Guideline for semantical interoperability: Implementing national reference terminologies in French healthcare and welfare sectors

Phase 4 – Implementation

Summary

November 2019 - Version 1
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1 Introduction

With the surge of modern medicine and technological innovations within the information systems sector, the French healthcare system has never produced that much data. However, at the time of “big data » and « personalized » medicine, one must admit that this information remains underused in healthcare and welfare sectors. A major reason for this lies in the lack of common standards for collecting, analyzing and contextualizing data. Yet, standardized coding for medical information is fundamental for improving the quality and security of primary and secondary care. It also enables monitoring more accurately patient’s pathway as well as it helps controlling healthcare spending. This significant contribution to medicine, epidemiology, and economy is a major reason for undertaking the construction of a common language for information systems’ interoperability in healthcare and welfare sectors.

Nowadays, “the Systematized Nomenclature of Medicine - Clinical Terms” (SNOMED CT) appears as a key technology to address the aforementioned challenges. It is an international comprehensive terminology covering the largest range of clinical specialties and operational needs. By establishing semantic alignments between terminologies of different kinds and specialties, healthcare professionals can standardize data capture, classify and share any clinical information. It therefore contributes to care coordination, medico-economic management, research, and epidemiology.

Regarding its qualities and potentialities as a pivotal terminology, previous studies had assessed the opportunity of a French adoption of SNOMED-CT. However, acquiring SNOMED CT leads to significant impacts: contractual engagements, costs, and difficulties of implementation. Considering this, the ASIP Santé conducted, upon the request of the “Délégation à la Stratégie des Systèmes d’Information de Santé” (DSSIS), a fourth phase of the study with the aim of analyzing the opportunity to purchase the SNOMED-CT, its impacts and the fundamental requirements for its implementation. Several possible scenarios have been identified that must clarify public authorities’ decision on the best strategy to adopt. The following study also presents some European and international contextual elements.

This summary presents the main conclusions of the fourth phase of the study requested by the DSSIS. This study aimed to clarify the implementation of reference terminologies in France; to assess the potential opportunity that represents the SNOMED-CT and to specify the strategy to adopt in the case of a membership of SNOMED International.

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1 The study of reference terminologies in the healthcare and welfare sectors has been conducted in four phases. Each of it was concluded by the publication of a report.

2 Methodology and conducted works

This study has compiled distinct work methodologies, with the aim of bringing concrete elements to the following four sections:

- The legal section: investigation of legal aspects of a French membership to SNOMED International;
- The use section: investigation of current and future uses of SNOMED CT in France and abroad;
- The organizational section: economic, technical and organizational analysis of the adoption of SNOMED CT;
- The requirement section: requirements and opportunity assessment of a potential membership to Snomed International.

To conduct these four distinct investigations, a preliminary literature review had been pursued (analyzing in priority the European study ASSESS CT and other complementary articles). The research team had also led interviews with more than twenty French sector stakeholders (software publishers, doctors, researchers...) and around twelve foreign countries. Three workshops, composed by software publishers federations, officials and scientists had been organized to approve the recommendations elaborated from the distinct sections.
3 Key findings

This study identifies twelve key lessons on the SNOMED CT’s uses and adoption strategies:

1. The SNOMED CT is a rich, comprehensive and worldwide-acknowledged terminology. It appears to be a serious candidate to embrace the role of reference terminology; aiming to semantic interoperability in the French healthcare sector. Operating into a multiple-terminological ecosystem, the SNOMED CT could also undertake the function of a pivotal terminology.

2. Countries that had already adopted SNOMED CT present mixed results: the SNOMED CT is more used in historical countries, where it is already integrated into professional software (USA, UK, and Australia) but uses are less spread in other countries, especially in Europe.

3. In France, interviews and workshops organized with industrial, institutional, professional and scientific stakeholders have not highlighted an urgent need for SNOMED CT’s adoption. Moreover, if France buys the SNOMED CT, industrials wish that its use remains optional.

4. SNOMED CT represents a high potential for specific use cases in several fields (epidemiology, public health, research, primary/secondary care and hospital/hospital data sharing, prescription’s security, standardization of medical biology exams’ results, cross-countries data sharing), yet, the potential gains of its adoption are unclear including for the current user countries in Europe.

5. SNOMED CT’s adoption entails important impacts at the organizational, financial and governmental levels. Moreover, existing solutions within the publishers’ market appear to be not mature enough to consider its quick integration.

6. Membership fees to SNOMED International in addition to implementation costs of SNOMED CT remain difficult to evaluate. At this time, they represent the main barriers to its adoption within the countries considering joining SNOMED International.

7. The seriousness of financial, organizational, technical impacts and challenges of the SNOMED CT implies to adopt a gradual approach for its acquisition. Its scaling must be prioritized on specific use cases and pilot projects involving the whole ecosystem.

8. Implementing a multi-terminological ecosystem’s governance with a specific organization in charge of managing skills and terminological resources; aiming to develop a strong expertise and relying on a multi-terminology server; is a basis for future semantic interoperability, which can include SNOMED CT.

9. This organization must be entirely public with the aim to ensure equality in industries’ relationships and competition.

10. In the case of an adoption of SNOMED CT, a national strategy must clarify its scaling and use in France.

11. Ongoing debates between the European Commission and SNOMED International open the possibility of a European license subscription to SNOMED International.

12. The International Classification of Diseases (ICD) – an ontological nomenclature with no marginal cost – published by the WHO in June 2018, represents a potential candidate as pivotal terminology on specific case uses.
4 Privileged trajectory

Considering SNOMED CT’s advantages and limits underlined by these mixed key findings, this study elaborates distinct scenarios. The steering committee of this study chose one privileged trajectory, estimated at 11.99 million euros over a 4-year period and based on:

1) The implementation of semantical resources governance. This organization will be composed of a strategic steering committee, an advisory body, and a public project contracting entity. Public calls for tenders will maintain equal competition between various production units.

2) The identification of a national terminology center in the healthcare and welfare sectors in charge of distributing and monitoring distinct terminological resources as well as providing related services.

3) The implementation of a multi-terminology server able to integrate and publish current and future terminologies.

4) The progressive integration of different terminological resources.

5) The gradual potential scaling of the SNOMED CT for specific use cases during an experimental 3-4 year period. At the same time, a comparative study about other terminologies; such as the ICD 11; must be conducted.

6) In the mid-term, a membership to SNOMED International, in the case of the evidence of its added value compared to other nomenclatures.

Figure 2: Recommended trajectory by the ASIP Santé for the potential adoption of SNOMED CT
The final report of the European study ASSES-CT shares the same conclusions:

1) Any decision concerning the adoption and the role of a terminological resource (including the SNOMED CT) must be part of a global and coherent strategy based on clear and shared priorities to optimize the semantic interoperability’s advantages.

2) The SNOMED CT is the best available reference terminology for scaling e-health in Europe at the cross-country, national and regional levels.

3) The SNOMED CT must be part of a semantic ecosystem which includes international aggregation nomenclatures and user interface terminologies (multilingualism, data sharing).

4) The adoption of the SNOMED CT must be realized progressively, by developing at first, priority use cases’ sub-sets responding to interoperability requirements and expanding them in the future.

5) Specific mechanisms must be implemented to ease and coordinate the cooperation in terms of semantical resources between European member states. National centers for terminologies will be the first basis to a shared European governance.

From these converging conclusions between the final report of ASSES-CT and this study, a coherent trajectory was planned. This strategy advocates for strengthening governance and rationalizing semantical resources before acquiring a new terminology.

The closing steering committee of this study nominated the ASIP Santé as the national contracting authority for terminologies in the healthcare and welfare sectors. After this nomination, the Agence decided to rename the “Centre de Ressources et Compétences en Terminologies” (CRCT) into the “Centre de Gestion des Terminologies en Santé » (CGTS). This center will have the responsibility to publish the terminological resources through a single, public and free portal thanks to its multi-terminology server. It will provide support services to industrial users aiming for more coordination between production units.
5 Appendix

5.1 Presentation of the privileged scenario

The privileged scenario presents the following characteristics:

| SNOMED International Membership | • Implementation of governance, a center for terminologies resources and expertise and a multi-terminology server.  
|                               | • Membership regarding the results of the « Proof of Concept » projects and the ICD 11 performance. |
| Scenario Description           | • Implementation of POC, with the funding from affiliate licenses starting from 2018, to test the SCT in five target use cases.  
|                               | • In case of too many affiliate licenses required, purchase of a national license for an experimental 3-4-year period (big data experiment, prescription...)  
|                               | • Prospection with the ICD 11 arrival. |
| Terminologies used             | • Value sets SNOMED CT for case uses (15-20k per case)  
|                               | • ICPC |
| SNOMED CT Translation          | • 20 000 concepts maximum per case use |
| Technical Organization         | • Fundamental requirement: Multi-terminology server |
| Team                          | • 2 to 4 FTW in the first time (chief project, IS, terminologist experts) |
| Budgetary Estimation           | • The total cost for this scenario is up to 6.54 million euros over a 4-year period in the case of POC implementation mobilizing no more than 250 affiliate licenses.  
|                               | • The total cost for this scenario is up to 10 million euros over a 4-year period in the case of a full acquisition of the national license. |
| Potential Exit                 | • Evaluation at 24, 36 or 48 months then scaling. |

Table 1

A pros and cons analysis had been conducted for this scenario:

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Opportunity to capitalize on international experiences</td>
<td>• Cost of the national license</td>
</tr>
<tr>
<td>• Francophone cooperation reinforced</td>
<td>• Complex management of affiliate licenses</td>
</tr>
<tr>
<td>• Possibility to explore the SCT during an experimental period for concrete case uses</td>
<td></td>
</tr>
<tr>
<td>• Developing French expertise about the SCT</td>
<td></td>
</tr>
<tr>
<td>• Making the SCT available for private actors</td>
<td></td>
</tr>
<tr>
<td>• Assessment of the SCT within the international terminological ecosystem (ICD 11)</td>
<td></td>
</tr>
</tbody>
</table>

Table 2
## 5.2 Financial analysis

### 5.2.1 Assumptions

The table below presents different assumptions used to realize the financial estimation of the aforementioned scenario.

<table>
<thead>
<tr>
<th>Cost Items</th>
<th>Assumptions</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Governance implementation</td>
<td><em>Not estimated</em></td>
<td></td>
</tr>
<tr>
<td>2 Center for terminological resources and expertise</td>
<td><em>1 FTW: €100 000/year</em></td>
<td></td>
</tr>
</tbody>
</table>
| 3 Implementation of a SMT  
*Hypothesis of an existing tool’s purchase* | *Investment of €1m over 2 years*  
*Maintenance costs: 1 FTW*  
*Annual license: between €100 000 and €200 000/year* | *Estimation by the LIMICS* |
| 4 Progressive integration of the terminologies | *Depending on the terminologies, public market for the production units* | |
| 5 SNOMED International Membership | *No membership: €0*  
*National membership: €609 994 of admission fees + €609 994 annually (starting from the first year)*  
*Affiliate licenses: €1 514,2³/license/user* | *SNOMED International Documentation* |
| 6 SNOMED CT Translation⁴ | *€5 per concept*  
*Translation of the SNOMED CT in its integrality (400 000 concepts): €2 000 000*  
*Translation of 20 000 concepts: €100 000* | *Cf. Appendix 5.2.3.* |
| 7 NRC (SNOMED CT) | *1 FTW: €100 000/year*  
*Project management support: €200 000/year* | *Ratio Denmark/Sweden: 0.25%* |
| 8 Semantical alignment of the SNOMED CT | *25% of the translating cost* | |
| 9 Support to SNOMED CT’s uses | *Support and pilot projects for the SNOMED CT.*  
*Hypothesis of 1 million euros allocated 90% in the first three years and 10% in the fourth year.* | *Sweden: €1.5m*  
*Norway, Denmark: not budgeted* |

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³ Data 2018 from the website snomed.org, $1 772 with a tax change rate of 0.8545, the 25th of July, 2018.
5.2.2  Detailed costs

5.2.2.1 Cost of the terminological ecosystem’s structuration

The cost of the terminological ecosystem’s structuration entails four main characteristics:

- the implementation of a terminologies governance; not budgeted;
- the implementation of a center for terminological resources and expertise;
- the implementation of a multi-terminology server;
- the progressive integration of terminologies.

<table>
<thead>
<tr>
<th>Cost Item</th>
<th>Details / Assumptions</th>
<th>Y0</th>
<th>Y0+1</th>
<th>Y0+2</th>
<th>Y0+3</th>
</tr>
</thead>
</table>
| Center for terminological resources and expertise | • Progressive establishment from 7 to 9 FTW to manage potential issues coming from the terminologies’ integration.  
• Annual subcontracting budget of approximately €200k. | 900 | 900  | 1100 | 1100 |
| Implementation of a multi-terminology server  | • Investment of €1m over 2 years  
• Maintenance costs: 1 FTW – €100 000  
• Annual license: between €100 000 and €200 000/ year - €150 000 | 750 | 750  | 250  | 250  |
| Total over 4 years                            |                                                                                       | 6 000 |      |      |      |

Table 4

5.2.2.2 Costs of adopting the SNOMED CT

The present table shows the detailed budgetary estimation of scenario 3’ for elements directly attributable to the SNOMED CT’s acquisition.

<table>
<thead>
<tr>
<th>Cost Item</th>
<th>Details / Assumptions</th>
<th>Y0</th>
<th>Y0+1</th>
<th>Y0+2</th>
<th>Y0+3</th>
</tr>
</thead>
<tbody>
<tr>
<td>SNOMED International Membership</td>
<td>Additional membership fees only the first year.</td>
<td>609</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National license</td>
<td>License annually paid. Amount based on the French GNI.</td>
<td>609</td>
<td>609</td>
<td>609</td>
<td>609</td>
</tr>
<tr>
<td>Translation in French of the SNOMED CT</td>
<td>Translation in function of initiated projects. Basic hypothesis of 20 000 translated concepts per year (depending on the initiated case uses). Target cost of €5 per concept. Contribution of SNOMED International: €150 000/4 years.</td>
<td>62,5</td>
<td>62,5</td>
<td>62,5</td>
<td>62,5</td>
</tr>
<tr>
<td>Semantical Alignments</td>
<td>Alignment of the SNOMED CT with existing terminologies. Hypothesis: 25% of translation costs</td>
<td>25</td>
<td>25</td>
<td>25</td>
<td>25</td>
</tr>
</tbody>
</table>
| NRC                                           | Approximately 2 FTW to maintain the totality of the issues linked with the SNOMED CT scaling (training, alignment, extensions development, changing supports, involvement in SNOMED International governance, steering) with an annual subcontracting budget of €200k approximately.  
In addition to the previous FTW, resources, and skills. | 400 | 400  | 400  | 400  |
| Uses support                                  | Hypothesis of €1m/year allocated up to 90% in the first three years and 10% in the fourth year. | 300 | 300  | 300  | 100  |
| Total                                         |                                                                                       | 2 005 | 1396 | 1396 | 1 196 |
| Total over 4 years                            |                                                                                       | 5 995 |      |      |      |

Table 5
Phase 4 – Implementation of reference terminologies

The cost of adopting the SNOMED CT would be up to approximately 5.9 million euros over four years. To this amount, the costs of the governance’s reorganization and the management of the healthcare and welfare sectors’ terminologies (6 million euros) must be added, hence a total maximum cost of 11.99 million euros for this scenario.

5.2.2.3 Cost of translating SNOMED CT

The information obtained from foreign experiences enables to draw an overview of the potential cost that would represent the terminology’s French translation:

<table>
<thead>
<tr>
<th>Country</th>
<th>Translation Process</th>
<th>Number of translated concepts</th>
<th>Translating Period (years)</th>
<th>Translating cost (€/people)</th>
<th>Translating cost (€)</th>
<th>Cost/Concept (€)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>6 translators, 4 monitoring doctors, and an experts committee. Use of a support platform of the Danish developed translation.</td>
<td>32 000</td>
<td>1</td>
<td>-</td>
<td>270</td>
<td>8,4</td>
</tr>
<tr>
<td>Sweden</td>
<td>Between 20 and 30 mobilized staff. Process ensured by a specialized society and checked by experts.</td>
<td>300 000</td>
<td>2,5</td>
<td>-</td>
<td>10 000</td>
<td>33,3</td>
</tr>
<tr>
<td>Belgium</td>
<td>NRC in charge of translating but sub-contracts depending of the sub-sets. First « hand-made » translation. Then, development of a translating tool. Specific multilingual issue in Belgium.</td>
<td>90 000</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Argentina</td>
<td>-</td>
<td>300 000</td>
<td>-</td>
<td>6</td>
<td>540</td>
<td>1,8</td>
</tr>
<tr>
<td>Denmark</td>
<td>The Danish translation has been realized in its integrality by external service providers.</td>
<td>300 000</td>
<td>3</td>
<td>-</td>
<td>1 600</td>
<td>5,4</td>
</tr>
</tbody>
</table>

Table 6

Considering these estimated costs, the potential gains and the above table, the theoretical translating cost is estimated up to 5 euros per concept. This estimation doesn’t consider the potential expertise pooling with other francophone countries.