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the eHealth Network

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Draft

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Acronyms

Acronym	Description
AI	Artificial intelligence
AMO	Ability, Motivation, Opportunity model
DHL	Digital Health Literacy
EC	European Commission
eHEALS	eHealth Literacy Scale
eHN	eHealth Network
EHR	Electronic Health Record
GP	General Practitioner
HP	Health Professional
ICT	Information and Communication Technologies
ID	Identification
IT	Information Technology
JAsEHN	Joint Action to support the eHealth Network
KPI	Key performance indicator
MB	Megabyte
mHealth	Mobile Health
MOOC	Massive Open Online Courses
MS	Member State
MWP	Multiannual Work Programme
NFC	Near Field Communication
NGO	Non-Governmental Organisation
WHO	World Health Organization
WP4	Work Package 4

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1. Background

This draft policy framework is a deliverable of eHAction Work Package 4 (WP4) – Empowering People. eHAction is a Joint Action of the member states (MS) supporting the eHealth Network (eHN) and the third Multiannual Work Programme (MWP 2018-2021) [1] of the eHN. eHAction aims to promote the use of information and communication technologies in health development. WP4 is led by Estonia and the Netherlands and focuses on people empowerment in relation to the use of eHealth.

1.1 Purpose

People empowerment is one of the four priority areas in the MWP 2018-2021 [1]. Ageing populations and a rising amount of chronic diseases result in an increased need for healthcare. Patients need to be informed and provided with the right digital means, as well as possess adequate digital health skills in order to take active part in their healthcare process. A recent EU report [2] on the state of play of patient access to eHealth data found that people empowerment through eHealth was embedded in almost all national policies of MS. However, the implementation of such policies varied greatly from member state to member state. In this draft policy framework, the current state of play with regards to people empowerment, eHealth across MS and the desired state of the art is provided. It proposes a framework for the increase of the use and adoption of eHealth in order to achieve higher levels of people empowerment. The framework will lead to a policy proposal for MS and Europe and is aligned with the strategic goal of the eHN to work towards the implementation of patient-centred eHealth solutions in all MS for sustainability of healthcare systems.

1.2 Scope and definitions

People empowerment is a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important [3, 4]. However, patients are, by definition, already considered 'ill'. Gaining control over decisions and actions affecting health is important for many more people than just the 'patients'. With a patient also comes a healthcare worker, a caregiver, family and many other groups that are not included within the term 'patients'. Furthermore, the 'healthy' part of the population should be able to express needs and concerns on their health as well. In this way their health can be maintained. It is therefore important to include all the groups of the population involved with either health or illness. Therefore, the term 'people empowerment' will be used throughout this document.

eHealth is the use of information and communication technologies (ICT) for health and it captures the use of different digital tools in the healthcare process. In the context of this draft policy framework, this is a broad term capturing mHealth, patient access and use of data and telehealth [7].

mHealth includes the use of mobile communication devices in health and well-being services covering various technological solutions, which support self-management and measure vital signs such as heart rate, blood glucose level, blood pressure, body temperature and brain activity. WHO defines mHealth as "medical and public health practice supported by mobile

devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices” [5].

Patient access and the use of data includes people having access to their own health data e.g. electronic health records (EHR). New technologies such as mHealth and telehealth allow patients and health professionals to exchange health data electronically.

Digital Health Literacy refers to digital skills related to accessing and using online health data. It includes accessing, understanding, appraising and using (personal) online health data. It is important to differentiate between the terms ‘digital literacy’, ‘health literacy’ and ‘digital health literacy’:

- 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.
- Health Literacy reflects the ability to understand, appraise and use health-related information. This is important for understanding information from healthcare providers and information in print form and digital information.
- Digital Health Literacy refers to the ability of citizen 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.

For Task 4.3, digital literacy will be defined as the ability of a people to seek, find and access online data and information. Digital health literacy will be defined as the ability of a citizen to understand and appraise online data and information once found, and the ability to translate the online data and information into actions to improve a person’s health.

Telehealth encompasses the delivery of healthcare services by health professionals using ICT to provide clinical and non-clinical services – preventive, promotive and curative healthcare services, research and evaluation, health administration services [6].

1.3 Methodology

Literature/desk research and a survey among MS were undertaken to produce this draft policy framework. The AMO model, consisting of components that shape participant characteristics and contribute to the success of the system [8], was used for the survey design and for the analysis of the literature and survey responses. The components of the AMO model are:

- **Ability** refers to the knowledge and skills citizen need to have in order to be empowered. It is a function or capacity to perform, including variables such as age, knowledge and education.
- **Motivation** captures the extrinsic and intrinsic motivation of the citizens to use eHealth and how their motivation can be influenced. It is the willingness to perform, including variables such as social satisfaction, personality and values.
- **Opportunity** refers to the availability of, and accessibility to solutions provided, as well as the involvement of citizens in the process. It includes variables such as working conditions, tools, materials, leader behaviour, procedures and time.

The literature was accessed via different search engines (Google Scholar, PubMed) as well as from public EU sites. The reports and studies were analysed using qualitative content analysis method and the findings are proposed in chapter 2 based on 34 articles.

The actual state of play regarding eHealth implementation in MS was researched using a questionnaire. The survey consisted of 41 questions and was sent to both the leadership council

and the steering council of the eHAction. The MS were encouraged to share the survey with multiple organisations within their country in order to carry out national consultation rounds. MS had two months to consolidate responses from different national stakeholders (closing date: March 2019). The analysis of the survey was done using qualitative content analysis. The data collected from the survey can be considered as representative as the responses were collected from 16 MS and national consultation rounds within MS were carried out with different stakeholders to provide a wide spectrum of viewpoints regarding the topic. The section on actual state of play includes information from the surveys that were selected after aggregating, analysing and benchmarking the data across MS which brought out trends and state of the art regarding the topic. Several examples are given to illustrate the status of eHealth in MS.

2. Theoretical State of Play

Health services and information delivered through eHealth can make a real impact on people empowerment. Better and easier access to information and care, ease of information exchange and digital tools for self-management of diseases can lead to better health outcomes and be a more efficient and equitable way to deliver healthcare. It can foster patient-centred care where patients are true partners in the management of their health and wellbeing, making shared decisions with their health professional [9].

In this section, the theoretical state of the art of eHealth and digital tools for people empowerment is described. Analysis of literature and previous initiatives is done to provide an overview of how mHealth, patient access and use of data, digital health literacy and telehealth are related to people empowerment, concerning the components of the AMO model: ability, motivation and opportunity (section 1.3).

2.1 mHealth

mHealth applications have seen a rapid development over the past years, with currently more than 165,000 apps publicly available in Europe [10]. mHealth has the potential to improve healthcare systems by improving efficiency, communication, costs, and quality of healthcare services. Citizens can use mHealth tools with different objectives and for many reasons, e.g. for collecting information of themselves and using it to monitor their health status or sharing the data with their physician who can provide continuous monitoring from the distance with the support of mHealth solutions. mHealth apps help citizens manage their own health and support healthy living [11-13].

mHealth supports people empowerment with health-related activities and affect the ability, motivation, and opportunity of citizen to be empowered (table 1) using text messaging, platforms, apps, sensors that track vital signs and health activities and cloud-based computing for collecting and analysing health data. mHealth serves a variety of purposes with functions including diagnostics, event tracking, data collection, decision support, communication, and education. In the table below, different ways of how mHealth improves the ability, motivation and opportunity of citizen to be engaged and empowered are stated.

Table 1. mHealth related to the ability, motivation and opportunity of citizens to be empowered

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> • Educates users • Citizens can gain access to useful information anytime and anyplace • Improves self-management • Citizens can measure vital signs that will contribute in their health assessment • Support to diagnosis and treatment through integration with medical records and monitoring of chronic conditions 	<ul style="list-style-type: none"> • Motivational rewards in exchange of healthy behaviour • mHealth tools are often generalisable to match the needs of the specific patient-consumer and therefore motivate the empowerment 	<ul style="list-style-type: none"> • Access to patient data • Enable the exchange of medical information • Gain access to information anytime and anywhere • Measure vital signals that will contribute in their health assessment • Support to diagnosis and treatment through integration with medical records and monitoring of chronic conditions

		<ul style="list-style-type: none"> • Functions designed to support a collaborative relationship between patients and providers
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There are barriers as well as enablers of mHealth implementation. Citizens need to have a certain level of technological competence and digital literacy to be able to use mHealth solutions and to be empowered. Besides patients, specialists too need training, education and advocacy in order to engage and implement the apps in their practice [15]. In addition, professionals need background information, i.e. the evidence base of the apps/devices in order to use and recommend them to patients [16]. Demands for an increase in theory-based applications have been made [17]. Professionals are more likely to use and recommend apps in which they have been involved [18]. Other enabling factors are the usefulness of the app and interoperability [14,16] and personal factors that shape people engagement and experience with mHealth [17]. Personal factors influence participants' motivation to engage with applications and vice versa. People were proven to be motivated for more physical activity because of the application usage and the awareness to exercise was increased. Use of mHealth solutions over long periods of time has shown positive changes in attitudes, beliefs, perceptions and motivation [16, 17]. The table below includes barriers and enablers derived from the literature related to mHealth's ability to positively affect people empowerment due to challenges related to implementation and adoption.

Table 2. Barriers and enablers related to mHealth successfully empowering people

	Ability	Motivation	Opportunity
Barriers	<ul style="list-style-type: none"> • Professionals' lack of familiarity with equipment and procedures • Professionals' lack of training, education and advocacy • Lack of technological knowledge 	<ul style="list-style-type: none"> • Unrealistic expectations for mHealth • Solutions not adapted for physician • Perceived complexity and resistance from physicians • High lack of time and workload • Lack of sense of urgency/value • Privacy and security concerns • Conservative culture 	<ul style="list-style-type: none"> • Lack of readiness among key stakeholders • Lack of enabling policy • Conflicting priorities • Lack of governance • Medicolegal issues • Poor cost-effectiveness • Lack of reimbursement models • Lack of implementation support • Lack of evidence of clinical utility and scientific research • Lack of integration and interoperability
Enablers	<ul style="list-style-type: none"> • Personal factors which shape people engagement and experience • Provider's capacity • Perceived ease of use • Content appropriate for the users (relevance) 	<ul style="list-style-type: none"> • Willingness to use among patients and providers • Awareness of the objectives and/or existence of mHealth • Familiarity, ability with mHealth • Agreement with mHealth (welcoming/resistant) • Support and promotion of mHealth by colleagues 	<ul style="list-style-type: none"> • Involvement of app development • Usefulness and interoperability of the app • Assessment frameworks in place • Observability (observance, control, verification of the solutions)

		<ul style="list-style-type: none"> • Compatibility (with work process) • System reliability or dependability • Accuracy of the system • Quality standard • Outcome expectancy (leads or not to desired outcome) 	<ul style="list-style-type: none"> • Communication and collaboration between different stakeholders • Materials resources (access to mHealth) • Human resources (IT support, other) • Training • Management (strategic plan to implement mHealth)
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2.2 Patient access and use of data

The widespread implementation of electronic health records (EHR) has led to new ways of providing access to healthcare information, allowing patients to view their medical notes, test results, medicines and so on [20-22]. EHR portals are gaining more attention from governments, that consider this technology as an asset for the future sustainability of the national healthcare systems [19]. EHRs have the potential to empower patients by providing them with easier access to their health records, allowing them to exert more control over their health records. Thereby, they are becoming more responsible and more active in their own care while facilitating communication with their health professionals. In 2017, the Joint Action to support the eHealth Network (JAseHN) surveyed 29 countries to determine the extent of European patients' access to EHR information. It turned out that 15 EU MS provided patients with access to EHR via a single national EHR system and in 9 other MS patients accessed their EHR information via multiple systems based on regions and/or health domains [2]. Utilisation of EHR portals has most commonly been associated with small changes in patient empowerment and activation. Portal use was also positively associated with better health outcomes in various study populations [23]. Some studies reported improvements in medication adherence, disease awareness, self-management of disease and a decrease in office visits. Also, an increase in preventative medicine and an increase in extended office visits, at the patient's request for additional information, was observed. The results also show an increase in quality, in terms of patient satisfaction and customer retention, but results on medical outcomes are weak [24].

Table 3. Patient access and use of data related to the ability, motivation and opportunity of citizens to be empowered

Ability	Motivation	Opportunity
	<ul style="list-style-type: none"> • Deeper understanding of their health condition. • Direct access to accurate information, clinical test results. • Monitor patient's health between clinic visits. • Improves self-management of citizens 	<ul style="list-style-type: none"> • EHR accessibility improves recall and understanding of health information and patient involvement • Patient empowerment and activation • Better health outcomes

Nevertheless, the adoption rate of EHR systems from healthcare providers internationally is not as high as expected. Several factors are related to the adoption of EHR portals. The most frequently mentioned barriers in analysed studies were cost, technical concerns, lack of

technical support, and resistance to change. Other barriers that appear in multiple studies include the lack of interoperability and user-friendliness. Policy makers should consider incentives to reduce implementation cost, possibly aimed more directly at organisations that are known to have lower adoption rates, such as small hospitals in rural areas [25]. Other studies underlined the need to redesign EHRs in a way that will better educate patients during medical visits [26]. Physicians, on the other hand, have a great impact on the overall adoption level of EHRs. It is therefore critical to identify ways to make EHR systems more attractive and user friendly for both physicians and patients [27]. Patient-perceived enablers of use are encouragement by health professional (HP), access/control over health information, and enhanced communication. Two themes were found related to patient-perceived barriers to use: lack of awareness/training and privacy and security concerns [28]. In addition, patients' interest and ability to use patient portals is strongly influenced by personal factors such as age, ethnicity, education level, health literacy, health status, and having a role as a caregiver. Healthcare delivery factors, mainly provider endorsement and patient portal usability, also contribute to patient's ability to engage through and with the EHR portal [22].

Table 4. Barriers and enablers related to patient access and use of data to successfully empower people

	Ability	Motivation	Opportunity
Barriers	<ul style="list-style-type: none"> • Higher age • Lower social economic status • Lower educational level • Lack of computer knowledge • Language barrier • Information overload • Low (digital) health literacy 	<ul style="list-style-type: none"> • Lack of awareness • Concerns about privacy, confidentiality • Safety • Bad design of the EHR portal, liability issues • Resistance to change • Preference for personal communication • Apathy • Lack of urgency • Low expectations or uncertainty about results 	<ul style="list-style-type: none"> • Lack of bandwidth • No technical support for technology-challenged staff • High costs for HCP • Lack of implementation models • Legal/regulatory restrictions • Low software speed • Lack of proper infrastructure • Lack of good access to internet • When both professionals and users are deployed, users are scaled up more slowly • Complexity of process and the number of players • No direct relation with healthcare provider • Low rate of EHR systems adoption internationally • Lack of interoperability • Adaptation of individual clinic workflow preferences is needed
		<ul style="list-style-type: none"> • Clear vision (aim/purpose/ benefits of EHR portal) • Trust 	<ul style="list-style-type: none"> • Health benefits of sharing information • High adoption among organisations • Policy in organisation

Enablers		<ul style="list-style-type: none"> • Early adopters in network • Publishing best practices and use cases to inform about benefits • Readiness to invest in improvement • High expectations of users 	<ul style="list-style-type: none"> • Involvement of citizens in policy • Interoperability
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2.3 Digital health literacy

Digital health literacy (DHL) goes beyond searching for general health-related information on the internet. Citizens need to be comfortable accessing and using their own health information via mHealth, EHR systems or telehealth. The JAseHN report indicated a lack of understanding by survey respondents from 29 countries as to the difference between digital literacy and digital health literacy, with the emphasis in policy being on digital literacy [2].

Table 5. Digital health literacy related to the ability, motivation and opportunity of citizens to be empowered and barriers and enablers for adoption

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> • Educate citizens about their health status • Gain access to useful information any time and any place 	<ul style="list-style-type: none"> • Deeper understanding of their health condition. • Improves self-management of citizens 	<ul style="list-style-type: none"> • Patient empowerment and activation • Better use of mHealth, EHR portals and telehealth

The DHL of citizens in Europe was investigated in 2014 on behalf of the European Commission. Around 60% of European citizens used the internet to search for health-related information within the previous year. This percentage is lower among older people. Barriers to online search of information are reliability, content, usefulness and understanding. At least 90% knew how to navigate the internet and to find the desired information. However, 40% did not trust online health data [29]. Factors related to digital health literacy include age, experience, health literacy, education, income and culture [30]. Citizens with lower socio-economic backgrounds, citizens experiencing vulnerabilities, or citizens in old age may struggle to keep up with technological advancements. Digital health literacy skills of citizens with different health conditions, risk factors and socioeconomic backgrounds could be improved by eHealth interventions [31], such as Massive Open Online Courses “MOOC” and educational programmes [32].

Table 6. Barriers and enablers related to digital health literacy successfully empowering people

	Ability	Motivation	Opportunity
Barriers	<ul style="list-style-type: none"> • Less experience with internet • Anxiety to use mobile phone, computer or internet. • Privacy concerns • Poor understanding and poor quality of information • No parental mediation • Low income • Low educational level 	<ul style="list-style-type: none"> • Reluctance to learning • No confidence with using online information • Negative attitude towards eHealth 	<ul style="list-style-type: none"> • Distracting information • Lack of information in mother tongue • Overload with information quantity • No access to computer/internet • Less opportunities in rural area
Enablers	<ul style="list-style-type: none"> • Improvement of skills through measurement of DHL (e.g. eHEALS) and through e-learning • Experience in lifespan • Reading ability • Ability to collect and qualify the data • Educating professionals 	<ul style="list-style-type: none"> • Gaining support from others • Trustworthiness for citizens • Openness to learning • Ease and confidence with using online data • Readability: attractive visual/audio content • Social network 	<ul style="list-style-type: none"> • Easily accessible • Cultural relevant information • Assessing community support • Provision of resources through networks • Policy/action plan on DHL in HP • Involvement of citizens in policy on DHL • Provision of a framework for the digital communication of health information • Use of early adopters in HP

2.4 Telehealth

Telehealth offers a vast amount of potential benefits to achieve and maintain patient empowerment [35-37]. Telehealth promises benefits for access to care, cost-effective delivery and distribution of limited providers and supports the current transition in healthcare systems, from traditional hospital-centred care towards patient-centred care [34]. Moreover, studies have observed a positive impact of telehealth on disease self-management, clinical outcomes, adherence to treatment and care, as well as health behavioural and lifestyle changes [38-40]. Remote consultations and monitoring can deal with some of the non-urgent inquiries, can reduce office visits and other healthcare encounters, can replace time-consuming, burdensome face-to-face consultations and clinic visits [41]. Telehealth extends and improves primary care, enables immediate assessment and triage, increases access to high-demand specialty care, facilitates behavioural health support and telehealth advances chronic disease management and home care [42]. EU co-funded pilot projects on telemedicine have shown that telemedicine improves the quality of life of several patient groups. Meanwhile, studies have shown that it also reduces hospital admissions and visits to the general practitioner [43]. In the table below, different ways of how telehealth improves the ability, motivation and opportunity of citizens are provided.

Table 7. Telehealth related to the ability, motivation and opportunity of people to be empowered

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> • Empowers patients to take an active role in their healthcare • Supports clinical education programmes, for patients and clinicians. • Patients can easily integrate their healthcare into their daily life, instead of frequent doctor's visits 	<ul style="list-style-type: none"> • Increases patients' confidence to stay independent/at home • Improves support for patients and families: patients can stay in their local communities where their relatives can easily visit them. Recovery is faster when patients are close to home • Patients can be diagnosed and treated more quickly in distant locations • Lower travel costs and missing work, income savings to patients who would otherwise need to commute to an urban location • Less time is spent by the patient in waiting rooms • Some doctors charge less for a telehealth consultation than they would for an average in-person visit 	<ul style="list-style-type: none"> • Increases access to healthcare (remote or rural areas) • Improves health outcomes: patients diagnosed and treated earlier often have improved outcomes and less costly treatments • Assists in addressing shortages and misdistribution of healthcare providers: specialists can serve more patients using telehealth. • Improves organisational productivity. • Specialists "team up" with local healthcare providers to improve disease management. This reduces complications and hospitalisations. Also, test results can be quickly sent to specialists for second opinions • Reduces the need for hospital re-admissions. • Home monitoring programmes can reduce high cost hospital visits, high cost patient transfers and other emergencies

Successful implementation and long-term adoption of telehealth solutions require substantial efforts to be concentrated on selection of appropriate interventions and tailoring of system design to meet the disease specific needs of target user groups [41]. Telehealth solutions substantially impact the patient and health professional relationship in the context of healthcare provision. Patients highly value the ability to monitor, track and influence their own health status. They feel better educated and actively engage and share their experiences with peer-patients or professional moderators. However, there are also barriers. Patients are also interested in having personal contact with their health professional and are concerned about the quality of care given by telehealth [42]. Also, healthcare providers perceive telehealth solutions as an additional service, increasing their workload due to necessary data review and timely response. Therefore, telehealth solutions must be seamlessly integrated and avoid disrupting the health professional's existing workflow. Below you can find a table of the main barriers and enablers for telehealth implementation.

Table 8. Barriers and enablers related to telehealth adoption

	Ability	Motivation	Opportunity
	<ul style="list-style-type: none"> • Digital skills 	<ul style="list-style-type: none"> • Privacy and security • Resistance to change • Competing priorities 	<ul style="list-style-type: none"> • Bandwidth • Lack of legislation or regulations governing telehealth programmes

<p>Barriers</p>			<ul style="list-style-type: none"> • Inadequate coverage and payments/lack of funding • Costs associated with technology • Lack of technological infrastructure in underserved areas • Regulation • Data accuracy and ease of use
<p>Enablers</p>	<ul style="list-style-type: none"> • Keeping the user in mind • Frontline staff acceptance 	<ul style="list-style-type: none"> • Consumer demand 	<ul style="list-style-type: none"> • Value-based reimbursement • Health policies view the contribution of information and communications technologies as an essential and central component rather than an add-on for delivering healthcare services and improvements in health • Experimentation and clinical learning • Experiencing patient and clinical benefits

2.5 Conclusion

The conclusion will be written in the final version of this deliverable.

3. State of play

[Still in progress; the content is based on 19 completed surveys]

In this chapter, the actual state of play of people empowerment among the MS is provided. It contains the survey results of 19 MS (figure 1) with for example an overview of the main barriers and enablers for the further adoption of mHealth, patient access and use of data, digital health literacy and telehealth in the MS in order to increase people empowerment.

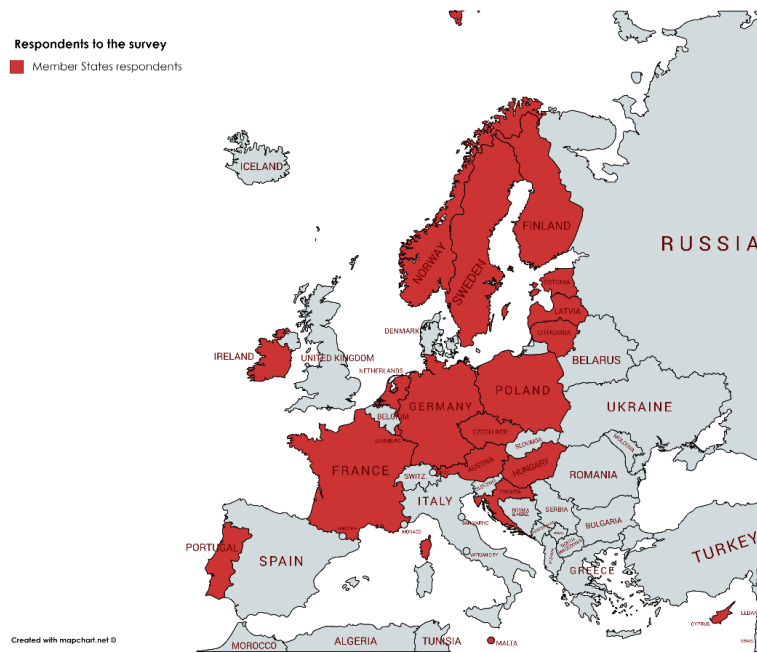


Figure 1. MS respondents to the survey

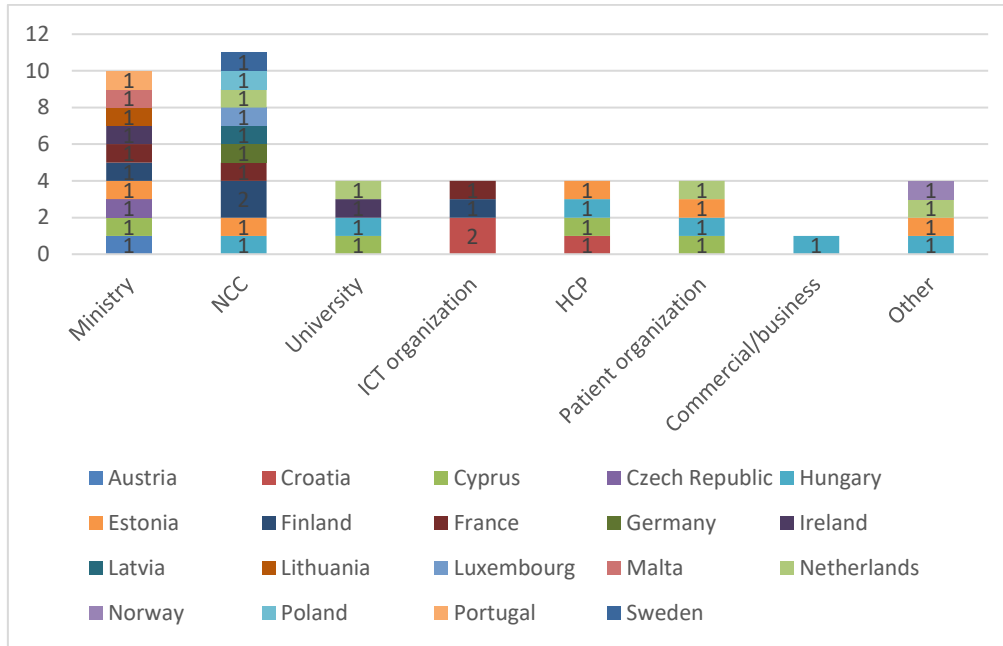


Figure 2. Patient access and use of data respondents to the survey based on organisations

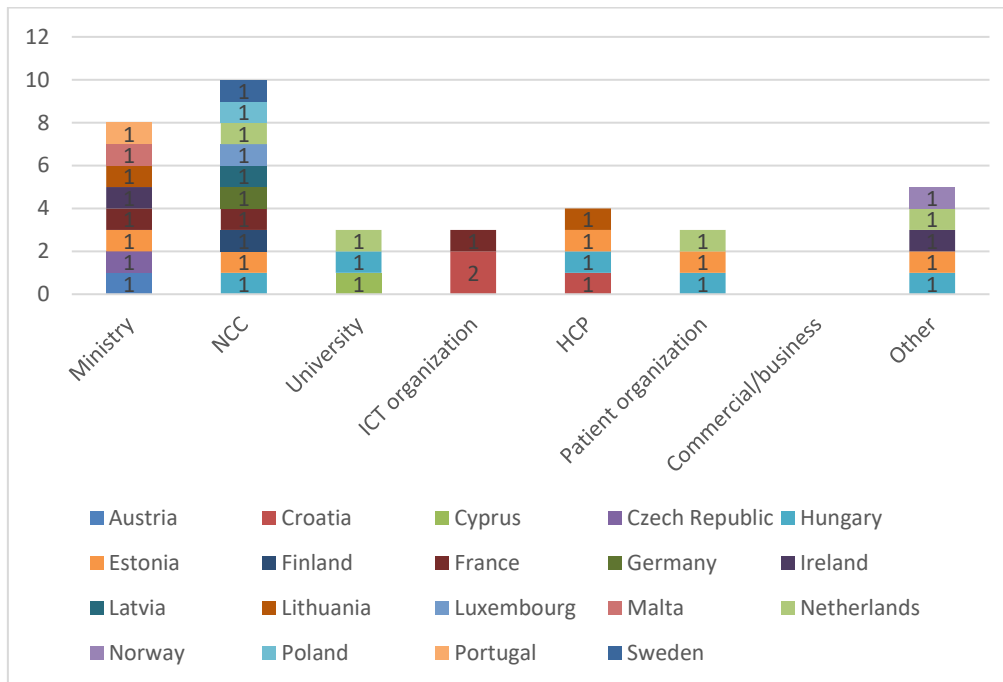


Figure 3. Digital (health) literacy respondents to the survey based on organisations

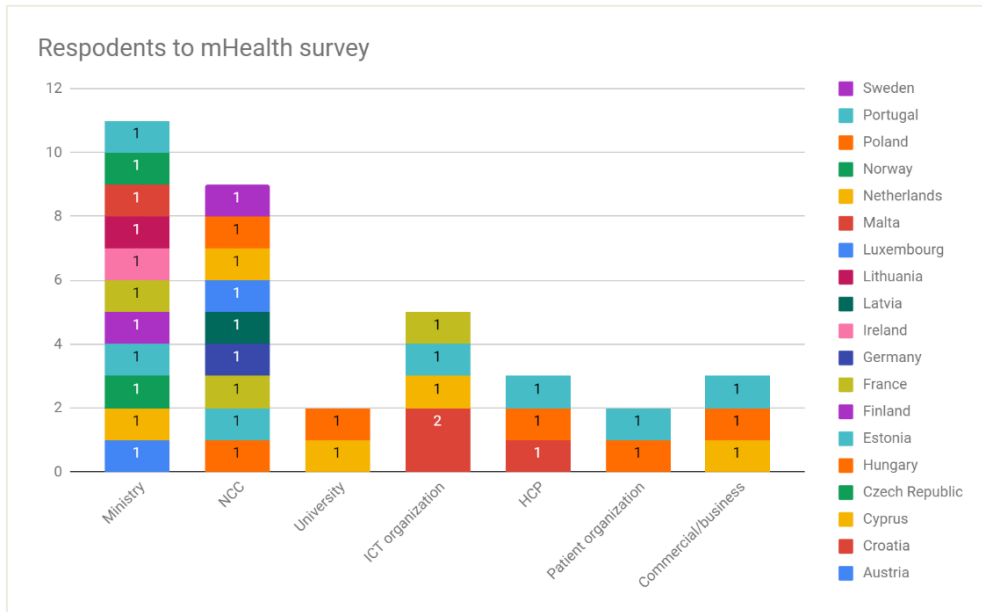


Figure 4. mHealth respondents to the survey based on organisations

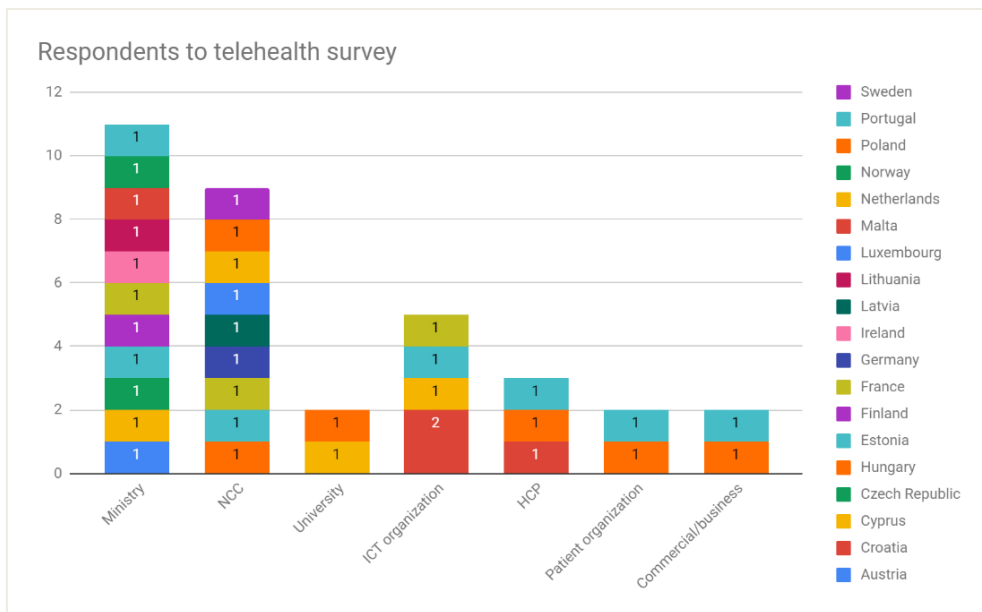


Figure 5. Telehealth respondents to the survey based on organisations

3.1 mHealth

What is observed in the responses are the use of eHealth solutions as the means to reduce administrative burden, to collect and provide data for medical services, and to address the most obvious bottlenecks that have been identified in the provision of primary care. There are several factors that enable citizens to use mHealth solutions. Most of the MS indicated that the necessary infrastructure, including wireless and mobile communication networks coverage, is already in place. Several MS highlighted the importance of a comprehensive national strategy with some of them being already in the implementation process and others only in the development stages or non-existent at all. For instance, Malta treats mHealth as an integral part

of its wider Digital Health strategy, which is linked to the National Health Systems Strategy and the Digital Malta strategy.

Almost all countries highlighted a distinction between the features of mHealth applications for patients and applications for health professionals. For patients, the most common applications endorse solutions that offer the ability to: a) provide scientifically sound, understandable and unbiased information on different health topics, b) enable patients to directly contact their GPs or other healthcare providers to book appointments and/or ask specific questions about their condition and treatment, c) share information, do reviews and provide feedback to doctors, health professionals, emergency health specialists, hospitals and clinics, d) manage diseases in a personalised manner (mostly on the basis of virtual coaching, e.g. a virtual coach that helps patients monitor their condition and treatment), self-management tools for the detection of early warning signs of relapse (thus empowering patients to contact service providers when required) and access to various health-related online services (e.g. tools and guidance to quit smoking, improve physical health or improve diet, etc.). For health professionals, most applications focus on the potential to communicate and mass-educate targeted groups of patients and on the ability to offer medical consulting services online.

The forces that drive patients and HPs to use and access applications are found to be in the spectrum of providing to the citizens: a) a better view of their condition, b) the means to plan their treatment together with professionals, and c) continuous and individual guidance towards behavioural change. However, some other interesting approaches have appeared in the survey, especially in the Estonian analysis. For example, some applications have been linked with vouchers for different goods or free internet data, based on the level of usage of the application (e.g. number of steps the users are taking daily). Finally, motivational factors are given for avoiding bureaucratic issues when citizens use applications for public health programmes and public health services.

The use of applications among MS mostly have to do with the storage, retrieval and exchange of medical data either offline or in real-time. For example, in Austria one application is for monitoring health data of diabetes patients by means of transmission of the data from the medical device via NFC or Bluetooth Low-Energy to the mobile phone and the medical centre. Other applications provide opportunities to establish an active informed dialogue between the patient and his health professional and/or other patients with similar medical conditions. These applications allow the patients to recognise and understand trends and patterns in their own health behaviour, physical activity and critical monitored values. The patients are therefore continuously empowered to take an active role in raising the quality of and adherence to their own healthcare treatment. Another example linked with data monitoring has to do with the opportunity to build applications with alerting systems, medicine reminders, and self-administration markers analysis. Finally, applications with interactions and feedback from the users provide the opportunities to overcome several conditions such as speech-related problems and to virtually connect to health professionals easily.

Citizens are using smartphones on a day to day basis. Nevertheless, it is still not enough to ensure wide usage of mHealth apps in healthcare. One of the main barriers preventing higher usage of mHealth is digital literacy which is elaborated in section 3.3. While some MS report greater availability of training and inclusion of health professionals in the process of educating citizens, others report health literacy not being supported strategically at all. Most of the

respondents emphasise the importance of motivating the relationship between doctor and patient, as well as including citizens in the development process of mHealth apps to meet their needs and be practical to use. Pricing policies and reimbursement schemes were listed as the greatest motivators to use mHealth solutions. In addition, citizens find it convenient to be able to access all the data in one place. Quite a few countries have reported public campaigns playing a great role in promoting apps and the benefits of mHealth. Also, it has been noted that mHealth is being developed more in the private field rather than in the public sector. Several MS noted that certain groups of citizen might have limited access to mHealth, therefore age, social and financial status of the population groups targeted with certain solutions should be kept in mind while designing the programmes. Lastly, MS highlighted the importance and the potential of hackathons. Big companies often organise hackathons for mHealth tools. With the involvement and input from the Ministries of Health, it can be a great tool to address current needs, develop new apps and facilitate life for citizens.

Most barriers and enablers to the adoption of mHealth turned out to be alike between MS. The most significant healthcare system related barriers were seen in the readiness among professionals, as well as in the lack of enabling healthcare policy which could be a result of lack of strategic power. Professional attitudes towards mHealth were also seen as a barrier. Assessment framework was seen in the questionnaire answers as an enabling factor in mHealth usage and the implementation process. The enabling factor in the questionnaire was the usefulness of the app. Interoperability was reported as a vital factor for the use of mHealth solutions.

Table 9. Most common reported barriers and enablers for the adoption of mHealth.

	Barrier	Enabler
<i>Health system specific</i>	<ul style="list-style-type: none"> • Lack of enabling healthcare policy • Lack of readiness among healthcare providers • Privacy & security concerns • Conflicting priorities • Conservative culture. • Lack of adoption support 	<ul style="list-style-type: none"> • Communication and collaboration between different stakeholders • Assessment frameworks in place • System reliability or dependability • Quality standardisation • Human resources (IT support, other) • Management (strategic plan to implement mHealth)
<i>Business case related</i>	<ul style="list-style-type: none"> • Lack of implementation support • Lack of reimbursement models • Cost-effectiveness of mHealth apps • Market size 	-
<i>User related</i>	<ul style="list-style-type: none"> • Lack of time and workload • Perceived complexity and resistance from physicians • Solutions not adapted for physicians • Language related barriers 	<ul style="list-style-type: none"> • Willingness to use among patients and providers • Awareness of the objectives and/or existence of mHealth • Support and promotion of mHealth by colleagues • Provider's capacity

<i>Application specific</i>	<ul style="list-style-type: none"> • Lack of integration & interoperability • Lack of evidence of clinical utility 	<ul style="list-style-type: none"> • Perceived ease of use • Content appropriate for the users • Compatibility (with work process)
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3.2 Patient access and use of data

Eight MS state that citizens have access to their own health data. The amount of data available online varies among MS with health information on patient's visits, e-prescriptions, referrals and discharge letters being the information that is most frequently accessible in electronic form. There is one MS that reported having an online platform solely for private healthcare while several others noted having a common infrastructure for public and private healthcare services. Several MS are in the development phases of creating tools for their citizens to access and use health data with the launch of these platforms soon. Although the majority of MS provide access to health data for citizens, the extent to which patients use their data is unclear. Interestingly, in Finland over 38% of the population used eHealth services to browse their personal data in 2018. This wide usage of eHealth services is expected, considering that development of eHealth in Finland started in 2010. Presumably, a long history of eHealth services is an important component in ensuring the extensive and successful usage of eHealth among citizens. To ensure equal use of state and municipality services, Latvia is conducting a pilot project to facilitate access to health data for citizens with limited access to internet, Citizens without electronic identification tools and citizens lacking digital literacy. Lastly, several MS mentioned adopting a strategy to ensure patients' access to their own health data online.

The trend among MS is to opt for a centralised eHealth portal. This solution provides various motivation for both patients and professionals, such as storage of up-to-date information, shared access to information for patients and professionals, and availability of digital services (e.g. booking of visits to specialists, e-referrals). Some countries offer reimbursement schemes for the use of eHealth solutions which are embedded in their national system, and/or attractive pricing policies that encourage the use of eHealth services. National planning was seen in many responses to promote and increase the development and usage of eHealth solutions for IT companies in the private sector. Other examples of promotion of patient access and use of data are found in NGO initiatives that provide information on existing market solutions and success stories in different countries regarding the value of eHealth services for citizens.

Some MS choose alternative ways and develop private healthcare application networks that motivate citizens to monitor their own health and wellbeing, and tackle risk factors. There are common motivation factors for both approaches: quick access to information (e.g. patient data, medical treatment documentation), control over own health data, and involvement in the healthcare process. Several MS referred to transparency of healthcare as a motivation. It includes minimisation of bureaucracy and transparency in true costs of healthcare. Among all MS, there is a high expectation that digital services should be available, which means that it is not motivation that is lacking, but that limited digital services are available.

The majority of MS named personal ownership, and easily available and up-to-date health data as the main enablers to use eHealth services. Some highlighted that engagement and support from health professionals also contribute and motivate citizens. Privacy and lack of digital literacy were listed as the main barriers. Digital literacy plays a significant role and is a significant

barrier knowing that healthcare services are used more by the elderly than by other age groups. Some countries outlined that often, difficult medical language might discourage patients from browsing their eHealth data.

Table 10. Most commonly reported barriers and enablers for the adoption of patient access and use of data

	Barrier	Enabler
1.	Privacy	Personal ownership
2.	Lack of digital literacy	Available data online
3.		Support from health professionals

3.3 Digital health literacy

Ten MS have taken initiatives to improve digital health literacy. There are initiatives aimed towards patients, relatives and professionals. In many MS, this is part of improvement of digital literacy in general, not of digital health literacy. Four MS stated that digital skills are a necessity for health professionals to be able to get employment. Only one MS has developed a health strategy in connection to digital health literacy. Four MS listed a national digital strategy as an enabler for achieving digital literacy. National strategies include digitalisation strategies that aim for digital skills and help citizens become familiar with digital tools and services and therefore, have the ability to follow and participate in digital transformation based on their own situation.

As a means to increase motivation in achieving digital health literacy, six MS listed initiatives in the educational area as important. These are either by education at an early age, access to customised and easily understandable information, or platforms with health information. Only one MS has a programme to reduce illiteracy and a special effort to strengthen women's involvement in society. Several MS identified the importance of interaction between citizens and policy makers/initiative representatives in order to review the current situation and tailor the literacy programme accordingly.

Access to education or e-learning was listed by three MS as an opportunity to enhance digital health literacy. In one MS, checklists are provided to help in communication with citizens with low digital skills, be it a doctor or an e-services company. There are services that can help guide the health professionals in determining on which level of digital skills their patient is. There are also services that give a patient with low reading skills the opportunity to access information about medication. Another MS gave an example of the opportunity for citizens to get individual guidance in using e-services on site at local institutions.

The key facilitator to ensure digital health literacy is training. Training should be accessible for everybody; health professionals should also support and sometimes coach patients. In addition, digital literacy with emphasis on health should be a part of the school curriculum. Informative videos, guidelines and other informational material should be made available to support citizens and improve their skills. Anxiety while using electronic services was listed as the main barrier related to the lack of digital literacy in general. The elderly population is often reluctant to use eHealth services due to lack of knowledge and skills in working with technologies. Also, some groups might not have regular access to internet or cannot afford digital devices.

Table 11. Most common reported barriers and enablers for the adoption of digital health literacy

	Barrier	Enabler
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1.	Anxiety	Training
2.	Aging population	Support from health professionals
3.	Limited access to internet/technologies for some groups	User friendly, accessible information and guidelines

3.4 Telehealth

Most telehealth applications in the MS concern access to high-quality, timely personal healthcare, services for patients at home and creation of mobile nursing jobs based on a patient centric philosophy. Other solutions focus on the ability to provide access to educational material, consultations with medical specialists, scheduling of medical appointments and /or getting access to laboratory tests, etc. Some applications describe long-distance diagnostic systems, including telemonitoring of patients with heart deficiencies, patients with chronic diseases, and the elderly population. In addition, several applications have been documented that involve the recording of fixed measurements, responses to clinical questions and bio-signals acquisition that are tele-transmitted for an initial evaluation of a patient remotely. Finally, online national support services and teleconsultations have been described in the survey responses that enable citizens to access high quality healthcare services.

Various promotional activities can lead to increased motivation. Several MS listed activities promoting telehealth (and/or eHealth in general), with initiators ranging from NGOs and local authorities to a national telehealth centre, providing support and coordination on a national level. It provides the possibility for citizens and especially the elderly to exchange information about their conditions and socialise. Recommendations and guidelines for specific eHealth solutions have also been observed in some countries to promote solutions that are tailored to users' needs and proper use (i.e. routines and procedures for telehealth services).

Other means of increasing motivation include ensuring ease of use of telehealth solutions and tailoring them to users' needs. It has been pointed out that providing these services to patients free of charge may increase motivation. Some MS provide health insurance benefits when citizens make use of telehealth services by significantly reducing the reimbursement costs. Similarly, grants or research and innovation funds are stimulating the development and implementation of novel telehealth solutions. Telehealth raises awareness on specific health problems, both in patients and medical care providers, and the increased feeling of safety and trust due to the ability to get multiple opinions from many experts on a specific problem motivates citizens towards choosing telehealth solutions. The upgrading of institutional services with eHealth/telehealth systems is by itself a strong motivation for using these services considering the solutions such as the computerisation of nursing services which provides a comfortable way for both patients and professionals to manage diseases such as foot ulcers when patient data and periodic consultations can happen seamlessly between patients and specialists.

The opportunity of using telehealth solutions, both for patients and healthcare providers, is increased through reimbursement models for telehealth services (through private and/or public insurance providers), as well as providing equipment, software platforms and infrastructure. According to the survey, reimbursement schemes are very limited, with most of the models still to be developed. In most cases, the provision of equipment is up to the healthcare providers, with some exceptions. The opportunities highlighted through the aggregation of the responses

have to do with access to healthcare services for distant populations and/or elderly and disabled individuals. In addition, although some MS documented national and private sector initiatives that promote and finance training events for educating citizens to exploit the benefits of telehealth applications, in most of the cases these initiatives are taken privately and are not part of national programmes. Other opportunities involve the participation of citizens to get multiple medical opinions, and review of feedback for health professionals and/or medical centres. Independent measures and KPI's are set in some countries to quantify the level of usage for eHealth services, and national strategies are planned accordingly. Finally, a legal framework to support these services and health professionals and/or citizens to exploit the benefits of telehealth has also been observed in the responses from some countries.

Table 12. Most common reported barriers and enablers for the adoption of telehealth

	Barrier	Enabler
<i>Health system specific</i>	Privacy and security Costs related to technology	
<i>Business case related</i>	Inadequate coverage and payments/lack of funding Lack of legislation or regulations governing telehealth programmes	Value-based reimbursement Policies consider telehealth as essential and central components
<i>User related</i>	Competing priorities Digital skills	Consumer demand Frontline staff acceptance
<i>Application specific</i>		Experimentation and clinical learning Experiencing patient and clinical benefits

3.5 Other people empowerment topics

Besides the assigned four tasks MS were asked in what way the following topics concerning people empowerment are currently a policy matter, ranging from “no topic at all” (1) to “hot topic” (5).

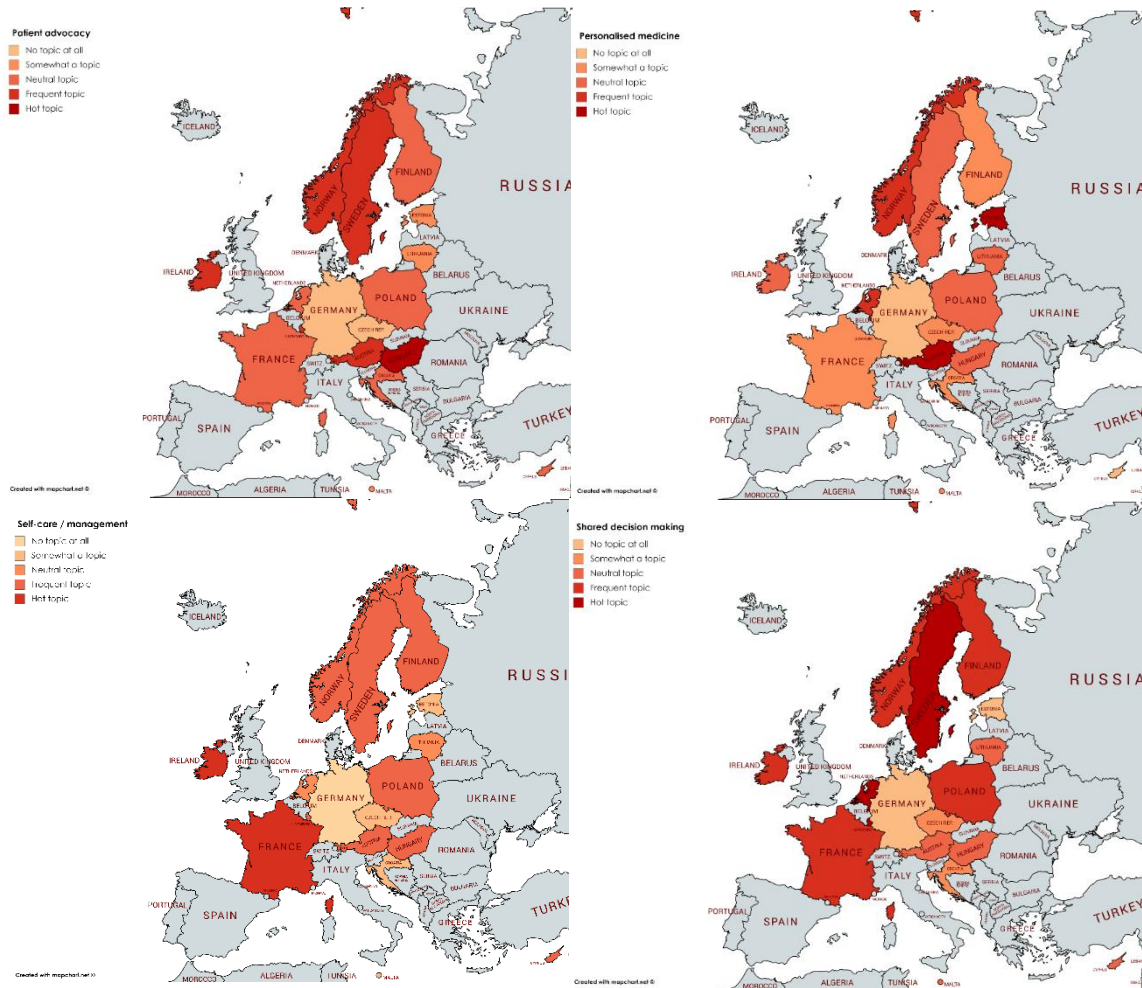


Figure 6. Indication of policy MS for four people empowerment topics

3.6 Patient engagement framework

The patient engagement framework is developed by the HIMSS¹ foundation to guide HCP in developing and strengthening their patient engagement strategies. It consists of six levels of patient engagement, starting with the level of ‘inform me’ and ending with ‘support my e-community’ (appendix 1). In the survey of this WP, the MS were asked to indicate on what level their MS is (figure 7).

¹ HIMSS is a global, cause-based, not-for-profit organization focused on better health through information and technology. HIMSS leads efforts to optimize health engagements and care outcomes using information and technology. HIMSS, headquartered in Chicago, serves the global health IT community with additional offices in the United States, Europe, and Asia, derived from: <https://www.himss.org/himss-faqs>

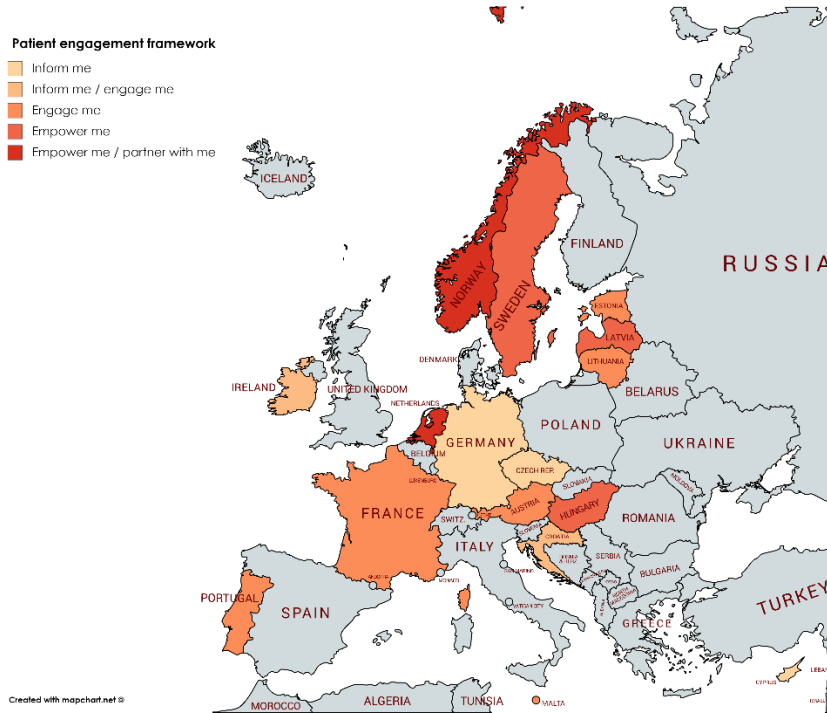


Figure 7. Indication of MS of level on patient engagement framework

Most of the MS (n=6) are on level 3 – engage me. Other MS indicate to be on level 1 (n=3), level 2 (n=2), level 4 (n=3) and level 5 (n=2). None of the MS indicate to be on level 6.

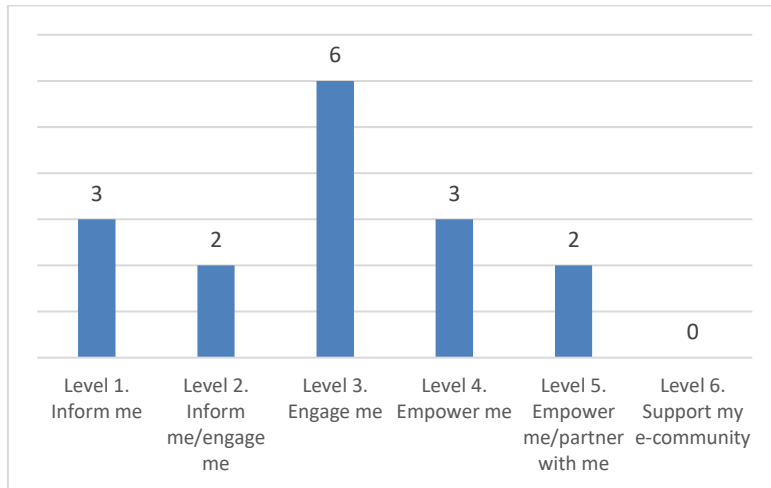


Figure 8. Number of MS on levels of patient engagement framework

3.7 Conclusion

The conclusion will be written in the final version of this deliverable.

4. Gap analysis

[Still in progress; will be completed in the final deliverable for the November eHN meeting]

This chapter depicts the gap between the theoretical and actual state of the art of eHealth for people empowerment among MS.

4.1 mHealth

[in progress]

4.2 Patient access and use of data

[in progress]

Table 13. *[In progress]*

	Theoretical		Actual
	Barriers	Facilitator	
<i>Ability</i>	Age, Socio-economic status, Educational level Lack of computer knowledge, Language barrier Privacy, confidentiality, safety, Information overload, Low literacy	Personal ownership and control of data Involvement of citizens in design digital health literate	
<i>Motivation</i>	Bad design, Liability issues, Resistance to change Preference for personal communication, Unawareness/Apathy/lack of urgency, Expectations f.e. uncertainty of results	Clear vision (aim/purpose/benefits), Trust, Early adopters in network, Readiness to invest in improvement, High expectations of users	
<i>Opportunity</i>	Lack of bandwidth, Availability of technical support, Lack of technology- challenged staff, Costs, Lack of implementation models, Legal and regulatory restrictions, Software speed, Privacy, confidentiality, safety, Infrastructure, No access to computer / internet, When both professionals and users are deployed, users are scaled up more slowly, Complexity of process and the number of players,	Benefits of sharing info for better care, High adoption among organisations, Policy in organisation, Compensation, Involvement of citizens in policy	

	No direct relation with healthcare provider, Interoperability		
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4.3 Digital health literacy

[in progress]

Table 14. [In progress]

	Theoretical		Actual	
	Barriers	Facilitator		
<i>Ability</i>	Less experience with internet, mobile phone Anxiety: computer, internet, privacy, Poor understanding: quality of info, No parental mediation, Low income, Low educational level	Improvement of skills through e-learning, Experience in lifespan, Reading ability, Ability to collect and qualify the data, educating professionals		
<i>Motivation</i>	Reluctance to learning, no confidence with using online information, Negative attitude towards eHealth	Gaining support from others, Trustworthiness, Openness to learning Ease/confidence with using online data, Readability: attractive visual/audio content, Social network		
<i>Opportunity</i>	Distracting information, Lack of info in mother tongue, Overload with information quantity, No access to computer/internet, Less opportunities in rural area	Easily accessible, Cultural relevant information, assessing community support, Provision of resources through networks, Policy/action plan on DHL in HP, Involvement of citizens in policy on DHL, Use of early adopters in HP		

4.4 Telehealth

[in progress]

4.5 Conclusion

The conclusion will be written in the final version of this deliverable.

5. Best practices

[Still in progress; the content is based on 16 completed surveys]

In this chapter the two best practices on mHealth, patient access to and use of data, digital health literacy and telehealth are shown for all MS. Criteria for selection were the scope of implementation (national or local level), the adoption rate, the effectiveness, cost-effectiveness and (expected) outcomes on health or people empowerment.

5.1 mHealth

Ability

1. Zdravlje.net - Croatia².

The applications involve a mobile patient portal that enables patients to directly contact their GP via text based secure channel, to schedule an appointment online, to request a prescription of medication they take in their chronic therapy and to log their measurements of blood glucose and blood pressure. Dom zdravlja Zagreb-Centar has promoted mHealth solutions as a means to reduce administrative burden and promote quality to its employees, has conducted a campaign aimed at patients to adopt the mHealth solutions and has participated in dialogue with actors in regional and national administration to foster the adoption of the mHealth solutions. This has resulted in high adoption rates in some cases, and positive feedback from health workers and patients alike.

2. Omaolo - Finland³.

Omaolo is a national e-service where citizens can assess their own symptoms and social care needs and can send the information to social and health professionals and make appointments based on needs and symptoms. This app supports self-care and self-service as well as improves results, quality, availability and productivity.

Motivation

1. Telia Active - Estonia⁴.

Telia Active involves the integration with activity sensors. Users can report the number of steps and as a motivational package, free internet data is given for steps. The company gives 5 MB of internet for every collected 1000 steps, in total 50 MB per day. This method was found to be very effective and clever to motivate people for moving by giving free internet data.

2. Samengezond – Netherlands⁵.

The Netherlands provides apps by healthcare insurance companies to stimulate citizens in healthy behaviour like the Menzis – Samen gezond.

² <https://dzz-centar.hr/zdravlje-net/>

³ www.omaolo.fi

⁴ <https://active.telia.ee/sammud-internetiks>

⁵ <https://samengezond.menzis.nl/apps/detail/1>

Opportunity

1. The Appsök - Sweden⁶.

Appsök helps people with disability to find apps that support everyday life; the unit for rehabilitation & health at Healthcare Provision Stockholm County is providing a service that manually validates apps on several accessibility areas.

2. Gesundheitsdialog - Austria⁷.

Gesundheitsdialog Diabetes mellitus supports the continuous real-time monitoring of health data from diabetes patients by means of transmission of the data from the medical device via NFC or Bluetooth Low-Energy to the mobile phone and the medical centre. The application serves the need to establish an active informed dialogue between patients and their health professionals. In context of this dialogue the patient's diabetes diary is then discussed and compared with monitored blood glucose levels, medication data, nutrition, physical activity and extraordinary events such as fever. The different parameters are illustrated in easy-to-understand charts or diagrams and examined by the patients together with their health professionals. Patients can recognise and understand trends and patterns between their own health behaviour, physical activity and critical monitored values.

5.2 Patient access and use of data

Ability

1. One People – One Journal programma nbygger - Norway⁸.

The One People – One Journal programme nbygger works to fulfil the government's goal to modernise the ICT platform and a common journal solution for the health and care sector. Necessary health information must follow the patient throughout the patient's course. All stakeholders should have easy, secure access to health data/digital services; for quality improvement, health monitoring, management and research.

2. P1 – the National Health Platform - Poland⁹.

Implementation of the national system *P1 – the National Health Platform* aims to provide access to all Polish citizens to their medical data, enabling them to authorise medical personnel to access their data (e-Prescription, e-Dispensation, e-Referral, Internet Patient's Account).

Motivation

1. myHealth - Malta¹⁰.

Some Maltese citizen need to be able to access their own health data without having a very high degree of digital literacy, using an application that is as easy to use as popular social media (such as Facebook), but without compromising privacy or security. 'myHealth' aims to provide user-friendly access, even using mobile devices, without all users having to have

⁶ <https://www.appsok.se/om-appsok>

⁷ <http://www.ge-breitenstein.at/e-health/gesundheitsdialog-diabetes>

⁸ https://www.eiseverywhere.com/file_uploads/e1508f0c5a68501b5071a8ce1d466eb6_170221_HDC_Lunch_Bergland.pdf

⁹ <https://pacjent.gov.pl>

¹⁰ www.myhealth.gov.mt

a high level of digital literacy. Maltese citizens are generally well motivated to take good care of their health; this motivation is increased through myHealth.

2. My Kanta - Finland¹¹.

My Kanta is a national health data portal which has legal basis. It has an obligation to work 24/7. Healthcare staff are obliged to share information about it with patients. My Kanta provides citizens free online access to their own medical records and electronic prescriptions that are archived in Kanta Services from public and private healthcare services. Citizens can send prescription renewal requests, receive consent-related information, give their consents and restrict them, and give their living wills and organ donation wills. Citizens can also view and delete their own health and wellbeing data which they have entered into the national personal health record through the wellbeing applications. My Kanta pages are available to all citizens who have a Finnish ID number and an electronic identifier for logging into the service. Guardians can check data of their children under the age of 10. A person's right to act on behalf of a minor is based on the relationship of the person to the child. Information on the relationship status between a guardian and a minor is recorded in the National Register (The Finnish Population Information System¹²). In 2018, My Kanta pages were used by over 38% of the population.

Opportunity

1. VIPP - The Netherlands¹³.

VIPP is an implementation programme to give patients access to their own medical data. VIPP aims to achieve that all patients have digital access to their own data (consultation information, lab or other research results, specialist letters and medication data). VIPP is an implementation programme; hospitals, rehabilitation centres and categorical institutions¹⁴ participate in this programme. Patients are better informed about their own health. Health professionals can expect a patient who is better able to think along and decide in treatment processes. VIPP was developed by the Dutch Federation of hospitals, in collaboration with the Ministry of Health, Welfare and Sport (VWS). An institution can apply for an assessment on achieved results by a certified audit firm. (A handbook has been written for the final test, stating how the assessment takes place. This handbook can be found on the website of the national government). The implementation runs until December 2019.

2. MedMij - The Netherlands¹⁵.

MedMij offers the solution for digitally sharing data with the patient. The MedMij Appointment System ensures that a healthcare provider does not have to make separate links with all available personal health environments. The information exchange is standardised and safety requirements are met. MedMij aims to provide everyone who wants it with their own health data in one personal health environment. Such an environment - an app or website - must be able to communicate with the care information systems of healthcare providers in a secure and familiar way. MedMij sets the rules for this.

¹¹ <https://www.kanta.fi/en/my-kanta-pages>

¹² <http://vrk.fi/en/population-information-system>.

¹³ <https://www.vipp-programma.nl/>

¹⁴ Institutions focused on specific diseases or patients.

¹⁵ <https://www.medmij.nl/>

5.3 Digital health literacy

Ability

1. Joint development initiated in the Connected Health Cluster - Estonia¹⁶.

Educational programme for physicians to make them “smart customers”, a programme initiated in the Connected Health Cluster. The aim is to improve digital skills among physicians.

2. Online eHealth learning platform - Lithuania¹⁷.

Centre of Registers has established an online eHealth learning platform to support both health professionals and patients. Platform contains text information and videos on how to access and use health data. In addition, Centre of Registers regularly organises training for health professionals. Citizens need to have access to internet to acquire skills and knowledge for health literacy.

Motivation

1. Digital Strategy - Sweden¹⁸.

Strategy for digitalisation is divided into five goals. The first goal is to increase the ability of citizens to use mHealth solutions: Digital skills - The digital skills goal entails everyone being familiar with digital tools and services and having the ability to follow and participate in the digital transformation based on their own situation.

2. MySNS Seleção - Portugal¹⁹.

Citizens are motivated to obtain, process and understand health literacy due to the need of the modern world that demands a proactive approach to gain more knowledge on health to make appropriate decisions and preferably through a reliable and easy channel on the internet that deals with the topics on health literacy (digital motivation). There are also other initiatives such as (1) digital platforms for improving the knowledge on health (2) the integration of robotics and computing in the primary school curriculum.

Opportunity

1. eHealth4all - The Netherlands²⁰.

The eHealth4all programme is initiated by Pharos. This programme includes instruction and materials for developers and users of eHealth on digital health literacy. The aim is to encourage and support developers of eHealth and healthcare providers on digital health literacy, to make websites, apps and other eHealth applications understandable and usable for everyone, including people with a low level of education, limited health skills or a migrant or refugee background.

2. De Kijksluis²¹ / Beeldsluis²² - The Netherlands.

¹⁶ <https://ttu.ee/taiendusoppijale/koolituskalender/algavad-koolitused/algavad-koolitused-2/?id=26999&koolitus=9315>

¹⁷ <http://mokymai.esveikata.lt/pranesimai-ir-naujienos-pacientams>

¹⁸ <https://www.government.se/information-material/2017/06/fact-sheet-for-sustainable-digital-transformation-in-sweden--a-digital-strategy/>

¹⁹ <http://mysns.sns.gov.pt/mysns-selecao/>

²⁰ <https://www.pharos.nl/over-pharos/programmas-pharos/ehealth4all/>

²¹ <https://stichtingkijksluiser.nl/>

²² <https://www.beeldsluiser.nl/>

“De Kijksluiters” is a library of 5,000 animated videos, in which the most important information from the package leaflet of a medicine is explained in understandable spoken language. “De Kijksluiters” is developed for citizens to access this at home. Kijksluiters is available in several languages. De “Beeldsluiter” is a visual leaflet. It is a leaflet with information on the medication, presented through a video. In order to watch a visual leaflet you require by law an RVG-code or EU-number. This can be found on the casing of the medicine.

5.4 Telehealth

Ability

1. Luscii platform – the Netherlands²³.

Many countries have platforms, or health portals with access to healthcare services. The services can be to make an appointment with your doctor, having access to your own EHR or reading your lab results. Some platforms are specifically designed for the monitoring of chronic diseases, such as the Luscii platform from the Netherlands. The Luscii platform is a digital health platform created to support health professionals in the daily care of their patients. Luscii gives the ability to HP to monitor their patients at home and communicate with them remotely. It has a lot of usage within the country, since half of the hospitals are using this tool and it is supported by 94% by insurance companies.

2. Dignio – Norway²⁴.

The other telehealth service is from Norway, called Dignio. With the Dignio system, the health services are delivered where the patient is. The patient receives a tablet with the MyDignio app along with relevant measuring equipment. The patient performs fixed measurements, responds to clinical questions and registers symptoms. The results are automatically transferred to the Dignio Prevent clinical decision support system. Health personnel follow up the values that come in and provide individual follow-up. The patient acquires knowledge of his or her own health and illness and can make well-founded choices in daily life. The system is mobile and independent. With the solution, health personnel and patients have a secure communication tool and the open patient record provides the patient with knowledge and control in his or her own life.

Motivation

1. The MUDA initiative – Portugal²⁵.

This is a good example of cooperation between very different stakeholders in Portugal to work together to help and encourage citizens to increase their motivation to use digital services.

2. CSAM – Norway²⁶.

²³ <https://luscii.com/>

²⁴ <https://www.dignio.no/helseoppfolging>

²⁵ <http://www.meiosepublicidade.pt/2017/03/initiative-muda-imagem/>

²⁶ <https://www.csamhealth.com/>

This is a promising and motivational telehealth practice to connect citizens/patients with healthcare providers. CSAM is a comprehensive self-care and health counselling solution that simplifies the interaction between patients and their healthcare provider. The platform includes user and professional portals, as well as mobile applications. It is currently used by service providers in the public, private, social care and welfare sectors.

3. Braster - Poland²⁷.

With respect to motivation, Braster is an interesting practice to empower women and give them a tool for self-care and self-control. With Braster a woman can prevent breast cancer – in-home breast examination system. Braster detects the thermal changes associated with the development of breast cancer: vascularisation of tumours and their faster metabolism. Intuitive application makes it easy for women to perform the examination every month.

Opportunity

1. Digital services – Portugal.

To have a national policy regarding the use of digital services throughout the country is an advantage. It motivates citizens to use digital services provided by all agencies or private companies in many areas of their lives. Portugal has an Agency (Agency for Administrative Modernisation) that is responsible for modernising the administrative sector by promoting and developing programmes that are used by other agencies in the country. Digital services provided by the Ministry of Health is part of such a programme.

2. Sunnaas hospital – Norway²⁸.

Sunnaas hospital in Norway has used telemedicine as an integrated part of their treatment in all clinics for close to 10 years. Videoconferences are used in many scenarios like: interdisciplinary collaboration meetings, in consulting specialists in other hospitals, and follow-up video conferencing when the patient has returned home. A cost-benefit analysis of a telemedicine pressure ulcer project showed that¹: a. video consultation accounts for only 15% of the cost compared to the attendance clinic. b. video consultation accounts for only 3.2% of the costs compared to admission. The success factors at Sunnaas hospital when implementing telehealth solutions have been:² Key personnel / enthusiasts: + Own posts that facilitate operations and development, + Systematic work at team / service level, + Anchoring in management over time.

3. ePerearstikeskus – Estonia²⁹.

The third practice found with respect to the opportunities under the AMO model is the ePerearstikeskus, a Self-Care Portal from Estonia. The Perearstikeskus is a digital GP office provided to GPs and patients. Patients can set and change visit time, ask questions from GPs, request recurring prescriptions, request health certificates, and close sick leave certificates. This self-care portal is used among patients and doctors in 12 different family physician clinics for safer communication.

²⁷ <https://www.braster.eu/en>

²⁸ <https://www.sunnaas.no/sunnaas-rehabilitation-hospital>

²⁹ <https://www.eperearstikeskus.ee/patient/>

4. CarnaLife – Poland³⁰.

The last best practice is CarnaLife, an AI-based analytical telemedicine portal from Poland. It enables patients to record the results of medical examinations and, as a result, quicker analysis by specialists. It is a CE marked solution for medical specialists. Data analysis is performed based on intelligent algorithms that interpret and prioritize results requiring immediate intervention by doctors. CarnaLife is a software developed by MedApp S.A., a Polish IT company launched in 2015 with international achievements and awards.

5.5 Conclusion

The conclusion will be written for the final version of this deliverable.

³⁰ [\[https://www.carnalife.io/en\]](https://www.carnalife.io/en)

References

1. Multiannual Work Programme 2018-2021
https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20171128_co01_en.pdf
2. European Commission (2017) JAseHN 7.5.1: REPORT on EU State of Play of Patient Access to eHealth Data.
3. European Patients' Forum <http://www.eu-patient.eu/whatwedo/Policy/patient-empowerment/>
4. WHO (2009) Guidelines on Hand Hygiene in Health Care: First Global Patient Safety Challenge Clean Care Is Safer Care.
5. WHO https://www.who.int/goe/publications/goe_mhealth_web.pdf (mHealth)
6. European Commission. Chain of Trust. 2013. Understanding patients' and health professionals' perspective on telehealth and building confidence and acceptance. <http://www.eu-patient.eu/globalassets/projects/chainoftrust/epf-report-web.pdf> (Telehealth)
7. WHO <https://www.who.int/ehealth/en/> (eHealth definition)
8. Appelbaum, E. Bailey, T. Berg, P. & Kalleberg, A. (2000) Manufacturing advantage: Why high- performance work systems pay off. Ithaca, Cornell University Press
9. Eysenbach, G., 2001. What is eHealth? Journal of Medical Internet Research, 3(2), e20
10. Kao H-Y., Wei C-W., Yu M-C., Liang T-Y., Wu W-H. & Wu Y.J. 2018. Integrating a mobile health application for self-management to enhance Telecare system. Telematics and informatics 35, 815–825.
11. Lai A. M., Hsueh P.-Y.S., Choi Y. K., Austin R. R. "Present and Future Trends in Consumer Health Informatics and Patient-Generated Health Data." IMIA Yearbook of Medical Informatics (2017).
12. Paglialonga A, Lugo A, Santoro E. "An overview on the emerging area of identification, characterization, and assessment of health apps." Journal of Biomedical Informatics 83 (2018): 97-102.
13. Ammenwerth, E. "From eHealth to ePatient: The Role of Patient Portals in Fostering Patient Empowerment." EJBI (2018): Vol. 14(2): 20-23.
14. Pierce B., Twohig M.P. & Levin M.E. 2016. Perspectives on the use of acceptance and commitment therapy related mobile apps: Results from a survey of students and professionals. J of Contextual Behavioral Science 5(4) 215–224.
15. Chen J., Lieffers J., Bauman A., Hanning R. & Allman-Farinelli M. 2017. The use of smartphone health apps and other mobile health (mHealth) technologies in dietetic practice: a three countries study.
16. Hoj T.H., Covey E.L., Jones A.C., Haines A.C., Hall P.C., Crookston B.T. & West J.H. 2017. How Do Apps Work? An Analysis of Physical Activity App Users' Perceptions of Behavior Change Mechanisms. JMIR mHealth and uHealth 5(8) E114.
17. Carter C.D., Robinson K., Forbes J. & Hayes S. Experiences of mobile health in promoting physical activity: A qualitative systematic review and meta-ethnography. Plos One 13(12)
18. Ziefle M., Klack L., Wilkowska W. & Holzinger A. 2013. Acceptance of telemedical treatments – A medical professional point of view. Berlin. Int. conference on human interface and the management of information 21–26, 325–334.
19. Tavares J., Oliveira T. New Integrated Model Approach to Understand the Factors That Drive Electronic Health Record Portal Adoption: Cross-Sectional National Survey. <https://www.ncbi.nlm.nih.gov/pubmed/30455169> J Med Internet Res. 2018 Nov 19;20(11): e11032. doi: 10.2196/11032.
20. Goldzweig CL, Orshansky G, Paige NM, Towfigh AA, Haggstrom DA, Miake-Lye I, Beroes JM, Shekelle PG. Electronic patient portals: evidence on health outcomes, satisfaction,

- efficiency, and attitudes: a systematic review. *Ann Intern Med.* 2013 Nov 19;159(10):677-87.
21. Verstraete E, Koehorst AM, van Os-Medendorp H. Does the patient benefit from real-time access to one's electronic record? Evaluation of the patient portal in University Medical Centre Utrecht, the Netherlands. *Ned Tijdschr Geneeskd.* 2016;160: D325. Dutch.
 22. Irizarry, T, DeVito Dabbs A, Curran CR 2015 Patient Portals and Patient Engagement: A State of the Science Review. *J Med Internet Res.* 2015 Jun 23;17(6): e148. doi: 10.2196/jmir.4255.
 23. Risling, T, Martinez, J, Yong, J, Thorp-Frosilie N. Defining Empowerment and Supporting Engagement Using Patient Views From the People Health Information Portal: Qualitative Study 2017 *JMIR Med Inform.* 2018 Sep 10;6(3): e43.
 24. Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *J Med Internet Res.* 2015 Feb 10;17(2): e44.
 25. Kruse CS, Kristof C, Jones B, Mitchell E, Martinez A, (2016). Barriers to Electronic Health Record Adoption: a Systematic Literature Review.
 26. Vishwanath A., Scamurra SD., (2007). Barriers to the adoption of electronic health records: using concept mapping to develop a comprehensive empirical model. *Health Informatics Journal*, 13(2), 119-134.
 27. Asan O., (2017). Providers' perceived facilitators and barriers to EHR screen sharing in outpatient settings. *Applied ergonomics*, 58, 301-307.
 28. Powell KR. Patient-Perceived Facilitators of and Barriers to Electronic Portal Use: A Systematic Review. *Comput Inform Nurs.* 2017 Nov;35(11):565-573.
 29. European Commission, Flash Eurobarometer 404 European Citizens Digital Health Literacy, November 2014, available at: http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_404_en.pdf
 30. Chesser, AK., Keene Woods, N., Smothers, K. & Rogers, N. (2016). Health Literacy and Older Adults: A Systematic Review. *Gerontology & geriatric medicine*, 2.
 31. Jacobs, RJ, Lou, JQ., Ownby, RL. & Caballero, J. (2014) A systematic review of eHealth interventions to improve health literacy. *Health Informatics Journal* 1–18.
 32. IC-Health 2019. Improving digital health literacy through MOOCs. <https://ichealth.eu/the-project/partners/> (Jan 2019)
 33. Kvedar J, Coye MJ, Everett W. Connected health: a review of technologies and strategies to improve patient care with telemedicine and telehealth. *Health Aff Proj Hope.* 2014 Feb;33(2):194–9.
 34. Epstein RM, Fiscella K, Lesser CS, Stange KC. Why the nation needs a policy push on patient-centered health care. *Health Aff (Millwood).* 2010 Aug;29(8):1489–95
 35. Goetz M, Muller M, Matthies LM, Hansen J, Doster A, Szabo A, et al. Perceptions of Patient Engagement Applications During Pregnancy: A Qualitative Assessment of the Patient's Perspective. *JMIR MHealth UHealth.* 2017 May 26;5(5): e73
 36. Birkhoff SD, Smeltzer SC. Perceptions of Smartphone User-Centered Mobile Health Tracking Apps Across Various Chronic Illness Populations: An Integrative Review. *J Nurs Scholarsh Off Publ Sigma Theta Tau Int Honor Soc Nurs.* 2017 Jul;49(4):371–8.
 37. Hamine S, Gerth-Guyette E, Faulx D, Green BB, Ginsburg AS. Impact of mHealth chronic disease management on treatment adherence and patient outcomes: a systematic review. *J Med Internet Res.* 2015;17(2).
 38. Nissen L, Lindhardt T. A qualitative study of COPD-patients' experience of a telemedicine intervention. *Int J Med Inf.* 2017 Nov; 107:11–7
 39. Devi BR, Syed-Abdul S, Kumar A, Iqbal U, Nguyen P-A, Li Y-CJ, et al. mHealth: An updated systematic review with a focus on HIV/AIDS and tuberculosis long term management using mobile phones. *Comput Methods Programs Biomed.* 2015 Nov;122(2):257–65.

40. Mathavakkannan S, Bowser M, Doyle S, Hoare A, Rehsi G. Promoting patient empowerment and sustainability in kidney care using telemedicine. *Int J Integr Care*. 2014;14(8).
41. Barello S, Triberti S, Graffigna G, Libreri C, Serino S, Hibbard J, et al. eHealth for Patient Engagement: A Systematic Review. *Front Psychol*. 2015; 6:2013
42. Deloitte, 2016. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/public-sector/us-fed-empowering-patients-with-telehealth.pdf>)
43. <http://www.carewell-project.eu/home.html>
44. Healthcare innovation, Heather Landi, June 19, 2017, <https://www.hcinnovationgroup.com/population-health-management/telehealth/news/13028790/survey-77-percent-of-consumers-interested-in-virtual-doctor-visits>.

Appendix 1. Patient engagement framework

