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DRAFT Report

on

EU state of play on patient access on eHealth data

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TABLE OF CHANGE HISTORY

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V2	29-03-2017	FINAL UPDATE	LINDA KEANE & ELISE PETERS
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LIST OF ABBREVIATIONS

ACRONYM	DEFINITION
EHR	ELECTRONIC HEALTH RECORD
PMR	PERSONAL MEDICAL RECORD
WP	WORK PACKAGE
MS	MEMBER STATES
EMR	ELECTRONIC MEDICAL RECORD
PHR	PERSONAL HEALTH RECORD
HCP	HEALTH CARE PROVIDER
GP	GENERAL PRACTITIONER
POC	POINT OF CARE
CEF	CONNECTING EUROPE FACILITY
CDA	CLINICAL DOCUMENT ARCHITECTURE
POC	POINT OF CARE

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1. Executive Summary

This report has been developed as part of the JAseHN project. It is an interim draft report on the current state of play in the EU regarding patient access to electronic health record data. The purpose of the report is to provide an overview of relevant EU projects and a summary of the current state of play within each member state.

Methodology

A literature review and desk research were the primary research activities undertaken to produce the report. Considering patient access to eHealth data, projects relating to patient empowerment in general, interoperability and patient identification were reviewed. A desk research template was designed to allow for the capture of information at both national and regional levels, whichever was most applicable, but within a consistent structure i.e. mapped to the eHealth interoperability model levels. The desk research results drive further research activities:

- Design of an online survey
- Follow-up of specific aspects with individual countries
- Identify particularly interesting examples of innovation

The results of which will be compiled into a final report in November, 2017.

Main Findings

7 relevant EU projects are summarised in this report:

Patient empowerment in general:	
PALANTE	The PALANTE project offers some insights into the impact on patient empowerment of having access to personal health data, as well as other eHealth services for specific populations and groups. Although the PALANTE report had a wider remit than JAseHN T7.5, its conclusions regarding the impact on patient empowerment are relevant to the JAseHN T7.5 recommendations.
SUSTAINS	A collection of "patient oriented services" was designed to "improve patient information flows, enhance patient empowerment and to promote "sustainability within healthcare". The value of the SUSTAINS project to Task 7.5 is in the specification of services that can be used as a possible construct to compare the functionality of patient portals in MS.
Interoperability and cross-border healthcare projects:	
epSOS	This large scale pilot project provided: - Patient Summary: a digital summary of your medical status to make abroad care better and more efficient, especially helpful in an emergency situation. - ePrescription: a digital drug prescription, so you can pick up your medication in a participating pharmacy abroad.
EXPAND	EXPAND took care for the legacy of epSOS for evolving the components, like the OpenNCP and the terminology services, from pilot stage to actual deployment in Europe in the frame of CEF.
eStandards	eStandards is advancing eHealth interoperability and global alignment of

	standards.
PARENT	A Joint Action to support the EU Member States in developing comparable and interoperable patient registries in clinical fields of identified importance (e.g. chronic diseases, medical technology).
Electronic identification as a requirement for patient access:	
STORK and STORK2.0	With the help of STORK, patients from foreign countries could be identified using their national electronic ID. The eHealth pilot of STORK 2.0 has successfully formed a bridge between the e-government and the healthcare sector and brought, for the first time in history, cross-border eID to eHealth.
eSENS	The objective of e-SENS in the e-Health domain is to facilitate cross-border access to health services within the EU countries.
EU digital literacy levels and the ability of its citizens to avail of eHealth services:	
EU Digital Scoreboard	The EU Digital Scoreboard is a visualisation tool that allows the view to explore some of the key dimensions of the European information society. Using the indicator group eHealth, four measures are examinable across EU member states: 1. Seeking online information about health. 2. Making an appointment with a practitioner via a website 3. GPs using electronic networks to transfer prescriptions to pharmacists 4. GPs exchanging medical patient data with other healthcare providers
Digital Skills Indicator	The Digital Skills Indicator which assesses digital literacy levels of countries within the EU based on the DigComp framework shows that just over 40% of individuals in the EU are considered to have insufficient digital skills and 20% have none at all.

Table 1. Relevant EU projects

Regarding the broad topic of patient access to electronic health record data, findings from the desk research highlight the fact that there is such a variety of systems in place, at both national, regional and local levels reflecting the differing national policies and priorities. MS are at varying stages of implementation of their eHealth agendas. Digital literacy levels are either not addressed specifically in relation to accessing EHR data or else dealt with as part of overall national strategy for upskilling the population.

18 country summaries are included in this report:

Country	***Case Study***
Austria	Elektronische Gesundheitsakte (ELGA) is the nationwide, patient centred EHR/PHR system which provides patients, doctors, hospitals, care facilities and pharmacies having a treatment relationship an easy access to patient's health records.
Belgium	Belgium created an action plan 2015-2018 concerning eHealth with objectives to be achieved by 2019. Action 10, which is about creating access to health data for patients started in October 2015 under the responsibility of FOD public health.
Croatia	Croatia's Patient's Portal encompasses personal medical and administrative data for a single patient in a digital form, and actively involves patients who

	are able to see all of their prescribed and issued medications, as well as medical findings and discharge summaries. The Patient's Portal is part of a larger e-Government project called e-Citizens.
Finland	The first national patient access service for citizens was created as part of the national health information system, Kanta, 10 years ago. 'My Kanta' pages is a portal in the national Kanta services, which provides access to one's own EHR data, prescription data, log information and consent management.
France	The French electronic health record - Dossier medical partagé (DMP) - is a public project launched in 2004 by the French Ministry of Health allowing each citizen to have electronic access to their clinical past and their current health status. Three main phases ran until 2016.
Germany	A patient-controlled personal electronic health record (PEPA) developed, implemented, and applied for chronic care of patients with colorectal cancer during a research project at Heidelberg University funded by The Federal Ministry of Education and Research (BMBF).
Hungary	Two use cases in Hungary are outlined: Patient access to the database of the National Health Insurance Fund (NEAK, formerly OEP) Patient access to their clinical data at a particular hospital (Brothers Hospitallers of Saint John of God)
Ireland	A secure web-based epilepsy electronic patient record (EPR) supports the clinical care of over 7,000 epilepsy patients in Ireland and increasing. As part of the PISCES (Providing Individualised Services and Care for in Epilepsy) project, a prototype web-based patient portal is currently at pilot testing phase.
Lithuania	The Lithuanian eHealth system (Electronic health services and infrastructure cooperation system – ESPBI IS) is integrated at national level and enables all Lithuanian citizens to access their electronic health records via a web portal.
Luxembourg	Dossier de Soins Partagé (DSP)('Dossier of Shared Care') is currently being deployed in a pilot phase (patients with long-term conditions), under which so far ~23 000 DSP have been created. Patients access their EHR via a web portal. General deployment of DSP is expected during 2017.
Malta	Malta's myHealth portal facilitates patient access to an aggregated copy of existing electronic health data stored in the various operational systems located in Government healthcare facilities and has been in operation for 5 years.
Portugal	1.5 million Portuguese citizens (15% of total population) have access to their EHR via the Citizen Portal in the northern region of the country. It is intended to extend this functionality to all citizens.
Romania	The Electronic Health Record (Dosarul Electronic de Sanatate – DES) (EHR) in Romania is a public service provided by the National Health Insurance House (CNAS) (Order no. 1123/849/2016, art.5). It is provided for all patients who are obliged through Law 95/2006 (concerning the

	reform of the Romanian healthcare system) to be insured in the national system of social health services. Additionally, the EHR system is also offered to all medical service providers, to be used for all types of medical services, and both for institutions who have a contract with the CNAS, as well as for the ones who do not (Order no. 1123/849/2016, art.9). The use of the EHR system is currently mandatory for all healthcare providers.
Slovakia	The Slovakian National Health Portal is being developed by the Slovakian National Centre of Health Information as part of phase 1 of the national ehealth programme, project ESO1. The National Health Portal is currently at pilot stage.
Spain	There are different types of projects in Spain: regional projects led by regional governments and national projects. The use case described in a national level project to give a patient common access to the clinical documentation generated in different regions and is currently provided by all Spanish regions but 1. Patients can access their EHR providing that they have an eID and internet access. Potentially, 35.726.423 patients have access.
Sweden	The National Patient Overview (Nationell patientöversikt –NPÖ) and Swedish Medical Records (Journalen) are both national projects launched by INERA, a private company owned by county councils. The NPÖ allows health care professionals to directly access patient's medical records. Journalen (Medical Records) allows the general public to read information from their own medical records online. All 21 county councils' health care providers have implemented NPO and 18 have implemented Journalen.
The Netherlands	The current EHR in the form of the 'Landelijk Schakelpunt' (LSP) is subsidized by the healthcare insurances and consists of 44 regions where there are various regional patient portals. The MedMij program establishes rules for the exchange and use of health data to ensure that any citizen/patient who wishes to collect and use health information from many sources in a secure online environment is able to do so.
The UK	Healthcare in the UK is provided in each home country: England, Northern Ireland, Scotland and Wales each manage their own healthcare systems. As a result, variations in policy and priorities exist. Online GP services are available in both England and Wales and the use case describes England's National GP project which gives patients access initially to transactional services and the ability to view parts of their electronic health record.

Table 2. Country EHR related case studies

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'[1].

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, is a report on the current state of play in Europe regarding patients' access to their eHealth data.

On October 27, 2016 the information paper for this task was adopted. In the short timeframe since then a limited literature review has been conducted along with desk research on task members own and neighbouring countries. An online survey has been prepared and has been distributed to the MS ministries of health and an analysis of survey responses received will be included in the final report in November, 2017.

2.2 Purpose

This draft report is an intermediate deliverable for task 7.5 of the JAseHN project. It is intended as an interim report on the current state of play in the EU regarding patient access to electronic health record data. The purpose of the report is to identify and summarise EU projects within the scope of task 7.5 and provide an overview of each country in relation to the current state of play regarding patient access to their electronic health record information.

This report will be used as the basis for further research including:

- Design of an online survey
- Follow-up of specific aspects with individual countries
- Identify particularly interesting examples of innovation

The results of which will be compiled into a final report in November, 2017.

2.3 Scope

<u>Electronic health record</u>

For this task we refer to the HIMSS definition of electronic health records; "The EHR is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. There is the possibility to create, save and share a full, long term form EHR and a short, portable patient summary. It consists of core operational functionalities like e-prescribing, imaging and case management. It has the potential to grow into a comprehensive national record, accessible to health and social care professionals, and also to patients, service users and carers[2].

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

[2] http://www.himss.org/library/ehr

Furthermore, the explanation from HealthIT is being used; "EHRs are built to go beyond standard clinical data collected in a healthcare provider's office and are inclusive of a broader view of a patient's care. EHRs contain information from all the clinicians involved in a patient's care and all authorized clinicians involved in a patient's care can access the information to provide care to that patient. EHRs also share information with other healthcare providers"[3].

Electronic medical record

We define electronic medical records (EMRs) as "digital versions of the paper charts in clinician offices, clinics and hospitals. EMRs contain notes and information collected by and for the clinicians in that office, clinic or hospital and are mostly used by healthcare providers for diagnosis and treatment"[4].

Personal health record

"Personal health records (PHRs) contain the same types of information as EHRs, but are designed to be set up, accessed and managed by patients. Patients can use PHRs to maintain and manage their health information in a private, secure and confidential environment. PHRs can include information from a variety of sources including clinicians, home monitoring devices and patients themselves"[5]. For this task we scope this information to health data from clinicians.

Digital and health literacy

Digital literacy refers to the skills required to achieve digital competence, the confident and critical use of information and communication technology (ICT) for work, leisure, learning and communication[6]. The ability to provide patients with access to their health data can be facilitated through the use of technologies, mostly through the internet. For citizens to use the internet and other technologies, it is important to have decent digital literacy skills. It is important to make a distinction between the terms 'digital literacy' and 'digital health literacy':

- Digital Health Literacy refers to the ability of citizens to understand and appraise online health information. It can also be interpreted as the ability to use electronic services and devices to manage one's own health.
- Digital Literacy refers to generic digital literacy skills around the use of technology in a variety of everyday tasks, including accessing one's own online data.

Portability of Data

Portability of health data means the availability of an individual's electronic health record, ideally a patient summary, in a cross border jurisdiction, to facilitate routine, elective or emergency healthcare by appropriate, designated clinicians.

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[3] https://www.healthit.gov/providers-professionals/faqs/what-are-differences-between-electronic-medical-records-electronic

[4] https://www.healthit.gov/providers-professionals/faqs/what-are-differences-between-electronic-medical-records-electronic

[5] https://www.healthit.gov/providers-professionals/faqs/what-are-differences-between-electronic-medical-records-electronic

[6] http://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:Digital_literacy

The portability of health data is contingent on the existence of a robust, secure, trusted and interoperable patient summary. In order for this portable data to deliver direct care benefits, clinicians need to be able to determine the provenance of received information, rely on it appropriately and re-collect only the data necessary to support robust decision-making.

Factors for consideration in cross-border sharing of patient data include data protection and privacy regulations, with data demonstrably collected and maintained in accordance with EU and national data protection legislation. Access authorisation processes must be explicit, with patient consent or, where this is not possible, i.e. in medical emergencies, the authorisation policies and authorisations of individuals need to have been predetermined and be recognised in all participating countries (to enable real-time and appropriate disclosures). Mechanisms are needed to enable the shared health data to become part of locally held health records and be re-usable for research and quality management purposes, either with consent or acceptably de-identified.

It must be possible to ensure and to verify that a patient summary is only sent to a recognised healthcare provider who is in charge of that patient at that time.
The communication needs to verify that the sender is a trusted information source. It must not be permitted to share identifiable patient records without patient knowledge, whether this occurs for direct patient care, for reimbursements or for other purposes[7].

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[7] http://www.trilliumbridge.eu/

3. Methodology

In the initial phase of the task a theoretical framework was developed based on the AMO model (which has its origins from MacInnis and Jaworski (1989)[8]). This exercise was conducted to:

- Tackle all aspects of the deliverables, i.e. patient access, digital literacy, portability and architectural questions.
- Explore the possibility to also include motivational aspects where awareness of the possibilities to access health data and attitudes towards the possibility to access are being studied.

A stakeholder mapping exercise was conducted to identify possible stakeholders involved in the task:

- Government, EU, Competence Centres, IT and Consultancy companies involved in EHR projects have contributed to the findings of this Draft Report for T7.5, Deliverable 1.
- Patient and Clinical representative bodies and Citizens are planned for consultation in later stages of the project to produce the Final Report for T7.5, Deliverable 1.

The refined eHealth Interoperability Framework, (endorsed by eHN, Nov 2015) was referenced in both the construction of the desk research template and the online survey. The purpose of using the framework was:

- To provide a robust structure around which to construct the research template and survey
- To ensure no areas with regard to EHR implementations were overlooked
- To act as an informal 'check' that the right questions were being asked to the right people

A draft report was produced based on initial desk research to provide a short overview for each country.

The desk research process and results:

- Suggest a structure to be applied in gathering material through the survey (thus adding opportunities for comparison)
- Allow for follow up on specific questions with individual countries
- Allow for the potential to follow up particularly interesting examples of innovative facilities or practices

Two research methods produced the content of this report: a literature review and desk research.

3.1 Literature review

Projects relevant to the task focus were reviewed in relation to this report and additional searches were carried out online to identify other relevant published literature and digital literacy statistics.

The European Commission has published a document "eHealth projects - Research and Innovation in the field of ICT for Health and Wellbeing"[9], which offers an overview of the most current European (co-)funded projects.

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[8] MacInnis, D.J. & Jaworski, B.J. (1989). *Information Processing from Advertisements: Toward an Integrative Framework*. Journal of Marketing, 53, 1-23.

In the light of patient access on eHealth data the projects can be categorised as "patient empowerment in general", and, focusing on the cross-border dimension, "interoperability" as well as in "patient identification" projects. Therefore, the following projects will be reviewed:

Patient empowerment in general:

- PALANTE
- SUSTAINS

Interoperability & cross-border healthcare projects:

- epSOS
- EXPAND
- eStandards
- PARENT

Electronic identification as a requirement for patient access:

- STORK and the STORK2.0 eHealth pilot – cross-border patient access to health data
- eSENS

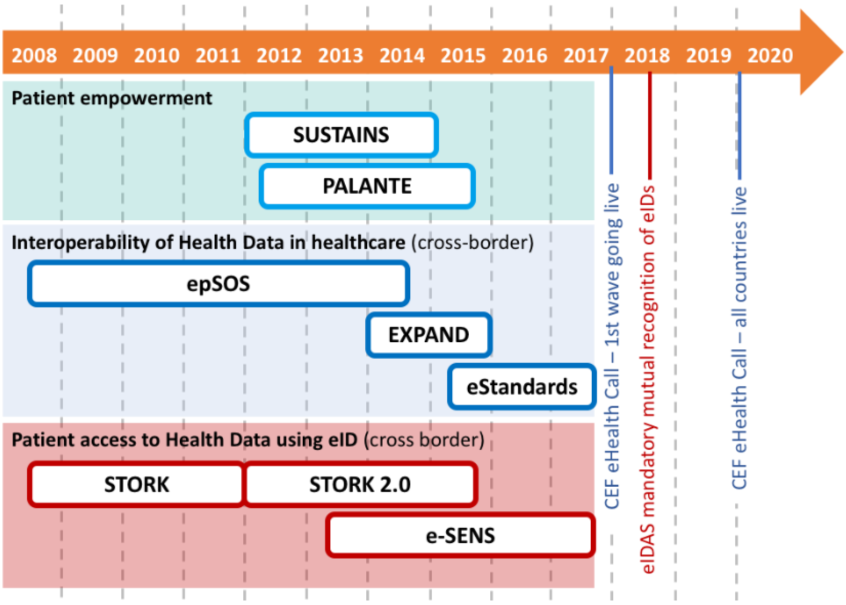

Figure 1. eHealth projects timeline

The projects reviewed for this report essentially all lead to the Connecting Europe Facility (CEF).

The CEF eHealth Digital Service Infrastructure (eHDSI or eHealth DSI)[10] is addressing the challenge brought about by the increased mobility of EU citizens coupled with the advancements of digital technologies requiring both health policies and health systems across the European Union to be more and more interconnected, more interoperable.

The eHDSI is the initial deployment and operation of services for cross-border health data exchange under the Connecting Europe Facility (CEF).

eHDSI sets up and starts deploying the core and generic services, as defined in the CEF, for Patient Summary and ePrescription.

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[9] http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=2852

[10] eHDSI_SP-Overall-Intro_v4_20161207-1100.pdf

eIDAS Regulation: (2014) requires Member States to mutually recognise eIDs from other Member States:

- By September 2018, any Member State that provides public services using an eID must recognise eIDs from other Member States;
- Until then Member States can notify their national eID schemes to make them available through the eIDAS Network;
- For this, they need to make their national eID schemes interoperable across borders.

CEF eID supports Member States in defining technical specifications, sample software and financially supports deployment in Member States.

eIDAS Regulation and CEF eID building blocks could provide a meaningful way for cross-border patient identification and authentication in the case of eHealth[11].

3.2 Desk Research

Desk research was carried out by task 7.5 contributors initially focusing on their own country. A desk research template was developed to drive the research effort and ensure consistency of approach. For full coverage of the EU each task contributor was allocated a 'linked' neighbouring country and asked to complete a similar research exercise in so far as was possible. Desk research results were submitted in English.

3.2.1 Own country research

Three approaches were taken:

1 Online search for information under the seven headings of the desk research template.
2 Telephone interview with relevant expert/s structured around the desk research template, and responses documented.
3 Forward desk research template to a relevant expert/s who would complete the document.

Advantages and disadvantages of each approach, as experienced during the task, are summarised below:

Approach	Advantages	Disadvantages
Online search	Straightforward, can be done immediately, not dependent on the assistance and co-operation of others.	Not the fastest method. Risk of limited information being made available online.
Structured telephone interview with relevant contact/expert	Saves the contact's time; a maximum duration for the call, set in advance, could persuade the contact to assist. Points can be clarified there and then.	Dependent on identifying the relevant expert and securing their time and assistance. Expert may not have all answers at the time e.g. statistics, further investigation may be required.
Expert/Contact enters answers to the desk	Less effort required by the researcher - they 'hand over' the	Dependent on identifying the relevant expert and securing

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[11] eHDSI_SP-Overall-Intro_v4_20161207-1100.pdf

research template questions directly into the document	template to the expert. More likely to get qualitative data such as statistics and relevant web links for follow-up.	their time and assistance. Greater effort required by the contact. No opportunity to clarify points.

Table 3. Desk Research methodologies comparison

3.2.2 Linked country research

The quality of the information obtained from a neighbouring 'linked' country depended on an existing contact in that country willing to a. complete the desk research template and b. translate the information into English. Where an existing relationship with relevant contact points did not exist, the members of the JAseHN project were contacted for assistance, with mixed results. Where no contact was made in the linked country, online research was attempted but language issues meant that it was not possible to perform an in-depth research exercise online alone.

3.3 Further Research

An online survey was developed and submitted to the sPSC on 23rd February, 2017 for dissemination to all MS, including a request to cascade the survey invitation to appropriate contacts. At the point of submission of this version of the draft report, four countries have submitted complete responses. The survey will be live until the 30th April, 2017. Survey results will be incorporated into the final version of this report due November, 2017.

- Survey and desk results will be compared to identify gaps or inconsistencies which will then be clarified.
- Survey results will be analysed by level and also by categories in order to provide a comparison of countries across key areas.
- The results of this analysis will feed into the main findings of the final report.

4 Main Findings

4.1 Relevant EU Projects

4.1.1 Patient empowerment in general

PALANTE

The PALANTE[12] project offers some insights into the impact on patient empowerment of having access to personal health data, as well as other eHealth services for specific populations and groups. It defines patient empowerment as the patient's ability "to make informed decisions about their health, take an active role in their care and collaborate effectively with their healthcare team", and proposes that this is positively correlated with the use of information and communication technologies. The project focused on the implementation, scaling up and optimisation of seven demonstration pilots based on the concept of secure and user-friendly online access by citizens to their medical/health data.

The PALANTE investigations concluded that the impact of the eHealth services examined was dependent on three main considerations, education, information and communication:

- Education: patients must learn how to interpret any health data they access, and to use it to manage their conditions.
- Information: data accessed by patients is diverse, referring alerts and notifications about treatments, appointments reminders etc., as well as personal health information or documents.
- Communication: to engage patients, their preferred means of communication must be used (e.g., texts, video, email, calls).

Although the PALANTE report had a wider remit than JAseHN T7.5, covering examination of the impact of electronic health records, appointment/booking systems, ePrescription, lab tests, radiology, discharge reports and emergency episodes, its conclusions regarding the impact on patient empowerment are relevant to the JAseHN T7.5 recommendations. Several factors were found to be relevant to the degree of engagement that eHealth services fostered:

1. Trust in the healthcare system is positively correlated with the ease of use and usefulness of the technology;
2. An active “social” context (living with other adults and having a job) triggers a positive impact on patient empowerment;
3. Increasing age is associated with low perceived ease of use for some services, but not with low perceived usefulness.

PALANTE investigated communities which had relatively mature eHealth implementations, but notwithstanding that, it concluded that the "Empowered Patient is already a reality in Europe". In addition, the final report cautioned that Europe is a very diverse continent and that it would not be feasible to create and implement a "one-size-fits-all" solution, stating that interventions depend on local policy, conditions and resources.

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[12] www.PALANTE-project.eu

SUSTAINS

The SUSTAINS[13] project ran from January 2012 to December 2014 and was related to key action 13 of the Digital Agenda for Europe:
Key Action 13[14]: undertake pilot actions to equip Europeans with secure online access to their medical health data by 2015 and to achieve by 2020 widespread deployment of telemedicine services

The SUSTAINS Consortium of 13 was composed of regions in the EU leading in the area of innovation in services for citizens, and a number of user and professional associations.
The aims[15] of the project were to:

- Empower patients by giving them access to their Electronic Health Record (EHR) and other online services
- Enhance the quality of care by developing the partnership between the patient and the healthcare professional
- Increase efficiency and economy through access to the EHR
- Build upon existing experience
- Understand the legal and ethical aspects of access to the electronic record
- Measure the impact and satisfaction levels across citizens, patients and healthcare professionals with such services.

To achieve these aims a collection of "patient oriented services" was designed to "improve patient information flows, enhance patient empowerment and to promote sustainability within healthcare"[16]. The collection of services[17] based on patient access to electronic health records were:

Service Type	Service
1: Self-Management of the EHR	Examine the electronic health record
	Patient input to the EHR
	Mask sensitive data in the EHR
	Integration of data in relation to patient's self-monitoring
2: Online Interaction for Administrative Matters	Book or rebook a consultation/diagnostic exam
	Pay a service fee
	Change GP (when moving or similar)
	Update demographic data
	Delegation of access to family or informal carer by patient power of attorney
	Consent for the export of EHR data to the epSOS Patient Summary
3: Online Interaction of Patients and Health Professionals	Fill out a Health Declaration Form
	Ask a question to a physician/nurse
	Notification services (reminder messages, SMS, email etc.)

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[13] http://www.sustainsproject.eu/
[14] http://europa.eu/rapid/press-release_MEMO-10-200_en.htm
[15] http://www.sustainsproject.eu/sustainsproject/attachment/sustains_newsletter_jan14.pdf
[16] http://www.sustainsproject.eu/sustainsproject/attachment/leaflet2_projectbriefing.pdf
[17] http://www.sustainsproject.eu/services/

	Integration of Decision Support Systems
4: Online Access to Health and Healthcare Information	Print out drug and lab list before travelling abroad or outside region
	Consult audit trail
	Track referrals
	Access to health insurance data
	Access to data on health services costs

Table 4. Collection of services

SUSTAINS then worked to implement these services through 11 pilot programmes in 9 EU countries.

The table below shows the stated intentions of the SUSTAINS pilot partners for the update of the services at the time of the project's implementation[18].

(Green = service committed and up and running, Yellow = service committed not up and running)

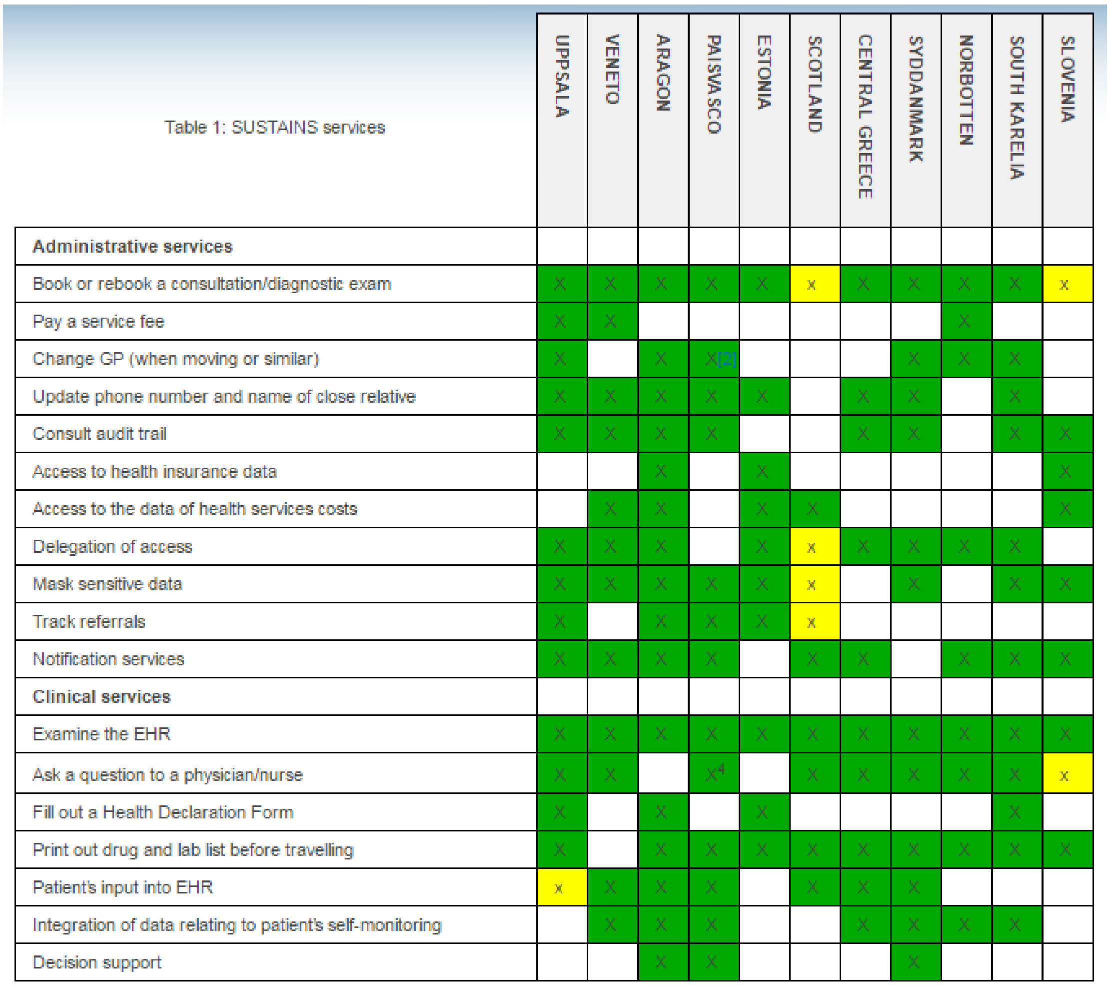

Table 1: SUSTAINS services	UPPSALA	VENETO	ARAGON	PAISVASCO	ESTONIA	SCOTLAND	CENTRAL GREECE	SYDDANMARK	NORBOTTEN	SOUTH KARELIA	SLOVENIA
Administrative services											
Book or rebook a consultation/diagnostic exam	X	X	X	X	X	x	X	X	X	X	x
Pay a service fee	X	X							X		
Change GP (when moving or similar)	X		X	X[2]				X	X	X	
Update phone number and name of close relative	X	X	X	X	X		X	X		X	
Consult audit trail	X	X	X	X			X	X		X	X
Access to health insurance data			X		X						X
Access to the data of health services costs		X	X		X	X					X
Delegation of access	X	X	X		X	x	X	X	X	X	
Mask sensitive data	X	X	X	X	X	x		X		X	X
Track referrals	X		X	X	X	x					
Notification services	X	X	X	X		X	X		X	X	X
Clinical services											
Examine the EHR	X	X	X	X	X	X	X	X	X	X	X
Ask a question to a physician/nurse	X	X		X4		X	X	X	X	X	x
Fill out a Health Declaration Form	X		X		X					X	
Print out drug and lab list before travelling	X		X	X	X	X	X	X	X	X	X
Patient's input into EHR	x	X	X	X		X	X	X			
Integration of data relating to patient's self-monitoring		X	X	X			X	X	X	X	
Decision support			X	X				X			

Figure 2. Service Uptake Table

The following is a summary of the project's Deployment Plan[19] providing a high level overview of the deployment of SUSTAINS services, and consequently an overview of the state of play on patient access to electronic health records as at the end of the project, December 2014.

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[18] http://www.sustainsproject.eu/serviceuptaketable/

Sweden

In the case of Sweden, two separate County Councils participated in SUSTAINS. In Uppsala County, SUSTAINS services are offered as routine to the entire population; 18% of the resident population has already used a service at least once. The pilot in the County Council of Norbotten ran from December 2013 to December 2014, reaching a total of 1,583 patients. The County Council of Norbotten will offer all SUSTAINS services with the exception of „Examine the EHR" during 2015 with plans for the „Examine the EHR"-service to be made available in 2016.

Region Skåne started 17th March 2014 when the service was offered to all residents. By the end of 2014, Skåne have 31,582 users. • County of Västmanland have started with a small pilot; by the end of 2014, they have 1,135 users.

Italy - Veneto

Most of the SUSTAINS services in the pilot site in Asolo, Veneto Italian region were already routinely delivered to citizens at the time of the project. A Ministerial Decree in 2013 established that all the Italian regions should put in place their regional EHR by June 2015.

Spain - Aragon

The SUSTAINS services are currently offered as universal services for the whole population (16 years and older)of the Basque Country, so services are already deployed in the entire region. Efforts were being concentrated on increasing usage of the service.

Estonia

All persons who are registered in the Population Register of Estonia can access the SUSTAINS services or any other eHealth services for patients via the National Patient Portal (www.digilugu.ee) provided that they have an ID-card, Mobile-ID and Internet connection.

Scotland

The target group for Scotland was composed of patients suffering from a specific chronic illness. The already established Patient View service (for kidney patients) added SUSTAINS services to its functionality. Usage grew from 30,000 to 40,000 in the period of the project.

Greece

Two small-scale pilots were conducted in Greece with difficulties when it came to extracting concrete results.

Denmark

Many of the SUSTAINS services were already offered nationally in Denmark with further services planned for implementation in 2015.

Finland – South Karelia

South Karelia started to develop eServices to its citizens in 2011 and added SUSTAINS services during the project. The most popular eServices at end of 2014 were: ask a question from nurse,

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[19] http://www.sustainsproject.eu/sustainsproject/attachment/d312v11.pdf

self-monitoring data, and fill out health declaration forms. There were 20,000 registered users in eService platform (Hyvis.fi) at the end of November 2014 with a potential future national reach of 1,200,000 inhabitants.

Slovenia

ZZZS is the sole compulsory health insurance provider in Slovenia and during the SUSTAINS project, ZZZS introduced a new portal and some electronic services for insured citizens, mainly access to health insurance personal information, which marked the beginning of the Slovenian EHR project[20].

The value of the SUSTAINS project to Task 7.5 is in the specification of services that can be used as a possible construct to compare the functionality of patient portals in Member states. The SUSTAINS project also carried out research in the areas of ethics and consent in relation to EHRs which may be useful in making recommendations for T7.5 deliverable 2 report.

4.1.2 Interoperability & cross-border healthcare projects

Focusing on cross-border patient access to health data and considering the different languages in the European Union aspects like sematic interoperability based on standards and code schemes are of major importance, e.g. for high quality automated translation services. Such services were developed and piloted in the EU Large Scale Pilot epSOS.

epSOS

epSOS (www.epsos.eu) is short for European patient Smart Open Services. This large scale pilot project provided:

- a Patient Summary: a digital summary of your medical status to make abroad care better and more efficient, especially helpful in an emergency situation.
- ePrescription: a digital drug prescription, so you can pick up your medication in a participating pharmacy abroad.

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[20] http://www.sustainsproject.eu/

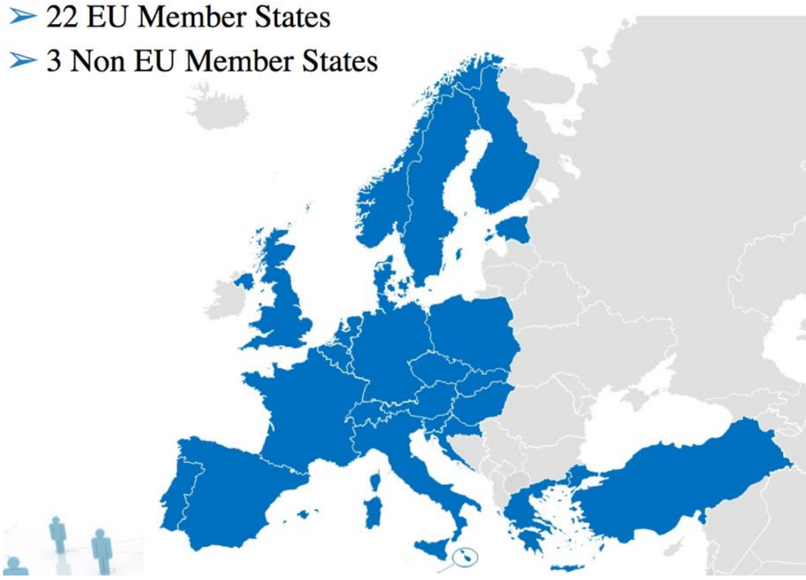

Figure 3. epSOS participating nations

The consortium of the epSOS project was composed of 45 members from 22 EU member states and 3 non-EU member states. They included national health ministries, national competence centres, social insurance institutions and scientific institutions as well as technical and administrative management entities.

The guideline for Patient Summary[21] and for ePrescription[22] were maintained and developed further by EXPAND and JAseHN. The latest versions were adopted by the eHealth Network in November 2016 as basis for CEF eHealth. Duration: 2008-2014.

EXPAND

EXPAND took care for the legacy of epSOS for evolving the components, like the OpenNCP and the terminology services, from pilot stage to actual deployment in Europe in the frame of CEF. Further information had been published under www.expandproject.eu (currently offline). Duration: 2014-2015.

eStandards

eStandards is advancing eHealth interoperability and global alignment of standards. The project experts are joining up with stakeholders all over Europe and globally to build consensus on eHealth standards, accelerate knowledge-sharing, and promote wide adoption of standards. The proposal's ambition is to strengthen Europe's voice and impact, while reinforcing the bridges across the Atlantic and among Member States with epSOS, eSENS, Antilope, and EXPAND. An eStandards Roadmap and associated evidence base, a white paper on the need for formal standards, and two guidelines addressing how to work with: (a) clinical content in profiles and (b) competing standards in large-scale eHealth deployments, will be pragmatic steps toward alignment and convergence. Further information: www.estandards-project.eu, Duration: 2015-2017.

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[21] https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co10_en.pdf
[22] http://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co091_en.pdf

PARENT

PARENT (Patient Registries iNiTiative)[23] was a Joint Action co-funded by the EC and some Member States (May 2012 – 2015). The overall objective of PARENT JA was to support the EU Member States in developing comparable and interoperable patient registries in clinical fields of identified importance (e.g. chronic diseases, medical technology.) One goal was to support MS in developing comparable and coherent patient registries in fields where this need has been identified (e.g. cross-border health services, chronic diseases, rare diseases, medical technology and its assessment). Although the focus was on enabling the use of secondary data for public health and research purposes the cross-organisation and cross-border aspects of this project may be useful in developing recommendations about portability of patient eHealth data.

4.1.3 Electronic identification of patients

Online patient access needs secure and high quality electronic identification. Within the epSOS world - before being medically treated by a HCP - the patient needs to be uniquely identified. In epSOS identification took place using paper-based documents only. By the help of STORK, patients from foreign countries could be identified using their national electronic ID.

STORK 2.0 eHealth Pilot

The first STORK (Secure idenTity acrOss boRders linKed) project (2008 till 2012) established a European eID Interoperability Platform that formed a basis allowing citizens to establish new e-relations across borders, just by presenting their national eID.[24] The LSP STORK 2.0 continued the realization of a single European electronic identification and authentication area. It built on the results of STORK, establishing interoperability of different approaches at national and EU level, eID for persons, eID for legal entities.[25]

The importance and the need of eID in eHealth and in cross-border healthcare has been clear for years. On a political and strategical level, the "eHealth Governance Initiative (eHGI)" underlined the importance of a solution for eID in eHealth at the beginning of STORK 2.0. The eHealth pilot of STORK 2.0 has successfully formed a bridge between the e-government and the healthcare sector and brought, for the first time in history, cross-border eID to eHealth.

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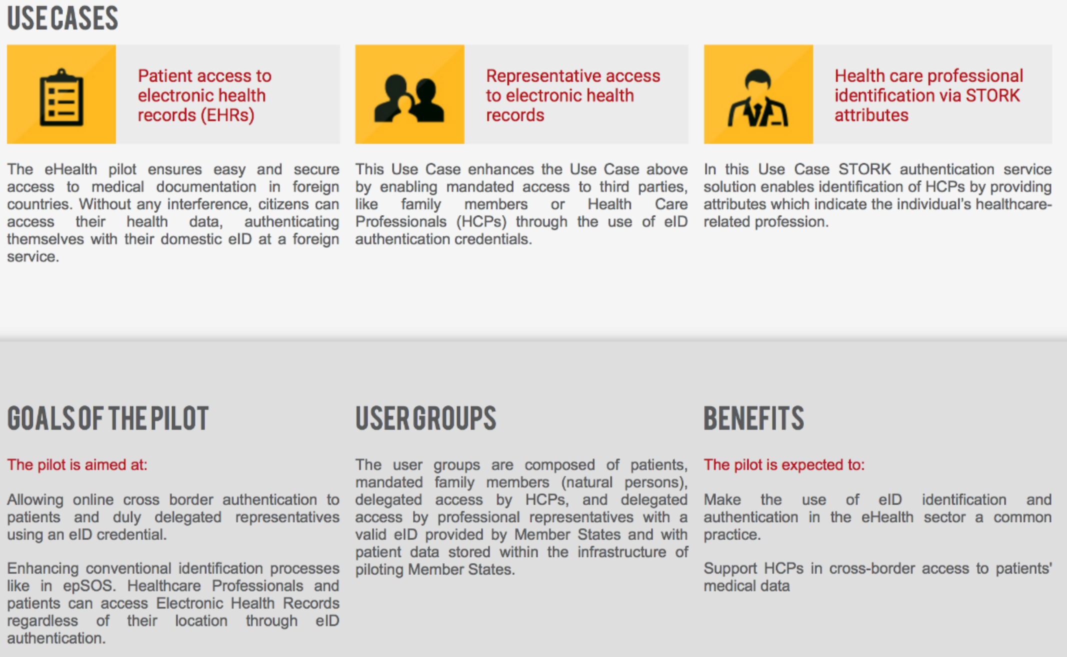
[23] http://patientregistries.eu/

[24] https://www.eid-stork.eu

[25] https://www.eid-stork2.eu



USE CASES

Patient access to electronic health records (EHRs)

The eHealth pilot ensures easy and secure access to medical documentation in foreign countries. Without any interference, citizens can access their health data, authenticating themselves with their domestic eID at a foreign service.

Representative access to electronic health records

This Use Case enhances the Use Case above by enabling mandated access to third parties, like family members or Health Care Professionals (HCPs) through the use of eID authentication credentials.

Health care professional identification via STORK attributes

In this Use Case STORK authentication service solution enables identification of HCPs by providing attributes which indicate the individual's healthcare-related profession.

GOALS OF THE PILOT

The pilot is aimed at:

Allowing online cross border authentication to patients and duly delegated representatives using an eID credential.

Enhancing conventional identification processes like in epSOS. Healthcare Professionals and patients can access Electronic Health Records regardless of their location through eID authentication.

USER GROUPS

The user groups are composed of patients, mandated family members (natural persons), delegated access by HCPs, and delegated access by professional representatives with a valid eID provided by Member States and with patient data stored within the infrastructure of piloting Member States.

BENEFITS

The pilot is expected to:

Make the use of eID identification and authentication in the eHealth sector a common practice.

Support HCPs in cross-border access to patients' medical data

Figure 4. The three STORK 2.0 eHealth Pilot Use Cases

The STORK 2.0 eHealth pilot used eID identification and authentication in the eHealth sector. In epSOS, health care providers (HCPs) could access a patients' medical data hosted in the patients' home country. The HCP needed conventional identifiers (e. g. social security number) at the point of care (PoC) in order to identify and authenticate the patient. The eHealth pilot of STORK 2.0 complemented what has already been achieved by epSOS in terms of adding an electronic alternative to the epSOS identification process, by allowing a patient to access her data stored abroad all by herself as well as by introducing patient representatives and HCP identification.

The pilot was aligned with major decisions and recommendations made and issued by the European Union and other relevant groups. The High Level-eHealth-Governance Group HLeHGG prioritised eID management in eHealth as high, the key action 13 of the Digital Agenda recommends equipping Europeans with secure online access to their medical health data by 2015. Furthermore, the pilot was fully in line with Patient Rights Directive 2011/24/EU and Data Protection Directive 95/46/EC as well as Art. 29 Data Protection WP131 on providing strong authentication mechanisms for eHealth.

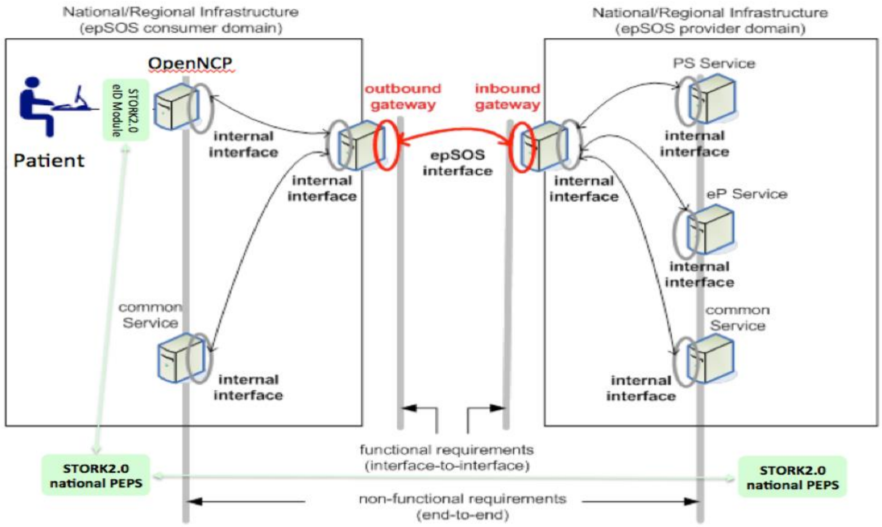


Figure 5. epSOS/EXPAND OpenNCP – STORK2.0 eID integration

Finally, the pilot performed all three use cases in production cross-border environments. The derived pilot architecture with required attributes and trust mappings was proven in a successful interoperation between STORK, epSOS and national infrastructures.

The results of STORK 2.0 formed a basis for further developments in eSENS and for eIDAS-conform go-live of cross-border healthcare in CEF.

<u>eSENS – focus on eIDAS[26] and the eHealth pilot</u>

The aim of e-SENS[27] is to facilitate the deployment of cross-border digital public services through generic and re-usable technical components, based on the building blocks of the Large Scale Pilots. The consolidated technical solutions, with a strong focus on e-ID, e-Documents, e-Delivery, Semantics and e-Signatures, aim to provide the foundation for a platform of "core services" for the eGovernment cross-border digital infrastructure foreseen in the regulation for implementing the Connecting Europe Facility (CEF)[28].

The objective of e-SENS in the e-Health domain is to facilitate cross-border access to health services within the EU countries. The cross-border health services domain is now largely regulated by Directive 2011/24 EU on the application of patients' rights in cross-border healthcare, which provides the overall legal framework for the Patient Summary and ePrescription pilot within the e-SENS project. Furthermore, the e-Confirmation pilot, which addresses administrative issues when accessing healthcare abroad, builds forward on Regulations 883/2004 and 987/2009 on the coordination of social security systems. The pilots aim to improve the efficiency of the process for healthcare providers, health professionals and patients by enabling the electronic exchange of medical data and insurance information in cross-border settings. The pilots build on the experiences of the epSOS, NETC@RDS and ENED projects, extending their workflows into new areas.

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[26] http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1487685272857&uri=CELEX:32014R0910
[27] https://www.esens.eu/content/about-project
[28] https://ec.europa.eu/cefdigital/wiki/display/CEFDIGITAL/eHealth and https://ec.europa.eu/inea/en/connecting-europe-facility/cef-telecom/apply-funding/2015-cef-telecom-call-ehealth-2015-cef-tc-2015

Piloting scenarios[29]

ePrescription/Patient Summary

This use case creates conditions for citizens to receive equivalent health care in a member state other than their country of usual residence in the EU, supported by information available in the Patient Summary from their country of residence. It offers electronic access to key medical information by a physician in the country of treatment, thus improving continuity of care and patient safety. Furthermore, the pilot supports the obtaining of medication prescribed in a home country in other EU/EEA Member States.

Example use case:

In the Patient Summary case, a person seeks care support abroad and wishes to share a Patient Summary located in the country of affiliation with a local health professional. The health professional identifies the patient with her e-ID token, such as an e-Health card, and receives a copy of her Patient Summary which has been translated into the professional's language. This information is valuable for providing safer health care to the citizen.

In the ePrescription case, a person goes to a pharmacy to obtain medication prescribed in her country of affiliation. He/she presents an e-ID token, such as an e-ID card, used in the home country. The pharmacist identifies and authenticates the citizen as the person requesting dispensation, and requests access to active ePrescription list. The pharmacist selects the particular ePrescription to be dispensed. If the stated medical product is not available, the pharmacist consults available tools to find substitutes, and offers an equivalent medicine. An e-Dispensation report is returned to the country of affiliation to provide details on the dispensed medicines.

Duration: 1st April 2013 – 31st March 2017

Participants: 19 EU Member States, 1 non EU Member State

Patient Access[30]

In the Citizen Lifecycle domain the purpose is to empower citizen to access their eHealth data. A Patient Access pilot will gain experience and thus get the eHealth domain prepared for the eIDAS Regulation (Regulation 910/2014 on electronic identification and trust services for electronic transactions in the internal market). This is relevant because in many Member States some health services are public sector services and consequently the September 2018 deadline for mutual eID recognition stemming from the eIDAS Regulation applies. The Austrian epidemic surveillance register EMS ("Epidemiologisches Meldesystem") was selected as the use case. The aim was to test one service provider (Austrian "EMS") with one foreign country identity provider (Denmark) and this was achieved.

4.1.4 Digital Literacy

EU usage of eHealth Services

The EU Digital Scoreboard[31] is a visualisation tool that allows the view to explore some of the key dimensions of the European information society[32] (Telecom sector, Broadband, Mobile, Internet usage, Internet services, eGovernment, eCommerce, eBusiness, ICT Skills, Research and

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[29] https://www.esens.eu/content/e-health

[30] http://wiki.ds.unipi.gr/display/ESENSPILOTS/5.5.1+-+Patient+Access+-+Use+Case+Overview

[31] http://digital-agenda-data.eu/

[32] http://digital-agenda-data.eu/datasets/digital_agenda_scoreboard_key_indicators/indicators

Development) through the interactive creation of charts and tables. These indicators allow a comparison across European countries as well as over time. The follow charts have been created using this tool to focus on the use of eHealth services (Indicator group: eHealth).

Seeking online information about health.

The chart displays the percentage of individuals (aged 16-74) in the EU who have used the Internet to seek information about health: injury, disease, nutrition, improving health, etc[33].

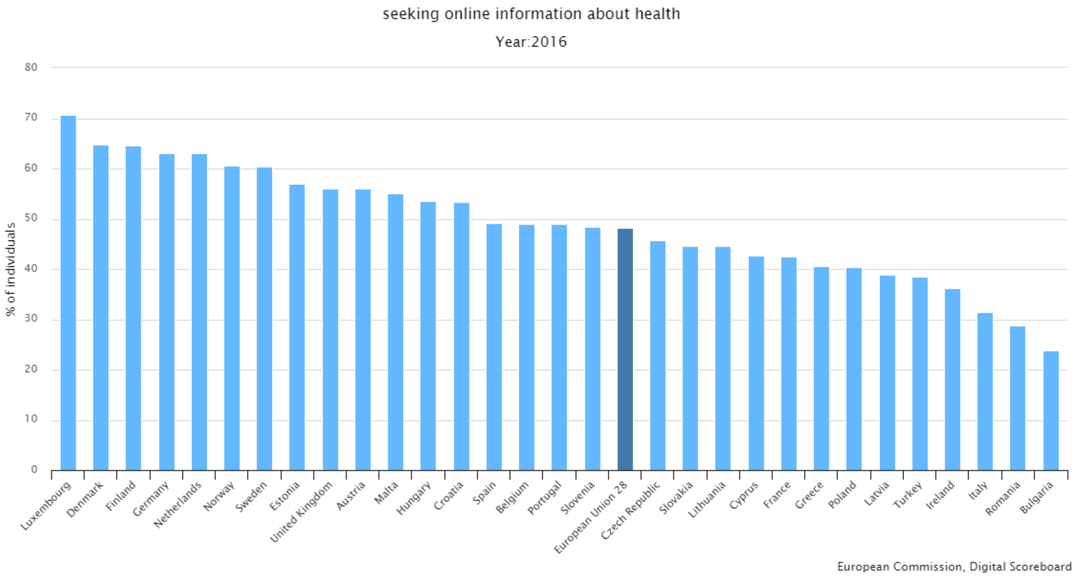

Figure 6. Percentage of individuals seeking online health information

Making an appointment with a practitioner via a website[34].

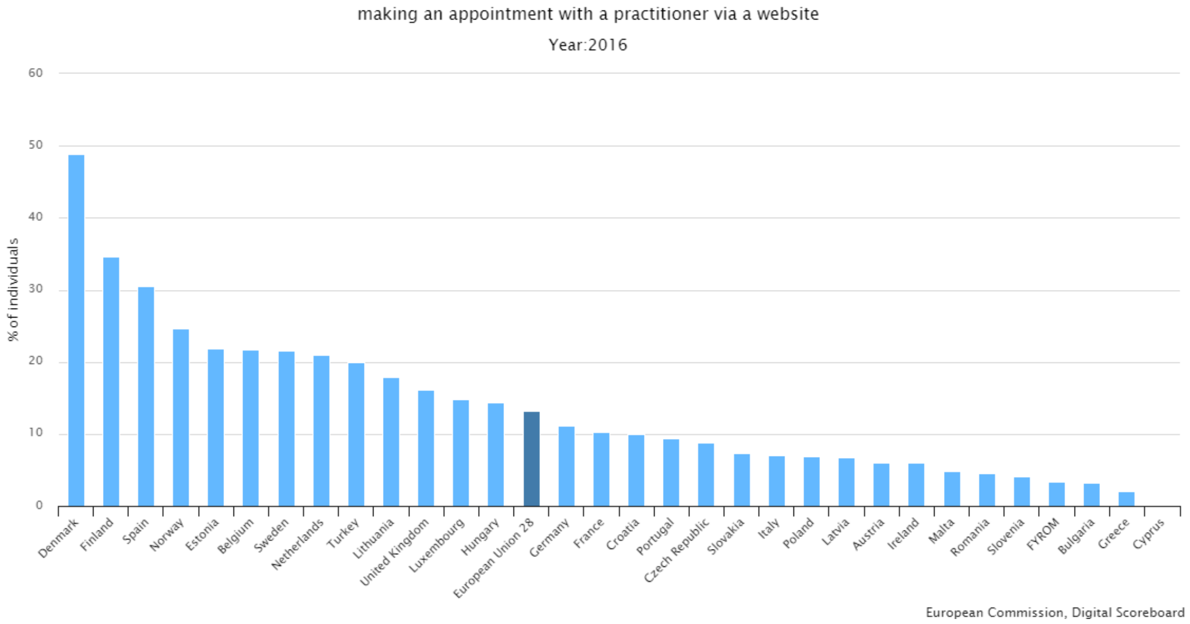

Figure 7. Percentage of individuals making an online appointment

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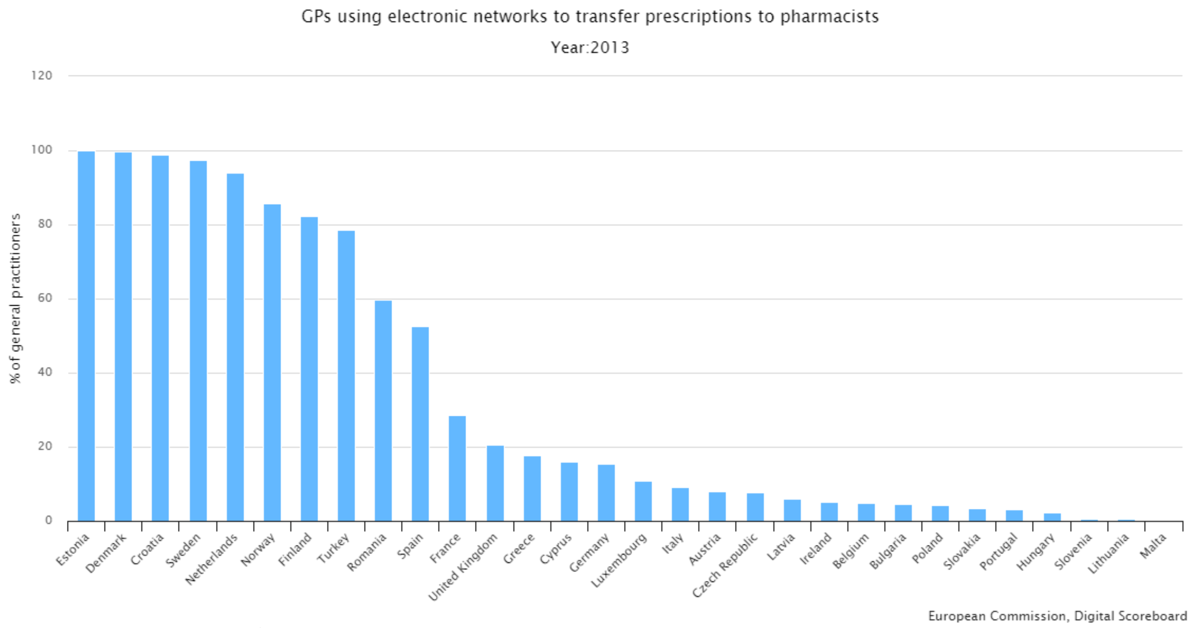
[33] Eurostat, Table isoc_bde15cua: Internet use and activities

[34] Eurostat, Table isoc_bde15cua: Internet use and activities

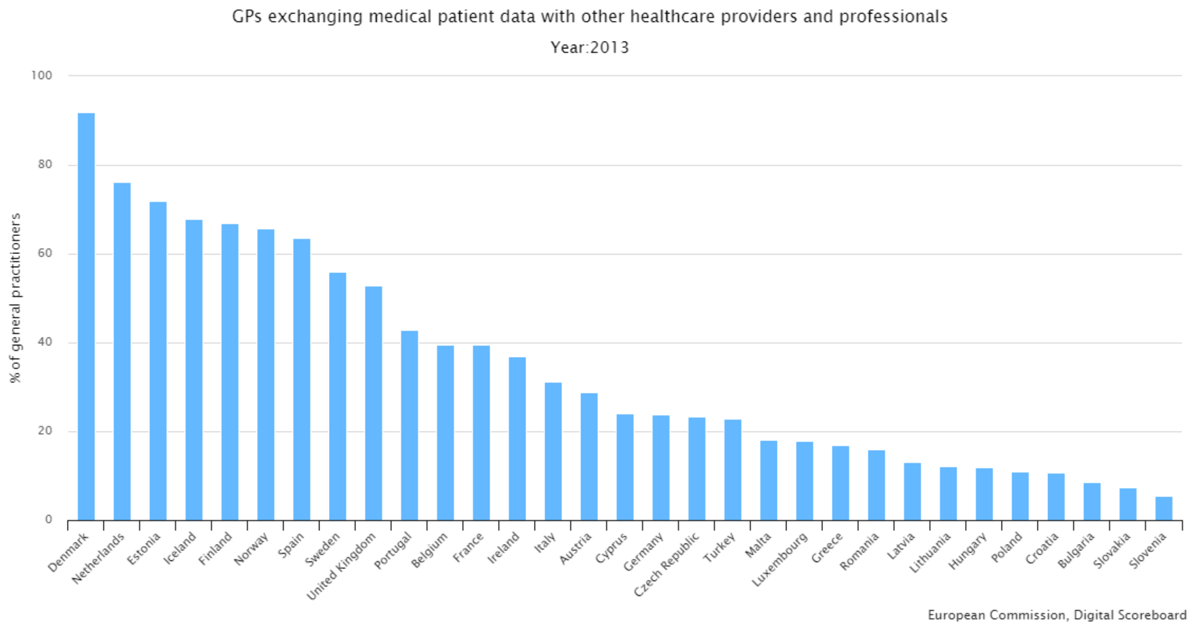
GPs using electronic networks to transfer prescriptions to pharmacists 2013[35].



European Commission, Digital Scoreboard

Figure 8. Percentage of GP's using electronic networks to transfer prescriptions to pharmacists

GPs exchanging medical patient data with other HCPs 2013[36].



European Commission, Digital Scoreboard

Figure 9. Percentage of GPs using electronic networks to exchange medical data

DigComp

The European Digital Competence Framework for Citizens, (also known as 'DigComp') was developed by the Joint Research Centre's Institute for Prospective Technology Studies on behalf of DG Employment, Social Affairs and Inclusion. The DigComp framework[37] describes what

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[35] Studies committed by DG Connect to monitor the adoption of eHealth technologies by General Practitioners: 2007, 2013

[36] Studies committed by DG Connect to monitor the adoption of eHealth technologies by General Practitioners: 2007, 2013

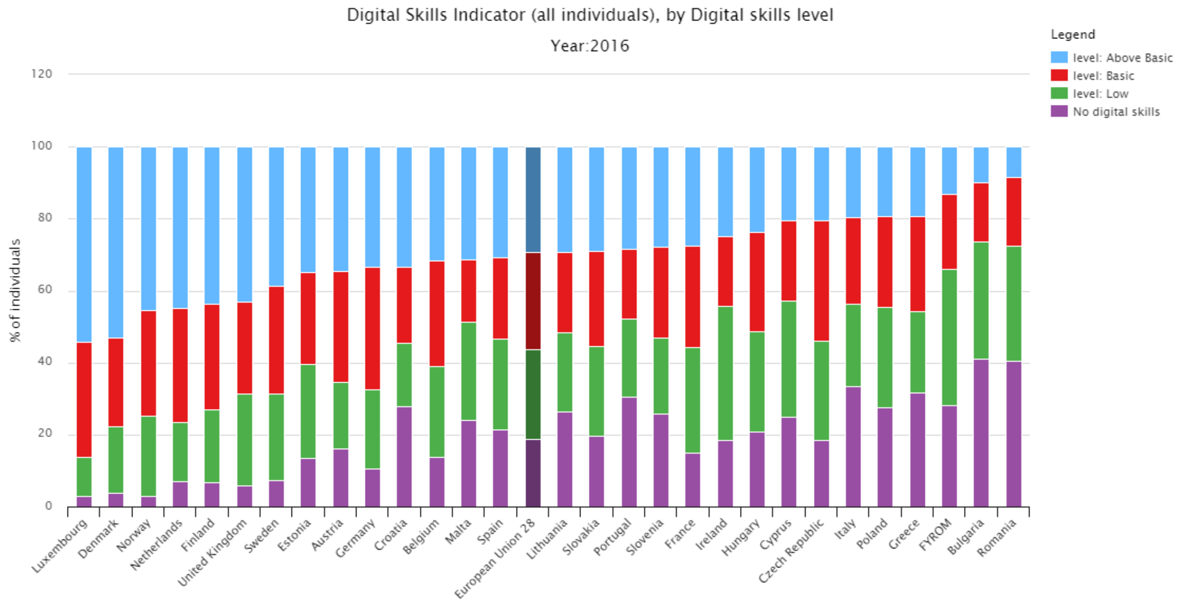
[37] http://ec.europa.eu/newsroom/dae/document.cfm?action=display& doc_id=9979

digital competence is and groups the competences in five areas: Information and data literacy, Communication and collaboration, Digital content creation, Safety and Problem solving.
Today, being digitally competent means that people need to have competences in each of these five areas.

Digital Skills Indicator

The chart shows the digital literacy levels of countries within the EU based on the DigComp framework. Data relates to persons that have been using the Internet during last 3 months of and attributed a score on the four digital competence domains: information, communication, content-creation and problem-solving, depending on the activities they have been able to do.

- Above Basic – individuals having above basic skills in all four domains
- Basic – Individuals having at least basic skills in all four domains.
- Low – Individuals without basic skills in at least one of the four domains.
- No digital skills – Individuals that have not used the Internet in the last 3 months or at all[38].



European Commission, Digital Scoreboard

Figure 10. Digital Skills Indicator

Significantly, just over 40% of individuals in the EU are considered to have insufficient digital skills and 20% have none at all.

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[38] Eurostat, Table isoc_sk_dskl_i: Individuals' level of digital skills

4.2 Country Summaries

4.2.1 Austria

4.2.1.1 Use Case/system Name

Elektronische Gesundheitsakte (ELGA).

4.2.1.2 Policy and background

ELGA is the nationwide, patient centred EHR/PHR system which provides patients, doctors, hospitals, care facilities and pharmacies having a treatment relationship an easy access to patient's health records. Health records such as medical reports on a person are created at various health facilities. ELGA networks this data and makes it available electronically.[39] The main objectives of ELGA are:

- Patient empowerment
- Optimised therapy by improved collaboration
- More quality through better knowledge
- Easier workflows

ELGA was established and is owned by the Austrian Ministry of Health, the nine provinces, and the national public health insurance. The ELGA-go-live took place in December 2015 in two provinces. In 2016 the nationwide roll-out was continued for hospitals in all the nine provinces. The roll-out to medical doctors and pharmacies is ongoing. In the frame of CEF it will enable seamless cross-border care and secure access to patient health information between European healthcare systems, particularly with respect to the exchange of Patient Summary and ePrescription/eDispensation.[40]

4.2.1.3 Care process

The patient has full control over their own data by e.g.:

- Access to medical documentation including medication
- Manage (grant/refuse) access to specific healthcare professionals and providers
- Mandate other (non-health professional) people (relatives etc.) enabling to act on behalf of the patient
- Check the access logs (every access is recorded)
- Opt-in or opt-out of ELGA (per default every citizen is participating in ELGA)

The access to ELGA is done via the central health portal https://www.gesundheit.gv.at by logging in to ELGA using electronic signature (with a citizen card or, more popular, the smartphone).

More than 10% of Austrian citizens are possessing an active mobile signature, that can be used as access key to ELGA (800.000 of the overall about 8 million population are able to access their health records). The amount of signatures is increasing each month.

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[39] http://www.bmgf.gv.at/home/EN/Health_care_services/ELGA/

[40] Herbek et al: The Electronic Health Record in Austria: a Strong network between health care and patients. Eur Surg (2012) 44/3

4.2.1.4 Information

ELGA is implemented as a patient centred, distributed IT system based on IHE profiles. It provides for a decentralized storage of health data (e.g. test results, medical images) in repositories within the respective organisation of origin. The few central components are for the identification of patients and health service providers as well as for authorization management.

4.2.1.5 Application

The core of every ELGA Area is the Repository for the storage of ELGA documents (such as test results and discharge letters) whereas the Document Registry contains only meta data and links to ELGA documents. The ELGA Documents are structured and classified in a standardised form according to the HL7 CDA Rel.2 Standard. The Central Authorisation System is the key component for the storage of roles and rights and thus the basis for the strictly security oriented access management of ELGA.

4.2.1.6 Infrastructure

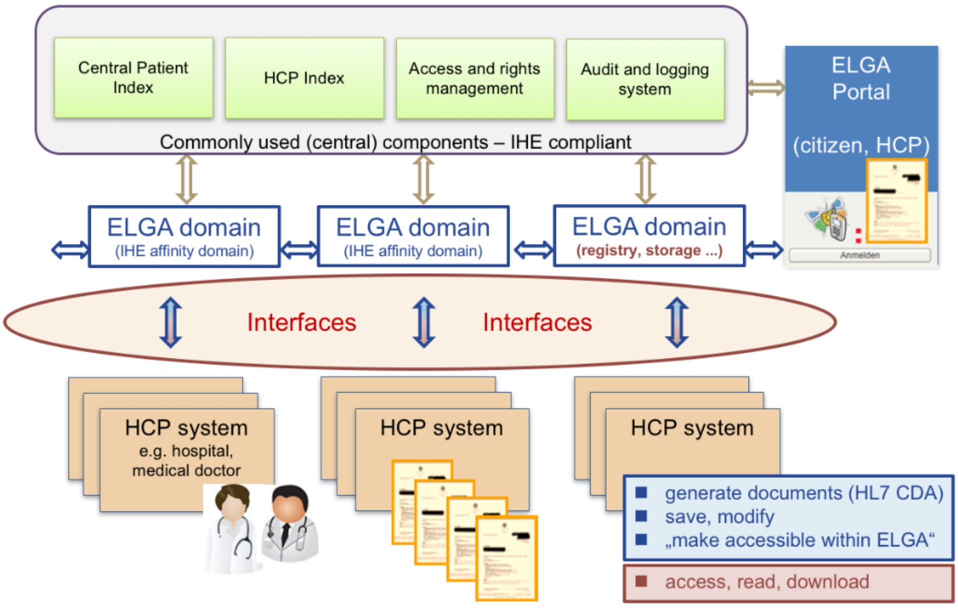

Figure 11. ELGA architecture overview

The information contained in the ELGA follows “semantic interoperability” by requiring the HL7 Clinical Document Architecture (CDA), Release 2.

Medical content is normally strictly separated from administrative content within a CDA document. Merely administrative data and the document metadata are located in the so-called “CDA header”. The “CDA body” contains medical information in a human-readable format. In addition, machine-readable data can be embedded in order to support semantic interoperability.[41]

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[41] http://www.bmgf.gv.at/cms/home/attachments/1/7/2/CH1538/CMS1458292318057/1511_elga_the_electronic_health_record_in_austria.pdf

4.2.1.7 Digital Literacy

The health portal https://www.gesundheit.gv.at provides information and introduction videos. ELGA profits also from governmental initiatives in order to increase digital literacy. Specific ombudsman offices are in operation in every province.

4.2.2 Belgium

4.2.2.1 Use case/system name

www.plan-egezondheid.be

4.2.2.2 Policy and background

Belgium created an action plan 2015-2018 concerning eHealth with objectives to be achieved by 2019. Action 10, which is about creating access to health data for patients, is relevant for this task. The action started in October 2015 under the responsibility of FOD public health. This action consists of the following steps:

- Create a framework for access (control) and the function to add information for the patient
- Create a governance structure which controls this framework
- Create a communication strategy to inform citizen/patients about online access to health data and other functions with regard to information sharing[42].

On www.patientconsent.be citizen can be informed about initiatives for online access to their health data.

To achieve the objectives, the governments in Belgium, both the federal government as the states, will connect and set up, for example, a common governance structure which is intended to ensure the political and operational coordination of this action plan.

4.2.2.3 Care process

No information available.

4.2.2.4 Information

The relevant objectives regarding the patients to be achieved in 2019:

- The patient has access to all own patient information. In the meanwhile, there will be an exploration whether it's achievable to build a platform (PHR) on which patients can combine all their information with tools for analysis, for example for translation of difficult terms in the record to better understand it and improve the health literacy. The patient can also include their own information. The health insurance funds crossroads and other sources, such as living wills for organ donation and euthanasia, can also provide additional information to be added on the platform.
- The patient has access to his/her PHR via different routes, for example via an application on a smartphone.
- The patient will not receive any information on paper from the healthcare professional. The service which was provided by the professional will be electronically transferred to the insurance fund, the prescription is available on the medication schedule, evidence of

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[42] http://www.plan-egezondheid.be/wp-content/uploads/Actiepunt-10.pdf

incapacity is electronically forwarded to the employer, the patient will receive his receipt in his mailbox, etc. Preliminary condition is that the patient gives his/her informed consent.

4.2.2.5 Applications

The objective for 2019 is to give patients access to his/her PHR via different routes, for example via an application on a smartphone.

4.2.2.6 Infrastructure

With regard to semantic operability Belgium works with SNOMED-CT and LOINC. Secondly, Belgium makes use of national codes, for example RIZIV. The major challenges are mapping of existing/future/local/international systems and also making the overview- and interface tools available. Belgium also looks at the clinical building blocks as developed by Nictiz.

4.2.2.7 Digital literacy

No relevant information available.

4.2.3 Croatia

4.2.3.1 Use case/system name

Patient's Portal.

4.2.3.2 Policy and background

The Patient's portal encompasses personal medical and administrative data for a single patient in a digital form, and actively involves patients who are able to see all of their prescribed and issued medications, as well as medical findings and discharge summaries. The Patient's Portal is part of a larger e-Government project called e-Citizens. E-Citizens is an information backbone, which communicates with other public administration services, which encompasses several public services aimed at Croatian citizens. The e-Citizens system consists of:

- the Central Government Portal which is the public part of the system
- the Personal User Mailbox
- the National Identification and Authentication System.

The collaboration is achieved on the Central Government Portal from where Patient's Portal can be accessed.

4.2.3.3 Care process

In the Patient's Portal, the patient is able to view his/her medical information but cannot modify it. The system automatically updates patient information based on the EHR which is accessible for the HCP. However, the patient is able to restrict access to his health information via the Patient's Portal. All Croatian citizens can access the Patient's Portal by using the ePass system of authorization.

4.2.3.4 Information

On the Patient's Portal patients can see prescribed and dispensed medicines, test results and discharge records from in-patient and outpatient hospital and other medical care. Also they can see names of their elected GP, dentist and gynaecologist for women and paediatrician for children. The system automatically updates patient information based on the EHR that is accessible to the Health Professional.

4.2.3.5 Applications

There is no time limitation to storing data. The Patient's Portal is accessible via internet browser.

4.2.3.6 Infrastructure

The records in Patient's Portal are created from data collected from GP's, gynaecologist and paediatrician offices and in hospitals and are stored in the Croatian Health Insurance Fund's central healthcare information network (CEZIH).

4.2.3.7 Digital literacy

No available information.

4.2.4 Finland

4.2.4.1 Use case/system name

'My Kanta pages' → http://www.kanta.fi/en/omakanta

4.2.4.2 Policy and background

In Finland (5.5 million inhabitants), eHealth has been a priority in health care development since the mid-1990s. The health care system in Finland has this far been one of the most decentralized in the world, but is currently undergoing major reforms in order e.g. to reorganize service providers into larger units, planned to be put into operation by 2019. The first national patient access service for citizens was created as part of the national health information system, Kanta starting 10 years ago. 'My Kanta' pages is a portal in the national Kanta services, which provides access to one's own EHR data, prescription data, log information and consent management. My Kanta provides the citizen access to his/her own patient information archived in the Kanta Patient Data Repository e.g. from electronic health records by health care organizations that have joined the Kanta systems. My Kanta communicates with other national infrastructure services using web service interfaces.

The data accessible via My Kanta is the data that has been recorded by the healthcare units in the Patient Data Repository or the Prescription Centre of Kanta as well as data from the national Patient Data Management Service. The health records are archived in a technically uniform format, which enables the transferability of the data from one system to another.

My Kanta has been accessible to all citizens of the geographical areas that have joined the Kanta services since 2010 with a practically full national coverage as of 2016. First it contained only prescription data, but today EPR data is also available. The contents are being continuously expanded. My Kanta is being complemented with a new platform for the management of citizens' personal health information PHR (Omatietovaranto). The implementation will utilise the Kanta services and open interfaces. Citizens themselves will make the decisions regarding the storage of their information on the platform and its disclosure using the applications to be built on the platform.

eHealth and e-welfare have been identified as an important tool in modernizing health and social care. According to the strategic objectives set for 2020;

- Citizens should be able to use online services and produce data for their own use and for the professionals no matter where they live.
- Reliable information on well-being and services are to be available and assist citizens in promoting their own well-being or that of their family and friends.
- Information on the quality and availability of services is to be made available in all parts of Finland and to be used in the selection of service provider.

Kela is responsible for the technical infrastructure of Kanta and its' services and for the National Medication database. Cards for identification of professionals are provided by the Population Register Centre (VRK) supported by information provided by Valvira (the National Supervisory Authority. Nationally standardized codes and classifications are managed by THL and distributed via the National Code Server. The Ministry of Social Affairs and Health is responsible for the strategic planning and management whereas THL is responsible for the operational management.

4.2.4.3 Care process

My Kanta can be accessed on the Kanta services website at www.kanta.fi or under the direct URL www.omakanta.fi. Clients log into the service with their own bank IDs, electronic ID (HST) cards or mobile certificates. Anyone aged 18 can access their own electronic prescriptions as well as medical details from their EHRs. Minors can view prescriptions and health records that have been recorded in the Kanta services since 1 August 2016 and request a renewal of the prescription. A minor cannot acknowledge receipt of information, give a consent or refusal, or draw up an organ donation testament or living will. When a minor turns 18, they will also see their personal information saved in the Kanta services before 1 August 2016. Parents and carers were given the opportunity to act on behalf of their children in My Kanta in October 2016. At first, this right applies to children under 10 years of age. An increasing number of parents and carers can now manage their children's issues in My Kanta. Patients are yet not allowed to enter own information into My Kanta.

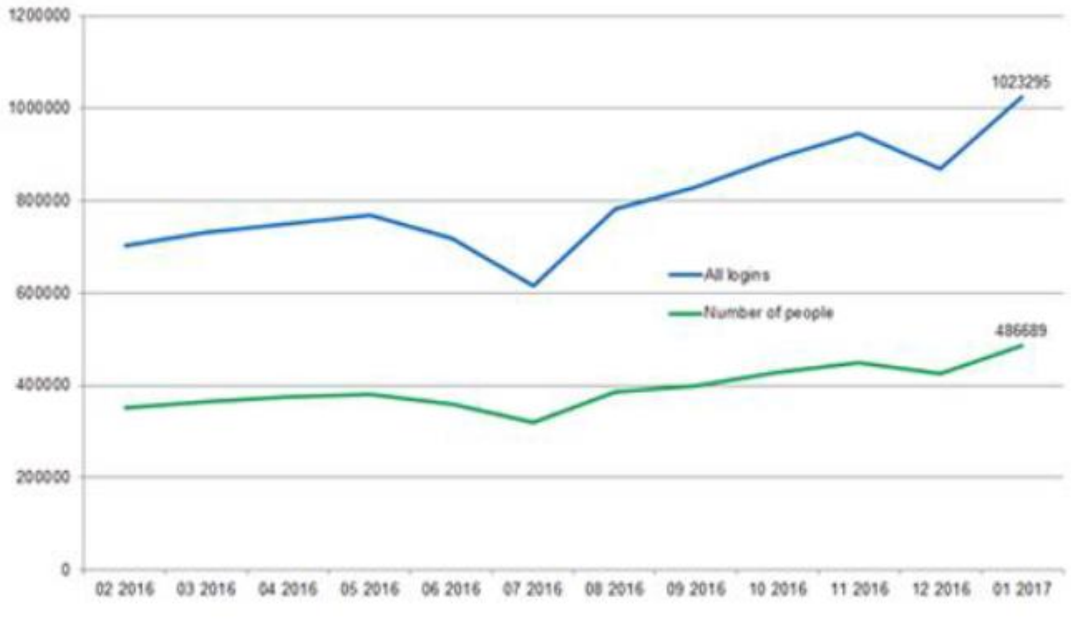

Figure 12. The use of My Kanta, February 2016 – January 2017

From the launch of the service until 28.2.2017 there were 21.264.732 log-ins. There were 9.285.657 log-ins in 2016 and 1.496.392 individual users in 2016.

Documents of individuals	5.474.985
Consents entered	2 397 829
Refusals entered	50 878
Organ donation wills	163 559
Living wills	38 197

Table 5. Accessibility and number in Kanta

4.2.4.4 Information

Electronic prescription information

Electronic prescriptions and drugs purchased are shown in My Kanta for 2.5 years from the date the prescriptions were issued. The patient can send a request for a renewal of an electronic prescription to the healthcare provider.

Summary of electronic prescriptions

My Kanta permits printing of a summary of a person's electronic prescriptions. One can print either all of the patient's electronic prescriptions or all the prescriptions with medicines outstanding. The patient can request a summary printout by the doctor or nurse in the healthcare unit or at the pharmacy. When travelling abroad, patients should take along a summary of their electronic prescriptions.

Electronic patient data

In My Kanta, the patient can see the information recorded in healthcare services and view almost all their patient data recorded in outpatient care. In-patients can see a summary of their entered medical treatment records. If necessary, professionals can delay entries showing in My Kanta pages for reasons related to the treatment.

The medical records remain in My Kanta pages for the statutory period of time. The service also shows details of which healthcare units have accessed your medical records.

Patients must be informed that their medical records are entered in the Patient Data Repository. They can also read the information in My Kanta and confirm receipt at the same time. Patients can give their consent to their medical records being disclosed to other health service providers via the Patient Data Repository. If the consent has been given, the records can be utilised in treatment situations. Patients can also issue a refusal of disclosure in My Kanta concerning their medical records entered in the Patient Data Repository. Patients can refuse disclosure of information from a certain visit, treatment period, or a certain public healthcare patient register. A minor has the right to decide whether to show their information to their parents or other guardians if the minor has been assessed by a healthcare unit to be mature enough to decide on their own treatment. In such a case, the healthcare unit can deny parental access to the minor's information in My Kanta Pages.

The citizen can also enter wishes regarding his/her care in My Kanta. Such wishes comprise living wills and organ donation testaments.

By the end of 2017 Kanta services will be extended with the new Personal Health Record functionalities. Citizens will be able to store their own health-related data such as results of online health risk tests or measurements performed at home. Citizens will be able to enter their own data through various PHR applications developed by national and regional projects or by software vendors. It will be possible to enable healthcare professionals to access this data if the citizen has given their consent for this. The PHR platform is based on the emerging standard HL7 FHIR.

In the future also social service information and documents will be accessible via My Kanta. In addition, making secondary use of the EHR data possible is one of the main focuses at the moment.
In addition the following data will be made available according to plans: medical certificates, vaccination summaries, treatment summaries-, referrals and care plans.

Patient data management service
The nationwide patient data management service is maintained as part of the Kanta service. Information about patients' declarations of intention and consents are recorded in the patient data management service, including:

- Information about the fact that a patient has been informed of the nationwide patient data management service (Kanta services)
- Patients consent to sharing patient data
- Withdrawal of consent
- Refusals to share patient data
- Withdrawals of refusals to share information
- Living will
- Patients stand on organ donation

The possibility to give authorization to other person is not yet implemented, but is planned to be within a few years' time. This would be needed particularly in the case of elderly people.
On the level of the Point of Care patients can see who accesses their information. In case of suspicion of malpractice also log information concerning the individual use can be tracked. The Patient Data Repository log and control services ensure that patient records are used in compliance with data security and legislation. All uses and disclosures of patient records are entered in a log which permits ex-post control.

4.2.4.5 Applications

No data is saved to My Kanta as it is a portal. The data in the EHRs are retained for 100 years or until death. The prescription and its dispensing events are stored in the Prescription Centre for 2.5 years after the issue date. After that, the prescription and dispensing records are archived for 20 years in the Prescription Archive, after which they are destroyed. One can log in into My Kanta using either bank IDs, mobile certificates, or electronic ID card (HST card). Only persons who have a Finnish ID number can log into My Kanta Pages.

4.2.4.6 Infrastructure

My Kanta communicates with other national infrastructure services using web service interfaces and also has access to certain log data at the database level. My Kanta does not have direct database access to patient health data.

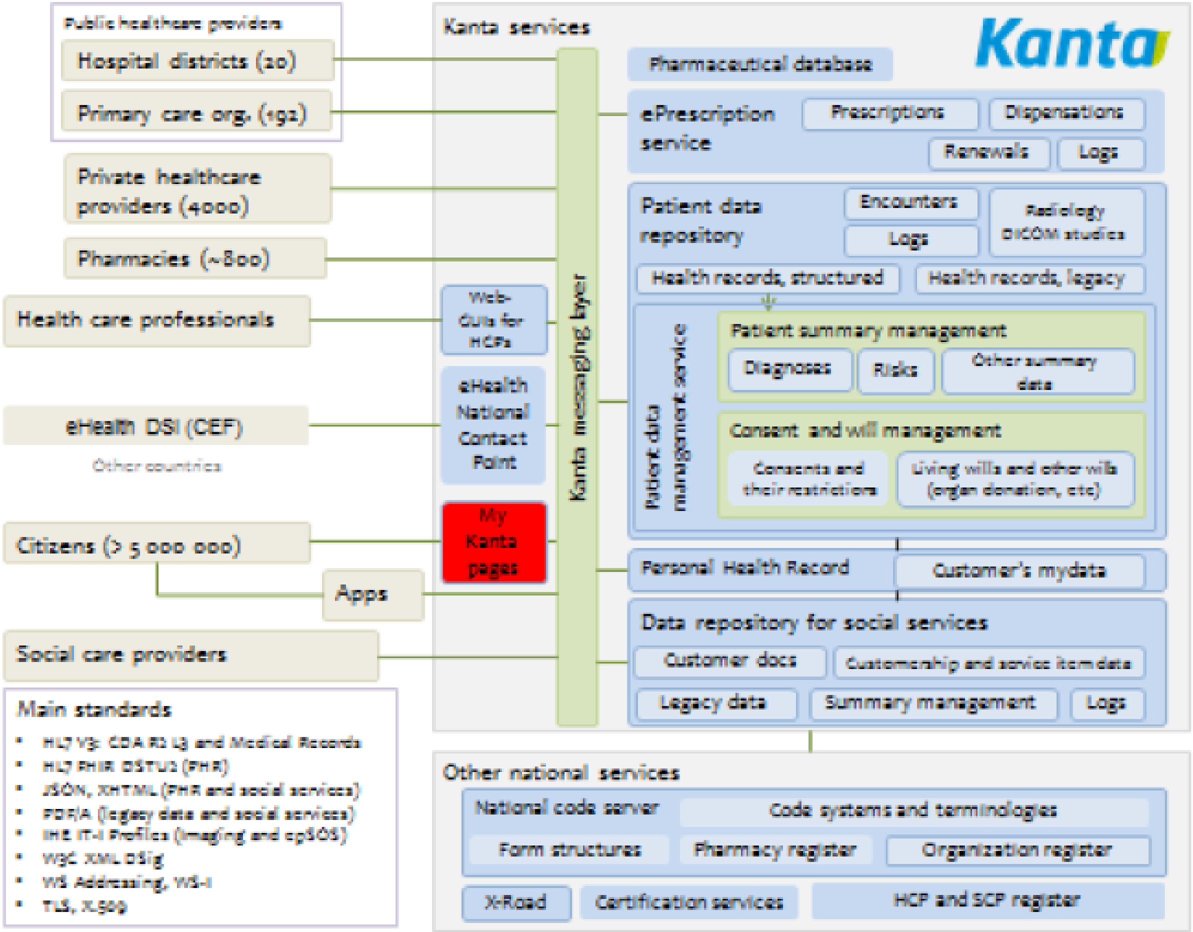

Figure 12. Infrastructure Kanta

4.2.4.7 Digital literacy

Finnish people use the internet for a wide variety of purposes, and they possess good capability in terms of both IT skills and attitudes to use internet and mobile-based services in the area of social welfare and health care. People regard the selection of online services as narrow and expect new services to be launched.

According to Statistics Finland, in 2014 already 90% of Finnish people aged 16–74 used internet-based e-services, and the majority of them had network connections at home.
According to a Citizen survey conducted in 2014 70% of the respondents disagreed to the statement: I do not possess enough IT skills to use the electronic services. In the same survey the self-rated usability and utility of e-services were studied with three statements. User experiences of the existing electronic portals were by and large positive. The most useful services in the users' opinion were the Mielenterveystalo, i.e. a mental health portal (88% of users considered it useful) and My Kanta (77% of users considered it useful).

4.2.5 France

4.2.5.1 Use case/system name

Dossier medical partagé (DMP).

4.2.5.2 Policy and background

The French electronic health record - DMP- is a public project launched in 2004 by the French Ministry of Health allowing each citizen to have electronic access to their clinical past and their current health status. There were three main phases[43]:

1. The pilot phase (2004)

In order to implement the French EHR, a public interest group for the DMP is created in April 2005. The first experiment stage started in 2006 for a few months, from June to December of 2006. During these months, 38200 DMP were created in 17 pilot areas. This pilot phase has demonstrated that the DMP project is achievable.

2. The renewal of the DMP (2009)

In 2009, the public interest group becomes the French Agency for eHealth (ASIP Santé). The deployment phase of the DMP starts in December 2010 and since the 5th of January 2011, French citizens are able to ask the creation of their own electronic health record to a health care professional. Since April 2011, patients can also consult their DMP on their own via internet.

3. DMP : second generation (2016)

The 2016 law for the modernization of the Health system transfers the DMP to the French National Health Insurance Fund, ASIP Santé is no longer in charge of its national deployment and of running the system. The deployment strategy chosen in France by the French National Health Insurance Fund for the DMP is regional, even if the final objective is to display it throughout the country. The deployment of the DMP "second generation" starts in December 2016 into nine departments using the local public health insurance offices.

The main objective is to deploy at a large scale the French EHR and give to every beneficiary of National Health Insurance the possibility to have a DMP. Another objective is to create a mobile app for patients to access their DMP. Currently, the connexion to an EHR must be done via a web platform (mon-dmp.fr).

As the French government eHealth agency, ASIP Santé is in charge of the definition, promotion and ratification of reference frameworks, standards, and products or services that contribute to the interoperability, security and use of health information systems and telehealth. ASIP Santé is also in charge of ensuring that these standards and products are appropriately applied. ASIP Santé is a major contributor to IHE; it is co-chairing several international technical committees that produce integration profiles.

CNAMTS (Caisse Nationale d'Assurance Maladie des Travailleurs Salariés) is the most important French national Health Insurance Fund dedicated to Salaried Workers. It can rely on its own

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[43] Cf. dmp.gouv.fr

existing network of more than 100 regional funds in the whole territory with dedicated resources for the dissemination and the training of Healthcare Professionals.

4.2.5.3 Care process

Patients can choose to ask for the creation of their DMP:

- During a medical examination with an authorized HCP equipped with the adapted informatics tools;
- Directly in their local healthcare insurance office;
- Online on the DMP website (this service is currently available for 9 areas on the French territory).

For the creation, patients need their insurance card "Carte vitale" and they need to give their consent.

After the creation of a DMP, patients can have access to it at any time directly on the website "mon-dmp.fr" using their ID and password. They have a personal area on which they can consult their data, ask to hide some contents or documents to some HCP except to the referring doctor and be aware of the addition of new documents in their EHR.

At any time, patients have the possibility to:

- end the access authorization to a HCP;
- close the EHR, however data will be saved for ten years but won't be accessible;
- ask for a copy on paper or CD-ROM by filling in an online form.

4.2.5.4 Information

The DMP includes the following data:

- Data about the owner of the record such as :
    - Data on its identity and identification;
    - Medical data about the prevention, health status and follow-up;
    - Data provided by the owner himself;
    - Data about the prescription of medicinal products originating from the Pharmaceutical Record (not yet completely available);
    - Data about organ and/or tissue donations.
- Data about the identity and contact details of legal representatives if needed;
- Data about the identity and contact details of the trusted person;
- Data about the identity and contact details of the people who should be informed in the event of an emergency;
- Data about the identity and contact details of the referring doctor;
- Data about the owner consents for the creation and the accesses to the DMP.

Patients are free to create an EHR, they have different rights on their medical record:

- Handle the access, authorize or block the access to a given HCP, accept or not the use of glass breakage in case of emergency;
- Interfere in the content : add some documents to his/her EHR, ask a HCP not to add a specific document, hide some content and ask to delete a document (except for the referring doctor);

- Close his/her DMP.

Patients can see the entire history of the actions realized on their EHR: who accessed the information, when and for what purpose, including glass breakage access.

4.2.5.5 Applications

The data in the DMP are stored as long as there are regular accesses to the record.
There are two options to destroy the data retained in the system:

- When a patient chooses to close his/her EHR, data are stored for ten years from the date of closing. The data stored in the DMP are then destroyed.
- If the patient does not use anymore his/her EHR, the data are stored for ten years from the date of the last access to the DMP and after this deadline they are destroyed.

Patients can access their DMP via a website (mon-dmp.fr). A mobile app will be implemented and deployed soon. To open an EHR, patients need their social security number and their insurance card the “carte vitale”. With this information, a national identifier is generated, it is essential for HCP to access patients’ EHR. There is one exception for doctors working for the emergency medical assistance service, in case of an emergency they can access the EHR without using the national identifier.

4.2.5.6 Infrastructure

The DMP displays the history of the patient health insurance reimbursements. This integration is currently available only for the patients having a DMP in the nine pilot areas.

4.2.5.7 Digital literacy

According to a 2016 survey, the statistics related to digital skills in France are the following:

- 82% of the population is equipped with a computer, 65% with a smartphone and 40% with a digital tablet.
- 85% of the French have an internet access via their landline connection, 60% via their smartphone.
- 100% of the 12-39 years old are web users compared to 78% for people over 40 years.

About the French health system, the statistics below are coming from the survey “Etude Santé” by Deloitte and IFOP in 2015. They interviewed a panel of 2000 French citizens.

Four out of five patients in France think that it is important to be able to access their electronic health record. 84% report that they must be able to update their EHR on their own. 61% of the French population would like to have their results analysis available online.

However, the existing eHealth services are not broadly deployed among the population:

- 14% are using the DMP
- 35% are using health websites
- 8% are using health app
- 7% are using connected devices for health
- 47% of the population does not use any of these services

For 84% of the population, they rarely exchange data by email with the HCP.

In France, the digital skills are sufficiently deployed among the population and on the entire territory. A majority of people has a regular access to the internet, so access to an electronic health record shouldn't be a problem to French citizens. However, according to the statistics, we can conclude that the French population does not take advantage of these digital skills to develop their eHealth uses.

4.2.6 Germany

4.2.6.1 Use Case/system Name

Persönliche einrichtungsübergreifende elektronische Patientenakte (PEPA).

4.2.6.2 Policy and background

A patient-controlled personal electronic health record (PEPA) was developed, implemented, and applied for chronic care of patients with colorectal cancer during a research project at Heidelberg University funded by The Federal Ministry of Education and Research (BMBF). Aim of this study was to explore perceived benefits and concerns regarding the complexity of illness and cross-sectoral health care pose challenges for patients with colorectal cancer and their families.

4.2.6.3 Care process

PEPA allows for the exchange of medical data between all interested groups, including the patients themselves. A PEPA contains medical reports and findings including, for example, x-rays, CT scans and MRIs. The patients can safeguard their information and access all content.

4.2.6.4 Information

Personnel involved in conducting the study were responsible for authenticating patients and generating the user accounts. Thereafter patients have access via Internet with optional access per mobile app and can:

- View Lab results, all kind of letters, observations, images, medication
- Add, modify and delete self-generated content.
- Manage access rights, grant access to, or hide information from care delivery organization or care providers at any time
- See who accessed their information and what information was accessed

The study personnel was responsible to authenticate patients and to generate a user account.

4.2.6.5 Applications

Portal applications are being used, connected to IHE-based middleware, document registry and repository. The patient can access his data through a web-based patient portal with optional access per mobile app. The data is retained in the system until the patient deletes it.

4.2.6.6 Infrastructure

Hospitals and caregivers that participate in the project are already integrated with PEPA, including interfaces to their local systems. Hospital systems, portals for professionals and patients are all connected through a common middleware that implements the IHE actors that are relevant. The provided functionality encompasses security, access policies, identity management, document registry and repository. Interface technology is based on IHE-ITI profiles, therefore it supports exchange with other EHR domains (e. g. querying patient-related medical information from other EHR domains).

4.2.6.7 Digital Literacy

All users within the study were trained on the system. A user handbook was provided to participants and a hotline was established (email and phone) to provide support to users.

4.2.7 Hungary[44]

4.2.7.1 Use Case/system Name

- Patient access to the database of the National Health Insurance Fund (NEAK, formerly OEP)
- Patient access to their clinical data at a particular hospital (Brothers Hospitallers of Saint John of God)

4.2.7.2 Policy and background

Proper information – in written and oral form - of the patient about his health condition is an obligation of the treating physician. However, it is still not the general practice that patients receive a copy of all of their data after a hospital stay. The discharge report they receive is an extract of the full medical record. On the other hand, National Health Insurance Fund collects coded data of all GP's, in- and outpatient secondary care episodes as well as all prescriptions. These data serve primarily reimbursement purposes and hence does not contain all details. E.g. medical procedures (examinations, interventions) are recorded in a coded form, but the result of tests are not included. This database contains about 3 million hospital cases, 80 million outpatient cases and 170 million prescriptions per year. Since the mid of first decade of this century patients have access to their own records in this database through the central governmental portal. The current governmental policy is to improve the patient access to all of their medical data. To make it possible these data will be stored in the central eHealth system called Electronic Health Information Service Space (EESZT).

4.2.7.3 Care process

USE CASE 1.

This is a follow up system that does not effect on current care process. There is a significant delay between the care episode and the availability of the data (about 2-3 month). The reason is that these data are processed for reimbursement and inserted into the database only after completing the procedure. Data can be seen from two perspectives, i.e. patient view and physician view, but there is no essential difference between. About 1.5 million citizens have registered themselves on the central governmental portal. All of them can access their health data, but there are no usage statistics.

USE CASE 2.

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[44] http://www.ksh.hu/docs/hun/xftp/idoszaki/ikt/ikt13.pdf
https://www.ksh.hu/docs/hun/xftp/idoszaki/ikt/ikt14.pdf

About 150 patients used the system actively at least once. The most common usage is to download and print lab test results from the system. This prevents the patient to visit the hospital just for the results. Printed results are often handed over to treating physicians outside the hospital (e.g. GP's).

4.2.7.4 Information

USE CASE 1.

Date are defined as a minimum basic data set principle, most of data are coded. The most important data elements are:

- Date of service
- Service provider
- Referring service provider ID,
- Diseases (ICD 10 codes)
- Procedures (only major interventions for inpatient care) coded according. The coding scheme is the Hungarian adaptation of ICPM.
- For prescriptions (only if dispended): prescribed drug, ICD 10 code, dispensation date, prescribing physician.

These data are readable by the patient but there is no possibility for him/her to add, alter, delete or hide the data. The same data are available for physicians actually treating the patient, but patients have the right and possibility to make it invisible on an opt-out basis.

Access for patients is granted by the central governmental portal, where citizens can register themselves. The authentication system of the governmental portal is integrated to the database of NEAK. Once patients authenticate themselves on the portal, they have to type in their social insurance ID in order to access their data. Patients cannot grant access to any third party.

Currently there is no information about patient having access to the log data to see who accessed their data. However this functionality is implemented in the EESZT that will be launched this year.

USE CASE 2.

The available content covers full EHR (both in- and outpatient records) and lab test results.

4.2.7.5 Applications

Data preservation is regulated by the Medical Data Act for both use cases. The general rule is 30 years, but none of the current systems contains data recorded originally on paper before the implementation of the EHR system. There are no special system requirements for accessing these data. For both use cases a simple internet browser is sufficient. Throughout the whole health care system the general ID for patients is the health insurance number (TAJ). This is used together with credentials for accessing the central citizen portal for USE CASE 1. For USE CASE 2 there is a double ID system, both TAJ and the local hospital patient ID are used to identify the patient.

4.2.7.6 Infrastructure

The system from use case 1 is integrated with the central citizen portal but this is just for user identification and authorization. The system in use case 2 is not integrated to any other service.

4.2.7.7 Digital Literacy

Data on computer literacy in Hungary are scarce, partly unofficial, out of date and incomparable All estimations say that the level of digital literacy somewhat lower than the European average.

4.2.8 Ireland

4.2.8.1 Use Case/system Name

Providing Individualised Services and Care for in Epilepsy (PISCES).

4.2.8.2 Policy and background

The Health Service in Ireland is in the middle of a major digital transformation which began in December 2013 with the publication of the Department of Health's eHealth Strategy for Ireland[45]. The strategy identified priority projects:

- National Health Identifier Infrastructure
- Development of Patient Summary Records
- Online Access to Health Information
- National Patient Portal

Following on from the strategy eHealth Ireland[46] was established as a division within the Health Service Executive to bring improved population wellbeing, health services efficiencies and economic opportunity through the use of technology-enabled solutions. A first CIO for the Health Service Executive and CEO of eHealth Ireland, Richard Corbridge, was appointed. eHealth Ireland's Knowledge and Information Plan[47] (2015) builds upon the eHealth Strategy and one of the strategic programmes is the Electronic Health Record[48].

During 2016 a number of projects were implemented to put the foundations in place for a national Electronic Health Record. These included:

- Building and populating the national Individual Health Identifier (IHI): the unique ID with which patients will access their EHR information. The legislation to enact this is currently ready for signing into law.
- The first completely digital hospital in Ireland: Cork University Maternity Hospital
- ePrescribing
- eRefferals

Three 'Lighthouse Projects[49]' focusing on Epilepsy, Bipolar and Haemophilia patients were also instigated to build an understanding of the benefit of an EHR in the Irish healthcare system. (The Epilepsy lighthouse project is the use case described here.)

The business case for the National Electronic Health Record project is currently pending approval from the Department of Health.

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[45] http://www.ehealthireland.ie/Knowledge-Information-Plan/eHealth-Strategy-for-Ireland.pdf
[46] http://www.ehealthireland.ie/
[47] http://www.ehealthireland.ie/Knowledge-Information-Plan/Knowledge-and-Information-Plan.pdf
[48] http://www.ehealthireland.ie/Strategic-Programmes/Electronic-Health-Record-EHR-/
[49] http://www.ehealthireland.ie/Lighthouse-Projects/

4.2.8.3 Care process

Providing Individualised Services and Care for in Epilepsy (PISCES)[50] is one of the three Lighthouse Projects. PISCES is demonstrating how eHealth technologies can improve quality and safety of care for people with epilepsy by supporting:

- more precise diagnosis and treatment (genomic medicine)
- more proactive services (electronic patient portal to own health record)
- personalised care pathways

A prototype web-based patient portal has now been developed in consultation with epilepsy patients and clinicians and is currently at pilot testing phase with a selected group of patients, their parents and carers from Dublin and shortly, Cork, cities.

The objectives for the epilepsy patient portal are to:

- Support patients and residential carers to prepare for a clinical engagement.
- Be easily understood by a member of the public without a clinical background.
- Increase a patient's knowledge about Epilepsy.
- Allow patients validate their epilepsy EPR summary.

The portal will not be a helpline or emergency service.

Overall approximately 40,000 Irish adults suffer from epilepsy.
13,000 adults have complex epilepsy, requiring frequent contact with healthcare services and having ongoing needs. Of these 13,000 adults, 7,000 have an electronic epilepsy patient record (as distinct from an electronic health record).

Three scenarios are being specified for the patients' use of the portal:

1. Validation of the EPR

Patients will see a summary of their epilepsy patient record. If data is missing e.g. medications not listed, seizure episode not recorded etc. the patient can add a message to request that the record be validated. The processes to act on this message at the clinical side are currently being worked out.

2. Plan Clinical Engagement

In advance of a clinical engagement patients will be able to plan their clinical encounter by uploading:

- Topics they want to discuss at their clinical encounter
- What their goals are around lifestyle e.g. within 12 months I want to be confident enough with managing my epilepsy to be able to do a course
- The clinician will be able to view this data in advance of a meeting and so tailor the engagement around the patient's objectives.

3. Test Patients' Knowledge of Epilepsy

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[50] http://www.ehealthireland.ie/Library/Document-Library/Pisces-Newsletter-Vol2.pdf

Patients will be asked to complete small questionnaires via the portal to test their knowledge of epilepsy. Depending on the results, interventions can be planned to increase the patient's knowledge of their condition and so increase the ability of the patient to manage their condition.

4.2.8.4 Information

Patients have an Epilepsy ID number which is the hospital patient management system number combined with an internal system ID. Patients will view a summarised version of their EPR. The next phase is to incorporate the national Individual Health Identifier into the EPR – the PISCES project will be one of the early adopters of this.

Apart from patients the following roles have access to the epilepsy EPR:

- Hospital clinicians and nurses
- Nurse support hotline operated by Beaumont Hospital
- GPs
- Other healthcare providers such as specialist epilepsy clinics
- Care centres in the case of elderly and/or patients with intellectual disabilities

The level of access is determined by whether the person involved has a legitimate role in the care of a patient. Full rights - Read/Write – Read only – limited view etc.

4.2.8.5 Applications

At the national specialist centre for the treatment of epilepsy, clinicians view the EPRs via the hospital intranet. In other hospitals and care settings the epilepsy EPR sits separately.

A nurse-led telephone advice line operated by the national specialist centre access the patient's EHR e.g. in the event of a seizure. The consultant epileptologist simultaneously accesses the same record and they discuss the case by phone. The nurse then gives advice to the patient and notes the event.

4.2.8.6 Infrastructure

A secure web-based epilepsy electronic patient record (EPR) has been developed and is now in daily use supporting clinical care of over 7,000 epilepsy patients in Ireland and increasing. A prototype web-based patient portal is in pilot testing phase. Ergo, a technology company, Microsoft Ireland and the Health Service Executive built the initial service infrastructure to host the patient portal.

4.2.8.7 Digital Literacy

Digital literacy aspects are not being addressed yet in relation to the PISCES project but will likely come out of the pilot as it is pushed out beyond the initial patient focus groups. In Ireland, the Department of Communications, Climate Action and Environment fund a national programme called 'Digital Skills for Citizens[51]' where free training is provided to assist citizens in becoming confident in the use of online services.

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[51] http://www.dccae.gov.ie/communications/en-ie/Digital-Strategy/Pages/Get-Citizens-Online.aspx

4.2.9 Lithuania

4.2.9.1 Use Case/system Name

National eHealth system (Electronic health services and infrastructure cooperation system – ESPBI IS).

4.2.9.2 Policy and background

The public health system in Lithuania consists of 10 public health centres, subordinated to the Ministry of Health, and a number of specialized agencies with specific functions. At the local level, municipal public health bureaus carry out public health monitoring, health promotion and disease prevention[52].

Lithuania‘s Progress Strategy "Lithuania 2030" was adopted by the Parliament in 2012[53]. Currently the Ministry of Health has started a project of national eHealth system implementation. The first stage of the project will cover creation of core elements, such as common standards, nomenclature, registries and four main functionalities. These are the registration of patient visits, exchange of clinical and administrative data; creation and sending referrals for consultations/treatment as well as inputting and receiving results; creation and sending of referrals for diagnostics (laboratories, medical images) as well as receiving and storing result; execution of registration for an appointment (consultation, treatment, tests)[54].

4.2.9.3 Care process

All Lithuanian citizens can access their electronic health records. At the moment there is no relevant statistics to the use case.

4.2.9.4 Information

In the table below the list of documents patients can see when they access their EHR:

ID	Document
1.	Stationary treatment description
2.	Ambulatory treatment description
3.	Diagnostic order
4.	Diagnostic order (response)
5.	Description of medical image
6.	Vaccination
7.	Laboratory order
8.	Laboratory order (response)
9.	Pathology order
10.	Pathology order (response)
11.	E-prescription
12.	Issue of medication
13.	Birth certificate
14.	Certificate of mandatory health check
15.	Health passport
16.	Card of mandatory health check
17.	Drivers medical certificate

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[52] http://www.ehealthforregions.net/about-us/partners/lithuania.html

[53] http://www.digitalhealth.net/news/22848/lithuania-approves-new-ehealth-strategy

[54] https://www.e-tar.lt/portal/lt/legalAct/d215c1104d5811e5b0f2b883009b2d06

18.	Death certificate
19.	Perinatal death certificate
20.	Health certificate for child
21.	Patient summary

Table 6. Accessible documents for patients

The data stored in the ESPBI IS is accessible by the patients. The possibility to register and access the database is allowed via a special national internet portal. Direct right of a patient to update, modify and erase EHR content has not been established. Therefore, the patient cannot be held liable for erasing key medical information in EHRs. The national legislation ensures that the patient's EHR personal data is kept in ESPBI IS database throughout the life of the patient and for 3 years after his death. At the end of this period the patient's personal data is stored in the archive of ESPBI IS for 75 years. Health data might be used for secondary purpose (e.g. scientific research or statistics) under the particular conditions as provided in applicable laws.

The patient can access electronic health records using the portal www.esveikata.lt. The patient can identify himself using:

- mobile electronic signature
- cryptographic usb key
- cryptographic card
- from a banking system
- from e-government gateway

Patients can specify authorisation to another user in the system. In addition, parents can access their children's electronic health records. Patients cannot see who and when accessed electronic health records but the patients can see who and when created or modified electronic health records.

4.2.9.5 Applications

Electronic health services and infrastructure cooperation system (ESPBI IS) was launched for patients and practitioners in 2015. Since that time data is collected in the system. Patients can access their electronic health records using any web browser. Patients are identified by the Electronic Health History number (ESI number) or/and personal identification number.

4.2.9.6 Infrastructure

The national eHealth system is integrated at national level. Hospital information systems are integrated into national eHealth system through services.

4.2.9.7 Digital literacy

At the moment there is no data on the percentage of the population who have the digital literacy skills necessary to access their electronic health record. In the Figure below Internet access of households, 2009 and 2014 (% of all households) is provided. In 2014 66% of households had internet access[55].

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[55] http://ec.europa.eu/eurostat/statistics-explained/index.php/Information_society_statistics_-_households_and_individuals/lt

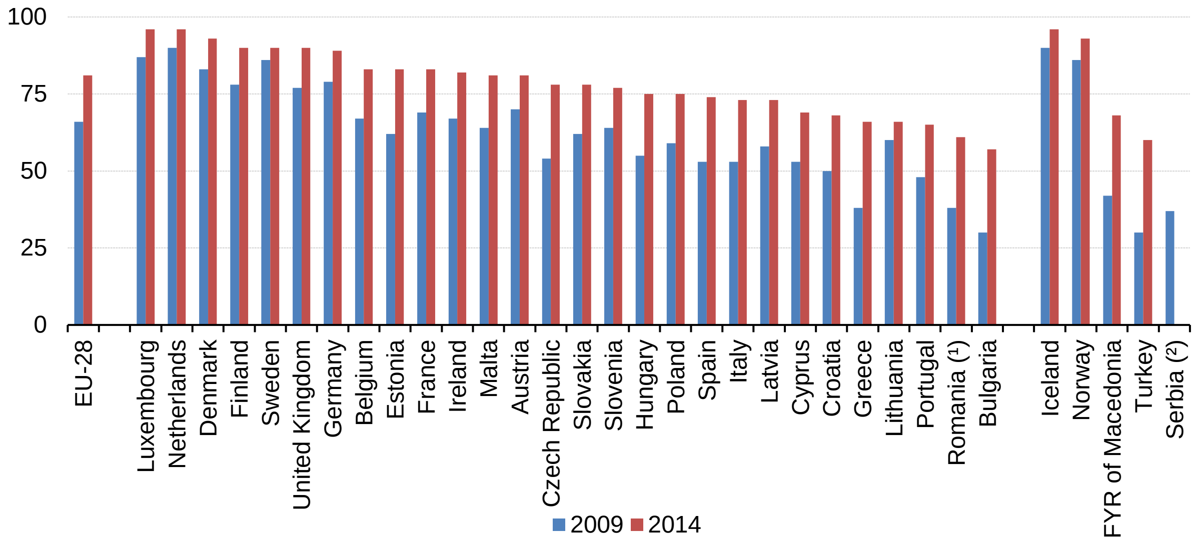

Figure 13. Frequency of internet use, 2014 (% of individuals aged 16 to 74)

Frequency of internet use in Lithuania (2014):

- Used in the last three months 72%
- At least once a week (but not every day) 12 %
- Daily use 57 %

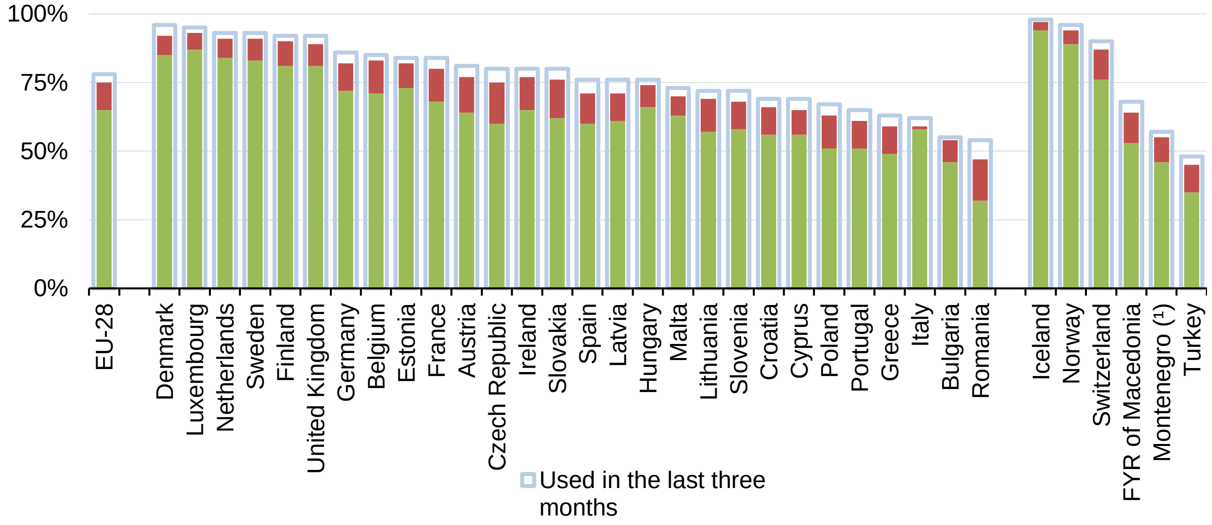

Figure 14. Frequency of internet use, 2014

Individuals who ordered goods or services over the internet for private use in the 12 months prior to the survey (% of individuals aged 16 to 74) in Lithuania:

- 20 % (2012)
- 26 % (2014)

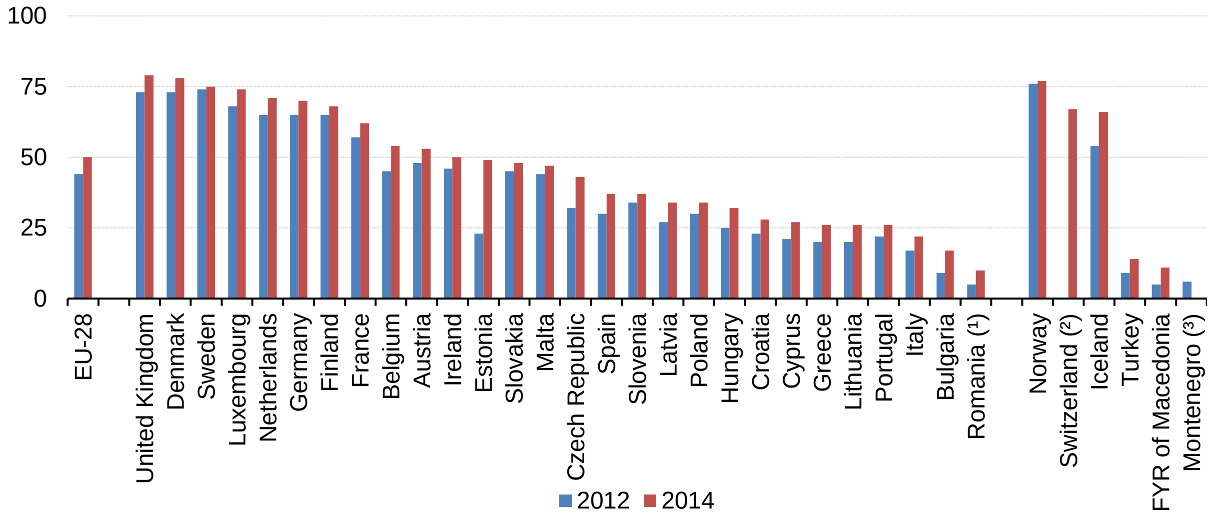

Figure 15. Individuals who ordered goods or services over the internet for private use in the 12 months prior to the survey, 2012 and 2014

4.2.10 Luxembourg

4.2.10.1 Use Case/system Name

Dossier de Soins Partagé (DSP) ('Dossier of Shared Care').

4.2.10.2 Policy and background

In October 2006, the government of Luxembourg launched the first eHealth action plan and in September 2010 decided to create a national Agency (Agence eSanté) in charge of implementing, deploying and operating a national e-Health Platform for the exchange and sharing of health data, as well as applications and health information systems at national level.

Agence eSanté created the national eHealth services platform, offering amongst others the national DSP. The eHealth platform is operational since January 2014. The DSP is currently being deployed in a pilot phase, under which so far ~23 000 DSP have been created. General deployment of DSP is expected during 2017.
For the pilot phase a particular category of patients was selected as base, i.e. **patients suffering from long-term conditions** and having signed a « referential doctor convention" with a particular GP or Paediatrician (named the "*médecin referent*", MR). To supervise and share health data, 2 documents have to be registered into the DSP:

- The patient summary: deposited by the MR on a regular basis
- The summary of health benefits: deposited yearly by the National Health Fund i.e. Social Security Institution.

Since September 2015, the pilot phase has been enlarged with **volunteer patients** (i.e. patients who have not signed a referential doctor convention but who wish to have a DSP and to that extent, introduce a (opt-in) formal request with AeS), representing currently ~500 patients.

However, each person affiliated to one of the social security funds (affiliation obtained via the Joint Social Security Centre) has the right to have a DSP.

It is a double-sided model with:

- Institutions having and keeping their own Electronic Medical Records with very detailed health information related to the patient.
- eSantéLux platform offering the DSP, centralising relevant electronic health records containing the patient's essential health related information that needs to be exchanged between healthcare professionals for the sake of the patient's continuity of care.

The electronic health record of the patient is stored in a national, centralised architecture. The DSP service does not replace the Electronic Medical Records held by the healthcare professionals (private persons or institutions), only relevant and pertinent medical information is shared by healthcare providers into the electronic health record of the patient.

4.2.10.3 Care process

The patient is required to activate his/her account within 30 days of receipt of Agence eSanté's notification letter. Should the patient not activate his account or not close it within those days, then the account will be automatically activated, at which point the DSP can be accessed and fed by patient and healthcare professionals.

4.2.10.4 Information

The patient has full control over his/her DSP and can:

- Manage, grant, restrict and refuse access to relevant healthcare professionals
- Render certain data inaccessible to certain healthcare professionals with the exception of his/her primary care physician and a hospital emergency department's healthcare professionals
- Grant permanent access to the DSP to a trusted medical circle; health professionals selected by the patient with whom he/she has a trusted relationship
- Designate other (non-health professional) people as a 'DSP assistant' who will get almost the same access rights to the DSP as the patient
- View who has accessed the DSP
- Close his/her DSP at any time
- Reopen his/her DSP within 10 years of its closure
- Record and disseminate information in the dedicated 'personal expression space
- Download/extract content from his/her electronic health record, at any time, as CDA documents
- Consult all data in his file, except data made temporarily inaccessible by the healthcare professional, including:
  - Discharge summary from a hospital
  - Patient summary
  - Prescriptions, Dispensation
  - Reports from Laboratories
  - Plan of care summary for home care
  - Radiology reports
  - Functional status assessment evaluation notes from social and care institutions

The project is in a pilot phase, concentrating on those patients affected by long term illnesses in the first instance and more recently expanded to include volunteer patients. Usage statistics on the number of DSP opened based on the limited pilot target group of 60,000 patients (50,000 patients with long-term illness + 10,000 volunteer patients), are as follows:

(60,000 target population)	2015		2016	
	%	Number	%	Number
New DSPs	34.90	20,941	3.00	1,803
Cumulative number of DSPs	34.90	20,941	37.90	22,744

Table 7. DSP and number of patients

4.2.10.5 Applications

As long as the DSP is open the data will not be deleted. After closing the DSP, the data will be deleted after 10 years or if the fate of the patient concerned is unknown, at the age of one hundred and fifteen years. In addition, in the event of the patient's death, the DSP shall be closed upon transmission of the date of death by the Social Security Entity or upon receipt by the Agency of a death certificate. In this case, the data in the EHR is deleted one year after closing.

A Web-based Portal is in place, which allows Patients to gain access, control and manage their EHR online: www.esante.lu. The identifier of the EHR is a non-public identifier, which is also mainly not known by the patient. Instead, the identification of a patient and his associated EHR is done by a mapping between other identifier and the EHR identifier via an MPI (Master Patient Index) system. Therefore mainly the unique national identifier of a person defined by the national person register is used, which is a 13-digit (11 relevant + 2 checksum digits) numeric identifier. This identifier is stored on the eID – Card and is also printed on the surface of the social security card.

4.2.10.6 Infrastructure

The EHR of the patient is stored in a national, centralized architecture. Relevant and pertinent medical information are shared by healthcare providers into the EHR of the patient. The access for the patient to his/her EHR is provided via a web-based portal application. For the Smartcard-based authentication of the patient, WS-Security is used and the IHE-XUA profile is supported.

The medical information of the EHR is stored in HL7 CDA documents. These documents, which have to respect our specifications, contain medical information in narrative text and also partly coded information. The main set of document types (like laboratory reports, radiology report etc.) are stored as CDA Level 1 documents, a structured Header containing a PDF-A/1 compliant document with the medical content. The structured Header as well as the Metadata needed for the XDS.b transactions, are based on commonly agreed Value-Sets (on national level), which are based on Code-systems from HL7, Loinc and others. Apart from these CDA L1 documents, work on fully structured documents (CDA L3) is on the way, using also ICD-10 and probably SNOMED-CT.

The portability of the data with the EHR of the patient is ensured by:

- The patient is able to download/extract content from his EHR (or the whole health record itself) at any time, as CDA documents
- Health providers can connect from within their primary application, to access/consult/retrieve/share information of/into the EHR of the patient

- Health providers can use the Health Provider Portal, which is provided as a service of the national eHealth Platform, to access/consult/retrieve/share information from/into an EHR of the patient

For enabling this, the vendors of the software used by health providers, had to integrate and to implement the Interoperability Framework provided by AeS. There is a certification procedure in place, which vendors have to follow, including tests to perform and evidences to provide, to receive the permission to access the platform services with their applications.

4.2.10.7 Digital Literacy

Patients who do not have the digital literacy skills to access the system can designate a DSP assistant. The Agence eSanté helpdesk offers technical support via phone, email or face-to-face appointments. Communication and awareness raising activities are organised by AeS, including regular information meetings with health professionals, local health associations and institutions and occasionally through local press.

4.2.11 Malta

4.2.11.1 Use Case/system Name

myHealth portal.

4.2.11.2 Policy and background

The concepts underpinning Malta's myHealth portal were first developed in the Ministry's internal eHealth strategy for the years 2009-2013. The policy aims of myHealth are twofold:

1) To provide citizens with direct access to personal health data collated from different health care providers, hence empowering patients to take control over their own health.
2) To reduce the communication gap between secondary healthcare (mainly provided by Government hospitals) and primary healthcare (mainly provided by private family doctors).

The MyHealth system does not create its own health data. It facilitates access to an aggregated copy of existing electronic health data stored in the various operational systems located in Government healthcare facilities i.e.

- Case Summaries are those recorded by doctors at Mater Dei Hospital in the Electronic Case Summary (ECS) system and copied to the myHealth database within 48 hours of the records being finalised by the discharging doctor.
- Lab Results are passed from the iSOFT Laboratory Information System (LIS) to the iSOFT Clinical Manager (iCM) system, while Medical Image Reports are those passed from the GE Centricity Radiology Information System (RIS) to iCM with 25 hours.
- The current Pharmacy of your Choice (POYC) medicines entitlement data is retrieved in real time.
- The clinic appointments are those recorded on the Patient Administration System used in Government hospitals and health centres.

4.2.11.3 Care process

All patients who have a valid national eID number and password can access the personal health data that is available through the myHealth portal.

Maltese citizens use their electronic Identity (eID) number to access their myHealth account (created automatically for them) to:

- Retrieve copies of their Electronic Case Summaries or investigation results (lab results and medical image reports)
- Check on upcoming appointments at hospital
- Check their current entitlement to medicines under the Government's "Pharmacy of your Choice" scheme
- Set up email notifications
- Grant authorisation to doctors (by 'linking' with them) and patient delegates to access their data

4.2.11.4 Information

Patients may view the data only, they may not add, modify, delete or hide the data. Patients' delegates access myHealth to help patients who are unable or unwilling to access the myHealth portal directly.

By the end of 2016 (Malta's total population is approximately 421,000):

- 7,866 patients had made use of the myHealth portal
- 11,158 patients used the offline consent functionality
- 181 doctors have accepted online links with patients through the portal from 19,024 patients

4.2.11.5 Applications

The myHealth portal (www.myHealth.gov.mt) was specifically designed to facilitate access by patients and their chosen doctors to personal health data over a secure Internet connection and has been in operation for 5 years.

4.2.11.6 Infrastructure

The myHealth portal was born out of close collaboration between the Information Management Unit of the Ministry for Health and the Malta IT agency (MITA), which is the Government's principal IT agency.

4.2.11.7 Digital Literacy

Patients may appoint a delegate if he or she lacks the knowledge, skills and competences to access MyHealth. In September 2015, an offline consent system was created through which patients could give their chosen doctors access to their personal health data through myHealth, even though they themselves didn't ever log into the myHealth portal.

4.2.12 Portugal

4.2.12.1 Use case/system name

Patient electronic health records in the North of the country.

4.2.12.2 Policy and background

The technological development of the Electronic Health Records (EHR) in Portugal started with the implementation of the integration mechanisms required for the assembly of all the relevant individual health records available throughout the databases of the primary and secondary healthcare providers. This information is then verified by the GP and, once validated, the EHR is activated.

4.2.12.3 Care process

In a first phase, only more general and critical information regarding the patient was available: episodes, allergies, diagnoses and laboratory data. Subsequently, it was sent to the discharge as well as made available in patient summary. The patient's active medication, chronic and non-chronic medication, was also made available.

Patients have access to their EHR by the Citizen Portal (Web Portal) and have to be registered in the National Health Service (NHS). It is intended to extend this functionality to all citizens (in all country and not only North).

At this moment there are almost 1.5 million Portuguese people (15% of the total population) who can have access to their EHR since they are registered in the Citizen Area.

Date	New Users	Total Users	Access with Password	Access with National Card
Sex, 2017/01/06	961	1428151	7392	107
Sáb, 2017/01/07	345	1428496	2977	57
Dom, 2017/01/08	474	1428970	4067	60
Seg, 2017/01/09	1169	1430139	11535	122
Ter, 2017/01/10	1246	1431385	10365	107
Qua, 2017/01/11	1312	1432697	10333	104
Qui, 2017/01/12	1265	1433962	9472	101
Sex, 2017/01/13	997	1434959	7536	89
Sáb, 2017/01/14	339	1435298	3625	61
Dom, 2017/01/15	403	1435701	3958	77
Seg, 2017/01/16	1288	1436989	10779	139
Ter, 2017/01/17	1278	1438267	9934	124
Qua, 2017/01/18	1194	1439461	9123	110
Qui, 2017/01/19	1179	1440640	8340	123
Sex, 2017/01/20	**931**	**1441571**	**7119**	**78**

Table 8. New and total users

4.2.12.4 Information

The patient currently has access to their allergies, diagnoses, chronic medication, summary of their medical history, as well as the vaccines and in the future surgical procedures.

The patient may add new information, for example allergies. But all new information requires validation from the GP. The patient may also hide all his/hers EHR. All patients with the NHS number are able to access this information. Patient information is only available to professionals if the patient authorizes it. Whenever the patient's information is accessed the patient has information of who accessed it, which institution and the date and time of access.

- There are 4.5 million PS automatically created, of which around 2500 PS were validated by the general practitioner.
- In numbers we are talking about:
    - 38 thousand allergies;
    - 25 million usual medications.
- Patients can:
    - Access to EHR
    - Hide all EHR
    - Add new information
    - Give authorization to Practitioner can access EHR

4.2.12.5 Applications

Patients can access via the portal web and via a mobile app and health professionals via the local clinical system by using their NHS patient id (a unique patient number with 9 digits). Data is retained for 20 years.

4.2.12.6 Infrastructure

Currently there are integrations with other systems, such as the Medical Electronic Prescription - EHR are available to check the patient's allergies and chronic medication (service integration). This information (EHR) is still migrated to the local databases in order to be accessible to the Citizen's family physicians.

4.2.12.7 Digital literacy

According to the ILS-PT Survey – a Portuguese application of the Health Literacy Survey in Europe (HLS-EU) – 51% of the Portuguese population have an excellent or sufficient health literacy level[56].

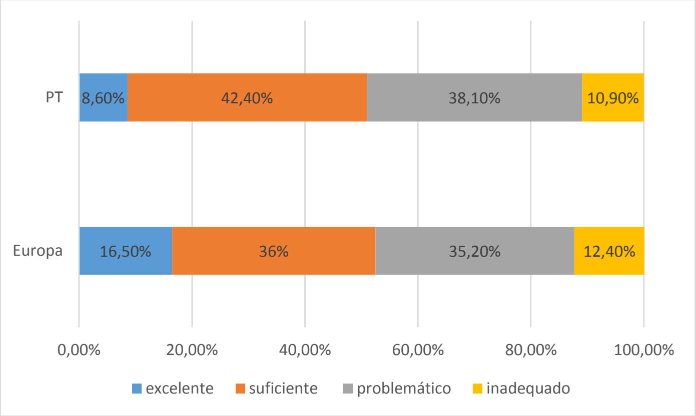

Figure 16. Health literacy levels

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[56] ILS-PT, 2014, CIES-IUL/ Fundação Calouste Gulbenkian e HLS-EU Consortium (2012)

A national survey identified 4 users profiles and reveals that almost 50% of the population use internet almost every day (15, 5% do it daily), that corresponds to the most qualified and younger peoples[57]. 1/5 of the Portuguese population (elderly people with lower incomes and educational resources) is the most vulnerable group to the internet use (the ILS-PT also reveals that this group is also the most vulnerable in the health literacy levels).

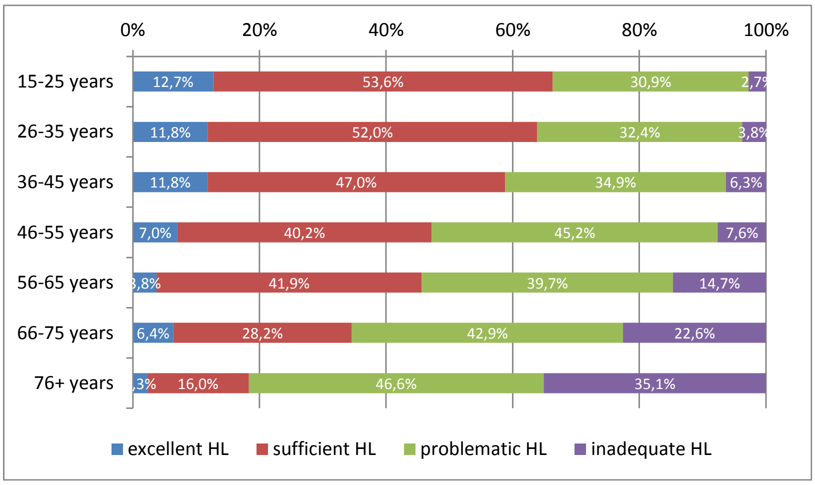

Figure 17. Health literacy levels by age

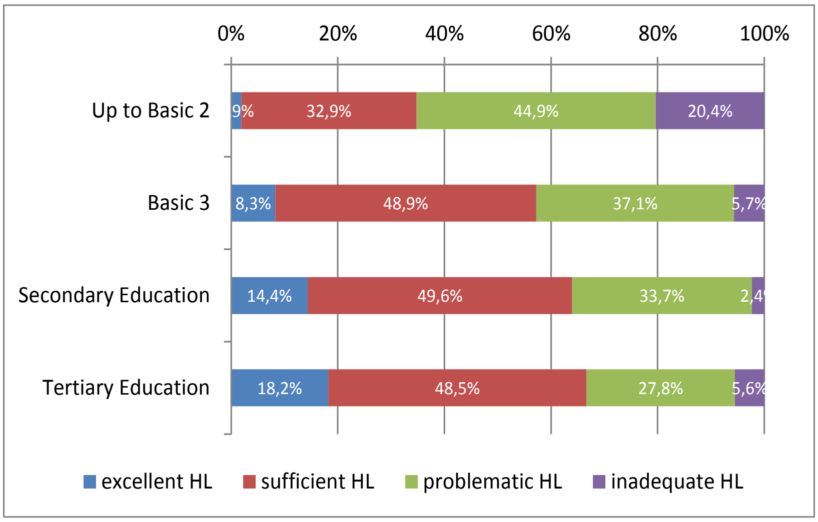

Figure 18. Health literacy level by education

To support and define the best way to get people attention and give helpful important health information, there is a group (composed by patients and citizen's associations, physicians and nurses) in SPMS that is working how to get people-centred health digital information.

4.2.13 Romania

4.2.13.1 Use case/system name

National Electronic Health Record (EHR) - Dosarul Electronic de Sanatate (DES).

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[57] Inquérito SER, 2010, CIES-IUL/ Fundação Calouste Gulbenkian

4.2.13.2 Policy and background

In February 2011, the CNAS (Romanian National Health Insurance House), initiated a 24-month project co-financed through the European Regional Development Fund and in partnership with the Ministry of Communication and Information Society, to develop and implement the EHR (CNAS, 2011). The system was finalized and launched as a pilot in 2014, and in November 2016 it became mandatory to be used nationally.

The National Health Strategy 2014-2020, within the general objective 6, strategic objective 6.1., states the importance of advancing the adoption of ITC into health services in Romania. It also describes the limited capacity for facilitating access of patients and the general population to relevant health information. Thus, the development of an Integrated ITC System in the Field of Public Health (SIISP), which would integrate multiple data sources and information, was articulated as a priority. The strategic actions laid out in the national strategy were ensuring standardization, integration and interoperability in the informatics system in the health sector; the development of the information technology needed to manage essential components of the health system (such as national registries, public acquisition systems); building and consolidating digital competencies in healthcare system workers; building and consolidating disease registries as well as outcome registries; consolidating and developing new ITC solutions regarding e-health projects (including EHR and the Electronic Prescription) (Ministry of Health, 2014).

The main institutions involved in the development of the EHR are the Ministry of Health (with responsibilities in overseeing the implementation of the system) and the National Health Insurance House – CNAS (with responsibilities of developing and implementing the EHR as part of the Health Insurance Information Platform). In addition, in terms of the use of the data, the two institutions are granted access to de-identified data for statistics, analyses and public policy purposes. In the development of the EHR, four private companies were also involved in the process, with the role of developing and implementing the technology to support the EHR (including the applications). The development contract was allocated to one company through a public acquisition process, which was supported and/or subcontracted the others in the process (CNAS, 2014).

4.2.13.3 Care process

Patients access the EHR using a dedicated portal (www.des-cnas.ro), only after authentication. In order to initiate the authentication process, patients need to obtain from a medical provider enrolled in the system, a security matrix. Using the security matrix, patients can configure an access password to be used for future logins.

The perspectives included in the EHR, based on the users defined in the legislation as having editing rights, are of medical professionals and of the patient (or legal representative). The medical professionals have editing right on all modules, except the "Medical antecedents declared by the patient" module, which can only be edited by the patient (or the legal representative).

4.2.13.4 Information

The EHR system records data into five modules:

Emergency summary data

Integrates data on diagnosed allergies and intolerances, prosthetics and other internal medical devices, transplants, medical procedures relevant for emergency situations, existence of an arteriovenous fistula, chronic diseases, hematologic conditions relevant for emergency situations, infectious diseases relevant for emergency situations, current medical treatments and recent hospital admissions.

Medical history

Comprises diagnosed allergies and intolerances, chronic diseases, medical history of diagnosed conditions (other than allergies and chronic), medical interventions and procedures, medical services and immunizations, pharmaceutical treatments administered within clinical studies.

Medical antecedents declared by the patient

Comprises family medical history, physiologic and pathologic antecedents, information about alcohol, tobacco, caffeine and drug consumption.

Medical documents

Contains information from medical observation charts for continuous and day hospitalizations, specialist consultation charts, referrals for clinical and paraclinical investigations, recommendations for home care, recommendations for medical devices, prescriptions issued by doctors and dispensed by pharmacies.

Personal data

Contains the patient's full name, date of birth, unique insurance code (CID), gender, age and blood type (Order no. 1123/849/2016, art.8).

Patients have viewing options for all modules.

From the platform, patients (or their legal representatives) can access and view the information in the health record, manage access policies to the record, manage treatment preferences (consent for donation, resuscitation, blood transfusions), as well as view the history of accessing events of the record (when it was accessed and what procedures were conducted during the event). The patient (or their legal representative) also has editing rights for one section of the record, the "Medical antecedents declared by the patient" module (EHR User Manual for Patients).

In order to receive initial access permission to an EHR, patients (or their legal representative) need an initial security matrix, which can be requested from any medical provider who uses the system. The security matrix is a table with eight lines and eight columns, and contains a code randomly generated by the system. Patients (or their legal representative) need to provide an identification document, and based on that, the healthcare provider can immediately generate and print a security matrix, which is valid for three days. Using this security matrix, patients can generate a password using the dedicated portal, and subsequently access the EHR. If the security matrix expires (it is not used to configure a password for 3 days), the patient needs to request a new one from a healthcare provider. The number of security matrixes which can be generated for one patient is not limited, however only one matrix (the one last generated) is valid at a time. The matrix is offered to the patient in a print form (one copy). Patients need to sign that they have received it, and fill in a declaration and consent for use of medical information in the EHR system. By signing this document, patients acknowledge that they agree with the terms and conditions of access of data and medical information specified in H.G. 34/2015 which regulates the use of the EHR.

According to decision 34/2015, data is retained in the system for as long as the patient is alive. Upon death, the EHR of the patient is archived in the DES system. De-identified data can be further used, except for the case where a legal disposition has been issued against this practice. The decision also specifies that at the end of the archiving period the data contained in the EHR is destroyed; however the document does not specify the length of this archiving period.

There is no information available, from governmental sources, regarding the use of the system. However, a press release published on the website of the developer of the EHR system reports that by December 2016, 8 million Romanians have an active EHR and 10.092 family physicians and 295 hospitals have connected to the system and have submitted medical information (UTI, 2015).

4.2.13.5 Applications

For both groups (healthcare providers and patients) access to the system is granted with the online portal, however through different sections of the web application. Healthcare providers also have the option of integrating the system in their existing data management systems, and communicate with the platform via these applications.

4.2.13.6 Infrastructure

The Information Technology Platform for Health Insurance comprises the EHR, the Unique Integrated Information System (SIUI), the national health insurance card system, and the national system for electronic prescriptions. The CNAS is responsible with integrating the systems as well as with other existing e-Health systems, in order to efficiently use information for the development of health policies (Decision 34/2015, Background Note).

4.2.13.7 Digital literacy

In 2015, Romania had the lowest percentage of population who used the internet on a regular basis (52%) in the EU; in addition, 32% of the population reported to have never used the internet, a percentage which is significantly higher than the EU average (16%) (European Commission, 2016). Furthermore, the 2014 The Digital Agenda Strategy for Romania, sets strategic goals in improving digital literacy and internet usage. Its associated indicators are to increase by 2020 the percentage of individuals using the internet regularly to 60%, increase the percentage of individuals from disadvantaged categories using the internet to 45%, and to decrease the percentage of individuals who have never used the internet to 30% (Ministry for Information Society Romania, 2015). However, even if these objectives would be attained by 2020, a significant proportion of Romanians would still not be able to independently use their EHR.

Starting with November 2016, the EHR is mandatory to be used by all healthcare providers. Thus, all patients technically have access to their electronic health record if they initiate the process with a healthcare provider.

4.2.14 Slovakia

4.2.14.1 Use Case/system Name

National Health Portal.

4.2.14.2 Policy and background

Slovakia approved the strategic document proposing a national eHealth system in 2008. The Ministry of Health of the Slovak republic (MoH SR) in cooperation with the National Centre of Health Information (NCZI) are responsible for advancing the eHealth agenda of Slovakia. Work to build the Slovakian national system has been ongoing since 2010 in a phased basis:

Phase 1.
- Patient summary – PS plus HER + so called EZKO,
- Electronic prescription,
- National health portal.

Phase 2.
- Electronic allocations,
- EHealth legislation.

Phase 3.
- Cross-border interoperability and other services.

The National Health Portal is being developed by the Slovakian National Centre of Health Information as part of phase 1 of the national eHealth programme, project ESO1. The National Health Portal is currently at pilot stage.

4.2.14.3 Care process and information

No information available.

4.2.14.4 Applications

No information available.

4.2.14.5 Infrastructure

No information available.

4.2.14.6 Digital Literacy

In NCZI, a team is responsible for branding of National health Information system by creating for example information and promotional materials and articles.

4.2.15 Spain

14.2.15.1 Use case/system name

Access of patients from almost all Spanish Regions.

14.2.15.2 Policy and background

There are different types of projects:
- At regional level where the information showed is decided by the regional government.
- At national level based on the legal framework where the conditions of the services and the documents exchanged have been defined by a national working group. This is the use

case for this report. In this use case, a patient has a unique common access to the clinical documentation generated in different regions.

The national project started in 2008. A national body governs de National Healthcare Service (Consejo Interterritorial del Sistema Nacional de Salud) where all regions and the ministry of health are represented. In this national body agreements were made to launch the project and to approve its definition. This body also supervises the continuity of the project.

Nowadays, this service is provided by all Spanish regions but 1. This region has developed a regional project that is now being integrated in the national project.

There is collaboration among the different regions (Regional Healthcare Services) and the central government (Ministry of Health) to set up a national network to exchange documents and give access to the patient to their EHR.

14.2.15.3 Care process

Patients can access their EHR at any time providing that they have an eID and internet access.

Nowadays, only patients with eID can access the documents, the role of the guardian has not yet been accomplished. Potentially, 35.726.423 patients have access.

14.2.15.4 Information

As it is stated in the Real Order 1093/2010 there are main types of documents that can be exchanged: Patient Summary, clinical discharge record, image reports, laboratory reports, nursing reports and emergency reports. In addition, they can also see information related to the access of a HCP to their clinical data. The information provided is the date of access, the type of document the HCP has seen and PoC.

Patients have the ability to access all clinical information that is available in the system. In addition, they can hide the documents they don’t want to be exchanged in the system. The patient can make a complaint if he/she doesn’t agree with the access to one of their documents. The Regional Healthcare Services set up the applications to provide the access.

14.2.15.4 Applications

At this moment the data is retained forever. Legally it has to be retained at least 10 years.

It’s a web-based application. Some regions have developed their own application and most regions are using a reference model application developed by the Minister of Health.

Different types of eID are being used, for example a national eID (DNI) and eID electronic certificates. Some regions have an electronic certificate associated to their healthcare card. All of them have to allow a substantial identification from the Directive perspective. Within the system patients are identified with the healthcare regional number and the region where they are adhered. In addition, they can be identified with the national healthcare number.

14.2.15.5 Infrastructure

National Central Node is communicated with the Regional Nodes via web services. In addition, Regional Nodes are communicated with their own patient registers to obtain the national healthcare number, and with their EHR systems to provide the documents. Each region has its own implementation design, but mostly is based in web-services. Central node is also communicated to the National Patient Register and to the eHNCP.

14.2.15.6 Digital literacy

No information available.

14.2.16 Sweden

14.2.16.1 Use case/system name

Nationell patientöversikt (NPÖ) and Journalen.

14.2.16.2 Policy and background

The National Patient Overview (Nationell patientöversikt – NPÖ) and Swedish Medical Records (Journalen) are both national projects launched by INERA, a private company owned by county councils. The idea with NPÖ is that health care professional should be able to directly access patient's medical records that are kept by other health care providers. Journalen (Medical Records) on the other hand, allows the general public to read information from their own medical records online. The general public accesses this service through Healthcare Guide 1177's e-services.

All of the 21 county councils' health care providers in Sweden have implemented NPO at this point and 18 have implemented Journalen (3 county councils' health care providers will implement Journalen during this year). The objective is to have full production in all 21 counties by 2020.

Traditionally the health and medical records have been kept regionally by the different health care providers, which are generally the county councils in Sweden. All health care providers (e.g. county council and others) are responsible for their own patient journal system(s). By 2012 all county councils had fully implemented EHR in hospitals, psychiatry and primary care. There is, though, no common national database for patient journals. In order to increase cooperation and allow care providers to access patients' records stored at another provider, the National Patient Overview (Nationell patientöversikt – NPÖ) was initiated several years ago.

14.2.16.3 Care process

The National Patient Overview is accessed via a web interface and requires a login with strong authentication (using the SITHS cards for caregivers). All healthcare and social services staff who have access to patient information must be listed in the national electronic catalogue service that is used to clarify who works for which provider and what is the function of each employee.

Patient information is available at all times which have improved the patient safety, and new information that enters the system is immediately available.

Journalen is accessed via Healthcare Guide 1177's e-services and requires a login with strong authentication (using the SITHS cards for caregivers) with BankID or eID. Not all information is provided in the medical records online, there are some restricted areas for instance medical records for patients whom are victims of abuse and for the time being records from psychiatry is allowed in 6 county councils health care providers. There is also a restriction of age; children of 13-18 years old do not have access.

The NPO is deployed nationally in the 21 county councils of Sweden. The Journalen is deployed nationally in 18 county councils of Sweden. Approximately 20 000 patients log on every day, there are 1 million users as of today. Approximately 20 000 patients log on to Journalen every day, there are 1 million users as of today.

14.2.16.4 Information

The following patient information is collected, stored within the system:

- Patient: personal identification, next-of-kin, possible need of interpreting services, etc.
- Attention and alert signals: hypersensitivity to drugs, severe illness/on-going treatment, healthcare restrictions, infectious diseases, out-of-structure attention signal
- Diagnoses
- Care services: primary care, specialist care, home help, home care, disability services, special residential needs
- Medication: pharmaceuticals prescribed by the care provider, dispensed at Swedish pharmacy
- Care contacts: historical and future contacts (hospital, primary care unit or private)
- Care documents: final report, admittance report, daily report, primary care notes, primary care summary, specialist notes, other documents
- Status: PADL, functional disabilities
- Care plans: various type of care plans for the patient
- Examination results: clinical chemistry, microbiology, ECG with sound and pictures over a link, image diagnostics with sound and pictures over a link, consultations

The National Patient Summary shows whether the patient has consented to making information accessible. The patient can block information that he or she does not wish another care unit to see. Patient can access log details, specify contents to be logged, and specify the duration for keeping the logs. In the long term, the National Patient Overview and Journalen (Medical Records) will also make it easier for a patient to gain greater insight into, and influence over, his or her own care.

Children between the ages of 13-18 are not allowed to use Journalen (Medical Records), their custodian can access their medical records until the child turns 12 years old.

14.2.16.5 Applications

Healthcare data is owned by the Counties. NPÖ uses the HealthShare product of Intersystems that enables decentralized storage of data and keeps data as it is with healthcare organization, enabling the use of already existing systems. It provides connectivity among these systems for data exchange via the national network. NPÖ has adapted international standards for data structure, content, and communication. The general public accesses Journalen through Healthcare Guide 1177's e-services. Medical Records uses the same technical connections to the Service Platform as the National Patient Overview service.

14.2.16.6 Infrastructure

In 2012, Orebro County Council and Tieto worked together to develop a mobile platform for anytime, anywhere access to patient information available through NPÖ. NPÖ and Journalen use the same technical connections to the Service Platform.

14.2.16.7 Digital literacy

Journalen allows the patient to give his or her consent to another relative or representative to read the information in the medical records online, therefore if there are any digital literacy it becomes a non-issue.

14.2.17 The Netherlands

14.2.17.1 Use case/system name

Regional patient portals, LSP, MedMij.

14.2.17.2 Policy and background

The coordination of the implementation of the national EHR was the responsibility of the Ministry of Health, but after rejection of the EHR law in 2011 by the First Chamber, a new EHR was coordinated by the 'Vereniging van Zorgaanbieders voor Zorgcommunicatie' (vZVZ) in the form of the 'Landelijk Schakelpunt' (LSP) subsidized by the healthcare insurances. The main difference between both EHR's was the change from a national system to regional systems[58].

In 2013, vZVZ edited the structure of LSP and documented this in an agreement between various parties in healthcare. The LSP is divided in 44 regions based on partnerships. Each region manages the LSP for his own region and supports the implementation of the EHR. Within each region general practitioners, (hospital) pharmacists and specialists can share patient information when the patient has given his permission. Hospitals can exchange information between regions. On national level there is not a central database with saved patient information.

Online access to health records for patients is one of the three objectives to be achieved in 2020 that were formulated by the Minister of Health, Welfare and Sport (VWS) in 2014. These objectives were announced in the Letter to Parliament on eHealth and healthcare improvement (Minister and State Secretary of Health, Welfare and Sport 2014). The objective for online patient access is as follows:

"Within 5 years 80% of the chronically ill have access to their own medical records. For the other patients this is 40%." (Minister Schippers & Staatssecretaris van Rijn, 2014).

14.2.17.3 Care process

Because of the many regional practices, there are different policies in place. By creating standards it is possible to connect the different EHRs. In addition, guidelines are created for structured exchange of information between GPs and other health care providers.

To monitor the objectives created by the ministry, Nictiz publishes the eHealth monitor each year. A part of the brief outline of the 2016 monitor is as follows:

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[58] https://www.vzvz.nl/page/Zorgconsument/Het-LSP

Medical specialists are catching up on the use of electronic records. By now, 86% keeps electronic records. They are however not yet fully satisfied with the electronic records. Nearly half of medical specialists state that the time they spend registering information in the records is not in line with what they gain by using it. Proper electronic record-keeping is a first (but not the only) precondition for electronic information exchange. General practitioners can exchange information with other parties, such as pharmacies and laboratories, electronically. However, they have barely succeeded in doing so with home care organizations, nursing homes, the district nurses or with services for social support to municipalities. Medical specialists are not able to share all electronic information with other hospitals, pharmacies and laboratories[59].

Online access for patients is slowly but surely on the rise. There is a gradual increase in the options doctors offer for this, including online access to medication details. So far, it is not yet common practice for patients to add information to their own record:

- Approximately 10% of participants with chronic conditions have online access to their medical records at one or more caregivers.
- Since 2014, patients can access at an increasingly higher percentage diagnosis results from GP's (from 8% in 2014 to 15% in 2016) and in the ePrescription (12% in 2014 to 22% in 2016).
- 22% of the participating patients can access online prescribed medications from their GP's in 2016.
- 4% of the patients can add notes or measured health values to their medical records at medical specialists and 8% can do that at GP's[60].

Luxemburg & Willems (2016) indicated that the number of hospitals offering a patient portal is three trippled in one year to 23% in 2016. Nictiz (2016) confirms that 25% of the hospitals are offering a patient portal in 2016[61].

14.2.17.4 Information

To give not only professionals, but also the patient access to and coordination on their own patient information, the idea of personal health record (PHR) is initiated which is now coordinated under the program MedMij (Patiëntenfederatie Nederland, 2015; Informatieberaad, 2015). At this moment the MedMij program is active to ensure that any citizen/patient who wishes to collect and use health information from many sources in a secure online environment is able to do so. MedMij establishes rules for the exchange and use of health data. Products and organizations who wishes to be part of the MedMij environment must adhere to these rules, so that they share and secure health information and patients can use their products safely[62].

In addition, in September 2016 the government announced an Acceleration Program information exchange between patient and professional (VIPP). The goal of this program is that all Dutch citizens have access to their own medical records in 2020. The program runs until the end of 2019 and has the following objectives[63][64]:

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[59] Summary: a brief outline of the 2016 eHealth monitor
[60] Summary: a brief outline of the 2016 eHealth monitor
[61] Onderzoek M&I partners/ www.hoeonlineisjouwziekenhuis.nl
[62] http://www.medmij.nl/
[63] https://www.nvz-ziekenhuizen.nl/onderwerpen/vipp-programma

Patient and information:

- Healthcare institutions can provide the patient on July 1, 2018 minimum download of medical data;
- Each care facility has a secure patient portal on December 31, 2019 and/or a link to a Personal Health environment in which the healthcare organization can upload standardized medical information for the patient;
- Realizing development (additional step) before the end of the grant date.

Patient and medication:

- Each healthcare organization can consult a digital date list of medication (providing information) as part of the medication process in the inpatient and outpatient setting by July 1, 2018;
- Each healthcare organization can offer medication prescriptions digitally as a notice and / or prescription on December 31, 2019;
- Each healthcare organization can provide a standardized topical medication list (including medication appointments) digitally to the patient at discharge according to current medications Directive on December 31, 2019.

Every citizen (from the age of 12) has the right to access their personal health data. For every child under 12 years, its parents are allowed to access the information. Family members can access the patients' health data when this patient has given permission. When certain information is incorrect, this can be adjusted. Personal health data is being kept for 15 years, but every citizen can ask to delete this data before these 15 years or keep it longer than 15 years. The healthcare professional has the right to ignore this request. It is also possible to request changes to the health data, but this request can be ignored by the healthcare professional.

In addition, every citizen can access specific information about health costs and what kind of care is consumed during the year at their health insurance company. When care is consumed by a citizen, they need to pay the health insurance company. By accessing their online environment at their insurance company they can see their invoice(s) and consumed care[65].

14.2.17.5 Applications

Because there are different EHR's and PHR's in place, there are several development projects that try to improve the common structures, coding, etc. such as:

- The multiannual program 'Registratie aan de Bron' of the Dutch Federation of University Medical Centres and Nictiz that creates structure by definition and maintenance of Care Information Building Blocks, and realizes clarity and uniqueness of commitment in the primary process;
- The terminology centre Nictiz, which mainly works on promoting unity of language, unified coding, etc.

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[64] https://www.rijksoverheid.nl/onderwerpen/subsidies-vws/inhoud/beleidskader-subsidiering-versnellingsprogramma-informatie-uitwisseling-patient-en-professional

[65] https://www.consumentenbond.nl/zorgverzekering/zorgkosten-checken

14.2.17.6 Infrastructure

For healthcare professionals to get access to LSP, they need to identify by their unique healthcare identifier pass and pin code. The patient can give permission for healthcare professionals to enter their health data on the website https://www.ikgeeftoestemming.nl/ or by writing to healthcare professionals by opt-in.

At this moment, patients do not have access to the national exchanged information by healthcare professionals via the internet, because of security issues. Patients can authenticate themselves by DigiD, but this level of security is not enough to give online access to medical patient data. It is possible for citizen to access the overview of healthcare providers who asked permission to see their health data through the website of VZVZ or get notifications by email when a healthcare provider requested patient information. This is done by their identical information, i.e. their citizen service number.

14.2.17.7 Digital literacy

In March 2017 a motion on digital skills in care has passed, because of the increased use of digital support in care and the need to increase the necessary digital skills for caregivers and patients. To support, for example, the elderly and illiterate different skills are required from current and future health care professionals. The Government is requested, in cooperation with the Ministries of Interior, Social Affairs, Health, Economic Affairs and Education, to establish a long-term objective leading to an increased digital literacy in The Netherlands[66].

14.2.18 United Kingdom

14.2.18.1 Use Case/system Name

National GP EHR Project. (England)

14.2.18.2 Policy and background

Healthcare in the UK is provided in each home country; England, Northern Ireland, Scotland and Wales each manage their own healthcare systems. As a result, variations in policy and priorities exist.

PatientView - Renal[67] is an example of a patient-facing system that is in operation in all four regions, catering specifically for kidney patients. It is run on a non-profit basis with support initially in 2004 from the Department of Health in England, Scotland and Wales and since then with EU and other project funds.

Online GP services are available in both England and Wales.

A snapshot of each region is provided here before going into the English National GP EHR project in more detail.

Northern Ireland

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[66] https://ecp.nl/actueel/kamer-neemt-motie-digivaardig-zorg-aan/

[67] http://rixg.org/patientview2/howto/where/

The Northern Ireland Department of Health is responsible for healthcare in Northern Ireland. A statutory organisation called the Health and Social Care Board (HSCB)[68] commissions health and social care services. E-Health and External Collaboration is a business unit within the HSCB. The eHealth and Care Strategy[69] (2016 – 2020), developed by the HSCB, includes mention of new services such as "booking of GP appointment and ordering repeat prescriptions online and a web portal to help people self-care and give them access to their own personal health records.[70]" Since 2013, the Northern Ireland Electronic Care Record (NIECR) computer system holds electronic healthcare information on patients including:

- Lab tests
- x-rays
- Referrals
- Investigation requests

Current plans include the development of online resources to allow patients to interact with the Health and Social Care system including providing patient access to their own electronic health records. The Electronic Health and Care Record (EHCR) programme71 is currently preparing a business case to seek approval to proceed to procurement and a series of public engagement 'discovery days' were held in February 2017 to raise awareness of the project.

Scotland

NHS Scotland's most recent eHealth Strategy covers the period 2014 – 2017. Development on a new Digital Health and Social Care Strategy 2017 – 2022 has begun.
The Emergency Care Summary (ECS)[72] holds demographic, allergy and medication information for 5.5 million patients in Scotland.
Patient platforms for chronic conditions such as PatientView - Renal[73] and MyDiabetesMyWay provide digital tools for patients with conditions which best lend themselves to effective self-management and co-production with clinicians.

Wales

In Wales a national Individual Health Record[74] (IHR) was implemented in 2005 for use in out-of-hours and emergency care settings. The IHR is an extract of a patient's GP record. NHS Wales in their strategy document "Informed Health and Care: A Digital Health and Social Care Strategy for Wales[75]" commited to providing citizens with online access to their information held in the GP practice electronic system by April 2017. The MyHealth Online portal currently gives patients the opportunity to:

- book GP appointments
- order repeat prescriptions

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[68] http://www.hscboard.hscni.net/our-work/ehealth-and-external-collaboration/

[69] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/interactive-ehealth-strategy.pdf

[70] https://www.health-ni.gov.uk/publications/ehealth-and-care-strategy

[71] http://www.hscboard.hscni.net/our-work/ehealth-and-external-collaboration/electronic-health-and-care-record-discovery-days-2017/

[72] http://www.nisg.scot.nhs.uk/currently-supporting/emergency-care-summary

[73] http://www.ehealth.nhs.scot/case-studies/ecs-for-patient-view-renal-patients-take-the-lead-to-reduce-errors-in-medicine-prescriptions/

[74] http://www.gprecord.wales.nhs.uk/home

[75] http://gov.wales/docs/dhss/publications/151215reporten.pdf

- update their general details such as change of address

England

In England, the National Health Service (NHS) Summary Care Record[76] (SCR) was first introduced nationally in 2008. The NHS 'Five Year Forward'[77] strategy document published in 2014 states that within five years citizens will be able to access their medical and care records (including in social care contexts) and share them with carer or others they choose.

The National Information Board[78] works with the Department of Health to develop strategic priorities for data and technology. Their 'Personalised Health and Care 2020[79]' framework document (Nov 2014) set the targets of providing patients with access to GP records through approved apps by 2015 followed by access to all health data held by hospitals, community, mental health and social care services by 2018[80]. The National GP project described here came out of this framework document.

Case study: National GP EHR Project (England)

GP systems in England have been computerised for approximately 10 years. The functionality to give patients access to their electronic health record has been there for some years but not 'switched on'. The National GP project was established to give patients access initially to transactional services i.e. appointments and repeat prescriptions and they can also view parts of their electronic health record. The project has been underway for 3 years – these first three years have been about encouraging use of the system. Years 1 and 2 focused on the GPs using the system and year 3 has broadened the project out to patients. Teams in individual practices has been bringing patients into the system.

The aim is to reach 10% of patients registered to use transactional services by April 2017. There's no target currently for patients viewing their health record data.

14.2.18.3 Care process and information

Patients register online to use the system through the NHS Choices[81] (the health information services site of the English NHS), followed by a verification process. The National Patient Demographic Service gives every patient in England a NHS number. This is the unique identifier for a patient and is separate to a social security number. Patients use their NHS number to access the system. Patients can make appointments and order repeat prescriptions. Patients cannot send messages, make comments or upload information. They have view permission only, no edit or update permissions.

The system offers the ability for patients to view parts of their GP health record but this is not the current priority. In terms of the health record there are three levels of data:

1st level = core data = medication, allergies, adverse reactions

2nd level = coded clinician entries, results etc.

3rd level = free text and documents

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[76] https://digital.nhs.uk/summary-care-records
[77] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
[78] https://www.gov.uk/government/organisations/national-information-board
[79] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf
[80] https://www.england.nhs.uk/2014/11/leaders-transform/
[81] http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/gp-online-services.aspx

Data would be most commonly viewed at the first level and far less often at the second and third levels.

14.2.18.4 Applications

There are 4 main suppliers of GP health record systems. Each of these suppliers were encouraged to provide a patient portal (if they didn't already). There is no one consolidated patient portal in this case. NHS policy is be to approve patient-facing applications rather than build a patient portal themselves. The online GP systems currently in use are:

- EMIS – Patient Access
- INPS – Patient Services
- Microtest – The Waiting Room
- PAERS – i-Patient (for GP practices using EMIS)
- TPP – SystmOnline

14.2.18.5 Infrastructure

See applications section above.

14.2.18.6 Digital Literacy

There is no specific digital literacy training for users of online GP services. Barclays Bank run a 'Digital Eagles' initiative which provides training for citizens on using online transactional services. The skills would be applicable to this project but it is a more general digital literacy initiative. Teams in individual GP practices are responsible for promoting the system and supporting their own patients in its use. This will vary from practice to practice.

15 References

Referenced documents Romania:

CNAS (2011). Press release: Launching the project "Integrated informatics system for the Electronic Health Record", available online at http://www.cnas.ro/media/postFiles/post-82.pdf [accessed December 10th 2016).

CNAS (2014) Electronic Health Record: general Information on the project, available online at http://www.cnas.ro/media/pageFiles/Informatii%20generale%20proiect%20-%20Dosarul%20Electronic%20de%20Sanatate.pdf [accessed January 10th 2017]

EHR User Manual for Patients, available online at https://ehr.des-cnas.ro/cnasportalext/manual/Manual%20DES%20pacienti%20v2_1.pdf [accessed January 7th 2017]

European Commission (2016). Working document of the commission services – Romania's Country Report for 2016, SWD (2016) 91 Final, Brussels, 26.02.2016, available online at http://ec.europa.eu/europe2020/pdf/csr2016/cr2016_romania_ro.pdf [accessed January 5th 2017].

Ministry of Health Romania (2015). National Health Strategy 2014-2020 "Health for Prosperity": Annual report concerning the state of implementation 2015. Available online at http://www.ms.ro/wp-content/uploads/2016/09/Raport-Implementare-SNS-2015.pdf [accessed December 13th 2016]

Ministry of Health Romania (2014). National Health Strategy 2014-2020 "Health for Prosperity". Available online at http://www.ms.ro/2016/10/04/8008/ [accessed December 13th 2016]

Ministry for Information Society Romania (2015). National Strategy concerning the Digital Agenda for Romania 2020, available online at http://ec.europa.eu/epale/sites/epale/files/strategia-nationala-agenda-digitala-pentru-romania-20202c-20-feb.2015.pdf [accessed December 7th 2016]

UTI (2015). Currently, more than 8 million Romanians are enrolled in the Electronic Health Record, available online at http://ro.uti.eu.com/ [accessed December 13th 2016]

16 Annexes

Annex 1 – Desk Research Template

Please use this template *as a guide* to do a case study where patients have access to their electronic records in your country – the *'use case'* referred to throughout this template.

- The use case could relate to a single specialised area e.g. In Ireland the MN-CMS Project is the design and implementation of an electronic health record for all women and babies in maternity services in Ireland which has just gone live in one maternity hospital.
- Alternatively, if patient electronic health records exist on a regional or national basis then that should be the case study.

The purpose is to capture the *current state of play* so focus on facts, not future strategies or plans. You may use multiple documents as sources of information in your research such as policy documents, eHealth strategies/plans, monitoring documents, project reports etc., and reference appropriately. In completing this template please expand on the topics and questions raised. Every country is different so if there is information relevant to Task 7.5 Deliverable 1, but not captured here, then please add it. If you cannot find information on a particular question from existing documents/policies/papers please indicate how or from whom the answer might be obtained and please include any relevant contacts that may be useful in future task activities.

Country	
Use Case	

Level 1:	**Legal and Regulatory**

1. What legislation and/or regulatory guidelines apply to the use case? (e.g. What patient rights apply to the use case?)

Level 2:	**Policy**

1. Please give a brief background on the history and development of patient access to electronic health records as is relevant to the use case.
2. Is there a policy that applies to the use case, specifically covering patient access to electronic health records?
3. Are there any specific objectives regarding patient access to electronic health records within the use case? If yes, what are they?
4. What kind of collaborations are there between organizations and/or government?
5. What kind of agreements and contracts exist between these organizations?

Level 3:	**Care Process**

1. What kind of care processes in relation to patients accessing electronic health records are involved in this use case? (e.g. How do patients access their electronic health record?)

2. What kind of perspectives are involved in the use case such as the patient, the guardian, care professionals, government etc.?
3. For each perspective, what do these processes look like?
4. How many patients have access to their electronic health records in the use case?
5. Are there any usage statistics relevant to the use case?

Level 4: Information

1. What kind of information do patients see if they access their electronic health records?
2. For the use case, what permissions are granted to patients in relation to accessing their electronic health records? (e.g. the ability to access, modify, delete, hide all or parts of their electronic health records)
3. What permissions are granted to care professionals in relation to a patient's electronic health records in the use case?
4. Who is responsible for granting access permissions to patients in the use case?
5. Who has the power to give consent? (e.g. Is there functionality that allows a patient to give authorisation to another within the use case?)
6. Can a patient see how accesses their electronic health records in relation to the use case?

Level 5: Applications

1. How long is the data retained in the system?
2. In relation to the use case, what kind of system(s) is used to facilitate patient access to their electronic health records?
3. What kind of software is used to facilitate patient access to their electronic health records?
4. What format does the patient health identifier(s) of the electronic health record in the use case take e.g. based on a national id or social security id, or other code or character set?

Level 6: Infrastructure

1. Is there integration between the use case technical infrastructure and any other technical infrastructure in your country? (e.g. Does the use case system communicate with any other systems at the database level?)
2. If yes, how?

Additional Aspect: Digital Literacy

1. Is there data on the % of the population who have the digital literacy skills necessary to access their electronic health record in the use case or in general? (By relevant Demographic/Geographic/Education and Experience breakdown if available)
2. Is there a recognised deficit in digital literacy skills among citizens – backed up by statistical evidence?
3. How is this being addressed in relation to patient's ability to access their electronic health record in the use case or in general?

Annex 2 – Legislation

The following details relevant legislation that applies to patient access to his/her electronic health record information.

Austria	The most important legal basis is the Austrian Health Telematics Act 2012. In addition to national aspects it covers a profound basis to participate in the peer-to-peer network for the cross border exchange of health information. The work activities following the CEF participation[82] have started in January 2017 and are implementing the main legal, organisational, semantic and technical guidelines and specifications, namely: - EU General Data Protection Regulation - for organisations and for individuals[83] - Directive 2011/24/EU on the application of patients' rights in cross-border healthcare[84] - EU "eIDAS Regulation" - No 910/2014 on electronic identification and trust services for electronic transactions in the internal market[85] - Guidelines on an Organisational Framework for eHealth National Contact Point[86] - Governance model for the eHealth Digital Service Infrastructure during the CEF funding[87] - General Guideline cross-border exchange of health data[88] - ePrescription Guideline cross-border exchange of health data[89] - Patient Summary guideline cross-border exchange of health data[90] - Legal Agreement (as soon as there is a formal endorsement by the eHN) - The EXPAND revision of organisational, semantic and technical requirements and specifications[91]. - The Austrian Electronic Health Records Act – EHRA: https://www.ris.bka.gv.at/Dokumente/Erv/ERV_2012_1_111/ERV_2012_1_111.html
Belgium	<u>**Legislation**</u> Law of 22 August 2002 on the rights of the patient (hereafter referred to as 'Law 2002'): §1. The patient is, towards the professional practitioner, entitled to a carefully tracked and safely stored patient record. Upon request of the patient, the professional practitioner shall add documents provided by the patient into the patient file. §2. The patient has the right to access his own patient record.

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[82] https://ec.europa.eu/cefdigital/wiki/display/CEFDIGITAL/eHealth
[83] http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679
[84] http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1487684996418&uri=CELEX:32011L0024
[85] http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1487685272857&uri=CELEX:32014R0910
[86] http://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20151123_co01_en.pdf
[87] http://ec.europa.eu/health//sites/health/files/ehealth/docs/ev_20151123_co02_en.pdf
[88] http://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co092_en.pdf
[89] http://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co091_en.pdf
[90] https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co10_en.pdf
[91] http://www.expandproject.eu (currently offline)

	§3. The patient is entitled to a copy of the whole or part of the respective patient record, against a cost price. Each copy shall mention that it is strictly personal and confidential. The request of the patient shall immediately and at the latest within 15 days be responded. The copy of the patient record may be used only for strictly personal purposes and shall be treated confidentially. The professional practitioner can refuse a copy if he has clear indications that the patient is put under pressure to communicate a copy of his record to a third party. Article 9(3) of Law 2002 does not specify that patients shall have remote access to their patient record[92]. After the death of the patient the husband, the (legal) partner and relatives to the second degree of the patient have the right to access the patient's information if their request is motivated sufficiently and is specified and the patient themselves didn't object.
Croatia	Croatia has several laws in place regarding giving patients access to health data. These laws are the following: - Law on Health Protection (Official Gazette 150/08, 71/10 – 22/14) - Compulsory Health Insurance Act (Official Gazette 150/08) - Health Insurance Act (Official Gazette 150/08, 94/09, 153/09, 71/10, 139/10, 49/10, 22/12, 57/12, 123/12) - Law on the Protection of Patient Rights (Official Gazette no. 169/04, 37/08) - Law on the Protection of Personal Data (Official Gazette 103/03, 118/06, 41/08, 130/11, 106/12 - Law on Data Secrecy (Official Gazette 79/07, 86/12) - Regulation on the Method of Keeping, Preservation, Collection and Disposal of Medical Documentation of - Patients in the Central Health Care Information System of the Republic of Croatia (Official Gazette 82/10) - Regulation on the Use and Protection of Data Contained in the Medical Documentation of Patients in the - Central Health Care Information System of the Republic of Croatia (Official Gazette 14/10) - Regulation on the Method of Keeping of Personal Health Care Files in Electronic Form (Official Gazette 82/10) - Regulation on the Data Secrecy and the Right to Information Access in Croatian Health Insurance Fund (internal act), June 2015
Finland	**Act on the Electronic Processing of Client Data in Social and Health Care Services.** Under the Act on the Electronic Processing of Client Data in Social and Health Care Services, public healthcare and most private organisations are obliged to enter patient records in a nationally centralised archive. Deployment of the centralised archive is mandatory for private healthcare organisations, if they have an electronic system for long-term storage of patient records. The aim of the Act is to further the data security of patient information

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[92] National legislations concerning patients' right to access their medical records as transposition of A 4(2)f and 5(d) of the Cross Border Healthcare Directive. European Commission, DG Health and Food Safety

	processing, patients' access to information, and provision of healthcare services with better patient safety and efficiency. Patients must be informed about electronic prescriptions and Patient Data Repository in advance. The law also guarantees that patients are entitled to check the information stored on them. Patients also have the right to information as to where their medical records have been transferred between healthcare organisations. **Act on the Electronic Prescriptions** The Act on Electronic Prescriptions provides that introduction of electronic prescriptions is mandatory for pharmacies, healthcare units, and self-employed persons with practices in healthcare units' premises. The aims of the Act on Electronic Prescriptions are to improve patient and drug safety and to make prescribing and dispensing of medicines easier and more efficient. The healthcare unit will tell the patient about the electronic prescription system. The information may be given by e.g. a nurse or doctor. As well as verbal information, a leaflet on electronic prescriptions will be given. At the doctor's appointment, the patient is given a set of patient instructions. It contains details of all the medicines prescribed this time, as well as instructions on how to take them. From the patient's point of view, the information is the same as on a paper prescription. When the electronic prescription is renewed and no changes made to it, the patient instructions remain the same. The patient instruction sheet should be taken along to the pharmacy, as it speeds up the service. The acts and decrees are available in Finnish and in Swedish only http://www.kanta.fi/en/lainsaadanto. Both the Act on the Electronic Processing of Client Data in Social and Health Care Services and the Act on Electronic Prescriptions are being revised in 2017 in order to enable both the healthcare and social welfare services to be included in the Kanta services, in order to support the national health and social services reform as well as to enable a national PHR solution called “Omatietovaranto”. It is also suggested that Finland will adopt an opt-out model (Healthcare legal basis) both in the Act on the Electronic Processing of Client Data in Social and Health Care Services and for electronic prescriptions and that both the healthcare and social welfare data will be stored in one joint county customer registry. http://www.kanta.fi/en/lainsaadanto
France	The legal framework for the French EHR is very complex because it combines various legal documents: - The law of the 13th of August 2004 on the French National Health Insurance. This law creates the DMP. It defines the conditions and modalities to implement the DMP, specifying the rights of patients and healthcare professionals. This law prevents labour doctors and advising doctors working for private insurance companies from accessing the DMP to. - The Articles L. 1110-4 and L.1111-7 from the French Public Health Code foresee the use of the DMP under the strict respect of patients’ rights, their privacy and the confidentiality of their

	data. The decrees implementing these articles (4th of January 2006 on the hosting of personal health data, 15th of May 2007 on confidentiality) provide confidentiality framework to host personal health data and establish the mandatory use of the CPS (electronic ID card created especially for health care professionals) in case of access of personal health data. - The law of the 30th of January 2007 on the organization of specific health care professions gives the possibility to HCP working in emergency medical assistance centres to access the patient EHR without collecting his consent before. This law also creates the "Dossier Pharmaceutique" (Pharmaceutical Record) in order to provide the DMP with complementary data. The use of the national identifier is made mandatory for the conservation, transmission and exchange of personal health data. - The 2007 Social Security Financing Act provides two main principles for the French EHR: the creation of a unique portal to facilitate the access to patients and HCP, and the right to hide certain data. This law sets ten years as the required duration to maintain an EHR. - The "Hospitals, Patients, Health and Territories" Law (in July 2009) enables the creation of the French Agency for eHealth (ASIP Santé). This agency will be in charge of implementing the DMP and of elaborating security and interoperability frameworks related to the health sector. - The decree n°2016-914 linked to the 2016 Law on modernization of our health care system changes the name of the French EHR : from "Dossier medical personnel" (personal electronic health record) it becomes "Dossier medical partagé" (shared electronic health record). The deployment of the DMP will now be in the hands of the French National Health Insurance Fund (CNAMTS). The decree defines the rights and permissions of patients and HCPs about the uses of the DMP. The decree n°2016-914 linked to the 2016 Law on modernization of the health care system is the foundation of the DMP policy. The French electronic health record – DMP – is a public project launched by the French Ministry of Health allowing each citizen to have electronic access to their clinical past and their current health status. This project was launched in 2004. There were three main phases linked to the development of the DMP. In 2016, about 600 000 DMP have been created[93].
Germany	General: Patients generally have the right to access their care record (§ 630g BGB, Gesetz zur Verbesserung der Rechte von Patientinnen und Patienten", Patientenrechtegesetz of 20. Feb. 2013). Informed consent of the patient is generally required for Medical treatment, this includes documentation and care record.

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[93] Cf. dmp.gouv.fr

	The right of informational self-determination over personal data also applies to medical data, it is based on the general personal rights of German constitution. General German and European rules for privacy and IT-security apply. This includes rules and recommendations published by the Federal Office for information security (BSI). Confidentiality is required by professional rules and enforced by penal law § 203 Strafgesetzbuch (StGB). Project-specific: Patients can grant specific healthcare professionals access to documents, and revoke the access right any time. This builds on the general preservation of confidentiality of medical care, which may be released by the patient. Future: German legislation demands nationwide infrastructural support for electronic health records and patient access by the end of 2018 (SGB V).
Hungary	There are two basic laws regulating patient`s right to access their health data: - Act CXII of 2011 on Informational Self-Determination and Freedom of Information ("Privacy Act") - Act XLVII of 1997 on Processing and Protection of Medical and Other Related Personal Data (Medical Data Act) These laws define the conditions of accessing personal and particularly health data and declare that the patient has right to access and copy their own data. Except cases declared by law, exclusively the patient has the right to hide or disclose his/her own medical data.
Ireland	Citizen's access to personal data is covered by Data Protection legislation. The main Irish law dealing with data protection is the Data Protection Act 1988. The 1988 Act was amended by the Data Protection (Amendment) Act 2003. The 2003 Amendment Act brought Irish law into line with the EU Data Protection Directive 95/46/EC. All Sections of the Acts are in force. The Health Identifiers Act, of July, 2014, provided for the establishment and maintenance of national registers for Individual Health Identifiers (IHI). The Act clearly sets out what information will be captured to uniquely identify any person who is using a health or social care service in Ireland. A Privacy Impact Assessment on the IHI was also developed. Although a Privacy Impact Assessment is not a legal requirement, it is an effective way to demonstrate how the processing of personal data complies with data protection legislation.
Lithuania[94]	In general the Lithuanian EHR system is based on the concept that data

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[94] http://ec.europa.eu/health//sites/health/files/ehealth/docs/laws_lithuania_en.pdf (2014)

	of EHRs are the property of the patient. Therefore, the patient has a right to access all documents. It appears that the content of EHR could be also downloaded, although it is not detailed in the legislation. As an exception sensitive documents can be hidden from the patient for instance specific cases when a patient has been diagnosed with cancer but still ignores it. The current rules provide patients only with the right to review their EHR (Article 6 of the Order No V-761 and Article 49.1 of the Order No 1057). Therefore, the right of a patient to update, modify and erase EHRs content has not been established. However patients would have a right to request modification, update or removal of information that is no longer correct or complete. Health professionals need to be properly authenticated before acceding to EHRs. The law does not provide different categories of access for different health professionals. It is planned that the authentication will be performed through the special internet portal, professional access or via internal IS of healthcare institution integrated with ESPBI IS. According to Article 3 of Order No V-76150 access to ESPBI IS will be granted for users of the system pursuant to the principle "need to know". Users of ESPBI IS will have access rights only to the data in the extent necessary for their direct activities. Particular health professionals are allowed to access data of EHR even if a patient decides to hide such information. The right to see all of the patient's EHR personal data is recognized to the patient's family physician, healthcare professionals providing primary medical care to the patient, health professionals who carry out the patient's medical examination (court, specialized, psychiatric, psychological or other) and providing findings on the risk of patient's working conditions, military medical experts when they are required for the patient military medical examination to be carried out.
Luxembourg	This is the origin for the publication of the law of 17/12/2010, which covers 2 articles described below. - Art 60ter, which is at the origin of the creation of AeS: Agence eSanté became operational in 2012. - Art 60quater, which is at the origin of the creation of the DSP. The patient's access to his/her DSP is one of the fundamental rights defined by art 60quater of above mentioned law, more precisely by its paragraph (4) which stipulates that every patient has the right to access his/her DSP and has the right of information on the actions of access performed, and by whom. These 2 articles of the law of 17/12/2010 form the legal basis for the deployment of the DSP. However, the grand-ducal decree ("Règlement Grand Ducal") applying the law is currently under finalization and represents an additional agreement between healthcare professionals and government, and will allow the general deployment of the DSP to all Luxembourg health insured patients. It needs to be specified that law foresees the right to hold a DSP, but it does not oblige patients to maintain one, nor healthcare professionals to

	use it, except for the "primary care physician (or: referential doctor") (Médécin referent) whose task it is (a.o.) -according to art 19 of aforementioned law of 17 December 2010 - to "follow up on the content of the DSP".
Malta	There are no specific Maltese laws or regulatory guidelines that apply to the myHealth portal. Chapter 440 of the Laws of Malta (Data Protection Act) applies in general, as it does to all processing of personal health data and electronic health record-keeping.
Romania	The Electronic Health Record (*Dosarul Electronic de Sanatate – DES*) (EHR) in Romania is a public service provided by the National Health Insurance House (CNAS) (Order no. 1123/849/2016, art.5). It is provided for all patients who are obliged through Law 95/2006 (concerning the reform of the Romanian healthcare system) to be insured in the national system of social health services. Additionally, the EHR system is also offered to all medical service providers, to be used for all types of medical services, and both for institutions who have a contract with the CNAS, as well as for the ones who do not (Order no. 1123/849/2016, art.9). The use of the EHR system is currently mandatory for all healthcare providers. These providers are defined in article 3, point 2, of the decision 34/2015 as any entity authorised by the Ministry of Health to provide medical services, medication and medical devices, according the existing legislation. Decision 34/2015 also stipulates that not using the EHR is sanctioned according the existing dispositions stated in the contractual agreements between healthcare providers and the CNAS – in the case of healthcare providers who have a contract - or sanctioned by the Ministry of Health according to the in force legislation, in the case of healthcare providers who do not have a contract with the CNAS (Order no. 1123/849/2016, art.10). The legal framework for the implementation of the Romanian EHR is set out by the decision 34/2005 which approves the methodological norms concerning the use and data collection of the patient electronic health record (26.01.2015), as well as the national order 1123/849/2016 for the approval of the data, information and operational procedures needed for the use and functioning of the patient electronic health record (12.10.2016). In addition, in the implementation of the EHR, law 677/2001 regarding the protection of individuals regarding the processing of personal data and the free circulation of this data, sets out the limits of its uses. Law 677/2001 focuses on guaranteeing and protecting the rights and fundamental freedoms of individuals, especially the right to an intimate life, both family life as well as private, with respect to the processing of personal data. Consequently, Decision 34/2015 also states that the use, summarizing or processing of data and information from the EHR in other scopes than the ones laid out by the methodological norms of implementation, is legally sanctioned according the stipulations of law 677/2001. Also the legal document specify the owners of the data within

	the EHR are the patients and they have the right to manage how this data is used, as well as to decide the terms of its use.
Slovakia	The national eHealth law was approved in 2013 and more times novelised.
Spain	There are several laws that provide a legal framework for this service: - Law 41/2002, of November 14th, regulatory basis for patient autonomy, rights and obligations with respect to clinical information and documentation (BOE of November 15th 2002). Its article 18 states that the patient has the right to access their health record. - Law 16/2003, of May 28th, on the cohesion and quality of the National Health Service (BOE 128, of May 29th). It is stated in both laws (third additional disposition of the Law 41/2002 and article 56 of the Law 16/2003) that the Ministry of Health, Social Services and Equality has the mandate to coordinate the electronic exchange of clinical information to allow the access of the patient and of the professionals with the requirements needed to assure the quality of the continuity of care and the confidentiality and integrity of the information. In addition, the types of documents that can be exchanged and its structure are indicated in the Real Order 1093/2010, of September 3rd, that approves the minimum dataset of the clinical documents at the National Health Service.
Sweden	Swedish legislation is rather general with regard to the health data to be included in EHRs. EHRs are regulated by the Personal Data Act Law from 1st of July 2008. All data processing of patient's health care records has to be done in accordance with the Personal Data Act. For specific subject there is corresponding legislation but it has to be based on the Personal Data Act. The Act is adapted to modern technology and is designed to facilitate the exchange of information between care providers and patients, but always with the integrity of the patient in mind. For example, only staff with whom the patient has a current care relation, and to whom the patient gives his or her consent, are entitled to read the NPÖ. The same applies to Journalen, the patient gives his or her consent to another relative or representative to read the information in their medical records online. The National eHealth strategy for accessible and secure information in health and social care (2010). Inera together with Swedish county councils and regions collaborated and produced a regulation for Journalen. The regulation is the regulatory framework of which all county council can rely on[95].

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[95] http://www.sustainsproject.eu/cgibin/WebObjects/foretag.woa/2/wa/page?id=publicdocuments&wosid=2LcVAcFojUYpE866NTseNM&key=sustainsproject; http://www.skane.se/en/Health-care/rules-and-rights-in-health-care/your-medical-records/

The Netherlands	The Netherlands rely on general health and data protection legislation. There are no specific laws to regulate EHRs. For the purpose of this study, the following legislation is relevant: - *'Wet geneeskundige behandelingsovereenkomst'* (WGBO): sets out requirements, among other things, on (i) professional confidentiality, (ii) the duty to maintain and save medical records and (iii) patients' rights. The WGBO requires healthcare providers to keep a medical file with regard to the treatment of the patient. The medical file must contain notes regarding the health of the patient and the medical proceedings as well as documents containing such data, to the extent necessary for the treatment of the patient. The obligation to keep a medical file can be met by means of a paper file or a digital file. The WGBO does not make any distinction in this regard. It is also stated that patients have the right to gain access to their health data and a copy needs to be provided when requested. - *'Cliëntenrechten bij elektronische gegevensverwerking'*. The healthcare provider's obligation to only disclose the client's medical data by means of an electronic exchange system insofar as the client has explicitly granted consent; The client's right to grant, at the client's discretion, general consent for all healthcare providers connected to the electronic exchange system, or specified consent to disclose all or specific information to a certain healthcare provider or categories of healthcare providers to be specified by the client; The condition that explicit consent for consulting information or making a copy of it has been granted by the client within the context of the treatment relationship in question; The disclosure of information by the healthcare provider to the client about the client's rights in the event of electronic information exchange and how the client can exercise those rights; Offering the client inspection, by electronic means or by means of a copy of the records and/or of the client information that have been disclosed; A right of the data subject to request access to log data; An access injunction of the electronic exchange systems against healthcare insurance companies, company medical doctors, insurance companies' medical advisors and medical examiners. - '*Wet bescherming persoonsgegevens'* (WBP). This act implements the provisions of the European Directive 95/46/EC. This act contains rules on the processing of personal data of citizens, whether it is on paper or electronic. Limits the processing of personal data concerning a person's health and stipulates that responsible parties must implement appropriate technical and organizational measures to secure all personal data against loss or any form of unlawful processing. - *'Wet gebruik burgerservicenummer in de zorg'* (Wgbsn-z). To identify

	each person and to improve data exchange in healthcare. Requires healthcare providers to use the Citizen Service Number (BSN) of the individual concerned and to establish the client's BSN when processing personal data in providing care. Other requirements that healthcare providers must comply with when processing BSN, such as identification of the patient and security measures. - *'Regeling gebruik burgerservicenummer in de zorg'*. Under this regulation the processing of the citizen service number by healthcare provides must comply with NEN 7510. - *'Geneesmiddelenwet'* (Gmw). Prohibits the online prescription of medicinal products to persons who the prescriber has not personally met, or who the prescriber does not know of or of whom the prescriber does not have a medication history available. Requires explicit consent of the individual concerned for the electronic application, consultation and storing of laboratory results. It furthermore follows from the Gmw that electronic prescriptions must be provided with an electronic signature. - *'Wet publieke gezondheid'*. The law has a wide range with a broad impact on healthcare. Part of this law is the Youth Health Care. Municipalities are required to ensure that the youth healthcare organizations are using digital files for the registration of necessary data. The youth healthcare is one of the few medical fields where an electronic registration of medical data is stated in a law. - *'Gedragscode Elektronische Gegevensuitwisseling in de Zorg'* (EGiZ). Provides practical guidelines for healthcare providers and partnerships to meet current regulations and applies when personal data is processed via an electronic device. This is a feature that allows national and regional health information systems to be linked to each other or to share and exchange personal data.
United Kingdom	Legislation governing access by patients to their health records[96]: - The Data Protection Act 1998 – governs rights for living individuals to access their own records. The right can also be exercised by an authorised representative on the individual's behalf. - The Access to Health Records Act 1990 – governs rights of access to deceased patient health records by specified persons. - The Medical Reports Act 1988 – governs the right for individuals to have access to reports, relating to themselves, provided by medical practitioners for employment or insurance purposes

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[96] http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07103#fullreport