DELIVERABLE

Project Acronym: **ASSESS CT**
Grant Agreement number: **643818**
Project Title: **Assessing SNOMED CT for Large Scale eHealth Deployments in the EU**

**WP1 D1.4 Current and Future Use of SNOMED CT**

Authors:

<table>
<thead>
<tr>
<th>Authors</th>
<th>Institution/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giorgio Cangioli</td>
<td>HL7 Foundation</td>
</tr>
<tr>
<td>Catherine Chronaki</td>
<td>HL7 Foundation</td>
</tr>
<tr>
<td>Kirstine Rosenbeck Goeeg</td>
<td>Aalborg University</td>
</tr>
<tr>
<td>Anne Randorff Højen</td>
<td>Aalborg University</td>
</tr>
<tr>
<td>Daniel Karlsson</td>
<td>Linköping University</td>
</tr>
<tr>
<td>Marie Christine Jaulent</td>
<td>Institut National de la Sante et de la Recherche Medicale</td>
</tr>
<tr>
<td>Virpi Kalliokuusi</td>
<td>Terveyden ja Hyvinvoinnin Laitos</td>
</tr>
<tr>
<td>Päivi Hämäläinen</td>
<td>Terveyden ja Hyvinvoinnin Laitos</td>
</tr>
<tr>
<td>Reza Fathollah Nejad</td>
<td>Hochschule Niederrhein</td>
</tr>
<tr>
<td>Ronald Cornet</td>
<td>AMC</td>
</tr>
<tr>
<td>François Macary</td>
<td>Phast</td>
</tr>
<tr>
<td>Laura Sato</td>
<td>HSCIC</td>
</tr>
<tr>
<td>Pim Volkert</td>
<td>Nictiz</td>
</tr>
<tr>
<td>Rika Vuokko</td>
<td>Terveyden ja Hyvinvoinnin Laitos</td>
</tr>
<tr>
<td>Stefan Schulz</td>
<td>Medizinische Universität Graz</td>
</tr>
<tr>
<td>Estefâñia Araújo</td>
<td>Clinical Terminologies Centre in Portugal - SPMS</td>
</tr>
<tr>
<td>Rémy Choquet</td>
<td>BNDMR, APHP</td>
</tr>
<tr>
<td>Dipak Kalra</td>
<td>EuroRec</td>
</tr>
<tr>
<td>Veli Stroetmann</td>
<td>Empirica</td>
</tr>
<tr>
<td>Vesna Kronstein Kufrin</td>
<td>Hrvatski zavod za zdravstveno osiguranje (HZZO)</td>
</tr>
<tr>
<td>Zlatko Boni</td>
<td>HZZO</td>
</tr>
<tr>
<td>Tatjana Pavešković</td>
<td>HZZO</td>
</tr>
<tr>
<td>Martina Orešković</td>
<td>HZZO</td>
</tr>
</tbody>
</table>

**Project co-funded by the European Commission within** H2020-PHC-2014-2015/H2020_PHC-2014-single-stage

**Dissemination Level**

<table>
<thead>
<tr>
<th>PU</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>PP</td>
<td>Restricted to other programme participants (including the Commission Services)</td>
</tr>
<tr>
<td>RE</td>
<td>Restricted to a group specified by the consortium (including the Commission Services)</td>
</tr>
<tr>
<td>CO</td>
<td>Confidential, only for members of the consortium (including the Commission Services)</td>
</tr>
</tbody>
</table>
# Revision History, Status, Abstract, Keywords, Statement of Originality

<table>
<thead>
<tr>
<th>Revision</th>
<th>Date</th>
<th>Author</th>
<th>Organisation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.1</td>
<td>13/Apr/2015</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>First Outline</td>
</tr>
<tr>
<td>0.2</td>
<td>18/May/2016</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>Case Study section</td>
</tr>
<tr>
<td>0.3</td>
<td>02/Jun/2016</td>
<td>R. Choquet</td>
<td>APHP</td>
<td>Provided the 2nd implementation case for the Rare Disease case study.</td>
</tr>
<tr>
<td>0.4</td>
<td>07/Jun/2016</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>Added CH and FR National Reports. Assessment of Annex II requirements.</td>
</tr>
<tr>
<td>0.5</td>
<td>10/Jun/2016</td>
<td>V. Kufrin, T. Pavešković, M. Orešković</td>
<td>HZZO</td>
<td>Focus Group and Literature Review sections</td>
</tr>
<tr>
<td>0.6</td>
<td>27/Jun/2016</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>Added BE National Reports</td>
</tr>
<tr>
<td>0.7</td>
<td>01/Jul/2016</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>Reorganized Appendices; Questionnaires, EU-US workshop, Revision Workshop Sections</td>
</tr>
<tr>
<td>0.8</td>
<td>07/Jul/2016</td>
<td>D. Karlsson</td>
<td>Linköping University</td>
<td>IHTSDO Overview section; added Swedish implementation case</td>
</tr>
<tr>
<td>0.9</td>
<td>12/Jul/2016</td>
<td>G. Cangioli</td>
<td>HL7 Foundation</td>
<td>Final Draft</td>
</tr>
<tr>
<td>0.10</td>
<td>14/Jul/2016</td>
<td>P. Volkert; C. Chronaki, G. Cangioli</td>
<td>Nictiz; HL7 Foundation</td>
<td>Revision of Conclusions, Figure 1 and Abstract. Added other IHTSDO agreements</td>
</tr>
<tr>
<td>0.11</td>
<td>22/Jul/2016</td>
<td>P. Volkert; T. Pavešković, M. Orešković; G. Cangioli; R. F. Nejad; MC Jaulet</td>
<td>Nictiz; HZZO; HL7 Foundation; Hochschule Niederrhein; INSERM</td>
<td>General document revisions. Added the section &quot;Overview of European eHealth research projects in the field of Interoperability, cross-border healthcare and clinical research.&quot;</td>
</tr>
<tr>
<td>0.12</td>
<td>31/Jul/2016</td>
<td>R. Conet, D. Karla, D. Karlsson; P. Hämäläinen; C. Chronaki; G Cangioli</td>
<td>AMC; Linköping University; THL, Europec; HL7 Foundation</td>
<td>General document revisions.</td>
</tr>
<tr>
<td>1.0</td>
<td>21/Nov/2016</td>
<td>G Cangioli</td>
<td>HL7 Foundation</td>
<td>Post Final Review revision</td>
</tr>
</tbody>
</table>

**Date of delivery**


**Status**

final [✓] /[ ]

**Abstract (for dissemination)**

ASSESS CT has investigated the suitability of SNOMED CT to act as a core reference terminology supporting EU-wide eHealth deployments. Work package 1 has contributed to this by investigating existing experiences in the use of this and other large-scale terminology systems. Actual experiences have had to be complemented by expert consensus, because empirical evidence and formal evaluations are still limited. Given the complexity of this topic a mixed methods approach was used including a literature review, online and interview questionnaires, focus groups, workshops and feedback on interim findings during conference presentations and invitation only events. This report will interplay/feed into D4.3 and D4.4 to support recommendations on further actions. In the context of PHC34 cooperation the final version will be used to provide input to several future eStandards deliverables including D2.2, D2.3, D3.4, D3.5, D5.3, and D6.3

**Keywords**

Current use, terminologies, case studies of terminology use, European Standardization Regulation, IHTSDO policies

**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.
Table of Contents

1 Executive summary .................................................................................................................. 6
  1.1 Key findings and study outcomes ...................................................................................... 8
  1.2 Conclusions ......................................................................................................................... 11

2 Glossary .................................................................................................................................. 15

3 Aim and scope of the deliverable ............................................................................................. 16

4 Methodology ............................................................................................................................. 18

5 Stakeholder Registry ................................................................................................................. 20

6 Overview on IHTSDO Structure, Processes, Positioning .......................................................... 21
  6.1 Content Development ......................................................................................................... 22
    6.1.1 IHTSDO Content Development .................................................................................. 22
    6.1.2 Content Development Outside IHTSDO .................................................................... 22
    6.1.3 IHTSDO tools .............................................................................................................. 23
  6.2 SNOMED CT Education ...................................................................................................... 23
  6.3 SNOMED CT Licensing ...................................................................................................... 23
  6.4 Collaboration with Other SDOs .......................................................................................... 24
    6.4.1 IHTSDO – Regenstrief Institute Collaboration (SNOMED CT – LOINC) ................. 24
    6.4.2 IHTSDO – HL7 Collaboration Projects ..................................................................... 24
    6.4.3 IHTSDO – DICOM agreement .................................................................................... 25
    6.4.4 Other agreements ........................................................................................................ 25

7 Focus groups ............................................................................................................................... 26
  7.1 Methodology and set up of focus groups ............................................................................ 26
  7.2 Themes and MS Report on Focus Groups .......................................................................... 27
    7.2.1 Theme 1: Current terminology usage ......................................................................... 27
    7.2.2 Theme 2: Benefits of adopting new terminologies .................................................... 28
    7.2.3 Theme 3: Barriers for extended terminology adoption and use .................................. 28
    7.2.4 Theme 4: Enabling factors for extended terminology adoption and use .................... 29
    7.2.5 Theme 5: Recommendations ...................................................................................... 29
  7.3 Final note ............................................................................................................................. 30

8 Questionnaires .......................................................................................................................... 31
  8.1 Introduction ....................................................................................................................... 31
  8.2 Stakeholders ....................................................................................................................... 31
  8.3 Overview of European countries ........................................................................................ 33
  8.4 Overview of non-European countries ............................................................................... 36

9 Case Studies ............................................................................................................................... 39

10 Literature Review ...................................................................................................................... 45
  10.1 Published scientific literature ............................................................................................. 45
    10.1.1 Overview ..................................................................................................................... 45
    10.1.2 Results ....................................................................................................................... 45
  10.2 SNOMED CT-Expo .......................................................................................................... 49
    10.2.1 Elaboration of Implementation and Use Case ............................................................ 49
  10.3 National Reports ................................................................................................................. 51
ASSESS CT – D1.4

10.3.1 Switzerland ................................................................. 51
10.3.2 France ......................................................................... 52
10.3.3 Belgium ..................................................................... 53
10.3.4 Norway ..................................................................... 54
10.4 Overview of European eHealth research projects in the field of Interoperability, cross-border healthcare and clinical research ......................................................... 55

11 EU-US Workshops ................................................................ 56
11.1 First workshop .................................................................. 56
11.2 Second workshop .............................................................. 57
11.3 Conclusions ..................................................................... 59

12 Revision Workshops ............................................................... 61
12.1 Report on 1st revision workshop ........................................ 61
12.2 Report on 2nd revision workshop ....................................... 61
12.3 Report on final Workshop .................................................... 62

13 Assessment of Annex II: Requirements for the Identification of ICT Technical Specifications .................................................. 63

14 Conclusions ....................................................................... 65
14.1 Enablers for semantic interoperability ................................. 66
14.1.1 Policies, governance and management of terminologies ..... 66
14.1.2 Terminologies bindings to information models ................. 66
14.1.3 Clear context of use for relevance and effectiveness ...... 66
14.1.4 End user satisfaction and usability matter ..................... 67
14.1.5 Awareness raising and education on terminology implementation and use ......................................................... 67
14.1.6 Semantic Infrastructure offering terminology services ..... 67
14.2 SNOMED CT as a core reference terminology in a terminology ecosystem ................................. 68
14.2.1 The need for a terminology ecosystem .......................... 68
14.2.2 SNOMED CT as reference “core” terminology ............... 68
14.2.3 The role of SDOs ........................................................... 68
14.3 Suggested approaches for introducing SNOMED CT ............ 68
14.3.1 Step-wise, use-case-based, incremental approach ............ 68
14.3.2 International Cooperation and stakeholder engagement ... 69
14.3.3 Impact Assessment on the business architecture ............. 69
14.4 Strategic long-term benefits .............................................. 70
14.4.1 Robust maintenance process ......................................... 70
14.4.2 Support to clinical languages (map to user interface terminologies) ................................................................. 70
14.4.3 Ease the reuse of data .................................................. 70
14.4.4 Standardization of EHR content ................................... 70
14.5 Challenges ...................................................................... 71
14.5.1 The need for further evidence of benefits ......................... 71
14.5.2 Market maturity ............................................................ 71
14.5.3 License policy and costs ............................................... 71
14.5.4 Other costs ................................................................. 71
14.5.5 Lack of expertise .......................................................... 72
14.5.6 Actual and perceived complexity ................................... 72
List of Figures

Figure 1 - ASSESS CT WP1 European Country Involvement .......................................................... 7
Figure 2: ASSESS CT WP1 investigations engaged 34 countries globally. .................................................. 7
Figure 3 - ASSESS CT WP1 : Summary findings for current use of SNOMED CT and other key terminologies in healthcare ...................................................................................................................... 12
Figure 4 - ASSESS CT WP1 Deliverables Organization ............................................................................. 16
Figure 5 - Overview of ASSESS CT WP1 goals and the means used for their realization ....................... 18
Figure 6 IHTSDO member countries [retrieved from http://ihtsdo.org/members] ........................................ 21
Figure 7 - Responses distribution per Country (Stakeholders Questionnaire) .......................................... 32
Figure 8 - How could you score the current usage of SNOMED CT in your country? [Mean score] ............................................................................................................................... 33
Figure 9 - What are according to you the main reasons for which your country is not currently an IHTSDO member? .............................................................................................................. 36
Figure 10 - Naming convention and concepts relationships used for the “use cases assessment” .......... 39
Figure 11 - Percentages of the Focus Categories with further breakdown of “Implementation and Evaluation” ................................................................................................................................ 47
Figure 12 - Number of papers by elaboration of implementation (Total = 61) ...................................... 48
Figure 13 - Number of papers by use case (Total = 61) ............................................................................... 48
1 Executive summary

ASSESS CT has investigated the suitability of SNOMED CT to act as a core reference terminology supporting EU-wide eHealth deployments.

Work package 1 “Current Use of SNOMED CT” addressed mainly ASSESS CT objective #1 “investigate the use of SNOMED CT” and assessed if SNOMED CT satisfies the requirements for the Identification of ICT Technical Specifications of the EU standardization regulation, annex II. This document summarizes the key findings of D1.1, D1.2, D1.3, offering additional findings and conclusions, in the final step of an iterative progressive elaboration.

Information about past and current use as well as future prospects for SNOMED CT use was collected and elaborated in the EU Member States and beyond building on the informative and relevant eHGI information paper, and establishing a solid baseline and knowledge background on how terminologies are managed.

| Table 1: Measures of achieving Key Objective #1: Investigate the use of SNOMED CT |
|---|---|---|
| **Parameter** | **Target** | **Coverage of the Study** |
| Level covered | EU / Cross-Border National eHealth programs Regional | Number and type of sources used for the literature review |
| Type of countries covered | At least 5 focus groups in IHTSDO members (EU) 4 focus groups in non-IHTSDO members | Type of stakeholders/ experts involved 350 experts involved |
| Percentage of EU countries | At least 75% | No. national focus groups established |
| Dimensions reported | All dimensions identified by stakeholders | Workshop organized before fifth month 6 Expert Workshops and meetings (2 EU/US) |

Empirical evidence of nation-wide use and formal evaluations of SNOMED CT was found to be limited both in IHTSDO and non-IHTSDO countries. Given the complexity of this topic, a mixed methods approach was used including a literature review, online and interview questionnaires, focus groups, workshops and feedback on interim findings during conference presentations and invitation only events. Over 350 different experts, from 34 countries including 24 EU Member States, contributed to these actions.

- A stakeholder registry of 350 members was established and used in project activities.
- 9 focus groups in 5 IHTSDO member countries (Belgium, Denmark, Sweden, Netherlands, and Portugal) and 4 non-member countries (Croatia, Finland, France, and Germany), addressed five main themes (i.e. Current terminology usage; Benefits of

---

1 By core terminology we mean the large reference terminology that plays a pivotal role within the terminology ecosystem in terms of conceptual coverage and linkage to other terminologies that supplement it.


---

Page 6 of 72
adapting new terminologies; Barriers and enabling factors for extended terminology adoption and use; and Recommendations) and aimed at “collecting European views on current and future terminology use in the health care sector, with a special focus on the role of SNOMED CT.” (See D1.1 and D1.2, section 7 below).

Figure 1 - ASSESS CT WP1 European Country Involvement

Figure 2: ASSESS CT WP1 investigations engaged 34 countries globally.

- **Questionnaires** were adapted for stakeholders, EU Member states overview, and countries beyond the EU. **34 countries were involved globally** (see figure 2) and **138 stakeholders responded**. (See D1.1 and D1.2, and section 8 below).

- **Two EU-US workshops** invitation-only were held in March 2015 and May 2016. **Two revision workshops and final conference** were held in May 2015, October 2015, and June 2016 (see D1.1 and sections 11 and 12 below).

- A literature search was conducted for publications between 2013 and 2015, and **242 eligible papers were examined**. Additional grey literature material including **35 presentations from the SNOMED CT Implementation Showcase (2013) and EXPO (2015)**, and **four national investigation reports**, were also examined (see Deliverables 1.3 and section 10 of this document).
• **5 case studies (covering 10 implementation cases)** were studied in detail as concrete example drivers for the selection and adoption of terminology systems (see Deliverables 1.3 and 1.4 as well as section 9 in this document):
  1. Cross-border Exchange of Patient Summaries: Problem Lists
  2. ERNs Rare Disease (RD) Registry
  3. National/Regional Exchange of Patient Summaries: Problem Lists
  4. National/Regional Exchange of Lab Procedures / Results
  5. National/Regional Exchange of Lab Pathology Procedures/Results.

### 1.1 Key findings and study outcomes

The **stakeholder registry** including more than 350 experts from 34 countries (24 from Europe) reflects the broad engagement of the eHealth community in Europe and beyond, in capturing accurately the current use and future prospects of SNOMED CT. Moreover, this stakeholder registry will be updated, shared with other PHC-34 projects serving as an important resource in follow-up activities. For a detailed account of its synthesis, see D1.1 and section 5.

IHTSDO was formed in 2007 as a non-profit membership organization and its core product is SNOMED CT. As of June 2016, 28 countries are its members. Its governance structure comprises the general assembly that elects the management board and the members’ forum acting in advisory capacity. The mission of IHTSDO is to ensure SNOMED CT is accepted as the global common language for health terms in an international effort that utilizes the skills and efforts of experts from around the world. Member countries operate national release centers and develop national extensions they are encouraged to share with others members. IHTSDO invests on education with three free courses offered throughout the year (Fundamentals, Implementation, and content development theory). IHTSDO collaborates with other SDOs offering use of specific subsets e.g. agreement with DICOM (7000 terms), Regenstrief (on LOINC), INSERM (Orphanet), GS1 (GTINs), and HL7 (in progress). IHTSDO is also the current chair of the Joint Initiative on SDO Global Health Informatics Standardization\(^3\). Although SNOMED CT seems to fulfil the assessment criteria for the Annex II of the requirements for the identification of ICT Technical specification, in regards to Criterion 4, point (b) the concept of “reasonable costs” is very subjective, context dependent and difficult to quantify, and eventually the dependent on the actual use of SNOMED CT. Several stakeholders felt that the current license cost structure is a barrier for the start-up phase. The IHTSDO structure, collaboration with other SDOs and the degree to which SNOMED CT is consistent with the requirements of the EU legislation are further addressed in Deliverables 1.1, 1.3 and sections 6 and 13 of this document.

The reports of the nine country **Focus Groups** (FGs), despite country differences including IHTSDO membership there were shared common elements. On current use, FG identified the lack of extensive evidence in the form of best practices and examples to support accurate evaluation of the potential consequences of adopting SNOMED CT as a core terminology. Administrative use of terminologies was much more prevalent and on occasion classification systems used beyond original scope. FGs also identified the tight link between terminologies and use case, i.e. purpose of use.

On barriers and enabling factors for extended terminology use, FGs identified a list of perceived and actual benefits of using SNOMED CT as a reference terminology for providers and vendors. They highlighted the potential impact in the marketplace induced by internationalization of ICT vendor solutions. Sharing work, improving quality and creating globally shared resources were some of the benefits highlighted. Among barriers for extending terminology use, several FGs indicated the lack of governance strategies supporting semantic interoperability. In that context, the SNOMED CT license cost was perceived as critical barrier in the decision-making or start-up phase. More broadly low awareness of return on investment and cost of change management including resistance to

---

3 [http://www.jointinitiativecouncil.org](http://www.jointinitiativecouncil.org)
change, fear of administrative burden, fear of overcoding/undercoding, and comfort of free text were noted.

Enabling factors frequently reported also as recommendations were awareness of benefits, clear directions on health terminology use, incremental step-wise use case based adoption, easy access to terminologies, associated resources and tools, professional training, use case pilots, and adaptations to the business model of SNOMED CT overcoming the perceived all-or-none policy of IHTSDO.

FGs recommended establishment of national terminology competence centers, allocation of human resources, mandated use of selected terminologies, as well as extensions and improvements to SNOMED CT. An iterative phased use case driven implementation approach supported with tools, maps, translations and ready to use subsets linked to information models was advocated. Finally, the value of FGs as such was recognized and it was recommended that they are repeated in the original countries and be extended in other member states.

**Questionnaires:** The 138 individuals from 15 European countries that responded to the stakeholder questionnaire confirmed the low level of evidence, and highlighted limitations in supporting cross-border patient data exchange and recommended a centralized European reference terminology. SNOMED CT is the preferred option for that when combined with suitable policies and legislation, clarity on licensing, availability of high quality maps, and increased collaboration among organizations and experts. As regards use of SNOMED CT, three groups of countries could be identified: high use (UK), medium use (Sweden, Malta, Netherlands, Denmark, Finland), and low use (Estonia, France, Germany, Greece, Austria, Italy, Belgium, Croatia, Luxemburg).

European Country overview questionnaires confirmed the limited use of SNOMED CT with adoption “in progress” or “under consideration” even among the 10 IHTSDO members in Europe. A national terminology strategy is under discussion in 50% the responders, and 14 countries have a National Competence Center(s) for Terminologies. The use of terminology tools in authoring and administration of terminology assets such as value sets, code systems, etc., seems to be on the rise. Web publication is the top means for distributing terminologies, with increasing use of local or central terminology services. The main reported use of SNOMED CT is as reference terminology. France uses SNOMED CT also as aggregate terminology for research purposes. Just the UK and Malta use SNOMED CT as reference, aggregate, and interface terminology. The 9 countries that reported use of SNOMED CT employ pre-coordinated concepts, while only three use the additional descriptive power of SNOMED CT. Introduction of SNOMED CT follows a project or use case based approach in the early startup phases, with some countries e.g. UK, NL, gradually moving towards a mixed or centrally managed approach. UK, Sweden, Spain, and Denmark use the full SNOMED CT core with national extensions. Estonia, Netherlands, Portugal, Malta, and Belgium follow an approach based country specific subsets. The translation and the collection of synonyms are nationally coordinated in most countries recognizing the need international cooperation. For almost all non-IHTSDO members (with the exception of Austria, Bulgaria and Luxembourg) the most cited reasons for not being a member are the License Costs and the perceived absence of national policies on semantic interoperability.

Questionnaires from IHTSDO member countries beyond Europe confirmed the lack of extensive evidence on the use SNOMED CT and Israel, Malaysia, and New Zealand report that adoption is still “in progress”. Most countries reported top down use of the full SNOMED CT core with national extensions, which differs from the leading European approach, which appears to follow the use-case driven subset development. All countries reported using pre-coordinated SNOMED CT concepts.

Ten implementation cases of the selected use cases were studied including description of terminologies adopted, analysis of the decision process, identification of drivers, benefits and challenges experienced. The adopted approach and level of maturity varied. Countries that have jurisdictional policies and competence centers working on semantic interoperability
(e.g. England, Netherlands) have mature processes for terminology management that take into account also more aspects of terminology use and reuse. The importance of establishing international collaboration for peer learning and exchange of experience has been recognized. The eventual choice of terminologies is sometimes only partially driven by the “fitness for purpose”, and may depend on “non-functional” dimensions such as terminology availability in that setting. In the UK pathology report or the French Laboratory and Rare Diseases Registries cases, the combination of non-conflicting international code systems was the preferable solution and collaboration among SDOs facilitated coordinated use (e.g. LOINC and SNOMED CT for lab reporting or Orphanet and SNOMED CT for rare diseases). Several use cases such as epSOS and the clinical building blocks in NL, highlighted the tight binding between terminologies and information models. Moreover, quality of data may also depend on the actual capability of systems to capture and show data as expected.

Literature search in PubMed and Embase on “SNOMED” between 2013 and 2015 in English resulted in 242 eligible papers. 27% dealt with implementation & evaluation: 26 papers use SNOMED CT to retrieve or analyze patient data; 15 papers use SNOMED CT for research purposes, 12 papers describe SNOMED CT implementation in the daily clinical practice and very few evaluate the merit of SNOMED CT. Comparing with 2013 Review of Lee⁴, the percentage of papers addressing implementation increased, suggesting higher uptake of SNOMED CT in practical clinical use. The clinical problem list followed by procedures and laboratory results is where SNOMED CT is used the most. No publications addressed the EU rare diseases registry use case or the cross-border or national / regional exchange of patient summaries suggesting that use of SNOMED CT for these use cases is limited.

The ‘SNOMED CT-Expo’, the annual international IHTSDO conference presenting implementation projects and use cases from all over the world, provided insights on real world implementation issues in 35 presentations from 16 countries. The top issues addressed were mapping to other terminologies (21), using inference (6), and SNOMED CT subsets (5).

National reports commissioned from Switzerland, France, Belgium, and Norway added to the evidence we considered. Switzerland commissioned a report on eHealth Semantics and Content for Switzerland, which offered a critical analysis of main terminologies and a roadmap for their adoption proposing a governance structure that would advance semantic interoperability through stakeholder consensus. The report recommended specific terminologies and the evaluation of SNOMED CT in specific domains. It also recommended a single Swiss institute for coordinating resources (inspired by DIMDI in Germany) and a family of Swiss standards for local characteristics to be developed, maintained, and used free of charge. In 2016, Switzerland joined IHTSDO and eHealth Suisse was assigned as the national release center.

The French Ministry of Health asked ASIP Sante to make a study on reference terminologies taking into account governance, implementation and use, considering this a priority for semantic interoperability. The study identified information models, coded concepts, value sets and vocabulary bindings, code systems, mappings, as well as standard terminology services as the bricks of semantic interoperability. Upon its conclusion, on February 1st 2016, the study recommended setting up national governance of semantic resources for health and social care in France, and SNOMED CT and ICPC2 to the existing healthcare framework.

In 2010, Belgium started a preliminary research for the development of a terminology server offering a controlled medical vocabulary for the health domain. The 2013 report “Guidelines Belgian terminology Diagnoses” described a reference terminology for Diagnoses based on SNOMED CT in French and Dutch. It described the concept selection methodology, compared pre and post coordination describing when and how to use them and addressed management of translations. An iterative process with three runs plus a reconciliatory activity

was chosen for concept selection and translation and involved Dutch and French speaking clinicians. The associated roadmap 2014-2018 focuses on clinical use of terminologies and smart end-user interfaces, highlighting the need for training, good governance, stakeholder involvement, investment in tools, and multilateral terminology validation.

In 2015, the Norwegian directorate for e-helse (eHealth) assessed the suitability of SNOMED CT for the Norwegian health services. The report recognizes arguments for and against Norway joining IHTSDO including scope and complexity, but also limitations of EHR systems on fully supporting process, decision support and semantic search. Among, the five options considered from “do nothing” to “join IHTSDO and plan for wide SNOMED CT adoption”; “Enrollment in IHTSDO with an exploration period” was recommended. In the 3-year exploratory period, a team working on SNOMED CT will increase competence on a common standardized terminology, launch a study to explore processing of structured records and decision support, follow ICD-11 developments, make SNOMED CT subsets available for dental needs and archetype development. A follow-up evaluation of SNOMED CT will be carried out after three years.

The two EU/US workshops in 2015 and 2016 allowed sharing of expertise and best practices in the context of the EU/US MoU for cooperation in the area of eHealth. Several large Health Systems like Kaiser Permanente (55M records), which has its own terminology infrastructure called Convergent Medical Terminology (CMT), rely on SNOMED-CT and LOINC. J Campbell (Nebraska MC) pointed out the role of interface terminology to make SNOMED CT implementation successful. Overall SNOMED CT use in US is mainly to support Meaningful Use and is mapped to local codes (Mayo Clinic). Jim Case from the US National Library of Medicine (NL) presented the US Value Set Authority (VSAC) offering terminology services to the Meaningful Use Program including mappings all for SNOMED CT and ICD-10-CM. Prof. Chris Chute (John Hopkins) expressed the hope that ICD11 will bridge post-coordination with classification. It was confirmed that SNOMED CT is the preferred reference terminology and needs to be used with other terminologies, classifications, and coding systems. Thus, the possibility of setting up a counterpart of NLM VSAC in Europe, an approach that should be consented by member states, was suggested noting that the use cases of the eHealth Digital Services Infrastructure (eHDSI) could play a role in pooling resources, sharing lessons learned and exchanging experiences. The conclusions the EU/US workshops were: (a) address SNOMED CT from an infrastructure perspective; (b) Determine ways to facilitate incremental standardization; (c) Consider the potential of a “Pan-European” counterpart to NLM; (d) Determine (clinical) use cases e.g. Ambient Assisted Living, Learning Health System, International Patient Summary; and (e ) Stimulate mutual learning and exchange of resources.

The two revision workshops and the final conference attended by project participants and external experts helped set direction for the project and consolidate findings from different strands of the project. The first workshop in May 2015 clarified the direction of the project towards real use cases, and clarified the three options: adopt, abstain, and alternate. The second workshop in October 2015, discussed the findings of the focus groups, questionnaires and concrete examples from NHS England were presented. The final workshop, in June this year, presented the draft project recommendations stressing their impact on the cross-border exchange of health data and on clinical research. The need for education but also the right of patients and physicians to express themselves in their language was noted. Full translation of SNOMED CT was not considered a precondition to rollout SNOMED CT, and the urgency of maintaining the epSOS vocabularies for the eHealth DSI was stressed.

1.2 Conclusions

In synthesis, the findings and outcomes from these empirical investigations, grouped under five headings have been discussed during the ASSESS CT revisions workshops and continuously refined.
First, the study instruments employed to assess current use of SNOMED CT, identified specific **enablers for semantic interoperability**:  

1. **Policies, governance, and operational management of terminologies.** A recurrent theme in focus groups, questionnaires, country interviews, case studies, and workshops was the importance of national strategies, clear governance, supporting policies, and commitment of resources to the operational management of terminologies.

2. **Terminology bindings to information models.** Case studies and questionnaires pointed out that fitness-for-purpose of a terminology cannot be evaluated independently from the information model adopted; the availability of agreed information models at different levels; and the context of use. Considerations should not be limited to exchange of data but also to the initial high quality data capture.

3. **Clear context of use for relevance and effectiveness.** Focus groups, literature review, and experts quoted during workshops supported that terminologies should be assessed and used within a very-well specified purpose and context, since when used outside their purpose they lose relevance and efficiency.

4. **End user satisfaction and usability tools.** The response of several stakeholders suggested that usability and end-user satisfaction are critical factors for the acceptance and adoption of SNOMED CT and for that matter, any terminology. The availability of tools, the awareness of the benefits and the effectiveness in supporting clinical business processes are ways to overcome the perceived complexity of browsing, identifying and selecting terms.

5. **Awareness raising and education on terminology implementation and use.** Several focus groups, especially the Croatian, French and Portuguese pointed out the need to promote awareness of individual and organizational benefits. Input from several countries including France, England, and Portugal, national reports, and case studies highlight engagement and education of stakeholders.

6. **Semantic infrastructure supporting terminology services.** Several stakeholder questionnaires and the French national study identified terminology services as an enabler for the introduction of SNOMED CT.

Second, the role of **SNOMED CT as a core reference terminology in a terminology ecosystem was identified**. All evidence supports the position that neither SNOMED CT nor any other terminology can be the unique solution. Multiple terminologies are needed and SNOMED CT was suggested by several stakeholders as a good candidate for the cross-border exchange of data assuming license issues are resolved. However, reference terminologies should be related to national and international aggregation/classification.
terminologies to support secondary use and administrative processes. In this context, the role of SDOs is critical in reducing conflicts and gaps among terminologies, enabling collaborative use of terminologies.

Third, the **suggested approaches for introducing of SNOMED CT** include:

1. **Step-wise, use case based incremental approach.** Focus groups, workshops, stakeholder questionnaires and country interviews suggest that such an approach, when coherent with the general semantic interoperability strategy, possibly starting from inadequately covered domains that provide concrete advantages to stakeholder, with a realistic investment plan for the cost of introduction to be commensurable to scope.

2. **International Collaboration strategy and stakeholder engagement.** Country questionnaire from several countries including UK, Finland, Portugal, etc., suggest that stakeholders should be engaged every step of the way, not just for the target scenario. Moreover, workshop participants reflected that international cooperation is crucial to focus the efforts and share experiences on specific practical topics of interest, and contribute to improvements in interoperability of cross-border services and sustainability of the eHealth digital service infrastructure.

3. **Impact assessment on the business architecture.** Based on the UK experience as reflected in workshop participation and case study, assessing the impact of introducing SNOMED CT on the clinical processes i.e. how the business process should change, should be addressed before other technical aspects such as impact on applications.

Forth, as far as **strategic long-term benefits** of using SNOMED-CT, current use suggests:

1. **Robust maintenance process.** Experts participating in the first revision workshop and EU/US workshop suggested that the evaluation should take into account that IHTSDO assures a transparent and robust maintenance process.

2. **Maps to user interface terminologies.** Several projects e.g. CMT (Kaiser Permanente), NLMC (UK), Dutch Thesaurus for diagnoses reported in workshops suggest that SNOMED CT in fact, can play an infrastructure role supporting mapping of national or local user interface terminologies to clinical language.

3. **Easy reuse of data.** Stakeholder questionnaires, focus groups, workshops, and case studies suggest that as a reference terminology SNOMED CT may facilitate interoperability and reuse of data across domains and jurisdictions ensuring data quality and traceability across the patient trajectory.

4. **Standardization of EHR contents.** Stakeholder responses and the Canadian questionnaire support that adoption of SNOMED CT as a reference terminology may contribute to standardization of eHealth systems.

Finally, as regards challenges of SNOMED CT:

1. **There is need for further evidence.** All study instruments suggest that use of SNOMED CT is limited regional / national scenarios or at the European level and that hinders the capability of providing robust evaluation.

2. **Market maturity.** Stakeholder questionnaires suggest that the EHR market, despite progress in the recent years is still immature, even if some vendors consider adoption of SNOMED CT an opportunity.

3. **License policy and costs.** This is a recurrent theme across all study instruments. Even though people recognized that license costs are a small fraction of the overall costs, supporting actions and policies easing initial adoption were suggested by individual stakeholders, focus groups and workshops. On many occasions, it was suggested that the license agreement negotiated should be tied to the scenario of use.

4. **Knowledge investment and terminology maintenance.** Beyond the direct costs i.e. licensing, questionnaires and expert feedback in workshops suggested that there is a knowledge investment that should not be underestimated. The organizational costs of setting up and operating the National Release Centers, supporting functions such as translation and synonym management should be accounted for.
(5) **Lack of expertise.** Several questionnaires, focus group and workshops identified the knowledge gap regarding SNOMED CT and other terminologies.

(6) **Actual and perceived complexity.** Responses to questionnaires suggest that actual and perceived complexity of SNOMED CT is a barrier that needs to properly managed, to allow its wide adoption. It is suggested that the complexity seen by end users and other stakeholders be commensurate to the scenario of use.

In summary, there is little evidence of using SNOMED CT in regional/national scenarios in Europe and around the world. A *step-wise, use-case-based, incremental*\(^5\) *approach*, coherent with national semantic interoperability strategy building on international collaboration and global standards, can work for the introduction of SNOMED CT.

IHTSDO assures a **transparent** and **robust maintenance process**, provides support to **clinical languages** by mapping user interface terminologies and facilitates **reuse of data** across different clinical domains, care settings, languages and jurisdictions. A critical perceived barrier for adoption of SNOMED CT is **license cost** and policy. Already forms of exploratory licenses are emerging (e.g. Norway) and a specially negotiated license on behalf of the EU has been considered for an EU terminology services infrastructure. In any case, **supporting actions and policies for facilitating the initial adoption of SNOMED CT are strongly suggested.** With a view to the eHDSI under CEF, the case of **Member States which will use specific SNOMED CT sub-sets only for cross-border services (transferring or displaying terms),** should be carefully studied and handled.

---

\(^5\) Incremental does not mean that growth is not governed. Introduction plans take into account the global interoperability goals and the identified strategies, in order to avoid that too focused use case based solutions are progressively adopted leading to a global incoherent solution.
2 Glossary

(ICD) AM  ICD - Australian Modification
(ICD) CA  ICD - Canada
(ICD) CM  ICD - Clinical Modification
AMT  Australian Medicines Terminology
API  Application Programming Interface
ASIP  Agence des Systèmes d’Information Partagés (de Santé)
ATC  Anatomical Therapeutic Chemical (Classification System)
C-CDA  Consolidated CDA
CCI  Canadian Classification of Health Interventions
CDA  Clinical Document Architecture
CiBB  Clinical Information Building Blocks [Netherlands]
CiMI  Clinical Information Modeling Initiative
DCM  Detailed Clinical Models
DHD  Dutch Hospital Data [Netherlands]
DICOM  Digital Imaging and Communications in Medicine
DMP  Dossier Médical Personnel (Now renamed “Dossier Médical Partagé”) [France]
DOW  Description of Work
DRG  Diagnosis-Related Group
eCRTS  epSOS Central Reference Terminology Server
EDQM  European Directorate for the Quality of Medicines
eHGI  eHealth Governance Initiative
EHR  Electronic Health Record
epSOS  European Patients Smart Open Services
ERN  European Reference Network
EU  European Union
FG  Focus Group
F-MDS-RD  French national Minimum Data Set for Rare Diseases [France]
FSE  Fascicolo Sanitario Elettronico [Italy]
GP  General Practitioner
GUI  Graphical User Interface
HGVS  Human Genome Variation Society
HIS  Hospital Information System
HL7  Health Level 7
HPO  Human Phenotype Ontology
ICD  International Classification of Diseases
ICD-O  International Classification of Diseases for Oncology
ICF  International Classification of Functioning, Disability and Health
ICN  International Council of Nurses
ICNP  International Classification for Nursing Practice
ICPC  International Classification of Primary Care
ICT  Information and Communications Technology
IHE  Integrating the Healthcare Enterprise
IHTSDO  International Health Terminology Standards Development Organisation
LIS  Laboratory Information Systems
LORD  Linking Open data for Rare Diseases
MLDS  (IHTSDO) Membership License & Distribution Service
MOF  Ministry of Finance
MOH  Ministry of Health
MS  Member State
NCP  National Contact Point
NCRS  NHS Care Records Service
NHS (UK)  National Health Service (UK)
NHS  National Health System
NLMC  National Laboratory Medicine Catalogue [UK]
NPD  National Program for Data collection
NRC  National Release Center
OMIM  Online Mendelian Inheritance in Man
OWL  Ontology Web Language
PBCL  Pathology Bounded Code List [UK]
PHR  Personal Health Record
PMSI  Programme Médicalisé des Systèmes d’Information
PS  Patient Summary
R&D  Research & Development
RD  Rare Diseases
RF2  Release Format 2 (IHTSDO)
ROR  Regional Oncologic Registries
SDO  Standard Development Organisation
SIOP  Semantic InterOPerability
UCUM  Unified Code for Units of Measure
UK  United Kingdom
US  United States
WGM  Working Group Meeting
WHO  World Health Organization
WHO-FIC  WHO Family of International Classifications
WP  Work Package
XD-LAB  Sharing Laboratory Reports [IHE Profile]
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, future prospects for the usage of SNOMED CT (and other terminologies). This has been performed covering as much as possible the 28 Member States (MS) of the European Union, other European countries that have been involved to some extent in the European eHealth context (e.g. the epSOS Participating Nations)⁶ and also a selected numbers of Non-European countries. For each MS, building on the informative and relevant eHGI information paper⁷, some relevant aspects concerning the use of clinical terminologies have been investigated, e.g.: how terminologies are managed; how semantic interoperability issues have been addressed; what are the national policies and guidelines (if any); if there are terminology infrastructures services; types and costs of licenses; costs 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, have been investigated by collecting, if possible, the concrete facts (experiences, evidence) that support the opinions expressed.

D1.1 presented the methodological approach, instruments and early results from collected questionnaires, conducted interviews, workshops, and focus groups. D1.2 continued this work with further results from questionnaires, and outcome of the focus groups. D1.3 integrated the updates coming from EU-countries questionnaires and focus groups with new experiences about the use of terminologies from non-European IHTSDO member countries, literature review results, and case study assessment. These actions involved relevant experts and inputs from workshops. All those results have been wrapped-up in this final deliverable D1.4 integrating them with the results of the EU/US experts meeting and additional findings that have been collected in the last months of the project.

As described above, this deliverable summarizes all the activities and results obtained by the ASSESS CT Work package 1 and can be used as guidance for browsing the more detailed information reported in the other WP1 deliverables and in the Appendixes.

---
⁶ Even if formally not totally correct, here and hereafter the concept of MS is used in a wide sense as European country.
This deliverable is organized per topics. In particular, it provides the summaries about:

- The general description of the methodology adopted for achieving the WP1 objectives (Section 4 - Methodology), including information about the Stakeholder Registry (Section 5 - Stakeholder Registry)
- An overview of the most significant aspects of the IHTSDO structure, processes, and positioning. (Section 6 - Overview on IHTSDO Structure, Processes, Positioning)
- The methodology applied and the results of the focus group activities. (Section 7 - Focus groups)
- The methodology applied and the results of the questionnaires realized (Section 8 - Questionnaires), in details: the stakeholders questionnaire (§ 8.2); the overview of European countries (§ 8.3); the overview of non-European countries (§ 8.4).
- The methodology applied for performing the case studies assessment and the summary of the results (Section 9 - Case Studies)
- The Literature Review methodology and results (Section 10 - Literature Review), including: published scientific papers (§ 10.1); SNOMED CT Expo presentations (§10.2); National Reports (§ 10.3) and European research projects (§ 10.4).
- The topics discussed and the main conclusions and recommendations of the EU-US experts workshops (Section 11 - EU-US Workshops)
- A report of the Revision Workshops (Section 12 - Revision Workshops)
- The results of the assessment concerning whether SNOMED CT satisfies the requirements for the Identification of ICT Technical Specifications of the EU standardization regulation, Annex II8 (section 13 - Assessment of Annex II: Requirements for the Identification of ICT Technical Specifications)

Moreover, Appendix A includes the elaborated results of the questionnaires; Appendix B provides additional details about the Literature Review, the case study assessment; the Regulation (EU) No 1025/2012 Annex II Assessment; and of the second revision workshop.

---

4 Methodology

WP1 aims to support the global ASSESS CT project objectives to "investigate the fitness of the international clinical terminology SNOMED CT as a potential standard for EU-wide eHealth deployments" by (a) investigating the use of SNOMED CT across EU (and beyond) and (b) assessing if SNOMED CT satisfies the requirements for the Identification of ICT Technical Specifications of the EU standardization regulation, annex II.

To achieve those goals appropriate strategies and tactics have been discussed and formalized based on the BMM formalism; and an action plan has been defined. Section 4 of the Assess CT Deliverable D1.1 provides further details about the adopted global methodology. The specifics of the methodology used for each of the adopted instruments (e.g. questionnaires, focus groups, Literature review) are described in the dedicated sections.

Since the initial results were largely based on beliefs and expectations rather than observed impact or benefits, key experts strongly recommended the project team to focus WP1 efforts primarily on intensifying and repeating the focus group discussions where necessary and desirable. This should be realized through an iterative revision process including expert validation workshops, questionnaires and stakeholders interviews. This methodology was deemed superior to a Delphi study.

350 experts/stakeholders from 34 countries (26 EU MS)

Figure 5 - Overview of ASSESS CT WP1 goals and the means used for their realization

Figure 5 provides an overview of the instruments employed in WP1. The results of those investigations are described in the dedicated sections.

The coverage of these different empirical investigations by country is given below in Table 1.

---

9 This goal includes also the comparison of "the SNOMED CT adoption scenario (ADOPT) with (a) defining a semantic interoperability framework without SNOMED CT (ALTERNATIVE) and (b) doing nothing at the EU level (ABSTAIN)."

10 (a) Trigger, encourage, and support Rich Policy Dialogues and Mutual Learning (b) Enforce the Stakeholders Involvement (c) use a "meet-in-the-middle" staged approach (d) Continuous Monitoring of results and indicators (e) Learn to Adapt (Agile) (f) adoption multiple investigation instruments.

### Table 1: Study coverage

<table>
<thead>
<tr>
<th>Countries</th>
<th>Contacted</th>
<th>Stakeholders Quest.</th>
<th>Country Overview Quest.</th>
<th>Focus Group</th>
<th>Case Study Assessment</th>
<th>Stakeholders Registry</th>
<th>Lit. Review</th>
<th>Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Belgium</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓(*)</td>
</tr>
<tr>
<td>Cyprus</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Croatia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Denmark</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Estonia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Finland</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>France</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓(*)</td>
</tr>
<tr>
<td>Germany</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Greece</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hungary</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ireland</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Italy</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Latvia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Lithuania</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Malta</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Netherlands</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Poland</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Portugal</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Romania</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Slovakia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Slovenia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Spain</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sweden</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Switzerland</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓(*)</td>
</tr>
<tr>
<td>Norway</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓(*)</td>
</tr>
<tr>
<td>Australia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Canada</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>India</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Israel</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Malaysia</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>New Zealand</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Uruguay.</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>USA</td>
<td>Note 2</td>
<td>Note 2</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

| EU Member States (28)   | 28 (100%) | 15 (54%) | 21 (75%) | 9 | 10 cases | 24 (85%) | 15 (54%) | 19 (68%) |

(*) Reports on national studies on semantic interoperability and terminology usage.

Note 1: 242 eligible Scientific Papers; 4 National Reports; and 35 SNOMED CT EXPO presentations. See Appendix B for more details about this review.

Note 2: Experiences on the usage of SNOMED CT in US have been collected during the EU-US expert workshops.
5 Stakeholder Registry

Collecting evidence in ASSESS CT has been realized through the broad engagement of experts and stakeholders. In that regard, the establishment of a stakeholder registry early on in the project was deemed key to the success of the project. The process for the set up and update of the stakeholder registry has been described in the ASSESS CT deliverable D1.1. 350+ stakeholders have been involved covering 24 European countries (Austria; Belgium; Bulgaria; Croatia; Czech Republic; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Italy; Luxembourg; Malta; Netherlands; Norway; Portugal; Slovakia; Slovenia; Spain; Sweden; Switzerland; United Kingdom); and 8 Non-EU countries (Australia, Canada; India; Israel; Malaysia; New Zealand; U.S.; Uruguay).

Here is an overview of the synthesis of the stakeholder registry: 124 gave their consent in being included in the stakeholder registry through the stakeholder questionnaire forms; 37 answered the country overview questionnaire form (for both EU and Non-EU countries); 44 (of a total of 53 registrations) participated to the 1st workshop; 22 new stakeholders (on a total of 58 registrations) registered to the 1st workshop; 6 additional attended the final workshop (on a total of 28); 54 (on a total of 118) are focus groups attendees; 28 were members of the eHealth Stakeholder Group. The remaining has been identified through direct contacts.
6 Overview on IHTSDO Structure, Processes, Positioning

Since 2007, SNOMED CT is owned by the non-profit organization International Health Terminology Standards Development Organisation (IHTSDO). With the vision that global standards for health terms are an essential part of improving the health of humankind, the mission of IHTSDO is to ensure SNOMED CT is accepted as the global common language for health terms in an international effort that utilizes the skills and efforts of experts from around the world.

IHTSDO is a membership organization\textsuperscript{12}. IHTSDO is owned and governed by its 28 member countries (as of July 2016). Of the 28 member countries, 14 are currently also EU member countries its governance comprises the General Assembly and the management board, which is elected from the General Assembly. The Member Forum is an advisory body to the Management Board of the organization, and its role is to facilitate collaboration and cooperation between the Members. The Vendor Liaison Forum also advises the Management Board and allows vendors to provide input into SNOMED CT development. Member countries operate National Release Centers and manage national extensions to SNOMED CT. The 28 member countries have in total 24 official languages (not counting the more than 20 official languages of India) and only seven countries have English as an official language. This situation is not reflected on the IHTSDO management level: of the 12 members of IHTSDO management staff 11 are native English speakers and 8 are from the UK.

![Figure 6 IHTSDO member countries retrieved from http://ihtsdo.org/members](http://ihtsdo.org/members)

SNOMED CT has a comprehensive clinical scope and the main application of SNOMED CT is for use inside the Electronic Health Record (EHR). IHTSDO’s 2015-2020 Strategic Directions\textsuperscript{13}, as approved by the General Assembly in October 2015, are: (a) Demonstrate successful large-scale implementations of SNOMED CT; (b) Remove barriers to adoption for our customers and stakeholders; (c) Enable continuous development of our product to meet customer requirements; (d) Provide scalable products and services that drive SNOMED CT adoption. (e) Set new trends and shape new technologies that increase the overall use of SNOMED CT. Additional information on IHTSDO structure, processes, and positioning can be found in Deliverable 1.3, chapter 6.

\textsuperscript{12} IHTSDO Articles of Association version 16: http://www.ihtsdo.org/resource/resource/142

\textsuperscript{13} IHTSDO Strategic Direction 2015-2020: http://www.ihtsdo.org/resource/resource/276
6.1 Content Development

6.1.1 IHTSDO Content Development

IHTSDO applies a development methodology based on the Open Universal Process\(^\text{14}\) for the development of SNOMED CT content. This methodology is followed by IHTSDO staff as well as by a growing number of Consultant Terminologists undertaking content development projects. Content development projects can be started either as a response to requests from SNOMED CT users or after internal review of SNOMED CT content issues. The process includes a number of phases, from Inception through Elaboration, Construction and Transition when the content is released for the use by SNOMED CT users.

SNOMED CT is currently updated twice a year, but IHTSDO member countries may have a more frequent release schedule for parts of the terminology.

IHTSDO uses cloud-based collaborative tools, e.g. Confluence and JIRA, to manage content development projects and to manage project communication and documentation. All IHTSDO members have access to these tools. There are as of June 2016 about 600 unresolved issues in the SNOMED CT Content issue tracker where about 500-550 are currently being worked on by IHTSDO staff or consultant terminologists. In the last years, the average number of resolved issues is higher than the added ones\(^\text{15}\). The strong variability of the processing time, in dependence on the complexity and the impact of the issue (some issues may require years), does not allow however to provide a meaningful global average processing time. Member countries play an important role in prioritizing issues through the IHTSDO Members Forum.

Included in the SNOMED CT Content Development process is the identification of quality criteria. Each content project must identify quality criteria in order to assess the quality of any proposed solutions. A terminology testing methodology is also currently being formalized.

IHTSDO has recently released an on-line SNOMED CT quality evaluation tool openly available (http://qa.snomed.org). Currently, general descriptive statistics about the most recent SNOMED CT release is presented. This includes statistics about added, changed, and deactivated concepts and descriptions. The tool also presents some statistics about potentially problematic patterns in the current release, such as redundant assertions.

6.1.2 Content Development Outside IHTSDO

In addition to content development done by IHTSDO, most IHTSDO member countries add additional content to SNOMED CT and many of them add large amounts of content. For non-English-speaking countries, translation leads to addition of descriptions in the nationally used languages. In the spirit of collaboration, the norm is that member extensions are shared with the community, for example through the IHTSDO SNOMED CT browser. According to the affiliate license agreement, members are required to share content with IHTSDO and/or other members if requested. There are identified risks of not sharing extensions, for example in the introduction of duplicate content and divergence from the international release, and cross-border interoperability might be jeopardized by not sharing content with members.

Member countries may also extend SNOMED CT content by adding new concepts. New concepts can be added for serving a local or national need for country-specific content, where there is no international need. For example, this may include administrative content based on national legal requirements, but also, SNOMED CT extensions can be used to distribute clinical content with a national scope. For example, the national drug dictionaries of the UK, Singapore, and Australia are developed and distributed as SNOMED CT extensions. These drug dictionaries add levels of specificity to the generic drug content provided with the international release of SNOMED CT.

\(^{14}\) http://epf.eclipse.org/wikis/openup/

\(^{15}\) In 2015, 72 issues were created and 212 were resolved. So far in 2016 21 have been created and 61 resolved.
A further reason for adding content to a national extension of SNOMED CT may be that the priorities of the member country or other licensees might be different from the priorities of the IHTSDO. Thus, a member country can add content to a national extension more swiftly than requesting the IHTSDO to add this to the international release. The content may then be added to the international release at a later stage according to the priorities of the IHTSDO as determined jointly by the members.

### 6.1.3 IHTSDO tools

IHTSDO is developing tools supporting the use and development of its products (the SNOMED CT terminology, mappings, translations, etc.) according to IHTSDO member priorities. Tools developed in house, or by consultant developers, are made available as open-source software.

Tools developed so far include a (multilingual) SNOMED CT terminology browser, a mapping tool, a terminology distribution and licensing server, and authoring tools used for SNOMED CT production. Tools soon to be deployed include a translation tool, a subset (RefSet) tool, and a batch-authoring tool.

### 6.2 SNOMED CT Education

Education on SNOMED CT is available from a number of sources including IHTSDO, IHTSDO member countries, academic institutions, vendors, and teaching companies. Many resources are available on-line and many resources are free.

IHTSDO currently provides a set of three courses: the SNOMED CT Foundation Course (30-35 hours), the SNOMED CT Implementation Course (for people involved in SNOMED CT implementation, 80-90 hours), and the SNOMED CT Content Development Theory Course (for people involved in content development, e.g. in a national extension). The courses are provided on-line, at no cost, but with a limited number of attendees following an application process. The courses build on each other; so for example, the Foundation Course is a prerequisite for the Implementation Course. SNOMED CT Foundation Course opportunities are provided monthly and IHTSDO aims to allow applicants to start within eight weeks after application. The SNOMED CT Implementation Course is scheduled to take in students every three months, The SNOMED CT Content Development Theory Course first started early 2016.

The IHTSDO courses are provided in English but some member countries, for example Sweden, provided courses in their native language as an add-on to the IHTSDO-provided courses. IHTSDO member countries have provided various e-learning resources, including courses, webinars, slide decks, YouTube videos, etc.

Additionally, there are books specifically about SNOMED CT and many generic health informatics books include a chapter about clinical terminologies, and SNOMED CT specifically.

### 6.3 SNOMED CT Licensing

Any use of SNOMED CT requires a license unless explicitly stated, as described in Deliverable 1.3. However, the SNOMED CT documentation may be used without a SNOMED CT license. Tools developed and/or owned by IHTSDO have been released with open-source licenses.

---

16 See: https://github.com/ihtsdo
17 http://browser.ihtsdotools.org/
18 https://mapping.ihtsdotools.org/
19 https://mlds.ihtsdotools.org/
20 Available from: http://snomed.org/doc
6.4  Collaboration with Other SDOs

6.4.1  IHTSDO – Regenstrief Institute Collaboration (SNOMED CT – LOINC)

The agreement between IHTSDO and Regenstrief Institute (developing LOINC) states that the two organizations should avoid duplication of work and allow effective support for providers who implement combinations of SNOMED CT and LOINC. IHTSDO has agreed to not create new SNOMED CT concepts in the areas covered by the agreement with the exception that IHTSDO may add content in response to member requests, i.e. the agreement allows the IHTSDO to support member countries who are not using LOINC with new content as long as the content does not originate from LOINC and as long as the request is supported by two or more member countries.

The IHTSDO – Regenstrief collaboration dates back to 2009 when a collaborative project with IHTSDO, Regenstrief Institute, and IFCC-IUPAC was initialized with the aim of testing a joint, distributed way of working and a proposed model for representing laboratory medicine content in SNOMED CT. The project ended successfully in October 2009 and negotiations between IHTSDO and Regenstrief Institute commenced. An agreement was signed in 2013\(^1\). A mapping project started in January 2015 aiming to create SNOMED CT expressions corresponding to LOINC terms as well as direct mappings between LOINC parts and SNOMED CT concepts\(^2\). So far (as of April 1 2016) 13 620 LOINC terms have been mapped to SNOMED CT expressions and 4 051 LOINC parts have been mapped to SNOMED CT concepts.

The agreement is further detailed in D1.3, chapter 6.3.

6.4.2  IHTSDO – HL7 Collaboration Projects

An agreement on international collaboration between IHTSDO and HL7 was signed in 2014 and an updated agreement was signed in 2016. The agreement includes a separate SNOMED CT development licensing agreement, which allows access to the entire international release of SNOMED CT to those developing HL7 international standards. IHTSDO has proposed to HL7 the development of a subset of the SNOMED CT international release including concepts and descriptions, which would be free for use within HL7 products by anyone globally. Examples of use would include HL7 value sets and metadata. As of July 2016 this subset and corresponding agreements have not yet been realized. A similar proposal has been given to IHE.

Further, IHTSDO has agreed to accept requests for new content from the HL7 terminology authority, which coordinates terminology issues within HL7 products. IHTSDO is also collaborating on the development of the TermInfo implementation guide and in HL7 FHIR and HL7 CIMI terminology binding projects.

Already in 2004, the TermInfo project was established to elaborate on the problem of consistently using terminologies inside information models. The project was adopted by HL7 in 2005 and in May 2006 a Draft Standard for Trial Use (DSTU), an implementation guide for using SNOMED CT in HL7 version 3, was balloted and approved. The document was later jointly published by IHTSDO and HL7. In 2011, work started on an update to the document for CDA R2 and this new version was balloted and approved in 2014. Currently (June 2016) work is done on using SNOMED CT with FHIR resources.

The TermInfo document for HL7 version 3 and for CDA R2 contains a set of rules for use of SNOMED CT when there is an overlap between the information model and the terminology. E.g. both SNOMED CT and HL7 version 3/CDA R2 contain means for describing finding

\(^1\) https://loinc.org/collaboration/ihtsdo/agreement.pdf

\(^2\) LOINC terms represent tests or observables and LOINC parts are the constituents of those LOINC term representations, e.g. a LOINC term might be "sodium concentration in plasma" and the LOINC parts then are sodium, concentration, and plasma.
sites and TermInfo provides implementation guidance on when and how to use the HL7 information model attributes and the SNOMED CT concept model attributes respectively.

6.4.3 IHTSDO – DICOM agreement

An agreement between IHTSDO and DICOM, signed in March 2016, allows a subset of 7,000 SNOMED CT concepts and descriptions to be used for free and globally within DICOM standards. A similar agreement has been proposed for HL7 standards and IHE resources (see above).

6.4.4 Other agreements

The partnerships signed by IHTSDO and other organizations are not limited to those indicated in the previous paragraphs, to be mentioned among the others: the IHTSDO – WHO agreement signed in 2010 for the collaboration about the linkage between the ICD-11 classification and SNOMED CT; the agreement with INSERM about Orphanet, whose scope is that of providing additional rare disease content for SNOMED CT, including preferred terms/synonyms and text definitions; and a complete linkage between SNOMED CT and Orphanet; the agreement with GS1, for the development of guidance/principles for linking SNOMED CT and Global Trade Item Numbers (GTINs) that can be applied at the national/local level. Others agreements can be found in http://www.ihtsdo.org/about-ihtsdo/partnerships.
7 Focus groups

7.1 Methodology and set up of focus groups

During the Assess CT project, focus groups had been established in nine EU member states, including 5 IHTSDO members (Belgium, Denmark, Sweden, Netherlands, and Portugal) and 4 non-IHTSDO members (Croatia, Finland, France, and Germany).

A focus group is a small group led through an open discussion by a skilled moderator. The dimension of the group needs to be such to generate a rich discussion without leaving out any of the participants. Focus groups go a step beyond surveys and questionnaires in an effort to understand things at a deeper level. Focus groups can help produce qualitative data with focus on preferences and beliefs. While reviews, interviews and questionnaires might help us to answer what experiences stakeholders might have, the focus groups (and interviews) help us to get stakeholders to reflect on why they experienced something, which factors influenced something, what would lead to better results in the future, how and why participants’ views differ.

Focus groups are structured around a set of carefully prepared questions, which move from general to specific. Discussion should be such that it stimulates and influences the thinking and sharing of ideas, so that participants may even change their thoughts and ideas in the course of the focus group proceedings. After the first analysis within the project team, a first set of candidate countries have been selected and contacted for evaluating the possibility of establishing a Focus Group (FG). Considering the significant commitment and added value for the capture of timely and meaningful information, the initial set of countries has been chosen among the project members.23 For supporting the evaluation of the possibility of creating a FG, guidelines have been created providing some general concepts and methodologies about FGs24 (what they are useful for, how to organize them, the role of facilitator, how to manage a focus group…). The agreed aim of the ASSESS CT Focus Groups was to collect:

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

A set of five common themes were selected to facilitate comparable results from country FGs, i.e. current terminology use, benefits of adopting new terminologies, barriers and enabling factors for extended terminology adoption and use, and recommendations. Beyond these themes, each country FG could extend those topics with specific questions, and/or introduce a limited number of additional country-specific topics. In a common approach, facilitators kept track on how many members of the focus group agreed with the conclusions and asked for details on why they did not agree. The FG guidelines define in more details the aim, the questions to be discussed, and how to assure comparable results among the different country focus groups of this project (see D1.1).

Despite the heterogeneity among focus groups, there are some 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 would be very interesting. Moreover, FGs 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 were perceived as critical barriers in the decision-making /start-up phase.

23 Country selection criteria, set-up of the focus groups, their aim and the themes treated have been described in D1.1
24 The complete guidelines is in the Appendix 2 of the deliverable D 1.1
It was 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 strategies the usage of terminologies (or more in general to semantic interoperability) that may have a European and global impact. Such an approach would perhaps help recognize the importance of a long-term European terminology strategy, which is key to realizing sustainable incremental semantic interoperability when implementing convergent national and European eHealth strategies.

7.2 Themes and MS Report on Focus Groups

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 in some of questions that 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 group; the cultural differences; the expectations that each country put on this activity; and last but not least IHTSDO membership.

This minor heterogeneity should not be considered negatively, it is 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 also been used, beyond the ASSESS CT project objectives, as a means 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 was in fact presented to the MoH and was adopted for policy decision making on the national level. 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 terms of other countries experiences, new perspectives and relationships for national purposes.

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

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

7.2.1 Theme 1: Current terminology usage

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

However, several groups pointed out – from different perspectives - the tight link between terminologies and purposes of use or use cases and how this should be taken into account for any evaluation.

An attempt of categorizing the purposes 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 terminologies (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.

---

25 Individual Focus Group reports from each Country are included in the D 1.2 and D 1.3 and their appendixes.
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 in the clinical practice.

### 7.2.2 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, the improved quality of data may facilitate the secondary and research use of EHR data, and, moreover, quality control, (clinical) decision supporting systems and benchmarking.

- Finally, several focus groups also emphasize the role that a “core” terminology/ies like SNOMED CT may play in the EHR system marketplace with mutual benefits for vendors and providers and favoring the internationalization of the national ICT vendor solutions.

### 7.2.3 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 is the Finnish report that provides a wide and detailed analysis of the potential national impact.

However, there are elements that have been transversally mentioned by different groups, for example:

- 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.

- low awareness of the actual return of investment in this field (not limited to the economic aspects). This referred to both the organizational and the individual level.

- lack of governance strategies for supporting semantic interoperability.\(^{26}\)

- high “cost” of change management: Management of change is a long incremental process (see for example the Dutch experience) that needs to address human resistance to change, fear of administrative burden, comfort of legacy systems and free text entry.

- lack of user-friendly implementations

- fear of overcoding or undercoding, loss of information or superfluous information

---

\(^{26}\) 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 are reported in D4.1 and D1.3.
• need for training to fill the current deficiency of terminologists and their competences
• absence of and limited investment on the development and the management of translations, mappings.

An element that has been mentioned by several groups is the license 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 completely evaluated / experienced yet.

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

7.2.4 Theme 4: Enabling factors for extended terminology adoption and use

There are factors that may potentially enable the adoption and use of terminologies and are to some extent 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 in this field.
• supporting resources available for implementation of terminologies: including guidelines and mapping with reimbursement terminologies.
• wide availability of supporting tools and software that link SNOMED CT to the background
• incremental step-wise adoption
• easier access to terminologies and supporting tools
• professional training and education on the use of SNOMED CT
• launch of pilots focusing on specific use cases
• adapt the business model of SNOMED CT

7.2.5 Theme 5: Recommendations

It is in general believed that SNOMED CT is the best available 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 are 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
- Make available supporting tools, maps, translations, ready to use subsets linked to information models.
- Allocate enough human resources for enabling the adoption and the use of SNOMED CT as well as of the other semantic resources including information models.
- Promote the identification of solutions for overcoming the perceived “all-or-none”-policy of IHTSDO and facilitating the evaluation/adoption of SNOMED CT by non-member countries.\(^{27}\)

### 7.3 Final note

As demonstrated by the ASSESS CT experience, the establishment of 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 issues, and also on promoting the cooperation among countries.

Repeating this valuable experience in the future, possibly extending the organization of focus groups to other EU countries, was strongly advocated. 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 a European impact. Relying on them, topic-focused cross-countries discussion groups may also be created for supporting specific practical topics.

\(^{27}\) In separate sessions it has been discussed how IHTSDO provides special licences and allows for special agreements for facilitating the adoption of SNOMED CT.
8 Questionnaires

8.1 Introduction

Questionnaires have been one of the primary instruments adopted since the beginning (i.e. during the preliminary investigations) to reach with relative ease, a large number of stakeholders; to capture knowledge, perceptions and facts related to the use of clinical terminologies (with a focus on SNOMED CT) and in the initial phase also to profile the stakeholders to be included in the stakeholder registry (when consent was provided).

Those goals have been realized through three questionnaires:

- “Stakeholders” questionnaire surveyed the views and experience of selected stakeholders. It is described in detail in § 7.2 of the ASSESS CT deliverable D1.1
- “Country overview” questionnaire captured information about the use of terminologies in the European countries (described in detail in § 7.3 of D1.1),
- “Modified country overview” questionnaire adapted the questionnaire to selected non-European countries members of IHTSDO, to collect additional experience on the use of SNOMED CT around the world. (see § 5.2.1 of deliverable D1.3).

The methodology followed for developing, publishing and selecting the target population has been the same for all three instruments. In summary: (a) the questionnaire objectives were identified, refined and agreed; (b) based on those objectives, and considering the target population involved, a first set of questions was drafted, shared and discussed in the WP1 team considering contributions from other WPs and external experts; (c) the content of questionnaire was consolidated and the on-line questionnaire was implemented; (d) the on-line questionnaire was reviewed and tested/piloted by WP1 members; (e) the on-line questionnaire was refined and distributed.

More details about the methodology and the guidelines used for selecting and engaging the target population is provided in D1.1 section 7.

8.2 Stakeholders

The stakeholders’ questionnaire was sent to stakeholders selected from all European Member States. 138 responses from 15 countries were at the end received (see following figure).
A good coverage was achieved for both the different roles and the kinds of involvement with terminologies identified. A relatively high percentage of those interviewed declared to have been involved in cross-border healthcare activities (just under 30%): mostly of them through EU funded projects. About 30% of respondents indicated limitations of current terminologies in supporting cross-border patient data exchange: the “lack of common/reference terminologies” and “inadequate terminology strategies and policies (including legislation)” were the types of issues most frequently mentioned. 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; this combined with suitable policies and legislations; availability of mapping and increased cooperation among organizations and experts.

The large majority of respondents (> 60%) claimed that in their country, SNOMED CT has a very limited use or it is not used at all. By normalizing these responses per country, we can classify them in three main classes (see figure below):

- 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 limitedly used. Finland is border line between this two classes [green]
- the United Kingdom (England) that is the only one in which SNOMED CT is substantially used in some contexts and domains [gold]

---

29 The score has been calculated assigning an integer from 0 (not used) to 4 (widely used) to each class and calculating the arithmetic mean.
The questionnaire also investigated the perceived and the experienced benefits and risks of SNOMED CT and of other international and local terminologies: a summary of results, including the classification of the free text responses, have been provided in section 5.1 of deliverable D1.2. To be noted that only a little percentage provided experienced benefits (and risks) and in most cases they refer to development of solutions and research (rather than to end users benefits); this rate is higher than for the believed benefits.

The preferred approach to coding clinical facts was the direct selection of terms by clinicians during data entry; the second option was the usage of processing mechanisms for coding data using SNOMED CT: few people considered the post-hoc clinical coding the most practical approach for coding.

Finally, 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, even though most of those answers include also the conditions under which this assertion should be read (e.g. resolution of the license issues).

A summary of the main results is provided in § 5.1 of D1.2; a complete questionnaire report is included in D1.4 Appendix A.1

### 8.3 Overview of European countries

The motivation, the design, the target selection and engagement, and the processing of the overview of European countries questionnaire have been described in ASSESS CT deliverables D1.1 and D1.2. Responses from 22 countries in Europe (21 EU Member States) have been received: Austria; Belgium; Bulgaria; Croatia; Czech Republic; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Italy; Luxembourg; Malta; Netherlands; Portugal, Slovakia; Spain; Sweden, United Kingdom; plus Norway.

The results of the Country Overview were prepared and shared with the interested parties for the content review and therefore shared during the revision workshops. All the received changes have been tracked and considered for this deliverable.

Hereafter a synthesis of the main results is reported; a wider summary, including some graphs, can be found in section 5.1 of deliverable D1.3. A complete questionnaire report is available in D1.4 Appendix A.2.

The questionnaire confirms the limited usage of SNOMED CT for the large majority of the interviewed countries. In fact, adoption is in most cases ‘in progress’ or ‘under consideration’ even if 10 of the 22 respondents are already IHTSDO members.
Almost all the countries use terminologies at the national level for secondary or administrative purposes or for very specific use cases. **A national strategy for terminology is under discussion for about 50% of the countries.** 60% of the countries declared to have a National Competence Center(s) for Terminologies: AT, BE, BG, DK, EE, FI, DE, NL, NO, PT, SL, SP, SE, UK.

The large majority of the interviewed countries, with the exception of Austria, Slovakia, Spain and United Kingdom, asserted that currently several domains are not 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; Vaccines. With the exception of Bulgaria, Denmark, Malta and Slovakia, all the countries declared to use terminologies defined at the national level, covering specific areas. Some recurring cases are drugs nomenclature / classification; procedures; codes for accounting.

The authoring and administration of the terminology assets (value sets, code systems...) seem to be in most cases (about 50%) managed not using terminology systems/services, but through other means (excel files). However, with the new data, the percentage of countries that declare to use a set of terminology systems increased, while only about 20% indicate to adopt centrally controlled terminology systems (Sweden, UK and Spain).

Almost all the countries use the Web publication as a mean for distributing terminologies. Only 7 (Netherlands; Estonia; Greece; Spain; Austria; Finland; Czech Republic) over 22 (about 30%) declare to use local or central terminology services.

About 40% of countries assert that no tool or technology is 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...); few refer to user interfaces solution to help code selection.

Almost all the countries that have introduced, or intend to introduce SNOMED CT have indicated a **project / use case based** approach as the reference approach, with the exception of Sweden, Portugal and United Kingdom (top down approach). However, a mixed approach should be considered for those countries, as explicitly mentioned in the UK response. Regarding the Netherlands, the project-based approach used in the start-up phase, is progressively turned towards a centrally managed approach.

Twelve countries of the twenty-two responding (> 50%) indicated that SNOMED CT was not applied to any of the care settings. Only the UK seems to have a wide coverage in the use of SNOMED CT over almost all the care settings (in-patient and primary care as the most mentioned settings).

Thirteen countries (AT, BE, HR, CZ, FI, DE, GR, IT, NO, HU, LU, SK) of the twenty-two responding (> 50%) have answered the question about how SNOMED CT is actually used as “not applicable”. As those countries with the exception of Belgium are not IHTSDO member countries this is interpreted as that SNOMED CT is not used.

Malta and United Kingdom declared that they are using SNOMED CT as reference, aggregate and interface terminology; France as reference and aggregate terminology for the indicated use cases (research); the Netherlands, Spain, Portugal and Estonia as reference terminology.

In the reference terminology use cases SNOMED CT is often also used for data capturing, with the exception of France and Portugal. Sweden (“Other”) indicated that “codes are used for transfer of patient data to registries, but not for data capture / patient records yet”, which seems to fall into the aggregate case; Denmark (“other”) that is used for “data harmonization”.

The 9 countries that reportedly use SNOMED CT (EE, MT, NL, SE, UK, PT, DK, SP, FR) use SNOMED CT pre-coordinated concepts and three of them (NL, UK, DK) use the additional descriptive power of SNOMED CT.
For about half of the countries interviewed (~ 40%) no impact on existing terminologies is expected by the introduction of SNOMED CT in their country.

For about half 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 (9), in four cases (DK, UK, SP, SE) the full SNOMED CT core has been considered; while, a RefSet\footnote{A RefSet (Reference set) is a distribution format used by IHTSDO for subsets and other derivatives products. In this context is used as synonymous of Subset (using the IHTSDO jargon) or of Value Set (using the HL7 jargon). Members of a set can be defined extensionally (i.e. enumerated) or intentionally (e.g. rule-based).} based approach has been chosen by the other 5 countries (MT, NL, BE, PT, EE) (55%). About half of respondents indicate that “Clinicians and Terminology Experts” was the role involved (or to be involved) in the RefSet selection, while about 35% consider this topic not applicable or under evaluation.

The percentage of ‘not applicable’ or ‘to be defined’ answers increased to more than 60% for the same type of question when applied to the indicated use cases (i.e. not only for the introduction or national adoption of SNOMED CT). Only UK indicated “The Full SNOMED CT core with national extensions is being used”, “National Refsets” have been indicated for Estonia and Netherlands and Portugal, and “Several Refsets” for Malta, Belgium, Denmark and Spain.

The translation and the collection of synonyms is nationally coordinated and realized for the majority of the countries for which this answer is applicable. The international cooperation aspect is a key factor 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).

Country-specific ongoing activities and future plans are described in Appendix 3.

For almost all the non-IHTSDO member countries (with the exception of Austria, Bulgaria and Luxembourg) the License Cost is the most cited reason for which a country is not a member. It is very interesting to note how the perceived absence of national policies on semantic interoperability (somehow related to the low perception of this need and to the absence on national programs) is also indicated by almost half of these countries. No one believes that the choice is related to the limited fitness for purpose. Figure 9 summarizes the complete set of results.
About 70% of the respondents for the NON-IHTSDO member countries indicated that they are aware "about any current or past plan, discussion or evaluation regarding the adoption of SNOMED CT" (Austria, Croatia, Finland, Germany, Italy, Luxembourg, Norway and France).

8.4 Overview of non-European countries

The motivation, the methodology adopted for the overview of non-European countries questionnaire have been described in ASSESS CT deliverables D1.3 § 5.2. Responses from 7 Non-European IHTSDO members Countries have been received: Australia; Canada; India; Israel; Malaysia; New Zealand; Uruguay.

The complete report has been shared well in advance with respondents for their review. No change requests have been received.

Evaluations and comments provided in this report refer only to the responses collected by this questionnaire and do not pretend to be representative of the global situation of the Non-European IHTSDO member countries.

Hereafter is reported a synthesis of the main results; a wider summary, including some graphs, can be found in section 5.2 of deliverable D1.3. A complete questionnaire report is available in D1.4 Appendix A.3.

The majority of the interviewed countries (>50%) claim to have in-progress adoption of SNOMED CT (Israel, Malaysia and New Zealand), even with New Zealand recognizing SNOMED CT as a "key element of the national digital health strategy going forward (…) mandated for clinical information systems in the public health sector". Implementation is moreover "underway in a number of projects, including the national EHR". Canada and Australia declared that is “nationally adopted for health and social data”. In India it “is mainly adopted for health and social data at the organizational (e.g. hospital, local project) level”.

This result differs from the result for the European IHTSDO members countries for which the “Adoption of SNOMED CT at the national level is in progress” happens for 80% of the cases against 10% for the other two cases (national and local adoption). About 80% of the interviewed country representatives assert that they are using nationally adopted terminologies for a wide range of use cases, while this case is reported by only 40% of the responding EU countries. On the contrary, the percentage of countries that assert to use them for secondary or administrative usages (EU 80% - non-EU 70%) is quite comparable.
The percentage of countries that do not have national competence centers is much lower than that of European respondents (14% non-EU compared to 40% EU). This is coherent with the fact that this survey covers only IHTSDO member countries that are requested to establish a National Release Center, while the EU-countries responses include also non-IHTSDO members.

All respondents declared that they use international terminologies at national level. ICD-10 (with or without local extensions) is the most commonly used terminology, SNOMED CT is mentioned by 70% of respondents and only two indicated LOINC.

The majority of the respondents (with the exception of India, Malaysia and New Zealand), asserted that there are relevant domains that are currently not covered by nationally used terminologies. This percentage (about 60% for non-EU countries) is however lower than that of the EU countries (about 80%). Domains mentioned span across very different types of classes of information and use cases. The most cited ones are: Lab Procedures (as in Europe); Procedures (as in Europe); Medications.

The authoring and administration of the terminology assets (value sets, code systems...) seems to be managed for the large majority of the cases (> 60%) using central terminology systems / services and publishing data on the Web. Almost all the countries assert that tools or technologies are used for facilitating the usage of nationally adopted terminologies, in comparison with 50% of the interviewed EU countries. Most of the mentioned tools refer to solutions for supporting the access and the distribution of terminologies.

Contrary to EU countries, where almost all those using (or planning to use) SNOMED CT indicated the project / use case based approach as the preferred approach for introducing use of SNOMED CT for health and/or social care data, the majority of non-EU countries (Australia, Malaysia and Uruguay) indicated the top down approach as the preferred one, while only Canada and New Zealand follow a project/use case based approach.

No countries indicated to use SNOMED CT for aggregating data (while in EU Malta and UK do). Only Israel considered this question as “Not Applicable”, compared to the nine to fourteen cases identified in the European survey. Malaysia claims to use SNOMED CT only as a reference terminology, all the others (Australia, Canada, New Zealand and Uruguay) use it as both reference and interface terminology.

With the exception of Uruguay, all the respondents using SNOMED CT declared to use pre-coordinated concepts. Malaysia; New Zealand and Uruguay indicated to use the SNOMED CT compositional syntax, while only England and the Netherlands declared to do it among the EU respondents. The full SNOMED CT description logic seems to be used by two countries (Malaysia; New Zealand) of six; in comparison with the two (NL, DK) of twenty-two (ten IHTSDO members) derived from the European questionnaire.

Challenges and planned (or applied) solutions are described in the following table.

<p>| Table 2 - Main challenges of the transactional scenario and how it has been managed |
|-------------------------------------------------|---------------------------------------------------------------|
| <strong>Country</strong> | <strong>Main challenges (or what will be according to your current evaluation) of the transactional scenario</strong> | <strong>How those challenges have been managed (or are planned to be managed)</strong> |
| Australia | Changes to existing established software. New software readily adopts, but existing systems need incentives / compensation. Vendor resistance. Decision makers’ lack of understanding of what is actually needed to achieve their objectives. Lack of skills throughout healthcare and IT professions regarding utility and Opportunities of terminology-based approach when combined with robust, standardized and clinically relevant information model (the focus on IT based | Implementation assistance and compensation / incentive programs Centralized approach with limited engagement with Healthcare organizations at this stage and virtually none with clinicians who are logical adopters and champions. |</p>
<table>
<thead>
<tr>
<th>Country</th>
<th>Main challenges (or what will be according to your current evaluation) of the transactional scenario</th>
<th>How those challenges have been managed (or are planned to be managed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>Reaching vendors and stakeholder before system are procured.</td>
<td>Planned: Vendor engagement; RFP language; Outreach. For Canada, alignment with US requirements where applicable is important as most of our vendors are US based and we are a small market population wise for the vendors to make Canadian specific modifications.</td>
</tr>
<tr>
<td>Israel</td>
<td>Funding! HMO's and government hospitals request funding from MOH, which was not allocated yet.</td>
<td>There have been negotiations between the MOH and MOF.</td>
</tr>
<tr>
<td>Malaysia</td>
<td>We avoid implementation at the transactional level but opt for the back-end approach because we will not be ready and because many vendors and countries could provide an insight into the front-end approach if we decide to do that later</td>
<td>We chose this type of approach which is more manageable to us before we embark to this approach.</td>
</tr>
</tbody>
</table>
| New Zealand | 1) Getting a very wide variety of stakeholders engaged and involved is always a big piece of work, but I feel we have been able to secure support of key players and are in a very good place on our SNOMED CT journey.  
  2) Mapping existing coding systems / terminologies to SNOMED is often required. Currently the single biggest challenge is to complete the migration from Read to SNOMED CT in relation to personal injury claims (big business in NZ) and in primary care. GP systems use Read and not SNOMED CT. Replacing ICD-10-AM in point of care applications is the biggest challenge in hospitals. | 1) Through stakeholder engagement and relationship management.  
  We are taking a top-down, cross-government agency approach to drive the change so that health providers cannot but avoid moving to SNOMED. We are using the very strong advocates for SNOMED developed through our pilot projects to win the hearts and minds for the change. |
| Uruguay   | Adoption barriers. Requires to simplify encoding at the doctor’s desk                           | Using Terminology services for semi-automatic encoding             |

Respondents from about half of the countries declared that the full SNOMED CT core has been selected and national extension defined when SNOMED CT was introduced, which is really different from what is shown by the EU country survey, where the privileged approach was the one based on the development of use case specific RefSets and in which only the UK declared to have adopted the “full SNOMED CT” approach. This answer is perfectly in line with the top down approach stated above.
9 Case Studies

The goal of this task\(^{31}\) is to investigate, for a set of concrete cases, the processes and the drivers in the selection and the adoption of terminologies to support the selected use cases. Where available we also collected evidence on the benefits and challenges experienced. The following figure summarizes the different kinds of “cases” considered in this assessment.

---

\(^{31}\) “Use case evidence-based assessment” task in the DoA.
Table 3 - Case Study Selection Criteria (to be satisfied by at least one of the assessed case)

<table>
<thead>
<tr>
<th>Criteria for selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some cases should be in routine use in healthcare</td>
</tr>
<tr>
<td>Cases should cover both primary and secondary (e.g. health registries) use of data</td>
</tr>
<tr>
<td>Cases should cover a range of health specialties</td>
</tr>
<tr>
<td>Cases should cover both “closed” (i.e. well identifiable with defined coded concepts) and “open-ended” (i.e. that requires compositional syntaxes and/or free text for being fully expressed), e.g. laboratory medicine vs. anamnesis</td>
</tr>
<tr>
<td>Cases should cover different levels of granularity, i.e. from holistic to sub-specialized use cases</td>
</tr>
<tr>
<td>Cases should cover both common and rare cases</td>
</tr>
<tr>
<td>Cases should cover different jurisdictional contexts (e.g. European (cross-borders), National, Regional...)</td>
</tr>
<tr>
<td>Cases should be ranked considering the potential impact on EU eHealth policies (e.g. highest ranks for Patient Summary, ePrescription, PARENT related cases....)</td>
</tr>
</tbody>
</table>

Based on those criteria and on the inputs collected from experts, from the surveys realized and from other projects,32 five case studies were therefore assessed considering ten implementation cases:

1. Cross-border Exchange of Patient Summaries: Problem Lists [case #1]
   a. The European Cross-border exchange of PS (epSOS/EXPAND) [epSOS]

2. ERNs Rare Disease (RD) Registry [case #2]
   a. Selection (or detection) of RD patients from care setting (EHR) to include in registries or cohorts: French national registry for rare diseases [FR - RD]
   b. Implementation Case 2: Harmonizing RD registries to enable data re-use across Europe [RD-Reg]

3. National/Regional Exchange of Patient Summaries: Problem Lists [case #3]
   a. Italy: the Fascicolo Sanitario Elettronico [IT-FSE]
   b. Dutch Diagnosis Thesaurus project [NL-DT]
   c. Sweden: the National Program for Data collection. [SE - NPD]

4. National / Regional Exchange of Lab Procedures / Results [case #4]
   a. Laboratory Reports in the French “Dossier Médical Personnel (DMP)” [FR-Lab]
   b. National/Regional exchange of laboratory procedures & results in Finland [FI-Lab]
   c. Swedish National Patient Summary: the NPU terminology [SE-Lab]

5. National/Regional Exchange of Lab Pathology Procedures/Results33 [case #5]
   a. The NHS Diagnostics Data Service [EN-Pat]

The assessment involved also external experts as Laura Sato of HSCIC UK; François Macary, responsible for the French study on reference terminologies for ASIP Santé; and Rémy Choquet of APHP France and co-coordinator of the WP5 RD-ACTION EU Joint Action.

An extended summary of the methodology is provided in deliverable D1.3 § 7.1 Methodology a complete description in D1.4 Appendix B.3 §1 - Case studies selection process. An extended summary of implementation cases is provided in D1.3 section 7 "Case Studies"; a detailed report of the assessments is provided in D1.4 Appendix B.3.

The following table summarizes per case study, and implementation case, how much the drivers for adoption identified by WP4 apply to the selected cases: it is one of the drivers for adoption (Yes); it is not a driver for this case (No); it applies only partially (Partially).

---

32 E.g. Trillium Bridge; eStandards

33 Case studies 4 and 5 have been kept separated since Pathology and Laboratory are usually considered two distinct domains, however several similarities have been identified between them in term of terminology used and selection process, such that for the purpose of this investigation they might be considered a single case study.
**Legend:** The icon provides a snapshot of how much that driver applies to this case. The score is used for deriving grouped results (3 Yes – 1 No)

<table>
<thead>
<tr>
<th>Icon</th>
<th>Is Applicable?</th>
<th>Assigned Score</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Icon" /></td>
<td>Yes</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><img src="image" alt="Icon" /></td>
<td>Partially</td>
<td>2</td>
<td>• Yes in future</td>
</tr>
<tr>
<td><img src="image" alt="Icon" /></td>
<td>No</td>
<td>1</td>
<td>× With Caveats</td>
</tr>
</tbody>
</table>

Table 4 – Overview of the level of application of drivers for adoption per implementation case

<table>
<thead>
<tr>
<th>Driver</th>
<th>Better quality and safety of care to individual patients</th>
<th>Enriched EHR data exchange for continuity of care</th>
<th>Cost reduction (in the healthcare system)</th>
<th>Optimizing reimbursement uses</th>
<th>Analysis (secondary) uses</th>
<th>Cross-border information and knowledge sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>epSOS</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>FR-RD</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>RD-Reg</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>IT-FSE</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>NL-DT</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>SE-NPD</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>SE-Lab</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>FR-Lab</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>FI-Lab</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
<tr>
<td>EN-Pat</td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
<td><img src="image" alt="Icon" /></td>
</tr>
</tbody>
</table>

Based on the above defined score (3 Yes – 1 No), a mean applicability score has been calculated globally (Table 5) and per case study (Table 6).
If all the high-level drivers, with the exclusion of optimizing reimbursement, received globally almost the same score (substantially applied); by analyzing this result per single detail, we notice that:

- more complete coded documentation;
- better overview of each patient’s information;
- Improved patient safety;
- reduce duplicate data capture;

are actually the main reasons for which terminologies have been selected and used.

Zooming into the case specific results (Table 6), it is interesting to note – as reasonable - how the drivers’ score depends on the use case considered:

- Cross border information and knowledge sharing is a key driver for cross-border services (Rare disease registries and patient summary exchange)
- Analysis uses for rare disease registries and lab results
- Cost reduction for the rare disease registries
- Enriched EHR data exchange for the continuity of care for lab results
- Better quality and safety of care for rare diseases and lab results

Taking into account the indications for future uses (see Table 4), an increase of most of the drivers are expected for the national/regional exchange of the Patient Summary use case. This can be interpreted as a sign of the relative youth of this kind of service: for which narrow scenarios of use are currently considered with the purpose to extend them in the future.
In terms of general lessons learned, the assessment showed a large variability of approaches and level of maturity.

There is a dependency between the presence of jurisdictional policies for semantic interoperability and organizations with the mandate of working on this topic (e.g. ASIP Santé, HSCIC, …) and the maturity of the selection process (dimensions considered, drivers, stakeholder involvement; assessments; follow-up; wideness of the scope, re-usability; …).

The existence of those policies is usually connected with the availability of financial and human resources to support them. The lack of time and resources availability may lead to choices that are sometimes only partially driven by the “fitness for purpose”, but may depend on other “non-functional” dimensions, for example the availability of those terminology in that setting. In fact, as any other kind of project, also the introduction and usage of terminologies depends on the “Project Pyramid” dimensions (quality, scope, resource and time). Thus, we may have cases in which a specific terminology is used mainly because it assures the minimum impact in that setting; it, is the case for example of the problem list for epSOS or for the Italian Patient Summary; there are other cases where different choices are made focusing more on the capability of assuring a better description of the clinical statements and on the reuse of these data, considering however investments to be done for enabling this, it is the case for example of the Lab report for the NHS project and France.

Somehow related to the previous element, the dependency between the terminologies used and the main (or the initial) driver for introducing terminologies in that context: where terminologies were introduced mainly for administrative/monitoring purposes (e.g. reimbursement, registry, ..) classification are the most used solutions, and their usage is sometimes also extended to other purposes; different choices are experienced when the main driver is the clinical process and secondary uses are seen as a derived product of the main process34.

Often, even when considering a single domain, semantic needs are not covered by a single code system would: the combination of different international code systems that better fit for purpose is usually the preferable solution (see e.g. the UK pathology report or the Rare Diseases Registries cases). This becomes even a more winning solution when:

- identified terminologies are complementary and not conflicting;
- supporting mapping are (or are going to be) developed (see e.g. the case of LOINC and SNOMED CT; or Orphanet and SNOMED CT, the Dutch thesaurus)

34 The case of the Dutch diagnosis thesaurus seems to be a sort of exception of this schema.
tools are made available for enabling this cooperative usage (see e.g. the Linking Open data for Rare Diseases tool in France).

For several cases (e.g. Lab, NHS, epSOS, Rare Diseases), **stakeholder engagement** has been considered a key element for the success; and in some cases normative requirements (e.g. France, India, Malaysia) or national endorsement (e.g. New Zealand, Australia) are used as a leverage for moving forward the national digital health strategies.

The tight **binding between terminologies and information models**, to be used for specific scopes and use cases, have been pointed out in several examples (epSOS, France, UK, Clinical Building Blocks in NL and others).

However even if terminology and information models used for exchanging data are important for semantic interoperability, this goal cannot be achieved if the **quality of** the captured and presented **data** is low (see for example the epSOS case), due for example to a lack on the EHR-systems' capability of capturing and showing the data as expected. Semantic interoperability shortages may happen if there is no common understanding and agreement by the sending and the receiving HPs on the meaning of what is captured and shown.

The assessment enforced the concept that each terminology is conceived for satisfying a specific set of use cases and scopes and when used outside those purposes the terminology loses relevance and efficiency.

The existence of a defined governance process is a common element of several cases (epSOS, France, UK, Rare Disease Registry) as well as the availability of organized entities for the day-by-day terminology management (including distribution). Their absence is felt as a critical factor in some of the reported cases (European Cross Borders care, Fascicolo Sanitario Elettronico).

Finally, the importance of establishing international collaborations for knowledge exchange has been recognized.

Other common concepts that we can find transversally in several cases are:

- Secondary use of data as a seamless product of a well-designed primary process (e.g. cases from France, NHS, Sweden, Netherlands);
- Attention to the legacy terminologies management (incorporation of terms, mapping development) (e.g. cases from France, NHS, Finland, Netherlands);
- Coordination among projects or, in other words, each single project shall be inserted into a wider jurisdictional strategy;
- Reduction of duplicate data capture (e.g. cases from France, NHS, Sweden, and Nederland).
10 Literature Review

10.1 Published scientific literature

10.1.1 Overview

The objective of this study was to investigate the use of SNOMED CT by providing an overview of published scientific literature. The last comprehensive literature reviews on this topic were published by Cornet et al. in 2008\(^{35}\) and Lee et al. in 2013\(^{36}\) (in the latter referred to as ‘2013 Review’). The 2008 review focused on papers published between 1996 and 2006 including all versions of SNOMED available until that time.\(^{37}\) The 2013 Review focused only on SNOMED CT papers published between 2001 and 2012.

Moreover, compared to the 2008 Review, for the 2013 Review the classification criteria were enhanced. For this Literature review, we used the practical experience of both the 2008 and 2013 studies and customized the classification criteria to our main objective within ASSESS CT. Because Work Package 1 is attempting to provide evidence on the current use of SNOMED CT worldwide, it was considered as eminent to produce more granularly processed results for papers dealing with implementation and evaluation.

However, this literature review still enables the reader to have a comprehensive, global and systematized overview of all currently published scientific literature on SNOMED CT.

The methodology of the Literature Review has been described in many details, starting with the identification of relevant publications, in Document D1.3, paragraph 8.1, Methodology. Papers had been identified performing searches with the keywords “SNOMED” and “Systematized Nomenclature of Medicine” between 2013 and 2015 in PubMed (http://www.ncbi.nlm.nih.gov/pubmed) and Embase (http://www.embase.com). All the papers selected for our study were either written in English or at least the abstract was in English.

A web-based application was developed that catalogued the abstracts and papers, and enabled the reviewers to independently classify the papers according to four main categories:

- SNOMED CT Focus category that referred to the focus of the paper
- Usage category
- Medical domain
- Country

Functions were also available for the reviewers to compare their results with each other as well as to add comments. Details on the Classification Criteria used can be found in the D1.3 § 8.1.2.

10.1.2 Results

The searches on PubMed (n=189) and Embase (n=214) resulted in 304 unique papers. 62 publications were considered as being ineligible. The full bibliographic list of the 242 eligible papers with the naming of their respective groupings and classifications is available in D1.4 Appendix B.5 § 4. A summary of the main results, including graphs and tables, is available on D1.3 § 8.2, detailed results have been reported in D1.4 Appendix B.5 § 2.

---

37 SNOP, SNOMED, SNOMED II, SNOMED Version 3.0, LOINC codes integrated into SNOMED, SNOMED Version 3.5, SNOMED RT and SNOMED CT
As Dennis Lee et al. wrote in their article “A Survey of SNOMED CT implementations”, there were three main types of SNOMED CT-related implementation challenges mentioned by the interviewees: post-coordination, subsets, and data retrieval.

- Post-coordination: The interviewees did not have a good strategy on how to design a post-coordination interface that was intuitive and unobtrusive, and second, clinicians were not willing to split their input into separate terms.
- Subsets: The main challenge was how to craft a subset for domains that were broad as concepts could not be easily restricted to a hierarchy or parts of a hierarchy.
- Data retrieval: Data retrieval using the hierarchy was challenging for three reasons (the hierarchy is constantly changing with each release of SNOMED CT; the hierarchies were not always conducive for data aggregation, and therefore clinicians could end up with unexpected results.

The great majority of papers were published by authors from the United States, which at first sight is not as surprising as the few numbers that have been produced in the UK. Overall, two thirds of the papers were published from authors of IHTSDO-member states; even though a not negligible share comes from non-IHTSDO-members, which can stand for the increasing interest in SNOMED CT in the scientific community of these countries.

Pharmacology, oncology, pathology, and cardiology belong to the most prominent medical specialties that are represented in the publications, even though the vast majority of papers are not dealing restrictedly to a special domain. The relatively high number of pathology papers certainly is reasoned by SNOMED CT's historical genesis from this specialty, whereas cardiology’s and oncology’s high-ranking representations go hand in hand with their epidemiological significance as widespread diseases of our today’s society.

The majority of SNOMED-CT-related publications were theoretical papers, followed by papers that deal with SNOMED CT implementation & evaluation. Papers on pre-Development and design make a share of 19% of the total and 17 percent of papers were grouped in the category “Indeterminate”, which consists of editorials, letters to journals and results of surveys, literature reviews, and systematic reviews, but also papers that referenced SNOMED CT very briefly as a standard terminology.

Figure 11 shows how the papers were split among Focus categories.
Focusing on the implementation papers, 26 use SNOMED CT to retrieve or analyze patient data; 15 papers use SNOMED CT for research purposes; 12 papers describe scenarios where SNOMED CT is implemented in daily clinical practice, while a very small number deals with evaluating and proving the merit of SNOMED CT. There is a significant increase in the proportion of papers addressing SNOMED CT implementation. In the 2013 Review, 52 out of 488 papers (11%) were in this category, whereas now 61 out of 242 (25%) papers addressed implementation. This suggests an increase in the actual uptake of SNOMED CT for practical clinical use.

In the majority of articles dealing with the implementation of SNOMED CT, the terminology was used for the collection, recording and potential processing of problems and diagnosis, and a slightly fewer number deals with procedures recorded in patient summaries or laboratory procedures. The positioning of SNOMED CT as a terminology for "all of medicine" is clearly supported by the use of SNOMED CT in a large variety of clinical domains, ranging from nursing to pathology, from emergency medicine to chronic care and from primary care to intensive care.

Even though they are not directly comparable data, it is interesting to note that the percentages referring to the use of post coordinated expressions (16%) and description logic (23%) are closer to the results of the EU countries questionnaires (about 20 % for both) rather than the equivalent derived for non-EU IHTSDO member countries (50% for post coordinated expressions and 30% for the description logic).

Figure 11 - Percentages of the Focus Categories with further breakdown of “Implementation and Evaluation”
The clinical problem list is the use case in which SNOMED CT is used the most, followed by procedures and laboratory results. There was no publication found that treats the EU rare diseases registry use case. Moreover, no single article was treating the cross-border or national/regional exchange of patient summaries. These findings suggest that the use of SNOMED CT for multi-institutional or even multinational use cases is still limited, which may be related firstly to the individual effort required to obtain, configure and implement SNOMED CT in various information systems, and secondly to the fact that SNOMED CT in itself is only a part of a solution for cross-organizational exchange of information.

Twelve identified articles mainly describe where SNOMED CT is implemented in a daily clinical practice. With a few exceptions, these routine patient care implementations take place in the United States. However, all other presented clinical practice cases are not country-specific and therefore their results are transferrable to other countries. Nor can it be assumed that the findings represent the actual distribution of worldwide clinical use implementations.

A total of 26 publications were classified as describing implementations where SNOMED CT is being used to retrieve or analyze patient data for secondary questions. Two countries protrude: Nearly half of the articles were published in the United States, followed by six from Australia. Thus, these articles do not specify details and descriptions on the SNOMED CT implementation case, yet they serve as hints to where and in which setting it is already being in use.

As a limitation, it has to be highlighted that we only reviewed papers catalogued in PubMed and Embase and only included papers that were published in English or had an English abstract. Both the results of the 2013 Review and the findings in the framework of this deliverable show that the majority of implementations are not published in the scientific literature or are not captured in PubMed or Embase.

Therefore, little evidence (22% of total eligible papers) on SNOMED CT implementations could be generated from this review, although among these a small number actually describes daily clinical and practical use of SNOMED CT. However, we should also note that the number of publications has risen strongly in the last years, with 8 of them stating the benefits of SNOMED CT and more than 50 concerning implementations.
To quote once again Dennis Lee et al. and their article *A survey of SNOMED CT implementations*, we should say that none of the initiatives had carried out extensive evaluations to determine the benefits of using SNOMED CT. The interviewees were, however, able to describe some of the benefits they had observed: direct data entry, data reuse, content coverage and subset development, and legibility.

- **Direct data entry**: the large number of synonyms in SNOMED CT enabled clinicians to record the exact diagnosis they had in mind in contrast to post-coding.
- **Data reuse**: Organizations that used SNOMED CT in conjunction with ICD cross maps were able to re-use the data that was captured via SNOMED CT to generate ICD codes for billing and statistical reports.
- **Content coverage and subset development**: Interviewees felt that SNOMED CT provided them with the best content coverage for their use cases compared to other terminologies.
- **Legibility**: legibility of the patient record was one of the immediate benefits in one project that made the switch from a paper-based system to an electronic system using SNOMED CT.

He also says that this study examined the implementation of SNOMED CT in healthcare organizations in terms of design, use and maintenance issues involved.

### 10.2 SNOMED CT-Expo

Materials produced by organizations outside the traditional commercial or academic publishing and distribution channels have been considered as a valuable source for global SNOMED CT implementation cases as well. Among them are the presentations from the annual ‘SNOMED CT-Expo’, an international IHTSDO conference that dedicates a special stream to institutions to present their implementation projects and use cases from all over the world.

Pre-selected presentations have been therefore reviewed using an approach and sub-classification derived from the scientific papers review, here briefly summarized.

#### 10.2.1 Elaboration of Implementation and Use Case

To further specify the implementation scenario, it was considered to classify the relevant papers by the elaboration of implementation and to group them into given use cases. It is important to mention that this sub-classification only applied to publications, which were grouped into the two focus categories “Implementation & Evaluation”, i.e. into the usage categories: Research, Clinical Practice, Retrieve or analyze patient data, Prove merit.

**Table 7 - Sub-classification by Elaboration of Implementation with respective definitions**

<table>
<thead>
<tr>
<th>Elaboration of Implementation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Done by local interface terminology</strong></td>
<td>The paper describes an implementation including local terminology applied in user interfaces where that local terminology is distinct from the descriptions provided by the terminology (here SNOMED CT)</td>
</tr>
<tr>
<td><strong>Mapping to other terminologies</strong></td>
<td>The paper describes an implementation including mapping between entities in the terminology (here SNOMED CT) to entities in other terminologies and/or classifications</td>
</tr>
<tr>
<td><strong>Using inference</strong></td>
<td>The paper describes an implementation including use of terminological reasoning, as provided for example by description logic classifiers</td>
</tr>
<tr>
<td><strong>Using post-coordination</strong></td>
<td>The paper describes an implementation including use of post-coordinated expressions [<a href="http://www.snomed.org/faq?id=faq_WhatIsASnomedCtExpression">www.snomed.org/faq?id=faq_WhatIsASnomedCtExpression</a>]</td>
</tr>
<tr>
<td><strong>Using reference sets</strong></td>
<td>The paper describes an implementation including use of one or more reference sets in addition to a single language reference set [<a href="http://www.snomed.org/tlg?id=trg2upd_change_detail_struc_overview">www.snomed.org/tlg?id=trg2upd_change_detail_struc_overview</a>]</td>
</tr>
</tbody>
</table>
All ‘SNOMED CT-Expo’ presentations talk about the implementation of SNOMED CT, and they are classified by the above mentioned category and by the country that the implementation was referred to.

A full list of the selected presentations is reported in D1.4 Appendix B.6, including the title; the URL; the country; the type (Elaboration of Implementation) and a short description. The reported table groups the listed presentations also per use case.

In summary, the analysis of presentations shows the following results:

**Total number of presentations: 35**

<table>
<thead>
<tr>
<th>Elaboration of Implementation</th>
<th>Number of presentations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Done by local interface terminology</td>
<td>1</td>
</tr>
<tr>
<td>Mapping to other terminologies</td>
<td>21</td>
</tr>
<tr>
<td>Using inference</td>
<td>6</td>
</tr>
<tr>
<td>Using post-coordination</td>
<td>0</td>
</tr>
<tr>
<td>Using reference sets</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
</tr>
</tbody>
</table>

Total number of countries involved: 16

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of presentations</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>8</td>
</tr>
<tr>
<td>Uruguay</td>
<td>6</td>
</tr>
<tr>
<td>Argentina</td>
<td>4</td>
</tr>
<tr>
<td>France, Denmark</td>
<td>3</td>
</tr>
<tr>
<td>Sweden, Spain, Chile, UK</td>
<td>2</td>
</tr>
<tr>
<td>Netherlands, Singapore, Belgium, Australia, Malaysia, Canada, Portugal</td>
<td>1</td>
</tr>
</tbody>
</table>

Most of the presentations talk about mapping SNOMED CT to other terminologies and some of them are connected to electronic health record or patient medical record. As the medical data exchange is a very important issue among EU member states and wider, it is necessary to have the unique terminology. It was also presented that the use of SNOMED CT can improve patient safety in the process of drug prescription. It was also mentioned that SNOMED CT is an Inclusive Information Model and that it can be used for Interoperable Allergy List Data.

In one of the presentations, it was highlighted that the health data representation is a big challenge for the implementation of health information systems and even more for electronic health record (EHR) data entry and the acceptance of physicians, who prefer to document health care findings, processes, and outcomes using “free text”. Healthcare Information Systems (HIS) should capture the clinical data in a structured and preferably coded format to support research and enable decision support programs used at the point of care. This is also important for supporting interoperability among EU member states.

---

38 (a) Medication and allergies to support decision support system (b) Laboratory reports and orders (c) Combined Utilization of SNOMED CT with LOINC for Comparative Effectiveness Research; (d) EU Registries (e) OrphaNET (rare disease network) (f) Patient Summary: Problem; (g) Patient Summary: Allergies (agents, reaction, manifestation of), type of intolerance (h) Patient Summary: Medication List (i) Patient Summary: Surgical Procedures (j) Patient Summary: Medical (implanted) device (k) Patient Summary: Autonomy / Invalidity (l) Patient Summary: Social History (smoke, alcohol intake, diet ...).
10.3 National Reports

10.3.1 Switzerland

In 2011 the eHealth Suisse\textsuperscript{39} mandated the HES-SO (Haute Ecole Spécialisée de Suisse Occidental) and ii4sm (International Institute for the Safety of Medicines) to prepare a report on Ehealth Semantic and COntent for Switzerland (ESCOS). The report starts with a short introduction to the semantic interoperability and on the main interest groups. The Swiss, the European (epSOS) and some other countries (e.g. Nordic Countries) initiatives around semantic interoperability and semantic standards are described. A methodology for the evaluation of terminologies and information models within the Swiss eHealth strategy was described: OpenEHR (Open Electronic Health Record) and HL7 CDA (Health Level Seven Clinical Document Architecture) were presented and evaluated; and a critical analysis highlighting strengths and weaknesses of the main terminologies realized. A roadmap for Switzerland was indicated, it includes a governance structure. The approach suggested by the report was not that of imposing standards but to achieve this result via consensus, involving companies producing medical records, physician associations and hospitals to create a sustainable infrastructure for all partners in the health system.

The report asserts the several standards can be recommended for their use in specific domains such as LOINC for the management of laboratory data, ICD for coding diagnoses and ATC for grouping patient’s medication with some limitations. Some standards should be tested and might become useful in the long run but might not be suitable for an immediate application, such as SNOMED and MedDRA; these standards should be tested in some domains as they have strong expressiveness and could become useful in these domains.

It was recommended that:

- a single Swiss institute for coordinating resources for the biomedical field, surveying international developments and also maintaining existing or translating new resources would be established. This coordination institution can be inspired by similar structures like the DIMDI in Germany.
- a Family of Swiss Standards (FaST) to respond to the main local characteristics was developed, maintained and translated; making such standards available free of charge to health professionals in Switzerland in a sustainable way.

For concrete proposals, two main criteria in the evaluation of terminological standards were identified:

- patient safety;
- systematic implementation of the standard.

Based on these two priority criteria the following setup was recommended:

- **Absolutely needed** to implement any basic eHealth strategy: ICD-10-GM, CHOP, EDQM, UCUM, GS1, swissINDEX, ICPC;
- **Of strategic interest** for specific types of users (e.g. pharmaceutical industries, lab vendors, tumor registries, PACS vendors...): WHO-ATC, WHO-ART, CDISC, LOINC, ICD-O, DICOM/RadLex, NIC/NOC;
- **Of interest** to prepare for convergence and future developments in the field: ICNP, SNOMED CT\textsuperscript{40}, ICF, MedDRA.

\textsuperscript{39} The eHealth coordination body of the confederation and cantons that is responsible for the implementation of national eHealth strategy. http://www.e-health-suisse.ch

\textsuperscript{40} Switzerland has recently become IHTSDO member.
10.3.2 France

In 2014, after having identified the priority areas with the involvement of the main health actors, the French Minister of Health and the Délégation à la Stratégie des Systèmes d’Information de Santé (DSSIS) agency, committed ASIP Santé to make a study on reference terminologies taking into account several dimensions (e.g. governance, implementation, use) considering this a priority within the scope of the semantic interoperability.

This work has been planned in three phases (1) a background analysis including basic notions, terminology resource requirements, inventory of the reference terminologies available for the health and social sector. (2) The analysis of the needs and usages of terminologies realized involving vendors, professionals and other French and international stakeholders (3) Propositions that aim to present the scenarios for the governance of terminologies in France. All three phases have been completed. The results of the two first phases are available for public comment since May 2015\textsuperscript{41}. The 3\textsuperscript{rd} phase was completed on February 1\textsuperscript{st}, and concluded in favor of the setting up of national governance for semantic resources for health and social care in France, and in favor of adding two terminologies to the existing framework for healthcare: SNOMED CT and ICPC-2. The report of this phase 3 is not published yet.

The main aspects identified by the first phase have been the enforcement of the concept of semantic interoperability as key factor for interoperability; the determination of the bricks for the semantic interoperability: information models; coded concepts; value set (and vocabulary bindings); code systems; mappings (associations); availability of standardized terminology services.

The analysis of the needs and the survey on the usage of terminologies has been therefore realized by ASIP Santé involving using different means (e.g. meetings, interviews):

- Vendors present in the Health and Social ICT sector in France
- Representatives from Institutions, researchers and users in France,
- International Organizations working with terminologies

A large consensus on the study conclusions has been reached above all from the vendors; few comments were received from the health care providers.

The analysis has pointed out:

- the multitude of terminologies that insists on the health and social sector, even when a single domain is considered;
- The fact that each terminology is conceived for satisfying a specific set of use cases and scopes, when used outside those purposes the terminology loses relevance and efficiency.

Selection criteria for terminologies have been defined, in line with the criteria defined by Article 8 of the «Guidelines on Minimum / Non-exhaustive Patient Summary Dataset for electronic exchange in accordance with the Cross-Border Directive 2011/24/EU »

- Fitness for purpose for the considered use case
- Long term sustainability and scalability
- International standard
- Multilingualism and native support for synonyms in each language
- Costs / benefits ratio

\textsuperscript{41} http://esante.gouv.fr/actus/interoperabilite/publication-du-rapport-de-la-phase-2-diagnostic-dans-la-cadre-de-l-etude-sur
10.3.3 Belgium

In 2010 Belgium started a preliminary research for the development of a terminology server for the health domain with the aim of improving the semantic interoperability also through the development of a controlled medical vocabulary (CMV)\(^{42}\). In this context, the report «Serveur de Terminologie: Recherche Préliminaire en rapport avec le développement d’un serveur belge de terminologies dans le secteur de la santé. [Partie 2/3] [2010](http://www.bmia.be/data/Rap_part2_V01_1.pdf) was analyzed. This part of the report starts with an overview of relevant international terminologies for the continuity of care\(^{43}\); a survey of the usage of terminologies by vendors; a summary of some European (epSOS) and international initiatives and an inventory of Belgium terminologies and initiatives (including registries), that showed a large variety of solutions and approaches. This first analysis enforced the pivotal role of SNOMED CT, with the suggestion of the acquisition of a SNOMED CT license\(^{44}\) and to establish international collaborations for the translation process. A clinical example based presentation of the general philosophy of usage by end users was done; providing also an overview on how the care reality is formalized through the terminology and linguistic conceptualization process and how this conceptualization impacts on the terminologies strategies. The role of the tools (including NLP techniques and ontologies); of the controlled vocabularies and of the context-dependency of the granularity was highlighted for gaining on productivity and quality of information. This part ends with a summary of the advantages of the introduction of a terminology server as supporting tool for interoperability, and recommendations on (high level) functionality: be the trusted source of information; provide interfaces for the sync with applications; support validation workflows; facilitate the context dependent code mapping and the coding and the management of terminologies.

An update to the first document has been done in 2011 [http://www.bmia.be/data/rap3_v01.pdf](http://www.bmia.be/data/rap3_v01.pdf) and in 2012 [http://www.bmia.be/data/Rap2_part1_V01_0.pdf](http://www.bmia.be/data/Rap2_part1_V01_0.pdf) to consolidate the methodology and the nucleus of a preliminary controlled medical vocabulary (CMV). A 2013 update version of the report “Guidelines Belgian terminology Diagnoses” was also kindly provided, describing a reference terminology for Diagnoses based on SNOMED CT and translated into French and Dutch. This report describes the methodology followed for the selection of concepts; compares pre and post coordination describing when and how to use them and how translations are managed. The selection of concepts includes also the rules followed for the “eliminations” of concepts (e.g. ambiguity, vagueness...), that implies the substitution of some pre-coordinated concepts with post-coordinated ones. An iterative process was chosen for the selection and the translation of concepts (the paper describes three runs plus a reconciliation activity) involving Dutch and French speaking clinicians.

The presentation (PPT file) provided by Luc Nicolas and titled “SNOMED-CT: Vers une nouvelle terminologie médicale” [2014]\(^{45}\) was also analyzed: it includes an overview of the BE eHealth roadmap (2014-18) putting the focus on clinical usage of terminologies and on the role of smart end-user interfaces. Some lessons learned were also presented including the need of:

- Training for human resources;
- Good Governance (terminology center);
- Stakeholders involvement;

---

\(^{42}\) The CMV is a restricted set of concepts to support, from a clinical point of view, the communication between medical doctors (GPs and Specialists). It is not intended to substitute international terminologies. It is an independent Belgian terminology which is linked to SNOMED CT as it will be linked to other relevant classifications and coding systems. It uses unique Belgian identifier (IBUI).

\(^{43}\) Including SNOMED CT, ICPC, the ICD family; terminology for nursing (ICNP, NANDA-International, Nursing Intervention Classification (NIC), Nursing Outcome Classification...); for prescription (LOINC, ATC) and others uses (e.g. International Classification of Functionality, Disability and Health (ICF), An overview of Base of Knowledge (MeSH, the French Haute Autorité de Santé and of the NHS Clinical Knowledge Summary (CKS))

\(^{44}\) Limited to the users of the terminology server to better investigate the SNOMED CT adoption.

Involvement of clinicians;
Early investment in an appropriate management tools;
Smart and performing users interfaces;
Bi / multi-lateral terminology on term validation and translation;
Announcement effect on users and the industry;
Knowledge of tools and interfaces available.

10.3.4 Norway
The Norwegian “Direktoratet for e-helse” has recently conducted an assessment about the SNOMED CT terminology suitability for the Norwegian health service. The report's intent is to contribute to a decision by the national enrollment in IHTSDO. The report has considered three focus areas: the health professional suitability, implementation and ICT issues; and organization and management. Three perspectives were considered for the evaluating suitability: health professional; patient-oriented work processes and coverage and fitness for purpose for selected usage scenarios. A good coverage was determined in selected areas, with potential added value in terms of the opportunity for a more detailed secondary use of data, several national concepts and an unambiguous terminology across processes, departments and national borders. Areas like dental health, anatomical localization, symptoms, substances in relation to allergies, organisms, clinical measurements and observations, findings and interpretations, not adequately covered by codes, was identified as possible candidate areas for the introduction of SNOMED CT. Coverage lacks have been identified as well in some health-related areas as nursing.

Meeting with countries using SNOMED CT (UK, Sweden, Finland, Denmark and Portugal) and vendors has been reported analyzing, among the others, the usage of pre-coordination versus post coordination; the usage in conjunction with information models; organization and management challenges. Based on other experiences an incremental approach was suggested for translation, considering however a centralized management model to discipline the use of terminology.

The report recognized good and valid arguments both for and against enrolment in IHTSDO for Norway: there are implementation challenges related to the SNOMED CTs scope and complexity; there are lacks in EHR systems on supporting support scenarios analysis, process and decision support and semantic search fully. On the other hand, there are no good alternative terminologies with the same clinical scope, granularity and international reach as SNOMED CT.

Five options were analyzed for the Norwegian scenario from “do nothing” to “join IHTSDO and plan for a SNOMED CT wide adoption”. The “Enrolment in IHTSDO with an exploration period” was at the end recommended, considering centrally coordinated implementation of SNOMED CT; initiating a three-year study; and making a new evaluation after this exploration period.

This recommendation is conditioned by the conclusions of the ASSESS CT project and by possible European investment in SNOMED CT. This will provide in fact a stronger political guidance for the future and the development of SNOMED CT.

In brief, the report recommended to

- Enrol in IHTSDO
- Establish an expertise team working specifically on SNOMED CT / common standardized terminology
- Work to raise the level of competence regarding common standardized terminology / SNOMED CT

46 https://ehelse.no/Documents/Nasjonale%20utvalg/NUFA/Beslutningsgrunnlag%20SNOMED%20CT%20sammendrag%20v1.0.pdf
- Establish a study, which includes SNOMED CT in future comprehensive terminological targets for structured records and processing and decision support
- Follow the development of ICD-11
- Make SNOMED CT available to those who have immediate needs - dental and archetypes development
- Make a new evaluation and decision on further implementation of SNOMED CT after the 3 years exploration period

10.4 Overview of European eHealth research projects in the field of Interoperability, cross-border healthcare and clinical research

A review of European eHealth research projects in the field of Interoperability, cross-border healthcare and clinical research have been realized identifying eleven projects (Antilope; epSOS; eStandards; EXPAND; openMedicine; Trillium Bridge; VALUEHEALTH; SemanticHealthNet; Salus; TRANSFoRm; EURECA) for which essential information have been provided. For five of them (EURECA, eStandards, SemanticHealthNet, VALUEHEALTH and OpenMedicine) a wider abstract has been produced, including the link with the ASSESS CT work. The Projects overview table and the selected projects summaries are reported in Appendix B.7.
11 EU-US Workshops

In order to gather experts opinion regarding
1. The current use of SNOMED CT in the US
2. The lessons that Europe can learn from their experiences
3. The potential for EU-US collaboration

Two workshops involving European and US experts were organized (see attendees table below): the first was held on March 29th 2015, in conjunction with the Trillium Bridge Workshop, in Brussels, the second in Amsterdam on May 3rd 2016. The list of participants is provided in Appendix B.8 of this deliverable.

11.1 First workshop

In the first workshop, the very preliminary results of ASSESS CT were shared and a set of agreed questions discussed in an unstructured way. Hereafter is provided a short summary of the meeting (further details can be found in D1.1 section 8).

The US scenario is very fragmented, and no one is entitled to speak on behalf of “US”, the vision that all the patient information can be annotated with SNOMED CT is not applied in all the US. This is due to the preexistence of “legacy” value sets and the absence of financial incentives to facilitating the adoption. As a result, the usage in hospitals is still lower than in academic environments. The main use of SNOMED CT in US is mainly for supporting the Meaningful Use, even if it is not really actively used for the cross-organization communications.

Kaiser Permanente is using SNOMED CT in its EHR-S for about 55 million records for describing any information about the patient that can be coded in the EHR. ICD-10 is mainly related to administrative and financial usage. Kaiser Permanente makes usage of the SNOMED CT description logic and of the inferences (associations) not only limited to the hierarchical relationship. (Coded) Information is captured (and displayed) using interface terms. Interface terms – based on SNOMED CT - have been defined for being used by clinicians, but also for patient (patient friendly display Name). Clinicians are allowed to ask for new pre-coordinated concepts, developing clinician-specific synonyms. Those local extensions are handled as formal SNOMED CT extensions. This solution, even if it requires strong investments, appears to be the most efficient.

Mayo Clinic is an Academic Organization smaller than Kaiser Permanente. SNOMED CT is used only for coding the problems in the problem list for the Meaningful Use Purposes. For this use case a mapping with the legacy terminologies used has been done. Mayo is considering for the future ICD 11, that will allow for post coordination with classification, and will share a common ontology layer with SNOMED CT.

NLM is not a terminology user but provides services for terminologies. It is the US IHTSDO Release Center, it acts as National Value Set Authority (creates contents and value sets for supporting the MU) and provides mappings for SNOMED CT and ICD-10-CM. The role of NLM is essential in facilitating the use of SNOMED CT, since you cannot use it just “as it is”: NLM provides an open value sets library, creates tools managing them and assuring the integrity along the code system versions.

The discussion then moved to the issue of post vs pre-coordination: it was pointed out that usually clinicians prefer pre-coordination, where researchers want instead post-coordination. However, the usage of post-coordination requires a bigger learning curve, since users need to have a full knowledge of the description logic. Moreover, in the balancing between these two choices, the amount of information that the human being is able to get when it get a “complex” concept (cognitive learning) needs to be taken into account. Most EHR-S cannot
support the complexity of the description logic of SNOMED CT, in general when supporting only the post-coordination is considered. However, in these last years, thanks to the Meaningful Use program, Vendor products are more robust in term of capability of handling SNOMED CT.

11.2 Second workshop

A full day workshop involving a wider audience was then organized in Amsterdam: a presentation of the ASSESS CT interim results was done and it was debated “what has been uncovered as the real "value add" of SNOMED CT over existing practices and alternatives"; in particular, how to gather knowledge and information on how to set up in Europe an organization like National Library of Medicine (NLM) (and VSAC); the reasons why cost-benefit assessment of SNOMED CT is more difficult than that in other field\textsuperscript{47} and the significant progresses in education made by IHTSDO concerning SNOMED CT. The role of SNOMED CT was also questioned: some suggested that it should be seen as an infrastructure with huge advantage in secondary use and decision support. SNOMED CT as an infrastructure implies equal benefits where SNOMED CT as an interface terminology implies harder and more expensive implementation in smaller countries. Other argued that it should be seen as both infrastructure and interface terminology, allowing pooling of resource to fill the gap between terminology selection and implementation and solving the problem of both task duplication and inability to collaborate. One major concern has been directed to the licensing cost. It seemingly obstructed the adoption and spread of SNOMED CT and was considered as not only a hurdle, but more like a deal-breaker. To overcome this, the business model that justifies this cost should be clear, convincing and transparent to display how the hurdles can be overcome along the process and eventually lead to positive meaningful results. Another barrier to implementation is the translation: the question here is if it is necessary to have a complete translation of the whole terminology to start with or if it could be initial mapping and then progress step by step. The Danish experience shows that even a Danish official translation is not fitting as an interface terminology and was not the focus in the current implementation projects; additional terms are added and the translations in other countries are consulted to borrow best-suited terms. The large-scale installations in the US could be used as a basis for the EU incremental strategy (reuse US experience): selecting the batch of top concepts as first step can help cost reduction in translation. MSs are eager to learn from each other, it will be beneficial to create a network of experts and decision makers to facilitate collaboration and experience sharing across MSs.

The second half of the workshop was then dedicated to the US presentations. James Case, NLM, presented the role of NLM in coordinating the national support for semantic interoperability standards. James Campbell, Nebraska Medical Center, described the experience at the University of Nebraska Medical Center, introducing SNOMED CT: the characteristics of a Reference terminology were described and the role of interface terminology to make the SNOMED CT implementation successful was described. One success factor is to make a clear policy statement about standards after thoughtful deliberation and incentivize to deal with barriers to deployment. NRCs should be developing understandable guidance to vendor community regarding protocols and expectations of change management; possibly including version management expectations of vendors. Christopher Chute, Johns Hopkins University, provided an update on ICD-11 and SNOMED CT harmonization. Jamie Ferguson, Kaiser Permanente, gave an overview of the Terminology management with SNOMED CT at Kaiser Permanente (KP): KP uses an enterprise terminology called Convergent Medical Terminology (CMT), based on SNOMED CT and LOINC, that includes end user terminology, standard terminology, administrative

\textsuperscript{47} (a) costs include many non-monetary costs which render difficult measurement and calculation; (b) although many benefits can be theoretically seen in monetary terms, the practically measurement is very troublesome; (c) it is indeed very difficult to distinguish between the benefits brought by terminology and those brought by ‘digitalization/semantic framework’; (d) as the maturity in each country is different, it is very difficult to arrive to see the benefits, but an incremental approach to costs would help.
codes, patient/population query and decision support, and terminology request process. CMT leverages the internal structure of SNOMED CT, including poly-hierarchy and description logic (formal definitional attributes), and provides the ability to query different ways to identify subsets of patients through the terminology. Since the implementation of CMT in 2003, the quality of care in KP care facilities has improved and number of malpractice cases has constantly decreased. Significant cost savings were proven and detailed reconciliation at the individual record level proved in every case the new methods produced results that are more accurate. Robert Hausam, ONC, gave an overview of the Interoperability Standards Advisory (ISA). ISA aims to provide industry with a single, public list of the standards and implementation specifications. In the 2016 version, SNOMED CT was recognized as the best available terminology standards and implementation specifications for 15 out of 27 clinical data interoperability need.

A follow up discussion on the US experiences was then made. In US many different terminologies are recommended due to different reasons: e.g. some are requested by legislation; standards advisory choose many different sources, some even not covered by SNOMED CT. NLM has no obvious partner in EU, thus there is no way to collaborate on value sets. This points again to the need for a pan-European governance body to register all terminologies. One possibility is creating an NLM counterpart for Europe where it is already recognized as a part of the trillium bridge projects with higher level collaboration. The current MVC maintenance body in Europe should be examined and see if it could be transformed to meet the needs of such governance body. Concerning whether governments trust the standardization community, it was noted that this is country specific, however it is necessary to avoid standardization mismatch, joint efforts and harmonization are needed to leverage in an international community. Governments should be involved in Joint Initiative Council (JIC). Larger EU framework for national government coordination may be needed. Governments must make clear what they need and what they want and partner with JIC and existing SDOs, to avoid the rise of just another SDO. The government’s role is essential in giving a direction, so that the community can be mobilized and follow. It was noted how the IHTSDO has changed over the time (form a sort of profit-oriented company in the US in 80s-90s to neutral third party today). US experts believe that, despite the licensing cost being a psychological barrier, the community has in general positive views on the adoption of SNOMED CT. NLM receives increasing feedback from professional societies, as well as from vendors who respond to enquiries of customers, concerning SNOMED CT; it is recognized as the de facto standard for clinical terminologies in US. It is the most consistent and comprehensive terminology in terms of both breadth and depth, where ICD is not an alternative. The concept model and description logic allow analytics avoiding duplication of effort and facilitating big data use case. Other than that, SNOMED CT is well-maintained and changing to meet user’s need as IHTSDO is embarking upon a near to medium term near-real-time release. It is responsive to the needs of the clinical community. (Kaiser Permanente) The value case for the investment into the EHR strategy was built on operational measures improvement e.g. shorter hospital stay, etc. The current value case is very different, including big data analysis; using semantic web tools with logic analysis and reasoning; taking advantage of the description logic of SNOMED CT, all of which are very difficult to be measured and presented. An important aspect to be considered is the long term time horizon surpassing political cycle (10-year business case time horizon for KP). Concerning a step-wise approach to coordinate adoption between member state, pan-European content management organizations should work in a more federated way and collaborate with organizations such as Kaiser Permanente, Nebraska, Mayo. The extension of content will benefit the whole EU. As about how to prioritize actions in practice, there remains a great difference between the EU and US settings. It is important to put the focus on how to improving care with terminologies and not only on what SNOMED CT can do. In this sense, consistently agreed use cases are needed. In IHTSDO,

---

48 What were the impacts, what were the major hurdles and how were they overcome, what lessons have been learned?
there is currently no carryout of cross-terminology, cross-information model work. However, Kaiser Permanente donated their investment and their artefacts e.g. cross maps, interface terms are also available (KP artefacts public available).

Then Robert Stegwee, from CEN, introduced the International Patient Summary (IPS) subjects and a conversation on the use of SNOMED CT to express clinical problems and procedures in the IPS was made. Each country has its own summary specification and different notions for PS; it might not be realistic to expect existing specifications to be abandoned. Yet, IPS can be a common denominator for European guidelines as a starting point for user requirement. It is suggested to collect actual events (e.g. via a website) in order to get better focus for the specification of the IPS. A modular approach should be taken starting with planned care and escalating uses cases. As directed to the need for unscheduled care, it requires minimal value set. The scope should be kept narrow even if extended to unscheduled care setting. Existence of IPS helps decision making on a national level. As seen in epSOS, only about half of the European countries (13) have some kind of PS. The question here is that when such great harmonization effort is still needed on EU level, how difficult it will be to achieve EU-US harmonization. Still, take France as an example, some countries are inclined to adjust their own existing standard to match international standard. Even governance aimed at being highly inclusive, frequency and cycles of standards will still be different due to institutional differences. The term “clinical problem list” has discrepancy of definition across European countries, as well as between EU and US. It is often called list of diagnoses including sometime also relevant surgical procedures. It is recommended that the possibilities of joint work, e.g. on harmonization of value sets, should be explored. The ontological structure of SNOMED CT can be exploited for querying even only with “simple” value sets. Some suggested that the goal is to draw all elements for a value set from the same source. However, it is pointed out that SDOs encourage content drawn from different sources to address more use cases and to fill gaps making sure that different value sets are connected. Nonetheless, EU-US cooperation should be leveraged to avoid duplication of effort. The legal and ethical aspects of IPS in Europe and the ability to connect with other initiatives, such as ePrescription, have to be taken into account. Future use cases for IPS should be planned care and orphan diseases.

11.3 Conclusions

Because, as the North American experience stresses, SNOMED CT can be a solution only in combination with other terminologies, classifications and coding systems, an approach to its adoption must be agreed upon between member states. It is important that member states share their lessons learned from implementing a concrete use case and here the EC (through the Connecting Europe Facility, for instance) can play a role in managing the process of member states becoming aware of each other and exchanging experiences.

Governance should be nevertheless left up to each member state and the problem remains that governments are still not convinced of adopting SNOMED CT. One suggestion is to define the adopt scenario more precisely with a clear description of the steps. A business model can elucidate what the workflows with actors are and what the sequence of activities is.

A starting point would be to focus on small, relatively non-controversial archetypes of issues (like value sets) in order to illustrate how SNOMED CT works. The implementation of an EU international use case would be advanced by approaching vendors and offering them market coverage in exchange for their efforts.

The final recommendations according to different stakeholders are summarized as follows:

- Address SNOMED CT from an infrastructure perspective;
- Determine ways to facilitate incremental standardization with minimal overhead from the incremental approach, and,
• Consider the potential of a “Pan-European [NLM]”.
• **Determining (clinical) use cases** e.g. Ambient Assisted Living, Learning Health System, International Patient Summary
• stimulating **mutual learning and exchange of resources**.

Recommendations for **future EU-US collaboration** are:
• Common data sets repository;
• Aggregated data; and
• Collaborating on managing the world of standards.
12 Revision Workshops

12.1 Report on 1st revision workshop

On Friday, 22nd May 2015, the First Expert Workshop of the ASSESS CT project was held at the Federal Public Service (FPS) Health, Food Chain Safety and Environment. 53 stakeholders attended this workshop, covering different roles and countries. This includes also an IHTSDO representative as observer, and three representatives from the European Commission. The scope of this workshop was to present the project, socialize the approach followed by the different work packages and the preliminary results; stimulate the discussion about the treated themes and collect feedback about the work done and the next steps. A brief background document was shared in advance with the registered stakeholders in order to help them prepare for the workshop discussions. For what concern WP1 the initial results from the national survey and the focus groups were presented; as well as the three scenarios that scope the whole project: Adopt, Alternative, Abstain.

In the following discussion, it was voiced the importance of assessing the contribution of a terminology (or other standard) for specific scopes / use cases and the need not to use terminologies beyond their scopes. It was then suggested to move the discussion about scenarios from a pure theoretical view to real usage across countries (e.g. cancer registries), looking at the existing success stories. It was asked to clarify the generic statement about the meaning of adoption and not to reverse the order between cross-borders and national use: the quality of exchanged cross-border data cannot be high if that of local data is “poor”. Cross-border exchange should not be limited to patient data, but should be also used for the measurement of quality of care. It was stated that the idea of a single terminology that solves all the needs is not applicable and depending on the scope different terminologies are (and should be) used. Even though SNOMED CT does not have the whole content, it could however be used as a backbone onto which other terminologies can be built. It was put in evidence that for the choice of a terminology not only the content is important, but also its maintainability (epSOS adopted this criterion in its selection) and the role of international collaboration to remove barriers and reduce costs. Finally, SNOMED CT should also be considered a language for the development of future innovative solutions: technology may be the demanding force for a universal (clinical) language in Europe.

The discussion shifted then to the alternative scenario, some questions were raised about the actual meaning of the abstain and alternative scenarios; Denmark has found that alternative classifications cannot easily be extended to additional use cases; others that existing classifications cannot be used for new purposes - many were built for purely statistical purposes and therefore cannot be often used for clinical documentation. However, it was stressed that even if SNOMED CT is adopted the need of having alternatives for billing, reporting, comparisons remains.

A more details summary on the first workshop is available on D1.1.

12.2 Report on 2nd revision workshop

On 13th October 2015, the second ASSESS CT validation workshop was held in Berlin. Its scope, for WP1, was to validate the results obtained by the Focus Groups and Questionnaires and gather inputs for the second phase of the project. This was realized sharing in advance with the participants the most relevant49 results derived from the focus groups and questionnaires. Results and challenges were then presented during the workshop and attendees were asked to provide feedbacks - using on line questionnaires – on them. A general agreement about the conclusions derived from the focus groups and questionnaires was obtained by respondents, with a larger consensus on “Strategic long

49 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.
term benefit” of SNOMED CT and issues related to license and costs. All the proposed topics have been evaluated as relevant for further discussions with a special focus on approaches to be followed for the introduction of SNOMED CT; market maturity and lack of evidence of benefits. A concrete experience on how SNOMED CT has been implemented in England was therefore presented by Andrew Perry. Finally, the candidate case studies identified by WP1 were described, along with the criteria that were agreed and how those cases covered those criteria.

During the follow-up discussion, it was suggested to consider in the overall analysis the needs of the European Reference Network (ERN) and of the eHealth Network. It was also asked to better define and distinguish between different kinds of cases the project had to deal with in order to help the prioritization. Concerning the current lack of evidences on widespread use of SNOMED CT, it was suggested to carefully consider the time scale (several years) needed for evaluating the return of investments. Finance and Public health were indicated as two important drivers for terminology adoption. Some comments were made about the important, but not unique, role of terminologies in semantic interoperability; the extensibility capability of SNOMED CT and licensing issues.

A wider summary is provided in D1.3 § 9.1.

12.3 Report on final Workshop

The ASSESS CT final conference took place on 2016, July 1st in Lisbon, Portugal. The conference was held in the form of a workshop during which draft recommendations that were previously elaborated by the consortium were presented to the audience. Each presentation was followed by a discussion with the audience who was meant to critically evaluate these items and to provide feedback and guidance for revision by the consortium.

Even though the workshop was meant to be conceived mainly for the global recommendations (ASSESS CT WP4), during the discussion some of the topics covered by ASSESS CT WP1 were covered as well. Hereafter is a summary of the most significant feedbacks related to this:

- The case of the European non IHTSDO member countries that for the time being are planning to use SNOMED CT only for cross borders services have to be carefully taken into account and a specific recommendation build on that should be created.
- Education is critically important, also for the builders of the ecosystem and their funders.
- From experiences world-wide, clinicians want to express themselves in their own language, as do the patients. We should not impose on the world, the clinicians, the patients a computer generated languages, and we should encourage systems that permit them to work with their own words, linked and mapped to international reference terminologies. It was argued that for cross border we need the concepts of the Reference Terminology to cross the border, not the local terms. We need micro-environments where the use of particular acronym or term means in context. The computer will figure it out. KP has massive end-user tools (even permitting individual extensions). It should not be a worry that users use particular terms, if it is done in context.
- epSOS vocabularies are no longer maintained, yet they require continuous management.
- The full translation of SNOMED CT is a challenge, it is not an absolute precondition to introduce SNOMED CT; a big translation project is not the best way to start a SNOMED CT implementation process. In the Netherlands, interface terminologies for procedures and findings are developed; Denmark did a lot of work on translation but does not use it. Sweden is in a similar situation.
13 Assessment of Annex II: Requirements for the Identification of ICT Technical Specifications

This section summarizes the results of the assessment about the capability of SNOMED CT to satisfy the requirements for the Identification of ICT Technical Specifications of the EU standardization regulation, annex II\(^50\). The referred norm and the results of this assessment are documented in D1.4 Appendix B.1 Regulation (Eu) No 1025/2012 Annex II Assessment.

The assessment of SNOMED CT against the criteria listed in the ANNEX II of the above mentioned regulation considers both the SNOMED CT terminology as a standardization product\(^51\) and the technical specifications (e.g. http://snomed.org/compgrammar.pdf) associated to that terminology.

No negative responses have been identified for the assessed criteria. Hereafter some relevant notes are reported.

**Criterion 1:** the second part of the criterion assert “… implementations do not hamper interoperability with the implementations of existing European or international standards”.

In the assessment we need to distinguish the standard product, that is the terminology actually released by IHTSDO and the technical specifications, that are the rules and procedures used to develop, maintain and use that terminology. Technical specifications - per se – do not affect the implementations of existing European or International standards. On the contrary, the implementation of the standard product may have an impact on them; the impact may vary depending on the type of the standard implemented e.g. other terminologies, service specifications or data model. Is important to note that any agreement on the use of any standardized terminology necessarily results in, often expected, impact on implementations. This standard product however doesn’t avoid the use of other standards, on the contrary, this is requested for getting technical and semantic interoperability; neither the introduction of SNOMED CT technically precludes the usage of existing solutions, if terminology mapping techniques are applied. To improve the coexistence with other standards and mitigate the barriers, several initiatives have been taken by IHTSDO, with the cooperation of other SDOs.

**Criterion 2:** “… as they do not conflict with European standards, …”.

For evaluating this criterion the definition of European Standards has been considered as provided in the point (4) of this norm (“European standards are adopted by the European standardization organizations, namely CEN, Cenelec and ETSI.”). Based on that, at this stage of the investigation, no potentially conflicting standards have been identified. Examples of European standards considered are ISO/EN 1828:2012 (“Categorial structure for terminological systems of surgical procedures”) and the EN 1614:2006 EN 1614 (“Health informatics - Representation of dedicated kinds of property in laboratory medicine”).

**Criterion 4, point (b): “specifications are publicly available for implementation and use on reasonable terms (including for a reasonable fee or free of charge)”**

The concept of “reasonable” is very subjective, difficult to quantify and context-dependent: different opinions have been collected about this point through the performed investigations (focus groups, questionnaire, expert workshops…).

The evaluation if the SNOMED CT fee is “reasonable” strongly depends on the purpose, the context and the extension of use of SNOMED CT. The SNOMED CT


\(^{51}\) “Standardisation can cover various issues, such as standardisation of different grades or sizes of a particular product or technical specifications in product or services markets….” from the Regulation (EU) No 1025/2012
License cost structure has been identified by several non-IHTSDO member countries as a barrier, above all in the decisional/start-up phase; even though it is only a small part of the overall routine costs. The potential cost per care record could be reasonably low if extensively used. A large subset of SNOMED CT concepts (about 7000) have been made available globally free for use in DICOM standards (other similar agreements are on the way with other SDOs e.g. HL7, IHE...). Special agreements can be negotiated for evaluation or start-up purposes (see e.g. the case of Switzerland). Free licenses can also be obtained for research purposes. The IHTSDO specifications are always free for use.

In conclusion the evaluation of this criterion is context-dependent taking into account at least the purpose and the scenario of use and the type of agreement negotiated or applied in that context.

In particular the case of Member States which will use specific SNOMED CT sub-sets only for cross-border services (transferring or displaying terms), should be carefully studied.

Criterion 4, point (e.i): “…specifications whenever possible are performance oriented rather than based on design or descriptive characteristics…”

At this stage of assessment, there is no definitive position on how this sub-criterion applies to SNOMED CT. For the time being, the performance orientation has been interpreted in terms of domain coverage, maintainability, extendibility, responsiveness, etc. All those properties are taken into account in the standards development and decision-making processes of SNOMED CT.
14 Conclusions

This section summarizes the most relevant results that have been derived from the investigations realized by WP1. Those statements have been initially drafted in D1.2; enhanced through the stakeholders and experts involved in the second ASSESS CT validation workshop and integrated with new results of case assessments and questionnaires in D1.3; and finally refined and reorganized considering the feedback coming from the non-European experts and the final project conference.

CAVEAT: the statements included in this section encapsulate opinions, beliefs and reported experiences. Please refer to the single reports of the investigations indicated for details about the sources that have been used to determine them.

Statements (in normal font) have been grouped under sub-sections and for each statement a reference to the results of investigations that justify it is provided (in italic font).

Concepts such as reference or core terminology frequently occur. The definitions for these proposed by ACCESS CT have been reproduced below from Deliverable 4.3.

Reference terminologies describe the meaning of terms of a domain, together with the properties of the objects that these terms denote, in a neutral sense, i.e. uncommitted to any specific purpose. Representational units of reference terminologies are commonly called “concepts”. The meaning of concepts should be the same across languages. It is given by textual definitions, formal definitions and/or maximally unambiguous terms / labels in different languages. Reference terminologies are not however expected to cover the complete scope of a language.

A core reference terminology is a large reference terminology that plays a pivotal role within a terminology ecosystem, in terms of conceptual coverage and linkage with other terminologies. Yet it is not expected to cover the totality of concepts. In most terminology ecosystems it has therefore be supplemented by other reference terminologies. Whenever reference terminologies overlap, clear mappings should be defined.

Aggregation terminologies are systems of non-overlapping classes in single hierarchies, used for data aggregation and ordering. These terminologies are also known as classifications, e.g. the WHO classification. Aggregation terminologies are typically used for health statistics and for reimbursement.

User interface terminologies are collections of all terms that are used in written and oral communication within a group of users, for example in a data entry form in a healthcare IT system. User interface terms tend to be ambiguous. This requires that entries in user interface terminologies need to be described not only in terms of the natural language they belong to, but, if needed, also by dialect, time, clinical specialty and professional group. User interface terminologies acquire their semantic import by linkage to reference terminologies. Interface terms constitute value sets for data entry as well as dictionaries underlying human language processing systems.

54 Please refer to this deliverable (D1.4) to identify the WP1 deliverables in which the results of each investigation, either as summarized either as detailed report, have been documented.
14.1 Enablers for semantic interoperability

14.1.1 Policies, governance and management of terminologies

- **Semantic interoperability requires well-defined strategies, supporting policies and jurisdictional commitment** (including human and financial resources, incentives, and jurisdictional normative requirements) for all the levels involved; including governance and operational (day-by-day) management processes and committed entities.
  
  - The assessment of the case studies showed how countries that have jurisdictional policies and mandated entities (e.g. competence centers) working on semantic interoperability (e.g. England, Netherlands) have mature processes for terminology management (dimensions considered, drivers, stakeholder involvement; assessments; follow-up; wideness of the scope, re-usability;...). (D1.3). The essential role of supporting strategies and policies was put in evidence also in several questionnaires (D1.2) focus groups (D1.2 and D1.3) and expert workshops (see e.g. D1.4). The contribution of the US Value Set Authority Center (VSAC) in supporting the US Meaningful Use project has been pointed out by the US experts (D1.2 and D1.3) suggesting that also Europe set up that kind of a team.

- As any other kind of project, the effort required and the type of results obtained on the path towards achieving semantic interoperability depends on the weight given to the “Project Pyramid” dimensions (quality, scope, resource and time), in which the fitness-for-purpose (quality) is not an independent dimension.
  
  - See e.g. the results of the case study assessment (D1.3) or of the French Focus Group (D1.2 and D1.3)

- There is a dependency between the terminologies used (sometime independently of the scope) and the main (or the initial) driver that triggered the adoption of terminologies in this context.
  
  - Where the process was mainly driven by administrative/monitoring purposes (e.g. reimbursement, registry,..) the typical classifications are the most used solutions, and their use often extended beyond their initial purposes. Different choices are made when the driver is the clinical process and the secondary use (e.g. reporting) is seen as a “derived product”. The report shows that classification systems are the most frequently used terminologies (in particular the ICD family and ATC). (see stakeholders questionnaire and focus group results D1.2; or case study assessment (e.g. epSOS or Italian PS cases) D1.3.

14.1.2 Terminologies bindings to information models

- **Terminologies are only "one piece of the cake"** of semantic interoperability (SIOP): the fitness-for-purpose of a terminology cannot be evaluated independently from the information model adopted; the availability of agreed information models (at different levels). The binding of the selected terminologies to these models (including implementation challenges) are key elements as well. On the other hand, it was noted that SIOP it is not limited to the exchange of data on the wire.
  
  - In almost all case studies assessed, the combination of models and terminologies was considered. (D1.3) Several notes from the stakeholders questionnaire and experts involved (D1.2) pointed out this aspect.

14.1.3 Clear context of use for relevance and effectiveness

- **Terminologies** have to be used and assessed only within well-specified purpose and context of usage.
  
  - Focus group results (D1.2), expert opinions expressed during the workshops (D1.2); grey literature review (national reports) (D1.4) evidenced how terminologies used
outside their purposes lose relevance and efficiency. Any assessment has to be made considering the purpose a specific terminology has been designed for. However, it is not an uncommon practice, for some classification systems (ICD, ATC,..) to be used beyond their intended scope, since they are often the only terminologies actually available for use in some jurisdictions.

14.1.4 End user satisfaction and usability matter
- **Usability** and **end user satisfaction** are critical factors for the acceptance and adoption of SNOMED CT (as well as for any other terminology). This implies several aspects such as:
  - the availability of tools that facilitate the use of the terminology;
  - awareness about the benefits;
  - its effectiveness in the real business (i.e. clinical) processes.
- Several stakeholder questionnaire responses recognized as a potential challenge the usability of SNOMED CT and the actual or perceived\textsuperscript{55} complexity (e.g. on browsing, identifying and selecting terms) (D1.2); this challenge has been point out by almost all of the national reports (D1.4) and by most of the focus groups (D1.2). Kaiser Permanente in its presentation described how this problem has been overcome in its organization (D1.4). The availability of smart tools and education was mentioned in most of the focus group reports as essential factor for facing this issue (see e.g. the French and the Portuguese focus groups reports (D1.3), the questionnaires results (D1.2), and the case studies assessments (e.g. FR, UK, Rare Diseases ;..) (D1.3).

14.1.5 Awareness raising and education on terminology implementation and use
- **Raising awareness** about individual and organizational benefits is a critical point. This implies:
  - Education;
  - Stakeholder involvement;
  - The availability of pilots and proof of concepts;
  - The sharing of best practices;
- Most of the focus group reports, especially the Croatian, the French and the Portuguese pointed out the need to promote awareness about individual and organizational benefits (D1.3). Several documented strategies take into account the involvement of stakeholders and their education. (case study assessment (D1.3) national reports (D1.4); Focus Groups (D1.2 and D1.3) see e.g. French, English and Portuguese cases). Lack of education (knowledge) about SNOMED CT, terminologies and semantic interoperability has been also identified as one of the inhibiting factors (see e.g. questionnaire results D1.2)

14.1.6 Semantic Infrastructure offering terminology services
- The availability of a “Semantic Infrastructure” (i.e. supporting Terminology Services, Management Systems, and Servers) have been identified as an enabler for the introduction of SNOMED CT and other terminologies.
  - Cited in several stakeholder questionnaires (D1.2); in some national study (D1.4 see e.g., the French study about terminologies).

\textsuperscript{55} Very different opinions have been collected on this point, being highly context dependent (how I’m using SNOMED CT, what I’m using of SNOMED CT, what tools are available, what is the level of maturity...)

Page 67 of 72
14.2 SNOMED CT as a core reference terminology in a terminology ecosystem

14.2.1 The need for a terminology ecosystem

- Any semantic interoperability strategy needs to consider the **coexistence of a set of standard terminologies**. Neither SNOMED CT, nor any other terminology, even limiting the scope or the domain, can be the “unique” solution. The ecosystem may include several kinds of health care terminologies (reference, aggregation, ...).

  - **Almost all evidences gathered confirm that vision:** see e.g. Questionnaires (D1.2) Revision Workshop (D1.3) Portuguese focus group conclusions (D1.3); case study assessment (D1.3): Rare Disease Case, Lab & Path reports; Kaiser Permanente and other US experiences (D1.4)...

14.2.2 SNOMED CT as reference “core” terminology

- There is a general recognition about the role of **SNOMED CT as a reference “core” terminology within this eco-system.**

  - **The very large majority of the Stakeholders questionnaires indicated SNOMED CT as a suggested candidate for the exchange of health and social data cross-border, when combined with suitable policies and legislation, licensing conditions balanced with the type (size) of use, availability of high quality maps, and increased collaboration among organizations and experts (D1.2).** Similar opinions were gathered during the experts Workshops and from the case study assessment (D1.2, D1.3 and D1.4).

- **Reference terminologies of this eco-system should be related to national and international aggregation terminologies (e.g. ICD, DRGs) to support secondary uses** and administrative processes (e.g. reporting, reimbursement...).

  - **The capability for a seamless reuse of the clinical information captured through reference terminologies was described as one important enabling factor by several stakeholders and experts (see e.g. D1.2 questionnaires and focus groups; case study assessment).**

14.2.3 The role of SDOs

- In this context, **SDOs play a critical role** in reducing conflicts/gaps among terminologies, enabling cooperative usage of multiple terminologies;...

  - **see e.g. the agreement between LOINC and IHTSDO and its impact in the Lab & Path Report cases (D1.3) to be mentioned also the publication by IHTSDO of mapping resources, as that released twice per year from SNOMED CT to ICD-10 classification terms**.

14.3 Suggested approaches for introducing SNOMED CT

14.3.1 Step-wise, use-case-based, incremental approach

- A **step-wise, use-case-based, incremental** approach, coherent with the general semantic interoperability strategy, is the suggested method for the introduction of SNOMED CT:

---

56 Hopefully international and cooperating

57 http://www.ihtsdo.org/snomed-ct/mapping-to-other-terminologies/existing-mappings

58 Incremental does not mean that growth is not governed. Introduction plans take into account the global interoperability goals and the identified strategies, in order to avoid that too focused use case based solutions will be progressively adopted leading to a global incoherent solution.
possibly starting from inadequately covered domains and cases that can provide **perceivable advantages for stakeholders** (see e.g. the Portuguese Focus Group results);

- foreseeing a **realistic investment** (see e.g. the French Focus Group results);
- having cost of introduction commensurate to the scope (see e.g. questionnaires and French focus Group).

- **There are several evidences derivable from the focus groups and workshops reports** (D1.2 and D1.3); the stakeholder and country overview questionnaires (D1.2) and assessed cases (D1.3 and D1.4) that a meet-in-the middle incremental approach should be preferred one. Although top down approach is declared to be used by countries as Australia, Malaysia, UK and Uruguay, in the interview with the English experts, it was stated that a use case based approach would be preferable. (See D1.2).

### 14.3.2 International Cooperation and stakeholder engagement

- **Engage stakeholders** for managing the challenges of the transitional, and also target, scenarios^59^.
  - To secure support of key players have been identified as essential for the success of the introduction of terminologies (and SNOMED CT), this emerges from the several strategies form semantic interoperability as described by NHS England; Finland, Portugal, France, Belgium, Australia, New Zealand, Canada… (see the results of the country overview questionnaires D1.3; case study assessments D1.3; Focus Groups D1.2 and D1.3).

- **International cooperation** is crucial to:
  - focus the efforts on what is essential and mitigate the related challenges: e.g. starting the acquisition of multilingual interface terms (translations) from the most frequently used terms, learned from experiences of other countries.
  - Source 2nd EU-US experts workshop (D1.4) and several focus groups (D1.2)
  - Share experiences on specific practical topics of interest (e.g. lab reporting) by establishing topic-focused international and European discussion groups.
  - Indicated by several sources: stakeholders’ questionnaires and workshops (D1.2); case study assessment (e.g. NHS Pathology Report case); focus groups (e.g. Croatia D1.2)

- Better contribute to improve semantic interoperability for cross-border services.
  - For what concerns the European scenario, it is suggested that focus group meetings are repeated in the future, possibly extending them to other countries, in order to discuss specific issues of practical interest, which may have impact on terminologies in particular and on semantic interoperability in general. Such meetings should mediate between national and European contexts and should contribute to a better understanding of how this may relate to the eHealth Digital Service Infrastructure (eHDSI under CEF) Member State Expert Groups (eHMSEG)^60^ (D1.2)

### 14.3.3 Impact Assessment on the business architecture

- In order to evaluate the impact of the introduction of SNOMED CT, and to plan the right actions as a consequence of this, it is worth initially focusing on the **impact on the business architecture**, e.g. how the business (clinical) processes should change. Only

^59^ The introduction of new terminologies requires in general a revision of the business processes and the management of the change management from the legacy to the new terminologies. This transitional phase requires a strong involvement of all the actors that may be involved in such a change.

^60^ See e.g. ec.europa.eu/health/ehealth/docs/ev_20151123_co02_en.pdf
after that, the impact on the other “technical” aspects (e.g. the impact on application and technical infrastructures) could be evaluated.

- This suggestion comes mainly from the NHS experience (see e.g. questionnaires results; workshops and case study D1.2 and D1.3), even if also other feedbacks in that direction can be derived from experts of other countries (D1.2 and D1.3)

14.4 Strategic long-term benefits

14.4.1 Robust maintenance process

- Beyond current SNOMED CT evaluation processes (e.g. fitness for purpose, gaps), IHTSDO assures a transparent and robust maintenance process, which has to be considered as a strategic long-term benefit.
- see e.g. results of the 1st experts workshop (D1.2) or the conclusions of the EU-US workshop (D1.4)

14.4.2 Support to clinical languages (map to user interface terminologies)

- As core reference terminology SNOMED CT may play an “infrastructural role” providing support to national user interface terminologies mapping the clinical language (jargon, short forms, spelling variants) to widely usable terminology content.
- During the EU-US workshop, there was also debate on the possible role of SNOMED CT as an interface terminology (see D1.4). There are several positive experiences in which SNOMED CT is used to map (and as basis for) user interface terminologies see for example the case of the English NLMC project (D1.3); the Dutch thesaurus for Diagnoses (D1.3); the CMT used by Kaiser Permanente (D1.4)

14.4.3 Ease the reuse of data

- As a core reference terminology SNOMED CT may facilitate the interoperability and the reuse of data across different clinical domains, care settings and jurisdictions; in particular 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”.
- There is a general recognition of this “pivot role” of SNOMED CT as it emerged from the stakeholder questionnaires & focus group results (D1.2); from the workshops results (D1.2, D1.3 and D1.4), that is supported by concrete evidence reported, for example in some of the case studies (e.g. the case of the mapping between the LOINC codes and the post coordinated SNOMED CT expressions used for reasoning purposes (D1.3)); or reported experience (as the case of Kaiser Permanente (D1.4).

14.4.4 Standardization of EHR content

- The introduction of SNOMED CT may play a role in the standardization of the EHR content, and therefore in the marketplace of EHR systems and related solutions.
- This opinion initially indicated in the stakeholders responses (D1.2) has been confirmed also by the some country questionnaires (e.g. the Canadian response to the questionnaire was “we are a small market population-wise for the vendors to make Canadian specific modifications”)

---

61 For the benefits indicated in this paragraph the caveat reported at the begin of section 14 applies, as for the other conclusions.
14.5 Challenges

14.5.1 The need for further evidence of benefits

- The use of SNOMED CT in regional/national scenarios is in general limited. There is a low availability of evidence/best practices/examples about the usage of SNOMED CT at the European level; this limits also the capability of providing a correct evaluation of the potential consequences of SNOMED CT adoption.
  
  - This is confirmed by several sources (see questionnaires (D1.2 and D1.3), EU-US workshop (D1.4); case study assessment (D1.3)). Australia, England for specific uses, and Kaiser Permanente in the U.S are exceptions. Many countries report ongoing projects that use SNOMED CT in limited settings. (questionnaires D1.2 and D1.3). Also some findings of the literature review suggest that the use of SNOMED CT for multi-institutional or even multinational use cases is still limited, which may be related firstly to the individual effort required to obtain, configure and implement SNOMED CT in various information systems, and secondly to the fact that SNOMED CT in itself is only a part of a solution for cross-organizational information exchange.

14.5.2 Market maturity

- With some exceptions, the feedback collected indicate a low maturity of the EHR system (ICT) market for the use of SNOMED CT, although some progress has been made in the last years.
  
  - Stakeholders questionnaire results (D1.2), expert feedbacks (Workshops D1.2); support this statement. However some of the vendors involved in the workshops saw this as an opportunity for the market (see also the previous section), confirmed by the fact that for example vendors involved in the French study on reference terminologies were mostly in favor of the SNOMED CT choice (see the French implementation case D1.3).

14.5.3 License policy and costs

- The current SNOMED CT license cost and policy is largely perceived as a critical barrier, above all, in the decisional / start-up phase when the potential benefits of its adoption have not yet been evaluated or experienced completely. Even though many people have recognized that licensing costs only constitute a small part of the overall routine costs, supporting actions and policies for facilitating the initial adoption of SNOMED CT are strongly suggested.
  
  - This is a recurrent point that has been raised by several organizations through different sources (questionnaires, focus groups, workshops,..) (D1.2, D1.3, D1.4). It has been analyzed in the Assessment of Annex II: Requirements for the Identification of ICT Technical Specifications (D1.4) and largely discussed in the EU-US meeting (D1.4). (refer to them for details). In summary we can assert that this evaluation (if it is an actual or just perceived barrier) strongly depends on the purpose, the context, the scenario of use of SNOMED CT and on the type of agreement negotiated or applied in that context in relation to the scenario of use.

With a view to the eHDSI under CEF, the case of Member States which will use specific SNOMED CT sub-sets only for cross-border services (transferring or displaying terms), should be carefully studied and handled.

14.5.4 Other costs

- Beyond the direct cost (e.g., license), SNOMED CT requires a non-negligible initial knowledge investment that has to be correctly considered (steep learning curve). Moreover the organizational cost for setting up and maintain the NRC, the process of
**translation and synonym management** - including term selection, translation, quality assurance and support of the IHTSDO procedures - has a strong impact on costs, expertise required, time and challenges for the adoption of SNOMED CT.

- Substantially all the investigations performed (Questionnaires, experts feedbacks, focus groups, 2nd EU US workshop,…(D1.2, D1.3, D1.4) ) put in evidence how the license is only a part (often not the most relevant) of the overall costs that have to be sustained for introducing and using SNOMED CT. A more detailed analysis of the costs structure, based also on WP1 results, has been reported by ASSESS CT WP3.

### 14.5.5 Lack of expertise

- Many countries and organizations face a lack of knowledge and expertise regarding SNOMED CT (see related items on education and learning curve)
  - Source questionnaires, focus groups, workshop (see e.g. D1.2)

### 14.5.6 Actual and perceived complexity

- The actual, or perceived, complexity of SNOMED CT, in all its different aspects (e.g., logical and ontological foundations, compositional syntax, versioning and extension management, collaboration process with IHTSDO, software implementation, user perception) is a barrier that **has to be properly managed**. Different means for each of these challenges (like for example education, software investments) has to be identified and adopted in order to overcome them or hide the complexity of SNOMED CT to the users.

  - Similar considerations, similarly to those for the license cost issue, can be put about the topic of the “complexity of SNOMED CT”. This is an issue that has been raised by several stakeholders, see e.g. D1.2 stakeholder questionnaire results; but at the same time identified as a perceived, rather than a real, problem by other experts (see e.g. the results of German focus group D1.2). Both positions are valid depending on the perspective considered; on one hand there is an intrinsic complexity to the reality that SNOMED CT describes that has to be handled; on the other hand the level of complexity seen by the end-users needs to be commensurate to the scenario of use (in most cases, as well described by the Kaiser Permanente experience, the clinician may not care about the type of terminology he/she is using). Therefore how much SNOMED CT is perceived as “complex” depends on the level of knowledge; on how much the front end (EHR or EMR) and back-end tools available are “smart”; on the type of usage (e.g. pre- vs. post-coordination); on the level of maturity of the organization.