

One step closer to patients' rights

FINISH



START



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PATIENTVIEW

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Campaigning for the legalization of patients' rights in Europe

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Introduction	page 6
ACN's eight-year campaign	
A conference at Strasbourg	
How to win over politicians and influence people	
Doubts and opposition	
ACN's standpoint	
European Patients' Rights' Day around Europe	page 14
France	
Hungary	
Italy	
Latvia	
The Netherlands	
Poland	
What should the EU role be on patients' rights?	page 22
The view of an East European politician	
The view of a pan-European patient organisation	
The view of a health professional	
The view of a patient	



Introduction

On April 23rd 2009, the European Parliament voted a Directive—the ‘Application of Patients’ Rights in Cross-Border Healthcare’—past the first administrative barrier towards becoming law. When eventually a legal reality, the Directive will give EU citizens the right to seek medical care within other Member States than their own. Patients with a rare disease will be given especial priority under the terms of the Directive. People requiring medical care outside the hospital setting will not need to gather any prior authorisation. However, patients seeking hospitalisation in another Member State would still need authorisation from their relevant national reimbursement body.

This cross-border patients’ rights’ Directive, which was backed by 297 Members of the European Parliament (MEPs)—120 other MEPs were against the measure, while a further 152 abstained from voting—still has a great many bureaucratic hurdles to jump before it can be adopted into law. However, if all goes as planned, a Luxembourg patient with a rare cancer, say, who needs specialist treatment unobtainable at home, will have the right to go to, say, Germany to receive it, and to have the costs of the treatment paid for by their home country. Similarly, someone living in London who would have to wait months for a hip replacement could perhaps have the operation performed more quickly in a French city. When the Directive is finally law, The European Commission expects that 780,000 patients a year will travel to another Member State for healthcare.

The Directive builds upon a number of landmark judgments made by the European Court of Justice (ECJ), which established that healthcare provision is governed by the same EU rules on the free movement of goods as any other service industry. Once the Court had set that precedent, seeking treatment abroad became possible (in theory) for European citizens.

The European Parliamentary vote of April 23rd 2009 was groundbreaking for several reasons—not least because health and



healthcare have, until very recently, always been viewed as a sovereign matter for Member States, and, as such, outside the jurisdiction of the EU. Another reason is that this was the first time the Commission and Parliamentarians have ever acknowledged that patients have rights distinct from, and beyond, those enshrined in human rights' legislation.

ACN'S OWN 2002 EUROPEAN CHARTER OF 14 PATIENTS' RIGHTS

THE RIGHT TO ..

- ▶ PREVENTIVE MEASURES.
 - ▶ ACCESS.
 - ▶ INFORMATION.
 - ▶ CONSENT.
 - ▶ FREE CHOICE.
 - ▶ PRIVACY AND CONFIDENTIALITY.
- ▶ RESPECT OF PATIENTS' TIME.
- ▶ QUALITY STANDARDS.
 - ▶ SAFETY.
 - ▶ INNOVATION.
- ▶ NO NEEDLESS SUFFERING OR PAIN.
 - ▶ PERSONALISED TREATMENT.
 - ▶ COMPLAIN.
- ▶ COMPENSATION.

Active Citizenship Network's eight-year campaign

Among those pleased by the outcome of the European Parliamentary vote was Rome-based Active Citizenship Network (ACN). A more internationally-oriented offshoot of the large Italian civic group Cittadinanzattiva, ACN has been campaigning on behalf of European patients' rights for eight years. ACN believes that widespread acceptance of the validity of patients' rights in Europe is a key means of ironing out inequities in the delivery of treatment and care—the presence of which are evidenced by the significant differences in life expectancies that are still to be found across EU Member States.

ACN runs a two-pronged mission. Firstly, the organisation is advocating for official EU recognition of a European Patients' Rights' Day (EPRD), to be held every April 18th, and to be celebrated throughout the EU. The Day would aim to raise awareness of the importance of patients' rights. And, secondly, ACN wants to be sure that the legal basis of patients' rights goes beyond the right to travel abroad to receive care, and embraces 14 other rights, all linked around the subject of receiving top-quality care within their own country of residence. In 2002, working with 12 other citizens' organisations, the Italian group drafted this set of 14 rights—known as the European Charter of Patients' Rights [see box, left]. ACN is pressing for the Charter to be enshrined into EU law.

ACN has fought a long, hard campaign. The group's staff have been in countless meetings with health professionals, lawyers, and politicians. They have marshaled efforts to generate research data for the cause, and have encouraged media campaigns. Their

activities have been supported by various industry tradesbodies, political parties, pharmaceutical and medical device companies, plus the European Commission.

HSCNews International has occasionally written about ACN. What made the April 23rd 2009 Parliamentary vote a particular highpoint, though, was that it showed how patient advocates could, with perseverance, influence healthcare policymaking in the EU. ACN can rightly claim responsibility for getting the subject of patients' rights into the EU political vernacular.

**'PATIENTS' RIGHTS: A GROWING EUROPEAN CONCERN AND FRAMEWORK FOR ACTION',
ACN CONFERENCE, EUROPEAN PARLIAMENT BUILDING, STRASBOURG, APRIL 22ND 2009**

THE SPEECH MADE AT ACN'S
APRIL 22ND 2009
CONFERENCE BY EU
COMMISSIONER FOR HEALTH,
ANDROULLA VASSILIOU, CAN
BE SEEN ON VIDEO ON THE
HOMEPAGE OF THE ACN
WEBSITE:
[HTTP://
WWW.ACTIVECITIZENSHIP.
NET](http://www.activecitizenship.net)

A conference the day before the crucial Parliamentary vote

The day before the European Parliamentary vote, and as the closing event for European Patients' Rights' Day 2009, ACN hosted a conference at the Parliament's Strasbourg building. Attending were some of the numerous patient groups that had contributed to the EPRD, and MEPs who include the topic of patients' rights among their special interests. EU Commissioner for Health, Androulla Vassiliou, who proposed the cross-border patients' rights' Directive (and who ACN persuaded to become the patron of EPRD), gave the opening address. Since taking office in March 2008, Commissioner Vassiliou has championed the cause of patients' rights, and holds a clear position on the subject:

"Patients' rights reaffirm fundamental human rights in healthcare—rights such as the protection of dignity and integrity, and the promotion of respect for the patient. These fundamental rights are in line with the spirit of the EU's Charter of Fundamental Rights.

With healthcare systems becoming increasingly complex, and as medical practice becomes more specialised, there is a risk that it could also become more impersonal. It is becoming increasingly common for patients to be seen by a number of different health professionals during their treatment. This could make it difficult for patients to build trust, and to understand their treatment plan.

The condition under which the patient enters a healthcare setting is important. People who are sick may be feeling vulnerable, angry, frightened, or worried (to name a few, very natural, emotions). I think it is important to better understand the conditions that patients actually face, and ensure that healthcare becomes more patient-centred. Patients should play an active role—understanding and determining their own treatment options."

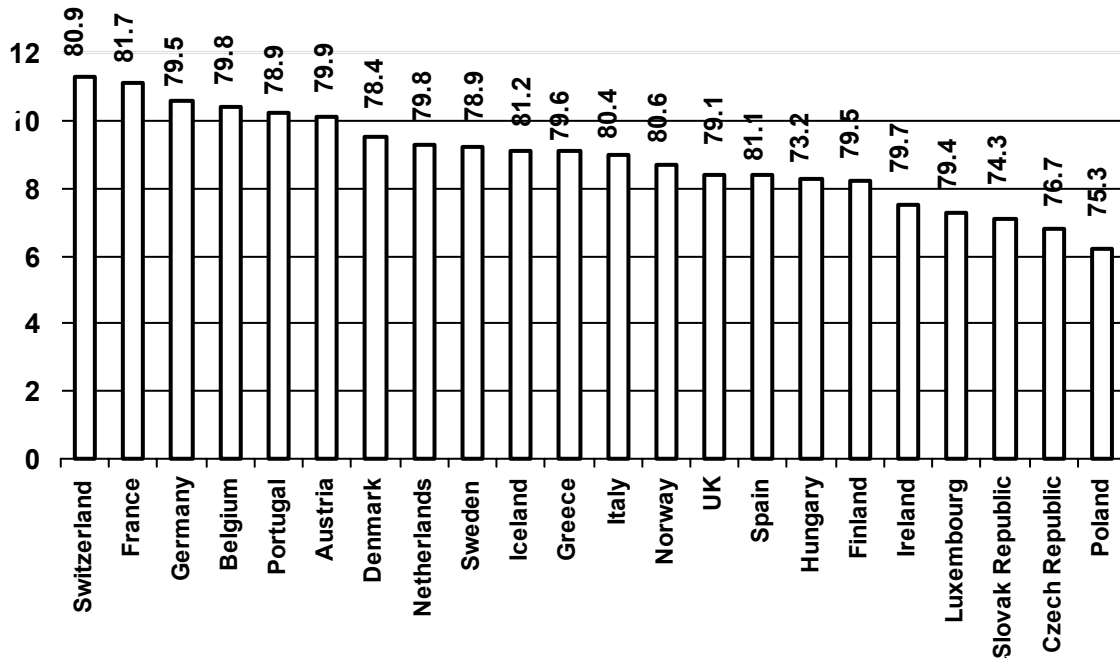
The Commissioner paid tribute to ACN for developing its European Charter of Patients' Rights. Such accolades are not easy to come by. ACN's achievements in bringing together the political will for change cannot be underestimated (especially since the organisation is not traditionally regarded as being one of the core members of the European patient lobby).

Health expenditure as a share of GDP: OECD countries, 2006 [latest available data]

Height of columns indicates % of GDP.

Numbers on top of each column is average life expectancy, 2006.

The chart clearly shows that little relationship exists between health spend and life expectancy.



Source: OECD

How to win over politicians and influence people

Almost from the start of its campaign on patients' rights, Active Citizenship Network's Melody Ross, who has overseen the project since its inception, tried to engage the support of EU policymakers and MEPs. In its earlier days, though, ACN rarely saw the contentious subject matter of patients' rights gain any political endorsements. Politicians of all parties were reluctant to award rights to patients that could allow populations greater leverage in challenging (and even in changing) national healthcare systems. Additionally, some politicians in western Member States feared an influx of healthcare 'tourists' from eastern Europe—patients newly armed with civic rights to high-quality western healthcare.

Patients-rights.eu: a website of the ALDE party



Winning support from the three big parties

But by 2006, the initial political reluctance to associate with the cause of patients' rights was largely over, and ACN began to make inroads into the EU political scene. At that time, the group managed to win the attention of MEPs from the Alliance of Liberals and Democrats for Europe (ALDE), the third-largest party in Parliament.

ALDE warmed to the notion of patients' rights—a cause in keeping with the party's core principles of personal freedom and self-fulfillment. By 2008, the ALDE party had positioned patients' rights at the top of its agenda, ready for the June 4th 2009 European Parliamentary elections. Graham Watson, leader of ALDE, told the audience at the Strasbourg conference:

“ACN was responsible for drafting the European Charter of Patients' Rights. This is a progressive project, putting information into the hands of patients, and spelling out the rights and entitlements of citizens across Europe. ALDE is proud to support that agenda.”

ALDE's manifesto calls for standardised safeguards to be instituted into the healthcare provision of all European citizens, and it endorses ACN's European Charter of Patients' Rights. “After all,” said Mr Watson, “the internal market actively promotes the free movement of goods and labour. But the mobility of citizens is undermined if they fear that their health cover is compromised. It shouldn't be—on moral grounds, on political grounds, and now, on legal grounds, too.”

British MEP Liz Lynne, also of the ALDE party and Vice-President of the Parliament's Employment and Social Affairs Committee, described to the Strasbourg meeting the poor record in upholding patients' rights borne by some EU countries (such as the UK)

“Cross-border healthcare has always been around for people who can afford it. This legislation opens up the same opportunity to all people, irrespective of income. It must now be backed by the UK government.

“Why should a patient have to lose their sight waiting for a cataract operation, or spend months in agony waiting for a hip replacement, when they could get treatment sooner in another Member State—sometimes at a lesser cost to the country of origin?”

“If a clinician advises treatment that cannot be provided at home, then we need a legal framework to ensure that the patient can seek it elsewhere.”

—Liz Lynne, press release on the cross-border healthcare Directive, April 23rd 2009.

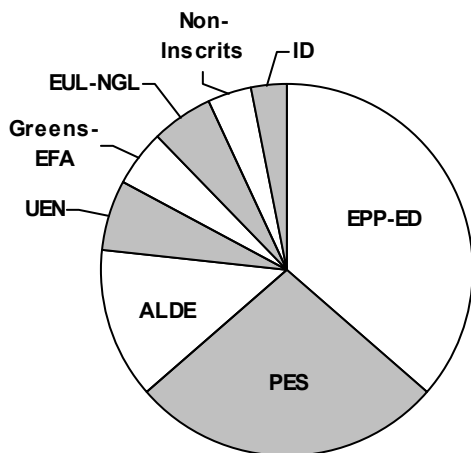
when compared with Finland and the Netherlands—especially in the area of patient safety. She emphasised the need for an EU code of conduct to tackle certain widespread healthcare problems, such as hospital-acquired infections (HAIs).

To support its political campaign for patients’ rights, ALDE has launched a provocative multilingual website, <http://www.patients-rights.eu>. Mrs Karin Riis-Jørgensen, an MEP from Denmark, and the ALDE shadow in the EU Committee on Internal Market and Consumer Protection (IMCO), explained the website’s purpose to the Strasbourg meeting. Patients-rights.eu provides information that helps Europeans be clear about their rights to seek treatment in another Member State, and to get the cost of the treatment reimbursed. The website also carries a petition that garners public support for EU intervention on patients’ rights.

A minimum of 393 votes are needed for an absolute majority for the Directive in the European Parliament. The ALDE party has 99 MEPs. Active Citizenship Network, therefore, has also had to persuade MEPs of other political hues of the importance of the patients’ rights cause.

ACN received another boost to its campaign when John Bowis, Conservative MEP and Spokesman for the Conservatives and the European People’s Party/European Democrats (EPP-ED) on the Environment, Public Health and Food Safety Committee, was appointed the European Parliament’s rapporteur on the European

Composition of the European Parliament [% of total of 785 MEPs] as of May 2009



ALDE = Alliance of Liberals and Democrats for Europe.
 EPP-ED = European People’s Party/European Democrats.
 EUL-NGL = European United Left/Nordic Green Left.
 Greens-EFA = European Greens/European Free Alliance.
 ID = Independence/Democracy.
 PES = Party of the European Socialists.
 UEN = United for Europe of the Nations.
 Non-Inscrits = MEPs not attached to any of the above.

Commission's Communication on Patient Mobility and Healthcare Development in the EU. Mr Bowis is a long-standing, widely-respected Parliamentary campaigner on health issues. Writing in the favoured newspaper of Brussels bureaucrats, the *European Voice*, on February 2nd 2009, Mr Bowis stated that the EU needed to clarify its rules on cross-border healthcare provision if it was to improve the lives of all European patients (not just the richest). Mr Bowis' article called for a new system of reimbursement to ensure that European citizens receiving care abroad would have the care automatically paid for by their country of origin.

Mr Bowis' leadership in the fields of patient mobility and patients' rights has galvanised support from others in the EPP-ED party, which holds the largest number of MEPs in the European Parliament. The party espouses greater protection for consumers, and equity in access to treatment and care.

The Party of the European Socialists (PES) are also strong enthusiasts of ACN's patients' rights campaign. In 2007 PES supported two resolutions in Parliament that stated there was a need to include in European legislation a Common European Charter of Patients Rights based on the work done by NGOs and that these rights extend not only to cross border care but to every citizen within the EU. The Socialists, however, chose to refrain from endorsing the April 23rd Directive because the proposed legislation was not expansive enough and did not cover all EU citizens, but only those who traveled abroad for care.

Explaining the PES position, Catuscia Marini, an Italian MEP, told the ACN conference that healthcare should not be treated like any other industrial sector, and that the EU should retain its historical regard for healthcare as 'different'. While the Directive affords rights to people seeking healthcare across borders, it will do little, she added, to protect the public who receive healthcare at home. PES suspects that some Member States, confident that their patients can obtain high-quality services in neighbouring countries, may use the Directive as an excuse to reduce healthcare provision to their citizens. Such Member States will still have to pay for their patients' care abroad, but will be spared the much-heavier costs of maintaining elements of the healthcare infrastructure. She believed that all EU citizens should be afforded similar healthcare rights.

Addressing the doubts

Taken together, MEPs from ALDE and EPP-ED were enough to get the Directive passed in Parliament. But ACN knows that doubts about the merits of the Directive are maintained by enough MEPs of all parties to impede the ultimate adoption of the Directive (or, at least, the Directive in its current form). These doubts among the wider body of MEPs will need to be overcome if ACN is ever to see its goal of patients' rights attained.

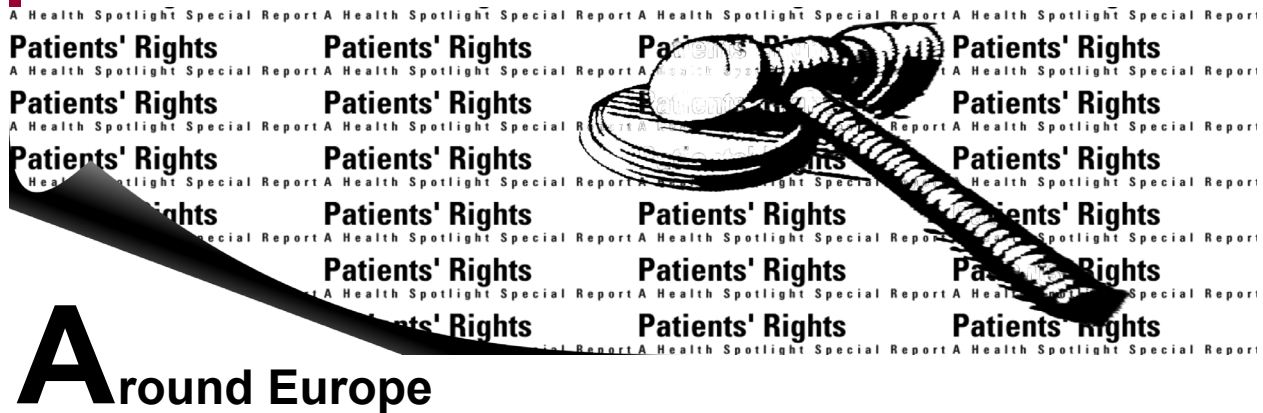
Speaking at the Strasbourg conference, Mrs Cristina Gutiérrez-Cortines of the EPP-ED reported her concerns about the Directive from the standpoint of an MEP from Spain. Although she said that she would vote for the Directive the next day, Mrs Gutiérrez-Cortines would do so knowing that the measure did not meet all her expectations. In some cases, she said, the Directive would give European patients living in a European country which was not their own greater healthcare rights than those enjoyed by the country's own citizens. Spain, for instance, contains 1½ million non-Spanish Europeans. Mrs Gutiérrez-Cortines insisted that the Directive would allow these individuals the right to choose their own doctor in Spain—a privilege denied in Spain to the Spanish people themselves.

Writing in a February 12th 2009 special issue on healthcare in the *European Voice*, Margrete Auken of the Greens/EFA stated:

“The problem is not that the proposal aims to improve the situation for the 3% of Europeans who choose to go abroad for treatment. It is that it does so at the expense of the 97% who stay in their home country for treatment. Creating an internal market in which patients with money can shop around for healthcare services jeopardises systems that are based on universal access, solidarity, equal territorial accessibility, and democratic control.”

Active Citizenship Network is aware of such criticisms. Indeed, at its 2008 conference in Gorizia, Italy, Charlotte Roffiaen, then Director of ACN, added her voice to fears that the proposed EU legislation (the forthcoming Directive) would do little to protect the vast majority of patients within their own countries. She also wondered whether the Directive might, in the end, backfire, and widen the healthcare gaps between the poorest and richest Member States, so that only the latter would be able to afford the costs of treatment abroad for their citizens.

This is why ACN views the Directive as just the first step in its campaign to secure patients' rights for all European citizens.



Around Europe

European Patients' Rights Day (EPRD) on April 18th 2009 saw events held across Europe—all campaigning for the creation of legal structures that could uphold patients' rights throughout the continent. Some 32 different patient/civic groups from 22 Member States led the Day's activities. Other healthcare stakeholders also became involved, however, and, in some cases, even offered long-term commitments to introduce measures to protect specific privileges for patients. This level of engagement greatly impressed the European Commissioner for Health, Mrs Androulla Vassiliou, who backed EPRD unreservedly.

A number of the organisers of the events were invited to ACN's April 22nd 2009 Strasbourg conference to talk about their achievements during the Day. They were also asked to explain why they supported the establishment of the Day. Commissioner Vassiliou commented on their presentations:

"I am very pleased that motivated people from Member States have joined forces in the common good of better healthcare for all in Europe. All people are potential patients who will need healthcare some time in their lives. The European Union plays an important role in maintaining public health—including the provision of rights for patients who cross borders within the EU to obtain healthcare abroad."



France

Organiser: Assistance Publique Hôpitaux de Paris (AP-HP).

Activity: Survey measuring the extent to which patients' rights are implemented in the AP-HP.

Stated success: Getting buy-in to the idea of patients' rights from health professionals and other healthcare workers.

Stated obstruction: Lack of awareness about the subject of patients' rights among the public and health professionals.

Why the EPRD?: Raising the profile of patients' rights.

A legal framework for patients' rights?: Endorsed by the AP-HP.

Laure Albertini is Director of Patients' Rights and Associations at the Assistance Publique Hôpitaux de Paris (AP-HP), the public hospital system of Paris. The AP-HP is a huge infrastructure of 38 hospitals and 120,000 employees (of whom 90,000 are health professionals). Ms Albertini became involved with ACN in 2008, when the AP-HP system first circulated ACN's European Charter of 14 Patients' Rights throughout itself, creating webpages dedicated to patients' rights' issues [<http://www.aphp.fr/site/droits/droits.htm>].

The exercise was followed up by an early-2009 survey of AP-HP health professionals that aimed to determine the extent to which patients' rights were being respected throughout the AP-HP network. Questions asked in the survey included:

- Who represents patients in the hospital?
- What is the role of the ombudsman?
- Is the respect for privacy an obligation?
- Can patients ask for a copy of the Charter?

Additionally, interviews conducted with patient representatives, and doctors and nurses were placed in an online video.

Ms Albertini told the Strasbourg conference that the implementation of patients' rights is still patchy throughout the AP-HP network, and that constant pressure will have to be directed at health professionals and administrators if patients' rights are to be recognised in standard medical practice.



Hungary

Organiser: Hungarian Civil Liberties Union (HCLU).

Activity: Multi-stakeholder conference.

Stated success: Creation of national umbrella group to campaign on patients' rights.

Stated obstruction: Need to attain better dialogue with the Ministry of Health.

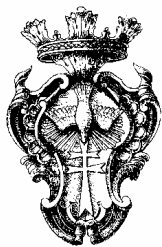
Why the EPRD?: To have a day to focus on patients' needs.

A legal framework for patients' rights?: HCLU is in support.

Stefania Kapronczay is employed by the Hungarian Civil Liberties Union (HCLU), an independent foundation formed in 1994. Ms Kapronczay described to the Strasbourg conference the current state of patients' rights' legislation in her country. She said that the Hungarian Health Act of 1997 guaranteed patients' rights in various healthcare subject areas, including: abortion; appointing a guardian to represent a patient's interests; euthanasia; people with a disability; protection of medical data; and reproduction. But

little has been done on the ground to ensure implementation of the Act, noted Ms Kapronczay.

To mobilise support for further action on implementation, the HCLU organised a large conference on EPRD. The meeting was attended by senior representatives of the National Health Council, which is the government body charged with maintaining the continuity of long-term health policy, and with enforcing the rights of users of the Hungarian health and social services. Health professionals representing the Association of Hungarian Medical Societies were present and offering support. Representatives from 50 patient groups (and other healthcare stakeholders) were also in the audience. The conference saw the first steps taken to create a national umbrella group of patient organisations with the specific remit to support campaigns for patients' rights.



Italy

Organiser: Local Health Authority, Rome (ASL RM E).

Activity: 3-year programme to implement patients' rights within a healthcare setting.

Stated success: Getting buy-in from health professionals and other health workers.

Stated obstruction: Lack of awareness among the public and health professionals.

Why the EPRD?: Raising the profile of patients' rights.

A legal framework for patients' rights?: Endorsed by ASL RM E.

AUSL

ROMA

On May 14 the Italian Senate unanimously approved the European Charter of Patients Rights called on the Italian government to take a lead in the European Council to promote the European Charter of Patients Rights in each member state.

During 2007-2008, the local health authority in Rome, ASL Roma, undertook an internal audit to qualify and quantify how effective the agency was at upholding the patients' rights outlined in ACN's Patients' Charter. The study found that the city's health services are mostly oriented towards fulfilling the economic objectives of the region's budget-control plans. Furthermore, a progressive reduction in staff numbers has been undermining the ability of health workers to afford patients their rights.

Following the study, an action plan was drawn up to raise awareness among health workers of their duties and responsibilities towards patients' rights. The action plan also hoped to trigger new levels of partnership between the healthcare services and users, with the objective of improving the quality of care delivered.

ASL Roma has committed itself to a three-year project, launched to coincide with the EPRD, to incorporate the 14 patients' rights in

ACN's Charter. Once the project is completed in September 2011, ASL Roma plans to monitor the impact of the 14 rights.



Latvia

Organiser: Pacientu Ombuds (Patients' Rights Ombud Office).

Activity: Multi-stakeholder conference and media relations.

Stated success: Consensus on ways to improve patients' rights in areas of safety.

Stated obstruction: The low priority given in Latvia to the healthcare system.

Why the EPRD?: A mechanism for all stakeholders to exchange views.

A legal framework for patients rights?: Being promoted by Pacientu Ombuds.

Liene Sulce explained to the Strasbourg conference that Pacientu Ombuds is an NGO founded in 2008 with the support of the Ministry of Health and the country's largest hospital, Riga Eastern. The new organisation, said Ms Sulce, acts as a professional mediator in disputes about patients' rights between patients and healthcare professionals. Pacientu Ombuds also provides information and advice, and raises public awareness, about major difficulties facing Latvian patients.

"Patients' Rights' Day is a European-level activity that is building up a spirit among European citizens that they are inhabitants in every EU Member State."

—Liene Sulce,
Pacientu Ombuds,
European Parliament,
Strasbourg,
April 22nd 2009.

As part of its support for European Patients' Rights' Day, Pacientu Ombuds ran a conference attended by 140 participants from the patient advocacy and hospitals sectors, policymakers, and politicians from the Latvian Parliament. Also at the conference was Georgs Andrejevs, a Latvian MEP who is a member of the EU Committee on Environment, Public Health and Food Safety. Key topics addressed at the Pacientu Ombuds conference were patients' rights in Latvia and across the EU; mental health, and why Latvia has one of the highest suicide rates among young people in Europe. Discussions on patient safety examined Latvia's involvement in the European Union Patient Safety Network (EUNetPaS).

The conference was regarded as pivotal. It enabled an exchange of views on patients' rights, patient safety and mental health between the entire spectrum of healthcare interests. Areas of need were identified, including: high-quality information for patients and health professionals about patients' rights; understanding the criteria for quality and risk management in medicine; the problems associated with medical practitioners' reportage of errors (and the need for their greater cooperation if levels of patient safety are to improve); and communications between patients and medical practitioners. Ms Sulce said that far more work and a strategic vision is needed in Latvia, a country

where healthcare is not considered a political priority. The amount spent on the national healthcare scheme is low, and looks set to decrease further.

The Patientu Ombuds conference concluded that health insurance in Latvia (including the compensation element to protect patients) needs to be better coordinated. Practitioners' reporting methods in cases of medical errors must also be improved.

Ms Sulce applauded the idea of a European Patients' Rights' Day. She felt that it provided a mechanism by which patients can interact with other healthcare stakeholders as (ostensibly) equal partners. Moreover, Patientu Ombuds regards ACN's European Charter of Patients' Rights as a "very significant document" that should be harnessed to promote patients' rights in Latvia.



The Netherlands

Organiser: Zorgbelang.

Activity: National survey of patients and providers.

Stated success: New findings about patients' attitudes to cross-border healthcare.

Stated obstruction: Differing bureaucracy levels among healthcare systems inhibits the flow of patients across borders.

Why the EPRD?: Need for protection of patients' rights EU-wide.

A legal framework for patients rights?: Endorsed by Zorgbelang.

Karin Kalthoff of Zorgbelang reported to the Strasbourg conference that her organisation is a federal- and local-government-funded umbrella group for patient organisations in the Netherlands. Zorgbelang has 4,000 member patient groups that specialise in issues of chronic disease or disability (or which may be parents' associations). Its main function is to act as an advocate for patients and their representative patient groups. By providing information on patients' rights and guidance on complaints procedures, Zorgbelang aims to empower patients.

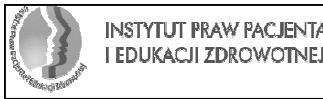
Zorgbelang has previously been involved in an EU-wide project on cross-border healthcare. The organisation took part in the 'Evaluation of Cross-Border Regions in the European Union' (Euregio) Project [<http://www.euregio.nrw.de>], an initiative financed by several governments, including that of Germany and the Netherlands, and the Wallonia (southern Belgium) regional government. The project, which ran from 2004 to 2007, explored (among other subjects) the possibility of using cross-border care

to relieve waiting lists for medical treatment. In the case of the Netherlands, some of the longest waiting lists impact upon orthopaedics patients, who can wait 9-12 months to get care. In Germany, the equivalent waiting lists might be a mere one month. Ms Kalthoof insisted that, ideally, patients should be able to obtain treatment and care in the neighbouring Member States with the shortest waiting times. However, she said, this is far from being the case in practice—although little accurate data exists about the true levels of cross-border care, or about the experiences of the patients involved.

Ms Kalthoof described how Zorgbelang supported EPRD by conducting a national online survey of 3,170 patients and 228 healthcare providers, gathering opinions on cross-border care between the Netherlands and Germany. The exercise was supplemented by regional debates. The results were presented to the Netherlands Ministry of Health on April 18th 2009, ahead of the introduction of the government's proposed new Bill of Patients' Rights in September 2009. (Unfortunately, the Minister was unable to attend the presentation meeting.)

The survey's key finding was that the opportunities available from cross-border care were often blocked by the incompatible nature of the bureaucracies of Member States' various healthcare systems. The survey also found that the majority of its respondent patients regarded access to top-quality treatment as more important than having their care situated conveniently near to home. Respondent patients desired information about the facilities available, and they wanted the freedom to choose the location of their treatment. They also wished for the right to complain if any care they received abroad was inadequate.

Zorgbelang, concluded Ms Kalthoof, believes that cross-border care should be made available to all—not just to patients who have the self-determination to seek it out themselves. Zorgbelang would like the applications forms for reimbursed cross-border healthcare in another country to be massively simplified.



Poland

Organiser: Instytut Praw Pacjenta i Edukacji (Institute for Patients' Rights and Health Education).

Activity: Workshops and press conferences.

Stated success: Promoting the creation of a repository for healthcare performance data.

Stated obstruction: Lack of awareness of patients' rights among the public and healthcare professionals.

Why the EPRD?: Raising the profile of patients' rights.

A legal framework for patients rights?: Endorsed by the Institute.

Magda Bojarska of the the Instytut Praw Pacjenta i Edukacji informed the Strasbourg conference that the Institute had been founded in 2004 by Father Arkadiusz Nowak, an HIV/AIDS activist, to promote and raise awareness of patients' rights. The Institute now numbers some 200 patient groups among its partners. Ms Bojarska offered examples of the types of activities undertaken by her organisation—and drew attention, in particular, the Institute's 'Patients' Academy' that has helped 120 patient associations to teach the art of advocacy. The Academy has government backing, and is sponsored by EFPIA, the European tradesbody representing pharmaceutical companies in Europe, as well as by PhRMA, EFPIA's US equivalent.

Ms Bojarska noted that while Poland offers patients some protection of rights within the national healthcare system, patients' rights are expressed in the form of a Charter that is not legally binding and is weakly enforced. Both the public and the medical profession lack information about patients' rights. Meantime, patients in Poland have poor access to treatment and drugs, and experience difficulties in getting hold of their medical records if they wish to see them. Their privacy is inadequate, as are the levels of safety afforded patients in hospitals.

Although Polish people may seek their medical care in other parts of the EU, the National Healthcare Fund (NFZ) only pays for emergency cases, or if the diagnostics tests or the treatment are not available at home. Anyway, added Ms Bojarska, little patient-friendly information about the subject of cross-border care exists in Poland.

Efforts to strengthen patient protection have appeared in the form of a new draft patients' rights law, which was enacted by the Polish Parliament in 2008, but later vetoed by the President. Ms Bojarska intimated that the proposed law will be voted upon again in 2009, and the hope is that it will pass into legislation by 2010.

Patients' rights theoretically available in Poland—but not always respected

Right of equal access to publicly-financed healthcare services.

Right to proper and clear information on personal health status, diagnostic and treatment procedures, health risks, and prognoses.

Right to access own medical records and documentation.

Right to confidentiality of all health and personal data.

Right to respect of physical and mental integrity.

Right to consent to, or refuse, treatment.

Right to complain, and to receive compensation.

The law includes the establishment of a new institution for monitoring patients' rights, and for their enforcement.

Ms Bojarska said that the Institute played its part in the activities surrounding European Patients' Rights' Day by holding a press conference on the topic of patients' rights and the EPRD, in Cracow on April 17th 2009, co-hosted by the Polish Society of Medical Law. The Institute also ran a workshop for senior representatives from 60 patients groups on April 24th-25th 2009.

At these events, the Institute laid out its recommendations for improving patients' rights in Poland. One of the most interesting is the creation of national information centres to exchange information on healthcare among Member States. Such data ought to include information on waiting times for healthcare services in each country, observed Ms Bojarska.

The Institute is continuing to promote EPRD and the European Charter of Patients' Rights through its website [<http://www.prawapacjenta.eu>].



W hat should the EU role be on patients' rights?

ACN's April 22nd 2009 Strasbourg conference invited people from a number of different walks of life to comment on what role they believed EU institutions should take in according patients' rights to European citizens. The conference was trying to find out just how far individuals thought the EU should 'interfere' in national healthcare policymaking. A *European Voice* article of February 12th 2009, 'Health Quarterly: Patients' Rights', by Jennifer Rankin, set the scene for an increasing sense that change might be in the air:

"For years, EU institutions have clashed over balancing the individual's demands for the best-possible treatment against the collective wish for an affordable, efficient, healthcare system. The debate has been intensified by governments' fears that the EU is 'interfering' beyond its competence. Although healthcare remains a national competence, EU court rulings have introduced a European dimension that cannot be ignored."

The view of an East European politician

First to the podium was Dr Antonyia Parvanova, a Bulgarian MEP belonging to the National Movement Simeon II, itself part of the ALDE party. Medically-qualified Dr Parvanova works actively in the area of patients' rights—for example, promoting access to genetic screening for newborn babies.

Ms Parvanova contended that the question may not be so much what EU institutions can do—rather, how they can catch up with changes already sweeping healthcare as a result of decisions from the European Court of Justice, or even the efforts made by her own ALDE party over the last three years.

She insisted that Europeans should not have to live with varying rights to compensation, information, pain avoidance, privacy, or safety, simply because they reside in separate countries. If EU

europatientrights.eu

A new website outlining the general situation on patients' rights in Member States is now available at

<http://europatientrights.eu>

The site has been provided by the Centre of Biomedical Ethics and Law, at the Catholic University of Leuven, Belgium.

institutions do not intervene in national healthcare systems, they are effectively protecting the worst elements of these systems, and enabling them to continue existing unfair practices. The passage of the Directive on cross-border rights, argued Ms Parvanova, should be just the beginning.

Bulgarians would certainly welcome intervention, she said. The rights accorded European patients seeking care abroad are more than those given to Bulgarian patients seeking care in their own home country. Bulgaria has a clutch of laws that affect aspects of patients' rights. Two new bills have been introduced to Parliament to clarify the position of patients within Bulgaria's healthcare system. Efforts to pass the legislation have been thwarted, however, largely by opposition from the Socialist party, which comprises a significant force within the current governing coalition.

In part, concluded Ms Parvanova, any moves at national intervention made by the EU would be complicated by the European Commission's own internal structural divisions. Thus, DG Sanco, for instance, runs separate committees on public health and consumer protection, while the Competition Directorate looks at patient information. Greater uniformity of purpose and co-operation are needed in the ranks of the Commission, she said.

The view of a pan-European patient organisation

The Brussels-based European Patients' Forum (EPF) is an umbrella group for 38 European and national organisations that collectively represent 150 million of the continent's patients. The EPF strives for a number of goals—perhaps the chief being equitable healthcare in Europe. As such, the EPF regards ACN's patients' rights' framework as a crucial contribution to achieving impartiality in the delivery of treatment and care for Europe's citizens. Nicola Bedlington, Director of the EPF, outlined to the Strasbourg conference how patient movements like the EPF are bringing pressure for change to bear on Brussels institutions.

Ms Bedlington told the conference that the Directive on patients' rights in cross-border care does not provide a universal remedy for patients seeking equality in treatment and care. It does,

though, represent a “crucial step forward”, since it acknowledges the importance of patients, placing them at the centre of proposed reforms. Furthermore, the Directive defends patients’ rights of access to effective technologies, information, quality, and safety—irrespective of the Member State in which they might live. This is why, declared Ms Bedlington, the EPF intends to work closely with all of the relevant EU institutions to “bring this valuable Directive to life.”

Ms Bedlington also praised ACN for the part it has played in raising awareness of patients’ rights, and for its efforts in gaining acceptance for the European Patients’ Rights’ Day (EPRD). The Day, she said, provides a springboard for local, regional, and national activities to honour the cause of patients’ rights. Issues of community-based healthcare (CBHC), health literacy, and patient safety can all be given further political prominence under the wing of the Day. Ms Bedlington thanked ACN for its work in monitoring and evaluating the application of patients’ rights in different countries, as well as for engaging with patient groups around Europe. ACN was, she commented, instrumental in creating an effective campaigning movement for improved rights for patients.

EPF’s Manifesto

For its part, the EPF launched a September 2008 Manifesto, ‘150 Million Reasons to Act’, to lead up to the June 2009 European Parliamentary elections, and to press for a higher priority for healthcare from the European Commission—“Patients want action now”, declared Ms Bedlington. The EPF Manifesto includes the following requests:

- Equal and timely patient access to safe, effective diagnosis, treatments, and support.
- Information and resources that will allow patients to be partners in determining their own care.
- A patients’ voice to be heard in Brussels and throughout the European Union.

Ms Bedlington informed the conference that the launch of the EPF Manifesto was supported by a number of MEPs, including John Bowis, rapporteur for the Directive, who has called patients’ rights a core issue. “We need to recommend the Manifesto campaign to politicians not present at its launch. By working together, we can make a difference with the Manifesto”, Ms Bedlington reported MEP Bowis as saying at the Manifesto

launch. Since then, the EPF has run a number of workshops with its members, circulating the message of the Manifesto, not just at Brussels level, but nationally, as well.

The reach of the PGEU

By 2009, the PGEU had 400,000 members scattered across 30 countries, including EU Member States, EU Candidate Countries, and members of the European Free Trade Association (EFTA).

With 46 million European citizens visiting a pharmacy every day, the PGEU believes that it is well able to understand the issues affecting patients' rights to medical treatment, and to information about that treatment.

The movement of price differentials among medicines in one EU country (2003-2009)

Quoting figures from pharmaceutical research company IMS Health, Mr Chave of the PGEU mentioned at the Strasbourg conference that the price differentials of the cheapest and most-expensive drugs in Denmark have widened since 2003. That year, the top-10% most-expensive drugs were 50 times more costly than the 10% of medicines falling in the lowest price bracket.

In 2009, that difference had increased to 500 times, with expensive drugs remaining costly, but cheap, generic (non-branded) drugs pouring onto the market.

The view of a health professional

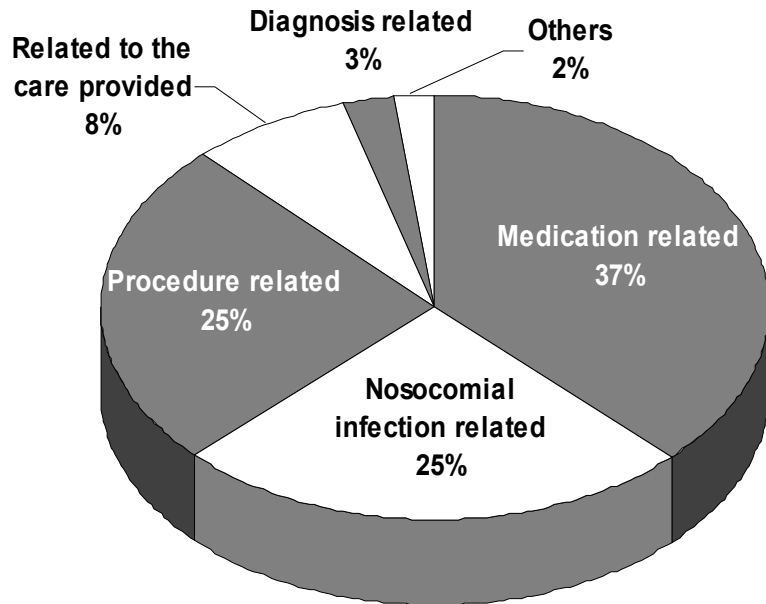
John Chave is the Secretary General of the Pharmaceutical Group of the EU (PGEU), which is the association representing community pharmacists across Europe. Mr Chave explained to ACN's Strasbourg meeting why the PGEU is well-positioned to comment on the needs of patients. His organisation has lent its complete backing to ACN's campaigns, particularly in the subject areas of PGEU expertise: medical treatment and patient information.

According to Mr Chave, the EU faces enormous medical challenges. The continent is filling up with an ageing population, an increasing proportion of whom are taking medication. The PGEU estimates that as many as one third of EU citizens aged over 70 have five or more chronic diseases. Some 65% of people over 70 years old are taking an average of three drugs per day; while another 35% are taking 5-8 drugs per day. A surprising number of older citizens are taking more than 13 drugs a day. Yet, often, these patients are ill-informed about the adverse effects of the drugs—never mind the wide price differentials that exist among medicines. Cash-strapped health authorities face tough decisions when deciding whether expensive drugs should be reimbursed by national health systems. Unsurprisingly, governments tend to err on the side of recommending the cheapest products. Decisions that are taken, though, said Mr Chave, should be made in the context of a patients' rights agenda.

Aside from the issue of price, patients also need to be alerted to the importance of the need to be sure of the safety of the medicines prescribed. Up to 37% of adverse events taking place in healthcare settings are medicine-related—for instance, as a result of inappropriate prescribing or dispensation of drugs. Furthermore, said Mr Chave, medical institutions or countries are often slow to adopt newly-available, more-effective drugs, thereby denying patients access to them.

The PGEU therefore espouses that patients should be provided with four important rights in their medical treatment: the right to

Adverse events in healthcare settings



Source: ENEAS, 2006

safe medication; the right to medication at reasonable prices, but optimal reimbursement; the right to access new, effective drugs as soon as they become available; and the right to high-quality care and advice—all rights to be applied whether the patients live in urban or rural locations.

Therefore, the challenge to EU institutions, concluded Mr Chave, is to put patients' rights at the heart of policy in subjects of acknowledged EU competence, such as pharmaceutical legislation. In matters in which the EU has little or no authority, the European Commission can still play a role in facilitating co-operation and best practice among Member States. In the PGEU's view, "the EU must continue to develop world leadership in solidarity-based healthcare. But patients' rights are more important than the Lisbon Agenda." The Lisbon Agenda aims to make the EU the world's most competitive, knowledge-oriented economy.

The view of a patient

The ACN Strasbourg conference was next addressed by a patient, Nicolas Decker. In 1998, after an eight-year battle, Mr Decker won one of the first landmark cases on the rights of patients to cross-border treatment heard by the European Court

of Justice (ECJ). Mr Decker, a Luxembourg lawyer, went to the ECJ after his request to be reimbursed for the purchase of spectacles from a provider in another Member State was denied by his home country. The ECJ decided in favour of his reimbursement request.

Mr Decker is now a campaigner for patients' rights, and belongs to the two-year-old European Patients Empowerment for Customised Solutions (EPECS) [<http://www.epecs.eu/web/sites/home/index.php>], a network of self-help patient organisations from Belgium, Germany, and the Netherlands.

Mr Decker informed the Strasbourg conference that cross-border healthcare accounts for a tiny proportion (perhaps 1%-2%) of total healthcare spend across the EU. Yet significant opportunities exist for one relatively-inexpensive form of cross-border care—

The Malta Health Network—a new group

Anthony Guillaumier (chairman)

<http://mrc.org.mt/page.asp?p=17222&l=1>

Attending the ACN Strasbourg conference was Antionette Shah, who was, in part, responsible for helping found the Malta Health Network (MHN) in November 2007. The MHN is an umbrella organisation that seeks to gather together the major patient groups in Malta (about 45, in all). The Network is currently 30 strong.

Ms Shah, the Manager of the Malta Hospice Movement [<http://www.hospicemalta.org>], explained to the Strasbourg conference that the Network hopes to give Maltese patients a powerful new voice—much needed because the patient-group fraternity in Malta is fragmented, and, as such, is usually unable to influence health policy at home or abroad. Indeed, said, Ms Shah, the Maltese government did not officially recognise the existence of patient NGOs until 2008. These groups must now register with a government-appointed Commissioner if they wish to fundraise and undertake lobbying activities. Charities in Malta are now also required to undertake annual audits, possess a statute, and staff their boards with volunteers only (government representatives are disallowed from sitting).

The MHN is currently building relationships with the media and government—among which it has been well received. The Network was active on European Patients' Rights' Day 2009, holding a workshop to introduce its patient group members, and to raise awareness among them of the European Charter of Patients' Rights. The event was attended by a representative from the Ministry of Social Policy.

hospitals in neighboring countries sharing patients, and complementing each other's services.

But Mr Decker confessed to being less enthusiastic about the cross-border Directive than some of the previous speakers. He expressed his doubts:

“The patient is the most important element of healthcare. The patient is paying for healthcare as a taxpayer, or within a national insurance system. Following the ECJ decision, politicians are now waking up to the fact that cross-border healthcare has to be legalised. The Directive is a step back compared with the advances made by the ECJ. According to jurisprudence, cross-border patients can only be refused reimbursement in special circumstances. The way the Directive is worded, however, reimbursement is only granted to cross-border patients in exceptional cases.”

Mr Decker concluded that if cross-border care is to be effective, patients will need information about what treatments and services are available in Member States' national healthcare systems, including where, and at what price.

In conclusion

Teresa Petrangolini, Secretary General of the Rome-headquartered Cittadinanzattiva (the founding parent organisation of Active Citizenship Network), wound up the day's proceedings at the Strasbourg conference by saying that the progress made so far towards the goal of patients' rights could not have happened without the widespread support for, and dissemination of, ACN's 2002 European Charter of Patients' Rights. She intimated that, following the European elections of June 2009, ACN intends to step up its campaigning to secure the institution of European Patients' Rights' Day. ACN will also concentrate on monitoring patients' rights throughout Europe, and the collection of best practice in patients' rights within Member States.

As Melody Ross of ACN pointed out;

“In general we think it is important to highlight that the European Charter and European Patients' Rights Day are a citizens' initiatives. This is not just about patients' but rather more broadly about citizens and their concern that everyone should have access to quality healthcare that health is a right and healthcare services are part of the common goods which we all have responsibility to protect and take care of. We all need to work together--European institutions, national health authorities, health professionals, industry and citizens-- to guarantee the sustainability of our healthcare system. The European Charter of Patients Rights can provide a common framework for action and for making health policy decisions. For that reason ACN, together with other organisations throughout Europe, will continue to work to make the 14 patients' rights a reality not just a proclamation. “

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