

3rd WP7 meeting
Istituto Superiore di Sanità, Roma
July, 2-3, 2015

Patient Empowerment: a lever for change

Putting truly the patient at the centre
of health policy



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European Patients' Forum

Mission and Vision of EPF

European Patients' Forum:

- umbrella organisation
- active since 2003
- 65 member organisations



Our Mission!

- “To ensure that the patient community drives health policies and programmes that are adapted for their final users, patients.”

A Definition of Patient Empowerment

“ A **multi-dimensional process** that helps people **gain control** over their own lives and increases the capacity of people to act on issues that **they themselves define as important**. ”

Luttrell et al. (2009), Understanding and operationalising empowerment. Overseas Development Institute working paper.

Three levels:

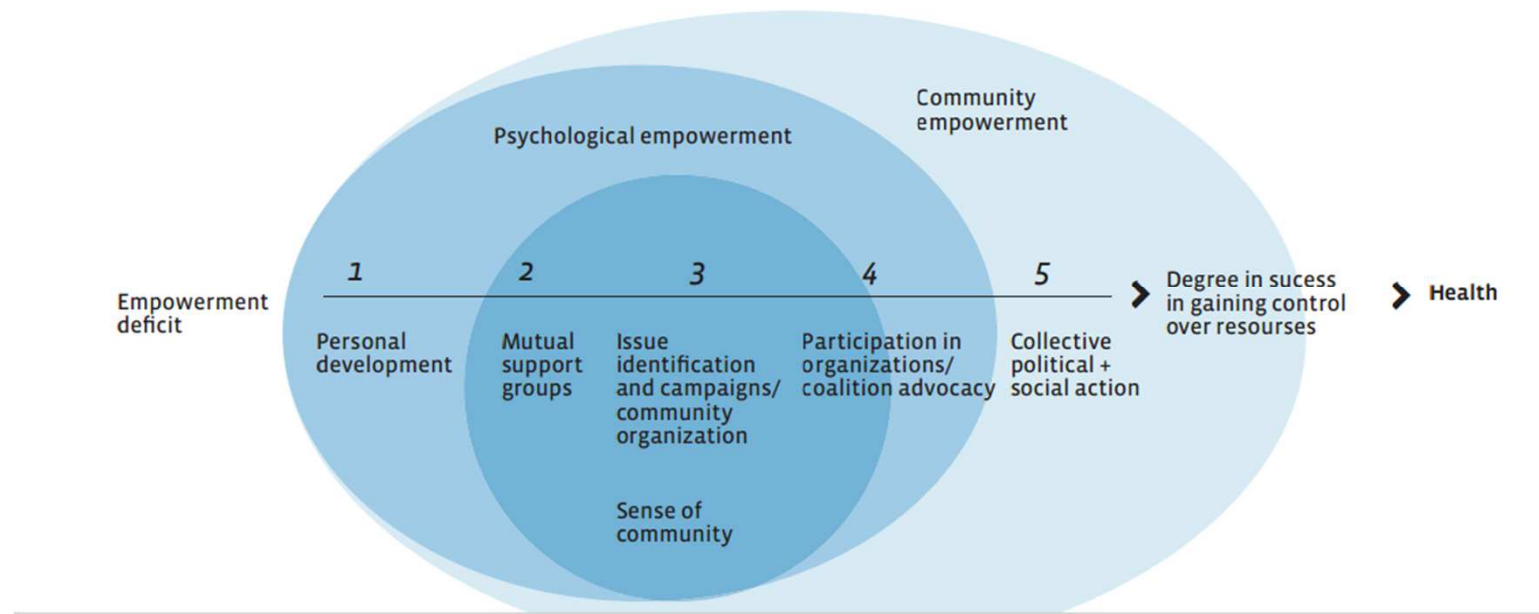
- Micro (individual patient)
- Meso (organisational level)
- Macro (policy level)



Personal
empowerment

Community
empowerment

Individual and Community Empowerment



Model of the critical components of community empowerment and the process by which it may be achieved (Rissel, 1994, s 43)

(Dis)empowerment is a major issue

Burden of chronic disease

Impacts of illness: physical, psychological, emotional, social, financial ...

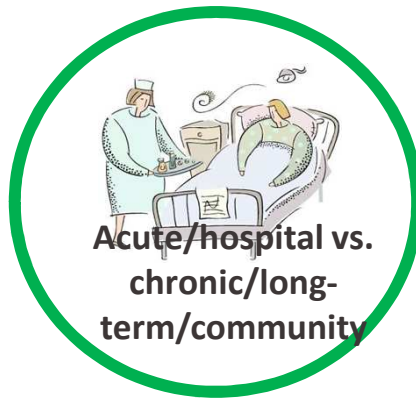


Health system difficult to navigate:
patients often feel disempowered in their interactions with “the system” – having to fight to get what they need

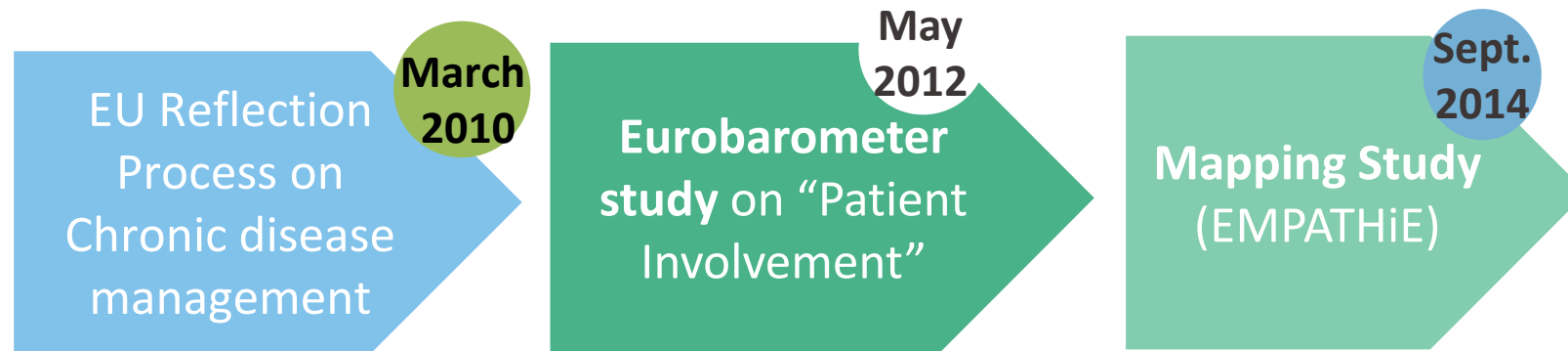
(Dis)empowerment: contributing factors

- **Micro level:**
 - Lack of communication between patient and healthcare professional
- **Meso level:**
 - Care delivery processes and design of the environment
- **Macro level:**
 - (Lack of) Information to patient
 - Implementation of patients rights laws
 - Opportunity for patients to participate in health policy
 - (Lack of) Transparency of the system

EU Policy challenge: Health systems



EU Policy Context



Chronic disease patients are *more knowledgeable and motivated* to be involved in their care – also *more critical* of health system



EU Policy Context

Patient-centredness recognised as a key dimension of quality



Expert panel opinion on **EU's future quality of care agenda** (incl. EPF)

Case for further work at EU level to define and measure it

WWW.CHRODIS.EU



"Pockets" of empowerment in existing EU regulations and soft laws

Cross-border healthcare

Quality and Safety of medicines

Medical devices

EPF

Self-management: a networking approach



ENOPE – European Network for Patient Empowerment

An informal network of like-minded organisations promoting patient empowerment through evidence-based programmes and innovative action

Implementing evidence-based programmes on chronic disease self-management (based on [Stanford model](#))

Organising international conferences and events

Advocacy and awareness-raising, training for CDSMP trainers

Good practice

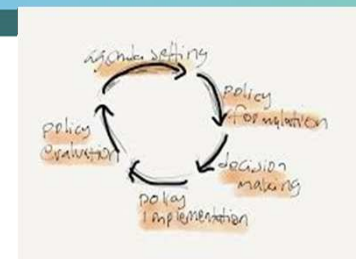
Designing care around patient needs



**Patient =
Expert**



Patient Experience ≠
patient satisfaction
surveys



Involve patients
throughout the
policy cycle



Involve POs at
provider AND policy
level



EPF: **Value + model**
to facilitate patient
involvement

**Patient
involvement is
key to
developing
services so they
really meet the
needs of (all)
patients**

Patient-centred innovation



Innovation that is important for patients

- Priority-setting for research
Better alignment of innovation with real needs

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Need to involve patient throughout the innovation chain

Co-design research/patient-centred clinical trials, pricing and reimbursement decisions...

- Better quality research results
- Strengthened trust and acceptance of research

Patient involvement in regulation



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH



"patient groups ... have helped to provide valuable insights"

"Engaging with these stakeholders gives the Agency and the public more confidence and reassurance in its outcomes."*

since 2005

Patients & Consumers' Working Party (PCWP)

34 POs

Full members of MB, COMP, PDCO, CAT and PRAC

Pilot phase: Observers at CHMP

Assessment of EPARs, PIL, safety information, scientific advice, protocol assistance...

- ➔ **Patients at all capacity levels**
- ➔ **"Level the ground" support system**

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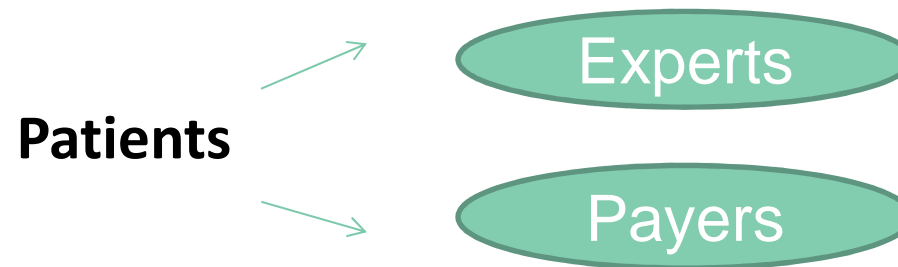
* European medicines agency: Fifth report on the interaction with patients' and consumers' organisations (2011) published in 19 September 2012.



Patient Involvement in HTA

WHY?

Because patients are concerned with the impact new health technologies have on their lives



What do patients ask for?

- Involvement, Transparency, Accountability to trust HTA
- More informed decision: Patients can tell how the technology better fits into their daily lives
- Consideration of quality of life and extra-clinical benefits

WP7 Diabetes: a case study on strengthening health care for people with chronic diseases.

An example of policy action at European level

the EPF Campaign on Patient Empowerment

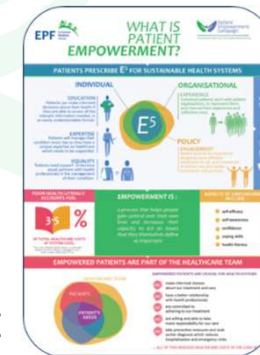
Campaign on Patient Empowerment



One-year patient-led campaign



- Why? To promote a common understanding and call for an EU strategy on Patient Empowerment
- Who? EU health Stakeholders & decision-makers
- When?
 - May 2015: major launch conference
 - November 2015: development of a Roadmap & Charter to advocate at the EP
 - June 2016: Exhibition at the European Parliament



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

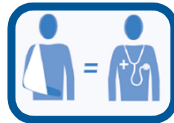
Campaign on Patient Empowerment

Campaign messages

- EDUCATION



- EXPERTISE



- EQUALITY



- EXPERIENCE



- ENGAGEMENT



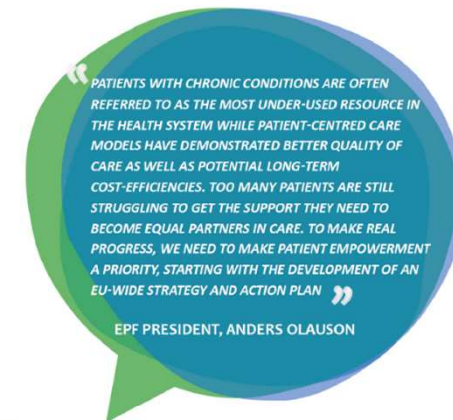
→ Patients prescribe **E⁵** for Better Health Systems!

Campaign on Patient Empowerment



Want to get involved?

- Show your support to the campaign
- Spread the word!
- Share good practices
- Share your testimonial



EPF PRESIDENT, ANDERS OLAUSON



www.eu-patient.eu/campaign/PatientsprescribE/

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

The Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle (JA-CHRODIS)*



Co-funded by
the Health Programme
of the European Union

* This presentation arises from the Joint Action addressing chronic diseases and healthy ageing across the life cycle (JA-CHRODIS), which has received funding from the European Union, under the framework of the Health Programme (2008-2013).