

A background network diagram consisting of numerous small grey dots connected by thin grey lines, forming a complex web of connections. A large, stylized logo is centered in the upper half of the image. The logo features a thick, dark grey curved line that starts from the right, loops around a small circle, and then extends downwards. To the left of this graphic, the word "ASSESS" is written in a large, dark grey, sans-serif font. To the right of the graphic, the letters "CT" are written in a large, red, sans-serif font.

ASSESS CT

**Assessing SNOMED CT for Large Scale
eHealth Deployments in the EU**

ASSESS CT Recommendations

December 2016

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Abbreviations

AT	Aggregation Terminology
ATC	Anatomical Therapeutic Chemical Classification System
CEF	Connecting Europe Facility
CEN	European Committee for Standardization
CIMI	Clinical Information Modelling Initiative
EHR	Electronic Health Record
eHDSI	eHealth Digital Service Infrastructure
FHIR	Fast Healthcare Interoperability Resources
HL7	Health Level-7
ICD	International Classification of Diseases
ICPC	International Classification of Primary Care
IHE	Integrating the Healthcare Enterprise
IHTSDO	International Health Terminology Standards Development Organisation
ISO	International Organization for Standardization
RT	Reference terminology
SDO	Standard development organisation
SIOP	Semantic Interoperability
SNOMED CT	SNOMED (Systematized Nomenclature of Medicine) Clinical Terms
UIT	User interface terminology
UMLS	Unified Medical Language System



About ASSESS CT

Semantic interoperability in healthcare is the ability to exchange health related data with unambiguous and precise meaning that is shared between stakeholders. It is of value in a large number of heterogeneous scenarios of primary and secondary use of health data. For example, fine-grained coding at the point of care is expected to improve the overall quality of clinical data. Safe decision support systems depend on high-quality meaningful data to be interwoven with formalised clinical guidelines. 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, quality metrics and patient safety intelligence.

The goal of ASSESS CT was to make a significant contribution to the debate on semantic interoperability of eHealth services in Europe. The project, integrating a broad range of stakeholders, investigated whether the clinical terminology SNOMED CT, a potential terminology standard for improving semantic interoperability, would be fit for EU-wide eHealth deployments.

In a joint 18 months effort, the ASSESS CT consortium addressed this challenge by looking into a number of issues related to the current use of SNOMED CT such as concrete reasons for adoption / non-adoption of SNOMED CT, lessons learned, success factors, type and purpose of use, multilingualism, cultural differences, strengths and weaknesses.

By means of literature review, survey, interviews; focus groups and workshops, the project reviewed the current state of use of SNOMED CT, the fulfilment of semantic interoperability use cases, known technical and organisational drawbacks, and the way SNOMED CT is improved and maintained.

ASSESS CT employed established evaluation approaches from social science and scrutinised adoption against two alternative scenarios: to abstain from actions at the EU level, or to devise an EU-wide semantic interoperability framework alternative without SNOMED CT.

The project also analysed the impact of SNOMED CT adoption from a socio-economic viewpoint, encompassing management, business, organisational, and governance aspects.

Validation of all working tasks, both political and domain-specific, was secured through workshops with a number of distinguished international experts.

This brochure presents and discusses five main recommendations, with an explanation about the origin of the recommendation, and with an overview of the recommended actions.

For a better understanding of the recommendations, this introduction elaborates on the distinction between three different types of terminologies, and on the place of SNOMED CT in this typology.

Health care terminologies 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 terminology 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. This is assured by maximally unambiguous terms / labels in different languages, by textual and / or formal definitions. If underpinned by a formal foundation, RTs coincide with what is usually called formal ontologies.

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 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 essential to choosing a core reference terminology, which is, however, 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, specific classifications or nomenclatures may be used for reimbursement.

Neither RTs nor ATs are expected to cover the complete scope of end user languages. Their translation into all languages where they are used is not mandatory, provided this role is fulfilled by user interface terminologies.

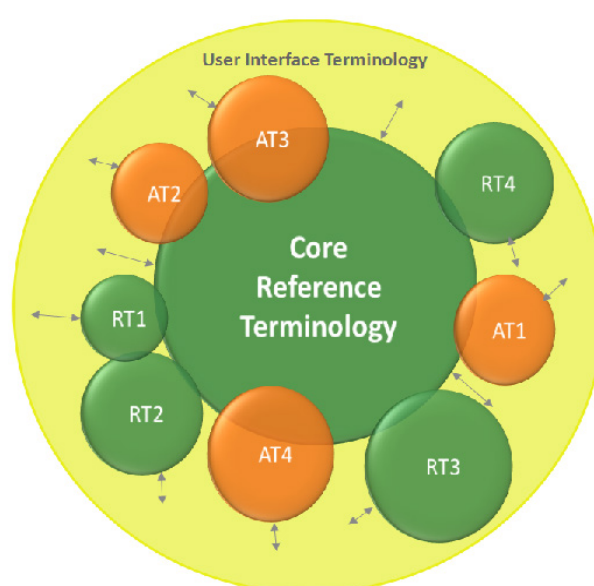
User interface terminologies (UITs) are collections of terms that are used in written and oral communication within a group of users, for example in a data entry form in a healthcare IT system or in clinical documents. User interface terms tend to be ambiguous. This requires that entries in user interface 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.

An end user interface for a specific natural 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.

UITs provide value sets for data entry as well act as dictionaries for human language processing systems.

Health terminologies, in general, can be furthermore described by their scope, e.g., clinical specialty (e.g. neurology, surgery, cardiology etc.), their domain (such as disorders, procedures, drugs etc.), and by the groups of users they target, which include health professionals (physicians, nurses) and laypersons. The latter group especially matters for specific interface terminologies, named consumer 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 organisations for international use. It should be noted that political borders and linguistic boundaries do often not coincide.



The role of different terminologies in a terminology ecosystem

RT = reference terminology
AT = aggregation terminology

Policy and strategy recommendations

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

The following recommendations 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 in 2016.

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



Recommendations at a glance

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 optimising 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, wherever 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.

2. 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.

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

No country sees SNOMED CT as a stand-alone solution, but rather as an important part of the national terminology infrastructure.

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 priority use cases, and expanding these sets over a number of years.

Such incremental use, 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.

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).

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.



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 optimising the benefits of semantic interoperability in health data, and of the overarching eHealth strategy of the European Union and its Member States.

Semantic Interoperability (SIOP) in healthcare is the ability to exchange health related data with unambiguous and precise meaning that is shared between stakeholders. It is also important in the broader context of social care and the Internet of Things (IoT).

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 (EHR) 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 additional effort.

Semantically explicit clinical data support filtering of EHR content by relevance, the generation of summaries out of large and complex patient records communications as well as navigational support within them. Automated semantic annotations of 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 quality need to be considered.

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 of 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. It 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 requirement of call topics and funding 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.

Recommended actions

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 these drivers are entirely within the border of a single national health system, or whether 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 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 (or in many cases ring-fenced) for activities, services and expertise that need to be

funded and provided at a national level. These include 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. This uptake is needed 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 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.

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 CEN/ISO EN13606,
- 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.

Recommendation 2

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

A main advantage is SNOMED CT's content coverage, which is superior to any other terminology. This makes it the most complete point of reference for health related concepts and related terms in many languages. It is assumed that a semantic interoperability strategy as described above will necessitate larger sets of terminology content, making content coverage an important factor.

In its role of core reference 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 examined by ASSESS CT, 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.

- 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.

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. Equally important is to show that tools to support this process have been built.

Recommended actions

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

Regarding SNOMED CT's maintenance organisation, the IHTSDO, further work on SNOMED CT should prioritise:

- The alignment with semantic standards (Semantic Web),
- The revision of several subhierarchies with known quality issues (e.g., qualifiers, procedures),
- The identification of content that is only understandable in national contexts,
- 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, openEHR) and architectures,

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

Recommendation 3

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

No terminology has the potential to cover all interoperability needs alone. Cross-border services depend upon 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 if 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 WHO family of classifications (ICD, ICPC, and ATC). Elaborate mappings between SNOMED CT and these aggregation terminologies have been constructed. However, the application of these mappings for retrieval of coded information is intensive with systems only based on SNOMED CT and requires further development.

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 ATC, necessitate a smooth transition and probable concomitant use of heterogeneously classified data for still a number of years.

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 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 solutions for harmonising RTs with ATs.

Current quality indicators for evaluating prescribing operate are based on classification systems for drugs and diagnoses. Until formal evidence for the effectiveness of SNOMED CT-only solutions is provided, the reluctance to let go of established methodologies and fear of disruptive effects caused by longitudinal data collections will prevail. User interface terminologies and sophisticated terminology binding of 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 the lack of SNOMED CT translations into many European languages. ASSESS CT has shown that 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 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. The fact that interface aspects are not sufficiently addressed where only a Fully Specified Name (FSN) is available for a given language, gives rise to an opportunity, for 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 makes a monolithic approach impossible. SNOMED CT as a core reference will not and should not serve as a centralised container for clinical language expressions in 24 official languages of the EU. On the contrary, SNOMED CT should play the role of a hub, which connects user interface terminologies and value sets of different provenances, in different languages and dialects, serving a variety of user needs.

It is clear that merely translating SNOMED CT FSNs and preferred terms does not solve the problem of patients and professionals who do not speak English or are non-native English speakers. Although, such a translation could be helpful for the most commonly used terminology content, it 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 clinical communication between and among 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 focusing the efforts on what is essential e.g., starting the acquisition of multilingual user interface terms from the most frequently used terms, learning from experiences of other countries. The option of a *de novo* construction of a European core reference terminology may be tempting when dealing with a small set of concepts. However, the larger such an artefact grows, the more caution it will require, in order to avoid the 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 to 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.

Specific standardized linguistic resources for the management of words and phrases, with their synonyms, acronyms, variations, deflections, dialects exist. 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

In order to promote patient safety, engagement and empowerment, and avoid care duplication, all stakeholders, including the patients and their families, must be able to interpret coded clinical documentation. As a consequence, user interface terminologies must consider

both lay language and professional jargon in the native language of patients and caregivers from various disciplines. Addressing 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. Harnessing the pivotal role of the core reference terminology can facilitate communication between patients and health care professionals, at least at a lexical level.

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. Various tailored options are possible with user interface terminologies/technologies providing the SNOMED concept is also stored or referenced.

A managed relationship between the user interface and the core reference terminology and international aggregation terminologies is required, 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 responsible for both the strategic decisions in information management and the routine work of keeping their healthcare information systems supplied with standardized and updated terminologies. Often, these organisations are in charge of not only terminology, but also various 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 terminology eco-system to provide a reliable link to national and international aggregation terminologies (e.g., ICD, procedure classifications, and DRGs), in support of 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 of proprietary systems to communicate with one another. Vendors have often built 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 professionals

In the past years, many sub-disciplines of healthcare professionals 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 should therefore be encouraged to provide important contributions to domain-specific terminological resources, thus playing a very active role in the adoption of a core reference terminology, spanning the different disciplines.

Recommended actions

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, 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). There is also a need to support research and the development of tools that aim at improving the precision of manual and automated code assignment. Expertise needs to be developed and an educated workforce is required, including terminologists, specialists in human language technologies and human-machine interfaces, clinical modellers, etc.

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 demonstrators.

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 priority use cases and expanding these sets over a number of years.

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 advantages. The piloting costs must be commensurate to the scope of these projects, and a realistic investment should be planned.

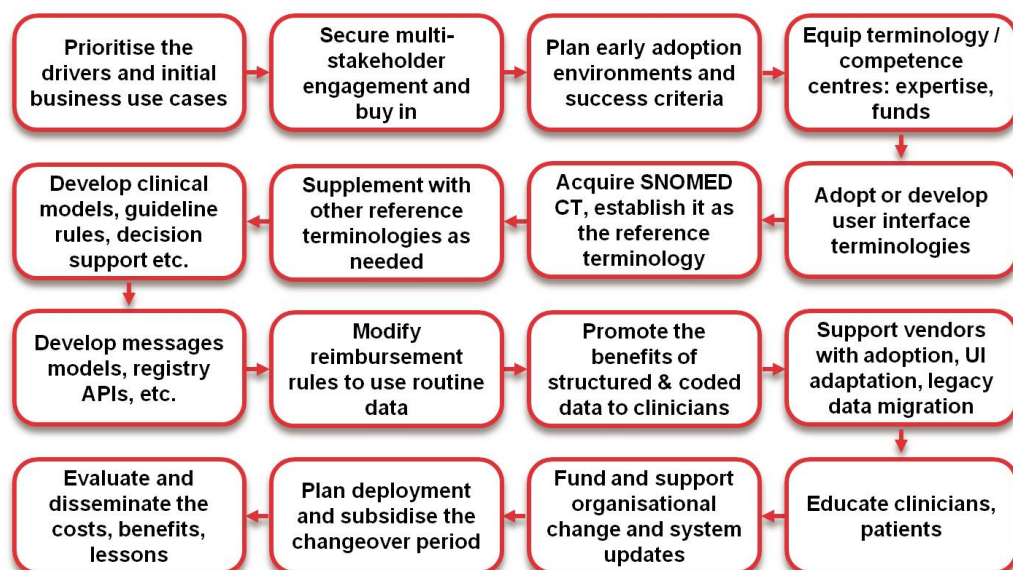
Incremental - as opposed to iterative - means that each pilot use case must be complete and lead to benefits in itself. Pilot use cases should ideally include implementation in software, use of terminology in clinical practice and for secondary purposes as well as evaluation of cost and benefits compared 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 use case-based solutions that are too focused and would lead to an incoherent solution upon wider adoption.

The benefits of terminology ecosystems 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 on semantic interoperability, terminologies, and ontologies in general as well as on SNOMED CT in particular. Information about added value for organisations, healthcare providers, and health authorities must be provided. User acceptance requires that terminology resources are easily available in a standardised format.



An example workflow for enhancing semantic interoperability involving the use of SNOMED CT

Recommendation 5

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

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. In addition, 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).

Terminologies, associated clinical information models, and other semantic interoperability assets should be publicly available for implementation and use on reasonable terms (with an affordable fee or free of charge) to the ICT industry and to healthcare providers, across Europe, in order to enable semantic interoperability and to underpin cross-border health services.

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

Recommended actions

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 physicians, 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 outcome of these decisions.

In this context, the EU could invite standards 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. The EU might consider funding exchange programs for capacity building for terminology projects.

A short term action plan with regard to eHealth Digital Service Infrastructure, 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 Infrastructure 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 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. 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 [ASSESS CT D4.4 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 health-care 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. It 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 operationalisation 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 capitalize on the experience in Member States and assure sharing and exchange of research findings, best practice experiences, multidisciplinary expertise.

A special focus of these coordinated efforts is seen in the need to demonstrate a positive cost-benefit ratio of implementing SNOMED CT. Coordination should be pursued in collecting relevant economic information from existing evaluations and data as well as in exchanging good practices in a centralised manner (e.g. as part of an EU observatory).

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.



ASSESS CT recommendations for SDOs

Arising from recommendation 1

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.

Arising from recommendation 2

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.

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.

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.

Arising from recommendation 3

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 care actors and patients, across Europe.

Arising from recommendation 4

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.

Arising from recommendation 5

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.

Recommended further reading

Key ASSESS CT Deliverables

D1.4 Current and future use of SNOMED CT

This report investigate existing experiences with the use of SNOMED CT, as well with that of other large-scale terminology systems. Actual experiences required complementary expert consensus, because empirical evidence and formal evaluations remain limited. Given the complexity of this topic a mixed methodology was used, including a literature review, online and interview questionnaires, focus groups, workshops and feedback on interim findings during conference presentations and invitation only events.

D2.3 Multilingual and multidisciplinary study of terminology coverage and quality

This document describes two studies that scrutinize the fitness for purpose of SNOMED CT, compared to other terminology settings. Terminologies were tested for coverage and agreement in clinical text annotation, as well as in manual binding to clinical information models. The latter use case showed a better performance both regarding concept coverage and agreement for SNOMED CT. The former showed equivalence of English SNOMED CT free text annotations to an alternative, UMLS-based scenario. The Swedish SNOMED CT version was superior, but the French and Dutch versions, where only translations of a subset were available, were inferior to the alternative.

D2.4 Use of terminologies for representing structured and unstructured clinical content

This report introduces the notion of user interface terminologies in contrast to reference terminologies. Three terminology settings (SNOMED CT against an alternative, UMLS-derived hybrid terminology and a local terminology collection), are analysed under user interface terminology aspects. It investigated the coverage of such interface terms in these three terminology scenarios against clinical text samples in six languages, using natural language processing and manual annotations. It furthermore proposes a method on semi-automated creation of user interface terms and describes its implementation, ongoing maintenance and formative evaluation.

D3.3 Cost-benefit analysis and impact assessment

This deliverable addresses the need to provide economic evidence to serve as the basis for investigating the fitness of the international clinical terminology SNOMED CT as a potential standard for EU-wide eHealth deployments. The literature analysis showed that previous work focuses predominantly on technical issues of SNOMED CT implementation, and wherever costs and benefits are discussed, they are descriptive and not quantified. The IHTSDO through a business case study has taken significant steps towards filling the gap by providing costs and benefits complemented by first quantification attempts and evidence collection. Our work builds on previous efforts in the area but goes beyond by offering a robust framework for assessment of costs and potential benefits – with the aim to provide quantifiable figures to serve decision and policy makers in Europe.

D4.4 Policy and strategy recommendations

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 up to August 2016.

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