EMPATHiE

Empowering patients in the management of chronic diseases

FINAL SUMMARY REPORT

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Executive summary

EMPATHiE Project has analysed patient empowerment (PE) for patients with chronic diseases. The results of this project include:

- A catalogue of best practices in PE, that has found four types of promising strategies: *established effective practices* (such self-management support and patient education); *recent innovative practices* (such as virtual interactive platforms and tele-monitoring through smart-phones); *shared decision making practices* and *systemic changes regarding the model of care* (such as the chronic care model).
- An analysis of barriers and facilitators of PE in Member States, the results of which suggest that policy agenda should consider: focusing on better education of patients and public, improving education of healthcare professionals in holistic thinking and communication skills, specific restructuring of healthcare delivery and a central common electronic record accessible by patients and professionals.
- A proposal of a method to validate transferability of good practices on PE and an assessment matrix, conceived not just as an assessment tool, but also as an improvement tool, directing attention to factors hindering transferability.
- And, four possible scenarios of EU collaboration on PE over the next ten years.

Overall and regarding future actions of European collaboration on patient empowerment the analysis of stakeholders' preferences suggests that the formulation of a European strategy and action plan would be welcomed. In addition some action towards the creation of a common repository of best practices and tools, the development of common indicators and an improved evidence base on PE would also be welcomed by a majority of stakeholders.

1. Introduction: Context and purpose

Europe has a high burden of chronic diseases: they are associated with premature morbidity, loss of healthy life years and are responsible for 86% of all deaths [1]. In fact, WHO considers the rise in chronic diseases an epidemic and estimates that it will claim the lives of 52 million people in the European Region by 2030[2]. Tackling chronic diseases is a crucial issue and one of the core priorities of all EU health systems.

Patient empowerment has been associated with the strategy to tackle this issue and as such it is conceived as a core value of a modern patient-centred health system. It has been advocated by the Council Conclusions on Common values and principles in European Union Health Systems[3] and has been recognized as a way to prepare health systems for the future (EU health ministers informal meeting in 2012). In fact the Danish Presidency stated that patient empowerment should be a cornerstone of the EU approach to chronic diseases.

Some related issues have been already addressed, remarkably the EU has taken action to secure patients' rights to make their own choices in whichever healthcare system their treatment takes place through the EU Directive on patients' rights in cross-border healthcare[4].

However the concept of patient empowerment is still not clearly understood and it is often used interchangeably with terms such as 'patient involvement' or 'patient-centred care'. In fact across Europe the understanding is still mixed it might be associated with only specific interventions such as the use of eHealth tools by patients, or even perceived as a potential threat to healthcare professionals authority and patients health, as identified in the Eurobarometer study on patient involvement, published by the Commission in May 2012[5].

In this context, the overall purpose of the current project is to help understand the concept of patient empowerment - meaning a principle of patients making informed choices - as a prerequisite to the exercise of patient rights and in this study, focused on chronic diseases. The specific objectives of the tender are:

· To identify existing best practices in patient empowerment
· To identify advantages of and barriers to empowering patients
· To develop a method to validate transferability of good practices, considering the context of other chronic diseases, patient characteristics and specificities of health systems
· To develop scenarios of EU future collaboration on patient empowerment.

3. Project framework

Building on the bioethical principle of patients' autonomy, a new paradigm has been developed reflecting a development from paternalist models towards more equitable/collaborative models of clinician-patient interaction[6]. In this process several different approaches have been taken, most relating to patients conceived as self-determining agents with some control over their own health and healthcare, rather than as passive recipients of healthcare [7-8].

Working definition of Patient Empowerment

There is no single widely accepted definition of patient empowerment [9]. For the purpose of this project and after reviewing different sources [10-11], the EMPATHiE consortium developed working definitions for patient empowerment and empowerment interventions. The following definition stresses patients' active and central role in the process:

An **empowered patient** has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being.

Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition to the extent that they wish to do so; to become "co-managers" of their condition in partnership with health professionals; and to develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.

Conceptual framework

Taking into consideration the proposed working definitions and after a detailed review of existing frameworks[12-13], the following conceptual framework was prepared to guide the development of the project. (Fig 1), including 4 key elements:

1. The central circles represent the three main dimensions of patient empowerment strategies reported in the literature: Educational, information provision & health literacy interventions, Self-Management and Shared (treatment) decision making.
2. The conceptual framework includes both strategies aimed at patients & professionals.
3. Circles represent the three possible different levels for implementation of the strategies: micro (initiatives at centre level), meso (programs of implementation, usually at regional level, but also at local and national level) and macro (high level policy plans at national or European level or national/European level).
4. Finally the conceptual framework also presents the outcomes of interest defined for this project.
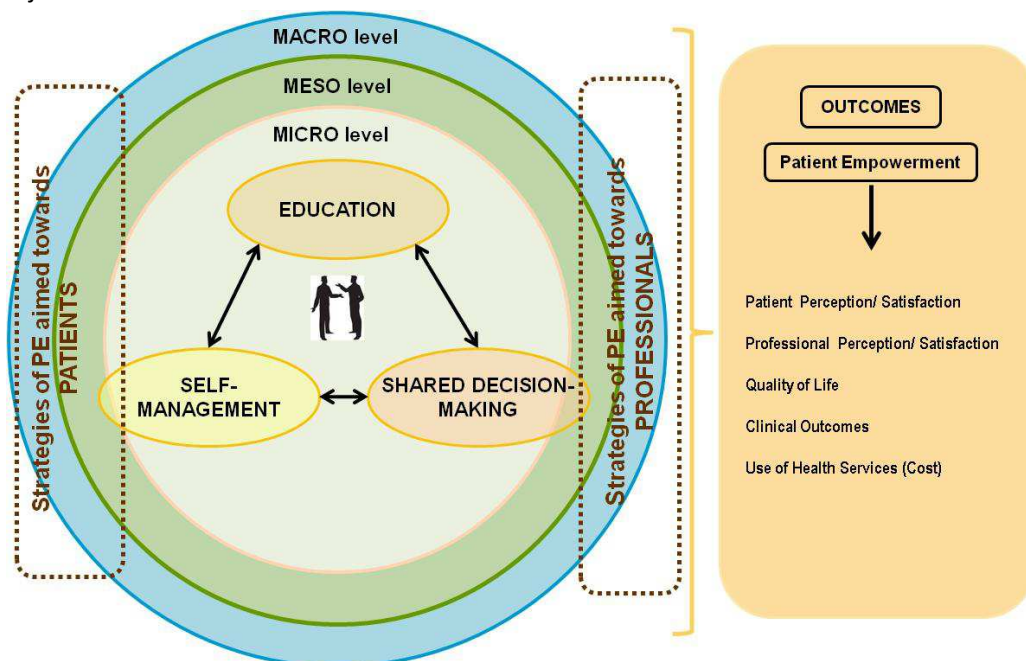

Fig.1 Conceptual framework guiding EMPATHIE development

4. Project design

The specific objectives of this project were articulated in 4 work packages representing two major phases:

o **the analysis phase** including work packages (WP) 1 and 2, aiming to identify best practices for patient empowerment and to present a clear identification of advantages and barriers to empowering patients

o **the transferability phase** including WP 3 and 4, aiming to develop a method to validate transferability of good practices, taking into account the context of other diseases, patient characteristics and specificities of health systems and to develop scenarios of EU future collaboration on this subject

As it is illustrated in the relevant areas below, the findings of each WP feed naturally into successive WPs, so that WP2 benefits from the results of WP1, WP3 from WP1 and WP2, and so forth.

The project has not only analysed the problematic of patients with a single chronic condition, it has also analysed the problematic and empowerment strategies related to patients with multiple morbidities ,as this requires a different approach towards the organization of health systems. The project has focused on chronic care, covering the main groups of chronic diseases, specifically cardiovascular disease, respiratory diseases, diabetes and also mental health conditions, schizophrenia and chronic depression, acknowledging that these latter conditions are the second highest cause of disability in Europe.

Methods applied in this project include literature reviews involving published and grey literature, qualitative research methods (focus group and expert interviews) quantitative information through surveys and different forms of consultation with experts. For each objective, the methods used are presented in detail in the corresponding section.

5. Description of main results

Following are the main results of the project for each specific objective:

> *Objective 1.* **To identify models of best practices for patient empowerment**

The goal was to identify existing best practices aimed at empowering patients along with their success and failure factors, with a focus on the management of chronic diseases. The result is a catalogue of best practices in patient empowerment.

Methodology: In order to achieve those goals three strategies were followed to retrieve information paired with their respective analyses: 1) Literature overview; 2) Expert and relevant stakeholder survey and 3) Identification of key relevant European initiatives.

- *Overview of the literature:* a literature overview was carried out (review of systematic reviews, SR) on interventions addressed, primarily or secondary, towards patient empowerment between 2000 and 2013, (the search strategy is detailed in Deliverable 1). Target population include:
    o Patients with chronic respiratory diseases (COPD or Asthma)
    o Patients with chronic cardiovascular diseases
    o Patients with chronic diabetes (type 1 and 2)
    o Patients with severe mental illness (schizophrenia or chronic depression)

o   Complex patients (co-morbidity) or

o   Health or social professionals dealing with the described chronic patients

Advantages of patient empowerment strategies were measured through the outcome measures selected: Patient Empowerment related measurements, Patients' perception & satisfaction, Professional perception & satisfaction, Quality of Life, Clinical Outcomes, Use of Health Services (ER, Cost, time…) or Patient-provider relationships.

Selected articles were extracted collecting intervention characteristics, outcome measures and scientific quality (AMSTAR)[14]. All SRs were classified as presented in table 1). An in depth analysis was carried out to detect success and failure factors including context, patient and provider characteristics, content, timing of the intervention (start, length and frequency) and follow up.

Expert and relevant stakeholder survey: The second strategy was a survey targeting 35 relevant experts and stakeholders across Europe. The objective was to identify further initiatives and best practices already existing in Europe and perhaps not yet included in systematic reviews.

European initiatives: the third strategy was a review and analysis of the information published on initiatives funded within the Framework of the Health Programme, the Framework Programme for Research and Innovation and interventions identified within the European Innovation Partnership on Active and Healthy Ageing. The second section of the strategy consisted of a review of initiatives identified through the European Union Joint Action on Patient Safety and Quality of Care (PaSQ).

_Main results__:_ Best practices were selected following two criteria: impact (strong/intermediate evidence on the impact) and the scientific quality of the review (AMSTAR higher than 5). Applying those requirements 101 systematic reviews (including more than 2300 individual studies) were finally included in the catalogue of practices of patient empowerment (for complete list of references see ANNEX 1.

 A descriptive analysis yielded relevant information regarding the distribution of SR by target condition and type of intervention. Most of the interventions reported in the studies were addressed to patients at micro or meso level, contrasting with a more reduced presence of interventions specifically targeting healthcare professionals or mixed approaches. There appears to be a predominance of interventions targeting diabetes, representing 28.7% of the selected SRs, followed at a distance by interventions targeting chronic respiratory conditions, representing 25.7% of the SRs, cardiovascular, 12.9%, mental health conditions, 10.9% and with those specifically focused on complex patients being the least represented in the SRs, just 1% (with a 20.8% of the SRs targeting a mix of chronic conditions).

For the main dimensions of patient empowerment addressed, a predominance of interventions focused on self-management, namely 47% of selected SRs, followed by interventions focused on education and health literacy, representing 35% of selected SRs and 12% targeting multi-dimensional interventions, with shared-decision making being the least represented (only 5%).

The catalogue, in table 1, reflects the identified practices by condition and dimension (with sub-groupings by specific intervention characteristics, when relevant), according to the level of evidence (for a more detailed summary of the catalogue see ANNEX 2).

Table 1. Summary of evidence on practices on patient empowerment

Intervention	DIAB	CARDIO	RESPIR	MENT	COM	MIXED
Educational, information provision & health literacy						
Face-to-face						
Patient education, generic approach (individual and/or group)	+++ (3) / ++ (2)/ NC(1)	NC (1)	++ (1) / NC (3)			++ (1)
Education targeted at caregivers (with or without patients)		++(1) / NC (1)	++ (2) / NC (1)			
Education targeted at minorities (culturally adapted or not)	++ (1) / NC (1)		++ (1)			
Nurse–lead education	+++ (1)					
Education by lay leaders						++ (1)
Education in the community settings	++ (1)		NC (1)			
Education delivered in groups exclusively	+++ (2)					
Education delivered individually exclusively	++ (1)					NC (1)
Psycho-educational programs			NC (1)	+++ (1)		
Virtual or technology mediated						
Patient education through multimedia and/or ICT		+++(1) ++(1)		NC (1)		++ (1)
Self-management						
Face to face						
Self-management support, generic approach (individual or group)	+++ (1)	+++(1)/ ++ (2)	+++ (2)	NC (1)	+++(1)	++ (1)
Support targeted at caregivers (with or without patients)				++ (1)		
Support targeted at minorities (culturally adapted or not)			NC (1)			
Nurse lead support intervention			NC (1)			++ (1)
Peer support interventions	NC (1)			NC (1)		
Integrated multidisciplinary team-lead support interventions			+++ (1)			
Self management delivered in groups exclusively				+++ (1)		
Behaviour change techniques			+++ (1)	NC (1)		+++ (1)
Life skills programs				NC (1)		
Self-monitoring	++ (1)		NC (1)			
Virtual or technology mediated						
Mixed technologies support programmes for self-management	+++ (1)	+++ (1)/ NC (1)	++ (1)/ NC (1)			
Lay leaded mobile phone						++ (1)
Mobile phone	+++ (1)					NC (1)
Web-based	NC (1)					+++(1) ++(2)NC(1)
Applications for Smartphone and tablets			NC (1)			++ (1)
Tele-monitoring	++ (3)					NC (1)
Mixed (face to face + virtual or technology mediated)						
Mixed (face to face + virtual or technology mediated)support	NC (1)	NC (1)				++ (1) / NC (3)
Shared decision making						
Individualised management and action plans			++(1)/NC(2)			
Patients' decision aids and professional training in SDM				NC (1)		++ (1)
Multi-dimensional approaches						
Multi-dimension (multiple individual interventions)	++ (2)/NC(1)	++ (2)				++ (1)
Multi-dimension (system approach)	+++(1)/NC(1)		+++(1)/++(1)	+++(1)/++(1)		

Legend:
+++ : What works (conclusive evidence on positive effect)
++: What might work (intermediate evidence on positive effect)
NC : There's not enough evidence to conclude
(number): indicates the number of systematic reviews

A first remark regarding the results is that, in general terms, when comparing an intervention targeting patient empowerment with usual care there is a tendency to obtain (at least partially) positive results.

Within this general positive tendency some specific interventions emerge as the most effective: **self-management support interventions across all conditions and different formats of patient education for diabetic patients.** It is also worth pointing out **that recent innovative practices (such as virtual interactive platforms and tele-monitoring through smart-phones) present a positive tendency, mainly in diabetes and cardiovascular conditions.** And finally, **systemic changes regarding the model of care (such as the chronic care model),** seem to yield positive results. A detailed commentary for each condition can be found in Deliverable 1.

It is important to highlight that analysis of similar interventions can report different levels of effectiveness, which could be due to multiple factors such as targeted condition, specific components of the intervention, patient and provider characteristics, contextual factors and outcome measures used. When possible those were tackled in the analysis of success and failure factors.

In this line, the study of the effect appears to indicate that, to a significant degree, success and failure factors are related to the targeted behaviour which in turn is mediated by the type of condition in which it is applied.

For diabetic patients a clear success factor in educational interventions was the presence of a nurse in the team (or nurse-lead interventions). These educational intervention do not need to be long, however follow-up and intensity were detected as success factors. Related to self-management, the inclusion of behavioural approaches and peer-supported interventions tend to be associated with positive results.

Common success factors across different interventions for diabetic patients were to target patients with poor glycaemic control at baseline and for interventions to be cultural or age tailored. A detected barrier was that successful interventions required an investment in additional resources, which could limit their generalisation.

Successful factors for cardiovascular patients include education with a focus on self-management and specific habits that are easy to change, regular reinforcement and intensity of the intervention. Regarding provider characteristics, multidisciplinary teams seem to achieve good results. Regarding the timing of the intervention, the closeness to the moment of discharge was identified as a success factor.

The major failure factor associated with cardiovascular patients was the difficulty of maintaining behaviour change in the long term.

For patients with chronic respiratory conditions success factors in self-management interventions were the use of support groups and local input to home-based settings. Although there is still not enough evidence for a firm conclusion, a potential success factor associated with the use of action plans appears to be the focus on self-treatment of exacerbations.

For mental health conditions the training of professionals in principles of shared decision making was identified as a success factor. Regarding patient characteristics, the willingness of the patient to participate was also a success factor; contrasting with those patients that had a long history of psychiatric treatment whose institutionalisation might pose a barrier. In addition the intensity of intervention for patients, for types of intervention across all dimensions, was identified as a success factor.

In general terms: regarding education, it has to be highlighted that even with such interventions patients still face difficulties in detecting symptom worsening and take corrective actions. For technology or Internet mediated self-management a general success factor was easy access, especially 24h access or access at home. In addition, for those interventions younger patients tend to benefit more than their older counterparts.

Practices on shared decision making were least reported in the literature and no clear pattern of success and failure factors emerged.

For multidimensional systemic interventions the inclusion of organizational components, targeting providers, system level characteristics or a combination of the chronic care model seem to be more successful than those addressing a single element of the system of care.

Key relevant European initiatives were identified through multiple sources. Through the survey of experts and after filtering the responses for the basic inclusion criteria (target population and focus on patient empowerment) 32 projects of interest were identified (mainly at macro and meso levels). From The SANCO Health Programme, Framework Programme for Research and Innovation and interventions identified in European Innovation Partnership on Active and Healthy Ageing 14 relevant projects were identified from the Compilations of Good Practices in the following areas:

- o   Prescription and adherence action at regional level: Action Group A1
- o   Prevention of functional decline and frailty: Action Group A3
- o   Integrated Care: Action Group B3
- o   Age-friendly Environments: Action Group D4

The analyses of the identified relevant interventions were structured around the main variables of interest that were developed for the literature overview.

A further 22 projects were detected and analysed from the PaSQ Joint Action. Although those practices do not provide sufficient information on their effectiveness to include them within the literature review in the analysis of best practices, they have been very useful for illustrating the conclusions regarding best practices derived from the literature review in the work package report and to help draw suggestions for future EU scenarios.

Table 2. Examples of European interventions

Source	Initiative	Country*
Survey	The Expert Patients Programme	UK (R)
Survey	The House of Care	UK (R)
Survey	In the footsteps of the patients	Denmark (L)
PASQ	Patient Empowerment/"Your guide to safer care"	Sweden (N, R, L)
PASQ	RIU-T: Approach of a national health strategy to vulnerable contexts and populations	Spain (N, R, L)
FP5-7 (RN 102852)	Empowering patients to lead fully mobile lives	Germany
IC-B3	EMPOWER Personalised Guidance Service For Patient Empowerment	Spain, Sweden, Italy, Denmark and Estonia (R)
IC-B3	PHE – Project (Positive Technological Innovation as a Driver of People Health Engagement)	Italy (R)
(N,R,L) signals the level of application (N = National, R= Regional, L=Local)		

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Objective 2. To identify facilitators and barriers for empowering patients

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The aim was to provide an analysis of possible facilitators and barriers to patient empowerment in managing chronic diseases in general, by chronic disease groups (e.g. cardio vascular disease, respiratory diseases, chronic mental health and diabetes) and differentiated by types of patients

(e.g. by age and socioeconomic status) and also to identify possible facilitators and barriers to patient empowerment that are specific to the different health systems.

Methodology: Data was retrieved through focus groups and a survey in EU Member States, EFTA/EEA and accession countries. National contact points (NCPs) were identified in each country. The goal of the focus group was to identify key aspects for the analysis of facilitators and barriers to patient empowerment. One focus group was scheduled in each country with approximately 12 participants, representing different target groups: patient representatives, healthcare professionals, healthcare managers and policy makers or health authorities.

To collect data from the focus groups in an efficient way, the content of the discussion was inserted into a pre-structured mind map by the moderator or an assistant. The data was then analyzed by the project team to provide an aggregate vision of results. Categorization of contents was based on the general framework of the project and was done by three independent experts.

A survey**,** based upon the qualitative information that was collected through the focus groups, was carried out to validate the data and to prioritize the aspects that need to change to improve patient empowerment in their country in the future. The questionnaire was translated into the native language where necessary and provided to respondents through an online survey tool.

 In each country the top 5 topics, identified as the highest priorities that need to change to improve patient empowerment were identified. Furthermore, the prioritized topics by country, by respondent category (patient, healthcare professional, healthcare manager, competent authority/expert) and by European region were differentiated. To facilitate the analysis of facilitators and barriers the different chronic conditions were classified into the following categories: Stable/conservative chronic diseases, Progressive chronic diseases, Psychiatric diseases and Rare diseases. Differentiation of countries by European regions, was made using welfare regime typology proposed by Esping- Andersen[15] and adapted by Ferrera to include southern countries[16]. A validation workshop was carried out to discuss findings and their possible inconsistencies with all consortium members.

Main results: In total information was successfully retrieved from 26 countries. Six countries were not included, since it wasn't possible to successfully engage an effective national contact point: Austria, Cyprus, Hungary, Liechtenstein, Luxemburg and Poland. For each of those countries several people were approached via various routes; however, none of them able to participate. Important factors that influenced the decision were the availability of resources needed to carry out the requested activities, and time constraints (for a breakdown of participation by country see ANNEX 3).

In 18 countries a focus group was carried out as well as the survey**.** More than 170 persons (50% of them patients) provided their input of important topics for patient empowerment to the focus groups. Focus groups were developed in three periods. The second ones were only able to add one new clustered aspect to the analysis (stigma in mental health patients) and the last group did not provided any extra clustered topic to the analysis, so it was concluded that most probably the exercise had reached content saturation.

From focus groups 952 important facilitators and barriers were identified and aggregated into 19 topics that were felt to be important for patient empowerment and could act as facilitators and barriers depending of their implementation (see Table 2). Globally 1/3 of the mentioned topics were facilitators and 2/3 barriers.

Table 3. Frequency of topics mentioned in the focus groups, differentiated by whether it was mentioned as a (current or future) facilitator or (current or future) barrier.

Topics	Current facilitator	Current barriers	Future facilitator	Future barriers	Total facilitator	Total barriers	Total
1. It helps that the healthcare professional has a holistic view of the patient	21	16	1	19	22	35	**57**
2. It helps that the patient and the healthcare professional have a good interaction with each other	20	19	4	8	24	27	**51**
3. It helps if the patient feels responsible for his/her own health*							
4. It helps that the patient is well educated	21	13	3	19	24	32	**56**
5. It helps that the patient has contact with other patients	8	5	1	6	9	11	**20**
6. It helps that the patient participates to develop and deliver healthcare services*							
7. It helps that the patient is supported by his/her social network	10	5	1	5	11	10	**21**
8. It helps that the healthcare professional is well educated	16	22	2	23	18	45	**63**
9. It helps that reliable information is available	10	10	2	18	12	28	**40**
10. It helps that patients have equal opportunities in healthcare	5	19	5	6	10	25	**35**
11. It helps that there are well functioning patient organizations	28	6	9	32	37	38	**75**
12. It helps that healthcare is personalized	15	27	2	36	17	63	**80**
Organization: It helps that healthcare…							
13. is well coordinated							
14. professionals work together	48	85	9	72	57	157	**214**
15. professional has time to communicate with the patient							
16. uses new technologies							
17. It helps to have national strategies and programs on patient empowerment	17	9	8	18	25	27	**52**
18. It helps to have financial incentives based on patient outcomes	5	38	7	27	12	65	**77**
19. It helps to prevent or decrease stigmatization of patients*							
*Other important aspects (less frequently mentioned)	40	50	5	16	45	66	**111**
Total	**264**	**324**	**59**	**305**	**323**	**629**	**952**

A great variety of facilitators and barriers in current and future healthcare were mentioned in the focus groups. A quick view of examples by disease stage, type of patients and at health system level is provided in table 3. More insight into what participants actually reported in the focus groups and examples for each sub-category can be seen in Annexes 1 and 2 for the WP2 deliverable.

Table 4. Examples of facilitators and barriers

Sub category	Examples facilitators and barriers (current and future)
Generic	patient as an equal partner; coaching role professionals; shared decision making; coordination between professionals; peer to peer contact; written information not only oral; focus from what people can't do to what they can do
Disease-specific	
Stable or conservative	discuss topics of ordinary life; increase patients' knowledge about their condition; online information; stigma slows the acceptance
Progressive	social skills of professionals; good relationship between patient and professional; time for the patient; integration of treatment for other diseases
Psychiatric	psychiatric risk has consequences on relationships and employment; acknowledge uniqueness of individual; 24/7 availability of care; carer supports patient
Rare	symptoms are not clear or not recognized; stigma; peer support; specialized centres for genetic conditions; increase patients' knowledge

Type of patients	
Co-morbidity	better motivation to change lifestyle; professional fragmentation; different conditions are treated separately; teamwork professionals
Age	attention different stages of life; appropriate communication between patient and professional, e.g. email, phone, letter; age specific patient education
Socio-economic status	relation between SES and being more motivated and better able to understand and take responsibility; attention for different groups of patients: vulnerable patients, cultural background, low self-management competencies, low education
Health system	attitude change; professional role patient organizations; technology supports the coordination of care; implementation of best practices; fragmented services; lack of time; a culture of payment by results; payment is not depending on fact whether you take care about yourself or not at all; free choice of a service provider

The survey was prepared on the basis of the topics identified in the focus groups. It was answered by 869 persons in 26 countries (50% of them patients). Five top clustered topics prioritized as important for achieving patient empowerment are represented in table 5 (for a complete table comparing levels of agreement of the survey see ANNEX 4):

Table 5. Priority for respondent types related to the overall priority.

Overall Priority	Clustered topics important for patient empowerment	Priorities			
		Patients	Healthcare professionals	Healthcare managers	Authorities or experts
1	It helps that the healthcare professional has enough time to communicate with the patient	1	3	4	2
2	It helps that the healthcare professional has a holistic view of the patient	2	5	3	1
3	It helps that healthcare is well coordinated	4	2	1	4
4	It helps if the patient feels responsible for his/her own health		1	2	3
5	It helps that healthcare professionals work together	5	4		5
6	It helps that the patient and the healthcare professional have a good interaction with each other	3			
7	It helps that the healthcare professional is well educated			5	

Priorities were also different by European region (see ANNEX 5) but they do not show such clear differences.

To address each one of these priorities, suggested actions or agenda topics were also identified to improve patient empowerment in the EU. These actions were shared with WP4 to develop the EU scenarios. We summarize here the most relevant ones for the different Health system levels:

1. *Level of patients and the public.* Patients and the public should be educated about health, prevention and empowerment through national public health campaigns, e.g., starting in schools. Patients should also be educated about their condition and its management. Patient organizations or expert patients could play a role in the education of patients. Reliable and accessible information about health, diseases and care options are also important.

2. *Level of healthcare education.* Healthcare professionals should be educated in the holistic approach of patients, psycho-social factors in physical health, communication, interaction, coaching and self-management support.

3. *Level of organization of care.* New concepts of healthcare are needed to provide care in a way that empowers patients. For example: longer consultation time (and reducing the number of consultations), multidisciplinary teams and/or consultations, and a care coordinator to organize care across different services.

4. *Level of the healthcare system.* A central electronic health record is needed for all patients, which should be shared in patients and healthcare professionals and should be available in all healthcare institutions.

> *Objective 3.* To develop a method to validate transferability of good practices, taking into account the context of other diseases, patient characteristics and specificities of health systems

Methodology: The work of this WP was based on the findings of previous WPs: the catalogue of best practices and success and failure factors identified in WP1, as well as key aspects and barriers and facilitators identified and stakeholders priorities for change and required strategies identified in WP2. The methodology for reaching the objectives was largely based on literature reviews concerning innovation, adoption and emergence of Good Practices in organizations; especially from social science and improvement science research. The literature review started out with basic articles from each field and was enlarged based on snowball criteria. First a model for transferability was selected based on considerations of theoretical strength, completeness and feasibility of application and then findings were classified according to this model and the related concepts.

Main results: From the literature review the difference between a **"practice** "which represents long term performance of a group and an "**intervention**" which is usually short-term (frequently studied through Randomized Controlled Trials) clearly emerged. The transferability method was foreseen to be focused on "practices" though the aim of EU collaboration is to transfer establish consolidated practices and not just those interventions which are in the phase of implementation or evaluation. Also the importance of recognising disempowering practices was stressed as well as their likely impact in the patients' journey.

 In the literature not much is written specifically about transferability of practices. However, related concepts of relevance have been studied extensively and an overview of this literature is presented in Chapter 3 of the WP report. These include the multifactorial nature of change processes proposed by Pettigrew [17] (see below) and further developed for health care change processes by Gröl [18], Robert and Fulop [19]. The importance of the context was analysed (see for example Bate [20]) as well as the literature on diffusion of innovation (Greenhalgh [21]) and the concept of assimilation, which goes beyond implementation and adoption. The recent analysis of feasibility of patient engagement methods by Grande [22] was included. These different inputs were put together to provide a basis for the suggested methodology to assess/validate the transferability of good practices on patient empowerment (GPPEs).

We suggest, as a basis for the transferability method, the adoption of the Pettigrew model of change [17], where not only the content of a change is of importance but also the context and process. This model is based on the assumption that "Context + Practice content + Implementation Process → Outcome". The method also considers the importance of the transfer process and the context, practice content and implementation process at the new site (Fig 2).
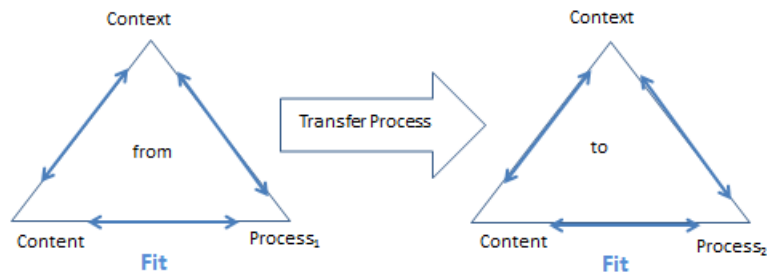
Fig 2. Transferability model from one setting to another based on modified Pettigrew

Transferability has been operationalised on the basis of the theory of Diffusion of Innovation. The ease by which an innovation spreads that has been studied extensively, especially by Everett Rogers (Diffusion of innovation – in many editions from 1962 to 2003). A number of criteria have been suggested. For service innovations, Greenhalgh et al [21] have translated these criteria: 1) relative advantage; 2) low complexity; 3) trialability; 4) observability; 5) potential for reinvention; 6) fuzzy boundaries; 7) risk; 8) task issue; 9) nature of knowledge required (tacit/explicit) and 10) technical support. Furthermore the review also pointed the importance of taking into account when designing the transferability assessment/validation method the possible existence of interaction between practices, the cumulative effect of practices and the importance of analysing whether new practices require paradigmatic shifts in meaning creation (sense-making) for the people involved.

 Based on the previously described findings an assessment matrix is proposed, that aims to support and validate transferability of best practices and describe and evaluate factors related to the earlier application as well as in the proposed new application. The method we present should not be seen as only an assessment or validation tool – rather, it should also be regarded as an improvement tool. It directs attention to factors hindering the transferability of a promising Practice for Patient Empowerment. Especially, it directs attention to those factors that are barriers but are potentially changeable. Improvement efforts should concentrate on those underlying factors – how to improve the conditions for the transfer of Good Practices in Patient Empowerment.

The assessment matrix (table 5, below) has the following assessment elements:

I. Site(s) of earlier applications (Healthcare system or specific type of healthcare provider, e.g.: primary care or secondary care of importance for the GPPE)
II. Chronic/Long-term condition(s) in earlier applications
III. Patient characteristics of importance for the GPPE (other than condition)
IV. Site of new application of the practice
V. Chronic/ Long-term condition(s) in new applications
VI. Patient characteristics of importance for the GPPE (in new applications)
VII. The GPPE seen from a provider point of view
VIII. The GPPE seen from the patient point of view

Assessment of the different elements was proposed to be performed using only three levels for each element:

1   Positive for transferability (Beneficial, Yes, similar, etc.)
0   Neutral (neither especially positive nor negative for transferability)
-1   Negative for transferability

Table 6: Proposed assessment matrix for Good Practices on Patient Empowerment (GPPE)

GPPE	Description		
Site(s) of earlier applications			
HC system(s) of earlier applications w.r.t. GPPE			
Strategic fit (Vision, Mission, …) w.r.t. the GPPE			
Climate of importance for the GPPE, for example leadership issues			
Kind of provider (Primary, secondary or tertiary)			
Cultural/climate elements of importance for the GPPE			
Support structures of importance for the GPPE			
strategic fit			
resources			
patient networks			
technology/artefacts in support			
other (specify)			
Chronic conditions in earlier applications			
GPPE Degree of disease dependence	1 - None	0 - Some	-1- strong
GPPE maturity at the original site(s)	1 - Mature	0 - Some	-1 short
Patient characteristics of importance for the GPPE in earlier applications			
New site			
New HC system(s)			
Strategic fit (Vision, Mission, …) w.r.t. the GPPE	1 - Yes	0 - Some	-1 - No
Climate of importance for the GPPE	1 - Yes	0 - Some	-1 - No
for example leadership issues	1 - Yes	0 - Some	-1 - No
others specify	1 - Yes	0 - Some	-1 - No
New provider			
Similar kind (w.r.t. GPPE)	1 - Yes	0 - Some	-1 - No
Cultural/Climate fit for GPPE	1 - Yes	0 - Some	-1 - No
Support structure of importance for GPPE	1 - Yes	0 - Some	-1 - No
strategic fit w.r.t. GPPE	1 - Yes	0 - Some	-1 - No
resources of importance for GPPE	1 - Yes	0 - Some	-1 - No
patient networks of importance for GPPE	1 - Yes	0 - Some	-1 - No
technology/artefacts of importance for GPPE	1 - Yes	0 - Some	-1 - No
other (specify) of importance for GPPE	1 - Yes	0 - Some	-1 - No
Existence of disempowering practices/structures	1 - No	0 - Some	-1 - Yes
Disempowered professionals w.r.t. GPPE	1- No	0 - Some	-1 - Yes
New condition			
Degree of similarity w.r.t. GPPE	1 very similar	0 -Some	-1 very different
Patient characteristics of importance for the GPPE (similarity)			
Degree of similarity	1 very similar	0 -Some	-1 very different
Description from provider point of view			
Extra work required	1 - Less work	0 - Some	-1 - More work
Perceived evidence of facilitators	1 - Yes	0 - Some	-1 - No
Complexity	1 - No	0 - Some	-1 - Yes
Observability	1 - Yes	0 - Some	-1 - No
Adaptability	1 - Yes	0 - Some	-1 - No
Perceived risk	1 - No	0 - Some	-1 - Yes
Trialabity - stepwise introduction	1 - Yes	0 - Some	-1 - No
Needed paradigmatic shift	1 - No	0 - Some	-1 - Yes
New knowledge needed	1 - No	0 - Some	-1 - Yes
Technology/artefact support	1 - No	0 - Some	-1 - Yes
Description from patient point of view			
Dependence on other empowerment components	1 - No	0 - Some	-1- Yes
Extra work required	1 - No	0 - Some	-1 - Yes
Perceived evidence of facilitators	1 - Yes	0 - Some	-1 - No
Complexity and difficulty	1- No	0 - Some	-1 - Yes
Emotional	1 - positive	0 - Neutral	-1 -Negative
Perceived risk	1 - No	0 - Some	-1 - Yes
Stepwise introduction	1 - Yes	0 - Some	-1 - No
Adaptability	1 - Yes	0 - Some	-1 - No
Technology/artefact support	1 - Yes	0 - Some	-1 - No

As mentioned, for evaluation of a specific GPPE we do not suggest a simple counting of points but rather considering them carefully within the overall assessment. It is assumed that a number of individuals are making the assessment of each dimension of the transferability model and after that agreeing on a consensus-based summary. In the consensus process it is important that the group members first make their own assessments and indicate why they have made a certain judgement. After that, we envisage the group engaged in a dialogue on each assessment element and, where opinions differ, a dialogue around the arguments for the different assessments starts. Especially, it should direct attention to factors that are barriers but are potentially changeable – the important thing in the use of this tool is to reflect on the perceived -1's so that these negative elements for transferability in one way or another can be remedied.

 Of course this implicitly indicates a weighting of the different elements of the model but such a weighting cannot, according to our judgement, be made automatically using predefined weights for all situations. It is a thought-through process that is informed by the assessment elements – not an automatic process – with the ambition to enhance a more profound understanding of various aspects of the process. One minus at a critical element may be an indication of overall poor transferability. Thus the ultimate usage should be a strategy for improvement with related action steps.

The method has been tested with three post-hoc interventions based on its publications: a) a culturally sensitive training package in diabetic patients from the UK [23], b) the Chronic Disease Self-Management Program (CDSMP) from the US. (Lorig et al [24]) and c) the Stanford Chronic Care Model (Wagner et al [25]), looking to transfer to the Swedish healthcare system and also to transfer a Healthcare system as discussed by Todorova et al [26]). In these cases the assessment matrix was able to identify some weak areas that could need strategies to address them when considering transfer of these practices.

After this piloting the proposed method was submitted for evaluation of face validity and suggestions on their possible implementation to three EU specialists in public health policy and chronic care and empowerment approved by CHAFEA (the Consumers, Health and Food Executive Agency) and their suggestions were used to improve the final document.

 The method suggested in this study is based on theoretical results obtained from empirical studies not directly addressing transferability of practices and how practices are assimilated in organisations. Thus important aspects might have been missed. It is important to study transfer processes as such to gain more insights. Thus, in parallel with the application of the method suggested in this study we should also critically reflect on the method and try to improve it, for example by application to good practice examples from the EIP on AHA as proposed in the full report on WP2.

In reflecting on the assessment elements, the paradigmatic nature of changes necessary for some GPPEs emerges as a probable barrier to transferability in general cases. Therefore strategy for the introduction of GPPEs should be considered, particularly, it is essential that where paradigmatic shifts are necessary, some simpler and less demanding GPPEs are tried out first. Educational interventions should be tried out e.g. through continuing professional education (CPD) to change perceptions in the current health care system (transformational learning as discussed by Mezirow (2000) comes to mind). PE should also be an important topic in basic health professional education to assure sustainability. The problematic healthcare situation in some member states with lower GNP, as identified in the full WP2 report, is undoubtedly a barrier to PE, especially for patients with scarce economic resources.

The objective was to define *scenarios of possible EU collaboration on PE* (between countries, stakeholders and the EU Commission) in order to inform decision-making at EU level on future cooperation.

Methodology: The methodological approach followed the path of a stakeholder consultation in the shape of two stakeholder workshops, an online survey, and a number of personal interviews with representatives of key stakeholder organisations.
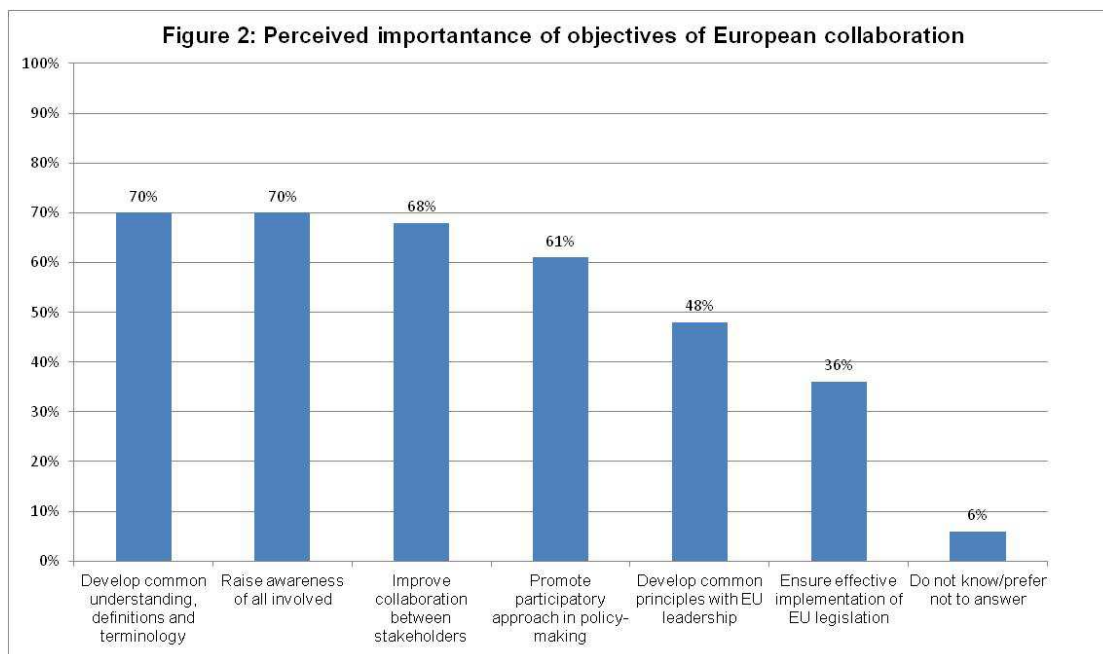
As a first phase a stakeholder mapping was developed, which was completed on the basis of information drawn upon later stages of the process. The consultation process was informed by the available literature identified in WP1, and barriers and facilitators found in WP2. The specific methods – workshops, survey and interviews – all followed a semi-structured approach and had a main focus on qualitative information. WP3 data on transferability was also considered. Initial scenarios were developed based on input from WP1 and 2, taking the conceptual framework of WP1 as a starting point. The three main (although overlapping) elements of PE identified in the conceptual framework were used to develop 13 initial short scenarios: one or more scenarios were developed around each of the three elements of patient empowerment interventions: educational, information provision and health literacy, self-management, and shared decision-making. Major barriers/facilitators identified in WP2 were also used as inspiration for initial scenarios: information to patients; health professionals' skills and attitudes; care coordination, etc. Some of the scenarios were deliberately provocative in nature, aimed at stimulating ideas and discussion. Based on feedback from workshop 1 and subsequent analysis, some of the initial scenarios were discarded. Some were merged with other scenarios and the resulting five draft scenarios were discussed in depth in the second workshop using the criteria for feasibility/transferability assessment that had been developed.

A set of feasibility criteria used for selection and prioritisation of scenarios was developed with input from WP3 and stakeholder workshops. This was also used to formulate questions for stakeholder survey and interviews. Based on the outcomes of this process, a final set of scenarios was then selected and described.

Main results: The stakeholder map included 35 organizations at EU level, besides EU policy organizations. Twenty-one key stakeholders participated in the first workshop including representatives of patients/carers, academics, health professional/student organisations, representatives from industry, policymakers, payers and health NGOs. The participants considered that the overall EU collaboration objective should be *to achieve concrete improvements in health care for the patients taking as a starting point their expectations*. A second objective was to *find the best ways to reach that goal*, and focused on exchange of best practice and working methods. Results of workshop 2 include more detailed feedback on timeframes and specific challenges and on the proposed milestones for each scenario for further development for EU collaboration. Twenty-eight stakeholder representatives attended workshop 2, with similar balance of representation compared to workshop 1.
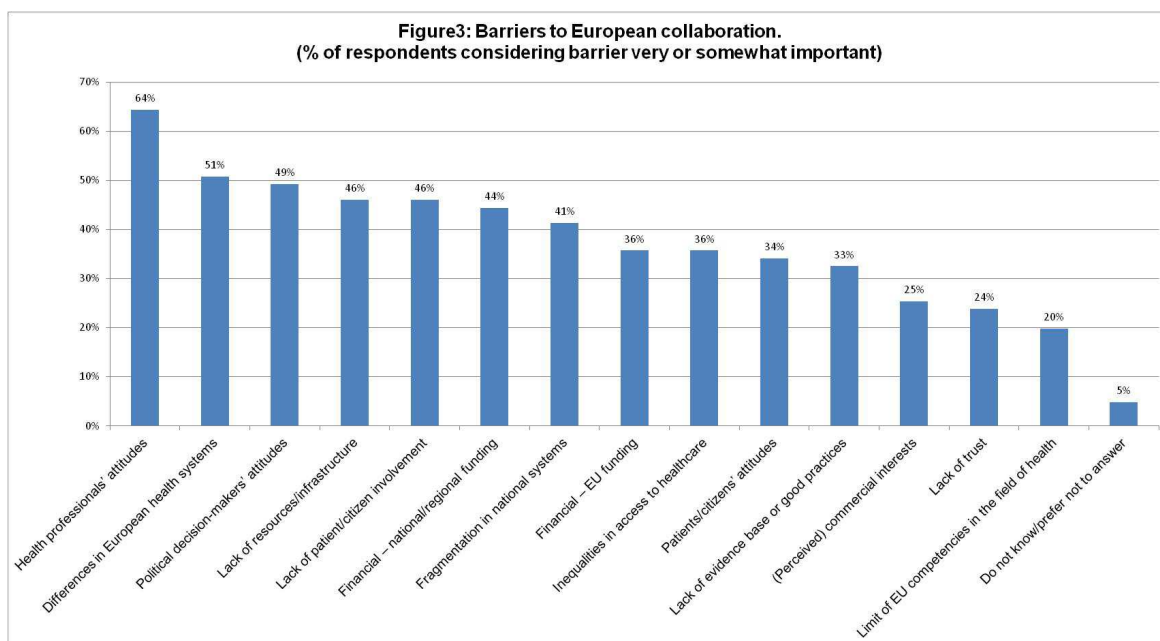
A total of 104 respondents completed the EMPATHiE WP4 online survey. The breakdown of stakeholders found the most frequent category mentioned to be "patients/ consumers" followed by "hospital/health managers", "doctors", "nurses", and "other health professionals". Most respondents (88.5%) considered promoting patient empowerment as either very or

somewhat important and envisaged their role in supporting patient empowerment in terms of improving care coordination, providing reliable, unbiased information, and providing education and training to health professionals. The great majority of respondents (82.3%) were also positive regarding the idea of collaboration at EU level. Percentage of stakeholders considering each type of objective *'very or somewhat important '*is shown below:

EU-funded research* was most frequently mentioned as an appropriate scope of EU collaboration (62.4%), closely followed by development of *European level indicators and monitoring* (56%). Voluntary collaboration driven by stakeholders was slightly more popular than collaboration driven by the European Commission. Legislative review was least popular as the scope of EU collaboration (mentioned by 20.8%).

Regarding concrete outputs of a collaboration process, 73% of respondents would like to see *an EU strategy and action plan on patient empowerment*. Most would also like to see a *common repository of best practices and tools*, comparable data at European level, a stronger scientific evidence base and common indicators to measure empowerment. Interestingly, a sustainable network of cooperation was also popular as an output of European collaboration. New EU legislation was mentioned by only 15.7% of respondents. Barriers to successful EU collaboration could be seen in Figure 4.

Figure3: Barriers to European collaboration.
(% of respondents considering barrier very or somewhat important)

In addition to the online survey, 40 stakeholder representatives were interviewed. The results broadly validated the information gained from the online survey and workshops, whilst providing more nuanced feedback and qualitative detail.

From the results of all of these processes four final scenarios were developed including consideration of the key feasibility criteria – effort to start collaborating, effectiveness in achieving PE, perceived costs, EU added value, benefits and perceived risks, and disadvantages and success factors. *All four scenarios were deemed possible to realise* at least partly; all four were rated as at least moderately effective in achieving PE (or effective/necessary in combination with other activities), and all were deemed to provide at least medium and often high "EU added value".

There were some differences between the survey and interviews regarding the frequency with which different scenarios were selected for analysis by stakeholders: most strikingly, the networking scenario was most frequently chosen by survey respondents, but it was the least popular with interviewees. This scenario was seen both in terms of being a potential outcome of collaboration as well as a method of working that could be applied to the other scenarios. The participants in workshop 2 recommended that it should not be included in the final report as a separate scenario, but rather as a general working approach.

The scenarios on information and professional skills were prioritised both in the survey and in interviews, whilst the scenarios on transparent quality information and self-management through technology received more divergent responses.

The scenarios are presented in a table format in the main WP report in the order they were prioritised by stakeholders. We very briefly summarize them below:

Scenario 1: **"The informed patient"** European collaboration focuses on ensuring that patients and citizens have easy access to information and health literacy covering all aspects of health, including prevention, treatment options, evidence-base for different treatments, and lifestyle advice.

Scenario 2: **"New professional skills, knowledge and attitudes"**, European collaboration focuses on ensuring that health professionals have the right skills, knowledge and attitudes to practice patient-centred healthcare, providing an enabling context for PE.

Scenario 3: **"Self-management supported by technology"**, eHealth solutions, such as telemedicine, electronic health records, remote monitoring, etc. become part of mainstream healthcare. European collaboration focuses on developing and implementing effective ICT resources and tools for patients and professionals to support PE through self-monitoring and self-management.

Scenario 4: **"Transparent quality data for patient choice"**, European collaboration focuses on facilitating patient choice through making available transparent and comparable information on quality of care

All of these scenarios are considered by stakeholders as useful for patient empowerment and as providing EU added-value; all stakeholder groups expressed willingness to collaborate on each of the scenarios. It is clear that no one scenario on its own will be capable of addressing all aspects of empowerment satisfactorily – due to the complexity of the concept and the many factors affecting PE. Therefore, multiple approaches will undoubtedly be needed. Stakeholder's preference is for *concrete actions*, preferably linked to existing initiatives, which should support and not undermine national initiatives. Patients' involvement is considered a "sine qua non".

6. Conclusions and recommendations

We summarise here some of the main conclusions of the project:

➢ **1. Catalogue of good practices**: **interventions targeting patient empowerment tend to present positive results (when compared to usual care).** Further research is still needed to determine under which specific circumstances different intervention types provide better results.

➢ The overview found an extensive number of systematic reviews of patient empowerment interventions targeting chronic patients and yet **literature on interventions specifically targeting complex patients or professionals is still substantially under-developed**.

➢ Most systematic reviews analysed are focussed on patients at a micro or regional level. Key relevant European initiatives identified were mainly focussed at meso and macro levels. Although those practices do not provide the necessary information on their effectiveness to include them in the analysis of best practices, they have illustrated the conclusions regarding best practices and draw suggestions for future EU scenarios. **Stronger evaluative work on meso and macro level initiatives is needed**.

➢ Similar interventions yield different results depending on multiple factors such as specific components of the intervention, targeted condition, patient and provider characteristics, contextual factors and outcome measures. **This puts in the centre the importance of analysing success and failure factors for each practice.** In spite of a marked underreporting of contextual elements on the scientific literature, our analysis identified many other relevant factors that might be useful in future intervention designs.

➢ In general terms three groupings seem to emerge based on the evidence of their effect:

   o **Best practices with conclusive evidence such self-management support interventions across all conditions and different formats of patient education for diabetic patients.** For those, further research would benefit by homogenizing intervention characteristics and outcome measures.

   o **Recent innovative practices (such as virtual interactive platforms and tele-monitoring through smart-phones) present a positive tendency but still need further research,**

particularly regarding the ideal combination between more traditional care and these innovative practices.

- o **Shared decision making:** even though it is one of the highest potential levels of patient involvement there is still not enough evidence to conclude what model is the most effective for the targeted conditions in this study.
- o **Systemic changes regarding the model of care (such as the chronic care model), seem to yield positive results**. However this field has been less explored and conclusions on its effect should be taken with caution.

➢ **2. In the qualitative study of facilitators and barriers for PE**: from the perspective of patients (representatives), healthcare professionals, managers and experts (authorities, researchers and policy makers) 19 clustered topics emerged as being perceived to be important for empowering patients in their management of chronic diseases.

There was no strong differentiation between facilitators and barriers of patient empowerment, since almost every aspect was described in both senses.

➢ **Five clustered aspects were considered to have high priority** for creating change in Europe:
- o The healthcare professional has enough time to communicate with the patient
- o The healthcare professional has a holistic view of the patient
- o Healthcare is well coordinated
- o The patient feels responsible for his/her own health
- o Healthcare professionals work together

➢ **Recommendations**: The survey, though not randomly selected in the countries, allowed identification of consistent stakeholder priorities and the future developments needed to strengthen patient empowerment. This study can be seen as building on and consistent with the results of the Eurobarometer qualitative study on patient involvement of May 2012[5].

European collaboration could focus on developing the five prioritized key aspects that arise from the survey, and on developing the selected scenarios, below. Suggested policy agenda areas at different levels include: **focus on better education of patients and public, improved education of healthcare professionals in holistic thinking and communication, specific restructuring of healthcare delivery and a central common electronic record accessible by patients as well as professionals**.

➢ **3. A method to validate transferability of good practices on PE** has been proposed and an assessment matrix developed. The method is not to be seen exclusively as an assessment tool – rather, it should also be regarded as an improvement tool, directing attention to factors hindering the transferability of a promising Good Practice for Patient Empowerment, especially, to factors that are barriers but are potentially changeable.

Recommendations: A protocol is proposed for the further assessment/validation of the model using Good Practice examples derived from the WP1 catalogue.

➢ **4. Possible scenarios for EU collaboration.** Patient empowerment is considered an important area by all stakeholder representatives consulted, and all actors feel they have something to contribute. European collaboration on patient empowerment is seen in a positive light, in fact, *73% of the WP4 survey respondents would like to see an EU strategy and action plan on patient empowerment*. The development of an improved evidence base, a common repository of best practices and tools to have common indicators and comparable data would also be highly rated by respondents were.

➢ The most important stakeholder groups for successful collaboration are deemed to be patients, consumers, and health professionals particularly doctors and nurses.

➢ The most frequently identified barrier relates to *attitudes* – particularly those of health professionals but also political decision-makers. *Divergences between European health systems* and *financial resources* are also recognised as important barriers, often in the context of different capacity between different Member States. In fact, funding was highly prioritised as a critical success factor: dedicated funding at national level was among the top 3 success factors for each scenario

➢ From the overall consultation process the four final scenarios were developed with consideration of the effort needed to start collaborating, effectiveness in achieving patient empowerment, perceived costs, EU added value, benefits and perceived risks, barriers and success factors. The scenarios are:

   o **"The informed patient",** focusing on ensuring that patients and citizens have easy access to information and health literacy covering all aspects of health, including prevention, treatment options, evidence-base for different treatments, and lifestyle advice

   o **"New professional skills, knowledge and attitudes",** focusing on ensuring that health professionals have the right skills, knowledge and attitudes to practice patient-centred healthcare and providing an enabling context for patient empowerment.

   o **"Self-management supported by technology",** focusing on eHealth solutions, such as telemedicine, electronic health records, remote monitoring, etc. becoming part of mainstream healthcare. European collaboration implies developing and implementing ICT resources and tools for patients and professionals to support patient empowerment through self-monitoring and self-management.

   o **"Transparent quality data for patient choice",** focusing on facilitating patient choice through making available transparent and comparable information on quality of care.

➢ **A European network for facilitating patient empowerment** is seen both in terms of being a potential outcome of collaboration as well as a method of work that could be applied to develop and strengthen the above scenarios.

This part of the study has confirmed that **there is a strong interest by all the key stakeholders concerned, and a will to collaborate at European level on patient empowerment**. Stakeholders' preference is for concrete actions, preferably linked to existing initiatives. It is respectfully suggested that the Commission consider the implications of this study, and the direction it signposts. The formulation of a **European strategy and action plan on patient empowerment as a starting point** is recommended, would be welcomed by a large majority of stakeholders. Actions taken towards the **creation of a common repository of best practices and tools, the development of common indicators** in order to achieve comparable data and **an improved evidence base** on PE, would also be welcomed by a majority of stakeholders. Current initiatives, such as the PaSQ JA, Chrodis JA and the European Innovation Platform on Active and Healthy Ageing provide opportunities for synergies and building on the work that is already underway.   .

Future Scenarios

Scenario 1: "The informed patient"	
Focus of collaboration	Ensuring patients' and citizens' easy access to information and health literacy covering all aspects of health, including prevention, treatment options and their evidence-base, and lifestyle advice. Access to information and health literacy were identified in the EMPATHiE study as fundamental to patient empowerment. The "informed patient" is already becoming reality in many cases, patients are becoming more knowledgeable, engaged and networked with each other at all levels from local to global.
Collaboration focuses on achieving the following milestones:	
Within 2 years	Stakeholders agree on a set of quality criteria for health-related information to patients. Existing information resources and related EU provisions are mapped and evaluated, with gap analysis and recommendations for future actions.
Within 5 years	The EC publishes a policy document setting out an action plan on health literacy. A new legislative proposal on the rights of patients to information may be published based on the analysis of existing legislation.
Within 10 years	Information resources, including web portals, are in place in every Member State (MS) and at EU level. These are developed based on existing identified best practice and with input from patients. A mechanism is developed to assess impact on patient empowerment and health outcomes.
What is needed to start:	Areas of highest importance and relevance to patients, professionals, educators and industry must be identified; then areas of common interest must be prioritised. A clear focus and vision are needed to ensure coordination between different levels of action. To avoid duplication, existing evidence-base and quality checklists from MS and stakeholder groups are collected to create a basis for development whilst learning from others. A mechanism is needed to evaluate quality of information tools, using the agreed criteria. It is vital to solve the trust issue from the outset, given the need for involvement of both public and commercial stakeholders. Action should be linked with EU strategies on e- and mHealth.
Opportunities and challenges:	*Patients* gain access to consistent quality information on prevention and treatment, more involvement and balanced relationships with professionals. A comprehensive EU approach can support empowerment at national level, when patients see what is happening in other countries. However, If patient groups are not involved in developing information, it may not meet their needs – particularly those of vulnerable or disadvantaged groups. If clear quality standards are not defined, information may not be trusted; inadequate or incorrect information may have adverse effects. Lack of Internet access could present a risk of inequality for parts of the population. *Professionals* benefit from patients' capacity to take a more active role in care, especially in chronic diseases, that can lead to less hospitalisation and less or different needs for medication in the long run. Some may fear undermining trust, or pressures to access latest products, and how to reach patients at risk of exclusion. Enough time is needed to interact with patients. Quantitative measures of quality should be balanced with individual needs. *Health systems* can see improved quality of care and adherence, leading to better health outcomes and less burden to the system in the long run. An improved evidence-base and comparability of indicators and best practices developed from this scenario, as well as mutual learning, can support effective healthcare decision-making. Concerns centre on monitoring costs, impacts, and how to manage the quality of information. EU initiatives should not hamper existing national actions.
Costs	Costs are likely to be low at EU level but possibly significant at national level, affecting mainly public health authorities – but this will vary as already some MS have existing resources in place. Short-term milestones would not involve much cost, but long-term solutions will be require human and material resources for setting up and maintaining information portals. Patient groups are keen to contribute, but will need funding from national or EU sources.
EU competences	As EU competences are limited in this area, some stakeholders feel it may be difficult to go beyond existing EU legislation. On the other hand, MS are already obliged to set up information portals under existing EU legislation and these could be leveraged to take a wider approach encompassing health more generally. A European network of collaboration was seen as a method of working that could be applied to the above scenario.

Scenario 2: "New professional skills, knowledge and attitudes"	
Focus of collaboration	Ensuring that professionals have the right skills, knowledge and attitudes to practice patient-centred healthcare, providing an enabling context for patient empowerment. Professionals' skills, knowledge and attitudes were identified by EMPATHiE as important barriers/facilitators to empowerment. Training needs to change towards a more patient-centred, integrated approach, and currently practising professionals' skills need further development. Key aspects include shared decision-making and soft skills – communication, empathy and partnership. New roles may be developed to meet patients' needs. Patients should be involved in professional training and design of curricula.
Collaboration focuses on achieving the following milestones:	
Within 2 years	Assessment of patients' needs is conducted and a common skill-set for patient-centred healthcare is agreed. Existing best practice is identified.
Within 5 years	Minimum training requirements and common training principles are agreed and, based on this, modules are developed to be integrated in professional training at different levels.
Within 10 years	A training curriculum is established in all MS according to common principles. Professional educators "train the trainers" in the new ways, ensuring quality. An impact assessment is undertaken to assess effect on health outcomes and patient experience.
What is needed to start:	There is willingness among stakeholders to collaborate at European level. Despite diversity of current education systems, some existing information and initiatives can be used as starting points, such as the Joint Action on Health Workforce. Incentives, e.g. CME credits, need to be defined, along with a robust evidence-base or set of good practices to support decision-making. Dedicated funding is needed and concrete, measurable outcomes should be defined. One concrete proposal was for health professionals to follow the care pathway of a few patients each year, which can give a powerful reminder of their perspective.
Opportunities and challenges	*Patients* benefit from breaking down attitudinal barriers to empowerment, and better quality of care as empowerment becomes an explicit goal of professional training. Care coordination and teamwork (major barriers/facilitators of empowerment) should be addressed as part of professional competences. Quality standards need to be set high, not to the lowest common denominator. *Professionals* benefit from improved professional development, including CDP, self-development and higher job satisfaction. Some professionals may be resistant to change or fear loss of authority. There are concerns about costs and time needed for training; many feel that pressures of the workplace are a barrier. The impact of EU actions may be difficult to translate to the micro-level where health professionals work. Divergent guidelines across the EU will need to be addressed. The generation gap may delay things but is also an opportunity: young professionals will be more able to complete the paradigm shift. Existing collaborations at EU level should not be duplicated. *Health systems* benefit from a common skill-set across EU which helps build a flexible workforce and ensures more consistent standards of care. MS will need enough freedom to adapt proposals to their own context, and to define the right mix of incentives to ensure acceptance. Concerns focus on costs of implementing (e-)learning programmes, and the complexities of engaging the workforce on a large scale.
Costs	Costs are likely to be moderate to high. Short term milestones can be achieved relatively easily, but implementation can be costly. Care and training providers would be mainly affected; organisations would need to budget for implementation of education programmes. Health professionals would also be affected. E-learning modules may be less costly, but will still cost time. Resources may need to be reallocated from other parts of the budget.
EU competences	MS are responsible for health professionals' education, but there are existing frameworks at EU level such as the Action Plan on the Health Workforce which addresses future skills needs, workforce planning and improving recruitment and retention. The revised Directive on recognition of professional qualifications refers to continuous professional development for certain professionals, minimum training requirements and development of common training principles respecting MS competencies. An informal forum for collaboration exists through the EC Working Group on Health Workforce, which could be developed to include patients and work together with the EC Working Group on Patient Safety and Quality of Care.

Scenario 3: "Self-management supported by technology"	
Focus of collaboration	Developing and implementing ICT tools to support patient empowerment through self-monitoring and self-management. Self-management is a key aspect of patient empowerment in the EMPATHIE framework, and there is positive evidence concerning support programmes; ICT also has potential to improve system efficiency. mHealth applications are a particularly quickly emerging area, but few tools currently focus on interactive chronic disease self-management. Electronic health records shared by patients and health professionals play a key role. Despite the acknowledged challenges, stakeholders agree that ICT is the future of healthcare and should be addressed at European level.
Collaboration focuses on achieving the following milestones:	
Within 2 years	The EC maps existing projects, identifying areas of self-care which can most reduce the burden on health systems. Resources to support patients' use of eHealth/mHealth are developed based on existing evidence and good practice. Guidelines are agreed to enable patient access to electronic health records.
Within 5 years	Guidelines for user-driven development of self-management support apps are agreed, including reimbursement and indicators for measuring added-value for empowerment. An online resource is set up to help people find apps to fit their needs. Comparable certification requirements are agreed for health apps in MS.
Within 10 years	Quality-assured eHealth and mHealth resources to support empowerment and engagement of patients with chronic diseases are available and reimbursed across the EU.
What is needed to start:	Existing initiatives including standards and operability should be identified and built on, but shifting the focus to patient-centredness. User involvement must be embedded to ensure apps meet the needs of real people. Stakeholders need to establish trust from the beginning; industry should share data and collaborate to avoid duplication. The legislative framework for devices should be clarified. A patient reporting system should be implemented so safety and quality issues with apps can be fixed and prevented.
Opportunities and challenges	*Patients* benefit from access to their data, easy ways to connect with others and support for self-management. Technology can improve access to care, but it needs to be an integral part of effective service delivery, not an "add-on." Services need to be available and covered under rules that ensure equity for patients. Data privacy needs to be addressed in a way that creates trust and confidence. Main risk seen by both patients and professionals is that ICT will be seen as "the answer" to empowerment at the expense of other factors. Other risks include the burden of using technology for some patients, language barriers, accessibility across the EU, and commercial interests involved in developing apps. *Professionals* benefit from easier communication with patients and peers, greater self-management and patient involvement. ICT can facilitate their work as long as systems are designed for the end-users. Quality control and commercial interests should be managed. Scarce resources and cost of ICT projects, together with patient take-up of tools, legal aspects, responsibility and accountability, are main concerns. *Health systems* may see potential especially in remote areas to improve access, as well as lower costs in the long run due to greater patient engagement. They can learn from other MS experiences in implementation. Challenges include compatibility with local standards, legal frameworks and privacy. Different health systems add a layer of complexity.
Costs	A moderate to high-cost scenario, but one that offers high EU added value. Starting collaboration is fairly low cost. Costs down the line will affect MS and the organisations that adopt and maintain applications. For patients, cost issues relate to reimbursement.
EU competences	This was not considered a barrier to collaboration on technology: an existing legal basis for collaboration of eHealth already exists in Directive 24/2011. Other possibilities are offered by the Internal Market. Frameworks for ICT in health, such as the eHealth Action Plan and mHealth strategy, should include a specific collaboration focused on empowerment. The Horizon 2020 programme includes eHealth services with strong user involvement, and digital health literacy as areas for funding. The European Innovation Partnership on Healthy and Active Ageing (EIP-AHA) could provide another framework for development, sharing and evaluating specific solutions through its action groups on integrated care and adherence.

	Scenario 4: "Transparent quality information for patient empowerment"
Focus of collaboration	Facilitating patient choice through making available transparent information on quality of care. Choice is a key factor in patient empowerment, while transparency is driven by the desire for continuous improvement and the recognition that citizens have a right to know about healthcare quality. Patient-centeredness of care is an important quality criterion for providers and systematic mechanisms for feedback from patients and families need to be put in place to identify areas for quality improvement.
Collaboration focuses on achieving the following milestones:	
Within 2 years	Common standards are adopted for information on healthcare quality to patients and citizens. A common definition of "patient-centeredness" of care is adopted at EU level, with indicators for measuring this.
Within 5 years	MS agree common quality criteria in the context of the Cross-Border Healthcare Directive. The EC sets up a resource of comparable information on quality for citizens. MS implement feedback mechanisms on the patient experience and a minimum data set for clinical results, using existing tools.
Within 10 years	Transparency of quality information in all MS, comparable quality standards across the EU, and comparable information on patient-centeredness is in place.
What is needed to start:	Stakeholders think it is relatively difficult to start collaborating on quality but that it provides high EU added value, particularly if integrated with scenario 1. In some MS there are existing initiatives towards transparency of quality which should be shared. It is vital to engage professionals, and to link to existing international collaborations. A clear political commitment is key at national level where resources are allocated. For this, a robust evidence-base is needed.
Opportunities and challenges	*Patients* benefit from more informed choices regarding care, including treatment and shared decision-making. Impact on empowerment would depend on the accuracy of quality information: inaccurate information can undermine trust in the system. Patient involvement is critical to ensure that quality standards reflect what is most valued by patients and inspire public trust. *Professionals* benefit from quality improvement and implementation of best practices, with information shared across borders. Generalists would be able to better support patients' choices for specialist treatment, while specialists would improve quality in areas that are measured, particularly when evaluated by patients. Challenges relate to resistance to transparency of performance data and perceptions of vulnerability and risk, legal issues and the risk of overly target-driven medical practice. *Health systems* benefit from continuous quality improvement, standardised indicators and common benchmarks, resulting in comparable information at regional, national and international levels to aid decision-making; as well as a more transparent process of supervision. The scenario fits with many MS existing national agendas on quality improvement. Defining standards may be a challenge given the complexity of quality: wrong criteria or indicators may have adverse effects. Other concerns relate to inequalities between MS and willingness to align with commonly agreed standards.
Costs	Start-up costs are likely to be low: common standards require mainly resourcing from the EC to coordinate the process. Long term, the scenario is likely to be moderate to high-cost due to the need to have in place mechanisms to measure quality. Costs at MS level would depend on what already exists in the country: IT programmes can be a significant cost item, as can the production and translation of information for patients. Costs would mostly affect public authorities and providers in MS. On the other hand, stakeholders feel the scenario offers high EU added value: supporting continuous improvement strategies, generating comparative data and benchmarks for evidence-based decision-making.
EU competences	A legal base for collaboration exists through Directive 24/2011 which requires transparency of quality and safety standards and international collaboration. Quality indicators have been developed by international organisations such as the OECD and the ECHI; but no agreed indicators currently exist to measure patient-centeredness or patient empowerment. An existing structure for collaboration on safety and quality of care exists through the European Commission WG which meets biannually, but which does not currently include all health stakeholders. The ongoing Joint Action on Patient Safety and Quality of Care (PaSQ) is due to set up a permanent network with MS and stakeholders, subject to mandate and funding.

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