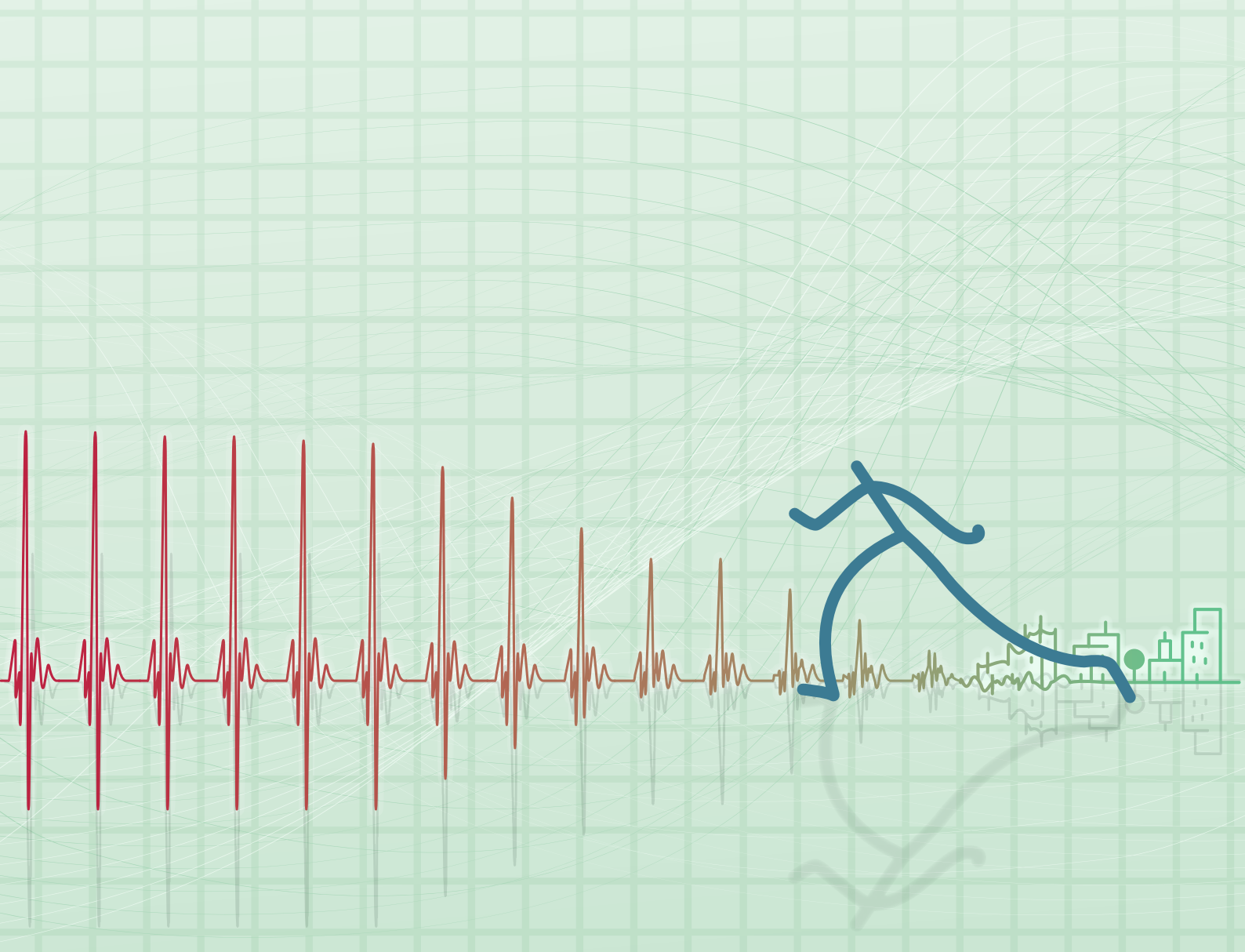




# THE EU CHARTER OF PATIENTS' RIGHTS

## A civic Assessment

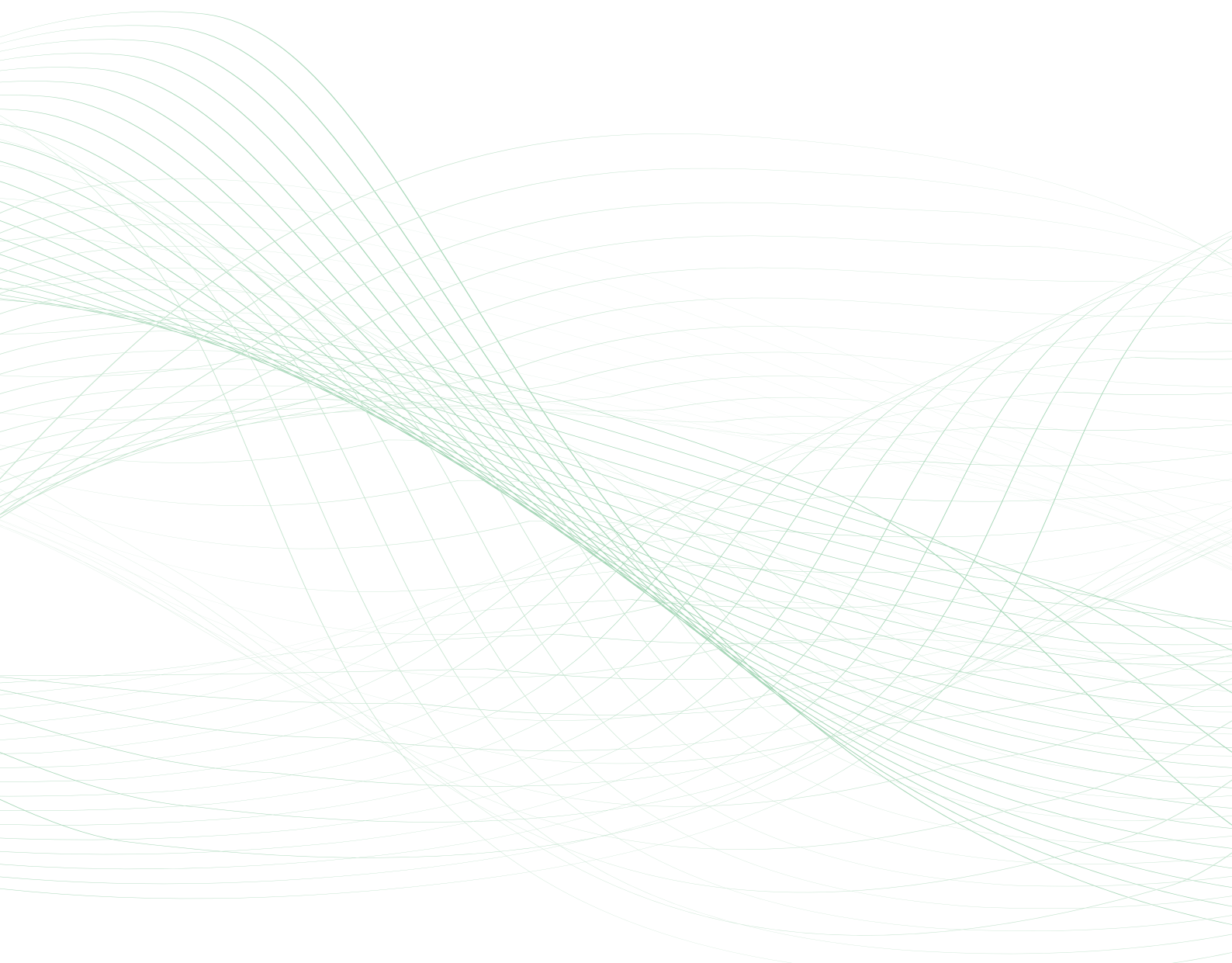


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# FIRST PART

## INTRODUCTION

### 1. PROJECT BACKGROUND

The main background components of the project are reported below.

#### 1.1 The Italian initiative of the Tribunal for Patients' Rights and the growth of civic activism in Europe

The pioneering initiative of Cittadinanzattiva's Tribunal for Patients' Rights, active in Italy since 1980, can be considered the first building block of this project. The Tribunal for Patients' Rights mobilizes common citizens and users as actors of health policymaking in concrete ways and presently involves some 5,000 people as permanent activists nationwide.

Among the components that characterize this initiative and have special relevance to this project are the following:

- **establishment of** 80 local Charters of Patients' Rights, through level collecting claims and reports from patients and users of health care structures, both public and private, at the local level;
- **organization of** Patients' Rights Centres inside some 200 Italian hospitals, with the aim of checking troublesome situations, preventing threats to patients' rights and promoting organizational and material changes, in addition to cultural and behavioural changes in the management of care;
- **establishment of** call centres at the local and national levels with the aim of providing citizens with information, advice and counselling on access to and the quality of health services, as well as on the protection of their rights;
- **organization of** a network of lawyers and forensic physicians to support citizens in the promotion of legal actions in case of damage, medical errors and/or refusal of care;
- **promotion of** specific campaigns and programs aimed at innovating health services regarding, for example, safety in and quality of hospitals, prevention of medical errors, pain therapy, waiting lists, free access to medicine and reduced waste of technical and financial resources;
- **coordination of** a Coalition of more than 130 associations for the chronically ill, in order to promote a common policy aimed at putting the rights of chronically ill patients at the centre of the health system.

Moreover, the Tribunal for Patients' Rights acts as a permanent interlocutor with national and regional governments, professional associations, trade unions, and industries. Over the years it has had a concrete effect on legislation, public budgeting and organizational and professional behaviour in addition to public awareness of patients' rights.

Among the innovations that this initiative has given rise to is the practice of "civic information", that is, the production of data and information by organized citizens, using both expertise and established knowledge, as well as producing new information based on their own experience as citizens involved in public problems and acting in certain policy fields. This experience has led also to the development of a methodology referred to as a "Civic Audit". Cittadinanzattiva currently uses this methodology in evaluating health services, consumer issues, education services, civil defence activities and etc. This methodology has been adapted and applied to this project.

This initiative would not have value abroad if not for the willingness to collaborate that has been exhibited from the start by many other citizen and patient organizations from all over Europe. From the first meeting in 2001 to the present, the staff of ACN have always had the collaboration of

associations that are spread across Europe and which have a strong commitment to protecting citizens' rights in the health-care systems in their own countries and in the wider European community.

## 1.2 The EU Charter of Fundamental Rights and Health

Another background component of crucial importance is the 2000 Nice Charter of Fundamental Rights. Its relevance is linked to two aspects. First, the Charter is the juridical source that recognizes the individual rights of people living in the European Union. Second, the Charter makes the European Union responsible for the implementation of its content.

Moreover, some specific rights established in the Nice Charter have a direct link to issues regarding patients' rights and can be considered as a legal basis of the European Charter of Patients' Rights itself.

Article 35 of the Charter provides for the *right to health protection* as the "*right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices*".

Article 35 specifies that the Union must guarantee "*a high level of protection of human health*", meaning that health and health care are both an individual and social good. This formula sets a guiding standard for national governments, which does not stop at the "minimum guaranteed standards", but aims for the highest level, notwithstanding differences in the capacity of the various systems to provide services.

## 1.3 The European Charter of Patients' Rights

### *Why a Charter on Patients' Rights*

Despite their differences, national health systems in European Union countries place the same rights of patients, consumers, users, their family members and vulnerable sectors of the populations at risk. Even though solemn declarations of the "European Social Model" on the right to universal access to health care have been repeatedly made, there are a number of constraints that bring the reality of this right into question.

European citizens cannot continue to accept the affirmation of rights in theory only, denied in practice due to financial limitations. Budgetary constraints, however justified, cannot legitimize the denial or compromise of patients' rights. Therefore, it is unacceptable that rights are established by law and then not respected, or promised in electoral programs and then set aside when that new government comes to office.

It was for these reasons that in 2002 ACN, together with some 15 citizens' organizations operating at the national and European level, drafted a European Charter of Patients' Rights. The main objective of the Charter is to strengthen and bring greater awareness concerning patients' and citizens' rights, which are presently at risk in all EU countries.

### *The 14 Patients' Rights*

The fourteen patients' rights seek to make the fundamental rights mentioned in the Charter of Nice applicable and appropriate to the current transition process in health services.

1. Right to Preventive Measures
2. Right of Access
3. Right to Information
4. Right to Consent
5. Right to Free Choice
6. Right to Privacy and Confidentiality
7. Right to Respect of Patients' Time
8. Right to the Observance of Quality Standards
9. Right to Safety

10. Right to Innovation
11. Right to Avoid Unnecessary Suffering and Pain
12. Right to Personalized Treatment
13. Right to Complain
14. Right to Compensation

### ***Active citizenship as a right***

In order to promote and verify the implementation of the patients' rights, the European Charter also proclaimed certain active citizens' rights, which mainly concern groups of organized citizens (patients, consumers, advocacy groups, advice-givers, self-help groups, voluntary and grassroots organizations, and etc.). These groups have the unique role of supporting and empowering individuals in the protection of their own rights. These rights are linked to the rights of civic association, contained in article 12, section 1, of the Charter of Fundamental Rights and are:

- the right to perform general interest activities;
- the right to carry out advocacy activities;
- the right to participate in policy-making.

### **1.4 The first experience of Assessing patients' rights**

In 2005, ACN proposed a project to monitor the implementation of the European Charter of Patients' Rights in the fourteen EU member states (Luxemburg excluded) in order to begin promoting and implementing the Charter while at the same time putting in practice European active citizenship.

The aim was to put citizens at the centre of Health Policy, transforming their role from mere targets and users of health services to active citizens participating in health care policymaking and, at the same time, to produce information on the actual implementation of patients' rights at the EU level.

A Patients' Rights Matrix was established with **174 indicators** which collected and analysed information, assigned scores, identified critical elements and good practice and, finally, proposed an action plan. The final Report was presented in Brussels on 2007 on the occasion of the 1st European Day of Patients' Rights.

In the 14 member states 42 hospitals were visited (direct observation at only 5 hospitals because of the refusal of authorities to provide information to partner organizations); 82 experts interviewed; 14 partner organizations operating at the national level involved in monitoring hospitals, interviewing key persons and answering questionnaires.

This first experience had both limits and values. The main result was the opportunity to test a research methodology (Civic Audit, Patients' Rights Matrix) to be used to create an appropriate database concerning patients' rights at the European level.

Policy Recommendations were included at the end of the Report, **still very present in the strategy of ACN.**

- a. Patients' rights must become the common point of view and a standard for managing policies on health care
- b. Existing data and information on health care at the European level should be enriched with patients' rights-focused ones
- c. Financing of health structures should be conditioned to the success in respecting patients' rights
- d. Action must be taken towards the changing of cultural, professional and organizational models

### **1.5 The idea of a European Day of Patients' rights**

The framework of the first assessment initiative was the promotion of the first European Day of Patients' Rights. The idea for this day was proposed by many associations participating in ACN initiatives and projects. The main goal was to promote an official day to talk about patients' rights in Europe. Hundreds of initiatives were organized in the different European countries. The Charter

was translated into 16 languages and more than 80 associations have participated in the different editions. The Conferences organized in Brussels were successful and many European interlocutors (Parliament, EU Commission, ESCC) participated and provided their support. In 2011, the EU Commission (DG Sanco) decided for the first time to support the 5<sup>th</sup> European Day. This is a very positive result and shows the awareness of EU and Member States concerning the implementation of patients' rights and their willingness to make commitments to concrete action.

## **1.6 Why this second Report**

The reasons for the Assessment that we promoted in 2010 are very similar. In this moment in Health policies reform it is particularly important to: reinforce alliance-building between organisations and groups, enlarging participation in the assessment (20 countries); producing civic information for policy input; being proactive, not only reactive, citizens; building partnerships with all of the stakeholders in the Health sector (professionals, local institutions, companies, universities, etc.); and, last but not least, sharing and learning from each other.

It is evident that public policies on health care in Europe are still mainly focused on economic and financial matters. Data coming from public sources (comparable official data and legislation on national situations) lack significant information on the concrete condition of patients, consumers, and users facing health services. This is why we need to produce new information and, at the same time, change the role of citizens in the health care system. One of the aims of this Report is to empower citizens' organizations and help them to become actors in Health policymaking.

## **1.7 Steps forward in the European context for patients' rights**

Since the establishment of the European Charter of Patients' Rights in 2002, there has been a dramatic improvement in the public debate on patients' rights in Europe, thanks in part to the Charter itself. This is testified by several documents, reports, and position papers delivered by public institutions (European Council, European Commission, European Parliament, Economic and Social Committee), citizens' organizations, and experts<sup>1</sup>.

Three main points seem to emerge from the present debate on patients' rights in Europe.

First, it can be said that the issue has become part of the European policy agenda. It concerns both public institutions and the policy community at large and has as a starting point the application of the principle of equality to the issue of patient mobility by the European Court of Justice<sup>2</sup>. This principle has recently been recognized by the new Directive on Patients' rights on cross-border care, which is a landmark for these policies (see chapter n. 7).

Second, public institutions are becoming increasingly aware that they have to take responsibility for the issue of patients' rights at the Community level, adding a European level of intervention to those developed in the member states.

Third, there is a greater recognition for the need to establish a clear framework of common principles and standards for the protection of patients' rights in Europe, to be implemented everywhere and in every case, and not only in the case of patients' mobility.

This is a significant result, since up until now health care has been considered an exclusively national competence. This competence had not yet been exercised in a shared way among the national states. In addition, it was not considered that certain fundamental rights are at stake in health systems and as a consequence the European Union must take general responsibility and must exercise this responsibility in concrete ways.

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<sup>1</sup> See, for example, Council of the European Union (2006); EU Health Policy Forum (2005); European Commission (2004), (2006b), (2006c); European Commission, High Level Group on Health Services and Medical Care (2006); European Observatory on Health Systems and Policies (2005); European Parliament (2005); Patients Associations (2005).

<sup>2</sup> Judgments of the Court of Justice of the European Communities ("European Court of Justice") in Decker (C-120/95, 28 April 1998); Kohll (C-158/96, 28 April 1998); Geraets-Smits & Peerbooms (C-157/99, 12 July 2001); Vanbraekel 7.



## 1.8 Project Rationale

Without a doubt, this ongoing process is very positive, and the policy of the European Charter of Patients' Rights may be considered a successful initiative even for this reason alone. Nevertheless, it cannot be forgotten that the core issue at hand is the actual condition of citizens who are patients, users and consumers of health care. From this point of view, a huge effort remains for improving health facilities' capacity to deliver services that are accessible, of high quality and centred on the rights of patients.

If we want to continue to move forward in developing a policy on patients' rights in Europe, it is crucial to put the question of the actual condition of citizens who use European health facilities on the table, and to take this issue into account when discussing – and, more importantly, when deciding on – the sustainability of health systems. To this end, data issuing from citizens' groups can help fill information gaps in the official sources.

Moreover, the fact that citizens organized in associations and movements operating at the national level are involved with full responsibility in such activity is a concrete example of the principles of "European Active Citizenship" program, currently under implementation in the European Union, being put into practice. 2011 was proclaimed the European Year of voluntary activities promoting active citizenship. The assessment of the patients' rights in the different Countries is a very concrete action to promote this aim and to invite the interlocutors, the State members and the European Institutions to take this effort into account.

## 2. HEALTH POLICIES IN EUROPE

### 2.1 Introduction

For the fulfilment of the second survey of the European Charter of Patients' Rights, it seemed necessary to accompany the field work with a recognition, however summary, of certain current tendencies in European health care services. In all of the countries, in fact, the welfare systems are called into question, with greater or lesser intensity, with tangible and relevant reflections on the life of citizens.

The adopted point of view is obviously that of the citizen "expert", capable of picking out the questions that are most relevant to the relationships established by services with users and to the safeguarding of rights, while aspects that require specific, technical competencies in order to be treated were, necessarily, left in the background. Despite this limitation, recognition has permitted the individuation of certain questions of great general relevance, such as the existence of common ground between different systems, the problems of sustainability and a possible new approach to the challenge of universal rights.

The principle source used was the documentation available on the website of the European Observatory on Health Systems and Policies of WHO and, in particular, the *Health Care Systems in transition* reports relative to 54 countries, of which 40 are European<sup>3</sup>. This basic information was integrated with other data, in particular that of OECD<sup>4</sup> and of the *Euro Health Consumer index 2009 (HCP, 2009)*, with the reports of the *European Patients' forum*,<sup>5</sup> with the publications available on the website *saluteinternazionale.info* and with consultation of other texts cited below.

### 2.2 Health systems in Europe: a puzzle with some important common ground

The **differences** between the health care systems of the different European countries are considerable from all points of view. As regards **outcomes**, the regional office of WHO detects major gaps in all of the parameters (WHO, 2010b); it is enough to consider that the difference between the maximum and minimum life expectancy is more than 20 years among males and more than 10 years among females.

The **per capita spending** detectable in the OECD tables for 2008 runs from a maximum of 5003.00 dollars in Norway to a minimum of 1213.00 dollars in Poland. The **public coverage** of total health care spending is on average higher in Europe than in other parts of the world. The field of variability between the guaranteed levels in individual countries is however quite broad. The OECD revealed a maximum of 84% in Luxembourg and a minimum of 68% in Slovakia (and in some countries not included in the OECD tables, the level of coverage could be even lower). They have good reason to believe that, if the statistics included all of the countries, they would find even wider gaps.

From the **institutional perspective**, as noted, there are two categories of systems, those called Bismarck, sustained by an insurance system, and those of the Beveridge type, founded on general taxation. The line of demarcation is not always clear, and one also encounters mixed solutions. According to the Euro Health Consumer Index 2009, different systems produce different outcomes. The five best Bismarck systems (Holland, Austria, Germany, France and Switzerland) attain the best performances under the profile of the general relation between cost and benefit while, if one limits the analysis to health results, the values detected in the five best Beveridge systems (Sweden, Denmark, Norway, Finland and Italy) are the highest.

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<sup>3</sup> <http://www.euro.who.int/en/home/projects/observatory/publications/health-system-profiles-hits/full-list-of-hit>

<sup>4</sup> [http://www.oecd-ilibrary.org/social-issues-migration-health/health-key-tables-from-oecd\\_20758480](http://www.oecd-ilibrary.org/social-issues-migration-health/health-key-tables-from-oecd_20758480)

<sup>5</sup> <http://www.eu-patient.eu/>

There are still wholly revealing differences in the **organization of services** (hospitals, clinics, paths for diagnosis and care) and of relations with and between professionals. If one considers that some states (for example Germany, Austria, Spain, the UK and Italy) are organized on federal or regional bases with high levels of autonomy, one may retain that, in the territory of the Union, there are at least 50 health care organizations that are markedly different from one another.

In this context of tremendous variability, it is possible to detect at least **three significant pieces of common ground**. The **first** is the **constant development in a European dimension** of health politics – especially after the adoption of the Charter of Nice of 2000 - in an environment in which the reserve of national states seemed unquestionable and inviolable. It is a highly complex process, which has been the subject of in-depth and highly analytical research (Mossialos et al., 2010) and that can be concretely verified, by citizens, in two particularly clear areas: the extension of the possibility of access to care without borders, which will be further discussed below, and the emergence of a **primary nucleus of common rights for all European citizens**. The proclamation of the European Charter of Patients' Rights, which took place in 2002, had recognizable confirmations in the European agenda (Moro, 2009, pp. 178 – 184; EESC 2007) and a large number of member states, in the last ten years, have adopted measures that recognize and reinforce the rights of self-determination (informed consent, access to health care documentation, second medical opinions, privacy, free choice, complaint and compensation) (EPF, 2009; Toth 2010).

A **second** significant aspect is that, considering both those of general structure (Beveridge/Bismarck) and those with specific organization of services, all systems tends to articulate themselves – in extremely variable ways - in **three levels of government**: national, regional and community (WHO, 2010a). The national level, normally, determines the amount of available resources, establishes and verifies the requirements of professionals and facilities, issues targeted norms and checks the quality of services, and tends, ever more frequently, to delegate organizational and managerial functions to lower levels. The regional level (absent in the smallest states) sees to the planning and regulation of services. The third level - that of community - takes responsibility for the concrete distribution of services, and civic participation can take on particularly intense forms.

The **third** piece of common ground is the propensity, to which we will return below, to transfer a significant part of the services from hospital to territory and to develop **forms of assistance that are more centred on patients**.

### 2.3 Problems of sustainability

As noted, **health care spending tends to increase due to powerful intrinsic dynamics** including the lengthening of the average lifespan, the availability of effective cures for various chronic diseases, and the development of diagnostic technology.

This inevitable tendency has generated and generates serious problems of economic compatibility that are further intensified by the **economic and financial crises** of recent years. All of **the health care systems are under pressure** and have had to cope with significant changes.

In positive terms, research on sustainability has generated a higher level of attention to the improvement of the relation between cost and benefit, stimulating the development of quality systems and of important disciplines (for example, Evidence Based Medicine or the Health Technology Assessment). The functions of regulation and control are tending to assume greater efficacy and greater relevance and this seems to have beneficial effects on the management of systems.

Measures have also been adopted, however, that are directed towards rationing services, reducing the area of direct public intervention and increasing the co-partnership of citizens. In the Bismarck systems there is no evidence, at the moment, of mechanisms for the selection of patients on the

part of insurers, but some governments hold it necessary to monitor the phenomenon, above all in protection of the disabled and the chronically ill (de Jong et al., 2008). One notes, moreover, and even in the most advanced Beveridge systems, such as those of Scandinavia, notable disparity between rural areas and the cities and among different socio-economic groups, in terms of equity and access (Valerio and Fabbrini, 2011).

*“The key factor seems to be the overall responsiveness of the national system, and the capability to implement strategic changes. Under external pressure, visible in the past few years, individual countries take very different measures to keep healthcare sustainable, ranging from deep systematic reforms to defensive restrictive measures on the level of provision and access. Apparently, some national healthcare systems experience a sort of inertia to any change. On the other hand, quick learners like Estonia or Slovakia have had the questionable advantage of facing a crisis so threatening that it became an opportunity to redesign the whole approach to healthcare”* (HCP, 2009, p.26).

## 2.4 Universality: an open challenge

Utilizing the traditional norms of equity and universality, the reduction of the level of protection of citizens caused by the above-cited measures already appears appreciable and could increase further. Which is to say, the processes of exclusion could increase dangerously and, in fact, in all of the countries, research is under way, to various degrees of intensity, on appropriate countermeasures.

Missing at this time are the space and the competencies indispensable for the analytical examination of this activity. It is relatively easy, nevertheless, to see a rather widespread inclination towards compensating for the reduction of rights protection with **the empowerment of citizens** and professionals and with the **development of forms of subsidiarity**. The clearest case is the Big Society project currently under discussion in the UK, which proposes a radical transformation of the health care system, informed by these criteria (NHS, 2010).

The **empowerment** of citizens has **two distinct components**. The **first** is tied to the **recognition and reinforcement of the rights to self-determination** already noted above and to the development of information systems and of e-Health. A new figure seems to emerge from these processes, that of the **“powerful user”**, capable of autonomously picking out and evaluating information, of choosing among opportunities and of participating in safeguarding activity. Truth be told, there few countries in which this set up is adequately sustained. It is often the case that informational support is lacking, while the right to free choice turns out to be, in reality, powerful conditioned. It remains to be demonstrated, moreover, that this greater capacity for interaction is sufficient, on its own, to compensate for the reduction of the level of protection. The tendency exists, however, and merits consideration.

The **second component** of individual empowerment is tied to **patient centred care**. Starting from a strictly ethical perspective, the personalization of treatment and of relations with professionals is generating new organizational approaches and new procedures that ensure *“the achievement of a series of outcomes, such as improvement of the quality of life, longer lifespan, contained costs for assistance (for example, fewer diagnostic verifications, fewer hospital recoveries) and the reduction of inequalities in health”* (Maciocco 2010). One must remember, however, that the success of personalized home treatment, in the most intense cases, requires a greater commitment of both the organizational resources (for example, the identification and training of caregivers) and the economic resources of the families involved. Their socio-economic and/or cultural level takes on a strategic value and could be the cause of concrete discrimination to the advantage of those who are strongest.

The politics of the **development of subsidiarity** is less clear. If one takes a top down perspective, on the one hand there seems to be a **transfer of power and of competencies to the local level** under way (often limited, however, by acute financial constraints), while on the other hand there are emergent **forms of support for social concerns that carry out collective interest activity**. Adopting a bottom up point of view reveals the **widespread capacity** – confirmed by some studies conducted in Italy (Agenas, 2010) – of citizens organized in various ways, of services and of professionals to interact at a community level and **to produce organized responses to needs with innovation solutions and with the mobilization of additional resources**. Such a capacity, however, is often limited by bureaucratic procedures and by administrative discretionary power.

These considerations permit the statement that the **empowerment of citizens and horizontal subsidiarity may be considered strategic resources for a transformation of services capable of joining compatibility and universality**. In particular they permit the interpretation of the latter not as a simple application of abstract principles of equality but as a capacity to adapt services to the concrete situation of the individual (and in particular the most fragile subjects), eliminating wastefulness, valuing personal and local resources and countering the dangers of social exclusion.

**This requires, however, a new and precise acceptance of responsibility on the part of public institutions**, which cannot excuse themselves from the work of sustaining the processes of reorganization, of keeping watch over quality, safety and efficacy of care and assistance, of intervening to support those who are weakest and of ensuring equity of access and sufficient financing.

If, however, the formal recognition of certain "low cost" rights for citizens and of certain extra competencies for the community were to become an excuse for reducing responsibility to the simple transfer of financial resources (which would probably be insufficient), the universality of the health care system could be radically compromised.

### 3. PROJECT METHODOLOGY

As stated previously, the ACN project, directed towards monitoring the implementation of the European Charter of Patients' Rights in the European Union member states, began its work in 2005 with research carried out between 2005 and 2007 in 14 countries.

The objectives of this project are:

- to proceed with the work of gathering and increasing information on patients' rights, given the scarcity of same and keeping in mind the fact that such information is normally not taken into consideration on a European level;
- to involve national citizens' organizations in the work of producing civic information, which may be considered a new form of active participation in European policymaking;
- to give value to the already-existing information on a European level, gathering together the pertinent data deriving from official statistics and other sources.

In the implementation of this second round of assessment work, the methodological approach adopted in 2005 has been substantially confirmed, with a few changes having been made based on information that emerged from the first project.

#### 3.1 The "Civic Information" Approach

The project and methodology of this assessment work is inspired by the method of civic information proposed by many scholars and employed with notable success as a reference model for the work carried out by Cittadinanzattiva in Italy (Wildavsky, 1993; Rubin, 1993; Lamanna - Terzi, 2005; Moro, 1998, 2005a).

Civic information may be defined as *the capacity for organized citizens to produce and use information to promote their own policies and participate in public policymaking*, in the phase of definition and implementation as well as that of evaluation.

According to this method, when citizens, in spite of their presumed lack of competence in the public sphere, organize themselves and take action together in the realm of public policy, they are able to produce and use information deriving from experts and other sources, as well as from their own direct experience with the problem being addressed.

In this project, such a method is implemented by involving civic organizations in the collection of information, through direct observation of hospital facilities and interviews with hospital authorities, which gives them the possibility to put into practice the right to participate in the evaluation of services and policies. This is, without a doubt, the most innovative aspect of this work, despite the difficulties and obstacles encountered in both rounds of assessment work, since the activity conducted by citizen groups in the course of detecting data did not appear to be common practice in the majority of countries.

#### 3.2 The Assessment Project and the Civic Audit Matrix of the patients' rights

The study was directed towards evaluating the state of implementation of the European Charter Patients' Rights in the European Union member states. This was done by collecting three types of information, plus a fourth type, added as a complement in order to integrate the picture of information provided.

- A. The first type of information concerns the degree to which institutional bodies (government, public administration, Ministry of Health, etc.) are promoting norms, policies and actions relevant to the interests of the European Charter of rights. These components, diverse in type and in significance (from initiatives already fulfilled, to norms with possible gaps in their implementation), testify to the level of attention paid to patients' rights at a national level. With respect to the project of 2005, this first category of information was redefined, as it previously comprised only legislation.
- B. The second type of information concerns *the actual conditions of the citizens* who use the health care system and, consequentially, the concrete experiences of all those who have needed to turn to a hospital or a day hospital service. We report, for example, on the time necessary to get a diagnostic exam or a surgical intervention in a hospital, on the existence of certain services to hospital patients, such as cultural mediation or interpreting services, on communication methods between patients and medical personnel, on the availability of health care equipment, and etc.

This is information collected by citizens using a method well-established in Italy, that of the Civic Audit and therefore via varied sources and direct observation of health care facilities. According to the terms used previously, a Civic Audit is an application of an aspect of civic information that involves the direct production of information by citizen organizations through the collection of data regarding the issue at hand.

The methodology of the Civic Audit permits the linking up of data accessible to citizens, through direct observation or through requesting information from the authorities (formalized as indicators), with a synthetic evaluation of the aspects characterizing the relationships between citizens and services (information, comfort, accessibility, safety, pain management, chronic and oncological care, participation and etc.). Each aspect (considered as a "factor of evaluation") is associated with a group of indicators. Each indicator is associated with a value, based on comparison with the respective standard obtained from official documents. The average of these values permits the calculation of an index of standards compliance (in Italian, *Indice di adeguamento agli standard*, or IAS).

The Civic Audit is carried out by mixed groups of professionals and voluntary citizens who, after appropriate training and with the technical assistance of Cittadinanzattiva, the national agency for civic evaluation, see to all of the necessary operations: collection of data through direct observation and filling out of questionnaires, insertion in national software, data analysis, identification of non-conformity and of corrective actions and review of evaluation reports (Lamanna - Terzi, 2005; Terzi – Tanese – Lamanna, 2010) .

In this and in the previous study, each right of the European Charter was considered as a factor of evaluation and therefore tied to a group of indicators corresponding to fundamental phenomena relevant to the end of evaluating the implementation level of the right under examination.

The process led to the identification of a group of **88 indicators** regarding the 14 patients' rights plus the right to active citizenship, to reveal the actual conditions of hospital patients.

The indicators were drawn from literature, legislative and institutional sources and documents produced by citizen organizations, scientific associations and etc., and were selected on the basis of five criteria:

1. relevance, or the level of bearing on the questions and problems concerning each right;
2. sensitivity, or capacity to register changes (for the better or for the worse);
3. precision, or capacity to report in a precise and focused way on the phenomena one intends to register;
4. accessibility, or availability without added costs with respect to those provided for in the project budget;
5. concreteness, or capacity to register even the most concrete aspects of reality.

With respect to 2005, the Matrix was updated through the elimination of some indicators and addition of new ones.

Among these, 8<sup>6</sup> were taken from those utilized for the Euro Health Consumer Index. The complete *Matrix of Patient's Rights* is found in Appendix A.

C. The third type of information regards the cognitive patrimony of civic organizations, in the conviction that such organizations, given the type of experience and work that they are engaged with, offer a wide range of information regarding health and the health care system.

D. The fourth type of information, as stated above, does not contribute to the evaluation of the state of rights implementation, but is gathered and included in order to integrate the reading and interpretation of the other blocks of information, and to provide a more complete picture.

This type of information consists in *statistical data* collected by international agencies with the aim of documenting and describing, in a comparative way, the health conditions of the population and the various factors that determine these conditions (including the management of health care systems). The study conducted in 2005 demonstrated the limits of these statistics in describing the state of rights implementation. These limits probably derive – it was stated – “*from a distortion regarding such sources, which concentrate, for example, on output (which is to say on what the health care systems have done) rather than on outcome (which is to say on what actually happened to any persons concerned); which give priority to services rather than to demand and the encounter between supply and demand; which strive to identify macro-phenomena while the actual condition of patients consists of diverse micro-phenomena which also have a relevant quantitative dimension*” (ACN, 2008).

Nevertheless, on some themes pertaining to the rights, there are sometimes some statistics available that offer information that is useful for integrating the other sources and for getting a general picture of the state of the implementation of a right. Some indicators were therefore taken into consideration, directly or indirectly, regarding phenomena tied to the implementation of rights.

The entire group of indicators, or rather the 156 indicators comprising the information contributing to evaluation (A, B, C) plus the 18 indicators derived from the elaboration of already-existing statistical data, defining a *Matrix of the Patients' Rights*.

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<sup>6</sup> This is the original text of the borrowed indicators, which has been slightly changed and adapted for this assessment project: Right to second opinion; Access to own medical record; Register of legit doctors; Web or 24/7 telephone HC info with interactivity; e-transfer of medical data between health professionals; Major non-acute operations <90 days; Cancer therapy <21 days; CT Scan <7 days.



*Synthetic Matrix of the Patients' Rights*

RIGHTS	A	MH	B	HCKL	C	PO	INDD PER RIGHT	OS
		N. OF INDD.		N. OF INDD.		N. OF INDD.		N. OF INDD.
1 - Right to preventive measures	INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS	2	ACTUAL CONDITIONS OF PATIENTS	/	CITIZENS' POINT OF VIEW	2	4	4
2 - Right to access		/		7		2	9	4
3 - Right to information		5		11		2	18	/
4 - Right to consent		3		5		2	10	/
5 - Right to free choice		2		/		2	4	1
6 - Right to privacy and confidentiality		2		8		2	12	/
7 - Right to respect of patients' time		2		12		2	16	/
8 - Right to the observance of quality standards		4		4		2	10	/
9 - Right to safety		3		10		2	15	2
10 - Right to innovation		/		6		2	8	5
11 - Right to avoiding unnecessary suffering and pain		1		4		2	7	2
12 - Right to personalised treatment		3		12		2	17	/
13 - Right to complain		3		3		2	8	/
14 - Right to compensation		4		3		2	9	/
15 - Right to active citizenship		4		3		2	9	/
INDICATORS PER SOURCE		38		88		30	156	18

Labels: MH: Questionnaire for the Ministry of Health; HCKL: Hospital Check-list; PO: Questionnaire for the Civic Partner Organization; OS: Official Statistics.

### 3.3 Sources of Information and Technical Tools

#### *The Sources*

For the collection of these types of information, four sources were utilized:

#### *a. An Official from the Ministry of Health*

The Ministry of Health is clearly a qualified source of information and in a position to provide official information on norms, policies, actions and initiatives in the field of health care.

#### *b. Direct Observation of Hospitals and Meetings with Responsible Authorities*

Direct observation of hospitals was, as in the previous investigation, a primary source of information. Partner organizations visited up to 5 hospitals per country. In the course of the visits:

- direct observation was conducted in many different areas of the hospitals (emergency ward, common areas, and some hospitalization areas) towards detection of the indicators;
- questions were posed to the responsible hospital authorities, towards the detection of those indicators which, whether due to time constraints (the visit was scheduled such that it could be fulfilled within a single workday) or technical reasons (for example the presence of protocols or guidelines), cannot be subject to direct observation or are not easy to find.

The hospitals to be visited in each country were identified on the basis of the following indications:

- **Category 1 - Population greater than 35,000,000**
  - Germany, France, UK, Italy, Spain and Poland
    - 5 major hospitals (all 5 hospitals may be in the capital or they may be distributed in the following manner: at least 3 hospitals in the capital and 2 other hospitals may be in the second and/or third largest city)
- **Category 2 - Population between 7,000,000 and 25,000,000**
  - Romania, Netherlands, Greece, Portugal, Belgium, Czech Republic, Hungary, Sweden, Austria, Bulgaria
    - 3 major hospitals (all 3 hospitals may be located in the capital or may be divided in the following manner: at least 2 hospitals in the capital and one hospital in the second)
- **Category 3 - Population between 2,000,000 and 7,000,000**
  - Slovakia, Denmark, Finland, Ireland, Lithuania, Latvia, Slovenia
    - 2 major hospitals (both hospitals should be located in the capital)
- **Category 4 - Population less than 2,000,000**
  - Estonia, Cyprus, Luxembourg, Malta
    - 1 major hospital located in the capital city

The visits included different areas of the hospital (emergency ward, common areas, and some hospitalization areas).

#### ***c. Partner organizations as qualified sources of information on the state of patient rights in each country***

The information gathered from the Ministry of Health, direct observation in hospitals and meetings with their responsible authorities was integrated via an interview with the partner organizations, in the conviction that, given the type of experience and work that they are engaged with, offer a wide range of information regarding health and the health care system and that, in particular, they are in a position to be aware of episodes of serious rights violations, by virtue of their role as protectors of citizens' rights.

#### ***d. Statistical data at a European level***

This source was used to provide information on the state of rights implementation deriving from other research perspectives.

The pursuit of information about the implementation and the effectiveness of patients' rights was carried out through 2009 and updated during the first months of 2010. The aim was to gather statistical data available for most of the European countries, deriving from comparable sources. Starting from the list of indicators pertaining to each right in our first report, a more comprehensive list of indicators was written up. Official statistics compiled by Eurostat, OECD and WHO, as well as by well-known organisations devoted to the analysis of specific health issues, have been analysed.

In particular, looking for structured and comparable information for analysing the current transformations and the degree of implementation of patients' rights, first level information coming from existing official statistics databases (Eurostat database, WHOSIS Informative System, WHO's Health for All System, as well as from OECD's Health Indicators System) has been collected.

In addition, the search involved:

- numerous European surveys addressing health topics, such as Eurobarometer, the European Social Surveys, the European Survey on Income and Living Conditions (EU-SILC);
- reports, documentation and websites of national and European organisations that collect information about European health care systems;

- reports, documentation and websites of national and organisations that collect information about specific health topics.

Data coming from these sources were selected when found to:

- answer indicators' information needs in a pertinent way;
- be sufficiently comparable;
- be available for the majority of European countries.

This search resulted in the collection of data for indicators belonging to six rights (the right to prevention, the right to access, the right to free choice, the right to safety, the right to innovation and the right to avoid pain). The lack of official information about some rights was considered an indicator of weakness on the implementation of the right at stake.

The data from this source of information have been processed by ACN: the scores of indicators have been obtained according to specific classes or brackets of values, often established ex-post, based on the interpretation of data.

### ***The Tools***

The selected sources were consulted through the employment of many different *technical tools* for data collection, including:

- a questionnaire to present to the Ministry of Health;
- a check-list to use during hospital monitoring, comprising a series of questions for the hospital authorities and a list of observations to be made;
- a questionnaire to present to the partner organizations.

### **3.4 Scores and indexes (PRES - Patients' Rights Euro Scores)**

In order to permit a more "immediate" reading of the results of the investigation, a score was calculated for every indicator. The value of the score (from 0 to 100) expresses the degree to which the information gathered respects the legitimate expectations held by citizens.

This means that for each indicator belonging to each of the three types of information described above, 100 was given whenever it was verified to be the best situations, which is to say:

- when the Health Ministry gave a positive response regarding the existence of actions, norms and initiatives that, from the perspective of the citizens, are particularly important for the implementation of patients' rights;
- when the citizens verified the presence in hospitals of services or received a positive response from the Hospital Directors regarding the existence of actions, initiatives or services relevant to respect for the conditions of patients;
- when the civic partner organizations did not report having direct knowledge of any violations of patients' rights

"Zero" was assigned when verified to be the worst situation (a completely negative response, negative observation, etc.). Partial points were assigned, for example 25, 50, 75, when, for some indicators, the responses provided or observations made identified intermediate situations. In the case of evaluating many hospitals (or many Ministries)<sup>7</sup>, and in all the cases of indicators detected through more than one question, the point value of the indicator was calculated as an average.

The possibility was offered to be exonerated from some responses in that they could be considered not applicable (N.A.) in certain facilities or contexts.

In these cases, the indicator carries no weight, neither positive nor negative, in calculating the average score.

In the few cases in which it was impossible to find data, the same method applied, but in the summary tables reporting indicator scores, an entry of N.R. (not received) was made.

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<sup>7</sup> See paragraph 3.5 "Development", in this chapter.

All of the indicators were grouped together based on classes of merit, according to the score attained:

0-40	<b>WEAK</b>
41-70	<b>SUFFICIENT</b>
71-90	<b>GOOD</b>
91-100	<b>EXCELLENT</b>

Indicators detected through the Questionnaire addressed to Civic Partner Organizations (types of information “C”) have a particular nature, because they cannot be considered as pure indicators, but better as “sentinel events”: when found, they denounce the presence of serious obstacles for citizens; when not found, they do not indicate absence of violations, which might have happened all the same.

These indicators have been analysed considering values attained by the countries participating, which were grouped together based on classes of merit, according to the score attained:

0-20	<b>Countries with violations regularly found</b>
21-60	<b>Countries with violations frequently found</b>
61-80	<b>Countries with violations rarely found</b>
81-100	<b>Countries with violations occasionally/ never found</b>

For each of the three groups of information gathered via the three sources described above, a score was calculated that derives from the average of the scores attained for all of the indicators detected for that right:

- **score** for **Institutional actions for patients’ rights**: norms, policies and actions relevant to the interests of the European Charter of rights gathered from the Ministry of Health;
- **score** for **Actual conditions of hospital patients**: the concrete experiences of all those who needed to turn to a hospital or a day hospital service gathered through observations made in the hospitals or the questions asked of the Hospital Directors;
- **score** for **Alerts from Civic Organizations**: violations of patients' rights, of which partner organizations have direct knowledge.

The synthetic evaluation of each right was then formulated by calculating a general **index** as an average<sup>8</sup> of the scores of the three groups of information, which therefore represent the three components in which the score for the right is articulated.

The rights were evaluated according to the following labels, based on the value reached by the general index:

0 – 50	NOT RESPECTED
51 – 60	HARDLY RESPECTED
61 – 70	PARTLY RESPECTED
71 – 90	ALMOST RESPECTED
91 – 100	FULLY RESPECTED

<sup>8</sup> In the general Index, the score for “Alerts from Civic Organizations” has contributed as a weighted average, calculated considering the populations of the single countries. Sources for populations: <http://europa.eu> - data 2007 - For Macedonia: <http://ec.europa.eu/enlargement> - data 2006.

## 4. DEVELOPMENT

The project began in 2009, with ACN establishing a working group to re-design the methodology of the monitoring process and its respective tools. A training meeting with the civic organizations involved in the monitoring were held in Brussels (May 2010) to discuss methodological and operational features of the project. The research was carried out in 21 of 29 European Countries (27 EU members + Macedonia e Croatia) since in Austria, Luxembourg, Denmark, Czech Republic, Sweden, Slovenia and the Netherlands it was not possible to identify a partner organization to take part in the project. A list of the partner organizations that participated are in Appendix B of the report.

The implementation of the monitoring process took place from May until October 2010. In general, the most difficult aspect of this phase was obtaining the authorization from the hospitals and then actually being able to set up a meeting with hospital authorities to complete the questionnaire for gathering the hospital information and to observe the hospital services. The compiling of the information from the various countries took place between October and December 2010. The partners of the project inserted all the information gathered in the "Civic Audit on-line database". In January and February the research staff analyzed the data and drafted the report.

However during the monitoring phase there was difficulty in collecting the following information:

- in Croatia the hospital authorities and the Ministry of Health refused interviews;
- in Germany hospital authorities refused interviews, therefore the partner organization answered himself the questions addressed to the hospital director;
- in France has been possible to monitor only 4 Hospitals out of 5;
- in Poland has been possible to monitor only 4 Hospitals out of 5;
- in Greece has been possible to monitor only 2 Hospitals out of 3;
- in Portugal has been possible to monitor only 1 Hospital out of 3;
- in Finland has been possible to monitor only 1 Hospital out of 2;
- in Latvia has been possible to monitor only 1 Hospital out of 2.

In the end a total of 56 hospitals were visited (see in Appendix B for the list of the hospitals visited in each country). With respect to the Ministries of Health, there were one interviewed for each Country, but in Belgium in Spain and in UK our partners interviewed 2 different authorities (see the list in the Appendix B for the details). Regarding the questionnaire for the civic organizations, a total of 70 citizens/patients' organizations were involved to reach 47 completed questionnaires. (Appendix B has the list of organizations interviewed in each country.)

The most significant fact emerging with respect to the implementation of the research in the hospitals was *the refusal of hospital authorities in Germany and in particular in Croatia, where, it was impossible to conduct the research at all*. The research in these countries, therefore, lacks this information, which was otherwise collected in the other countries. However, it is important to point out that *such a refusal is in itself an indicator of the lack of transparency and openness of those countries' hospital authorities in relation to active citizens, and can therefore be considered a result, though unfortunately a negative one, of the research*.

The research work was directed by ACN staff under the coordination of Melody Ross and included Alessandro Lamanna and Ilaria Vannini who cooperated in the phase of the methodological design. Daniela Quaggia coordinated the networking and the national partners' monitoring work. Rosapaola Metastasio, developed the "Civic Audit on-line database" for this project and cooperated with Lamanna, Alessio Terzi and Teresa Petrangolini from Cittadinanzattiva in the data processing and

setting up of this report. Davide Integlia collaborated for the Chapter on the Directive on cross-border Health care.

#### 4.1 Value and Limits of the Research

In view of the highly experimental and innovative nature of the research, there are a number of aspects, which should be pointed out regarding its limits and value.

The main *limits* can be summarized as follows:

- apart from the European-based statistical research results, the results coming from the Patients' Rights Matrix do not reflect a sample with a full statistical significance and value, because of the low number of people interviewed and hospitals visited;
- indicators related to each right are not necessarily homogeneous and have a different value according to the content of each right and to the research constraints; moreover the number of indicators vary from right to right;
- the research does not take into account the differences between the national health care systems, in terms, for example, of financing, public or private ownership or delivering of services, and so on.

As for the *value*, the following can be stated:

- the research provides information on the state of patients' rights by identifying phenomena that can be considered indicators of attention towards those rights;
- it reflects an approach to health care issues based on the point of view and the condition of citizens, patients or users of health facilities;
- it makes it possible to begin comparing different national situations from the point of view of the attention to patients' rights;
- it enabled the setting up and testing of a research methodology, which can be further and more widely used to build an appropriate database regarding patients' rights on a European basis, which could then be used together with other sources in health care-related issues.

Particular attention must be given to the collection of information in hospitals. On the one hand, the 56 hospitals visited are clearly not a statistically significant sample, neither at the national nor European level; on the other hand, most of them are still 56 of the largest and most important health facilities in Europe and for that reason can be considered as a point of excellence at the national level. Therefore, what occurs in these structures is meaningful.

## SECOND PART

### 5. PRES: Patients' Rights Euro Scores The Rights Cards

## HOW TO READ THE RIGHTS CARDS

This chapter presents 15 cards, one for each of the rights of the European Charter of Patients' Rights that were monitored. The cards describe the assessment from a civic perspective on the status of the rights in Europe and according to the degree of respect paid to the right.

Each card presents the results of all the indicators concerning the corresponding right, detected via the different sources consulted and assessed through scores (for further details concerning scores, indexes, etc., please see the chapter 3 "Project methodology", paragraph 3.4 "Scores and indexes").

### Preliminary Information

Each card has the same structure\* and contains the following information boxes.

An introductory box contains a synthetic assessment of the right. The 5 possible categories, identified by a symbol, are: *(below only one category is highlighted, as an example)*



This assessment is assigned through an index, obtained by the mean value of the scores reached by, at maximum, three components or sources of data (groups of indicators).

A curly bracket introduces a chart that illustrates (through tick symbols) which of the possible sources have been consulted or used for assessing that right: if the tick symbol is present, it means that in the card the reader will find a chart containing indicators collected through that source.

The possible sources:



The last "source", **ANOTHER PERSPECTIVE**, must be considered as additional information provided to complete the picture, and **does not contribute to the synthetic assessment**: for this reason it is always out of the curly bracket, below the others.

The charts contain the indicators detected (in rows) and the participating countries (in columns). In order to facilitate the reading and comprehension of the data, the indicators are presented in increasing order based on the average score attained by the sum total of participating countries: the first line is therefore always occupied by the indicator with the lowest average score. For this reason the logical order according to which the evaluation structure was constructed is sometimes lost.

\* Please note that *not* all the rights have been assessed through all the sources of indicators. Please see the chapter on project methodology to consult the matrix of indicators, schematized according to the types of tools used (e.g.: sources of data) as useful towards understanding the representation of the individual rights.



Moreover, please note that the spelling and writing out of the indicators was synthesized and abbreviated as needed for graphic reasons. It is however possible to consult the complete indicator Matrix in its original version in APPENDIX A.

The last column on the right is always dedicated the mean values attained by the indicators in all participating countries.

The assessment of indicators is expressed through the following coloured labels:



### The content of the cards

The scores and indicators are illustrated in the following order:

- ▲ The assessment of **Institutional actions for patients' rights**, with a corresponding **score** attained by the group of indicators collected by citizens through a questionnaire addressed to the **Ministry of Health** and illustrated by the chart.
- The assessment of the **actual conditions of hospital patients**, with a corresponding **score** attained for the group of indicators collected in hospitals:
  - **An overview of hospital index scores in each of the 20 countries**: a chart showing the mean values attained by all hospitals evaluated in each country (the name of every country is followed by the number of hospitals assessed). The same colours (see the above labels) indicate the assessment attained.
  - **Citizens have questioned Hospitals Directors on the following**: a chart illustrating the group of indicators collected by citizens through questions for the Hospital Directors.
  - **Citizens have directly observed the following in hospitals**: a chart illustrating the group of indicators collected by citizens through direct observation inside hospitals.
- **Alerts from Civic organizations**: a chart illustrating the group of indicators collected by citizens through a questionnaire addressed to the Civic Partners Organizations providing the opportunity to report any violations of the right that they have direct knowledge of. The score of this source is not shown, but it does contribute to the synthetic assessment of the right.

For these types of indicators the labels are:



- ◆ **Another perspective**: a chart illustrating selected statistical data which were already existing and available and then processed and assessed by ACN and which were chosen to integrate the reading and interpretation of the previous indicators. The chart reports the number of countries in which the situation described by each indicator is either weak, sufficient, good or excellent.

### Abbreviations for indicators

com. = communication  
dept. = department  
leg. = legislative  
N.A. = Not Applicable  
perc. = percutaneous  
tel. = telephone

cor. = coronary  
gov. = governmental  
nat. = national  
N.R. = Not Received  
recommend. = recommendations

## THE RIGHT TO PREVENTIVE MEASURES

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

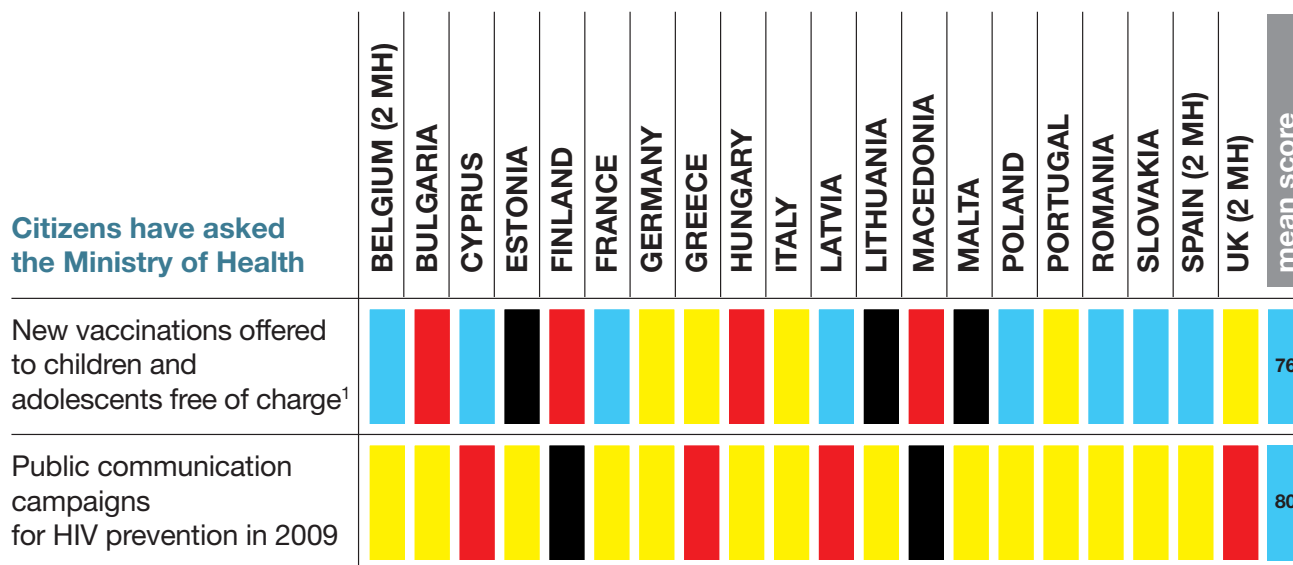
FULLY RESPECTED



- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

## ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 78/100



Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The communications campaigns for HIV prevention were widely circulated (14 countries out of 20 distributed it country-wide) and most of the countries are adding vaccinations - for which there exists a strong practice - with new vaccines made available in recent decades by the progress of scientific research. The vaccination indicator is fully satisfactory in 5 countries and is reaching a good level in 8 countries.

In general, the indicators under consideration display a good average value, although in some countries they are behind.

1. - Hepatitis B Vaccine  
 - Meningococcal Conjugate Vaccine  
 - Haemophilus influenzae type B Vaccine  
 - Pneumococcal Vaccine  
 - HPV Vaccine

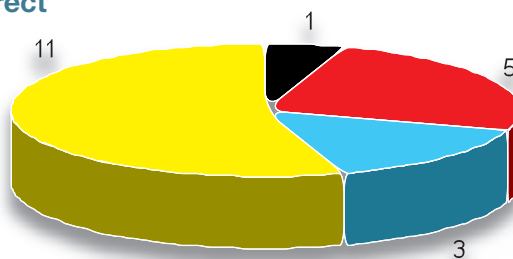
## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- immunization programmes (vaccinations);
- screening programmes.

Source: Active Citizenship Network, 2011



**number of countries with violations regularly found**

**number of countries with violations frequently found**

**number of countries with violations rarely found**

**number of countries with violations occasionally / never found**

Violations of the right to prevention were not found (or were found only occasionally) in the majority of countries, as indicated in the illustrative chart. The fact that frequent violations of this right were verified in 6 countries (and in one country, regular violations) is an important warning and not to be underestimated.

Nevertheless, our civic partner organizations have reported that other cases have come to their attention which cannot be categorized in terms of the violations identified by the indicator described above, and which from their point of view might nonetheless constitute violations of the right to prevention.

## ANOTHER PERSPECTIVE

Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

### Number of countries by statistical indicators

Percentage of citizens that have a perception of effectiveness of an information campaign on AIDS	3	10	6	
Percentage of one-year-olds vaccinated last against: diphtheria, tetanus, measles	2	6	11	
Status of cervical cancer screening programme (Population based, Nationwide, Rollout complete, Planning)	2	9	2	6
Status of breast cancer screening programme (Population based, Nationwide, Rollout complete, Planning)	1	5	13	

WEAK

SUFFICIENT

GOOD

EXCELLENT

The data refer to only 19 Countries, because Official Statistics concerning Macedonia were not available.

Source: 2011 Active Citizenship Network's processing of statistical data from: Eurobarometer Special 240/2006; WHO – Database 2008; European Commission - Report on the implementation of the Council Recommendation on cancer screening, 2008.

The culture of prevention appears to be well-rooted in Europe, above all insofar as concerns traditional vaccinations, but the system does include some “flaws” in relation to the screening programs in some countries.

The status of the right to access was examined by taking into consideration two different aspects, both tied to the definition of this right as expressed in the Charter.

## THE RIGHT TO ACCESS - physical

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

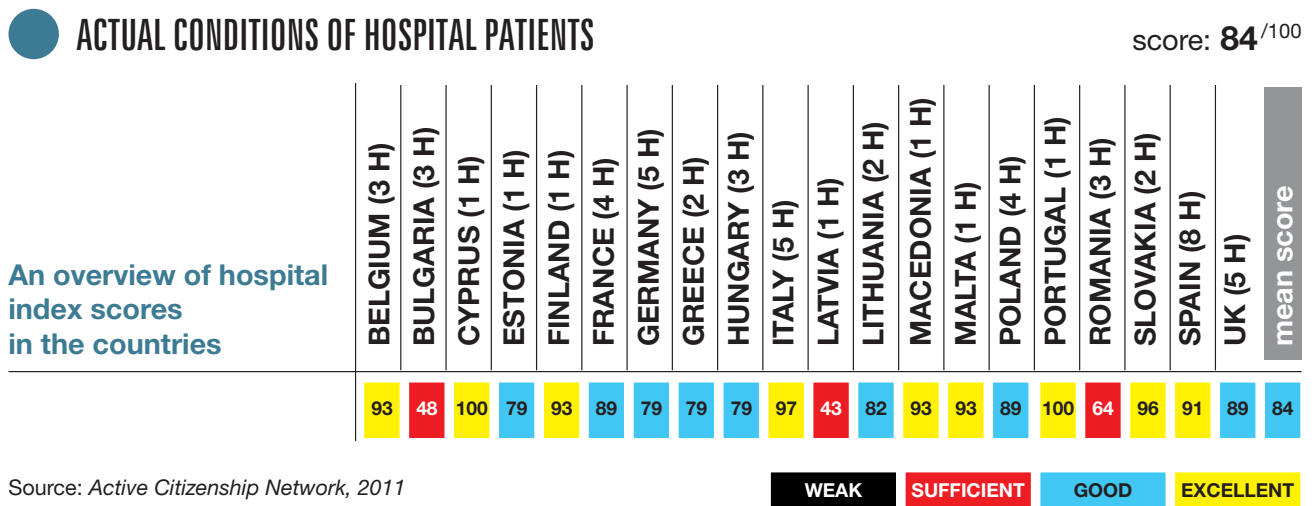
**ALMOST RESPECTED**

FULLY RESPECTED

●●●●○

- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

One aspect concerns actual physical access to health care facilities, considering all elements that can either favor or obstruct the possibility for users to access a health care facility in order to receive care or visit a relative or friend. This aspect is not explicitly declared in the right but, given its “elementary” nature, it can be considered a fundamental requisite for the full implementation of the principles expressed in the right to access. The evaluation of this aspect was carried out through direct observation in the hospitals by monitoring groups.



The scores attained by the hospitals are good and the situations in the hospitals assessed in the 20 countries are quite homogeneous: only 3 countries scored below the mean score.

<b>Citizens have directly observed in Hospitals</b>	<b>BELGIUM (3 H)</b>	<b>BULGARIA (3 H)</b>	<b>CYPRUS (1 H)</b>	<b>ESTONIA (1 H)</b>	<b>FINLAND (1 H)</b>	<b>FRANCE (4 H)</b>	<b>GERMANY (5 H)</b>	<b>GREECE (2 H)</b>	<b>HUNGARY (3 H)</b>	<b>ITALY (5 H)</b>	<b>LATVIA (1 H)</b>	<b>LITHUANIA (2 H)</b>	<b>MACEDONIA (1 H)</b>	<b>MALTA (1 H)</b>	<b>POLAND (4 H)</b>	<b>PORTUGAL (1 H)</b>	<b>ROMANIA (3 H)</b>	<b>SLOVAKIA (2 H)</b>	<b>SPAIN (8 H)</b>	<b>UK (5 H)</b>	<b>mean score</b>
Free use of the parking lot	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	WEAK	GOOD	GOOD	EXCELLENT	GOOD	WEAK	WEAK	WEAK	EXCELLENT	WEAK	GOOD	WEAK	WEAK	58
Reserved parking for disabled persons	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	WEAK	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	82
Patients with motor difficulties dropped off at the main entrance	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	WEAK	WEAK	EXCELLENT	WEAK	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	83
Structural barriers which have not been remedied	EXCELLENT	WEAK	EXCELLENT	WEAK	GOOD	GOOD	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	84
Street signs near the hospital indicating its location	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	88
Hospital entrances clearly marked	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	WEAK	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	92
Hospital accessible by public transportation	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	99

Source: Active Citizenship Network, 2011



The right to hospital access emerges as being decisively strong. The sole indicator with a low score is that of the free use of parking lots. Physical access and orientation of patients towards reaching the facilities appear to be standards that are by now shared at a European level, although in some countries serious gaps remain.



MINISTRY OF HEALTH  
 HOSPITALS  
 Questions for Directors   
 Directly observed   
 CIVIC ORGANIZATIONS  
 ANOTHER PERSPECTIVE

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.

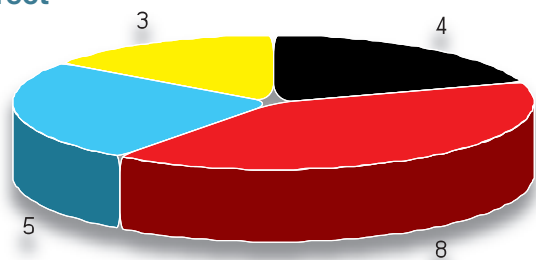
## ALERTS FROM CIVIC ORGANIZATIONS

score: 46<sup>/100</sup>

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- discrimination on the basis of financial resources;
- place of residence;
- kind of illness.



Source: Active Citizenship Network, 2011



Moreover at a European level, **frequent** other cases (not corresponding to the kinds of violations described by the indicator illustrated in the chart), were verified which, from the point of view of the organizations, could constitute violations of the right to access, as well.

Therefore, the image that emerges from the direct experience of the civic organizations is very grave. These organizations report an overall high frequency of violations in relation services (financial resources, place of residence and kind of illness), as illustrated in the above chart.

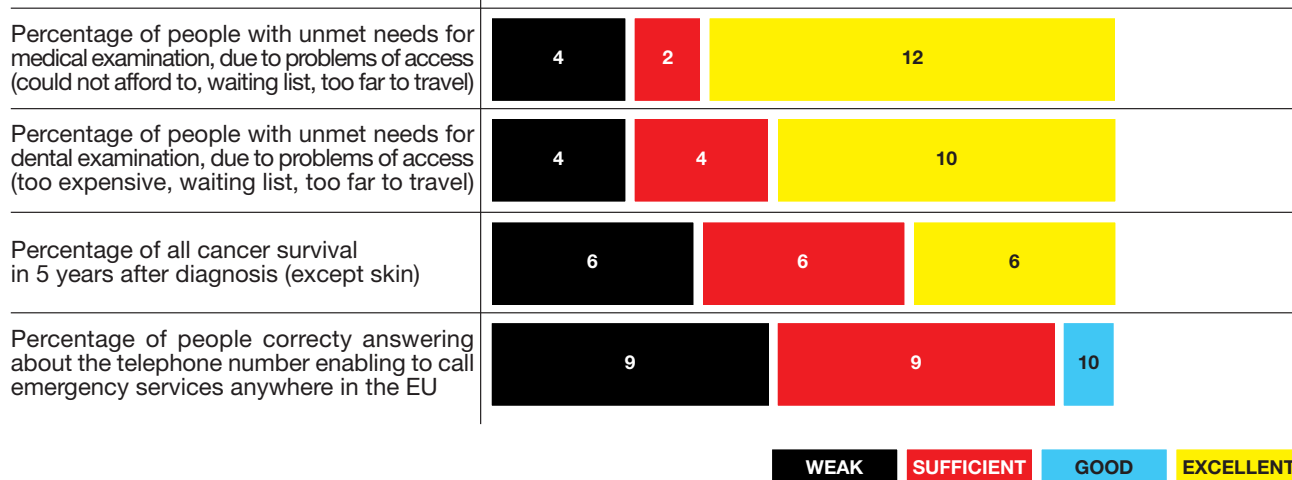
Civic partner organizations found no or only occasional violations in only 3 countries out of the total 20.

## ◆ ANOTHER PERSPECTIVE

### Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

#### Number of countries by statistical indicators



*The data refer to only 19 countries, because Official Statistics concerning Macedonia were not available.*

*In cases in which the total number of countries is less than 19, this is due to the non applicability of some indicators in certain countries.*

*Source: 2011 Active Citizenship Network's processing of statistical data from: Eurostat Database 2008, Eurostat Database 2009; Wilking, Jonsson, Karolinska Institutet; Eurobarometer Flash Report 228/2008.*

These statistical indicators have been chosen as expressly referring to that which is established in the Charter: access to needed health services.

As the chart illustrates, statistical information would seem to confirm and reinforce the reports of violations and obstacles to access presented by the civic organizations.

It is important to underline that in as many as 12 countries the situation of the percentage of the survival of all cancer patients 5 years following diagnosis, which is a very significant indicator for the issue of access, is "low" or, at maximum, "sufficient": this indicator is relevant because there is unanimous consensus on the fact that differences among countries concerning the survival of cancer patients are mostly due to the disparities in access to the various phases of the diagnostic therapeutic process (screening, antitumoral drugs, etc.).

It is also important to underline that knowledge of the emergency phone number common to all European countries (112) is low. This number is a tool that should guarantee immediate access to emergency health services.

## THE RIGHT TO INFORMATION

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

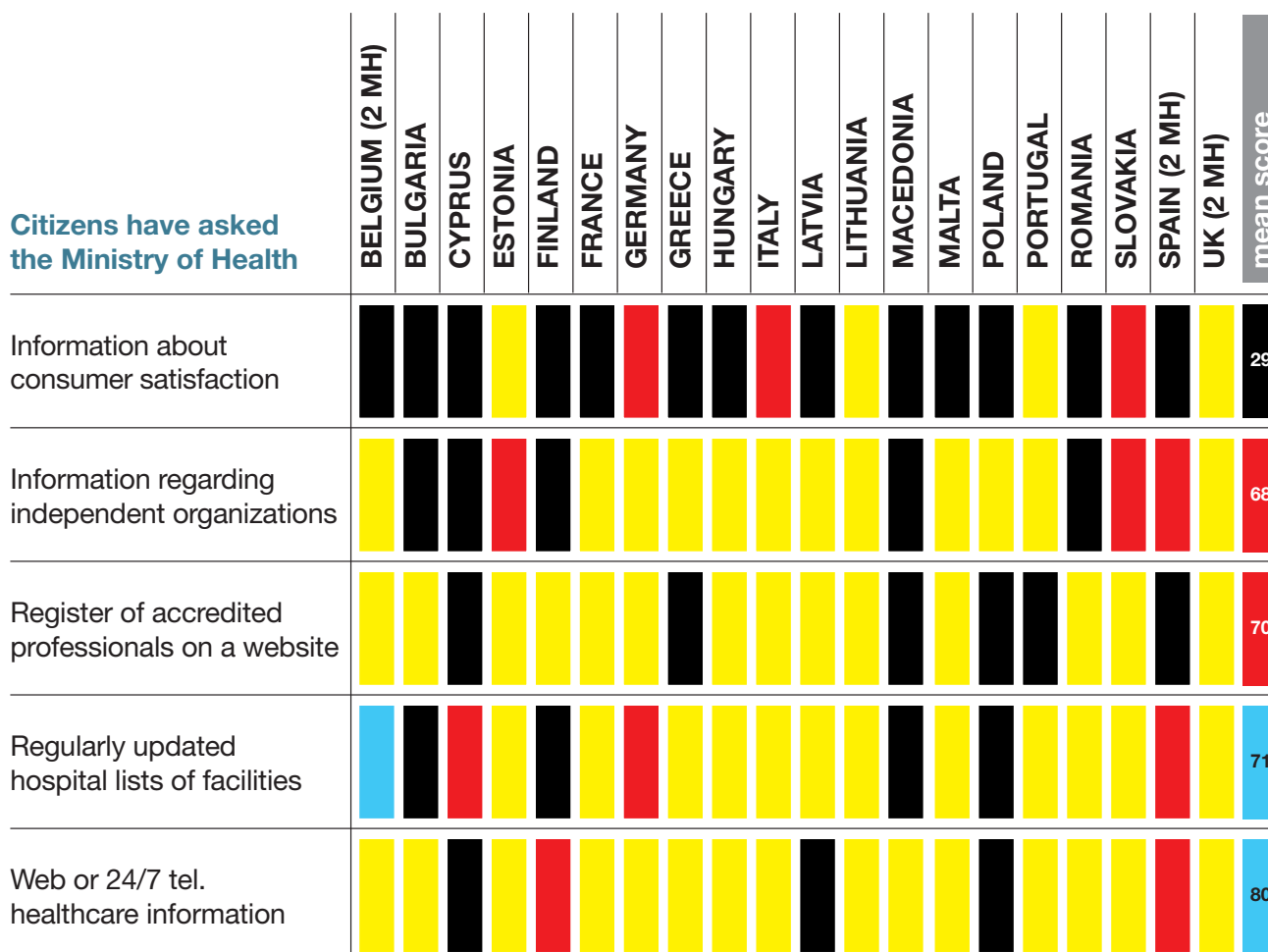
FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: **63**<sup>/100</sup>



Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The overall score for institutional actions relevant to the patients' right to information is quite low, due in particular to the 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.



## An overview of hospital index scores in the countries

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
	79	56	57	77	76	74	38	73	63	72	75	54	57	70	64	73	69	61	78	66	67

Source: Active Citizenship Network, 2011



The situation of this right in the hospitals assessed is only sufficient. Moreover, none of the countries attained an excellent score.

## Citizens have asked the Hospital Directors

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score	
Free clinical records for patient	WEAK	WEAK	WEAK	EXCELLENT	EXCELLENT	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	NA	EXCELLENT	GOOD	WEAK	32	
Free telephone number	SUFFICIENT	SUFFICIENT	SUFFICIENT	EXCELLENT	SUFFICIENT	WEAK	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	WEAK	SUFFICIENT	SUFFICIENT	53
Percentage of records provided within 30 days in March 2009	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	NA	SUFFICIENT	WEAK	EXCELLENT	SUFFICIENT	SUFFICIENT	EXCELLENT	EXCELLENT	NA	EXCELLENT	SUFFICIENT	EXCELLENT	NA	EXCELLENT	GOOD	GOOD	84	
Possibility for patients to receive hospital record after discharge	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	95

Source: Active Citizenship Network, 2011



An accrued reading of indicators asked to Hospital Directors shows that the possibility for patients to receive hospital records after discharge can be considered a shared European standard, while there is a widespread problem regarding the patient access to free clinical records.

The existence of a free information line is still far from being realized.

Regarding the issue of clinical records, please refer to the chapter "Citizens' organizations working plan".

Citizens have directly observed in Hospitals	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
Hospital websites - contents <sup>1</sup>	WEAK	WEAK	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	SUFFICIENT	WEAK	SUFFICIENT	SUFFICIENT	SUFFICIENT	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	SUFFICIENT	WEAK	38
Indicated areas for voluntary and public interest associations	GOOD	WEAK	WEAK	WEAK	WEAK	GOOD	GOOD	WEAK	SUFFICIENT	GOOD	EXCELLENT	WEAK	WEAK	EXCELLENT	SUFFICIENT	GOOD	WEAK	WEAK	SUFFICIENT	WEAK	43
Places <sup>2</sup> for distribution of inpatient information materials	EXCELLENT	SUFFICIENT	WEAK	EXCELLENT	GOOD	EXCELLENT	WEAK	GOOD	WEAK	GOOD	WEAK	WEAK	WEAK	GOOD	WEAK	WEAK	SUFFICIENT	SUFFICIENT	GOOD	WEAK	51
Information sheet on patients' rights, made publicly available	EXCELLENT	SUFFICIENT	EXCELLENT	WEAK	NA	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	WEAK	72
Information sheet about the hospital and the regulations, made publicly available	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	WEAK	EXCELLENT	EXCELLENT	83
Regularly updated hospital services directory at the main entrance	EXCELLENT	WEAK	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	86
Reception (office or desk for receiving the public and providing information regarding the services)	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	SUFFICIENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	95

Source: Active Citizenship Network, 2011



As regards information components checked directly by monitoring groups, the situation of the hospital websites is clearly weak: for the hospitals assessed, not a single country attained a good score.

The hospitals of only 7 countries attained a score of at least “good” for the indicator concerning indicated areas for voluntary and public interest associations: we can confirm that the active citizens are viewed as intruders. This situation is probably linked to the obstacles encountered in many countries by the monitoring groups during hospital visits and in obtaining information from the health authorities.

The presence of an information office or desk is widespread throughout Europe, and in general the situation regarding the provision of information materials is good.

It is interesting to note that it is easier to find information sheets about regulations than it is to find information sheets about patients' rights.

In general, from the three indicators that attained either weak or sufficient scores, one may observe a significant lack in the completeness of website contents: among other things, “hot” issues such as wait times and benchmarking among hospitals are missing.

**1. List of contents checked:**

- List of services provided
- Opening times
- How to make an appointment
- Wait times for principle exams and treatments
- How to reach the hospital
- Possibility of scheduling an appointment (for exams/visits/etc.) online
- Diagnostic exams that patients can receive via the Internet
- Data on the outcomes of the health care services administered

**2. Possible answers:**

- Data on the outcomes of the health care services administered compared with data from other hospitals (benchmarking)
- Quality Score that covers a range of areas including patient safety, cleanliness and wait times etc.
- Quality Score compared with the scores of the other hospitals.
- available at the main entrance of the hospital
- given by hospital personnel to patients at admission (at the entrance)
- may be downloaded from hospital websites

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- *medical records;*
- *information regarding health status during check-ups or hospitalizations;*
- *information about suitable health services when necessary;*
- *information about innovative treatments available in other European countries.*

Source: Active Citizenship Network, 2011



The alerts from civic organizations are very serious: in as many as 17 countries out of 20, violations of the right as concerns essential information topics, set by the indicator, have been either frequently or regularly found.

The synthetic assessment of this right is indeed deeply influenced by the situation reported by Partner organizations.

**GENERAL COMMENT:** the decidedly negative evaluation of the right to information in Europe (hardly respected) that emerges from this assessment is still more serious when one considers that the right to information is a “soft” right: the implementation of the majority of actions and initiatives necessary for improving respect for this right are neither cost-intensive nor time-intensive for institutions and hospital management. To give an example: the cost of hospital websites has already been sustained and they only need to be updated and/or integrated.

3. By Europe is here meant the group of the European countries participating in this project.

## THE RIGHT TO CONSENT

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

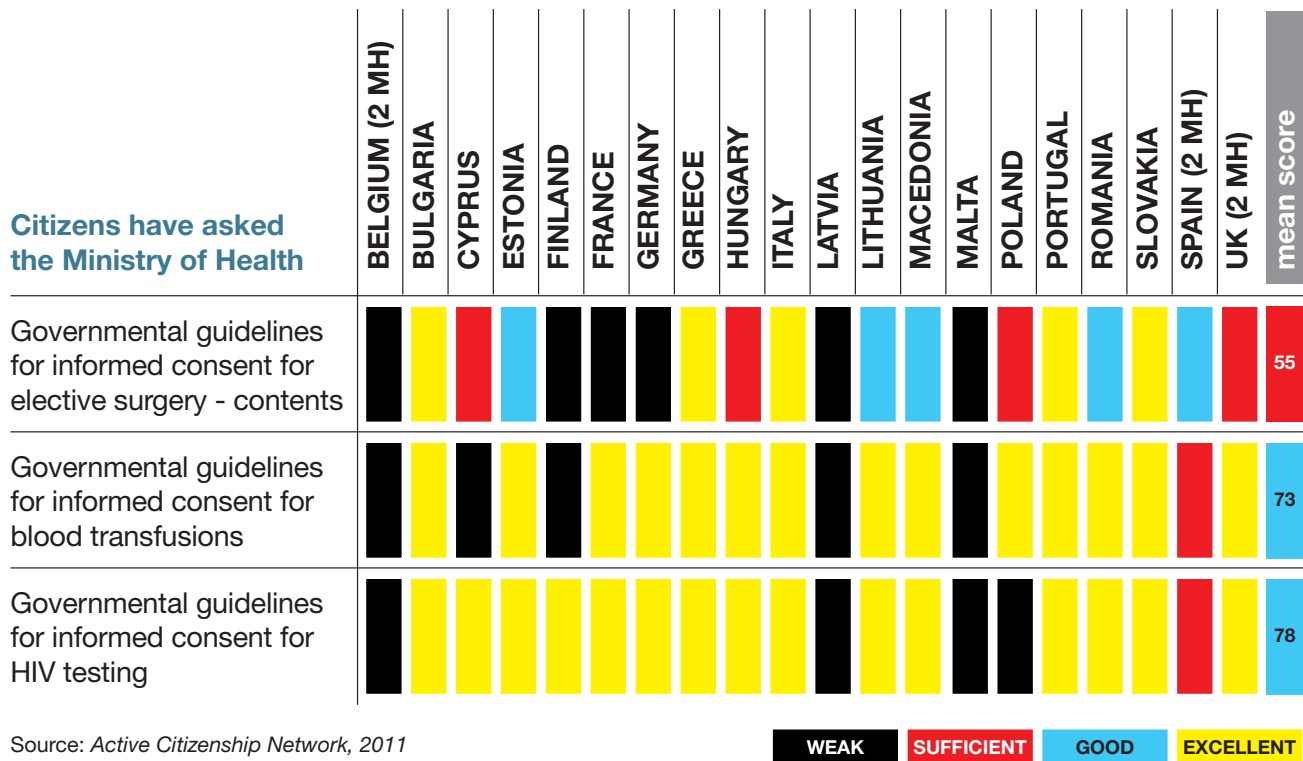
FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: **68**<sup>/100</sup>



At the level of government, on the one hand the majority of countries demonstrate a good level of attention to “informed consent” in the cases of blood transfusions and diagnostic HIV testing, while on the other hand a minority of countries (4 or 5) do not have such guidelines in place. The situation regarding surgical interventions is “barely sufficient”.

## An overview of hospital index scores in the countries

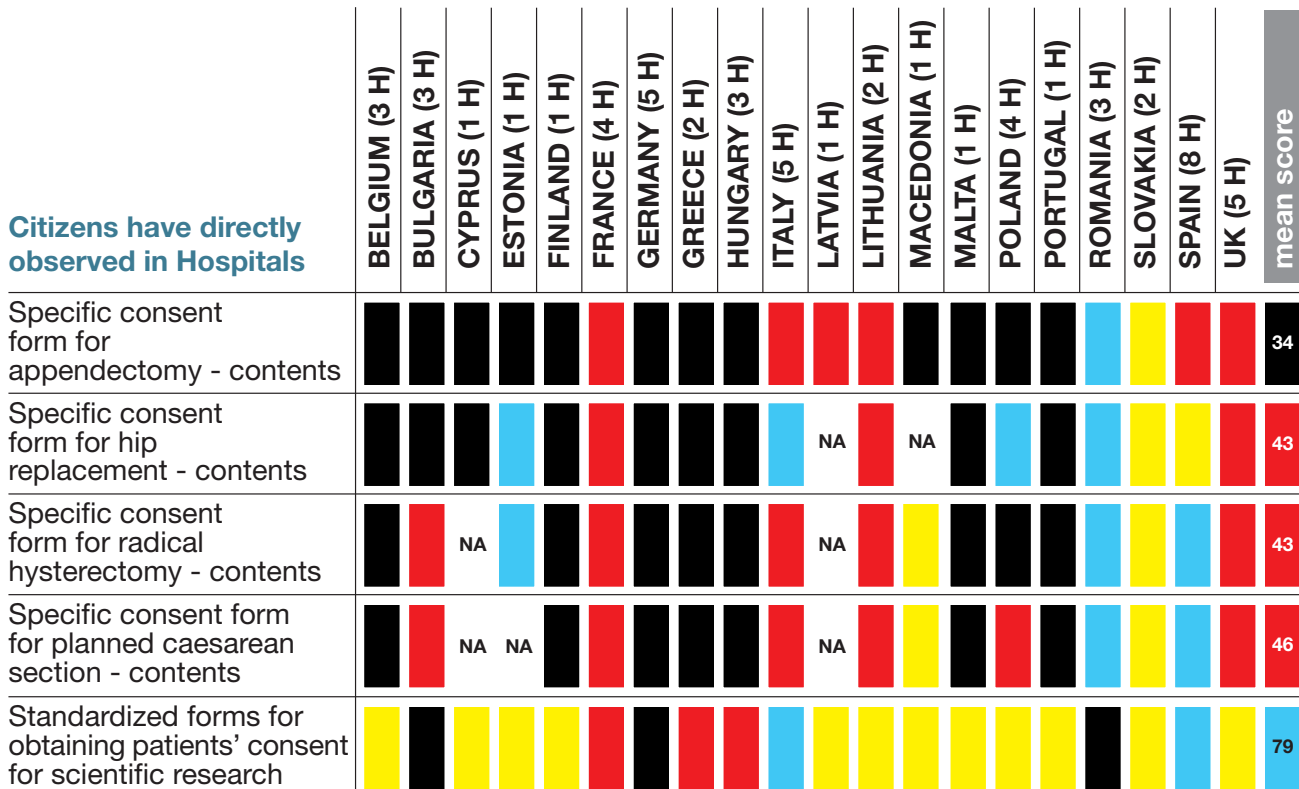


Source: Active Citizenship Network, 2011



The hospital profile concerning the issue of “consent”, as studied using the selected indicators, is quite critical, revealing a score lower than that attained by “institutional actions for patients’rights”, and an unbalanced (and interesting) distribution of countries.

## Citizens have directly observed in Hospitals



Source: Active Citizenship Network, 2011



A problem regarding specific consent forms with proper contents for certain elective surgery operations clearly emerges. The peculiar European<sup>1</sup> situation, in which there are sensitive differences among countries and common coherence within individual countries, require further data and a special reflection upon the meaning of “consent” in order to build a shared concept from a civic point of view (please see the chapter “Citizens’ organizations working plan”).

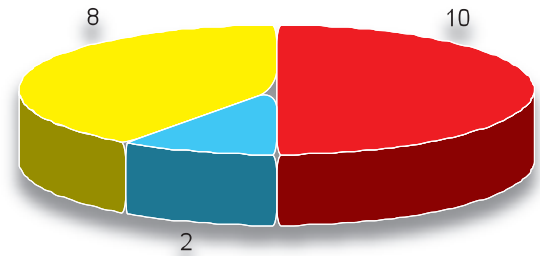
1. By European is here meant the group of the European countries participating in this project.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- *diagnostic procedures;*
- *treatment provided without patients' consent*




Source: Active Citizenship Network, 2011

  
number of  
countries with violations  
regularly found

  
number of  
countries with violations  
frequently found

  
number of  
countries with violations  
rarely found

  
number of  
countries with violations  
occasionally / never found

From the answers given by civic partner organizations, and when considering the overall situation, cases of violations of the right concerning diagnostic procedures and/or treatments provided without patients' consent have not been detected with worrying frequency, as violations have not been found regularly in any of the countries.

Nevertheless it is important to not ignore the fact that frequent violations were reported in ten countries.

2. Please keep in mind the particular nature of these, which cannot be considered as pure indicators, but better as "sentinel events": when found, they denounce the presence of serious obstacles for citizens; when not found, they do not indicate absence of violations, which might have happened all the same.

## THE RIGHT TO FREE CHOICE

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED

●○○○○

▲ MINISTRY OF HEALTH

● HOSPITALS

Questions for Directors   
Directly observed

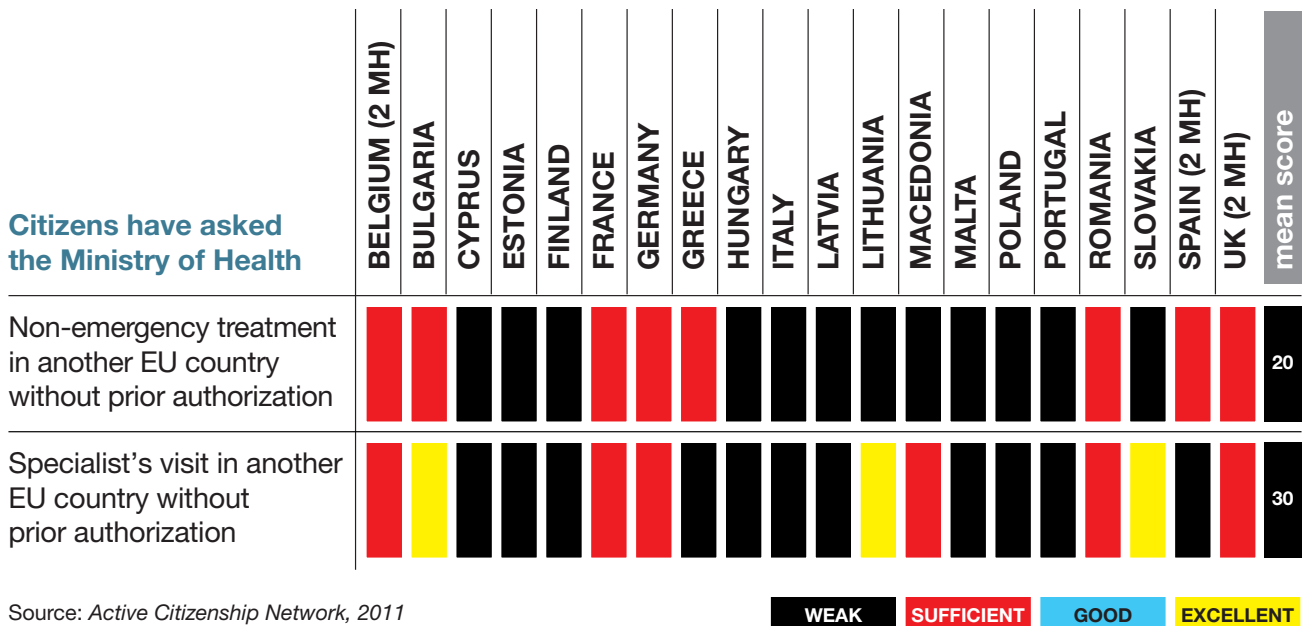
■ CIVIC ORGANIZATIONS

◆ ANOTHER PERSPECTIVE

The synthetic assessment of this Right is peculiar, as it derives solely from information provided by Civic Partner Organizations. This decision is due to the contextual elaboration of the European Directive on care without borders: it is therefore preferred to not contribute the indicators detected via the Ministries of Health (see below), which concern innovative actions that could be implemented by governments in order to favour the health-related mobility of patients, to the evaluation.

The European Directive on care without borders, which this Report views from a civic perspective, sets significant goals for governments and health care authorities, which ACN, together with other civic organizations, will need to verify through future monitoring in order to check on the progressive implementation of the right to free choice of health care at a European level (please see also the chapter "Citizens' organizations working plan").

## ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS



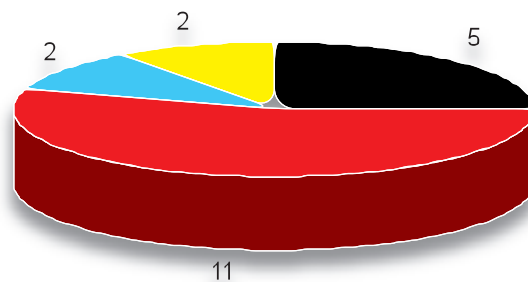
The information gathered is nevertheless interesting, as it reveals the willingness of some countries to begin to favour patient mobility.

## ALERTS FROM CIVIC ORGANIZATIONS


Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- difference in fees between public and private hospitals;
- incentives to seek treatment in certain hospitals or centres;
- coverage of supplementary insurance for only some hospitals;
- need to get authorization for some treatments;
- indigent patients may only be treated in certain hospitals.




Source: Active Citizenship Network, 2011

  
number of  
countries with violations  
regularly found

  
number of  
countries with violations  
frequently found

  
number of  
countries with violations  
rarely found

  
number of  
countries with violations  
occasionally / never found

In 16 of the 20 countries being monitored, the civic partner organizations reported that they directly found frequent or regular violations of the right to free choice: this worrying result demands a deeper investigation of the individual issues detected.

The right to free choice is recognized in principle in all of the countries, but is often in fact limited by organizational procedure, by limits imposed by insurance companies or by other factors.

A recurring practice is that of imposing preventive authorizations on determinant treatments. This occurs very frequently according to 40% of the organizations interviewed and, according to the same source, is absent in only 4 countries.

In the case of insurance systems it occurs with variable frequency and the conditions of destitution and poverty notably limit the number of hospitals that are actually accessible. Other limitations arise from the differences in costs and reimbursements between public and private hospitals, a problem that recurs in 11 countries and is absent in only 3 cases. Complementary insurance can also result in a reduction in the number of hospitals that can be actually accessed. Finally, according to 60% of the organizations interviewed, administrative authorities and insurers tend to provide incentives for access to determinate hospitals and centres, making the route to access easier (or more difficult). In sum, what emerges is a “choice” that is not in fact very free and that is burdened with many obstacles.

## ANOTHER PERSPECTIVE

Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

### Number of countries by statistical indicators

Percentage of people who feel to have enough choice in choosing regular medical doctor



The data refer to only 19 countries, because Official Statistics concerning Macedonia were not available. In cases in which the total number of countries is less than 19, this is due to the non applicability of some indicators in certain countries.

Source: 2011 Active Citizenship Network's processing of statistical data from: European Social Survey – Round 2.

**WEAK** **SUFFICIENT** **GOOD** **EXCELLENT**

Although only one indicator has been entered in this box, the result is significant because it takes people's perceptions into consideration and strengthens the results that emerged from the others indicators, revealing general weakness in terms of respect for the right to free choice.



## THE RIGHT TO PRIVACY and CONFIDENTIALITY

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

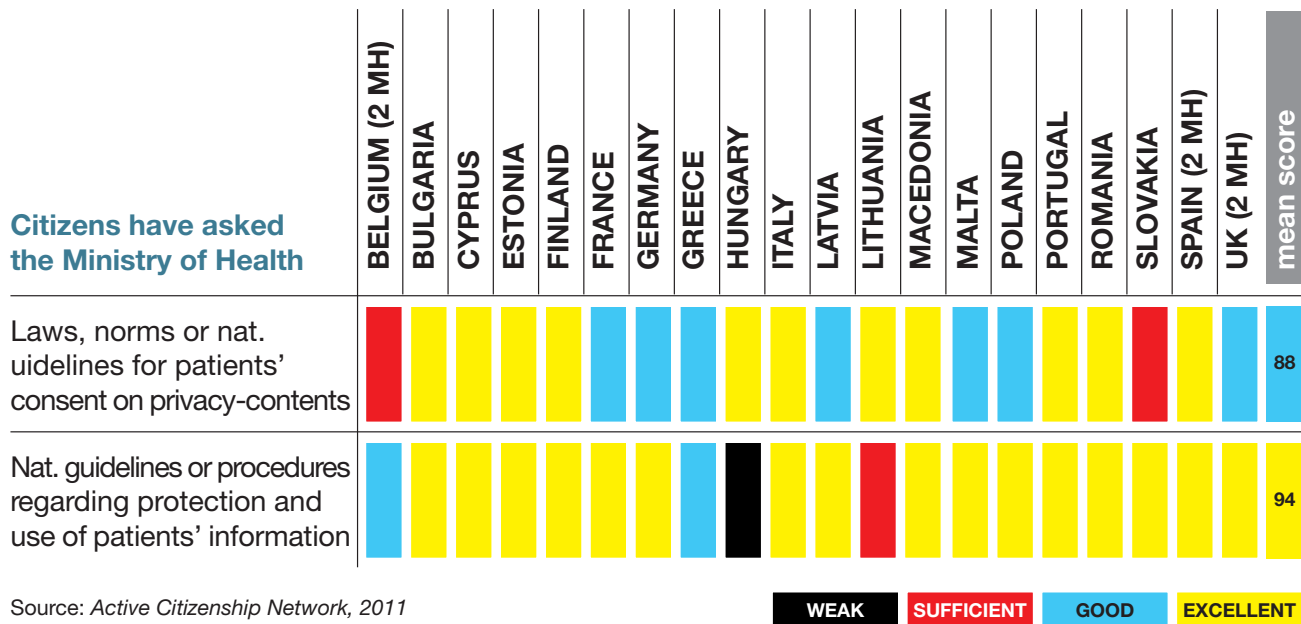
FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS  
Questions for Directors   
Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: **91** /100



Institutional actions for patients' rights, here specifically regarding laws, norms or guidelines that ensure patients' consent to the use of his or her personal information and the protection of patients' information, have attained an excellent score: the second indicator would appear to be an unquestionable standard throughout Europe<sup>1</sup>.

1. By Europe is here meant the group of the European countries participating in this project.

## An overview of hospital index scores in the countries

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
	78	90	64	83	86	79	94	73	75	93	76	66	100	69	89	64	78	88	76	70	80

Source: Active Citizenship Network, 2011



The level of respect of the right to privacy and confidentiality in the hospitals assessed is also very good: there are no weak countries and only five attained a merely sufficient score.

## Citizens have asked the Hospital Directors

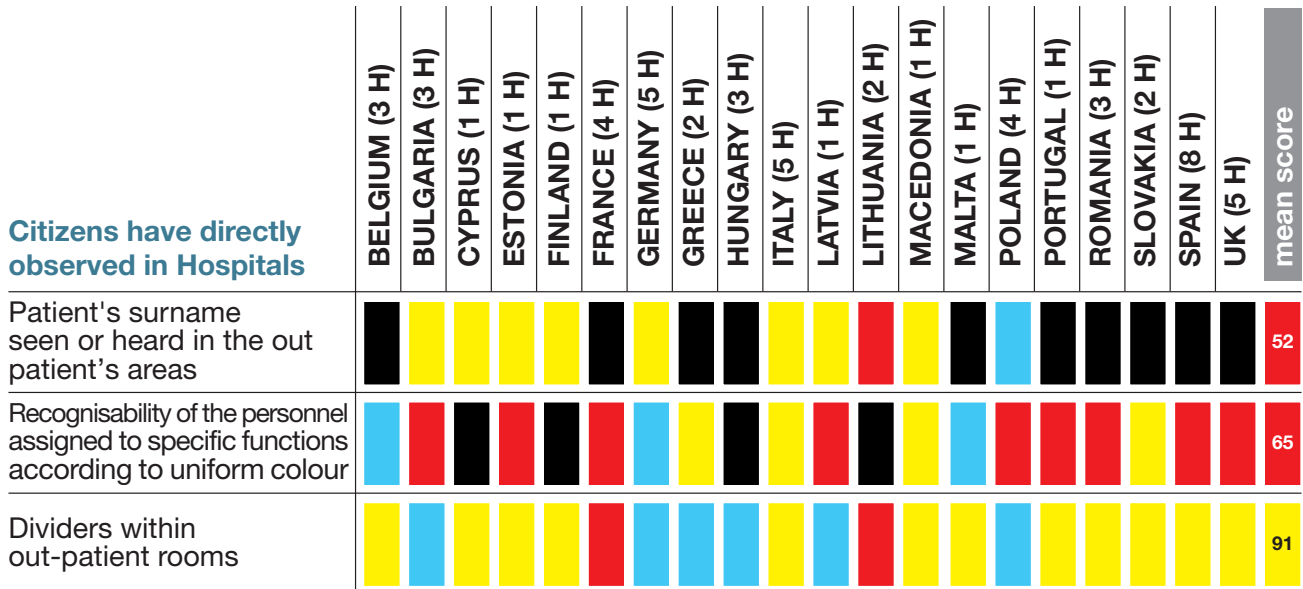
	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
Single rooms for terminal patients and their families, if requested	EXCELLENT	GOOD	GOOD	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	GOOD	SUFFICIENT	GOOD	EXCELLENT	EXCELLENT	GOOD	GOOD	WEAK	GOOD	EXCELLENT	GOOD	GOOD	75
Cases of the non-authorized circulation of medical information	SUFFICIENT	EXCELLENT	SUFFICIENT	EXCELLENT	SUFFICIENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	SUFFICIENT	84
Information on the possible presence of students during visits	SUFFICIENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	86
Cases of the non-authorized circulation of medical records	GOOD	GOOD	SUFFICIENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	87
Violation of the confidentiality of HIV/AIDS patients	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	96

Source: Active Citizenship Network, 2011



Regarding actions which are the responsibility of Hospital Directors, and in general concerning the protection of patients' privacy, the outline is good, given that common attention to this issue emerges from the data, with only a few, however significant exceptions.

In particular, the level of common protection of confidentiality of HIV/AIDS patients is reassuring.



Source: Active Citizenship Network, 2011



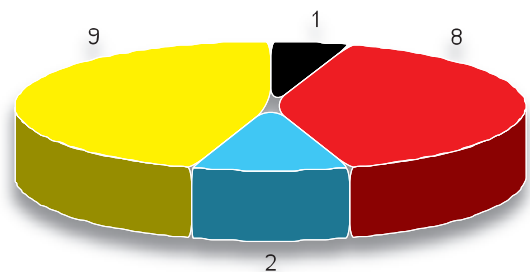
Critical situations have been revealed through citizens' direct observation. These include: a worrying diffusion of cases in which a patient's surname can be seen or heard in outpatient areas and the failure to identify personnel assigned to specific functions by uniform colour.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- normative medical information disclosed to non-authorized persons;
- patients' case files disclosed to non authorized persons.



Source: Active Citizenship Network, 2011



This information box completes, and helps towards the partial re-consideration of, the previous indicators: notwithstanding the answers given by the Hospital Directors interviewed, civic organizations in eight countries found frequent violations concerning normative medical information disclosed to non-authorized persons, and patients' case files disclosed to non-authorized persons. In one country violations have even been regularly detected.

Moreover, at a European level there have been **frequent** cases which cannot be categorized in terms of the violations identified by the indicator described above and which, from the perspective of the organizations, might nonetheless constitute a violation of the right to privacy and confidentiality.

**GENERAL COMMENT:** comparison of the "excellent" and "very good" scores attained for the indicators detected at the institutional and hospital level, with the frequent violations of the right to privacy found by the partner organizations, leads one to conclude that in this area there is a serious problem of improper behaviour and practice and of poor compliance with norms (which, one has seen, there are).

## THE RIGHT TO RESPECT OF PATIENTS' TIME

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED

●○○○○

▲ MINISTRY OF HEALTH

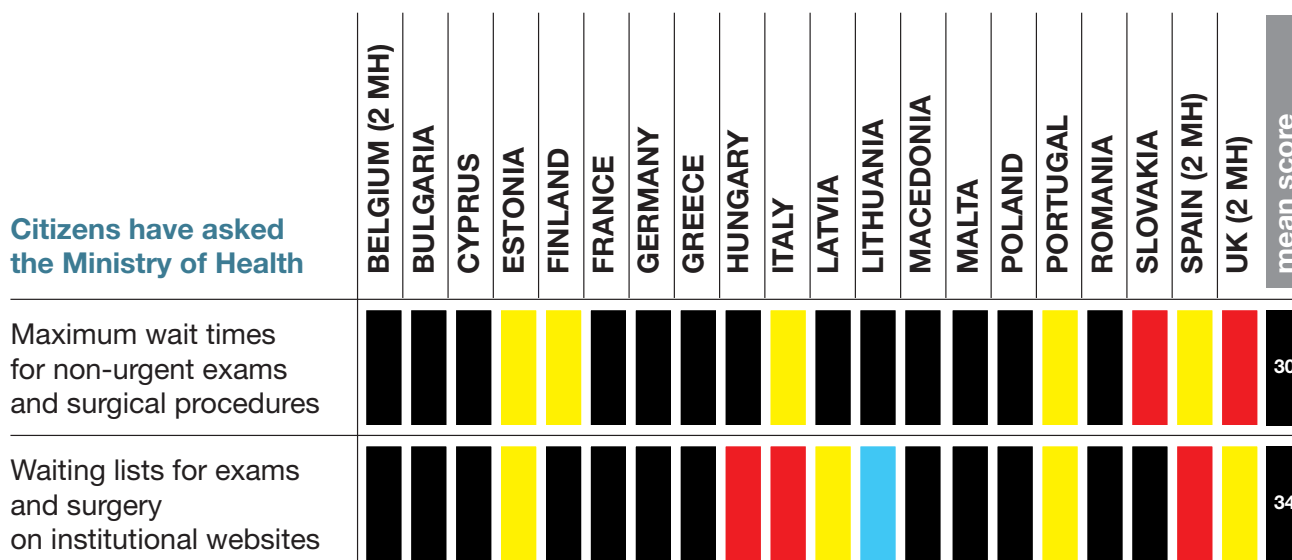
● HOSPITALS  
Questions for Directors   
Directly observed

■ CIVIC ORGANIZATIONS

◆ ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

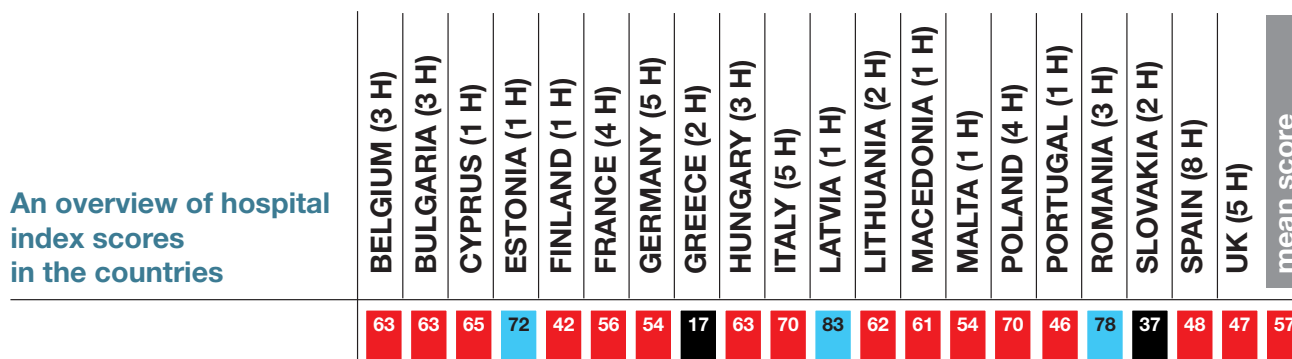
score: **32**<sup>/100</sup>



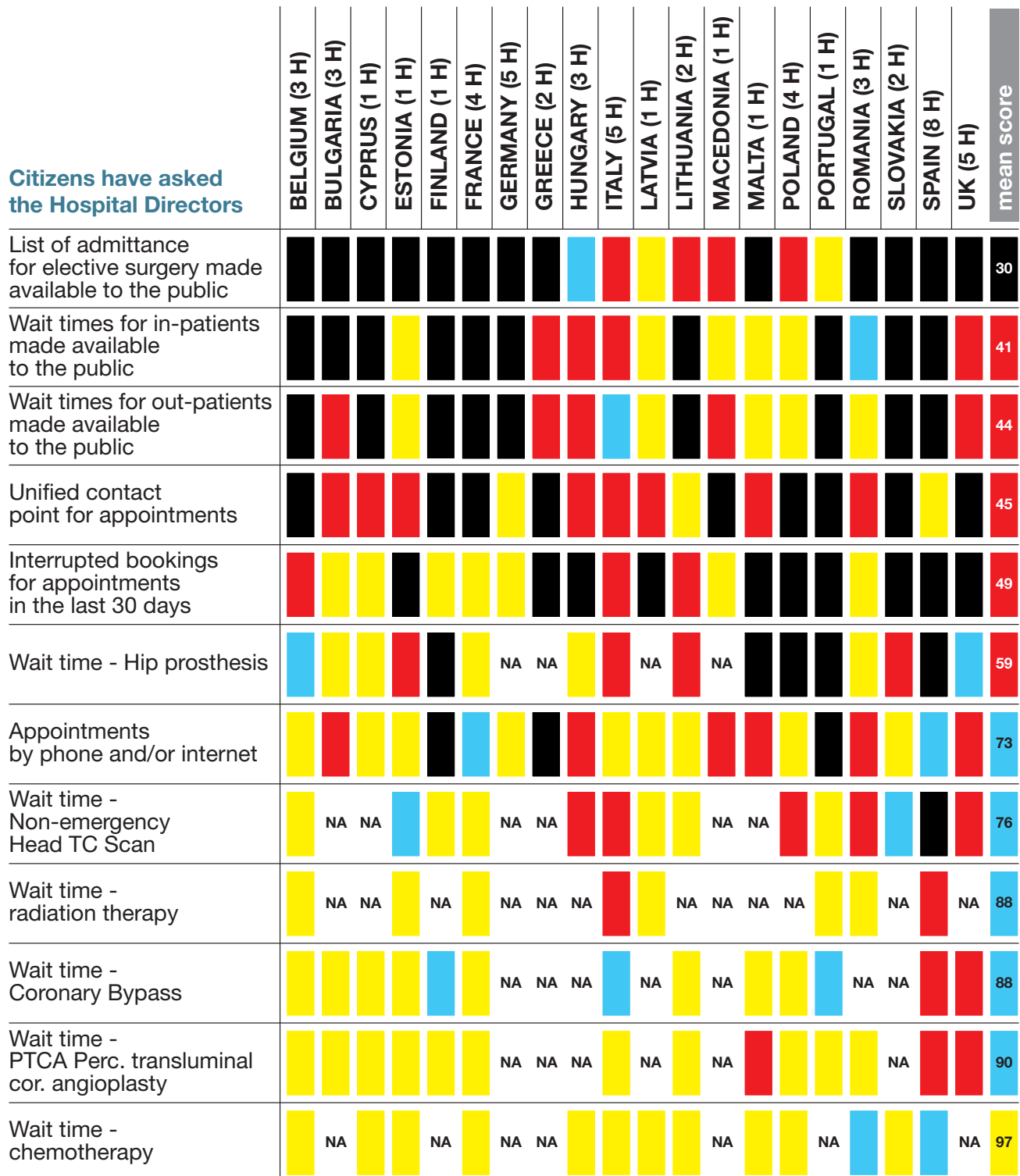
As the chart illustrates, the profile of institutional actions for the patients' right to respect for their time is clearly weak: maximum wait times for both non-urgent exams and surgical procedures have been established in only four countries. A problem of transparency also emerges, as it is only possible in 4 countries for citizens country-wide to find information about waiting lists for diagnostic exams, treatments and elective surgery on institutional websites.

### ● ACTUAL CONDITIONS OF HOSPITAL PATIENTS

score: **57**<sup>/100</sup>



Observing the overview of the level of attention to this right in the hospitals assessed, the level attained is only sufficient, and only 3 countries attained a good score.



Source: Active Citizenship Network, 2011



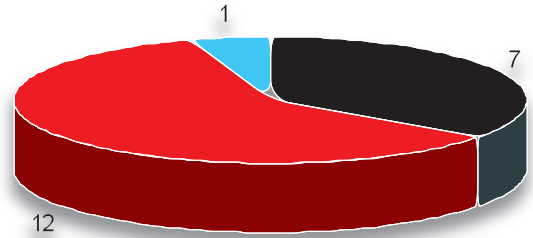
A widespread phenomenon appears to exist that consists in tied-up waiting lists for one or more of the exams reported. This specific phenomenon, clearly detected in 15 out of 20 countries, constitutes a type of hidden restriction to access to health care that can be considered a form of service rationing. This picture is accompanied by a lack, detected in numerous countries, of the basic tools that permit citizens to deal with this situation, and that are elements revealing attention to citizens, including publicly-available lists of admittance for elective surgery, publicly-available wait times for in-patients, publicly-available wait times for out-patients and a unified contact point for making appointments. The indicators relative to patient wait times for some surgical interventions and treatments attained a better level. But only in the case of chemotherapy does one note a shared capacity throughout Europe to guarantee all cancer patients a wait time of less than 21 days.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation 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.*




Source: Active Citizenship Network, 2011

  
number of  
countries with violations  
regularly found

  
number of  
countries with violations  
frequently found

  
number of  
countries with violations  
rarely found

  
number of  
countries with violations  
occasionally / never found

The consequences of this difficult situation concerning wait times – emerged from the above-analysed indicators, detected through the Minister of Health and the Hospitals – are highlighted by the alarming situation denounced by the civic organizations: in 19 countries out of 20 they reported regular or frequent violations concerning illness that worsened because of a delay in treatment; illness worsened because of a delay in diagnosis (due to wait times); and excessively long wait times for specific exams. These indicators emphasize not only the elemental issues concerning time, but also the serious consequences that citizens suffer because of delays in treatment or diagnosis.

## THE RIGHT TO QUALITY

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 59/100

	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score	
Citizens have asked the Ministry of Health																						
List reporting quality ranking of health services	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	10
Nat. gov. accreditation programs for health services <sup>1</sup>	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	64
Nat. centres for guidelines for clinical practice	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	80
Quality improvement in academic curriculum of health professionals	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	83

Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The average score attained for the indicators detected at an institutional level for the right to quality is merely sufficient. Standing out among the indicators is the nearly complete absence of nationally-issued lists reporting the quality ranking of health services, with the sole exception of the United Kingdom. In regards to this situation, it is worth highlighting the diversity among the various systems. In Slovakia, for example, the indicator was not held to be compliant because these lists are published by the insurers, and therefore by those who pay, and not by the institutional websites. It is possible for citizens to inform themselves about the quality of the facilities, but not through use of official sources. >>>

1. A standard is considered compliant when the accreditation program is: at a national level; related to government through the Ministry of Health or a Governmental Agency; of governmental legal status. If a program does not meet all of these requirements, the score of the indicator can vary from zero to partial values.

>>> The indicator for the presence of national governmental accreditation programs for health services reveals consistent underdevelopment in many countries. In this case, too, differences between systems are revealed. For example, in Germany there are various accreditation programs that cover all of the different branches of health care. Some of the programs are acknowledged by the government, while others are not. The institutions offering accreditation programs are either commercial (these being in the majority) or non-profit (a small minority).

Quality and accreditation, as with other sectors, are areas of intervention in which the European Union could move more quickly and interact positively with the discussions underway in many countries.

## ACTUAL CONDITIONS OF HOSPITAL PATIENTS

score: **69**/100



Source: Active Citizenship Network, 2011



Hospitals in some countries attained a very high score. The majority, however, were found to fall within a merely sufficient range. The average value is merely sufficient.



Source: Active Citizenship Network, 2011



The data reveal a low-level of attention to adhesion to public accreditation programs and to voluntary forms of accreditation / certification. This is also the case for attention to the measurement of patient satisfaction (moreover it must be noted that in many hospitals the health authorities do not know whether or not national accreditation programs exist). The level of diffusion of quality units is higher, being more or less homogeneously present in the majority of the hospitals observed.



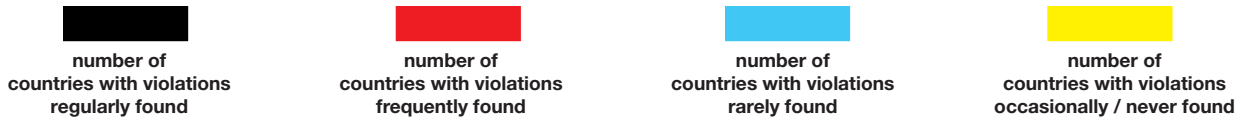
## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- *right to the observance of quality standard (in cases in which the total number of countries is less than 20, this is due to the inapplicability of one or more indicators in certain countries).*

Source: Active Citizenship Network, 2011



As the chart clearly illustrates, in 11 countries out of 19 Civic Organizations have reported and registered frequent cases of violations of the quality standards established by national legislation for health services providers. In one country violations have even been found regularly.

It is worth reporting the quite alarming testimony of the Cypriot partner organization: this organization had to request inapplicability for the questions relating to this right because “so far, national legislation for health services providers does not include any formal quality standards”.

## THE RIGHT TO SAFETY

NOT RESPECTED

**HARDLY RESPECTED**

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 42/100

	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score
Citizens have asked the Ministry of Health	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Legal protection for people who report an adverse event	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Nat. recommend. for implementation of "WHO Surgical Safety Checklist"	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Legal provision of an information system concerning adverse events	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■

Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The profile of the right to safety that emerges from the responses provided by the Health Authorities is worrying. The analysis as concerns the governmental level was conducted based on observation of the existence or absence in the monitored countries of 3 actions that must be implemented, among so many others, in order to raise the level of safety in health care systems. It does emerge that some countries are implementing these actions, but in as many as 17 countries no form of legal protection has been established for people who report an adverse event. Moreover, in as many as 9 countries there are no national recommendations for the implementation of the "WHO Surgical Safety Checklist".

An overview of hospital index scores in the countries

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
	86	74	83	95	80	89	78	80	75	89	85	71	70	90	66	90	84	94	86	83	82

Shifting attention from the institutional level to hospital assistance, the situation improves notably. The indicators relative to the safety of hospital assistance, as measured by citizens, attained a rather high score in almost all of the countries under consideration. One should bear in mind that, in matters of safety, values deemed acceptable must be very close to the maximum score. It is therefore necessary to ask: how much is missing (and what and where) in order to achieve full safety for all hospital patients? The chart below helps to identify the “black holes”.

Citizens have asked the Hospital Directors

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score	
Fire resistant areas easily reached by people with disabilities	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	SUFFICIENT	NR	WEAK	WEAK	GOOD	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	63
Hospital guidelines that take into account the WHO Surgical Safety Checklist	SUFFICIENT	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	NR	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	76
Priority codes for triage procedure in Emergency Departments	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	NR	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	89
Updated report (not later than last year) on hospital infections	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	NR	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	99
Procedure for reducing the risks of transfusions	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	NR	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	99
Procedure for hand-washing	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	NR	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	99

It is interesting to note that the measures of pertinence to hospital directors and relative to the prevention of infection considered in this questionnaire – procedures for hand washing and for reducing the risk of transfusions and updated reports on hospital infections – can now be considered unquestioned safety standards at a European<sup>1</sup> level.

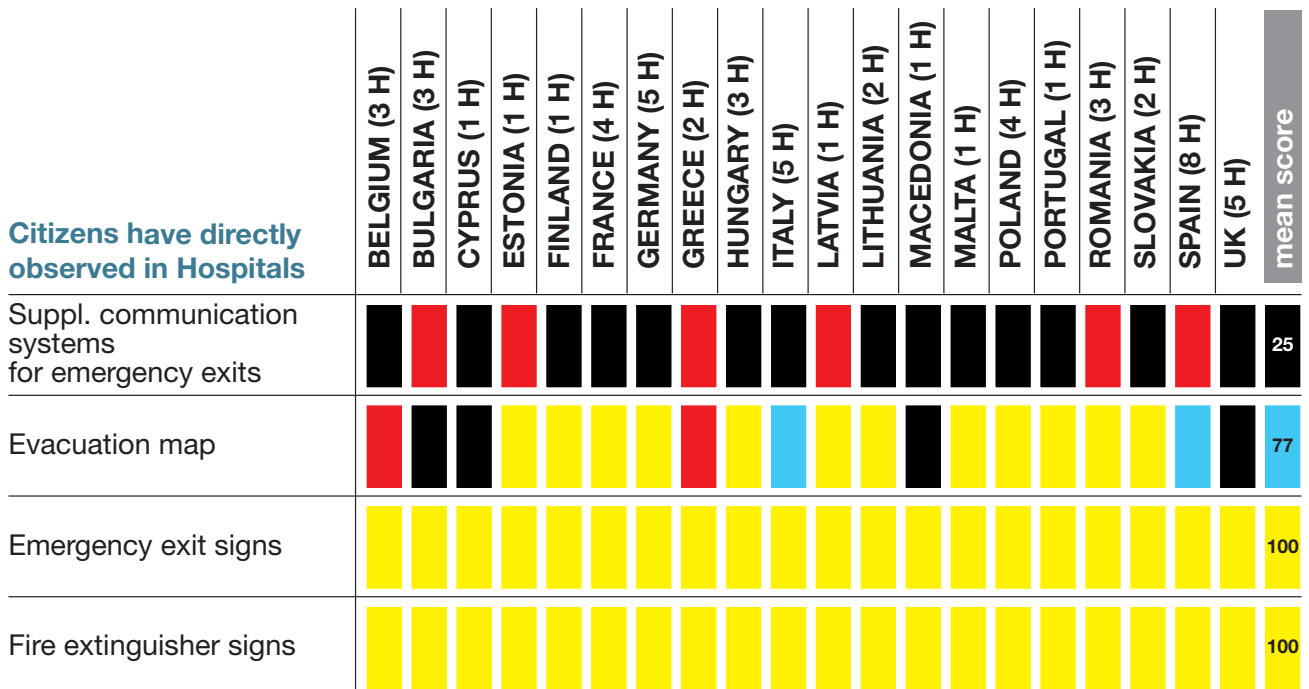
It is very worrying, however, that the number of fire resistant areas that can be easily reached by people with disabilities remains low.

It is important to observe that the countries in which hospitals lack guidelines for taking the “WHO Surgical Safety Checklist” into account are also countries in which the Ministers declared that they had not provided national recommendations for the implementation of such Checklist (the single exception is Hungary, where the hospitals observed had not yet received the government recommendations).

Source: Active Citizenship Network, 2011



1. By European is here meant the group of the European countries participating in this project.



Source: Active Citizenship Network, 2011



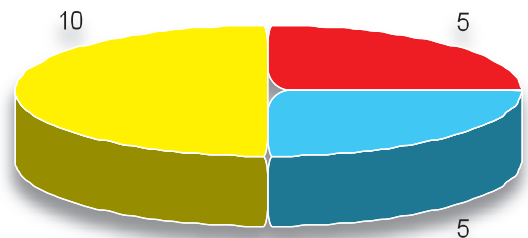
Insofar as concerns building safety, one notes the uniform presence of such basic elements as emergency exit signs and fire extinguisher signs. This is a clear strong point. But once again, the safety of vulnerable patients (the disabled) attains a very negative score, as demonstrated by the recurrent absence of supplementary communication systems for emergency exits.

## ALERTS FROM CIVIC ORGANIZATIONS

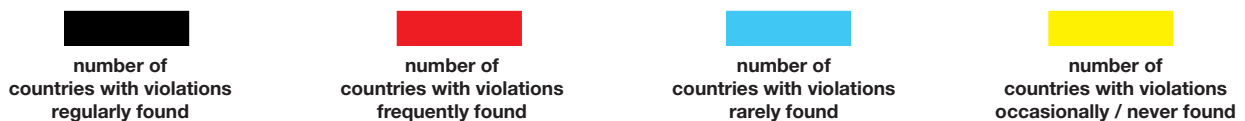
Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- misidentification of patient;
- incorrect drug or incorrect dose or delayed or omitted administration;
- surgical operation on the wrong site;
- loss or mix-up of exams;
- accidental fall of the patient from his/her bed or stretcher;
- gauze or instruments forgotten inside the patient
- incorrectly administered anaesthesia with lethal effects.



Source: Active Citizenship Network, 2011



Civic organizations have not found frequent violations concerning the situations listed above in the majority of countries. It is revealing, however, that these same organizations, as one may see below, are critical of the level of adherence to the right to safety in the majority of the countries, due to frequent verification of other situations that cannot be categorized in terms of the cases here considered.

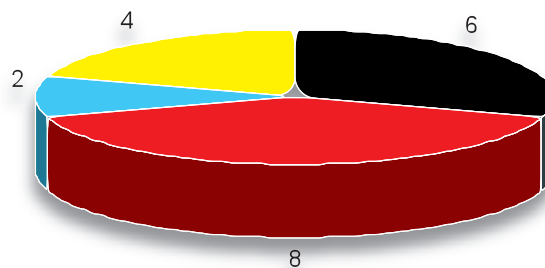
## Other cases that, according to organizations' point of view, can constitute a violation of the right to safety

**number of countries with violations regularly found**

**number of countries with violations frequently found**

**number of countries with violations rarely found**

**number of countries with violations occasionally / never found**



Source: Active Citizenship Network, 2011

## ANOTHER PERSPECTIVE

Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

Indicators:

- *Screening donated blood units:*  
*System in place for organising inspections and control measures of blood establishments;*  
*National guidelines for the assessment of at risk sexual behaviours;*  
*System in place for the reporting of serious adverse events and serious adverse reactions;*  
*Penalties laid down for infringements of the national provisions adopted pursuant to the Directive;*
- *Percentage of MRSA infections (Methicillinresistant Staphylococcus Aureus).*

### Number of countries by statistical indicators

Screening donated blood units	2	8	9
Percentage MRSA infections	13	4	2

The data refer to only 19 Countries, because Official Statistics concerning Macedonia were not available.

Source: 2011 Active Citizenship Network's processing of statistical data from: EARSS Database and National Sources (9).

**WEAK** **SUFFICIENT** **GOOD** **EXCELLENT**

The number of countries found to be weak in terms of the indicator regarding the frequency of MRSA infections (due to Methicillin-Resistant Staphylococcus Aureus) is worryingly high, since in the case of health and social-health facilities this is an indicator of the quality of interventions aimed towards prevention of the transmission of infections from person to person in a service environment.

## THE RIGHT TO INNOVATION

NOT RESPECTED

HARDLY RESPECTED

**PARTLY RESPECTED**

ALMOST RESPECTED

FULLY RESPECTED



- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

## ACTUAL CONDITIONS OF HOSPITAL PATIENTS

score: **71** /100

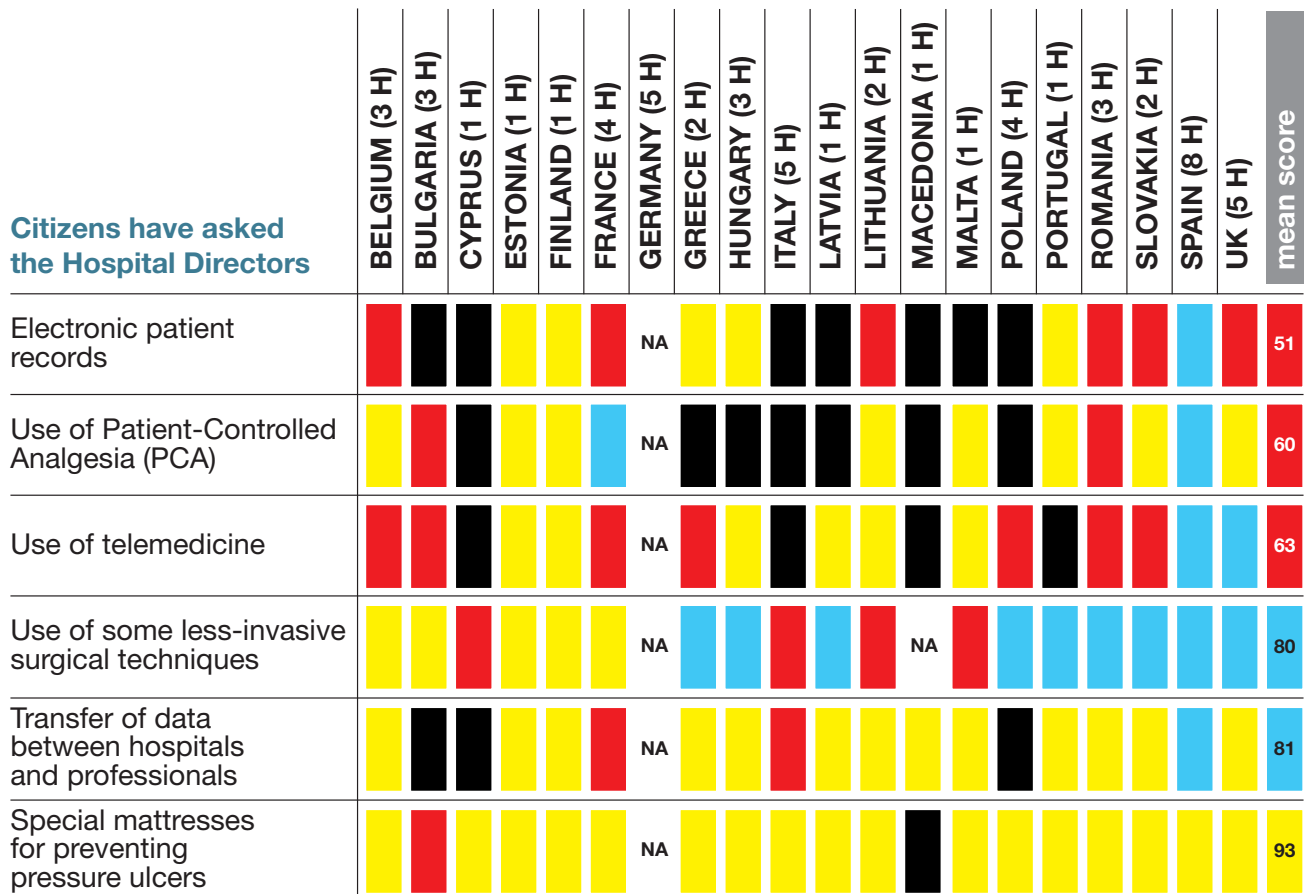
An overview of hospital index scores in the countries

COUNTRY (NUMBER OF HOSPITALS)	SCORE
BELGIUM (3 H)	88
BULGARIA (3 H)	58
CYPRUS (1 H)	25
ESTONIA (1 H)	100
FINLAND (1 H)	100
FRANCE (4 H)	70
GERMANY (5 H)	NA
GREECE (2 H)	75
HUNGARY (3 H)	86
ITALY (5 H)	48
LATVIA (1 H)	63
LITHUANIA (2 H)	86
MACEDONIA (1 H)	20
MALTA (1 H)	78
POLAND (4 H)	38
PORTUGAL (1 H)	81
ROMANIA (3 H)	79
SLOVAKIA (2 H)	82
SPAIN (8 H)	85
UK (5 H)	87
mean score	71

Source: Active Citizenship Network, 2011



Although the average score attained by the hospitals is “good”, one may observe a certain variability among the scores of the various countries, in that all four assessment classes are represented.



Source: Active Citizenship Network, 2011



The indicator with the lowest score is that of electronic patient records: this practice has been adopted by all hospitals in only 5 countries. The use of Patient Controlled Analgesia (albeit with several “gaps”) and of telemedicine is bit more widespread.

There is only one element indicating a degree of innovation that can be fully considered a reality in European<sup>1</sup> hospitals: use of a special mattress with foam, air, gel or water, designed to prevent pressure ulcers.

1. By European is here meant the group of the European countries participating in this project.

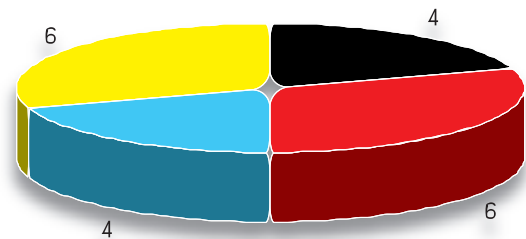
## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- delays in the introduction of innovative diagnostic tests;
- delays in the introduction of innovative treatment;
- delays in particular areas of medical research;

Source: Active Citizenship Network, 2011



**number of countries with violations regularly found**

**number of countries with violations frequently found**

**number of countries with violations rarely found**

**number of countries with violations occasionally / never found**

As the chart clearly illustrates, the distribution of violations detected in the 20 countries is highly varied. While in ten countries violations were rarely or never found, it is essential not to ignore the other 10, in which violations concerning delays in the introduction of innovative diagnostic tests, delays in the introduction of innovative treatment and delays in particular areas of medical research were reported frequently and, in 4 cases, regularly.

The synthetic assessment of this right is based on the data from civic organizations. This right is only “partly respected”, despite the generally “good” score attained by the hospitals.

## ANOTHER PERSPECTIVE

Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

### Number of countries by statistical indicators

Percentage of General Practitioners who use the following electronic network for transfer of patient data: Lab results from laboratories; Admin data to reimbursers; Medical data to care providers / professionals



Percentage of General Practitioners who use Electronic Patient Record (EPR - Electronic recording and storage of individual administrative patient data) in primary care



Average time delays (in days) between marketing authorization and effective market access (hospital and retail combined) of all new substances to patients



Availability of new pharmaceutical drugs for cancer through the national health system (year of launch date): Capecitabine, Gemcitabine, Imatinib



Availability of medical technology (nr. per million of population): Computer Tomography Scanners, MRI units, Radiation therapy equip., Lithotriptors



The data refer to only 19 countries, because Official Statistics concerning Macedonia were not available. In cases in which the total number of countries is less than 19, this is due to the non applicability of some indicators in certain Countries.

Source: 2011 Active Citizenship Network's processing of statistical data from: European Commission Benchmarking ITC use among GP's in Europe 2008; EFPIA 2009; OECD - Health data 2009; Wilking, Jonsson, Karolinska Institutet and National Sources 10a and 10b.

**WEAK** **SUFFICIENT** **GOOD** **EXCELLENT**

The reading of the information included in this box completes the profile of the implementation of the right to innovation: the statistical indicators above, pre-existing, have been purposely selected in that they are also relevant from a civic point of view. The situations emerging from the data are clearly quite critical, particularly concerning innovation and supply of information in the area of primary care (including a weak level of the use of electronic patient records among General Practitioners).



## THE RIGHT TO AVOID UNNECESSARY SUFFERING and PAIN



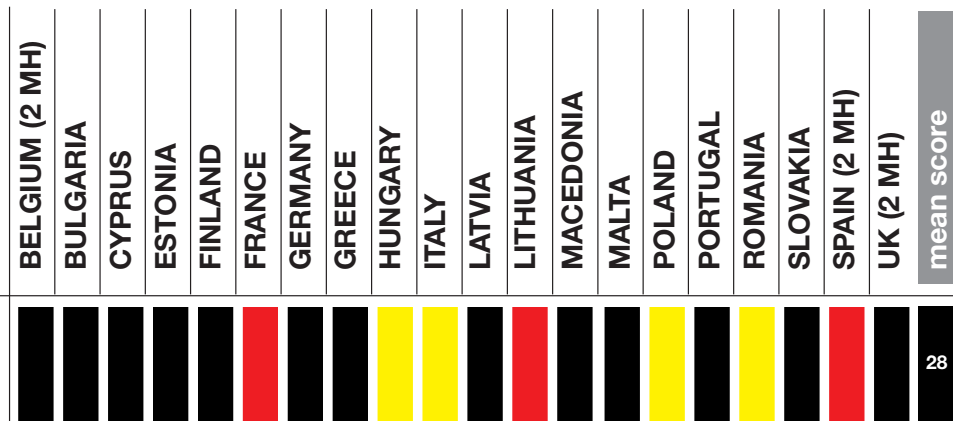
- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 28<sup>/100</sup>

#### Citizens have asked the Ministry of Health

Gov. study on nat. norms concerning the use of pharmaceutical narcotics



Source: Active Citizenship Network, 2011



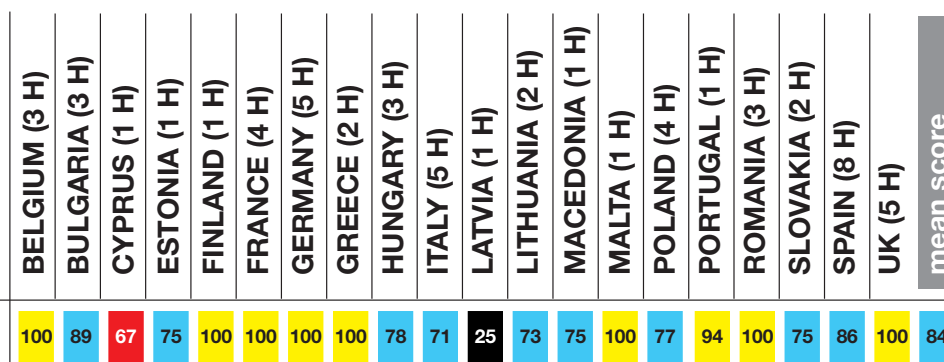
For the right to avoid unnecessary suffering and pain, only one indicator was investigated at the institutional level. This indicator reveals a strong lack of attention throughout Europe to research on whether existing national norms are overly restrictive regarding the control of pharmaceuticals by national health care systems, in terms of hindering prescriptions, distribution or medical treatments that use pharmaceutical narcotics. In the past 3 years, this research was not carried out in 13 countries. In 3 countries, research was not conducted because it had already been previously done.

This result is in and of itself revealing and makes it obligatory to question the reasons for which governments have not undertaken this kind of research.

# ACTUAL CONDITIONS OF HOSPITAL PATIENTS

score: **84**/<sup>100</sup>

## An overview of hospital index scores in the countries



Source: Active Citizenship Network, 2011



## Citizens have asked the Hospital Directors



Source: Active Citizenship Network, 2011



A better score was attained for the profile of the condition of patients in hospitals, according to the indicators utilized – which reflect contact between citizens and health care facilities in terms of the issue of pain. In particular, pain therapy service after surgery is a service that is by now more or less present in the hospitals observed in all participating countries. Moreover, citizens are informed of its existence.

One may also note a reassuring diffusion of the patients' pain intensity measurement and of the possibility for women giving birth to obtain epidural anaesthesia during labour, free of charge. Citizens are likewise informed about these services.

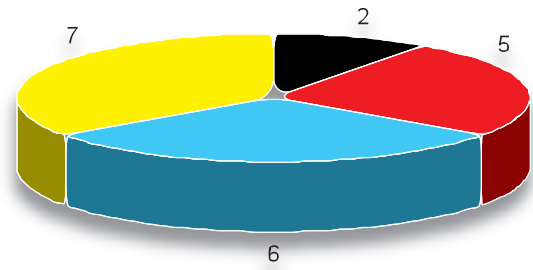
## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- morphine not administered when recommended by the international procedures on severe pain treatment;
- painkillers not administered when needed or after painful treatments;
- lack of measurement of post-surgical pain in the case of all surgical operations;
- presence in national drug control laws or norms of obligations binding the prescription of pharmaceutical narcotics in such a way that might result in the excessive limitation of physician and/or patient access to pain therapy.

Source: Active Citizenship Network, 2011



**number of countries with violations regularly found**

**number of countries with violations frequently found**

**number of countries with violations rarely found**

**number of countries with violations occasionally / never found**

Despite the strong presence of services and initiatives aimed at reducing unnecessary suffering in hospitals, the picture presented by the organization partners is not very positive. Frequent or even systematic violations of the right to avoid pain were found in 7 countries.

Moreover, frequent cases were also found which, while not classifiable in terms of the situations described by the above-analysed indicator, may be defined from the point of view of the civic organizations as violations of the right to avoid unnecessary suffering and pain.

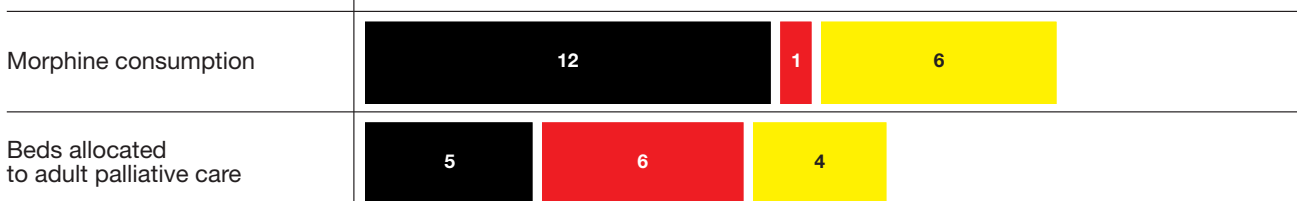
This gap suggests that effective respect for this right is blocked by organizational behaviour and resistance that diminish the efficacy of available services and hospital initiatives.

## ANOTHER PERSPECTIVE

Selected statistical data, chosen to integrate the reading and the interpretation of the previous indicators and gathered from a civic point of view.

The following chart reports the number of countries in which the situation described by each selected indicator is either weak, sufficient, good, or excellent.

### Number of countries by statistical indicators



In cases in which the total number of Countries is less than 19, this is due to the inapplicability of some indicators in certain Countries.

Source: 2011 Active Citizenship Network's processing of statistical data from: International Narcotics Control Board - Global Morphine Consumption, 2008; EAPC Task Force on the development of Palliative Care in Europe 2005.

It is interesting to observe the situation regarding morphine consumption in health care environments, an indicator used by WHO to broadly trace the progress made towards improving cancer pain relief: as many as 12 countries out of 18 are classified as "weak" in this area.

When this result is viewed in relation to the scant diffusion of research on whether the existing national norms are overly restrictive regarding control of pharmaceuticals (see the box relating to "Institutional actions for patients' rights"), it confirms the existence of powerful resistance. Half of the countries found to consume an insufficient quantity of morphine have not conducted any studies of this kind in the last three years (Cyprus, Estonia, Finland, Greece, Latvia, and Malta).

## THE RIGHT TO PERSONALIZED TREATMENT

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: **93**<sup>/100</sup>

Citizens have asked the Ministry of Health	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score
	Leg. indications for non-discrimination: culture and religion	Good	Good	Good	Weak	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Weak	Good	Good	Good	Good	Good
Leg. indications for non-discrimination: gender	Good	Good	Good	Weak	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	93
Leg. indications for non-discrimination: age	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	98

Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

From the legislative perspective, widespread attention to the struggle against discrimination is evidenced by the issuance of norms, with the sporadic exception of a few countries.

An overview of hospital index scores in the countries

COUNTRY (HOURS)	SCORE
BELGIUM (3 H)	82
BULGARIA (3 H)	33
CYPRUS (1 H)	19
ESTONIA (1 H)	63
FINLAND (1 H)	82
FRANCE (4 H)	74
GERMANY (5 H)	72
GREECE (2 H)	19
HUNGARY (3 H)	72
ITALY (5 H)	61
LATVIA (1 H)	50
LITHUANIA (2 H)	39
MACEDONIA (1 H)	38
MALTA (1 H)	79
POLAND (4 H)	63
PORTUGAL (1 H)	60
ROMANIA (3 H)	23
SLOVAKIA (2 H)	69
SPAIN (8 H)	75
UK (5 H)	78
mean score	58

Source: Active Citizenship Network, 2011



Such attention at a national level does not appear, however, to include practical and concrete attention (hospital assistance) as regards this right. Legislative indications are uniformly present everywhere, but there are significant gaps in effective implementation in health care facilities.

The following chart clarifies this point.

<b>Citizens have asked the Hospital Directors</b>	<b>BELGIUM (3 H)</b>	<b>BULGARIA (3 H)</b>	<b>CYPRUS (1 H)</b>	<b>ESTONIA (1 H)</b>	<b>FINLAND (1 H)</b>	<b>FRANCE (4 H)</b>	<b>GERMANY (5 H)</b>	<b>GREECE (2 H)</b>	<b>HUNGARY (3 H)</b>	<b>ITALY (5 H)</b>	<b>LATVIA (1 H)</b>	<b>LITHUANIA (2 H)</b>	<b>MACEDONIA (1 H)</b>	<b>MALTA (1 H)</b>	<b>POLAND (4 H)</b>	<b>PORTUGAL (1 H)</b>	<b>ROMANIA (3 H)</b>	<b>SLOVAKIA (2 H)</b>	<b>SPAIN (8 H)</b>	<b>UK (5 H)</b>	<b>mean score</b>
Cultural mediator service available or on call	EXCELLENT	WEAK	WEAK	WEAK	EXCELLENT	GOOD	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	EXCELLENT	GOOD	SUFFICIENT	35
Sign language interpreters available or on call	SUFFICIENT	WEAK	WEAK	WEAK	EXCELLENT	SUFFICIENT	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	EXCELLENT	SUFFICIENT	WEAK	WEAK	EXCELLENT	WEAK	EXCELLENT	36
Visiting hours - weekdays	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	EXCELLENT	GOOD	WEAK	SUFFICIENT	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	EXCELLENT	EXCELLENT	WEAK	WEAK	EXCELLENT	WEAK	37
Visiting hours -Sundays and holidays	SUFFICIENT	WEAK	WEAK	EXCELLENT	SUFFICIENT	EXCELLENT	GOOD	WEAK	SUFFICIENT	SUFFICIENT	WEAK	SUFFICIENT	WEAK	WEAK	EXCELLENT	EXCELLENT	WEAK	WEAK	EXCELLENT	WEAK	44
Choice of meals	SUFFICIENT	SUFFICIENT	WEAK	EXCELLENT	WEAK	SUFFICIENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	WEAK	WEAK	EXCELLENT	EXCELLENT	WEAK	WEAK	WEAK	WEAK	GOOD	EXCELLENT	49
Religious assistance (various religions) available or on call	GOOD	WEAK	WEAK	EXCELLENT	EXCELLENT	SUFFICIENT	SUFFICIENT	WEAK	GOOD	SUFFICIENT	WEAK	WEAK	WEAK	EXCELLENT	SUFFICIENT	EXCELLENT	WEAK	GOOD	WEAK	EXCELLENT	53
Foreign language interpreters available or on call	EXCELLENT	WEAK	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	WEAK	SUFFICIENT	WEAK	EXCELLENT	WEAK	WEAK	EXCELLENT	SUFFICIENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	61
Procedures to ensure a medical second opinion	SUFFICIENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	WEAK	SUFFICIENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	WEAK	WEAK	EXCELLENT	EXCELLENT	GOOD	72
Psychological Support Service in specific situations	EXCELLENT	WEAK	GOOD	SUFFICIENT	EXCELLENT	EXCELLENT	GOOD	SUFFICIENT	EXCELLENT	SUFFICIENT	EXCELLENT	SUFFICIENT	EXCELLENT	SUFFICIENT	SUFFICIENT	WEAK	GOOD	EXCELLENT	SUFFICIENT	GOOD	72
Play areas in paediatric wards	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	86
Appropriate furnishing in paediatric wards	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	SUFFICIENT	SUFFICIENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	89
Parents' presence allowed 24 hours a day: sleep & eat	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	SUFFICIENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	GOOD	EXCELLENT	EXCELLENT	EXCELLENT	95

Source: Active Citizenship Network, 2011



There are very serious gaps with respect to the personalization of care regarding sensitive indicators, which intercept patient conditions in hospitals: the linguistic aspect (interpreting service, both classic and, above all, sign language) and the cultural aspect (cultural mediator and religious assistance).

Visitor hours attain a very low average score and are tied to hospital culture.

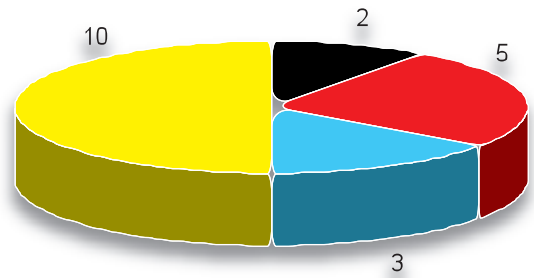
Only children, and as a consequence, parents, seem to receive widespread protection, given that special measures and services have been adopted more or less everywhere.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- the impossibility for parents to assist their child 24 hours a day during his/her hospitalisation;
- the hospitalised patient could not find religious assistance, according to his/her faith;
- the hospitalised patient could not communicate because of lack of a mediator or interpreter.



Source: Active Citizenship Network, 2011

number of countries with violations regularly found

number of countries with violations frequently found

number of countries with violations rarely found

number of countries with violations occasionally / never found

Despite the reported gaps, the situation regarding violations of the right to personalized treatment, described by the indicator and verified by the civic organizations, is quite positive in comparison to many other rights. Violations of this right were found frequently, however, in 5 countries and even regularly in 2.

## THE RIGHT TO COMPLAIN

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

## ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 77/100

	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score		
Citizens have asked the Ministry of Health	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	SUFFICIENT	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	53	
Gov. program to receive and analyse complaints	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	78
Independent organizations assisting citizens	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	100

Source: Active Citizenship Network, 2011

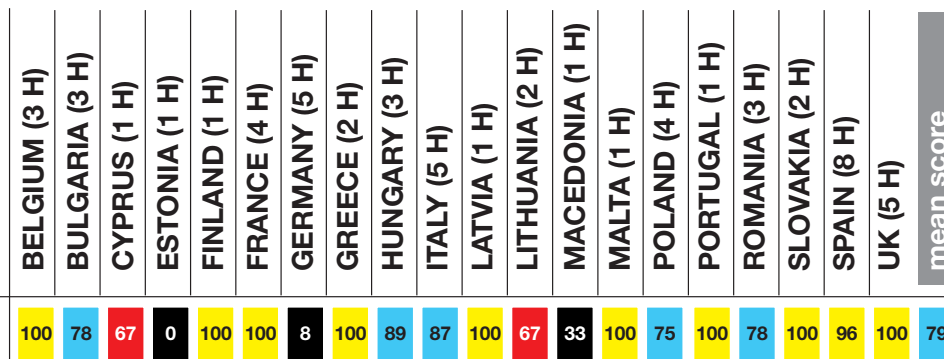
WEAK SUFFICIENT GOOD EXCELLENT

Independent organizations to help citizens present complaints are active in all countries participating in the project. Governmental programs for receiving and analysing complaints regarding health services (hotlines, public relations offices), are less widespread, but the mean score is generally good.

The primary lack in terms of action taken by health authorities is the failure to have published a report of complaints presented by citizens within the last two years. Such a report has been produced in only 9 countries out of 20. Something else of particular significance emerges from the data: in 8 Countries, programs for receiving and analysing complaints exist but the results remain unpublished by the health authorities. This reveals a problem of transparency and scant intention to take action towards detecting critical situations.



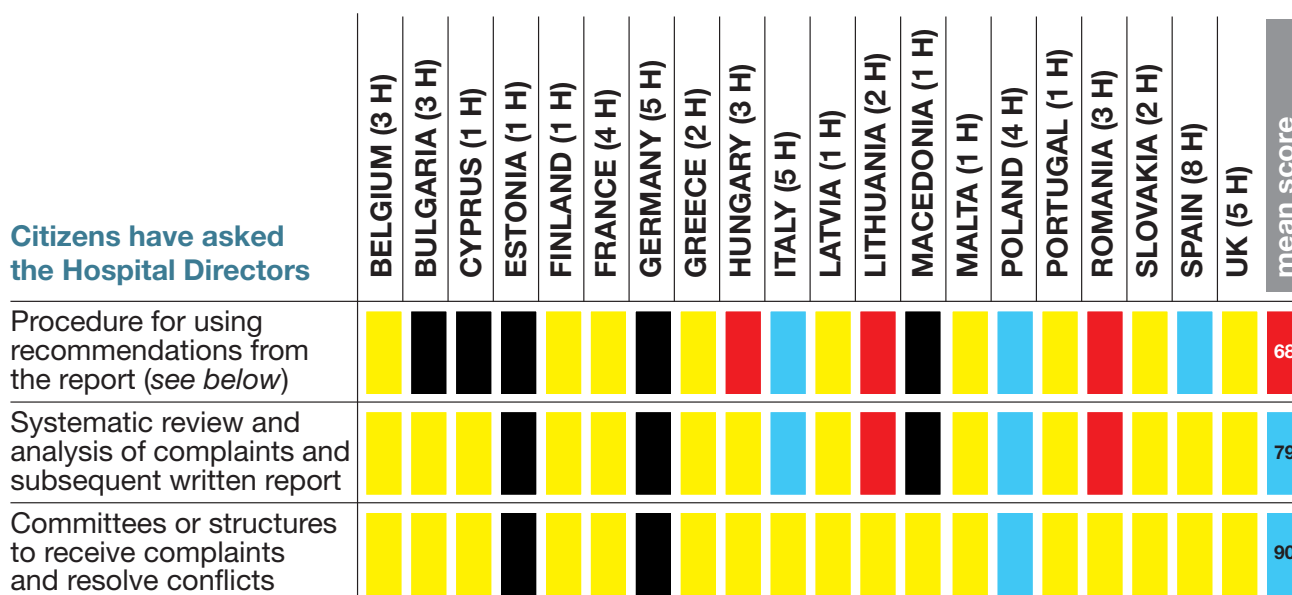
## An overview of hospital index scores in the countries



Source: Active Citizenship Network, 2011



## Citizens have asked the Hospital Directors



Source: Active Citizenship Network, 2011



Although the mean score of hospital conditions for patients is “good”, these results are significant because they reveal areas that lack willingness to positively employ citizens’ complaints towards improving services. In several countries this is also true at the hospital level, in that citizens can file complaints but often there are no systematic reviews or analyses of complaints, and nor are reports of complaints received. Moreover, it is even more difficult to find an established procedure designed to incorporate recommendations based on the reports, which should in fact be the sole purpose of receiving complaints on behalf of hospital authorities.

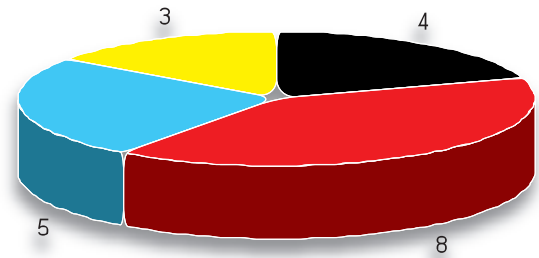
Considering these reflections on the results illustrated in the two information charts above, although the mean scores are sufficient, the suspicion remains that although the filing of complaints is facilitated, even through organizational measures, such complaints are not often taken into consideration as useful sources of information for the management of services (and this is not a fact that pleases citizens).

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- *lack of response to citizens' complaints;*
- *response to citizens' complaints given after an excessively-long period of time;*
- *threats, intimidation or retaliation towards patients who have complained or denounced inadequate health care services.*




Source: Active Citizenship Network, 2011

  
number of  
countries with violations  
regularly found

  
number of  
countries with violations  
frequently found

  
number of  
countries with violations  
rarely found

  
number of  
countries with violations  
occasionally / never found

This suspicion is confirmed by the highly alarming situation that emerges from the questionnaires filled in by the partner organizations. Violations of the right to complain concerning the situations described by the indicator have been detected frequently in 8 countries and regularly in 4. Violations have been found occasionally or never in only 3 countries.

## THE RIGHT TO COMPENSATION

NOT RESPECTED

HARDLY RESPECTED

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: 78<sup>/100</sup>

	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score
Citizens have asked the Ministry of Health	Good	Good	Weak	Good	Good	Good	Good	Good	Good	Good	Weak	Good	Good	Good	Good	Weak	Weak	Good	Good	Good	75
Commissions outside the regular litigation process	Good	Good	Weak	Good	Good	Good	Good	Weak	Good	Good	Good	Good	Good	Good	Good	Weak	Good	Good	Good	Good	78
Hospital insurance	Good	Good	Weak	Sufficient	Good	Good	Good	Weak	Good	Good	Good	Good	Sufficient	Sufficient	Good	Weak	Good	Good	Good	Good	83
Independent organizations which provide legal aid	Good	Good	Weak	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Weak	Good	Weak	Good	Good	Good	Sufficient	83

Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The profile for institutional actions for the right to compensation is good. One may note a widespread presence of independent organizations that provide legal aid. Insurance for hospitals also results as a fairly well-established fact. Cyprus and Portugal stand out for systematic gaps in terms of actions or structures guaranteeing this right.

# ACTUAL CONDITIONS OF HOSPITAL PATIENTS

score: **54** /100

## An overview of hospital index scores in the countries

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
	44	22	33	33	83	75	67	0	72	83	33	83	0	33	75	17	89	83	71	90	54

Source: Active Citizenship Network, 2011



The level of respect for the right to compensation in hospitals, studied utilizing indicators similar to those preceding, is considerably weaker by comparison.

## Citizens have asked the Hospital Directors

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score		
Independent committees supporting an agreement on compensation	WEAK	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	GOOD	38	
Additional insurance for hospital doctors	WEAK	WEAK	EXCELLENT	WEAK	EXCELLENT	GOOD	NR	WEAK	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	WEAK	WEAK	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	59
Hospital insurance	EXCELLENT	WEAK	WEAK	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	WEAK	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	EXCELLENT	65

Source: Active Citizenship Network, 2011



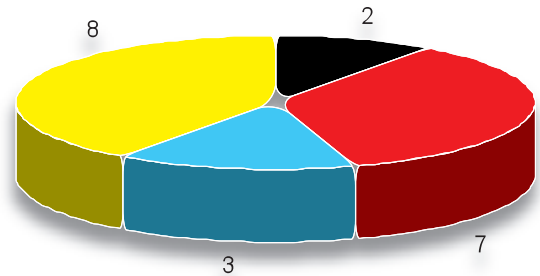
The almost total absence of committees or structures, independent from the hospital, to help parties reach a final agreement on compensation is particularly evident. The monitored hospitals are also very lacking in the area of insurance.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- civil cases that lasted over 6 years;
- cases in which citizens were unable to find doctors willing to provide forensic evidence against other doctors, in cases of medical error;
- citizens who have been subjected to threats, intimidation or other pressures due to the fact that they are asking for compensation from a doctor or hospital;
- citizens who suffered damages resulting from medical error received, through alternate means (non judicial), an offer of compensation less than the value of the damage suffered.




Source: Active Citizenship Network, 2011

  
number of  
countries with violations  
regularly found

  
number of  
countries with violations  
frequently found

  
number of  
countries with violations  
rarely found

  
number of  
countries with violations  
occasionally / never found

The image relative to violations of the right to compensation, provided by the indicator detected by the partner organizations, reveals some critical situations. In 8 countries, cases of violations were found either never or very rarely. It is important to remember, however, that this does not imply an absence of events of this type, but only an absence of reporting. In 3 further countries, the cases are rare. But in as many as 9 countries, violations are either frequent or systematic.

## THE RIGHT TO ACTIVE CITIZENSHIP

NOT RESPECTED

**HARDLY RESPECTED**

PARTLY RESPECTED

ALMOST RESPECTED

FULLY RESPECTED



- ▲ MINISTRY OF HEALTH
- HOSPITALS
  - Questions for Directors
  - Directly observed
- CIVIC ORGANIZATIONS
- ◆ ANOTHER PERSPECTIVE

### ▲ INSTITUTIONAL ACTIONS FOR PATIENTS' RIGHTS

score: **47** /100

	BELGIUM (2 MH)	BULGARIA	CYPRUS	ESTONIA	FINLAND	FRANCE	GERMANY	GREECE	HUNGARY	ITALY	LATVIA	LITHUANIA	MACEDONIA	MALTA	POLAND	PORTUGAL	ROMANIA	SLOVAKIA	SPAIN (2 MH)	UK (2 MH)	mean score	
Citizens have asked the Ministry of Health	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	33
Group for Quality Assurance that includes citizens	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	38
Legislation or measures regarding the right to evaluate quality	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	45
Use of civic and patients' information for evaluating health policy	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	73
Civic verification of respect for patients' rights	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	73

Source: Active Citizenship Network, 2011

WEAK SUFFICIENT GOOD EXCELLENT

The indicators concerning institutional actions for the right to active citizenship require little comment: implementation of this right through public and legislative acknowledgment is far from sufficient.

## An overview of hospital index scores in the countries

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
	78	78	33	33	33	100	7	33	89	53	100	33	67	0	58	100	22	100	83	93	60

Source: Active Citizenship Network, 2011



The situation in the hospitals is only slightly better, and in many of the countries monitored, hospitals are weak in this area.

## Citizens have asked the Hospital Directors

	BELGIUM (3 H)	BULGARIA (3 H)	CYPRUS (1 H)	ESTONIA (1 H)	FINLAND (1 H)	FRANCE (4 H)	GERMANY (5 H)	GREECE (2 H)	HUNGARY (3 H)	ITALY (5 H)	LATVIA (1 H)	LITHUANIA (2 H)	MACEDONIA (1 H)	MALTA (1 H)	POLAND (4 H)	PORTUGAL (1 H)	ROMANIA (3 H)	SLOVAKIA (2 H)	SPAIN (8 H)	UK (5 H)	mean score
Periodic consultations of citizens' organizations	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	GOOD	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	51
Common initiatives done in partnership regarding quality	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	57
Possibility for users to evaluate the quality of out-sourcing	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	71

Source: Active Citizenship Network, 2011



The only indicator that has attained a good mean score is that of the possibility for users to evaluate the quality of the out-sourcing of certain services and products. Nonetheless, this indicator also has significant gaps. Of grave seriousness is the lack of periodic consultations of the representatives of patients or citizens organizations on general or specific issues and common initiatives done in partnership together (hospital authorities and patient-citizens organizations) regarding the quality of service over the last two years.

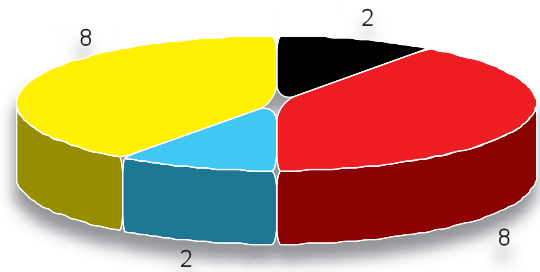
Weaknesses and critical situations, relative to the indicators detected through the Ministry and the hospitals, are evident at an average level. There are however some countries that have chosen to engage in concrete involvement with citizen organizations.

## ALERTS FROM CIVIC ORGANIZATIONS

Civic organization partners reported that they have direct knowledge of the following rights violations:

Violation concerning:

- Citizen organisations which have not been able to provide information;
- Citizen organisations which have not been able to carry out auditing and verification activities regarding health services;
- Citizen organisations which have not been able to directly intervene in situations in which rights are violated or inadequately protected;
- Citizen organisations which have not been able to submit information and proposals, or have not been given feed-backs to their proposals.



Source: Active Citizenship Network, 2011



As the chart clearly illustrates, the 20 participating countries are sharply divided into two groups. Partner organizations found frequent violations identified by the indicator in 8 countries, and regular violations in 2.

Moreover, the organizations report **frequent** cases of violations that cannot be directly categorized in terms of the situations provided by the above-described indicator, but that, from the organizations' perspective, could nevertheless constitute violations of the right to active citizenship.

**GENERAL COMMENT:** The significantly negative profile of respect for the right to active citizenship clearly constitutes a result that is of fundamental relevance, perhaps the greatest relevance, to the aims of the present assessment work carried out by and with civic organizations. It sets a precise mandate for the civic world and European institutions that there is work to do: it is a weighty endeavour, which possibly needs to be carried out in collaboration.



## 6. CITIZENS' ORGANIZATIONS WORKING PLAN

One of the results of the work carried out by the civic organizations to evaluate the state of the implementation of the European Charter of Patients' Rights is that of having initiated a *process* through which to construct a **shared framework for making patients' rights easily demandable**.

The work completed for the drafting of the charter and identification of the 14 rights does not ensure, in and of itself, significant results if not preceded, or at least accompanied, by the construction of this shared framework.

There are two steps to this process. The first consists in the initiation of work to set up a *basic vocabulary of patients' rights*. The second focuses on the careful verification of improvement in each of the countries as regards the specific issues that have emerged: this verification consists mainly of checking on progress towards the acquisition of common terminology, which is necessary to citizens for being able to more effectively monitor the presence of certain elements or services through civic assessment work.

### 6.1 Drafting a Basic Vocabulary of Patients' Rights - Step 1

The two assessment projects carried out so far were preceded by numerous meetings between the civic organizations in order to share the indicators and their meaning. Despite this, difficulties of comprehension continued to sometimes emerge during field work, deriving from the varied terminology existing across Europe. The work that one carried out to explain and translate the various concepts according to their local operational realities is important in that it makes it possible to make the rights concrete even in spite of very different contexts.

Therefore, in addition to identifying indicators and issues that are critical from the pure point of view of the approach to assessment (presence/absence of services and compliant/not compliant indicators), other kinds of critical issues have been identified by staff at the ACN headquarters: **terminological difficulties** and **problems of awareness** of one's own rights.

Concerning the first, in some cases there have been difficulties for partner organizations concerning the meaning of certain concepts, which carries the risk of affecting the correct gathering of data and answers. It was necessary for ACN to invest additional effort in explaining and agreeing the meaning of certain indicators and terms. Gathering homogeneous data across Europe, given such different health systems and cultures, can, of course, be difficult. One notes, that is to say, that the "language of health care" is different from one place to the next and the same terms often allude to different concepts, as one will see in the following examples.

Regarding the second issue, the ACN has become aware that, in many countries, civic organizations are not very strong and are not provided with the proper tools for playing a role in claiming citizens' rights. This chapter includes some examples in order to clarify the problems impeding the real possibility of demanding rights. These problems emerged during the carrying out of this project and are often due to lack of information or even awareness of citizens' specific rights.

The ACN believes that these types of difficulties definitively constitute a further **result**-a "collateral" result but possibly more significant - of the assessment work and provide added value: they have, in fact, signalled the strong need set up a *basic vocabulary of the rights*, which ought to be useful for citizens (as well as for institutions).

Further reflection is therefore needed, and this chapter is aimed at starting this process, with the explicit goal of a **shared framework for making patients' rights easily demandable** at the European

level: the ACN intends to invite civic organizations to collaborate, together with institutions, on a general reference framework towards facilitating the demand for patients' rights.

Some examples of issues have been selected from among those that emerged while carrying out the project and these are reported and developed here, as they need to be defined and deepened, according to the approach described above:

### a. Clinical record

The methodological structure of this assessment work includes several indicators concerning clinical records, which deal with different aspects and are therefore related to the corresponding rights (right to information, right to privacy and confidentiality, right to innovation).

A civic definition of "clinical record" is here drafted, based on available indicators.

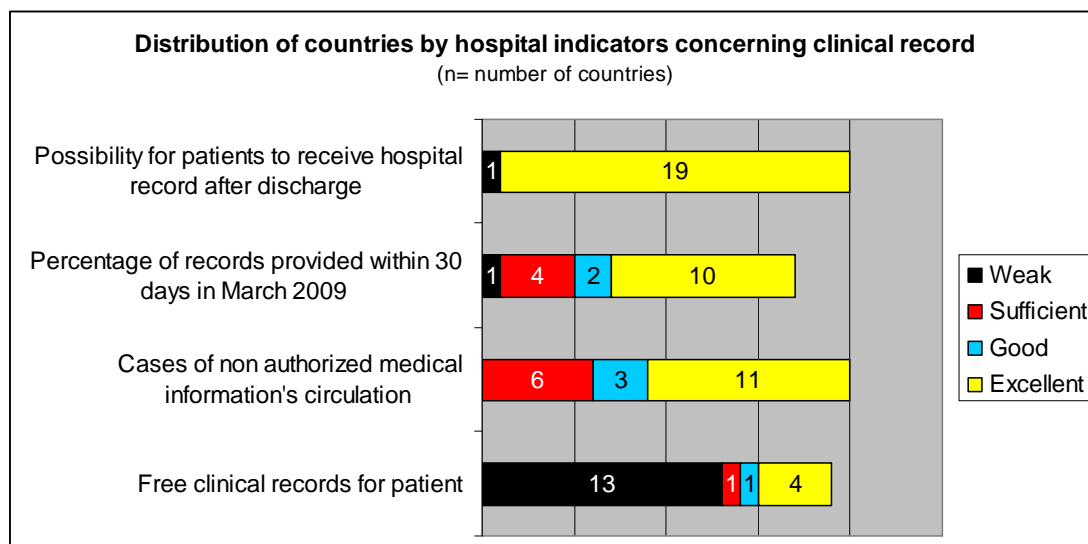
*Patients all over Europe should be able to demand:*

- the option to receive a copy of their hospital records after discharge from the hospital, including **all of the documents** related to the reason the person was hospitalized, for example: exams, results, diagnosis, etc.
- to get these records free of charge
- that hospitals provide such records within 30 days
- that their medical records are in no case given to an unauthorized person
- that no violations of the right to information concerning medical records occur.

Moreover, another element included among the indicators regarding clinical records, which may be considered an innovative goal for the middle to long term, is here reported towards the completeness of this outline:

- The increasing diffusion of the use of electronic patient records<sup>9</sup> in hospitals.

A synthetic look at the data gathered<sup>10</sup>:



In cases in which the total number of countries is less than 19, this is due to the inapplicability of some indicators in certain countries.

Source: Active Citizenship Network, 2011.

<sup>9</sup> For example, a unique clipboard-sized, hand-held computer known as a "pen tablet" and a computer database server to which such tablets are wirelessly networked. Medical providers and support staff use the wireless pen tablets to provide immediate access to patient records and to enter patient information during the hospital visit.

<sup>10</sup> For more details about data results, please see the "Right to information Card" and the "Right to privacy and confidentiality Card".

While the overall “quality” of respect for these indicators is good or excellent, the following must not be ignored: the common requirement to pay for a copy of the clinical record, the 5 countries with long wait times for receiving the record and the 7 countries in which cases of violations of patients’ privacy in hospitals have been reported.<sup>11</sup>

Moreover, as explained above, problems with terminology and information emerged that are not detectable by the indicators. Here are some examples:

### ***What do we mean by...? Some experiences reported by our partner organizations***

Regarding the definition of “clinical record”, as intended in this assessment work, the referent person from the Romanian Partner Organization wrote to ACN:

*“In hospitals in our country, patients receive a “ticket out of the hospital”, where the diagnosis and recommendations are specified”.*

It was necessary to explain that a *“hospital discharge ticket”* cannot be considered a clinical record, because such a summary, or discharge letter, does not include all of the documents relating to exams, etc.

Regarding the possibility of receiving a copy of the clinical record after discharge and finding data on the number of clinical records provided within 30 days, the same referent person explained his difficulties in obtaining the answer:

*“I have contacted all three hospitals for the number of requests for medical records and the only response I received from two hospitals is that patients do not require medical records and that in our country clinical records are only required by police or by the Institute of Legal Medicine. So this information is not recorded.*

*A copy of the medical records may be required in special cases, such as if a patient requests an additional investigation. Our law states that patients may ask, but usually they do not require a copy of their medical records, the hospital discharge ticket is sufficient.”*

It is easy to suppose that in this country there is a transversal problem concerning awareness of one’s rights: authorities do not even make a calculation due to the very small number of people requiring a copy of their medical records. This fact is, of course, very surprising, and permits us to deduce that, very probably, citizens simply do not know they can demand a copy of their clinical records!

### **b. Informed consent**

Informed consent is a very important and heartfelt issue for ACN and for civic organizations in general.

For assessing the right to consent in hospitals, the presence of specific consent forms for surgical interventions with certain contents have been chosen as indicators of attention paid to the patients’ right to consent in hospitals. The selection of these indicators, then shared with the civic network, has of course been based on the orientation of some countries, including Italy, which is sensitive to this topic.

While processing the data, we realized that the existence of specific consent forms with certain contents is quite rare, and that the situation is highly varied in the participating countries.

In this project, citizens have directly checked hospital wards for the use of specific consent forms for the following surgical interventions:

- appendectomy
- hip replacement
- radical hysterectomy
- programmed caesarean section

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<sup>11</sup> As regards violations of the right to information concerning, among the others, clinical record, please see also the “Right to Information Card”.

and have verified whether each consent form included the following information:

- patient name
- name of the procedure
- site of the intervention (organ, side, body level)
- collateral effects of the treatment or procedure
- diagnosis and reason for the procedure
- percentage of risk associated with the treatment
- possible alternative treatments and respective percentage of risk
- patient declaration regarding the comprehension of the information provided
- signatures of both doctor and patients
- possibility to cancel consent at any moment

The results:

Hospital indicators: direct observation	BELGIUM 3 H	BULGARIA 3 H	CYPRUS 1 H	ESTONIA 1 H	FINLAND 1 H	FRANCE 4 H	GERMANY 5 H	GREECE 2 H	HUNGARY 3 H	ITALY 5 H	LATVIA 1 H	LITHUANIA 2 H	MACEDONIA 1 H	MALTA 1 H	POLAND 4 H	PORTUGAL 1 H	ROMANIA 3 H	SLOVAKIA 2 H	SPAIN 8 H	UK 5 H	MEAN	
Specific consent form for appendectomy - contents	WEAK	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	SUFFICIENT	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	34
Specific consent form for hip replacement - contents	WEAK	WEAK	WEAK	GOOD	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	N.A.	WEAK	N.A.	WEAK	GOOD	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	43
Specific consent form for hysterectomy radical - contents	WEAK	SUFFICIENT	N.A.	GOOD	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	N.A.	WEAK	EXCELLENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	43
Specific consent form for programmed caesarean section - contents	WEAK	SUFFICIENT	N.A.	N.A.	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	N.A.	WEAK	EXCELLENT	WEAK	SUFFICIENT	WEAK	WEAK	WEAK	WEAK	WEAK	WEAK	46

Source: Active Citizenship Network , 2011.

Label:



From the results in the chart above, a problem concerning common sensitivity to and conceptualization of the meaning of consent is clearly evident. An example of this is reported below.

***What do we mean by...? Some experiences reported by our partner organizations***

In answer to the ACN headquarters’ request for clarification, our referent person from the Slovak Partner Organization replied: *“In the hospitals observed, there are not four different specific consent forms. There is only one general consent form, which starts with the description (or name) of the respective procedure and consequently contains all required information. The patients’ right for information is however one of the most frequently violated rights. It is quite common, that Slovak doctors will not tell the patient what is wrong with them and will simply send them home with a prescription and plan for the cure.”*

The indicators regarding consent forms in this case have been considered in compliance anyway, but it is worth reporting this experience and the comments in the testimony.

All of the considerations expressed so far indicate that ACN intends to open the issue of the right to consent for further reflection, to be shared throughout the civic world, starting with support for the interpretation of the collected data.

In “Patients’ rights in the European Union”(EPF, 2009), it is demonstrated that all of the European countries have stated or established - in diverse ways or legislative sources, from constitutional level laws to operative ones - indications and norms concerning informed consent.

It is therefore clear that there is a different approach to informed consent, which is important to explicate. This is why we deem it important in this case to understand how one may effectively fulfil the patients' right to informed consent in European hospital, how to correctly monitor this right and what the criteria must be.

### **c. Active citizenship**

Another significant issue that can be considered a result of this project is that concerning active citizenship.

In relation to the actual work of active citizenship, major difficulties were encountered that reveal the existence in this area of problems relative to, on the one hand, a shared definition of the concept of active citizenship and, on the other hand, recognition of the right.

The obstacles already described (see chapter 3, paragraph 3.5 "Development") - in some cases such as to lead to the impossibility of participating in this project – regarding the encounters of civic organizations in some countries provide a clear example of this category of problem. Citizens frequently encountered difficulty accessing hospitals in order to gather data or obtaining the collaboration of hospital authorities for provision of the necessary information.

The European Charter of Active Citizenship (ACN, 2006) establishes, among other things, the right of civic organizations to evaluate the activity carried out by public or private entities in terms of respect for the rights of citizens. The survey conducted to evaluate the state of implementation of the Charter itself (ACN, Fondaca 2008) demonstrated that this right is the one that most consistently encounters obstacles, especially at the national level. The difficulties met by the partners, just described, confirm this statement.

This information is also significant in terms of the goals of the present research. In fact, from the perspective of setting up actions aimed to make Rights demandable, it is fundamental to highlight what one means by "active citizenship" and how the right to exercise it must be implemented and made concrete. For this reason, indicators designed to verify implementation have been built into the methodological structure.

Despite the predetermined logic for detecting the indicators, it is also up to the citizens to recognize the possibility to carry out research activity of this kind, in the fulfilment of which they are already "practicing" active citizenship.

In other words one may affirm that possession of the possibility to concretely monitor respect for the right to active citizenship already constitutes, in itself, the exercise of this right.

As anticipated, here is a report offering further testimony to the diversity of attitudes to civic activism.

#### ***What we do we mean by...? Some experiences reported by our partner organizations***

A civic partner organization from Belgium requested "inapplicability" for all of the questions regarding the right to active citizenship in the questionnaire addressed to them, providing the following - quite alarming - reasons: *"the participation of citizens is either not at all or scarcely registered in Belgian law. Patients' associations do exist but are not officially recognized, and have no recognized role. Only 3 platforms are officially recognized (...). Representatives of platforms sit on the Federal Committee (Commission) for patients' rights. This Committee (Commission) monitors the application of the law and can be called by Minister of Health.*

From this example, a further recurrent difficulty emerges for the exercise of the right to active citizenship. This is the tendency for public institutions to discriminate against civic organizations on the basis of criteria for representation that are not always transparent and are in any case unilaterally defined (ACN, Fondaca 2008, Moro, 2009, chapter 6).

## 6.2 Towards the future – Step 2

The aim of building a **shared framework for making patients' rights easily demandable** at a European level must be considered as a pure process, and the chapter in this report represents only the ***first step*** of this working plan.

The *second step* of the work will consist in the careful verification of improvements concerning these specific issues in the countries involved, by which we mean checking on progress towards the adoption of common terminology, which is necessary for citizens for monitoring the presence of certain elements or services.

Moreover, there it will be absolutely necessary to check the implementation of the European Directive on cross-border healthcare and, more generally, on the right to free choice (see chapter n. 7).

This action will only be possible if the right to active citizenship is simultaneously reinforced. Important support for this proposal could come in the form of a further resolution of the European Parliament, recently approved, on the development of civic dialogue (EP, 2009), which also recommends the promotion of more intense and more effective rapport between European institutions and civic organizations.

Finally, an important commitment for ACN and other partner organizations involves **training** the less "strong" civic organizations and providing them with more specific and widespread **information**, in part by sharing experiences and exchanging best practices: the role that can be played by these elements (training and informing) can make all the difference, as civic organizations in their own communities could then increase awareness among citizens and strengthen their power to demand their rights.

## THIRD PART

### 7. THE DIRECTIVE ON THE RIGHTS OF PATIENTS TO CROSS-BORDER HEALTHCARE: THE CIVIC POINT OF VIEW

Citizens and associations waited for quite some time for this Directive, which makes it easier to move, "within the fullness of rights", among the European Union member states in order to obtain the health care services that one needs. Much of the content of the Directive derives from comparisons and dialogue that took place between the European Commission for Health and consumer policies, European Parliament and citizens' associations, including ACN, which fought to get the contents of the Charter of Patients' Rights included in the Directive.

#### 7.1 The Directive on cross-border healthcare

The fact that the title of the Directive speaks of patients' "rights" demonstrates that this normative intervention puts forward new meanings regarding the relation between citizen-patients and health care systems. It is the intention of the Directive to define clear rules in order to facilitate safe and high quality access to health services in the European Union, ensuring the mobility of individuals patients seeking health care services in a member state other than their own.

##### *A. The facilitation of health care mobility*

The goal of the Directive is to facilitate the mobility of individuals-patients of the European Union in terms of access to the health care services of all member states. In practice, the Directive intends to homogenize the relevant procedures and make it easier to request health care services in a European Union member state other than the patient's own. By "health care services" is meant all services offered by health care facilities and professionals towards the end of evaluating, maintaining or restoring the patient's health.

##### *B. The request for health care products*

The Directive does not merely apply to situations in which a patient coming from Member State A requests reimbursement for care requested and issued from the health care services of Member State B, but also applies to prescriptions and the distribution and issuing of drugs and medical devices when these are provided in the context of health care service (and not, for example, for commercial ends). In particular, reimbursement for medicinal products and medical devices is provided for, both when requested in a member state other than that of residence and in reference to the member state in which the prescription was fulfilled: this means that one may request the reimbursement for products prescribed in one's state of residence and requested abroad, as well as for products both prescribed and requested in a member state other than that of residence.

### ***C. The responsibility of the states Member states as service suppliers***

It is highlighted in the text of the Directive that member states and the health care facilities operating in their territory and supplying health care services must provide:

- appropriate information, on patient request, on the standards and guidelines that presuppose the supply of the health care services;
- information regarding the availability, quality and safety of the services;
- transparent and clear invoicing practices;
- transparent and clear pricing information;
- clear information about authorizations issued to the health care facility;
- the fundamental right to privacy;
- a copy of the health care reports once services are issued.

### ***The Principle of Non-Discrimination (Services and Prices)***

The member states that issue treatment must not discriminate based on patient provenance, both insofar as regards the conditions of issuing treatment and as regards the definition of prices for services. For patients coming from other member states, conditions and prices must be the same in relation to those practised for patients in their own territory.

### ***The member states to which the patients requesting care abroad belong***

These are responsible for the reimbursement of the cost of cross-border care and must provide all of the necessary information regarding the type of service that the individual may request abroad based on the type of health insurance he or she has in his or her country of origin. This will also determine the need to clearly and unequivocally define the services to which citizens have rights, in a health care system based on a universal model. Moreover, every member state must provide assistance to patients through the identification of "national points of contact".

### ***D. Reimbursement***

Article 8 of the Directive states that the member state to which the patient requesting care and health care products abroad belongs must guarantee the reimbursement of the cost of the services or products requested. The reimbursement is provided for in terms of the limits of the health insurance possessed by the patient and may not exceed the cost of the health care service received abroad, in case this was less than the amount necessary for the issuing of the same service in the state of provenance. To offer a hypothetical example in which spirometry costs 100 euros in France, and 120 euros in Italy: if an Italian requests a spirometry in France, he or she will obtain a reimbursement of 100 euros, not 120 euros.

### ***E. Quality of care and rights***

On reception of the Directive, the state to which the patient requesting care abroad belongs must adopt normative terms such as to ensure that the patient has the same rights that he or she would have received in case he or she had requested and received – in a comparable situation – the service in his or her state of provenance.



## ***F. Procedure for requesting reimbursement***

Article 10 affirms that the member states, on receiving the Directive on cross-border care, must implement an administrative procedure for the use of care abroad and for requests for the relative reimbursements. This procedure must be non-discriminatory and based on objective criteria. Moreover, it must be clear, accessible and suitably publicized. Through this procedure, all of the health care services requested abroad and covered by the patient's own health insurance may be used by the patient; therefore, one does not request an authorization for every service. It is possible to activate the service, receive the service and request the reimbursement from the state of provenance. There are, however, exceptions provided for in article 9, which require prior authorization for health care services that regard:

- recoveries that required an overnight stay in hospital facilities;
- services that require use of highly-specialized or very costly infrastructures or medical equipment;
- treatments that present high risks for the patient

## ***G. Limits of reimbursement***

The Directive establishes that the provisions contained in the Directive on cross-border care must not influence the legislation or regulation of the member states regarding the organization and financing of health care services that do not concern situations of cross-border care. Moreover, they do not oblige, in any way, a member state to reimburse costs for services provided by private institutions that do not belong to the public system or that are included in public social security systems. In case of legal questions, the juridical system of the member state in which the treatment is issued is valid. From that evidenced in the text of the Directive, the right to request cross-border care may not be applied to health care services that request assistance for a medium-long duration of chronic illness, and similarly does not apply to organ transplants. Moreover, the prior authorization provided for in article 9 could limit the reimbursement relative to extremely expensive services. This exception is reinforced by the possibility for a member state to limit the reimbursement if it notably compromises the economic and financial equilibrium of the social assistance model of the patient's state of provenance.

## **7.2 Reception of the Rights of the European Charter**

Of the 14 rights of the European Charter of Patients' Rights, those most greatly absorbed by the Directive are 6 in number.

**Right to Access**-The Directive on cross-border health care is directed in opposition to the great fragmentation in access to care provided by the various forms of federalism throughout Europe. This is the right to access medicinal products or medical devices, as well as (and perhaps included in the previous two) health care services and therapeutic procedures issued by facilities located in and referring to the health care systems of countries other than that of origin (or if it does not coincide with the member state in which the patient has health insurance).

Regarding the problem of equal access to care, the Directive on cross-border health care breaks down the barriers between states and broadens health care options, from the moment that each citizen of a member state of the Union can refer to the entirety of European territory in making his or her choice of care.

**Right to Information** – The right to information is also broadly absorbed by this Directive. In fact, as stated previously, all of the member states must activate clear "national points of contact", towards the end of cooperation in situations of cross-border care and of providing the information requested by citizens who wish to cross the borders of their own state to request care abroad.

***Right to Free Choice*** – The right to free choice of health care services and products is the right that is the most greatly expanded by this Directive. In fact, rendering clear and homogeneous the procedures for requesting health services in a state other than that of provenance makes the possibility available to European citizens throughout the entire territory of the European Union, no longer limited to the confines of one's own state. The territory of reference becomes, therefore, enormous in comparison to that to which the citizen referred prior to this Directive.

***Right to Innovation*** – This Directive also expands and improves the right to access the best care and innovations available on the market. The expansion of the choice of facilities that issue health care services, and the expansion of the market with reference to drugs and medical devices permits a citizen of one member state access to an innovation introduced anywhere on European Union territory. As seen previously, the right to request a product in another state remains in place regardless of where the prescription was issued. In fact, one may request a prescription in one's own state, State A, and request the drug or device in another member state, State B. Taking Italy as a specific example, this would permit the breaking down of extant barriers with territorial therapeutic formularies. Moreover, one may request both the prescription and the product in a member state different from that where one holds health insurance (B) – this possibility, if fully absorbed, could put national pharmaceutical markets into direct competition, as well as those of medical devices. In fact, if a patient or doctor wishes to prescribe a drug not yet launched in his or her own state of provenance, but that can theoretically be prescribed throughout the European Union because – for example – it was approved by EMA or simply because it can be prescribed in another health care system, he or she may purchase it and request reimbursement from his or her own state, if of course the purchase of the drug or device is covered by his or her health insurance.

***Right to Complain and to Compensation*** – This Directive has a clear position regarding the right to complain: it in fact provides that the judicial system that must be kept in consideration is that of the state in which the care is issued. This, however, can limit the margins of action for the citizen, since it will be certainly more complicated to demand compensation if the place of jurisdiction is an external state and not one's own.

***Right to Privacy*** – It also provides for explicit reference to the protection of personal data in cross-border health care.

### **7.3 Summary**

The Directive simplifies and tends towards standardizing the procedures for requesting health care services, medicinal products and medical devices in a member state different from that in which the patient has health insurance. The reception of this Directive, opening the market frontiers for health care services and devices, produces an expansion of the possibility of choice and the right to access for patients who reside in European Union territory. Cross-border health care exists now, but the procedures to be followed are different among the member states. The provision of standardized and homogeneous procedures therefore permits the European citizen to enlarge his or her possibilities of choice, and constitutes an extraordinarily significant step in the process of integrating the health care systems of member states.

Of the 14 rights of the European Charter of Patients' Rights, the rights to access, information, innovation (with its enlargement of the possibilities for care and for requests for drug products and medical devices), privacy and compensation have been absorbed. It will be necessary, however, to understand the ways in which this Directive will be implemented by the member states, and above all how the various exceptions will be declined by the national judicial systems:

- it will be necessary to understand how limits will be absorbed to the free request for care abroad through prior authorization (article 8) for those services requiring the use of very expensive or highly specialized equipment;

- limits to reimbursement in reference to health insurance; in this case it will eventually be necessary to explicate the benefits that health insurance provides to those who are coming from a universal health system;
- limits to be evoked regarding the risk of compromising the economic and financial equilibrium of the welfare model of the state to which the patient belongs, and which must ensure the reimbursement of care.

In order to avoid the risk of a member state invoking these limitations over very generic issues, thereby thwarting the freedom of patients to request external care, the determined work of citizens' associations is necessary for the diffusion of information about the innovative content of the Directive, for the role that these could play in relation to the "national contact points" provided for in order to orient the citizen and for patient assistance in cases of controversy or contention.

Against the objection that some individuals, above all from the world of patients' associations, have made about the need to privilege service improvements in individual countries relative to the enlargement of the possibilities for care abroad, it is important to underline that this Directive, recognizing certain rights and eliminating barriers, will oblige every state to do its best to ensure those rights and possibilities within their own territory, in order to avoid excessive expenses and debt. The recognition of some rights moreover represents a precedent that is placed in the hands of citizens' associations who, with the Directive as backing, can then muster the courage to claim their receipt in their state of residence.

## 8. CONCLUSION

### 8.1 Work in Progress and Four Themes

The assessment presented in these pages may be considered a new branch of the experimental process that was initiated in 2002 with the proclamation of the Charter and which made visible the existence of a European civic movement for patients' rights. The safeguarding of the right to health was an area for "the development of the content and practice of European citizenship that could have a significance and reach that goes beyond the specific field in which [the process was carried out]" (Moro, 2009, p. 184).

As always happens in the course of experimental work, field application caused methodological problems to emerge that can nevertheless facilitate further development. The matrix of indicators, for example, will certainly need to be adjusted – and this work will be an opportunity to reinforce collaboration among partners – but it contributed to highlight problems of language and comprehension that are far from banal, such as those treated in the chapter, *Citizens' organizations working plan*. Similarly, it will be necessary to improve means of data collection but, as one has seen, this is not simply a technical question but concerns the concrete recognition of the right to active citizenship on the part of institutional interlocutors.

Given these specifics, it seems possible to therefore affirm that the assessment highlighted certain issues and identified corresponding directions for the development of the work. From this view we have taken the opportunity to concentrate attention on four themes: the general status of the right, the situation encountered in different countries, the development of the European framework for the right to health and the issues to be resolved towards the training of "empowered users".

### 8.2 The General Status of the Rights

In the chapter Patient's Right Euro Scores, the values of the scores of the individual rights were calculated and analytically explicated. Ordering these values from low to high, the rights may be grouped in five levels:

- Not respected score up to 50
- Hardly respected score between 51 and 60
- Partly respected score between 61 and 70
- Almost respected score between 71 and 90
- Fully respected score above 90

In order to correctly evaluate the right to access, as has been seen, it is necessary to distinguish between physical access to hospitals (transportation, parking, absence of barriers, etc.) and access to care and treatments.

Classification of the level of implementation of the rights on the basis of the scores:

<b>Right</b>	<b>Assessment</b>	<b>Mean score</b>
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 AVOIDING 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>

Source: Active Citizenship Network.

\*Only considering Civic Partner Organizations answers.

As can be easily seen, no single right may be considered fully implemented. The methodology adopted for this assessment is notably different from that utilized for the preceding survey and the countries involved are, in part, different. Nonetheless, one finds the same three rights having the worst scores: respect for patients' time, free choice and access to care. One must conclude therefore that these three areas are effectively the most critical and that this is true in almost all countries.

In effect ,the poor result of these three rights, as already observed previously (ACN, 2007), is connected to a single problem, that of the crisis of the "European Social Model" insofar as concerns the universal right to health care and the consequential reduction of levels of protection. A further sign, related to this, comes from the mediocre performance of three important rights dependent on facilities, being those relative to safety, quality and innovation. In particular, regarding "innovation" the official statistics reveal very widespread gaps relative to the availability of certain innovative drugs and certain technologies.

At the top of the classification one finds four rights (personalized treatment, prevention, privacy and physical access) which, as one will see below, may be considered as factors characteristic of European health care systems, independent of which model is adhered to (Bismark or Beveridge).

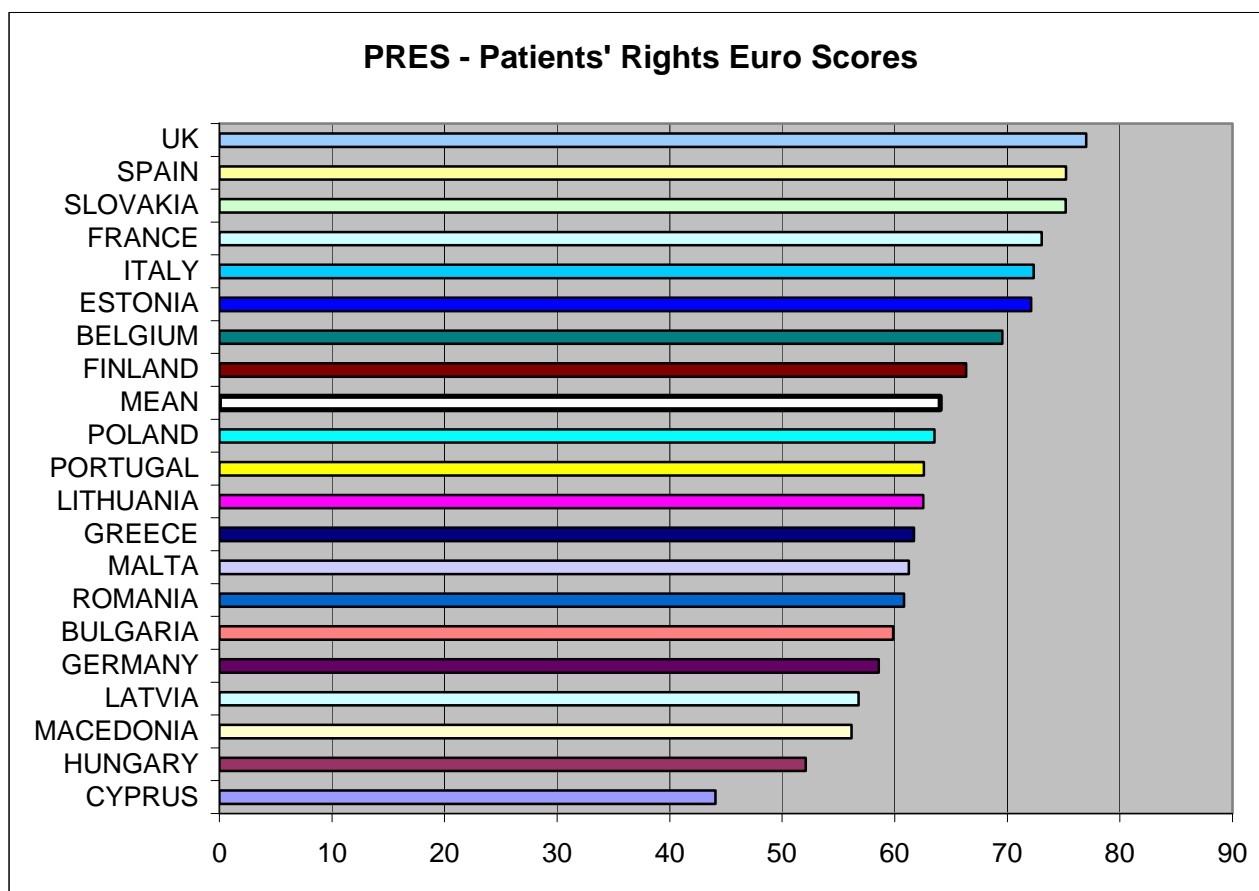
Three rights characteristic of the empowered users result as partially respected (consent, compensation, and complaint) and this fact, with some slight variation, finds verification in the previous survey. The rights to active citizenship and information attain unsatisfactory results. This poses problems concerning coherency, to which we will return below.

Finally, one must forcefully underline the unacceptably low score for the Right to avoid unnecessary suffering and pain, above all considering the fact that, as has been seen, the governments of only four countries have deemed it necessary to conduct research on the existence of national norms that excessively restrict the possibility to prescribe and distribute pharmaceutical narcotics and on measures to be adopted to avoid that this causes citizens unnecessary suffering.

### 8.3 The Situation in Different Countries

The calculation of PRES related to individual countries was directed towards highlighting the existence of a wide field of variability rather than establishing classifications. It is also necessary to remember that the scores are the result of a matrix that is not directed towards evaluating the quality or general efficacy of a system but rather, and more simply, towards attention to the rights proclaimed by the European Charter.

Patients' Rights Euro Scores in the different European countries:



Source: Active Citizenship Network , 2011.

In this case, as well, one does not find situations in which the implementation of the rights may be considered reasonably complete and, even in the best case (that of the UK), a scant level of respect for the ideal situation remains above 20% and must therefore be considered significant.

It is also probable that, due to the diversity of systems and of organizations, the relevance and pertinence of the proposed indicators vary notably from country to country. The evaluation of these variations will be an integral part of the above-mentioned work to improve the indicator matrix.

Moreover, every partner organization will utilize the data of its own country as well as benchmarking data for detailed public comparison with experts and authorities.

A group of eight countries results above average and includes Slovakia and Estonia, where strong dynamics towards adjusting the system are under way, as also noted by other observers (HCP, 2009, p. 26).

On the other hand, six countries attain PRES of less than 60, one of which is Germany. This result, which is partly surprising, could depend on the fact that the verification of some indicators would have required a survey on the level of Laender. This however bears on, and even more directly, lack of collaboration on the part of hospital authorities, which made part of the matrix inapplicable.

More generally, the comparison of countries highlights a decidedly broad field of variability, with a gap equal to around 40% separating the best situation from the worst. For the rest, as one has seen and as the figures of the preceding bar charts confirm, residence can be a powerfully discriminating factor even in cases in which the implementation of a right depends more on attention to the individual than on structural conditions.

#### **8.4 Development in a European Framework**

In the chapter relative to policies, the existence of significant common ground between European health care systems was already revealed. The investigation conducted from the point of view of citizens and their rights permits the enrichment and itemization of a number of other characteristics shared by and present in the majority of the countries involved.

A first contribution in this regard comes from the analysis of the four rights that attained the best scores.

The first of these is physical access. Throughout all of Europe, hospitals are well-signed and can be reached by citizens with relative ease and almost always by public transportation. This fact is not a given and is far from banal.

Regarding the right to privacy and confidentiality, civic organizations denounced systematic violations in only one country and some standards are shared<sup>12</sup> by all of the countries:

- the presence of National guidelines or procedures regarding the protection and use of patients' information;
- the absence of Violations of the confidentiality of HIV/AIDS patients;
- the presence of Dividers inside out-patient rooms.

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<sup>12</sup> Standards considered "shared" are those which are respected in at least 90% of the situations examined.

In the case of the right to preventive measures, there are no shared standards, but systematic violations were reported in only one country and vaccination and screening programs are fairly widespread.

The all in all positive outcome for the right to personalized treatment is principally due to the existence, in nearly all of the countries, of legislative measures against gender and age discrimination. Less impressive is the hospital situation in which the only shared standard concerns the possibility for the parents of assisting the children 24 hours a day, with support for food and a place to sleep.

A second contribution to the concrete definition of common ground among European health care systems comes from the revelation of the existence of twelve additional standards that are generally shared. These concern:

- Safety (presence of an updated report on hospital infections and of procedures for reducing the risk of transfusions and for hand washing, presence of emergency exit signs and fire extinguisher signs);
- Avoiding unnecessary pain (pain therapy service after surgery);
- Complaints, due to the presence of independent organizations in all of the countries and to the related diffusion in hospitals of committees or structures for receiving complaints and resolving conflicts;
- Information, with the presence in almost all of the hospitals of offices or desks for receiving the public and providing information regarding services;
- Time (wait times for PTCA and chemotherapy of less than 21 days);
- Innovation, with the supply of special mattresses for preventing pressure ulcers.

The existence of shared standards is, evidently, the result of the maturation of a common culture nourished by international guidelines, scientific congresses and the diffusion of good practices, but also by a growing sensitivity towards human rights and development of European citizenship.

This observation ought to invite, on the one hand, European institutions to more actively intervene in certain high-profile processes, such as the definition of quality standards and of accreditation procedures and, on the other hand, the overcoming of obstacles that impede the full development of active citizenship.

The Charter of Nice, the Lisbon Treaty, the same resolutions already adopted by numerous institutions but also the European Charter of patients' rights and the right to active citizenship, make an extremely positive context available in this regard.



## 8.5 Training "Empowered users"

As already revealed, in recent years various countries have adopted measures directed towards recognizing and promoting certain rights, and in particular those relative to consent, free choice and complaint and compensation. It was also noted that this ought to contribute to the training of "empowered users", capable of facing reductions in protection caused by the crisis of the European social model.

The results of this assessment provide useful information for taking stock of the actual status of the implementation of the rights, which in order to be effective, should be supported with good information and by the work (conscious, recognized and favoured) of active citizenship.

The result is not particularly satisfying. The right to free choice is one of the least implemented and is often actively blocked, as demonstrated by the reports of civic organizations. The concrete realization of informed consent – always recognized by law or even by Constitutions – clashes with the problems discussed in the chapter *Citizens' organizations working plan*.

As regards the right to complain, the same organizations detected cases of absent, late and/or inadequate responses in all but three countries, therefore feeding the suspicion that, in reality, complaints are often not taken seriously. It is a fact, furthermore, that the national and hospital authorities in many countries do not carry out any systematic analysis of citizens' reports. If one links this fact with others revealed in the survey – such as the unsatisfactory diffusion of customer satisfaction surveys and the systematic exclusion of citizens from quality panels and from verifications of quality itself – one finds very precise information regarding the real meaning of the centrality of the citizen. In the best cases (but not always), the citizen is the primary *object* of attention; as a rule he or she is not recognized, save for exceptional cases, as a *subject* capable of producing relevant information and evaluations.

The right to compensation, according to the civic organizations, was systematically or frequently violated in nine countries, and hospitals, with rare exceptions, lack committees or structures, independent from the hospital, to help parties towards reaching a final agreement on compensation.

The average level of information support is low. Violations were reported and the informative content of hospital websites found to be scarce or mediocre in all but two countries. Computerization advances slowly, above all among the GP which in half of the countries do not keep patient data on electronic support and are very rarely in a position to provide more advanced functions.

Certain obstacles to the full implementation of active citizenship were already reported and the general level for this right is mediocre.

These surveys, important in and of themselves, take on strategic relevance in the context of promoting "empowered users" as a response to the crisis of the social model. The encouragement and development of such figures cannot be guaranteed solely by the formal ruling of a few rights but requires full recognition of active citizenship and the enacting of appropriate support policies. The elimination of the situations of non-conformity revealed by this investigation could be a good step forward in that direction.

## 9. FINAL RECOMMENDATIONS

The considerations discussed up to this point confirm that what is presently at stake is the safeguarding and development of the universality of health care systems, not only as a statement of principle but as a concrete criterion for the organization and management of services. The guarantee of a sufficient flow of resources is, clearly, a necessary condition of this aim and must not be considered as a simple cost to be contained but rather as a real and true investment. The taking of responsibility for fragile subjects must in all cases be guaranteed, as with attention to avoiding situations in which illness becomes cause for social exclusion.

In order to be effective, financial coverage must be accompanied by policies that recognize and implement the citizens' rights already indicated and which are restated below, organized into three general categories.

1) The first regards the reduction of inequality in treatment among European citizens. An important step in this direction was taken with the approval of the Directive on cross-border healthcare which, however, must be integrated with further measures, including:

- The definition and diffusion of shared quality and safety standards that are concretely owed to citizens, independent of place of residence;
- A concrete definition of the right to informed consent and access to clinical documentation;
- The removal of impediments to the exercise of the right to free choice, formally recognized by all countries involved and reducing conditions imposed by administrations and insurers to a bare minimum;
- The promotion of respect for the right to time and access to care, with policies for wait time reduction and of waiting list management.

2) The second area is that of building "empowered user" capable of interacting authoritatively and appropriately with health care services and towards the construction of clinical directions. In this context, the practice of the right to active citizenship, established in the European Charter of Patients' Rights (to lead general interest activity, to carry out safeguarding activity, to participate in policymaking) must be supported and guaranteed throughout the European Union as an expression of European citizenship. The prevention of active citizens from collecting information and cooperating in the evaluation of rights, as already denounced in the first investigation in 2007 (ACN 2007), must not continue. A further fundamental action is protection of the right to information: all organizations must guarantee accurate information about their services and it must be possible, through independent and recognized sites (such as that of the NHS in the UK), to access meaningful and relevant data on the quality and safety of health care facilities.

Finally, the concept of patient centred care must be further developed as the basis of strategies to rationalize services and as a safeguard of essential levels of protection. A first step towards this aim could be the elimination of obstacles to the appropriate use of opiate analgesics.

**3)** The third area refers to the development of subsidiarity: local communities must be positioned to freely make use of their own resources without useless bureaucratic obstacles. This assumption of responsibility must however be facilitated by an adequate and certain flow of financial resources which cannot be revoked at discretion, as well as by a group of actions for the support and training of local leadership, starting with already existing civic organizations.

## APPENDIX A

### Matrix of Patients' Rights: list of indicators

*h.d.* = Questions for Hospital Director

*d.o.* = direct observation

<b><u>1. RIGHT TO PREVENTIVE MEASURES</u></b>
<b>Level 1: Ministry of Health</b>
Vaccinations offered to children and adolescents free of charge
- Hepatitis B Vaccine
- Meningococcal Conjugate Vaccine
- Haemophilus influenzae type B Vaccine
- Pneumococcal Vaccine
- HPV Vaccine
- Public communication campaigns for HIV prevention in 2009, throughout the country
<b>Level 3: Civic Organization</b>
- Violation of the right to prevention concerning: immunization programmes screening programmes
- Cases of violation of the right to prevention
<b>Another Prospective</b>
- Status of breast cancer screening programme (Population based; Nationwide; Rollout complete; Planning)
- Status of cervical cancer screening programme (Population based; Nationwide; Rollout complete; Planning)
- Percentage of one-year-olds vaccinated last year against: diphtheria tetanus measles
- Percentage of citizens that have a perception of effectiveness of an information campaign on AIDS

<b><u>2. RIGHT TO ACCESS</u></b>
<b>Level 2: Hospital</b>
- Street signs near the hospital indicating its location (d.o)
- Hospital entrances clearly marked (d.o)
- Structural barriers which have not been remedied (d.o)
- Patients with motor difficulties dropped off at the main entrance (d.o)
- Hospital accessible by public transportation (d.o)
- Free Use of the Parking lot (d.o)
- Reserved parking for persons with disability (d.o)
<b>Level 3: Civic Organization</b>
- Violation of the right to access concerning: Discrimination on the basis of financial resources Place of residence Kind of illness
- Cases of violation of the right to access
<b>Another Prospective</b>
- Percentage of all cancer survival in 5 years after diagnosis (except skin)
- Percentage of people with unmet needs for medical examination, due to problems of access (could not afford to, waiting list, too far to travel)
- Percentage of people with unmet needs for dental examination, due to problems of access (too expensive, waiting list, too far to travel)
- Percentage of people correctly answering about the telephone number enabling to call emergency services anywhere in the European Union

### 3. RIGHT TO INFORMATION

#### **Level 1: Ministry of Health**

- Availability of hospitals' list specifying facilities and services provided, updated every year
- Consumer satisfaction information related to health services clinical performance, provided by health authorities
- Register of accredited doctors and other health professionals available and readily accessible on a web site
- Web or 24/7 telephone healthcare information available
- Availability of information regarding independent organizations that can provide information and advise to citizens

#### **Level 2: Hospital**

- Free telephone number (h.d.)
- Possibility for patients to receive hospital record after discharge (h.d.)
- Percentage of records provided within 30 days in March 2009 (h.d.)
- Free clinical records for patient (h.d.)
- Reception (office or desk for receiving the public and providing information regarding the services) (d.o)
- Regularly updated hospital's services directory in the main entrance (d.o)

Hospital web site with these contents:

- List of services provided
- Opening times
- How to make an appointment
- Waiting times for the principle exams and treatments
- How to reach the hospital
- Possibility of scheduling an appointment (for exams/visits/etc.) on line
- Diagnostic exams that patients can receive via internet
- Data on the outcomes of the health care services administered
- Data on the outcomes of the health care services administered compared with the data of other hospitals (benchmarking)
- Quality Score that covers a range of areas including safety of patients, cleanliness and waiting times etc
- Quality Score compared with the scores of the other hospitals

(d.o)

- Information sheet about the hospital and the regulations that concern the inpatients available to the public (d.o)
- Information sheet on patients' rights available to the public (d.o)
- Accessibility of the information materials about the regulations that concern the inpatients and patients' rights (d.o)
- Indicated areas for voluntary and public interest associations (d.o)

#### **Level 3: Civic Organization**

- Violation of the right to information concerning:  
medical record;  
information regarding health status during checkups or hospitalisations;  
information about suitable health services when necessary;  
information about innovative treatments available in other European countries
- Cases of violation of the right to information

### 4. RIGHT TO CONSENT

#### **Level 1: Ministry of Health**

Governmental guidelines requiring the use of an informed consent form for elective surgery that include the following aspects:

- The consent must be given 24h before the intervention
- The language of the form has to be accessible
- Legal representation when required have to be present
- The right to refuse the intervention
- Governmental guidelines for informed consent for blood transfusion
- Governmental guidelines for Informed consent for HIV test

#### **Level 2: Hospital**

Specific consent form for appendectomy with the following information included:

- Patient name
- Name of the procedure
- Site of the intervention (organ, side, body level)
- Collateral effects of the treatment or procedure
- Diagnosis and reason for the procedure
- Percentage of risk associated with the treatment
- Possible alternative treatments and respective percentage of risk
- Patient declaration regarding the comprehension of the information provided
- Signatures of both doctor and patients
- Possibility to cancel consent at any moment

(d.o)

<p>Specific consent form for programmed caesarean section with the following information included:</p> <ul style="list-style-type: none"> <li>- Patient name</li> <li>- Name of the procedure</li> <li>- Site of the intervention (organ, side, body level)</li> <li>- Collateral effects of the treatment or procedure</li> <li>- Diagnosis and reason for the procedure</li> <li>- Percentage of risk associated with the treatment</li> <li>- Possible alternative treatments and respective percentage of risk</li> <li>- Patient declaration regarding the comprehension of the information provided</li> <li>- Signatures of both doctor and patients</li> <li>- Possibility to cancel consent at any moment</li> </ul> <p>(d.o)</p>
<p>Specific consent form for hysterectomy radical with the following information included:</p> <ul style="list-style-type: none"> <li>- Patient name</li> <li>- Name of the procedure</li> <li>- Site of the intervention (organ, side, body level)</li> <li>- Collateral effects of the treatment or procedure</li> <li>- Diagnosis and reason for the procedure</li> <li>- Percentage of risk associated with the treatment</li> <li>- Possible alternative treatments and respective percentage of risk</li> <li>- Patient declaration regarding the comprehension of the information provided</li> <li>- Signatures of both doctor and patients</li> <li>- Possibility to cancel consent at any moment</li> </ul> <p>(d.o)</p>
<p>Specific consent form for hip replacement with the following information included:</p> <ul style="list-style-type: none"> <li>- Patient name</li> <li>- Name of the procedure</li> <li>- Site of the intervention (organ, side, body level)</li> <li>- Collateral effects of the treatment or procedure</li> <li>- Diagnosis and reason for the procedure</li> <li>- Percentage of risk associated with the treatment</li> <li>- Possible alternative treatments and respective percentage of risk</li> <li>- Patient declaration regarding the comprehension of the information provided</li> <li>- Signatures of both doctor and patients</li> <li>- Possibility to cancel consent at any moment</li> </ul> <p>(d.o)</p>
<ul style="list-style-type: none"> <li>- Standardized forms used to get patients' consent for scientific research</li> </ul>
<p><b>Level 3: Civic Organization</b></p> <ul style="list-style-type: none"> <li>- Violation of the right to consent concerning diagnostic procedures and/or treatments provided without patients' consent</li> <li>- Cases of violation of the right to consent</li> </ul>

<p><b><u>5. RIGHT TO FREE CHOICE</u></b></p>
<p><b>Level 1: Ministry of Health</b></p> <ul style="list-style-type: none"> <li>- Possibility, for citizens of all regions and in any case, of visiting a medical specialist in another EU country without prior authorization, with the visit free of charge or partly subsidized</li> <li>- Non emergency treatments - even hospital treatments - in another EU country without prior authorization, with the treatment free of charge or partially subsidized, for citizens of all regions and in any case</li> </ul>
<p><b>Level 3: Civic Organization</b></p> <ul style="list-style-type: none"> <li>- Violation of the right to free choice concerning: <ul style="list-style-type: none"> <li>Different fees in public and private hospitals;</li> <li>Incentives to seek treatment in certain hospitals or centres;</li> <li>Coverage of supplementary insurance only for some hospitals;</li> <li>Need to get authorization for some treatments;</li> <li>Indigent patients only able to be treated in certain hospitals</li> </ul> </li> <li>- Cases of violation of the right to free choice</li> </ul>
<p><b>Another Prospective</b></p> <ul style="list-style-type: none"> <li>- Percentage of people who feel to have enough choice in choosing regular medical doctor</li> </ul>

## 6. RIGHT TO PRIVACY AND CONFIDENTIALITY

### **Level 1: Ministry of Health**

National guidelines or procedures regarding protection, use and disclosure of patients information which ensures the patient and/or their legal representative are informed in a manner appropriate for the patient's communication needs regarding the following:

- What kinds of information are being recorded and retained
- The purposes for which the information is being recorded and retained
- What protections are in place to ensure non-disclosure of their information
- What kinds of information sharing will usually occur
- Of the choices available to them about how their information may be used and disclosed
- About their rights to access and where necessary to correct the information held about them within healthcare records
- The information required to be provided to them by national law implementing Directive 95/46/EC
- Country specific legal provisions or principles governing disclosure

Laws, norms or national guidelines that include the following recommendations:

- A doctor can only provide information on a patient if the patients has given his/her consent
- In cases when there is physical limitation or inability to understand the patient's consent regarding his/her information and there is not immediate risks to the patients health, a third person will be given responsibility (doctor, family, partner)
- If the patient is conscious he/she has the right to decide who his/her information should be communicated when in the emergency room or in a hospital ward
- The list of patients awaiting treatment should never be posted in a place open to the public with or without the description of the pathology, neither should the clinic records be visible to anyone other than the authorized personnel
- The most vulnerable people (persons with disability, minors, and older people) as well as patients that have undergone a specifically invasive procedure have the right to be given particular attention to protect their dignity for example in the reanimation ward there should be privacy during visiting hours even if that means using temporary structures
- A patients privacy, when giving or receiving information regarding their health condition, should be guaranteed by providing specific areas other than where other patients are waiting their turn
- The sharing of patients information (diagnostic results and clinic file) with other people is regulated

### **Level 2: Hospital**

- Single rooms for terminal patients and their families if requested (h.d.)
- Cases of non authorized medical information's circulation (h.d)
- Cases of non authorized medical records' circulation (h.d.)
- Violation of the confidentiality of HIV/AIDS patients (h.d.)
- Information on the possible presence of students during the visits (only for teaching hospitals) (h.d.)
- Dividers inside out-patient rooms (d.o.)
- Patient's surname seen or heard in the out patient's areas (d.o.)
- Identification of the personnel functioning by uniform colour (d.o.)

### **Level 3: Civic Organization**

- Violation of the right to privacy and confidentiality concerning:  
Normative medical information disclosed to non-authorized persons;  
Patients' case files disclosed to non-authorized persons
- Cases of violation of the right to privacy and confidentiality

## 7. RIGHT TO RESPECT OF PATIENTS' TIME

### **Level 1: Ministry of Health**

- Information on the waiting lists for diagnostic exams and treatments available on institutional websites throughout the Country
- Information on the waiting lists for elective surgery available on institutional websites throughout the Country
- Maximum waiting times for specific exams that are not urgent
- Different waiting times based on clinical priority
- Maximum waiting times for specific surgical procedures that are not considered urgent

### **Level 2: Hospital**

- Diagnostic or therapeutic treatment (only for outpatients) impossible to get appointment in the last 30 days (not due to technical reasons) (h.d)
- Percentage of cancer patients that were able to begin radiation therapy in less than 21 days in 2009 (h.d)
- Percentage of cancer patients that were able to begin chemotherapy in less than 21 days in 2009 (h.d)
- Percentage of patients that have waited less than 7 days time for Non-emergency Head TC Scan in 2009 (h.d)
- Percentage of patients operated on with Coronary Bypass that have waited less than 90 days (h.d)
- Percentage of patients operated on with PTCA Percutaneous transluminal coronary angioplasty that have waited less than 90 days (h.d)
- Percentage of patients operated on with Hip prosthesis that have waited less than 90 days (h.d)

- List of admittance for programmed hospitalisation of elective surgery available to the public and consultable respecting the national norms on privacy (h.d)
- Waiting times available to the public for the following services for out-patients: diagnostic exams, specialist visits and therapies. (h.d.)
- Waiting times available to the public for the following services for in-patients: surgeries (including day surgery) and Radio therapies. (h.d.)
- Unified contact point for appointments (h.d.)
- Appointments for specialists made by phone and or internet (h.d.)
<b>Level 3: Civic Organization</b>
- Violation of the right to respect of patients' time 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
- Cases of violation of the right to respect of patients' time

## 8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS

### **Level 1: Ministry of Health**

National governmental accreditation programs for health services  
National centers for developing, collecting and distributing guidelines for clinical practice  
Quality improvement included in the academic curriculum of doctors and nurses (health professionals)  
List on quality ranking of health services

### **Level 2: Hospital**

Hospital involvement in public accreditation programs (h.d)  
Hospital voluntary accreditation/certification based on the present International existent model (ISO 9000, EFQM, Joint International Commission etc.) (h.d )  
Quality unit (h.d)  
Studies to measure patients' satisfaction in the last two years; results available to the public; actions carried out to better the quality of service (h.d)

### **Level 3: Civic Organization**

Violation of the right to the observance of quality standards  
Cases of violation of the right to the observance of quality standards

## 9. RIGHT TO SAFETY

### **Level 1: Ministry of Health**

Provision in the legislation of the use of a system to gather information regarding adverse events by health care professionals (operators)  
Provision in the legislation of the legal protection for people who report an adverse event in so far that the information shared can not be later used in a judicial procedure  
National recommendations for the implementation of the "WHO Surgical Safety Checklist"

### **Level 2: Hospital**

Hospital guidelines taking account the WHO Surgical Safety Checklist (h.d)  
Procedure for reducing the risk of transfusions (h.d)  
Updated report (not later than last year) on the hospital infections (h.d)  
Procedure for hand washing (h.d)  
Priority codes in triage procedure in Emergency Department (h.d)  
Fire resistant areas easily reached by people with disabilities (h.d)  
Emergency exit signs (d.o)  
Fire extinguisher sign (d.o)  
Evacuation map (d.o)  
Supplementary communication systems for emergency exits (d.o)

### **Level 3: Civic Organization**

Violation of the right to safety concerning:  
- misidentification of patient;  
- incorrect drug or incorrect dose or delayed or omitted administration;  
- surgical operation on the wrong site;  
- loss or mix-up of exams;  
- accidental fall of the patient from his/her bed or stretcher;  
- gauze or instruments forgotten inside the patient  
- incorrectly administered anaesthesia with lethal effects.



Cases of violation of the right to safety
<b>Another Prospective</b>
- Percentage MRSA infections (Methicillinresistant Staphylococcus Aureus)
- Screening donated blood units: System in place for organising inspections and control measures of blood establishments National guidelines for the assessment of at risk sexual behaviours System in place for the reporting of serious adverse events and serious adverse reactions Penalties laid down for infringements of the national provisions adopted pursuant to the Directive

## 10. RIGHT TO INNOVATION

### **Level 2: Hospital**

- Use of telemedicine (h.d)
- Electronic patient records (h.d)
- Transfer of medical data between hospital's professionals and GP, other professional (h.d)
- Use of the following less invasive surgical techniques: Laparoscopic Cholecystectomy Laparoscopic Prostatectomy Microendoscopic discectomy (MED) Minimally invasive direct coronary artery bypass (MIDCAB) Laparoscopic Inguinal hernia repair Laparoscopic Repair of paraesophageal hernia (h.d)
- Use of Patient Controlled Analgesia (PCA) (h.d)
- Special mattress with foam, air, gel or water, designed to prevent pressure ulcers (h.d)

### **Level 3: Civic Organization**

- Violation of the right to innovation concerning: Delays in the introduction of innovative diagnostic tests; Delays in the introduction of innovative treatment Delays in particular areas of medical research.
Cases of violation of the right to innovation

### **Another Prospective**

- Availability of medical technology (num. per million of population): Computer Tomography Scanners MRI units Radiation therapy equip. Lithotriptors Mammographs
- Availability of new pharmaceutical drugs for cancer through the national health system (year of launch date): Capecitabine Gemcitabine Imatinib Irinotecan Oxaliplatin Rituximab Trastuzumab Vinorelbine
- Average time delays (in days) between marketing authorization and effective market access (hospital and retail combined) of all new substances to patients
- Percentage of General Practitioners who use Electronic Patient Record (EPR - Electronic recording and storage of individual administrative patient data) in primary care
- Percentage of General Practitioners who use the following electronic network for transfer of patient data: Lab results from laboratories Admin data to reimbursers Medical data to care providers / professionals Admin data to other care providers Prescription to pharmacies Medical data cross border

## 11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN

### **Level 1: Ministry of Health**

- Governmental study in the last 3 years to determine whether the existing national norms are overly restrictive in respect to the control of pharmaceuticals within the National Health care System hindering the prescription, distribution or medical treatment that use narcotic pharmaceutical and consequent changes made

### **Level 2: Hospital**

- Patients' pain intensity measurement for:

General surgery

Orthopaedics

Oncology

Gynaecology (h.d)

- Training of personnel on pain therapy in the last two years (h.d)

- Labour epidural anesthesia free of charge, which patients are informed of (h.d)

- Pain therapy service after surgery, which patients are informed of (h.d)

### **Level 3: Civic Organization**

- Violation of the right to avoid unnecessary suffering and pain concerning:  
morphine not administered when recommended by the international procedures on severe pain treatment;  
painkillers not administered when needed or after painful treatments;  
lack of measuring post-surgical pain in case of all surgical operations;  
existence in national laws or norms on drug control obligations on the prescription of narcotic pharmaceutical that may result in excessively limiting the access of doctors or patients to pain therapy.

- Cases of violation of the right to avoid unnecessary suffering and pain

### **Another Prospective**

- Number of beds allocated to adult palliative care per million population

- Amount of morphine consumption (mg per capita)

## 12. RIGHT TO PERSONALIZED TREATMENT

### **Level 1: Ministry of Health**

- Legislative indications regarding non discrimination and personalized care taking into account diversity of culture and religion

- Legislative indications regarding non discrimination and personalized care taking into account difference in age

- Legislative indications regarding non discrimination and personalized care taking into account differences in gender

### **Level 2: Hospital**

- Choice of meals (h.d)

- Religious assistance available in the hospital or on call 24 hours a day for:

Protestants

Anglican

Catholic

Orthodox

Jewish

Muslim

Other (h.d)

- Psychological Support Service to assist patients and their families in specific situations:

oncological patients and their family

transplant patients and their family

women in the Emergency Room who have suffered violence

other (h.d)

- Procedures to ensure that patients may demand a second opinion, with or without having to pay extra (h.d)

- Visiting time extension during weekdays (h.d.)

- Visiting time extension during Sundays and holidays (h.d.)

- Foreign language interpreters available in the hospital or on call (h.d.)

- Sign-language interpreters available in the hospital or on call (h.d.)

- Cultural mediator service available in the hospital or on call (h.d.)

- Play areas inside pediatric wards (h.d.)

- Appropriate furnishing inside pediatrics wards (h.d.)

- Parents' presence allowed 24 hours a day with an appropriate place to sleep in the room and with use of cafeteria (h.d.)

### **Level 3: Civic Organization**

<p>Violation of the right to personalized treatment concerning:</p> <ul style="list-style-type: none"> <li>- the impossibility for parents of assisting their child 24h during his/her hospitalisation;</li> <li>- the hospitalised patient couldn't find religious assistance, according his/her faith;</li> <li>- the hospitalised patient couldn't communicate because of lack of a mediator or interpreter.</li> </ul>
- Cases of violation of the right to personalized treatment

### 13. RIGHT TO COMPLAIN

<b>Level 1: Ministry of Health</b>
- Independent organizations to assist citizens in presenting their complaints
- Report by health authorities on the complaints presented by citizens published in the last two year
- Governmental published program to receive and analyze the complaints regarding health services (hotline, public relation office)
<b>Level 2: Hospital</b>
- Committees or structures to receive complaints and resolve conflicts (h.d)
- Systematic review and analysis of the complaints received and a report written (h.d)
- Established procedure set-up to incorporate recommendation from the report (h.d)
<b>Level 3: Civic Organization</b>
- Violation of the right to complain concerning: Lack of response to citizens' complaints; Response to citizens' complaints given after a too long period of time; Threats, intimidations or retaliation towards patients that have complained or denounced inadequate health services.
- Cases of violation of the right to complain

### 14. RIGHT TO COMPENSATION

<b>Level 1: Ministry of Health</b>
- Hospitals insurance
- Commissions/structures operating outside the regular litigation process
- Independent organizations which provide legal aid free of charge or at a reduced cost
<b>Level 2: Hospital</b>
- Hospital insurance (h.d)
- Additional insurance for hospital's doctors (h.d)
- Committees or structures to help the parties in reaching a final agreement on compensation, independent from the hospital (h.d)
<b>Level 3: Civic Organization</b>
Violations of the right to compensation concerning:
- Civil cases that lasted over 6 years
- Cases where citizens are not able to find doctors that would give forensic evidence against other doctors in cases of medical error
- Citizens that have been subjected to threats, intimidations other pressures due to the fact that they are asking for compensation from a doctor or hospital
- Citizens that having suffered damages resulting from medical error have received through alternative forms (non judicial) an offer of compensation less that the value of the damage received
- Cases of violation of the right to compensation

## 15. RIGHT TO ACTIVE CITIZENSHIP

### **Level 1: Ministry of Health**

- Right for patients/citizens to carry out activities to verify and control the effective respect of patients' rights in the health system, explicitly stated in the legislation
- Health care legislation or other documented measures regarding right for citizens organizations to evaluate or fix standards regarding the quality of health care services
- Group for Quality Assurance with the representation of providers, insurers, professionals and citizens
- Legal recognition that information produced by citizens and patients organizations should be used for evaluating health policy

### **Level 2: Hospital**

- Common initiatives done in partnership together (hospital authorities and patient-citizens organizations) regarding the quality of service in the last two years (h.d)
- Periodic consultations of the representatives of patients or citizens organization on general or specific issues (h.d)
- Possibility for users to evaluate the quality of the out servicing of certain services and products (h.d)

### **Level 3: Civic Organization**

Violations of the right to active citizenship concerning:

- Citizens organisations which have not been able to give information
  - Citizens organisations which have not been able to carry out auditing and verifying activities regarding health services
  - Citizens organisations which have not been able to intervene directly in situations of violation or inadequate protection of rights
  - Citizens organisations which have not been able to submit information and proposals, or have not been given feed-backs to their proposals
- Cases of violation of the right to active citizenship

## APPENDIX B

### The numbers

Countries: 20  
Hospitals: 56  
Ministries: 23  
Organizations : 70

### BELGIUM

#### Partner Organizations:

**Belgium 1 (Flemish- part):** Vlaams Patiëntenplatform vzw

Contact person: Klaartje Bruyninckx [klaartje.bruyninckx@vlaamspatientenplatform.be](mailto:klaartje.bruyninckx@vlaamspatientenplatform.be)  
[www.vlaamspatientenplatform.be](http://www.vlaamspatientenplatform.be)

**Belgium 2 (French-speaking part):**

**Ligue des Usagers des Services de Santé – LUSS asbl** [www.luss.be](http://www.luss.be)

Contact person: Sophie Lanoy [S.lanoy@luss.be](mailto:S.lanoy@luss.be)

#### 3 Hospitals monitored:

- Universitair Ziekenhuis Leuven Gasthuisberg (Lovenio) - Available acute care beds 1472
- Centre Hospitalier Régional de la Citadelle (CHR) (Liege) - Available acute care beds 1200
- Academic hospital Saint-Luc (Brussels) - Available acute care beds 964

#### 2 Ministry:

- Vlaams Agentschap Zorg en Gezondheid - Flemish Agency for Care and Health
- Ministère des Affaires sociales et de la santé publique

#### 2 Civic questionnaires filled in by:

- Vlaams Patiëntenplatform vzw + Federale Ombudsdienst Rechten van de Patiënt + verschillende ombudspersonen van ziekenhuizen + patiëntenverenigingen ('t Lichtpuntje, VAPA vzw, Stroke vzw, ME-Vereniging vzw, Uilenspiegel vzw, Belgische Vereniging voor Pulmonale Hypertensie vzw, Werkgroep Hersentumoren vzw, Ruggensteun vzw, CCV vzw, Hartekinderen vzw, CVA Kempen
- LUSS (Ligue des Usagers des Services de Santé) + Oxygène Mont-Godinne + Association de transplantés pulmonaires asbl + Psytoyens + Erreurs Médicales ASBL, + AMIS (Association des Médiateurs d'Institutions de Soins) + La médiatrice fédérale « Droits du patient » + Un médecin travaillant pour ATD Quart Monde.

## BULGARIA

### Partner Organization:

Index Foundation [www.index-bg.org](http://www.index-bg.org)

Contact person: Lucy Mincheva [indexfoundation@abv.bg](mailto:indexfoundation@abv.bg)

### 3 Hospitals monitored:

- St. Anna Multi-profile Hospital for Active Treatment (Sofia) - Available acute care beds 929
- 2nd Multi-profile Hospital for Active Treatment (Sofia) - Available acute care beds 244
- 4th Multi-profile Hospital for Active Treatment – (Sofia) EAD - Available acute care beds 111

### Ministry:

- Bulgarian Ministry of Health

### Civic questionnaire filled in by:

- International Institute for Health and Health Insurance – NGO

## CYPRUS

### Partner Organization:

Limassol District Committee for Examining Patients' Complaints

Contact person: Stella Playbell [playbell@cytanet.com.cy](mailto:playbell@cytanet.com.cy)

### 1 Hospital monitored:

- General Hospital of Nicosia Available acute care beds 30

### Ministry:

- Cyprian Ministry of Health

### Civic questionnaire filled in by:

- The Cyprus Association of Cancer Patients and Friends

## CROATIA

### Partner Organization:

Croatian Association for Patients' rights <http://www.pravapacijenata.hr/eng/>

Contact person: Dula Sunara [dula.sunara@st.t-com.hr](mailto:dula.sunara@st.t-com.hr)

## ESTONIA

### Partner Organization:

#### **Estonian Patient Advocacy Association**

Contact person: Anne Veskimeister [info@epey.ee](mailto:info@epey.ee)

### 1 Hospital monitored:

- The North Estonia Medical Centre (Põhja-Eesti Regionaalhaigla) in Tallinn - Available acute care beds 1245

### Ministry:

- Estonian Ministry of Health

### 4 Civic questionnaires filled in by:

- North Estonian Cancer Patients' Association
- Estonian Mentally Disabled People Support Organisation
- Estonian Diabetes Association
- Estonian Psoriasis Society

## FINLAND

### Partner Organization:

#### **Sosiaali-ja terveystöjen yhteistyöyhdistys YTY ry**

The Association of Voluntary Health, Social and Welfare Organisations (YTY).

<http://www.sostertyy.fi>

Contact person: Riitta Kittila

[Riitta.Kittila@sostertyy.fi](mailto:Riitta.Kittila@sostertyy.fi)

### 1 Hospital monitored:

- Meilahti Tower Hospital in Helsinki - Available acute care beds 335

### Ministry:

- Ministry of Social Affairs and Health (MSAH) <http://www.stm.fi/en/ministry>

### 9 Civic questionnaires filled in by:

- The Finnish Polio Association
- Pulmonary Association Heli
- Finnish Heart Association
- Finnish Central Organisation for Skin Patients
- The Association for Accident and Sickness Invalids
- The Finnish Association of the Deaf
- The Finnish Neuromuscular Disorders Association
- Hanko Street Mission
- The Finnish Blue Ribbon

## FRANCE

### Partner Organization:

CISS - Collectif Interassociatif Sur la Santé [www.leciss.org](http://www.leciss.org)

Contact person: Isabelle PONS [ipons@leciss.org](mailto:ipons@leciss.org)

### 4 Hospitals monitored:

- Hospital Pitié-Salpêtrière (AP-HP) in Paris - Available acute care beds 1613
- CHR (Regional Hospital Center) Orléans - Available acute care beds 920
- Hospital La Conception (AP-HM) in Marseille - Available acute care beds 804
- Hospital Necker (AP-HP) in Paris - Available acute care beds 540

### Ministry:

- French Ministry of Health

NANSOT Jean-Jacques - DGS - Responsable of associations and patients' representation mission

VISCONTINI Alexandre DGS - office of programming, synthesis and evaluation

ERNY Isabelle DGS - division rights, ethics, legal support

PERROT Sandrine DGOS - patient's rights

### 7 Civic questionnaires filled in by:

- 321 Cancer
- ACSAC (Association Contre la Spondylarthrite Ankylosante et ses Conséquences) Pays de la Loire
- ADMD (Association pour le Droit de Mourir dans la Dignité - Association for the Right to Die with Dignity)
- CISS region Centre
- Association E3M (orphan disease)
- Ligue Nationale Contre le Cancer
- CISS (Collectif Interassociatif Sur la Santé)

## GERMANY

### Partner Organization:

Bürgerinitiative Gesundheit DGVP e.V.

Deutsche Gesellschaft für Versicherte und Patienten [www.dgvp.de](http://www.dgvp.de)

Contact person: Katja Rupp [info@dgvp.de](mailto:info@dgvp.de)

### 5 Hospitals monitored:

- Campus Charité Berlin Mitte
- Benjamin Franklin Charite
- Helios Berlin Buch
- Vivantes Am Urban Berlin
- Vivantes Neukölln Berlin



**Ministry:**

German Ministry of Health - Health policy department

**Civic questionnaire filled in by:**

- Bürgerinitiative Gesundheit DGVP

**GREECE****Partner Organization:**

Europaiki Ekfrassi <http://www.ekfrasi.gr/en/framepage.html>

Contact person: Rania Papastavropoulou [ekfrasi@ekfrasi.gr](mailto:ekfrasi@ekfrasi.gr)

**2 Hospitals monitored:**

- University General Hospital Attikon - Available acute care beds 563
- Spiliopoulou Hospital "Saint-Helen" - Available acute care beds 31

**Ministry:**

Greek Ministry of Health - Director General of Patients Protection Service

**Civic questionnaire filled in by:**

- Europaiki Ekfrassi

**HUNGARY****Partner Organization:**

Hungarian Civil Liberties Union <http://tasz.hu/en>

Contact person: Stefania Kapronczay [kapronczay.stefania@tasz.hu](mailto:kapronczay.stefania@tasz.hu)

**3 Hospitals monitored:**

- Fovárosi Önkormányzat Uzsoki utcai Kórház, Budapest - Available acute care beds 850
- Szent Imre Kórház, Budapest - Available acute care beds 653
- Komlói Egészségcentrum Nonprofit Kft., Komló - Available acute care beds 165

**Ministry:**

Ministry of national Resources - Legal and Health Politics Department

**9 Civic questionnaires filled in by:**

- Betegjogi, Gyermekjogi és Ellátottjogi Közalapítvány
- Anonym AIDS Tanácsadó Szolgálat
- Afázia - Az Újrabeszélok Egyesülete
- Magyar Hemofília Egyesület
- Rákbetegek Országos Szövetsége
- Lisztérzékenyek Érdekképviseletének Országos Egyesülete
- Mozgássérültek Budapesti Egyesülete
- Pszichiátriai Érdekvédelmi Fórum
- Szószóló Alapítvány

## LATVIA

### Partner Organization:

Pacientu Ombuds <http://www.pacientuombuds.lv/lat/>  
Contact person: Liene Sulce [liene@pacientuombuds.lv](mailto:liene@pacientuombuds.lv)

### Hospital monitored:

- Children's Clinical University Hospital, Riga - Available acute care beds N/A

### Ministry:

Latvian Ministry of Health  
Daina Murmane-Umbrasko - Head of division of Health Policy Analysis and Planning  
Antra Valdmane Deputy Head of division of Treatment and Disasters

### Civic questionnaire filled in by:

- Patients Ombudsman + Support society for Leukemia patients + Riga Diabetes Association  
+ Oncology Patient Support Association "Tree of Life" + Children's Hospital Foundation

## LITHUANIA

### Partner Organization:

Council of Representatives of Patients Organizations of Lithuania

<http://www.pacientutaryba.lt/lt/index.php>

Contact person: Vida Augustiniene [info@pacientutaryba.lt](mailto:info@pacientutaryba.lt)

### 2 Hospitals monitored:

- Vilnius University Hospital Santariskiu Klinikos - Available acute care beds 1164  
- Vilnius University Emergency Hospital - Available acute care beds 770

### Ministry:

Ministry of Health of the Republic of Lithuania  
Arvydas Gabrilavicius. Personal Health Care Department, Deputy Director

### Civic questionnaire filled in by:

- Council of Representatives of Patients Organizations of Lithuania

## REPUBLIC OF MACEDONIA

### Partner Organization:

Center for Regional Policy Research and Cooperation "Studiorum"

[www.studiorum.org.mk](http://www.studiorum.org.mk)

Contact person: Filip Gerovski [filip.gerovski@studiorum.org.mk](mailto:filip.gerovski@studiorum.org.mk)

### Hospital monitored:

- Gynaecology and Obstetrics Clinic in Skopje - Available acute care beds 556

**Ministry:**

Macedonian Ministry of Health, Head of Department for EU integration

**Civic questionnaire filled in by:**

- CRPRC Studiorum

**MALTA**

**Partner Organization:**

**Malta Health Network** <http://www.maltahealthnetwork.org/>

Contact person: Antoinette Zahra [antonia.zahra@gov.mt](mailto:antonia.zahra@gov.mt)

**Hospital monitored:**

- Mater Dei Hospital (Ms. Marion Rizzo CEO (Chief Executive Officer)  
Available acute care beds 887

**Ministry:**

Ministry of Health, Elderly and Community Care

Dr. Miriam Dalmas, Director, Directorate for Policy Development, EU and International Affairs

**Civic questionnaire filled in by:**

- The Malta Hospice Movement

**POLAND**

**Partner Organization:**

Institute for Patient's Rights & Health Education <http://www.prawapacjenta.eu/>

Contact person: Bojarska Magdalena [magda@ippez.org.pl](mailto:magda@ippez.org.pl)

**4 Hospitals monitored:**

- Samodzielny Publiczny Centralny Szpital Kliniczny w Warszawie  
Available acute care beds 1027
- Szpital Kliniczny Dzieciątka Jezus" in Warsaw - Available acute care beds 690
- Szpital Wolski im. dr Anny Gostynskiej Samodzielny Publiczny Zakład Opieki Zdrowotnej  
Available acute care beds 318
- Uniwersytecki Szpital Kliniczny nr 1 im. Norberta Barlickiego" in Łódź  
Available acute care beds 13

**Ministry:**

Ministry of Health - Mrs Barbara Krystyna Kozłowska, rzecznik praw pacjenta (patient's rights ombudsperson), Jakub Bydło, Head of the Department of Social Dialogue

**Civic questionnaire filled in by:**

- Stowarzyszenie Amazonki Warszawa Centrum

## PORTUGAL

### Partner Organization:

**Associação PAR - Respostas Sociais**      [www.par.org.pt](http://www.par.org.pt)  
Contact person: Joana Ferreira Dias Maia Nogueira      [Joana.maia.nogueira@gmail.com](mailto:Joana.maia.nogueira@gmail.com)

### Hospital monitored:

- St. Joseph Hospital – Porto - Available acute care beds 1075

### Ministry:

Portuguese Ministry of Health

### Civic questionnaire filled in by:

- Associação Par – Respostas Sociais

## ROMANIA

### Partner Organization:

#### **Romanian Multiple Sclerosis Society**

Societatea de Scleroza Multipla din Romania      [http://www.smromania.ro/](http://www.smromania.ro)  
Contact person: Cosmina Dudu      [cosmina.dudu@smromania.ro](mailto:cosmina.dudu@smromania.ro)

### 3 Hospitals monitored:

- County Emergency Clinical Hospital, Cluj- Available acute care beds 1454
- University Emergency Hospital, Bucharest - Available acute care beds 900
- Elias University Emergency Hospital, Bucharest - Available acute care beds 700

### Ministry:

Romanian Ministry of Health  
Carmen Sotanga, Direction of health care, Deputy Director

### Civic questionnaire filled in by:

- Federation of Associations for Cancer Patients

## SLOVAKIA

### Partner Organization:

**Združenie na ochranu práv spotrebiteľov v Poprade**      [www.ombudspot.sk](http://www.ombudspot.sk)  
Contact person: Igor Elias      [igor.elias@ombudspot.sk](mailto:igor.elias@ombudspot.sk)

### 2 Hospitals monitored:

- Univerzitná nemocnica Bratislava - Available acute care beds 2928
- Univerzitná nemocnica Louisa Pasteura Košice - Available acute care beds 1516

**Ministry:**

Ministry of Health  
MUDr. Eugen Nagy

**Civic questionnaire filled in by:**

- Združenie na ochranu práv pacientov

**SPAIN****Partner Organization:**

Sociedad Española de Atención al Usuario de la Sanidad [http://www.seaus.net/index\\_0.htm](http://www.seaus.net/index_0.htm)  
Contact person: Fco. Carceles [pcarcelesg@gmail.com](mailto:pcarcelesg@gmail.com)

**8 Hospitals monitored:**

- Hospital Gregorio Marañón de Madrid - Available acute care beds 1540
- Hospital Donostia San Sebastian - Available acute care beds 1150
- Hospital Universitario Virgen de la Arrixaca - Available acute care beds 863
- Hospital universitario Son Dureta Palma de Mallorca/ I .Balears - Available acute care beds 838
- Hospital Clínico Universitario Lozano Blesa de Zaragoza - Available acute care beds 800
- Hospital universitario Germans Trias i Pujol Badalona/ Barcelona - Available acute care beds 638
- Hospital San Jorge de Huesca - Available acute care beds 315
- Hospital Moises Brogi de Sant Joan de Espi - Available acute care beds 310

**2 Ministry\*\*:**

- Ministry of Health -Servicio Aragones  
Teresa Antoñanza, Direccion General de Atención al Usuario/Cosejeria de Salud
- Ministry of health-Comunidad Valenciana  
Cristina M<sup>a</sup> Nebot Marzal, Jefa del Servicio de Coordinación de la Atención al Paciente/Dirección General de Calidad y Atención al Paciente/Consejeria de Salud

**2 Civic questionnaires filled in by:**

- Asociación de Personas con Linfedema de Aragón, ADPLA
- Alcer Ebro Civic organization

**UNITED KINGDOM****Partner Organization:**

Pelvic Pain Support Network <http://www.pelvicpain.org.uk/>  
Contact person: Judy Birch [judy\\_b@dsl.pipex.com](mailto:judy_b@dsl.pipex.com)

**5 Hospitals monitored:**

- Barts and the London - Available acute care beds 1024
- University Hospital of Wales - Available acute care beds 1000

- St George's Healthcare NHS - Available acute care beds 1000
- Royal Infirmary of Edinburgh - Available acute care beds 887
- St Mary's – London - Available acute care beds N/A

## **2 Ministry:**

- English/Welsh Ministry of Health

Sophia Callaghan Consultant in Public Health, Liz Kite Deputy Director of Corporate Affairs, Andrea O'Connell Deputy Director of Quality Improvement, Fiona Richardson Deputy Director of Specialist and Tertiary Commissioning, Matt Wain Head of Patient Safety, Ebi Sosseh Equalities and Human Rights Lead.

- Scottish Ministry of Health

Alastair Pringle, Head of Patient Focus and Equalities, Directorate of healthcare policy and strategy

## **2 Civic questionnaires filled in by:**

- Poole Hospital NHS Trust + " Patient Advice and Liaison Service " PALS + Pelvic Pain Support Network
- NHS Lothian (Scottish)

**ITALY**

## **Partner Organization:**

**Cittadinanzattiva Onlus**     [www.cittadinanzattiva.it](http://www.cittadinanzattiva.it)   [www.activecitizenship.net](http://www.activecitizenship.net)

Contact person: Daniela Quaggia     [d.quaggia@activecitizenship.net](mailto:d.quaggia@activecitizenship.net)

## **5 Hospitals monitored:**

- Hospital San Filippo Neri, Rome - Available acute care beds 367
- Sandro Pertini, Rome - Available acute care beds 357
- Policlinico Tor Vergata - Available acute care beds 341
- San Giovanni Bosco, Turin- Available acute care beds 326
- Presidio Ospedaliero di Acireale - Available acute care beds 119

## **Ministry:**

Ministry of Health,

Alessandro Ghirardini, Head of Quality Unit – General Directorate for Health Planning

## **Civic questionnaire filled in by:**

- Cittadinanzattiva Onlus

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## NATIONAL SOURCES

The partner organizations have integrated the missing data in the official statistics by consulting national authorities and sources. The full list of these additional sources is the following:

9. (Right to safety)  
Finland: *Finnish Red Cross Blood Service*  
Latvia: *National Blood Service*
10. (Right to innovation)

- a. Availability of medical technology (num. per million of population): Computer Tomography Scanners - MRI units - Radiation therapy equip. – Lithotriptors - Mammographs

Bulgaria: *Ministry of Health, Concept of Hospital Restructuring in the County, 2010.* ( *These data refer to hospitals only; no data on ambulatory facilities*).

Germany: *Mammography Screening Service*

Latvia: *The medical registry "LATMED": the database maintained by the State Agency of Medicines.*

Lithuania: *The State Health Care Accreditation Agency under the Ministry of Health*

Malta: *Medical Imaging Department, Mater Dei Hospital; to Radio Therapy Department, Sir Paul Boffa Hospital; to Urology Department, Mater Dei Hospital; to the Department of Environmental Health.*

- b. Availability of new pharmaceutical drugs for cancer through the national health system (year of launch date): Capecitabine – Gemcitabine – Imatinib/irinotecan – Oxaliplatin – Rituximab – Trastuzumab – Vinorelbine

Bulgaria: *Roche Bulgaria Product manager. Ordinance 23 of Ministry of Health; State Gazette. Elli Lilly Product manager; Novartis Product manager; National Drug Agency files.*

Cyprus: *The magazine "the scanner" February 2010; Department of inspection of machinery, Ministry of labour Panicos Demetriade; Oncology Centre of bank of Cyprus, director Alecos Stamatis; Pharmaceutical services Ministry of Health – Kontomeniotis.*

Estonia: *Environmental board. National Institute for Health Development. State Agency of Medicines.*

Finland: *Finnish Medicine Agency; NamWeb; National Medicine Database*

Hungary: *Országos Gyógyszerészeti Intézet – web site*

Lithuania: *The State Medicines Control Agency under the Ministry of Health.*

Malta: *Directorate for Pharmaceutical Policy and Monitoring, Ministry of Health, Elderly and Community Care.*

Slovakia *the State bureau for control of drugs – database of registered drugs.*

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