MEDICINES INFORMATION SOURCES AND SERVICES FOR CONSUMERS: A SPECIAL FOCUS ON THE INTERNET AND PEOPLE WITH DEPRESSION

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ACADEMIC DISSERTATION

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Abstract

The range of consumer health and medicines information sources has diversified along with the increased use of the Internet. This has led to a drive to develop medicines information services and to better incorporate the Internet and e-mail into routine practice in health care and in community pharmacies. To support the development of such services more information is needed about the use of online information by consumers, particularly of those who may be the most likely to use and to benefit from the new sources and modes of medicines communication.

This study explored the role and utilization of the Internet-based medicines information and information services in the context of a wider network of information sources accessible to the public in Finland. The overall aim was to gather information to develop better and more accessible sources of information for consumers and services to better meet the needs of consumers. Special focus was on the needs and information behavior among people with depression and using antidepressant medicines.

This study applied both qualitative and quantitative methods. Consumer medicines information needs and sources were identified by analyzing the utilization of the University Pharmacy operated national drug information call center (Study I) and surveying Finnish adults (n=2348) use of the different medicines information sources (Study II). The utilization of the Internet as a source of antidepressant information among people with depression was explored by focus group discussions among people with depression and with current or past use of the antidepressant(s) (n=29, Studies III&IV). Pharmacy response to the needs of consumers in term of providing e-mail counseling was assessed by conducting a virtual pseudo customer study among the Finnish community pharmacies (n=161, Study V).

Physicians and pharmacists were the primary sources of medicines information. People with mental disorders were more frequent users of telephone- and Internet-based medicines information sources and patient information leaflets than people without mental disorders. These sources were used to complement rather than replace information provided face-to-face by health professionals. People with depression used the Internet to seek facts about antidepressants, to share experiences with peers, and for the curiosity. They described that the access to online drug information was empowering. Some people reported lacking the skills necessary to assess the quality of online information. E-mail medication counseling services provided by community pharmacies were rare and varied in quality.

Study results suggest that rather than discouraging the use of the Internet, health professionals should direct patients to use accurate and reliable sources of online medicines information. Health care providers, including community pharmacies should also seek to develop new ways of communicating information about medicines with consumers. This study determined that people with depression and using antidepressants need services enabling interactive communication not only with health care professionals, but also with peers. Further research should be focused on developing medicines information service facilitating communication among different patient and consumer groups.
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List of original publications

This thesis is based on the following original publications, referred to in the text by the Roman numerals (I-V).


V Pohjanoksa-Mäntylä M, Kulovaara H, Bell JS, Enäkoski M, Airaksinen MS. E-mail medication counseling services provided by Finnish community pharmacies. Ann Pharmacother 2008;42:1782-1790

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Definitions of the key concepts

Antidepressant
Antidepressants are defined according to the Anatomical Therapeutic Chemical (ATC) classification system recommended by the World Health Organization (WHO) as non-selective monoamine reuptake inhibitors (NO6AA; synonymous to tricyclic antidepressants; TCAs), selective serotonin up-take inhibitors (NO6AB; SSRIs), monoamine oxidase type A inhibitors (NO6AG), and other antidepressants (NO6AX) (WHO Collaboration Centre for Drug Statistics 2009).

Consumer
The consumer refers to users of goods and services. In the context of pharmaceuticals and pharmaceutical services, those goods and services include medicines, medicines information services, and pharmacy services (Närhi 2006). This definition covers also patients (e.g., people with particular disorders and/or requiring medical care). When relevant in this thesis, terms ‘patient’ and ‘medicine user’ are used to make a distinction between consumers in general and consumers using medicines or requiring other type of medical care.

Concordance
Concordance is an approach to the prescribing and taking medicines (Royal Pharmaceutical Society of Great Britain 1997, Dickinson et al. 1999, Horne et al. 2005, National Institute for Health and Clinical Excellence 2007). At the core of the concordance is an agreement reached after negotiation between a patient and a healthcare professional that respects the beliefs and wishes of the patient in determining whether, when, and how medicines are taken. Concordance is synonymous with patient-centered care.

Depression
The International Classification of Diseases and Related Health Problems (ICD-10) uses an agreed list of ten symptoms of depression and divides the common form of major depressive episode into four groups: not depressed (fewer than two symptoms); mild (two to three symptoms); moderate (four or more symptoms); and severe or major (several symptoms with or without various psychotic symptoms, includes often also suicidal thoughts and acts and a number of somatic symptoms) (World Health Organization 2007). If appropriate, in the literature review part of this thesis, these definitions are used to have distinction between the different forms and levels of depression. In the empirical part of the thesis, ‘people with depression’ is used to refer to people with different levels of depression as the inclusion criteria did not differentiate participants according to severity of depression.

Drug information center
Drug information centers (DIC; also known as medicines information centers or drug information call centers), are medicines information services were people can call or otherwise contact health care professionals and inquire about medicines (Hall et al. 2006).
Due to the fact that the term ‘Drug information center’ is widely used in the literature, the term is also used in this study. Pharmacies and pharmacists can provide medicines information services (for example e-mail or telephone counseling services) that complement face-to-face counseling provided in pharmacies. ‘Drug Information Call Center’ is used when counseling via the telephone is concerned.

**Empowerment**

Empowerment is the enhanced ability of consumers to actively understand and influence to their health status (Rodwell 1996). Information is the core of the empowerment. Without sufficient information people can not engage in meaningful discussions or make thoughtful decisions regarding their care and treatments.

**Information behavior**

Information behavior refers to human behavior in relation to sources and channels of information. This includes both active and passive information seeking, and information use. Additionally, it covers the following functions: how people need (information needs), seek, give, and use information (Williamson 1998, Fisher et al. 2006).

**Internet**

The Internet is a network of computers that allow the transmission of data for multiple purposes through a common set of protocols according to a global address system. Electronic mail (e-mail), bulletin board systems (BBS), internet relay chat (IRC), and internet sites (www-sites) are forms for the exchange messages and interact via the Internet (Wood and Smith 2005).

**Medicines information**

In line with previous studies on medicines information and requirements for statutory information on medicines, medicines information covers: information on the identification of the medicinal product (the name, strength, and pharmaceutical form of the medicinal product); the therapeutic indications; information which is necessary before the medicinal product is taken (the contraindications, appropriate precautions for use, interactions, and special warnings); the necessary and usual instructions for proper use (the dosage, the route and frequency of administration); and information where the medicinal product is authorized (Directive 2001/83/EC). Due to the consumer approach in this thesis, also peer experiences in medicines taking are included in the definition. Medicines information (British) and drug information (American) are synonyms that refer to all kinds of medicines -related information accessible to the public via different sources and modes of delivery (face-to-face, written, electronic). For consistency, ‘medicines information’ is the term applies in this thesis with two exceptions: 1) term ‘drug information’ is used in original papers I, III and V; 2) drug information is also the terms used when discussing about drug information centers. This is due to the fact the ‘drug information center’ term is well established and widely used in previous literature.

**Medicines information services**

Medicines information services can be seen as services relating to provision of medicines information. In this study, medicines information service (synonymous to drug
information service) refers to a formal unit with appropriate resources and professional competencies engaged in the provision of medicines information (Hall et al. 2006). This includes also drug information call centers and e-mail medication counseling services provided by pharmacies.

**Mental disorder**
Based on the International Classification of Diseases and Related Health Problems (ICD-10) ‘mental disorder’ covers any mental illnesses, mental retardation, personality disorders and substance dependence (World Health Organization 2007). This definition includes also depression. The term ‘mental disorder’ is often used as a synonymous to ‘mental illness’. Due to avoid the dominance of the medical model, however, the most international clinical documents and some consumer organizations avoid the use of the term mental illness, preferring the term ‘mental disorder’ (American Psychiatric Association 2000, World Health Organization 2007). For consistency, the term ‘mental disorder’ has been used in this thesis. ‘People with mental disorders’ is used to refer to people with any mental disorders.

**Medication counseling**
The concept of medication counseling is closely related to the concepts of patient counseling, patient education, pharmacist-patient-communication and advice-giving. Those all have been used to refer to the communication about medicines between pharmacists or other health care professionals and patients (Vainio 2004, Puumalainen 2005, Puumalainen et al. 2005, Puumalainen and Kansanaho 2005, Shah and Chaewning 2006). For consistency, the term ‘medication counseling’ has been used in this thesis. ‘E-mail medication counseling’ is used in relation to counseling via the Internet and e-mail.
Abbreviations

ADR  Adverse drug reaction
ATC  Anatomic therapeutic chemical classification
DDD  Defined daily dose
DIC  Drug information center
EC   European Community
E-MAIL  Electronic mail
EU   European Union
FDA  Food and Drug Administration
FG(D)  Focus group (discussion)
FIMEA  Finnish Medicines Agency
FIP  International Pharmaceutical Federation
FSHS  Finnish Student Health Service
G10 European Commission Enterprise and Industry Directorate General High Level Group on Innovation and the Provision of Medicines
ICD-10 The International Classification of Diseases and Related Health Problems
MI  Medicines information
NAM  National Agency for Medicines
PIL  Patient information leaflet, package leaflet
PPP  Public-private partnership
SPC  Summary of product characteristics
SSRI  Selective serotonin up-take inhibitor
TCA  Tri-cyclic antidepressant
UP  University Pharmacy; owned by University of Helsinki
WHO  World Health Organization
WWW  World Wide Web
1 Introduction

The range of potential health and medicines information sources available to consumers is changing and diversifying along with the new information technology (The Council of Europe Expert Group on Safe Medication Practices 2007, European Commission. DG Enterprise and Industry 2007). According to previous studies, physicians and community pharmacies are among the leading sources of medicines information for consumers (Sleath et al. 2003b, Närhi and Helakorpi 2007b, Närhi 2007). Although the provision of medicines information has been recognized as a key strategy for promoting the safe and effective use of medicines, the provision of medicines information in face-to-face consultations has proved to be sub-optimal and not meeting the needs of all medicine users (Vainio et al. 2002, Cox et al. 2004, Puimalainen et al. 2005). As a consequence, consumers may seek additional information from a diverse range of sources increasingly including the Internet (Närhi and Helakorpi 2007b, Närhi 2007).

In June 2009, 50% of about 804 million people living within the Europe had access to the Internet (www.internetworldstats.com). Based on a study conducted in seven European countries, 71% of the Internet users had used the Internet to access health information in 2005 (Andreassen et al. 2007). In Finland, 30% of the total adult population has reported using the Internet for health information (Helakorpi et al. 2008), and more specifically, between nine and twenty percent of the medicine users to access information on their medicines (Närhi and Helakorpi 2007b, Närhi 2007). Although the Internet facilitates easy access to medicines information and helps consumers to take a more active role in health care, it challenges both consumers and health care professionals with regard to the quality, reliability, and availability of information. The Internet-based information on health and medicines has found to be highly variable (Griffiths and Christensen 2000, Christensen and Griffiths 2002, Graber and Weckmann 2002, Nemoto et al. 2007, Morahan-Martin 2004, Ferreira-Lay and Miller 2008, Griffiths and Christensen 2002, Martin-Faclam et al. 2004).

In October 2008 the European Commission High Level Pharmaceutical Forum highlighted the need to invest in high quality and accessible patient information on diseases and treatment options, particularly medicines (High Level Pharmaceutical Forum 2008b). According to the Pharmaceutical Forum, to be good quality, medicines information should be objective and unbiased, patient-oriented, evidence-based, up-to-date, reliable, understandable, accessible, transparent, relevant, and consistent with statutory requirements (High Level Pharmaceutical Forum 2008a). The Forum recommended that providing this information should be the responsibility of all stakeholders within healthcare. The needs of different types of individual and consumer groups using medicines should be taken into account in designing and developing medicines information and information services for consumers (European Commission DG Enterprise and Industry 2007).

People with mental disorders seem to have special needs for information about medicines. They have reported dissatisfaction with the quality and quantity of medicines information provided by health care professionals (Happell et al. 2004, Bell et al. 2005). As a consequence, they are frequent users of online health information (Haviland et al.
2003, Wagner et al. 2004, Powell 2006), and are more likely than those with other long term illnesses to search for health-related information online (Bansil et al. 2006). Little is known, however, about the role of the Internet as a source of medicines information compared to other sources of medicines information among people with mental disorders, particularly with depression. The goal of this study is to examine this gap in the literature. This study explores the role and use of Internet-based medicines information and information services by people with depression and using antidepressant medicines in the context of a wider network of information sources accessible to the public in Finland. The overall aim is to gather information for the development of consumer medicines information sources and services to better meet the needs of consumers.

The literature review for this thesis provides a conceptual, theoretical, and contextual framework of the study (Chapters 2 to 6). The purpose was not to test or use any particular theory, but theories and models were used to identify the study questions, to structure the analysis, and to interpret consumer needs for and use of different sources of medicines information. Theories and models used in communication research and in information behaviour were applied. Williamson`s Ecological Model of Everyday Life Information Seeking and Use (1998) was chosen as a key theoretical model of this study (Chapter 2). In line with Williamson`s (1998) model, the literature review summarizes the current research-based knowledge about the leading sources of consumer health and medicines information (Chapter 4). Additionally, the quality and reliability of the Internet-based medicines information is discussed (Chapter 5). The research on information needs and use of different sources of medicines information among people with mental disorders, particularly depression, is reviewed in Chapter 6. In order to capture the range of published articles relating to the topic, this review was based on the systematic literature search from the following databases: Medline, CINAHL, PsychInfo, and ISI Web of Knowledge. Detailed description of the search strategy is provided in Chapter 6. Special focus in the literature review is on the Internet, because the Internet is increasingly used source of medicines information. That is why also the empirical part of this thesis was focused on the Internet use for medicines information (Chapters 8-13).
2 Medicines information in theoretical context

2.1 Medicines information and related concepts

2.1.1 Medicines information

This study focuses particularly on medicines information. However, medicines information is seen as an important part of health and everyday life information, e.g., information people need in their everyday life in the contexts not relating to their work (Figure 1). This is based on the fact that medicines information has been commonly included as a sub-category in studies on health and everyday life information (Williamson 1998, Fox 2006). Consumers may not only want to have information on how to manage their medicines, but also information to make therapeutic choices (Newby et al. 2001). Therefore, it is suggested that medicines information should be provided within the wider framework of general health information (Newby et al. 2001, Raynor et al. 2007a, Commission of the European Communities 2008).

Medicines information (British) and drug information (American) are synonyms that are used to describe a variety of statements that relate to medicines. However, there is no single generally accepted or established definition. Instead, medicines information has been defined from several perspectives (Figure 1): the perspective of consumer, pharmaceutical industry, society, regulatory authorities or media depending on the purpose and approach of the study or on the context in which the term is used (Wahlroos 2003, Närhi 2006). The definition, content, and interest of communicating about medicines are related to the actors involved.

In a widest sense, the term ‘medicines information’ refers to all kinds of medicines-related information available to the public and health care professionals. Different sources and methods of delivery may also be included in the definition (Wahlroos 2003). The International Pharmaceutical Federation (FIP) Pharmacy Information Section has defined medicines information used in drug information centers and services as a process of providing information on the safe and effective use of therapeutic and diagnostic pharmaceuticals. Another definition defines medicines information as a system of knowledge and techniques that allows the transfer of knowledge about drugs, in order to optimize therapeutics for the benefit of patients and of society (Hall et al. 2006). Both of these definitions are restricted to the process of delivering information. They do not explain either who the user of medicines information sources and services is or the content of medicines information. In the EU legislation instead (Directive 2001/83/EC), the content of medicines information in patient information leaflets is defined as: information on the identification of the medicinal product; the therapeutic indications; information which is necessary before the medicinal product is taken; the necessary and usual instructions for proper use; and information where the medicinal product is authorized.
Figure 1. The concept of medicines information, its relation to everyday life information and examples of approaches influencing its definition and content, as well as values and motives for communicating about medicines. Everyday life information refers to information that people need in their everyday life in the contexts not relating to their work.

In this study, medicines information is considered from the perspective of the consumer. It refers to all kinds of medicines-related messages that can be communicated via different modes of delivery (face-to-face, written, electronically) and from different sources available to the public (Lilja et al. 1996). Medicines information includes information required by law, but also other information readily available to consumers (Grymonpre and Steele 1998, Ryan et al. 1998, Bouvy et al. 2002, Pohjanoksa-Mäntylä et al. 2002). In addition to evidence-based information on medicines, information may refer to intangible issues such as opinions of medical experts and experiences of peer consumers (Eriksson-Backa 2003).

2.1.2 Medication counseling and e-mail medication counseling

The concept of medicines information is closely related to the concepts of patient counseling, medication counseling, patient education, pharmacist-patient-communication, patient information and advice-giving. Those all have been used to refer to the communication between pharmacists and patients (Vainio 2004, Puumalainen 2005, Shah and Chaewning 2006, Puspitasari et al. 2009). Although communication between pharmacists and customers in community pharmacies has been actively studied there is neither established term to use nor consensus of what constitutes of good counseling or medicines information practice (Puumalainen 2005, Shah and Chaewning 2006). A recent
review of 39 studies on patient counseling (Shah and Chaewning 2006) found that most researchers have used the term counseling instead of advice-giving or education, and conceptualized pharmacist-patient communication as a pharmacist information providing activity. The United States Pharmacopeia (USP) Medication Counseling Behavior Guidelines are the only validated tool to measure the content of the counseling (Puumalainen and Kansanaho 2005, Puumalainen et al. 2005). In those guidelines, the term medication counseling has been used. It has been defined as an approach that focuses on enhancing the problem solving for the patient to improve or maintain quality of health and quality of life (Puumalainen and Kansanaho 2005, Puumalainen et al. 2005).

The term medication counseling is also used in this study when communication between pharmacists and consumers is referred to. The term e-mail medication counseling is used to describe counseling via the Internet and e-mail. Communication is seen as a dyadic two-way process involving a sender and a receiver in which the communicated information is understood by both the sender and receiver. Information behavior is used to refer to human behavior in relation to the sources and channels of information (Wilson 2006). This includes both active and passive information seeking and covers issues such as: how people need, seek, give, and use information.

2.1.3 Modes and sources of medicines information

Information can be accessed and delivered via different modes (face-to-face, written, electronic) and sources. Those sources can be classified as: personal or interpersonal sources; lay or professional sources; personal, institutional and media sources; and traditional (for example health care professionals) or e-technology-based sources (Williamson 1998, Gray et al. 2005, Cleary et al. 2008). E-technology is commonly understood to include the Internet and related technologies (Eysenbach 2000, Cleary et al. 2008). In relation to medicines information, e-technology is linked to the concept of telepharmacy (Angaran 1999). Although no formal definition exists, telepharmacy can be broadly understood to include all pharmacy services that can be provided remotely (Angaran 1999). This definition includes telepharmaceutical information sources such as pharmacy websites, e-mail medication counseling services (e.g., ask-the-pharmacist-services), and telephone services (Assemi et al. 2002, Bessell et al. 2002, Pohjanoksa-Mäntylä et al. 2002, Bessell et al. 2003, Zehnder et al. 2004, Holmes et al. 2005, Ghoshal and Walji 2006, Jariangprasert et al. 2007). Telepharmacy is synonymous to e-pharmacy. In this study, telepharmacy is used to refer to pharmacy services provided via the Internet and telephone.

2.2 Empowerment and concordance as background approaches of this study

Consumers may act as passive recipients or active seekers of information about their health and medicines they use (Williamson 1998, Gray et al. 2005, Hämeen-Anttila 2006). Traditionally, the role of consumer in health care has been passive (Royal Pharmaceutical Society of Great Britain 1997, Itkonen 2000, Hämeen-Anttila 2006). Health care professionals –primarily physicians- have undisputedly been the main and even the only
sources of all health and medicines information. The patient has been expected to obey the advice given by health care professionals (Royal Pharmaceutical Society of Great Britain 1997, Itkonen 2000). Particularly in the last 15 years this has been changing rapidly. After launching the concordance approach in 1997 (Royal Pharmaceutical Society of Great Britain 1997), increased emphasis has been placed on collaborative models of medication decision making and patient involvement in their own care (Coulter 1999, Horne et al. 2005, National Institute for Health and Clinical Excellence 2007). The concordance approach whereby patients and healthcare professionals interact as equals and establish a mutual therapeutic alliance has stressed the need for patients to become active participants in health care and take more responsibility over their own care in terms of self-management (Dickinson et al. 1999, National Institute for Health and Clinical Excellence 2007). This shift of power can be called as empowerment (Hämeen-Anttila 2006, The Council of Europe 2007). And as a consequence, consumers are increasingly knowledgeable about and interested in health-related issues (Schneider 2006). Although consumers form a heterogenous group with different needs depending on the disease and its stage, socio-economic status, coping strategies, health beliefs, degree of worries about changes in their health, and access to health services, many of them want to be actively involved in decisions relating to their own healthcare (Enäkoski 2002, Schneider 2006). For this purpose, they need information from or developed by health care professionals and may also seek it actively from a variety of sources (Council of Europe 2007, Närhi and Helakorpi 2007b, Närhi 2007) (Figure 2). This creates new pressures for health care providers to meet the growing need for medicines information and medicines information services facilitating empowerment.

Healthcare professionals, health service researchers, and policymakers increasingly see patients as well informed about their own diseases and treatments. They understand the importance of patient information for informed decision-making, adherence, and safe self-management (Gandhi et al. 2003, Garfield et al. 2004, Raynor et al. 2004, Horne et al. 2005, Kansanaho 2005, Hämeen-Anttila 2006, Schneider 2006, Council of Europe 2007, European Commission 2007, High Level Pharmaceutical Forum 2008b). The process in which patients and health care professionals collaborate in sharing ownership of a decision making is thought to improve therapeutic outcomes (Schneider 2006). With regard to mental disorders, empowerment and self-management approaches may also offer a solution to such problems as disempowerment, stigma and lack of resources in health care (Schneider 2006).

The empowerment and concordance are the background approaches in this study (Figure 2). In line with those approaches, the study is consumer centered. Consumers are seeing as active participants in health care who may seek medicines information from a multiple sources and modes of medicines information. Medicines information is seen as a tool to empower consumers and to enable safe self-management. These approaches have affected to the choices of the theoretical model (See 2.3.) and also the methods used in this study (Chapter 9).
**Figure 2.** Medicines information context and the goal of communicating on medicines. An electronic mode of information refers to information provided with the help of technological devices, such as Internet connection, interactive television, datalinks, and mobile communication. A written mode of information refers to PILs, other type of leaflets, books, articles, packages of medicinal products and medicine labels. (Source: TIPPA Project 2004, modified)
2.3 Theories and models to explain consumer information behavior: an ecological model of everyday life information seeking and use

Both information behavior and health communication researchers have used a variety of theories and models to explain consumer information behavior, information needs and utilization of different sources of information (Williamson 1998, Wilson 1999, Fisher et al. 2006, Cameron et al. 2009). Additionally, particular theories (for example social presence theory and social context cues theory) have been used to study online communication (Wood and Smith 2005). However, the majority of the previous studies on medicines information needs and sources have been descriptive, and only a minority have applied theoretical or conceptual framework. This is in spite of the fact that use of theoretical models may have provided a more coherent picture of consumers’ information needs and use of sources in information seeking (Rutten et al. 2005).

In this study, the Ecological Model of Everyday Life Information Seeking and Use (Williamson 1998) was applied to develop the study questions, to structure the literature review, and to explain and summarize the research findings. Similarly with other models of everyday life Information seeking (ELIS), this model concentrates on non-work – related information seeking and can be used to explain how people use different sources of information to meet their information needs (Figure 3). Williamson’s (1998) model is based on the multi-method study where more than 200 people aged 60 years and over were interviewed in Australia in 1992-1994. Later, the model was successfully applied to studies among different populations, settings, and to different types of study questions, including studies on user preferences for information type and on information needs and on seeking an online portal with breast cancer information (Williamson and Manaszewich 2002, Williamson 2006).

The Williamson’s Ecological Model of Information Seeking and Use (1998) suggests that while people purposefully seek information in response to their perceived needs (active or purposeful information seeking), they also observe their environment and acquire information or are informed about issues they were not always aware of but needed to know about (passive or incidental information acquisition) (Williamson 1998, Williamson 2006). Additionally, the model suggests that different information sources have different levels of importance. Personal networks (family, friends, relatives) and the media (newspapers, television, radio, magazines) are the most commonly used sources of information. They are also perceived as the most accessible. The institutional sources (such as hospitals, health care professionals and health authorities) are less used and perceived as less accessible sources of information. Williamson’s model (1998) is ecological in the point that it sets information seeking, acquisition, and use in the context of the variables which may have influence. Those variables include socio-economic circumstances, social- and cultural values, work situation, personal characteristics, affective influence (e.g. influence of personal feelings and fear of stigma), and physical environments such as availability of different sources of medicines information (See Chapter 3). Whereas traditional theories typically see communication as a one-way information transfer from sender to receiver in a particular situational environment (Lilja et al. 1996), the ecological model extends the situational approach to information seeking
and emphasizes the relationship between individual and environmental issues that enable or constrain seeking information from different sources (Williamsson 1998). The major strengths of the ecological model are: flexibility to include all variables; possibility to include multiple sources that may influence information seeking and use; and taking into account both the passive information acquisition and the active information seeking. Those all may affect also the seeking and use of health and medicines information. Therefore, the model was regarded as particularly suitable for this study.

Figure 3. *Ecological Model of Information Seeking and Use* (Williamson 1998, Modified).
3 Medicines information in the European Union and in Finland

3.1 Policy and practices in the European Union

Directives, regulations, and decisions by the European Union (EU) along with national laws, provide a binding framework governing the provision of medicines information to consumers in EU (Wahlroos 2003, Väänänen 2008). Regulations as specifically described and decisions for the addressed parties are enforceable as law in all member states. Also directives by the EU have binding legal force in each member state, but national authorities first must adapt their laws to meet the common directives. In addition to these binding requirements, European Commission and the Council of the European Union can make non-binding recommendations, resolutions, and communications to member states that may affect the provision of medicines information to consumers (See for example Commission of the European Communities 2008b). Directives bring different national laws into line with each other, and are especially common in matters that affect the operation of the single market, such as pharmaceutical products (Directive 65/65/EEC). In the EU, the responsibility for organizing and providing healthcare services, including community pharmacy services, is the responsibility of individual member states (Treaty of Amsterdam 1997, Article 152, Directive 2005/36/EC). Thus, there exist no harmonized rules applicable in all member states for medicines information services provided by health care institutions, including community pharmacies. This includes verbal and e-mail medication counseling in community pharmacies in EU (PGEU and HOPE 2006).

Instead, written medicines information has been included in the European legislation since the 1960s as a part of the authorization system of pharmaceutical products (Wahlroos 2003) (Table 1). The legislation concerning patient information leaflets (PILs; synonymous to package leaflets) has required a comprehensive written medicines information leaflet to be supplied to patients as a form of package insert in every medicine since the 1990s (Directive 92/27/EEC). Information content of the PIL must be in line with the summary of product characteristics (SPC), intended for health care professionals, and presented in a comprehensive form that can be understood by patients. This covers information on the identification of medicine, therapeutic indications, information patients need to be aware prior to taking the medicine, the dosage and instructions for use, adverse drug reactions, information about how to store medication, and date when the PIL was prepared (Directive 92/27/EEC). Just prior to the full implementation of this directive in 1999, recommendations on describing these issues in lay language were published in the EU Guideline on the readability of leaflets in 1998 (European Commission Directorate-General III Industry 1998, Raynor et al. 2007a, European Commission Directorate-General Enterprise and Industry 2009). This same guideline also contained the first recommendation concerning testing PILs with the consumers. In March 2004, the European Union introduced a new legal requirement with regard to PILs (Directive 2004/27/EC): all marketing authorization holders need to ensure that PILs reflect the results of testing them with target patient groups. Another new requirement was that PILs must be made available to people with vision impairment and the name of the product must be expressed in Braille format on the packaging.
Recently, a variety of initiatives have been undertaken to promote the accessibility and quality of medicines information in the EU (Table 1). A major initiative of the European Commission came from the High Level Group on Innovation and the Provision of Medicines (G10 Medicines) which was established in 2001 (European Commission Enterprise and Industry Directorate General 2002). This initiative brought together representatives of Member States, industry, mutual health funds and patients. The Group had the goal of encouraging innovation and competitiveness of the industry and of ensuring the satisfactory delivery of public health. In its report in May 2002 (European Commission Enterprise and Industry Directorate General 2002), the Group set out a framework of 14 wide-ranging recommendations, including the provision of information to patients. The Group highlighted the need to implement a workable distinction between advertising and information that would allow patients actively seeking information to guide their decision making and to develop standards about what constitutes good quality information about medicines. It also called for a public-private partnership (PPP) to look at the ways patients can have better access to good quality information on their medicines. This includes multiple ways how public and private bodies can collaborate and launch joint projects when there is interest in sharing experiences, resources and knowledge (High Level Pharmaceutical Forum 2007b, Commission of the European Communities 2008b).

To continue the implementation of the recommendations of G10, the European Commission established the Pharmaceutical Forum in 2005 (http://ec.europa.eu/pharmaforum/). The goal of the Pharmaceutical Forum was to find relevant solutions to public health concerns regarding pharmaceuticals, while ensuring the competitiveness of the European drug industry and the sustainability of the national health-care systems within European Union (EU). One of the three working groups under the Pharmaceutical Forum was the Working Group on Information to Patients. The aim of this working group was: 1) to advise the Commission on ways to improve the quality of, and access to, information on authorized medicines and related health issues to European patients, and 2) try to develop tools that could help patients to evaluate health information. The initiative was designed to focus on disease specific information, electronic and non-electronic dissemination of information and the availability of information in the healthcare environments (such as pharmacies and hospitals). The outcome of the 3-year process was a set of documents including the report on current practice with regards to provision of information to patients (Commission of the European Communities 2007a) and the conclusions and recommendations adopted in October 2008 (High Level Pharmaceutical Forum 2008b) (Appendix 1).

The communication from the Commission concerning the report on current practices with regard to the provision of information to patients (Commission of the European Communities 2007b) was based on Directive 2001/83/EC, introduced by Directive 2004/27/EC. This directive calls upon the European Commission to present a report to the European Parliament and the Council on “current practice with regard to information provision – particularly on the Internet – and its risks and benefits for patients”. The same directive also indicated that the Commission should, if appropriate, put forward proposals for an information strategy to ensure good-quality, objective, reliable and non-promotional information on medicinal products and other treatments. As a result, the legal proposal was presented by the European Commission in December 2008.
Directive and regulation concerning information to the general public on prescription medicines are included in the proposals of the ‘Pharmaceutical package’. The other proposals of the package deal with pharmacovigilance and counterfeit medicines. This legal proposal on information to patients indicates that pharmaceutical companies can disseminate information about their prescription-only medicines to the general public. Pharmaceutical companies can: disseminate: 1) only certain information about prescription-only medicines such as the patient leaflet or a different presentation of its contents and 2) only certain communication channels for the dissemination of information will be allowed. This includes the Internet and health-related publications as defined by the Member States. TV and radio are excluded; 3) Strict quality criteria must be met; and 4) Adequate and effective monitoring and control must be ensured.

The legal proposal and the work under the Pharmaceutical Forum have been criticized as being not properly representative in terms of consulting different types of consumer groups, being vague in defining key concepts, being secretive about methods and having conflict of interests between participants (Moynihan and Bay 2007, Velo and Moretti 2008, Richards 2008). However, the overall consensus is that there is a need to provide patients with understandable, objective and high-quality information on medicines. The work of the Pharmaceutical Forum benefited from the recognition that it represented a new and co-operative way of recognizing problems and finding solutions at the EU level. In addition, the reports by the Pharmaceutical Forum and European Commission are the only comprehensive attempts that have been made to synthesize the information on current practices of and to present initiatives to improve medicines information in EU countries. These reports highlight that, practices with regard to provision of medicines information for consumers and patients vary between different countries (Commission of the European Communities 2007a). As a consequence, EU citizens have unequal access to information across the EU. Variation in practices is particularly true with regard to Internet use and the role of public-private-partnership in provision of medicines information. In order to improve accessibility and quality of medicines information in EU and at the national level in EU countries, more detailed cross-country studies are essential. Additional information is needed particularly about the strengths and weaknesses of medicines information practices in different countries. Also, there exists a need for further scientific research to develop a more comprehensive understanding of consumer needs and preferences with regard to medicines information and information sources among particular patient groups (Raynor et al. 2007a).
Table 1. Milestones of medicines information to consumers in EU.

<table>
<thead>
<tr>
<th>Year</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1965</td>
<td>Directive 65/65/EEC: PIL needs to be attached to the marketing authorization application if inserted into the medicinal product</td>
</tr>
<tr>
<td>1975</td>
<td>Directive 75/319/EEC: PIL needs to be approved by the authority; minimum requirement to content; member states can require that PIL must be inserted in the medicinal product</td>
</tr>
<tr>
<td>1989</td>
<td>Directive 89/341/EEC: PIL must be inserted to the each medicinal product if all information required cannot be printed in the package</td>
</tr>
<tr>
<td>1992</td>
<td>Directive 92/27/EEC: A comprehensive PIL must be supplied to patients as a package insert in each medicine; wider requirements to PIL content; all information needs to be in line with the summary of product characteristics (SPC)</td>
</tr>
<tr>
<td>1998</td>
<td>A guideline on the readability of the label and package leaflet of medicinal products for human use; Revised in January 2009</td>
</tr>
<tr>
<td>2001</td>
<td>Setting up of a High Level Group on Innovation and the Provision of Medicines (G10 Medicines) by DG Enterprise and Industry</td>
</tr>
<tr>
<td>2002</td>
<td>Publication of the G10 report: Need to produce a workable distinction between advertising and information that would allow patients actively seeking information to be able to do so and; need to develop standards to good quality information on medicines; call for private-public partnership (PPP) to look at the ways patients can have better access to good quality information on their medicines</td>
</tr>
<tr>
<td>2003</td>
<td>Communication from the EU commission: “A Stronger European-based Pharmaceutical industry for the benefit of the Patient” – A call for Actions to G10; practical proposals for the implementation of the G10 recommendations; one recommendation was about the need to strengthen the quality and availability of information to patients</td>
</tr>
<tr>
<td>2004</td>
<td>Directive 2004/27/EC (Attached to Directive 2001/83/EC): calls upon the Commission to present a report to the European Parliament and the Council in 2007 on current practices with regard to information provision; particular focus on the Internet and its risks and benefits for patients; a new legal obligation relating to user testing of PILs with target patient groups</td>
</tr>
<tr>
<td>2005</td>
<td>High Level Pharmaceutical Forum established; one of the three working groups concentrated on Patient information from different perspectives: Pillar 1) non-statutory information, Pillar 2) statutory information, Pillar 3) accessibility of information</td>
</tr>
<tr>
<td>2007</td>
<td>Communication from the Commission concerning the Report on current practices with regard to the provision of information to patients on medicinal products</td>
</tr>
<tr>
<td>2008</td>
<td>Final conclusions and recommendations by the Pharmaceutical Forum: 1) Need to enhance quality of information; 2) Increase accessibility and dissemination of Information; 3) Generation of information by making the best use of all actors; 4) Continued momentum on Information to patients</td>
</tr>
<tr>
<td>2008</td>
<td>“Pharmaceutical Package” introduced with three legislative proposals relating to 1) pharmacovigilance, 2) information to patients, 3) counterfeit medicines. A public consultation on the legal proposal on information to patients in February 2008, results in May 2008</td>
</tr>
</tbody>
</table>
3.2 Policy and practices in Finland

3.2.1 Finnish health care system

Finland has a public health care system which is complemented with private, occupational, and student health services. Municipalities have the main responsibility for organizing and funding health care and social services (Järvelin 2002, Ministry of Social Affairs and Health 2005, Vuorenkoski 2007, Vuorenkoski 2008). This municipal system provides the largest share of health care services in Finland (for example about 70% of outpatient physician visits, about 60% of outpatient dentists visits and about 95% of inpatient care periods) (Vuorenkoski 2007).

Health care services can be divided into primary and secondary care. Health centers have the fundamental role in public primary healthcare (Kokko 2007, Vuorenkoski 2007, Vuorenkoski 2008). Based on national legislation, every municipality must have a health centre that provides primary health services. Additionally, the nation has been divided into hospital districts that are responsible for providing the municipal secondary health care services. Student health services are provided by the Finnish Student Health Service (FSHS, www.yths.fi), a nationwide organization that is funded by students, the Social Insurance Institution, university towns and the Ministry of Education. FSHS provides health and medical care, mental health as well as dental care services for more than 140,000 students enrolled at universities and tertiary-level science and art schools across Finland (Kokko 2007).

Since the gradual de-institutionalization starting in the early 1980s and continuing into the 1990s, and the 2000s, a majority of the mental disorders as well as other diseases are increasingly treated by the primary health care (Välimäki et al. 2009). This is reflected by the fact that the majority of psychotropic medicines are prescribed by general practitioners and dispensed via community pharmacies (National Agency for Medicines and Social Insurance Institution 2006). Thus, general practitioners and community pharmacists have a key role in counseling people with mental disorders. In addition to FSHS, the Nyyti Student Support Centre provided counseling and other services that promote mental well-being among students at Finnish universities and art academies (www.nyyti.fi).

3.2.2 Community pharmacy system as a part of health services in Finland and its role in medicines information

In Finland, both prescription and non prescription medicines are sold to the public only by pharmacies. Finland has a privately owned community pharmacy system consisting of about 800 pharmacy outlets. In addition to these outlets there are two university-owned pharmacies with 18 large outlets which have a special legal mission to support pharmacy education and research. Verbal medication counseling in community pharmacies has been required by law since 1983 (Table 2). Provision of medication counseling has been a strategic priority of Finnish regulatory authorities and professional organizations since the 1990s (Airaksinen 1996, Vainio 2004). This has resulted in the development of new medicines information databases, re-design of pharmacy premises to assure patient
privacy, national programs aiming to promote health and rational use of medicines, and training community pharmacists to provide medication counseling (Kansanaho 2005, Puumalainen 2005).

The first long-term attempt to promote medication counseling in Finland was conducted as a result of an initiative of the World Health Organization (WHO) EuroPharm Forum (a coalition of pharmaceutical associations in European countries) between 1993 - 1996. This project aimed at promoting rational use of medicines by encouraging consumers to ask questions about their medicines from community pharmacists (Airaksinen et al. 1998, Vainio et al. 2002). The Association of Finnish Pharmacists established a national strategy in 1997 to strengthen the role of community pharmacies in health care and to support the professional development of pharmacists. This strategy highlighted the importance of providing medicines information as part of medication counseling in community pharmacies. To implement this strategy and to promote long-term professional development in community pharmacies, a four-year national project (TIPPA) was started in 2000 (TIPPA Project 2004, Kansanaho 2005, Puumalainen 2005.). The TIPPA aimed at promoting rational use of medicines; decreasing negative effects of inappropriate use of medicines; and decreasing costs by enhanced counseling. An important part of the TIPPA Project was the implementation of the new patient counseling model based on concordance and two-way communication (Kansanaho 2005), and the development of instruments to measure the Quality of Patient Counseling (Puumalainen 2005). In addition to TIPPA, national long-term programs focusing on chronic diseases (asthma, diabetes, heart diseases) have been organized to encourage local co-operation between pharmacies and other health care professionals and to develop the competency and counseling skills of pharmacy staff. The development of medication counseling in Finland between the 1970-2004 (Vainio 2004) as well as TIPPA Project have been described in detail in previously published doctoral dissertations (Kansanaho 2005; Puumalainen 2005).

Although Finnish community pharmacies have been actively using information technology since the 1980s and Finland has among the highest rates of the Internet use in the world (www.worldstats.com), development of web-based pharmacy/medicines information services has been relative slow. Existing community pharmacy websites typically provide: information about hours of operation, contact information, the range of services provided, hyperlinks to reliable sources of drug information, self-medication guidelines, and reimbursement policies. The first online medication counseling service was begun in 1996 by the University Pharmacy (UP) owned by the University of Helsinki. The service was provided via a health-related Internet site where consumers could ask questions about their medicines from a pharmacist. Today, the University Pharmacy answers consumer e-mail inquiries via a drug information call-center (See Chapter 3.2.3.). There is no published information about the availability of other e-mail counseling services in Finnish community pharmacies. However, the number of such services is likely to increase in part because of pending changes in the Finnish national law that will facilitate the sale of medicines via the Internet (National Agency for Medicines 2008). As yet, however, no specific regulations or standards exist for Internet-based pharmacy services.
3.2.3 Complementing sources of medicines information

In Finland, there are two national drug information call centers where people can inquire about medicines (Table 2). The drug information call center of the University Pharmacy has operated since 1996. The call center provides people an opportunity to access information from a pharmacist on an anonymous basis. The drug information center is mainly designed to receive calls from consumers but it also functions as a help-desk for pharmacy staff and physicians. This national service is available 24 hours per day for the cost of a local telephone call (+0.4 €/ min). In 2009 a total of 237,000 calls were received. The Kuopio University Pharmacy established its call center in 1999. It has much lower volume of calls than the UP call center (www.klik.fi). In addition to community pharmacy operated drug information call centers, information on medicines can be obtained from the national Poison Information Centre and the Teratology Information Centre. They form an integrated unit operated by the Helsinki University Hospital (www.hus.fi).

Since 1999, every medicine dispensed must include a patient information leaflet (PIL). In recent years, access to PILs has been improved by making them available on the websites of the National Agency for Medicines in written and the website of Pharmaceutical Information Centre in written and audio format. The Pharmaceutical Information Centre (owned by the Pharma Industry Finland) publishes a consumer version (Lääkeopas) of the national medicines compendium (Pharmacia Fennica) which is commercially available as a book and freely available online. The information content of this compendium is based on the PILs, but the text is rewritten and shortened. Another useful resource is the patient versions of the national current care guidelines provided by the Finnish Medical Society Duodecim that are freely available for consumers via the Internet (https://kaypahoito.fi/). Since 2005, a medical online database called ‘Health library’ (www.terveyskirjasto.fi) has also been available for consumers. It was established and is maintained by the Finnish Medical Society. As in other EU countries, direct-to-consumer advertising of prescription medicines is not permitted in Finland (Directive 2001/83/EC).

3.2.4 Need for improvements in Finnish medicines information practices

Albeit a wide variety of medicines information sources and services are available in Finland, there is still a need for improvements. The need for better co-ordination and defining the roles and responsibilities of different medicines information providers have been discussed since the 1980s (Wallenius 1989). The Ministry of Social Affairs and Health organized a national meeting in 2003 aiming to tighten co-operation and co-ordination between different medicines information providers in Finland (The Ministry of Social Affairs and Health 1993). This meeting recognized the following issues with regard to medicines information practices in Finland: 1) need for better promotion of medicines information sources and services for consumers, 2) existence of commercial information providers that may have their own objectives, 3) need for complementing medicines information sources and services; e.g., the better use of the Internet in delivering medicines information, 4) need to consider additional funding of the services, 5) lack of co-operation and co-ordination of different medicines information providers, and 6) need
to clarify the role of different stakeholders, including pharmacists and physicians. Suggested solutions included better co-ordination and development of a national information strategy that would define the role of different information providers. Given that consumer medicines information context has substantially changed over time and the only multidisciplinary guideline on providing medicines information is from 1986 (Lääkeinformaation pelisäännöt 1986), there exists an obvious need to re-consider these issues. In order to do this, the Act and Decree (2009) on the new Finnish Medicines Agency (FIMEA) requires development of a national medicines information strategy. Further research on consumer needs and information behavior is essential to do this. The new medical authority FIMEA has started in November 2009.
Table 2. Milestones of medicines information for consumers in Finland.

<table>
<thead>
<tr>
<th>Year</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1961</td>
<td>Poison Information Centre (Located in the Helsinki University Central Hospital; answers to questions concerning prevention and treatment of acute poisonings on a daily basis around the clock)</td>
</tr>
<tr>
<td>1983</td>
<td>Pharmacists’ duty to counsel customers while dispensing prescription medicines and selling nonprescription medicines (Pharmacy Act 4/1928)</td>
</tr>
<tr>
<td>1984</td>
<td>The first consumer version of the medicines compendium (Called Lääkeopas; Provided by the Pharmaceutical Information Center, updated regularly)</td>
</tr>
<tr>
<td>1986</td>
<td>Multidisciplinary guidelines for patient information</td>
</tr>
<tr>
<td>1986</td>
<td>The first computerized drug information database to produce leaflets to consumers in community pharmacies (Called Resепti Risto)</td>
</tr>
<tr>
<td>1986-1995</td>
<td>A more advanced version of the computerized information database to produce leaflets to consumers in pharmacies (Called Elli)</td>
</tr>
<tr>
<td>1988</td>
<td>Facilities to assure privacy in community pharmacies required by the new Medicines Act (Medicines Act 395/1987)</td>
</tr>
<tr>
<td>1990-1995</td>
<td>WHO EuroPharmForum “Questions to Ask About Medicines” public awareness campaign</td>
</tr>
<tr>
<td>1994</td>
<td>Patient information leaflets through EU legislation (Full implementation in 1999)</td>
</tr>
<tr>
<td>1994</td>
<td>Teratology Information Service (Located in the Helsinki University Central Hospital; answers to questions concerning the pregnancy and lactation; every working day from 9-12 am)</td>
</tr>
<tr>
<td>1996-2001</td>
<td>Online ask-the-pharmacist service by the University Pharmacy (UP) (Provided via a health portal called Verkkoklinikka; developed and administrated by Neurocom Inc.)</td>
</tr>
<tr>
<td>1996</td>
<td>University Pharmacy (Owned by the University of Helsinki) drug information call center</td>
</tr>
<tr>
<td>1997</td>
<td>The professional strategy for community pharmacies (By the Association of Finnish Pharmacies) (The Associations of Finnish Pharmacies 1997)</td>
</tr>
<tr>
<td>1998</td>
<td>Codes of Ethics for Community Pharmacies (By the Association of Finnish Pharmacies and Finnish Pharmacists’ Association)</td>
</tr>
<tr>
<td>2000-2003</td>
<td>TIPPA Project (Operated and supported by the Ministry of Social Affairs and Health, the National Agency for Medicines, the Social Insurances Institution, the Association of Finnish Pharmacies, the Finnish Pharmacists’ Association, the University of Helsinki, the University of Kuopio, the Pharmaceutical Learning Centre, and the Kuopio University Centre for Training and Development). The follow-up program in 2004-2007.</td>
</tr>
<tr>
<td>2001</td>
<td>The Kuopio Medicines Information Centre (KMIC) (Founded by the Kuopio University Pharmacy, the Kuopio University Hospital Pharmacy, Kuopio University Hospital and the Faculty of Pharmacy of Kuopio University)</td>
</tr>
<tr>
<td>2005</td>
<td>National evidence-based medical online database for consumers (Called Terveyskirjasto; Provided by The Finnish Medical Society Duodecim; Developed in cooperation with Kela - the Social Insurance Institution of Finland, the Association of Finnish Local and Regional Authorities consists of the towns and municipalities in Finland, the Finnish hospital districts; Funded by Sitra - the Finnish Innovation Fund)</td>
</tr>
<tr>
<td>2009</td>
<td>The Act and Decree on the Finnish Medicines Agency (FIMEA)</td>
</tr>
</tbody>
</table>
4 Research on consumer sources of health and medicines information

4.1 Consumer use of different sources of health and medicines information

Multiple studies have explored consumer use of different sources of health and medicines information (Helakorpi et al. 1999, Newby et al. 2001, Helakorpi et al. 2002, Coleman 2003, Sleath et al. 2003b, Sparado 2003, Pennbridge, Moya and Rodrigues 1999, MacHaffie 2002, Helakorpi et al. 2005, Hesse et al. 2005, Närhi 2007, Närhi and Helakorpi 2007a, Närhi and Helakorpi 2007b, Ho et al. 2009). Studies concerning solely medicines information are described in Table 3. A majority of studies have been cross-sectional and asked consumers or a particular patient group to self-report the sources where they have obtained or preferred to receive information on health and/or medicines. Additionally, some studies have focused on consumer perceptions of the most trusted sources of information. A majority of these studies have been conducted in one particular country. The most comprehensive study on health information sources in Europe, Eurobarometer 58.0 (Sparado 2003), explored the sources of health information in the European Union in 2002 (n=16 067, an average 1000 people from each EU country). In consistent with other studies concerning consumer sources of health information (Pennbridge et al. 1999, MacHaffie 2002), Sparado et al. (2003) found that health care professionals including pharmacists, physicians, and chemists were the main sources of health information. Similarly with general health information, health care professionals are the most common sources of medicines information for consumers (Table 3). The range of information sources used is broad and includes also PILs, relatives, friends, traditional media, books, and the Internet. Based on previous studies, this is true in different settings and among different study populations. Although only limited evidence exists, the order of importance of different sources may vary between people using different type of medicines, for example between people using prescription vs. non-prescription medicines and between people using psychotrophic vs. other type of medicines.

Studies identifying the most preferred or trusted sources among consumers indicates the most used sources are also perceived as the most reliable ones (Hesse et al. 2005, Närhi 2007, Kummervold et al. 2008). Hesse et al. (2005) examined how a random sample of the public used, rated, and preferred different sources of cancer information. Albeit physicians were the most preferred sources of information, patients often sought information from the Internet before talking with their physicians. However, this study was about health information, not specifically about medicines information.

Consumers’ preferences for sources of information may vary, depending on the context, patient age, medication, medication knowledge, health status, and also the type of information being sought. Younger people and people with stigmatized disorders for example may prefer the Internet over the other sources of medicines information. Since utilization of information sources and services may change over time, it needs to be followed up. The majority of previous studies on the consumer use of medicines information sources found in the international literature come from Finland. Finnish studies (Helakorpi et al. 1999, Helakorpi et al. 2002, Helakorpi et al. 2005) are the only studies from EU countries that enable the investigation of the change in the consumer use
of medicines information sources over time. Accordingly, there is a need for longitudinal studies in other EU countries. There is also a need to examine the use of medicines information sources among different consumer groups. Further studies may find out how those people judge their personal need for different sources of medicines information in the different situations and stages of disease and its treatment.
Table 3. Studies concerning the use of consumer sources of medicines information (Närhi 2006, modified and up-dated).

<table>
<thead>
<tr>
<th>Study</th>
<th>Percentage of people reporting the use of a particular source of medicines information</th>
<th>Study design/Population/Medicines information concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Study design/Population/Medicines information concerned</td>
<td>Cross-sectional survey among people with mental disorders (n=81) in community setting in Liverpool; psychotropic medicines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-sectional interview study among a representative sample of Finns 15-74 years (n=1044), prescription medicines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-sectional survey; a representative sample of Finns 15-64 years (n=2315); prescription and OTC med.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-sectional survey of adults using prescription medicines in nonmetropolitan areas in 1997 (n=1700)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-sectional survey; a representative sample of Finns 15-64 years (n=3259); prescription and OTC med.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Customers in one community pharmacy in London in 2001 (n=25); prescription medicines</td>
</tr>
<tr>
<td>Study</td>
<td>Physician</td>
<td>Pharmacist</td>
</tr>
<tr>
<td>Donoghue 1993 (UK)</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Alanko 1999 (Finland)</td>
<td>63</td>
<td>63</td>
</tr>
<tr>
<td>Helakorpi et al. 1999 (Finland)</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>Tripp and Straub 2001 (USA)</td>
<td>50</td>
<td>24</td>
</tr>
<tr>
<td>Helakorpi et al. 2002 (Finland)</td>
<td>46</td>
<td>38</td>
</tr>
<tr>
<td>Coleman 2003 (UK)</td>
<td>76</td>
<td>32</td>
</tr>
</tbody>
</table>
### Percentage of people reporting the use of a particular source of medicines information

<table>
<thead>
<tr>
<th>Study</th>
<th>Physician</th>
<th>Pharmacist</th>
<th>Nurse</th>
<th>PIL</th>
<th>Relatives, Friends</th>
<th>Internet</th>
<th>Newspapers/Magazines</th>
<th>TV/Radio</th>
<th>Books, Guides</th>
<th>Advertisements</th>
<th>DIC</th>
<th>Study design/Population/Medicines information concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleath et al. 2003 (USA)</td>
<td>1 - 51°</td>
<td>58</td>
<td>7</td>
<td>-</td>
<td>32</td>
<td>19</td>
<td>4</td>
<td>5</td>
<td>3 - 5</td>
<td></td>
<td></td>
<td>Cross-sectional interview; people picking up an antidepressant refill prescription (n=81); a convenience sample of community pharmacies in North-Carolina (n=8); antidepressant</td>
</tr>
<tr>
<td>Helakorpi et al. 2005 (Finland)</td>
<td>44</td>
<td>35</td>
<td>10</td>
<td>32</td>
<td>8</td>
<td>6</td>
<td>8²</td>
<td>4³</td>
<td>-</td>
<td>5.5</td>
<td>0.2</td>
<td>Cross-sectional survey; a representative sample of Finns 15-64 years (n=3287); prescription and OTC</td>
</tr>
<tr>
<td>Närhi 2007 (Finland)</td>
<td>68</td>
<td>60</td>
<td>28</td>
<td>74</td>
<td>24</td>
<td>20</td>
<td>40</td>
<td>40/10</td>
<td>22</td>
<td>32</td>
<td>2</td>
<td>Cross-sectional survey; a representative sample of Finns 15-74 years (n=1004); prescription and OTC</td>
</tr>
<tr>
<td>Närhi and Helakorpi 2007a (Finland)</td>
<td>35</td>
<td>33</td>
<td>9</td>
<td>33</td>
<td>7</td>
<td>4</td>
<td>3²</td>
<td>3³</td>
<td>-</td>
<td>4</td>
<td>0</td>
<td>Cross-sectional survey; a representative sample of Finns 15-64 years that had used analgesics but no other medicines during the last week (n=502); prescription and OTC</td>
</tr>
<tr>
<td>Närhi and Helakorpi 2007b (Finland)</td>
<td>61</td>
<td>49</td>
<td>14</td>
<td>44</td>
<td>11</td>
<td>9</td>
<td>11²</td>
<td>6³</td>
<td>-</td>
<td>8</td>
<td>0</td>
<td>Cross-sectional survey; a representative sample of Finns 15-64 years; people who reported at least one source of medicines information (n=2348) were included; prescription and OTC</td>
</tr>
</tbody>
</table>

1 Psychiatric nurse, 2 Newspapers and books together, 3 TV and radio together, 4 Labels and patient information leaflets combined, 5 Prescribing physician (not primary care physician), primary care physician, and mental health specialist were separated
4.2 Health care professionals as sources of medicines information


Although some studies from US and Finland indicate that verbal medication counseling by pharmacists and physicians has increased during the 1990s and the 2000s, there is still need for improvement (Morris et al. 1997, Vainio 2004, Vainio et al. 2004, Puumalainen et al. 2005). During the TIPPA –project in Finland, progress in medication counseling practices in Finnish community pharmacies (a convenience sample of 60 pharmacies) was assessed by conducting a pseudo customer study with four annual follow-ups with using four different scenarios in 2000-2003 (Puumalainen et al. 2005). The scenarios focused on self-medication (one product and one symptom-based request) and on prescription medication (a new and a refill prescription for the same medication). Although some improvements appeared, counseling rates were low especially in relation to repeat prescriptions and product-related request. Recurring findings in a variety of studies has been that verbal counseling by physicians and pharmacists is often sub-optimal and does not meet the needs of all medicine users (Wiederholt et al. 1992, Lin et al. 1995, DeYoung 1996, Sleath et al. 2003, Happell et al. 2004, Young et al. 2006, Sleath et al. 2007). This is true even though appropriate information about medicines is important for enabling consumers to understand their options and express preferences with regard to informed decision making. Additionally, there is some evidence that medication counseling may increase satisfaction, recall, knowledge, and consumers’ adherence to their medicines (Kinnersley et al. 2009). Based on a recent systematic review of 17 randomized controlled studies which examined the effects of providing medicines information to people with mental disorders, this applies also to people with depression and using antidepressant medicines (Desplenter et al. 2006). Of 13 studies out of 17 which measured adherence, seven reported that the provision of medicines information increased adherence among people with mental disorders. No study demonstrated decreased adherence.

Studies both among pharmacies and physicians have found differences in counseling rates and content according to patient prescription status (new or refill), patient demographic characteristics (age, sex, and education) and therapeutic classes. The rate of
counseling provided with new prescriptions has been higher than counseling on refill prescriptions (Wiederholt et al. 1992, Sleath 1996, Aslanpour and Smith 1997, Vainio et al. 2002, Vainio 2004, Puspitasari et al. 2009). Elderly people have been reported to be less likely to receive counseling compared with the younger adults or parents of children (Aslanpour and Smith 1997). People who ask for information are more likely to be counseled than those who do not (Vainio et al. 2002). In pharmacies, counseling is more likely to be provided to antibiotic users than to users of long term medications such as gynecological and cardiovascular medications (Aslanpour and Smith 1997, Kansanaho et al. 2002, Vainio et al. 2002). Other previous studies also indicate that there is a discrepancy between the customers’ and health care professionals’ opinions on the amount and content of medicines information (Airaksinen et al. 1994). While consumers want to have information about therapeutic effects of the medications, such as the adverse drug reactions and interactions, pharmacists and physicians perceive this information as being less important (Airaksinen et al. 1994, Mottram and Reed 1997). Dosage and timing of the medication are frequently discussed, but information on adverse drug reactions and contraindications are less frequently discussed (Aslanpour and Smith 1997, Vainio et al. 2002, Puspitasari et al. 2009). An observation study conducted in Finland (Vainio et al. 2002) found variations in the rates of pharmacists` medication counseling. People picking up gynecological or psychotropic medicines were less likely to receive medication counseling than people with other classes of medicines. In line with this finding, Young et al. (2006) found that physicians provided less information about antidepressants to people with major depression than those with adjustment disorder. While physicians typically mentioned the medicine’s name, purpose, and adverse drug reactions, they failed to provide information about the anticipated duration of the treatment and expected delay in onset of clinical effect.

Although some differences may exist between people with different type of diseases, in general, only a minority of consumers ask questions about their medicines in a pharmacy or in physician encounters (Morris et al. 1997, Airaksinen et al. 1998, Cox et al. 2004, Sleath et al. 2007). People do not always want information or they do not know what questions they should ask about their medications (Airaksinen 1996, Airaksinen et al. 1998). It has been suggested that too much information may cause feelings of frustration or information overload for some people (Schommer et al. 2001). The review of 116 studies on communication between health care professionals (Stevenson et al. 2004) identified a number of potential barriers to communication and concordance that were associated with patients feeling unable to participate in the counseling; perception that it was not appropriate to participate; and with health care professionals not facilitating patient participation. In relation to people with mental disorders, the self-perceived stigma (e.g. an individual perception the public to stereotype and discriminate against a stigmatized group) which often accompanies the use of psychotropic medicines may add to the difficulty in asking questions in face-to-face contacts (Enäkoski 2002, Berger et al. 2005, Goldberstein et al. 2008).

With the increasing use of the Internet as a source of health and medicines information, health care professionals have had to rethink their strategies related to patient information and to change how they provide information. On way to improve communication and to complement face-to-face counseling is via e-mail. The importance of e-mail as a mode of
communication between consumers and health care professionals is estimated to increase (Brebner et al. 2006). E-mail counseling services provide consumers with an opportunity to direct health and medicines-related inquiries to a pharmacist or other health care professional effectively and privately (Assemi et al. 2002, Holmes et al. 2005, Brebner et al. 2006, Jariangprasert et al. 2007). It has been suggested that e-mail and the Internet may be particularly valuable ways for adolescents, people living in rural and remote areas and those having mental or other stigmatized disorder to access information (Gray et al. 2005, Berger et al. 2005, Leach et al. 2007). There are only few studies particularly about the pharmacy or pharmacists-operated e-mail medication counseling services for consumers (Assemi et al. 2002, Bessell et al. 2003, Holmes et al. 2005, Ghoshal and Walji 2006, Jariangprasert et al. 2007). Those studies suggest that people with mental disorders are frequent users of e-mail based medicines information services (Pohjanoksa-Mäntylä et al. 2002, Bouvy et al. 2002). They also suggest that the pharmacy-operated websites and e-mail counseling services are variable in their quality (Bessell et al. 2003, Holmes et al. 2005, Ghoshal and Walji 2006). However, the majority of studies concerning e-mail use in health care have concerned e-mail services provided by physicians (Patt et al. 2003, Umefjord et al. 2003, Houston et al. 2004, Brooks et al. 2006, Bhor and Mason 2006, Virji et al. 2006) or pharmacies operating solely online (Bessell et al. 2002, Bessell et al. 2003, Holmes et al. 2005). Little is known about the quantity or quality of e-mail counseling provided by community pharmacists. There are no previous studies about the e-mail medication counseling on antidepressant medicines. Research on e-mail counseling would be especially valuable for those developing regulations and standards for the Internet pharmacy practices and online sales of medicines.

4.3 Patient information leaflets (PILs) as sources of medicines information

Patient information leaflets (PILs) are among the most important sources of medicines information for consumers (See Chapter 3). For some consumers, they may even be the only information received about their medicines (Medicines and Healthcare products Regulatory Agency. Committee on Safety of Medicines 2005). The importance of PILs has been recognized, and a variety of studies have been conducted worldwide over the past few decades (Raynor et al. 2007a). Those studies have concerned the use of the written medicines information among consumers; consumer views on the content, value and role of written medicines information; the quality of the information; and the impact of this information for consumers (Koo et al. 2003, Raynor et al. 2007a, Nicolson et al. 2009).

The content and practices in providing PILs to consumers vary between different continents, making comparison and generalisability of the study results difficult (Raynor et al. 2007b). In Australia, law requires that a manufacturer’s leaflet – either as a package insert or computer generated in the pharmacy - be available with all prescription and pharmacist only (e.g., medicines sold only from pharmacies and by pharmacists) medicines supplied for the first time to a consumer (Raynor et al. 2007b). In the US, instead, a voluntary system of providing patient information leaflets started in the 1970s (Raynor et al. 2007b). The leaflets are briefer than the leaflets in Australia and in Europe and are computer generated in a pharmacy (Raynor et al. 2007b). The provision of the written medicines information in US has been facilitated by the national legislation
suggesting that the “useful written information” (i.e., accurate, non-promotional, specific, comprehensive, understandable, and legible information) should be provided to patients when they get their first prescription (Morris et al. 1997); the national legislation contained a target that 95% of the consumers get a leaflet with the first prescription by 2006 (US Department of Health and Human Services, US Food and Drug Administration 1996); the Action Plan for the Provision of Useful Prescription Medicine Information detailed the types of information to be included to fulfill the specific and comprehensive criteria. It also provides general guidelines for evaluating the accuracy, legibility, and comprehensiveness of written information (Steering Committee for the Collaborative Development of a Long-Range Action Plan for the Provision of Useful Prescription Medicine Information 1996). In spite of the nationwide efforts to increase the accessibility of the written medicines information, the research suggests that not all people receive written information from their community pharmacy although the situation has remarkably improved (Svarstad et al. 2003, Svarstad et al. 2005). A 2001 pseudo customer study (Svarstad 2005) showed 89% rate of receipt of information on new prescriptions dispensed (n=1538). In 2008 follow-up study (Kimberlin 2008), 94% of the pharmacies provided printed medicines information for filled prescriptions for lisinopril (n=343) and metformin (n=342). Similar findings have been recently reported from Australia (Vitry et al. 2009). In Vitry et al. (2009) a phone survey among Australians over age 15 year (n=1576), 46% of the respondents who reported getting prescriptions or OTC medicines declared that they “never or rarely receive written information on how to use a medicine apart from what is on the bottle or packaging”.

In terms of availability of the written medicines information, the situation is different in EU where PILs have been provided as a package inserts with all medicines since 1999 (Directive 92/27/EEC). However, people may not always read the PIL accompanying their medicines (Raynor and Knapp 2000, Raynor et al. 2005). Based on the recent systematic review of the studies on written medicines information, consumers read medicines information if they took responsibility for their own care, if the medicine was prescribed for a serious condition, a problem has previously been encountered with medicines. If a caregiver is involved, they want to learn how to take medicine, and to know about the potential adverse drug reactions to their medicines (Raynor et al. 2007a). Particularly they want to have information about adverse drug reactions, contraindications, taking medicine correctly, and purpose of taking the medicine. There may be differences in reading and interest in reading PILs according to individual factors such as the type and severity of the disease (Koo et al. 2006, Raynor et al. 2007a). A cross-sectional survey among Australians with rheumatology and pain conditions or hypertension (n=479) found that majority of the patients were interested and likely to read written information about their medicines, although not many were likely to actively seek it (Koo et al. 2006). Additionally, this study found that the interest in reading and seeking leaflets were associated with patient factors such as coping style, health literacy level, and disease state.

Based on the recent systematic reviews of the studies on the impact of the written medicines information available to consumers (Raynor et al. 2007a, Nicolson et al. 2009), there is some evidence that written medicines information can improve knowledge. However, there is no strong evidence to conclude whether this information is effective in changing attitudes and behaviors related to medicine taking. This has been due to the poor
quality of the studies, the different outcome measures and ways of presenting the written information in the interventions exploring the effectiveness of written medicines information. Given that no harmful effects of the written medicines information have been reported, however, the results of the previous studies are encouraging for consumers who want to learn about their medicines. As confirmed by previous studies, the combination of verbal and written information is the most effective to educate consumers (Desplenter et al. 2006). Additionally this combination is preferred by consumers (Raynor et al. 2007a).

The Raynor et al. (2007a) review suggests that consumers would like written information to help making decisions, particularly decisions about whether or not to take a medicine. They would value the information that is individually tailored, set in the context of the particular illness, and containing balanced information about the potential benefits and harms relating to their medicines. The review concluded that there is a gap between currently provided leaflets and information that consumers would value and find most useful. Other important conclusions were that: there is a need to develop methods of information provision flexible enough to allow uptake of varying amounts and types of information depending on different stages of an illness; that consumers should be involved at all stages of the process of producing medicines information; that more qualitative research is needed on how different type of patients and careers use medicines information in different settings and over time; and that there is a need to focus on the effectiveness, role and value of emerging Internet-based medicines information for consumers.

4.4 Drug information centers as sources of medicines information

One way to improve communication and offer additional information is via drug information centers (DICs); centers where people can call, or otherwise contact health care professionals and ask questions concerning medicines (Markind and Stachnik 1996, Hall et al. 2006, Närhi 2006). Previous studies reflect that those centers are useful in information provision for consumers and they may also have positive effect on patient outcomes, such as the prevention of a disease or its symptoms, or the reduction or elimination of the symptoms (Angaran 1999, Melnyk et al. 2000, Bouvy et al. 2002, Spinewine and Dean 2002). Additionally, it has been stated that they are important components of countries’ strategies for improving the use of medicines (The Council of Europe Expert Group on Safe Medication Practices 2007).

The first drug information centers were established in the 1960s in the United States (US) and in the 1970s in the United Kingdom (UK) (Rosenberg et al. 1995, Markind and Stachnik 1996, Angaran 1999, Rosenberg et al. 2009). Since then, drug information centers have offered evidence-based drug information to health care professionals and more recently to consumers (Rosenberg et al. 1995, Markind and Stachnik 1996, Angaran 1999). According to the Mullerova and Vlcek (1998), about 83 out of the 84 responding European DICs concentrated on providing information through telephone-based question-answer services. At the end of the 1990s, more than half (56%) of those services provided by DIC’s in Europe were targeted to health-care professionals and 43% to consumers (Mullerova and Vlcek 1998). Consumers have also been the most frequent user of those drug information centers providing information both to health-care professionals and consumers (Grymonpre and Steele 1998, Mullerova and Vlcek 1998, Bouvy et al. 2002,

There is limited information about the prevalence of the use of drug information centers among entire populations. However, the existing evidence indicates that the proportion of users of drug information call center services remains low among the public (Table 3). Little is known about the barriers and drivers of using those services among consumers. At this stage, the DICs are most commonly located in hospitals, medical centers or in Faculties of Pharmacy (Rosenberg et al. 1995, Markind and Stachnik 1996, Mullerova and Vlcek 1998, Hall et al. 2006). One potential provider of this kind of services could be community pharmacies, especially large chains that have the resources to establish and run a drug information center (Angaran 1999). However, no internationally published studies exist about community pharmacy operated drug information centers.

4.5 The Internet as a source of medicines information

4.5.1 General features of the Internet as a source of information

The penetration of Internet use has been rapid and worldwide. Internet use has increased almost three-fold between years 2000-2008. Fifty percent of the population in Europe in June 2009 (402,380,474 people) use the internet. The lowest proportion of Internet users in Europe was found in East Europe and the highest in the Nordic countries. In Finland, 83% of the population use the Internet (www.internetworldstats.com). A variety of sources exist via the Internet where people can access health and medicines information (Morahan-Martin 2004, Stjernsward and Ostman 2006). Those mediums include websites, bibliographic databases, bulletin board systems, online support groups, chat rooms, and e-mail. According to one estimate made in 2001 more than 100,000 websites provided health information (Dearness and Tomlin 2001). Worldwide, about 4.5% of all searches on the Internet are for health information and 6.75 million health-related searches are conducted online every day (Eysenbach and Kohler 2004, Morahan-Martin 2004,). The most frequently searched health topics include: information on symptoms and treatments of diseases; prescription medicines; new or experimental treatments; diets; and exercise (Fox 2006). Cross-culturally, a majority of health information seekers search for health information because they or someone they know has been diagnosed with a medical condition (Fox and Raine 2001, Fox and Raine 2002, Provost et al. 2003, Peterson-Clark et al. 2004, Fox 2006). A majority of health seekers search for information about a particular disorder or condition (Fox 2006). In 2001, 39% of Internet users in US sought mental health information (Fox and Raine 2002). Correspondingly, more than half (57%) of the Internet users in UK reported that they would use the Internet to find mental health information (Morahan-Martin 2004). A third of non-Internet users would be likely to seek help for mental health problems online (Morahan-Martin 2004). Depression and other mental health issues have remained among the ten most frequently searched health topics in US since 2002 (Fox 2006).
4.5.2 Prevalence of the Internet use for health and medicines information

A majority of studies on Internet use for health and medicines information come from US. One of the earliest nationally representative surveys of consumer use of the Internet as a source of health information was conducted in 1998 (Harris Interactive 2004). This survey found that 27% of the US adults over 18 years had searched for health information online. More recent estimates suggest that as much as 80% of adults with Internet access use it for health purposes and approximately 40% for seeking information on prescription or non-prescription medicines (Fox 2006). Although estimates of Internet use for health purposes vary widely in different studies, the actual numbers of Internet users reflect that the Internet has become an increasingly important source of health and medicines information (Diaz et al. 2002, Baker et al. 2003, Murray et al. 2003, Bundorf et al. 2006, Bansil et al. 2006).

In the Eurobarometer survey, nearly a quarter of the respondents (n=16 067) had used the Internet to obtain health information in 2002 (Sparado 2003). Internet use for health purpose in Europe varies between 11-47%. Such use is more common in western and Nordic countries than in southern and eastern European countries (Sparado 2003). According to a more recent study (n=7 903) among seven European countries, 44% of the total population and 71% of Internet users had used the Internet for health purposes in 2005 (Andreassen et al. 2007). In the same study, 42% of the 7903 respondents considered the Internet to be a good way of obtaining information on health-related issues. Based on another recent European study (Kummervold et al. 2008), the proportion of the Internet users had increased from 42% in 2005 to an estimated 52% in 2008. In addition to information seeking from the Internet-sites, people increasingly use the Internet as a communication channel (Andreassen et al. 2007, Baker et al. 2003). Andreassen et al. (2007) found that 27% of the Internet users had participated in interactive forums or self-help groups and 30% had interacted with health care professionals. Authors concluded that E-health services have already become an important part of health care for many people.

In Finland, 22% of adult men and 30% of women aged 15-64 years had used the Internet for health information in 2007 (Helakorpi et al. 2008). In the interview study among Finnish adults (more than 15 years old, n=3245), 46% of the participants and 73% of the Internet users perceived the Internet as either important or very important source of health information (Tarkiainen ym. 2005). Similarly with the international trend, the Internet use for medicines information in Finland has grown during the past ten years. This increase has been observed in an annual survey among Finnish adult population that has every third year since 1999 included a question about consumer sources of medicines information (Helakorpi et al. 1999, Pesonen 2000, Helakorpi et al. 2002, Helakorpi et al. 2005). In 1999, 1% of adult Finns reported that they have searched information on their medicines during the past 12 months. In 2002 and in 2005, the same figures were 3% and 6%, respectively. Reportedly, 9-20% of the medicine users had used the Internet for medicines information in 2005 (Närhi and Helakorpi 2007b, Närhi 2007).
4.5.3 Factors associated with the Internet use for health and medicines information

A majority of quantitative studies have concluded that more women than men search health information online (Diaz et al. 2002, Baker et al. 2003, Murray et al. 2003, Bansil et al. 2006, Bundorf et al. 2006, Renahy, Chauvin 2006, Andreassen et al. 2007, Kummervold et al. 2008). It has also been determined that young people, people with high income, high education, and individuals living in urban areas use the Internet for health purposes more frequently than older people, people with less-education, lower incomes, and living in rural areas (Diaz et al. 2002, Fox and Raine 2002, Baker et al. 2003, Haviland et al. 2003, Fox 2005, Fox 2006, Goldner 2006, Powell J 2006, Renahy and Chauvin 2006). The same applies to the medicines information online (Sleath et al. 2003b, Närhi and Helakorpi 2007b, Närhi 2007, Ho et al. 2009). Other factors associated with higher use of the Internet for health information include availability of the Internet access; home connection to the Internet; long travel time to source of care; stigmatizing or chronic disorder; and number of chronic conditions (Baker et al. 2003, Wagner et al. 2004, Berger et al. 2005, Bansil et al. 2006, Bundorf et al. 2006). Moreover, the Internet is particularly used for health information by college students and people with long-term diseases, particularly by those with mental disorders (Haviland et al. 2003, Wagner et al. 2004, Berger et al. 2005, Bundorf et al. 2006, Powell 2006).

Although numerous studies have explored sources of general health information (Sparado 2003, Andreassen et al. 2007), sources of medicines information among the general population (Helakorpi et al. 1999, Helakorpi et al. 2002, Helakorpi et al. 2005, Närhi and Helakorpi 2007b, Närhi 2007 ), and sources of medicines information among some other particular populations (Sleath et al. 2003b, Närhi and Helakorpi 2007a), it is difficult to estimate the actual use and value of the Internet for consumers as a source of medicines information. This is due to differences in study questions and populations, but also to the fact that details on survey questions and sampling methods, including non-response bias are not always presented in the reports. In addition, a majority of the quantitative studies particularly on the Internet use for medicines information have been descriptive and relied on binominal statistics in exploring associations between socio-demographic factors and Internet use (Helakorpi et al. 1999, Helakorpi et al. 2002, Helakorpi et al. 2005, Närhi and Helakorpi 2007b, Närhi 2007). More detailed analyses are needed to confirm previous findings and to control for possible effect caused by confounding factors. Based on the existing literature, the socio-demographic characteristics (age, gender, education, working status), number of chronic diseases, and mental health status would be important variables to control in further studies concerning the use of different sources of medicines information as they have found to associate with Internet use for general health information. Those variables are also included in the Williamson Model on Everyday Information Seeking and Use (1998) (See Chapter 2.3).
4.5.4 How and why people search and appraise online health and medicines information

In addition to prevalence of the Internet use, previous studies have described how and why people use the Internet for health and medicines information (Eysenbach and Kohler 2002, Peterson et al. 2003, Peterson-Clark et al. 2004). Studies have found that a majority of the people seeking health information use general search engines such as Google (Eysenbach and Kohler 2002, Fox and Raine 2002, Hansen et al. 2003, Peterson et al. 2003, Provost et al. 2003). Both their search and evaluation skills of the information they find may be limited (Eysenbach and Kohler 2002, Hansen et al. 2003, Morahan-Martin 2004, Peterson-Clark et al. 2004, Renahy and Chauvin 2006). Based on the review on the consumer use of the Internet for health information (Morahan-Martin 2004), these findings have been consistent cross-culturally and both in quantitative and qualitative studies. While quantitative studies have provided information about the prevalence of health and medicine information seeking among different populations and identified the most common ways to seek this information, qualitative interviews and observational studies have provided more detailed understanding of their information searching behaviors, skills and reasoning behind the searches. Qualitative studies have found that people typically use short phrases and non-sophisticated terminology, often with misspellings, when they search for information (Hansen et al. 2003, Morahan-Martin 2004, Peterson-Clark et al. 2004). They seldom go beyond the first pages (Berland et al. 2001, Eysenbach and Kohler 2002, Fox and Raine 2002, Hansen et al. 2003). Few consumers use systematic criteria for assessing information they have found online because they are not familiar with existing tools and guides that have been designed to help consumers in appraising the credibility of information (Eysenbach and Kohler 2002, Peterson et al. 2003, Bernstam et al. 2005). In observational studies, only the minority of participants has clicked on “about us” link in order to obtain information about the website maintainer, sponsors or aims/motives for having a website (Morahan-Martin 2004). However, there may be differences in the search and evaluation techniques of online information between people with different diagnosis (Morahan-Martin 2004).

Surveys on cancer patients indicate that the two main reasons patients turn to the Internet for health information are that they are dissatisfied with the information provided by their health care professionals and that they see a need for additional information (Chen and Siu 2001, Jenkins et al. 2001, McMullan 2006). They also search information before going to see their physicians; to find an explanation for their symptoms; and to confirm that all important aspects are being considered and medical tests run. A focus group discussion study from Australia indicates that searches concerning medicines may be done to complement or improve understanding of information received from physicians (Peterson-Clark et al. 2004). This can also be done to prepare for a doctor’s visit; to hear peer experiences; to decide whether to use medicines or not; to have information about alternative treatments; to-update on knowledge; or to have information about adverse drug reactions of own medication.
4.5.5 Advantages, disadvantages, and the importance of the Internet as a source of health and medicines information

The potential advantages and disadvantages of the Internet-based health and medicines information have been widely debated. An Institute of Health report from US describes the major drivers pushing the use of the Internet to obtain health care information (Mittman and Cain 1999). These drivers include consumer demand; increasing consumer experience with e-commerce and e-mail; the ease and low cost of obtaining diverse health care information. From the consumer point of view, advantages of the Internet include easy access to information; high volume and currency of information; potential to increase health information access in rural areas and to otherwise under-served populations; capacity for interactivity; potential for individually tailored information; potential to facilitate interpersonal interaction and social support; potential to empower patients and consumers; and potential for anonymity (Cline and Haynes 2001). Anonymity and avoidance of embarrassment may be particularly important for people with mental or other stigmatizing disease (Berger et al. 2005). Reportedly, people may find online information seeking on health issues easier than asking their health care professionals (Gordon et al. 2002).

At the same time, barriers that restrict Internet use for health information include concerns for privacy; weakness in browser and search engine technologies; uncertainty about the quality of information; consumer lack of skills to search and appraise online information; and lack of universal standards for communication (Mittman and Cain 1999, Cline and Haynes 2001). People in general, but particularly populations with higher incidences of diseases, minority ethnic groups, poor people, and older people may have limited access and/or skills to use the Internet. With few exceptions, studies reveal that the quality of online health and medicines information is highly variable (See Chapter 5). It has been suggested that poor quality information may has potential to cause physical, emotional and financial harm to consumers, although there is only limited evidence on this (Crocco et al. 2002).

Most health information seekers report that online information has positively impacted their decisions about their own or a loved one’s care (Fox and Raine 2001). Health information is used to fill an information void which can enhance consumer empowerment, coping and self-management, affect health-related decisions and behaviours. This applies to users, but also to their friends and family. Eysenbach (2004) (In Morahan-Martin 2004) has suggested that online cancer information can help patients gain control; reduce anxiety; improve compliance; create realistic expectations; promote self-care and participation; and generate perceptions of safety, security, and satisfaction. These results are in line with the findings of the Australian focus group study of Internet use for medicines information seeking (Peterson-Clark et al. 2004). In that study, most participants felt empowered by the online information they found, and they used it to play a more active role in decision making about their medication therapy. In the same study, however, some participants felt confronted with too much information and were not able to adequately evaluate the quality of information they found. The recent Cochrane review of 24 randomized controlled trials of interactive health communication applications (e.g. computer-based programmes which combine health information with online peer support,
decision support, or help with behaviour change) for people with chronic diseases concluded that users of those applications tend to become more knowledgeable, feel better socially supported, and may have improved behavioral and clinical outcomes compared with non-users (Murray et al. 2005). Another important conclusion was that there is a need for additional studies with larger sample sizes to confirm these findings; to determine the best way to deliver these applications; and to assess their influence on behaviors in different groups of people with chronic illness.

As previous studies have mostly been conducted among general consumers and among some particular patient groups, such as people with cancer, more research should be focused on comparing information seeking behaviors in different patient and consumer groups and in different countries. There is preliminary evidence that cross-cultural differences and differences according to diagnosis may influence study findings (Morahan-Martin 2004). Still, no qualitative studies on consumer online medicines information behaviors within EU countries, including Finland, have been published. Further studies on the advantages and disadvantages of online medicines information services should assess the clinical, humanistic and economic outcomes of such services.
5 Quality of the Internet-based health and medicines information

5.1 Reliability and quality of health and medicines information on the Internet

Many studies have been conducted to describe and critically appraise consumer health and medicines information found on the Internet (Hatfield et al. 1999, Eysenbach et al. 2002, Graber and Weckman 2002, Martin-Facklam et al. 2004). One of the earliest studies reviewed website advice on managing fever in children and concluded that websites varied widely in terms of accuracy, completeness, and consistency (Impicciatore et al. 1997). In a more current review of 79 studies on different types of health-related websites (Eysenbach et al. 2002), a majority (70%) of the studies concluded that quality is a problem, 22% remained neutral, and 9% came to a positive conclusion. Although study methods, rigor, measures of quality, and study population varied between studies, there exist enough evidence to say that Internet-based information on health is highly variable. This variation also applies to online information on medicines and mental health issues. With few exceptions (Morel et al. 2008), a majority of previous studies on online information on mental health have reported varying, but an overall poor quality information for disorders such as depression (Griffiths and Christensen 2000, Berland et al. 2001, Lissman and Boehnlein 2001, Griffiths and Christensen 2002, Nemoto et al. 2007, Ferreira-Lay and Miller 2008); schizophrenia (Kisely et al. 2003); attention deficit hyperactivity disorder (Kisely et al. 2003); and eating disorders (Murphy et al. 2004). It has been suggested, however, that the poor quality is not solely a problem in the Internet as mental health information in other media has found to be similarly limited (Bell 2007).

5.2 Criteria, tools, and initiatives to appraise the quality of health and medicines information on the Internet

Studying and assessing the quality of online information is challenging because the websites may relocate, change their format, and increasingly, provide content tailored to the individual reader. Websites are also becoming more interactive. Also, no single established definition or measure to good quality information exists (Lampe 2008). Silberg (1997) suggested four criteria for assisting users in evaluating the quality of health information on the Internet: authorship; listing of references; disclosure of financial interest; and currency. In addition to these four criteria, there are other criteria that may be important (Lampe 2008). Criteria can be classified by their applicability to various dimensions of online health information: epistemic (clarity, comprehensiveness, and accuracy of the content); ethical (transparency and honesty); economical (sponsor of the site); and technical (technical solutions, such as aesthetics, interactivity, privacy and data protection) (Lampe 2008). The type of information and the type of website determine which measures are applicable. In relation to information on medicines and diseases, it is possible to use traditional metrics, and evaluate if the information is in agreement with existing practice guidelines, e.g. current care guidelines (Purcell et al. 2002). Instead, literary or journalistic criteria may be more appropriate for personal narratives in
discussion forums. Also the intended audience influences the measures applicable to a particular type of content. For the consumers, information on health and medicines needs to be written at a comprehensible reading level (Purcell et al. 2002).

Since anyone can provide information online, information is rarely subjected to peer-review before publishing online. This is except for medical and pharmacy journals that can be accessed online. Instead, the quality and reliability of this information may be determined only by the publisher of a particular website. Different initiatives have been taken (Risk and Dzenowagis 2001) and tools developed (Wilson 2002) in order to measure and to increase the quality of online information, and to help users to discriminate between good and poor quality sites. Those tools can be roughly classified into six categories: the codes of conduct; quality labels; user guides; filters; third party certification; and Internet algorithms (Table 4). Codes of conducts refer to the sets of quality criteria that list recommendations for the development and content of websites (Wilson 2002). They can be used for self-assessment by website information providers and consumers. A quality label (logo or symbol) is located to the website and represents a commitment by a website provider to adhere to a code of conduct. The oldest and perhaps the best known quality label is produced by Health on the Net Foundation (www.hon.ch). User guidance systems are checklist-type tools that enable users to check if a site and its contents comply with a series of questions. Filtering tools, are applied manually or automatically, accept or reject whole sites of information based on preset criteria. Third-party certification is among most advanced approaches for quality rating as a third-party provides a label as a result of its own investigation (Wilson 2002).

The number of these tools has increased since 1996 when the first codes of conduct for health information on the Internet were produced (Garliardi and Jadad 2002, Purcell et al. 2002). In 1997, Gagliardi and Jadad identified 47 instruments to assess health information quality on the internet. Four years later, this number was 98 (Gagliardi and Jadad 2002, Purcell et al. 2002). All of the instruments were unvalidated (Gagliardi and Jadad 2002, Purcell et al. 2002). The most current review in 2007 identified 273 instruments to assess the quality of health information on the World Wide Web (Bernstam et al. 2005). Its` authors concluded that few of these tools are likely to be usable by their intended audience. In order to be usable, a self-assessment tool needs to be: available to consumers; require a limited number of assessable elements; and be readable. The existing tools may be too complicated, and consumers may lack understanding, time, energy and interest to use these tools in practise (Bernstam et al. 2005). A majority of quality assessment tools are available solely in English, which may prevent their use among non-English speaking populations. In addition, tools are not applicable, for example to the analysis of information in online communities, discussion forums and chat rooms.

More current and advanced approach to quality evaluation is FACT4 algorithm that may provide a partial solution for the shortcomings of previously mentioned more traditional quality appraisal tools. FACT4 (FACCCCT) algorithm undertakes the following three steps: 1) Find answer (to your question) and compare (information from different sources), 2) Check credibility of sources if conflicting information is found, 3) Check trustworthiness of sources if conflicting information is found (Eysenbach and Thomson 2007). In contrast to previous tools, FACT4 analyzes pieces of information (e.g. facts), not websites. Eysenbach and Thomson (2007) suggest that FACT4 is reliable, valid,
and usable approach for consumers. Like with the previous discussed tools, the FACT4 assessment process may be time-consuming for consumers, unless the tool is not connected with sophisticated tools or portals that automate the evaluation according to this algorithm.

Different users of the same online sources may have different needs and may evaluate them differently based on different criteria for quality. Consumers may want simple explanations and second opinion, whereas healthcare professionals may want evidence from clinical trials (Peterson-Clark et al. 2004). Given that people are often concerned about reliability, understandability and information quality and they trust their physician more (Hesse et al. 2005), physicians may support consumer information seeking on the Internet by recommending specific information sources and web sites. They may also encourage their patients to evaluate online content themselves and increase their awareness on existing tools and quality criteria. For this purpose, new tools or shortened and easily translatable versions of the previous ones would be needed.

Table 4. Classification of tools for rating quality of health information on the Internet (Wilson 2002, modified and up-dated).

<table>
<thead>
<tr>
<th>Tool</th>
<th>Example(s)</th>
<th>Cost to site provider</th>
<th>Burden to site user</th>
<th>Key potential beneficiaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code of conduct</td>
<td>eEurope (eEurope 2002)</td>
<td>Low</td>
<td>Low</td>
<td>Site provider and user</td>
</tr>
<tr>
<td></td>
<td>Internet Health Coalition (<a href="http://www.ihealthcoalition.org">www.ihealthcoalition.org</a>)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality label</td>
<td>Health on the Net (<a href="http://www.hon.ch">www.hon.ch</a>)</td>
<td>Medium</td>
<td>Medium</td>
<td>Site provider, site user, label provider</td>
</tr>
<tr>
<td>User guide</td>
<td>DARTS (<a href="http://www.nam.fi">www.nam.fi</a>)</td>
<td>Low</td>
<td>High</td>
<td>Site provider, site user, information provider</td>
</tr>
<tr>
<td></td>
<td>DISCERN (<a href="http://www.discard.com">www.discard.com</a>)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Checklist by US Food and Drug Administration (FDA) (<a href="http://www.fda.gov">www.fda.gov</a>)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Filter</td>
<td>Intute (Previously OMNI) (<a href="http://www.intute.ac.uk/healthandlifesciences/">http://www.intute.ac.uk/healthandlifesciences/</a>)</td>
<td>Low</td>
<td>Low</td>
<td>Site provider, site user, information provider</td>
</tr>
<tr>
<td>Third party certification</td>
<td>MedCertain (<a href="http://www.medcertain.com">www.medcertain.com</a>)</td>
<td>High</td>
<td>Low</td>
<td>Site provider, site user, information provider</td>
</tr>
<tr>
<td>Internet algorithm</td>
<td>FACT4 (Eysenbach and Thomson 2007)</td>
<td>Depends on how conducted</td>
<td>Depends on how conducted</td>
<td>Site provider, site user, information provider</td>
</tr>
</tbody>
</table>
5.3 The DARTS-tool for assessing online medicines information

The DARTS (Date, Author, References, Type, and Sponsor) is among the most current tools for assisting patients in assessing the quality of online medicines information (Figure 4). It is a checklist that was developed by one of the three Working Groups of the EU Pharmaceutical Forum, the Working Group on Information to Patients (http://ec.europa.eu/enterprise/phabiocom/comp_pf_en.htm). The DARTS was developed by incorporating content from other existing tools and a systematic review of existing quality criteria. The inclusion of scientific references, name and affiliation of the author, the date the site was last updated and the absence of financial interests were included as they have earlier been associated with one or more markers of reliable online medicines information. The type of the site was also included as part of DARTS (e.g. disclosure of target audience, scope and purpose) as it is a quality criterion described as being easy to validly use by consumers. The tool was not created to replace existing and more comprehensive checklists or quality criteria, but instead to act as a short and easy-to-use reminder for Internet users to assess quality when retrieving online medicines information. It was published on the website of the Pharmaceutical Forum in May 2007 and later also on the website of National Agency for Medicines in Finland (High level Pharmaceutical Forum 2007, www.nam.fi). The acronym “DARTS” was selected to facilitate the use of the tool. The five quality criteria of the DARTS tool were translated into Finnish for Finnish consumers by the National Agency for Medicines (www.nam.fi). The Finnish and the English version of the tool have the same content, but the Finnish version was named “KATSE” (“watchful eye”).
DARTS
Reliable Information on the Internet

1. Date (When was the information updated?)
2. Author (Who is the writer? Is he/she qualified?)
3. References (Are the references and sources of content valid?)
4. Type (What is the purpose of the site?)
5. Sponsor (Is the site sponsored and, if so, by whom?)

Figure 4. DARTS-tool for assisting consumers to appraise the quality of online medicines information (Närhi 2007).
People with depression as users of medicines
information and information sources: a review of the research

6.1 Depression, treatment of the depression, and utilization of antidepressant medicines

Depression is a common cause of disability to the individuals, and it accounts for an increasing global burden of diseases (World Health Organization 2001). Estimates suggest that major depression will be the second leading contributor of the global burden of diseases after ischemic heart disease by 2020 (Murray and Lopez 1997, World Health Organization 2001). In the Finnish population, the 12-month prevalence of major depression is 4.9% (Pirkola et al. 2005). In addition, 10-20% of the Finnish population suffers from depression at some point in their lives (Stakes 2005). Mental health disorders including depression are a leading cause for retirement from work due to disability, and the second most common reason for receiving daily illness benefits (Salminen 2004, The Social Insurance Institution of Finland 2008).

In addition to different types of psychotherapies, antidepressants are a commonly used and effective treatment particularly for moderate and major depression (The Finnish Medical Society Duodecim 2004, Arroll et al. 2009). In addition to depression, antidepressants are prescribed for a range of common mental disorders, for example anxiety disorders (Silho et al. 2006). In Finland, the use of antidepressants has increased seven-fold since the 1990s (National Agency for Medicines and Social Insurance Institution 2008). More than 388,139 people were dispensed an antidepressant in 2007. Selective serotonin re-uptake inhibitors are the most commonly utilized antidepressants. A majority of the antidepressant medicines are utilized in outpatient settings, making community pharmacies the primary source of antidepressant medicines. Although antidepressants are effective in treating moderate and severe depression, effectiveness may be reduced by poor patient adherence, and the lack of psychotherapy and other supportive health services (Maddox et al. 1994, The Finnish Medical Society Duodecim 2004, van Geffen et al. 2008). Thus, primary care physicians and community pharmacists play a key role in counseling patients on their medication and supporting the effectiveness and safety of their medication therapies.

Several evidence-based treatment guidelines have been published to improve the detection and treatment of depression (Hyler 2002, NHS 2004, The Finnish Medical Society Duodecim 2004). The Finnish Current Care Guideline suggests that minimum treatment time with antidepressant medicines for depression is six months after the remission of the symptoms (The Finnish Medical Society Duodecim 2004). However, premature discontinuation of the medication is common (Lin et al. 1995, Peveler et al. 1999, Melartin et al. 2005). Studies from other countries indicate that up to 38% of the patients having an antidepressant dispensed at the pharmacy do not obtain a refill (McGettigan et al. 2000, van Geffen et al. 2008). This may be explained by the fact that antidepressants may cause adverse drug reactions, such as gastrointestinal problems, palpitations, dizziness, restlessness, and sexual dysfunctions. These adverse drug reactions may be significant and troubling and they may start soon after taking the first pill, whereas
it may take several weeks before a therapeutic effect is perceived (Pestello and Davis-Berman 2008). This suggests that patients may associate symptoms of adverse drug reactions to the illness, leading them to conclude that medication is making them even worse (Demytymaere et al. 1997).

In addition to adverse drug reactions, the fear of dependency and lack of information about antidepressants are among commonly mentioned factors that may lead to early discontinuation (Donoghue 1993). In contrast, discussing about adverse drug reactions before and during treatment encourages the continuation of antidepressant therapy (Bull et al. 2002). However, patients with mental disorders are often unsatisfied with information received and would like to have more information from healthcare professionals (Alexius et al. 2000, Enäkoski 2002, Garfield et al. 2004, Happell et al. 2004, Pollock et al. 2004, Bell et al. 2005, Cleary et al. 2005, Perreault et al. 2006). During the treatment, patients generally also have questions and concerns about the use of antidepressant medicines that may lead patients to seek information from different information sources including the Internet (van Geffen et al. 2007).

Understanding what people with depression using antidepressant medicines want to know about their medicines and where they seek such information during their antidepressant treatment is important for the healthcare providers supporting and counseling patients. However, no comprehensive attempt has been made to synthesize the previous literature and findings relating to antidepressant information needs and information seeking from different sources of medicines information. This chapter reviews current literature about the medicines information behavior among people with depression. More specifically, four questions are considered: 1) What kind of information people with depression want about their medicines during the different stages of their treatment (information needs); 2) What sources do they use and what kind of information do they seek (information searched); 3) How and why do they use different information sources, and 4) What sources of medicines information do they prefer.

6.2 Literature search, data extraction, and characteristics of the studies on medicines-related information needs and sources among people with depression

The review was based on the systematic literature search of international medical databases Medline; Cumulative Index to Nursing and Allied Health Literature (CINAHL); PsychInfo; and ISI Web of Knowledge. The search was performed using the Medical Subject Headings (MeSH) and search terms “mental disorder”; “psychiatric disorder”; “depression”; “depressive illness”; “depressive disorder”; “antidepressive agent”; “antidepressant”; “medicines information”; “medication information”; “consumer health information”; “health information”; “patient concern”; “information need”; “information source”; “information seeking”; “physician”; “pharmacists”; “community pharmacy services”; “pharmacy services”; “product label”; “package insert”; “nurse”; “communication”; “communication media”; “internet”; “electronic mail”; “telephone”; “helpline”; “telephone service”; “call center”; “e-health”; and “e-technology”. The detailed search strategy is described in Appendix 2.
A review was restricted to literature published in 1992-2009 (literature search conducted in April 2009). This is because the launch of the Internet and SSRIs, as well as the shift from inpatient care to outpatient care occurred in the mid 1990s. It is likely that these developments have changed the way people search for information and take antidepressant medicines. Additionally, initial literature search at the beginning of this thesis project did not identify any relevant publications before these years.

Initially, the abstracts of articles identified in the literature search were reviewed. All abstracts were independently read by two researchers, and inclusion of specific articles was based on their mutual agreement with regard to relevancy. When the abstract did not contain sufficient information, the full-text was obtained for further review. The electronic database searches were supplemented with searching articles from the archives of own research group and screening of the reference lists of articles identified. Articles published in English that reported qualitative or quantitative research related to 1) the need for health or medicines information or 2) information seeking by adult inpatients or outpatients with either depression or mental disorders, including depression were included. Detailed inclusion and exclusion criteria are provided in Appendix 3.

The literature search identified 603 abstracts. Based on the review of abstracts, the articles that did not relate to the study questions were excluded. The full-text of 40 articles was obtained and read (Figure 5). Of those, 10 were excluded. The most common reason for the exclusion was that the study population was not defined in detail enough to say if people with depression were included in to the study, and it was not possible to do distinguish between information needs and/or seeking among people with and without mental disorders. A total of 30 relevant publications remained in the review (Appendix 4).

![Figure 5. Flow chart of the article selection.](image)

Characteristics of the articles were summarized and tabulated (Table 5). For each of the included articles, the data on the design and key findings were extracted and recorded. A coding framework was set up to code the findings on the study questions (See page 56).
Relevant articles were classified as articles about: 1) self-reported medicines information needs, 2) medicines information sources, or 3) both medicines information needs and sources among people with depression or people with other mental disorders including the depression. The typology of information needs was created inductively by listing all reported information needs that were mentioned in the articles. This same typology was used to code the consumer inquiries in the different sources of medicines information.

The self-reported information needs were described in four articles; information sources in 21 articles; and both information needs and sources in five articles (Table 5). In the majority of the studies concerning self-reported information needs, participants consisted solely of people with depression, and the study was focused especially on general information about medicines or specific information about antidepressants. In contrast, studies on information sources concerned typically health information seeking in general, not information seeking about antidepressants or other medicines. Additionally, the majority of studies included people with a variety of mental health disorders, not solely people with depression. Studies on health and medicines information sources related to issues people seek information about or ask from different sources. They also assessed consumer preferences for and perceptions of different sources information, and reasons and ways to use some particular sources of information. Internet was the main focus in ten articles. The studies included were conducted in eight countries, with the majority being from the US and UK.
Table 5. Characteristics of the articles included in the review on medicines information needs and sources among people with depression (n=30).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Needs (n=4)</th>
<th>Sources (n=21)</th>
<th>Needs and sources (n=5)</th>
<th>Total (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase of the antidepressant treatment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple stages/Not specified in the study</td>
<td>3</td>
<td>19</td>
<td>3</td>
<td>25</td>
</tr>
<tr>
<td>Initiation</td>
<td>1</td>
<td>-</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Discontinuation</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td><strong>Country</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>-</td>
<td>11</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>UK</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Other European country</td>
<td>-</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Australia</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quantitative/Cross-sectional</td>
<td>1</td>
<td>17</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Quantitative/Prospective/longitudinal</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Quantitative/Retrospective</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Publication date</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1992 – 1997</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1998 – 2003</td>
<td>-</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2004 – 2009</td>
<td>4</td>
<td>12</td>
<td>3</td>
<td>19</td>
</tr>
</tbody>
</table>

6.3 Information needs

Altogether 14 different types of information needs were reported in the literature, with adverse drug reactions (ADRs) being the most commonly reported (Table 6). The finding that people are concerned about and want information about ADRs was found in quantitative and qualitative studies, and in studies reporting information needs among outpatients and inpatients (Garfield et al. 2004, Zwaenepoel et al. 2005, Perreault et al. 2006, Hunot et al. 2007). Quantitative studies suggested that ADRs were among the most important issues that people with mental disorders wanted to know about their medicines. Perreault et al. (2006) pilot study using the 'Patient perspective on information questionnaire' (PPIQ) determined the level of satisfaction with information received and the information needs deemed the most important by outpatients with different types of mental disorders including the depression (n=86). In addition to general information on psychiatric services, the scale included questions about the medical treatments.
Respondents rated information on type and potential adverse drug reactions of their medicines as the most important issues about their treatments. In line with these results, Zwaenepoel et al. (2005) found that people with mental disorders in hospital setting most commonly wanted to have information on the adverse drug reactions of their medication (44% of the participants reported), mechanism of action (35%), indication or reason for using medicine (29%), and risk of the dependency (5%).

ADRs were mentioned also in all the three qualitative studies concerning information needs about medicines (Garfield et al. 2004, Powell and Clarke 2006, van Geffen et al. 2009). In the Garfield et al. (2003) interview study of 51 patients at the beginning of an antidepressant medication, participants reported the desire for ADR-information, but also the desire for more information about the role of medicines in recovery from depression. This was perceived as particularly important because of the lengthy nature of the recovery process during which fluctuation may occur. The importance of this information was further highlighted in discussions relating to the length of the treatment. The majority of participants had mistakenly believed that their medicine treatments would be short-term. In relation to timing of information, participants reported that they had difficulties in recalling information that their physician had given them at the time of diagnosis. They would have valued repeated opportunities to receive this. In the same study, participants also reported that as the symptoms of depression decreased they took a greater role in decision making. This indicates that information needs and preference of involvement in decision making are dynamic, dependent on experiences of the illness, recovery process and medication. The authors concluded that the development of strategies for the reinforcement of information would be advantageous. However, only two of the studies focused on information needs at the beginning of antidepressant treatment, while the others did not distinguish between information needs during different stages of treatment.

According to Van Geffen et al. (2009), an interview study conducted in the Netherlands (n=41), information needs varied widely among study participants with depression. In this study, many patients desired information on some particular issue that was derived from their personal concern or experience of taking antidepressant medicines. Some participants mentioned that they lacked information on how to identify adverse drug reactions and whether and when the effects of these reactions would ease. Contradictory findings were also reported as some participants did not want to have detailed information about adverse effects. They feared that such information might cause concerns and lead to the discontinuation of medication. Overall, participants thought that they would benefit from information tailored to their needs. They identified multiple barriers to communication in community pharmacies. These barriers included: information provision mainly restricted to dispensing new prescriptions; lack of time and privacy; lack of empathy; and a protocol-driven way of providing information. Similar findings on the perceived lack of information were reported by Powell and Clarke (2006). Additionally, they found that some study participants associated the lack of information with perceived lack of respect. Their findings on information needs were in line with other published work (Garfield et al. 2003, van Geffen et al. 2009). Partly based on the perception of the lack of information, participants in this study described how they sought information using technical sources such as textbooks and the Internet. Information seeking from these sources was perceived as empowering by participants. Participants reported that stigma
was commonly attached to mental disorders and it inhibited information seeking in face-to-face situations. Peer experiences were found to be beneficial due to their understanding the universality of mental disorders, their hopefulness based on their finding understanding and empathy. None of the studies compared information needs between gender, age-groups or people using SSRIs versus TCAs.

Table 6. Typology of information needs among people with depression based on the literature review. Types are presented in the order of frequency they appeared in the reviewed studies.

<table>
<thead>
<tr>
<th>Type of information need</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adverse drug reactions</td>
<td>Garfield et al. 2003, Zwaenepoel et al. 2005, Perreault et al. 2006,</td>
</tr>
<tr>
<td></td>
<td>Perreault et al. 2006</td>
</tr>
<tr>
<td>Dosage</td>
<td>Donoghue 1993; Garfield et al. 2003, Perreault et al. 2006</td>
</tr>
<tr>
<td>Length of the treatment</td>
<td>Garfield et al. 2003, Perreault et al. 2006</td>
</tr>
<tr>
<td>Interactions</td>
<td>Perreault et al. 2006, Zwaenepoel et al. 2005</td>
</tr>
<tr>
<td>Mechanism of action</td>
<td>Powell and Clarke 2006, Zwaenepoel et al. 2005</td>
</tr>
<tr>
<td>Process of recovery</td>
<td>Garfield et al. 2003</td>
</tr>
<tr>
<td>Consequences of long term use</td>
<td>Van Geffen et al. 2009</td>
</tr>
<tr>
<td>Type of medication</td>
<td>Perreault et al. 2006</td>
</tr>
<tr>
<td>Explanation of diagnosis</td>
<td>Powell and Clarke 2006</td>
</tr>
<tr>
<td>Other types of treatments</td>
<td>Powell and Clarke 2006</td>
</tr>
<tr>
<td>General information about own treatment</td>
<td>Nabeel et al. 2008</td>
</tr>
<tr>
<td>Discontinuation</td>
<td>Van Geffen et al. 2009</td>
</tr>
</tbody>
</table>

6.4 Information sources

6.4.1 Prevalence of use and factors associated to the use of different sources of information

Altogether 26 articles described information sources used by people with depression or used by people with mental disorders including depression (Appendix 4). Those concerned the prevalence of use; issues people searched for or ask from different sources; consumer perceptions of and preferences for different methods (verbal, written, electronic) and sources of information; and reasons why, how, and with what consequences people search
information from different sources of health and medicines information. Hunot et al. (2007) asked patients to identify all sources (from a given list of sources) where they had received information about health, and Sleath et al. (2003) where they had received information specifically about medicines. In both studies, healthcare professionals were the most commonly reported sources of information. In the study by Sleath et al. (2003), 58% of the patients reported receiving information from pharmacists; 51% from primary care physicians; 41% from mental health specialists; 32% from family members; and 19% from the Internet. Only two people reported the use of a toll free telephone helpline. This study from the US was the only one that reported specifically the use of different sources of medicines information among people with depression.

The majority of the studies focused on one source of information, most commonly on the Internet (Millard and Fintak 2002, Haviland et al. 2003, Wagner et al. 2004, Berger et al. 2005b, Bansil et al. 2006, Powell 2006, Leach et al. 2007, Santor et al. 2007, Khazaal et al. 2008, Oh et al. 2008). A recurring finding in these studies was that people with mental disorders, including people with depression, were more likely than consumers in general and people with other health conditions to use the Internet for health information (Haviland et al. 2003, Berger et al. 2005, Bansil et al. 2006, Powell 2006, Santor et al. 2007). Powell and Clarke (2004) conducted a survey on Internet use for mental health information among a representative sample of the British general population (n=917). In their study, 18% of all Internet users and 32% of Internet users with past history of mental health problems had used the Internet for information related to mental health. The relative importance of the internet was demonstrated by 24% of the study population identifying it as one of the top three sources of health information they would use if they have a mental health problem. In a more recent survey in a university hospital psychiatric outpatient clinic in Switzerland (Khazaal et al. 2008), 69% of the 200 Internet users searched information concerning health issues and 44% searched this information more than once a month. People with depression and other mental disorders were found to be 1.47-2.08 times more likely to seek health-related information from the Internet than those without these disorders (Haviland et al. 2003, Bansil et al. 2006). In other studies, younger age, higher income, higher level of education, higher degree of urbanization, chronicity of the disorder, the number of chronic disorders and a diagnosed stigmatized disorder have been associated with the increased use of the Internet for health information (Haviland et al. 2003, Wagner et al. 2004, Bansil et al. 2006, Berger et al. 2005, Powell 2006).

There is some evidence that people with depression may also be more likely to use other sources of health information than patients with other conditions (Wagner and Hibbart 2001). Wagner et al. (2001) surveyed a random sample of households in Boise Idaho, and two control cities about their use of self-care books, nurses, and computers for health information. They undertook a baseline assessment in 1996 and a follow-up assessment in 1998 after the Healthwise Communities Project (HCP) intervention. The community-wide intervention was specifically designed to give people health information and access to self-care resources. This intervention consisted of three parts: 1) a manual Healthwise handbook was sent to each household, 2) a toll-free health information and assistance telephone line, and 3) information stations with computer access set up in libraries, businesses and healthcare settings in the Boise area. To raise awareness of these resources, an extensive advertisement campaign was conducted. The intervention
increased the use of all three sources: self-care books, nurses, and computers for health information. Similarly with other previous studies, health and demographic factors (age, gender) were consistently positively associated with using those three information sources. However, people with depression used more of all three information sources. This finding was further supported by Sleath et al. (2003) who found that people with depression commonly receive information about their antidepressants from multiple sources. Additionally, Sleath et al. (2003) found that the use of multiple sources of medicines information was associated with increased medication adherence.

6.4.2 What people ask from different sources of health and medicines information

Multiple studies evaluated the type of inquiries that people with depression and/or using antidepressants made to different sources: to physicians (Sleath et al. 2003, Sleath et al. 2007), telephone based medicines information centers and services (Alderman and Ryan 1997, Taylor et al. 2006, van Geffen et al. 2007), community pharmacies (Badger et al. 2002, van Geffen et al. 2009), and the Internet (Pestello and Davis-Berman 2008). The range of inquires was well in line with the results of studies based on self-reports concerning medicines information needs among people with depression (Table 7). Particularly the finding that people inquire about adverse drug reactions, dose and dosage of their medicines, and interactions were common to the majority of the studies. This was true regardless of the study setting or information source involved. However, information seeking about sexual dysfunctions was reported only in a study analyzing antidepressant-medicines-related discussions (n=227 postings) on the popular anti-depressant medication message boards (Pestello and Davis-Berman 2007). In this study, common adverse drug reactions, adverse drug reactions influencing sexuality, general medical advice, and frustration with physicians were among the leading themes of discussion relating to antidepressant medicines. Most commonly discussions related to general physical adverse drug reactions such as stomach symptoms, insomnia, fatigue, weight fluctuation, headaches, but also emotional symptoms such as nervousness and anxiety. People described how they perceived weight gain as a problem that influences their sense of self and how they thought they appeared to other people. Additionally, people discussed their specific medications, proper dosages, lab and other medical tests, combining different medications, and variety of diseases. Often these discussions went beyond descriptions of symptoms, but included recommendations about which medicines to try given their symptoms. A quarter of all discussions were about adverse drug reactions influencing sexuality. In another study, Badger et al. (2002) found that people with depression very rarely discuss adverse drug reactions related to sexuality with pharmacists.
Table 7. Information sources and type of information sought from different sources of health and medicines information according to the literature review.

<table>
<thead>
<tr>
<th>Information searched or asked</th>
<th>Physician</th>
<th>Pharmacist</th>
<th>DIC</th>
<th>Internet</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adverse drug reactions related</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td>Pestello and Davis-Berman 2007</td>
</tr>
<tr>
<td>Timing of effect/Delayed onset of action</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Landers et al. 2002</td>
</tr>
<tr>
<td>Length of the treatment</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Badger et al. 2002, Landers et al. 2002</td>
</tr>
<tr>
<td>Dependency/addiction</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td>Badger et al. 2002, Landers et al. 2002</td>
</tr>
<tr>
<td>Indication and/or reason to use</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Badger et al. 2002, Landers et al. 2002</td>
</tr>
<tr>
<td>Consequences of long term use</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Landers et al. 2002</td>
</tr>
<tr>
<td>Discontinuation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Taylor et al. 2006, Van Geffen et al. 2007</td>
</tr>
<tr>
<td>o Whether to discontinue medication?</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>o When to discontinue medication?</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>o How to discontinue medication?</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>o What to expect during discontinuation?</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td>Khazaal et al. 2008</td>
</tr>
<tr>
<td>Other types of treatments</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>Khazaal et al. 2008</td>
</tr>
<tr>
<td>Mechanism of action</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>Sleath et al. 2003</td>
</tr>
<tr>
<td>Type of medicine</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>Sleath et al. 2003</td>
</tr>
<tr>
<td>Alcohol use during treatment</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>Badger et al. 2002</td>
</tr>
<tr>
<td>Safety of medicines during pregnancy</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Alderman and Ryan 1997</td>
</tr>
<tr>
<td>Stability/Storage</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Alderman and Ryan 1997</td>
</tr>
<tr>
<td>Effects on driving or working</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>Badger et al. 2002</td>
</tr>
</tbody>
</table>
6.4.3 Preferences for different modes of medicines information

Four studies (Donoghue 1993, Sleath and Wurst 2002, Zwaenepoel et al. 2004, Nabeel et al. 2008) concerned patients’ preferences for different methods and/or sources of medicines information. In a study by Donoghue (1993), the majority of patients (62%) felt that they had not been provided with adequate information. When asked where information should be available, 50% said that in hospitals, 63% in physicians’ surgeries, 72% in community pharmacies, and 74% in mental health day centers. The provision of information and the routine availability of patient information leaflets were seen as desirable by 90% of patients. Three studies concerned the preferences for oral vs. written information. In all three studies, participants preferred oral over the written information on their medicines. Health care professionals – particularly physicians - were the most preferred sources of medicines information in all studies. In the study by Sleath and Wurst (2002), 92% of respondents (n=83) chose the pharmacist as their first or second choice for providing them oral information. In contrast, only a minority of hospital patients have reported that they would like to have information about their medicines from pharmacist (Zwaenepoel et al. 2004, Nabeel et al. 2008). In the Zwaenepoel et al. (2004) study, approximately half of the patients (51%) preferred to have information from their physician. However, 32% of patients wanted to have information from more than one health care professional. Of the respondents, 10% did not wish to receive additional information. The authors concluded that people with mental disorders appear to have a need for information about their medication that is comparable to the needs in general medical practice.

None of the studies on preferences for methods and sources of medicines information covered electronic modes of information provision. However, two studies concerned consumer perceptions of the websites as a source of mental health information and compared the websites to more traditional sources (Leach et al. 2006; Oh et al. 2008). Leach et al. (2006) and Oh et al. (2008) examined characteristics that may influence belief in the helpfulness of websites as modes for delivering information about mental health. They surveyed Australians aged 18 years and older (n=3998) and 12-25 years (n=3746), respectively. Although participants preferred face-to-face counseling, the potential usefulness of the websites was recognized in both studies. Leach et al. (2006) concluded that there is a need for multiple modes of information delivery. Websites and other tools that maintain the anonymity may be preferred by those who choose to or find themselves dealing with mental illness alone. Oh et al. (2008) suggested that most young people were enthusiastic about accessing mental health information online.

The role of pharmacists, and drivers and barriers relating to counseling in pharmacy setting were examined by Van Geffen et al. (2009) in the Netherlands. In their qualitative interview study (n=41), the majority of participants considered physicians as the most appropriate sources of medicines information. The rationale was that physicians have enough information about diseases and also are the ones who prescribe medicines. Generally, patients were unfamiliar with the medication counseling role of pharmacists and regarded information from pharmacies as being limited. Half of the participants did not consider pharmacies to be appropriate information providers. Reportedly, participants perceived that pharmacists may feel uncomfortable providing information about
antidepressants. In community pharmacies there may also be lack of privacy and limited
time for personal contact. Furthermore, the participants had concerns about receiving
contradictory information from the different sources and about poor quality of verbal
counseling. In spite of these concerns, participants valued receiving information from
multiple sources.

6.5 How and why people search for information from the Internet
There is only one study about the reasons and ways people with depression use different
sources of medicines information (Khazaal et al. 2008). This cross-sectional survey about
the use of the Internet by patients with psychiatric disorders found that a majority of online
information seekers searched information about their diagnosis, treatments, and adverse
drug reactions relating to their medications. The information was found with relative
difficulty (56 +/- 27) measured by the score on a visual analogue scale ranging from 0 –
100. More than half of the respondents (55%) reported that the information they searched
for was incomplete or not found at all. Additionally, understanding the information found
was sometimes perceived to be difficult. People did not systematically assess the quality
of information that they had found. They were also not familiar with any quality
indicators. Internet use for health information was associated with knowledge of English
language and with the private access to the Internet. This study focused on health
information, not specifically on medicines information.

6.6 Methodological consideration of the published studies
Several limitations were identified in the published studies on information needs and
sources. Theoretical or conceptual framework was discussed only by Garfield et al. (2004)
and Landers et al. (2002). Garfield et al. (2004) used concordance as a background
approach and a rationale for examining information needs. However, it was not reported if
or how this approach impacted research questions, guided the development of the
discussion guide and reflected in the data analysis. Landers et al. (2002) used compliance
and concordance approaches as a framework for the data analysis. None of the studies
defined the key terms such as health or medicines information.

Some studies applied instruments that had not been validated or validation was not
reported (MacHaffie 2002, Powell and Clarke 2006, Khazaal et al. 2008). This makes
comparisons between studies difficult and potentially limits the validity of the results.
Comparability of the studies was further restricted by a substantial variation between study
designs, populations and questions included in the questionnaires. Some of the survey
instruments assessed if participants had ever received information about health and/or
medicines from particular sources (Haviland et al. 2003, Wagner et al. 2004, Sleath et al.
2003b, Millard and Fintak 2002); some other instruments asked about information sources
used during the past year or other specified length of time (Haviland et al. 2003, Wagner
et al. 2004, Berger et al. 2005b); and some papers did not even report the exact questions
(MacHaffie 2002, Khazaal et al. 2008b, Nabeel et al. 2008). Most of the studies were
cross-sectional and retrospective. Cross-sectional studies can only identify the views and
behaviors at one point of time. Additional studies observing actual behavior or following
individuals prospectively would be needed. Multiple studies were conducted in restricted settings (for example, among community pharmacy clients with depression or among patients treated in some particular geographical area, or in some particular hospital or clinic) (Donoghue 1993, Sleath et al. 2002, Garfie1 et al. 2003, Sleath et al. 2003, Zwaenepoel et al. 2005, Powell and Clarke 2006, Hunot et al. 2007; Khazaal et al. 2008). Many studies were also limited by small sample sizes or the use of convenience samples (See Appendix 4).

Population based studies focused mainly on the health information and the Internet and did not take into account the range of other sources of information available to consumers. There was no generalizeable information on relative importance and the role of the Internet among other sources of medicines information. Information needs were approached both quantitatively and qualitatively. Qualitative studies were mainly descriptive and limited to inductive data-analysis without developing theory. In contrast, information seeking from different sources was mainly approached by using quantitative methods. There were no qualitative or multi-method studies specifically on how, why, and with what consequences people with depression seek information or how they perceive the role of the Internet among other sources of medicines information.

6.7 Key findings of the review on information needs and sources among people with depression

There were numerous studies on medicines information needs and sources among people with mental disorders. Despite the methodological limitations of the published studies, the review provided a comprehensive view of the range of different types of information needs. The same types of information needs were reported in all included studies. ADRs, interactions, and practical information on how to take medicines were the most commonly reported information needs. The self-reported information needs were well in line with the inquiries people made about their medicines and with the information they searched from different sources. This reflects that published studies have managed to accurately describe the different type of information needs that people with depression may experience during the course of their treatment with antidepressant medicines. Additionally, the studies suggest that the types of information needs and concerns may be similar in different countries and among different study populations. Although the evidence is based only on few studies, this seems to be true also in Finland (Enäkoski 2002, Pohjanoksa-Mäntylä et al. 2002). Some information needs were specific to antidepressant medicines (such as delayed onset of action). However, in general, the types of information needs found in this literature review were similar to those reported in previous studies among consumers and patients (For example Dickinson et al. 2003).

Similarly with most consumers and patients, physicians and pharmacists were the most commonly used and preferred sources of medicines information for people with depression (See also Chapter 4). Previous studies suggest, however, that there may be some differences in how and why people use different sources of information. People with mental disorders, especially people with depression, were found to be more frequent users of the Internet for health information than people without those disorders. Based on this review, it can be hypothesized that this may be because people are often dissatisfied with
the information received from their healthcare professionals and/or they may experience a stigma or other barriers that inhibit information seeking and discussion in physician and pharmacy encounters. They may also value the Internet due to possibility to ask about sensitive issues anonymously and without face-to-face contact. Further research should be conducted to confirm these hypotheses. Further studies would use the typology of information needs developed in this review as a framework for the development of standardized assessment tools for surveying information needs among people with depression, and additionally, for assessing whether the information provided at different settings meets the needs of this particular patient group. Those settings may include antidepressant related websites and other Internet and e-mail based information sources and services.

This review identified gaps in the knowledge of information needs and sources of information available to people with depression. Given that population level studies on Internet use mainly focused on general health information among people with mental disorders, more information would be needed about Internet use specifically to obtain medicines information. This information would be important for health care professionals supporting and counseling people with mental disorders, and also to people maintaining and developing medicines information sources and services for consumers. There is preliminary evidence to suggest that people with different types of mental disorders may have different needs in terms of their use of and preferences for different information sources. Therefore, further research should focus on people with depression and/or some other particular type of mental disorder. Based on this review, it seems that people with depression and using antidepressant medicines may be a patient group that could benefit from the complementing sources of medicines information, such as the Internet. However, there are no studies on how information behaviour among people with depression compares and contrasts to that of other patient populations or general consumers. In order to have deeper understanding of information seeking behaviour among people with depression, further studies should apply qualitative methods and/or make use of method or data triangulation. In order to follow trends, more current and longitudinal studies would be needed. Given to the rapid increase in the Internet use among consumers and to the fact that the most comprehensive study on the information sources among people with depression was published in 2003 (Sleath et al. 2003a), this would be highly important. Longitudinal study designs would also enhance better understanding how information needs and use of different sources change during the course of antidepressant treatment. Although the evidence is limited, cultural differences may influence consumer information seeking behaviors. As a majority of the previous studies were conducted in UK and US, more studies would be needed from other countries to describe their practices.
7 Conclusions of the literature review (Chapters 2-6)

There is a need to develop consumer medicines information and information services both in EU and at the national level in Finland (Figure 6). The need is driven by the increasingly active role of consumers in health care and the increased use of the Internet as a source of health and medicines information. Furthermore, previous research has found that: 1) Face-to-face counseling by health care professionals is often sub-optimal; 2) Consumers have unmet medicines information needs and seek additional information from a variety of sources, including the Internet and e-mail; 3) The quality of health and medicines information available on the Internet is highly variable; and 4) People may experience difficulties in searching for and evaluating this information.

These issues have led the drive to incorporate the Internet and e-mail into routine practice in health care practice, including in community pharmacies. In order to meet the needs of consumers, more evidence should be generated on consumer needs and information behaviors; how and why consumers use particular sources of medicines information; how new sources and services are and can be integrated with other modes of communication; what are the actual impacts; and what populations are most likely to benefit from the new sources and modes of communication.

As reflected by the literature reviewed for this study, one of the populations potentially benefitting from these new modes of communications is people with mental disorders, particularly people with depression. They have been found to have un-met medicines-related information needs. They are also frequent users of the telephone and the Internet-based drug information services, and more likely to search for health information from the Internet than people with other long-term illnesses. However, there are no previous studies on how, why, and with what consequences people with depression use the Internet for medicines information; or how they perceive the role and value of the different sources of medicines information. Although the e-mail use for medicines information is likely to increase, there is little evidence on the availability and quality of e-mail counseling services provided by community pharmacies. No published studies exist about e-mail counseling specifically about the antidepressant medicines.
Figure 6. Summary of the literature review with implications for further research and strategic planning.
8 Aims of the study

This study explored the place and utilization of the Internet-based medicines information and information services in the context of a wider network of information sources accessible to the public in Finland. The overall aim was to gather information for the development of consumer medicines information sources and services to better meet the needs of consumers. Special focus was on the need for and utilization of Internet-based medicines information by people with depression and using antidepressant medicines. This patient group was selected, because it was identified as having unmet information needs in the early phase of the study (Literature review and studies I & II).

The specific objectives of the study were:

1. To identify consumer medicines information needs and sources
   a. To analyze and describe utilization of a community pharmacy operated national drug information call center (I)
   b. To analyze the sources of medicines information among people with and without mental disorders (II)

2. To explore the utilization of the Internet as a source of antidepressant information among people with depression
   a. How and why do people with depression access and utilize online antidepressant information? (III)
   b. How do people evaluate online antidepressant information and what is the perceived usefulness of the new quality assessment tool (DARTS/KATSE) developed by the Working Group on Information to Patients under Pharmaceutical Forum of the European Commission, in a medicines information search process? (IV)

3. To assess how community pharmacies have addressed the needs of consumers in terms of developing Internet-based medicines information services
   a. What is the availability of e-mail medication counselling services in Finnish community pharmacies?
   b. How comprehensive and accurate are the responses to antidepressant-related e-mail inquiries by those pharmacies providing this service (V)

In order to meet the objectives, the thesis consists of five original studies (Figure 7).
Figure 7. Study design. FGD = Focus group discussion, MI=medicines information, UP=University Pharmacy.
9 Materials and methods

9.1 Study design

This study was a multi-method study in which both qualitative and quantitative methods were applied to explore the research questions (Table 7). This process of combining different methods, approaches, and/or data is known as triangulation (Pope and Mays 1995, Smith 2002). Combining different types of methods ensures comprehensiveness of the study (Smith 2002). While qualitative and quantitative methods may explore similar topics, they will address different types of study questions (Britten et al. 1995). Quantitative methods are used to gather information that can be generalized to a wider study population and to explore statistical relationships between variables. On the other hand, qualitative methods are used to explore processes and patterns in people’s thoughts and behaviors (Barbour 1999, Smith 2002).

In this study quantitative methods were used to explore medicines information needs and sources among Finnish adult population (Studies I and II), and to assess the e-mail medication counseling services provided by Finnish community pharmacies (Study V). Based on the literature review and results of the studies I and II, the focus in further studies (III, IV) was on antidepressant information and people with mental disorders, particularly with those having depression. This was due to the fact that people with mental disorders were found to have un-met information needs and to be more active online health and medicines information users than people without those disorders (II). Additionally, psychotropic medicines were the most common group of medicines in the University Pharmacy (UP) Drug Information Call Center about which inquiries were received (I). Among psychotropic medicines antidepressants were the most common medications about which inquiries were received. In order to better understand online medicines information seeking of people with depression, quantitative information was supplemented with qualitative information from focus group discussions (III and IV). The choice of the focus group discussion method was supported by the fact that focus group discussions are empowering method to collect data (See Chapter 2.2.). Summary of the research methods and study participants is presented in Table 8. Detailed information on the study participants is available in original publications (I-V).
Table 8. Methods used in the original publications (I-V).

<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHODS</th>
<th>PARTICIPANTS</th>
<th>STATISTICS AND ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Cross-sectional study; calls made to the Helsinki University Pharmacy operated drug Information Call-Center over a one week period in 2002</td>
<td>Callers inquiring about prescription medicines in the UP Call-Center (n=942)</td>
<td>Quantitative analysis; descriptive statistics (frequencies, percentages)</td>
</tr>
</tbody>
</table>
| II    | Population survey; National Public Health Institute’s annual postal survey “Health Behaviour and Health among the Finnish Adult Population”, in 2005 | Respondents to the question about medicines information sources (n=2348) in the survey based on the random sample of Finnish adults (15-64 years, response rate 66%)  
  - People with mental disorders (n=228)  
  - People without mental disorders (n=2120) | Quantitative analysis; Descriptive statistics, chi-square –test, logistic regression |
| III, IV | Focus group discussions; six groups in 2007 | Focus group participants (n=29); people with depression and current or past use of antidepressant medicines, recruited from the capital area of Helsinki | Qualitative analysis; Thematic content analysis (inductive and deductive), constant comparative method, two researchers |
| V     | Virtual pseudo customer study; two antidepressant related e-mails to each study pharmacy in 2005 | Finnish community pharmacies indicating opportunity for e-mail counseling (n=161) in 2005 | Quantitative analysis; inventory of pharmacies e-mail counselling services, content analysis of pharmacy responses, a pre-structured scoring system, two researchers, Cohen’s Kappa Statistics |

9.2 Identification of consumer medicines information needs and sources

9.2.1 Analysis of the calls to the University Pharmacy drug information call-center (I)

All telephone calls made to the consumer lines of UP Drug Information Call Center were documented with a structured data-collection form during a one-week period in 2002. The form included details about the caller, matters and medications of concern, the length of calls, and data and time of the call (Appendix 5). The form was based on the previously used forms in the UP Drug Information Call Center that were modified for the purposes of this study. Before the study, the face validity of the form was assessed and the form was pilot tested by the staff of the call-center. The whole staff participated to data collection and was trained to undertake documentation. They were instructed to provide services in their usual manner and to fill in the form during or immediately following each call during
the study period. If the call concerned more than one medicine, the staff was instructed to mark the name of the medicine that the inquiry mainly concerned and to document only the concerns related to that medicine. The data were analyzed by using the Statistical Package for Social Sciences software (SPSS, version 10.0). For the analyses, medicines documented were classified according to the Anatomical Therapeutic Chemical (ATC) classification system ((WHO Collaboration Centre for Drug Statistics 2009). Detailed information on the methodology and description of the calls included into the study are available in the original publication (I).

9.2.2 A survey of the Finnish adult population (II)

Data were collected as part of The National Public Health Institute’s annual population survey “Health Behaviour and Health among the Finnish Adult Population” (Helakorpi et al. 2005). In order to enable generalisation, a random sample (n=5000) of Finnish adults aged 15 - 64 years was drawn from the National Population Register that includes everyone living permanently in Finland. A postal questionnaire was sent in April 2005 and was followed by three reminders to non-respondents during the next two months. The overall response rate was 66% (n = 3287; women 73%, men 59%). In the survey, participants were asked whether “In the past year (12 months), they had received information on the medicines they used?” This question was followed by a list of both professional and other medicines information sources available to consumers in Finland (Appendix 6). The same question had been included into the survey previously in 1999 and 2002. All respondents who reported using one or more sources of medicines information during the 12-months prior to the survey were included in the analysis (n=2348). Detailed demographic data of the respondents is available in original publication (IV, Table 2).

To identify individuals suffering from major public health concerns common in Finland, the questionnaire included a question asking whether “In the past year (12 months) the recipient of the questionnaire had been diagnosed with or treated for the following conditions”; high blood pressure/hypertension; high blood cholesterol; diabetes; coronary thrombosis or myocardial infarction; coronary disease or angina pectoris; coronary insufficiency; cancer; rheumatoid arthritis; degenerative disk disease or other back illness; chronic bronchitis or pulmonary emphysema; depression; other mental health disorder; asthma; and digestive illness. For analytical purposes, respondents were divided into groups of people with mental disorder (includes respondent with depression and/or other mental disorder, n=228) and people without mental disorder (n=2120). To measure and control for co-morbidity, the list of above mentioned 11 diseases was used to create a count of chronic diseases including mental disorders (0, 1, ≥ 2 chronic diseases).

The sources of medicines information and associated factors were analysed by computing descriptive statistics and using chi-square test for categorical variables. To control for confounding factors, logistic regression analyses were performed with different medicines information sources as dependent variables (Metsämuuronen 2006). Based on the chi-square test, the sources with significant association with mental health status were included. These sources included physicians, pharmacists, nurses, patient information leaflets, and the Internet. Age, gender, education, working status, number of chronic
diseases, and mental health status were simultaneously entered into the model as the independent variables. These variables were selected as previous studies have found that males, older, and less-educated people use less Internet for health information than females, younger, and people with more education (Bansil et al. 2006, Hesse et al. 2005). Furthermore, people with stigmatizing conditions (Berger et al. 2005), with chronic conditions (Bansil et al. 2006), particularly with mental disorders (Baker et al. 2003, Haviland et al. 2003, Wagner et al. 2004, Berger et al. 2005, Bansil et al. 2006, Powell 2006), are more frequent users of the Internet for health information than people without those disorders. Values of p<0.05 were considered as statistically significant. Statistical analyses were conducted by SPSS version 14.0 (SPSS Inc, Chicago).

9.3 Qualitative study on the Internet use for antidepressant medicines information among people with depression (III and IV)

9.3.1 Study design in the focus group study

Focus group discussions (FGD) were conducted in spring 2007 to qualitatively explore how and why people with depression accessed and utilized online antidepressant drug information, how they assessed the quality of online medicines information and whether the DARTS tool could assist in this process. Focus group discussions are an ideal method for exploring people’s experiences, opinions and concerns, and researching a previously unexplored topic, or one that is poorly understood (Britten et al. 1995). Focus group method enables interaction between the study participants, and thus provides an opportunity for the participants to stimulate each other to be explicit in their views, perceptions, and reasons (Kitzinger 1995). The discussion may also provide a supportive environment that encourages people to address sensitive issues (Britten et al. 1995, Barbour 1999). One advantage of focus groups is the group dynamic (e.g. debate within the group) which can act as stimulation for subjects who may be less articulate in face-to-face situation. Focus group discussions have previously been used to analyze experiences and perceptions about health care among people with mental disorders (Lester et al. 2005) and to analyze the consumer use of the Internet to search for medicines information (Eysenbach and Kohler 2002, Peterson et al. 2003, Peterson-Clark et al. 2004). Therefore, focus group discussions were chosen as a method to collect data also in this study.

Previous literature was used as the basis for developing a focus group discussion guide (Peterson et al. 2003, Peterson-Clark et al. 2004). The exact wording of the questions was not predefined and prompt questions were used to clarify themes. The discussion guide included seven main themes: 1) Experiences receiving information on antidepressants, 2) Antidepressant-related information needs, 3) Experiences using different sources of medicines information, 4) The Internet as a source of medicines information, 5) The methods and process of searching for Internet-based medicines information, 6) The evaluation of the quality of Internet-based medicines information, and 7) Perceived impact on the patient of Internet-based medicines information (Appendix 7). The guide was pre-tested for appropriateness and comprehensiveness, using a group of people with
depression (n=6). No significant changes were made to the discussion guide based on the pre-test. Therefore, the data from the pre-test was included in the analysis.

### 9.3.2 Focus group participants

A maximum variation sampling strategy was employed to achieve a cross-section of study participants from metropolitan Helsinki (Coyne 1997). People with depression were identified and invited to participate in the study with the assistance of three organizations: 1) Mieli Maasta; a national non-governmental patient organization that primarily caters to adults with depression (Mieli Maasta ry - Depression Alliance), 2) the Finnish Student Health Service; a National Foundation providing health and mental health care to all university students in Finland (Finnish Student Health Service), and 3) NYYTI; a peer-support centre for students to promote mental well-being by providing virtual support groups and counseling service (Nyyti ry - opiskelijoiden tukikeskus). Participants were recruited using a recruitment letter placed on these organizations’ websites, information boards and newsletters. People who consented to participate were invited to attend the focus group discussion at a specific time and location in Helsinki area.

The inclusion criteria for participants were 1) a present or past diagnosis of depression, 2) present or past use of an antidepressant drug, 3) use of the Internet as a source of antidepressant drug information during the previous 12 months, and 4) age of 18 years or more. People who were health or information technology professionals were excluded from the participation in the study. Twenty-nine Internet users with depression consented to participate. Detailed demographic data of the participants is available in original publication IV, Table 2.

### 9.3.3 Data collection and analysis of transcripts

Six focus groups (67-107 minutes duration) were conducted in different locations across metropolitan Helsinki. In order to facilitate open discussion, focus groups were conducted in the premises of the support groups and consumer organizations which were familiar and easily accessible to the participants (Smith 2002, Barbour and Kitzinger 2001). All focus groups were facilitated by the same moderator with two assisting researchers observing and taking notes. The moderator ensured that each participant had an equal opportunity to be involved in the discussion, and probed participants for opposing views about issues that arose. After gaining written informed consent, each focus group was digitally audiotaped. After the discussions, participants also completed a short questionnaire to gather demographic data and details about previous Internet usage.

The digitally audiotaped focus groups were transcribed verbatim. Each transcript was repeatedly read by a researcher while the coding frame was developed and continuously revised (Figure 8). A constant comparison approach was used in order to identify emerging patterns and key themes in the data (Silverman 2000, Boeije 2002). Single words, sentences or groups of sentences related to a particular theme were coded by one researcher. Another researcher verified the key themes identified by the first researcher, and any differences of interpretation were resolved through discussion. Once key themes
were identified, the transcripts were read by two researchers to detect any discussion that deviated from these themes.

**Figure 8.** *The iterative analysis process based on a constant comparison approach.*

### 9.4 Virtual pseudo customer study on e-mail medication counseling services provided by Finnish community pharmacies (V)

Websites of privately owned community pharmacies were identified from a comprehensive list maintained by the Association of Finnish Pharmacies (AFP). The websites of the two university-owned pharmacies were also included in the study. Websites of each pharmacy were systematically reviewed by one researcher to determine which pharmacies offered opportunities for e-mail medication counseling. The pharmacy was deemed to provide such opportunities if they: 1) maintained an electronic feedback form, 2) an online “ask-the-pharmacist” service, or 3) if they had a contact e-mail address listed on their website.

Three antidepressant-related virtual pseudo customer scenarios (e.g. concerns that pharmacists were supposed to respond to) were developed based on our previous study concerning medicines-related inquiries sent to a national web-based information service in Finland (Pohjanoksa-Mäntylä et al. 2002). The scenarios related to the three most frequently utilized antidepressants in Finland, and concerned common concerns related to use of antidepressants: 1) adverse drug reactions associated with fluoxetine, 2) sexual dysfunction and weight gain associated with citalopram, and 3) drug-drug interactions with mirtazapine. Those scenarios are described in the original publication (IV, Appendix 1). The scenarios were reviewed for face-validity by a multidisciplinary panel comprising a psychiatrist, a general medical practitioner, a practising community pharmacist and 5 lay people. The scenarios were worded in language commonly used by lay people and were
designed to reflect the content and complexity of requests routinely posed by antidepressant users.

Two of the three different scenarios (Appendix 8) were sent to each pharmacy deemed to provide the opportunity for e-mail medication counseling (n=165). Community pharmacies across Finland were divided into three groups based on their geographical location. The e-mails were sent in two phases to avoid neighbouring pharmacies receiving the same inquiry, or the one pharmacy receiving similar inquiries at the same time. The first 165 inquiries were sent in January 2005 and the remaining 155 inquiries in February 2005. Twelve e-mail accounts were created to send the inquiries, with different e-mail accounts used to send inquiries to pharmacies located in the same geographical area. Ten pharmacies replied to the first inquiry to indicate that they had a policy not to provide medication counseling by e-mail, and these pharmacies were excluded from participation in the second phase. After all the e-mail responses were received each pharmacy was informed in writing about the study and consent to participate was obtained. Four pharmacies that responded to the email inquiries did not provide consent to participate. Responses from these pharmacies were deleted and excluded from the analyses. Overall, there were 161 pharmacies included in the first phase of the study and 151 pharmacies in the second phase of the study. The responses from each of the pharmacies were analysed independently by two researchers using a structured form to determine accuracy, comprehensiveness, and availability of key information components. The inter-rater reliability of the scoring process was calculated for each scenario using Cohen’s Kappa Statistic (McGinn et al. 2004, Viera and Garrett 2005) Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 12.0 (Chicago, IL).
10 Results

This chapter describes the key findings of the original studies I-V, which are also summarized in Figure 13 (p. 88).

10.1 Consumer needs and sources of medicines information (I,II)

10.1.1 Consumer inquiries to the University Pharmacy Drug Information Call-Center (I)

The analysis of consumer calls to the University Pharmacy Medicines Information Call-Center found that people have additional information needs about their medicines, especially with regard to prescription medicines (I). The total number of calls documented during the one week study period was 2196. Of those calls, 43% (n=942) related to prescription medicines. A majority (77%, n=780) of the prescription medicines related calls were classified as therapeutic and pharmaceutical calls and were included in the analyses (See Figure 9). A majority of the therapeutic and pharmaceutical inquiries were received from women (77%), and people aged 20-60 years (82%). The callers mainly called about their own medicines (69% of the calls), calls concerning typically one medicine (78% of the calls). The calls most commonly related to the nervous system medicines with the ATC-classification N (20% of the calls) and antimicrobials with the classification J (18%) (Table 9). Of the ATC-subgroups, the highest rates of calls were in relation to NSAIDs (9% of the calls), antidepressants (6%), and penicillins (5%).
Table 9. Number of prescription medicine-related therapeutic and pharmaceutical calls (n=703) by therapeutic groups (ATC-classification). Main therapeutic groups are bolded. Only ATC-subgroups with more than 10 calls are mentioned.

<table>
<thead>
<tr>
<th>Therapeutic Group</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nervous system (N)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antidepressants (N06A)</td>
<td>20</td>
<td>143</td>
</tr>
<tr>
<td>Anxiolytics (N05B)</td>
<td>6</td>
<td>40</td>
</tr>
<tr>
<td>Antipsychotics (N05A)</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Opioids (N02A)</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Hypnotics and sedatives (N05C)</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Antiepileptics (N03A)</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td><strong>Antimicrobials (J)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Penicillins (J01C)</td>
<td>18</td>
<td>127</td>
</tr>
<tr>
<td>Macrolides, lincosamides and streptogramins (J01F)</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Other beta-lactam antibacterials (J01D)</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Viral vaccines (J07B)</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Quinolone antibacterials (J01M)</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Tetracyclines (J01A)</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td><strong>Musculoskeletal (M)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSAID (M01A)</td>
<td>13</td>
<td>91</td>
</tr>
<tr>
<td><strong>Genito-urinary tract (G)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormonal contraceptives for systemic use (G03A)</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Urologicals (G04B)</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td><strong>Cardiovascular (C)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholesterol- and triglyceride reducers (C10A)</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td><strong>Alimentary tract (A)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs for peptic ulcer and gastro-oesophageal reflux disease (A02B)</td>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td><strong>Respiratory system (R)</strong></td>
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<td></td>
</tr>
<tr>
<td>Other inhalants (R03B)</td>
<td>7</td>
<td>46</td>
</tr>
<tr>
<td>Adrenergics inhalants (R03A)</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td><strong>Dermatological (D)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other dermatological preparations (D11A)</td>
<td>6</td>
<td>42</td>
</tr>
<tr>
<td><strong>Blood (B)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antithrombotic agents ((B01A)</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td><strong>Sensory organs (S)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cytostatic and immunomodulants (L)</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Cytokines and immunomodulators (L03A)</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td><strong>Systemic hormones (H)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td><strong>Antiparasitic (P)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td><strong>Other (V)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

79
The most common information needs in the calls related to costs and reimbursements (26% of the calls), drug-drug interactions (14%), dosage of medication (14%), and adverse drug reactions (11%) (Figure 9).

![Figure 9](image_url). *Prescription medicines related therapeutic and pharmaceutical inquiries in University Pharmacy (UP) medicines information call-center (% of calls, n = 780). Calls may have included more than one inquiry.*

### 10.1.2 A survey on medicines information sources among Finnish adult population (II)

In a population survey of Finns aged 15-64 years in 2005 (II), 71% of the respondents (n=2348) reported receiving medicines information from one or more sources in the year prior to the survey. Physicians, pharmacists, and PILs were the most common sources of medicines information both among people with and without mental disorders (Figure 10). Based on the chi-square test, people with mental disorders (n=228) were significantly more likely to report receiving medicines information from their physician (p<0.001), pharmacist (p = 0.04), PIL (p = 0.003), nurse (p = 0.04), and the Internet (p < 0.001) than the respondents without mental disorder (n=2120). People with mental disorders were also significantly more likely to report more sources of medicines information than people without mental disorders (p<0.001). After adjusting age, gender, education, working status, and number of chronic diseases in the multivariate logistic regression (Table 3, original publication II), respondents with a mental disorder were more likely to use the Internet (OR 1.64, 95% CI 1.02-2.64) and PILs (OR 1.45, 95% CI 1.06-1.98) for medicines information than respondents without a mental disorder.
Figure 10. Medicines information sources among respondents with (n=228) and without mental disorders (n=2120) who reported using one or more sources of medicines information during a 12-month period prior to survey (% of the respondents).

10.2 Use of the Internet for antidepressant medicines information among people with depression (III, IV)

10.2.1 Three functions for the Internet use (III)

Based on focus group discussions (FGD), the Internet had three main functions for people with depression in relation to medicines (III). They used it 1) to seek facts about their antidepressant medicines (Content), 2) to network and share experiences (Community), and 3) to satisfy their curiosity or as a form of entertainment (Curiosity) (Figure 11). Sub-themes for those three main themes are described more in detail in Table 1 in the original publication III. The most commonly mentioned reasons for content focused information seeking took place when participants started or changed an antidepressant medicine. Many participants reported they were unable to absorb, or did not receive, all the information they required during their initial consultation with their physician. Participants also used the Internet to prepare for visits to their physician.

Internet use to network and share experiences involved efforts by people to maintain contact with the outside world and to share experiences with peers. This was perceived as particularly important when fatigue and lethargy prevented people from leaving their homes. Discussion forums and electronic support groups were used by some participants to read about other peoples’ experiences with taking antidepressant medicines. People particularly appreciated the anonymity afforded by these forms of communication. Some
participants reported searching for information and participating in discussion forums to satisfy their own curiosity or as a form of entertainment.

**Figure 11.** The main functions of the Internet use for searching antidepressant information among FGD participants (n=29). A representative quotation is presented for each function.

### 10.2.2 How the Internet was used (III)

Discussion related to how the Internet was related to the role of the Internet relative to other medicines information sources, and to the search strategies employed to find information. Physicians were seen as the primary source of antidepressant medicines information. The Internet was used to complement, not replace the information received from health care professionals. PILs supplied with dispensed medicines were typically read very closely. Most participants saw them as a useful source of medicines information, but some reported using the Internet to check the meaning of a medical term or to obtain additional information. Some participants reported being worried or confused by the lists of potential adverse drug reactions, but most agreed that this information should still be provided to patients. The Internet was often described as the first source of additional information consulted when specific or unexpected information needs arose, especially among students and younger participants. The Internet was seen as valuable because fear of stigmatization and potential embarrassment were seen to hinder communication in community pharmacies. Drug information call-centers were preferred over the Internet if an immediate answer was required.
Most participants searched for medicines information using only one familiar search engine, Google being the most often mentioned. Most participants searched information by typing the name of the antidepressant or a single word. Some people entered the web address of a specific site recommended by friends or which had been advertised. Many participants reported conducting multiple searches and comparing online information retrieved to information found on other online and offline sources of medicines information. Participants commonly used e-mail mainly to communicate with friends and peers, only one participant had communicated with her physician via e-mail. Most participants indicated they would be willing to communicate with their health care professionals by e-mail although some perceived their health care professionals would be poorly equipped to respond to their questions in this manner.

10.2.3 Self-reported effects of online medicines information (III)

The self-reported effects of access to online antidepressant medicines information were either emotional or behavioral. Most participants reported that they felt confident, relieved and reassured after reading online medicines information. Some participants initiated changes to their medication themselves, whereas others always consulted their prescribing physician. The Internet was perceived as a key contributor to the shift towards greater patient access to medicines information, which was described by participants as empowering. However, many participants were concerned about the quality and reliability of online medicines information, as well as their own ability to discriminate trustworthy from less trustworthy information.

In terms of behavioral effects, some participants described how they, or one of their friends or relatives, had decreased or increased a dose, discontinued taking a medicine, or decided not to take a medicine because of information they had obtained from the Internet. Some participants described the likelihood of experiencing an adverse drug reaction as the reason for not taking an antidepressant as prescribed. Conversely, some participants concerned about adverse drug reactions were reassured after reading online medicines information. After reading online information, some participants requested additional information about the risks and benefits of specific antidepressant medicines from their physician. However, lack of time in consultations with physicians was seen to limit the opportunity to do this.

10.2.4 How people with depression appraise online medicines information (IV)

In FGDs, most participants were critical of the online medicines information, but they did not systematically assess the quality of the information obtained. Also, participants had not used and/or were familiar with tools that were available to assist consumers in assessing online information. In all groups, participants were concerned about not being properly able to assess the quality of online medicines information. Participants were generally most willing to trust sites maintained by regulatory authorities and pharmacies. Websites maintained by pharmaceutical companies, single persons and discussion forums
were among the least trusted sources. Participants recognized that discussion forums contained mainly the narratives of individuals, often without adequate background information about that person’s medication or disease. This was seen to limit the usefulness of this information. The most commonly described way to assess the quality of online medicines information was cross-checking and comparison with other online and offline information sources.

10.2.5 Perceived usefulness of DARTS tool in appraising online medicines information (IV)

Most participants believed that the DARTS tool would assist them to discriminate between high and low quality online medicines information, but also to other kinds of written medicines information. Most participants appreciated that the DARTS tool was short, concise and included relevant issues (Table 3, IV). They also thought it would be beneficial for both information providers and users, and particularly valuable for people who had just begun to use antidepressants and/or the Internet. In addition, it was seen as particularly beneficial for school aged children. In contrast, two participants questioned whether they would use the DARTS tool in real life, since it would be too time-consuming to first try to find the tool and then systematically use DARTS to answer multiple issues for each information source they retrieved. One participant mentioned that the issues included in the DARTS tool should be “in your head and not on paper”.

Participants indicated that even with the assistance of the DARTS tool, it would still be challenging to evaluate online medicines information. Several participants cited examples of Internet sites they had visited where it was not clear whether the purpose of the site was to provide information or to market pharmaceutical products. Many participants described how websites may resemble professionally published documents and, therefore, have the potential to create a false perception that the information is authoritative and unbiased. Participants mentioned that a university degree after the name of the author does not necessarily guarantee that the author is appropriately qualified to write about that particular topic. Thus some participants felt that the DARTS tool should contain more information about how to assess authors’ qualifications and the purpose of the site.

10.3 E-mail medication counseling services in Finnish community pharmacies (V)

Thirty-percent (n=182) of the Finnish community pharmacies maintained a working website in January 2005. Ninety-four percent of these pharmacies provided the opportunity to obtain counseling by e-mail counseling; 13% (n=23) provided an ask-the-pharmacist service; 70% (n=127) included a feedback form on their website; and 79% (n=143) listed a contact e-mail address. Six percent (n=11) of the pharmacies with a working website did not offer the opportunity for e-mail counseling.

Pharmacies responded to 46% (n=74) of the e-mail inquiries in the first phase, and 63% (n=96) of the e-mail inquiries in the second phase, resulting in an overall response rate of 54% (n=170). Of those pharmacies who responded to at least one inquiry (n=115), 17% responded to only to the first inquiry, 36% to only the second the inquiry, and 47%
responded to both inquiries. Fifty-one percent of the responses were received within one day, 71% within two days, 83% within three days, 92% within four days, and 8% were not received until after four days.

The highest response rate (62%) was obtained for the scenario concerning mirtazapine and interactions (Scenario 3, Table 10). The lowest response rate (49%) was obtained for the scenario concerning citalopram, sexual dysfunction and weight gain (Scenario 2, Table 10). The score/maximum score ratio was highest for the scenario concerning fluoxetine and adverse drug reactions (Scenario 1), indicating the highest accuracy and comprehensiveness, and lowest for Scenario 2, indicating the poorest accuracy and comprehensiveness.

**Table 10.** Response rates and mean content scores for e-mail medication counseling responses according to scenarios.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Response Rate (%)</th>
<th>Mean Content Score (SD)</th>
<th>Maximum Content Score</th>
<th>Mean Content Score/Maximum Content Score Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 1 (n=55): Adverse drug reactions associated with fluoxetine</td>
<td>53</td>
<td>5.3 (2.6)</td>
<td>10.0</td>
<td>0.53</td>
</tr>
<tr>
<td>Scenario 2 (n=52): Sexual dysfunction and weight gain associated with citalopram</td>
<td>49</td>
<td>2.3 (1.3)</td>
<td>6.0</td>
<td>0.38</td>
</tr>
<tr>
<td>Scenario 3 (n=63): Interactions with mirtazapine</td>
<td>62</td>
<td>2.6 (1.4)</td>
<td>5.0</td>
<td>0.52</td>
</tr>
</tbody>
</table>

Pharmacists’ responses commonly included general information about treatment with antidepressant medicines (Figure 12), such as the consumer should avoid alcohol (81% of the responses, Scenario 3), selective serotonin re-uptake inhibitors (SSRIs) do not cause addiction (78% of the responses, Scenario 1) and that adverse drug reactions are often transient and may occur when commencing the treatment (78% of the responses, Scenario 1). The most frequently omitted content were encouraging words to facilitate safe and appropriate use of medicines (12% of the responses, Scenario 2) and the possible need to change a medicine due to adverse drug reactions (14% of the responses, Scenario 2).
<table>
<thead>
<tr>
<th>Scenario 1: fluoxetine</th>
<th>%</th>
<th>Scenario 2: citalopram</th>
<th>%</th>
<th>Scenario 3: mirtazapine</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adverse effects are usually transient and most commonly occur when commencing treatment (during first two weeks)</td>
<td>78</td>
<td>Adverse effects are usually transient and most commonly occur when commencing treatment (during first two weeks)</td>
<td>78</td>
<td>Patient should avoid alcohol use during treatment (if not possible, maximum one portion)</td>
<td>81</td>
</tr>
<tr>
<td>The most common adverse effects are digestive problems...</td>
<td>76</td>
<td>The drug may increase appetite and weight</td>
<td>25</td>
<td>Remeron® may decrease attentiveness, particularly when commencing treatment. If patient feels this effect, driving should be avoided</td>
<td>67</td>
</tr>
<tr>
<td>... and central nervous system effects</td>
<td>69</td>
<td>Since the adverse effects have persisted (Current Care guidelines: more than 6-8 weeks), medication may need to be changed</td>
<td>14</td>
<td>Diapam® (diazepam) and Remeron® (mirtazapine) can be used simultaneously with caution</td>
<td>46</td>
</tr>
<tr>
<td>Pharmacist motivates the patient and tries to ease her concerns</td>
<td>58</td>
<td>Use of encouraging words to facilitate safe and appropriate medication use</td>
<td>12</td>
<td>Sedative effect is usually transient and patient may be able to drive after she/he has used medicine for a while</td>
<td>37</td>
</tr>
<tr>
<td>Medication is usually effective for treatment of depression</td>
<td>46</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maximum effect will normally occur after 4 weeks</td>
<td>44</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To avoid withdrawal symptoms, discontinuation should be gradual</td>
<td>31</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adverse effects are normally mild</td>
<td>26</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absolute incidence of adverse effects described (in numbers or verbally)</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need to contact own physician</td>
<td>73</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication needs to be continued until physician is consulted</td>
<td>60</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less common adverse effects are decreased libido (3.0% of users) and weight gain (3.5%)</td>
<td>44</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since the adverse effects have persisted (Current Care guidelines: more than 6-8 weeks), medication may need to be changed</td>
<td>14</td>
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<td>Remeron® may decrease attentiveness, particularly when commencing treatment. If patient feels this effect, driving should be avoided</td>
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<tr>
<td>Diapam® (diazepam) and Remeron® (mirtazapine) can be used simultaneously with caution</td>
<td>46</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sedative effect is usually transient and patient may be able to drive after she/he has used medicine for a while</td>
<td>37</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommend patient discuss simultaneous Diapam® and Remeron® use with their physician</td>
<td>29</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 12. Proportion of pharmacies (%) providing correct key information components for scenarios. (Scenario 1: n=55, Scenario 2: n=52, Scenario 3: n=63)
11 Summary of the key findings

This study found that PILs and the Internet are both more commonly used sources of medicines information among people with mental disorders than people without mental disorders (Figure 13). Additionally it found that antidepressants are the second most frequent medicine group about which inquiries are received by the UP drug information call center. Focus group discussion participants commonly used the Internet: to complement antidepressant information received from a health care professional, to seek community support and peers’ experiences about the antidepressants, and for the curiosity. A majority of participants saw the Internet as an empowering source of medicines information although difficulties in searching and evaluating Internet-based medicines information were also reported. Many participants found the DARTS –tool, valuable and would possibly ask for additional information via e-mail from their health care professionals. This study suggests community pharmacies are potential providers of e-mail medication counseling services for consumers but at this stage these services are still quite rare and not used on a daily basis.
## Consumer Medicines Information Needs and Sources

<table>
<thead>
<tr>
<th>Information needs commonly relate to costs and reimbursements, interactions, dosage, and adverse drug reactions (I,III)</th>
<th>HCPs and PILs are the most commonly used sources of information (II,III)</th>
<th>PILs and the Internet are more commonly used among people with than without mental disorders (II)</th>
<th>Psychotropic medicines, particularly antidepressants, are most often inquired medicine group in the UP drug information call-center (I)</th>
</tr>
</thead>
</table>

People with mental disorders and using antidepressant medicines identified as a special population in terms of utilizing the Internet and telephone-based medicines information

## Use of the Internet for Antidepressant Information Among People with Depression

<table>
<thead>
<tr>
<th>Commonly used to complement information received from HCPs (III)</th>
<th>Three main reasons for use: to seek facts about antidepressants, to receive community support/share peer medicine taking experiences, and for curiosity (III)</th>
<th>Perceived an empowering tool, although information quality and own ability to appraise the quality were questioned (III,IV)</th>
<th>The DARTS tool may be useful for assessing the quality of online MI and act as reminder of quality issues in general (IV)</th>
</tr>
</thead>
</table>

## E-Mail Medication Counseling Services and Counseling on Antidepressants Provided by Finnish Community Pharmacies

<table>
<thead>
<tr>
<th>One-third of pharmacies had a website (V)</th>
<th>Only a minority actively offered counseling via e-mail (V)</th>
<th>Pharmacy responses to e-mail inquiries were of varying quality, response rate 55% (V)</th>
<th>Type of inquiry impacted pharmacy responses (V)</th>
</tr>
</thead>
</table>

**Figure 13.** Synthesis of the key findings. HCP = health care professionals, PIL = patient information leaflet, UP = University Pharmacy
This study focused on the consumer needs for and utilization of medicines information and information sources to develop consumer medicines information services in Finland. The special focus was on the needs of people with depression and those using antidepressant medicines. In this chapter 1) the key findings from each original publication (I-V) are summarized and compared with the results of previous studies; and 2) the methodological quality of the research is discussed.

Although medicines information needs and sources among consumers have been widely studied both internationally and nationally in Finland (See Chapters 4 and 6), this study provides multiple novel aspects. This is the first multi-method study on sources of medicines information among people with mental disorders, particularly with depression. Previous studies primarily focused on health and medicines information in general, and typically relied only on surveys (Wagner and Hibbart 2001, MacHaffie 2002, Millard and Fintak 2002, Haviland et al. 2003, Wagner et al. 2004, Berger et al. 2005, Khazaal et al. 2008) conducted among selected populations and using small sample sizes without random sampling (Donoghue 1993, Sleath and Shih 2003, Garfield et al. 2004, Zwaenepoel et al. 2005, Perreault et al. 2006, Powell and Clarke 2006). The use of multiple method analysis enables a more comprehensive understanding of medicines information behaviors than previous studies. The quantitative part of the analysis provides population based data especially on the utilization of different sources of medicines information by people with mental disorders, including people with depression. The qualitative part provides new insights into the use of the Internet by people with depression and using antidepressant medication. The study is different from existing literature which has primarily focused on consumers in general (Peterson et al. 2003, Peterson-Clark et al. 2004) or some other particular patient groups, such as cancer patients (McMullan 2006).

This study also provides information about the national drug information call center and the e-mail medication counseling services operated by community pharmacies (I,V). These services are timely issues both internationally and in Finland. In Finland, new national legislative proposals are under consideration which will facilitate the sale of medicines by the community pharmacies via the Internet. Additionally, the new Finnish Medicines Agency (FIMEA) begun in the autumn 2009 is developing a national medicines information strategy (The Act and Decree on the Finnish Medicines Agency). In developing this strategy, it is important to consider the role of all information providers and consumers and the value of setting standards for the information provision. This means that it is necessary to consider not only the role of the traditional sources of medicines information, but also the telepharmacy services such as the drug information call centers and e-mail medication counseling services. While previous studies have mainly concerned face-to-face counseling between pharmacists and consumers, e-mail and telephone counseling by community pharmacies has not been widely studied in Finland or elsewhere.
12.1 Key findings

12.1.1 Consumer needs of medicines information and information sources

This study suggests that people not only have medicines information needs, but also needs to use different sources of medicines information. The finding that most of the therapeutic inquiries in the UP Call Center were related to interactions, dosage, and adverse drug reactions of medicines is in line with the previous studies showing that the public wants more information about the therapeutic effects of medicines (Airaksinen et al. 1994, Melnyk et al. 2000, Newby et al. 2001, Närhi 2006). These findings are confirmed by the fact that adverse drug reactions and drug-drug interactions have been among the most common inquiries in other studies investigating drug information call centers and services (Alderman and Ryan 1997, Grymonpre and Steele 1998, Bouvy et al. 2002). They are also the issues that people in general (Dickinson and Raynor 2003), and with mental disorders in particular (Alderman and Ryan 1997, Garfield et al. 2004, Zwaenepoel et al. 2005, Perreault et al. 2006, Powell and Clarke 2006, Hunot et al. 2007, van Geffen et al. 2009), have reported that they want to know about their medicines. The importance of information on drug-drug interactions and adverse drug reactions was also highlighted by the focus group discussion participants in the present study. Some focus group discussion participants were concerned with the lists of potential adverse drug reactions described in PILs. These concerns provided the stimulus for people to seek additional drug information from other sources including the Internet. This finding highlights the need for health care professionals to discuss potential adverse drug reactions with patients when commencing antidepressant drugs. This is a task that many health care professionals may avoid (Tanskanen et al. 2000, Bull et al. 2002, Vainio et al. 2002), and a topic that patients may be reluctant to discuss with their physicians (Cox et al. 2004).

Similarly with previous studies, respondents to the population survey in this study self-reported use of a variety of information sources. Although widespread use of communication technologies have made available new sources of medicines information to consumers, health care professionals were rated as the primary sources of medicines information. This was also the case with people having mental disorders; including depression, although they more commonly used the Internet and PILs than people without those disorders. However, use of the Internet for medicines information was rare in both groups. Only 15% of the people with mental disorders self-reported Internet use for medicines information. This proportion is nearly three times smaller than the one reported in Khazaal et al. (2008) study among patients with psychiatric disorders (n=200) in a university hospital psychiatric outpatient clinic in Switzerland in 2007. These differences may be explained partially by the details of the Khazaal et al. (2008) study: It:1) concerned general health information instead of medicines information; 2) counted the proportion of the respondents using the Internet, not of the entire group of the respondents; and 3) was conducted among chronically ill outpatients possibly having several or more severe mental disorders. It is also noteworthy that population based studies have previously reported less frequent use of the Internet for health and medicines information than studies conducted among selected populations (for example Andreassen et al. 2007). This is important to keep in mind when planning Internet-based health and medicines.
information services. If the planners of medicines information services solely rely on the findings of the studies targeted to Internet-users or some other special groups actively using the Internet, it may mislead them in service design and prohibit access to services for some groups in need for them (e.g. the elderly and low-income people).

Given that health care professionals are the most important and preferred sources of medicines information for consumers today, health care professionals should assure that the information they provide is of good quality. Additionally, they should take overall responsibility for organizing medicines information sources and services for consumers. These conclusions were highlighted also by the European Commission Pharmaceutical Forum. If these conclusions are not heeded, there is a risk that health care professionals will be replaced by the other information sources operating online, such as online pharmacies and drug industry (Shiffman and Sweeney 2008). From this perspective, the national strategy for medicines information as well as qualitative research on consumer information behaviour is needed.

The finding in this thesis that people with mental disorders are more likely than other people to search for medicines information online is consistent with previous findings from studies concerning Internet use for health information among people with mental disorders (Haviland et al. 2003, Berger et al. 2005, Bansil et al. 2006, Powell 2006, Santor et al. 2007). The same trend was found in the use of call-center as a source of medicines information. Similarly with Dutch, Australian, and German studies on (Alderman and Ryan 1997, Ryan et al. 1998, Bouvy et al. 2002, Maywald et al. 2004) telephone services, people using psychotropic medicines were found to be active users of the UP Call Center in this study. Antidepressant users were, in terms of calling the service, more active than users of other psychotropic medicines. This finding, in addition to frequent use of the Internet and PILs, reflect that people with mental disorders and particularly using antidepressant medications have unmet information needs as also previously reported both in Finland (Enäkoski 2002, Pohjanoksa-Mäntylä et al. 2002) and internationally published studies (Alexius et al. 2000, Garfield et al. 2004, Happell et al. 2004, Bell et al. 2005, Cleary et al. 2005). In part, these findings support the findings by European Commission Pharmaceutical Forum and other research that people with different type of diseases may have different needs in relation to health and medicines information and information sources. This is particularly important consideration in developing interventions and strategies to meet the information needs of consumers. One of the consumer groups to consider is people with depression who are using antidepressant medicines.

One aspect that is important to keep in mind when comparing the results of different studies from different countries is the fact that use of the Internet is spreading rapidly in Europe and other continents. This may significantly influence the results; more current studies would probably give higher rates for Internet use among consumers. The results of the annual national population survey on “Health Behaviour and Health among the Finnish adult population” in 1999, 2002, 2005, and 2008, shows that the Internet use for medicines information has increased steadily in recent years (Helakorpi et al. 1999, Helakorpi et al. 2002, Helakorpi et al. 2005, Närhi and Helakorpi 2007b).
12.1.2 The role of the Internet among other sources of antidepressant medicines information

According to the focus group discussions, all existing sources of information were seen as having value in the consumer medicines information context. Physicians were seen as the primary source of medicines information, followed by pharmacists and PILs. This finding was consistent with previous Finnish and international research on the use of different sources of health and medicines information (For example Sleath et al. 2003, Hesse et al. 2005, Närhi and Helakorpi 2007b). Lack of time was perceived to limit opportunities for discussion during physicians’ visits and lack of privacy hindered discussion in community pharmacies. This was true despite the legal obligation to ensure patient privacy in Finnish community pharmacies, and also most pharmacies in Finland having built medication counseling stations designed to ensure privacy (Puimalainen 2005, Bell et al. 2007). Telephone services were valued because patients could obtain information in a timely manner when other sources of information were not available.

The Internet was used for three main functions: to seek facts about antidepressant medication, to receive community support, and for curiosity. The Internet was especially valued because information could be obtained anonymously. The Internet was mainly used to add to, not to replace information provided by health care professionals. Reasons cited for using the Internet were consistent with the findings of previous studies conducted among cancer patients and general populations: to prepare for a visit to a physician, to obtain information on current issues, to decide whether or not to use a drug, and to obtain a second opinion (Peterson-Clark et al. 2004, McMullan 2006, Andreassen et al., 2007). In contrast to previous studies, participants did not report dissatisfaction with written information or information provided by their health care professionals as a key reason for seeking online information. All medicine users routinely receive a PIL when their medicines are dispensed in the community pharmacy (Directive 89/341/EEC). The study participants highlighted the need to seek medicines information on the Internet due to the fear of stigmatization when seeking information from traditional sources such as pharmacists or physicians. These findings are consistent with previous research in relation to information seeking by people with mental illness (Berger et al. 2005, Powell and Clarke 2006).

The Internet also provided people with an opportunity to share medicine-taking experiences with peers. Internet communities may offer a valuable source of peer support and stimulate seeking treatment information from health care professionals (Powell et al. 2003). Supportive relationships may assist patients with depression to recover from their illness (Gladstone et al. 2007). The fact that people searched for peer support online may also indicate unmet-needs and a lack of support from health care professionals. Observation studies are needed to find out whether health care professionals apply the principles of shared decision-making and open disclosure of information to support self-management of treatment while communicating face-to-face with people with mental disorders. There is a need for qualitative research on the value of Internet to enhance consumer adherences and achieve positive treatment outcomes. Health care professionals could make better use of the Internet by providing interactive medicines information and
other services to support consumer medical treatment. The Internet is an underused resource in Finnish health care today.

Although previous studies have reported that people do not commonly ask questions about their medicines from their physicians or pharmacists (Airaksinen et al. 1998, Cox et al. 2004), the idea that people are ‘active consumers’ rather than ‘passive participants’ also seems clear. In addition to information receiving from health care professionals and incidental information acquired while monitoring the world (e.g., by reading newspapers and watching television), people with depression purposefully seek information to meet their information needs. Both the population survey and focus group discussion study among people with depression reflected that younger people, in particular, seek additional information from the Internet, while older people used and preferred traditional sources such as printed media as their main source of additional drug information. These findings are well in line with the Williamsson’s Model of Everyday Information Seeking and Use (1998) and previous studies on health and medicines information seeking from the Internet (Haviland et al. 2003, Wagner et al. 2004, Berger et al. 2005, Bansil et al. 2006, Powell 2006). These results highlight the need for healthcare professionals to actively inform younger people about good quality sources of medicines information online and older people about other available sources of medicines information such as telephone services and patient information leaflets.

Also in line with previous research and the Ecological Model of Everyday Information Seeking and Use (Williamson 1998, Närhi 2007), this study confirmed that information seeking and use of the different sources is affected not only by person-related variables (age, gender, values, experiences), but also situational (status of the disease and treatment) and environmental variables, such as availability of and access to information sources, cultural issues, and stigma. For example public and health care professionals’ negative attitude or perceived negative attitude toward mental disorders may influence help-seeking by people with mental disorders and provision of medication counseling provided in community pharmacies (Bell et al. 2010). Those factors act as drivers or barriers to the use of different information sources. This indicates that while it is important to focus on consumer/user perspective in developing medicines information and medicines information services and in any research concerning the use of those services, it is also important to study them in a wider context of the medicines information network in society. Efforts should be made to encourage providers of information and information services to make better use of different methods and channels of information provision, such as e-mail and discussion forums. Given that people both value and are concerned about the quality of the medicines information received via discussion forums, health care professionals may consider also including these forums on their sites. This may enable health care professionals’ to address concerns in the discussions and correct potentially inaccurate or misleading information. In order to meet the needs of different people, and different populations in different situations and surroundings, information needs to be disseminated through a variety of sources. In order to avoid polarization of the medicines information, some of the sources need to be non-technology-based. Still today, health care professionals are the medicines information sources of choice for many people. Pharmacies are easily available, and therefore they could more actively start promoting their medication counseling services and possibility to ask questions about medicines to
consumers. This is due to the following facts supported by this and previous studies: 1) not all people prefer or have access to the Internet; 2) the older populations are slower to accept computer-based sources for everyday life; and 3) that use of the Internet and drug information call centers are increasing but still uncommon.

12.1.3 Benefits of Internet-based medicines information on peoples’ attitudes and medicine taking behavior

Participants in focus group discussions reported that medicines information obtained using the Internet both positively and negatively influenced their attitudes and medicines taking behaviors. Negative attitudes and beliefs about antidepressant medicines may be linked to poor adherence (Brown et al. 2005), and a preference for alternative treatments (Cramer and Rosenheck 1998, Hunot et al. 2007). While negative attitudes and beliefs about drug treatment may be associated with non-adherence, the provision of drug information has been associated with improved drug adherence (Desplenter et al. 2006). Fifty-three percent of Internet users in the United States have reported that health information obtained via the Internet has influenced their health behaviours (Fox 2006).

Multiple participants in focus group discussions described performing reasoned decision-making in relation to their medicine taking. This was in spite of the fact that they were concerned about information quality and their own ability to evaluate the quality of the Internet-based medicines information. Particularly in later stages of the treatment process, many participants did not strictly follow health care professionals’ recommendations without engaging some reasoned process. They actively searched information about the medicine prescribed, considered the perceived risks and benefits and made their own decision about taking or not taking a medicine, or decreasing or increasing the dose. This is in line with the underlying philosophy of empowerment, in which consumers are being encouraged to increasingly take responsibility for their own health care in terms of self management. However, it should be kept in mind while interpreting these results, that participants in this study probably represent only the most social and active among people with depression. While obtaining Internet-based medicines information empower patients, it is critical that they have correct information. Therefore, health care professionals should encourage patients to shared decision making to contact their physicians regarding change in dosage or adverse drug reactions. Health care professionals should be aware of the ways in which their patients access and utilize online information when they prescribe, dispense or discuss antidepressant drugs. Although many focus group discussion participants perceived that they might have benefited by contacting their physician or pharmacists after reading additional information and reassessing their treatment, only few reported as doing so. Intervention programs could be targeted to health care professionals, particularly physicians, to spend more time with their patients and encourage communication via e-mail or web messaging in addition to providing better sources of online health information.

New initiatives to provide greater consumer access to online drug information may need to be accompanied by strategies for assisting people with depression in evaluating information quality. This is particularly important since the quality of depression and antidepressant-related information on the Internet has been found to be highly variable.
In this respect, core quality principles currently developed by the European Commission Pharmaceutical Forum and the DARTS tool may be useful. However, the focus group discussion study highlighted the fact that awareness about existing quality assessment tools has remained low. Those tools should be made as easily and as widely available as possible, and preferable in consumer preferred language. The DARTS tool has already been published on the website of European Commission Pharmaceutical Forum and on the website of Finnish regulatory authority. This is favorable as increased political attention and publicity may lead to increased awareness on quality issues among consumers and health providers. Also other strategies for disseminating information about these tools, including education in schools and antidepressant-related websites, were highlighted by focus group discussion participants.

12.1.4 Telephone and e-mail services as sources of consumer medicines information – do they meet the needs of consumer?

University Pharmacy drug information call-center, which receives more than 230,000 calls annually, is a large volume medicines information service. This large and increasing number of calls indicates that this type of telephone counseling service is needed and valued by the public. Furthermore, this study indicates that this kind of service has multiple functions. The public need it to obtain information about pharmacy services, but also to know more about their drugs, especially prescription drugs. Although at the population level use of drug information call centers is quite un-common, call centers may have important role for consumers especially when the distance separates the consumer and the health care professional. It is suggested that drug information call centers targeted to consumers hold also a promise for improving therapeutic outcomes (Talley 1996). Small pharmacies can not maintain such service for their customers. However, also small pharmacies could encourage their customers to call to the pharmacy with inquiries if needed. For the chain pharmacies this kind of service may offer a good opportunity to augment therapeutic counseling and also increase their customer base. Professional community pharmacy chains and big pharmacies could be potential providers of these services in the future to facilitate safe and appropriate use of drugs. However, a prerequisite for this is that the centers are committed to public health and health policy goals and they utilize evidence-based practices (Talley 1996). This same applies also to other medicines information services such as e-mail counseling services.

When this national study was conducted in 2005, a minority of Finnish community pharmacies maintained a working website but almost all of those with a website provided the opportunity for e-mail medication counseling. Only a few pharmacies offered a special online “ask-the-pharmacist” service. This, in addition to low response rates to e-mail inquiries, indicate that e-mail counseling is not yet part of the everyday activities in community pharmacies. Based on anecdotal feedback supplied by the study pharmacies in this study during the process of obtaining informed consent, some small pharmacies had not previously received medication-related e-mail inquiries. In addition to the increasingly utilized drug information call-centers, pharmacies could encourage their customers to make better use of existing e-mail medication counseling services. This is supported by
the fact that focus group participants in this study as well as consumers in previous studies have indicated they would value the opportunity to communicate by e-mail with their health care providers, e.g., physicians.

The response rate and speed of responding to e-mail inquiries were relatively low in this 2005 study. Obtaining a fast response may be particularly important with health and medication-related concerns, and when other issues that may affect consumer treatment decisions and wellbeing, are involved. Although not explored in this study, the long delays and low response rates may have been due to lack of time and/or not having a designated person who is responsible for reading and answering e-mails in the pharmacies. The topic of the inquiry and perceived difficulty of responding to antidepressant related inquiries may have impacted the response activity. This was indicated by the fact that both the response rate and accuracy of responses were lowest for the inquiry related to sexual dysfunction and weight gain associated with citalopram. Sexual dysfunction is associated with the use of many antidepressants and can naturally lead to patient dissatisfaction and decreased treatment adherence (Werneke et al. 2006). These are issues that medicine users and even professionals may find embarrassing to discuss, although, these are issues people frequently ask and discuss with their peers online (Pohjanoksa-Mäntylä et al. 2002, Pestello and Davis-Berman 2008). This also includes information specifically related to possible adverse drug reactions. Due to the potential for anonymity, and the opportunity to ask questions without face-to-face contact, the Internet might be a valuable source of drug information when stigmatized illnesses or intimate matters such as adverse drug reactions relating to sexual dysfunctions are concerned. Reportedly, uncertainty about the amount of information related to potential adverse drug reactions that should be provided to patients, and the possible corresponding negative impact on medication adherence, is a barrier to medication counseling in community pharmacies (Vainio 2004). This barrier may be even stronger when e-mail medication counseling is concerned because with e-mail medication counseling there is no opportunity for open-ended questioning and for pharmacists to interpret nonverbal cues and possible expressions of confusion. Further studies may analyze the pharmacy responses from the communication perspective.

In accordance with previous studies (Bessell et al. 2003, Holmes et al. 2005), the accuracy and comprehensiveness of the pharmacists’ responses varied between and within the three scenarios. Most pharmacies provided the key facts in their responses, but varied in the other information elements, e.g. in encouraging words and interpretation of the treatment information. The variation in advice content and quality across pharmacists has been recognized also in studies concerning verbal counseling in pharmacies (Vainio et al. 2002, Berger et al. 2005a). It is suggested that one reason for the variation in advice content may be due to lack of consensus among practitioners on certain treatment issues. Provision of contradictory information by pharmacists may cause patients to become confused and lead patients to question the validity of the information. Pharmacists should determine and consider patients’ prior knowledge about their medications when they counsel patients face-to-face or via e-mail.

Healthcare systems are developing worldwide and are embracing the concepts of consumer-health care professional partnerships and consumer self-management (Royal Pharmaceutical Society of Great Britain 1997, Car and Sheikh 2004). In this context, e-mail counseling provides new possibilities to facilitate accessibility of good quality
information on medicines. It is likely that patients and customers will increasingly seek alternative modes of communication like telephone and the Internet and e-mail for health information and for treatment advice (Baker et al. 2003, Car and Sheikh 2004). Internet and e-mail may offer an opportunity to expand the provision of community pharmacy services and to meet the drug information needs of patient groups that otherwise may not have their needs met. To ensure pharmacies are prepared to take advantage of these opportunities, they need to have knowledge about how to make safe and effective use of new technologies such as e-mail communication. Individual pharmacies and professional organizations may need to develop professional practice standards for e-mail medication counseling. These protocols may include measures designed to protect patient privacy and the pricing of e-mail medication counseling services.

12.2 Methodological considerations

In this study, method triangulation was used to ensure comprehensiveness of the study (Pope, Mays 1995, Smith 2002). Triangulation was found to be particularly useful for the following reasons: 1) the use of the quantitative methods, particularly a national survey and a virtual pseudo-customer study, enabled receiving nationally generalizable results, 2) qualitative methods provided deeper understanding of the consumer perspective on the use of medicines information sources, and 3) combining these different methods enabled comparison of the results from different sub-studies. By comparing the survey (II) and the UP drug information call center data (I), it was noted that they give a slightly different view of the prevalence of call center use. Compared to number of inquiries to the UP drug information call center, the number of people in our survey who reported that they had used a call-center as a source of medicines information was low. At least in part, this may be due to the consumer lack of knowledge on different sources of medicines information as was noted in the focus group discussion study (III). In the focus group discussions, some participants were not familiar with either the term drug information call-center or with existing call-centers in Finland.

Scientific rigour and quality of the research are commonly assessed in terms of validity, reliability, and generalizability of the results (Smith 2002). Validity refers to the extent to which an instrument or method measures what it is designed to measure. The reliability relates to the repeatability and internal consistency of the research. The generalizability (sometimes referred as external validity) is concerned with the extent to which the findings can be applied more widely to other settings or populations. The following section discusses about validity, reliability, and generalizability of the studies I- V. The original publications contain a detailed sub-study-specific discussion. This chapter summarizes the key issues and complements particularly the methodological discussion of the focus group discussion study (III and IV).

12.2.1 Analysis of the UP call-center data (I)

This sub-study was based on the data received from the national high-volume call center that receives more than 230,000 calls annually. The data collection instrument was pilot tested for validity prior the data collection. All staff who participated in the study received
prior training in the study protocols, but data collected were dependent on the accuracy of paper-based recording by the call-center staff. The data was found to be useful in identifying questions and concerns related to consumer daily use of medicines. Although more than two thousand calls (n=2196) were received during the study period, the cross-sectional nature of the study and small amount of the inquiries in different sub-groups impeded our ability to investigate trends or statistically analyze the information needs and differences between different type of inquirers (e.g. people inquiring about antidepressant medicines). However, previous studies reflect that consumer inquiries on psychotopic drugs may be similar to inquiries on prescription medicines in general in this study (Alderman and Ryan 1997, Pohjanoksa-Mäntylä et al. 2002).

Calls to call centers represent only a small proportion of all medicine users in Finland, which means that these results may not reflect the information needs of all medicine users. The study included 83% of telephone calls made to the drug information call center during the study period. The loss of the 17% may be a consequence of the staff workload during certain time periods. It is also possible that the nature of the calls was influenced by the season and media events at the time. Due to such a large percentage of calls being documented and the consistency of our results with those of previous studies, it is assumed that the results are the accurate reflection of calls received during the study period. However, future studies are needed to follow trends in utilization of UP call center. In order to do follow-ups more effectively, systematic reporting and documenting of all inquiries and the pharmacist responses would be needed. This type of practice would also enable assessment of whether pharmacists have the necessary skills and the knowledge to appropriately address specific concerns in different type of inquirers. Similar suggestions for future studies have also been suggested by other researchers of this area (Mullerova and Vlcek 1998, Grymonpre and Steele 1998). Future studies may also seek to validate the recording accuracy by audio taping and independently analyzing a random subset of the telephone calls made to the drug information call center. Nevertheless, given that most calls to the drug information call center concerned only one medicine, it is likely that the recording accuracy was high in this study.

12.2.2 A population survey among Finnish adult population (II)

The survey was based on a national representative population sample with 66% response rate (Helakorpi et al. 2005). This gives quite good generalizability of the results (Tolonen et al. 2006). The number of respondents who self-reported being diagnosed with depression was low in the data but their proportion was consistent with 12-month prevalence of depressive disorders among Finnish adults as studied in 2001 (Pirkola et al. 2005). The data available did not enable the analysis of respondents vs. non-respondents. However, participants were unlikely to have been representative of all Finnish adults with mental disorders. It is widely accepted that survey data may be affected by the characteristics of respondent (e.g. memory; knowledge; experience; motivation; and personality). All respondents may not interpret the questions as intended by the researcher. Given that the data were self-reported, some respondents may not have reported their mental disorder in order to avoid being labelled or they may not have remembered all the medicines information sources they had used. In order to ensure to validity of the question
on mental disorders among respondents, some validated depression screening instrument such as the Depression Scale (DEPS) could have been used (Salokangas et al. 1995). This study inquired about medicines information sources in the past 12 months. Previous studies asking medicines information sources during the last 6 months have demonstrated higher use of the Internet than those requiring longer recall (Närhi 2007, Närhi and Helakorpi 2007b). Since the same question on medicines information sources has previously been included in the survey, our results are comparable with results received in 1999 and in 2002 (Helakorpi et al. 1999, Helakorpi et al. 2002). The survey instrument used in this study did not make a distinction between spoken and written information, nor between information on prescription versus non-prescription medicines. The sources of information may have varied between these groups (Ho et al. 2009). Additionally, the survey did not include an operational definition of medicines information as has also been the case in most of other studies in the field. Therefore, this study reflects more perceived than actual sources of medicines information.

12.2.3 Focus group discussion study among people with depression (III, IV)

Generalizability is different in qualitative and quantitative research (Hämeen-Anttila and Katajavuori 2007). Qualitative research does not necessitate a random or a numerically representative sample, and the sample size is usually too small for statistical analysis (Barbour 1999, Silverman 2000, Hämeen-Anttila and Katajavuori 2007). It is suggested, however, that the interpretations based on the results can transferred to other situations and to other groups of people. Such extrapolation requires a critical judgement and a detailed description of the sample, setting, and research process. Silverman suggests variety of ways to ensure this transferability (Silverman 2000). In this study, comparison of the results to results from other research and purposive sampling were used (Coyne 1997, Hämeen-Anttila and Katajavuori 2007). Focus group discussion participants were purposively recruited via three different organizations in order to have different aged and type of people into the study. Information sources cited in focus group discussions were consistent with information sources reported in study II. Additionally, the information needs and reasons for the use of Internet-based medicines information were similar to those found in previous studies on health and medicines information seeking from the e-mail medication counseling services (Pohjanoksa-Mäntylä et al. 2002) and discussion forums (Pestello and Davis-Berman 2008).

Young adults are frequent users of the Internet (Gray et al. 2005). However, half of the participants in this study were over 50 years. This age group might have been more involved in patient organizations, and more interested to participate in the study. Ten participants were already retired, and thus, they may have had more time to participate than younger adults. Although previous research has suggested the views of members and non-members of mental health support groups may be similar (Crawford and Rutter 2004, Hill and Laugharne 2006), the participants in our study might have been more active information seekers and knowledgeable about drugs than people with depression in general. This suggests the need for caution about the transferability of the findings may be appropriate. Additional quantitative research and a random sampling technique would be required to obtain generalizeable results and to assess the relative importance of the
reasons cited by the focus group participants. As males were under-represented in this study, more interviews should be conducted among males. Further studies should include both focus group discussions and individual interviews, potentially also online.

In all qualitative research, the subjective role of the researcher is significant during the data collection and analysis (Hämeen-Anttila and Katajavuori 2007). In spite of the fact that the results obtained with qualitative methods represent the interpretation of one researcher in a particular context and time, various strategies have been proposed to increase the validity of qualitative research (Mays and Pope 2000, Silverman 2000, Hämeen-Anttila and Katajavuori 2007). Strategies used in this study include: the constant comparative method, comprehensive data treatment, deviant-case analysis, and using appropriate tabulations. The constant comparative method suggests that the qualitative researcher should attempt to find another case through which to test provisional hypothesis (Silverman 2000). The constant comparative method relates to comprehensive data treatment, as it involves inspection and analysis of the all parts of the data (Silverman 2000). During the analysis, deviant cases were actively sought out. In order to enable reliable and valid analysis, all focus group discussions were tape-recorded and transcribed verbatim. Coding and analysis was confirmed by two researchers. Emerging hypotheses were tested by comparing students to other groups and also comparing all the data fragments that arise in a single case. Themes emerged in discussion were tabulated and counted to demonstrate potential differences between different groups, to test and revise hypothesis, and to remove doubts about the accuracy of the impressions about the data. Tabulation of the main and sub-themes enabled the evaluation of the saturation point that refers to the point in which no new themes emerge in the analysis. In this study, saturation point was received after fifth interview.

12.2.4 Virtual pseudo customer study (V)

Pseudo customer studies are widely used and useful methods in studying face-to-face counseling in community pharmacies (Puormalainen 2005, Puormalainen et al. 2005, Berger et al. 2005a). More recently, they have been used to analyze the e-mail medication counseling between pharmacists and patients as was the case also in this study (Bessell et al. 2003, Holmes et al. 2005). The fact that all our e-mail scenarios related to antidepressants might have caused confusion in pharmacies operating in small communities and in areas with low Internet use. Potential for bias was minimized by using different e-mail accounts and by sending different inquiries to pharmacies located in a same city/area. Antidepressants might be a more challenging class of medication to counsel than many other classes of medication. It is difficult to determine whether the response rate and the quality of responses would have been different if other types of medications would have been involved. More research should be done by using different types of medications and scenarios, and by using real patients. Future research may also try to find out the actual prevalence of e-mail communication between customers and pharmacists. It is likely that there have been changes in Internet use and penetration of e-mail based counseling services in pharmacies after conducting this study in 2005. Further research should be conducted to consider this possibility. Future research may also include more detailed comparisons between pharmacies offering a designated “ask-the-
pharmacist” service and those simply listing an e-mail address or a feedback form on their website.

The coverage of the study was good, since pharmacy websites for this study were identified via a comprehensive list maintained by the Association of Finnish Pharmacies. Additionally, both university pharmacies were included. This means that these results are representative of all Finnish community pharmacies with websites and offering medication counseling via e-mail. In order to assure the reliability, each pharmacy response was scored independently by two researchers and the inter-rater reliability of the scoring was calculated for each scenario using Cohen’s Kappa Statistics (McGinn et al. 2004, Viera and Garrett 2005). The inter-rater reliabilities ranged from 0.870 to 0.935 indicating a good level of reliability.

12.3 Ethical considerations

All the study procedures were conducted in accordance with the good ethical practice, and when relevant, in accordance with the World Medical Association Declaration of Helsinki. Support to conduct the study was sought and obtained from the following organizations; 1) from University Pharmacy (call-center study), 2) from National Public Health Institute (a national population survey), and 3) the Association of Finnish Pharmacies (a virtual pseudo customer study). The identities of individual consumers were not recorded as part of data collect process in any sub-studies. Reading the cover letter and returning the completed survey was considered to be informed consent for participating the survey. Prior to focus group discussions, participants were mailed an information sheet. In this information sheet, participants were informed that the FGDs will be tape-recorded and the confidentiality of the discussion was emphasized. At the beginning of the each FGD session participants were asked to sign informed consent forms. In the e-mail pseudo customer study, after the responses were received all pharmacies were informed in writing about the study and consent to participate was obtained. Pharmacies were allowed to decline participation in the study, with four pharmacies doing so. All reports are written in a way that individual person can not be identified. All data were carefully documented in order to ensure confidentiality.
13 Conclusions

In order to meet the needs of consumers with different demographic backgrounds, diseases, and medicines, the current medicines information network in Finland needs further evaluation and development. As with general health information, people with mental disorders, including depression, use the Internet more actively for medicines information compared to people without mental disorders. Although people with depression perceive that they benefit from online medicines information and e-mail communication with health-care professionals, they need education and support for information searching and evaluation from personal contact with their healthcare professionals, including pharmacists. The pharmacist’s involvement in counseling already at the start of chronic therapies in a way that consumers are given opportunities to express their concerns, expectations and opinions about their medication is highly important. Community pharmacies are potential providers of e-mail medication counseling, although existing e-mail-counseling services need further development. The following more detailed conclusions can also be drawn based on this study:

1. Although a range of medicines information sources are used by the consumers, they regard health care professionals, including community pharmacists as major sources of medicines information. Health care professionals have an opportunity to use other sources – particularly the Internet and PILs – as tools to complement and supplement their communication on medicines with consumers.

2. People with depression use the Internet for three functions: 1) to seek facts about their antidepressant medicines (content), 2) to have peer support / share peer experiences of medicines use (community), and 3) to browse (curiosity). The Internet offers the possibility to obtain information anonymously, particularly about the intimate issues, and to communicate with peers.

3. Community pharmacies are potential providers of telephone and e-mail medication counseling services. However, more attention should be directed to responses to consumer e-mail inquiries and to the content of these responses if such services are made available.

4. A national strategic plan is needed for developing medicines information services and sources for consumers and improving coordination between service providers. The strategy, as well as the service development should make use of the modern information technologies.

5. Further research is needed to better understand medicines information seeking behaviors of consumers and the value of information in a successful medicines use process (see Chapters 13.1 and 13.2).
13.1 Implications for policy and practice

1. While developing a national medicines information strategy and medicines information services it should be noted that:

- Health care professionals are the main and preferred sources of medicines information among consumers. However, supplementary information should be provided by a variety of sources and methods of delivery.

- Special focus should be on the needs of particular populations including people with depression and using antidepressant medication as they were recognized as a patient group that is likely to benefit from the Internet-based medicines information and the possibility of e-mail counseling.

- Health care professionals should design new technology-based sources of information and also direct their clients to accurate and reliable sources of online medicines information. In order to promote partnership and discussions with patients, their peers, and health care professionals, health professionals may also wish to consider including discussion forums on their websites.

- In addition to focusing on the users of medicines information and information sources, it is important to study their needs and information behavior in the wider context of society.

- Drug information call centers operated by community pharmacies could complement face-to-face information provided by health care professionals. They may be best promoted particularly to older people as they may be more willing to use more traditional sources than the Internet. At this time, telephone services may not be adequately catering to elderly people and people at high risk of experiencing adverse drug events requiring information on their medicines.

- Patient information leaflets could be one potential route to disseminate information about other accurate and reliable sources of additional medicines information. This means that PILs should contain information about the existing drug information call centers and the Internet-based medicines information sources and services.

- In order to meet the needs of people with depression and using antidepressants, there is a need to make better use of new technologies in delivering medicines information. While considering a national medicines information strategies, a particular focus should be on online medicines information.
2. Health care professionals including physicians and pharmacists should discuss and encourage people to ask more about the potential adverse drug reactions and drug drug interactions of their medication when prescribing, dispensing and counseling people about antidepressant medicines. Intervention programs could be targeted to health care professionals, particularly physicians, to spend more time with their patients and encourage communication via e-mail or web messaging in addition to providing better sources of online health information.

3. New initiatives to provide greater consumer access to online medicines information may need to be accompanied by strategies to assist people with depression evaluating information quality.

4. Education on information evaluating and the use of existing quality assessment tools, such as DARTS, could be integrated into elementary school, high school, and university curricula.

5. Individual pharmacies and professional organizations may need to define professional practice standards for e-mail medication counseling. These protocols may include measures designed to protect patient safety, privacy and the provision on pricing of e-mail medication counseling services.

6. Individual pharmacies should develop standard operating procedures to ensure all medication-related inquiries are answered promptly and accurately. They may also consider listing their e-mail medication counseling policy on their website, the expected e-mail response time, and suggest that customers phone or visit their pharmacy if they require a more rapid response.

7. Pharmacists need to have the knowledge about how to make safe and effective use of new technologies such as e-mail communication. More education on e-mail counseling would be needed in this respect. Basis for the skills in e-mail counseling and written communication should be provided at the university, and thus, those issues should be included in pharmacy curricula.
13.2 Further research

For the purposes of planning and developing medicines information strategies at the national and EU-level, cross-country studies from the organizing and strategic perspective are imperative. Those studies should find out: who are involved in provision of medicines information for consumers; how receipt of information impact adherence and other patient outcomes; how the accessibility and quality of medicines information are assured; and what kind of co-operation exist between different stakeholders in producing and disseminating medicines information in different countries. Longitudinal studies are required to investigate whether sources of medicines information have changed over time. Quantitative data may be supplemented by qualitative research about sources of medicines information and information behaviour among different patient groups. These groups may include adolescents, older people, people with vision impairment, immigrants and people with different illnesses. Further research is needed also to determine whether the use and preferences for sources of medicines information differ between types of mental disorder.

Due to a drive to incorporate e-mail medication counseling into routine pharmacy practice, more evidence is needed about multiple issues. Future research should focus in more detail on patient and professional preferences for modes of communication. Previously Car and Sheik (2004) have suggested that future research on e-mail consultations in health care should cover issues such as: an appreciation how e-mail consulting can best be integrated with other modes of consulting; the influence of e-mail consulting on the patient-doctor relationship; and understanding about safety, education, and privacy issues. Given that e-mail medication counseling in the community pharmacies is still in its infancy, these same recommendations also applies to research in relation to pharmacy.

As this study focused on e-mail counseling with regard to antidepressants, results do not provide information about the quality of existing e-mail counseling in general. More research should be conducted using different types of medicines and scenarios, and by using real patients. Future research may also attempt to determine the actual prevalence of e-mail communication between customers and pharmacists. It is likely that the Internet use and penetration of e-mail medication counseling services in pharmacies have increased since conducting pseudo customer part in this study in 2005. Further research should be conducted to further changes. This future research may also include more detailed comparisons between pharmacies offering a designated “ask-the-pharmacist” service and those simply listing an e-mail address or a feedback form on their website. More information is needed about communication barriers and the way information is communicated by the pharmacist. Further research is also required to determine whether health care professionals are adequately trained to communicate with their patients via e-mail and what kind of education they need to do this successfully. Some health care professionals charge for e-mail consultations. Charging a fee for e-mail consultations may promote better service delivery by pharmacists. However, more research should be conducted on consumer willingness to pay for these services and also about the impact of these services on treatment outcomes. More research is needed also to evaluate the actual usefulness of the DARTS tool in practise and in relation to other quality assessment tools.
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Appendix 1. The final recommendations of High Level Pharmaceutical Forum Working group on Information to Patients, concrete implementing actions, and parties responsible of the actions.

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<tr>
<th>Recommendation</th>
<th>Action</th>
<th>Parties responsible of actions</th>
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| Recommendation 1: Enhance quality of information | 1. Implementation and use of core quality principles and their methodology of use  
2. Implementation of the identified key elements for information to patients in producing, assessing, and improving information  
3. Increasing the visibility of good information sources via EU health portal and ensuring that all principles developed are applied  
4. Commitment to share information about new initiatives regarding information  
5. Development of a common approach to quality assurance of information  
6. The ban of advertising prescription medicines to public should continue | European Commission | x | x | x  
Member States | x | x | x  
Relevant Stakeholders | x | x | x |
| Recommendation 2: Increase accessibility and dissemination of information | 1. Implementation of specific recommendations to increase accessibility and dissemination of health information in various healthcare setting and via effective communication formats including both electronic and non-electronic means  
2. Making visible the best practices identified and promoting co-operation to further exchange experiences  
3. The European Medicines Agency should continue its efforts in improving the database on medicinal products authorized in the EU and co-operation between all parties involved | European Commission | x | x | x  
Member States | x | x | x  
Relevant Stakeholders | x | x | x |
| Recommendation 3: Generation of information by making the best use of all actors | 1. Continued partnership and co-operation in producing and disseminating information to patients  
2. Exchange of information about the existing approaches in partners, structures and responsibilities and consideration of further collaborations  
3. Committing to minimum ethical requirements in partnerships: transparency, disclosure of financial and other support, definition of responsibilities  
4. Increasing the visibility of existing partnerships and collaborations | European Commission | x | x | x  
Member States | x | x | x  
Relevant Stakeholders | x | x | x |
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<th>Parties responsible of actions</th>
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| Recommendation 4: Continued momentum on information to patients | 1. Dissemination of outcomes of the Pharmaceutical Forum to all interested parties  
   2. Ensuring that the recommendations are followed up at the national level  
      - Undertaking a first review of what exists, and what has been created and/or improved following the recommendations within the next two years  
   3. Establishment of a process to evaluate the direct outcomes and follow-up of Pharmaceutical Forum | European Commission: x  
               Member States: x  
               Relevant Stakeholders: x |
Appendix 2. Search strategy.

**Step 1:** Librarian assisted literature search of using MEDLINE, CINAHL, Psychinfo, and Web of Science (1992 – April 2009) using combinations of MeSH terms and key-words described under.

**Ovid MEDLINE, PsycINFO, CINAHL** (from 1992-2009)
mental disorder* or psychiatric* or depression* or depressive* or antidepress* agent* or antidepressa*) and (medicines info* or drug information* or medication info* or consumer health info* or health info*) and (patient concern* or inform* need* or informat* source* or informati* seek* or physician* or pharmacist* or community pharmacy serv* or pharmacy serv* or product label* or package insert* or nurse* or communication* or communication media* or internet or electronic mail or telephone* or helpline* or telephone service* or call center* or e-health* or e-technolog*.

**Web of Science** (1992-2009)
(TS="mental disorder*" or TS=psychiatric* or TS=depression* or TS=depressive* or TS=antidepress* agent* or TS=antidepressa*) and (TS="medicines info*" or TS="drug information*" or TS="medication info*" or TS="consumer health info*" or TS="health info") and (TS="patient concern*" or TS="inform* need*" or TS="informat* source*" or TS="informati* seek*" or TS=physician* or TS=pharmacist* or TS="community pharmacy serv*" or TS="pharmacy serv*" or TS="product label*" or TS="package insert*" or TS=nurse* or TS=communication* or TS="communication media*" or TS=internet or TS="electronic mail" or TS=telephone* or TS=helpline* or TS="telephone service*" or TS="call center*" or TS="e-health*" or TS="e-technolog*")

**Step 2:** The electronic archives of the Drug Information Journal, International Journal of Pharmacy Practice, Psychiatric Bulletin, Journal of Mental Health, and the electronic archives of our own research group was searched for any additional relevant articles not identified in the original electronic database search.
## Appendix 3. Inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th></th>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
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</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td>- People with depression and/or using antidepressants and/or</td>
<td>- No people with depression or/using antidepressants included and/or concerned</td>
</tr>
<tr>
<td></td>
<td>- People with mental disorders including people with depression as one sub-group in the study and/or</td>
<td></td>
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<tr>
<td></td>
<td>- Healthcare professionals reporting questions asked by people with depression and/or using antidepressants</td>
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<tr>
<td><strong>Results</strong></td>
<td>- Self-reported information needs and use of different medicines information sources</td>
<td>- Information passively received from health care professionals (without asking or searching by self)</td>
</tr>
<tr>
<td></td>
<td>- Antidepressant-related questions asked or searched from different sources of medicines information</td>
<td></td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td>- Any type of qualitative or quantitative</td>
<td>- Randomized controlled trials if did not report information needs and/or information seeking about medicines before intervention</td>
</tr>
</tbody>
</table>
Appendix 4. Included and excluded articles.

Table 1. Included studies about health and medicines-related information needs and sources among people with depression.

<table>
<thead>
<tr>
<th>Study</th>
<th>Study year</th>
<th>Focus</th>
<th>Study population</th>
<th>Setting</th>
<th>Method</th>
<th>Key findings/Notifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donoghue 1993</td>
<td>-</td>
<td>Information needs and sources; concerns in regards to medication</td>
<td>A convenience sample of psychiatric patients (n=81) with current or past use of psychotropic medicines; 23% antidepressants; 31 females; Age: -</td>
<td>Outpatients in Liverpool area</td>
<td>A cross-sectional survey</td>
<td>Participants (62%) reported un-satisfaction to medicines information provided; most likely sources of information was friend or other non-qualified person.</td>
</tr>
<tr>
<td>Alderman and Ryan 1997</td>
<td>1996</td>
<td>Information sources; Inquiries on psychotropic medicines during a national medicines phone-in day</td>
<td>Psychotropic-medicines related calls (n=367); 56% antidepressants; 69% females; Age: -</td>
<td>Telephone help line</td>
<td>A cross-sectional analysis of telephone inquiries</td>
<td>Most commonly inquiries related to adverse effects (57% of calls), interactions (12%), and general drug information (10%).</td>
</tr>
<tr>
<td>Wagner and Hibbart 2001</td>
<td>1996 and 1998</td>
<td>Information sources; the use of medical reference books, telephone advice provided by nurses, and computers for health information</td>
<td>A random sample of people from three cities in USA (n=5,909)</td>
<td>Community</td>
<td>A cross-sectional survey</td>
<td>People with depression were more likely to use all three information sources than people with other type of diseases.</td>
</tr>
<tr>
<td>Badger et al. 2002</td>
<td>-</td>
<td>Information sources; what people ask about their medicines in community pharmacy setting</td>
<td>Pharmacists registered with Birmingham Health Authority</td>
<td>Community and hospital</td>
<td>A Cross-sectional survey</td>
<td>A majority (79%) of pharmacists reported that people with antidepressants ask them for information about their medication; Community pharmacists reported more often that people ask questions than pharmacists working in hospital setting; adverse effects, potential for addiction, and the reason for medication were the most commonly inquired issues.</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
<td>Study population</td>
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<td>Method</td>
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<tr>
<td>Landers et al. 2002</td>
<td>-</td>
<td>Information sources; pharmacists experiences and contributions to the management of mild to moderate depression and their interaction with patients</td>
<td>Pharmacists (n=20) in community pharmacies; 12 females; Age: 21-70</td>
<td>Community pharmacy</td>
<td>A qualitative interview</td>
<td>Patients’ questions on depression treatment in pharmacies related to: 1) purpose and justification of the need for medication; 2) treatment duration and dependency; 3) onset on therapeutic effect; 4) safety; 5) practical issues such as alcohol use during medication; and 6) management options and support.</td>
</tr>
<tr>
<td>MacHaffie 2002</td>
<td>2001</td>
<td>Information sources; use and trustworthiness of the sources of health information</td>
<td>A convenience sample of clients with severe and persistent mental illness (n=41); 24 females; Age: 20-89</td>
<td>Community</td>
<td>A cross-sectional survey</td>
<td>Non-psychiatrist physicians, psychiatrists, nurses and pharmacists provided most information about health and were rated also as the most reliable sources.</td>
</tr>
<tr>
<td>Millard and Fintak 2002</td>
<td>-</td>
<td>Information sources; use of the Internet to health management</td>
<td>Patients with chronic illness (n=10 069); 23% with depression; gender?; Age: -</td>
<td>Internet</td>
<td>A cross-sectional online survey</td>
<td>Reading online bulletin boards or news groups or communicating via them was most popular among people with gynecological conditions, diabetes mellitus, gastrointestinal disorders, depression, and chronic sinusitis. People with depression were also the second leading user group of e-mail lists focusing on healthcare.</td>
</tr>
<tr>
<td>Sleath and Wurst 2002</td>
<td>2000</td>
<td>Information needs and sources; medicines information received from physicians, pharmacists, and other health-care professionals; preferences for written and verbal information</td>
<td>English speaking patients with antidepressant medication (n=83) in North Carolina</td>
<td>Community pharmacies (n=8) in North Carolina</td>
<td>A cross sectional, quantitative interview study</td>
<td>Approximately 22% of patients preferred to receive antidepressant information verbally; 36% written, and 42% both written and verbally; less educated were more likely to want information verbally; no Internet-based information mentioned.</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
<td>Study population</td>
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<tr>
<td>Haviland et al 2003</td>
<td>2001</td>
<td>Information sources; the relationship between general medical, psychiatric, and psychosomatic problems and use of the Internet for disease and wellness information</td>
<td>Households (n=152,208) in USA; gender?; Age: -</td>
<td>Community</td>
<td>A cross-sectional survey</td>
<td>People with psychosomatic problems were the most frequent users of the Internet for health information, followed by people with psychiatric problems and people with general medical problems.</td>
</tr>
<tr>
<td>Sleath et al. 2003</td>
<td>1995</td>
<td>Information sources; how hispanic ethnicity influence physician-patient communication about antidepressants; question asking by patients</td>
<td>Patients with antidepressant medication (n= 403); 56% Hispanic; 71% females; Age: 23-83</td>
<td>Physician encounters</td>
<td>Audiotaped physician visits, patient interview, medical record and pharmacy prescription data</td>
<td>Minority of patients ask questions about their antidepressants. Most commonly asked questions related to: dose (11%), type of antidepressant medicine (8%), adverse effects (8%), technical information such as interactions and mechanism of action (7%).</td>
</tr>
<tr>
<td>Sleath et al. 2003</td>
<td>2000</td>
<td>Information sources; how patients sources of antidepressant information were related to antidepressant adherence</td>
<td>Community pharmacy customers/adult patients picking up their antidepressant prescription (n=81); Gender?; Age: -</td>
<td>Community pharmacies (n=8) in North Carolina</td>
<td>A cross-sectional interview</td>
<td>Most commonly reported sources were: pharmacists (58%), primary care physicians (51%), and mental health specialists (41%); patients reporting more than one sources of medicines information were more adherent to their medication than people with fewer sources.</td>
</tr>
<tr>
<td>Garfield et al. 2004</td>
<td>2003</td>
<td>Information needs; the level of patient involvement in decision making</td>
<td>People with depression and new course of antidepressant treatment (n=51); 57% females; Age: 18-65</td>
<td>Outpatients in London</td>
<td>Semi-structured qualitative interviews on two occasions (1-3 months after starting antidepressant treatment and 3 months later)</td>
<td>Participants experienced additional needs for medicines information relating to adverse effects, process of recovery, length of treatment, dependency, dosage; timing of information perceived important.</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
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<tr>
<td>Wagner et al. 2004 (USA)</td>
<td>2001-2002</td>
<td>Information sources; Internet use for health information</td>
<td>People with one or more chronic conditions (n=1980); 31% with depression; 58% females; Age: &gt; 21 years</td>
<td>Outpatients</td>
<td>A population survey</td>
<td>51% of people with depression reported using the Internet to seek health information during the year before the survey; Internet use varied by chronic conditions; those who had diabetes only, depression only, or two or more chronic conditions were more likely to use the Internet than people with hypertension only, cancer only, or heart problems only.</td>
</tr>
<tr>
<td>Berger et al. 2005 (USA)</td>
<td>2001-2002</td>
<td>Information sources; Internet use for health information</td>
<td>Respondents to a national survey with and without stigmatized illness (n=7014); 55% females; Age: 18-60 years</td>
<td>Community</td>
<td>A cross-sectional survey</td>
<td>People with stigmatized disorders were significantly more likely to use the Internet and E-mail for health information than those without stigmatizing disorders.</td>
</tr>
<tr>
<td>Zwaenepoel et al. 2005 (Belgium)</td>
<td>-</td>
<td>Information needs and sources; the need for information among psychiatric in-patients</td>
<td>In-patients with different type of mental disorders (n=279); 19% with a mood disorder; 45% females; Age: 18-82 years</td>
<td>Hospital patients in 11 hospitals in Flanders</td>
<td>A cross-sectional survey</td>
<td>Information needs related to: adverse effects, mechanism of action, indication, potential to cause addiction, interactions, and harmfulness of medicine.</td>
</tr>
<tr>
<td>Bansil et al. 2006 (USA)</td>
<td>2002-2003</td>
<td>Information sources; use of the Internet for health information among people with and without chronic disorders</td>
<td>Respondents (n=8 432) to national Health Styles Survey in 2002 and 2003</td>
<td>Community</td>
<td>A Cross-sectional survey</td>
<td>Respondents who reported chronic diseases were more likely to use the Internet to access health information, Internet use for this purpose was especially common among people with depression (OR=1.47; 95% CI, 1.27-1.37).</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
<td>Study population</td>
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<td>Method</td>
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</tr>
<tr>
<td>Leach et al. 2006 (Australia)</td>
<td>-</td>
<td>Information sources: the helpfulness of websites vs. books and health educators</td>
<td>A random sample of 3998 Australians; 59% females; Age: &gt; 18</td>
<td>Community</td>
<td>A Cross-sectional survey</td>
<td>More participants rated books and health educators as helpful compared to websites. Predictors of rating a website and book as helpful were younger age, belief that it is helpful to deal with mental disease alone and being presented with depression and early schizophrenia vignettes in comparison to chronic schizophrenia.</td>
</tr>
<tr>
<td>Perreault et al. 2006 (Canada)</td>
<td>-</td>
<td>Information needs; information needs and the level of satisfaction with information on specific components of services; to develop a scale for measuring patients’ information needs</td>
<td>Outpatients (n=86) with different type of mental disorders; biggest subgroup being people with affective disorders; 56% females; Age: 18-65 years</td>
<td>Outpatient clinics (n=2) affiliated with a psychiatric hospital in Montreal</td>
<td>An interview study</td>
<td>Information needs reported related to: the length of psychotherapeutic treatment, dosage, type of medication, objectives and ratio for treatment, and side-effects as issues they wanted to have information about.</td>
</tr>
<tr>
<td>Powell and Clarke 2006 (UK)</td>
<td>-</td>
<td>Information needs; To examine information needs and information-seeking behavior among adult mental health service users</td>
<td>Adults (n=36) with mental health problems and current or recent contact with mental health services; 25 females; Age: &gt; 18 years</td>
<td>Primary and secondary care patients in Oxfordshire area</td>
<td>A in dept interview</td>
<td>Participants reported: lack of information and respect from their healthcare professionals; information seeking from technical sources; perceived stigma inhibits information seeking; peers’ experiences are beneficial.</td>
</tr>
<tr>
<td>Powell and Clarke 2006 (UK)</td>
<td>-</td>
<td>Information sources; use of the Internet for mental health information</td>
<td>A random sample of individuals (n=917); Age: &gt; 18</td>
<td>General practice patients in Oxfordshire area</td>
<td>A population survey</td>
<td>The prevalence of the Internet use for health information was highest among people with current or past experience with mental health problems.</td>
</tr>
<tr>
<td>Taylor et al. 2006 (UK)</td>
<td>1997-2005</td>
<td>Information needs; prevalence of inquiries about discontinuation of antidepressants</td>
<td>Telephone calls (n=1753); Gender and age of the inquirers were not mentioned</td>
<td>A national medication helpline</td>
<td>A retrospective evaluation of telephone calls</td>
<td>Of the all calls (n=22,422), 1753 related to antidepressant discontinuation; calls were about all antidepressants marketed.</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
<td>Study population</td>
<td>Setting</td>
<td>Method</td>
<td>Key findings/Notifications</td>
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</tr>
<tr>
<td>Hunot et al. 2007</td>
<td>2000-2002</td>
<td>Information needs; the influence of patient antidepressant concerns, treatment preferences, and illness perceptions on adherence to antidepressants over a 6-months period</td>
<td>A cohort of 178 patients with newly issued antidepressant prescription; Age: 18 – 74 years</td>
<td>Primary care practices (n=5) in Southeast England</td>
<td>A longitudinal prospective cohort study</td>
<td>Specific concern about antidepressant adverse effects, general worry about taking antidepressants, and preference for other type of treatment were predictors of antidepressant non-use.</td>
</tr>
<tr>
<td>Pestello and Davis-Berman 2007 (US)</td>
<td>-</td>
<td>Information sources; experiences of taking antidepressant medication and its impact on the sense of self</td>
<td>Posting (n=227) on the five popular message boards; randomly taken postings from the total of 3243 postings</td>
<td>Internet</td>
<td>Qualitative analysis of postings</td>
<td>Postings generally addressed adverse drug reactions, especially relating to sexual dysfunctions, giving medical advice, and frustration with physician.</td>
</tr>
<tr>
<td>Sleath et al. 2007</td>
<td>2000</td>
<td>Information sources; Provider-patient communication about antidepressants among veterans with mental health condition</td>
<td>40 veterans using antidepressants; all males</td>
<td>Outpatients in North Carolina</td>
<td>Qualitative interview and observation</td>
<td>Not enough information provided; usually provider started discussion: only two people asked questions about their medicines; those related to...</td>
</tr>
<tr>
<td>Santor et al. 2007</td>
<td>2002</td>
<td>Information sources; the use and impact of a dedicated health information website for adolescents</td>
<td>All students attending grades 7 through 12 in three junior high schools and one senior high school (n=2054)</td>
<td>School</td>
<td>A cross-sectional survey</td>
<td>The use of health-related website and services was associated to: female gender, perceived need for professional help, high score on depressive vulnerability, and to severe mood problems.</td>
</tr>
<tr>
<td>Van Geffen et al. 2007</td>
<td>1990-2004</td>
<td>Information sources; patients’ concerns about and problems experienced with discontinuation of antidepressants</td>
<td>All calls to a national drug information call center, particular focus on antidepressant-related calls (n=6159); 72% females; Age: 21-60 years</td>
<td>Telephone service</td>
<td>A retrospective evaluation of phone calls</td>
<td>Concerns relating to discontinuation of antidepressants include questions on whether, when, and how to discontinue the medication, and what to expect during discontinuation.</td>
</tr>
<tr>
<td>Study</td>
<td>Study year</td>
<td>Focus</td>
<td>Study population</td>
<td>Setting</td>
<td>Method</td>
<td>Key findings/Notifications</td>
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</tr>
<tr>
<td>Al-Saffar et al. 2008 (Kuwait)</td>
<td>-</td>
<td>Information needs and sources; patients' view about verbal or written information for antidepressant medications in the psychiatric hospital</td>
<td>People with newly diagnosed unipolar depression (n=150) who had initiated antidepressant treatment; 30% females; Age: 20-59 years</td>
<td>Outpatients in department of the Psychiatric hospital in Kuwait</td>
<td>A randomized controlled trial; a questionnaire used to assess if participants understood the leaflets developed for the purposes of this study</td>
<td>Half of respondents were unsatisfied with information received from clinicians; 90% would have wanted to receive further information about therapy; both among control and counseling group psychiatrists were most commonly reported as sources of medicines information; among PIL-group, PILs were the most commonly mentioned sources; more people in control groups than in other groups were unsatisfied with information received about their medicines.</td>
</tr>
<tr>
<td>Khazaal et al. 2008 (Switzerland)</td>
<td>2007</td>
<td>Information sources; the use of the Internet by patients treated for a psychiatric disorder</td>
<td>People with different type of psychiatric disorders (n=319); 48% mood or anxiety disorder; 42% females; Mean age 40 years</td>
<td>Outpatient clinic in the University Hospital Lausanne</td>
<td>A cross-sectional survey</td>
<td>Among Internet users (n=200), 69% searched information on health issues and 44% searched for medical information more than once a month. Main topic they searched information about was their treatments (81%) and diagnosis (73%).</td>
</tr>
<tr>
<td>Oh et al. 2009 (Australia)</td>
<td>2006</td>
<td>Information sources; young people preferences for a website, self-help book, and face-to-face services</td>
<td>Young Australians (n=3746); Age: 12-25 years</td>
<td>Community</td>
<td>A cross sectional telephone survey</td>
<td>Most young people were open to idea of accessing mental health information online, especially for disorders that are often perceived as behavioral problems.</td>
</tr>
<tr>
<td>Van Geffen et al. 2009 (Netherlands)</td>
<td>-</td>
<td>Information needs and sources; patient perceptions of MI received at the start of SSRI treatment within the previous 6 months; potential role of the community pharmacists</td>
<td>41 patients with depression (61%), anxiety disorders (7%), nonspecific mood symptoms (6%), other (3%); first antidepressant prescription was received within the previous 6 months; 61% females; Age: &gt;18;</td>
<td>Community pharmacies (n=6) belonging to Utrecht University</td>
<td>Qualitative semi-structured telephone interview</td>
<td>Reported un-met information needs related to adverse effects, delayed onset of action, dependency.</td>
</tr>
</tbody>
</table>
### Table 2. Articles excluded after reviewing full-texts (n=10) and reasons for exclusion.

<table>
<thead>
<tr>
<th>Study</th>
<th>Reason for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ybarra ML, Suman M. Help seeking behavior and the Internet: a national survey. Int J Med Inform 2006 Jan;75(1):29-41. Epub 2005 Aug 29.</td>
<td>Study population was not defined in terms of their disease background.</td>
</tr>
<tr>
<td>DiFranco E, Bressi SK, Salzer MS. Understanding consumer preferences for communication channels to create consumer-directed health promotion efforts in psychiatric rehabilitation settings. Psychiatr Rehabil J 2006 Spring;29(4):251-7</td>
<td>Study population not defined in terms of their diseases.</td>
</tr>
<tr>
<td>Craven MA, Nikolau L, Allen CJ, Crustolo AM, Kates N. Patient education materials for mental health problems in family practice: does location matter? Patient Educ Couns 2005 Feb;56(2):192-6</td>
<td>About pamphlets display practises in 13 family physician offices, consumer needs or use of different sources were not reported.</td>
</tr>
<tr>
<td>Young HN, Bell RA, Epstein RM, Feldman MD, Kravitz RL. Types of information physicians provide when prescribing antidepressants. J Gen Intern Med 2006 Nov;21(11):1172-7</td>
<td>Study concerned patient-physician communication, did not report consumer information needs and/or question asking about medicines.</td>
</tr>
</tbody>
</table>
### Appendix 5. Data collection form for telephone inquiries.

**INFORMATION ABOUT THE INQUIRER:**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Inquirer called</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Male</td>
<td>1. &lt; 20</td>
<td>1. For her/him self</td>
</tr>
<tr>
<td>2. Female</td>
<td>2. 20-40</td>
<td>2. For somebody else. Please, specify.</td>
</tr>
<tr>
<td></td>
<td>3. 40-60</td>
<td>3. Not known</td>
</tr>
<tr>
<td></td>
<td>4. &gt; y60</td>
<td>4. Not known</td>
</tr>
<tr>
<td></td>
<td>5. Not known</td>
<td>5. Not known</td>
</tr>
</tbody>
</table>

**INFORMATION ABOUT THE MEDICATION:**

Inquiry was about:

1. Prescription medicines
2. Non-prescription medicines
3. Opening hours of the pharmacy
4. Telephone prescriptions
5. Something else, please specify?

Medicines mentioned: List all medicines mentioned during the discussion either by generic or brand name. 
Additionally, please mark the main topic of the discussion (NOTE! Mark only one medicine)

<table>
<thead>
<tr>
<th>The type of the medicine:</th>
<th>The course of the treatment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medicine taken as a course</td>
<td>1. Not started yet</td>
</tr>
<tr>
<td>2. Long-term medication</td>
<td>2. Started during the past week</td>
</tr>
<tr>
<td>3. Medicine that is taken &quot;when needed&quot;</td>
<td>3. Used more than a week &lt; month</td>
</tr>
<tr>
<td>4. Other, specify?</td>
<td>4. Used more than a month</td>
</tr>
<tr>
<td>5. Not known</td>
<td>5. Not known</td>
</tr>
</tbody>
</table>

**CONTENT OF THE DISCUSSION:**

Inquiry was about:

1. Effective substance
2. Indication/purpose of the medication
3. Mechanism of action
4. Dose
5. How to take a medicines
6. Discontinuation of the medication
7. Efficacy
8. Medicine use and alcohol
9. Drug-drug interactions
10. Adverse drug reactions. What specifically?
11. Contraindications
12. Medicine use during pregnancy and lactation
13. Dependency
14. Medicine use and driving
15. Formulation
16. Storage
17. Costs and reimbursements
18. Availability of the medicine
19. Other, what specifically? 

Result of the discussion:

1. Customer got a direct answer to the inquiry
2. The call was turned to the University Pharmacy
3. The customer was asked to contact outside of the University Pharmacy (for example to physician), where?

Length of the discussion:

1. < 1 min
2. 1-5 min
3. 5-10 min
4. > 10 min

This form was filled by: __________________ Date: __________________ Time: __________________

**Gender**

1. male  
2. female

**Year of birth 19 ______**

How many years have you attended school or studied full-time? Elementary school is included.

______ years

Are you at the moment mainly

1. at work  
2. partly at work, partly retired  
3. laid off  
4. unemployed  
5. student  
6. homemaker (also maternity leave, nursing leave)  
7. on sick leave (>6 kk)  
8. pensioned  
9. not at work for any other reason

In the past year (12 months) have you been diagnosed with or treated for the following illnesses by a doctor? yes

- high blood pressure  
- hypertension ........................................... 1  
- high blood cholesterol ...................................... 1  
- diabetes ...................................................... 1  
- coronary thrombosis, myocardial infarction ......................... 1  
- coronary disease, angina pectoris (=chest pain during exercise) .......... 1  
- coronary insufficiency ......................................... 1  
- cancer .......................................................... 1  
- rheumatoid arthritis ........................................... 1  
- degenerative disk disease, other back illness .......................... 1  
- chronic bronchitis, pulmonary emphysema .............................. 1  
- depression ..................................................... 1  
- other mental health disorder ................................... 1  
- asthma .......................................................... 1  
- digestive illness (gastritis catarrh, gastritis, ulcer) .................... 1
In the past week (7 days), have you used any pills, powders or other medicines?

yes

blood pressure medication ......................... .... 1
insulin...................................................... 1
diabetes medication ................................. .... 1
painkillers for headache .............................. 1
other painkillers ........................................... 1
contraceptives ............................................. 1
sedatives .................................................. 1
sleeping pills .............................................. 1
antidepressants .......................................... 1
vitamin and mineral preparations .................... 1
cough medication ........................................ 1
cholesterol medication ................................... 1
hormone replacement therapy
for women .................................................. 1
medication for erectile disfunction ................. 1

In the past year (12 months), have you received information on the medicines you have used?

yes

from a doctor ............................................. 1
from pharmacy .......................................... 1
from a public health nurse,
a registered nurse ..................................... 1
from family, friends .................................... 1
from newspapers, books ............................ 1
from radio, TV .......................................... 1
from advertisements .................................. 1
from internet .......................................... 1
from health food shops ............................. 1
from package legends ............................... 1
from service telephone ............................ 1
Appendix 7. *Focus group discussion guide.*

**INTRODUCTION**
- Introduction of the research and the researches, information of why there are two researchers involved
- Focus groups are group discussions organized around particular themes.
- Purpose is to keep discussion as open as possible. There is no right or wrong answers, and all viewpoints are equally important for us. We also want to hear different opinions, so if you do not agree with others, please tell us that.
- Explanation why the discussion is recorded and notes are taken.
- Participants are asked to avoid simultaneous speaking.
- Participants are asked to introduce themselves.
- Definitions of the terms drug information and antidepressant drug information: Drug information could be defined as any information considering the medication that the responder is using. This covers e.g. the effect, the use, dosage, price, reimbursement and possible adverse effects of the drug. Antidepressant information is information from only antidepressant medication.
- Personal details and things during the interview that could lead to identifying someone will be keeping secret.
- Results will be handled uncompromisingly confidentially and report so that no single person could be identified.

1. EXPERIENCES IN GETTING INFORMATION ON MEDICINES (Passive knowledge)
   - Have you got enough information from your antidepressants?
   - If you haven’t, what problems you have had with getting information?
   - Where have you got information about your antidepressants in **different stages of treatment process**?
     - Before doctors appointment (when patient are thinking about different treatment alternatives)
     - When medication prescription is ordered (doctors appointment, mental health professional, psychiatric outpatient clinic)
     - When medicine is pick up from pharmacy
     - During the use of the medicine
   - What kind of information?
   - Opinion of the information about antidepressant information provided by health professionals?
     - Doctor?
     - Pharmacy?
     - Nurse?

2. NEEDS IN INFORMATION ON MEDICINES IN FUTURE
   - What kind of information you would like to have concerning your medicines in future?
   - From whom/which sources?
   - When?
   - Is there some questions you can’t ask face-to-face from pharmacy or other health care professionals?
   - Other support needs during the treatment?

3. USE OF DIFFERENT SOURCES FOR MEDICINES INFORMATION (Active knowledge)
   - What kind of situations / why you have spontaneously searched for extra knowledge from your medicines?
   - How you have act in such situations?
   - Where have you search/look for extra information about your medicines?
     - Pharmacy?
     - Physician?
     - Nurse?
     - Telephone service?
     - Friends, relatives?
     - Magazines?
     - Books?
- What is the meaning of different sources of information? Advantages and disadvantages of different sources? What do you think about trustworthiness of these different sources of information?

4. THE INTERNET AS A SOURCE OF MEDICINE-RELATED INFORMATION
- What is your opinion about the Internet as a source of information on medicines, in particular antidepressants?
- Advantages / disadvantages?
- In what kind of situations you have searched information online? Why?
- What kind of information you have searched?
- How often are you looking for information about your medication from the Internet?

5. THE METHODS OF SEARCHING INFORMATION ON MEDICINES ON THE INTERNET
- How do you usually search information about medicines from Internet?
- Do you use the particular sites or search engines?
- What search engines have you used?
- What / Which organisations are maintaining the sites you are looking for?
- What sites you prefer?
- Have you used email for asking information about medicines? Why? When? What subject?
- Have you used discussion forums? Why? When? What forums?
- Advantages / disadvantages of different online sources?

6. THE EVALUATION OF THE QUALITY OF INTERNET-BASED INFORMATION ON MEDICINES
- Do you usually evaluate how do you evaluate the quality of the information you have found from the Internet?
- On your opinion which are the most important quality criteria of health related websites?
- Are you familiar with/Have you used some website rating tools?
  - DISCERN
  - HON
  - QUICK or some other?
- Experiences of using these tools?
- Do you usually compare information from different sources?
- What / Which sites are reliable on your opinion?
- DARTS: Their opinion about things that are in list, usefulness of the list and about the logo DARTS

7. IMPACT OF THE INTERNET INFORMATION ON MEDICINES
- What feelings have become after reading the information of the medicines from Internet?
- How has that knowledge affected your actions?
- Does the information you find from the Internet affect your way of using some medicine?
- Do you still ask from pharmacy or doctor something you have searched from the Internet?

8. OTHER COMMENTS
# Appendix 8. Description of the virtual pseudo customer scenarios and scoring criteria.

<table>
<thead>
<tr>
<th>SCENARIO</th>
<th>SCORING CRITERIA</th>
<th>SCORE</th>
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<tbody>
<tr>
<td>1. I am 30-year-old woman. I suffer from mood swings and anxiety. My physician prescribed me Seromex (fluoxetine) 10 mg medication. However, I have heard that Seromex may cause addiction and adverse effects. Therefore, I am afraid of starting medication. I have never used these kinds of medication before. My physician did not answer my question concerning adverse effects. What is your opinion of starting this medication? Is it effective? Can you tell me about possible adverse effects? How many people experience them? Are they tolerable? Can this medication cause addiction? Thank you for your answer.</td>
<td>• the medication is effective in depression and anxiety treatment &lt;br&gt; • the maximum effect normally occurs only after 4 weeks of use &lt;br&gt; • absolute incidence of adverse effects described (in numbers or verbally) &lt;br&gt; • adverse effects are normally mild &lt;br&gt; • adverse effects are usually transient and most commonly occur when starting treatment (during first 2 weeks) &lt;br&gt; • the most common adverse effects are digestive problems...&lt;br&gt; …and central nervous system effects &lt;br&gt; • these medications do not cause addiction &lt;br&gt; • withdrawal symptoms may occur while discontinuing the medication, so this is usually done gradually &lt;br&gt; • pharmacist motivates consumer and attempts to ease her concerns about taking medication</td>
<td>range 0-10 1</td>
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<td>2. I am 41-year-old lady. I have been on Cipramil (citalopram) 40 mg for 3 months. It has been very effective for my symptoms. However, I have gained weight during this period, about 7 kilograms. I also feel my appetite has increased. Is it possible that these symptoms could be caused by Cipramil? The medication has also affected my libido. Is this effect transient? This has been very problematic for my relationship. I have been wondering what to do, whether I should discontinue or change medication. Thank you in advance for your answer.</td>
<td>• the medication may increase both appetite and weight &lt;br&gt; • decreased libido (3% of users) and weight gain (3.5%) may occur but are less common adverse effects &lt;br&gt; • since the adverse effects have persisted for so long, it may be necessary to change medication (current guidelines indicate that more than 6-8- weeks of adverse effects may necessitate change of medication) &lt;br&gt; • need to contact physician &lt;br&gt; • continue medication until after consultation with physician &lt;br&gt; • use encouraging words to facilitate safe and appropriate medication use</td>
<td>range 0-6 1</td>
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<td>3. I am a 52-year-old man. I take Remeron (mirtazapine) for anxiety and depression. I started to use this medication about one week ago. I take the medication in the evening. I read in the patient information leaflet that I should not drink alcohol. How many hours after I take the medication is it safe to drink? Sometimes I drive to work by car. When I had the medication dispensed in the pharmacy, they said that the medication can cause drowsiness. Can I drive if I use this medication? I also use Diapam (diazepam). Is it safe to take these medications together?</td>
<td>• best to avoid alcohol use during treatment (if not possible, 1 portion maximum per sauna visit or meal) &lt;br&gt; • this medication may decrease attentiveness, particular at start of treatment (If this effect is felt, driving should be avoided) &lt;br&gt; • the sedative effect is usually transient, and it is usually possible to drive after becoming accustomed to medication &lt;br&gt; • diazepam and mirtazapine can be taken concurrently, with caution &lt;br&gt; • recommend discussing concurrent use of diazepam and mirtazapine with physician</td>
<td>range 0-5 1</td>
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