



Brussels, 29 April 2013

3RD eHEALTH NETWORK 14TH MAY 2013
COVER NOTE BY SECRETARIAT

Subject: Topic 1 - Set of data for exchange of patients' summary

Issue at stake / request to eHealth Network

The secretariat suggests a first strategic discussion about the set of data developed, tested and adopted, in the epSOS-project. As stated in the Multiannual Work Programme of the eHealth Network, the adoption of a guideline on a non-exhaustive list of data (to be included in patient's summary), is foreseen in the Network meeting in November 2013.

The eHealth Network members are requested to:

- discuss and comment on the information presented in this paper concerning the list of data for patients' summary ;
- discuss the usability of the patient summary dataset in a cross-border setting and provide the eHGI with the information how to strengthen the usability of a guideline on a non-exhaustive list of data;
- Express their ideas how a guideline would be used at national level;
- State if further involvement of stakeholders at EU level is preferred in the development of a guideline.

Summary of document

This discussion paper provides an overview of the information that is included in the patient summary defined in the epSOS-project. To achieve the adoption of a guideline in November, the secretariat proposes that the eHGI is mandated by the eHealth Network to work on a guideline that incorporates the datasets as displayed in the paper.

Format of procedure

Short introduction by co-chair Paola Testori Coggi, followed by a discussion of the eHealth Network Members on the issues presented in the paper.



GUIDELINES ON PATIENT SUMMARY SET OF DATA FOR CROSS BORDER ELECTRONIC EXCHANGE, UNDER THE CROSS BORDER DIRECTIVE

*Discussion paper for the eHealth Network
(prepared by DG SANCO, based on information provided by the epSOS-project)*

Introduction

The secretariat proposes this paper to **start a discussion on a non-exhaustive dataset for patient summary** that can be exchanged across borders. For this purpose, the secretariat provides the eHealth Network with a letter containing background information on the Patient Summary Dataset used in the epSOS-project¹ (appendix I).

As stated under priority 4 of the '*Strategic priorities of the eHealth Network Multiannual Work Programme*', the eHealth Network will deliver two final outcomes concerning exchange of patient summary in a cross-border setting:

1. Guidelines on non- exhaustive list of data to be included in patient's summary
2. Guidelines for cross-border electronic exchange of patients' summary data set

In line with the Multiannual Work Program, the Network has agreed to work toward the adoption of a non-exhaustive dataset during the 4th eHealth Network Meeting in November 2013. In order to give the Network Members efficient time to discuss this important topic, the secretariat produced this discussion paper. The secretariat would like to hear the input of the eHealth Network on the dataset for patient summary defined by epSOS. Based on this first discussion, the eHealth Governance Initiative (eHGI) will be asked to start the preparation of a guideline on non-exhaustive list of data.

Scene setting

Background

A patient summary can support the delivery of safe and high quality care to patients. This is also applicable in a cross-border setting. The purpose of a patient summary is to provide essential information about the patient and his/her medical history, which, in particular in the case of emergency care, can save lives and/or decrease the number of

¹ Smart Open Services for European Patients - Open eHealth initiative for a European large scale pilot of patient summary and electronic prescription

complication and medical errors. Furthermore, access to a patient summary can enhance the quality of care and strengthen patient safety, also in a planned care setting.

Patient summaries throughout European Member States and regions contain a variety of information. However, the focus lies on providing essential clinical and personal information with the aim to support the health professional in delivering high quality care. To enable cross-border exchange the Member States recognize the need to bring forth a guideline which contains a non-exhaustive list of data that are to be included in patients' summaries². This discussion paper focuses only on the variables included in the datasets defined by the epSOS-project. Related topics, such as the document structure of the patient summary and the required terminology standards, will not be addressed in this paper.

The epSOS-project

During its five years of activities, the epSOS project has gathered exceptional experience with cross-border exchange of patient's summary data. 23 participating nations collaborate within the epSOS project. Together they have brought forth use cases and specifications enabling cross-border exchange. The epSOS project is broadly recognized as the leading EU project concerning cross-border exchange of patient data.

DG SANCO asked the epSOS' Project Steering board to summarize the experience of epSOS and the specifics of the standardized set of electronic health data of patient summary that was agreed upon by the project beneficiaries. On the 13 February 2013, epSOS Project Steering board delivered the requested information. The secretariat based this discussion paper on the information as can be found in the document provided by epSOS.

Dataset in epSOS-project

Two datasets

Within the epSOS-project, a patient summary was defined as a “*dataset of essential and understandable health information*” that is made available “*at the point of care to deliver safe patient care during unscheduled care and planned care with its maximal impact in the unscheduled care*”. Due to the focus on unscheduled care (mainly provided in emergency situations), the dataset used in the epSOS-project, should provide the health professional with a summary of the most relevant information.

Because of the need to balance between the clinical purpose and the actual information Member States are currently able to exchange, the epSOS-project defined two divisions in the dataset:

² Directive on the application of patients' rights in cross-border healthcare (2011/24/EU)

1. *Basic dataset*: **essential health information** that is required from the clinical point of view to be sent to deliver safe care to the patient (focused in unscheduled care);
2. *Extended dataset*: defined as the minimum **desirable health information** from the clinical point of view to be exchanged. The fields are not compulsory in the epSOS pilot.

For project purposes, epSOS also defined a *Mandatory dataset*. This is a subset of the *Basic dataset*, and was introduced because at the time the project started, important data of the *Basic dataset*, was not available in some of the countries (e.g. not coded, not possible to be recovered). The *Mandatory dataset* was designed to enable exchange of patient summary between Member States based on the least common denominator of exchangeable data available in Member States within the scope and duration of the project. Hence the *Mandatory dataset* is not addressed in this paper.

Please find an overview of the *Basic dataset* and the *Extended dataset* below³.

³ The full epSOS list can be found in the attached letter of epSOS (13 February, 2013). This includes the values that were identified in the epSOS-project for the *Mandatory dataset*. A decision on the variable Insurance Number, is still pending. For the time being, this is included in the Extended dataset. In case of a discrepancy due to formatting between the data-set displayed in the discussion paper and the letter from epSOS exist, the information provided by epSOS is leading.

Basic dataset

The basic dataset consists of the following values:

PATIENT DATA		
VARIABLE (nesting level 1)	VARIABLES (nesting level 2)	VARIABLES (nesting level 3)
Identification	National Health Care patient ID	National Health Care patient ID
Personal information	Full Name	Given name
		Family name/Surname
	Date of Birth	Date of Birth
	Gender	Gender Code
Contact information	Preferred HCP/Legal organization to contact	Name of the HCP/Legal organization
		Telephone No
		E-mail
PATIENT CLINICAL DATA		
Alerts	Allergies and intolerances	Allergy description
		Allergy description id code
		Agent
		Agent id code
Medical problems	List of Current Problems/Diagnosis.	Problem/diagnosis description
		Problem Id (code)
		Onset time
	Medical Devices and implants	Device and implant Description
		Device Id code
		Implant date
	Major Surgical Procedures in the past 6 months	Procedure description
		Procedure Id (code)
		Procedure date
Medication Summary	List of current medicines	Active ingredient
		Active ingredient id code
		Strength
		Number of units per intake
		Frequency of intakes
		Duration of treatment
		Date of onset of treatment
PATIENT SUMMARY DATA (Information about the PS itself)		
Country	Country	Country
Patient Summary	Date Created	Date Created
	Date of Last Update	Date of Last Update
Author/Nature of the patient summary	Author of the patient summary	Author of the patient summary
Legal entity	Responsible of the PS data	Responsible of the PS data

Extended dataset

The *Extended dataset* consists of the following values:

PATIENT DATA		
VARIABLE (nesting level 1)	VARIABLES (nesting level 2)	VARIABLES (nesting level 3)
Contact information	Address	Street
		Number of Street
		City
		Post Code
		State or Province
		Country
	Telephone No	Telephone No
	E-mail	E-mail
	Contact Person/ legal guardian	Role of that person
		Given name
Family name/Surname		
Telephone No		
		E-mail
Insurance information	Insurance Number	Insurance Number
PATIENT CLINICAL DATA		
Alerts	Allergies and intolerances	Onset Date
History of past illness	Vaccinations	Vaccinations
		Brand name
		Vaccinations id code
		Vaccination Date
	List of Resolved, Closed or Inactive problems	Problem Description
		Problem Id (code)
		On set time
		End date
	Surgical Procedures prior to the past six months	Resolution Circumstances
		Procedure description
Procedure Id (code)		
Medical problems	Treatment Recommendations	Procedure date
		Recommendations Description
	Autonomy/Invalidity	Recommendation Id (code)
		Description
		Invalidity Id code
Medication Summary	List of current medicines	Pharmaceutical dose form
Social History	Social History Observations	Social History Observations related to: smoke, alcohol and diet.
		Reference date range
Pregnancy History	Expected date of delivery	Expected date of delivery
Physical findings	Vital Signs Observations	Blood pressure
		Date when blood pressure was measured
Diagnostic tests	Blood group	Result of blood group
		Date

Next steps: proposal for guideline

During the eHealth Network Meeting in May, the secretariat proposes to have a first discussion on the datasets defined by epSOS. Adoption of a guideline on a non-exhaustive list of data is foreseen in November 2013.

To achieve adoption in November, the secretariat proposes that the eHGI will be mandated by the eHealth Network to work on a guideline that incorporates the datasets as displayed above, and takes into account the experiences of the epSOS pilot. Activities in this process shall include (not exhaustive):

- Work within the eHGI, including relevant stakeholders, to develop a comprehensive guideline on a non-exhaustive list of data that are to be included in patients' summaries and that can be shared across borders.
- Evaluate use of set of data in patient summary in Member States;
- Meeting with epSOS representatives to clarify any outstanding issues;
- Formal consultation of the project steering committee of the eHGI;

The guideline, including a non-exhaustive dataset, must be ready for endorsement by the eHealth Network during the next meeting, which is planned in November 2013.

Issues for discussions

The secretariat proposes the following topics for discussion during the 3rd eHealth Network Meeting on the 14th of May 2013.

The eHealth Network is suggested to:

- **discuss and comment on the information presented in this paper** concerning the list of data for patients' summary⁴;
- **state their commitment to -and discuss the usability of- the patient summary dataset** in a cross-border setting and provide the eHGI with the information how to strengthen the usability of a guideline on a non-exhaustive list of data;
- Express their ideas how a guideline would be **used at national level**;
- State if further **involvement of stakeholders** at EU level is preferred in the development of a guideline.

⁴ The chair of the epSOS steering board, dr. Mårten Kivi, will be invited to give clarification.