ACTIVE CITIZENSHIP NETWORK

CITIZENS' REPORT ON THE IMPLEMENTATION OF THE EUROPEAN CHARTER OF PATIENTS' RIGHTS

Working paper
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Edited by Alessandro Lamanna, Giovanni Moro and Melody Ross

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1. Executive Summary

The survey

The rights are those set up in the European Charter of Patients' Rights by Active Citizenship Network (the European policy program of the Italian movement Cittadinanzattiva) in 2002: the Right to Preventive measures, Access, Information, Consent, Free choice, Privacy and confidentiality, Respect for patients' time, Observance of quality standards, Safety, Innovation, Avoidance of unnecessary suffering and pain, Personalized treatment, Complain, Receive compensation. The survey was conducted in 13 out of 15 "old" EU member countries (no data was collected in Belgium and Luxembourg), and will be expanded next year, to include the 10 new member and other European countries.

The survey consisted in defining a set of some 160 indicators relating to the 14 patients' rights, which were observed in each country through the following activities: interviews with 6 key persons and with the partner organizations, visits to the capitals' three main hospitals (including an interview with hospital authorities and the direct observation of a number of items), the collection of information on the existing laws and regulations at the national level to protect these rights, and the analysis of the comparable official data on issues regarding patients' rights. On this occasion, *Civic Audit* tools were applied, as they have been experimented in a number of public services by Cittadinanzattiva.

The survey was carried out in cooperation with 13 national-based citizens' organizations that were the partner organizations of this project. Some 70 key persons were interviewed and 39 hospitals were visited. The most significant fact to be reported with respect to the development of this research is *the refusal of hospital authorities from Germany, UK, Ireland and Portugal to provide information to the partner organizations*. Results coming from other sources have been successfully used so that these countries could still be included in this report. It is, however, important to point out that *such refusal is in itself an indicator of the lack of transparency and openness of hospital authorities from those countries in relating to active citizens, and can be therefore considered as such a result of the research, though unfortunately a negative one.*

Of course, the research data does not represent a statistically significant sample, as well as having other limits. Nevertheless, its findings have the value of identifying phenomena that can be considered as *indicators with respect to the level of attention* being given towards patients' rights. Moreover, it allows for the comparison of different national situations reflecting the condition of citizens, patients or users of health structures. It has also enabled the setting up and testing of a research methodology which can be further and more widely used, as well as the building of an appropriate base of data on patients' rights on a European basis, which can be used together with other sources in health care related issues. Finally, as for the collection of information in hospitals, it must be stated that, on the one hand, the 39 hospitals visited clearly are not a representative sample with full statistical significance; but on the other, they are in any case among the 39 largest and most important health structures in Europe. Therefore, they can reasonably be considered as points of excellency at the national level, which provide us with important information concerning the health care system.

This report is a working paper; a full report will be published in the coming months.

Emerging phenomena

From the analysis of the indicators of patients' rights the following main phenomena emerged:

1. Right to Prevention: little prevention in hospitals - Prevention of cancer that specifically affect women ... but the rest? - Public communication campaigns are growing

The involvement of hospitals in primary and secondary prevention activities is in general very low. Moreover, the availability of materials on prevention is very limited in most of the hospitals observed. In 11 out of 13 countries a good diffusion of screening activities related to cancers that specifically effect women have been reported. However, prevention activities regarding other diseases do not have the same diffusion. Public communication campaigns – a growing activity in all the countries surveyed with topics such as the prevention of HIV, sexually transmitted diseases, alcoholism, the fight against smoking and road safety being the most mentioned.

2. Right to Access[*]

Access to care: A limited universalism - What essential levels of care?

In all the countries the existence of groups of people not covered by national health services or confronting obstacles limiting their access to adequate care was reported. These obstacles are the lack of coverage by public insurance for health services considered essential to the public, the existence of administrative and/or economic obstacles to access services, and the access to drugs which have been approved in other countries, but not yet in their own.

Physical access: Accessibility, but not for all

A satisfactory widespread availability of facilities for public access to hospitals emerged in 11 countries out of 13. However, accessibility for persons with disabilities that are clearly marked was reported only in 8 countries out of 13.

3. Right to Information: Widespread facilities for citizens' information, but little material on hot topics - Active citizens seen as foreigners

In most of the countries' hospitals the existence of tools for the information of patients and users were reported (telephone number, information office, etc.). However, material regarding critical topics is the least diffused. It is the case of materials on waiting lists, on complaints received by the public and on patients' satisfaction and clinical performance.

Areas reserved to patients' and citizens' associations inside hospitals have been reported only in 6 out of 13 countries. This information is undoubtedly linked to the refusal of hospital officials of four countries to answer the monitoring groups' questions.

4. Right to Consent: Written consent, but not much informed

Standardized forms for gathering consent are widely diffused, but they are used more for scientific research rather than for invasive diagnostic exams and surgical operations. The content of consent forms emerged as being only partial and not exhaustive, especially for information concerning risks and benefits.

5. Right to Free Choice: A "free" choice with many obstacles

Some structural limitations to citizens' choices emerged in the majority of surveyed countries. They are: the need to get authorization for some treatments; different fees (and reimbursement) in public and private hospitals; coverage of supplementary insurance only for some hospitals, and thus the option of seeking treatment in just those few hospitals.

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[*] In the survey this right was divided in two dimensions: access to care and physical access, because of the very different nature of the scrutinized phenomena.

6. Right to Privacy and Confidentiality: To die in the hospital, how? Who gets medical information?

The survey reported a limited number of single rooms available for terminal patients in hospitals. On the contrary, examination rooms with dividers or curtains are quite widespread.

In 7 countries out of 13, situations when medical information was disclosed to non-authorized persons were reported.

7. Right to Respect of Patients' Time: Hidden rationing damaging citizens, without a security mechanism and without elementary tools

There is a widespread phenomenon of freezing waiting lists for one or more exams, which represents a hidden form of restricting the access to health care. The consequence of this practice can be seen in reported cases, such as cases in which an illness has worsened because of a delay in treatment; waiting time for important diagnostic exams too long and the need to use payable services due to the long waiting time.

Moreover, in general there doesn't exist an established time limit to receive diagnostic exams or therapeutic treatment from the time it was prescribed by the hospital doctor. In several countries it was reported the lack of tools enabling citizens to deal with this situation, such as the availability to the public of the waiting lists for diagnostic exams, a single, unified contact point for appointments; appointments for specialist and diagnostic exams made by phone.

8. Right to the Observance of Quality Standards: A widespread system for quality assessment, but privileging the easiest way of customer satisfaction, with controls but without sanctions and without involving citizens

Tools, procedures and institutions aimed at accrediting or certifying quality of services appears to be fairly common in the countries surveyed. Nevertheless, the most widespread form of quality assessment are studies on customer satisfaction, which are the least complex way to improve and check quality. Moreover, there are control activities on the fulfillment of standards, but sanctions for when these standards are not respected are limited, while imposing sanctions for the lack of respect of these standards is practically non-existent. Finally, involving citizens' organizations in the definition of these standards is reported only in one country, while no country reported citizens' involvement in the activities to monitor and control.

9. Right to Safety: Many risk-reducing actions in many countries - Still, too many reports of violations of this right - Safety of disabled underestimated - Serious deficiencies of emergency exits in some countries

From the survey a fairly structured practice aimed at reducing the risk of adverse events has emerged in the majority of countries. Nevertheless, cases of violation of the right to safety in the last year have been reported in 8 countries out of 13. In the hospitals surveyed, clearly marked evacuation routes for wheelchair users were observed only in two countries, while special evacuation procedures for wheelchair users marked on the map in one country only. Evacuation maps have been observed in hospitals of only 6 countries out of 13, while emergency exit signs were missing in the hospitals of two countries.

10. Right to Innovation: A two-speed innovation? - Delays

In seven countries out of 13 from the key persons interviews there was no significant evidence of the diffusion of new technologies. From the hospital visits, on the contrary, positive information emerged. This result probably means that, while in some central and big structures innovative technologies are currently used, in the rest of the country the level of their diffusion is definitely low. Widespread situations of violation of this right were reported, in particular delays in introducing innovative treatments and in medical research.

11. Right to Avoid Unnecessary Suffering and Pain: An upcoming issue - Still unnecessary pain

In most of the countries it resulted that this problem is beginning to be dealt with. However, appropriate and general programs of action exist only in a few countries. In about half of the countries surveyed, cases of violation of this right were reported, such as the lack of administrating painkillers or morphine even when international standards recommended their use.

12. Right to Personalized Treatment: Attention to diversities....but not in all countries - Top attention for children

In only about half of the countries there emerged a widespread and structured engagement in delivering health treatments according to different individual, social and cultural needs. While in almost all the countries, a high level of attention towards children's needs was reported.

13. Right to Complain: A well-defined route for citizens' complaints, but risking self-referentiality and lacking effectiveness

In all the countries there exists a structured procedure aimed at receiving and processing citizens' complaints. The majority of committees in charge of receiving and processing citizens' complaints, however, are not independent from the hospitals. In 12 countries there were reported cases of taking too long a time to respond to citizens' complaints, while in 2 countries a complete lack of response to citizens' complaints was reported.

14. Right to Compensation: Insurance policies, not ever existing - A good practice not much followed

In almost all of the countries there are insurances covering the compensation for possible damages to patients. Nevertheless, they do not always cover both provider and doctor but usually just one of the two. In two countries hospitals and doctors do not have any insurance.

In five countries, committees or structures to assist patients in reaching final agreements on compensation and/or on its amount, do exist and in almost all cases are independent from hospitals.

The degree of attention to rights

According to the above results, a classification of the rights in relation to the degree of attention they receive was set up.

General classification of Patients' Rights according to the Degree of Attention

DEGREE OF ATTENTION	RIGHT	SCORE
HIGH	Access – Physical	26
	Complain	26
	Privacy	25
	Information	24
	Safety	24
MEDIUM	Personalized Treatment	22
	Quality	21
	Innovation	20
	Avoid pain	20
LOW	Free choice	19
	Compensation	19
	Prevention	18
	Consent	18
	Access – Care	17
	Time	16

Score: min 9, max 27; average: 21
Active Citizenship Network, 2005

The low level of attention towards the rights to Free Choice, Access to Care and Respect for Patients' Time seems related the same fundamental problem, that is, the correlation between the crisis of the "European Social Model" and patients' rights.

The right to Prevention emerged as one of the lowest rights in terms of degree of attention, and the right to Innovation scored under the average. Even though Europe is probably the region of the world where, thanks to its welfare systems, the highest success in preventing diseases has been reached, this finding could be considered as a warning of a possible decrease in the commitment of governments and professionals.

In general, more than half of the patients' rights scored below the average mark. It denotes a very critical situation regarding the attention towards patients' rights at the national level. Moreover, those rights that scored in the highest cluster are not free from problems, as can be observed from the gathered phenomena.

Finally, it is not of minor importance the fact that a certain gap seems to exist between the concerns and priorities of the policymaking community and the main problems affecting patients' rights (for example, the right to privacy, the right to information, the right to complain are very central to the policymaking community and they are among those receiving the most attention; on the contrary, the right to time, the right to compensation and the right to innovation are really critical, but they do not seem to be considered important by the policymaking community).

Policy Priorities

On the basis of the results of the survey, the following seven priorities have been identified:

1. **Patients' rights must become a common point of view and a standard for making decisions on health care,** as well as a shared commitment of European and national institutions and of all the actors of health policies. The present critical situation of health services requires that a strong point of reference, clearly linked to the general interest, be identified. This point can be precisely that of patients' rights.
2. **Existing data and information on health care at the European level should be enriched with that regarding patients' rights**, by integrating the traditional methodologies and sources with those used in this survey, such as *Civic Audit* activities, which involve citizens as actors as well as sources in producing information.
3. **A European agenda on patients' rights** should be set up and implemented with an appropriate plan of action, involving both European and national authorities as well as health care stakeholders. Since patients' situation is a matter of fundamental rights, a stronger role of the EU should be established, while fully respecting national responsibilities.
4. **The practice of the "Rights of Active Citizenship**" stated in the European Charter of Patients' Rights (to perform general interest activities; to carry out advocacy activities; to participate in policy making), *should be supported and guaranteed in the whole European Union*, as an expression of European citizenship. It can no longer happen that active citizens are not allowed to gather information and cooperate in the assessment of rights, as occurred in this survey.
5. **The financing of health structures by governments and other payers must be conditional to the success of these structures in protecting patients' rights**. Appropriate standards and indicators should be identified and assessed, so that the ability to respect patients' rights becomes a competitive advantage in the health care market.

6. **Firm action towards the changing of cultural, professional and organizational models in health care must be taken**. As was shown by this survey, the protection of patients' rights does not only depend on financial matters, but is also linked to the behavior of professionals, the ways to manage services, and the attitudes of the public. They can and must change quickly.
7. Finally, **a patients' right-based approach is needed to deal with the new trends and emerging situations** that are going to characterize the European health care scenario. While our survey could collect information only on the existing factors affecting patients' rights, an approach based on patients' rights is needed to manage new situations, such as those related to *free movement* or the *EU enlargement*, as well as the measures and decisions that are now being discussed or that will be discussed, like the *liberalization of information on drugs* or the *use of biotechnologies*.

Section 1
The European Charter of Patients' Rights and the Monitoring project

This document presents the principal results and findings of the monitoring process of the European Charter of Patients' Rights carried out in the 15 old member states[1] of the EU. This project was a joint effort by Active Citizenship Network (ACN), the European policy program of the Italian movement Cittadinanzattiva[2] and the Tribunal for Patients' Right (TDM), the health policy program of the same movement along with civic organizations in each of the monitored countries.

The project is a follow up from the initial one started in 2002 with the drafting and promoting of the European Charter of Patients' Rights. The general aim of the project was to monitor the state of implementation of the 14 rights, as declared in the European Charter. In this section we will address both the European Charter of Patients' Rights and the monitoring of its implementation.

The European Charter of Patients' Rights

Why a Charter on Patients' Rights

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

The European citizens cannot continue to accept that rights be affirmed in theory, but then denied in practice, because of financial limitations. Budgetary constraints, however justified, cannot legitimise denying or compromising patients' rights. Therefore, it is unacceptable that rights be established by law, but then left not respected, promised in electoral programmes, but then put aside when new government comes to office.

For these reason, in 2002 ACN, together with some 15 citizens' organizations operating at the national and European level, drafted a European Charter of Patients' Rights.[3] The main objective of the Charter is to strengthen and bring greater awareness concerning patients and citizens' rights, which are presently at risk in all EU countries.

The EU Charter of Fundamental Rights and Health

The European Charter of Patients Rights also aims at making concrete and applicable certain rights present in the Nice Charter of Fundamental Rights, which is now a part of the European Constitutional Treaty.

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[1] Austria, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Portugal, Spain, Sweden, United Kingdom, plus Belgium and Luxembourg where the project could not be implemented (see below).

[2] www.cittadinanzattiva.it, www.activecitizenship.net

[3] This project and survey were sponsored by an unrestricted educational grant from Merck & Co., Inc., Whitehouse Station, New Jersey USA."

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

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

In addition to Article 35, the Charter of Fundamental Rights contains many provisions that refer either directly or indirectly to patients' rights, and are worth recalling: the inviolability of human dignity (article 1) and the right to life (article 2); the right to the integrity of the person (article 3); to security (article 6); to the protection of personal data (article 8); to non-discrimination (article 21); to cultural, religious and linguistic diversity (article 22); the rights of the child (article 24); the rights of the elderly (article 25); the right to fair and just working conditions (article 31); to social security and social assistance (article 34); to environmental protection (article 37); to consumer protection (article 38); the freedom of movement and of residence (article 45).

The 14 Patients' Rights

The fourteen patients' rights seek to make the fundamental rights mentioned above concrete, applicable and appropriate to the current transition process in the health services. These rights all aim to guarantee a "*high level of human health protection*" (Article 35 of the Charter of Fundamental Rights) and assure the high quality of services provided by the various national health services. They must be protected throughout the entire territory of the European Union.

14 Patients' Rights

1-Right to Preventive Measures
2-Right of Access
3-Right to Information
4-Right to Consent
5-Right to Free Choice
6-Right to Privacy and Confidentiality
7-Right to Respect of Patients' Time
8-Right to the Observance of Quality Standards
9-Right to Safety
10-Right to Innovation
11-Right to Avoid Unnecessary Suffering and Pain
12-Right to Personalized Treatment
13-Right to Complain
14-Right to Compensation

Active citizenship as a right

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

- Right to perform general interest activities
- Right to carry out advocacy activities
- Right to participate in policy-making

In order to begin promoting and implementing the Charter and put into practice a European active citizenship, ACN proposed in 2003 a project to monitor the implementation of the European Charter of Patients' Rights in then 15 EU member states.

The Monitoring Project: a concrete experience in European active citizenship

The right to carry out auditing and assessment activities in order to measure the actual respect for the rights of citizens in the health care system can be considered a basic activity of active citizenship. Carrying out this activity at the European level could therefore be considered a concrete and practical experience of exercising European active citizenship.

The project had the following objectives:

- To produce new information on the actual implementation of patients' rights.
- To change the role of citizens in the health care system from the traditional vision of citizens, seen as mere targets or users of health services, to the concept of them as active citizens involved in producing information with the aim of participating in the improvement of services and the policymaking process.
- To empower citizens' organizations as well as citizens themselves in the protection of rights and the caring for common goods such as health.

One of the most innovative activities of this process was to collect information through the direct observation of hospital facilities and interview hospital authorities. This gave citizens the opportunity to put into practice their right to participate in evaluating services and policies, as well as accrediting themselves with public institutions such as, the hospital administration and Ministry of Health. However, as well as being the most innovative part of this research, it also proved to be the most difficult, due to the fact the that this type of citizens' activity does not seem to be a ordinary practice in most countries. For many organizations it took a long time and required many attempts before they were actually able to have an interview with the hospital administration. Often, they were given the so-called "run around", as hospitals seemed to adopt a passive resistance approach, not recognizing the legitimate role of citizens to seek information regarding health care services. In the end, four countries (Portugal, Ireland, Germany and the UK) were not able to get an interview with hospital authorities.

Section 2
The Research Design and Methodology

Research design

The design of this research tried to meet the following requirements:

- Contribute to the creation of an initial data base regarding patients' rights, taking into account that information on patients' rights is presently lacking and, in the case where it exists, it usually does not have a European basis;
- Involve national-based citizens' and patients' organizations in an experience of *Civic Audit*, that is, in the production of their own information with the possibility to contribute in assessing public policies. This type of activity has been successfully experimented in Italy by Cittadinanzattiva on several issues and services, including health care at national and local levels for some time now;
- Give value to the existing information on a European basis, putting together pertinent statistical data.

Because of time and resource constraints, the research was implemented in the 15 "old" European Union member countries. The same will be done in the new EU member countries and other European countries in 2005-2006.

Methodology

The main methodological choices and strategies to implement this design have been the following:

- Translate each of the 14 patients' rights into a set of indicators able to be observed and measured;
- Identify a research field able to give reliable – though limited – information and at the same time able to make the research feasible according to the existing constraints.

On the basis of these requirements, the following methodological choices were taken and implemented:

- Five sources of data have been identified:
    - European-based statistical data;
    - Key persons operating in the health care at national level;
    - Partner organizations as qualified informers on the state of patients' rights in each country;
    - Hospital authorities responsible for hospital management;
    - Concrete situations able to be directly observed inside hospitals.
- Three research tools were then produced:
    - A questionnaire to be used for key persons and partner organizations;
    - A questionnaire on the existing legislation regarding patients' rights to be answered by the partner organizations;
    - A checklist to be used in monitoring hospitals, including questions to be put to hospital authorities and indicators to be directly observed by the partner organizations.

The implementation of the research was the following:

- Six key persons in each country were selected, reflecting this typology: a representative from the Ministry of Health; an expert in the health field; a representative of third-party payer (insurance); a representative from the doctors; a representative from nurses; a journalist specialized in health;

- The three main hospitals of the European capitals were chosen to be visited by the monitoring groups from the partner organizations;
- An expert from the Department of Demography of the Faculty of Statistics of the Rome La Sapienza University was asked to report on the existing statistical sources related to patients' rights, either directly or indirectly;
- Partner organizations were asked to self-administer the key persons questionnaire and to answer the questionnaire on legislation.

The above mentioned instruments were used to collect information regarding somef 160 indicators for the 14 patients' rights.

Development

The project started in 2003 with ACN establishing a working group to design the monitoring process and its respective tools. The methodology and tools were then discussed and enriched during a meeting with health experts and civic organizations held in November 2003[4]. After that the tools were implemented in Italy as a pilot test undergoing further changes. During this same time partner organizations were being identified and two meetings were held in Rome (April and June 2004) to discuss methodological and operational features of the project. The research was carried out in 14 out of 15 old EU member countries. In Luxembourg it was not possible to identify a partner organization available to take part in the project.

The implementation of the monitoring process took place from June until November 2004. In general the most difficult aspect of the monitoring process, as mentioned before, was getting the authorization from the hospitals and afterwards being able to actually set up a meeting with hospital authorities to complete the questionnaire for gathering the hospital information.

The collecting and compiling of the information from various countries took place in December. During January and February the research staff analysed the data and drafted the report.

The Belgian organization, having participated in the project, was unable to finalize its work and renounced in January. Since this happened at the end of the project, it was impossible to find a substitute. The Belgian part of the research will be implemented in 2005-2006 together with the other European countries, selecting a new partner organization.

In all the countries not all key persons answered the questionnaire, and in some countries there were only able to complete the visit and interview in two of the three hospitals. In total 39 hospital were visited out of which in 25 hospitals, both the direct observation and interviews with hospital authorities were carried out, while in 14 hospitals only the direct observation could be done. In respect to key persons interviews, there were a total of 70 experts.

The most relevant fact to be reported with regard to the development of the research is **the refusal of hospital authorities from Germany, UK, Ireland and Portugal to give information to partner organizations**. Therefore, the research in these countries lacks this part of the information collected on the other countries. Information coming from the other sources have been successfully used so that these countries could still be included in this report. However, it is important to stress that **such**

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[4] Participants in the expert meeting: Margrethe Nielson, Danish Consumer Council, Denmark; Martin Rusnak, International Neurotrauma Research Organization, Austria; Albert Jovell, Biblioteca Josep Laporte, Spain; Louiza Mavrommatis, KIDDA, Cyprus; Mariadelaide Franchi, BPCO, Italy; Alessandro Lamanna, Cittadinanzattiva; Fiorenza Deriu, University La Sapienza; Simona Sappia, TDM-Cittadinanzattiva; Giovanni Moro and Melody Ross, ACN-Cittadinanzattiva, Italy.

refusal is in itself an indicator of the lack of transparency and openness of the hospital authorities in those countries in relation to active citizens, and can be therefore considered a result of the research, though unfortunately negative.

The research was directed by the ACN staff, coordinated by Melody Ross and composed of Cecília Fonseca, Alessandro Lamanna and Giovanni Moro. Charlotte Roffiaen, Simona Sappia, and Stefano Inglese cooperated in the phase of the methodological design. Fiorenza Deriu, by the Department of Demography of the Faculty of Statistics of the Rome La Sapienza University, worked on the European statistical data related to patients' rights and Marianna Buonomo assisted in the data processing.

Value and Limits of the Research

Taking into account the high experimental and innovative meaning of the research, the following statements about its limits and value must be set up.

The main **limits** can be summarized as follows:

- Apart from the European-based statistical research results, the others do not reflect a sample with a full statistical significance and value, because of both the low number of people interviewed and hospitals visited;
- Indicators related to each right are not necessarily homogeneous and have a different value, according to the content of each right and to the research constraints, as well the quantity of indicators vary from right to right;
- The research does not take into account the differences between the national health care systems, for example in terms of financing, public or private ownership or delivering of services, and so on;
- The research cannot reflect what happens at a regional and local levels, even in the cases in which health policies are decentralized;
- The research does not (and could not) consider relevant problems related to the development of rights in the near future – for example the effects of freedom of movement inside the EU, possible changes in rules concerning information on drugs and consequences of biomedical research – being limited to only examining existing factors and phenomena.

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

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

Particular attention must be given to the collection of information in hospitals. On one side, the 39 hospitals visited clearly are not a sample with full statistical meaning, neither at the national nor European level. On the other side, they are still 39 of the biggest and most important health facilities in Europe and they can reasonably be considered as a point of excellency at the national level. Therefore, what does occur in these structures is meaningful.

This paper

This paper must be considered as only a working document for the 28 February – 1 March 2005 conference in Brussels. On the basis of the results coming out of the Brussels discussion a full report will be set up, including as well the extensive research done on the available statistical data and other pertinent materials produced during the survey, which only a synthetic version has been included as an appendix to this document.

In order to facilitate the reading of the tables reported from diverse sources in Section 3, they have been differentiated graphically by being given a specific border depending on the source of information contained in the table . Therefore, there will be

Tables reporting data from the key persons interviews

Tables reporting data from the hospital officials' interviews

Tables reporting data from the hospital direct observation

This report was edited by Alessandro Lamanna, Giovanni Moro and Melody Ross.

Section 3
A Review of the Indicators[*]

The first series of results we are going to present regard what emerged from the single indicators as a consequence of the information collected through the hospital visits and the key persons interviews. For each patient's right a special set of indicators was established. For the 14 patients' rights there were some 160 indicators identified.

Here are the results.

1. Right to Preventive Measures

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

During the interview with the hospital authorities, it was asked what primary or secondary prevention programs were being run at the moment for the public free of charge. The answers are summarized in the following table.

Table 1.1 - Currently running prevention program (by Hospital authorities)

Prevention Programs free of charge	Au	De	Fi	Fr	Ge*	Gr	Ir*	It	Ne	Po*	Sp	Sw	UK*	Tot
Screening programs for cervical cancer with Papanicolaou testing in women who have been sexually active	-	-	-	-		-		-	x		x	x		**3**
Screening programs for breast cancer with mammography for women aged 50 and over	x	-	-	-		x		-	x		x	x		**5**
Screening programs for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonscopy	-	-	-	-		-		-	x		-	-		**1**
Screening programs for hypertension in adults aged 18 and older	-	-	-	-		-		-	x		-	-		**1**
Screening programs to detect amblyopia and strabismus for all children prior to entering school	-	-	-	-		-		-	-		-	x		**1**
Campaigns against smoking	-	x	x	x		-		-	-		x	-		**4**
Detect drinking problems for all adult and adolescent patients	-	-	-	x		-		-	-		-	-		**1**
Prevention programs for HIV/AIDS	-	-	-	x		x		-	-		-	-		**2**
Prevention programs for other sexually transmitted diseases	-	-	-	x		-		-	-		-	-		**1**
Total	**1**	**1**	**1**	**4**		**2**		**0**	**4**		**3**	**3**		**19**

*Legend: X = reported in 2 or 3 hospitals; - = reported in 1 o no hospitals, * = data not available since the hospitals authorities refused to cooperate with their information*
Active Citizenship Network, 2005

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[*] In order to set up the following tables, the items that were considered as "present", and thus marked with an X, were those that have been directly observed or reported by the hospital authorities in 2 or 3 of the 3 hospital visited (in case where only two hospitals were visited, it was marked when they have been reported in all of the two hospitals). As for the information reported by the key persons and the partner organizations, the items have been marked with a X when reported by the majority of key persons, giving to the partner organizations a double value. Cases differing from these rules have been indicated in the tables.

Hospitals implementing the highest number of prevention programs are those in France and Netherlands, followed by Spain and Sweden. As for the issues dealt with, attention seems focused on cancers that affect specifically women and on smoking.

In Ireland, as well as in the UK, Germany and Portugal the hospitals refused to cooperate with the survey and provide the organizations with information. Therefore, the only data available was collected through the direct observation by the monitoring group.

With regard to prevention, the observation concerned the existence of notices or material in the lobby or outpatient area on various subjects referring to prevention.

In the following table the general results of this observation are reported.

Table 1.2 - Material made available to the public by the hospitals (direct observation)

Material on Prevention for the public	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Early diagnosis of tumors affecting women	-	-	x	-	-	-	x	-	x	-	-	-	-	**3**
Prevention of sexually transmitted diseases	-	-	-	x	-	-	-	-	x	-	x	-	x	**4**
Dental prevention	-	-	-	x	-	-	-	-	x	-	-	-	-	**2**
Quitting smoking	-	-	x	x	-	-	x	-	x	x	x	-	x	**7**
Treating alcohol dependence	-	-	x	x	-	-	x	-	x	-	x	-		**5**
Cardiovascular disease prevention	-	-	x	x	-	-	-	-	x	-	x	-	x	**5**
Neurovascular disease prevention	-	-	-	-	-	-	-	-	x	-	-	-	-	**1**
Domestic and recreational accidents	-	-	-	-	-	-	-	-	x	-	-	-	x	**2**
Nutrition	-	-	x	x	-	-	-	-	x	-	-	-	-	**3**
Total	**0**	**0**	**5**	**6**	**0**	**0**	**3**	**0**	**9**	**1**	**4**	**0**	**4**	**32**

Legend: X =observed in 2 or 3 hospitals; - = reported in 1 o no hospitals
Active Citizenship Network, 2005

In the Dutch hospitals there was material on 9 issues, 6 in France, 5 in Finland and 4 in Spain and the UK. Austria, Germany, Greece, Italy and Denmark showed the worst situation with regard to this indicator. It is similar to the situation regarding prevention programs run in the hospitals (excluding Germany, which has no available data).

The interviews with key persons has allowed us to incorporate the information gathered from the hospitals with a more extended vision to include the national contexts.

In the following table the result of this consultation is reported. It considers the existence, at the national level, of screening programs currently available free of charge.

Table 1.3 – Screening program existing at the national level (by key persons)

Screening Programs	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Screening programs for cervical cancer with Papanicolaou testing in women who have been sexually active	x		x	x	x	x		x	x	x	x	x	x	**11**
Screening programs for breast cancer with mammography for women aged 50 and over	x		x	x	x	x		x	x	x	x	x	x	**11**

table continued

Cont. Table 1.3 - Screening program existing at the national level (by key persons)

Screening Programs	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Screening program for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonscopy	x				x			x						**3**
Screening programs for hypertension in adults aged 18 and older	x										x			**2**
Screening programs for lipid disorders											x			**1**
Screening programs to detect amblyopia and strabismus for all children prior to entering school	x		x	x	x				x			x		**6**
Screening programs for diminished vision acuity for elderly											x			**1**
Detect drinking problems for all adult and adolescent patients											x			**1**
Total	**5**	**0**	**3**	**3**	**4**	**2**	**0**	**3**	**3**	**2**	**6**	**3**	**2**	**36**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

The key persons were also asked to give information on the existence of public communication campaigns carried out by health authorities. In the following table these results are reported.

Table 1.4 -Public communication campaigns (by key persons)

Public Communication Campaigns	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
HIV Prevention	x		x	x	x	x	x		x	x	x	x	x	**11**
Prevention of sexually transmitted diseases				x		x	x	x	x	x	x		x	**8**
Early diagnosis of tumors affecting women	x		x	x		x		x		x	x		x	**8**
Fight against smoking	x	x	x	x	x	x	x	x		x	x	x	x	**12**
Alcoholism	x	x	x	x			x	x		x	x	x		**9**
Nutritional disorders		x	x	x			x				x	x		**6**
Depression			x								x			**2**
Heart disease			x	x			x			x	x		x	**6**
Domestic accidents	x		x	x			x	x			x			**6**
Road safety	x	x	x	x		x	x	x		x	x	x	x	**11**
Dental care	x										x			**2**
Total	**7**	**4**	**9**	**9**	**2**	**5**	**8**	**6**	**2**	**7**	**11**	**5**	**6**	**81**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

Putting together the screening programs and public communication campaigns running at the national level, the following overview on the number of preventive measures implemented appears.

Table 1.5 -Summary: number of Preventive Measures (key persons)

Preventive Measures	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Screening Programs	5	0	3	3	4	2	0	3	3	2	6	3	2	**36**
Public communication campaigns	7	4	9	9	2	5	8	6	2	7	11	5	6	**81**
Total	**12**	**4**	**12**	**12**	**6**	**7**	**8**	**9**	**5**	**9**	**17**	**8**	**8**	**117**

Active Citizenship Network, 2005

The country with the greatest number of preventive measures identified is Spain, followed then by Austria, Finland, France, Portugal and Italy.

In general, Spain, Austria and Finland received good results, but the majority of key persons from those countries reported cases of violation of this right. This was also the case in Germany.

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 daily efforts of 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" character, 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.

1. Access to care

The accessibility to healthcare was assessed by asking the key persons if they were aware of any residents (either legal or illegal) unable to receive care free of charge. In the following table the results are reported.

Table 2.1 -Population not covered by health services (by key persons)

Population not covered by health services	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Existence of residents (legal or illegal) NOT covered :	x	x	x	x	x	x			x	x	x	x	x	**11**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

As the table clearly illustrates, this phenomenon appears as widespread, confirming one of the most relevant problems of European national health systems. Also in the case of the two countries not reporting the existence of groups excluded by health care (Italy and Ireland), the key persons agree on the existence of obstacles that in reality limit certain group of the population to fully benefit from the services guaranteed by the mandatory public insurance coverage.

Table 2.2 -Indicators of difficult access to healthcare services (by key persons)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Important health care issues not covered by health care package	x				x		x			x	x			**5**
Complaints and protests due to the lack of coverage by public insurance for health services considered essential by the public (services that patients must pay for and which are not reimbursed)		x		x			x	x	x	x	x	x	x	**9**
Lack of health care for patients with rare diseases					x		x			x			x	**4**
Complaints due to lack of specialized clinics to treat a particular rare disease								x		x	x	x	x	**5**
Lack of health care for patients with rare diseases					x		x			x			x	**4**
Complaints due to lack of specialized clinics to treat a particular rare disease								x		x	x	x	x	**5**
Forced migration to other countries to receive health care		x				x				x				**3**
Complaints due to administrative and/or economic obstacles to accessing services			x			x	x	x	x	x		x	x	**8**
Complaints and protests regarding access to drugs, which have been approved in other countries, but not yet in theirs.		x	x	x				x	x		x		x	**7**
Total	**2**	**3**	**3**	**3**	**3**	**2**	**5**	**4**	**3**	**6**	**4**	**4**	**5**	**47**

Legend: X = the majority of key persons interviewed identified this obstacles
Active Citizenship Network, 2005

The most generalized facts that indicate the difficult access to health care services, according to the key persons, are the lack of coverage by public insurance for health services considered essential by the public, administrative and/or economic obstacles in accessing services, impossibility to access to drugs available in other European countries.

Portugal, Ireland and UK are the countries where more events are reported, while Austria and Greece have the least.

Specific situations where the right to guaranteed equal access of health services without discriminating has not been respected were reported by the key persons and partner organizations of Austria, Finland, France, Germany, Ireland, Sweden, Portugal and the U.K.

Table 2.3 –Cases when the right to access has been violated in the last year (by key persons)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**
Cases identified by key persons	x	-	x	x	x	-	x	-	-	x	-	x	x

Legend: X =at least 4 key persons interviews identified cases when this right had been violated during the last year.
Active Citizenship Network, 2005

2. *Physical access*

As for the second dimension of the right to access, the information collected through the hospital observation presents the following situation.

Table 2.4 –Indicators for public access to hospital facilities (by direct observation)

Existence of:	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Street signs indicating the hospital's location	x	x	x	x	x	-	x	x	x	x	x	x	x	**12**
Main hospital entrance clearly marked	x	x	x	x	x	x	x	x	x	-	x	x	x	**12**
Accessibility for persons with disability clearly marked	-	x	x	-	x	-	x	x	x	-		x	x	**8**
NO structural barriers at hospital entrance	x	x	x	x	x	x	x	x	x	-	x	x	x	**12**
Possibility to drop off patients with motor difficulties at the main entrance	x	x	x	x	x	x	x	x	x	-	x	x	x	**12**
Public transport to hospital	x	x	x	x	x	x	x	x	x	x	x	x	x	**13**
Visitors parking	x	x	x	x	x	-	x	x	x	-	x	x	x	**10**
Reserved parking for persons with disabilities	x	x	x	x	x	-	x	x	x	-	x	x	x	**10**
Total	**7**	**8**	**8**	**7**	**8**	**4**	**8**	**8**	**8**	**2**	**7**	**8**	**8**	**89**

LEGEND: X= observed in 2 or more hospitals; - = reported in 1 o no hospitals,
Active Citizenship Network, 2005

These indicators generally appear present in most hospitals. Nevertheless, it must be noticed that accessibility clearly marked for persons with disabilities was reported only in 8 countries out of 13. The two most critical situations, based on the hospital observation, appear to be Portugal (two indicators only) and Greece (four).

3. Right to Information

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

A first set of indicators relate to how the hospitals make available basic information to the public. Here are the results.

Table 3.1 –Public access to information (by hospital authorities and direct observation)

Existence of :	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Telephone number the public can call (hospital interview)	x	x	x	x	▨	x	▨	x	x	▨	x	x	▨	**9**
Information office or service at the main entrance (hospital interview)	x	x	x	x	x	x	x	x	x	x	x	x	x	**13**
Hospital web site (hospital interview)	x	x	x	x	▨	x	▨	x	x	▨	x	x	▨	**9**
Regularly updated directory in main lobby (hospital observation)	x	x	x	x	-	x	x	-	x	x	x	x	x	**11**
Areas reserved for patient' associations (hospital observation)	-	x	-	x	-	-	-	x	x	-	-	x	x	**6**
Specific signs to indicate patients' association area (hospital observation)	-	x	-	-	-	-	-	x	x	-	-	x	x	**5**
Total	**4**	**6**	**4**	**5**	**1**	**4**	**2**	**5**	**6**	**2**	**4**	**6**	**4**	**53**

LEGEND: X= observed in at least 2 or more hospitals; - = reported in 1 o no hospitals, * hospital authorities refused to give an interview and answer questions
Active Citizenship Network, 2005

In all the countries it was observed the presence of an information office at the main entrance of the hospital. Among the other indicators, the most generalized was the existence of a regularly updated directory in the main lobby, the existence of a phone number the public can call and the existence of a hospital web site.

The less diffused indicators are, on the contrary, areas reserved for patients' associations and specific signs to indicate the patients' association area. They were observed only in Denmark, France (excluding the signs), Italy, Netherlands, Sweden and the UK.

In Germany only one indicator was observed; in Ireland and Portugal only two.

During the hospital visits it was also observed the presence of information material available to the public. The result is summarized in the following table.

Table 3.2 –Information material available to the public (direct observation)

Existence of :	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Information sheets about the hospital and the regulation concerning inpatients	x	x	x	x	-	x	-	x	x	-	x	x	x	**10**
Information sheets on the patients' rights (inpatients and outpatients)	x	x	x	x	-	x	-	-	x	-	x	x	-	**8**
Notices regarding waiting lists for diagnostic exams and surgery	-	x	-	-	-	-	-	-	x	-	x	x	-	**4**
Reports on complaints received from the public	-	x	-	-	-	-	-	-	x	-	x	x	-	**4**
Data on outcomes of health care service (patient satisfaction, clinical performance measures)	-	-	-	x	-	-		-	x	-	-	-	-	**2**
Data availability for benchmarking	-	x	-	x	-	-	-	-	x	-	-	x	-	**4**
Total	**2**	**5**	**2**	**4**	**0**	**2**	**0**	**1**	**6**	**0**	**4**	**5**	**1**	**32**

LEGEND: X= observed in at least 2 or more hospitals; - = reported in 1 o no hospitals
Active Citizenship Network, 2005

In this case, the situation is clearly differentiated in three conditions. The first is where there are many indicators reported. This is the case regarding information sheets on the hospital and its' regulation concerning inpatients, information sheets referring to patients' rights. The second is a when an average level of indicators is present, this regards notices concerning waiting lists, reports on complaints received from the public and the availability of data for benchmarking. The indicators that are least present refer to data on patient satisfaction and clinical performance.

Germany, Ireland and Portugal are the countries where the lowest number of indicators were observed. On the contrary in the Netherlands, all indicators were reported.

In all countries (UK, Portugal, Germany and Ireland no information was available) one can obtain a copy of their hospital records at a cost. Waiting times and costs for each country are summarized in the following table.

Table 3.3 -Availability of Hospital records: Time and cost (by hospital authorities)

Copy of Hospital Record	**Possibility of getting a copy**	**Waiting time (days)**		**Cost / sheet (euro)**	
		Max	Min	Max	Min
Austria	x	7	0	1,00	0
Denmark	x	7	0	0	0
Finland	x	3	7	NR	NR
France	x	30	8	0,47	0,10
*Germany					
Greece	x	7	5	0	0
*Ireland					
Italy	x	30	30	NR	NR

Table continued

Cont. Table 3.3 -Availability of Hospital records: Time and cost (by hospital authorities)

Copy of Hospital Record	**Possibility of getting a copy**	**Waiting time (days)**		**Cost / sheet (euro)**	
Netherlands	x	14	14	0,45	0,25
*Portugal					
Spain	x	NR	NR	0	0
Sweden	x	-	7	0,55	0
*United Kingdom					

LEGEND: X= reported in at least 2 or more hospitals; - = reported in 1 o no hospitals, * hospital authorities refused to give an interview and answer questions.
Active Citizenship Network, 2005

There is contrasting information from the key persons' interviews on the availability of waiting lists to the public in Italy and the Netherlands, while key persons do agree positively in Denmark, Sweden and France. According to the questionnaires, customer satisfaction information is provided by authorities in Italy, while information on clinical performance measures is provided by health authorities in Sweden (coronary by pass and open-heart surgeries; risk-adjusted acute myocardial infarction patient mortality index; risk-adjusted post-operative infection index; # heart-lung transplant patients and survival rates).

In the above mentioned countries there exist one or more organizations that provide the service of independent advisor.

In Austria, Greece and Finland the key persons consultation did not give positive results, since it did not allowed us to identify clear trends on the following items:

- Publicly available lists of hospitals;
- Consumer satisfaction information;
- Information on clinical performance and benchmarking;
- Organizations that perform the role of independent advisor.

In Germany, Ireland and Portugal, the consultation of key persons gave negative results. Only the following elements found were positive:

- Organizations that perform the role of independent advisor (Ireland, Portugal);
- Publicly available lists of hospitals.

No data on the possibility to obtain a copy of hospital records was available for these countries.

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

On this right, the research task was to gather information on the use of standardized forms for the getting of patients' consent, both in hospitals and in general.

The results of the hospital interviews are summarized in the following table.

Table 4.1 –Use of standardized forms for patients' consent (by hospital authorities)

Standardized Forms for:	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	**éUK**	**Tot**
Scientific research	x	x	x	x		x		x	x		x	x		**9**
Invasive diagnostic exams	x	-	x	x		x		x	-		x	-		**6**
Surgical operations	x	-	x	x		x		x	-		x	-		**6**
Total	**3**	**1**	**3**	**3**		**3**		**3**	**1**		**3**	**1**		**21**

LEGEND: X= reported in 2 or more hospitals; - = reported in 1 o no hospitals, * hospital authorities refused to give an interview and answer questions.
Active Citizenship Network, 2005

Countries where it was possible to collect this information seemed divided in two groups. One group formed by those countries where standardized forms are used both for scientific research, invasive diagnostic exams and surgical operations (Austria, France, Greece, Italy, Spain, Finland). The other group formed by countries where consent forms are used only for scientific research (Denmark, Netherlands and Sweden) .

Key persons' consultation has allowed us to highlight procedures used to get consent from patients, check the content of the forms used and to identify other possibly information sheets provided to patients relating to consent..

As for the use of forms for getting consent, there emerged in 9 countries.

Table 4.2 –Forms of getting consent (by key persons)

Existence of consent forms	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Pt**	**Sp**	**Sw**	**UK**	**Tot**
Existence of specific forms to get consent for high risk procedures	x		x	x	x		x	x		x	x		x	**9**

Legend: X =majority of key persons interviewed reported- yes
Active Citizenship Network, 2005

As for the content of these forms, the only point reported by the majority of the key persons regards the nature of the procedure. In general there is no information regarding risks, benefits and possible alternatives.

Table 4.3 –Information given in the forms (by key persons)

Forms give information on the following:	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Pt**	**Sp**	**Sw**	**UK**	**Tot**
Nature of procedure	x		x	x	x		x	x		x	x		x	**9**
Risks					x								x	**2**
Benefits	x													**1**
Alternatives														
Total	**2**	**0**	**1**	**1**	**2**	**0**	**1**	**1**	**0**	**1**	**1**	**0**	**2**	**12**

Legend: X =majority of key persons interviewed reported- yes,
Active Citizenship Network, 2005

Other information sheets are used in 5 countries only, and only in Netherlands the key persons reported the existence of information sheets on consent procedures in more than one language.

Table 4.4 –Other information sheets (by key persons)

Existence of other information sheets	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Pt**	**Sp**	**Sw**	**UK**	**Tot**
Information sheet on specific treatments	x			x			x		x		x			**5**
Information sheets available in more than one language									x					**1**
Total	**1**	**0**	**0**	**1**	**0**	**0**	**1**	**0**	**2**	**0**	**1**	**0**	**0**	**6**

Legend: X =majority of key persons interviewed reported- yes.
Active Citizenship Network, 2005

From the partial information available on the UK, Germany, Portugal and Ireland, it emerges that:

- In the United Kingdom and Germany the key persons report a frequent use of standardized forms including the description of the nature and risks of treatments;
- In Portugal and Ireland the key persons report a frequent use of standardized forms, but they do not provide information on their structure or content;
- In Ireland the use of other information sheets on specific treatments is reported as well.

Finally, in about one third of the countries, the key persons report cases of violation of the right to consent.

Table 4.5 -Cases when the right to consent has violated in the last year (by key persons)

Cases of violation	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Cases identified by key persons	x		x	x	x									**4**

Legend: X =at least 4 key persons interviews identified cases when this right had been violated during the last year.
Active Citizenship Network, 2005

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.

Many European countries in the last years have intervened concerning the possibility for citizens to freely choose, in the framework of their public insurance system, doctors or health structures, either enlarging or limiting this possibility. This occurs mainly in two ways:

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

Therefore, this issue is very complex and deeply rooted in the different national contexts.

Being aware of this situation and of the limitations due to the research design, the key persons consultation was chosen to gather information on the presence of various factors that can influence citizens' opportunity to make choices. The knowledge of these factors can indeed enable us to get an idea on the contexts that can favor or disfavor the practice of this right.

The key persons have been asked to give information on five factors concerning this right. Their responses are summarized in the following table.

Table 5.1 – Existing obstacles to the right to free choice (by key persons)

Obstacles	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Pt**	**Sp**	**Sw**	**UK**	**Tot**
Different fees in public and private hospitals	x	x	x	x	x	x	x			x				**8**
Incentives to seek treatment in private hospitals			x		x					x				**3**
Coverage of supplementary insurance only for some hospitals	x	x			x	x	x	x		x		x		**8**
Need to get authorization for some treatments	x	x	x	x	x	x	x	x	x	x	x	x	x	**13**
Indigent patients only able to be treated in certain hospitals					x					x				**2**
Total	**3**	**3**	**3**	**2**	**5**	**3**	**3**	**2**	**1**	**5**	**1**	**2**	**1**	**34**

Legend: X =majority of key persons interviewed reported yes
Active Citizenship Network, 2005

All countries reported the need to get authorization for some treatments, while in 8 out of 13 it was mentioned the existent of differential fees in public and private hospitals as well as the coverage of supplementary insurance only for some hospital. Moreover, there were a few mentions concerning the existence of incentives to seek treatment in private hospitals and that indigent patients are only able to be treated in certain hospitals.

The countries where only one of the five indicators was reported are the Netherlands, Spain and the United Kingdom.

Key persons were also asked about the existence of new measures adopted over the last year to limit free choice. The results are summarized here below.

Table 5.2-Trend to limit free choice (by key persons)

Trend to limit free choice	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
New measures adopted in the last year			x			x	x	x		x	x		x	**7**

Legend: X =majority of key persons interviewed reported yes
Active Citizenship Network, 2005

According to key persons, over the last year in more than half the countries further measures were adopted to further restrict the possibility of citizens to choose their health care services.

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.

During the hospital visits the following indicators were observed.

Table 6.1 – Right to Privacy (by direct observation)

Observations	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Dividers or curtains in the examination rooms	x	x	x	x	-	x	x	x	x	x	x	x	x	**12**
Single rooms for terminal patients	-	x	x	x	-	-	-	-	x	-	-	x	-	**5**
Observe or hear the surname of a patient	-	x	-	-	x	-	-	-	x	-	-	x	-	**4**
Total	**1**	**3**	**2**	**2**	**1**	**1**	**1**	**1**	**3**	**1**	**1**	**3**	**1**	**21**

Legend: X =observed in 2 or 3 hospitals - = observed in 1 or no hospitals
Active Citizenship Network, 2005

While examination rooms with dividers or curtains to protect the right to privacy do exist almost in all countries, it must be noticed that single rooms for terminal patients were observed only in five countries. On the other hand, in four countries in the majority of hospitals observed it was possible to hear the surname of a patient.

Key persons were asked also to refer to specific cases concerning the violation of confidentiality. Their answers are reported in the table below.

Table 6.2 -Cases of violation of confidentiality (by key persons)

Violations of Confidentiality	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Normative medical information disclosed to non-authorized persons				x	x	x				x	x	x	x	**7**
Patients' case files disclosed to non-authorized persons					x	x						x		**2**
Violation of the confidentiality of HIV/AIDS														
Total	**0**	**0**	**0**	**1**	**2**	**2**	**0**	**0**	**0**	**1**	**1**	**2**	**1**	**9**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

While no cases related to the violations of confidentiality regarding patients with HIV/AIDS were reported, in more than half of the countries the majority of key persons reported cases of medical information being disclosed to non-authorized persons.

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.

The first set of indicators relating to this right regards the existence of waiting times and procedures aimed at dealing with this problem. Here are the results.

Table 7.1- Indicators for the right to respect of patients' time (by hospital authorities)

	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Diagnostic or therapeutic treatment unavailable in the last 30 days - outpatient	-	x	-	x		x		-	x		x	x		**6**
Time limit established on waiting time	-	x	-	-		-		-	x		-	-		**2**
Waiting list available to public	-	x	-	-		-		-	-		-	x		**2**
Exist a single unified contact point for appointments	-	x	-	-		x		x	-		-	-		**3**
Appointment for specialist can be made by phone	-	x	-	x		x		x	x		-	x		**6**
Total	**0**	**5**	**0**	**2**		**3**		**2**	**3**		**1**	**3**		**19**

Legend: X =reported in 2 or 3 hospitals;- = reported in 1 or no hospitals; * hospital authorities refused to give an interview and answer questions.
Active Citizenship Network, 2005

In two thirds of the countries where this information was gathered there was reported the existence of treatments that have been unavailable in the last 30 days for outpatients. The possibility to get an appointment for specialist by phone was reported only in 6 out of 9 countries. Moreover, in only two countries (Denmark and Netherlands) there is a time limit established to receive diagnostic exams or therapeutic treatment from the time it was prescribed by hospital doctor. Finally, waiting lists are available to the public only in Denmark and Sweden.

As for waiting times, in almost all cases there exists differentiated access routes depending on the seriousness of the illness or its suspicion, consequently having a shorter access time for more urgent cases.

Table 7.2- Differentiated access routes for urgency (by hospital authorities)

Number of hospital	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Exists differentiated access route	2	2	2	3		3		3	2		2	3		**22**
Doesn't exist differentiated access route	1	1**	-	-		-		-	1		-	-		**3**
Total	**3**	**3**	**2**	**3**		**3**		**3**	**3**		**2**	**3**		**25**

*Number of hospitals reported: * hospital authorities refused to give an interview and answer questions; **Only for certain exams.*
Active Citizenship Network, 2005

Information on the waiting times for diagnostic exams coming from the hospital authorities seem to be quite adequate in the majority of countries. It must be noticed, however, the situations of Italy, Spain and Sweden which have some waiting times actually excessive.

Table 7.3– Waiting times for certain diagnostic exams (by hospital authorities)

Waiting times (n. days)	**AU**		**DE**		**FI**		**FR**		**GR**		**IT**		**NE**		**SP**		**SW**	
Echocardiogram **ECG**	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min
Urgent exams	0	0	-	-	1	0	1	0	0	0	68	2	0	0	15	0	7	0
Non-urgent exams	3	0	-	-	14	2	21	1	2	2	120	30	*	2hr.	90	47	42	24
No difference	0	0	0	0	-	-	-	-	-	-	-	-	0	0	-	-	-	-
Mammography	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min
Urgent exams	2	1	-	-	0	0	1	0	0	0	7	2	2	0	15	7	18	1
Non-urgent exams	10	10	-	-	0	0	35	2	2	2	120	15	*	5	90	33	30	28

Table continued

Cont. Table 7.3– Waiting times for certain diagnostic exams (by hospital authorities)

Waiting times (n. days)	**AU**		**DE**		**FI**		**FR**		**GR**		**IT**		**NE**		**SP**		**SW**	
No Difference	3	3	0	0	-	-	-	-	-	-	-	-	7	7	-	-	-	-
Total Body CAT	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min
Urgent exams	2 hrs	0	1	0	1 hr	0	1	0	0	0	4	2	5	0	15	8	7	0
Non-urgent exams	10	3	42	7	7	5	63	7	NR	NR	30	18	28	7	90	19	28	18
No difference	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

*Legend: * Information not available*
Active Citizenship Network, 2005
Note: In Germany, Ireland, Portugal, United Kingdom the hospital authorities refused to give an interview and answer questions

Also waiting times for some surgical operations highlight the critical situations, such as 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, and the 180 days for Cataract Surgery in Austria. In general, waiting times for Total hip replacement surgery tend to be too long in the most countries.

Table 7.4– Waiting times for elective surgery, no. days (Hospital interview)

	Au		**De**		**Fi**		**Fr**		**Gr**		**It**		**Ne**		**Sp**		**Sw**	
	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min	Max	Min
Cholecystectomy by laparoscopy	30	18	98	56	NR	RN	RN	NR	15	15	90	40	70	21	80	43	180	30
Tranurethal Resection of the Prostate	30	7	56	42	NR	NR	NR	NR	7	7	420	30	42	21	80	43	90	63
Cataract Surgery	180	30	84	56	NR	NR	NR	NR	NR	NR	90	64	60	0	80	43	90	90
Total hip replacement surgery	240	240	119	56	NR	NR	NR	NR	NR	NR	360	90	180	150	80	43	336	180
Coronary Bypass	42	28	63	63	NR	NR	NR	NR	NR	NR	120	30	35	35	30	30	21	21

*Legend: * Information not available NR= No response*
Active Citizenship Network, 2005
Note: In Germany, Ireland, Portugal, United Kingdom the hospital authorities refused to give an interview and answer questions

In all countries except Austria, key persons reported cases of violation concerning the right to respect patients' time. These violations have had in several cases serious consequences on citizens' health. Only in Germany was there just one out of the three cases reported.

Table 7.5 Cases of violation of right to respect patients' time (by key persons)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Cases in which an illness has worsened because of a delay in treatment		x	x		x		x	x	x	x	x	x	x	**10**
Waiting time for important diagnostic exams is too long		x	x	x		x	x	x	x		x	x	x	**10**
Need to use payable services due to the long waiting time		x	x	x		x	x	x		x	x	x	x	**10**
Total	**0**	**3**	**3**	**2**	**1**	**2**	**3**	**3**	**2**	**2**	**3**	**3**	**3**	**30**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

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.

As for the quality of health services, thanks to the survey some of the tools currently used in European countries to enhance health performances have been identified. The hospital interview results are summarized in the following table.

Table 8.1 -Indicators for right to quality (by hospital authorities)

	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Exist fixed performance standards	-	x	-	x		x		x	x		x	x		**7**
Standards set with participation of cons./pat. associations	-	-	-	-		-		-	x		-	-		**1**
Regard technical – medical performance	-	x	-	-		x		-	x		x	x		**5**
Regard human relations	-	x	-	-		x		-	x		x	x		**5**
Regard comfort	-	x	-	-		x		-	x		x	x		**5**
Exist periodic controls	-	x	-	x		x		x	x		-	x		**6**
Controls carried out with participation of consumer/patients associations	-	-	-	-		-		-	-		-	-		**-**
There are sanctions for violations of standards	-	-	-	-		-		-	-		-	x		**1**
Existence of a Quality Unit	-	x	x	x		-		x	x		x	x		**7**
Exist studies to measure patients' satisfaction	x	x	x	x		-		x	x		x	x		**8**
Total	**1**	**7**	**2**	**4**		**5**		**4**	**8**		**6**	**8**		**45**

*Legend: X =reported in 2 or 3 hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

The most widespread measures referring to quality in the hospitals resulted in patients' satisfaction studies and the establishment of a quality unit together with performance standards. Though in six countries out of nine in the majority of hospitals it was reported the existence of periodic controls, only in Sweden the existence of sanctions for violations of such standards were reported as well.

The countries that had more positive results in relation to these indicators are the Netherlands, Sweden and Denmark.

The kind of standards reported regard both technical and medical performance along with human relations and comfort. However, neither the process in defining these standards, nor their subsequent control are made involving citizens' organizations.

The consultation of key persons confirmed the above described situation with regard to Spain, Denmark, Netherlands and Sweden. In particular, people interviewed confirmed the existence of quality accreditation and certification of hospitals, as well as of standards regarding various aspects of health assistance (technical offerings, human relations, comfort). On the contrary, there was no agreement between the key persons on the involvement of citizens' and patients' organizations in defining the standards.

Only in the Netherlands and Spain was there some kind of consensus on the implementation of checks on the standards along with the existence of sanctions if these standards are violated (the Swedish key persons agreed on this point as well).

According to the key persons in Austria accreditation and certification procedures and standards do exist. Though they consider only technical offering while being subjected to periodical controls.

Information on Portugal, Germany, U.K. and Ireland are scant since data on quality coming from hospital authority's interview is missing. However. information gathered through key persons interviews are quite positive for both Germany and Portugal. They indeed highlight the existence of procedures to accredit the quality level of hospitals and fixed standards. The UK situation is better: there standards regard technical offerings, human relations and comfort. On the contrary, in Ireland the key persons do not refer any accreditation and certification procedure.

Finally, in six countries (France, Sweden, Austria, Finland, Germany, United Kingdom), the key persons reported cases of violation of this right happened in the last year.

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.

During the visit in hospitals, information on risk management systems was gathered. In the following table the results are summarized.

Table 9.1 – Indicators for right to safety (by hospital authorities)

Measures implemented	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Reporting procedure for near misses	-	x	x	x		-		x	x		-	x		**6**
Existence of an office or person in the hospital charged with coordinating activities for reducing the risk of infection	x	x	x	x		x		x	x		x	x		**9**
Existence of an office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions.	x	x	-	x		x		x	x		x	x		**8**
Protocols for controlling hospital infections	x	x	x	x		x		x	x		x	x		**9**
Total	**3**	**4**	**3**	**4**		**3**		**4**	**4**		**3**	**4**		**32**

*LEGEND: X= measures reported by 2 or more hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

The least registered standard is the existence of reporting procedure for near misses (6 countries out of 9). The other three were reported nearly in all countries. This leads us to hope that a system of control for the adverse events regarding patient safety is being establishes. These are a very important public health problem, both in terms of quality and of resources. A number of relevant practices are being implemented with the aim of reducing the number of these events.

During the visit in hospitals data on the existence of procedures for reporting risks were gathered. The results are summarized in the following table.

Table 9.2 -Procedures for reporting risks (by hospital authorities)

	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Hospital acquired infections	x	x	x	x		x		x	x		x	x		**9**
Burns from fires	-	x	-	x		x		x	x		-	x		**6**
Falls	x	x	-	x		x		x	x		-	x		**7**
Pressure ulcers	x	-	-	x		-		x	x		x	x		**6**
Preventable suicides	-	x	-	-		-		-	x		x	x		**4**
Failure to diagnosis or incorrect diagnosis	-	x	x	-		x		-	x		-	x		**5**
Failure to utilize or act on diagnostic tests	-	x	-	-		x		-	x		-	x		**4**
Use of inappropriate or outmoded diagnostic tests or treatment	-	-	-	-		x		-	x		-	x		**3**
Medication errors/adverse drug effects	-	x	x	-		x		-	x		-	x		**5**
Wrong-site errors; surgical errors	-	x	-	-		x		-	x		-	x		**4**
Transfusion mistakes	x	x	-	x		x		-	x		-	x		**6**
Total	**4**	**9**	**3**	**5**		**9**		**4**	**11**		**3**	**11**		**59**

*Legend: X =reported in 2 or 3 hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

The only procedure reported in all countries regards hospital acquired infections. Those reported less concern the use of inappropriate or outmoded diagnostic tests or treatment, failure to utilize or act on diagnostic tests and wrong-site errors/surgical errors. Sweden and the Netherlands are the countries where all the 11 procedures were reported; then Denmark and Greece (9). To the other extreme there are Finland, Spain (3) and Italy and Austria (4).

In the hospitals the existence of safety signs and procedures was observed by the monitoring groups. Here are the results.

Table 9.3 – Safety signs and procedures (by direct observation)

Existing Safety signs	Au	De	Fi	Fr	Ge	Gr	Ir	It	Ne	Po	Sp	Sw	UK	Tot
Emergency exist signs	x	x	x	x	x	-	x	x	x	-	x	x	x	**11**
Evacuation routes for wheelchair users clearly marked	-	-	-	-	-	-	x	-	-	-	-	x	-	**2**
Fire extinguisher signs	x	x	x	x	-	-	x	x	-	x	x	x	x	**10**
Evacuation map	x	x	-	x	-	-	-	-	x	-	x	x	-	**6**
Special evacuation procedures for wheelchair users marked on the map	-	-	-	-	-	-	-	-	-	-	-	x	-	**1**
Total	**3**	**3**	**2**	**3**	**1**	**0**	**3**	**2**	**2**	**1**	**3**	**5**	**2**	**30**

Legend: X =observed in 2 or 3 hospitals; - = observed in only 1 or no hospitals
Active Citizenship Network, 2005

What is really relevant regarding this data is that safety signs and procedures for wheelchair users were observed only in two countries: evacuation routes in Ireland and Sweden; and special evacuation procedures in Sweden only. In only one French and one Dutch hospital evacuation routes for wheelchair users and special evacuation procedures or evacuation maps were observed.

Key persons gave information on the implementation of some safety measures. Here are the results.

Table 9.4 – Safety measures being implemented (by key persons)

Safety measures implemented	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
protocols for the sterilization of medical instruments	x	x	x	x		x	x	x	x	x	x	x	x	**12**
protocols for the prevention of hospital infections		x	x	x		x	x	x	x	x	x	x	x	**11**
risk management techniques				x			x		x				x	**4**
epidemiological investigations of hospital infections			x	x			x				x	x	x	**7**
Total	**1**	**2**	**3**	**4**	**0**	**2**	**4**	**2**	**4**	**2**	**3**	**3**	**4**	**34**

Legend: X =majority of key persons reported yes
Active Citizenship Network, 2005

The fairly good situation of safety reported in the hospitals is confirmed by information coming from key persons, with the exception of Austria, Germany and UK.

Nevertheless, in some countries violations of this right have been reported. The most relevant come from Italy, Sweden, Finland, UK.

Table 9.5 – Cases of violation of the right to safety (by key persons)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Cases of violation to the right			x	x	x		x	x		x		x	x	**8**

Legend: X =at least 4 key persons interviews identified cases when this right had been violated during the last year.

10. Right to Innovation

Each individual has the right to access innovative technology, independently of economic or financial considerations.

The degree of attention to the right to innovation was surveyed checking the existence of certain innovative technologies in the hospitals.

Table 10.1 -Use of innovative technologies (by hospital authorities)

Innovative techniques	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	**°UK**	**Tot**
Telemedicine	x	x	x	x		-		x	-		-	x		**6**
Electronic patient records	x	x	x	x		-		x	x		-	x		**7**
Internet to access treatment appointments, medical referrals etc.	NR	x	-	x		-		-	x		-	x		**4**
Less invasive surgical techniques	x	x	x	x		-		x	x		x	x		**8**
Personal cards	-	x	NR	NR		-		-	x		-	-		**2**
Patients Controlled Analgesia (PCA)	x	x	x	x		-		x	x		-	x		**7**
Special mattress to prevent pressure ulcers	NR	x	x	x		x		x	x		x	x		**8**
Total	**4**	**7**	**5**	**6**		**1**		**5**	**6**		**2**	**6**		**42**

LEGEND: X= measures reported by 2 or more hospitals*; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

The four countries which reported a wider use of new technologies are Denmark, France, Netherlands, Sweden. Italy, Finland with Austria following closely, while Spain and Greece havee far less.

The key persons consultation differentiated situations on the diffusion of innovative technologies in health services. The number of different technologies that the majority of key persons in each country report in actual use are no more than 4 out of 7 proposed as indicators (Spain).

In about two thirds of countries, they are no more than 2 out of 7 innovative technologies used. Reports are concentrated almost exclusively on the use of less invasive surgical techniques and special mattress.

Table 10.2 - Use of innovative technology (by key persons)

Presence of the following procedures	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Telemedicine														**0**
Electronic patient records											x			**1**
Internet to access treatment appointments, medical referrals etc.					x									**1**
Less invasive surgical techniques	x	x	x	x	x			x	x		x	x	x	**10**
Personal cards			x								x			**2**
Patients Controlled Analgesia (PCA)				x									x	**2**
Special mattress to prevent pressure ulcers	x			x	x		x		x		x	x	x	**8**
Total	**2**	**1**	**2**	**3**	**3**	**0**	**1**	**1**	**2**	**0**	**4**	**2**	**3**	**24**

LEGEND: X = majority of key persons interviewed reported widespread diffusion
Active Citizenship Network, 2005

Finally, in eight countries key persons reported one or more cases of delays in introducing innovative diagnostic tests and innovative treatments and delays in particular areas of medical research.

Table 10.3 -Violations of the right to innovation (by key persons)

Cases reported of by key persons	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Delays in the introducing of innovative diagnostic tests			x		x		x	x			x	x	x	**7**
Delays in the introducing of innovative treatments			x		x			x		x	x	x	x	**7**
Delays in particular areas of medical research		x	x	x	x			x			x	x	x	**8**
Total	**0**	**1**	**3**	**1**	**3**	**0**	**1**	**3**	**0**	**1**	**3**	**3**	**3**	**22**

Legend: X =reported by the majority of key persons interviewed
Active Citizenship Network, 2005

About the right to innovation a clear difference between information coming from hospitals and from key persons emerges. The most likely explanation for this is that in the hospitals, because of their size and location in the capitals, the diffusion of innovative technologies is definitely over the average in relation to the countries' health structures.

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.

As for the situation of the care for this right, first of all data on the existence of tools for pain management were gathered.

Table 11.1 -Tools for pain management (by hospital authorities)

	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Existence of guidelines or protocols for pain management	-	x	x	x		x		x	x		-	x		**7**
Intensity of patients' pain is evaluated and noted at regular intervals	-	x	x	x		-		-	-		-	x		**4**
Intensity of patients' pain is evaluated and noted at regular intervals **	x	-	-	-		x		x	x		x	-		**5**
Existence of Pain Center/ Palliative Care Unit	x	x	x	x		-		x	x		x	x		**8**
Total	**2**	**3**	**3**	**3**		**2**		**3**	**3**		**2**	**3**		**24**

*Legend: X =reported in 2 or 3 hospitals; - = reported in only 1 or no hospitals; * hospital authorities refused to give an interview and answer questions; **only in some cases (certain wards or certain illnesses)*
Active Citizenship Network, 2005

A widespread diffusion of pain management tools can be seen in almost all countries surveyed. It must be added, however, that in 5 cases out of 9 the intensity of patients' pain is not evaluated in all cases, but only in some hospital divisions, or either in the case of patients with particular conditions.

Nevertheless, the pain management situation results definitely less positive from the key persons interviews. From this source also information on the situation of those countries where hospital authorities refused to cooperate is available.

Table 11.2 – Pain management rules respected in the country (by key persons)

Pain management rules respected:	Au	De	Fi	Fr	Ge	Gr	Ir	It	Ne	Po	Sp	Sw	UK	Tot
Ask about pain regularly	x	x		x	x		x		x	x	x	x	x	**10**
Trust the patient and family in their reports of pain and what relieves it		x			x		x				x	x		**5**
Choose pain control options appropriate (patient, family, setting)		x			x		x		x		x	x		**6**
Deliver interventions in a timely, logically and coordinated fashion	x	x		x			x		x		x			**6**
Empower patients and their family							x		x		x	x	x	**5**
Record pain												x	x	**2**
Total	**2**	**4**	**0**	**2**	**3**	**0**	**5**	**0**	**4**	**1**	**5**	**5**	**3**	**34**

Legend: X =majority of key persons reported yes
Active Citizenship Network, 2005

According to key persons, in the majority of countries (10 out of 13) it is a common habit to evaluate (even if sometimes) pain evaluation of patients', but this habit does not go together with the fulfillment of the requirements for effective pain management: for example, trust in patients' and families' reports (done in 5 countries only) or recording pain (2 countries only). Finally, there are critical situations in Italy, Finland and Greece, where no agreed information on the fulfillment of these rules emerged.

From the key persons it was checked if situations referring to a lack of pain management practices exist. The results are shown in the following table.

Table 11.2 -Cases of violation of the right to avoid unnecessary pain (by key persons)

Cases of violations	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**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		**3**
Total	**0**	**0**	**0**	**0**	**2**	**2**	**0**	**0**	**0**	**1**	**1**	**2**	**1**	**9**

Legend: X reported by the majority of key persons interviewed
Active Citizenship Network, 2005

It is relevant that in almost half of countries the majority of key persons report situations in which painkillers are not administrated when appropriate, and in three countries the majority of the key persons report also the lack of administration of morphine in cases recommended by international standards.

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.

A number of various kinds of services were chosen as general indicators relating to personalized treatment. Here are the result of the hospital interviews.

Table 12.1 -General indicators of personalized treatment (by hospital authorities)

Personalization of treatment	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Choice of meals (2 or more options)	x	x	-	x		-		x	x		x	x		**7**
Religious assistance available in the hospital or on call for more than three religions	x	-	x	x		-		-	x		-	x		**5**
Psychological support service to assist patients and their families in specific situations (more than 3 reported)	x	-	x	-		-		-	x		-	x		**4**
Written procedures to ensure that patients may ask for a second opinion	-	-	x	-		-		-	x		-	-		**2**
More than six hours a day available for visiting patients	x	x	x	x		-		-	x		x	x		7
Hospital offers foreign language interpreters	x	x	x	x		-		-	x		-	-		5
Hospital has cultural mediators	x	-	-	x		-		-	x		-	-		3
Total	**6**	**3**	**5**	**5**		**0**		**1**	**7**		**2**	**4**		**33**

*Legend: X =reported in 2 or 3 hospitals; ; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

The measures more frequently adopted are the choice of meals and the more than 6 hours visiting time. Then there is religious assistance related to different denominations.
In the following table contains the results on what religious confessions are covered by spiritual assistance in hospital are reported.

Table 12.2 -Religious assistance offered by the hospital (by hospital authorities)

Religious assistance available	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	****It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Anglican	-	-	-	-		-			-		-	-		**-**
Catholic	x	-	x	x		-			x		x	x		**6**
Jewish	x	-	x	-		-			-		-	x		**3**
Muslim	x	-	x	x		-			x		-	x		**5**
Orthodox	x	-	x	-		x			-		-	x		**4**
Protestant	x	x	x	x		-			x		-	x		**6**
Other	x	-	x	-		-			x		-	-		**3**
Total	**6**	**1**	**6**	**3**		**1**			**4**		**1**	**5**		**27**

*Legend: X =reported in 2 or 3 hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions; **Data unavailable*
Active Citizenship Network, 2005

Psychological support is of special relevance for persons in weak conditions. It is delivered in more than three difficulty psychological conditions in four countries. In the following table people benefiting of this assistance are reported.

Table 12.3 -Psychological support provided by the hospital (by hospital authorities)

	Au	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	****It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Terminal patients and their family	x	-	x	x		-			x		-	x		**5**
Transplant patients and their family	-	-	-	-		-			x		-	x		**2**
Women who have suffered violence	x	-	x	-		-			-		-	x		**3**
Patients in other conditions	x	-	x	-		x			x		-	x		**5**
Total	**3**	**0**	**3**	**1**		**1**			**3**		**0**	**4**		**15**

*Legend: X =reported in 2 or 3 hospitals; ; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions; **Data unavailable*
Active Citizenship Network, 2005

The highest attention in delivering health care according to different social and cultural needs of individuals emerged in the hospitals observed in the Netherlands, France, Austria, and Finland. On the contrary, Italy and Greece show a lack of attention to these needs.

As for the attention towards children who are patients the situation is definitely better. In this case Portugal and Greece, once again, are lacking:

- play areas;
- furnishings appropriate to the age of the patients;
- a place for parents to sleep in the room (Portugal only);
- Educational support for children (Greece only).

Table 12.4 -Special Attention for Children Patient (by hospital authorities and direct observation)

Paediatric Wards	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Play areas inside paediatric wards	x	x	-	N	x	-		x	x	-	-	x	x	**7**
Furnishing appropriate for the age of the patient	x	x	-	N	x	-		x	x	-	x	x	x	**8**

Table continued

Cont. Table 12.4 -Special Attention for Children Patient (by hospital authorities and direct observation)

Paediatric Wards	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Possibility for parents to be present for 24hrs,	x	x	x	N	x	x		x	x	x	x	x	x	**11**
Parents have a place to sleep in the room	x	x	x	N	x	x		x	x	-	x	x	x	**10**
Parents can use the cafeteria	x	x	x	N	x	x		x	x	x	x	x	x	**11**
Educational support for children undergoing long term hospitalization	x	x	x	N	-	-		-	-	x	x	x	-	**6**
Total	**6**	**6**	**4**	**0**	**5**	**3**		**5**	**5**	**3**	**5**	**6**	**5**	**53**

Legend: X =exist in the majority of paediatric wards observed -= no exist in majority of paedriatic wards observed N = no paediatric ward
Note: In Ireland wasn't possible to observe paediatric ward
Active Citizenship Network, 2005

Information coming from the key persons of the Netherlands confirms the positive picture that emerged during the hospital visits. As for countries where it was impossible to obtain information from the hospitals' authorities, the key persons interviews highlight an existence of:

- psychological support (Ireland, Germany, UK);
- spiritual support (Ireland, Germany, Portugal);
- the choice of meals (Ireland, Germany, UK).

Table 12.5 –Cases when the right to personalized treatment has been violated in the last year (Key persons interviews)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Cases identified by key persons	x				x						x	x	x	**5**

Legend: X =majority of the key persons interviews identified cases when this right had been violated during the last year
Active Citizenship Network, 2005

In Austria, UK, Sweden, Spain, and Germany cases of violation of this right have been reported.

13. Right to Complain

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

Relating to the right to complain, during the hospital visit the following data was gathered.

Table 13.1 – Indicators for the right to complain (Hospital interview)

Existence of:	Au	De	Fi	Fr	*Ge	Gr	*Ir	It	Ne	*Po	Sp	Sw	*UK	Tot
Committee or structures to receive complaints and resolve conflicts between the public and the hospital	x	x	x	x		x		x	x		x	x		**9**
Committee or structure independent of the hospital	x	x	-	-		-		-	x		-	x		**4**
Officially procedures for dealing with patients' complaints	x	x	x	x		x		x	x		x	x		**9**
Time limit for the hospital to respond to patient complaints	x	x	x	x		x		x	x		x	-		**8**
Period established is respected	x	x	x	x		x		x	-		x	-		**7**
Total	**5**	**5**	**4**	**4**		**4**		**4**	**4**		**4**	**3**		**37**

*LEGEND: X= reported in 2 or more hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

There seems to be institutions and procedures aimed at managing citizens' complaints in the majority of hospitals visited in nearly all the countries. However, it is important to highlight that in only 4 countries out of 9 the committees in charge of complaint management are actually independent of the hospital. These countries are Denmark, Austria, The Netherlands and Sweden. As well the information coming from key persons confirms this.

As for the countries where no data was available from the interviews with hospital authorities, the key persons reported that there exists fixed procedures for handling patients' complaints. In Germany, the existence of independent organizations engaged in assisting patients for their complaints was also reported. In Ireland and UK both the existence of fixed procedures for handling patients' complaints and the existence of independent organizations engaged in assisting patients for their complaints were reported as well.

In all countries excluding Netherlands the key persons reported cases of violations of this right during the last year, such as lack of response to citizens' complaints and too long time to respond to citizens' complaints.

Table 13.2 -Cases of violation of the right to complain (by key persons)

Cases of violations	Au	De	Fi	Fr	Ge	Gr	Ir	It	Ne	Po	Sp	Sw	UK	Tot
Lack of response to citizens' complaints	x				x	x	x	x			x	x	x	**8**
Takes too long to respond to citizens' complaints	x	x	x	x	x	x	x	x		x	x	x	x	**12**
Threats or intimidations towards patients that have complained														**0**
Total	**2**	**1**	**1**	**1**	**2**	**2**	**2**	**2**	**0**	**1**	**2**	**2**	**2**	**20**

Legend: X reported by the majority of key persons interviewed
Active Citizenship Network, 2005

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.

The hospital visit allowed us to collect information on some relevant aspects of the situation of this right. It is shown in the following table.

Table 14.1 –Indicators for the right to compensation (by hospital authorities)

Indicators:	**Au**	**De**	**Fi**	**Fr**	***Ge**	**Gr**	***Ir**	**It**	**Ne**	***Po**	**Sp**	**Sw**	***UK**	**Tot**
Hospital insured to compensate patients		x	x	x				x	x		x	x		**7**
Doctors within the hospital have additional insurance	x	x						x			x	x		**5**
Existence of committees or structures to assist patients reach final agreement on compensation	x		x	x					x			x		**5**
Committee or structures are independent from the hospital	x		x						x			x		**4**
Total	**3**	**2**	**3**	**2**		**0**		**2**	**3**		**2**	**4**		**21**

*LEGEND: X= reported in 2 or more hospitals; - = reported in only 1 or no hospitals; : * hospital authorities refused to give an interview and answer questions*
Active Citizenship Network, 2005

From the hospital interviews it can be observed that insurances are slightly more diffused among hospitals than among doctors and, above all, that there are cases where one or both are lacking.

On the other hand, in more than half of the countries the majority of hospitals have a committee to promote agreements on compensation between patients and their interlocutors. In 4 out of 5 cases they are independent from the hospital.

There emerges the negative situation of Greece that does not have any insurance policy for either the doctors nor the hospitals nor does it have any committee.

Table 14.2 -Indicators for the right of compensation (by key persons)

Indicators:	**Au**	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Hospital insured to compensate patients	x	x	x	x	x		x	x	x		x	x		**10**
Doctors within the hospital have additional insurance	x		x	x	x		x	x	x		x		x	**9**
Commission operating outside the regular ligation process	x		x	x	x								x	**5**
Indipendent organizations which provide legal aid free of charge	x		x	x	x			x				x	x	**7**
Total	**4**	**1**	**4**	**4**	**4**	**0**	**2**	**3**	**2**	**0**	**2**	**2**	**3**	**31**

LEGEND: X=majority of key persons have answered yes
Active Citizenship Network, 2005

Reality highlighted by the key persons' interviews concerning insurance policies is pretty much the same of that emerging from the hospital visits.

There emerged the existence of a group of five countries with commissions operating outside the regular litigation process and a group of seven of them with independent organizations which provide legal aid free of charge.

From the key persons the critical situation of Greece is confirmed while Portugal and Denmark appear in the same situation too.

The key persons were asked to report cases when the right to compensation has been violated in the last year. Below are their answers.

Table 14.3 -Cases when the right to compensation has been violated in the last year (by key persons)

	Au	**De**	**Fi**	**Fr**	**Ge**	**Gr**	**Ir**	**It**	**Ne**	**Po**	**Sp**	**Sw**	**UK**	**Tot**
Cases identified by key persons			x									x		**2**

Legend: X =at least 4 key persons interviews identified cases when this right had been violated during the last year.
Active Citizenship Network, 2005

Half of the Finnish and Swedish key persons report the existence of cases of violation of the right to compensation.

Section 4
Main Findings

The analysis of the indicators relating to the 14 patients' rights allows us to shed light on some relevant phenomena which characterize the state of patients' rights in Europe. This section is devoted to report these phenomena.

1. Right to Prevention

Limited prevention in hospitals

The involvement of hospitals in primary and secondary prevention activities is in general very low. Moreover, the availability of materials on prevention is very limited in the majority of the hospitals visited with the exceptions of Netherlands, France and Finland. With regard to this phenomenon it must be reminded that the European Region of WHO, in the Vienna Recommendations on Health Promoting Hospitals stressed the crucial role of hospitals as actors of prevention.

Prevention of cancers that specifically effect women … but the rest?

In 11 out of 13 countries a good diffusion of screening activities related to cancers that specifically effect women have been reported. However, prevention activities regarding other diseases do not have the same diffusion. As is the case of screening programs for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonscopy (reported only in 3 countries), screening programs for hypertension in adults aged 18 and older (2), screening programs for lipid disorders for men aged 35 years and older and women aged 45 years and older (Spain), vision screening programs to detect amblyopia and strabismus for all children before entering school (6), screening programs for diminished visual acuity for elderly persons (Spain), screening programs to detect drinking problems for all adult and adolescent patients (Spain).

Public communication campaigns are growing

HIV prevention (in 11 countries), prevention of sexually transmitted diseases (8), early diagnosis of tumors affecting women (8), fight against smoking (12), alcoholism (9), nutritional disorders (6), heart disease (6), domestic accidents (6), road safety (11 countries), are the topics of public communication campaigns – a growing activity in all the countries surveyed.

2. Right to Access

Access to care

A limited universalism

In all the countries the existence groups of people either not covered by national health services or facing obstacles limiting their access to adequate care was reported.

What essential levels of care?

In all 13 countries the presence of obstacles to accessing care was reported, from 2 in Austria to 6 in Portugal. In particular, these obstacles are:

- lack of coverage by public insurance for health services considered essential by the public (services that patients must pay for and which are not reimbursed) (9 countries),
- existence of administrative and/or economic obstacles to access services (8 countries),

- access to drug which have been approved in other countries, but not yet in their own (7 countries).

Physical access

Accessibility, but not for all
A satisfactory availability of facilities for public access to hospitals emerged from the survey, apart from two countries with a lesser level of attention (Greece and Portugal). However, accessibility for persons with disabilities clearly marked was reported only in 8 countries out of 13.

3. Right to Information

Widespread instruments for citizens' information …
In the most of hospitals visited the existence of tools for the information of patients and users emerged. They are, for example, a telephone number for the public to call, an information office at the main entrance, a hospital's website and an updated directory of available services in hospital (the last one excluding Germany and Italy).

… but little material on hot topics
While information materials on the hospital regulation and on patients' rights are diffused in the large majority of countries' hospitals, materials regarding critical topics are the least diffused. That is the case referring to material on waiting lists, on complaints received by the public and on data available for benchmarking which are present in 4 countries only; and of material on data outcome such as patients' satisfaction and clinical performance, available only in 2 country (France and Netherlands).

Active citizens seen as foreigners
Areas reserved to patients' and citizens' associations inside hospitals have been reported only in 6 out of 13 countries. This information is undoubtedly linked to the refusal of hospital officials of four countries to answer the monitoring groups' questions.

4. Right to Consent

Written consent …
Standardized forms for gathering consent are widely implemented, but they are used mostly for scientific research than for invasive diagnostic exams and surgical operations.

… but not informed
The content of consent forms emerged as being only partial and not exhaustive. Only in a few countries they report precise information on risks (2 countries) and benefits (1 country). Moreover, a limited diffusion of other materials aimed at informing patients in relation to informed consent was registered: only in 5 out of 13 countries the key persons reported the existence of these materials.

5. Right to Free Choice

"Free" choice with many obstacles
Some structural limitations to citizens' actually being able to make choices emerged in the majority of surveyed countries.

They are:
- Need to get authorization for some treatments (all13 countries);
- Different fees in public and private hospitals (and thus different reimbursements) (8 countries);
- Coverage of supplementary insurance only for some hospitals, and thus the option of seeking treatment in just those few hospitals (8 countries).

6. Right to Privacy and Confidentiality

To die in hospital, how?
The survey reported a limited existence of single rooms available for terminal patients in hospitals (existing in only 5 countries out of 9). On the other side, examination rooms with dividers or curtains was reported in 12 countries out of 13.

Personal data
In the hospitals of 4 countries monitoring groups happened to observe or hear the surname of patients.

Who can get medical information?
The key persons reported that in 7 countries out of 13 cases, the majority of key persons interviewed reported situations when medical information was disclosed to non-authorized persons.

7. Right to Respect of Patients' Time

Hidden rationing …
There is a widespread phenomenon regarding the freezing of waiting lists for one or more exams reported. This specific phenomenon was registered in 6 out of 9 countries. This situation represents a hidden form of restriction to the access to health care, that could be considered a form of service rationing.

… damaging for citizens …
The consequence of this practice can be seen in the cases reported by the key persons that occurred in the last year:
- cases in which an illness has worsened because of a delay in treatment (10 countries out of 13);
- waiting time for important diagnostic exams too long (10 countries out of 13);
- need to use payable services due to the long waiting time (10 countries out of 13).

… without a security mechanism …
To confirm this concerning situation a generalized lack of having an established time limit to receive diagnostic exams or therapeutic treatment from the time it was prescribed by the hospital doctor[5] emerged. The only two countries, where this mechanism was reported, were the Netherlands and Denmark.

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[5] Is there a time limit established for which the patient must wait to receive diagnostic exams or therapeutic treatment from the time it was prescribed by the hospital doctor (for example: the maximum waiting time to receive an angiography could be 12 weeks from the time of seeing a specialist, and the maximum waiting time for cardiac revascularization surgery could be 24 weeks from the time of angiography).

… and without elementary tools.
In several countries it was reported the lack of tools enabling citizens to face this situation:

- availability to the public of the waiting lists for diagnostic exams (present only in Denmark and Sweden);
- a single, unified contact point for appointments (reported only in Denmark, Greece and Italy);
- appointments for specialist and diagnostic exams be made also over the phone (lacking in 3 out of 9 countries).

8. Right to the Observance of Quality Standards

A widespread system for quality assessment….
Tools, procedures and institutions aimed at accrediting or certifying quality of services appears to be fairly common in the surveyed countries. Quality standards tend to regard not only technical and medical performances, but also human relations and comfort.

… but privileging the easiest way by customer satisfaction …
Nevertheless, the most used form of quality assessment are studies on customer satisfaction (reported in the hospitals of 8 countries out of 9), which is of course the least complex way to improve and check quality.

…. with controls but without sanctions…
Moreover, there are control activities on the fulfillment of standards, but sanctions for when these standards are not respected, are limited, while imposing sanctions for the lack of respect of these standards are practically non-existent (Sweden only).

… and without involving citizens.
Finally, involving citizens' organizations in the definition of these standards is reported only in the Netherlands, while no country reported citizens' involvement in the activities to monitor and control.

9. Right to Safety

Many risk-reducing actions in many countries
From the survey a structured practice aimed at reducing the risk of adverse events has emerged in the majority of countries.

Still, too many reports of violations of this right
Never the less, cases of violation of the right to safety in the last year have been reported in 8 countries out of 13.

Safety of disabled underestimated
In the hospitals surveyed, evacuation routes for wheelchair users clearly marked were observed only in two countries (Ireland and Sweden), while special evacuation procedures for wheelchair users marked on the map in Sweden only.

Serious deficiencies of emergency exits in some countries
Evacuation maps have been observed in hospitals of 6 countries out of 13 only, while emergency exit signs lacked in Greek and Portuguese hospitals.

10. Right to Innovation

A two-speed innovation?

From the key persons interviews in seven countries there was no significant evidence on the diffusion of new technologies. From the hospital visits, on the contrary, positive information emerged. This result could likely mean that, while in some central and big structures innovative technologies are currently uses, in the rest of countries the level of their diffusion is most definitely low.

Delays

Widespread situations of violation of this rights were reported. In particular:

- delays in introducing innovative treatments, in 7 countries;
- delays in medical research, in 8 countries.

11. Right to Avoid Unnecessary Suffering and Pain

An upcoming issue

In the majority of countries it resulted that this problem is beginning to be dealt with. However, appropriate and general programs of action exist only in a few countries.

Still unnecessary pain

In about half of the countries surveyed, cases of violation of this right were reported such as the lack of administrating painkillers or morphine even when recommended by international standards.

12. Right to Personalized Treatment

Attention to diversities....but not in all countries

In only about half of the countries there emerged a widespread and structured engagement in delivering health treatments respecting the individual’s different social and cultural needs. It regards, for example, contact with relatives, food, cultural diversities, religious services and psychological support.

Top attention for children

In almost all the countries, there exists a high level of attention towards children’s needs.

13. Right to Complain

A well-defined route for citizens’ complaints …

In all the countries there was reported a structured procedure aimed at receiving and processing citizens’ complaints, which involve committees to receive the complaints and mediate between the public and the hospital.

… but risking self-referentiality …

However, the majority of committees in charge of receiving and processing citizens’ complaints are not independent from the hospitals (5 out of 9 countries).

… and lack of effectiveness

In 12 countries there were reported cases that it takes too much time to respond to citizens' complaints while in 2 countries a complete lack of response to citizens' complaints was reported.

Insurance policies …

In almost all of the countries there are insurances covering the compensation for possible damages to patients. Nevertheless, they do not always cover both provider and doctor but usually just one of the two.

… non existing

In two countries (Greece and Portugal) hospitals and doctors do not have any insurance.

A good practice not followed

In five countries (Austria, Finland, France, Netherlands, Sweden), committees or structures to assist patients in reaching final agreement on compensation and/or on its amount, exist. In all the hospitals visited except in France they are independent from the hospital.

Section 5
European priorities

In the previous sections we have described the results coming from information collected on the *indicators* relating to the 14 patients' rights (Section 3); then, for each right we have highlighted the main *phenomena* emerging from the analysis of these indicators (Section 4). In this Section we will make two further, and final steps. Firstly, we are going to try to classify the patients' rights according to the *degree of attention* they receive. Secondly, we will recommend, on the basis of the results of the survey, some priorities and directions regarding a *European agenda on patients' rights*.

Synthetic data on the European situation

First of all, we have set up a list of the 14 rights according to the degree of attention to each of them, emerging from the survey data and information[6]. The list was then organized in clusters identifying rights with high-, medium- and low-degree of attention.

The result is summarized in the following table.

Table 5.1 General classification of Patients' Rights according to the Degree of Attention

DEGREE OF ATTENTION	**RIGHT**	**SCORE**
HIGH	**Access – Physical**	**26**
	Complain	**26**
	Privacy	**25**
	Information	**24**
	Safety	**24**
MEDIUM	**Personalized Treatment**	**22**
	Quality	**21**
	Innovation	**20**
	Avoid pain	**20**
LOW	**Free choice**	**19**
	Compensation	**19**
	Prevention	**18**
	Consent	**18**
	Access – Care	**17**
	Time	**16**

Score: min 9, max 27; average: 21
Active Citizenship Network, 2005

Of course, it was impossible to do the same operation with regard to national situations, because of the refusal of hospital authorities in Germany, Ireland, UK and Portugal to provide information, making it impossible to compare these countries with the others.

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[6] Data regarding each source (concrete situations observed, hospital authorities, key persons and partner organizations), completely or partially available, of each right in each country have been analysed and synthetically classified according to the number of positive or negative results. This classification was translated in a score, so that each right had a score and a general list on the degree of attention to the rights could be set up. Doing this operation, we have excluded those countries (Germany, Ireland, UK, Portugal) where one source lacked completely because of the refusal of hospital authorities to provide their information. Since the weight of hospital interviews differed from one right to another, putting the results of these four countries together with the others would have affected the homogeneity of results. Besides, it was verified that the situation of the four countries, not used in setting up the general classification of rights, reflects the situation emerging from the classification.

As for the above classification, it can be noticed that among the six worst situations in terms of care for patients' rights, three of them – the rights to Free Choice, Access to Care and Respect of Patients' Time – regard the same problem, that is, *the crisis of the "European Social Model"* on the side of the universal entitlement to health care. The starting point of the European Charter of Patients' Rights, namely that despite national differences patients' rights are at risk because of political orientations and financial constraints, seems to be definitely confirmed from this survey.

The fact that the rights to Compensation and Consent show a low degree of attention leads us to believe that the better situations showed by the rights to Complain, to Safety and to Information should be carefully considered. It could indeed mean that the commitment to put citizens first in health services risks remaining only superficial, while avoiding the harder issues. Good information must be linked to the practice of comprehensively informed consent on treatments; good policies on complaints management and on the safety of treatments must be linked to real possibility for citizens and patients to be fully compensated for possible damages.

The *right to Prevention* resulted as one of the lowest rights in terms of degree of attention. Though Europe is probably the region in the world where, thanks to the welfare systems, the highest success in preventing diseases has been reached, this result could be considered as a warning of a possible decrease in commitment of governments and professionals. The fact that the degree of attention towards the right to Innovation is below average in the above classification seems to confirm this risk.

In general, it must be stressed that *more than half of the patients' rights scored below the average* line (score 21). It denotes a very critical situation regarding the attention on patients' rights at the national level. Moreover, those rights that have been classified in the highest cluster are not free from problems, as it emerged in Sections 3 and 4. This must also be addressed.

It is not of minor importance the fact that *a certain gap between the concerns and priorities of the policymaking community and the main problems affecting patients' rights seems to be emerging*. For example, among the rights that show the highest degree of attention there are some that the policy community believes as the most crucial: right to privacy, right to information, right to complain. On the contrary, among the rights with the least degree of attention, there are some that the policymaking community does not even seem to consider significant, such as the right to time, the right to compensation and the right to innovation. In other cases, such as the rights to access to care, to consent, to prevention, to free choice there is a coincidence between the concerns of the policymaking community and the degree of attention shown by the survey.

A certain amount of synthetic information also comes from *the existing legislation* on patients' rights at the national level. In the following table the summary of the partners' information on the existing norms is reported.

Table 5.2 -Laws protecting patients' rights at the national level

Type of law / Right	**Constitution**	**General Law**	**Specific Law**	**Administrative Regulation**	**Charter of Rights**	**Total**
Prevention	7	10	6	2	1	**26**
Access	7	6	7	2	2	**24**
Privacy	7	5	8	1	1	**22**
Complain	2	7	6	4	2	**21**
Information	3	6	8	1	2	**20**
Consent	4	6	7	1	2	**20**
Quality	3	7	7	1	1	**19**
Safety	5	5	6	1	1	**18**

Table continued

Cont.Table 5.2 -Laws protecting patients' rights at the national level

Type of law / Right	Constitution	General Law	Specific Law	Administrative Regulation	Charter of Rights	Total
Avoid Pain	4	6	3	1	3	**17**
Pers. Treatment	2	4	3	4	2	**15**
Free Choice	2	6	5	1	0	**14**
Compensation	2	7	3	0	1	**13**
Time	1	5	4	1	0	**11**
Innovation	1	4	2	3	0	**10**
Total	**50**	**84**	**75**	**23**	**18**	

Active Citizenship Network, 2005

It must be stressed that in general *there is no correlation between the number of laws or regulations and the degree of attention towards patients' rights*. For example, Sweden and Germany, which are respectively among the best and the worst situations according to the information gathered, have more or less the same number and kind of laws and norms regarding patients' rights (respectively 10 and 13), while Netherlands and Greece, that seem to be at the two extremes as well, have the same high number of patients' rights-related laws, 32.

Information on existing national legislation has, nevertheless, two meanings that must be stressed.

Firstly, it must be noticed that, taking into consideration the last six rights in the classification related to the degree of attention and the last six rights in terms of number of laws protecting patients' rights, *three of them (to free choice, to compensation and to time) appear in both lists*. It could mean that those rights that are less cared for are further threatened by a low legal covering.

Secondly, it is evident that *laws and norms must be neither only proclaimed nor applied by tribunals, but also enforced through appropriate and effective policies*, started and supported by all the actors of health care: governments, citizens' organizations, professionals, third payers, pharmaceutical and other private companies, trade unions, the media, legal systems, scientific community. This is the reason why the following part of this section is devoted to identifying an agenda of policy priorities for the protection of patients' rights at the European level.

Policy priorities

On the basis of the results of the survey, the following seven priorities can be identified.

1. *Patients' rights must become the common point of view and standard for making decisions on health care*, as well as a shared commitment of European and national institutions and of all the actors of health policies. The present critical situation of health services requires that a strong reference point, clearly linked to the general interest, be identified. This point can be precisely that of patients' rights.

2. *Existing data and information on health care at the European level would be enriched with those regarding patients' rights*, integrating the traditional methodologies and sources with those used in this survey such as *Civic Audit* activities, that involve citizens not only as actors but also sources in producing information.

3. *A European agenda on patients' rights* should be set up and implemented with an appropriate plan of action, involving both European and national authorities as well as health care stakeholders. Since patients' situation is a matter of fundamental rights, a stronger role of the EU should be established, while fully respecting national responsibilities.

4. *The practice of the "Rights of Active Citizenship"* stated in the European Charter of Patients' Rights (to perform general interest activities; carry out advocacy activities; participate in policy making), *should be supported and guaranteed in the whole European Union*, as an expression of European citizenship. It can no longer happen that active citizens are not allowed to gather information and cooperate in assessing rights, as occurred during this survey.

5. *The financing of health structures by the governments and other payers must be conditioned to the success of these structures in protecting patients' rights*. Appropriate standards and indicators should be identified and assessed, so that the ability to respect patients' rights become a competitive advantage in health care market.

6. *Firm action towards the changing of cultural, professional and organizational models in health care must be taken*. As it was shown by this survey, the protection of patients' rights does not depend only on financial matters, but is linked also to the behavior of professionals, ways of managing services and attitudes towards the public. They can and must change quickly.

7. Finally, *a patients' right-based approach is required to deal with the new trends and upcoming situations* that are going to characterize the European scenario of health care. While our survey could get information only on the existing factors affecting patients' rights, an approach based on patients' rights is needed in managing new situations such as *free movement* or *EU enlargement*, as well as the measures and decisions that are now under discussion or going to be discussed, such as the *liberalization of information on drugs* or the *use of biotechnologies*.

APPENDIX 1

Official Data on Patients' Rights[*]

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).

The vaccination of children falls into primary prevention: in Europe the appraisal systems of such prevention measures are quite advanced and cover almost the entire population[7]. The diffusion of secondary and tertiary prevention is mapped out by the 2002 Eurobarometer Survey, with the data standardized within the Eurostat database. Through this survey, information can be found on the 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. Unfortunately, the prevention of breast cancer seems not to be too widespread, especially in the age group at higher risk (35-44 years).

Prevention also stands for healthy lifestyles. The ECHP (European Community Household Panel) survey[8], for which the most recent data dates back to 2001, shows that unhealthy habits, like excessive smoking, alcohol abuse and an unbalanced diet are more common in low socio-economic groups of the population.

2. Right to access

There are two main modalities through which access to treatment is guaranteed: the admission to hospitals and the generic and specialized medical examinations (including Day Hospital). The available information in the Eurostat database comes mainly from the administrative records from several European Union member States, where information on the number of hospital beds by type of stay, the number of doctors, of chemists and paramedical and assistance staff is collected.

The analysis of the number of beds by 100.000 inhabitants allows for the understanding of the health policies adopted in some countries. In North European countries, for instance, 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. One must, however, be very careful when comparing such information, as there is a lack of an adequate standardization in the definitions adopted in each country.

The right to access can also be achieved by facilitating the access to treatment centres in terms of reasonable time and less bureaucratic red tape. Having the services nearby may make the difference, especially to the elderly. The present trend seems directed at developing a network on the territory for patient assistance, through a regular contact with the family doctors that provide a proximity service both to the individual and to the family.

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[*] This note is taken from the study that Fiorenza Deriu, from the Department of Demography of the Faculty of Statistics of the Rome University "La Sapienza", has developed on the statistical data available at European level on patients' rights. The entire version of this Paper will be embodied in the final report of the survey.

[7] Data from the *Health For All Database*, World Health Organization, 2003

[8] The data from this survey can be found in the Eurostat database. Though, the latest available information dates back to 2001, when this survey was replaced by a new program called EUSILC.

The 1999 Eurobarometer survey, whose data are harmonized in the Eurostat database, provides interesting information on the time required to reach the family doctor and the nearest hospital. While the first one is reassuring the second one is a bit less. An excessive long time employed to reach the nearest hospital makes it more difficult to visit hospitalised family members and close friends, as well as increase the time needed to provide assistance in case of emergencies.

3. Right to information

Much progress has been made with respect to the right to information. Most countries possess information systems that help direct the citizen/patient to the nearest available and operating health services. However, these Web-based instruments are only accessible to those with a computer and access to Internet; it is usually the more vulnerable and fragile sectors of the population, those who are usually economically the weakest, who do not have such tools, or are simply too old to learn how to use them.

A number of indicators from the Community Survey on Information Technologies (ICT) show that 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. There are however striking differences among the EU countries: in North European countries and in the UK more than 50% of students use Internet to access to health information; in the Continent and in the Mediterranean this ratio decreases to 6%.

4. Right to consent

There is no information on the degree of application of this right. It is therefore necessary to find indicators that can provide adequate information on these aspects of the health practice, which are often avoided or underestimated. Moreover, it will be necessary to study the appropriate survey instruments which will allow for the data collection and the production of useful information needed to denounce when this rights is not respected.

5. Right to free choice

European health systems adopt different modalities with respect to the implementation of the right to free choice. Some systems have introduced gate-keeping mechanisms which force patients to go through a number of compulsory filters before accessing to particular therapies or specialized doctors. In other cases the citizen/patient is free to go to its family doctor, the specialized doctor, the outpatient service or the hospital with full autonomy.

An in depth study of the different health systems will allow the evaluation of the level of guarantee recognized, at least in theory, to the right to free choice. However, is very difficult to verify, in practice, its real implementation. The "Hit Summary" published by the European Observatory on Health Care Systems represents an invaluable instrument for the acquisition of such information.

One indicator, obtained from the ECHP, concerns the share of the population that turns to the family doctor or specialized doctor over a number of times. Meaning, the medical visits in outpatient room, indicator of the possibility of the citizen/patient to turn to a doctor regarding onset diseases.

6. Right to Privacy and Confidentiality

Monitoring the degree of enforcement of the right to privacy and confidentiality is quite difficult. For this right, as well as for some of the above-examined rights, it could be useful to combine quantitative survey systems (customer satisfaction surveys) and qualitative instruments to collect information, such as direct observation or focus groups, whose potential are in part expressed the present research.

7. Right to Respect of Patients' Time

This right concerns in particular the waiting times/waiting lists, a critical problem in most of the European health systems[9]. In a number of these, Finland for example, 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.

In July 2002, in Denmark 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. In 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. In Germany the situation is quite complex, as the modalities with respect to the supply of health services (including the waiting times) are negotiated between the doctors and the insurance companies. In Belgium, despite its fragmentation, the health system is being subjected to a number of reforms whose main advantages include the reduction of the waiting times. 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.

In Portugal, since 2002 the reform agenda is focusing on improving access to treatment. In this respect, measures have been implemented to reduce the waiting times for surgeries. In 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. In Italy, despite the efforts made with the recent reforms, the increase of the waiting times has led the population; especially those covered by integrated health insurances, to turn to the private sector. In the United Kingdom, the speediness of waiting lists represents an important efficiency indicator of the health system: For the monitoring, an indicator that measures the number of patients in waiting lists for 100.000 inhabitants (data not available) is calculated.

8. Right to quality

The respect of the right to quality services requires the establishment of standards to which the health infrastructures and health professionals should abide by from a scientific, technical, human

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[9] The information contained in this paragraph comes mainly from the *Hit Summary* of the European Observatory on Health care Systems or from the national reports.

and relational point of view. The instruments to ascertain the concrete adoption of quality standards and, most of all, their application in medical procedures, as well as the patients' satisfaction regarding the "humanization" of care is not easily verifiable. It can be done only by means of the analysis of the current regulations and surveys on customer satisfaction.

Unfortunately these surveys, when carried out, remain isolated cases, thus losing their validity that can only be expressed through a constant direct verification of the consequences of policies in the course of time. The establishment of quality standards has been one of the key issues of the political agenda of many governments but not always an easy one to solve due to the concurrent pressure to balance the national budgets.

9. Right to safety

For this right the same observations made concerning the need of having an alternative evaluation systems applies.

10. Right to Innovation

Economic and financial aspects, even if representing an indisputable limitation to certain choices, should not influence nor prejudice the right of the citizen/patient to access to innovative procedures and technologies, which are often very expensive.

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 the human rights of each individual.

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. Nowadays, transplants are a very sophisticated therapy that nevertheless should be considered a normal and not an extraordinary procedure. 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%[10]. The International Agency for Research on Cancer (IARC) provides the survival indicators for all tumors for adults and children in the EU countries[11].

11. Right to avoid unnecessary suffering and pain

This right comprises 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. Nevertheless, in many countries, it is difficult to access to these treatments or to centres specialized in pain therapy. The most appropriate facilities providing this kind of treatment are the hospitals of palliative treatment and the hospices.

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[10] Italian health website, *Nuovi farmaci che rendono più sicuro il trapianto,* Servizio Sanitario Web, by Didamed, 2004

[11] IARC (1999), *Survival of cancer Patients in Europe: the Eurocam-2 Study*, Scientific publication n.151. Lyon e Automated Childhood Cancer Information System, cfr. www.dep.iarc.fr/accis.htm

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 utilising opiates, etc. 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.

12. Right to personalized treatment

With the available information on the functioning of the different health systems it is very difficult to identify indicators that can provide an adequate representation of the effective achievement of this right. Each patient is a different case and it is difficult to set general standards. However, on the basis of the information on the functioning of hospital and the health facilities, it is possible to identify indicators on the orientation that determine the treatment: for instance the cases in which economical criteria prevail over the citizenship criteria based on rights.

The Eurostat database provides some interesting data on the average stay in hospital of patients by each type of diagnosis. This information, to be treated with caution when doing comparisons[12] shows how in some EU member States there is a tendency to provide health assistance at the patients' home in order to guarantee their stay in the family.

13. Right to complain

It was not possible to identify official data that could provide useful information to monitor possible violations of this right. In this respect, civic organizations could become an important control cluster inside health facilities to identify possible damages suffered by patients, as well as their outcomes and consequences.

14. Right to compensation

In order to monitor this right one should, on the one hand, study the strategies to identify cases of violation and on the other, promote the creation of legal statistical information specific to the health sector; the idea being to be able to count the number of compensation requests made as a result of health rights violations or of damages caused by actions of disservices concerning health matters and their outcomes. This kind of information would allow to better understand citizens' capacity to react when facing such violations, as well as the effectiveness of the judicial mechanisms in charge of ascertaining responsibilities.

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[12] These are administrative records made with specific goals, different from country to country. That is why comparison shall be made very carefully.

APPENDIX 2

List of the organizations involved in the project

Country	**Organization**
Austria	Women's Health Center Graz
Denmark	National Danish Association against Breast Cancer (Europa Donna)
Finland	Patientförbund (Finnish Patients' Association)
France	Missions Publiques en Europe (OMIPE)
Germany	Deutsche Gesellschaft fur Versicherte und Patienten e. V. (DGVP)
Greece	Forum For Health and Health Services
Ireland	Age Action
Italy	Cittadinanzattiva / Tribunale per i diritti del malato
Netherland	Stichting Fonds P.G.O: National Foundation for Patients, Handicapped and Elderly
Portugal	"Sempre Bem" – Association for the promotion of the welfare
Spain	Confederacion de Consumidores y Usurarios (CECU)
United Kingdom	The Patients Association
Sweden	Bröstcancerföreningarnas Riksorganisation-BRO (Europa Donna)

APPENDIX 3

List of hospitals observed and monitoring team

Austria
Monitoring Team: Sylvia Groth, Eva Rasky
Hospitals: 1. Krankenhaus der Stadt Wien-Lainz
2. Kaiser Franz Josef Hospital
3. SMZ Ost-Donauspital

Denmark
Monitoring Team: Susanne Knoth Clausen; Lis Truels Jensen
Hospitals: 1. Rigshopitalet, Copenhagen
2. Frederiksberg Hospital, Frederiksberg
3. Hvidovre Hospital, Hvidovre

Finland
Monitoring Team: Karl-Gustav Sodergard; Jenny Stenvall
Hospitals: 1. Helsinki University Central Hospital
2. Helsinki Public Health Care Center
3. Helsinki and Unsimaa healthcare district – Toolo Hospital

France
Hospitals : 1. Avicenne (Assistance Publique Hôpitaux de Paris)
2. Hôpital Européen Georges Pompidou
3. Hôpital Saint Antoine (Assistance Publique Hôpitaux de Paris)

Germany
Monitoring Team: Barbel Keim-Meermann
Hospitals: 1. Vivantes Klinikum Am Urban
2. Helios Klinik Am Buch
3. Charité Campus Mitte

Greece
Monitoring Team: Anastasia Christoforidou, Vivian Andria and Panagiota Kalou
Hospitals: 1. Ippokratio Hospital, Athens
2. Alexandras Hospital, Athens
3. Asklipiou Boulas, Athens

Ireland
Monitoring Team: Avril Bailey, Caitlin Gaffney
Hospitals: 1. Beaumont
2. St. James
3. Tallaght

Italia
Monitoring Team: Simona Sappia, Francesca Goffi, Francesca Moccia, Maria Vitale, Melody Ross
Hospitals: 1. San Giovanni - Addolorata,Roma
2. Policlinico Umberto I
3. San Camillo Forlanini

Netherlands
Monitoring Team: Dinant Haslinghus and Eva Volten
Hospitals: 1. Academic Medical Centre
2. Slotervaartziekenhuis
3. Free University Medical Centre

Portugal
Monitoring Team: Carla Marques
Hospitals: 1. Egas Moniz Hospital, Lisbon
2. Santa Maria Hospital, Lisbon

3. São Francisco Xavier Hospital, Lisbon

Spain

Monitoring Team: Ana Etchenique, Carmen Casado, Adriana Escardò
Hospitals: 1. Hospital de Mostoles
2. Hospital Ramòn y Cajal
3. Hospital Clinico San Carlos

Sweden

Monitoring Team: Ingrid Kössler, Kerstin Wåhleman
Hospitals: 1. Södersjukhuset AB, Stockholm
2. St. Görans hospital, Stockholm
3. Danderyds hospital

UK

Monitoring Team: Alan W. Hartley
Hospitals: 1. Leeds General Infirmary
2. Saint James Hospital Leeds
3. York District

APPENDIX 4

List of key-persons interviewed[*]

Austria
Ministry of Health
Dr. Iris Stamm and Dr. Dr. Reinhild Strauss, Federal Ministry of Health and Women, Adviser to Chief Medical Office
Health Expert
Dr. Claudia Wild, Institute of Technology Assessment of the Austrian Academy of Sciences, Senior Researcher
Health Expert
Dr. Odo Feenstra, Department of Public Health, Styria, Chief Medical Officer
Journalist
Mag. Annemarie Happe, Austrian Press Agency, Journalist science, education, and health
Nurse representative
Monika Klampfl Kenny, Styrian Department of Public Health, Chief Medical Nurse
Doctor representative
Dr. Reinhard Doerflinger, Physician`s Chamber of Vienna, Representative
Third Party Payer
Dr. Gert Klima, Dr. Michaela Pogantsch, Styrian Health Insurance

Denmark
Ministry of Health
Gertrud Backer, Embedslægeinstitutionen for Region IV, Chief of Department
Health Expert
Helena Alring, H:S Bispebjerg Hospital, Copenhagen, Patient Consultant
Journalist
Birgit Brunsted, Brunsted
Nurse representative
Ingrid Schultz, H:S Amager Hospital, Copenhagen, Nurse
Doctor representative
Dr. Michael Dupont, Organisation of General Practitioners, Chairman
Third Party Payer
Vibeke Krog, Topdanmark Livsforsikring A/S, Chief of Department

Finland
Ministry of Health
Mervi Kattelug, Ministry of Social Affairs and Health, Senior Legal Officer
Health Expert
Irma Kiikkala, The National Research and Development Centre for Welfare and Health, Manager
Journalist
Mardy Lindquist, Hufundstdsbladet
Nurse Representative
Mervi Flinkman, The Union of Health and Social Care Professionals, Officer
Doctor Representative
Markku Aarimaa, Finnish Medical Association, Chief Executive Officer
Third Party Payer
Maija Sakslin, Social Insurance Institution, Researcher

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[*] In the list of key persons are only the ones that gave permission to publish their names.

France
Ministry of Health
Denis Ducasse, Health Ministry, Hospital Organisation Officer
Doctor's Representative
Maurice Catinat, Ordre National des Médecins, National board member
Third Party Payer
Jean-Claude Poirier, Ile-de-France Regional Health Insurance Centre, Assistant manager
Health Expert
Ruth Ferry, CRIPS Ile de France, Chargé de Mission
Journalist
Eric Favereau, Libération
Nurse representative
Robert Caballero, EPS Maison Blanche, Director of Nursing

Germany
Health expert
Dr. Ekkekard Bahlo,
Journalist
Heike Rösch, Journalist of the Berufsverband der Arzt-, Zahnarzt- und Tierarzthelferinnen e.V.
Third party payer
Nina-Beata Björklund, BKK für Heilberufe

Greece
Ministry of Health
E. Prosykli, Ministry of Health and Social Solidarity, Head of the Independent office of Patients' Rights
Health Expert
T. Garani, National School of Public Health, Researcher
Journalist
Lora Pipili, Journalist of various Newspapers on health issues
Nurse representative
Dr. B. Margaritidou, Retired professor of nursing
Doctor representative
Dr. G. Patoulis, Association of Physicians, Member of Board
Third Party Payer
Ms. I. Antonopoulou, IKA, General Director of Health

Ireland
Doctor Representative
Dr. Ciaran Donegan, Beaumont Hospital, Dublin, Consultant Physician
Health Expert
Stephen McMahon, Irish Patients Association, Chairman
Journalist
Dr. Muiris Houston ,The Irish Times, Medical Correspondent
Third Party Payer
Sean Murray, BUPA Ireland Health Insurance, Director of Marketing
Ministry of Health
Des Treacy, Department of Health & Children Services for Older People, Community Health Division General Medical
Ministry of Health
Nuala Redmond, Department of Health & Children Services for Older People, Health Promotion Unit Mental Health

Italy
Ministry of Health
Francesco Taroni, Agenzia Sanitaria Regionale Regione Emilia Romagna, Director
Health Expert
Laura Pellegrini, Agenzia Sanitaria Servizi Regionali, Director
Journalist
Carla Massi, *La Stampa*
Nurse representative
Annalisa Silvestro, IPASVI, Presidente

Italy continued:
Doctor representative
Serafino Zucchelli, ANAOO – Associazione Medici Dirigenti
Third Party Payer
Lorenzo Bifone, Unisalute spa, General Director

Netherlands
Ministry of Health
Jos de Waardt, Ministry of Health Welfare and Sport, Head of the Section Ethics
Health Expert
Henk J. Smid, Netherlands Organization for Health Research and Development, Director
Journalist
Mariette de Bruijn, freelance journalist
Nurse Representative
Ria von Bonninghansen, Union Dutch Nurses, President
Doctor Representative
Marianne Stadlander, Order of Medical Specialists, Advisor
Third Party Payer
Maarten Boon,
Agis Health Insurance Company, Director of Strategy and Innovation

Portugal
Health Expert
Luis Ângelo Saboga Nunes, National School of Public Health, Universidade Nova de Lisboa, Professor
Journalist
Sofia Cristina Sabido Filipe, JASFARMA
Nurse Representative
Fernanda Dias, Administração Regional de Saúde de Lisboa e Vale do Tejo, Nurse
Doctor Representative
Maria Helena Cargaleiro Delgado, Health Centre in National Health Service, Primary Care Director
Third Party Payer
Maria Odete Rodrigues Azevedo Ferreira, Ministério da Segurança Social, da Família e da Criança, Specialist administrative assistant

Spain
Ministry of Health
Daniel Gonzalez Urra, Director General for Attention to Patients
Health Expert
Jose Manuel Freire, Instituto Carlos III – Escuela Nacional de Sanidad, Jefe Dpto. Salud Internacional
Journalist
Pablo Martinez Segura, Asociación Nacional de Informadores de la Salud, Vicepresidente
Nurse Representative
Carmen Lopez, UGF, nurse
Doctor Representative
Dr. Carlos Barra, UGT (Union)

Sweden
Ministry of Health
Catarina Andersson Forsman, National Board of Health and Welfare, Head of Department of Supervision
Journalist
Anna-Lena Haverdahl, Svenska Dagbladet, Medicine reporter
Doctor Representative
Eva Nilsson Bågenholm, The Swedish Medical Association, President
Third Party Payer
Lars Lööw, Disability ombudsman
Health Expert
Gunilla Ekvall, The Swedish Disability Federation, General Secretary
Nurse Representative
Eva Fernvall, The Swedish Association of Health Professionals, President