

## EPF's Response Statement

### Public consultation on Cross-border Healthcare – evaluation of patients' rights

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11 February 2021

The European Patients' Forum (EPF) has engaged extensively with Directive 2011/24/EU and welcomes the opportunity to comment. EPF has undertaken extensive measures to raise awareness amongst patient communities across the EU, through information materials for patient organisations and a series of regional and national meetings. We have also published several position statements and recommendations to policymakers and National Contact Points.<sup>1</sup>

Our work has identified the following priorities:

#### 1. Patients' rights

**Patients have a right to timely and affordable, high-quality care, information, and empowerment.**

The original purpose of the directive was to clarify patients' legal rights. For a right to be meaningful, people need to know they have it, and be able to exercise it in practice. An EU study in 2016 found that frameworks vary across the EU and there are weaknesses in the enforcement of rights. In addition, other factors such as health literacy can affect people's capacity to exercise their rights. EPF recommends that a framework for monitoring the realisation of patients' rights should be established at European level, including a clear mechanism to address complaints when patients feel their rights have been violated.

#### 2. Information for patients

**Information for patients should be re-evaluated.** Particularly, clear information about patients' entitlements, even within the domestic healthcare system, was a gap identified by our members. EPF compiled a summary of information that patients would need at different stages of the decision-making and healthcare journey, which could be taken as a reference. When it comes to receiving treatment abroad, financial implications of the choices available are quite important to know in advance.

#### 3. Equity of access

**All patients should have the right to timely, safe, high-quality healthcare** based on need rather than means, regardless of where they live, in accordance with the fundamental EU values of solidarity, equity and universality. Timely treatment reduces the burden on patients and families and can help lower long-term health costs.

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<sup>1</sup> <https://www.eu-patient.eu/policy/Policy/Patients-Mobility/>

While the Directive has led to progress in important areas such as eHealth, HTA and ERNs, it has yet to fulfil the main expectation of patients – namely to ensure access to treatment abroad when necessary. There remain unacceptable inequities between patients from poorer and wealthier countries. In EPF's view, the goal should not be to enable health tourism for wealthy consumers, but to redress fundamental health inequalities.

Key issues that present barriers to patients are the requirement for upfront payments and the low level of reimbursements. Member States could thus make more effective use of the Regulation when it is more beneficial for a patient. In addition, direct payments should be implemented to avoid burdening already vulnerable families further.

#### **4. Patients' involvement in assessing the Directive**

EPF calls for the involvement of patient organisations in assessing the Directive. The Commission should engage with patient organisations from several disease-areas, including rare diseases, cancer, but also others where access barriers exist, and patients would benefit from being able to have cross-border treatment.

*For EPF's full recommendations please refer to our position statement, attached and available [here](#), or visit our website at <https://www.eu-patient.eu/policy/Policy/Patients-Mobility/>.*