

Brussels, 19 January 2010

## ***EPF's Verdict: Cross-Border Healthcare***

The European Patients' Forum welcomes the draft Directive on cross-border healthcare, adopted today by the European Parliament. We have had a long and intense involvement in the Draft directive, having worked closely with the Commission, the EU Presidencies, and indeed MEPs throughout the first and the second reading to ensure that a patients' perspective was well reflected in the Parliament's position.

Though the compromise adopted today falls short of our ambitious vision, EPF nevertheless welcomes the Directive as it creates a legal framework codifying patients' rights into EU law. We believe that many aspects of the Directive can be built upon, to achieve better quality care for all patients.

Much of the value of the Directive lies in the basis it sets for future European cooperation in crucial areas, such as HTA, quality and safety, eHealth and rare diseases. We hope that Member States will be encouraged to uptake and make full use of the opportunities in these areas.

Specifically, while EPF called for more EU-level coordination on ***safety and quality standards***, the provisions for Member State cooperation, and the transparency requirements regarding national standards and guidelines will, we hope, contribute to on-going progress towards better patient safety and quality of care across the Union, whether at home or abroad.

Regarding ***Health Technology Assessment***, EPF is particularly pleased that the European HTA Network created by the Directive provides for the involvement of stakeholders, including patient organisations, in its functioning. This is a key provision in view of the growing contribution of HTA to the sustainability of health systems across the European Union, and the importance of knowledge sharing and transparency in this arena. Patients' involvement is essential to ensure that health services are genuinely patient-centred and address patients' needs effectively.

***e-health and telemedicine*** services form an essential support to patient safety and continuity of care across borders. While we welcome the creation of a European eHealth Network to foster cooperation between Member States and to draw up guidelines on cross-border patient data, this cooperation is weakened by being entirely voluntary, and with no stakeholder involvement. Furthermore, we regret that the Directive omits to apply the same safety and quality standards to eHealth as to non-electronic health services.

Regarding the ***costs to the patient of cross-border healthcare***, EPF advocated strongly for a system of direct cross-border payments in order to ensure equitable access and avoid patients and their families having to bear the financial burden upfront. The Directive does include such an option albeit on a voluntary basis. While this is clearly less than a perfect solution from the patients' viewpoint, the opportunity is there and EPF will work with its member organisations to engage in the implementation process at national level.

EPF was in favour of more limited justification for ***Member States to restrict patients' access*** to cross-border healthcare and the reimbursement of such healthcare. While we are pleased that there is finally a 'closed' list of reasons, and that any restrictions must be limited to what is "necessary and proportionate", it remains unclear under what criteria Member States shall judge what is necessary and proportionate. It is also disappointing that the Directive does not set out a specific time limit

during which patients must have a decision on prior authorisation. Given that what constitutes a “reasonable” time is left up to the national authorities to define, this may lead to inequalities between Member States.

The compromise on **rare diseases** is broadly satisfactory; while more could have been done it is a step in the right direction. Member State are encouraged to cooperate in developing diagnosis and treatment capacity, particularly through the creation of European Reference Networks with special focus on rare diseases. The possibilities offered by Orphanet and the existing Social Security Regulation for patient referrals abroad will be better exploited.

Another key issue from EPF’s perspective is **accessible, clear and reliable information** for patients, to empower them to make an informed choice. EPF welcomes the establishment of national contact points to provide such information, and the provision that these contact points will consult with stakeholders, including patient organisations. This is absolutely crucial to ensure that the information provided meets patients’ real-life needs and is provided in patient-friendly formats.

Much now depends on the way the Directive is implemented by Member States; its full impact on patients and all the other involved parties will only become clear in the course during the coming years. The **involvement of all relevant stakeholders in implementation and monitoring** will clearly be key to success. EPF, through its 47 member organisations across Europe, aims to engage actively in the implementation of the Directive to ensure that patients’ views are heard in that process.

EPF is preparing a detailed analysis of the draft legislation, next steps and proposed actions by the patient community at national level, which will be shared and discussed with our membership in the very near future.

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The European Patients’ Forum (EPF) is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe. We advocate for patient-centred, equitable healthcare, and the accessibility and high quality of that healthcare. EPF currently represents 47 patient organisations – national patients’ platforms and chronic disease-specific patient organisations at EU level. EPF reflects the voice of an estimated 150 million patients affected by various chronic diseases in the EU.