

Preamble/background

Patient empowerment is at the root of our vision and mission, as reflected in the European Patients' Forum's Strategic Plan 2014-2020:

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.

This Charter of patient empowerment has been developed by the European Patients' Forum and our member patient communities across Europe in the context of the campaign on patient empowerment. It encapsulates the fundamental principles of patient empowerment – by patients, for patients (and others). It is about what really matters. The Charter can be used as an advocacy tool to promote action and culture change, whether “on the ground” or at policy level.

Chronic diseases present a sustainability challenge for European health systems. This is usually seen in terms of funding – our health systems cannot cope financially with chronic conditions and the ageing population. But from a patient's perspective, the health systems are unable to cope because they do not meet the needs of patients with chronic conditions well.¹

Although financing of the health system plays a role (e.g. in terms of providing adequate numbers of healthcare professionals, appropriate therapeutic choices, comprehensive reimbursement...), often the system challenge has more to do with the way healthcare is delivered and services organised. Fragmentation of care is a major problem for patients, who often have to “fight the system” just to get the care they are entitled to.²

To cope with chronic diseases, health systems need to stop being disease-centred and adopt a person-centred approach, where self-management, community and specialist medical care and social care are integrated in highly personalised solutions centred on the needs of the patient. The patient, in this vision, is an active and equal partner and truly a “co-producer” of well-being. This implies changes at all levels in how care is structured and delivered. It also implies a profound change in medical culture and societal attitudes. And, it implies the empowerment of patients and their participation – not only in their own care, but also through patient organisations in policy-making, in evaluating and co-designing care services, and in research to develop new therapies that meet patients' needs more effectively.

The first European mapping study of patient empowerment, “EMPATHIE” (2014) identified three key areas of empowerment: information/education; shared decision-making; and self-management. These areas are mutually reinforcing, complementary and to some extent overlapping. Aspects of empowerment include self-efficacy, self-awareness, confidence, coping skills, health literacy, etc.^{3,4}

¹ Although the word “patients” is used for brevity, it should be interpreted as including the family as well. Moreover, although EPF as an organisation represent patients with chronic conditions, the same principles of empowerment appear to apply to any healthcare user – therefore in the context of this Charter any person coming into contact with the health system can be considered a “patient”.

² See for example [EPF paper on chronic diseases](#) (2012) and [healthy and active ageing](#) (2011).

³ The final summary report of EMPATHIE is available at http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf.

⁴ Health literacy refers to the (cognitive and social) skills of people that determine their ability and motivation to access and understand health-related information, judge its quality or trustworthiness, and to take appropriate action – e.g., regarding lifestyle choices, self-care and so on. For more information, see “Health Literacy. The Solid Facts” (WHO, 2013) available at http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf

EPF currently uses the following definition of empowerment:

Empowerment is “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.” Collective empowerment is “a process through which individuals and communities 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.”⁵

Empowerment is therefore *a goal as well as a process*. We can think of empowerment as a relational concept: on the one hand, an internal process whereby individual people increase their capacity to live well with chronic conditions in their daily life, as well as act within the healthcare, social, work and other environments. On the other hand, a systems issue, whereby the processes and structures people come into contact with (for example, but not exclusively, in the healthcare environment) can be empowering or disempowering.

At the individual level, (dis)empowerment often manifests in the patient-professional relationship; at organisation level, care processes or the design of the environment can be (dis)empowering; and at macro-level, factors that contribute to (dis)empowerment can include information to patients or the lack of it, implementation of patients’ rights laws, (lack of) opportunities for patients to participate in health policy, (lack of) transparency of the system, etc.

It is therefore important to bear in mind the collective dimension of empowerment, namely the importance of meaningful involvement of patient representatives and patient organisations in health policy and service design and evaluation with the aim to change the system to work better for all patients.⁶

It is neither simple nor necessarily linear: a patient can feel empowered in certain situations and disempowered in others. The 2015 EPF thematic campaign on patient empowerment is taking forward the key outcomes of EMPATHIE. EPF’s campaign aims to promote understanding of what patient empowerment means *from the patient perspective*. We want to raise awareness among political decision-makers and stakeholders and commit them to concrete activities to promote the empowerment and meaningful involvement of patients as equal and respected partners at all levels in healthcare.⁷

The key message of our campaign is “Patients prescribe E⁵ for sustainable health systems”. The 5 E’s of empowerment are:

- Education: We can make informed decisions about our health if we have the appropriate education and information tools;
- Expertise: We self-manage our condition every day, so we have a unique expertise and experience to contribute to the design and reform of health systems;
- Equality: We can make decisions about our health in equal partnership with health professionals;
- Experience: We are part of patients’ organisations that represent us and channel our experience and our collective voice;
- Engagement: We need to be engaged in co-designing more effective services and in research into new treatments – but we also need the engagement of wider society.

⁵ Developed for the EU Joint Action On Patient Safety and Quality of Care (www.pasq.eu), adapted from Luttrell et al. 2009 and the Duque project (www.duque.eu)

⁶ See [the EPF briefing paper](#) on patient empowerment (2015) for more elaboration of the concept of empowerment and other related concepts, such as patient involvement and health literacy.

⁷ See www.eu-patient.eu/campaign/PatientsprescribE/

In addition, we consider a sixth “E”, namely Equity. It is only possible to be an empowered patient if one first has access to high quality, patient centred care.

A note on patients’ rights

This Charter is a list of principles, not rights, although it relates closely to patients’ rights, which are in themselves derived from human rights. We recognise that a right is only meaningful if a person is able to exercise it in practice. One of the aims of empowerment is to equip people with awareness about their rights and the skills and tools to make use of those rights. Empowering practices (and elimination of disempowering ones) are needed in order to turn theoretical rights into a reality that patients can “live” in all their interactions with health professionals, healthcare organisations and the wider system.