

HSCNEWS INTERNATIONAL

Issue 41

February 2008

# *Winds of change?*

*The Patient as Activist*





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Data protection registration number: Z7133076

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# Winds of change?

*Spurred on by heightened public concerns about lifestyles and chronic disease, patients are turning into activists. Delays and deficiencies in healthcare services have hardened their perspectives. It may not be a role that patients welcome, but they are driven to take action when their child lies sick, or a loved one is in pain, and care and treatment falls short of expectations. Patient activists are adamant that they are riding the winds of change.*

## How the thinking behind universal healthcare has changed

One of the world's oldest universal healthcare systems, the UK's National Health System (NHS), is currently celebrating its 60th year. The architects of the system believed that the feelings of social solidarity in the UK in the years immediately following the Second World War could be utilised to promote an equitable system of care delivery. The system these 'wise men' set up involved citizens making regular financial contributions to the new NHS according to their individual economic means. In return, all could expect to enjoy the best healthcare on offer. As Aneurin Bevan, Minister for Health at the time the NHS was founded, noted in his book *In Place of Fear* (published in 1952): "The collective principle asserts that ... no society can legitimately call itself civilised if a sick person is denied medical aid because of lack of means".



Before the 1940s, rampant infection and illnesses associated with poverty and malnourishment were the main causes of death. Expectations were that health would improve and healthcare bills fall as

individuals gained access to care and treatment. Good, widely-accessible healthcare did indeed drop mortality rates from infection and respiratory disease. Life expectancies markedly improved in industrial societies (most notably among children). But populations then began to become prey to new forms of illness—cancer, coronary heart disease, stroke. Even today, these medical conditions remain common and incurable. The cost of treating and caring for the burgeoning numbers of the chronically ill has inflated the healthcare bills of every country (whether running a tax-based healthcare system or not) beyond the imagining of those 1940s visionaries.

### Healthcare rationing

By the 1990s, healthcare payers across the globe had no choice but to implement rationing (in much the same way as food was rationed in many countries during the Second World War).

As a result, healthcare systems of 2008 no longer supply all available medicines. Modern medical technologies are assessed for ‘cost-effectiveness’, and not all are reimbursed by the healthcare payer. Cheaper generic remedies are favoured in place of costly, new, brand-name drugs. Payers fight off patients’ insistence on receiving the best (and most-expensive) treatments by denying them the healthcare information they need to underpin any demands. Payers are careful, too, not to fall into the financial trap of attempting to meet the pressure for healthcare services. Instead, they try to cap requirements by making the process of accessing services long-winded and unattractive to patients. Hence patients wait sometimes lengthy periods for surgical operations. And, almost everywhere, gateway systems guard scarce resources by directing patients into a process of referral before they might be allowed to see a specialist.

### Record amounts of public spend

Despite having to endure major restrictions on access to the best healthcare, the public of 2008 spends record amounts in taxes and insurance contributions to healthcare systems. Yet they are experiencing what they regard as diminishing returns in services supplied and in quality of life. Germany, for instance—the originator of sickness and insurance funds—now has both one

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#### Definitions

Payers = Insurers or governments that finance a healthcare system.

Providers = Doctors or other health professionals who provide services to patients.

Users = Patients who use the system.

of the most costly healthcare systems in Europe and falling life expectancy.

The combination of rationing and high taxes/medical insurance payments is persuading ever more patients, carers, parents, families and friends to champion change in healthcare systems.

### **Patients' needs are ill-understood**

Patients today want healthcare systems to reflect their needs, as well as those of payers. Research conducted in 2007 by the UK-based QALYity Project, a loose alliance of patient organisations, academics, policymakers, and other experts, has illuminated the differences between the aspirations of patients and healthcare payers. The latter emphasise the importance of directing funds only at the parts of modern medicine that can demonstrate an evidence base (and, even then, in appropriate circumstances). Respondents to the QALYity Project's patient survey express different goals. They simply want to be included in society as normal, contributing members, and they insist that treatments and care should help them do that. Until a way is found to merge the two perspectives, battles between patients and payers will continue.

### **Caring for the chronically-ill**

Modern healthcare systems are ill-prepared to accommodate the oncoming surge of chronically-ill people. According to the London-based Alliance of Health

and the Future, an independent research organisation that studies the social effects of ageing: "Research in Europe suggests that most healthcare systems are ill-equipped to address the needs of the ageing populations they are meant to serve. Healthcare systems were founded on the principles of acute care, and focus on specialisation, efficiency, and expediency. Yet older patients presenting with chronic illness and co-morbidities require continuity of care that bridges across traditional medical boundaries and care settings". The QALYity Project has found as much.

## **This issue of HSCNews International**

With patients now increasingly involved in healthcare policy (and even medical research), this issue looks back over the last few years of contributions from *HSCNews*. We glance at the evidence that patients are more assertive, and consider the impact they are having on all levels of the healthcare system. We note the forces prompting patients to activism, and touch on the civic movement, human rights, personal advocacy, and volunteering. Finally, we ponder the future of patient activism.

## Examples of increased tensions

The following three examples illustrate the growing rift between patients and payers.

□ On Thursday, January 10th 2008, the UK House of Commons Health Select Committee, which advises the country's Parliament, called for a major review in the way that the government-appointed National Institute of Clinical Excellence (NICE) decides which treatments should be paid for by the National Health Service (NHS). The Committee's decision is probably not surprising, given current levels of public, patient, and industry dissatisfaction with the Institute's performance. Since NICE was founded in 1999, well over one third of its appraisals—42—have been challenged and gone to appeal. Nearly half of the appeals have been upheld.

□ On November 26th and 27th 2007, hundreds of national patient cancer groups from across the world descended on Brussels at the invitation of the European Society for Medical Oncology (ESMO), a body representing Europe's medical oncologists. ESMO used the event to announce the launch of a cancer patient advocacy forum intended to boost the advocacy skills of patient NGOs specialising in cancer. At the close of the session, Austrian oncologist Professor Heinz Ludwig, the chair of the ESMO Cancer Patient Working Group, emphasised the common desires shared by patients and their physicians. These include the wish to see new drugs approved and reimbursed, patients' rights respected, more high-quality information provided for patients, and better funding for cancer care. And that, insisted Professor Ludwig, was just for starters ...

□ Across the Atlantic, Diane Dorman, Vice President for Public Policy at the US-based National Organization for Rare Disorders (NORD), testified on December 4th 2007 before the Social Security Administration Public Hearing on Compassionate Allowances that "men, women, and children who are seriously affected by rare diseases (many of which are debilitating and/or life-threatening) are routinely denied Social Security Disability insurance, and are forced to venture upon a lengthy, and often expensive, appeals process. This is because nearly 100% of rare diseases are mentioned neither in the SSA *Listing of Impairments*, nor the UN's *International Classification of Diseases*".

## The patient desire for better quality of life

To find out what patients want from their healthcare, a loose alliance of patient organisations, academics, policymakers, and other experts—provisionally called the QALYity Project—met in 2006 to define ways in which patients’ quality of life (from the perspective of the patients, not their doctors) could be improved.

The Project was originally inspired by work conducted in a completely different subject area by the Happy Planet Index (HPI). A 2006 creation of the New Economics Foundation, the HPI gauges the success of countries according to ecological efficiency. Although the results of the QALYity Project’s efforts have only just been submitted for peer review, the initiative’s headline findings have already been endorsed by patient groups worldwide.

What the QALYity Project did was straightforward. It

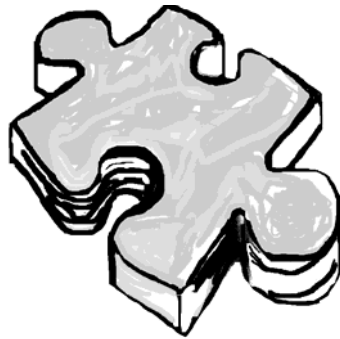
initially asked around 270 UK patient organisations to assess their own constituencies’ quality-of-life (QoL) needs. As the answers rolled in, a pattern soon emerged: patients’ QoL needs could be distilled down to 31 different interventions. Each of these fell, in turn, into one of three categories: improvements in access to (and in excellence of) treatments and care; improvements in physical wellbeing as a result of care; and having a better general outlook on life as a result of care.

The QALYity Project then asked over 3,400 patients from around the world to specify which of the 31 interventions was important to their personal situation. The survey results confirmed that the vast majority of patients hold both similar and differing perspectives on quality of life. All of the 31 quality-of-life indicators were deemed important (or very

important) by patients participating in the survey. But when the patients were requested to specify the most important indicator of all, “getting the correct treatment, support or care” drew the biggest vote from all types of patients, regardless of their medical condition, their age, background, or location.

Aside from this single issue of correct treatment, support or care, however, patients differ in what they want from their healthcare system. One third of the survey’s patients with arthritis, for example, singled out freedom from pain and discomfort, not having to fight the system for medical care, and feeling independent as their top QoL indicators. One third of the survey’s patients with multiple sclerosis, on the other hand, opted for living with dignity, retaining independence, having access to information, and knowing that scientists are working hard to find a cure.

The QALYity Project is spearheaded by Wales-based PatientView (an independent, global research-and-publishing organisation that studies the viewpoints of patients and patient groups) and Together4Health (a London-based consultancy). The Project’s first year of operations were funded by NovoNordisk, a Danish healthcare company specialising in diabetes. The QALYity Project’s two surveys were undertaken by PatientView. Survey results are being submitted for peer review. <http://www.patient-view.com/qalyity.htm>



# The evidence

## Patient-instigated campaigns (I)

Causes	Examples of campaigns by patient activists
Bioethics	<p>In 2007, the Coalition for Genetic Fairness gained significant support in the House of Representatives for its Bill, the Genetic Information Non-Discrimination Act (GINA). GINA is due to go before the Senate in 2008, where it must pass before gaining Presidential approval. The Coalition consists of over 600 advocacy organisations serving 25 million people affected by 1,000 conditions, and is the leading voice in the fight for federal protection from genetic discrimination.</p>
Better access to healthcare	<p>On December 15th 2007, the Bath, UK-based National Osteoporosis Society (NOS) won its appeal against the National Institute for Clinical Excellence (NICE) regarding primary and secondary prevention of bone fractures. The NOS was concerned that the NICE guidance was restrictive, and did not allow patients to be prescribed appropriate treatment to protect against future fractures. NICE now goes back to the drawing board to come up with revised guidance for a range of effective treatments.</p>
Carers	<p>On December 15th 2007, Pam Webster, incoming President of the Deakin West, Australia-Capital-Territories-based Carers Australia, reported that the organisation will push for progress for carers by working more closely with the new Australian government. Ms Webster emphasised: “Over the next few years, we need to ensure that the general community recognise the work that carers do, and the contribution that they make. I believe that government and decision-makers should involve carers in all levels of decision making. Carer involvement should result in flexible policies and adequate resources for service provision that will enable carers to have a real choice in their caring role”.</p>
Disease awareness (for instance, heart conditions)	<p>The Stop Sudden Cardiac Arrest Coalition (SCA Coalition), a virtual coalition of organisations committed to preventing sudden cardiac arrest (SCA), met with four co-chairs and the staff of the Congressional Heart and Stroke Caucus, to convince them of the importance of creating new legislation to boost public awareness about SCA. The Coalition is also requesting increased research into the subject, and improved access to life-saving SCA treatments. SCA is a leading cause of death in America, claiming more than a quarter-of-a-million lives each year. Since being founded in May 2007, the SCA Coalition has attracted a membership of 30 organisations from across the healthcare sector, including groups representing the interests of patients and healthcare professionals, and bodies from industry.</p>
Equality of care and treatment	<p>In November 2007, the Luxembourg-based Alzheimer Europe released its <i>Dementia in Europe Yearbook</i>, a publication that examines the social support offered to people with Alzheimer’s disease in different European countries. Vladimir Spidla, European Commissioner for Employment, Social Affairs and Equal Opportunities, praised the way that the <i>Yearbook</i> emphasises the social effects of Alzheimer’s disease (and other types of dementia) on patients themselves, and on their families and carers. Mr Spidla stressed “the need for improved training of medical and care professionals, as well as of family carers, to improve the care and support of people with dementia”.</p>
Hospital-acquired infections (HAIs)	<p>In July 2007, the UK’s Secretary of State for Health reacted to continued press coverage of hospital-acquired infections (HAIs) by providing additional funding for ‘frontline’ infection control in hospitals. The London-based Patients Association (PA) welcomed the move. But the PA has since remained concerned by the rates of HAIs, and emphasises that it continues to receive regular reports of HAIs from patients.</p>

## Patient-instigated campaigns (II)

Causes	Examples of campaigns by patient activists
Men's health	<p>In December 2007, Ian Banks, President of the Brussels-based European Men's Health Forum (MHF), called 2007 the most significant in the organisation's six-year history. Dr Banks pointed to several important developments for MHF, in particular, the first-ever EU men's health conference, in Lisbon, in November 2007, which, he said, confirmed the ascent of men's health up the EU agenda. The conference promoted the EMHF 2006 Vienna Declaration, a statement of intent about the future of men's health in Europe that has won the support of 28 Members of the European Parliament (MEPs), and dozens of EU and national government officials, as well as health professionals and academics.</p>
Patients' rights (including right of redress)	<p>Rome-based Active Citizenship Network (ACN, the international arm of Italian civic group Cittadinanzattiva), acting in coordination with a number of European citizens organisations, established a European Charter of Patients' Rights in 2002. The Charter contains the following 14 rights: the right to preventive measures; to access; to information; to consent; to free choice; to privacy and confidentiality; to respect of patients' time; to observance of quality standards; to safety; to innovation; to avoidance of unnecessary suffering and pain; to personalised treatment; to complain; and to receive compensation. ACN states that it based the rights on the Charter of Fundamental Rights of the European Union, and argues that they are pivotal to the healthcare services of European citizens. ACN has since surveyed the extent to which the rights are present in European countries. To raise awareness about the topic of patients' rights, the organisation has declared a day annually dedicated to it.</p>
Patient safety	<p>Numerous consumer organisations used the platform of World Consumer Rights Day in March 2007 to raise awareness about unethical drug promotion. Members of London-headquartered Consumers International (CI) ran activities in their respective countries and sent letters to local health authorities. CI said that unethical drug promotion can occur in several ways: making misleading or false claims about a medicine; deliberately suppressing information about the risks or side effects of a medicine; providing doctors with financial incentives to prescribe a medicine to consumers; and exploiting disease-awareness campaigns to promote a medicine, rather than to promote health itself.</p> <p>"These methods can ultimately lead to irrational drug use by consumers, with potentially fatal health risks", reiterated CI. The group wants consumer health to come above corporate profit, and is calling for transparency in disease-awareness funding, full disclosure of clinical trial data, and an end to 'gifts' for doctors.</p>
Smoking and other lifestyle factors	<p>When the EU published a report in November 2007 on the public response to its January 2007 Green Paper consultation, <i>Towards a Europe Free From Tobacco Smoke: Policy Options at EU Level</i>, the report noted that 311 comments on the Paper had been received. Of these, 45 were from European health NGOs, including groups from Bosnia and Herzegovina, Cyprus, Hungary, and Slovenia. The majority of commentators supported a full smoking ban in all enclosed workplaces and public places, with minimum exemptions on humanitarian grounds.</p>

# Shaping and changing the political agenda

If members of the public were asked to identify their neighbourhood's top ten health concerns, they would very probably mention issues which emerged into the spotlight as a result of the endeavours of patient activists.

The dangers of the hospital bug methicillin-resistant staphylococcus aureus (MRSA), the plight of carers, and improving access to healthcare services for everyone are just some examples of campaigns instituted by alert patient activists [for more, see tables on pages 10-11].

A glimpse behind the scenes shows why and how patient campaigns have become popular concerns.

## MRSA AND HAIs

Harrowing cases of unexpected hospital deaths and injury due to MRSA (a type of bacteria resistant to certain antibiotics) have been reported in the media of many countries (particularly Ireland, the UK, and the US) since the mid-1990s. Hospital-acquired infections (HAIs), of which MRSA is one of the most dangerous, were widely identified as a major public-health challenge by 2000. The need to mount a frontline attack on the problem was evident.

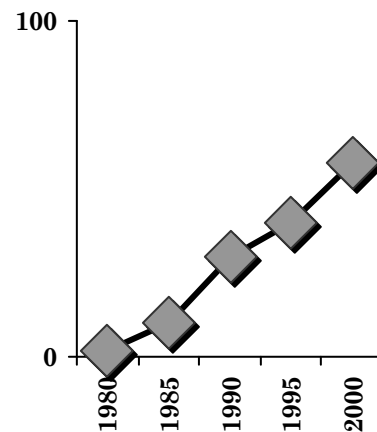
But, even as late as May 2005, a survey of health campaigners conducted by *HSCNews* found that patients in the three above-mentioned countries, where infection rates were thought to be highest, were postponing operations for fear of acquiring an infection. Margaret Dawson of the Kilkenny, Ireland-based group, MRSA and Families, told *HSCNews* at the time: "All of our 150 members contracted MRSA following surgery. Their families would certainly postpone having an

operation for fear of getting a hospital infection themselves". Ms Dawson formed her group in May 2005 after her husband contracted MRSA.

Lisa McGiffert, who was charged with running the Stop Hospital Infections campaign of the Washington DC-based Consumers Union (CU), said in the *HSCNews* May 2005 report on HAIs: "We have discovered that many US hospitals do only

... Continued on page 15

Incidence of MRSA among US hospitals that voluntarily report infections rates [% incidence]



Source: Centres for Disease Control and Prevention

## Patient crusaders

The media of many countries regularly stocks itself with stories of celebrities backing worthy causes that aim to alleviate disease and sickness and improve healthcare. But, perhaps far more remarkable, are the efforts of ordinary citizens who seek to influence shortfalls in their healthcare system, and even to campaign about deficiencies in national and international health policy. *HSCNews* has published numerous examples of such health crusaders, including the following four:

■ **Arguing for a proper diagnosis.** Arnold Juklerod died in 1998, but remains a cause célèbre in Norway. He was placed in a mental institution for being an eccentric, difficult person. When discharged, he refused to leave until declared sane—which the hospital refused to do. Juklerod's struggle won the support of the Norwegian public, and his story was made the subject of a film, 'For Your Own Good'.

■ **International recognition of the diabetes pandemic.** In October 2004, Clare Rosenfeld, a diabetic patient from Oregon, and only 17 years old, considered the possibility of persuading the United Nations to put diabetes onto its agenda. Despite the enormity of the task, she managed to garner support from heavyweight organisations like the American Diabetes Association (ADA) and the International Diabetes Foundation (IDF), both of which embrace health professionals as well as patients. Two years later, on December 20th 2006, the UN General Assembly passed a landmark resolution accepting that diabetes is a chronic, debilitating, and costly disease, and recognising the validity of the annual World Diabetes Day. This was the first time that the UN had acknowledged a non-infectious disease as a pandemic. To mark the passage of the UN Resolution, a blue circle was adopted as a logo. On World Diabetes Day, November 14th 2007, the image was projected onto major monuments around the world.

■ **Changing the law.** Katie Tookey, born in Auckland, New Zealand, in 2001, was diagnosed with biliary atresia and persistent jaundice at six weeks old. Doctors said that her life expectancy was likely to be limited. Still alive today, Katie will eventually have to go on a waiting list for a liver transplant. Unfortunately, New Zealand has few organ donors. So Katie's father, Andy, began to lobby for change, and formed the organisation GiveLife NZ. In 2006, he co-authored the Human Tissue (Organ Donation) Amendment Bill, which would change the law to prevent relatives overriding the wishes of a deceased registered organ donor. The Bill failed to pass through Parliament in November 2007. Mr Tookey is fighting on. On January 18th 2008, he reported a new initiative being introduced by GiveLife NZ: "It will be fairly controversial, but not as controversial as the presumed-consent system currently being debated in the UK. The UK feels the need to use radical measures to increase their donor rate, even though they have 15 donors per million of population, compared with New Zealand's mere 7 donors per million. If anything, we in New Zealand need to take more radical measures than them, but I am not sure that Kiwis are ready for such a huge leap in one go".

■ **Access to clinical trials.** In early 2001, at the age of 28, Jan Geissler was diagnosed with chronic myeloid leukaemia (CML), a rare and damaging cancer of white blood cells that mainly affects adults. At diagnosis, the only approved treatment options were stem-cell transplantation and interferon-Alpha. One new drug, Glivec, had shown promising results in the US in patients with CML. Luckily for Mr Geissler, a small trial in his home country, Germany, testing the tolerability of a combination therapy with Glivec, had elected to include him among the participants. Since those dark days, Mr Geissler has gone on to set up Leukämie-Online, a virtual network run solely by patients and their relatives. Today, the website is one of the largest online communities for German-speaking patients with leukaemia, and provides news and knowledge about progress in research and leukaemia therapy.

## Lobbying policymakers and changing the law

Successful lobbying groups are intent on changing policy and law. They provide viewpoints in consultation processes, harangue key government agencies and officials, place high-profile news stories in the media, and campaign in favour of new legislation. Some groups also win their arguments in court [*see last item, for instance*].

■ **Disagreeing with government policy.** When the UK government announced on November 21st 2007 that it would not ban the advertising and promotion of baby-milk substitutes, action groups argued that the government decision flew in the face of advice from the World Health Organization (WHO). Alison Baum, speaking for the London-based Breastfeeding Manifesto Coalition (BMC), an alliance of activists, politicians, and health professionals launched on May 7th 2007, said: “The Government’s proposals are an inadequate response to the problem, and will continue to put UK mothers and babies health at risk”. 17 BMC members insisted on meeting the Minister responsible.

■ **Involved in consultation processes.** On December 3rd 2007, New Zealand’s drug regulator, Pharmac, invited support groups to its inaugural stakeholder forum, so that they could find out more about the objectives of Pharmac, and provide input on the agency’s impact on patients. Around 140 representatives from consumer and patient groups, the pharmaceutical industry, government agencies, and the health sector attended the forum—a total far exceeding Pharmac’s expectations.

■ **Influencing policy guidelines.** The Downderry, Cornwall-based International Patient Organisation for Primary Immunodeficiencies (IPOPI) announced a major coup in October 2007. After significant discussions and lobbying by the group and by medical professionals specialising in the subject area, the World Health Organization reinstated immunoglobulins on its Model List of Essential Medicines (a categorisation of the ‘must-have’ medicines for all nations). Immunoglobulins had originally been in the List, but, in 2003, the WHO removed them. After this achievement, IPOPI is concentrating on compiling databases about the prevalence of primary immunodeficiencies worldwide, and about the availability of medical supplies.

■ **Changing the law.** On November 17th 2007, Mark Chambers and several hundred other disabled patients of Lagunda Honda Hospital, San Francisco, were moved out to independent living quarters with the supportive services they needed. The right to live independently outside a hospital was, however, only obtained after a protracted legal battle between the City and five advocacy groups representing the individuals involved, who were recipients of financial support from California’s Medicaid for the poor. The plaintiff in the landmark lawsuit, *Chambers v. San Francisco*, initially filed in October 2006, claimed that by continuing to confine residents who had been found able to live independently with assistance, the city violated the requirement of the Americans with Disabilities Act that people with a disability should be provided services in the “most integrated setting appropriate” to their needs. The victory has led to a new programme, called “Success at Home”, which will coordinate residents’ transition, matching each to federally-subsidised medical services, community supports, and subsidised housing, with linkage (as needed) to attendant and nursing care, vocational rehabilitation, substance-abuse treatment, mental health services, and assistance with meals. The five advocacy groups involved were:

- The Independent Living Resource Center of San Francisco (ILRCSF) acted as organisational plaintiff.

- Sacramento-based Protection and Advocacy Inc (PAI) acted as lead counsel.

- The Berkeley-based Disability Rights Education and Defense Fund (DREDF), the Washington DC-based AARP (American Association of Retired Persons) Foundation Litigation, and the Washington DC-based Bazelon Center for Mental Health Law each acted as co-counsel. Joining the advocates was law firm Howrey LLP (pro-bono).

Continued from page 12

*“People attend hospital to be cured, but find that their health is severely affected, and that their families are traumatised. This is a matter we must urgently confront.”*

Liz MacManus,  
Deputy,  
Joint Committee on  
Health and Children,  
Ireland,  
November 2005

minimal surveillance of infections, and many (probably most) don't do that very well. But we don't know, because there is no required reporting, nor any established standard of care to prevent these infections. Rather, the US prefers to react with antibiotic treatment after infection”.

**Taking action**

Appalled by the frequency with which HAIs were occurring, key health NGOs launched high-profile campaigns to provoke governments and healthcare systems into action. As well as MRSA and Families, and the Consumers Union, the Dublin-based Irish Patients' Association (IPA), the New York-based Persons United Limiting Substandards and Errors in Healthcare (PULSE), and the London-based Patients Association (PA) took up the cause.

These groups undertook research to discover the types of intervention most effective at combating HAIs. Visits were made to hospitals in Denmark, the Netherlands, and Sweden, where strategies to combat hospital infection had been successful. Valuable advice that simple interventions

reduce exposure to HAIs was then passed on to the public.

The groups called for systematic collection of data on HAIs to be made public. By end-2007, the CU had helped secure laws to that effect in 20 US states. The new results showed that rates of MRSA infection were even higher than originally suspected.

Following media coverage on poor hospital conditions, and political lobbying about the need to address the spread of HAIs, governments and healthcare authorities have formulated guidelines and injected funds to improve hygiene standards. Hospitals are implementing procedures to curb the bacteria problem. And, to ensure that they do, local support groups have sprung up to keep vigil over nearby hospitals.

**In 2008**

Campaigners believe that the HAIs situation has now improved, but emphasise that much more still has to be done. Cleanliness procedures remained varied throughout hospitals. Other HAIs are becoming as worrisome as MRSA. Optimum methods of reporting infection rates are being negotiated. Activists soldier on.

*“Carers are a remarkable group in society. They are a lifeline for the millions of people who rely on their compassion and dedication. We in government need to do more to listen to, and learn from, carers about how we can better provide the support they need, and the recognition they deserve.”*

Gordon Brown,  
when Chancellor of  
the Exchequer,  
UK,  
June 2007

## CARERS

One person above all is seen as responsible for bringing the subject of carers out of the shadows worldwide—British social worker Jill Pitkeathley. In the 1980s, she was among the first to elevate carers’ interests into an issue, becoming in 1986 Chief Executive of the group now known as Carers UK.

The UK media quickly grasped Ms Pitkeathley’s simple but worrying message that many of the country’s sick were being cared for, not by the National Health Service, but by forgotten family members—who were unpaid, unhappy, and unhealthy. As news stories about the plight of carers multiplied, the few carers’ groups already in existence in other countries noticed the recognition accorded their UK counterparts. The issue assumed international dimensions.

During the 1990s, carers’ groups emerged in Australia, Belgium, Ireland, the Netherlands, Sweden, and the US. The movement jumped the north-south divide and expanded into developing nations, where a social awareness of carers’ issues is on the rise. By 1998, the carers’ movement was able to mount its first international conference in

London. In 2004, national carers’ groups felt confident enough to launch a global carers’ umbrella organisation, the London-based International Alliance of Carers Organizations (IACO). Gail Hunt, Director of the IACO, stated in an interview with *HSCNews* in November 2006 that the carers’ movement had arrived: “The whole issue of family care is going to explode. The population is ageing. Women are working. Sooner or later, we will have to deal with these issues”.

### Taking action

The large number of carers’ groups and their members have provided the carers’ movement with political clout. Backed by research and data, high-pressure lobbying, and sophisticated public relations, the carers’ cause has made an impact upon policymakers.

Many countries operate schemes to compensate and support people who devote part (or all) of their life to care for someone close to them. Carers’ groups are now demanding such legislation. Carers UK, for instance, insisted in May 2007 that carers be legally protected from discrimination by their employers.

*“Pressure from patients has influenced attitudes within the European Commission. People there have woken up to the idea that health is a huge part of the economy.”*

Bernard Merkel,  
Head of the Health  
Strategy Unit,  
Directorate General  
for Health and  
Consumer Protection  
(DG SANCO),  
the European  
Commission,  
March 2007

## EQUITY

On March 19th 2007, Robert Madelin, Director-General for Health and Consumer Protection at the European Commission’s DG SANCO, made a speech at the *European Voice’s* Brussels conference, ‘Healthcare 2007: Diagnosing Our Future’. Mr Madelin said that neither the clinical experience nor the universal healthcare systems of European countries have alleviated variations in the health of people across the continent. People in Sweden, he mentioned, can expect to reach 78 years of age, whereas the life expectancy of Latvians is nearer 65.

The link between health and wealth gives the Commission the mandate to act to reduce the burden of ill health, argued Mr Madelin. Countries should see healthcare provision less as a burdensome cost, and more as an opportunity to improve national fiscal wealth.

The speech would have been impossible even just a few years ago. The principle of subsidiarity in the 1957 ‘Treaty Establishing the European Community’ has traditionally prevented the European Commission from dabbling in local healthcare politics. Bernard Merkel, head of the Health Strategy

Unit at DG SANCO, who also spoke at the event, explained the change in Commission thinking: “Pressure from patients has influenced attitudes within the Commission. People there have woken up to the idea that health is a huge part of the economy”.

After sustained lobbying, the European Commission has launched a new Health Strategy, ‘Together for Health: a Strategic Approach for the EU, 2008-2013’, on October 23rd 2007. The Strategy describes how the EU will attempt to improve the health of European citizens by bringing in measures to increase equity in access to care.

Lobbying in Brussels has gathered momentum following the creation of new pan-European patient organisations. In March 2007, PatientView (publisher of *HSCNews*) and Brussels-based Burson-Marsteller launched a Directory of pan-European health groups. The publication listed 140 groups—a figure that surprised even the relevant European Commissioners. The Directory’s second edition, released at the *European Voice’s* ‘Healthcare 2008’ conference, March 6th-7th 2008, Brussels, contains 45 more pan-European groups.

Whether operating together or separately, European patient organisations can exert pressure on the European Commission to accept that health and healthcare should be an important part of the EU remit. Patient organisations see the EU as immensely valuable. Only it can override the dictates of Member States, which, in healthcare matters, often focus more on cost cutting than on increased spending.

European politicians are taking pan-European activists seriously. Disease-related all-party informal groupings have multiplied. Many have been organised and run by patients and their representatives.

In April 2006, Health Equality Europe, an alliance of health stakeholders, published the results of interviews with senior policymakers. The report claimed that those interviewed recognised that the patient movement had become an integral part of the health/medical establishment, and regarded groups as effective representatives of popular patient views. Bar a few reservations, they also agreed that patient activists are highly valued at all political levels.

## BRANCHING OUT

Nearly all medical conditions or health problems (even those that affect only small numbers of people) have some form of representation in the form of specialised advocacy groups. Inventive ways are also being developed to ensure that patients, whatever their needs, gain some sort of representation and support. For instance, Jambes-based Rare Disorders Belgium is compiling a global database of patients of different rare diseases—just in case a would-be advocate needs to find patient members to back his/her cause.

PatientView’s database of 70,000 patient groups worldwide classifies patient organisations into 1,200 categories and subcategories. Included are groups that

support children’s medical needs, those dedicated to issues associated with blood cholesterol, and groups that provide medical support to homeless people. Groups range from those that are pure advocates to those that provide services 100% of the time.

Incredibly, patient activists are diversifying their activities. One of the latest (and most intense) areas of expansion is in accommodating the latest idea of government—“the democratisation of medical research”—or, put more plainly, “greater involvement of patients in the development of proposals for the conduct of medical research”. [For more, see the next page.]

### Support groups around the world specialise in the following types of cancer and cancer-related subjects

- Acoustic neuroma
- Adolescent
- Advocacy
- Bladder
- Blood
- Bone
- Brain
- Breast
- Carcinoid
- Cervical
- Chronic myeloid leukaemia
- Colon
- Colostomy
- Endocrine
- Neoplasia
- Eye
- Gastrointestinal
- Gist
- Gynaecological
- Haematology
- Head and neck
- Hereditary
- Hodgkin’s
- Kidney
- Larynx
- Leucodistrophy
- Leukaemia
- Liver
- Lung
- Lymphodaema
- Lymphoma
- Macroglobulinemia
- Melanoma
- Mouth
- Myeloma
- Neoplastic anaemia
- Neuroblastoma
- Oesophageal
- Ovarian
- Pancreatic
- Pelvic girdle
- Pituitary
- Pregnancy
- Prevention of
- cancer
- Prostate
- Rare
- Sarcoma
- Skin
- Stoma
- Testicular
- Throat
- Thymic
- Thymus
- Thyroid
- Vulval

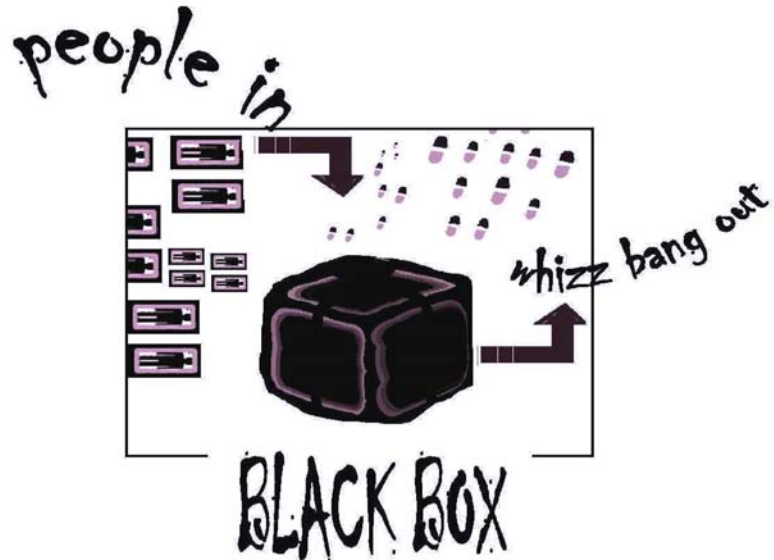
## Medical research—patients getting involved with the black box

Ask anyone in the street what they believe the term ‘medical research’ means. Most will be mystified by what they see as a complex scientific process. Some might talk about scientists ushering human ‘guinea pigs’ into laboratories to be tested with prototype ‘medicines’—to see if the new drugs are effective or ineffective (or possibly dangerous). If subjects in the clinical tests react well, then science may have produced another life-saving, ‘whiz-bang’ product. For the majority of the public, however, the whole process of medical research is more like an unintelligible black box. Patients and other ordinary mortals prefer to leave well alone rather than consider what they perceive to be the medical equivalent of rocket science.

That, at least, was the view until recently. In June 2007, at a seminar hosted by the James Lind Alliance (JLA) and *The Lancet*, held at in London at the Royal Society of Medicine (RSM), patients in the audience complained that clinical trials are primarily designed by doctors and scientists who have little idea of their wants and needs. They noted that neither most of the trial subjects (middle-aged white men) or the research settings (the sterile environment of the ‘black box’) reflect reality. The world outside the black box of research is populated by poor

people of different ages and ethnicities, each struggling to earn a living (or just to survive) in sometimes hostile surroundings. Faced with this degree of variety, the selective environment of the clinical trial can hardly expect to produce results of widespread practical relevance. Additionally, some of the meeting’s attendees felt that many studies retrace paths followed in previous rounds of testing, and should therefore be described as unethical experimentation.

The views aired at the RSM meeting are given credence by comments made to a survey of patients’ opinions on the topic of their quality of life, published by *HSCNews* in October 2007 [issue 39]:



- “I believe that medical professionals should not treat patients as idiots, just because they went to medical school and we didn’t”, wrote an Australian patient with an auto-immune condition. “That fact does not mean we don’t know what is going on with our bodies. They should listen to what we have to say, and not just go by recommendations from a text book”.
- “If a little-known or little-understood illness affects two million people in the UK”, asked an English patient with fibromyalgia, “why is chronic illness research not receiving funding, so that we can live a fairly ‘normal’ life, and not be made to feel that we are lazy spongers?”

- “Health professionals need to listen to us, and see us within the context of our whole lives”, insisted a Scottish person with a mental health problem, “so that they can support us in achieving the quality of life we want—not what they think we should have”.

Today’s patients are speaking up in the hope of getting some say in medical research. They would like research to reflect more of their needs. They want the opportunity to suggest the types of medical products that enter the R&D pipeline, and comment on how these products should be delivered to patients. They wish to specify what information can best help them comply with treatment.

Patients’ views have rarely been given credence by clinical researchers. Amazingly, the clinical research process has been perpetuated for decades without input from the ultimate consumer (the patient). No industrial sector could behave like this. Car or computer manufacturers, for example, would never dream of ignoring the opinions of the end-users of their products. Therein lies the road to commercial suicide.

### Levering open the black box

Around the world are modest patient- and citizen-inspired initiatives that, if reproduced across a wider canvas, could affect the direction and shape of clinical research.

Some already are. Few people can doubt that the current



preoccupation with HAIs gripping governments, medical professionals and the media is the direct result of grassroots lobbying. When a patient, family member, or loved one enters hospital with one complaint and exits with a far worse illness (or fails to come out at all), the concerned public raises voices on the matter. Investigation and protocols to combat infection are demanded. The press are quick to raise the alarm. Once pressure for change wells up, authorities are forced to react. In the case of HAIs, the public has already started dabbling inside the black box.

Other patient-inspired ventures may not have hit the news stands with quite the same impact, but all nonetheless represent an important transformation in thinking about citizen and patient involvement in medical research. Lobbying efforts by patients and their representative organisations go beyond fund-raising, or trying to protect the rights of the patients who act as research subjects, or other activities that used to mark the limit of patient-public interventions.

Citizens, patients, and even scientists, politicians, and civil servants are looking for

optimum methods of patient engagement. The Brussels-based, European Commission-funded, 2004-2007 ‘Meeting of Minds’ programme must rank among the most civic-minded approaches to public involvement. The project allowed citizens from nine European countries to meet experts in brain science to discuss and compare views on how developments in the discipline will (and should) alter people’s lives. The initiative’s conclusions on the value of new directions for brain science have been passed to European and national policymakers.

Some commentators and activists believe that the best way to connect with the public is to form partnerships or networks. One impressive alliance is that of the US-based Summit Series on Cancer Clinical Trials, started in 1998. The summits are financed by pharmaceutical companies, but the presence of patient representatives ensures that the approach is not pharma-led. The 11th Summit was held in Baltimore, Maryland, on January 10th-11th 2008.

Working along similar principles, the UK Clinical Research Collaborative (UKCRC) brings together the NHS, research funders, industry, regulatory bodies, Royal Colleges, patient groups, and academia, and aims to improve the quality of clinical research in the country.

The Collaborative has just launched a website [<http://>

www.peopleinresearch.org] that assists members of the public in contacting organisations which want to involve them in an active way in clinical research. The site explains that patients can make an impact “by helping to decide what gets researched, or possibly by carrying out part of the research”.

### Thinking ahead to ThinkWell

The forthcoming UK-based International Network for Knowledge about Wellbeing (ThinkWell) promises to be among the most daring of the latest experiments in user involvement in medical research. The inspiration of Amanda Burls, Senior Clinical Lecturer at the University of Birmingham, Thinkwell seeks to enable global communities to contribute to current health research.

Dr Burls brings to the project experience gained as Director of the West Midlands Health Technology Assessment Collaboration, an NHS-funded unit that undertakes systematic reviews and economic evaluations of health technologies and policies for the West Midlands region, working on behalf of NHS bodies like the UK’s National Institute for Clinical Excellence (NICE).

Scheduled for launch during the first half of 2008, ThinkWell holds up a vision of health research undertaken to an agenda set by the public. Such a scenario can also address public concerns about research. The

prospective Network’s many laudable aims include:

- The creation of tools to help lay people interpret risk (the benefits versus the adverse reactions of medicines or other clinical interventions) and make decisions about good and bad products.
- The development of methods of undertaking ethically-sound primary research (particularly randomised controlled trials [RCTs] via the Internet and the mass media).

### The medical benefits

Back at the James Lind Alliance/*The Lancet* June 2007 meeting, the audience managed to reach something of a consensus about what should be done to ensure that public and patient preferences are taken on board. The following suggestions were agreed:

- (1) Patients’ questions about their care and medical needs should be considered fundamental in the shaping of clinical research—although some caution should also be exercised. Patients may not fully versed in the latest scientific developments, and may be biased by information from pharmaceutical companies or from the media (a problem similarly faced by some clinicians).
- (2) The wider public can be engaged through conventional social research, exploring patient experiences of health, ill-health and treatment. Researchers can analyse and interpret the results, drawing

out the implications for research agendas.

- (3) More ‘real-world’ studies need to be undertaken, embracing all comers, and using more patient-relevant measures. Trials should recruit people from a wide range of age groups, and should incorporate ethnic and cultural diversity, as well as take account of the problems that older people sometimes experience with compliance.

If the above recommendations were to be common practice, then medical research might perhaps seem less mysterious to the man in the street, and public expectations of science’s capabilities become more realistic. Moreover, by working with the public, clinicians could help medical practice provide patients with kinder care—possibly even care of the sort referred to in the Hippocratic oath.

## Projects that seek to include patients and the public in medical research

Organisation	Website	Activity
Action Medical Research	<a href="http://www.action.org.uk">http://www.action.org.uk</a>	UK group that funds research to meet users' needs.
Alzheimer Society	<a href="http://www.alzheimers.org.uk">http://www.alzheimers.org.uk</a>	UK group that funds research to meet users' needs.
Coalition for the Advancement of Medical Research (CAMR)	<a href="http://www.stemcellfunding.org">http://www.stemcellfunding.org</a>	US coalition that ensures that the voices of patients, scientists, and physicians are heard in the debate over the future of regenerative medicine.
Consumers' Health Forum	<a href="http://www.chf.org.au">http://www.chf.org.au</a>	Australian forum that works with government to develop kits about community involvement in research.
Consumers United for Evidence-Based Healthcare (CUE)	<a href="http://apps1.jhsph.edu/cochrane/uscccc.htm">http://apps1.jhsph.edu/cochrane/uscccc.htm</a>	US coalition that helps consumer health advocates to include the promotion of evidence-based medicine in their campaigning.
Database of Uncertainties about the Effects of Treatments (DUETs)	<a href="http://www.duets.nhs.uk">http://www.duets.nhs.uk</a>	UK resource to help prioritise research with the support of relevant stakeholders, including patients.
European Brain Council (EBC)	<a href="http://www.europeanbraincouncil.org">http://www.europeanbraincouncil.org</a>	Brussels-based coordinating council that raises awareness about the need for scientific endeavour into the workings of the brain to fight neurological conditions.
European Platform for Patients' Organisations, Science and Industry (EPPOSI)	<a href="http://www.epposi.org">http://www.epposi.org</a>	Brussels-based patient-led partnership that aims to provide agreed strategies on European policy to be endorsed by patients, scientists, the medical community, and industry.
European Science Social Forum (ESSF) Network	<a href="http://www.essfnetwork.org">http://www.essfnetwork.org</a>	Platform of civic groups and health NGOs at EU level that seeks dilution of industry influence on the direction of medical R&D.
International Genetic Alliance (IGA)	<a href="http://www.worldmuscleforum.org/demo/iga/index2.htm">http://www.worldmuscleforum.org/demo/iga/index2.htm</a>	Netherlands-based alliance of patient organisations involved in genetics and biotechnology.
Involve	<a href="http://www.invo.org.uk">http://www.invo.org.uk</a>	Advisory group in the UK Department of Health charged with promoting public participation in research for the NHS, government-funded public health and social care.
James Lind Alliance (JLA)	<a href="http://www.lindalliance.org">http://www.lindalliance.org</a>	UK partnership of organisations that aims to identify and confront important uncertainties about the effects of healthcare treatments.
Meeting of Minds	<a href="http://www.meetingmindseurope.org">http://www.meetingmindseurope.org</a>	Brussels-based effort at public participation in developing an agenda for mental health research.
Qalyity Project	<a href="http://www.patient-view.com/qalvity.htm">http://www.patient-view.com/qalvity.htm</a>	UK alliance of stakeholders developing 'user-friendly' quality-of-life indicators.
Summit Series on Cancer Clinical Trials	<a href="http://www.cancersummit.org/making_progress.htm">http://www.cancersummit.org/making_progress.htm</a>	US platform in which clinical cancer research stakeholders (including patients) discuss ways of improving cancer clinical trials.
ThinkWell	To be launched mid-2008	Innovative new UK scheme to conduct user-directed clinical trials in virtual space.
UK Clinical Trials Collaborative	<a href="http://www.ukcrc.org">http://www.ukcrc.org</a>	Partnership between the NHS, research funders, industry, regulatory bodies, Royal Colleges, patient groups, and academia. Aims to elevate the quality of clinical research.

# S

## heer scale and diversity

Citizens of all ages and from all walks of life can be counted as patient activists today. Since 2003, PatientView, publisher of *HSCNews*, has assembled a database of patient groups and other health campaigning organisations. The database currently holds details on 70,000 groups worldwide, each of which contains individuals ardently concerned about some aspect of human suffering and eager to improve aspects of human health.

### Old and young

Included in the database are over 1,000 groups that specialise in older people's issues. Many of these organisations have histories that stretch back decades, to a time when older people's concerns typically focused on pensions, preparations for retirement, and securing the rights of the elderly within society. Today's worries about the increasing proportion of older people in populations, rising levels of chronic illness, shortages of healthcare services, higher out-of-pocket costs for healthcare, and the loss of dignity and respect afforded older people in hospitals,

have all forced older people's organisations to re-assess their policies. Thus:

■ On January 10th 2007, Wellington-based Age Concern New Zealand responded to figures released after a government nationwide census. The new statistics noted a significant rise in the total of older people in the population. Ann Martin, the Chief Executive of the organisation commented: "Increasing numbers of older people will require action by government, local authorities, health providers and all our communities". She continued: "Access to primary healthcare, as well as acute and palliative care, is vital for older people. They will have increased healthcare needs, but not as

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### A patient activist explains ...

The 36-year old UK academic and philosopher, Havi Carel, best known for her work on humanity's understanding of life and death, explains why she was motivated to become a patient activist. Writing in the UK newspaper, *The Independent*, on January 21st 2008, she discussed her personal response to the discovery that she had developed a terminal illness, lymphangioliomyomatosis (LAM). In the article, entitled 'Havi Carel: my 10-year death sentence', Ms Carel wrote:

*"I have become a patient activist, working for the LAM Treatment Alliance, trying to push forward research and drug trials. LAM is a disease that has few advocates because it is so rare. That is why I have become my own advocate, like many other women with LAM. We find it hard to accept that the world carries on as before, while we suffer from a terrible disease about which so little is known."*

## Maturing fast: three case studies

Three case studies provide some impression of the scale and speed of change in the patient movement:

■ **The mass expansion of the European cancer patient movement.** In the early 1990s, the cancer patient movement was dominated by large, relatively-longstanding cancer charities that mostly funded or conducted research (plus a few breast cancer groups). Male cancer patients, or patients with some other type of cancer than breast cancer, had no form of representation. That situation has completely changed by 2008. Patient support groups cover almost all types of cancers [see table on page 19]. Groups exist for cancer patients whose special needs stem from being a member of a particular ethnic background. Other groups are dedicated to helping cancer patients alleviate the fatigue or pain they suffer, or aiding patients who have undergone a certain type of treatment, or those who are receiving palliative care. Not all countries can claim such diversity within their cancer patient lobby, but discrepancies are being corrected. The cancer patient lobby is exceptional, not only because of the variety of groups it encompasses, but also in the ready manner with which these seemingly disparate organisations manage to work together. The Riemerling, Germany-headquartered European Cancer Patient Coalition (ECPC), for instance, was launched in 2003, and now has 250 members from across the 27 EU Member States representing the interests of all manner of patients with cancer. The ECPC maintains close ties with the European Society for Medical Oncology (ESMO), as well as with its core funder, the European School of Oncology. It acts as the Secretariat for MEPs Against Cancer (MAC), an informal group of European Parliamentarians trying to push cancer higher up the EU agenda. The ECPC holds regular member events across Europe. 2008 venues are: Brussels (Belgium), Florence (Italy), Lugano (Switzerland), and Stockholm (Sweden).

■ **The scaling-up of the Terrence Higgins Trust.** In 2007, the London-based HIV and sexual health charity, Terrence Higgins Trust (THT), celebrated 25 years of existence. THT was founded by the friends of one of the UK's first recorded deaths from AIDS, but has changed significantly since then. The organisation has undertaken a series of mergers, acquiring charitable HIV/AIDS groups from all over the UK. The enlarged THT now has 365 full-time staff, 1,000 volunteers, an annual income of £13.5 million [US\$26.3m; Euros 17.9m], and provides HIV services to 50,000 people. In the 1980s and 1990s, gay men were the Trust's core constituency. Today, its attention is on African people with HIV/AIDS.

■ **The merger between a pan-European patient group and its counterpart scientific society.** London-based PARE Manifesto is a loose association of arthritis/rheumatism groups from across Europe whose aim is to improve the quality of life of patients they represent. The group's manifesto was launched in 2001 as a call to action to raise the profile of the conditions, and to provide various types of reforms that could improve services and enable patients with the conditions to gain greater inclusion in society. As of January 1st 2008, PARE merged with the Zurich-based European League Against Rheumatism (EULAR), a scientific society. The new grouping is called People with Arthritis/Rheumatism in EULAR (PARE). The rationale behind the merger was not only to avoid unnecessary duplication of European patient initiatives, but also to access a more reliable form of funding, so that PARE could be more credible and independent when campaigning at European level. EULAR will provide the financial support for PARE's core activities.

... Continued from page 23

much as people might think. Most health expenditure is needed in the last year of life. Also important: older people should not be denied healthcare just because they are 'old'. A 70-year old who receives an operation may have 30 years or more of productive life ahead".

■ On August 15th 2007, the London-based English Community Care Association (ECCA), the country's leading representative body for independent care homes, responded to the UK Government's Joint Committee Report on *Human Rights of Older People in Healthcare*. Martin Green, Chief Executive of the ECCA, commented: "This is an important report which raises a lot of issues for health and social care providers. One of the issues that comes from the report is the subtle ageism that is at the heart of the health and social care system. This manifests itself in many ways, but particularly in the reduced levels of funding and resources that older people's services receive compared to other client groups". Mr Green continued: "Dignity and quality of care must be at the heart of every care service, and, when failures occur, we need to look not only at the services that have failed, but also at the society within which they operate. If older people are regarded as a low priority within society, this attitude will also impact on the way that they are perceived by the health and social care system. No excuses exist for

poor treatment. Those responsible must be forced to improve their practice".

■ In September 2007, the Brussels-based European Older People's Platform (AGE) launched a report on how to promote healthy ageing. The 40-page document, entitled *Healthy Ageing: Good Practice Examples, Recommendations, and Policy Actions*, pointed out: "Heath ageing is not just about prolonging life. It is about promoting the means to enable older people to continue to participate in society, and to cope with daily life. It concerns learning, the exchange of good practice, and the development of strategies and policies designed to promote older people's individual well-being and personal growth". *Healthy Ageing* provides an overview on the importance of promoting a positive and integrated approach to health by addressing a range of social, economic, housing, transport, new technology, education, and other relevant policies that affect health.

Individuals at the other end of the age spectrum (18 and under) also have specific and wide-ranging difficulties with current healthcare systems, treatment, and care. Concerns include a wish for greater confidentiality in sexual health advice, and for increased investment in health services dedicated to

the young. Groups specialising in the health and wellbeing issues of children and the youth are multiplying fast, and now account for 4% of all types of health-oriented NGOs. PatientView's database holds 3,000 such younger people's groups, including the following four examples:

■ The Utrecht, Netherlands-based You Act (the European Youth Network on Sexual and Reproductive Rights) was established in 2005 "to secure good information and youth-friendly services, so that young people can decide freely and responsibly about all aspects of their sexuality".

■ The Fitchburg, Massachusetts-based TeenAids was founded in 2006 to save young teenage lives around the world from the stigma felt by those affected by HIV/AIDS. The group involved US universities in its November 2007 global webcast aimed at encouraging peer education. Many teenagers affected by HIV/AIDS and linked to the group have gone into schools to help educate others of their own age about the dangers of the viral disease.

■ London-based CLIC Sargent is the UK's leading children's cancer charity, and offers all round care and support (including access to specialist nurses and doctors).

■ iEARN (International Education and Resource Network) is a non-profit educational telecommunications network with the primary purpose of assisting youth. One of its tasks is making a meaningful contribution to the health of young people. The Network comprises 20,000 schools and youth organisations in 115 countries.

### Women and men

Women's health issues have long tended to occupy centre stage in health politics.

Many of the subjects concentrated upon by the women's health movement have been established by the female struggle for equality in society.

At a conference on gender and health, held in November 2003 at the London-based King's Fund, Anna Coote, the then Director of the Fund's Public Health Programme, stated: "Women's demands for equity generally heightened their awareness of their special health needs, and led to demands for recognition of better health services for women. The feminist critique of healthcare, and women's call for control over their own bodies set in motion a development that would overthrow the patriarchal system of healthcare".

Men have proved less potent lobbyists, with the result that male health issues were overlooked in most countries for decades.

In its December 2003 issue, *HSCNews* (which attended the King's Fund conference) reported on the rise of the men's health movement. *HSCNews* mentioned that, with the sole exception of the

HIV/AIDS movement of the 1980s, men's health issues only began to gain significant exposure in the media when the first mass-market men's health magazines appeared in the US and in some European countries in the early 1990s. The new publications promoted an archetypal image of robust male health—the muscular body builder—and publicised the activities that could be enjoyed by healthy, high-earning males.

Later in the 1990s, male health issues began to spotlight prostate cancer and erectile dysfunction—medical conditions that had become more familiar to the public after the appearance of new treatments (Viagra being the best known for the latter condition).

Meanwhile, the gay men's movement was continuing to try to balance the promotion of sexual liberty with conveying the importance of preventive sexual health practices.

From about 2000 onwards, however, the men's health movement began to take a more holistic view of male health. Emphasis was being placed on adapting lifestyles to prevent male diseases, rather than on taking

medicines to cure them. Despite being relatively young and under-resourced, the men's health movement has now managed to draw international attention to major health-related differences between men and women.

At a time when lifestyle, rather than genetics, largely dictates the causes of death, more men die prematurely than women. On the whole, men are sicker than women. The gender of individuals is therefore an important determinant of life expectancy. Yet it is also one that is little recognised—particularly by policymakers—a situation that men's health groups want to rectify.

### **Ethnic minorities**

Each year, healthcare data in many countries reveal large health discrepancies between ethnic minority groups and the majority element of the population.

Such gaps exist for many complex reasons, including disparities in culture, patient income, healthcare funding, and approaches towards medical consultations.

But whatever the cause, patients from ethnic minorities need—and seek—support from like-minded fellow patients. Groups that specialise in the requirements of patients from differing cultural backgrounds are in the ascendency. For example:

- London-based Cancer Equality concentrates on addressing the inequities in cancer care faced by people from the black and minority ethnic and refugee communities. It aims to bridge the gap in existing services by providing information, and by raising awareness of the importance of cancer screening and risk reduction. Cancer Equality works in partnership with providers to reduce inequalities, and to make services more accessible and culturally sensitive.

- The New York-based Roma Health Project, supported by George Soros' Open Society Institute,

promotes the right of Romany people to appropriate, high-quality healthcare services. Projects are mostly based in Eastern Europe.

### **From Tahiti to Taiwan**

The health concerns of citizens and patients are not parochial matters. Although a person with HIV/AIDS requires completely different care and treatment from someone suffering from, say, hyperhidrosis (excessive sweating), more often than not the underlying concerns and needs of both sets of patients can be remarkably similar. Insufficient awareness of the problems linked to the disease, a shortage of healthcare funds, a lack of access to treatment and care, etc—these are commonalities that cut across disease boundaries.

Thus, the worries of patients living on the south coast of Tahiti will not only find resonance with their neighbours in the island's north, but even with patients in Taiwan:

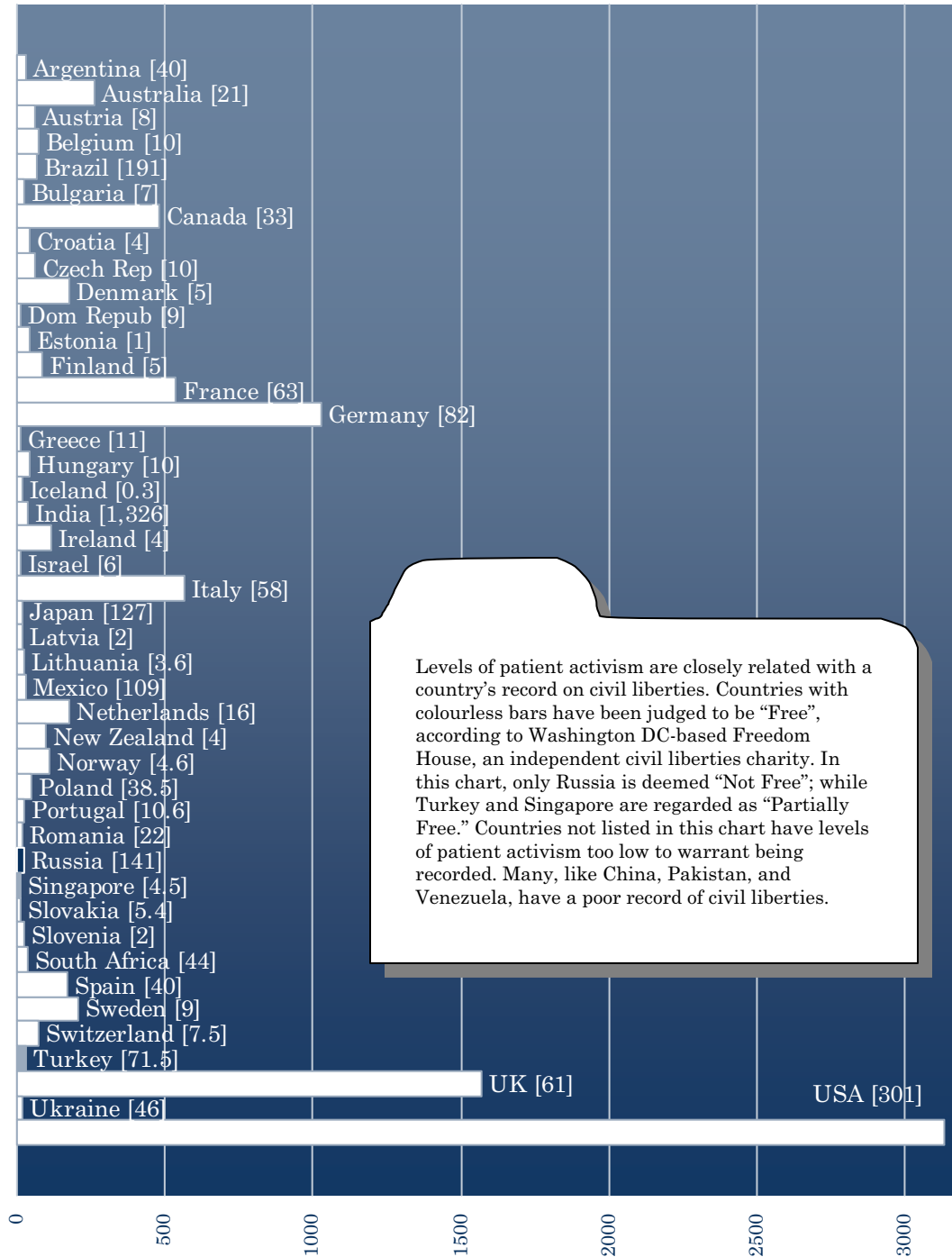
- Marie Bopp Dupont, a young Tahitian woman who was diagnosed HIV positive in 1998, is the founder of the Pacific Island AIDS Foundation in Tahiti (PIAF). The group hopes to create an

... Continued on page 29

## Comparative levels of patient activism On a scale of 1 to 3,500

[Bracketed figures = size of national population, in millions]

Sources: PatientView, GeoHive, and Freedom House



... Continued from page 27

HIV/AIDS-friendly environment, making it easier for people living with the condition to voluntarily disclose their status without fear of discrimination. The PIAF also wants the region to improve its HIV/AIDS policies, and achieve a reduction in the number of new infections.

■ A letter published in the *Journal of the Canadian Medical Association (CMAJ)* in January 2005 reported that Taiwanese patients suffering from a devastating complication of the endoscopic thoracic sympathectomy (ETS) surgery used to treat hyperhidrosis were insisting that the country's government take their problems and the risks of ETS surgery seriously.

Patient activists can now be found in every country. The scale of any activism, though, is not linked to size of national population. China, for example, has 1.32 billion people, yet only low levels of patient activism (mainly due to the country's poor human rights record). The numbers of patient activists, and the influence wielded by them, are determined by the presence (or otherwise) of a number of considerations, including: a philanthropic culture, a good government record on political and civil rights, the existence of mechanisms that allow citizens to challenge authority, and a prevailing

sense of solidarity that supersedes desires for individual freedoms. The chart on the previous page provides a roughly comparative guide to levels of patient activism (in terms of numbers of patient advocacy groups) in countries around the world. The chart is based on information drawn from three sources: PatientView's database of health campaigners; GeoHive's world population data; and the 2008 Freedom House report, *Freedom in the World*. The chart shows that patient activism is often strongest—although not exclusively so—in countries where political freedoms are greatest.

Until recently, the majority of patient activists were located in the western world—more precisely, in North America and in northern Europe. Today's geographic profile is of health advocates is different. Eastern Europe, in particular, has seen the flourishing of health advocacy since communism and totalitarianism gave way to democracy. Patient activism, though still muted, is even apparent in countries like China. For instance:

■ In February 2007, Dr Gao Yaojie, a retired doctor, was honoured by Vital Voices

Global Partnership, a Washington DC-based women's advocacy group. Dr Yaojie exposed a blood-selling scheme that infected thousands of Chinese with HIV. Chinese authorities sought to detain her from travelling to accept her prize. However, following international pressure, Dr Yaojie was allowed to travel to the US.

### In Eastern Europe

In September 2006, *HSCNews* ran a report pointing out that Eastern Europe's Communist countries of the 1917-1991 era made little effort to secure standards of healthcare for their citizens (the exception being the one-time Yugoslavia, which passed a 1970s law guaranteeing the healthcare rights of Yugoslavs). The oppressive centralisation of political activities in the period allowed populations to be prohibited from demanding that their health needs be met.

Matters have changed since the end of the Communist period. Eastern Europe has witnessed a massive explosion in the number of NGOs, including those campaigning on health issues. Financial support from the European Commission and the Soros Foundation have been forthcoming to many of these groups. The latter foundation was formed by the Hungarian-born magnate George Soros, to promote an open society in which "nobody has a monopoly on the truth, and where different people can hold different interests".

East Europeans are fully aware that they represent

the assertion of the positive values of democracy and the rejection of the old totalitarian ways. They work hard at being passionate and enthusiastic patient activists, as may be seen from the following examples:

■ In December 2006, Torun, Poland-based Pol-Familia [Association of Families and Caregivers of Persons with Mental Health Disorders and Institute of Patients' Rights and Health Education] responded to the European Commission's Green Paper *'Improving the Mental Health of the Population: Towards a Strategy on Mental Health for the EU'*. Pol-Familia stressed: "We regret that the quality of life of people with a mental disorder in our country is far below the standards of other EU countries. Basic problems include: lack of specialised care centres; no reimbursement of (and therefore no access to) the most effective therapies, using second-generation atypical drugs; and a lack of systemic and legislative solutions to enable people with a mental health problem to function actively in society". [Editor's footnote: Exactly one year later, on December 6th 2007, European Commissioner Markos Kyprianou announced that the mental health strategy proposed in the Green Paper had been scrapped in favour of a 'softer' Mental Health Pact. Many mental health groups were disappointed by the news.]

■ In April 2007, the Prague-based Svaz pacientů ČR [Czech Association of Patients] stated in a televised debate that the Health Ministry's planned introduction of healthcare fees for visits to the doctor, hospital stays and visits to the emergency wards, was not in keeping with the country's constitution.

■ On October 30th 2007, the Sofia, Hungary-based Association 'Women Without Osteoporosis' (WWO) launched a national exhibition on foods, nutritional additives, and diagnostic facilities intended to help prevent or treat osteoporosis. The exhibition was opened by Mrs Zorka Parvanova, wife of the Bulgarian president, and patron of the country's National Campaign Against Osteoporosis.

## Japan

Japan introduced a law in March 1998 permitting non-profit organisations to be recognised as legal entities. By 2002, almost 9,000 groups had formed in response, 60% of them dedicated to health, medical matters, or welfare. Commenting at the time on the emerging trend, Hideo Ishizuka, a researcher at the Tokyo-based Institute of Non-profit Health Care Cooperation (INHCC), noted that non-profits have become identified within Japanese society as “useful tools of mobilisation, leading to civic empowerment in social institutions”. Dr Ishizuka believes that health-oriented non-profits have been encouraged to spring up across the country by the historically high levels of male and female unemployment generated during Japan’s prolonged economic downturn. The unemployed seek paid jobs as caregivers, or give themselves meaningful activity as unpaid caregivers. The non-profits are able to utilise the ranks of the new caregivers, and fill a gap in service delivery in society.

## Thailand

An interesting report by Thailand’s Ministry of Health profiling the status of the nation’s health between 2001 and 2004 [[http://www.moph.go.th/ops/health\\_48/CHAP12.PDF](http://www.moph.go.th/ops/health_48/CHAP12.PDF)] holds a chapter dedicated to health advocacy in the country. Over the last two decades, Thailand, too, has witnessed a mushrooming of health NGOs. The report categorises the groups as either philanthropic or formed to tackle specific health objectives. Any government funding that they might receive is cause-related.

- More than 100 groups in Thailand have been created to combat HIV/AIDS. Many are financially supported by government.

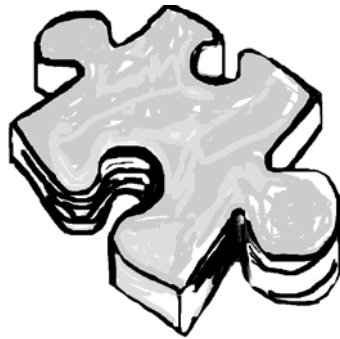
- Thai health NGOs specialising in reducing tobacco consumption helped see through two pieces of tobacco-related legislation in 1992.

- The Bangkok-based Jor Sor 100 Community broadcasts reports on traffic levels and road conditions. Community members send in their observations via cell phones or short-wave radios. The broadcasts are a safety measure, motivated by the fact that traffic accidents are one of the major causes of emergency patient admissions in Thailand.

## Brazil

NGOs have really only been active in Brazil for about the past 10 years.

- The Sao Paulo-based Associação Brasileira de Linfoma e Leucemia (ABRALE) is one of the first major patient groups to have emerged in Brazil. Formed in 2002 by a number of families of children with leukaemia, ABRALE sees itself as an advocacy organisation campaigning for better treatments. The group, however, is also active in the provision of practical services—it promotes early diagnosis, offers useful and relevant health information, arranges for blood donations, works to increase supplies for bone marrow transplants, and assist patients in paying for treatments.



# The forces at play

# Civic activism in healthcare?

Civic activism in healthcare occurs when individuals come together to fight for changes in the entire healthcare system, or to lobby on single-disease issues. Civic activism pervades almost every aspect of the patient movement.

Some patient activists see themselves as civil rights leaders. Others in the patient movement do not.

If distinctions are to be made, it could be said that patient activists who espouse concepts of choice and human rights are more wedded to the civil movement. Other patient groups see patients' rights as separate from, and more specialised than, the general body of human rights.

Strictly speaking, too, civil activists only seek to represent the concerns of their members. Patient groups, on the other hand, may act on behalf of a whole constituency (for example, patients with type-2 diabetes).

As the patient movement evolves, these classifications

inevitably begin to blur, and cross over into each other. But, whatever the nomenclature, patient activists form an important part of the patient movement, and do much to persuade the population at large of the merits of their particular crusade.

## Backed by governments

The tensions between national governments and international institutions of government have driven each to find civic activism acceptable. Both types of government seek to exploit civic activism's ability to siphon up public interest and direct it into causes of mutual interest. National government believes that regional activism can be harnessed to popularise its own new initiatives. International institutions, meanwhile, hope that local citizens will put pressure on national government to pledge support to their projects and programmes. The EU, for example, regards civic activism as a potential ally in any attempts to work around

Member States' subsidiarity on issues of health.

■ Speaking at the European Public Health Alliance's 'Health in the Enlarged EU' conference, in Bratislava, Slovakia, on April 16th 2007, Walter Baer, of the European Commission's Directorate G (Public Health) emphasised the crucial role that NGOs were playing during the consultation stage prior to the formation of the EU Public Health Strategy (launched on October 23rd 2007). He called such groups instrumental in helping implement and achieve the objectives of the Strategy at the regional level.

## The first signs

The first significant example of the legacy of civic activism influencing the patients' agenda was probably the US HIV/AIDS movement in the 1980s. It was founded by a diverse set of individuals who felt that their HIV/AIDS healthcare needs were being met neither by government, nor by the medical profession, or manufacturers of medicines. New York-based AIDS Coalition to Unleash Power (ACT UP) decided to use the American

Civil Rights movement's tactic of non-violent civil disobedience to draw attention to its constituency's healthcare plight. To this day, ACT UP continues to try to influence political decisions with picketing and rallies.

### Civil groups adopt health

Since those beginnings, civil groups have embraced a broader health agenda. The Teen Health Initiative (THI), for instance, created by the New York-based American Civil Liberties Union (ACLU) in 1997, seeks to secure better rights of access to care for young adults.

Similarly, Washington-based Public Citizen, which made its debut in 1971 by filing lawsuits to obtain a compensation system for airline passengers on overbooked flights, now dedicates a large part of its time to healthcare issues.

In Europe, the Brussels-based European Public Health Alliance (EPHA), enjoys the favour of the European Commission's Directorate-General for Health and Consumer Protection, and has emerged as one of the major health NGOs on the EU political scene. The EPHA's 1993 formation (states the

organisation in its 2006-2010 business plan) stems from the fear of European civil society groups that many EU governing institutions were only indirectly, and not directly, interested in public health.

The EPHA, whose member organisations number over 100, states in PatientView's forthcoming *European Patient Directory 2008* that its mission is "to promote and protect the health of all people living in Europe, and to advocate for greater participation of citizens in health-related policymaking at European level".

The EPHA is itself a member of the Brussels-based EU Civil Society Contact Group, which brings together eight disparate European NGOs. The Group aims to develop tool kits for other advocacy organisations that hope to make their voices heard in Brussels. Co-ordinator Regula Heggli describes its remit in the *European Patient Directory 2008* as: "Together, we work to develop the dialogue between civil-society organisations and EU institutions as an essential part of strengthening participatory democracy".

Rome-based Cittadinanzattiva (Active Citizenship)

is an Italian non-profit movement established in 1978 to promote a view of citizenship in which people exercise their powers (and their responsibilities) in public policies. In healthcare, Active Citizenship is best known for its efforts to establish patients' rights.

The Brussels-based European Aids Treatment Group (EATG) also puts citizens at the core of its philosophy, and notes in the *European Patient Directory 2008* that "since its foundation, the EATG has been at the forefront of the development of a civil-society response to the HIV/AIDS epidemic".

These organisations could be considered the busiest in the health-oriented civic movement. Citizen engagement lies at the heart of their approach—a concept that has been absorbed by more traditionalist patient organisations (sometimes without the latter even realising).

## Civic activism: a sketch

The term ‘civil society’ has been bandied about since Classical Greek times to indicate all manner of activities by citizens. Today’s most popular interpretation of the phrase—“that part of society not under government control”—dates back merely to the mid-1700s, when Adam Ferguson, a Scottish historian and philosopher, published his *Essay on the History of Civil Society*. Ferguson wrote: “Nations stumble upon establishments which are indeed the result of human action, but not the execution of any human design”—meaning that civil society does not require design and planning, but is a spontaneous phenomenon.

For much of the 20th century, civil societies were largely limited to neighbourhood groups, semi-formal trade unions, and religious organisations. These associations aimed to protect the weakest in society by providing them with services, and by representing their interests in the face of authority. Citizenship was generally taken to mean

individuals obediently performing duties to maintain a civil society. The public was able to influence national legislation, but only indirectly, through the ballot box.

Following two World Wars and the development of modern welfare states, citizens looked to governments to ensure that equity was upheld in society, and to shoulder the burden of the poor and disenfranchised. Even the US was not immune to the trend. President Johnson’s 1964 ‘Nationwide War on the Sources of Poverty’, spent billions of dollars of federal funds introducing training programmes. These bestowed much-needed resources on impoverished workers and farmers (as well as on entire local communities), and helped people organise and plan their own battle against poverty.

### The late 1960s

Major political upheavals in the 1960s led to a change in thinking about the future role of civic activists. The decade witnessed the birth of a civil rights movement, beginning

with a call by American black civil rights leader, Martin Luther King, for racial equality in work, income, housing, and security. The movement was given further impetus by student and worker uprisings in Europe and Latin America in 1968, and by street protests against the Vietnam war.

The next major influence leading to reform of civil societies came with the collapse of the Berlin wall in 1989 after weeks of popular unrest. The subsequent expansion of free-market economies, and the spread of liberal democracy into eastern Europe, initiated a new generation of civil society organisations based on the principle of individual freedoms and liberties.

The emergence of other social crises—such as global warming, economic recessions, or the threat of new pandemics—have also fuelled a mass expansion of the civic movement. The trend has been helped by the expansion of an educated middle class, and by the appearance of new communication technologies (such as the Internet).

*Sources for the civic activism and civil society section of this report:*

- The Blackwell Encyclopaedia of Political Thought*.
- ‘Civil Society in America: a Public Debate about Political Theory’, by Christopher Beem; an Institute for American Values Working Paper, 1996 [[http://www.americanvalues.org/html/wp\\_52.html](http://www.americanvalues.org/html/wp_52.html)].
- Adam Ferguson Institute [<http://www.rob.com/afi/prez.html>].
- ‘Untapped Potential: Civil Society and the Search for Peace’, Hassan Abdel Ati, Professor of Development Studies at the University of Khartoum, and director of EDGE for Consultancy and Research, 2006; and ...
- Conciliation Resources [<http://www.c-r.org/our-work/accord/sudan/civil-society.php>].

Nowadays, the term civil society is largely equated with working democracies in which a free and articulate public hold the unscrupulous nature of their governments at bay, while, at the same time, influencing policymaking themselves. Civic activist, unlike political activists, do not have as their main aim the replacement (or even the overthrow) of a government. Rather, they aspire to change the viewpoint of the existing government. (Though as we read earlier, politicians now are seeking to harness elements of civil society to push through government agendas. Begging the question, whether the tail is wagging the dog.)

In 1998, speaking at a congress in Sao Paolo, Brazil, the-then United Nations Secretary-General, Kofi Annan, stated: “A strong civil society promotes responsible citizenship, and

makes democratic forms of government work. A weak civil society supports authoritarian rule—which keeps society weak”.

In October 1999, the European Economic and Social Committee (ESC) of the European Commission hosted a convention entitled ‘The Civil Society Organised at European Level’. The foreword of the report on the convention’s proceedings summed up the latest understanding of the term ‘civil society’, and identified NGOs as its functional operatives: “In the major debate on civil society currently taking place in Europe, an attempt has been made to define organised civil society as the representation of more or less formalised groups and associations—voluntarily based, and legally regulated—which provide a bridge between

the expression of the will of the people on specific issues and those than represent them”.

The ESC text continued: “This does not mean a selfish and corporatist defence of special interests. Instead, their action is spurred by the fact that such a link between legitimate interests, rights, and duties is the very foundation of a universal democracy based on the civic and community awareness of the citizen”.

# P

## ersonal advocacy

Type the phrase ‘personal advocacy services’ (PAS) into the Google search engine, and you will generate around 3.5 million hits.

One website defines PAS as services intended to provide people with the opportunity and the wherewithal to represent their own needs, views, and choices, so that they can influence decisions that affect their lives.

Another website affirms that advocacy schemes support people by taking their side, and that advocacy promotes social inclusion, equality and social justice. Tool kits, visual materials, and guides all exist to help people struggling to find their way around bureaucratic hurdles.

PAS have partly emerged in reaction to a rise in social discrimination and exclusion accompanying widespread international migration. To counter the trend, national governments, international government bodies, and every manner of national institution and foundation have embarked on expensive public campaigns and interventions to promote

respect for human rights, and to encourage greater personal involvement from all levels of society. Choice, personal empowerment, and participation have become the popular by-words of the day.

It was therefore only a matter of time before patient activists began to extol the virtues of personal advocacy. Whether functioning on the international, the national, or the local stage, health campaigning groups are teaching their peers and the people they represent the art of advocacy. The goal is to ‘empower’ patients with the correct communicational skills, so that become able to fight their corner more effectively.

Examples of organisations that focus on empowering patients include:

■ *Salute e Diritti dei Cittadini [Health and Rights of Citizens, or What to Do, and How to Survive in the Italian Health System]*, written by Teresa Petrangolini and published in October 2007, is a book which draws on the experience of the founder of the Rome-based civic action

group, Cittadinanzattiva e del Tribunale per i Diritti del Malato [Tribunal for Patients’ Rights]. Over the years, Cittadinanzattiva has received descriptions of thousands of patients’ struggles with the Italian healthcare system. A lack of national standards, and the tangle of state and regional laws all serve to confuse Italian consumers about their rights within their healthcare system. *Salute e Diritti dei Cittadini* seeks to overcome the complications, and lists the author’s recommendations for coping with the challenges often faced by the country’s patients. [<http://www.cittadinanzattiva.it/content/view/1230/233/>]

■ The Silvi Marina, Italy-based Associazione Pathologie Autoimmuni Internazionale (APAI) [the International Association for Autoimmune Diseases] seeks to improve the quality of life of patients and their relatives by teaching self management.

■ Dr Gustavo López-Muñoz y Larraz, a Spanish lawyer, saw his daughter, Cristina, die as a result of medical negligence in 1966. At the time, few people in Spain were expert in the subject of medical negligence. To find out more about the world’s only existing movement for patients’ legal rights (albeit

in its infancy), Dr López-Muñoz y Larraz went to the US in 1967. He has since turned himself into an expert on medical negligence. In 1999, he founded the Madrid-based Fundación Pro-Pacientes 'Cristina', in honour of his late daughter. Fundación 'Cristina' helps patients learn about their legal rights—free of charge—and tries to build awareness of patients' rights among the Spanish public.

Patient activists from nations that are well-entrenched in advocacy pass their knowledge on to others in countries where fewer people are as skilled in lobbying and campaigning. For example:

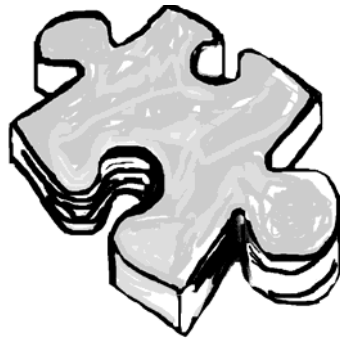
- The Brussels-based European AIDS Treatment Group (EATG) extended its activities into Eastern Europe as early as 2002 “to empower the HIV/AIDS community to access concepts of treatment activism and advocacy”.

- The European Cancer Patient Coalition (ECPC) organised a series of master classes for patient groups across Europe in 2005 and 2006. The classes provided a platform to exchange best practice and pass on the latest information on European health policies. The events also gave attending groups a chance to hear presentations from senior clinicians, regulators, and health professionals.

- As part of a conference it

hosted in Vienna, May 31st-June 2nd 2007, Brussels-based Mental Health Europe (MHE) held a ‘capacity-building’ seminar primarily directed at mental-health patient organisations located in the new EU Ascendant Nations. The meeting provided assistance and training for groups in those countries that wish to campaign on social exclusion.

- The Zurich-based European League Against Rheumatism (EULAR), a scientific body, merged in 2007 with London-based PARE-People With Arthritis/Rheumatism in Europe Manifesto. As EULAR writes in the *European Patient Group Directory 2008*: “The EULAR’s PARE patient associations are promoting the development of user-led organisations on a national, as well as an international, level”



In future?

# T he power of one

## Social entrepreneurs

The idea that individuals can inspire change in society seems to be thousands of years old. Such aspirationalists—ordinary people with innovative solutions to society’s most pressing social problems—were hailed as ‘social entrepreneurs’ in the 1960s and 1970s.

Bill Drayton is a classic social entrepreneur working for change. Formerly with the management consultancy McKinsey, he went on to found the Calcutta, India-based Ashoka in the early 1980s. Ashoka identifies and invests in social entrepreneurs that suit the organisation’s ideals (which includes the promotion of public health). Mr Drayton insists that almost 90% of the 2,000 or so entrepreneurs Ashoka has backed have successfully transmitted their ideas to other organisations, and almost 60% have had an impact on national policy.

## Patient activists

Patient activists like Geissler, Juklerod, López-Muñoz y Larraz, Rosenfeld, and Tookey [see pages 13 and 37-38], may not be social entrepreneurs in the strict sense of the term. They are inspired by a cause, rather than by innovative processes for effecting change. A loved one’s death; injustice at the hands of health providers; the sense of hopelessness that follows a diagnosis—these are all causes that have prompted hundreds of thousands (or even millions) of people to create their own self-help or advocacy groups. Their determination and dedication, and that of fellow patient activists, have gone some way towards stimulating a transformation in society. Patient activism is being recognised as a new, unique movement, and one that could have a profound impact on the way healthcare is run.

As the types of advocacy organisations proliferate, they ‘militate’ patients. For the sake of argument, we describe these radicals patients activists.

The term activism was first coined back in the early 20th century to describe political protestors. Today, the word can refer to anybody who stands up for a wrongdoing—at work, school, or on a broader policymaking platform.

Activists also like to effect change by influencing the people closest to them. This latter type of activity is sometimes referred to as grassroots activism. Patient activism encompasses all of these definitions.

## Now a movement

The numbers of patient activists (and groups they form) have gained sufficient weight and influence to constitute a movement. Supported by Internet technologies, a large body of volunteers, and a greater sense of individual worth, the patient movement is evolving rapidly.

In place of individuals acting in isolation is a community of health advocates, meeting regularly at conferences, and exchanging ideas. And, as

## **Pan-European groups at work**

*[as described in the European Patient Group Directory 2008]*

“Amsterdam-based AIDS Action Europe is a pan-European partnership of non-governmental organisations (NGOs). We aim to create a more effective response to the HIV/AIDS epidemics in Europe and its neighbouring countries.”

“Brussels-based Autism-Europe [A-E] wants to change perceptions, practice, and policy in order to guarantee equal access to high-quality services and treatment in the European Union for people with dementia (and their carers).”

“The Riemerling, Germany-based ECPC [European Cancer Patient Coalition] is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups (from the major to the rarer cancers). Nothing about us without us!”

“The Helensburgh, Scotland-based European Dystonia Federation [EDF] acts in a co-ordinating role for its members, and deals with people, organisations, and aspects of dystonia advocacy not accessible to national groups.”

“The St Denis, France-based International Union for Health Promotion and Education (IUHPE) European Region strives to solve challenges concerning health promotion in Europe.”

“Worcestershire, England-based Rett Syndrome Europe aims to represent the interests of people with Rett syndrome (and their families) throughout Europe, supporting them by promoting research, sharing knowledge, and increasing awareness of their health, educational, and social needs.”

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groups of patients get to know one another, organisations have coalesced, been absorbed into larger umbrella organisations, and formed new partnerships with other stakeholders interested in healthcare (even industry). All these activities are occurring at a regional, national, and international levels.

The outcome of these linkages is a vast flexible network, through which ordinary people have the potential to express their wants and needs at the

highest of political levels. Infighting, political differences, and fragmentation have prevented these networks from functioning to their full potential. Nonetheless, the foundations of forceful and effective patient activism at the grassroots have been laid. And, as the case studies throughout this report show, the impact of patient activism upon healthcare systems is already being felt.

—end—

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*HSCNEWS INTERNATIONAL*  
February 2008

PUBLISHED BY:  
PATIENTVIEW  
WOODHOUSE PLACE  
UPPER WOODHOUSE  
KNIGHTON  
POWYS, LD7 1NG  
WALES

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