



eHealth Network

RECOMMENDATION PAPER

on

**Patient Access to
Electronic Health Record Information**

eHealth Network

The eHealth Network is a voluntary network, set up under article 14 of Directive 2011/24/EU. It provides a platform of Member States' competent authorities dealing with eHealth. The Joint Action supporting the eHealth Network (JAseHN) provides scientific and technical support to the Network.

Adopted by consensus by the eHealth Network, Brussels, 15 May 2018

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LIST OF ABBREVIATIONS

ACRONYM	DEFINITION
EHN	E-HEALTH NETWORK
EHDSI	E-HEALTH DIGITAL SERVICE INFRASTRUCTURE
EHR	ELECTRONIC HEALTH RECORD
HCP	HEALTHCARE PROVIDER
MS	MEMBER STATE
GDPL	GENERAL DATA PROTECTION LEGISLATION
GDPR	GENERAL DATA PROTECTION REGULATION
HP	HEALTH PROFESSIONAL
PHR	PERSONAL HEALTH RECORDS
PIN	PATIENT INFORMATION NOTICE
WDP	WIDENING DIGITAL PARTICIPATION
WP	WORK PACKAGE

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Executive Summary

All MS are initiating or implementing eHealth innovations but not necessarily at the same pace. Empowering citizens to take a more active role in the management of their health is a current focus of EU policy and planning. The purpose of this report is to make recommendations to the eHealth Network (eHN) on patient access to Electronic Health Record (EHR) information, portability of such information and the ability of patients to access and understand available information (digital and digital health literacy). The scope is limited to systems that provide patient access to EHR information.

Research conducted in Deliverable 1 (D1) of task 7.5 showed that there are almost as many different approaches to patient access as there are EU member states. There is no way of ranking the progress of MS with no obvious patterns emerging. Other results on patient access show that almost all countries cover online patient access by policy, mostly nationally organised. 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. Lastly, digital literacy appears to be addressed in terms of overall digital literacy policy rather than specifically in relation to eHealth, with a lack of awareness on involving patients when increasing digital health literacy. These results lead to the creation of seven recommendations of which the following four recommendations are presented for adoption by the eHN members, as they are not being addressed by a distinct project or joint action:

- It is recommended that the eHN recognises the need for citizens living and/or working in more than one country to have secure online access to their dispersed eHealth data, in an integrated way.
- It is recommended that the eHN considers expanding actions on patients'/citizens' access in organising cross border portability in eHDSI developments.
- It is recommended that the eHN supports consistent policy development on patient access in MS that would promote patient access at a European level.
- It is recommended that the eHN considers organising a follow-up monitoring study after a period of time has elapsed, to capture ongoing developments in patient access to eHealth data in general (also outside the D1 scope 'access to EHR information') and usage of this data by patients.

1. Introduction

1.1 Background

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 was 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, 2017.

1.2 Purpose

The purpose of this report, Task 7.5 deliverable 2, is to use the task's deliverable 1 report (D1) on the state of play on patient access to make recommendations to the eHealth Network on patient access to Electronic Health Record information, portability of such information and the ability of patients to access and understand available information (digital literacy and digital health literacy).

1.3 Scope

When describing patient access in the D1 report and as a follow up in this recommendations report, the scope was limited to systems that provide patient access to EHR information. Personal Health Records (PHR) and associated applications are deemed to be outside of the scope. What is needed for patients to access their eHealth data and make good use of that data is also considered in this report i.e. in terms of data portability, digital literacy and digital health literacy.

Based on D1 findings and recognising relevant EU priorities as outlined in paragraph 1.4, this report presents four recommendations on patient access for adoption by the eHN members and three recommendations for information purposes.

1.4 EU Priorities

Empowering citizens to take a more active role in the management of their health is a current focus of EU policy and planning. The recommendations contained in this report consider and compliment EU priorities in relation to patient access to eHealth information for example:

H2020 Multi-Annual Work Plan 2018 -2020¹

Referring to: **Societal Challenge 1 - 'Health, demographic change and wellbeing':**

- "Timely and meaningful information and knowledge for personalised health and care services are essential for ...society and citizens."
- "Digital solutions can support ...self-empowerment of patients."
- "Funding for big data approaches that enable aggregation of a variety of new and existing data sources..."

¹ http://ec.europa.eu/research/participants/data/ref/h2020/wp/2018-2020/main/h2020-wp1820-intro_en.pdf

eHealth Network Multi-annual work plan 2018 – 2021 “eHealth in support for better health”²

Referring to: **Category A.2 Patient access and use of data:**

- “Giving patients' insight in their own medical history (electronic health records) will allow them to better manage their own health.”
- “The challenges on how patient generated data could be linked to clinical data should be addressed.”
- “A synergetic and coherent approach to patient access, share, and reuse of health data is the aim in the EU, taking the Member States' competencies and room for manoeuvre into consideration.”

2. Recommendations for Adoption

2.1 Cross Border Data Portability from the Patient’s Perspective

It becomes increasingly important to exchange patient data between countries to cater for the increasing mobility of EU citizens. The eHealth Digital Service Infrastructure (eHDSI) is about to exchange cross-border eHealth Information Services (CBeHIS), such as Patient Summary (PS) and ePrescription³. The objective is to prepare, deploy and operate National Contact Points for eHealth (NCPeH) in each of the MS.

While the current focus is on the exchange of patient data between health professionals, opportunities may exist to build upon current work and provide European mobile citizens with secure online access to their PS across countries.

There is a growing awareness of the benefits of empowering patients in the management of their own health and wellbeing by providing them with access to their EHR data. The findings from D1 show that almost all countries are offering patients access to their EHR data, or working on providing access, almost exclusively through online systems or portals that can be accessed from any location. Citizens living and working in different countries, may have a clinical history in each location and therefore their patient data is dispersed among those countries. Europe can offer help to these mobile citizens by focusing on how to create value from such scattered data:

Therefore it is recommended that the eHN recognises the need for citizens living and/or working in more than one country to have secure online access to their dispersed eHealth data, in an integrated way.

In addition, it is recommended that the eHN considers expanding actions on patients'/citizens' access in organising cross border portability in eHDSI developments.

² <http://jointaction3.spms.min-saude.pt/wp-content/uploads/2018/02/PROPOSAL-eHealth-Network-Multiannual-Work-Programme-2018-2021.pdf>

³ <https://ec.europa.eu/cefdigital/wiki/display/EHOPERATIONS/eHDSI+Mission>

A way forward: these recommendations are presented to the eHN members for adoption. If adopted, it is advised to review and take learnings from the focus area of Horizon 2020 titled: “Digitising and Transforming European Industry and Services”, which supports activities that enable the aggregation of a variety of new and existing data sources such as medical records, registries, social platforms and other data from a user-driven perspective. One action under the programme for Digital Transformation in Health and Care focuses on prototyping a European interoperable EHR exchange. An expected deliverable from this action is a citizen-centred secure but easy-to-use platform that is constantly accessible and portable within any other MS of the EU.⁴

2.2 Policy on Patient Access

Almost all countries cover patient access to EHR information in policy, mostly nationally organized. Two main categorisations can be made on MS policy objectives; programs and projects with the objective to create patient portals versus programs and projects to create standards for implementing patient portals. It could not be determined on what basis these policies were developed without further investigation, outside of the scope of task 7.5.1 (D1).

Naturally, MS have their own views on organising patient access within their country. If a European focus on patient access is considered important then the identification and development of common elements in MS policy will contribute to the progress of collaborative efforts on patient access at European level:

Therefore, it is recommended that the eHN supports consistent policy development on patient access in MS that would promote patient access at a European level.

A way forward: this recommendation is presented to the eHN members for adoption.

2.3 Capturing Patient Access – Reality and Progress

The D1 study highlighted the deployment of systems in two phases – allowing the patient view EHR information in phase 1 and interact with the information in phase 2 (e.g. uploading additional data, adding comments, posing questions of HPs, etc.). The current focus while predominantly on phase 1, is slowly moving to phase 2: patients actually using and interacting with the data. Beyond viewing their own static health information, the possibilities for patients to, for example, include their own measured data, are growing. One-way communication then evolves to two-way communication between the patient and HP and/or other relevant stakeholders.

With regard to patient usage, the majority of responses received were based on assumptions and statistics were not provided. The lack of available data indicated by respondents suggests that usage patterns in relation to patients accessing EHR information are not being monitored. Therefore, there is no way of quantifying the extent of such usage by patients.

⁴ <https://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/sc1-dth-08-2018.html>

The shift from 'viewing' to 'using' is expected to drive further engagement of patients with their eHealth data. It is important and beneficial for MS to understand developments in this rapidly evolving area of patient-driven health care.

Therefore, it is recommended that the eHN considers organising a follow-up monitoring study after a period of time has elapsed, to capture ongoing developments in patient access to eHealth data in general (also outside the D1 scope 'access to EHR information') and usage of this data by patients.

A way forward: this recommendation is presented to the eHN members for adoption.

3. Recommendations for Information

3.1 The Context of Patient Access

During the study for D1 it became evident (because of the variety and scope of the responses) that the topic 'patient access' and its additional elements are being interpreted in multiple ways. There lacked a consistent or common understanding of concepts such as a national EHR, multiple EHRs, online patient portals, PHRs, patient access etc., between MS.

In addition, even though the ability for citizens/patients to access their EHR information to some degree is embedded into current systems in almost all countries, survey results backed up by desk research point to large variations in the programs, pilots, projects and systems in place; for example:

- 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 pace of change and approaches to implementing patient access to EHR information varies from country to country; depending on, for example, different sorts of control: governmental versus market.
- There is a variety of standards in place in accordance with the variety of systems in place.

A better understanding of key terms and the variety of approaches within the context of patient access to EHR data will assist in the sharing of knowledge and experiences between MS and in future collaborations. MS patient representative associations are important contributors to developing this shared position of understanding at European level. One approach might be to 'plot' the concept of patient access on an overall framework where all the elements of patient access are discussed and agreed upon.

Therefore, it is recommended that the eHN encourages a common understanding of the context of patient access to be fostered among MS and to contribute to discussions on the development of a framework on patient access.

A way forward: this recommendation does not need explicit adoption by the eHN members because the subject of patient access is cited in task 4.2 of the next joint

action (eHAction). Work package 4 of eHAction relates to a policy framework on patient empowerment of which patient access is a part.

3.2 Digital Literacy and Digital Health Literacy

A citizen's ability to access and understand available EHR information is dependent on their digital literacy and digital health literacy. Digital health literacy goes beyond the digital literacy skills needed to browse the Internet, to find and to access information on government services - citizens also need skills to understand and appraise online health information before applying this understanding to actively manage their own health and care. "Citizen's digital health literacy is an essential element of eHealth deployment".⁵

Results of D1 show that the difference between digital literacy and digital health literacy is not fully understood, with the emphasis being on digital literacy rather than on digital health literacy. Secondly, digital literacy appears to be addressed in terms of overall digital literacy policy rather than specifically in relation to eHealth. Lastly, awareness with regard to the involvement of patients in increasing digital literacy levels is greater than the awareness to involve patients in increasing digital health literacy levels. When citizens have access to their data, it is important for them to understand data, so that they can put it to meaningful use:

Therefore, it is recommended that the eHN encourages awareness raising activities among MS on the importance of digital health literacy to citizens.

In particular, it is recommended that the eHN encourages actions/projects that focus on providing citizens with the opportunity to acquire the necessary digital health literacy skills to understand and appraise their EHR data.

A way forward: these recommendations do not need explicit adoption by the eHN members because digital health literacy is the subject of eHAction, Task 4.3.

⁵ <https://ichealth.eu/the-project/>