



The Value+

Policy Recommendations

Patient Involvement In
Health Programmes And Policy



Value+ was implemented by a Consortium led by European Patients' Forum (EPF) and consisting of the Confederation Health Protection (KZZ) – Bulgaria; Empirica – Germany; the European Institute of Women's Health (EIWH) – Ireland; the European Men's Health Forum (EMHF) – Belgium; the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) – Germany; the Health Policy Center of Lithuania (SPC) - Lithuania and the Spanish Patients' Forum (FEP) - Spain. Collaborating partners: Agrenska Foundation, European Federation of Allergy and Airways Diseases Patients' Associations (EFA), European Multiple Sclerosis Platform (EMSP), Mental Health Europe (MHE), Retina Europe.

The EPF was founded in 2003 to become the collective voice of patients and their families at EU level manifesting the solidarity power and unity of the EU patients' movement. EPF currently represents 40 member organisations – which are chronic disease specific patient organisations working at European level and national coalitions of patient organisations.

EPF reflects the voice of an estimated 150 million patients affected by various diseases in the European Union. EPF's vision for the future is high quality patient-centred equitable healthcare throughout the European Union.

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BACKGROUND

The Policy Recommendations on Patient Involvement in Health Programmes and Policy are one of the results of the two-year project “Promoting Patients’ Involvement in EU Supported Health-Related Projects - Value+” co-funded by the Public Health Programme. Value+ is based on the premise that the meaningful involvement of patients enhances the outcome of health projects, and through that patients can contribute effectively towards patient-centred, equitable healthcare policy throughout the European Union (EU). The focus of the project was thus to assess the status of patient involvement and to exchange information, experiences and good practice among key stakeholders.

Value+ confirmed the added value of involving patients in projects and policy in particular with regard to two fundamental aspects: patients have unique expertise due to living with a specific condition and their experience of healthcare; patient involvement contributes to a more transparent and democratic health policy making process.

We acknowledge as very important steps, policy developments at the European Commission (EC) level regarding inclusion, participation, and empowerment of citizens and patients. Amongst them:

The White Paper **Together for Health: A Strategic Approach for the EU 2008-2013** (October 2007) highlights that citizens’ and patients’ participation and empowerment need to be regarded as core values in all health-related work at the EU level. *“Building on the work on the Citizens’ Agenda, community health policy must take citizens’ and patients’ rights as a key starting point. This includes participation in and influence on decision-making, as well as competences needed for wellbeing, including health literacy”*¹. It is clearly recognized that citizens’ empowerment can also be supported by civil society, including patients’ groups and disease support and advocacy networks.

Patient involvement is also one of the operating principles put forward in the **Council Conclusions on Common Values and Principles** in the European Union Health Systems (June 2006): *“All EU health systems aim to be patient-centred; this means to involve patients in treatment and therapies, to be transparent, to offer them quality information and choice”*².

By grouping various health care related initiatives focused on patients into a single package, the **Europe for Patients campaign** moves towards achieving stronger patients’ empowerment.

The Council of Europe Recommendation No. R (2000) 5 on the development of structures for citizen and patient participation in the decision-making process affecting health care, recommends the governments of Member States *“to ensure that citizens’ participation should apply to all aspects of healthcare systems, at national, regional and local levels”* and (...) *“create legal structures and policies that support the promotion of citizens’ participation and patients’ rights, if these do not already exist”*³.

The Value+ project acknowledges the enormous progress represented by these milestones and the advances related to patient involvement achieved at many levels and in various health arenas. Nevertheless, there remains the concern that there is still a tokenistic approach to patient involvement.

1 http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf (Page 4)

2 <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF> (Page 3)

3 <https://wcd.coe.int/ViewDoc.jsp?id=340437&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75>



Value+ assessed a number of important areas where improvement is needed to achieve what the European Patients' Forum (EPF) defines as **meaningful** involvement of patients and patient organisations:

Meaningful Patient Involvement means that 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, according to the values and purposes of:

- *The participating patients or patient organisations*
- *Other participating organisations and funding bodies*
- *The quality of their experiences during the involvement activity.*

This definition can apply to involvement of individual patients or patient organisations in participatory or patient-led activities. It relates also to involvement of family members and carers acting as patient representatives where the patient is unable to represent himself/herself.

Value+ looked at involvement in projects exploring also how gender affects the involvement of patients. While it is clear that other issues of diversity must also be taken into account (e.g., ethnicity, disability), the gender parameter was examined in most detail as it plays a major role in the involvement of all patients regardless of other diversity criteria. Important benefits could be found from this approach if the generally limited understanding of the importance of gender in this context could be overcome. Value+ has therefore decided to include gender considerations in these recommendations.

Although the focus was on projects, the Value+ findings go beyond the specific project context and give important insights on involvement at programme and policy levels.

Meaningful and sustainable patient involvement can only be achieved through political commitment, changes in values and attitudes and institutional, structural and financial support and mechanisms.

These recommendations have been formulated as a result of the evidence emerging from Value+ and also through consultation with patient leaders at regional seminars in Lithuania in 2008 and Sofia in 2009. EPF member organisations and health stakeholders have also provided their input and views.

THE RECOMMENDATIONS

The recommendations outlined below are addressed to the European Commission, the European Parliament and the Member States. However, other health stakeholders⁴ have a key role to play in patient involvement and EPF shall be appealing to all of them to sign up to the recommendations in the spirit of partnership and dialogue.

These recommendations are the result of the findings of Value+ in relation to the assessment of patient involvement in health projects supported by the EC. They highlight the views of patients and patient representatives who expressed, through a survey, focus groups and seminars, the actions needed at various levels to achieve meaningful involvement. They are clustered around three themes that are key to achieving meaningful involvement of patients:

- The right to involvement
- Resources
- Capacity building.

The policy recommendations have not been numbered based on priority. They are all equally important.

Value+ has developed a number of tools that could support the implementation of the recommendations:

- Value+ Model of Meaningful Patient Involvement: Definition, Key Areas and Indicators, Assessment Tool, Levels of Involvement
- Toolkit for patient organisations and patients to support their involvement in projects as leader and partners
- Handbook for project co-ordinators and leaders of organisations aspiring to involve patients and patient organisations in their projects and activities.

The Right To Involvement

Whereas the right to participation of citizens in public life is well established, the same cannot yet be said about the right of patients to be involved in health-related decision-making. At the European Union and Member States' level, there exist legislation and policies around patients' rights. These, however, cover primarily medical and ethical aspects, and there is a lack of policies on the rights of patients to participate in decision-making; policy development, programmes and projects.

EPF calls on the European Commission, the European Parliament and the Member States to:

1. Develop, adopt and promote a policy instrument on patient involvement – also addressing diversity issues and the gender dimension of involvement – to be applied at European Union and Member States' levels.
2. Set a mechanism and develop guidelines to ensure sustainable patient representation in health committees/bodies, decision-making processes (local, national, European).
3. Develop/promote the adoption of a code of practice defining principles and values for working with patients and patient organisations as equal partners.
4. Set up monitoring and evaluation systems of patient involvement in:
 - EC-funded programmes and
 - Policy consultation processes at EU and Member State level

These systems should include indicators linked to diversity issues and gender.

This recommendation has synergies with Recommendation 5.



Resources

In order to be meaningful and sustainable, patient involvement needs financial, structural and institutional support. Financial resources earmarked for patient involvement are needed as well as appropriate mechanisms and support systems to access them.

EPF calls on the European Commission, the European Parliament and the Member States to:

5. Establish patient involvement as an eligibility criterion for project funding in EC health-related Calls. This criterion should be evaluated by the expert teams in charge of assessing and selecting projects – patient representatives should be involved in the teams. Guidelines for applicants and evaluators should be developed for this purpose.

Patient involvement should also be required as one of the terms of reference for the process review and outcome evaluation, which the projects are required to undertake.

This recommendation has synergies with Recommendation. 4.

6. Reinforce the mandate and capacity of bodies/offices in Member States delegated by the EC to be contact points for specific funding programmes so as to enable them to provide guidance and information to patient organisations.
7. Waive the co-financing percentage for patient organisations in EC Calls in consideration of the fact that they are not-for profit; most of them are run by volunteers and often do not have access to loans or bank guarantees due to their annual turnover.
8. Simplify application procedures and set up specific Calls for small size not-for profit organisations and other types of organisations that have limited capacity to meet eligibility criteria of current programmes.
9. Strengthen opportunities for patients' organisations to access funds from the European Social Fund and the European Regional Development Fund by:
 - Increasing awareness and visibility about health being now among the priorities of those funds
 - Earmarking a percentage of funds for not-for profit non-governmental organisations (NGOs) and simplifying application procedures
 - Providing good practice guidelines for public authorities in charge of managing the funds
 - Monitoring how Member States administer funds with a view to transparency and equity in healthcare.
10. Increase access to resources at Member State level by: setting up funding schemes for NGOs; reducing taxes for companies/individuals making donations to NGOs and reducing taxation to NGOs.

Capacity Building

Involving and being involved meaningfully is a challenge; various types of knowledge and skills are needed for all the stakeholders. There is often poor know-how related to patient involvement within the EU Institutions, the Member States, health stakeholders like hospitals, universities, researchers, health professional organisations, and patient organisations themselves. This is strongly reflected in the lack of mechanisms for planning, implementing and evaluating patient involvement.

EPF calls on the European Commission, the European Parliament and the Member States to:

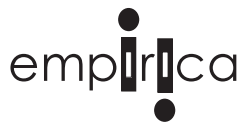
11. Invest in a European Centre of Excellence on Patient Involvement led by patient representatives involving a Network of Experts to ensure:
 - Sharing of knowledge and transfer of best practices for patient involvement
 - Wider dissemination of projects' results so that they are delivered to grassroots patients in an accessible way.
12. Establish Patient Involvement Units in the EC and Member States to provide information, guidance, good practices and capacity building. The units would make the liaison between the European Centre of Excellence on Patient Involvement and stakeholders at national level.
13. Invest in capacity building programmes for patient involvement targeted to EC and Member States' policy makers and civil servants, health professionals, researchers, project coordinators, patients and patient organisations and other key stakeholders of the health sector.

Value+ “Promoting Patients’ Involvement in EU supported health-related Projects”

PROJECT LEADER



ASSOCIATED PARTNERS



COLLABORATING PARTNERS

