

Response from the European Patients' Forum regarding the EC Consultation on Health Services

Key words: patients' rights, safety, accessibility, quality, equity, involvement of patients

Methodology around EPF's consultation with its membership in agreeing this response

The **European Patients Forum** (EPF) welcomes the Commission's initiative to consult on the issues to address through Community action on health services and is pleased to send its contribution.

The European Patients Forum was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of emerging EU patients' movement.

EPF advocates for patient-centred and equitable healthcare throughout the European Union. EPF facilitates exchange of good practice and challenging of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organizations at European level and at Member States level. EPF represents 23 European member organizations.

This response deals explicitly with the **patients' perspective** and does not address directly implications for health professionals and managers in relation to cross-border health care.

Methodology

A draft response was formulated on the basis of informal consultation with the EPF membership. This was circulated to all EPF members with a request for input by 24 January. A final response was circulated on 26 January and was endorsed by EPF membership. We also included input from other health NGO allies, such as Mental Health Europe (MHE).

Common Principles

In preparing this response, EPF has used as a framework the Council Conclusions on Common Values and Principles in EU Health Systems adopted in June 2006¹. These are **QUALITY, SAFETY, EVIDENCE BASE AND ETHICS, REDRESS AND PATIENT CONFIDENTIALITY**.

Question 1

What is the current impact (local, regional, national) of cross-border healthcare on accessibility, quality and financial sustainability of healthcare systems, and how might this evolve?

From a patients' perspective, there is enormous potential in the framework of future European action on health services to enhance access regarding highly quality treatments and services, particular in relation to rare diseases.

EPF also believes that significant advances in accessibility, quality and financial sustainability are possible though exchange of information, good practice and networks of centres of excellence, if sufficient resources are allocated, and the

¹ Council Conclusions on Common Values and Principles in EU Health Systems, 273rd Employment, Social Policy, Health and Consumer Affairs Council meeting, Luxembourg 1-2 June 2006, [on-line], the Council of the European Union, http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/89830.pdf, last accessed, 22 January 2007.

political momentum created through the health services consultation is appropriately harnessed.

There are however a number of broader considerations from a patients' perspective that are addressed in more detail in responses to later questions: these include:

- Potential fundamental inequalities regarding patients' access to health services across the European Union;
- Accessibility, quality and cost implications in relation to pre and post treatment and care and follow-up arrangements;
- Patient safety throughout cross-border treatment, pre and post healthcare, and redress;
- Mental health and stress implications for patients and carers when traveling abroad for treatment.

EPF and its members are of the view that, in general, patients want to benefit from high quality health-care as close to home and as quickly as possible and that travelling abroad for treatment should remain the exception and only pursued under specific circumstances. We would further argue that as far as possible, it should be medical experience and know-how that travel rather than the patient. In this regard, EPF encourages that information and communication technologies should support mobility and continuity of care and facilitate cross-border healthcare without the patient leaving his own country.

Question 2

What specific legal clarification and what practical information is required by whom (eg. authorities, purchasers, providers, patients) to enable safe, high-quality and efficient cross-border healthcare?

EPF believes that the way forward is a policy mix including a legally binding instrument, a political “tool”, for example a Patients’ Charter and, crucially, robust and effective management systems.

The European Court of Justice cases², brought about by patients’ themselves, and subsequent rulings have demonstrated clearly the need for legal clarity in this sphere that can only be achieved by a legally binding instrument at European Union level.

The effectiveness of such an instrument could be reinforced considerably by a political tool, such as a European Patients’ Charter, that clearly lays out circumstances where cross-border care is appropriate, and quality criteria in relation to all aspects of such healthcare delivery (pre and post treatment, access to information, safety, patient confidentiality, systems for redress, administrative procedures etc).

EPF considers that developments should result also from joint cooperation and political consensus between national, regional and local public authorities and purchasers, healthcare providers and patients groups.

At individual level, the issue of patients’ access to high quality, timely and accurate information, in their own language, is critical. This is particularly important before

² Case C – 158 /96 Kohll (198) ECR I – 1931, Case C – 120/95 Decker (1998) ECR I – 1831, Case C-368/98 Vanbraekel (2001), ECR I-5363, Case C – 157/99 Smith and Perbooms (2001) ECR I-5473, Case C – 56/01 Inizian (2003) ECR I-12403, Case C-8/02 Leichtle (2004) ECR I-2641, Case C-385/99 Müller-Fauré and Van Riet (2003) ECR I-4503, Case C-37204 Watts, judgement of May 2006 not yet published; [on-line], the European Court of Justice, <http://curia.europa.eu/en/content/juris/index.htm> last accessed 22 January 2007.

patients go abroad, with questions about the available options for care, their rights and entitlements, cost implications, administrative procedures involved, transport arrangements, and management before and after the main treatment. During their stay they seek information on their progress. After discharge they seek information on follow-up arrangements.

Sister patient organisations in specific disease areas across the EU Member States could play a useful support role in this process, to supplement the formal information received from health authorities. From this perspective, EPF encourages governments to support the effective running of non-governmental organisations (NGOs) representing patients groups. This will support and encourage patients' direct involvement in the decision-making process and will meet citizens' demand that the population and patients be central to the concerns of health policies and healthcare.

EPF welcomes that, in the framework of coordination of national social security schemes for health treatment during a temporary stay in another country³, the Commission introduced the European Health Insurance Card (EHIC)⁴. EPF encourages EU Member States governments to ensure that the European Health Insurance Card and the Form E112 are accepted by health-care service providers and that the regulation is applied in a legally valid manner.

EPF also believes it would be important to explore the potential contribution of the EU Health Portal in this regard, where the legal instrument could be explained in layperson's terms, together with the Patients' Charter, and made available in all EU languages. Research has demonstrated that there is "a need for a better recording of data and for a restructuring of the available data in more accessible ways. Online resources for patients could be user-focussed and tailor information according to the characteristics of the patient, i.e. their country of origin, destination country and

³ Council Regulation (EC) N° 1408/71 on the application of social security schemes to employed persons, to self-employed persons and to members of their families moving within community, [on-line], <http://eur-lex.europa.eu/LexUriServ/site/en/consleg/1971/R/01971R1408-20050505-en.pdf>, last accessed, 23 January 2007.

⁴ Communication from the Commission concerning the introduction of a European health Insurance Card, COMM(2003), 17.02.2003 [on-line], http://ec.europa.eu/employment_social/news/2003/feb/hicard_en.html, last accessed 22 January 2007.

personal circumstances, it could provide relevant information on many aspects of health services in other Member states, as well as facilitate the sharing of personal experiences”⁵.

In parallel with the development of an appropriate legal instrument, it will be hugely important to invest in robust, compatible and workable management systems to ensure transparent, straightforward and rapid administrative processes in relation to patient mobility. Burdensome, unwieldy bureaucracy or delays in decision-making regarding a patient receiving care abroad will undermine both the patient and ultimately the system.

In terms of pre-care and post care, there may be the need for medical records to be made available in the Member State where the treatment is provided. This may have privacy and language implications, and it is clear that eHealth could play a positive role here. Language could also be an issue in relation to “informed consent” matters.

⁵ Rosenmöller, Magdalena (ed) - Europe for Patients – Benefits and Challenges of Enhanced Patients' Mobility. Abstracts. Draft outline Final Book, Chapter 8 – Options for Change, Impact Analysis, page 21, [on-line], Research Project – Europe for Patients, http://www.iese.edu/en/files/6_25268.pdf , last accessed 22 January 2007.

Question 3

Which issues (eg: clinical oversight, financial responsibility) should be the responsibility of the authorities of which country? Are these different for the different kinds of cross-border healthcare described in section 2.2 above?

The country of origin shall remain financially responsible for the reimbursement of healthcare given to a legally residing person who obtains authority to receive healthcare in another EU Member State.

It is important to highlight that the “onus of proof” regarding why healthcare in another Member State is the preferred option, should never be placed with the individual patient, but rather a decision of healthcare professionals working with that individual.

EPF would further argue that it is important to examine carefully the mental health and well-being implications of patient mobility, even in patients and carers who have expressed a willingness and possibly preference to travel abroad for healthcare. This should be reflected in initial dialogue with patients regarding this option, and be assessed carefully during the course of treatment and post treatment care, recognising that interaction with the healthcare environment can be a stressful life event for patients.

When accessing healthcare in general patients may experience stress, fear and psychological burden, which may trigger depression and mental health problems. This involves physical or emotional reactions such as sleeping problems, nutrition problems, concerns about the ability to understand and cope with the information they receive about their conditions, guilt for having “imposed” their condition on the family, anxiety about discharge care, financial worries. These reactions may be augmented in the situation of patients who need to travel abroad.

Information provided by healthcare services to patients need to accurate, reliable and “handled with care”. Providing misleading or incomplete information as well as communicating it poorly can negatively affect patients’ mental health. In particular, the information provided should avoid generating unrealistic expectations or false beliefs about patient’s own health, treatment and care. Evidence shows that patients having realistic expectations are likely to cope better with their own health problems. Consequently, it is essential that provision of information leads to shared expectations between professionals and patients.

The patients’ autonomy and freedom of choice should be respected. Patients should be supplied with useful information enabling them to make their own judgments both on the health treatment and on their health status. The needs and opinions of the patients should be taken into account. The involvement of consumer and family organizations in service planning and delivery should be encouraged and increased.

From this perspective, EPF considers that a European action to promote and protect mental well-being of patients is important and in line with the European Commission’s Social Agenda⁶, with its focus on solidarity and prosperity.

⁶ *Communication from the Commission on the new Social Agenda*, COM(2005)33final, [on-line], the European Commission, Employment and Social Affairs Directorate-General, http://ec.europa.eu/employment_social/social_policy_agenda/spa_en.pdf last accessed 22 January 2007.

Question 4

Who should be responsible for ensuring safety in the case of cross-border healthcare? If patients suffer harm, how should redress for patients be ensured?

The “host” country, or country providing the healthcare is responsible for ensuring safety at the time of delivery, and appropriate provisions must be in place to ensure reasonable care prior and post that intervention either in the host country or in the country of origin. This would require an individualized patient-centred “contract” agreed on a bilateral basis.

Where error, negligence occurs or safety is compromised, the mechanisms for redress should be simple, effective, swift and easy to understand. This should be the responsibility of the health provider at that specific stage of health care provision.

EPF is of the view that in order to comply fully with the safety provision within Article 152 of the Treaty, it will be important to explore an additional safety net at EU level through a structure such as an ombudsman system for patients to address cases where the causal factors and origins compromising a patients' safety straddle both the host country and country of origin.

Question 5

What action is needed to ensure that treating patients from other Member States is compatible with the provision of a balanced medical and hospital services accessible to all (for example, by means of financial compensation for their treatment in “receiving” countries)?

In developments relating to health services we need to make absolutely sure that Community action is fighting health inequalities, rather than reinforcing them; that action in this area is in line with the European Social Agenda focussing on solidarity. From a broader social perspective, patients belonging to socially vulnerable groups (e.g. undocumented migrants, homeless people, Roma people, people with mental health problems, victims of trafficking, asylum seekers, etc) may face stigma, discrimination, no continuity of care, lack of knowledge about entitlements and financial obstacles. Future EU action must counteract concerns that only the wealthier, more educated patient benefit in reality from cross-border healthcare, and that this undermine overall quality of health services by distorting national priorities.

Linked to the issue of health inequalities – he or she should not be obliged to “pay up front”. Appropriate reimbursement arrangements should be agreed for incidental but directly related travel and accommodation costs. A low-income patient is more likely to be excluded from the cost reimbursement procedures, since they are unable, in most cases, to advance the incurred costs.

Another major consideration is the “waiting list” dilemma – what actually constitutes undue delay? The Watt’s ruling highlighted crucially that the decision on what amounted to undue delay should not be based on either the national health services waiting lists, or Government health targets, but rather on the individual’s medical conditions and circumstances. EPF would support this approach and strongly encourages Member States to take seriously into account the “waiting list” issue.

Question 6

Are there further issues to be addressed in the specific context of health services regarding movement of health professionals or establishment of healthcare providers not already addressed by Community legislation?

This question is not directed towards patient organizations. An important principle would be, however, to involve systematically representative patient organizations in a national or cross-border context on specific proposals.

Question 7

Are there other issues where legal certainty should also be improved in the context of each specific health or social protection system? In particular, what improvements do stakeholders directly involved in receiving patients from other Member States – such as healthcare providers and social security institutions suggest in order to facilitate cross-border healthcare?

This question goes beyond the remit of EPF *per se*, however, we would encourage liaison with national patient organisations, and their national platform, umbrella and/or consortia on this issue to ensure a patient perspective that is geared specifically to the socio economic, cultural, and realities of individual Member State.

Question 8

In what ways should European action help support the health systems of the Member States and the different actors within them? Are there areas not identified above?

EPF is of the view that EU action on health services is inextricably linked with other prominent spheres of health care policy at EU level, specifically information to patients, the new health strategy⁷ embracing core issues, health mainstreaming and global health challenges, as well as the Action Plan for a European e-health area⁸. It is clearly important to ensure an appropriate juxtaposition between all EU interventions on health, and a seamless, accessible approach that represent clear building blocks towards better health for EU citizens.

EPF strongly welcomes a European health strategy as a spring-board to mainstreaming health and believes that, for patients groups, there is much potential for progress through an EU-led approach.

As mentioned earlier, it would be useful to explore the practical added value of using the health portal as one potential vehicle in communicating the legal instrument, political tool and the management framework and “path” towards patient mobility in each Member State.

EPF believes that support is needed from the EC to further research and collection of good practices on patient’s cross-border mobility experiences. This would offer a valuable opportunity for mutual learning and identification of good practice.

⁷ *Health in Europe: A strategic approach. Discussion document for a Health Strategy*, [on-line], the European Commission, Health and Consumer Protection Directorate General, http://ec.europa.eu/health/ph_overview/Documents/strategy_discussion_en.pdf , last accessed 22 January 2007.

⁸ *e-Health – making healthcare better for European citizens: An action plan for a European e-health Area*, COM(2004) 356 [on-line], the European Commission, Europe Information Society Thematic Portal, http://ec.europa.eu/information_society/doc/qualif/health/COM_2004_0356_F_EN_ACTE.pdf , last accessed 22 January 2007.

EPF is of the view that there is a need for a framework for exchange and cooperation, which will encourage quality comparisons. The Open Method of Coordination (OMC) in the area of social inclusion and long-term care has provided good scope for addressing some patient-related issues. However, progress is necessary so that patients groups across the EU benefit from mutual learning through transnational exchanges and sharing of information and experiences.

EPF would also welcome a mechanism within the European Commission for linking the various Directorates General and structures which would have a direct relevance to patient issues. EPF believes that it is fundamental to advance the coordination between different policies both at EU level and national level.

On a more general note and in the background of the current debate on the EU Constitution, EPF believes that more regular and accessible information is needed from the European Commission to inform EU citizens about their rights. The Health Services consultation is highly timely and can be an opportunity for the EU to become closer and more relevant to citizens.

Question 9

What tools would be appropriate to tackle the different issues related to health services at EU level? What issues should be addressed through Community legislation and what through non-legislative means?

As mentioned earlier, EPF believes that action should be three-fold.

- 1) A binding legal instrument to offer clarity on cross-border healthcare that builds on existing jurisprudence;
- 2) A political tool such as a Patients' Charter that will serve to encourage public awareness and confidence;
- 3) Robust and compatible management systems to ensure patient-centred high quality delivery in practice that is not hindered by complex bureaucracy.

To complement these actions, it would be useful to explore whether initiatives in the framework the Open Method of Coordination, the Structural Funds and the EC Public Health Programme and eventually the Seventh Framework Programme on Research and Development could contribute towards knowledge building and information exchange in relation to cross-border health services and to monitor future application and utility.



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