

The Patients' Charter on Patient Empowerment

1. I am more than my health condition
2. I am empowered to the extent I wish to be
3. I am an equal partner in all decisions related to my health
4. I have the information I need in an easily understandable format, including my own health records
5. My health professionals and our health system actively promote health literacy for all
6. I have the ongoing support I need to manage my own care
7. My experience is a vital measure of healthcare quality
8. I can participate in evaluating and co-designing healthcare services so they work better for everyone
9. Through patient organisations, my voice becomes part of a bigger, united voice
10. Equity and empowerment go hand-in-hand - I want a fair deal for all patients

The Patients' Charter on Patient Empowerment

1. I am more than my health condition

Healthcare is fundamentally about human interactions. Being treated with respect, dignity and compassion and being seen as a human being with a life beyond one's health condition or status is a starting point of empowerment.

2. I am empowered to the extent I wish to be

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 our age, gender, ability, ethnic origin, religion or belief, socio-economic situation, sexual/gender orientation, identity, expression or characteristics. If patients wish to delegate a decision to someone else, this should be respected.

3. 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.

4. 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 format 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.

5. My health professionals and our health system actively promote health literacy for all

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.

6. 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 values, goals, family and other circumstances should be at the centre of a joined-up approach to care. Patients and families should be offered all relevant options in order to make meaningful choices, and the health/social care team should include the right 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 disease care.

7. 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 measures. Indicators for assessing the quality of healthcare should be defined also by patients themselves, and not only by what providers assume is important for patients. Patients' feedback should be actively encouraged, listened to, and acted upon.

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

Meaningful patient involvement as defined by EPF is based on the premise that patients have a unique expertise and 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.

9. 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. Patient organisations should be systematically supported, including financially, so they can accomplish these tasks effectively.

10. Equity and empowerment go hand-in-hand - I want a fair deal for all patients

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 health and social care 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.

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