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Report

The landscape of patient information in Germany

Status quo and Outlook

client
PhRMA

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Executive Summary

For the first time, a study on patient information on Rx drugs

- gives an overview of the status quo of internet-based pharmaceutical information for patients (desk research),
- identifies patient and public needs in regard to information and their expectations regarding the quality of information (focus groups) and
- conducts a survey of patient and public needs, gauging patient and public opinion on pharmaceutical information through the pharma industry (online survey).

It paints a heterogeneous picture of the structure of information available on the internet. Using 15 diagnoses, a twofold analysis looked at whether information on active substances or products was provided online and also whether this information corresponded to quality criteria laid down by the ÄZQ. First, information given by 78 objectively-chosen institutions was analysed; more than half of the information provided on substances and products fulfilled the quality criteria.

In a second approach, we documented the top 15 Google hits for (a) the name of the diagnosis and (b) the name of the diagnosis and the word “medication”. Up to 74 percent of the results failed the quality test. Sources not covered by the institutional approach were revealed: Commercial providers have optimised their domains for search engines and are active in supplying information to patients and the public at large on active substances and products.

In three focus groups with sufferers and next-of-kin of the selected diagnoses, hypotheses for patient information on medication were drawn up. These were:

- Some patient groups can be regarded as being highly competent in the use of media and information. Information should be clear and comprehensible. The credibility of information does not flow from individual providers, but rests on the comparison of different sites.
- The information is used in consultations with doctors, whose job it is to undertake the final categorisation and evaluation of any information. Doctors thus play a central rôle in patient information management.
- Patients are unaware of legal limitations on manufacturers concerning Rx drug information. The legal limitation on manufacturers from informing patients on Rx drugs is seen as annoying and antiquated.

- There are no particular misgivings or doubts among patients towards industry information. Information provided by the industry would be used by many patients as one source among many.

- The industry is seen as being especially competent in the area of research and development of new medicines.

These hypotheses were tested and confirmed in an online survey. Two samples were used: one was representative for 18 to 65 year old internet users (n=1,013), the other comprised patients and next-of-kin (n=1,020). The survey results show that:

- Patients look for information on medication in the context of illness. Institution-based searches are unusual.

- They value the access to information but see deficits in regard to the quality of information, reflecting the findings of the status quo analysis.

- Patients compare different sources when informing themselves.

- Two-thirds of patients and the public at large reject the ban on industry information.

- Information from manufacturers is welcomed by over 90 percent of patients and the public at large. There is a large willingness to use industry information as one source among many.

- Patients and the public at large see the added value of industry information in the areas of research and product development. 84 percent of patients and the public at large would use this information.

In sum, the study shows that patients and the public at large compare information from different sources when informing themselves and make up their own minds about what is trustworthy. Protecting patients from commercial interests is questionable in the face of information from the publishing sector and private equity-backed ventures. Patients and the public make up their own minds about what is trustworthy. As a result, they have no misgivings about being informed on Rx medication by the industry, as long as the information fulfils quality standards (comfortable, comprehensible, in context, serious and up-to-date). Information provided by the pharma industry as one source among others would be welcomed and used.

The added value of the pharma industry lies in information on research and product development. This is something the public and patients want and cannot imagine getting elsewhere. Doctors however remain the first port of call for patients, a majority of them reacting positively when well-informed patients discuss information with them.

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1 Introduction

1.1 Why this study? Background information to patient information in Germany

At present, the pharmaceutical industry in Germany is prohibited by the Pharmaceutical Advertising Act (*Heilmittelwerbegesetz*) from advertising to patients about prescription medicines.[1] The European Union has also regulated in a similar manner in Directive 2001/83/EG. Since 1992, the EU has differentiated between advertising and patient information.

On 20 December 2007, the European Commission published a report which concluded that the "rules and practices on what information can be available still vary significantly among Member States, which results in unequal access of patients, and the public at large, to information on medicinal products." [2] The report also concluded that patients are in general now better informed and more proactive regarding the treatment of their illnesses than they were in the past. The report also drew attention to the rôle of the internet in patient information, and in particular how providers of information on the internet have no or limited accountability toward citizens.

The Commission launched the public consultation "Legal Proposal on Information to Patients" on 5 February 2008 with the aim of reducing differences in access to information and ensuring the availability of good-quality, objective, reliable and non-promotional information on medicinal products throughout the EU. While upholding the ban on direct-to-consumer advertising of prescription medicines, the Consultation proposed making a clear distinction between advertising and non promotional information. By regulating the quality, the content and the means of the information provided, together with a quality monitoring scheme, the consultation suggested creating a framework for the industry to provide certain information on their Rx medicines to the public.

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[1] Paragraph 10 of the Pharmaceutical Advertising Act (*Heilmittelwerbegesetz*) states:

(1) Prescription medicines may only be advertised to physicians, dentists, veteranarian, pharmacists and persons legally entitled to trade in pharmaceutical products.

(2) Pharmaceutical products designed to eliminate sleeplessness or mental health problems or influence mood may not be advertised outside professional circles.

(1) Für verschreibungspflichtige Arzneimittel darf nur bei Ärzten, Zahnärzten, Tierärzten, Apothekern und Personen, die mit diesen Arzneimitteln erlaubterweise Handel treiben, geworben werden.

(2) Für Arzneimittel, die dazu bestimmt sind, bei Menschen die Schlaflosigkeit oder psychische Störungen zu beseitigen oder die Stimmungslage zu beeinflussen, darf außerhalb der Fachkreise nicht geworben werden.

[2] Communication from the Commission to the European Parliament and the Council concerning the report on current practice with regard to provision of information to patients on medicinal products in accordance with Article 88a of Directive 2001/83/EC, as amended by Directive 2004/27/EC on the Community code relating to medicinal products for human use {SEC(2007)1740} Brussels, 20.12.2007, COM(2007) 862 final.

The picture painted in the Commissions report and consultation document is mirrored in Germany. The statutory information sources about pharmaceutical products for patients are doctors and pharmacists. Due to time restrictions, advice and counselling have been reduced to a minimum. Various self-help groups and internet platforms have been active in trying to even out this advice deficit. However, the funding of these organisations is for the main lacking in transparency. Moreover, general quality standards are not present.

In a written answer to the Green caucus in the Federal Parliament,[3] the German government acknowledged the unsatisfactory situation regarding patient information, stating: "The provision of health information is, in the opinion of the Federal Government, a prerequisite for strengthening patient rights and therefore an important and necessary element in the continual development of the German healthcare system. We are in agreement with the European Commission that patients require comprehensive and trustworthy information if they are to be more involved in decisions affecting their health. It is also true that citizens are increasingly using the internet as a source of information. In the face of the increasing amount of information available online, the need to set higher standards is seen. Securing equal and high standards is a high priority for the Federal Government.

"The Federal Government is however on the whole critical of the means proposed by the European Commission to achieve this objective and expressed this in its reply of 7 April 2008. In particular, we must be very careful in considering whether there is any need at all to amend the existing legal situation."[4]

The Commission is due to publish its draft directive in October 2008.

With this in mind, more information is required regarding patient behaviour and needs. PhRMA thus commissioned Prognos AG to examine patient information on prescription medicine in Germany, focussing especially on the internet as a medium.

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[3] Deutscher Bundestag Drucksache 16/9031, 16. Wahlperiode: „Antwort der Bundesregierung auf die Kleine Anfrage der Abgeordneten Birgitt Bender, Dr. Harald Terpe, Elisabeth Scharfenberg und der Fraktion BÜNDNIS 90/DIE GRÜNEN – Drucksache 16/8830."

[4] Ibid, pp 2-3. Orginal text: *„Die Bereitstellung von Gesundheitsinformationen ist aus Sicht der Bundesregierung Voraussetzung für die Stärkung der Rechte der Patientinnen und Patienten und damit ein wichtiges und notwendiges Element der Weiteentwicklung des Gesundheitssystems in Deutschland. Konsens besteht deshalb mit der Auffassung der Europäischen Kommission, dass Patientinnen und Patienten, wenn sie stärker in Entscheidungen, die ihre Gesundheit betreffen, eingebunden werden sollen, umfassende und zuverlässige Informationen benötigen. Auch ist festzustellen, dass Bürgerinnen und Bürger das Internet zunehmend als Informationsquelle nutzen. Angesichts der zunehmenden Flut der hier angebotenen Informationen wird Bedarf gesehen, höhere Standards für die Angebote vorzugeben. Für die Bundesregierung hat die Sicherstellung einer einheitlichen und hohen Qualität der Patienteninformation deshalb eine hohe Priorität.*
Die zur Erreichung dieses Ziels von der Europäischen Kommission vorgeschlagenen Mittel sieht die Bundesregierung gleichwohl insgesamt kritisch und hat dies in ihrer Stellungnahme vom 7. April 2008 auch zum Ausdruck gebracht. Insbesondere muss sehr sorgfältig geprüft werden, ob eine Änderung der bestehenden Rechtslage überhaupt erforderlich ist." Translation Prognos AG

1.2 Objective of this study

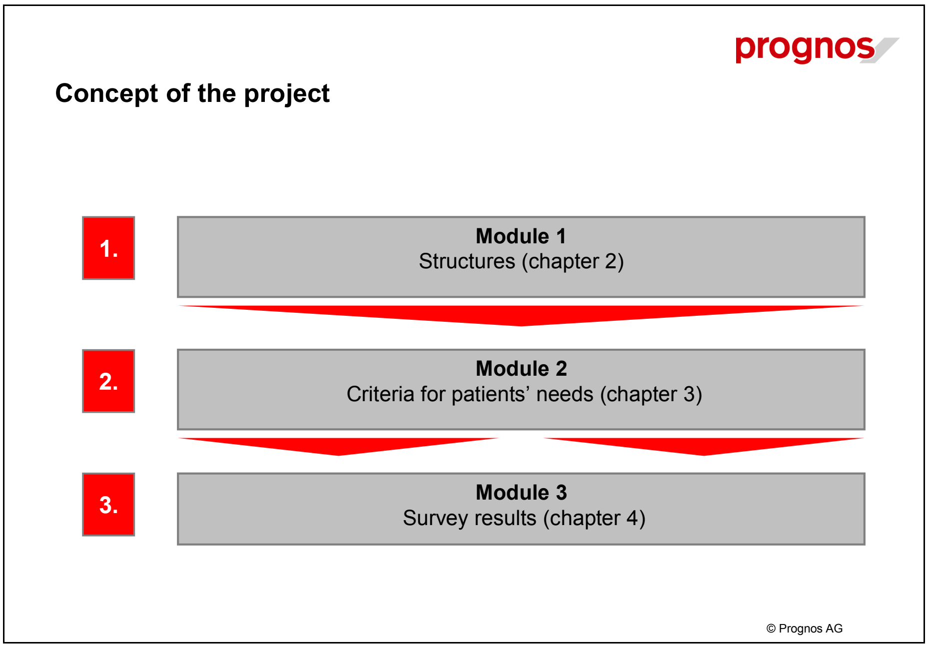
This present study for PhRMA will show for the first time what patients and the public at large think about information on Rx medication and whether they would welcome the industry as an information source. The objectives are:

- to obtain clarity and transparency regarding the structures of patient information on Rx pharmaceutical products in Germany,
- to determine the quality of advice (structural characteristics and contents)
- to uncover any possible information deficits
- to juxtapose the advice structures with the actual needs and requirements of patients,
- to establish the possible added value of additional information being provided by the industry in the framework of a pull strategy.

1.3 Methods

The study consists of three consecutive modules.

Figure 1: study concept



Concept of the project

1. **Module 1**
Structures (chapter 2)

2. **Module 2**
Criteria for patients’ needs (chapter 3)

3. **Module 3**
Survey results (chapter 4)

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Source: Prognos AG

Module 1 analyses the structure of internet-based patient information in Germany (desk research). It contains information on the source of information (e.g. organised by patients, care providers, insurance companies), addressees (e.g. general population, specific indications), financing (e.g. profit-orientated, non-profit) and contents.

The result is an overview of the structural features of internet-based patient information on medication in Germany (see Chapter 2).

Module 2 measured the quality of the information and advice structures. Apart from professional demands, the users' or patients' perspective is a crucial component when it comes to determining the quality of given information. Therefore, criteria were defined by means of group discussions (focus groups). In the focus groups patients and next-of-kin discussed criteria for information on Rx medication. They further discussed scenarios for future development. These results are in Chapter 3.

Module 3 was a representative survey of 1,000 members of the general public and also 1,000 patients or next-of-kin. The intention of this survey was to analyse patients' and the public's needs and expectations with regard to information and advice on Rx drugs. The results deliver further information on the quality of information, possible deficits and patients' requirements. The results are found in Chapter 4.

Recommendations for action and an impact assessment of any legislative change are not part of the present contract.

2 Status quo of pharmaceutical information for patients in Germany

2.1 Objective of the status quo analysis

The objective of the status quo analysis is to shed light on existing and relevant providers of information on pharmaceutical products to patients in Germany. The research did not explicitly differentiate between Rx and OTC medication; however, a concentration on Rx can be assumed by the limitation on selected morbidities. The research is structured in such a way as to take into account two general approaches to judging information, namely by

- accessing information via institutional actors or
- accessing information via morbidity.

In the first approach, the presumption is that patients' first port of call when researching are institutions. The research questions are therefore: who provides information? What information do they provide? What is the quality of the information? This approach reflects the thinking of German legislators.

In the second approach, the presumption is that patients seek information independently of institutional affiliation. The starting point is the morbidity and not an institution. The research questions are therefore: what is the problem? What information can be found? What is the quality of the information?

Within the two approaches we aim to show

- who supplies information to patients,
- whether the information available is aimed at patients,
- who finances the providers and
- whether the information fulfils quality criteria.

By doing this, we will be able to give an overview of the status quo of pharmaceutical information for patients on the internet. The result is an overview of the strengths, weaknesses and structural deficits of pharmaceutical information for patients in Germany.

2.2 Methods

2.2.1 Considered Morbidities

The amount of information available on the internet for patients is immense. For this reason, it was decided to carry out the status quo analysis for a select number of morbidities.

For this purpose, criteria were defined which enabled us to consider a broad range of morbidities. Finally 15 morbidities were selected from the following groups:

- Disease Management Programmes (DMP)
- Pharmaceutical underprovision
- well organised and informed patient groups
- rare conditions

DMP-Diseases

For some chronic diseases, the risk compensation mechanism of the statutory health system funds Disease Management Programmes. High prevalence, good documentation, and evidence based treatment modalities can be assumed for DMP-diseases as well as the interest of health insurance companies in informing the patients.

With the exception of breast cancer and type I diabetes all DMP indications are highly prevalent diagnoses. All DMP diseases have been included in the study:

1. Diabetes mellitus I and II
2. COPD
3. Asthma
4. Breast cancer
5. Coronary heart disease

Pharmaceutical Underprovision[5]

Furthermore, diseases with evidence of pharmaceutical underprovision are included in the study.

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[5] Rychlik (2007): Gutachten über die Unterversorgung mit Arzneimitteln in Deutschland

6. Dementia / Alzheimer's (treated as one condition)
7. Rheumatism
8. Leukaemia
9. Schizophrenia
10. Osteoporosis
11. Migraine

Some of these diseases (such as forms of rheumatism like gonarthrosis as well as osteoporosis and migraine) are included on the list of the most prevalent diagnoses of general practitioners. With dementia, Alzheimer's disease and schizophrenia, prevalent neurological morbidities are included.

Diseases with a well organized network of patients

The following morbidity has an exemplary organised network of patients, of whom a high level of information can be presumed:

12. HIV/AIDS

Rare diseases

A morbidity is defined as a rare disease if fewer than 5 out of 10,000 people (in relation to Germany's total population less than 40,000 cases) are affected. Selected diseases of this category complete our spectrum:

13. Cystic fibrosis (well known, intensive pharmaceutical treatment necessary)
14. Turner's syndrome (chromosomal condition, pharmaceutical treatment necessary)

2.2.2 Provider-related and morbidity related analysis

As briefly mentioned above, in order to cover a wide range of providers of pharmaceutical information, two different research approaches were adopted.

Provider-related (institutional) research

This approach considers many important institutions of the German health system (e.g. insurance companies, service providers, government authorities, patient groups, scientific bodies, commercial providers). One reason for the institutional research is that the first hits of internet search engines are often commercial links, thus making it hard to find internet domains from patient organisations and other (governmental) institutions. Therefore the scope of the study might be unduly limited. Less well-known domains or domains not optimised for search engines would not otherwise be found. Information stored on databases is also often not found with a Google search.

Morbidity-related research

Prognos documented and analysed the top 15 Google hits for the selected morbidities (e.g. "*Osteoporose*" for osteoporosis). We also widened the search terms to include the word "*Arzneimittel*" (medication). This approach was presumed to reflect the search strategies used by patients and the public at large (output-driven search).

Note on internet research

The internet research took place in the spring of 2008. Any content changes made to the websites since have not been documented. The research is therefore a snapshot of the situation found then. Furthermore, when finding information on pharmaceutical products, we were not able to differentiate between OTC and Rx medication. Due to the nature of the selected morbidities, a focus on Rx was assumed.

2.2.3 Quality criteria

The research resulted in a large data set about the present providers of pharmaceutical information. However, not all providers supply the relevant information. What was needed was a way of identifying not only who gives the information, but also evaluating the quality of the websites. A method was therefore needed to focus in on those providers who delivered both free information on prescription drugs and met quality standards.

The filter was devised which comprised the following steps:

- **Morbidity link:** was information given on the website to the morbidity at hand?
  The information must be linked directly to morbidities. Information about active pharmaceutical substances or products not placed in the context of morbidity-related usage was not considered.

- **Form of information**: was the information provided in the form of a text or a study on the website?
  In the internet many different types of communication such as informative texts, academic studies, online forums, chat rooms or links to other sources are commonly used. We only considered informative texts and academic studies.

- **Transparency**:

  - does the website include legals (conforming to Paragraph 5 of the German Telemedia Act – *Telemediengesetz*) requiring, for example, the name, address, contact details of the legal representative of the information provider (*Impressum*)?

  - Is the source or authorship of the information provided in the text? Or has the website alternatively been awarded a quality prize?

- **Target group**: is the information aimed at patients?
  In order to ensure the practicability of the study from a patient's perspective, only texts written specifically for use by patients or the public at large were considered. Papers written for scientists are excluded.

- **Pharmaceutical information**: is specific information given on active substance and on products?
  As a final criterion information about the active substances and or pharmaceutical products is required.

All the results were documented in a matrix. Changing the order of the filter criteria does not lead to different results.

These quality criteria conform to the patient guidelines for the evaluation of quality of internet information laid down by the German Agency for Quality in Medicine (ÄZQ)[6], with the exception of the following points:

- Date of information: many website software programmes update the date every time a change is made. The update is not solely limited to content change, but can also refer to correction of typos or punctuation. For this reason, we discounted this criterion.

- Unbiased formulation: we did not fulfil this criterion, as it is both subjective and requires an analysis of the language used.

- Third party opinion through patient organisations: very few websites fulfilled this criterion.

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[6] Cf. http://www.patienten-information.de/content/informationsqualitaet/checkliste#checklisten, retrieved 11 August 2008

2.3 Provider-related Research

2.3.1 Selecting information providers

The first step of the provider-related research is the selection of different players of the German healthcare system. An objective set of criteria was defined. Representatives of the insurance funds, providers and statutory bodies are included, whereas the interests of patients are represented by a variety of organized networks. In addition, commercial, scientific and other institutions were selected.

In total, 78 providers were selected:

- six statutory health insurance funds: the largest fund from each of the six types of fund was chosen (general local funds, company funds, substitute funds, trade guild funds, agricultural funds and mining/merchant navy funds). Although the general local funds and the trade guild funds have regional subdivisions, patient information is provided on the federal internet platforms. For this reasons, the federal websites were analysed. For all other funds, we analysed the sites of individual funds. The selected funds provide health cover for approx. two-thirds of the population.

- two of the largest private health insurance funds

- four relevant organisations named in Paragraph 2 of the Patient Involvement Regulation (*Patientenbeteiligungsverordnung*)

- seven relevant federal associations of healthcare providers named in section 4 of the Fifth Social Act (*SGB V Kapitel 4*)

- ten statutory bodies at federal level

- four well-known commercial providers

- thirteen medical societies representing the selected morbidities that are members of the AWMF - *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* (Association of the Scientific Medical Societies in Germany)

- five associations of medical specialists representing the selected morbidities that are members of the *Gemeinschaft Fachärztlicher Berufsverbände* (Group of Medical Specialists Associations)

- 22 patient organisations for the selected morbidities that are included on the NAKOS Green List (national clearing house for the encouragement and support of self-help groups)

- five further organisations deemed relevant but not necessarily members of the above named organisations

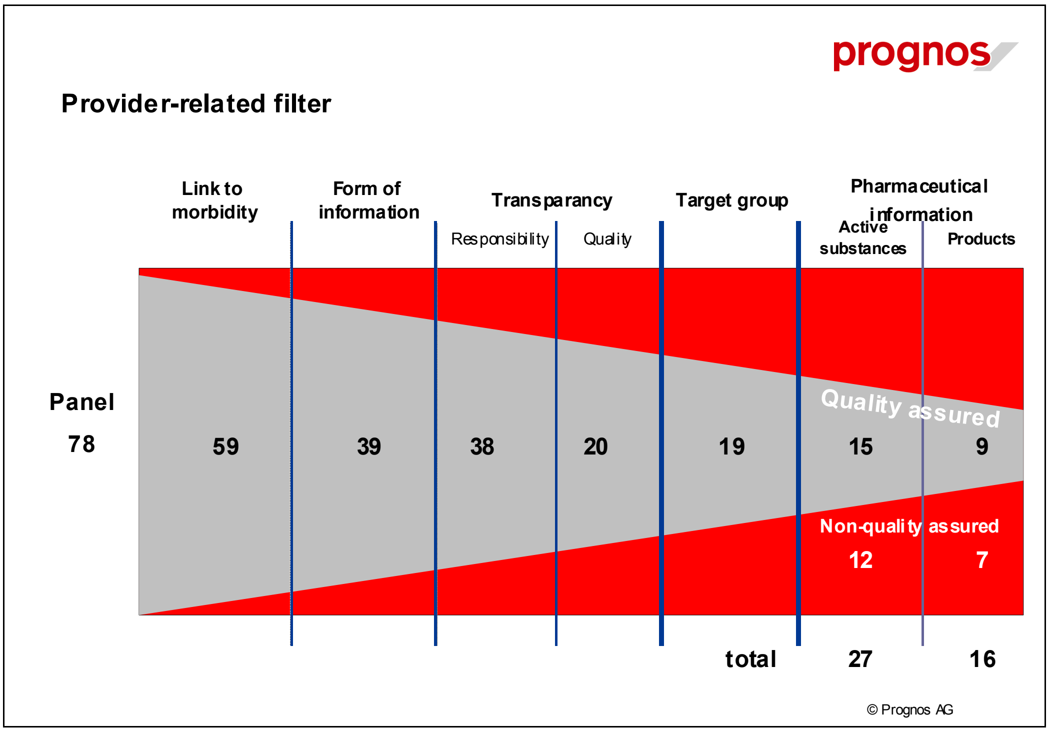
A full list of the organisations is included in Appendix 1.

2.3.2 Results

In total, 27 out of 78 institutions informed about active substances and 16 about pharmaceutical products. However, only 15 institutions informing about active substances and nine informing about products came through the filter.

The following figure gives an overview of the filter.

Figure 2: Filtering of information providers: institutional search



Source: Prognos AG

From an initial figure of 78 institutions, only about **one in five** fulfilled the criteria and provided information on active substances, whereas only **one in eight** provided information on pharmaceutical products. None of the Organisations named in Paragraph 2 of the Patient Involvement Regulation or the associations of medical specialists represented in GFB fulfilled our criteria (see Figure 3). Only one medical society represented in AWMF fulfilled the criteria (*Deutsche Krebsgesellschaft*), and only one statutory public body (*Stiftung Warentest*) came through the filter (although it must be noted that this information is not free of charge).

Figure 3: quality in the provider-related search

Category		**Non quality assured**		**quality assured**	
	total	**Active substances**	**or Products**	**Active substances**	**or Products**
Statutory Health insurance funds	**6**	2	0	2	0
Private Health insurance funds	**2**	0	0	1	0
Organisations named in Paragraph 2 of the Patient Involvement Regulation	**4**	0	0	0	0
relevant federal associations of health-care providers named in section 4 of the Fifth Social Act (SGB V Kapitel 4)	**7**	0	0	3	2
statutory bodies at federal level	**10**	0	0	1	1
commercial providers	**4**	2	0	2	2
medical societies represented in AWMF	**13**	2	1	1	1
associations of medical specialists represented in GFB	**5**	0	0	0	0
patient organisations listed on NAKOS green list	**22**	6	6	2	1
further relevant organisations / information providers	**5**	0	0	3	2
Total	**78**	**12**	**7**	**15**	**9**

Source: Prognos AG

Active substances

A total of 15 institutions informed about active substances and fulfilled the filter criteria (Figure 4).

The organisations that give the most information are the commercial providers. *Onmeda.de* gave information on active substances for all the morbidities except Turner's syndrome, *netdoktor.de* for all apart from Turner's syndrome and cystic fibrosis.

After these, the organisations which provided the most information were *Wikipedia*, statutory health insurance funds *AOK* and *Barmer*, as well consumer organisation *Stiftung Warentest*, the pharmacists' portal *APONET* and the Pharmaceutical Commission *AkdA*.

The health insurance funds are dependent on members' contributions, as are the federal associations of healthcare providers (institutional members). *Stiftung Warentest* receives a state grant and revenue from its consumer tests. The patient and medical societies are dependent on members' contributions, donations and sponsors. *Gesundfuchs* belongs to publicly-funded state body *IQWIG*.

With the exception of breast cancer, most information is provided on the DMPs. Next come the diseases with pharmaceutical underprovision. However, more institutions inform on morbidities such as rheumatism and osteoporosis than schizophrenia and leukaemia. Not surprisingly, fewer institutions gave information on HIV, cystic fibrosis and Turner's syndrome.

Twelve further institutions provided information on active substances but did not fulfil the quality criteria. These were:

- Statutory Health insurance funds: *BKK Bahn* (5 DMPs) and *IKK* (migraine)
- Commercial providers: *Gesundheit.de* (migraine) and *wissen-gesundheit.de* (dementia, rheumatism, migraine)
- medical societies represented in AWMF: *Deutsche Gesellschaft für Rheumatologie* (rheumatism, osteoporosis), *Dt. Migräne und Kopfschmerzgesellschaft* (migraine)
- patient organisations listed on NAKOS green list: *BApK* (schizophrenia), *Brustkrebs Deutschland* (breast cancer*), Deutsche AIDS-Hilfe e.V.* (HIV), *Deutsche Rheuma-Liga Bundesverband e.V.* (rheumatism), *Deutscher Diabetiker Bund e.V.* (diabetes) and *Netzwerk Osteoporose* (osteoporosis)

Spotlight on Onmeda and Netdoktor

Onmeda.de has according to “AGOF internet facts I/2008” 11.22 million page impressions, 1.85 million visits (IVW 07/08) and 830,000 unique users a month. Until June 2008, Onmeda was a subsidiary of Onvista AG, a German internet company with a varied portfolio in numerous sectors. Onvista is itself a 77 percent subsidiary of the French financial group Boursarama s.a. In addition, German publishing house Burda held 23 percent of the shares. In June 2008, Onvista was restructured and decided to concentrate on financial services. Onmeda.de was sold to gofeminin.de, the German arm of aufeminin.com, a French internet company noted on the Paris stock exchange. As of 11 August 2008, the German media group Axel Springer holds 79.7 percent of the shares in aufeminin.com. According to a Springer press release, Springer attaches great importance to the independent health portal, underlining its marketing potential. Its aim is to be the leading supplier of premium health information in Germany.

Netdoktor.de lists 11.1 million page impressions, 2.4 million visits and 1.2 million unique users a month, making it Germany’s largest commercial health portal. Netdoktor was bought by Holtzbrinck ELab GmbH, a 100 percent subsidiary of German publishing group Holtzbrinck, in 2007.

Figure 4: providers of information on active substances: provider-related search

Category	**Institution**	**Quality check**	**Coronary heart disease**	**Diabetes Mellitus**	**COPD**	**Asthma**	**Breast cancer**	**Dementia/Alzheimer's**	**Rheumatism**	**Schizophrenia**	**Osteoporosis**	**Leukaemia**	**Migraine**	**HIV**	**Cystic fibrosis**	**Turner Syndrome**	**Total**
Statutory Health insurance funds	AOK	yes	1	1	1	1	1	1	1	1	1	1	1	1	0	0	**12**
	Barmer	yes	1	1	1	1	1	1	0	0	1	1	1	0	0	0	**9**
Private Health insurance funds	DKV	yes	0	0	0	0	0	0	0	0	1	0	0	0	0	0	**1**
relevant federal associations of healthcare providers named in section 4 of the Fifth Social Act (SGB V Kapitel 4)	Arzneimittelkommission der Ärzteschaft (AkdÄ)	yes	1	1	1	1	0	1	1	0	1	0	1	0	0	0	**8**
	ÄZQ (www.patienten-information.de)	yes	1	1	1	1	0	0	0	1	0	0	0	0	0	0	**5**
	Gesundheitsportal der Apotheken (APONET)	yes	1	1	1	1	0	1	1	0	1	0	1	0	1	0	**9**
statutory body at federal level	Stiftung Warentest	yes	1	1	1	1	0	1	1	1	1	0	1	0	0	0	**9**
commercial providers	Netdoktor	yes	1	1	1	1	1	1	1	1	1	1	1	1	0	0	**12**
	onmeda.de	yes	1	1	1	1	1	1	1	1	1	1	1	1	1	0	**13**
medical society represented in AWMF	Deutsche Krebsgesellschaft (DKG)	yes	0	0	0	0	1	0	0	0	0	1	0	0	0	0	**2**
patient organisation listed on NAKOS green list	Deutsche Leukämie und Lymphomhilfe	yes	0	0	0	0	0	0	0	0	0	1	0	0	0	0	**1**
	Patientenliga Atemwegserkrankungen e.V.	yes	0	0	1	1	0	0	0	0	0	0	0	0	0	0	**2**
further relevant organisations / information providers	IQWiG (Gesundfuchs)	yes	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
	Kindernetzwerk	yes	0	0	0	0	0	0	0	0	0	0	0	0	0	1	**1**
	Wikipedia	yes	1	1	1	1	0	1	1	1	1	1	1	1	1	0	**12**
	Total	**15**	**10**	**11**	**11**	**12**	**7**	**9**	**10**	**7**	**11**	**7**	**12**	**5**	**3**	**1**	

Source: Prognos AG

Products

Nine institutions in total provided information about pharmaceutical products and came through the filter. The results are shown in Figure 5.

As with the active substances, it is the commercial providers who give the most comprehensive information. Also *Wikipedia* and consumer organisation *Stiftung Warentest* informed on products for more than half of the morbidities. APONET informed for half of the morbidities. Only one medical society (*Deutsche Krebsgesellschaft*) and one patient organisation (*Patientenliga Atemwegserkrankungen e.V.*) were left over, while the insurance funds did not provide information in products.

As to the distribution of morbidities, no discernible difference could be made between the DMP and underprovision groups.

Figure 5 gives an overview of these institutions and also the morbidities for which the substances are prescribed.

Seven additional institutions did not fulfil the quality criteria. These were:

- medical societies represented in AWMF: *Deutsche Gesellschaft für Rheumatologie* (rheumatism, osteoporosis).

- patient organisations listed on NAKOS green list: *BApK* (schizophrenia), *Deutscher Allergie- und Asthmabund e.V.* (asthma), *Deutsche AIDS-Hilfe e.V.* (HIV), *Deutsche Rheuma-Liga Bundesverband e.V.* (rheumatism), *Deutscher Diabetiker Bund e.V.* (diabetes) and *Netzwerk Osteoporose* (osteoporosis).

Figure 5: providers of information on products: provider-related search

Category	**Institution**	**Quality check**	**Coronary heart disease**	**Diabetes Mellitus**	**COPD**	**Asthma**	**Breast cancer**	**Dementia/Alzheimer's**	**Rheumatism**	**Schizophrenia**	**Osteoporosis**	**Leukaemia**	**Migraine**	**HIV**	**Cystic fibrosis**	**Turner Syndrome**	**Total**
relevant federal associations of healthcare providers named in section 4 of the Fifth Social Act (SGB V Kapitel 4)	ÄZQ (www.patienten-information.de)	yes	0	0	0	0	0	0	0	1	0	0	0	0	0	0	**1**
	Gesundheitsportal der Apotheken (APONET)	yes	1	1	0	0	0	1	1	0	1	0	1	0	1	0	**7**
statutory bodies at federal level	Stiftung Warentest	yes	1	1	1	1	0	1	1	1	1	0	1	0	0	0	**9**
commercial providers	Netdoktor	yes	1	1	1	1	1	1	1	1	1	0	1	1	0	0	**11**
	onmeda.de	yes	1	1	1	1	1	1	1	1	1	1	1	1	1	0	**13**
medical society represented in AWMF	Deutsche Krebsgesellschaft (DKG)	yes	0	0	0	0	1	0	0	0	0	1	0	0	0	0	**2**
patient organisation listed on NAKOS green list	Patientenliga Atemwegserkrankungen e.V.	yes	0	0	1	1	0	0	0	0	0	0	0	0	0	0	**2**
further relevant organisations / information providers	IQWiG (Gesundfuchs)	yes	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
	Wikipedia	yes	0	1	1	1	0	1	1	1	1	1	1	1	0	0	**10**
	Total	**9**	**4**	**5**	**5**	**6**	**3**	**5**	**5**	**5**	**5**	**3**	**5**	**3**	**2**	**0**	

Source: Prognos AG

2.4 Morbidity-related search

2.4.1 Introduction

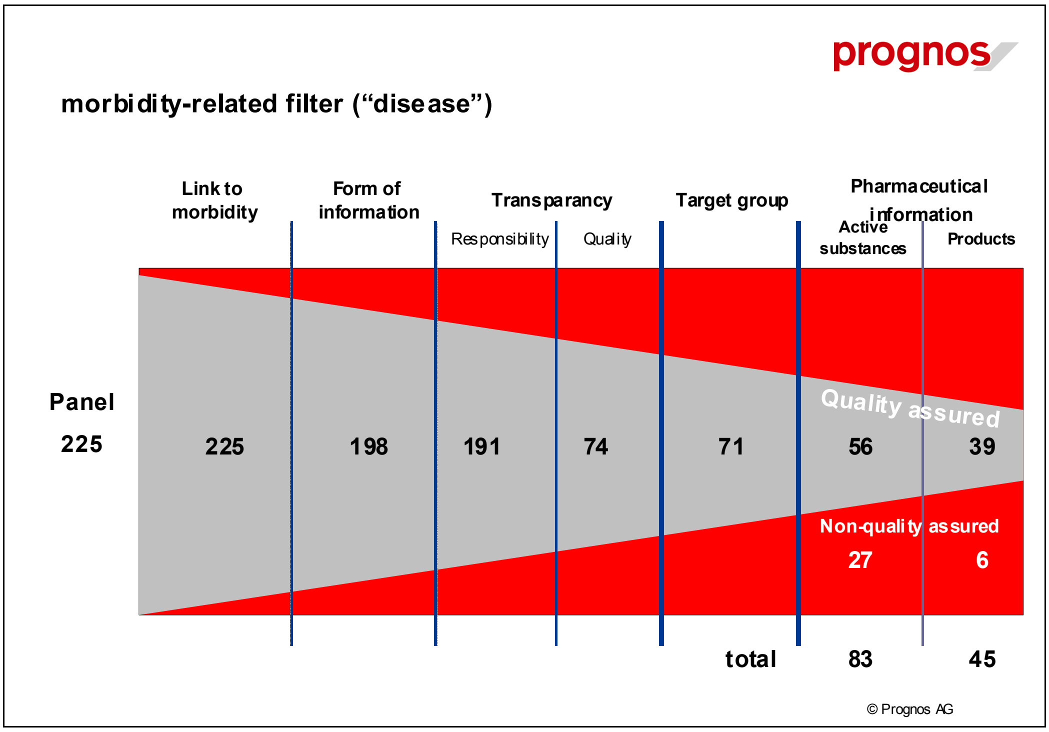
We also researched information on the morbidities independently of the institutions. Using Google's standard setting, this served to simulate the presumed behaviour of patients and the public at large.

Google's algorithm ranks the search results in accordance to the observed frequency of the search terms in its database. We referred exclusively to the hits of the first page and the first five hits of the second page. Our search terms were “disease" and "disease + drug" respectively. Each time, 225 pages (15 matches by 15 morbidities)[7] were successively subjected to the criteria named above.

As the websites were not chosen for institutional affiliation, the following will concentrate on the results of the filter and then group the results according to domains.

2.4.2 Searching using the morbidity terms

Figure 6: Filtering of information providers: morbidity search



Source: Prognos AG

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[7] For this part, dementia and Alzheimer's were treated as two separate morbidities.

Figure 6 shows the results when looking for the disease name.

The yield of websites giving information about both active substances and products is considerably higher than the institutional search: disregarding the quality criteria, **83 websites informed about active substances and 45 sites about pharmaceutical products.**

In total, 56 websites gave information on active substances and fulfilled the criteria. 39 sites gave information on products.

Active substances

The 56 websites fulfilling the active substance criterion belonged to thirteen domains.

Figure 7: providers of information on active substances: morbidity search

Domain	Coronary heart disease	Diabetes Mellitus	COPD	Asthma	Breast cancer	Alzheimer's	Dementia	Rheumatism	Schizophrenia	Osteoporosis	Leukaemia	Migraine	HIV	Cystic fibrosis	Turner Syndrome	Total
www.netdoktor.de	0	2	2	2	1	1	1	1	1	1	2	2	1	1	0	**18**
de.wikipedia.org	1	1	1	1	1	2	1	1	1	1	2	1	2	0	0	**16**
www.onmeda.de	0	0	1	0	0	2	1	1	1	1	1	1	1	1	0	**11**
www.patientenleitlinien.de	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	**2**
www.alzheimerinfo.de	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	**1**
www.aponet.de	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**1**
www.atemwegsliga.de	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	**1**
www.brustkrebs.net	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
www.brustkrebs-info.de	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
www.diabetes-deutschland.de	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	**1**
www.ueberleben-mit-brustkrebs.de	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
www.uni-duesseldorf.de (AWMF)	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	**1**
www.vitanet.de	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	**1**
Total	**2**	**5**	**5**	**3**	**5**	**5**	**6**	**3**	**4**	**3**	**5**	**4**	**4**	**2**	**0**	**56**

Source: Prognos AG

Netdoktor.de, *Wikipedia* and *Onmeda.de* are prominent (Figure 7). In addition to these, only *APONET*, the portal of the German pharmacists' association, and the *AWMF* featured in the institutional search. The other institutions can be grouped as follows:

- www.patientenleitlinien.de: a project of the university in Witten-Herdecke

- www.alzheimerinfo.de: a site run by Merz Pharma

- www.atemwegsliga.de: run by a patient organisation *Deutsche Atemswegsliga e.V.* that did not meet the selection criteria from the institutional search (NAKOS green list)

- www.brustkrebs.net: run by now defunct club *BleibGesund Kampf dem Krebs e.V.*; www.brustkrebs-info.de: run by *Brustkrebs Info e.V.*, which also did not meet the institutional criteria (NAKOS green list)

- www.diabetes-deutschland.de: site maintained by German Diabetes Society at Düsseldorf University.

- www.ueberleben-mit-brustkrebs.de: commercial site run by *Lifeline.de*, a subsidiary of *BSMO*, an internet company belonging to Axel Springer publishers.

- www.vitanet.de: commercial company offering health information belonging to *Kranich Vermögens- und Beteiligungsgesellschaft*, the portfolio company of Hans Werner Hector, a co-founder of software company SAP.

It is interesting to note that

- commercial companies such as *Netdoktor* and *Onmeda* have optimised their websites to be found on Google searches

- State bodies such as *IQWIG* or *Robert-Koch Institute* deliver no hits; they have not implemented a strategy to be found on *Google*

- the morbidities are more evenly represented than in the institutional approach.

27 further sites belonging to 19 domains did not fulfil the quality criteria. As above, the majority of these were not included in the institutional research. Those that did feature in the institutional research include *AkdA*.

Products

The 39 websites on products stemmed from six domains (see Figure 8).

Figure 8: providers of information on products: morbidity search

Domain	**Coronary heart disease**	**Diabetes Mellitus**	**COPD**	**Asthma**	**Breast cancer**	**Alzheimer’s**	**Dementia**	**Rheumatism**	**Schizophrenia**	**Osteoporosis**	**Leukaemia**	**Migraine**	**HIV**	**Cystic fibrosis**	**Turner Syndrome**	**Total**
www.netdoktor.de	0	2	2	2	1	1	1	1	1	1	2	2	1	1	0	**18**
www.onmeda.de	0	0	1	0	0	2	1	1	1	1	1	1	1	1	0	**11**
de.wikipedia.org	0	0	1	0	0	2	0	0	0	1	1	1	0	0	0	**6**
www.patientenleitlinien.de	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	**2**
www.atemwegsliga.de	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	**1**
www.diabetes-deutschland.de	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	**1**
Total	**0**	**3**	**5**	**2**	**1**	**5**	**4**	**2**	**2**	**3**	**4**	**4**	**2**	**2**	**0**	**39**

Source: Prognos AG

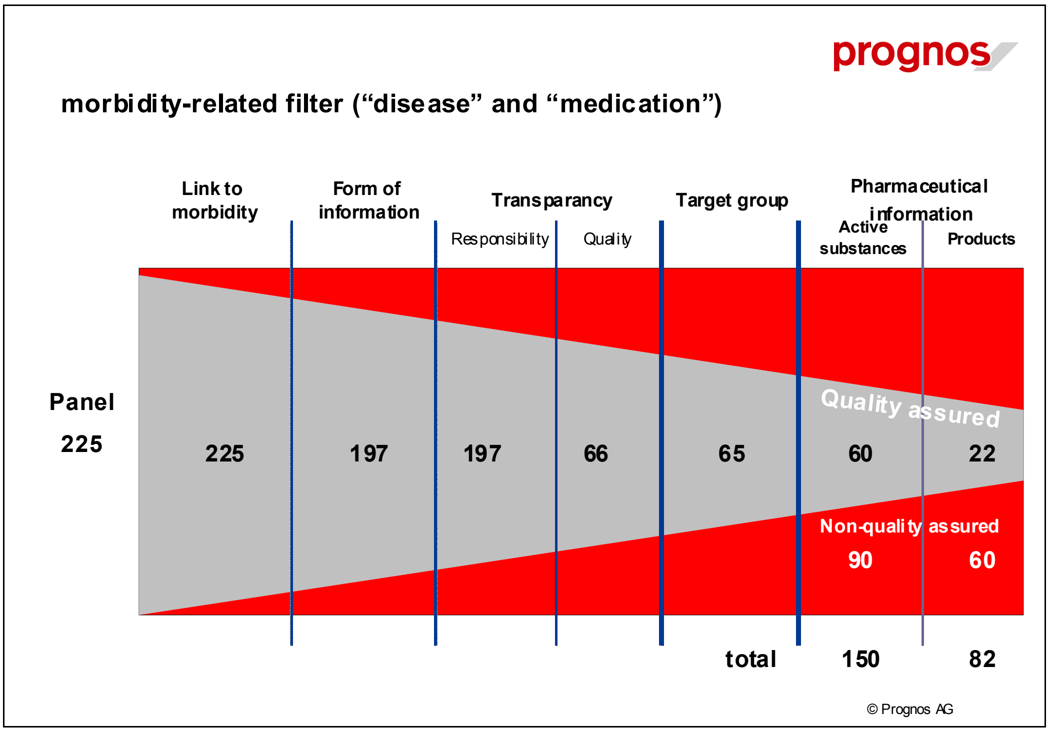
The six domains are identical to those listing information on active substances. Alzheimer’s and COPD are the morbidities listed most often, followed by dementia, leukaemia and migraine. Of the most often listed morbidities, only one (COPD) is a DMP.

An additional six websites belonging to two domains did not fulfil the quality filter. These were *meine-gesundheit.de* and *dr-gumpert.de*. The former is a commercial venture belonging to *Medizinische MedienInformations GmbH*, a subsidiary of *CMPMedica*, a British healthcare media company normally associated with drug information systems, including the *gelbe Liste* in Germany. *dr-gumpert.de* is run by a general practitioner.

2.4.3 Searching using the morbidity and medication

Figure 9 shows the results when looking for the disease name and the term “medication” (*Arzneimittel*).

Figure 9: Filtering of information providers: morbidity search with drugs



Source: Prognos AG

Disregarding the quality criteria increases the number of hits: 150 for active substances and 82 for products, doubling the amount of sites from the first morbidity related search.

The number of websites informing about active substances and meeting all filters was 60, roughly equivalent to the search without the term "medication". The number of sites naming products and meeting all filters fell to 22 (almost 50 percent fewer than the first morbidity related search).

Active substances

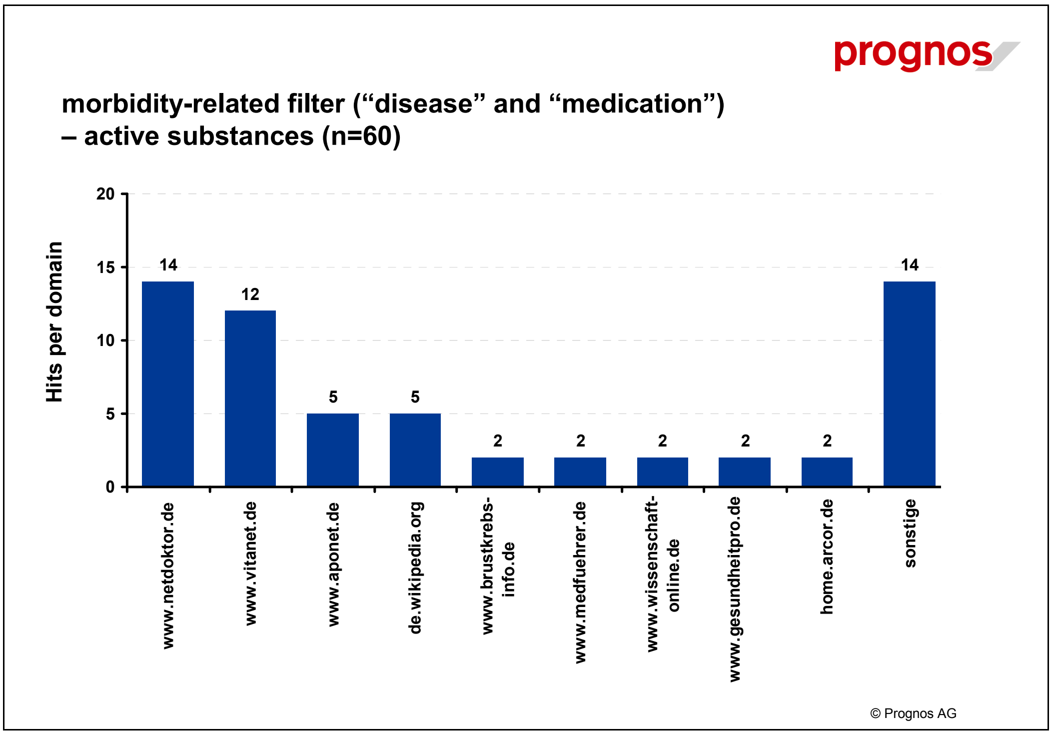
The 60 websites fulfilling the active substance criterion belonged to 23 domains.

The domains with the most hits were again *Netdoktor*, *Aponet* and *Wikipedia*. *Vitanet* is here more prominent than before (see Figure 10). The other sites with more than one hit were:

- www.brustkrebs-info.de (see above)
- www.medführer.de: the website of *Medführer GmbH*, 80 percent of which belongs to *HMC Curator*, the portfolio holding of Thuringian real estate agent Hans Jakob Hemmerich.

- www.wissenschaft-online.de: the website of a subsidiary of *Holtzbrinck* publishers, the *Spektrum der Wissenschaft Verlagsgesellschaft mbH*
- www.gesundheitspro.de: run by *Konradshöhe* publishing group, a medical publisher which publishes the *Apothekenumschau* magazine found at pharmacists.
- Home.arcor.de: these are private websites referring to schizophrenia.

Figure 10: providers of information on active substances: morbidity search



Source: Prognos AG

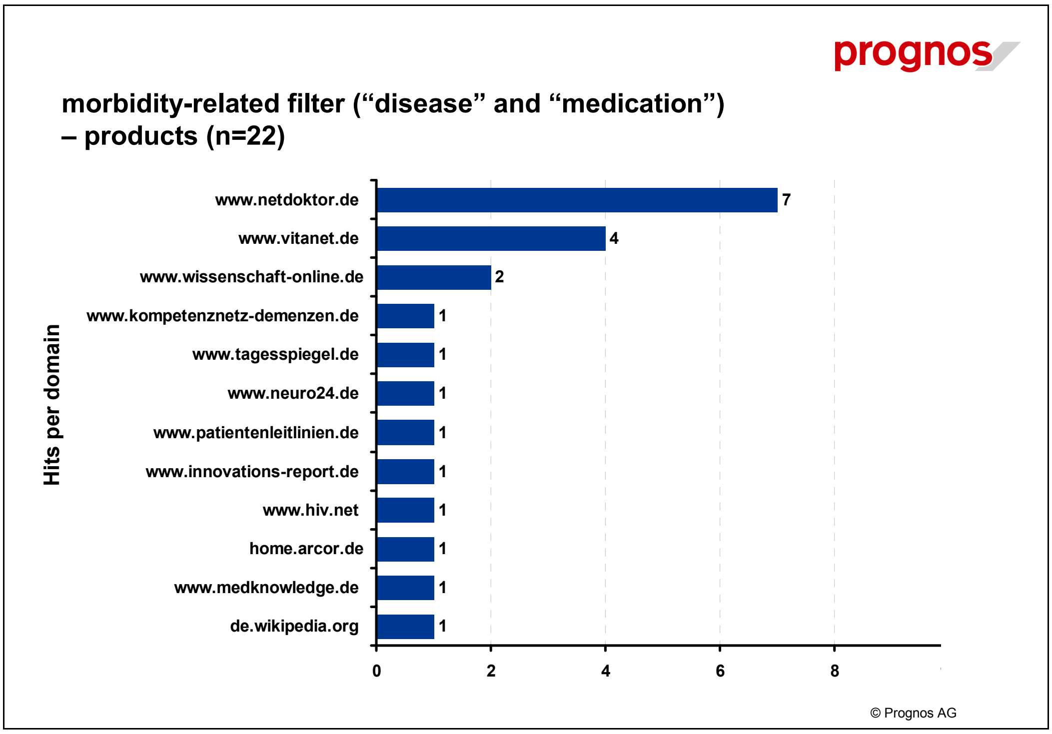
Another 90 sites belonging to 57 domains which gave information on active substances failed mainly at the quality criterion.

Products

Only 22 websites featuring products (out of a total of 82) made it through the filter. These came from twelve domains (see Figure 11).

Most of these also gave information on active substances. Of note is lower number of hits for *Wikipedia*, and the fact that different specialist domains are included, such as *neuro24.de* (homepage of a neurologist) and *hiv.net* (a private website run by a German physician).

Figure 11: providers of information on products: morbidity search



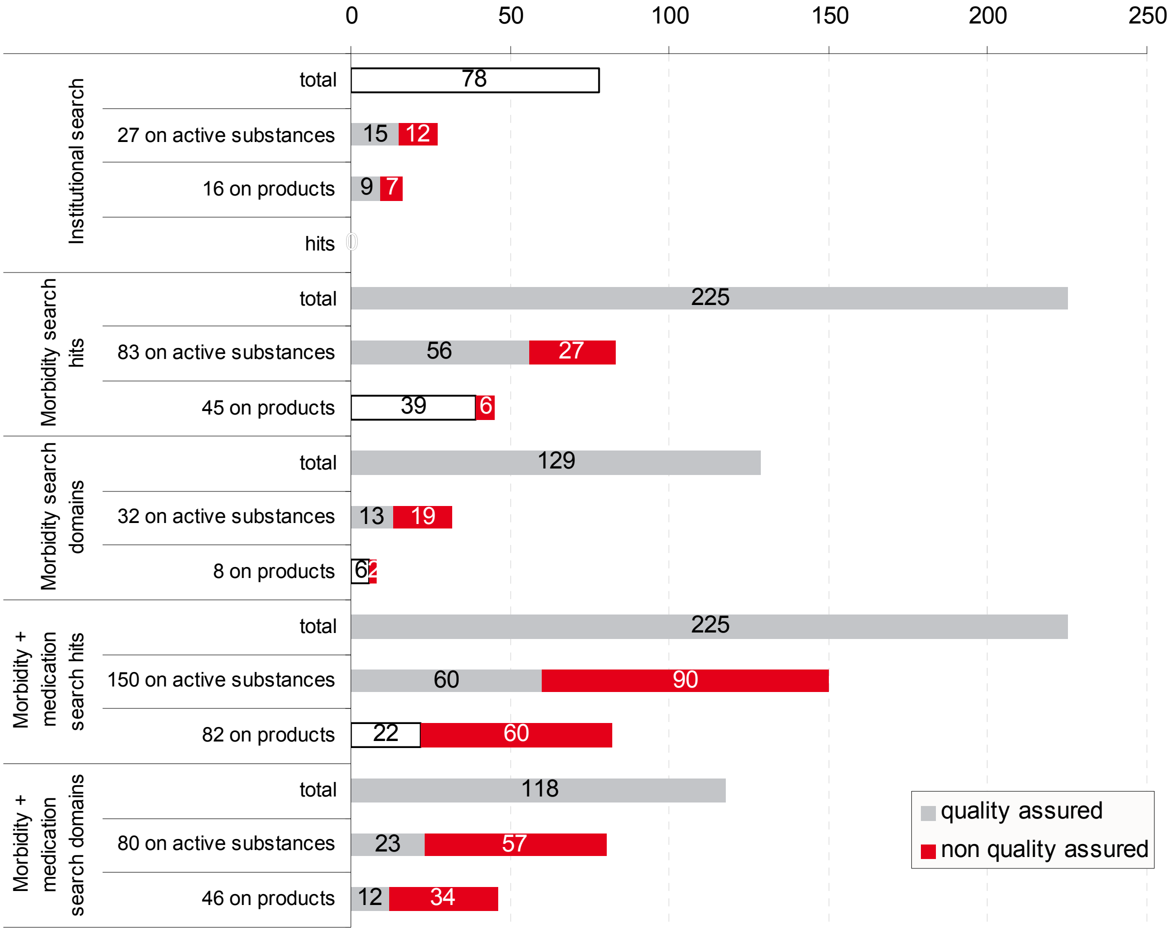
Source: Prognos AG

60 further websites from 34 domains failed the quality criteria. This is an extremely high number, and further demonstrates the heterogeneous pharmaceutical information landscape in Germany. Among these domains is *Testberichte.de* with nine hits, a site run by *producto AG*, which reproduces the reports of the consumers’ association *Stiftung Warentest*. A site with seven hits was *Medvergleich.de*, a site comparing online pharmacists belonging to *Koc Media GmbH*, the company behind many well known price comparison sites in Germany. The remaining domains produced one or two hits.

2.5 Conclusion

The aim of the status quo analysis was to show who supplies information to patients, whether the information available is aimed at patients, who finances the providers and whether the information fulfils quality criteria. For 15 selected morbidities, we took two different approaches. The first was an institutional approach; we defined 78 public and private bodies representing a wide range of interests in health. The second was independent of institutions; instead, we performed two sets of Google searches with different search terms and analysed the top 15 hits for each morbidity. By doing this, we achieved a comprehensive overview of patient information available for the selected morbidities. We did not differentiatie between Rx and OTC, but assumed an Rx bias due to the morbidities chosen. In each approach, we used ÄZQ criteria to identify sites with quality assured information on both active substances and products.

Figure 12: results at a glance



Source: Prognos AG

- 78 institutions were analysed. 27 provided information of active substances, of which 15 were quality assured. 16 informed about products, of which met the criteria. This is a quality quota of 56 percent.

- The first Google search concentrated on the name of the morbidity as search term and yielded 225 results belonging to 129 domains. 83 of these sites (on 32 domains) informed about active substances. For products the figure was 45 (eight domains). The majority of sites giving pharmaceutical information were quality-assured: 67 percent for substances and 87 percent for products. For the domains, the figures sink: 41 percent for substances and 75 percent for products. This is due to a number of more prominent domains having more hits.

- The second Google search was widened to include the word “medication” (*Arzneimittel*) beside the word for the morbidity. This yielded 225 sites on 118 domains. Here, the number of hits and domains increased greatly. 150 of these sites (on 80 domains) informed about active substances, for products the figure was 82 (46 domains). The percentage of quality-assured sites and domains was substantially lower than in the search for the morbidity name. Only 40 percent of the sites informing about substances and 27 percent about products were quality assured. For the domains, only 29 percent informing on substances and 26 percent on products fulfilled our criteria.

This demonstrates the following: **up to 74 percent of the results of a simple search consisting of the words “disease” and “medication” failed basic quality tests. The more specific the search, the greater the number of information providers and the greater the probability of being confronted with non quality-assured information** from a wide range of sources. This does not mean that the information is necessarily incorrect; just that it did not meet our quality criteria.

This presents a very heterogeneous picture of information on pharmaceutical products in Germany. Statutory bodies rarely feature on the direct search. Instead, commercial providers (usually publishing houses or other companies backed by private equity) and morbidity-related patient groups are pre-eminent.

Against this background, the question arises as to which approach is correct. Do patients turn to certain institutions for pharmaceutical information, or do they search independently of institutions? How do they act when confronted with this heterogeneous picture and what strategies do they employ when informing themselves about pharmaceutical substances and products?

3 Criteria for determining patients' needs

In the preceding chapter, we analysed the structure of pharmaceutical information for patients in Germany. We concluded that the information available falls short of quality standards. The status quo analysis did not however answer the question as to patients needs, whether they are satisfied with the status quo, and where they might see room for improvement.

To establish the criteria for patients' needs, group discussions (**focus groups**) were carried out. In the focus groups, patients and next-of-kin with one of the 15 morbidities who use the internet to inform themselves about their own or their loved one's illnesses discussed what information they look for, how they access it and what they use it for. They further discussed scenarios for future development.

The objective of the focus groups was to collect arguments and viewpoints from a patient perspective. The groups were facilitated openly yet objectively. The manual formed the basis for the structure and facilitation of groups. Due to this, further relevant points for PhRMA not uncovered in the status quo analysis could be included.

3.1 Choosing the participants

To achieve the objective of obtaining experience-based opinions on information on pharmaceutical products, the following selection criteria were drawn up:

- between 18 und 65 years old
- affected by one the morbidities used in the structural analysis, either as a patient or as next-of-kin
- regular internet users
- use of the internet to inform themselves about their own or their next-of-kin's condition.

Three groups met. Each group consisted of 10 persons and lasted three hours.

3.2 Sources of information, research experience and quality assessment

The first half of the discussions was aimed at gaining information on the following subjects:

- **sources of information and informational needs**: This part dealt with the sources used when looking for information on Rx medication and what sort of information was required. In addition, different medications and new pharmaceutical developments were discussed. As a result we were able to collate information on the sources used, the rôle played by the information providers, whether the patients researched Rx medication and also what their expectations regarding pharmaceutical information were.

- **Experience gained in research**: The aim here was to identify gaps and deficits by discussing how patients felt about the research for relevant information and also how satisfied they were with the experience and the results. As well as identifying their experiences, we were able to judge whether the information was helpful and also identify the strategies patients employ when looking for information. In addition, we could identify what patients did with the information.

- **Quality of the information**: In this part we discussed the quality and trustworthiness of information. Again, we discussed whether the information providers play a rôle in establishing trustworthiness and what constitutes trustworthiness from a patient perspective.

Although the participants used many information sources, the internet was the most important. They typically would gather information from many sites via a Google search and compare these. Sites were deemed good if they were clear and comprehensible. Industry sites were used only occasionally. This has to do with the search strategies: patients and their next-of-kin look for information about medication via diagnoses and morbidity. Participants noted that industry websites were not returned on their Google searches; this corresponds to the results of the status quo analysis. It is also an indicator that patients' research behaviour corresponds to the morbidity related approach presumed above.

Different medication to that already prescribed was not normally a priority for the participants. One notable exception was intolerance; in this case alternatives were sought, often in internet forums. New developments were especially interesting for those participants with rarer conditions.

The patients maintained – with the exception of sufferers of rarer conditions – that they found the information they require on the internet. Due to the amount of information on offer, however, the research is considered time-consuming. For this reason, clearly structured portals such as *Netdoktor* or *Wikipedia* were preferred. The incomprehensible medical language found on many sites was criticised. In general, the participants mistrusted individual information; information becomes credible if the same content appears in a number of sources. Patients and family members therefore compare information and draw their own conclusions on the trustworthiness of the information. On the whole, information was reliable if a source was named and the text was recent. Neutrality and independence were named as important, but become less significant in view of the plausibility strategy of comparing information.

Doctors were the main source of information about medication. Individual pharma companies were seen by some participants as biased. However, others doubted whether companies could afford to be anything but correct; the threat of litigation was presumed as a self-regulator. Patient organisations were seen as being most reliable, especially umbrella organisations.

Patients gather information to gain a better understanding of illness and to be certain what they are doing is correct. Some patients noted that they have used information found on the internet in discussions with their doctors. Others however feared a negative reaction.

3.3 Scenarios: predicting patient reaction

In the second part of the discussions, three scenarios for future use were discussed with the groups. These centred on a fictitious pharmaceutical company specialising in diabetes. The objective was to build on the insight gained in the first half of the groups and obtain indications for the acceptance and potential use of information provided by the pharma industry.

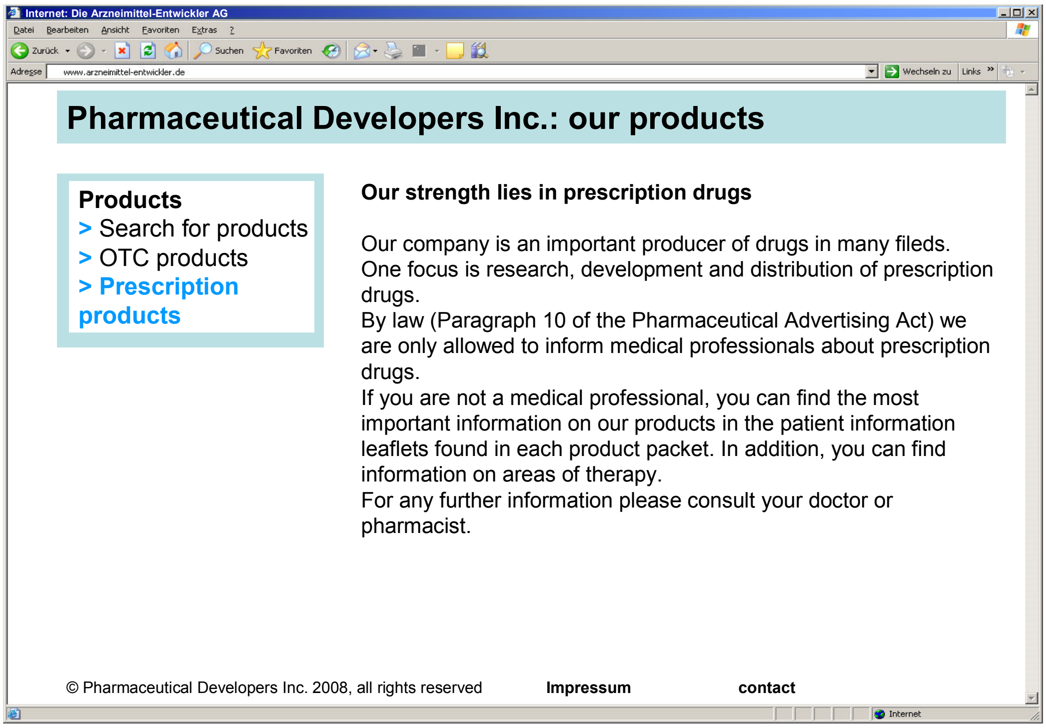
- Scenario I corresponded to the status quo and gave no information on Rx drugs.
- Scenario II corresponded to a patient-friendly version of a patient information leaflet on the internet with medical terms explained in plain German.
- Scenario III offered additional information of research results.

Scenario I: The following text was shown to the groups[8]:

---

[8] The original text in German read: „***Unser Schwerpunkt liegt auf rezeptpflichtigen Arzneimitteln:*** Unser Unternehmen ist ein wichtiger Hersteller von Arzneimitteln für viele wichtige Therapiegebiete. Ein Schwerpunkt liegt dabei auf der Erforschung, der Entwicklung und dem Vertrieb rezeptpflichtiger Arzneimittel. Informationen über rezeptpflichtige Arzneimittel dürfen wir gem. §10 HWG ausschließlich medizinischen Fachkreisen zur Verfügung stellen. Gehören Sie nicht zur Gruppe der med. Fachkreise, finden Sie die wichtigsten Informationen zu den Produkten in den Gebrauchinformationen, die Sie in jeder Produktverpackung als so genannte "Packungsbeilage" finden. Sie können sich zudem über die Therapiegebiete informieren. Für weiterführende Informationen zu verschreibungspflichtigen Arzneimitteln wenden Sie sich bitte an Ihren Arzt oder Apotheker." This is a slight modification of the text found on Pfizer's website: http://www.pfizer.de/produkte/rezeptpflichtige-produkte.htm; retrieved 1 July 2008

Figure 13: Scenario I



Pharmaceutical Developers Inc.: our products

Products
> Search for products
> OTC products
> **Prescription products**

Our strength lies in prescription drugs

Our company is an important producer of drugs in many fileds.
One focus is research, development and distribution of prescription drugs.
By law (Paragraph 10 of the Pharmaceutical Advertising Act) we are only allowed to inform medical professionals about prescription drugs.
If you are not a medical professional, you can find the most important information on our products in the patient information leaflets found in each product packet. In addition, you can find information on areas of therapy.
For any further information please consult your doctor or pharmacist.

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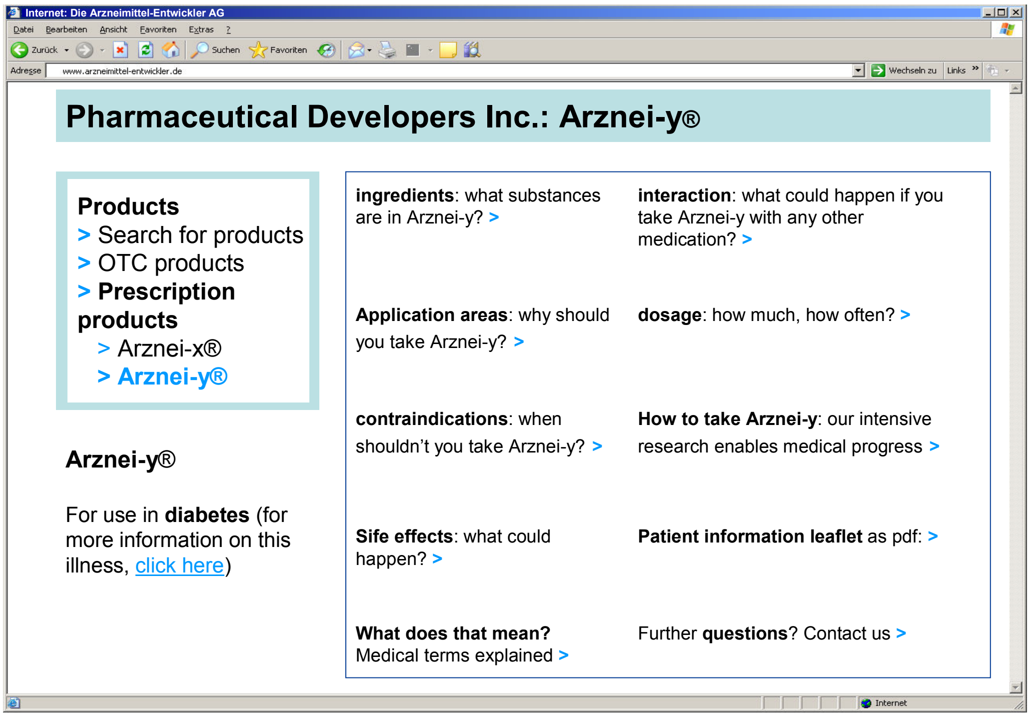
Source: Prognos AG

The participants were puzzled, if not angered by the text. Only a few participants expressed any understanding for the legal situation. Some participants felt the “doc-check” was intended to conceal information from patients: “Should patients be left in the dark about side-effects?” Others complained of disenfranchisement or found the text patronising; they were better informed than in the past and able to evaluate information themselves.

Most participants were ignorant of the legal situation; they presumed it was industry strategy not to inform them.

Scenario II consisted of the following mock-website:

Figure 14: Scenario II



Pharmaceutical Developers Inc.: Arznei-y®

Products
\> Search for products
\> OTC products
\> **Prescription products**
  \> Arznei-x®
  \> **Arznei-y®**

Arznei-y®

For use in **diabetes** (for more information on this illness, click here)

ingredients: what substances are in Arznei-y? >

interaction: what could happen if you take Arznei-y with any other medication? >

Application areas: why should you take Arznei-y? >

dosage: how much, how often? >

contraindications: when shouldn't you take Arznei-y? >

How to take Arznei-y: our intensive research enables medical progress >

Sife effects: what could happen? >

Patient information leaflet as pdf: >

What does that mean?
Medical terms explained >

Further **questions**? Contact us >

Source: Prognos AG

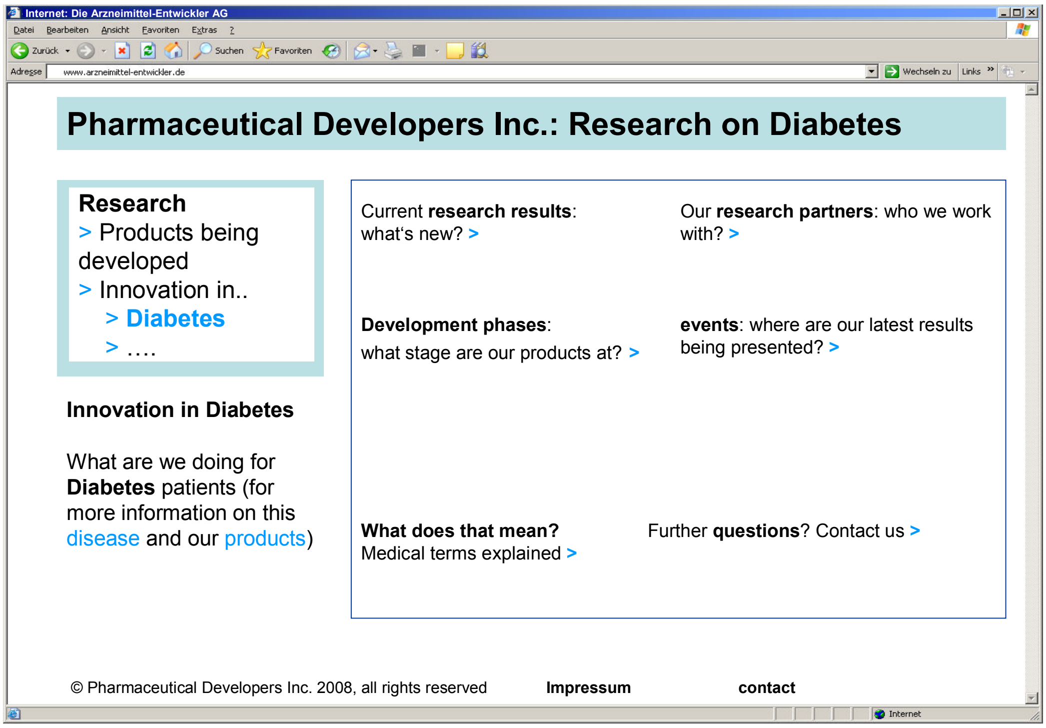
The scenario represents an interactive patient information leaflet. This was seen as facilitating comprehension. A downloadable version in large print was welcomed as being useful for those not able to read small print. Especially the explanation of medical terms was seen positively. Many participants expressed a desire for further information about the disease, e. g. by an internal link or links to other sites or to patient organisations.

Participants welcomed the scenario and stated they could imagine using industry sites as a supplementary source of information.

Scenario III built on the results of Scenario II and offered additional information on research results (Figure 15). This was also welcomed by the participants, many of whom could imagine using and profiting from this information. The pharma industry was deemed competent in this area. Especially the latest research results and the announcement of new products and substances were considered interesting. However, many participants thought that the competition between pharma companies meant this was an area of information the industry would be unwilling to share.

Some participants doubted whether companies would be entirely honest about research results. For this reason, standards were needed for the quality of the information given. Any information should be put into the context of the disease to make a comparison between sites easier.

Figure 15: Scenario III



Pharmaceutical Developers Inc.: Research on Diabetes

Research
\> Products being developed
\> Innovation in..
\> **Diabetes**
\> ….

Innovation in Diabetes

What are we doing for **Diabetes** patients (for more information on this disease and our products)

Current **research results**: what's new? >

Our **research partners**: who we work with? >

Development phases: what stage are our products at? >

events: where are our latest results being presented? >

What does that mean? Medical terms explained >

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Source: Prognos AG

3.4 Conclusions drawn from the focus groups

We can deduce the following criteria for the acceptance of industry information from the focus groups. Information should be

- Comprehensive (in context)
- Serious (sources)
- Comprehensible (explanation of medical terms)
- Up-to-date (research results etc.)
- Comfortable (interactive, service oriented)

In total, the results enabled us to draw up a number of hypotheses for a representative survey carried out in August 2008. These were:

- Some patient groups can be regarded as being highly competent in the use of media and information. Information should be clear and comprehensible. The credibility of information does not flow from individual providers, but rests on the comparison of different sites.

- The information is used in consultations with doctors, whose job it is to undertake the final categorisation and evaluation of any information. Doctors thus play a central rôle in patient information management

- Patients are unaware of legal limitations on manufacturers. The legal limitation on manufacturers from informing patients is seen as annoying and antiquated.

- There are no particular misgivings or doubts among patients towards industry information. Information provided by the industry would be used by many patients as one source among many.

- The industry is seen as being especially competent in the area of research.

4 What do patients want in regard to pharmaceutical information?

4.1 Basics of the online survey

The criteria formed the base a representative survey of approx. 1,000 members of the general public and also approx. 1,000 patients and next-of-kin. The questionnaire is in the appendix.

The survey was carried out in August 2008 and comprised two panels. One panel (n=1,013) was representative for 18 to 65 year old internet users. A second panel (n=1,202) was made up entirely of people suffering from an illness or people an ill next-of-kin.

The survey was carried out online by Innofact AG. An online survey was chosen over survey by telephone because:

- The study concentrates on information provided on the internet. The best way of reaching internet users is online.
- We could draw on a panel of approx. 400,000 participants, the largest such panel in Germany.
- Fewer participants drop out. Surveys can be completed in participants' own time (including work time, meaning the working population is reached).
- Participants give authentic answers without pressure from both interviewer and interviewee to round up.

Internet usage in Germany stands at 72 percent. In 2007, 19 percent of the population did not plan to the use the internet regularly. However, in 2002, this figure stood far higher at 40 percent.[9] Usage by the under 40s in 2008 stands at nearly 90 percent, for the 40 to 50 year olds at 78 percent, for the 50 to 60 year olds at 64 percent and for the over 60 to 70 year olds at 42 percent. Over 50 percent of men in the latter group are already regular internet users.[10] Increasingly, therefore, there is no difference between general representativity and internet representativity.

The survey consisted of two parts. The first part was answered by the patient and next-of-kin sample and aimed at discovering how this group inform themselves on illness and medication. The questions

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[9] Source: Allensbacher Computer- und Technik-Analysen, ACTA 1998 bis ACTA 2007

[10] Source: (N)Onliner Atlas 2008, a study of Initiative D21, carried out by TNS Infratest.

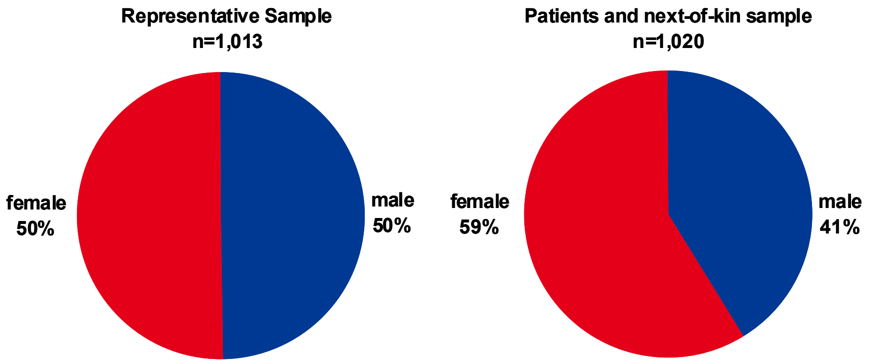
revolved around the sort of information they look for, what is important to them and what they do with the information.

The second part was answered by both the patient and next-of-kin sample and by the representative sample. The questions here focussed on whether the respondents could imagine using additional sources for pharmaceutical information and what added value can be gained from these sources.

4.2 Sample composition

The representative sample was made up of 1,013 persons, the sample of patients and next-of-kin of 1,020 persons.

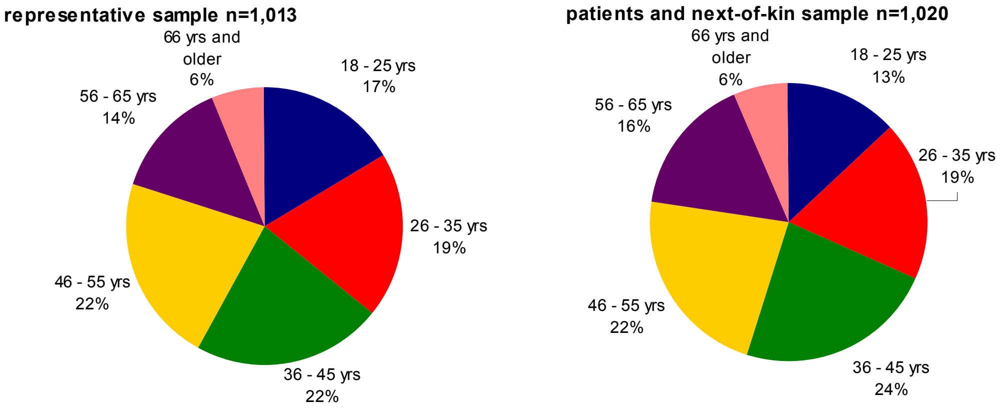
Figure 16: Composition of survey: gender



Source: Prognos AG

In the representative sample, gender was divided equally (Figure 16). The patients and next-of-kin samples however consisted of 59 percent females and 41 percent males.

Figure 17: Composition of survey: age



Source: Prognos AG

The age distribution is shown in Figure 17. The patient and next-of-kin sample differs only from the representative sample in that it – understandably – contains fewer younger people.

Figure 18 shows how the respondents were affected by illness. In the patients and next-of-kin sample, 65 percent suffered from a continual or continually recurring illness that had to be treated with Rx medication. 35 percent were next-of-kin. In the representative sample, 45 percent said they themselves suffered from a continual or continually recurring illness that had to be treated with Rx medication. This high figure reflects the wording of the question; it was not limited to chronic ailments. According to a study carried out by *TNS* for the *BKK* heath insurance fund, 79 percent of Germans went to see a doctor in the past year.[11] A study in 2000 showed that every second visit to a doctor results in a prescription,[12] and a study by *Infas* for *ABDA* published on 30 August 2008 stated that 40 percent of Germans regularly take Rx drugs.[13] This makes the result here credible and also underlines the relevance of the subject for the public at large.

Figure 19 shows the illnesses of the patients and next-of-kin sample. 44 percent of those who themselves were ill and used the internet for information on the illness had one of the morbidities selected for the structural analysis. Asthma, diabetes, migraine and rheumatism were named most often.

Of the other diagnoses named, high blood pressure, thyroid and back problems dominated.

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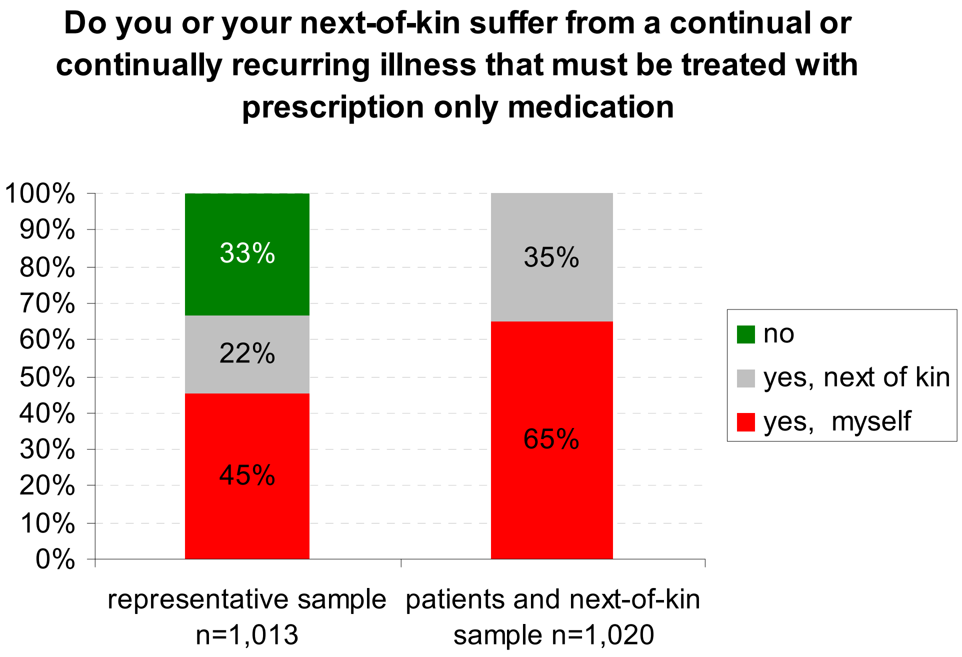
[11] Bevölkerungsumfrage BKK 2008, http://www.bkk.de/ps/tools/download.php?file=/bkk/psfile/downloaddatei/31/BKK_Arztbe4864c7397d2d2.pdf&name=BKK_Arztbesuchumfrage_200608.pdf&id=1444&nodeid=1444, retrieved on 15 August 2008

[12] Ferber, Liselotte von: Arzneimittelverordnungen: Patienten erwarten nicht immer ein Rezept, in: Deutsches Ärzteblatt 2000; 97(26): A-1794 / B-1518 / C-1416

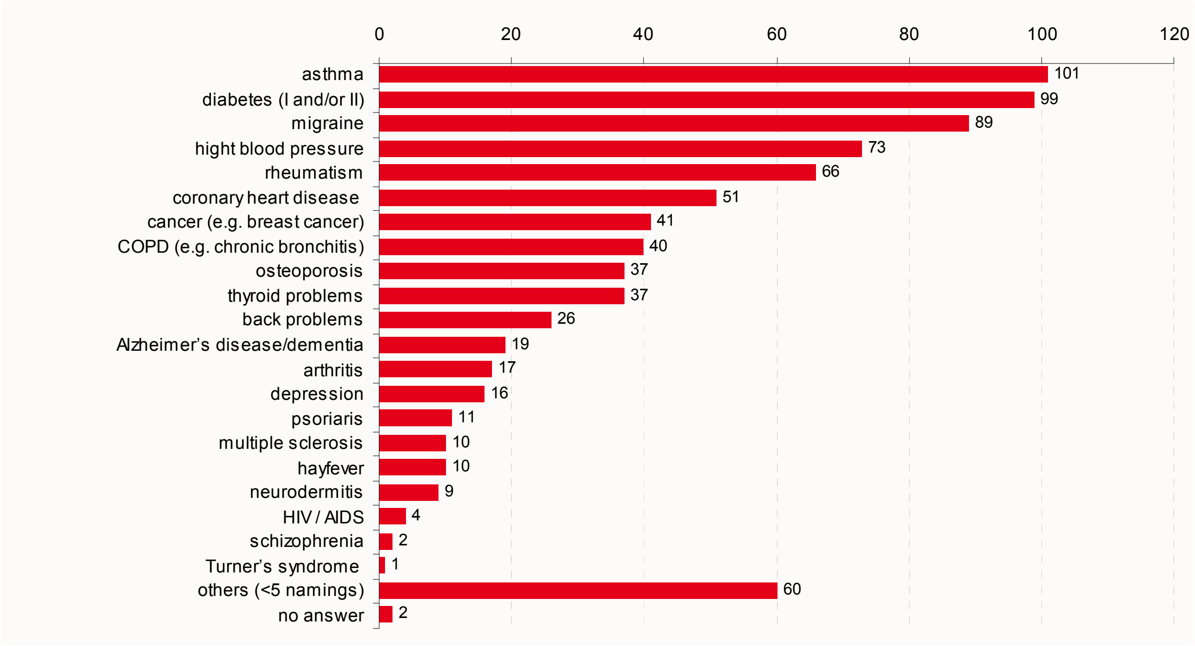
[13] http://www.presseportal.de/pm/7002/1255998/abda_bundesvgg_dt_apothekerverbaende

Figure 18: Composition of survey: affectedness of respondents



Source: Prognos AG

Figure 19: Composition of survey: diagnoses



Source: Prognos AG

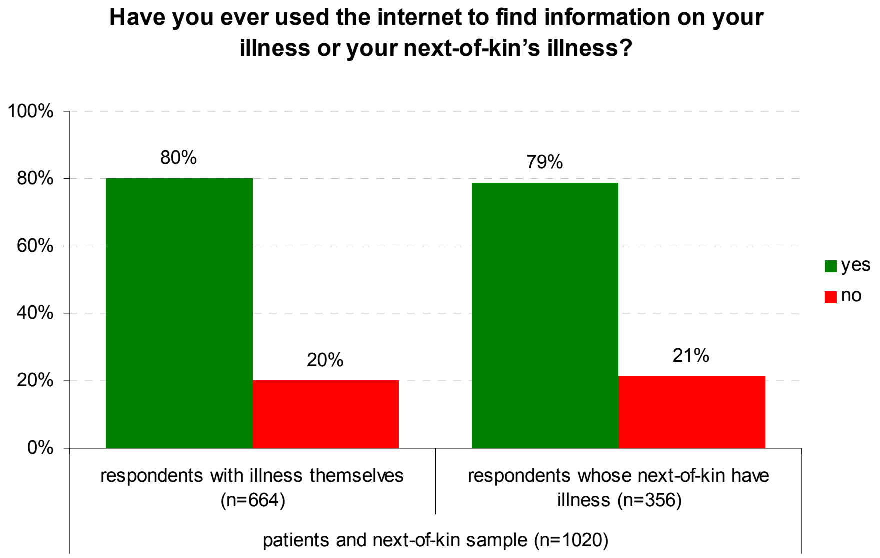
4.3 Results of the survey

4.3.1 Patients compare information from various sources but see room for qualitative improvement

The first hypothesis to be tested was: *"Some patient groups can be regarded as being highly competent in the use of media and information. Information should be clear and comprehensible. The credibility of information does not flow from individual providers, but rests on the comparison of different sites."*

Although media and information competence can be presumed from internet users, our aim was to determine whether patients were highly competent in information use, highly competent being defined through the application of plausibility checks when using information.

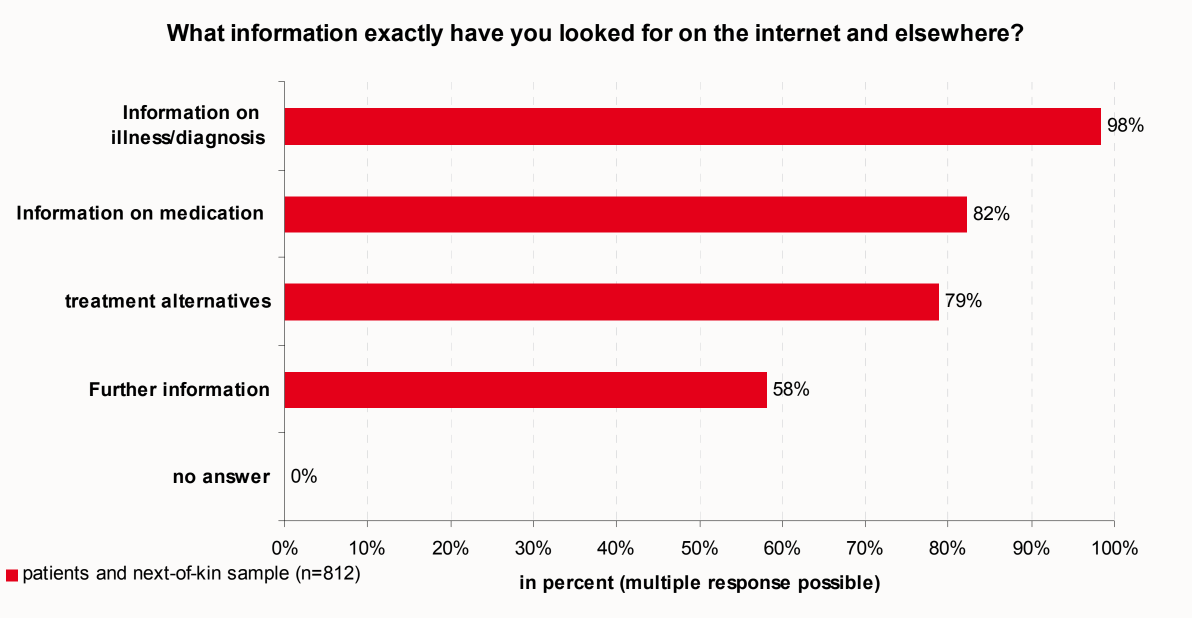
Figure 20: use of internet for illness-related information



Source: Prognos AG

The patient and next-of kin sample was asked if they have ever used the internet to find information on their illness or in their next-of-kin's illness (Figure 20). 80 percent of those with an illness themselves and 79 percent of those whose next-of-kin were ill replied that they used the internet to find relevant information. **The internet is therefore an accepted medium for patient information.** The respondents who answered yes proceeded to the next questions.

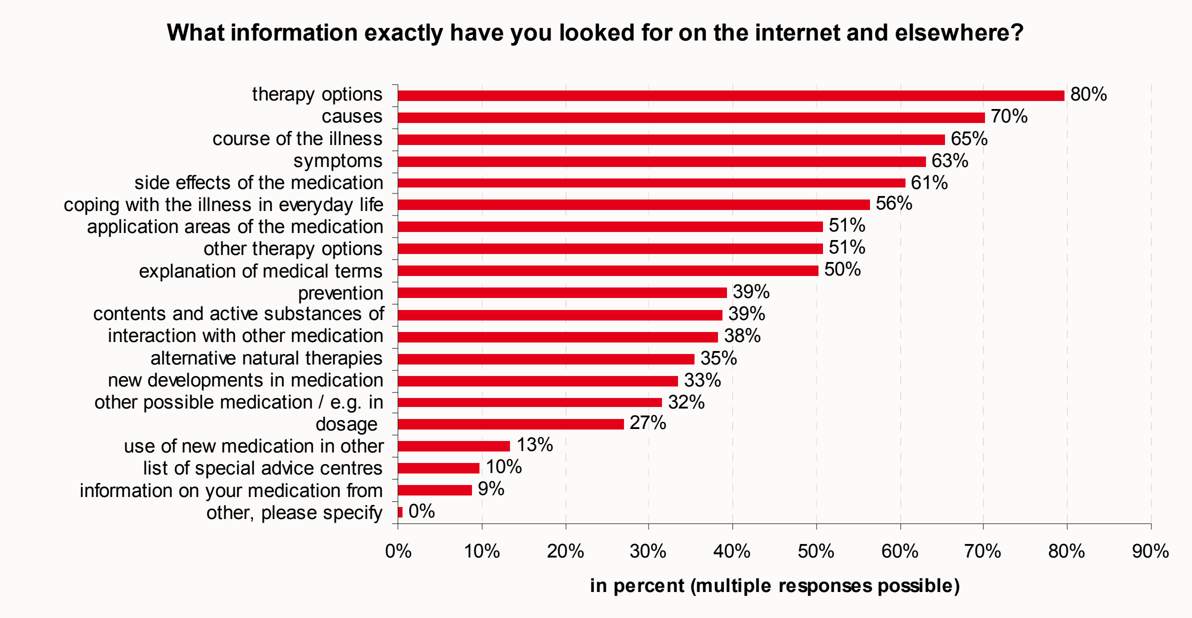
Figure 21: types of information



Source: Prognos AG

Illness or diagnosis is the key for patients and next-of-kin when looking for information; 98 percent have researched this. **A full 82 percent of patients and next-of-kin have already researched information on medication**, more than look for treatment alternatives (Figure 21).

Figure 22: types of information - details



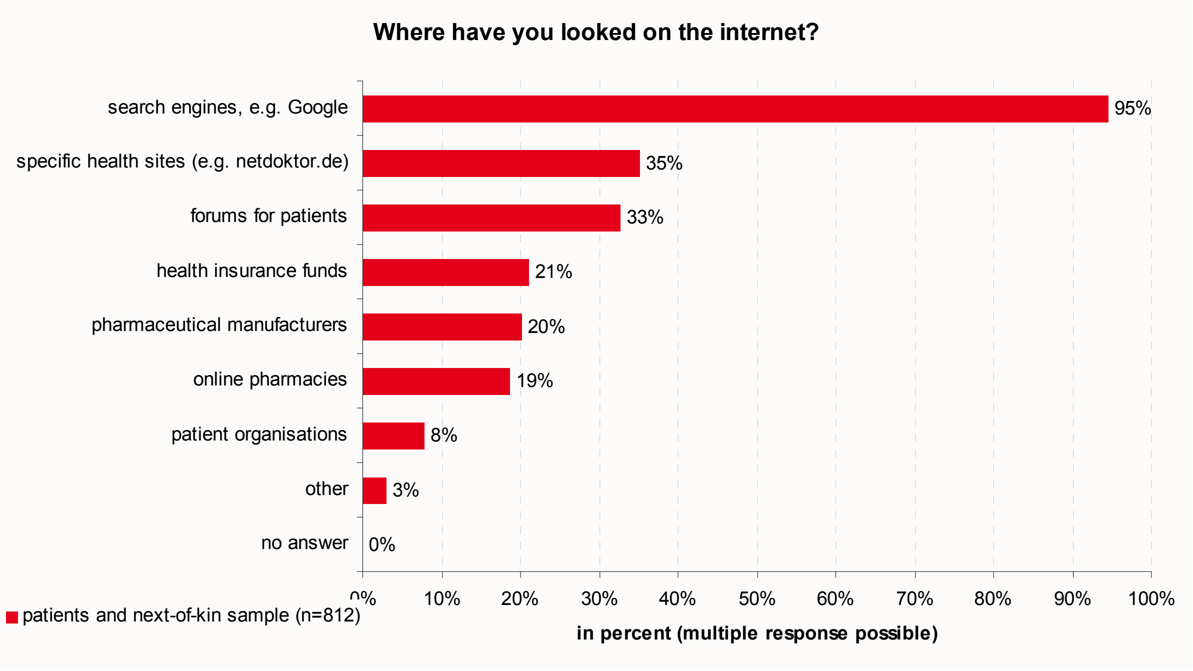
Source: Prognos AG

An analysis of the individual items which are most often researched shows that therapy options is the top choice with 80 percent, followed by causes of illness (70 percent), course of the illness (65 percent), symptoms (63 percent) and side effects (61 percent) (see Figure 22). Of the 82 percent of respondents who selected medical information, side effects were the second most-researched subject. **The choice of therapy options as the top choice shows that patients and next-of-kin want information on medication.**

95 percent of respondents named search engines as the place where they looked on the internet for their information (Figure 23). Other sites were also used, but by far fewer people: the next top namings were specific health sites at 35 percent, discussion forums at 33 percent, health insurance funds at 21 percent and pharma companies at 20 percent. **Search engines guide patients and their families through the internet.** This shows that patients do not aim for any one particular site; they are presented with options and use these to inform themselves.

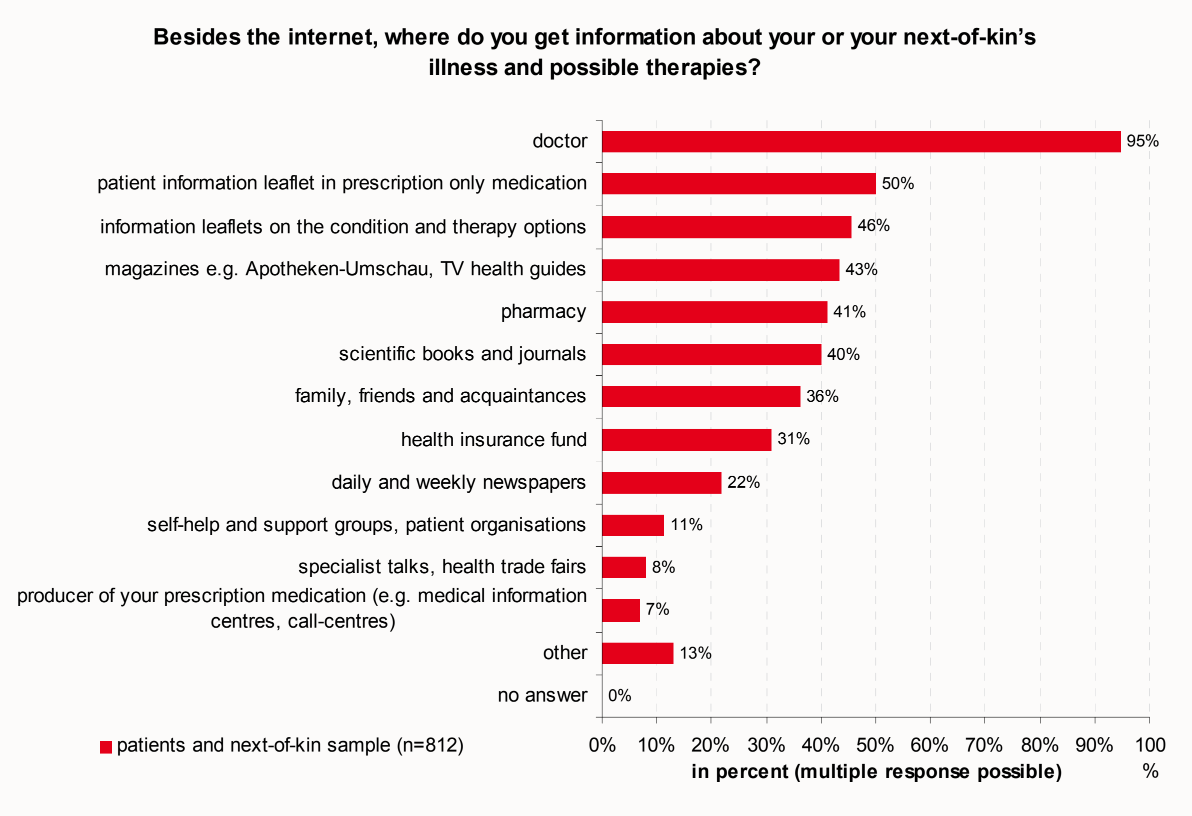
This behaviour reflects how patients act when informing themselves beyond the internet. **At 95 percent, doctors are clearly the main source of information** (Figure 24)**.** Patients complement the medical information given by the doctor by consulting a wide array of sources. 50 percent read patient information leaflets, 46 percent other information leaflets, 43 percent popular magazines and 40 percent ask their pharmacist. Thus **patients form their opinions from a wide range of sources.**

Figure 23: sources of internet information



Source: Prognos AG

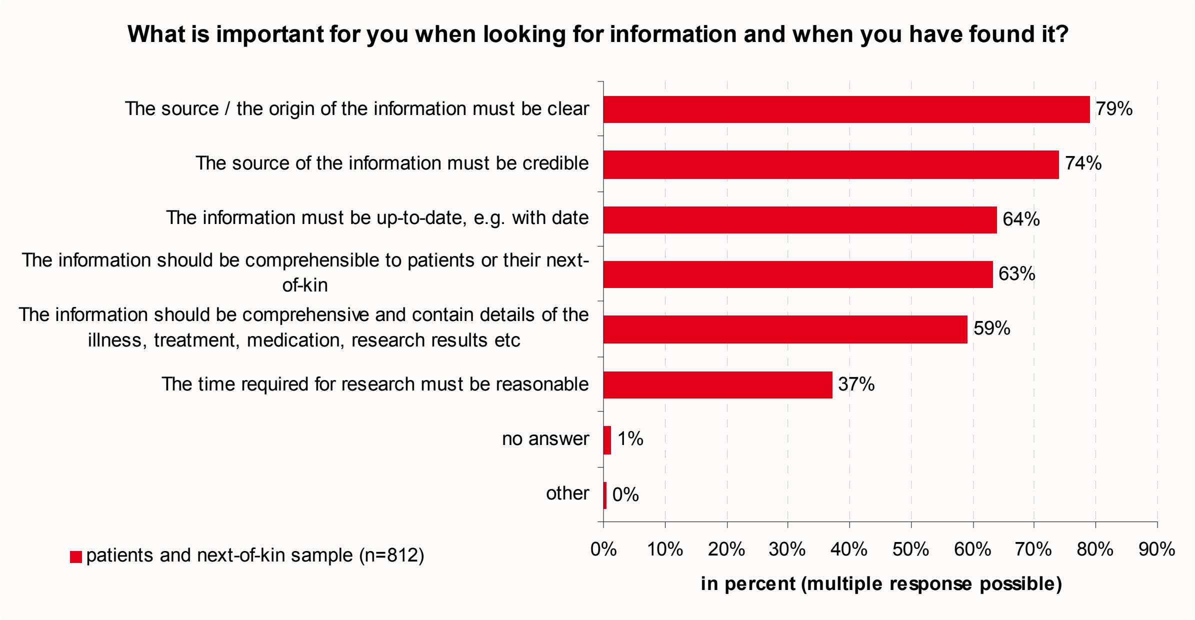
Figure 24: sources besides the internet



Source: Prognos AG

Information strategies found in the "real world" are therefore transferred to the internet: patients and their families collect information from different sources. But what do patients make of the information?

Figure 25: quality of information



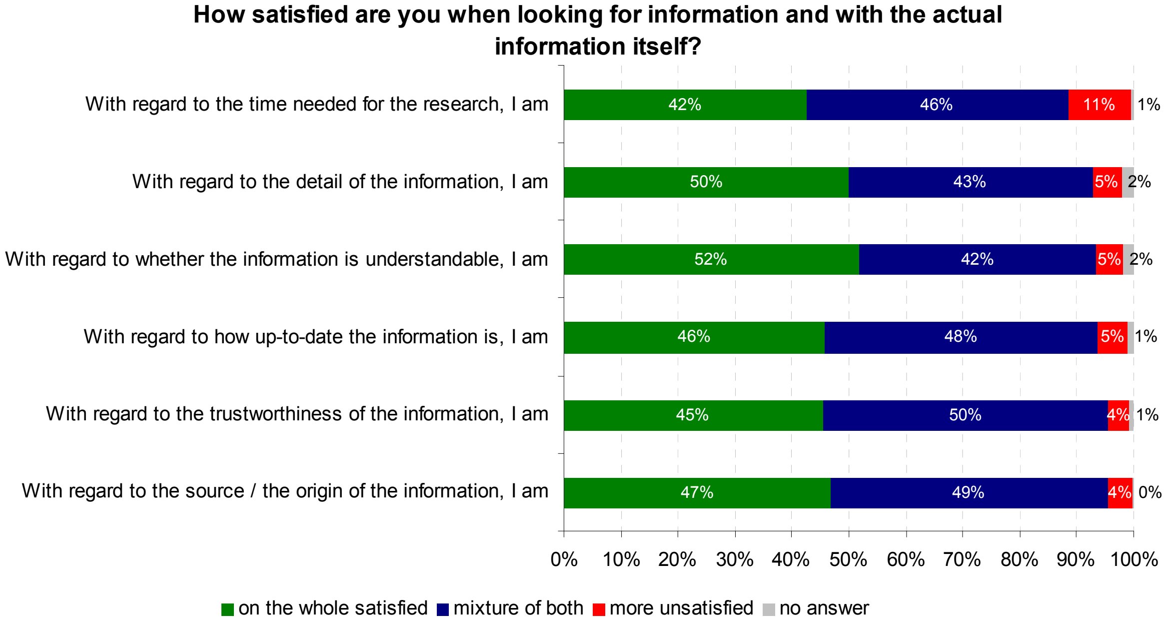
Source: Prognos AG

Paramount for patients and their families is transparency: they want to know the source of the information and they want the source to be trustworthy (Figure 25). These two options scored over 70 percent. Well over 50 percent of respondents stated it is also important that the information be up-to-date, understandable and comprehensive (meaning placed in context). Less importance was attached to the time required for research. 37 percent thought the time required to find information must be reasonable; a majority is prepared to invest time to find the right information for them.

This shows the **patients and next-of-kin perform critical checks on the information** they find. In combination with the comparison of sources established here, it suggests they do not trust any one source blindly. As a result, they are **highly competent** information consumers.

This is one reason why patients and their families are critical of the quality of the information they find (Figure 26). A majority is not entirely satisfied with the transparency of the information, with its trustworthiness, with how up-to-date it is or with time needed to find it. When combined with the importance of these factors (see Figure 25), transparency, trustworthiness and the age of the information become all the more important.

Figure 26: satisfaction with quality of information



Source: Prognos AG

The hypothesis is correct: **Patients are highly competent information users. They value information that is clear and comprehensible. They want trustworthy sources, but decide themselves whether information is trustworthy by comparing information they find from different sources.**

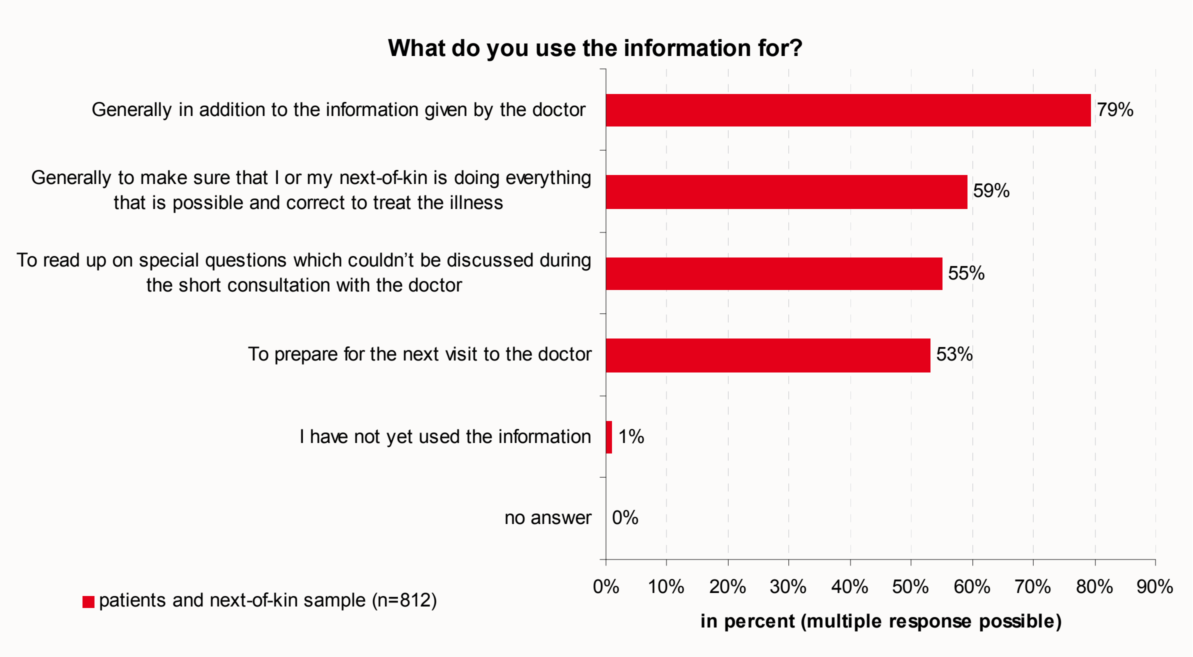
This finding is important when deciding which approach to patient information should be taken by regulators. Patients and next-and-kin do not look for information via institutions, but via the illness. In the structural analysis, the quality of information varied greatly depending on the approach taken. Of the sites returned by the search terms “morbidity” and “medication”, up to 74 percent failed our quality criteria. This is detected by patients and next-and-kin, who are not satisfied with the information on offer.

4.3.2 Doctors are the first port of call and support patients in the use of information

After establishing that patients and next-of-kin use different sources to find information and see room for improvement in the quality of the information, the question arises as to what they do with the information? The hypothesis was: *“The information is used in consultations with doctors, whose job it is to undertake the final categorisation and evaluation of any in-formation. Doctors thus play a central rôle in patient information management”*

Figure 27 shows how patients use the information they find. 79 percent state they use it in addition to the information given by the doctor. Here again, the central rôle of doctors is underlined. Selfinformation also reassures patients and their families: 59 percent use it to make sure they are doing their utmost in treating the illness. Another function is gain further insight which cannot be attained during short doctors' appointments (55 percent). It is however remarkable that **53 percent of patients and next-of-kin use the information to prepare their next visit to the doctor**. **This shows a majority of patients are pro-active, responsible users of information**. Only 1 percent of respondents stated they did not use the information.

Figure 27: use of information

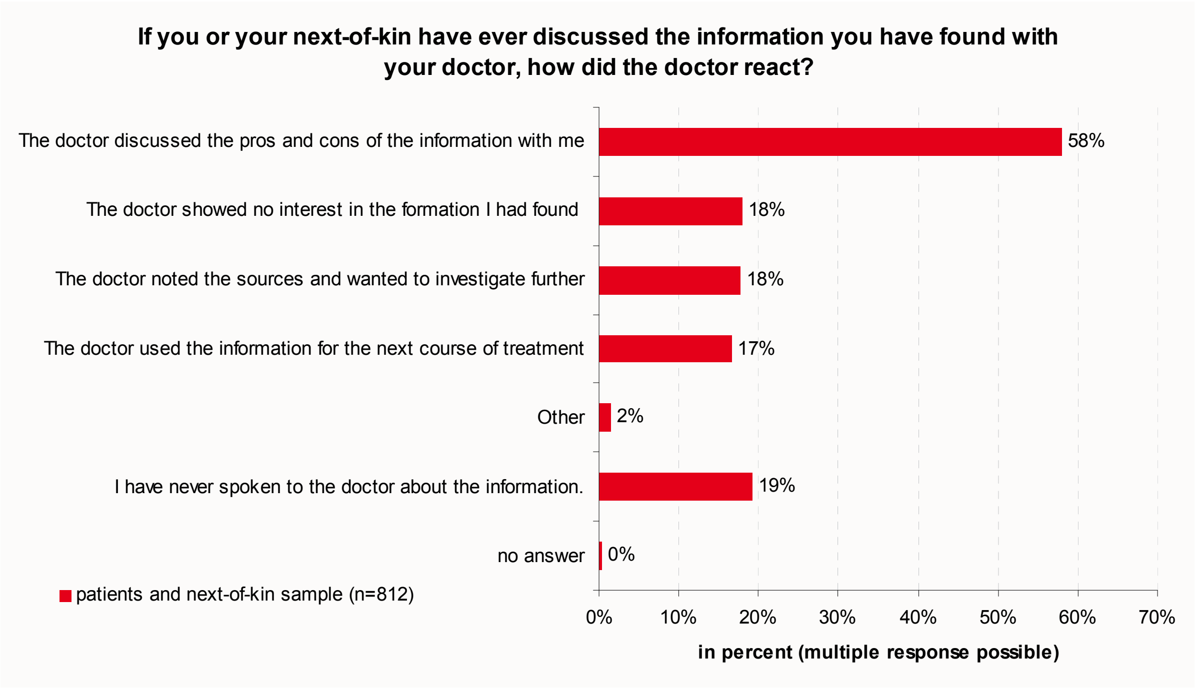


Source: Prognos AG

How do doctors react to proactive, responsible patients who come to their surgeries armed with information? The survey shows that only 19 percent of patients and next-of-kin have never spoken to their doctors about information they have found themselves. **This means that 81 percent of our sample has spoken to doctors about the information they have found.**

58 percent have been actively supported by their doctors: they discussed the pros and cons of the information with them. In only a fifth of cases (18 percent) had doctors not been interested in the information presented by the patients or their families (Figure 28). A further 18 percent said the doctor wanted to investigate further, and in 17 percent of cases respondents stated the doctors used the information directly for the next course of treatment. **Doctors react positively when patients ask them about self-researched information.**

Figure 28: reaction of doctors



Source: Prognos AG

The second hypothesis is therefore also correct: **Patients use the information in addition to what doctors tell them. Doctors are central to patient information management. A great majority of patients have spoken to doctors about the information, and these react positively, undertaking the final categorisation and evaluation of any information.**

4.3.3 Patients and the public at large reject the ban on industry information

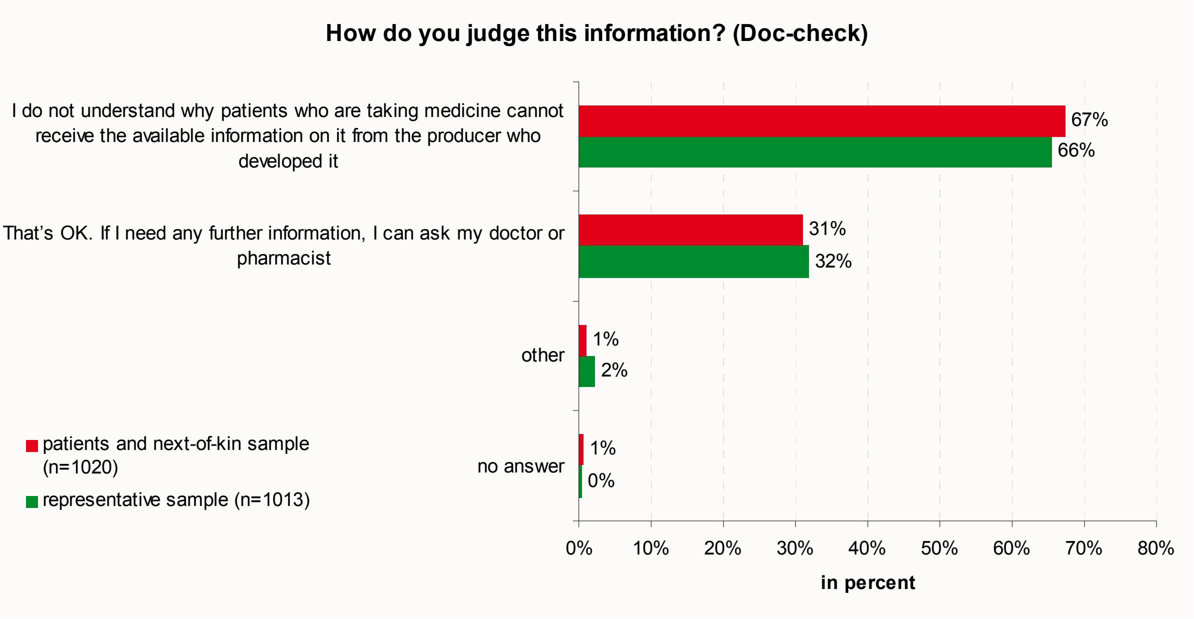
The next hypothesis stated: *"Patients are unaware of legal limitations on manufacturers. The legal limitation on manufacturers from informing patients is seen as annoying and antiquated."*

This question was posed to both the patient and next-of-kin sample and also to the representative sample. The groups were given the text shown in Figure 13 above and asked for their response. **Two-thirds of both samples reject the Doc-Check**, stating they do not understand why patients who are taking medicine cannot receive the available information on it from the manufacturers who developed it (Figure 29). The difference between the two groups amounted only to one percentage point. In the representative sample, there were no significant differences between the answers of the ill, the next-of-kin and the healthy respondents. The rejection was clear.

The reason for the rejection can be deduced from the answers given by patients and their families in the first part of the survey: **legal re-**

strictions on information do not sit well with patients' use of critical content comparison from various sources when informing themselves. The results here suggest this behaviour is not limited to patients; the public at large acts in the same way.

Figure 29: assessment of scenario I: Doc-Check



Source: Prognos AG

The hypothesis is borne out: **Patients and the public at large reject the ban on industry information.**

4.3.4 Patients and the public at large welcome and would use industry information

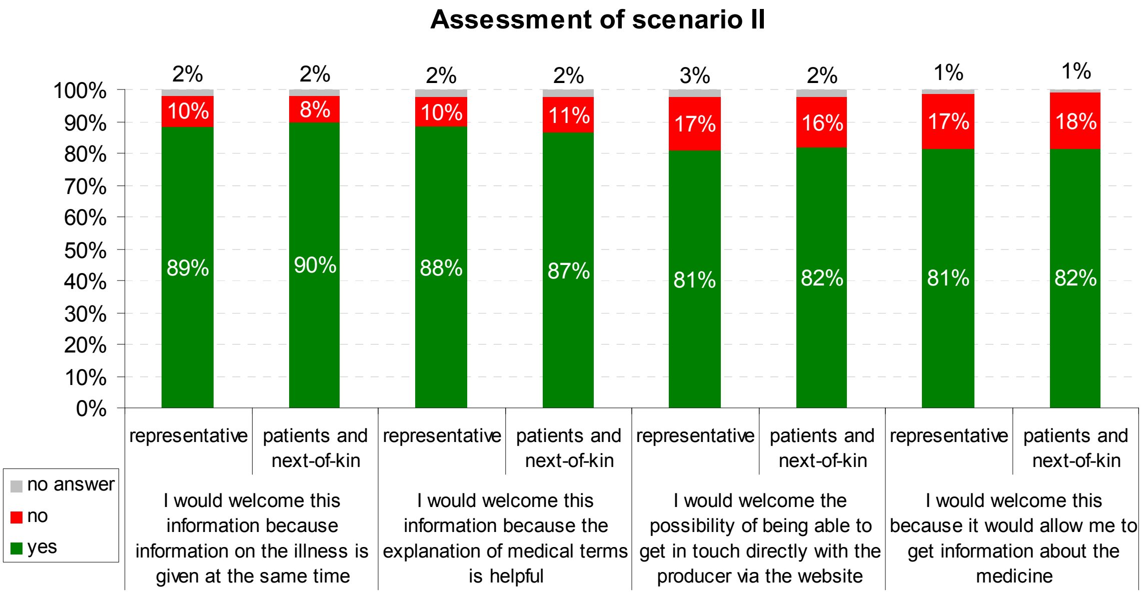
"*There are no particular misgivings or doubts among patients towards industry information. Information provided by the industry would be used by many patients as one source among many.*"

Both samples were shown scenario II, a company website showing components of patient information leaflets and a section explaining medical terms (see Figure 14). It was clear the information came from the industry. Respondents were asked whether they would welcome information because:

- information on illness is given at the same time;
- information on medicine is given;
- medical terms are explained;
- there is a chance to get in touch with the company.

Information from manufacturers is welcomed by both samples across the board. There were no significant differences between the two samples and within the samples between the ill, their next-of-kin and the healthy. 89 percent of the public and 90 percent of the patient and next-of-kin sample would welcome information on medication in the context of their illnesses. This correlates to the results from the first part: patients look for medication via the illnesses. **Over 80 percent of both samples would welcome information on medication** (see Figure 30). This in turns correlates to the answer given by patients and next-of-kin in the first part of the survey: 82 percent look for information on medication, as seen in see Figure 21.

Figure 30: assessment of scenario II: pharmaceutical information



Source: Prognos AG

Welcoming the possibility of something is not the same as being willing to use it. For this reason, we asked “on the whole, would you use this information?” (See Figure 31). The answer was clear:

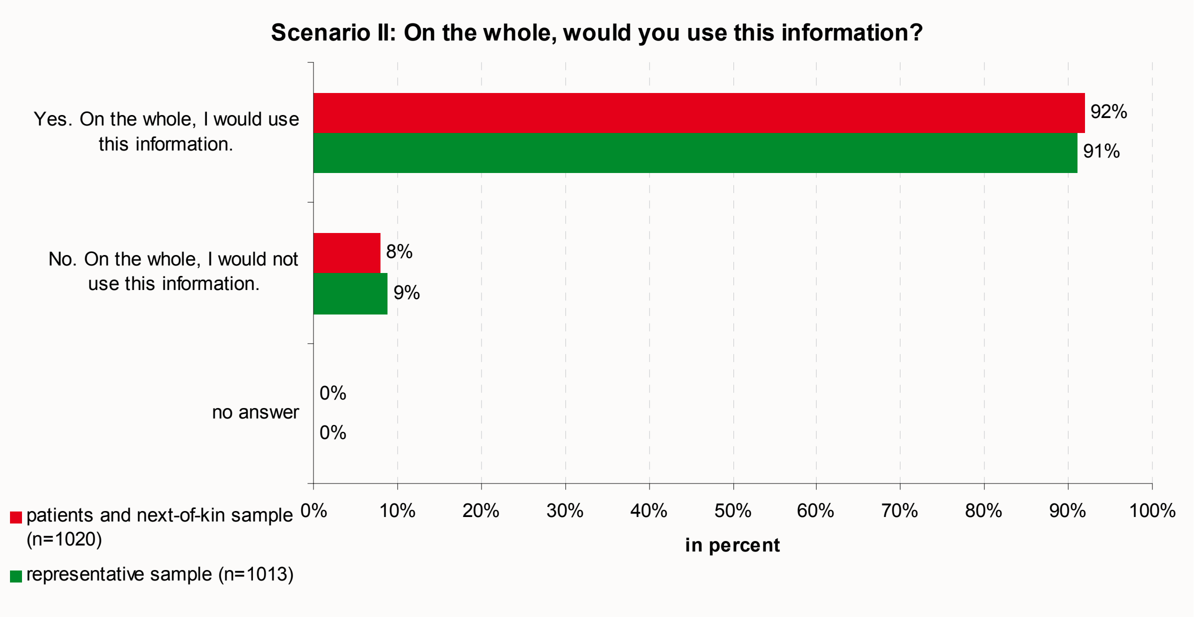
- **91 percent of the public said they would use information provided by the industry**
- **92 percent of patients and next-of-kin would use the information.**

This again fits in with the pattern shown above: patients (and the public) are willing to use a number of sources in their search for information.

It was clear the information provided came from the industry. The hypothesis is confirmed: **Information provided by the industry would be used by many patients as one source among many. There are**

no particular misgivings or doubts among patients towards industry information.

Figure 31: overall assessment of scenario II



Source: Prognos AG

4.3.5 Patients and the public at large would especially welcome industry information on research and product development

The last hypothesis to be tested is: "*The industry is seen as being especially competent in the area of research.*"

This was tested by means of Scenario III (see Figure 15). This clearly-marked industry website listed current research results, product development, research partners and events presenting results.

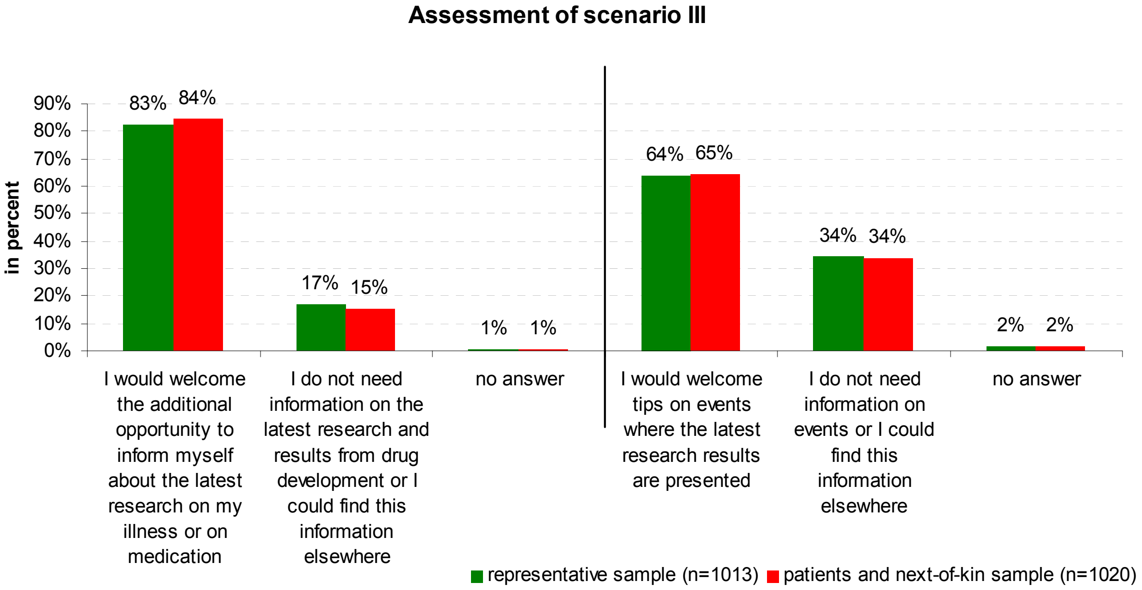
The results again showed minimal differences between the samples. Two questions were asked, whether:

- information on the latest research and development results would be welcomed,
- tips on events would be welcomed.

As with scenario II, the results were clear-cut (Figure 32). Well over 80 percent of patients and their families and the public would welcome information on the latest research and development. A smaller number would welcome event tips.

The result regarding research fits with the finding that patients (and the public) want information on medication, and also that up-to-date information is a decisive quality criterion for them when looking for information.

Figure 32: assessment of scenario III. Research information



Source: Prognos AG

As with Scenario II, a differentiation was made between welcoming something and actually wanting to use to (See Figure 33):

- **84 percent of both samples said they would use information on research provided by the industry**

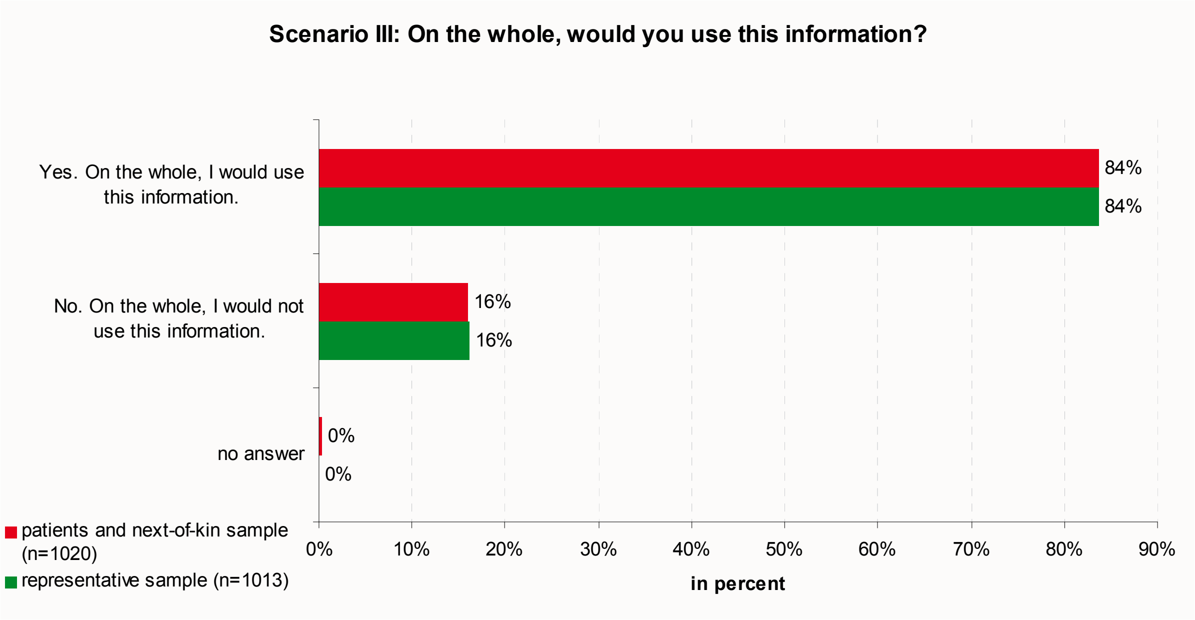
This high rate of approval is lower than the willingness to use Scenario II, but this is logical. The first part of the survey showed that patients want first and foremost information on their illnesses and medication. Treatment alternatives (such as new developments in medication) were ranked lower. The score of 84 percent however shows there is a clear willingness to use this information.

The last question asked whether respondents could imagine getting information from pharma manufacturers that they cannot get elsewhere. Again, the two samples answered similarly (Figure 34). **Patients and the public at large see research into illnesses and information on product development as something they cannot imagine getting from another source**.

Information on the state of play in other countries was of less interest, and only 18 percent of both samples said they could not imagine receiving other information than from elsewhere.

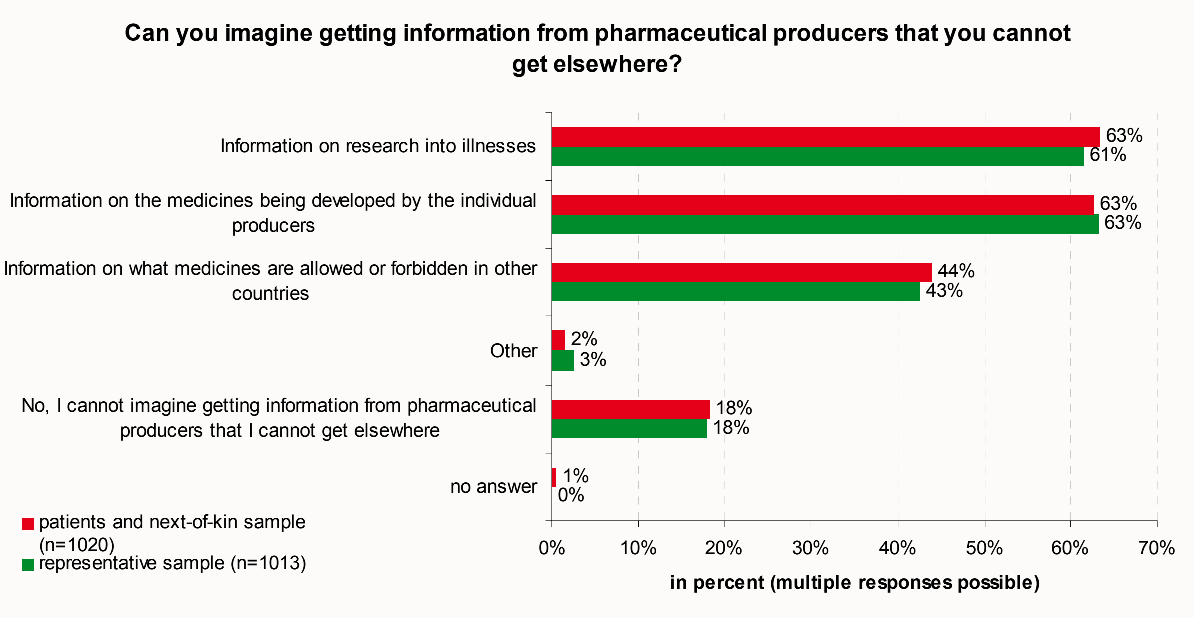
The hypothesis is thus confirmed: **The industry is seen as being especially competent in the area of research. Research is the industry USP.** This counts just as much for patient information as it does for other areas.

Figure 33: overall assessment of scenario III



Source: Prognos AG

Figure 34: industry USP



Source: Prognos AG

4.3.6 Results at a glance

- The results did not vary between the representative sample and the patient and next-of-kin sample.
- The internet is an accepted medium for patient information.
- Information must be placed in the context of the illness.
- A full 82 percent of patients and next-of-kin have already researched information on medication: patients and next-of-kin want information on medication.
- Search engines are the first port-of-call for patients and their families in the internet, not individual sites.
- Patients and their families are competent, responsible and proactive information users. They form their opinions from a wide range of sources. They perform critical checks on the information to assess its quality.
- Doctors are clearly the main source of information for patients. Information found elsewhere complements information given by doctors.
- 81 percent of patients and next-of-kin have spoken to doctors about information they have researched.
- In general, doctors react positively when patients ask them about self-researched information.
- Two-thirds of the public reject the ban on industry information.
- Information from manufacturers is welcomed across the board by both samples. Over 90 percent would use information on medication provided by the industry.
- There are no particular misgivings or doubts among patients and the public towards industry information. They would not discriminate between information provided by the industry and other sources.
- 84 percent of both samples said they would use information on research provided by the industry.
- Patients and the public at large see research into illnesses and information on product development as something they cannot imagine getting from another source.

5 Conclusion: The need for additional information through the industry

72 percent of Germans regularly use the internet. The structure of information available on the internet is however heterogeneous and of doubtful quality. Patients typically look for information via search engines, not via individual institutions. Up to 74 percent of the information found on the internet on active substances and products does not fulfil basic quality standards.

A representative survey into patient and public behaviour and needs with regard to pharmaceutical information shows that patients and the public at large

- look for information on medication in the context of illness. Instititional based searches are unusual;
- attach importance to the quality of information but see deficits in this area;
- compare different sources when informing themselves;
- see doctors as their first port of call. Doctors react positively when patients discuss information with them;
- decisively reject the ban on industry information;
- welcome information from manufacturers. There is a large willingness to use industry information as one source among many;
- see the added value of industry information in research and product development.

In sum, the study shows that patients and the public at large compare information from different sources when informing themselves and make up their own minds about what is trustworthy. As a result, they have no misgivings about being informed on Rx medication by the industry, as long as the information fulfils quality standards (comfortable, comprehensible, in context, serious and up-to-date). Information provided by the pharma industry as one source among others would be readily welcomed and used.

The added value of the pharma industry lies however in information on research and product development. This is something the public and patients want and cannot imagine getting elsewhere.

PROGNOS AG

Düsseldorf, September 2008