



## **D4.1 - Policy Framework on People Empowerment**

### **WP4 - Empowering People**

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To pave the way for a European policy proposal on people empowerment, this framework proposes an analytical approach to empowering people through digital health, and maps common issues to be addressed at Member State and EU level.

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### 3. Acronyms

Acronym	Description
AI	Artificial intelligence
AMO	Ability, Motivation, Opportunity model
COPD	Chronic Obstructive Pulmonary Disease
CVD	Cardiovascular Disease
D4.1	Deliverable 4.1 Patient Empowerment Framework
D4.2	Deliverable 4.2 Patient Empowerment Policy Proposal
DHL	Digital Health Literacy
EC	European Commission
ECDC	European Centre for Disease Control
EESC	European Economic and Social Committee
eHAction	eHealth Action
eHEALS	eHealth Literacy Scale
eHealth	Electronic Health
eHN	eHealth Network
EHR	Electronic Health Record
EMA	European Medicines Agency
ePAG	European Patient Advocacy Group
EPF	European Patients' Forum
ERN	European Reference Network
EU	European Union
EURORDIS	Rare Diseases Europe: a non-governmental patient-driven alliance of rare disease patient organisations
GP	General Practitioner
HCP	Health Care Provider
HEN	Health Evidence Network
HIMSS	Healthcare Information and Management Systems Society
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
N.A.	Not Applicable
NCC	National Competence Centre
NFC	Near Field Communication

NGO	Non-Governmental Organisation
NHS	National Health Service
NICE framework	National Initiative for Cybersecurity Education Framework
PCWP	Patient and Consumer Working Party
RVG-code	Register Verpakte Geneesmiddelen (Anatomical Therapeutic Chemical code / ATC- code)
SKIL	Senter for kvalitet i legekontor (Centre for Quality Development in Medical Offices)
WHO	World Health Organization
WP	Work Package
WP4	Work Package 4 - People Empowerment

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## 6. Executive summary

An ageing population combined with a growing prevalence of chronic diseases has resulted in an increased need for healthcare and requires countries to focus more on prevention and early diagnosis with the aim to improve the quality of life. Furthermore, as medicine has advanced, so have there been developments in the role of the patient. Today's patients expect to be treated as partners in their healthcare journey, taking a more active role in managing their own health. To meet this need, governments need to put more emphasis on empowering people.

The European Patients' Forum defines empowerment as "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". Digital health has an important role to play in this process. People need to be informed and provided with the right digital means, as well as possess adequate digital health skills in order to take control of their health. To help meet this need, the eHealth Network adopted "Empowering People" as one of its four key priorities to be tackled by the Multiannual Work Programme 2018-2021.

Based on that mandate, this policy framework sets out to clarify the role of digital health in people empowerment and identify and explain gaps in its usage to this end. It is intended to guide the thinking of MS in identifying key priorities that will form the basis of our recommendations. The four focus areas of the framework are **mHealth, telehealth, patient access and use of data** and **digital health literacy**, all of which are considered essential for an empowered population. The framework paves the way for a policy proposal, to be presented in November 2020 to the eHealth Network. The policy proposal shall include recommendations for Member States on activities to ensure comprehensive application of digital health for the empowerment of people. These recommendations shall be presented to the Member States represented in the eHN and are to be considered for adoption.

The drafting of this framework broadly took place in three stages. In the first stage, desk research was conducted to identify relevant studies and other written materials on digital health for people empowerment. Key learning points were extracted from these materials that now form the basis of chapters 1 and 2, providing evidence on how the four focus areas can contribute to the empowerment of people. The AMO model was used to guide the thinking process, considering empowerment a process dependent upon the Abilities, Motivations and Opportunities afforded to people. In the second stage, a MS survey was carried out to gain insight into the current state of play in MS when it comes to applying digital health for patient empowerment. The survey also set out to identify common barriers and enablers that affect the four focus areas. The survey responses, provided by a wide range of stakeholders from 19 MS, form the basis of chapter 3. In the final stage, an analysis was conducted, comparing theory to practice and extrapolating key conclusions identifying the need for further work. Feedback and contributions were solicited at each stage from a broad range of Member States that together represent the eHAction consortium.

The framework confirms that mHealth, telehealth, patient access & use of data and digital health literacy have all been shown to contribute to patient empowerment by increasing patients' ability, motivation and opportunity to become involved with and participate actively in their own health.

# 1. Background

This policy framework is a deliverable of eHAction Work Package 4 (WP4) – Empowering People, led by Estonia (MoSA) and the Netherlands (Nictiz). The four topics of this policy framework on empowering people are mHealth, telehealth, patient access and use of data, and digital health literacy. In order to understand the relation and influences among these topics and to empowering people, the scope, definition and relations are defined in this chapter. The drafting of this framework broadly took place in three stages: desk research, survey and analysis. More information on the methodology used is provided in appendix 1.

## 1.1 Purpose

eHAction is a Joint Action of the Member States (MS) supporting the eHealth Network (eHN) and the third Multiannual Work Programme (MWP 2018-2021)<sup>1</sup>. People empowerment is one of the four priority areas in this MWP. Ageing populations and a growing prevalence of chronic diseases result in increased healthcare demand and a need to focus more on prevention and early diagnosis with the aim to improve quality of life. Empowering people with the aid of digital health services helps to achieve this. People 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. 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 supported self-management of citizens with chronic 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 (HP)<sup>2</sup>.

This policy framework describes the current and desired state of play with regard to people empowerment through eHealth across MS. It proposes a framework to advance the use and adoption of eHealth in order to achieve higher levels of people empowerment. The framework will result in a policy proposal (D4.2) for MS and Europe. It is aligned with the strategic goal of the eHN to work towards the implementation of patient-centred eHealth solutions in all MS and to equip people with the adequate digital tools and skills for people empowerment.

## 1.2 Scope and definitions

The scope of this deliverable focuses on four topics: mHealth, telehealth, patient access and use of data and digital health literacy.

**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<sup>3</sup>. Patients are, by definition, already considered 'ill'. Gaining control over decisions and actions affecting health is important for many more people than just patients. With a patient also comes a healthcare worker, a caregiver, family and many other roles that are not included within the term 'patients'. Furthermore, the 'healthy' part of the population should be able to express needs and concerns regarding their health as well. In this way their health can be maintained. It is therefore important to include all the roles

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1 Multiannual Work Programme 2018-2021. [https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev\\_20171128\\_co01\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20171128_co01_en.pdf)

2 Eysenbach, G., 2001. What is eHealth? Journal of Medical Internet Research, 3(2), e20

3 European Patients' Forum <http://www.eu-patient.eu/whatwedo/Policy/patient-empowerment/>

of the population involved with either health or illness. Therefore, the terms 'people' and 'people empowerment' will be used throughout this document.

**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. The World Health Organization (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"<sup>4</sup>.

**Telehealth** encompasses the delivery of healthcare services by HPs using ICT to provide clinical and non-clinical services – preventive, promotive and curative healthcare services, research and evaluation, health administration services<sup>5</sup>.

**Patient access and the use of data.** The European Patients' Forum (EPF) provides a detailed definition of patient access by basing it on 5 A's – Adequate, Accessible, Affordable, Appropriate and Available. In this report patient access and use of data refers to people having access to their own online health data from e.g. electronic health records (EHR). The 5 A's are prerequisites to give patients access to their online data. In the policy framework at hand patient access and use of data is seen as a follow-up action; once accessing their health data online, they can use their data by for example changing, modifying, improving, deleting it<sup>6</sup>. Accessing and using health data is not limited to patients. People with good health should be able to access and use their data as well.

**Digital health literacy (DHL)** – for Task 4.3 digital literacy will be defined as the ability of people to seek, find and access online data and information. Health literacy will be defined as the ability of people 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. The combined definition of digital health literacy refers to the ability of people 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<sup>7</sup>.

## 1.3 Relations between the topics

The above topics all have to do with people empowerment in different ways. In an ideal situation, empowered people:

- have the requisite skills to use digital tools for their health, e.g. digital and health literacy (ability);
- have the motivation to take action on and care of their own health, e.g. access and use their health data (motivation);
- have the requisite digital solutions to guide them, e.g. mHealth and telehealth (opportunity).

People are empowered when all of the above elements are fulfilled as each of them influence and are dependent upon each other (figure 1).

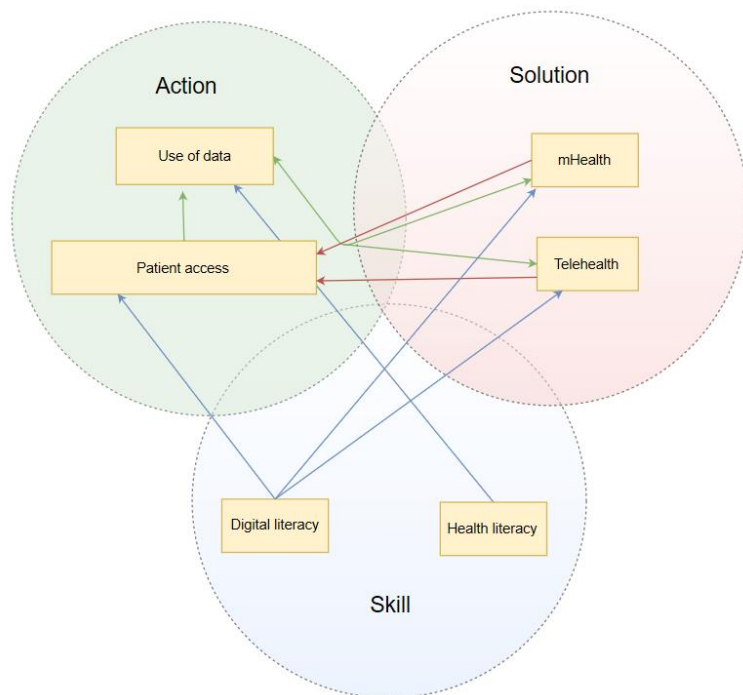
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<sup>4</sup> WHO [https://www.who.int/goe/publications/goe\\_mhealth\\_web.pdf](https://www.who.int/goe/publications/goe_mhealth_web.pdf) (mHealth)

<sup>5</sup> 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)

<sup>6</sup> <http://www.eu-patient.eu/News/News/epf-position-paper-on-access-from-the-patients-perspective/>

<sup>7</sup> Norman, C.D. & Skinner, H.A.(2006). eHealth Literacy: Essential Skills for Consumer Health in a Networked World. Retrieved from: <https://www.jmir.org/2006/2/e9/?xml>



**Figure 1. WP4 topics categorisation and relations**

## 1.4 Personas

Empowering people is ultimately about the people: their status, needs and capabilities, all of which need to be taken into account when developing digital health. In order to further clarify experienced and perceived issues with accessing, receiving and improving digital health, ‘personas’ are used in this framework. The personas are based on the “Blueprint on Digital Transformation of Health and Care for the Ageing Society”<sup>8</sup>, which has developed 12 unique personas based on their needs, age and employment status. Three personas (Rose, Nikos and Jacqueline) were selected and elaborated for the purposes of this framework, as they span the matrix from least to most health needs. This framework considers it important to address empowering solutions to both patients with existing conditions (e.g. Jacqueline) and also those who are not yet considered “patients” (e.g. Rose) and for whom empowerment is an important lever in prevention. Similar personas may be used by MS when planning digital health interventions, to better consider the particularities of the people that they seek to empower.

<sup>8</sup> eHAction WP4 took as a reference the European “Blueprint on Digital Transformation of Health and Care for the Ageing Society”. Adapting the reference of the European Blueprint to our approach, WP4 uses three personas (Rose, Nikos and Jacqueline) (table 1) in order to understand the demand-side perspective and to indicate that different patients have different health concerns and aspects and therefore different needs and solutions that could help.

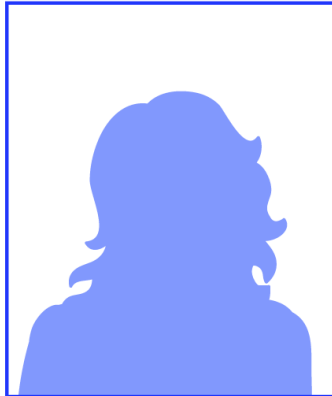
## ROSE, 10



### NEED STATUS

Generally Well

Good Wellbeing



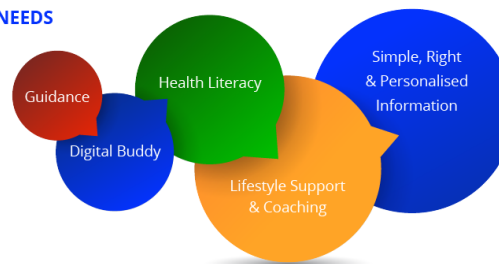
### HEALTH CONCERNS

- Inappropriate food intake; overweight
- Emotional eating (e.g. eating sweets when anxious)
- Risk of continuing to live an unhealthy lifestyle

### IMPORTANT ASPECTS

- Classmates make fun of her because of her weight
- Rose experiences frustration about her weight, which she sometimes takes out on friends and family

### NEEDS



### HOW CAN IT BE PROVIDED?

- mHealth tools and games
- Social aspect is important - networks
- Patient portal = advice
- Support for parents

Figure 2. Persona Rose

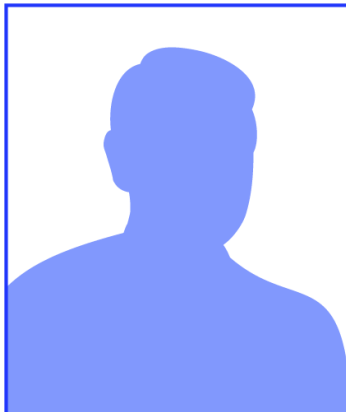
## NIKOS, 50



### NEED STATUS

Chronic Conditions

Social Care



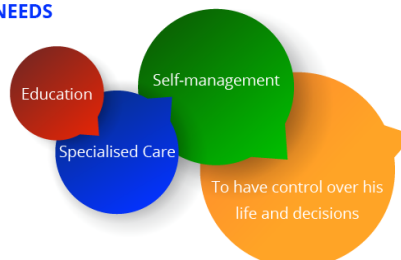
### HEALTH CONCERNS

- Diabetes, hypertension (high blood pressure), mild COPD
- Dyslipidaemia (abnormal amount of lipids in the blood)
- Occasional smoker, has been trying to quit smoking via nicotine gums/patches or medication for the past two years.
- Family history of cardiovascular disease (CVD)

### IMPORTANT ASPECTS

- He has non-routine work, which makes it difficult for him to follow his medication and lifestyle intervention (exercise, food) properly
- He is stressed from having to work more due to the financial crisis
- His care professional specialists can only meet him periodically because he lives too far away
- His dietitian has a private practice and Nikos cannot afford to cover the dietitian's fees for a consistent care plan

### NEEDS



### HOW CAN IT BE PROVIDED?

- Information about different options
- Advice
- Telehealth tools and remote monitoring; websites
- Affordable care
- Tools for self-management
- Reminders about medications
- Coaching, social connection with friends
- Behavioural change support

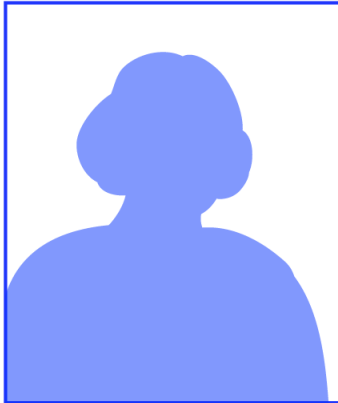
Figure 3. Persona Nikos

## JACQUELINE, 87



### NEED STATUS

Complex Needs



### HEALTH CONCERNS

- Several strokes
- Subject to falls
- Increasingly severe memory loss and cognitive disorders (hallucinations, anxiety)
- Hypertension (40+ years)
- Osteoporosis, Osteoarthritis
- Incontinence (2+ years)
- Breathing difficulties (breathlessness)

### IMPORTANT ASPECTS

- No longer able to get around and cope with basic daily living activities
- Seldom goes out, prefers to spend the time in her armchair sleeping
- Has had chronic pain for many years, sleeps badly
- Has mobility problems and all activities take a long time
- Her husband prepares basic meals; he does not sleep well due to Jacqueline wandering at night

### NEEDS

- Staying at home, being clean and happy
- Husband needs peace of mind

### HOW CAN IT BE PROVIDED?

- Remote access to healthcare providers
- Detection of adverse events (wearables, sensors > warnings)
- Assistance (HCP, social worker, other specialist)
- Medication tracking

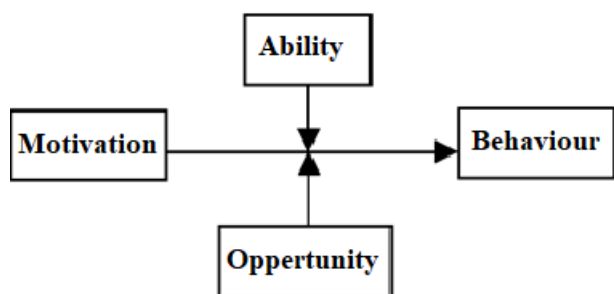
**Figure 4. Persona Jacqueline**

## 7. Theoretical state of play

In this chapter the four topics are described by two theoretical concepts, namely the *Ability, Motivation, Opportunity (AMO) Framework*, and *barriers and enablers for adoption*. An analysis of the literature, including work from previous initiatives such as the Joint Action to support the eHealth Network (JAseHN), has been performed in order to provide a theoretical overview of the AMO framework and the barriers and enablers for mHealth, telehealth, patient access and use of data, and digital health literacy.

### 2.1 AMO framework

Empowering people permits them to gain control of their health and increases their capacity to act on issues they consider important. By introducing the AMO framework, the underlying elements (AMO) influencing the behaviours of empowered people can be explained<sup>9</sup>. Thus behaviour can be managed by enhancing individuals' levels of the AMO elements<sup>10</sup>.



**Figure 5. AMO framework**

The three elements of the AMO framework are ability, motivation and opportunity<sup>11</sup>:

**Ability** refers to the extent to which people have the necessary competences (e.g. knowledge and skills) in order to achieve a certain outcome. It represents the capacity to perform, and it is dependent upon variables such as age, knowledge and intelligence. In this context it is the ability of people to engage in their own or others' health. A lack of ability implies that knowledge structures necessary to perform more complex operations either do not exist or cannot be accessed. If, for example, the ability to access and use information is low, patient data is uninterpretable.

**Motivation** is the desire or the action of people to gain and retain control over their own health and/or the ones they care for. Motivation incorporates readiness, willingness, interest and desire to engage. In the context of this policy framework, motivation is defined as people's desire or readiness to engage in their own or others' health.

**Opportunity** reflects the extent to which a situation is conducive to achieving a desired outcome. In this context it refers to the availability and accessibility of solutions provided, as well as the

<sup>9</sup> Appelbaum, E. Bailey, T. Berg, P. & Kalleberg, A. (2000) Manufacturing advantage: Why high-performance work systems pay off. Ithaca, Cornell University Press

<sup>10</sup> MacInnis et al. (1991). Enhancing and Measuring Consumers' Motivation, Opportunity, and Ability to Process Brand Information From Ads. Retrieved from: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.625.7542&rep=rep1&type=pdf>

<sup>11</sup> Gruen, T.W. et al. (2005). How e-communities extend the concept of exchange in marketing: An application of the motivation, opportunity, ability (MOA) theory. Retrieved from: [https://www.researchgate.net/profile/Thomas\\_Gruen/publication/247756303\\_How\\_e-Communities\\_Extend\\_the\\_Concept\\_of\\_Exchange\\_in\\_Marketing\\_An\\_Application\\_of\\_the\\_Motivation\\_Opportunity\\_Ability\\_MOA\\_Theory/links/0deec53cd486469631000000/How-e-Communities-Extend-the-Concept-of-Exchange-in-Marketing-An-Application-of-the-Motivation-Opportunity-Ability-MOA-Theory.pdf](https://www.researchgate.net/profile/Thomas_Gruen/publication/247756303_How_e-Communities_Extend_the_Concept_of_Exchange_in_Marketing_An_Application_of_the_Motivation_Opportunity_Ability_MOA_Theory/links/0deec53cd486469631000000/How-e-Communities-Extend-the-Concept-of-Exchange-in-Marketing-An-Application-of-the-Motivation-Opportunity-Ability-MOA-Theory.pdf)



involvement of people in the process. A lack of opportunity can for example arise when the right digital tools to gain control over one's own health do not exist or are inaccessible to those who need them, because of a lack of connection availability.

The document at hand poses two things:

1. The three elements are a prerequisite for an action to occur where lower scores of the elements reduce action and higher scores improve action. Whether an element is high or low in score differs from person to person. High scores of the elements are needed to get empowered people.
2. There is a strong dependency between the elements. The mutual influence they have on each other will depend on the personal situation. Consider, for example, Rose using mHealth applications to take care of her health. If Rose is not able to access an mHealth application because she does not *know* how to download the application (low ability), she may also be less *motivated* to do so because she perceives that doing this is more difficult for her. Again, how ability, motivation and opportunity interact to influence a particular person's level of empowerment is highly individual.

The table provides a non-exhaustive overview of the actions that increase the ability, motivation and opportunity for the chosen personas Rose, Nikos and Jacqueline.

	Rose	Nikos	Jacqueline
<b>Ability</b>	Rose needs to increase her health literacy by having support from her parents and a digital buddy who will guide her. In addition, simple and correct information needs to be provided.	Nikos needs to increase his self-management skills by getting information about different options, advice, coaching and support.	Jacqueline needs to have the support of social workers and HPs who have the ability to take care of Jacqueline and can assist her husband in helping her.
<b>Motivation</b>	Rose needs to be motivated by seeing the good things of living a healthy life, for example tracking her progress while losing weight.	Nikos needs to be motivated to live a healthier life by having continuous support when fighting addiction, creating social connections and having a personal care plan.	Jacqueline needs to be motivated to live a more comfortable life by having assistance from HPs and social workers.
<b>Opportunity</b>	Rose needs to have the opportunity of getting an appropriate mHealth solution with a digital buddy and the possibilities to interact better with other children and HPs.	Nikos needs to have the opportunity of getting an appropriate telehealth tool and monitoring tool with, e.g. the possibility of getting reminders about medications, advice about dealing with the stages of nicotine withdrawal and seeing his dietitian from his home.	Jacqueline needs to have the opportunity of getting an appropriate detection wearable and a tool with e.g. the possibility for remote access for HPs and medication tracking.
<b>Empowered behaviour</b>	Live a healthy lifestyle by losing weight and improving her diet.	Live a healthier lifestyle by quitting smoking, decreasing his stress level, doing his exercises and having a good food and medication intake.	Live a more comfortable lifestyle by unburdening her husband, reduce her sleep deprivation and having



			immediate help when falling or having a stroke.
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**Table 1. Possible increase of ability, motivation and opportunity to achieve empowered behaviour for the personas based on the AMO framework**

Opportunities, abilities and motivations are interlinked with the digital tools designed to increase them. A highly skilled person, for example, can effectively use a complex solution that does little to increase his ability (such as a decision support) while a less skilled person will have difficulties using this solution. In the next subparagraphs we explain how the four topics, under the right circumstances, can increase ability, motivation and opportunity and in this way contribute to empowering people.

### 2.1.1 mHealth

mHealth applications have seen a rapid development over the past years, with currently more than 165,000 apps publicly available in Europe<sup>12</sup>. mHealth has the potential to improve healthcare systems by improving efficiency, communication, costs, and quality of health related services. People can use mHealth tools with different objectives and for many reasons, e.g. for collecting health related information and using it to monitor their health status or sharing the data with their physician who can provide continuous monitoring from a distance with the support of mHealth, potentially in combination with telehealth solutions. mHealth apps help people manage their own health and support healthy living<sup>13,14,15</sup>.

mHealth supports people empowerment with health-related activities and affects the ability, motivation, and opportunity of people 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. The table below describes different ways in which mHealth improves the ability, motivation and opportunity of people to be engaged and empowered.

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> <li>• Educates users</li> <li>• People can gain access to useful information anytime, anywhere and with any device</li> <li>• Improves self-management</li> <li>• People can measure vital signs that will contribute in their health assessment</li> <li>• Support to diagnosis and treatment through integration</li> </ul>	<ul style="list-style-type: none"> <li>• Motivational rewards in exchange of healthy behaviour</li> <li>• mHealth tools are often customisable to match the needs of the specific patient-consumer and therefore motivate empowerment</li> <li>• Gamification, making health management more intuitive and enjoyable</li> </ul>	<ul style="list-style-type: none"> <li>• Access to patient data</li> <li>• Enable the exchange of medical information</li> <li>• Gain access to information anytime, anywhere and with any device</li> <li>• Measure vital signals that will contribute to their health assessment</li> </ul>

<sup>12</sup> 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.

<sup>13</sup> 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).

<sup>14</sup> Pagliarola 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.

<sup>15</sup> Ammenwerth, E. "From eHealth to ePatient: The Role of Patient Portals in Fostering Patient Empowerment." *EJBI* (2018): Vol. 14(2): 20-23.

with medical records and monitoring of chronic conditions	<ul style="list-style-type: none"> <li>• Motivational interventions provided at key junctions of behavioural change</li> <li>• Peer-support</li> </ul>	<ul style="list-style-type: none"> <li>• Support to diagnosis and treatment through integration with medical records and monitoring of chronic conditions</li> <li>• Functions designed to support a collaborative relationship between patients and HPs</li> </ul>
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**Table 2. How mHealth can increase the ability, motivation and opportunity for people to get empowered**

### 2.1.2 Telehealth

Telehealth offers a vast amount of potential benefits to achieve and maintain patient empowerment<sup>16,17,18</sup>. 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<sup>19</sup>. 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<sup>20,21,22</sup>. 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<sup>23</sup>. 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<sup>24</sup>. 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 (GP)<sup>25</sup>. In the table below, different ways of how telehealth improves the ability, motivation and opportunity of people are provided.

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> <li>• Supports clinical education programmes, for patients and clinicians.</li> <li>• Patients can easily integrate their healthcare into their daily life, instead of frequent doctor's visits</li> </ul>	<ul style="list-style-type: none"> <li>• Increases patients' confidence to stay independent/at home</li> <li>• Improves support for patients and families: patients can stay in their local communities where their relatives can easily visit them.</li> </ul>	<ul style="list-style-type: none"> <li>• Increases access to healthcare (remote or rural areas)</li> <li>• Improves health outcomes: patients diagnosed and treated earlier often have improved</li> </ul>

<sup>16</sup> 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

<sup>17</sup> 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.

<sup>18</sup> 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).

<sup>19</sup> 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

<sup>20</sup> Nissen L, Lindhardt T. A qualitative study of COPD-patients' experience of a telemedicine intervention. Int J Med Inf. 2017 Nov; 107:11–7

<sup>21</sup> 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.

<sup>22</sup> Mathavakkannan S, Bowser M, Doyle S, Hoare A, Rehisi G. Promoting patient empowerment and sustainability in kidney care using telemedicine. Int J Integr Care. 2014;14(8).

<sup>23</sup> Barelo 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

<sup>24</sup> Deloitte, 2016. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/public-sector/us-fed-empowering-patients-with-telehealth.pdf>

<sup>25</sup> <http://www.carewell-project.eu/home.html>

	<p>Recovery is faster when patients are close to home</p> <ul style="list-style-type: none"> <li>• Lower travel costs and missing work, income savings to patients who would otherwise need to commute to an urban location</li> <li>• Less time is spent by the patient in waiting rooms</li> <li>• Facilitates behavioural change</li> </ul>	<p>outcomes and less costly treatments</p> <ul style="list-style-type: none"> <li>• Assists in addressing shortages and misdistribution of HP: specialists can serve more patients using telehealth.</li> <li>• Patients can be diagnosed and treated more quickly in distant locations</li> <li>• Specialists “team up” with local HCPs to improve disease management. This reduces complications and hospitalisations. Also, test results can be quickly sent to specialists for second opinions</li> <li>• Reduces the need for hospital re-admissions.</li> <li>• Some doctors charge less for a telehealth consultation than they would for an average in-person visit</li> <li>• Home monitoring programmes can reduce complications and thus high cost hospital visits, high cost patient transfers and other emergencies</li> </ul>
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**Table 3. How telehealth can increase the ability, motivation and opportunity for people to get empowered**

### 2.1.3 Patient access and use of data

The widespread implementation of EHRs has led to new ways of providing access to healthcare information, allowing patients to view their medical notes and summaries, test results, medication and so on<sup>26,27,28</sup>. EHRs have the potential to empower people by providing them with (easier) access to their health records, allowing them to exert more control over their health data. Thereby, people have the opportunity to become more responsible and active in their own care while facilitating communication with their HPs in a more literate way. In 2017, 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. Nine other MS provide their EHR information to patients via multiple systems based on regions and/or health domains<sup>29</sup>.

Utilisation of EHR portals has most commonly been associated with small changes in people empowerment. Portal use was also positively associated with better health outcomes in various

<sup>26</sup> 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.

<sup>27</sup> 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 Geneesk*. 2016;160: D325. Dutch.

<sup>28</sup> 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.

<sup>29</sup> European Commission (2017) JaseHN 7.5.1: REPORT on EU State of Play of Patient Access to eHealth Data.

study populations<sup>30</sup>. 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 doctor's 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<sup>31</sup>.

Health information can come from many sources: hospitals, GPs, pharmacies, physiotherapists, radiotherapeutical institutes, but also from home care, self-measurements, genomics, etc. For people, all this information is offered separately, in separate silos, without integration, and although each solution provides the right information from the perspective of the healthcare organisation, for people it does not always provide the right overview and insight. Personal Health Environments (PHEs) strive to connect and bring together all health related information. They are a lifelong online tool for people to control their own health data: from treatment to medication, research results and vaccinations. By standardising the relevant information, information from different sources can be brought together, providing an integrated view of their own health situation.

This policy framework states for people to get (more) empowered their ability, motivation and opportunity needs to be on a high enough level. How patient access and use of data contributes to this is shown in the table below.

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> <li>• Deeper understanding of their health condition</li> <li>• Improves self-management of people</li> </ul>	<ul style="list-style-type: none"> <li>• Easier access to health data</li> <li>• Exert more control over health information</li> <li>• Enables more responsible and active role</li> </ul>	<ul style="list-style-type: none"> <li>• EHR portal gains access and improves recall and understanding of health information and patient involvement</li> <li>• Monitor patient's health between clinic visits</li> <li>• Direct access to accurate information, clinical test results</li> </ul>

**Table 4. How patient access and use of data can increase the ability, motivation and opportunity for people to get empowered**

## 2.1.4 Digital health literacy

Digital health literacy (DHL) goes beyond searching for general health-related information on the Internet; the digital age is beginning to impact the healthcare system. There has been a shift from devices that collect data to systems for those medical conditions. This changes the focus from health literacy to DHL and the information-communication between HP and the individual. Moving from health literacy to digital health literacy, also means shifting the paradigm from patients to persons and from managing health to empowering people to live a healthier life<sup>32</sup>. People need to be comfortable with accessing and managing their own health information via EHR systems, telehealth or mobile health systems, directly or through the integration of PHEs.

<sup>30</sup> 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.

<sup>31</sup> 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.

<sup>32</sup> Robbins, Dennis, and Patrick Dunn. "Digital health literacy in a person-centric world." International journal of cardiology 290 (2019): 154-155.

The JaseHN report on patient access indicated a lack of understanding by survey respondents from 29 countries as to the difference between digital literacy and health literacy, with the emphasis being on digital literacy. MS focussed more on policy with regard to digital literacy than on health literacy while both are equally important for the improvement of digital skills and increase of patient access<sup>33</sup>.

With the right skills and knowledge, user-generated information has turned communication from monologue, a unidirectional flow of information from HP to patient, into dialogue. This is followed by the fact that more knowledgeable people are more involved in decisions regarding their treatment and/or diagnosis, and also take more actions to achieve or maintain their health, with the result of feeling empowered<sup>34</sup>.

In the table below, different ways of how DHL improves the ability, motivation and opportunity of people to be empowered are stated.

Ability	Motivation	Opportunity
<ul style="list-style-type: none"> <li>Educate people about their health status</li> <li>Create a deeper understanding of their health condition and the possibility to make own decisions</li> </ul>	<ul style="list-style-type: none"> <li>Improve confidence and self-efficacy</li> </ul>	<ul style="list-style-type: none"> <li>Better use of mHealth, EHR portals and telehealth</li> <li>Gain access to useful information anytime, anywhere, from any device</li> </ul>

**Table 5. How DHL can increase the ability, motivation and opportunity for people to get empowered**

## 2.2 Barriers and enablers

Organisations and governments are increasingly becoming aware of the necessity of empowering people. To empower people, they need to take action to actually do something about the ability, motivation and opportunity of their citizens. They need to increase the adoption, with the help of this policy framework, of mHealth, telehealth, patient access and use of data, and digital health literacy. To facilitate further adoption an analysis of barriers and enablers was considered useful. These influence the decisions about the adoption of, for example, an mHealth application.

In this paragraph the barriers and enablers to the adoption of mHealth, telehealth, patient access and use of data, and DHL found in literature are shown. Throughout the process of literature searching, nearly 100 unique barriers and enablers were identified. For the sake of clarity, seven categories were created which cover all these barriers and enablers. These categories are health policy, core infrastructure, assessment, costs and reimbursement, integration, interoperability and user-centred.

The barriers and enablers relate directly to the AMO framework. For example, the categories "integration" and "interoperability" relate to the ability, motivation and opportunity of patients and professionals to use digital health solutions (apps, personal health environments etc): the better these solutions are integrated and able to exchange data with each other, the easier they are to operate and the more likely it is that the data they create gets used within the healthcare system. Likewise, overcoming barriers to reimbursement will increase access to digital solutions and thereby directly increase the opportunity for people to use them. A complete mapping of how the barriers

<sup>33</sup> European Commission (2017) JaseHN 7.5.1: REPORT on EU State of Play of Patient Access to eHealth Data.

<sup>34</sup> Robinson, Leslie. "Is digital health technology empowering patients?." Journal of medical radiation sciences 60.3 (2013): 79-80.

and enablers relate to the AMO framework is beyond the scope of this paper, however MS should strive to keep potential interconnections in mind. When planning interventions to overcome key barriers, MS would do well to plan a mix of activities that address all three components of the AMO framework.

In the upcoming chapters the identified enablers and barriers are categorised into one of these categories. For a definition of these categories, see appendix 2.

### 2.2.1 mHealth and telehealth

Although they differ in certain respects, the barriers and enablers for mHealth and telehealth can be considered jointly. Successful long-term adoption of both kinds of digital solutions for patient empowerment require substantial efforts towards the selection of appropriate interventions and tailoring of systems to meet the disease specific needs of target user groups<sup>35</sup>. This necessitates continuous monitoring and evaluation of the solutions, considering evidence of care. Citizens look to professionals to offer them effective digital solutions to improve their health<sup>36</sup>, professionals on the other hand need background information, i.e. the evidence base of the solutions in order to use and recommend them to patients. Here, efforts are ongoing towards a more evidence-based approach (e.g. NHS app library, Bertelsmann project, the PwC market study etc)<sup>37</sup> but such growing evidence is perhaps not yet fully recognised, including by health professionals<sup>38</sup>. Professionals are also more likely to use and recommend digital solutions when they have been involved in their development<sup>39</sup>. Moreover, research has shown that clinical leaders who have technical informatics skills and prior experience with IT project management are likely to show proactive leadership behaviours that are associated with successful organisational and clinical outcomes of IT solution adoption<sup>40</sup>.

People need to have a certain level of technological competence and digital literacy to be able to use digital solutions, which highlights the need for informing and guiding patients. Specialists in particular need training, education and advocacy in order to engage and implement novel solutions in their practice<sup>41</sup>. Transitioning to remote care may necessitate the creation of new job profiles and require new skills from HPs. This highlights the need for mHealth and telehealth to be seamlessly integrated with healthcare systems to avoid needless disruption of the HP's existing workflow. This can help address the concern that new solutions, particularly remote care solutions increase the workload of health professionals.

A list of enablers and barriers as found in the literature can be seen in the table below:

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35 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

36 [https://www.ipsos.com/sites/default/files/ct/news/documents/2019-06/ipsos\\_sopra\\_steria\\_digitalisation\\_des\\_parours\\_de\\_soin.pdf](https://www.ipsos.com/sites/default/files/ct/news/documents/2019-06/ipsos_sopra_steria_digitalisation_des_parours_de_soin.pdf)

37 [https://ec.europa.eu/health/sites/health/files/ehealth/docs/2018\\_provision\\_marketstudy\\_telemedicine\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ehealth/docs/2018_provision_marketstudy_telemedicine_en.pdf)

38 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.

39 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

40 Ingebrigtsen T, Georgiou A, Clay-williams R, et al. The impact of clinical leadership on health information technology adoption: systematic review. *Int J Med Inform.* 2014;83(6):393-405.

41 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.



Category	Barriers	Enablers
User-centred	<ul style="list-style-type: none"> <li>Professionals' lack of familiarity with equipment and procedures</li> <li>Professionals' lack of training, education and advocacy</li> <li>Lack of technological knowledge</li> <li>Unrealistic expectations</li> <li>Solutions not adapted for physicians</li> <li>Perceived complexity of solutions and resistance from physicians</li> <li>Lack of sense of clinical value</li> <li>Privacy and security concerns</li> <li>Conservative culture</li> <li>Patients wish to speak face-to-face with physicians</li> <li>Lack of ease of use</li> </ul>	<ul style="list-style-type: none"> <li>Personal factors which shape people engagement and experience</li> <li>Provider's capacity</li> <li>Keeping the user in mind</li> <li>Frontline staff training</li> <li>Familiarity, ability with digital tools</li> <li>Awareness of the objectives and/or existence of solutions</li> <li>Support and promotion of mHealth/telehealth by colleagues</li> <li>Consumer demand</li> <li>Experiencing patient and clinical benefits</li> <li>Perceived ease of use</li> <li>User involvement in solution development</li> <li>Experimentation and clinical learning</li> <li>Training</li> </ul>
Core Infrastructure	<ul style="list-style-type: none"> <li>Lack of technological infrastructure in underserved areas</li> <li>Bandwidth issues/internet access</li> </ul>	
Assessment (technology)	<ul style="list-style-type: none"> <li>Lack of evidence of clinical utility</li> <li>Lack of cost-effectiveness evidence</li> <li>Lack of data accuracy</li> </ul>	<ul style="list-style-type: none"> <li>System reliability or dependability</li> <li>Accuracy of the system</li> <li>Quality standards</li> <li>Assessment frameworks in place</li> <li>Observability (observance, control, verification of the solutions)</li> </ul>
Costs and Reimbursement	<ul style="list-style-type: none"> <li>Lack of reimbursement models</li> <li>Lack of implementation support</li> <li>Costs associated with technology</li> </ul>	<ul style="list-style-type: none"> <li>Having requisite material resources</li> <li>Having requisite human resources (IT support, other)</li> <li>Value-based reimbursement</li> </ul>
Health Policy	<ul style="list-style-type: none"> <li>Lack of readiness among key stakeholders</li> <li>Lack of enabling policy</li> <li>Conflicting priorities</li> <li>Lack of governance</li> <li>Medicolegal issues</li> </ul>	<ul style="list-style-type: none"> <li>Communication and collaboration between stakeholders</li> <li>Management (strategic planning)</li> <li>Information and communication technologies considered central components of healthcare services delivery</li> </ul>
Integration	<ul style="list-style-type: none"> <li>Lack of integration with workflow leading to increased workload</li> </ul>	<ul style="list-style-type: none"> <li>Compatibility with work process</li> </ul>
Interoperability	<ul style="list-style-type: none"> <li>Lack of interoperability</li> </ul>	<ul style="list-style-type: none"> <li>(Compatibility with work process)</li> <li>Interoperability of solutions</li> </ul>

**Table 6. Barriers and enablers related to mHealth and telehealth successfully empowering people**

## 2.2.2 Patient access and use of data

Based on the SmartHealthSystems study<sup>42</sup>, patient access to EHR has not reached the point of maturity in the 17 countries surveyed<sup>43</sup>. This study gives a ranking of these countries with an indication of how far they are with actual use of data. Estonia, Denmark and Israel are in the top

<sup>42</sup> BertelsmannStiftung (2018). SmartHealthSystems. International comparison of digital strategies. Retrieved via: [https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der\\_digitale\\_Patient/VV\\_SHS-Studie\\_EN.pdf](https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der_digitale_Patient/VV_SHS-Studie_EN.pdf)

<sup>43</sup> Countries surveyed are Australia, Belgium, Denmark, Estonia, France, Germany, Israel, Italy, Canada, England, Netherlands, Austria, Poland, Sweden, Switzerland, Spain and Portugal.

three, followed by Canada, Spain and the Netherlands. Germany, Switzerland and Poland are the bottom countries. The actual use of data is seen as the endpoint for the maturing of a digital health system, while political support and investments in the necessary infrastructure can be seen as antecedent factors. The study states that a correlation between policy activity, readiness and actual use of data can be expected.

Several factors are related to accessing and using patient data. 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<sup>44</sup>. Physicians, on the other hand, have a great impact on the overall adoption level of EHRs and the access and use of people to their data in those EHRs. Patient-perceived enablers of use are encouragement by 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<sup>45</sup>. 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. The full list with barriers and enablers found in literature are shown in the table below.

Category	Barriers	Enablers
User-centred	<ul style="list-style-type: none"> <li>• Lower social economic status</li> <li>• Lower educational level</li> <li>• Lack of computer knowledge</li> <li>• Language barrier</li> <li>• Low DHL</li> <li>• Higher age</li> <li>• Lack of awareness</li> <li>• Concerns about privacy, safety and confidentiality</li> <li>• EHR portal is not user-friendly</li> <li>• Resistance to change</li> <li>• Preference for personal communication</li> <li>• Lack of urgency</li> <li>• Low expectations or uncertainty about results</li> <li>• No direct relation with HP</li> <li>• Information overload</li> </ul>	<ul style="list-style-type: none"> <li>• Readiness to invest in improvement</li> <li>• Clear vision, aim, purpose, benefits of EHR portal</li> <li>• Early adopters in network</li> <li>• Trust</li> <li>• Health benefits of sharing information</li> <li>• Provide patient support (helpline)</li> <li>• HP as 'promoter' of patient access</li> </ul>
Core infrastructure	<ul style="list-style-type: none"> <li>• Lack of bandwidth</li> <li>• Low software speed</li> <li>• Lack of proper infrastructure</li> <li>• Lack of good access to internet</li> </ul>	
Assessment (technology)		

<sup>44</sup> Kruse CS, Kristof C, Jones B, Mitchell E, Martinez A, (2016). Barriers to Electronic Health Record Adoption: a Systematic Literature Review.

<sup>45</sup> Powell KR. Patient-Perceived Facilitators of and Barriers to Electronic Portal Use: A Systematic Review. *Comput Inform Nurs*. 2017 Nov;35(11):565-573.



Costs and reimbursement	<ul style="list-style-type: none"> <li>• High costs</li> </ul>	
Health policy	<ul style="list-style-type: none"> <li>• Lack of implementation models</li> <li>• Legal/regulatory restrictions</li> <li>• When both professionals and users are deployed, users are scaled up more slowly</li> <li>• Low rate of EHR systems adoption (inter)nationally</li> </ul>	<ul style="list-style-type: none"> <li>• High adoption among organisations</li> <li>• Policy in organisation</li> <li>• Involvement of patient and HPs in creating policy</li> <li>• Publishing best practices and use cases to inform about benefits</li> </ul>
Integration		
Interoperability	<ul style="list-style-type: none"> <li>• Lack of interoperability</li> <li>• Complexity of process and the number of players</li> </ul>	<ul style="list-style-type: none"> <li>• Interoperability</li> </ul>

**Table 7. Barriers and enablers related to patient access and use of data to successfully empower people**

### 2.2.3 Digital health literacy

The people in Europe were investigated in 2014 on behalf of the European Commission (EC). 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 for 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<sup>46</sup>. Personal factors related to DHL include age, experience, health literacy, education, income and culture<sup>47</sup>. People with lower socio-economic backgrounds, people experiencing vulnerabilities, or people in old age may struggle to keep up with technological advancements. DHL skills of people with different health conditions, risk factors and socioeconomic backgrounds could be improved by eHealth interventions<sup>48</sup>, such as Massive Open Online Courses (MOOC) and educational programmes<sup>49</sup>.

The European Economic and Social Committee (EESC) delivered a preliminary draft opinion on DHL in January 2019 with conclusions and recommendations. EESC endorses the EC's efforts to make DHL a high priority within the agenda of eHealth and involve citizens actively. It also refers to WHO Health Evidence Network report 57<sup>50</sup>, which concludes that 'central to health literacy is the development of skills through the life-course, including pre-school activities, formal instruction in schools and adult learning'<sup>51</sup>. EPF presented during the DHL public hearing in January 2019 organised by EESC. Challenging factors for people to take more responsibility on their health are a changing information landscape with EHRs, online portals (also via Google) and social media, a wave of too much information, wrong information and navigation through the information maze is challenging. Low health literacy makes it difficult to read a medicine information leaflet and find and

<sup>46</sup> 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](http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_404_en.pdf)

<sup>47</sup> Chesser, AK., Keene Woods, N., Smothers, K. & Rogers, N. (2016). Health Literacy and Older Adults: A Systematic Review. Gerontology & geriatric medicine, 2.

<sup>48</sup> Jacobs, RJ. Lou, JQ., Ownby, RL. & Caballero, J. (2014) A systematic review of eHealth interventions to improve health literacy. Health Informatics Journal 1–18.

<sup>49</sup> IC-Health 2019. Improving digital health literacy through MOOCs. <https://ichealth.eu/the-project/partners/> (Jan 2019)

<sup>50</sup> <http://www.euro.who.int/en/data-and-evidence/evidence-informed-policy-making/publications/2018/what-is-the-evidence-on-existing-policies-and-linked-activities-and-their-effectiveness-for-improving-health-literacy-at-national,-regional-and-organizational-levels-in-the-who-european-region-2018>

<sup>51</sup> EESC (2019). Preliminary draft opinion. Digital health literacy – for citizen-friendly healthcare in Europe in times of demographic change. Retrieved from: <https://memportal.eesc.europa.eu/Handlers/ViewDoc.ashx?pdf=true&doc=EESC-2019-00067-00-01-APA-TRA-EN.docx>

assess reliable health information. EPF also comes with challenges and opportunities for DHL for medicines; accessibility (availability, readability, portability), functionalities (e.g. for devices, search functions), up-to-date information and interactivity are opportunities. Challenges are limited access to computers and internet and no single portal at EU level as one-stop shop for information which should be controlled by a public authority, e.g. European Medicines Agency (EMA)<sup>52</sup>.

A full list with barriers and enablers found in literature are shown in the table below.

Category	Barriers	Enablers
User-centred	<ul style="list-style-type: none"> <li>• Less experience with internet</li> <li>• Poor understanding of information</li> <li>• No parental mediation</li> <li>• Reluctance to learning</li> <li>• No confidence with using online information</li> <li>• Negative attitude towards eHealth</li> <li>• Anxiety to use mobile phone, computer or internet</li> <li>• Privacy concerns</li> <li>• Distracting information</li> <li>• Lack of information in mother tongue</li> <li>• Overload with information quantity</li> <li>• Less opportunities in rural areas</li> <li>• Poor quality of information</li> <li>• Low income</li> <li>• Low educational level</li> </ul>	<ul style="list-style-type: none"> <li>• Gaining support from others</li> <li>• Trustworthiness for people</li> <li>• Openness to learning</li> <li>• Ease and confidence with using online data</li> <li>• Readability: attractive visual/audio content</li> <li>• Social network</li> <li>• Experience in lifespan</li> <li>• Reading ability</li> <li>• Ability to collect and qualify the data</li> <li>• Assessing community support</li> </ul>
Core infrastructure	<ul style="list-style-type: none"> <li>• No access to computer/internet</li> </ul>	<ul style="list-style-type: none"> <li>• Easy accessible</li> </ul>
Assessment (technology)		<ul style="list-style-type: none"> <li>• Provision of a framework for the digital communication of health information</li> </ul>
Costs and reimbursement		<ul style="list-style-type: none"> <li>• Provision of resources through networks</li> </ul>
Health policy		<ul style="list-style-type: none"> <li>• Improvement of skills through training and e-learning</li> <li>• Educating professionals who can then take on a role as 'ambassador/promoter'</li> <li>• Policy/action plan on DHL</li> <li>• Involvement of patients and HPs in creating policy on DHL</li> <li>• Cultural relevant information</li> <li>• Involvement of early adopter in creating policy</li> </ul>
Integration	N.A.	N.A.
Interoperability	N.A.	N.A.

**Table 8. Barriers and enablers related to DHL successfully empowering people**

<sup>52</sup> EESC/EPF (2019). The patient's role in digital health literacy. Retrieved from: <https://www.eesc.europa.eu/en/agenda/our-events/events/digital-health-literacy>



## 8. State of play among Member States

In this chapter the state of play of the four topics among MS is provided based on the AMO framework and the barriers and enablers. This is based on survey results from 19 MS. The survey questions can be found in appendix 3, the answers from the MS on the survey can be found in more detail in appendix 4.

### 3.1 AMO framework

The MS were asked in the survey to indicate for each topic how it increases the ability, motivation and opportunity of people to be empowered. They did this by describing one to three programmes or initiatives currently running in their country. A summary of these best practices is shown in appendix 6. The main results for mHealth, telehealth, patient access and use of data, and digital health literacy are shown in the paragraphs below.

#### 3.1.1 mHealth

The use of mobile health for patient empowerment in Member States was analysed by looking into practical applications of mHealth within the domains of “Ability”, “Motivation” and “Opportunity”. In total, 27 solutions were shared for ability, 28 for Motivation and 38 for Opportunity, with notable overlap.

Almost all countries highlighted a distinction between the features of mHealth applications for patients and applications for HPs. For professionals, most applications focus on the potential to communicate with and mass-educate targeted groups of patients, whereas for patients the focus is more on getting scientifically sound information about their health, communicating and sharing information with their GP, receiving virtual coaching and using other self-management tools.

In the realm of “Ability”, the vast majority of applications described by Member States enable citizens to measure vital signs for self-management. A significant proportion of solutions also enable citizens to gain useful information about their health condition or about relevant HPs. The answers do, however, demonstrate a lack of solutions designed to educate or coach citizens: so while information is made accessible, it is not being actively explained and reinforced. This is not to say that such educational solutions do not exist, but rather suggests that they are not recognised and/or provided systematically by Member States.

Under “Opportunity” one can see that a large proportion of solutions (82%) are again dedicated to accessing useful information, and a majority of applications enable some kind of exchange of medical information (e.g. booking appointments) as well as having some form of a collaborative relationship with health professionals. Meanwhile, very few solutions enable the measuring of vital signs. Looking at Ability and Opportunity together, one can observe that while applications to gather information about one’s condition do exist in significant numbers, very few such applications actually communicate this information to health professionals. In other words, while data about a patient’s condition is being gathered, it is mostly not being communicated to health professionals. Instances where this does happen tend to be confined to well-defined disease groups e.g. diabetics and asthmatics. This gap is only partially compensated for by the telehealth solutions described in the next section. It also emerges from the data that there is a dearth of solutions that are integrated with people’s official medical records.

While 28 solutions were listed for “Motivation”, it should be noted that some were simply international applications (e.g. Pokemon Go) that do not necessarily demonstrate the use of

mHealth for patient empowerment within Member States. Upon closer inspection it would appear that only about 5-6 solutions directly influence a person's motivation by offering rewards, peer-support, (daily) interactions with professionals, motivational messages or gamification. Most of the applications listed under "Motivation" influence motivation indirectly through practical use. In other words, by providing increased comfort and ease in dealing with one's health, they "motivate" patients to take a more active role in their health journey. One might argue that these applications actually increase "Opportunity" and "Ability" (and indeed there is much overlap), thereby making better use of the motivation people already have.

Examples of the initiatives for ability, motivation and opportunity are given in the table below.

Ability	Motivation	Opportunity
<b>Omaolo - Finland<sup>53</sup>.</b> 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 HPs 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.	<b>Telia Active - Estonia<sup>54</sup>.</b> 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 5MB of internet for every collected 1000 steps, in total 50MB per day. This method was found to be very effective and clever to motivate people for moving by giving free internet data.	<b>Gesundheitsdialog - Austria<sup>55</sup>.</b> 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 HPs. 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 HPs. Patients can recognise and understand trends and patterns between their own health behaviour, physical activity and critical monitored values.

**Table 9. Three examples of initiatives of MS for AMO**

### 3.1.2 Telehealth

What is apparent from the survey responses is that the majority of countries do employ telehealth systems to some extent, allowing citizens to have access to advanced healthcare services from a distance. Several of these systems have been claimed to lead to lower costs and offer patient-centred approaches. Large discrepancies nevertheless exist, with some countries developing telehealth to a large extent, and others not at all. Moreover, in most countries the use and deployment of telehealth services is fragmented, limited to a regional level and mostly driven by

<sup>53</sup> [www.omaolo.fi](http://www.omaolo.fi)

<sup>54</sup> <https://active.telia.ee/sammud-internetiks>

<sup>55</sup> <http://www.ge-breitenstein.at/e-health/gesundheitsdialog-diabetes>

research projects, individual hospitals, non-governmental organisations (NGOs) or small-scale private initiatives. In many countries national activities in this field have not yet started or are at their inception. Among the roughly 40 solutions submitted, only around 6 constitute national telehealth platforms that are accessible to all citizens, several of which are deployed in only one country. Among these, not all solutions are patient-facing or can be accessed from the patient's home, limiting their role in patient empowerment. Others are limited to only certain types of health professionals e.g. family doctors. Some solutions, while national, are only limited to specific patient groups. Having numerous fragmented telehealth solutions may cause problems in workflow, for example when there is no link between a country's EHR and the platforms used by patients to access telehealth services. A lack of platform integration can also disrupt the continuity of care and create misunderstandings among physicians. In line with the findings of the SmartHealthSystems study<sup>56</sup>, the survey responses demonstrate that there is still a way to go when it comes to telehealth adoption for patient empowerment on a health system level.

Another potential limitation alluded to in the data is that there is a lack of applications for monitoring vulnerable populations such as the elderly, pregnant women and patients with chronic diseases. This, however, might stem from countries being biased towards reporting more general solutions. Finally, we note that a large proportion of solutions are provided by the private sector, which could lead to inequity in healthcare. This, however, is not necessarily the case, as private providers can work closely with health authorities to ensure broader access to telehealth services, as is for example the case in Sweden. A number of other countries also describe good cooperation with the private sector.

Regarding the AMO model, most listed telehealth solutions fall under "Opportunity", with telehealth enabling access to healthcare from a distance, both through direct communication and telemonitoring to prevent complications and to avoid readmission. The solutions listed enabled patients to be diagnosed and treated quicker and from a distance.

Regarding "Ability", the telehealth solutions employed in Member States appear to contribute largely by facilitating the integration of healthcare into everyday life. For example, people with limited DHI have been described to use medical devices that track their relevant health indicators and, without their intervention, transfer the data directly to HPs who then provide a course of action. Nevertheless, most telehealth solutions do require patients to have at least basic digital skills, which can become a barrier to uptake, as we describe in the next chapter. Furthermore, responses demonstrate only a limited number of telehealth solutions to support clinical education programmes for patients and clinicians.

Regarding "Motivation", as is the case with mHealth, most telehealth solutions motivate through "practical use". Most Member States agree that telehealth allows faster patient care and follow-up. Therefore, the motivation to manage one's health is obtained simply through easier, speedier and more autonomous access to healthcare from one's own home. This is particularly true for patients in rural areas and with milder conditions. It must be noted that although telehealth has been shown to benefit behavioural change efforts, only one of the submitted examples (the Finnish YTHS MealLogger) makes use of this potential. This discrepancy could be due to an inherent bias within

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<sup>56</sup> [https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der\\_digitale\\_Patient/VV\\_SHS-Studie\\_EN.pdf](https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der_digitale_Patient/VV_SHS-Studie_EN.pdf)

the questionnaire towards solely health-focused solutions, whereas several behavioural change solutions in existence might be considered as part of the broader social care spectrum.

Ability	Motivation	Opportunity
<p><b>Telemonitoring for Chronic Diseases - Portugal<sup>57</sup>.</b></p> <p>In Portugal, public hospitals have the possibility to contract telemonitoring services with ACSS – the Central Administration of the Health System. There are three programmes available: Telemonitoring of COPD; Telemonitoring of Chronic Heart Failure and Telemonitoring of Acute Myocardial Infarction.</p> <p>The telemonitoring programmes consist of the installation, in the patient's home, of simple devices (usually portable and Bluetooth connected devices) for measuring vital signs suitable for the clinical evaluation of citizens' pathologies. These monitoring devices automatically transmit the data collected by the citizen to specialised services.</p> <p>With these telemonitoring programmes patients learn how to monitor their conditions, understand their symptoms, and learn what to do in certain situations. Citizens in the programmes receive training, most of the time in their own homes and have daily support available for taking their measurements.</p>	<p><b>YTHS MealLogger - Finland<sup>58</sup></b></p> <p>Finnish Student Health Service (YTHS) is a free-of-charge healthcare service for University and Polytechnic students. They provide preventive and curative healthcare. YTHS uses Meal-Logger in their digital weight management group. Students take pictures of their meal and a nurse comments on the pictures and gives them dietary information/hints. This enables students to participate in a weight management group without having to be physically present.</p>	<p><b>Primary health care online by an app or a website – Sweden</b></p> <p>Swedish healthcare is provided by the county councils to its citizens. At the same time, citizens have the right to seek care anywhere in the country. Private online providers all have an agreement with at least one of the county councils which makes it possible for them to operate on a national level. There are six active private providers: Capio Go, Doktor24, Doktor.se, KRY, Medicoo and MinDoktor (My Doctor)</p>

**Table 10. Three examples of initiatives of MS for AMO**

### 3.1.3 Patient access and use of data

Eight MS described current initiatives or programmes with the objective of offering people access to their own health data<sup>59</sup>. 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

<sup>49</sup> <http://www.ulsam.min-saude.pt/sem-categoria/telesauade-na-ulsam/>

<sup>58</sup> [www.yths.fi/hevi](http://www.yths.fi/hevi)

<sup>59</sup> MS were asked to indicate initiatives with regard to patient access and use of data, not especially specific to offering a patient portal, so this is not an indication of the total amount of MS offering online patient access.



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, people without electronic identification tools and people 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 medical appointments for specialised HPs, e-referrals). Some countries offer reimbursement schemes for healthcare providers (HCPs) for the development and use of eHealth solutions, 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 people.

Some MS choose alternative ways and develop private healthcare application networks that motivate people to monitor their own health and wellbeing, and tackle risk factors for getting ill. There are common motivating 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 data 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.

A prerequisite for the patient's ability to use the eHealth tools allowing him to access and use his health data is having some basic digital knowledge/competence (apart from having the device plus network access), particularly in the context of medical topics that tend to be perceived as more "complex/specific/delicate". Initiatives that enable/allow patients to access and use their data presuppose that citizens have sufficient knowledge. This shows it is ever more important, taking into consideration that numerous MS have eHealth digital tools in place (which give the patient the opportunity to have access), but that in case of insufficient digital competence these might become "missed opportunities" for patients to get access to their health data.

In the table below, three examples of initiatives in MS are provided.



Ability	Motivation	Opportunity
<b>One Citizen – One Journal programma nbygger - Norway<sup>60</sup>.</b> <p>The One Citizen – 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.</p>	<b>myHealth - Malta<sup>61</sup>.</b> <p>Some Maltese citizens 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 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.</p>	<b>1177 - Sweden</b> <p>One of the use cases from Sweden uses an older digital solution for a newer digital solution. The 1177 telephone number is commonly known – and trusted – for quality-assured healthcare advice, and has motivated people to use digital services that have become available through the website 1177.se.</p>

**Table 11. Three examples of initiatives of MS for AMO**

### 3.1.4 Digital health literacy

For people to avail of eHealth they must have a basic level of DHL. Ten MS indicated in the survey to have taken initiatives to improve DHL. There are initiatives aimed towards patients, relatives and HPs. In many MS, this is part of the improvement of digital literacy in general, not of DHL in particular. Four MS stated that digital skills are a necessity for HPs to be able to get employment. Only one MS has developed a health strategy regarding DHL. 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 people become familiar with digital tools and services. There are two main prerequisites to increase DHL:

1. general digital literacy programmes or initiatives by governments or other non-governmental organisations; many of these programmes start in primary schools or focus on special segments like ageing people;
2. the accessibility of portals with patient data – mainly these are the results of government sponsored programmes to provide access for citizens to health information – this data is supplemented by additional health-related information about prevention, wellbeing, etc.

To increase motivation in order to achieve DHL, 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. Many MS mentioned general government health programmes, or came up with additional information sources like a national health library, online health e-learning platforms. These platforms enable wider usage of eHealth services because citizens acquire needed skills and knowledge where to find and how to use their health data. In France, the public and health insurance strategy on digital inclusion has three key moments: detecting, accompanying, guiding. It is an active approach. In Hungary the META app is

<sup>60</sup> [https://www.eiseverywhere.com/file\\_uploads/e1508f0c5a68501b5071a8ce1d466eb6\\_170221\\_HDC\\_Lunch\\_Bergland.pdf](https://www.eiseverywhere.com/file_uploads/e1508f0c5a68501b5071a8ce1d466eb6_170221_HDC_Lunch_Bergland.pdf)

<sup>61</sup> [www.myhealth.gov.mt](http://www.myhealth.gov.mt)

pointed out as a main motivator; it is not just a tool providing information but an active planning service. If citizens know what is available online, it is in itself a key motivator on what and where to look for. Other reported factors influencing motivation were saving time and travelling less. Diminishing of bureaucratic obstacles was also a factor mentioned by Cyprus. In Sweden at eMedborgarveckan (eCitizen week), all the goals aim for the citizen to be motivated to take advantage of the possibilities that are available.

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 policymakers/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 DHL. Examples referred to the usage of a national health portal or electronic health record platform, e-learning platforms. In the case of the Netherlands a library of 5,000 animated videos was a main point with customisation. In the case of Norway the Norwegian Medical Association's central board decided to start a Centre for Quality Development in Medical Offices (SKIL). These initiatives are important as they provide opportunities for patients to actually use online services. However, empowering patients also includes addressing DHL levels and tailoring training options to different target groups, especially hard to reach groups.

Lastly, one MS provided checklists to help in communication with people with low digital skills, be it a doctor or an e-services company. There are services that can help guide the HP in determining on which level of digital skills their patient is, in order to increase it.

Ability	Motivation	Opportunity
<b>Joint development initiated in the Connected Health Cluster - Estonia<sup>62</sup>.</b>  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.	<b>MySNS Seleccção - Portugal<sup>63</sup>.</b>  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 knowledge on health (2) the integration of robotics and computing in the primary school curriculum.	<b>De Kijksluiter<sup>64</sup> / Beeldsluiter<sup>65</sup> - The Netherlands.</b>  "De Kijksluiter" 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 Kijksluiter" is developed for citizens to access this at home. Kijksluiter 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.

**Table 12. Three examples of initiatives of MS for AMO**

<sup>62</sup> <https://ttu.ee/taiendusoppijale/koolituskalender/algavad-koolitused/algavad-koolitused-2/?id=26999&koolitus=9315>

<sup>63</sup> <http://mysns.sns.gov.pt/mysns-seleccao/>

<sup>64</sup> <https://stichtingkijksluiter.nl/>

<sup>65</sup> <https://www.beeldsluiter.nl/>

## 9.3.2 Barriers and enablers

The MS were asked in the survey to indicate the main barriers and enablers for adoption of mHealth, telehealth, patient access and use of data, and digital health literacy. The results of this analysis are shown in the subparagraphs below.

### 3.2.1 mHealth and Telehealth

As explained above, the barriers and enablers for mhealth and telehealth can be considered jointly. For both topics combined, Member States listed barriers 238 times and enablers 164 times. Both these numbers are notably higher than for the following topics, due to variations in how the data was gathered. For mHealth and telehealth, Member States were offered a list of barriers and enablers to choose from, whereas for other topics the question was left more open. What is clear from both the background research and Member State responses is that technological barriers play a rather minor though not insignificant role nowadays, whereas institutional and economic barriers make up the majority. This is also reflected in MS responses claiming that the necessary core infrastructure is already largely in place. What Member State responses illustrate is a lack of enabling policy, legislation, regulations and governance for mHealth and telehealth, with conflicting priorities hindering further adoption. Legislatively, telehealth appears to be on a stronger footing, with several countries mentioning some form of legislation to enable telehealth services. As for a strategic approach, however, very few countries mention mHealth and telehealth as being part of a larger national strategy, as is also corroborated in the SmartHealthSystems study<sup>66</sup>. Symptomatic of this is a lack of proper assessment for these digital tools and hence also proper reimbursement. In some cases, reimbursement schemes are in place (e.g. when an insurance provider provides an app), but a more systematic approach appears necessary. Here too, telehealth appears to be slightly more advanced in countries, with some countries reporting either simple reimbursement of telehealth services (including equipment) or also grants and research and innovation funds stimulating the development and implementation of novel telehealth solutions. Overall, though, such reimbursement schemes exist in only a small number of countries, according to the survey. In most countries, the provision of telehealth equipment is up to the HCP.

From the perspective of the users, concerns over security and privacy appear significant, while most of the resistance seems to come from physicians. Aside from a lack of evidence of effectiveness, this resistance could also stem from the lack of integration and interoperability of mHealth and telehealth solutions, leading to a (perceived) increase in workload for already time-strapped physicians. MS responses do not indicate any systemic efforts to better integrate mHealth and telehealth into the workflow of physicians; rather, the data suggests fragmented approaches for both mHealth and telehealth. Nor is there much mention of educational efforts taking place to communicate the benefits of such solutions to physicians. As indicated above, evidence of effectiveness for, for example, remote care solutions already exists, but may not necessarily be communicated to health professionals. Quite a few countries do, however, mention public campaigns to communicate the benefits of mHealth and telehealth to the general population, including through a national telehealth centre. Interestingly, among the barriers reported by Member States, the wish of patients to see physicians face-to-face, as identified by the literature review, did not figure highly or indeed at all.

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66 [https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der\\_digitale\\_Patient/VV\\_SHS-Studie\\_EN.pdf](https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der_digitale_Patient/VV_SHS-Studie_EN.pdf)

The listed enablers illustrate a number of ways these issues might be overcome, starting with a more user-centric approach to developing novel digital health tools, adapting solutions to the needs and respective work processes of users while prioritising ease of use. Some MS highlighted the importance and the potential of hackathons as a potential tool to address current needs of users. So far such an approach has mostly been employed by the private sector, but it could also be of use to governments. Better engagement with patient organisations has also been pointed out as an enabler for developing solutions that match the needs and abilities of users. With particular regard to patient-facing solutions, such advances in ease of use could help compensate for a lack of digital health literacy.

Instituting quality standards and assessment frameworks for mHealth and telehealth solutions could help better meet the need for more rigorous evidence, while also addressing security concerns and paving the way for better reimbursement policies. MS and stakeholders pointed out that instituting patient preferences and experiences into assessment frameworks could also benefit ease of use. Only a few examples of systematic assessment could be gauged from MS responses, however (such as the Swedish national requirements for telehealth meetings<sup>67</sup>), indicating a significant gap to be overcome. Advances in this realm can only be possible when Member States adopt a strategic multistakeholder approach to mHealth and telehealth and recognise such technology as central to healthcare delivery. Last but not least, the need for proper training to use these solutions, both to overcome a lack of digital skills and adapt to changes in medical practices, needs to be highlighted. As physicians become more comfortable with digital tools for empowerment, they are more likely to recommend and teach them to patients. Currently, while some Member States report digital skills training activities, including for HPs, others claim such activities are completely unsupported.

Three additional barriers and enablers that were not a part of the MS survey but were pointed out during the second MS workshop were market failure (small fragmented markets leading to a lack of supply of innovative solutions), ensuring transparency of data governance and well defined security standards (for example as part of assessment).

Category	Barriers	Number	Enablers	Number
User-centred	<ul style="list-style-type: none"> <li>• Privacy &amp; security concerns</li> <li>• Lack of digital skills among patients and physicians</li> <li>• Conservative culture</li> <li>• Perceived complexity and resistance from physicians</li> <li>• Unrealistic expectations</li> <li>• Solutions not adapted for physicians</li> <li>• Solutions not easy to use</li> </ul>	76	<ul style="list-style-type: none"> <li>• Keeping the user in mind</li> <li>• Perceived ease of use</li> <li>• Consumer demand for digital tools</li> <li>• Familiarity, ability with digital tools</li> <li>• Awareness of the objectives and/or existence of digital tools</li> <li>• Training</li> <li>• Support and promotion of mHealth by colleagues</li> <li>• Willingness for experimentation and clinical learning</li> <li>• Providers' capacity</li> <li>• Experiencing patient and clinical benefits</li> </ul>	80

<sup>67</sup> <https://www.socialstyrelsen.se/publikationer2018/2018-11-2>

Core Infrastructure	<ul style="list-style-type: none"> <li>Lack of technological infrastructure in underserved areas</li> <li>Bandwidth issues</li> </ul>	6		0
Assessment (technology)	<ul style="list-style-type: none"> <li>Lack of evidence of clinical utility</li> <li>Lack of cost-effectiveness evidence</li> </ul>	14	<ul style="list-style-type: none"> <li>System reliability and dependability</li> <li>Accuracy of solutions</li> <li>Quality standards</li> <li>Assessment frameworks</li> <li>Observability</li> </ul>	29
Costs and Reimbursement	<ul style="list-style-type: none"> <li>Lack of reimbursement models</li> <li>Lack of implementation support</li> <li>Costs associated with technology</li> </ul>	41	<ul style="list-style-type: none"> <li>Having requisite material resources</li> <li>Value-based reimbursement</li> <li>Having requisite human resources (IT support, other)</li> </ul>	20
Health Policy	<ul style="list-style-type: none"> <li>Lack of legislation and regulations</li> <li>Conflicting priorities</li> <li>Lack of enabling healthcare policy</li> <li>Lack of readiness among key stakeholders</li> <li>Lack of governance</li> <li>Non-existent strategy</li> <li>Medicolegal issues</li> </ul>	68	<ul style="list-style-type: none"> <li>Communication and collaboration between stakeholders</li> <li>Information and communication technologies considered central components of healthcare services delivery</li> <li>Management (strategic planning)</li> </ul>	28
Integration	<ul style="list-style-type: none"> <li>Lack of integration</li> <li>Lack of time, high workload (solutions' lack of compatibility with work process adding extra time and effort for physicians)</li> </ul>	21	<ul style="list-style-type: none"> <li>Compatibility with work process</li> </ul>	7
Interoperability	<ul style="list-style-type: none"> <li>Lack of interoperability</li> </ul>	12		0
<b>Total</b>		<b>238</b>		<b>164</b>

**Table 13. mHealth and telehealth barriers and enablers per category**

### 3.2.2 Patient access and use of data

The MS answered in the survey with 48 barriers and 54 enablers for patient access and use of data. These barriers and enablers are categorised in the chosen categories as can be seen in table 14. The user-centred category has the most barriers and enablers, followed by core infrastructure and health policy. Few barriers and enablers were found for cost and reimbursement and integration.

Category	Barriers	Number	Enablers	Number
User-centred	<ul style="list-style-type: none"> <li>Low DHL level</li> <li>Privacy, fear of 'big brother'</li> <li>System is not easy to use</li> <li>Low general knowledge about the usage of medical data</li> </ul>	25	<ul style="list-style-type: none"> <li>Personal ownership</li> <li>Up-to-date data</li> <li>Easy access and use</li> <li>High DHL level</li> <li>Easy-to-use eID</li> </ul>	41

	<ul style="list-style-type: none"> <li>• Lack of interest</li> <li>• Data provided to patients in a non-engaging manner</li> <li>• Resistance to change – fear of new – both patient and professional side</li> <li>• Generation gap</li> <li>• Citizens prefer to delegate the work to professionals</li> <li>• Lack of awareness</li> <li>• Lack of reliable and easy to access healthcare information data in layman words</li> <li>• Utility for the patient</li> <li>• No training in the use of these technologies</li> </ul>		<ul style="list-style-type: none"> <li>• Responsive portal support services</li> <li>• Awareness of Information Technology (IT) &amp; Information Architecture (IA) efficacy (data sharing) to use to improve his own health</li> <li>• User-friendliness of portal</li> <li>• Personal assistance and support</li> <li>• Incentive</li> <li>• Secondary use of data</li> <li>• Data provided to patients in understandable manner</li> <li>• Transparency, detailed view on access logs</li> <li>• State-of-the art technical safeguards for data protection and data security</li> <li>• National scale education campaign about the importance of using medical data (personalised healthcare)</li> <li>• Citizens access health information on a single platform</li> </ul>	
Core Infrastructure	<ul style="list-style-type: none"> <li>• No broadband access/infrastructure</li> <li>• Citizens do not have electronic identification (eID) card or electronic signature</li> </ul>	7	<ul style="list-style-type: none"> <li>• Monitor complains/disputes, service delays and successful operations</li> </ul>	4
Assessment (technology)	<ul style="list-style-type: none"> <li>• Cost-effectiveness</li> <li>• High quality data</li> <li>• Clinical learning</li> </ul>	3	<ul style="list-style-type: none"> <li>• System reliability and dependability</li> </ul>	2
Costs and Reimbursement	<ul style="list-style-type: none"> <li>• Expensive investment</li> </ul>	1	<ul style="list-style-type: none"> <li>• Value-based reimbursement</li> </ul>	1
Health Policy	<ul style="list-style-type: none"> <li>• National strategy to develop, support, and regulate EHR systems and services</li> <li>• Medico-legal issues</li> </ul>	5	<ul style="list-style-type: none"> <li>• Trust and clarity about responsibilities and possibilities</li> <li>• Involvement of citizens and HCPs in the development of portals</li> <li>• (Governmental) programmes to stimulate use of portals/Personal Health Environment (PHE)</li> </ul>	3
Integration	<ul style="list-style-type: none"> <li>• Compatibility with work process</li> </ul>	1	<ul style="list-style-type: none"> <li>• Engagement with health professionals</li> </ul>	2
Interoperability	<ul style="list-style-type: none"> <li>• Not all data is available within the system, data silos exist</li> </ul>	6	<ul style="list-style-type: none"> <li>• Interoperability</li> </ul>	1
<b>Total</b>		<b>48</b>		<b>54</b>

**Table 14. Number of reported barriers and enables and examples per category for patient access and use of data**



Creating the opportunity for people is the most reported enabler, so that people can actually access and use their data. This data needs to be understandable and easy to use, so that people can act upon it and get engaged. Showing people the positive effects of accessing and using their data online is one of the most mentioned enablers. This can be done by national programmes showing the relevance and importance and offering people the right personal assistance while accessing and using their data.

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 HPs also contribute and motivate people. Privacy and lack of digital literacy were listed as the main barriers. Digital literacy plays a significant role and is a significant barrier as healthcare services seemed to be used more frequently by the elderly than by other age groups except for chronically ill people among all ages. Some countries outlined that for the layman medical language is often difficult to understand and might discourage patients from browsing and using their eHealth data.

In some cases the HP takes up the role of 'trainer'/'promoter' towards patient access and use of data: this presupposes that the HP has had due training to acquire DHL. This HP-as-trainer-model has several positive effects: it empowers the patient, enhances the role of the HP, and strengthens the HP-patient relationship. For example, the Netherlands have local healthcare organisations promote their patient portals to patients.

### 3.2.3 Digital health literacy

In the answers to the survey, 59 barriers and 71 enablers were reported with regard to DHL. Most barriers and enablers were reported for the user-centred category and the fewest for interoperability.

Category	Barriers	Number	Enablers	Number
User-centred	<ul style="list-style-type: none"> <li>• Low digital literacy</li> <li>• Lack of digital skills</li> <li>• Anxiety to start using new digital solutions</li> <li>• Lack of trust in privacy and security</li> <li>• Lack of understanding on the relevance of technology as a basis for medical improvement</li> <li>• Learning is lacking in older generations</li> <li>• Lack of confidence in accessing and using digital tools</li> <li>• People with lower levels of education tend to have more difficulties</li> <li>• Time consuming</li> </ul>	43	<ul style="list-style-type: none"> <li>• Training and education</li> <li>• Social supported initiatives</li> <li>• Easy-to-use eHealth platforms</li> <li>• Educational initiatives</li> <li>• Social engagement and support</li> <li>• Patient champions of digital health</li> <li>• Courses availability</li> <li>• Reliable and complete information</li> <li>• Increasing skills and confidence in using digital health</li> <li>• User friendly eHealth system</li> </ul>	45

Core Infrastructure	<ul style="list-style-type: none"> <li>No access to computers/internet and smartphone use</li> </ul>	2	<ul style="list-style-type: none"> <li>High internet coverage</li> <li>Development of easy to use devices and applications</li> </ul>	4
Assessment (technology)	<ul style="list-style-type: none"> <li>Data protection</li> <li>Lack of checklists for applications</li> </ul>	5	<ul style="list-style-type: none"> <li>Having a digital national agency</li> <li>Offering support</li> </ul>	4
Costs and Reimbursement	<ul style="list-style-type: none"> <li>Technologies are perceived as expensive</li> <li>EU funding is based on development – sustainability is problematic</li> </ul>	4	<ul style="list-style-type: none"> <li>Governmental funding</li> </ul>	2
Health Policy	<ul style="list-style-type: none"> <li>No clear support from authorities</li> <li>Lack of enabling policy</li> </ul>	3	<ul style="list-style-type: none"> <li>Improvement of health professionals' skills to coach</li> <li>Government entities promotion of eHealth</li> <li>Government push through policies</li> <li>Promoting public discussion about eHealth and show how using digital tools can be beneficial</li> </ul>	9
Integration	<ul style="list-style-type: none"> <li>Involvement of citizens in the process of development of applications</li> </ul>	1	<ul style="list-style-type: none"> <li>eHealth is important in disease prevention</li> </ul>	6
Interoperability	<ul style="list-style-type: none"> <li>Lack of public engagement in development</li> <li>Data ownership and control</li> </ul>	1	<ul style="list-style-type: none"> <li>Healthcare service providers focused on values of digital technology in healthcare</li> </ul>	1
<b>Total</b>		<b>59</b>		<b>71</b>

**Table 15. Number of reported barriers and enablers and examples per category for DHL**

The most reported enabling factor to improve the ability of DHL is training. Training should be accessible for everybody; HPs 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 people and improve their skills.

Anxiety and fear for security are the most reported barriers among Member States (15 MS). Lack of ability of users are also reported by 11 MS as a barrier. Some of the reasons reported for this lack of ability are an ageing population (4 MS) and educational/developmental reasons (3 MS). The elderly are 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. Costs and technology are also two important sources of barriers. Eight MS report having technology and cost issues, such as time consumption, support and government financing shortcomings and limitations.

User-centred subjects also have the most enablers reported, with training activities as the most common. This is verified across Europe (Austria, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Hungary, Ireland, Lithuania, Luxembourg, Malta, Norway and Poland). Education-related enablers (from school classes and educational programmes to availability of courses and senior universities to promote the use of computers) and social related enablers (support from relatives, good communication and engagement with social associations as well as public



discussions about technology in health) also are important enablers for DHL across Europe (Austria, Croatia, Cyprus, Estonia, France, Ireland, Poland and Portugal).

This trend towards user-centred barriers and enablers is expected when analysing the empowerment of people. People-related subjects are the most important barriers to overcome, from education, engagement, training, demographic differences, etc. Also, it is from people that come the most enablers, from social support, improvement of skills or educational initiatives.

Seven MS presented the involvement of governments and regional entities in policies regarding the digitalisation of health services as an enabler. Only 3 MS presented government involvement, or the lack of it, as a barrier to promote DHL.

Technology use and proliferation is an important enabler in 8 MS, namely the development of infrastructure, equipment and support on digital platforms. The table above shows the main barriers and enablers per category.

## 10. Other topics on people empowerment

Until now mHealth, telehealth, patient access and use of data, and digital health literacy are analysed and described as topics related to people empowerment. However, people empowerment is more than just giving people access to their data or providing them with innovative health solutions. Therefore, MS were also asked to indicate to what extent other topics concerning people empowerment are currently addressed in their country. These other topics are patient advocacy, personalised medicine, self-care management and shared decision making.

### 4.1 Patient Advocacy

As early as 1978, the World Health Organization (WHO) introduced the concept of participation and involvement of people in the planning and implementation of their healthcare. The modern use of the term “advocacy for health” gained momentum after the first international conference on health promotion (Ottawa Charter on Health Promotion, 1988), and later when the WHO’s “Health Promotion Glossary” (1998) made a first attempt to define the term as “a combination of individual and social actions designed to gain political commitment, policy support, social acceptance, and systems to support a particular health goal or programme”. What differentiates patient advocacy from health advocacy is the direct participation of those affected by the illness or condition<sup>68</sup>.

Good examples of the involvement of the patient groups are also to be found in Europe. Patient organisations such as EURORDIS (a European non-governmental patient-driven alliance of rare disease patient organisations) have developed a European Patient Advocacy Group (ePAG) for each European Reference Network (ERN) disease grouping. ePAGs bring together elected patient advocates and affiliated organisations, which ensure that the voice of the patient is heard throughout the ERN development process. Whilst these European initiatives are successful in practice, particular focus on patient advocacy is rather uneven among European countries (given the responses on the survey question).

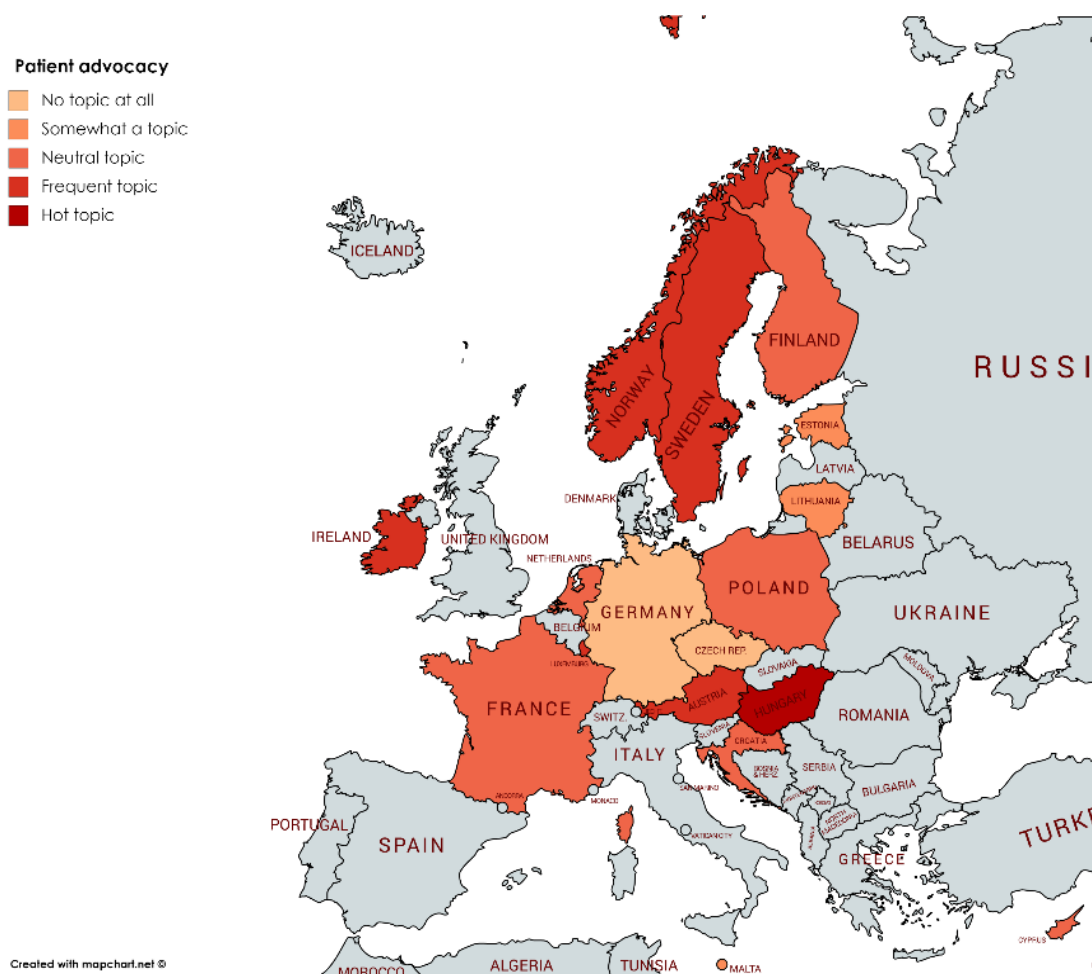
At EU level, good examples of patient advocacy can be found at institutions such as EMA, especially through the Patient and Consumer Working Party (PCWP), and at the European Centre for Disease Control (ECDC), as both institutions work closely with patient advocacy organisations to ensure patient representation at high level.

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<sup>68</sup> Wong-Rieger, Durhane. "Moving from patient advocacy to partnership: a long and bumpy road." *The Patient - Patient-Centered Outcomes Research* 10.3 (2017): 271-276.

**Patient advocacy**

- No topic at all
- Somewhat a topic
- Neutral topic
- Frequent topic
- Hot topic



**Figure 6. MS stages of patient advocacy**

More than a third of European countries see patient advocacy as a priority, with Hungary and Ireland considering it as extremely important aspect of people empowerment. Another third of respondents do not see patient advocacy as a relevant topic, whereas most of the countries consider it to be a neutral topic and tend to prioritise other fields of people empowerment. No specific trends have been observed, only that higher levels of importance are observed towards patient advocacy in Scandinavia.

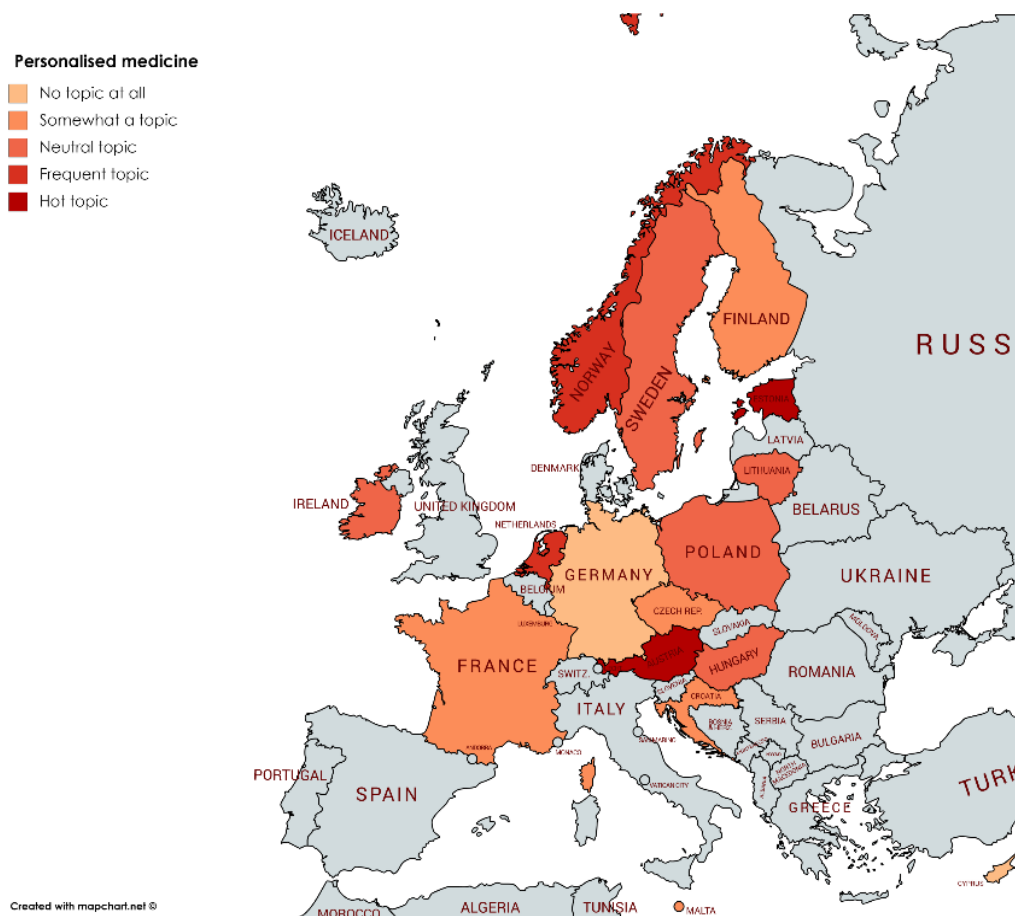
## 4.2 Personalised medicine

The Horizon 2020 Advisory Group has defined personalised medicine as "a medical model using characterisation of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention". This definition was also used by EU Health Ministers in their Council conclusions on personalised medicine for patients<sup>69</sup>, published in December 2015. Furthermore, the definition is followed by the International Consortium for Personalized Medicine. At the heart of personalised medicine is the understanding that people's health is highly individual, dependent on both varied intrinsic as well as extrinsic factors. This necessitates better collection and analysis of health data to

<sup>69</sup> <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=OJ%3AC%3A2015%3A421%3AFULL>

augment our understanding of and ability to account for the variation between individuals and therefore better prevent and cure disease.

Personalised medicine relates to empowerment by providing people with a more nuanced understanding of their own health, enabling them to make better choices. Furthermore, personalised medicine hinges upon having empowered patients, as a large proportion of the information that provides the key for better understanding health variation, lies within patient reported data, for example lifestyle data.



**Figure 7. MS stages of personalised medicine**

Member State responses indicate that, despite the 2015 Council conclusions, personalised medicine is still a “neutral” topic on average, and ranks somewhat behind other empowerment issues such as self-care and shared decision-making. Nevertheless countries like Austria, Estonia and Luxembourg place considerable emphasis on the topic, while the Netherlands and Norway also frequently touch upon it. Compared to other empowerment issues, personalised medicine is slightly more polarised, with significant gaps existing between countries that consider it a “hot topic” and countries that place little emphasis on it.

### 4.3 Self-care management

Studies have shown improvement in clinical outcomes in patients involved in self-management of their chronic conditions and that collaborative decision making between physician and patient leads to better adherence to medication, diet and exercise. These encouraging results have led to self-

care and self-management becoming increasingly important within healthcare provision<sup>70</sup>. The growing significance of self-management is partly due to the recognition of positive results when patients are empowered, but also because in the last decades the driver behind patients seeking healthcare has shifted from acute conditions to more chronic conditions.

The term self-management refers to all the actions taken by people to recognise, treat and manage their own care. In self-management the relationship between patients and their HPs is more of a mutual partnership involving collaborate care<sup>71</sup>. The Intrinsic Motivation Inventory (IMI) measurement device defines self-management as “systematic provision of education and supportive interventions to increase patients skills and confidence in managing their health problems including regular assessment of progress and problems and problem-solving support.”<sup>72,73</sup>.

To achieve successful self-management there is a need for a support network for the patient. This includes giving information, but more importantly providing problem-solving skills. Other important components for successful health-management skills include negotiating healthy behavioural change as well as disease specific skills and providing emotional support to the impact of disease. Regular follow-up also ensures active participation of disease management. To ensure successful self-management, treatment is best delivered through a team so that the patient is empowered enough to self-manage their condition<sup>57,74</sup>.

In self-management the patient makes daily choices regarding their illness which has led to a new disease paradigm where the patient and the health professional form a partnership<sup>58</sup>. This involves collaborative care to reach the goal of improved outcomes and can potentially, in the long term, lead to reduced costs. Giving patients access to their own EHR will improve their abilities to self-manage their health and the proper e-tools will improve their communication with their care teams<sup>75</sup>.

In our survey respondents from various countries were asked to rate self-care/management on a scale from “no topic at all” to “hot topic”.

We had four respondents from Cyprus, each labelling the importance of self-care/management on a different point on the scale, starting at 1 and going all the way to 4. Ireland had multiple responses as well, however both individuals filling out the questionnaire rated the topic at the top end of the scale with one respondent stating it was a very hot topic and the second respondent rated it as a hot topic. Since the responses of Cyprus varied significantly, it is difficult to say which result is truly representative of the Member State, since there is a difference in perspective between different types of organisations. Most countries provided only one response based on consultations with a variety of stakeholders, so likely a consensus was reached through discussion, which did not happen in these two cases.

Respondents from Cyprus and Germany were the only ones to rate the self-care/management at the lowest end of the scale. In responses from Estonia, Malta, Cyprus and Latvia the topic was placed

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<sup>70</sup> AHRQ: Self-management support page July 23 2019. <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/self/index.html>

<sup>71</sup> BMA: Self-care: question and answer. [https://www.bma.org.uk/-/media/files/pdfs/about%20the%20bma/how%20we%20work/professional%20committees/patient%20liaison%20group/plg\\_selfcare\\_jan2015.pdf](https://www.bma.org.uk/-/media/files/pdfs/about%20the%20bma/how%20we%20work/professional%20committees/patient%20liaison%20group/plg_selfcare_jan2015.pdf)

<sup>72</sup> Abramowitz and Bondheimer: Helping Patients help themselves: How to implement self-management support. California Healthcare foundation. <https://www.chcf.org/wp-content/uploads/2017/12/PDF-HelpingPtsHelpThemselvesImplementSelfMgtSupport.pdf>

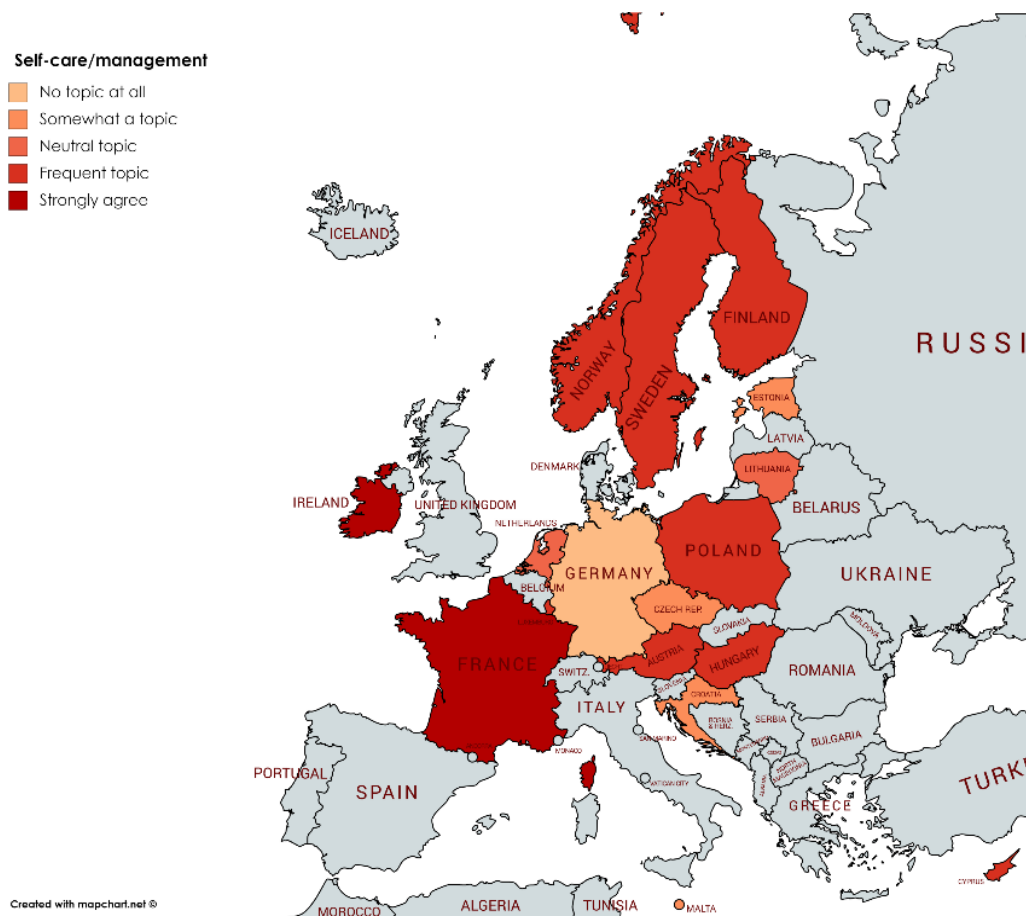
<sup>73</sup> NHS: Supporting self-management/self care. <https://www.england.nhs.uk/ourwork/patient-participation/self-care/> July 23 2019

<sup>74</sup> Bonderheimer T. Et al: Patient-self management of chronic disease in primary care. JAMA 2002, vol. 288 p. 2469-2474.

<sup>75</sup> Ricciardi L. et al, A national action plan to support consumer engagement via e-health. Health Affairs, 2012, vol. 32

at the second lowest point on the scale. The topic was considered to be neutral, at the middle point between “no topic at all” and “hot topic” by Finland, Netherlands, Cyprus and Lithuania. Poland, Cyprus, Norway, Ireland and Sweden rated the topic as a 4 on the 5 point scale indicating that self-care and management is considered important. The only two countries rating self-care/management at the highest point on the scale were France and Ireland.

Overall, the majority, 41%, of respondents believed that self-care/management was a hot topic in their country. Only 29% rated self-care/management at the low end of the scale, and 24% rated it as neutral.



**Figure 8. MS stages of self-care/management**

## 4.4 Shared decision-making

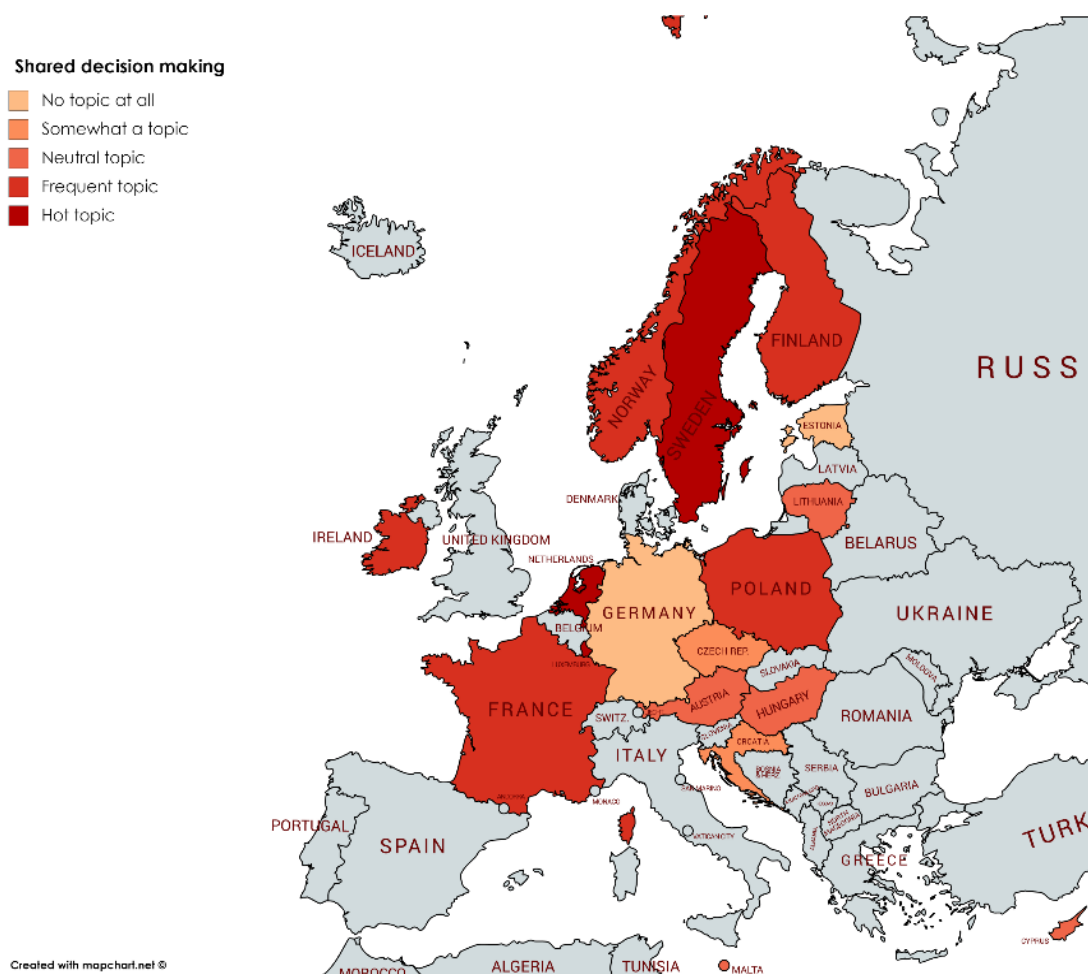
Patient empowerment is crucial to shared decision-making. Shared decision-making begins and ends with the patient. It is the process by which clinicians and patients work together to make a health decision after discussing options, potential benefits and harms, and considering the patient's values and preferences. Involving patients in their own treatment increases patient engagement and empowerment. Patients ultimately accept the responsibility of their health, and they can learn to solve their problems with information and support from the professionals.

The majority of the countries considered themselves to be within one of the top three engagement levels of the framework (~76% in total). Germany and Estonia put less emphasis on the issue. On average, shared decision-making, along with self-care, ranks slightly higher than other empowerment issues among Member States.



**Shared decision making**

- No topic at all
- Somewhat a topic
- Neutral topic
- Frequent topic
- Hot topic



**Figure 9. MS stages of shared decision making**

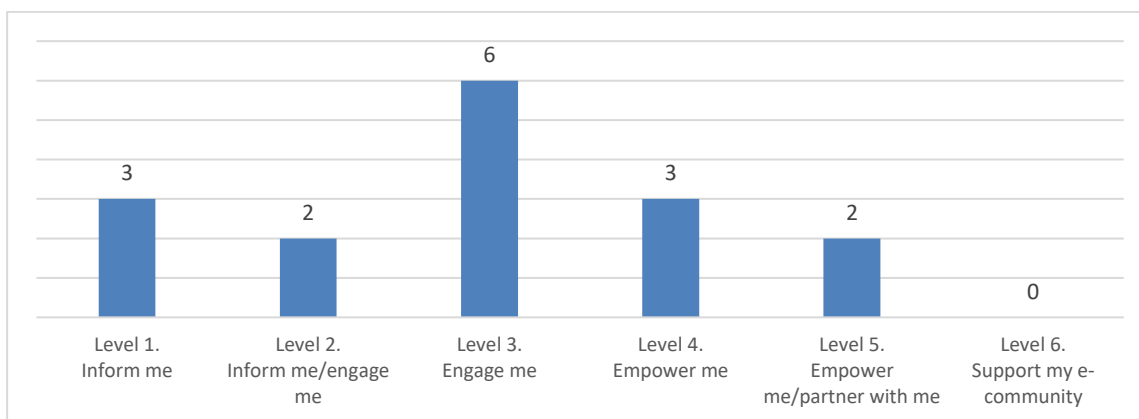
## 4.5 Patient engagement framework

A patient engagement framework has been developed by the Healthcare Information and Management Systems Society (HIMSS) to guide HPs in developing and strengthening their patient engagement strategies<sup>76</sup>. It consists of six levels of patient engagement, starting with the level of 'inform me' and ending with 'support my e-community' (appendix 5). In the survey of this work package (WP), the MS were asked to indicate on what level they would place their MS.

Almost all countries indicated their positions in the patient engagement framework. Some of them indicated two levels, to show that they are in between levels. Most of the countries are on level 3, in the 'engage me' phase (n=6). Other MS indicated being are on level 1 (n=3), level 2 (n=2), level 4 (n=3) and level 5 (n=2). None of the MS indicated being on level 6.

<sup>76</sup> 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 10. Number of MS on levels of patient engagement framework**

Latvia, Estonia, Lithuania, Sweden, Hungary, Norway and the Netherlands have made significant progress; others are lagging behind. In some countries (e.g. Estonia) eHealth infrastructure is developed, but patients cannot share information with HPs.

**Patient engagement framework**

- Inform me
- Inform me / engage me
- Engage me
- Empower me
- Empower me / partner with me



**Figure 11. Indication of MS of level on patient engagement framework**

## 11. 5. Conclusion

### General conclusions

- mHealth, telehealth, patient access & use of data, and digital health literacy have all been shown to contribute to people empowerment by increasing peoples' ability, motivation and opportunity.
- When planning digital health interventions for empowerment, MS would do well to take into consideration the ability, motivation and opportunity of the people they are targeting, and the barriers and enablers that affect these. In doing so, personas can be of value in better considering the real needs of the people to be empowered.
- An overarching key to better adoption of digital health for empowerment is ensuring trust in digital technology among all users, including patients, health professionals and regular citizens. This highlights the need to engage these stakeholder groups throughout the development of digital empowerment programmes, ensuring transparency and user-centricity.
- Out of all the stakeholder groups analysed and surveyed, HPs show the most resistance to the uptake of digital health for empowerment. At the same time, HPs are considered a key group to advance the empowerment agenda. This highlights the need to better address the particular concerns of HPs when advancing digital health programmes.
- All MS are working on relevant topics (e.g. shared decision making) with the objective of increasing people empowerment, but the focus between those topics differs. In addition, there is a difference between MS on levels of engagement. Most MS are on the middle level (engage me) while there are also MS on level 1 (inform me) and on level 5 (empower me).

### Telehealth and mHealth

- Telehealth and mHealth are both established topics within MS, but they are being deployed to a varied extent. For the vast majority of MS a systemic approach is lacking for both issues, and no MS has overcome all the barriers facing their adoption.
- Although both mHealth and telehealth contribute meaningfully to increasing patients' ability and opportunity to be empowered, there is still a lack of solutions that focus on a patient's motivation, for example in relation to behavioural change.
- Mobile applications are being used in MS to provide patients with useful information and help them gather vital signs. However, the information provided is rarely explained (e.g. by a virtual coach) and there is a lack of integration of apps with the work of healthcare professionals.
- Telehealth is being deployed to some degree in Member States to better help integrate healthcare into daily life, however, there is a lack of telehealth usage for educational programmes.
- Both mHealth and telehealth suffer from a lack of enabling healthcare policy, as well as a lack of legislation and regulation, stakeholder willingness and clear priorities.

- The majority of reported barriers facing telehealth and mHealth adoption were user-centred, with privacy and security concerns, as well as a lack of digital skills, figuring highly. Resistance to mHealth and telehealth is more pronounced among HPs than patients. This highlights the need for a variety of interventions.
- MS responses show that there is still room for improvement when it comes to educational activities around mHealth and telehealth, particularly when it comes to educating physicians, where training should also take into account the changing roles of doctors in relation to new modes of care.
- A separate issue for physicians when it comes to mHealth and telehealth is the concern over increasing workload. This illustrates a need to integrate such tools with existing work processes and ensure interoperability. Such activities are still largely lacking, particularly for mHealth.
- Telehealth, and particularly mHealth suffer from a lack of assessment and quality standards, which could in turn cause a lack of funding and reimbursement. Instituting more rigorous quality standards and assessment frameworks is therefore likely to contribute to overcoming a variety of issues, including user-centred, institutional and economic barriers.
- Governments are likely to benefit from employing a more user-centred approach to developing mHealth and telehealth, using means such as hackathons and working more closely with patient organisations and the private sector.

### **Patient access and use of data**

- The opportunity for people to access and use their online data is growing, because of the widespread implementation of EHRs and patient portals in MS. Once access is provided to people, they can see health data, such as clinical test results, lab results and medical images. The kind of information and amount of data provided by MS vary. The health data most frequently available online are e-prescriptions, referrals and discharge letters.
- There are different infrastructure models between MS, for example centralised and decentralised means to provide people with online access to their data. When employed correctly, both models can provide equal access to data. However, the level of opportunity for people to access their data can differ based on the infrastructure; e.g. the opportunity to access data for a citizen in one region can differ with a citizen in another region.
- People are motivated to access and use their online data when it is user-friendly and understandable (taking into account the different patient groups) and when trust, security and privacy issues are taken care of. Transparency is a key word in this. Personal factors, such as age, vary significantly between people, and influence the motivation and ability to access and use online health data.
- The main factor with regard to ability for people to access and use online health data is having digital knowledge/competence. Even though a MS is offering digital solutions, people can miss out because of low DHL.
- Once people are actually accessing and using their online health data, it is expected that they achieve a deeper understanding of their health condition, which can impact self-

management. Raising awareness and understanding are very important factors in this process.

- The most mentioned category for both barriers and enablers for patient access and use of data is the user-centred category. Costs and reimbursement and integration are the least mentioned categories. Taking into account that both are definitely important, it could be that these subjects are not at the top of everyone's mind when thinking of patient access and use of data.
- Health professionals are important enablers for the overall adoption of people to access and use EHR online data. It is important to engage them as well and take notice of their barriers, such as money and time. The most reported enablers are creating the opportunity for people to actually access their data online, understandable and up-to-date health information and personal ownership. The barriers mainly referred to by MS are privacy and lack of data.
- The actual use of data by people is not always monitored by MS. However, it is unclear whether the numbers are low because of experience barriers or lack of necessity because of being healthy. There is a need for better metrics on assessing people's access to data.

### **Digital Health literacy**

- There is a clear difference between digital and health literacy for HPs and patients which is not always understood and taken into consideration while creating policy by MS. In addition, the emphasis is more on digital literacy and less on health literacy, while health literacy is seen as just as important.
- The needs of people on health literacy are not yet defined; it is not only about giving medication, but also about informing on one's disease or lab results.
- HPs and the social environment are important motivators in the process of increasing DHL and can function as coaches or as a support system.
- Each solution needs a different DHL approach, because of the different types of services.
- To increase the opportunity, people need to be provided with online access to useful information any time, anywhere and from any device. To increase the ability and motivation, information and education are given as important factors.
- The most mentioned category for both barriers and enablers for DHL is the user-centred category. The most reported enablers are training and education which should be accessible for everyone at any place and any time, and the support of HPs and having a national DHL agency. The most frequently mentioned barriers are resistance to change from having anxiety and trust issues for online services and tools, and different population groups, e.g. elderly with different needs than younger people.
- The active involvement of citizens in creating DHL policy and the development of DHL through the life-course, such as training and education in primary school and adult learning is very important.

## Limitations of this framework

This framework draws conclusions from an extensive literature review as well as a detailed Member State survey. As much as possible, the limitations of our conclusions have been pointed out throughout the framework. All conclusions must be weighed against the fact that 10 Member States did not provide answers to the survey, which forms the basis for chapter 3. For that reason, we have tried to draw parallels with other studies to exemplify how our findings compare to previous ones. Furthermore, as the survey is by nature a self-report, the usual limitations of self-reported data apply.

The AMO model is a very efficient and demonstrative tool in general but the answers provided in the questionnaire were sometimes overlapping. Despite the brief description about the purpose and components of the model, the respondents sometimes could not differentiate between ability, motivation and opportunity. Often, the same answers were copied to two or all three items or simply one component was filled in and the others were left empty. Besides the misclassification of the AMO elements, another explanation could be that large, comprehensive national programmes and systems contain elements of all three aspects. Furthermore, to address the issue of misclassification, contributors were instructed to seek out misclassified initiatives when analysing survey responses.

## 12. Appendix 1. Methodology

The structure of this policy framework is based on the AMO framework, a model formed to explain performance outcomes. The AMO model includes a model consisting of three subjects: Ability, Motivation and Opportunity. Ability includes knowledge and skills needed for a certain outcome. Motivation encompasses the factors resulting in certain behavior. Opportunity refers in this framework to the availability and accessibility of solutions provided. These three factors are interrelated with each other, which in an ideal proportion can lead to empowering people.

For both AMO framework and barriers and enablers, desk research and a survey was conducted. The process started with an extensive literature/desk research for the four topics of this framework, namely telehealth, mHealth, patient access and use of data, and digital health literacy. The literature used and theoretical background research consists of 50 articles accessed via different search engines (Google Scholar, PubMed) as well as from public EU sites. Other input for the theoretical state of play was the information gathered during the WP4 workshop held in Amsterdam in October 2018. During the workshop, literature as well as perspectives on people empowerment were discussed. The reports and results were analysed using a qualitative content analysis method; the findings can be seen in chapter two, which provides an overview of the theoretical state of play of empowerment.

The actual state of play regarding eHealth implementation in MS was researched using a questionnaire. The survey consisted of 41 questions divided among the four topics, the AMO model, and barriers and enablers (the survey questions can be found in appendix 3). The survey was sent to both the Leadership Council and the Steering Council of eHAction to reach a high number of respondents. 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; the closing date was March 2019. The analysis of the survey was done using qualitative content analysis. The data collected from the survey can for the most part be considered as representative as the responses were collected from 19 MS and national consultation rounds within MS were carried out with different stakeholders to provide a wide spectrum of viewpoints regarding the topic. In a few cases, several responses were provided per MS instead of a consensus response, which made it difficult to discern the country's "true" position on matters. The section on actual state of play includes information from the surveys that was selected after aggregating, analysing and benchmarking the data across MS, which brought out trends and the state of the art regarding the topic. The results of this survey analysis can be found in chapters three and four.

Based on the results from both desk research, literature analysis and survey answers, the conclusion chapter is written.

The WP leaders coordinated this process. Contributors divided among the four subjects helped in doing the desk research, analyse the surveys and write certain parts for the report. The WP leaders were responsible for finalising the deliverable.

## 13. Appendix 2. Enablers and barriers categorisation

### Health policy

Health policy refers to decisions, plans, and actions that are undertaken to achieve specific healthcare goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people<sup>77</sup>. The health policy of a Member State influences the other categories concerning the perceived barriers and enablers. The lack or presence of legislation affects both the infrastructure and interoperability of digital health solutions as well as the integration, assessment and costs. These issues are complex and time-consuming to solve, demonstrating the need for a clear long-term strategy for patient empowerment through digital health. Therefore the greatest changes can be made with a change in policy or the development of a national strategy and prioritisation.

### Core infrastructure

Nationwide and local health agencies rely on basic infrastructure to monitor population health and respond to community health needs. It requires systematic data collection to monitor community health needs and identify underlying causes of health problems<sup>78</sup>.

The category 'core infrastructure' mainly includes nationwide internet access (broadband) and speed of the internet. The lack of internet access is a frequently mentioned barrier among all topics concerning patient empowerment. Since internet access is one of the main necessities of digital health, it could be an essential factor in increasing empowerment.

### Assessment (Technology)

The assessment (of technology) means estimating the effect of either (new) products, tools, skills or data used in mHealth, teleHealth, patient access and digital health literacy. It encompasses mentioned enablers or barriers such as cost-effectiveness, quality of data, cybersecurity or system reliability. Assessment is thereby known to play an important role in the cycle of acceptance and adoption. Assessment leads to higher-quality 'products', which can lead to a higher level of adoption<sup>79</sup>. The enablers and barriers in this category will therefore play an important aspect in the adoption of our topics and the achievement of empowerment.

### Costs and reimbursement

Healthcare reimbursement describes the payment that a hospital, doctor, diagnostic facility, or other HCP receives for giving a medical service<sup>80</sup>. This could either be cost-based reimbursement, which results in a payment to the HCP based upon the cost of the resources consumed to provide

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<sup>77</sup> A journal of healthcare communications. Healthcare policies. Imedpub. <http://www.imedpub.com/scholarly/healthcare-policies-journals-articles-ppts-list.php>

<sup>78</sup> Soucie JM. Public health surveillance and data collection: general principles and impact on hemophilia care. *Hematology*. 2012;17 Suppl 1(01):S144–S146. doi:10.1179/102453312X13336169156537

<sup>79</sup> A review of technology acceptance and adoption models and theories. Hamed Taherdoost. <https://reader.elsevier.com/reader/sd/pii/S2351978918304335?token=B46AE80B39D095F2D6266FC9C5157506D82C56F1BE83020D906E1EEE5BC4A599FBDD1AE87C2B7335C9757BFD4A00174>

<sup>80</sup> Understanding Healthcare Reimbursement. Verywell health. Trisha Torrey. <https://www.verywellhealth.com/reimbursement-2615205>



care, or prospective payment methods, which determine the amount to be paid to the HCP before the service is rendered<sup>81</sup>.

The barriers related to costs and reimbursement differ between the different groups. For people, the mentioned barriers were costs of telehealth equipment, EHR technology or smartphones in general. For HPs, the lack of costs and reimbursement mean the lack of funding mechanisms or the lack of implementation support. This also ties to the mentioned category of assessment, as clear assessment guidelines for determining the quality of digital technologies lay the groundwork for their reimbursement. One of the enablers for costs and reimbursement was value-based healthcare, where reimbursement for care is based on the quality of the care.

### **Integration and Interoperability**

In the healthcare industry, integration means the organisation and management of health services in such a way that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money<sup>82</sup>.

Interoperability is the ability of different information systems and software applications to communicate and exchange data and use the information exchanged. The use of standards and data exchange models enables this information to be shared between HCP, HP, patients, hospitals etc. regardless of the application being used<sup>83</sup>. In this way, interoperability is a driver of integration.

For people to be able and willing to use any given digital health solution, information systems have to be interoperable and compatible. Data has to be exchanged and reliable in all the digital environments, thereby facilitating the integration of the entire care process. However, this is still a common barrier.

### **User-centred**

The user-centred category refers to all aspects of using digital solutions connected to the person who uses it. The most frequently mentioned barriers can be categorised under user-centred issues of the digital environments. These mentioned barriers vary from perceived complexity for the users, to the conservative culture of the non-users. Support from social contacts or HPs is seen as an enabler together with awareness of the benefit. It is also mentioned as important to create digital environments with both patients as well as HP. The development and refinement should be in a co-creative form in order to improve use and therefore empower people.

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<sup>81</sup> Teaching Healthcare Reimbursement Systems Using System Dynamics Models. Michael H. Kennedy.  
[http://www.itdl.org/Journal/May\\_09/article03.htm](http://www.itdl.org/Journal/May_09/article03.htm).

<sup>82</sup> INTEGRATED HEALTH SERVICES. Technical brief. WHO. [https://www.who.int/healthsystems/technical\\_brief\\_final.pdf](https://www.who.int/healthsystems/technical_brief_final.pdf)

<sup>83</sup> Interoperability in Healthcare Systems. Successes and New Challenges to Value-Based Healthcare Management.  
<https://www.ehcos.com/en/interoperability-in-healthcare-systems-successes-and-new-challenges-to-value-based-healthcare-management/>

## 14. Appendix 3. Summary of the survey

Question	Answer options
<b><u>Contact information - all tasks</u></b>	
1. What is your country (and region if applicable)?	
2. What is the name of your organisation?	
3. How would you classify your organisation? <input type="radio"/> Ministry <input type="radio"/> NCC <input type="radio"/> University <input type="radio"/> ICT-organisation <input type="radio"/> Healthcare provider <input type="radio"/> Patient organisation <input type="radio"/> Commercial/business <input type="radio"/> Other, please specify	Open
4. What is your name?	
5. Please supply a contact email address	
6. Please supply a contact telephone number	
<b><u>AMO- Model - mHealth / Telehealth</u></b>	
<p>Please provide up to three best examples from your country, how mHealth/Telehealth is used to increase the ability, motivation and opportunity of citizens <b>to take care of their own health</b>. Describe, how many people are using these solutions and on which level are they implemented (e.g. national, regional, hospital-specific solutions).</p> <p>7a. How does mHealth/Telehealth increase <u>the ability of citizens to take care of their own health</u>? Please provide examples from your country.</p> <p>7b. How does mHealth/ Telehealth increase <u>the motivation of citizens to take care of their own health</u>? Please provide examples from your country.</p>	<p><u>Per example provide:</u></p> <p>Description:</p> <p>Name:</p> <p>Objective:</p> <p>Hyperlink:</p>

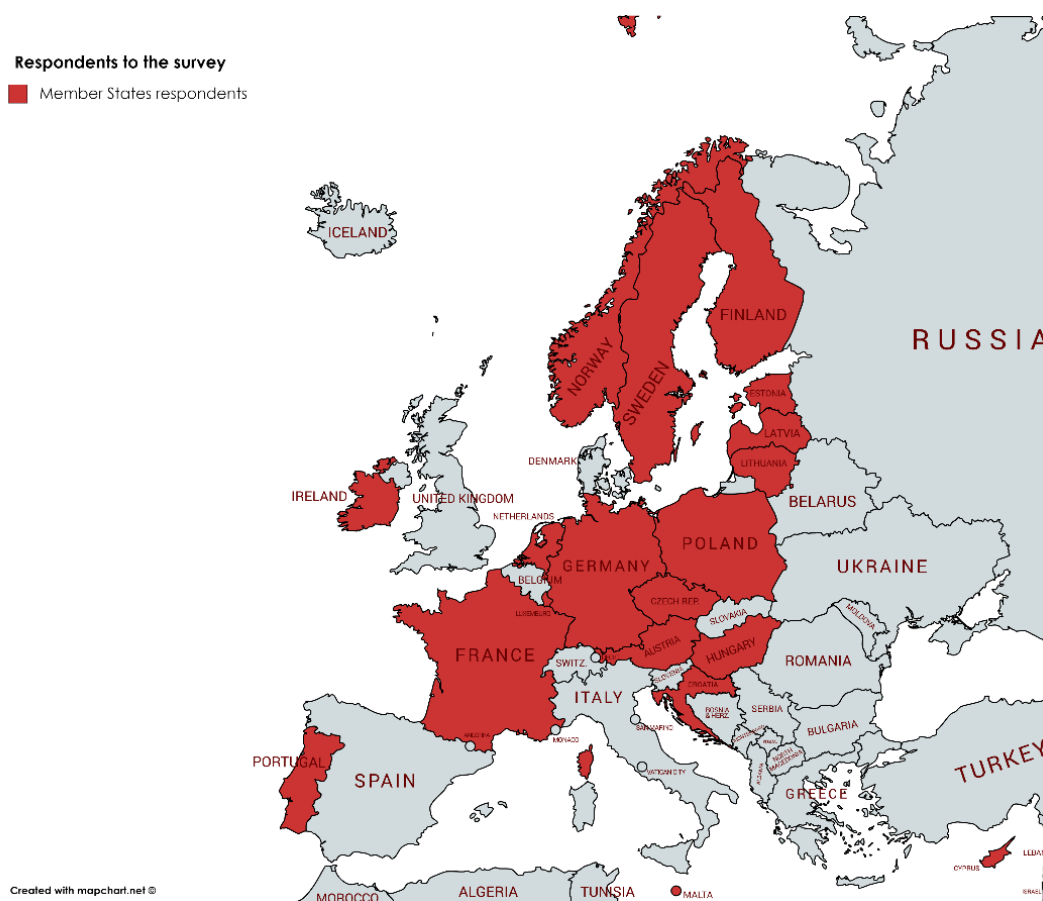
<p>7c. How does mHealth/ Telehealth increase <u>the opportunity of citizens to take care of their own health</u>? Please provide examples from your country.</p>	
<p>Can you describe if and how you work <b>on increasing mHealth/Telehealth adoption</b> within your country? Describe any measures you have taken or current initiatives. Please indicate for the different aspects of the AMO (ability + motivation + opportunity) model:</p> <p>8a How does your country ensure that citizens <u>have the ability to use mHealth/Telehealth solutions</u>? If possible, please describe the impact of the measures you have taken.</p> <p>8b. How does your country ensure that <u>citizens have the motivation to use mHealth/Telehealth solutions</u>? If possible, please describe the impact of the measures you have taken so far.</p> <p>8c. How does your country ensure that <u>citizens have the opportunity to use mHealth/Telehealth solutions</u>? If possible, please describe the impact of the measures you have taken so far.</p>	<p style="text-align: center;">Open</p>
<p><b><u>Barriers and Enablers - mHealth / Telehealth</u></b></p>	
<p>9. What are the main barriers and enablers for mHealth/Telehealth adoption? (choose seven main barriers and enablers for you country)</p>	<p><u>Health system specific barriers</u></p> <ul style="list-style-type: none"> <li><input type="checkbox"/>Lack of readiness among key stakeholders:             <ul style="list-style-type: none"> <li><input type="checkbox"/>healthcare providers;</li> <li><input type="checkbox"/>patient organisations;</li> <li><input type="checkbox"/>communities;</li> <li><input type="checkbox"/>other (please specify);</li> </ul> </li> <li><input type="checkbox"/>Lack of enabling healthcare policy</li> <li><input type="checkbox"/>Conflicting priorities</li> <li><input type="checkbox"/>Privacy &amp; Security concerns</li> <li><input type="checkbox"/>Lack of governance</li> <li><input type="checkbox"/>Unrealistic expectations for mHealth</li> </ul>

	<input type="checkbox"/> Conservative culture <input type="checkbox"/> Medicolegal issues <input type="checkbox"/> Non-existent strategy  <u>Business case</u> <input type="checkbox"/> Cost-effectiveness of mHealth apps <input type="checkbox"/> Lack of reimbursement models <input type="checkbox"/> Lack of implementation support  <u>User-centred barriers</u> <input type="checkbox"/> Solutions not adapted for physicians <input type="checkbox"/> Perceived complexity and resistance from physicians <input type="checkbox"/> Lack of time and workload <input type="checkbox"/> Lack of technological knowledge among: <input type="checkbox"/> Citizens <input type="checkbox"/> Physicians  <u>Application specific barriers</u> <input type="checkbox"/> Lack of evidence of clinical utility <input type="checkbox"/> Lack of integration & interoperability  <u>Other, namely:</u>
10. Are there additional thoughts/ideas you want to share with us with regard to mHealth? Please include an URL if available.	Open
<b><u>AMO- Model - Patient access and Digital health literacy</u></b>	
17. Please indicate how your country works on increasing patient access and/or use of health data. Can you do this by describing current national and/or regional programs and/or initiatives in the table below. Please complete the table for the different aspects of the AMO model.	<u>Per example provide:</u> Description: Name: Objective: Hyperlink:
<b><u>Barriers and enablers - Patient access and Digital health literacy</u></b>	
18. What enablers and barriers do citizens have regarding patient access and use of data? Indicate your priority for policy in your answer (number 1 is highest priority and so	Open

on). See the example below in the first row.																																									
19. Are there additional thoughts/ideas you want to share with us regarding patient access and use of data? Please include an URL if available.	<u>Open</u>																																								
<b><u>Patient Engagement - Digital health literacy</u></b>																																									
28. In what way do you involve citizens or patient organisations in your work regarding digital health literacy? (if not, please indicate so). Please include an URL if available.	<u>Open</u>																																								
<b><u>Patient Engagement Framework – All tasks</u></b>																																									
40. Please indicate to what extent the following topics regarding people engagement are addressed in your country?	<table border="1"> <thead> <tr> <th>Topic</th> <th></th> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th></th> </tr> </thead> <tbody> <tr> <td>Personalised medicine</td> <td>"no topic at all"</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>"hot topic"</td> </tr> <tr> <td>Self-care/management</td> <td>"no topic at all"</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>"hot topic"</td> </tr> <tr> <td>Shared decision making</td> <td>"no topic at all"</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>"hot topic"</td> </tr> <tr> <td>Patient advocacy</td> <td>"no topic at all"</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>"hot topic"</td> </tr> </tbody> </table>	Topic		1	2	3	4	5		Personalised medicine	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"	Self-care/management	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"	Shared decision making	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"	Patient advocacy	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"
Topic		1	2	3	4	5																																			
Personalised medicine	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"																																		
Self-care/management	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"																																		
Shared decision making	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"																																		
Patient advocacy	"no topic at all"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	"hot topic"																																		
<p>41. The Patient Engagement Framework is a model created to guide healthcare organisations in developing and strengthening their patient engagement strategies through the use of eHealth tools and resources.</p> <p>Where would you indicate your country on the patient engagement framework from HIMSS? For more information <a href="https://www.himss.org/himss-patient-engagement-framework">https://www.himss.org/himss-patient-engagement-framework</a> or see next page:</p>	<input type="checkbox"/> Inform me (column 1) <input type="checkbox"/> Engage me (column 2) <input type="checkbox"/> Empower me (column 3) <input type="checkbox"/> Partner with me (column 4) <input type="checkbox"/> Support my e-Community (column 5)																																								
Please, describe below why:	<u>Open</u>																																								

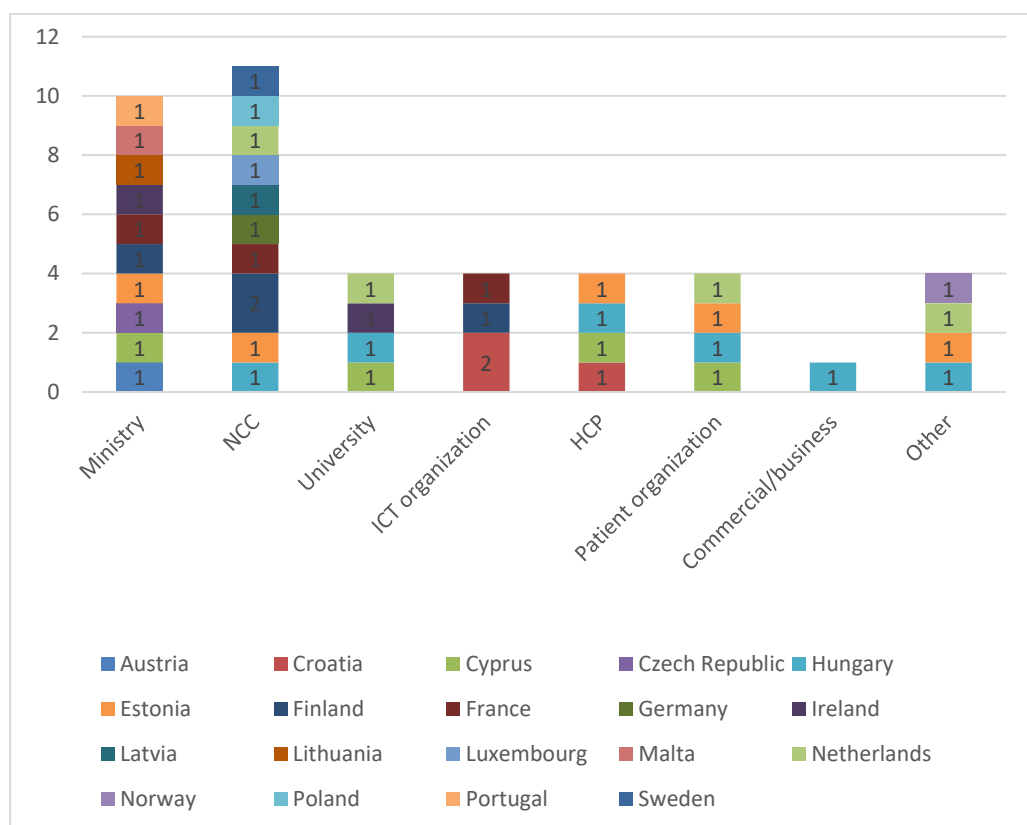
## 15. Appendix 4. Respondents survey results

This appendix includes more detailed information about the respondents of the survey. The figure below visualises which MS have completed the questionnaire, in total 19 MS.



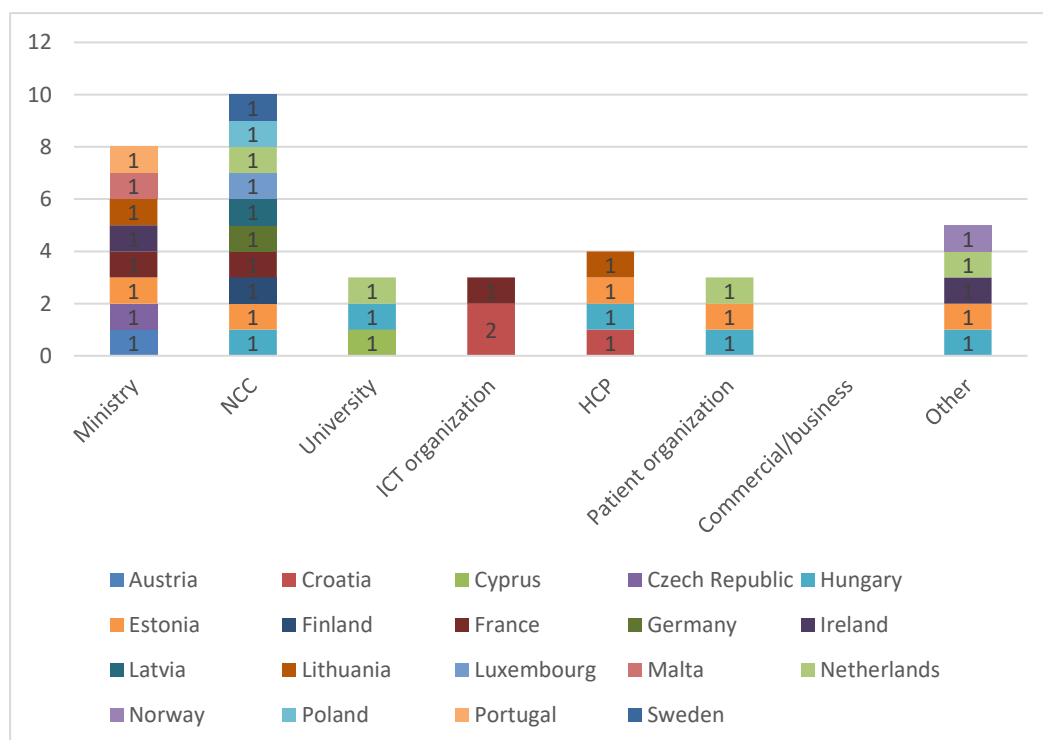
**Figure 12. MS respondents to the survey**

Figures 10 to 13 show what type of organisations completed the survey from which countries. Some MS asked different types of organisations to fill in the survey, to ensure more perspectives on the state of play in their country. Not all organisations completed the entire questionnaire; some only filled the parts relevant for their field of expertise.



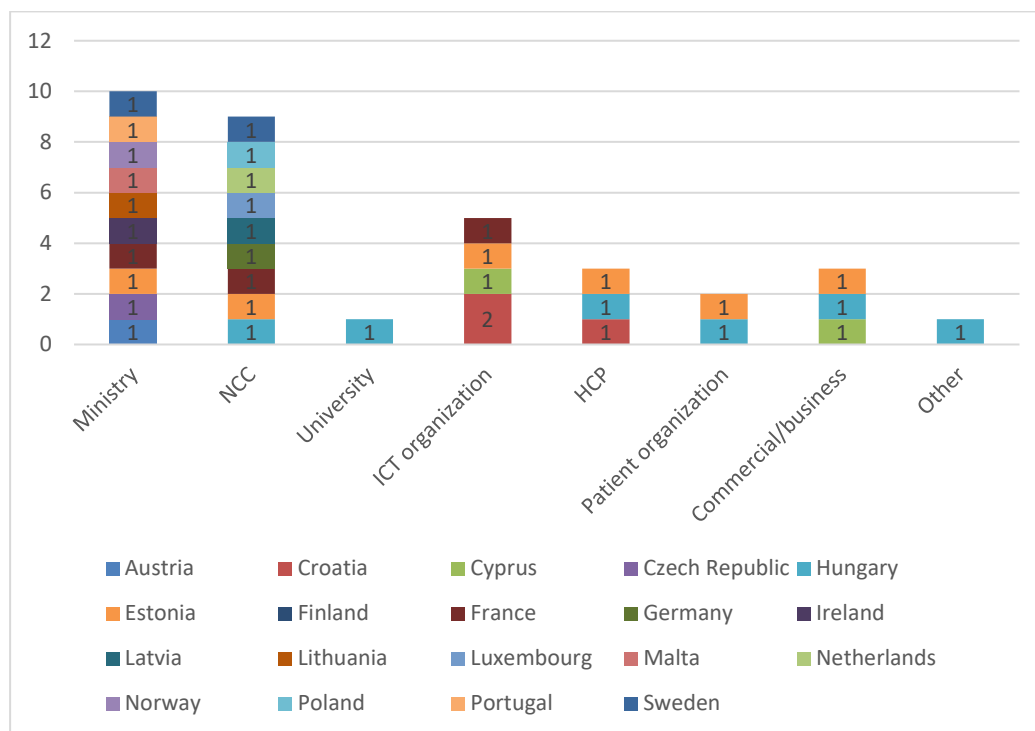
**Figure 13. Patient access and use of data respondents to the survey based on organisations**

Figure 10 shows that most of the respondents who completed the Patient Access part of the survey, were either Ministries or NCC (national competence centres). This is a recurring result for all the topics.



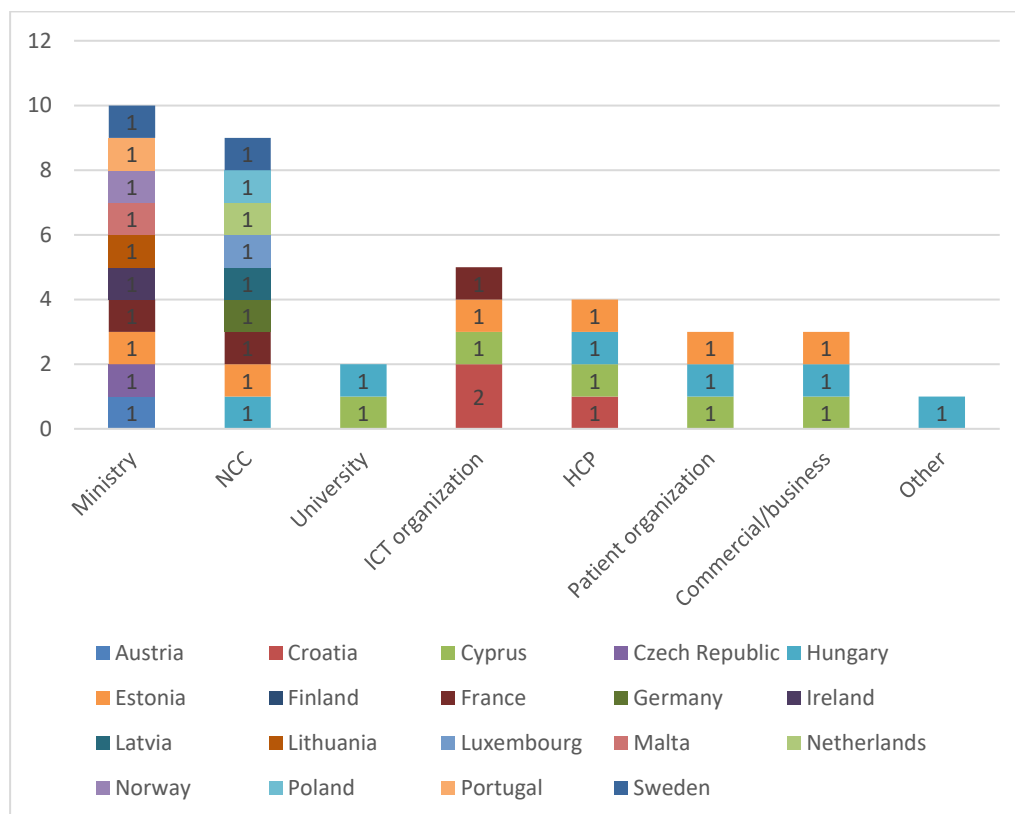
**Figure 14. Digital (health) literacy respondents to the survey based on organisations**





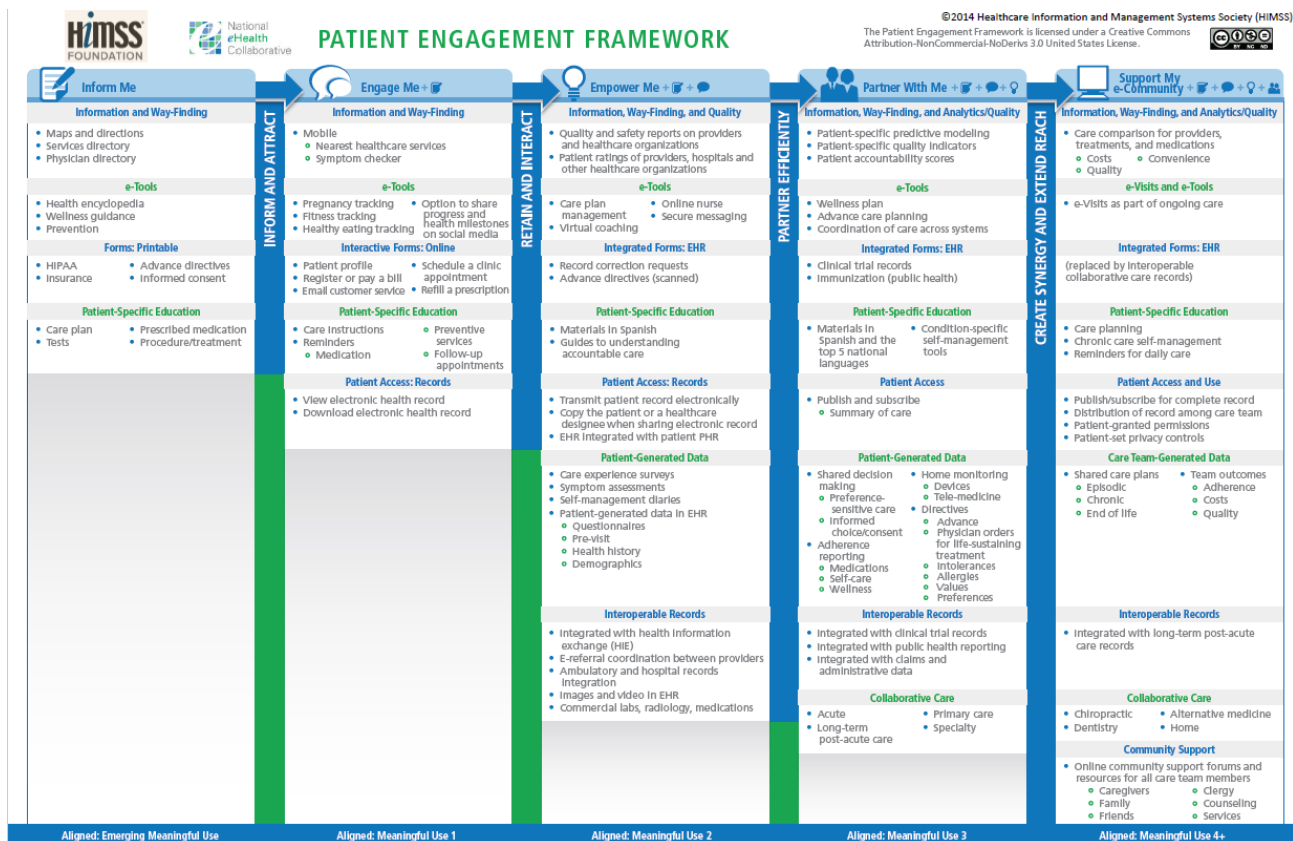
**Figure 15. mHealth respondents to the survey based on organisations**

The least common type of organisation who filled in the survey were commercial businesses. Organisations marked as 'other' included for example non-governmental organisations (NGOs) or health insurance funds.



**Figure 16. Telehealth respondents to the survey based on organisations**

## 16. Appendix 5. Patient engagement framework



## 17. Appendix 6. Best practices

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.

### mHealth

#### Ability

Zdravlje.net - Croatia<sup>84</sup>.

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.

Omaolo - Finland<sup>85</sup>.

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

Samengezond – Netherlands<sup>86</sup>.

The Netherlands provides apps via healthcare insurance companies to stimulate citizens in healthy behaviour. One example is Menzis – Samen gezond.

Telia Active - Estonia<sup>87</sup>.

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.

#### Opportunity

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<sup>84</sup> <https://dzz-centar.hr/zdravlje-net/>

<sup>85</sup> [www.omaolo.fi](http://www.omaolo.fi)

<sup>86</sup> <https://samengezond.menzis.nl/apps/detail/1>

<sup>87</sup> <https://active.telia.ee/sammud-internetiks>

### The Appsök - Sweden<sup>88</sup>.

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

### Gesundheitsdialog - Austria<sup>89</sup>.

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.

## Telehealth

### Ability

#### Luscii platform – the Netherlands<sup>90</sup>.

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 HPs in the daily care of their patients. Luscii gives the ability to the 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% of insurance companies.

#### Dignio – Norway<sup>91</sup>.

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

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<sup>88</sup> <https://www.appsok.se/om-appsok>

<sup>89</sup> <http://www.ge-breitenstein.at/e-health/gesundheitsdialog-diabetes>

<sup>90</sup> <https://luscii.com/>

<sup>91</sup> <https://www.dignio.no/helseoppfolging>

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

The MUDA initiative – Portugal<sup>92</sup>.

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.

CSAM – Norway<sup>93</sup>.

This is a promising and motivational telehealth practice to connect citizens/patients with HCP. CSAM is a comprehensive self-care and health counselling solution that simplifies the interaction between patients and their HP. 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.

Braster - Poland<sup>94</sup>.

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

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 are part of such a programme.

Sunnaas hospital – Norway<sup>95</sup>.

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

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<sup>92</sup> <http://www.meiosepublicidade.pt/2017/03/initiative-muda-imagem/>

<sup>93</sup> <https://www.csamhealth.com/>

<sup>94</sup> <https://www.braster.eu/en>

<sup>95</sup> <https://www.sunnaas.no/sunnaas-rehabilitation-hospital>

project showed that a video consultation accounts for only 15% of the cost compared to a clinic visit and only 3.2% of the costs compared to an admission.

ePerearstikeskus – Estonia<sup>96</sup>.

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.

CarnaLife – Poland<sup>97</sup>.

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 prioritise 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.

## Patient access and use of data

### Ability

P1 – the National Health Platform - Poland<sup>98</sup>.

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).

One Citizen – One Journal programma nbygger - Norway<sup>99</sup>.

The One Citizen – 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.

### Motivation

myHealth - Malta<sup>100</sup>.

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<sup>96</sup> <https://www.eperearstikeskus.ee/patient/>

<sup>97</sup> [<https://www.carnalife.io/en>]

<sup>98</sup> <https://pacjent.gov.pl>

<sup>99</sup> [https://www.eiseverywhere.com/file\\_uploads/e1508f0c5a68501b5071a8ce1d466eb6\\_170221\\_HDC\\_Lunch\\_Bergland.pdf](https://www.eiseverywhere.com/file_uploads/e1508f0c5a68501b5071a8ce1d466eb6_170221_HDC_Lunch_Bergland.pdf)

<sup>100</sup> [www.myhealth.gov.mt](http://www.myhealth.gov.mt)

Some Maltese citizens 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 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.

#### My Kanta - Finland<sup>101</sup>.

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 well-being data which they have entered into the national personal health record through the well-being 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 System<sup>102</sup>). In 2018, My Kanta pages were used by over 38% of the population.

#### Opportunity

#### VIPP - The Netherlands<sup>103</sup>.

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 institutions<sup>104</sup> participate in this programme. Patients are better informed about their own health. HPs 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.

#### MedMij - The Netherlands<sup>105</sup>.

MedMij offers the solution for digitally sharing data with the patient. The MedMij Appointment System ensures that a HP does not have to make separate links with all available personal health

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<sup>101</sup> <https://www.kanta.fi/en/my-kanta-pages>

<sup>102</sup> <http://vrk.fi/en/population-information-system>

<sup>103</sup> <https://www.vipp-programma.nl/>

<sup>104</sup> Institutions focused on specific diseases or patients

<sup>105</sup> <https://www.medmij.nl/>



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 HCP in a secure and familiar way. MedMij sets the rules for this.

#### ELGA Ombudsstelle - Austria.

The Austrian ELGA Ombudsstelle is a face-to-face service centre assisting citizens in the use and access of ELGA. It is part of a Governmental programme and provides the ELGA service line and services centres across the country (Ombudsstelle). The ELGA Ombudsstelle can access the ELGA data on behalf of the patient if they are not digital literate.

#### ELGA-Widerspruchstelle – Austria.

The Austrian ELGA-Widerspruchstelle provides a paper-based way of the digital opt-out service for citizens wishing to use opt-out from the use of ELGA via mail.

#### eGradani web based portal – Croatia.

The Croatian web based portal eGradani provides the citizen with a digital identity certificate through a microchip or a token, which will be changed for a better solution in the future.

## Digital health literacy

### Ability

#### Online eHealth learning platform - Lithuania<sup>106</sup>.

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

#### Joint development initiated in the Connected Health Cluster - Estonia<sup>107</sup>.

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.

### Motivation

#### Digital Strategy - Sweden<sup>108</sup>.

Strategy for digitalisation is divided into five goals. The first goal is to increase the ability of people 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

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<sup>105</sup><http://mokymai.esveikata.lt/pranesimai-ir-naujienos-pacientams>

<sup>107</sup> <https://ttu.ee/taiendusoppijale/koolituskalender/algavad-koolitused/algavad-koolitused-2/?id=26999&koolitus=9315>

<sup>108</sup> <https://www.government.se/information-material/2017/06/fact-sheet-for-sustainable-digital-transformation-in-sweden--a-digital-strategy/>

based on their own situation.

#### MySNS Seleção - Portugal<sup>109</sup>.

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

#### eHealth4all - The Netherlands<sup>110</sup>.

The eHealth4all programme is initiated by Pharos. This programme includes instruction and materials for developers and users of eHealth on DHL. The aim is to encourage and support developers of eHealth and HPs on DHL, 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.

#### Public National Health Portal – Austria<sup>111</sup>.

The Austrian public national health portal is an internet platform which offers independent quality assured and service-oriented information related to health and diseases. It is part of the Austrian governmental programme and provides the citizen with videos, tools, quizzes, links to related programmes, contact addresses and phone numbers.

#### e-skole – Croatia<sup>112</sup>.

e-skole is a national programme with multiple projects from 2015 to 2022 monitored by the Croatian Ministry of Science and Education. It aims to increase digital competence of teachers and students with purpose of keeping up with digital transformation of society, industry and health. Among other aspects the Ministry of Science and Education provides schools with the necessary equipment to educate students aged 7-18 with necessary knowledge and digital skills.

#### De Kijksluiter<sup>113</sup> / Beeldsluiter<sup>114</sup> - The Netherlands.

“De Kijksluiter” 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 Kijksluiter”

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<sup>109</sup> <http://mysns.sns.gov.pt/mysns-selecao/>

<sup>109</sup> <https://www.pharos.nl/over-pharos/programmas-pharos/ehealth4all/>

<sup>111</sup> <https://www.elga.gv.at/en/about-elga/index.html>

<sup>112</sup> <https://pilot.e-skole.hr/en/>

<sup>113</sup> <https://stichtingkijksluiter.nl/>

<sup>114</sup> <https://www.beeldsluiter.nl/>

is developed for citizens to access this at home. Kijksluiter 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.