

## Volume 14 - Issue 1, 2014 - News Review

### Patients Vote for a Healthier Europe

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#### Links

You are invited to sign the EPF Manifesto to support this campaign and therefore commit to include a patients' perspective in your work:

[www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/-support-EPFCampaign/](http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/-support-EPFCampaign/)

More information about the campaign:

[www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/](http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/)

#### Key Points

- *On 1 October 2013, the European Patients' Forum (EPF) launched a campaign ahead of the 2014 European elections.*
- *This campaign is an opportunity for the patients' community to be heard by the candidates and to help them to set the priorities for the new parliamentary session.*
- *Patients' views matter as they are 'experts by experience' living their chronic disease every day and they can therefore guide decision-makers on how to offer good quality care that is also cost-effective.*
- *All patients in the EU deserve equitable access to care, but this is not a reality for all.*

On 1 October 2013, the European Patients' Forum (EPF) launched a campaign entitled "Patients + Participation = Our Vote For a Healthier Europe" ahead of the 2014 European elections. This campaign is an opportunity for the patients' community to be heard by the candidates, and to help them to set the priorities for the new parliamentary session.

EPF knows from our 61 members throughout Europe - specific chronic disease groups at EU level or national coalitions of patients - that the challenges faced by patients' constituencies are enormous. Fundamental inequalities and lack of access prevail, even more as our population ages.

We need to ask ourselves what kind of society do we want, for us and for the future, and health is absolutely central to this. This is why the

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European Parliament Elections and new Commission 2014 represent a big milestone for patients in Europe to encourage politicians and policy-makers to commit to a healthier Europe.

EPF wants to create a sense of urgency and real imperative to address the fundamental roadblocks to patients' access to proper healthcare. We strongly believe that patients can be part of the solution to make health systems more effective and quality-oriented.

#### **Patients' Views Matter**

EPF asks European decision-makers to engage patients collectively and pro-actively through patient organisations in policy decision-making to ensure that all policies and practices reflect patients' real-life needs, preferences and capabilities.

Patients of all ages and conditions are 'experts by experience' as they live with their chronic disease every day and regularly use health services. They have a unique perspective on healthcare and know what works for them and what does not. They know what is most important to them and conversely, what services are not needed.

Patients are not cost drivers – on the contrary, patient-centred care models have been shown to be cost-effective as well as to increase patient satisfaction and often improve clinical outcomes.

The benefits of integrated, patient-centred care are seen in terms of reducing avoidable hospitalisations, more effectively allocated healthcare resources, better quality care throughout the "patient journey" and better informed, motivated and empowered patients.

This is why patients should not be seen as passive recipients of services and benefits, but as active citizens and partners in chronic disease self-management. They can guide decision-makers on how to offer good quality care that is also cost-effective, and improve the way healthcare services are designed and delivered.

Although patient involvement is recognised as one of the shared operating principles of European health systems, there is still wide divergence across the EU in the recognition of patients as a legitimate stakeholder group and in the level of their collective involvement.

#### **Empowered Patients, An Asset to Society**

Patients want to be full partners in the management of their conditions according to their individual capacities and situation. Patients need to be supported to be able to contribute to the sustainability of healthcare systems. Currently, this is not the case.

EPF asks European decision-makers to adopt an EU strategy on patient empowerment, which can be seen as a multidimensional process that helps patients gain control over their lives, increasing their capacity to act on issues that they themselves define as important.

To make genuinely informed decisions about their health and treatment, it is vital that patients can access all the relevant information needed to make those decisions, in an easily understandable format. Although empowerment is much more than 'patient education', the right information and resources are fundamental tools for it.

Health literacy is a key dimension of empowerment and encompasses not just accessing, comprehending and evaluating health information, but also relating the information to oneself and one's health, and transforming it into appropriate actions.

Across the EU, there currently is a lack of accessible, reliable and understandable health-related information that meets patients' needs, although core quality criteria have been defined at European level.

Health literacy also has a critical relevance for health inequalities. Wellinformed, health-literate people are more discerning about their health, make more informed choices and decisions and are more likely to seek earlier diagnosis and recover faster.

Conversely, people with low health literacy have poorer self-management skills, higher hospitalisation rates and more emergency visits. They have poorer overall health, more inappropriate and less effective use of healthcare resources.

The importance of health literacy is likely to increase as the population ages, chronic conditions become more prevalent, and online information sources proliferate; people are increasingly expected to become familiar with technologies such as eHealth, mHealth, genetic testing, etc.

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The degree to which healthcare systems are health literacy-friendly has a bearing on the equity of access. EPF believes that healthcare services must be designed to meet the needs of all patients, including those with low health literacy.

### **Breaking Down Access Barriers**

From a patient's perspective, health inequalities mean unequal access to medical and other care, and disparities in the quality of that care. Patients and families on low incomes are at risk of poverty as a consequence of ill-health and catastrophic health expenditures, which in turn affect their access to healthcare and the quality of care, creating a vicious circle.

Access to healthcare is a basic EU citizen's right, and one of the fundamental principles of European health systems together with safety, quality and equity. Treatment should be accessible to every patient who needs it, not only to those who can pay or who can make informed choices. Regrettably, this is not a reality for all.

Healthcare is accessible to patients when it is functionally available to the patient who needs it, e.g. it is possible to get an appointment without undue delay and without having to travel far, and when the cost is affordable.

There are huge disparities within the EU in the availability of treatments and their affordability, while health spending has stalled or fallen since 2009 in many member states. This means that existing inequalities are made worse by austerity measures such as new hospital fees, cuts in health insurance coverage or increased co-payments, against a background of rising unemployment and reduced incomes.

EPF held two conferences in partnership with our Bulgarian Member, the National Patient Organisation (NPO), one on "Health Inequalities in the 'New' EU Member States and Candidate Countries". The second one, which took place at the European Parliament on 26 June 2013, produced high impact results with the establishment of an EU partnership on patient access and equity and the setting up of an interest group of Members of the European Parliament (MEP) to address health inequalities and to promote equal access.

EPF calls for the support of these initiatives to ensure equitable access to healthcare for all European citizens, regardless of their background or ability to pay. The strategy should also identify the specific needs of different target populations, such as minority and disadvantaged groups, and develop actions to address them.

### **Patient Involvement, A Healthier Europe**

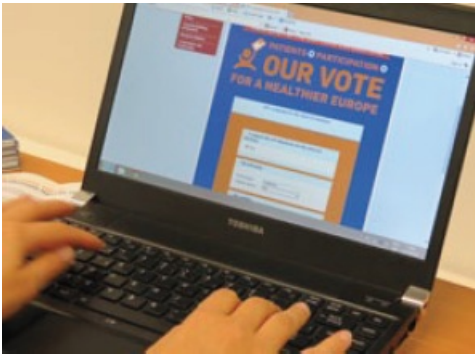
Patient empowerment and better access to high-quality healthcare present a challenge to the system and require specific strategies, including embedding meaningful patient involvement at every level in the health system.

Patient involvement is based on the premise that patients have a specific expertise derived from being patients, which is a valuable source of knowledge.

At individual level it can mean the extent to which patients – or their families or caregivers – participate in decisions related to their healthcare.

At the provider level (e.g. hospital), patients or their representatives play a role in improving healthcare using the specific experiences of patients as learning and educational tools to design better services.

At the highest or policy level, patients – through their representative organisations – contribute to shaping the healthcare system through their involvement in healthcare policy-making.



Picture 1. EPF Campaign online form ready to be signed



Picture 2. EU Health Commissioner Tonio Borg signing the manifesto

EPF calls for a clear framework supporting active patient participation in policy-making and the designing of care delivery systems. Patients as healthcare users need to be involved in designing more effective healthcare of the future, including research to deliver new and better treatments. Patient involvement is needed to determine what innovation adds in terms of real value and improvement to people's lives.

Although access to new and improved medicines is crucial in many disease areas, innovation should be based on a patient-centred approach. Being driven by patients' needs, it has great possibilities to lead to innovative solutions that meet the real needs of patients.

Research should be centred on patients' medical and social needs. There is therefore a requirement for increased policy attention and investment in this type of research. This can only be achieved if patients are meaningfully involved throughout the research process, from the 'idea' stage to the proven intervention.

The involvement in research projects of patient and other civil society organisations should be made easier with simpler rules, less bureaucracy, and adequate funding.

Professionals need also to develop the necessary skills and attitudes to adapt to the new patient role, shifting from a paternalistic medical model to a collaborative model.





Pictures. Top

EPF Campaign manifesto is translated in all EU languages

Middle

Annette Dumas, EU Public Affairs, Advisor for Alzheimer Europe and MEP

Dagmar Roth-Behrendt

Bottom

EU Health Commissioner Tonio Borg, EPF President Anders Olauson, MEP, Dagmar Roth-Behrendt

Empowering patients to get involved in research requires training to support their participation in scientific discussions and address the inherent imbalance of power between the 'expert' and the 'lay person'.

Some tools and good practices already exist, through the Value+ and PatientPartner projects, and this is also the focus of the European Patient Academy on Therapeutic Innovation (EUPATI).

Patient involvement is also needed at the other end of the chain, to ensure that cost/benefit assessment of innovative treatments takes into account their impact on patients' quality of life, and that they promote equitable access. Patients should be involved in Health Technology Assessments, appraisals, prioritisation and reimbursement processes at national level.

Advocacy and awareness is needed to increase understanding of the patient's contribution. Capacity building for patient representatives is required to address the inherent imbalances of power.

EPF represents the voices of an estimated 150 million of patients who are also voters and, when they will cast their ballot for the next EU Elections, they want to be confident and feel good about voting for a healthier Europe, where patients are seen as a part of the solution for high-quality, sustainable and cost-effective healthcare.

Published on : Sat, 8 Mar 2014