



You Impact! From Citizen Involvement to EU Policy Impact

*“Improving patients’ rights in the age of the Cross
Border Healthcare Directive”*

**From concerns to proposals:
towards an European Patients Centre Network**

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1. Current concerns
2. A practical example: the situation in Italy
3. Ongoing issues. What's still missing?
4. Towards an EPC-NET on cross-border healthcare
5. Open questions

- The transposition process has been slow and almost "in the dark";
- The involvement of citizens' organizations is yet to be considered a priority;
- Information to patients on their rights under the Directive is currently lacking;
- Member States seem much more concerned with technical and legal issues related to the adaptation and revision of the national legislation than with the management of the short term practical implications of these provisions;
- Associations disapprove that patients should anticipate the cost of treatment;
- The provisions of the Directive may be hindered by a cultural approach since health workers should be the first to be more open and available to patients from other countries.
- Language is the main obstacle in reading/understanding medical prescriptions;
- Cooperation among National Contact Points is still largely lacking;
- Within patient association, the lack of internal resources specialized in the topic;
- The “patient journey”: before leaving, during the stay, after.

Reasons:	%
Surgery	35
Innovative therapy	29
Diagnostic	18
Specialized consultation	13
Transplantation	5
Tot.	100

Therapeutic area	%
Oncology	32
Neurological disease	30
Rare disease	17
Cardiology	13
Orthopedics	8
Tot.	100

Problems:	%
Prior-authorization delayed	36
Lack of information	27
Authorization denied	23
Difficulty to obtain reimbursement	14
Tot.	100

Data from 269 reports received by citizens

Harmonization and standardization of data is far from being realized

- Data collection should be improved: only 17 of the 21 Member States who introduced a system of prior authorisation were able to supply data on applications for authorisation.
- A total of 109.223 such requests were recorded in 2014. Five Member States had fewer than 100 requests for information (Portugal, for example, recorded just 6).
- Ten Member States recorded more than 1.000 information requests.
- Three Member States alone accounted for nearly 75 % of the requests recorded: Germany (36.602); Finland (25.207); and Austria (15.536). These much larger figures are probably due to website visits being recorded as information requests in these three Member States.

Accessible and comparable information among healthcare structures and among countries

An integration of different European policies

- Introducing rules on mediation, ODR/ADR
- To integrate the principles of the Directive in the context of the EU mobility policy
- The experience of the ECC-Net in the healthcare

Starting from the experience of the European Consumer Centres Network (ECC-Net), promoted by EU Commission to manage cross-border issues in the consumer policy, to build a European Patient Centres Network (EPC-NET) with the direct involvement of patient organizations. Here its added values:

- Be a reference point for patients seeking care abroad when they need advice or support before, during or after their stay in another country,
- To be in touch with their counterpart in another country to facilitate the exchange of information or data collection as well as to share best practices, monitor citizens' problems and identify common solutions on cross-border healthcare.
- To strengthen the cooperation among other actors involved, such as the National Contact Points, the European Reference Networks.



- ✓ MEPs of the Interest Group “European Patients' Rights & Cross-Border Healthcare” are ready to support this proposal
- ✓ ACN is going to start a biannual communication campaign in the EU Countries, which is the first step towards this European Patient Centre Network

... what about YOU?

1. We are aware that the lack of economic resources does not encourage Institutions to undertake this solution, but please explain us **why consumers' issues on cross-border can be managed while patients' issues cannot?**
2. We are also aware that the EU Commission is directly accountable for consumers' issues in the European Union, while each Member State is responsible for its own Health system. Of course we are not suggesting changing the EU treaties, but just to find a common solution for common problems. **Why would you protect more a consumer when he buys a product abroad rather than a patient when he cover cost for a healthcare service abroad?**
3. Based on your experience, **what are the main challenges or concerns in your country for patients willing to travel abroad for care?** Have you got any data or significant case history you would like to share?

Thank you for the attention!



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