PATIENTS' RIGHTS IN EUROPE:
Civic Information on the Implementation of the European Charter of Patients' Rights

Final Report
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In cooperation with

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SECOND PART

4. Analysis of available statistic data

In order to collect the most comprehensive information about the level of implementation and the effectiveness of the 14 rights established in the Charter of Patients' Rights around Europe - in addition to the analysis of data from the interviews and the visits to the hospitals presented in the following chapters - an analysis of the comparable official data on issues regarding patients' rights was conducted by Dr. Fiorenza Deriu, from the Department of Demography of the Faculty of Statistics of the Rome University "La Sapienza". This study, enclosed in the report (see Appendix B), is the main reference of this chapter[1].

The main aim of this chapter is to verify, through the analysis of the data from the existing health statistics, the state of the Charter's rights implementation, by looking at the indicators, which directly or indirectly concern them. Starting from the indicators that exist at the European level[2] to monitor the many aspects of existing healthcare systems in the different EU countries, it was possible to identify a subset of indicators to measure the implementation of the rights established in the Charter (see table below).

Table 1.Available indicators in official statistics on the 14 Charter's rights

Rights of the Charter	*Available indicators*
Right to preventive measures *(Right n. 1)*	▪ Vaccinations against the principal infant and non infant infectious diseases; ▪ Preventive and screening tests for cardio-circulatory diseases, breast cancer and tumor markers; ▪ Hypertension monitoring; ▪ Prenatal care coverage; ▪ Monitoring of life styles, such as smoking, alcohol, and nutrition; ▪ Indicators of healthy life expectancy at birth and at 60 years; ▪ Indicators of the incidence for some infectious (hepatitis, pertussis, measles, rubella, mumps, tuberculosis, HIV-AIDS) and tumoral (breast, lung, digestive track, colon, etc.) diseases.
Right to access *(Right n. 2)*	▪ Public hospital facilities (number of beds per ward); ▪ Personnel employed in these facilities (doctors, pharmacists, dentists, nurses, midwives, also in relation to labor force); ▪ Frequency of the consultation of the general practitioner or a specialist by people; ▪ Hospital discharges for all principal diagnostic categories according to the International Classification of Diseases (ICDIX last revision); ▪ Time taken to reach hospital facilities, general practitioners and healthcare centers (out-patients clinics); ▪ Consumption expenditure of private households for health (at current prices and in percentage of total household consumption expenditure); ▪ Social benefits for sickness and health care as far as for disability in percentage of total benefits.
Right to information *(Right n. 3)*	▪ Population using internet to look up information on health, diseases, injuries and nutrition, divided by type of activity (active population, students and by age categories); ▪ Diffusion of the use of telemedicine services; ▪ use of the web to set up appointments with practitioners and specialists.

[1] Every information and data that are outside doctor Deriu's study will be explicitly quoted in the text.
[2] The only sources of structured and comparable statistics about patients' rights nowadays are Eurostat, Oecd and Word Health Agency.

Right to consent *(Right n.4)*	**Indicators to monitor the implementation of the right to consent are not available.**
Right to free choice (*Right n. 5*)	▪ Frequency of the consultation of the general practitioner or a specialist by people.
Right to privacy and confidentiality (*Right 6*)	**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**
Right to respect of patients' time *(Right n. 7)*	▪ The only information available has been extracted from the Hit Summary of the European Observatory on Health Care Systems or from national reports.
Right to quality standards (*Right n. 8*)	**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**
Right to safety (*Right n. 9*)	**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**
Right to innovation (*Right n. 10*)	▪ Diffusion of organ transplants; ▪ The average survival rate after five years for heart, lung, kidney and liver transplant patients. **At present, there is no available official and comparable information at the intra-European level on other innovative intervention procedures.**
Right to avoid unnecessary suffering and pain (*Right n. 11*)	▪ Use of opiates in pain therapy[3]. **With respect to the right to avoid suffering, no comparable indicators have been identified on the spread of palliative cures or access to such treatments.**
Right to personalized treatment (*Right n. 12*)	Indirect indicator: ▪ Average length of stay in hospitals. **No other indicators have been identified**.
Right to complain (*Right n. 13*)	**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**
Right to compensation (*Right n. 14*)	**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**

The existence and the scores[4] of the indicators analyzed allow one to assess the level of implementation and the effectiveness of each right of the Charter. However, before analyzing each right separately, it is possible to make an initial observation from the analysis of the table above, the presence of just a limited number of indicators for each right or rather the unavailability of indicators for some rights reveal the existence of problems and confirm the lack of a base for the implementation and the monitoring of the rights in question.

1. Right to Preventive measures

Health prevention comprises measures both to avoid the emergence of a number of diseases (primary prevention) through the control and the reduction of the risk factors and to stop its spreading or to reduce its consequences once they have occurred (secondary and tertiary prevention).

Available indicators that refer to the primary prevention are the percentage of coverage of vaccinations against the principal infant and non-infant infectious diseases, which are greater than 90% and cover almost the entire population[5].

The state of secondary prevention can be analyzed through data about:

- screening tests for cardio-circulatory diseases, breast cancer and tumor markers;
- hypertension monitoring;

[3] This indicator is not described on doctor Deriu's analysis.
[4] In the part that follows, data refers to the 14 countries that participated to this study, therefore the means calculated are not that of EU-15.
[5] Data from the *Health For All Database*, World Health Organization, 2003

- prenatal care coverage;
- incidence for some tumor diseases.

In particular, information[6] can be found on persons who have taken preventive exams using instrumental-diagnostic and manual instruments (mammography and manual breast controls) or who have participated in screening programs for the control of heart conditions and of the main tumor indicators.

The prevention of breast cancer seems not to be too widespread: the percentage of women reporting preventive examinations is, on average, low even for the older aged and most at risk categories (45,1% of women reporting preventive examinations as mammography by x-ray and 31,9% of that reporting preventive breast examination by hand). The same could be said about the participation in screening programs for hearth check-up and cancer test, to which, on average, respectively only 4,7% and 5,4% of European population between the age of 45 and 54 participate.

All the European countries encourage healthy life styles and, with respect to smoking, it seems that where information campaigns have been conducted with greater intensity they had been successful (Finland, Portugal and Italy).

Looking at country based data, Austria is the only European country in which the primary and secondary preventive system is guaranteed in all phases of life cycle while Netherlands seems to be the country more sensitive with respect to developing a culture of prevention.

Available data, in particular regarding the primary prevention, seem to show that there is an increasing chance for *the right for every individual to a proper service in order to prevent illness* to be carried out, thanks to the widespread culture of prevention existing all over Europe.

2. Right to access

Existing available indicators that could be related to the right of access to the health service are:

- number of beds per ward in public hospital facilities and of personnel employed in these facilities (doctors, pharmacists, dentists, nurses, midwifes also in relation to the labor force)[7];
- number of hospital discharges for all the principal diagnostic categories according to the International Classification of Diseases (ICDIX last revision)[8];
- frequency of the consultation of the general practitioner or a specialist by people[9];
- time taken to reach hospital facilities, family doctors and healthcare centers (outpatients clinics)[10];
- consumption expenditure of private households for health (at current prices and in percentage of total household consumption expenditure);
- social benefits for sickness and health care as far as for disability in percentage of total benefits.

[6] Coming from the 2002 Eurobarometer Survey, with the data standardized within the Eurostat database

[7] Data come from Eurostat database that collected mainly the administrative records from several European Union member States, about the number of hospital beds by type of stay, the number of doctors, of chemists and paramedical and assistance staff. This fact required caution when comparing these data as each national reporting system is affected by its own specific organization.

[8] Data come from Eurostat database that collected mainly the administrative records from several European Union member States. (see the note 6).

[9] Data come form the 2001 ECHP UDB European Community Household Panel, whose data are harmonised in the Eurostat database

[10] Data come from 1999 Eurobarometer survey, whose data are harmonized in the Eurostat database.

All over Europe, especially in the North, there is a significant reduction of the number of hospital beds available due to the policy of expanding outpatient assistance as well as day-surgery services (such as in Finland and Denmark) or to the policy of improving the efficiency and effectiveness of services, rationalizing the resources (such as in Italy). These reductions of hospital beds have been counterbalanced by the supply of alternative services (offered even by the private and non-profit sectors) limiting inconveniences everywhere except Spain, where it has led to an increase in waiting time and of people sharing the same hospital room, and Portugal, where the structural resources are inadequate and not distributed on the territory.

On average, the number of doctors per 100,000 inhabitants at European level is 370,0 with 8 countries out of 12 (for the other 2 countries this data is not available under this level). In all European countries the number of medical personnel seems to be lower than the actual demand: even in Spain and Italy, where the number of doctors is high and exceed the demand, there is a lack in qualified nursing personnel.

Analyzing the number of hospital discharges per 100,00 inhabitants for the different diagnostic categories (ICD diagnosis, virus infections, malignant neoplasms, Parkinson's disease, multiple sclerosis and complication of pregnancy, childbirth and puerperium), it seems that the lower rates of discharges are that of the highly invalidating diseases (such as Parkinson and multiple sclerosis). It means that there is a recourse to family assistance services and assisted healthcare residence facilities, that is however impossible to quantify because of the lack of available data.

During 2000, on average, 40% of European citizens had three or more consultations of general practitioners (in Austria, Belgium and Italy over 50% of population), and 16,8% of medical specialists (in Austria, Belgium and Greece more than one fifth of population).

Data about the easiness of access to the treatment centers show that most of the population (on average, about 80%), including people over the age of 65, is able to reach their general practitioner or the local ambulatory clinic in quite always less than 20 minutes, while reaching hospitals needs less than 20 minutes to about 50% of population, even the elderly. Despite the general proximity of treatment services, according to available data, there are some structural problems that don't allow European countries to implement effectively the right of access to the health services. Furthermore, it is noticeable that the only kind of available information refers to what the healthcare system offers without being able to measure the actual ability for patients or citizens to access the healthcare system and without taking into account the aspects referring to the actual demand of healthcare service.

3. Right to information

Right to information has to do with different types of information: technical and specific knowledge about health and the existence of health services available to citizens.

Much progress has been made with respect to these kind of information, through their dissemination on the web: most European countries possess information systems that help direct the citizen/patient to the nearest available and operating health services. Young people, in particular students, are the ones benefiting the most from the opportunities offered by internet and the new technologies when researching information in the field of medicine, nutrition, on accidents and on diseases, mainly in the North European countries and in the UK, where more than 50% of students use internet to access health information, while in the Continent and in the Mediterranean this ratio decreases to 6%[11].

[11] Data come from the 2003 Community Survey on Information Technologies (ICT)

However, these web-based instruments are only accessible to those with a computer and access to Internet, excluding the more vulnerable and fragile sectors of the population who do not have such tools or are simply too old to learn how to use them.

The available data or rather the lack of data about the right to information, in this case, do not allow one to evaluate how the right to be informed is implemented.

4. Right to consent

Data are not available regarding another fundamental aspect that also regards the right of information. This refers to the patients' actual knowledge and understanding of their state of health and illness, in order to *actively participate in the decisions regarding people's health* in order to give "informed consent".

Information is not available neither about patients' likelihood to be informed on their illness, nor the actual possibility of accessing to their own medical records and asking for their correction in case of errors, or about patients' understanding of medical language.

5. Right to free choice

Availability of data regarding the degree of implementation of *the right to free choose from among different treatment procedures and providers on the basis of adequate information* is limited to one indicator that concerns the share of the population that turns to the family doctor or specialized doctor over a number of times[12], that could be used as indicator of the possibility of the citizen/patient to turn to a doctor regarding onset diseases. During 2000, on average, 40% of European citizens had three or more consultations of general practitioners (in Austria, Belgium and Italy over 50% of population), and 16,8% of medical specialists (in Austria, Belgium and Greece more than one fifth of population).

Apart from this indicator, there aren't any others capable of assessing the degree of implementation of the right to free choice. As stated in Dr. Deriu's analysis, the only way to evaluate this right, at least in theory, is to study the different European healthcare systems[13], that seem to adopt different modalities with respect to the implementation of this right: some of them have introduced gate-keeping mechanisms which force patients to go through a number of compulsory filters before accessing particular therapies or specialized doctors; others foreseen the freedom of the citizen/patient to go autonomously to its family doctor, the specialized doctor, the outpatient service or the hospital.

6. Right to Privacy and Confidentiality

Indicators capable of assessing the degree of implementation of the right to privacy and confidentiality have not yet been identified.

7. Right to Respect of Patients' Time

The individual's right to *receive necessary treatment within swift and predetermined period of time* has been analyzed looking at available data about the waiting times/waiting lists[14]. It is a critical problem in most of the European health systems and, during the last years, almost all the European

[12] obtained from the ECHP (see note 7).
[13] about which it is possible to acquire information through the "Hit Summary" published by the European Observatory on Health Care Systems.
[14] As official European data about the issue of waiting time are not available, the data contained in this paragraph comes mainly from the Hit Summary of the European Observatory on Health care Systems or from the national reports.

countries are committing themselves to solve it, thanks to the implementation of specific policies or general reforms to the health care systems.
Some of them are having success:

- Finland, waiting times have been significantly reduced thanks to policies which have focused on establishing medical teams which have been assigned to a precise and territorially limited share of the population;
- Denmark, in July 2002, a law came into force establishing a limit of two months for the period in which patients shall make use of the requested health service;
- Sweden, in 1997, it was decided that after a defined waiting time the health service can be offered by another county and measures towards the strengthening of the territorial networks and the cooperation between family doctors and specialized doctors were introduced;
- Belgium, the health system is being subjected to a number of reforms whose main advantages include the reduction of the waiting times;
- Netherlands, in 2004 the Dutch government, following the adoption of a series of measures proposed by an ad hoc commission, has seen an improvement in the situation: 68% of those signed up on the waiting lists can today receive the requested service within 4-5 weeks;
- Spain, since 1996, a strategy of territorial decentralization has been adopted which has led to a reduction, on average, of 70% of waiting times in the ten regions that before the completion of the devolution process had been centrally administered;
- United Kingdom, the speediness of waiting lists represents an important efficiency indicator of the health system: for its monitoring, an indicator that measures the number of patients in waiting lists for 100.000 inhabitants is calculated (data not available).

On the contrary, despite their efforts to reduce waiting time, in Portugal and Italy, whose reform agendas in 2001 and 2002 focused on this issue, waiting lists remain an unresolved issue.

Information collected show that even though the margin of implementation of the right to respect patients' time is increasing all around Europe, more needs to be done much more in the future.

8. Right to quality

Indicators capable of assessing the degree of implementation of the right to quality services have not yet been identified.

According to Dr. Deriu's study the respect of this right requires the establishment of standards to which the health infrastructures and health professionals should abide by from a scientific, technical, human and relational point of view. Presently, the establishment of quality standards has been one of the key issues of the political agenda of many governments, even if it is not always an easy task to solve due to the concurrent pressure to balance national budgets. But, at the moment, it is not possible to assess the degree of implementation of this right at the European level through indicators linked to these quality standards.

9. Right to safety

Indicators capable of assessing the degree of implementation of the right to safety have not yet been identified.

10. Right to Innovation

An appropriate indicator to monitor the access to highly innovative health services is represented by the number of transplants carried out per million of inhabitants[15] and the average survival rate after the operation[16]. Nowadays, transplants are a very sophisticated therapy that nevertheless should be considered a normal and not an extraordinary procedure. While, on average, kidney and liver organ transplantations are quite widespread, respectively with 33,3 and 12,1 transplantations per 1 million of inhabitants, heart, lung and pancreas transplants are less diffused, respectively with 4,6 operations, 2,8 and 1,3 per 1 million inhabitants. The average survival rate after five years for patients from heart transplants is 80%, from lung transplants is 50-60%, for kidney is 70 to 90% and for liver transplants is 70%. At the national level, in the Netherlands there is a commission for the evaluation of the new technologies to help select those which will ensure high quality standards and the Health Insurance Fund also provides coverage for certain tissue and organ transplants. Nevertheless, policies aimed at strengthening and spreading a culture of organ donation are not too diffused, such as in Italy, where there is even a problem concerning waiting lists for transplantations.

The implementation of the right to innovation is often hindered by economic and financial aspects: they represent an indisputable limitation to certain choices, but should not influence nor prejudice the right of the citizen/patient to access to innovative procedures and technologies, despite their costs. In this respect, the Swedish "ethical platform" is an example, which deliberately guarantees medical services beyond any economic criteria. This system, although it makes the administration of public spending quite difficult (health expenditure is the highest among the former 15 members' EU in terms of % of GNP with 8.9%), is extremely respectful of the dignity and human rights of each individual.

11. Right to avoid unnecessary suffering and pain

The right to avoid as much suffering and pain as possible, in each phase of individual's illness consists in palliative treatment and pain therapy. The palliative treatment is directed to the patients affected by a disease that no longer responds to any other form of specific treatment.

These matters are well defined and studied: implications of the palliative treatment are accurately described by the National Council for Hospice and Palliative Care Services WHO-OMS of 1990 while in "*Palliative Cancer Care. Policy Statement based on the recommendations of a WHO consultation",* the World Health Organization conducted an exhaustive survey of the use of opiates in pain therapy. This indicator, which is considered to assess the pain management in healthcare system[17], occur in different amount around European countries: if varies from 39,315 daily doses per 1 million inhabitants in Ireland to a lower amount in the Netherlands (4,234), Austria (3,988), Finland (3,256), Italy (1,890), Portugal (1,723) and Greece (1,551)[18].
The most appropriate facilities providing palliative treatment are the hospitals of palliative treatment and the hospices. Nevertheless, in many countries, it is difficult to access these treatments or to centers specialized in pain therapy. The most common barriers to the use of such treatments are to be found in the insufficient economic resources available, in the cultural representation of pain as an unavoidable element of the disease, in the inadequate training of doctors on this issue and in the resistance to utilizing opiates, etc.

[15] Data come from 2003 Eurostat Database.
[16] Data come from Italian health website, *Nuovi farmaci che rendono più sicuro il trapianto, Servizio Sanitario Web*, by Didamed, 2004, while the International Agency for Research on Cancer (IARC) provides the survival indicators for all tumors for adults and children in the EU countries, described in IARC (1999) cfr. www.dep.iarc.fr/accis.htm.
[17] This indicator is monitored by the International Narcotic Control Board.
[18] OMS (2000).

According to Dr. Deriu's study, an indicator of the degree of implementation of this right could be the spread of palliative cures or access to such treatments, but no comparable information at the European level have been identified. The indicator, relating to the average amount of morphine per person utilized for therapeutic purposes[19], was identified from a ranking of 65 countries worldwide (of which 12 were considered for this study.

12. Right to personalized treatment

As stated in Dr. Deriu's study, monitoring the implementation of the individual's right *to diagnostic or therapeutic programs tailored as much as possible to his/her needs* is not easy, mainly due to the fact that each patient is a different case and it is difficult to set general standards. But looking at the available information on the health systems' fundamental orientations for treatment (for instance the priority or not of economic criteria over citizenship ones, based on rights) it is possible to use indicators that refers to the way in which patients are considered and, indirectly, to the right in question.

As a matter of fact, in different European countries some policies have been implemented to provide health assistance in the patients' home in order to guarantee their stay in the family. Available information referred to this issue are the average stay in hospital of patients by each type of diagnosis[20] (with the shortest length of less than a week for Italy and Sweden and the longest of 8-10 days for Finland, Austria and Netherlands) and the development of home care system around European countries or of equivalent measures such as specialized centers (for example, with Italy where the networks of assisted healthcare residences and social support centers for long admittance patients are predicted to increase).

Though hypothesizing that home care or turning to specialized centers allow more appropriate and specific care and treatments to patients, however, this kind of information is not sufficient for a comprehensive analysis of the state of the implementation of the right of personalized treatment.

13. Right to complain

It was not possible to identify official data that could provide useful information to monitor possible violations of this right.

14. Right to compensation

Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.

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Analyzing information collected with respect to the 14 rights of the Charter, three kinds of remarks can be made: first, regarding the availability of information on patients' rights; second, on the kind of information they provide and third about the contents and typology of the available information.

Regarding the first, it emerges that in only a few cases official data are available that allow one to assess the state of implementation of the right or, even if not sufficient, consent at least to hypothesize on the right's future development *(right to preventive measures, right to access and right to information*). However, sometimes, even if some data are available, they are insufficient to

[19] Developed by the International Narcotic Control Board in 1995, on the basis of a survey conducted in collaboration with WHO and 65 national Government.

[20] Data come from administrative sources, made with specific goals, different from country to country. For this reason comparison between countries shall be made very carefully.

assess the degree of implementation of the right (*right to free choice*) or too specific to be significant (*right to innovation*) and, therefore, need to be integrated with other information, such as data about new specific indicators (*right to access*). Moreover, available data are not often comparable at the European level and come from non-official sources of data (*right to free choice, right to respect of patients' time, right to personalized treatment*).

But, in almost half the cases, indicators useful for evaluating the level of implementation of the rights in question are inexistent and ad hoc indicators or new techniques of data collecting and analysis need to be created (*right to consent, right to privacy and confidentiality, right to quality standards, right to safety, right to complain, right to compensation).*

Regarding the second consideration, the main problem of concerning the official information is that it does not contain information on patients' rights. This is probably the result of a specific focus given to this information. Regarding this it can be mentioned, attention on outputs (what health systems have done) rather than on the outcomes (what actually happened to people); a priority given to the offer of services rather than on the demand and/or the encounter between offer and demand; an effort to identify macro-phenomena while the actual condition of patients is made of several micro-phenomena that even have a relevant quantitative dimension.

Regarding the third consideration, instead, some strengths and weaknesses about the implementation of patients' rights do emerge. The strengths regard the positive evolution that involves some rights such as the right to preventive measures, the right to information and the right to respect of patients' time. Even if the implementation of the last two rights still needs to be demonstrated effectively, some margins of improvement seem to exist. There are, however, weaknesses coming from the existing indicators' analysis. The main weakness regards the access to health services, increasingly difficult especially for patients with more serious diseases. Also information coming from data related to the right to innovation and the right to avoid pain, though very limited, confirm the existence of critical situations.

5. Information coming from National Legislations

The second source of information with respect to the state of patients' rights in Europe has been the legislation regarding these rights that exist at the national level. Partner organizations were asked to check for the existence of at least one law or regulation for each right in their countries. When possible, partners' data were verified in the light of a recent mapping exercise on the National Health Service carried out by the European Commission's High Level Group on Health Services and Medical Care, which partly covers patients' rights (European Commission 2006d)[21].

It must be stressed that this was not designed as an exhaustive research on the legal framework of patients' rights, but rather as part of this more general research on the degree of attention towards patients' rights in some EU countries. For this reason, what has been considered as relevant from the point of view of the countries' attention to rights was simply the existence of any national legal recognition, whatever it maybe whether constitution, general law, specific legislature, regulations, Charters etc. It is important to mention that the differences in legislation habits, such as the distinction between common law and continental law, characterizing the EU countries, were not taken into consideration neither was it be possible to verify to what extent the actual legislation in the countries surveyed favors the implementation of these rights.

The existence of only *one law* (whatever type: constitutional, general or specific kind) or regulation was considered an indicator of attention to patients' rights because the research team considered, there exists no direct relation between the number of laws and the implementation of the right. In other words, more laws does not necessary imply a greater level of attention to (and obviously not even a greater implementation of) patients' rights. One good and adequately implemented law can indeed be more relevant and effective than several specific laws and regulations on the same right that remains only on paper.

The following table summarizes the partners' information reported on the existing legislation.

Table 2: Number of countries where at least one national legislature exists regarding the 14 Patients' Rights

Right	**No. of countries**
Information	14
Consent	14
Quality	14
Prevention	12
Access	13
Privacy	13
Complain	13
Personalized treatment	11
Choice	10
Safety	11
Compensation	11
Avoid Pain	9
Innovation	7
Time	6

The rights to information, consent, quality and prevention are legally recognized in all the surveyed countries. In general, patients' rights show a high level of legal coverage. The three rights recognized less in national legislations are the right to avoid pain, the right to innovation and the right to time. The right to time is acknowledged in less than half of countries, while the right to innovation in hardly more than half of them.

[21] In UK this part of the research was not carried out by the partner organization but rather the research team collected the data from the already mentioned European Commission (2006d) and other national sources available on the Internet.

Let us now consider the existence of norms protecting patients' rights in the 14 countries. They are highlighted in the following table.

Table 3. Number of rights recognized in at least one legislative act by country

Country	No. of rights
Greece	14
Denmark	14
Italy	14
Portugal	14
Finland	13
France	12
Netherlands	12
Germany	11
Sweden	11
Austria	10
Spain	10
Ireland	8
Belgium	7
UK	8

In four countries (Greece, Denmark, Italy and Portugal) it results that all the 14 patients' rights have some legal recognition while in Ireland and Belgium only 8 out of the 14 rights have such recognition. As it was mentioned above, in some cases these differences could be due to different legal systems beside legislative customs.

What can be taken from these data can be summarized in two main points.

The first, at the national level in the majority of countries there seems to exist a good degree of legal coverage of patients' rights, observing a relevant level of attention.

The second point, it cannot be concluded that there is a general correlation between the legal recognition of patients' rights and their actual implementation. This means that a right established by law is not necessarily, for this reason, fully implemented in practice. As illustrated in the next section, in fact a number of rights that are fully or almost fully recognized in national legislations are not implemented well. On the other hand, it emerged in countries where several problems or incumbent risks do exist, patients' rights were widely recognized, and vice versa.

It is evident that laws and norms should be neither proclaimed nor applied only by tribunals, but also enforced through appropriate and effective policies, initiated and supported by all actors of health care: governments, citizens' organizations, professionals, third payers, pharmaceutical and other private companies, trade unions, the media, legal systems and the scientific community.

Another piece of information reported regards the kind of legal documents in which patients' rights were recognized. Partner organizations were asked to indicate if the rights were set up in a Constitution or stated as constitutional principles, in a general framework law, in specific legislation, in administrative regulations or in a charter of rights (intended as an official document). Since the question was if each rights was recognized in at least one legal document, we cannot consider the partners' answers as representing the entire national legislative framework. Nevertheless, the amount of information they provided has been so numerous (on average, they mentioned 21,6 legal documents for each country and 20 of them for each right) that reporting them can only enrich the available information on legislation.

The aggregated results for this information are summarized in the following table.

Table 4. Kind of legal documents where patients' rights are established at national level

Kind of documents	No. of docs	%
Constitutions	58	20,56
General laws	91	32,26
Specific laws	84	29,78
Administrative regulations	23	8,15
Charters of rights (official)	26	9,21
TOTAL	282	100,00

It can be noticed that more than 60% of documents mentioned are laws, of general or specific scope, while one fifth of documents are of constitutional rank, while a little more than 8% are regulations of administrative rank and more than 9% are official charters of rights. The ratios above mentioned can be better seen in the following chart.

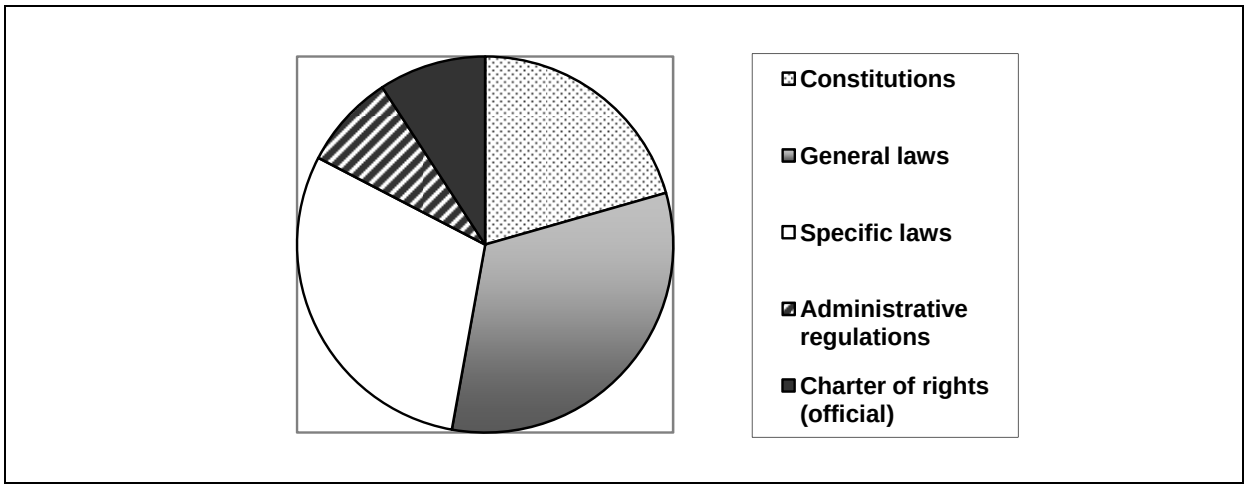

Chart 1. Kind of legal documents in which patients' rights are established at national level

A number of remarks can be made on these data. The first one is that, since constitutions are mentioned only in one fifth of the cases, it could be considered that patients' rights are not generally considered directly part of basic or fundamental rights, as it is in the European Charter of Patients' Rights, based on the EU fundamental rights. Secondly, the low number of administrative regulations is ambivalent in that it could mean on the one hand, that patients' rights are not reduced to just an administrative matter, while on the other hand they could risk remaining only on a level of principle or declaration. Finally, the amount of general and specific laws establishing patients' rights (more than 60% of all the documents reported) attests a relevant degree of attention to patients' rights, at least as a matter of principle.

In addition, with such a large number and diversity of laws that entitle patients' rights one can imagine that it must be quite difficult for citizens to know and understand their rights as citizens in regards to health and healthcare services.

Finally, this brief overview also allows us to see that the majority of rights (and in some cases all the 14 rights) are in some way legally recognized in each country. Therefore one could conclude that the European Charter in most part has legal foundation in the majority of countries studied.

6. The Civic Audit Information

As described in chapter 2, in order to collect information about patients' actual conditions at the European level, the research developed a series of actions, based on the civic audit methodology used by Cittadinanzattiva. These activities are the following:

- Direct observation of 3 main hospitals in the capital of each European country selected (DOH);
- Interview with hospital authorities responsible for management of the 3 hospitals that were directly observed (HA);
- Interview with 6 key persons operating in health care at the national level (KP);
- Questionnaire for partner organizations' to answer similar to the above mentioned ones (PO).

During these different activities, information was gathered on 174 indicators regarding the 14 patients' rights, verifying the existence or not of procedures adopted by the hospitals and health care services to guarantee the implementation of the rights in question.

This information collected, regarding the 14 Charter's rights, is analyzed on a right-by-right base. For each right the main critical and positive elements that can be extrapolated from the data collected are summarized.

In the section on each right are the following:

- **A List of indicators** used to verify the implementation of the right and grouped according to the source of information;
- **IAC Countries' score** which illustrates the score obtained for this right by each country according to the methodology described in chapter 2.5 Index of Actual Condition (IAC).
- **IAC Right score** reports the overall score this right obtained as well as the score range, which consists in the maximum and minimum points obtained by the other rights.
- **Critical elements and positive elements** that emerge in the implementation of the right**,** according to the different sources of information (DOH and HA; KP and PO), are reported. Specifically, there are:
    1. Among the Critical Elements:
        - facts and events with positive meaning that are observed in a limited number of countries (4 or less);
        - facts and events with negative meaning observed in a large number of countries (10 or more);
        - highly negative facts and events that were observed in a number of countries (less than 10).
    2. Among the Positive Elements:
        - facts and events with negative meaning observed in a limited number of countries (4 or less);
        - facts and events with a positive meaning in a large number of countries (10 or more).

- **Violations of this Right** that key persons (KP) and partner organizations (PO**)** knew – either directly or indirectly – during the last year are reported in a list by country.
- **Elements characteristic of the countries with the lowest score,** whether either alone or in combination, have been report and when it was possible the countries with these characteristics have been identified.
- Finally, there is a **brief comment** containing the main conclusions regarding the information collected.

6.1. Right to Preventive Measures

Every individual has the right to a proper service in order to prevent illness

Indicators Used

Direct Observation Hospital (DOH)

- Material on Prevention for the public *(Y/N)*
  - *early diagnosis of cancer affecting women*
  - *prevention of sexually transmitted diseases*
  - *dental prevention*
  - *quitting smoking*
  - *treating drug dependence*
  - *cardiovascular disease prevention*
  - *neurovascular disease prevention*
  - *domestic and recreational accidents*
  - *nutrition*

Hospitals authorities responsible for hospital management (HA)

- Primary and secondary prevention program *(Y/N)*
  - *cervical cancer PAP*
  - *colorectal cancer FOBT*
  - *breast cancer mammography*
  - *hypertension*
  - *lipid disorders*
  - *amblyopia and strabismus*
  - *diminished visual acuity*
  - *drinking problems*
  - *HIV/AIDS*
  - *other sexually transmitted diseases*
  - *smoking*

Key persons operating in health care at the national level and partner organizations (KP)

- Screening programs currently available free of charge in the health care system *(Y/N)*
  - *cervical cancer PAP*
  - *colorectal cancer FOBT*
  - *breast cancer mammography*
  - *hypertension*
  - *lipid disorders*
  - *amblyopia and strabismus*
  - *diminished visual acuity*
  - *drinking problems*
- Public communication caimpagns *(Y/N)*
  - *HIV*
  - *early diagnosis cancer affecting women*
  - *fight against smoking*
  - *alcohol abuse*
  - *nutritional abuse*
  - *depression*
  - *heart disease*
  - *domestic accidents*
  - *road safety*
  - *dental care*

IAC - Countries' Score

Preventive Measures	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	-	+-	-	+-	+	-	-	-	-	+	**-L**	+-	-	+*
KP and PO	+	+-	-	+-	+	+	+-	+	+	+	+	+-	+	+
	1	1	0	1	2	1	0	1	1	2	1	1	1	2

DOH: Direct Observation in Hospitals- HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA= only from one hospital L = Hospital Authorities missing

IAC - Right Score:

Prevention 15 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Direct Observation in Hospitals and Hospital Authorities

The results are:

- Limited diffusion of the following free primary or secondary prevention programs currently running in the hospital:
  - Screening programs for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (available only in *Belgium, Germany, The Netherlands, UK*);
  - Screening programs for hypertension in adults aged 18 and older (available only in *Belgium, The Netherlands, UK*);
  - Screening programs to detect amblyopia and strabismus for all children prior to entering school (available only in *Sweden, UK*);
  - Screening programs to detect drinking problems in adult and adolescent patients (available only in *Belgium, France, UK*);
  - Prevention programs for HIV/AIDS (available only in *Belgium, France, Greece, UK*);
  - Prevention programs for other sexually transmitted diseases (available only in *Belgium, France, UK*).

- Limited distribution of material on prevention for the public produced by the national health services on the following topics:
  - Early diagnosis of tumors affecting women (available only in *Finland, Ireland, The Netherlands, UK*);
  - Prevention of sexually transmitted diseases (available only in *France, The Netherlands, Spain, UK)*;
  - Dental prevention (available only in *France, The Netherlands, UK*);
  - Neurovascular disease prevention *(*available only in *The Netherlands, UK)*;
  - Domestic and recreational accidents (available only in The Netherlands, UK);
  - Nutrition *(*available only in *Finland, France, The Netherlands, UK)*;

Key Persons and Partner Organizations

The results are the following:

- Limited availability of the following free primary or secondary prevention programs currently running in the hospital:
  - Screening program for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonscopy (available only in *Austria, Germany, Italy*);
  - Screening programs for hypertension in adults aged 18 and older (available only in *Austria, Spain, UK*);
  - Screening programs for lipid disorders (available only in *Spain*);
  - Screening programs for diminished vision acuity for elderly (available only in *Spain*);
  - Screening programs for detecting drinking problems in adult and adolescent patients (available only in *Spain*).

- Limited existence of public communication campaigns carried out by public health services in the last year on the following topics;
  - Depression (available only in *Belgium, Finland, Spain, UK);*
  - Dental Care (available only in *Spain, Austria).*

Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospitals and Hospital Authorities

- There were no positive elements found.

Key Persons and Partner Organizations

The main results are the following:

- General availability of the following primary or secondary prevention programs free of charge in the health care system:
  - Screening programs for cervical cancer with Papanicolau testing in women who have been sexually active (*11 countries*);
  - Screening programs for breast cancer with mammography for women aged 50 and over (*11 countries*).

- Good diffusion of the following public communication campaigns carried out by public health services in the last year:
  - Fight against smoking (*13 countries*);
  - Road safety (*13 countries*);
  - Alcoholism (*12 countries*);
  - HIV prevention (*12 countries*);
  - Early diagnosis of tumors affecting women (*11 countries*);
  - Prevention of sexually transmitted diseases (*10 countries*).

Violations of this right identified during the last year

Right to Preventive measures	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
Cases identified by KP and PO		x		x								x		

Legend: X =majority of the key persons and Partner Organization interviewed identified cases when this right had been violated during the last year:

Elements characteristic of the countries with the lowest score

- Absence of screening programs currently available free of charge in the health care system, reduced number of public campaigns, absence of material on prevention available to the public in the hospital (*Denmark*).
- Reduced number of screening programs currently available free of charge in the health care system, absence of material on prevention for the public of the hospital (*Greece*).

Comment

There is evidence that in the majority of the countries screening programs and public communication campaigns, which are directed to prevention, exist.

The screening programs, however, focus on women's cancer and are not present in all of the countries. Moreover, only a few countries appear to have extended these initiatives to other forms of cancer, for which there are today efficient preventive diagnostic tools (colon rectal cancer).

The public communication campaigns cover a wide range of issues (smoking, road safety, alcoholism, HIV prevention and other sexually transmissible infections, women cancer prevention) and in a few countries they have also touched on other important topics (dental care, depression, etc.).

What also emerges is a poor diffusion of these prevention activities in hospitals. Traditionally, hospitals deal primarily with diseases and health treatment and care, but in recent years the World Health Organization, through the Vienna Recommendations[22], emphasized the need for hospitals to tackle health from a wider perspective, given the enormous potential they have in these fields.

Finally, as further evidence of this right's somewhat poor performance, there is the fact that only three countries obtained the highest score for this right (*France, The Netherlands and UK*).

[22] 3rd Workshop of National/Regional Health Promoting Hospitals Network Coordinators, WHO, 1997

6.2. Right to access

Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services

The state of the right to access was surveyed taking into consideration two different dimensions, both related to the definition of this right as expressed in the Charter.

The *first* dimension refers to what is explicitly stated in the right, that is, the *access to the health services needed*. This dimension was surveyed using the information reported by key persons.

The *second* dimension, on the other hand, refers to the actual *physical access* to health structures, meaning all elements that either favor or hinder the possibility for health care users to enter a health structure in order to get care or to visit a relative or a friend. This second dimension is not explicitly stated in the right. Nevertheless it can be considered, due to its "elementary" nature, as a basic requirement in order to fully implement the principles expressed in the right to access. The assessment of this dimension has been done through direct observation of the hospitals carried out by the monitoring groups.

2.1. Access to care

Indicators used

Key persons operating in health care at the national level and partner organizations (KP)

- Residents (legal or illegal) who are not covered by NHS *(Y/N)*
- Obstacles that in reality limit certain groups of the population from fully benefiting from NHS *(Y/N)*
- Facts that indicate the difficulty to access health care service *(Y/N)*
  - Important health care issues not covered in NHS package
  - Lack of health care for patients with rare diseases
  - Forced migration for health care
  - Complaints due to administrative and/or economic obstacles in accessing NHS services
  - Complaints and protests due to the lack of coverage by public insurance for health services considered essential by the public
  - Complaints and protests due to the lack of specialized centers for treating a particular rare disease
  - Complaints and protests regarding access to drugs which have been approved in other countries, but not yet in yours
  - Cases where this right has not been respected *(Y/N)*

IAC - Countries' Score

Access to care	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
KP and PO	+-	+-	+-	-	+-	+-	+	+-	-	+-	-	-	+-	-
	1	1	1	0	1	1	2	1	0	1	0	0	1	0

KP: Key Persons – PO: Partner Organization

IAC Right Score

Access to care 10 Max 26 Min 10

Critical Elements

Facts and events with negative meaning observed in a significant number of countries (10 or more)

Key Persons and Partner Organizations

- Existence of residents (legal or illegal) not covered completely by NHS (*11 countries*);
- Lack of coverage by public insurance for health services considered essential by the public (*10 countries*).

Positive Elements

Facts and events with negative meaning observed in a limited number of countries (4 or less);

Key Persons and Partner Organizations

- Forced migration to other countries to receive health care (present only *Denmark, Greece, Portugal);*
- Lack of health care for patients with rare diseases (present only in *Germany, Ireland, Portugal, UK*).

Violations of this right identified during the last year

Right to Access	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK
Cases identified by KP and PO	x			A				x			x		x	x

Legend: X =majority of the key persons interviewed and partner organization identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

- Residents (legal or illegal) who are not covered by NHS, obstacles that limit certain groups of the population from benefiting completely from NHS, and elevated number of situations that indicate a difficulty accessing health care service (*Italy, UK, Spain*).
- A elevated number of situations that indicate a difficulty in accessing health care service (*Portugal*).
- All key persons identified cases during the last year when this right was violated (*Finland*).

Comment

The results show that there are at least two concrete obstacles jeopardizing the protection of health, which are quite widespread among the countries:

- the existence of groups of people who do not have any health protection is a problem that Europe needs to confront;

- the existence of services, which are considered essential by citizens, but are not covered by health insurance, shows the need to try to reach a mutual understanding of what the common priorities should be in the field of health or at least try to reduce this perception gap between citizens and those managing healthcare.

The apparent low importance of the phenomenon of health migrations could actually be hiding an underestimation of the real dimensions of the phenomenon (which has been highlighted by numerous studies) on the part of the key persons. Only one country reached the maximum score on this right.

In general, the results show the need to work at the European level to ensure effective and equal access to treatment for all EU citizens, especially taking into account patient mobility.

2.2. Physical access

Indicators used

Direct Observation in Hospitals (DOH)
- Hospital entrances clearly marked *(Y/N)*
- Accessibility for persons with disability clearly marked *(Y/N)*
- Structural barriers which have not been remedied *(Y/N)*
- Street signs near the hospital indicating its location *(Y/N)*
  - Patients with motor difficulties dropped off at main entrance *(Y/N)*
  - Hospital accessible by public transportation *(Y/N)*
  - Parking for visitors *(Y/N)*
  - Reserved parking for persons with disability *(Y/N)*

IAC - Countries' Score

Access	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
DOH	+	+	+	+	+	+	+-	+	+	+	-	+	+	+
	2	2	2	2	2	2	1	2	2	2	0	2	2	2

DOH: Direct Observation in Hospitals

IAC - Right Score

Physical Access 25 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

- No elements were identified.

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospitals

The results are:
- Public transport to hospital (*14 countries*):
- Street signs indicating the hospital's location (*13 countries*);
- Main hospital entrance clearly marked (*13 countries*);
- No structural barriers at hospital entrance (*13 countries*);
- Possibility to drop off patients with motor difficulties at the main entrance (*13 countries*);
- Reserved parking for persons with disabilities (*12 countries*);
- Visitors parking (*11 countries*).

Elements characteristic of the countries with the lowest score
Presence only of "street signs indicating the hospital's location" and "public transport to hospital" (*Portugal*).

Comment
As highlighted by the indicators used, this specific aspect regarding the right to access seems to be respected in almost all of the countries. There are also positive results with respect to facilities for disabled persons.

6. 3 Right to Information

Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.

Indicators used

Direct Observation in hospitals (DOH)

- Information available to the public in the hospitals *(Y/N)*
  - Information regarding the hospital and regulations
  - Sheet on patients rights regarding inpatients and outpatients
  - Notices regarding waiting list for diagnostic exams and surgery
  - Reports on complaints received from the public
  - Data on outcomes of health services
- Data compared with other hospitals – benchmarking *(Y/N)*
- Areas for voluntary and public interest associations *(Y/N)*
- Indications where to locate the associations posted at main entrance *(Y/N)*
- Information service at main entrance *(Y/N)*
- Updating of the Hospital Directory *(Y/N)*

Hospitals authorities responsible for hospital management (HA)

- Telephone number *(Y/N)*
- Information Desk *(Y/N)*
- Hospital Website *(Y/N)*
- Possibility for patients to receive hospital record after discharge *(Y/N)*
- Average number of days to receive hospital record after discharge (*value)*

Key persons operating in health care at the national level and partner organizations (KP)

- Publicly available lists of all the hospitals, specifying their particular facilities and services *(Y/N)*
- Information centers where citizens can access these lists *(Y/N)*
- Lists are update periodically *(Y/N)*
- Health authorities provide directly or indirectly comprehensible consumer ratings ("consumer satisfaction" information) related to health services *(Y/N)*
- Possibility to make comparison between hospitals: benchmarking *(Y/N)*
- Health authorities provide directly or indirectly comprehensible information on clinical performance measures related to the health services *(Y/N)*
- Organizations that perform the role of Independent Advisor *(Y/N)*
- Cases where this right has not been respected *(Y/N)*

IAC - Countries' Score

Information	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	+-	+	+	+	+	**-L**	+	+	+*
KP and PO	-	-	+	-	+-	+	-	+	+-	-	-	+-	+-	+
	1	1	2	1	2	2	1	2	2	1	0	2	2	2

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA only in one hospital L Hospital Authorities missing

IAC - Right Score

Information	21	Max 26	Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Direct Observation Hospital and Hospital Authorities

The results are:

- Scarce diffusion in the hospitals of the following elements:
  - Notices regarding waiting lists for diagnostic exams and surgery (available only in *Denmark, The Netherlands, Spain and Sweden*);
  - Reports on complaints received from the public (available only in *Denmark, The Netherlands, Spain and Sweden*);
  - Data availability for benchmarking (available only in *Denmark, France, The Netherlands and Sweden*);
  - Data on outcomes of health care service regarding patient satisfaction and clinical performance measures (available only in *France and The Netherlands*).

Key Persons and Partner Organization

The main results are:

- Scarce presence of the following elements:
  - Health authorities provide directly or indirectly comprehensible information on clinical performance measures related to the health services (available only in *Sweden, Spain, Germany and UK*);
  - Health authorities provide directly or indirectly comprehensible consumer ratings ("consumer satisfaction" information) related to health services (available only in *Italy, Spain and UK*);
  - Possibility to make comparison between hospitals: benchmarking (available only in the *UK*).

Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation Hospital and Hospital Authorities

The results are:

- Good presence in the hospitals of the following elements:
  - Information office or service at the main entrance (*14 countries*);
  - Regularly updated directory in main lobby (*13 countries*);
  - Hospital web site (*13 countries*);
  - Information sheets about the hospital and the regulation concerning inpatients (*13 countries)*;
  - Telephone number of the hospital that the public can call (*12 countries*).

Key Persons and Partner Organization

The results are:

- Good presence in the hospitals of the following elements:
  - Publicly available lists of all the hospitals, specifying their particular facilities and services (*10 countries*).

Violations of this right identified during the last year

Right to information	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK
Cases identified by KP and PO	x			x							x	x	x	

Legend: X =majority of the key persons and partner organization interviewed identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

Presence only of an "information service or service at the main entrance" and "regularly updated directory in main lobby" along with negative responses from key persons to all questions regarding this right (*Portugal*).

Comment

In general, the results are quite satisfactory, even if the information tools more widely spread are quite "elementary" and aimed mainly at providing information on the available services being offered.

Lacking are those information tools directed at being accountable to citizens for the functioning of healthcare services (i.e. benchmarking, consumer ratings). Moreover, the key persons interviewed indicate that for a third of the countries there are cases of this right being violated, thus showing that citizens' expectations are not being met.

Also the presence of areas reserved to patients' and citizens' associations inside hospitals not quite yet widespread, not reaching even 10 countries. The fact that patients' and citizens' associations are not seen as part of the hospital could be linked to the obstacles encountered, in a number of countries, by the monitoring groups when visiting hospitals and the obtaining answers from health authorities.

What emerges is the need for a common effort to empower citizens in making choices.

6.4 . Right to consent

Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.

Indicators used

Hospitals authorities responsible for hospital management (HA)

- Existence of standardized forms to get consent from the patient *(Y/N)*
  - Scientific research
  - Invasive diagnostic exams
  - Surgical operations

Key persons operating in health care at the national level and partner organizations (KP)

- Specific forms to get consent from the patient *(Y/N)*
  - Nature of the treatment or procedure
  - Risks
  - Benefits
  - Alternatives
  - Information sheet on specific treatment or procedure *(Y/N)*
  - Information sheet or forms in more than one language *(Y/N)*
  - Procedures for involving minors or incapable adults in the informed consent process *(Y/N)*
  - Cases where this right has not been respected *(Y/N)*

IAC- Countries' Score

Consent	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
HA	+	+-	+-	+-	+	+	+	+-	+	+-	**L**	+	+-	+*
KP and PO	+-	+-	-	-	+-	+-	-	+-	-	+-	-	+-	-	+-
	2	1	0	0	2	2	1	1	1	1	0	2	0	2

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA only in one hospital L Hospital Authorities missing

IAC - Right Score

Consent 15 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Hospital Authorities

There were no elements identified.

Key Persons and Partner Organization

The main findings are:

- Limited use of specific forms to get consent from the patient which include the following information:
  - Risks (available only in *Ireland, UK*);
  - Benefits (available only in *Austria*);
  - Alternatives (not available in any country).

- Limited use (presence) of information sheets available in more than one language to inform patients on the procedure or treatment (available only in *Germany and The Netherlands)*.

Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

- Existence of standardized forms to get consent from the patient in scientific research (*13 countries*).

Key Persons and Partner Organization

- Specific forms to get consent from the patient (*10 countries*).

Violations of this right identified during the last year

Right to Consent	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Cases identified by KP and PO	x				x										**2**

Legend: X =majority of the key persons and partner organizations interviews identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

There is a limited use of standardized forms to get patient's consent in the hospitals visited. Key persons mentioned a lack of information sheets and consent forms in more than one language as well as a lack of information sheets on specific treatments.

Comment

Hospital observation highlighted a widespread use of standardized forms to get consent from patients in case of research (13 *countries)*, while less used are the forms in cases of invasive diagnostic exams e surgical operations.

The consultations with the key persons emphasized, instead, a use of consent forms with reference to the nature of the procedure. In general, there is no information regarding risks, benefits and possible alternatives.

6.5. Right to Free Choice

Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.

Indicators used

Key persons operating in health care at the national level and partner organizations (KP)

- Different fees in public and private hospitals (and thus different reimbursements) *(Y/N)*
- Incentives to seek treatment in certain hospitals or centres *(Y/N)*
- Coverage of supplementary insurance only for some hospitals, and thus the option of seeking treatment in just those hospitals *(Y/N)*
- Need to get authorization for some treatments (ex. for rehabilitative treatments) *(Y/N)*
- Indigent (poor, needy) patients only able to receive treatment in certain hospitals *(Y/N)*
- Right limited in the last year *(Y/N)*

IAC- Countries' Score

Free choice	**AUT**	**BEL**	**DEN**	**FIN**	**FRA**	**GER**	**GRE**	**IRL**	**ITA**	**NET**	**POR**	**SPA**	**SWE**	**UK**
KP and PO	+-	+-	+-	+-	+-	+	+-	+-	+-	+	-	+-	+-	-
	1	1	1	1	1	2	1	1	1	2	0	1	1	0

KP: Key Persons – PO: Partner Organization

IAC - Right Score

Free choice 14 Max 26 Min 10

Critical Elements

Facts and events with negative meaning observed in a significant number of countries (10 or more)

Key Persons and Partner Organizations

- The need to get authorization for some treatments (*14 countries*).

Positive Elements

Facts and events with negative meaning observed in a limited number of countries (4 or less)

Key Persons and Partner Organizations

- Incentives to seek treatment in private hospitals (present in *Belgium, Finland, Portugal*).
- Indigent patients only able to be treated in certain hospitals (present in *Portugal*).

Violations of this right identified during the last year

Trend to limit free choice	Aut	Den	Bel	Fin	Fra	Ger	Gre	Irl	Ita	Net	Por	Spa	Swe	UK	Tot
New measures adopted in the last year identified by KP and PO				x			x	x	x		A	x		A	**7**

Legend: X =majority of the key persons and partner organizations interviews identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

- All key persons agree that there is a trend aimed at limiting the right to free choice (*UK and Portugal*).
- The presence of all obstacles identified that limit the right to free choice (*Portugal*).

Comment

In recent years, many European countries have taken actions regarding the right for citizens to freely choose, in the framework of their public insurance system, doctors or health structures, either by extending or limiting this right. This has taken place mainly in two ways:

- by restructuring welfare health systems, with the aim of making them sustainable from a financial point of view;
- by recognizing a new, more autonomous roles of citizens in health systems.

In this context, it becomes evident that the situation is quite critical with reference to the respect of this right: only two countries scored the maximum IAC score; in *7 countries* the majority of the key persons interviewed (in *2 countries* all of them) agreed that there is a trend aimed at limiting the right to free choice. In addition, an obstacle to the free choice, such as “the need to get authorization for some treatments” was identified in all 14 countries.

Finally, it is important to point out the fact that a number of obstacles to free choice, even if they did not exceed the threshold of diffusion of 10 countries, were nevertheless quite widespread in many countries (the existence of differential fees in public and private hospitals in 8 countries, and the coverage of supplementary insurance only for some hospital in 7 countries).

6.6. Right to Privacy and Confidentiality

Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.

Indicators used

Direct Observation in Hospitals (DOH)
- Dividers between outpatient rooms *(Y/N)*
- Hear or see the patient's surname *(Y/N)*

Hospitals authorities responsible for hospital management (HA)
- Single room for terminal patients *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Cases where this right has not been respected - Normative medical information disclosed to non-authorized persons *(Y/N)*
- Cases where this right has not been respected - Patients' case files disclosed to non-authorized persons *(Y/N)*
- Cases where this right has not been respected - Violation of the confidentiality of HIV/AIDS patients *(Y/N)*

IAC - Countries' Score

Privacy & Conf.	**AUT**	**BEL**	**DEN**	**FIN**	**FRA**	**GER**	**GRE**	**IRL**	**ITA**	**NET**	**POR**	**SPA**	**SWE**	**UK**
DOH and HA	+-	+	+-	+	+	+	+-	+	+-	+-	+**L**	+-	+-	+*
KP and PO	+	+-	+	+	+-	+	+	+	+	+	+-	+-	+-	+-
	2	2	2	2	2	2	2	2	2	2	2	1	1	2

DOH: Direct Observation in Hospital - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA only in one hospital L Hospital Authorities missing

IAC - Right Score

Privacy 26 Max 26 Min 10

Critical Elements

Highly negative facts and events that were observed in a number of countries (less than 10)

Direct Observation in Hospital

- Seen or heard a patient's surname in the course of the direct observation in the hospitals (*Denmark, The Netherlands, Spain and Sweden*).

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospital

- Presence of dividers or curtains in the outpatient examination rooms (*13 countries*).

Violations of this right identified during the last year

Right to Privacy and Confidentiality	Aut	Bel	Den	Fin	Fra	Ger	Gre	Irl	Ita	Net	Por	Spa	Swe	UK	Tot
1. Normative medical information disclosed to non-authorized persons					x		X				x	x	x		**5**
2. Patients' case files disclosed to non-authorized persons							X						x		**2**
3. Violation of the confidentiality of patients with HIV/AIDS															**0**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

- Observe or hear the surname of a patient during the hospital observation and key persons mentioned knowing of cases when normative medical information was disclosed to non-authorized persons and/or patients' case files were disclosed to non-authorized persons (present in *Sweden*).
- The unavailability of single rooms in the hospital for terminal patients and key persons that mentioned knowing of cases when normative medical information was disclosed to non-authorized persons (present in *Spain)*.

Comment
This right reached the highest score of all the rights, and there no countries with a minimum score. In fact, however, the habit of reserving single rooms for terminal patients, does not reach the diffusion threshold of 10 countries (present only in *9 countries*).

There are only a few reports concerning serious violations, such as patients' case files being disclosed to non-authorized persons, and observing or hearing the surname of a patient. There are, however, no cases of violation of the confidentiality patients with HIV/AIDS.

One should, however, keep in mind the limits of the evaluation of this right, since there are not many indicators used.

6.7. Right to Respect of Patients' Time

Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.

Indicators used

Hospitals authorities responsible for hospital management (HA)

- Diagnostic or therapeutic treatment impossible to get appointment in the last 30 days *(Y/N)*
- Differentiated access routes for different levels of seriousness and urgency *(Y/N)*
  - *Ecocardiograms*
  - *Mammography*
  - *CAT*
- Maximum time period within which the hospital must provide the diagnostic and therapeutic treatments required for patients *(Y/N)*
- The hospital guarantee the patient can get treatment in another facility without additional cost if hospital cannot provide diagnostic or therapeutic treatment within the max. time *(Y/N)*
- Reimbursed cost when it is an additional cost *(Y/N)*
- Unified contact point for appointments *(Y/N)*
- Waiting lists for diagnostic exams and surgery available to public *(Y/N)*
- Appointments for specialists can be made by phone *(Y/N)*

Relevant but not taken into account for the scoring

- Waiting period for urgent exams *(value)*
- Waiting period for non urgent exams (*value*)
- Waiting time for elective surgery *(value)*

Key persons operating in health care at the national level and partner organizations (KP)

- Cases where this right has not been respected -Cases in which an illness has worsened because of a delay in treatment *(Y/N)*
- Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time *(Y/N)*
- Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time *(Y/N)*

IAC Countries' Score

Time	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	+-	-	+	+-	+-	-	-	-	+-	+	L	+-	+	+*
KP and PO	+	+	-	-	+-	+-	+-	-	-	+-	+-	-	-	-
	2	1	1	0	1	0	0	0	0	2	1	0	1	1

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

* HA only in one hospital L Hospital Authorities missing

IAC- Right Score

Time 10 Max 26 Min 10

Critical Elements
Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Direct Observation in Hospital and Hospital Authorities

- Limited use of the practice of establishing a "limit on waiting time" (except in *Denmark, Germany and The Netherlands*);
- Scarce presence of "waiting list available to public" (except in *Denmark, Sweden and UK*);
- Scarce presence of "a single unified contact point for appointments" (except in *Denmark, Greece, Italy and UK*).

Facts or events with negative meaning, even though observed in not a large number of countries (less than 10)
- The presence of diagnostic or therapeutic treatments that have been impossible to get an appointment in the last 30 days present in *9 countries*.

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospital and Hospital Authorities

- Existence of a differentiated access route for different levels for accessing certain treatments depending on seriousness and urgency (*12 countries*).

Violations of this right identified during the last year

Right to respect patient's time	**Aut**	**Bel**	**Den**	**Fi**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
1. Cases in which an illness has worsened because of a delay in treatment			x	A		x		x	x	x	x	x	A	x	**10**
2. Waiting time for important diagnostic exams is too long			x	A	X	A	x	x	x	A		x	A	x	**11**
3. Need to use payable services due to the long waiting time			x	A	X		x	x	A		x	x	x	x	**10**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
Key persons reported cases of violation concerning the right to respect patients' time in one or more of the following situations:
- Cases in which an illness has worsened because of a delay in treatment;
- Need to use services that the patient has to pay for due to the long waiting time.

Hospital Authorities reported the presence of two or more of the following situations:

- Diagnostic or therapeutic treatments that have been impossible to get appointment in the last 30 days;
- The absence of a differentiated access routes that take into account the urgency of treatment;
- The absence of a maximum time period within which the hospital must provide the diagnostic and therapeutic treatments required for patients.

Comment

This right has the lowest score, and in fact, there was only one indicator which scored positive in 10 or more countries.

Even those relatively simple measures, such as establishing a time limit on waiting time, waiting list available to the public or even, the existence of a single unified contact point for appointments, were recorded only in a few countries.

The existence of treatments that have been unavailable in the last 30 days for outpatients is so widespread that it is quite likely that there are closed waiting lists in most of the EU countries.

In this context, what is particularly striking is the fact that there have been many episodes of violation of this right in most of the countries; episodes, on which, in a number of cases, all the key persons and partner organizations interviewed agreed on. Among the episodes reported there is also the case of illnesses getting worst because of a delay in treatment. This episode can be considered a real "warning sign", in the sense that it is an episode which in itself highlights the gravity of the situation.

The data on the waiting time for diagnostic exams or surgeries have not been calculated when assigning the scores, due to the impossibility of setting a single standard for all the countries taken into consideration. Nevertheless, there are a series of critical situations, which have been highlighted in the table below.

Table – Waiting times for elective surgery, no. days (Hospital interview)

	Cholecystectomy by laparoscopy		**Tranurethal Resection of the Prostate**		**Cataract Surgery**		**Total hip replacement surgery**		**Coronary Bypass**	
	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min
Austria	30	18	30	7	180	30	240	240	42	28
Belgium	NR	NR	+360	NR	NR	NR	+360	NR	NR	NR
Denmark	98	56	56	42	84	56	119	56	63	63
Finland	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
France	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Germany										
Greece	15	15	7	7	NR	NR	NR	NR	NR	NR
Ireland	120	NR	60	NR	NR	NR	None	None	60	NR
Italy	90	40	420	30	90	64	360	90	120	30
Netherlands	70	21	42	21	60	0	180	150	35	35
Spain	80	43	80	43	80	43	80	43	30	30
Sweden	180	30	90	63	90	90	336	180	21	21

*Legend: * Information not available NR= No response*

The difficulties encountered in receiving necessary treatment within a swift and predetermined period of time are evident also when one examines surgical operations (the 336 and 240 days of maximum waiting time for Total Hip Replacement surgery in Sweden and Austria, the 420 days for Tranurethal Resection of the Prostate in Italy, the 180 days for Cataract Surgery in Austria). In general, waiting times for Total hip replacement surgery tend to be extremely long in most countries.

6.8. Right to Quality

Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.

Indicators used

Hospitals authorities responsible for hospital management (HA)

- Fixed standards *(Y/N)*
  - Set with participation of consumer association
  - Regarding technical offerings
  - Regarding human relations
  - Regarding comfort
  - With periodic controls
  - With controls carried out with participation of consumer associations
  - Sanctions for violations of standards
- Quality Unit *(Y/N)*
- Studies to measure patient satisfaction

Key persons operating in health care at the national level and partner organizations (KP)

- Procedures to accredit or certify the quality level of hospitals *(Y/N)*
- Fixed standards *(Y/N)*
  - Established with the participation of consumers' associations
  - Regard technical offerings
  - Regard human relations
  - Regard comfort
  - With periodic controls
  - With controls carried out with participation of consumer associations
  - Sanctions for violations of standards
  - Sanctions imposed
- Cases where this right has not been respected *(Y/N)*

IAC - Countries' Score

Quality	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	-	+	+	+-	+-	+-	+-	+	+-	+	L	+	+	+*
KP and PO	+-	+-	+	+-	-	+	+-	+-	+	+	+-	+-	+-	+-
	0	2	2	1	0	2	1	2	2	2	1	2	2	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

* HA only in one hospital L Hospital Authorities missing

IAC - Right Score

Quality 21 Max 26 Min 10

Critical Elements
Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Hospital Authorities

The results are:
- Scarce presence of standards set with the participation of consumer and/or patient associations (except in *Ireland and The Netherlands*);
- Limited practice of controls being carried out with the participation of consumer and/or patients associations (except in *Ireland and UK*);
- Limited/ scarce presence of sanctions for violations of standards (except in *Sweden and UK*).

Key Persons and Partner Organization

The main results are:
- Scarce presence/existence of fixed standards established with the participation of consumers' associations (except in *France*);
- Scarce presence of fixed standards with controls carried out with the participation of consumer associations (except in *France*);
- The absence of sanctions imposed for violations of standards (in all countries).

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

The main results are the following:
- A widespread presence of fixed performance standards (*11 countries*);
- A widespread presence of studies that measure patients' satisfaction (*12 countries*);
- A widespread presence of a Quality Unit (*11 countries*).

Key Persons and Partner Organization

The main results are:
- A widespread presence of procedures to accredit or certify the quality level of hospitals (*14 countries*);
- A widespread presence of procedures to accredit using fix standards (*13 countries*);
- A widespread presence of fixed standards regarding technical offerings (*13 countries*);
- A widespread presence of fixed standards regarding human relations (*12 countries*).

Violations of this right identified during the last year

Right to Quality	**Aut**	**Bel**	**Den**	**Fin**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
Cases identified by KP and PO				x	A									x	**3**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
All key persons mentioned the existence of cases when this right was violated. During the hospital interviews there resulted only studies that measure patient satisfaction.

Comment
The widespread presence of quality and standard certification procedures indicate that most of the European countries are developing policies aimed at promoting improvements in the quality of healthcare services.

However, these policies are apparently being developed without a real and concrete involvement of citizens, whether it be in the definition of standards (even those concerning relational aspects and comfort of services), or in the controls carried out. This lack of citizens' involvement testifies to the limits of these policies and to the fact that quality process in its different phases (plan, do, check, act) tends to be auto-referential. Most of the time, in this process, the actors are those managing or providing the healthcare services and almost never those using such services.

Finally, it is worth emphasizing the near absence of a control procedure capable of inflicting fines in case of quality standard violations. It is significant, however, that in this framework of apparent rules and procedures, there are countries in which all or the majority of the key persons agree on the presence of violations on the right to quality.

6.9. Right to Safety

Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.

Indicators used

Direct Observation in the Hospital (DOH)
- Priority codes in triage procedure in Emergency Room *(Y/N)*
- Emergency exist signs *(Y/N)*
- Fire extinguisher *(Y/N)*
- Evacuation maps *(Y/N)*
- Special evacuation procedures or routes for wheelchair users on map *(Y/N)*

Hospitals authorities responsible for hospital management (HA)
- Procedures for reporting the following *(Y/N)*
  - Hospital acquired infections
  - Burns from fires
  - Falls
  - Pressure ulcers
  - Phlebitis associated with intravenous lines
  - Restraint-related strangulation
  - Preventable suicides
  - Failure to diagnosis or incorrect diagnosis
  - Failure to utilize or act on diagnostic tests
  - Use of inappropriate or outmoded diagnostic tests or treatment
  - Medication errors/adverse drug effects
  - Wrong-site errors; surgical errors
  - Transfusion mistakes
- Reporting of near misses *(Y/N)*
- Office or person in the hospital charged with coordinating activities for reducing the risk of infection *(Y/N)*
- Office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions *(Y/N*
- Written procedures (protocols) for checking and reducing risks control of hospital infections *(Y/N)*
- Epidemiological investigations of hospital infections carried out *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Protocols for the sterilization of medical instruments *(Y/N)*
- Protocols for the prevention of hospital infections *(Y/N)*
- Risk management techniques *(Y/N)*
- Epidemiological investigations of hospital infections *(Y/N)*
- Cases when the right not respected

IAC Countries' Score

Safety	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+-	+	+	+-	+	+	+-	+	+	+	**L**	+	+	+*
KP and PO	+-	+	+-	+-	+-	+	+-	+	+-	+	+-	+	+-	-
	1	2	2	1	2	2	1	2	2	2	0	2	2	1

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA only one hospital L Hospital Authorities missing

IAC Right Score

Safety	22	Max 26	Min 10

Critical Elements
Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Direct Observation in Hospitals and Hospital Authorities

The result is:
- Scarce presence of special evacuation procedures or routes for wheelchair users marked on the map (except in *Belgium, Germany and Sweden*).

Key Persons and Partner Organization

There were no elements identified.

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospitals and Hospital Authorities

The results are the following:
- A widespread presence of emergency exist signs (*12 countries*):
- A widespread presence of fire extinguisher signs (*12 countries*);
- A widespread presence of an office or person in the hospital responsible for coordinating activities for reducing the risk of infection (*13 countries*);
- A widespread presence of procedures for reporting the following:
  - Hospital acquired infections (*13 countries*);
  - Falls (*11 countries*);
  - Burns from fires (*10 countries*);
  - Pressure ulcers (*10 countries*);
  - Transfusion mistakes (*10 countries*).
- A widespread use of written procedures (protocols) for checking and reducing risks control of hospital infections (*13 countries*);
- A widespread presence of an office or person in the hospital responsible for coordinating activities for reducing the risk of infection (*13 countries*);
- A widespread presence of Office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions (*12 countries*).

Key Persons and Partner Organization

The findings are:
- A widespread use of protocols for the sterilization of medical instruments (*14 countries*);
- A widespread use of protocols for the prevention of hospital infections (*13 countries*).

Violations of this right identified during the last year

Right to Safety	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Cases of violation identified by KP and PO				x					x		x		x	A	**5**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score

From the indicators used only the presence of Fire extinguishers were detected during the direct observation of the hospitals and the majority of key persons and partner organizations reported cases of violation of this right (*Portugal*).

Comment

The direct observations of the hospitals allowed us to verify important risk management practices that are widespread in most of the European countries and have reached satisfactory levels of diffusion.

Within this overall satisfactory situation, there are, however, a number of weaknesses, which, even if they concern only a few countries, are nevertheless significant. This is the case regarding the presence of evacuation maps in hospitals that do not reach even the threshold of 10 countries (8 countries), or the presence of emergency exit signs and fire extinguisher signs (absent in two countries). Moreover, there have been reported cases of violation of this right in 5 countries.

Finally, there is a critical element, which should be studied in view of the national norms; that is the low diffusion in hospitals of special evacuation procedures or routes for wheelchair users marked on the map.

6.10. Right to Innovation

Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.

Indicators used

Hospitals authorities responsible for hospital management (HA)

- Use of *(Y/N)*
  - Telemedicine
  - Electronic patient record
  - Internet
  - Personal cards
  - Special mattress to prevent pressure ulcer
  - Patient Control Analgesia
  - Less invasive surgical techniques
    - Laparoscopic Cholecystectomy
    - Laparoscopic Prostatectomy
    - Microendoscopic discectomy (MED)
    - Minimally invasive direct coronary artery bypass (MIDCAB)
    - Laparoscopic Inguinal hernia repair
    - Laparoscopic Adrenalectomy
    - Laparoscopic Repair of paraesophageal hernia

Key persons operating in health care at the national level and partner organizations (KP)

- Diffusion innovative techniques *(Y/N)*
  - Telemedicine
  - Electronic patient record
  - Use of internet
  - Less invasive surgical techniques
  - Personal cards
  - Use of special mattress to prevent pressure ulcer

- Cases when the right not respected: delays introducing innovative diagnostic tests *(Y/N)*
- Cases when the right not respected: delay in introducing innovative treatments *(Y/N)*
- Cases when the right not respected: delay in particular areas of medical research *(Y/N)*

IAC - Countries' Score

Innovation	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	-	-	+	+	+	L	-	+	+*
KP and PO	-	-+	+-	-	+-	+-	-	-	-	-	-	-	-	+-
	1	2	2	1	2	0	0	1	1	1	0	0	1	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* =HA from only one hospital, L= HA missing

IAC - Right Score

Innovation 14 Max 26 Min 10

Critical Elements
Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Hospital Authorities

- Limited use of Personal cards (except in *The Netherlands and Denmark*).

From Key Persons and Partner Organization

- Absence of Telemedicine (present in no countries);
- Limited use of :
  - Electronic patient records (available in *Spain*);
  - Internet to access treatment appointments, medical referrals etc. (available in *Germany*);
  - Personal cards (available in *Finland and Spain*);
  - Patients Controlled Analgesia: PCA (available in *France and UK*).

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

- Widespread use of:
  - Less invasive surgical techniques (*11 countries*);
  - Special mattress to prevent pressure ulcers (*12 countries*);
  - Patients Controlled Analgesia: PCA (*10 countries*).

Key Persons and Partner Organization

- A widespread use of less invasive surgical techniques (*10 countries*)

Violations of this right identified during the last year

Right to Innovation	**Aut**	**Bel**	**Den**	**Fin**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
1. Delays in the introducing of innovative diagnostic tests				x				x	x			x	x		**5**
2. Delays in the introducing of innovative treatments				x				x	x		x	x	x	x	**7**
3. Delays in particular areas of medical research			x	x	x				x			x	x		**6**

Legend: X =majority of the key persons interviews and partner organization identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
According to the majority of Key Persons there are limited to no use at all of innovative techniques (*Portugal and Greece*), as well the majority of Key Persons identified violations in all three cases *(Spain*) while Health Authorities mentioned there are few innovative techniques (*Greece, Spain, Germany).*

Comment
There seems to be an unexpected delay in the technological innovation of healthcare facilities, as reported in particular by the key persons. The key persons stated that there is little use in healthcare facilities of technologies like telemedicine, internet to access treatment appointments, medical referrals or even the use of personal cards or of patients controlled analgesia (PCA).

There are however, some differences between the information obtained from the hospitals and that from the key persons. The most likely explanation for this is that in the hospitals, because of their size and their location in the capitals, the use of innovative technologies is definitely above average in relation to the countries' health facilities in general.

6.11. Right to Avoid Unnecessary Suffering and Pain

Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.

Indicators used

Hospitals authorities responsible for hospital management (HA)
- Protocol for pain management *(Y/N)*
- Palliative Care Unit *(Y/N)*
- Pain Medicine Center *(Y/N)*
- Record pain scores *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Pain management procedure - Assess pain systematically *(Y/N)*
- Pain management procedure - Believe what the patient and family reports on pain *(Y/N)*
- Pain management procedure - Choose pain control options appropriate *(Y/N)*
- Pain management procedure - Deliver interventions in a timely, logical and coordinated manner *(Y/N)*
- Pain management procedure - Empower patients to self-manage pain *(Y/N)*
- Cases when the right not respected: not administrating morphine in cases when it is recommended by the international procedures *(Y/N)*
- Cases when the right not respected: not administrating painkillers in the case of or after painful treatments *(Y/N)*

IAC - Countries' Score

Avoid Pain	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	+-	+	+	+	+	+-	+-	+	+	+	L	+-	+	+*
KP and PO	+-	+	+	-	-	+	-	+	-	+	-	-	-	-
	1	2	2	1	1	2	0	2	1	2	0	0	1	1

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA in only one hospital, L; HA is missing

IAC - Right Score

Avoid Pain 16 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

From Hospital Authorities

- No elements were identified.

From Key Persons and Partner Organization

The results are the following:
- Limited use in countries of the following rules to pain management:
  - Record pain systematically (available only in *UK and Sweden*):

– Empower patients and their family to self manage pain (available only in *Germany, The Netherlands, Ireland and Sweden).*

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

The results are:
- The use of guidelines or protocols for pain management (*11 countries*);
- The presence of a Pain Center and/or Palliative Care Unit (*12 countries*).

Key Persons and Partner Organization

- No elements were identified.

Violations of this right identified during the last year

Right to Avoid Pain	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Not administrating painkillers in the case of or after painful treatments							x		x		x	x	x	X	**6**
Not administrating morphine in cases when it is recommended by the international procedures on severe pain treatment							x					x	x	X	**4**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
A limited use of pain management rules respected in the country; presence of cases of not administrating morphine in cases when it is recommended by international procedures; not administrating painkillers in the case of or after painful treatments identified by the majority of key persons (*Spain, Greece and Portugal*).

Comment
The diffusion of pain management tools seems to be somewhat limited in the hospital that were visited; yet this situation is even less satisfactory according to what was reported by key persons on the general picture of their own countries. According to these sources, in fact, the practices to evaluate pain and strengthen the ability of patients and their families to manage issues connected to pain and its control are not generally widespread.

It is worth highlighting that in 6 countries the majority of key persons reported one or more cases regarding the violation of this right.

6.12. Right to Personalized Treatment

Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his or her personal needs.

Indicators used

Direct Observation in Hospitals (DOH)
- Play areas inside pediatrics wards *(Y/N)*
- Appropriate furnishing inside pediatrics *(Y/N)*
- Parents can be present 24 hrs. day *(Y/N)*
- Place for relatives to sleep in the room that is appropriate *(Y/N)*
- Use of cafeteria for parents *(Y/N)*
- Educational support for children *(Y/N)*

Hospitals authorities responsible for hospital management (HA)
- Choice of meals *(Y/N)*
- Distribution of patients meal *(Y/N)*
- Religious assistance available in the hospital or on call for more than three religions *(Y/N)*
  - Protestants
  - Anglican
  - Catholic
  - Orthodox
  - Jewish
  - Muslim
- Psychological support service to assist patients and their families in specific situations (3 or more reported) *(Y/N)*
    - Terminal patient and their family
    - Transplants patients and their family
    - Women who have suffered violence
    - Patients in other conditions
- Procedures to ensure that patients may demand a second opinion *(Y/N)*
- Foreign language interpreters present at the hospital *(Y/N)*
- Cultural mediators present at the hospital *(Y/N)*
- More than six hours a day available for visiting patients *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Personalized support given in hospitals *(Y/N)*
  - Choice of meals
  - Psychological support for terminal patients and their families
  - Spiritual support based on personal
  - Cultural mediation and/or foreign language interpretation
  - Educational support for children hospitalized
- Cases when the right not respected *(Y/N)*

IAC - Countries' Score

Personalized Treatment	**AUT**	**BEL**	**DEN**	**FIN**	**FRA**	**GER**	**GRE**	**IRE**	**ITA**	**NET**	**POR**	**SPA**	**SWE**	**UK**
DOH and HA	+	+	+	+	+	+	+-	+-	+-	+	+ - **L**	+-	+	+*
KP and PO	+-	+	+	+-	+-	+	-	+	+-	+	+-	+-	-	-
	2	2	2	2	2	2	0	2	1	2	1	1	1	1

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA in only one hospital, L: HA missing

IAC - Right Score

Personalized treatment	21	Max 26	Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Direct Observation in Hospital and Hospital Authorities

- Limited presence in hospitals of procedures, which to ensure that patients may ask for a second opinion (except in *Belgium, The Netherlands, Finland and UK*).

Key Persons and Partner Organization

- Limited presence in the hospitals of Cultural mediation and/or foreign language interpretation (except in *Denmark, Germany, Ireland and The Netherlands*).

Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

Direct Observation in Hospital and Hospital Authorities

The main results are the following:
- In general the possibility of patients to choose their meals (*11 countries*);
- In general the parents of children in the hospitals can:
  - be present for 24hrs (*12 countries*);
  - use the cafeteria (*12 countries*);
  - sleep in the room (*11 countries*).

Key Persons and Partner Organization

- In general there is available spiritual support respecting personal beliefs (*10 countries*).

Violations of this right identified during the last year

Personalized Treatment	**Aut**	**Bel**	**Den**	**Fin**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
Cases identified by KP and PO	x								x				x	A	**4**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year A = all key persons

Elements characteristic of the countries with the lowest score

A limited number of elements regarding personalized treatment found in the hospitals as well as a negative response from the majority of key persons concerning the existence of these elements (*Greece*).

Comment

The results for this right are among the best, even though there are only 5 of the positive elements reported above. There are, in fact, other elements that emerged in the hospital visits, which reach levels of diffusion that are slightly lower, but which testify to the trend, in many countries, of trying to meet the needs of individuals and of different types of users. Among these, the most important ones are the availability of: religious assistance (more than three religions in *9 countries*); foreign language interpreters (*9 countries*); psychological support services to assist patients and their families in specific situations (3 or more reported in *7 countries*); and, finally, the possibility of parents' visits lasting more than six hours a day (*8 countries*).

In this situation, the only negative aspects reported by the key persons refer to the limited presence of cultural mediators in the hospitals, as well as the limited possibility for hospital patients to ask for a second opinion.

6.13. Right to Complain

Each individual has the right to complain whenever he or she has suffered harm and the right to receive a response or other feedback.

Indicators used

Hospitals authorities responsible for hospital management (HA)
- Fixed procedures for handling patients' complaints *(Y/N)*
- Committees to receive complaints *(Y/N)*
- Committee independent of the hospital *(Y/N)*
- Time limit to answer complaints *(Y/N)*
- Respect of the time limit *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Fixed procedures for handling patients' complaints *(Y/N)*
- Independent organizations to assist citizens in presenting their complaints *(Y/N)*
- Cases when the right not respected - - Lack of a response to citizens' complaints *(Y/N)*
- Cases where this right has not been respected - Too long to respond to citizens' complaints *(Y/N)*
- Cases where this right has not been respected - Threats, intimidations or retaliation towards patients that have complained *(Y/N)*

IAC- Countries' Score

Complain	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	+	+	+	+	+	L	+	+	+*
KP and PO	+-	+-	+	+-	+	+	+-	+-	+-	+	-	+-	+-	+
	2	2	2	2	2	2	2	2	2	2	0	2	2	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA in only one hospital, L: HA missing

IAC - Right Score

Complain 26 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Hospital Authorities

- No elements are identified.

Key Persons and Partner Organization

- No elements are identified.

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

The results are the following:
- Existence of Committee to receive complaints and resolve conflicts between the public and the hospital (*13 countries*);
- Existence of official procedures for dealing with patients' complaints (*13 countries*);
- Existence of a specific time limit for the hospital to respond to patient complaints (*12 countries*);
- A general respect for the time limit (*10 countries*).

Key Persons and Partner Organization

The results are:
- Existence of fixed procedures for handling patients' complaints (*14 countries*);
- Existence of independent organizations to assist citizens in presenting their complaints (*13 countries*).

Violations of this right identified during the last year

Right to Complain	**Aut**	**Bel**	**Den**	**Fi**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
1. Specific cases where this right was not respected															
2. Lack of a response to citizens' complaints	x	x					x	x	x			x	x	X	**8**
3. Too long to respond to citizens' complaints	x	x	x	x	x		x	x	x		x	x	x		**11**
4. Threats, intimidations or retaliation towards patients that have complained															**0**

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
According to the majority of Key Persons and Partner Organization, independent organizations don't exist to assist citizens in presenting their complaints (*Portugal*).

Comment
Together with the right to privacy, this is the right with the highest score. There are, however, cases of violation reported in all of the countries except for The Netherlands and Germany, which raise doubts about the actual respect of this right. The cases, in fact, concern the lack of response to citizens' complaints and/or the exceedingly long time to respond to citizens' complaints, which risk, moreover, to disappoint citizens' expectations and lower their trust in the institutions.

6.14. Right to Compensation

Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical or moral and psychological harm caused by a health service treatment.

Indicators used

Hospitals authorities responsible for hospital management (HA)
- Hospitals insured *(Y/N)*
- Hospital's doctors have additional insurance *(Y/N)*
- Committees or structures to assist patients in reaching a final agreement on compensation *(Y/N)*
- Committee or structures are independent from the hospital *(Y/N)*

Key persons operating in health care at the national level and partner organizations (KP)
- Hospitals insured *(Y/N)*
- Hospital's doctors have additional insurance *(Y/N)*
- Commissions/structures, operating outside the regular litigation process *(Y/N)*
- Independent organizations which provide legal aid free of charge or at a reduced cost *(Y/N)*
- Cases when the right not respected *(Y/N)*

IAC - Countries' Score

Compensation	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+-	+	+-	+	-	+-	+-	+	L	+-	+	+*
KP and PO	+	+	-	+-	+	+-	-	+-	+-	-	-	-	+-	+
	2	2	0	2	2	2	0	1	1	1	0	0	2	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization
* HA in only one hospital, L: HA missing

IAC- Right Score

Compensation 17 Max 26 Min 10

Critical Elements

Facts and events with positive meaning that are observed in a limited number of countries (4 or less)

Hospital Authorities

- No elements are identified.

Key Persons and Partner Organization

- No elements are identified.

Positive Elements
Facts and events with a positive meaning in a large number of countries (10 or more)

Hospital Authorities

- In general Hospitals are insured to compensate patients (*11 countries*).

Key Persons and Partner Organization

- In general hospitals insured to compensate patients (*12 countries*).
- In general the Doctors within the hospital have additional insurance (*10 countries*).

Violations of this right identified during the last year

Right to compensation	**Aut**	**Bel**	**Den**	**Fin**	**Fra**	**Ger**	**Gre**	**Ire**	**Ita**	**Net**	**Por**	**Spa**	**Swe**	**UK**	**Tot**
Cases identified by KP and PO				x									x		**2**

Legend: X =majority of the key persons and partner organization interviews identified cases when this right had been violated during the last year: A = all key persons

Elements characteristic of the countries with the lowest score
The majority of Key Persons and Partner Organizations noted the complete absence of all indicators or the existence only of an "Independent organizations which provide legal aid free of charge" or only the presence of hospitals being insured. (*Denmark, Greece, Portugal and Spain*).

Comment
Satisfactory results since there were no critical elements identified in any country. The signing of insurance policies on the part of hospitals and doctors seems to be a consolidated practice. Worthwhile highlighting are also those elements that have nearly reached the threshold of 10 countries, such as the presence, in hospitals, of committees to assist patients in reaching a final agreement on compensation (*8 countries*) and the presence of independent organizations providing legal aid free of charge (*7 countries*).