



# DRAFT RECOMMENDATIONS

## for

### Patient Access to Electronic Health Records

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## TABLE OF CHANGE HISTORY

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V4	10-11-2017	SUBMITTED TO SPSC AND WP4	LINDA KEANE ELISE PETERS

## LIST OF ABBREVIATIONS

ACRONYM	DEFINITION
<b>GDPL</b>	GENERAL DATA PROTECTION LEGISLATION
<b>PHR</b>	PERSONAL HEALTH RECORDS
<b>PIN</b>	PATIENT INFORMATION NOTICE
<b>WDP</b>	WIDENING DIGITAL PARTICIPATION
<b>WP</b>	WORK PACKAGE

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## 1. Executive summary

The findings of the deliverable 1 final report results in the following list of recommendations:

No.	Recommendation name	Action for eHealth Network
I	Model or Framework	Endorse
II	Digital Health Literacy	Endorse
III	Policy	Raise Awareness
IV	Portability	Raise Awareness
V	Services to Patients	Raise Awareness

Table 1 Recommendations and Actions

## 2. Introduction

### 2.1 Background

In May 2014 the eHealth Network adopted a Multi-Annual Work Plan 2015-2018 with four main areas to work on, namely Interoperability and Standardization, Monitoring & Assessment of Implementation, Global Cooperation & Positioning and Exchange of Knowledge. The work packages of the JAseHN project address the majority of the needs linked to these four priority areas. This report is related to the Exchange of Knowledge area and has been produced as part of JAseHN work package 7 (WP7) described as ‘actions undertaken to analyse and enhance the eHealth related communication between MS’<sup>1</sup>.

### 2.2 Purpose

All MS are initiating or implementing eHealth innovations but not necessarily at the same pace and therefore an analysis of the current situation in Europe is necessary. Task 7.5, deliverable 1, reported on the current state of play in Europe regarding patients’ access to their eHealth data. This report was delivered for information to the eHN meeting on November 28.

The purpose of this report, Task 7.5 deliverable 2, is to use the analysis within the deliverable 1 report to make recommendations for patient access to electronic health records. This recommendation report considers best practices to provide access to EHR data and data portability and effective ways to improve patient/citizen digital (health) literacy.

### 2.3 Rationale

D.1 data shows that there are almost as many different approaches to patient access as there are EU member states. There is no way of ranking the different countries and no obvious pattern emerged from the D.1 data. Even though citizens/patients have the ability to access their EHR information which is been embedded into current systems and processes in almost all countries, survey results backed up by desk research point to a large variety in the programs, pilots, projects and systems in place to provide patients with access to their electronic health record data at both national, regional and local levels. For example:

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<sup>1</sup> Proposal V4. *Grants for Actions Co-Financed with Member State Authorities (Joint Actions) (HP-JA)*. 3rd EU Health Programme. 05-05-2015, p. 12.

- The work to provide patients with access to their EHR information is organised at a national level in some countries and at a regional level in others.
- The data shows we are in the middle of a revolution; slow movers, fast movers, for some aspects a similar approach is taken (e.g. in offering functionality such as viewing, downloading and sharing EHR information), but on other aspects, there is a wide variety of approaches taken. The variety of responses reflect no common trend with regard to authenticating patients.
- There is a variety of standards in place according to the variety of systems in place.

One reason that could explain the variety of responses is that there is no consistency in understanding of key terms e.g. national EHR, multiple EHR's, patient access, health network exchange etc. It is also difficult to capture the full extent of the situation within a country by answering a limited number of targeted questions.

Almost all countries indicate that patient access to EHR information is covered in policy, mostly national organized, however it could not be determined on what basis this policy was developed without further investigation outside of the scope of task 7.5.

Results seem to indicate that systems are deployed in 2 phases – give the patient the ability to view patient information in phase 1, then provide the patient with the functionality to interact and do something with the information in phase 2. Based on the results, the current focus is now particularly on phase 1.

Digital literacy appears to be addressed in terms of overall digital literacy policy rather than specifically in relation to eHealth. Patient usage statistics were not provided in the majority of cases and some findings were based on the assumptions of the respondent e.g. guesstimates around patient access and usage of EHR information and the perceived opinions of patients regarding the advantages and disadvantages of having access to the EHR information. The lack of available data indicated by respondents may suggest that when it comes to patients accessing EHR information, actual usage patterns/trends are not being examined/monitored on an ongoing basis.

Based on the results there is a clear difference in patient involvement between digital literacy and health literacy; Awareness with regard to the involvement of patients to increase digital literacy is bigger than the awareness to involve them to increase digital health literacy.

### **3. Recommendations for Endorsement by the eHealth Network**

#### **3.1 Recommendation I: Model or Framework to describe situation**

A better understanding of key terms within the context of patient access will assist future collaborations between European countries, further development within this field and research into this topic. Communication and understanding of key terms will improve and data from member states will be more easily compared as everyone involved will be coming from the same position of understanding.

Proposed actions:

- A common understanding of a specific list of terms used in the context of patient access is reached e.g. EHR information, PHR data, patient access, national patient portal etc. to aid future understanding.
- Frameworks and models are developed to describe key aspects of patient empowerment, taking into account all relevant aspects/perspectives and mapping out the inter-relationships. These models are used in future research and to provide a consistent way of analysing data.
- A mechanism is created that facilitates an active sharing environment for those members who want to participate, putting emphasis on monitoring patient usage on an ongoing basis.

### **3.2 Recommendation II: Digital Health Literacy**

Knowing how to access an online patient portal is not enough if patients are to truly realise the benefits of having access to EHR information. It's important that patients understand the EHR information being presented to them so that they can actively manage their own health and care. Including patients in the development of systems where they are the key users will contribute to broader acceptance and use.

Proposed actions:

- At ministerial level, digital health literacy needs its own recognition, rather than failing under general digital literacy policy. The focus for the patient must be on understanding the information (rather than accessing it).
- Encourage greater cooperation with patient representative bodies and putting the patient at the centre of the development process.

## **4. Recommendations for Awareness raising of the eHealth Network**

### **4.1 Recommendation III: Policy**

Examine policy at a national level and comparing against European policy could help in aligning both and setting European policy that is more widely adopted at national level.

Proposed actions:

- Further examine MS policies in relation to patient empowerment, compared against European policy and identify good practice. Aspects to consider include: the purpose of the policy programme, the shape and pace of its development, if all policy originates from the same or diverse aims and objectives (e.g. patient empowerment, data protection or others), if there a common approach that can be embraced by the eHN.

### **4.2 Recommendation IV: Portability**

Consider two scenarios in relation to portability:

Scenario 1. Patients need access to their health data created and stored abroad.

Scenario 2. Patients need some sort of translation tool, so that information from their own country can be used by health care professionals in other countries.



When talking about portability of data between countries the health professionals have been the target, now we need to also target the patient. This may present different aspects and solutions. The world is changing to personal health environments; solutions that gives the patients environments that manages patient information. Those environments should be connectable to EHR systems. The ideas on a high level is that those two worlds should be connected. That goes beyond the idea that everything should be structured around EHR systems

Proposed actions:

- Develop a mapping between the EHR and the PHR environment so that we can talk about portability of patient health information in relation to the total concept and not just one narrow aspect of it.
- Raise awareness of the next big step in relation to patient access being interoperability → even if we cannot determine the state of play.

### **4.3 Recommendation V: Services to Patients**

Patient empowerment is more than just providing a patient with his/her with static health information. There is an evolution to 2-way communication which is not there yet because of interoperability issues.

Proposed actions:

- Provide guidance at EU level around technical/validation of the transfer of ownership of the data, showing best practice at a legal level.
- Agree and promote the fact that patient empowerment is more than just passively viewing own eHealth information.