

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 ÄZQ¹. 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.

¹ Ärztliches Zentrum für Qualität in der Medizin

- 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 upto-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.