

# The European Patients' Forum Manifesto for the 2014 European Elections 22-25 May 2014

---

## Patients' views matter Background Briefing No.1

---

The European Parliament Elections and new Commission 2014 offer a fresh opportunity for the European Patients' Movement to encourage politicians and policy-makers to commit to a healthier Europe.

We want to create a sense of urgency and real imperative to address the fundamental roadblocks to patients' access to proper healthcare and to demonstrate how patients can be part of the solution to make health systems more effective and quality-oriented. In other words, a healthier Europe, as outlined in our Manifesto "Patients + Participation = Our Vote for a Healthier Europe"



*We, patients of all ages and conditions, live with our chronic disease every day and regularly use health services. We have a unique perspective on healthcare. We are experts on what works for us and what does not. We can therefore guide decision-makers on how to offer good quality care that is also cost-effective.*

Europe's healthcare systems will need to change to meet the challenge posed by chronic diseases, an ageing population and the impact of new technologies.

Tackling chronic diseases is seen as a key requirement for the sustainability of European health systems and will inevitably involve greater investment in prevention and health promotion, but also changes to the way healthcare is delivered.

Chronic disease strategies and reflection on the sustainability of healthcare systems is a crucial area where patients can and must contribute.

#### Some key figures in Europe:

- Chronic diseases affect more than **80%** of people aged **over 65**
- The EU population aged 65+ is predicted to rise from 87.5 million in 2010 to **152.6** million in 2060
- The number of people aged **80+** is projected to almost **triple** (from 23.7 million in 2010 to 62.4 million in 2060)
- An estimated **70-80%** of healthcare costs are currently spent on chronic diseases (approximately €700 billion in the EU)

Source: Final report of the reflection process: Innovative approaches for chronic diseases in public health and healthcare systems. 11 November 2013. Available at [http://ec.europa.eu/health/major\\_chronic\\_diseases/reflecti\\_on\\_process/index\\_en.htm](http://ec.europa.eu/health/major_chronic_diseases/reflecti_on_process/index_en.htm)

## PATIENTS' VIEWS MATTER: THE PATIENT PERSPECTIVE

Patients are "experts by experience". Their perspective on chronic disease is unique: patients live with the condition every day, learn to manage it themselves with support from healthcare professionals, and by necessity learn to navigate the health system in order to get the right care. They are experts in the condition and its impact on all areas of life, including workplace, family and social interactions. 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.<sup>1</sup> In general, patients with chronic conditions are more likely and willing to get actively involved in their healthcare and also want to improve the way healthcare services are designed and delivered.<sup>2</sup>

<sup>1</sup> It is important to bear in mind that not every patient wants to get involved as an equal partner; but, given the right opportunities and support, many do.

<sup>2</sup> Eurobarometer Qualitative Study: Patient Involvement, May 2012

## THE PATIENTS' PERSPECTIVE IS KEY TO DEVELOPING HIGH-QUALITY, SUSTAINABLE HEALTH SYSTEMS

Patients know what is most important to them and conversely, what services are not needed. This may not necessarily mean investing less, but investing differently and more effectively. Given the opportunity, patients can provide invaluable insights for developing the healthcare system and ensure that strategies to address, for example, chronic disease are effective and result in high quality of care and improved quality of life.



*Patients are not cost drivers – on the contrary, when patients are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is not only better health outcomes and more engaged patients, but also lower costs.<sup>3, 4</sup>*

Healthcare reforms need to focus on providing high-quality care that meets patients' needs and results in concrete improvements in people's quality of life. Reform must not become a byword for cuts in healthcare budgets. Patient-centeredness is recognised as a core component of high-quality care.<sup>5</sup> Patient-centred<sup>6</sup> care models have been shown to be cost-effective as well as to increase patient satisfaction and often clinical outcomes.



A recent study in dermatology showed that a patient-centred online care model appeared to be cost saving from a societal perspective while maintaining similar effectiveness to standard in-office care.<sup>7</sup>

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.<sup>8</sup>

### EPF KEY SOLUTION: SYSTEMATIC PATIENT ENGAGEMENT AT ALL LEVELS

#### **We ask 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.**

<sup>3</sup> Mulley et al. "Patients' preferences matter: Stop the silent misdiagnosis", The King's Fund, 29 May 2012.

<sup>4</sup> Arterburn et al. "Introducing decision aids at Group Health was linked to sharply lower hip and knee surgery rates and costs", *Health Aff (Millwood)*. 2012 Sep;31(9):2094-104.

<sup>5</sup> R Jayadevappa and S Chhatre, "Patient Centered Care - A Conceptual Model and Review of the State of the Art", *The Open Health Services and Policy Journal*, 2011, 4, 15-25.

<sup>6</sup> Patient-centred care can be defined as "care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Institute of Medicine (2001), "Crossing the quality chasm: a new health system for the 21st-century"; summary available [here](#).

<sup>7</sup> Parsi K, Chambers CJ, Armstrong AW 2011 "Cost-effectiveness analysis of a patient-centred care model for management of psoriasis", *J Am Acad Dermatol* 2012;66:563-570.; Olsson et al. 2009: "A cost-effectiveness study of a patient-centred integrated care pathway" *J Adv Nurs* 2009 Aug; 65(8) :1626-35.

<sup>8</sup> See EPF's response to the European Commission consultation on the chronic diseases reflection process, available here: <http://www.eu-patient.eu/Documents/Who%20we%20are/News/EPF%20chronic%20diseases%20consultation%20response-Final.pdf>

Patient empowerment and involvement at all levels is needed to build high-quality, sustainable European healthcare systems of the future. Patient organisations are civil society NGOs that play an important role in the democratic process as proponents of patients' human rights. Patients act collectively through patient organisations to channel their expertise into decision-making most effectively. Although patient involvement is recognised as one of the shared operating principles of European health systems<sup>9</sup>, 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.

With appropriate support, patient organisations can be part of the solution to ensure the future sustainability and high quality of our healthcare systems. To achieve this, patients should be involved collectively and pro-actively through their representative organisations in policy decision-making to ensure that all health-related policies and practices at EU, national and regional or local levels reflect patients' real-life needs, preferences and capabilities.

To enable them to undertake this vital role, EPF calls for concrete action to support the functioning of patient organisations through appropriate institutional, structural and financial support mechanisms at EU and member state levels.

---

<sup>9</sup> Council Conclusions on Common values and principles in European Union Health Systems (2006/C 146/01).