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Final project report Cross Border eHealth Information System (CBeHIS)

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Preliminary remarks (eHealth Suisse)

To ensure that Switzerland doesn't build a closed system in the international exchange of medical data, eHealth Suisse was pursuing eHealth activities at European level for many years and was actively involved in various projects. However, the EU Commission announced in October 2018 that Switzerland can't longer participate in the European eHealth coordination committees. This is justified by the Directive on cross-border healthcare in the EU of 2013: It gives patients the right to be treated by a healthcare professional anywhere in the EU and to have the costs reimbursed. Because the European eHealth coordination is attached to this guideline and Switzerland didn't adopt it, co-operation is no longer possible, the EU Commission said. The Swiss Confederation and eHealth Suisse have taken note of the decision and are now considering the way forward.

Affected are the cooperation in "eHealth Action" and in the "Connecting Europe Facility" program.

University Hospitals of Geneva (HUG)

1. Background

This report describes HUG activities performed during the 2018 in relation with the participation of Switzerland to the Connecting Europe Facility and the CBeHIS.

The year 2018 was supposed to be the “go-live” year for Wave 1 and Wave 2 services, with the realization of the Swiss NCP Portal. However CBeHIS activity ended prematurely due to the exclusion of Switzerland from cross-border activities.

This report is therefore a final report on our participation to CBeHIS Waves 1 and 2.

2. Main activities

Apart from the regular coordination meetings between eHealth Suisse, Federal Office of Public Health (FOPH), HES-SO (Haute École de Gestion de Genève) and HUG (4 teleconferences and one face to face), activities performed during the reporting period can be grouped into several topics:

- Related to the JASeHN (Joint Action to Support eHealth Network) & eHMSEG (eHealth Network Member States Expert Group);
- Related to the OpenNCP (NCP: National Contact Point) community;
- Related to the development of the Swiss NCP Portal;
- Related to the maintenance of the National Contact Point.

2.1 Activities related to JASeHN & eHMSEG

HUG actively participated to the work of JASeHN and eHMSEG. One face to face eHMSEG was organized in Brussels and more than 15 teleconferences were dedicated to the establishment of the deployment plan and to discuss audit schema. Review work for the various deliverables occurred during the whole period.

Regarding auditing aspects, we had one 2 days pre-audit site visit in order to pre-assess our readiness level. This visit was of high value as it enabled us to better understand what is required for the audit and to identify the main gaps to be filled before applying for the formal audit.

Stéphane Spahni was invited to the “co-auditor training session” in Granges, Ireland. This 3 days-long workshop was intended for training future member states representatives participating to countries’ audits along with the auditors and DG-Santé members. The training session was attended by around 15 member states delegates and was located in Granges, Ireland.

Stéphane Spahni had then the opportunity to participate to the Czech Republic audit in June 2018. The 5 days long audit took place in Jihlava. This was an intense week of high interest and showed how the audit is conducted “live”, what has to be ready for the audit week. It also gave a lot of ideas on how to enhance our own documentation taking benefit from what was presented by the Czech Republic.

We also participated to the EHRxF (Electronic Health Record Exchange Format) task force aiming at providing recommendations on the exchange of the whole Electronic Health Record. Initial participation was by eHealth-Suisse (Jürg Bleuer) and then Stéphane Spahni (several tconfs and one face-to-face meeting).

2.2 Activities related to the OpenNCP

Four major activities took place during the 2018:

- Online pre-projectathons and projectathons tests took place in January 2018 (January 15th – February 16th), June 2018 (June 11th to June 22nd) and September 2018 (September 24th – October 26th). This was the occasion to validate the latest OpenNCP releases and to prepare the formal technical qualification tests that should have happen in October 2018. Participation to October 2018 test session was stopped half way due to the information that Switzerland will not be allowed to go live. All performed tests were however successfully validated by the dedicated validation team.
- One “OpenNCP Boot Camp” occurred in April 2018, attended by Rafael Jimenez.
- Two “Patient Summary workshops” were held, one of 2 days in coordination with the Semantic Task Force and one of 1 day. Different aspects related to terminologies and content of the Patient Summary were discussed at these occasions.

- A specific TESTA (Trans European Services for Telematics between Administrations) test week was organized in June 2018, enabling new Wave 2 countries to establish their TESTA connectivity.

Apart from these major events, regular teleconferences occurred during the whole period in order to discuss OpenNCP developments and to solve pending problems (more than 15 teleconferences). The OpenNCP Technical Work Group also had 7 teleconferences during this period (Stephane Spahni was OpenNCP TWG member until summer 2018, replaced then by Rafael Jimenez). Stéphane Spahni then moved to the OpenNCP Steering Work Group, which had 7 teleconferences during the participation period (until October 2018).

OpenNCP Governance:

- Stéphane Spahni was member of the OpenNCP Technical Work Group until August 2018, then member of the OpenNCP Steering Work Group (until October 2018);
- Rafael Jimenez was member of the OpenNCP Development Team until August 2018, then member of the OpenNCP Technical Work Group (until October 2018);

2.3 Activities related to the development of the Swiss NCP Portal

A NCP Portal has been developed, supporting the Patient Summary scenario. The portal is supporting several authentication tokens, as it does not manage users itself. It is designed for being called by already authenticated users, typically users authenticated in their own EPR portal.

Portal is developed with classical Web toolkits, making it simple to integrate into any environment.

Complementary developments are still required for a proper management of the patient consent. Indeed design and specifications were not complete at the time we stopped working on CBeHIS.

2.4 Activities related to the maintenance of the National Contact Point

Swiss OpenNCP installation was updated with new releases for each online PAT as well as for the TESTA connectivity week in June.

Official CEF PKI X.509 certificates were installed, as a preparation for the Go-Live configuration.

Maintenance work was also performed on the application producing the Patient Summary, in order to enhance it and to adapt it to newly available data from the HUG Clinical Information System as well as to updated Patient Summary eHDSI Specifications.

3. Problems encountered

No major problem were encountered until October 2018. Swiss participation was fully accepted and appreciated by member states and DG-Santé. However the EU Commission decided in October to exclude Switzerland from eHealth Projects (CBeHIS, eHealthAction). Switzerland is therefore no more allowed to participate to meetings (tconfs and face-to-face). Go-live is also suspended.

In case of a future re-start of the CBeHIS activities, several key aspects will need special care:

- Administrative and legal audit: the audit is very formal, and needs to be well prepared. The key lessons learned from the pre-audit visit and the participation to the Czech audit are: be prepared to answer to the question “how do you prove what you are saying” and be sure that all documentation is endorsed by a responsible person.
- Legal aspects and Legal Agreement: the CBEHIS legal agreement refers to GDPR and Cross-Border Health directive. Work to be compatible to these regulations has to be completed. Legal Agreement refers also the European “for juridique”, which may be a problem until an EU/Switzerland court is established. Lugano Convention may however be of some help.
- Patient Consent is a crucial part of the global infrastructure: it has to be well designed, for home patients (when acting as country-A) as well as foreign patients (when acting as country-B). Patient Consent is for sure a key element for being compatible with the Legal Agreement and European regulations.
- eID related requirements will be enforced by 2020: eIDAS (electronic IDentification, Authentication and trust Services) use may well be mandatory in the NCP Portal from 2020.

4. Meetings

HUG participated to:

- 1 face to face eHMSEG in Brussels;
- 3 days Patient Summary Workshop in Lisbon (2 days) and Brussels (1 day);
- 2 days OpenNCP Boot Camp in Brussels;
- 2 days pre-audit visit in Geneva;
- 3 days auditor training session in Dublin (extended to 6 days due to weather conditions!);
- 5 days co-auditor for the Czech Audit in Jihlava;
- More than 30 teleconferences related to OpenNCP;
- More than 20 teleconferences related to eHMSEG (mainly deployment plan and patient summary);
- Several national teleconferences and face to face meetings.

5. Next steps

No further activity is planned yet.

Documentation is being completed and stored on a central server (HUG WIKI server). The TEST NCP Server is kept running, however the TESTA connection is being stopped at the end of 2018.

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December 7th, 2018*

Haute École de Gestion de Genève (HEG)

1. Background

In 2018, the eHMSEG Semantic group mainly focused on the future changes in the MVC and the issues found after the Wave-1 formal tests. The Swiss semantic group also elaborated a new version of the Transcoding Tables following changes in the HUG Code Systems.

Meanwhile, as this year was also a go-live phase, we produced an extensive documentation w.r.t. our semantic activities to prepare for the formal audit.

Finally, as the EU Commission decided in October to suspend Switzerland from the cross-border projects, we decided, in coordination with e-Health Suisse and the HUG, to freeze all activities related to CBeHIS before the two last F2F planned for the end of the year.

2. Main activities

2.1 Activities following the Wave 1 FORMAL Test Events

After the eHDSI (eHealth Digital Service Infrastructure) formal Preparatory Pre-Production Test (PPT) of January, a number of problems were comprehensively reported. As some of these problems were related to Semantic aspects, the eHDSI Semantic group was actively involved with the Solution Provider to work on alternative solutions. Some of the observations we reported were critical, e.g. “We found some inconsistency between the ART-DECOR IG and the Gazelle Validators that blocked us from providing the coded data of the Vital Signs section of the PS.”

Further, we were in contact with Malta to provide answers to the specific issues detected during the End-to-End functional testing (from MT to CH). Part of these issues were related to the outdated Swiss transcoding (which included obsolete HUG codes) and were duly noted for the new release of the MTTC.

2.2 Activities related to the transcoding

New data were made available from the HUG Clinical Information System, whereupon we had to update the MTTC 2.2.2. 79'913 codes are now mapped with the European terminology (29'070 in MTTC 2.0). Allergy and drugs are henceforth better represented, respectively with 971 and 5'677 codes, but the major update is related to the ICD-10 (Illnesses and Disorders). This substantial inclusion of new mappings (around 47k) is due to the variance between 3 digits (EU) and 4 digits (CH) codes.

As required, the mapping was regulated by the rules fixed by the eHDSI community, and limited to the “one-to-one” and “many-to-one” situations (from CH to EU). Validation was first processed at HEG level and an integration test phase was planned with HUG, which revealed additional issues and led us to refactor the MTTC.

2.3 Activities related to the Master Valueset Catalogue

The previous MVC (release 2.2.2) was published in October 2017 and, following that, the eHMSEG Semantic group worked on the future MVC 2.3. Besides the minor changes on the different Value Sets, the main discussions were about the integration of Rare Diseases in the MVC - based on the Orphanet ontology - and the possible implementation of ICD-11 in order to anticipate future inclusion by 2022. Moreover, the change proposal might also cover the missing 4-digits and the 5-digits codes. Such a change proposal is not planned before Wave 3.

The replacement of SNOMED in the MVC is still a controversial issue. Alternatives are pushed by France (ICD, LOINC, etc.) and we (HEG team) decided to adopt a neutral position on this subject. Since Switzerland has a national license for SNOMED-CT we were in favour of its use in cases where it is appropriate (indeed, many small Value Sets could opportunely use SNOMED CT), but we also understand and defended the idea that other terminologies can be more appropriate for sake of cross-border exchanges (e.g. if shared by a large majority of partners).

Two other important tasks for the Semantic team were the review of the criteria for the selection of the code systems on which the MVC is based, and the guidelines for the “No information” and “Known absence” coding situations. Additionally, the group is also concerned by the use of the future EU List of substances in the eP / PS Medication Summary section, due to the implementation of the ISO IDMP Standards in the European Union.

3. Problems encountered

The main semantically-related problems reported this year concerned the mapping between the HUG nomenclature and the MVC. Granularity discrepancies were found: several HUG concepts with no equivalent in the MVC were identified. This is apparently due to the fact that the HUGs used non standards ICD-10 codes to code diagnosis. We also observed some typographic mistakes in the HUG nomenclature.

4. Meetings

The HEG team participated in the following event:

- Pre-Audit visit in Geneva (Luc)
- eHMSEG Semantic Face-to-Face in Brussels (1st and 2nd of March, Luc)
- Teleconferences related to OpenNCP community (3 Luc + Patrick)
- Teleconferences related to eHMSEG Semantic group (12 Luc)
- Teleconferences related to the Architecture group rebooted in 2018 (2 Luc)
- Monthly Swiss teleconferences and CBeHIS F2F (Luc and Patrick).
- Some F2F meeting with HUG, about the transcoding

5. Next steps

No further steps are planned for the moment due to the suspension of the project. However, we are ready to continue our work in case of future restart. We have acquired a significant expertise in translation, transcoding and validation, and developed automatic pipelines integrating manual expert validation steps. Last, we initiated a collaboration for the development of a French translation of SNOMED-CT based on an international cooperation coordinated by the French association Phast, which should continue in the future.

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