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ASSOCIAZIONE EUROPEA DEI MEDICI OSPEDALIERI  
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## Patients' Rights in Europe

### Evaluating the Present situation and constructing partnerships for the Future

*Rome, April 2006*

#### **Foreword**

While health care systems in the European Union (EU) are still largely national and differ from one country to the other, citizens' fundamental rights – among which the right to a high level of human health protection<sup>1</sup> – are the same all over Europe. Moreover, the financial problems all health care systems have to face in the EU, as well as the development of cross-border patients, contribute to increase the European dimension of the patient rights' question.

This is the reason why in 2002 Cittadinanzattiva / Active Citizenship Network (ACN)<sup>2</sup> drafted the European Charter of Patients' Rights, with the contribution of 12 citizens' organizations operating in the EU<sup>3</sup>. It states 14 rights of all individuals vis-à-vis healthcare, based on the European Charter of Fundamental Rights<sup>4</sup>. This Charter constitutes above all a set of objectives and a benchmark for health care systems and all stakeholders interested in improving patients' rights.

Moreover, it is essential to have homogeneous and reliable information on the present situation to favour the creation of partnerships among health care stakeholders, including citizens themselves, aimed at joining forces to improve patients' rights in Europe. However, the existing statistics are insufficient to fully assess the respect of these rights, since they do not cover all patients' rights and/or all EU countries, nor reflect the citizens' point of view. The available data on the rights of cross-border patients are still even more incomplete. Therefore, on the basis of these rights, ACN – together with a group of experts – established a set of indicators to measure their implementation in EU countries.

In 2003-2004, ACN and its partner organizations tested the indicators and the monitoring methodology in the 15 “old” EU countries; they presented the results in a conference in the European Parliament on 28 February and 1 March 2005. The main object of the present project is thus to extend the monitoring to all EU and candidate countries, involving more extensively in this evaluation other health care stakeholders – and especially public institutions.

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<sup>1</sup> Article 35 of the Charter of Fundamental Rights of the European Union.

<sup>2</sup> Active Citizenship Network (ACN) is a flexible network of more than 70 civic organizations operating in 30 European countries. Its mission is to promote the construction of a European “active citizenship”, meaning the exercise of powers and responsibilities of citizens in public policies.

<sup>3</sup> International Neurotrauma Research Organization, *Austria*; Fédération Belge contre le Cancer, *Belgium*; Danish Consumer Council, *Denmark*; Deutsche Gesellschaft für Versicherte und Patienten e. V. (DGVPV), *Germany*; KE.P.KA, *Greece*; Irish Patients Association Ltd, *Ireland*; ; Cittadinanzattiva / Tribunal for Patients' Rights, *Italy*; Nederlandse Patiënten Consumenten Federatie (NPCF), *The Netherlands*; Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP), *The Netherlands*; APOVITA, *Portugal*; Confederacion de Consumidores y usuarios (CECU), *Spain*; The Patients Association, *UK*. With the support of an unrestricted educational grant from Merck & Co., Inc., Whitehouse Station, New Jersey USA.

<sup>4</sup> The 14 Charter's rights are: rights to preventive measures, to access, to information, to consent, to free choice, to privacy and confidentiality, to time, to observance of quality standards, to safety, to innovation, to avoid unnecessary suffering and pain, to personalized treatment, to complain, to compensation. The full text of the Charter is attached in Annex 1.

## General objective and strategy

The general objective of the project is to produce reliable information on the implementation of patients' rights in Europe, as a basis for collaboration between the health care stakeholders for improving these rights.

The project strategy is:

- citizens' organizations will collect information on the respect of patients' rights in all EU and candidate countries, involving national and regional public institutions, as well as hospitals and health care professionals;
- the project methodology and results will be shared with all health care stakeholders, both at the national and the EU level, to favour the development of partnerships with the objective to improve the implementation of the rights.

## Specific Objectives

The specific objectives of the project are:

- to draft a European report in English on the level of implementation of patients' rights, containing a section on the situation in each EU Member State and candidate country.
  - This report will be based on data collected according to the civic audit methodology, i.e. a monitoring technology conceived and implemented by citizens themselves.
  - The 14 rights of the European Charter of Patients' rights will constitute the framework for the monitoring.
  - The monitoring will especially focus on the application of the 14 rights to cross-border patients.
- to involve regional and national public institutions, as well as hospitals, in the monitoring process.
  - Public institutions dealing with health care at the national and/or regional level will be involved from the beginning of the project as partners;
  - Public institutions and hospitals will be informed of the monitoring process in advance and invited to participate in its carrying out;
  - Part of the monitoring will be dedicated to the patients' rights already inserted in the national and EU legislations, as well as to the measures recently adopted by public institutions, hospitals and other stakeholders to improve their protection (good practices).
- to use the project results as a basis for the discussion on the priorities of patients' rights in Europe and the possible solutions to improve them.
  - The project results will be presented and discussed with citizens' organizations; public institutions; health care professionals; producers of medicines, medical products and medical devices; pharmacists; health insurances; etc.;
  - All interested stakeholders will then be invited to discuss common objectives and agree on possible commitments to concretely improve patients' rights in Europe.

## Methodology

### 1. The monitoring

The monitoring of patients' rights will have as a basis the methodology set up and tested by Active Citizenship Network in the 15 "old EU countries" in 2003-2004.

- This methodology, established in collaboration with experts in public health policies, statistics and sociologists, consists in a set of indicators defined for each of the 14 patients' rights of the European Charter, as well as instruments for the collection of the data such as

direct observation within hospitals, interviews of the hospital administrators, analysis of the national legislation, interviews of key persons, interpretation of statistical data, etc.

- The monitoring methodology will be adapted, in collaboration with the department of statistics of the University “La Sapienza” of Rome, to the specific goals and features of the present project to take into account:
  - The point of view and suggestions of the project partners on the existing indicators and instruments;
  - The greater involvement of public institutions and hospital staff in the monitoring process itself;
  - The extension of the monitoring from 15 to 28 countries;
  - The necessity to increase the sample used for the first survey in order to produce information on the national situations and not only on the European one;
  - The specific application of the 14 rights to cross-border patients.
- The monitoring will be coordinated and largely carried out at the national level by the Partner organizations<sup>5</sup>, which will be trained to the use of the instruments and the application of the methodology in a common meeting in Rome.

## 2. The participation of health care facilities in the monitoring

The participation of health care facilities, both in the phase of data / good practices collection, as well as in the discussion on how to improve patients’ rights in Europe, is fundamental. Several experiences already carried out by Cittadinanzattiva in Italy demonstrate that the audit of health care facilities is much more successful, both in terms of gathered information as in terms of following upgrade of the services, when it is carried out in collaboration with the audited structures.

Their participation will especially consist in the following activities:

- Facilitating the access to the their structure to the monitoring team and participating in the team itself;
- Answering questions regarding different indicators (interview with hospital direction);
- Participating in the presentation of the monitoring results.

Like in the case of good practices, a call for participation will be drafted by the project team, translated in all EU languages and disseminated by the project partners. Obviously, the characteristics and number of monitored structures will be determined in the methodology.

## 3. The collection of good practices on patients’ rights

One of the main European added-value of the project will be the identification and dissemination of good practices on the respect of patients’ rights in all participating countries. The target practices will be those promoted by public institutions (regulations, agenda setting, budgeting, participatory policy-making, etc.), health care facilities, health care professionals (as groups or individuals). The main objectives will be to identify the added-value and the reproducibility of such practices, so that other actors in different countries could implement them or use them as a model. It will be the basis for the concrete proposals contained in the final European report on possible solutions to improve patients’ rights.

The specific methodology for the collection of the good practices will be designed by the associated partners of the project after a research on similar projects.

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<sup>5</sup> The Partner organizations are national or local citizens’ organizations dealing with health from different points of view (patient organizations, consumer organizations, women organizations, etc.) which will participate in this project as partners, one in each of the interested countries.

A call for participation will be drafted by the project team, translated in all EU languages and disseminated by the project partners (regional governments; European associations of hospitals or health care professionals; civic organizations).

#### 4. Dissemination of the results

The communication of the monitoring results to the public will certainly be an important part of the project, since it will contribute to reinforce one of the Charter's rights, i.e. the right to information. Beyond that, it will be an occasion to discuss how patients' rights can be improved thanks to the contribution of all stakeholders, including European citizens themselves.

- Drafting of a final report in English

The main monitoring outcome will be the publication of a European report, based on the aggregate data. This report will:

- evidence the trends and priorities at the EU level;
- analyze the situation of the 14 Charter's rights in each participating country;
- include a focus on the application of the 14 Charter's rights to cross-border patients;
- make proposals for the improvement of these rights based on the collected best practices.

The purpose of this report will not be to stigmatize negative situations but, on the contrary, to examine their possible origins and reflect on achievable solutions.

- Dissemination of the final report

The monitoring final report will be published:

- On all project partners' websites;
- In a printed version, which will be distributed in occasion of the final project conferences, as well as in every conference dealing with health care in which the project partners may participate within 12 months of the reports' issuing.

- Presentation of the project results in European and national conferences.

- The final report will be presented in a conference organized in Brussels, in which will be invited to participate European representatives of health care stakeholders, EU institutions, national and regional institutions dealing with health, the project partners and all other participants in the project. The aim of the conference will be to enlarge the discussion on the project results and on the actions and measures which could be taken to improve the current situation. This event will include a press conference in order to disseminate the project results among European citizens as much as possible.
- The national reports will be presented in conferences organized in the capital and / or in important cities of each country, which will have the same objective as the Brussels conference. The participants will mainly be national representatives of health care stakeholders, the national and regional institutions and the participants in the project. They will obviously be open to the general public.

#### 5. Sharing the project methodology, implementation and results

Since this project does not only aim at collecting data on patients' rights, but also at creating partnerships for their improvement, it is essential to share and discuss the project methodology, implementation and results with all interested stakeholders.

- **Methodology**

Seminars of presentation will be organized by the project partners in every participating country before the start of the monitoring activities. The aim is to discuss the project objectives and methodology with representatives of the national and regional governments, of the health care facilities, of health care professionals, of the media, etc., and get their feedback, as well as their support. It will also be an occasion to give more information to the stakeholders interested in the collection of good practices on patients' rights on the methodology of this activity.

- **Implementation**

A second seminar with the same audience will be organized halfway of the project to examine and solve together the possible difficulties which may have emerged during the monitoring activities (difficulties to access health care structures, to get the interviews with the key persons, disagreements on how the monitoring activities are carried out, etc.). This seminar will be preceded by a meeting of all project partners, during which every participant will share with the others the problems he/she met, how he tried to solve them and whether the adopted solutions were successful.

- **Results**

The report will be sent to the participating stakeholders, as well as to all competent health care institutions, before its publication. A roundtable will be organized in every participating country with all interested parties in order to discuss the results and start to identify together the main priorities and first proposals to tackle them.

At the European level, the report will be sent in advance to the members of the High Level Group on Health Services and Medical Care, proposing to discuss its content in the framework of a meeting of the Group.

### **Follow-up**

The objective of the project follow-up is twofold:

- To formalize long-term partnerships at the regional, national and EU level in order to continue the dialogue initiated with the project and join competence, resources, etc. to improve patients' rights;
- To develop agreements between the partner organizations of the project, the national health care facilities and the national / local stakeholders in order to do the monitoring on a regular basis. It would be especially useful to measure the impact on patients' rights of the measures which may be adopted in the framework of the above-mentioned partnerships.

### **Timeline**

The project will last for 36 months, starting on 1<sup>st</sup> January 2007.

Half year/ Activity	1	2	3	4	5	6
<b>- Monitoring + participation of health care facilities</b>						
○ Methodology adaptation	X					
○ Dissemination of call for participation and collection of answers		X				
○ First partners' meeting (training + preparation of the monitoring)		X				
○ Collection of information			X	X		
○ Second partners' meeting			X			
○ Processing of information				X	X	

<b>- Good practices</b>						
○ Design of the methodology	X					
○ Call for participation		X				
○ Collection of the good practices			X	X		
<b>- Dissemination of the results</b>						
○ Drafting of the final report					X	
○ Publication of the final report						X
○ Final conferences						X
<b>- Sharing of information</b>						
○ First national seminars with stakeholders		X				
○ Second seminar with stakeholders				X		
○ Roundtables					X	