


PATIENTS' RIGHTS IN EUROPE: A CITIZENS' REPORT

Summary of meeting *organised by*
ACTIVE CITIZENSHIP NETWORK
at

THE EUROPEAN PARLIAMENT
BRUSSELS

February 28th to March 1st 2005

Written by
Health and Social Campaigners' Network

Commissioned by
Oxford Vision 2020

Published
March 2005

Contact details

Oxford Vision 2020

The Oxford Vision 2020 movement is dedicated to preventing the forecasted pandemic growth of chronic diseases (especially in low- and middle-income countries, and among poorer sections of society in the developed world).

Oxford Vision 2020 was started by the University of Oxford and a leading diabetes care company, Novo Nordisk A/S. The two bodies came together in support of the World Health Organization's May 2004 strategy to combat chronic diseases.

www.oxfordvision2020.org

Contact details for Oxford Vision 2020:

juwh@novonordisk.com

Health and Social Campaigners' Network International is part of PatientView

Contact details for PatientView:

Woodhouse Place, Upper Woodhouse, Knighton, Powys,
LD7 1NG, Wales

Tel: +44-(0)1547-520-965 Fax: +44-(0)1547-528-501

email: info@patient-view.com

www.patient-view.com/hscnetwork.htm

Registered address for PatientView: Clements House, 14-18 Gresham Street, London, EC2V 7NN, UK

Data protection registration number: Z7133076 VAT registration number: GB-760-985-885

Company number: 3944382

HSCNetwork is not responsible for the views expressed in this publication.

Copyright

© 2005 Oxford Vision 2020. All rights reserved.

This publication is the property of Oxford Vision 2020, and no part may be reproduced without permission, or passed on to any third party without the permission of Oxford Vision 2020.

PATIENTS' RIGHTS IN EUROPE: A CITIZENS' REPORT

Summary of meeting *organised by*
ACTIVE CITIZENSHIP NETWORK
at

THE EUROPEAN PARLIAMENT
BRUSSELS

February 28th *to* MARCH 1st 2005

Written by
Health and Social Campaigners' Network

Commissioned by
Oxford Vision 2020

Published
March 2005

Patients' Rights in Europe: A Citizens' Report

On February 28th to March 1st 2005, at a conference held in the European Parliament, Active Citizenship Network (an international network of civic, consumer and patient organisations) unveiled the preliminary results of a two-year study on the implementation of patient rights within 13 European healthcare systems—the first such appraisal ever made. The Active Citizenship Network study found that, without exception, European citizens do not have sufficient access to high-quality healthcare, medical innovation, or information about their healthcare choices. Attending the event were 140 health stakeholders (who were asked to provide feedback before Active Citizenship Network's final report on the study is released, later in 2005). The project was welcomed by all, including the European Commission. A summary of the preliminary report and the discussions that took place at the February/March conference is to be found in the next few pages.

Active Citizenship Network's two-year study was sponsored by Merck & Co. Active Citizenship Network plans to conduct a similar exercise in the EU 'ascendant nations' in 2005.

An exceptional study

The *Citizens' Report on the Implementation of the European Charter of Patients' Rights* was first circulated by Active Citizenship Network (ACN) to a select gathering at the European Parliament, between February 28th and March 1st 2005. ACN is a Europe-wide network of civic, consumer and patient organisations which was founded by the Italian civic movement, Cittadinanzattiva. The gathering at the European Parliament had been arranged to elicit feedback on the findings of ACN's EU-wide study, which was exceptional in a number of respects:

- The ACN study documented—for the first time in Europe—the degree to which Europeans are denied access to care.
- The study may probably have been the largest single undertaking by a health-oriented NGO on any subject—incorporating, as it did, the work of 13 health campaigning groups from the 'old' Member States of the EU [see table on next page].
- By employing NGOs to undertake field research ACN has developed a unique methodology. The approach was originally developed by Cittadinanzattiva, and aims to empower local activists by involving them in the data-gathering process. Some of these NGOs attended the conference and reported their experiences of the project.

“This was the first attempt to qualify and quantify healthcare provision across Europe from a patients' rights perspective.”

List of organisations participating in the <i>Citizen's Report on the Implementation of the European Charter of Patients' Rights</i>		
Organisation	Country	About the group
Frauengesundheitszentrum Women's Health Center, Graz www.fgz.co.at	Austria	Independent organisation. Part of the international womens' movement. Aims to promote self-determinism.
Brystkraeffforeningen National Danish Association Against Breast Cancer www.brystkraeffforeningen.dk	Denmark	Member of Europa Donna. Works to raise public awareness of breast cancer. Campaigns for appropriate screening, and optimal treatment and care, as well as increased resources for research.
Patientförbund Finnish Patients' Association www.kulutajaliitto.fi	Finland	Member of Finland's Consumer Association. Promotes patients' rights.
Observatoire des Missions Publiques en Europe (OMIPE)	France	Promotes health and encourages prevention among public services.
Die Deutsche Gesellschaft für Versicherte und Patienten e.V (DVGP) www.dvgp.de	Germany	Independent organisation. Aims to protect the interests of citizens within healthcare systems.
Forum for Health and Health Services	Greece	[No details available.]
Age Action www.ageaction.ie	Ireland	A network of groups that promotes improved policies and services for older people.
Tribunale per i Diritti del Malato (TDM) Tribunal of Patients' Rights www.cittadinanzattiva.it	Italy	Italian health campaigning body. Part of Italy's civic activist group, Cittadinanzattiva.
Patiënten Gehandicapten en Ouderenfonds (Fonds PGO) National Foundation for Patients, the Handicapped and the Elderly www.fondspgo.nl	Holland	Umbrella group which funds many major local disease-oriented organisations, plus groups that represent the interests of the elderly.
Sempre Bem (Always Well) of the Associação para a Promoção do Bem Estar (Association for the Promotion of Wellbeing)	Portugal	Focuses particularly on the needs of young people to stay healthy.
Confederacion de Consumidores y Usurarios (CECU) Consumers' Association ww.cecua.es	Spain	Madrid-headquartered organisation with branches in most parts of the country. Interests cover most aspects of consumer safety and social rights.
Bristcancerforeningarnas Riksorganisation (BRO) www.bro.org.se	Sweden	A member of Europa Donna.
Patients' Association www.patients-association.com	UK	Voluntary organisation that acts as the 'consumer voice' on healthcare in the UK.

Source: ACN and various organisations' websites, March 2005

How the project unravelled

The Patients' Rights project was initiated in 2002 as a result of activities conducted by the Tribunale per i Diritti del Malato (TDM), an ACN sister organisation. Since 1980, TDM has documented the problems that Italian citizens have experienced with their healthcare system (particularly within hospitals). ACN suspected that citizens all over Europe might be suffering similar difficulties, and that patients' rights to healthcare were being ignored or abused in countries outside Italy.

ACN insists that such neglect and misuse is unacceptable. Various charters, declarations and laws on the rights of patients have been enforced throughout the EU, including Article 35 of the EU Charter of Fundamental Rights (signed in Nice in 2000). The latter EU Charter guarantees a right to health, a right of access to preventive healthcare, and a right to benefit from medical treatment under conditions established by national laws and practices.

Active Citizenship Network (ACN)

Active Citizenship Network (ACN) was formed by the Italian civic movement Cittadinanzattiva (Active Citizenship) in 2001 as a loose network of 70 civic organisations from 30 European countries. The civic movement is a European phenomenon motivated by principles of solidarity. ACN aims to empower citizens to participate in policymaking for the protection of peoples' rights, and for the common good.

As its name implies, ACN seeks to promote the notion of active citizenship. It does so by encouraging European, national, or local civic organisations to become involved in public policy on a range of issues—in particular, health, consumer rights, and the environment.

ACN does not have members as such. Rather, the group conducts projects in collaboration with other national civic organisations. The network functions by:

- Collecting information from the national affiliates.
- Developing policies with civic organisations.

Projects include building a Patients' Rights' Charter [as discussed in the main text]; formulating principles to improve the defining criteria of civic organisations; and rethinking the principle of subsidiarity.

In areas of health, ACN draws on the expertise of two other offshoots of Cittadinanzattiva:

- Tribunale per i Diritti del Malato (TDM, the Tribunal of Patients' Rights), a programme that brings together various stakeholders and the public to lobby for local patients' rights charters and raised standards in hospitals. TDM provide a national advice service.
- Chronically-Ill Patients' Association (CNAMC), a national association of 120 organisations sharing common needs and advocacy positions.

For the moment, ACN is headquartered in Rome rather than Brussels. The location was a deliberate decision, emphasising that ACN is not a Brussels-centric lobbyist, but a group with a remit stretching across all of Europe, devoid of national or local bias.

ACN Patients' Charter

The 14 'immutable' rights

1-Right to preventive measures

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

2-Right of 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.

3-Right to information

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

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 prerequisite for any procedure and treatment, including participation in scientific research.

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.

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.

7-Right to respect for 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.

8-Right to observance of quality standards

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

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.

10-Right to innovation

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

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.

12-Right to personalised treatment

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

13-Right to complain

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

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 first step: drafting a European Charter of Patients' Rights

In 2002, ACN set about drafting its own European Charter of Patients' Rights. The group collaborated with a number of national civic organisations specialising in citizens' health. ACN's Charter was launched in Brussels on November 14th 2002, at a conference organised by its sponsor, MSD. The Charter stipulates 14 patients' rights [see previous page]. Many of the rights are threatened by the financial crisis in national welfare systems.

Aside from being a valuable tool for discussion and education, the Charter serves as an important reference point against which any healthcare system can be evaluated and monitored (no matter how disparate, and regardless of the demographics and epidemiology of national populations). During 2003, ACN travelled around Europe disseminating the Charter and preparing for the next stage of the patients' rights project.

Step two: monitoring Europe's record on patient rights

In the second phase of the project, ACN launched a process to monitor the levels of implementation of the Charter's 14 patients' rights. To help conduct the monitoring, ACN brought on board 13 key NGOs with differing interests in healthcare. This second part of the project, however, also hoped to move beyond monitoring. The project was additionally aiming to begin the empowerment of citizens—changing them from being “mere targets and users of health services, to active citizens engaged in producing information and participating in policymaking”. In short, the project itself can be regarded as a further device for promoting a ‘patients'-rights approach' to healthcare.

Working in conjunction with a bevy of experts, ACN formulated a number of tools and techniques that allowed it to translate its Patients' Rights Charter into a set of measurable indicators which could be consistently and reliably assessed on the ground. ACN opted for 160 different indicators to be collected in each country. Four different approaches to data collection were used:

- Partner organisations interviewed 70 key local stakeholders, which included medical professionals, journalists, payers (insurers) of healthcare, and representatives from the various nations' ministries of health.
- Partner organisations visited 39 main hospitals in each of the European capital cities. Unfortunately, hospital authorities in four countries (Germany, Ireland,

“In 2002, ACN drafted a European Patients' Charter with 14 basic rights that are based on citizens' own priorities.”

“The project was conducted by 13 NGOs in 13 countries, and surveyed 39 hospitals and 70 key local stakeholders.”

Portugal and the UK) refused to give out information to the partners.

- Partner organisations answered a questionnaire on their own country's patients' rights' legislation.
- ACN wrote a report on each country's existing healthcare official statistical sources.

The methodology for the monitoring process—first piloted in Italy—was rolled-out in 2004 across most of the 15 'old' EU Member States (Belgium and Luxembourg are due to be surveyed in 2005). Giovanni Moro, programme advisor to ACN, later pointed out some of the limitations of the survey, including: the moderate size of the samples; the focus on capital cities (rather than on regional or local resources); and a lack of consideration of national differences.

Nonetheless, ACN believes that it has been able to put together the first serious study on the implementation of 14 basic patients' rights in a number of healthcare systems in Europe. ACN also feels that its approach is well worth building upon.

Headline results

Taking each of the 14 patients' rights in turn, the main findings of the survey were as follows:

1-Prevention: *With the exception of screening for female cancers, preventive medical practice is almost absent in European hospitals*

Hospital authorities in the nine countries which agreed to take part in the survey (Austria, Denmark, Finland, France, Greece, Italy, the Netherlands, Spain and Sweden) were quizzed on the availability of the following screening programmes: for breast, cervical, and colorectal cancer; for hypertension; and for amblyopia (lazy eye) and strabismus (crossed eyes) in pre-school children. Hospitals were also asked about any campaigns they had mounted against smoking; on detecting drinking problems for adolescents and adults; and about their prevention programmes for sexually-transmitted diseases. Hospital authorities reported that—with the exception of screening for female cancers—preventive medical practice in hospitals hardly ever occurred. Prevention was not regarded as a core hospital activity.

“Patients’ rights of access to preventive medicine are not observed throughout Europe—a contravention of EU legislation”

2-Access to care: *Patients’ rights of access to care have been violated. For instance, regulators in some European countries have failed to approve medicines that are readily available abroad. Physical access to hospitals is good, however (except in Portugal and Greece)*

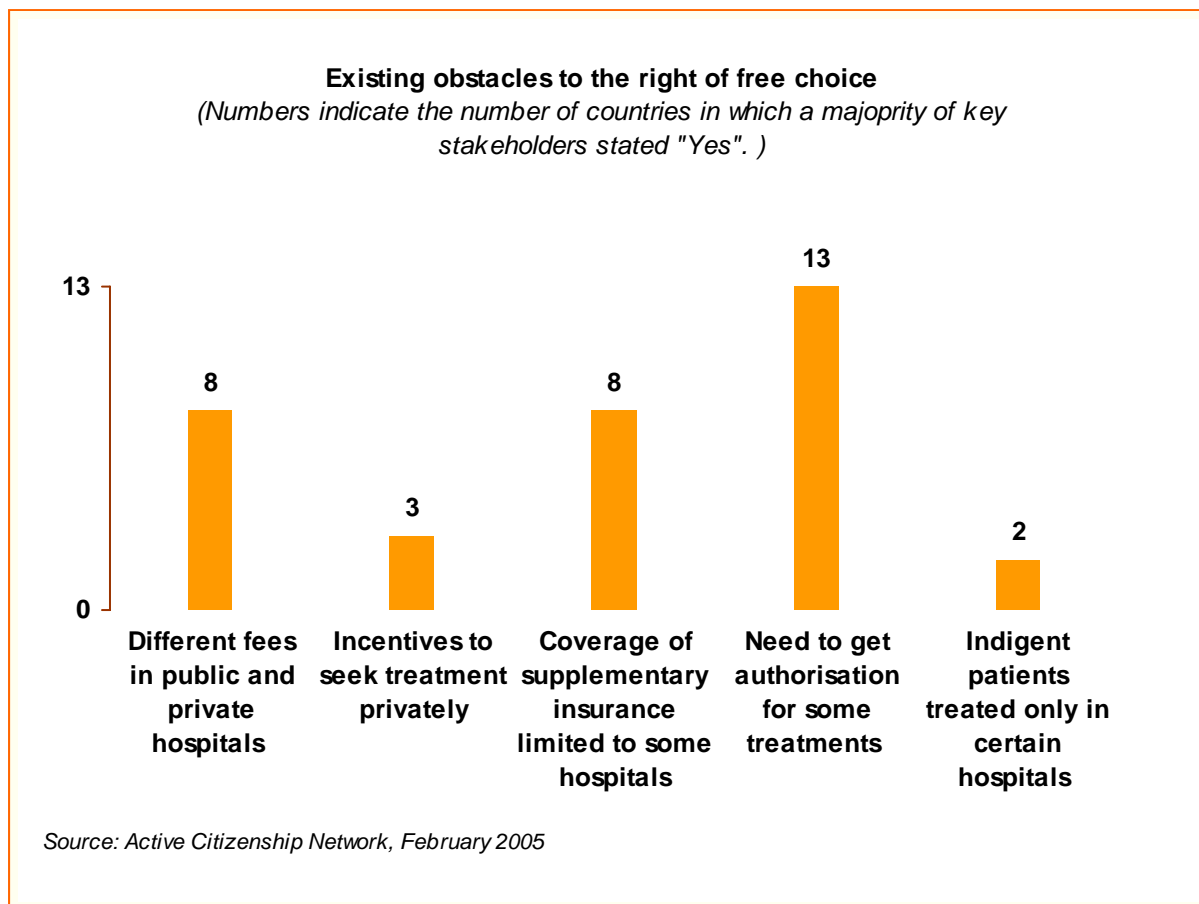
At least four key people interviewed in each of the following eight countries—Austria, Finland, France, Germany, Ireland, Portugal, Spain, and Sweden—knew of cases in which patients’ rights to access healthcare had been violated during the previous 12 months. The majority of stakeholders interviewed in the following seven countries—Denmark, Finland, France, Ireland, Italy, Spain and the UK—emphasised problems experienced by patients who were trying to access medicines which had been approved in other countries, but not yet in their own. By contrast, interviewees considered that physical access to hospitals is generally good in all countries (except in Portugal and Greece).

3-Right to information: *Although hospitals have created mechanisms to supply information to the public, the material actually provided is scant*

As judged by direct observation and in interviews with cooperative hospital authorities, the NGO partners in the survey found that instruments to convey information to patients are widespread. The following facilities are commonly available: information offices or services at the main entrance of hospitals (in 13 out of 13 countries); a regularly-updated directory in the main hospital lobby (in 11/13); good telephone access to hospitals (in 9/13); and hospital websites (also in 9/13). But the information supplied by these hospitals is limited. Only in the Netherlands and France is data about patient satisfaction and clinical-performance measures publicly available. Information about waiting lists and public complaints is also in short supply in nine out of the 13 countries.

4-Right to consent: *Forms to gain patient consent are common—but only for patient participation in scientific research. Efforts to gain the informed consent of patients are unimpressive*

Hospital authorities interviewed in nine European countries use standardised forms to obtain patients’ consent to participate in scientific research. In three out of the nine countries (Denmark, the Netherlands, and Sweden), though, such forms are not available for invasive diagnostic examinations or for surgical operations. Key people interviewed in one third of the 13 Member States criticised their country’s efforts to gain informed consent. People interviewed by NGOs in Austria, Finland,



France and Germany stated that they knew of cases in which a patient's right to consent was violated in the past year.

5-Right of free choice: *The free choice of patients to treatments and providers is restricted, because countries refuse to pay for all types of care to all types of people*

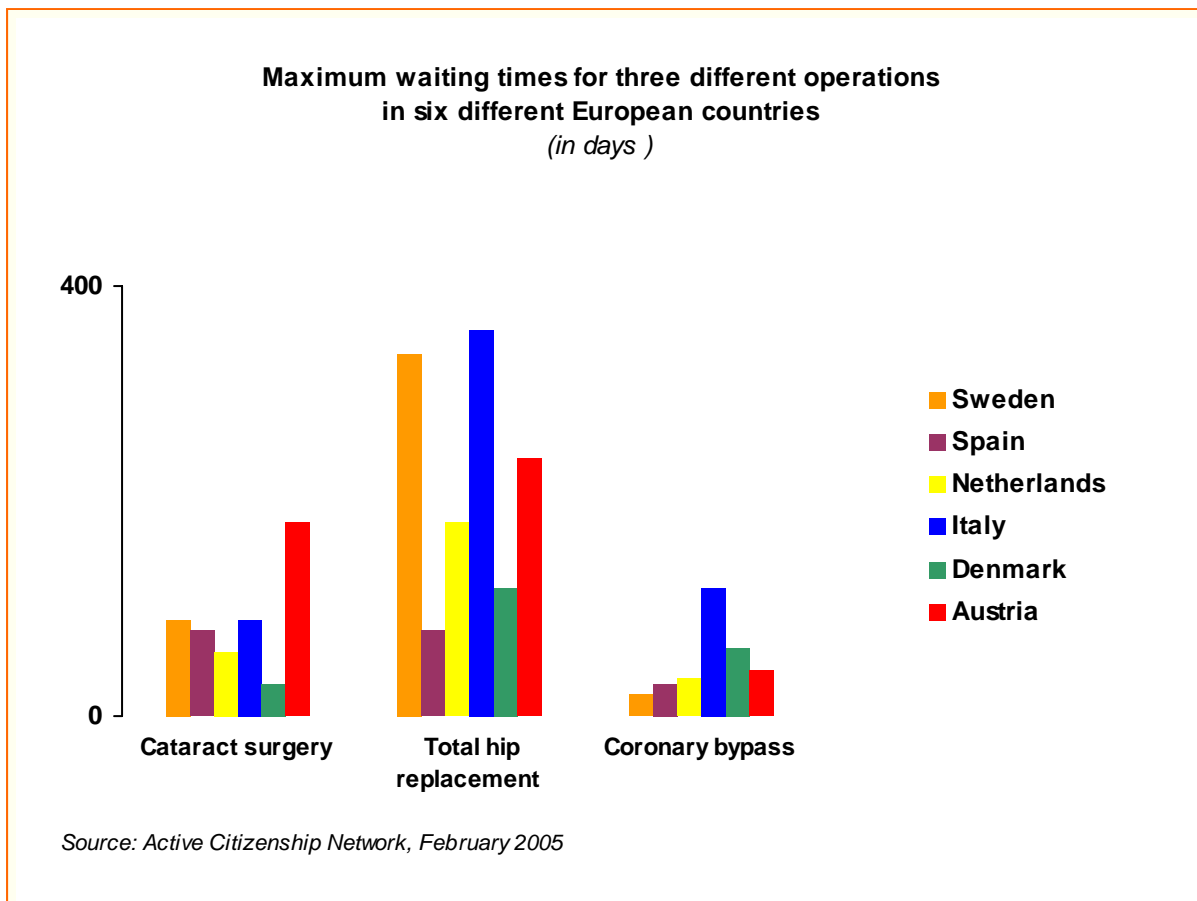
ACN identified a number of barriers preventing patients from choosing their own treatment procedures and providers. For example, the majority of healthcare stakeholders interviewed by the NGO partners in all of the 13 European countries said that doctors needed to obtain authorisation to prescribe some treatments.

6-Privacy and confidentiality: *Healthcare providers show little respect for patient privacy—above and beyond the traditional provision of curtaining in examination rooms*

Levels of privacy and confidentiality afforded patients are far from acceptable in Europe. NGO partners observed that terminally-ill hospital patients in eight of the 13 countries (Austria, Germany, Greece, Ireland, Italy, Portugal, Spain and the UK) were not placed in single-occupancy rooms. Key people who are well-acquainted with healthcare systems noted that personal medical information could be disclosed to non-authorised personnel in as many as seven of the 'old' EU countries (France, Germany, Greece, Portugal, Spain, Sweden, and the UK).

7-Respecting patients' time: *Hospitals consistently fall short of respecting a patient's need to be cared for within a specific and limited time span (a failing which can have serious consequences on citizens' health)*

Only in Denmark and the Netherlands had hospital authorities established a limit on patients' waiting times. Even in these two countries, outpatients could wait at least



30 days for some tests and treatments. The waiting times for major operations varied considerably across the 13 countries. Key people familiar with healthcare systems were aware of cases in which failures within healthcare systems led either to an illness worsening (due to time delays or overly-lengthy waits for important diagnostic tests), or of patients turning to the private sector because they could wait no longer for national systems to supply them with the care they needed. Austria was the single, more positive, exception in this category.

8-The quality of healthcare: *Health performance standards are set in hospitals throughout Europe—but with little regard to the needs of citizens*

Hospital authorities in all of the 13 'old' EU countries have instigated efforts to assess their levels of healthcare performance. Denmark, the Netherlands, and Sweden were furthest down the assessment track. However, no hospital authority involved citizens' organisations when setting its standards.

9-Patient safety: *All Europe's hospitals appear to take adequate precautions against hospital-acquired infections. Hospitals, however, are less effective at quashing the use of outmoded diagnostic tests or treatments. The needs of the physically disabled are often ignored*

All of Europe's hospitals appear to have instituted procedures for reducing hospital-borne infections. The majority of hospitals also seem to employ a person or run an office to coordinate the risks that can result from transfusions. However, very few hospitals consistently check on whether their diagnostic tests and treatments are outmoded. Evacuation routes for wheelchair users are clearly marked only in Irish and Swedish hospitals.

10-Accessing innovation: *The uptake of innovative medical practice is ad hoc throughout Europe*

Mainstream hospitals in the majority of the 13 countries employ minimally-invasive surgical procedures, and arrange special mattresses to prevent pressure ulcers. However, hospitals in only five of the 13 countries reported using electronic means to access patient data, treatment appointments, or medical referrals. Electronic communication was reported as being particularly poor in Finland, Greece, Ireland, Italy, Portugal and Spain. Key people knowledgeable about national healthcare systems noted delays in the introduction of novel diagnostic tests and/or treatments in Finland, Germany, Ireland, Italy, Portugal, Spain, Sweden, and the UK.

11-Avoiding unnecessary pain and suffering: *The management of pain in patients is inadequate in most of the European countries surveyed in this project*

In seven of the 13 countries (Austria, Finland, France, Greece, Italy, Portugal, and the UK), key people familiar with national healthcare systems stated that patients are not always given access to appropriate pain-managing technology. Observers in Germany, Greece and Sweden described cases of violations of international procedures on severe pain treatment with morphine.

12-Personalised treatment: *Few, if any, hospitals surveyed gave sufficient attention to the provision of personalised services for patients. Only the needs of children appeared to be well considered*

Patients in hospitals require and need specialised attention. Some patients may ask for religious assistance. Terminally-ill patients, or victims of violence, may need psychological support. Yet, few, if any, hospitals in Europe are able to boast comprehensive coverage for all of these patient concerns. The needs of children, however, proved to be well looked after in the majority of countries.

13-Making complaints: *Complaints procedures are faulty throughout Europe*

Hardly any hospitals run independent complaints procedures. Responses to patients' complaints are often unacceptably slow in coming. Interviewees in the Netherlands and Portugal reported cases in which citizens obtained no response at all to their complaints.

The Civic Audit

According to Alessandro Lamanna, director of the civic audit programme at Tribunale per i Diritti del Malato (TDM), the audit is "a critical and systematic analysis of health agencies' actions, promoted and implemented by citizens' organisations": The audit has three aims:

- To raise the profile of the patient's perspective among medical professionals.
- To encourage citizen participation in the improvement of the quality of their national health systems, and advance their interaction with healthcare management.
- To promote benchmarking and the development of comparative indicators to increase good practice.

In Turin, following a civic audit, patient onlookers noted a significant change for the better in patient waiting areas, the monitoring of GPs and home visits.

A rights-oriented approach to healthcare in Europe

Member States share a huge range of common healthcare principles. In practice, however, huge variations in the tradition, culture and operation of national healthcare systems perpetuate significant divisions between the approaches of each country. The reality is: all 25 current Member States run their own national healthcare services exactly as they please.

Although Article 35 affords citizens in Europe specific health rights, these relate to preventive practices only. Each country is free to interpret the health elements of the EU Constitution as it wishes.

Nonetheless, the EU is starting to take a bigger role in helping to frame health policy, so that Member States can be assisted in responding to new challenges (such as EU enlargement, new technology, or increases in patient mobility). The process is being accelerated because Europeans are searching for better healthcare in EU nations other than their own. We at DG Sanco are also looking at several new options to improve the quality of health information.

Formulating a rights-based approach to healthcare is probably premature at the moment. Member States are unlikely to sign up to the idea as yet.

It is important to remember that European bureaucrats—such as myself—are not democratically elected to jobs in the EU. Change, if it is to come, should be driven from the grassroots upwards. Here, I emphasise the importance of groups like Active Citizenship Network, which embraces NGOs that have come together from across Europe. Such networks, unfortunately, are under-resourced—which does not mean that the need for an articulate voice on patient matters should be muffled. In this sense, at least, the European Commission can provide logistical help.

Comments made by Bernard Merkel
Director of Health Strategy,
DG Sanco, European Commission

14-Getting compensation: *Except in Greece, hospitals and/or doctors carry insurance to compensate patients. In practice, compensation can sometimes prove hard to get*

With the single exception of Greece, hospitals and/or doctors in the 13 'old' EU countries are generally insured. Most have provisions for compensating patients after medical negligence or errors committed by the institutions. Six countries (Denmark, Germany, Ireland, the Netherlands, Portugal and Spain), however, failed to provide patients with access to independent organisations that offer legal counsel free of charge. Interviewees in Finland and Sweden spoke of cases during the past year in which patients' rights to compensation were being violated.

Comments from the floor

Around 140 people attended the ACN conference, including representatives from:

- 37 civic and patients' organisations (from 28 European countries).
- 15 European umbrella organisations.
- The ministries of health of Finland, France, Latvia, the Netherlands, Poland, Portugal, and Spain.

- German, Italian and Slovakian Members of the European Parliament.
- The European Commission's DG Sanco.
- The European Economic and Social Committee.
- The private sector.

The main issues raised by attendees were as follows:

A welcome initiative—which should be broader in scope

Conference attendees were generally supportive of a rights-oriented approach toward European healthcare—particularly in situations when patients are being called upon to take more responsibility for their care, and even to seek out healthcare providers abroad. A rights-based attitude possesses two great advantages: permitting unified standards to be achieved across Europe, while introducing a level playing field for healthcare delivery. On the other hand, qualifications include:

- Several NGOs felt that greater attention should have been given to their own particular specialities (in this instance, the health interests of women and older people).
- Other groups observed that a patient's right to optimum care, and the right to receive care near home (when appropriate), were not included in ACN's Charter.

Conference participants considered that the ACN project—despite its few shortcomings—should be broadcast more widely.

Methodology

Three major criticisms of ACN's methodology emerged at the conference:

1. Although the project made every effort to find performance indicators of relevance to all European Member States, differences within national healthcare structures did impact upon results.
 - In some countries (including Denmark, the Netherlands, and the UK) preventive medical practice is mainly performed in the primary/community setting, rather than in the secondary healthcare sector that ACN chose to explore. Any attempt to suggest that these countries are deficient in preventive measures, therefore, would be misleading.
 - Waiting lists function as a form of healthcare rationing in the UK (but not in France).
 - Patients in Greece can gain compensation through the country's Ministry of Health or via the courts (a fact overlooked by the survey).
2. The project should make a clearer distinction between government legislation (or official guidelines on healthcare practices) and implementation at ground level.
3. Lastly, all NGO partners selected for participation in the project should be independent from government.

The practical difficulties experienced by the NGO partners

A number of the NGO partners in the project spoke of the difficulties they found in implementing the methodology.

- NGO partners often had trouble finding key people who were sufficiently

acquainted with all the issues that needed to be discussed. Legal healthcare experts were especially thin on the ground. Those that were approached tended to regard their prospective contribution to the project as likely to be too complex and time-consuming. NGO partners therefore ended up doing much of the research work themselves.

- Hospitals were often reluctant to participate in the project, and sometimes became defensive. “Doctors believe that they care”, said a German NGO partner, “and felt affronted about being questioned about their work”. One NGO partner from the Netherlands, though, emphasised the importance of finding the right person within an institution.
- Medical professionals who were interviewed sometimes viewed the whole project with suspicion. Others might waste hours of the interviewers' time minutely discussing topics.
- In some cases, people being interviewed ‘toed the party line’ and ignored obvious faults within their own country’s healthcare system. Other interviewees referred to cases in which patients’ rights were violated, but proved reluctant to specify examples.
- Some of the vocabulary used in the ACN questionnaires was understood differently by individuals interviewed (one term that proved particularly open to misinterpretation was “high risk”).
- The whole process of contributing to the project absorbed far more of the NGO partners’ time and effort than they had envisaged at the outset. Part of the problem was that few interviewees had heard of ACN.

Conclusion

Dr Moro explained at the conference that the Patients’ Charter (and some aspects of ACN’s methodology) will be continually under review.

“It will be useful to expand the Charter, make it more robust, and link it more effectively to daily situations”, he said, “and to a general framework of human rights”.

Experience has shown that more training is required by the local civic groups involved in the monitoring process, stressed Dr Moro. And greater effort is needed in future to convince hospital authorities to become involved in civic audits.

*“Formulating patients rights
and promoting their
implementation are
incremental processes.”*

Dr Moro mentioned that ACN plans to draw up specific recommendations on the following topics:

- The importance of patients' rights, and the need for a European agenda.
- The necessity for more patient-relevant data.
- A requirement that patients' rights be respected when countries draft health reforms.
- And an escalation in efforts to promote a change in attitudes among health professionals toward the public and their patients.

Participants added their own ideas (which often echoed those of Dr Moro):

- **European countries need to be made aware of patients' priorities and the importance that should be attributed to advocacy organisations and citizens' groups.** In many European cultures, physicians retain a god-like status. The concept of patients' rights is perceived as threatening by professionals in nations where doctors are still seen as being close to infallible. Certain issues (such as a patient's individual free choice, and personalised medicine) are more readily pushed to one side by practitioners in these countries. A further erosion of rights occurs when increased decentralisation of healthcare budgets encourages doctors to concentrate on the priorities of a wider, whole-society attitude to care and treatment, rather than indulge the individual requests of patients—a trend that stands counter to a rights-oriented approach to healthcare.
- **Well-meaning national measures to support patients' movements should be backed up with appropriate investment.** NGOs need to be better financed, particularly if they are to adapt to a more active role in monitoring their healthcare systems, and playing a significant part in effecting change.
- **Concepts such as 'wellbeing', 'prevention' and 'health' have to enter common parlance—especially that of doctors.** Physicians in some countries (such as Greece), are still far from being familiar with the phrase 'health systems'. Instead, they refer to 'medical systems'—terminology that is altogether more familiar and comforting to them.
- **Questions about patients' rights should become an integral part of healthcare policymaking—rather than being added on later as an unimportant afterthought.**

A short postscript

People attending the ACN conference at the European Parliament could not fail to be impressed with the efforts of the Italian group. All took home the message that civic involvement can be a potent force for good and national endeavours can be greatly amplified when managed through European networks. Some NGOs walked away from the event convinced that—at long last—they might be able to change their world, instead of being peripheral onlookers. ACN had shown them how.



HSCNetwork International

A PatientView division

**Woodhouse Place
Upper Woodhouse
Knighton
Powys, LD7 1NG
Wales**

Tel: 0044-(0)1547-520-965

Fax: 0044-(0)1547-528-501

email: info@patient-view.com

www.patient-view.com/hscnetwork.htm

March 2005

Registered address for PatientView:

Clements House, 14-18 Gresham Street, London, EC2V 7NN, UK