DELIVERABLE

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D4.4 Policy and strategy recommendations – final report

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#### Abstract (for dissemination)

This deliverable makes recommendations to the European Commission and the eHealth Network on the strategic choices they should consider, at a European level and at Member State level, around the adoption of SNOMED CT, other terminology systems and other components of a coherent strategy to advance the level of semantic interoperability of health data across Europe. This final version of the deliverable reflects input from the consortium and consultation with international experts at meetings and via electronic means until August 2016.

#### Keywords

- Business driver, strategy, barrier, adoption, reference terminology, user interface terminology, aggregation terminology, semantic interoperability,

#### Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.
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<td>Anatomical Chemical Therapeutic Classification</td>
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<td>epSOS</td>
<td>Smart Open Services for European Patients</td>
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<td>eHDSI</td>
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<td>ICPC</td>
<td>International Classification of Primary Care</td>
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<td>ICT</td>
<td>Information and Communication Technology</td>
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<td>IHE</td>
<td>Integrating the Healthcare Enterprise</td>
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<td>IHTSDO</td>
<td>International Health Terminology Standards Development Organisation</td>
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<td>IoT</td>
<td>Internet of Things</td>
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<td>JAseHN</td>
<td>Joint Action to support the eHealth Network</td>
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<td>LOINC</td>
<td>Logical Observation Identifiers Names and Codes</td>
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<td>Master Value Catalogue</td>
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Executive Summary

The goal of ASSESS CT is to make a significant contribution to the debate on semantic interoperability (SIOP) of eHealth services in Europe. It focuses on SNOMED CT and studies its potential as a core reference terminology for EU-wide deployment.

This deliverable presents the main recommendations arising from the project. These are a distillation of the findings from many areas of project investigation, across its different work packages, and the results of consultations undertaken within Europe and with transatlantic colleagues on several occasions over the past year.

Methodologically, the adoption of SNOMED CT as a core reference terminology has been scrutinised against two alternative scenarios, viz. (i) to abstain from actions at the EU level, and (ii) to devise an EU-wide semantic interoperability framework alternative without SNOMED CT.

The first recommendation, based on a very strong consensus across all stakeholder groups within ASSESS CT, is:

**Any decision about the adoption and role of terminological resources, including SNOMED CT, must be part of a wider, coherent and priority-driven strategy for optimizing the benefits of semantic interoperability in health data, and of the overarching eHealth Strategy of the European Union and its Member States.**

A European terminology strategy should be part of an overarching European eHealth strategy. The strategy should support the principles of collecting clinical data once and using them multiple times, where allowed and required. Thus, administrative, public health and research information should almost always be derived from routinely collected clinical information.

This strategy should have Member State commitment and should consider human and financial resource implications, incentives, as well as technical and semantic requirements.

The second recommendation, reached after careful consideration and investigation is:

**SNOMED CT is the best available core reference terminology for cross-border, national and regional eHealth deployments in Europe.**

A main advantage is its content coverage, which is superior to any other single terminology, making it the most complete point of reference for health related concepts. Another advantage of SNOMED CT over a set of other clinical terminologies is its principled ontology-based architecture with a logic-based coordination syntax.

The third recommendation is:

**SNOMED CT should be part of an ecosystem of terminologies, including international aggregation terminologies (e.g., the WHO Family of Classifications), and including local/national user interface terminologies, which address multilingualism in Europe and clinical communication with multidisciplinary professional language and lay language.**
No country sees SNOMED CT as a standalone solution, but rather as an important part of the national terminology infrastructure.

The fourth recommendation is:

**The adoption of SNOMED CT should be realised incrementally rather than all at once, by developing terminology subsets that address the interoperability requirements for prioritised use cases, and expanding this set over some years.**

Such incremental use, but across all Member States, might be subject to specially negotiated licences on behalf of the whole of European Union. Solutions must be in place for legacy conversion, guaranteeing the continued exploitation of historical data, for user interface terminologies, and for assuring the continuation of global mortality and morbidity statistics.

The fifth recommendation is:

**Mechanisms should be established to facilitate and co-ordinate European Member State co-operation on terminology and semantic interoperability, including common areas of governance across national terminology centres, eHealth competence centres (or equivalent national bodies).**

This should maximise the value of Member State and SDO alignment on the approach to advancing semantic interoperability, including the implementation and deployment of SNOMED CT.

The prioritisation of the key drivers behind semantic interoperability, at European and Member State levels, is important in directing the downstream priorities of an implementation strategy. The Annex of this report discusses the main drivers, and their implications for implementing semantic interoperability including terminology resources.

An elaborate communication strategy with the scientific associations of health care providers (medical sub-disciplines, primary care physicians, allied health personnel) is needed to inform, educate and convince with regard to the necessity of semantic interoperability, well structured electronic health records, performant end user terminologies, suitable international reference and aggregation terminologies, and clinical documentation skills.
1 Introduction

The goal of ASSESS CT is to make a significant contribution to the debate on semantic interoperability (SIOP) of eHealth services in Europe. It focuses on SNOMED CT and studies its potential as a core reference terminology for EU-wide deployment.

As health care systems are organised nationally, the EU has not taken any steps so far towards the adoption of a standardised health terminology. Up until now, SNOMED CT has been (partly) introduced in 14 out of 28 EU member states. However, as the mobility of EU citizens and the internationalisation of health care services are increasing, the question of interoperability of health data gains importance.

ASSESS CT has studied the use of SNOMED CT as a potential core reference terminology for cross-border, national and regional eHealth deployment. It has analysed its fitness for clinical use and its impact on stakeholders. ASSESS CT has also collected and estimated costs for license, operation, localisation, mapping, maintenance, and training as well as developed a cost-benefit framework to assess and quantify benefits. It has investigated reasons for adoption / non-adoption, identifying success factors, strengths and weaknesses of this terminology. Results on all these topics are presented in the deliverables of the workpackages 1-3.

In this deliverable we concentrate on the recommendations for a terminology policy and strategy in Europe, resulting from ASSESS CT.

Five main recommendations will be presented and further discussed, with an explanation about the origin of the recommendations, and with an overview of their actionable implications.

For a good comprehension of the recommendations, this introduction will first elaborate on the distinction between 3 different types of terminologies, and on the place of SNOMED CT in this typology.

Health care terminologies¹ are key resources for semantic interoperability. They are artefacts that provide standardised meaning of human language expressions used in oral or written communication within a given domain. Multiple terminologies have been developed in multiple contexts of use. Together, these terminologies can form a “terminology ecosystem”. Sometimes, especially in multilingual Europe, such ecosystems can be highly fragmented and serve different functionalities, such as reimbursement, monitoring, mortality and morbidity statistics, quality assessment, registries, screening programmes etc.

In such ecosystems we distinguish several kinds of health care terminologies for which ACCESS CT has proposed the following definitions, which will be used in the remainder of this document.

Reference terminologies (RTs) 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 end user language, nor do they require to be translated into all languages where they are used, provided this role is fulfilled by user interface terminologies. Among the reference terminologies, 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

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¹ S. Schulz et al. German-Language Content in Biomedical Vocabularies. CLEF 2013 Working notes. CEUR Workshop Proceedings Vol.1179
other terminologies. The term “core” is used here to indicate the primordial role of this terminology in the ecosystem, not to indicate that only the most important or most frequent terms are considered. On the contrary, extensive coverage across multiple domains is at the essence for the choice of a core reference terminology. Yet it is not expected to cover the totality of concepts. In some terminology ecosystems for specialised disciplines it may be supplemented by other more focused and comprehensive reference terminologies. Whenever reference terminologies overlap, clear mappings should be defined.

**Aggregation terminologies (ATs)** are systems of non-overlapping classes in single hierarchies, enhanced by classification rules, as commonly used for data aggregation and ordering. Aggregation terminologies are also known as classifications, e.g., the WHO classifications ICPC, ICD, ICF, ATC and ICHI. International aggregation terminologies are typically used for epidemiological research and health statistics. On the national level, country specific classifications or nomenclatures may be used for reimbursement.

**User interface terminologies** are collections of 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 or in clinical documents. 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 also by dialect, time, clinical specialty and professional group. User interface terminologies acquire their necessary semantic import by linkage to reference terminologies.

A linguistic end user interface in a specific language needs to be strongly embedded in the language-independent RTs and ATs, as only then can it play an effective role in the terminology ecosystem.

User interface terms constitute value sets for data entry as well as dictionaries underlying human language processing systems.

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**Figure 1: Role of different terminology artefacts within a terminology ecosystem**

(RT = Reference Terminology, AT = Aggregation Terminology)

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2 Following the notion of interface terminology by Rosenbloom ST et al. Interface terminologies: facilitating direct entry of clinical data into electronic health record systems. J Am Med Inform Assoc. 2006 May-Jun;13(3):277-88. Epub 2006 Feb 24. Due to the different facets of the term “interface” (user interfaces vs. machine interfaces) ASSESS CT has coined the term “user interface terminology”
Health terminologies can be furthermore described by their scope, e.g., clinical specialty (e.g. neurology, surgery, cardiology etc.), their domain (such as disorders, procedures), and by the groups of users they are targeted to, which include health professionals (physicians, nurses) and laypersons. The latter especially matters for interface terminologies.

Finally, health terminologies are distinguished by their language and the jurisdiction where they are used. Multilingual terminologies are characterised by providing terms in more than one language. International terminologies are developed by supranational organisation for international use. It should be noted that political borders and linguistic boundaries do often not coincide.
2 ASSESS CT recommendations

Five main recommendations were issued by ASSESS CT and are first listed below, and then discussed in detail.

**Recommendation 1:** Any decision about the adoption and role of terminological resources, including SNOMED CT, must be part of a wider, coherent and priority-driven strategy for optimizing the benefits of semantic interoperability in health data.

**Recommendation 2:** SNOMED CT is the best available core reference terminology for cross-border, national and regional eHealth deployments in Europe.

**Recommendation 3:** SNOMED CT should be part of an ecosystem of terminologies, including international aggregation terminologies (the WHO Family of Classifications), and including national user interface terminologies, which address multilingualism in Europe and clinical communication with lay language and multidisciplinary professional language.

**Recommendation 4:** The adoption of SNOMED CT should be realised incrementally rather than all at once, by developing terminology subsets that address the interoperability requirements for prioritised use cases, and expanding this set over some years.

**Recommendation 5:** Mechanisms should be established to facilitate and co-ordinate European Member State co-operation on terminology and semantic interoperability, including common areas of governance across national terminology centres, eHealth competence centres (or equivalent national bodies).

In the following chapter, each recommendation is further described and explained, with reference to the evidence underlying, and with an indication of actionable implications.

In line with the description of ASSESS CT, the adoption of SNOMED CT has been scrutinised against two alternative scenarios, viz. (i) to abstain from actions at the EU level, and (ii) to devise an EU-wide semantic interoperability framework alternative without SNOMED CT. However it is clear that once the choice is made for the adoption of SNOMED CT, several distinct scenarios of adoption are possible and indeed already on their way, in all their variety, in different member states.
2.1 First recommendation

Any decision about the adoption and role of terminological resources, including SNOMED CT, must be part of a wider, coherent and priority-driven strategy for optimising the benefits of semantic interoperability in health data, and of the overarching eHealth Strategy of the European Union and its Member States.

2.1.1 Further elaboration of the recommendation

Semantic Interoperability (SIOP) in healthcare is the ability to exchange health related data with unambiguous and precise meaning\(^3\) that is shared between stakeholders. Semantic interoperability is of value in a large number of heterogeneous scenarios of primary and secondary use of health data. It is also important in the broader context of Social Care and the Internet of Things (IoT)\(^4\).

A European semantic interoperability strategy should be defined, reflecting a consensus on the prioritised drivers for semantic interoperability within and between countries. This strategy will need to be sustained with appropriate objectives, policies, coordination and continuous evaluation and fine-tuning. It should include a European terminology strategy, as part of an overarching European eHealth strategy. The strategy should support the principles of collecting clinical data once and using them multiple times, where possible. Thus, administrative, public health and research information should almost always be derived from routinely collected clinical information. This strategy should have Member State commitment and should consider human and financial resource implications, incentives, as well as technical and semantic requirements.

Fine-grained coding at the point of care is expected to improve the overall quality of clinical data. Regardless of the terminology chosen, it is a big step for clinicians to proceed from written notes or free text annotations in the electronic health record to coarse-grained coding of all aspects of clinical data at the point of care, such as Reason for Encounter, Diagnoses, Tests, Interventions. Clinicians expect adequate support and benefits in return for this extra effort.

Semantically explicit clinical data support filtering of EHR content by relevance, the generation of summary communications and navigational support within large and complex patient records. Automated concept extraction from unstructured and semi-structured textual resources is expected to raise the coverage of coded clinical content in those cases in which important information is only available in clinical narratives. Trade-offs regarding data need to be considered.

\(^3\) SemanticHealthNet Deliverable 4.5

\(^4\) Semantic Interoperability for the Web of Things. White Paper, August 2016. DOI: 10.13140/RG.2.2.25758.13122
Safe decision support systems depend on high-quality meaningful data to be interwoven with formalised clinical guidelines based on a shared terminology. The same applies to the generation of accurate safety alerts in multi-actor care pathways.

Data analytics depends on fine-grained data for benchmarking, service planning and commissioning as well as for evidence based strategic decision-making and outcome optimisation.

Cross border use cases include not only the support of cross-border patient care but also the sharing and comparing benchmarks and quality metrics and patient safety intelligence (adverse event reporting, pharmacovigilance, pharmaco-epidemiology, outbreak control).

Secondary use of clinical data addresses the needs of public health researchers and decision-makers and can be leveraged for population-wide screening, surveillance and prevention actions. Clinical and basic research depends on standardised cohorts and data sets, with important cross-border aspects in registries, rare diseases research and biobanking.

Finally, any decision about the adoption and role of terminological resources, including SNOMED CT, must be part of a wider, coherent and priority-driven strategy for optimising the benefits of semantic interoperability in health data, and of the overarching eHealth Strategy of the European Union and its Member States, as coordinated by the Joint Action to support the eHealth Network (JAseHN) and implemented in the eHealth Digital Service Infrastructure (eHDSI).

It should be a call topic and funding requirement that health ICT research projects and public-private collaborations be required to adopt a clear strategy for semantic interoperability and the adoption of standards, where relevant, such as the use of SNOMED CT and of interface and aggregation terminologies.

2.1.2 How have we arrived at this recommendation?

This first and most important recommendation of ASSESS CT, was reached with very strong consensus across all stakeholder groups.

ASSESS CT case studies showed a clear dependency between the presence of jurisdictional policies\(^5\) and the maturity of terminologies selection processes in terms of dimensions considered, drivers, stakeholder involvement; assessments; follow-up; scope, and re-usability of the solution (see D1.3). It showed as well that a wider semantic interoperability approach, which includes semantic assets like information models, process models, and guideline models, should be taken in account. Similar indications have been derived by the questionnaires, the focus groups results, the revision workshops and the grey literature\(^6\).

The idea of embedding the terminology issue in a clear semantic interoperability strategy was supported by several stakeholders and experts as demonstrated by the evidences gathered from the questionnaires (D1.2) focus groups (D1.2 and D1.3) and expert workshops.

Semantic interoperability is of course important for the EU mobility and internationalization. But also within EU member countries interoperability is essential for future developments such as the smooth transition from inpatient to outpatient care and multidisciplinary care supported by eHealth; the promises of the learning health system and big data. Currently, however, the needed interoperability is mainly lacking.

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\(^{5}\) Policies implies also assigned entities working on semantic interoperability

\(^{6}\) (see e.g., the French or the Swiss reports on semantic interoperability).
2.1.3 What are the actionable implications of this recommendation?

It is important to consider the implementation of a terminological ecosystem in the context of an overall semantic interoperability strategy. There are many complementary elements of an adoption strategy that need to be taken forward at the same time in order to optimise the use of the terminology system and to maximise the benefits from it. This includes determining the priority drivers for advancing semantic interoperability within health care. It is also important to consider whether the drivers are entirely within the border of a single national health system, or if there are particular areas of Member State co-operation (bilaterally, or at a European scale) that can influence and support the adoption strategy.

The implementation strategy needs to include some key decisions about how the different roles of terminologies (reference terminology, user interface terminology, aggregation terminology) will be realised and how these will reflect the words and phrases clinicians and others use in free-text communications or will see on data entry and review screens. Semantic interoperability does not necessarily require the entry of coded data by the user. Natural language processing approaches are becoming more and more powerful to analyse semi-structured or unstructured narratives and represent their content within a standardised semantic framework, at least for population-based use cases.

Budgets will need to be set, and often need to be ring-fenced, for activities, services and expertise that need to be funded and provided at a national level, such as the development of specialised subsets the creation of user interface terminologies, the translations of preferred terms, the development of clinical models and value lists, terminology distribution services, and expertise to support the ICT and health professional communities.

Specific decisions will need to be taken, ideally at a national or European level rather than in a fragmentary way, about key areas of terminology use such as the extent to which post-coordination will be supported. The implementation strategy also needs to determine the measures that will be provided for, and possibly centrally funded, to support wide-scale uptake of the terminology system, within products that capture, communicate and analyse health data, and within repositories and systems that process health data such as registries and reimbursement frameworks. Such measures may include financial incentive packages for the ICT marketplace and for health care provider organisations to invest in technologies and in training to increase the proportion of data that are well structured and coded, and to maximise benefits realisation.

Depending upon the priority scenarios for adoption, not all of the ASSESS CT recommendations will be relevant to each country or region, at a particular point in time. Further work is needed to examine the kinds of decision that need to be taken for different implementation scenarios, and the success strategies that might be of greatest importance for any given scenario.

Member states will have to decide to what extent they will

- promote standards for the structure of EHRs and telematics messages,
- make choices between HL7, openEHR, and EN ISO 13606,
- adopt recommendations of the eStandards project,
- use clinical building blocks, CIMI and FHIR models, and the IHE Profiles

Member States will have to ensure that the value sets of the accepted information and clinical models in the country are bound to international aggregation terminologies and reference terminologies. Ideally, local terms that constitute value sets should be part of national user interface terminologies.
2.2 Second recommendation

SNOMED CT is the best available core reference terminology for cross-border, national and regional eHealth deployments in Europe.

2.2.1 Further elaboration of the recommendation

ASSESS CT proposes SNOMED CT as the best available core reference terminology for cross-border, national and regional eHealth deployments in the EU, including its use for the European eHealth Digital Service Infrastructure (eHDSI). Please see section 1 of the report for definition of a reference terminology.

A main advantage is its content coverage, which is superior to any other terminology. This makes it the most complete point of reference for health related concepts. It is assumed that a semantic interoperability strategy as referenced above will necessitate larger sets of terminology content, making content coverage an important factor. In its role of core terminology SNOMED CT acts as mediator for supporting cross-domain scopes. SNOMED CT has a single license provider and leads over a set of other clinical terminologies with its single ownership and its single, principled ontology-based architecture and with a logic-based coordination syntax.

A single source for the core terminology will avoid the complexity of scope overlap, multiple licences, different change management approaches and release cycles.

However, it must be recognised that the evidence base for the effectiveness of the use of SNOMED CT in patient safety and decision support systems is slim, as systematic reviews on this issue indicate that other standardised terminologies or non-standardised proprietary terminologies were used in systems evaluated by randomized clinical trials.

2.2.2 How have we arrived at this recommendation?

Through workshops, focus groups and questionnaires, ASSESS CT has identified a set of key drivers for national adoption of a large-scale terminology as part of an overall strategy for semantic interoperability. These drivers include (i) Better quality and safety of care to individuals, (ii) Enriched EHR data exchange for continuity of care, (iii) Cost reduction, (iv) Optimising reimbursement, (v) Analysis (secondary) uses, and (vi) Cross-border information and knowledge sharing (see annex 1 for full description).

Naturally, exchange of information across national, linguistic, and institutional borders to support cross-border healthcare rights of EU citizens is an important driver for a European core reference terminology. However, it is noted by ASSESS CT informants that, to be viable, any cross-border effort needs to be aligned with in-border needs for semantic interoperability. Thus, national priorities are highly important for the European core reference terminology as well.
Cross-border health care, biomedical research, disease reporting, drug safety and patient safety require a sharable language to communicate and aggregate data across linguistic and national boundaries. The availability of a “centrally curated reference terminology, allowing local extensions” has been the most frequently suggested solution for overcoming the issues identified for cross-border exchange of patient data by stakeholders responding to the issued questionnaire (see D1.4 appendixes for final results).

This potential role was recognised by the very large majority of questionnaires respondents.

With a view to the eHDSI under CEF, the appropriateness is recognised of the terminology selection criteria defined in epSOS and the role of SNOMED CT as reference terminology for the concept domains\(^7\) for which SNOMED CT was selected, with potential for its extension to other domains.

An exercise was made to first define criteria\(^8\),\(^9\),\(^10\) for the choice of a core reference terminology for Europe, and then confront the characteristics of SNOMED CT with this list of criteria.

What characterize a good candidate for a core reference terminology in Europe?

The distinction can be made between internal and external criteria.

**Internal criteria**

- Provides representational units (“concepts”) in sufficient granularity across all areas of health care and of biomedical research
- Is explicit regarding scope
- Is independent regarding language, but supports the connection to language and context specific vocabularies
- Provides precise definitions of all representational units (“concepts”)
- Has a compositional architecture that allows fine-grained representations
- Can be harmonised with other terminological and semantic interoperability assets in use
- Is governed by a non-for-profit body that is controlled by end users and stakeholders and can provide a forum for terminology knowledge sharing and collaboration
- Catches up with the progress of the domain by periodic updates
- Meets quality criteria for standards
- Supports sophisticated navigation and post-coordination

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\(^7\) Concept Domain is a named category of like concepts (semantic type) that will be bound to one or more coded elements (e.g. Human language). In the context of eHDSI each concept domain correspond to a specific Value Set in the MVC.


• Follows current specifications for semantic interoperability assets
• Is supported by user-friendly tools and is easily implementable
• Supports computer processing and is rooted in a rigid, understandable upper-level model
• Has a maintenance process

External criteria

• Internationally used in other continents
• Criteria also identified in cross-border use cases (epSOS Patient summary)
• In use in EU Member States
• Existence of translation in different mapping services
• Cost of licenses, implementation and maintenance
• Compliance with the EU Regulation No 1025/2012 of the European Parliament and of the Council of 25 October 2012, on European standardisation, Annex II: Requirements for the Identification of ICT Technical Specifications

Quality assurance processes should be put in place to assure that all concepts are univocally understandable across users and languages. This requires a principled choice of the fully specified names and preferred terms, correct formal definitions and if necessary scope notes, as well as consistency between these three sources of meaning.

How does SNOMED CT meet these quality criteria?

• SNOMED CT is an international standard, maintained by a not-for-profit SDO (IHTSDO), which has countries and corporate users as members.
• SNOMED CT’s goal is to represent the electronic health record content. Fine-grained representations are guaranteed by its huge size as well as by a compositional grammar that facilitates composition of complex descriptions. This formalism can be translated into logic.
• SNOMED CT has its scope well delineated and establishes interfaces to supplementing terminologies that, together, form a set of reference terminologies for which SNOMED CT acts as core.
• SNOMED CT is open to be used in whatsoever linguistic context. It provides fully specified (maximally self-explaining) names in English and Spanish, which facilitate translations to other languages and the linkage to (sub-)language and (sub-)domain specific user interface terminologies.
• SNOMED CT clarifies the meaning of all representational units ("concepts") by three mechanisms: (i) fully specified names in English and Spanish, (ii) formal definitions using description logics, and (iii) English language text definitions (scope notes), still to a minor degree, but increasing.
• SNOMED CT is intricately linked to the Universal Medical Language System (UMLS) of the US National Library of medicine, and hence also to the main medical thesaurus for bibliographic information retrieval in the health sciences, Medical Subject Headings (MeSH)
• IHTSDO actively pursues harmonisation activities with other reference terminologies such as LOINC, and aggregation terminologies, such as ICD and ICPC, as well as with information model formalisms. In all of these cases SNOMED CT attempts to provide the basic ontological building blocks that allow to state equivalences to codes

SNOMED CT is regularly updated. SNOMED CT has an open and robust maintenance process, which obeys high quality standards. Backward compatibility is guaranteed through the release format RF2.

SNOMED CT increasingly follows specifications of the Semantic Web, regarding the management of identifiers as well as the compliance with syntactic and semantic specifications.

IHTSDO has recently put increasing effort on user-friendly tools, as exemplified by the SNOMED CT Web browser.

SNOMED CT is rooted in the concept model, a rigid upper-level framework, which continuously adopts ontological principles. This concept model also provides the basis for concept coordination and machine reasoning to detect subsumption and equivalence.

SNOMED CT is internationally used (North America, South America, Europe, Oceania, Asia)

SNOMED CT, with the conditions described in the WP1 assessment, is in (partial) use in several EU Member States.

SNOMED CT provides official translations in different languages for important subsets of terms.

No non-compliances have been identified in the assessment of the “EU Regulation No 1025/2012 Annex II: Requirements for the Identification of ICT Technical Specifications” even though further clarifications are needed in particular for the criteria 4-b “specifications are publicly available for implementation and use on reasonable terms (including for a reasonable fee or free of charge)”12.

Costs of licenses, implementation and maintenance has to be carefully evaluated in dependence of the purpose, the context, the scenario of use and on the type of agreement negotiated or applied in that context in relation to the scenario of use13.

The implementation complexity of SNOMED CT should be addressed14

The only other terminology that provides a single-source coverage of the whole medical domain is MeSH, which is oriented towards bibliographic information retrieval and not enough fine-grained for clinical documentation.

The WHO Family of Classifications (ICPC, ICD, ICHI, ICF, ATC) provide also a good coverage, under the governance of a single authority. These classifications have been created for specific use cases, which explain their architecture, which favours aggregations at the expense of granular description, and which does not facilitate multiple hierarchical contexts.

The ICD classification is geared towards the global collection of morbidity and mortality statistics, which is today operational world-wide. Virtually all current data collection efforts for drug utilization monitoring function with the ATC. Before these data collection systems can be replaced, the suitability of SNOMED CT for epidemiological research needs to be better documented.

ASSESS CT has shown that SNOMED CT already has a very high coverage of concepts used in clinical documentation artefacts15. This is consistent with pre-existing studies.

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12 See D1.4 § 13 for more details.
13 As widely described in the WP1 conclusions (D1.4)
14 See D1.4 conclusions for more details
15 See D2.3
SNOMED CT’s conceptual coverage, measured in samples of clinical information models, was significantly higher than the coverage of an alternative scenario, constituted by other, commonly used terminologies. If concept coverage is measured for clinical text samples, and the alternative is extensively expanded, there was no significant difference between the two scenarios. In contrast, the investments associated with an alternative terminology are, in light of the above, significant.

**What are the weaknesses of this choice?**

The current use of SNOMED CT in regional/national scenarios is in general limited. There is a low availability of evidences, best practices, or examples on its usage at the European level. This also limits the capability of providing a thorough evaluation of the potential consequences of SNOMED CT adoption. With some exceptions, the feedback collected indicates a low maturity of the EHR system market and a low adoption level by MS and end users for the use of SNOMED CT, although some progress has been made in the last years.

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 this change have not yet been evaluated or experienced completely. About 7000 globally free DICOM terms have been integrated in SNOMED CT\(^\text{16}\). Furthermore, the IHTSDO membership fee model could allow charging each member less as the number of members increases making European coordination efforts even more effective in reducing cost. Special agreements have been negotiated for evaluation or start-up purposes such as in the case of Switzerland and Norway; and free licenses can be obtained for research purposes.

The direct costs of adopting SNOMED CT (e.g. licensing costs) only constitute a small part of the overall costs. There is the initial knowledge investment to overcome a steep learning curve. Moreover, the organisational cost for setting up and maintaining national release centres, 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. In other words, many countries and organisations may face a lack of knowledge and expertise regarding SNOMED CT.

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) have to be identified and addressed in order to overcome them or hide the complexity of SNOMED CT to the users.

In conclusion, the evaluation is strongly context-dependent and should take into account at least the purpose and the scenario of use and the type of agreement negotiated or applied in the related context.

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\(^{16}\) Other similar agreements are on the way with other SDOs e.g., HL7, IHE, etc.
2.2.3 What are the actionable implications of this recommendation?

Further research is needed to decide whether SNOMED CT, as a core reference terminology, will be the principle means for representing clinical content of guidelines and of quality indicators.

Regarding IHTSDO, further work on SNOMED CT should prioritise:

- The alignment with semantic standards (Semantic Web),
- The revision of several subhierarchies with known issues (e.g., qualifiers, procedures),
- The identification of content that is only understandable in a national context,
- The identification of content that duplicates (or competes with) other existing standards or resources (geographical entities, professional roles, drugs, devices),
- The identification of content hitherto underspecified, which requires elucidation by textual scope notes or formal definitions,
- The role of the SNOMED CT context model, its ontological foundation and its relation to information model formalisms (e.g. HL7) and architectures,
- The revision of IHTSDO's licence policy, thus lowering the threshold for SNOMED CT trial and pilot use activities; and for non-native-English-speaking countries, for which the adoption process will be more costly

Concerns about SNOMED CT licence costs must be considered in the context of the total costs of accessing and deploying a semantic interoperability infrastructure. There should be collaborative European efforts to demonstrate the economic value of implementing SNOMED CT through evaluations and the sharing of evidence on national costs and benefits, pooling of resources, to support decision-making within Member States.

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.

In this context, it is suggested that more objective and measureable criteria will be defined for the evaluation of the “reasonable terms” defined by criteria 4-b of the EU Regulation No 1025/2012 Annex II: Requirements for the Identification of ICT Technical Specifications” and, based on them, that EC supports negotiations on agreements with IHTSDO on the development and licensing of semantic interoperability assets such as terminology subsets, to provide a transparent, legally acceptable and affordable basis for terminology usage.

It is crucial to demonstrate that language-specific user interface terminologies can be combined with SNOMED CT, even though SNOMED CT is not available in these languages, and that tools to support this process have been build.

Unlike other clinical terminologies, SNOMED CT has an ontology-based post-coordination mechanism, which allows not only building precise compositional expressions that permit a similar coverage as what is possible with natural language, but also maintaining precise semantic links with the constituting SNOMED CT concepts. Further work is advised to agree a European consensus on the extent to which post-coordination will be used, in order to balance the expressivity this empowers with the burden on users and ICT product vendors to implement solutions to create, export and import post-coordinated data.
2.3 Third recommendation

SNOMED CT should be part of an ecosystem of terminologies, including international aggregation terminologies (e.g., the WHO Family of Classifications), and including national user interface terminologies, which address multilingualism in Europe and clinical communication with lay language and multidisciplinary professional language.

2.3.1 Further elaboration of the recommendation

No terminology has the potential to cover all interoperability needs alone. Cross-border services require the selection of terminologies that meet several requirements, guaranteeing that a set of terminologies remains stable even if it supports an increasing number of services and use cases.

Neither SNOMED CT, nor any other terminology, even limiting the scope or the domain, can be the “only” solution. There is a need for a terminology ecosystem that may include several kinds of health care terminologies (e.g. user interface terminologies, aggregation terminologies).

The need for concomitant use of aggregation terminologies and SNOMED CT for legacy preservation and conversion

Most of the historical coded clinical data is stored with the classifications family of the WHO (ICD, ICPC, and ATC). Elaborate mappings between SNOMED CT and these aggregation terminologies have been constructed, but the application of these mappings for retrieval of coded information Intensive with systems, only based on SNOMED CT need to be further developed.

The long-standing historical data collection series for morbidity and mortality statistics, based on ICD, and the drug utilisation monitoring programs (e.g. Surveillance of Antibiotic Consumption), based on the ATC classification necessitate a smooth transition and probable concomitant use of heterogeneously classified data for still a number of years.

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17 Even when the usage scope is limited to a single domain (see e.g., the Laboratory case assessment in D1.3)
18 see the role of MVC/MTC in the epSOS case assessment D1.4
The need for concomitant use of aggregation terminologies and SNOMED CT for epidemiological purposes and quality indicators

Clinicians and researchers still need to be convinced that the current international classifications (or aggregation terminologies) used in epidemiological research, for coarse and somewhat fine-grained coding of reasons for encounter, symptoms, diagnoses, and causes of death can be successfully replaced by the use of SNOMED CT or by mapping solutions. Current quality indicators for evaluating prescribing operate also on the classical classifications for drugs and diagnoses. Until formal evidence for the effectiveness of SNOMED CT–only solutions is provided, reluctance to let go of established methodologies and fear for disruptive effects of longitudinal data collections will prevail. User interface terminologies and sophisticated terminology binding to several terminologies concomitantly may gradually induce trust in newer systems.

The need to build user interface terminologies in the native language of the health care actors

One known weakness is, nevertheless, the lack of SNOMED CT translations into many European languages. Indeed, for several languages like German, French or Dutch, local terms are currently better covered by other terminologies than by SNOMED CT. However, these terms are often locked in national terminologies (such as, e.g., for procedure coding), so that they do not contribute to cross-border interoperability.

In other languages into which SNOMED CT has been translated, there is no good coverage of the clinical jargon as preferred by clinicians. However, this gives rise to an opportunity, viz. the compilation of national, regional, domain-specific user interface terminologies, which are controlled by user groups and linked to the core reference terminology.

The richness of clinical language across Europe is prohibitive for whatsoever monolithic approach. SNOMED CT as a core reference does not mean that it will serve as a centralised container for clinical language expressions in 24 official languages. On the contrary, SNOMED CT should play the role of a hub, to which user interface terminologies and value sets from different provenances, in different languages and dialects, serving a variety of user needs are connected.

It is clear than merely translating SNOMED CT fully specified names and preferred terms does not solve the problem of patients and professionals who do not speak English or are not native speakers. However, this translation might be useful for the most commonly used concepts, but would not need to be exhaustive.

As such, national terminology building efforts should be seen as decentralised bottom-up activities, starting with a systematic collection of commonly used words and phrases in daily communication between patients and health professionals. In addition, input could come from commonly agreed value sets that fulfil priority use cases, each of which corresponding to a SNOMED CT subset, possibly with mapping to currently used international classifications.

International cooperation is crucial to focus the efforts on what is essential e.g., starting the acquisition of multilingual user interface terms from the most frequently used terms, learned
from experiences of other countries. The option of a de-novo construction of a European core reference terminology may be tempting for a small set of concepts. However, the more such an artefact grows, care should be taken that this not leads to a duplication of the content and maintenance efforts of SNOMED CT.

Consolidating SNOMED CT as a European core reference terminology is therefore an opportunity for having a central common ground in which multiple (interface) terminology building activities can be anchored.

**The need to build user interface terminologies rooted in the language of health care professionals**

A core reference terminology such as SNOMED CT is limited to represent normative and ontological aspects. Concept labels (fully specified names) should be as self-explanatory as possible, regardless of whether they qualify as good user interface terms. Close-to-user (interface) terms, short forms, meaning contexts, as well as morphological features of words are not part of reference terminologies, which explains the need to use reference terminology together with user interface terminologies.

While building user interface terminologies specific standardized linguistic resources exist for the management of words and phrases, with their synonyms, acronyms, variations, deflections, dialects. The ISO-norm for multilingual terminologies (Lexical Markup Terminology) can be used for this purpose, as demonstrated in the project BabelNet.

**The need for user interface terminologies in the language of patients**

Coded clinical documentation must be interpretable by all stakeholders including the patients and their families, for patient safety, engagement and empowerment, and to avoid care duplication. As a consequence, user interface terminologies must consider both lay language and professional words and phrases in the native language of patients and caregivers from various disciplines. Addressing the issues of multilingualism in Europe is a key policy in the European Union. A number of European Research Projects have clearly demonstrated the importance of this aspect for social inclusion. Exploiting the pivotal role of the core reference terminology can facilitate the communication between patients and health care professionals, at least at the lexical levels.

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19 Suggestions from the US experts during the 2nd experts meeting, request coming also from several focus groups discussions. See D1.4


21 http://www.lexicalmarkupframework.org/


23 www.babelnet.org


25 MIME Project: Mobility and Inclusion in Multilingual Europe: http://www.mime-project.org/
While SNOMED CT possesses many of the properties of an interface terminology, this is not necessarily what the user interacts with at the human/computer interface. All sorts of clever/tailored options are possible with user interface terminologies/technologies and as long as the SNOMED concept is also stored or referenced then all is well.

This obviously requires a managed relationship between the user interface, on the one hand, and the core reference terminology and international aggregation terminologies, on the other hand, with a number of opportunities for national and supra-national management efforts, possibly under an European Terminology Coordination Point).
The key role of ICT-departments within the health care organisations of primary, secondary and tertiary care

Healthcare organisations typically have ICT-organisations for managing both the strategic decisions in information management and the day-to-day work with keeping their healthcare information systems supplied with standardized and updated terminologies. Often, these organisations have responsibility not only for terminology, but for all kinds of semantic artefacts, including information models, and possibly workflow models or guidelines.

These organisations will be responsible for bringing the mappings to the core reference terminology of this eco-system to provide a reliable link to national and international aggregation terminologies (e.g., ICD, procedure classifications, and DRGs), in support secondary uses and administrative processes (e.g., reporting and reimbursement).

They will act as mediators between the end users and the national terminology centres and eHealth Platforms, and are advisors in the process of procurement of information systems from vendors.

Their key role should be acknowledged at the national and European level.

The role of the vendors

Vendors are at the forefront of technological development and their decisions on system architecture and coding systems shape the (in)ability to communicate between proprietary systems. Vendors have often build a strong relationship with customers in user groups, and hence in close encounter with their end users. They have been responsible for the end user interface in their systems. Vendors cannot be expected to bear the licence costs of international terminologies and the maintenance cost of linguistic resources for end user support in 24 European Union languages. Support for their crucial role and a strong voice in the governance of the SIOP strategy is needed.

The Role of the European scientific associations of health care providers

In the past years, many sub-disciplines of healthcare providers have created strong European associations, involved in cross-national research projects, guideline development and quality assurance. These associations can represent the professional end users of the new terminology ecosystems, and provide important contributions to domain-specific ontologies and terminological resources, and play a very active role in the adoption of a core reference terminology, spanning the different disciplines.

2.3.2 How have we arrived at this recommendation?

Input from this recommendation came from the deliverables of SemanticHealthNet26 and from the ASSESS CT policy workshops on the possible drivers of semantic interoperability.

26 These can be found at http://www.i-hd.eu/index.cfm/resources/ec-projects-results/semantichealthnet/
2.3.3 What are the actionable implications of this recommendation?

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) and the binding of the selected terminologies to these models (including implementation challenges) are key elements as well.

A European semantic interoperability strategy should support efforts that assure that a set of international aggregation terminologies is tightly connected to the core reference terminology and national user interface terminologies.

The creation and maintenance of artefacts that harmonise between different terminologies must be supported at the appropriate level (national, language-specific, European, international), orchestrated by a European-level terminology coordination mechanism.

Quality benchmarks must be developed and embedded into the terminology maintenance cycle. This includes feedback loops from terminology users to the terminology creators that must be implemented and their use encouraged.

Investment is needed in scaling up the development of clinical models that have been agreed by clinicians, represented using one or more of the existing international standards, having good coverage of high-priority clinical areas for shared care, and being consequently linked to reference terminologies. This requires creation and enforcement of strict terminology use and binding rules.

Candidate priorities for terminology harmonisation are:
- to support a consistent representation of patient trajectories with cross-professional boundaries (e.g., primary care, specialist medicine, nursing, social care),
- to develop point-of-care evidence summaries, quality indicators, and decision support systems
- to facilitate and enhance the use of reimbursement terminologies, to reduce missed claims and financial up-coding.

There is a need to invest more in sophisticated guidance and quality assurance methods, and to learn from past experience, to ensure high quality of the adopted terminology product(s). Also, there is a need to support research and the development of tools that aim at improving the precision of manual and automated code assignment. By extension, expertise and an educated workforce need to be developed in regards to terminologists, specialists in human language technologies and human-machine interfaces, clinical modellers and others which are enabled by clinical end user training, coding staff and data analyst training.

The access to national user interface terminologies needs to be smooth and fast, and in several formats (e.g., SQL and XML databases and semantic web triple stores). Usability and end user satisfaction are critical factors for the acceptance and adoption of all kinds of terminologies. This implies several aspects such as the availability of tools that
facilitate the use of the terminology, awareness about benefits, and effectiveness in the real business (i.e. clinical) processes through proof of concept demonstrators27.

2.4 Fourth recommendation

The adoption of SNOMED CT should be realised incrementally rather than all at once, by developing terminology subsets that address the interoperability requirements for prioritised use cases, and expanding this set over some years.

2.4.1 Further elaboration of the recommendation

The introduction of SNOMED CT would need to follow a stepwise, incremental approach (which is also preferred by countries that previously adopted a top-down approach like the UK), based on use cases coherent with a general semantic interoperability strategy.

Pilot use cases address domains that are inadequately covered by semantic assets and that can provide perceivable advantages28. The piloting costs must be commensurate to the scope of these projects, and a realistic investment should be planned29.

Incremental - as opposed to iterative - means that each pilot use case must be complete and lead to benefits in itself, e.g. coverage studies do per definition not demonstrate benefits for anyone. Pilot use cases should ideally include implementation in software, use of terminology in clinical practice and for secondary purposes as well as evaluation of cost and benefits compared to expectations.

The specification for a restricted set of business processes is much easier than trying to accomplish it for healthcare as a whole.

Incremental does not mean that growth is not governed. Introduction plans take into account the overarching interoperability goals and the identified strategies, in order to avoid that too focused use case based solutions will be progressively adopted leading to an overarching incoherent solution.

Figure 2 below illustrates example steps that might be considered for a national roadmap towards the adoption of SNOMED CT, as part of a holistic process towards achieving better semantic interoperability.

27 Supported by reports from the focus groups, especially the Croatian, the French, and the Portuguese ones.
28 See e.g., the Portuguese focus group reports
29 See e.g., questionnaires and French focus group
2.4.2 How have we arrived at this recommendation?

The intense discussions in the ASSESS CT Policy Workshop, responses from questionnaires highlighted the complexity of the adoption process of SNOMED CT and the dangers of a hasty and ill-prepared strategy to full implementation. Feedback from early implementation experiences from Sweden, Denmark, and Portugal reinforced the preference for an incremental approach.

2.4.3 What are the actionable implications of this recommendation?

The benefits of national and terminology eco-systems need to be demonstrated in research programs with regard to clinical and administrative decision support, patient safety, healthcare analytics and secondary use scenarios. National and European research funding organisations should consider commissioning evaluation programmes of innovative step-wise approaches.

The introduction of SNOMED CT needs to be supported by actions that raise awareness, together with education initiatives about semantic interoperability, terminologies and SNOMED CT, and by information about value-added for organisations, healthcare provider, and health authorities. User acceptance requires that terminology resources are easily available in a standardised format.

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30 Recommended: Semantic Web formats like SKOS, OWL, Linked Data
2.5 Fifth recommendation

Mechanisms should be established to facilitate and coordinate European Member State co-operation on terminology and semantic interoperability, including common areas of governance across national terminology centres, eHealth competence centres (or equivalent national bodies).

2.5.1 Further elaboration of the recommendation

ASSESS CT proposes that mechanisms be established to facilitate and coordinate European Member State cooperation on semantic interoperability, including common areas of governance across national terminology centres and eHealth competence centres (or equivalent national bodies) and pilot projects supporting common priorities. Also, it is crucial that facilities are made available to ensure coordinated development and maintenance of shared EU interoperability artefacts, including any SNOMED CT subsets or extensions (e.g. the extension to the EU cross border subset).

eHealth terminologies, associated clinical information models and other semantic interoperability assets should be publicly available for implementation and use on reasonable terms (including for a reasonable free or free of charge) to the ICT industry and to healthcare providers, right across Europe, to enable semantic interoperability to underpin cross border health services.

EU level use cases provide an excellent opportunity for creating jointly many of the artefacts needed to support the use case and leaving the localization end to each MS.

2.5.2 How have we arrived at this recommendation?

Requests for enforcing international cooperation on specific topics have been collected from questionnaires, focus groups, case study assessments (see e.g., the request of having focus groups on Lab and Pathology domains) and during the workshops (see the policy workshop and the EU-US experts meeting). Several inputs have been moreover gathered (see e.g. case study assessment results; US experience) about the need of having defined processes and assigned entity for governing terminology and support the operational management of the semantic assets.

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2.5.3 What are the actionable implications of this recommendation?

In order to evaluate the impact of the introduction of any core reference terminology, and to plan the right actions in 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 after that, the impact on the other “technical” aspects (e.g. the impact on application and technical infrastructures) could be evaluated.

The distributed, collaborative, use case driven development of local, language and discipline-specific user interface terminologies is a new area which poses challenges in education, organisation and tooling.

European scientific associations of primary care physician, allied health personnel, and medical specialists should be encouraged and supported to explore the relevance of the core reference terminology to their discipline and to integrate with their existing specialised reference and aggregation terminologies.

Competencies relevant for a terminology coordination point include biomedical informatics, medicine and healthcare, computer science, linguistics, and language translation.

National Terminology Centres are needed to make consistent terminology decisions that will influence semantic interoperability, including decisions on use of terms, representation of meaning, terminology binding to other semantic artefacts, as well as for value sets. Therefore, these organisations will need to have the mandate to make such decisions as well as the competencies to assure the quality of the outcome of the decisions.

In this context, the EU could invite standard development organisations (SDOs) to play a critical role in supporting that vision by reducing conflicts and gaps among terminologies, and enabling cooperative usage of multiple terminologies, as initiated in the eStandards Project.32

The EU might consider to fund exchange programs for capacity building for terminology projects.

A short term action plan with regard to eHealth Digital Service Infrastructure (eHDSI), funded by the Connection Europe Facility (CEF) is needed to promote the existing cross-border initiatives (ePrescription, Patient Summary, Registries of Rare Diseases), and later cross-national data collection projects such as the promotion of multinational clinical studies, clinical registries, pharmacovigilance, drug utilisation monitoring, etc.

It is the responsibility of each Member State to establish and execute a coherent semantic interoperability strategy, including the creation of an integrated national eHealth Infostructure with a terminology ecosystem, and cooperation in the European Cross Border Initiatives. Each Member State should decide on the pace of the incremental implementation of its terminology infrastructure.

User interface terminologies should be built for the official languages in each Member State, integrated with the core reference terminology for Europe, SNOMED CT. A national

32 http://www.estandards-project.eu
Terminology Centre should act as Release centre for SNOMED CT but also take on governance for other international aggregation terminologies, used in the country, including the mappings to SNOMED CT. Re-engineering of terminologies used for reimbursement should allow secondary use from clinical data. Mechanisms for legacy conversion and preservation should be in place, to assure continuity in clinical documentation and longitudinal epidemiological data collection. Competences from various disciplines should be mobilised to stimulate research product development, promotion and education in the user-friendly, correct use of the fine-grained clinical documentation. In all settings of health care (primary care and hospitals), and multi-disciplinary communication between health professionals and with the patients. An infostructure for the promotion of evidence-based clinical practice at the point of care and patient safety, based on guidelines and decision support systems should be in place. Each Member State is advised to reflect on the possible drivers for semantic interoperability (see annex), and prioritize among these drivers, in cooperation with the stakeholders in the country, including the vendors, and the ICT departments of the health care institutions.

The responsibility of the European Union and the European Commission is to support the Member States in their common quest for semantic interoperability in health, by promoting the importance of terminologies as cornerstones of interoperability and establish strong links with standards development organisations. The EU can organise high-level concertation between stakeholders across Europe, bringing together the creators and users of health information with industry, standards developers, clinical research communities and healthcare funders.

Legal advice is to be taken on the mechanisms for the EU to support the Member States in the representation and governance of IHTSDO.

The European Union could support the maintenance of a shared inventory of terminology and SIOP assets.

The European Union could harness the power of its very strong translation and interpreter capabilities to help Member States to develop sophisticated interface terminologies.

The need for coordination and expertise at the EU Level

The achievement in Europe of semantic interoperability in health requires the combination of a highly technical medical informatics approach, an orientation towards semantic web techniques and ontologies, a deep linguistic approach and respect for multilingualism.

Care should be given to avoid the multiplication of governance bodies. However, the complexity of the issues at stake in SIOP and more specifically in terminology in multilingual Europe may require a dedicated Terminology Coordination Point at the EU level in order to assist in the operationalization of high-level governance decisions.

This Coordination Point could be a voluntary effort of Member States, supported by the EU. A European Terminology Coordination Point could capitalise on the experience in Member States and assure sharing and exchange of research findings, best practice experiences, multidisciplinary expertise and build.

33 http://www.estandards-project.eu
The Member States in which one of the three working languages of the EU (English, French, German) is an official language, are well placed to take an initiative in this matter.

**2.6 Thematic overview of the recommendations supporting adoption of SNOMED CT as a core reference terminology in Europe**

In the following chapter comments on the ASSESS CT recommendations have been reorganised in a summary per theme.

**2.6.1 Terminologies for different functions**

SNOMED CT should be adopted as the core reference terminology in Europe. Its core status is justified by its size, coverage, and the fact that it relates to other specialised reference terminologies. Such other reference terminologies may cover geographic terms, professional roles, laboratory investigation results, drug and other product names and –omics and proteomics terms.

Neither SNOMED CT, nor any other terminology, can be the only widely adopted terminology, as none is comprehensive enough, and due to the extensive existing use and value of other terminology systems such as the aggregation terminologies produced by the WHO, tailored to specific use cases.

The European reference terminologies should be related to national and international aggregation terminologies used for incidence and prevalence reporting, benchmarking, comparisons and trends, reimbursement etc. such as to ICD, DRGs.

User interface terminology solutions (close-to-user terms, short forms, meaning contexts and morphological features of words) will need to be adopted or developed for each European language, and mapped to the European core reference terminologies. User interface terminology development should occur in a bottom-up fashion, prioritising cross-border and cross-language use cases.

**2.6.2 Complementary requirements and choices for information models, message models**

The semantic interoperability (SIOP) strategy should cover semantic assets such as information models, process (workflow) models, clinical guideline and decision support models, in addition to choices and usage of terminologies.

It is essential to coordinate the use of terminologies of different kinds with the development of information models, message structures, clinical models, and templates. Attention should be paid to the harmonisation of these models meeting the requirements of different health professions.

Large-scale activities between EU-wide terminology implementation and the various projects that develop information models need to be coordinated, quality assured and governed by a centralised organisational entity.

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34 https://en.wikipedia.org/wiki/Omics
Implementation guides for the binding of reference terminologies to clinical models should be developed and promoted.

Research and development initiatives need to be funded to elaborate on the interfaces between different semantic assets, like terminologies, clinical models, process and guidelines models.

Research and development initiatives need to be funded to elaborate on the use of reference terminologies inside healthcare information systems, to implement or enhance EHRs, clinical decision support systems, analysis toolboxes, and other similar systems.

2.6.3 Ontology resources to be developed or adopted

Terminology harmonisation methodologies must build on current work and should be based on open standards and ontological principles. This includes (i) query-based approaches for aggregation terminologies, using a query language like the IHTSDO expression constraint language, and (ii) ontology-based approaches, using semantic web languages to govern the mapping to other reference terminologies (e.g., LOINC).

Relevant parts of SNOMED CT should eventually become the reference ontology for other, widely used terminology systems.

SNOMED CT’s ontological building principles should be harmonised with principles elaborated by ontology engineering activities within the broader field of ontologies for biomedical research.

2.6.4 Clinical model development/adoptions, binding to terminology

Investment is needed in scaling up the development of clinical models that have been agreed by clinicians, represented using one or more of the existing international standards, having good coverage of high-priority clinical areas for shared care, and being consequently linked to reference terminologies. This requires creation and enforcement of strict terminology use and binding rules. SNOMED CT’s context hierarchy should be overhauled under these aspects.

The priorities for the content of terminology core sets and for the development of clinical models etc. must take into account the high-priority clinical areas for shared care and patient safety.

The scientific communities engaged in guideline development, care pathway construction and decision support should be engaged in a multidisciplinary effort to align terminologies, clinical models and processes around the complex patient with multi-morbidity.

2.6.5 Approach to the extent of post-coordination to be endorsed

Unlike other clinical terminologies, SNOMED CT has an ontology-based post-coordination mechanism. This mechanism allows building precise compositional expressions, which permit not only a coverage similar to what is possible with natural language, but also maintain precise semantic links with the constituting SNOMED CT concepts.

Further work is advised to agree a European consensus on the extent to which post-coordination will be used, in order to balance the expressivity this empowers with the burden on users and ICT product vendors to implement solutions to create, export and import post-coordinated data.
2.6.6 Developing extensions, subsets, RefSets and value sets

The SNOMED CT coordination mechanism allows the shaping of use case specific extensions, subsets, and value sets (using the specifications for SNOMED CT RefSets), which are fully interoperable with the core of SNOMED CT and bound to information models.

2.6.7 Terminology harmonisation: defining and maintaining cross-mappings to existing and legacy terminologies in use

A candidate priority for terminology harmonisation is to support a consistent representation of patient trajectories with cross-professional boundaries (e.g., primary care, specialist medicine, nursing, social care).

A candidate priority for terminology harmonisation is to facilitate and enhance the use of reimbursement terminologies, to reduce missed claims and financial upcoding.

For all harmonisation activities, incremental change is encouraged, especially for the use cases where the impact is largest.

2.6.8 User interface terms, language translation and quality assurance

International cooperation is crucial to focus efforts on what is essential e.g., starting the acquisition of multilingual user interface terms from the most frequently used terms, sharing experiences of other countries.

Coded clinical documentation must be interpretable by all stakeholders including the patients and their families, to enhance patient safety and to avoid care duplication. User interface terminologies must therefore consider both lay language and professional words and phrases in the mother tongue of patients and caregivers from various disciplines.

Quality assurance processes should be put in place to assure that all concepts are univocally understandable across users and languages. This requires a principled choice of the fully specified names and preferred terms, correct formal definitions and if necessary additional scope notes, with consistency between these three sources of meaning to be ensured.

The creation of language, user, and use case specific user interface terminologies linked to SNOMED CT, should be given priority over complete translations of SNOMED CT across additional European languages. A bottom-up evolution of user interface terminologies linked to SNOMED CT needs to be stimulated.

User interface terminologies must be treated as being descriptive, not prescriptive: they are not extensions to reference terminologies but separate artefacts that capture the language expressions used across users, clinical specialties, institutions, languages, dialects, and jurisdictions over time.

A robust content model for user interface terminologies is needed, taking into account multiaxial contextualisation, change and ownership management, addressing the complete range of clinical disciplines (starting with primary care, nursing, some medical specialist disciplines and patient groups). Such a model should follow existing standards, also incorporating linguistic and morphological features of its lexicon entries.

The current mix of user interface terminology aspects in the synonyms of the international SNOMED CT release should be re-assessed in the light of recommendations given for user interface terminologies as separate artefacts.
Existing expertise of research centres and enterprises that focus on computational linguistics and human language technologies should be capitalised on.

A Europe-wide health user interface terminology network or platform should be created and linked with other initiatives on terminology acquisition.

Content within an international terminology that is only meaningful or understandable in a national context should be clearly identified as such.

### 2.6.9 Legacy data conversion strategy

The effect of transitions to new coding systems on (dis)continuity of historical data trends should be investigated.

It is important to maintain the epidemiological continuity of international mortality and morbidity statistics (incidence/prevalence of diseases).

It is important to assure the ability to go back to examine a patients’ medical antecedents and past clinical data.

This will require the maintenance of historical mappings and hybrid terminology systems for quite long periods of time.

Clinicians and researchers should be informed about the new opportunities from more interoperable systems, with SNOMED as a core reference terminology, for future longitudinal analyses.

National reimbursement terminologies and data specifications for secondary use should be re-engineered into a closer alignment with routine clinical data collection and international reference terminologies, and not the other way around.

### 2.6.10 Terminology version management and distribution

- Version management of all terminology artefacts should consider the need for downward compatibility
- The update of terminologies should not have disruptive effects on the systems that use them
- Distribution mechanisms should reflect the state of the art of web-based software update and maintenance.

### 2.6.11 Terminology tooling requirements

Vendors are currently responsible for design/content of user interface terminologies. They will need national and super-national assistance to provide them (as a common good) with linguistic resources in the 24 official languages of the European Union.

Additional investments are needed for better tools for:

- The creation of subsets and harmonisation artefacts, their maintenance and distribution.
- Accurately binding clinical models to terminology and terminology subsets (e.g. Art-Décor, archetype editors).
- Acquiring, editing, crowdsourcing, maintaining, quality assuring browsing, mapping, and disambiguating user interface terms.
- The enforcement of coding guidelines and improving inter-coder agreement in cross borderer interactions.

**Figure 3:** Tools and services that may be required to support the successful adoption of SNOMED CT as a reference terminology

### 2.6.12 SNOMED CT licensing and license costs

The EC, supported by Member States, should negotiate for a pan-European licence for subsets of SNOMED CT terms required for (an expanding set of) cross-border eHealth services, for capturing, communicating and displaying or processing the terms.

Concerns about SNOMED CT licence costs must be considered in the context of the total costs of accessing and deploying semantic interoperable capability.

### 2.6.13 Terminology governance and evolution

An EU-wide agreement with IHTSDO for the pan-European use of SNOMED CT (including cross-border use) should provide the EU with a corresponding level of influence over IHTSDO decisions, including sufficient representation of non-English language groups in IHTSDO bodies and working groups.

A European governance process for semantic interoperability (SIOP) should be an integral element of European governance, and be put in place via the Joint Action to support the eHealth Network (JAsEHN).

Coordinating this process should be assigned to a operational structure capable of running all the processes to support this EU governance.
The creation and maintenance of artefacts that harmonise between different terminologies must be supported at the appropriate level (national, language-specific, European, international), orchestrated by a European-level terminology coordination point.

A European-level terminology coordination point must also monitor the need for harmonisation with new and existing terminologies in relevant areas for cross borderer interaction.

Quality benchmarks must be developed and embedded into the terminology maintenance cycle.

Feedback loops from terminology users to the terminology creators must be implemented and their use encouraged. An agile process to revise the contents of subsets, possibly within the framework of the pan-European licence agreement, should be foreseen.

2.7 Overview of the recommendations supporting terminology deployment and use at the national level

2.7.1 Deployment strategy and governance

A national terminology strategy should align with, and be part of, a European sound strategy for building and maintaining a semantic interoperability architecture for electronic health records, electronic messages and workflows in cross boarder interactions.

The introduction of SNOMED CT should follow a step-wise, incremental approach, based on (European, national or regional) use cases that are coherent with this European semantic interoperability strategy.

Member States should assure the availability of a wide variety of openly available terminological resources for international work (user interface terminologies, national reference terminologies, international reference and aggregation terminologies, and mappings between them). Guidelines on coding should be included in this harmonised process. National jurisdictional policies (including those assigned to entities working on semantic interoperability) are needed to prioritise the key drivers for semantic interoperability, to incentivise stakeholder involvement, to conduct assessments and evaluations, and to ensure the scalability and re-usability of the approaches taken.

The development of a national user interface terminology (covering the official languages and language variants) should take into account and benefit from a strong European cooperation with other Member States and with European healthcare professional scientific associations.

Healthcare funders can support the development by providing re-engineered reimbursement rules and data specifications for public health etc., and map these to international reference terminologies and to nationally adopted user interface terminologies. Member States should allocate dedicated budgets for the smooth adaptation of national terminology systems regarding reimbursement to the core reference terminology.

2.7.2 Education, training, user acceptance

The introduction of SNOMED CT should be supported by activities that raise awareness, together with education initiatives about semantic interoperability, terminologies and SNOMED CT.
The introduction of SNOMED CT should be complemented by information about its value to organisations including healthcare providers and health authorities. This promotion includes the sponsoring of pilots and proof of concept demonstrators, the promotion of best practices, cost-benefit evaluations, etc. in order to raise user interest, acceptance and satisfaction.

User acceptance requires that terminology resources are freely available in a standardised format.

Data creators (health care professionals, patients) need education and support to understand and accept the importance of high quality recording of clinical data at the point of care.

### 2.7.3 EHR system adaptation

Vendors should have free and easy access to pilot and test versions of adopted terminology systems.

Vendor specific (internal) terminology management and mappings should be stimulated.

Vendors must not be allocated responsibility, or assumed to be responsible, for the production and maintenance of user interface terminologies (in up to 24 languages), or have to take on the license costs for international reference terminologies.

Some examples of good approaches to promoting EHR system adaptation are listed below:

- User interface and application adaptions need to support end-user data entry well: to protect clinical end users from terminological complexity through smart and intuitive data entry technologies. (Note: to achieve higher data quality, it is important to guide clinicians to choose the right terms in their clinical and care context, both in structured data and free text entry.)

- Good care pathway systems are able to analyse the EHR content for a given patient in order to generate personalised alerts, provide prompts, make recommendations on the nature and timing of future care activities and orchestrate multi-actor workflows.

- Good real-time decision support matches between similar semantic representations of clinical data and guidelines/protocols.

- Good integration of documentation and process tools through semantics is targeted at improving care pathway guidance and enabling the analysis of care pathway adherence.

- Good semi-automatic generation of summaries, synopses, extractions and graphics (based on the semantic properties of clinical data) reduces clinicians' workload and can improve the quality and timeliness of shared care communications.

- Good handling of post-coordination is provided in an intuitive way, supported by appropriate user interfaces.

- Good cross-mappings and legacy data conversion is not undertaken by terminologists and data analysts alone: it should be validated by local clinical experts before data are exported so that the context of the data can be carefully preserved during the mapping process.

- Good legacy data migration strategies include the use of natural language processing to enable the use of clinical narratives for administration and analytics.

- Software and interoperability testing needs to be ensured

National semantic interoperability strategies should include incentives for the health record marketplace to align with the national and European strategy for semantic interoperability.
2.7.4 Other legacy system adaptations

Adaptations to reference terminologies should include:

- Disease and procedure registries;
- Central (e.g., national) health activity reporting and reimbursement systems, and international reporting;
- Population health screening and surveillance systems (e.g., infection control, pharmacovigilance).

2.7.5 Developing expertise

Expertise needs to be developed by terminologists, specialists in human language technologies and human-machine interfaces, clinical modellers etc.

Expertise is needed for training of clinical end users, coding staff and data analysts. This requires development of educational material, delivery of education programmes and onsite training, as well as the management of organisational change processes during terminology changeover.

2.7.6 Evaluations and research

There is a need to invest more in sophisticated quality assurance methods, and to learn from past experience, in order to ensure high quality of the adopted terminology product(s).

There is a need to support research and the development of tools that aim at improving the precision of manual and automated code assignment.

There should be eHealth Network-coordinated collaborative European efforts to demonstrate the economic value of implementing SNOMED CT through evaluations and the sharing of evidence on national costs and benefits, to support decision-making within Member States.

2.8 Overview of the recommendations to support and coordinate semantic interoperability and terminology development at the European level

- Promote the importance of terminologies as cornerstones of interoperability and establish strong links with standards development organisations.
- Bring together the creators and users of health information with industry, standards developers, clinical research communities and healthcare funders.
- Support and guide Member States in the (co-operative) construction of language specific end-user terminologies.
- Guide the development of future terminology standards and champion their adoption.
- Design or approve quality processes for reference and user interface terminologies.
- Advise on, and support where appropriate, the development of mappings between existing, institution specific data dictionaries and core terminologies.
- Support managing EU extensions to international terminologies, including content addition and maintenance, support managing terminology artefacts of different kinds: terms, concepts, maps, value sets, terminology bindings.
• Collect and process worldwide experience and learning of success strategies for scaling up semantic interoperability, of demonstrating value and deriving benefits from sharing and analysing semantically interoperable health information.

• Co-ordinate a network of stakeholder communities that collaborate to enable the development and successful adoption of terminology artefacts.

• Demonstrate the value-added of EU-level coordination, and assess economic and health impact, for improved cross-border healthcare provisioning as well as for national implementations and health systems.

• Stimulate the growth and sharing of expertise from biomedical informatics, medicine, computer science, computational linguistics, language translation and information science.

• Promote the need for R&D in smart, interoperable technology solutions.

• Support negotiations on agreements with IHTSDO and other SDOs on the development and licensing of semantic interoperability assets such as terminology subsets, to provide a transparent, legally acceptable and affordable basis for terminology usage.

• Highlight important gaps in the availability of SNOMED CT content and derived assets (such as value lists, translations, tools), and their licensing.

• Promote the use of user interface terminologies and SNOMED CT in EU-funded research projects.

2.9 Recommendations to Standard Development Organisations

The 5 recommendations formulated in ASSESS-CT have consequences for the work of Standard Development Organisations (SDOs), and can be reformulated to a series of specific recommendations to these organisations.

2.9.1 Arising from recommendation 1

1.1 SDOs and other relevant specification developers should each prepare clear and stakeholder-friendly guidance on how their various standards, specifications and profiles that represent or communicate clinical information fit together and can be used concurrently as part of a coherent semantic interoperability strategy, from the perspective of different stakeholder viewpoints and needs.

1.2 SDOs and other relevant specification developers should collaborate to produce an overview of how their different portfolios of interoperability assets align with each other and which ones can be adopted jointly to support different semantic interoperability business functions. This includes the binding of terminology systems to information models and other structured representations of health data.

1.3 SDOs and other relevant specification developers should establish mechanisms that maximise the alignment of their various semantic interoperability assets, within and between development organisations, now and in the future, and that they regularly update cross-organisational guidance to potential adopting stakeholder communities.

1.4 This co-operation should include bodies developing interoperability assets for health and social care, for clinical research and for life sciences data.
2.9.2 Arising from recommendation 2

2.1 Recognising that the primary role for SNOMED CT in Europe may be as a reference terminology, IHTSDO should prioritise maintaining and enriching the content and quality of the ontological underpinning and the concept hierarchies of SNOMED CT.

2.2 IHTSDO should negotiate, with the eHealth network and the European Commission, flexible licence arrangements to support Member States, individual ICT vendors and non-vendor bodies with adopting SNOMED CT as a reference terminology, at varying scales of piloting and actual use.

2.3 In areas where other terminology and classification systems are strong, such as laboratory investigations, medicines, genomics, IHTSDO should seek to align its concept hierarchies with these other systems, as far as possible without compromising on quality, so as to optimise the concurrent use of these other systems alongside SNOMED CT and the development of mappings between them.

2.4 SDOs and other relevant specification developers should seek to evolve their concept hierarchies to maximise alignment with SNOMED CT in areas of relevant cross coverage and adjacent coverage, so as to facilitate the development and maintenance of terminology mappings to a common reference terminology.

2.5 SDOs and other relevant specification developers should collaborate to provide guidance on their generalist and specialist reference clinical terminologies, in order to guide multiple stakeholders on how these different terminology products may be concurrent used, or differentially used for different areas of content coverage.

2.6 IHTSDO, European Member States and the European Commission must prioritise sponsoring more independent research of the benefits and challenges in using SNOMED CT as the principal (core) reference terminology to support health, care and research use cases.

2.9.3 Arising from recommendation 3

3.1 SDOs should collaborate with clinical professional organisations, the health systems of European Member States and with the European Commission in supporting the development and maintenance of end user interface terminologies in the native languages of health and care actors and patients, across Europe.

3.2 SDOs should collaborate with clinical professional organisations, the health systems of European Member States and with the European Commission in supporting the development of clinical models corresponding to clinical guidelines and bound to the SNOMED CT concept hierarchy.

2.9.4 Arising from recommendation 4

4.1 IHTSDO, European Member States and the European Commission must support and fund the development of training resources and adoption support tools (such as mapping tools) to facilitate the wider high-quality adoption of SNOMED CT as a reference terminology; these should be targeted at enabling stakeholders to contribute in each of their roles to better data quality and semantic interoperability, rather than only how to use the specific terminology.

2.9.5 Arising from recommendation 5

5.1 All SDOs contributing to the development and maintenance of semantic interoperability assets should be prepared to contribute to strategic and governance structures that become
established to support Member State co-operation in the adoption of a single core reference terminology for Europe.

5.2 SDOs should support the EC and eHealth Network in the establishment of shared semantic interoperability resources such as terminology services, cross-terminology mappings, language translations etc.
3 ANNEX: Drivers for Semantic Interoperability and Terminology Policy and Strategy

3.1 Introduction

This annex lists the drivers for a coherent strategy to advance the level of semantic inoperability of health data across Europe, in preparation of the formulation of recommendations to the European Commission and the eHealth Network on the strategic choices they should consider, at a European level and at Member State level, around the adoption of SNOMED CT, other terminology systems and other components of a strategy. This annex reflects input from the consortium and consultation with international experts during the project lifetime, and especially consultations during spring and summer of 2016. A thorough reflection on what the drivers are for Europe-wide transition of electronic health records and applications towards more, and more intense, semantic interoperability is necessary to decide on what the primary goals are of this transition. Then, and only then, recommendations can be formulated for the development of a strategy with action plans and timelines. Priorities in primary goals, and hence drivers, may differ between the European level and Member States. Therefore, it is important to have an overview of all the potential drivers, and to understand the relationship between setting of primary goals and the resulting technical and political decisions in Member States and at the EU level.

This Annex reflects on six drivers:

1. Better quality and safety of care to individual patients
2. Enriched EHR data exchange for continuity of care
3. Cost reduction in collecting data on health care
4. Optimising health care expenditures
5. Analysis (secondary) use of clinical data
6. Cross-border information and knowledge exchange

The annex is written with three roles for terminologies in mind:

- Reference terminologies, such as SNOMED CT, organising large collections of concepts, labelled with a unique term.
- Aggregation terminologies, such as the World Health Organisation Family of International Classifications: International Classification of Primary Care (ICPC), International Classification of Diseases (ICD), Anatomical Chemical Therapeutic Classification (ATC), and International Classification of Functionality (ICF).
- User interface terminologies, which deal with words and phrases as collected from end-users, supporting the interface with reference and aggregation terminologies, also in languages other than English.

Each driver will be briefly introduced. Then we will discuss for each driver:

- The potential benefits of adopting SNOMED CT as a core reference terminology;
- What needs to be done (action plans; issues and challenges to be considered; pitfalls to avoid; solutions and mitigations and external dependencies)
- The different perspectives of the relevant stakeholders (healthcare funders, healthcare providers and ICT solution providers, data creators, and data analysts), and
- Defining and measuring success.

The canvas adopted here is used to organise collected inputs from focus groups, surveys, literature reviews, experiments, expert consultations, as performed in the previous two work
packages. In gathering these inputs, we often refrained to reformulate the wording of excerpts of reports, in respect for the source of the information. These inputs have served as a basis to formulate the official final recommendations.

3.2 SIOP Driver 1: Better quality and safety of care to individual patients

3.2.1 Explanation of the driver

More complete coded documentation

The increasing complexity of patient care requires the content in the EHR to be unambiguous and understandable to multiple care providers and interpretable by computers, to be comprehensive and to provide relevant and rich detail. Fine-grained terminologies can therefore support more completely and accurately coded clinical documentation, provided that the user interfaces for selecting relevant terms are friendly and avoid overloading the clinician with too many choices or a complex system of navigating term hierarchies. The ability for computers to interpret coded EHR data is an important driver, since clinicians have much experience of interpreting handwritten and typed information that is in free text, received from other care providers: terminology systems bring little, if any, benefit for human readability purposes. Computable uses of EHR data include filtering and navigation of a large or complex patient record, the generation of summary screens, and the decision support and care pathway drivers mentioned below. Feedback by member states has drawn attention to the lack of rich enough terminology support for nurse documentation, clinical processes, rare and genetic diseases. This will need to be rectified to enable multi-professional shared records and patient empowerment.

Support of the adoption of point of care evidence based clinical guidelines

Care pathway systems need to be able to interrogate the EHR content for a given patient in order to generate personalised alerts, provide prompts, make recommendations on the nature and timing of future care activities, and orchestrate multi-actor workflows. (Note that electronic care pathways often make use of decision support components, but may include additional functions and make richer use of the coded content of an EHR, including workflow support.)

Improved patient safety

This is an expected outcome from all drivers, but relies primarily upon making computational use of coded data. It is important to recognise that the patient safety value of scaling up the level of semantically interoperable health data relies on the querying and retrieval of complete and relevant information about an individual patient, to present it to the clinician either directly or indirectly via a computed alert or recommendation. The level of granularity of the terms and data structures used to capture, store and exchange the EHR data must be sufficient to support correct safety alerts, without too many false positives or false negatives.

3.2.2 Benefits of different terminology roles

Additional research is needed for elaborating criteria for effective end-user interfaces to the EHR, facilitating fine graded coding at the point of care. To achieve higher data quality, it is important to guide clinicians to choose the right terms in their clinical and care contexts. The need to improve quality of data starts at the point of data capture. There is a need for excellent, sophisticated, end-user support, education and awareness of the use and value of
semantically interoperable records. The triplet of terminology, workflow, record structure are all important.

Better quality fine-grained terms that can represent expressions that genuinely match clinicians’ needs for documenting will result in more fine-grained EHR data for complete and accurate decision support. This can in turn lead to better care pathway guidance and allow for analysis of care pathway adherence. Such analysis may indicate the need for education and/or to change the pathway if needed. Fine grained data is the starting point.

This evolution can be greatly enhanced by providing the underlying terminologies (reference terminologies, aggregation terminologies and user interface terminologies) as open source resources, available in the ISO standards for conceptual and linguistic terminology systems.

The national terminology centres should not only act as distribution hubs for one international reference terminology. They should create and maintain local interface terminologies, as well as a range of international reference terminologies and aggregation terminologies. SNOMED CT should serve as a core reference terminology, with multiple, well maintained mappings. National terminology centres should assure the information strategy and choose and manage the licenses for all international terminologies.

In addition, the national terminology centres should cooperate at a European level to construct a common model and common maintenance tools for their national end-user and reference terminologies, and their mappings to and between multiple international terminologies.

It is possible that stimulating competition among vendors and relieving them from the responsibility to maintain terminologies will result in quick evolution to highly performant products.

A terminology strategy must be built for and with the end-users of these terminologies. Focus on the ergonomics of data entry at the point of care is essential. For the majority of data recording in routine care it should be possible that terms in the local language(s) or dialect(s) are available. Sense ambiguity, synonymy, and short forms like acronyms and abbreviations are characteristic for interface language, hence end-user interfaces should be enhanced by state-of the art language technology.

It should be remembered that Europe has multiple official languages, as indicated below.

<table>
<thead>
<tr>
<th>Language</th>
<th>Official EU Language Since</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch, French, German, Italian</td>
<td>1958</td>
</tr>
<tr>
<td>Danish, English</td>
<td>1973</td>
</tr>
<tr>
<td>Greek</td>
<td>1981</td>
</tr>
<tr>
<td>Portuguese, Spanish</td>
<td>1986</td>
</tr>
<tr>
<td>Finnish, Swedish</td>
<td>1995</td>
</tr>
<tr>
<td>Czech, Estonian, Hungarian, Latvian, Lithuanian, Maltese, Polish, Slovak, Slovenian</td>
<td>2004</td>
</tr>
<tr>
<td>Bulgarian, Irish, Romanian</td>
<td>2007</td>
</tr>
<tr>
<td>Croatian</td>
<td>2013</td>
</tr>
</tbody>
</table>

In parallel with the efforts for sophisticated terminological support, attention should be paid to the harmonisation of clinical models in health records covering all clinical specialties.

Coordination of terminology is also needed in the building of templates, archetypes, detailed clinical models, clinical building blocks within EHRs, as well for the labelling of entities (information nodes) in the architecture, as for the terminology binding of value lists to templates. Any proprietary system should adhere to one of the standards prevailing specifications for clinical models (openEHR, EN ISO 13606, HL7 templates and FHIR, CIMI models, Detailed Clinical Models).
Terminology binding of the value lists of common architectural entities should be harmonised, across vendors, across health care systems, and across countries, and take into account the local user interface terminologies and international reference and aggregation terminologies.

The development of new clinical models and the maintenance of existing clinical models should be governed by principles of semantic interoperability.

The naming of structural nodes in clinical models should be governed by a system similar to the ISO-CAT system for computational linguistic archetypes\(^{35}\).

Pragmatic, language-specific focus on core sets of concepts is recommended, based on the extraction of words and phrases from routine care documentation in specific user groups into frequency lists, and on servicing the needs of terminology binding to the architectural nodes of interoperable EHRs.

The terminology systems and the corresponding clinical models should be able to grasp the context of information in a framework of continuity of care and deal with uncertainty, a key aspect of medicine. Terms from user interface terminologies need to be linked to reference terminology, with SNOMED CT as the recommended core reference terminology within a terminology ecosystem.

Mappings will be needed between the reference terminologies and several domain-specific classifications (e.g., ICD for morbidity and mortality registration, ICPC for primary care documentation, ATC for Medication, and ICF for assessing functionality of patients).

In addition, most medical sub-disciplines will continue to use domain-specific classifications for research purposes.

Within each of the more than 40 medical disciplines, a careful assessment is needed of the necessity to keep using their traditional domain-specific terminologies, to design a pathway for integrated use with the core reference terminology SNOMED CT.

### 3.2.3 What needs to be done?

**Actions to be undertaken**

The European Commission should stimulated the input of expertise from medical specialties, biomedical informatics, computational linguistics, information science, and by professional translators, and fund the necessary research and smart technological developments.

Strong European support and guidance to Member States should be assured in the construction of user interface terminologies. The expertise of professional translation (especially the European infrastructure for translators and interpreters) should also be considered.

**Issues, challenges, and pitfalls to be avoided**

The biggest challenge will be the handling of legacy data, and having enough terminological expertise within each organisation to manage this; the cost may be a significant issue, as is the risk of losing historic data and losing continuity during the early stages of transition to new terminology system.

Publicly available support and QA of cross-mappings should be in place to help organisations facing these challenges. Cross-mappings and legacy data conversion cannot completely be done by the analysts, so it should be performed locally at each care site when data are exported, so that the context of the data can be carefully preserved during the mapping process.

\(^{35}\) [http://www.isocat.org/](http://www.isocat.org/)
The European Commission should assure the multilingual nature of Europe and stimulate the creation of a variety of language-specific user interface terminology systems that go far beyond the translations of just preferred terms.

This has to address the sheer size and complexity of SNOMED CT. A problem of solutions based only on SNOMED CT adoption is if one starts using it bit by bit, none has to use it all for it to work.

There is a need to invest more in sophisticated quality assurance methods, and to learn from past experience, to ensure high quality of the adopted terminology product(s).

**Solutions and mitigations**

It is important to pursue rigorous standardisation in the construction and maintenance of terminological resources. The use of ISO-Standards for multilingual user interface, reference, and aggregation terminologies and capitalisation on results of related projects like BabelNet should be considered. The linguistic resources to be created should also permit the application of semantic web techniques, and be publishable in Linked Open Data. Interactive platforms should be built for the production and maintenance of user interface terminologies.

Development of core sets (if possible at least partly as RefSets of SNOMED CT) should also be driven by use cases in decision support and quality assurance.

Important use cases are primary care, intensive care, drug information, and communication with patients, as well as the cross-border projects of the EU on patient summary and e-prescription). Special attention should also be given to the catalogues of value sets for (international) scientific registries.

There is a lot of relevant debate and discussion about terminology ease of use. These debates should not be ignored. There should be an (international) management system for users to report errors in terminologies that can be rapidly collated and disseminated.

**External dependencies**

The main external dependency is on the quality of national and international governance and funding. Free and easy access to terminology and semantic interoperability products for testing, not only for research but also in clinical settings might be supported by national or EC funding.

The key issue is the free availability (assured by European funding and funding by the member states) of all terminological resources for the eco-system. Vendors cannot be expected to be responsible for the production and maintenance of user interface terminologies in 24 languages, or to take on the license costs for international reference terminologies.

**3.2.4 Perspective of stakeholders**

**Healthcare funders**

Healthcare funders (public health policy makers, health services managers, national e-health platform leaders) are responsible to assure semantic interoperability in the procurement actions for IT-services. They should understand that achieving semantic interoperability is a long and cumbersome process, which will span many years and that there is no simple, single solution. Urgency should not serve as an excuse not to invest in basic and applied research in user interface issues, interoperable clinical model development, and linguistic technology.

Payers should adequately support the creation of national terminology centres, as partners of a European network, and with strong governance capabilities at the national level.

Healthcare funders should assure the availability of all terminological resources including mappings. Strict quality criteria should be set for high quality terminological tools, supporting
end-user data entry at the point of care, and making use of these open-source terminological resources.

Healthcare funders should ensure that the education of health care professionals and health literacy efforts for patients support the adoption of sophisticated, smart, simple to use systems for data entry at the point of care in certified interoperable electronic records.

Healthcare funders should ensure the cooperation of the scientific associations of the health care professions, and respect their discipline-specific classification systems.

Too much focus on immediate return on investment, cost reduction, and increased control over health care professionals may be counter-productive, as health care professionals may lose trust in the motives for change, and stop participating in construction of a new information infrastructure.

**Healthcare providers and ICT solution providers**

This stakeholder group combines healthcare organisations who procure and deploy ICT solutions and companies implementing the ICT solutions.

Implementers and the IT-departments of health services organisations must create the solutions for innovative user interfaces. In creating IT-environments, they should opt for open, interoperable systems, not for closed proprietary systems.

Implementers should be relieved from the responsibility of maintaining terminological resources, so that they can focus on the development of advanced functional applications, produced at a reasonable price. They should be assured that investments in interoperability and open systems are recognised and valued in procurement procedures.

Use cases should result in showcase applications that convince vendors and healthcare providers of the value of using terminologies (market creation through opportunities). Many vendors are reluctant to build systems with SNOMED CT due to its complexity and costs, and due to limited demand by purchasers or end users it. This is a bootstrapping problem: suppliers will not build with SNOMED CT until someone asks for it; buyers will not ask for this capability until it has been built and demonstrated.

A challenge and a success factor is how to promote and sell complete terminology ecosystems, based on SNOMED CT, as a smart terminology that can help to produce reliable and high quality data for clinicians - who normally are not keen on entering structured data.

Issues of ownership and processes in which the new development of terminology might take place need to be considered, to encourage data implementers in using the solutions.

**Data creators**

Data creators (health care professionals, patients) need to understand the importance of producing high quality clinical data. They should be assured that the same data should not be entered repeatedly. They should be motivated to provide extra efforts for high quality recording of clinical data at the point of care, considering not only financial incentives but by directly experiencing the impact of better quality data on the quality of patient care.

Access to practical guideline platforms and user-friendly decision support will be a strong driver for high quality data production.

External dependencies are tooling for intuitive input and real-time monitoring or assistance where data creators receive feedback and comments when entering data, which avoids initial data entry problems.

**Data Analysts**

Data analysts (researchers, quality auditors, reimbursement offices) should build systems that are able to work with the single clinical data entry in the EHRs, without demanding much
additional effort from the end-user. Reduction of the administrative burden could be a strong driver for high quality data entry at the point of care.

3.2.5 Defining and measuring success

Best ways of defining success for this driver

Success is achieved when some or all of the following requirements has been put in practice.

- There is generalised use of coded clinical registration data, in every encounter between patient and health care providers, and in the communication among health care providers, as well as for the communication in primary care between the GPs and allied health personnel, as in the communication between GPs and specialists, and between among specialists and departments in the hospital setting.
- The IT infrastructure of the country facilitates seamless care across settings, and multidisciplinary cooperation in complex care pathways.
- The IT infrastructure of the country ensures correct archiving of clinical data for later use in care, and availability of such data across different settings, despite historic and current differences in clinical models and terminologies.
- Sophisticated national and international information systems for point of care guideline support can be deployed on a national scale (in different vendor applications) in all EU member states, to ensure correct advice in the appropriate choices of diagnostic interventions and therapies, in accordance with the principles of evidence-based medicine, and to ensure the safe and error-free use of appropriate therapies.
- The cost of the health ICT-infrastructure is reasonable and compensated for by tangible benefits in terms of better and equitable care and less iatrogenic harm.
- Interoperable clinical models are available that are agreed by clinicians, conform to international standards, providing good coverage of high-priority clinical areas for shared care, ready and endorsed in a timely fashion.

Measurable outcomes for this driver

- Monitoring of the completeness and quality of coding in record keeping and telematics EHRs, patient summaries, EPDs in hospitals, referral letters, discharge letters)
- Number of patients with electronically accessible records spanning more than 10 years of history
- Percentage of time during patient – health care provider interaction devoted to coding.
- Accuracy of coding in contra-indications and allergies
- Percentage of patients with an accurate longitudinal medication list, spanning several years
- Percentage of physicians using certified point of care information systems with
- Number of health care providers with alert fatigue or disabling the alert systems
- Number of drug-related hospital admissions
- Number of fatal or near-fatal drug errors
- Number of health care providers participating in internal audits with quality indicators
- Cost of applying quality indicator systems
- The percentage of EHR systems operational in the country, capable of offering internal audit of clinical data with quality indicators, with different terminology systems including SNOMED CT.
- Satisfaction of health care providers and patients with ease of data entry into electronic health records and patient held records.
• The reduction in the need for ancillary coders in monitoring systems.

3.3 SIOP Driver 2: Enriched EHR data exchange for continuity of care

3.3.1 Explanation about the driver

Underpinning multi-professional collaboration

Patient care increasingly involves multiple professionals working in different care settings, forming a virtual team for every patient. Paper-based communications between such actors are a well-recognised point of failure leading to suboptimal and unsafe care. Electronic communications (such as electronic discharge summaries) can be transferred faster, but the bottleneck of staff time to compose such documentation remains. However, smart rules for the semi-automatic generation of summary communications can reduce that workload burden and improve the quality and timeliness of shared care communications.

Offering all relevant actors direct access to each other's records is another approach. However, without the filtering and navigational support referred to above, this can easily lead to information overload, missing key facts and will therefore fail to improve continuity of care. Care co-ordinators (case managers) to orchestrate care, as employed in some contexts, is expensive. Computable and semantically interoperable EHR data can be leveraged to flag up critical facts relevant to a particular multi-actor care pathway, and can flag up issues in the management of one condition that has bearing on another. However, the realisation of computable benefit from shared EHRs relies upon the existence of correspondingly computable care pathways, reminder systems, alerts etc. as discussed above under Driver 1.

Sharing EHRs with patients

Studies have shown that patients value access to structured data within their EHRs, sometimes simply to read their records but increasingly wishing to take advantage of applications and tools that help understand their data, generate charts and tables, highlight trends, support education about their health conditions, and enable patients to play active roles in self-care and care decisions, which needs to be supported by appropriate language.

Up to now, few personal health record (PHR) systems have used international terminology systems as might be used by healthcare professionals, and so the reverse flow of PHR data into EHRs prevents that PHR data is co-processed alongside EHR data. Recognising, though, that health professionals are not all comfortable with including patient generated or provided data into their EHR, this reverse flow might not be a strong decision-influencing driver. However, a national semantic interoperability strategy may include incentives for the PHR marketplace to align with that strategy.

3.3.2 Benefits of different terminology roles

It is very difficult, yet important, to build and contextualise a terminology system to match the needs of multiple caregivers working together in order to realise the benefits. Care collaboration need to be well-orchestrated and well-documented in order to be effectively evaluated, improved and replicated. The use of benchmarked and evidence-based pathways can be achieved only by combining standardisation, awareness, and a patient-centred solution.

Now standards for continuity of care will demand re-engineering of most clinical models and require new and challenging specifications for terminology binding. Context-relevant environments are needed since creating context for terms used can reduce the complexity of term choice. A multi-professional environment with structured collaboration and documentation gives awareness to the whole Plan-Do-Check-Act chain.
Multidisciplinary clinical models and clinical pathways provide an important relevance context for terms of different worlds of reference, and reduce the complexity for the end users. Patient-centred care requires that information as recorded in EHRs and in communicated documents (e.g., referral letters, discharge letters, patient summaries) need to be understandable by the patient. That underlines the demand for user interface terminologies that include lay terms. Ideally, they provide a corresponding lay term for most of the concepts of the core term collection, possibly also links to educational material. These national terminological efforts can be coordinated at the EU level and also support coded data entry by patients and facilitate (multilingual) communication between patients and health care providers, foster multilingual communication within the country (to an audience that is increasingly multilingual), and cross border flows of medical information.

In the construction of language-specific user interface terminologies and a core set of concepts for national health care, special care should be taken to align the needs of general practitioners, allied health personnel, medical sub-disciplines, public health, research and patients. This is a real challenge and will need care full study of frequency of use of words and phrases per discipline, as well as specific demands for terminology binding to domain-specific clinical models.

Multidisciplinary cooperation is based on cooperation between several highly specialised care givers, who all need to preserve their own expertise and sustain it by research. This research is often supported by domain-specific international aggregation terminologies (e.g., ICPC for general practitioners, or much more detailed classification of subdomains). It is an illusion that SNOMED CT will be able to obviate the need for this bewildering diversity in human attempts to categorise observations and processes. Medical specialists are very keen on the intellectual tools they have developed over the years, and which have helped them collect invaluable historical information. It will be hard to engage them in a process of cooperation to adopt new systems with unsubstantiated promises, if they are forced to abandon what was familiar to them. A reassuring approach may be to gradually integrate SNOMED CT in the update cycle of traditional or new domain-specific classifications, similar to the “common ontology” approach in SNOMED CT – ICD11 harmonisation.

Intuitive data entry is the most important success factor: applications and tools need to be easy to use, supporting multidisciplinary teams. Clinicians need to have support from experts, and even real-time feedback during data entry.

### 3.3.3 What needs to be done?

**Actions to be undertaken**

An intense round of revision of the clinical models and terminologies is needed to adapt national and European information architectures to new insights in the multidisciplinary care of complex, chronic patients within a continuous process of care. This should be preceded by a reflexion between disciplines on collaboration in health care and the repercussions of retaining traditional ICT-solutions.

The concepts embedded in the new EN ISO 13940 standard (Contsys) should be promoted among medical societies and specialised health care vendors. Systematic extension of terminologies towards communication with patients in lay language should be facilitated, with help of linguistic expertise, and in cooperation with existing national and international projects and initiatives.

**Issues, challenges, and pitfalls to be avoided**

A holistic view on terminology is challenged by the fact that that there is little consensus on the boundaries between clinical information models and terminologies, for which EU projects such as SemanticHealthNet and rules like the ones proposed by TermInfo have explored solutions.
The terminology has to be adaptable and flexible to varying data entry models, yet has to be expressive for represented artefacts. There is also the problem of how to deal with concept post-coordination as enabled by SNOMED CT.

The pitfall here is that coding and structuring of information can easily lead to a reduction of information quality that fails to capture the context, fails to include uncertainty (e.g., about diagnoses), fails to serve as a common language between disciplines, and creates yet another impediment to the communication between patient and health care professional.

**Solutions and mitigations**

One solution can be to build formal foundations that focus on the quality of data in health care. Technology also permits the development of self-learning systems based on raw or annotated corpora.

The scientific communities engaged in guideline development, care pathway construction and decision support should collaborate in a multidisciplinary effort to align terminologies, clinical models and processes around the complex patient with multi-morbidity.

Some user interfaces use immature technology and cognitive limitations that have yet to be addressed. State of the art academic research and innovative products from high tech companies need to be leveraged to support the user with the best possible entry and retrieval tools.

**External dependencies**

External dependencies may be so complex that everybody tends to wait for everybody else to move first. The interplay needed between societal movements, ICT-industry, national or EU policies, governance and funding will be complex and difficult to manage.

### 3.3.4 Perspective of stakeholders

**Healthcare funders**

The keys to success for maintenance and legacy data are adequate terminological expertise within organisations and the assurance of obtaining right documentation. Costs are sometimes too high for organisations individually, including protecting against the loss of historical data and thus breaks in continuity of care. Publicly available support and QA of cross-mappings will be needed to help organisations solve such problems. There is therefore also a dependency on external support.

**Healthcare providers and ICT solution providers**

Relevant components include the problem of making the right terminology choice, populating EHR systems with the right clinical models, the maintenance of the terminology and an assurance of preserving legacy data, and end-user interfaces. The repercussions on the internal demands for quality and on the business model (in terms of cost of quality assurance and maintenance of terminologies) are important and need to be taken into consideration.

**Data Creators**

A success factor is to choose clinical models that are commonly agreed by clinicians from several disciplines and organisations, at the same time respecting one or more international standards.

Challenges include user acceptance and covering all relevant activities within each care organisation. A critical mass of experts and participants is needed, to work together at the right moment, in order to choose the right models. These issues cannot be solved by organisations on their own but rely on international cooperation with international
organisations of health professionals. It is important to give organisations and the users a sense of ownership of the clinical models adopted. This could as well be seen as an external dependency: obtaining clinical endorsement from users. This would only work with the help of national information strategies, which are also implemented within institutions.

Data creators are often also data users, especially in the care of individual patients. They need to see that the outputs from good quality data provide insights that bring benefits to patients.

Data Analysts
It is the responsibility of data analysts to make sure that the data entered at the point of care is good enough to ensure valid secondary use. Data good enough to support sophisticated quality assurance and decision support systems will probably be well-suited for secondary analysis. Data analysts should be present in the process of the creation of clinical models and terminology binding, for their proper interest and to support the impact of clinicians on the design of ICT systems.

International efforts on creating registries for epidemiological research and public health management should be coordinated and aligned with efforts to structure electronic health records, telematics messages and to bind detailed clinical models to terminology.

3.3.5 Defining and measuring success

Best ways of defining success for this driver
To derive success drivers for terminology systems or EHR systems is not straightforward. Normally people speak about eHealth systems but seldom to terminology when referring to success drivers. The distinction here is “how does using this terminology make the use of an EHR or similar eHealth solution successful”.

One element is to ensure alignment of information locked in health records of the different disciplines or kept by patient, by defining common structures in national eHealth ICT architectural solutions. These solutions should gradually replace the container documents listed below:

- GP Electronic Health Record
- Specialist Electronic Health Record
- Allied Health Personnel Electronic Health Record
- Personal Health Record (PHR)
- Hospital Electronic Health Record
- Referral letter
- Discharge letter
- Advance Care Planning document
- Care Plan
- Patient Summary
- Case Report Form in studies
- Registry Report

Users will be motivated to use a new terminology system if the user interface is friendly and helps them to overcome the serious cognitive challenges of a large terminology system, and if they have confidence that their data will be accurate and usable for shared clinical care.

Success could also be achieved if the expectations of patients for consulting understandable medical information become so pressing that hospital systems, health care organisations and
independently working health care professionals can no longer function without adequate facilities to provide this understandable information in every day routine care. Success factors for end-user interfaces include users who are motivated and satisfied by the quality of the system and that the data produced is of high quality and accurate.

**Measurable outcomes for this driver**

- Number of patients with a reliable Patient Summary that is securely accessible by other care providers
- Percentage of Patient Summaries updated after significant clinical events (e.g. hospitalisation)
- Percentage of structured and coded discharge letters for communication across health care organisations and settings
- Number of EHR-systems incorporating principles of Continuity of Care
- Number of multidisciplinary health records in the management of patients with chronic multimorbidity
- Percentage of Patient Health Records, aligned with their GP’s EHR.
- Extent of readability for patients of health information in electronic health records

### 3.4 SIOP Driver 3: Cost reduction in collecting health care data

#### 3.4.1 Explanation about the driver

**Reduce duplicate data capture through better interoperability**

Healthcare information is often documented more than once, e.g., in findings reports, discharge summaries, reimbursement claims, a disease registry entry. Such documentation might initially be paper and later entered into a computer system, which is not only time consuming but misses out on any real time benefit that an ICT system could provide the author (such as validation checks, reminders, warnings).

**Capture reporting and reimbursement codes at source in a more efficient way**

The use of codes for reimbursement is generally aimed at optimising income, not cost reduction. A cost reduction element lies in reducing the duplicate effort to code for clinical care in the EHR and to code for reimbursement, quality monitoring and public health purposes, using different terminology systems. Reimbursement codes are generally more coarse-grained than clinical documentation codes, so reimbursement can be derived from clinical coding, but not vice versa. If mappings are used to derive reimbursement codes from fine-coded clinical data, changes to a reimbursement framework can be introduced at lower cost and minor disruption. However, reimbursement systems usually contain rules that have historically been attached to terminology systems like ICD, and so these rules would need to be revised, as well.

**Consolidate from multiple existing terminologies**

Most health systems presently use a mixture of terminology systems, for reimbursements, hospital activity monitoring, births and deaths, disease registries, screening programmes etc. Many of these systems are maintained by each country, including cross-mappings between them and to international terminology systems such as ICD. Several countries have expressed the interest in reducing this burden of developing and maintaining cross-mappings.
by using SNOMED CT as a reference. It is also being considered as a terminology to replace some of the national terminology system, thereby reducing even further the cost of maintaining local terminologies.

### 3.4.2 Benefit of different terminology roles

The benefits of enriched EHR data are not limited to better quality and safety of care, but also encompass cost reduction of data management and optimising reimbursement, which are convincing arguments especially for health care managers, less for clinicians, for whom investment in fine-grained coded information is quality of care improvement, multidisciplinary cooperation, quality assessment, research, and avoidance of duplicate data entry.

With single data entry, more time will be required at the beginning of the chain of the data flow, which then is compensated by the administrative burden caused by duplicate data collection requirements later in the chain will decrease significantly. Then, and only then there is a major benefit.

The end-user interface should provide the link to the concepts needed for quality assurance, health surveillance, drug utilisation statistics, epidemiological registration and research. National reimbursement terminologies and data specifications for secondary use should be re-engineered into a closer alignment with clinical data collection and international reference terminologies, and not the other way around.

International reference terminologies should not to integrate idiosyncrasies and rules of national administrative systems, in order to reach universal acceptance. This is guaranteed by the ontological architecture of SNOMED CT, which does not allow for expressing characteristics of aggregation terminologies, such as rules and residual classes.

The International Classification of Diseases (ICD) will remain the aggregation terminology of choice to produce world-wide mortality and morbidity statistics, at least for another decade. Hence, the harmonisation with SNOMED CT is crucial for the acceptance of the latter. Direct mapping are mostly not possible due to the current classification rules in ICD, which might be remediated with the release of ICD11. The current strategy is to express the meaning of ICD codes as queries on SNOMED CT encoded EHR content.

### 3.4.3 What needs to be done?

**Actions to be undertaken**

- Re-engineering of reimbursement terminologies rather than re-engineering international reference terminologies to meet the requirements for reimbursement.
- Harmonizing of reimbursement terminologies with terminologies for clinical data capture, especially SNOMED CT.
- Mapping terminology content needed for quality assurance, decision support, and clinical guidelines to the reference terminologies used for clinical data capture.

**Issues, challenges, and pitfalls to be avoided**

Many European countries currently have reasonably well functioning monitoring systems for drug utilisation, based on the Anatomical Therapeutic Chemical Classification (ATC). Changing this overnight to a new reference terminology with a new superstructure for drug group names could disrupt these long-standing achievements. A chaotic migration to a morbidity and mortality registration based on SNOMED CT only could disrupt the global statistics of the World Health Organisation.

On the other hand, the laborious alignment of many different databases and reporting systems for infectious diseases could be overcome by coding surveillance data within a common terminological eco-system.
Solutions and mitigations
This driver is the reason for the imperative need of a sophisticated user interface terminologies that can make the link the words and phrases used by patients and clinicians in the national language(s) to reference and aggregation terminologies. Training and education is needed for using the technology including promoting stakeholder engagement. The can be mitigated by providing financial incentives and organisational support.

External dependencies
Vendors and data creators must rely on the authorities who create rules and requirements for reimbursement. ICT systems can be used by governments to increase the complexity of rules, but impact analyses should be made, regarding the cost of adapting systems and documentation time required at the point of care.

3.4.4 Perspective of stakeholders

Healthcare funders
Reimbursement rules should be re-engineered and harmonised with local interface terminologies and SNOMED CT. For the latter, a simple mapping will not work; more sophisticated approaches will be necessary. Changes in reimbursement rules should not be implemented without impact analysis on data registration.

Healthcare providers and ICT solution providers
Sophisticated interfaces should be created, based on open-source harmonisation resources.

Data Creators
Data creators should be convinced that the benefits justify investing some extra effort in high quality data capture at the point of care in a consistent and comprehensive way.

Data Analysts
Data analysts should team up with clinicians in the building of user interface terminologies, clinical models and processes, and share with them a feeling of data ownership.

3.4.5 Defining and measuring success

Best ways of defining success for this driver
- Reduction of duplicate entry.
- Reduction in the number of coding staff.
- Cheaper collection of management data such as quality indicators, key performance indicators, common data sets for surveillance programmes and scientific registries.
- Reduction in the cost of maintenance of national reimbursement terminologies.
- Ability to flexible change of reimbursement rules at a reasonable cost, in the light of new public health policies. Increase of overall transparency and, according to this, the reduction of transaction costs

Measurable outcomes for this driver
The cost of duplicate coding for the collection of management data for hospital financing (e.g., 800 professional coders in Belgium for a population of 11 million) or for collecting quality indicators (80 million in the Netherlands) is high. Measurable outcomes could be:
1. Complexity and validity of the routinely collected quality indicators
2. Number of FTE employed in secondary coding of clinical data for administrative purposes
3. Costs for harmonising national aggregation terminologies for reimbursement mapping national reimbursement with international reference terminologies
4. Percentage of data in scientific registries, captured through primary data collection in Electronic Health Records.

However, empirical evidence for substantial cost reduction by reducing duplicate coding by introducing a complex core reference terminology is still to be confirmed in field studies.

### 3.5 SIOP Driver 4: Optimising reimbursement

#### 3.5.1 Explanation about the driver

The use of fine-grained clinical data can be the basis for generating more accurate activity and outcomes data, to map into reimbursement claims. This may reduce the likelihood of “upcoding”, i.e. an exaggerated interpretation of a patient’s care needs to raise the value of the treatment episode. Data reuse for reimbursement may also improve the completeness of claims and diminish the risk of missed claims. However, this will shift the burden of accurate data collection to the clinicians.

#### 3.5.2 Benefits of different terminology roles

The combination of data entry at the point of care, and data logging and time stamping are important methods to prevent *a posteriori* up-coding. Good end-user support might be necessary to avoid underreporting of claims, and make sure that the elimination of the classical coding workflow does not lead to unjustified loss of income for health care organisations.

A close link from clinical terminology to reimbursement terminologies provides the ability to verify reimbursement claims through clinical audit.

#### 3.5.3 What needs to be done?

**Actions to be undertaken**

A strong commitment should be taken towards administrative simplification, with trust-building efforts to reassure health care professionals.

**Issues, challenges and pitfalls to be avoided**

There are perverse incentives such as reimbursement schemes that discourage accurate and faithful clinical documentation. Decision makers should take the responsibility for enabling collaboration. They should ensure that their policies and management processes do not hinder the semantic interoperability solutions.

A pitfall is that health authorities and insurance organisation take advantage of the increased possibilities of data capture to:

- Increase their ability to pre-emptively screen candidate clients for actuarial risk, within the limits of privacy;
- Increase their ability to control health care professionals and change the balance of power within health care organisations.

Health care professionals and patients should be assured that voluntary participating in higher quality data registration will not have the effect of “digging your own grave” in terms of finances or penalties.
Solutions and mitigations

Strong data protection should remain guaranteed. Partners in healthcare could strive towards high-level agreements on objectives of data collection.

External dependencies

Healthcare professionals rely on governments to regulate misuse of data by health insurers or other agencies.

3.5.4 Perspective of stakeholders

Healthcare funders

A major challenge is the potential mistrust and fear that other people (e.g., insurance companies) may misuse the data. Transparency of how coded data will be used and consistency of definition is important.

Healthcare providers and ICT solution providers

Implementers can participate in creating build-in checks against upcoding (e.g., time stamping). Verification systems of completeness of claims can also be constructed.

Data Creators

Healthcare providers have the responsibility not to participate in upcoding practices and checking whether professional coders do not creatively interpret their clinical data.

Data Analysts

Data analysts need to be reassured that temptation of upcoding and the avoidance of under-reporting of claims does not introduce a bias that influences the validity of the data they are using. They should participate in checking procedures and data cleaning activities.

3.5.5 Defining and measuring success

Best ways of defining success for this driver

Optimising reimbursement is a success factor of a terminology, which is strongly supported by many stakeholders, considering how one could make use of the potential integration of EHR and administrative records. Incentives for cost reduction and better reimbursement schemes can have simultaneous effects on improved healthcare delivery. For example, clinical auditing to improve healthcare delivery and reduce mistakes is only possible with a smart terminology that simultaneously prevents upcoding.

- Avoidance of upcoding, resulting in fewer fraudulent expenditures as well as in a less biased data-collection and ill-informed health care policy and research
- Reduction of missed claims for the health care organisations

Measurable outcomes for this driver

- Reduced number of professional coders needed in an organisation, due to reduced need of purpose-specific manual coding
- The ability to verify reimbursement claims and other forms of administrative reporting by examining (auditing) the real data in EHR systems

However, the impact of introducing SNOMED CT as a core reference terminology on the complex processes of health policy through reimbursement is hypothetical and different to separate from general benefits of semantic interoperability.
3.6 SIOP Driver 5: Analysis (secondary) use

3.6.1 Explanation about the driver

Analytic uses of health data can be powerful drivers for adopting a coherent semantic interoperability approach, including focusing the uses of terminology. The list below gives examples of analytic uses that have been articulated by experts, used in pilot projects, and in most cases implemented in demonstrators. In some examples such as population health screening and disease registries, subject-level data needs to be incorporated. In others the analysis results are needed, which might be derived through pooling data extracts for central analysis or by distributing the queries through a federated network. However, they all require data from multiple sources across the health ecosystem to be combined and co-processed, and therefore to be semantically interoperable.

- Benchmarking, service planning, commissioning
- Evidence-based strategic decision-making and planning
- Outcome optimisation, improving efficiency
- Public health, surveillance, screening, prevention
- Scientific registries for special patient groups
- Cohort building to support prospective clinical trials

On the one hand, health data can only be combined if originally captured in a semantically consistent way, or can be mapped to a common representation for the analysis. In general, analysis use cases will not deliver benefits until a high degree of coding quality has been reached. This requires a significant preparatory effort, i.e. a revolution in documentation culture. This means that the capability to fulfil these purposes in a better way through a new or alternative terminology choice will depend upon the widespread use of that terminology in the source data. On the other hand, data items required for these purposes can serve as the focus for prioritising the development of user interface terminologies, and the intelligent gradual adoption of a core reference terminology.

3.6.2 Benefit of different terminology roles

High quality terminological resources will be the cornerstone of creating and optimizing functional learning health systems. We distinguish between internal secondary use and external secondary use.

Internal secondary use is quality audit and research on the clinical work by and for the health care professionals, in a continuous and voluntary effort by the health care professionals themselves to improve the quality of their everyday health care, as illustrated in the first driver.

External secondary use is health services management that is fuelled by utilisation and performance data, originating from the recording of clinical activities, with an analysis aimed at the proper management of health care, the optimisation of regulations, the health-economic fine-tuning of the financial funding mechanisms and actuarial optimisation of health insurance.

In addition, the daily stream of data from the clinical realm in primary and secondary care should be reused for basic and applied research purposes. Epidemiology, health economics, health services research, pharmacovigilance, pharmaco-epidemiology, comparative effectiveness research are disciplines geared to advancing the state of the art of knowledge, which will ultimately result in better public health care.

Especially for secondary use scenarios, user interface terminologies should provide a good coverage of the language expressions used in free-text documents, in order to benefit from this important unstructured or semi-structured content. The quest for high-quality data entry must not hide the fact that in most places coded data only comprises a minor part of EHR...
content. Particularly secondary use scenarios may require the identification of mentions of secondary diagnoses, past history, signs and symptoms, family history etc in clinical narratives. This requires well adapted NLP approaches together with high-coverage user interface terminologies, which should also include common abbreviations and acronyms.

3.6.3 What needs to be done?

Actions to be undertaken
Technical and content validation needs to be done. The validated sets of quality indicators (e.g., for potentially inappropriate prescribing), traditionally used for assessing quality of clinical work, can also be used as an ultimate test to assess the degree of semantic interoperability of data migrating from one system to another.

Collaboration should be carried out to report feedback to decision makers.

Issues, challenges, and pitfalls to be avoided
Fine-grained clinical data using better terminology systems can provide valuable feedback to healthcare delivery and enhancement. It must not be used primarily for monitoring and potentially penalising clinicians: there must be transparency about how clinical data will be monitored and used.

The link between input and output is that data creators are also data users. The success factor is to discover how data can be used in terms of a feedback loop to help healthcare delivery (Plan-Do-Check-Act chain) or change and enhancement.

Collaboration should take place to allow feedback when transferring data to decision makers or end-users.

Solutions and mitigations
Terminology servers bring order and structure into the input of data. Cross-mapping and/or legacy data conversion strategies are needed for different generations of data. How to transfer the data from the sources to some kind of analysis database with the context in which originally aimed at is another challenge.

Tools need to be developed that help end-users to harness the complexity of international reference terminologies and to manage standardised post-coordination of concepts. For secondary use scenarios, particularly query tools need to be developed and improved, which make full use of the value of multi-hierarchical aggregations in reference terminologies.

External dependencies
Member States are dependent on the willingness of other Member State to cooperate on these issues and on the European Union to support this international cooperation. External dependencies exist here in terms of benchmarking facilities made available across-border to support the feedback loop.

3.6.4 Perspective of stakeholders

Healthcare funders
Providers must insist on standardisation and interoperability of terminology, clinical models, terminology binding, and process modelling. They should support the efforts of member states on the national and international level, in a collaborative effort to maintain the user interface terminologies.

Particularly for secondary use scenarios, providers should harness the expertise of academia (computational linguistics, medical informatics, information science and ontology).
Healthcare providers and ICT solution providers

Implementers should compete and excel in developing tools making the most out of the roles of the different terminologies for the end-user.

Data Creators

Data creators and users should no longer accept mediocre user interfaces. They should ask for the best functionalities, available at the point of care. They should agree that extra effort is needed at the point of care to assure most secondary usages of information without duplicate data entry. They should be given guarantee that the results of their efforts will not be abused or used against them.

Data Analysts

Analysts need to have confidence in the quality of the data they receive and the result of their analysis. Technical and content validation should be in place. Analysts must participate the design of user interface terminologies and terminology binding efforts to ensure that no duplication of data entry is needed for their purposes.

3.6.5 Defining and measuring success

Best ways of defining success for this driver

Success factors include confidence in the results of analysis and reporting standards. Clinical research is usually undertaken across countries, and the ability to combine research data sets is therefore an important business driver. Indeed, the European Research Networks are the next priority for CEF services. There is value not only in sharing research data, but also in pooling analyses that have been computed on consistent data held in each country: there would be value in registries, biobanks, rare disease communities in the adoption of common semantic interoperability approaches, irrespective of how often subject level data might be shared between them.

Measurable outcomes for this driver

- Reduced labour cost of manual engineering in national or regional surveillance scheme for infectious disease
- Increase possibility for the application of automated sets of quality indicators, developed with and for the health care providers.
- Increased international, multicentre registries and research projects
- Improved efficiency and reduced cost of conducting clinical trials, especially regarding the recruitment of trial subjects.

3.7 SIOP Driver 6: Cross-border information and knowledge exchange

3.7.1 Explanation about the driver

The principal driver for investments in semantic interoperability at a European level, supported by EC funding, has been the cross-border healthcare rights of citizens. This has triggered projects, specifications, standards and profiles that handle the cross-border communication of patient summaries and prescriptions, primarily to support unplanned care e.g., holidaymakers, business travellers, overseas postings, military personnel, refugees. These services are targeted for early adoption by the Connecting Europe Facility.
There is now a momentum to extend these specifications and services to support cross-border planned care. However, information support for the cross-border flow of patients has overshadowed consideration of other benefits from Member State alignment of semantic interoperability strategies and approaches. Many of the analytics uses listed above do also have drivers for Member State collaborations and comparisons. These include gathering and sharing patient safety intelligence (e.g., adverse event reporting, pharmacovigilance, pharmaco-epidemiology, infection outbreak control), and sharing and comparing various benchmarks and quality metrics. There are, therefore, many reasons why Member States might wish to collaborate and benefit from collaborating around common terminology choices, and more broadly around common approaches to advancing semantic interoperability.

3.7.2 Benefits of the different terminology roles

Up until now, WHO classification systems have been the *de facto* languages for cross-border communication or healthcare outcome comparison, but are too limited in scope or not granular enough to achieve most of the clinical care drivers. A smart terminology is needed for multi-professional collaboration and to exchange records between different specialties. Recommendations are needed for the R&D and for the resources that the EC could sponsor, e.g., by creating resources of common value, and facilitate platforms for collaboration for user interface terminology development, especially for smaller European languages.

The collection, aggregation and cross-mapping to SNOMED CT of words and phrases for a core collection of concepts frequently used by health professionals could also be supported by the EC, whose role to enable collaboration and manage the process politically is important, also in terms of timeframe. In addition, the EU can play a crucial role for member states dealing with the excess cost of multilingualism.

3.7.3 What needs to be done?

**Actions to be undertaken**

The cross-border use cases need to be continued, especially with regard to the Master Value Sets, with guaranteed continuity and more sophisticated availability.

Smaller scale clinical data sets might also be useful to exchange across countries, such as laboratory and radiology results, medical device readings. In all of these cases semantically interoperable data is required, and clearly requires consistent use of information models, clinical models and terminology value lists. At present, many countries are planning to map locally captured and stored EHR data (in whatever structures and terms presently in use) to the data sets and vocabularies of the European Patient Summary Guidelines. This is clearly the lowest cost approach to conformance. Migrating the underlying EHR systems and repositories to natively capture, store and process patient summary data items in the formats of the European patient summary guidelines would not make sense if all other patient data are handled in the existing ways. It has also been noted by many countries and experts that the volume of cross-border patient flows is too low to justify significant investment by most Member States, unless that strategy can be aligned with other within in-border needs for semantic interoperability.

Clinical research is usually undertaken across countries, and the ability to combine research data sets is therefore an important business driver, as explained in driver #5.

On a short term and pragmatic level, Member State co-operation on semantic interoperability can enable sharing of costs (such as development of user interface terminologies, clinical model development, term translations, and development of Master Value Sets (e.g., epSOS), sharing best practices and quality assurance processes, and all countries being able to take advantage of internationally agreed definitions of concepts. This is not in itself a driver for investing in semantic interoperability, but may influence decisions about what semantic interoperability approaches to select.
3.7.4 **Perspective of stakeholders**

**Healthcare funders**

With the help of the European Commission, Member States will provide the infrastructure for the availability of the terminologies needed to support the projects Patient Summary (containing the current medication list), and ePrescription at the European level.

**Healthcare providers and ICT solution providers**

The demands of the initial cross-border use cases are relatively simple to implement, but not yet universally adopted. It should become part of the certification process of medical software developers.

**Data Creators**

It can be a test for the data creators to ensure as much as possible the update of the patient summary of their patients with imminent health hazards, complex treatments, to support unplanned health care in the country, unplanned health care outside the country. Travelers to other European countries should be given the opportunity to ensure that their essential medical data travel them, in a translation suitable for the visited countries.

3.7.5 **Defining and measuring success**

**Best ways of defining success for this driver**

Successful application in the use cases: Patient Summary and ePrescription.

**Measurable outcomes for this driver**

- Number of Patient Summaries and ePrescriptions exchanges between sender and receiver countries
- Number of countries in EU ready for these cross-border use cases.
- Number of international clinical trials based on data extracted directly from clinical records in at least three different countries.