide a specific type of service, it should seek to identify other resources that are able to meet the requirements of implementers and users in the Member country.

The following core competencies are typical for the work of an NRC. Some of these competency areas can be considered assignment-specific, as they will not be required as a constant competency within the NRC but are required to fulfill specific assignments, such as translation, mapping and development of Reference sets.

General competencies required	Terminology
	Technical and IT skills
	Communication
	Implementation
	Education
Assignment-specific competencies	Clinical and scientific domain specialty knowledge
	Linguistics and translation

Specific competencies required to undertake particular NRC related tasks are outlined in Table 2.



## Table 2 Competencies and skills required to undertake particular NRC tasks $\begin{tabular}{l} \blacksquare$

Tasks	Main competencies	Knowledge/Skills areas
Distribute International Release and National Extension	Communication     Technical/IT	<ul> <li>Communication with Affiliates, e.g. news updates</li> <li>Tooling support for access to the International Release and National Extension</li> </ul>
Manage extensions		
Content	<ul><li>Terminology</li><li>Domain specialty</li><li>Translation</li></ul>	<ul> <li>Content development</li> <li>Terminologies, description logic</li> </ul>
Technical	Technical/IT	Tooling support for extension development and management (See "Technical/IT" responsibility)
Manage Reference sets		
Content	<ul> <li>Terminology</li> <li>Domain specialty (clinical experts, etc.)</li> </ul>	<ul> <li>Reference set development and maintenance</li> <li>Domain insight, depending on the purpose of the Reference Set</li> <li>Concept selection <ul> <li>Logical and concept model</li> </ul> </li> <li>Search techniques</li> </ul>
Technical	Technical/IT	Tooling support for Reference set development and management (See "Technical/IT" responsibility)
Manage Mappings		
Content	<ul><li>Terminology</li><li>Domain specialty</li></ul>	Map development and maintenance     Knowledge of current practice for use of classifications and terminologies in the Member territory
Technical	Technical/IT	Tooling support for Reference Set development and management (See "Technical/IT" responsibility)
Browsing, Developing content, and Refsets, QA, Distribution	Technical/IT	<ul> <li>SNOMED CT technical specifications and File formats</li> <li>Software and database design and development</li> <li>Information modeling/information model standards</li> <li>SNOMED CT search and data entry techniques and software</li> <li>Authoring and distribution requirements</li> <li>Quality assurance techniques</li> </ul>
Manage translations	<ul><li>Terminology</li><li>Linguistics</li><li>Domain specialty</li></ul>	<ul> <li>Translation processes</li> <li>Concept definition</li> <li>Quality assurance</li> <li>Terminology authoring technology</li> </ul>
Change requests	<ul><li>Communication</li><li>Terminology</li><li>Translations</li></ul>	<ul> <li>Content development</li> <li>Terminologies, description logic</li> </ul>
	Technical/IT	<ul> <li>Terminology authoring tool</li> <li>Tooling support for change request submissions and management of change requests.</li> <li>(See "Technical/IT" responsibility)</li> </ul>
Education, promotion and training Engaging stakeholders	<ul><li>Communication</li><li>Implementation</li><li>Education</li></ul>	<ul> <li>Dissemination competencies</li> <li>Users and user needs</li> <li>Broad and deep knowledge of SNOMED CT, users and implementation aspects.</li> <li>Examples, use cases</li> <li>National health IT-infrastructure, current practices and regulation</li> </ul>



Implementation consultancy	<ul><li>Implementation</li><li>Technical/IT</li><li>Business         Analysis     </li></ul>	<ul> <li>Broad and deep knowledge of SNOMED CT, users and implementation aspects.</li> <li>Examples, use cases</li> <li>Implementation levels and technical opportunities</li> <li>Ability to understand requirements and relate to terminology</li> </ul>
Manage licenses (manually or automatically)	Communication     Technical/IT	<ul><li>Communication with Affiliates</li><li>Tooling support, e.g. license repository</li></ul>

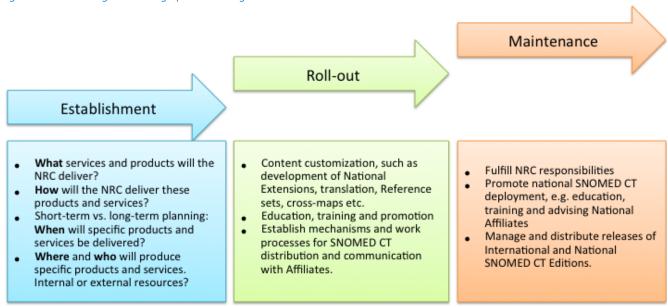
1 Note that the range of tasks that different NRCs undertake may vary.



## 4. NRC organization phases

Establishing a well-functioning NRC is not a trivial task, and awareness about the steps required to achieve an active and effective NRC is necessary in order to plan and recruit appropriately. The processes involved with setting up and running an NRC can be described in three phases: establishment, roll-out and maintenance.

Figure 3 Different stages of setting up and running NRCs



Each NRC can undertake a variety of responsibilities in order to facilitate implementation and use of SNOMED CT in the Member country. These responsibilities range from development, distribution and maintenance of SNOMED CT to support of SNOMED CT implementation projects, as well as education of people involved with SNOMED CT use and implementation. In the stage of establishing an NRC, it is vital to make decisions about which services will be provided and what national developments the NRC will undertake. These decisions also include deciding on the organization of the NRC, the work processes, the timetable and so on. It is of course possible for the scope of activity of the NRC to be increased (or decreased) in the future, as the needs change.

#### List of NRC establishment decisions

Prior to establishing an NRC, the following questions should be considered in order to be able to determine the best possible NRC organization and workflow, along with appropriate recruitment and training of staff to match the necessary NRC competencies for the planned national approach and goals. The list is not complete, but includes some core considerations that existing Members have found to be important.

#### NRC management decisions

Regarding NRC management, decisions need to be made about work processes, timetables and resource allocation.

- What is the planned timeline for the establishment and roll out of the NRC?
- What is the purpose/strategy for SNOMED CT in my country?
- What resources will be spent on tailoring the International Release to meet national requirements?
- Who will be responsible for managing specific work tasks?

Use of SNOMED CT with other terminologies, classifications and models

Typically a Member country also uses other terminologies, classifications systems or information models, and it is important for an NRC to have a clear strategy for how SNOMED CT is to align with the current or planned use of these other products in the Member country.

- What set of standard terminologies (in addition to SNOMED CT) will be used in the country? Are these required or suggested?
- Do you need mappings between SNOMED CT and other terminologies or classifications?
- Are there any interdependencies with other products (classifications/coding systems/information model initiatives) that would affect SNOMED CT releases, content, etc.?



#### National adjustment/extensions

An NRC should consider to what extent national SNOMED CT adjustments (translations, extensions, Reference sets, etc.) should be made to develop the SNOMED CT National Extension and conform this to the needs and desired use cases for the Member country.

- Do you need a translation of SNOMED CT into the language and/or dialects applied of our country?
- Do you need national Reference sets to constrain the amount of SNOMED CT concepts to be used within specific use cases, clinical domains, etc. and to support consistent use of SNOMED CT within these areas?
- Do you need national content (extensions to the International Edition of SNOMED CT) in order to meet specific national needs?
- Who will manage derivatives, for example Reference sets and mappings, in the longer term? The NRC or someone else?

#### Implementation and use cases

An NRC can take on very different strategies for supporting implementation and use of SNOMED CT in the specific Member country, and therefore an NRC should consider if, or to what extent, it will support specific SNOMED CT implementations. It should also consider how collaboration with the related stakeholders will be carried out.

- Who is responsible for what, for example in implementation projects?
  - What will be done at the national level?
  - What is the responsibility of the various stakeholders (NRC, clinicians, healthcare organizations, IT vendors, etc.)?
- Which organizations are already using SNOMED CT in the country and how will you engage with them?
- What level/type of support will you offer?
- Are there any priority use cases that you want to communicate?
- Do you intend to specify compliance standards for use of SNOMED CT in your country?

#### Education

An NRC should have a clear plan for its role with respect to SNOMED CT education and training of the various stakeholder groups within the country.

- Do you intend to offer any guidance documents over and above what IHTSDO provides?
- Do you intend to deliver training on SNOMED CT? At different levels?
- Will you translate all IHTSDO materials (beyond SNOMED CT terminology, e.g. education materials, translations guidelines, deployment guidelines) into your national language, or is use of English acceptable?

#### Tooling

It is important for an NRC to explore and discuss what specific tools are required to undertake the work of the NRC and to determine which tools will be used by the NRC.

- Will you use your own tooling or will you rely on IHTSDO's tools?
- What existing systems/processes/tooling do you already have in place that can be leveraged to fulfill your activities as an NRC?
- What tooling is required to support activities of your NRC? Where will these be obtained (from IHTSDO, vendors, in house development)?

Consideration of each of the above questions will lead to additional questions that need to be answered to obtain a realistic overview/estimate of the magnitude and types of resources required to achieve the identified goals. For example, it is not enough to decide that you want to make a translation of SNOMED CT into your national language. This decision also requires elaboration of when and how you plan to do this, who should undertake the work and availability of required funding.

#### Balance ambitions and resources

If an NRC decides to develop a wide range of services and products to support the use of SNOMED CT in the Member country, it will likely promote successful adoption of the terminology. However, it is important that the NRC set up ambitions and timelines realistic in relation to the resources available. Members should carefully consider and define the national visions for use of SNOMED CT in the Member country. Hence, Members should be clear about the way they expect SNOMED CT to be used, which again must align with the national strategy and infrastructure.

It can be useful to consider a stepwise development process, where the NRC prioritizes the initiatives that should be carried out immediately and sets aside initiatives could be scheduled later. This is better than setting the bar too high and initiating too many projects that are difficult to complete.

## Communicate with fellow NRCs

For every stage of NRC development it is essential to get in contact with other NRCs in order to gain insight to existing ways of organizing and running an NRC and to learn from others' experiences. IHTSDO facilitates communication between Members in different



ways, for example through workshops during the biannual face-to-face meetings or by participation in the Member Forum (described later in this document).

#### NRC governance

Every NRC needs a clear governance structure to ensure that the work of the NRC and the strategic decisions are continuously aligned with user needs, national strategic priorities, IHTSDO developments and initiatives, collaborators' work, etc. The NRC should therefore consider what governance structure would be suitable to fulfill the needs of the NRC, as the needs may vary depending on the extent of services and the National Extension the NRC decides to develop.

In the simplest form, NRC governance can be carried out as operational line management of the responsibility for directing the day-to-day work of the NRC. Alternatively, there may be a need for having formal committees to advise on the direction of the NRC. This could, for example, be necessary if a National Extension is developed, as this may entail the need of an editorial committee to define and maintain editorial policies and ensure that they are being followed.



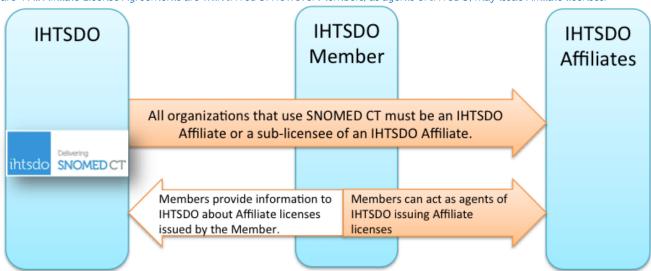
## 5. The role of NRCs related to SNOMED CT licensing

#### Affiliate Licenses

Organizations that develop or distribute products or services that include or provide access to SNOMED CT must be IHTSDO Affiliates. Organizations that use SNOMED CT must be either an IHTSDO Affiliate or a sub-licensee of an IHTSDO Affiliate. Becoming an Affiliate of IHTSDO requires an Affiliate License, which is a contractual agreement between IHTSDO and Affiliates.

Even though Affiliate Licenses are agreements between IHTSDO and Affiliates, Members often act as intermediate agents between IHTSDO and Affiliates by issuing the licenses. In this case, the NRC needs to provide information to IHTSDO about Affiliate Licenses issued by them. The SNOMED CT Affiliate License Agreement is a worldwide license for the use of the SNOMED CT International Edition. Acceptance of the License Agreement entitles an Affiliate to download releases of the SNOMED CT International Edition.

Figure 4 All Affiliate License Agreements are with IHTSDO. However Members, as agents of IHTSDO, may issue Affiliate licenses.



Full details of the conditions of use of SNOMED CT are provided by the SNOMED CT Affiliate License agreement. The notes on the next page highlight a few key points about the availability of Affiliate licenses, conditions of use and circumstances in which charges are applicable for use of SNOMED CT.

#### Obtaining an IHTSDO Affiliate License

- Applicants in IHTSDO Member countries are asked to check the relevant IHTSDO Member webpage for advice on how to apply
  for an Affiliate License within their country http://www.ihtsdo.org/members.
- Applicants who are not in an IHTSDO Member country, or are in Member country that does not currently provide a registration service, can apply for a license using the SNOMED CT Licensing and Distribution Service: https://mlds.ihtsdotools.org

#### Use of SNOMED CT in Member countries

IHTSDO does not charge for use of the SNOMED CT International Edition in Member countries. However, a Member is permitted to impose some conditions on use of SNOMED CT within its country.

#### Use of SNOMED CT outside Member countries

Affiliates are required to pay annual fees to IHTSDO for use in each hospital, clinic and other institution in a country that is not a Member of IHTSDO. The charges for this vary according to the wealth of the country.

Affiliates are also liable to pay fees if they expose SNOMED CT content in ways that enable it to be used in non-Member countries. This includes providing access to SNOMED CT via the Internet, in web application, mobile phone application or as part of a published specification or standard.



#### Provision of services that enable access to SNOMED CT in non-Member countries

Companies or organizations providing apps, web portals and other software that incorporates all or part of SNOMED CT, or publishing mappings or other materials that include all or part of SNOMED CT require the permission of IHTSDO and a license for these activities.

Those providing such access to these service or materials to another company or organization for use in a non-Member country must first confirm that that company or organization is an Affiliate Licensee. Furthermore, they must ensure the recipient of the services or materials understands its obligation to report and pay fees to IHTSDO for use in Non-Member countries.

#### Web-based SNOMED CT browsers

Web-based SNOMED CT browsers that allow SNOMED CT content to be viewed are currently regarded as a special case on which IHTSDO has published guidelines (see http://snomed.org/browserlicenseguidance). However, note that these guidelines only cover use to explore the content of SNOMED CT. They do not exempt those using SNOMED CT in Non-Member countries from obligation to pay fees for use.

#### National licenses

A Member may issue Affiliates with licenses for use of its National Extension of SNOMED CT (including translations, content additions and Reference sets). These licenses must include a requirement for the licensee to hold a SNOMED CT Affiliate License for the International Release. One way to achieve this is to include a copy of the SNOMED CT Affiliate License Agreement within the National License. In this case, care must be taken to ensure that the copy of this agreement is regularly updated with changes approved by IHTSDO.

The terms of the National License could be similar to the SNOMED CT Affiliate License but with the Member as the licensor and the National Extension as the licensed work. Alternatively, the National License might be part of a more general licensing policy for nationally owned works. However, IHTSDO requires that a licensee of a National Extension must also be a SNOMED CT Affiliate Licensee (i.e. a licensee with IHTSDO). A Member can meet this requirement by registering the Licensee's acceptance of the SNOMED CT Affiliate License Agreement.

Members can also impose additional requirements related to the use of the SNOMED CT International Edition in their countries. For example, a Member may require licensees to use of the National Extension when deploying SNOMED CT in its country. The formal responsibility of the NRC is to maintain a register of all licenses granted by the Member to Affiliates within the Member country. This register must include information about:

- 1. The identity of the Affiliate
- 2. The products provided under the license
- 3. The payment terms under the license (if any  $\Box$ )
- 4. Product usage in a non-Member country

If an Affiliate provides information about non-Member country use, the Member is obliged to inform IHTSDO of this so that the correct fees can be charged. In the event of termination of Membership, the former Member must submit the full register of all licenses it has issued to IHTSDO within 30 days.

Members are encouraged to share information about Affiliates they have registered that are based in or operating in other Member countries. They should also inform Affiliates about obtaining a National License in their country of origin.

Figure 5 Members manage licenses issued to Affiliates for national use of SNOMED CT





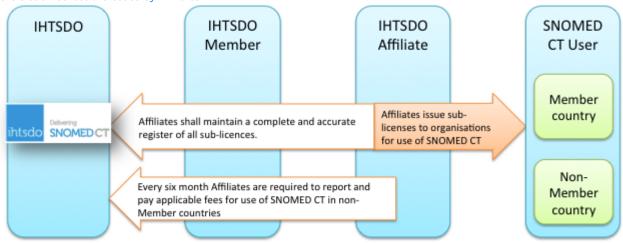
#### Sub-licenses

IHTSDO Affiliates can issue sub-licenses, to allow organizations/users to use SNOMED CT, as part of a software application or information system. An organization that is not itself an IHTSDO Affiliate is only permitted to use SNOMED CT in accordance with the terms of a sub-license issued by an IHTSDO Affiliate.

It is the Affiliate's responsibility to manage these sublicenses and make information about them available to IHTSDO. Affiliates are also required to report and make appropriate payments when SNOMED CT is used in non-Member countries. Sub-licensing is not an NRC function but NRCs need to:

- Understand that Affiliates are required to issue sub-licenses to organizations that use SNOMED CT enabled systems and services that they provide;
- Ensure that Affiliates and users in their country are aware of this requirement.

Figure 6 Sub-licenses are issued by Affiliates.



Members are not required to facilitate or manage sub-licenses. However, as the primary point of contact for the national Affiliates, an NRC should be able to support and guide Affiliates in matters related to the management of sub-licenses and to point Affiliates to the appropriate source of information within IHTSDO.

Licensing and Distribution of SNOMED CT - Tools

IHTSDO provides a platform for licensing and distribution of SNOMED CT for its Member countries. This service is named the Member Licensing and Distribution Services (MLDS) and enables the NRC to have a web based portal in the preferred language where Affiliates register and update their licensing information as well as download SNOMED CT and other related products. The NRC is responsible for translating the interface terminology, etc., but IHTSDO helps the NRC get started. Once registered in MLDS, an Affiliate can access the national distribution from the NRC as well as other NRC products, so long as the Member country is using MLDS. For more information about using MLDS in your country contact your Customer Relations Executive.

IHTSDO does not charge for use of SNOMED CT in IHTSDO Member countries. However, an IHTSDO Member country may charge Affiliates a small fee for cost recovery.



## 6. Implementation consultancy

A desirable function of an NRC is to act as a resource and advisory body for Affiliates. It is crucial for successful national adoption of SNOMED CT that Affiliates are able to obtain the required education, training and guidance. IHTSDO delivers a range of education and training resources, which are described in later sections. However, Affiliates may require further guidance on implementation aspects, on customization, or on SNOMED CT education for specific user groups. An NRC should clarify how it will support requests for education and implementation consultancy.

#### SNOMED CT users

In order to provide the most efficient support to national SNOMED CT users, the NRC should ensure that the available implementation and training resources are focused on the specific types of SNOMED CT users. The NRC must therefore have insight into the different aspects related to SNOMED CT implementation and use, know about the different types of SNOMED CT users, and understand the role and needs each of these groups of users with respect to SNOMED CT knowledge and skills.

Figure 7 illustrates three types of SNOMED CT users who have different needs with respect to learning about SNOMED CT. The knowledge required for users and professionals related to clinical data entry differ from the knowledge required for designers and developers. Moreover, users responsible for information management require more cross-disciplinary knowledge than healthcare professionals, being responsible for reconciling user needs, the terminological framework and system setup. Within the different types of SNOMED CT users there are various user roles, and the individuals in those user roles need to learn about SNOMED CT at various levels of detail and with different points of departure. These generic user types are intentionally broad. Individual Members may identify other user categories and subdivisions relevant to national circumstances taking account of different approaches to eHealth strategy and SNOMED CT implementation.

Figure 7 Three broad groups of SNOMED CT Users

Users	Designers and developers (of IT systems)	Terminology Developers	
Educators and trainers			
Clinical information entry	Decision support systems	Concept model designers	
Clinical information curation	Retrieval and analysis	Content authors	
Clinical information utilization	Communication standards	Translators	
	Terminology services	Map developers	
	Terminology artifact development	Subsets and constraint developers	
		Release process managers	

A description and examples of the different user groups can be found below: Users are those engaged in entry, storage, retrieval and/or reuse of clinical information. Examples

- Healthcare practitioners (clinicians, nurses, therapists, etc.)
- Medical coders and secretaries engaged in clinical data entry
- Clinical knowledge providers and publishers
- Clinical researchers
- Information analysts
- Managers of migration from pre-existing data to SNOMED CT representation

Designers and Developers are those designing, developing, configuring or deploying software systems that use SNOMED CT. IHTSDO has developed a Vendor Guide to support vendors understanding SNOMED CT implementation: http://snomed.org/vendorintro. Examples

- Healthcare solution providers designers and software developers
- System integrators
- Researchers and innovators
- · Clinical experts and others involved in customizing user interfaces and data entry protocols

Terminology Developers are organizations developing and distributing content and other artifacts such as subsets, maps, etc. Examples

IHTSDO



- National Release Centers
- Other institutions working with terminologies
- Researchers and innovators

Educators and trainers are those people involved with education and training of people involved with implementation and use of SNOMED CT.

Examples

• People with the sufficient knowledge to educate and train people within a specific user group and at the level required for the actual user.



## 7. Engaging stakeholders

Working with SNOMED CT and clinical terminology involves many different stakeholders with different objectives and different roles. An NRC can promote successful SNOMED CT adoption by engaging clinicians, vendors, system owners, etc. and supporting awareness of each stakeholder's role in the process of SNOMED CT adoption, implementation and use. However, engagement of users can be difficult, and it is therefore important that the NRC consider how best to engage the various stakeholders. Some Members choose to establish dedicated forums where users and vendors can be regularly updated on the latest initiatives and developments. Alternatively, newsletters and national conferences can be effective in maintaining communication and engagement with relevant stakeholders. For an NRC, such initiatives may also be used to encourage stakeholders to become involved in SNOMED CT development or implementation at an international level through involvement in IHTSDO, for example as participants in a Special Interest Group (see Section 14 - IHTSDO bodies and forums).

There are various ways to promote the engagement of stakeholders, but is important to approach the stakeholders selectively on topics which are relevant to a specific user group. If the user can see the point and feel convinced of the potential benefits and the importance of their engagement, they will be more likely to feel encouraged to participate and take responsibility.

Advice for engaging stakeholders:

- Disseminate SNOMED CT potential and benefits: Who is it for? What can it do? What are the benefits?
- Give examples that relate to the work of the specific stakeholder/user group.
- Engage in regular contact to give stakeholders the opportunity to raise issues (and get them resolved) collectively.
- Find SNOMED CT Champions: Find someone or a group that has successfully implemented SNOMED CT and leverage that success to engage others. Encourage these champions to tell others about their experience of the practical value of using SNOMED CT.
- Explain how SNOMED CT fits within the systems and standards already in use: Usually users don't know how SNOMED CT will influence current practice.
- Take on national initiatives: Focused subset and content development activities are very useful for engaging clinical groups.



## 8. Education and training

Users must be equipped with adequate knowledge and skills that enable them to practice the tasks of the specific user group. Moreover, it is important that users are trained to understand and conduct SNOMED CT implementation in accordance to the visions, strategy and infrastructure of the given Member country. The following sections consider the roles of IHTSDO and NRCs in education and training related to SNOMED CT.

#### IHTSDO Role in SNOMED CT Education

The overall role of IHTSDO in SNOMED CT education and training is to provide consistent information about SNOMED CT, advice about benefits and guidance on effective ways to use SNOMED CT in order to realize those benefits. In addition, wherever possible, IHTSDO shares its documents and training services in ways that enable NRCs to reuse, translate and customize them to meet national requirements. The documents, educational resources and services that IHTSDO provides to assist the process of learning about SNOMED CT are outlined below.

#### SNOMED CT Document Library

The SNOMED CT Document Library provides online access to a wide range of SNOMED CT related documents. These documents range from SNOMED CT introductions targeted at particular audiences, through to detailed specifications, specialized guides and reports. On the Document Library web pages you will find a short introduction to each of the documents, and a link to allow you to freely access these documents. These documents are available either for online browsing or as PDF downloads - and in many cases both formats are provided. Some documents include draft materials, and therefore readers should be aware of the status of the document or section, which is indicated either by textual status notes on individual pages or in the document preface.

The Document Library (http://snomed.org/doc) provides access to the key documents about SNOMED CT

Feedback from Members on the documentation is important for IHTSDO to ensure that the readers are provided with the best possible materials for learning about SNOMED CT. Members/users/readers are requested to provide any kind of feedback on the documentation, for example if clear faults or missing content are detected, or if there are some unclear parts that need clarification.

Comments on online documents can be posted as comments on the pages of the published document. For documents that are not available online, please look in the document for details of how to comment.

#### SNOMED CT E-Learning Courses

IHTSDO offers online SNOMED CT training courses. Currently these courses are available free-of-charge. However, each course has an application form that must be completed to sign-up for the course.

#### SNOMED CT Foundation Course

The objective of this course is to extend the depth and breadth of knowledge of SNOMED CT in the global community. The course aims to provide authoritative coverage of a broad range of topics related to SNOMED CT at a relatively basic level. It also enables the growth of more detailed understanding of SNOMED CT by enabling those who complete this course to join more advanced SNOMED CT E-Learning courses in future. This course is targeted at anyone seeking to acquire or demonstrate a broad foundational knowledge of SNOMED CT.

Applications are permanently open and all applicants should be offered a start date within 4 to 6 weeks of receipt of their application. Study is self-paced and is expected to require a total of 30-35 hours. The course must be completed within a maximum of four months but it is possible to complete it within as little as two weeks.

#### **SNOMED CT Implementation Course**

This course builds on knowledge gained during the SNOMED CT Foundation course. It provides an understanding of SNOMED CT that is sufficient for those engaged in various parts of the implementation process – from the decision to adopt SNOMED CT, through to specification and procurement and/or design and development of SNOMED CT enabled solutions, to deployment and practical use. Successful completion of the Foundation Course is a prerequisite for applying for this course. The first intake new intakes occur in January, May and September each year and capacity of each intake is limited. The course duration is 6 or 7 months with an estimated time commitment of 15-20 hours per month.



#### Content Development Theory Course

This course is initially aimed at National Release Center staff in Member countries that are developing or planning to develop a National Extension. It may also be of interest to other organizations that are developing SNOMED CT Extensions.

Successful completion of the Foundation Course is a prerequisite for applying for this course. The first intake new intakes occur in

Successful completion of the Foundation Course is a prerequisite for applying for this course. The first intake new intakes occur in January, May and September each year and capacity of each intake is limited. The course duration is 3 or 4 months with an estimated time commitment of 15-20 hours per month.

#### **Future Courses**

Other courses and specific additional course modules are under consideration for development in 2016.

#### Open Access E-Learning Presentations

A small collection of open SNOMED CT Starter presentations can be viewed without the need to login to an account on the server. They provide an introduction to some of the key benefits and features of SNOMED CT. This is a good place to start learning informally before joining a course. A growing collection of additional open access online presentations will become available in late 2016 to those who have created an account on the E-Learning Server without the requirement to enroll of a formal course.

#### SNOMED CT Challenge

The SNOMED CT Challenge is a randomly generated test consisting of ten questions. This open access service but requires you either to create an account or to login using a temporary anonymous account.

#### Other Educational Materials

The E-Learning Server also includes a set of pages that provides access to Other Educational Resources. The materials referenced in these pages are not part of the E-Learning service provided by IHTSDO. However, they include many interesting conference presentations related to SNOMED CT as well as links to SNOMED CT educational services provided by IHTSDO Members. The SNOMED CT E-Learning Center can be accessed via this webpage: https://elearning.ihtsdotools.org.

#### **IHTSDO** Training Schemes

IHTSDO hosts a Consultant Terminologist Program to train people in skills related to SNOMED CT development. The program recruits new participants once a year, with announcements appearing on the IHTSDO webpage. NRCs may be interested in nominating individuals who have an established understanding of SNOMED CT for this program, for example to train NRC staff.

#### Consultant Terminologist Program

This program is designed to train individuals who can assist the Head of Terminology and Head of Content to address content development issues and to develop editorial policies and procedures. One outcome for participants is to understand and describe the phases of editorial policy development and the differences between each phase.

To read more about this program and to see lists of former participants in this and other training schemes see: http://snomed.org/consultant-terminologist.

#### SNOMED In Action

IHTSDO has a website called SNOMED In Action, which offers Members and other users an opportunity to register SNOMED CT deployments and provide various details about specific SNOMED CT implementation and usages. Other Members and users may be inspired to follow these examples, or get in contact with persons and institutions that have been involved with specific SNOMED CT implementations.

IHTSDO encourages Members and other stakeholders and users to register their SNOMED CT deployments on this site in order to facilitate knowledge sharing and awareness about how SNOMED CT can be applied and how to reap its benefits. On this webpage you find an overview of different examples of SNOMED CT in use, and you also have the opportunity to register your own SNOMED deployment: http://www.snomedinaction.org.



#### NRC Roles in SNOMED CT Education

To address national implementation requirements, NRCs are encouraged to supplement or customize training resources published by IHTSDO. This includes translating documents and training resources where necessary. Education related to some specific aspects of national strategy may be well served by materials developed from scratch by the NRC. For example, if specific reference sets are to be used within specific clinical domains to meet specific reporting requirements, then guidance on the use of these Reference sets could be needed along with information about the reporting procedures.

Whether an NRC develops its own training materials or modifies resources provided by IHTSDO, it is important that any explanation of SNOMED CT be accurate and in accordance with the formal SNOMED CT specifications. Therefore, the NRC should regularly review the its SNOMED CT related training materials to ensure alignment with updates to International materials.

If an NRC takes on education of the national Affiliates and users, it is important that staff of the NRC have a broad and deep understanding of the different implementation levels and possibilities and can facilitate requests from different user groups. Alternatively, the NRC can advise or direct Affiliates to places and persons where they can get the appropriate guidance. The NRC must therefore be aware of people, nationally or internationally, who have the appropriate skillsets to educate and guide users on specific topics. A combination of internal and external resources to provide training and education is a reasonable solution for many NRCs. Individuals learn in different ways. The NRC may wish to consider delivering face-to-face or online training so that individuals get a chance to ask questions and develop their thinking. Short introductory sessions on the principles of SNOMED CT and a walk through the release are good ways to get people started. They may then find the reference materials much more accessible.

Tools for exploring the content of the International and/or

National Edition of SNOMED CT



## 9. Tooling

There are numerous tools that NRCs may need, depending on the extent to which they customize or extend the SNOMED CT International Edition.

The tools necessary for an NRC depend on what services the NRC will deliver and what approach the NRC will take to deliver its services. However, at a minimum, an NRC needs a platform where SNOMED CT can be made available to users, i.e. a tool to support distribution to users of the International Edition (received from IHTSDO) and potential National Extensions. Moreover, if the NRC decides to develop National Extensions, including a national translation or national Reference sets, tools are also required to support these tasks. Figure 8 shows various types of tooling that an NRC can use to support its work with SNOMED CT.

Figure 8 Tools useful for an NRC Work task Tool Tools for distribution of the International Release of SNOMED CT Distribution and National Extensions Tools for management requests for changes to the International Change requests and National Edition of SNOMED CT Development and Tools for development and management of Extensions, Reference customization sets, maps Tool for creating release files and for running QA rules etc. QA and file creation (so that release files can be quality assured before they are distributed to users)

Later sections of this document present the typical practice and tools related to each of the above work tasks.

#### IHTSDO Tooling service

Search and browsing

NRCs are free to choose or develop tools to enable distribution and management of SNOMED CT and national derivatives in their countries. However, IHTSDO puts great effort into development of IHTSDO tooling services, which represent a range of services and tools that have been made available to support IHTSDO, Members, and the Community of Practice. Over time, IHTSDO aims to include tools necessary to support the full range of essential NRC functions in its tooling services.

Tooling service developments are now based on the IHTSDO's Open Tooling Framework (OTF) and the source code is made available under an Apache v2 open source licence (where feasible). This framework is a set of standardized application programming interfaces (APIs), bound by a set of principles that define fundamental software services. These services are consumed by business applications, which are being developed to satisfy the tooling requirements of IHTSDO and its Members.

IHTSDO tooling services are listed at http://snomed.org/tools. This page provides a list of the tools' status and pointers to useful documentation for both users and developers.



## 10. SNOMED CT browsers

SNOMED CT Browsers are software applications or tools used for searching, navigating, viewing and reviewing terminology content. For NRCs that want users and potential users to increase and enhance their knowledge of SNOMED CT, it can be a good idea to make a SNOMED CT browser freely available.

A typical browser can locate concepts and descriptions by searching the text of descriptions (terms) or by entering SNOMED CT identifiers. Browsers may also provide a way to navigate the SNOMED CT hierarchies. Browsers may display views of various artifacts including the set of related descriptions, the hierarchical relationships and other defining relationships of a concept.

A variety of different SNOMED CT browsers are available online, as downloadable applications or as web-based applications. But a Member can also choose to develop its own SNOMED CT browser and make it available for national users. This is especially relevant if national customized SNOMED CT content is developed and should be browsable, such as translations, Reference sets, etc. An NRC may download and install for national use the IHTSDO open source browser. As this is open source, it is also possible to add functionality to it. If an NRC does this, its contribution of the components back into the open source repository may be highly beneficial for all Members.

On the IHTSDO webpage on SNOMED CT Browsers, IHTSDO provides a list of the different types of browsers available. It is possible to add items to this list if you are aware of other browsers that are not included. Browsers are eligible for inclusion in the list if they are freely accessible software applications that provide searchable access to SNOMED CT.

On the SNOMED CT Browser webpage it is also possible to access the SNOMED CT Members' Browser Requirements document, which presents a set of requirements for a SNOMED CT browsers as identified and prioritized by IHTSDO Members. IHTSDO Members may wish to make previews and releases of their National Editions (i.e. International Release + National Extension) available for review by stakeholders in their country. The shared understanding of required functionality outlined in this document is the first step towards ensuring widespread availability of browsers that meet these requirements.

- The IHTSDO Browser can be found here: http://browser.ihtsdotools.org.
- SNOMED CT Members' Browser Requirements can be found here: http://snomed.org/MemberBrowserReq
- An overview of some other SNOMED CT browsers can be found here: http://snomed.org/browsers
- Licensing conditions for use of online SNOMED CT browsers can be found here: http://snomed.org/browserlicenseguidance



## 11. Distribution of SNOMED CT

A core responsibility of an NRC is to make the International Edition of SNOMED CT and/or the National Extension of SNOMED CT available for Affiliates.

Every NRC must therefore be able to provide guidance on access to SNOMED CT, version control and management. Moreover, the NRC should be able to provide guidance to users on specific terminology services that are provided by the NRC, and in the use of national SNOMED CT developments, such as National Extensions, Reference sets, etc.

IHTSDO maintains and delivers shared content and derivatives  $^{\frac{1}{2}}$  that provide the foundation of SNOMED CT. This is known as the SNOMED CT International Edition.

SNOMED CT is distributed as sets of files containing terminology components and derivatives. These release files contain the basic data needed to implement SNOMED CT in various modes in a technology-neutral formats. The format, content and names of the files delivered conform to SNOMED CT specifications and guidelines published in Section 5 of the Technical Implementation Guide (http://snomed.org/tig).

Components represent the content of the terminology.

The standard SNOMED CT representation for content is as three interrelated files. The Concept file contains unique identifiers for clinical ideas, the Description file links human readable terms with identified concepts, and the Relationship file represents associations between identified concepts.

Derivatives facilitate the effective use of the terminology.

The standard SNOMED CT representation for derivatives is a consistent but flexible file format, known as the Reference set format. Reference sets can be used for a wide range of purposes including subsets, language preferences, ordered lists, hierarchies, annotations and mappings to or from other terminologies, classifications and code systems.

#### Access to SNOMED CT release files:

Members of IHTSDO and Affiliates outside of Member countries, both access the release files via IHTSDO's SNOMED CT Licensing and Distribution Services (MLDS).

All files distributed to Members are available from the "SNOMED CT International Edition" product page on MLDS, and can be accessed here: https://mlds.ihtsdotools.org/#/ihtsdoReleases/ihtsdoRelease/167

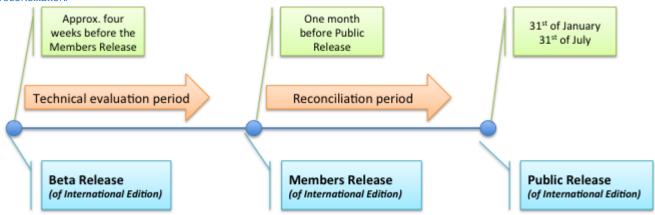
Access and information about MLDS can be found here: https://mlds.ihtsdotools.org.

IHTSDO has provided a guide on how to use SNOMED CT release files, and that guide is useful to gain knowledge on the content of the SNOMED CT release files and an understanding of how the data in the release files support the many uses of SNOMED CT. Guidance on how to use SNOMED CT release files can be found in the Technical Implementation Guide http://snomed.org/tig.

#### Release Lifecycle

IHTSDO provides regular updates to the SNOMED CT International Edition. SNOMED CT is released biannually on the last day of January and July each year. Although changes to this schedule are possible in the future, this release cycle has been maintained regularly since 2002. Similarly, Members and Affiliates that maintain Extensions should regularly release updated versions of their Extensions. Every release cycle of SNOMED CT follows a certain pattern, which is important for NRCs to be acquainted with, as this cycle reflects periods when an NRC must be prepared to conduct evaluations of the International Edition and reconcile the new release with existing national developments.

Figure 9 A National Edition of SNOMED CT must be aligned with the International Release of SNOMED CT and include time for reconciliation





#### Beta Release

Approximately two months before each new public release of the SNOMED CT International Edition, a Beta Release is made available to IHTSDO Members (NRCs). Although IHTSDO completes a thorough quality assurance (QA) process on each International Release, the Beta Release provides an opportunity for key stakeholders to perform independent QA on the files and provide feedback to IHTSDO prior to distribution of the final release. NRCs are expected to provide a written report on any issues encountered, to which IHTSDO will formally respond.

The Beta Release is only for QA use by Members. It should not be distributed to Affiliate Licensees or any other third parties without the permission of IHTSDO.

Examples of technical quality assurance tests applied to SNOMED CT releases:

- Standard technical QA SQL database gueries
- Testing the technical integrity of files
- Load testing loading data into a schema
- Assure integrity of release files
- Pick up integrity flaws with the files
- Acceptance test log ability to audit the release process

While IHTSDO undertakes these tests, an NRC may choose to replicate them or extend some of these tests in their own technical environments to provide additional quality assurance.

#### Members' Release

Regular changes to SNOMED CT are necessary in order to satisfy user needs and requirements and to improve the quality of SNOMED CT itself. An NRC must be aware that any change to SNOMED CT may have impact on National Extensions and guidance. Therefore, every release requires reconciliation to ensure that all National Extensions remain aligned with the International Edition. To accommodate this need for reconciliation, Members gain access to each International Release one month before the public release of the SNOMED CT International Edition. The purpose of this Members' release is to allow the NRCs to reconcile their national developments according to the new International Edition prior to the public release.

If SNOMED CT components (concepts, descriptions or relationships) are added or inactivated, an assessment of how these changes affect a National Extension is be required, and adjustments to the national developments may be needed. For example:

- Added concepts may require translation and may also be candidates for addition to national Reference sets.
- Inactivated concepts that members of a National Reference set may need to be replaced with an appropriate active concept.

#### Release files

With every SNOMED CT release three different release file types are made available:

- Full Release: containing the complete history of every component
- Snapshot Release: containing the current state of every component
- Delta Release: containing only the additions and changes since the previous release

The International Edition is provided in all three release types. However, as the Snapshot and the Delta can be generated from the Full Release, the specification only requires that organizations that maintain Extensions provide a Full Release of their extension. Guidance on import of the different release types can be found in the following section of Technical Implementation Guide: http://snom.ed.org/tig.

A SNOMED CT Derivative is a document, subset, set of maps, or other resource that consists of, includes, references or is derived from one or more SNOMED CT components. The standard computer processable representation for most types of SNOMED CT derivatives is a Reference set.



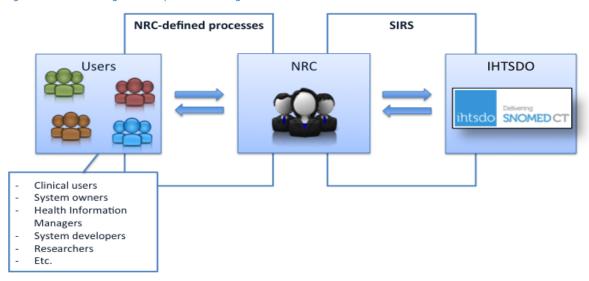
## 12. Change requests

SNOMED CT is developed for implementation and use in health IT systems, so it is essential for successful adoption that the terminology fulfill user requirements. To facilitate continued development and enhancement of SNOMED CT, IHTSDO is dependent on ongoing feedback from users. A significant responsibility of an NRC is therefore to provide IHTSDO with feedback from users in the Member countries on errors, limitations and suggestions for changes to the SNOMED CT content. Regarding management of change requests, each NRC must:

- 1. Maintain a record of problems and other issues reported within the Member country, and
- 2. Document, submit and support requests for proposed updates and enhancements to SNOMED CT

An NRC must therefore provide a mechanism for supporting requests from users, both related to the National Edition (where it exists) and International Edition of SNOMED CT. Requests for the International Edition should be communicated to IHTSDO, whereas requests for the National Edition must be managed locally.

Figure 10. NRCs manage user requests for changes to both the National and International Editions of SNOMED CT [1]



How user requests are submitted to the NRC is up to each NRC to decide. An NRC can choose to have its own request submission system, but the solution could also be a simple mailing system or a file-transfer system. This depends on the level of SNOMED CT use (and hence, the number of requests) within the Member country. An NRC could decide to have a simple system in the NRC-establishment phase and then launch a more sophisticated system when the number of requests increases.

#### SNOMED CT International Requests Submission System (SIRS)

SIRS is IHTSDO's online request submission system, which allows Member countries' NRCs and other authorized users to submit requests for change or addition of new content to the International Edition of SNOMED CT. Hence, all user requests for the International Edition of SNOMED CT should go via the NRC, and each NRC should have access to SIRS. Concepts of only national relevance should not be submitted to IHTSDO. It is the responsibility of the NRC to determine which request is specific to its country and which are of international relevance. NRCs should be aware of the editorial principles for SNOMED CT and only submit requests that meet those principles.

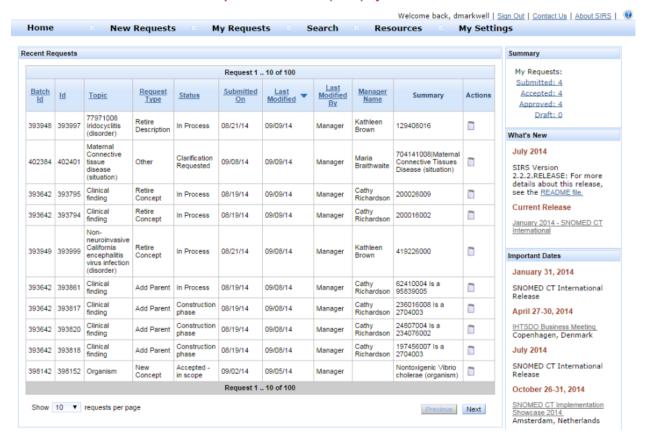
Requests submitted to SIRS are reviewed by IHTSDO Authors, and requests that meet the SNOMED CT International Edition inclusion criteria are added to the International Edition. SIRS is an online tool, which enables users to view the current status of all requests that have been made through the system, see Figure 11.



Figure 11 Screenshot from SIRS. Example of overview of requests submitted to the system.

INTERNATIONAL HEALTH TERMINOLOGY
STANDARDS DEVELOPMENT ORGANISATION

#### SNOMED CT® International Request Submission (SIRS) System



Users are notified by email when a request changes status (accepted, not accepted, in process, or clarification requested). If a request is not accepted, a reason is provided to the requestor. A requestor who is unhappy with the reason for not non-acceptance can appeal using a formal appeals process.

For up-to-date information about current arrangements and for access to SIRS see http://snomed.org/sirs

Change requests to the International Edition are submitted to IHTSDO via the online SNOMED CT International Request Submission (SIRS) system



## 13. Content development and SNOMED CT customization

For successful SNOMED CT adoption, it is important that the terminology conforms to the requirements of the specific use cases in the given country or within a given organization. In most situations this requires adjusting or extending the terminology, which can be done in various ways. IHTSDO authorizes Members and Affiliates to maintain and deliver additional components and derivatives known as SNOMED CT Extensions. These extensions are the formal way of conforming SNOMED CT to suit specific user requirements.

#### Extensions

IHTSDO Members may maintain and deliver additional terminology components and derivatives that adapt the terminology to meet specific national requirements. Moreover, IHTSDO Affiliates may also maintain and deliver additional terminology components and derivatives that adapt the terminology to meet the needs of a particular organization, customer or software solution. Extensions can therefore be distinguished as either National Extensions or Affiliate Extensions.

A National Extension may include:

- translation into the national language or adaption to a national dialect;
- additional content to support national policy objectives, a national drug dictionary or other specific requirements;
- derivatives that configure use of SNOMED CT content by specifying subsets of content to be used for particular purposes;
- · derivatives that map other code systems used in that country to or from SNOMED CT.

#### An Affiliate Extension may include:

- · additional content to enable a health provider organization or clinical specialty group to address its priority use cases;
- derivatives that configure use of SNOMED CT in ways that reflect the needs of a health provider organization or specialty;
- derivatives that configure the way SNOMED CT is used or presented to different customers using particular software applications;
- derivatives that map local or proprietary code systems to or from SNOMED CT.

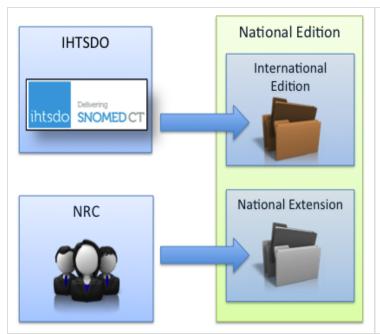
Development of National or Affiliate Extensions requires the NRC or the Affiliate to have a Namespace Identifier, which is assigned by IHTSDO. A Namespace Identifier is used to identify the origin and the affiliation of each extension component. An NRC has the responsibility to ensure that any deployment of SNOMED CT and other IHTSDO terminology product conforms to IHTSDO standards. An NRC therefore serves as a point of contact for Affiliates to obtain guidance and advice in the development and maintenance of Affiliate Extensions.

#### Extensions and Editions

The SNOMED CT International Edition can be used without any Extensions. However, a SNOMED CT Extension cannot be used on its own because all Extensions are dependent on the International Edition, and some Extensions are also dependent on other Extensions. Therefore, for each Extension there is a corresponding Edition that includes the Extension, the International Edition and any other Extensions on which it depends.

Figure 12 A National Edition includes both the National Extension and the International Edition





All organizations that maintain Extensions should make their Extension available as a separate set of files, even if they also provide a pre-merged Edition. This allows validation of the constituent parts of the Edition and also supports merges to produce bespoke Editions that combine several Extensions.

#### Translation

The International Release of SNOMED CT contains terms in US English, GB English and Spanish. However, SNOMED CT is designed to support multilingual use by enabling terms in any language to be linked to the same concepts. Many of the current IHTSDO Members do not use English as the primary language in the delivery of healthcare, and therefore Members may require a translation of SNOMED CT to achieve a national terminology resource and to support users in the correct interpretation of the SNOMED CT content. The responsibility for translation is with those Members that use a particular language in the specific Member country. However, while Members are permitted and encouraged to translate SNOMED CT, this is not an obligation of membership. Each Member should consider whether or not to translate SNOMED CT into the native language and/or dialect, given the actual visions for use of SNOMED CT within that Member country.

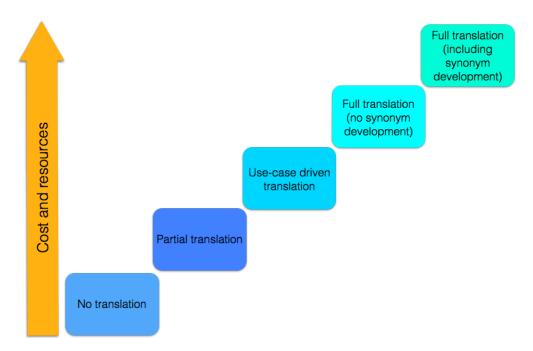
A number of IHTSDO Members have already translated SNOMED CT into their native languages. These translations are managed within each of the particular Member countries as National Extensions and have been created based on IHTSDO regulations but according to the particular Member's requirements. Each translation may be shared with other Members, and all Members have an obligation according to the Articles of Association to share their translations upon request.

#### Translation approaches

Translating SNOMED CT does not necessarily mean a translation of the full SNOMED CT International Edition. An IHTSDO Member can decide to translate parts of SNOMED CT to obtain a core set of components to be used within the country. Another approach is to translate concepts that are to be applied within a specific organization, clinical domain, etc., which means a more use-case driven translation.

Figure 13 Different levels of SNOMED CT translation





#### Translation Policy

IHTSDO believes that translations of SNOMED CT are very important because a translation can support SNOMED CT adoption due to enhanced understanding of the SNOMED CT content amongst the end users. Therefore IHTSDO has initiated a translation policy that reimburses a Member country for:

- 1. 100% of the cost of translating concepts, which will be considered the "core" or starter set;
- 2. The cost of translating one implementation document; and
- 3. The cost of one SNOMED CT course.

(The maximum payment for each Member will be 150,000 USD.)

More information about IHTSDO Translation Policy can be found here: http://snomed.org/TranslationPolicy

#### Translation Guidance

Together with Members, IHTSDO has produced documentation that assists Members who decide to translate SNOMED CT. The documentation should support effective translation processes and enable Members to learn from the successes of those that have already set out on this task. The documentation can be found on the IHTSDO website and includes the following:

#### Guidelines for Translation of SNOMED CT

This document describes important issues relevant to the translation of SNOMED CT, formulates recommendations, and establishes guidelines. The general guidelines may be used as a template to develop national guidelines. In addition to linguistic and terminological guidelines, the document includes general recommendations about the steps involved in a translation workflow process and information about source documents or references that must be made available to those involved in the translation process.

#### Guidelines for the Management of Translations of SNOMED CT

This document is a companion guideline to be used with the "Guidelines for the Translation of SNOMED CT" and offers recommendations on management of a translation project. The purpose is to help new Members undertaking translations to avoid mistakes and enable them to build on existing experiences.

#### A Methodology and Toolkit for Evaluating SNOMED CT Translation Quality

This document describes the use of IHTSDO methodology and toolkit for evaluating SNOMED CT translation quality and has been developed to conform to IHTSDO Quality Assurance Framework. The document also includes the actual toolkit and therefore is useful for any Members looking for translation support materials.

#### IHTSDO Quality Assurance Framework



The IHTSDO Quality Assurance Framework, with its supporting IHTSDO Quality Assurance Toolkit, was developed by IHTSDO Quality Assurance Committee and aims to support the development and reporting of Quality Metrics across all areas of IHTSDO activity, including organizational processes and support, data products (e.g. terminology reference data, mappings, translations, subsets), documentation, and IHTSDO-responsible services and tooling provisions.

Other resources are also available, mostly concerning the practical experiences of those who have undertaken translation development.

#### Reference set development

Many implementations of SNOMED CT do not require users to have access to the full set of content. Often just a part of the data related to a particular discipline or organization will be needed. It is possible to constrain the content required by the use of the subsets or Reference sets.

Reference sets are sets of references to SNOMED CT components. Simple reference sets contain just the information needed to define a subset. However Reference sets can be richer than subsets, as they can also include further information about the components and have been defined for other purposes such as mappings to other vocabularies or providing alternative hierarchical structures. Reference sets are distributed as tab-delimited text files with each row including a SNOMED CT component identifier for the Reference set member. There are also several standard fields that support versioning and additional fields defined to meet the requirements of specific Reference set types.

Full details on Reference sets and the Reference set format may be found in the Reference Sets Guide, which is part of the Technical Implementation Guide: http://snomed.org/tig.



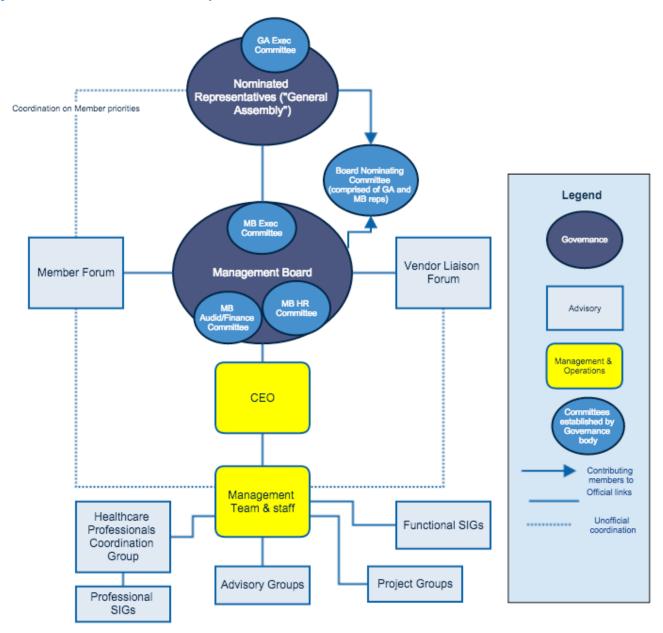
## 14. IHTSDO governance, advisory group and events

It is important that all Members are familiar with the existence and responsibilities of the different bodies and forums of IHTSDO in order for the them to know what roles and responsibilities the Member and, more specifically, the NRC plays (or can play) within these, but also to be acquainted with the support and benefit each Member can get by engaging in the different forums.

The bodies and forums of IHTSDO are the foundation for the continuous maintenance, development and distribution of SNOMED CT, and they provide the organizational framework for communication and collaboration between the different parts of the SNOMED CT community.

An overview of the different Bodies and Forums is shown in Figure 14.

Figure 14 - IHTSDO Governance and Advisory Structures





### General Assembly

The General Assembly is the highest authority in IHTSDO and contains one representative from each of its national Members. The General Assembly is collectively responsible with assuring that the Purpose, Objects and Principles of the Association are pursued and that the interests of IHTSDO are safeguarded. It can make binding decisions regarding all matters relating to IHTSDO, subject to and in accordance with the provisions of the Articles of Association, such as budget, work plan and strategic goals. It is recommended though not required that General Assembly representatives attend all meetings. Face to face meetings occur usually twice per year with occasional teleconferences and electronic voting.

#### Management Board

The Management Board is appointed by the General Assembly. Members have the opportunity to nominate delegates to the Board. The Management Board directs the Association and has the responsibility for key business decisions. It has at least three face-to-face meetings per year with teleconferences between these meetings.

The Management Board also appoints the Chief Executive Officer (CEO), who has day-to-day responsibility for running the organization. A Management Team, with members each responsible for a particular line of business, supports the CEO and directs the work or additional employees.

#### **Forums**

#### Member Forum

Each IHTSDO Member is entitled to choose a representative to the IHTSDO Member Forum (MF). The MF acts as an advisory body to the Management Board.

The MF is also a means for optimizing the collaboration and coordination among IHTSDO Member countries provides a means for Members to have discussions on specific Member issues. Moreover, the MF facilitates contact and communication between countries with similar foundations, needs, priorities, etc. It is recommended that each Member gets involved with and makes use of the MF. The MF can raise issues of concern to the Management Board and is asked by the Management Board for specific feedback on items. The MF is the conduit for communicating widely on consultations that IHTSDO may undertake. These consultations may include specific issues related to SNOMED CT content or IHTSDO documents, products and services. The MF is also a key player in determining which IHTSDO work items should be undertaken and prioritized.

#### Vendor Forum

The structure and role of the Vendor Forum (VF) is currently being revised as part IHTSDO's vendor strategy. As an expert group from a range of industry sectors, the VF will identify ways to facilitate use of SNOMED CT.

#### Advisory groups

Advisory Groups were established in June 2015 to conduct specific activities that contribute to the fulfillment of the Management Team's responsibilities or the organization's mandate. They are meant to be agile in nature, given the changing needs and direction of the organization, and therefore each group is reviewed on an annual basis to determine if it is still required or if changes in the Terms of Reference are needed. Generally the Advisory Group members have specific skills and abilities related to that particular group. The role of each Advisory Group is to provide advice to the applicable Management Team member(s) on specific areas that are included in the Terms of Reference to further the knowledge and direction of the organization. At the beginning of each year, each Advisory Group develops a group work plan outline, determines whether Task and Finish sub-groups are required, outlines any resource requirements needed, and lays out a set of measures in order to monitor the progress of the applicable group work plan. The organization, with the approval of the Management Board, may elect to seek approval for a separate budget items in the annual budget to assist the Advisory Groups in the completion of their approved work plans. All work plans are to be submitted to the CEO annually for review and approval.

NRCs should note that Advisory Group members are selected by two different nomination processes. The Terms of Reference of each Advisory Group describes which of the two is relevant (or if a combination of the two is used).

Member-based nominations

Member-based nominations are used when IHTSDO seeks to create a forum for IHTSDO staff to work closely with IHTSDO Members. Under this system, Members nominate representatives to serve on an Advisory Group, so the Advisory Group members are representing their Member countries. Typically the Management Team member who chairs the Advisory Group contacts the General Assembly and Member Forum representatives in May or June and invites them to nominate a representative with a particular skill set. IHTSDO then accepts all of those nominees or a subset of them. Any travel expenses of the Advisory Group members to attend approved face-to-face



events are then assumed to be the responsibility of the Member. A Member's refusal or inability to pay these expenses does not invalidate or prejudice the nomination in any way, and teleconferencing for those who cannot attend in person is a typical option. Standard nominations

Other Advisory Groups rely on a standard, open, skills-based nomination process. Advisory Group members selected through this process may submit to IHTSDO any approved travel expenses for reimbursement to attend approved face-to-face Advisory Group events (the IHTSDO Travel Policy has more information about approved expenses and means of submission).

Can Members nominate individuals to serve on Advisory Groups that utilize the standard nomination process? Yes. For example, you might nominate your NRC IT expert to serve on the Modeling Advisory Group, which uses the standard nomination process. IHTSDO might select her based on her skills. Who then pays for her travel expenses to attend an Advisory Group face-to-face meeting? She would be entitled (but not required) to submit her expenses for reimbursement from IHTSDO, because she is serving on the Advisory Group as an expert, not as a representative of her Member country.

Advisory Groups and their nomination processes as of 2015

Group name	Nomination process
Content Managers AG	Member-based
E-Learning AG	Mixed
Modeling AG	Standard
SNOMED CT Editorial AG	Standard
Software Development AG	Standard
Terminology Release AG	Standard
Tooling User AG	Member-based

#### Special Interest Groups

Besides the Standing Committees, a set of Special Interest Groups (SIGs) function as advisory bodies on issues related to their specific areas relevant to the strategic direction and resulting specific work areas of IHTSDO, its Members and the Community of Practice. The SIGs are open to anyone who is interested, and they are important for IHTSDO to ensure professional and pertinent input to the Management Board and the Standing Committees. Therefore it is also important that the NRCs encourage appropriate national Affiliates/users to engage in these groups, in order to support a broadly-based composition of the groups with high professional competency and experience.

Two types of Special Interest Groups exist. The Functional SIGs provide expert advice and feedback on core functional areas (e.g. education, translation, implementation, etc.) within the scope of IHTSDO work, from an international perspective. The functional SIGs report to one of the Standing Committees. The Professional SIGs provide advice to IHTSDO on relevant clinical aspects and a link to appropriate international clinical professional groups (e.g. nursing, pathology, etc.).

Further information about the SIGs and instructions for how to join can be found on the IHTSDO webpage: http://snomed.org/sig.

#### IHTSDO Collaborative Space - Confluence

Confluence is an online forum/space where the people within IHTSDO Governance and Advisory Bodies can communicate and share information. Confluence facilitates a range of types of communications, including written discussions, meeting announcements and document sharing.

IHTSDO Members, Affiliates, or other interested parties can gain access to the Collaborative Space to learn more about IHTSDO, SNOMED CT, or to participate in a Special Interest Group or a Project Group.

Information about Confluence is available at https://confluence.ihtsdotools.org

#### **IHTSDO** Meetings and Events

IHTSDO arranges two events a year. In April it holds a Business Meeting and in October a second Business Meeting is combined with the annual SNOMED CT EXPO. The venue of the October event varies each year and Members encouraged to submit proposals for hosting the event in their country.

**Business Meetings** 



IHTSDO Business Meetings include face-to-face meetings of the IHTSDO Governance Bodies, Committees and Forums. Business Meetings may also include face-to-face meetings of some of the Special Interest Groups.

While meetings of Committees and Special Interest Groups are open to observers, some sessions of other groups are closed and may only be attended by members of the relevant bodies.

A key part of each Business Meeting is the open meeting of the IHTSDO General Assembly, where the key strategic decisions, plans and achievements are made and announced.

#### SNOMED CT EXPO

The SNOMED CT EXPO is an open event for anyone interested in SNOMED CT and practical applications of the terminology. The event includes invited keynote speakers and several tracks of peer-reviewed presentations about SNOMED CT in general with a focus on implementation experiences and developments that facilitate more effective use of the terminology.

The EXPO also includes tutorials and workshops for those seeking greater understanding of SNOMED CT, an exhibition of vendor products that use SNOMED CT and a range of poster presentations on related topics.

The EXPO is the main annual event in the IHTSDO calendar for anyone interested in the use and development of the global healthcare terminology. In addition to the scheduled sessions, it provides an excellent opportunity to network with others with a shared interest in SNOMED CT.



## 15. Further information

The NRC Guide is intended as a useful starting point for National Release Centers. More detailed information and a range of informative documents and training materials can be accessed from the IHTSDO web site <a href="http://www.ihtsdo.org">http://www.ihtsdo.org</a>. The table below provides links to many of the key resources for further learning about SNOMED CT.

Topic	Key reference
General information about SNOMED CT Materials include a benefits paper, a very short introductory presentation and information about licensing.	http://www.ihtsdo.org  • http://snomed.org/benefits • http://snomed.org/snomedintro • http://snomed.org/license
SNOMED CT Document Library Access to a wide range of documents about SNOMED CT	http://snomed.org/doc
SNOMED CT Browsers The IHTSDO SNOMED CT browser and a list of other tools for exploring SNOMED CT content	http://browser.ihtsdotools.org http://snomed.org/browsers
SNOMED CT In Action Examples of how SNOMED CT is being used around the world.	http://www.snomedinaction.org
SNOMED CT Starter Guide A general purpose introduction to SNOMED CT which complements this guide.	http://snomed.org/starterguide
Vendor Guide The Vendor Introduction to SNOMED CT provides an informative practical introduction to SNOMED CT focused primarily on the needs of vendors and developers of EHRs.	http://snomed.org/vendorintro
SNOMED CT Technical Implementation Guide A detailed guide for designers and developers of SNOMED CT enable systems, tools and services, including release file format specifications	http://snomed.org/tig
SNOMED CT E-Learning Server Access to a growing range of online training resources about SNOMED CT. Including formal courses and open-access materials.	http://snomed.org/elearning http://snomed.org/openlearn
SNOMED CT Expo Presentations Presentation materials	http://snomed.org/expo
About IHTSDO  More information about the organization that owns and maintains SNOMED CT	http://snomed.org/newsletter http://snomed.org/events http://snomed.org/members http://snomed.org/advisory_group http://snomed.org/sig