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You Impact! From Citizen Involvement to EU Policy Impact

## Improving patients' rights in the age of the Cross Border Healthcare Directive

*An European debate and webinar among Institutions, experts, civic & patient organizations, students*

*Istituto Luigi Sturzo, Sala Rossa - Via delle Coppelle n.35, Roma*

*10.30 – 15.00*

*Rome, 4 of March, 2016*

### Preliminary research

#### Framework

[Active Citizenship Network](#), European branch on the Italian NGO of [Cittadinanzattiva](#), is participating at the European project "[From Citizen Involvement to Policy Impact \(U-Impact\)](#)" supported by the Europe for Citizens Programme of the European Union.

The project coordinates citizen involvement with the public authorities on national and European level in nine European countries (Albania, Belgium, Cyprus, France, Estonia, Italy, Romania, Spain) in order to increase the impact of citizen initiatives on the policy making process in the European Union. In this context ACN will organize a conference in Rome in the first half of 2016 on the topic of "Improving EU Citizens' Rights in the European Union". As the topic is very broad, Active Citizenship Network will focus on one of its expertise: strengthening and protecting patients' rights, as it is officially recognized by the EU Commission-DG Santé in the [EU Health Policy Forum](#) as European stakeholder in the fields of public health and healthcare.

#### Overview

Patients want to access cross-border health services when treatment is not available in their home country, when it is managed better elsewhere, or, as in the case of many border areas, when the nearest available care is in another Member State. Currently, cross-border healthcare accounts for approximately 1% of the overall EU public health spending – around €10 billion per year.

The [Directive 2011/24/EU on patients' rights in cross-border healthcare](#) has been regarded by many as a major achievement of the 'patient empowerment' policy promoted by patient organizations as well as European institutions, granting European citizens the right to access healthcare services in a different member state. Designed to address the obstacles deriving from the diversity of healthcare systems, such as the reimbursement rules and the delivery of healthcare services, the "Cross-Border Healthcare Directive" has established a general legal framework aimed at maintaining the sustainability of health systems while protecting patients' right to seek treatment outside their home country.



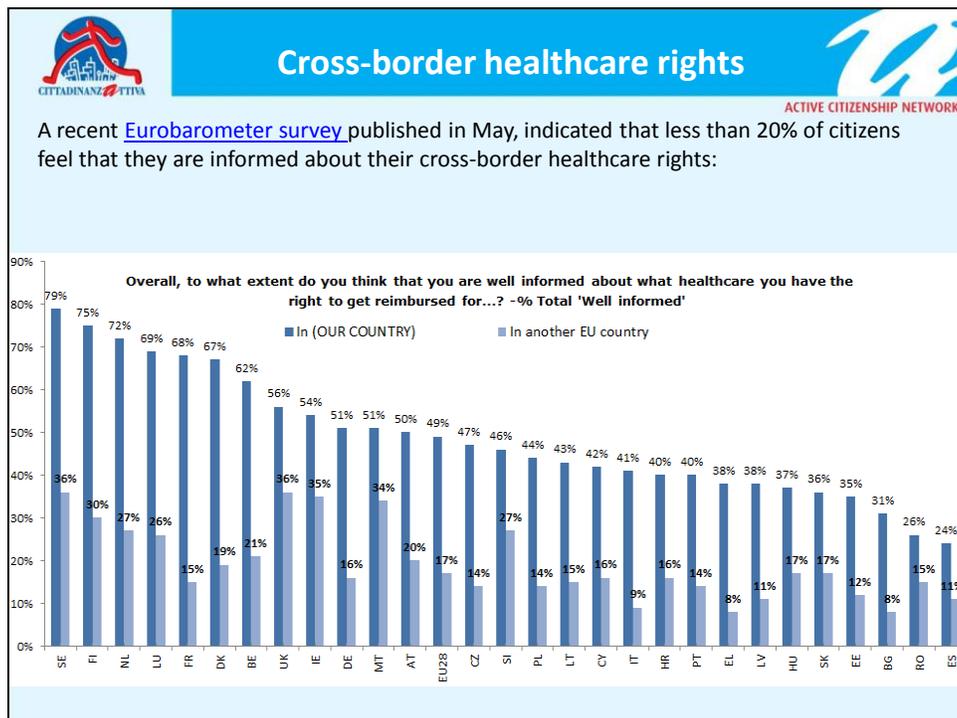


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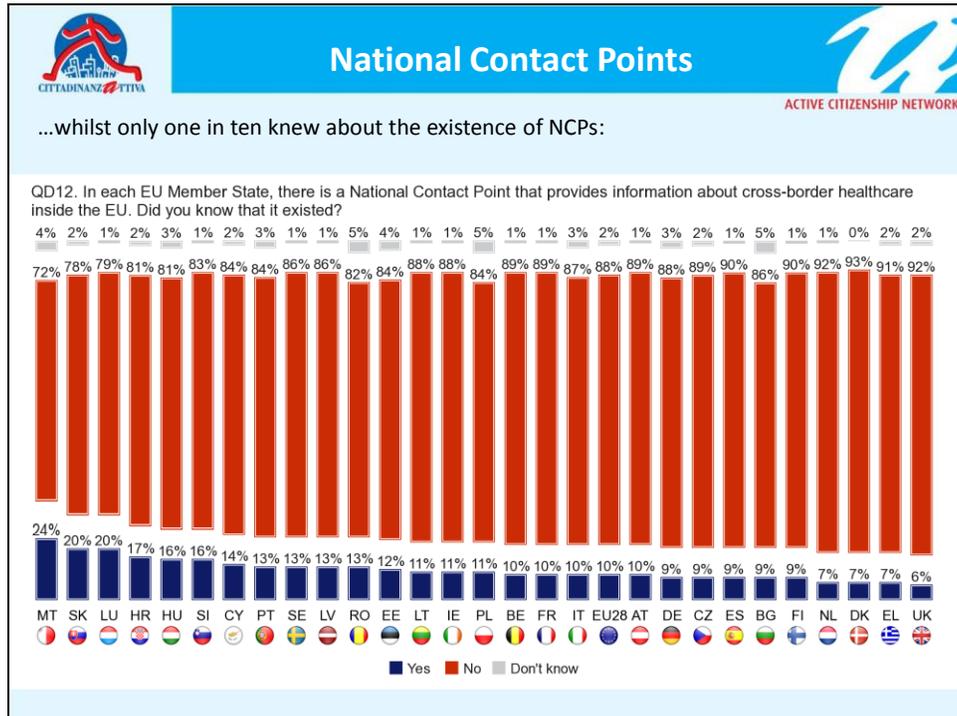
According to the World Health Organization’s report on ‘Cross-Border Healthcare in Europe’, the volume of patient mobility within the European Union remains relatively low as people are frequently unwilling to travel to other countries for care. On the other hand, where patient mobility exists, this has raised issues related to its impact for patients, health professionals and health systems.

The report on the state of play of the Cross-border Healthcare (CBHC) Directive, published by European Commission September 4<sup>th</sup> 2015, clearly shows that European citizens’ awareness about their right to choose healthcare in another EU country remains low. Less than two in 10 citizens feel they are informed about their rights in this area, and only one in 10 are aware of National Contact Points (NCPs).





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These aspects have provoked calls for better coordination of health systems and policies across the EU, resulting in the implementation of the ‘Cross-Border Healthcare Directive’. The impact of Directive 2011/24/EU will depend to a large degree on the knowledge of patients across the EU of their rights under the legislation and its potential benefits.

At the moment in EU only 2% of citizens had planned treatment abroad BUT, if properly adopted, the Directive can provide to reduce regional differences within each country, with benefits for the rest of 98% of the EU population. In fact we believe that not only the Directive can become a tool to find medical assistance in another country, but we also expect that in every place of care, in every country, region or local health service, every patient has equal rights to access to care, to information and free choice, to innovation, to quality and safety of care, to forward complaints. It is fundamental to clearly show that the innovative potential expressed by the Directive is strong and thus we are committed to work for its implementation.

**The aims of the initiative**

- Promote a constructive debate on a crucial achievement for European citizens and patients, the Directive on patients’ rights in cross-border healthcare, as well as on the current state of its implementation throughout Europe. The fact that the Directive title contains the words “patients’ rights” demonstrates that this normative highlights the relation between citizens/patients and healthcare systems.
- Discuss concrete actions in order to facilitate access to better and safer care for patients in the EU.
- Raise awareness through examples of a “grass-root” participation, how civic organizations can play an active role in the European policy making in the field of patients' rights.



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### The role of the experts in the debate

Panelist will be invited to discuss a “call to action” and a communication campaign that Active Citizenship Network will present during the event, and to answer the following questions:

1. 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?
2. What should be done at EU level because the transposition process would not only be a “problem” of single Member States but a coordinated action supervised by the EU institutions?
3. What can we DO and PROPOSE as a group of different stakeholders for a more effective implementation?

### Brief presentation of ACN

Active Citizenship Network (ACN) is one of the most widespread and flexible European network, composed by more than 100 civic, patients and users organizations. Established in 2001, it is coordinated by Cittadinanzattiva, the Italian non-profit organization founded in 1978, independent from any political affiliation, trade unions, private companies and public institutions.

The main objectives of ACN are the promotion of civic activism and participation in the political arena, and the protection of citizens’ rights, which are both the strength and the uniqueness of ACN.

Citizens are a key resource for democracy; they play an active role in society and should be given the opportunity to participate in current policy-making, starting from the healthcare field.

In 2002, after 20 years of experience carried out in Italy with its national branch Court of Patients’ Rights, Cittadinanzattiva decided to promote with its EU branch, Active Citizenship Network, the [European Charter of Patients’ Rights](#), involving patient organizations from 12 different EU countries. The Charter is used for civic assessment on the respect of a set of 14 patients’ rights all around Europe, and at the same time to provide a legislative common EU framework in the field of patients’ rights from a civic perspective<sup>1</sup>.

Recently, the EU Directive on the application of patients’ rights in cross-border healthcare officially recognizes the “right to free choice”<sup>2</sup> and the “right to information”<sup>3</sup> included in the European Charter of Patients’ Rights.

Article 6 § 1 of the Directive establishes that “Member States shall ensure that the national contact points consult with patient associations, healthcare providers and health insurance agencies”, recognizing and enhancing also the ultimate principle of the European Charter of Patients’ Rights, namely the “right to participate in policymaking in the health area”.

This was possible also thanks to the dialogue between the Commission, the European Parliament and citizens’ & patients’ associations, including Active Citizenship Network.

<sup>1</sup> The right to preventive measures; access care; information; consent; free choice; privacy and confidentiality; respect of patients’ time; observance of quality standards; safety; innovation; avoidance of unnecessary suffering and pain; personalized treatment; to complain; to receive compensation. All these rights, based on the Charter of Fundamental Rights of the European Union (art. 35), are crucial in matter of European citizens and healthcare services.

The majority of these rights are also embodied within the EU Council Conclusions on Common values and principles in EU Health Systems adopted in June 2006 and are highlighted inside the following official EU document: (EP Resolutions P6\_TA(2007)0073 and (2006/2275(INI); EESC Opinion (September 26, 2007).

<sup>2</sup> “Everyone has the right freely to choose among different treatments and suppliers on the basis of adequate information”.

<sup>3</sup> “Everyone has the right to access all information regarding their health status, health services and their use and all that scientific research and technological innovation provides”.



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In 2007, ACN received the Civil Society Award of the EESC for its work on patients' rights and launched the EU Patients' Rights Day. It is now celebrated every year on 18<sup>th</sup> April through local, national and EU events organized all over Europe. On May 2015, in occasion of the IX Edition of the European Patients' Rights Day, ACN launched the new [Member European Parliament Interest Group "European patients' rights and cross-border healthcare"](#), officially presented in the EU Parliament last December 2<sup>nd</sup>, 2015.

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