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## Final summary minutes, 3<sup>rd</sup> eHealth Network meeting 14 May 2013, Dublin

### Introduction

These draft summary minutes are prepared by the Secretariat of the eHealth Network in accordance with the rules of procedures. These summary minutes will be posted on the European Commission (EC) web site (<http://ec.europa.eu/health/ehealth>) once adopted.

### WELCOME AND OPENING

The eHealth Network has two chairs, Paola Testori Coggi, Director General of SANCO, as chair on behalf of the Commission, and Clemens-Martin Auer, Director General for Health Austria, who is chair on behalf of the Member States.

Paola Testori Coggi thanks the Irish Presidency for their hospitality as well as the organisation of the eHealth Network.

All Member States were represented. Croatia and Norway were observers. Switzerland was present on an ad-hoc basis.

No conflict of interest was declared.

The agenda was adopted unanimously.

### 1. POINT 1 OF THE AGENDA: SET OF DATA FOR EXCHANGE OF PATIENTS' SUMMARY

#### Introduction

The Commission Chair recalls Directive 2011/24, Article 14, about a non-exhaustive list of data that are to be included in patients' summaries. This is a fundamental pillar for real operational eHealth systems in Europe, but it is also expected to be a reference for work done at national level. It should stimulate patient safety during cross-border emergency care and ensure continuity and quality of care.

The document distributed to the eHealth Network Members is based on the experience of the epSOS project. This first discussion is to agree on taking as a basis the set of data, which was developed, tested and adopted, in the epSOS project, and which will be included in a guideline (foreseen to be adopted during the next meeting in November).

Furthermore, the guideline, though non-binding, should have Members' commitment to be used also at national level.

### **Discussion**

There is broad support from Members for the set of data as presented in the proposal. It is stated that a minimum set of data is needed in order to transfer information across borders, and that the epSOS project is the proper source to rely upon. It is appropriate to take a final decision on a guideline in November.

Most Members state that the value of a guideline is not only important for cross-border care but is most useful for the implementation of a minimum data-set at national and regional level.

Several Members advise to engage stakeholders in the development of the guideline, since they will be the potential users of it. The Members should inform stakeholders about the importance of a standardized patient summary at national level. Both for the safety of the patient in emergency care, as for the continuity of care during planned visits.

One Member mentions that Member States, who are not participating in epSOS, should check the usefulness of the data set for their own country. It recalls the importance to carry on the work concerning the coding, the terminology used, and the way the system is implemented. Another Member states that it should be clear for what kind of care the set of data is used. This Member is of the opinion that the guideline should focus on the emergency care, and therefore some parts of the basic data-set should not be in it.

Two Members reply that the Network should not preselect and filter the epSOS set of data. Professionals will select on the spot the relevant information in an emergency case.

One Member asks if health professional organisations have looked at the data set? A representative from epSOS reports that the project has been very keen on including clinicians and other stakeholders. The development of the data-set has been a robust process.

The Member State Chair mentions that the eHGI will anyway distribute a questionnaire about the data-set among professional bodies to check if it is a useful data set.

### **Conclusion**

- The set of data is specifically supported by 20 Member States. No Member State opposed the use of the set of data from epSOS to construct a guideline.
- The Chairs welcome the broad agreement on the usability of a guideline at national level. More advanced systems of course exist in some Member States and the eHealth Network should agree to work upon them.
- Members should consult their national stakeholders on the usability of the guideline at national level. Such consultation will also take place at EU level.

## **2. POINT 2 OF THE AGENDA: CONNECTING EUROPE FACILITY**

### **2.1. Report of on the Connecting Europe Facility (CEF)**

#### **Introduction**

Paul Timmers, Director in DG CONNECT, gives an update on the state of play of the current EC proposal for a regulation on a Connecting Europe Facility. A revised proposal is in the pipeline.

The initial proposal suggested support to sustainability and the role out of cross-border public services. The CEF should ensure a funding mechanism for European digital infrastructures for 2014-2020, notably for the exchange of information through electronic health records, and support their sustainability.

The initial CEF proposal had two components: digital services and broadband. The CEF gave a longer term perspective to put the digital services in place. These digital services are inspired by large scale pilots, like EPSOS, STORK, electronic procurement and e-justice. These projects have shown that the technology works. The Commission proposed a total budget of € 9 billion, € 7 billion for broadband, € 2 billion for digital services.

In the Multi Financial Framework (MFF) discussions, the Council significantly cut the budget for digital services down to € 1 billion. 12 digital services will be in competition to benefit from this reduced budget.

Paul Timmers warns about the following:

- The CEF will look for long term services, running 24 hours/day, not piloting.
- Services must be mature, have a business case and be sustainable, till 2020 and beyond.

Paul Timmers therefore advises the Members to look at the sustainability of eHealth services, as a condition for financial eligibility and support by the CEF. This is not an urgent call, but a position is needed in 2014.

Within a few weeks there will be a new proposal from the Commission. This will go to Council and Parliament. There will be a lot of interest from all competing domains<sup>1</sup>.

#### **Comments**

Upon request on one Member, Paul Timmers clarifies that the CEF will support the services that are available across Europe. If eHealth services have been identified as a priority for funding, such services should follow the specifics annexed to the proposal.

#### **Conclusion**

- The eHealth Network members are requested by the Chairs to inform their national counterparts in the Council about the importance of eHealth services in the CEF proposal.
- The eHealth Network should endorse a position paper on the CEF at its next meeting.

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<sup>1</sup> NB: The new draft regulation has been adopted by the Commission on 28 May 2013 and eHealth services have been identified as potential digital services to be deployed.

## **2.2. Strategic discussion on a policy proposal for a permanent structure to work on interoperability**

### **Introduction**

The Member State Chair introduces the concept of a ‘standing coordination group’, to serve as a permanent structure for facilitating cross-border exchange of data in the field of eHealth.

The standing coordination group (SCG) would concentrate on semantic and technical interoperability issues like eIdentification. The SCG would give a strong signal that the eHealth domain has a structural approach to work on interoperability in eHealth, therefore promoting eligibility for funding under the CEF.

The proposal has strong support from the steering committee of the eHGI but there is a need for political support from the eHealth Network.

### **Discussion**

Many Members support the idea of a SCG. There is work to be done to make the results of the large scale pilots more sustainable. The SCG could be the organisation to do this, and it could create efficiency in coordinating the different initiatives and projects.

Most Members are of the opinion that the proposal needs further refinement, specifically on the scope/mission, budget, deliverables and tasks.

Several Members suggest not duplicating the work of the eHGI. The eHGI and SCG could probably be merged, notably because of limited number of experts in smaller countries.

Some Members stress that the SCG should engage people selected by the responsible authorities for eHealth. Others stress that it should not replace bilateral arrangements between countries and regions.

One Member draws the attention on the need to discuss the current state of play on the databases for pharmaceuticals and devices. They could also be part of the CEF financing and should be discussed in the next eHealth Network meeting.

### **Conclusion**

- The Commission Chair notes the broad support for establishing a standing coordination group. Its mission and concrete tasks need to be well defined, and a roadmap must be presented for its work.
- The Member State Chair proposes to proceed by forming a team who will work on this and give it more body. A more detailed proposal will be ready for the Network during the meeting in November.

### **3. POINT 3 OF THE AGENDA: REPORT ON PROGRESS ON INTEROPERABILITY**

#### **Introduction**

The interoperability road map is a very important step to provide a clear picture how the eHealth Network wants to make progress in its main field. The SCG could be an important building block to implement it.

It was reported to the meeting that the road map as such could not be produced; it will be presented in November, building on a report paper delivered to the members at this meeting.

#### **Discussion**

##### *SNOMED CT*

Multiple Members support the proposal in the report that the Commission should look at the possibilities of the SNOMED CT terminology and that covering the licencing costs is a strong first signal.

Several Members express their worries that this process is not moving. The topic was discussed during the previous meeting and is again discussed now. It should be clear that there is a need to decide whether or not to move on this during the next meeting in November.

Some Members warn that licensing costs, even if paid by the EU budget, are just a small part of the implementing costs, which need to be covered by Member States.

Some Members are worried about the reaction of health professionals if Member States were forced to change their national coding system. Would SNOMED CT be mostly used for cross border exchange of data or also at national level?

Some Members indicate that it is not necessary to implement SNOMED CT in the whole health system or the whole terminology. Some areas can be selected. Countries have several codification systems but SNOMED CT is a strong translator.

One Member is not in favour of starting to negotiate about the use of SNOMED CT. First it should be clear what the use is, why it is needed, and if other coding systems are possible. There are also links to payment systems, thus a budgetary issue.

One Member suggests moving fast on this, before countries move in different directions. A list of priorities should be made and a study of different strategies must be done.

One Member points out that the WHO ICD coding is linked to SNOMED CT. In principle there is a need to pursue the analytical work done by epSOS on the different terminologies used.

##### *Patient access to health data*

One Member expresses reservations about access to the data by the patient and asks eHGI to investigate this further.

Paul Timmers reminds the Members that the eHealth Taskforce report said about this: "the data is yours, and your data is free to flow".

## **Conclusion**

- The Chairs agree on follow-up work needed on SNOMED CT, and to table a proposal during the meeting in November. They agree that the membership fee is not the issue but EU financing would send out a clear message to national institutions.
- The Commission Chair reminds that there will be a database on medicines by EMA, and a proposal on medical devices based on a unique identification code is now discussed.
- The Member State Chair agrees that access to patient data is a very complex issue, as highlighted in the Digital Agenda. Patient organisations want to have access but health authorities have different perspectives on patient empowerment. It is also closely linked to the proposed data protection regulation in the legislative pipeline.

## **4. POINT 4 OF THE AGENDA: EIDENTIFICATION FOR EHEALTH**

### **Introduction**

The Member State Chair introduces the topic. At the last meeting, the eHealth Network asked to investigate eIdentification as an important issue for eHealth. The eHGI organized a workshop in February. This workshop made clear that work still needs to be done on eIdentification in healthcare, to complement the proposed eID regulation. In health, the use of higher sensitive information is common, which is not well reflected in the regulation. The eID regulation might be very good for online identification but health care is much more on the spot.

### **Discussion**

No comments are made on the position paper and the proposed next steps.

### **Conclusions**

- Since no comments were made, the Chairs noted that the Members endorse the meeting document and suggest moving forward as proposed in the position paper.

## **5. POINT 5 OF THE AGENDA: REPORT ON DATA PROTECTION REGULATION**

### **Introduction**

The Commission Chair introduces the topic. The European Commission proposal aims at balancing access to health data for research and public health and securing the individual rights of the patient.

The LIBE committee is responsible for this proposal in the European Parliament. This Committee proposed changes that would go against the initial objectives. The vote on the amendments of the LIBE Committee is delayed and will not take place in May.

The eHGI has summarized positions to be defended for the health domain, notably on consent, right to be forgotten and safeguard measures for cross-border deployment and use.

## **Discussion**

One Member expresses that the national authority cannot support the wording in the paper. At national level there is no agreement that the current articles of the proposal are sufficient. The same Member informs that work with Justice Department is being done to clarify the current wording.

## **Conclusions**

- The Chairs conclude that the paper is broadly endorsed, taking into account the comment made. The Network will be again informed in November on the progress. The Commission Chair reminds that if the proposal is not adopted by March 2014, the new Parliament needs to start the reading from the beginning.

## **6. CLOSING**

### **Comments of the co-chairs**

The next eHealth Network meeting will be on 19 November in Brussels.

The preliminary agenda topics are:

- Adoption of the guideline on the data set for patients summary.
- Adoption of the roadmap on interoperability
- Adoption of the roadmap on common measures on eID for eHealth
- Report on SNOMED CT.
- Report of EMA on medicinal products databases.

### **Comments Members**

Some Members would like to be better prepared for the meeting. These are very important meetings for countries that are not represented in all expert groups of the eHGI. A preparatory meeting before the eHealth Network should discuss the topics on the agenda. If possible, the documents should be available one month before the Network meeting.

The Member State Chair declares that this is already the case. The Project Steering Board of the eHGI is the portal prior to the eHealth Network, where all the documents and agenda topics are discussed a month prior to the eHealth Network. Member States that are not part of the eHGI are very welcome to join in these meetings.