



D4.1 Policy framework on patient empowerment

Information note

WP4 Empowering people

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Abstract: This Information Note describes the scope of and approach for Work Package 4 'empowering people' to be discussed and agreed upon by the eHN members.

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Acronyms

Acronym	Description
EHR	Electronic Health Records
JA	Joint Action
MoSA	Ministry of Social Affairs
MS	Member State(s)
WHO	World Health Organization
WP	Work Package

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1. Background

The work of WP4 ‘empowering people’ investigates the state of the art of people empowerment across MS with regard to the following topics:

Task 4.1 - mHealth and health apps reliability

Task 4.2 - Patient access and use of data

Task 4.3 - Digital health literacy

Task 4.4 - Telehealth

Within this work package two deliverables are provided: a policy framework (D4.1) and a policy proposal (D4.2) (figure 1). Member states (MS) Estonia and the Netherlands are work package leaders. Several other MS are contributors and are indicated in Appendix 1.

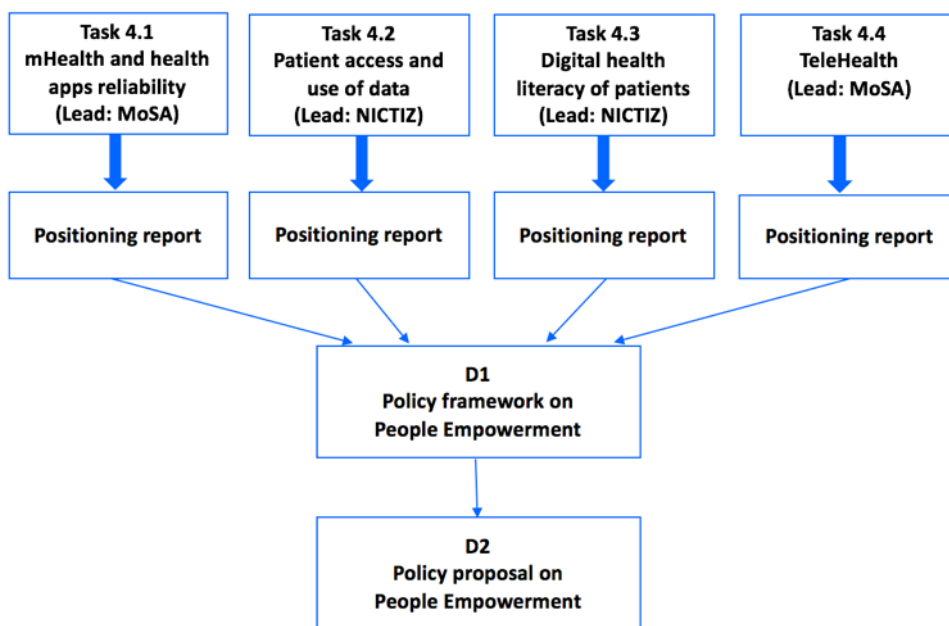


Figure 1. Work package, tasks and deliverables

2. Scope and definitions

To start the work for this WP, we need to define and scope the subjects. In this chapter we did this based on short desk research activities.

2.1 mHealth and health app reliability

mHealth is a sub-segment of eHealth and includes the use of mobile communication devices in health and well-being services covering various technological solutions, which measure vital signs such as heart rate, blood glucose level, blood pressure, body temperature and brain activities. 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”.

D4.1 proposes a framework on how to increase the adoption of mHealth apps among patients and healthcare professionals in order to achieve higher levels of patient empowerment across MS and what motivation measures should be used.

2.2 Patient access and the use of data

In order for patients to be true partners in health care, they should have access to their own health data which is commonly available in electronic health records (EHR). Communication between patients and healthcare professionals occurs traditionally through face to face or telephone contact. New technologies such as mobile health applications and telehealth allow patients and healthcare professionals to exchange health data electronically.

Task 4.2 will study the state of play of patient access and the use of data and propose a framework and policy recommendations to achieve common understanding across MS and facilitate improvement in how patients access their data and how they use it. The emphasis is on the patients' involvement with their EHRs and related issues (access rights, level of engagement, etc.).

2.3 Digital Health Literacy

The ability to provide patients with access to their health data can be facilitated through the use of technologies, mostly through the internet. The reason for providing citizens with their data is to encourage ownership of their own health. This way they are able to react to the health information they receive. For citizens to use the internet and other technologies and to understand their health data, it is important to have adequate digital literacy and health literacy skills.

It is important to make a distinction between the terms ‘digital literacy’, ‘health literacy’ and ‘digital health literacy’:

- Digital Literacy refers to generic digital literacy skills around the use of technology in a variety of everyday tasks, including accessing one's own online data.
- Health Literacy reflects the ability to understand, appraise and use health-related information. This is important for understanding information from healthcare providers and information in print form and digital information.

- Digital Health Literacy refers to the ability of citizens to understand and appraise online health information. It can also be interpreted as the ability to use electronic services and devices to manage one's own health.

For task 4.3, the term Digital literacy will be defined as the ability of a citizen to seek, find and access their online data. Digital health literacy will be defined as the ability of a citizen to understand and appraise their online data once found and the ability to translate the online data into actions to improve their health.

The deliverables for task 4.3 are to discover the extent to which citizens have the digital skills to seek, find, access and understand their online health data and recommend strategies for increasing digital health literacy levels in order to improve on the current state of play and propose a framework and policy to achieve common understanding across MS and to improve the access and understanding of health data for patients.

2.4 Telehealth

Telehealth encompasses the delivery of healthcare services by all healthcare professionals through the use of ICT solutions to provide clinical and non-clinical services – preventive, promotive and curative healthcare services, research and evaluation, health administration services and continuing education of healthcare providers. Telehealth is a term referring to remote healthcare, including services provided using telemedicine, as well as interactions with automated systems or information resources. Telemedicine services allow patients to interact with health professionals remotely for consultation or diagnostic purposes. It improves the access to healthcare not only for people with reduced mobility but also for those living in remote areas. Telemedicine services allow self-monitoring and remote monitoring by health professionals, potentially preventing further escalation of existing chronic conditions through early detection. This reduces unnecessary visits to doctors and potentially lowers healthcare costs, positively contributing to the sustainability of health systems.

D4.1 proposes a framework, how to use Telehealth services across MS in order to increase the engagement levels of patients and what motivation measures should be used.

3 Approach and methodology

To deliver both deliverables we will create a state of play report for each task with the objective to indicate what is happening in Europe and MS and get a good grip on the subject. These reports are not official documents, but are inputs for deliverable 1: the policy framework. This framework will lead to recommendations for MS and Europe, which will be indicated in deliverable 2: the policy proposal.

3.1 AMO model

In order to visualise the state of the art across MS regarding the level of people empowerment, the AMO model will be used. The AMO theory suggests that there are three independent work system components that shape participant characteristics and contribute to the success of the system. According to the theory, system interests are best served by a system that attends to the participants' ability, motivation, and opportunity (AMO).¹

As patient engagement is influenced by many factors which are investigated in the tasks of the WP, the model provides an approach to integrate the subtasks of the WP and compare different MS according to the level of patient empowerment. The AMO model is applied when designing the questionnaire and interviews, as well as when analyzing the results and providing the visualisation of the state of the art across MS.

Below is an overview of the characteristics of the AMO model and how they are going to be approached with regard to patient empowerment and subtasks of the WP:

- 1) Ability – Ability refers to the knowledge and skills the patient/provider has to have in order to be empowered. It includes the **digital skills** of patients and healthcare providers, as well as the **access to mHealth/telehealth solutions and/or personal data**.
- 2) Motivation – Motivation captures the extrinsic and intrinsic motivation of the participant. We are going to investigate how motivated patients are to use **mHealth/telehealth solutions and/or patient portals** and how their motivation can be influenced.
- 3) Opportunity – Opportunity refers to the availability of and accessibility to solutions, as well as the involvement of patients in the decision-making process. We are going to investigate what kind of **mHealth/telehealth solutions** exist on the market and to what extent patients are included in the decision-making in healthcare systems with the support of digital technologies, what are the reimbursement models of the digital solutions and how available and accessible the solutions are to citizens.

3.2 Overview of planned work

In order to successfully carry out the work of the WP and produce high quality deliverables, activities are divided into three main parts: desk research, consultation round, and analysis. Based on the

¹ [WWW] [www.study.com](https://www.study.com/academy/lesson/amo-theory-ability-motivation-opportunities.html) AMO Theory: Ability, Motivation & Opportunities. <https://www.study.com/academy/lesson/amo-theory-ability-motivation-opportunities.html> (Accessed 20.09.2018)

inputs from different phases, a policy framework will be proposed. Overview of different activities supporting this work is given in appendix 2.

1) Desk research: identification of a theoretical state of play

The work starts with desk research, which identifies patient empowerment and its relation to mHealth, digital (health) literacy, patient access to their own health data and telehealth in theory. Investigation of the topic is done with literature analysis. Theoretical state of play of patient empowerment will investigate how digital solutions should empower patients, what are the factors influencing this, and how to motivate patients to use digital solutions.

Case studies, best practice exemplars and other successful projects that may be emulated on a larger scale or cross-border are identified and previous JAseHN and other projects are reviewed in this stage.

2) Consultation: identification of actual state of play

During the consultation round, different perspectives of relevant stakeholders (appendix 3) across MS are investigated to identify the state of the art regarding patient empowerment – how MS are tackling existing healthcare challenges by empowering patients and what measures are being used.

The topics include: perspectives on mHealth assessment with an emphasis on reliability and patient empowerment and users' motivation to use mHealth solutions; digital literacy levels, current systems and usage statistics; opinions on the ease of access to electronic health records and other services, the desire to have access to such data and the likelihood that such a service would be used; opinions on how telehealth increases patient empowerment and investigation of ways how to incentivise the use of Telehealth solutions among patients and healthcare professionals.

Perspectives of different stakeholders will be obtained during the consultation rounds using questionnaire, focus group and semi-structured interviews. For designing surveys and interviews, the AMO model, which was described above, will be used. Using this data, the modelling of the level of patient empowerment across MS will be done using this model and all the MS will be put into "patient empowerment map" to visualise how MS differ from each other regarding this issue.

3) Analysis: identification of existing gaps between theoretical and practical state of play; identification of relevant policy measures to be applied to improve patient empowerment across MS

After obtaining the data from scientific literature and consultation round, analysis will be done using qualitative content analysis and benchmarking of the state of the art (consultation round) and theory (literature). Based on the gaps between theory and practice, relevant policy measures will be identified which will be further developed with stakeholders in order to propose finalised policy recommendations.

3.3 D4.1 – Policy Framework Structure

The table of contents of this deliverable will be as follows:

1. Theoretical positioning report
 - a. Overview of how eHealth can contribute to patient empowerment through the lens of the four tasks of this WP.
2. Actual state of play
 - a. Overview of how eHealth is used within eHAction member states for patient empowerment using the AMO model.
3. Analysis
 - a. Identification of gaps between the theoretical and the actual.
4. Best practices
 - a. Examples of good practices under each task of WP4 in various member states.
5. Steps forward to deliver D4.2
 - a. Plan for going from the policy framework to the policy proposal.

3.4 D4.2 – Policy Proposal Structure

The table of contents of this second deliverable will be as follows:

1. Description of policy options
2. Results of second round of consultation
3. Final policy recommendations

Appendix 1. Countries contributing to the WP

Country	Organisation(s)	Task 4.1	Task 4.2	Task 4.3	Task 4.4
Estonia	MoSA	6PM	-	-	6PM
Netherlands	Nictiz	-	6PM	6PM	-
Austria	ATNA ELGA GmbH GÖG	2.5PM	4PM	-	3.5PM
Croatia	HZZO	4PM	1PM	1PM	1PM
Cyprus	MoH-CY	3.3PM	2.2PM	-	3.3PM
Finland	THL	2PM	1PM	-	-
France	MoH-FR	4.5PM	-	-	0.5PM
Germany	Gematik	-	3PM	-	-
Hungary	NHSC	2PM	2PM	2PM	2PM
Ireland	ICS (DoH)		4PM	2PM	
Latvia	NHS	2PM	2PM	1.5PM	1.5PM
Lithuania	SAM	1.5PM	1.5PM	1.5PM	1.5PM
Luxembourg	AeS	-	1PM	-	-
Portugal	SPMS	-	-	2.5PM	2PM
Slovenia	NIJZ	-	-	-	3PM
Sweden	SEHA	2PM	2PM	0.5PM	0.5PM
Switzerland	eH Suisse	-	-	3PM	-

Appendix 2. Activities carried out within WP

Activity	How	Result
Study certain subjects about the topic people empowerment.	Desk research In order to define a common understanding on the four subjects, search within scientific databases (i.e PubMed and Google Scholar) is done. The results and recommendations from the study on telemedicine commissioned by DG SANTE and input from JAsEHN and other projects related to the topic are gathered as well.	<ul style="list-style-type: none"> - Scoping & definitions - Identification of relevant stakeholders - Identification of best practices
First face-to-face gathering to kick-off and analyse desk research findings.	Workshop	<ul style="list-style-type: none"> - Involvement of MS - Define common understanding and approach, scope, stakeholders and best practices - Define framework scores?
Define the level of empowerment across MS according to AMO model	Survey design, distribution and analysis To understand the perspectives and state of the art of empowerment of the patients, healthcare professionals, payers, and technology developers, a questionnaire and focus group interviews will be conducted with all these stakeholders.	Use collected information to identify the state of the art and provide policy framework
Define gaps, improvements, etc. for MS and EU	Survey results, interviews with stakeholders and defining policy framework	Use collected information to identify the state of the art and provide policy framework

<p>Give best practices for each task as examples</p>	<p>From desk research and other connections during the project. Investigation of ways to motivate and create incentives for patients to participate in their health process by adopting and using patient services will also be done.</p>	<p>1-2 best practices per task within countries as example.</p>
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Appendix 3. Consultation round with relevant stakeholders

Target Group	Possible Sources of Information
Citizen	Questionnaire (circulated in social media)
Patient	Questionnaire, focus group interview
Healthcare professionals	Questionnaire, focus group interview
Patients federation(s) (European Patient Forum)	Questionnaire, focus group interview
Payers	Interviews
Mobile Health Hub	Continuous consultations
mHealth and Telehealth solutions developers	Interviews

