



Health Consumer
Powerhouse



The Empowerment of the European Patient

Options and implications

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**The Empowerment of the European
Patient 2009**

– options and implications

Report

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Health Consumer Powerhouse

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Foreword: A time for rights and responsibilities

Exit the “grateful generation” of Europeans, taking doctors’ words for granted and trusting every hospital to be the best. Enter the “demanding generation” of active patients and health consumers, looking at healthcare with the same eyes as they watch all other services. This is a revolution of cultures.

In the aging Europe there is a growing need to involve patients and consumers in the healthcare processes, to balance demand to resources. It will be a matter of engagement in care decisions as well as financial matters. From this perspective the gap illustrated by our report is alarming. Expectations are not met, tools for user involvement are denied and a hierarchic healthcare system is maintained.

Some major impressions from this study are:

- Choice within healthcare still is far from what citizens and users expect; few Europeans have in practice the combination of legal rights and access to knowledge to make informed choices. This means that the systems tool-box still lacks communication with patients and consumers to improve delivery.
- The existence of financial incentives directed to the users and the standard of the national healthcare system generally seem to correspond.
- Patient empowerment is not necessarily costly. This is why middle-income countries are well represented in the upper segment of the Patient Empowerment Ranking. Patient opportunities are to a high degree a matter of political will; the power-play of today is not given.

There is a growing tension between the rights of the patient and her responsibilities. In this new era the top-down approach will have to leave together with hierarchy. The intricate balance between different interests more and more becomes a task for the empowered patient and consumer.

Healthcare is a strongly value-driven issue. Here the future of Europe will require a new mind-set, opening for the full engagement of care consumers. This report looks into the existing rights and options of European patients. A reality check, this study describes the conditions and the need for improvement. Where to find good examples for inspiration? Which are the implications on rights and responsibilities?

This study, like most other parts of the HCP work, is funded through unrestricted educational or development grants. We are happy to see Novartis SA supporting this report.

Johan Hjertqvist

President
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1. The essence of empowerment

Are European patients in an adequate position to ensure that they will receive the best care? Are the tools available to them fit for a modern society of information, choice and active involvement? Can the patient count on being able to navigate the healthcare landscape guarded by effective rights – or even like consumers in other areas of life?

Or are maybe these rights a mere reflection of a general political “democratisation” during the last century, not intentionally aiming to simplify citizens’ healthcare reality? Are patient and health consumer positions still too weak, or are they even made obsolete due to a lack of interest in driving co-operation towards modern healthcare systems?

Or to be short: is there a need to rethink patient and healthcare consumer rights?

The journey will not be easy. Every European healthcare system has evolved from a hierarchic model and was basically not designed for patient interaction, even less allowing for consumer empowerment. Even in the most progressive systems the transition has only come half-way.

So what is the European situation of today?

1.1 Healthcare a key matter

Health and healthcare are central issues to Europeans, but still care is not considered safe enough nor do citizens accept to seek care only where they are told to or referred by the doctor. When the European Commission polls its citizens regarding quality of life issues, this becomes evident. The October 2008 Eurobarometer indicates:

- “Health” was the asset most frequently associated with “happiness”.
- Responding to the question “What problem is right now of most concern to you personally?” healthcare was ranked the third most important matter.
- Almost four out of five EU citizens classify medical errors as an important problem in their country.
- One quarter of Europeans state that they have been directly affected by a medical error personally or in the family.
- A majority say they are willing to go to another EU country for healthcare.
- Four percent actually received medical treatment in another part of the EU.
- No less than 70 percent of the EU 27 population tends to believe that costs of healthcare treatment incurred elsewhere in the EU will be reimbursed by their own healthcare authority.

Another six-country survey¹ indicates that Europeans are ready to go abroad to have treatment: almost two out of three indicated such interest and an even larger share among younger people. The same study suggests there is a strong perceived relation between on one side access to information about your illness and on the other the standard of treatment; three

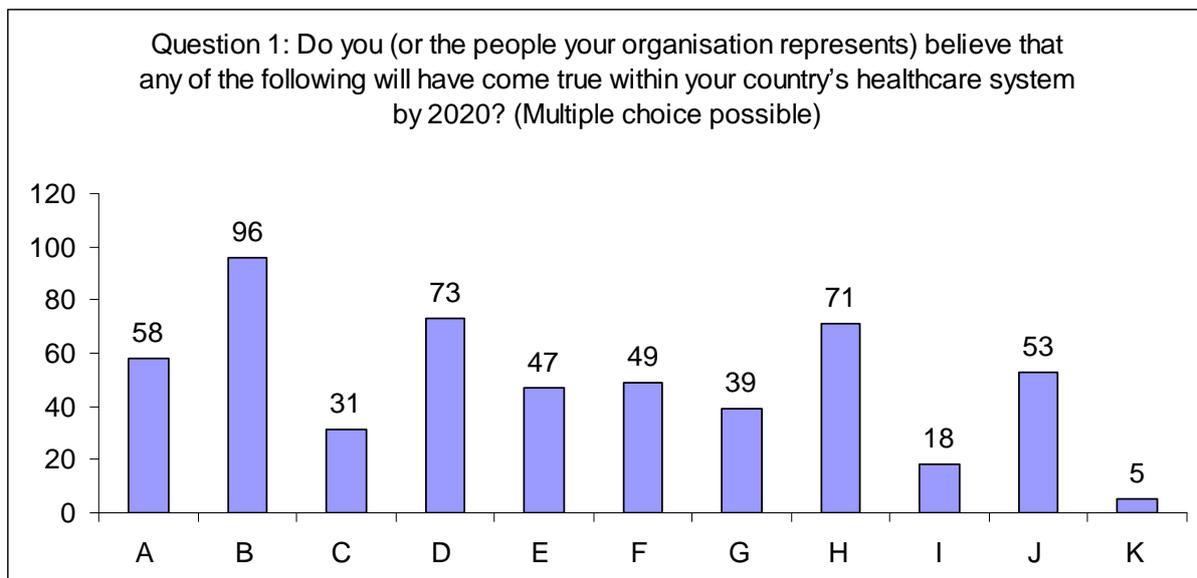
¹ Impatient for Change, Stockholm Network, 2004

out of four said that better information would improve the care given. Europeans clearly look upon healthcare information as an asset improving quality of life².

These are not the first pieces of research giving evidence to such health consumer empowerment values nor will they be the last. Healthcare needs to change and will fundamentally change as we grow to become more and more globalised and aware of new options and realities. Such forecasts were made by the study *The European Patient of the Future*³. HCP noticed similar trends in its own “2020 survey”⁴.

Interestingly, surveys from healthcare as well as from other strands of life seem to confirm the limited degree of trust in national authorities – and the EU level – to set the rules of the game. Perhaps patients become more inclined to take things into their own hands as they become aware of the problems with the healthcare system?

The 2020 HCP survey (including a number of patient advocates interviews performed by PatientView) provided food for thought, becoming an integrated part of HCP visions and values: that one should not expect “society” to take care of the weaknesses of the healthcare system but to prepare for action by patients, consumers and stakeholders to form the future. This is the view among polled patient advocates presented by the study:



- A.) **Patients' rights** are incorporated into national consumer rights' legislation.
- B.) Patients are guaranteed a **minimum level of healthcare services**.
- C.) Patients have the right to professional assistance if **they want to end their lives**.
- D.) To keep personal, out-of-pocket healthcare costs to a minimum, patients are **more actively engaged** in the management of their own healthcare than they were back in 2005.
- E.) Patients have access to a plentiful supply of **home care, telemedicine, and tests**.
- F.) Patients are obliged to maintain **medical savings accounts** to pay for their chronic care.

² Patients' right to information: a review of the regulatory and ethical framework. Casas et Parada, DENE Research Group, University of Barcelona, 1998

³ *The European Patient of the Future*, Coulter and Magee, 2003

⁴ The 2020 study, Health Consumer Powerhouse, 2004

- G.) If patients wish to be fully covered by insurance and/or national healthcare schemes, they must **consent to exercise regularly, stop smoking, and be vaccinated** (in accordance with government regulations).
- H.) Patients can **pay extra** insurance/tax if they want to access top-up services not automatically available from the national healthcare system.
- I.) Doctors and nurses have become merged into **a single category of professional healthcare provider**.
- J.) Pharmacists act as **treatment managers**, helping patients understand and choose the best treatment (in close co-operation with professional caregivers).
- K.) It depends.

These responses give signals about changing expectations: a minimum level of care reflecting worries about the sustainability of care with enlarged options for individual funding. Respondents within the European patient community expect a growing personal commitment regarding the financing and management of your own care but are not sure this will really force citizens to change life-style.

This attitude corresponds quite well with a fresh Swedish study⁵, reporting values among younger Swedish citizens. Consumer perspectives are on the march, increasing demand for care and empowerment. This very study forecasts growing restrictions regarding the access to healthcare at the same time as top-up solutions will become common in healthcare funding. In one of the strongest welfare states, the ground is shaking.

1.2 European equity?

There is huge variation of national legal frameworks policy attitudes across Europe; from actively supportive to just providing the most basic rights. The span in implementation is significant, from efficient to mere showcases. This condition reflects the current state of affairs as well as national democratic and cultural heritage. Within the European Union the situation of inequality causes significant problems. Commissioner Androulla Vassiliou has described the current situation explaining why these conditions are unsustainable⁶ :

“When you look across Europe, you see a huge health gap between countries and social groups. For example, there is a gap of 18 years in Healthy life years across the European Union between the best and the worst.

- *Is it acceptable that cerebro-vascular diseases kill 6 times more women in Romania than in France?*
- *Or that pneumonia kills 9 times more men in Slovakia than in Greece?*
- *Is this compatible with our humanitarian values?*

I believe the answer to all these questions is **no**.

The Commission has already made available €5 billion of the Structural Funds to help poorer regions invest in health. **But we will need to do more.**”

Expressing values of solidarity and equity, Commissioner Vassiliou stands on solid ground, though the interpretation might change in years to come. This cultural and political mindset has formed the European healthcare systems.

⁵ Opinion Hälsa, Kairos Future, Stockholm, 2009

⁶ Speech at the 7th European Business Summit, March 26 and 27 March 2009, Brussels

It is no surprise that there are few true financial incentives in the publicly organised and generally collectively funded healthcare systems. Such measures are contrary to what is perceived as European values. But around Europe patients can – given they have the resources – combine public and private care solutions. If they go fully or partially private, *e.g.* buying top-up insurance to get rid of user fees for appointments, or paying the full price to keep their patented medicines *et cetera*, they will have free choice of care. Such opportunities will probably grow, according to the forecasts above, and in the years to come can open for increased consumer engagement.

There is reluctance on the policy side towards offering advantages to people engaging in activities like prevention and life-style change. Rewarding healthy lifestyle with benefits such as lower health insurance premiums would very likely favour citizens with a good level of education and/or good financial means.

These conditions affect the design of national healthcare systems and restrict the existence of incentives for the patient to engage in prevention and self-management (though the providers of healthcare services might work under competition). As service provider reimbursement models are yet poorly developed for rewarding patient satisfaction and quality outcomes, the foundations for active choice among patients are weak. No more than three countries among the 31 ones included in this report offer a national provider catalogue supporting choice of hospital, and in a number of countries you do not have a free choice even if you can identify the best producers.

In Spain, to mention one country, the idea of choice within the National Health System has not yet impacted. There is a strong belief that the patient should turn to his local health clinic, where he can have a choice among the doctors in that clinic. Anybody wanting different options should better turn to private care. That means the patient has to carry the full cost; he cannot bring the public funding. There is still very little of public information about the clinics if you would like to compare or make own choices.⁷

As citizens ask not only for choice but also question the economic sustainability of healthcare there will be pressure for a stronger individual financial commitment. Traditional European values will clash with new economic realities. There will be a need for different solutions combining patient and consumer influence with sustainability.

Principles and reality

The principle of national sovereignty regarding healthcare policy and patient rights is sometimes seen as contradictory to the integration of the European healthcare market. The principle of subsidiarity is confronted by the pressure to equalise access and quality. But with the view that subsidiary means that decisions should be taken at the lowest possible level, this should not necessarily be an issue – not if this level means “patients”. The EU role would then be to protect the citizens when they exercise their rights – as with the consumer rights legislation.

The rights and conditions among the member countries do vary not only at the medical level or related to healthcare funding. The reality-check provided by the country ranking in this report makes clear the significant variations and inequalities, such as:

- With a handful of exceptions patients rights at the national level are fragmented and un-precise
- Regarding systematic information to patients and consumers Europe is a disaster area.

⁷ Interview with Jean Bernard, The Spanish Consumer Union, 2009

- Informal payments to the doctor as a condition for good access and care is common in more than half of the measured countries (not to be confused with ordinary, official co-payment in the form of user fees or insurance premiums).

Are these characteristics expressions of national strategies? Do the governments of Cyprus, Latvia and Portugal intentionally exclude patients from sharing the information in their medical records – or is this rather a part of a cultural heritage? Is the yet weak implementation of Internet or telephone help desk services a matter of how far the communications technology has impacted – or a conscious reluctance to open up?

In a country like the Czech Republic, as a representative of the CEE systems, access to medical records is an important asset of patients. To be able to share the MR information means a significant empowerment. From this the patient can build her own platform for discussion with healthcare providers. But even if you have the legal right, there has to be an understanding among doctors that opening the records is not a threat to the profession. Without convenient access to the record it is hard to drive a case of medical error or get an informed second opinion⁸.

The Patient Empowerment Report takes on the task of comparing and offering an overview of a number of patient qualities in healthcare (in practice often noticeable as inequalities) but as is easily understood, there are many more rules and rights to be examined to acquire the full picture. For practical reasons, the selection of indicators does not cover the full range of patient rights and opportunities. By picking a combination of patient rights with an indicative value we hope to comparatively reflect the patient empowerment situation. The report does not address functions such as waiting times, service level or quality of care – from the patient point of view key components of modern healthcare; such analysis are found in other HCP indexes⁹.

The key conclusions from earlier HCP work are still valid: patients in almost every European country lack the legal and practical capacity to fully interact with the healthcare system. This means that healthcare systems turn down the offering of a rewarding partnership with the users of healthcare, not exploiting this key source of experience. There are huge gaps between official statements and real life implementation of patients' rights.

1.3 National priorities

French patients – to pick just one example – on paper have far-reaching rights to participate in public decision-making, but the French patients' rights laws have rarely been implemented in real life (even if admittedly French patients can execute choice among doctors and care providers better than most other Europeans, due to culture and output of services). It looks as if the patient right law of 2002 here marks a significant improvement for French patients.

Portugal does not even try to give the impression that patients are empowered; with a low scoring in the Report ranking, the patient situation seems to be a political non-issue.

Spain performs almost as poorly even if more efforts are put into this area there. Sweden lands a mediocre position in this ranking partly due to the balance of power between the national government and healthcare regions, a balance which is effectively blocking significant progress when it comes to patient rights into binding legislation.

⁸ Interview with Jana Petrenko, head of the Czech Coalition for Health, 2009

⁹ Euro Health Consumer Index 2008, Euro Consumer Heart Index 2007, Euro Diabetes Care Index 2007; www.healthpowerhouse.com

Neighbouring Denmark – with a top score – again represents a different approach, with a central political decision to provide consumer information despite health regions not being overtly enthusiastic about the expansion of patient rights.

Some common patterns behind the situation in the respective country can be found. Not only those that might be expected: that there is a correlation between on one hand living standards, democratic tradition and openness of society and on the other well developed patient rights.

Strikingly, some new EU members from the CEE are doing well in this report, suggesting that a policy of patient empowerment is not only a reaction to the former Communist regime but could be used as a reform tool for society as well. Providing patients with significant rights should go hand in hand with the necessary reforms to alter the course into more market-inspired, insurance-based healthcare. Both to enhance the development but also to safeguard the citizens from potential negative side-effect while in a process of systems change.

As said, in most national systems there is a gap between rights on paper and in reality. Patient representatives often point to the nice legal words, proclaiming eternal human rights of patients, but without the implementation required to make the laws impact on public policy and the practical relations between patients and healthcare. At the end of the day patients' rights tend to prove weaker than budget restraints. There might be high policy ambitions but what is expressed "economic realities" often weigh more heavily.

There seems to be a general concern among patient groups that the present economic crisis will affect the patient position in a number of fields.

The right to access certain treatments may be clearly and unconditionally expressed – but meeting with budgetary restraints the law might have to give way. In a reform country like Estonia this threatens the situation of patients. In the present situation where every sixth Estonian now is unemployed of course there is a fear that the healthcare budget will be severely affected. When there is such a budgetary situation even well defined legal rights will be compromised. You can imagine that this will be a common pattern around Europe for the next few years¹⁰.

There are systems with well expressed rights but few or weak methods for individuals to take action if the rights are infringed. The Nordic no-fault malpractice insurance model is spreading only slowly, with Slovenia the single new applicant.

High entrance costs for taking legal action have a double negative effect since most people hesitate to initiate a legal procedure to ensure their rights¹¹. Remarkable cases, not the least in the European Court of Justice, show what power might emerge from the end of such a process. Patients' rights to cross border care and the access to various medical treatments have been expanded and established following on the Court's rulings.

In the many European countries where "informal payment" is expected, citizens need to take action themselves to make rights materialise. The existence of grey or black money in healthcare not only causes inequalities and a legal quagmire but in large parts of Europe also confuses the discussion about patient rights and responsibilities. Discussions around *e.g.* top-up solutions and co-payment strategies (and even basic co-payment like a certain, official user-fee per visit) from the beginning face an unnecessary uphill struggle.

When any expansion of co-payment, even to serve as incentive for risk-sharing or life-style change, tends to be interpreted as a limitation of social rights, the rights-versus-responsibility

¹⁰ Interview with Anne Veskimäe, the Estonian Patient Advocacy Association, 2009.

¹¹ The European Patient of the Future, Coulter and Magee, 2003

discussion is hindered. It complicates the development of new tools for information or evaluation. This issue needs to be recognized and managed.

1.4 Knowledge still dangerous

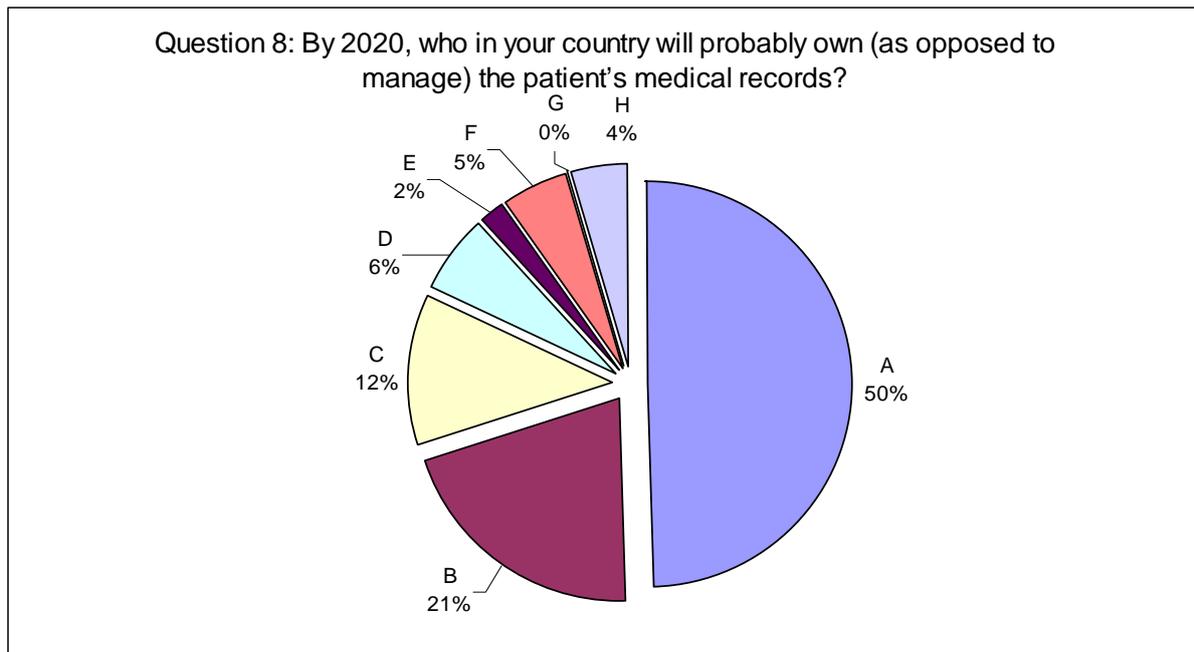
Are knowledge and experience among patients in practice welcomed by most healthcare systems around Europe? Noticeable is that rights to a second opinion or access to one's own medical record are in practice often categorised as a nuisance or complicating patient – doctor relations rather than a welcome opening for patients to engage in the treatment process and share their experience.

In every second European country it is found that the right to a second opinion is non-existent or infringed by legal un-clarity or a complicated process. In as many countries the right to access your own medical record is absent or significantly limited. Some might think that this is not an issue since the key source of information should be the professional. In background interviews with patient advocates they state that patients often hesitate to ask the doctor at risk of hurting the relation, as this kind of action can be perceived as mistrust or criticism. In some countries the only way to have a second opinion is to change your doctor – or even healthcare system, generally from public into private.

Again, these elementary rights supported by almost every political configuration are implemented slowly in the practical power-play of healthcare. But there is progress no doubt. It is nice to be able to put on record:

- In the first complete Euro Health Consumer Index (2006) ten out of 26 countries scored green on the right to a second opinion. 2008 – in the enlarged Index covering the 27 EU member systems (plus Switzerland and Norway as well as the EU candidate nations of Croatia and FYR Macedonia) – 14 of these scored green.
- 2006, patients could access their medical record without problems in 13 countries. 2008 the corresponding figure was 17. No dramatic progress but small steps ahead for mankind.
- 2006, no countries were found where patient organisations were effectively involved in the public decision-making while two years later no fewer than eight national systems scored green in this respect.

But from the HCP “2020 survey” it can be seen that expectations are higher. Patients believe that in the future, they will for example become the legal owners of medical records.



- A.) The patient (or the closest members of their family)
- B.) The patient's individual professional carer (the 'family' doctor)
- C.) Any professional carer responsible for the patient will have a share in such ownership
- D.) The official healthcare budget holder
- E.) Local government
- F.) The national government
- G.) A European Union body
- H.) A private health insurance company

And they are right that the sharing of information on equal base, between the individual and the system about the patient's case, is seldom routine and requests for access to information are often questioned or neglected. In practice doctors lack the time to sit down to explain and have a discussion. To patients with a long-term medical relation this is probably less of a problem, but to new-comers into the healthcare system or patients meeting different faces all the time, information quality is quite an issue.

Will the relevant information about the patient's conditions and therapy transfer safely to the doctor or the team taking over the case (or that of a demented mother or acutely ill child)? If a patient shifts from one insurer (or between public and private care) to another, will they be ready for her? Such questions make the present development in the EU of the right to communicate about treatment issues even more worrying.

1.5 The right of information under attack

There still is a general discrimination against patient and consumer influence over a key ingredient in modern healthcare: medication. In spite of the progress just mentioned, two out of three European countries still do not provide information about medicines in a fashion understandable to laypersons (what the report ranking calls "layman adapted pharmacopoeias"). Such open information sources mean that the patient himself can

investigate medication alternatives and learn about side-effects, as a base for discussion with healthcare staff or pharmacists.

Alarmingly the growth of better information in this respect is now threatened by the current proposal from the European Institutions that might very well prevent not only information from the industry but also from independent 3rd parties. And this attitude comes from the national level in the EU member states.

At this very moment, the Danish government pursues a case¹² in the European Court of Justice to make it illegal for an individual Danish GP to present information on his own website about medicines he prescribes himself! A Court approval of the claims would set the clock back many years and effectively put a ban on knowledge among patients when using modern communication methods.

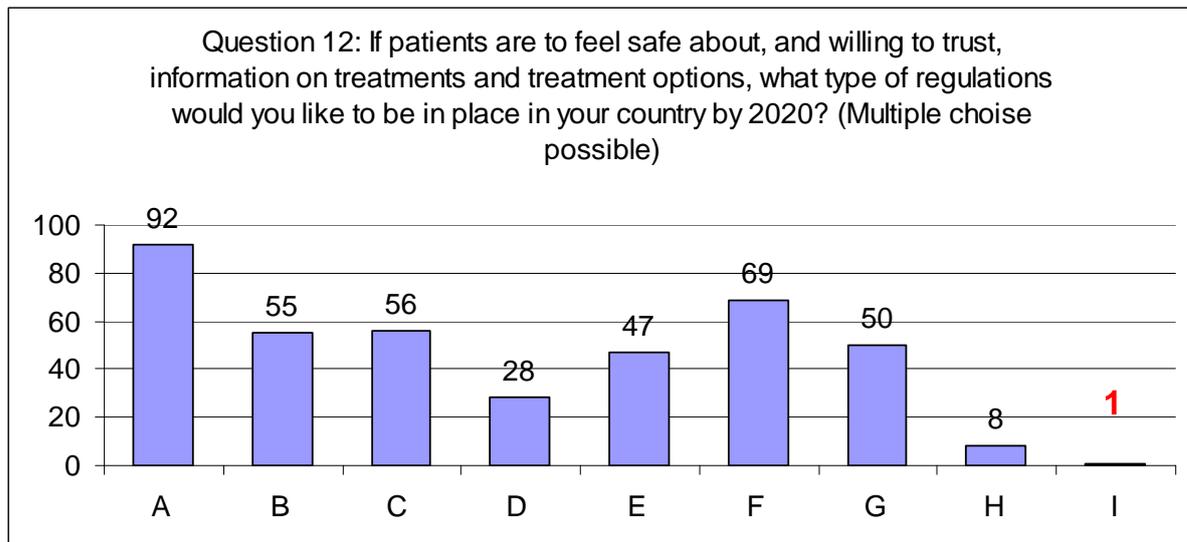
The European Commission plans for a proposal on information to patient would (is the HCP conclusion) mean a censorship on information about medicines by requiring pre-vetting by some kind of public authority. Though the policy level seems to think that patients would regard “official” public providers of information as the most reliable source, further examination suggests that individuals prefer a free flow of information where you can make your own pick. This is because the patients realise that while the pharmaceutical industry wants to make them use medicines to earn money, the government tries to save money. The truth about what patients need is somewhere in between and that they need to find out for themselves.

One of the EU countries with the strictest regulations on information about medicines is France. Sweden on the other hand has just implemented the directive banning direct-to-consumer drug advertising. Furthermore, Sweden still has a very liberal system when it comes to information on the Internet. Most pharmaceutical companies offer fully accessible information about diseases and therapies including their own products. A layman adopted pharmacopoeia (a book with all available drugs listed and explained) is since long sold to the Swedish public by the trade association for the pharmaceutical industry and is available on the Internet as well.

Still, according to the OECD Health Data 2008, Sweden spends USD 372 per capita on pharmaceuticals. France on the other hand spends USD 429 per capita (all figures in Purchasing Power Parity adjusted dollars; PPP\$). These differences exist despite the fact that drug prices in France are lower than in Sweden. France is basically one of the countries that have the highest per capita consumption of drugs in Europe. The assumption of access to information driving costs does hardly gain support from these statistics.

As found in the HCP 2020 survey what is needed is rather a base for an ISO certification or a similar arrangement regarding healthcare information. This is the “consumer-driven” approach: not putting a ban on certain information sources but ensuring the quality of information.

¹² <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2007:269:0035:0035:EN:PDF>



- A.) Quality labelling, such as environmental ISO certification of hospitals/clinics
- B.) EU guidelines
- C.) National advertising standards legislation
- D.) All information is pre-vetted by national government-appointed regulators
- E.) All information is approved by national government-appointed regulators
- F.) Policing by patient organizations
- G.) Policing by consumer organizations
- H.) The current situation is about right
- I.) By 2020, patients will be knowledgeable enough not to need safety assurances

The quality of information is a relevant consumer safety aspect. Websites and mailboxes are filled daily with information about diseases and cheap drugs. It seems strange that the stakeholders who produce and must take legal responsibility for the use of their products should be the only ones excluded from information around these very products.

Citizens of the new knowledge-based society will not accept to be classified as not of age regarding information about all the various components of therapies received: what therapies and medicines answer to my needs, how are they available, what are the risks of complications and are there alternative options?

The question is not whether we will see “an American system” in the EU but rather whether there will be a convergence between those the two big and more mature pharmaceutical markets. One thing is certain: as broken English is becoming if not the first so at least the second language among more and more of the EU citizens, they are already digesting everything published in the US. Today, access to knowledge is not a matter of money but of language skills.

HCP believes in a possible deal between these interests by the design of a “good information standard” that could be used for all healthcare information. Such a guideline should ideally be adopted also by US healthcare websites aimed at Europe.

1.6 Access still a critical issue

As shown by this report, access to services within reasonable time (or even within the time-frame promised by law or healthcare systems proclamations) is still far from guaranteed, in spite of significant investments in waiting list reduction in many countries. Some governments with chronic waiting-times problems now try to make waiting list transparency and competition among providers the tools to improve the situation, promising better reimbursement to providers offering sufficient access. Partly for this purpose, the UK is now transforming the NHS into a funding and purchasing umbrella and Sweden is under way to introduce far-reaching competition between primary care providers to improve access.

Hungary is an interesting example of how hospital performance data can be used as a strategic investment to drive choice with the purpose to affect hospital quality and access. To a government aiming to shake up the reform process it is a matter of setting the ball in play. Making patients and public aware of the existing variations in waiting times and quality outcomes can start a movement to reach a critical mass of more demanding consumers ready to make choices among providers. Powerful implementation generally requires reimbursement incentives, another controversial step.

Such an initiative attracting attention is the Hungarian Health Insurance Supervisory Authority, established in 2007 (<http://www.ebf.hu/index.php?m=0&l=en>). The task is to protect patient rights, registers information concerning the operation of health care institutions and the quality of health services. Zsombor Kovacs, the initiator and head of the authority, comments on the impact:

“The authority information website with performance data of hospitals has become popular but no secondary effects have become visible so far. It is too early to say if patients use the increasing transparency to make different kinds of decisions. The data set is based on international experiences and areas of consumer interest – issues like *delivery and birth, oncology, patient safety, patient rights and access to extra services.*”

The impact on reimbursement is a more distant matter. Hungarians are used to informal payment to have good care. It is difficult to create awareness that co-payment can mean anything different from under the table money to the doctor¹³.

Experience from the UK, where patients/consumers since 2003 have been able to access information providers like Dr Foster and NHS, illustrate that active search for knowledge does not necessarily result in active choices. Patients might end up in accepting the quality offered by the GP or hospital with which they already have a relation. Not taking action from the information gathered can also be an empowered decision.

Does this mean that information about choices lack value? Probably not – in the Impatient for Change Study, a majority of Europeans express that in every other field of society choice is a normal way to execute influence and have a say. Also the *Future of the European Patient* shows that choice by Europeans is regarded as essential.

Already a rather theoretical option of free choice seems to send signals through the system as policy formers and hospital managers take action to adjust to the new situation – even if the up-take in the population might be slower. The mere existence of information affects the climate and balance of power.

¹³ Interview with Zsombor Kovacs, head of the Hungarian Health Insurance Supervisory Authority.

1.7 Mobility – far from granted

The HCP sees the mobility of patients within the European Union as a positive since cross-border care will expose national healthcare capability and quality deficits and drive the search for information and transparency. Again, for a long time EU patients have had the legal rights to cross borders – but the practical empowerment is undermined by the governing level.

“The primary weaknesses in Europe are of a truly elementary nature: patients do want to have themselves treated abroad, but they fail to overcome bureaucratic obstacles, language barriers or to understand the completely different systems, “declared a leading expert of patient mobility, Dr. Magda Rosenmöller, at the European Health Forum Gastein¹⁴:

A most current illustration of the struggle between patient expectations and political resistance is the effort by Members of the European Parliament try to stop the adaptation of the European Commission proposed directive for patient rights to cross-border care.

The proposal has been delayed several times within the European Commission after a campaign from Paul Nyrup Rasmussen, chairman of the Party of European Socialists PSE. Recently, two of the committees in the European Parliament tried to postpone the vote so that the main committee should not be able to vote until after the June 2009 elections.

The HCP guess is that this action was taken with the hopes that a new commission and new parliament would withdraw the proposal and the issue would then be postponed for several years to come. But the majority in the parliament decided to overrule the minority, thereby forcing the players to the negotiation table. With some luck the leading committee will be voting on this issue the very same day as the launch of this report.

Unfortunately the compromise that seems to have been agreed upon is quite far from what HCP had wished for, providing member states with numerous possibilities to restrict information around the options available, to demand pre-authorisation of treatment, to deny citizens reimbursement for treatment and to restrict the portability of cross-border funding, compared with earlier commission proposals and amendments from various MEPs.

But not even these compromises provide any guarantees. Only a few EU governments seem to fully support the present patient mobility directive proposal and especially future presidency Spain are working hard against it.

From the patient point of view, the uncertainty about the case law formed by more than 20 years of ruling in the European Court of Justice is harmful. In some respects the Court has set clear benchmarks, while a number of issues from Kohl and Decker (1998), Smits and Peerboom (2001) to Watts (2006) are still open for interpretation, which is exactly what can be expected when case law is under development.

The right to cross borders is a perfect example of the gap between formal and effective rights of patients already mentioned. Europeans have the right but in practice it is severely limited. Not until there is legal clarity and well-designed advice for “healthcare tourists” will everybody have the same opportunities. As said by the slogan “Europe for patients”, the current Commission campaign¹⁵ (initiated along with the European Council current presidency trio and the European Patient Forum) , there is a need for equal chances regardless of education, language skills and contacts.

¹⁴ Patients’ Mobility and Health Systems in Europe: The Next Five Years. EHF 2004

¹⁵ http://ec.europa.eu/health-eu/europe_for_patients/news/index_en.htm

The Commission estimates suggest that the most ambitious regulations alternative could make 750 000 people move cross borders annually within the Union to attend hospital care¹⁶. That is 1.5 % of the EU population, indicating that a still small but probably growing group of patients – or their doctors – see a need to look for options outside of the national healthcare system. Already today, mobility seems to have reached a critical mass, provoking significant political discussion in Brussels. A Commission official said in discussions around this matter that through a long career in this organisation, he had never seen such politicisation around a healthcare issue as around this one.

Such an impact is another dimension of European patient empowerment – change is not achieved without real conflicts! True mobility in a pan-European perspective is one of the qualities measured in the ranking section of this report; here countries like Ireland and Denmark should empower patients by opening up for cross-border care.

1.8 How to turn whip into carrot?

Former Commissioner David Byrne claimed a couple of years ago that the future of public health will be characterised by global co-operation, global governance and global partnership.¹⁷ He is certainly right about the global part. As far as partnership goes, the HCP would be happy for that but believe/hope things will go even further. It will probably be empowered individuals and their networking abilities rather than grand scale intervention from authorities that will lead the way.

Regarding the European dominance of insurance-based funding systems there ought to be drivers for insurers to open up for development of experimental models to support patient and consumer choice, co-decision and engagement. But disincentives are still far more frequent than of incentives and the HCP does not recognize any significant development of new models of active partnerships between patient/provider/insurers mutual benefit, supporting prevention, early detection, self-management of care and rehabilitation.

Not even in the Netherlands, which now can be said to have a consumer-driven compulsory insurance system, there are economic incentives for life-style change. Diabetes prevention is a government priority but rewarding certain behaviour in this field seems hard. The insurers work rather with patient literacy and training¹⁸.

Around Europe co-payment typically is a tool to reduce demand (and in CEE, attempting to get rid of grey/black money). It is evident that out of pocket co-payment in the form of user fees for visits, treatment and medicines when introduced reduces demand. Such was the experience from the US when user fees for emergency care were tried during the 1990's¹⁹

Evidence given to HCP from countries like Germany, Slovakia and the Czech Republic suggest that 10 – 20 percent of the visits to primary care tend to disappear in the short run. Experience from Nordic countries indicates that the level of user fees also affect the choice between emergency room and family doctor care²⁰. In Denmark a visit to the listed GP is free, but there is a hefty fee for seeing a specialist without a referral from the GP.

¹⁶ Commission Working Document, Brussels 2008-07-02, SEC (2008) 2164

¹⁷ 2050: A health Odyssey

¹⁸ Interview with dr Nico van Rozing, head of the department of accountability and monitoring at the Dutch Healthcare Insurance Board, 2009

¹⁹ Selby JV, Fireman BH, Swain B.. *AHSR FHSR Annu Meet Abstr Book*. 1994

²⁰ User fees for healthcare in Sweden – a two-tier threat or a tool for solidarity; Frontier Centre For Public Policy, Winnipeg, 2002

So, are user-fees an advantage or disadvantage to patients and consumers? This does not go without saying.

There is a need to make more efficient use of healthcare resources. At the same time patients want more of their own say. Rather than refusing access to a certain service the system can put a limited, indicative price to the use. Such fees suggest that there are neither “free” lunches nor healthcare services at the same time referring to the individual to make the choice.

In Europe the common purpose yet is to reduce demand which can be rational from an efficiency aspect (provided it avoids causing harmful effects, i.e.) But you can also look upon user fees as a kind of deductibles, tools for sharing risk to reduce the effects of moral hazard often caused by information asymmetry in healthcare. While keeping the broad-based insurance philosophy providing access to all you can increase the signal system of risk, providing incentives to take on individual responsibilities, engaging in prevention, life-style change et cetera, action aimed to support good healthcare outcomes. With such an approach user-fees can develop to measures empowering patients with information and choices. But it takes systematic development to move into such a more operative mood.

The optimal level of co-payment has been researched by for example CPB Netherlands Bureau for Economic Policy Analysis²¹, building models to balance different interests such as access in relation to cost awareness.

This report is fully aware of the limitations of the present incentives systems but does in this experimental discussion land in preferring co-payment to not having co-payment. To let the patients just have a free voucher on healthcare will over time prove unsustainable, given growing demand and treatment opportunities, and does not indicate the proper respect for the ability among users to make balanced decisions. Co-payment opens for the development of systems to provide patients with *one* kind of tool and responsibility to manage their healthcare. This is why the report rating rewards countries using user-fees, as these still are the dominant – or only – economic incentive available. Again, there is a need to move forward to a strategy of true incentives.

Rewarding patients for doing the right thing rather than punishing them for doing wrong is common in the American insurance culture, while the compulsory European health insurance historically has proved far more reluctant to support life-style change or voluntary screening for health problems. Tendencies in this direction can be found also in countries like the Netherlands and Germany where active insurers promote healthy lifestyle by providing training for clients/patients/consumers and handing out various gifts to support physical activity *et cetera*. But still the scope and measures are much more limited.

1.9 Health Technology Assessment (HTA)

Evaluation of therapies and medical equipment is as such nothing new. The first institutionalised effort was made 1987 when the Swedish Council on Technology Assessment in Health Care (SBU) was organised (<http://www.sbu.se/en/>). But during the last decade the assessment has found more targeted purposes and procedures. Looking at HTA as a patient and consumer empowerment tool might be a bit far-fetched but no doubt from a user point of view value for money and relevant quality are important aspects.

²¹ CPB Discussion Paper 78; Co-payment systems in health care: between moral hazard and risk reduction, 2007

As the process moves on in most national healthcare systems to make best practice, national guidelines and outcomes evaluations more efficient and instrumental there is a risk that patient opinions in practice will be left out – or to be correct, never taken sufficiently into account. The patient collective might be included in the discussion around these tools but in practice this also means for the individual patients a weakened position compared to the before more individualised treatments strategies decided upon case by case by the physician. In this report ranking only two countries are rewarded full score for organised patient involvement in the HTA process.

The HTA procedures are developing. The huge EUetHTA (<http://www.eunethta.net>) effort has left the project status this year and is now gradually becoming operative, joining 25 national HTA bodies into a European network. Still few countries have introduced stable methods which allow evaluation from the patient rights perspective. The European Commission presses to conform with the European Transparency Directive (duration of decision making period, objectively verifiable criteria) and transparency regarding performance ought to be a key issue to everybody.

When the national Polish HTA authority was established in 2005 the ambition was to cover all kinds of procedures. In reality almost all resources were targeted to look into pharmaceuticals, partly because Poland had such a bad record regarding the introduction of new drugs. Transparency was a beacon – but reality did not exactly follow that route.

The aim was to build a system of open consultation where all opinions were welcome. But there were public doubts about the independence of the patient organisations. And the Minister of Health started to covertly influence the recommendations by the HTA authority to make them fit the Minister's expectations. Today no recommendations may be published until the Ministry of Health has given green light.²²

Wilk explains that the aim was to build a system of open consultation where all opinions were welcome. But there were public doubts about the independence of the patient organisations. And the Minister of Health started to covertly influence the recommendations by the HTA authority to make them fit the Minister's expectations. Today no recommendations may be published until the Ministry of Health has given green light.

After leaving the authority Wilk has started a NGO engaged in HTA policy and advocacy for transparency of decisions on public financing of health technologies.

If HTA or other assessment decisions are purely expert-driven it means a risk that patient experience will be left out, leaving a huge reservoir of knowledge and preferences aside.

Another question mark is about the width of the assessment activities of healthcare. From the cost-efficiency and patient safety aspect all elements of care, not only medicines, need to be evaluated. This means that today generally around 85 percent of the total healthcare resources are left without systematic scrutiny regarding outcomes.

HTA decisions are already questioned and looked upon as biased to the budget-control side, neglecting patient experience – we think this will only continue if not a more institutionalised role for patient organisations becomes part of the HTA process. That the European Commission recently started funding a number of pan-European patient groups might lead into a role-play where organisations provide representation into the process as a base for this

²² Interview with Norbert Wilk, former deputy head of the Polish HTA Authority, 2009. After leaving the authority Wilk has started a NGO engaged in HTA policy and advocacy for transparency of decisions on public financing of health technologies.

funding. Such a development would be logic to distance these groups from the funding by the pharmaceutical industry; a possible EC condition for accepting these organisations as credible voices of the patients.

But dependence of public authorities raises other questions. Public allowances are seldom free of conditions; here the EC support seems to be no exception. It still might force the organisations that want this kind of funding to focus on action other than what was the original idea of the organisation. Very few patient associations are after all created in order to participate in HTA processes...

An institutionalised position opens doors to influence but do also require compliance with the Brussels power game. This would hardly be unique for patient representation, rather a common tendency among stakeholders looking for a place at board tables.

At the national level you can distinguish a similar early tendency, with patient organisations in some countries becoming an integrated part of the welfare and healthcare apparatus. We would imagine that patients groups over time will be given a natural and integrated role as intermediaries and channels between the system and patients.

But following on the new communication opportunities and demand for informal networking there will be a growth of new patient structures, less attracted by the traditional way of organising things. In the US they already exist. They seem to focus on campaigns and opinion forming for a limited period of time or building communities instead of organisations with a formal membership and fees. Such new groups – www.patientslikeme.org is just one example – will live as long as the supporters feel that they get value back for their engagement. Such acquired knowledge and activism is hard to channel into the ordinary democratic decision processes but should be regarded an asset in the HTA process as well as in the design and improvement of service lines and procedures in healthcare production.

Patient knowledge and experience will have a market value and policy making potential especially with regards to the evaluations of pharmaceuticals, medical devices and therapy options available. A new era is approaching where all stakeholders of healthcare will need to engage much more actively and systematically with user experience.

Organisations like PatientView (<http://www.patient-view.com>) specialise in polling patients. The gathering of data around attitudes for continuous hospital improvement, assembling scientific data for a research project, investigating a different mix of public co-payment or a dialogue around adverse events in a certain treatment area are other fields with an expected growth of both private specialists and NGO initiatives. Here patient and consumer experience and opinions represent a significant value. The trade with such knowledge will change healthcare, the information economy and opportunities among industrious patient and consumer configurations.

As part of this trend, there will most likely be more and more freely available reimbursement assessments, recommendations and decisions. Outside of the profession, layman-adapted best practice is building, transferring strategic resources to individuals, NGO:s and different stakeholders. There might be a wish among governments and experts to run a "controlled" HTA process – n but are there not too many stakeholders and strong values involved to allow for a smooth ride? Is it realistic – or even desirable – to imagine such a process excluding what should be look upon the key player: the healthcare user?

1.10 The gap: deficit of patient power

An overall report conclusion is that there is a wide gap in most European countries between political rhetoric and patient reality. This gap is counter-productive, even harmful.

The empowerment deficit is unhealthy in a number of ways. Many patients have to wait with suffering and anxiety and possibly health risks as a consequence, without having the opportunity to move for a more accessible solution or being compensated. The lack of information reduces the opportunities to engage in your own healthcare. Quality information about therapies and providers as well as well designed co-payment systems can be first steps towards information expanding the potential for individual care management. The HTA process mentioned should be able to add significant output improving the common knowledge, at least if that will be part of a European strategy for healthcare information.

Such an aim would be entirely in line with the cost evaluation research performed by the public research institute KELA in Finland. In a 1993-2003 study applying a different strategy on the treatment of asthma and allergy, medication costs and GP visits actually doubled²³. But the disability cost savings (represented by sick leave, in-hospital stays et cetera) more than made up for the increase. Even discounting inflation the annual average cost saving per individual was EUR 300. The key rationale behind the success was a great education effort, targeting professionals as well as patients.

A higher degree of interaction benefits all. The Finnish example shows the upside of training and knowledge, supporting empowered action. The knowledgeable patient will be able to take on growing responsibilities, which has the potential for far-reaching change. There are ways to reduce the power deficit!

How will European governments deal with this deficit challenging equality, quality of care and patient influence? Will a half-hearted policy remain – or will there be a breakthrough for the empowered patient? There seems to be a reluctance to make more specific commitments to patients expressed in legal terms. What to expect from the European Union? And will empowerment follow mainly a “legalistic” road, with stronger formal rights, or a “value driven” lane, where better access to information and choice builds a pressure for change²⁴?

2. The patient empowerment story

In the beginning there were Victims. Then with better knowledge and abilities, Patients emerged.

“Patient” is derived from the Latin word *patiens*, the present participle of the verb *pati*, meaning “one who endures” or “one who suffers”. Patient is also the noun form of patience. This linguistic background is key in understanding the perception of how a patient should historically act and be treated by others. Today the situation is different.

During medieval times – when the first healthcare “systems” emerged (a rare elite in ancient Egypt, Inka or Roman Empire had some medical treatment) – medical care was offered on a generally charitable basis. The laymen/women (monks, nuns) participation was strong and questions regarding patient rights or participation in decision-making did not exist. These services were a gift from God, not to be negotiated.

During the centuries to come after that, organised healthcare continued to be a matter for the rich and mighty. In actual fact, medicine did not reach “break-even”; patient’s chances of survival became greater if the doctor showed up than if he did not, until roughly 1830 A.D. The reach of break-even was essentially due to the gradual abolishment of two directly

²³ http://www.cne.org/pub_pdf/2008_02_26_haahtela_asthma.pdf.

²⁴ Interview with Toivo Heinsoo, head of the Patients Rights public committee in Sweden, 2009.

harmful therapies: bleeding (to “restore the balance of bodily fluids”) and antimony²⁵ medication, which was used as a universal remedy well into the 19th century. General application of this knowledge was not widespread before 1900.

The military had a certain interest in healthcare. General conscription made it possible to recruit large armies, starting with the Napoleonic wars. The organisation of large-scale healthcare (especially surgery and treatment of epidemics) was first a military speciality. This whole process of hierarchy heritage, uniforms and belief in formal organisations still impacts healthcare structure.

Soldiers had not asked for their rights when the surgeon showed up, nor did the ordinary citizen in the very early welfare state. Public healthcare was blatantly paternalistic, even authoritarian. Basic healthcare, as well as pensions, education and other kinds of rudimentary welfare, came to be distributed under the auspices of guilds or governments, and the link between these services and duties of the individual was clear.

Authorities gave, based on expectations of return of the favours. Management theory would label a clear “top-down approach”. The patient had numerous obligations but no rights in the modern sense. The control of epidemics was the rationale behind public healthcare and far more important to the authorities than individual well-being.

The breakthrough of political democracy together with economic and scientific progress has since then changed the power game.

The progress of citizens’ rights during the decades around the First World War became the foundation for modern patient rights. The introduction of popular vote and clearly defined citizens’ rights created a foundation to articulate a wish for different social services, including healthcare. Scientific advancement between the world wars pointed to the potential to treat a growing number of diseases, not only increasing the number of patients but also their expectations.

Modern citizenship, was the idea, should not be limited to the rights to vote and participate in the formal political decision making but should also provide rights in other societal spheres, like work life, education, housing and healthcare. The growing political Labour and Social Democrat movements tended to look at these “social rights” as one entity. But social rights still were something you received as payback due to your labour.

In countries with a strong voluntary engagement in donation and provision of services, institutions not only organising patients but also involving in assembling funding for research and at the same time offering support-services and social networking, appeared early. The UK centres of voluntarism still play an important role in mobilising people and building relations between citizens and patients or disabled persons.

Self-help offering support (relations, member training, legal advice et cetera) are still the most common form of patient organisations in the CEE. But there is a significant change in major European countries towards expanded tasks and responsibilities. For example, in Germany the MS Society runs its own training of certified MS nurses. More and more professional action of this kind can be expected.²⁶

²⁵ antimony is a half-metal, chemically related to arsenic, and has no therapeutic value whatsoever – furthermore, the difference between “working dose” (the patient was showing beginning symptoms of antimony poisoning) and lethal dose was very narrow.

²⁶ Interview with Christoph Thalheim, secretary general of the European MS Platform, Brussels, 2009

Human rights

It would take a couple of more generations before explicit patient rights came on the table. The 1945 Charter of the United Nations and the Universal Declaration of Human Rights in 1948 followed 1950 by the European Convention of Human Rights did not address patient issues but more universal human rights.

The first step towards a more individualistic view of patients came with the HIV movement. Already in 1983 the Denver declaration²⁷ stated that “We condemn attempts to label us as 'victims', a term which implies defeat, and we are only occasionally 'patients', a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.’”

Similar efforts to shift the perception is being made by Robert Johnstone, President of Arthritis and Rheumatism International. He explained to HCP that he constantly needs to struggle with the same misperceptions “we are people with rheumatism”, not patients or even worse “sufferers”.

Sending signals of empowerment and a changing mindset new vocabularies as clients, consumers (becoming more and more frequent in NL and other insurance based systems) or “practicing patients” are found.

During the 1990's, rapid legal development took place, with the Principles of the Rights of Patients in Europe 1994 as a starting point. In spite of the complicated name the 1999 Council of Europe Convention for the protection of human rights (and dignity of the human being with regard to the application of biology and biomedicine) offers a patient rights catalogue, proclaiming basic patient rights.

Following on these signals there has been a growth of national patient rights regulations in almost every European country, albeit patient charters instead of formal rights laws are applied in some countries (see the list of national patient rights laws at end of report). There is – depending on political culture – a huge variation in impact, such as *re* the right of an individual to take legal action if denied a certain right or for discrimination depending on ethnical background or sexual behaviour.

In some systems patient rights are brought together within one general framework, in others there are many pieces of specialised legislation. Issues like access to information about your case can be found in principle laws on the right to read publicly generated information as well as in distinctly patient-focused legal regulation. The wide span regarding the legal situation between EU-citizens is problematic from an equality and cross-border mobility point of view²⁸.

This report is not a study of legal traditions or detailed design of each country's patient rights systems. It is rather an attempt to build a picture of to what extent European citizens in the capacity of patients or care consumers can expect a set of key qualities delivered by their healthcare systems. The “Empowerment of the European Patient - Options and Implications” – a first attempt to make such a study (inspired by the more general Euro Health Consumer Indexes, produced since 2004) – singles out a number of rights and opportunities to be compared. It has to be emphasized that these are not the only ones of interest for a rights and opportunities comparison – many more could be added. But as will be discussed below, the legal rights highway is not the only track to empowerment.

²⁷ <http://www.napwa.org/denverprinciplesproject/denver-principles.shtml>

²⁸ Patients rights in a European Health Care Market, Herman Nys, University of Leuven, 2001.

The HCP finds it essential that patient and consumer rights in healthcare can be executed in an efficient way and that there is a link between rights and access to well-serving healthcare. Together, such indicators can patient empowerment and introduce a debate of the need for further development.

But no doubt there is also a risk of a discrepancy between political rhetoric and patient reality.

Political declarations like the Human Rights mentioned above are too general and imprecise to serve as a manual of patient rights, though their value as ideological and ethical inspiration have been significant. But evidently governments at the same time can sign such declarations – advocating qualities such as maximum freedom of information to patients – as they restrict such rights. How the essence of rights’ laws is interpreted varies.

This suggests that patient rights in the original post-war context is an off-spring of political democracy and human rights, with “patient power” growing from the same tree as “citizens power” or “student power”. The separation of patient rights into social and individual rights confirms this political approach, with social rights expressing undertakings by the government and other public bodies with regard to the population as such. Social rights are often expressed as policy proclamations not always possible to quantify or assess (making them popular among governments, some critics say).

Social rights – essentially the right to become a patient – were the first to be recognised. This right, *i.e.* to be given publicly organised care, was the major political issue during the first half of the 20th century, before the broad acceptance of general healthcare. To become a patient and to be treated at all no doubt was a major achievement but said little about the content of care and the position of the patient when in care. Today, as overall access as such is un-controversial around Europe, the individual rights of being able to navigate the healthcare system to access the best care and have a strong say about the options has become the main issue.

Social rights are enjoyed collectively compared to individual patient rights which – to have any effect – should be expressed in absolute terms. Such a distinct design is a prerequisite for the legal impact of patient rights. In reality, today’s individual rights – such as to treatment in due time or to access your own medical record – are often not expressed precisely enough to put real power behind the phrasing. That the regulation is not legally enforceable, *i.e.* sanctions might be missing, is another weakness.

The patient empowerment status of 2009 indicates that still there is a social rights/public policy focus among most governments, giving the more hands-on individual patient rights lower priority. Considering the political power game, this is no surprise. Promising sweeping reform (often hard to assess other than at the poll station) goes better with the political machinery that pinpointing exact change, which can be evaluated, and which requires a clear idea about how to make patients and healthcare apparatus work together. That regional governments and hospital managers dislike somebody in the capital telling them how to relate to patients in daily life is certain.

Common public health campaigns on smoking restrictions, obesity, healthy diet, active ageing or safe driving might all be perfectly legitimate and serving a good purpose but in practice mean very little to a patient anxious to access her breast cancer treatment in time or to be able to have a second opinion. General proclamations of patient empowerment mean little if not boiled down to instrumental right to access and to use information, to make choices and to be able to count on high-quality procedures.

Or as the Active Citizenship Network²⁹ stresses in its project “European Charter of Patients’ Rights”, such rights must be possible to evaluate and analyse. That requires rather substantial wordings and measurable indicators.

A patient rights set of principles and standards should have such intentions and be of such weight that its key standpoints cannot be easily undermined or devalued by other pieces of law.

The Active Citizenship Network in 2007 made an assessment of how its suggested 14 concrete patient rights (the ACN Patient Rights Charter) were implemented. In areas like patient engagement there was an evident lack of influence of patients over the ways hospitals designed their quality standards, that the management of pain in patients generally was inadequate and that independent patient complaints procedures were rare among the surveyed European hospitals. These are some of many potential indicators to be used trying to assess the practical impact and respect of patients’ rights – all of them not formally regulated in national law. Other kinds of tools are patient-centred guidelines or codes, such as for example the European Code of Good Practice in MS³⁰ which sets standards for access to treatment and quality procedures.

Also medical profession organisations put an increasing weight to patient aspects, like the European Society of Cardiology in its guidelines. The cancer patient pain control guidelines developed for a US audience³¹ is relevant for Europe as well, to just mention a few references. There is an abundance of such sources building a rapidly increasing open bank of knowledge to patients and consumers.

Public policy campaigns have for long been dominant as expression of political will in the field of health. To deal with many of the challenges of tomorrow’s healthcare there has to be a different awareness of the individual patient (and her close networks) and the need to strengthen the individual rights. Politics has to move from general to specific. And politics will not be the sole arena; consumer – provider relations searching for what could be called win-win situations will expand the partnership zone, outside of the politically dictated game.

There is a growing interest in consumer information about healthcare. Yet there is no exact understanding of to what extent information affects the choice among therapies and service providers but already informed choice as an option has a certain impact. It makes the system listen better and hospitals more consumer-aware³².

The reasons behind patient rights reform has until now not been to empower patients in the sense of consumers, *i.e.* to break the rationing paradigm by facilitating access to healthcare services or to articulate a demand. Choice has typically not been a patient rights concern. Value-for-money aspects have been ignored. Such is the case probably because the citizens’ rights tradition has stressed healthcare as a public good, the equal-access character of which might be jeopardised by too much focus on choice.

A set of politically formulated legal rights has almost everywhere been regarded as the way to regulate conditions within the healthcare domain, everywhere funded through a high degree of collective arrangements. Healthcare has been – and still no doubt is – looked upon as a highly **politicised arena where the power play of democracy should reign. That means that the** emerging concept of healthcare consumerism, with a different set of values and

²⁹ European Charter of Patients Rights, Active Citizenship Network, 2002

³⁰ http://www.ms-in-europe.com/w3p_dokumentearchiv/1code08.pdf

³¹ (http://www.cancer.org/docroot/NWS/content/NWS_1_1x_New_Guidelines_Aim_to_Improve_Communication_Patient_Care.asp).

³² Interview with Tim Baker, Managing Director, Dr. Foster Research, 2009

logics, will clash with established rules and structures. Such a collision is already under way and the response by governments and legal frameworks to the growing call from consumers for co-operation and involvement will be decisive for the future regulation of rights and responsibilities.

What is the rationale of really listening to active patients and care consumers – except to comply with the abovementioned legal rights requirements? It has been easy to imagine the complications, from questioning the doctor-patient hierarchy to the need to print information leaflets.

Patients were supposed to follow the advice provided by their doctor or healthcare system. That fact that healthcare might improve by listening to the signals from below was still a provocative and even dangerous suggestion. During the reign of public health there has always been an anathema of “demand” versus “needs”. “Demand” has been treated like a vice, something threatening the system.

Demand had to be hindered while “need” was legitimate and sound. No wonder, “need” is defined by governments and doctors while consumers express “demand”. For long rationing through waiting lists looked like a reasonable pre-caution as well as user-fees to scare away “over-consumption” of healthcare services.

Not until the 1990s, with emerging “market reforms” in some countries, for the first time there was an acknowledgement that individual patients or consumers should be allowed access to specific knowledge. The purpose was to make them interact with the healthcare system or take informed decisions how to execute choice among providers. Under (what was imagined as) market-like conditions, the patient preferences were given a value as a marker.

If patients were allowed to choose among providers there might emerge a pressure for quality as some providers would attract more patients thus being better reimbursed. Competition for contract between providers would increase efficiency. (Often the most evident outcome of these early attempts to break up large established provision organisations was increased service productivity in combination with fictional business rationality among purchasers).

Like in other industries consumer preferences in healthcare has an information value to improve the design of services and administrative routines. Today any government understands (but necessarily not practices) that choice and competition is a driver for development. As shown by this report two out of three national healthcare systems allow for free choice among domestic providers, meaning that the basic condition exists for patients and consumers giving priority to quality. At the same time we can notice that very few countries offer a provider catalogue with a ranking of providers which of course makes it rather hard to exploit the full potential of the right to choose. Far from every country even has a register of legit doctors. Paying the care providers according to performance is still quite unusual. Here the NHS reimbursement reform for GP:s marks a first step.

A purchaser-provider split has always been a basic ingredient of health insurance systems and during the last ten years becoming frequent also in tax-funded systems. A long-term trend towards more centralised funding mechanisms combined with more and more decentralised provision solutions can be observed. Such a development responds to patient visions of more influence over the practical delivery of healthcare – but does it respond to a deeper involvement in the funding of healthcare, with new option to balance power with responsibilities?

Until recently the tax funded systems of Europe did not take consumer choice and competition among purchasers or providers into regard as a driver for systematic

improvement. On the contrary, these systems claimed that the absence of such mechanisms was the guarantee for solidarity, equity (and sustainable funding).

Today, increasing independence among tax-funded purchaser organisations contracting various service providers is becoming part of the public approach. But with few exceptions consumer priorities have been weakly or not at all reflected by this empowerment of political bodies and purchaser staff; the providers have been reimbursed according to their competitive offerings, not the choice among consumers. The introduction of “voucher” systems, giving the citizen the opportunity to bring her publicly generated funding to the selected doctor or clinic, moves – at least in principle – the power to the frontline: consumers and patients.

In insurance-based systems the insured/consumer has been able to indirectly affect the choice of providers via the design of the insurance package. But often it has been easier to make a judgement between the insurance companies or sick funds than between the providers included. The economic relation between insurer and provider has typically not been transparent and the active choice by patients has not significantly affected the reimbursement to the provider. This will change, a process starting as it seems in tax funded systems like the UK and now also in Sweden.

3. Background

3.1 The Health Consumer Powerhouse

Since 2004 the Health Consumer Powerhouse (HCP) has improved the layman information about European healthcare. HCP reports and consumer indexes have not only improved the knowledge about the pros and cons of the healthcare systems in 34 countries. HCP focus on access, information and user-friendliness has changed the perception of what constitutes high quality healthcare. According to the European Commission, today one of our partners, the HCP work is “extremely valuable”.

Today we have reached a level of understanding of the need for patient empowerment and healthcare consumerism but we see few actions taken on a policy level etc. We believe there is a need for guidance on the meaning and essence of patient empowerment with regards to division of power and responsibilities. Empowerment ought to be balanced by responsibilities. To measure patient empowerment in Europe today by deep-diving into the current extension of patients’ rights and looking into the implications for the responsibilities and effectiveness of the system.

3.2 Comparisons

Though still a somewhat controversial standpoint, HCP advocates that quality comparisons within the field of healthcare is a true win-win situation. To the consumer, who will have a better platform for informed choice and action. To governments, authorities and providers, the sharpened focus on consumer satisfaction and quality outcomes will support change. To media, the ranking offers clear-cut facts for consumer journalism with some drama into it. The potential for improvement is illustrated.

As heard a Minister of health expressing when seeing his country’s preliminary results: “It’s good to have someone still telling you: you could do better.”

3.3 Report scope

The aim has been to select a limited number of indicators, within a definite number of evaluation areas, which in combination can present a telling tale of the patient situation in the respective systems across Europe, including the implication for the responsibilities of patients. The purpose would be to make opinion leaders better understand that growing patient rights should and could be balanced by individual responsibilities into a functioning decisions structure. This report hopes to invite to a discussion on how the healthcare systems should be organized.

4. Countries involved

In 2005, the EHCI started with a dozen of countries and 20 indicators; this Report includes all 27 European Union member states, plus Norway and Switzerland, and the Candidate countries of Croatia and FYR Macedonia.

Countries included in the Euro Patient Empowerment Report for 2009:

Austria	Germany	Norway
Belgium	Greece	Poland
Bulgaria	Hungary	Portugal
Croatia	Ireland	Romania
Cyprus	Italy	Slovakia
Czech Republic	Latvia	Slovenia
Denmark	Lithuania	Spain
Estonia	Luxembourg	Sweden
Finland	Malta	Switzerland
France	Netherlands	United Kingdom
FYR Macedonia		

5. Results for 2009

Euro Patient Empowerment Index 2009

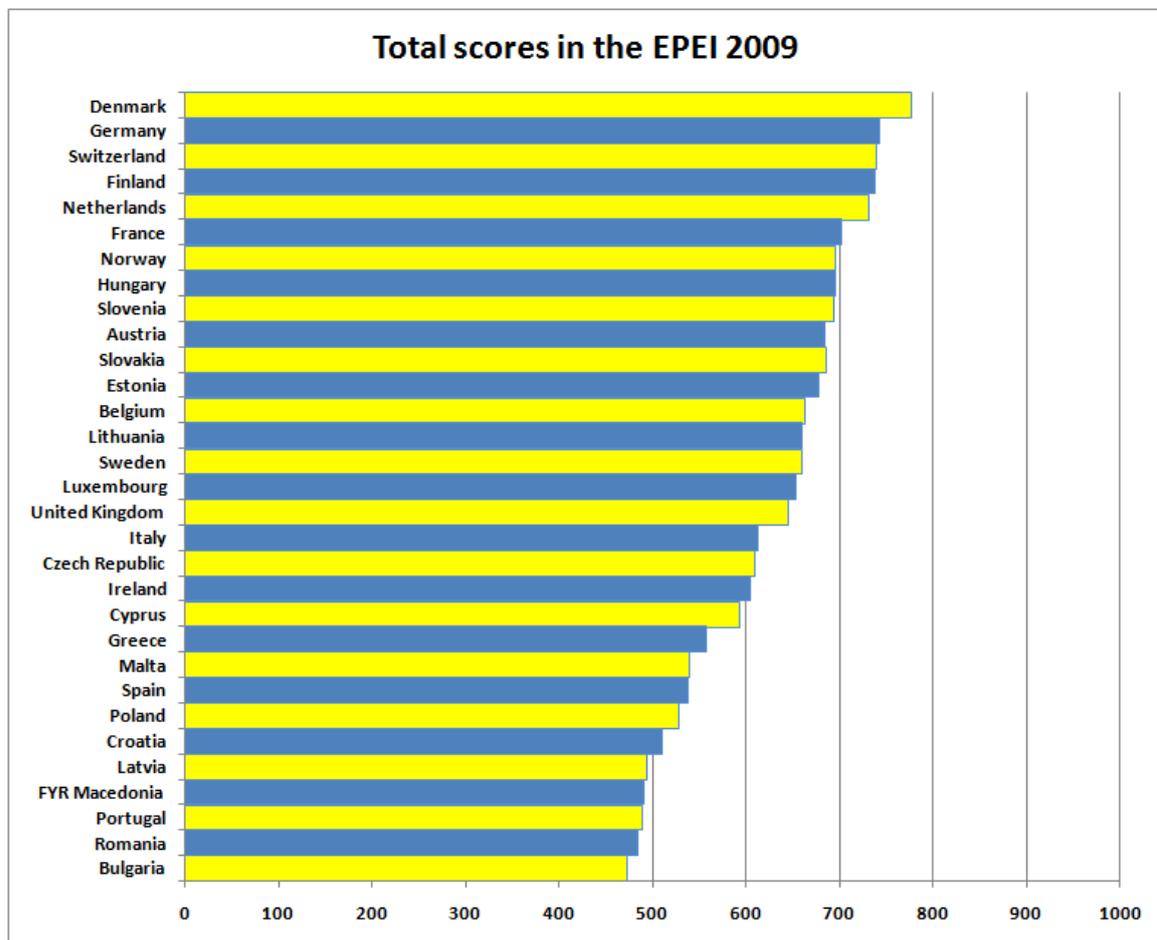
Sub-discipline	1. Patients' rights										2. Information					3. HTA		4. Financial incentives			Total score	Rank		
	1.1. Healthcare law based on Patients' Rights	1.2 Right to choose among providers, domestic	1.3 Right to choose among providers, EU	1.5 Direct access to specialist	1.6 Patient organisations involved in decision making	1.7 No-fault malpractice insurance	1.8 Right to second opinion	1.9 Access to own medical record	1.10 Voluntary national screening programme	Subdiscipline weighted score	2.1 Provider catalogue with quality ranking	2.2 Register of legit doctors	2.3 Web or 24/7 telephone HC info with interactivity	2.4 Letters (e.g. from specialist to GP) copied to patients	2.5 Layman-adapted pharmacopaeia?	Subdiscipline weighted score	3.1 Dedicated HTA agency with patient influence	Subdiscipline weighted score	4.1 Right to choose between insurances	4.2 Informal payments to doctors			4.3 Patient co-payment	Subdiscipline weighted score
Austria	●	●	○	●	○	○	●	●	○	352	○	●	○	○	●	200	○	53	○	○	●	80	685	10
Belgium	●	○	○	●	●	○	●	○	●	389	○	○	○	○	○	100	○	53	●	●	●	120	662	13
Bulgaria	○	●	○	○	○	○	○	○	○	259	○	○	○	○	○	120	○	27	○	○	○	67	473	31
Croatia	●	○	○	○	○	○	○	○	○	278	○	○	○	○	○	140	○	27	○	○	○	67	511	26
Cyprus	●	○	○	○	○	○	○	○	○	333	○	○	○	○	○	140	○	27	○	○	○	93	593	21
Czech Republic	○	○	○	○	○	○	○	○	○	296	○	○	○	○	○	180	○	53	○	○	○	80	610	19
Denmark	●	●	○	○	○	○	○	○	○	370	○	○	○	○	○	260	○	80	○	○	○	67	777	1
Estonia	●	●	○	○	○	○	○	○	○	352	○	○	○	○	○	220	○	27	○	○	○	80	679	12
Finland	●	○	○	○	○	○	○	○	○	352	○	○	○	○	○	240	○	53	○	○	○	93	739	3
France	●	○	○	○	○	○	○	○	○	389	○	○	○	○	○	180	○	53	○	○	○	80	702	6
FYR Macedonia	●	○	○	○	○	○	○	○	n.a.	278	○	○	○	○	○	120	○	27	○	○	○	67	491	28
Germany	○	○	○	○	○	○	○	○	○	370	○	○	○	○	○	200	○	53	○	○	○	120	744	2
Greece	●	●	○	○	○	○	○	○	○	370	○	○	○	○	○	120	○	27	○	○	○	40	557	22
Hungary	●	●	○	○	○	○	○	○	○	389	○	○	○	○	○	200	○	53	○	○	○	53	696	7
Ireland	○	○	○	○	○	○	○	○	○	278	○	○	○	○	○	180	○	53	○	○	○	93	604	20
Italy	○	○	○	○	○	○	○	○	○	333	○	○	○	○	○	160	○	53	○	○	○	67	613	18
Latvia	○	○	○	○	○	○	○	○	○	241	○	○	○	○	○	120	○	53	○	○	○	80	494	27
Lithuania	●	○	○	○	○	○	○	○	○	407	○	○	○	○	○	160	○	53	○	○	○	40	661	14
Luxembourg	○	○	○	○	○	○	○	○	○	407	○	○	○	○	○	140	○	27	○	○	○	80	654	16
Malta	○	○	○	○	○	○	○	○	○	259	○	○	○	○	○	200	○	27	○	○	○	53	539	23
Netherlands	●	○	○	○	○	○	○	○	○	352	○	○	○	○	○	220	○	53	○	○	○	107	732	5
Norway	●	○	○	○	○	○	○	○	○	389	○	○	○	○	○	160	○	53	○	○	○	93	696	7
Poland	○	○	○	○	○	○	○	○	○	315	○	○	○	○	○	120	○	53	○	○	○	40	528	25
Portugal	○	○	○	○	○	○	○	○	○	222	○	○	○	○	○	160	○	27	○	○	○	80	489	29
Romania	○	○	○	○	○	○	○	○	○	278	○	○	○	○	○	140	○	27	○	○	○	40	484	30
Slovakia	●	○	○	○	○	○	○	○	○	352	○	○	○	○	○	200	○	27	○	○	○	107	685	10
Slovenia	●	○	○	○	○	○	○	○	○	407	○	○	○	○	○	180	○	27	○	○	○	80	694	9
Spain	●	○	○	○	○	○	○	○	○	278	○	○	○	○	○	140	○	53	○	○	○	67	538	24
Sweden	○	○	○	○	○	○	○	○	○	333	○	○	○	○	○	180	○	53	○	○	○	93	660	15
Switzerland	●	○	○	○	○	○	○	○	○	426	○	○	○	○	○	140	○	53	○	○	○	120	739	3
United Kingdom	○	○	○	○	○	○	○	○	○	278	○	○	○	○	○	220	○	80	○	○	○	67	644	17

The scoring has intentionally been done in such a way that the likelihood that two states should end up sharing a position in the ranking is almost zero. It must therefore be noted that great efforts should not be spent on in-depth analysis of why one country is in 13th place, and another in 16th. Very subtle changes in single scores can modify the internal order of countries, particularly in the middle of the ranking list.

The 2009 total ranking of patient empowerment of healthcare systems shows a landslide victory for Denmark, scoring 777 points out of 1000, 33 points ahead of runners-up Germany with 744 points. Closely behind follow Switzerland and Finland with 739, and the Netherlands with 732 points.

5.1 Results Summary

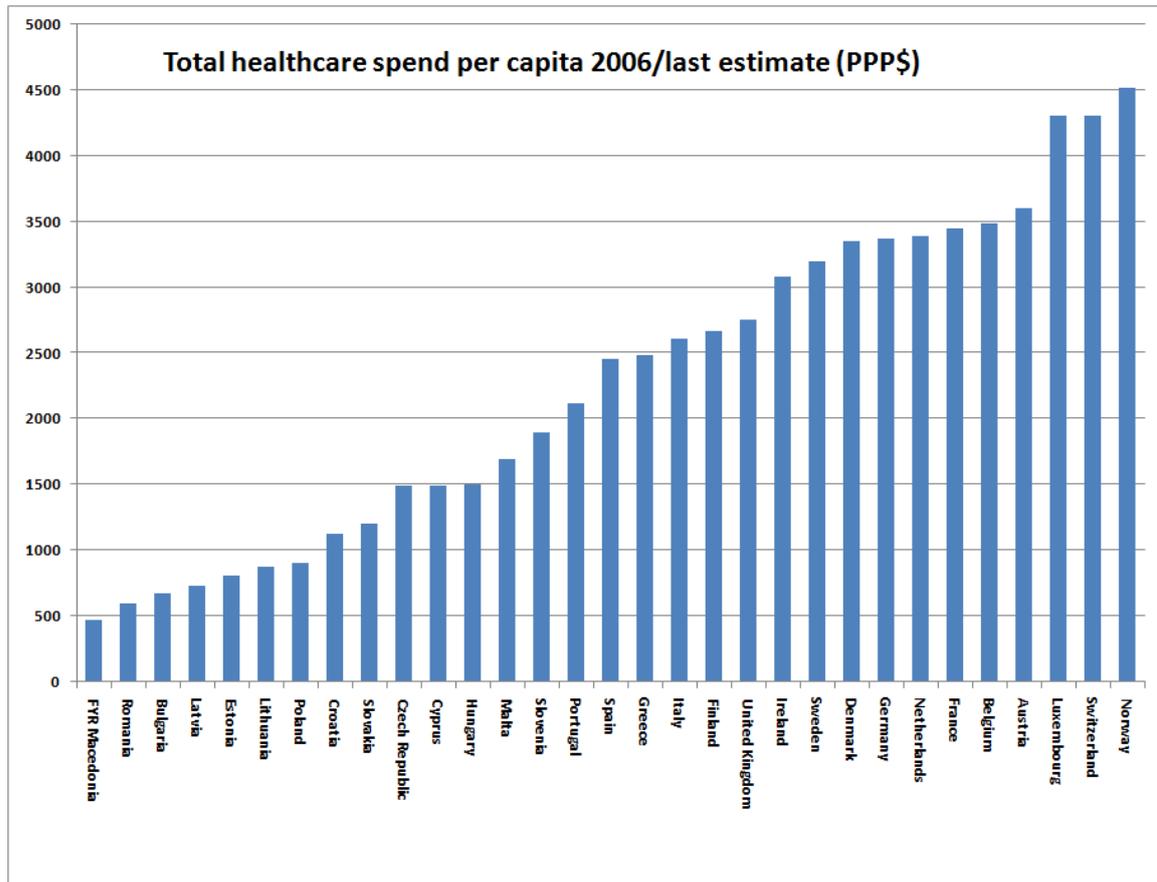
5.1.1 Total score



Graph 5.1.1.

For some reason, it seems as if being German-speaking is good for empowering patients. Germany, Austria and Switzerland would typically be seen as consumers' paradises for healthcare services, as anybody in these countries is essentially free to seek care anytime and anywhere they please, without experiencing significant waiting times. Particularly Germany, home to 85 % of the German-speaking population, does this without spending dramatically more per capita on healthcare, as can be seen from graph 5.1.2 below. (Speaking Dutch seems to be good, too; on the other hand, the HCP has to this date been unable to design a Healthcare Consumer Index, where The Netherlands do not appear in

the top three – five.) For why the German speakers do not win this ranking hands down, see below on sub-discipline Information!



Graph 5.1.2.

Among the Nordic countries, apart from overall winner Denmark, Finland is also doing significantly better than Norway and Sweden. It is difficult to find an explanation for this other than more courageous decision makers (slightly more decisive political culture?), leaving less room for phenomena such as reluctance in the medical profession to publish outcomes data on hospital level or an easily accessible registry of medical specialists. Particularly Sweden, which probably has the best supply of outcome data for healthcare in Europe but still has not come around to publishing all of it in a form readily accessible to the public, should be able to do better in the Report with a very modest effort. Swedish transparency initiatives are under way but still remain to pay off.

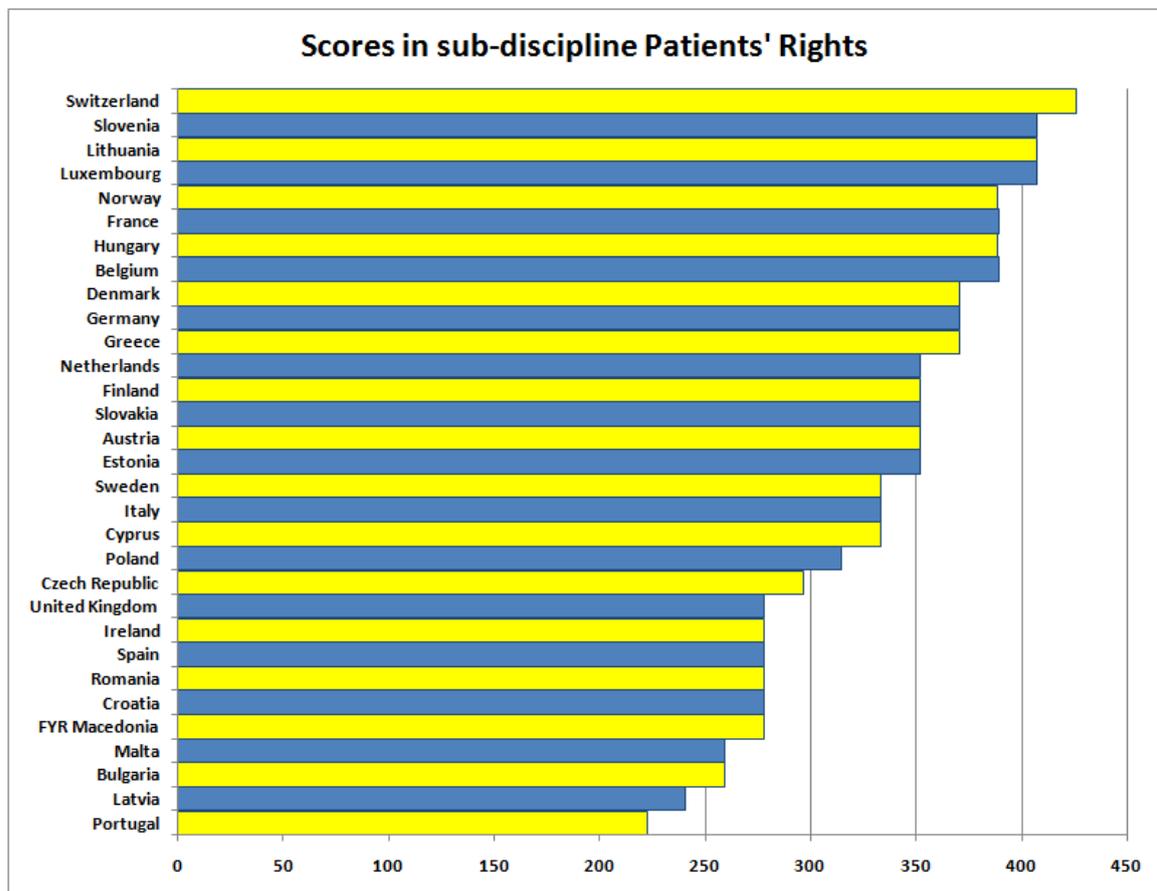
HCP staff paid a visit to the Danish Sundhedsstyret (National Board of Health) to discuss among other things the Danish www-published hospital quality ranking (www.sundhedskvalitet.dk), which has features such as “click your way down to the direct dial phone number of the Head of Clinic”. The obvious question for a Swede to ask was: “What do your doctors think of this?”, and the exact reply was: “They do not like it much, but our politicians have said ‘We don’t give a **** – we want this!’” There probably are more countries in Europe than just Sweden and Norway where that does not happen very frequently!

Some CEE countries, most notably Hungary, Slovakia, Lithuania and Slovenia, have made remarkable progress on citizen/patient rights and empowerment in recent years (the Euro Health Consumer Indexes for the period 2006 – 2008 confirm this).

As has been observed also in the EHCI, the large Beveridge healthcare systems of the U.K., Italy and Spain do not perform very well at empowering patients. It seems difficult to avoid the speculation that in tax funded systems, it happens easily that the primary loyalty of decision makers shifts over time from customers to the organisation they (are justly proud of) having built. Not surprisingly, that problem seems more difficult to master in large systems than in small, neat countries like Denmark and Finland. This lesson was also learned from watching the full-scale experiment on central planning for 300 M people, which was carried out just east of the EU border between 1917 and 1990!

If healthcare officials and politicians took to looking across borders, and to "stealing" improvement ideas from their EU colleagues, there would be a good chance for a national system to come much closer to the theoretical top score of 1000.

5.1.2 Subdiscipline Patients' Rights



Graph 5.1.3.

This subdiscipline shows Switzerland as the supreme winner, and again confirms where the shortcomings of the Beveridge model are most obvious. The subdiscipline accounts for a maximum of 500 points out of the total 1000 points possible.

Overall there are evident weaknesses in the implementation of patient and consumer rights: Half of the ranked countries do complicate or deny the right of a second opinion and one third effectively restricts the patient access to her own medical record.

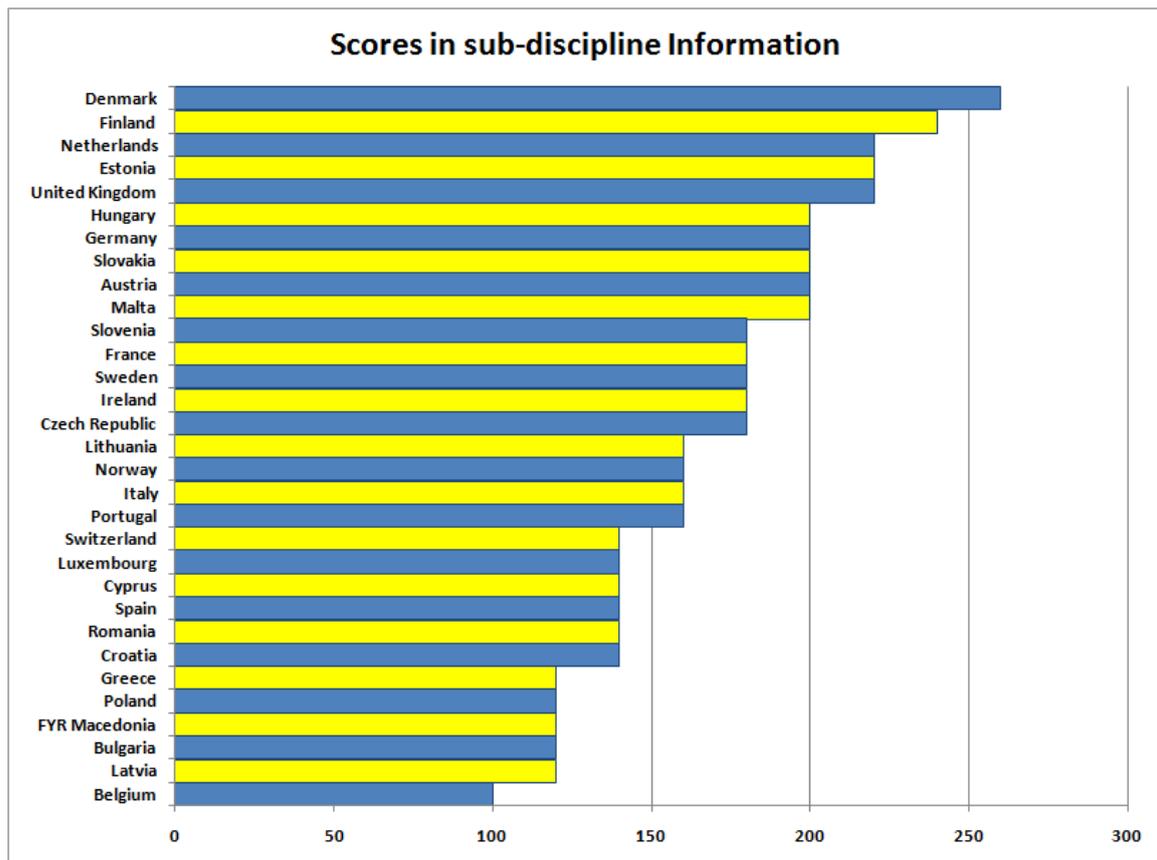
Looking into the principles behind the design of the healthcare systems choice is basically limited in large many countries; in one third there is no right to choose between service

providers within the country and no less than two thirds of the system denies direct access to specialists.

Still, the good scores of healthcare free choice paradises Switzerland, Luxembourg, France, Belgium and Germany are not sufficient for either to grab the total victory in the “Empowerment of the European Patient Ranking” for 2009. Why?

5.1.3 Subdiscipline Information

In order for a patient to be truly empowered, having lots of freedom of choice is not enough; true empowerment also involves having access to information to make informed choices.



Graph 5.1.4

The German-speaking “free choice paradises”, particularly Switzerland, seem to suffer from a traditional attitude to healthcare information, which essentially can be described as “If there is anything you need to know – ask your doctor (or possibly pharmacist)!” It is really encouraging that Germany, by the power of www.bqs-online.de, has joined the select group of countries (the U.K. and Denmark) making quality information on healthcare providers easily accessible by members of the public. In this field progress is very slow, meaning that in less than one third of the ranked countries there are any signs of consumer guidance in the form of a provider catalogue with a ranking. And full-blown web guides are to be found in just the three countries already mentioned.

Also, the federal structure of Germany, Austria and Switzerland does not help, just as the regionalized structure of Italy and Spain does constitute a problem for healthcare data availability.

Still, a short anecdote from another HCP visit to a (German-speaking) national statistics agency could illustrate what HCP believes to be a profound cultural streak as regards data

collection on healthcare performance: On being asked about the availability of certain parameters, the answer from the officials was: “No, there is no law requiring us to collect that data, so naturally we do not have that parameter.”

One good thing about having had a very centralized system since 1948 is that the U.K. has been scoring high on information indicators ever since the HCP started recording.

5.1.4 Subdiscipline HTA

The discussion on this one-indicator sub-discipline is conducted in sections 1.10 and 7.6.2. From a patient-consumer point of view a reliable assessment of medical quality is an essential asset, providing critical information to support safety, efficiency and choice. As the present discussion indicates there are different ways to perform HTA delivering different value. Trying to compare this value in a ranking is just the first step; development over time will provide further ground for assessing the procedures.

5.1.5 Subdiscipline Financial incentives

As is mentioned in Chapter 1, the work on the Report initially had the ambition to find examples of actual financial rewards to citizens in the form of *e.g.* cheaper health insurance premiums.

The prominent examples of patient empowerment-related financial incentives were those countries having a Bismarck-type (health insurance-based) healthcare financing system, in which citizens have a choice between different insurance providers. Such system is offered in six countries: Belgium, the Czech Republic, Germany, the Netherlands, Slovakia and Switzerland. In other Bismarck countries, insurers function according to geographic areas or groups of employees (railway staff being a common example).

Three out of four of the ranked countries apply official user co-payment in various formats. The involvement in healthcare prioritisation and cost-sharing via patient empowerment seems to be natural in the countries which usually do well in healthcare. Looking at the EHCI 2008 ranking, except Denmark who does well without a co-payment system, poor performers like Greece, Lithuania, Malta, Poland, Romania, Spain and even the UK lack official co-payment systems (though under the table-payments are common in the CEE).

A financial disincentive was included in the Patient Empowerment Ranking, “Under-the-table payments to doctors”, namely systems where patients need to make unofficial payments in order to obtain care at all, better quality care or to jump waiting lists. To the surprise of the research team some form of under-the-table payments was found in a couple of rather affluent Western European countries, such as Austria, France and Italy.

5.1.6 Country scores

There are no countries, which excel across the entire range of indicators. The national scores seem to reflect more of “national and organisational cultures and attitudes”, rather than mirroring how large resources a country is spending on healthcare. The cultural streaks have in all likelihood deep historical roots. Turning a large corporation around takes a couple of years – turning a country around can take decades!

5.2 Closing the gap between East and West

There seems to be a visible wave of legislation changes across the CEE, which results in patient empowerment.

For example, in the past years Slovenia introduced reform in the domain of access to specialists, no-fault malpractice insurance, and the right to second opinion, together with considerable improvement in the area of access to information (register of legit doctors, pharmacopoeia, and even a nice attempt to construct a true providers' catalogue with quality ranking); some of these changes being attributable to the introduction of an Act On Patients' Rights of 2008. In the Czech Republic, a systematic reform of healthcare legislation had impact on drug deployment speed; in Lithuania, the level of involvement of patient organisations increased in past years to a level higher than the majority of the wealthiest countries in the West.

Hungary improved a lot in the field of patient information by introducing the Doctor Info service with register of doctors and a nice attempt of provider catalogue, pharmacopoeia and other healthcare information.

The examples of Slovenia, Hungary, the Czech Republic and Lithuania are a good indication that an important improvement in patient empowerment can be done in one or two years, without the need to increase healthcare spending in a dramatic way. Usually it costs very little to initially incorporate the patients' rights in the national legislation or to make publicly available information already stored somewhere, such as a registry of doctors or information on pharmaceuticals.

Over time it might be different; if a government fears that more knowledgeable patients will be more apt to consume healthcare, keeping back rights and information might be rational in the short term. Forming a strategy for user interaction and shared responsibilities might be wiser. Hoping for ignorance as a sustainable position is hardly credible. In the Country Recommendations segment of this report we suggest that some countries give priority to improving information. Other frequent advice concerns patient rights law, choice among providers, direct access to specialists and financial incentives.

Also the newly included Candidate countries have adapted patients' rights in their legislation.

5.3 Transparent monitoring of healthcare quality

In 2005, Dr. Foster of the UK was the single shining star on the firmament of provider (hospital) listing, where patients could actually see which hospitals had good results in term of actual success rates or survival percentages.

In 2007, there were already a few more examples, where the Health Consumer Powerhouse believes that the most notable is the Danish www.sundhedskvalitet.dk, where hospitals are graded from ★ to ★★★★★ as if they were hotels, with service level indicators as well as actual results, including case fatality rates on certain diagnoses. Perhaps the most impressive part of this system is that it allows members of the public to click down to a link giving the direct-dial telephone number of clinic managers.

The German state company Bundesgeschäftsstelle Qualitätssicherung GGmbH, www.bqs-online.de, also provides results quality information on a great number of German hospitals, presently (March 2009) on 33 indicators.

There are also not-so-perfect, but already existing catalogues with quality ranking in Cyprus, France, Hungary, Netherlands, Norway and Slovenia!

5.4 Change under pressure

Some general beliefs about healthcare in Europe would say that the best performers are the relatively rich countries with a long tradition of full-coverage healthcare systems. It is therefore very difficult to score well for a non-western country. To some extent this can be true: generally speaking, outcomes need money and continuity. The HCP work is, nevertheless, not concentrated on outcomes to the same extent that the common comparative studies. GDP-correlated indicators have been avoided as best possible. Against the beliefs presented above, it must be admitted that the way to the top of the Euro Patient Empowerment Report is not too expensive; the key measures are: choice, patients' rights, information/transparency, quality measurements – and some of these cost little to introduce.

The key factor seems to be the overall responsiveness of the national system, and the capability to implement strategic changes. Under external pressure, visible in the past few years, individual countries take very different measures to keep healthcare sustainable, ranging from deep systematic reforms to defensive restrictive measures on the level of provision and access. Apparently, some national healthcare systems experience a sort of inertial status persistent to any change. As a result, some of the Good Old Europe countries slowly submerge. On the other hand, quick learners like Estonia or Slovakia have had the questionable advantage of facing a crisis so threatening that it became an opportunity to redesign the whole approach to healthcare.

Whether the present financial crisis will driver further reform remains to be seen.

5.5 Why do patients not know?

Each year, the results of the survey made in co-operation with Patient View for the Euro Health Consumer Index has been revealing an interesting fact: in some countries, the patients' organisations and health campaigners (even very respectful ones) do not know about some of the services available in their country. For example, the research team constantly finds negative answers on the existence of doctors' registries, pharmacopoeias, access to medical records etc. in countries where HCP researchers can easily find this kind of information even without the knowledge of local language. To sum up, probably the reason is that national authorities make considerable improvements, but miss out on communicating these to the wide public.

This sometimes also applies to some rather fundamental patients' rights, such as the right to a second opinion.

6. How to interpret the Report results?

The first and most important consideration on how to treat the results is with care.

The Euro Patient Empowerment report is an attempt at measuring and ranking the performance of healthcare systems on the aspect of Patient Empowerment. The results definitely contain information quality problems. There is a shortage of pan-European, uniform set procedures for data gathering.

But again, the HCP finds it far better to present the results to the public, and to promote constructive discussion rather than staying with the only too common opinion that as long as healthcare information is not a hundred percent complete it should be kept in the closet. Again, it is important to stress that the report displays consumer information, not medically or individually sensitive data.

While by no means claiming that the Report for 2009 results is dissertation quality, the findings should not be dismissed as random findings. On the contrary, previous experience from the general Euro Health Consumer Indexes reflects that consumer ranking by similar indicators is looked upon as an important tool to display healthcare service quality. The HCP hopes that the Report results can serve as inspiration for how and where European healthcare can be improved and does therefore also give recommendations for change in co-ordination with the launch of this report.

As already initially stated the Report and Ranking foundation is biased in the sense that patient and consumer empowerment are seen as assets, not burdens. That is why qualities like choice, access and financial incentives are regarded expressions for empowerment, adding important values and knowledge into the way healthcare works. Such an approach will reward some systems, depending on how well they respond to such criteria.

7. Construction of European Patient Empowerment Report

7.1 Indicator areas (sub-disciplines)

The report is, just like other HCP Indexes, built up with indicators grouped in sub-disciplines.

The indicator areas for the Report became:

Sub-discipline	Number of indicators
1. Patient rights	10
2. Information to patients	5
3. Health Technology Assessment (HTA)	1
4. Financial incentives	3

7.2 Scoring in the “Empowerment of the European Patient - Options and Implications” 2009

The performance of the respective national healthcare systems were graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of Green = good (●), Amber = so-so (◐) and red = not-so-good (◑). A green score earns 3 points, an amber score 2 points and a red score (or a “not available”) earns 1 point.

For each of the three sub-disciplines, the country score was calculated as a percentage of the maximum possible (*e.g.* for Information, the score for a state has been calculated as % of the maximum $3 \times 5 = 15$).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added up to make the final country score. These percentages were then multiplied by 100, and rounded to a three digit integer.

7.3 Weight coefficients

In the Report for 2009, the scores for the four sub-disciplines were given the following weights:

Sub discipline	Relative weight (“All Green” score contribution to total maximum score of 1000)	Points for a Green score in each sub-discipline
Patient rights	500	55.55
Information to patients	300	60.00
Health Technology Assessment	80	80.00
Financial incentives	120	40.00
Total sum of weights	1000	

Consequently, as the percentages of full scores were added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a national healthcare system is 1000, and the lowest possible score is 333.

7.3.1 Regional differences within European states

The Health Consumer Powerhouse is well aware that many European states have very decentralised healthcare systems. Not least for the U.K. it is often argued that “Scotland and Wales have separate HNS services, and should be ranked separately”.

The uniformity among different parts of the U.K. is probably higher than among regions of Spain and Italy, Bundesländer in Germany and possibly even among counties in tiny Sweden with a 9 million population.

Grading healthcare systems for European states does present a certain risk of encountering the syndrome of “if you stand with one foot in an ice-bucket and the other on the hot plate, on average you are pretty comfortable”. This problem would be quite pronounced if there were an ambition to include the U.S.A. as one country in a Health Consumer Index.

As equity in healthcare has traditionally been high on the agenda in European states, it has been judged that regional differences are small enough to make statements about the national levels of healthcare services relevant and meaningful.

7.4 Indicator definitions and data sources for the “Empowerment of the European Patient - Options and Implications”

Sub-discipline	Indicator	Comment	Score 3	Score 2	Score 1	Main Information Sources
1. Patients' rights	1.1. Healthcare law based on Patients' Rights	Is national HC legislation explicitly expressed in terms of Patients' rights?	Yes	various kinds of patient charters or similar byelaws	No	Patients' Rights Law (Annex 1); http://www.healthline.com/galecontent/patient-rights-1 ; http://www.adviceguide.org.uk/index/family_parent/health/nhs_patients_rights.htm ; ww.dohc.ie ; http://www.sst.dk/Tilsyn/Individuelt_tilsyn/Tilsyn_med_faglighed/Skaerpet_tilsyn_med_videre/Skaerpet_tilsyn/Liste.aspx ; http://db2.doyma.es/pdf/261/261v1n2a13048764pdf001.pdf .
	1.2 Right to choose among providers, domestic	Can patients freely choose a specialist clinic anywhere in the country?	Yes	Yes, severely limited	No, you "get sent" to a certain care provider	Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	1.3 Right to choose among providers, EU	Can patients freely choose a clinic in another EU country?	Yes	Yes, with pre-approval, but usually no problem	Yes, with pre-approval, but usually problems or time delays	Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008; https://www.retsinformation.dk/Forms/R0710.aspx?id=114195
	1.4 Direct access to specialist	Without referral from family doctor (GP)	Yes	Not really, but quite often in reality	No	Patients' Perspectives of Healthcare Waiting times in Europe; survey commissioned by HCP 2008. Personal interviews with healthcare officials; http://www.im.dk/publikationer/healthcare_in_dk/healthcare.pdf ; http://www.ic.nhs.uk/ ; http://www.oecd.org/datao
	1.5 Patient organisations involved in decision making		Yes, statutory	Yes, by common practice in advisory capacity	No, not compulsory or generally done in practice	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews.
	1.6 No-fault malpractice insurance	Can patients get compensation without the assistance of the judicial system in proving who among medical staff made mistakes?	Yes	Fair; e.g. > 25% invalidity covered by the state	No	Swedish National Patient Insurance Co. (All Nordic countries have no1fault insurance); www.hse.ie ; www.hiqa.ie .

	1.7 Right to second opinion	(For a non-trivial condition.)	Yes	yes, but difficult to access due to bureaucracy or doctor negativism	No	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Health and Social Campaigners' News International: Users' perspectives on healthcare systems globally, Patient View 2005. Personal interviews.
	1.8 Access to own medical record	Can patients read their own medical records?	Yes	yes, restricted or with intermediary	No	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Health and Social Campaigners' News International: Users' perspectives on healthcare systems globally, Patient View 2005. Personal interviews; www.dohc.ie .
	1.9 Voluntary national screening programme	% of population self-reporting having had b.p. and chol. check past 12 months	> 10 % above EU average indexed rate	within ±10 % of EU average indexed rate	> 10 % below EU average indexed rate	Special Eurobarometer 272 "Health in the European Union", Sept 2007
2. Information	2.1 Provider catalogue with quality ranking	"Dr. Foster" in the U.K. remains the standard European qualification for a "Yes" (green score). The "750 best clinics" published by LePoint in France would warrant a Yellow.	Yes	"not really", but nice attempts under way	No	http://www.drfooster.co.uk/home.aspx ; http://www.sundhedskvalitet.dk/ ; http://www.sykehusvalg.no/ ; www.bqs-online.de
	2.2 Register of legit doctors	Can the public readily access the info: "Is doctor X a bona fide specialist?"	Yes, easily accessible on www or print	Yes, but costly or difficult to find	No	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. National physician registries; Personal interviews.
	2.3 Web or 24/7 telephone HC info with interactivity	Information which can help a patient take decisions of the nature: "After consulting the service, I will take a paracetamol and wait and see" or "I will hurry to the A&E department of the nearest hospital"	Yes	Yes, but not generally available	No	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews; http://www.nhsdirect.nhs.uk/ ; www.hse.ie ; www.ntpf.ie .
	2.4 Letters (e.g. from specialist to GP) copied to patients	Do patients letters (e.g. from specialist to GP) go also to patients	Yes, always	Yes, frequently	Normally not	Survey commissioned by HCP from Patient View 2008. Interviews with healthcare officials.
	2.5 Layman-adapted pharmacopeia?	Is there a layman-adapted pharmacopeia readily accessible by the public (www or widely available)?	Yes	Yes, but not really easily accessible	No	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2006. Personal interviews. LIF Sweden. http://www.doctissimo.fr/html/sante/sante.htm ; http://www.legemiddelverket.no/custom/templates/gzInterlFrame____1548.aspx ; http://me
3. HTA	3.1 Dedicated HTA agency with patient influence	Is there a national agency with dedicated HTA responsibilities?	Yes, with layman representation	Yes	No	European Observatory Studies Series No 14, HEALTH TECHNOLOGY ASSESSMENT AND HEALTH POLICY-MAKING IN EUROPE: Current status, challenges and potential, M V Garrido, F B Kristensen, C P Nielsen, R Busse; Eur Observatory HiT reports, personal interviews.
4. Financial incentives	4.1 Right to choose between health insurances	Do citizens have a choice between providers of health insurance	Yes, freely and several alternatives	Yes, limited	No or "not applicable"	MISSOC; Mutual Information System on Social Protection, Organisation of social protection (Charts and descriptions), Situation on 1 January 2008, European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities

4.2 Informal payments to doctors	Mean response to question: "Would patients be expected to make unofficial payments?"	No	Sometimes; depends on the situation	Yes, frequently	Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews; http://www.nhsdirect.nhs.uk/ ; www.hse.ie ; www.ntpf.ie .
4.3 Patient co-payment	Are patients financially engaged in four aspects of healthcare delivery at the point of use	Yes, all 4	In 2 - 3	In 0 - 1	Piotr Woch, Milena Pavlova*, Wim Groot: <i>Patient cost-sharing arrangements in the 27 European Union member states</i> , * Maastricht University; The Netherlands. Personal interviews.

Table 7.4: Indicator definitions and data sources for the Report for 2009

7.5 “CUTS” data sources

Whenever possible, research on data for individual indicators has endeavoured to find a “CUTS” (Comprehensive Uniform Trustworthy Source). If data on the underlying parameter behind an indicator is available for all or most of the 31 states from one single and reasonably reliable source, then there has been a definitive preference to base the scores on the CUTS. As CUTS would be considered EUCID data, WHO databases, OECD Health data, Special Eurobarometers, and scientific papers using well-defined and established methodology.

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS, when available, is that data collection primarily based on information obtained from 31 national sources, even if those sources are official Ministry of Health or National Health/Statistics agencies, generally has high noise levels. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same question. For example, in the Euro Consumer Diabetes Index 2008, it was difficult to find answers to indicators like “Do you have nurse practitioners in your country?” or “Is diabetes foot (podiatrist) a recognized sub-speciality in your country?”. The reason is very simple: the definition of what is a diabetes nurse or a diabetes podiatrist and the amount of education and training required to qualify are different in every country. It has to be emphasized that also when a CUTS for an indicator has been identified, the data are still reviewed through cross-check procedures, as there have frequently been occasions where national sources or scientific papers have been able to supply more recent and/or higher precision data.

7.5.1 The “Rolls-Royce gearbox” factor

Another reason for preferably using CUTS whenever possible is the same reason why Rolls-Royce (in their pre-BMW days) did not build their own gearboxes. The reason was stated as “We simply cannot build a better gearbox than those we can get from outside suppliers, and therefore we do not make them ourselves”. For the small size organisation HCP, this same circumstance would be true for an indicator where a Eurobarometer question, the WHO HfA database, or another CUTS happens to cover an indicator.

7.6 Content of indicators in the Report for 2009

Where possible, CUTS - Comprehensive Uniform Trustworthy Sources - were used; see section “CUTS Data Sources” for more information on this approach, typical for HCP research work.

7.6.1 Patients' Rights

This sub-discipline is testing the ability of a healthcare system to provide the patient with a status strong enough to diminish the information skew walling the professional and patient.

This sub-discipline is a GDP non-dependent indicators' family. Even the poorest countries can allow themselves to grant the patient with a firm position within the healthcare system; and the Report is proving this observation again.

There are ten indicators in this sub-discipline:

1.1. Patients' rights-based national healthcare legislation

Is national healthcare legislation explicitly expressed in terms of patients' rights? If that is the case, is it in the form of a law or other legislative act? Are there professional ethical codes, patients' charters, etc.?

Sources of data: Personal interviews, web-based research, journals search. European Ethical-Legal Papers by KU Leuven. Non-CUTS data.

1.2. Right to choose among providers, domestic

(*i.e.* Do patients have a free choice of which hospital or clinic they want to go to after referral from primary care doctor?). This situation seems to be changing for the better, with *e.g.* the U.K. having instigated this as late as April 2008 – however, 2008 Index editions of the Heart Index, this has not been deemed to have fully taken effect yet for the U.K.

1.3. Right to choose among providers across borders in the EU

No country seems to really have taken this radical decision. Danish patients responding to the survey answered unanimously that they have that right, our input from several Danish patient organization says differently and it could not totally without reservations be confirmed by the Danish National Board of Health. Luxembourg gets a “cheap” Green score due to their long-standing tradition of seeking care in their neighbouring countries.

1.4. Direct access to specialist

Can patients see a specialist without first having to gain a referral from a primary-care doctor?

This indicator happens to be the most disputed of all in the history of HCP indexes. Although, or maybe consequently, we keep it and we must agree with the notion that “no significant effects of gatekeeping were found on the level of ambulatory care costs, or on the level or growth of total health care expenditure”³³

Sources of data: Patients' Perspectives of Healthcare: Waiting times in Europe; survey commissioned by HCP 2008. Personal interviews with healthcare officials; http://www.im.dk/publikationer/healthcare_in_dk/healthcare.pdf ; <http://www.ic.nhs.uk/> ; <http://www.oecd.org> . Non-CUTS data.

³³G Van Merode, A Paulus, P Groenewegen: Does general practitioner gatekeeping curb health care expenditure? J Health Serv Res Policy. 2000 Jan ;5 (1):22-6

See also Kroneman et al: Direct access in primary care and patient satisfaction: A European study. Health Policy 76 (2006) 72–79

1.5. Patients' Organisations in decision making

Do patient organisations have right to participate in healthcare decision making? Sometimes we find that patient's organisations are welcomed to get involved, sometimes they do it by law, sometimes they do it only informally, but usually, sometimes only formally without a real participation, sometimes not at all.

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews. Non-CUTS data.

1.6. No-fault malpractice insurance

Can patients get compensation without the assistance of the judicial system? Does the compensation prerequisite proving who among the medical staff made a mistake? Each year, the HCP research staff is meeting high healthcare officials who have never heard of no-fault malpractice system, such as that put in place essentially in the Nordic countries.

Source of data: Personal interviews, web-based research, journals search. Non-CUTS data.

1.7. Right to second opinion

As in other areas of human life, there are not many questions and conditions with only one right answer, in medicine also. Therefore, do the patients have the right to get the second opinion, without having to pay extra? Is it a formal right, but unusual practice, or well-established institute?

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Health and Social Campaigners' News International: Users' perspectives on healthcare systems globally, Patient View 2005. Personal interviews. Non-CUTS data.

1.8. Access to own medical record

Can patients readily get access to, and read, their own medical records? Hard to believe, at some places in Europe, the patient's personal data and integrity is so protected, that he cannot access his own medical record. This is remarkable, as the Data protection directive is very clear on the fact that the patient should have this right by law. Elsewhere, he cannot access it neither, but at least he is not being told it is for his own good.

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Health and Social Campaigners' News International: Users' perspectives on healthcare systems globally, Patient View 2005. Personal interviews; web and journal research. Non-CUTS data.

1.9. Voluntary national screening programme

Is there a *National screening programme (for CVD)*? As the Report does not award scores for policies, the data for this indicator come from the Special Eurobarometer on Health, September 2007. The % of positive responses to the question "Have you had a blood pressure check in the past 12 months?", and the same % on the question "Have you had a blood lipid check in the past 12 months?" were each indexed with the average EU

% set to = 100, and the average of these two indexes for each state used as the indicator data. Equivalent data were reported by the Swiss Bundesamt für Statistik. CUTS data.

7.6.2 Information to patients

“Empowerment” cannot be limited to an extensive set of Patients’ Rights, if patients cannot easily obtain the relevant information on which to base informed choice.

2.1. Provider catalogue with quality ranking

In 2005, Dr. Foster of the UK was the single shining star on the firmament of provider (hospital) listing, where patients could actually see which hospitals had good results in term of actual success rates or survival percentages.

In 2007, there are already a few more examples, where the Health Consumer Powerhouse believes that the most notable is the Danish www.sundhedskvalitet.dk, where hospitals are graded from ★ to ★★★★★ as if they were hotels, with service level indicators as well as actual results, including case fatality rates on certain diagnoses. Perhaps the most impressive part of this system is that it allows members of the public to click down to a link giving the direct-dial telephone number of clinic managers.

The German state company Bundesgeschäftsstelle Qualitätssicherung GGmbH, www.bqs-online.de, also provides results quality information on a great number of German hospitals, presently (March 2009) on 33 indicators.

Still, in 2009 “Dr. Foster” in the U.K. remains the standard European qualification for a green score (achieved also in Denmark and Germany), the “750 best clinics” published by LePoint in France would warrant a yellow, as a nice attempt, as in three other countries. The rest of the countries are desperately red.

Sources of data: <http://www.drfooster.co.uk/home.aspx> ; <http://www.sundhedskvalitet.dk/> ; http://www.sykehusvalg.no/sidemaler/VisStatiskInformasjon_2109.aspx ; <http://www.hiqa.ie/> ; <http://212.80.128.9/gestion/ges161000com.html> . Non-CUTS data.

2.2. Register of legit doctors

Can the public readily access the information: "Is doctor X a bona fide specialist?" Has to be a web/telephone based service and we do not score green for Yellow pages – with an exception of Luxembourg, where the chapter on physicians is yearly reviewed and approved by the Ministry of health. Very easy and cheap to implement, but still very difficult to find sources of information.

Sources of data: Patients' Perspectives of Healthcare Waiting times in Europe; survey commissioned by HCP 2007. National physician registries. Personal interviews; web and journal research. Non-CUTS data.

2.3. Web or 24-7 telephone healthcare info

Simple description of this indicator used in previous years' editions remains the same in 2008: Information which can help a patient take decisions of the nature: “After consulting the service, I will take a paracetamol and wait and see” or “I will hurry to the A&E department of the nearest hospital” The most comprehensive service of this kind is the British NHS Direct.

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews, web search. Non-CUTS data.

2.4. Patients' letters copied to patients?

Do patients' letters (*e.g.* from specialist to GP after a specialist examination) systematically and automatically go also to patients, as a separate copy for the patient? In some states, patients are employed as “postmen” carrying such letters back to their GP, sometimes sealed (Red score), sometimes open (Yellow).

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Personal interviews, web search. Non-CUTS data.

2.5. Layman-adapted pharmacopoeia

Is there a layman-adapted pharmacopoeia readily accessible by the public (www or widely available)?

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2006. Personal interviews. LIF Sweden.

<http://www.doctissimo.fr/html/sante/sante.htm> ;

http://www.legemiddelverket.no/custom/templates/gzInterIFrame_1548.aspx

Non-CUTS data.

7.6.3 Health Technology Assessment (HTA)

In recent years, Health Technology Assessment has been receiving increased attention by healthcare decision makers. The basic reason for this is that, particularly since the mid-1980's, there has been a virtual explosion of new methods and new technology entering medical practice.

The novel technologies create possibilities to cure previously non-curable conditions. However, the non-enterprise nature of healthcare financing frequently causes decision-makers to overlook the rationalization potential offered by many of the new technologies, and a more pronounced focus on the “strain on healthcare budgets” created by the new opportunities for previously unobtainable treatments.

Traditionally, HTA was very much kept within the rank and file of the medical specialist associations, with very little transparency even to healthcare administrators and politicians.

With the Swedish SBU (“Statens Beredning för Medicinsk Utvärdering”; the Swedish Council on Technology Assessment in Health Care) being established in 1987 as the first example, more and more European countries today have set up national agencies with the dedicated purpose of conducting HTA. This is particularly true for the last 3 – 4 years, which have seen many countries establish such agencies.

In this indicator, the existence of such a dedicated national agency has been given a Yellow score. If that agency has structured and regulated forms of patient/layman participation boards/committees, the score rises to Green (only Denmark and the U.K. were found to actually meet this condition³⁴).

Source of data: European Observatory Studies Series No 14, HEALTH TECHNOLOGY ASSESSMENT AND HEALTH POLICY-MAKING IN EUROPE: Current status, challenges and potential, M V Garrido, F B Kristensen, C P Nielsen, R Busse;

Eur Observatory HiT reports. Essentially CUTS data.

7.6.4 Financial incentives

In the development work for the report, research was done in order to find any significant efforts in European countries in the area of actively promoting healthy behaviour and healthy lifestyle of citizens by positive economic incentives. There are few such examples, mostly in the UK and the Netherlands, where studies of such efforts are starting to emerge. In the UK the treatment-to-target is starting to be evaluated.

Also, European healthcare with its strong emphasis on equity, shows a few examples of countries penalizing less healthy lifestyles by *e.g.* higher insurance costs or reduced access to care.

4.1. Right to choose between healthcare insurance providers

Some countries allow their citizens a choice of health insurance provider, some do not. As for any other qualified service, informed consumers making a choice between competing vendors should provide a potential for improved service and increased consumer satisfaction. It could be argued that the rather large number of countries operating tax-financed healthcare systems (“Beveridge systems”) should really be given a score of “not applicable” (n.a.). After careful consideration, the Report development team arrived at the conclusion not to make that distinction – from the patients’ point of view, the Beveridge systems definitely do not offer much choice of what institution provides healthcare coverage. These countries therefore more or less automatically get a “Red” score on this indicator.

Sources of data: **MISSOC** (Mutual Information System on Social Protection), *Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland; Organisation of social protection (Charts and descriptions); Situation on 1 January 2008*: Employment, social affairs & equal opportunities, Social

³⁴ There are other examples, such as Finland, which has one representative from the Finnish Consumers’ Association on its 20-person strong advisory board. That has still only been awarded a Yellow score, as the degree of patient influence would still seem modest. It might be that the Dutch situation could actually warrant a Green score; however, the *Gezondheidsraad* (the national agency) does not have patient participation – that is exerted through other national bodies conducting HTA.

protection and integration, **European Commission**, Directorate-General for Employment, Social Affairs and Equal Opportunities, Unit E.4, European Observatory HiT reports, personal interviews,

4.2. Informal payments to doctors

Mean response to question: "Would patients be expected to make unofficial payments?" with range of answers: plain "No!", "Sometimes, depends on situation" and "Yes, frequently". As an informal payment was considered any payment made by the patient in addition to official co-payment. This survey on informal payments is the first cross-European survey done ever on this problem.

The existence of informal payments was taken as a negative indication on patient empowerment.

Sources of data: Patients' Perspectives of Healthcare Systems in Europe; survey commissioned by HCP 2008. Non-CUTS data.

4.3. Patient co-payment

Indicator	Co-payment GP appointment	Co-payment specialist appointment	Co-payment Hospital in-patient services	Co-payment pharmaceuticals	Indicator score
Austria	☒\$	☒\$	☒\$	☒\$	4
Belgium	☒\$	☒\$	☒\$	☒\$	4
Bulgaria	☒\$	☒\$	☒\$	☒\$	4
Croatia	☺	☺	☒	☺	4
Cyprus	☒\$	☒\$	☒\$	☒	4
Czech Republic	☺	○	○	☒	2
Denmark	○	○	○	☒	1
Estonia	☒	☒	☒	☒	4
Finland	☒	☒	☒	☒	4
France	☒\$	☒\$	☒\$	☒\$	4
FYR Macedonia	☒\$	☒\$	☒\$	☒\$	4
Germany	☒\$	☒\$	☒	☒\$	4
Greece	○	○	○	☒	1
Hungary	○	☺	☺	☒	3
Ireland	☒\$	☒\$	☒\$	☒\$	4
Italy	○	☺	○	☒	2
Latvia	☒	☒	☒	☒	4
Lithuania	○	○	○	☒\$	1
Luxembourg	☺	☺	☺	☺	4
Malta	○	○	○	○	0
Netherlands	○	○	☒\$	☺	2
Norway	☺	☺	☺	☺	4
Poland	○	○	○	☒	1
Portugal	☺	○	○	☺	2
Romania	○	○	○	☒\$	1
Slovakia	☒	☒	☒	☒	4
Slovenia	☒\$	☒\$	☒	☒\$	4
Spain	○	○	○	☒\$	1
Sweden	☺	☒	☒	☒	4
Switzerland	☺	☺	☒	☺	4
United Kingdom	○	○	○	☒\$	1

Legend of symbols:

○	= no cost-sharing
☒	= cost sharing with exceptions for age and/or medical status
☒\$	= cost sharing with exceptions for income and/or age, medical status
☺	= cost sharing (Incl. additional insurance), no exceptions

Still today, most European healthcare systems are, to a dominating degree, funded in “collective” ways, by taxes or regulated insurance solutions. The HCP anticipates a growing discussion about additional ways to finance healthcare as the economic restrictions grow. We chose to show the collection of co-payment we managed to measure in order to give the final score in the report. Since the ambitions among healthcare systems to develop co-payment models are quite low in the area, co-payments are presented as a single indicator; hopefully the HCP will be able to come back with a further, more explicit story of how co-payments evolve across Europe.

We believe that co-payments have to develop, as the sustainability of present sources of funding will be questioned and the empowerment of consumers will open for co-payment perspectives. The recent debate and development in the UK about “top-up options” on new, expensive medicines and their implementation (a system where providers are paid based on performance, like in the US) is probably just an early reflection of this reality.

The cost-sharing structures of healthcare economic benefits differ substantially across Europe. However, the current use of co-payments must be regarded primarily as a cost containment / rationing mechanism rather than providing any degree of patient empowerment. For instance, prescription drug subsidies do vary a lot, but the research found no example of a country where a higher co-payment gives the patient a wider choice of medication unless the patient is prepared to pay the full cost, in which case any registered medication would be available to a patient carrying a prescription. The experiments with new insurance models that are taking place elsewhere in the world with regards to medicine have yet to come to Europe.

Still, it is a good first step if one starts using co-payments, like in the case of Czech Republic. If patients pay for more of the cost directly, it will be harder for the political level to put restraints on what could be used or not.

Also, some countries mix the progressivity of taxation rates into healthcare benefits by making co-payments income-dependent. This measure is a first step towards real payment – ensuring that certain groups are forced to learn to take their own decisions about healthcare.

Most states have exemptions from co-payments on grounds of age and/or medical status. (The data source wrongly notes Sweden as having no exemption on drug co-payments; this was indeed the intention in the last (1997) reform of drug subsidies, but at the last minute, the government proposition was changed to provide diabetics with drugs at zero patient cost.)

There are some ideological differences between groups of European states on the issue of co-payments. A number of states still provide healthcare free-of-charge at the point of consumption, particularly for primary care and out-patient specialist appointments. This is a decreasing phenomenon; the Czech Republic and Germany have recently introduced very nominal co-payments for appointments (EUR 1 per appointment and EUR 10 per three-month period respectively).

It can be noted that the three countries having the highest GDP/capita, Luxembourg, Norway and Switzerland, show a “no exemptions” attitude on co-payments, presumably reflecting an approach of wealthy nations that “Healthcare is so heavily subsidised, so anybody can afford the small co-payments”.

Co-payments give patients an increased choice: Danish patients can bypass the GP as gatekeeper and go straight to a specialist by paying the not-so-nominal fee of DKK 1000 (approx. EUR 130).

We also notice that more and more employers across Europe adopt healthcare insurances as both a risk eliminator for the employer and a bonus for the employee. The employee is given the right to benefit from private healthcare or avoid the queues.

7.7 How the European Patient Empowerment report was built

The method description for HCP Indexes is extensively treated in the reports on the Euro Health Consumer Index 2008 (<http://www.healthpowerhouse.com/files/2008-EHCI/EHCI-2008-report.pdf>) and the Euro Consumer Heart Index 2008 (<http://www.healthpowerhouse.com/files/euro-heart-index-2008.pdf>), from which

several of the indicators for the Report for 2009 were extracted. For method descriptions, please refer to those reports.

7. 8 About the Health Consumer Powerhouse

The HCP is a private company providing consumer analysis and information. HCP accepts unrestricted research or educational grants from institutions and companies and also sells healthcare-related information in the competitive intelligence market. The HCP does not accept grants from any entities measured in the indexes and reports.

The “Empowerment of the European Patient - Options and Implications” project was supported by a unrestricted grant by Novartis SA.

8. References

8.1 Main sources

The main sources of input for the various indicators are given in Table 7.4 above. For all indicators, this information has been supplemented by interviews and discussions with healthcare officials in both the public and private sectors. Interviews were also made with healthcare stakeholders.

8.2 Useful links

Web search exercises have yielded useful complementary information from, among others, these websites:

<http://www.aesgp.be/>

http://www.wrongdiagnosis.com/a/amputation/stats-country_printer.htm

<http://www.easd.org/>

<http://www.diabetes-journal-online.de/index.php?id=1>

<http://www.drfooster.co.uk/>

<http://www.rivm.nl/earss/>

<http://www.eudental.org/index.php?ID=2746>

http://europa.eu/abc/governments/index_en.htm

http://europa.eu/pol/health/index_en.htm

http://ec.europa.eu/public_opinion/index_en.htm

http://europa.eu.int/youreurope/index_sv.html

<http://www.eurocare.it/>

<http://www.ehnheart.org/content/default.asp>

<http://www.euro.who.int/observatory>

<http://www.escardio.org/>

http://epp.eurostat.cec.eu.int/portal/page?_pageid=1090,30070682,1090_33076576&_dad=portal&_schema=PORTAL

http://ec.europa.eu/health-eu/index_en.htm

<http://www.who.dk/eprise/main/WHO/AboutWHO/About/MH#LVA> (Health Ministries of Europe addresses)

<http://www.hospitalcompare.hhs.gov/>

<http://www.hope.be/>

<http://www.activemag.co.uk/hhe/error.asp?m=2&productcode=&ptid=3&pid=2&pgid=34&spid=> (Hospital Healthcare Europe)

<http://www.idf.org/home/>

<http://www.eatlas.idf.org/>

<http://www.hospitalmanagement.net/>

<http://www.lsic.lt/html/en/lhic.htm> (Lithuanian Health Info Centre)

<http://www.lse.ac.uk/collections/LSEHealthAndSocialCare/>

<http://www.medscape.com/businessmedicine>

<http://www.oecdbookshop.org/oecd/display.asp?TAG=XK4VX8XX598X398888IX8V&CID=&LANG=EN&SF1=DI&ST1=5LH0L0PQZ5WK#OtherLanguages> (OECD Health Data 2005)

http://www.oecd.org/department/0,2688,en_2649_33929_1_1_1_1_1,00.html (OECD Health Policy & Data Department)

<http://www.medscape.com/medline/abstract/15176130> (Patient Ombudsmen in Europe)

<http://aitel.hist.no/~walterk/wkeim/patients.htm> (Patients' Rights Laws in Europe)

<http://www.patient-view.com/hscnetwork.htm>

<http://www.pickereurope.org/>

<http://www.vlada.si/index.php?gr1=min&gr2=minMzd&gr3=&gr4=&id=&lng=eng> (Slovenia Health Ministry)

<http://www.lmi.no/tf/2004/Engelsk/Chapter%206/6.20.htm> (Tall og fakta)

<http://www.100tophospitals.com/>

<http://www.worldcongress.com/presentations/?confCOde=NW615>

<http://www.who.int/healthinfo/statistics/mortestimatesofdeathbycause/en/index.html>

<http://www.who.int/topics/en/>

<http://www.who.int/healthinfo/statistics/mortdata/en/>

<http://www.euro.who.int/hfadb> (WHO "Health for All" database)

<http://www.who.dk/healthinfo/FocalPoints> (addresses to Health Statistics contacts in Europe)

<http://www.who.int/genomics/public/patientrights/en/>

<http://www.waml.ws/home.asp> (World Association of Medical Law)

<http://www.wrongdiagnosis.com/risk/geography.htm>

8.3 Annex 1: Source documents for the Patients' Rights Indicator (in addition to feedback from national authorities).

<https://www.kuleuven.be/cbmer/page.php?LAN=N&ID=383&TID=0&FILE=subject&PAGE=1>

Patients' Rights Laws

Country	Name with Link	Language
Finland, 1992	Lag om patientens ställning och rättigheter (785/1992): http://www.mhbibl.aland.fi/patient/patientlag.html	Swedish
Netherlands, 1994	Dutch Medical Treatment Act 1994 : http://home.planet.nl/~privacy1/wgbo.htm	English
Israel, 1996	Patient's Rights Act : http://waml.haifa.ac.il/index/reference/legislation/israel/israel1.htm	English
Lithuania, 1996	Law on the Rights of Patients and Damage Done to Patients : http://www3.lrs.lt/c-bin/eng/preps2?Condition1=111935&Condition2=	English
Iceland, 1997	Lög um réttindi sjúklinga : http://www.althingi.is/lagas/123a/1997074.html	Swedish
Latvia, 1997	Law of Medicine (= The law on medical treatment): http://aitel.hist.no/~walterk/wkeim/files/Latvia_The_law_of_Medicine.htm	English
Hungary, 1997	Rights and Obligations of Patients (According to Act CLIV of 1997 on Public Health): http://www.eum.hu/index.php?akt_menu=4863 . The Szószóló Foundation supports patients' rights.	Hungarian / English
Greece, 1997	Law 2519/21-8-97	
Denmark, 1998	Lov om patienters retsstilling, LOV nr 482 af 01/07/1998	
Norway, 1999	Pasientrettighetsloven : http://www.lovdata.no/all/hl-19990702-063.html . Other Norwegian Health laws.	Norwegian

Georgia, 2000	The Law of Georgia on the Rights of patients	
France, 2002	LOI n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé (1): http://www.legifrance.gouv.fr/WAspad/UnTexteDeJorf?numjo=mex01000921#	French
Belgium, 2002	Act on Patients' Rights: http://www.lachambre.be/	Dutch / French
Switzerland, 2003	Patientenrechtverordnung 1991, Patientenrechtsgesetz ist in Vorbereitung: http://www.zh.ch/gd/aktuell/news/presseberichte/news_21_12_00_1a.htm	German
Russia	Fundamentals of The Russian Federation Legislation: On protection of citizens' health.	
Estonia, 2002	Draft of the Act on Patients' Rights PATSIENDISEADUS: http://www.riigikogu.ee/	Estonian
Romania, 2003	Legea nr 46/2003, legea drepturilor pacientului (Law of Patients' Rights): http://www.dreptonline.ro/legislatie/legea_drepturilor_pacientului.php	Romanian
Cyprus, 2005	European Ethical-Legal Papers N° 6 Patient Rights in Greece: http://www.eurogentest.org/web/info/public/unit4/ethical_legal_papers.xhtml#legal_5	English

Charters of the Rights of Patients

Country	Name with Link	Language
France 1974 and 1995	Charte du Patient Hospitalisé: http://www.ch-erstein.fr/charte/chartepatient.html	French
UK, (1991), 1997	The Patient's Charter for England: http://www.pfc.org.uk/medical/pchrt-e1.htm	English
Czech Republic, 1992		
Spain, 1994	Charter of Rights and Duties of Patients	
Ireland, 1995	Charter of Rights for Hospital Patients	
South Africa, 1996	PATIENTS RIGHTS CHARTER: http://www.hst.org.za/doh/rights_chart.htm	English
Portugal,	Patients' Rights Charter: Carta dos Direitos e Deveres dos Doentes	Portuguese

1997	http://www.dgsaude.pt	
Honk Kong, 1999	Patients' Charter: http://www.ha.org.hk/charter/pceng.htm	English
Poland, 1999	Karta Praw Pacjenta: http://wojtas_goz.webpark.pl/karta.html Polish Patients Association: Letter to Commissioner for Human Rights.	Polish
Slovakia, 2001	Charter on the Patients Rights in the Slovak Republic: http://www.eubios.info/EJ143/ej143e.htm	English
Austria, 2001	Vereinbarung zur Sicherstellung der Patientenrechte (Patientencharta): http://www.noel.gv.at/service/politik/landtag/LandtagsvorlagenXV/WeiterenVorlagenXV/795/795V.doc	German
Germany, 2001	Experts support patients' rights law: Sachverständigenrat tritt für Patientenrechte-Gesetz ein . The German health system is most expensive in EU, but only under average (World Health Report 2000: Rank 25) in quality of services. Petition der Bundesarbeitsgemeinschaft der Notgemeinschaften Medizingeschädigter: http://www.patientenunterstuetzung.de/Grundsuetzliches/Petition.pdf	German
Cyprus, 2001	Cyprus Patients Rights' Charter: http://www.activecitizenship.net/documenti/Cyprus_Charter_Patients_Rights.doc	English
Germany, 2002	Patientenrechtscharta: http://www.bag-selbsthilfe.de/archiv/jahr-2002/patientencharta/patientenrechte-in-deutschland/	German
Europe, 2002	Active Citizenship Network: European Charter of Patients Rights http://www.activecitizenship.net/projects/europ_chart.htm	English
Italy	Active Citizenship Network: Italian Charter of Patients Rights http://www.activecitizenship.net/health/italian_charter.pdf	English

Six years after the WHO *Declaration on the Promotion of Patients' Rights in Europe* (Amsterdam, 1994), more than eight countries (Denmark, Finland, Georgia, Greece, Iceland, Israel, Lithuania, the Netherlands and Norway) have enacted laws on the rights of patients; and four countries (France, Ireland, Portugal and the United Kingdom) have used Patients' Charters as a tool to promote patients' rights. (German version). *European Journal of Health Law* 7: 1-3, 2000: Lars Fallberg: Patients' Rights in Europe: Where do we stand and where do we go?