DELIVERABLE

Project Acronym: **ASSESS CT**

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

D4.2 Policy Workshop Validation Report with Experts and Member States

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PP	Restricted to other programme participants (including the Commission Services	
RE	Restricted to a group specified by the consortium (including the Commission Services	
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Revision History, Status, Abstract, Keywords, Statement of Originality

Revision History

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1	28/01/16	Veli Stroetmann	empirica	Draft summary of canvas
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Abstract (for dissemination)	This deliverable reports on the results from the policy workshop focusing on success criteria and operational strategies in SNOMED CT implementation. The findings of the workshop, validated by expert partners from member states and clinical terminology domain, underpin the quality and the acceptance of the ASSESS CT conclusions and recommendations.
Keywords	Business driver, strategy, barrier, adoption, 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This deliverable contains original unpublished work except where clearly indicated otherwise.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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1 Introduction

On January 14, 2016, a meeting of experts and policy makers was held in Brussels in preparation to the development of recommendations for the adoption of SNOMED CT and other large terminology systems, as part of a strategy towards advancing the semantic interoperability of health information.

This meeting was held within the framework of the EU-project ASSESS-CT.

The aim of ASSESS-CT is to examine, from an international perspective, the national experiences so far gained in the adoption of SNOMED CT and other large terminology systems. The project will ultimately publish recommendations to the eHealth Network, the European Commission and to other decision makers and stakeholders on the suitability of SNOMED CT as a potential standard for EU-wide eHealth deployments, from clinical, technical, financial, and organisational aspects. Such deployments might primarily serve within border interoperability purposes or cross-border information and knowledge flows, or both.

These recommendations will emphasise any added value of Member State cooperation on an aligned European adoption strategy, and will indicate the steps needed to develop and implement such an adoption strategy.

A first important next step on the journey towards developing the final project recommendations is to better understand the issues, challenges and success strategies that have been encountered in different countries that have some adoption experience of SNOMED CT or other large terminology systems. This was already documented in preliminary work in Work Package 1 (Deliverable 4.1: Portfolio of (best) practices), where issues and challenges were collated that have so far been uncovered during adoption programs and projects, and some mitigating success strategies were identified.

A second important next step, addressed in the Policy Workshop of January 14, 2016, was to make an inventory of the terminology roles (or targeted application areas) that different countries have prioritised, and to analyse how different adoption scenarios may address challenges in user interface, terminology binding, and exploitation of semantic services, complemented by non-technical aspect such as obtaining consensus about use, stakeholder involvement, education and financing.

The Policy Workshop was invitation-only. The invitees were chosen for their practical experience of developing or effecting adoption strategies for large terminology systems, or intention to develop such a strategy in the near future.

2 Workshop objectives

1. To define a range of terminology roles and adoption scenarios for advancing semantic interoperability that includes the use of SNOMED CT and/or other terminology systems, and for each to list some key business benefits that could be used to determine success. The list of business drivers in Deliverable 4.1 served as the input for this activity, along with emerging results from Work Packages 1, 2 and 3.

2. To agree the important contributing components of an adoption strategy for each terminology role, drawing on the list of operational components in Deliverable 4.1.

3. To identify, per terminology role, the most critical challenges to be overcome and propose possible mitigating success strategies.

4. Using the above results, to derive a decision tree that can enable a Member State or Region to determine their ideal terminology role(s) and adoption scenario(s) based on its prioritisation of business benefits and capability to implement a suitable adoption scenario. (It was recognised that this objective would be difficult to meet during the workshop itself, but could be an ambition to address afterwards.)

3 Organisation of the workshop

3.1 Introduction to the project and early results

After a quick round of participant introductions, an introductory plenary session presented a summary of the objectives of the ASSESS-CT project, the work packages and the workshop itself. This included a summary of the emerging results from each of the empirical Work Packages 1, 2, 3. (A summary of the project itself is not reproduced here, since this is available through other project deliverables.)

Key findings from Work Package 1:

- The possible role of SNOMED-CT as a reference terminology and mappings broker into a terminology eco-system
- The current lack of evidence of benefits
  - There is a low availability of evidences/best practices/examples on the usage of SNOMED-CT.
- Strategic long-term benefits
  - IHTSDO assures a transparent and robust maintenance process
- Licensing and cost issues
  - The SNOMED-CT license cost structure ("on/off") is a critical barrier in the decisional / start-up phase when the potential benefits of this change have not been yet completely evaluated / experienced.

Key findings from Work Package 2:

- Manual annotation results:
  - No significant difference in concept coverage and inter-annotator agreement between SNOMED and a UMLS extract (without SNOMED-CT)
  - High concept coverage for the Swedish version of SNOMED-CT but low concept coverage for all languages other than English, which shows the potential of SNOMED, where translation activities to major languages are ongoing
  - French and Dutch results need to be interpreted in the context of known incompleteness of these translations
- Very preliminary findings: SNOMED-CT outperforms other terminologies when annotating (English) clinical texts fully automatically. The evaluation of other languages is ongoing work
- Structured documentation: SNOMED-CT provides an advantage over selected alternative terminologies in that larger coverage is achieved without reducing reproducibility. Reproducibility may even be increased given sufficient SNOMED-CT training

Key findings from Work Package 3:

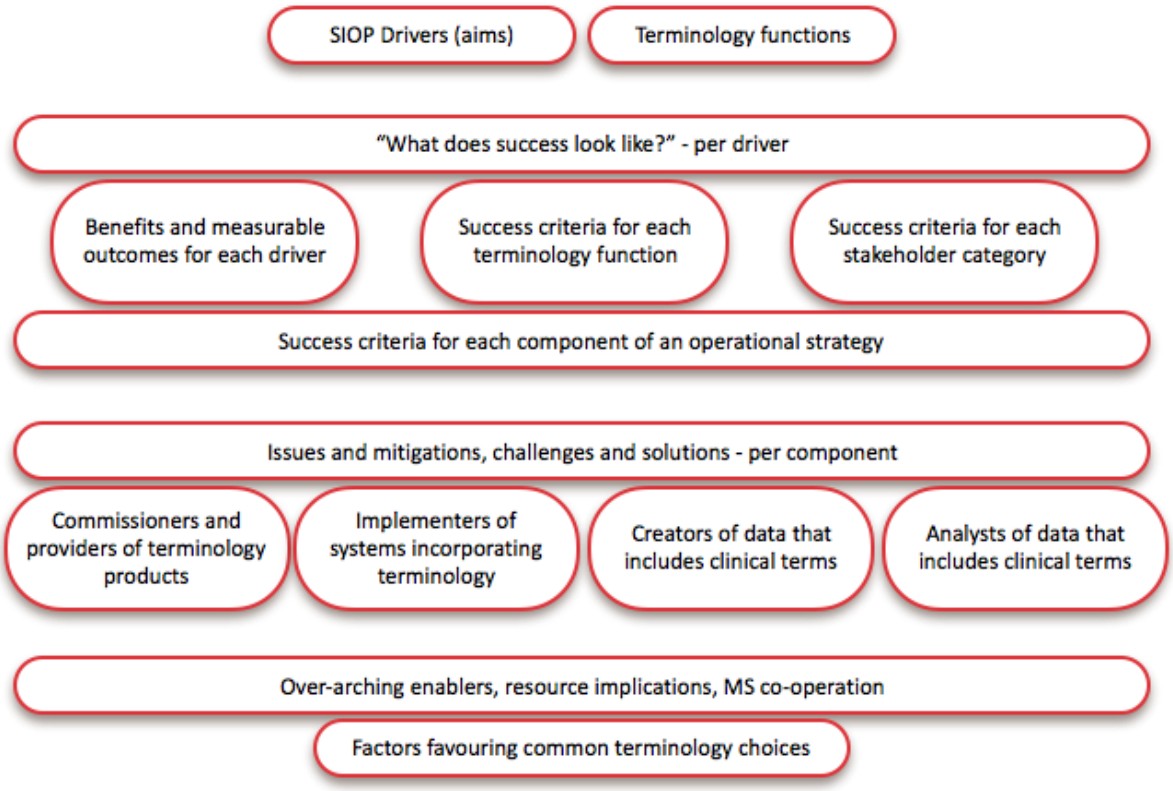
- Definitions and assumptions to the operationalisation/quantification of cost indicators developed – many are intangible or non-financial
- Benefits identification must focus on observed benefits as opposed to expected benefits:
  - 1) bottom-up: analysing focus group/ questionnaire outcomes to start constructing case studies with real evidence
  - 2) top-down: categorising benefit indicators focused on narrow, actually experienced benefits
  - Evidence (concrete numbers) of costs and benefits related to using SNOMED-CT in Denmark and Sweden collected during meeting in Copenhagen

First version of cost-benefit analysis tool is now available, but is meaningful only when project/country based.

3.2 Brainstorming sessions

Most of the workshop day, and the benefit from the participants' expertise, was channelled through breakout (brainstorming) sessions. Two brainstorming sessions were held, with 3 groups in each session. Groups of 4 to 6 participants discussed the challenging questions set for for each breakout session, using a canvas diagram, sticking yellow reminder cards with key concepts to the canvas. Figure 1 below provides a diagrammatic schema of how the breakout sessions were organised, along with plenary sessions to feed back the results of each break out group.

Figure 1: Diagrammatic schema for the breakout sessions



3.3 First brainstorming session: what does success look like?

This breakout session considered first what the end result would be of successful adoption of a well-suited terminology system, within an overall *infostructure* supporting good quality semantic interoperability. Participants were advised that the project was looking especially for contributions based on their experience, either personally or from the country of countries in which they have been working. Inevitably, though, some extent of expert opinion was needed to complement this and fill in the gaps. Three groups were defined, to address the three topics below.

Group A: SIOP DRIVERS

This group considered how success of an information and deployment strategy should be defined, and what could be the measurable outcomes for the formal evaluation of benefits:

…for each of 6 drivers towards Semantic Interoperability:

- Better quality and safety of care to individual patients
- Enriched EHR data exchange for continuity of care
- Cost reduction in Health Care
- Optimising reimbursement
- Analysis (secondary) use
- Cross-border information and knowledge

…for 4 types of stakeholders:

- Providers
  - Public Health departments, Health care agencies, Hospital Directions,
- Implementers
  - Vendors, IT-departments of Professional organisations, hospitals, Health Administrations
- Data Creators
  - Health care professionals
  - Patients
- Data Analysts
  - In science
  - In regulatory processes
  - In quality assurance

Group B: TERMINOLOGY FUNCTIONS: SUCCESS CRITERIA

Which terminology functions (see list below) would be most needed to achieve each of the six main drivers (see list above). What characteristics of the terminology or the way it is delivered would be most needed to ensure its success?

Group C: STAKEHOLDERS: SUCCESS CRITERIA

For each of the four stakeholder categories below, what are the actions and activities that most importantly need to be enabled for each of the six main drivers?

- Providers of terminology products and tools
- Implementers of systems incorporating terminology
- Creators of data that includes clinical terms
- Analysts of data that includes clinical terms

3.4 Middle plenary

Each facilitator summarised their group's conclusions in the first part of the middle plenary session. By taking the components of the operational strategy (from Deliverable 4.1) as a list of headings, the second breakout session endeavoured to map the success criteria and success factors identified from the previous breakout onto the operational components that most need to demonstrate each success.

3.5 Second brainstorming session: what are the main components of an operational strategy?

For each of the stakeholder categories listed below, consider the components of the operational (informatics and deployment) strategy presented earlier. For the most relevant components for each stakeholder category, what are the important:

- success factors
- issues, challenges, pitfalls to avoid
- solutions and mitigations
- external dependencies

Group 1: Commissioners and providers of terminology products

Group 2: Implementers of systems incorporating terminology

Group 3: Creators of data that includes clinical terms

Group 4: Analysts of data that includes clinical terms

3.6 Final plenary

The final plenary session looked at the overarching enablers that need to be put in place, and probably funded and driven, by Ministry level and other top-level decision-makers. There was particular emphasis on those that could be undertaken in collaboration across Member States, thereby highlighting the added value dimension of European cohesion.

4 Workshop findings

4.1 First brainstorming session: what does success look like?

4.1.1 Group A: SIOP DRIVERS

Highlights

Better use of terminology within EHR systems, leading to more accurate (fine-grained) clinical data, resulting in:

- more accurate clinical decisions, more accurate decision support
- better adherence to and evaluation of care pathways: safer and more effective care
- simultaneously optimize reimbursement (the ability to verify reimbursement claims by clinical audits)
- learning health system optimisation

Measured through:

- reduced registration burden due to increased level of completeness of quality indicators
- reduced number of ancillary coders due to reducing need of manual coding
- reduced labour cost of manual engineering in national or regional surveillance scheme for infectious disease
- the ability to verify reimbursement claims and other forms of administrative reporting by examining (auditing) the real data in EHR systems

Additional points

The breakout group focused on success drivers and relevant measurable outcomes, striving to come up with measurable outcomes. 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”.

Accuracy of data enabled by SNOMED-CT can lead to a change, namely more accurate decisions, fewer mistakes, better informed decisions. There can be no good EHR/eHealth system without a good clinical terminology.

Success drivers always seem to overlap with expected benefits, e.g. cost reduction and optimising reimbursement often link to better quality and safety of care and enriched EHR data.

Two examples of measurable outcomes:

1. Reducing the registration (data entry) burden on regional/national health system settings by increasing the level of completeness of quality indicators and reducing the effort needed to feed the quality indicators.
    - e.g. Holland spend 80 million Euro on the registration of quality indicators. This cost could be reduced by reducing the registration burden.
2. Reducing the number of clinical coders by reducing the extent of coding through the use of a clinical terminology. For example, Belgium aims to reduce its current number of 800 coders.

When talking about success factors of terminology, the group frequently came back to optimising reimbursement, 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 which simultaneously prevents up-coding.

Better quality fine-grained terms that can represent the expressions which 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.

Interoperability of EHRs cannot be achieved without terminologies.

Another measurable outcomes is illustrated by national or regional surveillance schemes for infectious diseases. At present there are many different databases and reporting systems, and manual engineering is needed to bring this surveillance data together. The labour cost of manual engineering saved by using a common terminology within integrated systems could be measured.

A challenge and a success factor is how to sell 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.

It is very difficult, yet important, to build and contextualize a terminology system to match the needs of clinicians in order to realize the benefits. Ongoing R&D with vendors is seeking to figure out the opinion of clinical users.

Use cases can be a way to show good use, from which vendors and providers can benefit from using terminologies (a kind of market creation through opportunities). Many vendors are reluctant to build system with SNOMED-CT as its complex, costly and no one (purchasers or end users) are asking for it. This is a boot-strapping problem: suppliers will not build in SNOMED-CT until someone asks for it; buyers will not ask for this capability until it has been built and demonstrated.

4.1.2 Group B: TERMINOLOGY FUNCTIONS: SUCCESS CRITERIA

Highlights

- For health data to work for different end users, it is most important to improve data quality directly during data entry, where guidance for clinicians to choose the correct clinical terms for their context of use will be needed.
- It is difficult to successfully implement and derive benefit from using only a small amount of SNOMED CT.
- Existing classification systems are the *de facto* language for cross-border comparisons, but will not help to achieve most of the clinical care drivers.
- Decision makers should take the responsibility for enabling collaboration, and ensuring that their policies and management processes will not hinder the development of terminologies and related semantic interoperability solutions.

Additional points

The following list of terminology functions was elaborated:

- End-user (Lexical/Unilingual)
- National reference terminology
- International reference terminology
- Aggregation terminology (terminology)

These four categories of terminology were perceived as an appropriate level of simplification within the group. The focus was on what kind of functionality is needed to achieve success.

The group focused on the data entry aspect, when talking about better quality and safety of care. For local translation, which can be used by different end users (patients, clinicians, other health professionals), the need to improve quality of data is already at the point of data capture.

One problem of SNOMED-CT adoption is if one starts using it bit by bit: one has to use it all for it to work.

Existing classifications like ICD are the *de facto* language for cross border communication or healthcare outcome comparison, but are not contributing much to the upper part of the matrix. 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. The EC could help to create resources of common value, and facilitate platforms for collaboration for end-user terminologies development. The collection, aggregation and cross-mapping to SNOMED-CT of popular terms used by health professionals could also be supported by the EC. The EC's role to enable collaboration and manage the process politically is important, also in terms of timeframe.

To achieve higher data quality, it is important to guide clinicians to choose the right terms in their clinical and care context.

eHealth networks are also receptors of recommendations, and for them the recommendations will need to be prioritised, though this was not the focus of this workshop. This workshop was intended to help better understand the landscape and background where those recommendations should be build on.

[The EC project officer in this breakout group was looking for a simplified description or recommendation for policy makers in Member States or the EC (simpler than the four categories of terminology function proposed here).]

4.1.3 Group 3: STAKEHOLDERS: SUCCESS CRITERIA

Highlights

- Governance is needed to set the boundaries for all players in the field, and with a mandate to define the priorities for standardization. A one-stop shop approach could be used to deploy data and regulation to all stakeholders, which can help standardization.
- Clinical models provide an important relevance context for terms, and reduce the complexity for the end user.
- Collaboration should be well-structured and well-documented in order to be effectively evaluated, improved and replicated.
- The strategy has to be multi-professional, patient-centred, yet standardized.
- There is a need for tools, education and awareness of the use and value of semantically interoperable records.
- The triplet of terminology, workflow, record structure are all important.

Additional points

Governance which sets boundaries and framework for all the players in the field needs a mandate. Standardization comes from the interaction of governance and mandate. A one stop shop can be used for access to authenticated data and regulations for all players, not only software tooling but also a kind of governance.

A context-relevant environment is needed since creating context for terms used can reduce complexity. A multi-professional environment with structured collaboration and documentation gives awareness to the whole Plan-Do-Check-Act chain.

A patient-centred, patient-oriented, and patient-understandable approach is important.

The use of benchmarked and evidence-based pathways can be achieved only by combining standardization, awareness, and a patient-centred solution.

We need tools but good tools are not available in the market because no vendor is building them. We also need education and awareness (metaphor: making it a habit for drivers to have ABS in a car).

With reuse of data, good common definitions and interoperability, the administration burden will decrease significantly, which is a major benefit.

Actions should relate to the essential triplet of terminology, workflow, record structure. Tools exist but are not yet used in action.

4.2 Second brainstorming session: what are the main components of an operational strategy?

4.2.1 Group 1: Commissioners and providers of terminology products

Highlights

- The most important success factors are free and easy access to pilot and test versions of the terminology, resolution of the licensing costs issue in non-SNOMED-CT countries, and the provision of education and training. Incentives and organizational support to collaborate may also be required.
- The main issue is the sheer size and complexity of SNOMED-CT. There is a need to invest more in sophisticated quality assurance methods, and to learn from past experience, to ensure high quality of the product.
- Investments should be made in developing user interface terms which are the synonyms that are really used by clinicians and self-learning system.
- The main external dependency is on the quality of national and international governance and funding.

Additional points

The challenge for gaining a holistic view of terminology, information models and workflow is that there is little consensus on informational models and boundaries despite EU projects like SemanticHealthNet which hoped to find solutions. One solution can be building formal foundations.

Free and easy access to products for testing, not only for research but also in clinical settings, is another success factor. The challenge is the license costs, which might be supported by national or EC funding.

Training and education is needed for using the technology including promoting stakeholder engagement. The can be mitigated by providing financial incentives and organisational support.

The high quality of products is another success factor but is challenged by the inherent complexity of the terminologies. Investment should be directed towards developing more sophisticated QA methods.

Past experience should be used to facilitate present and future development.

The terms provided should be close to users and transparent. Challenges with this include term acquisition and the degree of context dependence (quasi-synonymy). This is not only fragmented between dialects within a nation but also in sub-languages of clinical professions. The solution is to develop self-learning systems based on corpus linguistics, not only raw corpora but also clinically annotated corpora.

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 undertake pre- and post-coordination.

Nothing was written by this breakout group on external dependencies because at the end they perceived that almost everything depends on certain national or EU policies or governance and funding.

4.2.2 Group 2: Implementers of systems incorporating terminology

Highlights

- The most important success factor is clinical models that have been agreed by clinicians, represented respecting one or more of the existing international standards, having good coverage of high-priority clinical areas for shared care, ready and endorsed in a timely fashion; this needs to be driven through a national information strategy.
- 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 and for other management purposes.
- 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.

Additional points

The group defined implementers primarily as healthcare organizations who implement the solutions. However, the group noted that the term implementers comprises not only adopting organisations but also software companies.

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 group did not have time to discuss testing and qualification of implementation, but felt these to also be important.

A success factor is to choose clinical models that are commonly agreed by clinicians and ICT departments, at the same time respecting one or more international standards. Challenges include getting acceptance of users 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, for choosing the right models. This issues cannot be solved by organisations on their own but rely on international cooperation. 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: namely getting clinical endorsement from users. This would only work with the help of a national information strategy which is also implemented within institutions.

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 of 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.

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. Some user interfaces face the problem of an immature technology and cognitive limitations that have yet to be addressed. The solution to this relies upon state of the art academic research and products from high tech companies.

4.2.3 Group 3: Creators of data that includes clinical terms

Highlights

- Intuitive data entry is the most important success factor: applications and tools need to be easy to use, supporting multidisciplinary teams and promoting the recording of data for the use of others; clinicians need to have support from experts, RefSets and even real-time feedback during data entry.
- Data creators are often also data users, especially for the care of individual patients, and they need to see that the outputs from good-quality data provide insights that bring benefits to patients.
- There are perverse incentives such as reimbursement schemes that discourage accurate and faithful clinical documentation.
- Issues of ownership and processes in which the new development of terminology might take place need to be considered, to encourage data creators in using the solutions.
- 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.
- There should be an international management system for users to report errors in the terminology that can be rapidly collated and disseminated, even if the correction of the actual errors takes some time.

Additional points

Data creators hide the fact that there is a lot of relevant debate and discussion about terminology ease of use. This group focused on the input and output/use of data.

The first success factor for creators of clinical data, but also reflecting the perspective of implementers, was felt to be intuitive data entry. The challenges include how to deal with old habits and clashes with the new world, how to support multidisciplinary teams. Solutions could work through guiding input or through RefSets, and has to be derived from professional support. External dependencies are tooling for intuitive input and real-time monitoring or

assistance where data creators receive feedback and comments when entering data, to avoid initial data entry problems.

Incentives such as the reimbursement system might pose challenges on detailed and accurate data entry.

The IHTSDO license is another issue, not only the costs but also the ownership and processes which new developments might establish.

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. 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. External dependencies exist here in terms of benchmarking facilities made available across-border to support the feedback loop.

The EC should host the terminology management service internationally, to rapidly collect and share corrections across languages, but there is benefit from national adaptations and also national terminology management systems.

4.2.4 Group 4: Analysts of data that includes clinical terms

Highlights

- The major success factor for analysts will be increasing the proportion and quality of structured data.
- There will be a need for cross-mappings and legacy data conversion, which cannot all be done by the analysts and 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.
- 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.
- There is a need to invest in ontology resources, mappings and legacy system adaptations at every step of the way including education for data analysts.
- Collaboration should take place to allow feedback when transferring data to decision makers or end-users.

Additional points

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.

Success factors include confidence in the results of analysis and reporting standards. Technical and content validation also needs to be undertaken. Collaboration should be carried out to report feedback to decision makers.

Quality of ontology resources, mappings and legacy system conversion are all very important; education is needed.

5 Conclusion on Member State co-operation

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.

Smaller scale clinical data sets might also be useful for 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 the consistent use of information models, clinical models and terminology value lists.

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-border needs for semantic interoperability. 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 identified in this workshop also have drivers for Member State collaborations and comparisons. These include gathering and sharing patient safety intelligence (e.g. adverse event reporting, pharmaco-vigilance, pharmaco-epidemiology, Infection outbreak control), and sharing and comparing various benchmarks and quality metrics.

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 being able to pool analyses that have been computed on consistent data held in each country: there would be value in registries, bio-banks, rare disease communities adopting common semantic interoperability approaches, irrespective of how often subject level data might be shared between them.

On a short term and pragmatic level, Member State co-operation on semantic interoperability can enable sharing of costs (such as clinical model development, term translations, RefSet and value set development, sharing best practices and quality assurance processes, and all countries being able to take advantage of internationally agreed definitions of concepts). This collaboration is not in itself a strong driver for investing in semantic interoperability, but may influence decisions about what semantic interoperability approaches to select.

There are, therefore, many reasons why Member States might wish to collaborate and benefit from common terminology choices, and more broadly around common approaches to advancing semantic interoperability.

6 Annex 1: Agenda and participant list

6.1 Agenda

Thursday, 14th January 2016, 10:00-16:30h, Brussels

European Liaison Office of the German Research Organisations

Rue du Trône 98, B-1050 Brussels

Workshop objectives

- To define a range of terminology roles and adoption scenarios for advancing semantic interoperability that includes the use of SNOMED CT and/or other terminology systems.
- To list key business benefits to determine success. Business drivers in the Deliverable *Portfolio of (best) practices* (D4.1) will serve as the input for this activity.
- To agree the important contributing components of an adoption strategy for each terminology role, drawing on the list of operational components in D4.1.
- To identify the most critical challenges and propose mitigating success strategies.
- To derive a decision tree for EU Member States or Regions to determine their ideal terminology role(s) and adoption scenario(s).

Table 1: Workshop agenda

09:30-10:00	***Arrival and coffee***
10:00-10:15	**Welcome and introduction of participants** *Dipak Kalra*
10:15-11:00	**Plenary session: summary "*Portfolio of (best) practices" (D4.1)*** *Dipak Kalra*
11:00-13:00	**Breakout groups on:** • Drivers for semantic interoperability and success criteria • Stakeholders, terminology needs and adoption incentives
13:00-13:30	**Lunch break**
13:30-15:00	**Discussion and group work continued:** • Existing evidence and practical experience of developing/ effecting adoption strategies for large terminology systems • Critical challenges and solutions
15:00-15:15	**Coffee break**
15:15-16:15	**Summary: commonalities and differences across adoption scenarios**
16:15-16:30	**Final remarks and next steps** *Dipak Kalra*

6.2 Participant list

Table 2: Workshop participant list

	First name	Surname	Organisation
1.	Andrew	Perry	UK Terminology Centre, Health and Social Care Information Centre
2.	Arabella	D´Havé	Federal Public Service of Health, Food Chain Safety and Environment
3.	Catherine	Chronaki	HL7 Int. Foundation
4.	Daniel	Karlsson	Linköping University
5.	Dipak	Kalra	EUROREC
6.	Francois	Macary	Ministère des Affaires sociales, de la Santé et des Droits des femmes, France
7.	Gerald	Cultot	European Commission
8.	Hans	Van Belleghem	Twist BV/ Nictiz
9.	Heike	Dewenter	HS Niederrhein
10.	Ingrid	Mertens	Federal Public Service of Health, Food Chain Safety and Environment
11.	Jeremy	Rogers	SNOMED CT Implementation, Health and Social Care Information Centre
12.	Jeremy	Thorp	Health and Social Care Information Centre
13.	Luc	Nicolas	Federal Public Service of Health, Food Chain Safety and Environment, Belgium
14.	Meta	Geibel	European Commission
15.	Michèle	Thonnet	Ministry of Social Affairs and Health, France
16.	Michiel	Sprenger	NICTIZ, The Netherlands
17.	Päivi	Hämälainen	National Institute for Health and Welfare (THL), Finland
18.	Peter	Brosch	Federal Ministry of Health BMG, Austria
19.	Rainer	Thiel	empirica
20.	Rikard	Lövström	The Swedish Medical Association
21.	Robert	Van Der Stichele	Uni Gent
22.	Ronald	Cornet	AMC, dept of Medical Informatics
23.	Stefan	Schulz	Medical University of Graz
24.	Veli	Stroetmann	empirica

7 Annex 2: Breakout group canvases

Each breakout group collected its raw information on a canvas grid. These canvasses are produced below, although with recognition that these each contain a lot of shorthand and notes that might only be properly understood by those who participated in that group. These canvasses, contemporaneous notes, slides, pre-circulated material and transcripts of the plenary feedback sessions have been the date sources used to inform the body of this workshop report.

7.1 SIOP Drivers: Benefits and measurable outcomes

Table 3: SIOP Drivers: Benefits and measurable outcomes

	Providers	Implementers	Vendors	
Better quality and safety of care to individual patients • Care pathway auditing • Guidelines adherence (costs and safety)		• Accuracy of terms • More accurate decisions • Less mistakes/better informed • Information from labs -> measurement units		**Measurable outcomes:** • Registration burden, guide • Level of completeness • QA indicators • No. of coders per country
Enriched EHR data exchange for continuity of care Interoperability impossible without terminology	• CDSS only with quality clinical data • Learning health system			
Cost reduction • Adherence treatment guidelines • Surveillance without manual engineering	• Revalidation of professional education	• Lower costs & healthier citizens	• Less IT costs to society	
Optimising reimbursement • Transparency • “ICT -> DRG” to “SCT -> DRG”	• Healthcare planning also based on more accuracy			
Analysis (secondary) use				
Cross-border information and knowledge • Implementation of plans/adherence • Clinical audit against up-coding	• Post-marketing surveillance across EU	• Patient safety		

7.2 Terminology Functions: Success criteria

Table 4: Terminology Functions: Success criteria

	End-user (Lexical/ Unilingual)	National (EU) reference terminology	International reference terminology	Application classification terminology
Better quality and safety of care to individual patients • Facilitate coded data entry • Decision support	• Personalized data entry to support context (and prevent RTI)	• Context dimension/professional dimension?		
Enriched EHR data exchange for continuity of care • Multi-professional/setting collaboration • Communication with patients	• User interface integration. Push concepts from primary to secondary care and vice versa. • Lexical shell for patient preferred terms to communicate concepts to patient. • Contextual lexical definitions	• Broker terminology	• Broker terminology • Preferred level of hierarchy for concepts per type of health professionals	• Preferred level of hierarchy for concepts per type of health professionals
Cost reduction (in the healthcare system)	• Consumer. Patient.vocabulary. • Crowdsourced end-user vocabularies (bounded to unambiguous concepts)			
Optimising reimbursement		• Reimbursement coding system -> SCT		
Analysis (secondary) use • Public Health Management			• ATC -> SCT • ICD -> SCT	
Cross-border information and knowledge			• Lack of evidence for SCT yet	

7.3 Stakeholders: Success criteria

Table 5: Stakeholders: Success criteria

	Providers • Assets • Model the context (e.g. clinical models)	**Implementers** • EHR, hospital etc. • Health & clinical solutions • Create very intelligent UIs	**Data creators** • 1) user/input • Information literacy in health education	**Data analysts** • 2) users/output • Common indicators	**Resume of keywords** • Decrease administrative burden • Context reduce complexity • Multi-professional structured collaboration & documentation • Patient-oriented/centered/understandable • Benchmarking & evidence-based (pathways) • Common definition • Governance -> mandate • Standardization • One-stop shop • Tools • Education & awareness • ABS metaphor • Mandates to influence the record • Triplets
Better quality and safety of care to individual patients • Policy level driver (Public/population health = healthy population)	• Make minimal contextual parts (BBs) • Structured standards with minimized CMs • More completed coded document • Clean document of - Asset - Instruction of implementations - Description of use cases to be supported	• Improved & Efficient user interfaces • Better EHR systems to support more possibilities • Actual implementation of information standards	• Explain added value/train • Teaching/learning about semantics • Enabling decision support • Actual implementation of information standards	• Terminology-bound guidelines	
Enriched EHR data exchange for continuity of care • Terminology + workflow + structure • Bridging gaps (clinical & patients) • Patient/layman-	• Improved and complete terminology content • Multi-professional collaboration	• Use of standards -> allow working EHR systems market of component	• Crossing silos (GP/hospitals/nurse etc.)	• Crossing silos (GP/hospitals/nurse etc.)	

oriented terminology (synonyms for patients)					
Cost reduction (in the healthcare system) • For policy provider ensuring benchmarking (across the system & countries)	• Inventionize describing existing registries • Start early with new use case • Pooling of resources (e.g. within EU)	• Pooling of resources (e.g. within EU)	• Decrease admin burden (one time registration)	• Decrease admin burden (one time registration) • How to allow standardization and innovation	
Optimising reimbursement	• Common governance (including common rules of structured documentation • Consolidate from multiple terminologies (local, regional, national, international)	• Consolidate from multiple terminologies (local, regional, national, international)	• Finance deduction (less fraud & up-coding)	• Finance deduction (less fraud & up-coding)	
Analysis (secondary) use	• Refset development (terminology-binding) • Information model agreement • One-stop shop (national & EU registries)	• Analysis tool	• Populating and maintaining registries	• Align registers with EHR solutions • Good registers for secondary uses = analysis possibilities	
Cross-border information and knowledge	• Stimulate creation of national roadmaps • Diffuse knowledge in existing assets & use cases • Find solutions for licensing • Find core set for Europe			• Cross-border comparison of quality measures	

7.4 Commissioners and providers of terminology products

Table 6: Commissioners and providers of terminology products

Success Factors	Issues & Challenges	Mitigation & Solutions	External dependencies
• Holistic view of - Terminology - Info structure - Clinical workflow	• Little consensus on information models	• Formal foundation	
• Free and easy access	• License costs	• Community funding	
• Education/ training			
• Governance model & legal framework			
• Stakeholder engagement	• Lack of time	• Financial/organizational support	
• High quality product	• Inherent complexity	• QA methods	
• Learn lessons from the past			
• Close to use terms	• Term acquisition • Degree of context dependent synonymy	• Self-learning system of corpus linguistics	
• Adaptable/flexible to varying data entry models	• Expressiveness of represented artefacts (IM+terms) e.g. post-coordination		

7.5 Implementers of systems incorporating terminology

Table 7: Implementers of systems incorporating terminology

	Success Factors	Issues & Challenges	Mitigation & Solutions	External dependencies
• Adaptation of EHR with clinical models	• Clinically accepted common • Respectable standards • Incentives	• Get the acceptance of local users • Coverage • Critical mass at the right moment	• Cross-border cooperation • Ownership • Interoperation in national strategy • Incentives basket not only financial	• Getting clinical endorsement
• Maintenance and legacy data	• Adoption success • Terminological expertise • Higher participation and documentation	• Cost • Loss of history and continuity	• Public/QA cross-mapping	
• Testing and qualification				
• End-user interface	• Motivated and satisfied users • Assessing data accuracy	• Immaturity of technology • Cognitive limitations	• State of the art of academic research and high tech companies products	

7.6 Creators of data that includes clinical terms

Table 8: Creators of data that includes clinical terms

	Components of an operational strategy	Success Factors	Issues & Challenges	Solutions & Mitigation	External dependencies
INPUT	**Informatics strategy** ➢ Information models, message models ➢ Clinical model development/adoption ➢ Ontology resource ➢ Identifying iso-semantic representations ➢ Terminology choices for different functions ➢ Developing extensions, subsets, refsets, value sets, and binding to clinical models ➢ Defining and maintaining cross-mapping to existing and legacy terminologies un use ➢ Language translation and quality assurance ➢ Legacy data conversion strategy ➢ Approach to post coordination ➢ Terminology version management and distribution ➢ Licensing terms and license costs	• Idiot proof • intuitive • Plan, Do, Check, Act • Feedback Loop & Request for Change	• Old habitats and reference • Clashes with new world • Fin. system dependency block • IHTSDO licence (FIN+PROP)	• Lack of professional supporting e.g. Refsets • Total costs	• Tooling • More real time monitoring/ assistance
OUTPUT/ USE	**Deployment strategy** ➢ EHR system adaption ➢ Other legacy system adaptations ➢ Developing expertise ➢ Organizational change processes during terminology changeover ➢ Evaluation and research	• Insight of the effect in your data (regularly) • Quality of data	• Mistrust & fear (Input -> output)	• Transparency of definitions	• Data benchmark (you -> world)

7.7 Analysts of data that includes clinical terms

Table 9: Analysts of data that includes clinical terms

Components of an operational strategy	Success Factors • Context is king. Many different use cases.	Issues & Challenges	Mitigation & Solutions	External dependencies
Informatics strategy ➢ Information models, message models ➢ Ontology resource ➢ Defining and maintaining cross-mapping to ➢ Legacy data conversion strategy **Deployment strategy** ➢ EHR system adaption o UI and application adaption special UI, different request ➢ Other legacy system adaptations o Disease and procedures registries o Central (e.g. national) health activity reporting and reimbursement system and international reporting o Population health screening and surveillance systems (e.g. infection control, pharmacovigilance) ➢ Developing expertise o Development of educational materials Delivery of education programmes and onsite training	• Access to data, sources, method • Definition of aim, purpose, scope, output & report of analysis • Clear picture of data quality • Technical validation of data transmission • Content validation (e.g. compare analysis database data with original EHR with medical expertise) • Confident with their analysis results • Analysis adhering to reporting standards • Unified ways of documenting • EU level reporting tools for agreed use cases	• Ontology quality • Ensure data compatibility from different sources • Information model agreement & adoption • Consistent standard implementation	• Terminology server and refsets -> all vendors • Sampling measuring quality • Medical terminological competence via training	• SDOs, Health Department, Information model adoption • Unavailable of context of data collection • Many dependencies -> aim & context