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Plus
Members News, Publications, and Letters

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Healthcare in 2020: health campaigners' vision of the future

“

Technology is altering the way that modern medicine is practiced. In the early days (say, the 1950s), 'best practice' was regarded as the gold standard for high-quality care. At that time, diagnosis and treatment promised to improve survival rates. But today's developments in the field of genetics, information technologies, and nanotechnology are enforcing a more individualised approach to healthcare—and often outside the hospital setting. Concepts such as 'the average patient' are now viewed as outdated. And standards within modern medical systems are measured by different parameters, including: patient access to the best-available treatments and to non-institutionalised care; compliance with treatments; and, even—patient choice.

Inevitably, healthcare systems are having to address the new challenges posed by medical scientific advancement—and, more specifically, by the rise of user-centric healthcare, self-determination, and patient empowerment. The trend towards consumer-driven healthcare is already here. Today's patients conduct personal research, hoping to find out more about their own medical conditions. Health tourism surges, with patients travelling far and wide to get the best-possible or cheapest medicine. The tendency is bound to continue, given the low satisfaction rates with healthcare systems reported by patients and the public.

One thing is certain. Attitudes, systems, and policies will all change in European healthcare over the next decades. What Health Consumer Powerhouse is also seeking to discover is: how will such renovation occur?

”

—*EU Health Consumerism Policy 2020*, a draft report due to be published later in 2006 by Health Consumer Powerhouse (HCP). HCP is a pan-European research-oriented think tank based in Brussels and Stockholm.

HOW ADVOCATES SEE THE FUTURE OF HEALTHCARE

To discover what European healthcare advocates think about three important subjects—the advent of new healthcare technologies; the move towards more consumer-friendly healthcare services; and the consequences of both for healthcare policy—HCP invited PatientView [publisher of *HSCNews International*] to conduct a survey of health campaigning groups in European Union Member States.

This survey, entitled 'Health Consumerism 2020', took place between November-December 2005. Over 130 responses were received from 24 of the 25 EU Member States (no responses were returned from Malta). The preliminary results of the survey can be found in this issue of *HSCNews*. HCP is scheduled to publish a full survey report, *EU Health Consumerism Policy 2020*, later in 2006. [HCP's administrative costs for the project were covered by an unrestricted educational grant from Baxter World Trade.]

ARE EUROPE'S HEALTHCARE SYSTEMS USER FRIENDLY?

Health Consumer Powerhouse employs what it describes as a 'EuroHealth Consumer Index', a tool that aims to measure the user-friendliness of national healthcare systems. In June 2005, HCP conducted its first pilot test of the Index across 12 European nations. The 2005 EuroHealth Consumer Index found:

- Only one European country out of 12 offers a publicly-available quality ranking of healthcare providers.
- Two out of three national healthcare systems take longer than three weeks to initiate treatment of cancer.
 - Four out of the 12 systems offer patients direct access to specialists.
- Only four out of the 12 offer patients the right to a second opinion.
- Only four out of the 12 offer patients the ownership of their medical records.
 - Only six out of the 12 offer patients the possibility of paying out of pocket for better care.

ABOUT THE 'HEALTH CONSUMERISM 2020' SURVEY OF HEALTH CAMPAIGNERS

The survey asked health campaigners how four of today's healthcare phenomena might present themselves in 2020. These four forces—essentially by-products of the current technologically-intensive period in the history of modern medicine—are:

- ▶ **Greater patient mobility and information-hungry patients.** More patients travel to places where they know they can get higher-quality care and treatments. Patients actively seek out medical information. Both phenomena have occurred largely because cash-strapped healthcare systems are unable to offer all the healthcare services and treatments that are available internationally—to the dissatisfaction of patients.
- ▶ **A patient requirement for ownership of personal medical data** is a prominent topic of discussion in policymaking circles now that medicine is becoming increasingly digitised, and personal medical data more widely obtainable.
- ▶ **Patient demands for access to new prescription medicines.** These are expected to multiply as biotechnology gradually begins to deliver.

HCP also quizzed health campaigners about their overall vision of healthcare in 2020.

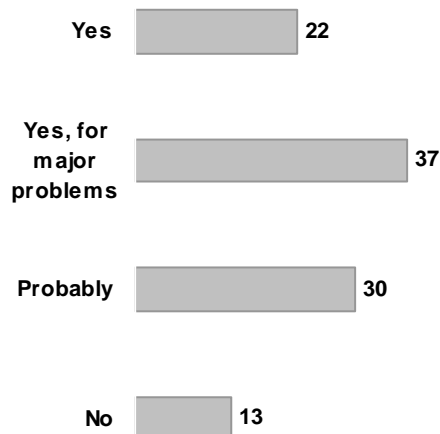
PATIENT MOBILITY

HCP's draft version of the *EU Health Consumerism Policy 2020* report maintains that current dissatisfaction with the standards and availability of healthcare services is causing patient mobility in Europe to increase.

Patient waiting times for surgery or care are a serious problem today, states HCP—even in countries that pride themselves on offering relatively high-quality care (such as Sweden or the Netherlands). A major predicament in other countries (particularly Poland, or even France) are low levels of access to new medicines.

HCP argues: "Obviously, not all countries can be world-leading in all specialities. Depending on the disease, patients might find more advanced methods of treatment abroad. Lower costs are also a factor that is slowly becoming an issue for patients—especially if they normally have to pay significant out-of-pocket sums for their treatment".

**Patient mobility:
normal practice in 2020?**
% of respondents [total=132]



Source: Health Consumer Powerhouse, 2006

What the survey has found

Almost 60% of the health advocates responding to the survey appear to concur with HCP's view that patient populations will be far more mobile in 2020. A further 30% of the respondents think that patients in their country will regard travelling long distances and staying overnight to receive their healthcare (whether abroad, or within the home country) as an entirely normal practice in 2020.

Respondents believe that the two factors most likely to convince patients to travel to another country for healthcare in 2020 will be a desire to receive higher-quality and/or otherwise-unavailable services. Some 70% judge that patients "will want access to interventions that are more technologically advanced than those in the home country". And 60% suspect that "the patient will want to access doctors or hospitals with a better reputation that those at home."

THE NETHERLANDS-BASED UMBRELLA GROUP STICHTING HOOFD HART EN VATEN (SHHV), WHICH REPRESENTS THE INTERESTS OF PATIENTS WITH DISEASES OF THE HEART AND BLOOD, TOLD THE SURVEY: "PEOPLE WITH A RARE DISEASE SOMETIMES WANT TO TRAVEL ABROAD FOR BETTER HEALTHCARE."

Implications

HCP's draft report contends that the increase in patient mobility will generate the following social and policy dilemmas:

- ▶ The fragmented structure of the EU means that populations remain nationally, rather than internationally, focused—a fact notably true in healthcare. Increased patient mobility may encourage citizens to feel side-lined by their own national healthcare systems if those same systems develop a taste for making money by treating wealthy foreigners. HCP makes the point: "Each country's citizens do not necessarily regard themselves as Europeans when it comes to healthcare. That might be why people are not prepared to give patients from neighbouring countries access to their 'own' healthcare institutions". A respondent from a UK-based cancer patient organisation agrees, and tells the survey: "Natives should be given treatment in their own country before it is offered to others from abroad".
- ▶ Patients will inevitably seek out information on the quality of foreign care (and the skills of foreign healthcare professionals) if they feel dissatisfied with the treatment provided in the home country. The trend will impose greater transparency and accountability on the healthcare systems of all EU Member States.
- ▶ Patient mobility will reveal cross-national inequities in healthcare throughout the EU. HCP insists that governments will then be required to answer tough questions from their electorates, such as: "Are you ready to let people die while waiting for a slow regulatory process to approve a new life-saving drug?"

PATIENT INFORMATION

Studies of patients by the Stockholm Network (a London-based European network of think tanks) have produced an interesting finding: patients believe that the quality of healthcare can be radically enhanced if the substance and quantity of information made available to them is improved.

INFORMATION ON TREATMENTS IN 2020

"I think that more information will be available. Which is good—but patients will still need to seek the GP for minor ailments. More education will be needed regarding overuse of antibiotics, herbal remedies for colds and flu, etc"—an executive from a UK patient organisation.

"A huge mistrust exists between consumers and government. Therefore, due to this, people will seek independent bodies to get their information, or will look for information from people they trust"—a Netherlands group that specialises in rare blood disorders.

"The media—a fast-developing way for patients to access information"—the UK-based National Society for Epilepsy.

"All options!"—the chief executive of the Nierpatiënten Vereniging Nederland (NVN) and the Munich-based European Kidney Patients' Federation (CEAPIR).

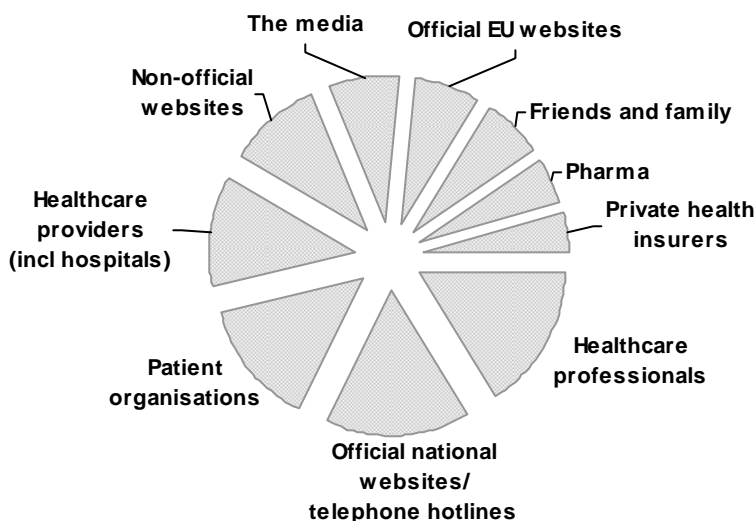
HCP emphasises the importance of information. “The amount and the sources of information are increasing, and at a continuously faster speed”, comments the *EU Health Consumerism Policy 2020* report. “New technology is being invented, and, since healthcare is a fundamental need, it seems always to be one of the first things the technology is used for. Hence, banning certain types of information will be of no use, since an active search will turn up the information anyway. The information is easily accessible. The only question is: how to ensure its quality?” HCP continues:

“With English gradually becoming Europe’s primary language, Europeans are already digesting everything published in the US. Patients know that they have to devote time to researching their illness and treatments if they are to receive the best-possible care.”

What the survey has found

Most health campaigners responding to the survey anticipate that information on treatment and treatment options in 2020 will come from official sources, such as

Where do you (or the people your organisation represents) believe that patients in your country will find information about treatments and treatment options (including alternative medicines) in 2020? % of respondents [total = 132]



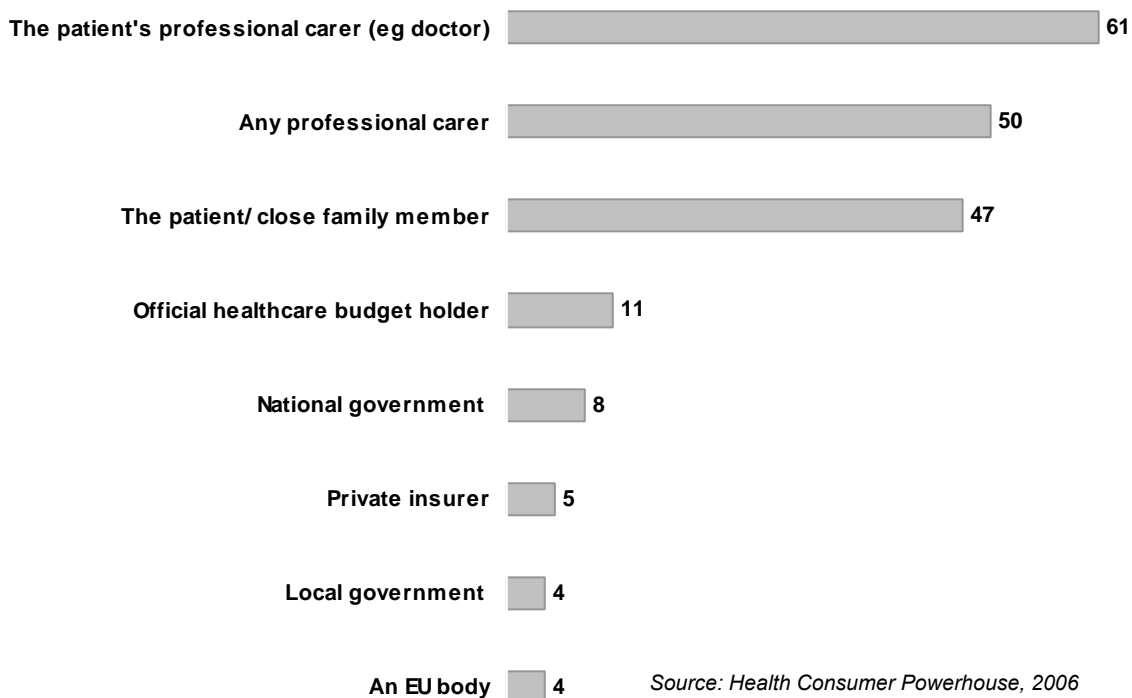
Source: Health Consumer Powerhouse, 2006

national government, trained professionals (pharmacists, doctors, nurses, etc), or healthcare providers. However, a significant number of the respondents also expect that non-official websites, the media, pharmaceutical companies, health insurers, and even their own organisations will be major suppliers of such information in 2020 [see chart on page 26].

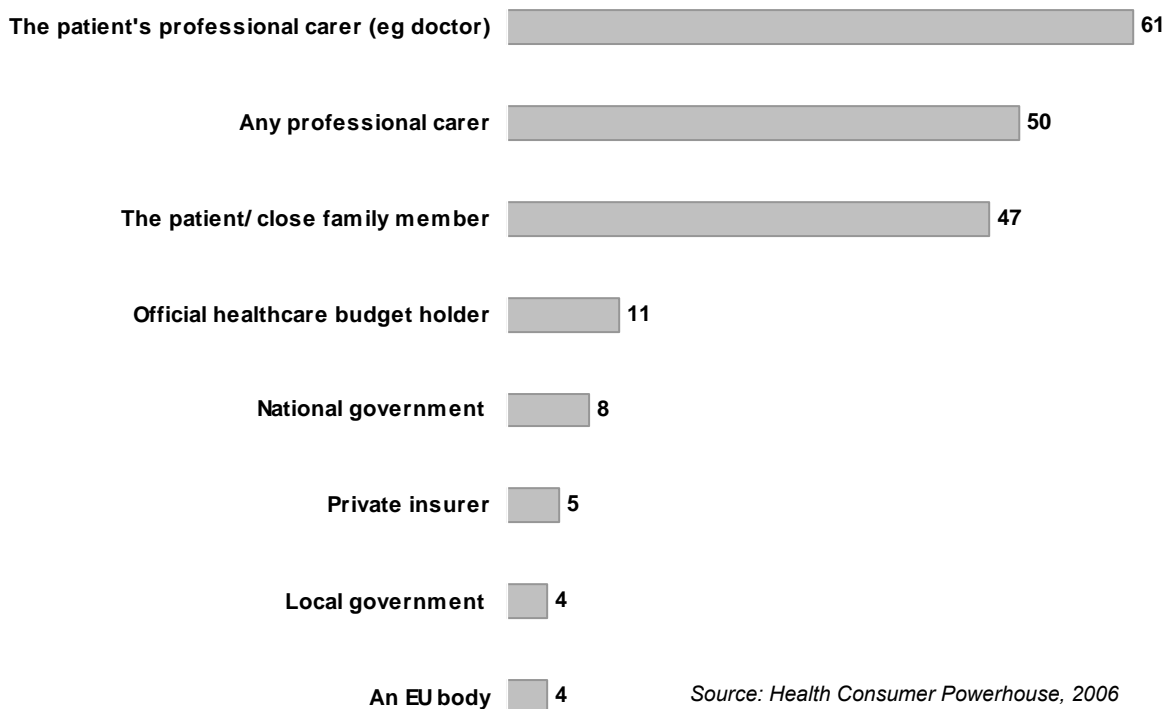
ACCESS TO, AND OWNERSHIP OF, MEDICAL RECORDS

Governments worldwide are throwing fortunes at information and communication technologies (ICT) in an effort to wire up all the fragmented parts of healthcare. The aim is to improve efficiencies, reduce duplication, and minimise medical error. At the heart of the new e-healthcare systems lies the electronic health record (EHR), containing all medical information

Who do you (or the people your organisation represents) believe will be responsible for managing the content of patients' medical records in your country by 2020?
 % of respondents [total = 132]



By 2020, who in your country will probably own (as opposed to manage) the patient's medical record? % of respondents [total = 132]



Source: Health Consumer Powerhouse, 2006

relevant to a particular patient. Patients, nonetheless, are wary of ICT. They worry whether the safeguards put in place are sufficient to protect their privacy and the confidentiality of personal medical data.

What the survey has found

The HCP-commissioned survey asked

patient groups and other health campaigners about both the management and the ownership of EHRs. HCP argues in its draft report that the responses to the question show a lack of agreement among groups as to where the overall responsibility for a patient's medical record will lie in 2020.

Just over 61% of the respondents suppose that the patient's doctor will be

responsible. But half also think that any professional carer (or the patients themselves) could hold the same function. Similar results were obtained regarding ownership of medical records.

The overall consensus from respondents appears to be that management and ownership should be the prerogative of the patient—but that, in all likelihood, the public will be denied the right.

ACCESS TO NEW PRESCRIPTION MEDICINES

One in three Europeans will develop chronic disease. An absence of medical cures mean that these patients have to learn to live with the pain and suffering from their illnesses. Biotechnology and other genetic technologies promise some future respite from crippling medical conditions. But, in an attempt to curb the high costs involved, regulators in many European countries are proving hesitant to approve (or authorise payment for) new treatments.

A report entitled *A Pan-European Comparison of Patient Access to Cancer Drugs*, published in September 2005 by the Stockholm-based Karolinska Institute, looked at the ability of cancer patients across Europe to access new, effective medicines. The study highlighted significant national variations. It found that cancer patients living in Austria, Spain and Switzerland can count on good and timely access to novel cancer therapies. By contrast, cancer patients in the Czech Republic, Hungary, Norway, Poland, and the UK will, as often as not, experience delays in their access to the same drugs.

What the survey has found

While 81% of the health advocates responding to the HCP survey maintain that patients in their country would continue to obtain their prescription medicines via the pharmacist in 2020, a significant percentage—more than one third—are sure that patients 14 or 15 years hence could also be getting

2020 AND MEDICAL RECORDS

"Probably anyone other than the patients themselves. Yes, there is a note of sarcasm here!"—health advocate from a UK organisation representing the interests of older people.

"I hope option A.) and B.) [The patient's individual professional carer (the 'family' doctor], I but fear that more likely will be options E.), F.), G.), and H.) [local government; national government; a European Union body; a private health insurance company]"—Parents of Autistic Spectrum Disorder Adults, Edinburgh (PASDA).

"Possibly a rights ban on option H.) [a private health insurance company], resulting in a more consumer-oriented system"—RehabCare, Ireland.

"Patients are taking more interest in their health. In the future, they will want to shop for the best care. This will mean carrying details of their health history and treatment received, along with medications prescribed"—an English health advocate.

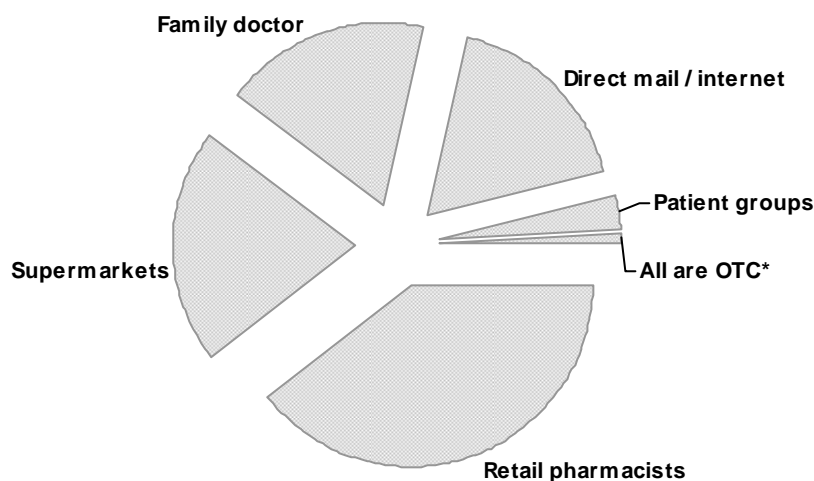
"Suffice to say that we all walk a thin line here. The patient should always make the final decision"—a Finnish patient group.

prescription medicines directly from the family doctor, from supermarkets, from direct mail, or over the Internet.

HCP's draft report suggests that patients (and customers) who are used to obtaining information on treatments and treatment options will probably start shopping around for their prescription medicines. The Scottish Patients' Association affirms the likelihood of the trend, stressing, though, that "medicines must be checked as suitable, and not as endangering to the patient".

Respondents' comments indicate, as well, that patients will continue to value professional advice. One UK health advocate notes: "I think that more medicine should be available over the counter. But a pharmacist should be on hand to advise. Patients with long-term and chronic conditions should be reviewed by a medical professional, with their health records present".

Where do you (or the people your organisation represents) believe that patients in your country will obtain prescription medicines by 2020? % of respondents [total = 132]



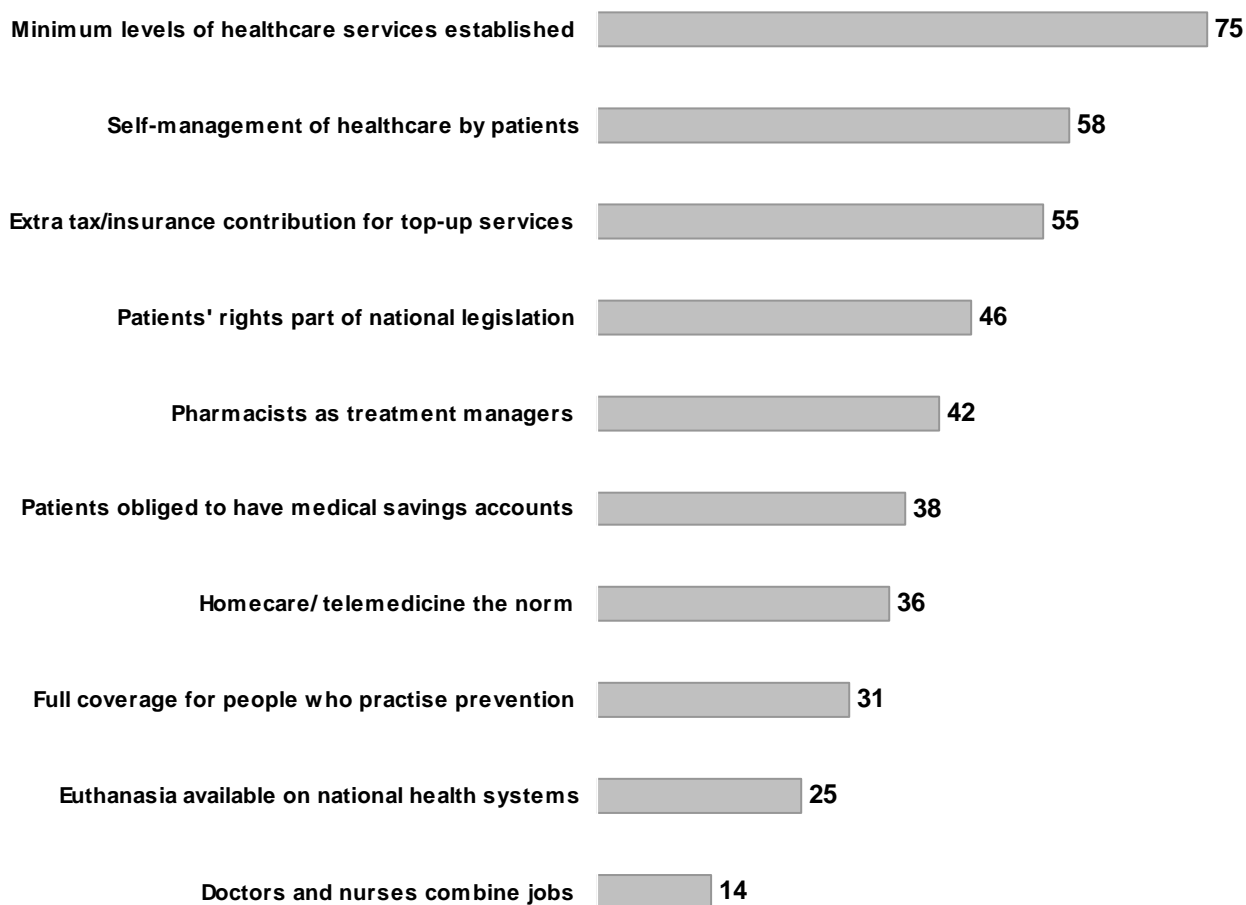
* Over-the-counter medicines

Source: Health Consumer Powerhouse, 2006

FUTURE HEALTHCARE SYSTEMS

Do you (or the people your organisation represents) believe that any of the following will have come true within your country's healthcare systems by 2020?

% of respondents [total = 132]



Source: Health Consumer Powerhouse, 2006

Across Europe, several prominent patient and civic organisations are campaigning for an EU constitution for patients—or, more specifically, for regulations that establish a basic set of patients' rights. The groups also want those rights to be policed and enforced at national level.

As one Dutch survey participant from the Netherlands recommends: "All governments need to change their attitude to legislation. At the moment, there is so much legislation that consumers do not know WHAT their rights are. Brussels is too far away. Each country needs to have legislation from Brussels on how to win the trust back from voters. One of the most frustrating problems with legislation is that if a country doesn't adhere to the rules, there is no follow-up—and this includes not only the governments themselves, but also Brussels."

What the survey has found

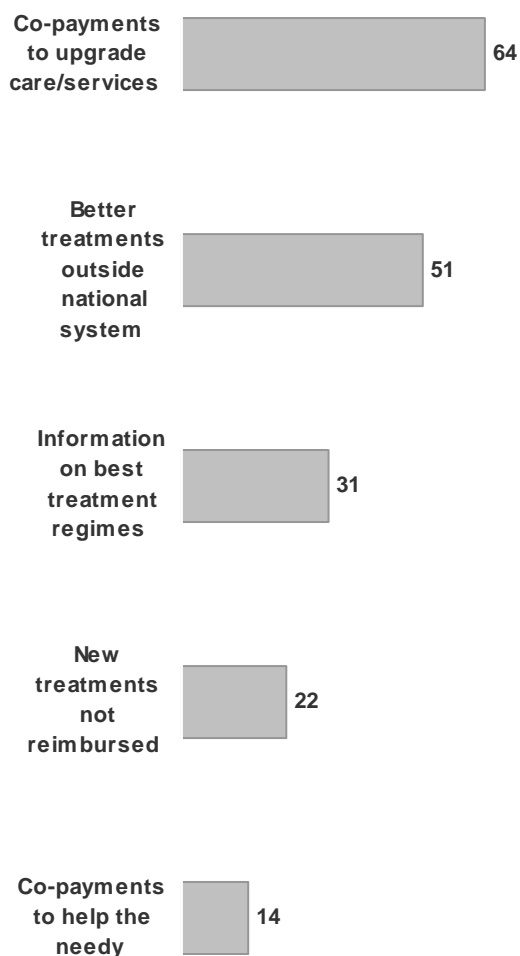
Three quarters of the health advocates responding to the HCP survey declare a belief that their national healthcare system will have established a minimum set of standards for healthcare services by 2020.

Respondents also conjecture that the patients of 2020 will be more actively engaged in the management of their own healthcare than their predecessors were in 2005/2006—if only to keep personal, out-of-pocket expenditure on healthcare to a minimum [see figure on previous page].

Continued on page 34

Will the average patient in your country readily pay for any of the following items out of pocket by 2020?

% of respondents [total=132]



Source: Health Consumer Powerhouse, 2006

THE EU AND HEALTHCARE

The EU's responsibility for healthcare is limited by article 152 of the EC Treaty (2002), which allows the EU to legislate only on issues of blood safety, organs, products of human origin, and phytosanitary and veterinary health. Any harmonising legislation in the area of public health is strictly limited by the notion of 'subsidiarity'—the EU term for not obstructing Member States' national responsibilities. All liability for the provision of healthcare services falls entirely with individual Member countries. The EU may only complement national policies in relation to improving public health, preventing human illness and diseases, and reducing sources of danger to human health. That said, EU institutions are increasingly being drawn into healthcare matters—including healthcare provision—in four main areas:

■ PATIENT MOBILITY

European patients are now afforded the freedom to move between Member States in search of healthcare. Healthcare providers, the European Commission deems, ought to be allowed to impart their services to all EU citizens. Such a right can, of course, be difficult for patients to apply, unless they can access information about the quality and suitability of the available treatment—and then learn how to achieve payment from their national healthcare system or health insurer.

■ PATIENT SAFETY

This topic is one of seven key issues on the agenda of an EU High-Level Group on Health Services and Medical Care (the Group is exploring the potential for cross-border collaboration on national health policies). Other matters on the Group's agenda: cross-border healthcare purchasing and provision; recruitment, quality assurance, and migration of health professionals; development of European centres of reference (for instance, for conditions requiring specialised care and a limited number of patients); assessment of health informatics technology; an overall health information strategy to address the availability of e-health services; and impact assessment of other EU policies on health. Some of these considerations will have a bearing upon patients' rights.

■ HEALTH AND CONSUMER PROTECTION

This subject is now the focus of an EU 'action programme'—a proposal from the Commission for EU action in the fields of health and consumer protection during 2007-2013.

■ RESEARCH

Framework Programme on Research (FP7) is a policy document that will dictate EU expenditure on research for the years 2007-2013. But, except in a few exceptional cases, the Commission is reluctant to play a frontline role tackling specific disease areas—which it still sees as a matter for Member States.

Continued from page 32

According to nearly two thirds of the survey's respondents, the people of 2020 will be willing to make supplementary co-payments to upgrade the care or services supplied by their national healthcare systems (receiving, perhaps, a private room in a hospital, or fast-track access that jumps waiting lists). Half of the patients of 2020 will be ready to pay for better treatments than those offered by their national health systems [see figure on page 32].

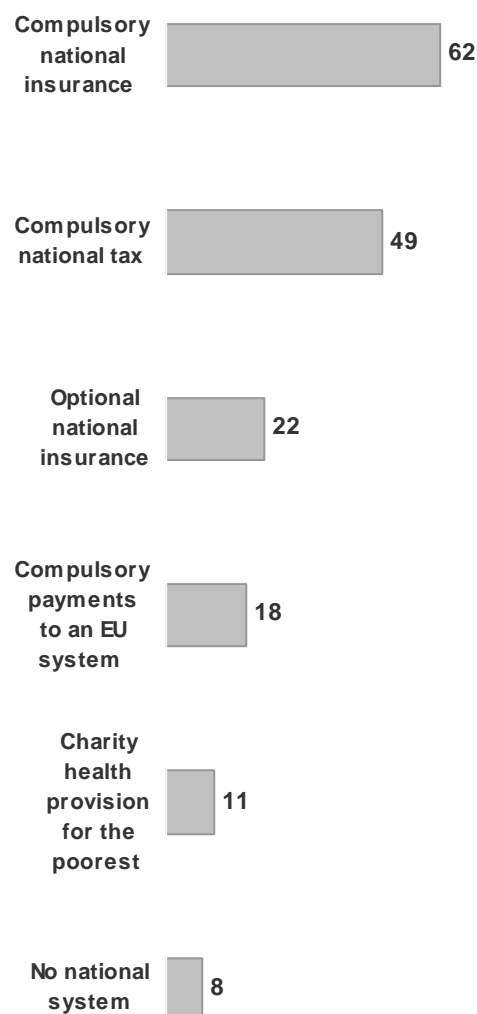
A positive vista?

Despite some anticipated consumer-oriented changes in healthcare systems, the majority of health advocates firmly argue that current payment systems for national healthcare systems will still prevail in Europe in 2020—partly because the continent's patients remain wedded to traditional national health systems founded on principles of social solidarity.

But survey respondents also submit that patients and the public are not entirely happy with every aspect of the administration of current healthcare systems. Some 60% of the respondents indicate that quality issues will continue to be set by national ministries of health and their agencies, rather than by users or those with vested interests in the medical outcomes—a situation that many of the survey participants found disturbing.

Which of the following systems will probably be paying for the major part of the healthcare costs in your country by 2020?

% of respondents [total=132]



Source: Health Consumer Powerhouse, 2006

"We think that the main decisions will be made by governments which don't have an idea about healthcare. Reducing costs is more important to them. We are now actually seeing this process in the Netherlands. Health professionals have little influence, except the groups which are 'in' with the government. We have been fighting for 15 years for a prevention programme. 80% of our members feel that their rights to know about their inherited illness have been waived. The government is still undecided. Human rights are therefore also waived", writes a patient organisation from the Netherlands representing the interests of patients with blood disorders.

"This [central control] is what I believe may happen", cautions one English health advocate, adding, "I fervently do not want it to happen".

The Cyprus-based Committee for the Protection of Rights of People with a Mental Handicap is also far from hopeful: "Please note the following regarding my responses. So far, all health issues in Cyprus have been considered/ managed from the perspective of doctors and policymakers. The public is not aware of the phrase 'empowerment of the patient'. The proposed National Health Scheme that has been enacted in 2001 is based on the policy of patients being subjected to paternalism and management by doctors. Therefore, questions 1.) to 11.) are answered with pessimism (low expectations)".

CONCLUSION

The findings of the November-December 2005 Health Consumer Powerhouse survey of European health campaigners show tensions within established state-controlled national healthcare systems—at a time when these same systems are being urged to adopt more user-centric procedures (a move that is, in fact, encouraged by governments). HCP articulates this tension in its draft report as a push towards individualised care (helped on by technology) within systems that are only equipped to deal with "average patients". The HCP draft report remarks that, as medicine and treatment plans are adapted to the physical and genetic profiles of individual patients (and to their cultural backgrounds), national healthcare systems that suit all will be rare.

PATIENTS TOP UP OR NOT?

In Germany, the US drug company Pfizer decided not to accord with demands made by the country's regulators and reduce the price of its cholesterol-lowering agent, Lipitor. In January 2005, Pfizer challenged the normal procedure by offering the drug through the healthcare system if patients were willing to pay the extra out of pocket. Pfizer also created partnership programmes for low-income users. But, for this treatment, at least, German consumers refused to pay up.

The city of Stockholm, Sweden, has a co-payment system for emergency visits to hospitals. The price is SEK 140 [US\$20; Euros 15] for children, and SEK 260 [US\$36; Euros 28] for adults.

Source: Health Consumer Powerhouse, 2006.

The HCP document insists that policymakers have failed to recognise the extent and potential impact of the consumer healthcare movement. By way of example, the organisation notes that Maria Rauch-Kallat, Austria's Federal Minister of Health and Women (and who currently holds the presidency of the EU Health Council), did not mention consumers and their needs in her contribution to *2050: a Health Odyssey*. This report, published on February 2nd 2006 by Brussels-based Health First Europe, is a collection of essays that hopes to encourage reflection and dialogue on the future of European healthcare.

A healthcare model for the future?

But what sort of healthcare systems could accommodate both the free-market concepts of consumerism and the principles of solidarity? In *2050: a Health Odyssey*, David Byrne, European Commissioner for Health and Consumer Protection, 1999-2004, insisted that the future of public health will be characterised by global co-operation, global governance, and global partnership. The European Commission interprets that to mean greater EU intervention in health matters.

It is an interpretation, however, that HCP does not share. The organisation declares, instead, that the consumer movement has a powerful influence upon healthcare—so much so that every European citizen will almost certainly have to shoulder much of the responsibility for individual healthcare. The state protection afforded to sick citizens, predicts HCP, will be a solid legal framework that ensures patients have access to transparent and honest information, gain full charge of their medical records, and possess the freedom to cross national borders to obtain the best-possible care. In time, HCP sees countries specialising in specific medical expertise and attracting the appropriate health professionals, whatever their nationality. Globally-applicable certification standards for healthcare providers should provide instantly-recognisable guarantees of quality, HCP forecasts.

HCP concludes *EU Health Consumerism Policy 2020* by calling for the drafting of an EU health consumer policy oriented towards 2020, and designed to take into account changes in tomorrow's healthcare.

MORE SELF-MANAGEMENT

"Patients, if given the skills, can do a great deal to look after themselves. Attitudes to healthcare need to change—both among healthcare practitioners and patients. Patients must understand that the National Health Service will support them in their care, but also realise that they are primarily responsible for ensuring that they look after themselves, and self care to improve their outcome (especially with long-term conditions)"
—individual from an English local diabetes group.

"Patients will profit from regular exercising, having optimal weight, etc, with decreased health insurance fees"—executive from the Slovak League Against Hypertension.

"I believe that the government will exert pressure on people to cover certain aspects of their healthcare. The above boxes ticked are not my opinion of what should happen. I feel that the number of boxes should increase, and that people should be able to buy their own health checks and medicines over the counter for common ailments"—English social care manager.

HSCNEWS INVITES READERS TO SEND IN THEIR COMMENTS
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HEALTH and SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL

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WITH THE OPINIONS OF HEALTH ADVOCATES
—THEIR HOPES, THEIR FEARS, AND THEIR PLANS FOR THE FUTURE

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