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INTERNET CONSULTATION IN MEDICINE

Studies of a text-based *Ask the doctor* service

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*To Maja, Linnéa, Anton
and the mystery of life*

SAMMANFATTNING [in Swedish]

Det övergripande syftet med denna doktorsavhandling har varit att belysa det nya fenomenet textbaserad medicinsk konsultation via Internet. Vi har studerat användningen av en *Fråga doktorn*-tjänst på nätet, frågat användarna hur de upplevt tjänsten samt tagit del av hur doktorerna som besvarat de medicinska förfrågningarna uppfattat det nya uppdraget.

Skriftlig kommunikation har fått en ökad betydelse både i allmänhet (t ex email, SMS, chat) och mellan vårdgivare och patient. Det blir allt vanligare att individer söker efter medicinsk information på Internet innan de vänder sig till sjukvården. Det finns också ett ökande intresse bland allmänheten av att få ta del av Internetbaserade sjukvårdstjänster inklusive läkarkonsultationer, både med läkare man tidigare haft kontakt med och med läkare som man inte har träffat. Vi har studerat den senare typen av läkarkonsultationer och då utgått från landstingsfinansierade Infomedicas (numera Sjukvårdsrådgivningen.se) *Fråga doktorn*-tjänst. Inom denna avgiftsfria tjänst har kommunikationen via nätet varit enbart textbaserad och den individ som nyttjat tjänsten har kunnat vara anonym.

Vi följde de första fyra årens användning av tjänsten (totalt 38 217 konsultationer) och fann att tre fjärdedelar av de som nyttjade tjänsten var kvinnor, vanligast i åldern 21 till 60 år. Tjänsten nyttjades under veckans alla dagar såväl dag som natt. Individer bosatta i tätbefolkade orter nyttjade tjänsten mest per capita.

De medicinska frågeställningar som användarna formulerade var mycket varierande. De flesta frågade för egen del. Nästan hälften av frågeställningarna var nya, dvs. hade inte tidigare blivit bedömda inom vården. Endast ett fåtal individer nyttjade tjänsten vid upprepade tillfällen. Tjänsten användes främst för en första bedömning av ett medicinskt problem, för att få ytterligare information om en medicinsk åkomma under pågående behandling inom vården, och för second opinion (andrahandsbedömning). Flertalet var nöjda, och vissa uttryckte att tjänsten fungerade väl som ett komplement till befintlig sjukvård. Nästan hälften av de som använt tjänsten och deltog i enkäten angav att de fått tillräcklig information och inte behövde gå vidare med sin förfrågan. De vanligaste skälen till att vända sig till en doktor på nätet var att det var enkelt och bekvämt, att man ville kunna vara anonym, att doktorer i vården var stressade, att det var svårt att få den egen tiden att räcka till för att söka vård, eller att man upplevde väntetiderna inom vården alltför långa. Ett flertal deltagare i enkäten angav att de var besvikna efter läkarbesök på grund av upplevda kommunikationsproblem och därför valde att vända sig till en doktor på nätet.

De familjeläkare som besvarade frågorna inom *Fråga doktorn*-tjänsten uppfattade sitt nya uppdrag som stimulerande, utmanande och lärorikt, trots att de inte kunde se frågeställarna öga mot öga eller göra en kroppsundersökning. Läkarna uppskattade möjligheten att kunna reflektera över förfrågan innan de svarade.

Internet innebär inte bara att hälsoinformation kan göras tillgänglig utan också att läkarkonsultation – för närvarande textbaserad – kan ske via nätet. Fysiska möten kommer även fortsättningsvis att utgöra fundamentet inom sjukvården, men Internetbaserad konsultation kan utgöra ett komplement och i vissa fall ersätta fysiska besök. För att möta efterfrågan på Internet-baserade hälsotjänster inklusive konsultationer föreslås att läkare och övrig berörd vårdpersonal samt studerande erbjuds utbildning inom området och att etiska riktlinjer upprättas.

ABSTRACT

The overall aim of this thesis was to cast light on the new phenomenon of Internet-based medical consultation. This was approached by studies of the use of an *Ask the doctor* service, by a web survey to the users who sent enquiries to the service, and by a questionnaire to the answering physicians of their respective experience of the service.

Written communication is becoming increasingly important, not only for communication between individuals outwith health care (e.g. by email, SMS and instant messaging), but also between doctors and patients. There is an ongoing shift in the way individuals look for medical information with an increasing number going first to the Internet before talking with their physicians. Also, there is an increasing interest from patients in accessing Internet-based services, including text-based consultations with doctors. These consultations can be part of the regular communication between a patient and his/her doctor or be carried out without any previous relationship. Our studies of the latter consultation type emanate from the free of charge *Ask the doctor* service at a Swedish public health web portal, Infomedica, financed by health authorities. At the *Ask the doctor* service, the communication has been merely text-based and the individual using the consultation service (here called the enquirer) might have been anonymous.

We followed the development of the first four years use of the service (38 217 enquiries), finding that the typical enquirer was a woman aged 21-60 years. Three quarters of the enquirers were women, thus exceeding the gender difference seen in regular health care. The service was used all times of the day and night, seven days a week, and it was most used in densely populated areas as defined from postal codes.

The enquiries submitted to the service included a broad variety of medical issues. Most enquirers asked on their own behalf. Almost half of the enquiries concerned a matter not previously evaluated by a medical professional. Only a few were frequent enquirers. The service was used e.g. for a primary evaluation of a medical problem, for getting more information on a medical issue under treatment, and for a second opinion. The most common reasons for turning to a doctor on the Internet were convenience, wish for anonymity and that doctors were experienced too busy. In free text a considerable number of participants expressed discontent and communication problems with a previous doctor as a reason to turn to the *Ask the doctor* service. Many participants expressed a view of the service as a complement to regular health care, and the majority were satisfied with the answer. Nearly half of the participants in the web survey stated that they received sufficient information in their answer and that they would not pursue their question further.

The family physicians answering the enquiries at the *Ask the doctor* service were stimulated and challenged by the new task, in spite of the limitations caused by the lack of personal meetings and physical examinations. The opportunity to reflect on the answer before replying was appreciated, and the task was regarded as having a high educational value for themselves.

The Internet not only allows easy access to medical information but also to medical consultation – to date mostly text-based. It is probable that in the near future an increasing number of doctors will adopt text-based communication via the Internet to be a natural part of their communication with patients. Therefore, training in text-based communication and carrying out Internet consultations should be integrated into the curricula of medical schools and of continuous professional development. Ethical guidelines should be established.

Key words: Internet; remote consultation; physician-patient relations; gender; access to information; ethics.

LIST OF PUBLICATIONS

The thesis is based on the following original papers, which will be referred to in the text by their respective Roman numerals in superscript.

- I** Umefjord G, Sandström, H, Malker H, Petersson G. Medical text-based consultations on the Internet: a four year study. Submitted.

- II** Umefjord G, Hamberg K, Malker H, Petersson G. The use of an Internet-based *Ask the Doctor* Service involving family physicians: evaluation by a web survey. *Family Practice* 2006;23(2):159-66.

- III** Umefjord G, Petersson G, Hamberg K. Reasons for consulting a doctor on the Internet: Web survey of users of an *Ask the Doctor* service. *Journal of Medical Internet Research* 2003;5(4):e26.

- IV** Umefjord G, Malker H, Olofsson N, Hensjö LO, Petersson G. Primary care physicians' experiences of carrying out consultations on the Internet. *Informatics in Primary Care* 2004;12(2):85-90.

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GLOSSARY, DEFINITIONS

Important terms in the thesis

Asynchronous: not occurring in real-time, not at the same moment.

Consultation: in the present thesis referred to as the communication process between a patient and a physician on a medical issue.

Doctor: synonymous to physician in the thesis.

eHealth: the application of information and communications technologies supplied by telecommunications or by the Internet in different kinds of health services.

Enquirer: a person sending medical enquiries to an *Ask the doctor* service.

Internet doctor: in this thesis, we have chosen the term 'Internet doctor' for a physician carrying out medical consultations on the Internet, and with whom the patient/enquirer has no previous relation.

Online: actively connected to the Internet or other computer network. To 'go online' means to connect to the Internet.

Participants: here, individuals who chose to participate and answer the questions of the web survey.

Synchronous: occurring in real-time, at the same moment.

Telemedicine: use of telecommunication technologies to deliver medical information and services to locations at a distance from the care giver or educator.

Text-based medical consultation: consultation based merely on written communication.

Web: short term for World Wide Web.

Web-based messaging system: a system for sending electronic messages via the Internet using web servers.

Web survey: survey carried out by using the Internet.

Other related eHealth terms

Medical consultation via the Internet has also been called *teleadvice*, *teleconsultation* and *online consultation*. If the consultation is mediated by email the term *email consultation* has often been used.

Concerning counselling given on the Internet by e.g. psychiatrists or psychologists, the terms *online therapy*, *web counselling* and *online counselling* are used. The umbrella term *telecare* refers to the delivery of health services, information and support to remote patients or consumers by using telephone, SMS, telemedicine, email or other Internet-based communication systems. A *telecarer* is a health professional who delivers telecare.

INTRODUCTION

The dialogue between the physician and the patient during the consultation has always been fundamental in the practice of medicine. With the introduction of the Internet, new opportunities have been provided for communication between a physician and a patient. An example is the recent phenomenon of physicians starting to carry out *text-based consultations via the Internet*. These consultations, that may take part without any previous relationship with the patient and without any face-to-face contact, raise a number of questions. What are the incentives for trying out this new option of consulting a doctor? How do the individuals consulting a doctor via the Internet regard the Internet-based consultation and the responding physician? What value can these consultations add to physical meetings in regular health care?

Internet-based medical consultation might have an impact on individuals as well as on health care providers. Thus, it is important to understand the opportunities and the limitations of this new method of consulting a doctor, the use of such a service and the perspectives of the physicians carrying out the consultations.

Medical consultations via the Internet are introduced at a time when significant changes are influencing health care e.g.:

- Increased demands on health care and hopes for IT solutions
- The empowered patient and the Internet
- Demands by patients for Internet-based services.

Increased demands on health care and hopes for IT solutions

In the early years of the 21st century, total health expenditures in Europe are rising sharply⁴⁷. Not only is the number of elderly people increasing, but also the demands for getting quick and advanced care. Another modern phenomenon is that an increasing number of citizens are more mobile when travelling, studying or working abroad.

Expectations are raised that IT (information technology; also called ICT = information and communication technology), the Internet and *eHealth** will reduce costs and make health care more efficient and accessible, including for the elderly. eHealth was introduced in the late 1990s¹⁰⁷ as an umbrella term for the application of IT in health services supplied by telecommunications or by the Internet¹¹⁸. Most governments and international organisations are

* e in eHealth stands for electronically mediated or supported.

supporting the development of eHealth*.

During the last decades in everyday health care, IT solutions are complementing the traditional methods of communicating in health care. Face-to-face meetings were subsequently partly replaced by telephone interactions, and telemedicine at a distance has become a tool for health services in rural regions. Home telehealth for surveillance of patients in their homes is an expanding area⁹³. Telerehabilitation³⁹ and information therapy⁷¹ are new concepts for electronic communication in the field of rehabilitation.

The Internet has been predicted to have major impacts on health care. Some examples of the expectations are:

- “On-line, computer-assisted communication between patients and medical data bases and between patients and physicians promises to replace a substantial amount of the care now delivered in person”⁹⁰
- “need for fewer doctors beyond 2010”¹⁶³
- “professional power of medicine is being challenged by the public availability of specialist knowledge”¹²⁵
- “e-mail also may result in fewer office visits, and visits may be more productive when patients do need to be seen”³.

The empowered patient and the Internet

The growth of the Internet has enabled *patient empowerment* in terms of helping people to be in control of their health with increased patient involvement in decisions on personal healthcare^{68 110 128}. Originally designated to become a secure military computer network, the Internet grew as an interconnected network of research units at universities in the 1970s and 1980s. In 1993 the interface was simplified by the introduction of *browsers*, graphic computer programmes for navigating on the Internet, e.g. *Internet Explorer*. Within a few years, the Internet boosted the use of computers, and profoundly changed communication patterns. The introduction of *email* and *instant messaging* (*‘chat’*) software revolutionised and speeded up interpersonal communication, including internationally, thus ‘shrinking’ the world.

The rapid increase of published scientific reports in medicine has made it hard for health care professionals to keep up with medical progress⁸⁰. To balance the information overload, health care professionals develop strategies for filtering

* e.g. the World Health Organisation in WHO eHealth Resolution¹⁵⁶, the European Union in eEurope 2005 eHealth⁴⁸, and the National E-Health Transition Authority in Australia¹¹¹.

medical information¹⁴⁹. Increasingly, this is done by using electronic sources, often also published on the Internet.

Public access to medical information

Thus, besides profoundly changing communication behaviour, the Internet has also opened public access to medical information previously restricted to health care professionals and researchers. However, the quality of the information may vary broadly⁵⁵, but as search engines e.g. *Google* are improving, the intention is that high quality web pages are presented first. Web pages on a wide range of medical issues are also provided by major official health services such as MedlinePlus in US¹⁰¹, NHS Direct Online in UK¹¹⁴, Sundhet.dk in Denmark¹⁴⁴ and Sjukvårdsrådgivningen.se in Sweden¹³⁸.

In 2003, more than 40% of the American¹² and 25% of the European population¹⁴⁰ had been turning to the Internet for information on health topics. Most individuals used a search engine rather than going directly to a web site when confronted with a specific health-related question^{53 62}. Of all searches on the Internet, 4.5% have been calculated to be health-related⁵⁴.

The health information found on the Internet is regarded as valuable^{40 62} and easy to find¹¹⁷, despite concerns about varying quality⁶². In a US study, 60% of Internet users felt that the information on the Internet was the 'same as' or 'better than' information from their doctors⁴⁰. In a New Zealand study, respondents valued the information found on the Internet more than a general practitioner consultation¹³⁴. However, while starting to be challenged as the primary information source on health issues^{1 79 82}, physicians remain the most trusted by patients when it comes to treatment decisions⁷⁹.

The changing role of the patient

The principle of *patient autonomy*, the patient's right to make the final decision regarding the health care, has gained widespread acceptance^{2 29}.

Shared decision making, the process by which doctor and patient share the responsibility of finding the treatment best suited for the patient, is replacing the previous roles when the doctor was solely responsible for treatment decisions^{65 100}. This process is facilitated by the Internet, making it simpler for patients to get access to information on different treatments¹³⁵.

The concept of *patient-centredness* similarly gives the patients a more central role than the traditionally *paternalistic*, doctor-centred, approach. The paternalistic paradigm of the relationship between the physician and the patient has gradually been abandoned in the last decades^{27 44}, being replaced by more patient-centred models focusing on the patient's own responsibility for taking part in treatment decisions. In the patient-centred consultation, the patient's

thoughts, questions and needs dominate the scene, and the doctor avoids interrupting the patient with interview-like enquiries. The role of the doctor is to be a medical expert, still enabling the patient to express the reasons for attending, the expectations, and how the patient him/herself interprets the symptoms⁷⁸.

Demands by patients of Internet-based services

Access to Internet-based healthcare services are becoming increasingly demanded by patients in several western countries^{36 62 67 108 155}. In Norwegian population studies, one tenth of the respondents said they might consider changing to a doctor who offered Internet-based services⁷. Similar findings were found in a US survey⁷⁷. In a Swedish 2005 population survey, the majority of respondents wanted a variety of Internet-based services such as online access to the health records including laboratory and test results, scheduling of appointments and prescription renewals³⁸.

The Internet is already used to a varying degree for treatments in health care, e.g. online self-help programmes based on cognitive behaviour therapy principles³² (see also p. 46).

Prerequisites for access to Internet-based health services are a computer, Internet access, computer literacy, knowledge of the existence of the web site's service, and the associated financial resources – if not a computer at work, at a library etc can be used. By the turn of the millennium, 80% of Swedes aged 15-64 years had access to the Internet either at home, at work or at schools and universities.

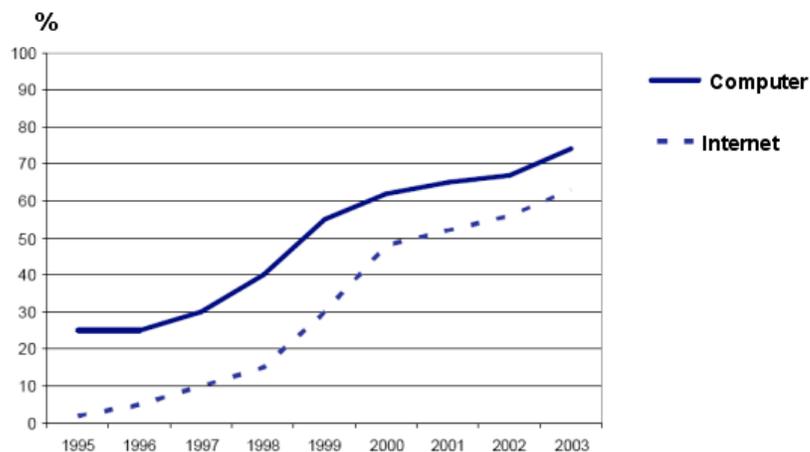


Figure 1. The percentage of Swedish population with access to computers and the Internet at home (reproduced with kind permission from World Internet Institute).

The digital divide

'*Digital divide*' is referred to as the difference between 'haves' and 'have-nots' concerning computers and Internet access. Low income, low education, lack of information literacy, minority status, old age and rural location have been shown to be barriers to accessing the Internet^{16 60 83}, creating 'informational blackholes'²⁵. In Sweden, the socio-economic digital divide has been less pronounced than in most other countries, but the divide still existed in 2003¹⁵⁸.

Except for socio-economic differences, there has also been an age-related divide with the highest Internet access among young adults and low middle-aged. Among the most frequent health consumers, the elderly, Internet access has been markedly lower, referred to as the '*grey digital divide*'¹⁰⁵. An example is that around one in ten men and just over one in twenty women aged 80 and over were using the Internet in the UK in 2002⁴⁵.

Gender differences

In Sweden by the turn of the millennium, Internet access was higher among men than women. However, the gap has narrowed during the last years¹⁵⁷. In the US, women are more likely to seek health information online than men^{61 63 117}, and while connected to the Internet women look for general health and medical information, information on specific diseases or medical conditions, treatment or procedures⁵⁶. At the same time, women harbour more fears about online risks and dangers than men do, and are more concerned about the credibility of health information found online^{56 74}.

Demands by patients of Internet-based medical consultations

An increasing number of patients are interested in consulting a doctor via the Internet. In a Danish primary care study half of the respondents wanted Internet-based consultations¹¹⁵. Of US patients, two thirds (66%) were interested in a '*virtual visit*' (a patient-to-physician encounter conducted using the Internet alone) for a simple medical problem, slightly fewer for a chronic medical problem⁶⁷. At an orthopaedic out-patient clinic in London, 36% of patients would undergo an Internet-based consultation, and a further 25% would consider this depending on the medical condition in question⁷⁰.

Demands from patients for further information as well as second opinions¹⁵¹ may be driving forces for the growth of Internet-based *Ask the doctor* services. In summer 2006, a Swedish medical library web site listed more than 100 *Ask the doctor & Second opinion services*⁸⁹, for which most addressed a specific medical diagnosis or speciality such as epilepsy, pain or neurology. At some of these services the enquirer is allowed to be anonymous in contrast to others. Some of the services are free of charge, others fee-based.

Types of Internet-based consultations in medicine

There are two major types of Internet-based medical consultations. In the first, there is an established relationship between the enquirer and the answering doctor. In the second, there is no pre-existing personal relation between the enquirer and the answering doctor (see Figure 2 and Table 1). These two consultation-types should be distinguished from each other, as different behaviour is required by the doctor. The former consultation-type is mostly part of the communication between a patient and his/her regular physician and includes not only medical enquiries but more often requests for other services such as follow-ups of treatments, prescription renewals, and reporting of lab results^{113 137 152}. This consultation-type has been referred to as type 2 provider-patient relationship⁵⁹ or type B encounter⁴⁹.

The other consultation-type without any pre-existing personal relation is mainly used at public medical web sites or special Internet-based consultation services of *Ask the doctor*- or Second opinion service-type, some of which are commercial, some not. This consultation-type has been referred to as type 1 provider-patient relationship⁵⁹ or type A encounter⁴⁹.

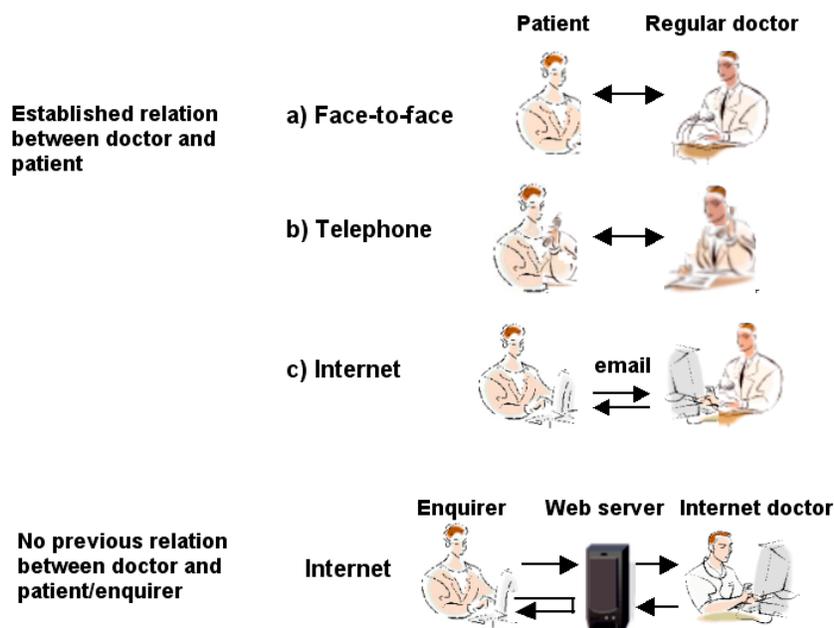


Figure 2. Different modes of communication between patients/enquirers and doctors. In an established relationship: a) The ‘classical’ doctor-patient face-to-face meeting, b) telephone, c) email communication between patient and regular doctor; Enquiries sent to a doctor on the Internet without any previous relation. See also table 1.

This thesis focuses on text-based medical consultation of no-previous-relation type via the Internet.

Table 1. Different types of Internet consultations in medicine (modified from Eysenbach⁴⁹).

	No pre-existing personal relation	Pre-existing personal relation
Mode of communication	Mostly text-based by email or web-based messaging. No face-to-face-meetings	Email or web-based messaging but also face-to-face meetings and telephone
Information access	Physician only has access to the information provided by the enquirer in text	Physician also has access to medical records, lab results, referral reports etc.
Physician's action	Response in text only (except at certain web sites for prescriptions of drugs)	Text response by email or web-based messaging but also other actions such as call for an examination, a prescription or a referral
Relationship	Informative, encouraging enquirers to learn about their medical conditions taking part of the decision making process	Part of the regular communication between a patient and his/her physician
Nomenclature	Type 1 provider-patient relationship (Ferguson) Type A encounter (Eysenbach)	Type 2 provider-patient relationship (Ferguson) Type B encounter (Eysenbach)

Previous experience of Internet-based medical consultations

The reported experiences on the use of Internet based consultation services without any pre-existing personal relation between the enquirer and the answering doctor mainly derive from clinics with a defined medical specialty:

- A paediatric gastroenterology clinic reported the experiences of 1001 email consultations between 1995 and 1998 concerning content and workload, finding that 69% of the enquiries included a specific question about the cause of a child's symptoms, appropriate diagnostic tests and/or appropriate therapeutic interventions²⁰.
- Of 70 unsolicited emails sent to a web site with a primary focus on cardiac arrhythmias, the most common requests (69%) were about therapy¹⁵³.
- When analysing 209 unsolicited email questions sent to a dermatological web site, it was found that 27% of the enquiries could not be done without seeing the patient⁵¹. A considerable number of enquirers expressed disappointment with previous doctors.
- Of 279 enquiries from laypersons to a dermatology and allergy clinic only 41% reported they had previously consulted a physician⁴².
- After content analysis of 793 enquiries submitted to a web site at an orthopaedics and sports medicine department, it was found that the most frequent purpose for the enquiry was to seek information (73%), followed by seeking advice (23%)¹³⁶.

AIMS

The main purpose of this thesis was to cast light on the new phenomenon of Internet-based medical consultation without any pre-existing personal relation between the enquirer and the answering doctor.

Specifically, the aims were

- to describe the users' age, gender, usage pattern, types of enquiries and usage in cities compared to less densely populated areas at an Internet-based *Ask the Doctor* service.
- to study how the *Ask the Doctor* service was used and evaluated by the enquirers.
- to find out the reasons for turning to a previously unrelated doctor on the Internet with a medical enquiry.
- to explore the answering Internet doctors' experiences of carrying out text-based medical consultations on the Internet.

MATERIALS AND METHODS

This thesis is based on four original papers describing different aspects of an Internet-based *Ask the doctor* service. We analysed the development of the service during the first four years, carried out a web survey of the users of the service and analysed the experiences of the physicians that answered the enquiries by a questionnaire. For an overview of Materials and Methods see figure 4, p. 20.

Infomedica's *Ask the doctor* service and the enquiry process

In October 1998, the non-commercial public health web portal, Infomedica (<http://www.infomedica.se>)*, financed by official Swedish health authorities, was launched by opening an *Ask the doctor* service. The service was open for public access 24 hours a day, seven days a week except for summer closure some years. Anyone was, free of charge, offered the opportunity to anonymously submit health- and disease-related enquiries to the service. After inputting gender and age in 5-years intervals (from November 2001 also postal code), the enquirer could freely choose what to ask about. The enquiry process is presented in figure 3.

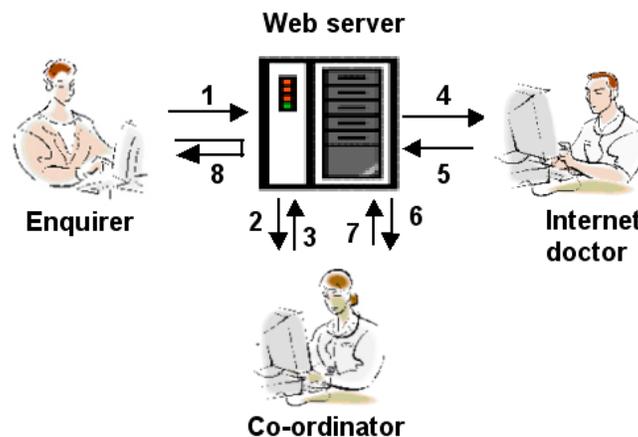


Figure 3. Enquiry process at Infomedica's *Ask the doctor* service: After typing the enquiry in a free text box and submitting it (1), a digit code was automatically randomly generated by the web server and provided on the enquirer's computer screen to be used later for accessing the answer (8). The co-ordinator read the incoming enquiry (2), classified it into a predefined category and distributed (3) it to the Internet doctor by the server's web-messaging system (4). The Internet doctor wrote and submitted his/her answer to the enquiry (5). The co-ordinator read (6) the answer and accepted (7) it for access by the enquirer (8).

* In 2005, the web portal changed its name to Sjukvårdsrådgivningen.se (<http://www.sjukvardsradgivningen.se/>)

A *Questions & Answers* database was subsequently built up at the service, but during the first years of the service the chance of finding an answer to a medical question from answers in the database was small.

The number of family physicians engaged (*'Internet doctors'*) increased from 12 at the start of the service in 1998, to 30 in the autumn of 2002. A total of six co-ordinators, also family physicians, read all the incoming enquiries, categorised the enquiry into predefined categories, answered some short enquiries and distributed the rest by the server's web-messaging system (figure 3). For quality assurance reasons, the co-ordinator also read all the answers, and a few of these were returned to the answering Internet doctor for revision. If the enquiry obviously included too little information to receive an answer, or if it was obvious that the reason for the enquiry was to get help with schoolwork etc, a standard answer was given. During 2002 a nurse co-ordinator was recruited for reading, categorisation and distribution of the incoming enquiries. The name of the answering physician was not presented to the enquirer until the answer was retrieved. The answering physicians were reimbursed by Infomedica.

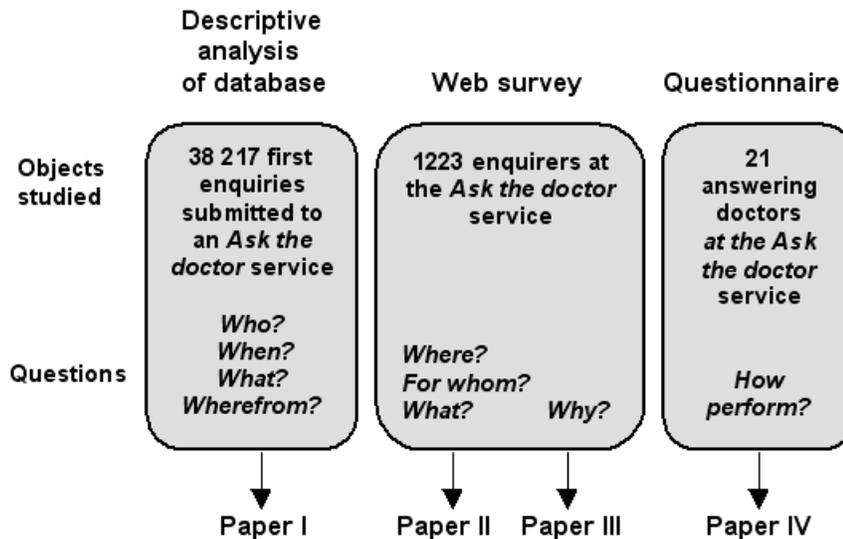


Figure 4. Study of an *Ask the doctor* service – overview of materials and methods.

Descriptive analysis the database of the enquiries (paper I)

The objective of the study¹ was to find out more about the users' age, gender, usage pattern, types of enquiries and usage in cities compared to less densely populated areas. We studied the development of the first four years use of the *Ask the doctor* service. The questions we wanted to explore were:

- How did the number of enquiries develop during the first four years of the service?
- What were the ages of the users?
- What types of enquiries were submitted?
- Did women's use differ from that of men?
- At what time of day and week were the service used?
- Was use more extensive in regions with few doctors?

Data

We analysed data from copies of the databases of Infomedica's *Ask the doctor* service from the period of October 1998 through September 2002. As the service swapped database systems in 2000, we merged the two databases, a Fox pro database (October 1998 to mid-November 2000) with a SQL database (mid-November 2000 through September 2002). Before analysis, some duplicate questions were excluded.

The databases included registration of time, the text of the enquiry, the answer from the Internet doctor, a numeric code for the answering doctor, a category that best matched the content of the enquiry, age class (5-years intervals) and gender of the individual that submitted the enquiry. During the course of the study, information of postal code and – if the enquiry concerned anyone else – age and gender of that person were added for registration.

Data analysis

Data were described by using SPSS for Windows version 11 (SPSS Inc., Chicago, US) except for registration of counties in 2004 when Publech version 3.0 (Ntech, Sundsvall, Sweden) software was used.

Web survey to the enquirers (paper II-III)

The objective of the web survey^{II III} was to investigate how an Internet-based *Ask the Doctor* service outside pre-existing doctor-patient relationships was used and evaluated by the enquirers.

Questions explored in paper II:

- From where did the enquirer submit the enquiry?
- Did the enquirer ask on his/her own behalf or for someone else?
- Had the enquirer, or the person on whose behalf he/she was asking, already seen a medical professional concerning the issue in the enquiry?
- What did the enquirer want to find out by submitting the enquiry?
- Were there individuals that used the *Ask the Doctor* service at numerous times?
- What was the enquirer's evaluation of the answer?
- Did the enquirer plan to pursue his/her question further after having received the answer?
- What other thoughts did the enquirer have concerning the answer to the enquiry, the *Ask the Doctor* service or how the service could be improved?

The objective of paper III was to answer the question:

- Why did the enquirer choose to send an enquiry to Infomedica's *Ask the Doctor* service?

Data

To answer these questions, we recruited the users of Infomedica's *Ask the Doctor* service to the web survey. The participants were informed that they would remain anonymous while responding to the survey. The survey was conducted from November 2001 through January 2002. The questions in the survey were formulated at several meetings. Questions included both multiple choice and free text formats. The fifteen questions in the survey are presented in Appendix 1.

In the web survey, 1223 of 3622 (34%) users of Infomedica's *Ask the doctor* service participated. During the three-month course of the survey, women not only submitted three quarters of the questions to the service but also dominated the participation in the survey (74% women vs. 26% men, figure 5).

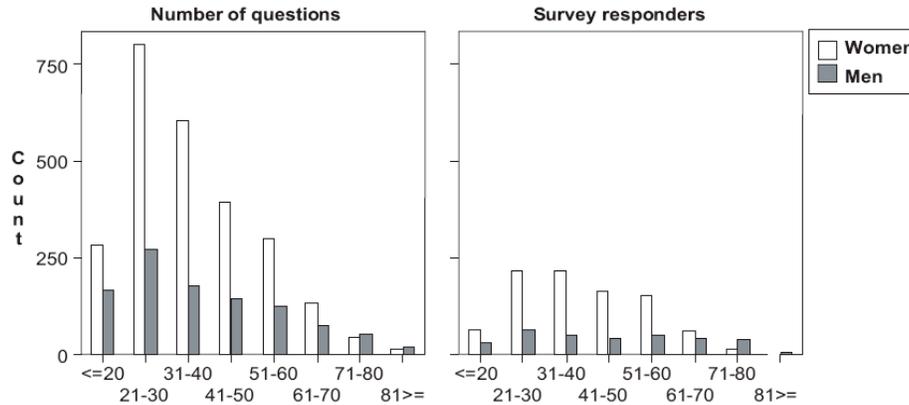


Figure 5. Number of enquiries sent to the service during the course of the survey and survey responders by gender and age.

Data analysis

As the analysed responses of the survey were combinations of multiple-choice alternatives and free text options, both a quantitative and a qualitative analysis were performed. The frequencies of the multiple-choice alternatives were computed using the Publech version 3.0 (Ntech, Sundsvall, Sweden) software.

In the qualitative analysis of the free text answers, we wanted to outline categories based on and conceptualised from the data instead of establishing the categories in advance¹⁴¹. All free text answers were transcribed. In a first step the free text answers were read and coded for meaning and content by two^{III} or three^{II} of the researchers separately. Codes were then discussed and sorted into categories in a joint session.

In the second step, all free text answers were reread and analysed regarding the established categories by the researchers together. In paper III, we found that a large number of free text answers contained several examples and different kinds of information. When we described the categories by their frequencies and relative proportions, a single answer could have been sorted into more than one category. In paper II, concerning the question on what the enquirer wanted to find out, the free text answers were more uniform, which is why we chose to assign each answer into only one category before presenting the results.

In the analysis of paper III the reliability of the coding and categorisation was discussed at a seminar by a group of researchers not involved in the study. As a result of their comments minor changes were made in the categorisation.

Questionnaire to the answering physicians (paper IV)

The objective of the study^{IV} was to explore the answering physicians' experiences of carrying out the text-based consultations at Infomedica's *Ask the Doctor* service. Among the questions explored in this study were:

- How did the doctors who carried out the text-based consultations on the Internet experience the task and his/her new role?
- Was the information content of the enquiries sufficient?
- What preparation was recommended to handle the challenges of the new role of Internet doctors?

Data

The method to find answers to these questions was a questionnaire given to 21 Internet doctors already carrying out text-based medical consultations at Infomedica's *Ask the Doctor* service. The questionnaire was answered by the doctors at a meeting (n=13) or at home (n=8). Of a total of 28 questions in the questionnaire, 12 were of six-graded fixed alternative-type with the opportunity to add free text. The remaining questions were answered by free text only or by a number.

In addition to personal data, the themes included in the questionnaire given to the Internet doctors were:

- previous computer and Internet experience
- quality aspects of the incoming enquiries (e.g. difficulty aspects of medical safety and familiarity with the content of the questions)
- information retrieval needed before answering
- training recommended before commencing as an Internet doctor.

Data analysis

An analysis of the free text answers was performed by two of the authors independently by the process of transcription, analysis of meaning and content, coding and grouping into themes. The results were presented in absolute numbers and as a percentage of the responding participants.

Comments on methods and limitations (paper I-IV)

Selection bias

Internet users are a selected sample of the population. Selection bias is a general dilemma in research, but is a more pronounced problem in online research. Data in the studies did not mirror Swedish citizens in general, but represented the limited sample of Internet users who knew about the *Ask the doctor* service and chose to send enquiries to the service.

The participants in the web survey^{II III} chose to turn to the Internet with their medical issues. We cannot exclude that they felt more positively about Internet-based consultations than a population that has never considered the possibility of consulting an Internet doctor would feel. The motivation to participate in the web survey might possibly increase both from satisfaction and from dissatisfaction with the answer from the Internet doctor. The conclusions of the present survey should not be generalised to the population as a whole, but it is reasonable to believe that the results are applicable to people who use Internet-based *Ask the doctor* services.

The cohort of answering family physicians was positively recruited^{IV}, thus the results are not representative of family physicians in general. It is likely that a number of family physician not involved in the service would not be comfortable either with communicating in writing or using the Internet.

Demographic data

As anonymity was shown to be an important factor for using the service^{III}, and as one quarter of the enquirers did not type his/her correct postal code, we cannot guarantee that all enquirers did not want to disguise his/her real age, gender, postal code or county.

Due to a technical error we had to exclude the time registration of the submission of the enquiry, and we finally chose to present one year's data from October 2001 to September 2002 (n=16 463).

Inter-rater reliability

The way the co-ordinator classified the contents of the enquiries^I, i.e. *inter-rater reliability*, was not evaluated. We cannot exclude that one co-ordinator would classify an enquiry differently than another co-ordinator would. The frequency of the categories should be interpreted with care since the contents of some enquiries might belong to several categories but were classified only into one.

Web surveys

Web surveys have the advantage of being executed at the responder's own pace. Disadvantages may be technical problems and different levels of computer experience, possibly leading to participation bias and contributing to lower response rates. Due to the relatively low response rate in our study^{II III}, the results should be regarded as hypothesis-generating, and it is possible that the 66% of users who did not participate in the survey had different opinions on the service.

The reliability of web surveys does not seem to be different from paper-and-pencil questionnaires¹²³. However, online participants have been found to be more overtly negative to previous counselling by their physicians than telephone respondents¹⁴⁸, suggesting that a spoken dialogue may restrain negative opinions¹⁷. This view was supported by free text responses in our web survey^{III} since we found a considerable number of participants being overtly dissatisfied with previous performances of physicians. Thus, web surveys could be an alternative to consider when it is important to get answers on sensitive issues such as an evaluation of patient satisfaction after an appointment with a physician.

Questions in the web survey and the questionnaire

The shorter a web survey is, the higher the response rate is likely to be. Trying to achieve an acceptable response rate in a web survey while still being able to gather sufficient information is a question of balance. Our solution to this dilemma was to combine quickly entered multiple-choice answer options with an open-ended text box. As a result, the survey could be completed within a few minutes.

In the fixed alternative questions in the questionnaire to the answering doctors^{IV}, we used a six-graded scale with no middle alternative. By using this method, the participant was forced to choose either a positive alternative or a negative⁵⁷.

RESULTS

Use, age and gender

The use of Infomedica's *Ask the doctor* service increased almost linearly during the first three years, with a slightly faster increase during the fourth year¹ (figure 6). On average, the increase in use was 28 enquiries per month.

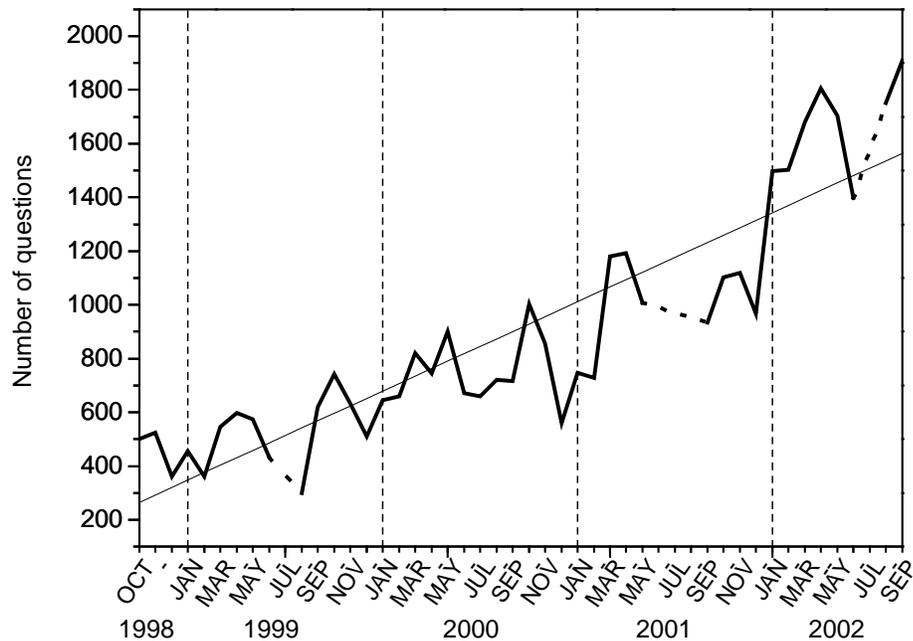


Figure 6. Number of enquiries submitted to the service month by month (n=38 217). The dashed lines indicate that during the months July 1999, June-July 2001 and July 2002 the service was closed.

The proportion of Swedes with access to the Internet at home in different age groups in 2002 is presented in figure 7a. If related to Swedish population in different age groups in year 2000, the proportional use of the *Ask the doctor* service was highest among young women (figure 7b). Among the elderly, the use was least, however this was also the case with Internet access.

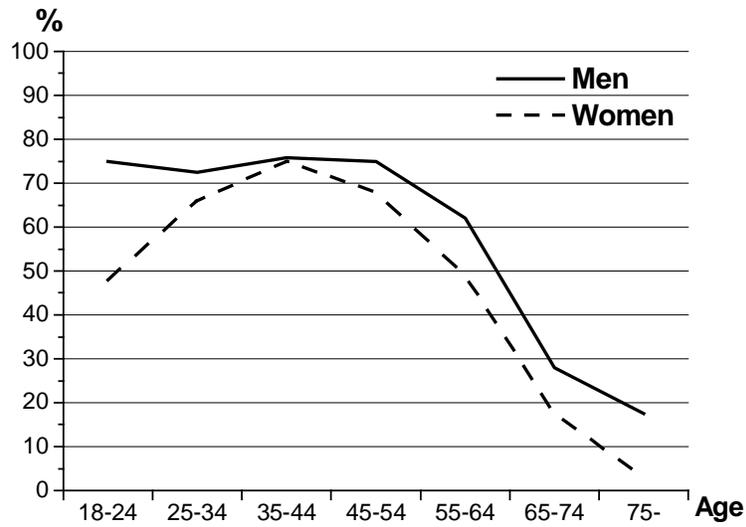


Figure 7a. Proportion (%) of Swedish men and women in different age groups with access to the Internet at home in 2002 (with kind permission from World Internet Institute).

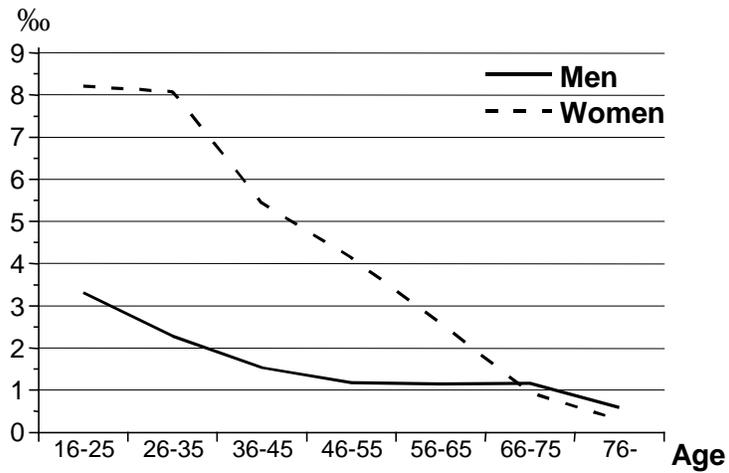


Figure 7b. Proportion (%o) of Swedish inhabitants in different age groups that submitted enquiries to an *Ask the doctor* service during a four-year period (October 1, 1998 – September 30, 2002) in relation to the population in Sweden year 2000.

Shortly after the commencement of the service in October 1998, women started to dominate use (figure 8) with the typical user being a woman aged 21-60 years. The service was used all day round, seven days a week. During the first working days of the week, more enquiries were sent to the service compared to the rest of the week. The number of enquiries sent during working hours was slightly higher than during evening hours.

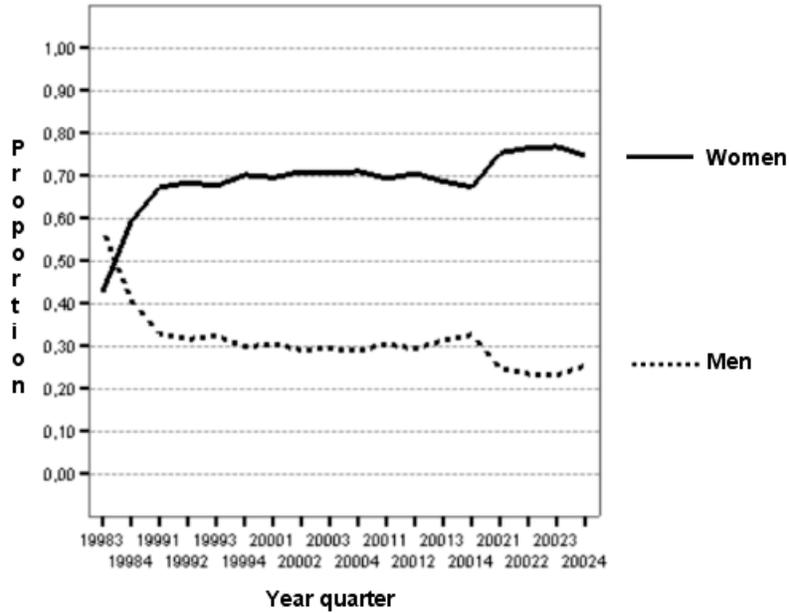


Figure 8. Proportion (ratio) of women versus men submitting enquiries to the *Ask the doctor* service over time. The sum for men and women at each time is 1.0.

Use in relation to population density

Use was more frequent per capita in densely populated areas as defined from postal code registration¹, except for the City of Malmö in the county of Skåne, where there was a local health web portal (table 2).

Table 2. Number of submitted enquiries to an *Ask the doctor* service during eleven months in relation to population density. Registration from November 1, 2001 – September 30, 2002.

Region	Population 2002	Number of submitted enquiries	Submitted enquiries / 1000 inhabitants / month
Densely populated areas			Mean 0.15
Stockholm city	1784730	3435	0.17
Göteborg city	311977	469	0.14
Malmö city	242602	236	0.09
19 biggest towns	1482154	2288	0.14
Subtotal	3821463	6428	
Sparsely populated areas			Mean 0.09
Rest of Sweden	5084553	5138	0.09
Missing		3672	
Total	8906016	15238	

Enquiries and answers

Types of enquiries submitted to the service

The enquiries submitted to the service included a wide variety of medical issues with all fields of medicine represented^I. The most frequent enquiry categories from women were ‘Symptoms and troubles’ (12%) followed by ‘Pregnancy and contraceptives’ (9%), ‘Joints, muscles and skeleton’ (8%) and ‘Female genital’ (7%). Men’s most frequent enquiry categories were ‘Male genital’ (13%) followed by ‘Symptoms and troubles’ (12%), ‘Skin’ (9%) and ‘Joints, muscles and skeleton’ (8%). In the male age group 0-20 years, 24% of the enquiries were on ‘Male genital’. Questions on ‘Heart and circulatory system’, ‘Tumours’ and ‘Brain and nerve system’ were proportionally more frequent from the age group >60 years.

From where, for whom, frequency of submitting enquiries

Most participants wrote their question at home, and 80% asked on their own behalf^{II}. Women asked more frequently about children, parents or other older relatives than men did. Almost half of the enquiries (45%) concerned a medical matter that had not been evaluated by a medical professional before. Two-thirds of the participants reported that their enquiry was the first one they had submitted during the last year. Only a few were frequent enquirers, but one participant had asked “10-15” times during the last year.

What the enquirer wanted to find out

When the participants responded to the question on what they wanted to find out by submitting their enquiry, a wish for an evaluation of symptoms was the most frequent answer^{II}, both as a multiple choice-alternative (table 3) and as a free text answer. One third of participants (33%) wanted a second opinion. A direct wish for more thorough information on a medical issue was expressed in a quarter (28%) of the free text answers.

Table 3. What the participant wanted to find out with their enquiry. Number and percent of participants who chose each option. The participant could choose one or more of the options and also answer in free text.

	Men (n=322)		Women (n=901)		Total (n=1223)	
		%		%		%
<i>“What did you want to find out by submitting your question? Please, choose one or more of the following alternatives”</i>						
I have symptoms and wonder what the problem may be	169	52	355	39	524	43
I wanted another doctor's opinion about the symptoms	105	33	294	33	399	33
I wanted more information on a specific disease	88	27	258	29	346	28
I wanted more information on a specific treatment	79	25	195	22	274	22
I wanted more information on a drug	40	12	105	12	145	12
Other, namely <i>(followed by a free text box)</i>	43	13	116	13	159	13

Satisfaction with the answers

Most participants (88%) found their question answered, and 82% of participants in all age groups were satisfied with their answer^{II} (table 4). Almost half (43%) said that they had received sufficient information. The service was appreciated for its convenience and flexibility, but also for reasons to do with the mode of communication such as the ability to reflect on the written answer without having to hurry and to read it more than once, *“a written answer is much better because it is hard to remember what the doctor told you. With a written answer you can return to the answer and read it again”*. Some participants also appreciated the language used in the answers, *“brilliant answer written for a layman”* and *“you feel like the doctor is talking to you”*. A considerable number of participants (155 of 1223) in free text overtly expressed an appreciation for the existence of the service as a complement to health care, *“excellent service that saves time as I do not have to go to the doctor in certain cases”*.

The participants were slightly more satisfied with the answers if the enquiry concerned a medical issue not previously evaluated by a medical professional.

The most common reason for dissatisfaction was that the answer was regarded as *'too short'*. There were also examples of misinterpretation of the enquiry, *"the Internet doctor partly misunderstood my complaints"*.

Table 4. Evaluation of the answer from the Internet doctor. Number and percent of participants to selected items.

	Men	%	Women	%	Total	%
<i>"Did you get an answer to your question?"</i>						
Yes, completely	169	53	499	55	668	55
Yes, partly	101	31	299	33	400	33
No, not fully	26	8	55	6	81	7
No, not at all	14	4	23	3	37	3
Not applicable	12	4	25	3	37	3
<i>"Are you satisfied with the answer?"</i>						
Yes	258	80	741	82	999	82
No, the answer was too short	29	9	73	8	102	8
No, the answer was too simple compared to my question	13	4	26	3	39	3
No, the answer came after too long time	2	1	9	1	11	1
No, the answer included too complicated words	1	0	2	0	3	0
Not applicable	19	6	50	5	69	6

Reasons for consultation

The reasons for turning to a doctor on the Internet for consultation are summarised in table 5 as defined by the result of the fourth question of the web survey^{III}. To answer this question, the participant could choose one or more of seven multiple choice-alternatives and/or in free text express his/her reasons. Among the multiple choice-alternatives, the most frequently chosen was 'convenience' (52%) followed by 'anonymity' (36%), 'doctors too busy to answer questions' (21%), 'difficult to find time to visit a doctor' (16%), 'difficulty to get an appointment' (13%), 'feeling uncomfortable when seeing a doctor' (9%) and 'not being able to afford a doctor's visit' (3%).

Among the free text answers, the most frequent was the wish to get a 'second opinion' expressed by almost one third (31%) of the participants who chose to answer in free text. 'Discontent with previous doctors' was found in one quarter (25%) of the free text answers. A 'wish to get a primary evaluation of a medical problem' as the reason was seen in 15%. Almost as many participants (14%) expressed reasons that were summarised as 'convenience, distance and time'. A few participants (4%) mentioned 'embarrassing concerns and worries' as reasons while another 4% expressed that they 'preferred written communication'. We also found examples of enquirers using the service partly because of difficulties of getting a face-to-face appointment with a doctor.

Table 5. Summary of reasons for sending enquiries to an *Ask the doctor* service without any ranking.

-
- It may be time-saving and more convenient than seeing a doctor in person
 - Wanting a primary evaluation of a non-urgent medical symptom, not being sure whether it is necessary to see a doctor or not
 - Dissatisfaction with previous doctors
 - Second opinion
 - Preferring to be anonymous, having sensitive or embarrassing questions
 - Discomfort when seeing doctors in person
 - Difficulties accessing health care, e.g. living in rural areas or remote locations
 - Seeking advice for another person such as a relative
 - Other needs that regular health care did not fulfil, such as the wish of getting more thorough information on a medical issue
 - Preference of written communication
-

Experiences of the answering physicians

The 21 answering Internet doctors at Infomedica's *Ask the doctor* service by year 2001, all experienced family physicians, found the task challenging, demanding and at the same time inspiring, giving reasons for updating of the medical knowledge^{IV}. Not seeing the enquirer face-to-face was experienced as a limitation, but could be handled by asking the enquirer to re-consult a doctor at his/her office. Other difficulties faced were that the enquiries might be short, not including important information, hard to interpret or raising an unfamiliar medical issue (table 6).

Table 6. The results of the question "What difficulties did you experience with the enquiries" in the questionnaire to the Internet doctors (n=21).

	Very often	Often	Rather often	Rather seldom	Seldom	Almost never
Too little information	0	8	9	3	1	0
Not familiar with the question	0	2	5	11	3	0
Hard to answer without examination	0	4	9	4	4	0

The asynchronous feature was appreciated as it allowed time to reflect and perform relevant information searches before replying. The sometimes unfamiliar enquiries motivated the Internet doctors to keep up with medical progress (figure 9).

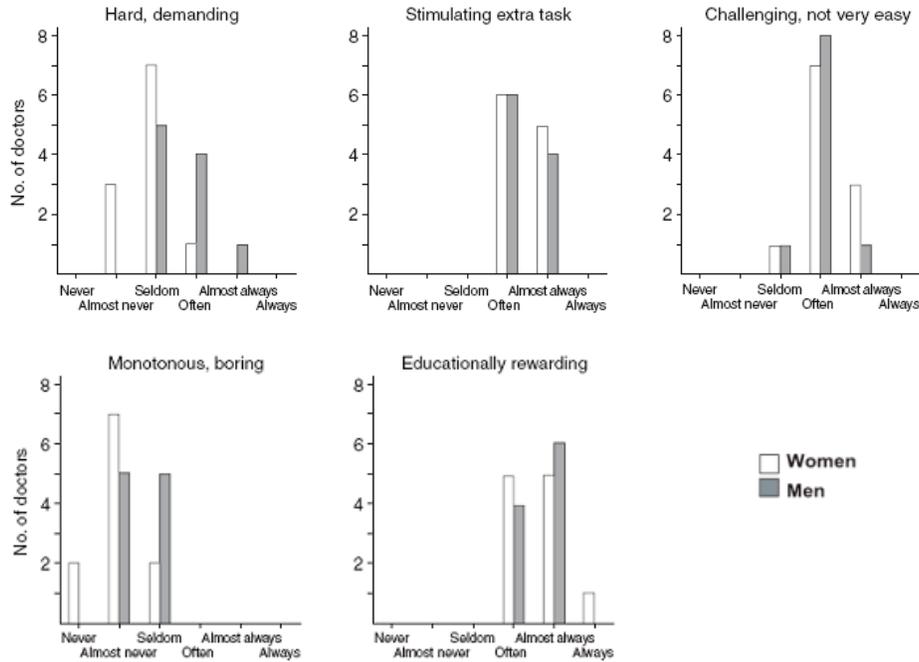


Figure 9. The results of the question "How do you as a doctor in general experience the task of being an Internet doctor?" (n=21). The Internet doctors had to evaluate the statement in the heading above each graph.

The Internet doctors recommended training before starting, i.e. training of skills necessary to find reliable, up-to-date medical information on the Internet and training in written communication using a plain, clear, distinct and easily understood language.

Concerning the future role of health services on the Internet, the majority of the participating Internet doctors (14 of 21) believed that health services to a small extent would partly replace regular health care. In free text answers the Internet doctors stressed that physical contact will remain the basis for the practice of medicine, but patients/enquirers might be empowered by the answers provided by an Internet doctor.

DISCUSSION

We found that text-based medical consultation on the Internet, carried out by family physicians, was used and appreciated mainly for its convenience, for getting a primary evaluation of a medical issue, and for the opportunity to get a second opinion and to anonymously ask sensitive questions. The service was used mostly by young and middle-aged women. Most participants found their question answered and were satisfied with the answer. Text-based medical consultation on the Internet may represent a complement to regular health care.

Characteristics of the users

Use, age and gender

We found an almost linear increase in incoming enquiries to the service during the four years of the study¹. Even so, though gradually growing, when compared to visits in regular health care, the use of the *Ask the doctor* service must be regarded as limited. This may partly be explained by the knowledge of the service being low during the years of the study. In 2003 only 7% of the Swedish population knew of Infomedica's web site that offered the *Ask the doctor* service¹⁶². Also, our study did not mirror the total use of *Ask the doctor* services in Sweden. In the late nineties, there were a number of eHealth web sites launching their services, some also offering answers to medical enquiries by physicians. There are no official statistics but a few years after the study Netdoctor.se's service reported receiving 1536 enquires per month in 2005 (Beckman, AC, personal communication 2006). Examples of possible reasons for not submitting enquiries to an *Ask the doctor* service are listed in table 7.

Table 7. Possible reasons for not submitting medical enquiries to an Internet-based *Ask the doctor* service.

-
- Lack of computer literacy
 - No access to the Internet
 - No knowledge of the service
 - Never considered the opportunity to consult an Internet doctor
 - Already in contact with health care, being satisfied with no further questions
 - Faced with a new problem realising that there is a need for
 - a dialogue with a health professional
 - a physical examination
 - Disapproving written communication
 - Financial reasons, if the service is fee-based
-

The predominance of users being young adults or middle-aged in our studies coincides with the finding that these age groups are more computer literate and frequent Internet users, but also that they are most interested in participating in shared decision making concerning medical treatment⁹⁴.

That relatively few enquiries emanated from the elderly population may be due to low access to the Internet. Nevertheless, some authors claim that the cognitive demands for using the Internet are low, and that the Internet seems especially well suited to the elderly, given its possibilities for social networking, leisure hobbies, and other services such as the delivery of food¹¹⁶.

Women seem to take advantage of the *Ask the doctor* service, as they dominated the use of it with three enquiries of four emanating from women. This contrasts to the Internet access which was slightly higher among men than women during the course of the study¹⁵⁷. However, Sweden has been pointed out as the country with the highest proportion of female Internet users¹³⁰.

Even aside the use of the Internet, in general women seem to be more eager to get health information than men. Being more involved in shared decision making than men, women prefer a collaborative style of communication with physicians⁴³. During visits at doctor's offices, women tend to ask more questions¹²¹ and they also receive more information¹³² than men. Furthermore, women are often the health advocates for family members. In the US, women has been shown to make three quarters of the health care decisions in the households⁶⁴. In our web survey^{II}, women also more frequently asked about relatives than men did.

Use in relation to population density

One of the advantages of the service was that it could be used anywhere on a computer with Internet access. We found a more frequent use of the *Ask the doctor* service in cities and bigger towns, where Internet access was higher than in non-urban areas^I.

In rural areas, the number of physicians per capita is lower than in cities. It is tempting to ponder that the non-urban inhabitant by way of compensation would use *Ask the doctor* services to get answers to non-urgent medical questions, i.e. to clarify if it is necessary to travel to a doctor's clinic. In the free text answers of the web survey, we found a number of examples of enquirers that used the service partly because of difficulties of getting a face-to-face appointment with a doctor^{II III}.

Enquirers and satisfaction with the answers

Perception of time seems to be a critical factor for satisfaction in health care. In both the multiple choice answers and the free text answers of the web survey^{III}, a substantial number of participants considered the waiting times in Swedish health care too long. A number of participants also found the promised answering time (less than one week) of the studied *Ask the doctor* service too long. In a study of a patient-physician web-based messaging system, patient satisfaction strongly correlated to answering time⁹⁶.

Overall, the majority of both men and women were satisfied with the answers they received from the service^{II}. People are in general positive about experiences in health care⁷³. This is valid not only in face-to-face-meetings but also in telephone consultations²³ and in telemedicine¹⁰³. The satisfaction with the answers from the Internet doctors at Infomedica's *Ask the doctor* service reported in our web survey was generally not superior to the satisfaction seen in other consultation types of health care. Apparently, most participants found the service easy to use, as there were no negative comments on the user interface in the free text answers. It is likely that the nature of the enquiry is of importance for satisfaction. Certain medical issues are difficult or even inappropriate to handle without a physical meeting. Probably, some participants were dissatisfied because they had not realised the limitations of *Ask the doctor* services, e.g. asking for a diagnosis of a skin disorder. To refine the service, further studies are required to distinguish what answers are regarded positively by the enquirer from answers that are not. As one of difficulties for the answering doctor was that the enquiry might include too little information^{IV} (table 6), it is likely that the quality of the answer would increase were it possible for the doctor to ask for additional information before answering.

Reasons for consultation

That convenience was a major reason for participants to choose Internet consultations^{III} might be explained by the all day round opportunity to submit the enquiry and to read the answer – the asynchronous feature. Other important reasons were anonymity, wanting a second opinion and a wish for deeper information on a medical issue (see table 5).

Anonymity

Several individuals may have intimate medical issues that are not easy to expose at regular face-to-face meetings in health care. One third of the participants in the web survey indicated anonymity as one of the reasons for turning to an Internet doctor^{III}. The fact that one quarter (24%) of the enquiries from the male

age group 0-20 years were categorised as ‘Male genital’ also underpins the need of a service where you are allowed to be anonymous when asking about sensitive areas^I.

Discontent with previous doctors and second opinion

Frustration with appointments with doctors is not an uncommon problem in regular health care^{18 86 119 122}, supported by our web survey^{III}. Discontent with previous doctors was a frequent theme in a considerable number of free text comments. When a patient leaves his/her doctor’s office, and finds out that he/she does not fully trust the evaluation of his/her doctor, what can the patient do? In this situation, he/she may go online to look for more information or to ask an Internet doctor.

In unsolicited emails sent to a dermatology clinic, frustration with previous encounters with physicians were expressed in seventeen percent of the emails⁵². One third of cancer patients seeking a second opinion expressed dissatisfaction with the first specialist¹⁰².

Patient’s wish for a second opinion may not only be due to unmet needs, communication difficulties¹⁴⁵, dissatisfaction¹⁴⁶ or distrust in the regular doctor, but also the individual’s wish to get the best care possible. To submit an enquiry to an Internet doctor may be the individual’s way to get a second opinion without risking that the regular doctor will get to know about it.

The importance of information

Information given by doctors is one of the most important success factors for several aspects of outcomes of health care, which also was supported by our web survey^{II}. Information given at a medical encounter has been shown to increase overall patient satisfaction^{131 139}, compliance to medical recommendations^{72 131} and medical outcome⁸⁸.

Patients often experience lack of sufficient information provided by doctors in their offices^{14 21}, e.g. prognostic information or diagnostic information⁸⁵. Of oncology patients in Canada, half reported having received insufficient information, and 71% actively searched for information themselves²⁸. In a US population survey, the most common frustrating experience after a visit to a physician was “*forgetting to ask all my questions when I’m with my doctor*”⁷⁶. Doctors, on their behalves, are not fully aware of patients’ wish for further information¹⁵⁰.

Information found at Internet searches help patients understand their medical problem, thus being beneficial for their decision-making ability and helping them taking better care of their health^{28 62 109}.

Communication and relationship

Written versus face-to-face communication

According to the free text answers in the web survey^{II III}, text-based communication has values complementary to oral communication in health care. A written message allows repeated reading without hurry at any time of day. The freedom of being able to submit an enquiry to *Ask the doctor* service from anywhere on an Internet-connected computer anytime was appreciated, however not always the delay of the answer.

During the last decade, written communication has become a natural part of many people's everyday life, partly replacing oral communication. Communication by email has become the most popular activity on the Internet⁵⁶. Sending SMS messages on cellular phones and participating in Internet chat sessions are other activities involving written communication, particularly popular among the youth and younger adults.

Some individuals, e.g. those who are more introvert than extrovert, may be more prone to express themselves by writing than talking¹²⁹. Writing might also be easier for anyone to express intimate matters or affectively laden thoughts, especially if the setting allows anonymity. Some people are more fine-tuned and more specific in written communication. The reflection on and formulation of one's health problems can give valuable, new perspectives to the writer, also exemplified by free text answers in the web survey^{II}. Doctors may also benefit from reading patients' narratives. By doing that doctors may understand their patients better and learn things they would not experience from textbooks⁸.

An important factor favouring communication in written form as a complement to oral, is that patients often do not recall or understand what the doctor has told them at face-to-face visits⁹⁵. A written supplement can increase both understanding and recall. Today's complexity of medicine with an increasing number of alternative treatment options, is another reason to provide more of the information in writing.

On the other hand, not everyone can effectively communicate their thoughts in writing due to e.g. cognitive factors⁵⁸. Also, the ease of submitting an enquiry to an *Ask the doctor* service may lead to enquiries that are not well thought out. This is probably more relevant when the service is free of charge.

Non-verbal communication

In text-based medical consultations on the Internet, the answering physician lacks the subtle information given by non-verbal communication. The body language, such as posture, gestures, voice, dress, facial expressions and smell, is missing in written communication. This kind of non-verbal communication is

important to correctly 'read' and understand the other person especially concerning emotional aspects¹³³. Younger persons are replacing facial expressions and sentiments by inserting *emoticons* i.e. ;-), ☺, ☹ in their messages, thus emphasising that they are joking, happy, sad etc. Notwithstanding this, the lack of information given by non-verbal cues makes it harder for the answering physician having to deal merely with the words of the enquiry. Not only is there a risk of misinterpretation, but also for that ambiguities in the enquiry text may activate the physician's imagination and fantasy, resulting in the risk of starting a *countertransference* reaction when the physician's own anxiety, wishes or antipathy are projected onto the enquirer³⁴. However, this is true with face-to-face meetings too.

An answer at an *Ask the doctor* service or in a patient information leaflet, no matter how well written it is, may still be misunderstood – but misinterpretations also occur in face-to-face meetings. Even well written, easy to understand, medical information is not equivalent to possessing knowledge *per se*³³. In a complex medical world, written information alone should not be the sole basis for sound medical decisions made by patients – both oral and written communication are required.

Doctor's role and the physician-patient relationship in Internet consultation

The family physicians that answered the enquiries at the *Ask the doctor* service studied regarded their new role as stimulating and challenging^{IV}. Some physicians stated that their answers might empower the enquirers. Numerous observers argue that the Internet has the potential to empower patients and transform the physician-patient relationship^{104 106 154}. Increased patient responsibility is facilitated by information supplied by web sites. Internet searches have been shown to empower patients, giving them a sense of being in control^{62 109}. Thus, the Internet catalyses the ongoing transformation of physician-patient relationships from 'Thank you, doc!' to 'Why, doc?'⁸¹.

Some concerns have been risen that the transformation in the physician-patient relationship as a consequence of patient's access to medical knowledge would contribute to a strained physician-patient relationship⁴. However, discussions of findings on the Internet with their physicians have been regarded positively by both parts^{22 28 109 124}.

Internet-based medical consultations may be regarded as an aspect of increasingly active information retrieval by patients. Ferguson⁵⁹ has stated that such consultations give rise to an entirely new type of '*provider-patient relationship*'. The answering Internet doctors "*don't really 'practice medicine' in the traditional sense*", they "*don't diagnose, treat, or offer the kind of authoritative and prescriptive advice*". Instead, they serve as '*couch-consultants*'. These doctors "*encourage e-patients to learn all they can about*

their medical conditions, to make their own decisions whenever possible, and to manage as much of their own medical care as they can”.

Informative/consumer model

Among the established models of physician-patient relationship, the Internet consultations described in the present thesis is most compatible with the *informative model* described by Emanuel and Emanuel⁴⁴. In this model, also called the *consumer model*, the role of the physician is to provide information to the patient, who then selects his/her therapy based on personal values.

The informative model has been criticised^{13 44} for eliminating the moral aspects of being a physician and reducing the interaction and impact of the relationship between the patient and the physician. However, text-based Internet consultation does not per se exclude moral elements in the answers, although the importance of the relationship is certainly reduced, particularly in a ‘one-time visit’. For some patients/enquirers obviously a personal relationship is not essential, or rather, not preferred since he/she chooses to be anonymous.

An ethically important component of a physician-patient relation is trust. Concerning trust in Internet medical consultation, Collste³⁵ has raised worries that “*the emotional component of trust is lacking in the case of the Internet doctor*”. In the web survey^{II} we found examples of the opposite. After reading the answer, an enquirer responding the survey wrote that he/she wanted to change his/her personal doctor to the Internet doctor, even asking for his/her address. Also, in psychotherapy delivered on the Internet, trust is seldom seen as a problem, rather the opposite is the case with risks of *transference reaction* involving idealising the online therapist¹⁴³. Another striking example of how trust can be established in a text-only relationship is the increasing activity of dating online^{75 97}.

Can Internet-based consultations replace visits at doctors’ offices?

Almost half (45%) of the participants in the web survey said they raised an issue not previously presented to health care professionals, and after reading the answer 43% had received sufficient information so as not to have the intention to pursue the question^{II}. Among the latter, it is probable that some enquirers could avoid a face-to-face visit to doctor’s offices. This was supported by a few free text answers explicitly stating that a visit was avoided. In a Norwegian primary care study, office visits were reduced by an average of one visit per year when patients were given the opportunity to use a web-based messaging system for communication with their regular doctor¹⁵.

In a number of free text answers in the web survey^{II}, participants said they used the service to see if it was necessary to see a doctor in person or not. This way of using the service is in line with the view of Neville¹¹² on regular patients’ email enquiries about clinical symptoms, who claims that these enquiries should

be regarded as a "form of triage to sort out who needs to be seen and when, and who may not need to be seen". Also, patients think that email may be useful for dealing with non-urgent medical problems⁹¹. However, not all doctors regard it as appropriate to evaluate a new symptom by email⁶⁶ and it is possible that some of the issues in the enquiries could be handled, for example, by a nurse at a telephone triage service.

Text-based medical consultations on the Internet vs. telephone triage

Concerning future health services, it may be of interest to ponder when asynchronous text-based medical consultations by physicians may be appropriate, and when synchronous nurse-led telephone triage may be more relevant (summarised in table 8).

Consultation on the Internet mostly provides an answer from a doctor, whereas telephone consultation services usually involve nurses. For emergency medical issues, the immediate response and the dialogue in telephone triage is relevant. Nurse-led telephone triage is also valuable for sorting out who needs to be seen/not seen by a doctor, by a nurse or self-care.

In established physician-patient relations, email consultation may be appropriate for follow-up of recently prescribed drugs, triage to sort out who needs to be seen/not seen at the doctor's office, renewals of prescriptions and administrative enquiries¹¹².

Internet consultation in the form described in our studies may be relevant when the enquirer wants to be anonymous or to get a second opinion. Also, when several treatment options exist, a written detailed answer can make it easier for the enquirer to understand the differences, with the opportunity to read the answer more than once. For non-urgent issues, text-based consultations may also be used for triage to sort out who needs to be seen/not seen face-to-face by a doctor.

Table 8. Different types of text-based medical consultations on the Internet vs. telephone triage

	Nurse-led telephone triage	Email consultation with regular doctor	Internet-based consultation with no previous relation with doctor
Communication	Telephone	Email	Email or via web-based messaging system
	Oral	Written	Written
	Synchronous	Asynchronous	Asynchronous
	Verbal dialogue	No verbal dialogue, but email correspondence or telephone contact may follow	No dialogue
Anonymity	Anonymity may be preserved	Anonymity not possible	Anonymity optional and often preferred
Appropriate for	Emergency issues	Non-emergency issues	Non-emergency issues
	Sorting out who needs to be seen/not seen by a doctor, by a nurse or self-care	Sorting out who needs to be seen/not seen by a doctor, by a nurse or self-care	Sorting out who needs to be seen/not seen by a doctor, by a nurse or self-care
	Advice on self care	Follow-up of treatments, prescription renewals, lab results	Intimidating issues and second opinions

Ethical aspects on text-based medical consultations on the Internet

The ethical* issues arising from the growing use of text-based consultations on the Internet are in many aspects different from those seen in regular health care. The relationship between the patient/consumer and the medical professional is different on the Internet (see p. 42). There may be a risk of harm, and it is of the greatest importance that any adverse effect will be reported. On the other hand, Internet-based consultation offers to the individual the opportunity to pose intimate questions that may be difficult to address in other circumstances. Anonymity and integrity are important ethical elements supported in text-based Internet consultations, as well as the individual's need for autonomy. Issues may also arise concerning privacy, confidentiality and security issues.

Further ethical issues of relevance in the present context are the incomplete and socially differentiated access to the Internet, communication aspects, and the need of ethical guidelines.

Healthcare delivery in a non-personal relationship

Probably, we will face an increasing amount of health care delivered by solutions not requiring a face-to-face communication. At first thought, it is easy to believe that good medical practice requires a personal face-to-face meeting, but in certain situations it should be ethically unacceptable to withdraw a treatment shown to be effective, just because it is given without any physical personal meetings involved.

Several common conditions such as depression³¹, panic disorder²⁴, phobias⁹⁸, headache⁵, insomnia¹⁴², eating disorders²⁶ and tinnitus⁶ have been shown to be relieved by self-help programmes based on cognitive behaviour therapy principles delivered by the Internet – treatments where there is no personal physical contact. If an individual finds his/her disease/condition embarrassing, or is living in a rural area where there are no medical professionals available, would it be unethical for him/her to undergo an online treatment or to get medical advice via the Internet by an *Ask the doctor* service?

* The World Medical Association defines ethics as “*the study of morality – careful and systematic reflection on and analysis of moral decision and behaviour, whether past, present or future*”¹⁶⁰.

Risk

In our studies, we have not found any examples of harmful events related to the Internet-based medical consultation. However, a small study of US doctors giving answers to medical questions via e-mail did find cases of potential harm. The researchers found that two of 17 doctors gave questionable answers to the enquirer, risking a delay in the patient receiving important medical treatment⁵⁰. In a UK study of Internet-using British physicians, 40% of respondents reported they had seen patients gaining physical benefits from the use of the Internet, while 8% reported physical harm, including possible deaths¹²⁴. However, in a 2002 review of published reports on harm related to the use of the Internet, just one report was found of a patient being physically harmed³⁷. Regarding the *Ask the Doctor* service studied, there are no adverse incidents reported yet (Hensjö LO, personal communication, August 2006).

There is a potential risk of misinterpretations in Internet-based medical consultation, as exemplified in the web survey¹¹, "*the Internet doctor partly misunderstood my complaints*". There is a risk that the individual in text-based consultation gives sparse, inadequate or even incorrect information, and thus the Internet doctor has to be cautious when answering the enquiry. Mistakes are less likely to appear with supervised training and licensing⁵⁰ before a doctor commences carrying out Internet-based medical consultation.

Internet-based medical consultation might also imply a risk of a negative impact on previous physician-patient relationships. When providing answers to enquiries via the Internet "*the information can be misinterpreted, simply wrong or out-of-date, or more up-to-date than that provided by the patient's physician*"¹⁵³. Thus, it is important to be careful, sensitive and diplomatic when providing the answers so as not to jeopardise the enquirer's relationship with the regular doctor.

Informed consent

When providing text-based consultation on the Internet, it is of great importance to clearly provide the enquirer with information on

- confidentiality issues, how the information provided by the enquirer will be stored, if material may become parts of medical records etc.
- security of the mode of communication, if encryption is used etc.
- issues inappropriate to use the service for, such as enquiries in emergency situations
- expected answering time
- ongoing research projects, polls etc (if any).

Training and licensing recommended

Presumably a growing number of physicians will be carrying out email consultations, but only a limited number of physicians will carry out consultations without any previous knowledge of the patient/enquirer.

Concerning education and licensing, we strongly agree that there is a need for ‘*cybermedical skills for the Internet age*’¹²⁷. In the medical schools of today should be included mandatory education on techniques of how to carry out literature searches on the Internet, how to clinically apply evidence based medicine and what to consider when communicating by e-mail with patients. Second, information on how to carry out consultations on the Internet, including the legal and ethical aspects, should be offered both in the curricula of medical schools and in continuous professional development (CPD). Third, for medical professionals planning to get involved in eHealth services, certification or licensing should be considered.

Need of ethical guidelines for delivery of Internet-based health services

Classical ethical guidelines for doctors such as the World Medical Association’s *International Code of Medical Ethics*¹⁵⁹ and the *Declaration of Geneva* do not address the ethical challenges implied by health services on the Internet. However, when comparing the delivery of text-based medical consultations of no-previous-relation type to the tenth paragraph of the Swedish Medical Association’s ethical code of 2002, “*the physician shall not give a patient advice or prescriptions without an examination or other sufficient knowledge on the patient*”¹⁴⁷, a conflict may arise particularly when the enquiry is short or ambiguous^{IV}.

With respect to email communication in health care, there are already a number of existing guidelines^{46 69 87}. There is also a strong need for establishing ethical guidelines for Internet-based consultations in the absence of a pre-existing patient-physician relationship. From the literature⁴⁹ and our own work^{IV}, the

principles presented in table 9 are suggested for inclusion in forthcoming ethical guidelines.

Table 9. Ethical principles of importance in Internet-based consultation without any previous relation between the enquirer and the answering doctor.

1. Always maintain the enquirer's privacy and confidentiality
 2. Avoid definitive diagnostic statements in the answers
 3. Be careful about being too definitive in answers, keep in mind that the enquirer's regular health professional often has more thorough information
 4. Use plain, easily understood language in the answers, and avoid unexplained medical jargon
 5. In general, encourage enquirers to be active, responsible and to be part of treatment decisions
 6. Avoid making negative remarks on the previous performances of the regular doctor or other health professionals
 7. Consider supervised training before starting to provide answers, and consider licensing for minimising the risk of harm and fraud
 8. Inform the enquirers of the inherent limitations of Internet-based consultation services
 9. Respect the principles of informed consent
-

Future role of the Internet in health care

In the future, responding to demands from patients/consumers, the cornerstone in the practice of medicine, face-to-face meetings, will likely be supplemented and sometimes replaced, not only by telephone as today, but also by synchronous or asynchronous communication by email, voicemail, SMS, web messaging or other electronic systems^{19 161}. These activities will be regarded as convenient, saving time and money for patients¹¹², possibly also for health care providers. Email directly from a patient to a physician, or via the staff at the office, are already demanded by patients, and will probably become commonplace. If and how physicians and health care providers embrace these new electronic communication activities remains to be studied. The opportunity for physicians to provide links to online resources such as informative web pages, images and photos, will not only be demanded by patients⁴¹, but might be timesaving for the physician⁶⁶ and increase patients' knowledge^{IV}. Physicians appreciate email communication with patients⁶⁶, but they also worry about increased workload¹²⁰, medicolegal risks⁸⁴ and not being reimbursed for the activities⁹².

As a consequence of the development in telephone and Internet communication technology, text-only online communication will probably increasingly be complemented or replaced by synchronous or asynchronous audio and visual communication by using microphones, web cameras and digital cameras.

Not only physicians but also other health professionals will start taking advantage of the online opportunities. Aside from self-help programmes based on cognitive behaviour therapy principles delivered by the Internet, psychotherapy delivered online is a growing phenomenon³⁰. Likewise, nurses⁹, dentists¹¹ and physiotherapists¹⁰ have started carrying out consultations on the Internet.

In a situation where daily life for an increasing number of people involves Internet-based activities, there are few reasons to believe that physician-patient communication will not also take advantage of the facilities provided online. A growing number of doctors and healthcare administrators believe that online communication between physicians and patients is no longer an "if" but a "when". In a 1999 survey, healthcare leaders predicted that more than 20% of all office visits could be replaced by an online equivalent by 2010¹²⁶. Before fully doing so, security issues such as encryption have to be regulated, routines for integration with medical records established and reimbursement issues solved. Also, the establishment of quality markers and standards of the information should be prioritised.

CONCLUSIONS

- In studies of a service for text-based consultations with family physicians on the Internet, we found an increasing use of the service during a four-year period, in particular among young and middle-aged women.
- The *Ask the doctor* service was used at all times of day or night, seven days a week. Almost half of the enquiries were submitted during evenings and nights.
- The use of the *Ask the doctor* service was widespread over the country but more frequent per capita in more densely populated areas.
- The Internet-based *Ask the doctor* service was consulted for several reasons such as convenience and saving time, the primary evaluation of a medical issue, dissatisfaction with previous doctors, the desire for a second opinion, a wish for deeper medical information, preference of being anonymous, having sensitive or embarrassing questions, or seeking medical advice for a relative.
- The family physicians that carried out the text-based medical consultations on the Internet found their new task to be stimulating and challenging with high educational value.
- Text-based consultations on the Internet offer to the individual the opportunity to pose intimate questions that may be difficult to address in other circumstances. Anonymity and integrity are important ethical elements supported by text-based Internet consultations, as well as the individual's need for autonomy. Thus, this consultation-type offers a complement to and in some cases may replace physical meetings in health care – although face-to-face-meetings remain the basis of the practice of medicine.
- Before starting to carry out text-based Internet consultations, training is recommended. Establishing of ethical guidelines should be prioritised.

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Appendix

Questions in the web survey of paper II and III:

1. Where were you when you sent your question to Infomedica's "Ask the Doctor" service?

- At home
- At work
- At a relative's or friend's home
- At a library, school or other public institution

2. Did you ask on your own behalf or for someone else?

- For myself
- Spouse/partner
- Own children
- Parents or other older relatives
- Others

3. Have you, or the person on whose behalf you are asking, already seen a medical professional concerning the issue in your question?

- Yes
- No
- Not applicable

4. Why did you choose to ask a question of Infomedica's "Ask the Doctor" service? Please, choose one or more of the following alternatives.

- It is difficult for me to find time to visit doctors
- I appreciate the opportunity to ask anonymously
- It is convenient to ask the question and to read the answer whenever it suits me
- It has been difficult to get an appointment at a regular health care unit
- I could not afford to see a doctor
- Doctors are so busy that they do not have time to answer questions
- I feel uncomfortable when I see a doctor
- Other, namely (followed by a free text box)

5. What did you want to find out by placing your question? Please, choose one or more of the following alternatives.

- I have symptoms and wonder what the problem may be
- I wanted another doctor's opinion about my symptoms
- I wanted more information on a specific disease
- I wanted more information on a drug
- I wanted more information on a treatment
- Other, namely (followed by a free text box)

6. Did you search in the Q&A library of previous questions to Infomedica's "Ask the Doctor" service before you wrote your question?

- Yes
- No

7. How many times have you previously submitted a question to Infomedica's "Ask the Doctor" service?

- This is the first time
- This is number (followed by a box for entering a number)

8. Did you get an answer to your question

- Yes, fully
- Yes, partly
- No, not quite
- No, not at all
- Not applicable

9. Are you satisfied with the answer

- Yes
- No, the answer was too short
- No, there were too many complicated words in the answer
- No, the answer was too simple compared to my question
- No, it took too long time to receive the answer

10. Will you pursue your question further after receiving an answer here?

- No, I have received enough information in the answer
- No, it was not that kind of a question
- Yes, with a previous doctor
- Yes, with a new doctor
- Yes, I will submit a question to another "Ask the Doctor" service on the Internet

11. Do you have other thoughts concerning the answer to question or to this "Ask the Doctor" service?

- No
- Yes, namely (followed by a free text box)

12. Do you have any ideas on how this service could be improved?

- No
- Yes, namely (followed by a free text box)

13. Your gender

- Male
- Female

14. Your year of birth

(box for entering a number)

15. Your postal code

(box for entering a number)