



Verbraucher-Zentrale
Hamburg e.V.
Kirchenallee 22
D-20099 Hamburg
Fon +49 40 24832-132
Fax +49 40 24832-290
kranich@vzhh.de

in cooperation with
Verbraucherzentrale
Schleswig-Holstein e.V., Kiel,
and MDK Schleswig-Holstein,
Lübeck

www.
patientennavigation.org

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Christoph Kranich
Dr. med. Karl D. Vitt
Bettina Berger
Ron Pritzkeleit

Consumer Information about Service and Quality in Health Care Systems in Europe

Vol. 1: Report

Authors

Christoph Kranich, educator, head of Health Services Department at the Verbraucher-Zentrale Hamburg

Karl D. Vitt MD, Medical Service of the Health Insurers (MDK) Schleswig-Holstein (up to May 2002), now self-employed, Lübeck

Bettina Berger, cultural scientist, Verbraucherzentrale Sleswig-Holstein, now Hamburg University, working on a project to train patients' and consumers' representatives to acquire scientific credentials

Ron Pritzkeleit, geographer, Institute for Cancer Epidemiology, Lübeck

Christoph M. Erben Dr, psychologist, Medical Service of the Health Insurers (MDK) Schleswig-Holstein, Lübeck

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1.1 Introduction

1.1.1 Project Application

On 8 July 1999, the "Call for the Submission of Special Projects according to Article 2, Paragraph c of Resolution #283/1999/EG: Actions towards the Financial Support of Special Projects Furthering Consumers' Interests in Member Countries Submitted in Particular by Consumers' Rights Organisations and Similar Independent Public Institutions" was published in the *Official Journal of the European Communities*. Under the heading of "Special Projects" its second chapter listed nine project fields. Field #3, "Consumer Information and Counselling" was divided into four points, the third of which read: "Projects through which consumer associations can develop *innovative information and communication services*. Such services may serve in an intermediary function between consumers and suppliers to help consumers identify the best offer." Applications were to be submitted by 15 September 1999.

Thus the *EU Commission* had formulated precisely what the staff of the *Verbraucher-Zentrale Hamburg* and the *Medizinischer Dienst der Krankenversicherung Schleswig-Holstein* (medical department of the health insurance providers Schleswig-Holstein) had been discussing for several years now (see 1.1.2.): as in other fields, transparency in the quality of offered services in the health care sector should allow patients to relate to doctors and other service providers as empowered *partners*.

In our application, we justified our request with our past *experience in patient counselling*:

"In our patient counselling service, which we have been offering since 1988 and which handles approximately 4,000 cases annually, questions about the quality of health care services are becoming increasingly frequent. "Can you recommend a good doctor for ... " is a common request.

We have hitherto been unable to answer such question since the quality of health care services, unlike those of other goods and services on offer, is largely unknown. Most data are not collected, and where they are – e.g. in the context of 'external quality management' by the providers – they are not made public.

Our only option to date has been the development of a leaflet helping patients to develop criteria to assess the quality of health care services themselves.

We believe that the currently operating sources of information about doctors, hospitals and other service providers are problematic for several reasons: They are not independent of service providers and insurers; their information is generally incomplete; they charge high fees and generally do not use a sliding fee scale according to the caller's income; their work is not subject to official control.

By now, we are frequently asked to judge the quality of information from these sources. Thus we have to point out their limitations without being able to offer a better alternative."

Our experience in *health care policy debates* led to similar conclusions:

"Health care systems usually display a remarkable lack of transparency to the consumer; Patients have services prescribed, they are moved through chains of providers and generally have their treatment determined by others.

In the context of an increasing marketisation of health care systems in Europe, insurers' clients and consumers stand to get greater freedom of choice: e.g. in Germany the choice is now not only, as before, between resident practitioners, but also between different insurers, hospitals, drugs, therapies and other services and service providers.

A competent choice in a fully developed market, however, is only possible if the consumers have access to independently collected information comprising the structure of health care in general as well as all services and service providers and their respective quality. Given the increasing integration of the European Union, an international perspective is equally necessary, as demonstrated by various judgments of the European Court of Law regarding health insurance (spectacles, orthodontal treatment) or care provision. (...)

With the financial support of the European Union, we seek to allow countries with underdeveloped transparency systems to learn from others and avoid repeating past mistakes."

The *goals of our projects* were summarised as follows:

"Patients, insurance clients and consumers need information about the services and quality of health care providers from public sources. Experience with such transparency and information systems in various European countries is to be collected, evaluated and put to practical use.

This will help consumers as well as the entire health care systems in countries that are as yet underdeveloped in this field."

The project was to be jointly managed by *three organisations*: the *Verbraucher-Zentrale Hamburg* as the main applicant along with the *Verbraucher-Zentrale Schleswig-Holstein* in Kiel and the *Medizinischer Dienst der Krankenversicherung (MDK)* Schleswig-Holstein in Lubeck.

By the end of March 2000, we were informed of the project's approval in principle. After agreeing on details, it was begun on 1 June 2000. The duration had been limited to no further than 30 October 2001, giving us 17 months.

1.1.2 The Concept of Patient Navigation

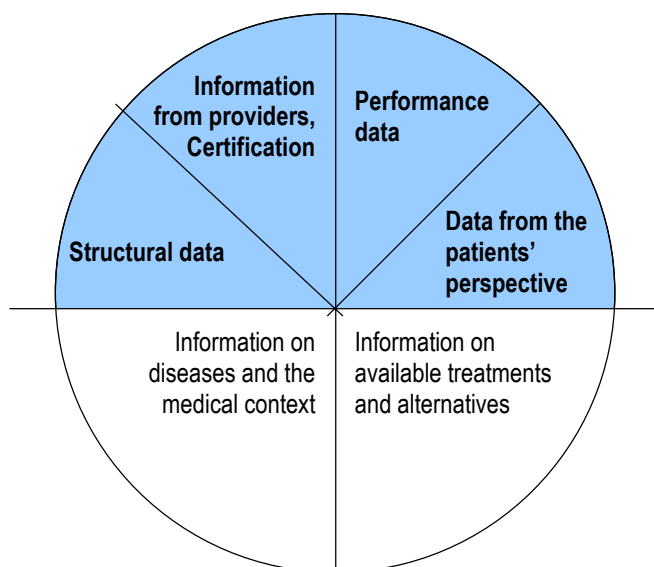
As early as 1995, members of the Verbraucher-Zentrale Hamburg and the Medizinischer Dienst der Krankenversicherung Schleswig-Holstein had formulated the need for greater transparency for patients. The leitmotif of the planned project was formulated as:

► **Every good medical treatment begins with information.**

We distinguished *two fields* of information relevant to patients:

1. Information on diseases and available treatment
2. Information on structures, services and quality of various health care providers, most of all their quality.

The PatientenNavigation project is mostly concerned with the second field. We illustrated the two fields in our *pie chart*, suggesting a further subdivision of relevant information:



Digression: What Information Do Empowered Patients Ask For?

Firstly: Data on disease and treatment

First of all, the patient wishes to know about her *disease* and the medical context – or perhaps why it is (as yet) impossible to determine exactly what she is suffering from. Information on diseases is available today from a multiplicity of sources ranging from the yellow press to the internet and popular and scientific publications, though the doctors in charge of treatment of course remain the main source.

Then the patient wants to be informed about possible *treatment* for her disease(s). She wants to know about alternatives in order to make responsible choices for her own life.

This information is widely available, though quality is patchy and thus patients are often left bewildered and unsure. This is countered by certifications such as the "Health on the Net" (HON) seal or the option of assessing quality with the help of the "Discern" handbook.

Secondly: Data on the Structure and Quality of Health Care and Available Services

Structural data are no longer a secret – they can be found in any phone book and are presented by many, mostly commercial, information providers through telephone hotlines or the internet. They are usually limited to a bare minimum of information such as that available from Medical Associations and *Kassenärztliche Vereinigungen* (Associations of practitioners accredited with the German health insurers). These last at least provide complete information. Data on such things as wheelchair access or foreign languages spoken are increasingly added now.

Information from the providers themselves and certificates offer important guidance for the choice of health care providers. They are a mixture of objective information and advertising, though. As certification gains ground in the health care system it becomes more important to inform patients about the meaning of a given certificate. Most of all it should not only be made public that a hospital has received e.g. a KTQ seal or TÜV plaque¹, but also on the strength of what results. The quality data must be publicly available.

At the core of the data pool in the health care system are *performance data*, e.g. the demographic structure of treated patients (indicating e.g. specialisation in geriatric cases), the length of stays, the type and frequency of treatments, the relation of invasive and preservative treatment, mortality, diagnoses and treatments, possible specialisation on certain illnesses and information on final results.

The last slice of the PatientenNavigation pie chart contains data from the patients' perspective gained from surveys and reports:

Patient surveys should avoid the pitfall of collecting mostly opinion rather than facts which can be usefully related to standards of treatment, patient information and bedside manner. Thus it will be possible to also gain useful information on areas the patients themselves can not competently judge.

Experience of patient groups and -organisations are widely circulated in the patients' self-help movement, but have not yet been systematically surveyed and evaluated. They represent an untapped reservoir of empiric knowledge specific to an indication that can be used within the context of a given disease.

1 KTQ stands for "Kooperation für Transparenz und Qualität im Krankenhaus" (cooperation for transparency and quality in hospitals), a cooperative venture of doctors', hospital and health insurance associations. See: <http://www.ktq.de>. The German "TÜV-plaque" is the seal of quality certifying a car as safe to drive for a two-year period. The *Technischer Überwachungs-Verein TÜV* (association for technical supervision) also surveys e.g. hospitals after DIN/EN/ISO 9000 ff.

Data from *complaint management systems* are useful indicators of problems and potentials for change – and, if they stand up to scrutiny, a means of identifying the 'black sheep' found in every profession.

For our project we had to take into account the lower half of the pie chart as well as the question how a given health care provider handles patient information and data on diseases and treatment alternatives can be important for a patient's choice. Some patients wish to know e.g. whether a doctor or hospital operates by defined standards, best practice guidelines or similar. Patients do, after all, have the right to treatment according to the state of scientific knowledge.

German social law phrases the matter thus: "The quality and effectiveness of services have to correspond to the state of medical knowledge and take account of medical progress" (Title 2, paragraph 1, sentence 3 SGB V).



The demand for greater patient or consumer *participation* also comes up in the context of a market-oriented reorganisation of health care systems.² However, we only consider a wider degree of choice between competing service providers useful if the patients have access to information about their structure, services and quality. Numerous information providers have been trying to establish themselves on this market for years, some through phone hotlines, others through websites and internet portals. The poor quality and patchiness of the information on offer has given us reason for concern, though. The independence of most information providers also remains questionable until legislation or other regulatory frameworks force them to disclose their interests.

We are also sceptical about the increasingly common *rankings* of health care institutions. In Germany, a weekly magazine has been publishing such rankings since the early 90s. Unfortunately, most patients are less interested in the absolute first on a (seemingly) objective scale but rather wish to know the provider most suited to their individual needs (individualised ranking). The readiness of the responsible and empowered patient to participate in a therapeutic cooperation with her doctors, shoulder responsibility and think economically requires adequate information. She must have access to all necessary information in a filtered and easily understandable form in order to make comparisons, act as a responsible equal in concert with the chosen therapeutic team and make her own decisions. In our mind the question of transparency is therefore inextricably linked to the redirection of every aspect of the health care system toward the patient.

That is the reason for our project being called PatientenNavigation. We regard navigation as a *cooperative approach* to patient support and want to distance ourselves from the paternalistic approaches of individuals and organisations that, eventually, always control the patient autocratically simply by believing that they know

2 Social Challenge to Health: Equity and Patients Rights in the context of health reforms, Fifth Conference of European Health Ministers, Warsaw, 7-8 November 1996

best what will help him. In this context, the term "pilot" is often used; the pilot guides ships into port where this task is beyond the captain. Navigation, on the other hand, merely points out the right way; you have to take it yourself. The instrument of navigation is the compass or signpost.



We had presented our PatientenNavigation project to many organisations, ministries and individuals since 1995 while *looking for partners*. We were invariably praised and encouraged – but not offered any material support. Official institutions (not least several state health ministers and the federal government) repeatedly referred us to the public health insurance companies. Especially if – as we suggested – information is to be the first step in treatment it would be logical to suggest financing through the public health insurers who, after all, bear the cost of treatment for the great majority of patients in Germany. It proved impossible to convince them of our paradigm that the patient (and not the doctor or health insurer) should choose the treatment and service provider. German health insurers are in competition and constantly look for fields in which they can distinguish themselves positively from their competitors, but support for patient autonomy appears to be an option for them only as long as it takes place under their control and with regard to their own interests, particular its marketing potential.

Thus a funding application to the EU seemed the best approach to realise our goal. This was not to be done by developing our own information service for patients, but rather by pooling the experience of European countries and making it available to those states – such as Germany – that have as yet not taken any steps towards quality transparency.

1.1.3 Boundaries and Limitation

PatientenNavigation is an extensive project that can only be realised step by step. That made it necessary to limit the project submitted to the EU for funding.

The first limitation has already been presented: instead of surveying all relevant information at once, we limited ourselves to transparency in the provision of *health care services*.

The second limitation concerns the fields surveyed within the health care system. We concentrated on *hospitals*. It is, of course, desirable for resident physicians, dentists, physiotherapists and other health care professionals to work as transparently as large institutions should, but in their case the personal relationship of trust with the patient plays a much larger role in protecting the patient's interests. Large institutions, on the other hand, often appear anonymous and frightening to patients. They frequently find nobody with whom a relationship of trust could be developed, having to blindly trust the faceless organisation because they depend on it. Building up trust between patients and the institution is particularly important in this often confusing field. The relationship between patients and nurses or doctors that is usually established quickly in the course

of treatment is surely indispensable, but these individual relations are hardly representative for the entire body of the hospital and may even be misleading.

After surveying and evaluating the experience with transparency in hospital services in various European countries, the next step would be to look into their applicability to other areas of the health care system.

1.1.4 Project Realisation

For the duration of the project the three cooperating organisations had a total of six staff members work on it.³ In addition, a part-time employee worked as a project coordinator at the Verbraucherzentrale Schleswig-Holstein⁴ and the employment office made two state-funded employment integration positions available to the office in Lübeck, giving us two further full-time staff.⁵ The team was completed by two foreign language experts for the Danish, Swedish and Norwegian⁶ and the Finnish⁷ health care system, so that a total of twelve persons were working on the project team.⁸

A division of our project into neatly divided phases was impossible; it would have required more time and preparation to research, which countries should properly be included into our survey. In view of the short time we opted for a pragmatic approach and visited those countries of which we could find out easily that they would be of interest to us. These were most of all the Netherlands, Great Britain and Denmark. In the course of our research we decided to include Austria, Finland and Sweden (with the very similar structure in Norway) as well. Germany provided our point of reference, with our questions and approaches being shaped by its health care system. A short visit to Spain convinced us that while there would certainly be great interest in our results in every European country, not every country could offer useful answers to our questions. Some countries were excluded simply for language reasons; we were, for example, very interested in France, but without better knowledge of the language the country remained a closed book. We heard of interesting developments in several East European countries, yet with those countries standing at the beginning of an – often rapid – development towards greater transparency they could not be considered for

3 Those are: in the Verbraucher-Zentrale Hamburg Christoph Kranich (as project leader), Ruth Greiner and Charlotte Henkel (both lawyers and patient counsellors); in the Verbraucherzentrale Schleswig-Holstein: Margrit Hintz (dietician) and Elisabeth Pott (administrative staff); at the MDK Schleswig-Holstein: Dr. Karl D. Vitt (medical doctor) and Dr. Christoph M. Erben (psychologist).

4 Bettina Berger (cultural scientist)

5 Ron Pritzkuleit (geographer) and Isburga Weber (clerical staff)

6 Susanne Thorsen-Vitt (dietician)

7 Ritva Leskinen (student of health care)

8 We would also like to thank: Volker Bach for German-English and English-German translation; Monika Lampe, head of the accounting department at the Verbraucher-Zentrale Hamburg for handling the project's finances; and the team of the Finnish sailors' church, Hamburg, for providing a perfect environment for our conference.

participation. The language barrier made the decision to not include them at this time easier.

Although we had decided to *concentrate* on two defined areas from the mass of information relevant for the patient – performance data and the patients' point of view – this proved difficult to maintain in practice. There were too many interesting developments in other aspects of the health care system, and often there were no concrete efforts made in the two fields.

We made a total of eleven journeys into eight countries (Great Britain: 2, Austria: 2, The Netherlands: 2, Denmark: 2, Finland, Sweden and Spain: 1 each). Preparation and completing the picture were aided by internet research.

Our first results were formulated in our interim report of 28 February 2001, which can be found (in German) on our website at <http://www.patientennavigation.org>.

1.2 Transparency and Performance Data

1.2.1 Information and Transparency

The science of information has only emerged in the last 50 years.⁹ It went through a long development from collating and evaluating predetermined information in a given document to establishing an independent definition of the very meaning of information. The Latin word *informatio* originally meant education before taking on the current meaning in the 19th century.

As a prelude to today's explosion of information, an explosion of documents had to be handled. The problem was keeping track of existing knowledge and ensuring access to the documents. It was only later that the content of archived documents was considered. Everyone concerned with information must also concern himself with the changes in the knowledge structure of a producer or recipient of knowledge.¹⁰ A further important step in the development of our understanding of information and the extension of its meaning was taking account of the role of communication processes.

Several divergent definitions of the term "information" have developed in the last few years. On the one hand, information is defined as something technical and tangible, such as the *knowledge potential* inherent in databases. In this definition the process of transmission, the information carriers such as books or discs, and the value of the transmitted information are accorded some importance. Basically, information is understood as a property or quality of physical objects.¹¹

A wider reaching approach does not view information as merely technical knowledge but sees it in the context of the knowledge contained and the process of understanding. According to Belkin,¹² information concerns

- ▶ human cognitive communication processes
- ▶ the idea of the desired information
- ▶ the effectiveness of information transmission
- ▶ the relationship between the information and its creator and
- ▶ the relationship between the information and its user.

9 All following quotes were taken from Capurro 1999; Ingwersen et. al. 1995 and 1996

10 Capurro 1999

11 Herrschaft 1996

12 Belkin, after Ingwersen 1995

Weizsäcker¹³ reduces the understanding of information to the thesis: "Only that, which is understood, is information". Or. More clearly: information is available knowledge that is made available to the user (information as communicable knowledge).¹⁴

If our idea of information is located so far in the territory of human communication we must also take account of the *processes of interpretation* connected with it. In child rearing, it is only the linguistic understanding that allows a later communication of information through language. Sender and recipient must share a common language to understand each other.

To talk about informing *patients*, adapting Capurro's "specialised information" category may be useful:¹⁵

- ▶ The common situation of patients, in being patients, means that we do not face individual users and their individual wishes but that their desire for information is shared specific to their situation. Thus, individual wishes for information are always social indicators.
- ▶ There are no 'bare' facts. Information only exists within the context of a theoretically and practically agreed framework, however temporary and mutable it may be.
- ▶ The communication process with the patient requires media through which content specific to the desired field can be transmitted. This requires a common basis of understanding and a shared desire.
- ▶ The term "information" as a meta-category basically means, that every statement can be characterised as the valid reply to a communicated question.¹⁶

This digression into the meaning of the term "information" elucidates that the provision of information to patients must take account of many different aspects. For one, there is the question what information is wanted. The desire for information is related to *uncertainty* and the wish to reduce this. In this, the recipient is central, the communication process secondary.¹⁷ The important aspect is the recipient's wish to end an unsatisfactory situation through information¹⁸ (the question, e.g., what information may be required for the patient to trust himself to a certain treatment or institution). It is important to keep in mind that this action contains a cognitive process in which the information producer influences the recipient through a meaningful information.¹⁹

13 Weizsäcker, in Capurro 1999

14 Capurro 1978

15 Capurro 1999

16 The important question, what questions are asked by patients, and thus what patients' information preferences are, has not been asked in the context of the project.

17 Wersig 1971

18 Ingwersen 1995 und 1996

19 Machlup et al 1983

The information process also changes situations. Every exchange of information has different informational *effects*. The knowledge situation changes.²⁰ This also depends on the existing knowledge structures. Potential information must always be seen in the context of the effect it has on its users. Only taking account of the user's desire and search for information defines content and mechanisms of transmission and allows measuring success. By defining wishes for information and taking account of the offer of information and existing interaction and navigation mechanisms I can analyse and evaluate the effect, both for the individual user and society as a whole.²¹

This brings us back to the *patient*. Only once we know, which information individual patients or patient groups want can we design appropriate information systems, realise interaction mechanisms, and measure success.²² We will not look into the problem of interaction and the furthering of desirable change through information that is largely specific to the patient situation. In the course of medical treatment, information is frequently not confined to the role of transmitting knowledge but aims at inducing behaviour change. This raises the demands made of form and content by an order of magnitude; the information is not merely supposed to transport and reaffirm knowledge, it must also raise interest and spur or induce action. The success of such information transmission then would only be complete (and thus measurable) once its contents were put to use and a (frequently necessary) change in behaviour occurs.

Another problem with information transmission that particularly occurs in health care has to be thematised, though. As explained elsewhere, the basis for orientation in the health care system is mostly composed of performance data. This information can only be compressed through selection, collection and *evaluation*. This leaves us with a problem, though: raw information is often uninterpretable. Let us illustrate this with a simple example. Under the heading of "heart attack" we could imagine two distinct categories useable for conveying information about hospital performance and allowing comparisons. These categories would be a) the average length of hospitalisation and b) the mortality rate, i.e. the proportion of admitted patients dying in hospital. To our knowledge, both categories are highly relevant for the evaluation of hospitals by (potential) patients.²³ However, the values in both these categories are hardly under the control of the hospital. They appear to depend far more on the structure of emergency medical services in its catchment area. A patient is more likely to be reached at an early stage in areas with a good emergency medical service infrastructure than in those where such services are thin on the ground. The former results in a lot of patients being admitted to hospital whose attacks are so severe as to give them little chance of survival. They usually die in intensive care within a short

20 Capurro 1999

21 Capurro 1999

22 Capurro 1999

23 For the purposes of this example we will disregard that treatment for a heart attack is usually not elective, meaning that patients rarely have any choice as to which hospital they will be treated in, being admitted as emergency cases.

period. In the latter case, emergency services frequently reach these patients significantly later and, given equal severity, will often be reduced to certifying death where an earlier arrival would have allowed reanimation, even though with little chance of survival. These patients are then not admitted to hospital and thus do not influence mortality statistics. In areas of good emergency services, on the other hand, the relatively higher mortality rate results in shorter average stays because hospitalisation statistics usually do not distinguish between patients dying in hospital and those being discharged alive.

Thus, a meaningful evaluation of these two figures is impossible without knowledge of the outlined background and a prima facie comparison of hospitals on their basis will distort the picture.²⁴ If nonetheless, as exemplified by the abovementioned scenario and other cases, transparency is to be the basis of orientation in the health care system and if said transparency is constituted by information, we must answer the questions:

- ▶ What constitutes transparency in health care?
- ▶ What information will be part of a transparency concept in health care?

It is obvious that the second question is very much secondary as we must first establish what *transparency* actually is or should be before we can deduce from this what information must be part of our transparency concept. To tackle this problem successfully, we must first change our perspective. The mere collection of sufficient amounts of data does not automatically produce the transparency required to navigate the health care system. The question of what constitutes (or should constitute) transparency can only be answered adequately if we ask ourselves first what purpose the result should serve, and from this conclude what kind of information will be necessary or useful for the purpose.

However clearly the need can be formulated, its realisation is considerably harder. Indeed, on looking at what passes for "information" and "transparency" in many European health care systems we find a deluge of raw, unprocessed data that is often enough more of a hindrance than a help to orientation in the respective system.

A further aspect surfaces when we consider the following: the "*health care market*" is not like other markets. This means orientation in the health care market can not be enabled by the same methods it is in other consumer markets but must adapt to the specific conditions of this one. The main reasons for this are:

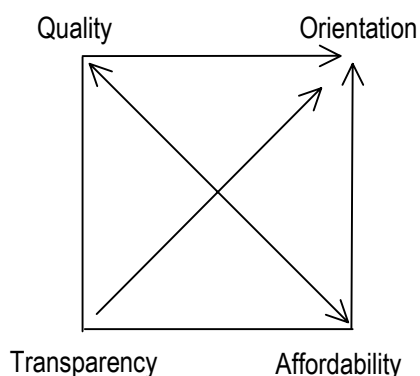
- ▶ In principle, health is a commodity in unlimited demand. Thus, the demand for health care services is equally unlimited in theory.
- ▶ Secondly, health can not be substituted by other goods; the consumer can not divert demand to other markets.

24 In this case the obvious is once again the enemy of the truth, as B. Russell pointedly remarks.

- ▶ Thirdly, health care services are potentially unaffordable. In many cases they can only be financed by a communal effort, being far beyond the financial capabilities of the single consumer.
- ▶ Fourthly, their quality (and cost-effectiveness) can often not be checked and evaluated by the consumer.

Two conclusions can be drawn here: First, the patient is a "customer" only to a very limited extent. He always remains a "patient", i.e. the passive object rather than active consumer of services. Secondly, there are two more incentives for developing transparency to consider. Aside from patient orientation, it may also serve to improve the quality and maintain the affordability of a publicly financed health care system.

If we take into consideration these aspects – the quality of services as an objective parameter and public financing (and thus affordability²⁵) – alongside patient orientation, we arrive at a system of four aspects that can be displayed in a *'magic square'* of health care akin to that known from macroeconomics.



Quality and affordability in health care mutually influence each other and both affect the options of (potential) consumers of health care. Transparency has a direct and, following to the abovementioned interdependence, indirect reinforcing effect on all three aspects.

In conclusion, we can define transparency in health care as the sum of all data and parameters that can serve to improve service quality, ensure continued affordability and allow orientation in the health care system.

This defines transparency-relevant information solely as information that can constitute useful parameters or data in this context.

Transparency is therefore constituted by deriving the parameters necessary for the concretisation of the abovementioned aspects of the "health care market" and supplying the data necessary for calculating these parameters. While doing this, we must take into account the interdependence of the three aspects. In principle all quality increases are positive, but they must also be viewed under the aspect of affordability to

25 After all, financing is also borne by people not (currently) using the health care system.

the public. Conversely, every chance for reducing costs should be taken as long as it will not significantly reduce the quality of care. Consumer orientation has to be reflected both under aspects of (objective) quality and affordability.

As far as transparency is concerned, the *German health care system* is underdeveloped in European comparison. While a surfeit of data is the main obstacle to transparency in many other European countries (e.g. Great Britain), treatment-specific information is still treated as a "trade secret" in Germany. Competition among the public health insurers only serves to exacerbate the problem. In this situation, the patients' right to transparency and orientation in the health care system must be accorded special consideration.

1.2.2 Performance Data as a Basis for Creating Systemic Transparency

One of the main goals of our projects was to establish how other EU countries make the quality of medical services transparent to patients.

At the individual level this appears comparatively simple. In an *ideal case* would simply be the comparison of a goal mutually agreed upon by doctor and patient prior to treatment with the degree of success in reaching it after the end of treatment. This covers all aspects of patient orientation: arriving at a diagnosis in cooperation, cooperatively developing a treatment strategy (by preference according to patient-friendly guidelines), choosing a service provider, carrying out the treatment and finally evaluating the success according to the derived outcome data. This would create perfect transparency for the individual patient (individual transparency).

A similar approach is possible for "*collective transparency*", the information of the totality of patients about the quality of all health care service providers. This can not simply be the sum of many individual transparencies – the individual interests and strategies would create a plethora of criteria that would overwhelm the patient looking for orientation. It is necessary to take the justified expectations and rights of the patients as a group – e.g. on the basis of standards and guidelines to be agreed upon between the medical professions and patients' organisations – as a basis and ideal and compare them with the existing outcomes of individual service providers. Our main points of interest in the spectrum of "collective transparency" is the quality of service provision and the service providers.

1.2.3 The Need for Transparency

Transparency in the quality of medical services is necessary for patients for many reasons. We distinguish four levels of justification.

Transparency Helping in the Choice of Service Providers

If the patient is to exercise his right to *self-determination* he must be able to choose between different providers of medical services. To do this, he needs information about these services. Transparency as a precondition of informed choice is most necessary in systems where the general practitioner does not act as a gatekeeper or only does so to a limited extent, where insurers and service providers operate separately, and where patients take an active part in the health care system (as is the case e.g. in Germany). However, patient self-determination needs to be assigned a high priority even in systems where the general practitioner has a strong 'pilot function' or the patients' choice is otherwise limited.

For transparency to be created and function as a useful aid in decision making two conditions must be met:

- ▶ The patient must be able under the law to choose between different service providers. Where the *general practitioner's* gatekeeper function is strongly established (as e.g. in Great Britain) the patient needs less aid in decisionmaking. Transparency will then help him to interact with his GP as an informed and self-confident partner and jointly make responsible decisions.
- ▶ On the other hand the patient must de facto be able to choose between different service providers. The health infrastructure of a country or system must allow the individual patient a choice between different providers. Countries where large *distances* separate comparable medical institutions (as e.g. in parts of Finland and Sweden) allow no meaningful choice in practice. De facto freedom of choice is also lost where *waiting lists* grow in importance to take on the character of exclusion criteria (as e.g. in Great Britain, Sweden, Denmark or Spain). In these cases the demand for transparency can come to seem nonsensical; where there is no choice, it becomes pointless. However, if we understand it as an unalienable patients' right it remains essential nonetheless and we must bear the fact that patients painfully experience the discrepancy between ideal and reality.

Transparency Driving Quality Development

In all health care systems, transparency also affects the development of the *quality* of services. The better the patient is informed about the quality of an individual provider's services the greater his ability to influence it. If service quality is fully transparent, patient choice between providers (and its effects) can be viewed as the most objective (and cheapest) method of patient surveys.²⁶

The distinction between state-funded health care system and those based on mandatory insurance (Bismarck-model) is important under this aspect as well:

- ▶ If insurers and service providers operate separately, as they do in mandatory insurance systems (e.g. in Germany), and both compete with others, transparency could theoretically create a market mechanism: patient choice would take on the

²⁶ In Germany this is called "voting with one's feet".

role of quality control. In practice this is currently prevented by two mechanisms: competition between insurers and service providers forcing the concealment of important data from competitors and the fact that health care is *not really a market*. The patients' demand for health-related services e.g. is not limited by their income as others – the various health insurers – pay for them.

- ▶ In state-funded health care systems the conditions for transparency are better. As funding institutions and service providers constitute a unit and the lack of competition²⁷ obviates the need for secrecy, such systems allow charting service and quality development by comparatively simple methods. The main problem in these systems is that the need for making services and quality transparent for patients is far less obvious. The stronger the position of the *general practitioner* as gatekeeper is, the less problematic it is for a given system to be transparent. The patient's restricted choice of service provider also restricts his options of influencing service and quality. This is particularly noticeable in Great Britain. The position of the GP as a gatekeeper with wide-ranging powers and the long waiting lists for hospital treatments²⁸ seem to have allowed considerable openness about service quality. Almost all performance data is publicly available. The main problem here is the *evaluation* of the data. As patients have only limited choice in service providers there is no need or incentive to the system to offer them help in understanding the data ("developing information from data"). Only the demands of patients and their organisation have recently spurred on development in this direction.

In Denmark and Sweden, where the position of the general practitioner is weaker than in Britain, the efforts of patients, health authorities and service providers have taken a clearer direction towards making transparency a driving force in quality development and have already made greater progress. The Danish *National Indicator Project* may serve as an example.

The Dutch model – a system partly funded through mandatory insurance with general practitioners functioning as gatekeepers, but involving the patients and their organisations in quality development (*consensus model*) – results in a generally more patient-oriented quality development, but offers the individual patient little help in choosing 'his' service provider. As patients' representatives have taken part in the development and implementation of the model, patient trust in the health care system as a whole appears to be greater and the demand for transparency and critical evaluation of quality correspondingly lower.

27 The lack of competition is eroding... In all the state-funded systems we surveyed, private providers are increasingly challenging the state system. The main advantage of private service or insurance providers is their having sufficient resources to have no waiting lists. 'Jumping the queue' by taking advantage of private providers is being countered by falling back on foreign resources in Britain as well as in Denmark and Sweden. This is intended to prevent the development of a 'two-class' health care system.

28 The influence of waiting periods on the choice of hospital has taken on so important a role as to almost completely eclipse all other quality aspects.

Transparency as 'Answerability' to the Patients

Alongside the abovementioned (and most important) aspects of the need for transparency of performance data, two more points need to be added. By making public the services provided and their quality, the state as a responsible party for the health of its citizens as it were *reports* to them on its management of the financial resources entrusted to it. Transparency would allow exposing misapplication of public funds for public debate. The use of public funds would be subject to more effective control – Germany, with its system of influential professional associations and autonomous insurers and service providers could serve as an interesting example here. Two globally observable tendencies – the aging of the population combined with a dwindling of public funds – make effective use of available resources more important than ever. Thus the demand for transparency as "answerability" constitutes a form of patient and citizen empowerment at the economic level.

Transparency Measuring Quality in European and International Comparison

The increasing global orientation and interdependence of modern societies provides a further aspect. We have already shown that transparency can be the driving force of quality development. In the course of globalisation – and the more concretely felt European integration – winning or maintaining the patients' trust in their national health care system is becoming increasingly important. Transparency can contribute to this. *Comparing* service quality can be of interest both to the state – e.g. to keep pace with development elsewhere and provide the development of sharp differences in quality between nations – and to patients, who have to learn to judge their own systems with its advantages (and shortcomings).

International comparison and European mobility are as yet little developed, but early signs can already be seen. Notable examples are the purchasing of health care resources in Germany by Denmark, Sweden, Norway and, in the near future, probably Great Britain and the European Court findings on the free exchange of goods and services (such as spectacles and orthodontal treatment) and old-age care insurance. These developments will be strengthened by the integration of the individual member states. The expansion of the European Union will also lend greater importance to the comparison of service quality. Even now the considerable price differences between the two countries have created "medical tourism" across e.g. the German-Polish border that is, as yet, limited to services the patients have to pay themselves (dentures or vision correction).

1.2.4 Data for Creating Transparency

In the following we will briefly show, what data are useful for creating transparency.

Structural Data

The transparency of structural data is the necessary first step in the provision of an aid in decisionmaking on which all further information must be based. Structural data are defined as information that describes a health care service provider independent of the services provided. This covers mainly such things as address, facilities (specialised wards, technical equipment etc.), foreign languages spoken, shopping and leisure activities, special services for family members... Important, though rarely available, structural data are the number and qualifications of the staff.

Addresses, the first and elementary part of structural data, were available in all countries. A listing of hospitals can be found everywhere, much aided by modern means of communication. Such listings are often equipped with a search function e.g. by postcode, especially on the internet. They are provided by service providers in the course of presenting themselves to the consumers as well as, in state-funded systems, in the internet presence of the health authorities, and by private information providers seeking to enhance their internet presence and broaden their appeal.

For the second part of structural data, the qualified set, no such homogenous picture can be painted. Hospitals themselves or, in state-funded systems, official sources often provide information on specialised wards. When it comes to equipment, facilities or hospital specialisations, the patient is already dependent on *information provided by the institutions themselves*. In some countries, registers ordered by specialist departments are provided centrally in some countries (e.g. in the Netherlands by diagnosis), in other countries (such as Germany) this depends on the work of patients' self-help groups or professional associations. In one country can we speak of a complete picture being provided. Data presented by private health care information providers – often offered on the internet – are usually voluntary, meaning that a hospital choosing not to 'advertise' through the information provider will not be as easily accessible to the patients. Independently screened information is rarely available. Some institutions (e.g. the *Patientvejleder* in Denmark) offer such information on request, but they are usually limited to their own geographic catchment area and offer this service in personal consultation, not as a general overview for independent public use.

Process and Performance Data

For the evaluation of the quality of medical services, process data would currently be the best source. As hospitals register this data for billing the insurer anyway, using them as an aid to orientation and quality evaluation offers itself. Process data comprise all *processes* in the treatment of patients such as e.g. length of stay, diagnoses on admission and discharge, medical procedures undertaken, multimorbidity in the shape of secondary diagnoses etc, age and sex...

Although such data existed in every country we surveyed – all case data in the Scandinavian countries are kept in national patient registers, Great Britain maintains Hospital Episode Statistics, the Netherlands the Nationwide Medical Register, Austria the Hospital Statistics, Germany undertakes data registration according to §310 SGB V and external quality control according to § 173 SGB V – they are hardly ever used for patient orientation. While these data are unavailable (in order to keep them from the competition) in mandatory insurance systems (such as in Germany), in state-funded systems (such as in Britain) they are publicly available, grouped by hospital or department. That alone does not yet constitute patient transparency, though. In spite of the wealth of data available (e.g. in Great Britain), patients are given no real help in deciding on a hospital. Firstly, the data are rarely presented in a form they can make effective use of, and secondly the criterion of waiting time still dominates patient choice.

The possibilities offered by the use of process data – for individual patient navigation over tracking the path of 'customers' to quality development – are manifold. The raw data could be developed into *indicators* such as operation quotas, the degree of "practice" (i.e. how often is a given procedure performed at a hospital), specialisation in certain age groups or diseases etc. Many indicators could be developed and offered to the patients in accessible and meaningful form for his orientation.

The beginnings of this development can be seen in Great Britain in *Dr Foster's Hospital Guide*. Patients are offered information on experienced quality in addition to structure data. The mortality in a given hospital, e.g., is not simply contrasted with that of others but judged by a standardised expected mortality rate. This takes into account e.g. whether a hospital treats many old patients suffering from several illnesses. The Danish Indicator Project develops the same kind of data, though they are not made available in the same fashion (see the presentation by Jan Mainz in volume 3).

Data from Quality Control and Certifications

Quality management data only represent a discrete group inasmuch as they are collected or collated for a distinct purpose. They are largely identical in nature to process data and the indicators derived from them, or data gained from surveys of patients and staff. In all countries surveyed, quality management data were intended almost exclusively for *internal use*. It is immaterial for this definition, whether evaluation took place within the institution or not – we often find systems of external quality management. In those cases the data are presented to designated institutions who then calculate average performance for many hospitals – in the ideal case nationwide – to give the hospitals providing data a benchmark for comparison and ranking. This approach is found in the Scandinavian Quality Registers, the registers kept by the *Prismant* Institute in the Netherlands and the mandatory external quality management in Germany. In all countries, the data is made available to service providers, in some cases also to insurers, but never to the patients.

It is important for certifications to be based on meaningful and detailed study and adhere to logical *standards*. Mandatory participation, as it is projected for the near

future in Germany, would also be helpful. Certificates that can not be used to distinguish, being 'purchased' for marketing purposes, are useless from the consumer's point of view. In these cases compliance with an agreed standard becomes the only relevant point, which is why the publication of the standards underlying such certificates has been demanded in many countries. Great Britain has shown some interesting developments here: The public *Commission of Health Improvement*, e.g., regularly publishes detailed reports on every hospital surveyed. On the basis of these results, a ranking system with a small, intuitive set of quality criteria was implemented, the so-called "star system".²⁹ Hospitals receive a ranking of between one and four stars, based on service quality. The future will show whether simplified ranking systems like this are practicable and acceptable to all parties.

Explicitly patient-oriented certifications, often demanded by patients, can make compliance in certain relevant aspects transparent. Examples would be the WHO certificates "Breastfeeding-Friendly Hospital" and "Baby-Friendly Hospital". A unique phenomenon is the Dutch "Harmonised Quality Certificate" (HKZ) given only to hospitals which implement criteria of patient orientation formulated by the patients' associations.

Indication-specific certifications allow the integration of structural, process and outcome quality. An example here would be the German ASD certificate for hospitals. This defines the requirements for treating and educating type 1 diabetics.

Outcome Data

Outcome data are comprised of objective data, based on measurable parameters, and subjective data, based on the judgement of patients, doctors and other participants in the treatment process. Examples for *objective* data are mortality rates and indication-specific morbidity data. Indicators are increasingly being developed for single indications, defining measurable, meaningful figures as parameters of outcome quality. *Subjective* data would include information on patients' quality of life, general health and the degree to which they are content with the services offered.

Awareness of the importance of outcome quality surveys has been on the increase internationally. The research is usually undertaken by public health science institutions. Decisionmakers at every level of the health care system increasingly ask them to set priorities in judging quality. The *European Clearing House of Health Outcomes (ECHHO)* networks and supports such efforts Europe-wide. Eva Bitzer from the *Institut für Sozialmedizin, Epidemiologie und Gesundheitssystemforschung (Institute of Public Health, Epidemiology and Health Care Research)* in Hanover joins many others in demanding state funding for large-scale comparative outcome research.

Such data become interesting for patients once they are available by service provider, allowing comparison (see following chapters). This would require agreed standards for

²⁹ This used to be called the "traffic-light system" until recently, as quality judgments were to be expressed in color terms of red-orange-green (see the presentation by R. Thompson in vol. 3).

survey methods. The *Austrian Health Ministry*, e.g., has developed guidelines for a unified measure of patient quality of life and contentment. The aim of such efforts is to arrive at comparative quality data through the use of identical methods and measures.

Mortality rates are a highly sensitive part of outcome data. In Britain, *Dr. Foster's Hospital Guide* provides standardised mortality rates for all hospitals. Without such standardisation, comparing mortality rates could lead to wrong conclusions. Hospitals treating a large proportion of multimorbid patients would, for example, appear less desirable than those performing (often unnecessary) surgery mostly on 'good risks'.

An important indication for judging the quality of a given institution is already available, though – the methods, criteria and emphases by which a hospital evaluates its performance data.

Data from Patient Surveys

Patients who have undergone treatment are often a source of valuable information about the quality of specific medical services. For this reason, patient surveys are undertaken in all surveyed countries. However necessary, they are beset with methodic difficulties, though.

Unfortunately it is still widely assumed that patients are unable to judge the quality of medical services. Yet the patients' perspective is clearly vital to judge whether a given service met *expectations*. Given the increasing number of chronic patients, mortality rates are losing out in importance to quality of life and the development of patients' overall health. These and other patient-defined outcome surveys are gaining ground in Europe. They are not yet useable for comparing individual hospitals, though, as the data are not sufficient, though such a comparison would be possible on a diagnosis-specific basis.

Data from Patient Complaints

Data from patient complaints can be viewed as input from *unsolicited, problem-oriented patient surveys*. Following the example of the manufacturing sector, the service industry is increasingly taking consumer complaints seriously as an incentive and pointer to improve the quality of its products. Health care still has plenty of catching up to do here. Accordingly, data from patient complaints are not used to provide service quality transparency in any surveyed country. Admittedly this could only be done meaningfully once transparency in the other data here outlined was in place. However, the handling of complaints by individual hospitals can already offer a useful indication of this institution's patient orientation.

In Great Britain, the number of complaints and the proportion of those responded to within the mandated time are made public.

In the Netherlands, the collation of complaint data allows a nationwide comparison of predominant reasons for and directions of complaints. The highly differentiated system of data collection allows the evaluation of the main problems encountered by patients, but it is too complex to be useable for patient orientation.

Modern management approaches strive to learn about the *patients' needs* and expectations prior to treatment in order to avert problems and mistakes from the start. As such approaches still represent the exception rather than the rule, though, hospitals should be pressured into greater patient orientation by external collection and publication of complaint data. A systematic evaluation of centralised patient complaint data could even be used to track undesirable developments in individual institutions or an increasingly confusing health care system as a whole. A local accretion of complaints of specific complaints in nationwide comparison could indicate a weak point in the system. Deficiencies in pain treatment in numerous hospitals in the Steiermark province (Austria) were discovered this way by the *Patientenadvokatschaft* (*patients' advocate*) and the staff given the requisite training.

1.2.5 The Transparency Discussion in North European Countries

We will only present brief overviews here. More details can be found in our country reports in Volume 2.

Great Britain – Consumer-Oriented Transparency or Data Dump?

Great Britain gives the appearance of great transparency and consumer orientation. The state-run health systems allows centralised data collection, management and evaluation. Transparency is demanded and thematised in official publications. The health ministry publishes annual hospital performance data on the internet and in print. Direct-mail patient surveys can be undertaken by a publicly funded health administration. State regulatory and supervisory institutions such as the *Community Health Councils*, which are authorised to inspect hospitals, get the authorities support and backing. The National Statistics Office holds conferences on the availability and accessibility of all kinds of statistics to the general population.³⁰ Institutes providing consumer-friendly processed data receive funding and support, allowing hospital guides based on comparative structural, process and outcome data such as *Dr. Foster's Hospital Guide* to be made available.

Yet on the other hand the whole system gives the appearance of a *data dump* as it has been unsuccessful in addressing the main problem besetting the British National Health Service – the long waiting periods for specialist treatment and hospital admissions.

Nonetheless the transparency discussion takes place at a comparatively much higher level than in Germany. The recently published *Bristol-Report* has provided new impulses. Extensive reports were initiated following the unnecessary deaths of several children in heart surgery. Detailed demands for transparent performance data are being voiced to provide an early warning system to avoid such events in the future.

30 A conference on data transparency in health care was held in November 2001.

The *Community Health Council association ACHCEW* has already put its authority behind these calls.

The Netherlands – Does Integrating the Patients Obviate Transparency?

The Netherlands have gone a long way in the discussion of the health care system's patient orientation. Attention to the *patient's perspective* was demanded in numerous projects and, in lengthy negotiations with the service providers, implemented. Patient's associations are a force to be reckoned with on the boards of many institutions. However, the demand for transparency serves mostly to facilitate comparative quality assessment at an institutional level, e.g. in confrontations between patients' associations and providers, rather than to aid individual patient orientation.

At the individual level, many institutions in various fields of the health care systems providing personal counselling to patients use transparency as an aid to personal choice. Examples include

- ▶ improved information access for patients both in stationary and outpatient treatment by specifically tasking hospital staff with it,
- ▶ a nationwide patient information infrastructure with *27 information and complaint offices (IKGs)*,
- ▶ the central development and implementation of guidelines for patient-friendly data presentation and their availability in institutions,
- ▶ comprehensive complaint management structures and the centralised collection and evaluation of complaints by the *Foundation for the Furthering of Complaint Management (SOKG)*.

The debate on collective transparency in the health care system takes place in a *public forum*, encouraged by the government. While there are no concrete results as yet, laws to allow funding to be given to patients' association to develop data-based quality information are being projected. This addresses demands raised by these associations several years ago. Details of the project are still subject to negotiation, though. The nationwide, independent data evaluation institute *Prismant* provides data to the public on the basis of specific legislation. The Hospital Association has so far only made public data on waiting times for specific treatment, these being judged the least problematic. Malpractice figures, having been demanded by patients' associations first of all, are not currently available in a solid form, being as yet based entirely on voluntary information provided by only a few institutions.

Denmark – transparency Discussions at the Collective Level

Denmark has the advantage of being a small, easily manageable country. This alone is not enough to explain the strong orientation towards consensus in the transparency debate, though. A defining feature of this debate in Denmark is the *nationwide discussion* of quality criteria and the form of their publication.

Hospitals provide diagnosis-specific process and outcome data by department, as yet on a voluntary basis. They allow a *nationwide comparison* of departments. A special

project in the context of a national quality development strategy is the *National Indicator Project (Det Nationale Indikatorprojekt – NIP)*. It aims to develop a model allowing the nationwide comparison of hospitals with transparent and accessible results. Continuous monitoring is also to ensure continuing quality in the individual hospital departments. The cooperative project develops quality indicators for publication for a given set of diagnoses including objective and subjective indicators of outcome quality. Mortality rates are assessed by diagnosis. Indicators are developed with the cooperation of all participants in care and treatment as well as professional associations and scientific institutions to ensure their universal *acceptance*. The presentation of the data is also determined by the effort to reach common baselines to avoid publishing accretions of data useless to the individual patient. Patient associations and initiatives are now introducing the hitherto neglected aspect of experienced quality into the debate. The transparency of all aspects of this debate justifies great expectations for the transparency of the resulting data.

Sweden – Transparent Patients or Progressive Data Transparency?

Sweden is well known for transparency in every aspect of public data – indeed, it is often criticised for the lack of privacy protection in its huge assemblages of data.

On the other hand, the development of useful data collection seems to be more easily possible, too. The development of so-called *quality registers* has advanced comparatively farther than it has in other European countries, as it has in Denmark. These contain personal data on diagnoses, treatment – outpatient and stationary – and outcomes, allowing a documentation of the complete course of an illness. Aggregate figures are published annually on the internet, ordered by hospital department and region.

The registers allow hospitals and other health care institutions to compare their own results with those of others under the aspect of *benefit to the patient*. There are over 50 diagnosis-specific quality registers founded by the medical associations as the foundation of systematic quality development in the clinical field. The development of national registers from existing regional ones is not yet complete, but progressing. Aside from scientific benefit, authorities hope to develop an *early warning system* to be used in the introduction of new methods and techniques. A continuous evaluation of data under the aspect of patient benefit is to help identify outmoded methods and replace them with more successful ones and point out unnecessary treatment. The data are also expected to be useful in reaching administrative and political decisions.

Patient associations (among others the WHO-certified non-governmental organisation *KILEN*) are reporting that data collections adopting the patients' perspective, such as those on side effects of drugs, hardly find the attention they deserve, though.

1.2.6 Existing Navigation Systems

The initial idea of the project was the provision of an information source independent of service providers to the patient, allowing him to choose the *appropriate provider* for his needs. In the course of our work it became increasingly clear that patients have very different needs, depending on their own understanding of patient self-determination. We can roughly distinguish three groups:

- ▶ Patients who need extensive information because they want to make their own decisions and accept responsibility for them,
- ▶ Patients who want to be informed extensively and understand the consequences of treatment (and malpractice), but leave responsibility to their doctor,
- ▶ Patients who leave responsibility almost entirely to their doctor and are not interested in further information.

It follows that beside the ‚pilot‘-physician ordering a certain treatment or transfer, independent counselling institutions and navigators are needed.

Criteria for 'Good' Pilots and Navigators

- ▶ The institution must be *independent of service providers* in order to be able to give information according to the patient's requirements. If its information originates with the providers, the risk of biased information being given is too high.
- ▶ There should be a comprehensive structure of recognisable institutions *nationwide*.
- ▶ The basis for individual counselling should be *evaluated performance data* on all service providers. These should include all the elements outlined above (structure, process and outcome quality data, patient judgement derived from complaints, patient surveys, health status measuring, quality of life assessment and patient evaluation of treatment quality). Existing knowledge from diagnosis- or target-group specific counselling should be networked and integrated.
- ▶ It should be a *sustainable institution*. Our understanding of sustainability includes the institution having
 - ▷ *financial security* (in the context e.g. of an official mandate coupled with funding) and
 - ▷ trained and *qualified staff*.

Internet information providers are not in themselves sufficient, as information is only derived from the individual evaluation of data and requires individual judgement. Offers by telephone call centers using counsellors given on-the-job training are not adequate to the needs of patients in an increasingly complex landscape of competing service providers, either.

The qualification of staff should include communicative ability, experience with health care studies and detailed knowledge of the various target groups and their counselling needs.

The General Practitioner as Pilot

The function of the general practitioner is different from country to country. In many countries, patients need their GP's approval as a gatekeeper or pilot in order to receive any specialist treatment. However, our survey shows that the GP rarely has sufficient objective information to fulfil this task. Richard Hibbs from the *Welsh Primary Care Research Network Capricorn* reports that general practitioners use *subjective information* far more frequently than they tend to report.³¹ Their decisions were largely based on experience and their integration into a social network, thus depending on the individual abilities of the physician.³² Questions by patients about areas of medicine outside his experience also frequently overtax the general practitioner. His task as a pilot confronts him with the demand to act as a counsellor and builder of trust. This *almost religious role* still assigned to the family doctor and his own 'addiction' to his paternalist position of authority clearly demonstrate the limits of a true partnership between doctor and patient.

This deficit is addressed in Britain by the ubiquitous schools of general medicine with their interdisciplinary approach (including communication training).³³ The setting of an established culture of family GPs shows, how *ambivalent* gatekeeper systems can be. Strict gatekeeper systems run the risk of abusing the decisive position of the general practitioner to the disadvantage of the patients if they do not support the physicians with solid interdisciplinary training, including communicative and interpersonal skills, and the integration into training and research efforts. Patients should furthermore be able to change their GP at will. Such fears are substantiated by everyday experience in several countries; in the Netherlands, the impossibility of the free change of general practitioners is one of the most common grounds for complaint while in Great Britain, GPs often remove patients from their roster for being old and expensive.

In Germany, things are different; The *free choice* not just of the general practitioner, but also of the specialist is valued highly. Nonetheless the general intransparency of the health care system has created great demand for independent information and counselling. "He who has the choice has the worries" a German idiom states, and these worries are not well alleviated by the GP as a pilot. Their position is relatively weak, in fact. The ratio of general practitioners to resident specialists in Germany is 40:60, the reverse of what is common in other countries (EU-average: 60:40). Only five medical schools maintain a chair for general medicine. The special importance of the GP's communicative ability, and the consequent need for a special interdisciplinary training, are increasingly being recognised, but are still far from standard.

31 See the presentation by Richard Hibbs in Vol. 3

32 This is proved by, among other things, the frequent questions from general practitioners about diagnosis-specified waiting lists recorded at the College of Health.

33 Edwards, Elwyn 2001

Research networks for primary health care, widely established in Britain, are rarely found in Germany.³⁴ The provision of specialist services, on the other hand, is usually doubled (from resident and hospital specialists). Clinical care is granted absolute priority to the basic healthcare provided by the resident general practitioner.

Another problem is the increasing influence taken by the pharmaceutical industry over general practitioners, adding to the uncertainty over the GP's motivations in ordering a given treatment.

Independent Counselling and Transparency Systems

We have found *patient counselling structures* in many countries. The most important are:

- ▶ *Community Health Councils (CHC)* in Great Britain,
- ▶ *Information and Complaint Offices* in the Netherlands,
- ▶ *Patient Advocates (Patientenanwaltschaften)* in Austria and
- ▶ *Patientenvejleder* in Denmark.

For further information on these institutions please turn to the country reports in volume 2. Here we will give a brief overview over the basic structures.

Great Britain

The *Community Health Councils (CHC)* are an independent element of the National Health Service with a legal mandate, providing a comprehensive network of 220 low-level, easily accessible offices. They network institutions in the community, provide information on structural data, patient self-help groups and outside providers, offer counselling on patients' rights and assistance with complaints and inform patients about the complaint channels. Their authority to inspect hospitals provides them with a source of information which they informally make available. They have few paid positions, most of their staff being volunteers. Training is offered by the *Association of Community Health Councils for England and Wales*.

The Netherlands

The Netherlands also have a comprehensive structure of patient information institutions. The *National Patient Information Service (Landelijke Informatiepunt voor Patienten = LIP)* provides information on complaint channels and patient support through a national telephone hotline and can refer patients to the appropriate institutions. About 30 regional *Information and Complaint Offices (Informatie- and Klachtenbureaus Gezondheidszorg = IKG)* are financed by the independent *Foundation for the Support of Complaint Management (Stichting Ondersteuning Klachttopvang Gezondheidszorg = SOKG)* and run by the regional platforms of the *Dutch Patients' Association (NP/CF)*. The IKGs aid the patients with all questions about

34 <http://www.rcgp.org.uk> (2001-12-12)

the health care system in general and complaint channels in particular. Complaint data are collected nationwide, but systematically collected and evaluated quality data on service providers are not available. The 2–3 full-time staff and many volunteers in each IKG are trained free of charge by the SOKG.

Austria

Patients' advocates (*Patientenanwaltschaften*) operate in every federal state on the basis of the Federal Hospital Law (*Bundeskrankenanstaltengesetz*). They are state-funded and independent, employing medical doctors, lawyers, nurses, psychologists and office staff. Their legal mandate covers complaint collection and allows them insight into patient files to process complaints. Patients' advocates are held in high regard and the regular data feedback from their complaint management is given commensurate attention. While they are not (at least not primarily) information providers, they show that it is possible to place patients' interests on a legally mandated basis and create effective structures of support.

Denmark

The main orientation for patients in Denmark is provided by the *patient's guide* (*Patientvejleder*). He acts as counsellor and guide in matters of waiting periods, illnesses diagnosed, pre- and poststationary treatment, administrative and judicial channels etc. In the event of complaints, he acts as a mediator between the patient and service provider.

The *Patientvejleder* is not fully independent. The offices are maintained at district level, subordinate to the local health administration which, in turn, operates the hospitals. This administrative tie-in of patient information, complaint management, hospitals and management allows for an uncomplicated handling of complaint data and ease of communication. On the other hand, the physical division of hospitals, hospital operators, and complaint managers still permits a complaint management culture to flourish and contribute to quality control.

The *Patientvejleder's* sources of information are the local and nationwide statistics mentioned above. However, he is neither able nor authorised to comment on the quality of a given service provider at present.

Germany

There are no nationwide networks of patient information providers in Germany. Some larger cities have *Patientenstellen* (*patient information points*) (affiliated with *Gesundheitsläden* in Bielefeld, Cologne, Munich, Berlin et al.). They have been operating for over 20 years, though mostly on a volunteer basis or through government labour market reintegration measures and other short-term project funding.

In about 10 states, the *Verbraucherzentralen* (Consumer Information Centers) offer health care information, counselling and support. The *Verbraucherzentralen* Hamburg

and Berlin have been active in the field for 15 years and are running an extensive complaint management effort.

Other patient counselling offers are diagnosis- or target-group specific such as the *Feministischen Frauengesundheitszentren (Feminist Womens' Health Centers)*, the counselling offices of the *Deutsche Aids-Hilfe (German AIDS support)*, the *Patienteninformation für Naturheilverfahren (patient information for natural medicine)* and many others.

Conclusions

Some countries provide patient information and support through nationwide, *independent structures*. Their staff is only partly qualified or adequately trained. Data that would allow them to judge the quality of a given service providers is available to them only rarely and in single cases.

Legal reform and a patient-oriented health policy have created the basis to build an infrastructure to allow patients access to reasonably comprehensive information in many countries. Conditions vary by country, though. Sustained effort is only possible if adequate *funding* and the continued employment of *professional* counselling staff are guaranteed. The staff must be trained to high levels of communicative ability and have a broad-based knowledge of the health care system taking account of the patients' perspective and allowing orientation in this highly complex professional environment.

Patient information systems are as yet largely limited to providing structural data. Existing information structures can remain in use, but should be expended to cover *quality information*. Where there are no comprehensive nationwide systems, creating them is a main precondition to effective patient information.

Quality data on health care service providers can be made available through a patient- and consumer-oriented policy. Legislation can create the *legal framework* to move institutions to greater transparency. Nationwide communication on the direction and goals of transparency creation are possible and can ensure wide acceptance. Informal knowledge on service quality such as is collected by self-help groups and patient associations can be collected and used. Patient information providers are often also used to collect information on the patients' perspective and transmit it back to the service providers (complaint management). Thus they can serve as important intermediaries between providers and patients and should be systematically expanded and put to use.

1.2.7 Methodic and Methodological Problems of Hospital Patient Surveys

Introduction

Throughout the last decades, manufacturing has been in the lead of the quality control debate. This is hardly surprising, given that the control of outcome quality – comparing

desired properties with existing ones – is relatively easy for industrial products that can be subjected to regularised tests. Structure and process quality are very much secondary in this context. Consequently, the quality debate in the service sector has long been dominated and handicapped by the paradigm of screw specifications. The two fields are hardly comparable. It has only been in the last ten years that other aspects of *service quality* have been emphasised. On the one hand, the increasing importance of certification has led to greater attention to structure and process quality while on the other hand the concept of customer orientation has taken center stage in judging outcome quality. This is also observable in the non-profit sector.

Increasing *competition* between providers has led to a noticeable interest in recording the patients' satisfaction with the services³⁵ in the health care sector, usually by means of surveys. Measuring patients' satisfaction and patient surveying have seen an almost inflationary development lately. Available methods range from simple, home-made approaches to the highly professional standardised methods of internationally operating, specialised providers and the market is set to keep developing.

Nonetheless a critical look at the methods and approaches on offer shows that their methodic and methodological³⁶ foundations remain *unclear* and central questions *unaddressed*. Recent guidelines published by the *Kooperation für Transparenz und Qualität im Gesundheitswesen (Cooperation for Transparency and Quality in Health Care – KTQ)* attempt at least to define minimum standards for patient surveys. Surveys where treatment aims are defined in a parallel effort by the doctor and patient are also still in their infancy.

The Basics of Patient Surveying

Some precise definitions are required to start with:

- ▶ We define *patient survey* as the (more or less standardised) recording of the experience and/or opinion of patients during or after receiving a health-care related service.

The central subject of this survey may be the health care services themselves or other, not strictly health-care related peripheral services (e.g. the quality of hospital food). The survey itself can concentrate on strictly objective facts as well as subjectively experienced patient satisfaction with these services.

- ▶ *Patient-orientation* in this context means concerning those aspects of a service that directly address the patient and elicit a subjective reaction in him.

35 We are avoiding the term "health care services" here as a number of not directly health-care related services have played a role in competition under the heading of 'patient orientation'.

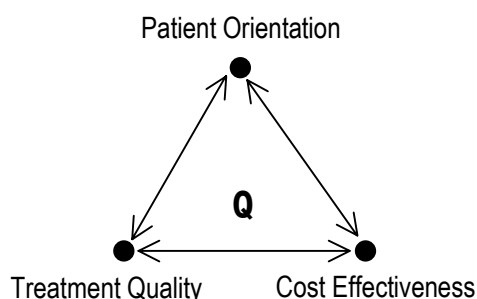
36 We define methodological problems as of a basic nature, concerning questions of the validity and reliability of patient surveys, while methodic questions concern the technical details of realising and conducting a survey. This distinction will become clearer as we progress.

- ▶ **Patient satisfaction** describes the (surveyed, subjectively judged) congruence between the experience of receiving a service and the (equally subjective) expectations of its effectiveness.

A **service** is defined as the influencing of circumstances regarding the patient through targeted action or inaction, irrespective of whether this action or inaction has already taken place or is only intended to (as in e.g. patient counselling over an impending treatment).

Thus, patient satisfaction can be said to mirror a narrow definition of service quality (in the abovementioned sense of a comparison of desirable and existing circumstances) in the field of patient-oriented health care services.³⁷ The patient survey then acts as the means of ascertaining that quality, a measuring instrument as it were. The thoughts to follow address this role as a measure of quality, its possibilities and limits, and will be limited to the realisation of patient surveys regarding stationary health care services.

Patient surveys aimed at measuring patient satisfaction with the received services (according to the above definitions) introduce a new aspect of outcome quality in stationary care. The traditional bipolar system of the paternalist paradigm, where the medical quality of treatment and cost-effectiveness in the provision of services constitute outcome quality, is expanded by this **cooperative approach** to a tripolar balance by adding the patient orientation of the service:



Methodological Problems

The main problem faced by patient surveys is not one of method or technique. It is rather **what value the answers to be gained have for the aims of the survey**. In other words: Does the answer to the question address its intent? This is hardly a trivial issue as the following example demonstrates:

If we want to assess the quality of hospital food by asking the question "Were you satisfied with the hospital food?", the patient's answer will mirror his individual expectation of satisfactory hospital cuisine. He provides a comparison of expected standards and existing quality. The resulting answers are then simply averaged out, resulting not in information on the factual quality of the food, but in an average

37 This is not an unimportant distinction, as we will see.

deviation from an (unknown) average expected standard or, more precisely, the difference between the mean experienced quality and the mean expected service quality standard. However, we still know neither the expected standards nor the average experience, the latter mostly not because it must be assumed that individual misconceptions are likely not to be independent but in some manner systematic.

It is precisely this, the collective distortion of experience, that poses the main problem for measuring patient satisfaction.³⁸ In this regard the difference between satisfaction surveys and surveys of objectively determinable facts exists only in degree.

Factors Influencing Perception

The perception of a stimulus depends on a number of interdependent parameters which, in turn, are tied into both the perceiving person, the stimulus, or the interaction between the two, the 'setting'. With regard to the influences dependent on the perceiving person we can distinguish between those, that operate randomly, and those whose effect distribution is normative. Similarly, the influences dependent on the perceiver can be divided into situatively changeable and situatively (more or less) stable ones.

The *perceivable quality* of a stimulus depends on

- ▶ the strength of the stimulus itself,
- ▶ a personal distortion effect, established across the group of perceiving individual,
- ▶ and the distortion effect tied to the stimulus itself (and, significantly, its presentation).

The *example* of hospital food quality lends itself well to demonstrating what we understand by parameters influencing perception. We must look at

- ▶ objectively establishable quality;
- ▶ influences on perception that vary unsystematically from individual to individual (such as individual taste or the importance accorded or not accorded to certain ingredients et. al.);
- ▶ influences on perception that vary within a given group of individuals according to more or less clear norms. These are mainly phenomena of social desirability and situation-dependent conditions of stimulus presentation – e.g. the objective quality of food will vary from time to time – or transsituative conditions – such as that the perceived strength of an acoustic stimulus depends on the ambient noise level or the perception of food quality perhaps on the more or less loving presentation of the meal etc.

These interdependencies describe a number of generally observable perception effects known to psychologists as halo-effect, figure-, background-, and contrast-

38 This is indeed the main problem of any satisfaction survey. The hospital surveys are particularly problematic for a number of reasons, but they are not principally different from surveys of bank customers, hotel guests, or staff members.

phenomenon, logical failure etc. These influence the ,correct' perception of the strength of a stimulus.

Thus the judging of a treatment-related quality stimulus by a group of patients depends, aside from the stimulus itself, on

- ▶ the strength of acquiescence (a tendency to positive statements) caused by social desirability
- ▶ the situation in which the quality stimulus occurs
- ▶ universally occurring effects known to perception psychology and
- ▶ the expected median standard of expected quality.

As long as these parameters (aside from stimulus strength) are inadequately known, few precise statements can be made on the validity and reliability of a survey.

Cognitive Dissonance

If our previous considerations are right, the judgment passed on the quality of hospital food may depend more on the general success of treatment, the friendliness of the staff, or the patient's insight that hospital food can "simply not be as good as home food" than on the factual quality of the food served. Here it is necessary to dissolve cognitive dissonance, as psychologists put it. Two stimuli that, while being individually connected, are perceived in strong opposition, have to be cognitively processed in a manner minimising this discrepancy. A habitual smoker cognitively dealing with the danger smoking poses to his life will either try to quit smoking or to minimise the perceived dangerousness.³⁹ The food in a hospital whose staff are doing their best to support me in my illness and alleviate my suffering can not really be bad – or, if it is, the reasons are outside the staff's control (the expected standard is adjusted). The more severe the patient's suffering and the greater his dependence on the efforts of the health care system, the stronger the pressure becomes to dissolve this cognitive dissonance towards the stronger emotion.

This is probably the reason why all instruments for measuring patient satisfaction uniformly show two phenomena being much stronger than in measures of satisfaction with other services: The distribution of responses is skewed strongly towards the positive end of the scale (high acquiescence), and the distribution of answers concerning several satisfaction items in the same sample equally tends to be very high in terms of score (strong implied-perception model).

Methodic Problems

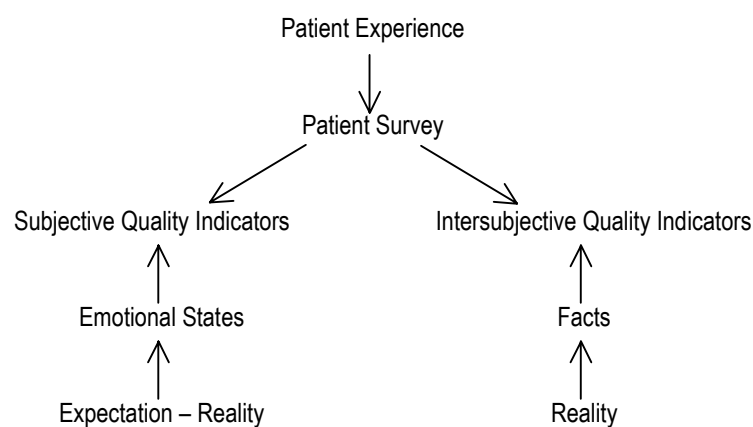
After having discussed the general methodological problems of hospital patient surveys it is now time to turn to the technical and methodic difficulties of a survey. Although there is no satisfactory theoretical model as yet, such surveys are after all

39 As the chain smoker said: "Whenever I read something about the dangers of smoking, I stop – reading."

being conducted and should be conducted, if only the better to develop our understanding of the problems.

Patient Experience

We return to the difference between a survey concentrating on subjective satisfaction and one surveying objectively establishable fact. It is, of course, possible for a survey to cover both areas. Along with *satisfaction* ("Did you enjoy lunch?"), *observation* may be surveyed ("Was lunch served on time?"). In the first instance, a comparison of expectation and reality is requested, while in the second the existing situation is mirrored.⁴⁰ We subsume both aspects under the term "patient experience".

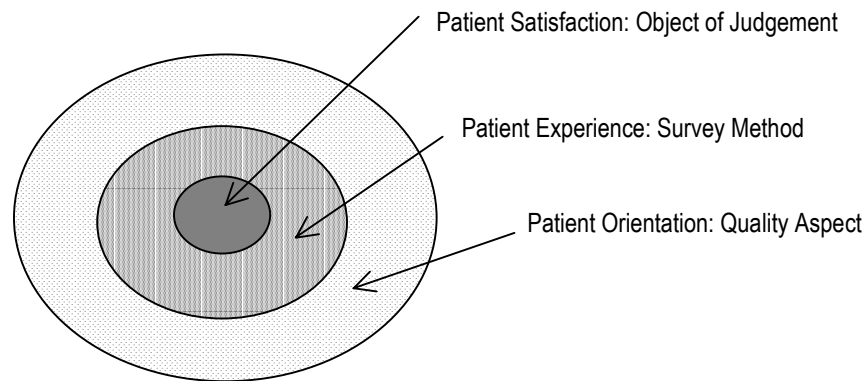


One is founded on subjective emotional state, the other on objective fact. An example may serve to illustrate the difference, but also the proximity of the two approaches. The survey item "Were you informed of necessary medication prior to discharge?" establishes an objective fact and can be answered in principle with a simple "Yes" or "No", while the question "Were you informed to your satisfaction regarding the need for continued self-medication after discharge?" requires a subjective judgement.

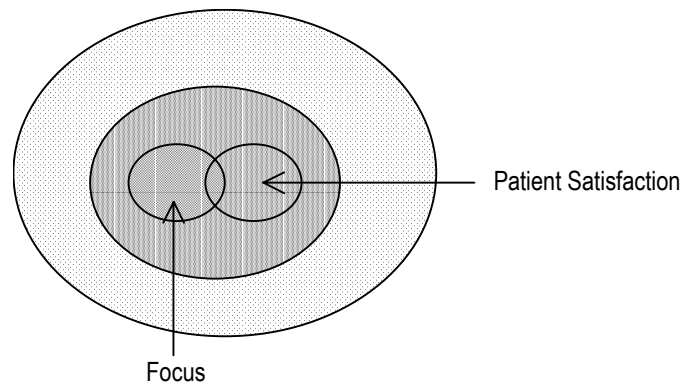
In this sense, patient satisfaction represents a judgement of the treatment situation and its attendant circumstances extending solely to indicators of subjective experience – or the subjective judgement of objectively established facts – i.e. a comparison against subjective reality.

Patient satisfaction, like general satisfaction or the individual estimate of one's own state of health, is part of *patient experience*. Surveying patient experience is part of the health care quality dimension of *patient orientation* and may be regarded as the most central aspect of this dimension. Taking account of the above ideas, we can arrange the three concepts as follows:

40 In view of the unsatisfactory results of mere satisfaction surveys, many patient survey conductors have turned to surveying only the bare facts (naturally not just on such trivial items as hospital food). As we will show this problem avoidance strategy does not really help matters.

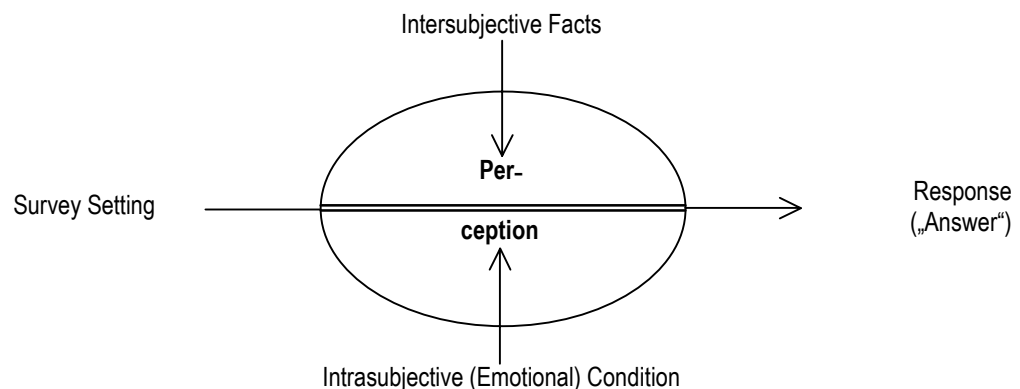


Patient Satisfaction need not be the central focus in this setup. It could equally well be e.g. patient involvement in treatment planning and accomodate an object off judgement that could, in principle, be documented entirely without patient input. The above representation could then be expanded:



However, the concept of patient satisfaction intersects every possible quality focus within the realm of patient orientation because the perception of quality is influenced by an (unspecific) satisfaction with overall treatment and the subjective judgement of precisely this item invariably influences the measure of overall satisfaction.

In every case where patient surveys were used to collect data, *patient perception* operated as the central mediator between the survey setting, the intrasubjective facts on the one hand, and the patient responses on the other:



Quality Criteria for Patient Surveys

In terms of survey methodics, questioning patients about their hospital experience can be classed as an *observation process*, irrespective of whether the object of our observation are objective facts or subjective experience (satisfaction). In either case the established range of observational-method quality criteria applies and can be used to evaluate an existing or projected survey.

The focus of a method-critical quality debate is the faithful representation of data i.e. whether the representation of the observation by the survey mirrors their reality. The faithful representation of a survey is generally viewed under two different and independent aspects, *validity* and reliability of the survey.⁴¹ We will follow this precedent. First we will look at some aspects of the *reliability* of patient surveys, then scrutinise the validity of these methods. A general understanding of the meaning of reliability and validity in terms of observational surveys is presupposed.

Reliability Problems

Survey reliability means, in simple terms, that mutually independent measuring of the same object under the same conditions will render the same results. Reliability therefore 'correlates a survey with itself'. This is usually tested by means of repeated surveys of the same object at different times (retest reliability). This presupposes the constancy of the object itself, of course. In patient experience we can generally presuppose that (provided the measuring does not take place before the end of the experience i.e. discharge from the hospital). Experience shows, however, that the retest reliability of patient surveys is strongly dependent on the *time elapsed* between hospital discharge and survey. Whether the deviation will tend towards the positive or negative can not be predicted theoretically. There are plausible reasons to expect either effect:

- ▶ With increasing distance in time, the pressure to dissolve a possible cognitive dissonance decreases; criticism becomes easier to formulate. This would support a deviation to the negative.
- ▶ At the same time it is well known that memory tends to represent events more positively than they were experienced. Points of criticism may be felt to have been less significant (or edited out entirely). This supports a deviation towards the positive.

Any hope, the two tendencies could compensate for each other in the individual case are surely misplaced and certainly not supported by experience.

Problems in Establishing Validity

The question of validity, the correlation of the survey results with reality, has to be answered separately for each aspect of patient experience. In the case of subjectively experienced objective facts this is relatively simple. All the more surprising, then, that

41 ... in the narrow sense of the act of surveying.

no empirical data are available yet. Survey results would have to be contrasted with the results of observations of the relevant facts made independently of the patients' perspective (and, for reasons of perceptual psychology, also independently of the physicians' perspective). The deviation between the two values will then determine the degree of perceptual distortion imposed by the patients' perspective.

Objective facts are not the focus of a patient survey's interest (under either aspect!), though. The aim of the survey is to measure subjective experience. Therefore the question of validity regarding any objective criteria can probably be regarded as negligible and we can assume that, given correct formulation of the question items, they will measure what they are designed to. In this case we speak of *construct-defined validity*.⁴² A better quality measure for a given patient survey under this aspect would be found in the internal structure of instrument and result in comparison with recognised instruments and in the opinion of experts (expert-defined validity).

Conclusion

We have found existing practices in patient surveying unsatisfactory and hardly helpful for our purposes. It seems designed currently to aid marketing and assuage the worries of hospitals. However, if we take *patient orientation* seriously as a third quality dimension we must also take seriously patient surveys as a measure of this and methodically develop them for this purpose.⁴³ Existing patient surveys are rather less than useful for this, and probably not intended for it either.

The time seems ripe to launch a research program to fill this gap. Existing material should be systematically surveyed and categorised and survey technique empirically developed on the basis of an appropriate methodic model in order to meet the requirements of a three-dimensional quality concept of clinical care and show the participation of the patient in producing health (from consumer to *co-producer*).

42 This is what is meant when psychodiagnosticians rather offhandedly say that "intelligence is what an intelligence test measures".

43 There are, of course, indicators for patient orientation that can be determined without involving the patients. It should not take much convincing, though, to see that this quality dimension at its core can not afford to ignore patient experience.

1.3 Complaint Management

Complaint data were part of our 'information pie' on the patients' side. Being '*answers to unasked questions*', complaints are an important form of patient statement as they almost always point to deficiencies in a given area. Service providers who use complaint data for quality improvement can save the costs of expensive quality consultants. Customers will happily identify their deficiencies for free – they have but to be asked.

In order to use complaint data in a patient navigation system, a developed complaint management system must already exist. Complaint data are of a particularly sensitive kind. To the mind of the service providers they often mirror the subjective satisfaction and (often irrational) expectations of the customer or patient more than any objectively justified claim.⁴⁴

As all other information, data from complaint management need to be *evaluated* and *processed* before being used in a navigation system

At the beginning of our project, complaint management data were only of peripheral interest as we knew of no complaint management system in Germany that could provide significant useful data of this kind. In the course of our research we found, though, that other countries are much farther developed here. Therefore we included the complaint management systems of the Nordic countries in our survey to find out whether there were sufficiently well developed systems to allow the publication of results without irresponsibly handing out sensitive, unchecked or biased data.

Normally the first step should have been to seek out existing complaint management systems in health care. We took the next one straightaway and developed criteria by which such systems could be evaluated from the patients' perspective. These were presented to our partners in the surveyed countries (see Volume 3). Naturally this could only yield a first attempt – seriously developing the field to the point of arriving at proven evaluation instruments would have required a project of its own – but we wanted to give an *impulse* to this development which can (and must) then take place in other ways.

We will first describe the criteria (part of which were adopted from those developed by the national association of *Community Health Councils*) and then apply them to the complaint systems of some of the countries surveyed.

44 On the basis of our experience with patient counselling we take a different view. We hold that every complaint is justified at its core – though not necessarily 'justified' in the sense of 'factually correct'. If, for example, a patient complains of pain for months after treatment even though doctors had assured him he would walk pain-free within three weeks of the operation, we must look where the failure lies: with medical quality (pain therapy or operative technique) or with prior information. If the doctors assured him readily that he would walk without pain weeks after the operation the patient surely has a right to expect this.

1.3.1 Judging Complaint Management Systems

Criteria from a patients' point of view

We adopted five criteria for evaluating complaint management systems from a patients' point of view from the *Association of Community Health Councils for England and Wales (ACHCEW)*:

- ▶ Receivers of complaints must be *visible*. Every patient in a hospital, every inhabitant of a city or country must know how and where to lodge a complaint and understand the procedure.
- ▶ They must be *easily accessible*. The best solution would be a unified point of access for all complaints, a 'one door' policy. We also think that easy physical access for all inhabitants of a country or region, proximity to the patient and the opportunity to personally lodge a complaint and speak to a competent complaint manager are important for this aspect.
- ▶ Complaints must be dealt with *quickly*.⁴⁵
- ▶ The organisations and persons handling complaints must be *impartial* – we would rather say *independent*. Handlers of complaints must not be part of the organisation being complained about or connected with it.
- ▶ Finally, complaint management must have the effect intended by the patient, it must be *effective*. That means not only that they are investigated and cleared up, but also that, if they are found to be justified, measures are taken to address the cause and perhaps even sanctions applied.

These criteria were developed for a country with a long tradition of complaint management – no matter whether this always works exactly as British patients' representatives would like it to. For a country such as Germany, with no established complaint management, we have suggested five further criteria:

- ▶ The complaint system must be *clearly regulated* and *codified*. A law would be best, though an administrative directive (e.g. by the state government or community council) is also possible. The worst solution, though still preferable to nothing at all, would be internal regulation by the organisation handling complaints.
- ▶ The complaint system must be *established and accepted* in the minds of all involved. It is not enough to use it for PR purposes to the outside and limit its effectiveness internally.
- ▶ The complaint system must be *multi-tiered*. There must be further instances beyond the easily accessible first receiver of the complaint (in case the complainant is not content with the handler's work or the handler feels overtaxed with the case). There also must be organisations organising and maintaining

45 "For some people the satisfactory resolution of a complaint is part of the healing process that follows a traumatic or upsetting event. If this process is protracted, it is more difficult for patients or relatives to recover from their experience. That is why speedy procedures with firmly fixed response times are important." (ACHCEW 1999)

complaint management. External organisations guaranteeing a maximum of independence are preferable.

- ▶ Complaint management demands *full-time trained staff*. Training should be based on a unified curriculum teaching the required legal and communicative knowledge and abilities. The staff should be networked nationwide and have a united representation to guard its own interests.
- ▶ Finally, complaint systems must be *transparent* under three aspects:
 - ▷ Transparent Process: patients must know what happens with their complaints and at what stage of the process they are at any given time
 - ▷ Transparent Outcome: patients must know what became of their complaint, whether it was found justified or not, whether someone was held responsible, what long-term consequences occurred, whether there were qualitative changes in organisation or process etc. Such feedback acts as a positive stimulus for further complaints.
 - ▷ Transparent Oversight and Comparison with other Organisations: complaints should be collected and evaluated at a higher level (regional or national) to render transparent flaws in the health system as a whole.

This gave us a total of ten criteria to evaluate complaint systems in a country or organisation which we can now apply to institutions or the complaint systems of entire health systems.

A System for Assessing Complaint Management

Our first step was to develop a system that could be applied to all institutions of complaint management we are aware of. For this purpose we had to distinguish between several types of complaint management systems:

- ▶ Systems aiming at a bilateral *solution* and possibly *consequences* in the quality management of the institution concerned. Here we must distinguish between hospital patients and outpatients.
- ▶ Systems aiming at material *compensation* for the patient. Here we distinguish between legal proceedings and systems aiming at settlements out of court (we will not look into legal proceedings here, though these would merit a study of their own).
- ▶ Systems aiming at *sanctions* or *punishment* of the guilty party. These are divided into professional and penal law (again, we will not look into penal law here and only briefly touch on professional law).

All forms of internal complaint management, being widely practised in manufacturing and occasionally in health care, were left out of consideration. We gained the impression that these systems often aim at improving economic efficiency rather than looking after the interests of patients.⁴⁶ Our interest focussed on organisations acting in

46 See the contribution by Roger Carbonell in Vol. 3

the *public interest* or being part of public administration and thus transcending the boundaries of a single organisation.⁴⁷

Thus we get six columns. Across these, we found *three levels* (as per multi-tieredness). We ended with the following system:

3rd level						
2nd level						
1st level						
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

This system could now be used to assess the complaint systems of the various countries we looked at. In our contribution to the conference (see Vol. 3) we suggested evaluating all countries represented by these ten criteria. Even though this was only possible in part and in a preliminary fashion due to lack of time, we will present the results of this assessment here. We do not want them to be seen as unassailable results but as an impulse to further refine and apply the system to complaint systems within Europe.

How We Judge

Assessment by our system was relatively easy. *Judging* the various complaint management systems in the various countries proved much harder. We had neither the time nor the means to be thorough – this would have meant judging each institution in a health system, then averaging the results for all similar institutions and thus, step by step, arriving at an evaluation for the entire country.

We risked taking the opposite path: first we tried a preliminary evaluation of a country's complaint system, checking our results by taking a closer look at separate types of institutions within it. We are aware that this can not yield valid and reliable results but thought it the best approach for a first test of the system.







We used a *six-level point system* to judge. Our initial suggestion to use the German school grade system ranging from 1 (very good) to 6 (inadequate) was met with puzzlement by our foreign guests as most European countries use systems with an opposite valuation (such as 10 (very good) to 1 (very bad)). We therefore decided to work with a modified form turning the German system on its head. Our grading scale, then, looks like this:

⁴⁷ A complaint system in which the complainant is expected to turn to the staff of an institution he is complaining against (which may well have given cause to the complaint in the first place) and, in the event of further dissatisfaction, to the same institution's management, does not fulfil these criteria.

Points	Significance
5	Excellent
4	Good
3	Satisfactory, Sufficient
2	Mediocre, Adequate
1	Inadequate, Bad
0	Nonexistent (or at best being locally tried)

We limited ourselves to judging the left half of our assessment system at this point, the systems handling 'simple' complaints without demands for material compensation and the ways of settling such demands out of court. However, we believe that legal systems of complaint management and compensation should be subject to the same expectations and scrutiny as those operating out of court.

For a detailed evaluation of an institution or system we use a graphic representation rendering the facts, as it were, in full colour:

	Points →	5	4	3	2	1	0
		 green	 light green	 yellow	 orange	 red	 white
↓ Criteria							
1. regulated and codified							
2. independent							
3. visible							
4. accessible							
5. multi-tiered							
6. professional							
7. quick							
8. effective							
9. accepted							
10. transparent							
	Total:						

1.3.2 The Complaint Management Systems in European Countries

We realise that we are demanding much when we apply these criteria to complaint management systems. However, we believe that this is justified. After all, the *patients* and their need for good complaint management are at the heart of our project.

We will not present the institutions in detail – that will be done in the country reports – but merely present the most important facts and our conclusions and evaluation.

Our survey will begin with the system that among the countries we looked into is both the most extensive and, we believe, that serves the interests of the patients best. Afterwards, for contrast, we will look at the German complaint management system. Then we will touch on discussions that were initiated at our conference between participants from various countries and are set to continue in the coming years. Finally,

we will sketch a possible future path to continue the debate on complaint management in health care.

The Netherlands

There is a multiplicity of institutions handling complaints, as the following graphic shows:

The Dutch Complaint Management System						
3 rd level	Inspectie voor de Gezondheidszorg Ombudsman					
2 nd level	Klachtencommissies	Klachtencommissies				
1 st level	Informatie en Klachtenbureaus Gezondheidszorg (IKG) [+SOKG] Regionale Patiënten/ Consumenten Platforms (RP/CP) Landelijk Informatiepunt voor Patiënten (LIP)	Klachten functionarissen [+VKIG]	Patiënten-vertrouwen personen (PVP) [+Stichting PVP]	Geschillen-commissie Ziekenhuizen		Tucht-colleges
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

Outpatients can turn to a number of state-funded but independent complaint receivers at the first level already.

- ▶ a nationwide telephone **information service** (*Landelijk Informatiepunt voor Patientten = LIP*)⁴⁸ offering information on complaint management and refers patients to the regional IKGs.
- ▶ about 30 **information and complaint points** (*Informatie en Klachtbureaus Gezondheidszorg = IKG*)⁴⁹ which, as the first local point of access, offer counselling and mediation for complainants.
- ▶ as many offices of the regional **patient and consumer platforms** (*RP/CPs*)⁵⁰ support institutions largely organised by patients and nonprofessional volunteers and supporting the IKGs.
- ▶ The IKGs are supported by a **nationwide foundation** for the support of complaint management (*Stichting Ondersteuning Klachtopvang Gezondheidszorg = SOKG*)⁵¹ which also supports the LIP.

48 Phone 030 2661661

49 <http://www.sokg.nl/frame3.htm>

50 <http://www.rpcp.nl>

51 <http://www.sokg.nl>

Hospital patients have access at the first level to *complaint managers* (*Klachtenfunctionarisse*) in hospitals who personally and directly receive and handle complaints. In psychiatric wards they are called *Patientenvertrouwenspersoon (PVP)* and their presence is mandatory.⁵²

The effectiveness of the first level is strengthened by a law that makes it mandatory to every institution in health care to establish a *complaint commission* (*Klachtencommissie*). As frequent meetings of these commissions tends to be expensive and involve a great deal of problems, institutions often support the first point of access well in order to receive and satisfactorily resolve many complaints there.

Evaluating the first level of the Dutch complaint management system alone already requires us to distinguish carefully. For example, the complaint managers in general hospitals have similar tasks to the *Patientenvertrouwenspersoon* in psychiatric wards, but must be seen as different with regard to certain criteria such as codification and independence. The PVP are mandatory and employed by a foundation that is completely independent of the institution they work in. Thus they score high on both counts. Complaint managers, on the other hand, are provided by the hospitals voluntarily and employed by them, thus scoring considerably lower.

Netherlands: Patientenvertrouwenspersoonen and Complaint Managers							
↓ Criteria	Points →	5	4	3	2	1	0
1. regulated and codified		●			●		
2. independent		●			●		

The complaint managers are not doing too badly under codification because a minimum of regulation by internal guidelines or statutes seems to be the rule and because the clear legal ramification of the second level places great pressure on the quality management of the first. Under independence they also score two points because their professional association, the *Vereniging van Klachtenfunctionarissen in Instellingen van Gezondheidszorg (VIKG)*, with 170 members has been developing an independent profile and strength. *Patientenvertrouwenspersoonen* in psychiatric wards, on the other hand, fulfil all our requirements, being mandatory and fully independent of the institution. The latter is reinforced by a policy of rotating them every few years in order to prevent their developing strong loyalties to the institutions.

In our conference, we tried to evaluate the complaint commissions in hospitals in a work group together the Dutch representatives.⁵³

52 It is confusing that other wards sometimes name their (nonmandatory) complaint managers *Patientenvertrouwenspersoon* as well.

53 Fons Dekkers, former director of the NP/CF (Utrecht) and Henk Vriend, *Patientenvertrouwenpersoon* at the *Ziekenhuis "Het Spitaal"*, Zutphen.

Netherlands: Complaint Commissions in Hospitals							
↓ Criteria	Points →	5	4	3	2	1	0
1. regulated and codified		●					
2. independent					●		
3. visible			●				
4. accessible			●				
5. multi-tiered		●					
6. professional				●			

The discussion showed, that evaluating even a single institution can be highly controversial.

1. We all agreed that the legal ramifications deserved a high score.
2. Opinions divided once we came to the question of independence. The hospital patient ombuds thought them highly independent, but patient representatives from numerous countries countered that, with the members of the commissions being in their majority employees of the hospital, they could hardly be considered independent.
3. When it came to visibility and
4. accessibility of the commissions, the accessibility of the complaint manager must be taken into account as he represents the commission's point of access.
5. The question of multi-tieredness was solved unanimously. The Netherlands are a model country in this respect.

A discussion of further criteria could not be undertaken due to time constraints. We gained the impression at times that the system of patient support in the Netherlands is so well supported that our critical look at boundaries and walls between the service and fund providers on the one hand and the patients on the other strikes the dutch as strange. Dutch patients appear *spoiled for participation*.

Germany

Complaint Management in the German Health System						
3 rd level					Landesberufsgesicht für Heilberufe (state professional court for the health care professions)	
2 nd level					Berufsgesicht für Heilberufe (professional court for the health care professions)	
1 st level	Verbraucherzentralen (Consumer Associations), Patientenstellen	Patientenfürsprecher (patients' advocates), „Ombudsleute“	Schlichtungsstellen/ Gutachterkommissionen d. Ärztekammern (arbitrators/experts' commissions of the Medical Associations)		Ärztammer (Medical Association)	
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

In our own country we found hardly any complaint management system for 'simple' complaints that do not demand material compensation. At least, there is no nationwide system, though there are certain isolated *models* (such as patient support in *Consumers' Associations* or *Patientenstellen* (offices of patients' associations)) as well as volunteer patient advocates (often called ombuds, though they hardly fulfil the high expectation this term carries). Individual institutions may score points here, but not Germany as a whole.

Only one complaint management system in Germany operates nationwide: the arbitrators and *experts' commissions of the medical associations*.⁵⁴ Only for them could we give an evaluation for the entire country. The result looks like this:

54 The further possibility of using the medical service of the health insurers for evaluating a complaint prior to legal action according to § 66 SGB V was not looked into at this point. This approach is even less visible to the patients than the experts' commissions and arbitrators, as it is accessible only through the health insurers. Describing and evaluating this system of complaint management, then, is much harder than with those presented here.

Deutschland: Gutachterkommissionen / Schlichtungsstellen der Ärztekammern		5	4	3	2	1	0
↓ Criteria	Points →						
1. regulated and codified						●	
2. independent					●		
3. visible					●		
4. accessible						●	
5. multi-tiered							○
6. professional			●				
7. quick					●		
8. effective					●		
9. accepted					●		
10. transparent						●	
Total: 17 out of 50					1,7		

The individual gradings were justified as follows:

1. They were established on a voluntary basis and though they are mentioned in numerous laws, they are not regulated by them.
2. They are financed exclusively by the medical associations, sometimes with support from the physicians' malpractice insurers. Patients' representatives are not involved. They are thus neither independent nor impartial. This is not affected by the fact that they are formally independent of the medical associations and mostly headed by lawyers. New developments point toward the involvement of patients' representatives. In the state of Rhineland-Palatinate this has already been mandated by law, but yet needs to be implemented.
3. Relatively few people are even aware of their existence. They are hardly established as a complaint system in the public consciousness. The fact that doctors and health insurers sometimes refer their patients to them may justify a second point.
4. They are accessible only in written form, by filling in a long form. There are no offices or counsellors to help the patients in the process.
5. They are neither multi-tiered nor aligned with any other system's upper levels.
6. The score for professionalism is relatively high (though this is balanced by limited transparency).
7. Decisions tend to take one to two years. That is considerably faster than the average trial, but still too long for extrajudicial complaint management.
8. An important aspect is the non-binding nature of their findings. Neither party is bound to abide by their decision, though it often serves to influence the decision in a subsequent trial. Thus they are more often effective in favour of the party complained against (the physician) than for the complainant.

9. Their acceptance among patients is evaluated differently. They are, of course, recommended by physicians and, for want of other alternatives, by insurers, but they are also often criticised for their lack of independence.
10. Neither the choice of medical experts nor the results of their work are sufficiently transparent. Results are presented annually – as a list of anonymous cases in the *Deutsches Ärzteblatt* (publication of the medical associations) – and then only to doctors, not to patients.

We can not compare our final result – 17 out of 50 points – with the systems in other countries because we could not yet arrive at a similarly complete evaluation for any of them. However, we hope to stimulate such a development in the coming years.

We can, however, apply a similar system to other countries we looked into and touch upon aspects of evaluation. We lay no claim to completeness but merely wish to stimulate continued work in this direction.

Denmark

The Complaint System in the Danish Health Care System						
3 rd level					<i>Lægeetisk nævn</i>	
2 nd level	<i>Patientklagenævn</i>	<i>Patientklagenævn</i>	<i>Patientklagenævn</i>		<i>Patientklagenævn</i>	
1 st level	<i>Patientvejleder</i>	<i>Patientvejleder</i>	<i>Patientforsikringen</i>			
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

The Danish representatives at our conference thought their system well regulated; fairly independent, visible, and accessible; sufficiently multi-tiered; fairly professional; rather quick and effective and moderately transparent. They were divided in their opinions on several criteria, among them independence, multi-tieredness and acceptance by all parties.

Sweden

Complaint Management in the Swedish Health Care System						
3 rd level	<i>Socialstyrelsen</i>					
2 nd level	<i>Förtroendenämnden</i>		<i>Landstingens ömsesidiga Försäkringsbolag (LÖF)</i>		<i>Hälsa- och sjukvårdens ansvarsnämnd</i>	
1 st level	<i>Patientnämnden</i>	<i>Patientombudsman</i>	<i>Patient-skade-nämnd</i>			
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

Opinions on the separate elements of the Swedish complaint system differed strongly depending on the perspective of the observer. The existence of a malpractice insurance independent of proof of responsibility on the one hand was viewed as an important institution for patients' rights. The Swedish insurance fund has been in existence since 1975, that in Finland since 1987, the Norwegian one since 1988 and the Danish since 1992.⁵⁵ In Sweden, a similar insurance for pharmaceutical side effects has been in existence since 1978. This institution was severely criticised by the representative of the NGO *KILEN*, that deals with cases of patients suffering from deleterious side effects, for its connections to the pharmaceutical industry and its unwillingness to accept and regulate cases. The other institutions similarly received lower scores because they are managed by the service providers and therefore not independent.

Finland

3 rd level						
2 nd level			<i>Potilasvahinkolautakunta</i> = Patient Damages Committee		<i>Terveysturvakeskus (TEO)</i> = State Office for Patient's Rights Protection	
1 st level	<i>Potilasasiainmies</i> = Ombuds	<i>Potilasasiainmies</i> = Ombuds	<i>Potilasvakuutuskeskus</i> = Patients' Insurance		<i>Lääninhallitus</i> = Local Government	
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

The representatives from Finland⁵⁶ drew a relatively positive picture of their country's complaint management system at our conference:

55 Pichler 1994.

56 Karl-Gustav Södergard from the Finnish Patients' Association and Ritva Leskinen, staff member of the PatientenNavigation Project and health care student in Hamburg.

Finnland: Das Beschwerdesystem							
↓ Criteria	Points →	5	4	3	2	1	0
11. regulated and codified		●					
12. independent				●			
13. visible			●				
14. accessible			●				
15. multi-tiered		●					
16. professional				●			
17. quick					●		
18. effective			●				
19. accepted	not graded						
20. transparent					●		
Total: 32 out of 45			3,6				

The complaint system is largely based on ombuds which every institution is obliged by law to appoint. Their independence may be questioned, though, since they are part of the service provider's structure. On the other hand they are very visible, known and accessible. The system has several tiers, but the base is often formed by inadequately trained people. Case handling by the Patients' Insurance is not particularly slow, but at 10 months on average was still found not fast enough. The effectiveness of the system as a whole appears to be satisfactory. Transparency remains to be desired, though, and the participants chose not to judge acceptance on grounds of the term being insufficiently clear.

Great Britain

The Complaint Management System in Great Britain						
3 rd level	Health Service Commissioner					
2 nd level	Independent Review Panel					
	Convener					
3 rd level	(Community Health Councils)		Action for Victims of Medical Accidents		General Medical Council	
	Local Solution					
	Outpatient	Hospital	Out of court	In court	Professional law	Penal law
	'Simple' complaints		Material compensation		Sanctions	

Regarding the British complaint system we must point the reader to the detailed description in our country report. It is currently being reevaluated and restructured, which made judging it in detail seem inappropriate at this point.

Conclusion

Our look at the complaint systems in northern European countries has not resulted in a complete, coherent picture, but it shows that it could be achieved with relatively little effort. A program for getting there could look like this:

Preliminary Theoretical Work

- ▶ First the *assessment system* we developed should be tested to see whether it is suited to all forms of complaint systems operated in the public interest.
- ▶ At the same time it should be seen whether the *criteria* for 'good' complaint management we developed together with the *Community Health Councils* will meet with approval from patients' organisation in all European countries. Otherwise they will have to be amended in cooperation with them and agreed upon as the 'complaint management standards' issued by European patients' representations.

Research

- ▶ As a second step, *research* would have to be done to assess and describe all elements of complaint management in the European countries.

Evaluation

- ▶ Each element or separate system would have to be *judged* according to the criteria agreed upon and where necessary amended by the European patients' organisations.
- ▶ *Total values* could be developed for entire countries or single branches of their system (e.g. complaint management for outpatients) by averaging the separate values. At this level, comparisons of systems and countries become possible.

We must leave it at these suggestions as the limitations of our project allowed for no more. It is our hope, though, that the approach presented here will prove fruitful in coming years.

1.4 Results and Conclusions

1.4.1 Conclusion

Our final conclusions are divided into two fields:

- ▶ How can Germany learn from other countries to provide patients and the public with information about the *quality of hospital care*?
- ▶ How can Germany learn to address *individual patient preferences* in order to provide every patient with the information he wants?

Quality Transparency

Publishing data on hospital quality is possible in principle in spite of the very different limitations imposed on it by conditions in the various countries (see Country Reports, vol. 2). This is the clear result of our study.

- ▶ *Structural data* on hospitals could be presented in much greater detail than has been the rule in Germany. Such information could be made public under the aegis or control of the ministry of health.
- ▶ *Process data* is also being processed in many countries. Using it in the interests of patients is a small step, but will depend on constellations of interests and influence.
- ▶ Throughout Europe, the development increasingly tends towards the publication of *outcome data*. These include objective figures (such as mortality figures) as well as subjective parameters (such as satisfaction or general health and wellbeing). Some of these data will require processing and even standardisation (as in the case of mortality), and interesting examples for both exist already.

Unlike in Germany, the publication of all these data in many countries is undertaken by influential state-run or state-supported institutions. In Germany, the lesson that *collecting, processing and publicising quality data* can serve to reduce unnecessary treatment and overcapacities and thus reduce health care costs as well as serve the interests of patients has not yet been learned.

At the level of collective transparency we can learn from other countries that a public debate (and a stronger involvement of the public) on questions of quality transparency in hospitals (and elsewhere) is possible and helpful. In the course of increasing *European mobility* and the unification of *European health standards*, Germany will soon face demand for quality data on its hospitals from other countries and foreign patients.

Necessary and helpful *preconditions of creating transparency* for hospital quality data are:

- ▶ A broad debate in society on the importance of transparency,

- ▶ A political, preferably *legal framework* obliging service providers to provide the necessary data,
- ▶ the opportunity for *independent institutions* to process and publicise the provided data in intelligible form,
- ▶ Nationwide, sustained and independent *information and counselling structures* to aid patients in using and individually evaluating the information,
- ▶ as well as access to service providers for inspection purposes for independent, external institutions and the publication of their findings.

Individual Patient Preferences

How are the individual patient's preferences taken into account to provide him with the information he wants? To date, there has only been an unsystematic jumble of projects in various states.⁵⁷

We have looked at the question of patient preferences mainly in terms of *problem-oriented patient satisfaction* in the form of complaints. All countries we surveyed (except Germany) have developed systems to collate and react to complaints. These are often based on legal frameworks or internal and external structures offering all-round support to the patient: one-stop information, counselling and complaint management. These institutions often have publicly funded, trained staff for counselling. This allows patient preferences to be rendered visible and used in nationwide comparisons. A constructive complaint culture could also help Germany to learn from mistakes for the future. An approach for further developing complaint management in Germany was given in the chapter on complaint management.

Numerous forms of perceiving patient preferences could be arrived at by integrating patients into the health system at many levels: research, the collection of patient information, health care staff training, or committees deciding on matters touching on the interests of patients. These and many other examples show that patients preferences can be taken account of at many levels.

1.4.2 Ten Stumbling Blocks for Germany or: What We Can Learn from Other Countries

- 1.) *Why are no nationwide detailed structure data on specialised issues (e.g. departments, staff qualification et. al.) provided to patients?*
Such data are already provided by the ministry of health in the Netherlands.
- 2.) *Why are there no national transparency guidelines giving patients the right to information on the quality of treatment, expected side effects, effects on their*

57 As patient preferences transcend the limits of the hospital as our focus, we have not been able to concentrate on them in the course of our study but they should be taken into account in further research approaches.

quality of life, alternatives to treatments and non-treatment options...?

The British General Medical Council already suggested such guidelines in 1999.

- 3.) *Why are there no nationwide research networks on primary care and general practice that can undertake long-term patient-oriented studies?*
In Great Britain, 40 such networks are united in a nationwide association. The Netherlands have an influential primary care research institute (NIVEL).
- 4.) *Why is there hardly a public debate and reaction to scandalous cases of malpractice?*
An example for positive reactions to serial malpractice is the *Bristol Royal Infirmary Inquiry* in Britain. This study had far-reaching consequences throughout the British health system.
- 5.) *Why is there no parliamentary ombuds reporting to parliament on cases brought to their attention?*
Many countries have such top-level complaint managers, e.g. *Britain's Health Commissioner* and similar persons in the Netherlands and Sweden.
- 6.) *Why are process and outcome data not centrally collected and evaluated to allow comparisons between individual health care service providers?*
Examples proving that this is possible include the *Dr Foster Institute* in Britain or the *Institute Prismant* in the Netherlands.
- 7.) *Why is there no compensation independent of personal responsibility, e.g. in the form of an insurance fund, to grant compensation to malpractice victims without years or decades of trials?*
Such models have long been in use in Scandinavia, and Austria is practising similar approaches.
- 8.) *Why are quality registers not managed accessibly and transparently enough to show what treatment is most suitable to what group of patients?*
Such quality registers have been developed in Sweden.
- 9.) *Why are there no nationwide independent structures for patient counselling and support that unify information, counselling and complaint management?*
Such structures are found in almost all northern European countries (Great Britain, the Netherlands, Denmark, Sweden...), as well as in Austria in the form of *Patients' Advocates*.
- 10.) *Why are there no moves towards developing a complaint culture in Germany?*
Nationwide complaint structures exist in other north European countries, such as the regional *Counselling and Complaint Offices* in the Netherlands, combined with a *Foundation for Supporting Complaint Management*, *Complaint Managers* and *Complaint Commissions* in hospitals etc.

Annex

Bibliography

- ACHCEW = Association of Community Health Councils for England and Wales (1999): The NHS Complaints Procedure. ACHCEW's Memorandum to the Public Administration Committee, June 1999, p. 10
- Capurro, R. (1999): Der Informationsbegriff in der Informationswissenschaft (web publication only)
- Capurro, R. (1978): Information. Ein Beitrag zur etymologischen und ideengeschichtlichen Begründung des Informationsbegriffes, Saur Verlag, Munich, New York, London, Paris
- Edwards, A. and Elwyn, G. (2001): Evidence-based Patient Choice – Inevitable or Impossible?, Oxford University Press, Oxford
- Herrschaft, I. (1996): Zur Bestimmung eines medienpezifischen Informationsbegriffs in: Nachrichten für Dokumentation 47, pp. 171-182
- Ingwersen, P. and Pors, N.O. (eds.) (1996): Information Science. Integration in Perspective, Royal School of Librarianship, Copenhagen
- Ingwersen, P. and Pors, N.O. (eds.) (1995): Information and Information Science in: Encyclopaedia of Library and Information Science, Vol. 56, Suppl. 19, pp. 137-174
- Machlup, F. and Mansfield, U. (eds.) (1983): The Study of Information. Interdisciplinary Messages, John Wiley & Sons, New York et al.
- Pichler, J.W. (1994): Rechtsentwicklungen zu einer verschuldensunabhängigen Entschädigung im Medizinbereich. Die Patientenversicherungsrechte in Schweden, Finnland und Dänemark, Böhlau Verlag, Vienna
- Wersig, G. (1971): Information – Kommunikation – Dokumentation, Verlag Dokumentation, Munich