EPF's Position on the Draft Report on Reducing Health Inequalities in the EU
8 December 2010

Introduction and background

The European Patients' Forum (EPF) is a not-for-profit, independent umbrella organisation of patients' organisations in the EU. EPF currently has 44 member organisations – national coalitions of patient organisations, and European-level disease-specific patient organisations. Collectively EPF reflects the voice of around 150 million patients affected by various chronic conditions. EPF advocates for high quality, patient-centred, equitable healthcare for all patients in the EU.

Equity is a crucial component of EPF's future vision for health, and EPF therefore welcomes the Draft Report on Reducing Health Inequalities in the EU, drafted by Mrs Edite Estrela MEP following the Commission's Communication in October 2009 titled "Solidarity in health: reducing health inequalities in the EU".

In this paper we set out our specific comments on the Estrela report with a view to ensuring that the needs of patients with chronic conditions are included in action on health inequalities. We do not address directly the issues linked to prevention and health promotion, though we are very supportive of the work of fellow health NGOs dealing with these issues at EU level. Our focus is on patient-centred disease management, the needs of patients diagnosed with a chronic condition, and their families.

EPF's position is based on consultation with our member organisations undertaken during the preparation of our response to the Commission's public consultation in 2008, and further discussions in EPF's Policy Advisory Group in 2009. We plan to undertake a further member consultation in early 2011, to gather more data and update the situation in view of the ongoing impact of the financial crisis, which continues to be felt by chronically ill patients across Europe.

General comments

Overall EPF welcomes the report as it builds on the Commission Communisation and addresses some important aspects of health inequalities, including the importance of addressing the gender dimension of inequalities; recognising that certain groups are more susceptible to vulnerabilities; and the need to adopt a "Health in all policies" approach, integrating key polices on social inclusion, social protection, employment, education and information society. However, we feel that the political debate on inequalities has centred so much on prevention and health promotion that it has somewhat eclipsed the importance of chronic disease management. In EPF's view health promotion, prevention and patient-centre disease management are inextricably linked, as we will explain below.

From this perspective, "health equity" when applied to patients can be equated with equity of access to high quality medical and other care, and the patient-centeredness of that care. There are presently huge disparities within the EU in many chronic diseases, both in access to healthcare and in the standards of care. Musculo-Skeletal Disorders (MSKD) and Multiple Sclerosis provide two examples where EU-wide data has been collected.[1]

Overall, EPF supports the five key proposals made by the Commission in its Communication "Solidarity in health: reducing health inequalities in the EU" which are reiterated in the Draft Report. We would like to provide our comments on these key areas as follows:

1. ***Meeting the needs of vulnerable groups***.
   The Draft Report refers to several groups whose needs should be given special attention: people in poverty, disadvantaged migrant and minority groups, people with disabilities, and older people.

   EPF contends that within the spectrum of "health equity" of citizens, *patients with chronic diseases form a clear and distinct constituency with particular needs*, which should be included in the consideration of health inequalities. Patients diagnosed with chronic diseases, and their families, are in a vulnerable position due to the effects of the illness itself, which are often very serious and disabling and have a physical, psychological and emotional impact on the person, their family and immediate environment. Patients are also dependent on having timely access to safe, high quality healthcare and other related support services. Other vulnerabilities are often linked to chronic illness – including the inability to work, direct and indirect costs of illness, loss of income and risk of poverty, social discrimination and stigma.

   Within the above-mentioned population groups there are also many patients with chronic diseases. For example, *older patients* should be considered as a distinct sub-group of the elderly, as well as of patients (paragraph 12). In 2011 EPF plans to undertake a consultation exercise to with its members to identify the specific needs of older patients, the results of which will feed into work around the Innovation Partnership on Healthy Ageing, as well as the 2012 European Year of Healthy and Active Ageing.

   Empowerment: a fundamental change agent
   Patient empowerment is a fundamental aspect of tackling health inequalities among patients with chronic diseases and their families. Empowerment is a process that helps people gain control over their lives, increasing their capacity to act on issues that they themselves define as important. EPF believes that *the empowerment of patients is not only a crucial component of patient-centred healthcare, but also an indispensable part of the future sustainability of European health systems*: to enable them to cope with future challenges posed by demographics, financial and structural reforms, increasing prevalence of chronic conditions, and new innovative technologies. Given these developments, and given the unique experience and expertise of patients in dealing with their condition, we believe patient involvement is key for improving the delivery of healthcare services and ensuring their cost-effectiveness.

   A great deal can be achieved towards empowerment through addressing factors such as *health literacy*, *access to high-quality information*, *attitudinal and cultural barriers*, and building an *enabling, patient-centred healthcare environment*. Patient organisations can play a highly

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[1] On MSKD, presentation given by Prof Ingemar Petersson, Research Director MORSE Programme, at a meeting of the Interest Group on Rheumatic and Musculoskeletal Diseases, European Parliament, 30 November 2010; on MS, the results of the European MS Barometer 2009, published in November 2010 and available at http://www.emsp.org/index.php?option=com_content&view=article&id=121:ms-barometer-2009-results&catid=55:multiple-sclerosis-information-dividend&Itemid=152

effective role in identifying interventions that work for different patient groups in different cultural and social contexts.

Quality information and health literacy

Information is a key dimension of empowerment; *well-informed patients, who are aware of their rights, have better access to health services and better quality of care*. More research is certainly needed on the economic implications of low health literacy, but one recent study indicates they may constitute up to 3-5% of the total healthcare costs.[2]

EPF calls for a *coherent EU-wide strategy on information to patients that encompasses health literacy and eHealth*, and involves patients' organisations in a meaningful way in the provision of health information, sharing of knowledge and good practices.[3] This could be particularly useful to reach out to specific patient groups who may potentially be in vulnerable situations, such as the young and the old, persons with mental illness and their families, minority and migrant groups. The work done by the Commission and Parliament on the legislative proposal for information to the public on prescription medicines should be seen as a starting point, and the Commission should be asked to present a proposal in the near future for a broad information and health literacy strategy.[4]

Patients' diverse and complex needs

These examples from the European Patients' Forum membership, though far from exhaustive, illustrate the urgency, diversity and complexity linked to patients' needs:

- The need to develop supplementary nutritional information in an accessible, effective format for children diagnosed with diabetes from a poor background and their parents;
- The need for translation and cultural adaptation of patient information leaflets and other materials in localities with a large migrant populations;
- The need to provide support for patients and their carers on low incomes, who as a consequence of ill health are vulnerable to poverty, which in turn affects their access to healthcare and the quality of care, creating a vicious circle;
- The information needs of older patients, as well as carers, who may have visual, hearing or other impairments that affect their ability to access and deal with information.

2. *Improving the data and knowledge bases (including measuring, monitoring, evaluation and reporting).*

While we agree that more research is needed to explore in depth specific aspects of health inequalities, it is EPF's view that there is already a very good body of extensive research on health inequalities across the EU using life expectancy and healthy life years as indicators. The key socio-economic drivers are well known. The existing evidence base should now be translated into coherent, targeted actions.

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[2] Eichler, Wieser and Bruegger, "The costs of limited health literacy: a systematic review", *Int J Public Health*. 2009;54(5):313-24.

[3] See the recommendations from EPF"s 2008 Spring Conference on Health Literacy, available online at http://www.eu-patient.eu/Initatives-Policy/Policy/Health-Literacy/ and EPF's position on the draft Directive on information to the public on prescription medicines: http://www.eu-patient.eu/Documents/Policy/PharmaceuticalPackage/EPF%20Statement_ITP.pdf

[4] See the explanatory statement by Mr Christofer Fjellner MEP, in his report of 19 October 2010.

EPF recommends that within the overall EU-level strategy on tackling health inequalities, specific actions should be targeted at patients, focusing on sharing of experiences and good practices from different Member States:

- Identifying and highlighting *good practices on how inequalities relating to specific patient populations are being addressed*, whether in physical or mental illness, urban and rural environments, or diverse cultural contexts. A mechanism should be developed to ensure that *critical success factors* identified in this way can be transferred into more ambitious, larger-scale policy and projects.
- Sharing of good practices and development of the *practical tools needed to facilitate shared decision-making* between patients and health professionals, to support greater patient empowerment and involvement especially in chronic disease management.
- *Research on the real impact of patient involvement*, the results of which could be used to design innovative partnerships between health professionals and patients; develop effective self-management practices: and to transfer identified good practices between Member States and between disease-areas.
- Identifying and sharing of *good practices in integrated management of chronic conditions*. One of the key gaps identified by patients with chronic illness is the gap between health and social care: a relationship that should be symbiotic, is often fragmented and even conflicting, because of organisational and budgetary constraints and poor coordination.

Indicators

EPF recommends that, in addition to the common indicators in the framework of the Social OMC, *specific patient-centred indicators* should be used for evaluating actions that relate to chronic diseases, including at least the following:

- Access to timely screening;
- Access to timely and safe diagnosis;
- Access to the necessary treatments, therapies and supports;
- Access to comprehensive information that meets specific quality criteria[5]
- Attention given to the 'whole picture' (people affected by physical illness can also suffer from mental illness and vice versa)
- Access to advice in matters of civil liability or insufficient quality of care provided by carers or institutions.

However, in addition to quantitative indicators, we believe it is vital to ensure a *direct patients' perspective* in order to understand the psycho-social impacts of health inequalities on individual patients, and their ability to interact with their healthcare environment and their quality of life. This is not an easy task, but crucial to move towards credible and truly patient-centred solutions. Patients' organisations have a key role to play in collecting such patients' evidence.

3. *Building commitment across society for reducing health inequalities.*

The active involvement of all stakeholder groups, particularly patients and patient organisations, in addressing health inequalities is crucial. Patient involvement does not only mean that

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[5] EPF recommends the Core Quality Principles of the Pharmaceutical Forum, endorsed by Member States in 2008: information should be objective and unbiased, patient-oriented, evidence-based, up-to-date, reliable, accessible, understandable, transparent and relevant. The Core Quality Principles are available online at: http://ec.europa.eu/pharmaforum/docs/itp_quality_en.pdf

patients can and should assume more responsibilities within their own treatment; it also includes meaningful involvement at policy level.[6]

EPF believes patient involvement is beneficial for the delivery of healthcare services and health policy, to ensure that services are developed with the patient's needs at the centre. We would recommend that *patient organisations should be actively involved* in all actions aiming to tackle health inequalities, insofar as they relate to the needs of patients with chronic conditions.

4. ***Making a more equitable distribution of health part of our overall goals for social and economic development.***
To do this effectively implies implementing the "health in all policies" approach and monitoring all policy activities at EU level for their potential impact on health inequalities. EPF strongly supports paragraph 15 which calls on the Commission to mainstream an "equity and health in all policies" approach in all EU internal and external policy; paragraph 10, which calls on the Commission and Member States to recognise health as part of fighting exclusion and to include indicators for health inequalities in the Europe 2020 strategy; and paragraph 14 on the use of EU Cohesion Policy and Structural Funds to address health inequalities.

For example, the needs of patients with chronic conditions must be considered in the context of *employment policy*, on a par with the needs of people with disabilities. Although not all people with disabilities are patients, and not all patients are disabled, nevertheless these groups overlap to some extent and encounter similar barriers.

The burden of disease has an impact not only on the lives of the millions of individuals living with chronic illness and their families, but also on the sustainability of health and social security systems and on the wider society. EPF believes that political and economic investment in reducing the disease burden on individual patients and maximising their quality of life, will reap social and economic dividends by *enabling people with chronic conditions to be economically active for longer, and place less burden on healthcare services*. This can release resources that can in turn be invested in prevention and health promotion activities.

5. ***Developing the contribution of EU policies to the reduction of health inequalities.***
Finally, notwithstanding the importance of a "Health in all policies" approach, in this context we would draw attention to several policy areas in health that EPF is actively involved in, which have possible implications for health inequalities, but also potential to help reduce them.

    a) *The draft Directive on patients' rights in cross-border healthcare*: The draft Directive can have a considerable impact on alleviating inequalities in access to healthcare for patients across EU Member States, provided that effective systems for handling direct cross-border payments are put in place. Without such a system, there is a risk of creating new inequalities between patients who can afford to travel and those who cannot.

    The Directive has also major implications for the continued improvement of the safety and quality of healthcare across all EU health systems, through mutual learning and the development and sharing of standards and guidelines. This is very much in line with existing EU-level actions, such as the new Joint Action on Patient Safety and Quality of Healthcare initiated in July 2010.

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[6] For definition of "meaningful patient involvement" see the report of the EU co-funded VALUE+ project, available online at http://www.eu-patient.eu/Publications/Conference-and-Seminar-Reports/

b) *The draft Directive on information on prescription medicinal products.* The legislative proposal on 'information to patients' includes important provisions concerning national information portals, which if set up will go a long way towards *equal access to information* on prescription medicines across the EU. But, as we have mentioned above, information on medicines is only one part – albeit an important part – of patients' total information needs. A comprehensive EU strategy on information to patients and health literacy should build on these proposals, incorporating the information elements from other legislative proposals (such as Pharmacovigilance and Falsified medicines), as well as the ongoing work at the European Medicines Agency on medicines packaging and labelling, with the active involvement of patient and other stakeholder organisations.

Conclusion

The evidence from EPF's membership indicates that patients with chronic illness constitute a distinct "constituency" that is collectively subject to vulnerabilities. EPF therefore calls for the needs of patients to be considered within any action on health inequalities. The concepts of patient empowerment, patient-centredness, and health literacy should be embedded in all EU actions tackling health inequalities insofar as they relate to the needs of patients with chronic conditions.

EPF will prepare a follow-up consultation with its member organisations in early 2011, to update the evidence from our membership regarding the continuing impact of the financial crisis on patients in various EU Member States.

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