



11TH eHEALTH NETWORK 9 MAY 2017, ST. JULIAN'S, MALTA
COVER NOTE BY eHEALTH NETWORK SECRETARIAT

Topic 7: Secondary use and access to health data (agenda point 14 and 15)

Issue at stake

This agenda topic covers 2 documents:

- 1) How to handle health data for purposes other than patient care (agenda point 14): this topic is for discussion at the eHealth Network meeting.
- 2) Draft report on the EU state-of-play on patient access of eHealth data (agenda point 15): this topic is for information. Because the topic "patient access to health data" is an identified category by the MWP sub-group, this document was forwarded to the sub-group for their consideration. Moreover, this topic is also a priority for the Estonian Presidency.

Summary of document

Agenda point 14 provides a description of good practices on how to deal with health data for other use than medical treatment. The document has a strong focus on the OECD Council recommendations on health data governance from January 2017. The document provides a set of principles, processes, standards, activities and compliance mechanisms. Furthermore, it provides recommendations and considerations on de-identification of health data.

Agenda point 15 is based on desk research and provides an overview from a number of EU Member States of what they have done on providing patients access to their health data. Task 7.5 health data as a patient's electronic health record data. The document looks into national legal provisions, the way the health system is organised, but also into the infrastructure that is in place to support the access of health data by patients. In support of this report, task 7.5 is conducting a survey that provides further input into the report. The final version of the report including the results of the survey will be presented to the eHealth Network at its 12th meeting in November 2017.

Main results up to now:

- There are a lot of differences in approaches and state of plays
- Despite being as specific as possible (definitions, scope, etc.) the responses already imply that there is not a common understanding/language in relation to eHealth definitions.

Furthermore, this report feeds into a follow-up document that entails recommendations for patient access to electronic health records scheduled for the 13th eHealth Network meeting in May 2018.

Below describes in short the milestones and the methodology that task 7.5 of the JAseHN will use to finalise the report under agenda point 15.

Milestones:

- April 2017: finalized the draft report based on desk research from 18 countries.
 - November 2017: deliver final draft report based on survey results and desk research
- State of play: the survey responses up to date are 16 countries

Approach:

- Collecting all survey results
- Analyse survey results and compare to desk research:
 1. Look for common trends
 2. Look at usage statistics, set benchmarks and identify common characteristics
 3. Look at other key indicators and do an analysis of the results, e.g. is regulation an incentive or a driver of adoption?

Questions to the eHealth Network with regards to deliverable under agenda point 13:

- Does the direction of the report comply with the needs of the Member States?
- Are the topics relevant for the countries?
- Do you agree with the proposed methodology to finalise the report?

Format of procedure in the eHN

The Member State co-chair introduces the topic and provides an explanation to agenda point 14. Then the Member State co-chair will give the floor to the task lead of agenda point 15 Mr. Sprenger who will present the preliminary report. The eHealth Network Members are then given the floor to provide comments and/or ask questions.