

EMPATHiE

EMPOWERING PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES



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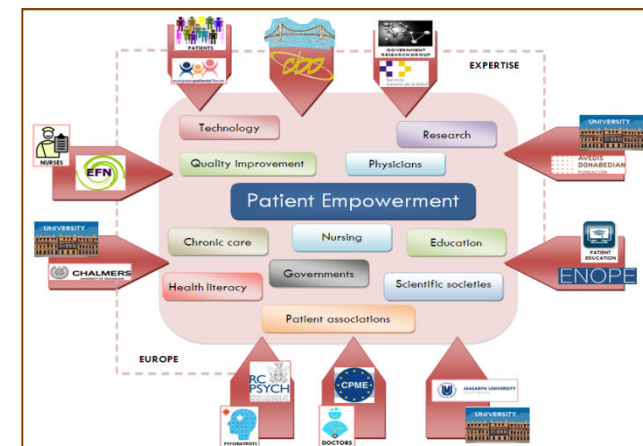


EMPATHiE Consortium

- Avedis Donabedian Research Institute (FAD) - Autonomous University of Barcelona
- Dutch Institute for Healthcare Improvement CBO)
- European Patients' Forum (EPF)
- Chalmers University of Technology
- Masaryk University (MU)
- European Network on Patient Empowerment (ENOPE) – Danish Committee for Health Education
- Royal College of Psychiatrists (RCPsych)
- Standing Committee of European Doctors (CPME)

Experts:

- Angle Coulter
- David Somekh MD
- European Federation of Nurses (EFN)
- Research Group. Servicio Canario de Salud. (Spain)



EMPOWERING PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES. OBJECTIVES:

To help understand the concept of Patient Empowerment as a prerequisite to exercise patient rights.

The specific objectives are:

To identify **best practices** for patient empowerment

To identify **advantages and barriers** to empowering patients

To develop a **method to validate transferability** of good practices

To develop **scenarios of EU future collaboration** on this subject

Target groups

Patients with chronic cardiovascular diseases (CVD or stroke)

Patients with chronic respiratory diseases (COPD)

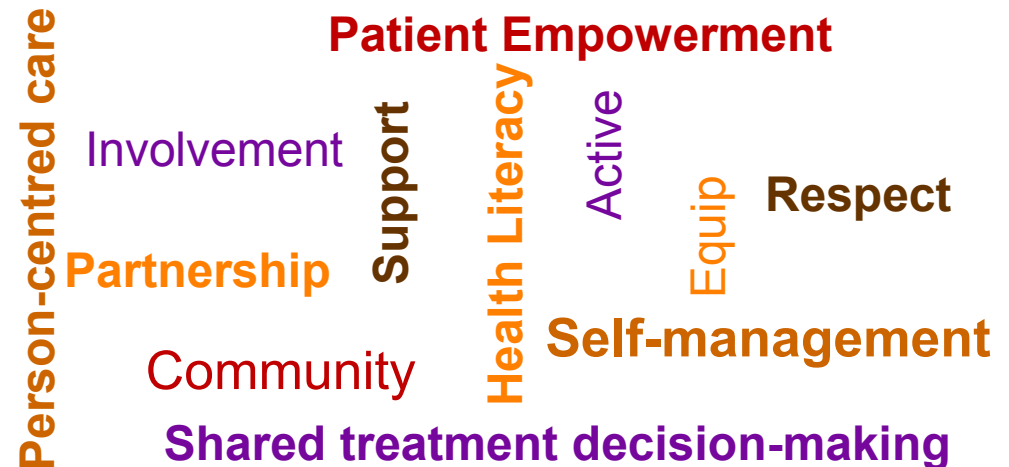
Patients with chronic diabetes (type 1 and 2)

Patients with mental health (schizophrenia or chronic depression)

Complex patients (co-morbidity)

Patient Empowerment – Operational definition

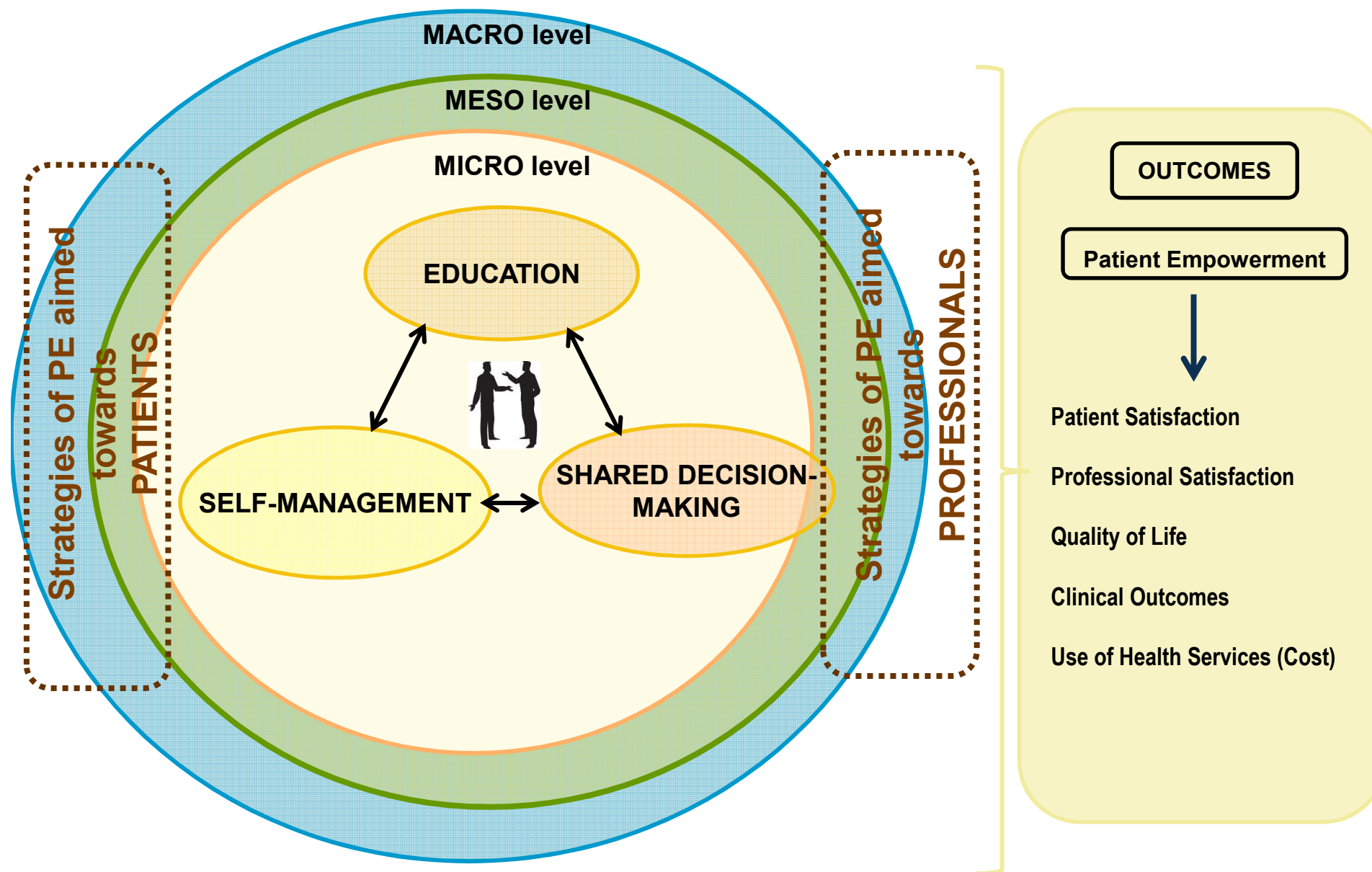
An **empowered patient** has control over the management of their conditions in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to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

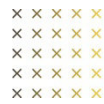


Patient Empowerment interventions – Operational definition

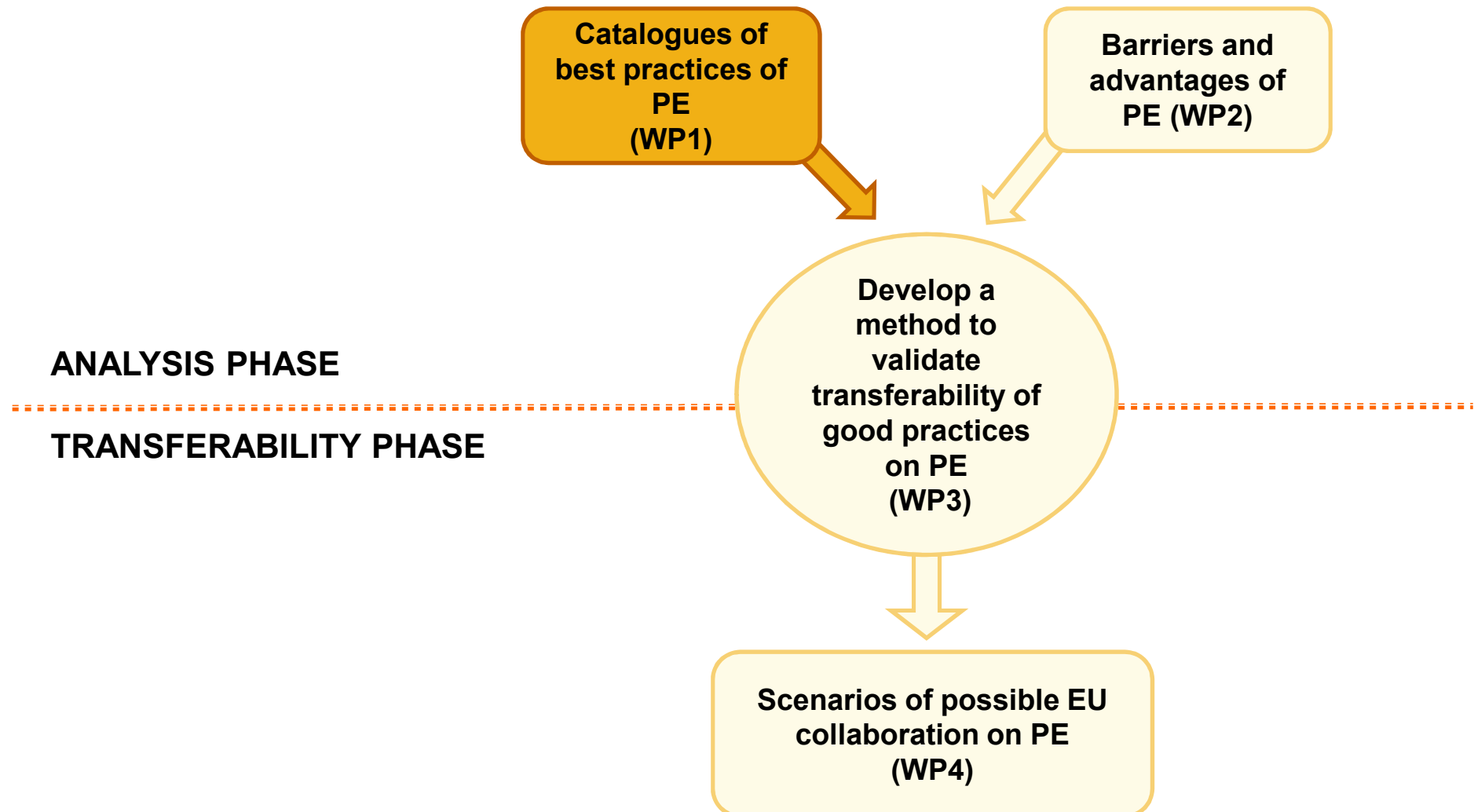
Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition, to create awareness and develop competences of healthcare professionals and improve the preparedness of healthcare system to tackle this paradigm.





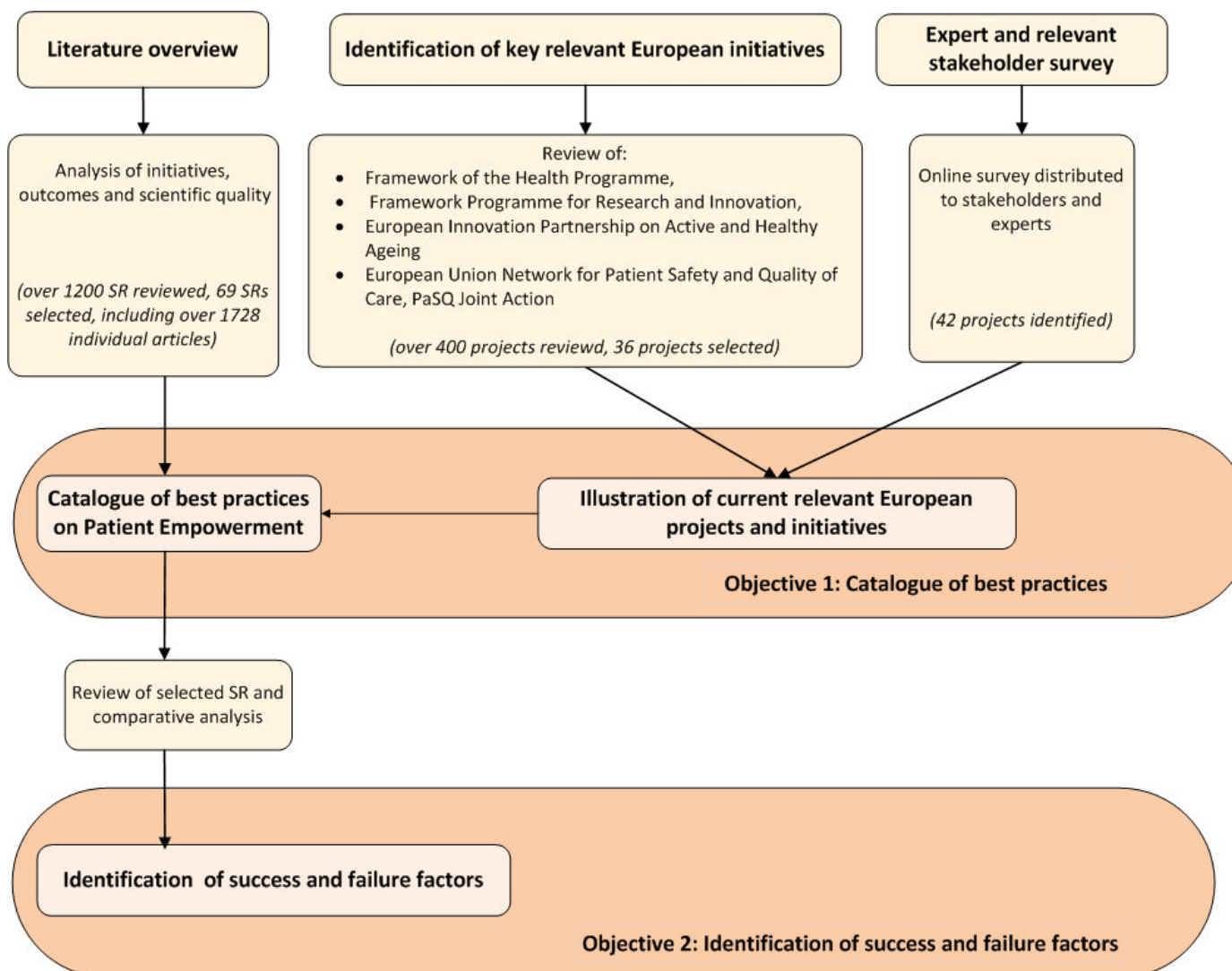


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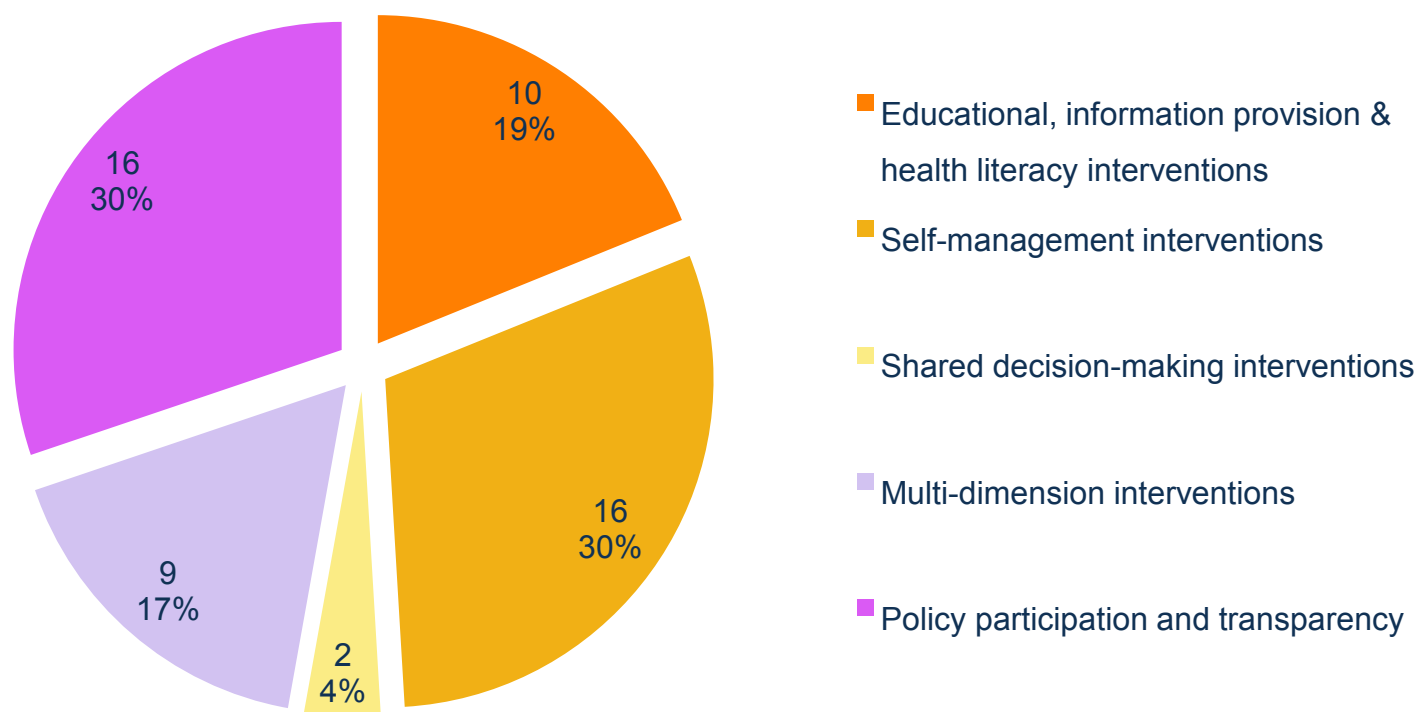


WP1 - CATALOGUE OF BEST PRACTICES - METHODOLOGY



WP1 - CATALOGUE OF BEST PRACTICES – DESCRIPTIVE RESULTS

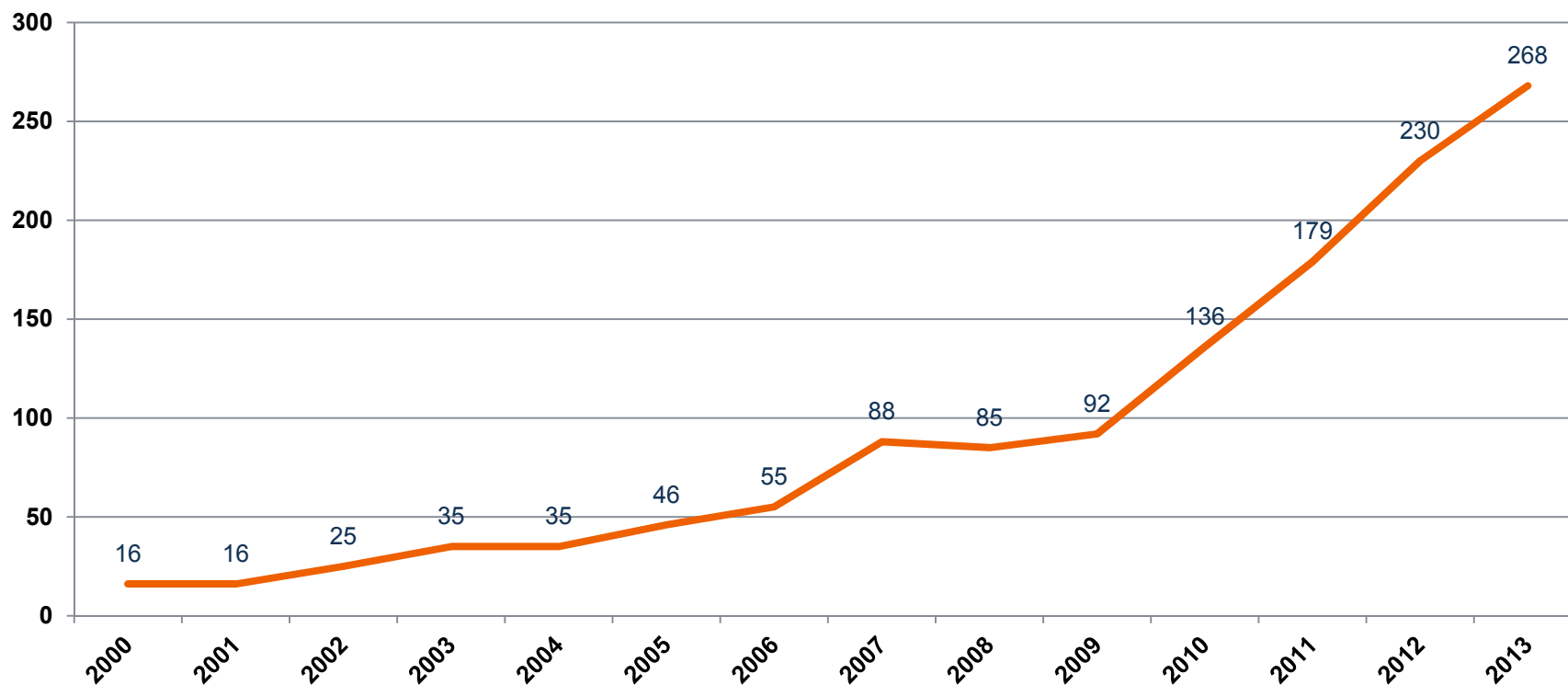
European Interventions - by dimension (N=53)



WP1 - CATALOGUE OF BEST PRACTICES – DESCRIPTIVE RESULTS

Presence on the Literature

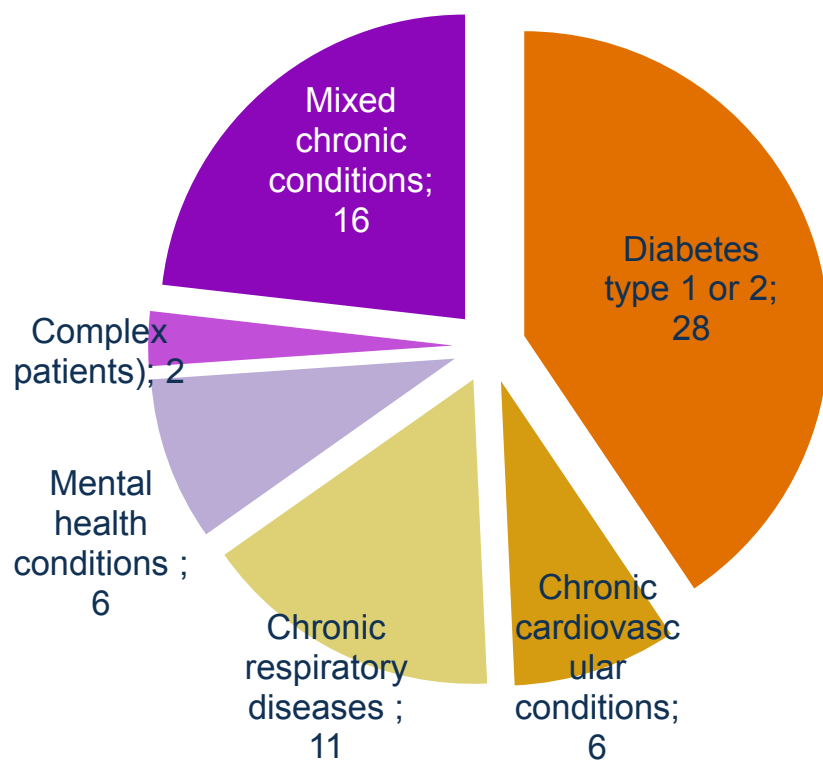
Number of systematic reviews focused on Patient Empowerment
(by year - not limited by condition)



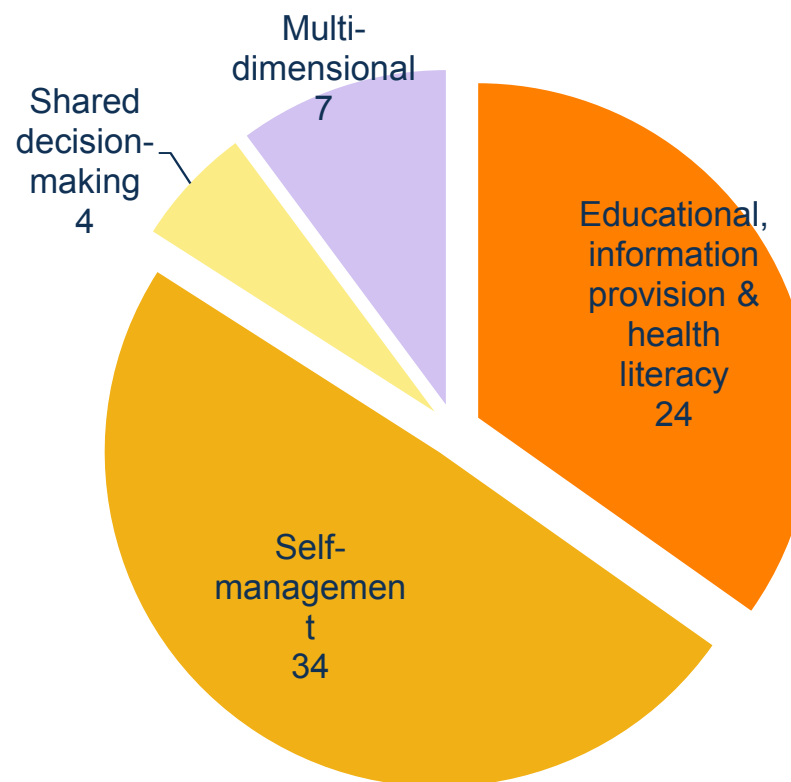


CATALOGUE OF BEST PRACTICES– LITERATURE REVIEW DESCRIPTIVE RESULTS (1118 SR)

Distribution by condition



Distribution by dimension



N= 69 SR; 1728 articles

WP1 – CATALOGUE OF BEST PRACTICES

Intervention	DIAB	CARDIO	RESPIR	MENT	COM	MIXED
Educational, information provision & health literacy						
<i>Face-to-face</i>						
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)		
<i>Virtual or technology mediated</i>						
Patient education through multimedia and/or ICT		+++ (1) / ++ (1)		NC (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

WP1 – CATALOGUE OF BEST PRACTICES (*continued*)

Intervention	DIAB	CARDIO	RESPIR	MENT	COM	MIXED
Self-management						
<i>Face to-face</i>						
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)			

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

WP1 – CATALOGUE OF BEST PRACTICES (*continued*)

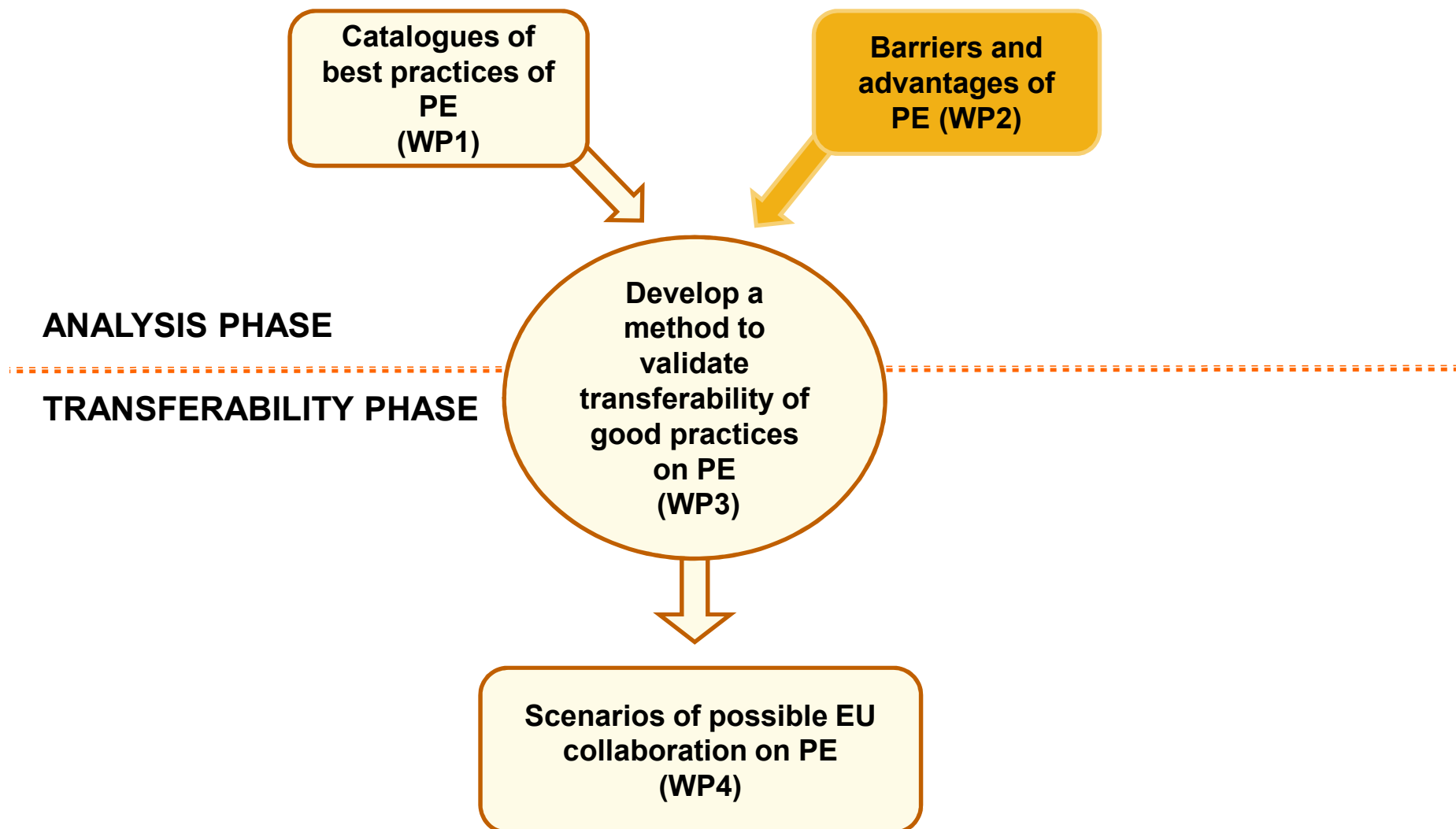
Intervention	DIAB	CARDIO	RESPIR	MENT	COM	MIXED
Self-management (continued)						
<i>Virtual or technology mediated</i>						
Mixed technologies support programmes for self-management	+++ (1)	+++ (1) / NC (1)	++ (1) / NC (1)			
Lay led mobile phone						++ (1)
Mobile phone	+++ (1)					NC (1)
Web-based	NC (1)					+++ (1) ++ (2) NC (1)
Applications for Smartphone and tablets			NC (1)			++ (1)
Tele-monitoring	++ (3)					NC (1)
<i>Mixed (face to face + virtual or technology mediated)</i>						
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



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Identification of 5 top clustered topics

Main Barriers and Facilitators (I)

Clustered topics	Advantages	Barriers
Patient education	Good information about your own disease	Patients access non-reliable information (Google, waiting room)
Reliable information	Information on practical support and solutions	Lack of informed choices
Personalized care	Personalized medication history (in plain language)	Inappropriate communication
Holistic view	Support on all important aspects of life: housing, relationship, employment, etc.	Consideration of the patient as a disease or treatment instead of a person living with a condition
Contact with other patients	Support by peers	
Patient organizations	More powerful patients unions/org.	Unclear legislation, lack of performance measures
Social support	Relatives give support	Lack of general environment involvement (municipalities, schools...)

Main Barriers and Facilitators (II)

Clustered topics	Advantages	Barriers
Interaction btw patient and professional	One contact person assigned and easily reachable	Lack of trust
Health care professionals - skills	Coaching skills education (part of professional education)	Professionals are not empathic enough
Organization	A single shared clinical history	Lack of time
Finance	Availability of different resources for support	Lack of financial incentives for PE
National programs	Awareness at national/European level	Lack of active promotion of healthy lifestyles
Inequity	Higher educated patients can assume a more active role	Added difficulty to motivate, educate (low socio-economic status)

Top 5 clustered aspects

Prioroty	Topics important for patient empowerment
1	It helps that the healthcare professional has enough time to communicate with the patient
2	It helps that the healthcare professional has a holistic view of the patient
3	It helps that healthcare is well coordinated
4	It helps if the patient feels responsible for his/her own health
5	It helps that healthcare professionals work together



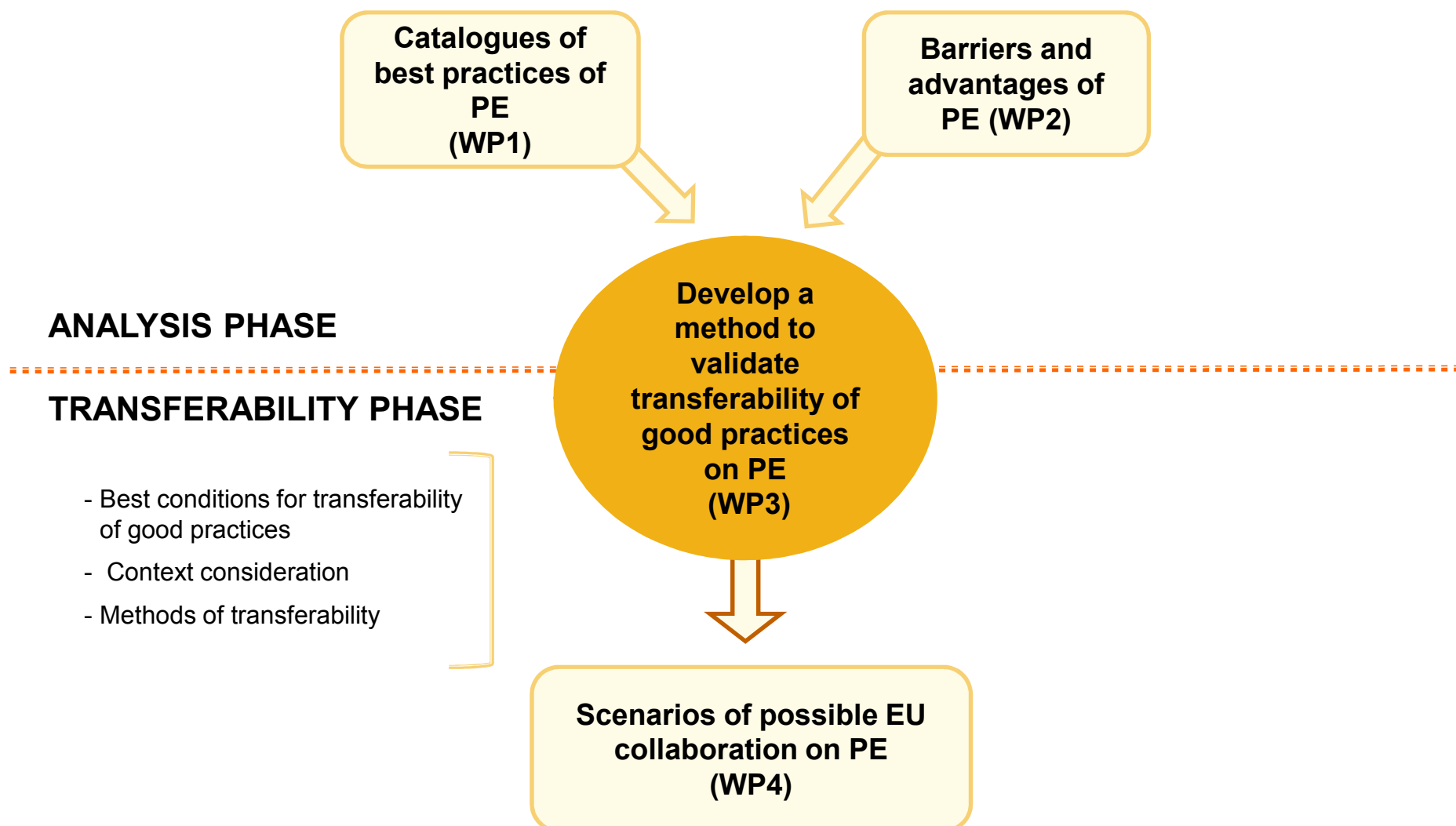
Results: Survey – Top 5 clustered aspects

Clustered aspects important for patient empowerment	Overall	Priorities (by group of respondents)			
		Patients'	Health care professionals'	Healthcare managers'	Authorities/ experts'
healthcare professionals have enough time to communicate with patients	1	1	3	4	2
healthcare professionals have holistic view of patients	2	2	5	3	1
healthcare is well coordinated	3	4	2	1	4
patients feel responsible for their health	4		1	2	3
healthcare professionals work together	5	5	4		5
patients and healthcare professionals have good interaction	(6)	3			
healthcare professionals are well educated	(7)			5	

Results: Survey – Top 5 clustered aspects

Clustered aspects important for patient empowerment	Overall	Priorities (by European Region)				
		Scandinavian	Bismarckian	Anglo-Saxon	Southern	Eastern
It helps that the healthcare professional has enough time to communicate with the patient	1		1		2	1
It helps that the healthcare professional has a holistic view of the patient	2	2	3	1	5	3
It helps that healthcare is well coordinated	3	1	5	2	1	
It helps if the patient feels responsible for his/her own health	4	5	4	3		2
It helps that healthcare professionals work together	5		2		4	4
It helps that the patient and the healthcare professional have a good interaction with each other	(6)	4				5
It helps that the healthcare professional is well educated	(7)	3		4		
It helps that patients have equal opportunities in healthcare	(8)			5		
It helps that the patient is well educated	(15)				3	

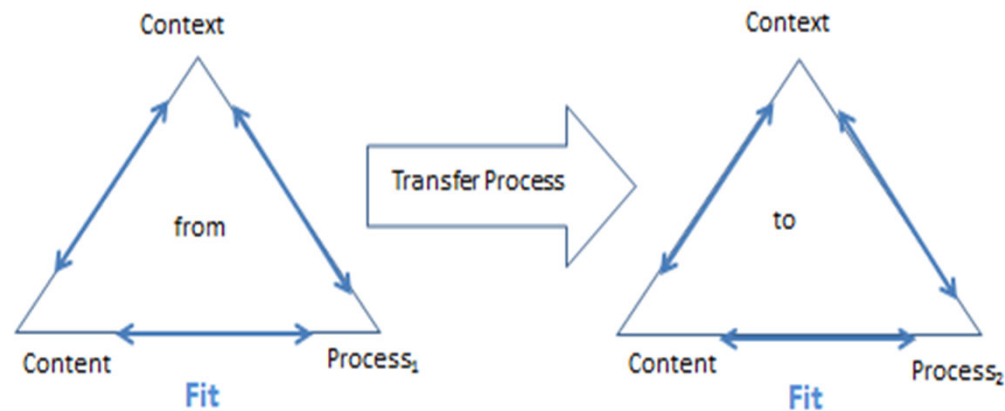
PROJECT PHASES



Method for transferability of good practices *(currently in development)*

“Practice content + Context + Implementation Process → Outcome”

Transferability - from → to
Content, Context and Process



- Fig 3. Transferability model from one setting to another based on modified Pettigrew

Assessment matrix for Good Practices on Patient Empowerment (GPPE)

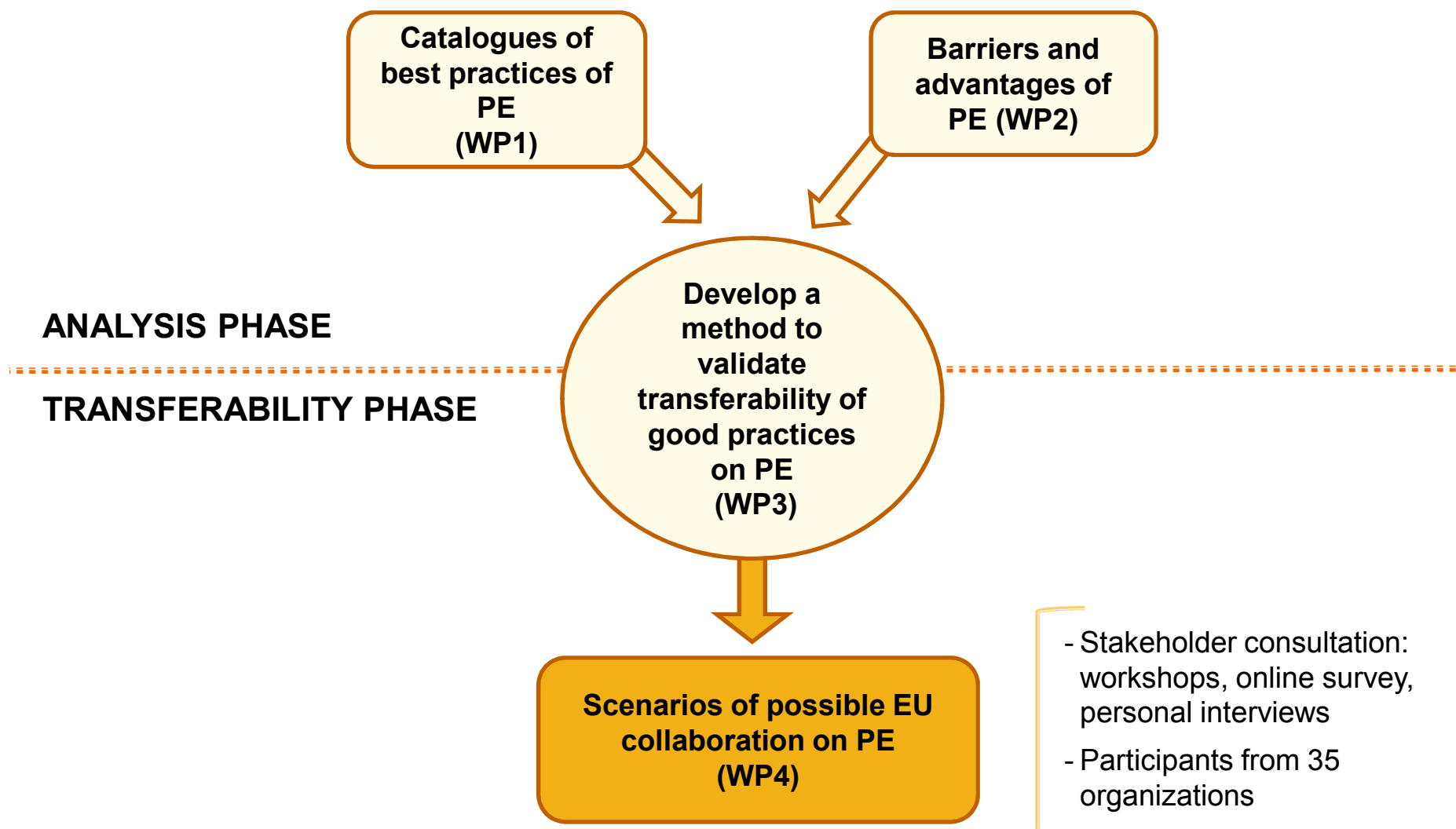
GPPE	Description
Site(s) of earlier applications	
HC system(s) of earlier applications w.r.t. GPPE	
Strategic fit (Vision, Mission, ...) w.r.t. the GPPE	
Climate of importance for the GPPE, for example leadership issues	
Kind of provider (Primary, secondary or tertiary)	
Cultural/climate elements of 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

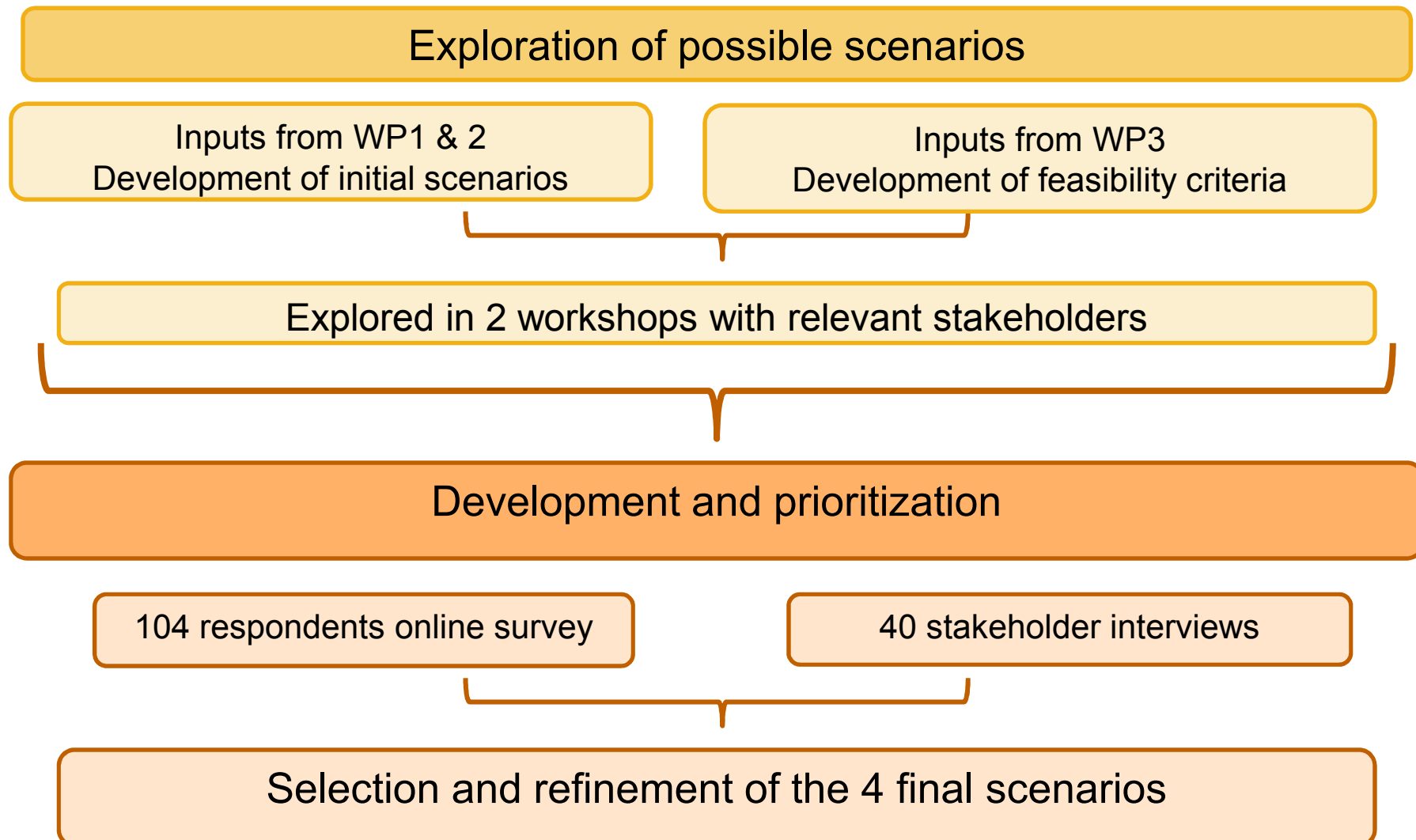
Assessment matrix for Good Practices on Patient Empowerment (GPPE) (*continued*)

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
	Trialability - 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



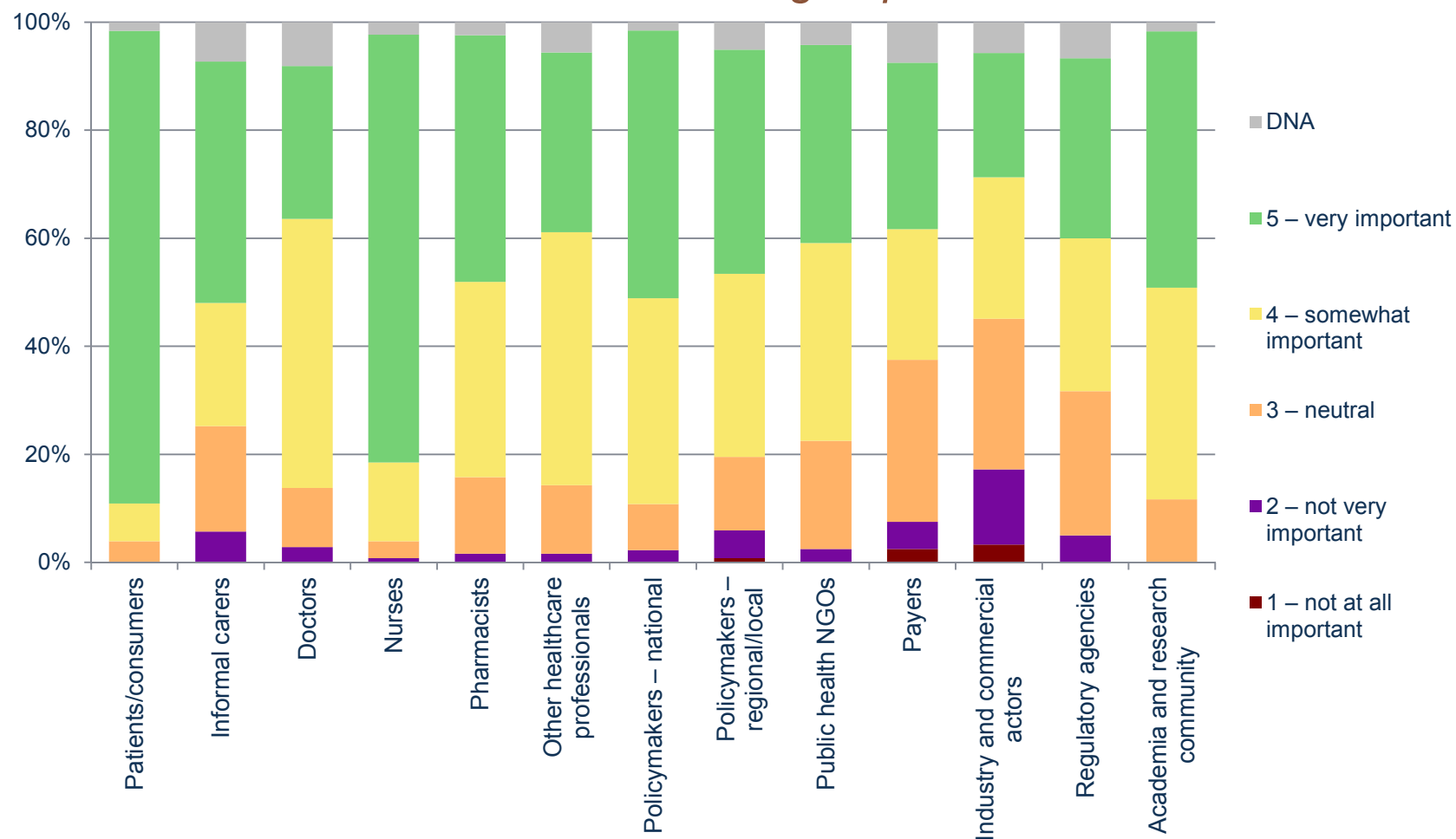
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WP4 Survey Descriptive results

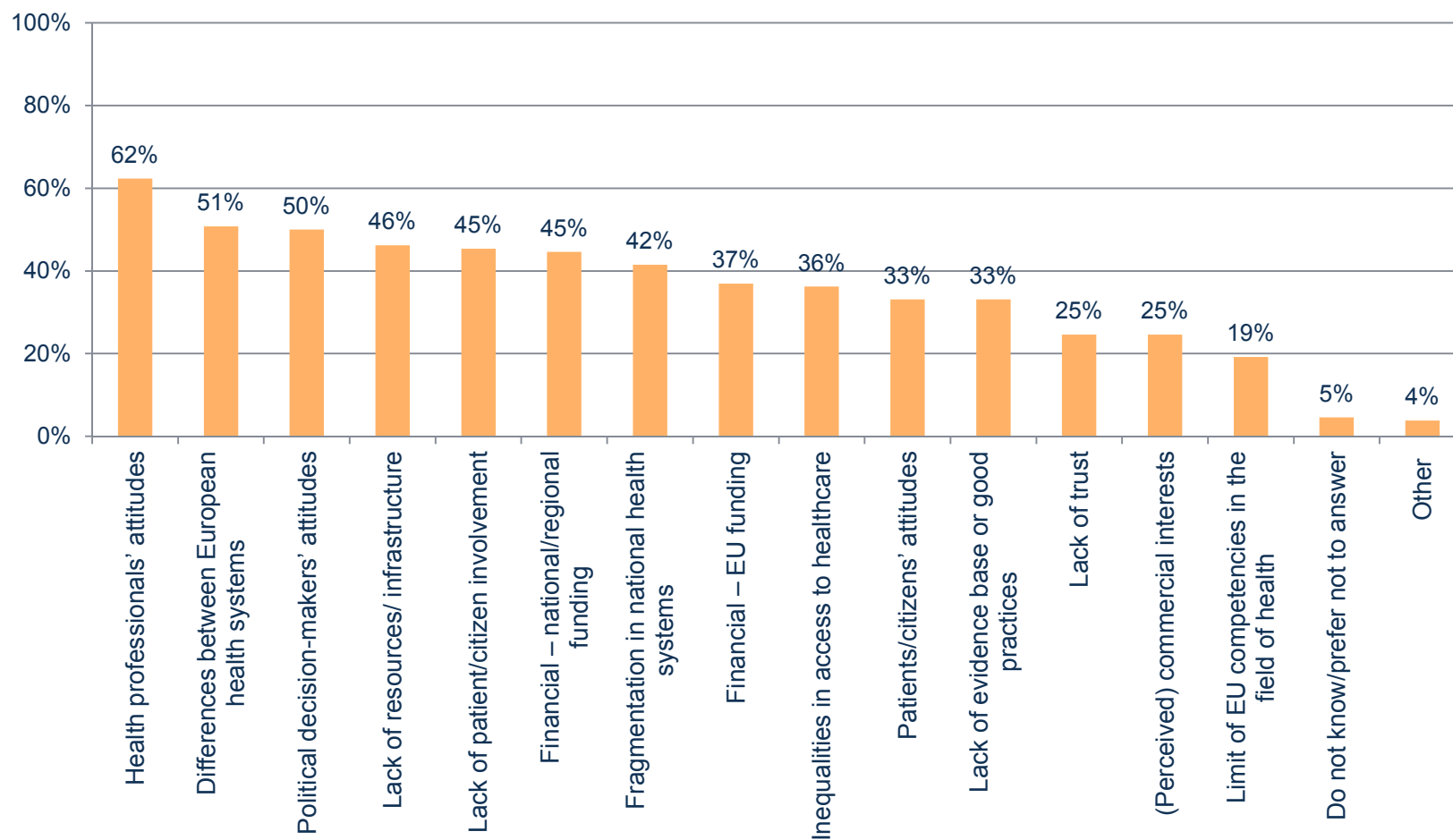
Relative perceived importance of patient empowerment by different stakeholder groups





WP4 Survey Descriptive results

Barriers to European collaboration



Scenarios of future EU collaboration

Scenario 1: “The informed patient ”

Focus of the collaboration	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. The “informed patient” is already becoming reality in many cases, patients are becoming more knowledgeable and engaged and also more networked with each other at all levels from local to global.
Milestones , collaboration focuses on achieving the following milestones:	
<i>Within 2 years</i>	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.
<i>Within 5 years</i>	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.
<i>Within 10 years</i>	information resources, including web portals, are in place in every Member State and at EU level. These are developed based on existing examples, identified best practice and input from patients. A mechanism is developed to assess impact of health information on patient empowerment and health outcomes.

Scenario 2: “New professional skills, knowledge and attitudes”

Focus of the collaboration	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 patient empowerment. Shared decision-making was identified as a key aspect of empowerment. Professionals’ skills, knowledge and attitudes are important barriers/facilitators of empowerment. Future training will need to change towards a more patient-centred, integrated chronic disease management; Training is oriented towards patient-centred values and patient involvement, including shared decision-making and soft skills – communication, empathy and partnership. Patients should be involved in professional training through participating in innovative practices and design of curricula.
Milestones , collaboration focuses on achieving the following milestones:	
<i>Within 2 years</i>	a needs assessment is conducted to assess the patients’ needs regarding health professionals’ skills. A common skill-set for patient-centred healthcare is agreed, and existing best practice is identified.
<i>Within 5 years</i>	a minimum training requirement and common training principles are agreed, based on which modules are developed to be integrated in professional training at different levels.
<i>Within 10 years</i>	a training curriculum is established in all MS according to common principles. Professional educators “train the trainers” in the new ways, ensuring quality.

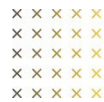
Scenarios of future EU collaboration

Scenario 3: “Self-management supported by technology”

Focus of the collaboration	<p>eHealth solutions, such as telemedicine, electronic health records and remote monitoring are mainstreamed into an integrated care approach. European collaboration focuses on developing and implementing ICT resources and tools for patients and professionals to support patient empowerment through self-monitoring and self-management. eHealth and mHealth are rapidly developing and particularly quickly emerging market, but most of these target the consumer market and fewer focus on interactive self-management. Surveys show that mHealth is still used by a minority of people. eHealth/mHealth tools can help patients manage their condition mostly at home, providing motivation and support. Electronic health records, where patients can access and add data to their own record which is shared with health professionals, play a key role. Despite the acknowledged difficulties regarding interoperability and data protection, stakeholders broadly agree that ICT is the future of healthcare.</p>
Milestones , collaboration focuses on achieving the following milestones:	
<i>Within 2 years</i>	The EC maps all existing projects, with the aim of identifying those areas of self-care which can most reduce the burden on health systems. Resources and tools to support patients' use of eHealth/mHealth applications are developed, based on existing evidence and good practice. Guidelines are agreed to enable patient access to electronic health records.
<i>Within 5 years</i>	Guidelines for user-driven development of self-management support applications are agreed, including guidelines for reimbursement and indicators for measuring added-value, focused on patient empowerment and self-management.. Comparable certification requirements are agreed for health apps in MS. An online resource is set up to help people find safe and high-quality health apps that fit their needs
<i>Within 10 years</i>	quality-assured eHealth and mHealth resources to support empowerment and engagement of patients with chronic diseases are disseminated, taken up and routinely reimbursed across the EU.

Scenario 4: “Transparent quality data for patient empowerment”

Focus of the collaboration	<p>European collaboration focuses on facilitating patient choice through making available transparent and comparable information on quality of care. Choice is regarded as a key factor in patient empowerment – in this scenario it includes provider choice <i>and</i> therapeutic choice. Patient-centredness of care is considered an important quality criterion adopted by organisations and practitioners. Transparency regarding quality data is driven by the desire for continuous improvement and the recognition that citizens have a right to know about healthcare quality.. Systematic mechanisms to collect feedback from patients and families need to be put in place to identify areas for quality improvement.</p>
Milestones , collaboration focuses on achieving the following milestones:	
<i>Within 2 years</i>	common standards are adopted for provision of information on healthcare quality to patients and citizens. A common definition of “patient-centredness” of care is adopted at EU level, with indicators for measuring this.
<i>Within 5 years</i>	MS agree a set of quality criteria in the context of the Cross-Border Healthcare Directive. The EC sets up a resource of comparable information on quality of care for all citizens. MS are asked to implement a feedback mechanism for patients to provide information on the patient experience, and a minimum data set for clinical results, preferably using existing tools e.g. the OECD survey.
<i>Within 10 years</i>	there is transparency of quality information on healthcare providers in all MS, comparable quality standards for healthcare across the EU, and comparable information on patient-centredness.



Main conclusions

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.

Extensive number of systematic reviews of patient empowerment interventions targeting chronic patient and yet **literature about complex patients and interventions specifically addressed to professionals is still substantially under-developed.**

Stronger evaluative work on meso and macro level initiatives is needed.

The survey, though not randomly selected in the countries, allowed identification of consistent stakeholder priorities and the future developments needed to strengthen patient empowerment.

European collaboration could focus on developing the five prioritized key aspects that arise from the survey, and on developing the selected scenarios. 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.**

Main conclusions

The method to validate transferability of good practices on PE, should also be regarded as an improvement tool, directing attention to factors hindering the transferability of a promising Good Practice for Patient Empowerment. Especially, it directs attention to factors that are barriers but are potentially changeable. A protocol is proposed for the further assessment/validation of transferability

Possible scenarios for EU collaboration. Patient empowerment is considered an **important area by all stakeholder** and all feel they have something to contribute. **European collaboration on patient empowerment is seen in a positive light** (*73% would like to see an EU strategy and action plan*). Other outcomes of collaboration highly rated were an improved evidence base, a common repository of best practices and tools, common indicators and comparable data.

The formulation of a **European strategy and action plan on patient empowerment as a starting point** is recommended, given that is what the large majority of stakeholders seem to favour. We would also recommend that some action is 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. 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 actions of our group

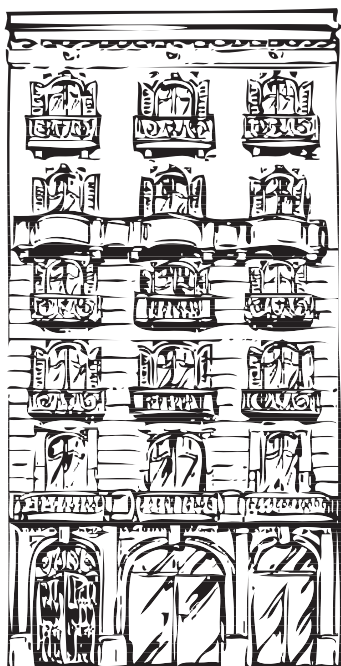
Platform of experts in self-care (PiSCE)

Link with self-care in minor conditions (PiSCE)

Continuing participation in Joint Action PASQ
(FAD & EPF)

Contribution to European Innovation Partnership
on Active and Healthy aging

THANK YOU FOR YOUR ATTENTION



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**AVEDIS
DONABEDIAN**
INSTITUTO UNIVERSITARIO-UAB

BARCELONA
C/ Provença, 293, pral.
08037 Barcelona
Tel.: +34 932 076 608

MADRID
Paseo de la Castellana, 141
(Edificio Cuzco IV)
28046 Madrid
Tel.: +34 917 498 046

BOGOTÁ
Carrera 7ª 123-24, Of. 503
101100 – Bogotá
Tel: +57 1 744 99 76

fad@fadq.org **www.fadq.org**

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