Drug information for consumers and patients –
a review of the research

Ulla Närhi
DRUG INFORMATION FOR CONSUMERS AND PATIENTS –
A REVIEW OF THE RESEARCH

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Summary
This publication is aimed at summarising the research carried out into the dissemination of drug information intended for patients and consumers. The change from paternalism to partnership encourages patients to participate in decision-making about their treatment. Patients need valid information in order to be able to make these decisions.

Patients most commonly want information about the adverse effects of medicinal products, followed by information about the efficacy as well as the duration and costs of treatment. Physicians and pharmacists in the first instance, and then nurses, relatives and friends, are considered as the most common sources of drug information. Consumers may find it difficult to recognise drug regulatory authorities as a source of drug information. Pharmaceutical companies produce large quantities of drug information, but the borderline between advertising and information can be volatile.

Written drug information can decrease the amount of misunderstanding, and patients can return subsequently to the information provided. Package information leaflets are often used as a source of drug information, but patients may not understand the information completely. About half of the European Union citizens had access to the Internet in the end of 2005, and the number of consumers and patients searching for drug information on the Internet is increasing. The quality of information obtained from the Internet is variable and consumers may find difficulty in discovering and recognising valid drug information.

In the future, new technological inventions will provide new opportunities for disseminating drug information, but conventional tools such as leaflets and booklets about drug information will still be of value. More drug information appropriate to the needs of special groups, e.g. elderly people, children and disabled persons, should also be available.
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FOREWORD

Despite the safety, efficacy and quality of a medicinal product, the outcome of the therapy will not be successful if the patient is unable to carry it out. Information about the medicinal product and its safe and correct use constitute an essential part of pharmacotherapy in health care systems.

A research group ‘Planning for Pharmaceutical Policies’ was set up by the National Agency for Medicines (NAM) in Finland at the beginning of 2005. The aim of the group is to produce academic studies and papers which could serve as a background for political decision-making and public discussion. Drug information for the general public is one of the main subjects of the research.

Patients’ access to good quality drug information is also one of the main themes within the European Union. It is one of the subjects of the Pharmaceutical Forum which was launched by the European Commission in 2005. The work of the Forum is based on the recommendations of the G10 Medicines High Level Group in 2002.

One of the aims of this review is to serve as background material for developing drug information for consumers and patients. I am very grateful to the author, Dr. Ulla Närhi, for her valuable work in producing this review. Understanding the wide possibilities for improving the quality and availability of validated drug information may help us in our work of safeguarding public health and promoting the rational use of medicines.

Helsinki, February 2006

Director General, Professor Hannes Wahlroos
1 INTRODUCTION

Patients and consumers need valid drug information. They should at least be aware of the basic issues about medicines in order to be able to deal with their medication.

Ways to improve drug information have been thoroughly studied. The main issues in these studies have been the sources and tools of drug information, the problems involved in drug information and the ways that drug information should be improved in order for it to benefit consumers and patients most efficiently.

This report is aimed at summarising the research carried out into the dissemination of drug information for patients and consumers. Drug information may be defined, for example, from the perspective of a patient, pharmaceutical industry, population, society, regulatory authorities and/or media. The perspective of a patient or a consumer is used in this report. The main emphasis lies on the more recent studies published, but included are also less recent studies of high quality. Each section ends with summary points, which include the basic information on the topic.

The studies were searched for with the aid of the MedLine database. The search terms used were ‘drug information’, ‘medical information’, ‘patient information’, ‘Internet’, ‘written drug information’, ‘drug information services’, ‘package inserts’, ‘information sources’ and ‘patient information leaflet’.

For the purpose of this report, ‘information’ is described as the data and knowledge that sources of intelligence (human and artificial) use to support their decisions (Wyatt and Sullivan 2005). ‘Information need’ can be defined as an individual’s capacity to benefit from information (Consumers’ Association 2003). According to WordNet, an English language lexical database, ‘consumer’ can be defined as a person who uses goods and services. ‘Patient’ refers to a person who requires medical care (WordNet), which, in turn, can for example be the provision of medicines.

2 DRUG INFORMATION: FROM PATERNALISM TO PARTNERSHIP

Consumers choose the way in which they treat their illnesses. The alternatives include e.g. an evaluation requested from a doctor and the self-treatment of symptoms. Self-treatment is mostly treatment with medicines. If medicine treatment is chosen, the consumer should know how to apply it correctly (Coulter et al. 1999, Dosani 2005). Appropriate drug information is also found to improve the results of treatment (Melnyk et al. 2000) and adherence to medication (Koo et al. 2003).

Drug information for patients has traditionally been disseminated from above downwards (Coulter 1999). Health care professionals, especially physicians, decided what kind of care and information the patient needed. The physicians were responsible for the care; they knew how the medicines worked and what was required to get them to work. Consequently, they were in the best position to define the needs of their patients. The model of paternalism has nowadays been replaced by partnership, which means self-determination by patients (Coulter et al. 1999, Itkonen 2000).

The idea of partnership encourages patients to become involved in the decision-making concerning their own treatment (Coulter 1999). Patients and physicians are considered as partners in care and ‘co-producers’ of treatment decisions (Consumers’ Association 2003). Equality in doctor-patient relationships is also emphasised by the principle of concordance (www.concordance.org). Drug prescription and compliance with instructions for use are based on a partnership between the patient and the health care professional. The patient is encouraged to talk about any problems associated with his or her medication, and the problems are solved together. The solutions are discussed at the following appointment and the patient’s situation is monitored. The decisions about whether to
comply with the decisions are nevertheless always made by the patient.

For the ‘decision aid’ to succeed, however, the patient should be given sufficient information about the disease and the treatment alternatives, and also about any potential adverse effects associated with the treatment (Coulter et al. 1999). The idea of partnership, which is novel in the context, is a challenge for health care professionals (Arora et al. 2005). They should be taught a new approach to their patient, including skills of interaction and human relationship (Elwyn et al. 1999, Towle and Godolphin 1999). Patients should also be taught to play an active role in the treatment of their own diseases and to make decisions (Towle and Godolphin 1999, Osborn 2000).

‘Decision aid’ improves knowledge, reduces conflicts in decision-making and stimulates patients to be more active in making decisions without increasing their anxiety (Murray et al. 2001a, Murray et al. 2001b). However, the effects of ‘decision aid’ on patients’ outcomes (e.g. quality of life) remain uncertain (O’Connor et al. 1999).

Valid information about the medication may reduce the enthusiasm or reluctance for the treatment (Guillaume and Bath 2004). However, patients have differing needs, willingness and readiness to understand and manage drug information. Consequently, the drug information available and ways of dissemination should be varied.

Summary points:

• Patients and health care professionals can be considered as partners in health care.
• A change of concept, from paternalism to partnership, encourages patients to participate in the decision-making about their treatment.
• Patients need valid information to be able to make decisions.
3 WHAT KIND OF DRUG INFORMATION IS REQUIRED?

3.1 The content of drug information

The minimum content of drug information can be considered as the amount of the information that a patient needs for carrying out safe and effective treatment (Airaksinen et al. 1994). For prescribed medicines, this includes information about the purpose of the medicine and information about (Hermann et al. 1978, Airaksinen et al. 1994):

- adverse effects and interactions of the medicine
- whom to contact in case of problems
- use with alcohol
- how to use the medicine
- mode of action
- storage, purpose, duration and dosage of the medicine

3.2 The need for information

In their search for information, consumers may be passive (material distributed along with the medication, the press, radio and TV), or active (they seek information themselves from various sources or, for example, directly from health care professionals). Active search for information by the consumers themselves is constantly on the increase (Newby et al. 2001).

Studies show that consumers are mostly keen on finding information about any potential adverse effects of drugs (Melnyk et al. 2000, Newby et al. 2001, Nair et al. 2002). The second biggest attraction is the question of the level of efficacy of a certain medicinal product in a certain disease (Newby et al. 2001, Nair et al. 2002). Information is also sought about the duration and cost of the treatment as well as the reason why the drug was prescribed (Nair et al. 2002).

Questions about collateral and adverse effects of drugs (about a third of the questions), and the use of and indications for drugs (less than a third of the questions) have been most of those received at drug information centres (Finland and Germany) or on drug information theme days (Australia). Among the various drug groups, most of the questions are about medicines for the cardiovascular system or the nervous system. (Allen and Aldermann 1995, Maywald et al. 2004, Ojala and Kröger 2005)

3.3 Information about adverse effects

Information about any adverse effects of drugs is a relevant part of drug information. In addition to the characteristics of the adverse effects, the consumer also needs to know what to do when adverse effects occur. Information about the severity, likelihood and extent of the adverse effects has an influence on the use of the drugs. The biggest influence is exerted by knowledge of the severity of the adverse effects (Berry et al. 2002a). A small number of severe adverse effects is experienced as something more threatening than a larger number of less severe adverse effects (Berry et al. 2002a). The medicinal product may also be omitted owing to fear (Berry et al. 2002a).

The information given should be appropriate. The consumer should be made aware of the type of side effects, which may occur without scaring him or her unnecessarily. According to the study by Berry et al. (1998), patients did not ‘like’ explanations that describe side effects. They were also less likely to take the medication if given such explanations. The provision of additional explanatory information about severe adverse effects may be beneficial (Berry et al. 1998). Information about the means to avoid possible adverse effects is experienced as positive (Berry et al. 2002a).

It is recommended in an EU guideline (1998) that the frequency of side effects should be
described in the package information leaflets using one of five verbal descriptions: ‘very rare’ (up to 0.01%), ‘rare’ (0.01% to 0.1%), uncommon (0.1% to 1%), ‘common’ (>1% and <10%) to ‘very common’ (10%+). If exact data about the frequency are available, numbers can be given in per cent. However, consumers may find it difficult to understand how common a certain adverse effect is in practice (Berry et al. 2002b, Berry et al. 2002c, Berry et al. 2003, Knapp et al. 2004). A British study carried out a survey among 18-55-year-old students asking them how frequent they thought adverse effects were. If the frequency was expressed with words ‘very common’, the survey participants concluded that 65% of the users of the drug were estimated to be affected by the adverse effect (Berry et al. 2002b). If the frequency was expressed in figures (‘the side effect occurs in 15% of those who use the drug’) the survey participants estimated 20% of the users of the drug to be affected by the adverse effect. In the group in which the frequency was described verbally, the adverse effects were estimated to be more severe and the likelihood of being afflicted oneself was considered higher. The group which had received a verbal estimate was less likely to use the drug than the group which had received a numerical estimate (Berry et al. 2002b).

In another study, 120 adults on simvastatin or atorvastatin therapy were asked to determine the frequency of side effects when the information was given in verbal form ‘common’ or ‘rare’ or in numerical form ‘2.5%’ or ‘0.04%’. Patients overestimated the frequencies given in both the verbal and the numerical forms, but the overestimate was much higher in the verbal form. (Knapp et al. 2004)

Also health care professionals (doctors) tend to overestimate the likelihood of adverse effects, when EU guideline descriptors (very common, common, uncommon, rare, very rare) are used (Berry et al. 2003). The future challenge will be to produce a phraseology of risk that is sufficiently flexible in taking into account different perspectives, as well as the changing circumstances and contexts of illness and its treatment (Berry et al. 2003).

**Summary points:**
- Patients most commonly want information on adverse effects.
- This is followed by the information about the efficacy of the medicine in certain diseases as well as information about the duration and costs of treatment.
- Patients tend to overestimate the likelihood of adverse effects.
- More attention should be paid to the model describing the frequency of the adverse event.
4 SOURCES OF DRUG INFORMATION

Consumers have several sources of drug information available to them. Nevertheless, many patients would like to have even more drug information. This applies to patients in both outpatient and inpatient care (Howard et al. 1999, Kerzman et al. 2005).

Studies about the sources or tools of drug information often ignore the definition of ‘drug information’. It may refer to many kinds of drug information, for example, to a mention about the type of the medicine or to a large lecture about the adverse effects of a certain medicine. The consumer may also consider advertisements and other commercial information leaflets as drug information. Even though drug information may not have been defined, studies can nevertheless reveal the sources from which consumers believe they have received the information.

Table 1 shows the results of studies where consumers or patients have been asked where they have received the information from. In most of the studies consumers or patients were able to name more than one source or tool. The most common source of drug information is the doctor, the second most common being the pharmacist. Studies with the main intention of discussing issues associated with drug information, other than sources, have also shown similar results (Newby et al. 2001, Nair et al. 2002, Hicks et al. 2005). In addition to obtaining information from doctors and pharmacists, information is mostly obtained from nurses, relatives and friends.

The doctor is often the most important source of information for patients suffering from a chronic or severe disease. According to Rutten et al. (2005), cancer patients, for example, receive most of their drug information from health care professionals (27.3%, of which 43.7% from doctors and 28.2% from nurses). This is followed by written material (books, leaflets, journals, 26.2%), relatives and friends (18.8%) and organisations and scientific resources (14.2%).

4.1 Doctors

During appointments, the most natural person to inform patients about the drug prescribed to them is their doctor. The advice could also be tailor-made, at the same time pinpointing precisely the aspects with which the patients are advised to familiarise themselves, in respect to their own situation (Buck 1998, Shakib and George 2003). In an ideal situation, the patient could at the same time ask questions in which further clarification is sought.

About what aspects of drugs, then, should the doctors talk with their patients? According to a British study (Berry et al. 1997), doctors consider the most important aspects to be interactions with medication prescribed for long-term use, detailed instructions for the administration of the drug, and lifestyle changes. Among the patients, however, greater importance was given to information about possible adverse effects, about the actual effect of the drug and about lifestyle changes (Berry et al. 1997). Patients preferred the explanations that did not convey negative information (e.g. information about possible adverse effects of the medication) to those that did convey some negative information (Berry et al. 1997).

4.2 Pharmacists

Since patients mostly buy their medicines from pharmacies, pharmacists have an important and natural duty to supply drug information. A supply of thorough drug information is especially important in situations where the patient does not attend doctor’s appointments. A pharmacist may in fact be the only health care professional with whom the patient is in touch and from whom the patient may receive information in relation to his or her disease.

Advice on the choice of medicines is also required when the patient is looking for self-care medicines. The symptoms are evaluated and the treatment is assessed on the spot, which requires competence and skills from the pharmacists.
Table 1. Sources and resources for drug information

<table>
<thead>
<tr>
<th>Study</th>
<th>Per cent of respondents reporting as a source or resource for drug information</th>
<th>Study population and notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physician</td>
<td>Pharmacist</td>
</tr>
<tr>
<td>Donaghue 1993</td>
<td>27</td>
<td>27</td>
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<tr>
<td>Alanko 1999</td>
<td>63</td>
<td>63</td>
</tr>
<tr>
<td>Helakorpi et al. 1999</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>Tripp and Straub 2001</td>
<td>50</td>
<td>24</td>
</tr>
<tr>
<td>Helakorpi et al. 2002</td>
<td>46</td>
<td>38</td>
</tr>
<tr>
<td>Coleman 2003</td>
<td>76</td>
<td>32</td>
</tr>
<tr>
<td>Vainio et al. 2004</td>
<td>97</td>
<td>99</td>
</tr>
</tbody>
</table>

¹ not received any information about his/her medicines; ² psychiatric nurses; ³ cannot say; ⁴ newspapers and books together; ⁵ TV and radio together; ⁶ labels and package information combined
Consumers usually take a positive attitude towards pharmacies and the drug information they provide. Finns, for example, consider the pharmacy to be a relevant part of health care, the satisfaction with pharmacy services in Finland is high and the advice given by the staff is relied upon (Airaksinen 1996). Customers expect nevertheless a more active and spontaneous input from the pharmacists in the advice given (Airaksinen et al. 1993). Enhancing the guidelines and advice given by pharmacists can improve the outcome of treatment (Närhi et al. 2000), increase the information the patients have about their disease, and improve the attitude of the patients to their medication (Närhi et al. 2001). The importance of pharmacists, especially in the treatment and treatment compliance of patients with chronic diseases, is great (Närhi 2001). Pharmacists value concordance and tend to see customers as partners (Kansanaho et al. 2004).

The information provider may nevertheless not necessarily be capable of assessing the type of information the patient would want or need. The understanding of pharmacists about what information customers should be provided with has been found to differ from the customers’ understanding (Airaksinen et al. 1994). A study carried out at the beginning of the 1990’s reported that customers want information about possible adverse effects of drugs and drug interactions, whereas the pharmacists considered the dosage and storage of drugs to be more important (Airaksinen et al. 1994).

The drug information given at the pharmacies may also be influenced by the type of drug
the patient is prescribed. It has been found that most advice given has been on antibiotics and least on gynaecological products (Vainio et al. 2002). Other factors affecting the advice given include the pharmacy’s routine practices and the advisor’s own activity and whether the patient has used the drug before (Vainio et al. 2002).

Active and inquisitive customers receive more drug information compared with more passive ones (Airaksinen et al. 1998, Vainio et al. 2002). How should the consumers be activated and made to enquire about their drugs? According to the study, customer campaigns, for example, have hardly any effect (Airaksinen et al. 1998). The main reasons for not wanting advice from the pharmacist are, that the patients have either used the product before or have already received advice elsewhere, generally from the physician (Taylor 1994).

4.3 Drug regulatory authorities

Drug regulatory authorities are a good source of drug information, because they have in their possession the pre- and post-marketing documentation about the medicinal product. Before granting the marketing authorisation, pharmaceutical companies provide drug regulatory authorities with the documentation they have about the medicinal product. The authorities then evaluate this documentation. Safety information about the medicinal product continues to be provided to the authorities even after the product is launched on to the market.

The literature does not provide studies on drug information provided by drug regulatory authorities. However, drug regulatory authorities produce and distribute large volumes of drug information. Basic information about medicines, i.e. summaries of product characteristics (SPCs) and package information leaflets (PILs), is available on most National Competent Authority (NCA) websites (Närhi 2005, unpublished). The NCA websites mostly present information aimed at pharmaceutical companies, pharmacies and health care professionals, but they also present information aimed at the general public (Närhi 2005, unpublished).

Recognising drug authorities as a source of drug information may be difficult for consumers. It is even difficult for the researchers: studies concerning sources of drug information have not mentioned ‘drug authorities’ as an alternative.

4.4 Drug information centres

A drug information centre is a unit, which those in need of drug information can telephone, or contact by other appropriate means in order to obtain the required information. Many hospital pharmacy-based medicine information help lines also provide drug information services (Raynor et al. 2000). The drug information services are constantly available to all those in need of information, from health care professionals to consumers. Health care professionals, mostly doctors and pharmacists, handle the queries.

In the literature, there are only few articles reporting the work carried out in drug information centres. For example, Kuopio Medicines Information Centre (KMIC) is a drug information centre operating in Finland and offers its services to both consumers and health care professionals. It is a non-profit and independent organisation founded by the Pharmacy of Kuopio University, the Hospital Pharmacy of Kuopio University Hospital and the Faculty of Pharmacy of Kuopio University. (http://www.klik.fi)

Over 11,000 contacts with the Centre were documented in 2004. Two thirds of the queries were received from patients or their relatives (Ojala and Kröger 2005). The majority of the queries were about drugs used for the nervous system, and the second highest number of queries was about drugs for the alimentary tract and anti-infective agents (Ojala 2005).

A centre has been set up in Germany which patients may contact with their queries about treatment and drugs. The Drug and Therapy Information Centre (DTIC) is located at the Institute of Clinical Pharmacology at the Dres-
The quantity of drug information published in different newspapers and journals is huge. However, the quality of information varies considerably, making it hard for consumers to estimate the quality of a given piece of information.

In the USA, the Division of Drug Information is the unit to which the public is able to direct queries about human drug products (http://www.fda.gov/cder/offices/DDI/default.htm). It is staffed by working pharmacists and other health professionals who provide expert advice and guidance. On average, per month, they answer approximately 3,000 e-mails, 4,000 telephone calls and 600 letters. They also have a website, Drug Information Pathfinder, providing links to information on specific drugs, drug development, drug application process, drug imports, and other topics (www.fda.gov/cder/Offices/DDI/pathfinder.htm).

A one-day drug information campaign in Australia has been described during which over 2,000 phone calls were received, i.e. an average of 167 calls per hour. The campaign day had been abundantly advertised in the media in advance. Cardiovascular drugs were on top of the list of the queries (35.2% of the calls) and the majority of the issues discussed related to adverse drug reactions (66.2% of the queries). (Allen and Alderman 1995)

4.5 The printed media

Newspapers and journals publish a large number and great variety of articles about drugs, varying from Letters to the Editor to articles with a factual content. However, the quality of information is also variable and the consumer may have difficulties in distinguishing between good and poor quality information.

Newspaper and journal articles about drugs may contain defects. A Canadian study examined articles about drug effects published in newspapers. The chosen subjects of the study were five medicinal substances, which required a prescription, and the corresponding medicinal products, which were launched on to the Canadian market between 1996 and 2001. Articles (n=193) that referred to at least one benefit or harm from any of these five drugs were included. The study showed that over two thirds (68%) of the articles did not mention a single very severe known harmful effect, but all articles included the mention of at least one benefit. Only 4% of the articles mentioned contraindications, 32% mentioned drug costs, 46% mentioned drug alternatives and 16% mentioned non-drug treatment options such as exercise or diet. (Cassels et al. 2003)

Articles and guidelines produced by health care professionals may also contain defects. Another Canadian study published in 1999 analysed medical articles in newspapers. The newspapers studied contained articles written by doctors; this time the subjects of the examination were articles written for the elderly. Advice given in half (50%) of the articles was considered deficient and almost a third of them (28%) contained advice, which was in fact unsafe.
According to the authors, inaccuracies in the articles written by professionals were, for example, a direct result of the shortness of the articles; issues were radically shortened, and the advice given was too general. Doctors well familiar with their subject may not necessarily be able to write an account, which would be correctly understood by its readers. (Molnar et al. 1999)

4.6 The pharmaceutical industry

4.6.1 Drug information or drug advertising?

The pharmaceutical industry generates and collates vast amounts of drug information. A large proportion of this material remains confidential or is shared with regulatory authorities, and a smaller proportion including promotional material and information to patients is publicly available (Collier and Iheanacho 2002).

Pharmaceutical companies are a valid source of drug information for the product they have made, and they have the documentation about the efficacy and safety of the product (Collier and Iheanacho 2002). When informing patients and consumers about the product, the borderline between drug information and advertising may be problematic (Bell et al. 2000). In the best cases advertisements not only offer information about drugs but also about the treatment of diseases or symptoms. In addition to giving direct information about their own products, the pharmaceutical industry may also sponsor drug information produced by other parties (e.g. patient organisations) (Toiviainen et al. 2004).

According to an American study from the year 2000, informative and good quality drug advertisements can be found, but the majority of the advertisements contain very little information. All the advertisements included in the study, gave the name of the condition treated by the promoted drug, and a majority provided information about the symptoms of that condition. However, the advertisements seldom provided information about the drug’s mechanism of action, its success rate, treatment duration, alternative treatments, or behavioural changes that it could promote. (Bell et al. 2000)

The use of the Internet as the source of drug information is on the increase (Shepperd et al. 1999). Pharmaceutical companies often maintain their own webpages, in which symptoms and treatment alternatives for a specific disease are discussed. This type of advertising is called indication-related marketing. The chief purpose of the webpages is nevertheless to market one’s own products: the webpage is, after all, maintained by a pharmaceutical company (Coulter 2001).

The information content of pharmaceutical industry websites about treatments for erectile dysfunction was the object of evaluation in an American study. The first results of an information search with a browser and using the drug name were links to the pharmaceutical company webpages. The links usually led to webpages comparable to those of indication-related marketing, and the contents were evaluated. The text about the medicinal product, including the adverse effects, efficacy, other treatment alternatives and price, was not sufficient for a patient. According to the researchers of the study, the purpose of the pages was to market, not to disseminate information. (Waack et al. 2004)

On the webpages of a drug marketing company, information about the risks of use and adverse effects of a drug are more difficult to find than about its benefits (Hicks et al. 2005). Any negative information is placed in a corner where it is not immediately visible. To find it, it is often necessary to scroll down or to click to the next page (Hicks et al. 2005). Any positive information is given a more prominent place.

4.6.2 Direct-to-consumer advertising

In Europe, direct-to-consumer (DTC) advertising of prescription medicines is prohibited. In the USA and New Zealand, prescription medi-
cines may be marketed to the public – but the printed advertisements must contain a given section of information which contains certain details about the drug in accordance with the SPC (Palumbo and Mullins 2002). Consumers may have difficulties in understanding these brief summary sections (Kaphingst et al. 2004). Prescription drug advertisements directed at the public often conclude with the advice that one’s own doctor should be asked whether or not the drug in question is the best alternative for the patient. Doctors often prescribe the medicine that the patient requests, but they are often ambivalent about the choice of treatment (Mintzes et al. 2002).

DTC advertising has been said to increase patients’ awareness, which may prevent under-diagnosis of the diseases (Bonaccorso and Sturchio 2002, Young et al. 2005), to encourage the partnership between the patient and the doctor (Holmer 1999, Rosenthal et al. 2002), and overall to improve patients’ knowledge about medicines (Holmer 1999, Eichner and Maronick 2001).

However, most advertisements have been reported to provide a minimal amount of health information (Bell et al. 2000, Young et al. 2005, Woloshin et al. 2001). DTC advertising may help the patient to discuss the condition and its treatment with the doctor (Sumpradit et al. 2002, Robinson et al. 2004), but DTC also encourages patients to seek treatments they do not need (Kravitz 2000, Weissman et al. 2004, Mintzes 2002, Kravitz et al. 2005). The advertisements send a strong signal that prescription drugs can be considered just like any consumer products (Findlay 2001).

In the USA, DTC advertising has increased the consumption and sales of prescription drugs (The Kaiser Family Foundation 2003). Retail sales of the 50 most heavily advertised drugs rose by 32% from 1999 to 2000 compared to 13.6% for all other drugs combined (NIHCM 2001). At the same time, the number of prescriptions for the 50 most heavily advertised drugs rose by 24.6%, compared to an increase of 4.3% for all other drugs combined (NIHCM 2001).

According to the National Institute for Health Care Management (NIHCM), among the questions being asked about DTC advertising by public policy are (NIHCM 2001):

- Are DTC advertisements inducing consumers to press their doctors for specific drugs?
- Are doctors complying with such requests?
- Are the advertisements driving consumers to desire expensive new brand name drugs when less expensive drugs might be better in some cases?
- Are the advertisements leading to the inappropriate clinical use of some drugs?
- Do DTC advertisements contain sufficient information on the potential side effects of drugs?
- How much of the recent rise in drug spending can be attributed to DTC advertising?

4.7 Patient organisations

Patient organisations often play an important role in the patient’s own management of the disease. Through them patients can receive information about their diseases and treatment. Patient organisations operate as a forum, where patients may discuss their own needs and desires and obtain hints about treatment management. (www.patientsorganizations.org)

Patients suffering from the same disease often like to exchange information. Many patient organisations maintain e-mail discussion groups, where people with the same disease can share their experiences and offer advice as necessary (www.patientsorganizations.org/index.pl). Alertness is required from patient organisations, and the contents of discussion groups should be monitored (Jadad 1999).

Patient organisations also collaborate with the pharmaceutical industry. A study in the year 2003 showed 71% of Finnish patient organisations reporting that they received financial support from pharmaceutical companies (the response percentage in the study was 65%, and consequently, the true situation may somewhat differ from this). The financial support consisted, for example, of advertising space bought...
by the companies in the publications of the patient organisation, drug company participation in various events, financing the publications of the organisation, participation in projects, and donations. Additional forms of aid included dissemination of drug information and expert help. There were patient organisations that did not get any financial support and the maximum support was over 58,000 euros per a year (in 2002). A total of 55% of the patient organisations considered the financial aid given by pharmaceutical companies either important or very important. Collaboration was experienced as somewhat problematic. 60% of the patient organisations reported subsequent disadvantages as a result of the collaboration: fear for losing independence and objectivity, becoming labelled as a subsidiary, difficulty in assessing the quality of information received, insufficient or irregular co-operation. (Toiviainen et al. 2004)

According to a study from the 1990’s, the information disseminated by patient organisations is mostly of good quality. Readability and design of the leaflets made by the organisations were shown to be superior to those made by pharmaceutical companies and commercial vendors of patient information. Inserts from pharmaceutical companies and commercial vendors were found to be more difficult to read than leaflets produced by the organisations. (Basara and Juergens 1994)

Summary points:

• Physicians and pharmacists firstly, and nurses, relatives and friends secondly, are considered the most common sources of drug information.
• Drug regulatory authorities produce and distribute drug information, but consumers may encounter difficulties when considering the drug authorities as a source of drug information.
• National drug information centres give drug information both to consumers and health professionals.
• Pharmaceutical companies produce extensive amounts of drug information but the borderline between advertising and information can be volatile.
• Ample information is also available in newspapers, magazines and advertisements, but consumers should be able to evaluate the quality of information.
• Patient organisations give information about the treatment and also peer support to patients.
5 METHODS OF DRUG INFORMATION

5.1 Tools of drug information

Information about drugs can be given in both verbal (e.g. by person, by phone, via the media) and written (e.g. leaflets, newspapers and journals) form. Consumers are to an ever-increasing degree searching for drug information on the Internet (Shepperd et al. 1999).

According to studies carried out among patients and consumers, the most popular tools of drug information are package information leaflets (PILs), followed by newspapers and magazines, and radio and TV (Table 1). Consumers also consider drug advertisements as tools of drug information. In most studies, the respondents were able to name more than one tool.

Dickinson and Raynor (2003) have named some features of an ideal source or tool of drug information:

- Accurate, up-to-date, reliable, and practically useful.
- Accessible in language, format, and tone.
- Available at different levels of detail at different times.
- Informative about conditions as well as treatments.
- Striking a balance between a treatment’s beneficial and adverse effects.
- Available at the time of a consultation and consistent with the best advice.
- Linked to other reliable and consistent sources of advice and information.
- Capable of customisation or personalisation.

Several points in the list are appropriate for written drug information or drug information available via the Internet.

5.2 Verbal drug information

Drug information given face-to-face is personal and may be tailored according to patient needs. This type of information is also interactive. Communication with an expert is valued by consumers. Patients with a chronic disease, for example, prefer to enquire about drugs from their doctor or nurse, with whom they already maintain a therapeutic relationship (Raynor et al. 2004).

If the interaction is good, and if the patient feels that he or she is taken seriously and his or her problems are dealt with properly, the absorption of the information given is also improved. Patients in pharmacies tend to value their interaction with the pharmacists more than the information they get (Ried et al. 1999).

5.3 Written drug information

The advantage with written information is that the patient is able to return to the information given and check the details as necessary. Patients have a restricted capacity for understanding information given orally. Even the slightest piece of information given in writing improves the understanding significantly (Johnson et al. 1986). The possibility of misunderstanding of drug information given in written form is smaller than that given face-to-face.
Written drug information increases patients’ knowledge, compliance and satisfaction (Weinman 1990, Gibbs et al. 1990). However, it may also increase anxiety or lead, for example, to premature cessation of therapy due to fear of possible adverse effects (Koo et al. 2003).

Consumers do read and value drug information given in written form (Mottram and Reed 1997, Koo et al. 2002). However, their reading and understanding vary, and information in the written form may not necessarily be available when needed. The ability to utilise written information is influenced both by factors associated with the consumer (ability to understand text, way of reacting to things, demographic factors), factors associated with the content of information (the comprehensibility and ways of presentation of information) and factors associated with the environment (e.g. timing and the situation in which it is presented) (Koo et al. 2003, Koo et al. 2005).

For self-care medicines, pharmacists could encourage the patient to open the package in the pharmacy while, at the same time, giving verbal information to the patient. The pharmacist could then point out the leaflet and encourage the patient to read it at home (Raynor and Britten 2001a).

5.3.1 Drug information leaflets

For the purposes of this paper, the meaning of ‘drug information leaflets’ is that of written instructions for use of the drugs or for the treatment of a disease with drugs. These leaflets are produced, for instance, by pharmaceutical companies, patient organisations and drug regulatory authorities. Their aim is generally to give basic information about the treatment and medication associated with diseases, but the leaflet may also have been produced for the purpose of promoting sales.

The quality of information in the leaflets may vary. A Canadian study compared the patient information leaflets produced by drug companies which described the effect of one medicinal substance (cisapride) with similar patient leaflets approved by the USA drug authorities. The leaflets produced by drug companies contained neither information about the most severe adverse effects, nor any instructions for the patients on how they could identify them. (Sukkari and Sasich 2001)

The comprehensibility of a leaflet is dependent on its contents and the manner in which drug information is given. At least two ways of handling drug information can be distinguished: the paternalistic way, ‘the patient education’ discourse with the emphasis on the consumer’s passive role, which is to be educated, and the consumer-centered way, the ‘patient empowerment’ discourse with the emphasis on the consumer’s active participation. These two directions have, nevertheless, become closer to one another. (Dixon-Woods 2001)

5.3.2 Package information leaflets

The requirements for giving drug information in a form of package information leaflets (PILs) have in some form been part of the EU’s pharmaceutical legislation from the very beginning (Wahlroos 2003). According to Directive 2001/83/EC amended by Directive 2004/27/EC, the package leaflet shall be drawn up in accordance with the summary of product characteristics (SPC) and it shall reflect the results of consultations with target patient groups to ensure that it is legible, clear and easy to use.

Marketing authorisation holders are expected to test the readability and comprehensibility of their leaflets (Directive 2004/27/EC). The content of the PIL is acceptable when 80% of consumers are able to answer each question correctly. The test should be reproducible, for instance, after amendments have been made in the leaflet.

Package information leaflets do affect health outcomes: patients want them and use them (Kenny et al. 1998). Studies show that between 47% and 89% of patients read the PIL accompanying the drug package (Vander Stichele et al. 1991, Bandesha et al. 1996, Raynor and Knapp 2000, Raynor et al. 2005).
According to a study by Vander Stichele et al. (1991), 7% of the respondents declared that neither they nor their relatives read the PILs, and 4% of them maintained that the relatives did read them, but they themselves did not. Of those who read the PILs, 86% found them useful, 71% complete, but difficult to remember (52%) and to understand (57%) (Vander Stichele et al. 1991). They focused their attention mostly on adverse effects and dosage and dosing guidelines (Vander Stichele et al. 1991). A more recent study (Raynor and Knapp 2000) reported that of those, who had fully read the PIL, 11% described the text of the leaflet to have led to a result involving contact with either a doctor or a pharmacist.

However, four years after publication of the package leaflet guidelines (European Commission 1998) significant numbers of consumers and patients are still not obtaining, noticing or reading the leaflets supplied with the medicines (Raynor et al. 2005).

Drug consumers do mostly read through the leaflet accompanying the drug package, but they have difficulties in understanding it due to, for example, the length or poor readability of the text (Bandesha et al. 1996, Baker 1997). Studies have also reported of difficulties in understanding the contents of the PIL produced in accordance with the sample given by the European Commission in 1998 (Dickinson et al. 2001). The text is too long, contains too many words, and the necessary information is difficult to find (Dickinson et al. 2001).

In the UK, the medicine authority (MHRA) has set up a Patient Information Working Group for making recommendations to improve drug information. This group has published a report ‘Always Read The Leaflet – getting the best information with every medicine’, which focuses on the value of PILs as drug information source for medicine users. They recommend, that a glossary of lay terms for describing adverse effects should be developed, tested and enlarged. The information needs of children, young people and carers as well as patients who have difficulty in accessing the information in the usual PIL should receive particular attention. (MHRA, Committee on Safety of Medicines 2005)

Package information leaflets are nevertheless not a solution to the patients’ problem of finding information. The information contained in them becomes available only in association with the drug, i.e. not until the product is purchased. The information in the leaflet only relates to that particular drug and there is no information about the advantages compared with other alternatives. (Raynor and Britten 2001a, Raynor and Britten 2001b)

A well-designed PIL provides the patient with a sufficient quantity of information in adequately comprehensible form. This also extends challenges to pharmaceutical companies (Amery and Van Winkel 1995). According to Mansoor and Dowse (2003), the following features contribute to the location and understanding of the information:

• short, easy-to-read and highlighted headings for navigating through the leaflet
• bullet points and broken paragraphs, as opposed to solid text, for attracting attention
• large spaces between paragraphs and important points, rendering the leaflet less intimidating
• large print size that improves legibility

5.3.3 Labelling of medicinal products

Drug information is also available to the consumer in the form of labelling of the medicinal products. The package insert may inadvertently be discarded, but the outer packaging is often retained. The text in the drug package labelling is often in small print and concise, in which case it may be difficult to decipher or understand (Kalsher et al. 1996, Sansgiry and Pawaskar 2005). The informative aspects of the medicine packaging are influenced, for example, by the colouring, illustrations and layout of the text (Kauppinen 2004). Illustrations such as pictograms make it easier to absorb the information (Kalsher et al. 1996).

In relation to self-care medicines, drug packag-
The Internet contains overwhelming amounts of information, and consumers are tempted in many ways. The Internet is a natural tool for obtaining information especially for adolescents.

Es serve as an important source of information. The packaging should provide adequate information about the therapeutic indication and correct use of the drug (Bradley et al. 1994). In a study on packages for two self-care product categories, analgesics and cold preparations, it was found that labels in colour with bigger font size, all capital font type, bigger picture size and symbol-type picture may be easier to understand than black-and-white labels with smaller font size, normal font type, smaller picture size and photograph type pictures (Sansigary et al. 2001). An effect of package design variables on evaluation of self-care medication information was also found: vivid package designs could enhance the intention to purchase self-care products, but they did not increase consumers’ ability to comprehend information given on the label (Sansigary et al. 2001).

5.4. The Internet

5.4.1 The Internet as a means of dissemination of drug information

Use of the Internet expressed in percentage of the population in the European Union member states is shown in Table 2. At the end of 2005, the Internet was being used by about half (49.8 %) of the population in the European Union. The smallest proportion of Internet us-

<table>
<thead>
<tr>
<th>European Union</th>
<th>Internet usage penetration (% population)</th>
<th>Usage % in EU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>56.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Belgium</td>
<td>48.7</td>
<td>2.2</td>
</tr>
<tr>
<td>Cyprus</td>
<td>31.0</td>
<td>0.1</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>47.0</td>
<td>2.1</td>
</tr>
<tr>
<td>Denmark</td>
<td>69.5</td>
<td>1.7</td>
</tr>
<tr>
<td>Estonia</td>
<td>50.0</td>
<td>0.3</td>
</tr>
<tr>
<td>Finland</td>
<td>62.5</td>
<td>1.4</td>
</tr>
<tr>
<td>France</td>
<td>43.0</td>
<td>11.3</td>
</tr>
<tr>
<td>Germany</td>
<td>59.0</td>
<td>20.8</td>
</tr>
<tr>
<td>Greece</td>
<td>33.7</td>
<td>1.7</td>
</tr>
<tr>
<td>Hungary</td>
<td>30.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Ireland</td>
<td>50.7</td>
<td>0.9</td>
</tr>
<tr>
<td>Italy</td>
<td>48.8</td>
<td>12.7</td>
</tr>
<tr>
<td>Latvia</td>
<td>35.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Lithuania</td>
<td>28.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>58.9</td>
<td>0.1</td>
</tr>
<tr>
<td>Malta</td>
<td>78.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>65.9</td>
<td>4.8</td>
</tr>
<tr>
<td>Poland</td>
<td>27.8</td>
<td>4.7</td>
</tr>
<tr>
<td>Portugal</td>
<td>58.0</td>
<td>2.7</td>
</tr>
<tr>
<td>Slovakia</td>
<td>42.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Slovenia</td>
<td>48.5</td>
<td>0.4</td>
</tr>
<tr>
<td>Spain</td>
<td>38.7</td>
<td>7.1</td>
</tr>
<tr>
<td>Sweden</td>
<td>74.9</td>
<td>3.0</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>62.9</td>
<td>16.7</td>
</tr>
<tr>
<td>European Union</td>
<td>49.8</td>
<td>100.0</td>
</tr>
</tbody>
</table>
ers was found in eastern Europe and the biggest in the Nordic countries, the Netherlands and Malta. However, the proportion of Internet users was not very high in some western European countries either, e.g. in Spain and in France. The Internet usage in countries outside the EU varies from 2.4% (Albania) to 75.9% (Iceland). (www.internetworldstats.com)

Health information seems not to be among the most commonly sought topics on the Internet. A random sample of search terms entered into a search engine was analysed in a study. Of the 2,985 search expressions, 2,827 (94.7%) were classified as non-health related, 3.6% were referred to as health-related and 1.7% received an inconsistent classification (Eysenbach and Köhler 2004). Less than a tenth (8.1%) of the health-related searches were medicine-related (Eysenbach and Köhler 2004). In general, information on general health and specific disorders appears to have a very low priority for people using Internet search engines (Phillipov and Phillips 2003).

For obtaining information, the Internet is a natural and familiar tool especially for adolescents (Coleman 2003, Gray at al. 2005). Obtaining information on the Internet is for many easier than, for example, using books, health care professionals or package inserts as the resource (Gray et al. 2005). However, the Internet based information and interactive discussion do not necessarily affect patients’ disease management (Bruce et al. 2005). The overwhelming amount of information available on the Internet may also make decision-making more difficult (Hart et al. 2004).

Almost all of the 18 to 44-year-old participants in an American study carried out at the end of the 1990’s had occasionally used the Internet, whereas only 46% of the 60-year-olds and older had. A third (31%) of those under the age of 60 were reported as having searched the Internet for information associated with health or medicines. Those on higher earnings searched the Internet for information associated with health or medicines more commonly than those on lower earnings, and those with a higher education more than those with a lower education. (Brodie et al. 2000)

Examples of advantages and disadvantages associated with the use of the Internet in information search are shown in Table 3. The indisputable advantage of the Internet is its ease of use and speed. The Internet makes interaction possible, and queries of a more sensitive nature can be put to experts (Pohjanoksa-Mäntylä et al. 2002). Among cancer patients, website users (modern technology) were more likely than

Table 3. The Internet as a source of drug information: benefits and disadvantages (Eysenbach and Jadad 2001, Eysenbach and Diepgen 2001, Pohjanoksa-Mäntylä et al. 2002).

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact is made with a large number of people</td>
<td>People may have limited access to the Internet</td>
</tr>
<tr>
<td>Interaction is made possible via discussion and feedback</td>
<td>The authors or the owners of the site may be difficult to recognise</td>
</tr>
<tr>
<td>The availability of multimedia such as the combination of sound/effects and text</td>
<td>The information needs updating</td>
</tr>
<tr>
<td>Speedy communication</td>
<td>Information which may be harmful and injurious to the health is easily found and quickly spread</td>
</tr>
<tr>
<td>Information may be searched for and questions asked anonymously</td>
<td>The quality of information is difficult to confirm</td>
</tr>
<tr>
<td>Information on intimate issues is easy to search for</td>
<td></td>
</tr>
<tr>
<td>Consumer-oriented</td>
<td></td>
</tr>
</tbody>
</table>
telephone helpline users (old technology) to request factual information and less likely to request information on sensitive topics (Hardyman et al. 2005). The subjects of the study tended to use the Internet for searching information about ‘depression and cancer’ and about ‘death, dying and bereavement’ and the telephone helplines for information about ‘finance, legal, patients’ rights’ (Hardyman et al. 2005).

When consumers search the Internet for drug information, they often use a search engine (Eysenbach and Köhler 2002, Hansen et al. 2003). Users of the Internet tend to explore only the first few links on general search engines when seeking health information (Flanagan and Metzger 2000, Eysenbach and Köhler 2002). In practice, consumers very seldom check any ‘about us’ sections of websites, try to find out who the authors or owners of the site are, or read disclaimers or disclosure statements (Eysenbach and Köhler 2002).

One study examined the quality of online information pertaining to one specific problem (androgen deficiency in the ageing male). Of the 4,927 websites searched, 1.44% and 0.60% of relevant websites were identified by general and medical search engines, respectively. The overall quality of online information was poor. Medical search engines were no better than general search engines in sourcing consumer information. The best among the general search engines was Google and among the medical search engines www.hon.ch. (Illic et al. 2003)

5.4.2 The quality of drug information available on the Internet

The whole spectrum of information available on the Internet varies a lot (Curran and Oh 2001). As the contents of webpages are hardly at all supervised, the information available may be incorrect or even harmful. Consumers using the Internet may have difficulties in finding complete and accurate information on health problems (Berland et al. 2001, Illic et al. 2003).

It is as easy to obtain information about harmful substances as it is about good substances, and the quality of information may vary (Halpern and Pope 2001). Adolescents and children are perhaps not able, or lack the capacity, to assess the quality of information as well as older users of the Internet can (Gray et al. 2005). A high level of reading ability is required for the comprehension of the health information given at websites (Berland et al. 2001).

The subject of a study published in 1999 was the quality of four websites offering drug information, maintained by pharmaceutical companies and commonly used by the public. Only two of them disclosed all the prescription drugs available on the market and intended for the treatment of a certain disease (Hatfield et al. 1999). The majority, but not all, of the information was relevant. An evaluation was made in 2002, however, which stated that the quality of health information on the Internet was improving (Pandolfini and Bonati 2002).

There are some research results available concerning the confidence that consumers show in the drug information obtainable on the Internet. If a person relies on the drug information obtained in the conventional way (written and verbal information), he or she is also likely to rely on the information obtained via the Internet (Menon et al. 2002). Consumers with a positive attitude towards drug information obtained using the more conventional methods also have a positive attitude towards information obtained using the more recent methods (the Internet) (Menon et al. 2002). People consider the information on the Internet to be as credible as that obtained from television, radio and magazines, but not as credible as newspaper information (Flanagan and Metzger 2000.). However, web users with a political interest consider the online newspapers and online candidate literature to be more credible than those of their counterparts with a more conventional means of dissemination (Johnson and Kaye 1998). No difference exists between news magazines and issue-oriented sources.
5.4.3 Information which is harmful or detrimental to the health

Potent and hazardous substances, medicines and narcotics are easily obtainable via the Internet together with instructions for their use. The instructions, for instance, for use and dosage of substances intended for intoxication are available to all. Web based data on psychoactive substances have influence on the drug use practices of adolescents (Boyer et al. 2005).

‘The Vaults of Erowid’ (www.erowid.org) is an example of a website that can be potentially harmful. This website is concerned with chemical substances; the site is also used by experts. It is divided into four sections: Plants & drugs, Mind & spirit, Freedom & law and Arts & culture. The information given at the site is of good quality, but information is given of both ‘good’ and ‘bad’ substances. According to the heading, the site is intended for giving information about both harmful and good use of substances; ‘documenting the complex relationship between humans and psychoactives’. The site deals with harmful substances in the same way as it deals with the useful ones, and information is given, for example, on the use of a useful substance for intoxication purposes. Despite the fact that the site is not actually promoting the use of the substances as intoxicants, the instructions given do make it easy to use them as such.

Finding information on individual substances is easy by using search engines. Gamma hydroxybutyrate (GHB) is a CNS depressant. A search engine result with GHB gives 2,740,000 hits (Google, accessed 24 November 2005). The website offers specific instructions for the reconstitution of the substance, its dosage, use, supplementary dosages and overdose, and for the avoidance of feeling sick.

5.4.4 Is it possible to influence the quality of information available on the Internet?

The Internet is not a solution to the problem of dissemination of drug information as such (Bessell et al. 2002). In the best instance, the consumer can use the Internet for obtaining relevant information of which he or she is able to make use. The consumer does nevertheless not necessarily know whether the information given is reliable (Wax 2002, Eysenbach et al. 2002). Incorrect instructions may be harmful to the consumer (Eysenbach et al. 2002).

A number of organisations have developed guidelines and codes by which they attempt to supervise the content of webpages associated with health. Codes have been developed for example by EFPIA (European Federation of Pharmaceutical Industries and Associations, www.efpia.org) and the American Medical Association (AMA, Winker et al. 2000). The instructions by EFPIA concern pages intended for both health care professionals and the public, and it recommends pharmaceutical companies themselves to use the guidelines in their internal supervision.

Guidelines for AMA websites describe principles for content (e.g. definition; site ownership; site viewing; viewer access, payment and privacy; funding and sponsorship), principles for advertising and sponsorship, principles for privacy and confidentiality, and principles for e-commerce (Winker et al. 2000).

Perhaps the criteria which have received the most publicity in Europe are those of the Code of Conduct (HONcode) for the health/medical domain that was initiated by the Health On the Net Foundation in 1996 (Boyer et al. 1998). At their website (http://www.hon.ch) it is possible to insert a website address, keywords or text into a search machine to find relevant, reliable sources of information in that area. The principles of the code are (http://www.hon.ch):

1. Authority
2. Complementarity
3. Confidentiality
4. Attribution
5. Justifiability
6. Transparency of authorship
7. Transparency of sponsorship
8. Honesty in advertising and editorial policy
For a webmaster wishing to support this initiative and adhere to HONcode principles, a short questionnaire has been created about the quality of the website. This questionnaire provides the option to abide by the HONcode principles and includes the default HONcode logo linked to the HONcode’s webpage. (Boyer et al. 1998)

No code system or guidelines alone are of course adequate to supervise the information available on the Internet (Silberg et al. 1997). The use of the criteria is on a voluntary basis. The producers of the information themselves should assess their pages by using the criteria. There may be errors involved in the granting of stamps or certificates, or the contents of the webpages may have been changed later. A logo or a certificate is easily misused, and they have even been found at charlatan sites (Eysenbach 2000a). Logos can be misunderstood by consumers as ‘an award’ (Eysenbach 2000a).

The minimum tools of quality management of health information on the Internet include (Eysenbach 2000a):

• Educating consumers.
• Encouraging self-regulation of health information providers.
• Evaluating information by third parties.
• Enforcement, in case of fraudulent or positively harmful information.

Consumers need to be educated on how to discriminate between trustworthy and less trustworthy information. Encouragement of self-regulation may need third-party evaluation. Enforcement requires feedback from Internet users and procedures for evaluating complaints, including the possibility of taking appropriate measures such as the blacklisting of unreliable information providers. (Eysenbach 2000a)

The most important of these is the influencing of consumers. Consumers should be taught to filter the information received, i.e. to distinguish between reliable and unreliable information (Eysenbach 2000b). It should be possible for the consumer at least to identify the author of the webpages, the source of information, possible sources of error and the date of publication (Eysenbach 2000b). Consumers should also be more efficiently informed about the means by which the quality of the pages may be assessed. Publicity should also be given to the tools available on the Internet, with which to assess Internet pages (Eysenbach and Diep 2001). One way of doing this is through the preparation of manuals and other written material to which the consumer could resort when searching for reliable information on the Internet (Coleman 2003).

Summary points:

• Drug information that is given face-to-face is interactive and the information can easily be tailored according to the patients’ needs.
• Written drug information can decrease the amount of misunderstanding and patients can return to given information afterwards.
• Package information leaflets are often used as a source of drug information, but patients may not understand the information completely.
• About half of the European Union citizens have access to Internet in the end of 2005. The number of consumers and patients searching for drug information on the Internet is increasing.
• The quality of information obtained from the Internet is variable and consumers may have difficulties in finding valid drug information.
• Educating consumers, encouraging self-regulation of health information providers, evaluating information by third parties and the use of enforcements can be tools for quality management.
6 SPECIAL NEEDS FOR DRUG INFORMATION

A large proportion of drug information is generated with the needs of healthy and adult consumers in mind. The need for information among special groups, for example the elderly, children, or the disabled, may actually be greater than that of healthy consumers. They should also be offered drug information in a format appropriate to them and with their special needs in mind.

The font size of written information should be adequately large and easily distinguishable in order that those with impaired eyesight should be able to read it. A clear layout and use of colours make the absorption of information easier (Raynor and Yerassimou 1997). The text in package inserts may be incomprehensible and difficult to understand especially by the elderly or those of little ability (Bandesha et al. 1996, Rolland 2000).

Children have the right to receive drug information which they are able to understand. The United States Pharmacopeia (USP) has published ten guiding principles for teaching children and adolescents about medicines (www.usp.org/audiences/consumers/children/principles.html). According to these principles, children should receive information about medicines and their use as part of health education in school (Bush et al. 1999, www.usp.org/audiences/consumers/children/principles.html). Medicine education should include information about the general use and misuse of medicines, as well as information that will enable them to avoid poisoning through the misuse of medicines. The teaching contents and method of delivery should be adapted according to the child’s age and ability to understand the information given, and modified accordingly (Menacker et al. 1999, Hämeen-Anttila et al. 2006).

Many special groups need drug information aimed particularly at them. Children, for example, have the right to receive drug information which they are able to understand.

A large proportion of the world’s population is illiterate. Pictograms are illustrations designed to help in the delivery of drug information to the illiterate and have been found to be helpful in the absorption of knowledge (Hanson 1995, Dowse and Ehlers 2001). Pictograms improve the comprehensibility of drug information (Mansoor and Dowse 2003, Knapp et al. 2005), but misunderstanding them is also a possibility (Knapp et al. 2005). They are useful in combination with small print size or when the print is not legible (Kalsher et al. 1996). They may also be valuable for individuals who are not proficient with language (Kalsher et al. 1996), for the elderly and for those with decreased literacy skills (Hanson and Hartzema 1995).

Information leaflets with both written text and illustrations (e.g. pictograms) are the most popular ones among consumers (Sojourner and Wogalter 1997). Leaflets with text alone are considered superior to leaflets containing only pictograms (Sojourner and Wogalter 1997). Pictograms render the texts more readable and comprehensible, causing the issue to stick more easily in the mind (Sojourner and Wogalter 1997). Studies carried out on Finnish children did not, however, show that the use of pictograms in the package inserts would have improved the comprehensibility of the drug information they contained (Hämeen-Anttila et al. 2004).

Summary points:

- Most of the drug information is formulated for ordinary consumers.
- Drug information appropriate to the needs of special groups, e.g. elderly people, children and disabled persons, should also be available.
7 FUTURE CHALLENGES

In the future, consumers will to an ever-increasing degree and at a more equal level than before be participating in the decision-making concerning their own health care, and this development should be encouraged (Coulter 2002). There are a number of tools to empower patients (Coulter 2002):

- Recognising patients’ expertise.
- Offering informed choice, not passive consent.
- Training in shared decision making.
- Evidence-based decision aid for patients.
- Public education concerning the interpretation of clinical evidence.
- Patient access to electronic health records.
- Surveys of patients’ experience in order to prioritise quality improvements.
- Openness and empathy with patients (or parents) following occurrence of medical errors.
- Public access to comparative data on quality and outcomes.

Greater responsibility taken on consumers for their own health and health care could be cost saving if it results in reduced frequency of contact with health care professionals (Eysenbach 2000b). We could speak of evidence-based patient choice, EBPC (Eysenbach and Diepgen 2001, Holmes-Rovner et al. 2001). For this purpose the consumer should have the opportunity to receive adequate amounts of correct information. The patient should also have the opportunity to choose among a variety of treatment options.

Consumer health informatics and e-health are emerging future trends. The concept of e-health includes electronic health information and services available over networks such as the Internet, and related technologies such as digital TV/WebTV, wireless media such as Web-compatible mobile phones and personal digital assistants (PDAs). The use of these media as a resource for drug information will increase as time goes on. (Eysenbach and Diepgen 2001)

According to the manifesto of the eEurope website of the European Union, each European citizen would by the end of 2003 have had the opportunity to access confidential patient information (eEurope 2000). This aim has not been achieved. If the aim were to be achieved, there could in future be a need for professionals who, by using information technology, could advise consumers online and guide them to sources of correct information (Eysenbach 2000a). Patients could also receive assistance in deciding whether they should approach a health care professional for advice or whether they could manage the situation on their own (Eysenbach 2000a, Eysenbach 2000b).

Incorporation of consumer perspectives into the quality of health care was the subject of a paper by Cleary and Edgman-Levitan published in 1997. The claims are still valid. From a drug information perspective, the summary of future challenges could include:

- Collection of information from representative samples of diverse people about the value they place on different types of drug information.
• Conducting research into the level of understanding and interpretation of different individuals in respect of drug information and decision-making about health care.
• Developing methods for creating and presenting evaluations of data.
• Developing models which would put the need for general drug information and the needs of specific groups into balance (e.g. chronic conditions, disabled people, elderly persons, children).
• Developing databases of patient-oriented drug information to enable patients and doctors to understand one another in making decisions.
• Developing models for the effective dissemination of drug information.
• Expanding the use of interactive systems enabling patients to communicate directly with other patients with similar conditions.
• Developing methods to evaluate different strategies to improve quality (e.g. consumer choice vs. efforts of planning vs. regulation).

Summary points
• New technological inventions will provide new opportunities for disseminating drug information.
• The need for accurate drug information will increase, but the needs will vary.
• In the future, conventional tools such as leaflets and booklets on drug information will still be of value.
• There should be an increased emphasis on informing consumers about how to recognise valid and reliable drug information.
According to the research results, the following conclusions can be drawn:

Patients and consumers:

• The volume of and ease of access to drug information for patients and consumers should be increased, including the means by which they may evaluate the quality of the information. The information about the tools for evaluating should be published in the media, for example, in newspapers and magazines.

• Patients and consumers should be instructed and encouraged to use interactive Internet tools (e.g. www.discern.org.uk, www.quick.org.uk), the purpose of which is to train consumers to check the quality of information.

• The basic advice given to consumers about medicines should be increased. The advice could, for example, consist of instructions for making the right decision about whether to use self-medication or to ask a health care professional to make a diagnosis of the symptoms. Health education about medicines should start at school.

• Patients and consumers should be encouraged to take more responsibility of their own treatment and make evidence-based patient choices.

• Drug information available to patients with special needs should be increased. Individuals with low literacy skills, the blind and those with poor eyesight, as well as the elderly and children, need drug information appropriate for their needs.

Health care professionals:

• Health care professionals should encourage patients to take a bigger responsibility for their own treatment. The professionals should receive more education about skills of interaction and human relationship.

• Consumers want drug information particularly from doctors and pharmacists, and this makes the dissemination of drug information an important part of their work. They should be capable of assessing the type of information the patient would want or need. Drug information should be tailor-made to include specific information appropriate to each patient.

• The pharmacists have a very important place in the provision of drug information e.g. about self-care medicines. They should be able to help the patient to deal with the treatment.

• Doctors and pharmacists need to do more co-operation, e.g. make local agreements about the content of the information.

Drug regulatory authorities:

• The drug authorities should consider themselves more definitely as a valid source of drug information also for patients and consumers. Many EU Member States publish SPCs and/or PILs of medicinal products at their websites, but other drug information intended for the consumers should also be available. This should include instructions for the correct use of medicinal products.

• Consumers and patients should be better informed about the role of the authorities in drug information and medicinal care.
The pharmaceutical industry:

- Pharmaceutical companies possess the key information about medicinal products, which makes the dissemination of drug information to patients and consumers a great challenge. The drug information produced and distributed by the pharmaceutical industry should be transparent and include details about the producer of the information readily available to consumers.
- Direct-to-consumer advertising increases the consumption and sales of prescription drugs. There are also problems associated with inappropriate use of medicines. The experience in the USA does not encourage allowing DTC advertising to the public in Europe.
- More information to assist the consumer in the comparison of the product with other treatment options should also be available.

Written drug information:

- Recommendations for improving the readability of PILs, including print size, type, colour, syntax, Braille and size of paper have been set. In the future, even more detailed information will be given. Fulfilling the recommendations should be studied further. Has understanding of the contents improved among patients? What other improvements should be made?
- The comprehensibility of information given about possible adverse effects, including their frequency, should be improved.
- Written drug information should also be transparent. Patients and consumers should at least be able to recognise the origin, author, the possible sponsor and date of preparation of the information available.

The Internet and new information technology:

- The use of new technology should be increased in the dissemination of drug information. This includes e.g. electronic health information and services available over networks and related technologies (digital TV/WebTV, wireless media, personal digital assistants).
- EMEA has been mandated to create a database of the information about medicinal products authorised in the European Union (www.eudra.org/euteleproj/europharm/index.htm). Such a database, with easy access to health care professionals, patients and the general public would improve the dissemination of drug information. However, there are many issues involving the use of the database that should be resolved. These are e.g. updating and the language of the information. The information should be regularly updated and available in all European languages.
- Information available on the Internet should be reliable, and there should be transparency of authorship and sponsorship.

In general:

- There are many kinds of consumers and patients. Not everyone has the opportunity to make use of information technology, and this may increase inequality. Drug information should still in the future be available in many different forms, both written and verbal, and it should be mediated by several different means.
- In order to improve the drug information more research into the needs, opportunities and attitudes of the individual consumer and patient concerning the drug information needs to be carried out.
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