DELIVERABLE

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WP1 D1.2 Report from the Focus Groups and Delphi study

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Revision History, Status, Abstract, Keywords, Statement of Originality

Revision History

Revision	Date	Author	Organisation	Description
0.1	07/07/2015	G.Cangioli	HL7 Foundation	First Outline
0.2	14/07/2015	G.Cangioli	HL7 Foundation	Included contribution from HR, DK, DE.
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0.4	27/07/2015	G.Cangioli	HL7 Foundation	Included contribution from FR and DE.
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Abstract (for dissemination)	This document presents the results of the focus groups and of the Questionnaires and serves as an intermediate report about the usage of terminologies in Europe (and beyond), with a special focus on SNOMED CT			
Keywords	Focus groups, Questionnaire			

Statement of originality
This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

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1 Executive summary

"Current Use of SNOMED CT" runs parallel to other streams of work in ASSESS CT to obtain background information on the current extent of **adoption** of SNOMED CT and other international terminology systems, and the experiences of use across Europe and in selected countries outside Europe. The eHealth Governance initiative was the first to review the use of SNOMED CT across the European Union[1]. This information formed the basis of our work and is updated within the ASSESS CT project with input from discussions, workshops, interviews, questionnaires, as well as country focus groups (FG).

Besides information on the current use of SNOMED CT, ASSESS CT is concerned with collecting information on the current and emerging policies of IHTSDO including cooperation with other SDOs and their local chapters, user groups, or affiliates.

Deliverable D1.2 continues the work of D1.1 presenting updated results gathered by mid July 2015 on country based focus groups and of the results of questionnaires developed for investigating the usage of terminologies in Europe (and beyond), with a special focus on SNOMED CT.

The results of the EU/US focus group and the First Validation Workshop, is conceptually still part of this report but documented in the ASSESS CT deliverable D1.1, along with the methodology and detailed objectives of WP1: Current Use of SNOMED CT.

It should be noted that the evidence base from the literature, from interviews and focus groups and case studies is all weak and largely based on beliefs and expectations rather than observed impacts or benefits. Key experts therefore strongly recommended to the project team to focus WP1 efforts primarily on intensifying and repeating the focus group discussions where necessary/desirable, and on an iterative revision process through the expert valiation workshop, the questionnaires and stakeholder interviews, instead of performimg a Delphi study. Given that several project partners have significant academic experience in conducting Delphi studies, we took their opinion and it was collectively decided that this method would not be likely to yield valid results.

1.1 Study coverage

At the time of delivering of this document a significant number of Member States have been involved in the ASSESS CT activities with a good geographical coverage, described by the following tables and figures[2]:

Member States (28)	Contacted	Stakeholders Quest.	Country Overview Questionnaire	Focus Group	Stakeholders Registry	Workshop
Austria	✓	✓	✓		✓	✓
Belgium	✓	✓	✓	✓	✓	✓
Bulgaria	✓					
Cyprus						
Croatia	✓	✓	✓	✓	✓	✓
Czech Republic	✓		✓		✓	
Denmark	✓	✓	✓	✓	✓	✓
Estonia	✓	✓	✓		✓	

[1] EHGI Information Paper: Making use of SNOMED CT: Key questions and status as of September 2013. http://ec.europa.eu/health/ehealth/docs/ev_20131119_co5_3_en.pdf

[2] Please note that this information about coverage is referred to the status at the end of August, questionnaires reports are based on responses received by mid July.

Member States (28)	Contacted	Stakeholders Quest.	Country Overview Questionnaire	Focus Group	Stakeholders Registry	Workshop
Finland	✓	✓	✓	✓	✓	✓
France	✓	✓		✓	✓	✓
Germany	✓	✓	✓	✓	✓	✓
Greece	✓	✓	✓		✓	✓
Hungary	✓				✓	
Ireland						
Italy	✓	✓	✓		✓	✓
Latvia						
Lithuania						
Luxembourg	✓	✓	✓		✓	
Malta	✓	✓	✓		✓	
Netherlands	✓	✓	✓	✓	✓	✓
Poland	✓					
Portugal	✓		✓	✓	✓	
Romania	✓					
Slovakia	✓		✓		✓	
Slovenia	✓				✓	
Spain	✓				✓	
Sweden	✓	✓	✓	✓	✓	✓
United Kingdom	✓	✓	✓		✓	✓
	24 (86%)	**15 (54%)**	**16 (57%)**	**9**	**21 (75%)**	**13 (46%)**

Other European – non-EU member state countries have been contacted as well with the following results:

Member State	Stakeholders Quest.	Country Overview Questionnaire	Stakeholder Registry	Workshop
Switzerland			✓	
Norway			✓	✓
Turkey				

France, Switzerland and Belgium have moreover contributed to the survey providing results of national studies related to the current use of SNOMED CT and other terminologies.

As shown in section 5.1 "All stakeholders questionnaire" a good coverage for all the identified roles has been achieved for different roles in healthcare (see Figure 4) and in particular for involvement with terminologies (see Figure 5).

Additional contributions are expected to be received by several countries in the upcoming months. Those contributions will be processed and documented in a second stage and integrated in the final deliverable D1.3.

The following figure provides a synthesised representation of countries' involvement by the end of August 2015.

Figure 1 – ASSESS CT WP1 Country Involvement (last update end August 2015)

1.2 Member state focus groups

Up to the end of August 2015, focus groups had been established in nine countries. In addition, a discussion group with the US was established and had its first meeting. The 9 EU Member States include 5 IHTSDO members (Belgium, Denmark, Sweden, Netherlands, and Portugal) and 4 non-IHTSDO members (Croatia, Finland, France, and Germany). Country selection criteria, set-up of the focus groups, their aim and the themes treated have been described in D1.1.

So far, 8 out of the 9 country-based focus groups have had at least one focus group meeting. 7 out of 9 debated all the 5 themes agreed: (1) current terminology usage; (2) benefits of adopting new technology; (3) barriers for extended terminology and use (4) enabling factors for extended terminology adoption and use; (5) recommendations. France plans to complete the focus group activities in September 2015; Portugal scheduled the first meeting of the focus group on September 23rd.

The complete reports have been instead documented in Appendix 1. Summary of key findings for each country appear in section 4 and 4.9

Despite the heterogeneity among focus groups, there are common elements to be reported: the tight **link between terminologies and purpose of use/use cases;** the **perceived and actual benefits** of using SNOMED CT as reference terminology**;** the impacts of the standardization in the EHR system marketplace with mutual benefits for vendors and providers, favoring the **internationalization of the national ICT vendor solutions**. Stepping up training woud be very interesting. FGs moreover pointed out the **low availability of evidence/best practices/examples** that limits the capability of providing an accurate evaluation of the potential consequences of SNOMED CT adoption as a core terminology. There was also strong evidence that the **lack of governance strategies** for supporting

semantic interoperability and the **SNOMED CT license cost** are perceived as critical barriers in the decision making /start-up phase. More details are given in § 4.9 General remarks / conclusions.

It is suggested that this experience with the FGs could be repeated also in the future, possibly extending it to other countries. This could accelerate MS engagement and stimulate the discussions on specific concrete themes related to the usage of terminologies (or more in general to semantic interoperability) that may have a European and global impact.

1.3 Stakeholder registry

A stakeholder registry has been implemented with a target to include 300 stakeholders in different roles (decision makers, terminology experts/authorities, industry, users) covering 75% of the European Union Member States. ASSESS CT also identified the members of the eHealth stakeholders group as a target group not only for engagement, but also for dissemination. At this time, in addition to members of the eHealth stakeholders group another 268 stakeholders have been identified covering 23 European countries (see table above for details).

1.4 Questionnaires

Two questionnaires, one for general stakeholders and a country overview questionnaire have been developed and tested, before been applied to the wide population. The responses received by July 9th 2015, have been processed and reported in this deliverable. At that time, 136 responses had been received coming from 14 countries (Austria; Belgium; Croatia; Denmark, Estonia; Finland; France, Germany; Greece; Italy; Malta; Netherlands; Sweden, United Kingdom) for the stakeholder questionnaire and responses to the country overview questionnaire from **14 Member States**: Austria; Belgium; Croatia; Czech Republic; Estonia; Finland; Germany; Greece; Italy; Malta; Netherlands; Slovakia; Sweden, United Kingdom[3].

A draft report of the Country Overview results was prepared and shared with the interested parties for reviewing purposes. All the received changes have been tracked and considered for this deliverable.

1.5 Stakeholder responses to the questionnaire

The general stakeholder questionnaire reported as preliminary result in D1.1 has been integrated with new responses and additional results. A summary of the main results has been documented in § 5.1. The complete report is included in Appendix 2. The updated study substantially confirms the main results about the usage of SNOMED CT (very limited or not used at all), benefits, challenges, etc., obtained in the preliminary analysis as described in Deliverable D1.1.

1.6 Country overview

This questionnaire confirms the *limited usage of SNOMED CT*: for the large majority of the interviewed countries adoption is characterized in most cases as “in progress” or under consideration. Almost all the countries use terminologies at the national level for *secondary or administrative* purposes and less than half have established National Competence Center(s) for terminologies: AT, BE, EE, FI, DE, SI, SE and UK. With few exceptions, countries declared that there are relevant domains for which national-wide terminologies are used (e.g. procedures). The project/use case approach is the preferred method for introducing SNOMED CT. In the large majority of reported cases pre-coordinated concepts are used for SNOMED CT. For non-member countries, license Costs is the primary reason

[3] The response from the United Kingdom, collected during a meeting organized with UK representatives, is included in this report with the caveat that the answers reported need to be explicitly validated by respondents.

mentioned for not joining IHTSDO. 70% of non-member country representatives are aware of discussions concerning possible adoption of SNOMED CT.

1.7 Conclusions

Several facts, opinions, experiences, and beliefs have been gathered through the national focus group investigations. Based on those results, list of statements that summarize relevant[4] aspects have been derived and reported in section 7 of the deliverable "Conclusions". They mainly refer to :

- the role of SNOMED CT as a reference terminology and mappings broker;
- use cases for adopting SNOMED CT: e.g. terminology have to be used and assessed within specificied purposes or contexts of usage, and should not be used beyond their purposes
- the current lack of evidence of benefits: SNOMED CT has in general a limited usage, consequently there is a low availability of evidence/best practices/examples.
- (low) market maturity and potential impact of the adoption of SNOMED CT: e.g. SNOMED CT may play a role in the standardization of the EHR content, and therefore in the EHR-S market;
- strategic long term benefits: IHTSDO assures a transparent and robust maintenance process;
- pre conditions for pursuing semantic interoperability: e.g. well defined strategies, supporting policies and jurisdictional commitment;
- usability and users acceptance: e.g. the usability – in all their different perspectives - is a critical factor in the adoption and acceptance process;
- licensing and cost issues: e.g. the SNOMED CT licence cost is a critical barrier in the decisional / start-up phase when the potential benefits of this change have not been yet completely evaluated / experienced;
- suggested approaches for introducing SNOMED CT: a step-wise, use case based, incremental approach is the suggested method for the introduction of SNOMED CT, possibly starting from inadequately covered domains.

The identified statements will be discussed in the 2nd Workshop on Octorber 2015, and used as input for the definition of recommendations that will reported in the deliverables of WP4.

[4] Relevance is evaluated either because it is mentioned more times in questionnaires, FGs and/or during the workshop; or because deemed to be particularly noteworthy.

2 Glossary

ATC	Anatomical Therapeutic Chemical (Classification System)
EDQM	European Directorate for the Quality of Medicines
eHGI	eHealth Governance Initiative
epSOS	European Patients Smart Open Services
EU	European Union
FG	Focus Group
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICPC	International Classification of Primary Care
IHTSDO	International Health Terminology Standards Development Organisation
MS	Member State
NRC	National Release Center
SCT	SNOMED CT
SDO	Standard Development Organisation
US	United States
WP	Work Package

3 Aim and scope of the deliverable

The goal of ASSESS CT is to collect and elaborate information about past and current use and, where applicable, about future prospects for the usage of terminologies with a focus on SNOMED CT. This is being performed covering as much as possible of the 28 Member States (MS) of the European Union building on the informative and relevant eHGI information paper[5], and possibly also other European countries that have been involved to some extent in the European eHealth context (e.g. the epSOS Participating Nations)[6]. For each MS, we extended our knowledge of how terminologies are managed, investigating aspects surrounding the use of clinical terminologies including how semantic interoperability issues have been addressed including national policies and guidelines, terminology infrastructures services, type and cost of license, cost for maintaining a national terminology, timelines, and milestones of adoption, as well as lessons learned, expectations, perceptions, and beliefs. Those, and all the other aspects documented in the reports, will be investigated collecting the concrete facts (experiences, evidences) that support the opinions expressed.

D1.1 presented the methodological approach, instruments and early results from collected questionnaires, conducted interviews, workshop, and focus groups. D1.2 continues this work with further results from questionaires, and outcome of the focus groups.

It should be noted that the evidence base from the literature, from interviews and focus groups and case studies is all weak and largely based on beliefs and expectations rather than observed impacts or benefits. Key experts therefore strongly recommended to the project team to focus WP1 efforts primarily on intensifying and repeating the focus group discussions where necessary/desirable, and on an iterative revision process through the expert valiation workshop, the questionnaires and stakeholder interviews, instead of performimg a Delphi study. Given that several project partners have significant academic experience in conducting Delphi studies, we took their opinion and it was collectively decided that this method would not be likely to yield valid results.

The scope of deliverable D1.2 is to report the results, gathered by mid July 2015, of country based focus groups and of the questionnaires developed for investigating the usage of terminologies in Europe (and beyond), with a special focus on SNOMED CT. The results of the EU/US focus group and of the First Validation Workshop (as part of the initially agreed Delphi Study approach) are only referenced here since they are documented in the ASSESS CT deliverable D1.1. Details about the overall methodology, including goal and objectives of work package 1 “Current Use of SNOMED CT” are also provided in D1.1. The structure of this deliverable is organised per activity accomplished, in particular it provides:

- The relevant results of the focus group activities as available at the time of the delivery of this document. (Section 4 "Report on Focus Groups”). The focus group reports are documented in Annex 1: Focus Groups Reports
- A report of the All Stakeholder Questionnaire based on the answers received by July 9th, 2015, coming from 14 countries. (See section 5.1).
- The complete results are included in:Annex 2: All stakeholder questionnaire
- A report of the Country Overview Questionnaire based on the answers received by July 9th, 2015, coming from 14 countries. (See section 5.2)
- The complete results are included in:Annex 3: Country overview questionnaire
- A report of the EU / US discussion group, as reference to the results documented in D1.1. (Section 6.1 Report on EU US discussion group)
- A report of the 1st Revision Workshop, as reference to the results documented in D1.1 (Section 6.2 Report on 1st revision workshop)

[5] EHGI Information Paper: Making use of Snomed CT: Key questions and status as of September 2013. http://ec.europa.eu/health/ehealth/docs/ev_20131119_co5_3_en.pdf

[6] Even if formally not totaly correct here and hereafter the concept of MS is used in a wide sense as European country.

4 Report on focus groups

The focus group instrument has been selected in ASSESS CT for the purpose of producing qualitative data with focus on preferences, perceptions, and beliefs. In fact, focus groups (but also interviews) help the project team capture stakeholder reflections on why they experienced something, which factors influenced their views, what would lead to better results in the future, how and why the views of participants differ. Where instead, reviews, interviews and questionnaires might help the project to answer about **what** experience stakeholders have.

A set of Member States have been carefully chosen based on identified criteria, described in the ASSESS CT Deliverable D1.1, for the aim of collecting:

European views on current and future terminology use in the health care sector, with special focus on the role of SNOMED CT.

Up-to-date, nine country focus groups have been established: 5 members of IHTSDO (Belgium, Denmark, Sweden, Netherlands and Portugal) and 4 non-members (Croatia, Finland, France, Germany). So far 7 out of 9 debated all the 5 themes agreed: France is planned to complete it on September 2015; Portugal scheduled the meeting on September 23rd.

The results of each country based focus group – as available at the time of the delivery of this document – have been summarized in the following sections. Additional information will be integrated in the final deliverable D1.3

4.1 Belgium

4.1.1 Focus group organisation

Facilitator

Hans van Belleghem, independent consultant and owner at Twist

Focus group composition

Thierry Klein (Public School of Health ULB); Sven Van Laere (Vrije Universiteit Brussel); Paquay Louis (Wit-Gele Kruis Vlaanderen); Zwaenepoel Lieven (VAN - Vlaams Apothekers network); Tom Henkens (APB); Olivier Le Moine (Hopital Erasme); Luc De Keyser (xperthis); Fierens Christophe (AZ Klina Brasschaat); François Van Hees (eHealth-platform).

Meeting(s)

The Belgian focus group was held on June, 24th 2015. Federal Public Service of Health, Food Chain Safety and Environment, Place Victor Horta 40-box 10, 1060 Brussels-Eurostation – room 01C273 Magritte A

4.1.2 Methodology

To analyze the results of this focus group, the NVivo Version 10.2.1 software was used. NVivo is a comprehensive qualitative data analysis software package. The software can be used to organize and analyze interviews.

The entire interview/discussion of the focus group was recorded. Based on the recordings, a transcript was made. This transcript was imported into NVivo Version 10.2.1 for research.

Before coding the data, a pre-constructed coding scheme was build. It consists of a node hierarchy, containing the parent nodes, was build based on the themes that would be elaborated during the discussion of the focus group.

4.1.3 Report on discussed themes

Theme 1: Current terminology usage

The Belgian Action Plan on e-health 2013-2018 endorses the use of a standardized terminology (principally consisting of SNOMED CT). Currently, there are **few "complete" implementations** of SNOMED CT; **other systems, mainly classification systems**, such as ICPC2, ICD-9-CM, ICD-10, are instead in use….It has been pointed out how terminologies used for unambiguous clinical registration and classification purposes need to be distinguished.

The awareness of the need for **structured information** is present, but the implementation is not complete. Furthermore, every research company and every professional organizes the concepts they want to use in local registers, which lead to a plethora of systems. Free text is also still frequently used.

Main **considerations** and **challenges** with regards to use of SNOMED CT implementation are on: the level of **granularity**, the awareness that **SNOMED CT is not "perfect"** nor complete, the **issues** with regards to the use of **post-coordination** and the clarification of the objectives of the use of such a system. (i.e. if information are structured for the right reasons, namely the sharing of information and interoperability).

Theme 2: Benefits of adopting new terminologies

Several benefits of SNOMED CT have been discussed: being an **international system** it creates opportunities for cooperation. The finer granularity leads to **richer information** that may enable multidisciplinary inputs. The adoption of a **common language for information exchange** by all professionals, reduces errors and improves patient care and safety,

allowing also better documented EHRs. Related to this, the **reuse of information** for secondary purposes (e.g. registry) and the non-duplication of data entering. The adoption of SNOMED CT is felt to make possible the **consultation of the record by the patient**. Finally, it is believed that SNOMED CT can help to collect **structured information,** even if attention should be paid on the right balance between what it is possible and what it is needed to be captured: i.e. avoid "over-coding".

Theme 3: Barriers for extended terminology adoption and use

For what concern the barriers, the (end users) **resistance to change** (from free text to coded documentation), as well as the **fear of loss of information** should be managed, (medicine is not an exact science and sometimes a certain nuance is needed which cannot be found in or expressed by means of a code system). Free text should be allowed and tools should help on this. Somehow related to this is the fear of losing connection with legacy systems. The group believes that there is a **lack of user-friendly implementation**: suitable and intuitive interfaces have to be provided to providers. Somehow related to the resistance to change, the fear of increasing the **administrative burden** (the biggest reason for burnout amongst physicians in the US is due to the implementation of registration systems) and of capturing **irrelevant information** (see above about the "over-coding"). Finally, the risk of having **fragmented information**, due to the possibility of SNOMED CT to describe concepts in different ways (pre/post coordination) and also to the fact that different professionals can add pieces of information that need to be combined to build up the complete picture of the patient, was pointed out.

Theme 4: Enabling factors for extended terminology adoption and use

The group identified enabling factors: the availability of **appropriate tools**, many of which may not permit the use of free text. **Minimum requirements** for EHR systems should be determined; system **objective** should be **clear** and well understood by users and the **right incentives for the effective use** of the terminology should be adopted. It has also deemed that, at least for the domains for which proof of concepts are being developed, **translations** and **mappings** (to enable the secondary use) should be available.

The **patient empowerment** is considered an important factor (mobile health can help on this), as well as the **training** of professionals.

Finally, **proof of concepts** are needed, starting with specific domains and specialties: is not needed that all the domains are implemented at once.

Theme 5: Recommendations

A phased approach is preferred, starting small on the base of proof of concept and use cases. When introducing the terminology, attention for legacy conversion is needed. Training is needed on different levels, in the field and during education.

A centralized approach, coordinated by the national release center is needed, with clear objectives on the use of the terminology.

Supportive tools and features, such as maps, translations and subsets need to be available.

4.1.4 Remarks / conclusions

Adopt, Alternative and Abstain scenarios: the group indicated that SNOMED CT should be used as reference terminology taking into account the above mentioned recommendations.

4.2 Croatia

4.2.1 Focus group organisation

Facilitator

Vesna Kronstein Kufrin , Project Manager and Zlatko Boni - HZZO (Croatian health insurance fund)

Focus group composition

Aleksandar Džakula (School of public health “Andrija Štampar”); Josipa (Josie) Kern, prof. (School of public health “Andrija Štampar”); Miroslav Mađarić (KBC Zagreb - University hospital center Zagreb); Vanesa Benković (Solpharm Ltd, Edward Bernays First College of Communication Management, University of Zagreb Medical Faculty); Karmen Lončarek (KBC Rijeka (Clinical hospital center Rijeka); Faculty of medicine Rijeka, Department of Ophthalmology); Maja Vajagić (Croatian Health Insurance Fund - HZZO); Sandra Mihel (Croatian Institute of Public Health - HZJZ); Siniša Košćina (IN2); Darko Gvozdanović (ENT)

Meeting(s)

Individual interviews: Miroslav Mađarić – 17.03.2015; Maja Vajagić – 10.03.2015; Aleksandar Džakula – 24.03.2015; Josipa Kern – 26.03.2015;

Meeting 1 – Preparatory meeting : 23.04.2015.

Meeting 2 – Focus group meeting: 30.04.2015., HZZO, Zagreb, Margaretska 1

1.7.- 4.7.2015.- In Motovun, on a Conference on the health care system and health care policy – HZZO presented Assess CT project and basic information about SNOMED CT. In the discussion following the presentation participants expressed concern about the introduction of new terminology systems in the areas with existing classification but they would like to see usage of SNOMED CT or some other terminology that would enable interoperability in the areas where data is not structured yet. Focus was on national interoperability rather than international one.

4.2.2 Methodology

Before the focus group meeting Croatian project team identified 10 participants and held individual interviews with participants in order to better identify their area of expertise, knowledge of SNOMED CT and international interoperability. Participants were selected from different stakeholders of the health care system (health care professionals, public health, IT providers). They also have knowledge about health care terminologies even if they don’t actually use them in their everyday work.

Focus group session was held at CHIF. They were given a presentation on SNOMED CT. A presentation on SNOMED CT was also held at the start of the meeting. The focus group was conducted according to the accepted FG guideline; first the short presentation and discussion on five suggested themes. The discussion was recorded and analyzed.

4.2.3 Report on discussed themes

The terminologies currently used in Croatia (ICD-10, ICD-9, ATC…) enables a good overview of resources used in the health care system.

All agreed that implementation of SNOMED CT could further help us to make evidence based decisions since it is more detailed and could provide better quality of data.

The main barrier remains the costs and especially education of medical staff. From limited knowledge we have on SNOMED CT, it is not clear how translation might impact interoperability.

Since SNOMED CT requires a big change in the health care system, focus group members recommended that further research include possible implications that SNOMED CT implementation might have on all stakeholders.

Theme 1: Current terminology usage

Croatian healthcare system is organized at 3 levels. International clinical terminologies identified by participants that are in use in Croatian health system are: ICD-10, ICD-9, ATC, ICF, internationally accepted scales (i.e. for decubitus) and terminologies related to certain diseases (i.e. BIRADS).

Healthcare professionals also use locally developed terminologies for administration and payment purposes (local DRG system). Members moreover mentioned that for quality data analysis and strategic planning unique terminology should be implemented. One that could be used for interoperability on all levels of healthcare system (primary, secondary and tertiary) on national and international basis.

Focus group participants, but not all of them, mentioned that there are disadvantages of above mentioned terminologies in use because some terminologies might not be adequately used. But all of them think that the existing terminology (ICD-10) is insufficient for collecting relevant and high-quality data required for analysis and evidence based decision making in all areas of health care. Also, those terminologies in use do not provide interoperability among all participants in the health care system.

Theme 2: Benefits of adopting new terminologies

SNOMED CT's ability to improve interoperability on national and international levels was the main benefit highlighted in the discussion. Others include introduction of structured data where it doesn't exist now. Also better research capabilities in terms of new areas that would be recorded e.g. location and circumstances of injury in children. Better quality data would contribute to evidence based decision making. Focus group member expect SNOMED CT to be introduced in academic settings so new generation of doctors would fully appreciate the possibilities it provides. There was a consensus among all members that implementation is a step forward. Everything mentioned would ensure better quality of patient care.

Theme 3: Barriers for extended terminology adoption and use

There is reluctance to substitute existing terminology because it took a long time to implement the current terminology and it is an ongoing process of involving all the users to provide better quality data. The group agreed that new terminology would have to be implemented at educational level first. Costs of licensing, implementation, education and maintenance are of great concern since there is a lack of evidence that benefit is worth the added cost. Difficulties in translation due to lack of experts needed.

Participants agreed on these barriers and it was obvious that a lack of experts would hinder implementation and for the new terminology it would take a long time to reach the current level of data quality.

Theme 4: Enabling factors for extended terminology adoption and use

In Croatia, each healthcare stakeholder could reap benefits from something that would work better than what we have now. Of course, those benefits often involve a joint effort from all stakeholders. When we define all levels of usage and all stakeholders, the next phase should be to determine what the common interest is. Each stakeholder should first recognize his own individual benefits and then we all should work towards the common interest. That should link two stakeholders with a common interest and engage them to accept the baseline for interoperability. The main factor that everybody identified was funding. Based on previous experience of difficulty of implementing terminologies we would like to see guidelines that take into account best practice examples. Also since our whole payment system is based on ICD-10 it would be beneficial if SNOMED CT was mapped to current reimbursement

terminologies. There is a need for reaching a national consensus or an EU wide consensus in order to ensure the continued effort from all the stakeholders.

Theme 5: Recommendations

SNOMED CT seems to be a good solution for improving semantic interoperability in the health care system; however, recommendations on implementing SNOMED CT could be given only **after piloting some critical use cases** and finding **examples of good practice**.

We are not familiar with any other known international terminology that could solve interoperability problems in a way that SNOMED CT can.

We realize that SNOMED CT could not solve all semantic interoperability problems. It should be used with other international terminologies or other terminologies should be mapped to SNOMED CT. Collaboration between industry and other stakeholders needs to be established.

Other Themes

The Croatian healthcare system is one of the few in Europe that is completely open to the public and perhaps one of the most simple in terms of organizing and financing healthcare. It can be defined as simple because of one insurer, a relatively small number of types of contractors and service providers. In the whole health care system, there are not many participants. Several layers of stakeholder participation were discussed with regards to introducing interoperable solutions such as SNOMED CT.

The first level is the interoperability between the health workers themselves, e.g. two health workers communicate using the same unique terminology.

The second level could be the communication towards the patient, when the patients need to receive information about their condition. It is not important if patients use it later when they want to get a second opinion or for some other purpose, but when they do, they should get the information that is based on a solid and accurate terminology.

The third level is sending the information from the health system for payment purpose where precision is again very important.

The fourth level is about the communication between an insurer or any other payer of health services communicates and the patient. Common terminology can be used to determine whether the service is covered by health insurance or not.

These are four possible relations in which the terminology may be used. Outside of that, which is a group of users who are now in the healthcare system (health care workers, patients and the health insurance fund which pays for the health services). Therefore, the first ring consists of users, and the second circle includes Ministry of Health, scientific research agencies, public health institutions and all others who are not participants in the first circle, but use information from it daily. And then it can be said that the terminology shouldn't be used on the individual but on the population level. We can even say that the first circle is a circle of individual users, related to a particular person, and the other one is dealing with population monitoring where the terminology is very important for accurate monitoring.

4.2.4 Remarks / conclusions

As far as Croatian Healthcare system is quite simple with only one national insurance company, relatively small number of types of contractors and service providers, we could be chosen to pilot the SNOMED CT implementation for some use cases.

Also we think that the interoperability on the EU level is very important and possible only if there is core terminology (like SNOMED CT).

Implementation of the unique terminology would be supported by the stakeholders only if they find their own interest, e.g. to decrease costs. The usage of the common terminology in everyday work shouldn't demand extra work, so it should be simple and self-explanatory (especially in information systems in use).

4.3 Denmark

The focus group has been formed using inclusion criteria that ensured a broad range of perspectives from policy makers, vendors, and implementers of clinical terminologies in Denmark. In addition, participants were selected so that there would be a balanced view of the benefits and shortcomings of using SNOMED CT compared to other terminologies. Consequently, people involved in health terminology related work, but without using SNOMED CT, were selected as well as those working with SNOMED CT.

4.3.1 Focus group organisation

Facilitator

Kirstine Rosenbeck Gøeg, scientific assistant, Department of Health Science and Technology, Aalborg University.

Focus group composition

Kell Greibe (National SundhedsIT, Dansk SNOMED CT release center/ The National eHealth Authority, Danish SNOMED CT release center); Ulla Lund Eskildsen (Kommunernes Landsforening/Local Government Denmark); Janni Lerche Andersen (NNIT); Gert Galster (Capitol region Denmark); Helle Møller Johannessen (National SundhedsIT/; The National eHealth Authority); Henrik Lindholm (Cambio); Dorte Markussen (Region Northern Denmark)

Meeting

27th of April, Copenhagen

4.3.2 Methodology

The focus group was conducted as agreed in the overall focus group guideline. When conducting the interview, the five themes have been clustered into two overarching topics, prioritized rather than enforcing the themes, in order to optimize the flow of discussion. The observations have been therefore then mapped back to the five themes agreed during the analysis of the transcript.

An evaluation session was held together with the Swedish focus group to reflect and discuss terminology standardization visions.

4.3.3 Report on discussed themes

Theme 1: Current terminology usage

The Focus group members stated that it did not make sense to talk about the success/failure of a terminology without discussing scope. Decision support, reporting/auditing, reimbursement and communication have standardized terminologies as a part of the solution. The focus group members involved in terminology-related work in Denmark, they mentioned e.g. communication (e.g. NPU), administration (SKS) and one implementation project use SNOMED CT for information management. In Denmark, the level of standardization at implementation is still discussed. It is unresolved whether to implement terminologies and classifications for current use e.g. only reporting to registries or future use e.g. advanced analytics and decision support. Based on their experience, the focus group members stressed that terminologies should not be stretched out of scope, just because they are successful for well-defined purposes. In addition, terminologies should reflect reality to such an extent that it makes sense for all stakeholders, and be updated as the world changes.

Theme 2: Benefits of adopting new international terminologies (or better use of existing terminologies)

The focus group members came up with several reasons for adopting new terminologies. One was when problems are not solved by current approaches e.g. safer prescriptions require more granularity than the current ATC based terminology offers and SNOMED CT is explored as an alternative. Another reason mentioned was to allow communication and outcome measurements in areas where no decision on terminology have been made. E.g. nursing documentation has no agreed terminological reference in Denmark. Other reasons mentioned was to ease communication between different stakeholders, to support requirements of a more efficient health system, to improve the semantics of the databases underlying clinical information systems for big data related uses. As a general note, the focus group members emphasized that they do not dream of new terminology systems, but rather the benefits that improved use of ICT can provide in health. Terminologies are seen as a building block.

Theme 3: Barriers for extended terminology adoption and use

During the focus group several barriers for terminology was emphasized and discussed. So, there seemed to be a general consensus among the participants that significant barriers exist for use of terminologies.

The types of barriers mentioned in the discussion relates to different factors, such as a **lack of implementation/methodology-oriented knowledge** in terms of **best-practice guidance** on how to structure clinical documentation using terminologies and tools supporting this. Moreover, there is an unclear incitement for implementations, i.e. awareness about what **benefits to actually gain from terminology investments**, which were also considered highly costly. Finally, lack of governance strategies were also argued as a barrier.

Theme 4: Enabling factors for extended terminology adoption and use

The Focus group members mentioned that the general enabling factors of **having clear governance decisions on health terminology use**, having **resources** available for implementation of terminologies and having **guidelines** for implementation. In implementation organizations each sub-implementation needs a well-defined purpose, for example it should be clear how it gives better treatment for patients or how it helps cross-organizational communication, and it should also have a positive business case and be coordinated with other tasks. It also enables use in implementation organizations that the required terminologies are used as the basis of reimbursement. For SNOMED CT specifically, it would enable to break down the implementation by **introducing one subset at the time**. In addition, **mapping SNOMED CT to current reimbursement** related terminologies would also enable implementation because changing reimbursement scheme or requiring double registrations could be avoided. The vendors present in the focus group stressed that they had to be able to trust that the adoption and implementation of a certain terminology is a national decision to justify investment.

Theme 5: Recommendations

Focus group members argued that this had already been mentioned in the discussion of barriers and enablers, but **they highlighted the need for handling multiple concurrent terminology systems** e.g. Danish SKS, SNOMED CT and ICF especially to resolve reimbursement specific challenges. High quality maps were seen as a possible solution.

4.3.4 Remarks / conclusions

Denmark is an IHTSDO member, and SNOMED CT has been **translated into Danish, but routine use mostly remains**. Several classifications are routinely used e.g. ATC, ICD10 and NPU. According to the focus group members, it did not make sense to discuss whether it was necessary to **change the current use of terminology without discussing scope**. For

reimbursement and administration existing systems was perceived as well-suited, but for some use cases current terminology usage could be/or are in the process of being improved e.g. representing **clinical meaning, cross professional communication, decision support, safer medication, audit and big data use cases**. For some, but not all use cases SNOMED CT was explicitly mentioned as a solution. Some focus group members stated the risks implementing SNOMED CT as a core terminology. For example, they mentioned the lack of governance decisions, demonstrator projects, knowledge and tools as barriers. The focus members stressed that they did not see the implementation of some terminology as a goal in itself, rather they wanted **connected health services and utilization of patient information** for multiple purposes, whatever **combination of terminology, information models, systems and organizational change that would require**. Standardization of terminology was perceived as one building block.

4.4 Finland

4.1.1. Focus group organisation

The National Institute for Health and Welfare, THL organized two focus group sessions that were held on May 5th and May 26th. All together 11 experts participated (5 and 6) to the sessions. The invited experts were selected within network contacts of the Finnish ASSESS CT project team. All those experts that had availability in their calendar for the proposed meeting times, accepted the invitation and expressed extensive interest in discussing SNOMED CT and other terminologies. For two interested experts not available at the planned meeting times, additional interviews were arranged. The sessions were held at the locations of THL and the discussions followed the themes prepared in the ASSESS CT project. Prior to the meeting elementary material on the ASSESS project and SNOMED CT was given out to the experts.

Facilitator

Dr. PhD Päivi Hämäläinen acted as the facilitator of the two focus group meetings. She works as a leading expert at the National Institute for Health and Welfare and participates in the Finnish ASSESS CT team. The ASSESS CT project team participated in the focus group interviews as inspectors and did not participate in the discussion, however as experts they, when asked, supported the discussion with information.

Focus group composition

Vesa Jormanainen (National Institute for Health and Welfare (THL)); Heikki Virkkunen (National Institute for Health and Welfare (THL)); Pirkko Kortekangas (Hospital District of Southwest Finland); Helena Kääriäinen (National Institute for Health and Welfare (THL)); Peter Nyberg (The Finnish Medical Society Duodecim and Duodecim Medical Publications); Petri Pääkkönen (Finnish Medicines Agency); Mika Tirkkonen (Fimlab Laboratories); Annika Koivisto (The National Social Insurance Institution); Pekka Laurila (HUS - The Hospital District of Helsinki and Uusimaa); Timo Kaskinen (Salivirta and Partners); Maarit Laaksonen Cancer Society of Finland).

Meeting(s), see above.

4.4.1 Methodology

The sessions were held at the locations of THL. Prior to the meeting elementary material on the ASSESS project and SNOMED CT was given out to the experts. The material included a Power Point introduction to the ASSESS CT project and an introductory description on SNOMED CT. This material was provided to minimize the time spent in introduction. The participating persons shortly introduced themselves and after that the discussions followed the themes prepared in the ASSESS CT project. The discussions were recorded after receiving consent to do so and literated. The text was analyzed by picking up all the different discussion parts referring to each topic. After that the meanings and themes from the text around each topic was collected. Since the discussions were held in Finnish, and the collected pieces of information were translated to English at this point and reported as a result. Two experts (Timo Kaskinen and Maarit Laaksonen) were interviewed separately because they had time constrains in participating to the group meetings. These discussions were not literated, but the main messages were included in the report.

4.4.2 Report on discussed themes

Theme 1: Current terminology usage

Finland does not have a national license for SNOMED CT and the practical experiences on the usage come only from using the SNOMED International -93 English version mainly for

pathology. In Finland, the nationally referred and used common code sets are shared via the THL code server and incorporated in to EPRs. The usage of the code sets from the code server is based on legislation. The system is not a terminology system but a set of various national and international classifications/code sets. The following were noted; ICD-10, ICPC 2, ATC, classification of procedures, NMT, FinLOINC, FinMESH, terminology for social security and SNOMED CT in the epSOS pilot. Pros and cons of the current code sets were not discussed here. Finland has an established operational platform for ongoing discussion on this area and the participants wanted to concentrate on the SNOMED issue.

Theme 2: Benefits of adopting new terminologies

The discussion was mainly around a possible terminology system such as SNOMED CT versus the current situation of developing the national system from the existing grounds. SNOMED would give **some new needed concepts** that are currently lacking. International terminologies would give new platforms for **international collaboration** and promote **cross border exchange of patient data**. On the national level a terminology system could act in the background and bind together the current pieces of the national health information infrastructure. It could also improve the quality of searching information from IT-products, databases and web-sites. It would help in **operating with common language synonyms** for the patients and it could act as a translator between the languages of different professional groups. It could improve the IT-solutions for clinical decision making and other handling of patient data and thus improve quality and safety. Interoperable use of health care terms in Europe and beyond would improve the market choices available for the Finnish health care providers and IT companies when purchasing and selling health care IT. It could improve possibilities for research and data mining, however the Finnish language is not very suitable for data mining. The field of pathology was discussed more in-depth because it is special issue in Finland. **Upgrading the usage of old SNOMED codes for pathology** in to the modern version, was seen beneficial for pathology and bio banking. The field of medicine administration was also discussed more in-depth. A **common terminology for the active substance** in medicine products would be urgently needed.

Theme 3: Barriers for extended terminology adoption and use

In Finland SNOMED CT is like a black box. It is difficult to make any judgements on the usability of SNOMED CT in the Finnish circumstances, because there is no experience nationally and there is lack of information on experience in other countries.

The costs/benefit question is essential. It is not clear how much additional benefit SNOMED would give when compared to the current Finnish system and how much additional work and costs the implementation would mean. Translation of full SNOMED CT to Finnish would create costs. The Finnish adaptation of SNOMED CT would have to be multilingual[7]. Adoption would mean **costs from changes in the IT systems, training,** etc. and finding qualified people for the implementation of SNOMED CT may be difficult.

There **are doubts about the usability of SNOMED CT**. It may be difficult to map the current Finnish health information structures with SNOMED CT and implement it to current Finnish IT-systems. Additional **national extensions** would be needed. It is difficult to create good processes for upgrading the terminology system.

The **change management** would be difficult. There is also a risk that **developing IT solutions would take the lead instead of development from professional needs** and change could slow down other developments because so much resources and energy would be tied to this large scale implementation project

There are concerns about the **true value of SNOMED CT in international collaboration**. Implementing a new terminology would not help in international collaboration as such, if it has to be connected to other international work in standardization of terms and concepts.

[7] Finland is bilingual, Finnish and Swedish. However, since there are some differences between the Finnish-Swedish and the Swedish-Swedish, transaltions from Sweden cannot be reused as they are and a dedicated effort for the Swedish transaltion has to be allocated.

SNOMED CT does not have any international benefits if the **critical mass of adaptors is not big enough**.

Theme 4: Enabling factors for extended terminology adoption and use

In Finland there is a need to learn more about SNOMED CT. The SNOMED implementation needs proof of perceived benefits to gain user acceptance.

Partial and step-wise implementation was seen as an enabling factor. SNOMED CT could be implemented as a **reference terminology that would run in the background of EPR systems**. The clinical change would be smaller and promote the adoption. Translating only chosen subsets would give more flexibility. Using SNOMED CT to support translations to different (also national) languages and support the use of different synonyms in professional terminologies and lay language, would increase usability.

Usability of the IT solutions with integrated SNOMED would be enabling, for example good search capabilities. Better IT solutions for clinical decision support would motivate the clinicians to use the adopted terminology. The adoption could also be further motivated as improvement of or tools for health care process management.

The **collaboration of different international stakeholders would be important and enabling. Active Finnish participation in the IHTSDO would be supportive**.

Resources for the license and the implementation work would be enablers.

The implementations process should be well managed. The different professional groups and specialties could be activated in to participation. **Training and arranging support** during the adaptation phase would be supportive. The authorities and different stakeholder groups would need to have clear roles in the implementation.

Theme 5: Recommendations

SNOMED CT should be seen as a tool to go forward in the modern ways of handling health care information structures. However, Finland should not start a process of translating the full SNOMED CT. If a political decision to purchase the license to Finland is made, **mapping the SNOMED CT terms with the codes of the current Finnish health information infrastructure** would be a more useful way to start the implementation. This should be started with only a **few chosen subsets as pilots**. Also subsets that are still needed by professionals but currently lacking from the Finnish information structures should be identified and the possibly translated. All stakeholder groups should be given possibilities to participate in the different phases of the SNOMED implementation. **An organization, for example THL, should be given the task to take a lead and coordinate the implementation efforts**.

Nationally there is no need to wait for the European level decisions on the SNOMED CT license. It is important to make national decisions and be prepared to **understand SNOMED CT** before such decision would be on the European table.

No alternative choices to SNOMED CT as a large scale international health care terminology system can be identified and it is likely that SNOMED CT will in some way support the continuous development of cross boarder services. Finland should become an active member of the IHTSDO and benefit from mutual learning.

4.4.3 Remarks / conclusions

Both Finnish focus groups ended with the same recommendations and there was no objection to them in the groups. The only issue with some variation of opinions **was the translation of SNOMED CT**. No one supported the full translation but the proportion of SNOMED CT that should be translated was estimated differently by different experts.

4.5 France

4.5.1 Focus group organisation

The French focus group is composed of 8 members what have been contacted based on the following criteria:

- They represent one type of stakeholders that were suggested in WP1 guidelines
- They have a good knowledge of SNOMED CT. Some of them may have experimented with it concretely in research projects.
- They regularly practice regulatory and enforceable terminologies used in France.

For ANSM (Agence nationale de sécurité du médicament et des produits de santé) and ASIP Santé (Agence des Systèmes d'information Partagés de Santé), we included two members in order to represent all opinions.

Facilitator

Marie-Christine Jaulent, Research Director at INSERM, Head of LIMICS (research unit UMR_S1142) : http://www.limics.fr/en

Focus group composition

Stéfan Darmoni (Rouen Unversity Hospital LITIS lab (EA 4108)); Michèle Thonnet (French Ministry of Health); Christel Daniel (APHP - CSS Patient); Philippe Manet (ANAP : Agence Nationale d'Appui à la Performance des établissements de santé et médico-sociaux.); Vingent Maugis (ANAP); François Macary (ASIP-Santé); Jean Charlet (AP-HP); Thierry Dart (ASIP-Santé); Rémy Choquet (AP-HP)

Meeting(s)

Meeting 1: March 19th 2015. It was a teleconference to inform the participants about the ASSESS CT project and the role of the focus group (1 hour)

Meeting 2: March 30th 2015. The first face to face meeting in Paris. This meeting was dedicated on the presentation of the questions that should be debated and how the moderator will organize the brainstorming questions. This meeting was really important to prepare the ASSESS CT French Focus group meeting and in particular to install the spirit within the group. (2h)

Meeting 3: May 4th 2015. The ASSESS CT French Focus group meeting (3h)

4.5.2 Methodology

This section summarizes the main aspects of the methodology applied. Please refer to Appendix 1 for a wider description of that methodology including the agreed questions.

The first step has been the identification of participants: the selection has been made assuring: the coverage of all the relevant stakeholder categories; the coverage of the current points of view in France about the adoption of SNOMED CT; the people attitude of having open and spontaneous discussions to maximize the number of different ideas and opinions collected.

The initial phase has been dedicated to build the team and to explain the aim of this focus group and the rules of the game (there are no right or wrong answers; all information are captured in anonymous format…). In the first face to face meeting, the project and the five themes have been introduced and the most convenient formulations of the questions in the French context has been agreed: 8 main questions (from general to specific) have been therefore defined.

The first three themes have been debated so far, the discussion on the remaining topics is planned to be completed on September 2015.

4.5.3 Report on discussed themes

Theme 1: Current terminology usage

In the brainstorming section, it was important for the participants to share the same knowledge about regulatory and enforceable terminologies used in France. They spent some time to identify the terminologies that cover the main usages and the discussion concerned what terminology is used for what in various situations?

The Focus group identified real usages of terminologies (working applications) according to a use cases categorization. They discussed around 3 types of use cases: (1) Medico-Economic and Facturation, (2) Production of Care, (3) Care Coordination where these terminologies are successfully used. They take some time to list them.

Theme 2: Benefits of adopting new terminologies

This question was expressed in the following way: " Do you think there is a need for new terminologies, (such as SNOMED CT) or do you think there is a need to improve (extend) the implementation of current terminologies (reference and local)?"

The discussion focused on what are the usual practices in 4 identified contexts: Care Production, Care Coordination, Public Health, and Research. They focused on the reuse of data for Public Health and Research. For interoperability purposes, the ASIP agency has developed an interoperability framework at the national level but other interoperability frameworks exist and are used in specific domains (e.g. rare diseases).

The benefits of adopting new terminologies are related to the need of doing so. The focus group discussed what are today the priority use-cases in France in the 4 identified contexts and for each of them, they shared their points of view about some needs that are not fulfill by the actual used terminologies.

Theme 3: Barriers for extended terminology adoption and use

This question is supposed to be debated in September 2015. However the focus group started to answer this with a more specific question: What are the strengths and weaknesses of the current use of terminologies according to the set of use cases to be covered? They listed the following:

Weaknesses

- Licences, cost
- Updates (national/international) by Learned Societies
- Distribution of versioning resources
- Distribution of multilingual resources (if international use case)
- Integration to Information Systems (IS): implementation of coding in two ways (1) catalogue of Items to fill forms, (2) free text coding

Strengths

- PMSI (Programme Médicalisé des Systemes d'Information)
- Share/exchange of clinical information from one care facility to another, including at the international level (DMP) supported by the interoperability framework

Specific issue according to use cases

- Care Process: Coverage/Granularity of existing terminologies
- Care Coordination: Integration of data structures (value sets, binding)
- Reuse of data: Representing the context necessary for the re-interpretation (most often recoding)

4.5.4 Remarks / conclusions

France is not a member of IHTSDO. There are many regulatory and enforceable terminologies that are used in several concrete use cases. The development of a national

interoperability framework of health information systems is the cornerstone of the work of ASIP Santé and a reference for anyone who wishes to create an e-health project in France. An important review work has been done by ASIP Santé regarding the use of terminologies and this work was the basis of the discussions in the French Focus group. SNOMED CT is not perceived badly regarding the content of the terminology but it is not perceived as a unique solution. The question is more "why should we drop the other terminologies?". However, people in the focus group remain divided and some of them are currently willing to work with SNOMED CT in specific applications. Generally speaking, the main concerns of the French Focus group are about translation and licensing. Further discussions are forecasted during the project timeframe.

4.6 Germany

4.6.1 Focus group organisation

Facilitators

Prof. Sylvia Thun, MD; Hochschule Niederrhein, Medical Doctor and Professor of Information and Communication Technologies in Healthcare

Reza Fathollah Nejad, MA; Hochschule Niederrhein, Health Economist, Research Assistant and Scientific Project Coordinator at the Niederrhein University of Applied Sciences

Focus group composition

Christoph Gessner, PhD (Gematik (Association for Telematic Applications of the Electronic Health Card)/ HL7-Germany); Kai Haitmann, MD (HL7-Germany, Heitmann Consulting and Services); Zain Elabdin, BSc (ZOZLAIN); Tarik Idris, BSc (InterComponentWare AG); Jörg Caumanns, PhD (Fraunhofer FOKUS); Frank Oemig, PhD (AGFA Healthcare); Klaus Urban (Frey ADV GmbH); Daniel Flemming, PhD (Osnabrueck University of Applied Sciences); Stefanie Weber, PhD (DIMDI (German Institute for Medical Documentation and Information) ; Bernd Schuetze,PhD (Deutsche Telekom Healthcare); Lars Treinat (ZTG Center for Health Telematics and Telemedicine); Wolfgang Orthuber, DDS (University of Kiel); Sylvia Thun, MD (Niederrhein University of Applied Sciences, HL7-Germany)

Meeting(s)

Meeting 1

09.06.15, Cologne (adjacent to the 2. German Interoperability Forum 2015), Duration: approx. 2 hours

4.6.2 Methodology

First, potential experts in the field of eHealth were identified and invited. It was perceived as practicable to hold the focus group Meeting somehow in connection to the German Interoperability Forum, which usually takes place 4 times a year and deals with interoperability themes of data in the German healthcare sector. It is organized by the HL7-Germany, IHE-Germany, the German Institute for Standardization (DIN), the German Association of Healthcare IT (bvitg), and others. As depicted in the “focus group Composition” (see above), we tried to perfect the group with scientists, researchers and practitioners.

According to the guidelines for conducting a focus group, which was developed and agreed upon by all members of Workpackage 1, the questions were processed and prepared for the German focus group Meeting in July.

The questions were grouped in to 5 themes, translated into German language, and were integrated in to a PowerPoint-Presentation. Although the information was already provided in the invitation Email, another PowerPoint presentation was produced to depict the ASSESS CT project to the participants and illustrate how the German focus group is to be classified within the overall task of the project and especially in Workpackage 1.

It was planned to go through the questions by showing one slide theme by theme. At the beginning of the discussion, we provided the disputants with some basic discussion rules: Each theme will be discussed by 10-15 minutes and in the end there will be one more 10-minute slot for a final discussion round.

The discussion was recorded with the help of a smartphone (voice) and a written protocol was taken by a facilitator and a research assistant. The protocol was translated into English, revised as regards to content and sent to the participants for further revision and validation before going into the final draft.

4.6.3 Report on discussed themes

Theme 1: Current terminology usage

Germany is not an IHTSDO member and has no national license for SNOMED CT. However, there are several free affiliate licenses for the use of SNOMED CT within the scope of scientific projects.

For Germany, it can be made a rough distinction between terminologies used for administration and billing purposes and those used for clinical practice and nursing. For reimbursement in the inpatient care ICD-10-GM (for diagnosis) and OPS (for procedures) are decisive for the genesis of the G-DRG (German Diagnoses Related Groups) which is the basis for billing. In the outpatient care, EBM (Einzelbewertungsmaßstab) is the billing classification. The private health care sector uses their own codes and classifications. LOINC is used for laboratory results. Many individual terminologies (also in-house-versions) are used in nursing, while it has to be pointed out that the level of use is anyhow very low. Several other terminologies are used in rehabilitation, pharmaceutical and other branches of the healthcare system. Despite the rag of terminologies, there is a significant lack of alternatives for clinical document management systems.

Theme 2: Benefits of adopting new terminologies

The ability of SNOMED CT to ease and improve interchange and interoperability of healthcare data was the outstanding benefit highlighted in the discussion. Thereby transferring data in between different stakeholders were mentioned: between healthcare professionals for treating patients according a pathway (e.g. Disease Management Programs), for medical treatment of patients in the international context (such as holidaymakers, businessmen, soldiers, foreign patients, etc.), and for data exchange within health care providers or companies (e.g. laboratory chains, insurances, etc.). **Precise health data and statistics may provide excellent input for strategic management decisions within hospitals**. Given that SNOMED CT is already explicitly elaborated in terms of systematization and customization, the German health care system may highly profit from that groundwork without re-inventing and investing again in a new terminology. Also, most of the software systems which are used in Germany have also been developed here, so an adoption of SNOMED CT could lead to a competitive advantage due to such terminology extensions. Finally, SNOMED CT was seen as very well usable beyond data exchange specifications. Furthermore, the participants were asked to name characteristics of an ideal terminology system.

Theme 3: Barriers for extended terminology adoption and use

The participants' answers very broadly identified major barriers for the extended terminology usage and adoption, especially that of SNOMED CT.

There was a large consensus that the **perceived complexity and not the real complexity of the use of SNOMED CT** is one of the major barriers for its implementation. Moreover, the fact that SNOMED CT's national adoption is strictly **bound to a license fee and a membership in the IHTSDO is perceived as significantly hindering**. Yet, it was explicitly mentioned that not only the fee is not as high as perceived comparing to other changes and optimizations in clinic's IT architecture but also membership issues are clearly defined by the IHTSDO. These facts highlight the big lack of information by implementers and health care professionals in Germany and also led to another issue explicitly raised: **the deficient evidence shown by projects or studies conducted in Germany**, although it was noted that there should be higher acceptance in using **European evidence** easily transferrable to the German setting.

Theme 4: Enabling factors for extended terminology adoption and use

Investment money and further financing was perceived as one of the major enabling factors. There was also proved to be an increasing ability and necessity of data interchange, backed by the high rate of electronic medical documentation in the German healthcare system. An important distinctive feature is that Germany – unlike many other EU Member States – already has an institution which is responsible for medical documentation for more than 40 years (**DIMDI**).

The government initiated "eHealth law" has put **eHealth related issues on a larger political agenda**. One of its intentions is to **develop standards for interoperability**. Although controversially discussed, it was mentioned that some physicians have a high level of suffering because of lacking documentation possibilities.

Besides existing enabling factors, it was suggested to create **incentives by providing them with information about potential benefits for institutions' medical controlling and management**.

Theme 5: Recommendations

It was nearly unanimously agreed that there is the essential need to **establish a terminology competence center (TCC) on the national level.** This TCC should be commissioned to work on **national terminology extensions and translations, maintenance, international knowledge exchange, publication issues, training, promoting and positioning**. There should be relevant laws and guidelines in connection with a **migration concept** be implemented. The implementation process should be revised in such a way that wherever there is still no terminology in use, users should be obliged to implement existing international terminologies before starting to use or create a national one. The use of SNOMED CT should be mandatory, however a law could regulate that Medical Associations are being consigned to determine the use of specific terminologies in their specialist field. More collaboration between industry and terminology authorities should take place. In order to promote interoperable terminologies, users only get support from TCC when they use international terminologies (e.g. SNOMED CT). Last but not least, there is a need for **highly specialized terminologists.**

Others Themes

The IHTSDO should change their pricing system: instead of an "all-or-none"-policy, they should offer a **free use of up to 100 codes/concepts or free Value Sets**. There should be a coordinated activity for the use of SNOMED CT for certain use cases, like there was one for the Electronic Patient Summary (eArztbrief)-project in order to successfully fill the gaps. The participants asked for **more SNOMED CT related projects being evaluated**.

4.6.4 Remarks / conclusions

In Germany there is a **plurality of terminology and classification uses, by some experts also perceived as too many.**

The disadvantages of SNOMED CT are neither its quality nor its applicability, but its **licensing** which is wrongly perceived as too complex. Thus, the first step should be to promptly overcome the license barrier. As further decisive steps, there should be efforts for communicating and promoting **SNOMED CT's benefits, legacy problems should be solved and a catalogue of concrete recommendations should be provided**. Alternatively, **more projects within the framework of free affiliate licenses** should be undertaken. Projects should be well-designed in terms of scope, size, and time frame. Nevertheless, it was highlighted that at the EU level there are already existing results for benefits that may be easily transferrable to the German setting.

4.7 The Netherlands

4.7.1 Focus group organisation

Facilitator

Hans van Belleghem, independent consultant and owner at Twist

Focus group composition

Ronald Cornet (AMC; Linköping University); Huib ten Napel (RadboudMC); Renate Kieft (V&VN [Dutch Nurses' Association]); Felix Cillesen (Catharina hospital); Yvonne Heerkens (NPi - Dutch Institute of Allied Health Care); Pim Volkert (Nictiz)

Meeting(s)

Meeting 1: 13th May 2015

4.7.2 Methodology

First, potential experts in the field of eHealth were identified and invited. Unfortunately due to time constraints the invited physicians were not able to attend.

According to the guidelines for conducting a focus group, which was developed and agreed upon by all members of Workpackage 1, the questions were processed and prepared for the Netherlands focus group Meeting in May.

A PowerPoint presentation was used to depict the ASSESS CT project and support questions.

The discussion was recorded with the help of a smartphone (voice) and the protocol was translated into English, revised as regards to content and sent to the participants for further revision and validation before going into the final draft.

4.7.3 Report on discussed themes

Theme 1: Current terminology usage

In the Netherlands, 4 types of terminologies are distinguished:

- Administrative (ICD-10);
- Clinical (LOINC);
- Reference (SNOMED CT);
- Interface (DHD Diagnoses-Thesaurus)

Ideally, Clinical and Interface Terminologies are used in clinical practice, and mapped to SNOMED CT as reference terminology, from which administrative codes can be derived. However, currently administrative systems, ICPC1, ICF, DSM-5, ISO9999 (GPH – Generic Product Codes for devices), DBC (Diagnosis-treatment-combinations) are also used in clinical practice, and there is little interconnection yet. In May 2015, ICD-10 is manually determined by clinical coders.

The emerging DHD Diagnoses-Thesaurus aims at providing an interface terminology to SNOMED CT from which ICD-10 and DBC-codes can be derived.

Theme 2: Benefits of adopting new terminologies

- Semantic interoperability between various care providers
- Secondary use: clinical decision support; care pathways; research
- Unambiguous reference for decision rules, quality indicators, etc.
- Reducing the number of terminology systems EHR implementers (and care givers) have to deal with (UMLS: 177 sources; Bioportal: 447 ontologies)

Theme 3: Barriers for extended terminology adoption and use

Implementation takes time. The Netherlands have been IHTSDO-member since 2007, only since a few years some uptake of SNOMED CT is seen in systems such as ColonIS (for the national colon cancer screening program), in a system for optometrists, and in the national program on generic data for patient transfer.

Further barriers mentioned in the Dutch focus group are the need for more mappings between SNOMED CT and other terminologies, and an improved coverage over all domains (e.g., allied health professionals, nursing).

Pilots / proofs of concept are needed to show implementability, usability, and quality and completeness of contents.

Finally, the absence of a **Dutch translation of SNOMED CT** introduces a barrier for use in the Netherlands.

Theme 4: Enabling factors for extended terminology adoption and use

In the Netherlands, April 2013, the Dutch Federation of University Medical Centers (NFU) launched a program on Point-of-Care Data Capture. This program consists of 4 elements for 2013-2015:

- implementing uniform healthcare documentation
- obtaining buy-in from healthcare professionals
- facilitating standardized healthcare documentation
- increasing public awareness and transparency on use of healthcare data

For this, it will help to make interface terminologies available in Dutch. There is no need to start with translating all of SNOMED CT.

Proof of concept is needed to demonstrate how interface terminologies, reference terminologies and classifications interrelate.

Good software supporting use of terminologies will help their adoption and use.

Mapping the (structure and) content of registries to SNOMED CT will provide a stimulus for using SNOMED CT in clinical practice.

Theme 5: Recommendations

Complement and correct SNOMED CT with those parts that are currently inadequately covered, such as allied health professionals, nursing, care & cure.

Perform a **proof of concept** demonstrating the effectiveness and efficiency of capturing and using data with SNOMED CT as a reference terminology

Extend the **concept model of SNOMED CT to get more ontological rigor**

Harmonization of data requests for secondary use is needed: clear definition of data elements and relevant values, with a limited number of value sets for each data element

Coordinate and provide guidance on the **content for non-clinical use**

Training and awareness raising on use and reuse of SNOMED CT.

Translation of relevant parts of SNOMED CT into Dutch.

4.7.4 Remarks / conclusions

ADOPT, ALTERNATIVE, ABSTAIN? Intent to ADOPT, but this requires proof, further development and mappings, and keeping classifications (ICF, ICD, ICHI, ISO9999) in place + LOINC for clear identification of data elements.

We had difficulties to get care-givers to attend the focus group meeting.

In the Netherlands the healthcare is highly digitized. Major providers like hospitals and GPs already use Health information Systems for many years. Replacing their legacy content by terminologies like SNOMED CT and LOINC is a challenge.

4.8 Sweden

4.8.1 Focus group organisation

Focus group invitations were sent out to individual stakeholders selected for having firsthand experience of terminology development, management, governance, or implementation and to cover the categories National terminology organizations, Policy makers, Vendors, and Terminology implementers. Eight participants accepted the invitation, but the vendor representative was at the time of the meeting not available. As it turned out, the focus group had a relatively strong representation from the Swedish national board of health and welfare. Also, the overall composition of the focus group would give the group some bias towards national projects as opposed to local implementation. However, at least for SNOMED CT, the major implementation projects are currently nationally driven.

The meeting was arranged in cooperation with the organization of the Danish focus group. After the focus group session, a joint Danish-Swedish session was held to further discuss terminology implementation issues.

Facilitator

Daniel Karlsson, Linköping University, facilitated the focus group.

Focus group composition

Ann-Helen Almborg (National Board of Health and Welfare); Lotti Barlow (National Board of Health and Welfare); Lars Berg (Nordic Centre for Classification in Health Care); Kristina Bränd Persson (National Board of Health and Welfare); Erika Ericsson (National Board of Health and Welfare); Britt-Marie Horttana (Swedish Association of Regions and Local Authorities, National Quality Registries, Örebro County); Rikard Löfström (Consultant)

Meeting(s)

The meeting was held in Copenhagen adjacent to the IHTSDO Business meeting on April 27 2015.

4.8.2 Methodology

The objectives of the focus group were adopted from objectives discussed in the work package, but the group was allowed to set the focus of discussion. The focus group meeting was recorded and transcribed verbatim for further analysis. The themes and example questions were shown to the focus group participants, but the participants were instructed to relate freely to those questions. At certain points during the focus group session, to ensure coverage of themes, participants were asked to summarize their opinions related to the specific themes.

While there was, and still is, some confusion around the word “terminology,” especially in relation to classifications, in the focus group, in this analysis the following words are used with the specified meaning. It is assumed that participants of the focus group would agree with the meanings but not necessarily with the words assigned to those meanings:

- Clinical terminology – terminology intended for use in the documentation of the care of an individual
- Classification – terminology intended for secondary purposes, with fixed groups including residuals
- Terminology – classification or clinical terminology

4.8.3 Report on discussed themes

Theme 1: Current terminology usage

Sweden has been a member of IHTSDO since 2007, but **implementation of SNOMED CT is limite**d. Use of standardized terminologies in Sweden is today mainly based on use of international and national **classifications**, which are often **used as clinical terminologies in addition to their use for statistics and reimbursement**. For example, ICF categories have been used as a structure for the free text health record. Several current projects aim to implement both SNOMED CT and other terminologies in some combination. For example the national quality registries and a database of reasons for antibiotic use.

Theme 2: Benefits of adopting new terminologies

The focus groups participants saw the continued need to maintain usage of classifications, both for secondary and primary purposes, together with an increased use of SNOMED CT, **and particularly to harmonize (the use of) SNOMED CT with the international classifications**. It was thought that patient mobility cannot be achieved without standardization of health information, including the need for standardized terminologies. Further, the healthcare industry, including providers, pharmaceutical and biomedical technology industry, needs standards to enable benchmarking of results.

Theme 3: Barriers for extended terminology adoption and use

Three main barriers were identified by the Swedish focus group. There is currently a lack of **good examples** which explain the benefit of standardized terminologies, at least on the national level. Also there is lack of essential competencies, both on the side of the users of health information and, particularly, when procuring health information systems. Those who depend on high quality data do not always have the required information management knowledge. Another barrier is the lack of **governance and coordination**. **Implementation of standards needs to be centrally managed**. Different attempts at improving the health information infrastructure are often not coordinated.

Theme 4: Enabling factors for extended terminology adoption and use

Enabling factors mentioned by the focus group participants included good examples of terminology use, as mentioned in Theme 3. Further, central decisions about terminology use and stakeholder engagement are seen as important factors. Terminologies should have a sound quality assurance system, something which exists for SNOMED CT and the international classifications, but which might be harder to achieve for national terminology systems. **Easy access to terminologies**[8] is another enabling factor highlighted by the focus group participants.

Theme 5: Recommendations

The focus group participants thought that there really **was no alternative to adopting SNOMED CT on the EU level**. Sweden has already made this decision on the national level. If there is an EU decision on health terminologies, the decision should relate to both SNOMED CT and other terminologies, mainly the international classifications. Any terminology-related work has to include work on information structure as well. It is not sufficient to only consider terminologies but the terminologies in their information structure context.

4.8.4 Remarks / conclusions

Sweden was one of the founding members of IHTSDO in 2007. **A translation of SNOMED CT into Swedish is actively maintained**, but actual implementation is although growing,

[8] This includes several aspects: licensing issues, cost, high quality technical distribution, version update infrastructure, etc…

still at a low level. **Classifications, both national and international, are the mainly used standardized terminologies**. The participants saw the need for classifications being used together with SNOMED CT. A main barrier to extended terminology adoption was the lack of good examples. **The focus group participants saw no real alternative to adopting SNOMED CT on the EU level, but that that an EU terminology strategy should include not just SNOMED CT but also other terminologies serving different purposes.**

4.9 General remarks / conclusions

4.9.1 Premise

Slightly different approaches have been followed by each focus group in debating the themes agreed in the guidelines. Differences may be noticed in the level of detail some questions have been discussed; on the types of information actually gathered (facts, opinions); on the level of abstraction to which the five themes have been discussed and reported.

There are several, easily understandable, reasons for that: the fact that different facilitators have been used in each focus groups; the cultural differences; the expectations that each country put on this activity.

This minor heterogeneity should not be considered negatively, it being a sign of felt participation, indirectly reflecting also the perspectives, the needs and the expectations that each country brought into this activity. In fact, for most of the countries, the ASSESS CT focus groups have been also used, beyond the ASSESS CT project objectives, as a mean to discuss about terminologies and SNOMED CT usage at the national level. A concrete example of this – among the others - is the Finnish case: the results of the focus group will be in fact presented to the MoH for possible internal (National) usage. Another interesting element, pointed out by the Croatian representatives, has been the possibility of using the results of the ASSESS CT WP1 activities (including Focus groups) in term of other countries experiences, new perspectives and relationships for national purposes.

These elements reflect the added value of the ASSESS CT project national eHealth standards infrastructure developments.

The following sections summarize – per each of the discussed themes – the main ideas discussed.

4.9.2 Focus group themes

Theme 1: Current terminology usage

The first theme, used also for warming-up the discussion, has been one of the themes that showed the biggest differences in the approach used by the facilitators: someone in fact focused more on facts (i.e. what are the terminologies actually used..) (e.g. France); others on more general aspects related to the usage of terminologies (e.g. Denmark).

Several groups however pointed out – from different perspectives - the **tight link between terminologies and purpose of use or use case** and how this should be taken in account for any evaluation.

An attempt of **categorizing the purpose of use or typical use cases** (e.g. Administrative, Clinical,..) was made by some of the focus groups. As expected, different categories were identified.

An interesting element has been the frequent **absence of interconnection between those classes of used terminologi**es (see e.g. Netherlands and Croatia).

The **administrative/classification purposes seem to be the most frequent class** of use for terminologies. There are classifications like those of the ICD family or ATC that are transversally mentioned by several groups linked to reimbursement and statistical purposes.

Some groups (e.g. Sweden) indicated how sometimes the **classification systems are used beyond their real scope**. The risk of using terminologies beyond their real scope has also been explicitly mentioned also by the Danish group.

Finally, another interesting point emerging from some reports has been the distinction between the availability/suitability of terminologies and their actual use[9] in the cinical practice.

Theme 2: Benefits of adopting new terminologies

There are common elements that different groups have identified in their discussions, considering specific local cases or generic benefits.

The benefits hereafter reported are in large majority believed benefits.

- The possibility of **covering areas** for which there is a local **lack in the usage of terminologies** - independently on the reasons of this perceived shortage (low granularity, missed agreement, etc.). In this case the possibility of accessing and contributing to the knowledge of IHTSDO is seen as an added value. Two reports (FI and DK) mentioned the medicine/ prescription case related to the usage of ATC as one of the possible areas.
- Another aspect transversally mentioned is the potential role of SNOMED CT as **reference terminology** for facilitating the **interoperability in cross-domains, cross-settings** and/or cross-countries contexts, facilitating for example the binding of "the current pieces of the national health information infrastructure".
- In this context, improved quality of data may facilitate secondary and research use of EHR data, and moreover, quality control, (clinical) decision supporting systems and benchmarking.
- Finally, several focus groups emphasize also the role that a **"core" terminology/ies like SNOMED CT may play in the EHR-S marketplace** with mutual benefits for vendors and providers and favoring the internationalization of the national ICT vendor solutions.

Theme 3: Barriers for extended terminology adoption and use

The discussion about barriers is one of the themes in which the differences among groups are well identifiable: in term of wideness of the analysis, level of abstraction and type of focus (general barriers of terminologies vs local impact of the SNOMED CT adoption). As an interesting example of this the Finnish report that provides a wide and detailed analysis of the potential national impact.

There are however elements that have been transversally mentioned by the different groups, for example:

- The **low availability of evidence/best practices/examples**. This limits also the capability of providing a **correct evaluation of the potential consequences** of the SNOMED CT adoption.
- Related to this, **the low awareness about the actual return of investments** in this field (not limited to the economic aspects). This referred both to the organizational and the individual level.
- The lack of **governance strategies for supporting semantic interoperability**.[10]
- The "cost" of change management process: it is a long incremental process (see for example the Dutch experience) that implies the need of managing the human resistance to changes, including the fear of administrative burden, the comfort of legacy systems and free text (supporting tools may help on this)

[9] Note of the author for future discussion to be investigated why terminologies are not used when available and suitable.

[10] The lack of governance strategies has been mentioned by several experts. WP1 and WP4 are further investigating what particular areas of governance were felt most to be lacking. The results will be reported in D4.1 and D1.3.

- The lack of user-friendly implementations
- The fear of overcoding or undercoding, loss of information or superfluous information
- Need for training to fill the current deficiency of terminologists and their competences
- The costs for translation, mapping and terminology management.

An element that has been mentioned by several groups is the licence cost: even if many people recognize that this is only a part of the overall routine costs, it is identified as a non-trivial barrier in the decisional / start-up phase when the potential benefits of this change have not been yet completely evaluated / experienced.

Some groups have identified **the international collaboration / adoption of SNOMED CT as a possible mean for mitigating some of the above mentioned barriers**.

Theme 4: Enabling factors for extended terminology adoption and use

There factors that may potentially enable the adoption and use of terminologies and for some extend related to the identified barriers and they are:

- Increased awareness/knowledge of the actual individual and organizational benefits. This implies education, pilot/proof of concepts, best practices.
- Clear directions on health terminology use: this implies clear policies, governance, and allocation of human and financial resources, incentives. This is believed to be a sensible point for directing vendor investments on this field.
- Supporting resources available for implementation of terminologies: including guidelines and mapping with reimbursement terminologies.
- Availability of supporting tools and software that link SNOMED CT to the background
- Incremental step-wise adoption
- Easier access to terminologies
- Launch of pilots focusing on specific use cases
- Adapt the business model of SNOMED CT

Theme 5: Recommendations

It is in general believed that SNOMED CT is a good solution for improving the semantic interoperability and that there are no other equivalent alternatives for the usage at the EU-level as reference terminology. However it is not supposed that SNOMED CT is the “solution” that solves all the issues, other (international) terminologies are expected in fact to be used as well, depending on the use case.

High quality maps should be available, in particular with terminologies used for reimbursement.

Several recommendations reported are directly related to the enabling factors discussed in theme 4, as education, proof of concept availability, awareness raising, guidelines for implementation, etc. Others indirectly derivable from those. like:

- Establish **terminology competence centers** at the national level, responsible for national terminology extensions and translations, maintenance, international knowledge exchange, publication issues, training, promoting and positioning.
- Mandate by law the use of selected terminologies.
- Complement and correct SNOMED CT with those parts that are currently inadequately covered
- Adopt an iterative phased use case driven implementation approach to build best practices and guidelines
- Supporting tools, maps, translations, ready to use subsets linked to information models

- Promote the identification of solutions for overcoming the “all-or-none”-policy of IHTSDO and facilitating the evaluation/adoption of SNOMED CT by non-member countries.

4.9.3 Final note

As demonstrated by the ASSESS CT experience, the establishment of the country-based focus groups has provided results that go beyond the specific objectives of the project, having a positive impact also at the national level on the discussion about terminologies, on raising the awareness about the semantic interoperability problems and on promoting as well the cooperation among countries.

It is suggested that this experience could be repeated also in the future, possibly extending the realization of focus groups also to other countries. This could expedite MS involvement and stimulate the discussions on specific concrete themes related to the usage of terminologies (or more in general on the semantic interoperability) that may have an European impact.

Relying on them, topic -focused cross-countries discussion groups may be created as well for supporting specific practical topics.

5 Report on questionnaires

The delivering of questionnaire has been one of the primary instruments adopted in the preliminary investigation phase. This instrument has been used to reach with relative ease, a large number of stakeholders and to capture preliminary feedback about knowledge, perceptions and facts around the use of clinical terminologies (with a focus on SNOMED CT): it has been also used to profile the stakeholders to be included in the stakeholder registry (when consent is provided); and finally to capture from a selected number of Member States/Regions representatives information about the usage of terminologies in those countries.

Those goals have been realized through two distinct questionnaires, labeled as:

- the “all stakeholder” questionnaire describe in § 5.1
- the Country overview questionnaire described in § 5.2

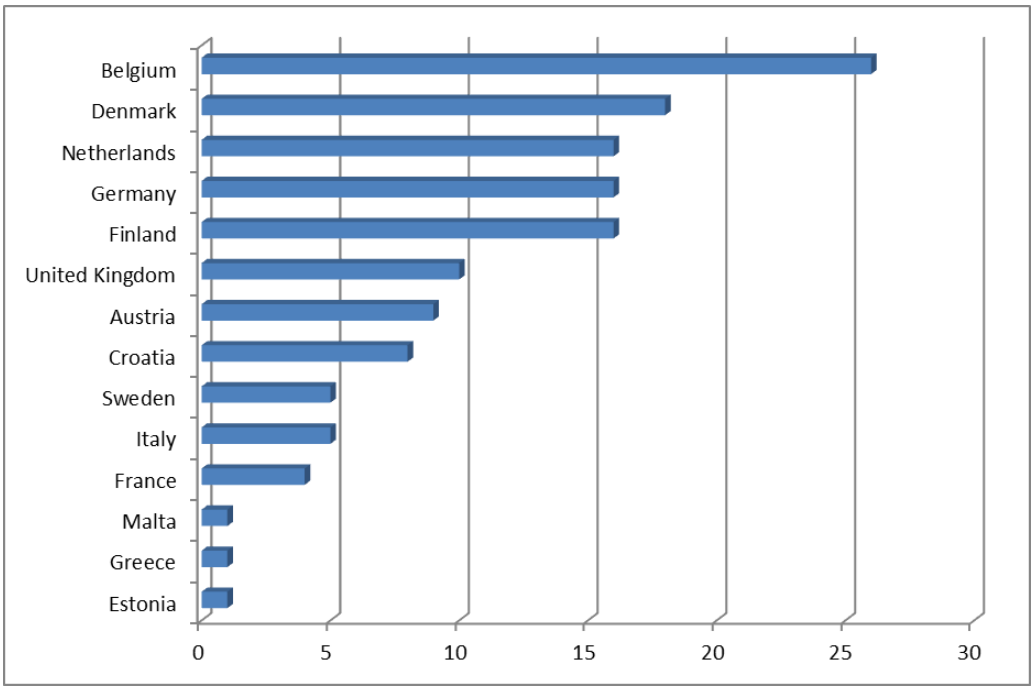
The way those questionnaires have been designed; stakeholders and experts selected and engaged; and on line questionnaires delivered and processed is described in the ASSESS CT Deliverable D1.1.

In the following sections are reported the results concerning all the responses received by July 07, 2015. Further answers are planned to be collected in order to increase the coverage of this survey in the next months. The final results will be reported in Deliverable D1.3.

5.1 All stakeholders questionnaire

This report is based on the **136** responses gathered before the July 9th 2015, coming from **14 countries,** so distributed:

Figure 2 Completed Responses per Country (Stakeholders Questionnaire)



At the time of delivering this document, responses from Luxembourg have also been received. Additional answers from other European countries are expected to be received as well. They will be processed and documented in a second stage and integrated in the final deliverable.

Hereafter is provided a report of the questionnaires received, according to the structure of the Country Overview questionnaires.

5.1.1 Your contact details & about your role and experience with terminologies

This section provides an overview of the characteristic of the stakeholders that participated to this survey.

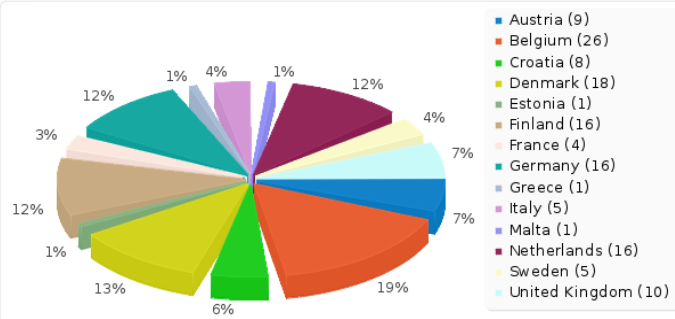


Figure 3 shows the percentage of participants per country.

A good coverage for all the identified roles has been achieved both for roles in healthcare (see Figure 4) and for the kind of involvement with terminologies (see Figure 5).

Figure 3 - Stakeholders per Country

For the first role, there is a little prevalence of Health care and ICT professionals and a minor, but still significant number of members of advocacy groups. Most of the role indicated as “Other” could be easily remapped into one of the classes already identified.

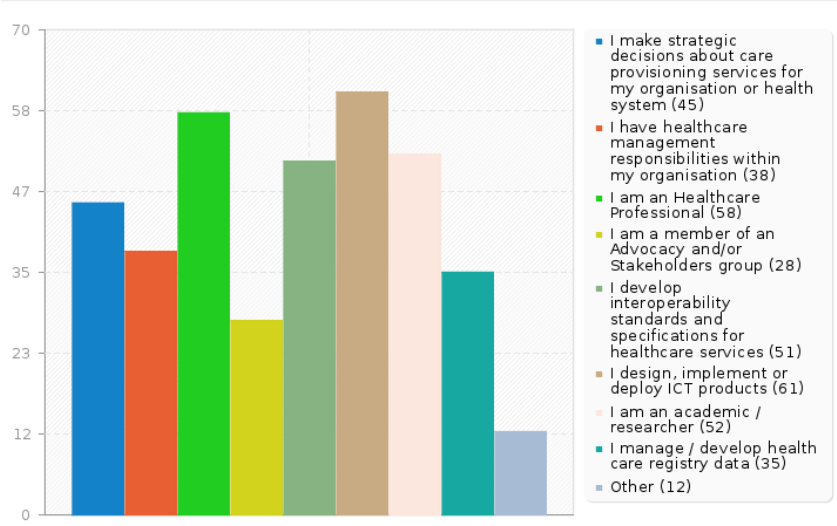
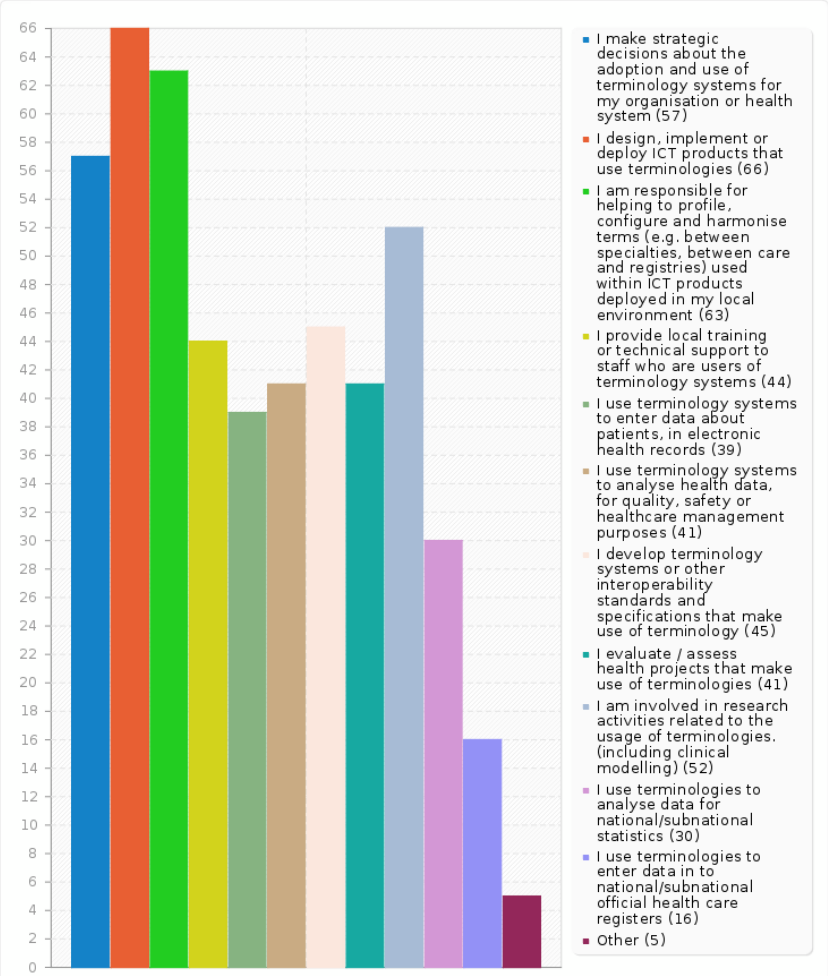


Figure 4 Stakeholders roles in healthcare



For what concerns the involvement with terminologies there is a little, but not negligible percentage of people, involved in registries or statistics. The highest populated categories have been instead those related to ICT products. It is interesting to note how the third most frequent class has been that of strategic decisions makers. Even in this case most of the "other" responses could be remapped in one of the existing classes. For further details about hose answers please refers to Appendix 2.

Figure 5 Stakeholders involvement with terminologies (questionnaire)

A relatively high percentage of those interviewed declared to have been involved in cross-border healthcare activities (just under the 30%): mostly of them through EU funded projects like epSOS, Trillium Bridge, SHN, PARENT JA, EHR4CR, EXPAND, but experience are not limited to those projects (e.g. INTERREG Italy-Slovenjia "Patient without borders").

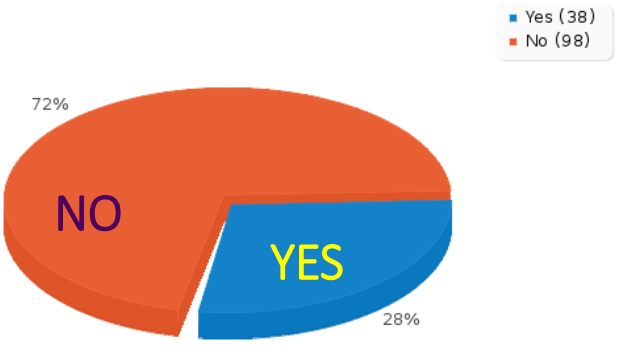


Figure 6 Have you been involved in cross-border healthcare activities (e.g. pilot projects)?

About the 30% of respondents indicated limitations of current terminologies in supporting cross-border patient data exchange. Those limitations can be classified as:

- Lack of **common/reference** terminologies
- Need to **combine** several terminologies

- Issues with **mapping** to local terminologies
- Issues with **licensing** terminologies
- Need for **translations** that do not exist yet
- Lack of **good quality structured and coded** data (in the source EHR systems)
- Inadequate terminology **strategies and policies** (including legislation)
- Lack of common information models

As displayed in the figure below the most frequently mentioned issue is the lack of a common/reference terminology (label "1") followed by inadequate terminology strategies and policies (label "2).

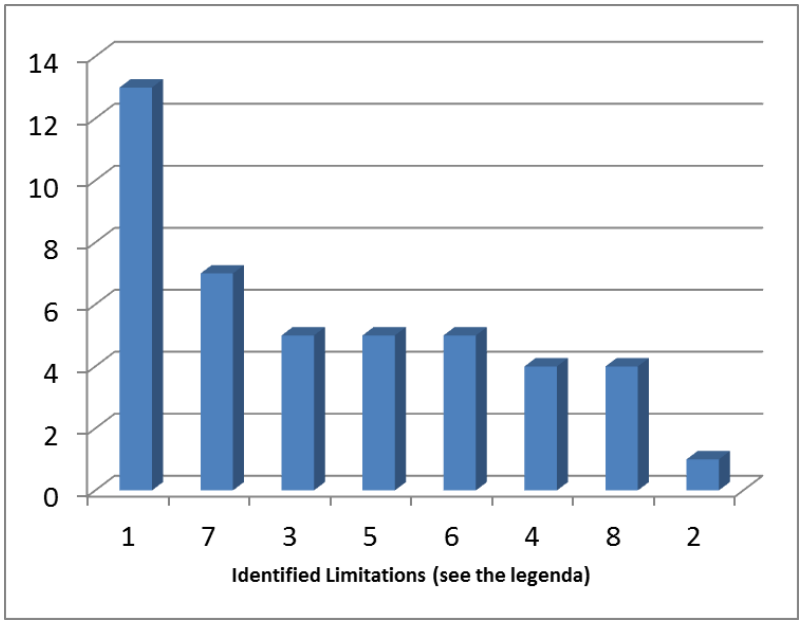


Figure 7 – Frequency of the identified limitations for the cross-border exchange of patient data.

Legend: [1] Lack of common/reference terminologies; [2] Need to combine several terminologies; [3] Issues with Mapping to local terminologies; [4] Issues with Licensing terminologies; [5] Need for translations that do not exist yet; [6] Lack of good quality structured and coded data (in the source EHR systems); [7] Inadequate terminology strategies and policies (including legislation); [8] Lack of common information models

The solutions suggested in supporting cross-border patient data exchange by the same percentage of respondents (about the 30%) can be classified as followed:

- Availability of a **centrally curated reference terminology,** allowing local extensions
- Availability of **mapping** to local/national terminologies
- Reduce license costs
- Availability of **translations**
- Provide support for multi-terminologies environment
- Enforce the usage through suitable policies and legislation
- Change management processes
- Increase cooperation among organizations and experts, learn from existing experiences
- Education
- Improve the EHR-S capabilities for facilitate the end-users activities

The most favored proposed solution for overcoming those problems was the adoption of a centralized European reference terminology, for which SNOMED CT may be the most appropriate solution (label “A” of the figure below). This combined with suitable policies and legislations (label “F”), availability of mapping (label “B”) and increased cooperation among organizations and experts. (Label “H”).

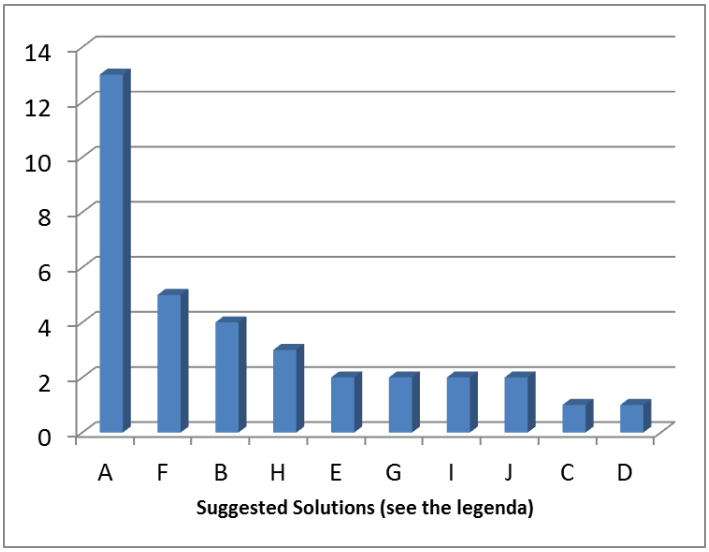


Figure 8 – Frequency of the suggested solution for the cross-border exchange of patient data

Legend: [A] Availability of a centrally curated reference terminology, allowing local extensions; [B] Availability of Mapping to local/national terminologies; [C] Reduce License Costs ; [D] Availability of translations; [E] Provide support for Multi-Terminologies environment; [F] Enforce the usage through suitable Policies and Legislations; [G] Change Management processes; [H] Increase cooperation among organizations and experts, learn from existing experiences; [I] Education; [J] Improve the EHR-S capabilities for facilitate the end-users activities

5.1.2 Your views on the use of terminologies

In order to profile the perceived level of knowledge of SNOMED CT of the respondents, and indirectly how SNOMED CT may impact their job it has been asked to rate the level of knowledge about SNOMED CT for the job roles indicated. About the half of people believe they have some knowledge and that it would be useful to learn more to be able to use it in their job. It is interesting to compare this result with the fact that training and education is indicated as one of the enabling factors in the country overview questionnaire.

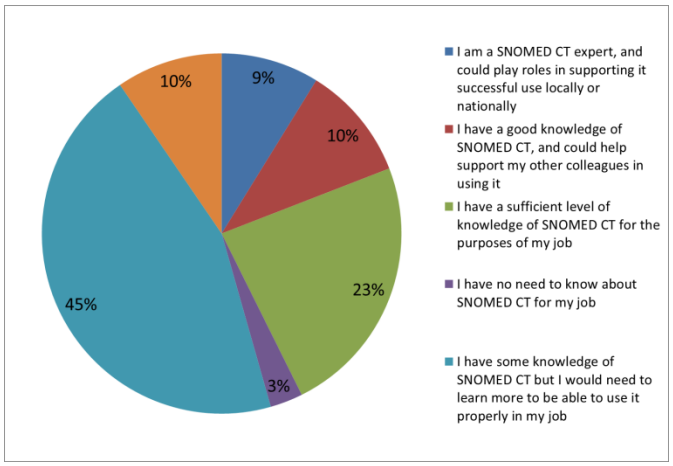


Figure 9 – How stakeholders rate their level of knowledge of SNOMED CT

In Appendix 2 all the comments associated to the given responses as well as the list of the international terminologies used in their countries (including the context) has been provided.

Concerning the international terminologies used in each country ICD 9, ICD 9 CM, ICD 10 (with or without local modification), ICD 10 CM, ATC, ICPC have been the most frequently mentioned terminologies. Classification (reimbursement) purposes were the most cited context of use.

The large majority of respondents (> 60%) claimed that in their country SNOMED CT a very limited used or not used at all.

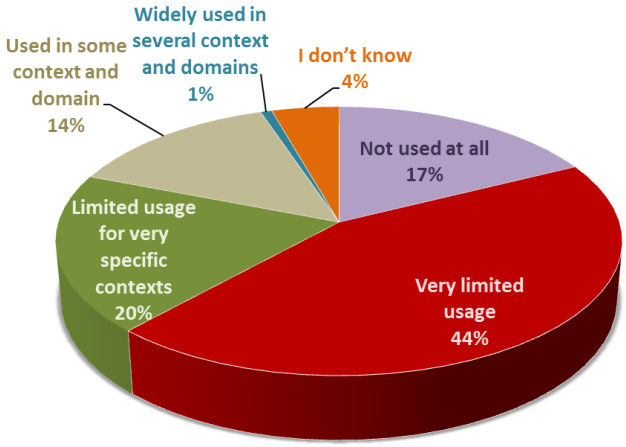


Figure 10 How could you score the current usage of SNOMED CT in your country?

The following figures show the same response distributing the answer per country, normalized (Figure 11) and as a mean score (Figure 12).

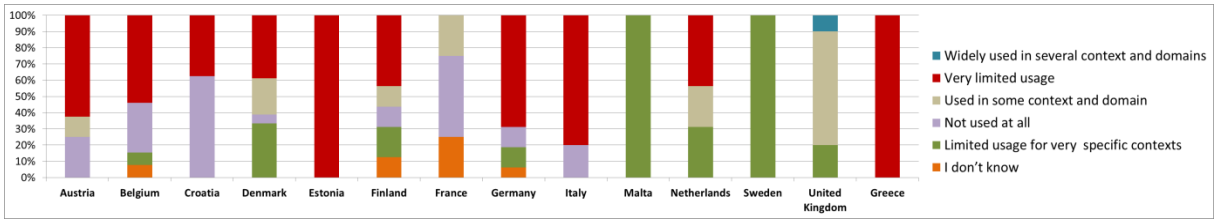


Figure 11 How could you score the current usage of SNOMED CT in your country? [Normalized distribution]

The score has been calculated assigning an integer from 0 (not used) to 4 (widely used) to each class and calculating the arithmetic mean.

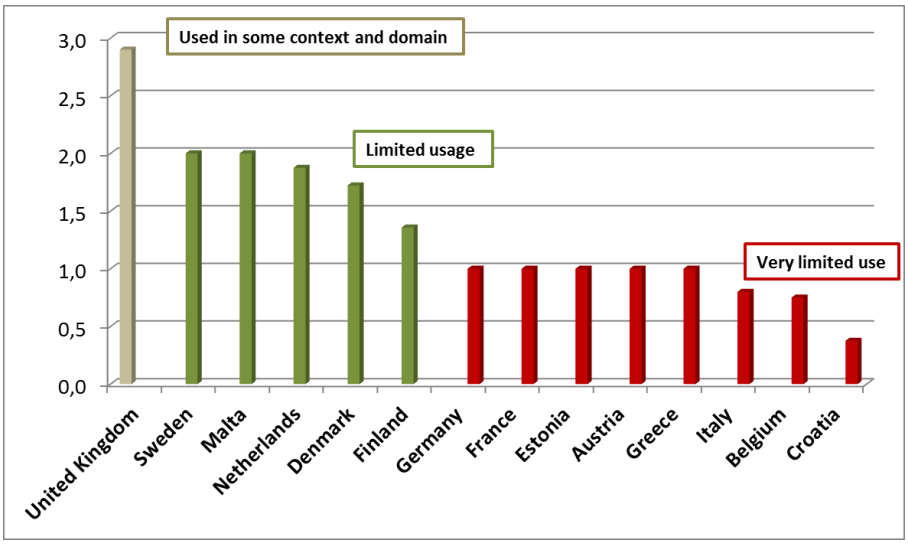


Figure 12 How could you score the current usage of SNOMED CT in your country? [Mean score]

From this distribution we can identify three main classes of countries:

- non-IHTSDO member countries that have a very limited SNOMED CT usage (or less) [red]
- IHTSDO member countries like Denmark, Netherlands, Malta and Sweden in which SNOMED CT is limited used. Finland is border line between this two classes [green]
- the United Kingdom (England) that is the only one for which SNOMED CT is substantially used in some contexts and domains [gold]

5% of respondents believe that there are no benefits from using SNOMED CT (this percentage is almost recurring in all the questions related to SNOMED CT). Several detailed responses have been provided about the believed benefits, the complete list of these responses can be found in Appendix 2. These "main believed benefits" can be summarized into the following, non-orthogonal, classes:

- Improve the semantic interoperability for local/national and cross-countries exchange of health data.
- Improve the clinical documentation for structured EHR contents. (complete coverage of several domain, standardization of EHR contents, granular detailed terminology)
- Support for EHR contents translations
- Unification of EHR
- Used to enable comparability for quality assessment and policy making for health care providers.
- facilitate, improve the extraction, the comparison and the reuse of information (non-redundant data capture, better data quality, cross organizational data integration) for several purposes [reference terminology]: registry; quality measures; medical decisions support; public health reporting; national and international benchmarking; research; "traceability across the patient trajectory"….
- Improve the patient safety
- Availability of description logic ontological representation of some medical concepts
- Improve efficiency, reduce cost (possibility of using "economies of scale in the expensive process of knowledge representation")
- Robust maintenance process (Strategic long term benefit)

As mentioned above details about the believed benefits are reported in Appendix 2, however it is interesting to note how it has been also pointed out the "clinical" purpose of SNOMED CT respect to other classification systems (as ICD family) widely used for administrative purposes (and not only); the fact that real benefits, are mainly strategic (in a long term perspective) and that can be actually reached when broadly implemented; how for getting the semantic interoperability terminologies (and SNOMED CT) terminologies have to be used in relation with detailed information models (terminology binding).

About the 9% of respondents didn't indicate any specific believed risks, constraints or challenges with SNOMED CT. Similar considerations done for the believed benefits can be applied as well for the risks (refers to Appendix 2 for details). The main classes of believed problems identified have been:

- Costs (terminology license, refset definition, software licenses, training, EHR-S implementation, translation)
- Absence of translations, maps with used terminologies (mainly for reimbursement purposes)
- Management of the transactional scenario (change management)
- Coexistence with other terminologies

- Quality and consistency issue
- SNOMED CT complexity (description logic, compositional syntax, versioning management, IHTSDO collaboration, implementation in software)
- Lack of knowledge/expertise
- SNOMED CT learning curve
- End-users acceptance: usage of coded data, resistance to change, availability of appropriate tools for supporting users in clinical settings.
- Low EHR-S (ICT market) maturity
- **Lack of supporting policies**[11] (including countries commitment).

Some distinctions between the complexity and the "perceived" complexity have been done (this subject came out also in the German focus group discussion). It has been also put in evidence the need of having a critical mass before actually gaining benefits from the adoption of SNOMED CT and the fact that SNOMED CT has to live in a terminologies eco-system being not a " silver bullet' that solves everything by itself."

About the 55% (77 over 136) of interviewed asserted that they have no direct experiences with SNOMED CT. Considering the remaining responses (59) about the **18 %** of respondents (11) declared that they **have not experienced benefits** from SNOMED CT.

As a general comment, for the experienced benefits, the percentage of benefits related to development of solutions and research (rather than the end users) is higher than for the believed benefits. This is coherent with the limited and often focused current use of SNOMED CT in the clinical settings. Some examples of cases in which benefits have been experienced are :

- Clinical research / clinical trials / datamining - better identification and extraction of data (from EHRs)
- Clinical information modeling (e.g. CIMI)
- Usage as reference terminology ("use as an interlingua" for multi-terminologies environment, cross-domains interoperability)
- Improved care provisioning (better description/identification of medical concepts, reuse of knowledge, multiple domains coverage)
- Standardization in specific care settings/domain (e.g. primary care, drugs, devices)
- Improved products value ("more effective and wider uses of clinical data entry")

Detailed responses are documented in Appendix 2.

Just less than the 25% (32 out of 136) of interviewed asserted that they have no direct experiences with international terminologies. Considering the remaining responses (104) the **18 %** of respondents declared that they **have not experienced additional benefits** from those international terminologies.

Comments provided can be grouped into two main types: general advantages of using (good quality) terminologies and terminology/use case specific notes. Several answers seems to be related to which international terminology is used and for which purpose rather than which advantages have been experienced. General advantages are in some extend similar to those indicated for SNOMED CT: reuse of knowledge, support semantic interoperability and comparison of data across countries, support for decision supporting systems. Several notes are referred to the ICD family for classification related purposes. Some contrasting opinions about LOINC have been also provided. Details in Appendix 2.

[11] This statement addresses different aspects (directly or indirectly mentioned in the comments in Annex 2), such as the need for reliable strategic directions in order for vendors and decision makers to define their strategic plans and optimise investment strategies for their scarce resources; the availability of investment for setting up the needed (management) organizations, tools and infrastructures required for supporting the semantic interoperability; the strong political and management commitment required to adequaltely support the change management process in its different aspects; etc.

About the 35% (49 over 136) of interviewed asserted that they have no direct experiences with local terminologies. Considering the remaining responses (87) the **17 %** of respondents declared that they **have not experienced additional benefits** from those local terminologies.

Experienced type of benefits with local terminologies can be summarized into:

- Fulfill local needs or gaps for specific domain (most cited procedure, billing, drugs)
- Personalization (for Interface terminologies)
- Simpler to be used / learned; faster to be implemented
- Flexibility

Several notes have been added for specifying the conditions in which these benefits could be experienced (and some drawbacks associated). E.g. the need of mapping these terminologies with the International ones; the distinction between short term and long term benefits; constrains related to local normative requirements.

More than the 50% (74 over 136) of interviewed asserted that they have no direct experiences with SNOMED CT. Considering the remaining responses (62) less than the **10%** of respondents (5) declared that they **have no challenges experienced** from SNOMED CT.

Similar considerations differences between believes and experiences, as those done about the experienced benefits, can be repeated also for this question. Moreover some of the notes provided seem to be related more to believes than to experiences.

The main classes of experienced challenges have been:

- License and translation costs (time and resources)
- Absence of translations, local extension and synonyms; absence or lack in existing maps.
- Limited adoption, absence of valuable reference experiences
- Quality and consistency issue (update life-cycle, hierarchies validation; gaps / missing concepts)
- SNOMED CT complexity: compositional syntax, browsing and selection, local extensions management.
- SNOMED CT learning curve
- Implementation issues (CDA and FHIR; storing data in existing clinical systems; terms browsing and selection)
- End-users acceptance
- Low EHR-S (ICT market) maturity
- **Lack of commitment.**

Just less than the 30% (38 over 136) of interviewed asserted that they have no direct experiences with international terminologies. Considering the remaining responses (98) the **11%** (11) of respondents declared that they **have not experienced challenges or problems** from those international terminologies.

The type of comments provided spans from very specific issues related to well specified and narrow conditions to generic comments, even for the same kind of issue (e.g. insufficient granularity). There are several comments that seem to be related to the usage of some terminology (e.g. ICD 9) beyond their effective scope; about this point please refer also to the Danish or Sweden focus group discussion. With this in mind, and referring to Appendix 2 for detailed results, a set of classes of experienced challenges have been identified:

- Translation costs (time and resources)
- Management of the transactional scenario (change management e.g. from ICD-9 to ICD-10)

- Quality and consistency issue (not enough granularity; missing concepts; “codes has same code but changed concept”)
- Supporting procedure and tools for terminologies management (e.g. versioning)
- Lack on governance
- Coexistence of multiple terminologies (mapping, conflicting information, variable granularity)
- Missing link with administrative/economic related terminologies
- Fulfillment of national/local needs
- End-users acceptance

About 30% (41 over 136) of interviewed asserted that they have no direct experiences with local terminologies. Considering the remaining responses (95) the **20%** (19) of respondents declared that they **have not experienced challenges or problems** from those local terminologies. Most of the comments provided refer to generic issues, the most frequently type of issues mentioned have been (further details in Appendix 2):

- Lack of semantics
- Lack of interoperability
- Maintenance and consistency issues
- Reusability of information outside the original jurisdictional or medical domain
- Lack of standardization
- Low scalability
- (lLong/medium term) highest costs (maintenance, mapping, quality costs)

As clearly Figure 13 shows, the preferred approach to coding clinical facts is the direct selection of terms by clinicians during data entry; as second option the usage of processing mechanisms for coding data using SNOMED CT: few people consider instead the post-hoc clinical coding the most practical approach for coding.

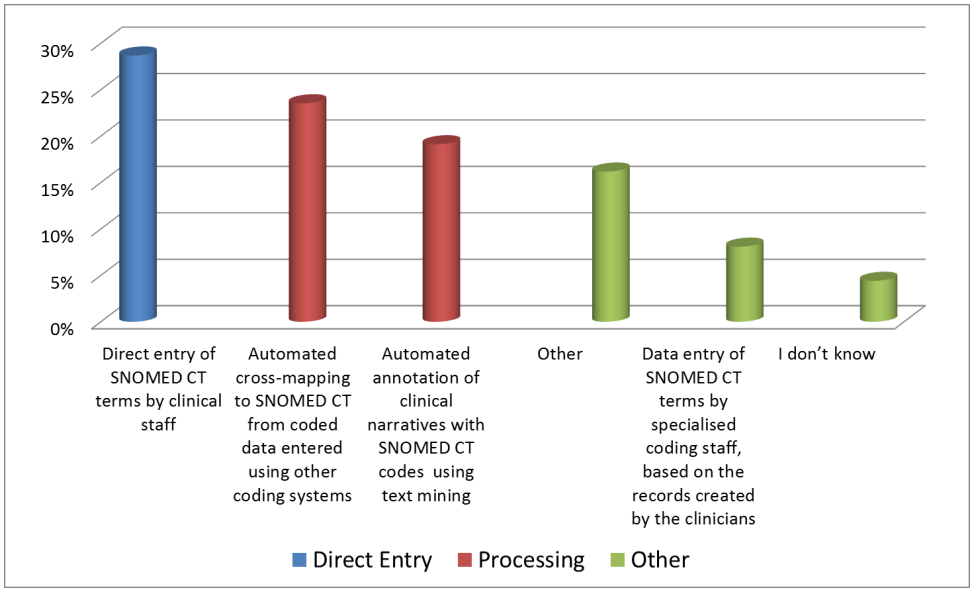


Figure 13 Which are practical approaches to coding clinical facts about a patient with SNOMED CT?

In most cases the “other” option has been selected to point out the fact that the approach should be context dependent, or might be a combination of the proposed solutions.

It is interesting to note that although the score about the usage of SNOMED CT is relatively low, the large majority of replies indicates SNOMED CT as a suggested candidate for the exchange of health and social data cross-border having a good coverage of most of the medical domains and being "the only broadly available terminology that can (when translated) overcome the language barriers". This positive answer should however be read under well specified conditions and with identified caveats[12]. Like the fact that it might be **one of the** terminologies used, the answer may refer to specific use cases, the need in any case to support mapping with other terminologies (including legacy local terminologies), and other challenges identified by the previous questions (license cost, complexity, etc.).

Refer to Appendix 2 for the complete list of comments.

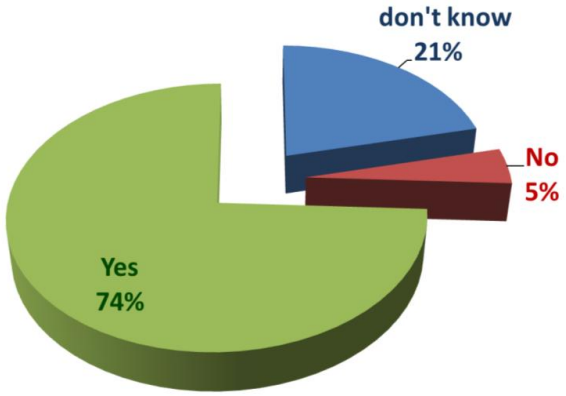


Figure 14 According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-border?

5.2 Country overview

This report is based on responses gathered before the July 9th 2015, covering **14 Member States**: Austria; Belgium; Croatia; Czech Republic; Estonia; Finland; Germany; Greece; Italy; Malta; Netherlands; Slovakia; Sweden, United Kingdom.

The response from the United Kingdom, collected during a meeting organized with UK representatives, is included in this report with the caveat that the answers reported need to be explicitly validated by the respondents.

Responses from Denmark, Luxembourg and Portugal have been also received after that date; additional responses from the other European countries are expected to be received in the next months. All those responses will be processed and documented in a second stage and integrated in the final deliverable (D1.3).

A draft report of the Country Overview results was prepared on Mid July and shared with all the interested parties for the content review.

All the received changes have been tracked and considered for this deliverable.

The complete report is available on Appendix 3, a summary of the main results is provided in the following sections.

5.2.1 About your country

This section of the questionnaire aims to provide an overview of main characteristic of each country. The answers collected confirm the *limited usage of SNOMED CT*: for the large majority of the interviewed countries in fact the adoption is in most cases in progress or under consideration. (Figure 15)

[12] About the 40% of people answering YES added a comment.

Almost all the countries use terminologies at the national level for *secondary or administrative* purposes or for very specific use cases. Almost an half of countries claims that a national strategy for terminology is under discussion, (see Table 1 for details)

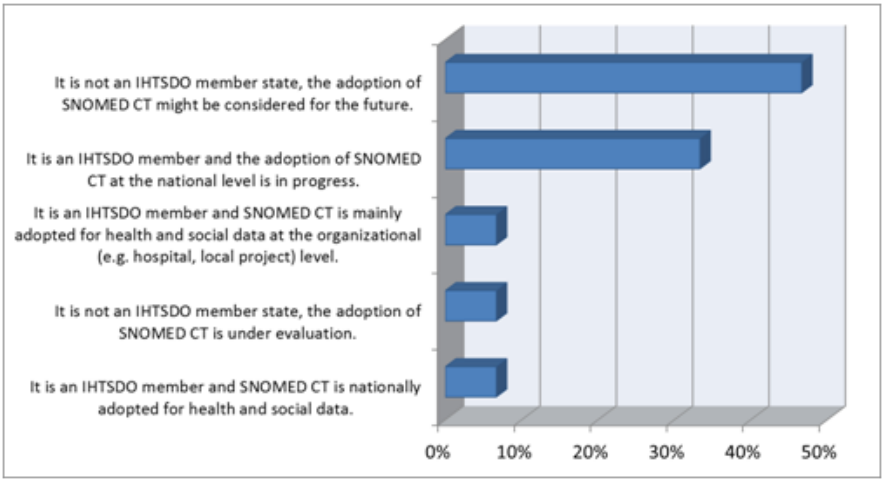


Figure 15 - Which statement describes your country best (IHTSDO membership and SNOMED CT adoption)

Less than half of the countries declared to have a National Competence Center(s) for Terminologies: AT, BE, EE, FI, DE, SI, SE and UK. (See appendix 3 for details). This is an important aspect to be taken in account also in the perspective of terminology policies at the national level.

Table 1 - Which of the following statements apply to your country (usage of terminologies at the national level)

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
There are terminologies used at the national level for health and social data, for a wide range of use cases (e.g. in a nation-wide EHR/PHR).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
There are some terminologies used at the national level for health and social data, for very specific use cases (e.g. prescription, pharmacovigilance).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
There are terminologies mainly used at the national level, for secondary or administrative purposes (e.g. reimbursement; governance; costs-control; registries…).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
There is a need for terminologies for health and social data at the national level (e.g. nation-wide EHR/PHR), but a national terminology strategy is still under discussion.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
There is no need for terminologies to be used at the national level for health and social data.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

(*) To be explicitly validated

Concerning the question about the usage of international terminologies at the national level only the Czech Republic has asserted to not use it. ICD-10 (with or without local extensions) and ATC are the most commonly used (even if with different scopes) [See Appendix 3 for details]

The large majority of the interviewed countries, with the exception of Austria, Slovakia, and United Kingdom, asserted that relevant domains are not actually covered by nationally used terminologies.

Domains mentioned spans across very different types of classes of information and use cases. The most cited ones have been:

- Lab Procedures
- Procedures
- Allergies
- Medical Devices

It should be considered for future investigations the analysis of the reasons of the lack of usage of terminology for those domains at the National Level. For example challenges related to the selection and adoption of terminologies; lacks on agreed information models and tools for capturing those data as structured and coded information; etc.

With the exception of Malta and Slovakia, all the countries declared to use, at the national level, national defined terminologies covering very different areas. Some recurring cases are drugs nomenclature / classification; procedures; codes for accounting (details in Appendix 3).

The authoring and administration of the terminology assets (value sets, code systems,..) seems to be for the large majority of cases (> 50%) managed not using terminology systems/services, but alternative solutions. In the most cases by means of excel files.

Table 2 - How are the nationally adopted terminologies are managed (administration; authoring;…)

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Through a central terminology management system	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Through a set of terminology management systems	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Through a central terminology service	□	□	□	□	□	□	□	□	□	□	□	□	□	□
I don't know	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Other	□	□□	□	□	□	□	□	□	□	□	□	□	□	□

(*) To be explicitly validated

Almost all the countries use the Web publication as a mean for distributing terminologies. Less than the 50% use local or central terminology services.

Table 3 - How are the nationally adopted terminologies made available for usage ?

Member State	AT	BE	HR	CZ	EE	FI	DE	DE	GR	IT	MT	NL	SI	SE	UK (*)
Through a central terminology server	□	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Through local terminology services	□	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Published on the web (e.g. RF2, ClaML, excel, pdf,..)	□	□	□	□	□	□	□	□	□	□	□	□	□	□	□
I don't know	□	□	□	□	□	□	□	□	□	□	□ 13	□	□	□	□
Other	□	□	□	□	□	□	□	□	□	□	□	□	□	□	□

(*) To be explicitly validated

About half countries (BE, HR, CZ, EE, IT, SI) asserts that no tools or technologies are used for facilitating the usage of nationally adopted terminologies. Most of the mentioned tools refer to solutions for supporting the access and distribution of terminologies (terminology servers, web browsing tools,..).

Table 4 summarizes a potential classification of the comments[14] provided about the methodologies applied for facilitating the usage of nationally adopted terminologies by end users (refer to appendix 3 for details).

Table 4 - Methodologies applied for facilitating the usage of nationally adopted terminologies by end users

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Facilitated access	□	□		□		□	□			□				
No specific methodologies			□					□	□		□	□		

[13] Indicated as No in the questionnaire but the comment "Published on the web" has been added.

[14] Most of the responses seem to be related more to technological solutions used rather than methodologies applied, those answers have been interpreted as a way for facilitating the accessibility to terminologies and classified in such a way.

applied, No Answer														
Normative requirements	□				□		□							
Education						□							□	□
Stakeholder involvement						□								□

(*) To be explicitly validated

5.2.2 About SNOMED CT adoption and usage

Almost all the countries that have, or are going to introduce SNOMED CT, indicated a **project / use case based** approach as the reference approach, with the exception of Sweden and United Kingdom (top down approach). A mixed approach should be however considered for those countries, as explicitly mentioned in the UK response. For what concern Netherlands the project based approach used in the startup phase, is progressively turned towards a centrally managed approach (embedded in national policy documents and projects).

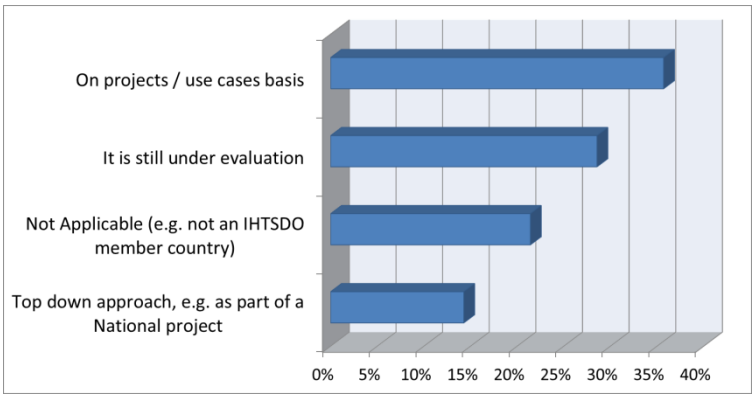


Figure 16 - Which approach has been followed in your country for introducing SNOMED CT as a terminology for health and/or social care data

The following table reports the answers provided by each country about the use cases/purposes for SNOMED CT.

Table 5 - For which use cases/purposes is currently used SNOMED CT in your country

Member State	For which use cases/purposes is currently used SNOMED CT in your country
Austria	Maybe in international research activities.
Belgium	Use cases under development
Croatia	SNOMED CT is currently not in use.
Czech Republic	None
Estonia	Pathology use case; infectious disease use case; defining the technical data field.
Finland	We have so far identified only the use of old versions of SNOMED in pathology. We participated in eSOS-project in defining Patient Summary but did not pilot it. epSOS eP was piloted.
Germany	Not applicable
Greece	for R/D projects.
Italy	Research (limited use); International projects (e.g. epSOS);
Malta	Creation of clinical vocabularies based on SNOMED CT concepts, with mapping to standard classifications (ICD-10, ICD-9-CM, ATC).

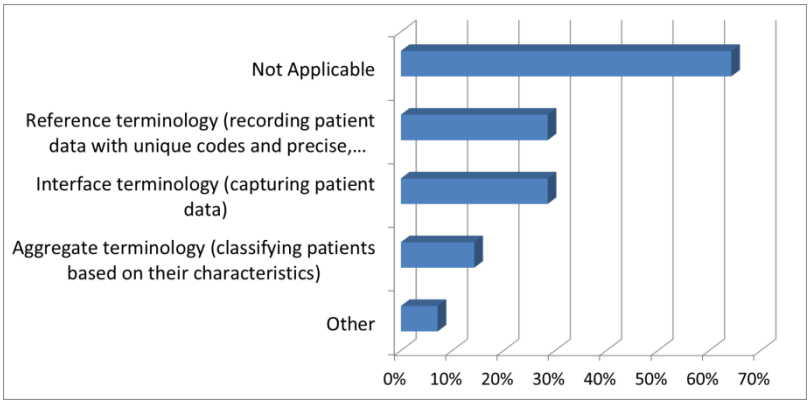
Member State	For which use cases/purposes is currently used SNOMED CT in your country
	Coding of other clinical concepts as the need arises. Coding of concepts in the Electronic Case Summary system and the National Patient Summary system (pilot project).
Netherlands	National Diagnosis reference set for hospital Ophthalmology diagnosis and procedures reference set Clinical research databases
Slovakia	Not decided yet
Sweden	National coding system for safer prescribing of drugs (not yet live). For transfer of patient data to registries ("quality registries") - going live in 2015.
United Kingdom (*)	In England used in many settings including primary care, secondary care, community care and mental health. Used for recording all reusable information pertinent to delivery of health care - most commonly for procedures and diagnoses though expected to expand as systems become more sophisticated. Also beginning to be used for secondary uses extracts.

(*) To be explicitly validated

Nine countries (AT, BE, HR, CZ, FI. DE, GR, IT) of the fourteen responding (> 60%) have indicated as not applicable the question about how SNOMED CT is actually used.

Malta and United Kingdom declare to use SNOMED CT as Reference, Aggregate and Interface Terminology;

Netherlands and Estonia as Reference and Interface terminology.



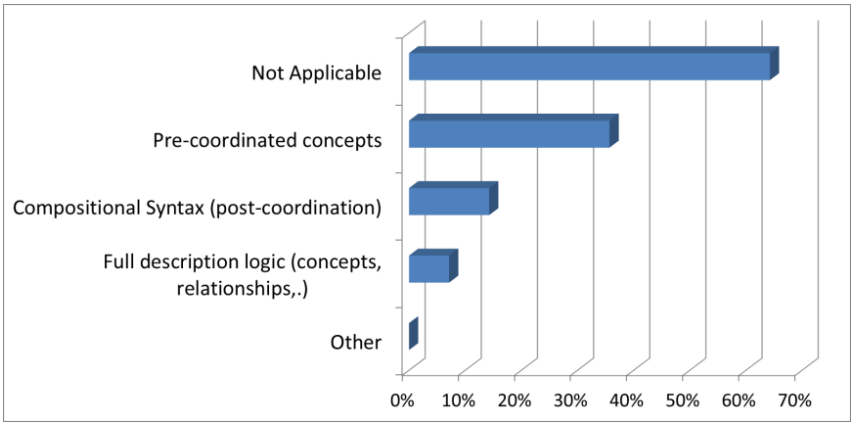
When used as reference terminology SNOMED CT it is always used also for capturing data.

Sweden (“Other”) indicated that “codes are used for transfer of patient data to registries, but not yet for data capture/patient records”

Figure 17 - For the indicated use cases how SNOMED CT is actually used

Coherently with the previous question, the same nine countries have indicated as not applicable the question about the “what of SNOMED CT is actually used”.

All the remaining 5 countries (EE, MT, NL, SE, UK) use the SNOMED CT pre-coordinated concepts, two of them use also the compositional syntax (NL, UK) , and only one (NL) declares to use the full SNOMED CT description logic. (Figure 18)



For about half of the countries interviewed no impact on existing terminologies is expected by the introduction of SNOMED CT in their country. (see Appendix 3 for the details)

Figure 18 - For the indicated use cases what of SNOMED CT do you actually use

The answers about the experienced, or expected, impacts of the introduction of SNOMED CT in the existing IT architecture (including software) can be classified according to the categories listed in Table 6. It is interesting to note how UK faced the problem starting from the Business Architecture from which all the other consequent impacts can be derived, following an Enterprise Architectural approach.

Table 6 - Could you briefly describe what has been (or what will be according to your current evaluation) the impact of the introduction of SNOMED CT in the existing IT architecture (including software)?

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Update of the existing EHR-Systems				□					□					
Semantic Infrastructure (e.g. Terminology Services/Systems)				□					□				□	
Under Evaluation					□							□	□	
Answers to be clarified, no answers	□						□	□						
Unspecified changes in the ICT architecture			□			□								□
Changes due to the redesign of the business process														□

(*) To be explicitly validated

Table 7 summarizes the types of answers provided about the experienced or believed main challenges of the transactional scenario (i.e. moving toward the adoption of SNOMED CT). Table 8 the suggested, or applied, means for overcoming them. (Additional information is provided in Appendix 3).

Table 7 - Could you briefly describe what has been the main challenges (or what will be according to your current evaluation) of the transactional scenario (i.e. moving toward the adoption of SNOMED CT)?

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Answers to be clarified, no answers	☐						☐	☐						
Education of end users		☐		☐								☐		
End users Acceptance									☐	☐	☐			
Adoption by Vendors		☐		☐							☐			
Education of IT industry														
Translation		☐		☐							☐			
Mapping						☐			☐					
Terminology governance									☐					
System Usability									☐	☐				
Vendor engagement		☐												
Regulation		☐												
Unspecified challenges			☐											
Low maturity in using terminologies													☐	
Business process changes														☐

(*) To be explicitly validated

Table 8 - Could you briefly describe how those challenges have been (or are planned to be) managed

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Answers to be clarified, no answers	☐			☐			☐	☐						
Education (training, guidelines)		☐			☐				☐	☐			☐	
International Collaboration		☐												
Actualization of the National Action Plan for e-health		☐	☐						☐					
Expert Involvement						☐								
To be Evaluated									☐					
Competence Center									☐					
Functional Specification for the Software										☐				
Focused Projects & RefSets											☐			
Academic collaboration												☐		
Business Process Revisions														☐

(*) To be explicitly validated

For the large majority of the countries interviewed the actual or planned approach for the introduction of SNOMED CT has not been yet identified, or the question is considered not applicable. Considering only positive responses in two cases (UK, SE) the full SNOMED CT core has been considered; a RefSet based approach has been used instead in the 80% of the cases. (Figure 19). The large majority (60%) of the total indicates the “Clinicians and Terminology Experts” the role involved (or to be involved) in this initial selection.

The percentage of not applicable or under definition answers increase to more than 60% for the same type of question applied to the indicated use cases (i.e. not only for the introduction

of SNOMED CT). Only UK indicated that "The Full SNOMED CT core with national extensions is being used, "National Refsets" have been indicated for Estonia and Netherlands, and "Several Refset" for Malta and Belgium.

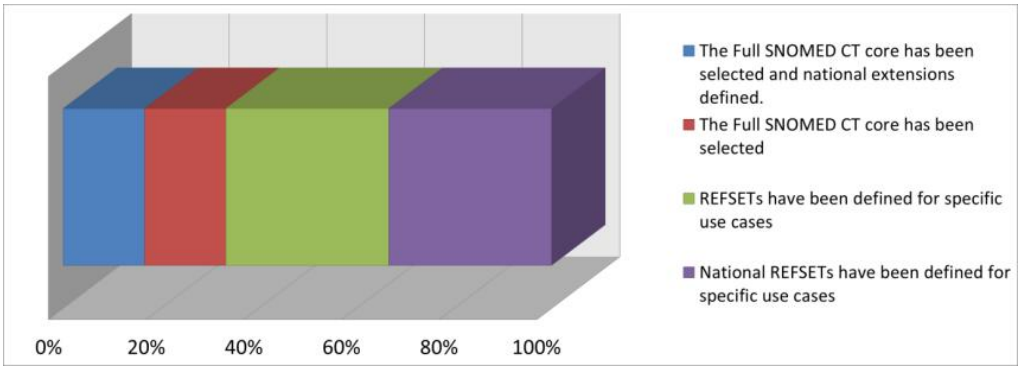


Figure 19 - What has been the content selection approach applied (or planned to be applied) for introducing in your country SNOMED CT

Figure 20 shows what is the approach followed for translating terms (and collect possible synonyms). The translation and the collection of synonyms is Nationally coordinated and realized for the majority of the countries for which this answer is applicable. It is interesting to point out the international cooperation aspect pointed out by Belgium in its comment. When applicable both the roles of Terminology experts and Professional translators have been that mainly indicated in the translation of terms (only Sweden indicated also Clinicians).

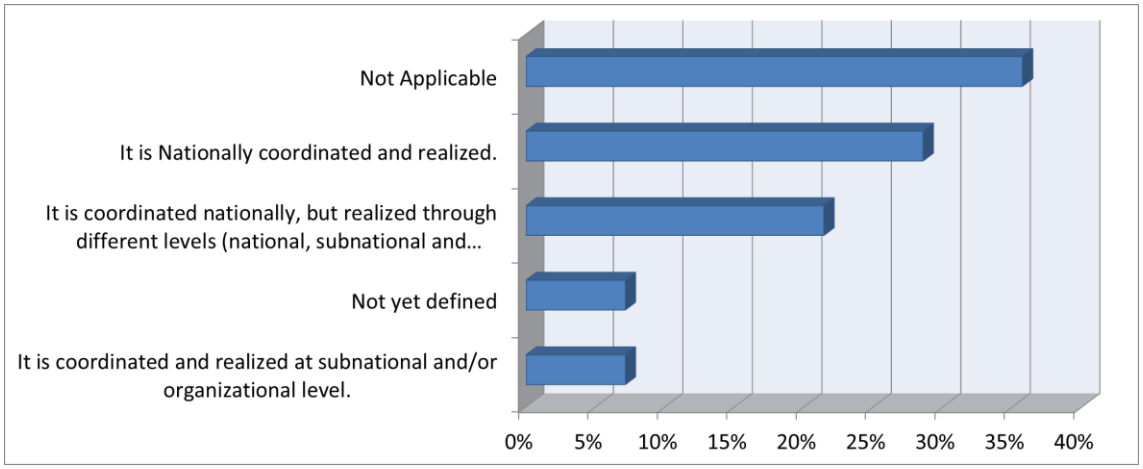


Figure 20 - What is the approach followed for translating terms and collect possible synonyms

Countries specific on-going activities and future plans are described in Appendix 3.

5.2.3 About non-IHTSDO member countries

All the countries that provided an answer about the reasons for not joining IHTSDO, have indicates the Licence Cost as one of the motive, no one has checked on the contrary the limited fitness for purpose. Figure 21 summarize the complete set of results.

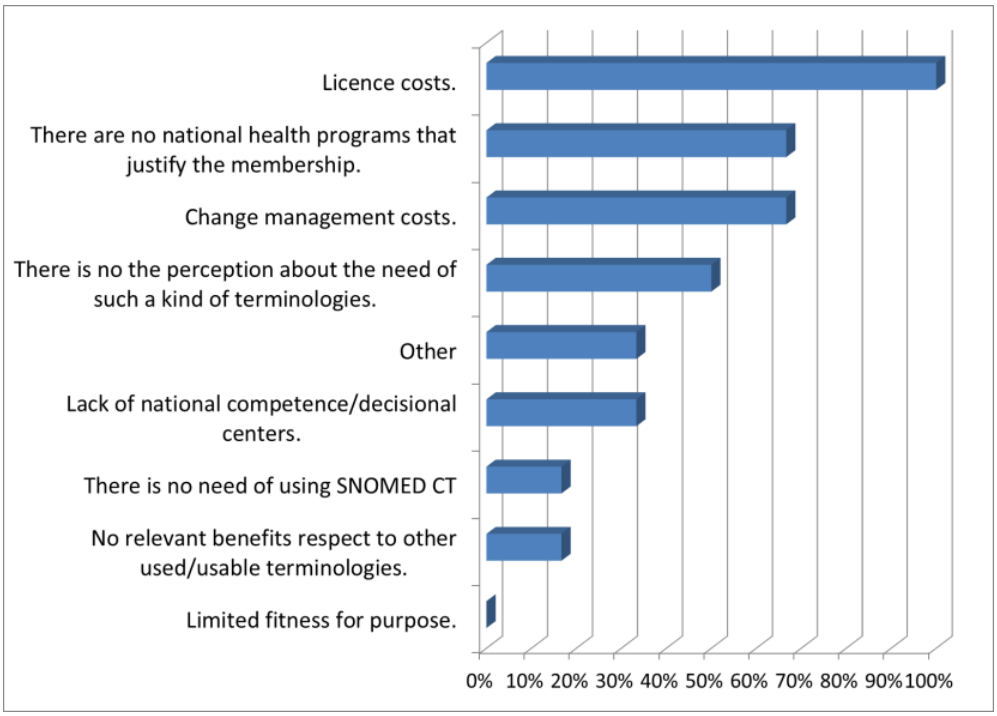


Figure 21 - What are according to you the main reasons for which your country is not currently an IHTSDO member

About the 70% of the answering countries about the question “about any current or past plan, discussion or evaluation regarding the adoption of SNOMED CT” answered Yes (Austria, Croatia, Finland, Germany and Italy).

6 Other reports

6.1 Report on EU US discussion group

The report on the EU US discussion group held on 2015, March 23th, in Brussels in conjunction with the Trillium Bridge Workshop, is included in the ASSESS CT deliverable D1.1.

6.2 Report on 1st revision workshop

The report on the 1st Revision Workshop group held on 2015, May 22nd, in Brussels is included in the ASSESS CT deliverable D1.1.

6.3 Stakeholder registry update

The process for the set up and update of the stakeholder registry has been described in the ASSESS CT deliverable D1.1.

The project identified the EU eHealth stakeholder group (potential participants in consultation and target group to receive press releases and newsletter).

At the date of delivering of this document, beside the 28 people of the eHealth stakeholder group described in D1.1 other 268 stakeholders have been identified as of August 28th, 2015, covering 23 European Countries: Austria; Belgium; Croatia; Czech Republic; Denmark; Estonia; Finland; France; Germany; Greece; Hungary, Italy; Luxembourg; Malta; Netherlands; Norway; Portugal; Slovakia; Slovenia, Spain; Sweden; Switzerland; United Kingdom.

124 gave their consent in being inserted in the stakeholder registry through the all stakeholder questionnaire form; other 30 answering the country overview questionnaire form; 44 (on a total of 53 registrations) registering to the 1st workshop; 54 (on a total of 87) are focus groups attendees; the remaining 16 through direct contacts.

7 Conclusions

Several investigational activities have been performed (country-based focus groups; questionnaires, workshop discussions) and the preliminary results have been shared and discussed with experts engaged across all of Europe.

These different means allowed to collect facts, opinion, experiences, beliefs and gather different perspectives. The results of these investigations have been reported in the dedicated sections above.

Considering these results, a list of statements that summarize the most relevant[15] aspects has been derived:

The role of SNOMED CT as a reference terminology and mappings broker

- Neither SNOMED CT, nor any other terminology, is supposed to fullfil all the needs, and therefore to be used as the "unique" terminology.
- A terminologies eco-system should be considered, in which SNOMED CT is a core terminology, playing the role of reference terminology for facilitating the interoperability across different clinical domains, care settings and jurisdictions.
- Classification systems, mainly used for statistical reporting or administrative purposes are the most frequently used terminologies (among them are the ICD family and ATC).
- The coexistence of SNOMED CT with other terminologies has to be correctly managed. In the transactional, and likely also in the target scenario the availability (or the development) of maps with code systems used for administrative purposes/rembuirsement is deemed to be critical for the success of the adoption.

Use cases for SNOMED CT adoption

- Terminologies have to be used and assessed only within well specificied purposes or contexts of usage.
- Terminologies should not be used beyond their purposes, although this is a not uncommon practice. This happens usually with classification systems since they are often the only terminologies actually used at the jurisdictional level.
- SNOMED CT may facilitate the extraction, the comparison and the reuse of information (non-redundant data capture, better data quality, cross organizational data integration) for registries; quality measures; medical decisions support; public health reporting; national and international benchmarking; research; "traceability across the patient trajectory".
- With very few exceptions, relevant domains are deemed to be not actually covered by nationally used terminologies. The most cited domains are: Lab Procedures; Procedures; Allergies; Medical Devices.
- In the large majority of reported cases only pre-coordinated SNOMED CT concepts are used for SNOMED CT adoption.

The current lack of evidence of benefits

- With few exceptions (e.g. Kaiser Permanente in the US, or England for specific contexts), there is a limited usage of SNOMED CT both in EU and in US. Even in IHTSDO member countries the usage is often still marginal.

[15] Relevance is evaluated either because it is mentioned more times in questionnaires, FGs and/or during the workshop; or because deemed to be particularly noteworthy.

- There is a low availability of evidences/best practices/examples on the usage of SNOMED CT. This limits also the capability of providing a correct evaluation of the potential consequences of the SNOMED CT adoption.

Market maturity and potential impact of the adoption of SNOMED CT

- There is a low maturity of the EHR systems (ICT) market for the usage of SNOMED CT, although some progress has been made in the last years.
- The introduction of SNOMED CT may play a role in the standardization of the EHR contents, and therefore in the marketplace of EHR systems and related solutions.

Strategic long-term benefit

- Beyond any current evaluation about SNOMED CT (e.g. fitness for purpose, gaps), IHTSDO assures a transparent and robust maintenance process that has to be considered as a strategic long term benefit.

Pre-conditions for pursuing semantic interoperability

- The fitness for purpose and/or the availability of a terminology in a specific context doesn't imply its actual usage in real processes. There are several reasons reported for that: challenges related to the selection and adoption of terminologies; lack of agreed information models and tools for capturing those data as structured and coded information; etc.
- Semantic interoperability is not just a matter of exchanging data on-the-wire.
- The choice of terminologies is only one aspect to be considered for the semantic interoperability: the availability of agreed information models (at different levels), the usage of the selected terminologies within those models [vocabulary binding] (including implementation challanges) are elements that should be taken seriously into account.
- Semantic interoperability requires well defined strategies, supporting policies and jurisdictional commitment (including human and financial resources, incentives, jurisdictional normative requirements).
- Terminologies require governance and management: there is however a lack of supporting National Compentence Center(s).
- The availability of a "Semantic Infrastructure" (i.e supporting Terminology Services, Management Systems, Server) is a relevant factor for the introduction of SNOMED CT (and other terminologies).

Usabilty and users acceptance

- The usability – in all its different perspectives - is a critical factor in the adoption and acceptance process: experiences have been reported concering the actual or perceived complexity of SNOMED CT (e.g. on browsing, identifying and selecting terms).
- The end user acceptance plays an essential role in the adoption of SNOMED CT (or any other terminology). This implies several different aspects such as availability of tools that facilitate the usage of terminology; awareness about the benefits; and effectiveness in the real business (i.e. clinical) processes.
- Raising awareness about individual and organizational benefits is a critical point. This implies education, availability of pilot/proof of concepts, best practices, etc.

Licensing and cost issues

- The SNOMED CT licence cost is a critical barrier in the decisional / start-up phase when the potential benefits of this change have not been yet completely evaluated / experienced. Even though many people recognize that this is only a part of the overall routine costs, supporting actions/policies for facilitating the initial adoption of SNOMED CT are strongly suggested in order to overcome the “all-or-none”-policy of IHTSDO.
- Beyond the direct cost (e.g., licence), SNOMED CT requires a non negligeable initial knowledge investment that has to be correctly considered (steep learning curve).
- Many countries and organisations face a lack of knowledge / expertise regarding SNOMED CT
- The actual, or perceived, complexity of SNOMED CT, in all its different aspects (e.g., description logic, compositional syntax, versioning and extensions management, collaboration process with IHTSDO, software implementation) is a barrier that has to be properly managed. Different means for each of those challenges (like for example education, software investments) have to be identified and adopted in order to overcome them or hide the complexity of SNOMED CT to the users.
- The translations and synonyms management process - including the terms selection; the actual translation; the quality assurance; the support for the IHTSDO procedures - has a strong impact in term of costs, expertise, time and challenges for the adoption of SNOMED CT.

Suggested approaches for introducing SNOMED CT

- A step-wise, use-case-based, incremental approach is the suggested method for the introduction of SNOMED CT, possibly starting from inadequately covered domains. Note: the cost of introduction should be commensurate to the “project” scope.
- There is a shared belief that benefits can be obtained with SNOMED CT when a “critical mass” in the usage of this terminology is achieved.
- To evaluate the impact of the introduction of SNOMED CT, and plan the right consequent actions, it’s worth to start with the impact on the Business Architecture (i.e on how the business - including clinical - processes should change) and therefore derive how the other architectural layers (application, technical) should be adapted, following an Enterprise Architecture approach.
- Most of the elements discussed are inter-related and could not be faced independently from the other aspects. For example, the usability is a critical factor; supporting tools play an essential role for usability; the availability of suitable tools depends on the market; vendors may invest in SNOMED CT (or other terminology) and related products if clear directions are provided.
- The international collaboration is an enabling factor for mitigating some of the challanges (sharing of maps, translations, lessons learned in the transactional scenarios, etc.).

Moreover, based on the experience in the focus groups, it is suggested that ***focus group meetings are repeated in the future***, possibly extending them to other countries, for supporting the discussion on specific practical themes that may have impact on terminologies (or more in general on the semantic interoperability), and acting as mediator between the national and the European contexts.

Relying on them, ***topic-focused cross-country discussion groups*** may be created as well for supporting specific practical topics of interest.

8 Annex 1: Focus groups reports

This Annex reports the detailed focus groups translated notes, associated to each of the agreed themes, as derived from the original transcriptions collected during the focus groups meeting(s). Methodolgies applied by each group for accomplishing this task are described in the "Methodology" sections below.

8.1 Belgium

8.1.1 Focus group organization

Facilitator

Hans van Belleghem, independent consultant and owner at Twist

Focus group composition

Name	Organization	Role
Thierry Klein	Public School of Health ULB	Scientific Collaborator
Sven Van Laere	Vrije Universiteit Brussel	Kandidaat PhD
Paquay Louis	Wit-Gele Kruis Vlaanderen	verpleegkundig coördinator
Zwaenepoel Lieven	VAN (Vlaams Apothekers network)	Member of the board
Tom Henkens	APB	Software Liaison
Olivier Le Moine	Hopital Erasme	Medical co-Director EHR
Luc De Keyser	xperthis	solution consultant
Fierens Christophe	AZ Klina Brasschaat	Head of Medical Registration Department
François Van Hees	eHealth-platform	Program manager

Meeting(s)

The Belgian Focus Group meeting was held on June 24th, 2015.

Location: Federal Public Service of Health, Food Chain Safety and Environment, Place Victor Horta 40-box 10, 1060 Brussels- Eurostation – room 01C273 Magritte A

8.1.2 Methodology

Software

To analyze the results of this focus group, NVivo Version 10.2.1 was used. NVivo is a comprehensive qualitative data analysis software package. The software can be used to organize and analyze interviews.

Data source

The entire interview/discussion of the focus group was recorded. Based on the recordings, a transcript was made. This transcript was imported into NVivo Version 10.2.1 for research.

Coding the data

Before coding the data, a pre-constructed coding scheme was build. It consists of a node hierarchy, containing the parent nodes, was build based on the themes that would be elaborated during the discussion of the focus group.

8.1.3 Report

Introduction

The Belgian focus group was held on June, 24th 2015.

Location: Federal Public Service of Health, Food Chain Safety and Environment, Place Victor Horta 40-box 10, 1060 Brussels- Eurostation – room 01C273 Magritte A

Participants

Moderator: Hans van Belleghem (Twist)

Klein	Thierry	Public School of Health ULB	Scientific Collaborator
Van Laere	Sven	Vrije Universiteit Brussel	Kandidaat PhD
Louis	Paquay	Wit-Gele Kruis Vlaanderen	verpleegkundig coördinator
Lieven	Zwaenepoel	VAN (Vlaams Apothekers network)	Member of the board
Henkens	Tom	APB	Software Liaison
Le Moine	Olivier	Hopital Erasme	Medical co-Director EHR
De Keyser	Luc	xperthis	solution consultant
Christophe	Fierens	AZ Klina Brasschaat	Head of Medical Registration Department
Van Hees	François	eHealth-platform	Program manager
Bosman	Robin	eHealth-platform	Standars and interoperability analyst
Filip	Veldeman	BMIA	President
Verdonckt	Lambda	Zorg en Gezondheid	ICT in de eerste lijn
Alexandre	Siau	UZLeuven	IT
Jonas	Vandermosten	UZLeuven	IT
Luyten	Leon	UZA	Hoofd medische informatie

Informed consent

An informed consent form was presented, explaining the objectives of the focus group and asking to consent to analysis of the data. All participants signed the form.

Results

Current use of the terminology

Perceived strengths and weaknesses of the current situation:

- *To what extend are they useful?*
- *Strenghts: in what situations/for what use cases are they useful?*
- *Weaknessess: In what situations/for what use cases are they not useful?*

Coded information

Belgium has a national Action Plan on e-health 2013-2018 in which the use of a standardized terminology, principally consisting of SNOMED CT, is endorsed. (www.rtreh.be)

Currently, there are currently **few "complete" implementations** of SNOMED CT itself, different implementation approaches in different domains are being prepared.

There is use of **other systems, mainly classification systems**, such as ICPC2, ICD-9-CM, ICD-10, … As in the Netherlands, a distinction is needed between terminology systems used for unambiguous clinical registration and terminology systems used for classification purposes. GPs use a proprietary thesaurus within their electronic patient records, with a unique identifier called IBUI. However, tying these different systems together calls for translations between those systems, which could be avoided by the use of SNOMED CT.

There is a need for **structuring information**. The awareness of the need for structured information is present, but the implementation is not complete. For example, only 10% of the GPs are estimated to work with structured information. Furthermore, when it comes to clinical research, every research company and every professional organizes the concepts they want to use in local registers, which lead to a plethora of systems. And free text is also still frequently used.

Use cases

Main considerations and challenges with regards to use of SNOMED CT implementation are on: the level of granularity, the awareness that SNOMED CT is not "perfect" nor complete, the issues with regards to the use of post-coordination and the clarification of the objectives of the use of such a system. With regards to the latter referral is being made to the U.S. where "clinical documentation specialists" are employed to optimize the clinical documentation from a financial perspective, i.e. for reimbursement. So, information that is being structured is not always being structured for the right reasons, namely the sharing of information and interoperability. Pharmaceutical and drug information is also structured, but from a logistic point of view.

Coverage

Code	Node hierarchy	References coded	% Coverage
T1	Current use	29	10,21
T1.1	Few complete implementations	5	1,98
T1.2	Other systems, mainly classifications	10	3,20
T1.3	Structuring information	6	2,21
T1.4	Main challenges and considerations	8	2,82

Benefits of using the terminology

Benefits in adopting more international terminologies than what are implemented now:

- *For which use cases do you see benefits in extending the use of international terminologies?*
- *Specifically: for which use cases do you see benefits in using SNOMED CT?*
- *What would be an ideal situation in terms of use of terminologies in the health sector?*
- *What would characterize terminologies that live up to these requirements?*

Coded information

International system: the fact that it is an international system and not something local or limited to the territory creates opportunities for cooperation and decreases the burden of maintenance and further development.

Granularity leads to **richer information**: different objectives for clinical information exchange may lead to a minimum level of granularity and hence to richer information. The sharing of information and the use of a common language with high granularity may lead to a multidisciplinary input and refinement of information. Reuse of information will lead to a HER

that is better documented and contains more information. After all, when information has to be entered manually, for example in registries, some physicians might be reluctant to enter the information twice and only complete the registry.

Common language for information exchange: if everybody uses the same standard for documentation, the exchange of information is facilitated. Terminology is considered to be a "link" between information and between professionals.

Correct information: electronic exchange of information, using one code system by all professionals, leads to less errors and thus to better care and patient safety. It prevents duplication of information from paper to an electronic record. It also prevents information being translated from one system to another within an EHR of electronic information exchange through messaging.

Secondary use of data: use of the terminology permits to reuse this information to automatically complete the registries, which are a true administrative burden.

Consultation of the record by the patient becomes a possibility. For a professional it is not possible to document the complete patient record in a way that the patient can understand everything. Sometimes there is need of a certain degree of granularity, specialised terms and descriptions that are not understandable for patients. With SNOMED CT this becomes possible.

Structured information: nurses are in need of a structure to put their information into and to make sure they enter all the information that is needed. SNOMED CT can help with that. However, a balance is imperative between the information that is needed and all the information that is possible to capture as much of the reality that is possible. In practice this lead to "over-coding".

Coverage

Code	Node hierarchy	References coded	% Coverage
T2	Benefits	35	22,04
T2.1	International system	2	0,95
T2.2	More information	4	1,92
T2.3	Correct information	8	3,64
T2.4	Secondary use of data	8	7,29
T2.5	Patient empowerment	2	0,83
T2.6	Structured information	2	1,04
T2.7	Common language for exchange	9	6,37

Barriers for using terminology

Barriers stopping the adoption or use of international terminologies:

- *What are the reasons why international terminologies are not adopted and used more extensively? (Alternative formulation: what are the barriers to adoption and use of international terminologies?*
- *What are the barriers in you organizational context? (Alternative formulation: to what extend do the barriers currently exist in your organization?)*
- *Discuss the importance of the barriers when looking beyond your own organization e.g. seeing your countries development as a whole.*
- *How can barriers be overcome?*

Coded information

Resistance to change: evolution from documenting by means of free text to structured documentation by means of codes. Could be overcome by permitting the use of free text, reference is made to tools allowing for this.

Fear of loss of information: medicine is not an exact science, sometimes a certain nuance is needed which cannot be found in or expressed by means of a code system. The use of SNOMED CT itself is also considered to be a mapping, namely from clinical reality to SNOMED CT. Since any mapping implies information loss, so does the use of SNOMED CT, regardless of its granularity. Fear of loss of connection with legacy systems.

Lack of user-friendly implementation: providers need to build a suitable and intuitive interface, implementation is not equal to mirroring a paper record into an electronic record, coders (documentalists) could help physicians to improve clinical documentation, but due to the current financial restrictions and the structural underfinancing of hospitals, this approach will probably not be possible.

Fear of irrelevant information: as stated before, a balance is imperative between the information that is needed and all the information that is possible to capture as much of the reality that is possible. In practice this lead to “over-coding”.

Fear of administrative burden: the biggest reason for burnout amongst physicians in the US is due to the implementation of registration systems.

Fragmented information: a SNOMED CT concept can formed in different ways, by choosing one concept or by combining several concepts together. If the link to combine the concepts is not there, the result is fragmented information. Also, different professionals can add pieces of information that need to be combined to build up the complete picture of the patient. This is compared with the construction of an image out of different pixels.

Coverage

Code	Node hierarchy	References coded	% Coverage
T3	Barriers	34	13,76
T3.1	Resistance to change	3	1,37
T3.2	Fear of information loss	7	2,28
T3.3	Lack of user friendly implementation	10	4,64
T3.4	Fear of irrelevant information	5	1,76
T3.5	Fear of administrative burden	7	2,42
T3.6	Fragmented information	2	1,28

Enablers for using the terminology

Enabling factors could promote the adoption and use of international terminologies

- *What enables adoption and use of international terminologies?*
- *What enabling factors are already in place?*
- *Which enabling factors are missing?*
- *Discuss the importance of the enabling factors when looking beyond your own organization e.g. seeing your countries development as a whole.*

Coded information

The **appropriate tools** need to be available, such as the user interface, which may of may not permit the use of free text. Tools are on the horizon, which can be used to transform free text into terminology or classification systems.

A **clear objective** of the system: systems that have a clear objective that is known by the user are effectively used in practice, such as the Belgian nomenclature. It has a clear objective and is being registered; physicians know these codes by heart.

Determine the **minimum requirements** for EHR systems and use the **right incentives for effective use** of the terminology and audit to see if EHR systems fulfil the minimum requirements. Incentives with regards to the EHR requirements should be aimed at providers and not at the users of the systems. Incentives with regards to the use of the terminology can be aimed at the user and focus on secondary use of data and administrative simplification. For example, using the terminology prevents from having to fill out the registries

Translations of the terminology are needed. Translations should at least be made for certain domains, namely the domains for which proof of concepts are being developed. Also, translations between the terminology and other systems are needed in order to enable secondary use.

Patient empowerment, by means of which a patient can consult and complete his own record. The terminology permits the use of terms understandable to patients. Mobile health systems can be of use.

Proof of concept is needed, starting with specific domains and specialties. Meaning that implementation approaches do not need to cover all domains at once. However, certain specialties, such as geriatric medicine cover a very broad range of concepts which makes it difficult to pinpoint the concepts needed. Also, patients often have health problems related to more than one specialty.

Training of professionals on the field is needed, but training should also start from universities and schools.

Coverage

Code	Node hierarchy	References coded	% Coverage
T4	**Enablers**	**52**	**25,58**
T4.1	Appropriate tools	8	4,08
T4.2	Clear objective	9	4,80
T4.3	Minimum requirements and adequate incentives	16	7,60
T4.4	Translations	4	2,59
T4.5	Patient empowerment	4	2,15
T4.6	Proof of concept	7	2,57
T4.7	Training	4	1,78

Recommendations, suggestions, comments

How to take action based on the information they have shared in theme 1-4:

- *What would you recommend as the next steps in terminology adoption and usage?*
- *Which enabling factors would you suggest to support these steps?*
- *Who is responsible for these enablers?*

Coded information

A phased approach is preferred, starting small on the base of proof of concept and use cases. When introducing the terminology, attention for legacy conversion is needed. Training is needed on different levels, in the field and during education.

A centralized approach, coordinated by the national release center is needed, with clear objectives on the use of the terminology.

Supportive tools and features, such as maps, translations and subsets need to be available.

Coverage

Code	Node hierarchy	References coded	% Coverage
T5	**Recommendations**	**32**	**13,82**

Conclusion

- *Adopt, alternative abstain.*

(*) A lot is possible with SNOMED CT, but different opinions with regards to the implementation of this systems exist and will be hard to align.

Code	Node hierarchy	References coded	% Coverage
T6	**Adopt-Alternative-Abstain**	**14**	**16,04**
T6.1	Adopt	11	3,93
T6.2	Alternative	2	11,76
T6.3	Abstain (*)	1	0,35

8.2 Croatia

8.2.1 Focus group organization

Facilitator

Vesna Kronstein Kufrin , Project Manager and Zlatko Boni - HZZO (Croatian health insurance fund)

Focus group composition

Name	Organization	Role	Note
Aleksandar Džakula	School of public health “Andrija Štampar”	Assist. Professor MD, specialist in public health	Works at the Department of Social Medicine and Health Care in School of Public Health Andrija Štampar, an expert in the area of improving health policy and health systems. Also, he is the organizer of Motovun summer health school and conference on health care system and health care policy
Josipa (Josie) Kern, prof.	School of public health “Andrija Štampar”	Retired professor, MSc, PhD	Coauthor of a book “Medical informatics”. This book completely describes many aspects included in

Name	Organization	Role	Note
			health care system, informatisation process. It systematically explains basic topics important for the elementary use of information technologies, as well as sophisticated ones which can widen the reader's knowledge and understanding of all segments related to IT apprehensions and processes.
Miroslav Mađarić	KBC Zagreb (University hospital center Zagreb)	Chief Information Officer	Profound knowledge of processes in hospitals and related information systems
Vanesa Benković	Solpharm Ltd, Edward Bernays First College of Communication Management, University of Zagreb Medical Faculty	Director CEE Market access and Public policy	Postgraduate at Medical Faculty, Leadership and management in Health and Health Services, cooperates with public health and health management in health research projects
Karmen Lončarek	KBC Rijeka (Clinical hospital center Rijeka) Faculty of medicine Rijeka, Department of Ophthalmology	Head of the Institute for Palliative Medicine, MD, PhD, Ass. Prof.	Participates in several international public health projects. Has published several scientific papers in international biomedical journals. Writes articles for various newspapers
Maja Vajagić	Croatian Health Insurance Fund (HZZO)	Senior inspector for medical affairs, terminology expert	Works at the Department for contracting Hospital Services in CHIF, has worked on system for diagnostic therapeutic procedures (DTP), DRG system
Sandra Mihel	Croatian Institute of Public Health (HZJZ)	Public health expert	Active in Counselling Centre for HIV / sexual health
Siniša Košćina	IN2	IT industry representative (Program manager)	Designing healthcare software and managing eHealth projects
Darko Gvozdanović	ENT	IT industry representative Solution Area HealthCare Information Systems Manager	Member of the Board HL7 Croatia, Manager Engagement Practice eHealth

Meeting(s)

Individual interviews

- Miroslav Mađarić – 17.03.2015.
- Maja Vajagić – 10.03.2015.
- Aleksandar Džakula – 24.03.2015.
- Josipa Kern – 26.03.2015.

Meeting 1 – Preparatory meeting

23.04.2015.

Meeting 2 – Focus group meeting

30.04.2015., HZZO, Zagreb, Margaretska 1

1.7.- 4.7.2015.- In Motovun, on a Conference on the health care system and health care policy – HZZO presented Assess CT project and basic information about SNOMED CT. In the discussion following the presentation participants expressed concern about the introduction of new terminology systems in the areas with existing classification but they would like to see usage of SNOMED CT or some other terminology that would enable interoperability in the areas where data is not structured yet. Focus was on national interoperability rather than international one.

8.2.2 Methodology

Before the focus group meeting Croatian project team identified 10 participants and held individual interviews with participants in order to better identify their area of expertise, knowledge of SNOMED CT and international interoperability. Participants were selected from different stakeholders of the health care system (health care professionals, public health, IT providers). They also have knowledge about health care terminologies even if they don't actually use them in their everyday work.

Focus group session was held at CHIF. They were given a presentation on SNOMED CT. A presentation on SNOMED CT was also held at the start of the meeting. The focus group was conducted according to the accepted FG guideline; first the short presentation and disccusion on five suggested themes. The discussion was recorded and analysed.

8.2.3 Report

Project:	ASSESS CT - Assessing SNOMED CT for large scale eHealth Deployments in EU
Objective:	Gather expert opinions, beliefs, and attitudes regarding the European views on current and future terminology use in the health care sector, with a special focus on the role of SNOMED CT
Themes:	- Current terminology usage - Benefits of adopting new terminologies – Focus on SNOMED CT - Barriers for extended terminology adoption and usage - Enabling factors for extended terminology adoption and usage - Recommendations
Date:	30.04.2015.
Location:	Zagreb, Margaretska 3, HZZO
Attendance:	**Moderators:** Vesna Kronstein Kufrin, Zlatko Boni
	Participants:
	Aleksandar Džakula, Andrija Štampar - Academic Researcher Josie Kern, prof. - Academic Researcher Miroslav Mađarić, KBC Zagreb - Chief Information Officer Vanesa Benković - Farmacoeconomics Karmen Lončarek, KBC Rijeka - Clinician / health Professional Maja Vajagić, HZZO - Terminology expert (NON SNOMED)

Sandra Mihel, HZJZ – Domain public health expert
Siniša Košćina – IN2 - Industry Representative
Darko Gvozdanović – ENT - Industry Representative
Martina Orešković - HZZO

Introduction: SNOMED CT presentation. Purpose of the focus group and ground rules.

Current terminology usage

Croatia is not member of the IHTSDO and does not have a national license for SNOMED CT. In Croatia there are distinctions between terminologies used for administration purposes and those used for clinical purposes. For reimbursement ICD-10 is used in order to generate Croatian DRG (Diagnosis Related Groups) and Croatian Diagnosis Related Procedures, which is the basis for billing and reimbursement. For medicines ATC is used. Also, a number of other terminologies (ICF, internationally accepted scales, terminologies related to certain diseases) are used in certain procedures. Since payment is linked to services provided there is a lot of data for analysis purposes but the quality of data remains an issue. Main disadvantage of terminologies in use is their insufficient precision and quality. Also they do not provide interoperability among all stakeholders in the health care system.

We also raised a question of advantages and disadvantages of the terminology participant currently use. What are strengths and weaknesses with regards to usage of clinical terminology?

There was a disagreement over the adequate usage of the available terminology.

With existing terminology it is impossible to collect relevant and high-quality data required for analysis and decision making in every field of medicine.

Also, existing terminology does not provide interoperability among all stakeholders in the health care system.

One of the participants summed up the main issue of terminology use in Croatia.

„Overall for our discussion, I would like to divide question about terminology usage - we need to define if I use it as an end user and actually depend on it in a certain way because it helps me in my work or I am forced to use it because someone else in that interoperability communication chain has some benefit from my usage. These are two dimensions. When we use system analytics in public health, we want a better, more accurate classification, we want to do it in the best possible way. The issue of quality, if you bring in this dimension too, to analyse the quality, not of the data itself, but also what it is done after that, that may be a third dimension in which somebody, with the help of some terminology, investigates.“

Benefits of adopting new terminologies

The focus group members came up with several reasons for adopting new terminologies. One was when problems are not solved by current approaches e.g. safer prescriptions require more granularity than the current ATC based terminology offers and SNOMED CT is explored as an alternative. Another reason mentioned was to allow communication and outcome measurements in areas where no decision on terminology have been made. E.g. nursing documentation has no agreed terminological reference in Denmark. Some other reasons were mentioned, to ease communication between different stakeholders, to support requirements of a more efficient health system, to improve the semantics of the databases underlying clinical information systems for big data related uses. As a general note, the focus group members emphasized that they do not dream of new terminology systems, but rather the benefits that improved use of ICT can provide in health. Terminologies are seen as a building block.

Experts expressed a strong interest in using SNOMED CT within the whole health care system and have therefore identified two examples where there is current lack of quality data.

- Injury management: Injuries are a big unrecognized public health problem and many would like to see injuries well documented. Work related injuries especially result in huge personal and societal cost. Relevant data would enable us to increase preventive measures.
- Oncology treatment management: Croatia has bad outcomes in certain oncology treatments that are not easy to explain using current data. New terminology would help us to make changes to the treatment of oncology patients.

Both examples are identified as a „grey zone“ with lack of sufficient analysis which could lead to better use of resources and better patient outcomes.

Barriers for extended terminology adoption and usage

There is reluctance to substitute existing terminology because it took a long time to implement the current terminology and it is an ongoing process of involving all the users to provide better quality data. Group agrees that new terminology would have to be implemented at educational level first. Costs of licencing, implementation, education and maintenance is of great concern since there is a lack of evidence that benefit is worth the added cost. Focus group members expect great difficulties in translation due to lack of experts needed. Also since our payment system is based on ICD-10, there should be a consensus among all stakeholders on the best way to implement SNOMED CT.

Participants agreed on these barriers and it was obvious that lack of experts would hinder implementation and for the new terminology it would take a long time to reach current level of data quality. We addressed this issue once again to the audience at a health conference in Motovun, Croatia. There were present lots of representatives from their field of medicine and the aversion towards implementing SNOMED CT, or any terminology that would make big changes to the current system, was much greater because they know that a lot of work would be up to them. After a brief presentation it was clear to them that there are benefits but they did not consider them to be worth the extra work.

To conclude, focus group was comprised of a good number of stakeholder representatives that could, based on previous experience, contribute to the discussion in a constructive way. They proposed good first steps which we discussed next.

Enabling factors for extended terminology adoption and usage

Previously members expressed concern regarding readiness for learning and cooperation of personnel using the new terminology system. Who would really have benefits from using it, where does the responsibility for the implementation and updates lie and who is responsible for proper usage of the terminology?

In Croatia, each healthcare stakeholder could reap benefits from something that would work better than what we have now. Of course, those benefits often involve a joint effort from all stakeholders. When we define all levels of usage and all stakeholders, the next phase should be to determine what the common interest is. Each stakeholder should first recognize his own individual benefits and then we all should work towards the common interest. That should link two stakeholders with a common interest and engage them to accept the baseline for interoperability.

The main factor that everybody identified was funding. Based on previous experience of difficulty of implementing terminologies we would like to see guidelines that take into account best practice examples.

Education is another important aspect. Education for the stakeholders, especially for a new management in health care that would be experienced in the benefits of new terminology and how best to use it.

Also since our whole payment system is based on ICD-10 it would be beneficial if SNOMED CT was mapped to current reimbursement terminologies.

The legal framework on different levels of confidentiality concerning different categories of medical data would have to be in place.

There is a need for reaching a national consensus or an EU wide consensus in order to ensure the continued effort from all the stakeholders.

Recommendations

SNOMED CT seems to be a good solution for improving semantic interoperability in health care system, however, recommendations on implementing SNOMED CT could be given only after piloting some critical use cases and finding examples of good practice.

We are not familiar with any other known international terminology that could solve interoperability problems in a way that SNOMED CT can.

We realize that SNOMED CT could not solve all semantic interoperability problems. It should be used with other international terminologies or other terminologies should be mapped to SNOMED CT. Collaboration between industry and other stakeholders, needs to be established.

Croatia is a good recipient for this terminology.

We are very suitable for piloting it, and we can do it because our public health system, financial management and our health institutions are a part of the public sector. We have the implementation prerequisites, and we have identified use cases, such as injury management and oncology treatment management so we are a fertile ground for testing SNOMED CT. We also have all the handicaps associated with it, for example, we do not have systematic planning, and we don't have high quality analyses of the health care system. Our experience is limited but we can embrace changes for the better, to the best of our ability.

8.3 Denmark

8.3.1 Focus group organization

Facilitator

Kirstine Rosenbeck Gøeg, scientific assistant, Department of Health Science and Technology, Aalborg University.

Focus group composition

Name	Organization	Role	Note
Kell Greibe	National SundhedsIT, Dansk SNOMED CT release center/ The National eHealth Authority, Danish SNOMED CT release center	Health informatician /MD	Policy maker and SDO role. He has been the lead on a Danish project regarding a medication terminology based on SNOMED CT
Ulla Lund Eskildsen	Kommunernes Landsforening/ Local Government Denmark	Consultant and Project manager	Policy maker role. She works for Local Government Denmark which is a central organization for municipalities. She has been the project lead of a national project that aims at utilizing SNOMED CT, ICF and other clinical terminologies, for home care documentation
Janni Lerche Andersen	NNIT	Subject Matter Expert	Vendor role. Jannie is part of an EHR implementation project where NNIT together with EPIC handle the vendor side of

			Sundhedsplatformen/health platform which is a common EHRs project of two Danish regions, where SNOMED CT will be part of the implementation.
Gert Galster	Capitol region Denmark	Health informatician /MD	Implementation role. Gert works at the regional side of Sundhedsplatformen. He is working with implementation of classifications and terminologies.
Helle Møller Johannessen	National SundhedsIT/ The National eHealth Authority	Health informatics specialist	Policy maker role. She is the lead of NPU use in Denmark. NPU is a Nordic laboratory terminology which has been in routine use in Denmark for the past 10 years.
Henrik Lindholm	Cambio	Product manager	Vendor role. Henrik have earlier been employed as implementer of EHR systems at hospitals and regions. The implemented Cambio systems in Denmark do not currently include SNOMED CT.
Dorte Markussen	Region Northern Denmark	Project consultant	Implementation role. She works at the regional side of a regional EHR-implementation project. She has written her master's project about SNOMED CT, and been part of a SNOMED CT pilot project in the region. The current status is, that the region have decided not to implement SNOMED CT.

Meeting

27th of April, Copenhagen

8.3.2 Methodology

The focus group was conducted as agreed in the overall focus group guideline. When conduction the interview, the five themes have been clustered into two overarching topics, prioritized rather than enforcing the themes, in order to optimize the flow of discussion. The observations have been therefore then mapped back to the five themes agreed during the analysis of the transcript. An evaluation session was held together with the Swedish focus group to reflect and discuss terminology standardization visions.

8.3.3 Report

Current terminology usage

As a general comment the respondents were very focused on answering the questions within a certain scope. For them it did not make sense to talk about successful or unsuccessful terminologies, but rather whether certain clinical terminologies served their purpose within different clinical information systems, and lead to expected outcomes.

A lot of the current health documentation is based on unstructured notes or semi-structured forms supported by local terminologies. The focus group discussed that whether this is a problem depends on the use of the collected patient information. When you have to retrieve, update and communicate information you need some degree of standardization. For local purposes, the focus group did not agree on the level of structure and standardization needed. Those arguing for less structure argued that clinical notes for everyday clinical work

is most often only used by the personnel working the next shift, and consequently further structure would not be purposeful. Those arguing for structured documentation mentioned that we do not know what we would like to use the information for in the future, and if we want to support automatic reporting/audits, big data and decision support structure and terminological standardization is a requirement. In addition, even day-to-day documentation in some organizations is so unstructured that double documentation, even within one system and one organization is a major issue.

Generally the focus group discussed that whenever you need to retrieve data for decision support, reporting/auditing, reimbursement and communication, standardized terminologies should be part of the solution. Both SKS, NPU and SNOMED CT was mentioned and discussed. In addition, two Danish terminology projects, which have not yet been implemented was used as examples. The examples were FSIII a Danish common terminology for home care, which is based on a collection of clinical terminologies including ICF and SNOMED CT, and the Danish medication terminology which is based on SNOMED CT. These will be discussed in more detail in theme 2, which regards improvements of the current situation. This is not a full list of all health terminology implementations in Denmark, but rather examples of use that made it possible for participant to express opinions and views.

- NPU is perceived as successful for fulfilling communication needs for primary and secondary purposes in laboratory medicine, which is often very distributed. The terminologies should work together with structured forms and messages, and they add value because they carry meaning. **(routine use)**
- SKS (health sector classification system) is the central administrative terminology. It mainly consists of ICD10 and NSCP (NOMESCO Classification of Surgical Procedures). SKS is used as a basis for reimbursement. The focus group discussed that it is important to use clinical terminologies as intended and it was highlighted that as long as you used SKS as an administrative terminology it was fine, but that it did not necessarily reflect the clinical context in which it was registered **(routine use)**
- Right now, an EHR implementation project uses SNOMED CT for tagging clinical content/clinical models in their information system. This is done not to lose control of the clinical models e.g. different ways to document a blood pressure, which again leads to different places of storing the information in the database. The implementation project is tagging ad hoc with SNOMED CT right now, and at a later stage they will use it for quality control e.g. to avoid redundancy. **(as part of EHR implementation project)**

The focus group highlighted that when implementing terminology systems they should be used as intended. For example, the NPU terminology is challenged because changes are requested by laboratories that go beyond the scope of the terminology. In addition, the terminology system needs to reflect reality to such an extent that it is useful for all stakeholders, and it has to be updated so that it continuously reflects reality. Examples were the changing Danish health organization terminology which was first not useful for hospitals, and after updates it was better for hospitals but still not useful for municipality care e.g. home nursing. Example of challenge of update, NPU was mentioned again because it costs a lot of resources to keep laboratory terminologies updated after the discovery of gene technology.

Summary of overall views of focus group members:

- It does not make sense to talk about the success/failure of a terminology without discussing scope. Decision support, reporting/auditing, reimbursement and communication have standardized terminologies as a part of the solution
- Level of standardization at implementation is still discussed. It is unresolved whether to implement terminologies and classifications for current use e.g. only reporting to registries or future use e.g. advanced analytics and decision support

- Terminologies are used in Denmark for e.g. communication (e.g. NPU), administration (SKS) and an implementation project use SNOMED CT for information management.
- Terminologies should not be stretched out of scope, just because they are successful for well-defined purposes
- Terminologies should reflect reality to such an extent that it makes sense for all stakeholders, and be updated as the world changes (especially the medical field)

Benefits of adopting new terminologies

Adoption of new international terminologies or better use of existing terminologies depends on whether you have to solve problems not solved by your current approach. One example brought forward in the focus group was the shortcomings of the Danish medication documentation, where Denmark mainly uses "Taksten" which is a price list based on ATC-codes. The purpose of "Taksten" is simply to keep track of medication prices, but it cannot be used for registering the connection between medications and allergies. For example, the granulation level of ATC is not sufficient to support decision support use cases. "Acetylsalicylic acid in combination with other substances" covers both combination with codeine (*Kodymagnyl*) and combination with caffeine (Treo) which seriously limits the application area. There is an ongoing Danish national project that explores the use of SNOMED CT for medication and allergy documentation and decision support. This requires the Danish NRC to build an extension for products approved in Denmark, and update it more than bi-yearly (release cycle not determined). What you would get is a framework where the relationships between products, substances and allergies were well-defined, so that e.g. a prescription would include looking up whether a patient have known allergies related to any of the substances in the prescribed product. **(National project, pilot studies about to start)**

Adoption of new terminologies is likely to occur in areas where no decisions have been made on the standardization of medical documentation. For example, in Denmark there is no agreed standard terminology for nursing documentation beyond 12 overall nursing areas have been defined and approved at government level. Nurses in Denmark have expressed a need for structured documentation and have been discussing which terminologies to use. Still, a preferred reference terminology does not exist and nothing is in use yet. A reference nursing terminology would be a benefit in the communication between sectors e.g. hospitals nurses and nursing homes/home nurses e.g. when patients are discharged from hospitals. But also for outcome measurements e.g. the ulcers and wounds that we are treating, how long does it take for them to heal? **(Discussion not related to a specific project)**

Right now part of this problem is addressed by implementing FSIII for home nursing. But the main intension for FSIII is not to communicate between sectors, but to communicate with different professionals within municipality care/home care i.e. not only nurses but also home care personnel, physiotherapists etc. In the first stage of FSIII, ICF is used for reporting patient functional ability before unset of care and SNOMED CT is used for nursing documentation. However, SNOMED CT is also used as a reference terminology to ease communication between different stakeholders. **(National project, pilot studies about to start)**

The ongoing change of healthcare changes documentation requirements. It was discussed in the focus group that short mean durations of stay at hospitals means that personnel that have to respond to many patient problems within very short timeframes. We need systems that support reaching the right medical decisions for example to improve patient safety and protect health care personnel from making mistakes. **(Discussion not related to a specific project)**

When focus group members are asked for their 5-10 years vision, they discuss that they do not dream of terminology systems. They dream of connected systems and system functionalities, where health terminologies are just a building block. The connected systems and functions are needed to help to do the right things at the right time and support care trajectories without waste of time. They also envision that future healthcare will allow

transparency and retrieval possibilities for various types of patient information including what the patient reports and requests. Clinical terminologies were also seen as a building block for improving the semantics of the databases underlying clinical information systems. Using these databases for big data would allow you to see new patterns that could potentially be used in prevention, treatment, research etc. **(Discussion not related to a specific project)**

Summary of focus group members reasons for adopting new international terminologies or better use of existing terminologies:

- When problems are not solved by your current approach e.g. safer prescriptions require more granularity than the current ATC based terminology offers and SNOMED CT is explored as an alternative.
- To allow communication and outcome measurements in areas where no decision on terminology have been made. E.g. nursing documentation has no agreed terminological reference in Denmark.
- To ease communication between different stakeholders. Different stakeholders may use different coding systems, but it is explored in the Danish FSIII project whether SNOMED CT can be used as a reference terminology to ease communication
- To support requirements of a more efficient health system, e.g. we need ICT support to support decisions to maintain a high level of patient safety.
- To improve the semantics of the databases underlying clinical information systems for big data related uses e.g. prevention, treatment, research etc.
- The focus group members do not dream of new terminology systems, but rather the benefits that improved use ICT can provide in health. Terminologies are seen as a building block.

Barriers for extended terminology adoption and usage

Below is a list of barriers mentioned by the members of the focus group. The arguments from the participants for each perceived barrier is not listed here, but is currently kept in a Danish background document. The barriers could be sorted in different ways e.g. thematic e.g. cost barriers, knowledge and tooling barriers etc or by stakeholder groups, but this decision should be taken at the level of the joint analysis of all European focus groups.

1. If all the stakeholder types that have to use the terminology have not been included in the process of defining it, you risk terminology that does not fit the everyday documentation needs
2. Strong feelings regarding local terms
3. Lack of Danish synonyms in the SNOMED CT translation
4. Time consuming to develop and implement terminology systems
5. If the benefit of increasing the standardization-level of the clinical documentation is not clear you risk standardizing to standardize.
6. No national decision have been taken on how to implement SNOMED CT in Denmark
7. Coding not associated with reimbursement is more likely not to be adopted than coding associated with reimbursement
8. Lack of flexibility in the way we implement terminologies i.e. the ability to easily develop value sets when we need them for our information system implementations and retire them when they are no longer needed
9. If we decide to implement SNOMED CT, there is a price to pay today in terms of time and effort, and there *might* be a reward sometime in the future
10. Lack of implementation/methodology-oriented knowledge in terms of best-practice guidance on how to structure clinical documentation and lack of good tools that supports this. E.g. graphical tools that would allow you to examine and explore terminologies would help implementation. (Notice that focus group members did not want knowledge about terminologies, but about *how to use* terminologies)
11. In terms of building knowledge, it is seen as a barrier that Denmark is a small country

12. Information system implementation projects are limited by the capabilities of the available systems including its terminology support.
13. It is expensive for vendors to change the terminology-support-service in a clinical information system, especially if the terminology-support is part of the system core. In addition, the vendors lack knowledge on how they could get the return on such an investment
14. When the existing health IT-infrastructure is working, it makes return on investment unclear for potential terminology implementers as well as government officials. For example, this is mentioned as the reason why incentives grants are not used by the Danish terminology governance bodies.
15. SNOMED CT subsets could be a reasonable approach to make implementation easier, but it requires a lot of effort, which is expensive. (Focus group does not agree on this, others argue that subset development is a cost-effective way to implement SNOMED CT)
16. The capabilities of SNOMED CT are overemphasized compared to the work needed to make it useful for specific purposes
17. Danish stakeholders are prejudiced against SNOMED CT because it contains many codes and each code is long and in a format that clinical personnel cannot understand. Stakeholders think implementation is overwhelming and many do not understand that clinical personnel are not meant to ever see the codes.
18. End users are perceived as a barrier whenever changes in information systems imply that end users have to change behavior.

Enabling factors for extended terminology adoption and usage

The following list includes all enablers identified from the transcript, including indirect enablers drawn from the list of barriers. The balance between what is a benefit/successful implementation and what is an enabling factor is not clear, which is reflected in the replies from the focus group members, in the following an enabling factor is understood as an actual action that someone could take to improve the likelihood of a successful implementation. This definition limits the list compared to a more inclusive list of enablers and benefits.

Focus group members expressed that terminology implementation can be enabled by:

1. Breaking down SNOMED CT implementation by implementing one SNOMED CT subset at a time
2. Having clear governance decisions on health terminology use, having resources available for implementation of terminologies and having guidelines for implementation.
3. Each sub-implementation needs a well-defined purpose, for example it should be clear how it gives better treatment for patients or how it helps cross-organizational communication
4. If terminology implementations were a prioritized focus area for Danish regions, with a positive business cases that would justify investment, and coordinated with other projects that also have to be carried out in Danish regions.
5. Using terminologies as a basis for reimbursement
6. If SNOMED CT is widely implemented it would enable use to have a mapping to the existing reimbursement related classifications, so that we did not have to code twice or change reimbursement scheme drastically
7. Vendors have to trust that the adoption and implementation of a certain terminology is a national decision to justify investment.

Indirect enablers drawn from the list of barriers:

1. Stakeholder involvement and ownership is crucial for adoption of a terminology (related to barrier 1)
2. Synonym development so that local language is reflected (related to barrier 2 and 3)

3. Improving training of implementers with focus on *how to* implement terminology in a flexible manner supported by state-of-the-art terminology service tools (related to barrier 8 and 10). This possibly includes improving the knowledge base and terminology service tools available

Recommendations

Focus group members argued that this had already been mentioned in the discussion of barriers and enablers, but they highlighted the need for handling multiple concurrent terminology systems e.g. Danish SKS, SNOMED CT and ICF especially to resolve reimbursement specific challenges. High quality maps were seen as a possible solution.

8.4 Finland

4.1.2. Focus group organization

The National Institute for Health and Welfare, THL organized two focus group sessions that were held on May 5th and May 26th. All together 11 experts participated (5 and 6) in the sessions. The invited experts were selected within network contacts of the Finnish ASSESS CT project team. All those experts that had availability in their calendar for the proposed meeting times, accepted the invitation and expressed extensive interest in discussing SNOMED CT and other terminologies. For two interested experts not available at the planned meeting times, additional interviews were arranged. The sessions were held at the locations of THL and the discussions followed the themes prepared in the ASSESS CT project. Prior to the meeting elementary material on the ASSESS project and SNOMED CT was given out to the experts.

Facilitator

Dr. PhD Päivi Hämäläinen acted as the facilitator of the two focus group meetings. She works as a leading expert at the National Institute for Health and Welfare and participates in the Finnish ASSESS CT team. The ASSES CT project team participated in the focus group interviews as inspectors and did not participate in the discussion, however as experts they, when asked, supported the discussion with information.

Focus group composition

Name	Organization	Role	Note
Vesa Jormanainen	National Institute for Health and Welfare (THL)	Head of unit of operational steering of the health and social care information infrastructure. (OPER)	Physician, specialist of public health. Experience in the health care information infrastructure implementation. No practical experience on SNOMED CT but high understanding of the Finnish information infrastructures
Heikki Virkkunen	National Institute for Health and Welfare (THL)	Chief physician in the unit of operation steering (OPER) (see above)	Physician, specialist of anesthesiology. The leading expert on the Finnish national health care information infrastructures. Good knowledge on the Code server. Theoretical understanding of SNOMED CT, has participated in epSOS in the definition work of patient summary.
Pirkko Kortekangas	Hospital District of Southwest Finland	Medical expert on health care	Physician, specialist of neurology. Working in a hospital district with

		information	the implementation of the national health information infrastructure. Has also acted as a consultant in several national projects. Theoretical understanding of SNOMED CT, but since no license in Finland, no practical experiences
Helena Kääriäinen	National Institute for Health and Welfare (THL)	Research professor at THL	Physician, PhD, specialist of genetic medicine. Fields of expertise and research, rare diseased, bio banks, laboratory. Represent Finland in several groups and committees such as EUCERD. Understanding of old versions of SNOMED CT in connections to rare diseases/genetics.
Peter Nyberg	The Finnish Medical Society Duodecim and Duodecim Medical Publications	Development manager	He is an expert of medical terminology. Duodecim is the leading organization in Finland for medical terminology development. The main work is focused in development of systems for evidence based decision making in clinical care. Good knowledge of SNOMED CT, UMLS and other terminologies.
Petri Pääkkönen	Finnish Medicines Agency	Development manager	Expert in the field of medicine safety. The Finnish representative in several EU activities around medical safety/ medicine information architecture.
Mika Tirkkonen	Fimlab Laboratories	Pathologist	Fimlab Laboratories provides laboratory services, education and research in Pirkanmaa, Central Finland and Tavastia regions. The public health care sector is the biggest customer. The laboratories were created by outsourcing public sector laboratories. Fimlab provides pathology services. The old modified versions of SNOMED in use.
Annika Koivisto	The National Social Insurance Institution	Development manager, pharmacist	Leading the work of implementation of the national health information structures in to the national ePrescription and medication summary systems.
Pekka Laurila	HUS - The Hospital District of Helsinki and Uusimaa	Chief physician at HUS laboratories.	Physician, PhD, specialist of pathology, expert on laboratory quality assurance. Has usage experience on old versions of SNOMED CT:
Timo Kaskinen	Salivirta and Partners	Expert	Has expertise on standardization, HL7 and others, has a long experience in defining the technical aspects of information

			infrastructures in Finland. Has know-how on vendor expectations. Salivirta & Partners is a management consultancy working in the field of **IT and Operations Development. has not worked with SNOMED CT:**
Maarit Laaksonen	Cancer Society of Finland	Chief physician	Responsible for the running and development of the Finnish National Cancer Register. Know-How on old versions of SNOMED codes.

Meeting(s), see above

8.4.1 Methodology

The sessions were held at the locations of THL. Prior to the meeting elementary material on the ASSESS project and SNOMED CT was given out to the experts. The material included a Power Point introduction to the ASSESS CT project and an introductory description of SNOMED CT. This material was provided to minimize the time spent in introduction. The participating persons shortly introduced themselves and after that the discussions followed the themes prepared in the ASSESS CT project. The discussions were recorded after consent to do so and transcribed. The text was analyzed by picking up all the different discussion parts referring to each topic. After that the meanings and themes from the text around each topic was collected. Since the discussions were held in Finnish, and the collected pieces of information were translated to English at this point and reported as a result. Two experts (Timo Kaskinen and Maarit Laaksonen) were interviewed separately because they had time constrains in participating to the group meetings. These discussions were not transcribed, but the main messages were included in the report.

8.4.2 Report on discussed themes

Finnish focus group views on current and future terminology use in the health care sector, with special focus on the role of SNOMED CT

THL organized two focus group sessions that were held on May 5th and May 26th. All together 11 experts participated (5 and 6) in the sessions. The invited experts were selected within network contacts of the Finnish ASSESS CT project team. All those experts that had availability in their calendar for the proposed meeting times, accepted the invitation and expressed extensive interest in discussing SNOMED CT and other terminologies. For two interested experts not available at the planned meeting times, additional interviews were arranged. The sessions were held at the locations of THL and the discussions followed the themes prepared in the ASSESS CT project. Prior to the meeting elementary material on the ASSESS project and SNOMED CT was given out to the experts.

The participants represented authorities for implementation and standardization of the national health information services, terminology expertise, health care providers that are involved in the usage/implementation of health information structures (electronic patient records and pathology reports), expertise on rare diseases/bio banks, and authorities working with information structures of medication. Additional theme interviews were conducted with an expert from the IT development/vendor side and an expert from the cancer register.

Theme 1: Current terminology usage

Finland does not have a national license for SNOMED CT and the practical experiences on the usage come only from using the SNOMED International -93 English version in the

hospital laboratory systems mainly in pathology specialty. Some central hospitals have also used Finnish terms for pathology concepts of older SNOMED versions. The terms have been upgraded and localized separately in different hospitals and, thus, the term sets are not interoperable with each other. The term sets consist mainly of topography and morphological diagnosis.

In Finland, the nationally referred and used common code sets are shared via the THL code server. The code sets are incorporated in all electronic patient records equally. The code server does not provide any universal terminology systems such as SNOMED CT, but various national and international code sets and terminologies. The following classifications and code sets were noted in the focus group discussions; ICD-10, ICPC 2, ATC, classification of procedures, NMT, FinLOINC, FinMESH, and terminology for social security.

The usage of SNOMED CT in the epSOS pilot was also mentioned. Finland participated in defining the common datasets for the patient summary and secured the interoperability of the used SNOMED CT terms to national code sets but did not pilot. The cross boarder transfer of ePrescriptions was piloted and the code sets needed were made interoperable.

Theme 2: Benefits, needs, and expectations of adopting new terminologies

Since Finland has already adopted the national health data infrastructures with coding and classification systems and the use of structured documentation (based on HL7 CDA R2 standard) in electronic health records, there was no discussion on pros and cons of full free text systems versus systems with structures or semi structured as such. The discussion was around a possible adoption of an extensive terminology system such as SNOMED CT versus the current situation of developing the national system from the existing grounds and with diverse classifications and terminologies to be used in the National Archive of Health Information

The current Finnish health information data structures lack some concepts. Several areas were mentioned such as health care processes, roles in healthcare, hematology, harmonization of data on implants and more granularities to documenting the diagnosis of rare diseases and genetic disorders. This situation could possibly be improved with the introduction of SNOMED CT terms. The health care data that is recorded in a standardized way could improve the possibilities of using the data.

Improving the possibilities for *international collaboration* with more interoperability of patient data was mentioned in general. Certain specific fields were mentioned as important, for example, collaboration in the fields of medical implants, cross boarder research and care of rare diseases, bio banking, health care research, international developing and consulting in pathology, medicine safety and cross boarder ePrescriptions. Harmonizing the terminology within EU with a solution that is also used across the Atlantic, could create a big Europe-US area where interoperability of eHealth information could be possible. Usage of SNOMED CT could improve the possibilities for international comparison and benchmarking.

In addition to benefits from a standardized terminology, some benefits from belonging to the SNOMED CT IHTSO family were still reckoned. For example; Finland could give expertise to the IHTSO in bringing terms for social care in to the terminology.

Most of the discussion was about *benefits on the national level*. There is a national need for a reference terminology that would act in the background and bind together the current pieces of the national health information infrastructure. A reference terminology that would work in the background of the national system would make it possible to link different translations and synonyms to chosen official coding. A terminology could also improve the quality of searching information from IT-products, databases and web-sites.

The benefits are grouped by different stakeholder groups below:

1. The patients:

- Terms from the daily spoken language could be linked to medical terms for solutions that support the participation of the patient in his/her own health care. For example it would be possible to build better IT-solutions for risk tests and self-care.

2. The professionals:
   - Standardization of terms would improve the mutual understanding of different professional groups and different specialties. This could be managed also by a background reference terminology that would make it possible to build up "translations" between different professional languages.
   - A reference terminology would improve the possibilities to build good interoperable IT-solutions for clinical decision making.
   - Give possibilities to more usable solutions for entering data in to electronic patient records.
   - Improving the quality of speech recognition.
   - Could improve the quality of care and lead to decline in medical errors.
3. The health care providers:
   - Interoperable use of health care terms in Europe and beyond would improve the market choices available for the Finnish health care providers when purchasing health care IT.
   - Improving the possibilities for national comparison and benchmarking. Benchmarking for efficiency would improve from common definitions for procedures and services.
   - Possibilities for better tools for developing health care processes.
4. The health care IT-sector:
   - A terminology would give new possibilities to develop good search engines.
   - SNOMED CT could possibly improve the possibilities of the Finnish IT-sector in the European (global) market.
5. Research and secondary use of data
   - Improving the quality of and possibilities in research.
   - Improving the possibilities for data mining.
   - Improving the possibilities to extract data for research from speech recognition.
   - Could improve possibilities for secondary use of data because the data structures would not need to be defined in advance to recording the data in to IT-systems.

The field of pathology was discussed more in-depth: Finland has been using old SNOMED CT codes for pathology specialty, but different hospitals have incorporated new terms from different sources and done localizations separately from each other. There is no interoperability in the current situation. Adapting to the current version of SNOMED could mean a way out from the current use situation and development of a common national system for the pathology coding. The adaptation would help for interoperability issues, but at the same time, save resources from local management efforts. Pathologists from different hospitals give support to this idea, but without a nationally lead project, there are no resources to cure the present situation. There is a grave need for harmonization to improve interoperability inside hospitals, between hospitals and internationally.

Since pathologists use their own coding based on old version of SNOMED, and clinicians use ICD-10, a common reference terminology could give new possibilities to develop better systems that support the care processes wherever pathology data plays a role. Also in the

daily clinical work the collaboration between the pathologist and the clinician could improve if the used terminology had a common understanding. This could reflect to improving the quality of mutual understanding in consultations from both the side of the request and the reply in both national and international consultations. Further, it could be easier to manage the ICDO-3 upgrades. In general, the quality of the data in pathology could improve, and along with it, the quality of statistics in the field of pathology and the information in the National cancer register. The harmonisation of the terminology in pathology could give new opportunities for developing better IT-solutions for pathology.

The field of medicine administration was discussed more in-depth: There is an urgent need for a common terminology of the active substance in medicine products. The Anatomical Therapeutic Chemical (ATC) classification system used at the moment is not comprehensive enough. A common terminology would help in handling information on medications in the National pharmaceutical database for the Social Insurance Institution (Kela) and from there support interoperability in different IT solutions connected to the national ePrescripiton system and in handling medication orders and data in electronic patient record systems. A common terminology is needed also for international collaboration in the field of medicine safety and developing cross boarder ePrescription services. It is important to be able to map the active substance with the product name of the medicine products. In addition to the active substance, also terminology on package and package size needs harmonisation.

The fields of bio banking and genetics were discussed more in-depth: The standardization of terms could improve the collaboration of bio banks both nationally and internationally. On the base of that it could improve the usability of the bio banks for research. For genetics the current ICD-coding is not granular enough.

Theme 3: Barriers for and risks of extended terminology adoption and use

Concerns about the true value of starting to use SNOMED CT in the national health information infrastructures

- It is not possible to see all the potential consequences of the possible change process in advance neither nationally or internationally. Different choices have different kinds of possibilities as well as different interdependences or dependences and constraints.
- In Finland SNOMED CT is a black box. It has been difficult to make any judgements on the usability of SNOMED CT in the Finnish circumstances because no one can see and test it without the license. People talk about it but hardly any have actually seen it. Also, there is very little information available about the true user cases and experiences from the countries that have the license. It seems that real life examples of good solutions with SNOMED CT have not yet been seen. Known experiences from data mining are not impressive. It has been asked if it is fair that we have to first buy the license, and then start to find out if we want it or not or even how we could actually use it.
- As the benefits of SNOMED in use are yet scarce, maybe our current health information infrastructures including the plans to develop the infrastructure further are good enough and SNOMED CT would not give any additional benefits, only additional work and costs.
- There are doubts about the usability of SNOMED CT. Has its international implementation been slow because SNOMED CT is too big and too clumsy from usability viewpoint? The amount of terms is huge and so is the amount of relationships and alternative terms for coding even with the processed subsets. It may be too large terminology to be implemented for professional use to document patient information in actual care context. With all the synonyms it may also be too big to be manageable in a usable way in the IT-systems. It may be difficult for different IT systems to adjust to SNOMED CT if they have already been developed without it, like

the ones used in Finland are. How big changes the adoption of SNOMED would mean to current Finnish health care IT systems?

- SNOMED CT is not a full, readymade and adaptable solution for Finland. It does not have all the pieces of information structures that are needed in Finland, so a national extension would have to be kept on the side. Also when terms already exist, it may be difficult to map all the current Finnish health information structures to SNOMED CT. Some choosing would have to be made. This may be difficult due to the structures already implemented in the systems and also due to possible user groups' biases and conflicting interests.
- In Finland we would have to include the social care and social services into our national health and social care information structures because the services provided by both sectors are becoming even more integrated. There is no international support or readily adoptable reference information model for this.
- Translation of full SNOMED CT to Finnish would create lots' of costs and there is no evidence from other countries on benefits of a full translation. However, it is also difficult to decide how much translation would be sufficient as the terminology cannot be evaluated without a license. Not all international medical terms do have usable Finnish terminology available, but patient access to their information would need translation of all relevant terms that might pop up in patient charts. The experts have different opinions on how much to translate.
- Finland is already fully digital in documenting patient information. When new versions of terminology concepts and codes are released, they are mapped with already existing code sets or older versions of same code sets. The IT systems need to be able to read also old EPR data and laboratory charts, which means that all the older versions of terms and code sets have to be kept available. The older versions are all managed in the national code server, but we cannot evaluate how the version management would function with SNOMED CT. For example, the current pathology coding is so scattered that building IT systems that could handle also the old term is likely to be impossible. The separate development and various versions of code sets would increase the need of managing different versions, which means further costs.
- Finnish is a very complicated and difficult language for data mining and thus expectations on better availability of data with data mining would possibly not be fulfilled.

Concerns around choosing the full terminology or subsets

- If all terms are standardized and patient data documented solely in structured format, clinically relevant and needed level of freedom of expression is lost.
- If the terminology goes too much into small details it might increase the risk of inaccurate documentation.
- Translations of all SNOMED terms would be a big effort and intertwined with professional interests that might escalate to conflicts.
- Terminology work means a huge workload also in creating possible subsets of SNOMED CT.
- If Finland would choose to use only subsets of SNOMED CT, it would be difficult to handle the possible impacts that the subsets have to one another because it is likely that there would be predictable and unpredictable relationships or dependences between them. We could not have truly isolated subsets.

Concerns around the implementation effort and resources of starting to use SNOMED CT in the national health information infrastructures

- Implementing SNOMED CT in Finland would require know how and resources. In addition, the implementation would demand financing and an administrative body for the license and organizing the adoption process.
- Changing to use SNOMED CT would be a big effort. Also, when something new is implemented, it is human to resist the change.
- Learning to use SNOMED CT would take lot of time and effort.
- There is a risk that developing IT solutions would take the lead instead of development from professional needs.
- Implementation of a new terminology system is slow and can also slow down other developments because so much resources and energy would be tied to this large scale implementation project. For example the vendors could freeze their current work on usability improvements.
- Developing a wholly new terminology and adapting to a new way of documenting would require lot of work on different fields, for example, in genetics (coding of mutations versus diagnosis).
- Implementation of SNOMED CT into current EPR-systems may be difficult.
- It would be difficult to find enough professionally qualified and enthusiastic people to support and participate in the implementation of SNOMED CT. There is a greater need for know-how for translations and mapping that may be currently even available in Finland.
- It would be a large and difficult task to train people and make SNOMED terminology or its sub sets usable enough to be accepted. It would be difficult to motivate average clinical professionals that are not interested in terminology development as such. It would be difficult to show them the immediate benefits that would pay back the efforts and strain of learning new ways of documenting their daily work. If the change process would not be managed well, the new way of documenting could still uphold all current issues of inaccurate or insufficient recording of patient data. I.e. the result would still be poor quality coding, just with different codes.
- The Finnish adaptation of SNOMED CT would have to be multilingual from the start also for national issues (Swedish, Same, possibly English…). The pathology needs also Latin. This increases the effort and costs of both implementation/translation and management when in use.
- It is difficult to create good processes for upgrading the terminology system. How can e.g. clinical requirements be updated and at the same time the system kept coherent? It would be difficult maintain information structure interoperability as localizations in Finnish local context could block interoperability.
- If the new chosen terminology differs a lot from those that are currently used, the change management would be difficult.
- Always when a new term or a synonym is added there is a risk for misunderstanding

Concerns about the true value of SNOMED CT in international collaboration

- An international terminology is demanding because different concepts have different meanings in different surroundings. This creates risk to common understanding. Examples can be found from existing terminology issues related to health care professionals and health care system terminology.
- Defining the concepts in detail well enough for mapping national and internationally would be difficult and a big job.

- The ASSES CT work should have more experience from also the vendor side participating. Maybe they have not been heard well enough. They have a big role in the implementation in the international surroundings.
- A single terminology would not help in solving all the issues of ePrescriptions. For example it would not confirm that a medicine sold as A in Finland is sold as B in France.
- Implementing a new terminology would not help in international collaboration as such, if the terminology adaptation is not connected to other international work in standardization of terms and concepts. For example in the area of medicine safety the adaptation would have to follow official European development, based on its hegemony. Furthermore, if different countries do not start using same terminologies, the cross border collaboration, for example, would not benefit from it.
- The adaptation to SNOMED CT does not have any benefit if the critical mass of adaptors is not big enough, both nationally and internationally. Finland cannot be alone with the decision to adopt SNOMED CT. Benefits for and from international collaboration come true only if other countries also adopt SNOMED. How could we be sure that other countries would change their terminologies and processes accordingly? Some progress could be made in cross boarder care issues, such as, the patient summary and ePrescription, but for example, international interoperability of for example pathology codes would demand additional development effort.
- SNOMED CT IHTSDO may not be able to give enough support to individual countries if wide implementation in different countries is to be carried out. There are previous experiences of lack of support with the old SNOMED CT terms.
- Regarding SNOMED CT implementation, international trends and administrative efforts may be in conflict. The choices made would have to be in line with the European/global standardization efforts. It would be difficult to ensure sufficient international collaboration, for example, in terminology for medication data. Which has more policy and implementation power in the long run, EMA or SNOMED CT IHTSDO in ePrescription issues?
- There are different international practices in the field of pathology and genetics on how the requests and results are documented or how genetic change and morphology information is formatted. This would be a difficult area for national and international standardization of concepts, but nonetheless, it is one area where there already is active international collaboration and exchange of information that should not be forgotten in the possible development.
- Transferring full text masses in cross boarder context would likely never work.

Theme 4: Enabling factors for terminology adoption and use and practical issues on the implementation

Partial and step-wise implementation as an enabling factor

When preparing for the national decision making regarding SNOMED CT, there is still a need to study more about the different use cases around the world. It would be important to learn more about SNOMED CT to be sufficiently informed before planning possible implementation in Finland.

SNOMED CT could, instead of a full translation, be implemented as a reference terminology that would run in the background of EPR systems. Mapping it with the information structures and code sets currently in use would minimize the effort and cost of the translations needed. The clinical change from the professional user perspective would be smaller and the adoption could progress step by step. There would likely be no need to translate the full SNOMED CT. Creating subsets would give more flexibility in the timing of translations and implementation as a whole. However, coordination between different sub sets should be

managed well. It could be possible to find available international subsets that would help the step by step process.

The international harmonization does not have to be universal in the Finnish context, as it is only needed in areas where benefits from interoperability can be gained. It would be important to identify the parts/subsets that are important in international collaboration and give more national freedom to other parts.

In international collaboration a way to manage the harmonization and the differences between various subsets should be created. The collaboration of different international stakeholders would be important. Fields such as cross boarder care, pathology, genetics, bio banking, rare diseases and medication safety were identified by Finnish experts. Nordic collaboration and a Nordic set of codes could be one solution to improve SNOMED CT implementation in the field of pathology.

Expected and experienced benefits from the implementation are needed for successful implementation.

The SNOMED CT implementation needs proof of perceived benefits to gain user acceptance. If the new terminology would be seen as something clearly better than what we are currently using, it would create a psychological support to the implementation.

Using SNOMED CT to support translations to different (also national) languages and support the use of different synonyms in professional terminologies and lay language, would increase usability of the new terminology and enrich the available terminology selection , but also keep it possible to use the familiar terms. .

The usability of the IT solutions with integrated SNOMED CT would be important. For example good search capabilities in the ICT solutions would increase usability and support user acceptance.

In the IT solutions with integrated SNOMED CT it would be important to be able to document patient data both with higher level terms and with as much particularity as needed using more accurate terms on deeper level of terminological hierarchy. Also a capability to process the terminological code structures directly from clinical text with data mining solutions would give distinct benefits for using clinical data. The potential benefits would increase even more if automated reporting systems could be built based on the data mining solution.

Better solutions for clinical decision support would motivate the clinicians to use the adopted terminology. The adoption could also be further motivated as improvement of or tools for health care process management.

Readiness for and participation in the adaptation

Resources for the license and the implementation work should be decided prior to other planning. The cost of the license is realistic. The implementations process should not be too bureaucratic and slow, but still, a long enough transition period is needed.

In Finland the standardization of national health information structures has already progressed on a good level and people are used to coding and terminology issue at work. This gives readiness for the adaptation if it is the outcome. The different professional groups and specialties could be activated in to participation in the translation and implementation work of SNOMED CT. Hearing the voices of the end users of the terminology or its subsets would support the implementation. For example the physician groups in the field of laboratory of medicine and pathology would most likely have no resistance of the uptake of SNOMED CT.

Training and arranging support during the adaptation phase is needed to help professionals with their efforts. Training and open communication covering also the system vendors are needed from the early stages on. The ICT vendors could also support the training efforts of professionals.

The authorities and different stakeholder groups need to have clear roles in the implementation. The upgrading of the terminology and/or its subsets should be well

organized and managed. Some kind of administrative power for the implementation is needed, some rules and recommendations etc. but fully mandatory implementation would hardly improve user acceptance.

The quality of SNOMED CT as a terminology and participation in the IHTSDO

SNOMED CT seems to be the only available international medical terminology with a strong standardization organization behind it, so it seems to be the most feasible if a choice towards adaptation of such terminology is to be made. SNOMED CT is comprehensively made and the know-how level in the terminological work is high.

Active Finnish participation in the IHTSDO would support bringing Finnish experiences and needs in to the discussion and also help dissemination of information from the IHTSDO to Finland. But these actions would also require Finnish national expert networks or a national working committee as well as qualified persons as representatives from Finland.

Theme 5: Recommendations

- No alternative choices of a large scale international health care terminology system can be identified and it is likely that SNOMED CT will be in some way included into the continuous development of cross boarder services. When the international classification for diseases ICD-11 will mature it is also likely to be closely related to SNOMED CT. For these reasons it is important to start learning more about SNOMED CT also in Finland.
- SNOMED CT should be seen as a tool to go forward in the modern ways of handling health care information structures. However, Finland should not start a process of translating the full SNOMED CT. Mapping the SNOMED CT terms with the codes of the current Finnish health information infrastructure would be a more useful way to start the adoption process without too much changes for the end users. A mapping effort for all currently used Finnish code sets would be likely to improve the quality and coherence of the current coding.
- The way forward could be to purchase the SNOMED CT license and launch projects on chosen terminology subsets to evaluate the possibilities and benefits from mapping current code sets with SNOMED CT. Also subsets that are still needed by professionals but currently lacking from our information structures should be identified. The potential subsets would require translations and localizing effort. ICT vendors should be given possibilities to participate in these phases of the SNOMED CT implementation as well as other stakeholders and professional groups, clinicians in primary and secondary care included. All available know-how in Finland should be identified and activated. For example, the work done previously on the Finnish Metathesaurus based on UMLS could be studied.
- It would be important to pilot SNOMED CT and study its possibilities of different chosen subsets to support translations between all nationally official languages and between professional and lay terminologies.
- Finland should become an active member of the IHTSDO and benefit from mutual learning.
- THL should take a lead in these efforts, but the implementation itself should be organized as a national effort with a common steering board etc. The THL's existing experts groups on health care classifications and patient information structures should be included in these processes. They could help especially with the clinical terms.
- There is no need to wait for the European level decisions on the SNOMED CT license. It is important to be prepared and trained to understand SNOMED CT before such decision would be on the European table. .

- To conclude: Both focus groups ended with the same recommendations and there was no objection to them in the groups. The only issue with some variation of opinions was the translation of SNOMED CT. No one supported the full translation but the proportion of SNOMED CT that should be translated was estimated differently by different experts.

8.5 France

8.5.1 Focus group organization

The French focus group is composed of 8 members what have been contacted based on the following criteria:

- They represent one type of stakeholders that were suggested in WP1 guidelines
- They have a good knowledge of SNOMED CT. Some of them may have experimented it concretely in research projects.
- They regularly practice regulatory and enforceable terminologies used in France.

For ANSM (Agence nationale de sécurité du médicament et des produits de santé) and ASIP Santé (Agence des Systèmes d'information Partagés de Santé), we included two members in order to represent all opinions.

Facilitator

Marie-Christine Jaulent, Research Director at INSERM, Head of LIMICS (research unit UMR_S1142) : http://www.limics.fr/en

Focus group composition

Name	Organization	Role	Note
Stéfan Darmoni	Rouen Unversity Hospital *LITIS lab (EA 4108),*	Physician, head of the BioMedical Informatics Department Head of CISMEF *in the TIBS team (Information processing in biology and medicine).*	Terminology expert role, Researcher. CISMeF (Catalogue and Index of Medical Resources on the Internet and its search engine tool 1 Multi-terminology information retrieval 2 Multi-terminology automatic Indexing European Health Terminology/Ontology Portal pts.chu-rouen.fr & www.hetop.eu
Michèle Thonnet	French Ministry of Health	PhD In applied mathematics, e-Health official representative of the French ministry, member of the strategic committee of the health technologies national network, member of the board of European projects (epSOS,	Government official role. Health, information systems and security specialist, with more than 20 years experience and over 180 publications. She held different positions in the pharmaceutical industry as well as the computer one including the international standardisation, and in public agencies before joining the French health ministry.

		CALLIOPE,..) and international NGOs (HON: Health On the Net Foundation).	
Christel Daniel	APHP - CSS Patient	MD, PhD Responsible of the team : "referentials and clinical information reuse for research development"	Health professional, terminology expert Currently is in charge of data governance, terminological systems and clinical research informatics at AP-HP. Project Manager Healthcare Interoperability at ASIP Santé (Governemental agency) in 2010. Coordinator of the TeRSan (ANR TecSan). Leader of the WP4 Semantic Interoperability work package of the EHR4CR project (IMI call). Key topics include: clinical research informatics (standard-based integration of clinical information systems and clinical research applications (HL7, CDISC)), knowledge representation, bio-medical terminologies and ontologies, terminology services for clinical information systems. IHE Anatomic Pathology co-chair, Member of DICOM WG26, HL7 France, HL7 Pathology SIG and CDISC France.
Philippe Manet	ANAP : Agence Nationale d'Appui à la Performance des établissements de santé et médico-sociaux.	Physician, Manager :Projects in relation with new information technologies in the context of "Numerical Hospital"	Policy maker He was previously project manager in HAS for the certification of drug prescription software at the hospital.
Vingent Maugis	ANAP	Responsible for knowledge management. Standard terminologies	
François Macary	ASIP-Santé	PhD, Author of official documents for Health Information Systems Interoperability Framework (HIS-IF)	Terminology expert, policy maker International project leader in interoperability standards development for healthcare information and communication technologies. Chair of HL7 france from 2004 to 2006 Cochair : IHE Integrating the Healthcare Enterprise (2003 – 2009)
Jean Charlet	AP-HP	Researcher	Leading researcher in Assistance Publique – Hôpitaux de Paris

			(Parisian Hospitals). He is also responsible for the GRACQ, French working group on the knowledge engineering (http://www.irit.fr/GRACQ). His research themes relate mainly to medical ontologies and documents. Jean Charlet also studies how the Electronic health record can be combined with ontologies in order to build systems with a good usability.
Thierry Dart	ASIP-Santé	MD Author of official documents for Health Information Systems Interoperability Framework (HIS-IF)	He was formely leader for Health Record Systems (HRS) implementation at the HEGP - European Hospital Georges Pompidou (APHP)
Rémy Choquet	Ap-HP	PhD in Medical informatics Operational director of the National database for Rare Diseases (Necker hospital for children, AP-HP).	Domain's expert for e-Health He's current activities deal with national interoperability of care-generated data (EHRs and registries) by the rare diseases excellence centres in France (BNDMR). But also in biomedical knowledge integration of diagnostic, genetic and phenotypic datasets into semantic databases for rare disease diagnostic coding support (LORD). He has also strong interests in data privacy and regulation issues. He is also co-leading the WP5 on the new european joint action on rare diseases (RD-ACTION). He's main interests are : medical informatics, health informatics, clinical research informatics, ontologies, data quality, data integration, semantic interoperability, public health, rare diseases, health IT strategy, management, data privacy.

Meeting(s)

Meeting 1 : March 19th 2015. It was a teleconference to inform the participants about the ASSESS-CT project and the role of the focus group (1 hour)

Meeting 2: March 30th 2015. The first face to face meeting in Paris. This meeting was dedicated on the presentation of the questions that should be debated and how the moderator will organize the brainstorming questions. This meeting was really important to prepare the ASSESS-CT French Focus group meeting and in particular to install the spirit within the group. (2h)

Meeting 3: May 4th 2015. The ASSESS-CT French Focus group meeting (3h)

8.5.2 Methodology

The first step of the methodology was to identify the participants in order to cover all the stakeholder categories we wanted to include. We were careful to cover all the current points of view in France about adopting Snomed-CT and we were vigilant to invite people in good spirit to adopt an open and spontaneous format, generating a maximum number of different ideas and opinions from as many different people as possible. The participants are terminology expert, health professional, domain expert for eHealth, policy makers, academic researcher and government official.

Since France is not an IHTSDO member, it was important to convince people about the importance of the focus group and the relevance of the ASSESS-CT project. We spent some time in a first teleconference to explain the role and format of a Focus group. In particular, the focus group aims at producing qualitative data (preferences and beliefs) from discussion instead of on individual responses to formal questions. Although it is not mandatory that opinions are representative, the choice of the participants ensures the representativeness. The following important statements were made:

- It is a brainstorming format. Focus group members do the talking while considering a question
- There are no right or wrong answers
- What is said in the room stays here
- The moderator will capture everything that has been said, but will not identify any one in the report.

In a first face to face meeting, it was important to present more in detail the project and the 5 themes to ease the analysis of the focus group output from different countries. One important aspect of this step was to decide with the focus group what were the convenient formulations of the questions in the French context. The role of the moderator was to position these questions within the 5 themes. We ended up with 8 main questions (carefully prepared questions which move from the general to the specific):

- What is the current state in France in terms of terminologies usage? (Since France is not an IHTSDO member, the current state reflects the ALTERNATIVE or ABSTAIN scenario)
  - What are the success stories (the working current use cases)?
- What are the priority use cases for the country?
  - What are the Strengths and Weaknesses of the current use of terminologies according to the set of use cases to be covered?
- Do you think there is a need of new terminologies, (such as SNOMED CT) or do you think there is a need to improve (extend) the implementation of current terminologies (reference and local)?
- What are the main barriers you identify for adopting international terminologies (eventually new ones) rather than local ones? (ALTERNATE versus ABSTAIN scenario)
- What are the main barriers (and fears) for adopting SNOMED CT as a facilitator for integration and interoperability?
  - Do you think the SNOMED CT can be used as “reference” terminology for clinical terms
- What will be the facilitators to overcome the barriers?
  - What will be the different steps and the local challenges?
  - Is that an option in the current situation (already existing facilitators)?
- What would you recommend as the next steps in terminology adoption and usage (at the level of the country and the EU)?
- Who is responsible of the enabling factors (at the level of the country and the EU)?

8.5.3 Report

French views on current and future terminology use in the health care sector, with special focus on the role of SNOMED CT Meetings

Telco : mars 30th , 1 hour
Face to Face meeting : may 4th , 2 hours
Face to Face meeting : may 19th , 1 hour

1) What is the current state in France in terms of terminologies usage ?

The discussion concerned what terminology is used for what in various situations. The Focus group produced a table of the required/optional use of terminologies. A glossary explaining the different acronyms is given at the end of the document.

Regulatory and Enforceable Terminologies. These terminologies are used in domain/use cases such as medico---economic, Care, Public Health or Research
Effective use of International Terminologies in their French version
ICD-10 - ATC for molecules – EDQM – MedDRA – UCUM - HL7 vocabularies –TNM
LOINC is used is the context of regional Healthcare territories (“Territoires de Santé Numérique”)
Effective use of National or local terminologies
GHM – GHS – NABM – NGAP – CSARR - CIS – CIP- UCD - SNOMED 3.5 VF
ATC for drugs : here ATC has been adapted according to the official Drug database in France
CCAM is used for national exchange of data

Regulatory Terminologies. These terminologies are used in domain/use cases such as Public Health, Care and Research
Effective use of International Terminologies in their French version
ICPC2 – ICF
SNOMED CT is integrated by some industrials in their healthcare solution
Effective use of National or local terminologies
CIF
Hospitals have also many local catalogues. Some of them are sometimes merged to allow interoperability (example in radiology)

2) What are the success stories (the working current use cases) ?

The Focus group identified real usages of terminologies (working applications) according to a use cases categorisation. They discussed around 3 types of use cases : (1) Medico--Economic and Facturation, (2) Production of Care, (3) Care Coordination

Medico---Economic and Facturation
Effective use of International Terminologies in their French version
ICD-10 - ICF

Effective use of National or local terminologies
CCAM– GHM – GHS – CCAM- NABM – NGAP – CCAM – CSARR- CIS – CIP- UCD - GHM - GHS - CIF - LPP/Cladimed - ALD

Care processing (production)
International
ICD-10 – Orpha – ATC - EDQM - MedDRA - UCUM
Administrative data
LOINC - TNM - ICPC2 – ICF
SNOMED CT (via affiliated licence)
National
CIM-10 VF - CCAM - CIS - CIP - UCD - CIF - LPP/Cladimed - ALD
SNOMED 3.5 VF
RPPS : medical specialties (given CNU, CNOM)
ROR (structures)

Care coordination
International
ICD-10 - Orpha
Administrative data
LOINC - UCUM - TNM
National
CIM-10 VF - CCAM - NABM - NGAP - CSARR - CIS - CIP - UCD - GHM - GHS - CIF
LPP/Cladimed - ALD
SNOMED 3.5 VF

Public Health at the national level
International
ICD-10 – Orpha - ICF
National
CIM-10 VF - CCAM - NABM - NGAP - CSARR - CIS - CIP - UCD - GHM - GHS - CIF -
LPP/Cladimed - ALD

Public Health at the international level
International
ICD-10 - Orpha - ATC - EDQM - MedDRA - UCUM - LOINC – TNM - ICPC2 - ICF

Administrative data
National
CIM-10 VF – CCAM - NABM - NGAP - CSARR - CIS - CIP - UCD – GHM-GHS - CIF - LPP/Cladimed - ALD - SNOMED 3.5 VF

3) What are the priority use cases for the country ?
    1. Do you think there is a need of new terminologies, (such as SNOMED CT) or do you think there is a need to improve (extend) the implementation of current terminologies (reference and local)?

For this question, the discussion focused on what are the usual practices in 4 identified contexts: Care Production, Care Coordination, Public Health, Research. They focused on the reuse of data for Public Health and Research. For interoperability purposes, the ASIP agency has developed an interoperability framework at the national level but other interoperability frameworks exist and are used in specific domains (e.g. rare diseases).

1) Care Production
There is no interoperability framework provided by the authorities for coding, except for IHE intrahospital pathways.
The activity consists in the production of CRH, CRO, Patient summary, Orders (lab, imaging, pharma (ePrescription), Results (lab, imaging), disease specific observation and clinical pathways/care plans, multidisciplinary clinical meeting.

Priority of use-cases :

- Problem list : This use case needs a terminology with a better granularity than ICD10 within the hospital. For ambulatory medecine, the need is fullfill with the CISP (Classification internationale des soins primaires), the french version of ICPC.
- Clinical information for indication, contraindication, prescription (diagnostic and therapeutic acts including information about costly drugs): This use case needs a terminology with a better granularity than ICD10. Today specific terminologies for Allergy and Intolerance Information (among others) are missing.
- Appropriate prescription of drugs: This use case needs a better classification of drugs. Here, there is a need of an ontological organisation.
- Appropriate prescription of biology exams: This use case needs a national catalogue (may be Top 300 LOINC ?)
- Appropriate prescription of imagery exams: This use case needs a national catalogue

2) Care Coordination.

This has to do with Sharing and Exchanging. There is a necessity to be compliant with the interoperability framework provided by ASIP santé. The information must be coded and structured.

Exchange/Sharing of CRH, CRO, Patient summary, Orders (lab, imaging, pharma (ePrescription), Results (lab, imaging), disease specific observation + clinical pathways /care plans, multidisciplinary clinical meeting

3) Reuse in Public Health

There is a necessity for coding and structuring

There is no necessity to respect the French interoperability framework (ASIP). However, it is necessary to respect one interoperability framework of the national or international Public Health regulatory bodies. It is for example the case in the BNDMR project.

Priority of use-cases :
- Transmission/access to clinical data. Sources: CRH, CRO, Patient summary, Orders (lab, imaging, pharma (ePrescription), Results (lab, imaging), disease specific observation + clinical pathways/care plans, multidisciplinary clinical meeting. For this use case, there are national registries (cancer, rare diseases), surveillance, alerts : INVS. There is a need for international registries for surveillance (pharmacovigilance, infectious diseases, antibioresistance), OHDSI/OMOP ?

4) Reuse in Research

There is a necessity for coding and structuring
There is no necessity to respect the French interoperability framework (ASIP). However, it is necessary to respect one interoperability framework of the national or international Public Health regulatory bodies

Priority of use-cases :
- Transmission/access to clinical data. Sources: CRH, CRO, Patient summary, Orders (lab, imaging, pharma (ePrescription), Results (lab, imaging), disease specific observation + clinical pathways/care plans, multidisciplinary clinical meeting. For this use case, there are specific entities URC (Unité de Recherche Clinique) at the national level. At the international level, there is a need to promote multicentric trials and to access biobanks.

4) What are the Strengths and Weaknesses of the current use of terminologies according to the set of use cases to be covered ?

Weaknesses
- Licences, cost
- Updates (national/international) by Learned Societies
- Distribution of versioning resources
- Distribution of multilingual resources (if international use case)
- Integration to Information Systems (IS): implementation of coding in two ways (1) catalogue
- of Items to fill forms, (2) free text coding

Strengths
- PMSI
- Share/exchange of clinical information from one care facility to another, including at the national level (DMP) supported by the interoperability framework

Specific issues according to use cases
- Care Process
  - Coverage/Granularity of existing terminologies
- Care Coordination
  - Integration of data structures (value sets, binding)
- Reuse of data

- Representing the context necessary for the re-interpretation (most often recoding)

Remaining questions for next meetings

- What are the main barriers you identify for adopting international terminologies (eventually new ones) rather than local ones ? (ALTERNATE versus ABSTAIN scenarii)
- What are the main barriers (and fears) for adopting SNOMED CT as a facilitator for integration and interoperability?
  - Do you think the SNOMED CT can be used as “reference” terminology for clinical terms
- What will be the facilitators to overcome the barriers ?
  - What will be the different steps and the local challenges ?
  - Is that an option in the current situation (already existing facilitators) ?

Glossary

1) International terminologies

ICD-10 (CIM-10 in French)	The International Classification of Diseases
ATC	Classification of active ingredients of drugs according to the organ or system on which they act and their therapeutic, pharmacological and chemical properties
ICF (CIF in French)	International Classification of Functioning, Disability and Health
UCUM	The Unified Code for Units of Measure
MedDRA	Standardised medical terminology to facilitate sharing of regulatory information internationally for medical products used by humans
HL7 vocabularies	Coded vocabulary terms used in HL7 information structures,
EDQM	Quality standards for safe medicines and their safe use.
ICPC2	International Classification of Primary Care
SNOMED CT	Systematized Nomenclature of Medicine Clinical Terms
LOINC	Logical Observation Identifiers Names and Codes
Orpha	Classification of rare diseases
TNM	Classification of Malignant tumors

2) National terminologies

CIP	Fichier contenant toutes les présentations des spécialités du Répertoire des Spécialités Pharmaceutiques.
CIS	Fichier contenant toutes les spécialités du Répertoire des Spécialités Pharmaceutiques.
LPP/Cladimed	Classes de dispositifs médicaux
CCAM	Classification Commune des Actes Médicaux

GHM	classification medico---économique des hospitalisations en médecine, chirurgie, obstétrique et odontologie (MCO)
GHS	système général harmonisé de classification et d'étiquetage des produits chimiques
NABM	Nomenclature des Actes de Biologie Médicale
NGAP	Nomenclature générale des actes professionnels
CSARR	Catalogue spécifique des actes de rééducation et réadaptation
UCD	Unité Commune de Dispensation
SNOMED 3.5 VF	Systematized Nomenclature Of Medicine International 3.5 Version française
ALD	Affectations de longue durée

3) Others

CRH	Comptes Rendus Hospitaliers
CRO	Comptes Rendus Opératoires
PMSI	Programme de médicalisation des systèmes d'information
DMP	Dossier Médical Personnel
BNDMR	Banque Nationale de Données Maladies Rares
INVS	Institut National de Veille Sanitaire

8.6 Germany

8.6.1 Focus group organization

Facilitators

Prof. Sylvia Thun, MD; Hochschule Niederrhein, Medical Doctor and Professor of Information and Communication Technologies in Healthcare

Reza Fathollah Nejad, MA; Hochschule Niederrhein, Health Economist, Research Assistant and Scientific Project Coordinator at the Niederrhein University of Applied Sciences

Focus group composition

Name	Organization	Role	Note
Christoph Gessner, PhD	Gematik (Association for Telematic Applications of the Electronic Health Card)/ HL7-Germany	Technology & Innovation	-Chair HL7 Germany, Co-Chair HL7 Germany Technical Committee "Terminology", Member of DIN working committee "Health Informatics - Terminology", Member of ISO/TC 215/WG 3 Semantic Content, Member of ISO/TC 215/WG 6 Pharmacy and medicines business. -Experience in teaching, training and consultancy in health informatics, including terminology issues (LOINC, SNOMED CT, ICD, and MeSH) and communication standards (HL7, DICOM, IHE).

			-Work in gematik as expert for eHealth standards and their application for national and international eHealth projects. Actively contributing to European projects (EXPAND, JAseHN) in various project groups.
Kai Haitmann, MD	HL7-Germany, Heitmann Consulting and Services	CEO HL7-Germany	Kai Heitmann is a consultant for information and communications technology in the health sector with over 15 years of experience in this field. He is involved in European application and architectural projects as well as training and workshops. His focus is on Germany and the Netherlands. He has Expertise in the field of IT-standards and their utilization. He has been in the standardization environment for many years, and among others has worked as a board member of HL7 International and HL7 Germany.
Zain Elabdin, BSc	ZOZLAIN	Clinical Workflow Manager	Many years of experience in healthcare IT, especially with Hospital Information Systems, subsystems, and systems integration, optimization of integration processes with the use of communication standards (HL7, XML, xDT) as well as HL7- and IHE-information models
Tarik Idris, BSc	InterComponentWare AG	Business Development Manager EMEA	At ICW responsible for: -standardization (including messaging, structured documents, and terminologies), -product definition, including terminologies delivered as part of the ICW products, -sales to healthcare provider organizations (which may need to consider licensing costs for their terminologies in their buying decisions) -business development for resellers, OEM partners, etc. (who need to be able to address the licensing of the ICW products they use/offer to their own customers)
Jörg Caumanns, PhD	Fraunhofer FOKUS	Head of Competence Center E-HEALTH	Dr. Jörg Caumanns is Head of the Competence Center E -HEALTH - Platforms and Solutions for Connected Health at the Fraunhofer Institute for Open Communication Systems FOKUS . Previously, he was employed as a research assistant at the Fraunhofer Institute for Software and Systems Engineering ISST in Berlin . In R&D project for the electronic health card, he was employed as an operative project manager. In this role he was

			responsible for planning and coordinating the work content as well as for the overall architecture. Since early 2006, Dr. Caumanns leads project for the development of electronic case files, initiated by the German Hospital Association (DKG) and private hospital chains.
Frank Oemig, PhD	AGFA Healthcare	Standards & Interoperability, HE Region DACH IT BD	Dr. Frank Oemig has been with AGFA HealthCare GmbH/ Solution Management since summer 2006. He is part of the committee- , working-group- and/or board level of HL7-USA, Germany-HL7, IHE-Germany, bit, DIN and GMDS managing interoperability issues. In previous activities, he spent several years as a Product Manager, Systems developer, consultant for system integration issues and coach for communication standards. The early foundations for his activities today were set in 1983 by an Medical informatics education. In 2011 he received his doctorate on the subject of architecture and knowledge representation. Moreover, he is the author of many articles on the topics of interoperability, communication standards, terminologies, and ontologies.
Klaus Urban	Frey ADV GmbH	Project Manager/ Developer in Healthcare	Project Manager ORS1 for the Frey Group (ORS1 is the of the trial project of gematik with 2 times 500 users)
Daniel Flemming, PhD	Osnabrueck University of Applied Sciences	Research Assistant	Since 2007, Daniel Flemming is Research Assistant at the Osnabrueck University of Applied Sciences. There, he works in the “cognITH health”-project: Cognitive Basics of Cooperation: Concepts for an Optimized IT in Cooperative Project Planning.
Stefanie Weber, PhD	DIMDI (German Institute for Medical Documentation and Information)	Head of Working Group “Medical Concept Systems”	
Bernd Schuetze,PhD	Deutsche Telekom Healthcare	Data Privacy and Data Security	Bernd Schuetze has clinical experience for more than 10 years, has been familiar with IT implementation and use in hospitals for more than 20 years and has high competencies in the field of data protection in health care
Lars Treinat	ZTG Center for Health Telematics and Telemedicine	Scientific Project Manager	Lars Treinat is Sociologist and holder of the holder of the gmds-certificate "Medical Informatics.” He is Project Manager at the ZTG Center for Health Telematics and Telemedicine. ZTG advises and supports the Federal Land of North Rhine-Westphalia (NRW) with

			the installation of the cross-regional register for health professions, the setup of the cancer register in NRW, and the introduction of electronic reporting of notifiable diseases and agents.
Wolfgang Orthuber, DDS	University of Kiel	Research Assistant	Focus on development of a framework for Domain Spaces resp. free user defined metric spaces on the web. (http://numericsearch.com)
Sylvia Thun, MD	Niederrhein University of Applied Sciences, HL7-Germany	Professor of Information and Communication Technologies in Health Care, Secretary General of HL7-Germany	Sylvia Thun is Professor of Information and Communication Technologies in Health Care at the Niederrhein University of Applied Sciences since 2011. Previously, the Medical Doctor and Engineer dealt with It standards, drug information, terminologies and ontologies at the German Institute for Medical Documentation and Information (DIMDI). She is part of the Management Boards of HL7-Germany and IHE-Germany. Moreover she is the Deputy Chairwoman of the DIN NAMed. She is co - author of the books "Handbook of Best Practices of Integrated Clinical Pathways" and "Handbook of Best Practices in Healthcare IT " and holder of the gmds-certificate "Medical Informatics."

Meeting(s)

Meeting 1

09.06.15, Cologne (adjacent to the 2. German Interoperability Forum 2015), Duration: approx. 2 hours

8.6.2 Methodology

First, potential experts in the field of eHealth were identified and invited. It was perceived as practicable to hold the Focus Group Meeting somehow in connection to the German Interoperability Forum, which usually takes place 4 times a year and deals with interoperability themes of data in the German healthcare sector. It is organized by the HL7-Germany, IHE-Germany, and the German Institute for Standardization (DIN), the German Association of Healthcare IT (bvitg), and others. As depicted in the “Focus Group Composition” Table (see above), we tried to perfect the group with scientists, researchers and practitioners.

According to the guidelines for conducting a Focus Group which was developed and agreed upon by all members of Workpackage 1, the questions were processed and prepared for the German Focus Group Meeting in July.

The questions were grouped in to 5 themes, translated into German language, and were integrated in to a PowerPoint-Presentation. Although already being provided with information by the invitation Email, another PowerPoint presentation was produced to depict the ASSESS-CT project to the participants and illustrate how the German Focus Group is to be classified within the overall task of the project and especially in Workpackage 1.

It was planned to go through the questions by showing one slide theme by theme. At the beginning of the discussion, we provided the disputants with some basic discussion rules: Each theme will be discussed by 10-15 minutes and in the end there will be one more 10-minute slot for a final discussion round.

The discussion was recorded with the help of a smartphone (voice) and a written protocol was taken by a facilitator and a research assistant. The protocol was translated into English, revised as regards to content and sent to the participants for further revision and validation before going into the final draft.

8.6.3 Report

Theme 1: Current terminology usage

Question discussed:

- Which terminology systems are being used now?
- To what extend are they useful? (Strengths and weaknesses)

Billing

- ICD-10-GM (German Modification),
- OPS (Operationen- und Prozedurenschlüssel; the German modification of ICPM),
- EBM (Einzelbewertungsmaßstab)
- GOÄ (Gebührenordnung Ärzte)
- a lot of „in-house"-terminologies for own purposes;
    - **weakness:** although the individual clinics gather data for the same question or problem, it is not possible to compare and to merge the data from the different sites
- lots of terminologies (rather catalogues), but no standardized terminologies, which provide the information that is needed
- many key tables, i.e. those of the KBV (Kassenärztliche Bundesvereinigung/ National Association of Statutory Health Insurance Physicians): collection of terms (de facto no code systems or terminology, rather tables)
    - they fulfill a legal mission
- there is a division line between 2 groups of terminologies:

  1. for administration and billing purposes

  2. for clinical use and nursing

  … And therefore you have to consider an appropriate usage

Statistics

- ICD-10: originally invented for statistical purposed, and nowadays used for billing and refunding

Laboratory:

- LOINC: **Strengths:** semantically well described, perfect for laboratory use,
  No good alternatives to LOINC
  Weakness: not applicable for data management
  Contains incomplete definitions, e.g. not defined units
    - LOINC is often being "assaulted": many LOINC-codes are being customized to the own specific objective, although the axis forces another semantic content
    - in the epSOS-Project the problem was solved by requesting new LOINC codes

- it will always be incomplete. Free standardized online definitions (especially of multidimensional quantitative spaces) should be possible by all users for a general solution for all users. Same with directives (with possible conversion factors) which can handle redundancy.

Nursing:

- rate of usage: less than 10% (according to “IT-report”)
- NANDA-I (North American Nursing Diagnosis Association – International)
  - NIC (Nursing Interventions Classification)
  - NOC (Nursing Outcomes Classifications)
- German Commercial systems:
  - EMP (Emailfähiges Managementhandbuch Pflegedokumentationssystem);
  - Apenio (atacama Software GmbH)
- Clinical Care Classification (similar to ICD-10 architecture)
- ICMP, **Strengths:** all-rounder for nursing, belongs to WHO classification-familiy

  Weakness: low rate of usage
- apart from these: lots of in-house coding systems in nursing

Rehabilitation:

- ICF (International Classification of Functioning, Disability and Health)

Pharmaceuticals:

- PZN (pharmaceutical central number): **Weakness:** Uniqueness over long-lasting records not guaranteed
- ATC/DDD, **Weakness:** in Germany, it is only permitted to use it in specific contexts, in Germany: vague (or even invented) coding of dosage forms concerning orifices of the body and/or the anatomy of the body (most recent example “eMedikationsplan” (Electronic Medication Plan)

Science/ Texts

- MeSH: recently licensed in Germany (for free), classification of texts

Units of Measurement:

- SI (International System of Units)
- UCUM (Unified Codes for Units of Measure)

Devices:

- GMDN (Global Medical Device Nomenclature)
- UMDNS (Unified Device Nomenclature System)

Radiology

- RadLex

Others:

- HL7-internal terminologies/ FHIR-terminologies (partially, only some subsets)

- often terminologies are used, because there are no other choices, although they are not designed for the specific use case: therefore their use can lead to deficient results
- in many of my projects we actually would have to use SNOMED CT, because there were no other suitable terminologies, but it was perceived as too costly by decision-makers
- lack of terminologies especially for document management systems
- good base of terminologies in the areas diseases (findings), procedures, and laboratory
- terminologies usually have their own specific purposes; the best would be if we had a terminology that can cope universally with all scenarios: an all-rounder

Theme 2: Benefits of adopting new terminologies

Question discussed:

- For which use cases do you see benefits in extending the use of international terminologies?
- For which use cases do you see benefits in using SNOMED CT?
- I must say for me, who also writes specifications for other countries, SNOMED CT can easily be used to write specifications, because in all those uncommitted cases, you can brilliantly help yourself with the use of SNOMED CT
- usable beyond different data exchange specifications
- can be used everywhere, where data are being exchanged: patients are being treated less frequently in a local setting, different specialists are located at different places
- has a specifically defined semantic, generated by the work of others, which doesn't need to be repeated in Germany again
- Transfer of patients' medical data in the international context, i.e.: German patients with an international insurance, soldiers, foreign patients who come to Germany for medical treatment
- Great benefit in laboratory data communication: cross-border exchange of information, even between different parts of a laboratory chain within Germany
- generated data can be used in different contexts for different purposes, preserving the defined semantics of that data
- the use of international terminologies would highly improve reimbursement processes with insurance companies of German patients who have been treated overseas Problems often occur due to the use of different terminologies and/or concepts
- collected data eventually have to be communicated at one time (in the medium or long-term), so at least at that time an appropriate terminology has to be found
- an automated pre-processing of data is desired in order to cope with Big Data (intelligent filter function)
- Ressource savings: The German healthcare system can highly profit of preliminary, high-quality work which was already done abroad. Only a translation and local mapping is needed.
- the reusability of data within the same or in a different context is increased by the use of international terminologies, especially for registers, billing, and quality assurance, which then leads to debureaucratisation, avoidance of redundancy, and cost savings

Question discussed:

- What would characterize an ideal terminology system?
- Being universal, possibly for multiple purposes
- mapping country-specific characteristics (a "German Modification", so to speak)
- granular, being able to retrieve dedicated concepts, but also more general concepts
- being able to connect concepts via relationships
- legal security which provides unproblematic use of the terminology in products as well as in the product development, at customers' site: unproblematic transmission to others
- copyright
- enabling mapping from legacy systems
- poly-hierarchical and cross-linked → ontology (searchable and browsable)
- testable and reproducible with correct definitions
- possibly with a well-established approach for terminology extensions
- well-established coordination mechanism for maintenance of terminology within an international community

- official authority for administration and support

Theme 3: Barriers for extended terminology adoption and use

- you will find several results for the same case:

  →example: “left”, “right”; in the ophthalmology section of SNOMED CT there are special concepts for “left eye” and “right eye”; here you have a selection problem due to fine granularity

    - that’s why education is needed, special knowledge how the terminology is built up and for what purpose you can use it or not
- many international specifications like HL7-CCD or MS (medical summary) among others use SNOMED CT and therefore are not usable because Germany has no IHTSDO-license
- Lack of national version/ translation
- Liable to pay costs (license fee)
- Uncertainty about license agreement content and use restrictions, although there are clear specifications from the IHSTDO: thus mostly because of lack of knowledge
- Complexity of the terminology;
    - Yet this argument can be refuted:
    - depends on, whether the users have to deal directly with the terminology or is there a user interface or a user toll interposed?
    - You can easily bind SNOMED CT concepts (as a reference-terminology) in the background to a user interface with list box entries (codes), which are easy to handle and health care professionals (HCPs) are already familiar with. Thus, HCPs won’t even realize that SNOMED CT is set behind their user interface.
- High effort with terminology maintenance
- German users are inhibited to express themselves in English in their documentation
- Health professionals in Germany have a negative connotation with coding in general, which is depicted as time-consuming and labor-intensive. This negative connotation is being transferred to international terminologies as such although those often are able to ease their work
- There is a lack of terminologists/ terminology experts: We need professional terminologists in order to be able to handle terminologies appropriately; the provision of browsers is not sufficient, for coding you need professional knowledge

Question discussed:

- Was are the barriers or reasons why Germany has not yet become a member of the IHTSDO?
- Historic reasons: in the 1970s a professor from the University of Münster translated SNOMED into German, without having any official mandate or license. Juridical conflicts followed which still are existing

  Lack of manpower, time and resources are not convinced about the benefits of standardized terminologies in general and SNOMED CT in special (“nobody really wants such a thing, certainly not the medical fraternity”)

- policy decision-makers and ministries

Question discussed:

- Which projects in Germany have proven that SNOMED CT is useful?
    - Too little empirical evidence of benefit in Germany
    - If there were no license issues, there would certainly be more projects

    - There a too little examples in the literature on typical German discharge letters or on the typical way how German physicians express themselves (the Anglo-Saxon way of expression is different and therefore the German users get discouraged in using international terminologies)
    - Contrary opinion: in my opinion license fees are not a problem compared to the expenditures that you have for example with introducing an HIS (hospital information system)
    - The configuration and mapping of a com-server is far more expensive than the IHTSDO-license fee for one clinic
    - The SNOMED CT license fee for a large clinic in Germany costs as much as 1 day of configuration work
- if you want to avoid using SNOMED CT, alternatively manpower is invested into the use of other terminologies and the mapping back and forth. These are indirect costs which cannot be numbered
- you have to differentiate between factual barriers and perceived barriers
- it is perceived as too complex and therefore decision makers vehemently are opposed to it
- for an implementer it doesn't make any difference which coding-list he has to map to
- We have a typical chicken or the egg causality dilemma: Because we believe that barriers like license fees or any other excuses exist, we do not make projects in Germany; and due to the fact that we don't make any projects we believe that SNOMED CT is dispensable
- Decision-makers postpone licensing and implementing SNOMED CT because of perceived complexities. In companies and health institutions that are not internationally active license texts in a foreign language oftentimes are being queued within their legal departments. This is true more than ever when the decision-makers aren't convinced in the first place.
- No support by users and decision-makers
- If there were a countrywide license, not only the license fee barriers would disappear, but it would significantly ease the handling of the terminology in product development and in use, because there wouldn't be the necessity to obtain necessary rights
- There is a problem of a perceived cost-benefit-ratio
- benefits for data-management within the clinic, but problems of data exchange between carers, because no one else is using SNOMED CT
- Many stakeholders simply don't see the necessity for coding in the first place
- In Germany there are no legal requirements of introducing SNOMED CT: no laws
- There should be a law that obliges all stakeholders to first look for any existing, international terminology before developing and/or creating a national one
- To say that just because there is no law that obligates the use of SNOMED CT in Germany is the reason why SNOMED CT is so rarely being used is not correct. In Germany there is no law for using LOINC either, nevertheless it is being used.

<u>Question discussed:</u>

- Is SNOMED CT ready for use?
- SNOMED CT has gaps and holes and will never be fully complete (that also applies to other terminologies), yet very much is covered by it
- Allergy table of the University of Heidelberg: Weaknesses in coding due to the lack of relations, post-coordination was needed
- In real-time applications abroad the rate of post-coordination is around 5% only
- SNOMED CT is not perfect, yet the best on offer. So the task for Germany is to Find the errors, eliminate them, and contribute to further development. You cannot keep complaining that concepts are missing, and at the same time not contributing in any kind. You will not find anything better than SNOMED CT.

- It will be always incomplete. A solution for all users could be offering “free standardized online definitions”. “Online" means that every definition has a URL on the web and is freely accessible in a standardized file on the web. Definitions of multidimensional quantitative spaces can efficiently cover a great range of possibilities. “SameAs”-directives (with possible conversion factors) can handle redundancy.

Theme 4: Enabling factors for extended terminology adoption and use

- Money, Financing
- The „eHealth-law“ in the first place has put eHealth related issues on a larger political agenda. One of its intentions is to develop standards for interoperability
- physicians‘ level of suffering (controversially discussed)
- increasing ability and increasing necessity to interchange data
- high rate of electronic medical documentation in the German healthcare system
- what distinguishes Germany from other countries is that we already have an institution which is responsible for medical documentation for about 40 years (DIMDI). Other countries first need to establish comparable institutions.

we have to create incentives for the users, for example inform them, that they can highly profit from the data for their strategic management within their clinic or medical practice:

“How many appendix surgeries have we had this week?”

- Strategic consequences could improve the quality of treatment

- Added value could only be realized, if I am able to show what kind of support-systems operate behind the terminology interface. Thus, the adoption of a new terminology in the first place does not automatically lead to added value
- most of the software systems which are used in Germany, have also been developed in Germany. An adoption of SNOMED CT could therefore lead to a competitive advantage.

Theme 5: Recommendations

Question discussed:

- What would you recommend as the next steps in terminology adoption and usage?

in your organization?

- toolsupport on all levels
- recruiting of terminologist and creating terminologist posts

in Germany?

- official German translation (especially because of different understanding of concepts), transferring concepts
- creation and installation of a “Terminology Competence Center” consisting of experts whose tasks are
  - working on the transfer of concepts into the national setting and not only translate them
  - Terminology maintenance
  - Translation
  - International knowledge-exchange and communication
  - Issuing publications
  - Offering and conducting training courses (skills development)
  - Promotion and product positioning

-on EU-level?

- Translation (with the help of a translation engine)

- Potentially also on this level: creation and installation of a “Terminology Competence Center”

- Laws and guidelines together with a migration concept
- Adequate access
- Gradual launch
- the deeper you go into the medical documentation domain more you realize that you need SNOMED CT
- opportunities should be given to experiment, i.e. free access or easier access for projects
- obligation: use of international terminology before creation of a new national solution
- absolutely no need to replace ICD-10
- Wherever there is still no terminology in use, you can start with the application of the new terminology (e.g. SNOMED CT), because wherever you already have legal regulations it will be hard to replace existing terminologies (such regulations mostly stay for about a 10-year period)
- Start with EpSOS value sets, or immunization, allergies, HL7-tables
- Potential use in DMP-documentation and quality sheets
- Emergency data sets like in the AKTIN-project
  - There are lots of decided terminologies for certain areas, which are compact and manageable; however, at those areas where we still haven’t got any terminologies available you can make use of “all-rounders” like SNOMED CT
  - Especially for billing and documentation of Disease Management Programs (DMPs), I don’t see any need for using SNOMED CT; what interests could somebody have to code medical data of East-German DMP-patients in SNOMED CT?
  - we should have a law that provides incentives, e.g. a law that
  - the terminology shouldn’t be explicitly mentioned in the wording of the law, because laws usually need plenty of time before they get changed and/or updated. A better solution would be to recommend the use of up-to-date-terminologies
    - e.g. in the medical device market the use of UMDNS is regulated by law, although many other terminologies are long seen as much more eligible
  - a law could regulate that Medical Associations are being consigned to determine the use of specific terminologies in their specialist field
  - While SNOMED CT is being rolled out, the use should be incentivized and projects should be supported, because a free access only does not automatically lead to more utilization and application
  - the Technology Competence Center (TCC) should be involved in every single project concerning the terminology and accompany them
  - responsibility management: meaningful collaboration between the industry (which is near to the users and knows what they need) and the authority (TCC)
  - legal regulation in the nature of providing incentives, i.e. only if you use SNOMED CT , you will get support from the Terminology Competence Center (TCC), otherwise no support. However, the choice of terminology should be mandatory.

Others Themes

- coordinated activity, e.g. „eArztbrief“ (Electronic Patient Summary), successively fil the gaps
- rare evaluation of projects: only a few number run over into practice; projects are being promoted but rarely evaluated
- You should be able to buy 10, 20 or 30 SNOMED CT codes, which you need for the Electronic Patient Summary for finally solving that issue for Germany.

    - again, you have the chicken-egg-dilemma: We don't do that, because we don't have the license, and since we don't have the license, we cannot get any empirical evidence.
- here, the IHTSDO doesn't show any cooperation: no free usage for selected value sets
- the IHTSDO is like an extraordinary restaurant, which is unfortunately not situated at a main street, but at a side street. That is why it is widely unknown. The restaurant could offer free appetizers at the main street in order to win new customers. But what IHTSDO is doing is that they even sell these appetizers for a certain sum. This is not the way it should be.
- the IHTSDO should change the pricing: instead of a "all-or-none"-policy, they could offer a free use of up to 100 codes/ concepts

8.6.4 Remarks/ conclusions

- The disadvantages of SNOMED CT are neither its quality nor its applicability, but its licensing which is wrongly perceived as too complex
- Thus, the first step: Overcoming the license barrier
- More Communication and Promotion of SNOMED CT-benefits
- in 2035 even the last one will recognize that SNOMED CT should have been introduced already in 2010
- more empirical evidence of SNOMED CT's benefits
- more terminologists or terminology experts
- concretion of SNOMED CT project design: scope, size, time frame
- solving legacy system problems
- concrete recommendations of action
- most of the discussion today was too vague
- concretion of scenarios and operational areas (use cases)
- we have to distinguish between evidence for benefits in Germany and in the European Union. In the EU you'll find many success stories that underline the benefit of SNOMED CT. Those are absolutely transferrable to Germany and therefore there is no need to imploringly look for German benefit projects.

8.7 Netherlands

8.7.1 Focus group organization

Facilitator

Hans van Belleghem, independent consultant and owner at Twist

Focus group composition

Name	Organization	Role	Note
Ronald Cornet	AMC Linköping University	Visiting associate Professor@Linköping University Assistant Professor@AMC	ASSESS CT participant
Huib ten Napel	RadboudMC	senior researcher	head of WHO FIC NL
Renate Kieft	V&VN (Dutch Nurses' Association)	advisor	advisor for V&VN (Dutch Nurses' Association) on classifications and standardized nursing language

Name	Organization	Role	Note
Felix Cillesen	Catharina hospital	Enterprise Information Manager	
Yvonne Heerkens	NPi - Dutch Institute of Allied Health Care	Program leader "terminology & technology"	
Pim Volkert	Nictiz	Coordinator at Terminlogy Center @ Nictiz Coordinator SNOMED CT National Release Center	ASSESS CT participant

Meeting(s)

Meeting 1 : 13th May 2015

8.7.2 Methodology

First, potential experts in the field of eHealth were identified and invited. Unfortunately due to time constraints the invited physicians were not able to attend.

According to the guidelines for conducting a Focus Group which was developed and agreed upon by all members of Workpackage 1, the questions were processed and prepared for the Netherlands Focus Group Meeting in May.

A PowerPoint presentation was used to depict the Assess-CT project and support questions.

The discussion was recorded with the help of a smartphone (voice) and the protocol was translated into English, revised as regards to content and sent to the participants for further revision and validation before going into the final draft.

8.7.3 Report

Hans van Belleghem, independent consultant and owner at Twist (facilitator)
Ronald Cornet – AMC & Linköping University; ASSESS CT participant (minutes)
Huib ten Napel – head of WHO FIC NL; senior researcher RadboudMC
Renate Kieft – advisor for V&VN (Dutch Nurses' Association) – on classifications and standardized nursing language
Felix Cillesen – Enterprise Information Manager Catharina hospital
Yvonne Heerkens – NPi terminology & technology (ISO 9999 & ICF);
Pim Volkert – Nictiz, Coordinator SNOMED CT National Release Center; ASSESS CT participant

Introduction by Hans van Belleghem

Pim & Ronald summarize the ASSESS CT project.

ASSESS CT has support from the owner of SNOMED CT, the International Health Terminology Standards Development Organization (IHTSDO), which is however not a partner in the project to enable ASSESS CT to be impartial. WHO is not a partner in the program. The only Standards Development Organization (SDO) involved is HL7.

Theme 1 – Current use of terminology

RIVM wrote a report on terminologies used in the Netherlands: Internationale classificaties in Nederland. Nut, toepassing en noodzaak (2011).

There is a lot of discussion about terminologies in the Netherlands, but their active use is very limited. For example, nursing terminologies NIC, NOC and NANDA are frequently discussed, but hardly used in Dutch practice.

ICD is one of the terminologies that are actively used for cause of death, and morbidity.

Distinction is needed between terminology systems used for unambiguous clinical registration and terminology systems used for classification purposes.

Reasons for use/intention to use terminologies are sometimes unclear.

4 categories: administrative (ICD-10); Clinical (LOINC); Reference (SNOMED); Interface (IMO; DHD Diagnoses-Thesaurus)

ICF is mentioned as a terminology system that is used in practice. Also ISO9999 is much used, among others by insurance companies for reimbursement, and by Vilans (a knowledge center regarding long-term care) for its overview of patient aids (Hulpmiddelenwijzer).

Terminology systems are complementary: interface, reference and administrative systems are ALL needed.

SNOMED CT aims to be a reference terminology. A drawback may be that many concepts have no (full) definition. It can be argued whether this is a large problem. Concepts such as hypertension or diabetes mellitus may be primitively defined, nonetheless they are clearly understood by clinical users.

It is recognized that internationally there are alignments, e.g., between nursing terminologies and SNOMED CT.

Still in many places work is done on paper, which does support limited forms of encoding of information, but which lacks the benefits that full-blown use of terminologies can offer.

Simple systems such as OMAHA are more successful than an elaborate system such as NANDA

Usability of systems is still low, clinicians use paper in many creative and very efficient ways

In the Netherlands, an interface terminology on SNOMED CT for capturing diagnoses is being gradually introduced. This is the DHD diagnoses-thesaurus. It is currently used in a few university hospitals, and does not yet cover all disciplines(currently 22 disciplines are covered), but it is expected that currently missing disciplines will be added during 2015. Furthermore validation of the contents and the mappings to ICD, DBC and SNOMED CT will be undertaken in 2015.

It is mentioned that in the United Kingdom in 2016 all GPs should use SNOMED; in 2020 all of healthcare should use SNOMED. It is positioned as the standardized clinical vocabulary for all care givers.

Summary:

There is a lot of talk about many terminologies, but there are few real implementations

Exceptions (terminologies which are broadly used): ICD, ICPC, ICF, DSM-5, ISO9999 (/GPH – generieke productcodes hulpmiddelen); all are classifications used for primary registration. Physicians do not use ICD-10, the medical coders do the coding.

Still in many places a lot of paperwork happens, limiting the adequate use of terminologies.

Various types of terminologies are needed: interface, reference, administrative

Mappings between terminologies are insufficient, it is a challenge to get those right

Various systems use their own language and their own ordering principles

Theme 2 – Benefits of a new terminology for registration of patient information

It seems to be a long shot…

The good thing about different systems is that they are used for different purposes, e.g., registration, clinical reasoning, guideline development, reimbursement, research, and for different types of information, e.g., disorder, procedures, targets, etc.

Benefits:

- Semantic interoperability between various care providers
- Secondary use: clinical decision support; care pathways; research

- Unambiguous reference for decision rules, quality indicators, etc.
- Reducing the number of systems EHR implementers (and care givers) have to deal with (UMLS: 177 sources; Bioportal: 447 ontologies)

Theme 3 - Barriers

In the Netherlands, the use of SNOMED CT has been promoted since 2007. From early 2008 to mid-2014 25 introductory courses were organized. This has mainly led to “indirect adoption”, for example in the DHD diagnoses-thesaurus. One domain that embarked on adopting SNOMED CT is that of optometrists. Furthermore, SNOMED CT is applied in definitions of datasets, for example the “generieke overdrachtgegevens”, i.e., generic data for patient transfer, and ColonIS, the Dutch colon cancer screening program. All these efforts have thus far not led to storage and use of SNOMED CT concept identifiers and their (formal) definitions.

Lack of mappings between various terminologies

Classifications work relatively well; using detailed terminologies is terra incognita

Quality of existing terminologies, including SNOMED CT, is an issue

Completeness over many sectors (e.g., allied health professionals, nursing) is an issue

There is no proof yet of adequate implementation of a system such as SNOMED CT. A pilot is needed to provide proof, at least proof of concept. Issues are implementability, usability, and quality and completeness of contents

The absence of a Dutch translation of SNOMED CT introduces a barrier for use in the Netherlands. Such a translation is needed, although it may not be necessary to translate “all of SNOMED CT”.

Maintenance of reference sets can be a barrier, as these need to be synchronized with the semi-annual release of new versions of SNOMED CT.

Theme 4 – Enabling factors

In the Netherlands, April 2013, the Dutch Federation of University Medical Centers (NFU) launched a program on Point-of-Care Data Capture. This program consists of 4 elements for 2013-2015:

- implementing uniform healthcare documentation
- obtaining buy-in from healthcare professionals
- facilitating standardized healthcare documentation
- increasing public awareness and transparency on use of healthcare data

Make interface terminologies available in Dutch. There is no need to start with translating all of SNOMED CT.

Proof of concept is needed to demonstrate how interface terminologies, reference terminologies and classifications interrelate

Good software supporting use of terminologies is needed.

Mapping the (structure and) content of registries to SNOMED CT will provide a stimulus for using SNOMED CT in clinical practice.

Provide mappings in ongoing projects, such as generieke overdrachtgegevens.

Theme 5 – Recommendations

Complement and correct SNOMED CT with those parts that are currently inadequately covered, such as allied health professionals, nursing, care & cure.

Perform a proof of concept demonstrating the effectiveness and efficiency of capturing and using data with SNOMED CT as a reference terminology

Extend the concept model of SNOMED CT to get more ontological rigor

Harmonization of data requests for secondary use is needed: clear definition of data elements and relevant values, with a limited number of value sets for each data element

Coordinate and provide guidance on the content for non-clinical use

Training and awareness raising on use and reuse of SNOMED CT

Conclusion

ADOPT, ALTERNATIVE, ABSTAIN?

Intent to ADOPT, but this requires proof, further development and mappings, and keeping classifications (ICF, ICD, ICHI, ISO9999) in place + LOINC for clear identification of data elements

8.8 Sweden

8.8.1 Focus group organization

Focus group invitations were sent out to individual stakeholders selected for having firsthand experience of terminology development, management, governance, or implementation and to cover the categories National terminology organizations, Policy makers, Vendors, and Terminology implementers. Eight participants accepted the invitation, but the vendor representative was at the time of the meeting not available. As it turned out, the focus group had a relatively strong representation from the Swedish national board of health and welfare. Also, the overall composition of the focus group would give the group some bias towards national projects as opposed to local implementation. However, at least for SNOMED CT, the major implementation projects are currently nationally driven.

The meeting was arranged in cooperatively with the organization of the Danish focus group. After the focus group session, a joint Danish-Swedish session was held to further discuss terminology implementation issues.

Facilitator

Daniel Karlsson, Linköping University, facilitated the focus group.

Focus group composition

Name	Organization	Role	Note
Ann-Helen Almborg	National Board of Health and Welfare	Classification implementer and developer	Implementer and developer of ICF and the Swedish national classification for social care interventions
Lotti Barlow	National Board of Health and Welfare	Governance perspective	Project leader for the Swedish SNOMED CT implementation project 2007-2011, Swedish representative of the IHTSDO member forum
Lars Berg	Nordic Centre for Classification in Health Care	Classification implementer and developer	Head of the Nordic Centre for Classification in Health Care, original developers of NSCP
Kristina Bränd Persson	National Board of Health and Welfare	Governance perspective	Head of department at National Board of health at the time of joining IHTSDO and during the initial SNOMED CT implementation project
Erika Ericsson	National Board of Health and Welfare	Swedish SNOMED CT	Developer of and daily responsibility for Swedish SNOMED CT

		NRC	extension. Swedish representative of the IHTSDO member forum
Britt-Marie Horttana	Swedish Association of Regions and Local Authorities, National Quality Registries, Örebro County	Terminology implementer	Leading the mapping of national quality registry information to standardized terminologies, including SNOMED CT and classifications
Rikard Löfström	Consultant	Terminology implementer	Project leader for the first national project implementing SNOMED CT in practice

Meeting(s)

The meeting was held in Copenhagen adjacent to the IHTSDO Business meeting on April 27 2015.

8.8.2 Methodology

The objectives of the focus group were adopted from objectives discussed in the work package, but the group was allowed to set the focus of discussion. The focus group meeting was recorded and transcribed verbatim for further analysis. The themes and example questions were shown to the focus group participants, but the participants were instructed to relate freely to those questions. At certain points during the focus group session, to ensure coverage of themes, participants were asked to summarize their opinions related to the specific themes.

While there was, and still is, some confusion around the word “terminology,” especially in relation to classifications, in the focus group, in this analysis the following words are used with the specified meaning. It is assumed that participants of the focus group would agree with the meanings but not necessarily with the words assigned to those meanings.

- Clinical terminology – terminology intended for use in the documentation of the care of an individual
- Classification – terminology intended for secondary purposes, with fixed groups including residuals
- Terminology – classification or clinical terminology

8.8.3 Report

Theme 1: Current terminology usage

While current SNOMED CT use is limited in Sweden, other terminologies have a long history in Sweden. Terminology is easier to implement and results are generally better in domains where there are already clear information requirements and existing structures. The most prominent Swedish examples are the national quality registries, with a history since the 1970ies of collecting structured health information for secondary use.

There is at the same time an increasing understanding of the need of structured and standardized care documentation, both on the side of the care providers and the side of users of coded information such as registry keepers. However, there has to be the right incentives for users or implementation will suffer.

The division between clinical terminologies and classifications is blurred in that classifications are widely used in the documentation of the care of individuals, i.e. as a clinical terminology. Also clinical terminology implementation projects make use of classification coded data as it is often readily available in health information systems. Still, there are clear differences between clinical terminologies on the one hand and classifications on the other: e.g. primary vs. secondary intended use, development agility vs. stability, details vs. groupings.

Some examples of current terminology implementation projects and/or usage mentioned by the focus group participants are:

- Coding of health documentation as to allow secondary use primarily by quality registries. SNOMED CT and classifications are used to specify content in national scope quality registries, of which there are approx.. 100.
- Reason for medication order - SNOMED CT plus Swedish extension is used to specify reasons for medication order nationally. [Not implemented yet, in development]
- "The Infection Tool" – SNOMED CT is used to code reasons for prescribing antibiotics. Implemented in routine practice.
- "Lifestyle information" – SNOMED CT and ICD is used for coding lifestyle information [in development]
- Coding of procedures for reimbursement, mainly based on coding of diagnoses and procedures using ICD and the Swedish version of the Nordic Classification for Surgical Procedures extended with non-surgical procedures
- Coding of care interventions using KVÅ and KSI, used for documentation for care of individuals in addition to use for reimbursement
- ICF categories are used as a structure for the mainly free text EHR.

Theme 2: Benefits of adopting new terminologies

The focus groups participants see the continued need to maintain usage of classifications, both for secondary and primary purposes, together with an increased use of SNOMED CT. They considered the need to harmonize SNOMED CT and the international classifications, with ICD 11 as a good example.

Central to EU is the mobility of both patients/clients as well as health services and products, e.g. health information systems. This cannot be done without standardization.

> *"How are they supposed to solve patient mobility directive at EU level if you allow everyone to do as they want."*

There is also a demand from the health care industry, including health care providers, the pharmaceutical and biomedical technology industry, etc., for enabling benchmarking of health results and this requires health information standards including terminology standards.

Theme 3: Barriers for extended terminology adoption and use

The focus group participants thought that the main barrier for extended adoption and use of standardized terminologies are the lack of good examples. There are currently very few good examples using terminologies to bring benefits to health care and although the number of national projects using standardized terminologies is increasing there is a need for having more such projects showing and explaining the need for structure in health information, learning from an being inspired by international examples.

> *"...you have to get some kind of concrete real example. And there are such examples but in English and not in Swedish. I mean, they're no less real than if they were in Swedish"*

Lack of essential competencies, both when procuring information systems and for users of the health information systems, is also a barrier. Also, health professionals need to be aware of the possibilities following structuring of health information, and this may happen only when the individual care providers see the practical benefits. There will almost certainly be resistance from health professionals because structure may mean more work, with benefits seen in other ends or in other places. Also, structuring information, maintaining the terminologies and doing the mapping is a significant amount of work.

> *"Those who depend on good quality of data should also have the knowledge of what is required of information management."*

Lack of governance is another barrier. Currently in Sweden it is perceived that not enough is centrally managed. Here, the EC may influence the situation in a positive way by making policy decisions.

> *"The problem's not that you do not leave freedom. The problem is that no gives an authoritative direction. Freedom and creativity we have no shortage of in the member countries."*

There is also a lack of coordination between different attempts at improving health care information structure. This is certainly also true for the use of classifications and clinical terminologies together.

Further, cultural differences between member countries are seen as a barrier that might be harder to address. There are differences in how the professional language is seen and how important it is to have a language specific inter- and intra-professional terminology as opposed to using English. Differences in health care culture, e.g. euthanasia, are an issue.

Often, the current situation is, if not perfect, at least acceptable by care providers.

> *"People feel that they 'have what they need because standards are not set higher' or 'it will be just fine as it is today' ... and 'the system I use does not have the capabilities so why should I bother. I'll call and talk to someone instead or I use the fax.' "*

Theme 4: Enabling factors for extended terminology adoption and use

As noted in Theme 3, a major enabling factor is to have good examples of terminology use, but other enabling factors are mentioned.

Easy access to terminologies is important to allow use of those terminologies. E.g. when a new web application for accessing SNOMED CT was provided it was seen as a barrier lifted. This depends on having licenses which enable use of the terminologies

Central decisions or other statements from stakeholders, e.g. as made by the Belgian physicians' society concerning the use of SNOMED CT or NHS England regarding terminology use, are seen as important.

That SNOMED CT and classifications are both needed and that they need to work together is stressed by the participants of the focus group. In order to coordinate this combination of classifications and clinical terminologies mapping is seen as important.

It is thought that IHTSDO and SNOMED CT as well as the international classification have quality assurance systems in place which are also seen as an important enabling factor for terminology use. In a purely national context, such systems might be hard to maintain.

Theme 5: Recommendations

The focus group participants thought that there really was no alternative to adopting SNOMED CT on the EU level, e.g. for the patient mobility directive but also to support an EU wide market for health IT solutions. Sweden has already made this decision on the national level.

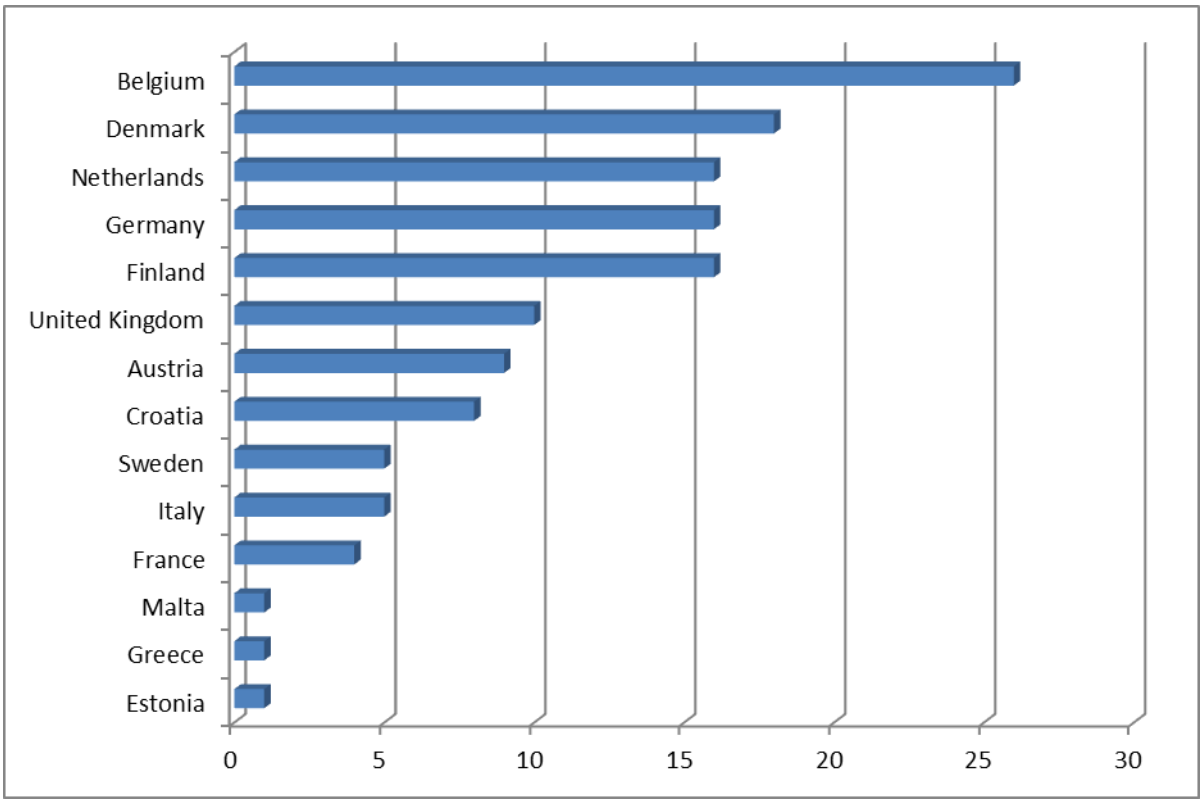
If there is a EU decision on health terminologies, the decision should relate to both SNOMED CT and other terminologies, mainly the international classifications. There is still a need to have terminologies for both clinical use and for secondary uses of health information.

Terminology work has to include work on information structure as well. It is not sufficient to only consider terminologies but the terminologies in their information structure context.

9 Annex 2: All stakeholder questionnaire

This report is based on the **136** responses gathered before the July 9th 2015, coming from **14 countries** have been collected, so distributed:

Figure 22 Completed Responses per Country



At the time of publication of this document responses from Luxembourg have been received. Additional answers from the other European countries are expected to be received as well. They will be processed and documented in a second stage and integrated in the final deliverable.

Hereafter is provided a report of the questionnaires received, according to the structure of the Country Overview questionnaires.

9.1 Your contact details & About your role and experience with terminologies

This section provides an overview of the characteristic of the stakeholders that participated to this survey.

Figure 23 shows the percentage of participants per country, Figure 24 the primary language of respondents.

Figure 23 - Stakeholders per Country

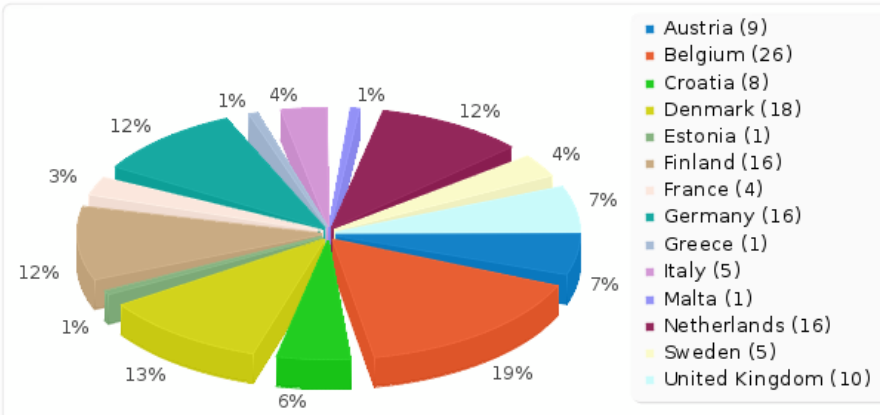
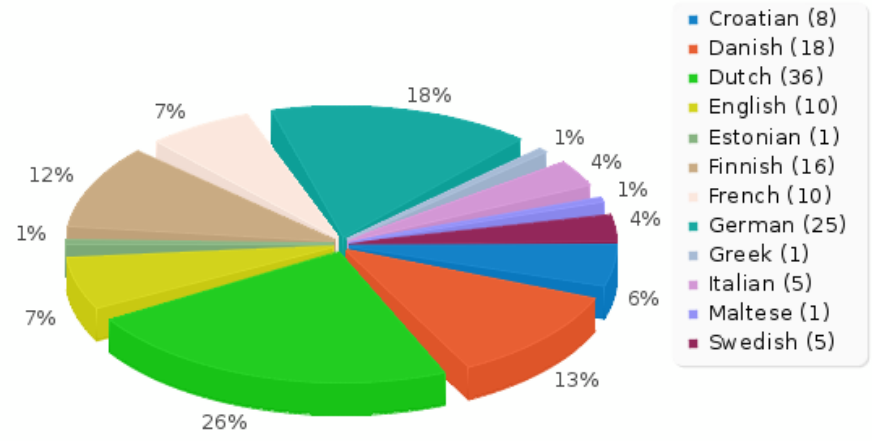
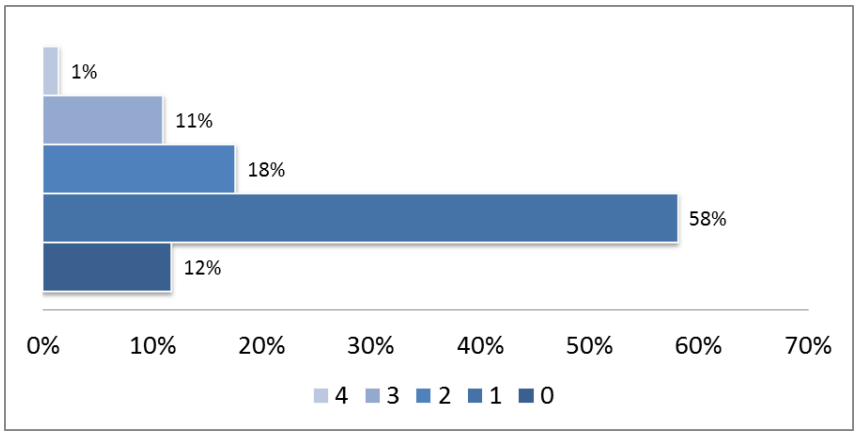


Figure 24 - Primary language Stakeholders



The 88% of respondents claims secondary languages, Figure 25shows the distribution per number of languages known.

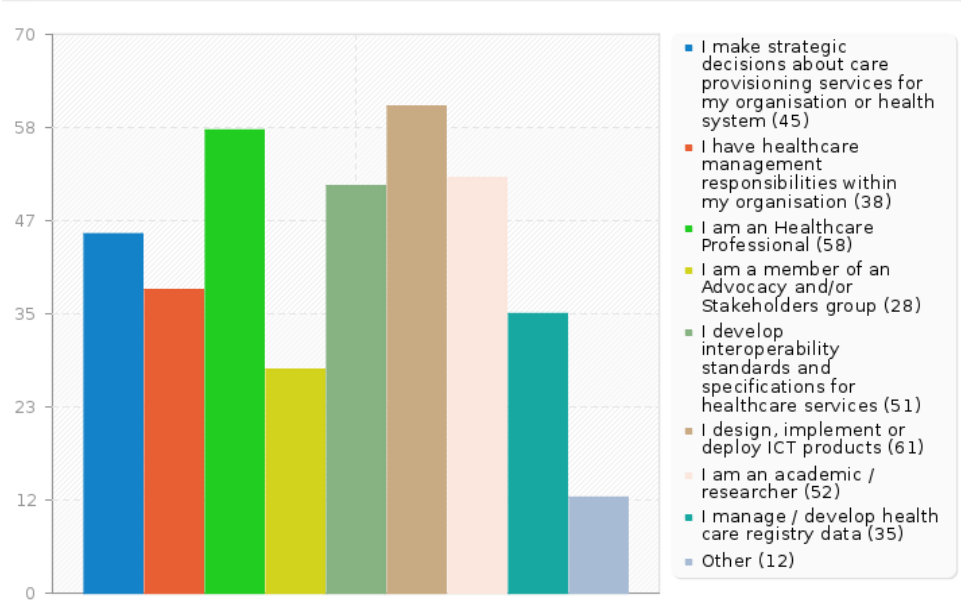
Figure 25 - Number of secondary languages of the Stakeholders



9.1.1 How would you classify your role(s) in healthcare

A good coverage for all the identified roles has been achieved, with a little prevalence of Health care and ICT professionals and a minor, but still significant number of members of advocacy groups.

Figure 26 Stakeholders roles in healthcare

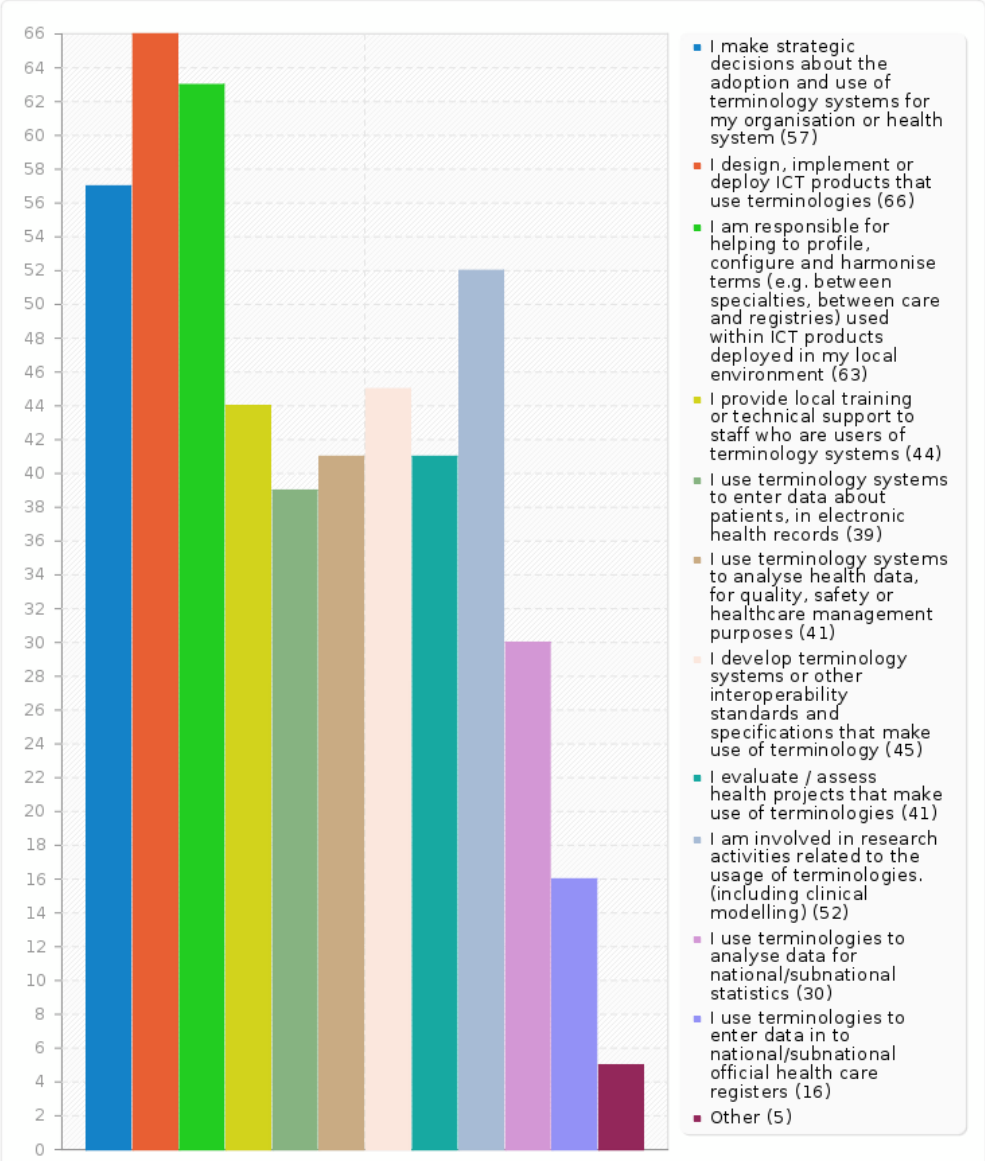


Most of the role indicated as “Other” could be easily remapped into one of the classes already identified. Hereafter the details:

- Strategic Adviser
- Information specialist
- presidency of TC215 at Croatian Organization for Standardization
- biobank development
- I have responsibilities within disability services
- Policy advisor
- member of groups who makes decisions about documentation
- Quality assessing ICT products
- Business developer responsible for helping to profile, configure and harmonize terms used within ICT products deployed in my local environment, who also takes part in moving my organization towards structured and standardized EHR content.
- IHE-NL user chair
- Medicines regulatory agency information management
- director of several healthcare IT businesses

9.1.2 With respect to terminologies, how would you classify your role(s)?

Figure 27 Stakeholders involvement with terminologies (questionnaire)



Also for the type of stakeholder involvement respect to terminologies a good coverage for all the identified classes has been achieved.

Even in this case most of the “other” responses could be remapped in one of the existing classes. Hereafter the details:

- I consult on cost benefits and feasibility
- Translation of terminologies
- I participate in specifying EHR system requirements and improvements, and in developing strategies for health record content management within my organization for the purpose of attaining a higher level of standardization and structure.
- I manage a company that undertakes health data transformation
- I'm involved in WHO and IHTSDO activities

Please provide more details about your involvement with terminologies, including which ones you use

The table below lists the details about stakeholder involvement with terminologies and how this related with the provided classification.

Legend:

[1] I design, implement or deploy ICT products that use terminologies
[2] I am responsible for helping to profile, configure and harmonise terms (e.g. between specialties, between care and registries) used within ICT products deployed in my local environment
[3] I provide local training or technical support to staff who are users of terminology systems
[4] I use terminology systems to enter data about patients, in electronic health records
[5] I use terminology systems to analyse health data, for quality, safety or healthcare management purposes
[6] I develop terminology systems or other interoperability standards and specifications that make use of terminology
[7] I evaluate / assess health projects that make use of terminologies
[8] I am involved in research activities related to the usage of terminologies. (including clinical modelling)
[9] I use terminologies to analyse data for national/subnational statistics
[10] I use terminologies to enter data in to national/subnational official health care registers

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Focus on SNOMED CT, linking to some local (interface) terminologies. Mainly research, geared towards practical use.	□	□	□	□	□	□	□	□	□	□
Responsibilities as an expert in the national design and implementation and alsi onternational collaboration	□	□	□	□	□	□	□	□	□	□
I'm part of a software engineering team that develops, tests and deploys computer assisted coding tools that make use of natural language processing and ontologies for ICD-9, ICD-10, OPS, SNOMED CT, LOINC and ATC. SNOMED CT is part of the Health Data Dictionary (HDD),an extensive metathesaurus maintained by our US Terminology Services team.	□	□	□	□	□	□	□	□	□	□
ICD-10-WHO, ICD-10-GM, OPS, ATC, LOINC, UCUM, OCD-O, ICF, GMDN, eClass, Snomed CT	□	□	□	□	□	□	□	□	□	□
ICD10 OPS SNOMED	□	□	□	□	□	□	□	□	□	□
ICD 10 Selecting IT tools for coding	□	□	□	□	□	□	□	□	□	□
IHE, EFA	□	□	□	□	□	□	□	□	□	□
Responsible for the Italian MeSH translation. Responsible for the Italian Thesaurus in Bioethics	□	□	□	□	□	□	□	□	□	□
I am involved in mapping terminologies to classifications	□	□	□	□	□	□	□	□	□	□
progress notes/problem list design and evaluation. ICD-10, SNOMED CT,	□	□	□	□	□	□	□	□	□	□
I use ICD9 and ICPC for research in the Primary Care setting	□	□	□	□	□	□	□	□	□	□

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
- working in TC215 - Medical Informatics education at University School of Medicine (medical students at graduate and postgraduate level; nurses at undergraduate and graduate level)	□	□	□	□	□	□	□	□	□	□
At the moment we use terminologies developed in-house for recording personal health information. Our diseases table is based on ICD-9 I believe	□	□	□	□	□	□	□	□	□	□
I am a member of the board that makes decisions about terminologies used in Finland. In my organization i am responsible for ICT projects.	□	□	□	□	□	□	□	□	□	□
I am developing a shared, harmonised data base for clinical data that ia availalabe for researchers and clinical administration	□	□	□	□	□	□	□	□	□	□
I develop a SNOMED CT based Danish drug terminology. I develop a national clinical decision support system that uses SNOMED CT widely.	□	□	□	□	□	□	□	□	□	□
SNOMED CT teaching- and research-activities	□	□	□	□	□	□	□	□	□	□
Responsible for organisation´s patient safety register data, Responsible for developing specified classifications in my organisation, Researcher in the area of informatics (classifications, data structures), Member of national terminology development group.	□	□	□	□	□	□	□	□	□	□
- teaching terminologies to medical and computer science students for many years - studying terminologies theoretically - implementing lots of tools for terminology-based structured data entry, enabling interoperability and data analysis in student degree theses and research projects.	□	□	□	□	□	□	□	□	□	□
DIMDI is developing, maintaining and publishing teminologies and classifications for all kinds of health data (diagnoses, procedures,drugs and pharmaceuticals, medicinal products and many more) As well DIMDI is involved in scientific support for strategic decisions in Medicinal Product safety decisions (Aktionsplan AMTS), the development of databases and applications for medicinal Products (PharmNet.Bund), the use of databases and applications providing Medicinal Product information, the development of Medicinal Product Dictionaries in Regulatory in Europe (EUTCT) and many more projects involving terminologies and standards	□	□	□	□	□	□	□	□	□	□
development of Danish Municipaliti subsets for use in nursing home care (situation/status/condition - work)	□	□	□	□	□	□	□	□	□	□

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Information of the functioning and disability of individuals is needed in numerous purposes in social and health care. Hundreds of outcome measures are in use, many of them without evidence of validity and reliability. In 2007, based on a broad collaboration of partners in research and clinical institutions, a national network TOIMIA was formed. The network aims at improving the quality of the measurement and harmonizing the measures and terminology. I am running the terminology groop..	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I am involved in the development of a new laboratory information system for HUSlab, and especially for the Division of Pathology. We need to implement a new terminology system for our new LIS. I amd also involved in mas sceeening programs for the prevemtion of cervical cancer, in collaboration with the National Mass screening and cancer registry.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I help to implement Epic system in Capital Region & Region Zealand in Dk. Used terminologies: Coded Epic terms, SKS, IUPAC, NPU, SNOMED CT. Train staff to use and understand the bennifits of using standardized terminology in the EHR.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Portavita is member of HL7, IHE and supporter of CIMI. We have a Snomed license and implement it in our international Integrated Care Systems. We are SaaS supplier and also help our customers to use the data for analytics.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I teach to both engineers and medical doctor some issues about terminology and related standards in Medical Informatics. I design and develop ICT products that use terminologies. Specifically, my software automatically collect data from EHR to feed local/subnational repositories for clinical trial reasons.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
As projectmanager for several national health registers I promote and use all available standards to automatically fill the register and re use the primary health data. Always use standards for terminology (SNOMED/LOIINC..) and infrastructure (CDA/XDS)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Collaboration with national authorities concerning national terminologies and classifications Maintenance and updating classifications Collaboration with international bodies like Wonca / WICC	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I support the adoption of standard terminologies when possible - Terminologies such as SNOMED are suggested in meetings and stakeholders in health. currently am supporting the attendance for the Foundation Course.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Use on daily basis in our companys system	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I am the technical responsible of the LOINC Italia workgroup, which develops and manages the Italian version of the standard LOINC since 2010. I am also involved with terminologies related to the disease condition of the patient (i.e. ICD)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
As a policy maker we try to convince health care parties to make information standards and agree upon which terminologies to use in order to be able to exchange information between Healthcare providers	□	□	□	□	□	□	□	□	□	□
I am responsable in the hospital for de service that now codes everything in de dossiers in ICD 10.	□	□	□	□	□	□	□	□	□	□
Have been making tools and sytematic use of it inn all units in a hospital. Guidelines and documentations match.	□	□	□	□	□	□	□	□	□	□
GP Guard software developper	□	□	□	□	□	□	□	□	□	□
Was ibnvolved in integrating terminologies into EHR systems in the 90's, clinical statements as well as drug database development and usage.	□	□	□	□	□	□	□	□	□	□
Evaluating the suitability of medication and patient data and the underlying defintions and coding for the detection, documentation and prevention medication-related problems. Project partner in the evaluation of the "Federal patient focused medication plan" Project Partner in the development and evaluation of CPOE/CDSS systems with a focus on Medication safety. Project Partner in the intersectoral communication of patient and medication data.	□	□	□	□	□	□	□	□	□	□
We are manufacturer of a HIS called 'myMedis' / 'cHMS'. We use ICD and OPS catalogs for documentation, grouping and billing of patient cases, and offer reporting for a variety of medical and financial aspects. Billing involves esp. German DRG, PEPP, ZEs, BPflV and some private billing variants. Lots of the billing is triggered by OPS documentation. ICD and OPS is also used for quality assurance as defined by §137 SGB V. We use LOINC as part of CDA doctors' letters.	□	□	□	□	□	□	□	□	□	□
- Using terminologies to develop ICT able to detect adverse drug events/reactions - using terminologies to standardize and to operationalize drug information for computing drug knowledge in clinical ICT -research about British Drug Extensions in Snomed CT for use in German healthcare systems	□	□	□	□	□	□	□	□	□	□
Development of EHR based on SNOMED CT	□	□	□	□	□	□	□	□	□	□
Participation in terminology development, evaluation and selection of interoperability standards including terminologies, decisions and reports on the use of terminologies	□	□	□	□	□	□	□	□	□	□
-	□	□	□	□	□	□	□	□	□	□
I promote the use of terminology systems in general. In case of radiology I promote the use of Radlex	□	□	□	□	□	□	□	□	□	□
With my backgroud as a health professional I use classifications and Snomed CT in order to standardize the input into information systems	□	□	□	□	□	□	□	□	□	□

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. Within my hospital: implementing diagnoses and procédures in SNOMED CT 2. In the frame of the research project Imediate ("Interoperability of Medical Data through Information extraction and Term Encoding"): SNOMED CT expert	□	□	□	□	□	□	□	□	□	□
I develop a decsion support system which supports the use of multiple classifications and terminolgoies and which maps terms from supported terminologies into an internal vocabulary of concepts that are then used to refer to various clinically relevant concepts and used to build decision support rules. I regularly use search engines for various terminologies to find relevant codes to map to new concepts related to new decision support rules being developed. I use ICD-10 and ATC (and some Finnish national coding systems) on a daily basis in clinical work and also during ICT development activities. Other coding systems I use more infrequently during ICT development are LOINC, SNOMED CT, READ, ICD-9.	□	□	□	□	□	□	□	□	□	□
Swedish National Release Center for SNOMED CT	□	□	□	□	□	□	□	□	□	□
I help for developing systems to increase healthcare quality in primary healthcare multidisciplinary teams: from data registration to decision support system and communication purposes.	□	□	□	□	□	□	□	□	□	□
I have designed an original method to offer semantic interoperability within an health information system and with his ecosystem. The method has been implemented within an hospital information system and deployed in more than 100 hospitals in France. Binding of concepts to terminology is one part of this.	□	□	□	□	□	□	□	□	□	□
I am the lead for Snomed CT based use and applications.	□	□	□	□	□	□	□	□	□	□
I develop tools to manage and align reference terminologies (such as Snomed, Loinc, NABM, Meddra, who-art,CIM-O,...), use them to annotate structured ou unstructured resources and therefore facilitating interoperability in e-Health systems.	□	□	□	□	□	□	□	□	□	□
Text Mining solutions: indexation of documents, similarity, categorization	□	□	□	□	□	□	□	□	□	□
Also reviewing Swedish national IT-message standards, which include subsets of terminologies for specific fields.	□	□	□	□	□	□	□	□	□	□
From my sub-role of Product manager for eHealth solutions in IN2, I'm involved in designing Healthcare IT systems and implementing them on both, national and health intitution, levels. Since almost all products today have data exchange functionalities in the scope, terminologies are a must.	□	□	□	□	□	□	□	□	□	□
Fimea deploys international standard terminologies in our systems and data repositories and disseminates them further on to national healthcare systems and service providers.	□	□	□	□	□	□	□	□	□	□
I am clinical lead in developing an information sharing platform across multiple healthcare enterprises in South Devon.	□	□	□	□	□	□	□	□	□	□

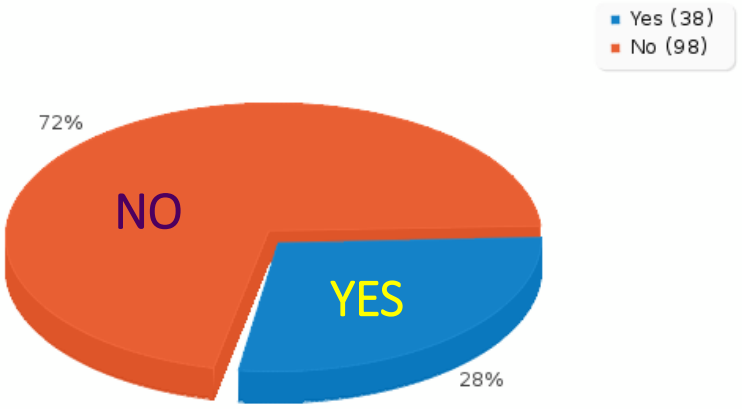
See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
One of my companies is directly involved in the processes of NHS health data extraction, migration and transformation. As such we are daily handling OPCS-4, ICD-10 and to a very limited extent Snomed	□	□	□	□	□	□	□	□	□	□
Deployment of data models that have embedded terminology	□	□	□	□	□	□	□	□	□	□
Snomed CT I am chair of the technical committee of the UK Professional Record Standards Body for health and social care (PRSB), which is responsible for assuring the processes used for developing technical artefacts based on PRSB clinical standards. This includes the use of terminology, but our role is reviewing the development process not the detailed content of the artefact specification.	□	□	□	□	□	□	□	□	□	□
We develop and implement terminology servers	□	□	□	□	□	□	□	□	□	□
I'm responsible for the design, implementation and quality assurance of UKTC interoperability products that allow data coded in READ2 to be translated to CTV3 (and vice versa) as well as from READ2 or CTV3 to SNOMED CT. I frequently use READ2, CTV3, SNOMED CT, OPCS, ICD10, ICD-O and occasionally use UICC and ICPC-2.	□	□	□	□	□	□	□	□	□	□
As member of WHO-FIC network: I'm involved in the development of ICD-11 (on the IT side, including experimentation of prototype tools based on it), on the revision of ICF, and very lightly on ICHI. As member of the WHO-IHTSDO JAG: I'm involved in the ICD-11 SNOMED CT harmonization process.	□	□	□	□	□	□	□	□	□	□
SNOMED CT (evaluation), MeSH, UMLS, ICD-10, Austrian Procedure Catalogue (for coding health interventions), ontologies (e.g. Gene Ontology, Human Phenotype Ontology), ...	□	□	□	□	□	□	□	□	□	□
ICD 10 ATC ICPC2	□	□	□	□	□	□	□	□	□	□
I only use ICD-10-CM and PCS.	□	□	□	□	□	□	□	□	□	□
Harmonised terminologies are a key element in health care registers. Use of same terminologies for same disease is required to allow for national and international comparison of data.	□	□	□	□	□	□	□	□	□	□
On behalf of the Austrian Ministry of Health, I have been responsible for the development of a terminology that enables the collection of data from the ambulatory care sector in Austria. The code system is based on the French CCAM.	□	□	□	□	□	□	□	□	□	□
PLEASE NOTE THAT THIS A SUPPLEMENT TO MY PREVIOUSLY SUBMITTED QUESTIONNAIRE. I HAVE ADDED A COMMENT TO THE QUESTION "What would you personally believe to be the possible risks, constraints or challenges with adopting SNOMED CT in your organisation ?"	□	□	□	□	□	□	□	□	□	□

See the Legend above	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
I'm collecting data about deaths in hospital care in order to get statistical analysis and promoting quality researches. I'm coupling death's analysis with RHM recording wich uses ICD10 CM and PCS and is part of hospital's funding in Belgium. I'm interested in SNOMED for its future implication in health recording systems and specially for its use in Digital Patient Record.	□	□	□	□	□	□	□	□	□	□
member of IHTSDO Dental SIG	□	□	□	□	□	□	□	□	□	□
I am responsible for taking clinically relevant information and developing them into clinically appropriate data formats for Cerner's Population Health Management Solutions. Day to day tasks include mapping and standardising locally coded content to Cerner defined terminologies and a range of standard terminologies and classifications including SNOMED CT, ICD-10 and LOINC. I also worked on several NHS implementation projects developing algorithms that query the patient record system and identify patients based on SNOMED CT, ICD-10 and locally coded data entered at the point of care to help facilitate clinical trials recruitment. I also analyse Cerner data warehouse query tools which create powerful reports based on subsumption queries making use of SNOMED CT's hierarchy and 'is-a' relationships.	□	□	□	□	□	□	□	□	□	□
I work on connecting terminologies with clinical models; ways of referencing terminology concepts, value sets, and constraining terminology use to ensure clinical safety. SNOMED CT, LOINC, ICDx, other nursing, ICF, ICPC, also HL7 vocabularies etc.	□	□	□	□	□	□	□	□	□	□
I do research on terminologies in order to implement software that provides good medical decision support. Only national Code-Systems can be used at present, as Snomed cannot be used in Austria. I used to work in the UK with Snomed CT and I am missing the connections (the semantic network) between information as the national code systems do not provide these connections	□	□	□	□	□	□	□	□	□	□
Code clinical findings using SnomedCT	□	□	□	□	□	□	□	□	□	□
select / propose the use of terminologies to be used in Greece as a stakeholder group member	□	□	□	□	□	□	□	□	□	□

9.1.3 Have you been directly or indirectly involved in cross-border healthcare activities (e.g. pilot projects or European support action projects dealing with the cross-border flows of patient information) ?

A relatively high percentage of those interviewed declared to have been involved in cross-border healthcare activities (just under the 30%): mostly of them through EU funded projects like epSOS, Trillium Bridge, SHN, PARENT JA, EHR4CR, EXPAND, but experience are not limited to those projects (e.g. INTERREG Italy-Slovenjia "Patient without borders").

Figure 28 Have you been involved in cross-border healthcare activities (e.g. pilot projects)?



Projects Involved
epSOS, EXPAND, Antilope, eHGI
I've contributed to the specification of the Common Terminology Services Interface specification in the EpSOS project.
epSOS
epSOS; Expand; eHealth Network;
PARENT JA
Carewell project
organizing congress on interoperability (ISHEP)
epSOS
BBMRI, EHR4CR, Epsos, ECRIN
interoperability of the European clinical biobanks (bbmri.eric collaboration)
epSOS
EpSOS
across municipality borders
When holding national position as head of national classification unit, supervising EpSos work packages.
Epsos, ePrescription Guideline, ISO IDMP (ISO 11615, 11616, 11238, 11239)
We are involved in European innovation projects (EU FP7) on big medical data and IOT solutions. We were the first to implement Snomed in a Nictiz project in The Netherlands.
ALCOTRA - CALIRES
indirectly in ePsos.
Communication standards for passing patients across borders between primary and secondary healthcare
interreg
AIM project 1994 (?)
* Reviewer of epSOS * MedShare * Liverdoc * HITCH

Projects Involved
* Antilope
DACH-Terminologie Workshops
PSIP
epsos, ehealthMonitor
Indirectly: epSOS, Trillium Bridge, Antilope, many different networking activities.
Radlex Structured reporting in Radiology
PSIP project 2007-10
ADR PRISM (French Government Funding) which aims at providing pharmacovigilance professionals with a source of information heretofore unexplored outside some rare studies conducted by research teams: patient discussion forums. The VIGITERMES project (ANR funding) which consist firstly in guiding information retrieval and access to available resources and secondly, in improving signal detection in pharmacovigilance.
Fimea has monitored European cross-border prescription initiatives and pilots (epSOS).
epSOS, Trillium
EU-US Interoperability project; Continua Health Alliance; SMART-on-FHIR platforms
Semantic HealthNet
PARENT SemanticHealthNet
epSOS
INTERREG Italy-Slovenjia "Patient without borders", Telemedicine WG
When I used to work for a multinational German Software Company we were researching for THE ultimate code system for medication, diagnoses, allergies, Lab-values etc. to be able to provide medical decision support on all plattforms in all countries.
epSOS, Trillium Bridge, EXPAND, Stork, Calliope, Antilope, etc

9.1.4 From your knowledge and experience of the cross-border exchange of patient data, what are the main limitations or problems with the currently available terminologies?

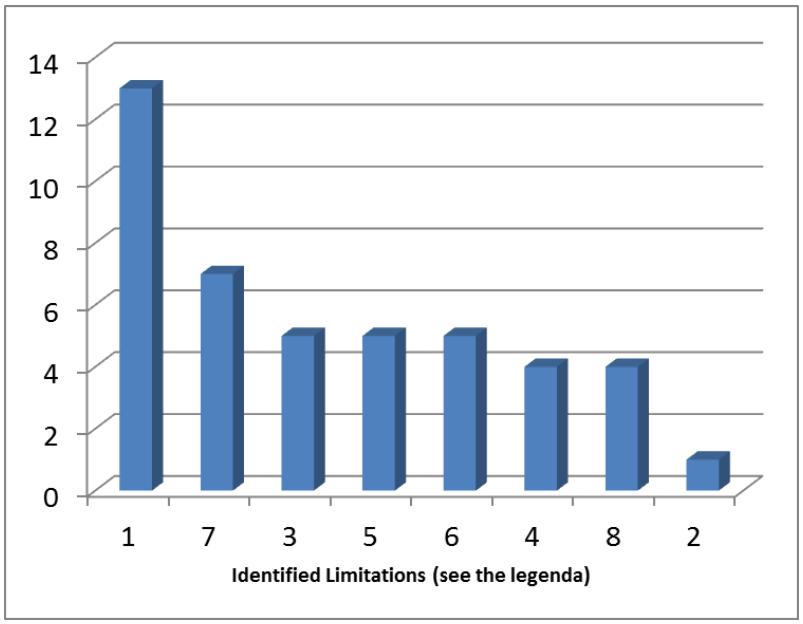
About the 30% indicated limitations of current terminologies in supporting cross-border patient data exchange (responses have been reported hereafter).

A set of classes of limitations have been therefore derived from the provided answers. Responses have been classified according to this classification (see table below):

- Lack of **common/reference** terminologies
- Need to **combine** several terminologies
- Issues with **mapping** to local terminologies
- Issues with **licensing** terminologies
- Need for **translations** that do not exist yet
- Lack of **good quality structured and coded** data (in the source EHR systems)
- Inadequate terminology **strategies and policies** (including legislation)
- Lack of common information models

As displayed in the figure below the most frequently mentioned issues is the lack of a common/reference terminology (label “1”) followed by Inadequate terminology strategies and policies (label “2).

Figure 29 – Frequency of the identified limitations for the cross-border exchange of patient data.



Legend: [1] Lack of common/reference terminologies; [2] Need to combine several terminologies; [3] Issues with Mapping to local terminologies; [4] Issues with Licensing terminologies; [5] Need for translations that do not exist yet; [6] Lack of good quality structured and coded data (in the source EHR systems); [7] Inadequate terminology strategies and policies (including legislation); [8] Lack of common information models

Main Limitations	Occurrence of the identified limitations (see the legenda above)
Interoperability does not exist. Sharing data can not be done on data level.	
The most important limiting factor for cross-border interoperability is the absence of a standard or reference terminology with a granularity that permits unrestricted and precise mapping to regional, country specific terminologies. Extending the domain coverage in a consistent and timely manner is the greatest maintenance challenge for such a standard terminology.	1
licences translations national extensions politics	4,5,7
The fact that in many countries unstructured and uncoded practices exist. Furthermore the lack of a broadly available coding system all over Europe.	6,1
Organisational	7
Interoperability, bridging current to new ones.	

Main Limitations	Occurrence of the identified limitations (see the legenda above)
1. ICD-10 is used in most countries in Europe but does not give enough information on patient's problems (e.g. no therapies) 2. ICPC is usable in PHC (gives also medical procedures), but not used in many countries, even in Croatia is not mandatory 3. many data (e.g. anamnesis, status)are in free text format - language dependent 4. format and content of EHR/EMR is not standardized	1, 6
1. Primary data is unstructured 2. the data structures are unharmonized, even at the national level 3. When primary data uses a standardized terminology, there is no natural language support (mapping from lay/professional terms to standard terminology) 4. The semantic and logical structures of the available terminologies do not correspond to lay/professional thought models 5. Different terminologies in different countries/languages	1, 6, 8
key terms should be able to translate to any European language which does not apply to all terminologies used	5
in many countries - the codes are either missing completely (only descriptive data available), - they use national codes that are extremely difficult to map with the international codes, - or they use different version of international codes	1, 3, 6
The lack of a common drug terminology made epSOS choose ATC codes for the exchange of substances. This made combination drugs a problem since ATC doesn't express these precisely enough. Also the fact that ATC has many codes for one substance is a problem.	1
legislation	7
that decision-makers lack knowledge and skilled manpower to invest in new infrastructure and in re-engineering the existing systems	7
- uneven use of structured data between different countries (including also classifying process quality) - lack of unified descriptions when using codes - no unified classifications	1, 8

Main Limitations	Occurrence of the identified limitations (see the legenda above)
- Terminological gaps - License restricted terminologies only available for some countries - Countries use different terminologies/ classifications - Missing international classification of procedures - Missing mappings/cross-tables, m:n mappings between national and international classifications and terminologies - Missing translations of international terminologies - Necessity for combination of multiple terminologies (e.g. even Snomed CT is not enough to describe drugs unambiguously) - Drug representation (strength, dose form, package size…) - Different standards (e.g. strength is used differently in some European countries) - Unique identification of medicinal products (active ingredient, sub ingridients, combinations…) - Missing european/international catalogue of medicinal products - Different use cases require different granularity or different presentation of data (for Medicinal Products: Regulatory, Reimbursement, Drug safety aspects) - National legal requirements in health care are different across Europe, so terminologies can only be the " common denominator", creation of extensions (to add national specifics) and subsets (form Europe to National requirements) will be necessary. - Limited access to electronic Versions of Terminologies (EDQM Standard Terms)	1, 2, 3,5, 7
If a potential country does not have a licence it is not clear	4
In this specific Project there was no direct use of terminology standards and we had to apply extra-work to interpreter data	
multiple Languages	5
The doctors use different terminologies, ICPC to ICD-10	1
lack of standard and interchangeability	8
* quality of data entry * absence of a fully agreed "meta thesaurus" * competing terminologies or rather coding systems * absence of structure more especially in Snomed : difficult/impossible to hook decision support at the correct level of granularity * too much focus on clinical statements, medication and lab * not enouh focus on clinical signs and procedures * no briidging between the health professions	6, 1, 7
Akzeptanz, Entscheidungsstrukturen, keine Transparenz	
none that I know of	
their clinical fitness, localized availability, low degree of familiarity at stakeholders, lack in implementation experts for ICT systems	1
Difficulty of use in daily practice	
time consuming for who am I doing this the unfamiliarity with terminology there is more than one. not able to chose	1, 7

Main Limitations	Occurrence of the identified limitations (see the legenda above)
lack of a European terminology on medical devices and procedures (ICHI not yet operational)	1
Mapping of different terminologies is a challenge which has not been solved so far.	3
From our point of view lack of consistent and validated European data on active substances and medicinal products is a problem for cross-border healthcare.	1
Incomplete, outdated	1
Specialist knowledge requirements, not user friendly, not complete, slow to update	
As far as I know, the UK has had only limited involvement with epSOS or Trillium Bridge. Primary care Read codes are the predominant terminology in the UK as other care sectors make minimal use of terminologies. Although Read codes are subsumed by Snomed CT, this poses a significant limitation. Other countries use wholly different systems such as LOINC or national proprietary standards.	
Attempting to solve very difficult issues e.g iso-semantics as a pre-requisite to getting started.	
we need mapping and translation to normalize terminologies across europe	4, 5
Some are very standardized and translated but also with very specific use cases (ICD in particular). There is not an internationally agreed standard for healthcare procedures. SNOMED CT might have almost everything, but is so large that is very difficult to translate it in minor languages like Italian.	1, 5
For every domain you need to map to the national code-system: diagnoses: icd-10 at,ge,who ..., ICPC-2, medication: PZN-de,PZN-at,hospindex,INN, ... allergies: nothing or proprietary Lab-values: looots of proprietary names	3
transcoding, existence and prevalence of national versus international terminologies,limited use Snomed due to IPR limitations and cost.	3, 4

9.1.5 What would you suggest as the ideal solutions or approaches to overcome those problems?

About the 30% suggested ideal solutions in supporting cross-border patient data exchange (responses have been reported hereafter).

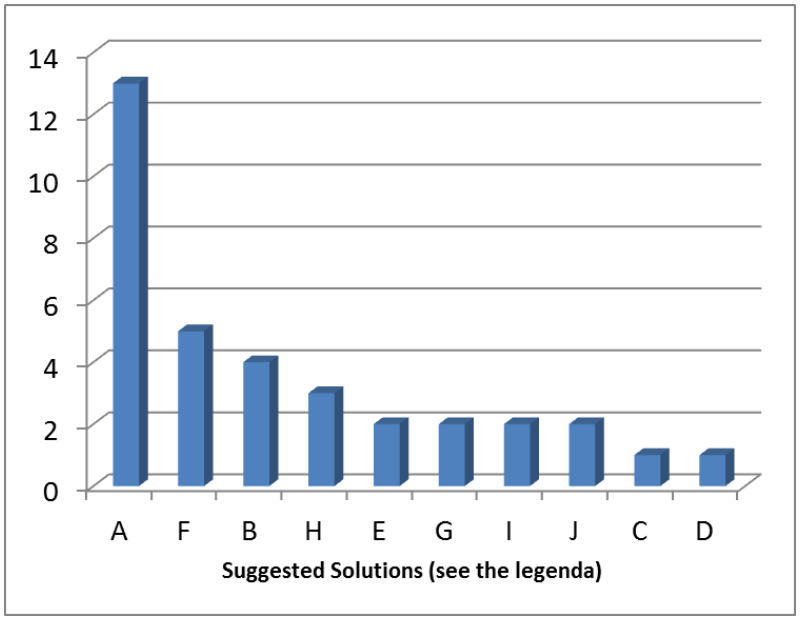
A set of classes describing possible types of solutions, approaches to be adopted for overcoming the identified challenges have been therefore derived from the provided answers. Responses have been classified according to this classification (see table below):

- Availability of a **centrally curated reference terminology,** allowing local extensions
- Availability of **Mapping** to local/national terminologies
- Reduce License Costs

- Availability of **translations**
- Provide support for Multi-Terminologies environment
- Enforce the usage through suitable Policies and Legislations
- Change Management processes
- Increase cooperation among organizations and experts, learn from existing experiences
- Education
- Improve the EHR-S capabilities for facilitate the end-users activities

The most favored proposed solution for overcoming those problems was the adoption of a centralized European reference terminology, for which SNOMED CT may be the most appropriate solution (label “A” of the figure below). This combined with suitable policies and legislations (label “F”), availability of mapping (label “B”) and increased cooperation among organizations and experts. (label “H”).

Figure 30 – Frequency of the suggested solution for the cross-border exchange of patient data.



Legend: [A] Availability of a centrally curated reference terminology, allowing local extensions; [B] Availability of Mapping to local/national terminologies; [C] Reduce License Costs ; [D] Availability of translations; [E] Provide support for Multi-Terminologies environment; [F] Enforce the usage through suitable Policies and Legislations; [G] Change Management processes; [H] Increase cooperation among organizations and experts, learn from existing experiences; [I] Education; [J] Improve the EHR-S capabilities for facilitate the end-users activities

Suggested ideal solutions or approaches	Occurrence of the identified limitations (see the legenda above)
For those tasks that are identified as cross boarder issues, a common standard has to be and "mapped to national termonologies"	A, B
Adoption of a centrally curated reference terminology that allows decentralized, customized country and enterprise extensions by all countries involved in the cross-border exchange.	A
laws and recommendations	F

Suggested ideal solutions or approaches	Occurrence of the identified limitations (see the legenda above)
Agree upon a common coding system, and have national extensions and translations	A, B
Resource building and change management projects followed by eHealth projects	G
Better cross functional cooperation in HC organizations, more experts included.	H
define (internationally accepted) standardized medical terminology which should include definitions of disease/status (like MeSH), drugs (like ATC), and medical procedures in all of medical specialties; coding of such terms could be of use	A
Natural language mapping by big data and artificial intelligence	
to find a root terminology to which essential terms (for care) and terminologies may be mapped	A
one shared nomenclature that is - regularly updated, electronic version with high coverage - translations into different languages available - mapped to many other ontologies - SNOMED CT is the best at the moment	A,B, D
Use SNOMED CT's drug hierarchies. The exchange of a SNOMED CT product code would remove the problems of ATC and remove the necessecity of many other classifications used i epSOS (UCUM for units etc)	A
Common legislation in EU on exchange of (health) data across national borders as well as local / domestic legislation in this area.	F
research projects in collaboration between universities and national governance bodies to identify the presence and nature of the problem	H
- possibly (when thinking the large scale) an EU based classification server which distributes the classifications/ terminologies used - Snomed CT could solve issues but is challenging to develope (economical restraints)	A
- Fill terminological gaps (missing concepts, missing terminologies) - Solve terminological constraints in existing terminoloigies (e.g. unique identification of medicinal products) - Reduce license and cost barriers, best would be, if terminologies were freely available - Enhance accessibility (e.g. INN, edqm) - Stimulate development of missing international classfications/terminologiese, e.g. ICHI - Stimulate development of international/European drug database - Analyse results of international interoperability projects to improve available terminologies - Transparent and open Change Management process and an expert board covering expertise in different fields of expertise (Regulatory and Health Care). - Allow extensions for specific use cases (for National Extensions)	A, C, G, H
Only look at the country of origin of the supplier! It will help spread Snomed	
Use of standardized SOA based application like CTS2	

Suggested ideal solutions or approaches	Occurrence of the identified limitations (see the legenda above)
A Language eg English should be adopted as a reference version, through the use of a graph data model the different languages can point to the same term within the reference language.	
Use same terminology, or, have transcription system. Is already build in primary healtcare	A
standardisation	
$ extended metathesaurus * multi-coding done by the applications * integrated ontologies to support appropriate coding * context registration * signs and findings, measurements,...	J
Die Analyse, Entwicklung und Pflege in die Verantwortung einer Organisation legen.	
- ban the usage of paper-based technologies in healthcare (no kidding!) - align software industry to use common terminology standards by law (like market registration for drugs - framework of terminology standards in the medical devices act)	F
Education, user friendly user interface design, terminology services integrated with everyday use of systems, synonym dictionaries, personalization of data entry in systems, context sensitive use of value sets	I, J
users need benifits structured data entry if not time consuming gives better quality of documentation and the possibility also for a user to (data)mine 'their' data	I
Adopt a multiterminology approach currently, there is not a single terminology able to handle all the medical complexity	E
to have a centralized and specialised authority and to adopt a standard terminology	F
Building and maintaining a central database (being planned in the European Medicines Regulatory Network ICT development roadmap).	A
a central managed and translated terminology authority	F
Pre-associations of terminologies to useable document objects such as form fields in CDAs	
Snomed CT, if global licensing and usability can be adequately resolved.	A
Just get on and use e.g SNOMED CT to record values of key data points with minimal use of post-coordination	A
Look at the epSOS conclusions	
National interface terminologies possibly mapped to SNOMED CT, even covering only subsets of the whole terminology.	B, A
Snomed everywhere for everybody	A

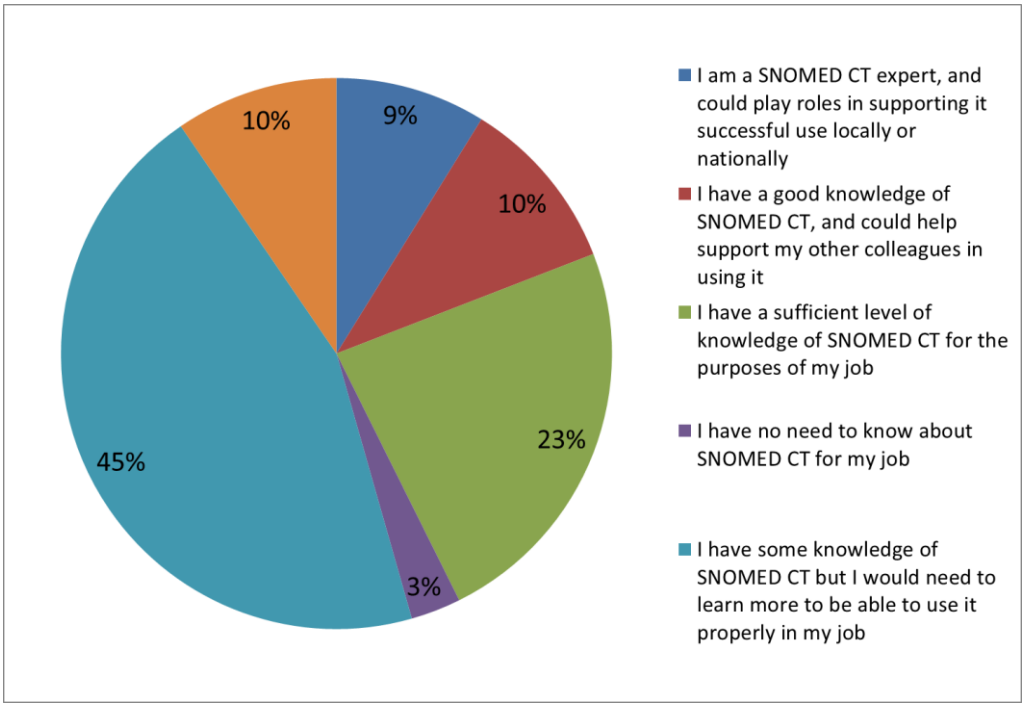
Suggested ideal solutions or approaches	Occurrence of the identified limitations (see the legenda above)
propose an international set of terminologies to be adopted with a pan-european licence to enhance free access to terms from EU Member States, with central maintenance and consultation processes.	E

9.2 Your views on the use of terminologies

9.2.1 How would you rate your level of knowledge about SNOMED CT for the job roles you indicated above ?

In order to profile the perceived level of knowledge of SNOMED CT of the respondents, and indirectly how SNOMED CT may impact the their job it has been asked to rate the level of knowledge about SNOMED CT for the job roles indicated. About the half of people believe to have some knowledge and that it would be useful to learn more to be able to use in their job. It is interesting to compare this result with the fact that training and education is indicated as one of the enabling factors in the country overview questionnaire

Figure 31 – How stakeholders rate their level of knowledge of SNOMED CT.



Hereafter the list of comment associated to some of the responses

How would you rate your level of knowledge about SNOMED CT for the job roles you indicated above. Comment	
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	Since our country is a non memeber, there is no way to explore and learn the terminology

How would you rate your level of knowledge about SNOMED CT for the job roles you indicated above. Comment	
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	very basic knowledge
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	Not being a health professional (my basic background is math) but as the medical informatics educator I need to explain the basic concept of standardization in medicine and healthcare, different classifications/terminologies etc. to my students
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	Yet,I would like to learn more
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I'm not a terminolog, but has a fine understanding of SNOMED CT to classify input data in health IT systems
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	It is difficult to rate own knowledge.
I am a SNOMED CT expert, and could play roles in supporting it successful use locally or nationally	Starting about 1985 with early versions of SNOMED I continuously dealt with studying and using SNOMED in diverse projects. Theoretically and more or less actively I was involved in the further develepments (specific in Germany) and in the logic-based migration to SNOMED CT internationally.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I am responsible for strategy
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	Specific interests in microbiological tassonomy
I know almost nothing about SNOMED CT, although it is relevant to my job	The following answer option is missing: I simply do not know if SNOMED CT is relvant or will become relevant as I do not know it's features.
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	I agree that international used terminologies would facilitate data exchange and research. Until now, in Germany Snomed isn't relevant for billing and we have no current requests from our customers to include Snomed for other reasons, so I will follow Snomed related discussions, but I believe we'll include this only if any of our customers wants this and is also willing to pay for the efforts put into implementation.
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	partake in e-learning course
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	The availability and size of the terminology have been limiting factors and since no direct projects related to Snomed CT have been carried out there has not been any real reason to learn more

How would you rate your level of knowledge about SNOMED CT for the job roles you indicated above. Comment	
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	Need to learn more to be able to further contribute to strategic decisions and EHR system requirement specifications. Need to learn more to use SNOMED CT for everyday tasks and supporting colleagues in doing so.
I know almost nothing about SNOMED CT, although it is relevant to my job	I need it as soon as I am able to use it in daily practice. The software systmems that I use now doesn't help me in adopting
I am a SNOMED CT expert, and could play roles in supporting it successful use locally or nationally	1. Within my hospital: implementing diagnoses and procédures in SNOMED CT 2. In the frame of the research project Imediate ("Interoperability of Medical Data through Information extraction and Term Encoding"): SNOMED CT expert
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I do not have a firm grasp of the technical details of more advanced concepts, such as what are allowable forms of post-coordination or how canonicalization works.
I know almost nothing about SNOMED CT, although it is relevant to my job	I don't know if it is relevant.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I know very deeply Snomed 3.5 and can be considered an expert about it.
I have a good knowledge of SNOMED CT, and could help support my other colleagues in using it	I am more an ontologist than a terminologist.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	Evaluation of the Text Mining solutions using SNOMED
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	Expect to learn even more in the future.
I have some knowledge of SNOMED CT but I would need to learn more to be able to use it properly in my job	Unfortunately, penetration of any terminologies into Member States legal framework is almost zero, and ICT projects suffer from that by having to justify use (and initial cost) to the client.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I am principally involved in strategic decisions regarding the development of our health IT software and thus do not need a detailed level of knowledge about Snomed
I have a good knowledge of SNOMED CT, and could help support my other colleagues in using it	I tend to learn a bit more when I need it, I do not have expert knowledge.
I am a SNOMED CT expert, and could play roles in supporting it successful use locally or nationally	I've been a member of one IHTSDO standing committee or another for the last 8 years.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	SNOMED CT is not used in Austria ... I had a special research interest in SNOMED CT. This is why I received a research license for it and used it to assess the quality, proplems ...

How would you rate your level of knowledge about SNOMED CT for the job roles you indicated above. Comment	
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	I am a Medical Documentalist by Profession and know about SNOMED CT because of this specialised education. I do not need this knowledge regularly, but have made use of it as a documentation expert, who has been asked for expertise in the question whether or not Austria should implement SNOMED CT.
I know almost nothing about SNOMED CT, although it is relevant to my job	I have theoretical knowledge without sufficient practice
I have a good knowledge of SNOMED CT, and could help support my other colleagues in using it	I am a registered SNOMED CT Implementation Advisor after completing IHTSDO's 2013/2014 SNOMED CT Implementation Advisor Scheme in 2013/2014.
I have a sufficient level of knowledge of SNOMED CT for the purposes of my job	SNOMED CT, from a technical use perspective appears to be changing significantly, and although I am an ex standing committee member, I am probably out of date on various aspects.

9.2.2 According to your knowledge, what are the international terminologies used in your country for the exchange of health and social data? If possible briefly indicate also in which context they are used

ICD 9, ICD 9 CM, ICD 10 (with or without local modification), ICD 10 CM, ATC, ICPC have been the most frequently mentioned terminologies. Classification (reimbursement) purposes the most cited context of use.

In the following table the International terminologies indicated by stakeholder for each country.

Member State	International terminologies used in your country for the exchange of health and social data
Austria	HL7, ICD-10, ICD-O, TNM
Austria	ICD (for diagnoses information)
Austria	ATC ICD-10 KAL - Derivat of CCAM in austria
Austria	ICD-10. There is no international terminology used countrywide which refers to procedures or medications. Some institutions (health insurances) use ATC.
Austria	ICD-10, ATC (partly).
Austria	ICD-10
Austria	ICD-10 (Austria) ICPM (partly) SNOMED CT (partly)
Austria	ICD-10
Austria	ICD-10

Member State	International terminologies used in your country for the exchange of health and social data
Belgium	ICD-9
Belgium	icd9 ; 2015 transition to icd 10
Belgium	F.e MKG (medical data) & MVG (nursing data)
Belgium	ICD-9
Belgium	ICD 9 ICD 10
Belgium	ICD9
Belgium	None
Belgium	ICD-10 in secondary or tertiary care ICPC-2 in primary care
Belgium	ICD 10, PCPS , ICD ONCO
Belgium	ICD-9/10 ICPC2 NANDA-NIC-NOC
Belgium	ICPC2 and ICD10
Belgium	* ICD-9-CM, ICD-10, ICD-1AM (superior) * ICPC2 * ATC, National Drug Code (package)
Belgium	ICD-9&10,IBUI,ICP2
Belgium	ICD9 CM, ICD10 CM and PCS, ICDO WHO, ICPC2
Belgium	ICD-10 for registration of hospital data
Belgium	ICD-9-CM and ICD-10-CM, ATC in the context of healthcare financing and reimbursement, ICD-10-WHO and ICPC-2 in the context of clinical continuity of care and data registry
Belgium	ICD-9, from 2015 ICD-10
Belgium	ICD-9 for DRG purposes. Cancer data registers.
Belgium	ICD9, ICD10 - ICPC-2
Belgium	any
Belgium	ICD-10
Belgium	ICD-10 is used since 01/01/2015. Is not realy a terminology in the sense of SNOMED. Before ICD-9. The health care governement is looking to start with the introduction of SNOMED
Belgium	ICD-9, soon switch to ICD-10
Belgium	ICD10 CM/PCS is actually mandatory for hospital stays recording in order to provide funding for general hospitals WHO ICD10 (CIM 10) is used for regional and national death's statistics
Belgium	in dentistry none
Croatia	ICD10, DRG, ATK for drugs, Microbiology Test Result Name ...
Croatia	ICD coding
Croatia	ICD 10, ATC, rarely SNOMED

Member State	International terminologies used in your country for the exchange of health and social data
Croatia	ICD - 10, ATK codes for drugs, from the perspective of Health Insurance fund we use mostly ICD-10 codes for the purposes of DRG system and the analytics of certain indicators
Croatia	ICD-10, ATC
Croatia	ICD-10
Croatia	ICD-10
Croatia	HL7 CDA level 2 and RIM are used from modelling national eHealth system documents. Lower level systems (e.g. hospital infromation systems) don't use anything.
Denmark	ICD-10 (+local codes) NPU SNOMED CT ICF NCSP
Denmark	ICD-10 (disease registration in the national database) ATC (drugs) ICF (Evaluation of function) ICPC2 (General practise)
Denmark	using ICD10 classification for registration og diagnose, procedure and operations codes in health it. SNOMED CT is'nt used very much. Few systems has it incorporated
Denmark	ICD-10 ICPC NPU SNOMED CT
Denmark	ICD10 (sort of) NPU (sort of) SnomedCT ICPC (sort of)
Denmark	hopefully in the future for both - that's the plan
Denmark	ICD10, Snomed, Iupac, Snomed CT
Denmark	To exact data to clinical databases and for nationale registrers. To pay the organisation for the services to the patients - DAG.
Denmark	SKS NPU IUPAC SNOMED CT
Denmark	ICD-10 and some national terminolgies in some part also ICF
Denmark	Exchange of data is primarily done using codes from the SKS classification which contains a number of international terminologies - ICD10, parts of Snomed CT, ...
Denmark	DRG, SKS, SNOMED CT, (VIPS)
Denmark	ICD-10
Denmark	We use ICD-10
Denmark	SKS classification
Denmark	SKS

Member State	International terminologies used in your country for the exchange of health and social data
Denmark	All used in epSOS
Estonia	SnomedCT, Loinc, ICD-10
Finland	ICD-10, ATC, ICPC2 NCSP, registries and EHR:s some parts of Loinc (modification) in EHR:s ICF, research, development Old versions on SNOMED in pathology
Finland	ICD-10, ATC, etc.
Finland	some epsos snomed in pathology
Finland	many coding systems
Finland	ICPC2- the reason for the appointment ICD10- diagnosis
Finland	I have read about the system, used their web site, compared the system with other terminologies, but no experience in practise
Finland	WHO ICD-10, Nordic Classification of Surgical procedures, ATC-classification (anatomic therapeutic), ICP-2 (primary care), LOINC, Standardized international nursing classifications. ICF is on the development phase. Also some international-based measurement tools.
Finland	In the field of pathology it's variable - rather modified usage of "snomed" - WHO ICD-0 is commonly used in tumor pathology.
Finland	icf ..
Finland	SNOMED ICD10
Finland	ICD 10, ICPC, ATC Subsets of Snomed (Pathology)
Finland	Numerous, including ICD-10, ICPC, ATC, ICNP, MeSH
Finland	ICD-10 (doctors diagnoses, disease statistics), ICPC (doctors/nurses diagnoses), ATC (drug codes for medication lists), FinLOINC (subset/extension of LOINC, physiological measurements such as BP, weight, height).
Finland	European standard terminologies for medicines (EDQM, EUTCT).
Finland	ICD-10, ICD-O-3, SNOMED
France	ICD10 CCAM (French) LOINC MedDRA Orphanet for rare diseases ATC for drugs SNOMED International
France	ICD-10 french version. French national classification of acts. Drugs classifications. LOINC. Snomed 3.5
France	To my knowledge, these at least are used to code data records and annotate contents : MEDDRA, WHO-ART, LOINC, NABM, CIM-10, CIM-O, SNOMED CT, SNOMED 3.5, etc.
France	MESH SNOMED

Member State	International terminologies used in your country for the exchange of health and social data
	MEDRA
Germany	ICD-10-GM for monitoring individual and populational morbidity and mortality, OPS for determining healthcare services and G-DRG for economical monitoring, reimbursement and service level negotiation, LOINC for the standardized transmission of laboratory results, ATC for monitoring drug usage and consumption, HL7 value sets for transmission of information across hospital subsystems.
Germany	ICD-10-WHO (death certificates) ICD-10-GM (DRG) ATC (billing, statistics) gmdn (medicinal products) ICF Reha ICD-O cancer registries
Germany	UMLS - scientific projects LOINC - lab data NCIt - e.g. SDTM (lab data) CDASH
Germany	Icd10, Ops, Loinc
Germany	There are no international terminologies that are used by a number of organisations high enough to make any significant impact.
Germany	In Germany only few terminologies are mandated by the German regulation for the coding of some sort of data by healthcare providers, e.g. ICD-10-WHO, ICD-10-GM, OPS (for procedures), ICD-O-3 and TNM for oncology, ATC/DDD for drugs, etc., see http://www.dimdi.de/static/en/klassi. There are a few other terminologies like ICF, UMDNS (for med.products), etc. that might be used but for there is no official mandate. For these and other terminologies like Nursing (e.g. ICNP), LOINC, UCUM, SNOMED CT that are used in a few projects more or less successfully there is a strong hesitation to support teir use by some kind of offical governance.
Germany	ICD-10: recording of health data for all kinds of evaluations, reimbursement, quality and savety aspects, statistics ICD-O: for cancer registries ATC/DDD: drug information MeSH: for database indexing and multiple research purposes UMDNS: for medicinal products UCUM and LOINC: in use in some projects
Germany	ICD-10, ICPM, ICF
Germany	HR7 ICD10 MEDRA ATC PZN
Germany	ICD, LOINC, Sie kennen die Problematik. Einzelne Terms, Codetabellen etc. werden in HL7, IHE, DICOM etc. genutzt.
Germany	ICD and OPS for documentation, billing, quality assurance, prescriptions, doctor's letters
Germany	TA3-data, ICD-10,
Germany	LOINC, ICD-10, ATC WHO

Member State	International terminologies used in your country for the exchange of health and social data
Germany	what means "international terminologies"? This question is semantically imprecise! Germany uses e.g. ICD, but there are German modifications=localisations und therefore not really "international". The same with ATC (Anatomical Therapeutic Chemical Classification System)for pharmaceutical substances.Due to national modifications incompatible with ATC used in other countries an therefore a high-risk area in cross-border exchange of data when used for health provision.
Germany	ICD ATC MedDRA
Germany	ICD 10, OPS, LEP, NANDA, Allergies, HL7, Rosetta
Greece	ICD 10, ICPC-2, CPT, ATC or reduced subsets for those.
Italy	US NML Medical subject headings. Used for library catalogues, patient information databases and websites, research projects indexing.
Italy	ICD 9 CM 2007
Italy	Mainly, ICD 9 - LOINC - MeSH
Italy	ICD-9-CM is mandatory by law in the Hospital Discharge Letters. LOINC and ATC are going to be as such with an upcoming Government Decree about the national EHR. As far as I know, ICD-10 is strongly used in psychiatry and SNOMED CT codes are used in pathological anatomy. ICPC-2 is used among General Practitioners.
Italy	ICD for mortality (10) and morbidity statistics (9-CM), ICD9-CM for financial aims. ICF in many small and isolated contexts including School (after a call for projects from the Ministry of Education), labour and work placement (ICF Lavoro), rehabilitation, etc. SNOMED3 with regional dialects (...): pathology reports in most Institutes, and also sent to tumor registries. ICD-O-3: tumor registries. ATC: drugs. ISO9999: maybe not officially, assistive devices. DRG (based on ICD9-9-CM): reimbursement. I'm sure there is also something other.
Malta	only through Epsos and mapping of local vocabularies to Snomed - do not know the specifics myself.
Netherlands	DSM-IV and DSM-V ICD-9 & ICD-10 SNOMED CT ICPC-1, ICF, OMAHA
Netherlands	ICD-9, ICD-10 (payment and accountability) SNOMED small scale, experiments LOINC ICPC-1 Dutch version
Netherlands	Primarily ICD9 and 10
Netherlands	Icdo and icd and snomed
Netherlands	SNOMED ([some]hospitals), CINEAS (rare diseases), LOINC (pathology labs)
Netherlands	ICPC, ICD, ICF, DSM
Netherlands	icd9, icd10, snomed-ct, LOINC, ICPC,
Netherlands	SNOMED CT LOINC ICD-9

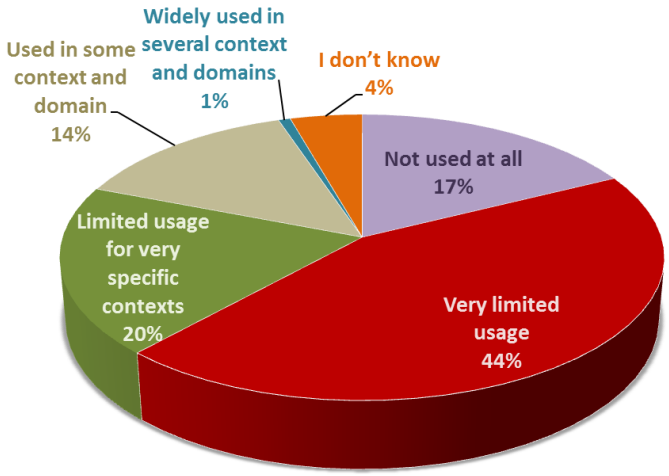
Member State	International terminologies used in your country for the exchange of health and social data
	ICD-10
Netherlands	ICD10 - diagnoses entered by physicians
Netherlands	Unfortunately to many different formats but new initiatives for exchange mostly on Snomed and Loinc
Netherlands	ICD, SNOMED, ICDO3, LOINC, FHIR
Netherlands	ICD10 LOINC ICF
Netherlands	Only one terminology, which is just at the beginning of being used: Snomed CT. Many different classifications, like ICD-10, ICPC-1, ICF, Omaha, DSM-V, etc
Netherlands	SNOMED CT Icd 10 Icd 9 Loinc (Radlex) DBC (DRG) DSM G-standaard
Netherlands	ICD-10
Netherlands	The following nursing classifications are used in the Netherlands: Nanda-diagnosis, Nursing Intervention classification, Nursing Outcome classification, Omaha-System, ICF. We would like to use SNOMED CT as a model not only to exchange nursing data across health care settings, as well as to collect nursing data at national level.
Sweden	ICD, ICF, etc, see http://www.socialstyrelsen.se/terminologi (Or ask Daniel Karlsson...)
Sweden	ICD, ICF, SNOMED CT.
Sweden	The internationl classifications are used extensively in Sweden. But they have limitations which are covered by Snomed CT. But the implementation of Snomed CT is slow and hampered by economic and structural restraints. Just now I am working on a national project aiming at stanardize reasons for prescription of drugs.
Sweden	ICD-10, ICF, SNOMED CT
Sweden	I'm not sure if all these are INTERnational, and not sure that list is complete: * A little Snomed-CT-SE, but slowly growing... * ICD-10 (and ICD-10 primary care codes) * ICF and ICF-youth subset * ATC for medications * [Swedish OID numbers for terminologi systems (and versions)] * NPU-code for lab * The Unified Code for Units of Measure http://unitsofmeasure.org/ * UDI-standard for some medical equipment/appliecies will probably come * Country codes: http://en.wikipedia.org/wiki/ISO_3166-1_alpha-2
United Kingdom	READ, SNOMED. We also use clincal codes including ICD10 and OPCS.
United Kingdom	OPCS-4 and ICD-10 with a very limited use of SNOMED
United Kingdom	SNOMED CT ICD (various)

Member State	International terminologies used in your country for the exchange of health and social data
	LOINC (in some devices)
United Kingdom	Snomed CT - dm+d (drug dictionary), used in electronic transmission of prescriptions ICD - hospital activity coding for payment and statistical analysis
United Kingdom	SNOMED, ICD, Read
United Kingdom	ICD-10 READ CTV3 SNOMED CT
United Kingdom	READ2, CTV3 and SNOMED CT currently co-exist in primary care, but data sent to the National Summary Care Record is only SNOMED CT coded. ICD10, ICD-O, OPCS-4 and to a lesser extent SNOMED CT drive secondary care. Data captured in secondary care is typically reported to the centre by means of abstracting it onto numerous dedicated datasets.
United Kingdom	Primary care: Read codes Secondary care: ICD 10 and OPCS 4.1 Mortality: ICD 10
United Kingdom	SNOMED CT and ICD-10 are the international terminologies used in the UK. SNOMED CT is being used to support the recording of clinical information, in a way that supports data management and analysis to support patient care, while enabling data extraction and data exchange. ICD-10 is a statistical tool that requires adherence to and application of specified definitions and rules to enable accurate, consistent and comprehensive capture of data for secondary purposes. ICD-10 is not intended or designed for point of care recording by a clinician.
United Kingdom	UK - READ, GP supplier terminologies, e.g. EMIS etc; some SNOMED CT. In research, many other terminologies.

9.2.3 How could you score the current usage of SNOMED CT in your country ?

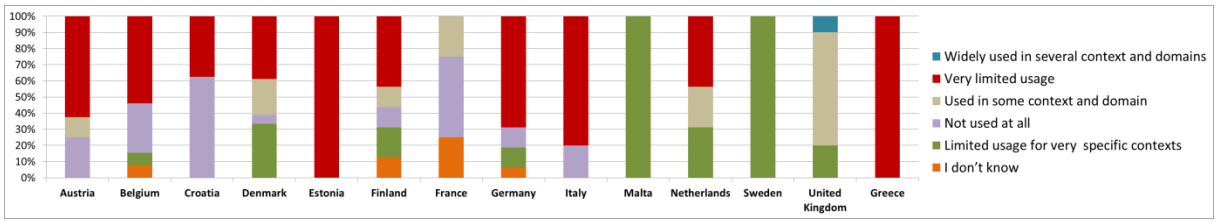
The large majority of respondents (> 60%) claimed that in their country SNOMED CT a very limited used or not used at all.

Figure 32 How could you score the current usage of SNOMED CT in your country?



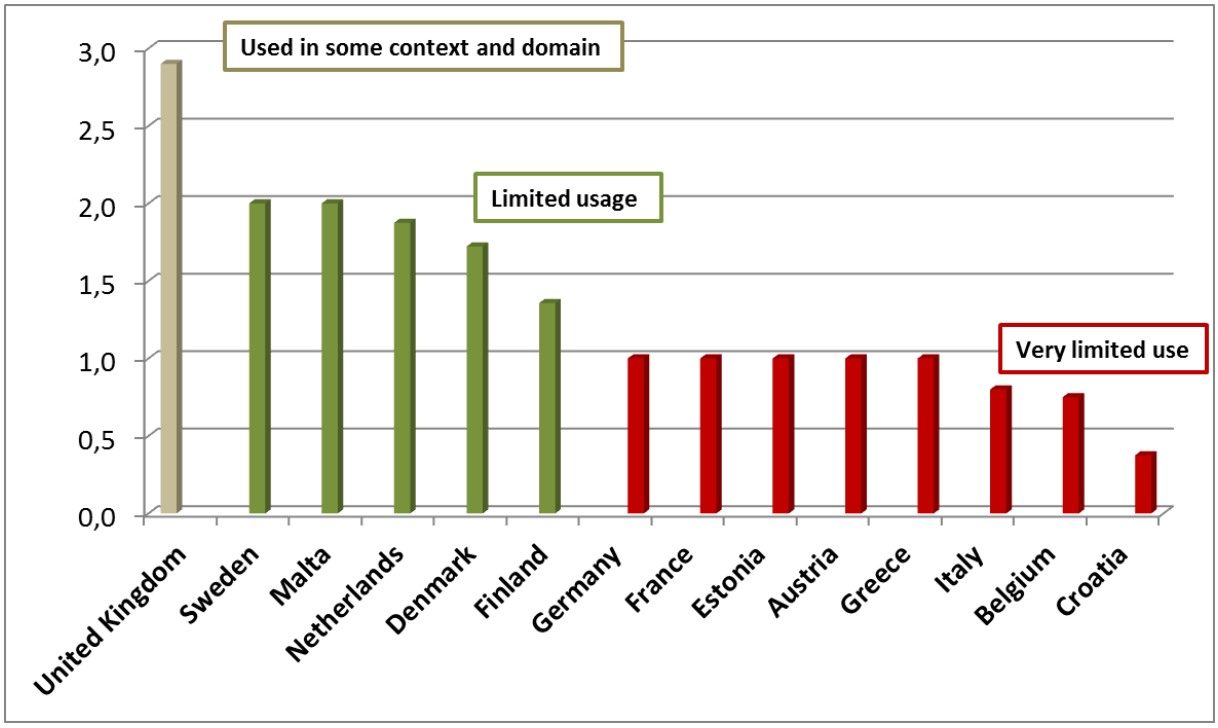
The following figures shows the same response distributing the answer per country, normalized (Figure 11) and as a mean score (Figure 12).

Figure 33 How could you score the current usage of SNOMED CT in your country? [normalized distribution]



The score has been calculated assigning an integer from 0 (not used) to 4 (widely used) to each class and calculating the arithmetic mean.

Figure 34 How could you score the current usage of SNOMED CT in your country? [mean score]



From this distribution we can identify three main classes of countries:

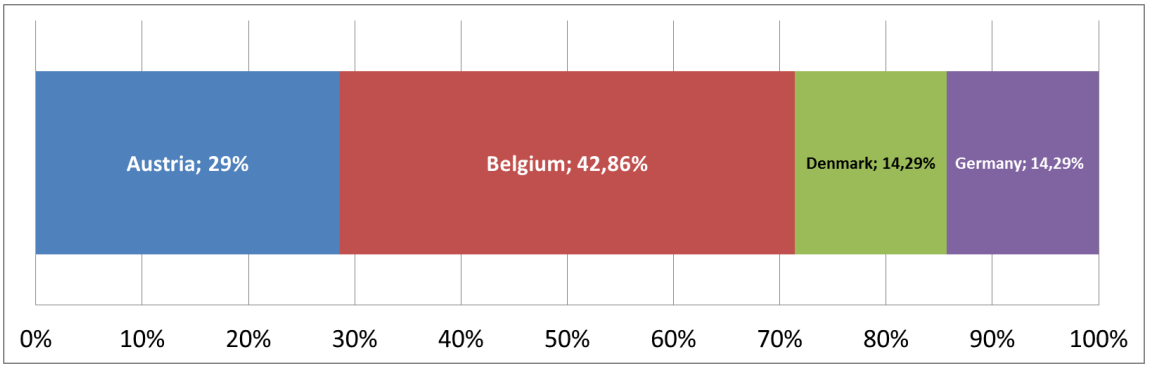
- non-IHTSDO member countries that have a very limited SNOMED CT usage (or less) [red]
- IHTSDO member countries like Denmark, Netherlands, Malta and Sweden in which SNOMED CT is limited used. Finland is border line between this two classes [green]
- And the United Kingdom (England) that is the only one for which SNOMED CT is substantialy used in some context and domain [gold]

9.2.4 What would you personally believe to be the main benefits of using SNOMED CT in your organization?

The 5% believes that there are no benefits (this percentage is almost recurring in all the questions related to SNOMED CT).

The following figure shows the distribution of the no benefits answers per country

Figure 35 Distribution of the "no benefits" answers per country



Only one comment has been added for this selection: *"Decision to implement ICD-10 is taken by federal government of Belgium. It has no sense to use two standards of classification"*

The complete list of responses has been included in the table below. These "main believed benefits" can be summarized into the following, non-orthogonal, classes:

- Improve the semantic interoperability for local/national and cross-countries exchange of health data.
- Improve the clinical documentation for structured EHR contents. (complete coverage of several domain, standardization of EHR contents, granular detailed terminology)
- Support for EHR contents translations
- Unification of EHR
- used to enable comparability for quality assessment and policy making for health care providers.
- facilitate, improve the extraction, the comparison and the reuse of information (non-redundant data capture, better data quality, cross organizational data integration) for several purposes [reference terminology]: registry; quality measures;medical decisions support; public health reporting; national and international benchmarking; research; "traceability across the patient trajectory"….
- Improve the patient safety
- Availability of description logic ontological representation of some medical concepts
- Improve efficiency, reduce cost (possibility of using "economies of scale in the expensive process of knowledge representation")
- Robust maintenance process (Strategic long term benefit)

Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
Austria	get easy access to value sets that are needed for structured clinical documentation, e.g. allergy documentation, microbiology studies
Austria	As SNOMED CT is a strong and comprehensive terminology, it could help to improve semantic interoperability in health care (e.g. health data exchange, EHR...) but also be used to enable comparability for quality assessment and policy making for health care providers.
Austria	Could be used for the European Patient Summary, but is not essential for it. Could be used for ELGA (health care record).
Austria	better medical decision support, better medication handling, ability to exchange coded medical information
Austria	standardized healthcare-data exchange not even between organisations in Austria, but also with other countries.
Belgium	probably very useful when broadly implemented
Belgium	standardisation of medical coding in patient files. This will enhance outcome studies.
Belgium	unique sense of medical concept --> measure activity, compare, follow procedure, finance impact (ratio cost/ revenue based on diagnosis). Clinical decision support. Snomed seems to be more "clinical" and less adminstrative in comparison with ICD
Belgium	SNOMED CT provides not only is-a relations, but extra relations make it possible to reason about data
Belgium	Especially useful for the coding of issuesnot provided by higher quality terminologies
Belgium	Standardization and portability. terminology more close to clinical language
Belgium	1. Within my hospital: implementing diagnoses and procédures in SNOMED CT 2. In the frame of the research project Imediate ("Interoperability of Medical Data through Information extraction and Term Encoding"): SNOMED CT expert
Belgium	registring clinical data, semantical interoperability
Belgium	As an initial benefit I see Snomed CT as the unifying source for configuration data specifying acts, events, etc... that are now rather sourced ad-hoc.
Belgium	ineteropperabilitie between care providers
Belgium	efficiency-safety-comfort
Belgium	structuring the EHR - standardisation - use of structured terminology to feed clin. decision support
Belgium	cleaner dokters notes and discharge letters. Universal language for diagnoses and procedures. Possibility to automaticaly deviate some diagnoses and procedures into ICD-10 codes
Belgium	standardization of terminology which will benefit benchmarking
Belgium	use of health recording systems directly by physicians is expected to build up a satisfactory Patient's Digital Record for internal use
Belgium	interoperability
Croatia	better insight into clinical practice for public health reporting
Croatia	Better follow up on actual usage of services, better control over costs, easier faster handling daily job for physicians, more time for patients.
Croatia	better data analytics from hospitals

Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
Croatia	Learning on SNOMED CT means learning on interoperability in healthcare, getting bases for development of standards in medicine/healthcare
Croatia	Better interoperability and data management
Croatia	Better interoperability
Croatia	Standardization, availability of data over different technologies and lower cost on IT maintenance.
Denmark	My organization is NRC for SNOMED CT. The organization does not really use SNOMED CT, but of course, we believe that there are benefits for better clinical documentation using SNOMED CT.
Denmark	My organisation is the National Release Center of SNOMED CT so we don't use it ourselves, but i believe that there are majoe clinical advantages to introducing it in practise.
Denmark	Better coding, code decision support, strengthening of relations across the code hierarchies and better use of data extraction for research, statistics and in time returned as evidence-based clinical decision support (in short time).
Denmark	Grouping/aggregation of concepts and artefacts that can be mapped to SNOMED CT.
Denmark	data registret as part af daily work, to be used for information, kommunication,exchange
Denmark	First the need to be national guidelines about SNOMED CT - and the reporting for the payment should link to SNOMED CT - or link between SKS to SNOMED CT. It is all about the money and national demands.
Denmark	Open standard - Interoperability between countries.
Denmark	Better retrieval of documentations for the patient, for the organisation and for reseach
Denmark	to be able to recognize, rediscover,recycle data for the use in patient trajectory and use of research
Denmark	Useful structure and depth in detail in different clinical use cases as documentaion in a patient record and dicision support
Denmark	Genfinde og genbruge data
Denmark	Think that it will be better in several ways. But, it is very expensive to change the modules that use terminologies in our systems, - all modules in the suite must be rebuild to get advance. And, you must be sure, that all necersary relations between Snomed CT codes are available, otherwise it is not usefull. Think that the relations are the only important difference form the system we have now in our company product. The core functionality are all 100% based on terminologies, on a monoaxial matter.
Denmark	possible to continue care from 1 unit/sector to another and make benchmarking and registration easyer
Denmark	Decision support. Rapporting
Denmark	better and more precise clinical documentation
Estonia	Granulated coding of clinical findings, ease to interoperate fith national discahrge letters' database (E-Health Foundation)
Finland	It could be used to map and tie together national coding and support international collaboration and modernize the termonologhy in the field of pathology

Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
Finland	-help in structurizing data -help in translating EHR systems -help in interoperability between national registries and localö EHRs -help in utilizing international knowledge (care pathways etc)
Finland	no spesific benefit for us but from national viewpoint there might be benefits
Finland	International benchmarking
Finland	definatively beneficial - makes clinical medicine international - more than ICD -could be part of decision support
Finland	Better quality in health records, ensuring patient safety
Finland	In the field of pathology (diagnostics) there is clearly need for common usage of terminology and coding both in epidemiological and personal (patient) health care reasons. It would also be essential for quality research purposes (ie common biobank database/ metafiles usages). Snomed is widely used in other scandinavian countries and to have similar coding system would be beneficial for in larger context (epidemiological research).
Finland	Harmonization of diagnostic work. Better statistics, resulting in better management of processes and operations as a whole.
Finland	Would make it possible to describe clinical concepts very accurately, in theory.
Finland	According to current knowledge using SNOMED CT would provide our organization with no major benefits.
Finland	Regularly updated list of cancers and other diseases that should be reported to the cancer registry.
France	if SNOMED CT will become free of charge (as MeSH, Orphanet, NCIT or LOINC), I think it has a great future to handle a lot of medical problems
France	It would allow to generate an ontological representation of some medical concepts.
France	to ease interoperability between different standard terminologies as using it as a pivot terminology to align between them with expected limitations though
France	A widely accepted standard with a significant coverage
Germany	The availabilty of SNOMED CT would enhance the development of user oriented clinical applications that leverage structured data entry, natural language processing of free text in the electronic patient record. Secondary data usage, simple and advanced data analytics would profit from standardized reporting and big data predictive modelling using common hierarchical concept structures.
Germany	interoperability detailed medical knowledge cost reduction
Germany	data export/reporting a lot easier data integration between different organisation MUCH easier non-redundant data capture
Germany	Interoperability

Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
Germany	One possible source for defining value sets for EFA / IHE metadata that would make usage of the sepcifications truly interoperable. I think the use of ANY commonly agreed on terminology would be more important than the question which one it is to be.
Germany	Apart from OBO ontologies with quite heterogeneous quality SNOMED CT is a profound, powerful, practical and relevant ressource available for teaching (e.g. "real" application of Description Logics) and research. The openess and transparency (enabled by IHTSDO) make it possible to criticize and improve structure and content continuously.
Germany	- semantic clearness of medical documenation - semantic interoperability between information systems - possibility for decsision support mechanimn
Germany	Dokumentationsqualität, "echte" medizinische Dokumentation
Germany	Our HIS in used only in Germany and Austria. ICD/OPS is mandatory for billing and sufficient for data analysis requested and implemented until now.
Germany	technically seen a lot of possible improvements in health data exchange processes and improvements for health information systems interoperability.
Germany	common terminology for research and studies; interoperability between IT Systems
Greece	SNOMED CT is extremely rich. two issues need to be addressed: 1. cost of use if a huge barrier 2. training and awarness activities needed
Italy	The main advantage is would be to share a common terminology.
Italy	A more integrated treatment of a complete set of terms
Italy	The chance to have a more structured and complete system to express the complexity of the clinical event; the cross-border interoperability since its large diffusion
Italy	I cannot tell about my organization of course, but referring the Italian situation, the FSE effort naturally asks for some underlying semantic interoperability support that could be easily SNOMED CT (or some unmanageable national effort with similar contents). From that, a secondary yet valuable result would be an easier coding of SDOs (and death certificates) through mappings.
Malta	Standardisation of Clinical Terms and the use of annotations to help non clinical staff to understand clinical terms
Netherlands	Multiple use of data, based on single recording with clinical detail.
Netherlands	Unification of EHRs Extraction of information out of EHRs (Quality Indicators, etc) Portability towards abroad
Netherlands	it enables exchange of information. It enables exchange of protocols, decision support systems across institutions.
Netherlands	Possibility ti use internationally
Netherlands	I see the benefit of the clinician using SNOMED to enter what he sees and does, for the clinical coder later to check whether this has been transferred into the correct ICD-10/11 codes and ICHI codes.

Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
Netherlands	standardization, exchange of data, clinical decision support, benchmarking, research, accountability
Netherlands	Better interoperability with other health care information systems. More complete coverage of diseases, surgeries, allergies etc.
Netherlands	standardization regarding exchanging data and (international) research. Ultimately leading to better patient care.
Netherlands	Re-usability in other countries.
Netherlands	Possibility to exchange and reuse data between systems by keeping the content reliable.
Netherlands	layman's translation of medical terminology
Netherlands	It will help in standardisation of registration between Healthcare providers.
Netherlands	structuring data, quality less errors financial obligation
Netherlands	SNOMED CT can support interoperability of nursing data.
Sweden	For the first time we'll get access to a granular detailed terminology system covering many areas of healthcare. Essential to structured EHR content.
Sweden	As a means of standardizing EHR content that are already structured or that are structurable. For an information producer: to specify what one's EHR content means. For an information consumer: to identify what information is received and specify what information is requested. SNOMED CT may be beneficial irrespective of implementation in EHR systems: as a tool for revising existing templates, headings, and fixed-value sets; as a basis for developing new templates etc.; as a common point of reference when contents and templates are shared; as a basis for setting up requirements for EHR systems that support structured content.
Sweden	To standardize the medical records in order to exchange information within a country and between countries.
Sweden	National standard for semantic interoperability
Sweden	As IT-vendor we are depending on customer requirments, which in turn reflect national decisions. On a long-term (inter)national level an extensive use of Snomed-CT would be valueble for semantic interoperability. It needs though be closely related (term-binding into) some kind of detailed information models. like specialized openEHR/CIMI models.
United Kingdom	Standardising semantics where it is important for analytics and for sharing core information.
United Kingdom	We will adopt SNOMED within our software products if and when the NHS commits fully to a SNOMED programme
United Kingdom	The best answer is to refer to the desiderata in this paper http://www.ejbi.org/img/ejbi/2011/2/Conley_en.pdf
United Kingdom	Strategic long term benefit of adopting a unified terminology to support semantic interoperability. No immediate benefit.
United Kingdom	allows interoperability

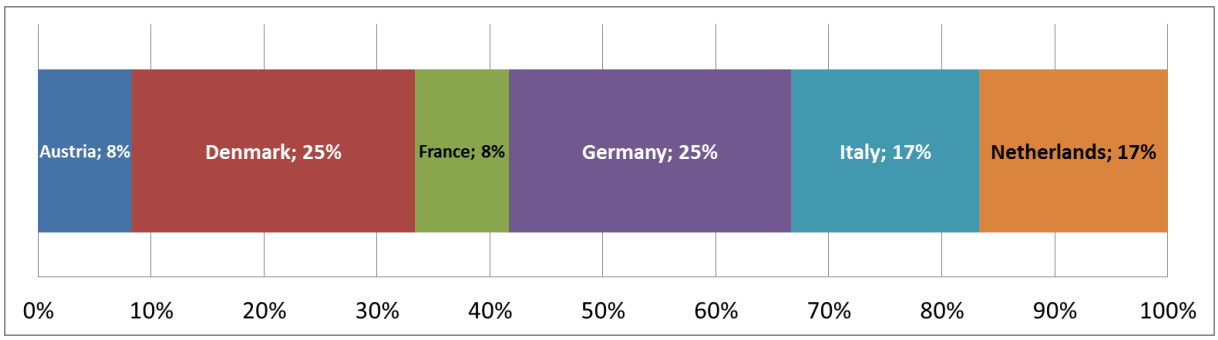
Member State	What would you personally believe to be the main benefits of using SNOMED CT in your organisation- - comment
United Kingdom	Economies of scale in the expensive process of knowledge representation; no country has the time or the native expertise to go it alone. SNOMED's technical design is intrinsically more flexible, so it's far more likely that we can hammer it into a shape that fits elegantly within the evolving informatics architecture of the future than would be possible with intrinsically more rigid and limited schemes like ICD or ICPC.
United Kingdom	Designing our systems to capture clinical data such as problems, diagnosis and procedures in a terminology standard which is widely used and approved prevents reinventing the wheel. Structured clinical data is required for assisting performance improvements initiatives, required to support patient identification for research programmes integrated in the EMR, and will support population health management. With the introduction of the Health Information Exchange (HIE) platform that is currently being used to share information between non-Cerner and Cerner systems, we are now looking at evaluating options with regards to making use of structured data from primary care via the Medical Interoperability Gateway (MIG). We are currently looking to expand our portfolio of offerings to the EU to include our Population Health Management platform, HealtheIntent http://www.cerner.com/solutions/population_health/healthe_intent/ which also depend on receiving data from non-Cerner systems, and aggregate, map/standardise, transform and reconcile data. Receiving the data from non-Cerner systems in SNOMED CT will significantly reduce the mapping effort.
United Kingdom	SNOMED CT technology (representation, tools when more mature) could be very useful. If done correctly, national and also vendor vocabularies could be mapped into a SNOMED structure to enable standardised referencing, management etc.

9.2.5 What would you personally believe to be the possible risks, constraints or challenges with adopting SNOMED CT in your organisation?

About the 9% of respondents didn't indicate any specific believed risks, constraints or challenges with SNOMED CT.

The following figure shows the distribution of the no issues answers per country. No comments have been provided associated to this statement.

Figure 36 Distribution of the "no issues" answers per country



The following table summarize per country the believed risks, constraints or challenges with SNOMED CT.

The main classes of believed problems identified have been:

- Costs (terminology license, refset definition, software licenses, training, EHR-S implementation, translation)

- Absence of translations, maps with used terminologies (mainly for rembuirsement purposes)
- Management of the transactional scenario (change amanagement)
- Coehexistance with other terminologies
- Quality and consistency issue
- SNOMED CT complexity (description logic, compositional syntax, versioning management, IHTSDO collaboration, implementation in software)
- Lack of knowledge/expertise
- SNOMED CT learning curve
- End-users acceptance: usage of coded data, resistence to change, availability of appropriate tools for supporting users in clinical settings.
- Low EHR-S (ICT market) maturity
- **lack of supporting policies** (including countries commitment).

Some distinctions between the complexity and the “perceived” complexity have been done (this subject came out also in the German focus group discussion). It has been also put in evidence the need of having a critical mass before actually gaining benefits from the adoption of SNOMED CT and the fact that SNOMED CT has to live in a terminologies eco-system being not a “ ’golden bullet’ that solves everything by itself.”

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
Austria	as SNOMED CT is extremely comprehensive, this could lead to problems. Possible ambiguities within SNOMED CT could lead to replication and other problems. Challenges regarding the licensing, language (German version)
Austria	Cost of license, cost of implementation
Austria	Huge expenditure of technical, financial, timely and personal ressources needed to implement the national SNOMED CT agency. Annual costs are in no relation to the given benefits: The use of SNOMED CT for the European Patient Summary is not mandatory, the use for ELGA is so limited that the licence fees seem too expensive. The technical implementation at the doctors' offices seems huge. Also, there is very little know-how in SNOMED CT available in Austria.
Austria	Main risk apart from financial aspects: There is no validated German translation available. Austria does not have the ressources or expertise, respectively, to translate the terminology.
Austria	translation might be an issue, main issue ist however that noone in Austria seems to bother to do research for practical use of snomed as it cannot be used anyway - so there are no snomed experts that are able to implement software. another issue is that snomed was not used for electronic data exchange projects like ELGA
Austria	adopting needs from local terminologies within the healthcare organisations to change to any international Standard (e.g. the language-barrier)
Belgium	Lack of knowledge
Belgium	learning curve ???
Belgium	need for efficient EPD - lack of interest of physicians to use coded terminology
Belgium	more constraints for clinicians (in comparison with free text) some errors/ approximation with the choices of code (clinicians are not expert in

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
	codifcations) --> tools needed to help (natural language --> code) Specific funding is mandatory (to pay training, to pay software licences)
Belgium	some loss of detail in information.
Belgium	Loss of information
Belgium	How to provide subsets (refsets) for a particular purpose since SNOMED CT is thta big and that extensive
Belgium	No money to adapt ICT and insure intagration of all info in medical dossier.
Belgium	learning time
Belgium	I don't see how to link decision support that's linked to several keywords and/or to a lower granularitty keyword
Belgium	structured EHR acceptance
Belgium	Lack of standardization (granularity and pre-post- coordination)
Belgium	no programmers/analyst able to implement snomed in any informatic system, complexity of snomed to be managed by any information system resulting in a lack of conviviality, maintenance and evolutivity, lack of interface terminology well structured (the upper layer of the system which should be done by linguists and include acronyms, flexions...)
Belgium	As long as Snomed CT is not required for significant reimbursement purposes it will be used only opportunistically.
Belgium	implementation in daily practice.
Belgium	cost conservatism
Belgium	no certified dutch translations
Belgium	If the choice for implementation is free it won't start for a long time. Dokters will rebel against very structered notes and discharge letters. Coding personal may get scared that they will loose there jobs.
Belgium	collaboration of physicians to document the EPD
Belgium	An initial unusual workload for physicians may lead to noncompliance
Belgium	enormous work for implementation, financial costs, Healthcare workers reluctancy to change
Croatia	mapping to ICD10 is challenging
Croatia	Bridging from ICD system, no time for education, limited time for adoption, funding of the change. Also, issues around set of different providers for IT software in primary and secondary HCP.
Croatia	MIgration from ICD10 or parallel usage of these two classifications/nomenclatures.
Croatia	usage and coding in hospitals
Croatia	The challenge is how to organize education on SNOMED CT
Croatia	Challenge for system development and monitoring
Croatia	Cost of introduction and implementation, and slow adoption from end user.
Denmark	large complexity and very timeconsuming
Denmark	This question is so (!!!) dependent on what "adopting SNOMED CT" actually means.

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
	Please make this question operational!
Denmark	every one seems to haev the impression that they are very special - and therefore not able to minimice there documentation to be standardised
Denmark	Report and billing takes place in ICD10
Denmark	Not understanding the SNOMED CT concept model. Inconsistent use of SNOMED CT.
Denmark	We need more qualication in accordance to SNOMED CT
Denmark	Hiding the complexity of Snomed CT for end users
Denmark	Existing use of other classifiactions and terminologies and how they can interact with SNOMED CT or be substituted by SNOMED CT
Denmark	At det talte sprog ikke svare til det dokumenterede!
Denmark	The price for rebuilding all modules in a whole and big healthcare suite of modules.
Denmark	a lot of work by defining the right words, and more systematic way - nor easy for everyone
Denmark	we need a map to ICD10 first - for billing reasons
Estonia	Main constraint is poor user interface desingn, causing extra work to medical professionals.
Finland	The costs and the working time for implelemtation versus benefits
Finland	-cost
Finland	Facilitation of collaboration in specific contexts
Finland	to do it alone would break the link to national terminologies
Finland	Health care professionals are fed up with new tasks, so SNOMED would have to be completely automatically imbedded in the patinetdata systems
Finland	Very expensive, if the implementation and development of the systemis not well planned and executed
Finland	Large organization of 22 000 employees - how to train and implement (resources)? Challenges of EHR (now total of 260 programs)
Finland	I've been told that Snomed may not be specific enough - however, I would assume that this problem could be handled for secondary (more freely applicable) coding (which is in our pathology LIMS in a way used anyway). For biobanking the common primary classification would be great, subclassification do change anyway with growing knowledge - which is seen in WHO blue books editions
Finland	Slow learning, resistance to changea nd slow adaptation.
Finland	We don't have any products that support the use of Snomed CT currently. The maintance of the data in Finnish will be quite heavy and expensive.
Finland	Need for translation, education and ensuring uptake by professionals
Finland	Huge number of concepts, complex "grammar", multiple ways of coding the same thing. Needs tooling to make use in clinical settings easy, predictable, consistent.
Finland	Overlap with other medicines related terminologies and non-compliance with them.
Finland	Too extensive terminologies. Pathologies don´t want to adopt that many new codes and start to use only a subset of those. That would make a data too robust and ruin the comparability as these in-house rules (we only use this and this and this) are not

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
	necessary the same in different laboratories.
France	Currently, very expensive
France	No french translation which is mandatory. 300 concepts whilst SNOMED 3.5 has proven it could cover the needs with 100 concepts. More concepts mean difficulty of choice for HCPs
France	To fully understand its organisation, definitions and usages in order to avoid misleading use it in e-health applications
Germany	The software components using SNOMED CT will need at first an augmented effort to develop, maintain, assure quality and synchronize with other terminology intensive applications. Increased production resource consumption increases costs per software license.
Germany	costs no use case too complicated to use not implementable (post - coordination)
Germany	Implementation score
Germany	a) A real success of adopting SNOMED CT in one organisation depends mainly on the national adoption together with lots of accompanying measures like providing secondary ressources, e.g. mappings to ICD-10, OPS, etc.; indexed Value Sets like VSAC in USA, indexed knowledge sources like dm+d in UK; etc. => Regarding the necessary version management this is very, very complex and costly. b) Different to most existing terminologies pre- and postcoordinate SNOMED CT codes and code expressions are complex and can be evaluated not just by simple SQL-Queries but by sophisticated "structural" or "logical" evaluations. => Suppliers of clinical software and developers of communication interfaces (e.g. HL7 V2, xDT or EDIFACS (in Germany)) face a huge and costly challenge. c) Due to a weak national governance most actors in healthcare delivery, healthcare industry etc. have a "wait-and-see" attitude. They are not convinced to make profit of using a standard terminology like SNOMED CT as almost nobody (who have to pay for it) is asking for it. d) The few "success stories" are limited to few projects in English speaking countries. Apart from theoretical projects it is not clear what are the practical outcomes of adopting SNOMED CT by the existing Member States. e) For adopting SNOMED CT experts are needed. However there are less and less younger academic and non-academic people with the necessary expertise (at least in Germany).
Germany	costs
Germany	Pflegeaufwand, Entwicklungskosten und weitere Investitionen werden nicht durch Anwender/Industrie getragen.
Germany	Implementation costs without customers willing to pay for. Limited probability any of our customers would use Snomed documentation for other purposes. Implementation shouldn't be too hard as we have the annual changing coding catalogs and tools as the already integrated DIACOS could provide Snomed codes as far as I know.
Germany	In a hospital/health providing organisation there should be no direct contact with Snomed CT. Snomed CT should be an integral (software)part or component of ICT systems used in healthcare organisations.Therfore this question should primarily directed to software providers in healthcare and their speciality departments for e.g.

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
	quality management, software usability, etc.
Germany	efforts to map terminologies used so far to snomed ct
Germany	update of description catalog; versioning issues
Greece	1. cost of use if a huge barrier 2. training and awarness activities needed
Italy	Possible problems with fees
Italy	SNOMED CT, as is, is large and someone calculated in about 70 person years the cost of its translation. While time ago I somewhat believed that an Italian translation could be useful, it is unlikely we are able to sustain its translation in time, due to the absence of policies and long term choices, so better to concentrate on subsets or also interface terminologies.
Malta	Complexity of Systems and Human Resources.
Netherlands	Quality issues with SNOMED CT core and with derived work, such as translations, mappings and interface terminologies.
Netherlands	#1 challenge is how to get data in, i.e. user interface
Netherlands	no risks, no constraints, but implementation challenges. Clinical documentation by providers should change from free text to structured data documentation. Long way to go.
Netherlands	The greatest risk would lie in the necessity of good mappings (and good maintenance of these)
Netherlands	Complexities at level of data entry; more complexities at level of data aggregation.
Netherlands	time consuming, clunky interface, education, harmonization between medical doctors
Netherlands	Our terminologies are translated in English, German, French, Spanish for export of health information to a USB stick. Unfortunately there seems to be no German translation of Snomed and the terminology is too large for us to translate. Also we would need more knowledge of Snomed, also implementing Snomed would be complex.
Netherlands	complexity and use of other (older) terminologies like e.g. PALGA uses previous version in national database, Endobase using ICD10 etcetera.
Netherlands	Everybody uses its own classification. Mapping these to SNOMED CT might mean that information will be lost. However, using SNOMED CT directly will probably not happen on short term.
Netherlands	what's in for me. saves it time for me in the long run
Netherlands	The comparability with data of other countries.
Sweden	If we add SNOMED CT to the systems in very different ways without coordination, e.g. without shared information models (archetypes etc.)
Sweden	• Decision makers are preoccupied by other duties, oblivious to existing problems with EHR content and/or waiting for sharper directions from national authorities. • Decision makers are reactive rather than proactive – there is a tradition of letting national and local IT development projects take lead in content development. In effect, the EHR vendor's decisions and other IT-related activities make the decisions for the health care providers, so to speak. Perhaps solutions would be more system neutral if it were the other way around? • Decision makers are reluctant to implement yet another "code system" due to weak understanding of the relationship between SNOMED CT and existing classifications,

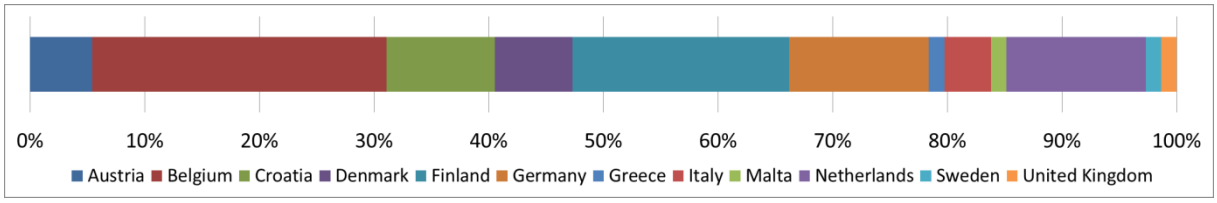
Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
	such as ICD and ICF. • National and international SNOMED CT releases are relatively infrequent. • EHR system development is too slow, which among other things owe to the fact that a large group of customers with partly different interests and agendas must synchronize their requirements. • Clinical expertise and adequately trained mapping personnel will be difficult and take time to obtain. • Clinicians must be motivated to change their ways of working, for instance accepting new ways of input (including a higher level of structure and less free text) and understanding why clinicians and patients can benefit in the long run, although the short-term effects are conceived of as problems.
Sweden	There are economical and structural constraints. The structural ones are due to the informations systems already implemented. Normally they don´t have the appropiate information structure so in most cases you have to replace the present systems and that is time-consuming and expensive.
Sweden	Still little knowledge in Swedish health care organisations about SNOMED CT and controlled vocabularies in general. The National Board isn't responsible for the implementation of SNOMED CT in the health care systems.
Sweden	Underestimation of the amount of work to get it into production software across IT-bounderies. And overestimation of the benefits, SNOMED CT is no "golden bullet" that solves everything by itself.
United Kingdom	Capturing clinical terms as a part of workflow.
United Kingdom	To adopt SNOMED ahead of mandatory use across the UK would be a highly expensive and commercially risky venture with very limited benefits
United Kingdom	Complexity, inefficiency, gaps
United Kingdom	No real benefits until there is a critical mass of implementation. Challenge is making such a complex terminology usable for clinicians.
United Kingdom	the perceived complexity
United Kingdom	Trying to implement post-coordination other than in very simple use cases.
United Kingdom	Biggest risk and challenge are building the capacity to change, and overcoming the vested interest in the status quo, both commercially by suppliers and centrally in government departments.
United Kingdom	The size, design and broad scope of SNOMED CT can present some challenges to simple search of SNOMED CT in browsers embedded in different sections of the EMR. Search functionalities can return too many results or too little. There is no single approach to improving the way SNOMED CT are searched, retrieved and selected for data entry. The effectiveness of SNOMED CT searches and data entry for each domain and context needs to be considered to help increase the utility of SNOMED CT for data entry and the overall adoption of clinical applications. As SNOMED CT adoption is increasing and more products are being implemented in the EU that utilise SNOMED CT, there are likely to be challenges over version control resulting from movement of concepts and inactivation of concepts between releases and changes in the concept model. A maintenance process will need to be implemented to impact assess SNOMED CT content changes on new and existing Cerner products (e.g. decision support tools) to mitigate any clinical safety risks.
United	Right now, it remains difficult to deal with - over-complex tooling; lack of clear

Member State	Believed risks, constraints or challenges with adopting SNOMED CT in your organization
Kingdom	software and technical specifications other than the data, eg. RF2. A softare representation of structured ref-sets remains obscure for example. Mapping of local vocabularies needs much better tooling and possibly underlying technology. If SNOMED is to be used for a growing number of types of terminology e.g. measurement units, drugs, etc (which I am not convinced it can do well), the IHTSDO organisation would need to be widened out significantly to include experts on these many other areas.

9.2.6 What benefits you have already experienced in your own organization through the use of SNOMED CT?

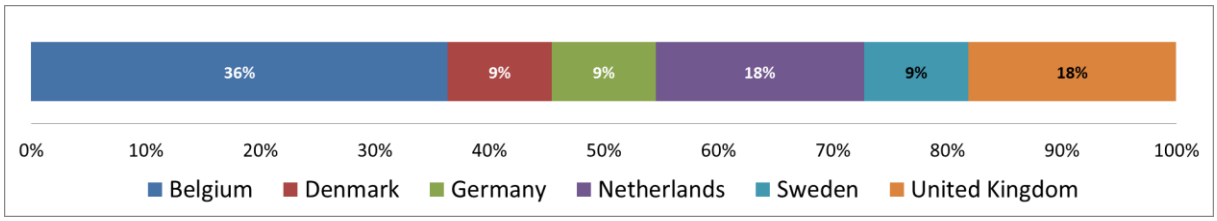
About the 55% (77 over 136) of interviewed asserted that they have no direct experiences with SNOMED CT. The following figure shows the distribution of the no experience answers per country. It can be noted how there is not a tight relationship with the IHTSDO membership.

Figure 37 Distribution of the "no experience" answers per country



Considering the remaining responses (59) about the **18 %** of respondents (11) declared that they **have not experienced benefits** from SNOMED CT. The following figure shows the distribution of the "no experienced benefits" answers per country.

Figure 38 Distribution of the "no experienced benefits" answers per country



Between them however 5 people (2 from Belgium, 2 from Netherlands, and one from UK) in the question about experienced challenges of SNOMED CT claimed to not have experience.

As a general comments, for the experienced benefits, the percentage of benefits related to development of solutions and research (rather than the end users) is higher than for the believed benefits. This is coherent with the limited and often focused current use of SNOMED CT in the clinical settings.Some examples of cases in which benefits have been experienced are :

- Academic EHR projects
- Clinical trials / datamining (better identification and extraction of data)
- Clinical information modeling (e.g. CIMI)

- Usage as reference terminology (“use as an interlingua” for multi-terminologies environment, cross-domains interoperability)
- Improved care provisioning (better description/identification of medical concepts, reuse of knowledge, multiple domains coverage)
- Standardization in specific care settings/domain (e.g primary care, drugs, devices)
- Improved products value (“more effective and wider uses of clinical data entry”)

Detailed responses are documented in the following table.

Member State	What benefits you have already experienced in your own organisation through the use of SNOMED CT.
Austria	standards-compliant use of international CDA Templates (IHE PCC) would not have been possible
Austria	SNOMED CT is already well developped. Codelists are available that can be used for many purposes.
Austria	When I used to work in the UK, coding was really easy - now it is a pain in the neck
Austria	standardization within header-Information of medical documents for the austrian EPR (called "ELGA")
Belgium	see above
Belgium	interoprability (f.i. in surgery procedures)
Belgium	It is a useful framework for positioning products in a roadmap.
Croatia	I have no experience with SNOMED CT in my organisation
Denmark	Center of SNOMED CT so we don't use it ourselves, but i believe that there are majoe clinical advantages to introducing it in practise.
Denmark	none for SNOMED CT yet because the clinicians is'nt ready for this and the goverment request only ICD-10 codes. Very much for ICD-10 used in statistics and business intelligence
Denmark	SNOMED CT is very usefull when teaching biomedical students how to model and design systems and share data
Denmark	We are using SNOMED CT for tagging various artefacts. Alternativly we would have to develop a comprehensive classification.
Denmark	We are in development state - there are / seems to be oppertunities
Denmark	Only litle experierence. And the benefits could be more precise clasifications of patient health data.
Denmark	SNOMED CT it not used in the existing EHR in the organisation. The coming Epic system (which includes the SNOMED CT Diagnosis hierarchy) has not yet been implemented at the hospitals in the 2 regions. Will go-live May 2016)
Denmark	Help to use the right concept and use the definition to explain the concept
Denmark	Better understanding of Medical concepts
Denmark	better care for the patient because of opportunity to use experience. Audits on a better level.
Denmark	Instead of developing our own terminology / classification it was useful to use parts of the SNOMED CT content instead e.g. describing the microorganisms in a lab result

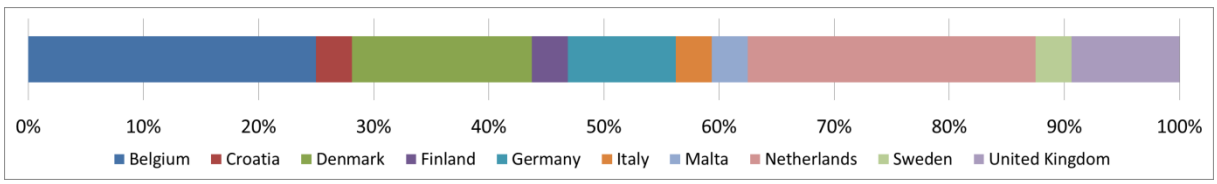
Member State	What benefits you have already experienced in your own organisation through the use of SNOMED CT.
Denmark	better data normalization
Estonia	Easy to perform queries.
Finland	Facilitation of collaboration in specific contexts
Finland	In biobanking the use of snomed in pathology is fine
France	SNOMED CT covers a lot of the medical domain; could be used as a major terminology (but not alone at that stage) to represent medical problems
France	possibility of an ontological classification of concepts
France	to be able to use it as a pivot terminology in order to "translate" some other terminologies from one to another
France	We only evaluated SNOMED with encouraging results.
Germany	The volume of work and revenue of the terminology services and NLP teams in maintaining the Healthcare Data Dictionary has increased. The content coverage and quality of the products implementing HDD has been augmented. Customer satisfaction has increased.
Germany	good to build value sets of "everything" good to use (precoordination)
Germany	very useful in academic EHR projects
Germany	Interoperability and need to define clinical terms exactly
Germany	As DIMDI is only a provider of terminologies and classifications, a clear benefit cannot be specified.
Germany	Export of data using Snomed CT beside a lot of other terminologies
Italy	Very limited experience, possibile benefits from the internal organization of the term in a sort of onthology.
Italy	Again not in my organization, but the process of harmonization between ICD-11 and SNOMED CT is having some positive effect on the quality of ICD-11, coming from the logical comparison with SNOMED.
Netherlands	Understanding of the meaning of data (to be) collected gets more clear
Netherlands	We are still developing
Netherlands	One dictionary. Use it in the analysis.
Netherlands	The use of SNOMED in the CDA communication from existing applications like PALGA and Endobase/CLinical Assistant/Chipsoft was complex to develop as they are not used to it. Hard to finf the correct Snomed codes for projectteam. We need expert for that which costs too much
Netherlands	clinical trials datamining
Sweden	Helps discussions and value-set selections
Sweden	It is possible to standardize and express with great exactitude the matters dealt with in medical care. That is of outermost importance when you document in medical records. The standarized terminology also makes is possible to exchange information between helath providers, health providers and regional/national registries etc
United Kingdom	We have not adopted SNOMED due to the lack of commitment by the NHS

Member State	What benefits you have already experienced in your own organisation through the use of SNOMED CT.
United Kingdom	Aligned to National Information Board consistency... In 100,000 genomes project it is mandated and thus support is available.
United Kingdom	some standardisation with national systems from primary care
United Kingdom	Use of dm+d (SNOMED based)
United Kingdom	Successful use as an interlingua : reduces the time otherwise required to author a report specification in parallel for multiple different deployed terminologies. Provides a single target language for Summary Care Record.
United Kingdom	SNOMED CT improved the value of our products by enabling more effective and wider uses of clinical data entry such as diagnoses, co-morbidities, allergies and procedures, into our clinical documentation modules. Our healthcare providers have experienced benefits such as accessing more relevant clinical data at the point of care, and conducting useful data analysis and audits based on the entry of SNOMED CT coded data. SNOMED CT improved support for clinical coders as it enabled integrated third party systems such as 3M Medicode and Dialect to display a suggested list of diagnoses and procedures to choose and encode based on SNOMED CT encoded data captured in the EMR system and the SNOMED CT to OPCS-4/ICD-10 cross maps. SNOMED CT based rules, described above, have helped researchers in European institutions by identifying potential patients for their clinical trials based on the trials' inclusion/exclusion criteria and SNOMED CT encoded data that are entered at the point of care. The use of the SNOMED CT hierarchy has enabled more patients to be identified as the rule queried patient records which either contain SNOMED CT descriptions that are synonymous to the concept used in the algorithm or contain the subsumed lower level concepts.
United Kingdom	In openEHR, through the various networks like CIMI, SHN, and working with US terminology users like Mayo and Intermountain, it is clear that progress is being made e.g. on URI referencing of terms, value sets; ability to do archetype-term binding.

9.2.7 What benefits you have already experienced in your own organisation through the use of international terminologies?

Just less than the 25% (32 over 136) of interviewed asserted that they have no direct experiences with international terminologies. The following figure shows the distribution of the no experience answers per country.

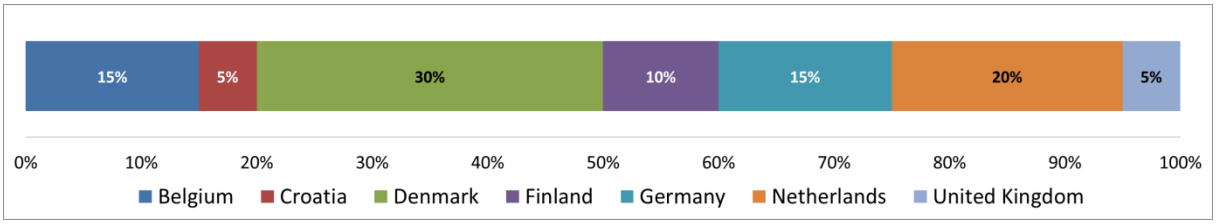
Figure 39 Distribution of the "no experience" answers per country



Considering the remaining responses (104) the **18 %** of respondents declared that they **have not experienced additional benefits** from those international terminologies.

Six of them indicated that they have "no experience" in the challenges question. The following figure shows the distribution of the "no experienced additional benefits" answers per country.

Figure 40 Distribution of the "no experienced additional benefits" answers per country



The only comment associated to no additional benefits comes from Germany and it is the following *"Not unified and competing terminologies in the field(s) of medication safety and pharmacovigilance require individual solutions so far"*

Comments provided can be grouped into two main types: general advantages of using (good quality) terminologies and terminology/use case specific notes. Several answers seems to be related to which international terminology is used and for which purpose rather then which advantages have been experienced. General advantages are in some extend similar to those indicated for SNOMED CT: reuse of knowledge, support semantic interoperability and comparison of data across countries, support for decision supporting systems. Several notes are referred to the ICD family for classification related purposes. Some contrasting opinion about LOINC has been also provided. Details in the following table

Member State	Benefits experienced in your own organisation through the use of international terminologies
Austria	it is better to use established and quality controlled vocabulary than invening from scratch
Austria	ICD (for coding of diagnoses) helped to gain transparency regarding diagnoses and therefore supports comparability in order assess the quality of health care and support policy makers (regarding Austrian public hostpitals)
Austria	ATC; ICD 10; international comparability of analysis
Austria	ICD-10: a terminology that is used worldwide. No ressources needed for development, only ressources needed for the implementation of the terminology. Fulfills the basic needs even though there are restrictions in it.
Austria	are there any REAL international terminologies (apart from LOINC which is not widely used apart from labs)
Austria	standardized documentation with ICD-10, partly with ICPM
Austria	international comparability (ICD-10)
Belgium	More rationalisation, ability to be financed by health authorities
Belgium	ICD-9 and DRG: analysis of HSMR, mark penetration hospital, performance of length of stay
Belgium	ICD 9 is used as a tool for the funding of the hospital (paying of the hospitalization based on diagnosis/ AP DRG)
Belgium	data availability for management purposes
Belgium	NANDA & NIC for research purposes
Belgium	WONCA international understandable
Belgium	* ICD * ATC >> Hierarchical coding (corrected where needed) enables integrated decision support at different levels of granularity

Member State	Benefits experienced in your own organisation through the use of international terminologies
Belgium	Standardization and portability. terminology more close to clinical language
Belgium	Feedback of the MBDS (financing the hospital through DRGs)
Belgium	share data, analyse data, sharing the same langage between professionnals
Belgium	We have used ICD-9 since over 20 years. As it is coded after the facts and outside the medical record, it is only used for financial issues, not for clinical reasons. Benchmarks are folloxing 3-4 years later, which is to late for clinicians.
Belgium	ICD-9 provided little if any benefits for medical practice.
Belgium	ICD-10: pathology ranking
Belgium	use of HSMR to detect issues (excess mortality) in certain domains ICD-9
Belgium	ICD9 (actually ICD10)has been proposed also for Patient's Digital Record
Croatia	semantic interoperability, good clinical practice
Croatia	ICD10 is in general and mandatory usage for diagnoses coding. Of course, no other information is collected in coded form, which is disadvantageous.
Croatia	comparison with the results from other countries
Croatia	ICD-10 - health status (dg) in my country and internationally compared with other countries (e.g. CVD being the leading cause of death in Croatia)
Croatia	Better interoperability and data management
Croatia	Using HL7 standard we managed to implement many different interfaces via one standard module. Of course, HL7 just a transport system, not a full terminology.
Denmark	Not many benefits internationally yet, but soon it will be of importance
Denmark	Used ICD-10 and SNOMED CT, se answer above
Denmark	ICF - has - en a moderated form been used for visitation, effort to make the work more standardised.
Denmark	SKS includes a long list of international classifications and makes it possible to collect patient data in a DK national register (LPR). The objective of LPR is to ensure a Statistic foundation to use for hospital planning, hospital statistic and research.
Denmark	NPU ICD-10 (SKS)
Denmark	All modules in the whole suites are based on a terminology module. With no terminology, no suite!
Denmark	use ICD10 for diagnosis and exchange of data between systems.
Estonia	Easy to eprform individual queries
Finland	The data in the registreis can be used for internationally comparable statistics and research
Finland	Facilitation of collaboration in specific contexts
Finland	We have data that we can comapre nationally and internationally.
Finland	on going research collaboration, only initial experience
Finland	Definitely basis for good quality data, data transfer possible etc
Finland	ICD-O, easy to find and applicable in tumor pathology through new editions of WHO classification

Member State	Benefits experienced in your own organisation through the use of international terminologies
Finland	Some improved communicatioon, better diagnostic practices.
Finland	Standards are the key element in interoperability and passing information from one health care provider to another, establishing national archive system, statistics, developing services etc
Finland	Reuse of extensive expert work performed for the terminologies, compatibility between systems
Finland	Common (international) terminologies make it easier to use codes describing clinical data in our decision support system.
Finland	EDQM/EUTCT provide the basis for unic identification of medicinal information and thus enable consistent data exchange between various national and international actors within the pharmaceutical sector and healthcare.
Finland	Annual cancer statistics are base on ICD-O-3 topography and morphology codes. We have used plain text to produce ICD-O-3 based codes. We could use codes used in the laboratorios and hospitals directly if these were the same.
France	standard representation of medical problems using ICD10, LOINC, MedDRA, Orphanet, ATC... +
France	a reference terminology is useful to index medical information and to communicate with external systems and teams. Our experience is restricted to exchanges in France so the international or local status does not provide added value.
France	For example, being able to describe patient records using a national terminology and trasnmitting results using international terminologies if necessary
France	We evaluated MeSH with satisfying results
Germany	The adoption of ICD-10 and in the majority of european countries has improved precision in the primary documentation and analytics of morbidity, mortality and healthcare resource consumption.
Germany	able to do DRGs, statistics, billing, Qualityassurance, DMP, cancer registries, medical registries
Germany	UMLS is a fantastic meta-terminology for research purposes
Germany	Icd10 payment Ops payment
Germany	a) Although a bit historic I would like to mention the GALEN project in the nineties where (apart from lots of theoretical insights influencing heavily the field) a procedure classification in France (CCAM) was produced (somehow analogous to ICD-11 based on a content model). Other features (SDE, multiling. lang. generation) are still impressive. b) In a national research project (BMBF project ORNET) the IEEE 11073 nomencature for medical devices is used. Nevertheless the involved industrial partners are difficult to convince to adapt to the standard. c) OBO ontologies are getting more and more important in biomedical research and are used for interconnecting OMICs data, but ... d) It should be said that due to the national mandate mainly focussed on ICD-10 (and OPS (?)) it is used in many, many applications in healthcare. Often its restriced structure and completeness is critized, however it is never be created (~1850) for those tasks (like drug safety) but only for supporting statistics. FINALLY: It is a good question why OBO ontologies are accepted (somehow as de facto standards => by researchers) and ICD-10 alternatives are not accepted by healthcare professionals. The incentives are different. The additional effort for high quality clinical data entered by peope A are needed and used by people B.

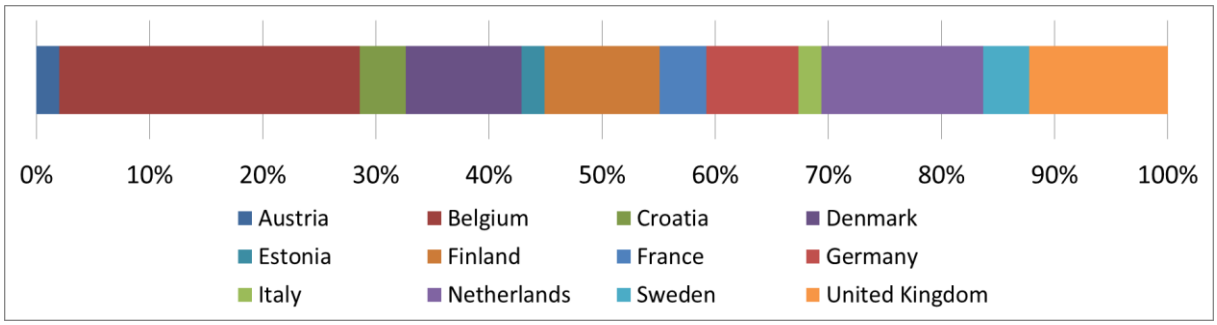
Member State	Benefits experienced in your own organisation through the use of international terminologies
Germany	As DIMDI is only a provider of terminologies and classifications, a clear benefit cannot be specified.
Germany	LOINC: feels unstructured, sort of chaotic, codes not human understandable
Germany	Interoperability
Germany	semantic interoperability of the products of our organisation with other healthcare information systems
Germany	Support of interoperability (Rosetta RTM)
Greece	terminologies can lead to reducing clinical errors contain cost and increase quality of healthcare analytics
Italy	My organization uses US NLM Medical Subject Headings both for indexing and cataloguing, in Italian and in English
Italy	For Primary Care we use ICPC. My international organitation the Wonca International Classification Committee is in contact with IHTSDO to try to create a REF sets for cross mapping
Italy	The use of LOINC made possible lab data sharing and comparison
Italy	Data are easily manageable and more precisely defined. Data could be reused by different clinical professionists as they are fully understandable and this avoids time and monet waste
Netherlands	Comparability of (mainly) epidemiological data in an international context (via ICD-9 & ICD-10)
Netherlands	You can prove you really are prepared for the future
Netherlands	structuring data made Pacs possible
Netherlands	Omaha System has been implemented in one PHC service, which resulted in a national lobby to implement Omaha System within all PHC services in the Netherlands. Beside, a national lobby arised to use NNN (nanda, nic, noc classification) to support nurses in hospitals. The Dutch Nurse Association stimulate the use of classifications, because standardized nursing languages will be achieved. However, by using different classifications, it will be difficult to exchange nursing information or collect uniform data at national level.
Sweden	SNOMED CT pilot project funded by national release center provided improvement of knowledge, useful contacts. ICD, ICF provides structured documentation of diagnoses and functioning, disability and health (to some extent), statistics.
Sweden	I have worked for many years with the family of classifications from WHO. They are used extensively in the health care sector for follow up on local/regional and national levels. They are also used as a foundation for DRG and similar secondary systems
Sweden	National statistics
Sweden	Possible to integrate to some national registries like medication databases, and statistical reporting on diagnosis, etc
United Kingdom	In order to provide the data transformation services we do it is essential that our software combines the ability to handle all terminologies/coding systems in current use as previously mentioned
United Kingdom	Its more theoretical than actual at the moment.

Member State	Benefits experienced in your own organisation through the use of international terminologies
United Kingdom	Allows coding of data in primary care systems (read) and for secondary care activity data (ICD)
United Kingdom	Data harmonization across multiple sources
United Kingdom	As well as the experiences of using SNOMED CT described above, we implemented modules to support the entry and extraction of ICD-10 coded information enabling timely activity reporting for reimbursement and billing purposes.
United Kingdom	openEHR tries to provide enabling technology that allows terminology users to realise benefits. LOINC in particular provides a usful and widely accepted approach to lab coding. ICDx remains widely used, e.g. in Netherlands, much of Europe, Turkey etc.

9.2.8 What benefits you have already experienced in your own organisation through the use of local terminologies ?

About the 35% (49 over 136) of interviewed asserted that they have no direct experiences with local terminologies. The following figure shows the distribution of the no experience answers per country.

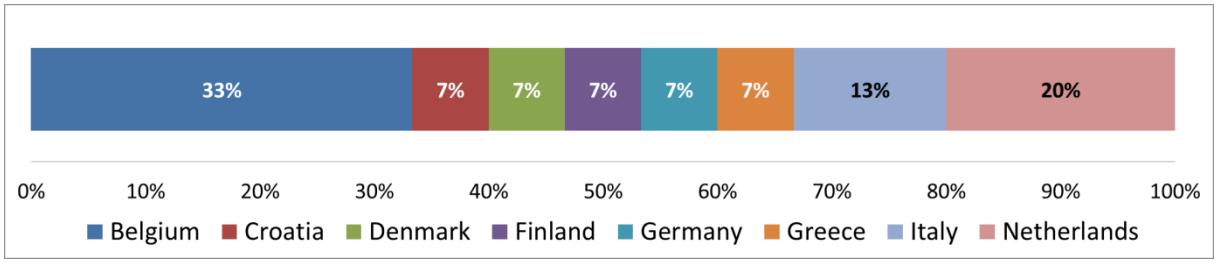
Figure 41 Distribution of the "no experience" answers per country



Considering the remaining responses (87) the **17 %** of respondents declared that they **have not experienced additional benefits** from those local terminologies.

Three of them indicated that they have "no experience" in the challenges question; five of them that are no challenges with local terminologies. The following figure shows the distribution of the "no experienced additional benefits" answers per country.

Figure 42 Distribution of the "no experienced additional benefits" answers per country



Notes added have been: Denmark: "Retrival of data is difficult" ; Finland: "Local terminologies enable standardization of local matters but may not be compliant with international standards unless built on top of them." ; Greece"local terminologies have created the tower of Babel the healthcare sector is confronted with."

Experienced type of benefits with local terminologies can be summarized as follows:

- Fullfill local needs or gaps for specific domain (most cited procedure, billing, drugs)
- Personalization (for Interface terminologies)
- Simpler to be used / learned; faster to be implemented
- Flexibility

Several notes have been added for specifiying the conditions in which these benefits could be experienced (and some drawbacks associated). E.g. the need of mapping these terminologies with the International ones; the distinction between short term and long term benefits; constrains related to local normative requirements;…..

Austria	**Local terminologies are useful if international terminologies do not contain the needed concepts**
Austria	Austrian Procedure Catalogue(for coding of health interventions) helped to gain transparency regarding health interventions and therefore supports comparability in order assess the quality of health care and support policy makers (regarding Austrian public hostpitals). Within the framework of the Austrian performance-based hospital financing system (based on modified DRGs), this lead to shorter hospitalization duration.
Austria	health Service Research needs routine data
Austria	The Austrian terminology for documentation of procedures could and can be adopted to specific needs, when necessary. There are annual updates to it. Is used for refundation within hospitals.
Austria	comparable statistics
Austria	Self-determination and usual language
Austria	possbility of own design
Belgium	Rationalisation, better exchange of informations
Belgium	3BT uses ICPC2 and ICD10
Belgium	* Local / national terminologies are useful mainly in absence of international standards * Some concepts require "pick lists". National pick lists are useful then e.g. in case of migration of a patient within the country
Belgium	Local terms for surgical procedures
Belgium	share the same langage between professionals, efficient clinical communication
Belgium	Low branched personalized pick lists appear to be the only practical way for physicians to register relevant clinical data during visits and rounds. These should be cross mapped in the back ground with the international coded terminologies
Belgium	3BT thesaurus makes coding with ICPC-2 possible
Belgium	own hospital terminology in EHR
Croatia	semantic interoperability at local level
Croatia	Usual epidemiology, monitoring, invoicing benefits.
Croatia	Only for billing.
Croatia	Better clinical data management
Croatia	Limited expirience with improved definitions and proper use of terminology in health care management.

Austria	**Local terminologies are useful if international terminologies do not contain the needed concepts**
Denmark	Better data, saving time, higher safety - basically its better than pen and paper but its not standardizet enough.
Denmark	we have some local terminologies in our system and most of them is mapped to code (ICD-10) few too SNOMED CT.
Denmark	Speed of development.
Denmark	there are challanges - need for organizational implementation and control
Denmark	fast and easy to create new registry templates. Local developed tool enables full overviw of applied terminology
Denmark	Easy to maintain and expand and easy to learn for new colleague.
Denmark	Fits the local context understanding. Easy to learn for new employees in the specific context.
Denmark	Easy to fit the local needs of clinicians
Denmark	Nurses gets better overview of the patients, more uniform documentation
Denmark	En mulighed for at genfinde og genbruge data...når vi er enige hvor og hvad vi dokumenter.
Denmark	Local terminologies are used to create diffent parts of new lists, lookups and much more. Secure that data are available in a structured way for analyzing for quality, research, management and other purposes. Think it would be possible to use Snomed CT as monoaxial in some parts, but when started creating local terminologies, Snomed CT was not known in Denmark
Denmark	possible to get data for a large group of patients, quality improvement and number of tasks...strategic desisions
Finland	The organisations are obligated by law to use certain national coding/terminologies. This makes it possible to create a national sharable EHR archive and good quality statistics, researech
Finland	Facilitation of learning and quality development through benchmarking. Facilitation of research
Finland	extremely important key to interoperability
Finland	Data that can be used when making decissions and developing health care locally.
Finland	esasy to modify, get new versions
Finland	I prefer using of national/ international terminologies.
Finland	terminologies helps you to find the information you need
Finland	See comments above
Finland	Fit for use, fit for local / national requirements
Finland	Local terminologies tend to be simpler to use and easier to extend/develop further according to local needs.
France	French terminologies (including interface terminologies at the Rouen level) TerSan project funded by the French Resarch Agency for interface terminologies in biology and imaging
France	a reference terminology is useful to index medical information and to communicate with external systems and teams. Our experience is restricted to exchanges in France so the international or local status does not provide added value.

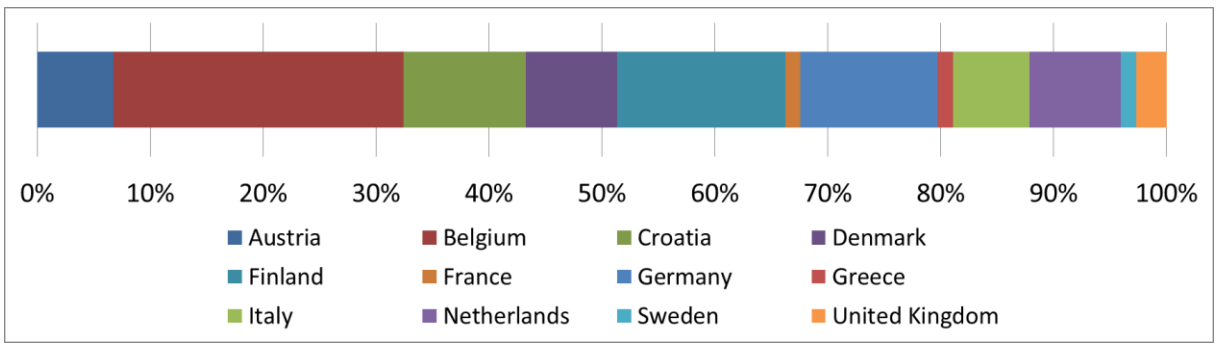
Austria	**Local terminologies are useful if international terminologies do not contain the needed concepts**
France	End users have no choice than using some local terminologies in their daily work, as it can be more precise and adapted to the use cases they manage.
Germany	The flexibility of the Healthcare Data Dictionary, which allows the usage of legacy local enterprise terminologies but normalizes these to standard terminologies but enables external reporting, benchmarking and analytics. Both local legacy terminologies and standardized terminologies are needed, since standard terminologies cannot cover all the user's terminology requirements.
Germany	billing (OPS)
Germany	local terminologies are flexible
Germany	Interoperability
Germany	Mainly specific interface terminologies for enabling structured data entry. Interestingly, the few existing standards are not used originally, e.g. - gastroenterology, adopted from MST - neuroradiology, adopted from RadLex - pathology, adopted from guidelines, ...
Germany	As DIMDI is only a provider of terminologies and classifications, a clear benefit cannot be specified.
Germany	Overcomming coding gaps. Documenting conditions that cannot be adequately documented using international coding systems and defintions.
Germany	Schnelle Entwicklung, Zuständigkeiten liegen bei den verantwortlichen Organisationen
Germany	German ICD/OPS is sufficient for current billing, qa and reporting needs, but codes need to be differentiable by manually adding free text as they are not differentiated from medical point of view. In Austria we have other catalogs but basically the same situation. We don't need to correlate German and Austrian data so this is no problem for us so far.
Germany	Interoperability
Germany	semantic interoperability of the products of our organisation with other healthcare information systems
Italy	We developed the Italian Bioethics Thesaurus and we use it for indexing documentation on this topic, collected in the Sibil database www.iss.it/sibi. Our terminology was integrated in the European project Ethicsweb www.ethicsweb.eu
Italy	We translated local lab terminologies in LOINC, with some extra-work
Malta	Standardisation
Member State	Benefits experienced through the use of local terminologies
Netherlands	Medication is properly standardized using G-standaard. This helps detecting medication interaction and contra-indication.
Netherlands	standardized DBC terminology (diagnoses and zorgactiviteiten) enable comparison of activities between institutions.
Netherlands	Quite a lot. GPs in the Netherlands are using 50-plus local coding tables for various areas of medical information, varying from history taking, complaints and diagnoses, treatments, referrals, laboratory outcomes, results of functional tests, prescribing drugs, registring medical contra-indications, registring drug intolerances, etc, etc.

Austria	**Local terminologies are useful if international terminologies do not contain the needed concepts**
Netherlands	I am an integrated care system supplier I must interchange with GP and hospital (basically a nightmare). But we can do it.
Netherlands	Faster implementation. I prefer to use any terminology rather than none.
Netherlands	exchange of data financial organising my department-hospital
Sweden	Some level of common EHR content within (parts of) my organisation.
Sweden	They are useful when you begin to follow up an area in health care. But they are almost never well thought-out so you will soon discover the limitations.
Sweden	Same as above (local = national codes, but not international). Thus even more integrations between IT-systems. Each integration often have a mix of international and national codes.
United Kingdom	Business analytics only
United Kingdom	as above - they are mandatory to the successful use of our software
United Kingdom	2.6 billion coded EPR items are entered annually in UK primary care using either READ2 or CTV3. Drives Quality and Outcomes Framework.
United Kingdom	Cerner specific terminologies were designed to capture discrete data in various sections of the patient record system. The terms are locally defined resulting in a good coverage of terms and shorter implementation timelines. These terms are easily interpreted and understood locally.

9.2.9 Have you already experienced or observed any challenges with using SNOMED CT in your organisation?

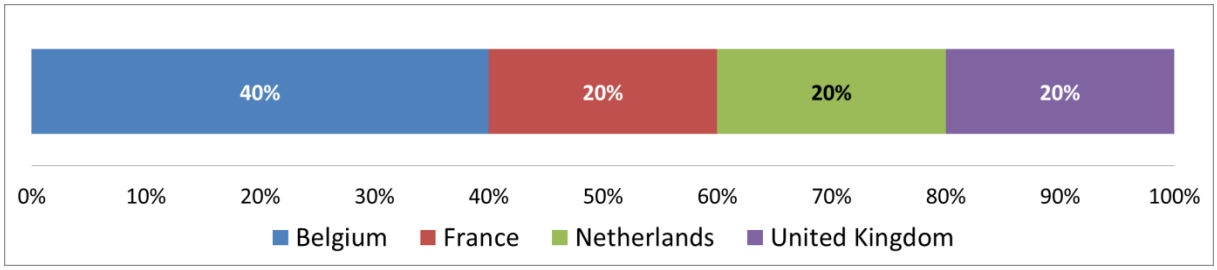
More than the 50% (74 over 136) of interviewed asserted that they have no direct experiences with SNOMED CT, among them only 64 asserted also to not have experience with SNOMED CT in the benefit question (see above). The following figure shows the distribution of the no experience answers per country. It can be noted how there is not a tight relationship with the IHTSDO membership.

Figure 43 Distribution of the "no experience" answers per country



Considering the remaining responses (62) less than the **10%** of respondents (5) declared that they **have no challenges experienced** from SNOMED CT. The following figure shows the distribution of the "no experienced challanges" answers per country.

Figure 44 Distribution of the "no experienced challanges" answers per country



Similar considerations as those done about the experienced benefits concerning differences between believes and experiences can be repeated also for this question. Moreover some of the notes provided seems to be related more to believes than to experiences.

The main classes of experienced challenges have been:

- License and translation costs (time and resources)
- Absence of translations, local extension and synonyms; absence or lack in existing maps.
- Limited adoption, absence of valuable reference experiences
- Quality and consistency issue (update life-cycle, hierarchies validation; gaps / missing concepts)
- SNOMED CT complexity: compositional syntax, browsing and selection, local extensions management.
- SNOMED CT learning curve
- Implementation issues (CDA and FHIR; storing data in existing clinical systems; terms browsing and selection)
- End-users acceptance
- Low EHR-S (ICT market) maturity
- **lack of** commitment

Member State	Have you already experienced or observed any challenges with using SNOMED CT in your organisation
Austria	it can be hard to pick the right concepts
Austria	SNOMED CT must be licensed. Annual fees are high; even higher are the costs of the initial implementation of SNOMED within the country.
Austria	apparently there are different domains within snomed which are not properly interconnected
Belgium	Since SNOMED CT is not the actual standard, not many people are will to provide cooperation in e.g. coding the data of a patient just to test it
Belgium	structured EHR acceptance
Belgium	not yet, too early: SNOMED CT is not really available as a standard belgian terminology
Belgium	Without official translations there is little traction.

Member State	Have you already experienced or observed any challenges with using SNOMED CT in your organisation
Belgium	need of (international) refsets)
Denmark	SNOMED CT is not updated often enough, the hierarchies are not clinically validated and it lacks concepts.
Denmark	Yes. It's very complex and timeconsuming
Denmark	time-consuming to learn how to use
Denmark	SNOMED CT is a complex terminology. Hence, users have to be trained.
Denmark	Only a small group of practitioners have been involved so fare
Denmark	time consuming to find the correct terms. not covering the full need of terms
Denmark	Hard to learn and navigate thought.
Denmark	Can be hard to find the exact concept / term the user is looking for, and the outcome can be overwhelming. If synonyms and/or clinical friendly terms and/or patient friendly terms are not developed for the single SNOMED CT concept, it can be nearly impossible to use SNOMED CT in a GUI. Developing of Pre- and post coordination would be a benefit to match the complex need in a EHR.
Denmark	Would prefere at national and international level that we need to use SNOMED CT.
Denmark	very complex. few nurses are able to get an overview, but used "in the background"(as not visible, but used to stack documentation) very useful
Denmark	SNOMED CT quality in specific areas e.g. origin of the Drug Allergy sub-hierarchy
Denmark	We need local extension and synonyms
Estonia	Time-consuming data entry
Finland	Serious translation difficulties. Problems with semantic & logical structures
Finland	no experienced cahllenges but rumours of Snomed perhaps is not optimal for whatever needs of coding
Finland	Here answer from my national role: definitely challenge with our difficult language (Finnish) - how to translate in a reliable way etc.
Finland	Translation challenges, perceived complexity
Finland	Mapping SNOMED codes to our decision support system's internal concepts is challenging due to the multitude of ways of coding the same situation. Searching for codes is complicated and often I feel unsure whether I have found all relevant codes. Searching / use of SNOMED with current tooling tends to take more time than searhcing / use of e.g. ICD-10.
France	we found incoherences.
France	SNOMED has less coverage than MeSH in Biological data
Germany	Customers that submit new concepts or relationships for adoption in SNOMED CT have to wait until the life-cycle of the standard terminology permits their curatory, peer-reviewed integration. The integration of the new items can sometimes take a prohibitively long time in which they are not able to cover facts in the electronic patient record. This leads to the necessity of creating provisory local extensions until the concepts are available. When concepts are available all software solutions using the provisory workarround need to be updated.

Member State	Have you already experienced or observed any challenges with using SNOMED CT in your organisation
Germany	post-coordination teaching implementing in CDA/FHIR
Germany	it's not licensed for general hospital use
Germany	High coding effort
Germany	a) The overall story and basic facts about structure and services can be explained quickly. However, practically there is a challenge to present and convince healthcare professionals of the valuable deep concept knowledge. After five minutes there is a feeling of "lost in hyperspace" when traversing through SNOMED CT, even when - in the meanwhile - there are quite good browsers. b) Around 2003 there have been a not-authorized "raw" German translation discussed in a closed user group for evaluation. This experience showed a lot of serious challenges with translating SNOMED CT. The translation issue should at least be treated carefully.
Germany	As DIMDI is only a provider of terminologies and classifications, a challenge with the use of SNOMED CT cannot be specified.
Germany	the long-term missing of a German translation!
Malta	mainly through Epsos and mentioned to be used for possible future projects.
Netherlands	- Understanding the added value - Making it fit for use (creating an interface terminology which is adequate and available in Dutch) - dealing with post-coordination - storage in clinical systems (long ConceptIDs seem to be a challenge for some vendors)
Netherlands	where to start yes or no translate (into Dutch) How to find valuable results in Always partial implementations
Netherlands	Acceptation of DHD diagnosis thesaurus (dutch translaton of snomed) is hard.
Netherlands	We are trying to develop services
Netherlands	We have experienced that some of the international SNOMED - ICD-10 mapping was not applicable to the Dutch situation
Netherlands	We're using a CMS called Drupal to record (among other things) measurements. For the temperature measurements, we chose to the measurement method as a Snomed CT code. Drupal lets us create a 'measurement method' field as key-value pairs, but it does not provide a way to record that the keys are snomed (or any other code). Also, we could not find a snomed code for measuring temperature in the ear.
Netherlands	We do not always find the right code and we are no medical professionals.
Netherlands	hard to find the right codes
Netherlands	Landelijke Basisregistratie Ziekenhuiszorg (LBZ) time consuming for clinicians
Sweden	Many of the EHR systems etc. that we use today do not support a sensible use of SNOMED CT and it's structure/hierarchies.
Sweden	Snomed CT has to be used in a standardized infoormation structure. For now there is no national or international consensus on the design of that structure.

Member State	Have you already experienced or observed any challenges with using SNOMED CT in your organisation
Sweden	The complexity of SNOMED CT makes it hard to promote implementation.
Sweden	Swedish national board of health tried to change OID for the whole Snomed-CT-SE. Thus the identifier for the whole terminology. This was stopped when they realized it was only an huge IT-cost, without any benefits. It reveals the low technical understanding of importance to keep identifiers stable over eternal time.
United Kingdom	Not part of clinical process. Clinical coders do not like working with SNOMED
United Kingdom	Basically the lack of commitment across the NHS
United Kingdom	See above ...what would you personally....
United Kingdom	Attempting iso-semantics
United Kingdom	Poor supplier implementations of search and browse. Variations in supplier roll out of new releases of SNOMED CT content.
United Kingdom	The adoption of SNOMED CT encoded data into the clinical record was believed to be a challenge as users perceive SNOMED CT not having an extensive coverage of concepts for their clinical domains. As a consultancy organisation, we have been recommending techniques to improve the way in which SNOMED CT concepts can be found such as removing/applying filters applied to the embedded search functionalities or constraining the set of terms to allowable concepts only (e.g. pick lists). Users are sometimes not aware that term additions and modifications can be requested either to their National Release Centre (NRC) or directly to the IHTSDO via the SNOMED CT International Request Submission system if their country does not have a NRC. I have observed a lot of cultural differences with regards to the way the data is being recorded. Not all healthcare providers are using structured data capture and free text data entry is still being done.
United Kingdom	SNOMED CT tooling remains problematic. IP rights remain obscure/potentially problematic. For clinical modelling development of value sets, there remain great difficulties in definitively determining correct content of term bindings and some ref-sets, due to huge number of arbitrary pre-coordinated terms. THere remain serious issues with self-consistency.

9.2.10 Have you already experienced or observed any challenges with using other international terminologies in your organisation?

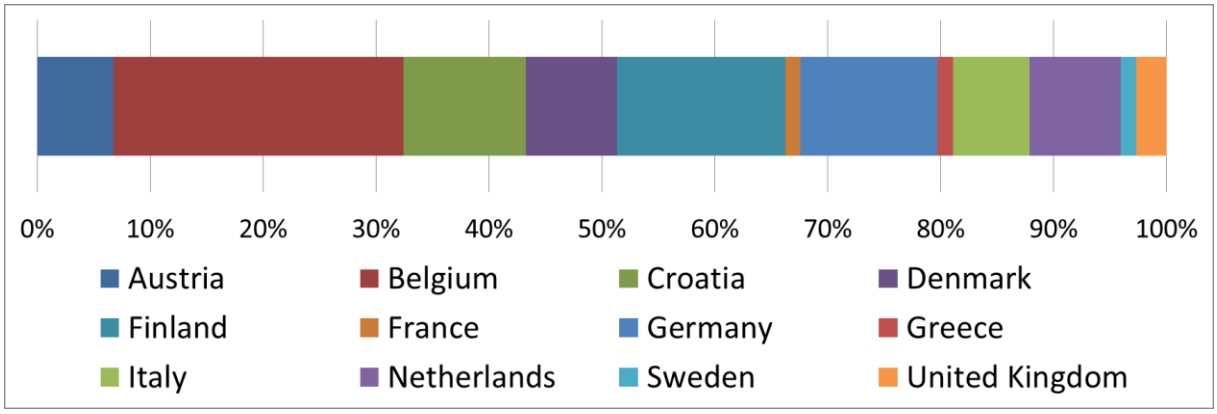
Just less than the 30% (38 over 136) of interviewed asserted that they have no direct experiences with international terminologies, among them only 22 (about the 60%) asserted also to not have experience with SNOMED CT in the benefit question (see above).

Six people indicating they have “no experience”, asserted also that international terminologies do not provide additional benefits.

Eigth, provided indications about experienced additional benefits with international terminologies.

The following figure shows the distribution of the no experience answers per country.

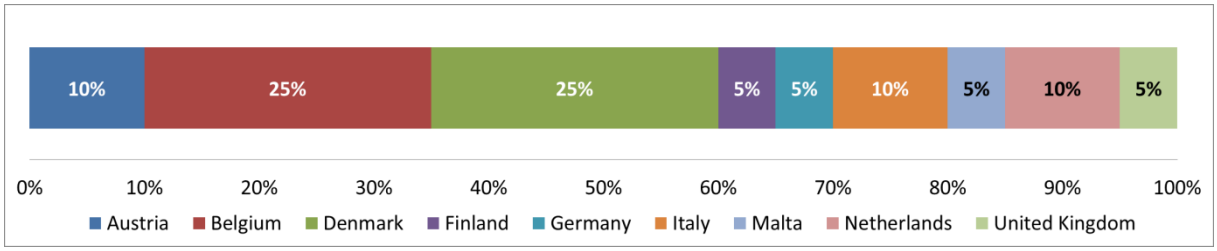
Figure 45 Distribution of the "no experience" answers per country



Considering the remaining responses (98) the **11%** (11) of respondents declared that they **have not experienced challenges or problems** from those international terminologies. Three of them claimed to not have experiences in the benfits related questions and six do not see "additional benefits" with international terminologies.

The following figure shows the distribution of the "no experienced challanges" answers per country.

Figure 46 Distribution of the "no experienced challanges" answers per country



The type of comments provided spans from very specific issues related to well specified and narrow conditions to generic comments, even for the same kind of issue (e.g. insufficient granularity). There are several comments that seem to be related to the usage of some terminology (e.g. ICD 9) beyond their effective scope; about this point please refer also to the Danish or Sweden Focus Group discussion. With this in mind, and referring to Appendix 2 for detailed results, a set of classes of experienced challenges have been identified:

- Translation costs (time and resources)
- Management of the transactional scenario (change management e.g. from ICD-9 to ICD-10)
- Quality and consistency issue (not enough granularity; missing concepts; "codes has same code but changed concept")
- Supporting procedure and tools for terminologies management (e.g. versioning)
- Lack on governance
- Coehxistance of multiple terminologies (mapping, conflicting information, variable granularity)
- missing link with administrative/economic related terminologies
- Fullfilment of national/local needs
- End-users acceptance

Member State	Experienced or observed challenges with using other international terminologies.
Austria	sometimes noc granular enough / missing concepts
Austria	Regarding the Project
Austria	Change of Revision /over time in timelines
Austria	ICD-10 is not popular with General practicioners, as it does not cover issues referring to healthy patients very well. Annual updates made by the German DIMDI are not always implemented in Austria completely. Basically, Austria uses a modified Austrian German version of the ICD-10.
Austria	coding ICD is very difficult if you want to do it properly. The provided Software (ID Diacos, Semfinder) are nice but als deliver a lot of crap. If the people who have to code are not properly trained the end up with wrong codes without realizing it. It gives me shivers sometimes when I think that healthcare planning relies on proper ICD coding ...
Austria	high conversion effort
Belgium	Learning curve, some reluctance to change habits
Belgium	codification is a "post processing" activity based on the medical report. Sometimes difficult to resume a stay with one code
Belgium	* being able to register at a low and at a high level of granularity
Belgium	ICD-9 not usable clinically
Belgium	Moving from ICD9 to ICD10 in 2015-2016
Belgium	The gaps between epidemiology and clinical work, the gap between communication and clinical work, lack of multidisciplinary team work culture, access to clinical information (decision support system)
Belgium	We have used ICD-9 since over 20 years. As it is coded after the facts and outside the medical record, it is only used for financial issues, not for clinical reasons. Benchmarks are folloxing 3-4 years later, which is to late for clinicians.
Belgium	A long time ago with ICD-9 but as it was needed for reimbursement purposes it was adopted (despite itself)
Belgium	coding in Belgium is used as a tool for financing hospitals. Gaming can not be excluded
Belgium	No satisfactory compliance by physicians in using ICD for Patient's Digital Record
Belgium	complexity and need of (international) refsets)
Croatia	adoption time curve, synchronization, not established authority ...
Croatia	Shortcomings in ICD10, e.g. no proper etiology classification.
Croatia	quality of coding
Croatia	only with ICD-10, ATC and ICPC
Croatia	Positive experiences only.
Croatia	Additional cost on having specialized people.
Denmark	YES ICD-10 is used very much
Denmark	teaching material in Danish language
Denmark	see comment above

Member State	Experienced or observed challenges with using other international terminologies.
Denmark	The work with Epic terminolgy in Epic system (not an international terminology), shows that it can be hard to translate and understand a term / a concept which is only used in "Epic world".
Denmark	It needs to be multihiarakily
Denmark	ICN-P very broad in terminology, and therefore useful for a nurse, but do not trigger any economy in Denmark, therefore in no interest according to economistin the organisation
Denmark	Some ICD-10 codes has same code but changed concept. This is a big problem, when the same codes has been used for years. Must never be the same code with different concepts over time.
Finland	Updates are always needed and working with them internationally is a bigger job and national interstes are not always heard.
Finland	we will have an international EHR system translated into Finnish, would have been easier if snomed CT had already been translated into Finnish
Finland	Serious translation difficulties. Problems with semantic & logical structures
Finland	It`s a challenge to get everybody to use terminologies as they are supposed to be used.
Finland	training of the heath care professionals is failing too often -ICD is not very informative, is not working well for example in cancer
Finland	As regarding all terminologies the use is not always appropriate due to busy work.
Finland	Since we tend to use ICD-O (WHO blue books) - it is not well applied other than tumor pathology.
Finland	I am using ICF -terminologies
Finland	Updating process may need more resources than expected, implementation of terminologies may not support data entry in an optimal way. There is a lack of good entry classifications
Finland	Slow uptake, translation and governance challenges
Finland	- ATC sometimes poses challenges when developing decision support content that aims to detect an active ingredient in a drug, because these can not always be fully deduced from ATC codes (e.g. ATC:N02AA58 dihydrocodeine, combinations contains combination drugs with codeine, but does not specify the other active ingredient, which may be e.g. ibuprofen or paracetamol) - RxNorm is pretty complicated compared to ATC - LOINC is also quite complicated due to the sheer number of codes, some of which seem very similar at first look and differ e.g. in measurement method etc.
Finland	No internal issues but some challenges in coordinated maintenance with key stakeholders.
Finland	List of ICD-10 codes currently in use in Finland do not follow WHO ICD-10 codes in 2015. New ICD-10 codes haven´t been updated in the national code server or [presumably] in the hospitals either.
France	Difficulty to represent with sufficient granularity medical problems using ICD10
France	we also found incohérences.

Member State	Experienced or observed challenges with using other international terminologies.
France	Our main challenges is about interoperability and thus about aligning these different terminologies. Another challenge is about managing versions and history of changes for each terminologies.
France	MESH was integrated in our Text Mining solutions for the normalization of extractions with better coverage for biological texts.
Germany	Variations in granularity of the ICD-10-GM and SNOMED CT determine the need of refining certain concept hierarchies to permit content coverage and to prune others in order to enhance practicability and appropriateness to the needed level of detail.
Germany	good to handle easy to use with adequate IT-systems
Germany	see above.
Germany	E.G. for drug related terminologies: - Integration of “legacy data”, which date from times before international terminology was in place (EDQM Terms) - Higher level of granularity is required, international terminologies have to be extended for specific activities (ATC-Code) - INN names are not available for all substances
Germany	Coding and definitions used in ICD10 and in SMPCs of drugs are imcompatible. This renders several key medication safety features of most, if not all, COPE/CDSS systems on the market useless.
Germany	
Germany	LOINC, ICD-10, ATC WHO are working properly for drug safety analysis.
Germany	the impossibility to map or merge national with international terminologies satisfiable. there is always a lack in covering use cases
Germany	difficulties in annotating drug information (from smpc) to terminologies
Germany	see above update issues due to inconsistencies
Greece	translations and transcoding are main challenges
Italy	The use of an international terminology for indexing, cataloguing, and for publishing allows my organisation to be part of a standardized process. Interoperability of data is another challenge that could be overcome by the use of a standardized international terminology.
Italy	Some social and cultural resistances by healthcare professionals because they consider international terminologies in terms of more strict control and/or more work.
Italy	It is difficult to let things change, in particular when statistics is involved. Any transition regarding ICD can be slowed down by the fear of breaking temporal series.
Netherlands	Introduction of ICD-10 has been often delayed due to the discontinuity it creates. Same goes for introduction of APACHE IV in ICU to replace APACHE II. No direct mapping exists, which requires double classification to overcome the discontinuity.
Netherlands	Icdo
Netherlands	mapping LOINC to the Dutch GP coding table for laboratory results can be challenging, since concepts between the clinical point of view is not necessarily the same as the 'laboratory' point of view.

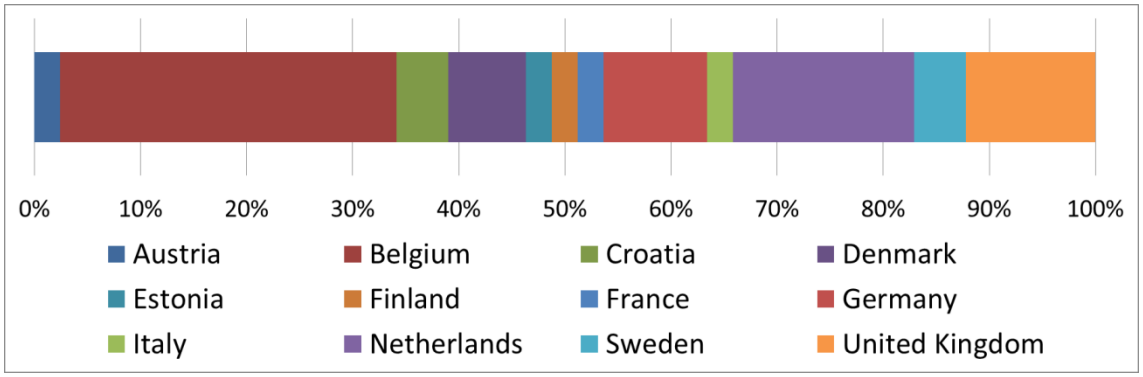
Member State	Experienced or observed challenges with using other international terminologies.
Netherlands	ICD10, time consuming, doctors see no value, coding is too limited
Netherlands	Yes Loinc (and ICD but that is a classification system)
Netherlands	users and vendors must work together. that takes time.
Netherlands	Although not used in the Netherlands, the International Classification of Nursing Practice (ICNP) is also a nursing terminology, developed by the ICN (International Council of Nurses). Even though we are not primary focussed at this terminology, it is specifically intended for use by and for nurses. Somehow I find it important that a nursing problem list of SNOMED CT matches with the nursing problem list of the ICNP (notice: I have limited knowledgde).
Sweden	See the question above
Sweden	The classifications ICD-10 and ICF are not granular enough for documentation of individual health data. But since they are already implemented in Swedish health care systems, there is a resistence to using SNOMED CT instead.
Sweden	Same as above for ICD-10-SE version change. The ID for a terminology is outside the terminology itself, but still extremly important out of a technical perspective.
United Kingdom	LOINC does seem more straightforward.
United Kingdom	challenges with interfaces to assist healthcare professionals coding at the point of data capture
United Kingdom	No authoritative machine readable forms of ICD10 or ICDO.
United Kingdom	Conflicting information, variable granularity
United Kingdom	The cross-mappings between ICD-10 and SNOMED CT is only semi-automatic has sometimes compromised the quality of the suggested list of ICD-10 terms displayed for clinical coders to choose from and encode.
United Kingdom	LOINC has a completely different design, and can be challenging to compute with, but as it is used in a simpler way - mainly to identify lab analytes / test elements, the difficulties are not particularly important.

9.2.11 Have you already experienced or observed any challenges with using local terminologies in your organisation?

About the 30% (41 over 136) of interviewed asserted that they have no direct experiences with local terminologies. With the exception of very few (3) there is an almost complete overlapping with people asserting “no experiences” in the benefits related questions.

The following figure shows the distribution of the no experience answers per country.

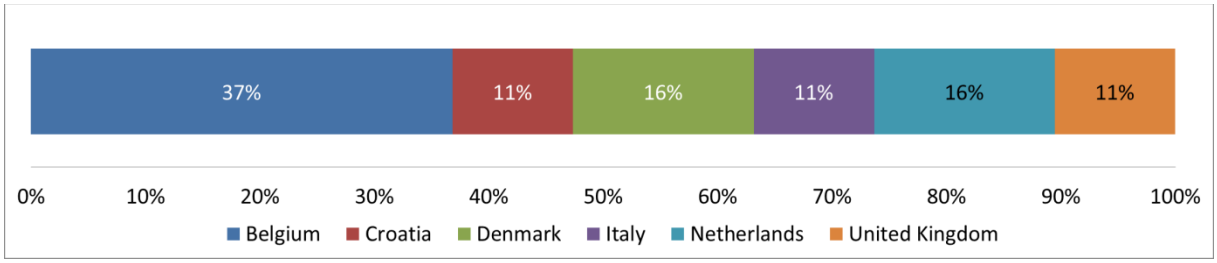
Figure 47 Distribution of the "no experience" answers per country



Considering the remaining responses (95) the **20%** (19) of respondents declared that they **have not experienced challenges or problems** from those local terminologies. Five of them claimed to not have experiences in the benefits related questions and other five do not see "additional benefits" with local terminologies.

The following figure shows the distribution of the "no experienced challenges" answers per country.

Figure 48 Distribution of the "no experienced challanges" answers per country



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Most of the comments provided refer to generic issues, the most frequently type of issues mentioned have been (further details below):

- lack of semantics
- lack of interoperability
- maintenance and consistency issues
- reusability of information outside the original jurisdictional or medical domain
- lack of standardization
- low scalability
- (long/medium term) highest costs (maintenance, mapping, quality costs)

Member State	Experienced or observed challenges with using local terminologies
Austria	Yes, building terminologies is very difficult. Completeness, the right granularity and structure as well as DEFINING the concepts are hard
Austria	lack of semantics lack of interoperability ambiguous classes information contained in code description --> not acessible by multiaxial architecture
Austria	maintainance and consistency

Member State	Experienced or observed challenges with using local terminologies
Austria	It is basically not the main responsibility of a Health Ministry to DEVELOP terminologies that fit a country's needs. However, this is the way it works in Austria: the Ministry of Health develops and maintains the terminology for the documentation of procedures, and also maintains the Austrian modifications of the ICD-10.
Austria	local terminologies often cover only what some people just needed for their domain, but not what would be needed to build up a proper medical decision support
Austria	local procedure-catalogues
Austria	difficult international comparability
Belgium	* rarely sufficiently complete * consensus difficult if not imposed
Belgium	interoperability between appointment system, OP scheduling, EPR, billing and coding systems (MBDS)
Belgium	increase of data registration
Belgium	Bad questionnaire!
Belgium	The maintenance of local terminologies that are not national is unsustainable.
Belgium	different EMR makes implementation not easy
Croatia	same as above + incompatible with wider context
Croatia	Many issues related to problems with linking it to DRG coding.
Croatia	No mapping to International terminologies.
Denmark	Lots of problems which requires mapping or manual handling of data due to the lack of standardization.
Denmark	Yes. There are both benefits and disadvantages of using local codes. Benefits are you are in control of ALL data and apply them widely throughout own IT system. The disadvantage is the exchange of data between other systems can be a problem if there is not a common language.
Denmark	A noticeable risk of creating duplicates. Structural challenges.
Denmark	We are at the moment testing the selected subset for undestanding and use
Denmark	Hard to navigate thought
Denmark	Can be hard for anyone else outside the specific organisation to understand and compare data.
Denmark	Se above
Denmark	Limited interoperability, diversity in documentation practices
Denmark	very difficult to implement because its a new way of documenting. Nurses has to be strict to the decisions
Denmark	At der forsat er et behov for eller ønske om ikke at være struktureret...struktur er styrende for sproget.
Denmark	No - it work absolutely ok and as intended. One thing could have been better, we have used a lot of time to be precise in definitions of codes and concepts - easyer if a existing classification could hav been used, but in midt zeros, only a few official Danish classifications was available, and that's the reason that we have to make our owns.
Denmark	decide level of details

Member State	Experienced or observed challenges with using local terminologies
Finland	We work with them daily (over 300 different classificatiosn/coding systems) and there are always challenges, but we have a system.
Finland	nationally terminologies are chosen from different sources: interoperability problems with international vendors
Finland	Semantic drift and needs for "extensions" of terminologies
Finland	the needed ict services are missing
Finland	It`s a challenge to get everybody to use terminologies as they are supposed to be used.
Finland	training of the heath care professionals is failing too often
Finland	As above
Finland	example: In a nordic collaboration I have faced difficulties in a non-neoplastic disease research which could have been over-came had we used snomed
Finland	Big country, so there is many way to express the same things
Finland	see above.
Finland	See the comments above
Finland	Limited compatibility on international level, mapping challenges
Finland	-Some organizations have used an abbreviated text form (intended for human display, not coding) to code laboratory measurements, and there are multiple ways to write these strings (e.g. hemoglobin could be "B-Hb" or "B -Hb") -Local laboratories may invent their own numeric codes which may collide with similar self-invented numeric codes in another organization
Finland	No direct observations but risk of overlaps and conflicts with international terminologies as well as challenges in efficient maintenance of terminologies.
Finland	Laboratorios have made some in-house codes and rules. These affect e.g. the cancer incidence statistics of certain cancers if certain sites of origin are missing.
France	very difficult to map two interface terminologies coming for two hospitals
France	we also found incohérences.
France	same as above.
Germany	Enterprises and institutions using local terminologies are encouraged to continue using these but mapping them to the standard terminologies which enables information exchange between clinical subsystems and consistent secondary, analytical usage of data. This is a very tedious task which requires subject matter experts to perform an initial mapping of all local terminologies to the Healthcare Data Dictionary and then maintain this mapping as new local terminologies are updated. However the effort of migrating all subsystems to use the reference terminology directly is tremendously higher as mapping.
Germany	good to handle easy to use with adequate IT-systems
Germany	local terminologies are not scalable and need A LOT resources
Germany	High maintenance cost

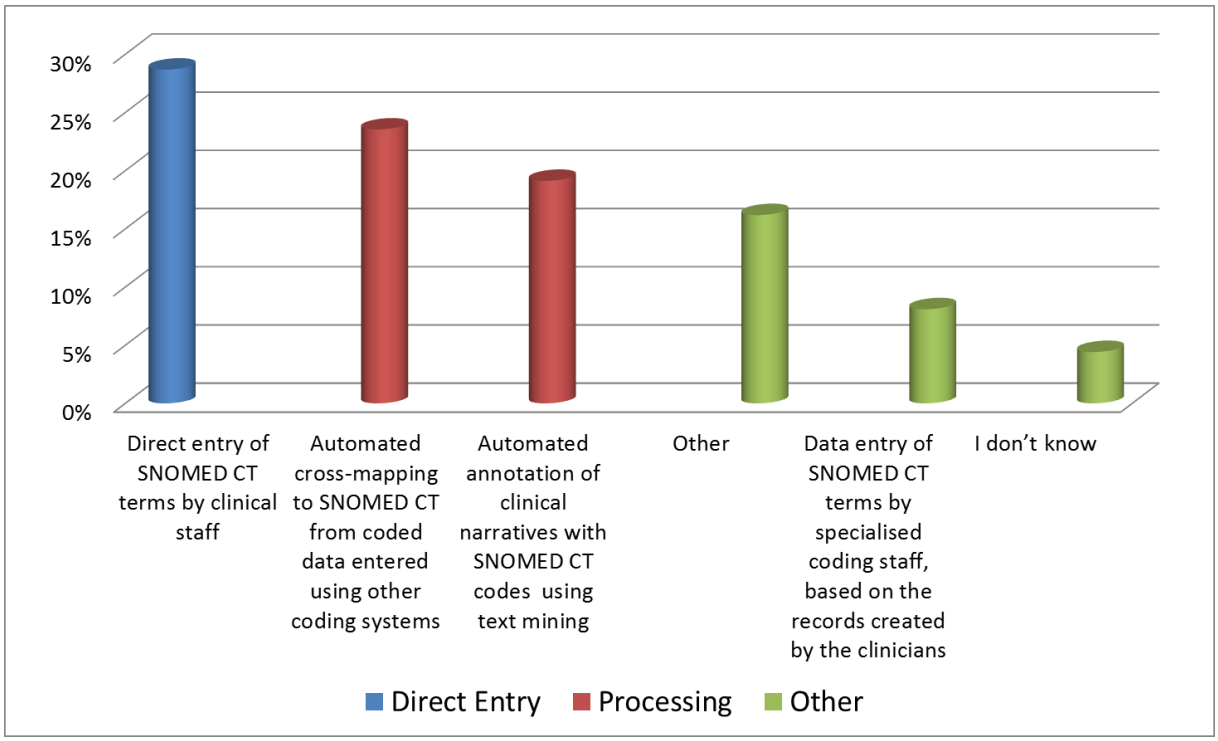
Member State	Experienced or observed challenges with using local terminologies
Germany	The SDE experiences mentioned above shows a typical problem in assessing terminologies: Services based on terminologies are a kind of "Enabling technology". Hence, their benefit depend on the whole complete application. A chain is only as strong as its weakest link. Wherever there is a problem (for technical, usability, etc.) the benefit of an involved terminology can not be demonstrated properly. In our project: Structured data entry (independent of being based on proper standard terminologies and equipped with profound added values) is still not accepted by most healthcare professionals.
Germany	E.g. for drug related terminologies: - Lack of harmonization of decision making across users and maintainers of a systems - Terminology expertise in not available in all departments - Legacy data cannot be overcome, mapping to current terms is required
Germany	Yes, no adequate possibilioties to include coding of local definitons into commercial patient record software.
Germany	Keine Abstimmung zwischen den zuständigen Organisationen
Germany	see 3 questions up
Germany	PZN, ASK are working properly for medication management.
Germany	the lack of knowledge engineers able to design and build medical ontologies based on local terminologies required to implement computable medical knowledge management (e.g. clinical decision support systems)
Germany	difficulties in annotating drug information (from smpc) to terminologies
Greece	It systems cannot communicate efficiently with local terminologies. in some cases each HCP has different terminologies, custom terminologies
Italy	In ISS Library we used a local terminology which did not allow dialogue with other institutions and was not coherent sometimes.
Italy	Local terminologies bring idiosincrasy and make clinical content diffucult to be understood
Malta	ability to maintain a centralized terminology in a decentralized environment.
Netherlands	Really local (i.e., home-grown) terminologies pose quite a maintenance burden.
Netherlands	alignment between medical specialties, time consuming, workflow issues
Netherlands	not well nationally maintained (lot of local differences in implementation)
Netherlands	hard to agree on which terms and terminology
Netherlands	Birads is adopted. Clarity for clinicians.
Sweden	Relating local terminology to national and international. Keeping track of local terminology in the absence of an underlying system of concept. Developing a local terminology against the clock (related to the deadline of an IT implementation project). Relating terms for EHR headings to “real terms”, i.e. not being able to separate interface terminology from reference terminology.
Sweden	They are just useful locally, never suitable on a regional or national level.
Sweden	Unclear responsibility on national level for existing national terminologies or code sets (in Sweden typical the "V-TIM 2.2" code lists).

Member State	Experienced or observed challenges with using local terminologies
United Kingdom	Not integrated into Acute Trust or community systems. GP systems use Read.
United Kingdom	Significant costs associated with constructing and maintaining crossmaps between different local terminologies. Naive technical design makes it hard or impossible to undertake certain forms of maintenance, including where legally required.
United Kingdom	As local terminologies are proprietary, it makes querying of multiple databases more cumbersome and effort is required to map and standardise the locally defined terms. Moreover, not all mappings of local terms to standard terminologies are exact and considerations need to be made to avoid mapping terms inappropriately.

9.2.12 Which of the following do you believe to be the most practical and usable approaches to coding clinical facts about a patient with SNOMED CT?

As clearly Figure 13 shows, most respondents favored the direct selection of terms by clinicians during data entry; as second option the usage of processing mechanisms for coding data using SNOMED CT: few people consider instead the post-hoc clinical coding the most practical approach for coding.

Figure 49 Which are practical approaches to coding clinical facts about a patient with SNOMED CT?



In most cases the "other" option have been selected to point out the fact that the approach should be context dependent, or might be a combination of the proposed solutions.

Hereafter the notes associated to the other option.

- Combination of structured entry in user forms and natural language processing within freetext fields
- all of theses, depends on the use case
- annotated data entry fields with SNOMED codes

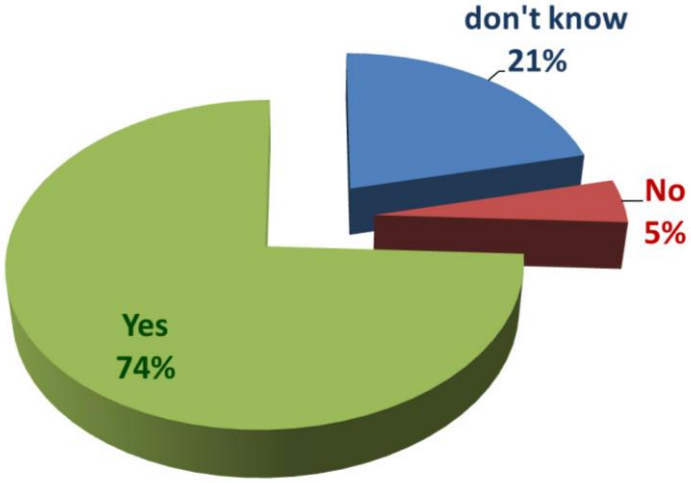
- attaching snomed terms to data entry fields in his/pdms applications
- we are using displayterms
- The snomed code is behind the User Interface. They would only see the natural language.
- Having spcialized staff structuring clinical records to fit the needs of clinicians and annotate this with SNOMED CT
- Depends of the way the software are build and th euserinterface. Hard question to answer
- sollte evaluiert werden!
- Not necessarily letting clinicians know that SNOMED CT concept codes are hidden behind end-user interface headings, phrases, or fixed-value sets.
- Contextual Pick list (sct fully specified name without the concept id) + free text together
- There should be pilot programmes to assess different options. It may be necessary to specify the most usable options locally e.g. at the organizational or even departmental levels during configuration of EHR's taking into account local coding needs (e.g. a cardiologist will need to code certain types of data, while a family physician will need other kinds of data). Clinician's workflows must be taken into account, and the resulting systems need to be tested in real clinical settings before taken into wider use.
- Automated cross-mapping to SNOMED CT from coded data using the method I designed
- direct entry of snomed ct terms by clinical staff using all but terminology browsers.

9.2.13 According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-borders ? (please indicate in the comments the reasons of your answer)

It is interesting to note that although the score about the usage of SNOMED CT is relatively low, the large majority of replies indicates SNOMED CT as a suggested candidate for the exchange of health and social data cross-border having a good coverage of most of the medical domains and being “the only broadly available terminology that can (when translated) overcome the language barriers”. This positive answer should however be read under well specified conditions and with identified caveats[16]. Like the fact that it might be **one of the** terminologies used, the answer may refer to specific use cases, the need in any case to support mapping with other terminologies (including legacy local terminologies), and other challenges identified by the previous questions (license cost, complexity, etc).

[16] About the 40% of people answering YES added a comment.

Figure 50 According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-border?



Hereafter the list of comments associated to the options selected

According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-borders ?	
I don't know	We don`t have enough knowledge of SNOMED
I don't know	Hard to say in a clear way, because I think the need for exchange data maybe is a 'wrong' or oldtime question. Think that crossboarder informations must be store in same system, and that reduce the need for exchanging. If you use Snomed Ct or another system doesn't matter, just both sides use same.
I don't know	Heard of major complexity wich makes GP's afraid of using it..
I don't know	The idea of a unified data format sounds good. The absence of a working system that satisfies everones needs should serve as a warning that such a data set may be difficult, if not impopssible to define. I received not enough information on SNOMED along with this with this survey to judge its capabilities and use.
I don't know	Es gibt keine belastbare oder zumindest im deutschen Markt anerkannte Evaluation. Eine Meinungsbildung auf Grundlage des geringen Wissens in D ist kontraproduktiv.
I don't know	This is the question Access CT has to answer. ;)
I don't know	I'm not sure if it should be, but I believe that it could be. A large multilingual terminology with set of unique codes for concepts should be fit for international data exchange. Due to the fact that the same terminology can be used for exchange within a country, region, health care provider and so on, SNOMED CT can potentially be an all-purpose basis for different types of exchange.
I don't know	I am not enough expert in SNOMED CT to judge its appropriateness in generalising its use for cross-borders exchanges.
I don't know	That there should be a standard is of course right but whether this should be SNOMED is questionable as it depends on the extent to which how many countries are committed to it and how necessary it is to exchange to data across boarders

According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-borders ?	
I don't know	Magnitude is a PRO for SNOMED, cost are a CON
I don't know	I think that there is no more complete and comprehensive terminology than SNOMED CT. However, the fact that a terminology is complete does not make it easy to use or easy to implement. For Austrian needs, there are other, less expensive solutions possible.
I don't know	In principle it should be at some point. It is not yet clear to me that wholesale use for this purpose would bring benefit outweighing the likely considerable cost of implementing its use. Cleaned up content and better tooling and software libraries and services would be a great help.
I don't know	Details about snomed CT are unknown
No	Dream on...
No	No until there are national guidelines and how often do you need to exchange data (that are clasfficied) cross borders. The text will be very helpfull for the main purpose of treatment
No	Klinik stoler ikke på data de ikke selv føder - selv inden for egen region gentages anamnese, prøver og undersøgelser!
No	SNOMED CT is expensive. I have reasons to believe that many EU countries can´t afford that.
Yes	I do not know of any other clinical terminology that covers broadly and deeply enough to do this.
Yes	A terminology is needed, SNOMED CT or something else and SNOMED CT is one possibility.
Yes	Due to it's good coverage of all medical domains SNOMED CT is a good start in solving cross-border interoperability. However language extensions, mapping to country mandatory and local legacy terminologies is a 'sine qua non' requirement.
Yes	SNOMED is the only broadly available terminology that can (when translated) overcome the language barriers
Yes	, provided it will be defined as a mandatory terminology.
Yes	As mentioned above, though I know that snomed has its weaknesses, having ONE commonly agreed on terminology would outweigh any such weaknesses.
Yes	1) not only Snomed but also LOINC 2) to a limited extent: 'meaningful use', eg. diagnoses, treatments, contra-indications and the like. Certainly not the medical day-yo-day narrative.
Yes	We don't do much cross-border exchange of health data, but for us it would be beneficial if Snomed were available in a German and French translation.
Yes	In specific, probably limited contexts, as one (but not the only) reference terminology.
Yes	health data: -it would be the first step to right direction -provides possibilities to automatised processes
Yes	yes, because an international reference terminology helps improve cross-cultural understanding within and between borders - nationally or internationally
Yes	I believe that Snomed CT is future tool for better data - so you should use it at all levels of data exchange
Yes	maybe.. whit time..

According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-borders ?	
Yes	Snomed CT is probabaly the only available system that can realistically be expected to be adapted by a wide range of olrganization internationally.
Yes	International health risks, International disease prevention, Improving international health,research...
Yes	Yes, standards are always welcome, the challenge is to enforce it through legislation, however, to be of benefit a standard should be and open standard and free to use.
Yes	For any international data usage the terminology must be unified without losing usability for local needs. The transformation must be automatic as no-one wants to and has the time for coding a second terminology.
Yes	If proper mappings can be managed (perhaps not possible)
Yes	use of only Snomed CT is optimistic.
Yes	If agreed upon internationally
Yes	See http://www.epsos.eu/
Yes	but as one among many may be one important but a lot of medical knowledege is still lacking in SNOMED CT therefore, a multiterminology approach sounds the best solution (using UMLS)
Yes	Eventually, when the obvious complexity-related challenges with codifying and interpreting the codes have been solved.
Yes	with some limitations
Yes	One of the terminology system that should be used
Yes	SNOMED CT is a very good standard
Yes	This is a long-term goal. I see no better alternative today. But need to be: a) subsets b) which are term-bound into clinical context (read detailed clinical information models) c) codes invisible to endusers, instead bound to labels and pick-lists. --- These infomodels with termbinding of subsets of codes, must be shared on international level to be useful for cross-boarder exchange. Probably even more interresting to share medical knowlegde defined in an international way, than to share patient data.
Yes	Providing that compliance with medicines related standard terminolgies is ensured.
Yes	There is something of a tipping point to this question and how can one not support its well researched principles? However only a few specialists need to know details.
Yes	What else would you use?
Yes	Existing standards like ICD are increasingly unfit for the purpose of analysing population-level data nationally, and so are correspondingly of less use in sharing population data cross-border. If the data to be shared is individual-level, then the is no other contender for its representation - especially if the requirement is to represent and share information about the process of delivering care, and not just the reasons for it.
Yes	Nevertheless, there are some issues with SNOMED CT that need to be resolved. Also the enormous size of SNOMED CT could cause problems (especially regarding usability)
Yes	As an unified terminology system because of people moving more and more

According to your knowledge and perception do you think that SNOMED CT should be used for the exchange of health and social data cross-borders ?	
Yes	Yes depending on whether local, regional laws, national, EU data protection laws permits the exchange of health and social data cross-borders. If the exchange of this data is permitted, I believe that SNOMED CT provides a vehicle for enabling the interpretation of clinical information on each side of the border. The terminology supports multilingual use and inherent structure of the terminology can recognise national and local extensions.
Yes	Snomed is probably not the perfect "coding"system, but there nothing better either ...
Yes	No cost implications should be foreseen thought

10 Annex 3: Country overview questionnaire

This report is based on responses gathered before the July 9th 2015, covering **14 Member States**: Austria; Belgium; Croatia; Czech Republic; Estonia; Finland; Germany; Greece; Italy; Malta; Netherlands; Slovakia; Sweden, United Kingdom.

The response from the United Kingdom, collected during a meeting organized with UK representatives, is included in this report with the caveat that the answers reported need to be explicitly validated by respondents.

Responses from Denmark, Luxembourg and Portugal have been also received after that date; additional responses from the other European countries are expected to be received in the next months. All those responses will be processed and documented in a second stage and integrated in the final deliverable (D1.3).

A draft report of the Country Overview results was prepared on Mid July and shared with all the interested parties for the content review.

All the received changes have been tracked and considered for this deliverable.

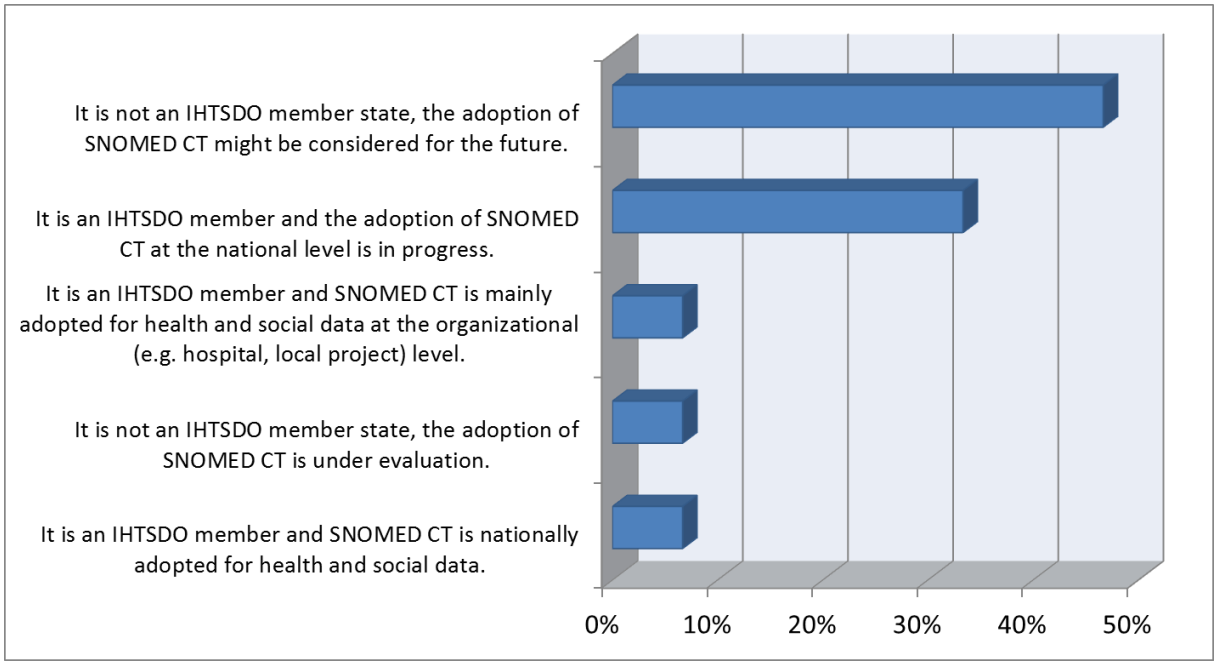
Hereafter the consolidated report.

10.1 About your country

This section of the questionnaire aims to provide an overview of main characteristic of each country.

10.1.1 Which statement describes your country best (IHTSDO membership and SNOMED CT adoption)

Figure 51 - Which statement describes your country best (IHTSDO membership and SNOMED CT adoption)

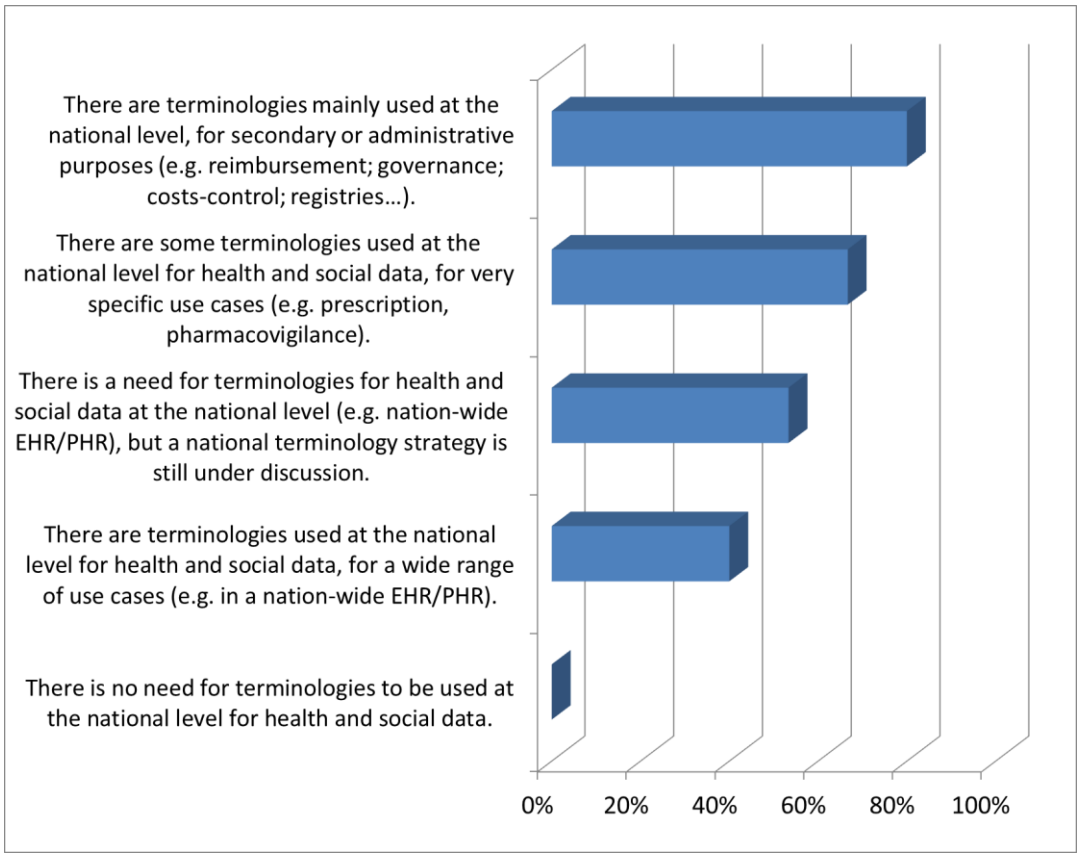


This questionnaire confirms the current limited usage of SNOMED CT in the interviewed countries: for the large majority of them the adoption is in fact in progress or under consideration.

Member State	Which statement describes your country best -	Comment
Austria	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Belgium	It is an IHTSDO member and the adoption of SNOMED CT at the national level is in progress.	Early stages, use case based approach
Croatia	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Czech Republic	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Estonia	It is an IHTSDO member and the adoption of SNOMED CT at the national level is in progress.	
Finland	It is not an IHTSDO Member State, the adoption of SNOMED CT is under evaluation.	
Germany	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Greece	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Italy	It is not an IHTSDO Member State, the adoption of SNOMED CT might be considered for the future.	
Malta	It is an IHTSDO member and SNOMED CT is mainly adopted for health and social data at the organizational (e.g. hospital, local project) level.	The intention is to adopt SNOMED CT as a national standard. However, to date implementation has been at the organisational level.
Netherlands	It is an IHTSDO member and the adoption of SNOMED CT at the national level is in progress.	
Slovakia	It is an IHTSDO member and the adoption of SNOMED CT at the national level is in progress.	
Sweden	It is an IHTSDO member and the adoption of SNOMED CT at the national level is in progress.	
United Kingdom (*)	It is an IHTSDO member and SNOMED CT is nationally adopted for health and social data.	NRC supports the UK and all (England, Wales, Scotland, North Ireland) contribute to IHTSDO membership. The strategies and the approaches are however different across the 4 countries. This questionnaire mainly describes England for which there are several uses cases where SNOMED CT is the adopted solution.

(*) To be explicitly validated

10.1.2 Which of the following statements apply to your country (usage of terminologies at the national level)



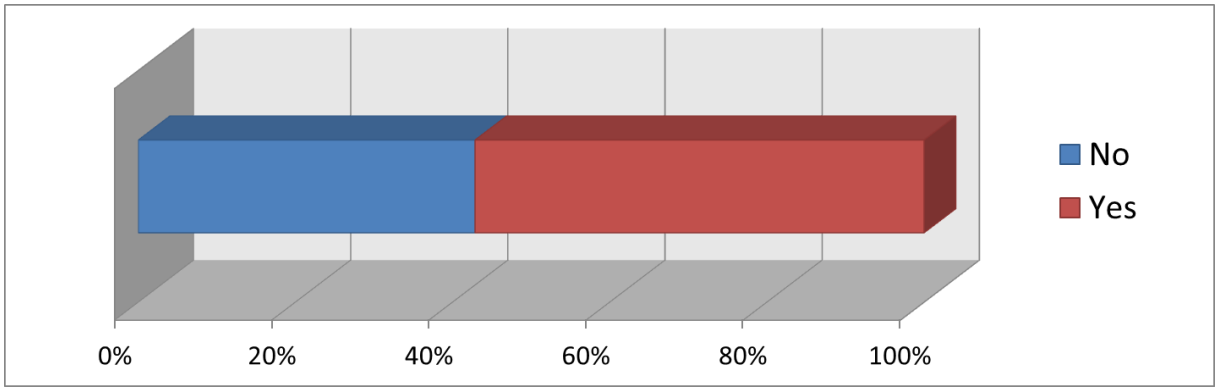
Almost all the countries use terminologies at the national level for secondary or administrative purposes or for very specific use cases. Almost an half of countries claims that a national strategy for terminology is under discussion.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
There are terminologies used at the national level for health and social data, for a wide range of use cases (e.g. in a nation-wide EHR/PHR).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
There are some terminologies used at the national level for health and social data, for very specific use cases (e.g. prescription, pharmacovigilance).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
There are terminologies mainly used at the national level, for secondary or administrative purposes (e.g. reimbursement; governance; costs-control; registries…).	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
There is a need for terminologies for health and social data at the national level (e.g. nation-wide EHR/PHR), but a national terminology strategy is still under discussion.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
There is no need for terminologies to be used at the national level for health and social data.	□	□	□	□	□	□	□	□	□	□	□	□	□	□

(*) To be explicitly validated

10.1.3 Is/are there national competence center(s) for terminologies in your country ?



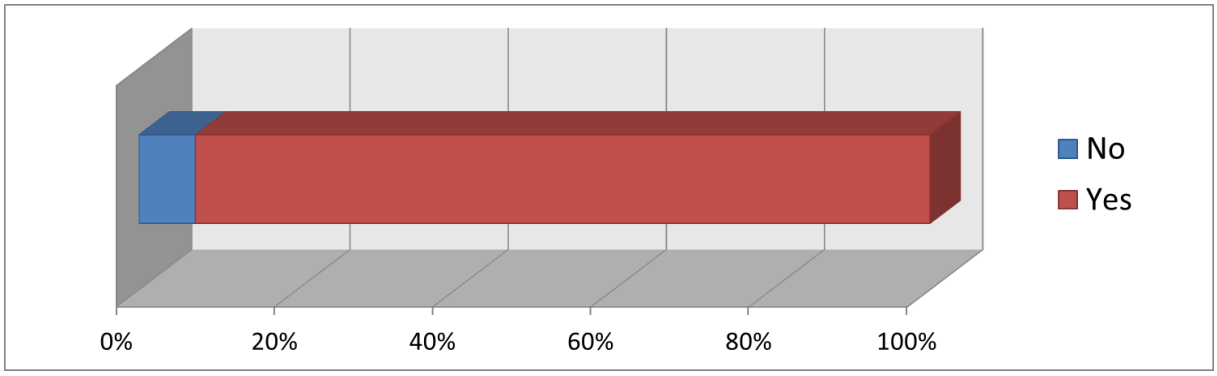
Less than half of the countries declared to have a National Competence Center(s) for Terminologies: AT, BE, EE, FI, DE, SL, SE, UK. (see table below). This is an important aspect to be taken in account also in the perspective of terminology policies at the national level.

Member State	National competence center(s) for terminologies	
Austria	Yes	Federal Ministry of Health, ELGA (EHR)
Belgium	Yes	Belgian NRC, known as the Terminology Center, governance rests with stakeholders defined by the National Action Plan e-health 2013-2018
Croatia	No	
Czech Republic	No	
Estonia	Yes	The Institute of Estonian Language, Medical Terminology Comission
Finland	Yes	The National Institute for Health and Welfare (THL) has this role by law
Germany	Yes	Medical terminologies, classifications and standards are maintained by DIMDI (German Institute of Medical Documentation and Information) for the use at national level.
Greece	No	

Member State	National competence center(s) for terminologies	
Italy	No	There are National representative organizations for specific terminologies: e.g. LOINC Italia for LOINC; the Italian Collaborating Centre for the WHO-FIC (Friuli Venezia Giulia Region); etc. Even if the Health policies are under the responsibility of the Ministry of Health, there is not for the moment a specific competence center dedicated to terminologies.
Malta	No	
Netherlands	Yes	Nictiz
Slovakia	Yes	Narodne centrum zdravotnickych informacii
Sweden	Yes	SNOMED CT National Release Centre National Release Centre for WHO classifications/other national classifications
United Kingdom (*)	Yes	National Release Centre (NRC) serving the UK: is supported by a number of UK governance and editorial functions

(*) To be explicitly validated

10.1.4 Are there international terminologies used nationally for health and social data ?



Concerning the question about the usage of international terminologies at the national level only the Czech Republic has asserted to not use it. ICD-10 (with or without local extensions) and ATC are the most commonly used (even if with different scopes) [See table below for details]

Member State.	International terminologies used nationally for health and social data: name, scope, and - if known - who is responsible for them.
Austria	ICD 10 BMG 2014 - Health Ministry LOINC - ELGA ATC - AGES
Belgium	LOINC - laboratory ICD-10 - different uses e.g. causes of death ICPC-2 - general practitioners ICD-10-CM/PCS - policymaking and reimbursement purposes - Federal Public Service ICD-O - research - cancer registry ICF - occupational medicine APR-DRG - grouping of ICD-10-CM/PCS for reimbursement purposes - Federal Public Service

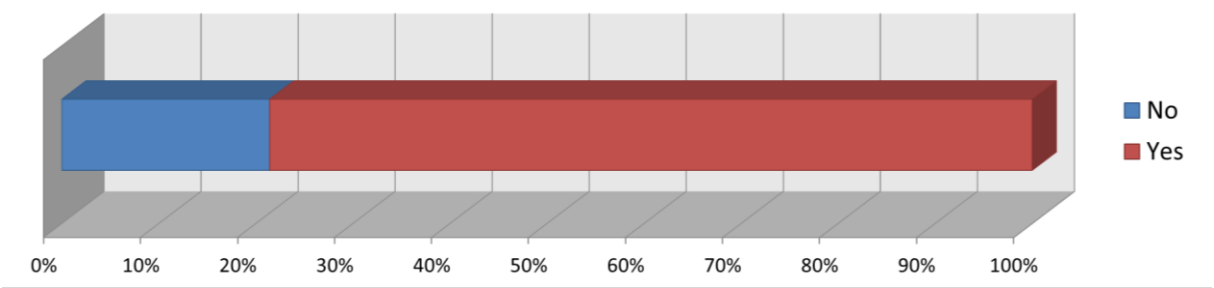
Member State.	International terminologies used nationally for health and social data: name, scope, and - if known - who is responsible for them.
Croatia	ICD-10 ATC
Czech Republic	No International Terminologies used for health and social data at the national level.
Estonia	ICD-10-for diagnosing and statistics-Ministry of Social Affairs; ATC-drug prescriptions-Republic of Estonia Agency of Medicines; International Standard Codes for the Representation of the Names of Countries-Statistics Estonia; UICC TNM-for cancer diagnosis-Estonian Cancer Association; LOINC-for laboratory procedures-Estonian Laboratory Medicine Association (in the near future it will be ours); International Standard Classification of Occupation - Estonian Statistics.
Finland	ICD-10 (THL) ICD-0-3 (Cancer Society + THL) ICPC2 (Association of Munincipalities + THL) International classification of Nursing (localization, Yhe University of Eastern Finland + THL) The Nordic Classification of Surgical Procedures (THL) ATC (The Finnish Medicines Agency) ICF (THL) FinLoinc (THL) EN/ISO:9999: Assistive products for persons with disability
Germany	ICD-10 –for diagnosis-coding in mortality, for morbidity national adaptation was created (ICD-10-GM, German Modification, see below) – responsibility for german version at DIMDI ICD-O-3 –for coding of oncology diagnosis – responsibility for german version at DIMDI ATC/DDD – for coding of drug information – responsibility for german version at DIMDI ICF – ICF-terminology in use for all kinds of applications in rehabilitation medicine – responsibility for german version at DIMDI UMDNS – for coding of medical devices – responsibility for german version at DIMDI EDMA – for coding of in-vitro devices Provided for national use, but not fully implemented: UCUM and LOINC - for coding of Labratory information MeSH and UMLS - The medical thesaurus MeSH (Medical Subject Headings) and the UMLS (Unified Medical Language System) as a metathesaurus and semantic network are used for cataloging of library holdings, indexing of databases and improvement of retrieval.
Greece	ICD10 diagnosis and for reimbursment purposes - MOH ATC drug control - greek drug authority ICPC-2 eP system CPT considered for medical procedures not established yet MOH
Italy	ICD-9-CM:2007 – procedure accounting purposes (DRG) ; morbidity statistics ; other clinical contexts (e.g. Patient Summary) - Health Ministry EN/ISO:9999: 1998 - Assistive products for persons with disability (as part of the national nomenclature) - ATC - Drugs classification - AIFA ICD 10 mortality statistics ICD-O-3: tumor registries. MedDRA pharmacovigilance

Member State.	International terminologies used nationally for health and social data: name, scope, and - if known - who is responsible for them.
Malta	ICD-10: Used at national level for classification of diseases ICD-9-CM: Used by Government hospitals for classification of surgical operations and other procedures ATC: Used by certain Government Health Service departments for classification of pharmaceutical products ICPC: Used by Government Health Service departments for classification of concepts in the primary health care sector
Netherlands	ICD-10: Classifications/Mortalities: RIVM (WHO-FIC), for statistical and analytical purposes ICF: Functioning: RIVM (WHO-FIC) Omaha Systems Support - Omaha Systems, some home care organizations Raiview – Some Eldery homes Nanda (Nic/Noc) – Some hospitals ICPC(1) for GP's ATC EN/ISO:9999 LOINC – In some labs
Slovakia	ICD – 10./SK – DRG- International Statistical Classification of Diseases and Related Health Problems 10.version Slovak republic Diagnosis Related Groups (responsibility: Urad pre dohlad nad zdravotnou starostlivostou) ATC- Anatomical Therapeutic Chemical classification system (responsibilty: Statny ustav kontroly lieciv), LOINC- Logical Observation Identifiers Names and Codes INN- International Nonproprietary Names EDQM- European Directorate for the Quality of Medicines & HealthCare UCUM- The Unified Code for Units of Measure
Sweden	ICD-10 - National Board of Health Welfare
United Kingdom (*)	LOINC (in some devices) READ2, CTV3 currently co-exist in primary care with SNOMED CT Secondary care: ICD 10 and OPCS 4.1 Mortality: ICD 10

(*) To be explicitly validated

10.1.5 Are there relevant domains for which you feel that – in your country – Nationally adopted terminologies are missing ?

The large majority of interviewed countries, with the exception of Austria, Slovakia, and United Kingdom, asserted that relevant domains are not actually covered by nationally used terminologies.



Domains mentioned spans across very different types of classes of information and use cases. The most cited ones are :

- Lab Procedures
- Procedures
- Allergies
- Medical Devices

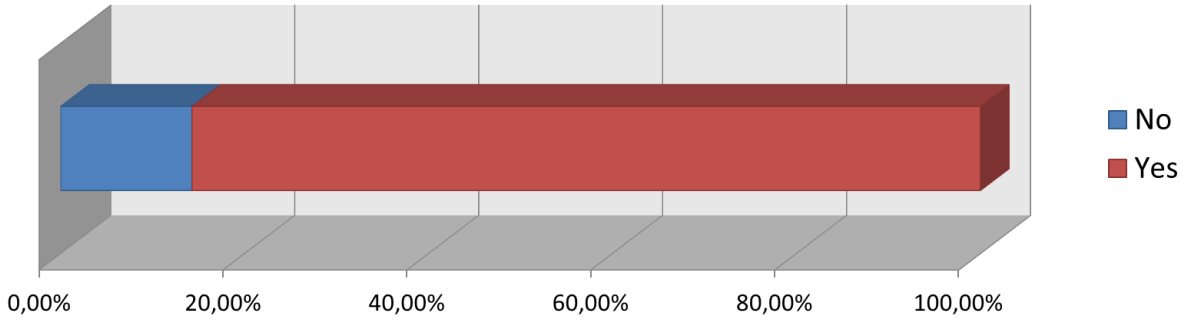
It should be considered for future investigations the analysis of the reasons of the lack of usage of terminology for those domains at the National Level. For example challenges related to the selection and adoption of terminologies; lacks on agreed information models and tools for capturing those data as structured and coded information; etc.

Member State.	**Relevant domains for which is felt that Nationally adopted terminologies are missing**	
Austria	No	
Belgium	Yes	Health care - different domains - semantic and technical interoperability Health care - different domains - reuse of date and administrative simplification Health care - patient safety and decision support Rare diseases Health care - research
Croatia	Yes	Most healthcare data is unstructured; clinical terminologies missing; terminologies used mostly for administrative and financial purposes.
Czech Republic	Yes	lab procedures - mapping to LOINC is needed allergies - often uncoded
Estonia	Yes	We are heading towards the thinking that more and more international terminologies could be in use. We would like an international terminology to be use for diagnoses because ICD-10 is more for statistical uses, also we are analysing possible international terminologies for procedures, administrative health services, dental care.
Finland	Yes	Anatomy, clinical status, expressed as free text in many contexts
Germany	Yes	The adopted terminologies for national do cover only a certain range of areas. For specific applications sometimes nationally accepted and adopted terminologies are missing (infectious disease reporting, cancer data reporting throughout all different sections of data collection, etc.). Projects are ongoing to evaluate the necessity of alignment of different terminology solutions for local applications that are in place or to adopt a new international terminology
Greece	Yes	lab procedures, clinical procedures

Member State.	Relevant domains for which is felt that Nationally adopted terminologies are missing	
Italy	Yes	Allergies (agents, type of reactions,..) - often uncoded Illnesses (for clinical purposes) lab procedures - locally defined procedures (for clinical purposes) substances (excluding the ATC classifications) vaccinations medical devices
Malta	Yes	Lab procedures: local dictionaries are used (rather than LOINC)
Netherlands	Yes	Procedures Nursing terminologies Lab Allergies Medical devices
Slovakia	No	
Sweden	Yes	Several domains - in general local (and not national) terminologies are used.
United Kingdom (*)	No	All the needed domains are covered by the selected terminologies, even if activities are in progress for improving some of them.

(*) To be explicitly validated

10.1.6 Are there Nationally defined terminologies used at the national level for health and social data ?



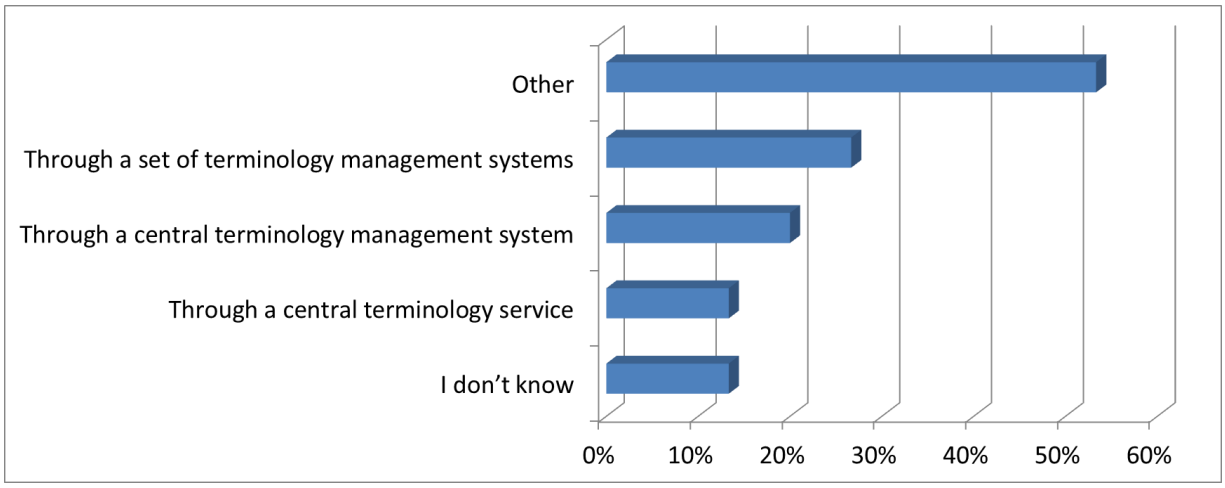
With the exception of Malta and Slovakia, all the countries declared to use, at the national level, national defined terminologies covering very different areas. Some recurring cases are drugs nomenclature / classification; procedures; codes for accounting (details below).

Member State	Nationally defined terminologies used at the national level for health and social data	
Austria	Yes	Procedures Catalogue - Health Ministry Intensive Care Classification - Health M Pharma-Zentralnummer - AGES maybe others

Member State	Nationally defined terminologies used at the national level for health and social data	
Belgium	Yes	
Croatia	Yes	National version of DRG-type terminology (HZZO)
Czech Republic	Yes	SUKL ID (national drug registration ID) - SUKL is responsible NCLP (national list of lab procedures) - Group of vendors is responsible DASTA CODELISTs (national vocabulary for communication protocol (like HL7 Vocabulary)) - Group of vendors is responsible List of procedures (procedure -> payment) - General Health Insurance Company
Estonia	Yes	medical specialities - for defininf the speciality of healthcare worker-Health Board; Classification for Nations-Estonian Statistics; List for health services-Estonian Health Insurance Fund; many other smaller value sets.
Finland	Yes	We have over 250 classifications/ code-systems for health and social care available via the national code server. THL is responsible. http://91.202.112.142/codeserver/
Germany	Yes	ICD-10-GM – for diagnosis-coding of morbidity information Alpha-ID – more detailed code for coding of diagnoses PZN (Pharmazentralnummer) – for identification of drug packages OPS (Operationen- und Prozedurenschlüssel) - Procedure coding system
Greece	Yes	medical procedures for reimbursement purposes
Italy	Yes	AIC (national drug registration ID) – medicinal product identification – AIFA Gruppi di Equivalenza - medicinal product clustering – AIFA
Malta	No	
Netherlands	Yes	G-Standard - Pharmacy: Z-index PALGA - Pathology: Palga NHG tables - Modified ICPC: NHG DBC – Equivalent of DRG's Cineas – Rare deceases
Slovakia	No	
Sweden	Yes	National/Regional classifications for procedures
United Kingdom (*)	Yes	OPCS4 - procedures READ codes (Clinical Terms Version 3) Imaging codes

(*) To be explicitly validated

10.1.7 How are the nationally adopted terminologies are managed (administration; authoring;…)



The authoring and administration of the terminology assets (value sets, code systems,..) seems to be for the large majority of cases (> 50%) managed not using terminology systems/services, but alternative solutions. In the most cases by means of excel files.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Through a central terminology management system	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Through a set of terminology management systems	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Through a central terminology service	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I don't know	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (see below)	☐	☐ ☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

(*) To be explicitly validated

Other

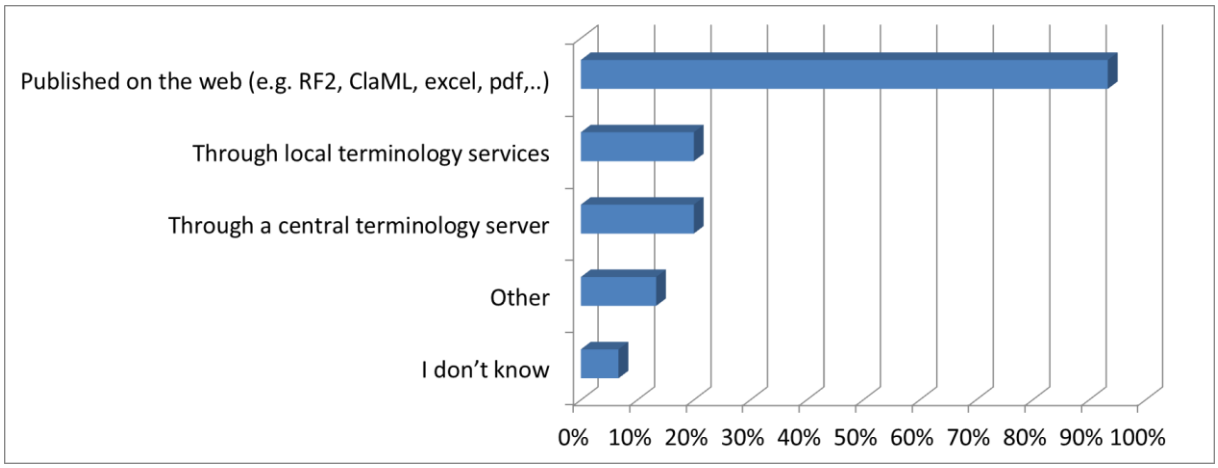
- Austria: MS Excel Spreadsheet
- Belgium: define "terminology management system"
- Czech Republic mostly in MS Excel
- Estonia some are managed in our organization, some in other organizations
- Greece no enforcement for common data sets
- Italy local solutions (e.g. excel)
- Malta They are managed manually using standard office automation tools, without a specific terminology management system.
- Netherlands Each terminology has its own tooling and/or excel sheets
- Germany: Not specified

Additional Information

Austria	Procedures and IC maintained yearly, Pharma - connected to authorisation
Belgium	Basic systems: Locally developed applications, flatfiles, ... A central terminology management system, with authoring is lacking.
Croatia	Currently, no system for national DRG-type terminology administration is used. DRGs are managed via MS Excel Spreadsheets. Updates are managed manually at HZZO.
Estonia	We do not have common system for managing terminologies, usually the organization that develops the terminology will also be the manager in the future. But this is in some change in Estonia at the moment, some of the terminologies are moving to our organization.
Finland	We have a code server and a system of expert groups (20+) for defining and upgrading the codes/classifications.
Germany	DIMDI uses a central terminology and classification management system for most of its classifications
Greece	some terminologies has been brought to Greece in Greece by the national school of public health some others via Universities and Academia some adopted by the MoH no basic maintenance scheme the eP system has increased awareness and national needs.
Sweden	The international/national/regional classifications are managed by the unit for classifications and terminology at the National Board of Health and Welfare. The SNOMED CT release centre is located in a different part of the NBHW.
United Kingdom (*)	A number of bespoke tools for terminology editing/distribution, request submission, mapping to classifications and supporting mapping from legacy terminologies. In the order of 5/6 different tools. Authoring Tooling pre-existed IHTSDO workbench.

(*) To be explicitly validated

10.1.8 How are the nationally adopted terminologies made available for usage ?



Almost all the countries use the Web publication as a mean for distributing terminologies. Less than the 50% uses local or central terminology services.

Member State	AT	BE	HR	CZ	EE	FI	DE	DE	GR	IT	MT	NL	SI	SE	UK (*)
Through a central terminology server	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Through local terminology services	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Published on the web (e.g. RF2, ClaML, excel, pdf,..)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I don't know	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (see below)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

(*) To be explicitly validated

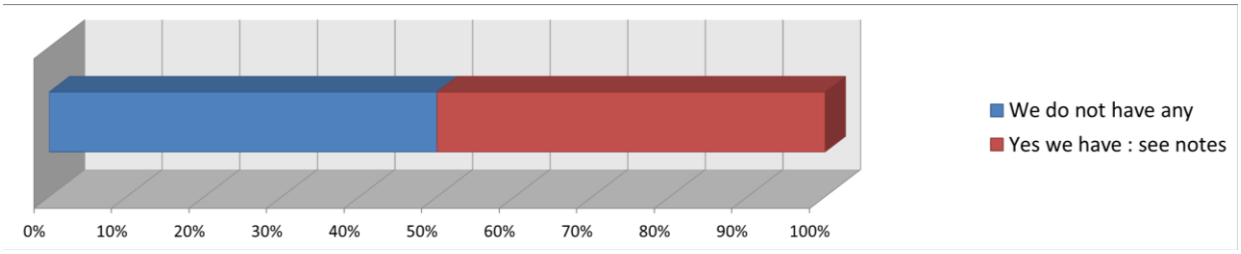
Other

- Belgium: Made available as reference files, in some cases integrated through APIs with data capture screens.
- Sweden: via email exchange

Additional Information

Estonia	See above, delivered via the code server, also published guides for usage
Finland	International and national terminologies and classifications are published on the open web via the code server. They all can be downloaded as Excel sheets, XML and. text formats. In addition some major classifications are available as published/electronic books (ICD-10, Surgical procedures). When a license to share the codes openly via the web is needed, it has been asked for from the license owner. Some licenses have costs that are covered with state funding from THL budget.
Germany	Excel spreadsheet containing the national DRG-type terminology is published on the web and publically available. Discussions about the need for a central (national) terminology server have recently started, but today it doesn't exist.
Malta	Published on the web

10.1.9 Tools and technologies that have been applied in your country for facilitating the usage of nationally adopted terminologies by end users



About half countries asserts that no tools or technologies are used for facilitating the usage of nationally adopted terminologies. Most of the mentioned tools refer to solutions for supporting the access and distribution of terminologies (terminology servers, web browsing tools,..). Please refer to the following table for further details.

Member State	Please describe what tools and the technologies have been applied in your country for facilitating the usage of nationally adopted terminologies by end users	
Austria	Yes we have : see notes	Public terminology server, published on health ministry website www.bmg.gv.at; www.gesundheit.gv.at
Belgium	We do not have any	
Croatia	We do not have any	
Czech Republic	We do not have any	
Estonia	We do not have any	
Finland	Yes we have : see notes	The national code server, usage guide books, information on the code server web site.
Germany	Yes we have : see notes	The tool in use for most classifications provided by DIMDI is a toolkit that was developed in a joined effort with WHO and which is specially customized to fit the needs of classification and terminology users (CTK, i.e. Classification Tool Kit).
Greece	Yes we have : see notes	some terminologies available via the web by MoH or other institutes.
Italy	We do not have any	
Malta	Yes we have : see notes	In some systems (e.g. Electronic Case Summary system), ad hoc software functionality facilitates the choice of terms for diagnoses, procedures and pharmaceutical products. Standard internet-based browsing tools and other reference materials are also used.
Netherlands	Yes we have : see notes	We use the ART-DECOR platform for browsing, editing and extension mamanagement. The SNOMED CT NRC is also using SnowOwl.
Slovakia	We do not have any	
Sweden	Yes we have : see notes	Web browsers for ICD10 and SNOMED CT
United Kingdom (*)	Yes we have : see notes	Distribute browsers for terminologies. End user can browse the content in order to make a subset User Interfaces: No national requirement. National procurement of EHRs required SNOMED CT to be included and thus left with system supplier. Some guidance on user interfaces provided.

(*) To be explicitly validated

10.1.10 Methodologies applied in your country for facilitating the usage of nationally adopted terminologies by end users

The following table reports the answer provided. Most of responses seem to be related more to technological solutions used rather than methodologies applied, those answers can be however interpreted as a way for facilitating the accessibility to terminologies and classified in such a way.

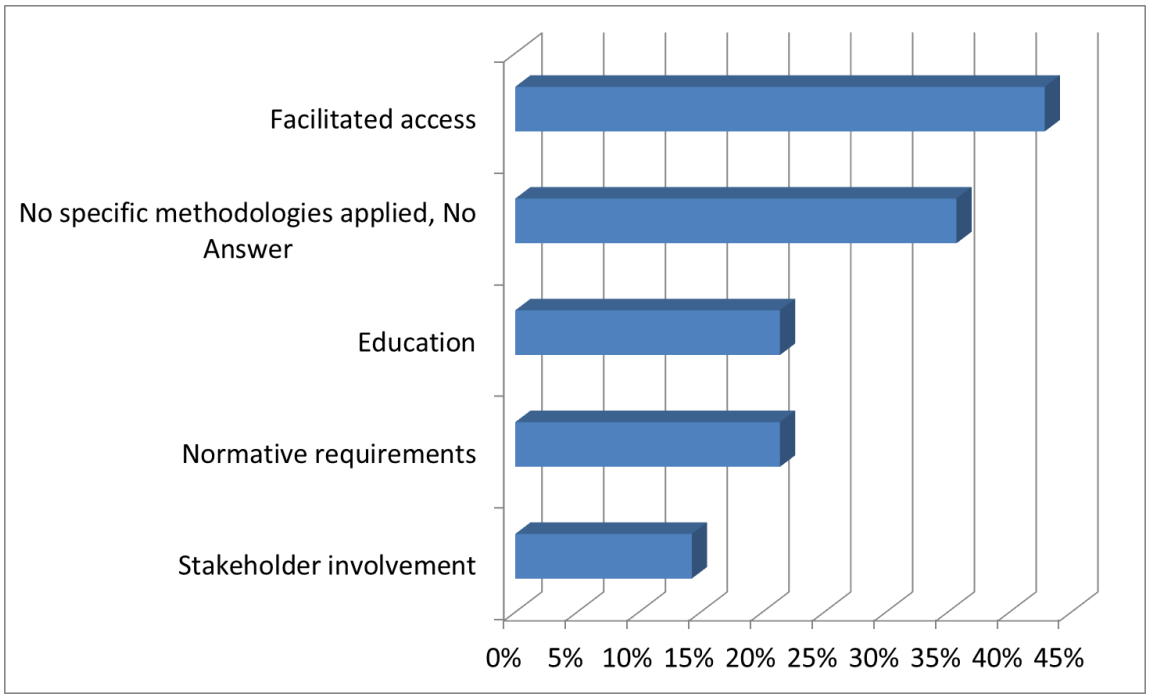
Member State	Please describe what are the methodologies that have been applied in your country for facilitating the usage of nationally adopted terminologies by end users -
Austria	Public terminology server, published on health ministry website www.bmg.gv.at; www.gesundheit.gv.at
Belgium	e.g. Implementation of the MLDS of IHTSDO that can be used to distribute RF2 files, and other services made available by IHTSDO
Croatia	There is no methodology used for facilitating the usage of nationally adopted terminologies by end users
Czech Republic	All is distributed simply by implementation in software (HIS/LIS)
Estonia	We basically have the obligations from the legislation that make the end users use the nationally adopted terminologies.
Finland	Available free of charge via web, wide participation of experts from different stakeholder groups, published guides, work shops, training, legislation
Germany	Some national terminologies are mandatory to use by law, e.g. the ICD-10-GM
Greece	n/a
Italy	no one
Malta	In some systems (e.g. Electronic Case Summary system), ad hoc software functionality facilitates the choice of terms for diagnoses, procedures and pharmaceutical products. Standard internet-based browsing tools and other reference materials are also used.
Netherlands	Initially topic focused projects were supported by the NRC when opportunity came up. Now Snomed is also designated as the clinical terminology in some national projects like Diagnoses thesaurus for hospitals, clinical building blocks for university hospitals and national nursing problem list.
Slovakia	Administrative Activities
Sweden	Training of users and implementers.
United Kingdom (*)	Support for contents: Identify the “content” that experts want in a system, match to equivalent content in SNOMED CT. A number of subject matter experts who provide the NRC with editorial and implementation guidance and support decision making in relation to the UK Extension and implementation products and guidance. There is regular engagament with national professional bodies on the development of both content and refsets. Education: - Guidance, workshops, webinars

(*) To be explicitly validated

Based on the responses provided a set of classes have been identified and answers remapped into them. The following table and figure summarize this classification.

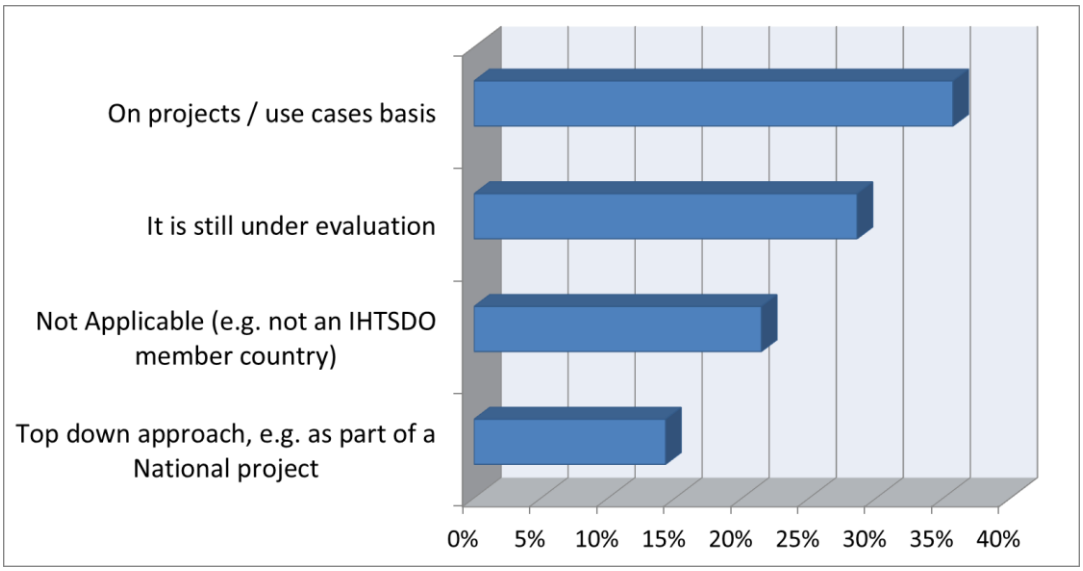
Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Facilitated access	□	□		□		□	□			□				
No specific methodologies applied, No Answer			□					□	□		□	□		
Normative requirements	□				□		□							
Education						□							□	□
Stakeholder involvement						□								□

(*) To be explicitly validated



10.2 About SNOMED CT adoption and usage

10.2.1 Which approach has been followed in your country for introducing SNOMED CT as a terminology for health and/or social care data



Almost all the countries that has, or is going to introduce SNOMED CT, has indicated the **project / use case based** approach as the reference approach, with the exception of Sweden and United Kingdom (top down approach). A mixed approach should be however considered for those countries, as explicitly mentioned in the UK response. For what concern Netherlands the project based approach used in the start up phase, is progressevly turned towards a centrally managed approach (embeeded in national policy documents and projects).

Member State	**Which approach has been followed in your country for introducing SNOMED CT as a terminology for health and/or social care data-**	
Austria	Not Applicable (e.g. not an IHTSDO member country)	
Belgium	On projects / use cases basis	
Croatia	It is still under evaluation	
Czech Republic	Not Applicable (e.g. not an IHTSDO member country)	Ministry of Health just paid the licence fee. No central strategy, no university research.
Estonia	On projects / use cases basis	
Finland	It is still under evaluation	
Germany	Not Applicable (e.g. not an IHTSDO member country)	
Greece	It is still under evaluation	
Italy	Not Applicable (e.g. not an IHTSDO member country)	
Malta	On projects / use cases basis	So far, SNOMED CT has been used in specific situations, e.g. to guide the construction of local dictionaries, and in specific projects, such as the National Patient Summary and the epSOS Project. It is expected to be used on a wider basis in upcoming National projects, such as the National Electronic Health Record and the

		National ePrescription System.
Netherlands	Formerly on projects / use cases basis. Now it is increasingly embeeded in national policy documents and projects.	
Slovakia	It is still under evaluation	
Sweden	Top down approach, e.g. as part of a National project	So far national Projects have been considered the best approach, but since interest and level of knowledge of SNOMED CT is growing, the next step will probably be "use case basis" with support from the national level.
United Kingdom (*)	Top down approach, e.g. as part of a National project	A mixture of 1 and 2.

(*) To be explicitly validated

10.2.2 For which use cases/purposes is currently used SNOMED CT in your country

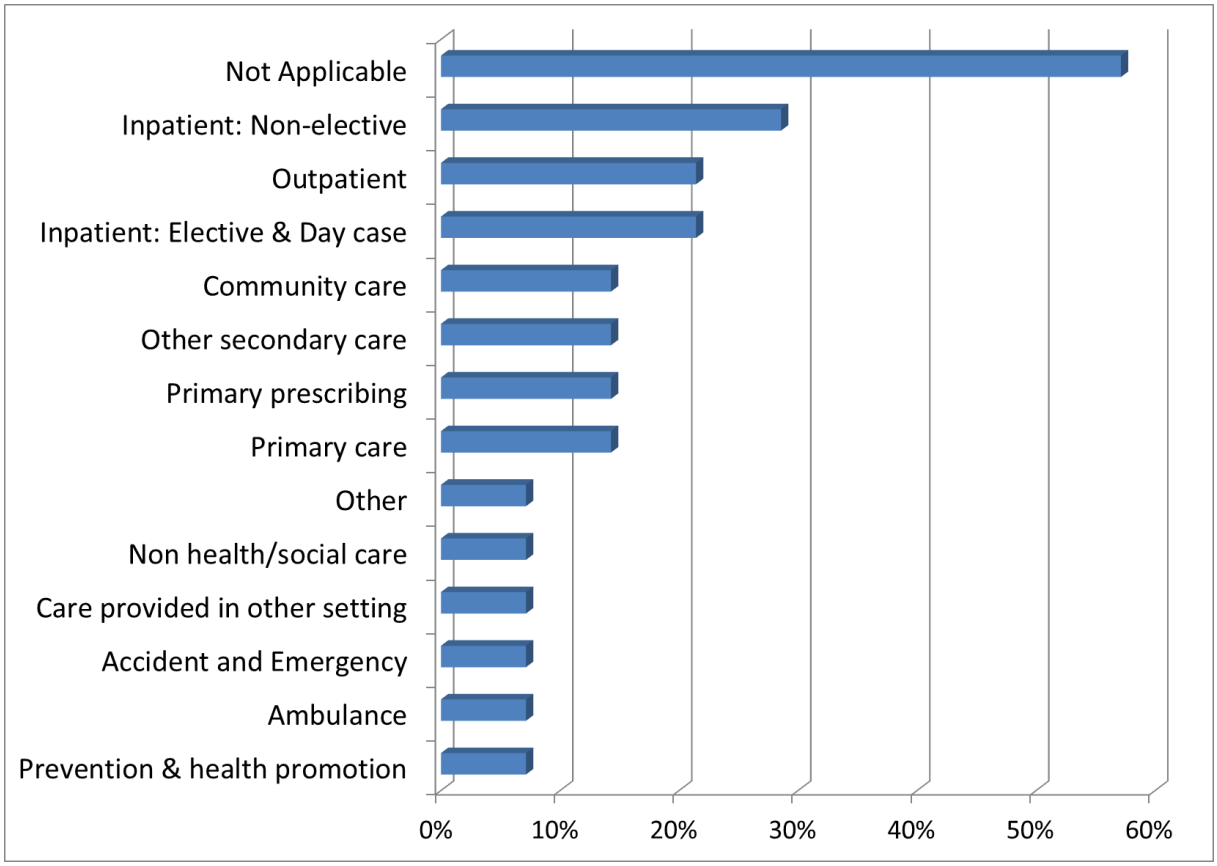
The following table reports the answer provided. Use cases/purposes have been described at a very different level of detail, in dependence also on the extend of usage of SNOMED CT in that country.

Member State	For which use cases/purposes is currently used SNOMED CT in your country
Austria	Maybe in international research activities.
Belgium	Use cases under development
Croatia	SNOMED CT is currently not in use.
Czech Republic	none
Estonia	Pathology use case; infectious disease use case; defining the technical data field.
Finland	We have not so far identified only the use of old versions of SNOMED CT in pathology. We participated in eSOS-project in defining Patient Summary but did not pilot it. epSOS eP was piloted.
Germany	Not applicable
Greece	for R/D projects.
Italy	Research (limited use); International projects;
Malta	Creation of clinical vocabularies based on SNOMED CT concepts, with mapping to standard classifications (ICD-10, ICD-9-CM, ATC). Coding of other clinical concepts as the need arises. Coding of concepts in the Electronic Case Summary system and the National Patient Summary system (pilot project).
Netherlands	National Diagnosis reference set for hospital Optholomogy diagnosis and procedures referens set Clinical reseearch databases
Slovakia	Not decided yet
Sweden	National coding system for safer prescribing of drugs (not yet live). For transfer of patient data to registries ("quality registries") - going live in 2015.

Member State	For which use cases/purposes is currently used SNOMED CT in your country
United Kingdom (*)	In England used in many settings including primary care, secondary care, community care and mental health. Used for recording all reusable information pertinent to delivery of health care - most commonly for procedures and diagnoses though expected to expand as systems become more sophisticated. Also beginning to be used for secondary uses extracts.

(*) To be explicitly validated

10.2.3 In which care settings is SNOMED CT used



Eight countries of the fourteen responding (> 50%) do not consider any of the care setting indicated as applicable.

Only UK seems to have a wide coverage spanning over almost all the care settings.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Not Applicable	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Prevention & health promotion	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Primary care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

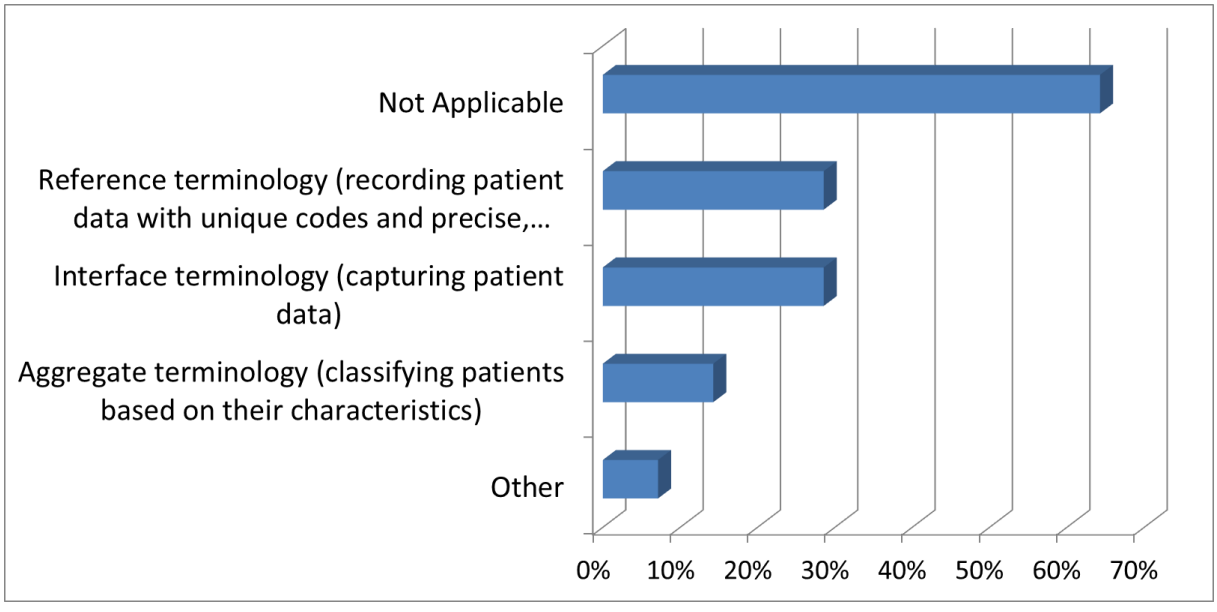
Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Primary prescribing	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Inpatient: Elective & Day case (patient that comes into hospital for treatments/procedures and is dealt with and released in the course of one day)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Inpatient: Non-elective	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Outpatient	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other secondary care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Ambulance	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Accident and Emergency	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Community care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Care provided in other setting	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Non health/social care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (see below)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

(*) To be explicitly validated

Other

- Finland: We suspect possibly some use in pathology

10.2.4 For the indicated use cases how SNOMED CT is actually used



Nine countries (AT, BE, HR, CZ, FI. DE, GR, IT) of the fourteen responding (> 60%) have indicated as not applicable the question about how SNOMED CT is actually used.

Malta and United Kingdom declare to use SNOMED CT as Reference, Aggregate and Interface Terminology;

Netherlands and Estonia as Reference and Interface terminology.

When used as reference terminology SNOMED CT it is always used also for capturing data.

Sweden (“Other”) indicated that “codes are used for transfer of patient data to registries, but not yet for data capture/patient records”

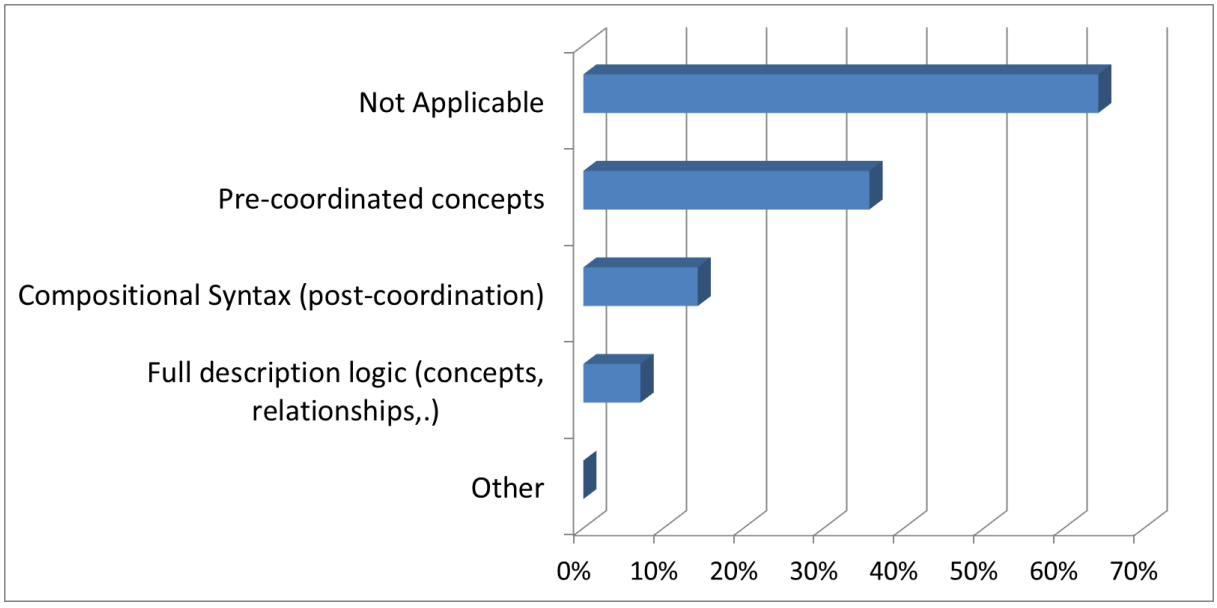
	Interface terminology (capturing patient data)	Reference terminology (recording patient data with unique codes and precise, formal meaning)	Aggregate terminology (classifying patients based on their characteristics)	Other
Austria	Not Applicable			
Belgium	Not Applicable			
Croatia	Not Applicable			
Czech Republic	Not Applicable			
Estonia	Yes	Yes	No	No
Finland	Not Applicable			
Germany	Not Applicable			
Greece	Not Applicable			
Italy	Not Applicable			
Malta	Yes	Yes	Yes	No
Netherlands	Yes	Yes	No	No
Slovakia	Not Applicable			
Sweden	No	No	No	Yes
United Kingdom (*)	Yes	Yes	Yes	No

(*) To be explicitly validated

Other

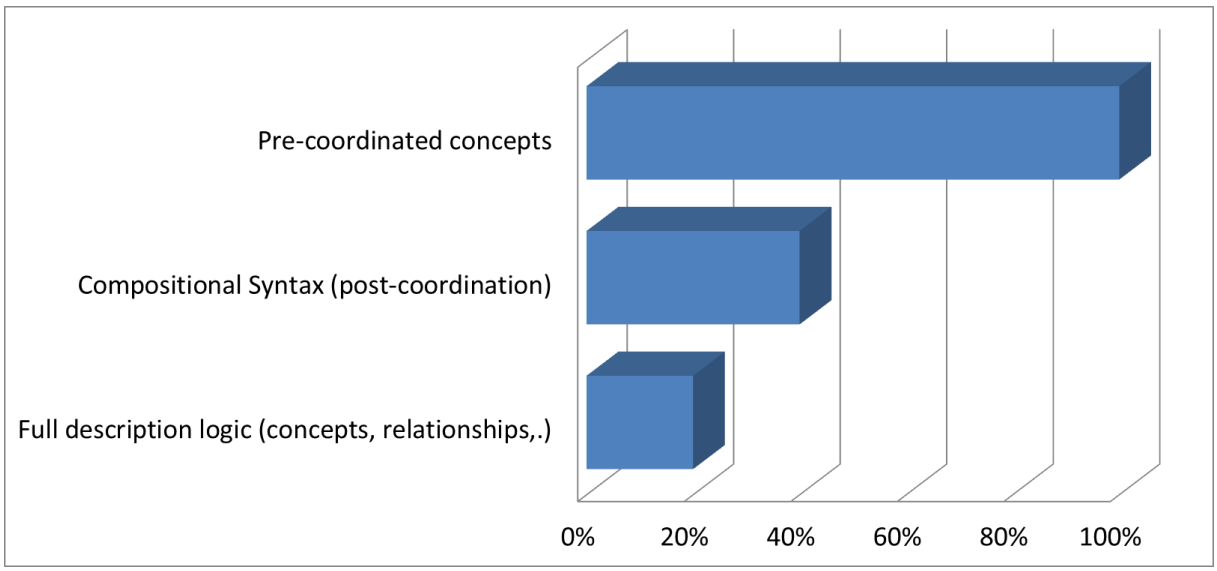
- Sweden : “codes are used for transfer of patient data to registries, but not yet for data capture/patient records”

10.2.5 For the indicated use cases what of SNOMED CT do you actually use?



Coherently with the previous answer, the same 9 countries have indicated this question as not applicable.

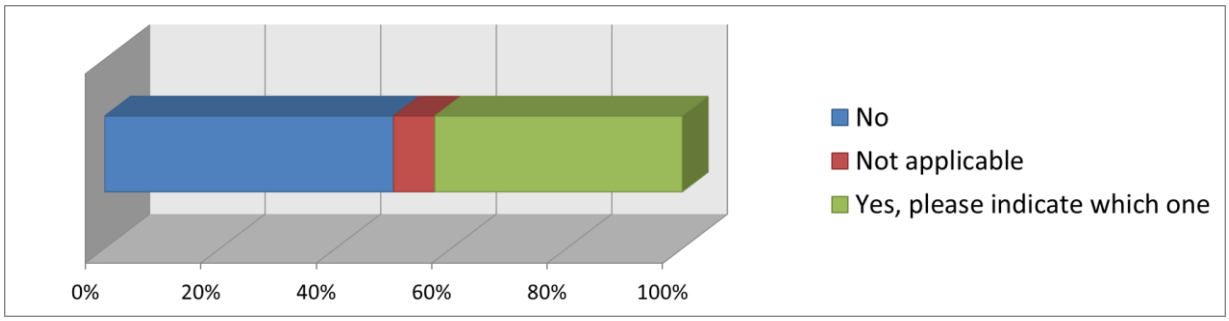
All the remaining 5 countries (EE, MT, NL, SE, UK) use the SNOMED CT pre-coordinated concepts, two of them use also the compositional syntax (NL, UK) , and only one (NL) declares to use the full SNOMED CT description logic.



Member State	Pre-coordinated concepts	Compositional Syntax (post-coordination)	Full description logic (concepts, relationships,.)
Austria	Not Applicable		
Belgium	Not Applicable		
Croatia	Not Applicable		
Czech Republic	Not Applicable		
Estonia	Yes	No	No
Finland	Not Applicable		
Germany	Not Applicable		
Greece	Not Applicable		
Italy	Not Applicable		
Malta	Yes	No	No
Netherlands	Yes	Yes	Yes
Slovakia	Not Applicable		
Sweden	Yes	No	No
United Kingdom (*)	Yes	Yes	No

(*) To be explicitly validated

10.2.6 Did (or will) the introduction of SNOMED CT in your country affect existing terminologies



For about half of the countries interviewed no impact on existing terminologies are expected by the introduction of SNOMED CT in their country.

Member State	Did (or will) the introduction of SNOMED CT in your country affect existing terminologies	
Austria	Not applicable	
Belgium	No	As a general principle, SNOMED CT is not considered to be a competitive system
Croatia	No	
Czech Republic	No	After Snomed CT is translated (if ever), harmonization is perceived in all matching domains.
Estonia	Yes, please indicate which one	We will replace the national terminologies with the SNOMED terminology.
Finland	Yes, please indicate which one	All of them
Germany	Yes, please indicate which one	All national terminologies for the use in the medical field might be affected because intense mapping and adaption is needed before joined use. Parallel use of two systems can only be handled, if automatic joined use is possible. Otherwise the additional workload for the user will be tremendous. Therefore the national and international terminologies currently in use in Germany will have to be revisited, mapped or adapted one by one
Greece	Yes, please indicate which one	
Italy	Yes, please indicate which one	ICD-9-CM
Malta	No	Behavioural changes may be necessary, but no substantive impact is expected on existing terminologies per se.
Netherlands	Yes, please indicate which one	less local terminologies
Slovakia	No	

Member State	Did (or will) the introduction of SNOMED CT in your country affect existing terminologies	
Sweden	No	
United Kingdom	Yes, please indicate which one	READV2 CTV3 NICIP

10.2.7 Could you briefly describe what has been (or what will be according to your current evaluation) the impact of the introduction of SNOMED CT in the existing IT architecture (including software)?

The following table reports the answer provided for this question.

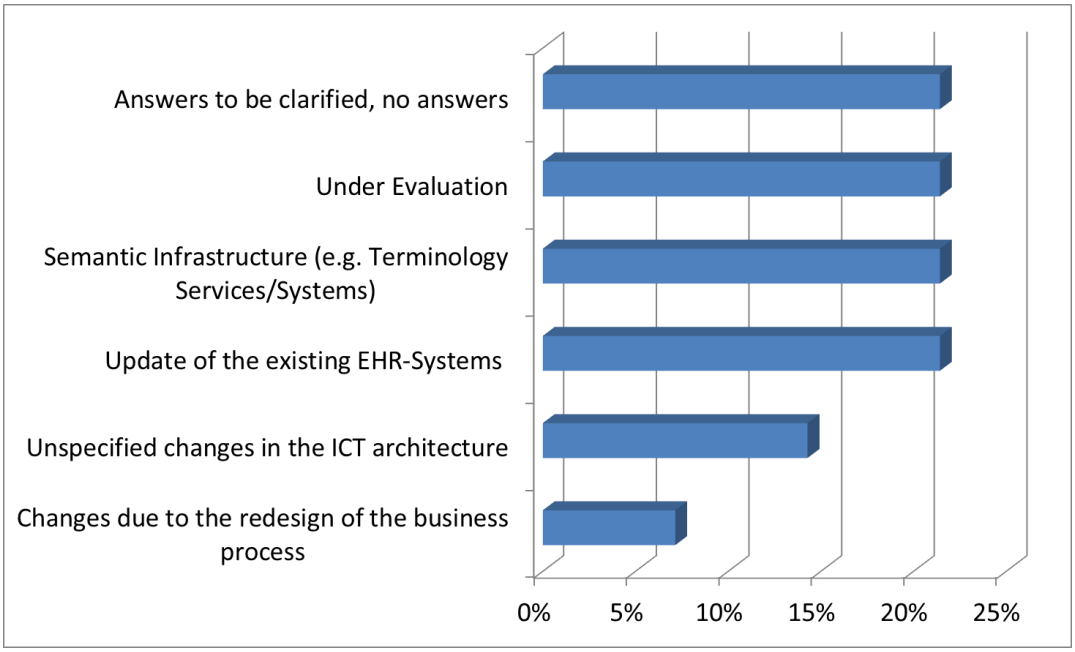
Member State	Could you briefly describe what has been (or what will be according to your current evaluation) the impact of the introduction of SNOMED CT in the existing IT architecture (including software)
Austria	SNOMED CT introduction not decided.
Belgium	This depends on the implementation approach. Different implementation approaches are possible with different impact.
Croatia	IT architecture will have to be changed significantly.
Czech Republic	Snomed CT is too complex for current level of ICT industry. Anyway establishing a central terminology service will be the first step.
Estonia	So far the adoption hasn´t influenced because we have used the RefSets that fit into our IT architecture. Possible impacts in the future we haven´t analyzed very thoroughly so far.
Finland	Chosen subsets from SNOMED CT would be mapped to existing terminologies. This would likely mean some changes to the used ones. Since everything is digital in Finland, all changes mean changes in national and local health care ICT systems such as EPRs, but the main components, the way the health information infrastructure is structured (information architecture) would not change
Germany	not applicable
Greece	
Italy	The large adoption of terminology at the national level (not limited to SNOMED CT) should require the development of a semantic infrastructure (Terminology servers/services) at the national level. (including also the support for the mappings). This would also implies the adaptation of the consumer systems. Morevover it will require the update of most of the used EHR-S (e.g. that used by GPs) for facilitating the capture and the representation of structured and coded data.
Malta	The impact is expected during the introduction of SNOMED CT in major projects at national level (National EHR, National ePrescription system). The aim is to include look-up and capture of SNOMED Clinical Terms within the core functionality of the software.
Netherlands	On one hand more complex as implementing Snomed the 1st time is really different than other content On the other hand less complex as the number of sources will reduce.

Member State	Could you briefly describe what has been (or what will be according to your current evaluation) the impact of the introduction of SNOMED CT in the existing IT architecture (including software)
Slovakia	We did not do such evaluation yet
Sweden	Very Little experience of this so far, but it has started discussions about the need for a national terminology server.
United Kingdom (*)	redesign of the business processes re-engineering of the IT system for supporting the new processes

(*) To be explicitly validated

The answers about the experienced, or expected, impacts of the introduction of SNOMED CT in the existing IT architecture (including software) can be classified according to the categories listed in Table 6. It is interesting to note how UK faced the problem starting from the Business Architecture from which all the other consequent impacts can be derived, following an Enterprise Architectural approach.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK
Update of the existing EHR-Systems				□					□					
Semantic Infrastructure (e.g. Terminology Services/Systems)				□					□				□	
Under Evaluation					□							□	□	
Answers to be clarified, no answers	□						□	□						
Unspecified changes in the ICT architecture			□			□								
Changes due to the redesign of the business process														□



10.2.8 Could you briefly describe what has been the main challenges (or what will be according to your current evaluation) of the transactional scenario (i.e. moving toward the adoption of SNOMED CT)?

The following table reports the answer provided for this question.

Member State	Could you briefly describe what has been the main challenges (or what will be according to your current evaluation) of the transactional scenario (i.e. moving toward the adoption of SNOMED CT)-
Austria	N.A. SNOMED CT introduction not decided!
Belgium	Training, education and information of users and software providers, translation, vendor engagement, regulation
Croatia	Changes will have to be made on legal, organizational, semantic and technical levels. Challenges are expected on all levels.
Czech Republic	1) Translation of Snomed CT (substatial work) 2) Education of all HIT industry. 3) Education of healthcare professionals to understand the need for conding.
Estonia	Translation has been one of the challenges. And also from technical point of view, how to unite SNOMED CT logic and HL7 v3 based CDA documenst
Finland	We need to do the mapping. The main challenges is that we have lots of information structures that are missing form SNOMED CT.
Germany	Not Applicable
Greece	a five to ten yards plrs
Italy	end users acceptance support for mapping system usability terminology governance
Malta	Although the initial challenge is to establish and implement the necessary software functionality, the main challenge is likely to be the changes that will be required in the behaviour of health professionals.
Netherlands	- availability of Dutch terms/concepts - adoption by caregivers - adoption by vendors
Slovakia	- training of the workforce, - setting up of training establishment
Sweden	There's very little tradition of using standardized/controlled terminology in patient data documentation and the level of maturity when it comes to using such systems has been fairly low.
United Kingdom	Change all the supporting administration tasks including payment, measure of the activities, quality measures. (It was not just a problem of mapping but of redesign of the whole business process)

Based on the responses provided a set of classes have been identified and answers remapped into them. The following table and figure summarize this classification.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Answers to be clarified, no answers	☐						☐	☐						
Education of end users		☐		☐								☐		
End users Acceptance									☐	☐	☐			
Adoption by Vendors		☐		☐							☐			
Education of IT industry														
Translation		☐		☐							☐			
Mapping						☐			☐					
Terminology governance									☐					
System Usability									☐	☐				
Vendor engagement		☐												
Regulation		☐												
Unspecified challenges			☐											
Low maturity in using terminologies													☐	
Business process changes														☐

(*) To be explicitly validated

10.2.9 Could you briefly describe how those challenges have been managed (or are planned to be managed)

The following table reports the answer provided for this question.

Member State	Could you briefly describe how those challenges have been managed (or are planned to be managed)
Austria	N.A. SNOMED CT introduction not decided!
Belgium	Training, education: participating into IHTSDO's SNOMED CT Foundation and Implementation courses International collaboration efforts on translation accord to IHTSDO translation guidelines Actualization of the National Action Plan for e-health
Croatia	If SNOMED is accepted in Croatia, HZZO will coordinate all the activities regarding the implementation on all levels. Currently, there is no strategy for managing SNOPMED CT implementation challenges.
Czech Republic	Such a big change cannot be planned. It will simply be revolution.
Estonia	Regarding to translations-we are workng on developing our own guidelines based on the IHTSDO-s guidelines and searching for suitable persons. Regarding to the HL7

Member State	Could you briefly describe how those challenges have been managed (or are planned to be managed)
	issue we used the extra translation code next to the code element.
Finland	If we decide on the purchase of SNOMED CT license, we would start looking for suitable subsets together with the expert working groups
Germany	not applicable
Greece	
Italy	this describes how might be managed not how they have been planned to be managed. No plan fo SNOMED CT is in place. training make end users aware about the value proposition create a terminology governance group supported by well defined policies.
Malta	In the case of the software, the challenge will be addressed through the specification of the software functionality and the setting of data standards. In the case of the behaviour of the health professionals, the plan is to provide training and support and to implement terminology reference sets that are relevant to the health professionals in question.
Netherlands	- Working with reference sets - start a project for (targeted) translation of Snomed
Slovakia	By communication with the universities
Sweden	Training of users and implementers
United Kingdom	Enabling the business process to be supported by SNOMED CT Prevent the business process by legacy terminology

Based on the responses provided a set of classes have been identified and answers remapped into them. The following table and figure summarize this classification.

Member State	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK (*)
Answers to be clarified, no answers	□			□			□	□						
Education (training, guidelines)		□			□				□	□			□	
International Collaboration		□												
Actualization of the National Action Plan for e-health		□	□						□					
Expert Involvement						□								
To be Evaluated									□					
Competence Center									□					
Functional Specification for the Software										□				
Focused Projects &											□			

RefSets														
Academic collaboration														
Business Process Revisions														

(*) To be explicitly validated

10.2.10 Could you summarize the main steps accomplished for the adoption of SNOMED CT

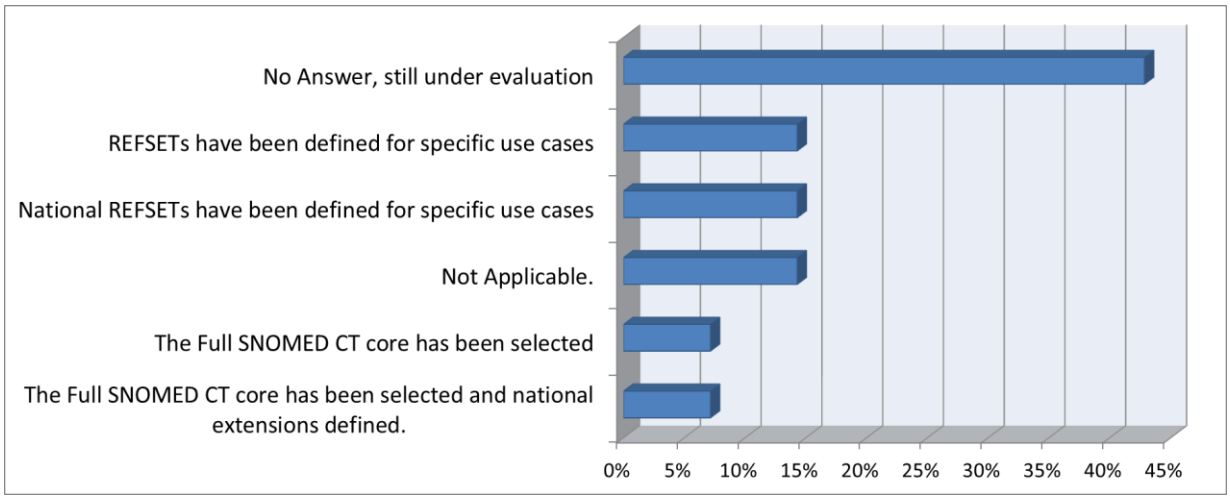
The following table reports the answer provided for this question.

Member State	Main steps accomplished for the adoption of SNOMED CT
Austria	N.A. SNOMED CT introduction not decided!
Belgium	2013: membership IHTSDO, concept selection, translation 2014: use case approach, concept selection, translation 2015: RefSetting, translation QA, updating
Croatia	First steps undertaken for stakeholder analysis. Negotiations underway.
Czech Republic	My guess only: Approved translation of core concepts will be done in 2020
Estonia	2014 we were in analytic phase and had some test use cases 2014-today we are moving project based adoptions
Finland	We have had a small evaluation study in 2009 and some negotiations with SNOMED CT IHTSDO and are now participating in ASSESS CT to gather more information on SNOMED CT.
Germany	not applicable
Greece	no steps adopted yet
Italy	n/a
Malta	Before 2011: evaluation of the potential of SNOMED CT . 2011: Malta became a national member of the IHTSDO. 2011 onwards: practical use of SNOMED CT terms in the Electronic Case Summary system, the National Patient Summary system, and the epSOS project (2011-2014).
Netherlands	Ongoing - Training - presentations 2013 - Opthomology diagnose refset 2014 - Ophthalmology - Procedures refset 2014-2015 - Microbiology Organisms refset 2014-2015 - Diagnoses reference set 2015 – Nursing problem list
Slovakia	Not available yet

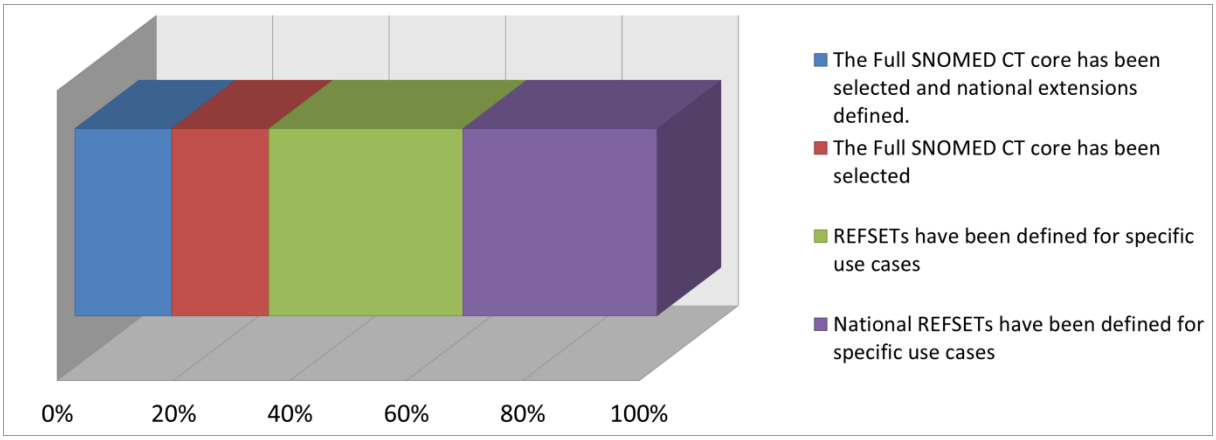
Member State	Main steps accomplished for the adoption of SNOMED CT
Sweden	2007-2010: Translation of core concepts (full translation) 2011-now: biannual releases of national extension including translated core concepts and added national concepts. 2014: addition of national synonyms started 2014: production of refsets started 2014-2015: collaboration with other national national projects such as the national information structure initiative, national project for transfer of patient data to quality registries; inclusion of standardized/coded terminology in nationel Clinical guidelines; creation of a national coding system for reasons for prescription.
United Kingdom (*)	2002 creation of UK extension for SNOMED 2010 content development (national specific content and capability for creating refsets)[proxy for involving professionals] 2010 professionaly validated set of maps from old coding schemes Work closely with IT companies in order to make them use SNOMED CT in a standard way.

(*) To be explicitly validated

10.2.11 What has been the content selection approach applied (or planned to be applied) for introducing in your country SNOMED CT



For the large majority of the countries interviewed the actual or planned approach for the introduction of SNOMED CT has not been yet identified, or the question is not applicable.

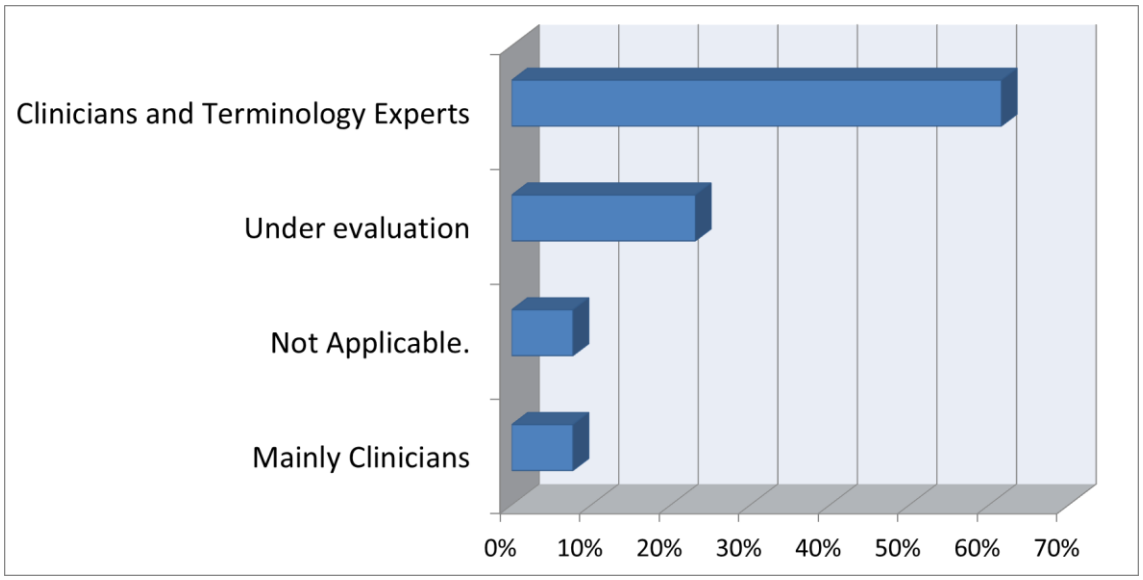


Considering only the positive responses in two cases the full SNOMED CT core has been considered; a RefSet based approach has been used instead in the 80% of the cases.

Member State	Content selection approach applied (or planned to be applied) for introducing in your country SNOMED CT
Austria	No Answer, still under evaluation
Belgium	REFSETs have been defined for specific use cases
Croatia	No Answer, still under evaluation
Czech Republic	Not Applicable.
Estonia	National REFSETs have been defined for specific use cases
Finland	No Answer, still under evaluation
Germany	Not Applicable.
Greece	No Answer, still under evaluation
Italy	Not Applicable.
Malta	REFSETs have been defined for specific use cases
Netherlands	National REFSETs have been defined for specific use cases
Slovakia	No Answer, still under evaluation
Sweden	The Full SNOMED CT core has been selected
United Kingdom (*)	The Full SNOMED CT core has been selected and national extensions defined.

(*) To be explicitly validated

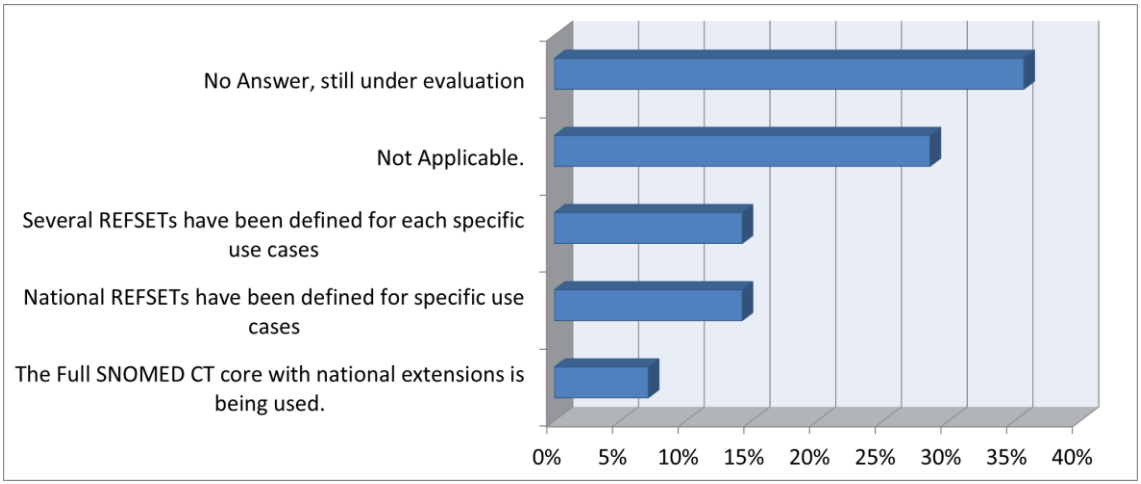
10.2.12 Who was (is planned to be) responsible for selecting the contents



The large majority (60%) of the total indicates the “Clinicians and Terminology Experts” the role involved (or to be involved) in the refset selection.

Member State	Responsible for selecting the contents
Austria	Under evaluation
Belgium	Mainly Clinicians
Croatia	Clinicians and Terminology Experts
Czech Republic	Not Applicable
Estonia	Clinicians and Terminology Experts
Finland	Clinicians and Terminology Experts
Germany	Clinicians and Terminology Experts
Greece	Under evaluation
Italy	Not Applicable
Malta	Clinicians and Terminology Experts
Netherlands	Clinicians and Terminology Experts
Slovakia	Under evaluation
Sweden	Clinicians and Terminology Experts
United Kingdom	Clinicians and Terminology Experts

10.2.13 For supporting the indicated use cases, which selection approach has been applied in your country



The percentage of not applicable or under definition answers increase to more than 60% for the same type of question applied to the indicated use cases (i.e. not only for the introduction of SNOMED CT). Only UK indicated that "The Full SNOMED CT core with national extensions is being used, "National Refsets" have been indicated for Estonia and Netherlands, and "Several Refset" for Malta and Belgium.

Member State	Selection approach applied in your country-
Austria	Not Applicable.
Belgium	Several REFSETs have been defined for each specific use cases
Croatia	No Answer, still under evaluation
Czech Republic	Not Applicable.
Estonia	National REFSETs have been defined for specific use cases
Finland	No Answer, still under evaluation
Germany	Not Applicable.
Greece	No Answer, still under evaluation
Italy	Not Applicable.
Malta	Several REFSETs have been defined for each specific use cases
Netherlands	National REFSETs have been defined for specific use cases
Slovakia	No Answer, still under evaluation
Sweden	No Answer, still under evaluation
United Kingdom	The Full SNOMED CT core with national extensions is being used.

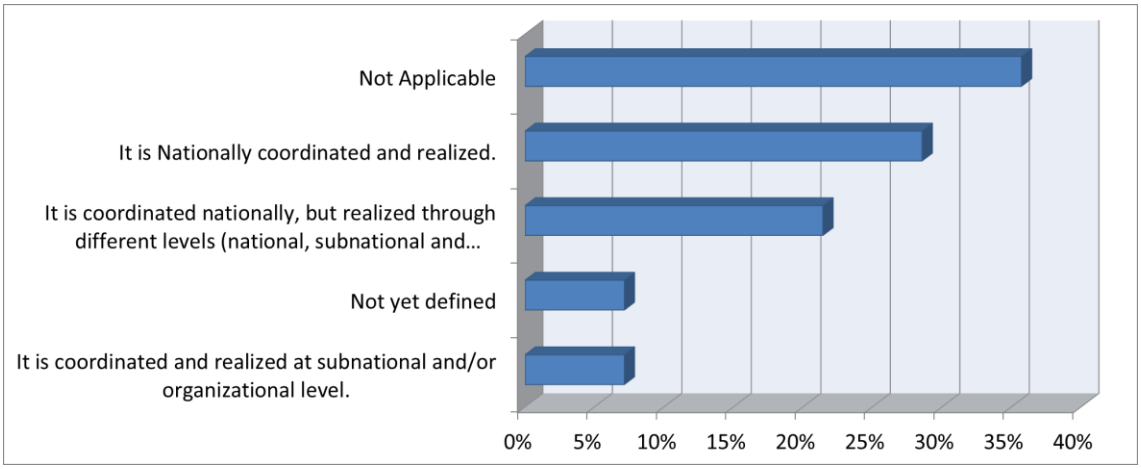
10.2.14 Can you quantify (and qualify) the selected SNOMED CT Refset(s)

The following table list the answers provided for the SNOMED CT Refset defined in each country

Member State	Can you quantify (and qualify) the selected SNOMED CT Refset(s) -
Austria	
Belgium	Nursing: 32.000 concpets Medicine: 80.000 concepts
Croatia	No REFSETS currently selected.
Czech Republic	
Estonia	3 pathology Refsets; 2 infectious disease Refsets.
Finland	Not available
Germany	Not Applicable
Greece	
Italy	
Malta	(Figures are not easily available). There are three Refets in current use: allergies, diagnoses and medications
Netherlands	Ophthalmology - Diagnoses: 600 Ophthalmology - Procedures: 38 Microbiology Organisms refset: 2500 Hosptial Diagnosis refset: 31 000
Slovakia	No areas are covered with SNOMED CT in Slovakia at the moment.
Sweden	Refset: Reasons for prescription, approx. 1400 concepts Refset: Lifestyle habits (used in connection with the national clinical guidelines for disease preventing methods), approx. 50 concepts Refsets with administrative concepts, approx 10 concepts in each.
United Kingdom (*)	Several hundred refsets for numerous sue cases. UK uses all of SNOMED CT Core, plus a UK Clinical Extension (more the 73,000 concepts), UK Drug (more 283,000 concepts) A significant number of national subsets/refsets of varying content and hence size including a number of speciality specific eg Renal exist. There is no single refset for national use and suppliers utilise all of SNOMED CT within their products.

(*) To be explicitly validated

10.2.15 What is the approach followed for translating terms and collect possible synonyms

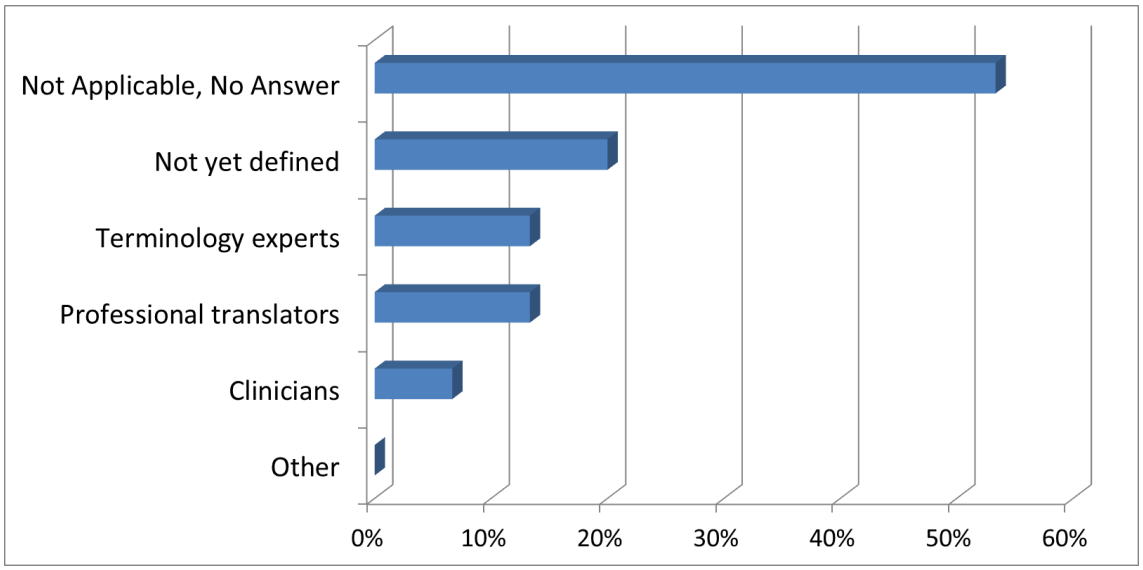


The translation and the collection of synonyms is Nationally coordinated and realized for the majority of the countries for which this answer is applicable. It is interesting to point out the international cooperation aspect pointed out by Belgium in its comment.

Member State	Approach followed for translating terms and collect possible synonyms	
Austria	Not Applicable	
Belgium	It is Nationally coordinated and realized.	Started nationally, completion international cooperation
Croatia	It is coordinated nationally, but realized through different levels (national, subnational and organizational).	
Czech Republic	Not Applicable	
Estonia	It is coordinated nationally, but realized through different levels (national, subnational and organizational).	
Finland	Not yet defined	
Germany	Not Applicable	
Greece	It is coordinated and realized at subnational and/or organizational level.	
Italy	Not Applicable	
Malta	Not Applicable	Standard English versions are used.
Netherlands	It is coordinated nationally, but realized through different levels (national, subnational and organizational).	
Slovakia	It is Nationally coordinated and realized.	
Sweden	It is Nationally coordinated and realized.	
United Kingdom (*)	It is Nationally coordinated and realized.	

(*) To be explicitly validated

10.2.16 Who is responsible for translating designations and collect possible synonymous



When applicable both the roles of Terminology experts and Professional translators have been that mainly indicated in the translation of terms (only Sweden indicated also Clinicians).

Member State	Clinicians	Terminology experts	Professional translators	Not yet defined	Other
Croatia	No	No	No	Yes	
Finland	No	No	No	Yes	
Germany	No	No	No	Yes	
Greece	No	Yes	Yes	No	
Slovakia	No	No	No	Yes	
Sweden	Yes	Yes	Yes	No	

10.2.17 What are the main on-going activities

The following table reports the answers provided about the on-going activities

Member State	What are the main on-going activities
Austria	N.A. SNOMED CT introduction not decided!
Belgium	Mapping SNOMED CT to ICD-10-PCS Completion translation process Review of registers
Croatia	No on-going activities regarding description translation.
Czech Republic	Review of ALL existing registers makes sense.

Member State	What are the main on-going activities
Estonia	Extending the pathology Refsets (inculidng translating the concepts); we are analyzing the possibilities of creating procedure Refsets and Refsets for administrative health services.
Finland	We are defining and delivering the national health and social care information structure. In this work we use international classifications/coding whenever available and do mapping like ICD-10-ICPC2
Germany	Not Applicable
Greece	setup a roadmap for the next years
Italy	n/a
Malta	Creation of specific refsets and their mapping to standard classification (ICD-10, ICD-9-CM, ATC). Planning for use within national-scale eHealth projects.
Netherlands	Creating reference sets Starting translation project Validating the Snomed CT - ICD-10 (v2014) mapping
Slovakia	There are no ongoing activities at the moment.
Sweden	Coding of patient data needed for transfer to the national quality registries. Providing user support to help health/social care services understand and start implementing SNOMED CT. National coding systems such as the reasons for presecription
United Kingdom (*)	The number of projects that use some form of SNOMED CT are innumerable, some in England which are national strategic initiatives and have been in live use for some years - eg Electronic Prescription Service, Summary Care Record and Choose and Book (referrals from primary care). All of these have subsequent phases which will extend the usage of SNOMED CT. As the UK has been working with SNOMED for some years there are also a number of projects that are led outside of the NRC and we provide advice as and when requested. Internationally the UK input into the collaboration on harmonisation of Medical Device nomenclature (GMDN) with SNOMED CT. Output is expected to inform the basis for the UK medical device extension to support prescribing, recording, and analysis of secondary care devices.

(*) To be explicitly validated

10.2.18 Could you briefly describe your future plans-

The following table reports the answers provided about the future plans

Member State	Could you briefly describe your future plans
Austria	Usage in ELGA has to be decided, no usage in general health documentation within the next years.
Belgium	Complete the translation of selected terms Complete RefSets Complete mappings National extension Putting in place a terminology management system Implementation projects

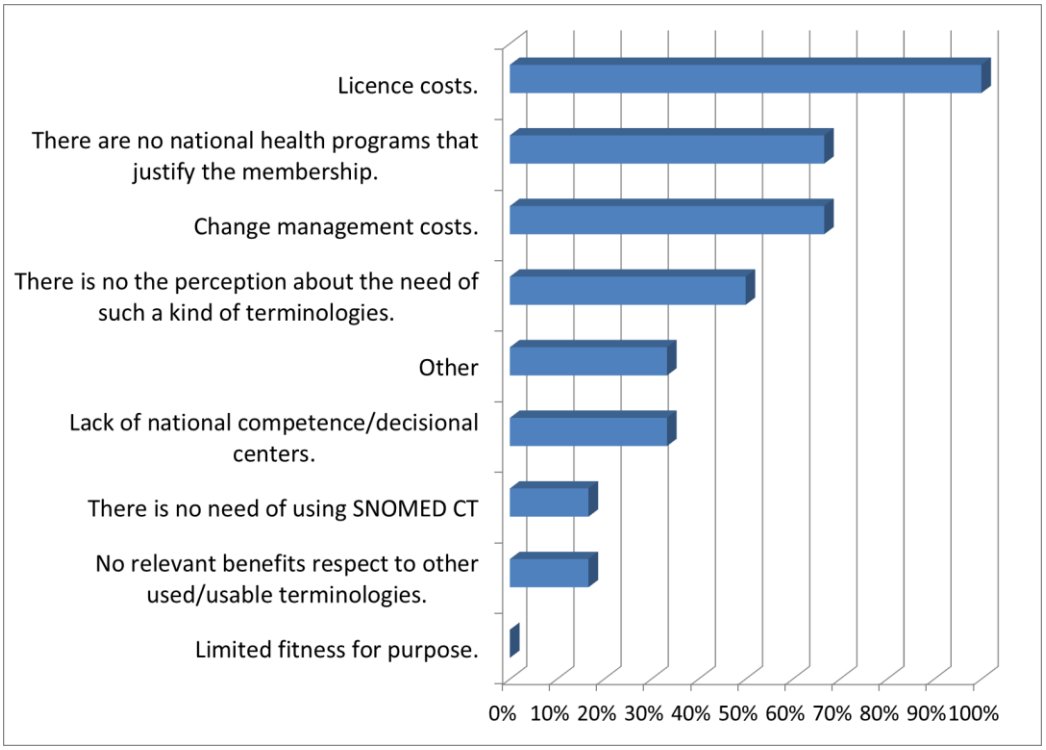
Croatia	Strategy for SNOMED CT implementation is under consideration. Further elaboration of the strategy depends on SNOMED CT adoption.
Czech Republic	There are attempts to institutionalize services for national terminologies in a body with a long-term secure funding.
Estonia	We are planning to initiate the translation project with the help of IHTSDO. Launching the first Estonian Extension. Managing and extending our existing Refsets. Broadening the knowledge about SNOMED as well as in our organization and also in Estonia.
Finland	We are evaluating the possible value of SNOMED CT and will use the work done within the ASSESS project and use the national stakeholder group that is created also for national discussions outside ASSESS. The results from the evaluation will be given for discussion and decision making to the MoH and national authorities.
Germany	not applicable
Greece	n/a
Italy	n/a
Malta	Introduction of SNOMED CT in major projects at national level (National EHR, National ePrescription system).
Netherlands	Translating 33 000 terms in 2015, another 100 000 in 2016
Slovakia	Translation of selected 200 terms.
Sweden	User support to selected Projects who want to start implementing a standardised terminology/SNOMED CT in information systems. Participate in study of national terminology server needs
United Kingdom (*)	- 2020 : the whole healthcare to be covered by a single terminology (SNOMED CT)

(*) To be explicitly validated

10.3 About non-IHTSDO member countries

10.3.1 What are according to you the main reasons for which your country is not currently an IHTSDO members

The following figure shows the distribution of indicated reason prevented to be a IHTSDO member. The percentage are calculated based on the non IHTSDO member responding countries



All the countries that provided an answer about the reasons for not joining IHTSDO, have indicates the Licence Cost as one of the motive, no one has checked on the contrary the limited fitness for purpose.

	AT	BE	HR	CZ	EE	FI	DE	GR	IT	MT	NL	SI	SE	UK
Licence costs.	□	◆	□	□	□	□	□	□	□	□	□	□	□	□
Change management costs.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
There are no national health programs that justify the membership.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
There is no need of using SNOMED CT	□	□	□	□	□	□	□	□	□	□	□	□	□	□
There is no the perception about the need of such a kind of terminologies.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Lack of national competence/decisional centers.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
Limited fitness for purpose.	□	□	□	□	□	□	□	□	□	□	□	□	□	□
No relevant benefits respect to other used/usable terminologies.	□	□	□	□	□	□	□	□	□	□	□	□	□	□

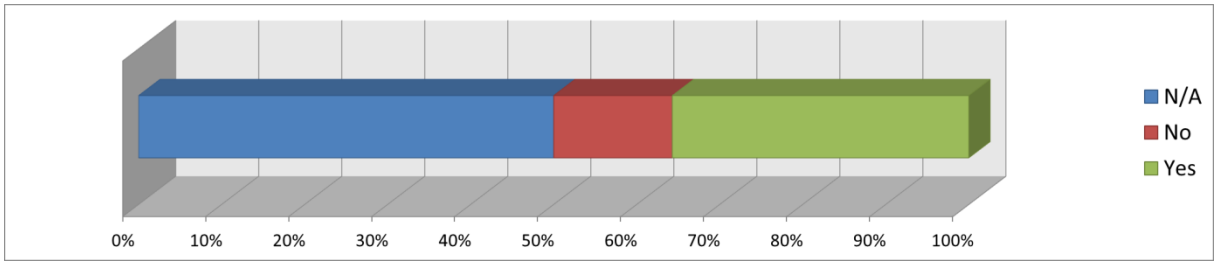
Other

- Finland: We do not know yet what to expect as the added value, international collaboration?
- Germany: High cost for mapping to national classifications and terminologies and for translation

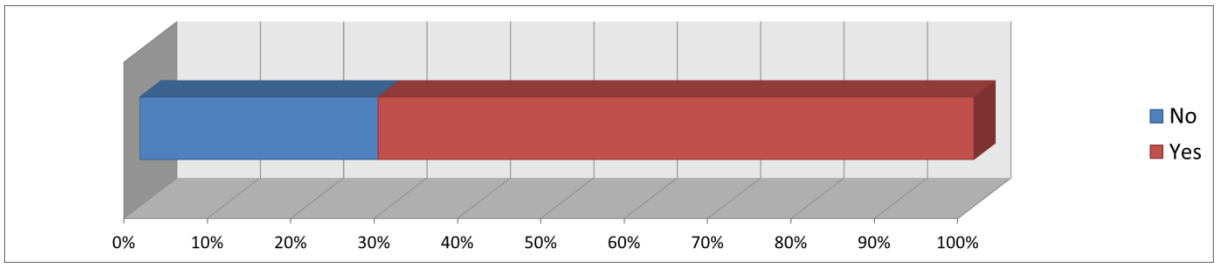
10.3.2 Are you aware about any current or past plan, discussion or evaluation regarding the adoption of SNOMED CT in your country

This question applies mainly to non IHTSDO member countries.

The following figure describe the global distribution of answers.



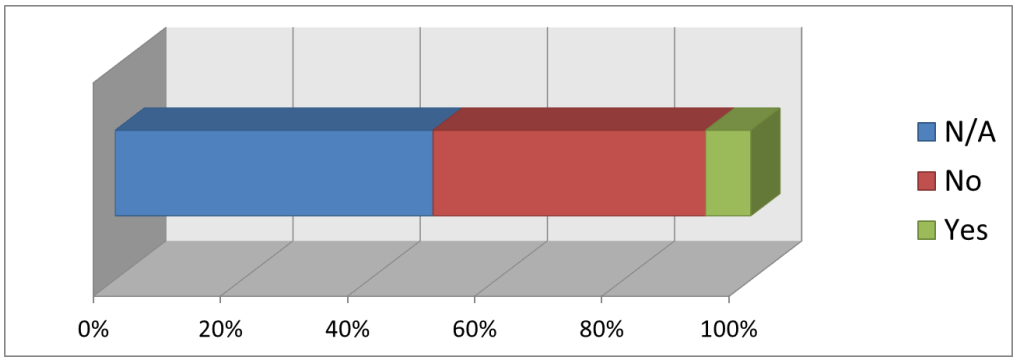
This one instead provides the response distribution considering only the Yes/No answers.



Member State	Could you provide any detail about the identified adoption strategy	
Austria	Yes	SNOMED CT introduction for a minor use in ELGA (national EHR system) is under discussion
Belgium	N/A	
Croatia	Yes	Previous discussions have been made on introducing SNOMED CT. Unfortunately, no steps have been made on the fitness analysis for SNOMED CT implementation.
Czech Republic	No	
Estonia	N/A	
Finland	Yes	See previous answers, evaluation, discussion, possible decision making and an implementation plan if the decision is to adopt in at least some user cases
Germany	Yes	In the realm of different projects there has been discussion of using SNOMED CT in the future but so far none of the discussions justified immediate decision to adopt SNOMED CT
Greece	No	strategy is under revision
Italy	Yes	Very preliminary thoughts have been made at the Ministerial Level

Member State	Could you provide any detail about the identified adoption strategy	
Malta	N/A	
Netherlands	N/A	
Slovakia	N/A	
Sweden	N/A	
United Kingdom	N/A	

10.3.3 Are you aware about any IHTSDO affiliate in your country ?



Member State		Affiliates you know and in which context they use SNOMED CT (if known)
Austria	No	
Belgium	N/A	
Croatia	No	
Czech Republic	Yes	EuroMISE LTD - for research
Estonia	N/A	
Finland	No	
Germany	Yes	There are very few research license holders to our knowledge, e.g the University of Krefeld
Greece	No	n/a
Italy	No	
Malta	N/A	
Netherlands	N/A	
Slovakia	N/A	
Sweden	N/A	
United Kingdom	N/A	