Internet-Based Patient Communication

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Acknowledgements

Summary

Objective

To investigate some of the consequences that electronic health communication has for patients, health professionals and society at large. The underlying studies investigate reasons patients provide for using online communication solutions, the current propagation and pace of Internet health communication, and whether such services would replace conventional health communication channels.

Methods

These objectives were addressed in three separate studies, all using different methodological approaches. The exploratory study used online questionnaires, receiving 492 responses. The population study used telephone interviews with 14,956 respondents from seven different European countries, while the intervention study was designed as a randomised controlled trial with a total of 200 patients.

Results

The results showed that patients found advantages in online communication, and some reported that it was easier to talk about sensitive subjects online.

For all the seven studied European countries, there was significant growth in the proportion of the population using Internet for health purposes in the period 2005-2007. More patients are using the Internet as an active communication channel, both for reaching health professionals and for reaching peers.

Direct electronic communication was shown to replace other communication channels, especially face-to-face consultations in family doctor settings.

Conclusions

Internet-based patient communication is starting to become an important part of today's health care systems. To some degree, conventional communication channels are being replaced by online alternatives. However, there still appears to be potential for further growth. It is clear that in addition to the practical advantages of asynchronous communication in flexibility and saved travelling time, such communication also gives patients the time they need to formulate their questions.

List of articles

1) Kummervold, P. E., Gammon, D., Bergvik, S., Johnsen, J-A., Hasvold, T., & Rosenvinge, J. H. (2002). Social support in a wired world: use of online mental health forums in Norway. *Nordic Journal of Psychiatry*, 56(1), 59-65.

2) Kummervold, P. E., Chronaki, C. E., Lausen, B., Prokosch, H-U., Rasmussen, J., Santana, S., Staniszewski, A., & Wangberg, S. C. (2008). eHealth trends in Europe 2005-2007: a population-based survey. *Journal of Medical Internet Research*, 10(4), e42.

3) Wangberg, S., Andreassen, H., Kummervold, P., Wynn, R., & Sørensen, T. (in press). Use of the internet for health purposes: trends in Norway 2000-2010. *Scandinavian Journal of Caring Sciences*.

4) Kummervold, P. E., Trondsen, M., Andreassen, H., Gammon, D., & Hjortdahl, P. (2004). Erfaringer med lege-pasient-kontakt over Internett. *Tidsskrift for Den norske legeforening*, 124(20), 2633-2636.

5) Bergmo, T. S., Kummervold, P. E., Gammon, D., Dahl, L. B. (2005). Electronic patient–provider communication: will it offset office visits and telephone consultations in primary care? *International Journal of Medical Informatics*, 74(9), 705-710.

1 Introduction

1.1 Background

The general use of the Internet has increased significantly during recent years. At the same time, use of the Internet for health purposes has grown (Eysenbach & Köhler, 2003; Baker et al., 2003; Hesse et al., 2005, Ybarra & Suman, 2006; Beckjord et al., 2007). For patients, the Internet has become a major source for receiving health information, but they are also utilising the medium more actively – in producing health diaries (Sittig, 2002; Kim & Johnson, 2002; Houston et al., 2004; Simons et al., 2005; Adler, 2006; Ball et al., 2007), in buying online medication and health products, and in communicating with other patients and health workers (Baker et al., 2005; Sittig, King, & Hazlehurst, 2001; Eysenbach, 2004).

Early on, the Norwegian authorities expressed a clear goal for patients to use the Internet in contact with the health system (Ministry of Health and Social Affairs, 2001), and has later repeated this goal (Ministry of Health and Social Affairs, 2004; Ministry of Health and Care Services, 2007). Patients were also embracing the new communication services, and the proportion of the Norwegian population wanting to communicate electronically with their doctor increased from 30% in 2000 to 45% in 2001 (Andreassen et al., 2002). Scepticism was undoubtedly greater among doctors than among patients (Høie, 2002). This was the starting point of this dissertation.

The primary motivation of this dissertation was to focus on some of the consequences of Internet-based patient communication, especially in relation to whether it would supplement or replace traditional health communication channels. In addition, the project analysed trends in Internet use for health purposes in general and the prevalence of online health communication in particular. The goal was to identify some potential limitations and possibilities of using Internet for communicating about health.

Communicating about health over the Internet is however slightly different from communicating about other issues. While the most common way of communicating one-to-one over the Internet is to use e-mail, this is not the case for communication between patients and health professionals. To understand this, it is necessary to look at the legislation. All health personnel have an obligation to ensure that sensitive health information is kept confidential. Sections 13, 15 and 16 in the Personal Health Data Filing

System Act and Section 21 in the Health Personnel Act[1] are the legal basis for this. These Norwegian laws are based on the EU directive[2] regarding the protection of individuals with regard to the processing of personal data. The way this directive is interpreted by the Norwegian Data Inspectorate implies that unencrypted e-mail is not a legal medium for communication between health professionals and patients.

There are two legal ways of getting around this: a) The communication is secured in a way that satisfies the regulations, or b) the data are depersonalised and does not concern identified patients, so that communicating it does not imply processing of personal data. In addition, there is always the possibility of using e-mail despite the regulations, effectively violating the law.

Prior to 2002 there was no secured electronic health communication available in Norway. The project PasientLink[3] was the first attempt at building such a service in this country. This project had research as its main priority, and the results are presented in Article 4 and Article 5. When the project was finished in 2003 all source code was released to the public, and the company Well Diagnostic developed the test program into a commercial product called MinDoktor. In 2007 MinDoktor became an integral part of ProfDoc, the major Norwegian system for electronic health records in GP offices. In parallel, since 2003, the company Deriga has offered the solution MedAxess for secure health communication. In 2006 Deriga was acquired by the company Visma Unique.

Hence, in Norway there are two commercially available technical solutions for patients who want to communicate with health personnel. Both solutions use a two-phase authentication, where patients will receive a single-use code sent to their mobile phone in addition to having to type a password to log on. Administratively, this means that all patients must register at the doctor's office to get a password. Less administrative work would have been involved if it had been possible to integrate this system with a third-party electronic national ID, but no such system with a sufficient security level is operational in Norway today.

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[1] **Full reference in Norwegian:** Lov 2001-05-18 nr 24: Lov om helseregistre og behandling av helseopplysninger (helseregisterloven), §§13, 15 og 16. Lov 1999-07-02 nr 64: Lov om helsepersonell m.v. (Helsepersonelloven), §21.
Full reference in English: Act of 18 May 2001 No. 24 on Personal Health Data Filing Systems and the Processing of Personal Health Data (Personal Health Data Filing System Act), §§13, 15 and 16). Act of 2 July 1999 No. 64 relating to Health Personnel etc (The Health Personnel Act), §21.
[2] Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
[3] The original Norwegian project name *PasientLink* is used throughout the text. An English translation would be *PatientLink*.

It should be noted that it varies how the above mentioned EU directive is applied and implemented in the national legislations across Europe, and in some countries it is more accepted to use e-mail for this purpose than in Norway. In the US there also seems to be a more liberal attitude toward using e-mail in direct patient-doctor interaction. The ethical guidelines of the American Medical Association merely state:

> "*Physicians should engage in e-mail communication with proper notification of e-mail's inherent limitations. Such notice should include information regarding potential breaches of privacy and confidentiality, difficulties in validating the identity of the parties, and delays in responses.*" (American Medical Association, 2008).

In addition to the secured communication channels where the identity of the patient is known, there exist several ways to communicate anonymously about health on the Internet. The most widely used are online discussion forums. Usually these forums are open for everybody to read, and you will have to give the service provider your e-mail address to be able to post messages. With regards to moderation, there are forums that are moderated by users, and forums where health professionals participate in the role of advisers or moderators. Article 1 examines some of these forums. Forums are today the most popular form of asynchronous health communication channels. There are also several synchronous chat services, like IRC and multiple web-based systems. However, these are all minor in volume of use compared to the asynchronous services.

1.2   Research Questions and Objectives

The main objective in this dissertation is to examine some of the consequences electronic health communication will have for patients, health professionals and society at large. To answer this, I examined the reasons patients provide for using online communication solutions. I also looked at the current propagation of such services and the pace of this propagation, and finally tested the actual effect of an implementation. This dissertation explores whether electronic health communication is replacing more conventional communication channels. The scope of this dissertation does not include addressing the health effects of electronic health communication.

The research questions were addressed in three separate studies, each with its own secondary research questions. The oldest study was conducted mainly to generate hypotheses. It was based on data from an online questionnaire, but the sample was not randomly selected. The main reason for including this study is to show the background

for how the hypotheses for the other studies were formed. This is referred to as *the exploratory study*.

Another study had the main objective of investigating trends and patterns of health-related Internet use, and specifically interactive use of the Internet for health purposes, like communicating directly with health professionals. It was based on a large representative sample, and used methods resembling epidemiology. This is referred to as *the population study*.

There was also a need for testing a service that enabled patients to communicate directly with their doctor. The objective was to investigate some of the consequences health-related communication over the Internet would have for patients, doctors and society at large. This study was designed as a randomised controlled trial, and is referred to as *the intervention study*.

Table 1 summarises the different studies, their objectives, and shows what articles are based on each study.

Table 1

Study	*Research questions and objectives*	**Article**
Exploratory Study	• **Generating hypotheses** • Why are people using the Internet for communicating about mental health? • Are there properties of online communication that could offer advantages in the development of online health services? • What role do users think health professionals should have in online forums?	1
Population Study	• **Use of Internet for health purposes** • What demographic variables determine health-related Internet use? • What changes are we seeing in health-related Internet use? • What trends are we seeing in communication between patients and health professionals?	2 and 3
Intervention Study	• **Consequences of health-related communication between patients and doctors over the Internet** • Will electronic communication supplement or replace conventional contact with the doctor? • When and how much are patients using this service? • How did patients and doctors experience use of the service?	4 and 5

This dissertation focuses primarily on services where there is a two-way communication, i.e., patient-doctor or patient-patient communication. Provision of information (one-way communication), for instance when health professionals make information available online, is an important part of health-related Internet activity. This aspect is also discussed in detail in Article 2 and Article 3. In this summary the use of the Internet for retrieving health information is, however, mainly used as a background variable.

1.3   Definitions

The title of this dissertation is "Internet-Based Patient Communication". The term is used for all online health communication involving patients, both patient-health professionals and patient-patient. The dissertation does not cover health communication involving only health professionals, and this is also reflected in the title. When the thesis uses the more popular term "Internet health communication", it is therefore still referring to communication involving patients. For variation, "online" and "electronic" are often used as alternatives to "Internet". Without exceptions, these are used as synonyms even if there is a slight technical difference.

In the population study, the terms "Internet health usage" and "Internet health user" are used. These terms have a wider meaning, and refer to all health-related Internet activity, including the reading of static health information.

In Article 2 the term "interactive Internet health services" is used. This is defined as all services that add an element of interaction and go beyond merely reading health information on the Internet. In the article, the term is used with reference to people who have 'interacted with health professionals they have not met face to face', 'participated in forums or self-help groups', 'ordered medicine or other products related to health or illness online' or 'interacted with a family doctor, specialist or other health professionals'. This term therefore goes beyond health communication, since it also includes services like ordering medicine over the Internet.

The individual articles report results using different levels of precision. The extremes are Article 1, which reports all numbers without decimals, and Article 3, where up to three decimals are used. This dissertation uses the same number of decimals that were used in the individual articles, unless otherwise stated in footnotes.

2   Materials and Methods

2.1   Exploratory Study

2.1.1   Aims

The focus of the study was online discussion forums for mental health. The study started in 1999, and at that point *Doktor Online* and *SOL Helse* were the only major health-related websites in Norway providing discussion forums. Four forums related to mental health on these sites were selected; with the themes "general psychiatry", "sexual abuse", "eating disorders" and "anxiety and depression".

All these forums were supervised by health personnel, and in 1999 this was the only way to communicate with health personnel online. No secured solution existed for communicating directly with health professionals. In this study all the participants were anonymous, which in itself raised several methodological challenges. These are discussed later in the dissertation.

The study population comprised people who had chosen to use an online discussion forum for communicating about mental health in Norway. The main aim of the study was to investigate what reasons respondents gave for participating online. The study was exploratory and investigated both who was using these sites and why they preferred this communication channel. In addition, the study focused on the role of participating health personnel and users' attitudes towards them.

2.1.2   Design and measures

No participants in these forums needed to state their own name. It was very likely that this anonymity was central to the way the forums worked, and it was hard to study the forums without taking this into account. A web-based questionnaire was posted on the forum's opening page for a three-week period.

The questionnaire posed follow-up questions based on the responses. Of a total of 80 items, a typical respondent usually answered 50-60 questions. The respondents were told that the questionnaire would take 15-20 minutes to complete.

In total 505 questionnaires were received. Of these 13 were deleted from the material for the following reasons: duplicate responses, incomplete questionnaires with less than 75% of the questions completed and responses not intended to answer the

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questionnaire. This left 492 subjects for analysis. The response rate was hard to calculate as there was no way to measure exactly how many people were in the target group. Comparing the number of unique nicknames appearing in the forums with the number of people claiming to have posted in the forums gives a response rate of 34% - but this is only valid for the posters. Using a similar method with respect to the posting frequency gives a response rate of 10% for people who had posted only once, while 39% of the active posters appear to be represented. A reasonable assumption might be that infrequent users, especially those not posting messages, have a low response rate, and that the response rate for all visitors is in the lower part of the 10-39% range. Since the sample has a bias regarding how active the users are, this also affects interpretation of the results. This is discussed in more detail later in the dissertation.

2.1.3 Analysis

This study had an exploratory aim and the quantitative analysis was mainly descriptive. Percentages and absolute numbers were reported, but no tests of significance were performed. The questionnaire had several open-ended questions, but the answers to these varied from single words to several paragraphs making it difficult to do a thorough qualitative analysis. Quotes from these answers are used only to illustrate and elaborate other results.

2.2 Population study

2.2.1 Aims

This study was part of the eHealth Trends project, a joint project between partners in Norway, Denmark, Germany, Greece, Latvia, Poland and Portugal. The main data source was surveys from 2005 and 2007 from all the countries listed above, and the main results are presented in Article 2. Article 3, while focusing on the Norwegian data only, also included data from a similar national survey conducted in 2000, 2001 and 2003.

2.2.2 Design and measures

The main focus of the study was to collect descriptive data about the use of various Internet related health services – including interactive services like electronic

communication with health workers. Another important focus was the importance of the Internet as a source of health information, demographics of the Internet health user and factors affecting Internet health usage. Since the study spanned several years, this enabled an analysis of the trends in the development over these years.

The questionnaire was written in English. It was based on the experiences from a Norwegian questionnaire used by the Norwegian Centre for Telemedicine. Some of the questions that worked well in the Norwegian survey were reused in the new survey. When consensus had been reached on the questionnaire a dual-focus approach was used in translating it into the languages of the seven participating countries. The dual-focus approach is a development of the back-translation method, and the goal is to reduce cultural bias and achieve conceptual equivalence rather than equivalence in wording and grammar (Erkut et al., 1999).

Professional polling agencies were used to conduct computer-assisted telephone interviews (CATI). Representative samples were drawn from the population. The general design was that sampling should continue until 1000 respondents[4] had answered. Since the response rate varied with age and gender, the 2005 sample was weighted to adjust for this. In 2007 this was achieved by constructing quotas for age and gender based on census data.

2.2.3   Analysis

Both articles 2 and 3 focus on changes in Internet health usage from 2005 to 2007. The articles however use slightly different statistical methods for the estimations. In Article 2 the CIs are derived by Gaussian approximations of the distributions of the sum of strata frequencies or sum of ratios of strata frequencies. Significant change was determined when the CI of the mean difference did not contain 0. In article 3 changes in proportions were tested for significance using chi-square tests. For continuous variables ANOVA was used.

All reported CIs are 95%. The data was analysed using SPSS 15.0 (SPSS for Windows, 2006) and R 2.5.1 (R for Windows, 2006).

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[4] 2000 respondents in Portugal in 2005.

2.3   Intervention Study

2.3.1   Aims

This study was part of the project PasientLink. The project was initiated by the Norwegian Centre for Telemedicine with financial support from the Norwegian Directorate for Health and Social Affairs. The project started in 2001 with an intervention period running from October 2002 to October 2003.

In 2002, the only possibility to communicate with health professionals over the Internet was by participating in anonymous groups. Privacy regulations clearly stated that identified communication about health over the Internet was prohibited by law. There was no way for health professionals to communicate online without violating the privacy legislation in effect.

The project PasientLink was an attempt to build and obtain approval for a security solution allowing identified communication between patients and their family doctors, as well as to design a randomised controlled study for measuring the effects of this communication.

The project's technical track involved designing and coding a secure solution for sending messages between patients and doctors. By using a standard web browser, the patient in the intervention group could log in to PasientLink using a password and a single-use code sent to their mobile phone. The patient was then presented with a web-based, e-mail-like interface that could be used for sending text-based messages to their doctor. The patients were notified by SMS when the doctors had answered their message. From the doctors' side this was included as part of their inbox in their electronic patient record system.

2.3.2   Design and measures

The study was designed as a randomised controlled trial (RCT). Two hundred patients were recruited from Sentrum Legekontor, a general practitioners' office in Tromsø with six doctors. All recruited patients expressed willingness to participate in a research project involving the possibility of communicating with their doctor through the Internet. Access to the Internet was a prerequisite for participating in the study.

The patients were divided into a control group and an intervention group. To make the groups equivalent, and thus comparable, the participants were stratified into three groups before randomising: a) all over 60 years, b) men under 60 years and c) women

under 60 years. All the patients gave permission for counting office visits and telephone calls to the doctors' office up to one year prior to the project start. The control group received only standard care in the study period. The intervention group received access to the PasientLink service in addition to standard care.

The patients were told not to use the service for acute problems. They were also told to expect up to a 3-day response time. Apart from that, there was no restriction on frequency, length of messages, or topics. The main purpose of the design was not primarily to get experience from use, but to create an environment that was as close as possible to what a future service might look like. The goal was to estimate how much such a service would be used and how it would affect other communication channels to the doctors' office (mainly telephone and office visits). For this reason, no reminders were sent to the users in the intervention period encouraging them to use the service.

Data were collected from multiple sources. At the start of the study a survey was conducted in the waiting room of Sentrum Legekontor while patients were recruited to the study simultaneously. Data from this study was used in Article 4 to compare the demographics of the users participating in the study with the users at Sentrum Legekontor.

At the end of the study a questionnaire was sent to all participants addressing issues about both their general experience of the online service and their use of other health services. Response rates to the questionnaire were 93% for the intervention group, and 73% for the control group (in total 83% of the participants). This questionnaire was the main data source in Article 4.

After the intervention period had ended, health personnel at the doctors' office went through the electronic health record for each participating patient and counted all registered office visits, phone consultations and letters. This was done for both the control group and the intervention group for a period one year prior to the intervention and the year of the intervention. This was the main data source for Article 5.

2.3.3 Analysis

In Article 4, differences between the number of telephone/visits to the doctors' office for the control group and the intervention group were evaluated to determine whether electronic communication did replace traditional channels.

Article 5 expanded upon this approach. Here health record data was used going back one year in time, and ANCOVA was used to correct prior differences in the groups. Telephones and visits were also split to examine these channels separately.

In Article 4 and Article 5, SPSS 11.5 (SPSS for Windows, 2002) was used for data analysis.

3 Results

3.1 Results Exploratory Study - Article 1

An average of 78% of the participants comprised women, varying from 65% in the forum "Anxiety and depression" to 92% in the forum "Eating disorders". A majority of the users (65%) had previously been in contact with health care services due to mental health problems.

The main focus of the study was to explore why people were using online forums for discussing mental health. One of the main findings was that a total of 75% of the participants found it easier to discuss sensitive information online than face-to-face. Likewise, asking only people that had posted to the forum, 46% said they had discussed topics online which they felt unable to discuss offline.

The study showed that most users (62%) perceived the online forum as a supplement to their use of conventional health services. Six percent reported reduced use of conventional health care services as a result of using online forums, and the same percentage reported increased use. However, 19% reported a qualitative change in their use of offline health services; that they felt they had gained increased knowledge and understanding of mental problems, health care services and their rights, and of what to expect from the health services.

In general, users appreciated the participation of health professionals in the forums. Sixty-eight percent felt that the professionals should take an active part in the discussion, while 16% felt that the professionals' main role should be to monitor the activity. However, only 3% said that the professionals should not attend the forums.

3.2 Results Population Study - Article 2

The study showed that the majority (52.2%, 95% CI 51.3-53.2) in the seven European countries studied use the Internet for health-related purposes. This was an increase from 42.3% (95% CI 41.3-43.3) in 2005. Significant growth was found in all the seven participating countries, in all age groups and for both men and women. A more in-depth analysis of the Norwegian population is presented in Article 3.

Two interesting demographic details are discussed in the article. First, in 2005 a higher proportion of young women compared to young men were using the Internet for

health purposes. The difference was clearly significant (95% CI 7.6%, 4.5-10.7). This difference increased in 2007 to 11.1% (95% CI 8.3-13.9). Second, for the older age groups men were overrepresented as Internet health users.

The study showed that the Internet was perceived as one of the major health information channels. In 2005, 40.3% (95% CI 39.2-41.4) considered the Internet either an "important" or a "very important" source of health information. In 2007, this percentage had increased to 46.8 (95% CI 45.7-47.9). At the same time the study showed a decline in the reported importance of other traditional mass media like TV, radio and newspapers.

A total of 11.1% (95% CI 10.4-11.8) had interacted with health professionals they had not met in real life, an increase from 8.2% (95% CI 7.6-8.8) in 2005. The participants were also asked whether they had participated in health-related forums or self-help groups. In 2007, 9.9% (95% CI 9.2-10.6) said they had done this, compared to 7.0% (95% CI 6.4-7.6) in 2005. Ordering medicines online increased from 5.5% (95% CI 4.9-6.0) in 2005 to 8.5% (95% CI 7.8-9.1) in 2007. The last question concerned communication with previously known health professionals or family doctors over the Internet. This number was 6.9% (95% CI 6.3-7.4) for 2007 and 3.6% (95% CI 3.2-4.1) in 2005.

All these interactive services were combined in the analysis. An estimated 22.7% (95% CI 21.7-23.6) of the population used the Internet for at least one of these services in 2007, an increase from 15.3% (95% CI 14.5-16.1) in 2005.

3.3   Results Population Study - Article 3

This article was partly based on the same data material as Article 2, but contained only results from Norway. However, as mentioned in the Methods section, while the international article was based on data from 2005 and 2007, additional Norwegian data was available for some of the questions from 2000, 2001, and 2003. This enabled expanded analyses related to these questions, including long-term forecasts.

The percentage of the population that had used the Internet for health purposes increased from 19% in 2000 to 67% in 2007. The article used a simple logistic model to estimate that this might increase to 84% in 2010.

The results from Norway show significant age differences in health related Internet use. In all the studied years there were more people under 45 using the Internet for health purposes than people over 60.

This article also included education as a variable. In 2007, 41.8% (95% CI 34-49[5]) of those with no more than completed primary education, 63.3% (95% CI 59-68[6]) of those with secondary education and 79.6% (95% CI 76-83[7]) of those with tertiary education reported that they had used the Internet for health purposes.

The article reported numbers for health-related activities in a slightly different way than Article 1, as it reported these for the sub-population "Internet health users". The article did not report how many users had been in contact with previously known health professionals, but it did report that 29.1% (95% CI 24.6-33.7) of the Internet health users in 2007 had been in contact with health professionals that they had not met face to face. The corresponding figure was 27.1% (95% CI 22.6-31.6) in 2005. Participation in forums and self-help groups changed from 20.8% (95% CI 16.7-24.7) in 2005 to 23.2% (95% CI 19.0-27.4) in 2007.

The importance of the Internet as a source of health information increased in Norway. It rose from the seventh most important source of information in 2005 to the fifth most important source in 2007. Still, face-to-face interaction, both with health professionals and with friends and family, was rated as the most important source.

3.4   Results Intervention Study - Article 4

The article reports that the 100-person intervention group sent from 0-18 messages each. In total 48 of the patients used the service and they sent an average of 3.3 messages each. The participating doctors sent 9-65 messages each. These were all figures from the system logs. These logs also showed that the usage patterns differed between patients and doctors. While the doctors primarily used the service when they started in the morning, around lunch and right before closing time, the patients' use was more uniform. Apart from a small peak right before lunch, they used the service all day and evening – and even at night (Figure 1).

[5-7] One decimal was inadvertently left out in the article when these confidence intervals were reported. I have chosen to report the numbers with as many decimals as in the printed article.

Figure 1
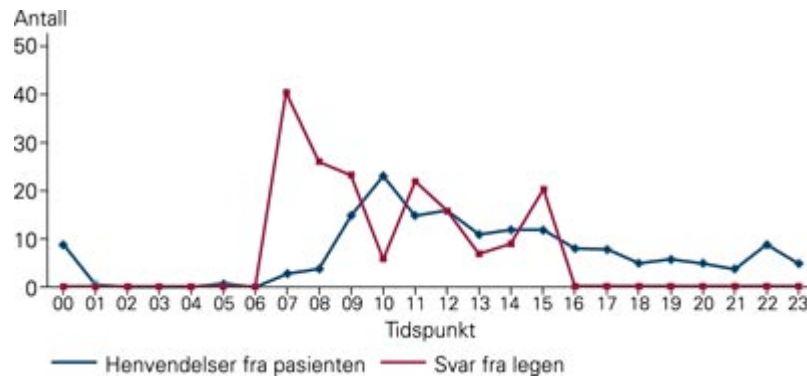
Source: Article 4. Questions from the patient in blue. Answers are in red.
The y-axis is the number of messages, while the x-axis is the time of day.

Questionnaires were used to let patients provide information about the purpose of use. The most common use was to get answers about health and illness (41%), followed by routine renewal of prescriptions and sick note renewals (22%). Purely administrative tasks like scheduling an appointment or to get the results from tests accounted for 11% and 4%, respectively.

One of the main questions prior to the study was whether some patients would overuse the service, and as a consequence become burdensome to the doctor's practice. This question was approached in several different ways. According to the questionnaire responses, patients felt their message replaced a consultation in 32% of the cases, a phone call to the doctor in 35% of the cases and an inquiry to the doctors' secretary in 17% of the cases. In 4% of the cases it replaced other forms of contact with doctor or hospital. In 12% of the cases, it did not replace any contact with the health service.

In addition, the patients in both the intervention group and in the control group were asked how many times they had contacted the doctor's office. The intervention group had an average of 3.19 (95% CI 2.44-3.94) consultations (visits and telephone calls) with the doctor in the period, compared to 4.45 (95% CI 3.60-5.29) consultations for the control.

The users answered a four-point scale from "completely unimportant" to "very important" for determining how important various factors were for their use of PasientLink. The answers "important" and "very important" were combined. Practical reasons like "I can use PasientLink outside normal office hours" and "It saves time" were

rated highly by almost all users (95-98%). The statement "I get more time to explain what I want" was rated high by 66%, while "It is better to get the doctor's answer in writing than verbally" by 44% and "It is easier to express oneself in writing than verbally" by 34% of the users.

Thirty respondents (41%) from the intervention group had chosen not to use PasientLink in the one-year trial period. The main reasons for not using the service were that they did not have any need for primary health services in the period (43%) and that they did not think PasientLink was suitable for the specific contact – mainly because of a perceived need for physical tests or examinations (30%). Eight respondents (27%) reported technical problems in using the service. Of the 30 respondents not using the service, 26 (87%) said that they expected to use such communication services on a later occasion.

Based on the interviews, all doctors appeared to emphasise that they regarded this as an extra service to their patients. It was a practical tool, but not suited for more complex questions where dialogue and examination were needed. In general they thought the patients had been able to decide when it was appropriate to use the service, but there had been instances where patients had asked questions that were too complex to answer electronically. An appointment was then scheduled for them.

3.5 Results Intervention Study - Article 5

This article has the same study group as Article 4, with an intervention group and a control group. However, the data material was, as described in the Methods section, based on data from patient health records. Data was also collected prospectively for the one year period prior to the start of the intervention.

Of 200 patients in total, 199 patients completed the study period. Forty-six percent of those who were given access to the system (n=99) used it to send messages in the study period. In total 147 messages were sent, ranging from 0 to 17 messages per patient per year.

The year before the project started, the intervention group had a total of 447 consultations and 201 telephone calls. The control group had 425 consultations and 242 telephone calls. Since recruitment took place in the doctors' office, some reduction in office visits the following year was expected. The main point of interest was however if this reduction was relatively larger for the intervention group. A significant reduction in

the number of office visits (p=0.034) was found, but the reduction in the number of telephone calls was not statistically significant (p=0.258).

A categorisation of the messages was also undertaken, and subjected to an analysis. The results were to some degree comparable to the self-reported results in Article 4, though the categories were slightly different. Sixty-eight messages (46%) were either health-related questions or requests for test results. Twenty-nine messages (20%) were requests for prescription refill, while 11 were sick note renewals (7%). Sixteen messages (11%) were to schedule an appointment. Three messages (2%) were requests for a referral to a secondary care centre. The remaining messages (14%) either contained multiple requests or were in a form that the GP was unable to answer.

4 Discussion

4.1   Methodological Issues

This dissertation builds upon an exploratory study, a population study and an intervention study, and thus different methodological approaches corresponding to the different studies. The choice of methodology is decided on the basis of the research questions rather than by a belief that any of the methods are superior. However all methods have advantages and disadvantages, and these will be discussed in this chapter.

4.1.1   Exploratory study

Before examining the methods used in Article 1, it is also important to remember that the study was conducted in 1999. The study group comprised people using Norwegian forums related to mental health. In 1999 the forums were not really a selected sample of such activities, but, to our knowledge, very close to the complete activity in this area at that time. However, the participants were anonymous, making it difficult – if not impossible – to be able to randomly select a sample of users. To approach this as a randomised population survey was of course not possible, since the group studied was very small compared to the total population.

Other methods might have been considered – mainly qualitative approaches. There were however drawbacks here as well. The greatest problem, in fact, was a lack of information about how important anonymity was to the users. If this was a major issue for the users, it was hard to envision an appropriate and practical way of recruiting participants. One way of approaching new fields is not to draw a representative sample, but instead to do sampling based on theoretical saturation (Glacer & Strauss, 1967). This approach implies that sampling should continue until nothing new is discovered. However, even this would fail if people who value anonymity highly simply avoided being recruited. An approach with an anonymous questionnaire seems less likely to skew the sample in such a direction.

The main challenge in this study was representativity. The sample might very well be said to be self-recruiting. There are many reasons to claim that the sample most likely was more representative of the heavy users than of the less frequent users. In the article the frequency of actual postings for each nickname in the forums was compared with the frequency claimed in the survey. This was used for estimating the response rate.

With this method, the response rate appears to be 39% for regular posters, going down to 10% for those who had written just one post. However, since one respondent might have been using multiple nicknames, this estimate might be too conservative.

The results should be interpreted as more representative of the active user than as attitudes for average users within the sampling frame. The article was therefore mostly important in terms of generating hypotheses for later studies.

4.1.2   Population study

The survey was conducted by TNSGallup, using Computer Assisted Telephone Interviews (CATI). However, the actual questionnaire and the selection procedure were specified by the project team at the Norwegian Centre for Telemedicine.

Two separate methodological issues are worth mentioning. The first is related to representativity. Randomly selecting respondents based on telephone numbers is in general thought to be a good method for obtaining a representative sample. The main challenge with telephone surveys is the number of non-responses, because people did not answer the telephone or did not want to participate in the survey.

In telephone interviews a distinction can be made between contact rate and cooperation rate (Holbrook, 2008). When excluding non-contacts like incorrect numbers, disconnected numbers, and answering machines, 36% answered the survey in 2007. Holbrook (2008) reports a significant fall in response rate for telephone interviews in recent years, and found a response rate drop of 16% in an analysis of 113 surveys in the period from 1996 to 2003. The averages reported by Holbrook are also fairly close to what was experienced in the study. Even if the response rate was lower than what was ideal, it was probably unrealistic to get much higher rates using telephones interviews only.

To make sure that the sample had the same demographics as the population, quotas were used in 2007. Quotas were used for age (six groups) and gender. The telephone interview would then be ended if the respondent happened to be in a target group that had been filled. This method was not used in the 2005 survey. To adjust for possible demographic differences in the sample, the 2005 data was weighted on the basis of the same criteria. This was done mainly to avoid the possibility that differences in demographics could be the cause of effects found in the material. The focus of the study was to illuminate trends in the populations' use of Internet for health purposes. Therefore

it can be argued that the pace and direction of the change is even more important than absolute numbers. That said, there is nothing to indicate that the absolute numbers for the last survey are skewed.

The other methodological issue that should be mentioned is that this is a multi-country study. As described in the Methods section, a dual-focus approach was used for translating the questionnaire. Multiple languages are however always sub-optimal for getting comparable results. More important is the fact that the telephone interviews had to be conducted by different local agencies. In 2005 each participating country was responsible for choosing the polling agency. Concrete problems with individual polling agencies, like one agency failing to the report response rate, led to selection of one coordinating agency in 2007. This selection process included only agencies that had partners in all the countries. Consequently TNSGallup were chosen, with their office in Norway being the main contact.

Using one major polling agency solved several of the problems experienced in 2005. There were still some local differences that might have interfered with the sampling. One issue was that not all of the countries had mobile phone registers that made it possible to include these in drawing a representative sample. Mobile numbers were only included in Norway, Denmark and Latvia.

Another issue was related to the different educational systems. It was decided to use ISCED codes to enable comparison of the systems. ISCED – International Classification of Education – was created by UNESCO, and the latest version is from 1997 (ISCED97). The standard is often used when comparing educational systems, but in retrospect it turned out that several are having difficulties in the practical application of the ISCED to the actual educational qualifications (Schneider, 2008). Comparing the 2005 and 2007 data; it became apparent that some of the countries showed changes in the composition of education levels that could not be explained either by sample bias or by actual changes in the demographics. The only reasonable explanation was coding errors, and some of these could not be corrected by recoding. It was therefore decided to drop education as an explanatory variable. This is a drawback, since studies in the countries where the ISCED codes were valid, show that education most likely is a significant variable in explaining Internet health usage.

Income is one of the factors that might be a relevant explanatory variable regarding Internet usage. This was included in the original Norwegian surveys, but was

dropped since some of the partners did not think it was appropriate to ask about this in telephone interviews in their countries.

4.1.3   Intervention study

The main part of this study can be described as a randomised controlled trial. In Article 5 the design can additionally be described as a pretest-posttest control group design (Kazdin, 1998) where the dependent variable is the number of consultations.

The PasientLink had the basic design principles of a randomised controlled trial: randomisation and statistical endpoint comparison between intervention and control groups (Bruce, Pope, & Stanistreet, 2008, p 315-317). Another desirable component of RCTs is blinding. In medical trials this is often accomplished by using a placebo. However, it is usually impossible to blind the subjects when studying social phenomena like these. Blinding might instead be used on other levels in the research, like blinding coders and researchers. This procedure was not included in the project, but would not have been impossible to accomplish.

Another ideal that is often mentioned with RCTs is intention-to-treat. The basic idea is to show "effect of treatment intentions", rather than "effect of treatment". According to this principle, patients withdrawing from treatment are still included in the material. Considerations regarding whom to include or exclude might not be straightforward however. For instance, in the initial stages of the PasientLink-study one of the patients in the intervention group discovered that he did not have access to the Internet. Since this was an inclusion criterion the patient was deleted from the data set, and the analysis was performed with 99 participants. According to the principle of intention-to-treat, it could however be argued that he should still be included in the analysis.

Viewed in light of the methodological problems regarding representativity and generalisability discussed in connection with Article 1, 2 and 3, the design here immediately seems more robust. However, this RCT design also has its limitations. One of the major limitations is the number of participants, and it is usually considerably more expensive to scale studies designed this way. In the study there were 200 participants in total, divided between a control group and an intervention group. Regarding the reduction in the use of telephone calls, the null hypothesis could not be rejected. There is, of course,

always a risk of a type II error; i.e., that the decrease in telephone consultations was insignificant due to lack of power caused by the sample size being too small.

In addition, the sampling frame was limited. The participants were all recruited at Sentrum Legekontor in Tromsø. They all expressed interest in participating in electronic communication with their doctor, and the results are therefore not representative for the general population. Similarly, the reservation should be made that the patients at Sentrum Legekontor may not be representative of the general Norwegian or European population. Also, since only users in the waiting area were recruited, patients having problems in finding time to book an appointment might be underrepresented – and to some degree this group might be an especially important target group for this kind of communication service.

In generalising the results, it should be kept in mind that the estimated effects do not apply to the general population, but only to a group associated with similar restrictions to those mentioned above.

4.2   Substantive Issues

4.2.1   Potentials in text-based electronic communication

The starting point for the intervention study PasientLink was the results from the exploratory study showing that users wanted involvement from health professionals and that a great majority of the users found it easier to discuss personal problems online than face-to-face.

The finding that the users wanted professionals to take an active part in online health discussion forums was rather unexpected, especially since a great deal of the US literature had focused on the growing online forums as a self-help phenomenon (Madara, 1997; Salem, Bogat, & Reid, 1997). Self-help groups have been known to be sceptical about professional involvement (Chesler, 1990).

One of the main findings from the exploratory study was that the participants felt the online medium had some qualitative advantages, like making it easier to discuss sensitive issues. As mentioned earlier, it is not clear if this finding can be generalised to the total population. Generalisability is however not a necessity as long as some users – for instance patients with social phobia – are deliberately choosing this channel because of the positive effect it yields on a personal level.

From the study it was not apparent why the users felt the medium opened up for disclosure. One theory could be that this was caused by the anonymity created online. In general, the risk of experiencing social sanctions is minimised when the respondents cannot link the online person with the real-life person. Along the same lines, it has been argued that by hiding traditional imperative statuses like gender and age, the anonymous online conversation opens up new opportunities for social interaction, including disclosure (e.g., Turkle, 1995). A different theory is that it is the textual medium that is creating a room, or zone, for reflection (Suler, 2000). The central point here is that asynchronous media such as textual messages give the user the time needed to formulate questions and for strategic self-representation.

In the intervention study PasientLink, the doctor had met with the patient prior to the online communication and already knew the patient. While the communication in the explorative study was asynchronous and anonymous, the communication in the intervention study was non-anonymous and asynchronous. It was therefore an open question what effects to expect regarding perceived openness, since the advantages of increased disclosure could be more closely related to the asynchronity of the medium than to the anonymity.

In the intervention study these issues were addressed by asking people how important they felt different aspects of the service were. It is not clear how the results should be interpreted. Practical reasons were rated highly by the participants almost unanimously. In hindsight it is easy to explain why everybody agreed with positive statements like "it saves travelling time" and "I can use it outside regular office hours".

As reported in the Results section, 44% agreed with the statement "It is better to get the doctor's answer in writing than verbally", and 34% agreed with the statement: "It is easier to express oneself in writing than verbally". These results are more interesting by themselves than in direct comparison to the more obvious alternatives above. These relatively high numbers might indicate that the medium's advantages are not solely connected to whether the patients are anonymous.

To some degree these results are supported by the high percentage of messages that concerned more complex issues. A total of 41% of the questions concerned health and illness, and another 22% concerned prescription refills and sick note renewals. This is considerably higher than what was expected prior to the study. Other studies have also indicated that electronic communication would primarily be used for administrative issues and routine questions (e.g., Katz et al., 2003).

The results from our Norwegian study might have been affected by how the system was designed. Privacy regulation requiring complex two-phase authentication and the three-day response time made it more practical to ask quick questions by telephone. However, the service did actually replace consultations, and the responses from the patients indicated that several of them appreciated the qualitative aspects of asynchronous textual communication. At least some of the patients seemed to appreciate being given the opportunity and time to formulate their questions in writing. This implies, at least to some degree, that reasons for use go beyond the purely practical aspect of having an extra channel available.

4.2.2   Characteristics of the online patient

A decade ago, men were clearly overrepresented as users of the Internet (Ono & Zavodny, 2003). Only traces of this can be seen in the European studies from 2005 and 2007 among the older age groups. In the younger age groups gender differences for general Internet usage have vanished. An underlying trend that is fairly uniform for all the countries was that age was an important factor in explaining Internet usage. The Norwegian surveys did, however, show that the growth of Internet use was relatively larger among the oldest age groups, and it should be expected that age-related differences will be reduced in the future.

If one narrows the focus to the health users only, a different pattern appears. About 60% of all consultations in the Norwegian primary health care service are from women (Hunskår, 2006, p. 31). The characteristics of the Internet health consumer should be expected to be a combination of what characterises both the Internet user and the health consumer.

For the younger age groups there were significantly more women than men using Internet health services in 2005. This tendency strengthened in 2007. For the oldest age groups the picture was different. In this group, the growth was strongest among men. However, it appeared that much of this growth could be explained by the underlying growth of Internet use among older men.

The population study showed significant growth in all the interactive Internet health services from 2005 to 2007 for the European countries. As reported in Article 3, this growth in Norway was however only significant for ordering of medicines online.

As argued in Article 2, it is reasonable to assume that using interactive services is something primarily done by more experienced Internet users. It should then be expected that the growth in the use of the interactive services will follow that of the growth in Internet health, but with some delay. In addition to this, growth corresponding to the services that are launched on a national level should be expected. In Article 2 there are several examples of this. In Germany, for instance, there has been significant growth in the ordering of medicine following the introduction of new legislation in 2004. Another example is Denmark, where there has been a growth in direct online communication with a known doctor coinciding with a national launch of services providing this opportunity. Reporting only mean values will in many cases hide such local events.

4.2.3 Supplement or replacement

The intervention study PasientLink was concerned with whether this replaces existing service channels. Using slightly different data material, both articles registered such a change. Article 4 treated both visits and telephone calls as one variable, and found that they were significantly reduced. Article 5 treated consultations and telephone calls separately. In the article it was reported a significant reduction in the number of consultations, but the reduction in telephone calls was not significant.

Even with a significant reduction, it might still be hard to conclude that it really is time-efficient since it is not known if the reduction is large enough to compensate for the extra work. Both studies do however indicate that the reduction approximately corresponds to the number of electronic messages. It is also reasonable to assume that electronic messages do not take more time to answer than their alternative.

4.2.4 Future consequences for the patients and the health care system

The use of Internet for health purposes is expected to rise in the coming years. In parallel with this development it is expected that the use of more interactive services, like direct online communication, will increase.

How fast the use of electronic communication will increase is dependent upon several external factors. A considerable proportion of the patients appear to be interested in replacing parts of their consultations and telephone calls with a text-based electronic service. The results reported in Article 4 prompt speculation that given the number of patients who are currently interested in electronic communication, it would replace

around 10% of the total use of services. This number could increase with the growth in the Internet and Internet health use, and further increase if the healthcare system sees cost-benefit advantages related to such services, and decides to encourage patients to use them. There is however a clear upper limit to this number, as the majority of consultations requires the patient to be physically present in the doctors' office for examination. In the intervention study there was a reduction in telephone calls and consultations of 28%, and it is reasonable to believe that the potential upper limit of electronic communication in the primary health service is in the area of 25-30% of the total services.

In Norway doctors are compensated for electronic consultations[8]. To some degree this system does compensate for the time used answering the messages, but it is most likely too small to be a sufficient incentive for using electronic communication. If electronic communication proves to be more cost effective it might lead to doctors being able to add more patients to their lists, thus providing additional compensation. In some areas of Norway, for instance in the Oslo region, doctors however have problems filling their lists, and this would therefore not work as an economic incentive for communicating electronically with patients.

Today there are no longer any technical limitations hindering the introduction of electronic communication services in the healthcare sector. When patients become aware of this, there will also be an increased demand for this service. Patients might use access to electronic communication as a criterion when choosing a GP. This might work as a better incentive for doctors than increased reimbursement rates.

4.3   Ethical Issues

This dissertation focuses on how electronic communication can be used as part of a health service. As stated in the Research Questions and Objectives section, the health effects of electronic communication are outside the scope of this study. There are however several ethical issues that should be considered.

A general issue regarding Internet health services is that they create an even stronger focus on health and medical questions. The process where more and more areas of ordinary life are regarded as a health issue and within the domain of the health professionals is often termed medicalisation and healthism (Korp, 2006). One of the

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[8] A reimbursement rate called 1bd can be used for communication like letters and faxes, and might also be used for electronic communication.

major risks with this is that the end result is not a more enlightened and informed audience, but greater anxiety. An article based on the first results for the eHealth Trends study (Andreassen et al., 2007) showed however that it was twice as common to feel reassured as to experience anxiety after using the Internet for health purposes. Nevertheless, this does not rule out the possibility of an increased focus on health in general, and that the overall effect is negative.

A considerable proportion of the population does not have access to the Internet, and is therefore not able to use such services. It might be questionable to spend resources on services that not everybody has access to. A typical Internet user is young, well educated and has a high income. This is almost the opposite of what characterises a person with high demands for health services. It could be argued that by promoting online Internet health services, one is simply promoting better health services to the groups that are already well covered.

However, as the population study shows, this argument is losing some of its validity. There is an especially strong growth in Internet usage among elderly people, and with the reduced costs of Internet access it is likely that the importance of socioeconomic status and education will diminish. Today, there is probably more reason to be worried that small, marginalised groups are getting left behind than that there are major discrepancies among large demographic groups.

The fact that the Internet is not a medium to which everybody has access is still a problem that needs to be taken seriously. If a doctors' practice is considering reducing services like telephone hours in favour of Internet access, it should be kept in mind that some groups with access to the telephone still do not have Internet access. In Article 4 it is argued that the opposite may also apply. Internet communication might, since it is asynchronous, be viewed by other groups as more accessible and practical than limited telephone hours.

Apart from the macro perspective, there are also ethical considerations regarding individual online consultation. Article 1 described how much easier some users found it to talk about certain issues online. Several authors have pointed out that strategic self presentation is easier online (e.g., Turkle, 1995; Walther, 2007). However, when the patient is only presenting part of the total picture to the doctor, there is always a chance that the patient will deliberately or unconsciously leave out aspects vital to correct diagnosis and treatment. This is obvious a considerably greater challenge when the

patients are anonymous, and there are different ethical guidelines depending upon whether there are previous relations between the patients and the health care workers.

Umefjord (2006, p 48) refers to several examples of ethical guidelines for e-mail communications where there are pre-existing relationships. There are also other lists of ethical guidelines available (e.g., Bovi, 2003; Eggert & Protti, 2006, Appendix). A majority of these are however US-based and related to using traditional e-mail. They also mostly address issues specific to using unencrypted e-mail, i.e., informing the patient that this is an unencrypted channel, making sure you are communicating with the correct person, integrating the communication with a paper-based journal. The only major issues relevant to secured integrated communication solutions can be summed up as informing patients that this should not be used for urgent matters, estimating response time and telling doctors to avoid language that often fails in e-mail communication (for instance, sarcasm).

Communicating with unidentified patients where there is no previous relationship is more complex from an ethical point of view. Umefjord (2006, p 49) sums up his own work and a systematic review by Eysenbach (2000). In general the doctor should avoid definitive diagnostic statements and always keep in mind that there often is more thorough information available to the patients' family doctor. It is also apparent that this kind of communication requires the doctor to have a better understanding of the Internet medium and its limitations.

5 Conclusion

This dissertation has investigated some of the consequences electronic health communication will have for patients, health professionals and society at large. One initial question was what advantages and disadvantages patients saw in using online communication channels. Both anonymous and non-anonymous channels were studied, and patients' responses indicated that they saw this as a channel with its own distinct advantages – not merely as a time-saving tool.

Internet use, Internet health use and the use of more interactive health related Internet services are still growing in most of the European countries studied. One of the major research questions in this dissertation was whether these new services will replace traditional health channels, or if they just would be an addition. This was tested using an actual implementation. The study showed that at least for consultations with family doctors, electronic communication might replace some of the communication.

There are still several unanswered research questions. In particular, there seems to be a limited understanding of the role that anonymity and asynchronicity play in online interaction. This is essential for building effective electronic health services. This study also tested only one technical implementation. A different implementation – for instance one involving easier authentication – might have resulted in different use patterns. Here are several potential research projects.

The main question, however, still remains: Does electronic health communication in general have a positive health effect? It is my opinion that this question might be impossible to answer on a general level. The effect will depend upon several external factors, including how the systems are built and how use is encouraged. The goal should be to identify factors and processes that could in turn help us to create better and more efficient health services.

6 References

Adler, K. G. (2006). Web portals in primary care: an evaluation of patient readiness and willingness to pay for online services. *Journal of Medical Internet Research*, 8(4), e26.

American Medical Association. (2008, October 15). *Guidelines for physician-patient electronic communications*. Retrieved December 5, 2008, from http://www.ama-assn.org/ama/pub/category/2386.html

Andreassen, H. K., Bujnowska-Fedak, M. M., Chronaki, C. E., Dumiti, R. C., Pudule, I., Santana, S., Voss, H., & Wynn, R. (2007). European citizens' use of e-health services: a study of seven countries [Electronic version]. *BMC Public Health*. Retrieved December 5, 2008, from http://www.biomedcentral/1471-2458/7/53

Andreassen, H. K., Sandaunet, A. G., Gammon, D., & Hjortdahl, P. (2002). Nordmenns bruk av helsetilbud på Internett. *Tidsskrift for Den norske legeforening*, 122(17), 1640-1644.

Baker, L., Rideout, J., Gertler, P., & Raube, K. (2005). Effect of an Internet-based system for doctor-patient communication on health care spending. *Journal of the American Medical Informatics Association*, 12, 530-536.

Baker, L., Wagner, T. H., Singer S., & Bundorf M. K. (2003). Use of the Internet and e-mail for health care information: results from a national survey. *JAMA*, 289, 2400-2406. Erratum in: *JAMA*, 290, 334.

Ball, M. J., Smith C., & Bakalar, R. S. (2007). Personal health records: empowering consumers. *Journal of Healthcare Information Management*, 21, 76-86.

Beckjord, E. B., Finney Rutten, L. J., Squiers, L., Arora, N. K., Volckmann, L., Moser, R. P., & Hesse, B. W. (2007). Use of the internet to communicate with health care providers in the United States: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *Journal of Medical Internet Research*, 9(3), e20.

Bovi, A. M. (2003). Council on Ethical and Judicial Affairs of the American Medical Association: ethical guidelines for use of electronic mail between patients and physicians. *The American Journal of Bioethics*, 3(3), W-IF2.

Bruce, N., Pope, D., & Stanistreet, D. (2008). *Quantitative Methods for Health Research*. Chichester, England: John Wiley & Sons Ltd.

Chesler, M. A. (1990). The "dangers" of self-help groups: understanding and challenging professionals' views. In J. P. Powell (Ed.), *Working with self-help*. Maryland: NASW Press.

Eggert, C., & Protti, D. (2006). Clinical electronic communications: a new paradigm that is here to stay? *Healthcare Quarterly*, 9(4), 88-96.

Erkut, S., Alarcón, O., Coll, C., Tropp, L. R., & Garcia, H. A. V. (1999). The dual focus approach to creating bilingual measures. *Journal of Cross-Cultural Psychology*, 30(2), 206-218.

Eysenbach, G. (2000). Towards ethical guidelines for dealing with unsolicited patient emails and giving teleadvice in the absence of a pre-existing patient-physician relationship – systematic review and expert survey. *Journal of Medical Internet Research*, 2(1), e1.

Eysenbach, G. (2004). Tackling publication bias and selective reporting in health informatics research: register your eHealth trials in the International eHealth Studies Registry. *Journal of Medical Internet Research*, 6(3), e35.

Eysenbach, G., & Köhler, C. (2003). What is the prevalence of health-related searches on the World Wide Web? Qualitative and quantitative analysis of search engine queries on the internet. *AMIA Annual Symposium proceedings*, 225-9.

Glacer, B., & Strauss, A. L. (1967). *Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press.

Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., & Viswanath, K. (2005). Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of Internal Medicine*, 165(22), 2618-2624.

Holbrook, A. L., Krosnick, J. A., & Pfent, A. (2008). The causes and consequences of response rates in surveys by the news media and government. In J. M. Lepkowski, C. Tucker, J. M. Brick, E. de Leeuw, L. Japec, P. J. Lavrakas, M. W. Link & R. L.

Sangster (Eds.), *Advances in Telephone Survey Methodology*. New York: John Wiley & Sons, Inc.

Houston, T. K., Sands, D. Z., Jenckes, M. W., & Ford, D. E. (2004). Experiences of patients who were early adopters of electronic communication with their physicians: satisfaction, benefits and concerns. *The American Journal of Managed Care*, 10(9), 601-608.

Hunskår, S (Ed.). (2006). *Allmennmedisin*. Oslo: Gyldendal Norsk Forlag AS.

Høie, I. M. (2002). - Vi mailes, doktor! *Tidsskrift for Den norske legeforening*, 122(17), 1724.

Katz, S. J., Moyer, C. A., Cox, D. T., & Stern, D. T. (2003). Effect of a triage-based e-mail system on clinic resource use and patient and physician satisfaction in primary care. *Journal of General Internal Medicine*, 18(9), 736-744.

Kazdin, A. E. (1998). *Research Design in Clinical Psychology (3rd ed.)*. Needham Heights, MA: Allyn and Bacon.

Kim, M. I., & Johnson, K. B. (2002). Personal health records: evaluation of functionality and utility. *Journal of the American Medical Informatics Association*, 9, 171-180.

Korp, P. (2006). Health on the Internet: implications for health promotion. *Health Education Research*, 21(1), 78-86.

Madara, E. J. (1997). The mutual self-help online revolution. *Social Policy*, 27, 20-26.

McKenna, K. Y. A., & Bargh, J. A. (1999). Causes and consequences of social interaction on the Internet: a conceptual framework. *Media Psychology*, 1, 249-269.

Ministry of Health and Care Services [Helse- og omsorgsdepartementet]. (2008). *Samspill 2.0 – Nasjonal strategi for elektronisk samhandling i helse- og omsorgssektoren 2008-2013*. Oslo.

Ministry of Health and Social Affairs [Sosial- og helsedepartementet]. (2001). Si@ - *Elektronisk samhandling i helse- og sosialsektoren. Statlig tiltaksplan 2001-2003*. Oslo.

Ministry of Health and Social Affairs [Sosial- og helsedepartementet]. *S@mspill 2007 - Elektronisk samarbeid i helse- og sosialsektoren - Statlig strategi 2004-2007*. Oslo.

Ono H., & Zavodny, M. (2003). Gender and the Internet. *Social Science Quarterly*, 84(1), 111-121.

R for Windows. (2006). Release 2.3.1 [Computer software]. *R project*. http://www.r-project.org/

Salem, D.A., Bogat, G. A., & Reid, C. (1997). Mutual help goes on-line. *Journal of Community Psychology*. 25(2), 189-207.

Schneider, S. L. (Ed.). (2008). *The International Standard Classification of Education*. Mannheim: MZES.

Simons, W. W., Mandl, K. D., & Kohane, I. S. (2005). The PING personally controlled electronic medical record system: technical architecture. *The Journal of the American Medical Informatics Association*, 12(1), 47-54.

Sittig, D. F. (2002). Personal health records on the internet: a snapshot of the pioneers at the end of the 20th Century. *International Journal of Medical Informatics*, 65(1), 1-6.

Sittig, D. F. (2003). Results of a content analysis of electronic messages (email) sent between patients and their physicians. *BMC Medical Informatics and Decision Making*, 3(1), 11.

Sittig, D. F., King, S., Hazlehurst, B. L. (2001). A survey of patient-provider e-mail communication: what do patients think? *International Journal of Medical Informatics*, 61(1), 71-80.

SPSS for Windows. (2002). Release 11.5.1 [Computer software]. *SPSS inc*. http://www.spss.com

SPSS for Windows. (2006). Release 15.0.0 [Computer software]. *SPSS inc*. http://www.spss.com

Suler, J. R. (2000). Psychotherapy in cyberspace: a 5-dimensional model of online and computer-mediated psychotherapy. *CyberPsychology & Behavior*, 3(2), 151-159.

Turkle, S. (1995). *Life on the Screen: Identity in the Age of the Internet*. New York: Simon & Schuster, Inc.

Umefjord, G. (2006). *Internet Consultations in Medicine: Studies of a text based Ask the doctor service*. Umeå: Umeå University Medical Dissertations.

References

Walther, J. B. (2007). Selective self-presentation in computer-mediated communication: Hyperpersonal dimensions of technology, language, and cognition. *Computers in Human Behavior*, 23, 2538-2557.

Ybarra, M. L., & Suman, M. (2006). Help seeking behavior and the Internet: a national survey. *International Journal of Medical Informatics*, 75(1), 29-41.

Articles 1 – 5

Appendix