

THE PATIENT ORGANISATIONS' MANIFESTO

towards a truly participatory, democratic, and impactful involvement of patient organisations

The European Patients' Forum, on behalf of its member organisations,

As European citizens,

We expect EU institutions and national governments to recognise the value of early and meaningful involvement of patient organisations in policy development, health research, and healthcare practice. Structured patient engagement from the earliest stages can draw on the unique expertise and lived experience of patients and their communities to ensure better alignment with real patient needs, improved patient information and adherence, improved awareness and trust, and reduced costs to patients and to healthcare systems.

We expect national governments and EU institutions to actively seek structural input and collaboration from communities of patients, persons living with chronic conditions, and carers through their representative organisations.

We expect national governments and EU institutions to demonstrate their commitment towards person-centric healthcare systems through the implementation of ten fundamental principles of patient organisation participation:

Strengthen the framework for engagement

1. To demonstrate and strengthen public participation in the design, implementation, and evaluation of national and regional health policy, patient organisations should be actively engaged, to increase the accessibility, legitimacy, transparency, and accountability of the health system.
2. Seek and support the active engagement of patient organisations and embed their role in the formulation, evaluation, and decision-making processes at European, national and regional level, to foster solidarity, equity, mutual trust, sustainability, empowerment, and accountability.

Consultation and partnership

3. Integrate a dialogue with patient organisations, at the appropriate geographical level, to identify the most effective channels and mechanisms that foster meaningful and viable participation for NGOs. Where relevant, existing tools to support patient involvement should be utilised.
4. Involve patient organisations in the development of policies which are complementary to the health sector and quality of life, such as social affairs and social environment.
5. Enable patient organisations to be involved in all stages of policy development, including evaluation. Proactively seek and embed patient organisations' feedback on the impact of health policies on health equity.
6. Promote a genuinely democratic framework by institutionalising participatory processes and expand opportunities for patient organisations to contribute in a substantial manner.

Operational involvement of patient organisations

7. Actively seek patient organisations' meaningful inclusion in health technology assessment (HTA) and other relevant processes as key and equal stakeholders.
8. Involve patient organisations through formal participation in parliamentary committees, advisory councils, specialised and/or sectoral committees or working groups on health and related policies.
9. Support patient organisations' meaningful involvement by creating conditions for their participation and ensuring they have access to unearmarked (unrestricted), solid and long-term operating funding for their daily activities. Work with patient organisations to identify an appropriate, sustainable funding model to support their representative functions and role in the policy-making processes described above. Support the sustainability of existing efforts and the availability of resources already developed.
10. Acknowledge and endorse patient organisations as trusted partners for health and digital health literacy, recognising their role in improving patient education as well as in enabling the inclusiveness, capacity and skill building within the patient community across all generations.