

*EPSOS PROJECT*

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# Final report

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## TABLE OF CONTENT

<b>1. Introduction.....</b>	<b>3</b>
<b>2. Role in the project.....</b>	<b>3</b>
<b>3. Project phases.....</b>	<b>3</b>
3.1. Phase 1 .....	4
3.2. Phase 2 .....	5
3.3. Phase 3 .....	5
3.4. Phase 4 .....	6
3.5. Phase 5 .....	7
3.6. Phase 6 .....	7
3.7. Phase 7 .....	8
<b>4. Future.....</b>	<b>9</b>
<b>5. Meetings .....</b>	<b>9</b>
<b>6. Manpower.....</b>	<b>9</b>
<b>7. Index.....</b>	<b>11</b>

## ***1. Introduction***

Following the mandate given to the HUG by the FOPH on the 28th of October 2010, we joined the epSOS project on the 1st of January 2011 for a period of initially 36 months which was later on extended by 6 months until the 30th of June 2014. The goal was to participate to the epSOS project in order to set-up a Swiss National Contact Point (CH-NCP) and to implement the scenario "Patient Summary Country A", i.e. giving access from abroad through the CH-NCP to a specific document called "epSOS Patient Summary" for patients living in Switzerland. The participation to epSOS was also a way to better follow what is being done in Europe and to contribute to the evolution of cross-border communication of medical data.

In parallel, the Haute Ecole de Gestion de Genève (HES-SO) was responsible for the management of epSOS' terminological and semantic services.

This report summarizes the activities performed by the HUG and the HEG Geneva during this timeframe and enumerates the main lessons learned during the participation to the epSOS project.

## ***2. Role in the project***

HUG participated as a full member to the project in order to set up and operate a National Contact Point for Switzerland. The NCP has been connected to the Geneva's national infrastructure MonDossierMedical.ch which played the role of an approximation of a national electronic patient record.

An epSOS Patient Summary document generator has also been developed which produces the epSOS Patient Summary document out of HUG structured data and publishes it into the MonDossierMedical.ch regional health information exchange (HIE).

Activities were not only related to developments but also to strategic evolution of the project as well as to coordination. HUG assumed the roles of National epSOS Pilot Coordinator (NEPC) Technical Leader and of deputy NEPC. We were also heavily involved in the activities around the open source project OpenNCP - mainly for testing and evaluating the new solution.

The HEG participated to the epSOS project as subcontractor under the umbrella of the e-Health coordination body. The roles related to terminology management in epSOS are the following:

1. Terminology administrator (Arnaud Gaudinat): The terminology administrator is responsible for the management of content of the MTC (Master Translation Catalogue) in central services such as the CareCom's HealthTerm application, which also includes meta-data contents (e.g. country pairs);
2. Terminology manager (Patrick Ruch): The terminology manager represents its country for all decision related to the maintaining of the MVC (Master Valueset Catalogue) and MTTC (Master Transcoding and Translation Catalogue).

The HEG has also been intensively involved in the early developments of the OpenNCP with the writing of TSAM component and the authoring of test units for the component.

## ***3. Project phases***

The participation to the epSOS project can be divided into several phases:

1. An initial intensive learning phase: understanding epSOS, getting an overview of the (large) documentation, establishing contacts with the main partners;
2. The set-up of an initial NCP in order to participate to the projectathon;

3. Deeper understanding of the deliverables of the first phase of the project (epSOS I, 2008-2010) in order to be able to implement the selected scenario;
4. Validation of the NCP infrastructure, on a technical as well as organizational and juridical points of views;
5. Participation to the elaboration of the epSOS II scenarios;
6. Participation to the OpenNCP activities aiming at developing and operating an open source National Contact Point and migration towards the OpenNCP infrastructure;
7. Activities related to information and dissemination of epSOS results (during the whole project).

While phases 1 to 4 and 7 were foreseen from the beginning, phases 5 and 6 were implicitly added during the course of the project.

Similarly semantic-related activities can be split as follows:

1. Learning phase: establishing contacts with partners and identification of strategic partners;
2. Formal training: one-week training to operate the CareCom' health terminology services for two HEG staff members; self-training to acquire understanding of epSOS' documentation, process and workflow;
3. Terminological developments: set up a Master Transcoding Catalogue (i.e. the mapping of MonDossierMedical.ch electronic health records into the MVC);
4. Software developments and writing of specifications: set up of the Terminological Services and Interfaces to operate and maintain the MTC; coding of the interaction between the OpenNCP and of the associated test units;
5. Participation on feasibility studies of epSOS II scenario, in particular the e-Prescription;;
6. Continuous maintaining of MVCs (from 1.4 to 1.9) and MTCs;
7. Dissemination and sustainability (WP2.2) of epSOS results.

### 3.1. PHASE 1

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The first phase was essential for grabbing the essence of the work performed during the three years of epSOS I. epSOS produced a huge amount of documentation - documentation that was reviewed, consolidated and partly summarized during the last period of epSOS II. This is partly due to the fact that epSOS covered many aspects of the communication between two entities: organizational, legal (between countries, taking into account the European regulations as well as their implementation in the various participating nations), as well technical aspects had to be taken into account. Standards and guidelines have to be established on various topics (security, document format).

#### **Lessons learned**

epSOS deliverables tackle many aspects essential for the safe communication between two entities which do not share a same legal framework, language or data organization. Many problems had to be solved, and epSOS deliverables can provide a lot of hints and recommendations regarding these various aspects.

The final epSOS II deliverables have been completely reorganized in order to provide a consolidated view of all the work performed during the two phases (epSOS I and II). It is therefore highly recommended to work with the consolidated documentation and not with the earlier deliverables. All deliverables are available on the EU web site (<http://www.epsos.eu>) as well as on Project Place (which will be kept operational for the coming years).

Resource sharing, in particular of software and data types are relatively easy within epSOS contributors, in particular with governmental and publicly-funded institutions (regional or national public health agencies, universities, public research institutions...). Such an exchange is not necessary more challenging with commercial entities provided that clear licensing models have been defined (e.g. OpenNCP). epSOS has

demonstrated the relevance of using an Open Source Software development model (GPL v3), which is flexible enough to receive contributions from any kind of contributor. The main barriers with public bodies are usually caused by the risks associated with the uninformed use of the resource; the solution is usually the preparation of clear disclaimer.

The CareCom training in Copenhagen (two HEG staff members) was mandatory but the received training was very ad hoc and platform dependent. The close cooperation with epSOS I terminological managers was important to reduce localisation costs to the minimum (Master Transcoding Catalogue) and to avoid labour-intensive translation costs.

## 3.2. PHASE 2

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The second phase was quite intensive: indeed the first projectathon of epSOS II (the second projectathon for epSOS) took place in April 2011 in Pisa - 2 months after the kick-off for new countries. This implied a fast learning of what is a NCP and the initial set up of such an infrastructure. Thanks to the "NCP-in-a-box" deliverable of epSOS I, we did successfully set up our first NCP, based on TIANI Spirit software with additional epSOS-specific components. A rapid learning of the IHE test tools was also necessary in order to be able to participate to the projectathon.

The work to deliver an operational MTC was very intensive and the first version was not fully error-prone however, the quality was sufficient to successfully participate in the projectathon.

### Lessons learned

The main lessons learned during this phase are related to IHE testing:

- Tools for testing most of IHE profiles-based application do exist and are freely available: called GAZELLE, the testing environment enables the simulation of one communication party for testing the conformity of the implementation of the protocols. GAZELLE also includes tools for validating the content of various CDA documents, with detailed reporting on errors and missing sections. Such tools are essential for a software developer for validating his implementation.
- Most of the documents submitted for validation are freely available from the GAZELLE servers, making therefore a high value samples repository. These can be used as examples, helping in the creation of valid instances.
- Participating to a connectathon / projectathon (= connectathon dedicated to a certain domain / subject) is a unique experience that any integrator of IHE-based component should go through. It is an immersion into the IHE world, its testing / validation strategy and the numerous available testing tools. It also provides a unique market for establishing contacts with the main vendors active in the IHE world;
- The epSOS central services are not compliant with any standard terminology management services (neither CTS I not CTS II) - today the situation has not evolved.

## 3.3. PHASE 3

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Phase 3 was devoted to the implementation of the selected epSOS scenario: patient summary country A, and integration with the national infrastructure (MonDossierMedical.ch in this case). For this, an in-depth knowledge of the epSOS I deliverables relating to the patient summary and to the management of patient consent were required. A very good knowledge of the local infrastructure was also required as the patient summary is a kind of bridge between the two: data is coming from the local infrastructure and has to be understood by the epSOS infrastructure - with the support of the terminology server.

## Lessons learned

Various important lessons are coming out of this phase:

- Importance of terminologies: data which are not encoded according to some (good) terminology can hardly be transferred from one site to another - or as free text with no processing at all;
- Selection of terminologies: some terminologies are becoming unavoidable / a “de facto” standard in Europe; when defining standards for the exchange of information, these terminologies should be adopted in order to ease the future communication with other partners;
- Maintenance and evolution of terminologies: terminologies are evolving and the move towards the new version is not always easy. Moreover as a move to a new release generally does not alter the past, processes have to be able to cope with previous releases. Coordination of the use of common terminologies as well as their update is necessary;
- The storage of structured Electronic Health Records (EHR) is challenging for the transcoding services as the system must be able to maintain not only updated mapping tables but also an historical mapping tables since EHR are likely to contain outdated descriptors;
- The unambiguous mapping of some coding schema is virtually impossible unless we access to introduce very generic, medically poorly informative class descriptors (e.g. diagnosis procedure, surgery procedure) - such an option has anyway been rejected by epSOS’s terminology representatives due to the absence of consensus on this issue;
- The level of IT expertise in communities responsible for the management of terminological resources is relatively low so that the promotion of OSS solutions is difficult whereas the pricing of services for terminological services is poorly controlled.

## 3.4. PHASE 4

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This phase was concerned by the validation aspects of the Swiss NCP & patient summary. Once the technical infrastructure was ready, different validation tasks had to be performed in order to be allowed to go live:

- Technical validation:
  - IHE connectathon/projectathon in Pisa (April 2011) and Bern (May 2012);
  - On-line projectathon (i.e. validation with other partners through Internet using the live infrastructure) (September 2012 - February 2013);
- Semantic validation: validation of the transferred / translated / transcoded patient summaries by true physicians;
- Organisational validation: validation by experts on the basis of an in-depth description and self-assessment of the established environment. The self-assessment had to include a security validation (performed in our case by the HUG Security Officer);
- Final go-live approval by the Project Steering Board.

## Lessons learned

Going live with the communication of sensitive data between countries is not only a technical matter. Many different aspects have to be covered in order to establish a real and trustworthy communication channel with partners in different countries. epSOS deliverables do clearly document the different aspects that have to be covered in order to succeed.

The testing week of a connectathon / projectathon has a tremendous value: it is not only about doing tests with others, it is also about getting a deeper knowledge of the tested elements and working in close collaboration with other organisations as well as IHE specialists in order to solve the problems. The value

of performing a connectathon is far beyond just testing our own solution - it is a unique experience for enhancing your knowledge about IHE profiles and testing strategy.

Following guidelines and best practice may however lead to unexpected problems. One that has to be mentioned is related to authentication / encryption digital certificates: the security expert group adopted best practices for the X.509 certificates. While these requirements were fully understandable and reasonable, they lead to the exclusion of most of the commercial certification authorities as they do not comply with the defined rules (they certainly will in the future - epSOS is probably just "state of the art", while commercial authorities are a few years behind). For the Swiss NCP, we were able to negotiate the production of almost fully conformant certificates at a reasonable price with Swisscom: the only requirement we were not able to fulfil is related to the Trusted Services List. This list is maintained by the European Commission and contains pointers on national lists of cross-border trusted certification authorities. While a similar list do exist for Switzerland (authorities approved for digital signature), the fact that the inclusion of the Swiss list into the EU TSL was not part of the bilateral agreements. Hopefully relaxations to the security guidelines were approved and we were able to go live with these certificates.

Another point worth to mention is that going live is not just a one shot action! Keeping the infrastructure live means coordination with the other NCPs, synchronization of the terminologies, updating the digital certificates, regular checks of the availability of the service, etc. Some international coordination - administrative as well as technical - is mandatory in order to avoid one to one bilateral agreements which could lead to different requirements with different countries.

The original epSOS decision to use the HL7 CDA had side-effect as epSOS had to develop an epSOS-aware CDA to properly display patient documents. Non epSOS-specific viewers will be able to visualize epSOS document with minor visualization issues.

### 3.5. PHASE 5

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This phase was mainly a specification phase with review of the new deliverables. During this phase we were able to contribute to the focus of epSOS II services although we did not implement them.

Some epSOS II scenarios could be interesting in the future, like the Health Care Encounter Report (sent to country A after a hospitalization) or the Patient ACess (use of epSOS translation services by the patient to get his/her own patient summary in another epSOS-supported language).

On the semantic side, a feasibility study was conducted to explore the pro and cons of using SNOMED CT to perform e-Prescription. Completeness of medicinal products and dose-related information has been explored and consensus was difficult to reach between member states.

### 3.6. PHASE 6

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This phase represents unforeseen activities at the time of the signature of the contract. The EC contract requirements contained the provision of a fully Open Source solution. The NCP-in-a-box being based on a commercial product (TIANI Spirit), the development of a substitute for the IHE core modules had to be realized. Thanks to the work of a core group of 27 persons (developers, coordinators, testers, reviewers, supporters) from 12 countries, such a solution could be realized within less than 6 months for the initial release!

While we did not participate to the development itself, we were one of the early adopters which meant doing a quite significant testing and documentation reviewing work. The OpenNCP is now well established and serves as a basis for many follow-on projects in Europe and abroad. HUG is still contributing to the OpenNCP team and follows closely the evolution of the platform.

Although being live with the NCP-in-a-box solution in April 2013, we moved our piloting infrastructure towards the OpenNCP solution in summer 2013 after having validated it during the IHE projectathon in Istanbul (April 2013).

A comprehensive CTS II-compliant terminological server has been specified during that phase. The relevance of CTS II compared CTS I is very questionable for epSOS as epSOS would need in priority to have bulk upload/download synchronization services. Indeed in the current interaction model, national agencies use their own infrastructure and workflow (translation, review panels...) to maintain the MTTC. Then, the terminology administrators have to manually capture the mapping on the epSOS central services; thus introducing possible errors (misspellings, OID, erroneous codes...).

### **Lessons learned**

The first and most important lesson learned is that such a project is feasible - even with a so small number of persons over several time zones! The use of agile development methods proved to be very efficient. The very close collaboration between all willing persons resulted in tremendous work being realized.

A second important lesson learned is that a strong coordination of the evolution of the software - although it is Open Source - is required in order to guaranty its quality and conformance with IHE profiles. A structure for managing the evolution of the OpenNCP is being set up between the partners (countries, organizations, commercial partners) that have an interest in contributing or using the solution.

## **3.7. PHASE 7**

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This phase covered the whole duration of the project and is related to the participation to the various working groups (specification, validation, security, etc.) and to the dissemination of the results.

Due to the number of participants as well as to the ambitions of the project, many aspects had to be covered thus generating a quite large amount of documentation. Hopefully the deliverables were consolidated at the end of epSOS II in order to make the understanding of what epSOS realised more affordable to the newcomers.

This phase was also the framework for various presentations of the epSOS strategy and results to other stakeholders, in particular in Switzerland.

### **Lessons learned**

epSOS deeply influenced the world of the cross-border exchange of medical data. It is clearly seen now as the reference project for cross-border communication - especially thanks to the OpenNCP sub-project.

Assets produced by epSOS are being re-used by many continuing projects: e-SENS, EXPAND, Trillium Bridge and others.

The contribution and visibility of the MVC is also a key asset here, although we can regret that still today no public distribution of the epSOS's MVC is available.

Sharing of medical data between institutions working under different legal framework and using potentially different languages means a consequent amount of work in order to be realized. epSOS provides very detailed guidelines and recommendations on how to proceed, what to be careful at, what should be avoided. Among other points, the importance of IHE profiles has to be mentioned - and organizations intending to work on this domain should be aware of what IHE is, what it can offer and how it can be used.



## 4. Future

The epSOS project is finishing the 30<sup>th</sup> of June 2014. While other projects will make use and extend the OpenNCP services two are worthwhile to mention:

- eHealth Governance Initiative: a eHGI subgroup will take care of the coordination, administrative and juridic aspects related to the exploitation of the epSOS Large Scale Pilot infrastructure after the 30<sup>th</sup> of June 2014;
- EXPAND working group 5 will take care of the evolution of the OpenNCP and the technical aspects related to the OpenNCP.

The National Contact Point will be kept operational under a cantonal responsibility: the Direction Générale de la Santé (part of Geneva's Ministry of Health) decided to keep it operational at least until end of 2015. The operational aspects will be handled by the University Hospitals of Geneva. Implementation of additional scenarios or integration of the NCP into other infrastructures like STORK is open and will be evaluated and decided with respect to the costs and benefits.

## 5. Meetings

The main international events we attended are:

- Kick-off for countries joining epSOS II (Tallin, Estonia, February 2011)
- IHE Projectathon, Pisa, Italy, April 2011;
- Face to face WP meeting in Copenhagen, Denmark, August 2011
- Face to face WP meeting in Athens, Greece, November 2011
- IHE Projectathon, Bern, Switzerland, May 2012;
- Face to face WP meeting in Palma, Spain, November 2012
- IHE Projectathon, Istanbul, Turkey, April 2013;
- Face to face WP meeting in Sevilla, Spain, October 2013;
- eHealth Week in Athens, May 2014;
- epSOS final meeting in Stockholm, June 2014.

We also participated to NEPC tele-conferences (1 to 2 per month), as well as OpenNCP teleconferences (2 to 8 per month) and projectathon-on-line tele-conferences (up to 1 per day in autumn 2012 during certification of the national infrastructure for the go-live). We also had bimonthly conferences for epSOS activities related to sustainability (WP2.2).

## 6. Manpower

The workload in man-months devoted to the main topics by the HUG team during the period 2011 - 2013 is the following:

Task	MM	CHF
Understanding of epSOS	2	20'000.-
Setup of the initial NCP	3	30'000.-
Development of epSOS Patient Summary	4	40'000.-
Development of the National connector	1	10'000.-

Validation of the national infrastructure	5	50'000.-
Audit & validation for go-live	3	30'000.-
Contribution to the OpenNCP development	2	20'000.-
Installation & testing of OpenNCP, migration of the two NCP instances	6	60'000.-
Specification of use cases in epSOS II	2	20'000.-
epSOS Evaluation	4	40'000.-
Maintenance & exploitation	2	20'000.-
WP meetings, administrative tasks	2	20'000.-
<b>TOTAL</b>	<b>36</b>	<b>360'000.-</b>
	OFSP Grant	18
	State of Geneva (DARES) Grant	18
		180'000.-
		180'000.-

The workload in man-months devoted to the main topics by the HUG team during the period January 2014 - June 2014 is the following:

Task	MM	CHF
Contribution to the OpenNCP development and validation	0.5	5'000.-
Maintenance, update of the infrastructure & exploitation	0.5	5'000.-
WP meetings, administrative tasks	0.25	2'500.-
<b>TOTAL</b>	<b>1.25</b>	<b>12'500.-</b>
	State of Geneva (DARES) Grant	1.25
		12'500.-

In the following tables, we provide the details of the costs for the HEG Geneva (funded by e-Health):

Tasks	MM	CHF
CareCom training	0.5	5'000.-
Development of terminologie services and supporting tools	2	20'000.-
Validation of transcoding (trained physician)	1.2	12'000.-
Test and integration with national infrastructure	1	10'000.-
Contribution to the OpenNCP development	1	10'000.-
Specification of use cases in epSOS II	0.5	5'000.-
Administration and coordination tasks including meetings	1	10'000.-
MVC + MTC updates	3	30'000.-
<b>Total</b>	<b>10.2</b>	<b>102'000.-</b>

## 7. Index

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### ***F***

Future · 7

---

### ***I***

Introduction · 3

---

### ***P***

Project phases · 3

Phase 1 · 3

Phase 2 · 4

Phase 3 · 4

Phase 4 · 5

Phase 5 · 6

Phase 6 · 6

Phase 7 · 6

---

### ***R***

Role in the project · 3