

Health Terminologies: Criteria for decision making

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Summary of positions and discussion

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The purpose of this report is to give a brief overview of the discussions and main results of the WS. It focuses on Member States (MS) views illustrated in presentations, priorities and needs expressed during roundtable discussion, questions raised after presentations by experts or other MS representatives, etc. Our intention was to capture mainly MS concerns, and to summarise the main outcomes and action points without going into further details. All Power Point slides will be made available to the members of the eHealth WG, presentations by the experts are not being discussed here.

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1 Introduction / Setting the scene

In his introduction to the WS, *Ilias Iakovidis*, Deputy Head of Unit ICT for Health, pointed out that:

- Terminology is the heart of the record
- Most complex domain of eHealth
- Takes long time to understand
- Needs corporate knowledge (expertise) that continues
- Semantic interoperability is THE Issue for Europe to act
- This is the start of a process, continue as needed with help of *SemanticHEALTH* & *RIDE* projects
- Primary scope 'patient summary'

2 Overview of MS contributions and action points

2.1 MS presentations were made by:

NOTE: The presentations by MS were short 10 minute presentations on some topics. These statements are indicative only. By no means should these be considered as formal positions of MS.

2.1.1 Greece

- Priorities of Greek health policy:
 - Improve quality of health care, patient safety
 - Means: standardisation of processes
- Establish organisation for health standardisation
- Start simple, but move forward
- Willing to participate in joint EU process
- **Interoperability Strategy**
- Legal framework: Quality and Safety directly linked to digitisation and eHealth applications
- Standardisation
 - Strategic partnership with the Greek Standardisation Organisation - MoU
 - Services and processes first
 - Content (e.g. referrals, medical summaries)
 - Data (Identifiers, registries)
 - Terminologies and codifications, classifications
- Professional Involvement – the *Open Health Forum*
- Establish an *Information Authority and Competence Centre (KEPYSY)*

2.1.2 Ireland:

- Importance of standardisation
- Fragmentation is costly
- Domestic suppliers can't easily extend to EU market
- Self-regulatory capacity of sector is poor
- Need of government intervention
- Market oriented business-like approach
- New approach:
 - EC guidelines
 - CEN makes standards to fulfil essential requirements

2.1.3 Denmark

- Aim at single common models of concepts/terms
- *Reuse of primary data* is the driver for Semantic IOP
- Present IT is frustrating for the daily work of professionals
- Moving from messaging paradigm to *shared information*
- SNOMED CT a natural choice at this point of development
 - National proprietary solution too expensive
 - SNOMED CT the only terminology that fulfills all DK requirements
 - WHO must have an important role
- Invested in high quality SNOMED translation process
- Proof of the pudding: Copenhagen EHR system
 - pilot in a year

2.2 Roundtable results:

2.2.1 MS needs, priorities, open questions

Austria:

- Main interest in the issue from the *pay-by-performance perspective*, what is needed and what is important from this perspective?
- How good does the mapping from SNOMED to ICD-10 function?
- How does SNOMED support mapping to different registers of services rendered, for identification of fees to be charged (use for reimbursement)?
- What are the semantic implications of having different language-/ different culture-versions?

Finland:

- Is starting pilots on patient summary and use of terminology/for Public Health statistics, EHR system, looks at benefits

- *Integrating social and health care infrastructure* - Will SNOMED make it easier to integrate the social sector?
- *eSocial/Care project* - what data are needed to code, how common structure for both sectors, integrated terminology there.

Germany:

- Priorities stated in the law: patient safety, emergency data set, integrated healthcare
- Drug lists update (currently every 2 weeks)
 - How much of drug information is covered by SNOMED CT?
 - How often updated?
 - CEN to work on drug terminology?
- Policy makers need to have better understanding of the implications of SNOMED in terms of costs, efforts, acceptance by professionals
- Research/evaluation projects on pilot implementations in real settings (hospital, GP) are urgently needed, evidence on acceptance by physicians, effort involved, optimal user interface

Lithuania:

- Plans to sign the Agreement on the SNOMED SDO on April 01, 2006
- Pathology Centre has translated only some parts of SNOMED, only what is needed
- Very interested in international collaboration
- Question: Do we need LOINC in addition to SNOMED? Answer Snomed: Clinical LOINC is not integrated, only laboratory LOINC

Sweden:

- Interested in a thorough analysis of the consequences of joining the SNOMED SDO or not
- Starting two months work on a detailed analysis of needs and solutions, evaluation, assessment of pilot projects
- What are the expectations, benefits from shared terminology?
- Does use of SNOMED CT improve patient safety, to what extent?
- University doctors have expressed their need for terminology

Estonia:

- Does not have SNOMED experience
- How to acquire this to start a pilot in a key hospital?
- How to go from there to the primary care level?
- Use of EU structural funds to finance this?

Malta:

- Opening of a new hospital, introduction of an EHR system. Must do it right from the beginning in the 2 hospitals of the country, this is the only window of opportunity to introduce a clinical terminology standard.

- 2 national languages (English is the “working” language), therefore an increased requirement to adopt a terminology standard in English, but from the political point of view it is important to have the potential to localise the terminology at a later point in time (e.g. for non-English speaking citizens to have access to their records).
- Questions:
 - How is the localisation QA - what role does the SDO play here in the interest of the patient? (Answer "Create accreditation standards")
 - Elaborate more on the advantages of full membership of the SSDO
 - Possibility to buy a “small scale” standard?

The Netherlands:

- Starts with basic infrastructure of EHR, initial focus on medication to reduce cost of mismatch of information.
- Similarly: what is the central problem in Europe: Look at patient summary, and see what has to be solved there. Only then discuss SNOMED. Create policy awareness for such an approach.
EU highest priority is on interoperability, part of this is semantics. Part there from is patient summary, EU common denominator should be the medication summary
- No awareness in NL about SNOMED, little experience

2.2.2 Contribution by France

Perceived needs:

- Cross reference between clinical & biomedical info
- Integration of data from diverse sources
- Relationships between info/terminology model
- Linkage to indicators & statistics
- Understandable by diverse actors : citizen, HCP, GP...
- With automated methods & tools
- Harmonisation through all Europe at least
- Multilingual pathways

2.3 What to do next?

- To investigate the needs and views of different MS (nat.) stakeholders
- To appoint an ad hoc EU (Technical) Committee or Workshop (eHWG, CEN,...) with experts from Snomed, Galen, FMA, WHO FIC network, GO to define the outline of a work program for a Terminology / Ontology international coordinated development
- To *assess the Danish model as a case study for MS*: Snomed SDO choice : compare - criteria/method

The main issues for future decisions

- Are MS aware of the role of clinical terminology among different other factors ? (architecture, messages, security, information model, etc)
- Are MS ready to invest on this topic, how much (clinical terminology / terminology artefacts) for which Added Value ?
- Is an European ICT coordination or support (as option 2 or 3) useful for MS and able to strengthen European R&D in the world (links with WHO, roles) ?
- Is Snomed CT to day the “golden reference” for any national language and for any use (proof of usage)?

The four potential options

- Each Member State follows its *specific and separate developments* - costly, but option needed now or not?
- European ICT *development “from scratch”* normal engineering, ontology, multilingual terminologies
plus National diffusion and training
- *European ICT development* based on a consensual list of clinical terms (SNOMED CT ?) based reverse engineering, ontology, multilingual terminologies)
plus National diffusion and training
- SNOMED SDO (proposal with adjustment, multiple traditional translations (see DK) , clinical validation, transforming tools for different users)
plus National diffusion and training

2.3.1 The debate

- Need of *more knowledge, sharing of experience*:
- *Evaluation* of different terminologies: uses, proven benefits, costs of translation, implementation and sustainability
- What are the *hidden costs* (for users, the health system, ...)?
- ROI, what % of all terms is really needed, business case for terminologies?
- Evaluation of implementation projects, lessons learned
- Assessment of the *Danish experience* in translating and later of its implementation of SNOMED
- Do we need other terminologies, classification if we have SNOMED, e.g., LOINC (lab is integrated in SNOMED, but not clinical LOINC)
- *EU highest priority: interoperability, part of it – semantic interoperability (translation)*
- *EU common denominator: patient (medication?) summary* -look at terminology issues (needs, uses) from this perspective
- Do we need a *bottom-up* or a *top-down* approach? Or both?
- *User needs*: is there a push from health professional organisations to introduce terminology, will they use it?

- Will SNOMED make integration of social care easier or more difficult – *concept of social care, aging society, especially important for Europe*
- User interface (EU research focus) very important but outside the scope of SNOMED
- Needed: a management model for translation, a leading international organisation to permanently organise this task
- What are our *future needs*??
- Open source approach?
- How to involve CEN etc. to avoid segmentation of EU market (SNOMED licence prohibits use by industry in another Member State – do we need an EU licence)?
- What factors will influence an implementation, when and where?
- Smaller MS would profit from pilot projects
- Bigger MS have problems with legacy systems
- Collecting terms nationally vs. translating SNOMED
- Concept based translation vs. concept development
- *Concrete evidence* for added value needed
- Reliable evidence/information/details on present real usages (quantities, experience, proven benefits etc.) needed
- Technology to really make use of this is still not there, only planned to become implemented in MSs
- Intermediate stage to associate with SSDO for countries available? (to run pilots before joining)
- User involvement: patient, GP, specialists, professional bodies – develop a *strategy for user involvement*
- International cooperation helpful? Use eHealth WG for this? Special Interest Group (SIG) of MS?

2.4 Homework:

2.4.1 SNOMED SDO

- Identify SNOMED CT implementations that:
 - Have real, reliable data demonstrating good ROI
 - Have potential to demonstrate ROI
- Case studies of concrete pilot implementations, esp. not English based ones (application fields, process, costs, benefits, lessons learned, sustainability consequences)
- Provide validated evidence on market share in various (major, non-English) countries
- Illustrate how SNOMED supports the integration of social care / case study
- Consider entry level membership

2.4.2 MS

- Define precise requirements for additional workshops, e.g. with respect to

- deeper knowledge needed on concrete aspects (which do you have in mind?) of use of terminologies, ontologies, classifications, ... (like team-based health care, trans-border needs, quality assurance, public health applications, statistics, reimbursement, management, support for (clinical) research, knowledge management, medication, ...)
- priority areas of application in your health systems, needs perceived, intended usage
- List your priorities in order of relevance, so that clear tasks can be defined

2.4.3 EU/projects

- Arrange for an inventory on costs of developing and sustaining terminologies and classifications
- Organise follow-on workshop(s)
 - more background on terminology 'theory'
 - in conjunction with eHealth WG meetings
- Make Canadian materials available