

OVERVIEW OF EPF'S WORK ON PATIENT EMPOWERMENT

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“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

Why patient empowerment?

- The patient's role is undergoing a transformation : from passive recipient to active and equal partner
- Moves towards “patient-centred” healthcare (in theory)
- Health systems need to change – chronic disease, ageing, technology, financial constraints – sustainability challenge
- HS not “performing” = meeting patients' needs
- Everyone agrees: patient empowerment = good...
 - ... BUT does everyone see in the same way?
 - ... does everyone have the same goal?
 - ... How to achieve real empowerment?



EPF Campaign 2014



“EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY

We want to be full partners in the management of our conditions according to our individual capacities and situation. We need to be empowered to do so.

...

Adopt an EU strategy on patient empowerment, including an action plan on health literacy and high-quality information for patients on all aspects of our care”



“ A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE ”

Definition?



“ A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE ”

Some working definitions...



Empowerment = a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important”

(PaSQ, adapted from Luttrell et al. 2009)

Empowerment = a process through which individuals and groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take (political, social, and cultural) action to meet those needs

(PaSQ, adapted from Duque project <http://www.duque.eu/>)

Empowerment is a process, non-binary, non-linear. There can be degrees of empowerment, and these can change over time.

Some working definitions...

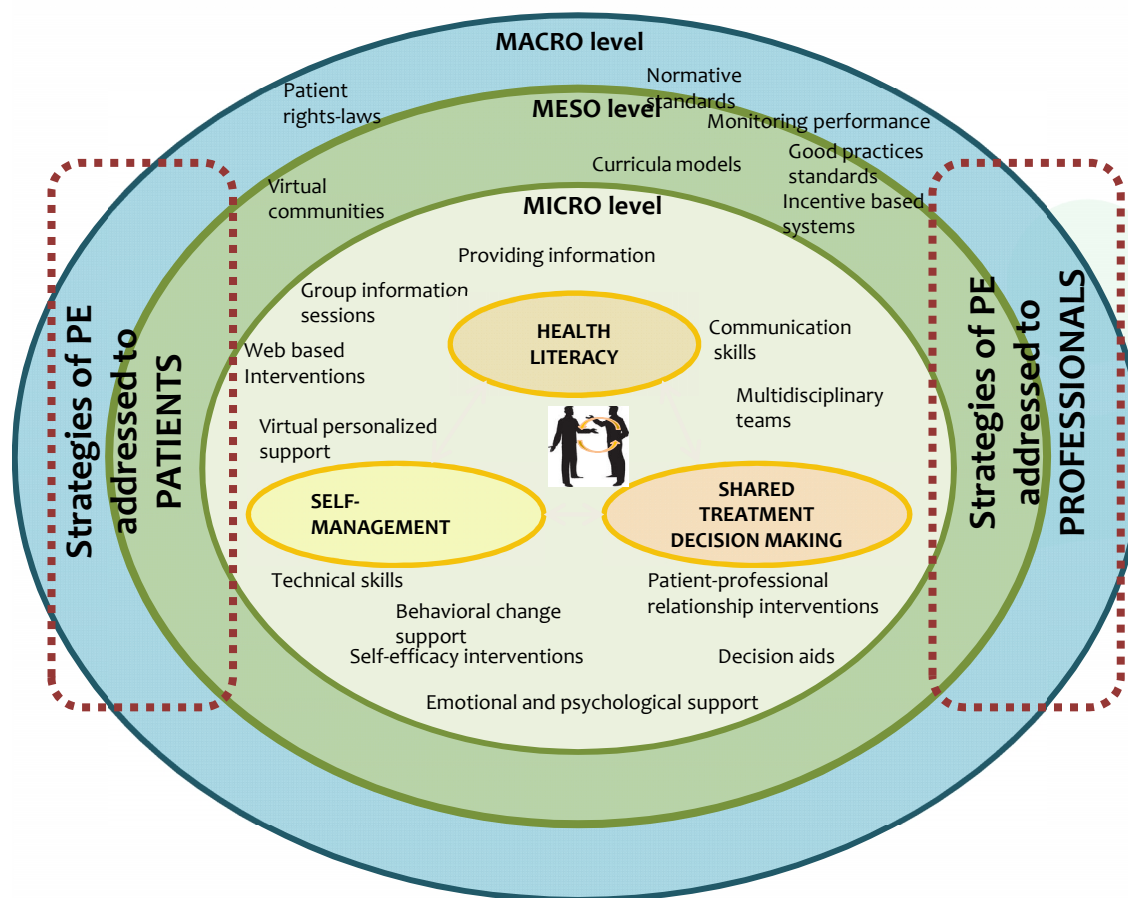
An *empowered patient* has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve 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;
- become “co-managers” of their condition in partnership with health professionals;
- develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.

(working definition proposed to EMPATHIE)

EMPATHIE: 3 facets of empowerment



- Health literacy
 - Information, ICT tools, system factors...
- Self-management
 - Skills, behaviours, self-efficacy, psychological-emotional support...
- Shared decision-making
 - Relationship
 - Decision aids
 - Communication
 - HCP skills, attitudes...

SUSTAINS: dimensions of empowerment



1. Knowledge: relationship between the patient's understanding of health information and ability to make effective use of it
 - Understanding health information
 - Understanding the disease and its implications
2. Control: extent to which the patient takes an active role for managing her/his health status and the condition
 - Monitoring the treatment and its progress
 - Adherence to treatment plans and disease-related life-style adjustments
3. Participation: extent to which the patient actively participates in the decision-making process with professionals
 - extent to which the patient is prepared for consultations
 - extent to which the patient actively participates during consultation

SUSTAINS, unpublished (not for external dissemination)

Reference points at EU level

- The “twin” reflection processes:
 - Chronic diseases
 - Health systems sustainability
- Patient empowerment identified as key factor
 - but perceived primarily in terms of self-management and “consumer choice”
- EC: “strategy on patient empowerment”
- EMPATHIE tender – mapping study (-> Sept 2014)
- WHO roadmap for integrated, coordinated health service delivery



Goal 4: Patient Empowerment

To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

GOAL 1: Health Literacy

To promote access for patients and their informal carers to information and education that enables them to make informed choices about their health.

Key Performance Indicators



(long-term: until 2020)

1. EPF is successful in *identifying good practices* and *promoting development and implementation of strategies* for involving patients in decision-making and management of their condition, in partnership with healthcare professionals and according to their preference for active engagement
2. EPF is successful in contributing to *identifying and raising awareness of patient rights and responsibilities* arising from patients' more active involvement in decision-making and management of their condition

Action areas – Strategic Plan 2020



- Mapping and exploiting effectively existing materials, documentation and tools
- Research to enhance ‘patient evidence base’: working with research/academia, EPF own research project?
- Collecting evidence on patients’ direct experiences across the EU member states
- Collaborating with healthcare professionals’ organisations to identify/drive best practices
- patients’ rights
- patient-centred health/social care (role of patient empowerment in it)

Useful links



- EPF Campaign Manifesto and background papers
<http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/>
- EPF Strategic Plan 2014-2020
<http://www.eu-patient.eu/Documents/Library/Strategic%20Planning/EPF%20Strategic%20Plan%202014-2020%20Final.pdf>
- EPF paper on the EU chronic disease strategy
- EPF paper on the EIP-AHA
- ENOPE:

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 - but perceived primarily in terms of self-management and “consumer choice”
- EMPATHIE outcomes – Sept 2014
 - Mapping, barriers, scenarios for EU collaboration
- EC: “strategy on patient empowerment” (for new Commissioner)
- [WHO roadmap](#) for integrated/coordinated health service delivery



Extra: Health literacy

“the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.” (WHO, www.who.int)

“the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena.” (Kickbusch et al, 2005)

“people’s knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.” (Sorensen and Brand 2013)

Extra: Patient involvement



Individual: the extent to which patients and their families or caregivers, whenever appropriate, participate in decisions related to their condition (e.g. through shared decision-making, self-management) and contribute to organisational learning through their specific experience as patients [in patient safety: reporting adverse events or participation in root cause analysis after an incident]

Collective: the extent to which patients, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation, design and delivery.

(adapted from PaSQ and Value+)

- Micro
 - Individual patient, relationship with health professional, family context
 - e.g. self-management skills, shared decision-making process...
 - HCP are a very significant interface with the healthcare system, (dis)empowerment often manifests at this juncture
- Meso
 - Health care organisations / environments, care delivery processes can be (dis)empowering
 - e.g. design of the environment, how quality is assessed, patient feedback systems...
- Macro
 - Policies, programmes at national (regional) and EU level
 - e.g. information to patients, patients' rights laws, EU legislation, health professionals' training curricula...