Charter on Patient Empowerment

2nd Round of Consultations

# Introductory note

One of the concrete deliverables of the EPF thematic campaign on patient empowerment (2015-2016) is a patient-led Charter on Patient Empowerment. The Charter should encapsulate the fundamental principles of patient empowerment – “what really matters” to patients. It is more about principles than concrete actions. However, it can be used as an advocacy and political tool to promote actions on the ground and at policy level, during and after the EPF campaign, which concludes with an event at the European Parliament in June 2016. The aim is that this document should be co-developed with and “owned” by patient communities across the EU, and supported by other stakeholders.

**Format**

The Charter will be designed as a two-sided poster comprising 10 points – the “ten commandments” or 10 principles of empowerment. The 10 principles will be displayed alone on one side and together with short explanatory paragraphs and references/external links on the other side. Each heading statement in bold should reflect one fundamental principle. The explanatory paragraph underneath provides nuance, context and/or examples.

We will also have an online “leaflet version”, which will incorporate the preamble.

In future we envisage that the Charter will be translated into some other languages.

**About this 2nd draft version**

A first draft Charter was drafted based on key messages from the EPF conference on patient empowerment held on 20-21 May 2015 and the outcomes of the mapping study on patient empowerment, EMPATHIE. The EPF Working Group on Patient Empowerment discussed the draft and their input was incorporated. Subsequently the draft was sent again to the working group as well as the wider EPF membership and participants of the conference for feedback. This second draft incorporates feedback from that round of consultation.

**Next steps**

The present draft will be sent for a second round of consultation until end of February 2016. The final version of the Charter will be approved by the EPF board. During the 2016 Annual General Meeting we will present and celebrate the Charter and invite members to give us some nice ideas on how they will use it in future activities.

# 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]](#footnote-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]](#footnote-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, 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]](#footnote-3),[[4]](#footnote-4)

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]](#footnote-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 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 evaluation and design with the aim to change the system to work better for all patients.[[6]](#footnote-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]](#footnote-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.

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.

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# THE PATIENTS’ CHARTER OF EMPOWERMENT

Draft

1. **My health status does not define me as a person / I am more than my health status**

Healthcare is fundamentally about human interactions. For patients, being treated with respect, dignity and compassion and seen as human beings with a life beyond their health condition is a starting point of empowerment.

Notes: the two alternative statements have been proposed for point 1. Please indicate which you prefer and/or any adjustment you suggest.

“Holistic” was removed as someone said it would not be easy to understand/translate.

1. ***I am / can be* empowered to the extent I wish to be, regardless of who I am**

No-one is beyond empowerment, though some people may need more support. The right strategies should be adopted for specific needs, particularly to encourage the voices of those who may be in a vulnerable or marginalised situation. All patients should be supported and enabled to have a say in their care, according to their capabilities and wishes, and regardless of their age, gender, ability, ethnic origin, religion or belief, socio-economic situation, sexual/gender orientation, identity, expression or characteristics. If a patient wishes to delegate a decision to someone else, this should be respected.

Notes: “I am” (which is more active) was suggested as opposed to “I can be” (which refers to potential). Please indicate which you prefer.

Is “regardless of who I am” clear enough without the explanation?

1. **My knowledge and experience form part of all decisions about my health / I am an equal partner in all decisions related to my health**

All health-related decisions, whether long-term care planning for complex needs or one-off treatment/prevention decisions, should be the result of a shared decision-making process between the patient and the healthcare team. Patients manage their chronic condition themselves most of the time. Patients and professionals need to build a relationship based on mutual respect, share information and engage as equal partners in dialogue about treatment preferences, priorities and values.

Notes: the two alternative statements have been proposed. Please indicate which you prefer and/or any adjustment you suggest. (“ Nothing about me without me” was also suggested, but we felt that is a too familiar a slogan from other contexts.)

1. **I have the information I need in an easily understandable format, including my own health records.**

Patients have the right to receive information they need and want, in the right amount and at the right time, in simple enough language to enable them to make choices according to their wishes. The right not to receive information should be respected. In addition, patients should be able to freely access their own health records and be considered the co-owner of their data, having a say in how that data is shared and used. Information for patients should be co-designed with patients to ensure it is good quality.

Note: to clarify the distinction between points 4 and 5, this point is more about the right to information. The language has been slightly simplified. The message about use of patients’ data has been nuanced to be fully in line with EPF’s position on the EU DPR.

1. **My health professionals, organisations and the wider system recognise and promote health literacy for everyone**

Health literacy is more than information: it is about being able to search out, judge and use health information to make good health decisions in all areas of life. Low health literacy affects health and can reinforce other inequalities. It is an individual challenge but also a system challenge: healthcare professionals, organisations and systems are often difficult for people to “navigate”: they need to adapt so that all users, including people with lower health literacy, are able to understand and easily access the services they need. Tools include simplified messaging, visual and other ways of presenting information, and sensitivity to the different needs of groups and individuals. The WHO (2013) recommends that health literacy should be recognised as something people need to function well in modern society, and that health literacy programmes should form an essential part of strengthening health systems.

Note: this point has been revised to clarify it, focusing on the system rather than the individual. The explanatory paragraph will be slightly shortened.

1. **I have the ongoing support I need to manage my own care**

Individual patients’ needs to manage their care and life in the context of their personal goals, values and circumstances is the starting point of integrated care. Patients should be offered the whole range of care options that might be relevant so as to make a meaningful choice among them. The healthcare team should include the right functions/roles, skills and knowledge to support effective self-management. Self-management education should be made widely available in the community as part of integrated chronic care.

Note: this point has been refocused on self-management which is an important dimension of empowerment. The point was made in consultation that the original wording was too focused on access.

1. **My experience is a vital measure of healthcare quality**

The patient experience should be adopted as a key metric in assessing the quality of healthcare. This does not mean tick-box exercises such as “satisfaction surveys”, but meaningful (including qualitative) patient-centred process and outcome measures. Indicators for assessing healthcare’s quality should be defined by patients themselves, and not by what providers assume is important for patients. Patients’ feedback should be encouraged, listened to, and acted upon.

1. **I can participate in evaluating and co-designing healthcare services so they work better for everyone.**

Meaningful patient involvement as defined by EPF[[8]](#footnote-8) is based on the premise that patients have a specific expertise and experiential knowledge: “Only the patient sees the whole journey.” Patients can identify gaps in provision, but also superfluous or unwanted services, helping make healthcare more effective and efficient. Patients also have a fundamental democratic right to be represented at all levels of the planning, delivery and review of healthcare services, policy and legislation; their involvement should be built into formal structures and processes, and it should be valued.

Note: the word “can” was challenged by one person, but in our view it expresses potential or opportunity; also not everyone wants to participate at that level – so we keep it.

1. **Through patient organisations, my voice becomes part of a bigger, united voice.**

Individual patients can be powerful advocates based on their own personal experiences and circumstances. In addition, patient organisations put forward views representing a constituency of patients, through a consultative, democratic process. Patient organisation representatives are chosen to represent patients’ views at the policy level, and they understand that they are representing a broader perspective than just their own. Patient organisations should be systematically supported, including financially, so they can accomplish these tasks effectively.

Note: this point was challenged by one person who pointed out that great individual patient advocates are not always part of patient organisations. That is true, and we strengthened the first sentence to reflect that. Nevertheless, EPF is a membership-based organisation and the statement as it is currently formulated is strongly supported by our internal working group members.

1. **Empowerment needs equity of access / I fight for equity in health for all / *something like that***

To be an empowered patient, one first needs access to high-quality care. Many patients are not getting even basic treatment. Our vision as a patient community is for all patients to have equitable access, without discrimination, to high-quality healthcare that is designed to meet their needs. This requires political change to ensure the rights of all patients are respected, to fight the inequalities that persist in health across the EU, and to make health a priority in all policies at national and EU levels.

Note: equity of access and fair treatment was a recurring point in the feedback received. We propose to formulate the last point around equity, as it is another “E word”, which is also a prerequisite of the other E’s at the end of the day. This point can function as a conceptual bridge to the forthcoming access campaign as well.

Please suggest a powerful statement that ideally keeps the “I” but connects it to “we” / “all”!

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”. [↑](#footnote-ref-1)
2. See for example [EPF paper on chronic diseases](http://www.eu-patient.eu/globalassets/policy/chronic-disease/epf-chronic-diseases-consultation-response-2012.pdf) (2012) and [healthy and active ageing](http://www.eu-patient.eu/globalassets/policy/ageing/ageing-epf-response-integrated-final.pdf) (2011). [↑](#footnote-ref-2)
3. The final summary report of EMPATHIE is available at <http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf> . [↑](#footnote-ref-3)
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> [↑](#footnote-ref-4)
5. Developed for the EU Joint Action On Patient Safety and Quality of Care ([www.pasq.eu](http://www.pasq.eu)), adapted from Luttrell et al. 2009 and the Duque project ([www.duque.eu](http://www.duque.eu)) [↑](#footnote-ref-5)
6. See [the EPF briefing paper](http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/epf-briefing-paper--patient-empowerment.pdf) on patient empowerment (2015) for more elaboration of the concept of empowerment and other related concepts, such as patient involvement and health literacy. [↑](#footnote-ref-6)
7. See [www.eu-patient.eu/campaign/PatientsprescribE/](http://www.eu-patient.eu/campaign/PatientsprescribE/) [↑](#footnote-ref-7)
8. “Patients *take an active role in activities or decisions that will have consequences for the patient community*, because of their *specific knowledge and relevant experience as patients*. The involvement must be planned, appropriately resourced, carried out, and evaluated as to its outcomes, impact and the process itself, according to the values and purposes of all participants.” (EPF project “VALUE+”, 2009). [↑](#footnote-ref-8)