



**U-Impact! From Citizen Involvement to EU Policy Impact**

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

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## **The EU Charter of Patients' Rights A civic Assessment**

Active Citizenship Network has developed two European Assessment programmes on the respect of the European Charter of Patients' Rights

The last study (2011) was done by collecting three types of information

- A. **Institutional** actions for patients' rights
- B. Actual conditions of **hospital** patients
- C. Alerts from **civic organizations**

Involving: **20** countries, **56** hospitals, **23** Ministries of Health and **70** civic organizations

# An overview of the results

Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS – care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
<b>TOTALS - MEAN VALUES</b>	<b>PARTLY RESPECTED</b>	<b>62</b>

## Right to Respect of Patient Time – NOT RESPECTED

### At Institutional level

Only in 4 countries maximum **waiting times** both for specific exams and not urgent surgical procedures have been legally established.

Moreover a problem of **transparency** emerges, both at institutional and at hospital level, as citizens can hardly find information on the waiting lists for diagnostic exams, treatments and elective surgery.

### Worrying indicators from hospitals

publicly-available lists of admittance for elective surgery: hospitals of only 3 countries at least “good”

publicly-available wait times for in-patients and out-patients: only 6 countries scored “excellent”

### Alerts from civic organizations - violations concerning:

illness worsened because of a delay in treatment;

illness worsened because of a delay in diagnosis (due to waiting times);

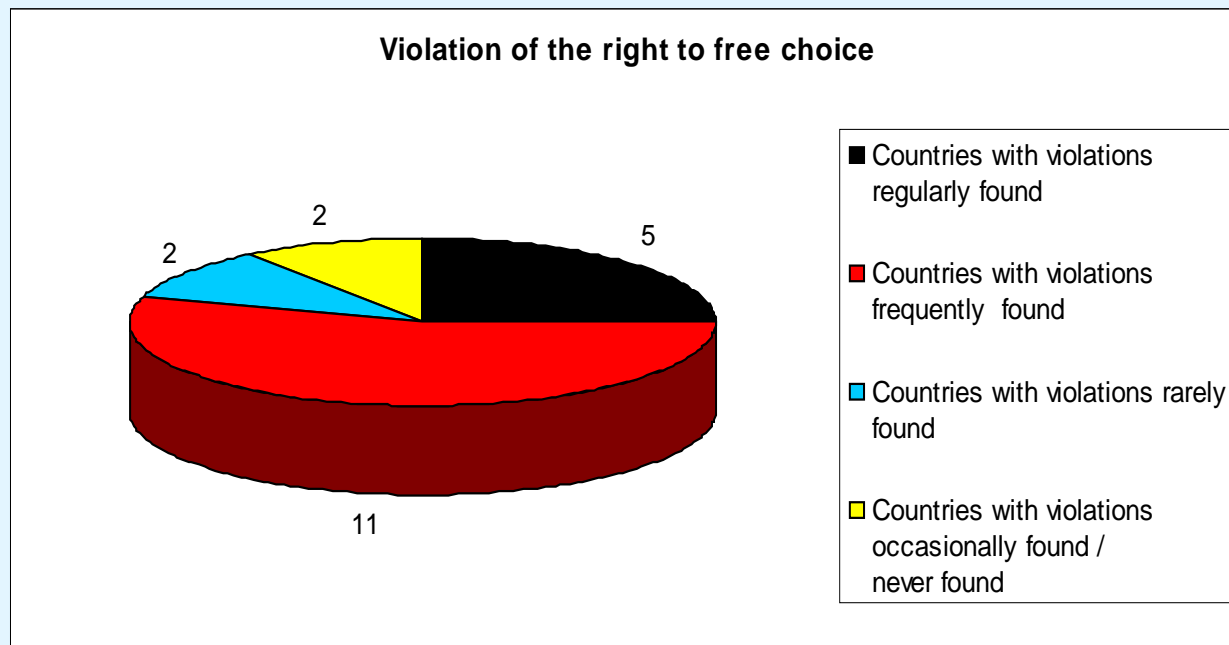
excessively long waiting times for specific exams

## Right to Free Choice – NOT RESPECTED

A **peculiar assessment**: based only on **violations** detected by civic organizations

### Violations concerning:

- Incentives to seek treatment in certain hospitals or centres
- Coverage of supplementary insurance for only some hospitals
- Difference in fees between public and private hospitals
- Need to get authorization for some treatments



## Right to Free Choice – NOT RESPECTED

- Free choice is recognized in principle in all of the countries
- Often actually limited by: organizational procedure and insurance companies rules
- According to 60% of the civic organizations, administrative authorities and insurers tend to provide incentives for access to determinate hospitals and centres

**In sum, what emerges is a “choice” that is not in fact very free and that is burdened with many obstacles**

## Right to Access – NOT RESPECTED

For a correct evaluation of the right to access, it is necessary to distinguish between:

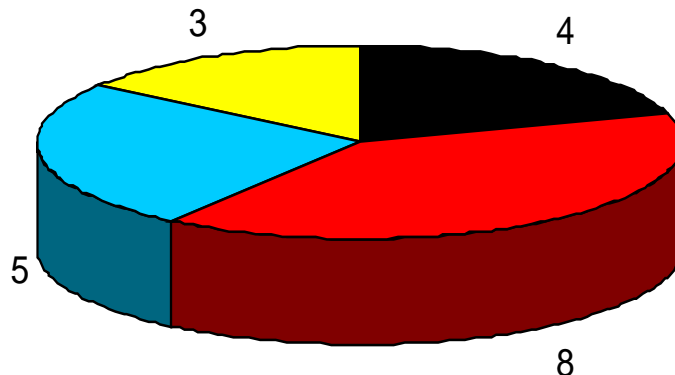
“physical access” to hospitals (transportation, parking, absence of barriers, etc.):  
ALMOST RESPECTED (the “best” score)

“access to care”: this aspect refers to that which is explicitly declared in the right: access to needed health services. This aspect was examined by means of information reported by civic organizations, which responded to a questionnaire regarding cases, if any, of violations of the right of access to care: NOT RESPECTED



The image that emerges from the direct experience of the civic organizations is very grave. These organizations report an overall high frequency of violations

## Violation of the right to access concerning: Discrimination on the basis of financial resources Place of residence Kind of illness



- Countries with violations regularly found
- Countries with violations frequently found
- Countries with violations rarely found
- Countries with violations occasionally found / never found

## Right to Information – HARLDLY RESPECTED (score 54/100)

Common failure by health authorities to provide information about consumer satisfaction related to health services' clinical performance: only 4 countries are in compliance with this indicator.

The indicators for the availability of **regularly updated hospital lists specifying facilities** and services provided and the availability of a healthcare information service have attained good mean scores, but some critical situations are evident

### In hospitals:

- patient' access to free clinical records: only 4 excellent
- scarce existence of a free information telephone number
- insufficient informative contents of websites (mean score 38)

What deeply lowers the synthetic PRES index is the high frequency of **violations** denounced by civic organizations.

This bad result is even more serious, since this right is particularly **relevant from a civic perspective** and deal with matters of **accountability** and **transparency** of institutions

## The mediocrity: quality and safety

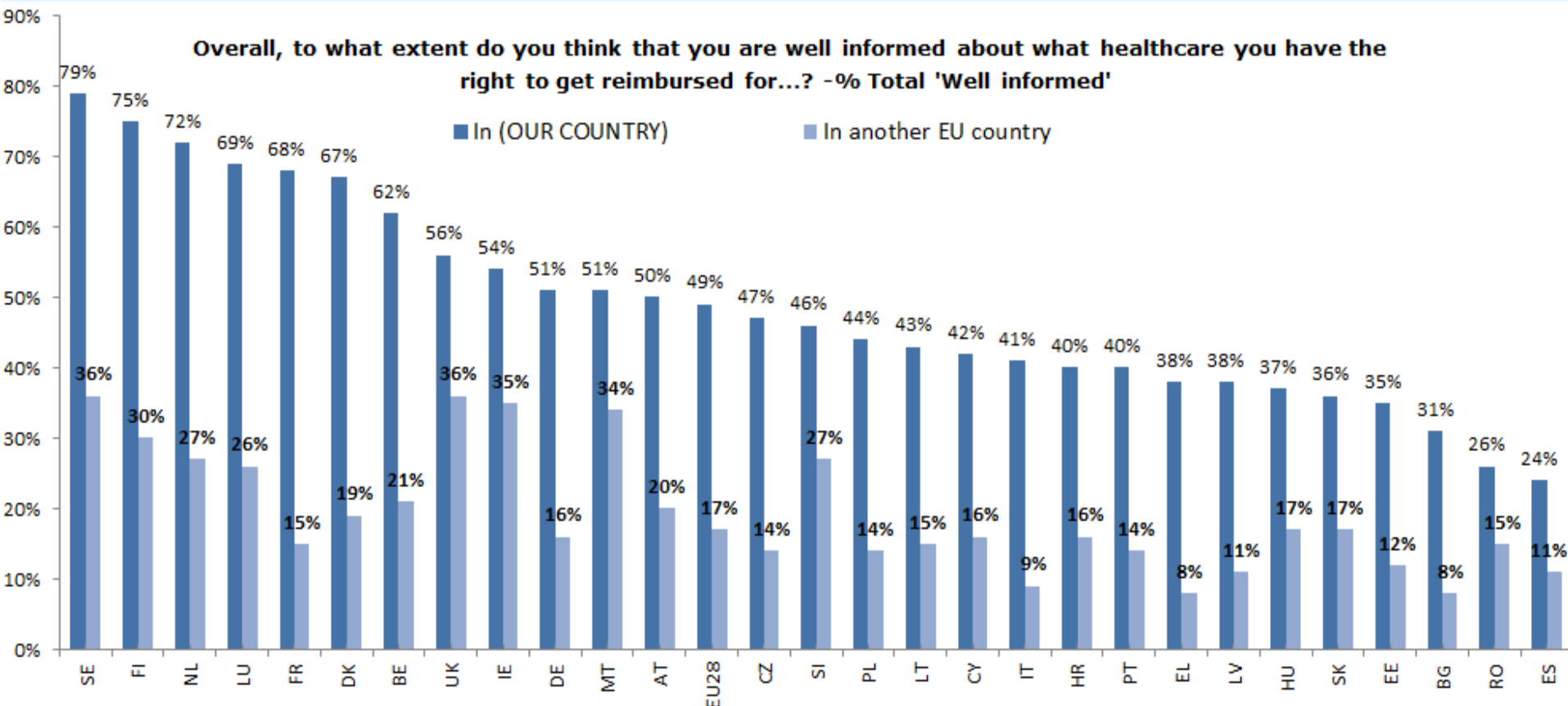
### RIGHT TO OBSERVANCE OF QUALITY STANDARDS:

Absence of nationally issued lists reporting the quality ranking of health services

### RIGHT TO SAFETY

In 17 countries out of 20 no form of legal protection has been established for people who report an adverse event.

A recent [Eurobarometer survey](#) published in May 2015, indicates that less than 20% of citizens feel that they are informed about their cross-border healthcare rights:



If citizens do not know their rights, they cannot stand for them and, above all, **exercise** them.



# The Respect of Patients' Rights: a civic assessment at the EU Level



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