

“EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY”

Conference Report – Executive Summary

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Thon EU Hotel, Brussels

For several years, EPF has advocated strongly for patient empowerment to feature centrally in EU health policy-making. This is why EPF participated as a key partner in the EMPATHIE (Empowering Patients in their Health Management in Europe) Consortium, which delivered its final report on a mapping study of patient empowerment across the European Union to the European Commission at the end of September 2014. The report, entitled “[Empowering patients in the management of chronic diseases](#)”, reflected on the concept of empowerment as well as existing good practices, barriers and facilitators. The EPF Conference aimed to take the recommendations from the EMPATHIE mapping study forward to explore the key facets of empowerment and call for action at all levels, by all stakeholders.

Patient empowerment should be an intrinsic value, a human right. The Alma Ata Declaration issued by the World Health Organisation (WHO) as far back as 1978 stated that: “The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare”. It was declared in 2006 that patient involvement is a common operating principle in the health systems of the European Union. However, today this is still not the patient’s experience on a daily basis.

EPF’s definition of patient empowerment refers to a dynamic, non-linear process:

“ Patient empowerment is a process that helps patients gain control over their lives, increasing their *capacity to act* on issues that *they themselves* define as important... a process through which patients *individually and collectively* are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take action to meet those needs. ”

This cannot be imposed from the top down, nor will it involve a revolution from the bottom up – change needs to be effected at all levels, through both individual and collective action by patients.

Much of the way healthcare is delivered at the moment assumes that health professionals have all the answers and that the patient’s role is entirely passive. Traditional practice styles create dependency, discourage self-care, ignore the patient’s preferences, undermine the patient’s confidence, do not encourage healthy behaviours and lead to fragmented care.



Therefore, what we need to do is to focus on informing and empowering patients. We know that when patients have the knowledge, skills and confidence to manage their own health and healthcare, they are more likely to make healthy lifestyle choices, make informed and personally relevant decisions about their treatment and care, adhere to treatment regimes, experience fewer adverse events and use less costly healthcare. Once we stop disempowering patients, they can begin to empower themselves.

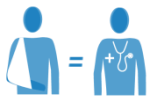


The Conference considered in detail some of the many ways in which patients can be empowered and engaged. This is not rocket science – many are things that patients and health policy experts have been telling us for some time:

Health literacy: We know that there is a huge thirst for information about health. Information on its own can be empowering, but we must also make sure that patients have access to reliable answers to their questions at the time when they need it. Health literacy is not just about the passive absorption of information; it means having the skills to apply one's health knowledge in daily life.



Professional skills and attitudes: Changing healthcare professionals' attitudes towards taking a holistic approach to the patient – training them to see him/her as a person rather than a collection of symptoms to be “managed” – requires a dual approach: professional organisations must aim to raise awareness and educate their members, but there is also a need for structural and organisational changes decided at the policy level.



Self-management of chronic conditions: If one makes the generous assumption that a health professional will spend on average 3 hours per year (one 15-minute consultation per month) in direct contact with a patient living with a chronic condition, that leaves 8,757 hours per year during which the patient must manage his/her own condition. Therefore, self-management support is central to dealing with the biggest problem for every healthcare system in the EU: how best to manage chronic conditions.



eHealth and mHealth: The results of a number of eHealth and mHealth evaluations are now emerging, and they are largely disappointing. One of the basic problems is that investors and developers are taking technological innovation as their starting-point rather than identifying problems from the patient perspective and then devising solutions. The result is that we have a lot of very clever kit in search of a problem to solve. This gap must be closed: we need more engagement with the patient experience in order to realise the enormous potential for eHealth and mHealth to empower patients.

Methodology for measuring patient empowerment: A wide range of indicators to assess facilitators/barriers for patient empowerment exist and are being used, and several scales to assess patient empowerment indirectly also exist. However, patient empowerment or related concepts tend not to be measured broadly and directly as an outcome in comparative studies.

Everyone may agree that patient empowerment is “a good thing”, but do all actors see it in the same way, and do they agree on how best to achieve it?

We still need to change attitudes and move healthcare systems towards making patient empowerment a practical reality for all. Patient empowerment also brings wider benefits.



Healthcare systems face changes; there are challenges relating to chronic disease, ageing and technology, and there are also financial constraints – the “sustainability challenge”. Far from being cost drivers, empowered patients are part of the solution for sustainable patient-centred healthcare systems.

The pressure for real change towards patient empowerment is coming from the patients’ organisations; they are becoming much more focused in terms of what they are asking for, and the politicians are starting to listen. There are plentiful references to patient-centred care, shared decision-making and health literacy in policy documents, so we know that patient empowerment is on the policy agenda.

Costs are increasingly driving government decisions on health. What has not been tried so far is to embrace patient empowerment on a scale that will produce significant cost savings and other benefits. Given today’s new situation, we could soon be seeing a cultural revolution in healthcare delivery. Talking positively is easy; making it happen on the ground is the real challenge.



A single conference – however good – will not change hearts and minds. This is why EPF is launching a major year-long campaign on patient empowerment; the first one ever at EU level. EPF believes the time is right to make patient empowerment known and understood in every part of Europe; but more, to make sure that it is seen as integral to ensuring high-quality, patient-centred sustainable health systems of the future.

The Conference has taken the first steps towards formulating a powerful “Charter of Patient Empowerment” over the coming year. The aim is to build on the fundamental principles identified in the workshops and the other outcomes of the Conference to arrive at a common set of principles of patient empowerment expressed in the 10 points of the Charter. The work on the Charter will feed into the drafting of a “Multi-stakeholder Roadmap to Patient Empowerment” that will outline the critical journey we need to take. The Roadmap will provide the basis of proposals for concrete actions to be taken by European policy-makers and healthcare stakeholders.

The campaign slogan says it all: **“Patients Prescribe E⁵ for Sustainable Health Systems”**. We patients are no longer passive – we are active, decisive, and assertive, ready to play our rightful role at both the collective and individual level. If supported, we can make a difference to the quality and sustainability of healthcare systems.



This conference and campaign is a joint initiative of EPF and the Robert Bosch Stiftung, with the support of Amgen and GSK