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CHRODIS+

IMPLEMENTING GOOD PRACTICES FOR CHRONIC DISEASES

Belgrade, December 3-4, 2018

WP7

Patient Involvement and Patient Empowerment

Valentina Strammiello, European Patients' Forum

 @EUCHRODISplus

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About EPF



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A strong European Patient Movement...



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Mission and vision



Our Vision!

“All patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.”



Our Mission!

“be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access to care in Europe.”

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Our Strategic Goals



Health Literacy



Healthcare Access and Quality



Patient involvement



Patient Empowerment



Sustainable Patients' Organisations



Non-discrimination



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Patient Involvement and Patient Empowerment: why do we need them?



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Patient Involvement is:



A right!



“The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.”

Alma-Ata declaration primaires – Principle IV (1978, WHO)

Necessary

Looking at the current challenges :

- **Health systems need to change** – chronic disease, ageing, technology, financial constraints – sustainability challenge
- Health / social system is difficult to navigate
- **The patient’s role is undergoing a transformation:** from passive recipient to active and equal partner

Useful

- Patients have unique knowledge that comes from experience
- Make sure that the services are patient centric
- For a better and more sustainable healthcare system

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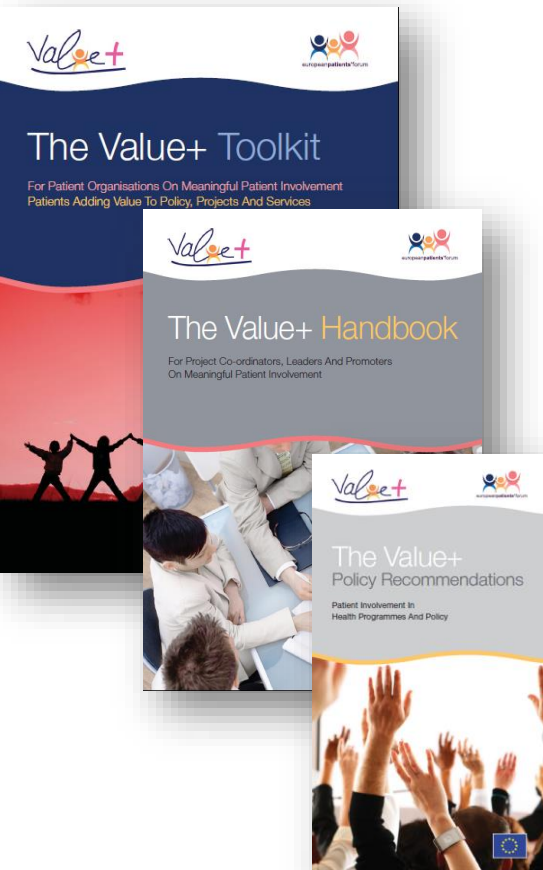


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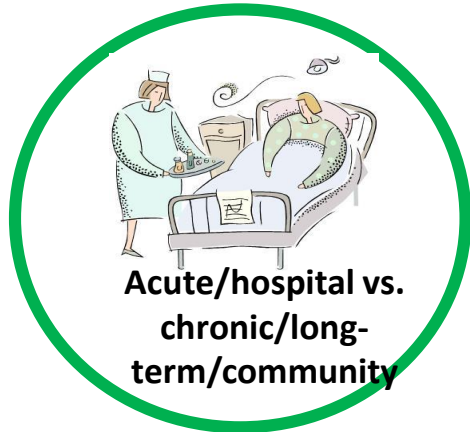


What is “meaningful patient involvement”?

- **Meaningful Patient Involvement** = patients take an active role in activities that impact patients, *because* of their specific knowledge and relevant experience that they bring to the process.
- Patients’ *experiential expertise* is valued and they are seen as **genuine partners**
- Patients’ contribution is recognised and adequately compensated
- It is **planned in advance, “built in” to the design, resourced, and evaluated for its impact** from the perspectives of all participants
- Patients are not approached at last minute as a “tick box” exercise
- The opposite of tokenism – collaboration & partnership
- **EPF Value+ Toolkit and Handbook** offer guidance how to realise MPI – to be updated in the near future



EU Policy challenge: Health systems



European health systems: Sustainability challenge



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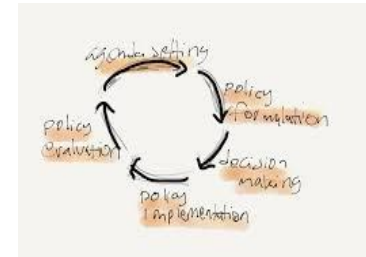
Designing care around patient needs



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



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(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



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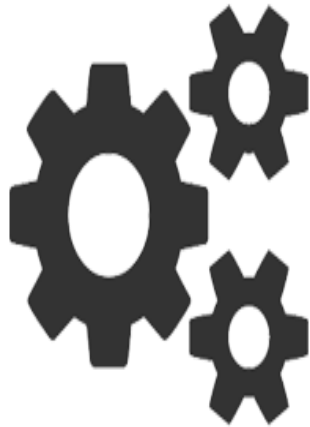
OK
but
what is
Patient
Empowerment?



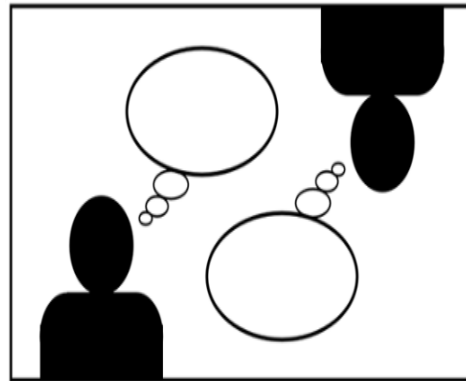
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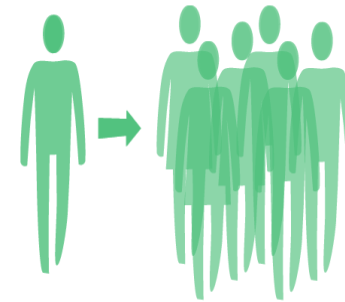
Our definition of empowerment



A process: non-binary, non-linear



Cannot be imposed from top-down



Individual + Collective



Patient Empowerment vs Patient Involvement



Two different things

Patient empowerment is *a process* that helps patients gain control over their lives, increasing their *capacity to act* on issues that *they themselves* define as important”

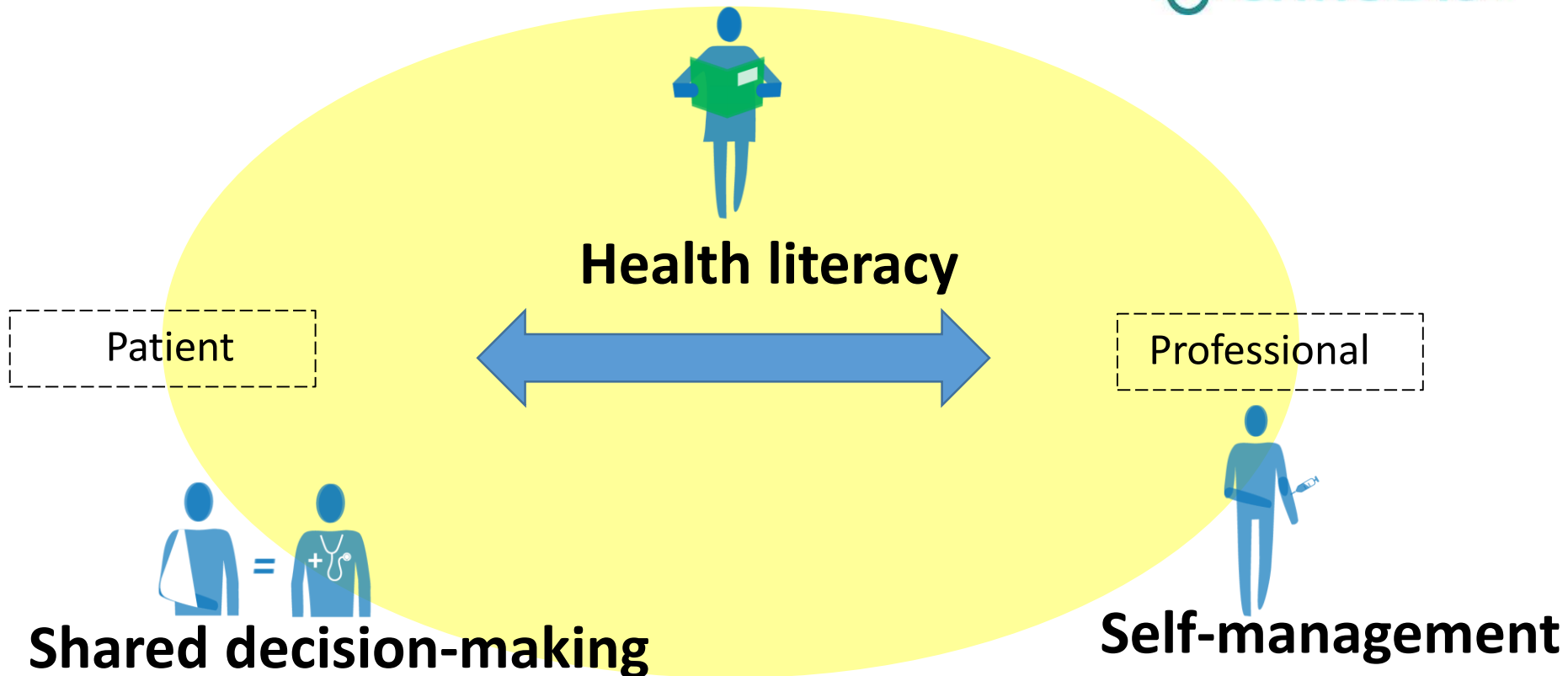
(Adapted from JA-PaSQ, 2012)

“Patient involvement is the idea of involving patient on a individual and systemic level in decisions related to their conditions and the shaping of the healthcare system”

(Adapted from JA-PaSQ, 2012)



3 key dimensions of empowerment



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Aspects of empowerment



- Support tools (bottom up) & enabling environment (top down)
- Participation to the extent that patients wish
- Confidence, self-esteem and coping skills to manage impact of illness in everyday life
- What it is **not**: consumerisation; burden; blame



Our definition of empowerment



Everyone agrees: patient empowerment is good

BUT!

...Does everyone see in the same way?

... Does everyone have the same goal?

... How to achieve real empowerment?

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Do patients want to be more empowered?



- **92%** of patients are willing to play a more active role in managing their own condition

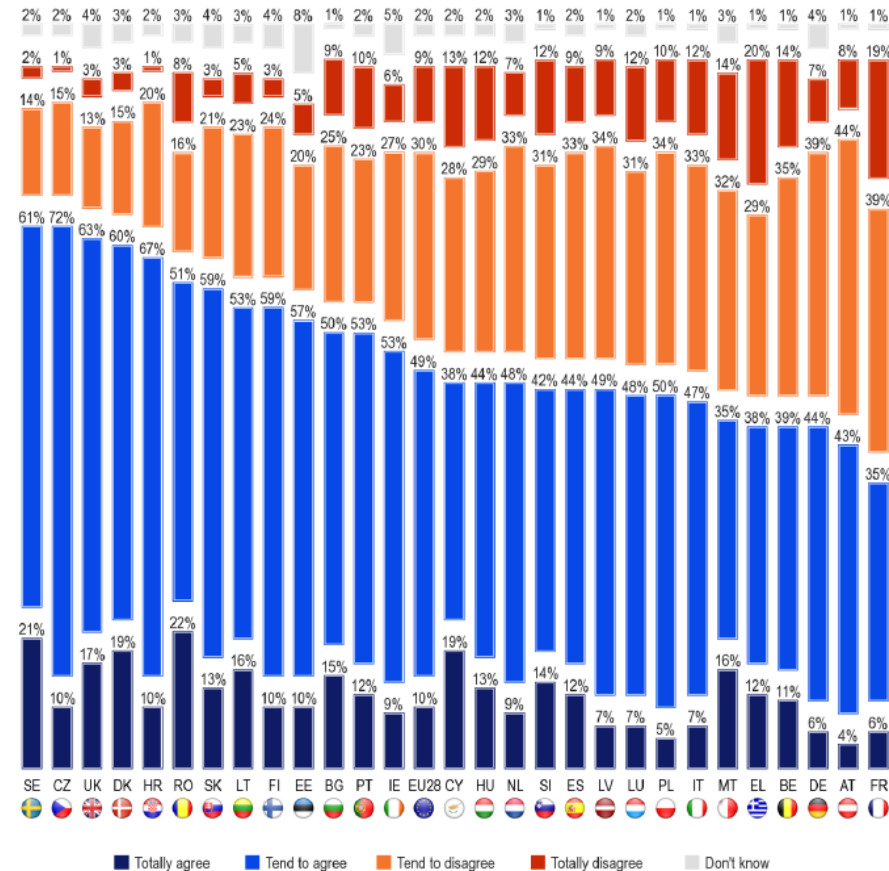
- **60%** of patients (and 70% of HCP) would be willing to use eHealth in the short-medium future

- ... but only **48%** think they are ready to handle the additional responsibilities presented by eHealth

- Similar trends for HCPs



Q21.7. For each of the following statements please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree. You trust the information from the Internet to make health-related decisions



© Eurobarometer, Sept 2014

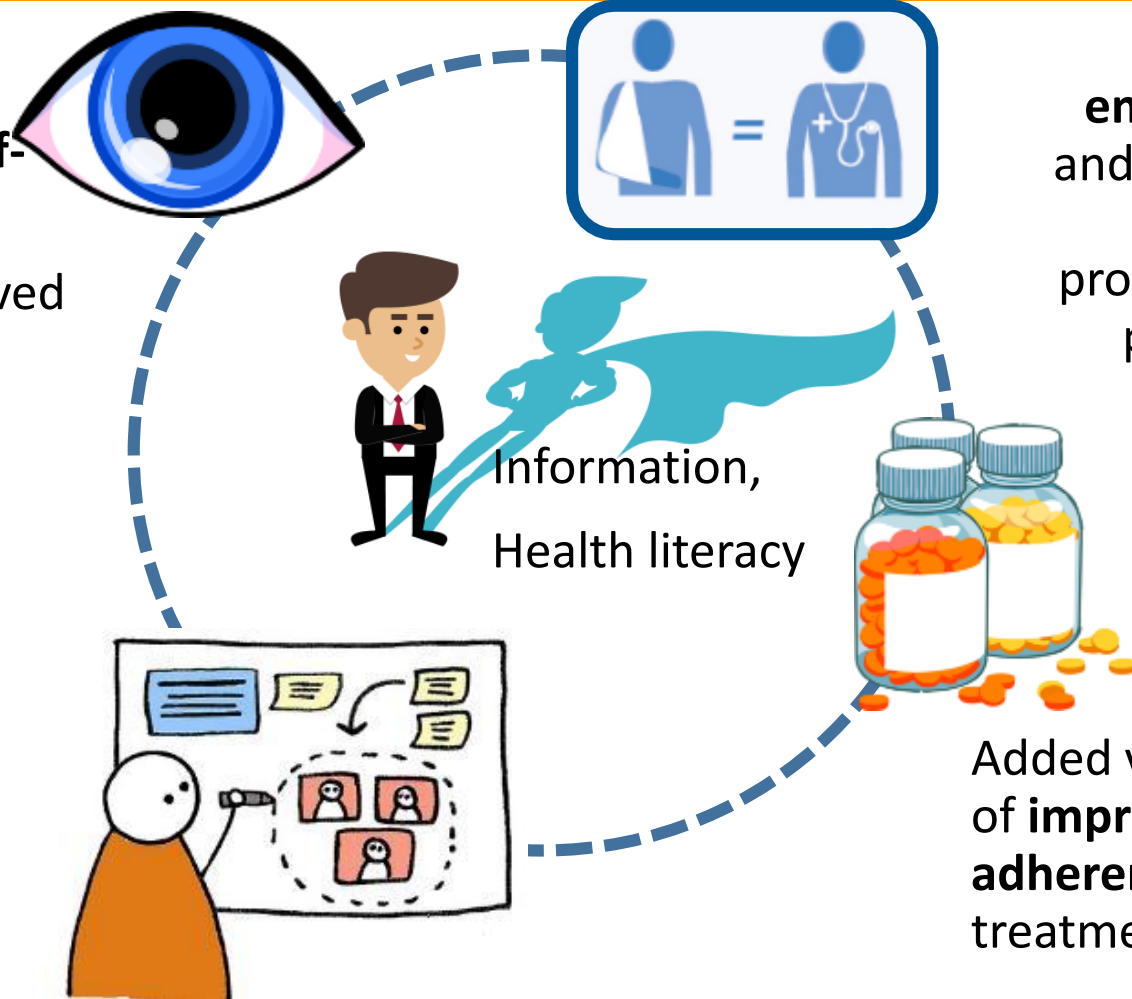


Patients' expectations of digital health care

Facilitates chronic disease management, **self-management**

And leads to improved **quality of life**

Patient centred care as opposed to disease centred and **better integration** of healthcare



Patient empowerment and involvement in the care process as equal partners with HCPs

Added value in terms of **improved adherence** to treatment



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EPF Campaign on Patient Empowerment

For who? Patients, EU health stakeholders & decision-makers

The message: “Patients Prescribe”

- EDUCATION
- EXPERTISE
- EQUALITY
- EXPERIENCE
- ENGAGEMENT



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

Campaign on patient empowerment

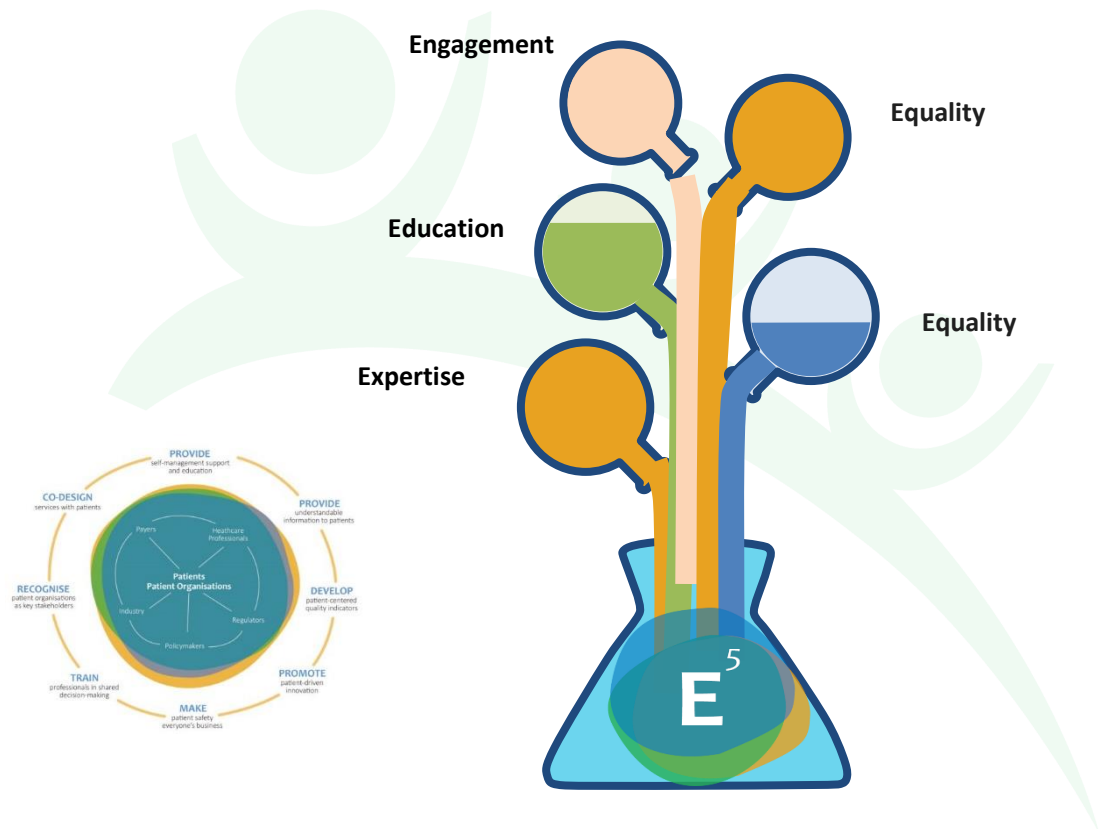
01 **Education.** Making informed decisions with the right information and support.

02 **Expertise.** Patients' unique expertise derived from lived experience is a valuable resource.

03 **Equality.** Equal partnership between patients and professionals.

04 **Experience.** Patients' organisations channel the patient community's collective voice.

05 **Engagement.** Patients as well as the whole society for better health services and policy.





- The “Patients’ Charter”
 - Outcomes of the conference
 - Approved by EPF Members
 - **Patient Empowerment in 10 points**
- A “Roadmap to Patient Empowerment”
 - Outcomes of the conference
 - **Propose concrete actions**
- [A toolkit on Patient Empowerment](#)

An example| I' m still me

The I statements

I'm still me
... a narrative for coordinated support for older people

Independence

- I am recognised for what I can do rather than assumptions being made about what I cannot
- I am supported to be independent
- I can do activities that are important to me
- Where appropriate, my family are recognised as being key to my independence and quality of life

Community interactions

- I can maintain social contact as much as I want

Care and support

- I can build relationships with people who support me
- I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me
- Taken together, my care and support help me live the life I want to the best of my ability

Decision making

- I can make my own decisions, with advice and support from family, friends or professionals if I want it

The third narrative on person-centred, coordinated care describes the way older people want high quality coordinated care to support them, from their perspective.

EPF's commitment

- Follow up on the Patient empowerment campaign → initiative on “mainstreaming” meaningful patient involvement in all areas of health systems
- The “innovation agenda” links with the “empowerment agenda” → towards a health(care) policy and systems that is person-centred and needs-driven
- EPF will develop a **patient-led framework on good practice in patient involvement – what “good” looks like:**
 1. Health system: e.g. co-design, evaluation, research, patient-driven technology solutions...
 2. Pharmaceutical R&D: the PARADIGM project
 3. Continued patient empowerment through EUPATI



“From doing to ...
to doing (better) with patients”



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Thank you for your attention

The Joint Action on Implementing good practices for chronic diseases (CHRODIS PLUS)

This presentation arises from the Joint Action CHRODIS PLUS. This Joint Action is addressing chronic diseases through cross-national initiatives identified in JA-CHRODIS to reduce the burden of chronic diseases while assuring health system sustainability and responsiveness, under the framework of the Third Health Programme (2014-2020). Sole responsibility lies with the author and the Consumers, Health, Agriculture and Food Executive Agency is not responsible for any use that may be made of in the information contained therein.



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