
Volume 13, Issue 3/2011 - Patient-Centred Management

Putting Patients First

With this issue's cover story on patient-centred management, who better to talk to than Tomasz Szlagowski, Board Member of the European Patients' Forum (EPF) and General Director of the Federation of Polish Patients. (E)Hospital spoke to Mr. Szlagowski to find out the main issues affecting European patients and what hospital managers can do to improve patient experience.

Firstly, Tell Us a Bit About the European Patients' Forum

EPF was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement. We currently represent 50 member organisations, which are chronic disease-specific patient organisations working at European level, and national coalitions of patient organisations. EPF's vision for the future is high quality, patient-centred, equitable healthcare throughout the European Union.

By pooling the resources of its members, EPF works on horizontal issues affecting all European patients and supports individual members' initiatives that will benefit the community. EPF facilitates exchange of good practice and challenging of bad practices on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member State level.

Our five core strategic goals are:

- To promote equal access to best quality information and healthcare for EU patients, their carers and their families;
- To ensure meaningful patient involvement in EU health-related policy making, programmes and projects;
- To ensure the patients' perspective, including issues around human rights and quality of life, is heard in developments at EU level on health economics and health efficacy (health, wealth and equity);
- To encourage inclusive, effective and sustainable representative patient organisations; and
- To nurture and promote solidarity and unity across the EU patients' movement. No patients' organisation is too small to contribute to our work.

We work closely with the European Institutions, and other stakeholders in the health area, for example through providing our input in public consultation or in legislative processes relevant for patients (thanks to our members' expertise), and in several European stakeholder groups such as the European Medicines Agency's Patients and Consumer Working Party, or the European health policy forum. We are also involved in several European projects in partnership with stakeholders at European level or/and with Member States.

What are the Key Activities of the EPF at the Moment?

EPF is working on many health-related policy areas, to mention a few examples: Patient involvement in clinical trials and research and ageing (through the organisation of a conference on the Rights and Needs of older patients and through the European Partnership on active and healthy ageing).

We are also very involved in the discussions on the "pharmaceutical package", the last proposal still in discussion, information to the public on prescription medicines, is a key topic for patients. In this debate we have strongly advocated to uphold patients' right to clear, accurate, unbiased and accessible information. In our view this proposal should not be an end in itself but rather the first step in an EU wide health literacy strategy. We believe it is crucial to empower patients to manage their condition, to make choices in their daily life about their health, and to navigate the healthcare system. It is also a key strategy to tackle health inequalities.

EPF is also involved in projects and initiatives related to topics such as patient involvement in e-health and health technology assessment, safety and quality of care, young patients' involvement and patient education.

EPF also recently started to work with member organisations to help them participate in implementation at national level of recently adopted European directives.

In your opinion, what are the main issues affecting patients today?

Health inequalities across and within Member States are undoubtedly a major issue affecting patients. This can take very diverse forms:

- Unequal quality and safety of healthcare services across Europe. There are wide disparities in patient care outcomes in different Member States including within countries and regions.
- Unequal access to treatment (including disparities in pricing and reimbursement of treatment).
- Lack of patient education/poor health literacy in certain geographic areas or among vulnerable groups is another issue, strongly related to inequalities, with many negative consequences: Little or no knowledge of medical care and medical conditions, poorer compliance rates and health status, increased hospitalisations, increased healthcare costs, etc.
- Some disparities also come from a lack of capacity building for professionals.

- Discrimination/stigma in healthcare and other areas of life such as employment.
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In addition there are various pressures on governments to control health expenditures, which ultimately can negatively affect patients. The economic crisis and some measures aimed at stabilising the economy have worsened the situation for patients in many countries and tend to widen the socio-economic disparities between groups. The demographic change which affects patients (the number of patients with chronic diseases is growing), health professionals (shortage), and the healthcare system as a whole as demand grows, is an important challenge which, if not addressed adequately, can worsen the situation.

Though the role of patients is changing and they are increasingly empowered, they are also faced with new threats to their safety such as illegal online pharmacies. They have to face obstacles to their empowerment and involvement in health related decisions and research projects. Though they are expert in living with a chronic condition and have an experience of healthcare system, and though as end users they have a legitimate right to be involved, they are often not treated as adequate or equal partners.

This is Your Chance to Speak Directly to European Hospital Managers. What Should They be Doing to Improve Patient Experience in Their Hospitals?

One key message we receive from our member organisations is the need for better coordination and integration in care. Patients have to face obstacles relating to the organisation and delivery of healthcare, which include financial structures, productivity targets and attitudinal barriers. The result of organisational and financial fragmentation is that patients need to spend significant time and energy in "fighting the system" just to get the services they need.

Our member organisations provided us with examples of the lack of coordination within the hospital: "the doctors may want to introduce a simple innovation that makes care better and cheaper, but the hospital laboratories may be against since because the system is organised in such a way that the laboratory will lose "productivity" and therefore related income". Solutions should be found, in cooperation with patients, to enable them to manage their own situation for as long as possible, with sufficient support from professionals, as appropriate. Better collaboration between health and social care is important to achieve this, and hospital managers could have a role in encouraging it.

Hospital managers should also encourage the change in patient-healthcare professional relations, ensuring adequate training for healthcare professionals to work in concordance with patients, and effective dialogue. Better communication is a key issue, as currently patients don't receive as much information as they wish while healthcare professionals believe they supply enough information. This would lead to better adherence, better health outcomes and patient empowerment.

In addition, a more holistic approach to health, including physical, mental and societal aspects is needed. Taking into account comorbidities and long-term associated problems that affect patients such as functional limitations, psychological symptoms, social problems (isolation, impossibility to work, and financial impact of illness) is also fundamental. This can be achieved in hospitals through adequate organisation and training.

We would also generally advise hospital managers to gather and use patients' experience to improve access, quality and safety of care in the hospital: Patients can offer the richest source of information in relation to what they witness in the hospital during their stay, the failures in the systems and good practices, from beginning to end.

Is the EPF Satisfied with the New European Cross-Border Healthcare Directive? Has it Gone Far Enough in Terms of Ensuring Patient Reimbursement and Safety and Quality?

EPF believes the directive is an important milestone for patients: It creates a legal framework for the patients' right to seek healthcare in another Member State and to be reimbursed for it. It also provides a legal basis for enhanced European cooperation in key areas of healthcare. We have had a long and intense involvement in the draft directive, having worked closely with the Commission, the EU Presidencies, and MEPs throughout the first and the second readings to ensure that a patient perspective was strongly reflected.

However the directive falls short on some aspects we considered crucial:

Reimbursement is one area where we had a more ambitious vision. Throughout the process we strongly advocated for a system of direct cross-border payment, to prevent patients and their families having to bear the financial burden upfront. This was in our view crucial to ensure equal access. The directive does leave that option open, but on a voluntary basis. While the compromise is less than we asked for, this point did encounter a lot of resistance so its inclusion in the text is in itself an achievement.

In spite of this, the directive is still a step forwards for patients in this respect, as they are now entitled to reimbursement for the costs of cross-border healthcare as they would under the benefits of their national health insurance system. We welcomed in particular a flexible approach of reimbursement of "a similar healthcare" rather than strictly the same. There is a list of exceptions, but it is limited. One particular point is that application for prior authorisation from patients must receive an answer in a "reasonable time limit", which is not clearly defined. When implementing this, it is important to ensure that patients have access to treatment and care without unnecessary administrative delays.

EPF welcomed provisions for mutual cooperation and transparency on **safety and quality**. Member States will be required to make their national standards and guidelines publicly available. The directive also requires Member States to cooperate with each other on safety and quality standards and guidelines, and to ensure that information in their national/ local registers on specific health professionals' right to practise is made available to other Member States. The directive also contains provision to ensure better continuity of care, patients who have received treatment in another Member State are entitled to a record of the treatment, and if medical follow-up proves necessary, the home country must provide the same follow-up as for treatment received in its territory. We believe this is also crucial for patient safety and quality of care. In summary, though we would have wanted more coordination at EU level on quality and safety standards, we believe these provisions can pave the way towards better cooperation between EU Member States, and ultimately towards better patient safety and quality of care across the Union.

As for the **impact on patients**, it will depend a great deal on interpretation and implementation by Member States. Many provisions in the directive are optional, or leave room for interpretation. Ensuring that patient organisations at a national level are involved in implementation is in

our view key to ensuring this directive is truly beneficial for patients.

One key provision of the Directive is the setting up of national contact points where patients can get information. Patients' organisations should be meaningfully involved to ensure the information given meets high quality principles, and corresponds to patient needs. In addition, the directive offers possibility to build on cooperation between Member States in areas such as e-health, rare diseases and HTA.

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