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Patients' rights

Analysis of discussions at Active Citizenship Network's March 29th 2007 Brussels conference, 'European Patients' Rights Day'

On March 29th 2007, the Rome-based civic organisation Active Citizenship Network (ACN) held a conference at the European Parliament in Brussels to highlight the need for patients' rights in Europe. The event served a number of purposes—firstly, drawing attention to ACN's campaign for an official 'European Patients' Rights Day'. Secondly, ACN used the occasion to release the results of a monitoring exercise it has been conducting into the level of respect accorded patients' rights in 14 EU countries [see pages 22–26]. Thirdly, the conference marked the launch of ACN's Manifesto on Patients' Rights in Europe [see page 21].

In all, the Brussels conference was part of ACN's continuing efforts to secure legal recognition of a basic set of entitlements for European patients. ACN, partnering 12 other national citizens' organisations, first set out these entitlements in November 2002, in the form of a 14-point European Charter of Patients' Rights [see page 19].

Just two weeks before the ACN conference, the European Parliament passed a Resolution on the provision of cross-border healthcare, emphasising "the need to incorporate a common charter of patients' rights in the future European Community framework, in order to ensure that such rights are exercised in practice across borders, and in the home country". ACN considers that the Resolution gives its campaign extra credibility and impetus.

ON THE DAY

The topicality of the ACN conference's subject matter drew over 150 delegates, representing the interests of patients, the public, policymakers, healthcare providers, legislators, payers, and industry. Opening remarks were made by Philippe Brunet, Deputy Head of the Cabinet of Markos Kyprianou (European Commissioner, Directorate-General for Health and Consumer Protection). Twelve Members of the European Parliament (MEPs) also gave testimony of their support for ACN's European Charter of Patients' Rights [see page 20]. The 12 are interested in patients' rights for the following reasons:

Universal coverage: a citizens' right

The Alliance of Liberals and Democrats (ALDE) has often supported rights-based causes (including rights to health and healthcare). The Alliance sees universal healthcare coverage as crucial for social cohesion and stability.

Inefficient healthcare systems cause unnecessary sickness (and even death)

Member States face similar challenges in endeavouring to ensure that their healthcare systems are equitable, safe, and sustainable. But attempts to find the right balance can lead to patients' rights being ignored. Thus, even within a single country, disparities may exist in access to, the quality of, and the range of healthcare services available. As a result, thousands of EU citizens are dying from diseases like cancer every year, simply because

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The 14 rights in the ACN European Charter of Patients' Rights

All of the countries in the European Union—despite differences in their national healthcare systems—afford patients and public the right of access to healthcare. Often, however, financial constraints limit such access—a practice that Active Citizenship Network (ACN) finds unacceptable.

To allow patients and providers alike to be aware of the extent of patient entitlements, ACN, supported by 12 other European civic groups, drafted a European Charter of Patients' Rights (first published in November 2002). The 14 rights in the Charter embody the international position on fundamental rights expressed by the EU and other recognised international agencies. One of the most noteworthy of the Charter's sources is the EU Charter of Fundamental Rights, which was signed in Nice, Italy, in 2000 [http://www.europarl.europa.eu/charter/default_en.htm]. The EU Charter is a cornerstone of the yet-to-be-ratified European Constitution [http://europa.eu/constitution/index_en.htm].

The 14 ACN rights fall into two categories:

- (1) Societal rights, which place an obligation on citizens to ensure that everybody is treated equally, without discrimination. Included in this category are the rights to access, information, quality, safety, and innovation.
- (2) Individual patients' rights (which are sometimes held distinct from human rights) allow people to claim to freedom

The European Charter of Patients' Rights
1. The 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 for patients' time.
8. Right to observance of quality standards.
9. Right to safety.
10. Right to access innovation.
11. Right to freedom from unnecessary pain.
12. Right to personalised treatment.
13. Right to complain.
14. Right to compensation.
<i>Source: ACN</i>

of action. Included in this category are the rights to prevention, consent, choice, privacy, time, complaint, avoidance of pain, personalised treatment, and compensation.

Since the Charter's launch in 2002, ACN has continually refined its understanding of the factors and issues associated with each of the rights.

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their treatment is below standard, or is provided too late.

Gender and age inequalities prevail in healthcare systems

Marie Panayotopoulos-Cassiotou, an MEP from Greece, is a defender of the right of European women to benefit from quality healthcare and treatment during pregnancy and maternity, and the right of children to expect that medicines have been specially produced for their age group. “Only half of the drugs used by children have been tested for

that purpose”, said Ms Panayotopoulos-Cassiotou at the ACN conference.

Medicine’s interest in the genetic background of disease does not take into account the value of health-promoting social changes

Some of the MEPs attending the conference believe that modern medicine focuses too much on the genetic elements of disease, and not enough on the social and economic factors that underpin illness. Such an argument stipulates that long-term improvements in diet, education, working conditions, and other social factors, allied to preventive measures, have had a more beneficial impact on life expectancy than medicine. These various social advances also reduce social inequities generated by ill health.

12 MEPs who support patients’ rights in Europe

Adamos **Adamou**, Confederal Group of the European United Left / Nordic Green Left, Cyprus.

Ilès **Braghetto**, European People’s Party (PPE), Italy.

Marco **Cappato**, Alliance of Liberals and Democrats (ALDE), Italy.

Jolanta **Dickute**, ALDE, Lithuania.

Françoise **Grossetete**, le Groupe du Parti Populaire Européen (Démocrates-Chrétiens) et des Démocrates Européens (PPE-DE), France.

Marian **Harkim**, ALDE, Ireland.

Marios **Matsakis**, ALDE, Cyprus.

Marie **Panayotopoulos-Cassiotou**, PPE, Greece.

Antonyia **Parvanova**, ALDE, Bulgaria.

Giovanni **Pittella**, PSE, Italy.

Heide **Rühle**, Group of the Greens / European Free Alliance, Germany.

Nicola **Zingaretti**, PSE, Italy.

The short-term nature of politics prevents the creation of social programmes that could promote health

Other MEPs draw attention to the weakness of any system of relying solely on politicians for delivering major change. Policymakers, being elected, only operate on short-term, limited-period mandates. Governments therefore often prefer to concentrate on investments that deliver ‘quick-fix’ gains (such as the building of a hospital), rather than look at underlying social determinants.

Medical paternalism can deny patients their right of choice—but doctors have rights, too

Patients need a safe and empowering environment with good governance to secure their right of choice. But patients’ rights should be respected without denying the rights of healthcare professionals, who should be free to prescribe as they see fit.

Patients also require information as a right

Françoise Grossetete, a French MEP, insists that urgent action is needed to address the problem of discriminatory access to healthcare information in Europe.

Unavailable treatment in the home country justifies cross-border patient mobility

The public should be able to travel to care when treatments are unavailable at home or delays in receiving treatment are too great. The European Court of Justice's decision to allow such access should become a right for all European citizens, and not just be dependant on the ability of the patient to obtain reimbursement.

Healthcare could be given a higher priority in the European internal market

The right of cross-border access to high-quality care may encourage Member States' healthcare systems to strengthen their services, leading to better overall care across Europe.

ACN's Manifesto on Patients' Rights in Europe

ACN is calling on the European Parliament to support two initiatives on patients' rights:

- Inclusion of a Common Charter of Patients' Rights into the future Community framework.
- Institution of an official European Patients' Rights Day.

The twin proposals build on the following past activities and decisions:

- ACN's 2002 European Charter of Patients' Rights.

- The Charter of Fundamental Rights of the European Union (especially article 35, on healthcare).

- The European Court of Justice's case law on cross-border care.

- The European Parliament's Resolution on Patient Mobility and Healthcare Developments in the EU, June 2005. [http://www.iese.edu/en/files/6_15408.pdf]

- The European Council's Conclusions on Common Values and Principles in EU Health Systems, June 2006.

[http://www.eu2006.at/en/News/Council_Conclusions/0106HealthSystems.pdf]

- The European Commission's Consultation Regarding Community Action on Health Services, September 2006.

[http://ec.europa.eu/health/ph_overview/co_operation/mobility/docs/comm_health_services_comm2006_en.pdf]

- The European Parliament's Resolution on Community Action on the Provision of Cross-Border Healthcare, March 15th 2007.

[<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+MO TION+B6-2007-0098+0+DOC+PDF+V0//EN>]

The evidence on patients' rights

Giovanni Moro, President of Rome-based Fondaca (or Active Citizenship Foundation, a sister organisation of ACN that specialises in promoting civic activism) said at the March 2007 ACN conference that he expects patients' rights to become an official part of European policy. He is certain that the differences in the speed of access to health services, and the varying condition of healthcare services among the Member States, are core issues for the European Commission.

But before policymakers can change European healthcare policy, the EU needs to know more about the circumstances of patient care in individual countries, advised Mr Moro. For this reason, ACN decided to conduct ground and desk research on the extent to which the 14 rights of the ACN Patients' Charter are respected by the healthcare services of 14 of the 15 'old' EU Member States (ACN was unable to find a research partner in Luxembourg). Preliminary results were released in February 2005, after which methodologies were reviewed and improved.

The study was finally concluded with the launch of the report, *Patients' Rights in Europe: Civic Information on the Implementation of the European Charter of Patients' Rights* at the March 2007 conference. The following article summarises Mr Moro's conference presentation of these results.

A 'CIVIC AUDIT'

To help 'audit' patients' rights throughout Europe, ACN recruited 14 partner patient or citizen organisations (one per country). Each group was asked to conduct a civic audit of three leading hospitals in its own country, to determine the extent to which these facilities

Legal recognition of patients' rights in 14 of the 'old' EU Member States

Right	Number of countries (out of 14 surveyed) legally upholding the right
Consent	14
Information	14
Quality	14
Access	13
Complain	13
Privacy	13
Prevention	12
Compensation	11
Personalised treatment	11
Safety	11
Choice	10
Pain avoidance	9
Innovation	7
Time	6

Source: ACN, 2007

respected the European Charter of Patients' Rights. On the subject of a patient's right to safety, for example, auditing groups had to determine whether hospitals ran protocols for any of the following: the sterilisation of medical instruments; the prevention of

hospital-acquired infections (and the supervision of such efforts); risk management; reporting of adverse drug effects (and many other untoward events); and complaints procedures.

Observers from the partner organisations assessed a total of 174 qualitative and quantitative indicators in the inspected hospitals. Whenever possible, they also consulted the authorities responsible for hospital management—not always successfully, however. In Portugal, for instance, hospital authorities made no information forthcoming. In the UK, only one hospital authority co-operated.

Additionally, each partner organisation interviewed six experts on that particular country’s national healthcare system—academics, journalists, management executives from payers, Ministry of Health civil servants, or doctors managing health professional bodies. The partner organisations themselves gave additional expert testimony on the subject of patients’ rights in their country.

Finally, partner organisations were asked to compile information about their countries’ legislative efforts in furthering the cause of patients’ rights.

STATISTICAL ANALYSES

ACN asked Dr Fiorenza Deriu from the Faculty of Statistics in Rome’s La Sapienza University to conduct a Europe-wide review of available official statistics, with the intention of quantifying the degree of implementation of patients’ rights in the 14 Member States under review. Only six of the 14 countries turned out to possess relevant data.

Number of patients’ rights legally recognised by each of 14 of the ‘old’ EU Member States

Country	Number of the 14 patients’ rights legally upheld in the country
Denmark	14
Greece	14
Italy	14
Portugal	14
Finland	13
France	12
Netherlands	12
Germany	11
Sweden	11
Austria	10
Spain	10
Ireland	8
Belgium	8
UK	7

Source: ACN, 2007

... continued on page 25

'Index of Attention to Patients' Rights'

Active Citizenship Network had **three main sources** of information for measuring whether patients' rights were upheld in each of the 14 EU countries it examined:

- (1) Information from official statistics.
- (2) Information from analysis of the existing legislation.
- (3) Information from a so-called 'Civic Audit' (which included direct observation of three subject hospitals, plus interviews with the hospitals' authorities, plus interviews with key experts and with partner organisations).

A points system was allocated according to the source of information, with the largest numbers of points going to the Civic Audit, as follows:

- (1) Information from official statistics elicited a maximum score of 0.25 when more than one statistical indicator suggested that a specific patient right was being upheld. 0.1 was scored in the case of one indicator. Otherwise, the score was zero.
- (2) Information coming from legislation elicited a score of 0.25 if a piece of legislation was recognised as upholding a specific right. Otherwise, the score was zero.
- (3) Information from the Civic Audit elicited a maximum score of 2 for each specific right upheld in a country. If direct observation at the hospital and/or interviews with hospital authorities indicated that a right was being upheld, this was scored 1. If interviews with key experts and/or partner organisations indicated that a right was upheld, this was scored 1. The minimum score in both cases was zero. If the results for direct observation at the hospital and/or interviews with hospital authorities indicated an uncertainty as to whether a right was upheld, then the score was 0.5. If the interviews with key experts and/or partner organisations indicated an uncertainty, then the score, similarly, was 0.5.

Two exceptions to these rules

- (1) *Right to access.* Two parameters were used to measure access: access to healthcare, and physical access (for instance, wheelchair access to a hospital). Patients' rights to access to healthcare were assessed via interviews with key experts/partner organisations only. Physical access was measured by direct observation and/or interviews with hospital authorities only. In each case, final scores were doubled, to bring the point scheme in line with those of other patients' rights measured.
- (2) *Right to free choice.* Evidence was obtained exclusively from interviews with key people and/or partner organisations. Again, all scores were doubled, to bring the point scheme in line with those of other patients' rights measured.

Maximum scores

- (1) The maximum score for each right per country was the sum of the maximum scores attainable from the three sources of information—2.5.
- (2) The maximum score for any country was 37.5 (2.5 [maximum score for each right] x 15 [the number of rights measured, access measured by two separate parameters]).
- (3) The maximum score for any right across all countries was 35.

Case example: the right to preventive healthcare measures—in Austria

- (1) Information from official statistics. Austria has much information on preventive practices. A score of 0.25 was therefore allocated.
- (2) Information from legislation. Austria has laws safeguarding people's rights to preventive healthcare measures. A score of 0.25 was therefore allocated.
- (3) Information from the Civic Audit. No data was obtained by direct observation at hospitals or through interviewing hospital authorities. However, key experts and the partner organisation were positive that preventive practices were being upheld in Austria. A score of 1 was allocated.

The total score for Austria on preventive measures was therefore 1.5 out of a possible 2.5.

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An ‘Index of Attention to Patients’ Rights’

Bringing together all the data from its various sources, ACN has concluded its monitoring project by compiling an Index of Attention to Patients’ Rights (IAPR). The Index shows that patients’ rights scoring the lowest number of IAPR points—in other words, rights largely ignored by Member States—are mostly those focused on the *person*. For example, patients’ rights to have their time respected, to have freedom of choice, and to give informed consent, are all poorly defended within EU Member States. Rights relating to *societal responsibilities*, by contrast, rate among the highest scorers of points in the ACN Index.

Mr Moro conjectured that the dichotomy may be caused by European governments having difficulty in placing citizens as holders of rights at the heart of healthcare systems. Consequently, governments pay little attention to grassroots opinions when preparing and implementing healthcare programmes.

IAPR scores also showed a significant variation between countries. Discounting Portugal—which only produced a limited amount of information—country scores ranged from 17 for Greece to 29.5 for the Netherlands (out of a possible maximum of 37.5). Mr Moro considered that the cause of harmonisation of patients’ rights has clearly got a long way to go in the EU.

The IAPR data has enabled ACN to draw up a list of healthcare priorities for each country. ACN believes that Austria, for instance, needs to improve patients’ rights to quality care; Denmark falls down on rights to compensation, consent, and preventative measures; while Finland is deficient in rights to consent, access to care, respect for patients’ time, and so on.

Concluding his comments to the conference, Mr Moro outlined the major policy priorities that ACN has adopted in light of the study’s results:

IAPR rankings for each of the Charter’s 14 rights across 14 countries

* Note that the right to access is measured in two ways (access to care and physical access).

Right	IAPR score (35 is the maximum possible)
Information	28
Physical access	26.4
Personalised treatment	25.15
Safety	24.75
Quality	24.5
Prevention	20.5
Compensation	19.75
Pain avoidance	19.65
Consent	19.5
Innovation	19.25
Free choice	18.9
Access to care	17.75
Time	12.9

Source: ACN, 2007

- (1) Patients’ rights should become embedded as a core principle in each countries’ healthcare delivery system.

- (2) Data on healthcare at the European level would be enriched if information on patients' rights were incorporated.
- (3) Patients' rights should be included on the European agenda.
- (4) Support should be provided to the practice of active citizenship (allowing citizens to act as advocates and participate in policymaking).
- (5) Governments and other payers should finance healthcare structures that uphold patients' rights.
- (6) Governments should reform the current cultural, professional, and organisational models of healthcare.
- (7) A patients'-rights-based approach is required to deal with new challenges (such as EU enlargement, the liberalisation of public information on drugs, and the use of biotechnologies).

IAPR score per country

Country	IAPR score (35 is the maximum possible)
Netherlands	29.5
France	28.5
Germany	28.25
Belgium	27.25
UK	26.5
Denmark	26
Austria	25
Ireland	24.5
Sweden	24.25
Italy	24
Finland	23.5
Spain	20
Greece	17
Portugal	10

Source: ACN, 2007

COMMENTS FROM THE FLOOR

Conference attendees were generally supportive of ACN's European Charter of Patients' Rights. However, they also mentioned some potential barriers to any successful adoption of the Charter.

Are patients really a special case?

Lucien Bouis, a representative from the Brussels-based European Economic and Social Committee (EESC), a forum in which interest groups provide their points of view on EU issues, argued that patients' rights are simply a single element of the rights of human beings, not a separate category of rights. Patients themselves, said M. Bouis, want to be 'entire' human beings in society. The point was backed by Lara Garrido-Herrero, Secretary-General of the Brussels-based European Public Health Alliance (EPHA), a network of 80 not-for-profit organisations working in the field of public health. She emphasised that people—whether they are healthy or not—have rights.

A collective response to patient rights?

M. Bouis warned that health professionals will need to respond positively if the rights of patients are to be upheld. The duties and responsibilities of doctors and nurses will inevitably alter if patient entitlements are changed. Further training of healthcare professionals, and networking with them, will be vital, he said.

Legal implications

Francesco Ronfini, from the Office for International Health and Social Affairs Department, Veneto Region, Italy, and co-author of *Cross-Border Health Care in Europe*, argued that the different approaches to patients' rights currently taken by Member States hamper any common EU-wide approach to realising the 14 patients' rights of the ACN Charter. Some countries, remarked Dr Ronfini, take a very broad view—treating patients' rights as part of a wider awareness of civil rights in general. In the Netherlands, on the other hand, assurances given to patients form part of a legally-binding framework. Meanwhile, in Italy, patients' rights are not legally binding, and exist only in the form of charters (which are merely aspirational in nature).

Financial implications

A conference attendee from the Prague-based Koalice Pro Zdraví (Coalition for Health), a patients'-rights-oriented health NGO, added that the concept of a common set of patients' rights will elude Europe as long as national governments continue to regard healthcare systems as a cost. Germany spends nearly 9% of GNP on healthcare, noted the delegate, while Poland spends 3%. Polish patients accordingly lack access to certain cancer treatments readily available in Germany.

Conclusion

Despite the above reservations, such a serious meeting on the subject of patients' rights would be unthinkable a few years ago. A search of the European Union's <http://Europa.eu> website on the subject "patients' rights" currently elicits as many as 142 documents. The earliest reference to the topic appeared in 1995, in the context of Sweden's mental health reforms. The majority of the 142 hits date from 2000, and many refer to the work of ACN.

Patients' rights: charters and laws across Europe

CHARTERS	LAWS
France, 1974 & 1995	Finland, 1992
San Marino, 1989	Netherlands, 1994
UK (1991), 1997	Lithuania, 1996
Czech R., 1992	Iceland, 1997
Spain, 1994	Latvia, 1997
Ireland, 1995	Hungary, 1997
Portugal, 1997	Greece, 1997
Germany, 1999-2001	Denmark, 1998
Poland, 1999	Norway, 1999
Slovakia, 2000	France, 2002
Italy, 2000	Belgium, 2002
Austria, 2001	Estonia, 2002
Germany, 2002	Switzerland, 2003

Source: *Cross-Border Health Care in Europe*, European Observatory on Health Systems and Policies, Published by the WHO, 2005.

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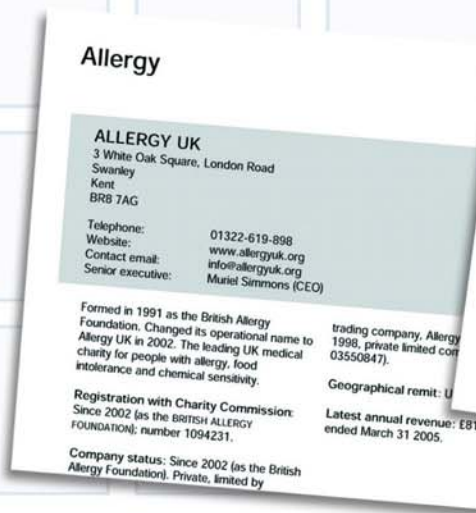
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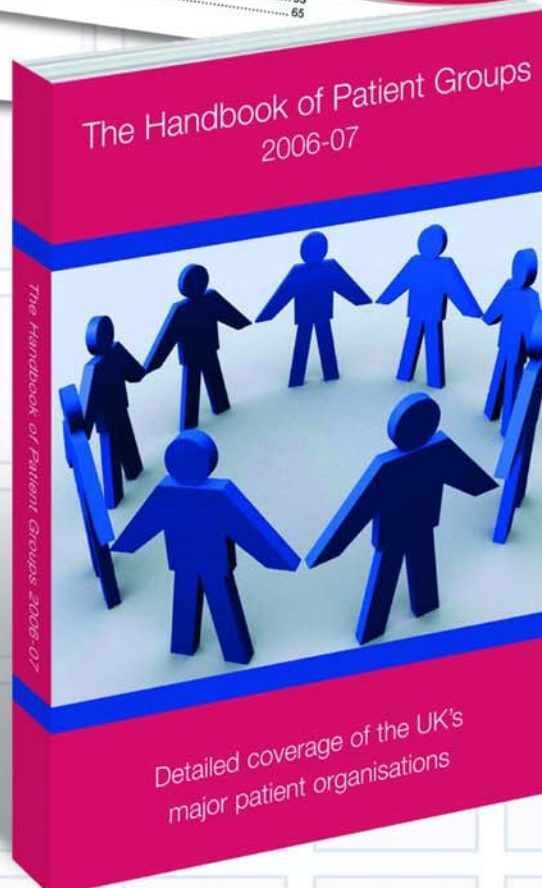
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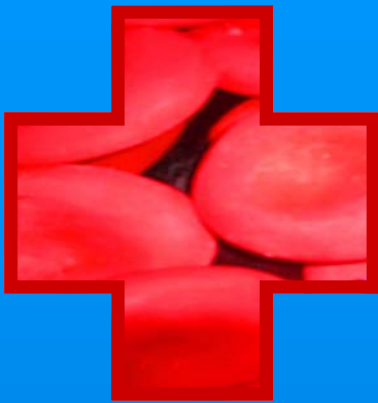
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