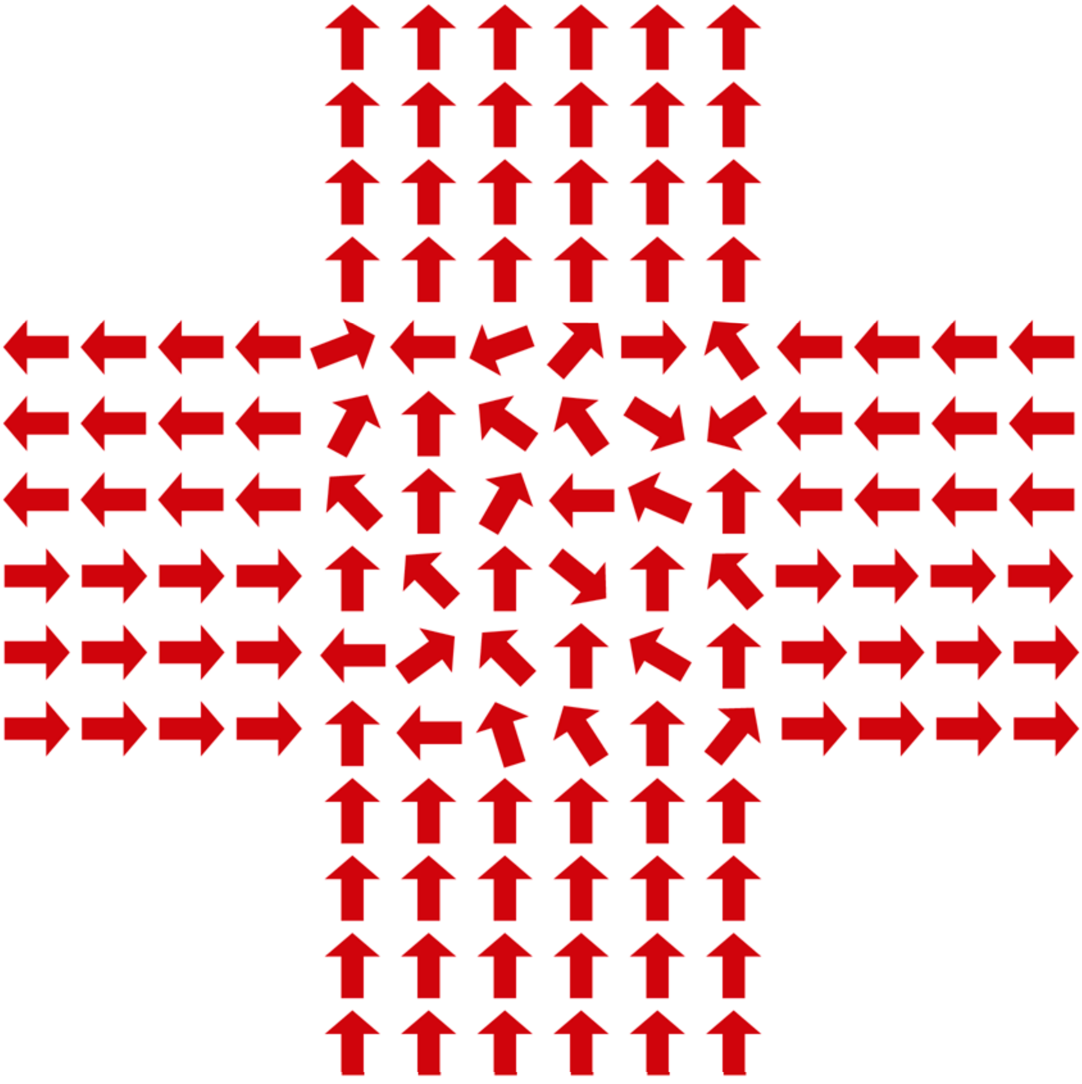
Health Consumer Powerhouse



CROSS BORDER CARE EU

How to choose the best hospital

A study of hospital information portals in five European countries

Health Consumer Powerhouse

Cross border care EU:
How to choose the best hospital?
- A study of hospital information portals in five EU countries

Report

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Foreword: Do you want to choose the best EU hospital?

Do you buy a mobile phone without reading the tests in media? Would you dare to invest in a new home without investigating the qualities and obligations (not mentioning the price and monthly costs)? Do you go for a holiday travel, repair your car or visit the theatre without trying to learn some about what you can expect to achieve?

Probably not. You are an active consumer who wants to be in charge – or at least no doubt have a say. But with healthcare – according to some people even more important than flat screen TVs or home insurance – active comparisons among care providers are still rare. As shown by numerous HCP studies there is a growing awareness of access and quality gaps in European healthcare which you would like to navigate, but generally still a deplorable lack of consumer information to support your choice.

Though slowly emerging, help is under way. In a growing number of countries there are Internet portals offering information to make comparisons among hospitals and here and there between family doctors as well. Some of the best examples, displayed in this report, allow you to make a ranking among the providers, but still the user friendliness leaves a lot to wish for. But the signal is there: to make you as a care consumer or patient better involved in your treatment more information of services and outcomes must be made available. At the end of the day, one question counts: who offers the best value for money?

This will become the overall key question, as Europe for decades will be nurturing the debt crisis putting the searchlight on delivery of healthcare (better value for money or rationing of services are the two main alternatives for most indebted governments).

Here the care consumer can become a powerful player – when aware of the performance gaps in healthcare and if ready to make active choices to get the best out of the stressed industry called healthcare. In this study we have portrayed five countries with different kinds of (more or less) user-friendly web portals aiming to inform citizens in need of a hospital or general practitioner visit of the qualities and capacity of such care providers. In Europe these portals are the state of the art, most likely to be followed by many more countries as the healthcare integration of the EU advances, with more cross border care and hunt for the best examples.

But we are not there yet. There is still a long way to go, as not even these top notch portals, built for years with a lot of money, seem to deliver what consumers and Internet visitors really look for. The new EU cross-border care directive steps up the information requirements. We expect member states governments to look for good examples how to organise and deliver user information, another reason to present some good examples and reflections on healthcare information. To make a difference this systematic mobility information will have to be quite ambitious, offering facts and advice in a wide field, from legal conditions for medical travelling to how to protect you from medical errors, from the design of foreign healthcare systems to the quality outcomes for standardised treatments in all hospitals concerned. And so forth…A tall order indeed! That governments now will be expected to offer this kind of information is a proof of how the EU integrates!

The drive for information is partly value driven, as especially new generations of care consumers have grown up with frequent consumer information, rankings and Internet search a daily guide to most fields of life. Why should a hospital treatment be exempted (though you still pay only a small if any part of the cost yourself, a situation that might change)? Partly it is a matter of governments introducing open benchmarks as a strategy to make the publicly regulated welfare sector more efficient. The long term political ambition might even be that visitors to healthcare take advice from quality performance comparisons, turning to the providers who deliver the best care, not only the nearest hospital or the family doctor you have consulted since decades. And if patients go for hospitals with short waiting lists or even vacancies the total healthcare economy might gain, as all resources become engaged. This is a likely political perspective.

Though still in an early stage of development, benchmarking of hospitals and doctors is a matter that engages care consumers. When the Health Consumer Powerhouse for this report asked patient groups to give us their view of how patients use these kinds of information systems we got a massive response around Europe. More than 1 000 responses – all time high for a Patient View survey– indicate that people take an interest but still do not really know how to use these tools and how to interpret the answers they get.

Building from this vivid interest HCP will try to make this study a social media project with a longer life span, inviting follow up comments to the initial study on our HCP blog (http://blog.healthpowerhouse.com). We welcome this opportunity to work together with patient and consumer groups in Europe. The blog will stay open till January 2011 for a discussion about our findings and how to advance user-friendly healthcare information.

This study, like most other parts of the HCP work, is funded through unrestricted educational or development grants. We are happy to see MSD Europe Inc. supporting this report and hope that the field of growing care provider benchmarking will gain further interest.

Brussels, November, 2010

Johan Hjertqvist

Founder & CEO

Health Consumer Powerhouse

1. Summary

In this report the Health Consumer Powerhouse presents the results from the study "*How to choose the best hospital?*" During this investigative work, the HCP team conducted a research on hospital information portals in five European countries: the Netherlands, Denmark, Germany, the United Kingdom and Sweden. These IT portals were analysed on aspects such as user-friendliness and *quality of care information* (QCI). Furthermore, a questionnaire about the use and effectiveness of such hospital information portals from the patients' point of view was distributed in 32 European countries and evaluated afterwards. The survey indicates huge patient interest in issues of information and choice in healthcare.

The main conclusions that we draw together in this report reflect today's picture of QCI in all major European countries. The Internet as an information source, which is available 24 hours and 7 days a week, plays a leading role in all thinkable areas of a consumer's life. In healthcare however, it is still in its baby shoes and QCI has a long way to go before it can become a serious alternative to other information sources.

Throughout our survey we've come to see that the impact of hospital IT-portals as a source of information for patients remains low. In healthcare, people still tend to make their choices based on other grounds, such as the traditional family GP or the hospital around the corner. One possible explanation for this might be that the consumer is generally in doubt about the reliability and credibility of Internet information in healthcare. Also the question remains unanswered, on what ground patients are ready to make active decisions about an often complicated question such as hospital treatments: independently or in close dialogue with healthcare professionals, peers and relatives. Emotional barriers from a lay-person's perspective, as fear and a general feeling of powerlessness, seem to be one of the reasons why patients tend to stick to their traditional choices.

The type of information presented on hospital information portals should evolve around at least four pillars: quality of treatment, waiting times, patient experience and patient satisfaction. None of the portrayed IT portals performs well in all four aspects. Treatment quality seems to be the main focus, but it is rarely communicated in a user-friendly way. In some cases it is displayed in an over-simplified way, where vital consumer information is missing. In others, consumers face a long list of indicators, which seems overwhelming for a lay-person's know-how. So in the end, the consumer's approach is missing in all of these portals.

There is no doubt however, that there is a need for a development of hospital/healthcare information portals, which by the way could go hand in hand with the *new EU directive on cross-border healthcare*. Patient mobility requires information to patients and there will be a demand for each Member State to maintain national contact points to inform patients about

the availability of healthcare, quality outcomes, safety standards, access to medication, administrative procedures, complaints and appeals etc. Even price information might evolve from this new directive. Hospital information portals naturally will become another information source for patients.

But if then patients start making choices for hospitals, which are delivering better quality for the least price, the interesting question comes up: will this drive hospitals to better quality outcomes? In maternity and pediatric care, consumers already have a strong tendency to compare the services offered by the diverse hospitals. As a matter of fact hospitals are increasingly adapting to the consumer's preferences. If we take a look at this trend in service quality, how will it develop in a couple of years further?

It might be the case that quality of treatment will increase even more, because the consumer is choosing for the best option. The link between active choice and improved quality outcomes is an area waiting for further research!

2. Why bother to make a choice?

If you can, avoid having a heart treatment at the Sundsvall hospital in northern Sweden. Or in Mora in the heart of Dalecarlia. Or in Halmstad, south of Gothenburg.

Why so?

Because the heart clinics in these city hospitals have a poor performance, with a fatality rate double the national Swedish average. When an investigative TV program recently compared the performance of Swedish heart care, this was big news to the public (though HCP indexes in Sweden for some years already had indicated similar results).

There are different explanations to the quality outcomes variations, of course. In some hospitals there might be medical mistakes and accidents affecting the statistics, which is bad enough. It is even worse if a hospital – which proved to be the case in Sundsvall – ignores or even refuses to comply with best practice, as expressed by national medical guidelines and official recommendations.

Might save your life

Survival is of course the key thing but having to wait for an angioplasty intervention (part of the recommended procedure) is also of importance to heart patients. According to the same TV program, at the University hospital of Lund (in southern Sweden) an emergency case will be treated this way within two hours. In Sundsvall you will be sent home and have to wait eight months for the same intervention that restores the blood circulation around the heart.

Would it not be essential to Swedish heart patients to know of such circumstances and huge gaps in service, attitude and outcomes within every field of hospital treatment? Of course! Watching such a ranking at your PC screen it would take some cold nerves – or apathy – to accept the referral from your family doctor to go to the Sundsvall heart clinic (though emergency cases have less of a choice, of course). Already survival ratings as well as information whether a certain clinic follows national guidelines would be essential – and alarming – knowledge.

The performance of heart clinics is not a secret in Sweden, as excellent national quality registers regularly produce detailed information about every clinic. But in reality this data has been a professional affair, formally available to everybody but presented in a way that requires medical and statistical skills to interpret. It would be like asking the potential buyer of a car to call the factory for product information, delivered in an unsystematic way and difficult to interpret…

None of the above mentioned hospitals will probably attract any medical travellers from other parts of Sweden and even less the EU. But to support future mobility, there will have to be transparency, compatibility, fresh data and not the least a high degree of user-friendliness.

In 2004 HCP started publishing Swedish indexes based on registry data, a step which by then was highly controversial as the politico-medical establishment neither was used to nor exactly loved the idea of suddenly being scrutinised and compared. But our initiative was fairly soon accepted and since some years public performance ranking has become quite common in Sweden (though a national hospital portal is still missing).

The first Swedish Consumer Index was followed already in 2005 by our first pan-European Index, of which HCP has since published around 30 overall measurements (Euro Health Consumer Index) as well as disease specific indices (heart, diabetes, HIV/AIDS et cetera). There is no secret that not only better transparency has been the HCP goal but as well to support European mobility, highlighting gaps and good examples.

Six years after our first Index, EU decides to open up member state healthcare for cross border care, a decision the consequences of which will gradually impact and already in the next few years require far better navigational information for care consumers. In this perspective not even the best hospital guides analysed by this report will prove enough – not to mention the information black holes still typical for most EU countries!

Disaster

What people want to learn about is how reliable the hospital is under ordinary conditions and in the long run. Most decisions among patients, relatives and the medical profession will happen in daily life, when you prepare a referral for a planned treatment and want to investigate the best options in an un-dramatic way. Or when a patient wants to use the today common right to pick another hospital to avoid long waiting for an operation.

But to avoid plain disaster – hopefully rare but the more awful when it happens – is another way to use healthcare performance information. The following revolting UK example points to very different conditions from the Swedish heart example we just described (but with the common denominator that alert lay-person information could have addressed the problems).

In February this year BBC reported about severe failures of patient safety and treatment at the NHS Stafford hospital in the UK:

"In 2009 a damning report from the Healthcare Commission, a NHS watchdog, said it had found appalling standards of emergency care at the trust and said patients would have died as a consequence of the deficiencies it found.

The chairman and chief executive of the trust, which runs an accident and emergency department at Stafford Hospital, stood down in March last year.

Health Secretary Andy Burnham said the government and the trust's new board would accept all 18 of the inquiry's recommendations contained in a 900-page report.

"(The) report lays bare a dysfunctional organisation at every level and appalling failures of basic care over the period between 2005 and March 2009," he said.

The most basic elements of care were neglected, it said.

"Calls for help to use the bathroom were ignored and patients were left lying in soiled sheeting and sitting on commodes for hours, often feeling ashamed and afraid. Patients were left unwashed, at times for up to a month," it said.

"Staff failed to make basic observations and pain relief was provided late or in some cases not at all”.

"The standards of hygiene were at times awful, with families forced to remove used bandages and dressings from public areas and clean toilets themselves for fear of catching infections, according to the BBC reporting."

This probably was an extraordinary case, where you hardly sit waiting for bad, publicly announced figures of patient satisfaction surveys to gradually make an impact. But if every hospital or provider is required to do regular surveys among patients and their relatives you can often have an early warning, as gross neglecting of patient needs usually is linked to bad organisation of the workforce. If the outside world starts noticing that certain hospitals again and again acquire low scores for patient and relative satisfaction, action will be unavoidable.

French infections

In France, without any national hospital outcomes portal, there are a number of initiatives to improve transparency, especially within media. The L´Express magazine for example does an annual benchmark of hospital infections, including more than 300 French hospitals (www.lexpress.fr/palmares/hopitaux/default.asp). The outcomes are presented in print as well as the L´Express website and qualify in our report as a good example how to fight hospital infections, a growing menace to healthcare around the world.

The L´Express ranking offers a hands-on tool if you want to reduce the risk of having infection while your stay in the hospital: At the website you can pick the (geographical) department you look for, select a given hospital and check the infection rate put into relation to the one among the best French hospitals. In the Seine Estuary department (Bouche de Seine), for example, try to avoid staying at the hospital in Yventon, ranked no 273 among all the 337 hospitals in the measurement. For infections, this hospital scores no more than 58 of potential 100%. Then the Barentin hospital in the same department, with close to 90% score and ranked as the 21st best in France, gives a more credible impression.

At this website you can as well follow the development over the last years and notice what kind of measures have been successful in fighting killer bug infections. This is essential, accurate and user-friendly care consumer information about serious, even life-threatening conditions that should be available in every country! Good media work, serving a watch-dog purpose!

Why bother?

These are a few examples suggesting that there are important variations of access, service ambition, treatment outcomes, access to rehabilitation and medication, follow up procedures and so forth among European hospitals – not only between countries or regions but as well in the same city (or even between clinics in the very same hospital and between family doctors sharing a practice). And that transparency regarding the performance can have a number of positive effects on the delivery and quality of care, among hospitals and GP clinics:

- The “grateful generation” of Europeans, taking doctors’ words for granted and trusting every hospital to be the best, is almost history. The “demanding generation” of active patients turning into health consumers, looking at healthcare with the same eyes as for every other service, is becoming more and more present. In the aging Europe there is a growing need to involve patients and consumers in the healthcare processes, to balance demand to resources. It is a matter of engagement in care decisions as well as a financial one. Without offering these citizens tools for empowerment and choice they will hardly accept larger responsibilities, in the form of time-consuming efforts on behalf of themselves or close relatives or to make economic sacrifice (co-payment, additional insurance et cetera).
- Naming and shaming is a powerful tool, rewarding the best and putting the searchlight on poor performance. Doctors are a competitive kind and seldom accept to stay at the bottom of a rank. Hospitals work in a confidence market and want to avoid the bad performance stamp. For every care provider a loss of reputation can severely affect the income, as patients become more volatile and the reimbursement more and more often is a fee for service; losing a patient might mean losing money rather than avoiding costs.
- To the medical profession better transparency would provide important support when referring patients for a treatment. Today many referrals are based on old knowledge, informal connections, hearsay and so on – a stable performance rating would probably not replace these other sources but offer a substantial complement, increasing the probability of a successful outcome.
- Payers and contractors are gradually moving into paying care providers according to services delivered, where the quality of performance (far too) slowly start affecting the payment. Some more sophisticated and business oriented payers have already built in quality criteria in the contracts and reimbursement schemes. In such a case it will be essential to both parties to be able to rely upon benchmark systems to evaluate the delivered quality.
- The EU already is a major policy player in European healthcare. The new Cross-border Care Directive will put at pressure at national governments to improve reporting and transparency on not only legal issues but as well with regard to performance. In an integrated healthcare services market consumer information will be key. An open EU hospital benchmarking system will be a likely medium-term outcome as well as a list indicating the price in every country for certain standard

treatments. Such shocking transparency will gain us all. What could not a "McHip Index" tell you about the competitiveness among clinics doing hip replacements?

- The mobility funding mechanism of the EU system can be described as a "portable voucher", meaning that the patient can bring the cost for the same treatment in her country of residence to the foreign hospital. Especially if this proves insufficient and you (or your insurance company or government) accordingly will have to "top up", the price discussion will be unavoidable.

The response of our Patient View poll among more than 1 000 European patient activists suggests that they appreciate web information about quality outcomes and that such information would affect the choice among patients looking for a treatment. More about this survey in chapter 8.

A strategic step

The most successful healthcare systems around Europe start implementing consumer information and guidance systems as a strategic element. Not only the Health Consumer Powerhouse takes such measures into regard when ranking the performance of healthcare systems. Even more interesting is that frontrunner healthcare systems, such as Denmark and the Netherlands, themselves look upon our evaluation, rewarding information access, as a proof of their leading position. We are even ready to state that advanced information solutions designed for the citizens is an essential criteria improving the capability of the system to deliver quicker and better healthcare services.

In the Dutch market oriented healthcare reform competition for insured citizens and active consumer choice are essential mechanisms. A driving force behind the Danish portals is to increase the involvement of citizens and patients and to engage their knowledge to improve prevention and treatment. Here better user information is an absolute condition. Often reluctantly other EU governments will start drawing the very same conclusion.

As explained by this report, in the whole of the European Union care consumers in only four out of presently 27 member countries can have comprehensive, national information about what services the hospitals offer and – maybe even more important – how well hospitals perform. To be sure that your hospital is not only close to where you live but that it also delivers high quality services, increasing your chances of a safe and full recovery, should be essential, as we see it.

3. Study aim and design

For the first time patients and care consumers in some European countries can access information providing guidance among healthcare service producers, based on quality outcomes. Historically and systems-wise there has been a blatant lack of such public, organised lay-person information. Healthcare systems such as in Denmark, UK, Sweden, Germany and the Netherlands now start applying high-quality consumer information as a strategic tool to improve outcomes among hospitals and other providers. The aim is to make patients actively choose among providers, which would drive the quality outcomes.

This study aims to investigating to what extent patients/consumers in key European countries are familiar with and use performance-based guide and ranking systems such as www.sundhedskvalitet.dk, www.nhsdirect.org.uk, www.vårdguiden.se and similar web portals in these countries.

Further we are curious to know if active consumers do follow the quality marks provided by these hospital portals, well aware that such an evident impact probably will be difficult to distinguish already at this early stage of the information development. In healthcare confounding factors are common and the field of user information most likely is no exception.

Last but not least you can question whether this kind of existing guidance will be enough – as inspiration or a model – when in the next few years member state governments of the EU will be expected to put together mobility information, allowing for patient decisions of cross-border care. Here member country experience of hospital information can contribute to coherent, user-friendly, cost-efficient cross border care information design!

The scope

The expansion of user-related healthcare information centres on the Internet. This means that we will look into available Internet information for the public (i.e. patients, consumers, tax payers and so forth). We will neither analyse general or public health sites nor compare digital health information designated to the medical profession and patient organisations or dedicated to specific diseases and conditions.

Our scope is “navigational information” aiming to guide Internet-users looking for the most available, well performing, service oriented and attractive care provider solutions. In reality we talk of hospitals/clinics and - if such information at all exists - family doctors and GP’s.

Neither have we studied “old” information sources, such as handbooks, manuals, lists of doctors and so on. We focus on Internet portals, as the web already is the main resource to navigate health and healthcare and quickly develops further into more interactive and user friendly applications. This definition does not exclude print (or radio/TV) as a valuable source of information; on the contrary, in our “open consultation” for this report with patient organisations we have noticed a concern for such ways to present information, as Internet can have clear disadvantages to people with poor eye sight, lack of Internet experience and so forth. But with respect for such opinions, in this study we focus on web information sources.

Our main concern is whether the web visitor can access data to compare the performance among the care providers (hospitals/primary care doctors). Is there information supporting the user to find the “best” provider, according to his/her needs and priorities? That is why we do not give marks neither for elementary information of no or limited value (address, phone number, when the hospital was built et cetera) nor facts without any relation to the potential performance (the number of doctors at the hospital says nothing of the quality of care).

Combined sources

The report combines desk and web research with a major patient poll about the use of available websites. This poll, performed by Patient View (www.patient-view.com), was made as an Internet survey, during April-May 2010. The poll attracted more than 1 000 answers by patient activist and groups in 30 countries. As could be expected the participants are unevenly distributed, with a higher response rate in countries more advanced in public information and/or with healthcare as a high priority matter among the citizens. Having this diversified EU map in mind you can expect some member countries to push forward while others will be slow to start moving.

Key questions

Some of the questions this study would like to answer are:

- Is there user-friendly websites containing up-to-date information about the quality of treatment results in different hospitals/clinics in your country?
- Do patients consult these websites?
- How relevant is this information regarded?
- Do users actually take advice from all these rakings and information sites, so they more often choose healthcare providers with the best clinical performance?

Good examples

The study will look for good examples and key learning from concerned nations. Which are the remaining information gaps with regard to care provider quality comparisons? What further improvements would be essential? This limited study hopes to add to the knowledge and examples advocating the need for radically improving choice-supportive information to patients and consumers.

Measuring the criteria for information to patients we have taken into regard the European Patients Forum requirements for patient-oriented and reliable information and similar quality discussions.

The difficult link

Does informed patient choice affect the quality outcomes? This might be the long term purpose of care provider benchmarking but of course it is still controversial, as patients traditionally have turned to the geographically closest hospital and GP's are chosen for many other reasons than delivering top medical.

As there has been and still is a lack of open data and comparisons and not the least large many confounding factors complicating conclusions with regard to the link between outcomes information and a change of behaviour among patients, we will basically trust patient judgements to provide a first answer. We suspect hard data will still be hard to find, for reasons discussed in chapter 9. Our survey among patient activists and organisations around Europe here has provided valuable insights.

Generally the respondents tend to believe that high ranking of hospitals will attract patients – but it remains to be seen if such a belief in reality converts into factual behaviour. Anyhow, this signal suggests that change is under way in Europe and that declared outcomes quality eventually will become a provider factor for recruiting patients.

Welcoming further comments!

For the first time trying a "social media strategy" for communication about the highly subjective and maybe even irrational issues of patient choice we will turn to the audiences at our blog (http://blog.healthpowerhouse.com) and Facebook to engage further in commenting on this report. We hope for a continuous discussion and learning following on this report. Already spontaneous patient advocate comments have improved our understanding of the subject.

4. Hospital benchmarking websites

You could imagine that such an essential and critical service such as hospital care would be well exposed information-wise at the Internet. In the year 2010, when almost every pizzeria, car wash or cleaning service runs a website of their own – not to talk of banks, airlines or recruitment companies – you might expect a strong presence of hospitals, maybe even family doctors, on the web.

Such is not the case, at least when we look for information beyond what already is available in the phone directory, i.e. name, address and phone number of the healthcare provider. There are examples of most ambitious hospital or hospital group websites, such as www.qualitaetskliniken.de. But they are rare, indicating that provider information in healthcare is either treated as a non-issue or selectively distributed under the patient – doctor relation.

This becomes even more evident if we look for user-friendly ranking of provider characteristics and outcomes, designed to support the Internet visitor to access information compare performance. On the Internet, comparisons are in general the lay person method to form a foundation for a choice. You compare the offers for a mobile phone, a second hand sofa or a hotel weekend. Or even better, you consult one of the many websites offering to rank such offers: http://recombu.com/, http://www.pricerunner.de/ , http://www.preloved.co.uk/ or www.hotelpricescompare.com.

These kinds of services assist you to make an informed choice – and, as importantly, they promote the best performance and punish providers offering low value for money. Competition for market shares and reputation generally drives quality and lowers prices.

Or, as stated by what is called Pearson´s Law, “That which is measured improves. That which is measured and reported improves exponentially.”

Information portals

There are, according to the Euro Health Consumer Index (2009), no more than three EU countries offering this kind of layperson adopted websites benchmarking healthcare services, aiming to facilitate an active choice among consumers and patients: UK, Denmark and Germany. Since then the Netherlands have undergone a development of healthcare Internet portals and qualify in the top group of countries.

In another group of countries there are websites providing regional comparisons or information about the performance within a disease area. Some initiatives are public, others are private, often arranged by a newspaper or consumer organisation.

In most countries though, there are no structured provider benchmarks at all.

From the view of consumer empowerment, society transparency, cost effectiveness and Internet impact the EU conditions 2010 still are deplorable. But we notice light in the end of the tunnel. To meet the expectations from EU citizens and care users there must be a radical improvement of consumer information about healthcare – or the collective healthcare systems will have to confront a most complicated, even hostile, future.

It is now not a question if is but when the EU cross border care directive will be in place, opening for a regulated mobility within the union with regard to planned treatments, i.e. in hospital procedures. Out of hospital and primary care treatments will not require pre-authorisation and can continue to develop as have been the case during the last decades.

To make planned treatments in other member countries better available patient information will be absolutely essential. As shown in this report, not even in the most advanced member states you can count on accessing information about hospitals which is good enough to allow for a reliable, well-informed choice! And here we talk of home-turf conditions, without the complications represented by foreign languages and cultural values, legal requirements and so forth.

Presently the Directive asks for the country where the patient lives (country of residence) to provide the full description of the pre-authorisation and funding system to support its´ residents to go for cross border care. And when it comes to the available healthcare services it will be the country of treatment to inform about the services, quality systems, patient safety, prices (if applicable) et cetera valid for this country. The language issue has diplomatically been left open, meaning that different approaches will appear adding to the information challenge. In five years time the European Commission is supposed to assess what has happened.

This is no doubt a tall order to most national governments – least demanding to the countries in this study, well ahead of the other member states and with an advanced information culture and practice. And by far the worst to countries lagging behind with regard to openness, data access and competitiveness in healthcare and being reluctant, or even hostile, to the whole idea of cross-border care mobility. The final wording of the Directive is still open and might be somewhat watered down but will still increase the pressure at national institutions to improve healthcare performance information to the public.

Already the technical design will be challenging – but here governments can gain from already existing portals. In the next chapter we will look into a number of these systems, offering ideas and experience for future efforts.

5. Comparison of existing hospital information portals

5.1 The Netherlands – top of Europe

The Netherlands has a population of around 16 million people, which - given the small size of the country (42 000 square kilometers) - makes it the EU member country with the densest population. There are 395 Dutch per square kilometer. The GDP per capita is 41 063 USD (2008)[1].

Country characteristics

Since the reform in 2006 there is a compulsory health insurance system. Everybody is obliged to buy insurance, if necessary with public subsidies. The insurance companies cannot refuse clients and have to offer policies at the same price.

The family doctor /GP has a strong position. First you have to consult your GP to have a referral to a specialist. The primary care committees (representing the GP's) makes contracts with the insurance companies, deals which can vary with regard to volume, services and quality. Hospitals are reimbursed following DRG principles, but this system as well as the GP contracting is under development. We expect the new centre-right Dutch government to move in the direction of further market orientation, within the politically regulated scheme.

The Netherlands won the 2009 Euro Health Consumer Index (EHCI), for the second year in a row - the first time this has happened since the EHCI started in 2005 - and with an outstanding margin. As the Netherlands are expanding their lead among the best performing countries, the Index indicates that the Dutch might have found a successful approach. It combines competition for funding and provision within a regulated framework. There are information tools to support active choice among consumers. The Netherlands have started working on patient empowerment early, which now clearly pays off in many areas. And politicians and bureaucrats are comparatively far removed from operative decisions on delivery of Dutch healthcare services[2].

Internet use

[1] OECD StatExtracts, http://stats.oecd.org/index.aspx?queryid=2309

[2] http://www.healthpowerhouse.com/images/stories/press_release_general.pdf

According to the Internet World Statistics 88.6% of the Dutch population uses the Internet in 2010. This makes them the second most developed Internet nation in the European Union after Sweden[3]. So it is only logical that the government can and does provide information through the Internet.

With regard to hospital care, the Dutch Healthcare Authority, (NZa)[4] found that information on medical quality has improved since 2006, but that it is still limited. The transparency on medical quality of hospital care will be further developed through a project of the Healthcare Inspectorate[5]. The Inspectorate is developing indicators for medical quality and aims at having 80% transparency in hospital care in 2011. Information on experiences of patients is still limited, but it is already becoming more transparent. However, the available information does not yet correspond to the information needs of the patients.

Today the picture already looks quite different as the research for health related information on the Internet has increased rapidly. A report from the British marketing research group tns healthcare followed by an online survey in February 2010 shows that a big majority of survey participants in the Netherlands is using the Internet to search for information concerning their health. Most users prefer an independent and self-reliant search for information concerning health, pharmaceuticals and medical conditions. The consumers are especially interested in websites that offer comparisons on services from different hospitals.[6] Later on in this chapter we will look into two major websites (www.independer.nl and www.kiesbeter.nl) and analyze their pros and cons from a consumer's perspective.

Hospitals and clinics

In 2009 there were 93 hospital organizations, with altogether 141 hospital locations and 52 outpatient clinics. In addition to *general* hospitals, offering the full spectrum of hospital care, there are independent treatment centres (ZBCs) that provide selective non-acute treatments, covered by basic health insurance, for admissions shorter than 24 hours. Examples include cataract surgery or varicose veins surgery. In 2009, there were 198 of these independent treatment centres in the Netherlands.

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[3] Internet World Stats, http://www.internetworldstats.com/stats9.htm#eu

[4] Nederlandse Zorgautoriteit, www.nza.nl

[5] Inspectie voor de Gezondheidszorg, www.igz.nl

[6] TNS healthcare (February 2010): Kiezen in de zorg door de ogen van de consument.

General practitioners

General practice in the Netherlands is considered fairly advanced. The *huisarts* (home doctor) administers first line, primary care 24 hours a day, 7 days a week. Patients can not consult a hospital specialist without a required referral. Most GP's work in private practice although more medical centers with employed GP's are seen. Many GP's have a specialist interest, e.g. in palliative care.

Practically all GP’s in the Netherlands use an electronic medical record system. Data from these records are extracted and used to monitor GP care in the Netherlands. The database Netherlands Information Network of General Practice (LINH)[7] holds longitudinal data on morbidity, prescriptions and referrals on about 340 000 individuals. Data is collected from a representative network of about 180 GP’s throughout the Netherlands. The database enables health services research and quality-of-care research. The results are used for health policy and epidemiological purposes.

Quality information on healthcare provision receives a great deal of attention in the Netherlands. It is needed by patients to make informed choices and therefore important for the proper functioning of managed competition.

Consumer information portals

As mentioned earlier, there are a number of Dutch websites that are consulted by healthcare consumers:

Independer - www.independer.nl started in 1999 and became the biggest online adviser in the Netherlands. It has about seven million users per year and 250,000 registered clients. The website offers independent advice and market wide product comparisons in two major sectors: finances and healthcare. For financial services Independer.nl receives a bonus of the bank or insurance company whenever a consumer chooses to make a request via the website or closes a deal with the bank/insurance company. Within healthcare, the site covers information on hospitals, specialist clinics, revalidation centres and primary healthcare practices in the Netherlands.

When you are searching for a hospital in your proximity, you are definitely interested in the quality performance of the hospital. In this case, performance is measured by the independent research institute MediQuest[8], which is collecting data from various sources, such as the Inspectie voor de Gezondheitszorg, the Zichtbare Zorg Ziekenhuizen[9], the Vereniging Kind

[7] Database Netherlands Information Network of General Practice, www.nivel.nl

[8] MediQuest, www.mediquest.nl

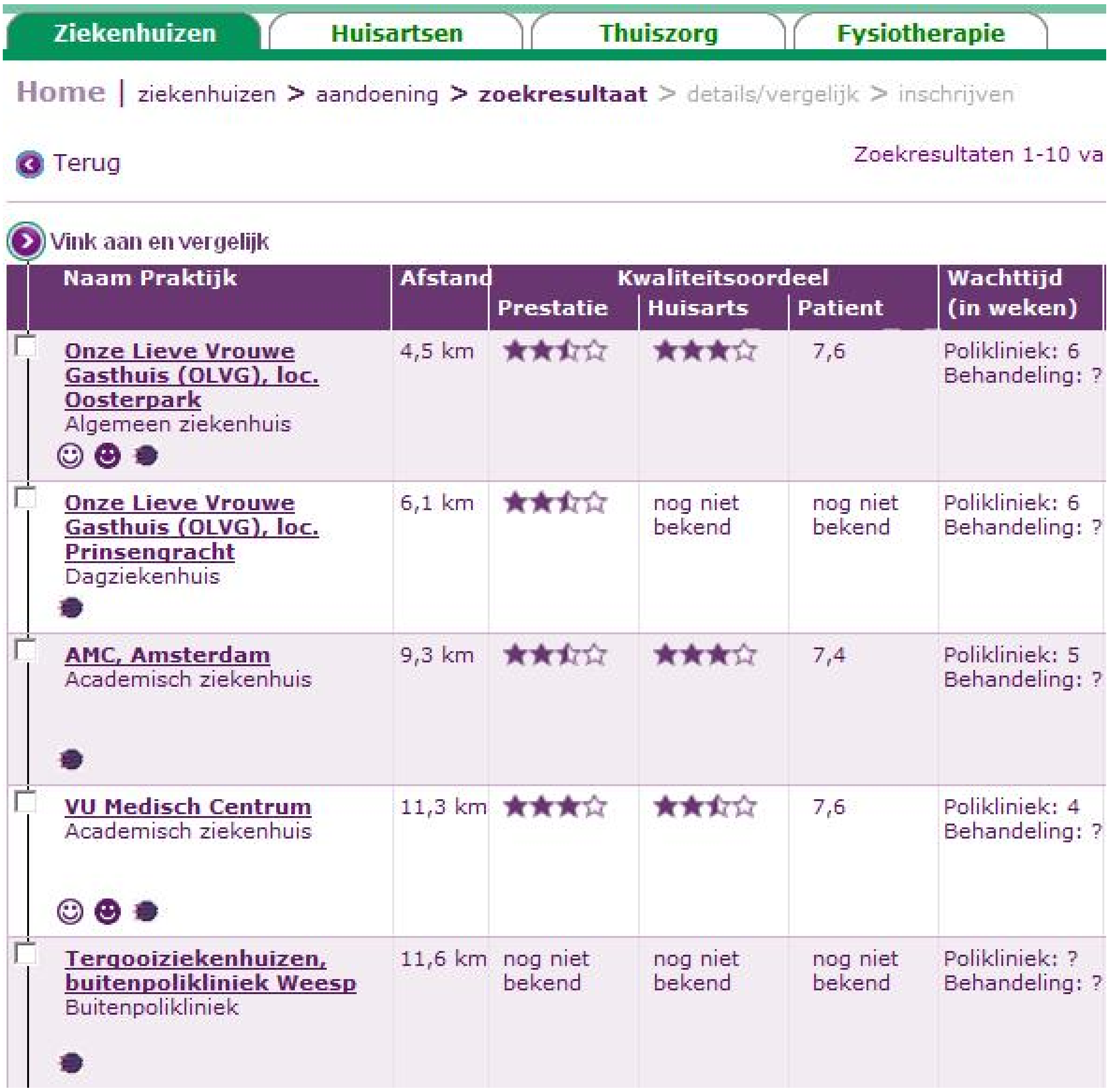
[9] Zichtbare Zorg Ziekenhuizen, www.zichtbarezorg.nl

en Ziekenhuis[10], the Haart&Vaatgroep[11] and last but not least the MediQuest clinics data base. The collected data is then being analyzed and cross-checked by MediQuest. Thanks to these quality reports the user has an overview of the hospitals with the best treatment quality, treatment transparency, hospital quality and hospital transparency.

MediQuest gives up to four stars for best performances (see Figure 1, Kwaliteitsoordeel, Prestatie). What the user doesn't see though is for what medical treatment these performance rates apply to. So whether you are a heart patient or in need of a hip replacement, you will have to trust that the hospital performs well in **both** cases. This is definitely a weakness from our point of view. The same counts for waiting times (Wachttijd). MediQuest collects this information directly from hospitals, however it only gives a general number (in weeks), which doesn't specify between medical treatments, e.g. heart disease or breast cancer removal. This method limits the information value.

[10] Vereniging Kind en Ziekenhuis, www.kindenzienkenhuis.nl

[11] Haart en Vaatgroep, www.haartenvaatgroep.nl



Ziekenhuizen | Huisartsen | Thuiszorg | Fysiotherapie

Home | ziekenhuizen > aandoening > zoekresultaat > details/vergelijk > inschrijven

Terug

Zoekresultaten 1-10 va

Vink aan en vergelijk

Naam Praktijk	Afstand	Kwaliteitsoordeel Prestatie	Kwaliteitsoordeel Huisarts	Kwaliteitsoordeel Patient	Wachttijd (in weken)
Onze Lieve Vrouwe Gasthuis (OLVG), loc. Oosterpark Algemeen ziekenhuis	4,5 km	★★½☆☆	★★★☆	7,6	Polikliniek: 6 Behandeling: ?
Onze Lieve Vrouwe Gasthuis (OLVG), loc. Prinsengracht Dagziekenhuis	6,1 km	★★½☆☆	nog niet bekend	nog niet bekend	Polikliniek: 6 Behandeling: ?
AMC, Amsterdam Academisch ziekenhuis	9,3 km	★★½☆☆	★★★☆	7,4	Polikliniek: 5 Behandeling: ?
VU Medisch Centrum Academisch ziekenhuis	11,3 km	★★★☆	★★½☆☆	7,6	Polikliniek: 4 Behandeling: ?
Tergooiziekenhuizen, buitenpolikliniek Weesp Buitenpolikliniek	11,6 km	nog niet bekend	nog niet bekend	nog niet bekend	Polikliniek: ? Behandeling: ?

Figure 1: Hospital comparison on www.independer.nl

The general practitioners' reports (see Figure 1, Kwaliteitsoordeel, Huisarts), which offer information on hospitals that were chosen by GP's for further treatment of patients, are a different story. Here Independer.nl offers numerous criteria for comparison, such as:

- Medical expertise;
- Readiness for cooperation;
- Communication during treatment;
- Logistics and organization;
- Patient friendliness and
- Overall impression.

Since May 2005, the Consumer Monitor Independer started collecting data from users of Independer.nl about their hospital experience (if the treatment was not longer than two years ago). The data collection includes valuable information on the expertise of doctors, the patient care, the discharge procedure and the after-care. Users were also asked if they would choose the same hospital again (see Figure 1, Kwaliteitsordeel, Patient).

In our eyes, the two report systems, general practitioners' and patients' reports, offer very valuable information to the consumer about the quality of treatment and the quality of the hospital (see Figure 2, *Oordeel van huisartsen over het specialisme* and *Oordeel van patiënten over deze instelling*).

Oordeel van huisartsen over het specialisme	
Algeheel oordeel over medisch specialisme	★★★☆
Medische deskundigheid m.b.t. specialisme	★★★½
Logistiek & organisatie (servicegerichtheid)	★★½☆
Patiëntvriendelijkheid	★★★☆
Samenwerking met de huisarts	★★★☆
Communicatie met huisarts gedurende opname	★★½☆
Oordeel van patiënten over deze instelling: ICM	
Polikliniek bezoek	
Respect voor de patiënten	7,9
Deskundigheid van de arts(en)	7,8
Informatieverstrekking aan de patiënt	7,4
(Dag)opname	
Deskundigheid van de arts(en)	7,9
Kwaliteit van de verzorging	7,7
Kwaliteit ontslagprocedure en nazorg	7

Figure 2: GP's and patients' quality score on www.independer.nl

Kiesbeter - www.kiesbeter.nl was launched and is financed by the Ministry of Health, Welfare and Sports in the Netherlands. In 2009 the site has counted over 4,3 million visitors. On a daily basis, 12 000 - 17 000 users visit the site. When Dutch users search for information about health on the internet, over 20% put their trust into kiesbeter.nl. About 30% of the site users indicate that the information they found was useful.[12]

The site consists of four main sections: Patient information, medical information, healthcare insurances and healthcare providers:

- Patient information includes a list of and links to patient organisations in the Netherlands. Also other information such as privacy issues can be found here.
- The medical information consists of a very detailed description of medical conditions with clear diagrams and images, including a simple definition and explanation, possible causes, the grade of severity, prevention possibilities and information on when it is necessary to consult a doctor. It is very user-friendly and uses simple language.
- The part of the healthcare insurances shows all important data on today's policies. You can start a comparison of healthcare insurances and coverage, which is vital information when it comes to the question what you actually get for your money.
- Within the section of the healthcare providers, you can compare hospitals and specialist clinics and also find general information on primary healthcare providers.

A quick tour

We took a quick tour through Kiesbeter and will discuss a medical example: hip replacement. By typing the medical term into the required field and indicating your postcode and preferred distance to the hospital, a list of all hospitals in your proximity is displayed. Also medical facilities are shown so that you can make a choice of preference. Your search results show the following information:

- Name of the hospital;
- Address and distance to your home and
- Quality report (if available).

Quality reports are collected directly from hospitals and give you access to information that might be of great interest to you as a patient. All hospitals listed on the website have provided Kiesbeter.nl with their quality reports. The NZa seems to do its job accordingly and works closely together with the hospitals on increasing transparency of patient information. So what information can you as a hip patient find there?

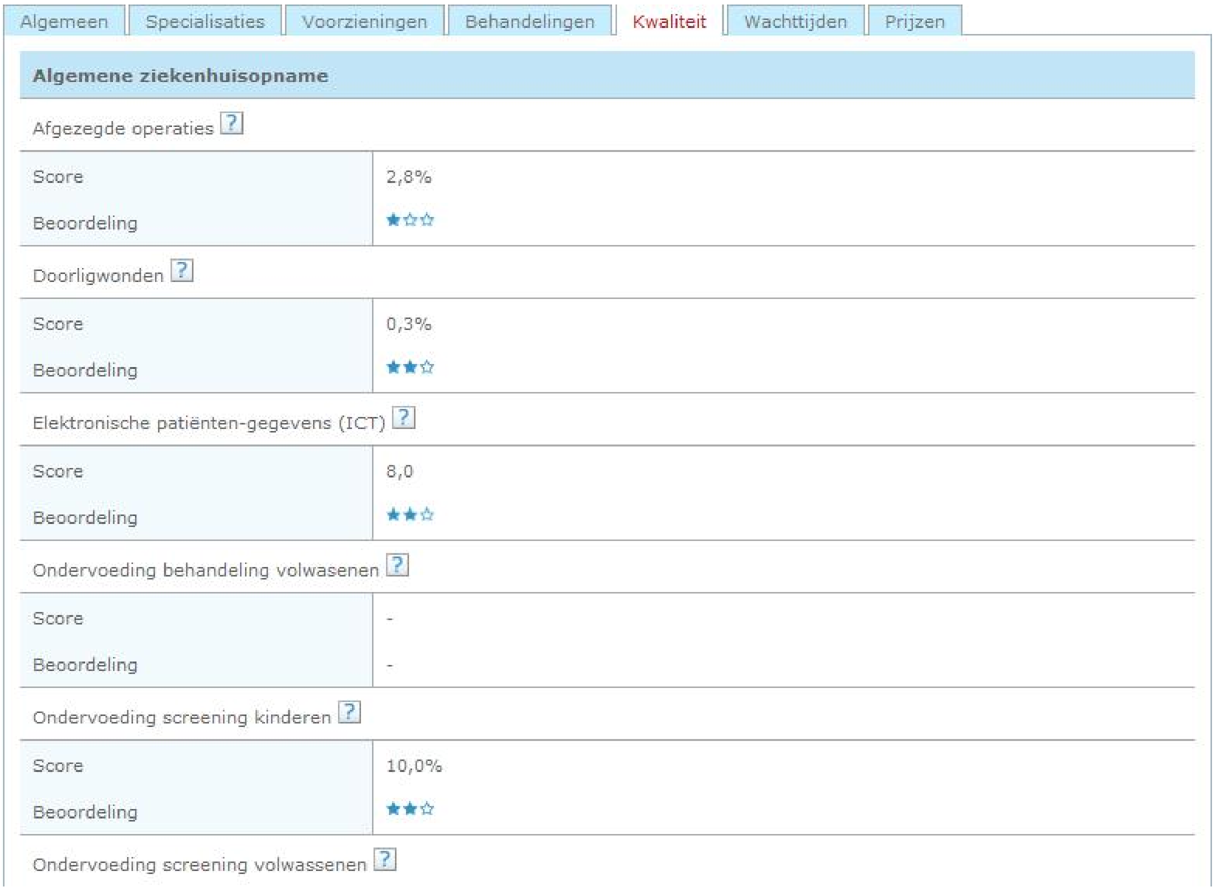
[12] Marketing dashboard, Kiesbeter.nl, fourth quarter 2009

After reading the general hospital information and its medical specialties you will find data on medical supply, as for example the availability of a CT-scan or the opening times of the emergency department (open 24 hours/seven days a week or only open at office hours). It is easier and more convenient to make a CT-scan right on spot instead of having to be referred to another specialist and wait for hours, days or even longer to get to your results. Further information includes data on general supply, such as the number of hospital beds. What might be again of vital interest for you is data on medical treatments, for example: Is the hospital specialised in hip-replacements?

On basis of these quality reports, Kiesbeter.nl is giving out quality ratings for each hospital. The maximum rating is three stars for best quality. Indicators for quality are for example:

- Number of operated patients;
- Number of cancelled operations;
- Number of wound infections;
- Availability on electronic patient data;
- Is there screening for malnutrition?
- Pain indication after operation;
- Number of hospital infections;
- Number of emergency operations within one day and
- Mortality rates.

All indicators are well-explained, so that you as a patient can grasp in how far they have an effect on the quality rating. What is confusing is the fact that besides this rating of maximum three stars there is also a score number (sometimes in percent), which gives no further explanation what it relates to (see Figure 3, Quality rating on www.kiesbeter.nl). This is definitely a minus point for the Kiesbeter.nl website.



Algemeen | Specialisaties | Voorzieningen | Behandelingen | Kwaliteit | Wachttijden | Prijzen

Algemene ziekenhuisopname	
Afgezegde operaties ?	
Score	2,8%
Beoordeling	★☆☆
Doorligwonden ?	
Score	0,3%
Beoordeling	★★☆
Elektronische patiënten-gegevens (ICT) ?	
Score	8,0
Beoordeling	★★☆
Ondervoeding behandeling volwasenen ?	
Score	-
Beoordeling	-
Ondervoeding screening kinderen ?	
Score	10,0%
Beoordeling	★★☆
Ondervoeding screening volwassenen ?	

Figure 3: Quality rating on www.kiesbeter.nl

Quality reports also include waiting times, assumed that the respective hospital has provided Kiesbeter.nl with that information. The waiting times are not listed for all medical treatments but at least for some, such as cardiology and breast cancer for example or the waiting time for a CT-scan.

Another interesting kind of information included in quality reports is the cost for the treatment. You can find a list of costs for some operations and treatments (e.g. implant for a hip-replacement), indicated on a daily cost level. Even if you do not pay for the treatment all by yourself - and within the EU you very seldom do – the price information will become valuable, as cross-border care will become more common. The new EU directive means that the government of residence shall pay for medical treatment in another EU country up to the cost level of the corresponding procedure in the resident country. For a more expensive treatment you have to pay the difference yourself. No doubt the price information will become critical to make patient mobility a reality.

An overall positive conclusion that we could draw from Kiesbeter.nl is that the comparing procedure on quality information can be applied also on segments such as medical services for disabled persons, medical services at home and nursing and care. In these cases experience reports filled in by patients and personnel serve as another interesting source of user information.

The following table compares the services between www.independer.nl and www.kiesbeter.nl:

www.kiesbeter.nl		www.independer.nl
yes	**Hospital/specialist clinic comparison**	yes
quality reports from hospitals	**Quality sources**	• independent quality reports of performance • GP reports • patient reports
• medical/general supply • treatment specialties • number of operated patients • number of cancelled operations • availability on electronic patient data • and many more • costs • waiting times	**Quality indicators**	• medical expertise • care and after-care • cooperation doctor/patient • communication during treatment • discharge procedure • logistics and organization • patient friendliness • overall impression • waiting times •
• general information • no performance quality	**Primary care**	• general information • no performance quality
www.kiesbeter.nl/ medicijnen	**Information on pharmaceuticals**	no
easy to use but doesn’t display all information that could be of interest to the user	**User's manual**	easy to use but doesn’t display all information that could be of interest to the user
• patient information • patient organisations • medical information • healthcare insurances • extra plus point: quality reports on medical services for disabled persons, medical services at home and nursery/care	**Other links**	• car insurance • mortgage • loan • risk and life insurance

5.2 Denmark – “small is beautiful”

Like the Netherlands, Denmark is a small European country with 5.5 million inhabitants living on 43 000 square kilometers. This means 130 Danes per square kilometer. The GDP per person is 36 808 USD (2008)[13].

Country characteristics

Danish public healthcare is tax funded. Within the publicly regulated system self-employed GP’s and publicly owned hospitals co-exist. There is a strong family doctor culture, with no co-payment if you visit your own GP but with high co-pay if you are not listed or visit a different GP. To see a specialist you need a referral. There is a free choice among hospitals beyond the maximum waiting time of 30 days. This free choice is a Danish cornerstone, supported by information efforts.

Internet use

Latest data (2010) in Denmark shows that 4,750,500 people are actively using the Internet[14]. This means that over 86% of the Danish population is actively online.

Background

According to HCP ranking, Denmark is a top performer in Europe with regard to consumer and patient information. In the last Euro Health Consumer Index (2009) we put the Danish healthcare information system as the best. And our Patient Empowerment Report (2008) found that if also patient rights are included Denmark was the frontrunner for patient empowerment. The information web portals to be portrayed in this study in no way contradict our statement.

There a few things that can explain the Danish progress:

- Small country with a rather centralised structure;
- Political commitment to transparency;
- Transparency as a strategic tool for improvement of access and outcomes.

[13] OECD StatExtracts, http://stats.oecd.org/index.aspx?queryid=23066

[14] Internet World Stats, http://www.internetworldstats.com/stats9.htm#eu

There are two nation-wide Danish web portals to be taken into regard when looking into user-friendly information design: www.sundhed.dk and www.sundhedskvalitet.dk. The titles might be slightly confusing but use a very simple and functional vocabulary: in Danish "health" and "quality of health". In this study we will focus on sundhedskvalitet.dk, which is designed to promote the right to make an informed choice among all Danish hospitals. But also sundhed.dk offers valuable tools for empowerment.

Hospitals and specialist clinics

There are twelve hospitals in the capital region of Denmark, twelve in Sjælland, 20 in Syddanmark, 20 in Midtjylland, five in Nordjylland and 20 private hospitals in the whole of Denmark.

General practitioners

Self employed GPs, of which there are roughly 3,700 (in 2002), technically private practices, operate wholly within the public healthcare system, acting as gatekeepers to specialists and hospitals. Patients must register with a GP of their choice with practice within 10 km of their home. They have the right to change their GP every 6 months, but in practice Danes rarely change doctor. Each GP has about 1,600 patients. The number of practising GPs in each county is subject to collective agreements negotiated between the counties and the GP section of the Danish Medical Association. The result is an even distribution across the population[15].

Consumer information portals

There are two nationwide IT-portals in Denmark:

Sundhed - www.sundhed.dk aims to be the electronic highway for overviews and efficient communication between patients and healthcare and among members of the medical professions. After preparations since 2001, the portal was launched at the end of 2003. Denmark by then already had a history of web information about health and healthcare as the Danish Society of Pharmacists had been providing such information (actually under the label sundhed.dk, the name to live on, but now under the mixed stewardship of not only the pharmacists but also the Ministry of Health and the Federations of Danish healthcare regions and local governments).

The basic content of the sundhed.dk is about public health and prevention. There are lexica on diseases, a medical handbook, information about patient networks and much more. Such

[15] http://www.civitas.org.uk/pdf/Denmark.pdf

information is today rather conventional and does not target the active choice for a certain hospital or service provider but offers background information. Sundhed.dk also contains a number of tools for citizens who want to navigate the healthcare system:

- A Vejviser ("guide") service, where you indicate what kind of medical service you look for and where (a GP, a dentist, a psychologist, an emergency room, a pharmacy et cetera) and you will have the contact information (and if you want to locate every hospital in for example the Copenhagen region, you will get them here).

- Quality outcomes for a number of diseases, with performance shown on regional and hospital level (there are five healthcare regions in Denmark), which among many other results point to a huge variation within the success rate with regard to blood sugar control among diabetics or to what extent patients are offered a structured training program as part of their rehabilitation.

- Waiting times for a large number of treatments and services, to support the freedom of choice among hospitals.

- A user-friendly pharmacopoeia, offering a list of all medicines registered in Denmark, for what purpose, the content of the package leaflet and so forth. Soon there will be information about counter-indications between different pharmaceuticals.

Better prepared patients

Sundhed.dk has gained much international attention. The portal CEO, Mr. Morten Elbæk Petersen, explains that the success behind the portal should not be measured by the number of visitors but rather upon the effect that Danish patients now are significantly better prepared for the meeting with healthcare, that the citizens know whom to turn to and that the portal will save time for the medical staffs in their daily work.

He explains some of the visions for the portal:

- To bring together all information about Danish healthcare, to make it possible to make choices between treatments and locations;
- To allow doctors to discuss the patient treatment through ITC and to use different kinds of telemedicine;
- To make it possible for patients to read their medical records from home;
- All information about the treatment should be accessible regardless where you are treated (but only to the patient and involved medical staff) and
- To provide the medical professions with decision support to meet the patient.

Sundhedskvalitet - www.sundhedskvalitet.dk is the dedicated web portal to support and facilitate active choice among hospitals and other care providers. The overall aim is to make patients engage in their healthcare. As the forerunner sundhed.dk this portal is a public initiative and administrated by a public partnership.

Since 2009 the free choice of hospital in Denmark means that you are entitled to a referral to a private clinic (contracted by the public healthcare) or another public hospital if your regional health authority cannot offer you a treatment within one month after referral.

The sundhedskvalitet.dk portal provides many different kinds of data about the quality and service at Danish hospitals. The main strategy is to present performance indicators for each unit, allowing for a comparison with other hospitals and national averages.

A portal visitor, you can take a look into the portal from three different perspectives:

- Disease and/or treatment;
- Key data for each provider and
- Region.

The data is delivered by Danish sources such as quality registries that already exist but in this case it is presented in a more user-friendly way.

Kidney stone

Assume that you suffer from kidney stone and want the smoothest possible procedure, i.e. to “blast” the stone through an ultra sound treatment (does not require an operation, though you need to stay in the hospital for a few days). The www.sundhedskvalitet.dk lists the available clinics for such a procedure, with a star rating (1-5 stars), indicating an overall quality performance (see Figure 4, Quality performance on www.sundhedskvalitet.dk).

From the group of around 15 Danish providers of this kind of un-bloody kidney treatment (listed by the portal) you can look deeper into the structure and learn about the timely access conditions. How large a percentage of the patients treated for this diagnosis at the clinic had to wait more than 30 days (which is the Danish guaranteed maximum waiting)?

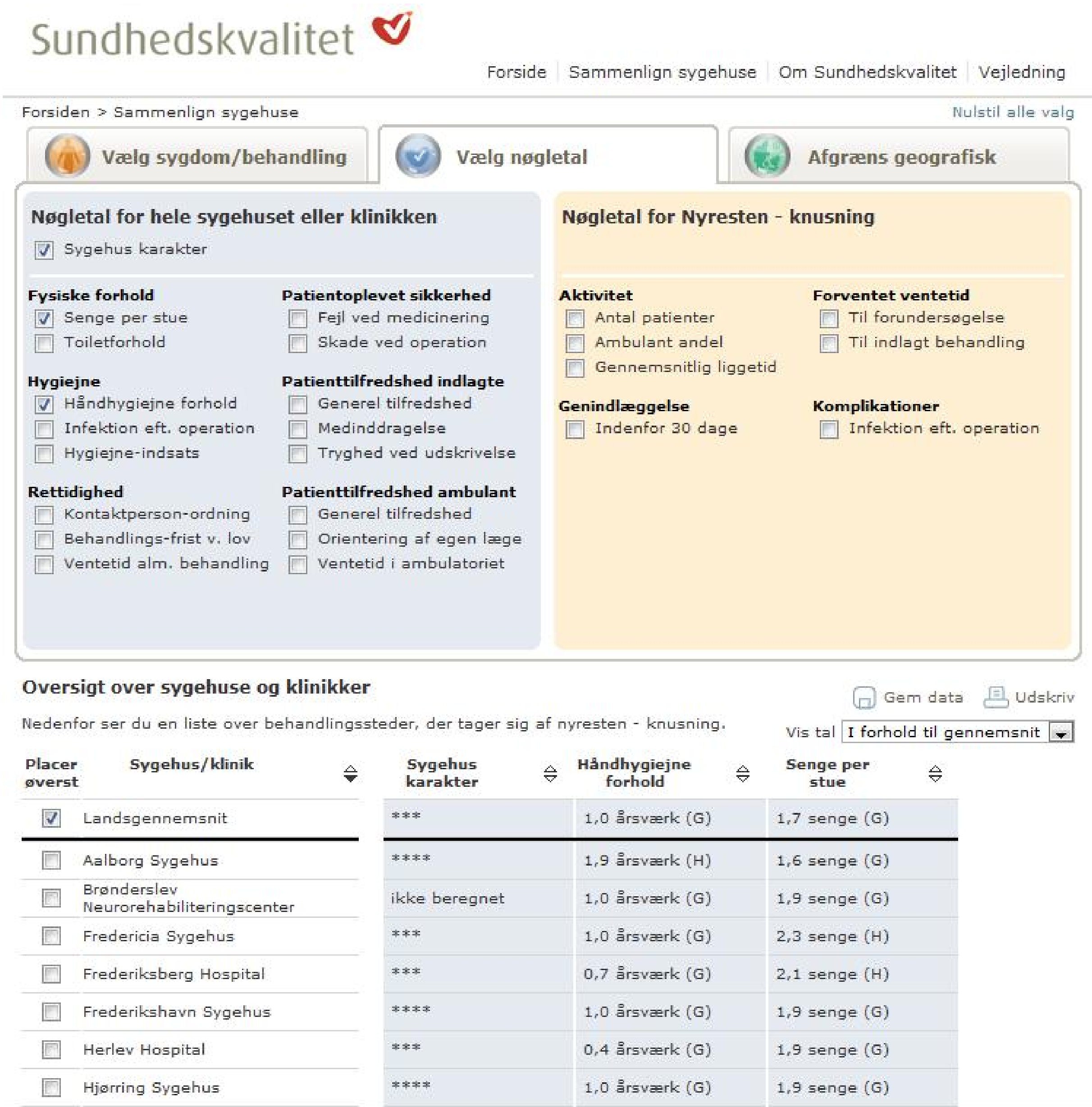


Figure 4: Quality performance on www.sundhedsqvalitet.dk

To locate the clinic that looks the best for blasting your stones away you can as well learn about the:

- Waiting time for treatment (after that the clinic has received the referral from your doctor);
- Complication rate, related to the treatment (according to patients reporting and opinions);
- Patient satisfaction level;
- Number of patients treated for this problem in the clinic;

- Average length of patient stay in the hospital;
- Share of patients returning for a re-operation/treatment within 30 days and
- Key data about service and standards, such as hospital hygiene, medical errors, number of beds per room et cetera.

All together the active Danish patient has a good backing to navigate the system to locate good healthcare. There is a lot of useful information at the two portals, but as goes for every existing public website a lot remains to do with regard to structure and design before you have a really simple and user-friendly tool.

The next page shows you the services and offers of the two IT-portals in an overview:

www.sundhed.dk		www.sundhedqvalitet.dk
yes, on a regional level	**Hospital/specialist clinic comparison**	yes from three perspectives: • disease and/or treatment • key data for each provider • region
public sources such as quality registries	**Quality sources**	• public sources such as quality registries
• quality outcomes for a number of diseases • waiting times for a large number of treatments and services	**Quality indicators**	• complication rate • patient satisfaction level • number of patients treated for this problem • average length of hospital stay • share of patients returning for a re-operation • key data about hospital service and standards • waiting times
yes	**Primary care**	no
yes (www.medicin.dk)	**Information on pharmaceuticals**	no
no	**User's manual**	yes (with film clips for guidance)
patient networks, such as www.hjertedebat.dk	**Other links**	no

5.3 Germany – a web revolution

Here we step up from the small EU members to the no 1, measured from population and economy. Germany has over 82 million inhabitants on 357 000 square kilometres, which means 230 persons per square kilometre. Like in the Netherlands such a density provides the foundation for large many hospitals. The GDP per capita is 35 432 USD (2008)[16].

Country characteristics

Germany has a diversified health insurance system, with multiple solutions, insurers and providers offering a wide choice to consumers. For most German patients, the cost of hospital treatment is taken care of by the compulsory general social security health insurance. Visiting your family doctor/GP costs you a low co-pay. You can pick your doctor and generally have a choice among hospitals within your insurance package.

Germany is the home of the "Bismarck model" for healthcare, common in large parts of continental Europe. This approach typically builds from multiple payers and providers. Care facilities such as hospitals can have different kinds of owners or sponsors: public, private non-profit or public for-profit. Such systems generally have good access and well developed patient choice. In contrast to Denmark and UK (and other "Beveridge" or single-payer countries) waiting times rarely is a problem to be tackled by better care consumer information. In Germany quality or value for money concerns seem to be the main driver (a discussion to be elaborated in chapter 7).

Internet use

There are 65,123,800 Internet users in Germany, which places it amongst the top ten countries using Internet in Europe[17].

Room for choice

There are about 2 000 acute care hospitals in Germany. They differ by sponsorship and by service level, which means that there is a reason to inform yourself about what kind of conditions you can expect.

[16] OECD StatExtracts, http://stats.oecd.org/index.aspx?queryid=23066

[17] Internetworldstats, http://www.internetworldstats.com/stats9.htm#eu

Sponsorship responsibility can be with:

- Government, on the local level – i.e. towns and counties – or on the state level, where the federal states are responsible for university hospitals as part of their responsibility for education – overall 55% of all hospitals are government-carried.
- Free-non-profit institutions like the big churches with their federations, the Red Cross with its nurse societies and other non-profit organizations – 38%.
- Private for-profit companies and hospital chains - 7%.

Costs and Payment for treatments

Patients who are not members of the social security health scheme generally have to pay their own bills and it is their own responsibility whether their private insurance will actually refund the costs. Foreign patients are generally considered to belong to this group when they are admitted into a hospital for voluntary (i.e. non-emergency) treatment.

The chairmen of clinics mostly have the license to treat such self-paying patients as private patients and invoice their services directly. Thus, these patients receive several bills: One from the hospital and one or more – if other physicians were involved, like the radiologist, the surgeon, the laboratory physician – from the physicians who were medically responsible for the treatment.

Not everybody knows however, that there is no need to contract these costly services if you want to economize on the costs: If you do not opt for the additional private physician care, you will be served by the other senior and junior residents in the team, like the majority of the patients and with usually no less success.

Hotel standards

German hospitals frequently have the double-bed-room as regular standard. In these hospitals, additional payment may only be asked for accommodation in a single-bed room. If, however, the hospital has three or more beds-per-room wards as regular standard, an additional charge will also be invoiced for double-bed accommodation. These surcharges were regulated some years ago and now generally range around 80 to 100 Euro per night for the single-bed, 50 to 70 Euros for accommodation in the double-bed room. This is also not a compulsory cost factor: You can opt for the additional comfort and pay the price - or share the room with one or two other patients, depending on the hospital you choose.

For the hospital services, i.e. medical treatment, nursing care and accommodation, a new pricing system has been introduced by federal legislation in the beginning of 2004. A general catalogue of about 900 DRGs (diagnosis related groups) provides fixed overall prices which may not differ dramatically between hospitals. A complete list of these DRGs would exceed the scope of this article, but it is possible to get rough cost estimates from hospitals based on the known diagnoses.

One speciality of the German health system is the well developed rehabilitation sector: Separate clinics continue the treatment of patients after the acute phase and, with the help of special procedures and facilities, e. g. physical therapy, ensure the best-possible outcome of medical procedures. This follow-up treatment must be booked separately, and a normal stay of about 21 days will incur another sum of 2,500 to 3,000 Euro.

During the stay in a hospital, the costs of using telephone and internet access (which is being offered by most hospitals), will be charged separately according to consumption, the use of the mostly available TV is frequently included.

For outpatient treatment in private practice, there is a special government-regulated price list called GOÄ - Gebührenordnung für Ärzte. Here, prices for most of the activities and procedures that can happen during diagnostics and treatments are fixed.

The same procedure will also be applied when the medical activity took place in a hospital on inpatient basis, if the physician has concluded a treatment contract with the patient to this effect.

Often the insurance company assists in the economic aspects of the treatment but anyhow, compared to single-payer systems, being a German patient takes a little more of engagement and decision-making, at the same time as the opportunities to have an influence is better. Again, this should be a fruitful environment for user information!

GP's

A *Hausarzt* in Germany is either a general practitioner with his/her own independent practice or a doctor who is employed at one of the many medical care centers. In most cases, it is the first contact person for the patient, together with the pharmacist. In severe cases or emergencies, the GP also does house visits for patients who cannot come to his practice. Important for the relationship between the GP and the patient is the trust that they both share. In the ideal case the GP knows about the medical history of his patient (anamnesis). That is why the GP is often referred to as the family doctor.

The Health barometer 2009 (see Figure 5) shows that on a scale between 1 (least) to 4 (most) consumers voted with 3.49 when they were asked how much trust they would put in their GP.

The Internet as a trusted source was only ranked at 1.81[18] . These numbers show how important the GP is considered in Germany.

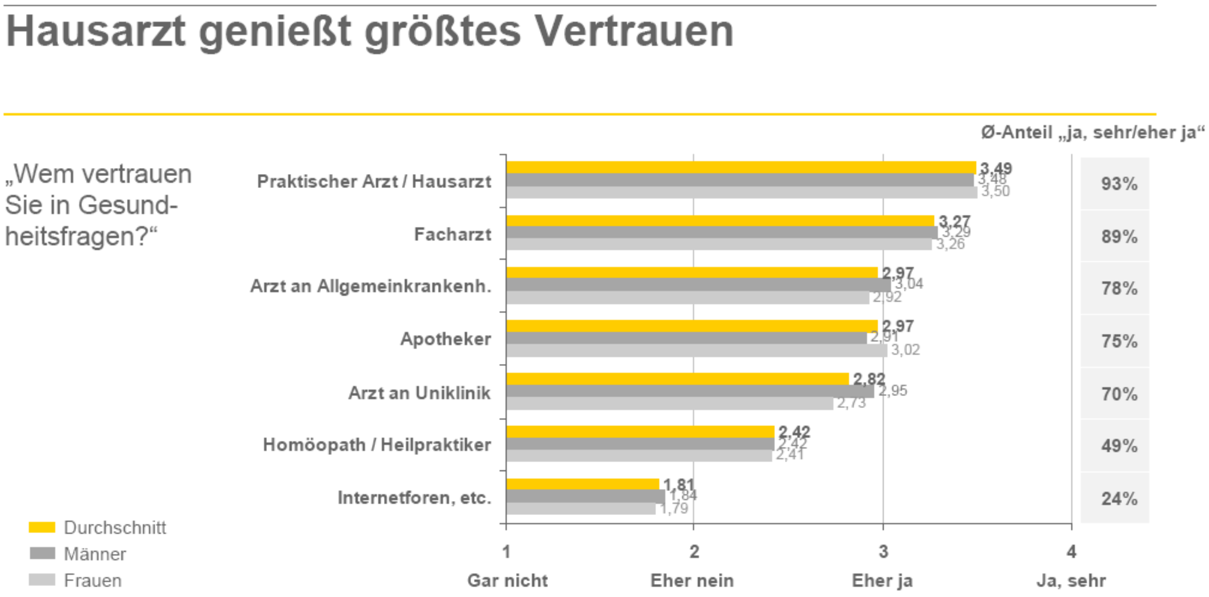


Figure 5: Health barometer 2009, Ernst & Young

Talking about quality

Quality and patient security in Germany is taken very seriously. Therefore the umbrella organization BQS[19] was founded in September 2000 by the Medical Association Bundesärztekammer[20], the German Hospital Association Deutsche Krankenhausgesellschaft e.V.[21] and the central association of health insurance companies Spitzenverbände der Krankenkassen[22] to act as an organ for benchmarking and quality comparison.

BQS offers a central service for data processing on a national level, so that all hospitals and healthcare agencies have access to an analysis of their own data[23].

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[18] Ernst & Young Gesundheitsbarometer, 2009, http://www.ey.com/Publication/vwLUAssets/Gesundheitsbarometer_2009/$FILE/Studie_Gesundheitsbarometer_2009.pdf

[19] Institut für Qualität- und Patientensicherheit, www.bqs-institut.de

[20] Bundesärztekammer, www.bundesaerztekammer.de

[21] Deutsche Krankenhausgesellschaft e.V., www.dkgev.de

[22] Spitzenverbände der Krankenkassen, www.gkv-spitzenverband.de

[23] Gemeinsamer Bundesausschuss, http://www.g-ba.de/institution/themenschwerpunkte/qualitaetssicherung/qualitaetsbericht

Both the hospital comparison websites that we analyzed more in detail use BQS quality reports.

Weisse Liste - www.weisse-liste.de was founded by the Bertelsmann Foundation[24] and the umbrella associations of the biggest patient- and consumer organisations in Germany. It is sponsored solely by project funds from the Bertelsmann Foundation. This is what you call a private-private partnership. This internet portal informs patients and their family members about the service and quality of healthcare at approximately 2 000 hospitals in Germany.

Dr. Brigitte Mohn, chairwoman of the Bertelsmann Foundation, says that the portal shows information to patients ”straight from the horse’s mouth” [25], which in other words means that patients have access to optimal information about their own healthcare. After doing the test ourselves, we have come to the conclusion that the comparison procedure is indeed well explained. The patient has the option to go through an individual search process with the help of a search assistant (*Suchassistent*). This method is time-demanding but fruitful for a layperson’s knowhow. More experienced users can skip the search assistant and get to their result within three steps.

We took the beginner’s option and searched for hospitals performing hip replacements. Our search involved 13 steps:

- Step 1: Shows a list of hospitals offering hip replacements.
- Step 2: Shows how often hip replacement patients were treated on secondary disorders, which were not the reason for hospital admission in the first place but also needed medical attention.
- Step 3: Shows hospitals with chosen preferences for care centres.
- Step 4: Shows a list of hospitals with the chosen treatment specialty.
- Step 5: Shows all hospitals with doctors who have a specialist qualification with respect to the hip replacement treatment/operation.
- Step 6: Shows the contingent of medical personnel in relation to the number of patients, (meaning how many patients does a doctor or nursing staff treat in average per year, so how much time is available for each patient?).
- Step 7: Shows the availability of special therapeutic personnel in the hospital.
- Step 8: Shows the medical equipment at the clinic.
- Step 9: Shows other kinds of nursing care offered by hospital (such as physiotherapy).
- Step 10: Shows the performance capacity (meaning the frequency of the treatment or operation that was performed in the hospital can be an indicator for experience and competence of the hospital?).

[24] Bertelsmann, www.bertelsmann.de

[25] Dr. Brigitte Mohn, Chairwoman, Board of Directors of Apoplectic Stroke Aid Foundation and Chairwoman of the Bertelsmann Foundation

- Step 11: Shows the quality performance according to BQS-procedure.
- Step 12: Shows the ambulant capacity of the hospital (meaning is there a specialist practitioner to assure after-treatment?).
- Step 13: Includes information about non-medical criteria as accessibility, equipment of hospital and rooms, catering and other service offers.

The list is now complete and here we are with a table, displaying all marked hospitals and indicating how often a hospital has been chosen by us as a favourite (see Figure 6, Quality list on www.weisse-liste.de).

markierte Krankenhäuser vergleichen

Sortierung: Anzahl Punkte

Name	Entfernung in km	Fachabteilungen	Schwerwiegende Begleiterkankung	Versorgungs-schwerpunkte des Krankenhauses	Fachabteilungs-bezogene Ver-sorgungsschwerpunkte	Ärztliche Qualifikation	Personelle Ausstattung	Spezielles therapeutisches Pflegepersonal	Apparative Ausstattung	Medizinisch pflegerische Leistungsangebote	Leistungskennzahlen	Qualitätssicherung im BQS-Verfahren	Ambulanzen	Nicht-medizinische Serviceangebote	
Klinikum der Universität München *München*	6				●	●		●	●	●	●			●	☐
Krankenhaus Barmherzige Brüder München *München*	6					●		●	●	●	●		●	●	☐
Klinikum rechts der Isar der Technischen Universität München *München*	4				●	●		●	●	●				●	☐
Städtisches Klinikum München, Klinikum Schwabing *München*	1			●	●			●	●	●					☐
Klinikum Dritter Orden *München*	4	●				●				●			●	●	☐
Klinikum Harlaching *München*	7				●				●	●			●	●	☐
WolfartKlinik *Gräfelfing*	12						●		●	●	●			●	☐
Isar Kliniken GmbH *München*	3	●							●	●				●	☐

Figure 6: Quality list on www.weisse-liste.de

All this comparison data is based on hospital quality reports that according to German law have to be admitted every two years by all hospitals. Patient satisfaction is another part that flows into the quality outcome data of the hospitals. For this purpose, patients are handed out a Patients' Experience Questionnaire (PEQ) two to eight weeks after their hospital stay. Distribution of the questionnaires is voluntary for each hospital.

Once the questionnaires are filled out and have been returned, the hospitals send them to the accredited questionnaire assessment institute. As a result, patient experience has an influence on the overall rating. Users have direct access to the PEQs on the Weisse-Liste portal.

Another service of the site is a diagnosis translator for a better comprehension of medical terms. Detailed information about medical conditions can be found over the external link: www.unabhaengige-patientenberatung.de.

Qualitätskliniken - www.qualitaetskliniken.de was launched in June 2010 and it is the biggest national IT portal in Germany. It provides patients and medical staff with useful comparisons on quality outcomes of hospitals. It is aimed to be the most transparent, open and comprehensible evaluation method for patients with no professional medical pre-knowledge. The portal is an initiative by the three biggest private hospital organizations in Germany, Asklepios Kliniken GmbH[26], Rhön-Klinikum AG[27] and Sana Kliniken AG[28]. 160 hospitals with over 3.5 million patients are part of these organizations. Other members such as hospitals/clinics, patient organisations, health insurance providers, universities, scientific institutions, patients etc. are welcome to join the portal.

The financing is provided by membership fees and donations. So far the German government has taken an interest in the portal but hasn't offered any participation. It has initiated a benchmarking project that will identify further involvement.

The motto of Qualitätsklinken is: "If we look at the costs we reduce quality. But if we look at quality we reduce costs." And indeed, the user of Qualitätskliniken can very quickly and simply have an individual hospital comparison result. Within three clicks, valid results for individual hospital comparisons are displayed.

A button system shows you where on a scale of 100% the hospital is ranging within four quality categories:

- Medical quality;
- Patient security;
- Patient satisfaction and
- Admission satisfaction.

You have flexibility in those four categories and can choose your preferences individually. The evaluation and presentation of a hospital covers about **400** quality indicators within these four categories. Of course not all of those 400 are shown every time, but rather those that are of importance in your individual hospital comparison. The indicators are all well established and tested by independent institutions, such as the BQS and the IQME[29]. Next to quality comparisons there is also general information about the hospitals and information about other offers and services, such as the medical equipment.

[26] Asklepios Kliniken GmbH, www.asklepios.com

[27] Rhön-Klinikum AG, www.rhoen-klinikum-ag.com

[28] Sana Kliniken AG, www.sana.de

[29] Institut für Qualitätsmessung und Evaluation, www.iqme.de

Hips again

Look for a specific disease Qualitätsklinken.de offers a variety of outcomes data. If you as a patient in need of a hip replacement want to compare the medical quality of German hospitals you will find indicators such as (see Figure 7, Quality indicators on www.qualitaetskliniken.de):

- procedure related numbers of treatments;
- the number of successful operations;
- the duration time of operations;
- patient difficulties after the operation and
- the number of infections/haematoma or other complications after the operation.

Figure 7: Quality indicators on www.qualitaetskliniken.de

Indicators measuring patient security can be disinfection and hospital hygiene, pharmaceutical therapy security (e.g. all patients above 65 years of age have to be checked on the kidney function), complaints done by patients, the availability of a critical incidence reporting system, the technical check of life-saving instruments, the security in operation room (according to WHO definitions) etc.

Patient satisfaction

Patient satisfaction is measured by patient experience reports and gives you information about:

- Medical care of doctors and nursing staff;
- Sufficient information from doctors and nursing staff;
- Personal treatment from doctors and nursing staff;
- Availability of nursing staff;
- Food satisfaction;
- Hygiene satisfaction;
- Hospital admission procedure;
- Waiting times during examination procedure;
- Discharge procedure from hospital and
- Success of treatment.

Admission data

Following indicators are measuring the satisfaction level of the patient at the time of his/her admission:

- Waiting time before getting admitted to one specialist department at clinic;
- Accessibility of competent medical contact persons;
- Cooperation with doctors of the specialist department at clinic;
- Satisfaction level with letters written by doctors;
- Satisfaction level with medication upon discharge;
- Satisfaction level of treatment results and
- Recommendation to friends/family: yes/no.

What is positive about Qualitätskliniken is that it really serves as an interactive portal, where results are being displayed according to your individual medical needs and preferences. The graphics show in a simple manner, where on a quality rating of maximum 100%, your respective hospital is ranging. This gives you a quick overview and valid information, which you could use and discuss for example with your GP when talking about your referral to a hospital.

As shown, www.qualitaeskliniken.de offers huge amounts of data, generally well designed in a user-friendly manner. There are a lot of survey-based opinions, providing a strong patient input, something more and more people look for. Still there are no individual user remarks of opportunity to add own comments or share experience from hospital visits – a quality we expect will be standard procedure in the next few years.

The table with the two German IT-portals looks as following:

www.weisse-liste.de		www.qualitaetsklinken.de
yes	**Hospital/specialist clinic comparison**	yes
• quality reports by hospitals • BQS reports • patient experience questionnaires (PEQs)	**Quality sources**	• quality reports by hospitals • BQS reports • IQME reports • and other independent research institutes • patient satisfaction reports • patient admission reports
• treatment quality and success • medical equipment • number and qualifications of doctors and medical staff • relation to and information from doctor/nursing staff • service to the patient • readiness for further recommendation of hospital • and many more • no reports on waiting times	**Quality indicators**	• treatment quality and success • duration time of operation • number of infections • mortality rates • hospital hygiene • medical care, treatment and information of doctors and nursing staff • availability • readiness for further recommendation • and many more • waiting time before admission • waiting time during examination procedure
pilot project on quality ratings of general practitioners will be published in autumn 2010	**Primary care**	no
no	**Information on pharmaceuticals**	no
time-consuming but offers individual results in the end	**User's manual**	• simple and clear • three steps to get to valid results
www.unabhaengige-patientenberatung.de	**Other links**	links to hospital quality reports

5.4 United Kingdom – where it all started

The UK with a population of 61 million inhabitants and 245 000 square kilometres is well populated, with 250 persons per km. This is roughly the same level as Germany. The GDP per capita (PPP) is 35 630 USD (2008)[30].

Country characteristics

The United Kingdom has decentralised the responsibility for healthcare to its constituent countries, which mainly fund healthcare through national taxation. The delivery of services takes place through public providers. Within the public NHS system purchasing responsibilities have gradually been transferred to local bodies: primary care trusts (PCTs) in England, primary care partnerships in Northern Ireland, health boards in Scotland and local health boards (LHBs) in Wales. The "devolution" means that policy will vary within UK. That patients in England now have got the right to choose among HNS hospitals does not have to mean that the same rules go for Scotland or Wales.

Compared to continental Europe the healthcare system is still homogeneous. Coverage is available to 100% of the population. Privately owned hospitals count for 5 percent of the beds. General practitioners (GP's), a corner stone in NHS, are self employed while hospitals receive activity-based and contract financing. The new centre-right UK government says it wants to strengthen the GP position further (family doctors since long serve as gatekeepers) by allocating significant funds for contracting of services to the GP's.

UK has been a forerunner in Internet information about healthcare services. Dr Foster, a privately owned entrepreneur, started its website www.drfosterhealth.co.uk already ten years ago. In the UK we will look into this hospital portal (with the annual hospital guide) and the public NHS Choices portal.

Internet use

According to the latest information on Internet use 51, 442,100 people in the UK are using the Internet. This is 82.5 % of the UK population. [31]

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[30] OECD.StatExtracts, http://stats.oecd.org/index.aspx?queryid=23111

[31] Internetworldstats, http://www.internetworldstats.com/stats9.htm#eu

Hospitals and specialist clinics

There are 379 hospitals in England, 109 hospitals in Wales, 223 hospitals in Scotland and 31 in Northern Ireland.

GP's

Visits to GP surgeries are free in all countries of the United Kingdom, but charges for prescription only medicines vary. Wales has already abolished all charges, and Scotland has embarked on a phased reduction in charges to be completed by 2011. In England, however, most adults of working age who are not on benefits have to pay a standard charge for prescription only medicine of £7.20 per item from April 2009.

NHS Choices - http://www.nhs.uk is an organic growth of the initial NHS telephone based hotline. It covers England and contains not only information on hospitals and primary care, but also pharmacies, dentists and opticians. For Wales, Scotland and Northern Ireland there are separate Information Services.

The NHS Choices offers comparisons of hospitals/specialist clinics through a wealth of data for each hospital, from parking space to medical outcomes. Patient opinions are presented, both from surveys in the hospital and from NHS. Since NHS Choices is a part of NHS it is difficult to say if the site offers "own" data. Outcomes are few, except for infections. A lot of data is actually for the trust the hospital belongs to, not the hospital itself.

So, what indicators / facts does the site show?

Measuring of and comparison between hospitals is done by no less than 63 indicators, from compliance with administrative routines to publishing of patient opinions. You can compare unlimited numbers of hospitals, although more than 4-6 at a time becomes unwieldy[32].

It is possible already at the listing of all hospitals to sort them after "excellent quality" or "lower than average mortality" (apart from sorting by alphabetical or distance).

A search for the best specific medical treatment shows the following indicators for the hospital (hip replacement, whole of England) will show not only the above indicators but as well (see Figure 8, Comparison of London hospitals performing hip replacement, www.nhs.uk):

[32] http://tinyurl.com/2vk9h7g

- Number of operations performed;
- Waiting times for patients last year (percentage that got examination and treatment within 18 weeks);
- Time in hospital after treatment;
- Patient outcomes (percentage with unplanned readmissions, survival rate) and
- Wound infection rate (percentage, MRSA rate).

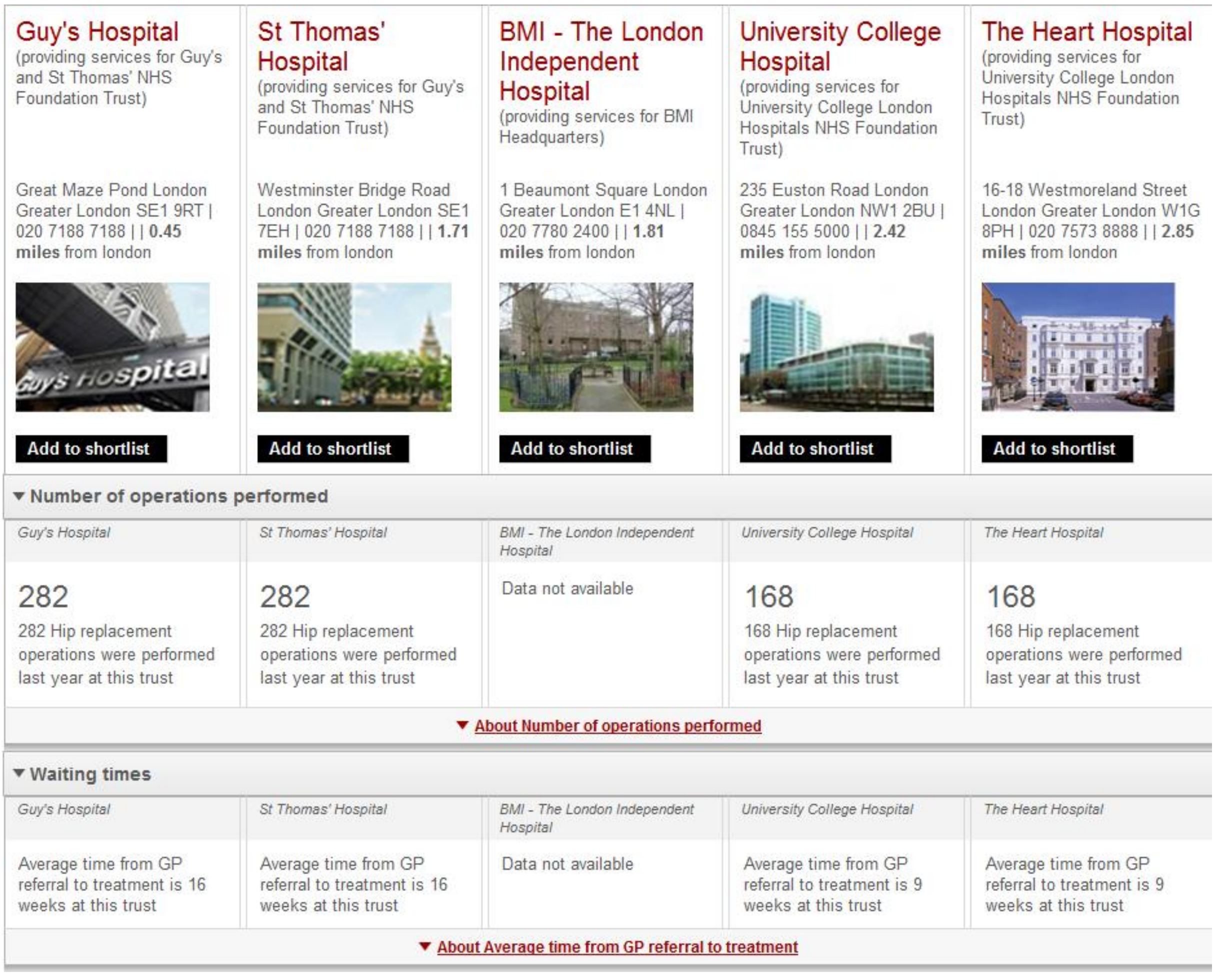

Figure 8: Comparison of London hospitals performing hip replacement, www.nhs.uk

Which hospitals to look for – and to avoid?

The site is very big, and closely connected to other NHS sites such as NHS Direct or Care Quality Commission. Sometimes it is difficult to recognize exactly on which site you are, or which function you are using.

To find the hospital with best results – chose "filter for particular condition" and where you live, name the condition, change the distance to "anywhere" and "sort after excellence".

However, the number of hard medical indicators is limited, so the search will show if the trust follows recommended procedures rather than the medical excellence or results of the hospital.

The NHS Choices also provides a medicines guide with both "search by treatment" and "search by medicine" options. Only information on the active ingredient, not the medicine by name/brand is provided here. It contains information about interaction, side-effects and so forth. Basically it is a useful service, but it's badly designed with regard to user-friendliness.

Further points about NHS Choices are:

- It lacks a user manual to navigate the portal.
- There is a self-help guide for some limited disease areas such as asthma.
- It provides lots of additional useful services on the site, such as information for carers, on drug/alcohol abuse, live well-advices and a lot more.

NHS Choices is the official, tax-financed site for 51 million people, and it shows. As a portal visitor you get the feeling that NHS Choices is too big and would gain from being divided into smaller, more distinct sites. According to an article in the Independent, the government was accused of "hiving off" parts of the NHS in order to make £60 million worth of savings in the next few years[33]. Rumours say that the NHS branch NHS Choices will be closed down completely as the new UK government aims to making the GP the key player in the healthcare system – potentially shrinking the room for patient choice.

Dr Foster - www.drfosterhealth.co.uk is a private-public cooperation, where Dr Foster today is a main provider of analysed performance data to different parts of NHS but as well offers information services to the public.

The Hospital Guide[34] (see Figure 9), covers the 30 most common operations performed by the NHS in England and answers to patient questions such as:

- What is the waiting time for treatment?
- How long can I expect to stay in hospital?
- Will I need to stay overnight?
- What is the risk of me having to return to hospital urgently?
- Who are the consultants that may treat me?

[33] http://www.independent.co.uk/news/uk/home-news/government-accused-of-nhs-selloff-over-cuts2043949.html

[34] http://www.drfosterhealth.co.uk/hospital-guide

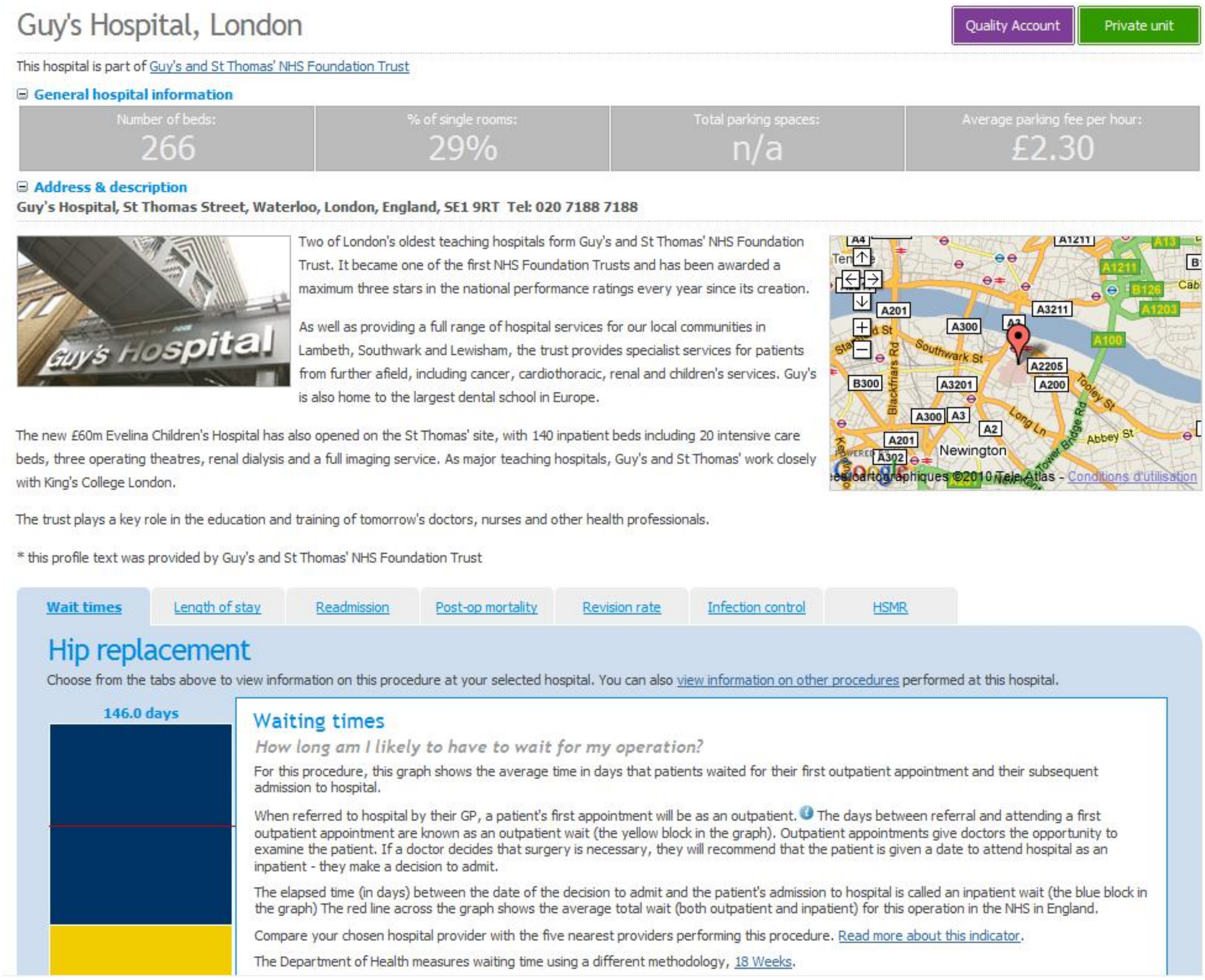

Figure 9: Quality information on hip replacement, www.drfosterhealth.co.uk/hospital-guide

The Guide covers a lot of data about hospitals, consultants and maternity wards. You can enter the search by looking for:

- A certain procedure;
- A certain hospital;
- (by a NHS trust).

Procedures

If you type in the procedure you are interested in – we stick to hip replacement as the subject - you will find about 50 hospitals in London within a radius of 25 miles (or 40 km) from where you live (postcode) that offer such a treatment.

For each hospital you will find the same information with regard to hip replacement as if you already initially look for a specific hospital (below).

Hospitals

Each hospital is overall presented with a short written description of the hospital (location, profile, educational branch and so forth) and in figures:

- Number of beds
- % single room
- Parking spaces
- Parking fee (parking information might look a bit banal, but has proven to be a key question to many relatives and visitors to hospitals; useful consumer information)

Under the header "*Quality account*" the following data is available:

- Patient safety – 13 indicators
- Clinical effectiveness – 18
- Patient experiences – 8

If there is a *birth unit* or *a private care unit* (becoming more and more common within NHS hospitals) there are key indicators describing their activities.

For emergency hospitals the A&E (*accident and emergency*) report is shown by eleven indicators – of maybe limited immediate interest to a patient with acute needs as you (relatives, ambulance staff etc.) probably give priority to rapid access, but useful of course for future needs and to purchasers, commissioners/politicians, media and index makers.

Hospital doctors/consultants are shown with speciality, data of degree, hospitals that the consultant practiced at, et cetera. This might be a useful service if you actively want to avoid a certain doctor or to learn about the background of the medical team.

Patient experience

HCP regularly looks for ways at websites to assemble patient experience and views. The Hospital Guide reports on how patients grade a number of functions at each hospital, such as:

- Does the hospital treat patients with respect and dignity?
- Does the hospital have a specialist palliative care team available 24/7?
- How many operations were cancelled due to missing notes?
- What are the waiting times for hospital-based out-patient treatments?

This information is generally picked from national patient surveys. A forum for patient self-reporting is as important. The Dr Foster portal offers three such ways:

- NHS Choices (http://www.nhs.uk/Pages/HomePage.aspx);

- I want Great Care (http://www.iwantgreatcare.org) and
- Patient Opinion (http://www.patientopinion.org.uk).

You can deliver comments at the main NHS site or use I want Great care to give – and read about - specific opinions about a doctor or a clinic. Patient Opinion offers the channel to write about your experience of a certain incident or meeting with healthcare. These self-experienced stories have become popular reading and are a useful tool for daily improvement work within UK healthcare.

User-friendly?

As described here, the Guide contains a lot of information about each hospital. Does the site as well offer easy comparisons between hospitals/specialist clinics?

Yes – but in a very limited way. Comparisons for all hospitals can only be done on "patient safety score", but that is an aggregated number and details are not shown except for one hospital at a time[35].

The Guide provides no way except Excel to compare the performance between different hospitals. The information as such is relevant and might be indicative, given that you want to make sure that a certain hospital (of your choice or by referral) meets your requirements. That is one possible way to do the search.

Your GP says that he/she will refer you to hospital X and you want to make sure it is good and safe enough. Then it might be appropriate and handy to be able to use the information (often expressed by traffic sign colours, as for HCP indexes) to tick off if there are any alarming indications, for hospital infections, re-operation frequencies or if the hospital complies with the regulations for reporting of safety incidents, et cetera.

As with NHS Direct a lot of data is available, but it is not designed for easy consumption. Neither is there any good instruction to the site. And all searches for hospitals have to give a post code – not "London", but EC1A 9LA-style. The upside is that you can look for services close to where you live (you can indicate the acceptable distance to the hospital from your post code area). The downside might be that for a full comparison you have to know many post codes.

So, if you use a different search technique and want to be able to compare many indicators and hospitals at the same time to have a better overview, the Hospital Guide is not very practical. That does not diminish the value of a huge data base – if you know how to exploit all this information…

[35] http://www.drfosterhealth.co.uk/quality-accounts

The Hospital Guide sticks to healthcare provision – there is no information about pharmaceuticals. However there is a health & medical dictionary at the site.

For an overview see our table with both website comparisons on the following page:

www.nhs.uk		www.drfosterhealth.co.uk
yes	**Hospital/specialist clinic comparison**	yes
• reports from hospitals • NHS reports • patient opinion reports	**Quality sources**	• NHS Choices • I want Great Care • patient opinion
• 63 indicators showing information such as • number of operations performed • waiting times for patients last year • time in hospital after treatment • patient outcomes (percentage with unplanned readmissions, survival rate) • wound infection rate	**Quality indicators**	• patient safety – 13 indicators • clinical effectiveness – 18 indicators • patient experiences – 8 indicators
yes	**Primary care**	no, only information about hospital doctors/consultants
yes, but very user-unfriendly	**Information on pharmaceuticals**	no, but there is a health and medical dictionary
no	**User's manual**	no
information for carers, on drug/alcohol abuse, live well-advices etc.	**Other links**	• therapist guide for homeopathy, chiropractic, herbal medicine, osteopathy and acupuncture • birth guide to compare maternity care • consultant guide to find a specialist • and more

5.5 Sweden – trailing behind

Sweden has 9.4 million inhabitants, spread over 450 000 square kilometres. It means in average 23 inhabitants per one square kilometre, to compare to Denmark or the Netherland with ten times that density. To the design of the hospital system, such conditions count. The GDP per capita (PPP) is 36 789 USD (2008)[36].

Country characteristics

The public healthcare is funded by taxes and administered by elected healthcare regions/county councils. These regional bodies are still a powerful policy player in relation to the (in healthcare) weak national level. The regions can decide if to apply a purchaser-provider split or to implement a DRG reimbursement system for hospitals. There is a movement towards fee for service, especially in primary and maternity care, following on recent free choice reform.

The weak point in Swedish healthcare has for long been the lack of a family doctor culture. During the last years there have been national government initiatives to increase transparency and performance documentation, to support informed choice, completion and entrepreneurship in healthcare. To improve access is a major concern, with a waiting time “guarantee” of 90 days. If you cannot have a treatment within that time frame you can turn to a hospital in another part of Sweden.

Sweden use to be among the top competitors in the world for implementation of ITC. That is the case also in healthcare, if you look for administrative and intra-professional applications, but hardly for patient information. The lack of a strong national hand to drive such initiatives puts Sweden far behinds countries such as Denmark or UK. A nation-wide healthcare information service (www.1177.se) is taking shape, but yet only for treatment advice on phone and Internet. There is a connecting information site but only for primary care (www.beta.1177.se). The www.vardguiden.se , a regional initiative in Stockholm, provides some good ideas.

Internet use

8,397,900 people are using the Internet in Sweden in 2010, which makes 92.5 % of the Swedish population[37].

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[36] OECD.StatExtracts, http://stats.oecd.org/index.aspx?queryid=23108

[37] Internetworldstats, http://www.internetworldstats.com/stats9.htm#eu

Hospitals

The exact number of hospitals in Sweden is difficult to find, since they are organized in different ways for all 21 county councils. For example the county council of Blekinge has two hospitals, placed 100 km apart and both count as full service hospitals, although fairly small and without offering advanced treatments. Sweden has several private specialist clinics (operating within the public funding scheme) that perform eye surgery, hip replacement, advanced examinations (CAT/PET scans) but no "full hospital service". Included in the list are formal hospitals that actually act as combined geriatric and primary care centers but with some limited capacity for more advanced treatments like surgery. All in all Sweden has between 80 and 90 hospitals.

GP's

A person seeking care first contacts a clinic for a doctor's appointment, and may then be referred to a specialist by the clinic physician, who may in turn recommend either in-patient or out-patient treatment, or an elective care option.

Omvård – www.omvard.se is a private imitative financed by the Confederation of Swedish Enterprise. It builds from publicly available data from national Swedish authorities - no independent research.

This website offers information, comparisons and patient reviews for both primary care and hospitals. The site is organized on healthcare region/county council level, why a comparison of all 21 county councils will demand a lot of cut and paste.

Each hospital is shown with results for:

- Patient security (2 indicators);
- Waiting times;
- Diabetes (7 indicators);
- Intensive heart surgery (7 indicators);
- Hip replacement (4 indicators);
- Obstetrics (6 indicators), divided first time-repeated;
- Dialysis (2 indicators) and
- Stroke (3 indicators).

The results are shown as percentage of fulfilment / total numbers, and in relation to the national average.

It is possible to compare with the three closest hospitals or one named hospital, but only indicator for indicator (only intensive heart surgery is ranked by a total score). A “top of Sweden” benchmark is not yet achievable for any treatment. A curious consumer can cut and paste the data for all hospitals in an Excel page – not very user-friendly, though.

It is easy to use the site within these limitations. A very disturbing practice is that Omvård.se splits the information over several web pages. The diabetes section for each hospital displays four indicators on page 1, and three indicators on page 2. Why not show all seven on page one, thereby giving an over-view to the reader? And of course it is not possible to locate the “best hospital” at Omvard.se.

There is no information available on pharmaceuticals and the site does not provide a “user’s manuals” for healthcare.

www.vardguiden.se is aimed towards primary care and health advice. Vårdguiden is the medical guide for the Stockholm county with only two million inhabitants, so this is an unfair comparison. But since Vårdguiden has been the best Internet-based health information site in Sweden, we included it. However, it offers only one indicator regarding outcomes – cataract surgery.

It is fairly easy to find information on waiting times, but only within the Stockholm county, leaving out 20 of 21 county councils. The site provides a link to the national waiting time database and a description of the Swedish treatment guarantee. We didn’t find it user friendly or useful.

For each primary care centre the user has the possibility to view results of the national patient survey. This data is only available for primary care and not for hospitals or specialised care. The data overview also gives no access to free text comments.

Another negative point of the site is that it is not possible to leave comments regarding experiences of healthcare.

As Sweden does not offer a nationwide IT-portal on hospital comparisons, we don’t include a table here.

6. How user-friendly and reliable are the portals?

After having looked into the hospital portals, described in the previous chapter, we came to the conclusion that four different aspects were of great importance for a successful IT-portal:

- Firstly, can the user find information about the treatment quality of the respective hospital?

- Secondly, can the user find information on waiting times for his/her medical treatment?

- Thirdly, can the user read about other patient experiences online?

- And fourthly, can the user leave comments about his/her own medical experience?

This led us to identifying the following four categories for comparison: is there user-friendly information available to help the visitor to locate:

- best treatment;
- quick treatment;
- patient comments and
- how to leave comments.

The following matrix shows how well these hospital portals perform in those four categories, indicating a green dot with good performance (quite useful/supportive), a yellow dot with medium performance (useful) and a red dot with bad performance (not really simplifying choice).

	Best treatment	Quick treatment	Patient comments	Leave comments
independer.nl	🔴	🟡	🟢	🔴
kiesbeter.nl	🟡	🟡	🔴	🔴
sundhedsqvalitet.dk	🟡	🟢	🔴	🔴
weisse-liste.de	🟢	🔴	🔴	🔴
qualitaetskliniken.de	🟢	🟢	🟢	🔴
nhs.uk	🔴	🔴	🟡	🟢
drfoster.uk	🔴	🔴	🟡	🔴
omvård.se	🟡	🟡	🔴	🔴
vårdguiden.se	🔴	🟡	🔴	🔴

1. Which hospital / doctor have achieved the best treatment results?

Green: Treatment results are shown at the website and it is possible to sort the results from best to worst. Or there is already a complete “top ten hospitals” ranking.

Yellow: Treatment results are shown, but not in a way that makes it easy to locate the best hospital/doctor. Results may only be shown for one hospital at a time, or in alphabetic order without any possibility to sort.

Red: Less useful/easily available than above.

2. How to get a quick treatment?

Notice: this is more or less two questions. Firstly “how do I get treatment quickly”, then “What is the waiting time for this treatment at different hospitals”.

Green: Easy to find this information and offers a good overview of waiting times in the country.

Yellow: There are waiting times information available, but difficult to use (for example only waiting times for one hospital at a time). The waiting times could also be old, or several hospitals may not reveal their waiting times.

Red: Less useful/easily available than above (no waiting times, or less than half of the hospitals).

3. How to share comments with other health consumers?

Still, this service is rarely existing but highly appreciated by patients and other visitors to information websites. “Learning by peers” is a common method in many other selection processes among consumers and lay persons. That is why we value such an opportunity also at hospital information websites.

Green: Easy to find, easy to read and some structure of the comments – for example sorting by subject or level of satisfaction.

Yellow: Comments are shown, but not in an organized way. It could also be difficult to access the comments.

Red: Less useful/easily available than above.

4. How do I provide comments about my own medical experiences?

Again, user input is not very common but valuable, not the least to other patients. Such information ought to be quite significant to administrators and politicians as well. To guide cross border care movements patient experience from international treatments and advice how to navigate will be a real asset.

Green: Easy to find and use. If there is an identification function it should be easy and quick to log into. A reasonable design would be a structured sheet to fill in, but with free text possibilities.

Yellow: Difficult to find and/or less user-friendly. May be without space for free text comments or simply exhausting to use (for example – 40 questions).

Red: Less useful/easily available than above.

Patient opinions disregarded

Our evaluation indicates that you generally get mediocre and even poor support from these portals if you look for solid data on quality of care and how to avoid waiting. With regard to patient opinions there are even less options, still not regarding the ideas among the users of healthcare services as valuable enough to be exposed. Contrary to most other consumer information the very limited attention to patient opinion and assessment is striking, even alarming.

EPF criteria:

The European Patient Forum (EPF), an umbrella organisation of European patient groups (http://www.eu-patient.eu/), has put up a set of criteria with regard to the reliability and quality of website information on medicines. Looking for an external quality reference we have taken a look into if such a standard might be applicable at hospital information websites as well. EPF asks for web information to be:

- Evidence –based;
- Up to date;
- Reliable;
- Understandable;
- Accessible;
- Transparent;
- Relevant and appropriate;
- Consistent with statutory information.

We find that the reviewed hospital portals are designed along various modes, depending among other things on the purpose of the website and the local information culture. Such conditions partly explains why some countries are ahead of others (but hardly why a sophisticated ITC environment such as Sweden lags behind).

Common data sources behind the hospital portals are: public statistics/reporting (principally as reliable as the quality of public statistics) and/or data generated within privately owned hospitals or hospital groups. Regardless of origin most performance data seem to be linked to reimbursement reporting (DRG based reporting et cetera). Dr Foster UK process large volumes of data from medical records and procedures for evaluation and data mining, used as well by NHS Choice. The German Qualitaetskliniken.de gather own data from the hospitals within the group.

Other kind of data, such as service levels within hospitals, and patient satisfaction figures, are generally generated by surveys and patient interviews, according to more or less standardized methods. Generally the portals do not provide much information about the assessment and validation process behind the data from which the ratings are formed. On what basis the information is up-dated at the portals is another question without too many answers at the web.

The idea behind the portals is of course to make hospitals data and comparisons available to the public. The content is fairly easy to understand with a basic understanding of healthcare and experience of how Internet data is presented. As already explained, the logic and design often remains to be improved. The medium as such of course limits access by people with a handicap, such as blindness, poor sight or dyslexia. The fact that still large groups of Europeans for different reasons do not turn to the Internet for healthcare information is a major limitation (also stressed by our patient survey).

Is then the Internet information relevant? This is a good question, which we touch on in this study. Do the portals offer the kind of information, advice and guidance that patients, consumers, users, relatives and stakeholders are in need of and ask for?

As said, the relevance is far from evident, as few governments and initiators have set up clear definitions for the purpose of the portal. Without such clarity it is hard to judge on the relevance of the content and whether the portal fulfills the goals or not. Assessments require clear measurable goals with regard to not only visitor volumes or size of content but to the impact on performance and quality as well.

Nowhere have we found any public regulations or framework making clear that a certain kind of healthcare service provider information should be compulsory – or forbidden. Compared to the strict EU and national level ban on marketing to the public of prescribed pharmaceuticals there are few if any rules on the presentation of hospital information. More by tradition than modern, rational judgment doctors (and lawyers and other categories) in many countries have been denied to market themselves to the public but today there seem to be few restrictions concerning hospitals. What is no doubt confusing is that in most countries there are still no official minimum requirement with regard to quality information at hospitals and other care givers. Accordingly, there are few criteria for a measurement of how well existing hospital portal information fit officially formulated standards.

7. Can I find the best GP on the web?

What information on primary care is available at healthcare portals?

The Netherlands

On www.huisartsen.nl you can find the GP of your choice via typing the name of the doctor into the search field, or via entering your postcode/place of residence and your preferred distance to the doctor's practice. The search result shows you the address, phone number and opening times of the doctor's practice. For an appointment you will have to contact the GP via phone, sometimes there is an email address available.

Other links, such as the contact info to patient and consumer organizations and a link to the Merck manual medical handbook, where 3000 medical conditions and treatments are described in simple Dutch, are provided on huisartsen.nl.

Kiesbeter.nl has a similar display of information if you are searching for primary care data, which includes the name of the GP/primary care center, address, phone number, opening times and the website (if available). Some GP websites provide the possibility for user registration, which allows prescriptions online.

Independer.nl goes a bit further and shows some more useful information on your GP. For example, you can see whether it is a male or female doctor and the number of registered patients at the GP's practice. This might be of interest for you when you would like to know if the GP is preferred by many or rather a few patients. Also registrations of new incoming patients are being displayed. Furthermore you can find more indebt information about the GP's career background, such as the university of graduation and graduation year. Registration as a user on independer.nl has definitely advantages: patients can get an appointment with a GP and a repeated prescription online.

Denmark

www.sundhed.dk also offers general information when you are searching for a general practitioner in your proximity. The name of the GP, the contact info of his/her practice, opening and consultation hours, the age and the sex of the GP, his/her medical specialisation, and years of practice are all displayed at:
Sundhedsvæsenet / Vejviser / Resultatliste / Kontaktinformation[38].

[38] http://tiny.cc/jn9yh

Germany

Qualitaetskliniken.de and Weisse-Liste.de do not provide information about primary care, such as general practitioners. However, Weisse-Liste is running a pilot project on quality ratings of general practitioners. The results are based on patient experiences and will be published in autumn 2010.

Since January 2004, quality management (QM) is obligatory for all doctors' practices in Germany. QM is a useful instrument for optimising work procedures and quality of products and services. The Association of Statutory Health Insurance Physicians in Germany (KBV)[39] has a leading role in the assessment of quality and development in doctor's practices. It designed a quality management system, called QEP[40], which stands for Quality and Development in Practices, and it offers seminars on QEP. The method is based on a set of indicators and on a manual, adapted to the demands of doctors' practices. The system is organized in modules and can be implemented step by step. So far it counts 23.000 registered QEP users. About 400 of these users have the QEP-certificate.

The *European practice assessment* (EPA)[41] is another example of a quality management system, offered by AQUA[42]. The key aspect is the development and validation of a set of indicators and tools describing the organizational aspects of primary care practices. The intention of the EPA instrument is to allow management and organization of medical practices to be measured and evaluated at regional, national and international levels with an educational approach. EPA does not measure quality indicators of all primary care practices in Germany, but it is the market leader. So far about 1 600 primary care practices in Germany have a certificated EPA label.

United Kingdom

Dr Foster shows no information on primary healthcare, which could be of use for the consumer, but with the NHS portal it is another story[43]. The user has the possibility to get a list of all GP's in his/her area, and can indicate his/her preferred distance to the GP's practice. You can remove GP's that don't receive new patients from the list, or add a "must have" out of eleven indicators. However there is only data on access and services of the GP. The indicators don't provide any data on quality outcomes or education of the GP.

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[39] Kassenärztliche Bundesvereinigung, www.kbv.de

[40] Qualität und Entwicklung in Praxen, www.kbv.de/qep/11469.html

[41] Europäisches Praxisassessment, www.europaeisches-praxisassessment.de

[42] Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen, www.aqua-institut.de

[43] http://tinyurl.com/28oe6ww

- GP's at this place (number and gender) and languages spoken;
- Appointments out of office hours (1830-08 or weekends) ;
- Patient opinions on telephone access, booking appointments, getting their "own" doctor, satisfaction with opening hours and possibility to book an appointment within 48 hours;
- Services at the primary care centre;
- Patient opinions of the service;
- Patient opinions of the centre;
- Location and parking;
- Reception of new patients.

Sweden

Sweden is showing a bit more information about its general practitioners than the previous countries. On the website Doktorsguiden[44] each primary care centre is described with contact data, a map and four subgroups with following indicators

- Patient survey (8 indicators);
- Access (3 indicators);
- Medical results (6 indicators) – "following guidelines" and
- Asthma and allergy (5 indicators).

Each indicator is only shown with the others in the subgroup. You can't see a total score with all 22 indicators for a primary care centre (except for the already mentioned cut and paste-method).

Another search engine to find doctors in Sweden is the IT-portal GoDoc[45]. Here patients can type a disease and/or treatment and the site shows all clinics, which offer the specific treatment. Patients can also ask for a geographical placing by choosing a county council and city level. Respective waiting times are also displayed.

GoDoc is a useful service because it gives information on primary care practices, which is not easy to find elsewhere on the web. For instance, you can find an overview of all practices offering laser treatment or paediatric care in Stockholm. However GoDoc doesn't offer any information on medical quality, types of treatment or medical successes/failures. Neither does the site offer any opinions from earlier patients, links to the national patient survey or any other comparative information that could be useful for an active health consumer.

[44] www.doktorsguiden.se

[45] www.godoc.se

8. Patient opinions about quality outcomes portals

So, having looked into a number of information solutions in key EU countries and asked European patients about their view, what are our impressions? Do hospital guides at the Internet, presenting quality of care information (QCI), attract visitors? How do patients look upon such services? And does access to information affect what choice patients make?

About the patient survey

In April 2010 we invited activists and groups in 31 European countries to participate in a survey on patient information. The objective was to assess the extent to which the healthcare consumers in the different countries of Europe are able to make key choices about hospitals and medicines in 2010.

A questionnaire of four questions (see appendix) was designed and put online for anonymous and easy access to all health campaigners and translated into the respective European languages. The independent organisation Patient View (www.patient-view.com) conducted the survey and distributed the questionnaire to patient organizations in Europe. The response rate was massive: over **1 000** respondents participated in the survey. This showed us, that there is a huge interest in this field and that patients are concerned about where to find useful information about their health-care.

Of course the results do not show absolute numbers, as the majority of respondents came from UK and Germany, the countries with the highest population numbers. But nevertheless we can identify a trend for each country. Countries with less than ten respondents haven't been included in the result analysis.

The impressions we got from the survey added to a great extent to our knowledge. The realistic picture of today's patient is, that he/she wants to be better informed about his/her own health and wishes to make more independent decisions when it comes to healthcare providers. So far, hospital information portals only exist in five European countries, and the information they provide is not always user-friendly and accurate. The rest of the countries are lagging behind when it comes to digital data on healthcare. This is definitely a future challenge for the respective governments.

Talking about the empty spaces of IT-information in healthcare: quality information on GP's is almost completely lacking on the web. Still quality information about treatments abroad is another white spot (to be improved following on the new EU cross-border care directive).

Patient survey impressions

1. Public knowledge about the existence of Quality of care websites

Countries that do have hospital comparison websites such as the Netherlands (NL), Germany (DE), Denmark (DK) and the United Kingdom (UK) score relatively low when it comes to the public awareness of the existence of such a website. Let's take a look at Figure 10 on the following page: we can see that those countries are closest to the 50% mark of the x-axis, which shows the public knowledge about the existence of Quality of Care websites. Considering the fact that none of them reaches the 50% mark, let's call this a somewhat shocking result. The general conclusion here might be that the public healthcare sector does have a lot of reforms in these countries but the governments will have to do more marketing in the future, in order to "spread the word" about the existence of such Quality of Care websites.

Sweden has the lowest scores from our "round of five", which shows that respondents gave a realistic estimate of the typical healthcare situation in Sweden. With some exceptions, there are no websites on hospital comparisons and county councils are doing everything to keep it that way. The generally high use of information technology from both government and public doesn't have the same impact when it comes to healthcare. Patients are still opting for the hospital around the corner, although waiting times might be longer than in a hospital, which is 100 kilometer further from their home. The readiness for mobility is rather low and the awareness of choice stays also low. An explanation might be the fact that Sweden does not provide a lot of information in healthcare.

The results of all other countries give a pretty realistic view about the situation in the rest of Europe. In most countries such websites don't exist and consumers are well aware of that. But in some cases, such as France (FR) and Belgium (BE), respondents showed a tendency to answer this question more positively.

"False positivity"

In France information on hospital comparisons can be found in annual rankings published by journals as *Le Point* and *L'Express.* Until today, no hospital comparison website exists in France. Yet quite a high number of respondents have the idea that such a website/or more such websites do exist. A possible interpretation for this "wishful thinking" might be that people in countries with a lot of information on healthcare and a user-friendly environment have rather positive impressions. As a matter of fact respondents tend to think that this information is also available on a website.

This "false positivity" can also be seen in Belgium (BE), where respondents named ordinary hospital websites, which only give general facility information and no real hospital ranking. In Belgium the consumer organisation *Test d´Achat* presents some quality ranking of healthcare, in combination with strong consumer attitudes with regard to choice in healthcare a possible explanation why Belgian patients might over-estimate the access to hospital information at the web.

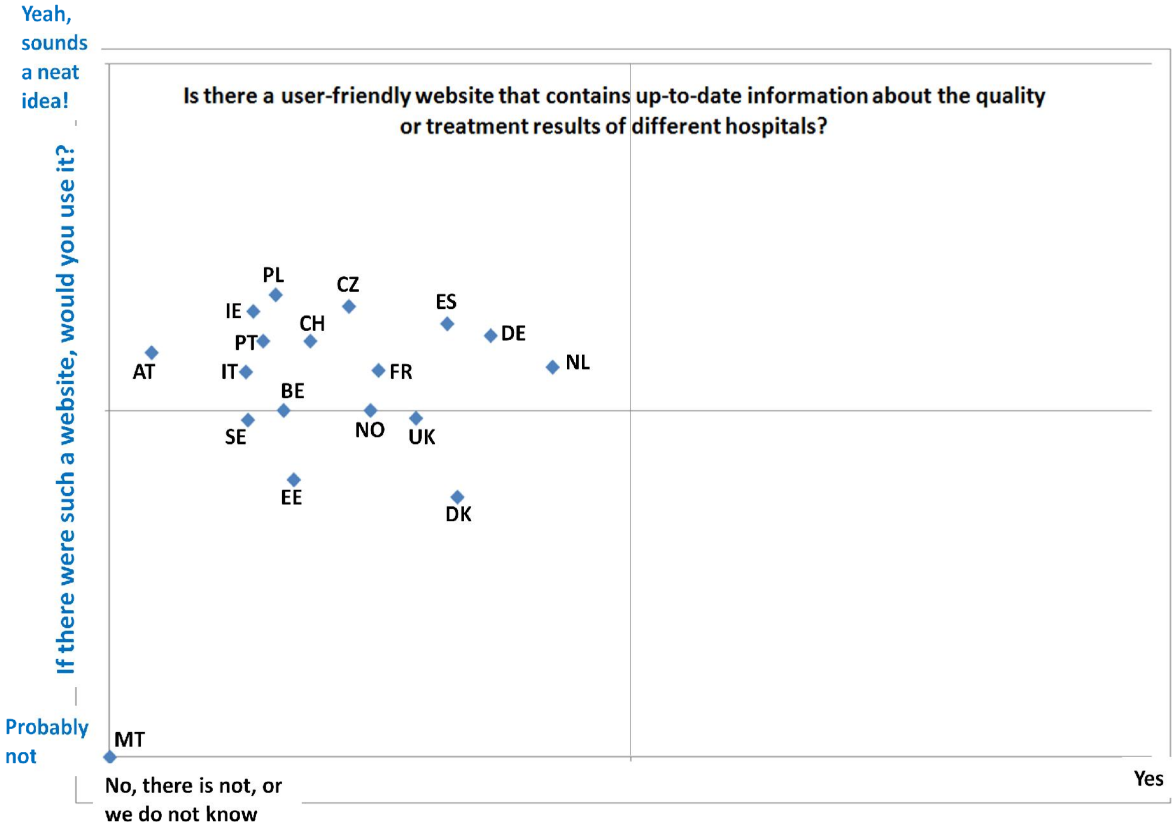

Figure 10: Note that no country reaches the "50% mark" for public knowledge about the existence of Quality of Care websites (the X-axis)!

2. Estimated use of Quality of Care websites

If we take a look at the survey question, whether patients would make use of such a website (assumed that it exists) we can see that patients in most of the countries would gladly welcome a hospital comparison website (see y-axis). In almost all countries – except Sweden and UK, who are slightly below, and Estonia and Denmark who are definitely below the 50% mark) - over 50% of the respondents think that such a website/or more websites would be a neat idea.

UK and Denmark, the forerunners who implemented hospital comparison websites (Dr. Foster and sundhedskvalitet.dk) as the first ones in Europe, score unexpectedly low. Respondents in both countries don't seem to cherish the information they could find on these websites – a signal worth discussing further.

3. Does the information affect patients' choice?

Most of the countries responded quite positive to this question, which gives the impression, that people really believe that such a Quality of Care Information portal would affect the patients' choices. Let's take a look at Figure 11 on page 71, in particular the y-axis: most countries reach over 50% in their estimation of the IT-effect on the consumer.

The UK and Denmark once again score low, when it comes to the impact of such websites. Especially in Denmark our expectations were not confirmed and respondents answered rather low to the question if such a website would affect the patients' choice. Here patients seem to still make their choices in healthcare on other grounds, such as the traditional choice for the family GP and hospital around the corner. We can also observe similar trends in the UK.

Norway and Switzerland, the rich countries in the pot, especially indicate big expectations when it comes to their choices in healthcare. They would like to be able to choose the very best option because they have comparably high expenses in healthcare. Their price-quality awareness is therefore high.

Portugal and Ireland score low on this question and don't think that information on such a website would affect their patients' choice. One possible interpretation for their low scoring might be the fact that both of them show high waiting times in healthcare. As a matter of fact the expectations of the patients are lower. They are happy to get a treatment at all and don't consider themselves as to have the option for choice.

Overall, the Netherlands followed by Germany, scores highest in almost all categories. Both countries can be identified as the front runners in digital healthcare information and the peoples' awareness of such information. Patients have a high interest in quality and are very choosey when it comes to healthcare.

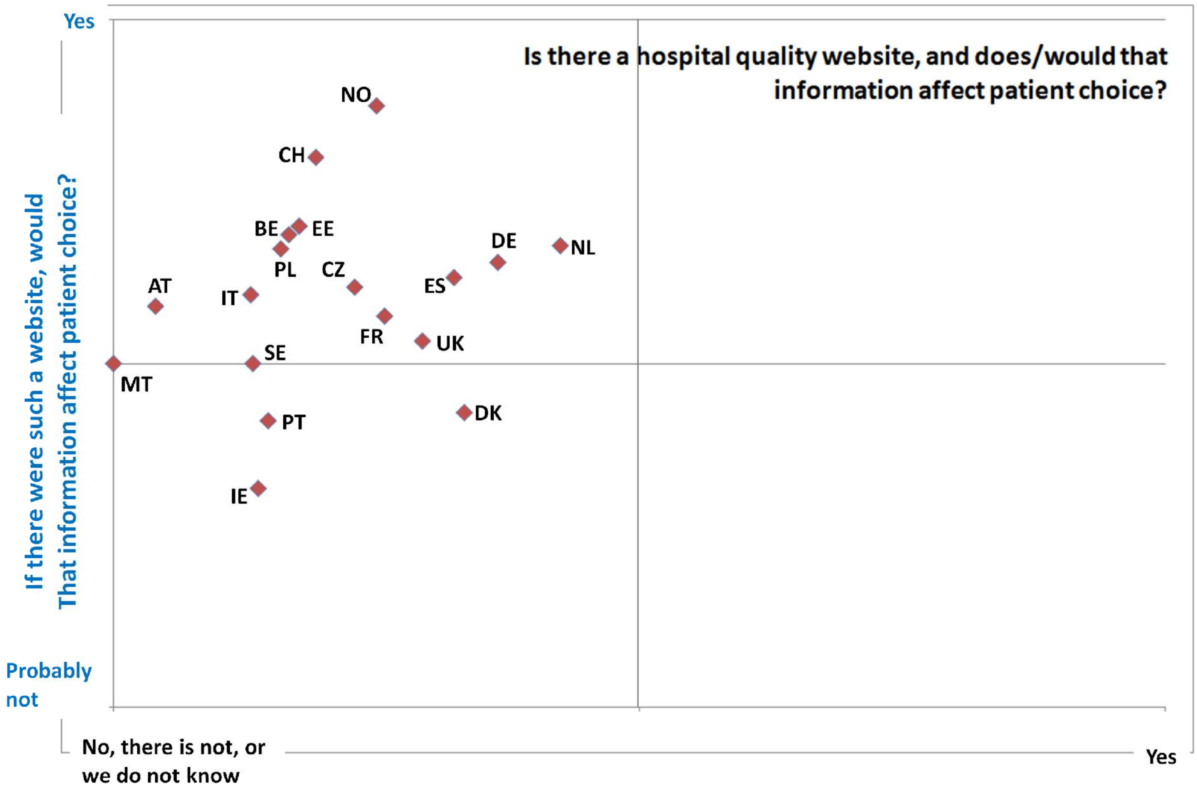

Figure 11: In most countries consumers think that information on Quality of Care websites would affect patient choice of hospital.

9. Conclusions and visions

QUALITY OF CARE INFORMATION (QCI) AS A DRIVER OF HEALTHCARE QUALITY

It is highly likely that consumer access to information about quality of care can become a powerful driver of quality improvement in European healthcare.

At the present time, however, this study suggests that patients/care consumers in Europe:

a) are not very well informed about the QCI solutions existing – comprehensive national hospital web solutions exist in the UK, Denmark and Germany, with good efforts being made in the Netherlands, the region of Tuscany in Italy and various non-systematic solutions in other countries.

b) are not really accustomed to executing a free choice of hospital/clinic, particularly not in “waiting-list” territories such as the Nordic countries, the British Isles, Spain, Italy, Portugal and others, where patients traditionally have been, and still seem to be, more focused on obtaining treatment at all rather than on choosing the best caregiver.

c) are interested in QCI mainly when motivated by a situation of true choice; the 2006 healthcare reform in the Netherlands, with a true choice of healthcare for all citizens, is probably the underlying reason why the Dutch show the highest interest in and awareness of QCI solutions. Likewise, in Belgium, where accessibility to healthcare, and thereby choice, has been excellent for a long time, consumers do show an interest at the same time that hospitals show great reluctance to publish QCI to their very mobile customers.

d) will be influenced by other factors influencing choice of caregiver, such as friends’/relatives’ experience, proximity, friendliness of staff and/or financial matters, meaning that any significant effects of QCI driving improvement of healthcare services will probably not be observed for a number of years. The two geographies to watch probably are the Netherlands, and also Germany, as Germans do have a tradition of consulting this type of information for other goods and services, and as there is a growing realization among German care consumers that a myriad of smallish general hospitals cannot all be good at everything.

Background

The fact that patients are interested in getting more information about healthcare and its quality has been known for 30 – 50 years, as can be seen from some of the references in the following section.

It is axiomatic that in order to consider quality of care when choosing among healthcare providers, consumers must be able to acquire information about quality of care in a form that they can understand and use. Until recently, little information on the quality of healthcare has been available to consumers. Examples of quality of care information historically having become available to consumers include release of government-generated hospital mortality data gathered by the United States Health Care Financing Administration (HCFA)[46] and by some hospital associations. At present, however, quality of care information is increasingly being generated by government agencies, consumer organizations, the popular press, and healthcare organizations.

Behind this movement you can recognize not only the growth of legal patient empowerment but as well a shift in the perception of healthcare, from anonymous public good to more of a demand-driven consumer service. The general impact from the Internet society, with comparisons and rankings as a daily tool for decision-making among individuals and households, no doubt adds to the picture. You could expect governments on all levels to start using such benchmarks as a strategy to improve access and productivity by exposing performance gaps between care providers, in the long run a potential cost control mechanism. But such awareness still seems to be premature.

Consumer choice

There is insufficient empirical study of the question of whether the availability of QCI influences consumer choice of physicians or hospitals to conclude that such information does or does not have a significant impact.

Consumers are the individuals or groups (e.g. families) who make decisions to use health services, and to choose specific care providers, such as physicians or hospitals.

Providers of healthcare are physicians and hospitals. While QCI may affect the use of non-physician providers or alternative healthcare settings, consideration of these other providers is beyond the scope of this report.

Quality of care information (QCI) is information about the presence/absence, or worth (from poor to excellent), of different dimensions of healthcare -- technical, interpersonal, and amenities of care. QCI involves comparison with a standard of acceptable quality or with the

[46] http://hcfa.hhs.gov

facilities or performance of other healthcare providers. The information portals included in this study generally are at early steps of the QCI ladder, offering data to the web visitor to draw own conclusions rather than delivering benchmarks according to a certain (minimum) standard.

Consumer information use

The active care consumer looking for a foundation to make informed choices meets a number of obstacles and challenges. The first barrier is usually a lack of available information. Consumers often have great difficulty in obtaining useful information on the quality of the local hospital and physician services. Lack of information may reflect the costs associated with gathering and disseminating the information, or may occur because hospitals or regional financing bodies actively discourage such information provision. Disagreement among experts about the appropriate type and form of information is another deterrent to making information available.

The second environmental barrier is provision of the wrong kind of information. Consumers may find available information too technical or too complicated to be of use. Similarly, information on trivial or irrelevant aspects of health services is likely to be ignored in consumer decision making (and such information is still predominant within healthcare, such as data on when the hospital was built, the number of beds and so forth – information saying nada about how good the hospital might be on solving my healthcare problems). It is the consumer perception of what *is* relevant and useful for making choice decisions that is the critical factor in the effectiveness of information.

Building effective information

There are three possible approaches to building effective consumer information environments:

(a) Increase the *benefits* of information acquisition and use,

(b) Increase the *ease of access* to information, and/or

(c) Decrease *costs* of information acquisition and use.

Processability of information is the critical variable in building effective consumer information environments.

Processability is affected by:

(a) How information is presented,

(b) The types of processing used by consumers, and

(c) The types of choice tasks consumers face. In brand choice situations in which consumers have little prior experience, consumers tend to prefer information presented in a format encouraging choice[47],[48].

Consumer knowledge and sophistication

Even if consumers desire information about the quality of healthcare, they will be unlikely to use it correctly unless they understand it. Research[49],[50] on the sophistication of consumers about medical care, and the extent to which they are able to process information for healthcare choices, provides mixed evidence on this matter.

Healthcare providers make decisions about whether to provide information to patients based on their own views of patients' levels of knowledge. Several studies[51],[52] comparing objective measures of patient knowledge with physician impressions report similar findings: Physicians appear to routinely *underestimate* their patient's level of knowledge about technical medical matters. Thus, the withholding by physicians of medical and health information as "too difficult for patients to understand" may be unwarranted.

Patient satisfaction

Consumer evaluation of medical and hospital care of high quality physician and hospital care has often been studied within the framework of "patient satisfaction," a concept that appears to be correlated with evaluation of the quality of care. Typically, favorable perceptions of quality are associated with greater satisfaction.

Consumer and provider views of quality of care are similar, but not entirely congruent, since clients place greater weight on interpersonal aspects and the amenities of care. Irrespective of whether professionals believe that consumer opinions of the quality of care are valid, an understanding of consumer evaluation of the quality of medical care is essential to the success of any attempts to use expert-generated QCI to influence consumer choice of healthcare.

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[47] Russo, J. E. (1988). Information processing from the consumer's perspective. In: E.S. Maynes (Ed.), *The frontier of research in the consumer interest*, pp. 185--217. Columbia, MO: American Council on Consumer Interests.

[48] Bettman, J. R. (1979). *An information processing theory of consumer choice*. Reading, MA: Addison-Wesley.

[49] General Mills (1979). *Family health in an era of stress: The General Mills' familyreport 1978--1979*. Minneapolis, MN: General Mills, Inc.

[50] lnguanzo, J. M., & Damier, B. (1987). Consumer expectations on the rise: 1984--1986 data. *Trustee*, July, pp. t --6.

[51] McKinlay, J. B. (1975). Who is really ignorant -- Physician or patient? *Journal of Health and Social Behavior, 13, 115-- 152.*

[52] Pratt, L., Seligman, A., & Reader, G. (1957). Physicians' views on the level of medical information among patients. *American Journal of Public Health, 47,* 1277--1283.

Effects of information about health-related behavior

It appears that knowledge can be influential under certain types of circumstances: when there is a readiness toward action, few barriers, and available information about desirable actions. Information on the quality of care will sometimes be acquired under such circumstances, and thus may help consumers to make decisions about which physicians and hospitals are best.
The Dutch healthcare reform in 2006 seems to have provided such a set of circumstances. The results of the present study cannot be interpreted as the Netherlands having the best access to QCI, but rather that the focus on choice created by the reform resulted in an unusually high consumer awareness of QCI.

Consumerism in healthcare

Inadequate effort to acquire and process information, as a reflection of lack of consumer motivation, can be a significant consumer-based barrier to effective use of information. The likelihood that patients/consumers will seek and use information about the quality of care depends in part on their propensity to adopt an active consumer stance in healthcare decisions.

Consumer assertiveness in medicine is inconsistent with traditional authority relationships between physicians and patients. Medical care has traditionally been characterized by professional control of information and marked by a disproportionate supplier influence on the demand for services. Open information provided by a broad selection of sources is part of the grand shift from a strict intelligence hierarchy to “information democracy”, with openings for everybody to access knowledge to affect her situation.

There is some indication that consumerism in healthcare will increase as the public learns that QCI is available. Studies of patient desire for health information suggest that there is great and often unfulfilled interest in information regarding health and medical care.
Studies[53],[54],[55] over the past 50 years have repeatedly found that patients want much more information about their diagnosis and treatment than they receive. While these findings are not necessarily directly applicable to consumer interest in QCI, they suggest that it may be possible to promote active consumerism when quality of care information becomes readily available.

[53] Cartwright, A. (1967). *Patients and their doctors.* London: Routledge and Kegan Paul

[54] Ley, P., & Spelman, M. S. (1967). *Communicating with the patient.* London: Staples Press.

[55] Pratt, L., Seligman, A., & Reader, G. (1957). Physicians' views on the level of medical information among patients. *American Journal of Public Health, 47,* 1277--1283.

Non-use benefits of information

The main focus of this report is to assess the extent to which QCI is likely to influence consumer choice of physicians and hospitals in Europe. However, it is important to note that even if consumers do not benefit directly through choosing better quality health services, non-use benefits of QCI may also occur. Non-use benefits are those benefits of information provision that accrue to all consumers, regardless of whether or not they acquire and use the information. Providing quality of care information may indirectly benefit consumers by stimulating competition, leading to improvement of services and innovation in a number of ways[56].

First, QCI provision may shift the basis of competition among healthcare providers to quality of care issues. That is, some providers may realize that QCI reveals the quality of their service to be inferior. As providers adjust their allocation of resources to increase the quality of the care they provide, all consumers (not just those who acquire and use the quality of care information) may benefit.

Second, provision of QCI may have the non-use benefit of inspiring consumer confidence in physicians and hospitals in general. Even those consumers who do not actively seek and process quality of care information tend to perceive such information provision as exerting discipline on the healthcare marketplace and increasing physician and hospital accountability.

A third non-use benefit may accrue because quality of care information provision may simplify the consumer's decision task. That is, under a well organized and proactive QCI provision system, consumers may feel that they do not have to seek information since such information has already been acquired and processed by regulators and/or patient advocacy groups.

Rational and emotional barriers of web-search

It is difficult to answer the question, whether consumers really follow the advice they find on these websites. A study by Ferro[57] shows that rational and emotional barriers play a significant role in the prediction of consumer’s behaviour. In general it is not easy to make a prediction on the consumer’s choice because the field of healthcare is considered to be so complex. As a matter of fact, the layperson cannot be expected to make the right choice based on the information he/she seeks and finds on the internet. The patient is confronted by a bunch of complicated rules and regulations so that in the end he/she has only a limited choice when it comes to personal healthcare. It is also apparent that, because professional healthcare

[56] Mayer, R. N. (1981). How information disclosure reforms benefit non-users of consumer information: A review. In: C. B. Meeks (Ed.), *Proceedings of the annual co@rence of the American Council on Consumer Interests,* pp. 129--133. Columbia, MO: American Council on Consumer Interests.
[57] Ferro (March 2010): Keuze informatie in de zorg: Het gevoel van informatie.

providers might often make mistakes in diagnoses and treatment proposals, patients have it even harder to make the right choices.

Moreover, patients tend to have a deep feeling of helplessness, especially when they experience a serious medical condition. They feel powerless and unable to make the right medical choice. More important than the information about the quality of the medical healthcare provider is the attention that is given to the patient. Even more so, a successful medical treatment highly depends on this attention. In the end, the experienced complexity of healthcare gives the overall impression that it is impossible to get the right information over medical questions.

As a consequence of these barriers, patients rather tend to have sporadic decisions in healthcare. Once they feel that their medical treatment has bad results, they start to compare their options. While comparing the offers, they don't rely on information about quality but rather on their feeling and experiences made by family members and friends. It is extremely difficult to measure this kind of decision making.

Does picking the best providers improve quality?

So far there has been no study that shows whether there is a direct link between patients' choices and quality outcomes hospitals. Already for the next few years, this potential dynamics will become absolutely critical. Many patient organisations that work with specific groups of patients, such as the *Breast Cancer Organisation* (www.borstkanker.nl) in the Netherlands, present their own rankings of hospitals and inform their patients whether the hospital fulfils the quality demands from a patient's perspective or not. One can only assume that breast cancer patients take this data very seriously and put their trust into the hospital with the best quality outcome. It is only logical to predict that hospitals will have to go for best performance; otherwise they will start losing patients.

What can be said for sure is that these rankings from patient organisations do have an effect on hospital policies. The Dutch organisation *Kind en Ziekenhuis* (www.kindenziekenhuis.nl) for example has published the names of all hospitals that were allowing parents to be with their child while it was receiving a narcosis. Since the publication of this classified information, parents are taking this information into account when choosing a hospital. After all, what parent wouldn't want to be with his child during such an intervening procedure? As a matter of fact more and more hospitals in the Netherlands are allowing parents to be with their child during the narcosis procedure.

So in the very end...

1. There seems to be a need for a strong driver behind the development of hospital/healthcare portals and there is no doubt that these portals are of great importance for the future of the digital healthcare information. But let's not forget: Not all hospitals can be good at everything, so it is rather the specific medical treatments that should be compared and not the hospitals.

2. Still information portals are built and designed from above – what ought to be relevant to the visitor to know about healthcare – rather than from below-visions of the fully navigational hospital guide. The natural way for patients/consumers to approach hospitals is their condition and who can be the best (or at least good enough) to solve their health problems. This basic aspect is far from given when you look at the construction of a public portal. (Here healthcare could probably learn a lot from the entertainment industry, since long providing user-friendly and attractive web solutions!)

3. The characteristics of the message (e.g., quality indicator content and format) influence its effectiveness. Simple messages are easiest for consumers to understand accurately and efficiently; however, care must be taken to avoid misleading format or content.
4. In healthcare, which is a highly complicated and emotionally charged field, patients would benefit from information that is presented in a way that provides guidance on how to evaluate a particular type of service. Until then, patients will prefer seeking advice from their doctor, pharmacist or friends/relatives rather than from an Internet portal.
5. Equal access for all: Patients with difficulties to read the information presented on the IT-portal, such as dyslexic or blind people, should also have access to the data, by choosing their hospital via a listening option on the website. And what about those, who don't have access to the Internet? It is clear that in those cases other communication mechanisms, such as telephone services, have to be developed and offered alongside
6. Still there is a long way to go even among the top performers before there are truly handy and user-friendly portals with high value content.

And how about cross-border care?

The new EU directive on cross-border healthcare is intended to allow all patients – and not only the best informed or richest – to enjoy a series of healthcare rights which have already been recognized by the Court of Justice of the European Union. In the future, patients will be allowed to receive all non-hospital healthcare (without pre-authorization) and all hospital healthcare (with pre-authorization) to which they are entitled in their own Member State in another Member State and be reimbursed up to the ceiling established by their own healthcare system.

An example: the directive aims to give patients the possibility of receiving the necessary healthcare faster. Patient mobility allows national waiting lists to be sidestepped legitimately, since it enables patients to benefit from available medical capacity in other Member States. Furthermore, medical progress means that healthcare cannot be provided locally for all diseases and must be provided across borders in some cases.

Slowly filling the vision of a cross-European healthcare landscape with content, well-serving information to support choice and smooth cross-border movements will be essential. This idea will soon come to test when every member state will be expected to build single point of access information systems. Here a lot can be learnt from already existing efforts, pointing to limitations and opportunities. One thing for sure: patients, consumers and champions of a free flow of healthcare information need to engage in this movement, to ensure that visions come true and do not get stuck in political delays and bureaucracy!

10. References
10.1 Useful links

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

http://www.asklepios.com
http://aqua-institut.de
http://www.bertelsmann.de
http://www.beta.1177.se
http://www.1177.se
http://blog.healthpowerhouse.com
http://www.bqs-institut.de
http://www.bundesaerztekammer.de
http://www.civitas.org.uk/pdf/Denmark.pdf
http://www.dkgev.de
http://www.doktorsguiden.se
http://www.drfosterhealth.co.uk
http://www.drfosterhealth.co.uk/hospital-guide
http://www.drfosterhealth.co.uk/quality-accounts
http://europaeisches-praxisassessment.de
http://www.ey.com/Publication/vwLUAssets/Gesundheitsbarometer_2009/$FILE/Studie_Gesundheitsbarometer_2009.pdf
http://www.g-ba.de
http://www.gkv-spitzenverband.de
http://www.godoc.se
http://www.haartenvaatgroep.nl
http://hcfa.hhs.gov
http://www.hjertedebat.dk
http://www.hotelpricescompare.com
http://www.huisartsen.nl
http://www.igz.nl
http://www.independer.nl
http://www.internetworldstats.com
http://www.iqme.de
http://www.iwantgreatcare.org
http://www.kiesbeter.nl
http://www.kiesbeter.nl/medicijnen
http://www.kindenzienkenhuis.nl
http://www.kbv.de
http://www.kbv.de/qep/11469.html
http://www.lexpress.fr/palmares/hopitaux/default.asp
http://www.medicin.dk

http://www.mediquest.nl
http://www.nhsdirect.org.uk
http://www.nhs.uk
http://www.nhs.uk/Pages/HomePage.aspx
http://www.nivel.nl
http://www.nza.nl
http://www.omvard.se
http://www.patientopinion.org.uk
http://www.patient-view.com
http://www.preloved.co.uk/
http://www.qualitaetskliniken.de
http://recombu.com/
http://www.rhoen-klinikum-ag.com
http://www.sana.de
http://stats.oecd.org
http://www.sundhed.dk
http://www.sundhedskvalitet.dk
http://tiny.cc/jn9yh (on www.sundhed.dk GP search)
http://tinyurl.com/2vk9h7g (on www.nhs.uk Hospitals in and around London)
http://tinyurl.com/28oe6ww (on www.nhs.uk GP practices in and around London)
http://www.unabhaengige-patientenberatung.de
http://www.vardguiden.se
http://www.weisse-liste.de
http://www.zichtbarezorg.nl

Appendix 1. Questionnaire used in the survey commissioned from Patient View for the "How to choose the best hospital?" study 2010.

About this survey

OBJECTIVE of this Health Consumer Powerhouse survey:
"To assess the extent to which the healthcare consumers in the different countries of Europe are able to make key choices about hospitals and medicines in 2010".

Dear health campaigner,

Health Consumer Powerhouse (HCP) is asking health campaigners across Europe to offer their opinions to help it compile the latest HCP research publication—TO CHOOSE OR NOT TO CHOOSE: CONSUMER INFORMATION ON HOSPITALS IN EUROPE.

TO CHOOSE OR NOT TO CHOOSE will look at how successfully patients in Europe in 2010 make key healthcare choices by using the information available in their countries.

If you would like to contribute your views on the level of choice experienced by your country's patients, this questionnaire is short—only 10 questions—and should take no more than about 5-10 minutes of your time to complete, depending on how much you wish to comment. All responses will be anonymous. You will find the questions on the next 2 pages.

The survey's closing date is Monday May 31st 2010 (but HCP would welcome your opinions before then, in order to draw up some initial trends).

To thank you for contributing your opinions to the study, and to allow you to read the results, PatientView, the survey manager, will send you (if you wish) the weblink to HCP's survey report, TO CHOOSE OR NOT TO CHOOSE, upon publication in June 2010.

Yours faithfully,
Dr Arne Björnberg and Johan Hjertqvist,
Health Consumer Powerhouse,
Brussels, Stockholm, and Winnipeg.

If you have any questions about this survey, please contact the survey administrator:
Louise Oatham, PatientView, Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, UK.
Tel: 0044-(0)1547-520-965
e-mail: info@patient-view.com

To continue the survey, just click 'NEXT'

……………………………………………

Section 1: The information available in your country about the quality of clinical outcomes

Firstly, could you please indicate in which European country you are based? (If you are an organisation with a European/international remit, could you respond on behalf of the country in which you, as a respondent, reside.) [Please select your country from the menu below.]

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

Question 1/10.
Do patients in your country have access to a user-friendly website that contains up-to-date information about the quality or treatment results of different hospitals/clinics in your country?

[Please tick one answer.]

a. Yes—and more than one such website exists.
b. Yes, one such website exists.
c. No such website exists.
d. I do not know.

Can you name any such websites? ....

[If you have answered "No" or "Do not know", please go straight to section 2, question 5, by clicking on the link 'Next' at the bottom of this page.]

Question 2/10.
If there is such a website (or websites):
Do you think that the patients with whom you are familiar consult the website (or some/all of the websites)?

[Please tick one answer.]

a. Frequently.
b. Sometimes.
c. Never.
d. I do not know.

Do you have any comments about your answer? ....

Question 3/10.
If there is such a website (or websites):
How relevant and useful do you think the patients with whom you are familiar find the information about the quality or treatment results of different hospitals/clinics?

[Please tick one answer.]

a. Very useful and relevant information.
b. Useful.
c. Not very useful.
d. Of no value.
e. I do not know.

Question 4/10.
If there is such a website (or websites):
Do you think that information about the quality or treatment results of your country's hospitals/clinics <u>really does affect the choices</u> of the patients with whom you are familiar, so that they more often choose healthcare providers with the best clinical performance?

[Please tick one answer.]

a. Yes, such information really does affect their choices.
b. Sometimes affects their choices.
c. Does not affect their choices.
d. I do not know.

Previous

Thank you for expressing your opinions. That concludes this survey by Health Consumer Powerhouse (HCP).

If you would like to be sent the weblink to HCP's new publication, TO CHOOSE OR NOT TO CHOOSE: CONSUMER INFORMATION ON HOSPITALS IN EUROPE, upon publication in June 2010, please note a contact email address here.

In exiting this survey, you will be taken to the home page of the Health Consumer Powerhouse website, in case you wish to look at HCP's various free publications.

In this report the Health Consumer Powerhouse presents the results from the study "**How to choose the best hospital?**"

The study takes a consumer and patient perspective. The report offers reality checks for policy makers, empowerment to patients and consumers and an opportunity for stakeholders to highlight weak and strong aspects of healthcare. The HCP work is done independently. We welcome unrestricted research contributions to fund our efforts.

All HCP reports are available at: **www.healthpowerhouse.com**

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