

The European Patients' Forum Manifesto for the 2014 European Elections

22-25 May 2014

Empowered patients are an asset to society

Background Briefing No.2

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 want to be full partners in the management of our conditions according to our individual capacities and situation. We need to be empowered to do so. Empowerment starts with tailored high-quality information and health literacy, to enable us to make informed choices about our treatment and care.

Empowered patients are good for health systems. We take responsibility for our care in equal partnership with health professionals. We also take preventive measures, seek earlier diagnosis and adhere to treatment, which can reduce healthcare costs in the long run.

Patient empowerment is a key element of future high-quality, patient-centred health systems. Patients need to be supported to be able to contribute to the sustainability of healthcare systems. Currently, this is not the case.

Patient empowerment also presents a challenge to the system and requires specific strategies, including embedding meaningful patient involvement at every level in the health system, thus supporting active patient participation in policy-making and the designing of care delivery systems.

WHAT IS PATIENT EMPOWERMENT, AND IS IT DIFFERENT FROM PATIENT INVOLVEMENT?

Empowerment can be seen as a multidimensional process that helps people gain control over their lives, increasing their capacity to act on issues that they themselves define as important.¹ It is a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.²

The concept of patient empowerment is often conflated with patient involvement (see [EPF Manifesto Background Briefing No.4, "Patient involvement = Healthier Europe"](#)), but although closely interrelated, these two concepts are not exactly the same.

Empowerment and involvement are multi-faceted concepts and can include, for example, the following aspects, ranging from operational to strategic: quality of information; health literacy; patients' rights such as informed consent; feedback systems to collect information on patient's experiences; training and education of health professionals in areas such as communication; and enabling care environments.

HEALTH LITERACY AND INFORMATION TO PATIENTS

Ultimately, empowerment strategies aim to realise the concept of patients and citizens as "co-producers" of health and as an integral part of the entire system. Although empowerment is much more than "patient education", the right information and resources are fundamental tools for empowerment. 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

¹ Luttrell et al., "Understanding and operationalising empowerment", Overseas Development Institute, Working Paper 308, November 2009

² Deepening our Understanding of Quality improvement in Europe (DUQuE); <http://www.duque.eu/>

understandable format. Currently there is across the EU a lack of accessible, reliable and understandable health-related information that meets patients' needs, although core quality criteria have been defined at European level.³



Health literacy⁴ is a key dimension of empowerment. It is both a means and an outcome, with the fundamental aim of empowering people to take control of their well-being in everyday life, both when healthy and when ill. Health literacy encompasses accessing, comprehending and evaluating health information, but also relating the information to oneself and one's health and transforming it into appropriate actions.

From a patient's perspective, the knowledge and competence gained through health literacy leads to the strength and empowerment needed to manage well a disease and its impacts on quality of life.⁵

Health literacy also has a critical relevance for health inequalities. Well-informed, 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.⁶

Although more research is needed on the economic impact of poor health literacy, a recent systematic review indicated that it may account for as much as 3-5% of total healthcare costs at system level (see the right-hand box for details).⁷



This is concerning in light of the results of the EU health literacy survey (HLS-EU)⁸ that showed nearly half of the respondents had limited health literacy.

The impact on limited health literacy on healthcare costs

Limited health literacy is associated with high health system costs. Limited health literacy cost more than US\$ 8 billion, an estimated **3–5% of the total health care budget** in Canada in 2009. In 1998, the United States National Academy on an Aging Society estimated that the additional health care costs caused by limited health literacy were about **US\$ 73 billion.**

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.

Patients' information needs are diverse and complex, ranging for example from the need for nutritional information in an accessible, effective format for children diagnosed with diabetes from poor

³ Final Conclusions and Recommendations of the High Level Pharmaceutical Forum, October 2008, available at http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/pharmaforum_final_conclusions_en.pdf

⁴ A definition was developed recently by the HLS-EU Consortium and others: "Health literacy is linked to literacy, and entails people's knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life and the life course." (Sørensen et al. "Health literacy and public health: A systematic review and integration of definitions and models", *BMC Public Health* 2012, 12:80).

⁵ Recommendations of the EPF Conference on Health Literacy, 8 -9 April 2008.

⁶ WHO/Europe 2013, "[Health literacy: the solid facts](#)".

⁷ "The costs of limited health literacy: a systematic review", Eichler K, Wieser S, Bruegger U, *Int J Public Health*, 2009;54(5):313-24.

⁸ http://ec.europa.eu/eahc/documents/news/Comparative_report_on_health_literacy_in_eight_EU_member_states.pdf

backgrounds and their parents; to translation and cultural adaptation of patient information materials in localities with large migrant populations; to the information needs of older patients and carers, who may have visual and hearing or other impairments that affect their ability to access and deal with information.⁹

EMPOWERMENT AS A CHALLENGE TO THE HEALTHCARE SYSTEM

The empowered patient needs a counterpart: the empowered health professional who welcomes the empowered patient and knows how to create an enabling healthcare environment. The patient's role may involve and even fluctuate during the "patient journey": at some points the patient may wish to simply follow the doctor's orders, whereas at others s/he may wish to share the decision or even take control. Professionals need to develop the necessary skills and attitudes to adapt to the new patient role, shifting from a paternalistic medical model to a collaborative model.

Improving citizens' health literacy is therefore critical, but this should be approached as a challenge to our current systems and a societal challenge for the future. Further research is needed to identify the specific health system characteristics that contribute to empowerment or act as barriers.^{10, 11} Patient organisations can play a highly effective role in identifying interventions that work for different patient groups in different cultural and social contexts.

EPF KEY SOLUTION: AN EU STRATEGY FOR PATIENT EMPOWERMENT

We ask European decision-makers to:

Adopt an EU strategy on patient empowerment, including an action plan on health literacy and high quality information for patients on all aspects of our care.

EPF calls for a comprehensive European strategy on patient empowerment that should include at least the following elements:

- Identification and implementation of **good practices in patient empowerment and involvement**; development of practical tools to facilitate shared decision-making between patients and health professionals; identification and implementation of effective self-management interventions;
- Concrete **strategy and action plan on health literacy and information to patients** (and citizens) relating to all aspects of health, from health promotion and prevention through to therapeutic options and self-management of chronic disease;
- Research on the **impact of patient involvement** on quality of healthcare, patient satisfaction and cost-effectiveness;
- Identification and sharing of **good practices in integrated chronic disease management**, both between primary and secondary healthcare providers, and between health and social care.

⁹ EPF statement on health inequalities, 2010.

¹⁰ WHO/Europe 2013, "Health literacy: the solid facts".

¹¹ HLS-EU presentation, 9 May 2012. More information about HLS-EU available at

<http://www.maastrichtuniversity.nl/web/Institutes/FHML/CAPHRI/DepartmentsCAPHRI/InternationalHealth/ResearchINTHEALTH/Projects/HealthLiteracyHLSEU.htm>