

THE FIRST DIRECTIVE FOCUSSED ON 'PATIENTS' RIGHTS' – WHAT DOES THIS REALLY MEAN FOR PATIENTS ?

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“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

Who are EPF?



- Independent, non-governmental advocacy organisation set up in 2003 – 64 member organisations
- Cross-cutting advocacy – issues that interest all patients with chronic conditions

- Vision

All patients in the EU have equitable access to high quality, patient-centred health and social care

- Mission

To ensure that the patient community drives policies and programmes that lead to positive changes for patients



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The EU Directive on cross-border healthcare



- Existing EU Regulations on social security systems – right to access healthcare in other MS in particular cases
- Patients’ rights evolved through judgements of the European Court of Justice (ECJ)
- The aim of the Cross-Border Healthcare Directive was to clarify the legal rights of patients across the EU
- The directive is not perfect – text evolved significantly during a long “legislative journey” – 2.5 years – final document is in many respects a compromise – gaps and areas of uncertainty remain
- Nevertheless, it is an important milestone for patients

Key benefits

- Recognition in EU law that patients have a right to cross-border healthcare and to be reimbursed
- Right to information – creation of NCP in each Member State
- Right to a copy of the medical record
- Right to appropriate medical follow-up
- Recognition of prescriptions made abroad
- Transparency of quality/safety standards for healthcare
- Legal basis for MS co-operation on eHealth and HTA, rare disease (European Reference Networks), quality/safety standards



Lithuania – why is the Directive important?



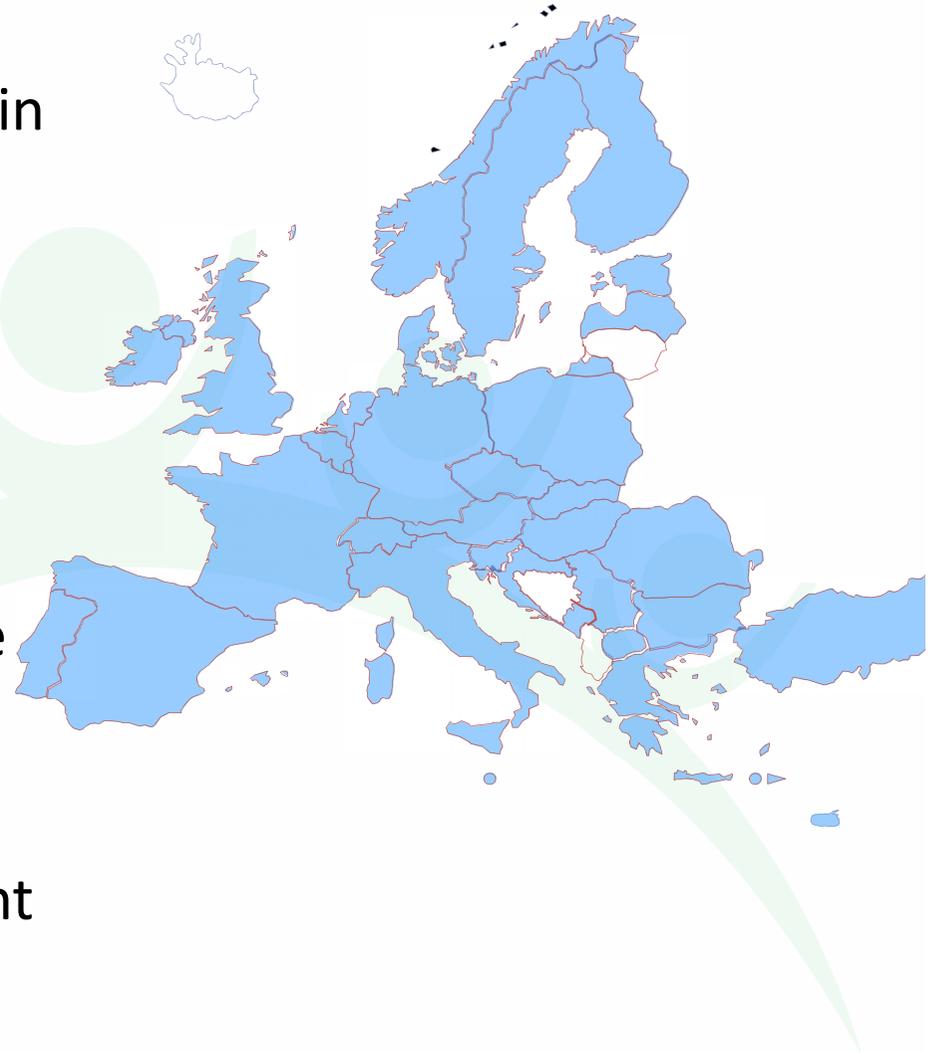
- Right to choose
- More flexible options for patients to get medical services as soon as possible – although only if they can pay upfront
- It will stimulate providers to strive for improving quality – important for patients in Lithuania who access care “at home”

Lithuania – national/regional context

- Lack of specialists
- Long waiting lists for specialist visits in some specialisms
- Dental care
- Rare diseases
- High cost of modern treatments, high co-payments
- Some Lithuanians go to Poland for treatment
- Barriers faced by patients in Baltic countries generally: upfront payments, low health literacy, lack of information about the Directive

Some areas of uncertainty/concern

- Implementation so far – MS are in different stages, will all comply?
- Equity – will cross-border healthcare be an option for all citizens?
- Information and support – will NCP become an enabling service or a gatekeeping mechanism?
- Establishing a continuous and transparent dialogue with patient organisations → Ministries of Health → and NCPs



Equity of access

- Directive: non-discrimination, principles of universality, access to good quality care, equity and solidarity –
- HOWEVER upfront payment will be a barrier for many
- EPF wanted a system of direct cross-border payments to ensure equitable access – Directive includes this but as a voluntary option
- Undue delays: is the “medically justifiable time limit” to provide treatment the same in Sofia, Dublin and Tallinn?



Reimbursement and upfront payment



- Reimbursement = same amount as “at home” for similar treatment
- MS obliged to cover only the cost of treatment (Article 7 (4)) – but can decide to reimburse the *full cost* of the treatment and extra costs, (Article 7(4), recital 34)
- Upfront payment – patient pays & claims back the expense afterwards
- MS must have a transparent mechanism for reimbursement – based on objective, non-discriminatory criteria (Article 7 (6))

Example

| | At home | Country A | Country B | Country C |
|----------------|---------|-----------|-----------|-----------|
| Treatment cost | €100 | €120 | €90 | €75 |
| Reimbursement | €80 | €80 | €80 | €75 |
| Patient pays | €20 | €40 | €10 | None |

- BUT patient pays upfront – claims reimbursement
- Travel & other costs not covered

Directive or Regulation?

- Sometimes it is better for the patient to access CBHC under the Regulations than the Directive (with prior authorisation)
- Regulations
 - only cover public-sector or contracted providers
 - require prior authorisation
 - BUT cover patient's actual costs
 - AND possibly better for rare diseases
- NCP is obliged to inform patient which regime is better

Direct payment options

- The Directive allows MS a possibility to reduce the financial burden on patients – by using prior notification (article 9(5))
 - Patient could obtain prior notification & receive written confirmation of the level of reimbursement before having the treatment – would help patients to calculate the costs
 - MS can put in place a mechanism for direct transfer of costs across borders (under existing mechanism for the coordination of social security systems (EU Regulation No. 883/2004))
- Voluntary – but patient organisations should advocate in favour of these options to increase equity of access

Information to patients (i)

- NCP must provide information on:
 - Patients' rights, Directive vs Regulations
 - Reimbursement and administrative procedures, prior authorisation
 - Procedures for appeals, redress, complaints
 - Information about healthcare providers
 - Quality and safety standards that apply, including healthcare providers' fitness to practice
 - Accessibility of hospitals
 - Cross-border prescriptions
- NCPS should provide all information needed for a patient to make an informed choice
- Easily accessible, available electronically, accessible to people with disabilities



Information to patients (ii)

- Healthcare providers should also provide the information needed to help patients make an informed choice:
 - treatment options and their availability
 - quality and safety of the healthcare
 - information on prices
 - clear invoices
- They must also provide information about their authorisation /registration status and professional liability insurance (Article 4(2)).



Information to patients (iii)

- These transparency provisions have a lot more potential than just to inform patients considering treatment abroad
- Patients and patient organisations can use them to get informed about their rights, the safety and quality of treatment and how it compares to other MS
- These tools can be used to push for better quality and access to healthcare also “at home”
- We hope they will lead to improvements across the EU, for all patients



Implementation and monitoring



25 October 2013: Directive is applicable

25 October 2015: First implementation report by EC

Key opportunity to assess whether the Directive is a success from the patients' perspective

Member States are obliged to help the Commission by providing all available information they have – patient organisations should give feedback to national authorities and to the EPF – your views on the strengths and weaknesses of the Directive

What can Patient organisations do?

- Engage with your NCP, give feedback on how it serves patients
- Ask your government to set up a system for direct payments and/or prior notification
- Give feedback to EPF EC on all aspects of implementation – how it “works” for patients (and when it doesn’t)
- Provide information on your organisation’s website
- Monitor the information provided on quality and safety standards – how can you use it to improve quality of care in your country
- Use the EPF tools



More information – links



[EPF position statements on cross-border healthcare](#)

[EPF “toolkit” on cross-border healthcare: guidance and recommendations](#)

[Core quality principles for information to patients and methodology for use](#)

[Value + resources for patient involvement](#)

[EPF position statements on health literacy and information to patients](#)

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