
Journal of Medical Internet Research

Journal Impact Factor (JIF) (2023): 5.8
Volume 2 (2000), Issue 1 ISSN 1438-8871 Editor in Chief: Gunther Eysenbach, MD, MPH

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Editorial

Towards ethical guidelines for e-health: JMIR Theme Issue on eHealth Ethics

Gunther Eysenbach, MD

(*J Med Internet Res* 2000;2(1):e7) doi:[10.2196/jmir.2.1.e7](https://doi.org/10.2196/jmir.2.1.e7)

Note added after publication: For debate see also Letter to the Editor JMIR 2000; 2:e13 and the response

The Internet is a vast resource for consumers, but to realize its full potential it is necessary to ensure the quality of information, or at least to help consumers to assess the quality of information. While the Internet and interactive health communication clearly has the potential to make patient-physician encounters more effective [1], a recent paper published in the Journal of Medical Internet Research showed that only 19% of Scottish GPs felt that they were "to use the time more effectively" if patients come with Internet printouts [2].

The principal dilemma of the Internet is that its anarchic nature is desirable as it fosters open debate without censorship, but at the same time it raises quality problems that could inhibit its potential [3]. However, a single or centralized review process, institution, or agency to ensure quality is neither desirable or realistic, since the Internet is a decentralized, global medium:

"Web 'publishers' of all stripes...should be free to post whatever they like and live with the consequences" [4]. We can call the resulting dilemma "farmer's dilemma," as any farmer battling with pests and weeds faces a similar problem: The more pesticides he uses, the more he inhibits the healthy growth of useful plants. Likewise, any "top-down" regulation on the Internet is prone to fail or to destroy "healthy" communication [3].

Instead, quality management of health information on the Internet depends on "bottom-up" mechanisms and essentially rests on four pillars - the "E's" (see [Figure 1](#)):

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

Figure 1. The four pillars of quality health information

Educating consumers

First, consumers need to be educated on how to "filter" [3] information, i.e. how to discriminate trustworthy information from less trustworthy information. Some basic criteria consumers could look at include authorship, sources of information, potential bias, and date of publication [4]. Other groups have developed interactive Internet tools which help users to evaluate information, i.e. to assess the quality themselves (<http://www.quick.org.uk>, <http://www.discern.org.uk>, <http://hitiweb.mitrectek.org/iq/default.asp>) [5]. For example, the DISCERN instrument [6] is a tool for assessing the quality of written patient information material. It has shown to be reliable for printed health information, but its validity has not been established for electronic information. An Internet version is currently being developed and awaits evaluation.

Encouragement of self-regulation and self-rating

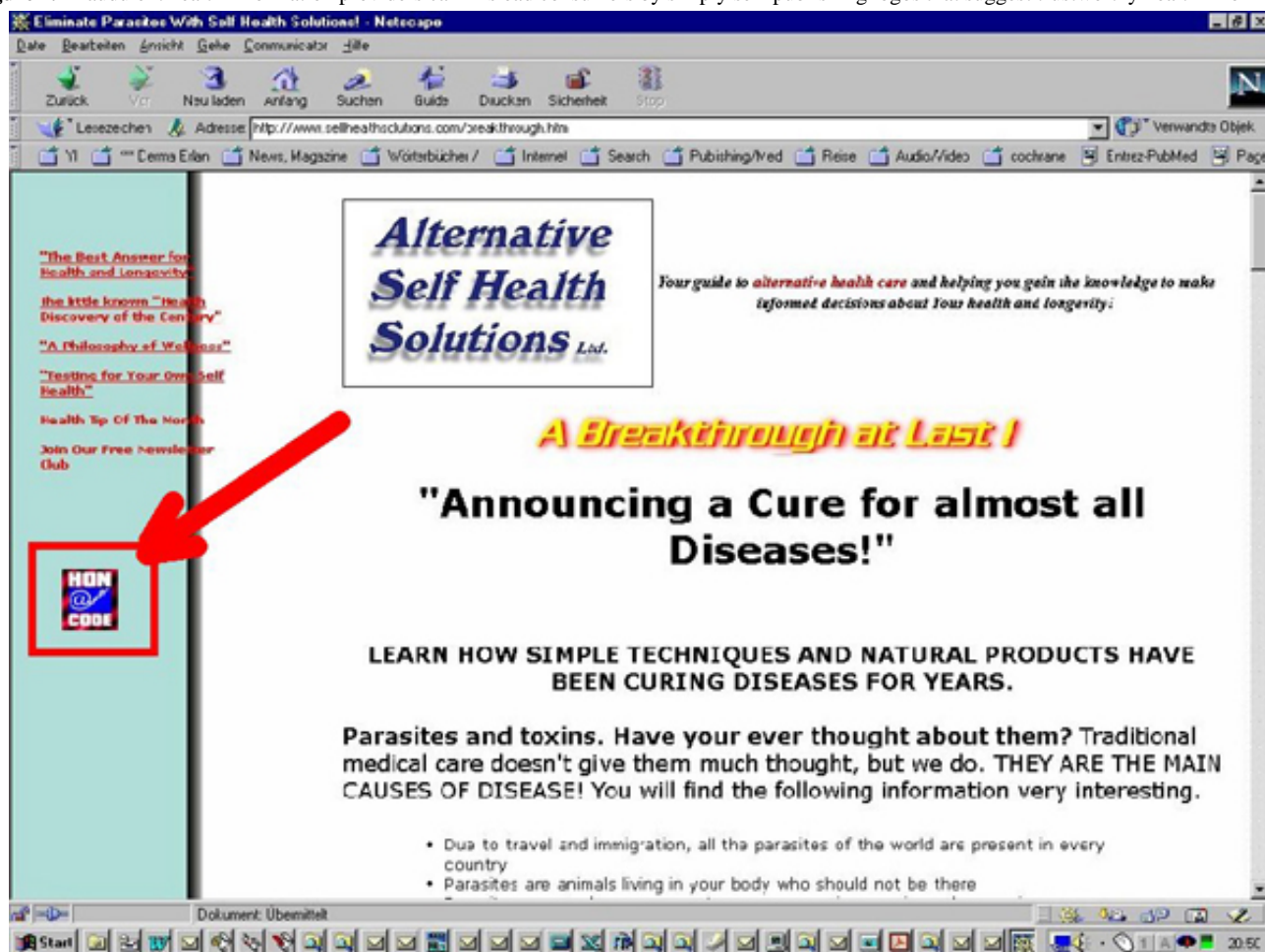
The second pillar consists of two different components. One component is self-rating of information providers, i.e. publishing of metainformation, which allows users to locate and filter

information automatically [3]. Information providers could, for example, include metainformation which indicates the target group of the information [7].

Another component is self-regulation. The Health on the Net Foundation has been among the first to suggest an ethical code for web publishers [8]. However, the suggested self-publishing of a logo (the HON-Logo) on the website of the information provider is problematic, perhaps even counterproductive; even quackery sites proudly display the logo (see Figure 2), and many consumers (and even health professionals) misunderstand the HON-logo as an "award". As the Health on the Net Foundation says, the HON-Logo was a "marketing trick," to make the HON Code well known.

However, without third-party evaluation and enforcement (which both will be addressed by the medCERTAIN project, see below), this ethical code is a toothless tiger. A more sophisticated system is needed, for example where the logo or "seal of approval" is generated dynamically by a third party (as planned in the medCERTAIN project described below).

Figure 2. Fraudulent health information providers can mislead consumers by simply self-publishing logos that suggest trustworthy health information



Self-regulation of industry suddenly became a hot topic in September 1999, when one of the leading health portals, <http://DrKoop.com> (see Figure 3a), was criticised for a lack of "web ethics." In an article published in the New York Times (see Figure 3b), the site (partly owned by former U.S. surgeon general Everett Koop) was criticized for having an inadequate distinction between editorial content and promotion. For example, DrKoop.com published a list of hospitals designated as "the most innovative across the country," not revealing that

these hospitals actually paid for the listing. Moreover, the site was criticized for calling advertisers "partners". Additionally, it was said that DrKoop.com violated medical ethics (the guidelines of the American Medical Association) by making money referring patients to other physicians: on the website, DrKoop.com published listings of clinical trials, receiving a fee paid by the clinical research company (Quintiles) for each patient "referral" - without revealing this fact.

Figure 3a. The DrKoop.com website with blurred borders between editorial content and advertising..

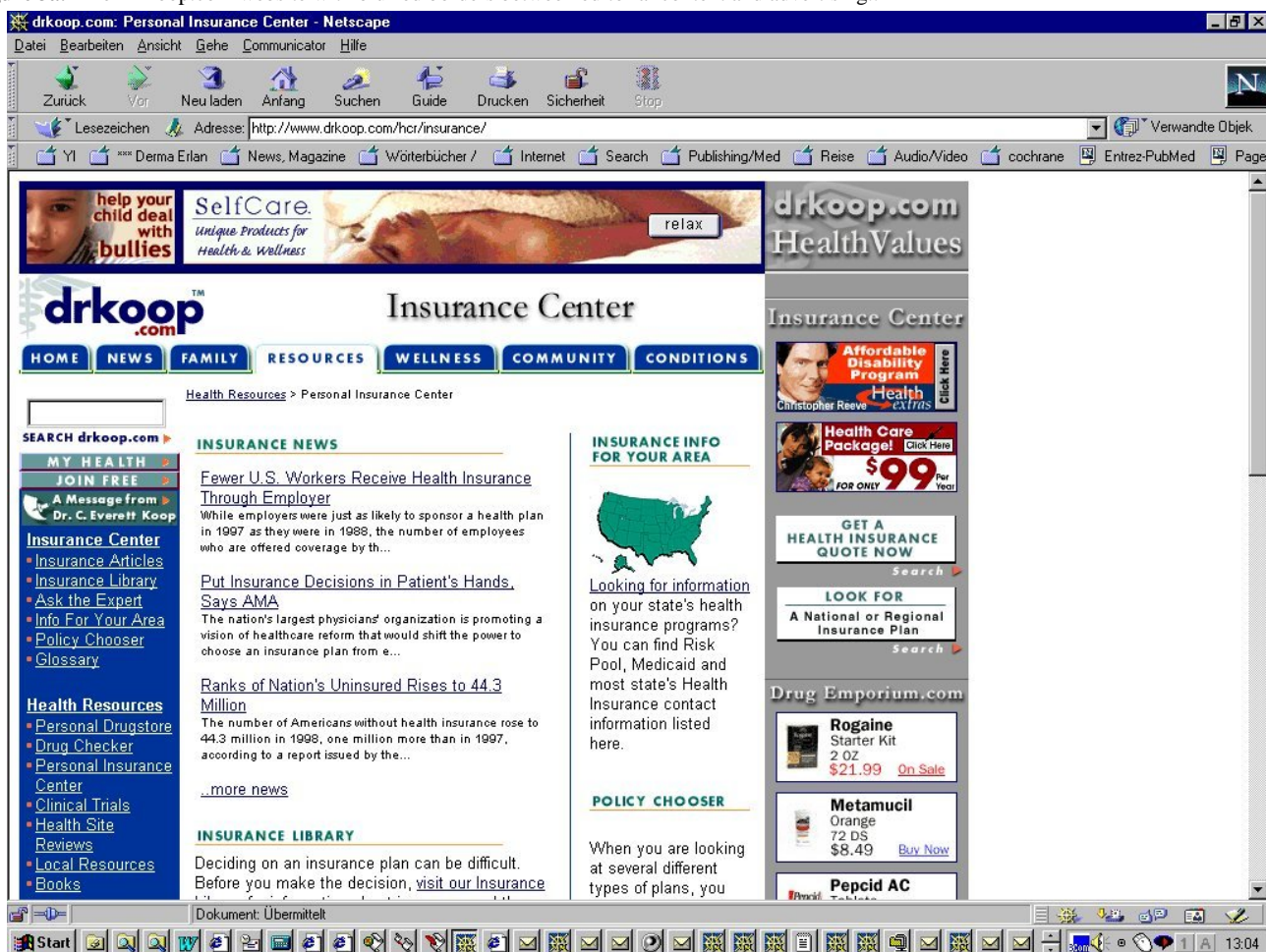


Figure 3b. ...was reproached by the New York Times due to their lack of "ethics."

Technology

The New York Times
ON THE WEB

September 4, 1999

Hailed as a Surgeon General, Koop Criticized on Web Ethics

By HOLCOMB B. NOBLE

During the eight years he held the post of U.S. surgeon general, Dr. C. Everett **Koop** became one of the country's most authoritative and recognizable public figures on the subject of health.

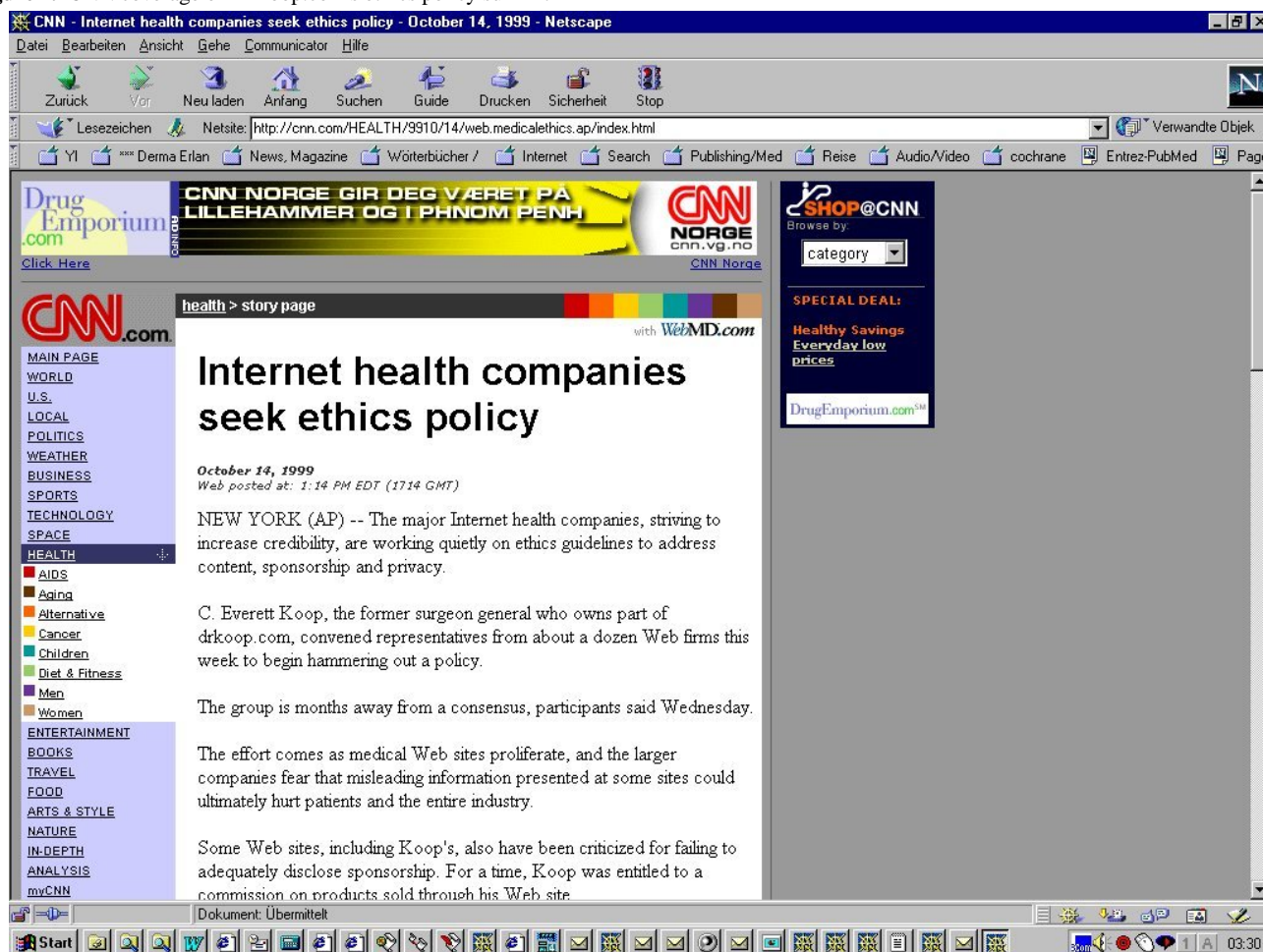
But more than a decade after leaving office, **Koop**, now 82, is facing criticism, from medical ethicists, including two representatives of the American Medical Association, consumer advocates and others.

Among the complaints are that his hugely popular health information Web site, DrKoop.com, has frequently blurred the line between its objective information and its advertising or promotional content,



The case was taken up by other media, and the loss of trust and reputation for DrKoop.com was considerable. As a consequence of this, DrKoop.com convened representatives from about a

dozen Web firms in October 1999 to begin hammering out an ethics policy (see [Figure 4](#)). However, the meeting ended with few concrete commitments.

Figure 4. CNN coverage of DrKoop.com's ethics policy summit

A few days later, on Wednesday, October 13, 1999, George Lundberg, editor in chief of the health portal Medscape and former editor of the Journal of the American Medical Association (fired for publishing a survey on sexual attitudes that coincided with President Clinton's impeachment), gave a keynote speech at the annual meeting of the Internet Healthcare Coalition (IHC), a non-profit organization mainly consisting of companies in the eHealth business [9], where he said: "The essence of professionalism is self-governance. Just as the International Committee of Medical Journal Editors, founded in 1978, has set the standards for how medical journal authors and editors should behave, the leaders of the e-health information enterprise should now set common standards for ethical behavior."

Two days later, the IHC announced it would organize a working summit in Washington D.C., on January 31st - February 1st, 2000, to forge a set of ethical principles for health-related Web sites. The summit was chaired by Helga Rippen and Ahmad Risk, both IHC Board Members (and also editorial board members of the Journal of Medical Internet Research). About fifty international experts were invited to the summit to meet in the rooms of the WHO/PAHO (World Health Organization/Pan-American Health Organization) in Washington. The attendees developed the guiding principles for a eHealth Ethics Code which addresses guidelines for Internet health information providers around issues like quality of content; commercial behaviour; privacy, security and

confidentiality; and use of the Internet in the practice of health care. A draft of this code is published in this issue of JMIR [10].

Evaluation

As mentioned above, self-regulation is only one step towards quality on the Web; two other steps are third-party evaluation and enforcement.

A recently-launched project named medCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net, <http://www.medcertain.org/>), funded by the European Union under the "Action Plan on promoting safer use of the Internet by combating illegal and harmful content on global networks" will tackle these issues, and therefore build directly on the work performed by the IHC. The project follows up the idea that the quality of health information and interactive applications on the Internet cannot and should not be controlled by a central body or authority, but instead information and applications must be evaluated and "labeled" in a decentralised and distributed way [3,11,12]. Labeling means to provide metainformation, i.e. to provide information about information, which may be descriptive or evaluative [7]. These information labels may be attached to other information on the web, and displayed whenever a user accesses a website. The medCERTAIN consortium plans to use the PICS standard (Platform for Internet Content Selection), which is compatible with every modern web browser. Whenever a user accesses a fraudulent web site, the browser requests a label from a third

party database, and can for example display a warning. Within the medCERTAIN project, a technical infrastructure is currently being developed which allows individuals, organizations, associations, societies, and other entities to digitally label (rate, evaluate, peer-review, give quality seals to...) online published health information using labels consisting of a standard computer-readable vocabulary (metainformation). The medCERTAIN consortium will also create different levels of certification for publishers of health information on the web (ranging from simple quality seals indicating the "good standing" of the site to "gold" quality seals indicating that the site has been peer-reviewed externally).

As mentioned above, the medCERTAIN project is one project funded under the "Action Plan on promoting safer use of the Internet by combating illegal and harmful content on global networks," adopted on December 21, 1998, by the Council of the European Union: "This action plan is a European Commission proposal for a number of initiatives from 1 January 1999 to 31 December 2002 with a total budget of 25 million Euro. The initiatives, created in close co-operation with industry, Member States and users, include a network of hot-lines, support for self-regulation, developing technical measures and awareness initiatives. The aim of the Action Plan is to ensure implementation of the various initiatives on how to deal with undesirable content on the Internet. It is designed to support non-regulatory initiatives for promoting safer use of the Internet" (<http://www2.echo.lu/iap/>).

While most of the initiatives under the Internet Action Plan are targeting content which could be harmful for children (pornography, violence), medCERTAIN proposes a system to establish a certification and rating system for rating and filtering of health information.

Enforcement

Enforcement requires feedback channels for worried consumers, procedures for evaluating complaints, and the possibility of appropriate measures such as labeling (blacklisting) of information providers who, for example, seriously violate ethical or legal standards. The EU Action Plan contains the concept of hotlines allowing concerned consumers to channel concerns; the medCERTAIN project will also contain feedback channels for consumers, which may lead to the re-evaluation of a site and retraction of a rating/certification.

Further articles in this issue

Aside from the draft version of the Washington Code of eHealth Ethics [10], this issue of JMIR further contains two reviews tackling the difficult issues of practicing medicine on the Web without a pre-existing patient-physician relationship (e.g. responding to unsolicited patient emails) [13] and the chances and challenges of e-psychotherapy [14]. Moreover we look into problems which are related to traditional problems of publishing ethics and academic misconduct [15,16]. Interestingly, this report on cyberplagiarism and the activities of the Journal of Medical Internet Research in this field, including a new policy that every submitted manuscript will be electronically scanned for plagiarism, have already attracted some media coverage [17] and may stimulate thought and debate in the publishing world about informatics tools which may detect academic misconduct and thereby enforce ethical conduct in publishing and research.

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Editor,

Journal of Medical Internet Research

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###Reviewer names will be inserted here### published 31.03.00.

Please cite as:

Eysenbach G

Towards ethical guidelines for e-health: JMIR Theme Issue on eHealth Ethics

J Med Internet Res 2000;2(1):e7

URL: <http://www.jmir.org/2000/1/e7/>

doi: [10.2196/jmir.2.1.e7](#)

PMID: [11720926](#)

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Editorial

Ethical and Legal Issues in Interactive Health Communications: A Call for International Cooperation

Roberto J Rodrigues

(J Med Internet Res 2000;2(1):e8) doi:[10.2196/jmir.2.1.e8](https://doi.org/10.2196/jmir.2.1.e8)

Cyberspace is a fast-changing, globally-networked, multicultural, and multilingual information environment with vast possibilities [1-9]. It calls into question national and international borders, cultural and ethical standards, regulations, and laws, which it bypasses and challenges [10-13]. In the health sector, self-care, drugs sold over the Internet, and providing access to technical knowledge and alternative forms of healthcare to the general public have destabilized drug regulatory mechanisms and the traditional physician-patient relationship.

The Internet offers unprecedented power to provide users of healthcare information - patients, professionals, families, caregivers, educators, researchers, insurers, regulators, and policymakers - with data of unprecedented timeliness, accuracy, depth, and diversity. The very qualities that make the Internet such a rich marketplace of ideas - its decentralized structure, global reach, leveling of access to the tools of publication, immediacy of response, and ability to facilitate free-ranging interchange - also make it an exceptional channel for potential misinformation, unethical use, concealed bias, covert self-dealing, fraudulent practices, and evasion of legitimate regulation.

There are many inadequacies concerning national and international controls and legislation, especially regarding the issue of jurisdiction; and urgent need for an internationally accepted policy framework that addresses basic rights and responsibilities of users and providers. Freedom of access to information and expression and the protection of users' data security and privacy are especially critical topics. Decisions and initiatives related to cyberspace law and ethics issues in health and healthcare must necessarily involve experts from a variety of knowledge domains involving civil and criminal law, medical ethics (bioethics), computing ethics, medical computing, and legal medicine.

Given the sensitive nature of health care information, and the high degree of dependence of health professionals on reliable records, the issues of integrity, security, privacy, and confidentiality are of particular significance and must be clearly and effectively addressed by health and health-related organizations and professionals. Two factors make the matter a subject of preeminent significance: the intrinsically sensitive nature of patient data; and the growing use of network computing, particularly the Internet, for healthcare information processing. The growth of off-site processing and storage of electronic health records by application services providers (ASPs) adds a new dimension to those issues.

Maintaining and safeguarding the integrity and physical protection of data and systems, privacy and confidentiality of individual health information, quality of content, and the protection of consumers and online health industry commercial interests against unethical practices, are the areas of greatest concern in the implementation and use of Internet and other interactive applications in health and healthcare.

Privacy involves many aspects [14-18], and the issue has been consistently one of the top concerns of users. The emergence of health data banks has given rise to fears related to privacy, right of access, and intended use of personal data. In many countries, proposals and actual reform of the laws have been enacted, according to which individuals are entitled to know what information is stored about them, who accessed that information, and what mechanisms are available to correct erroneous information [16,19-22]. Authenticity, reliability, and accuracy of the health-related information available on the more than 20,000 health sites that are available are major issues. Many websites are profit-driven, others promote unproven and even dangerous forms of treatment or products, while others may be good intentioned but contain misleading or false information. To ascertain the credibility, motives, sponsorship, and eventual conflicts of interest of websites is an extremely difficult task [3-5,17,23-27]. In the center of this "free-for-all," physicians are increasingly confronted with Internet-savvy patients who come to the consultation with a heap of downloaded material, ready to discuss his self-diagnosed condition and the latest mainstream or alternative treatments [4,28].

Electronic transactions involve important regulatory and legal issues not yet fully addressed. Vigilance in the maintenance of legal and ethical standards in the advertising, promotion, and sale of medical products through the Internet is required. Those standards include: approval of products, devices, and drugs by regulatory agencies at the site where the purchaser resides; the determination where the transaction occurred - in the purchaser's or the vendor's jurisdiction; and which courts and law will govern any disputes [29-31].

Although there is a general agreement among conscientious professionals that all health websites should be held to the same standard and that the introduction of some form of "seal of approval" is an interesting proposition, enforcement is still a nebulous area. Particularly in the international setting there are complex issues of jurisdiction not yet addressed by laws or agreements.

A number of organizations, government agencies, and scientific publishers have been active in the establishment of standards and methods to measure and assure credibility of health

websites. One of the first players is the Health on the Net Foundation, established in 1996 [32,33]. Another very active independent group more recently constituted, and congregating a large number of international stakeholders, is the Internet Healthcare Coalition [5,34,35]. Other groups include Internet [36-38] and scientific medical publishers [39], the American Medical Association, and European medical societies: for a discussion see [13]. Quality-assurance methodologies range from peer-review and professional authorship to open discussion in an open moderated or non-moderated forum and many approaches have been proposed in the evaluation, categorization, and labeling of health websites [24,40-47], the central issue being how to best protect the public interest.

Although security, privacy, and confidentiality are matters of concern in telecommunication-based clinical applications, and indeed major features of it, such applications raise new challenges regarding professional conduct and accountability, technical standards, licensure, and reimbursement [10,48]. Liability, model of care, and medical malpractice must be seen under a novel perspective as telemedicine involves more than one provider, usually geographically distant and subject to diverse practice and legal value systems.

The society and public authorities have the responsibility to make information considered as of "public good" universally available for educational, cultural, and social needs. The challenge is to define and implement concepts, such as public domain contents and universal access to networks and services; and to promote public welfare while encouraging private initiatives and protecting human dignity, personal rights, fair use, intellectual property rights, and rightful economic interests.

Traditionally, local standards are considered the yardstick against which health practice is evaluated, and they determine the parameters for eventual litigation. Remote conduction of health interventions brings forth, however, a whole new range of issues and ethical aspects in the telecare patient-provider relationship. Those issues have been reviewed and recommendations regarding a code of practice proposed [11,13]. Guidelines regarding the ethical and legal aspects of telemedicine are in the process of being developed by national and international trade, professional, and technical organizations and by national regulatory agencies. Medical software is increasingly considered as another form of a medical device. An extensive review of the legal aspects of telemedicine practice in the U.S. has recently been compiled in the Compendium of Telemedicine Laws [49].

Licensing and professional standards of care providers and regulation of e-commerce is done in many countries on a regional or state level. Validation of professional licensure, alternative and non-approved health practice, contending with fraudulent practice and misleading claims, regulation, and legal jurisdiction problems on a national and international basis are major regulatory and quality assurance problems in these circumstances.

The health sector has not addressed information security in a comprehensive manner. Healthcare organizations face a great variety of security, privacy, and confidentiality risks and must be made fully responsible for maintaining all aspects of security

and confidentiality of data and information. Eventual conflicts between data sharing, data security, and confidentiality must be addressed early in the process of systems procurement and development and after implementation. Some health organizations have implemented security features in their information systems, but most organizations do not have written rules or procedures for their employees who are authorized to access client's information, such as policies on disclosure of sensitive information, or personnel policies dictating the types of disciplinary actions that will be taken if staff violate policies. Nevertheless, regulations and technical standards for privacy assurance and maintenance of data integrity and access security must be reasonable, in terms of recognizing the realities of health care delivery, the variability of application environments, and the diversity of national ethical values and legal systems.

Developing countries are particularly affected by the rapid expansion of interactive communication technologies - increasingly, governments, professional organizations, advocacy groups, and users in developing countries have expressed their concerns about the impact of such happenings. Particularly, there is great apprehension about the reliability of healthcare information, new forms of health practice, advertising and commercial processes, content appropriateness, and privacy, as they pertain to the Internet. Multilateral or international agencies and national technical cooperation agencies are promoting the deployment of IHC applications, but have mainly focused on technological infrastructure development; little has been done regarding contents, human resources, impact evaluation, and ethical and legal aspects [1,4,8,50-53].

Ethical and regulatory questions, and national and international legislation addressing the many issues related to quality of information in the Internet, e-commerce, and telemedicine are a matter of present concern of many international organizations. The United Nations, and particularly UNESCO, the International Telecommunications Union (ITU), the World Health Organization (WHO), the World Trade Organization (WTO), regional trade blocks (European Community, NAFTA, MERCOSUR), and multilateral agencies such as the World Bank and the Inter American Development Bank have been in the forefront of initiatives directed to the promotion of exchanges in this area.

Those are urgent and controversial issues that must be addressed jointly and comprehensively by international organizations, national and international scientific and technical societies, service providers, industry organizations, and users' interest groups, and not only from the viewpoint of legal or commercial interests. The United Nations specialized agencies, government organizations, independent and nonaligned consensus groups [5,32,36,54-56], and trustworthy service and content providers [29,36-38] are particularly well positioned to spearhead the discussions leading to the development of innovative policies for the area and the establishment of an ethical code of conduct focused on content, advertising and privacy issues, and fraud detection designed to ensure that consumers are provided with health information that is reliable and safe.

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Conflicts of Interest

None declared.

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###Reviewer names will be inserted here### published 31.03.00.

Please cite as:

Rodrigues RJ

Ethical and Legal Issues in Interactive Health Communications: A Call for International Cooperation

J Med Internet Res 2000;2(1):e8

URL: <http://www.jmir.org/2000/1/e8/>

doi: [10.2196/jmir.2.1.e8](https://doi.org/10.2196/jmir.2.1.e8)

PMID: [11720927](https://pubmed.ncbi.nlm.nih.gov/11720927/)

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Review Paper

Ethical Issues in Providing Online Psychotherapeutic Interventions

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Abstract

The Internet offers psychotherapists a new communication medium through which they can deliver psychotherapeutic interventions that are appropriate to the medium. Yet online psychotherapy also offers new ethical challenges for therapists interested in providing online psychotherapeutic services. The differences between interactive text-based communication and in-person verbal communication create new ethical challenges not previously encountered in face-to-face therapy. This article will examine the Internet's potential for providing online psychotherapeutic interventions and will review the ethical issues involved with providing interactive text-based psychotherapy.

(*J Med Internet Res* 2000;2(1):e5) doi:[10.2196/jmir.2.1.e5](https://doi.org/10.2196/jmir.2.1.e5)

KEYWORDS

Internet; Psychotherapy; Psychiatry; Ethics; Quality of Health Care; Remote Consultation; Physician-Patient Relations; Professional-Patient Relations; Teleadvice; Electronic Mail

Introduction

The Internet provides a new medium for interpersonal communication that holds the potential for delivering forms of psychotherapeutic interventions that are appropriate to the medium. The challenges facing psychotherapists lie in discovering what types of interventions are appropriate to this new medium and in delineating the potential advantages and limitations inherent to this new communication format.

Mental health professionals are already exploring the usefulness of the Internet medium in delivering online psychotherapeutic interventions [1-3], and several professional associations have developed general guidelines for the online delivery of therapeutic services [4-6]. Simply practicing within recommended guidelines, however, does not release each individual therapist from the personal responsibility to be aware of, and to independently evaluate, the variety of ethical issues involved in the practice of online therapy. The obligation to act ethically cannot be transferred to an organization, but remains the personal responsibility of each therapist seeking to practice online.

The Internet provides several different communication systems, some of which are similar to in-person communication (e.g. video technology), some of which are similar to traditional print media (e.g. web pages), some are hybrids of interactive in-person communication and traditional written-word

communication (e.g. email and chat), and some are unique to the Internet medium (e.g. MOOs and MUDS). The ethical and pragmatic challenges facing psychotherapists seeking to use the Internet to deliver online psychotherapeutic interventions will vary depending upon which communication medium is being used.

This article will focus primarily on the use of email to deliver online psychotherapeutic interventions. While two-way video technology may someday become widely available, it is unclear whether it will ever gain acceptance as a common means of personal communication on the Internet. Two-way video technology has long been available for telephones, but people have not rushed out to buy video telephones. It is also questionable whether people will feel comfortable having video cameras in their homes. Cameras attached to personal computers may be viewed as an unwelcome intrusion into personal privacy. While interactive real-time video communication holds potential in a variety of health related interventions, the technology may remain limited to large organizational and hospital uses, without widespread dissemination into personal use. Should two-way interactive video become widely accepted and available, then it can be incorporated into delivering therapeutic interventions; and since video is a form of "-to-face" interaction, the ethical issues will, to a large extent, be similar to those encountered with in-person, face-to-face therapy.

Currently, however, email provides the backbone of interactive online communication, and it may hold the greatest potential for delivering psychotherapeutic interventions using the Internet [7]. The most significant feature of email is that it is text-based communication, and this is the source of its greatest strengths and its greatest limitations.

Issues Specific to Email Psychotherapeutic Interventions

As text-based communication, email is asynchronous (not in real-time), which allows the participants to communicate at their own convenience. The asynchronous nature of email can facilitate the client's perception of the therapist's availability, and may provide the client with a more intense psychological holding environment [8] than is available through a traditional in-person relationship. The perceived availability of the therapist may also enhance the client's ability to incorporate the therapist's presence into daily life. Rather than waiting for the weekly in-person session to discuss an issue, the client can instead write the therapist an email while the issue is still active, thereby evoking the therapist's psychological presence in the moment.

Asynchronous text-based communication also allows the parties involved to carefully consider and edit their communication, which is an advantage over real-time text or in-person communication. Even asynchronous video and audio communication do not offer the advantages of editing afforded by interactive text-communication. Asynchronous text communication actually involves writing small-scale essays, similar to traditional letter writing. The interactive nature of email communication comes from the speed by which these essays or letters are exchanged, which gives the illusion of greater interactivity than might actually be present.

Interactive text-based communication also involves the loss of the non-verbal social cues that provide valuable contextual information in conversation and can influence the interpretation of meaning in communication. Miscommunication may therefore be more likely with interactive email communication. The loss of physical social cues may also increase the client's tendency to project personal psychological material onto the blankness of cyberspace communication. This enhanced tendency toward projection of personal material in text-based communication may be helpful in some forms of psychotherapeutic interventions, and it may offer distinct advantages over in-person communication as well as a potential risk for increased miscommunication.

Nor does email need to be the sole intervention offered to clients. Email might be fruitfully integrated into a traditional in-person psychotherapy, allowing the client to continue the therapeutic process between in-person sessions with the therapist. The in-person therapist might prescribe certain writing assignments to the client, which can then be emailed to the therapist between sessions. The issues raised in the email can then be addressed during the in-person session. There is some evidence that persons may feel more comfortable self-disclosing through a computer [9]; and clients might use email communication to broach sensitive issues, such as past

experiences of abuse, that they may be unwilling to address during the in-person session. Having once raised the issue in email, it can then be dealt with more extensively during the in-person sessions.

Therapists might also incorporate email into cognitive/behavioral interventions. The in-person therapist can prescribe homework involving the monitoring of behavior or thoughts. This daily homework could then be emailed to the therapist, allowing the therapist more timely access to the client's progress. Daily emailing of homework to the therapist might also help motivate and reinforce the client's completion of the assigned homework on a daily basis. It would also allow therapists to monitor the intervention throughout the week; and if corrections to the behavior program are needed, they can be developed and incorporated into the program prior to the next in-person session. Incorporating email into a traditional in-person therapy holds the potential to increase the speed of therapeutic progress, the depth of material discussed, and cost-effectiveness of treatment [10].

Email clearly holds potential for delivering psychotherapeutic interventions, either by itself or in conjunction with a traditional in-person relationship. This potential has led increasing numbers of psychotherapists to begin exploring the use of email (and chat) to deliver psychotherapeutic interventions [1]. However, the use of a new communication medium involving interactive text-based communication raises unique ethical questions not previously addressed within the confines of the in-person therapeutic relationship. The delivery of therapeutic interventions solely through the Internet (i.e., not in association with an in-person therapeutic relationship) offers the most problematic ethical issues, and it will be those issues that will be focused on in the remainder of this article.

Guiding Ethical Principles

Ethical Responsibility to Provide Service

One of the initial ethical issues involves the responsibility of mental health professionals to provide services to meet the demand of consumers. While reservations may exist regarding the provision of online psychotherapeutic services, if consumers desire such services and if there is a reasonable expectation that online therapeutic interventions can be beneficial, then we have a professional obligation to address this demand. If mental health professionals do not step forward to provide these services, then consumers will be forced by the lack of response from the professional community to seek online therapeutic services from unlicensed and untrained providers. Inasmuch as there appears to be a reasonable expectation that some form of psychotherapeutic intervention can be developed that can appropriately be delivered using Internet text-based communication [7,11], it is incumbent upon the field of professional psychology to explore the ethical and professionally responsible delivery of online psychotherapeutic interventions. Yet, once we accept the obligation to explore the professional delivery of online psychotherapeutic services, then other problematic ethical issues emerge [12-15].

Do No Harm

The evaluation of the potential harms associated with any treatment intervention needs to be considered within the context of the potential benefits to be accrued from the intervention [16]. Only by considering both the potential risks and the possible benefits can we appropriately evaluate a proposed intervention. The simple presence of risk does not necessarily preclude the use of an intervention if it is sufficiently justified by the potential benefits. With interventions that have a reasonable likelihood of being beneficial for the client, the important issue becomes for the therapist to understand the nature of the risks, to minimize the risks to the extent possible, to fully inform clients as to the nature of the risks within the context of the possible benefits, and then to allow the clients to make an informed decision regarding their treatment options.

In assessing the risks of online psychotherapy it is also important to note that in-person psychotherapy is not without risks. In-person clients can become sexually attracted to the therapist and vice versa; therapists can be incompetent in the delivery of services; the therapist's confidential records are vulnerable to being stolen or viewed by unauthorized persons even if stored in a locked office and a locked file cabinet; miscommunication can occur during in-person therapy; and clients receiving in-person therapy can deceive and mislead the therapist. The issues with the delivery of online psychotherapy (e-therapy) are the extent to which traditional risks are enhanced in text-based communication, the possible emergence of novel types of risks not present in face-to-face therapy, and the degree to which the potential benefits justify the possible risks.

The use of email to deliver therapeutic interventions opens several areas of potential risk to online consumers. Clients of online services can be at greater risk for breaches in confidentiality [16,17]. This increased risk to confidentiality occurs at the therapist's end, at the client's end, in the transmission of information, and in the potential for legal subpoena of records. Therapists using the Internet to deliver therapeutic interventions should evaluate the security of their websites and computers against outside intrusions that would compromise client confidentiality. These intrusions might include high-tech invasions by hackers downloading files from the therapist's computer, to low-tech intrusions involving the inappropriate availability of the client's email to the therapist's office staff or family members. Therapists using the Internet to deliver online psychotherapeutic interventions may wish to consider installing systems which use firewalls, passwords, and backup data storage systems to increase the security of email communications and to protect against the inadvertent loss of clinical files resulting from computer malfunctions.

Online consumers of mental health services must likewise consider security issues on their end of the communication. Other persons who have access to the client's email, such as employers or family members, may be able to read stored copies of the client's email or incoming email from the therapist. Additionally, human error in addressing email has sometimes resulted in email being sent to the wrong person. Inadvertently sending private information meant for the therapist to a friend or family member can result in embarrassing and painful

situations for the client. Potential online consumers of mental health interventions need to be informed about these potential breaches of confidentiality in order to fully evaluate the possible risks versus the potential benefits of online psychotherapy.

Breaches of confidentiality can also occur as email is in transit. The potential vulnerability of email in transit may not, however, accurately represent its actual vulnerability in practice. While email may be intercepted in transit, it is unlikely that individual emails sent between private parties are actually intercepted and read from the incredible volume of email sent each day. Still, this potential breach in confidentiality needs to be understood and evaluated by clients before choosing to engage in online psychotherapy. Encryption technology can improve security of email communication, and online therapists may wish to make encryption of email routinely available to their clients.

Online mental health clients also need to consider the possibility that email records may be subject to subpoena. While professional communication with physicians and attorneys is considered legally privileged, it is unclear if this legal protection extends to psychotherapists. The standards for recognition of legal protection of privileged communication may also vary from one jurisdiction to another. Online psychotherapists should consider their policy regarding the disclosure of records in response to legal subpoena, and clients need to be informed about this possible breach of confidentiality.

The use of email to provide psychotherapeutic interventions also entails other risks to clients beyond those associated with the confidentiality of communication. For example, the loss of nonverbal cues significantly impedes the therapist's ability to make a full assessment and diagnosis. Important in-person cues, such as flattened or inappropriate affect, characteristics of speech, memory function, or physical evidence of a medical condition that may be associated with the psychological symptoms, are all lost in email communication. An impaired ability to make an adequate diagnosis will adversely affect the ability of online therapists to develop appropriate treatment plans and, as a result, the treatment interventions that are developed may be to the detriment of the client. Online testing may improve diagnostic capabilities [18], and gathering a full psychosocial history may be facilitated by online questionnaires; yet the loss of visual and auditory cues will still affect the therapist's diagnostic ability, and the impact of this diminished diagnostic capability needs to be carefully considered. Still, while problems making online diagnoses may limit the scope of issues appropriately addressed in online therapy, some types of online interventions, such as interactive journaling [7] or humanistic/existential approaches, may nevertheless be developed that are appropriate for delivery in a text-based format with some populations.

The increased potential for miscommunication in text-based therapy may also increase the risk of inadvertently harming clients and perhaps re-traumatizing emotional injuries disclosed during the course of online therapy. Text-based interactive communication is more vulnerable to miscommunication because it lacks the non-verbal cues associated with in-person communication that modify meaning and provide context for the interpretation of meaning. Furthermore, interactive text

communication is not the normal means of interpersonal communication for most therapists trained in in-person psychotherapy. Therapists may therefore lack the writing skills needed to express subtleties of meaning through the written word.

Working with psychological issues typically involves addressing conflicting client motivations involving a desire for self-disclosure aimed at securing help for painful personal issues, and competing motivations directed toward maintaining interpersonal defenses to preserve self-esteem and prevent re-traumatization of emotional injuries. Interactive text-based communication often sounds harsher than intended. Online miscommunication may result in clients feeling hurt because they perceive the therapist's response as being critical or rejecting. Online clients also do not have the benefit of the interpersonal holding environment offered by the in-person relationship in which to interpret and integrate the therapist's comments, and injured online clients may be more likely to simply withdraw from the relationship into the blankness of cyberspace, taking their injury with them. Since nonverbal feedback cues that might signal the miscommunication, such as the client's body language and facial expression, are not available in email communication, online therapists may often be unaware of the miscommunication and therefore will be unable to address the client's injury.

This possibility of emotional injury and re-traumatization may be further exacerbated by the increased self-disclosure and disinhibition associated with online communication [9,19]. While increased self-disclosure may be helpful in some therapy circumstances, it may also involve clients prematurely moving past defenses designed to protect them against emotional injury and re-traumatization. This may leave them more vulnerable to injury should they interpret a therapist's communication as being critical or rejecting.

Clients in online psychotherapy may also be at increased risk of harm if the online intervention is not effective in creating change in the client's life, yet offers enough solace so as to reduce the client's motivation to seek more beneficial in-person therapy. Consumers of online mental health services are at risk in this case not because of a direct effect of the online intervention, but because the online intervention prevents them from seeking treatments that will more effectively address their needs. However, e-therapy may also serve as a convenient and helpful entry into the mental health system for many persons who might benefit from therapy but who are reluctant to begin in-person therapy because of the social stigma associated with psychotherapy, their anxiety of addressing emotional issues, and the physical inconveniences of scheduling in-person therapy sessions. For such persons, the convenience and perceived anonymity associated with computer-mediated communication may encourage them to contact an online psychotherapist. Their initial online therapeutic relationship may help demystify psychotherapy and facilitate their entry into in-person mental health treatment.

The ethical practice of e-therapy requires that therapists develop a thorough understanding of all of these issues. Online discussion groups dealing with Internet psychology can help

therapists explore some of these issues. Yet, despite the therapist's professional evaluation of the issues involved with providing online therapeutic interventions, the ultimate issue is the degree to which the potential benefits justify the possible risks, and a decision on this issue can only come from a fully informed client. While mental health professionals can decide that the potential benefits associated with the intervention do not justify the risks, the opposite decision, that the benefits do justify the risks, can only be made by a fully informed client. Therapists seeking to provide online psychotherapeutic interventions must, therefore, be informed as to the potential risks so that they can take every possible precaution to reduce or eliminate those risks, and so that they can fully educate potential clients regarding the possible risks associated with e-therapy.

Providing Effective Interventions

While controversies exist as to what criteria should be used to evaluate the effectiveness of psychotherapy, in-person psychotherapy nevertheless has an extensive history and well-elaborated theoretical frameworks supporting its use. Both history and theoretical frameworks are missing from the practice of interactive text-based therapy, and it is currently unclear to what degree traditional therapeutic orientations and models can be translated into online, text-based communication. Most psychotherapy depends, to a greater or lesser degree, on the development of the therapeutic relationship [20-22]. However, it is precisely the nature of the therapeutic relationship that is most impacted by text-based communication.

The ethical practice of e-therapy requires the therapist to have a clearly delineated model of psychotherapy appropriate to delivery in a text-based format [7,18]. In the emerging field of online psychotherapy, it would also behoove the ethical practice of e-therapy if therapists remained close to empirically derived support for the interventions used until more experience is gained with regard to the medium of interactive text-based communication. Therapists providing online psychotherapeutic interventions should also contribute to the developing understanding of e-therapy by conducting quantitative and qualitative evaluations of the services they deliver.

Practicing Beyond the Boundaries of Competence

For psychologists, the Ethical Code of the American Psychological Association [23] specifically directs that psychologists should practice only within the area of their competence based on training and experience (Standard 1.04a); and that where standards for training do not yet exist, psychologists should "take reasonable steps to ensure the competence of their work and to protect patients, clients, students, research participants, and others from harm" (Standard 1.04c; p. 1600). Psychotherapists trained in traditional psychotherapy need to carefully consider whether they are competent to practice in an interactive text-based format, and to evaluate by what manner and training they achieved their competence in this new communication medium.

Interactive text-based communication offers an entirely new communication format that differs significantly from in-person verbal communication. The nonverbal cues that in face-to-face

communication provide valuable information that modifies meaning and aids interpretation of the communication are significantly absent in text-based communication. It takes considerable skill to communicate emotion and contextual intent solely through the written word. Text can often sound harsher than intended and, without contextual cues such as tone of voice and body language, text-based communication is more likely to be misunderstood and misinterpreted. With text-based communication there is also a greater likelihood of projective psychological material emerging in the absence of the physical presence which serves to ground in-person communication. Skill in verbal communication does not necessarily translate into skill in written communication, especially interactive text-based communication that involves a series of interpersonal interpretations within each exchange.

Without clearly delineated models for text-based psychotherapy, and without training in the subtleties of interactive written-word communication, therapists seeking to provide online psychotherapy need to carefully evaluate their current level of competence to practice in a text-based format.

Professional Accountability and the Redress of Grievances

Mental health professionals wishing to practice online also need to consider their legal authority to practice in a jurisdiction in which they are not licensed to practice [24]. This issue extends beyond the legality of their activity to include the rights of clients to redress grievances.

The ethical practice of online psychotherapy must provide for the client's ability to redress grievances. Clients should be clearly informed prior to beginning an online therapeutic relationship about the regulatory agencies and professional associations governing the therapist's work [5]. Still, simply being informed about oversight agencies may not offer online clients an actual ability to redress grievances when the therapist and client may live in separate jurisdictions separated by hundreds or even thousands of miles [24]. For example, while it may be possible for a client in India to file charges with an ethics board or Attorney General located in the therapist's home jurisdiction of Wisconsin, the practical limitations imposed by distance and the financial resources needed to overcome such limitations may leave the client unprotected in fact.

Laws governing the appropriate practice of psychotherapy, such as ordinances governing the release from confidentiality to report child abuse, may also differ from one geographic jurisdiction to another. When the therapist and client live in two different legal jurisdictions with differing laws regarding the practice of psychotherapy, which jurisdiction's laws take precedence and govern the client-therapist relationship?

In order to avoid the many problematic legal and professional issues related to practicing psychotherapy online, some therapists may be tempted to define their online work as psychoeducational rather than psychotherapeutic. While some online work can legitimately claim to be primarily educational, therapists treating individual clients across multiple sessions should carefully consider whether their work is primarily educational or therapeutic. One of the central issues in making

this distinction is whether the client perceives an individual professional relationship has been established. While it may be tempting to try and circumvent legal and professional liability for online work by defining it as psychoeducational, it creates significant ethical problems if such a definition misrepresents the service. Ethical problems can also arise if the online service being provided is held out as therapeutic on one web page, with a disclaimer of psychoeducational intent located on a separate web page. An ethically appropriate description of the online service must clearly, consistently, and accurately describe the intent of the service and the nature of the professional relationship involved.

Informed Consent

The absence of physical presence also impacts the ability to verify identity. Without the ability to verify identity the issue of treating minors without parental consent becomes problematic. Therapists seeking to practice online must evaluate what steps will be taken to verify the age of clients so as to not treat minors without the knowledge and consent of their parents.

In addition, the issue of informed consent is closely related to the issue of disclosure. As discussed earlier, in order to make an informed consent to treatment clients need to fully understand the potential risks and benefits associated with an intervention. Specific risks that clients need to be informed about involve the possibility that inadvertent breaches of confidentiality may occur with online communication, the experimental nature of online psychotherapeutic interventions and the possibility of unknown and unintended consequences, and the potential for miscommunication in text-based communication [25].

In some ways, however, the Internet offers advantages in developing an informed consent process. Professional web pages allow for multi-faceted and multi-layered discussion of relevant issues which remain constantly available on the Internet for clients to review. Web pages can address issues such as the potential risks involved with online treatment and the theoretical underpinnings of the treatment. The discussion of informed consent through email also allows for a documented record of the informed consent process.

Crisis Intervention Planning

Online psychotherapists need to consider plans for addressing the variety of crises that may present in therapy including suicidal clients, physical and sexual abuse, threats to harm others, and the possible discovery that the client's issues would more appropriately be addressed with intensive in-person therapy or hospitalization. Prior to beginning a therapeutic online relationship, therapists may wish to discuss crisis plans and develop in-person referrals local to the client in preparation for possible future crises. Such crisis planning should include obtaining a verified valid street address and phone number that would allow the therapist to invoke the local police should such an intervention become indicated.

Boundary Issues

Therapists interested in providing online interventions also need to consider the possible boundary issues involved with establishing an online therapeutic relationship. For example,

with instant message systems clients might be alerted every time the therapist is online and could send the therapist instant messages for chats every time the therapist signs onto the Internet. Clients might also access the therapist's personal web page or sign onto online discussion groups to which the therapist also belongs. In addition, some clients may continue to send the therapist emails after the termination of the relationship, and e-therapists will need to consider their response to such ongoing contact. Some clients may also use the Internet to harass or stalk current or former therapists.

Conclusions

The Internet provides new opportunities to provide beneficial psychotherapeutic interventions with clients. Yet in providing online psychotherapeutic interventions, therapists need to evaluate the degree to which the online clients are informed regarding the potential risks they are assuming, including the risk that because there is little formal research on the process

of online therapy, there may arise unforeseen and unanticipated problems. Therapists also need to evaluate their own competency to deliver text-based interventions and the source of this competency in their background and training. Before providing online therapy, mental health professionals also need to develop theoretical models for the interventions being used that are appropriate to delivery in a text-based format.

Therapists seeking to provide online interventions also need to become thoroughly familiar with the risks associated with e-therapy and with the professional guidelines being developed for the ethical practice of e-therapy. Online professional discussion groups devoted to Internet psychology may help by offering professional consultation regarding issues related to e-therapy; yet therapists cannot rely entirely on professional guidelines or online consultation, and must actively accept their personal responsibility for fully understanding, considering, and addressing the potential ethical issues involved with online therapy.

Conflicts of Interest

None declared.

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submitted 01.03.00; peer-reviewed by J Grohol; comments to author 15.03.00; revised version received 20.03.00; accepted 20.03.00; published 31.03.00.

Please cite as:

Childress CA

Ethical Issues in Providing Online Psychotherapeutic Interventions

J Med Internet Res 2000;2(1):e5

URL: <http://www.jmir.org/2000/1/e5/>

doi: [10.2196/jmir.2.1.e5](https://doi.org/10.2196/jmir.2.1.e5)

PMID: [11720924](https://pubmed.ncbi.nlm.nih.gov/11720924/)

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Special Case Report

Report of a case of cyberplagiarism - and reflections on detecting and preventing academic misconduct using the Internet

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Abstract

Background: The Internet is an invaluable tool for researchers and certainly also a source of inspiration. However, never before has it been so easy to plagiarise the work of others by clipping together (copy & paste) an apparently original paper or review paper from paragraphs on several websites. Moreover, the threshold of stealing ideas, whether lifting paragraphs or perhaps even whole articles from the Internet, seems to be much lower than copying sections from books or articles. In this article, we shall use the term "cyberplagiarism" to describe the case where someone, intentionally or inadvertently, is taking information, phrases, or thoughts from the World Wide Web (WWW) and using it in a scholarly article without attributing the origin.

Objective: To illustrate a case of cyberplagiarism and to discuss potential methods using the Internet to detect scientific misconduct. This report was also written to stimulate debate and thought among journal editors about the use of state of the art technology to fight cyberplagiarism.

Methods: A case of a recent incident of cyberplagiarism, which occurred in the *Journal of the Royal College of Surgeons of Edinburgh* (JRCSEd), is reported. A systematic search of the Internet for informatics tools that help to identify plagiarism and duplicate publication was conducted.

Results: This is the first in-depth report of an incident where significant portions of a web article were lifted into a scholarly article without attribution. In detecting and demonstrating this incident, a tool at www.plagiarism.org, has proven to be particularly useful. The plagiarism report generated by this tool stated that more than one third (36%) of the JRCSEd article consisted of phrases that were directly copied from multiple websites, without giving attribution to this fact.

Conclusions: Cyberplagiarism may be a widespread and increasing problem. Plagiarism could be easily detected by journal editors and peer-reviewers if informatics tools would be applied. There is a striking gap between what is technically possible and what is in widespread use. As a consequence of the case described in this report, JMIR has taken the lead in applying information technology to prevent and fight plagiarism by routinely checking new submissions for evidence of cyberplagiarism.

(*J Med Internet Res* 2000;2(1):e4) doi:[10.2196/jmir.2.1.e4](https://doi.org/10.2196/jmir.2.1.e4)

KEYWORDS

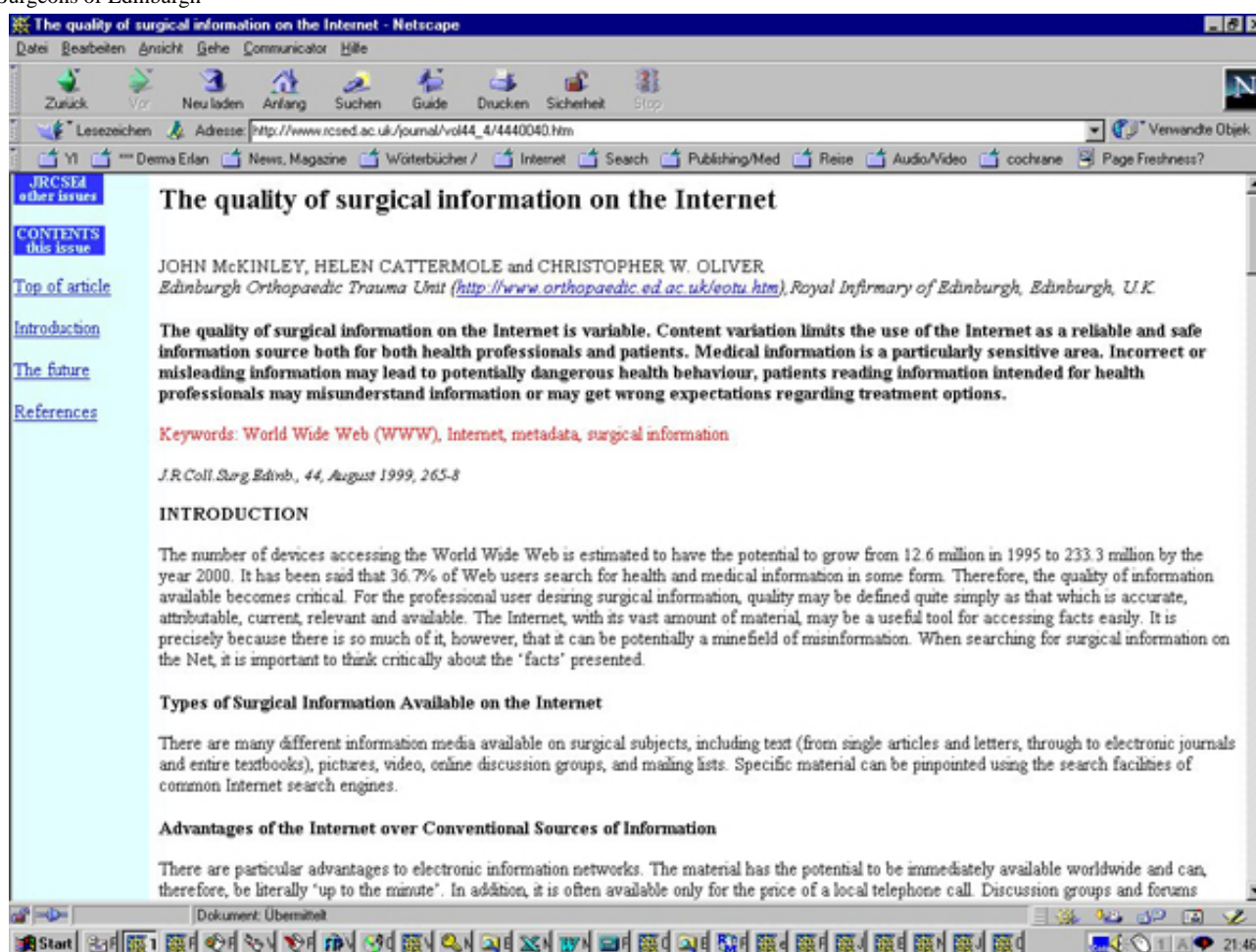
Ethics, Professional; Plagiarism; Scientific Misconduct; Publishing; Internet; Retraction of Publication; Copyright; Peer Review; Software; Information Retrieval

The JRCSEd Cyberplagiarism Case: Chronology of Events

On 5 August 1999, a paper titled "The quality of surgical information on the Internet" (see [Figure 1](#)) was published in the

Journal of the Royal College of Surgeons of Edinburgh (JRCSEd) [1]. The JRCSEd is a journal indexed in several bibliographical databases including Biological Abstracts, EMBASE, Current Contents, Index Medicus/MEDLINE, and others; and is published bi-monthly by the Royal College of Surgeons of Edinburgh.

Figure 1. The online version of the questionable article, which contained lifted phrases from the web, as published in the Journal of the Royal College of Surgeons of Edinburgh



After publication, it was determined that more than one third (36%) of this article consisted of phrases that were directly copied from multiple websites, without giving attribution to this fact. This can be labelled as plagiarism, which has been defined by the US Committee on Science, Engineering, and Public Policy as "using the ideas or words of another person without giving appropriate credit." The Committee continues by saying that plagiarism is a "strike at the heart of the values on which science is based. These acts of scientific misconduct not only undermine progress but the entire set of values on which the scientific enterprise rests" [2]. In this article, I will refer to this incident as an act of cyberplagiarism alluding to the fact that information from "cyberspace" (the Internet) was lifted into a scholarly article. The question of whether this incident of plagiarism was intentional or inadvertent should not be discussed here.

The case of cyberplagiarism

The following is a quick recap of the event: Shortly after publication of the article in question [1], the senior author (C.O.) announced the publication of the paper by sending out emails alerting those potentially interested in this paper; among the recipients was the author of this report (G.E.), who immediately recognised that significant parts of this paper were based on ideas presented in the article "Towards quality management of medical information on the internet: evaluation, labelling, and

filtering of information," published a few months earlier in the *British Medical Journal* (BMJ) [3]. This paper was not cited. This fact alone would probably not have fostered any further action taken alone, as probably every published researcher has experienced a similar situation.

But in this case it went beyond just a missed reference, as the authors of the JRCSEd article also took material from the website <http://medpics.org> (which was then posted on the site <http://www.derma.med.uni-erlangen.de/medpics/>) without attribution. More than half of the abstract consisted of sentences from this website, and also a subjective expression of an opinion ("We believe that one of the responsibilities of any health professional is to guide patients through health related information") was lifted unchanged from the website into the article. In total, at least three lengthy paragraphs (about 400 words, which constituted around 20% of the article) were taken practically unchanged from the medPICS website. A later comparison with the whole Internet using the tool at <http://www.plagiarism.org> (described below) identified further portions of the manuscript which had been taken from other websites, most notably another 350 words lifted without attribution from <http://purl.oclc.org/docs/core/index.htm>, a webpage copyrighted by the Dublin Core Metadata Initiative. Taken together, well over one third (36%) of the manuscript published in JRCSEd consisted of sentences that had been lifted directly and without

editing from other websites, (see plagiarism.org report, [Figure 2](#)) without attribution or giving credit to the originators.

The editor in chief of JRCSEd, Professor Oleg Eremin, alerted by the author of this report (G.E.), started an investigation. The editorial board concluded that "there has been a serious infringement of copyright." The electronic version of the article was permanently deleted from the journal website. The author of the plagiarism (C.O.) was asked to write a letter of apology for publication. In a subsequent issue of JRCSEd, the editorial board published a notice of the fact that parts of the manuscript were identical to online material published at <http://medpics.org> and about the withdrawal of the article [4]. C.O. himself apologized in a published letter [5] acknowledging that "my article contained certain paragraphs which are broadly similar to articles which he has published at <http://medpics.org> and which I did not reference in my paper" and saying that "it was entirely unintentional and occurred as a result of an oversight in the preparation of the manuscript." No reference was made to the fact that more than one third of the article was actually not only "broadly similar" but indeed taken unchanged from the web, nor to the fact that not only one website was exploited that way.

Using Informatics Tools and the Internet to Detect Plagiarism

The Internet, with its vast amount of information at the fingertips of every researcher, makes it easy to lift whole phrases and paragraphs into scholarly articles. This can be a useful strategy to gather material and ideas; such techniques, and also quotes from websites, are certainly legitimate, as long as the sources are acknowledged and quotes are clearly identified as such. As this case shows, researchers are not always successful in quoting properly and may even inadvertently end up committing plagiarism.

Luckily, the Internet can also provide some technical solutions for researchers to identify unintentional omissions of attributions and for journal editors and peer-reviewers to detect and fight

plagiarism. Although a number of informatics approaches are thinkable and could be applied routinely, not all of the possible approaches are in fact realised in the form of commercially available applications, and if they are, they are rarely used by researchers, journal editors, or peer-reviewers. In the following sections, I will review a number of possible approaches (which in part still wait for programmers to translate them into software).

Retrospective control: Checking submitted manuscripts against the web or a collection of articles

One possible approach is to check a manuscript (for example a manuscript that has been submitted to a peer-reviewed journal) against the whole World Wide Web (WWW) and/or another collection of published articles (such as the abstracts in MEDLINE, the full text articles in PubMed Central, or e-print servers), in order to identify similar or identical phrases. While generic search engines such as AltaVista could be used to search for simple phrases, they do not allow the user to check a whole manuscript against the Web. Moreover, they cannot detect simple word substitutions; thus, plagiarists may hide the true origin of their selections by simply replacing as many words as possible with synonyms.

A more sophisticated, specialized "search engine" to detect plagiarism has been developed by Barrie and Presti [6]: <http://www.plagiarism.org> was originally developed for professors to check the originality of student term papers. Term papers submitted for a class requirement can be checked against a database of other manuscripts collected from different universities, classes, and from all over the Internet.

To test the power of the system I submitted the questionable manuscript published in JRCSEd (see case report above) to the system. The plagiarism report was returned within 24 hours. The system not only flagged the paper as "medium original," but also highlighted 36% of the document as originating from different websites, most notably from the med-PICS and the Dublin Core metadata websites (see [Figure 2](#), [Figure 3](#), and [Figure 4](#)).

Figure 2. The plagiarism.org report detected similarities with twelve webpages (listed under "similar links"). The originality of the paper was rated as "medium."

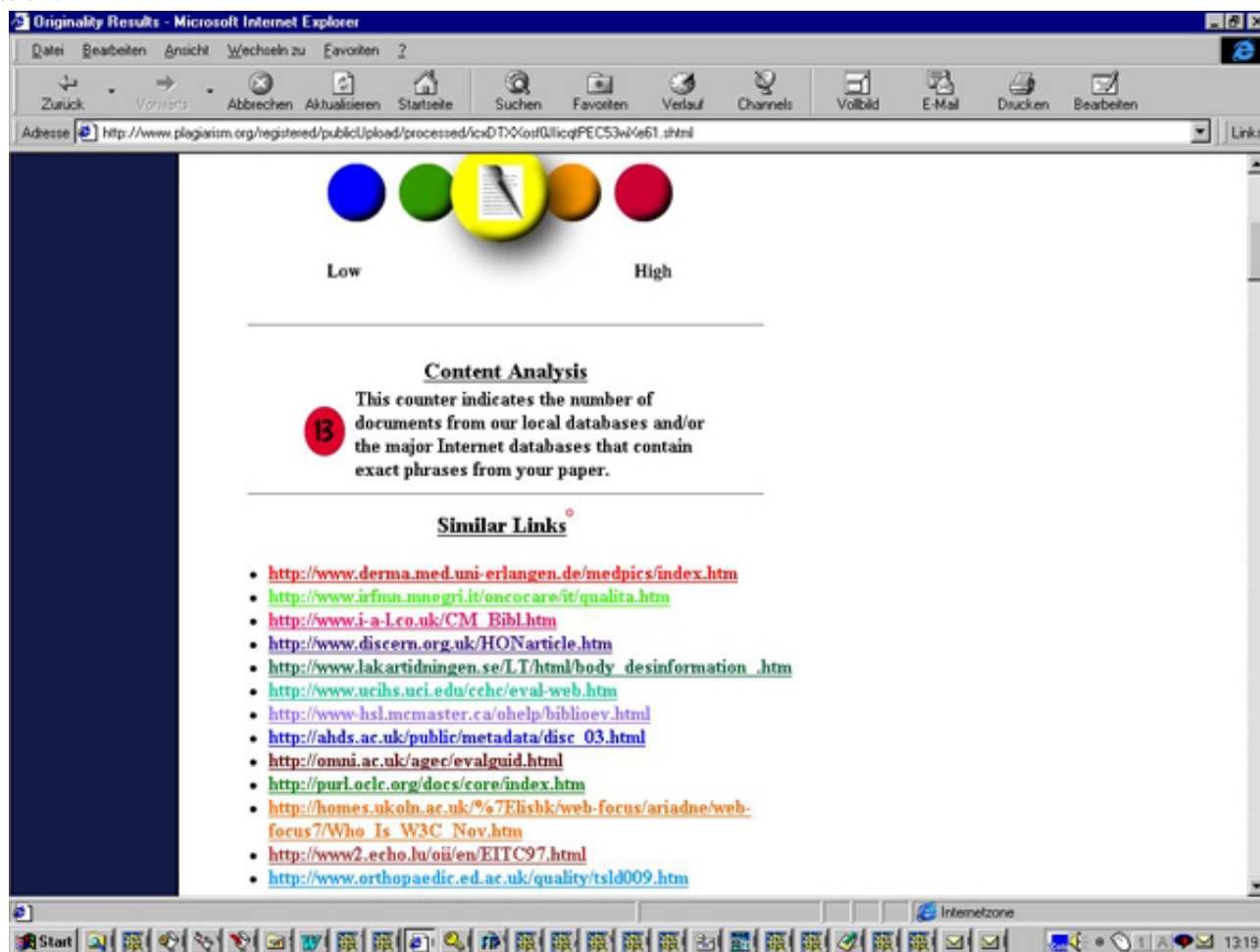


Figure 3a. Fig. 3a+b. The words which are underlined and highlighted red in the plagiarism.org report (a) were lifted from the website medpics.org (b)

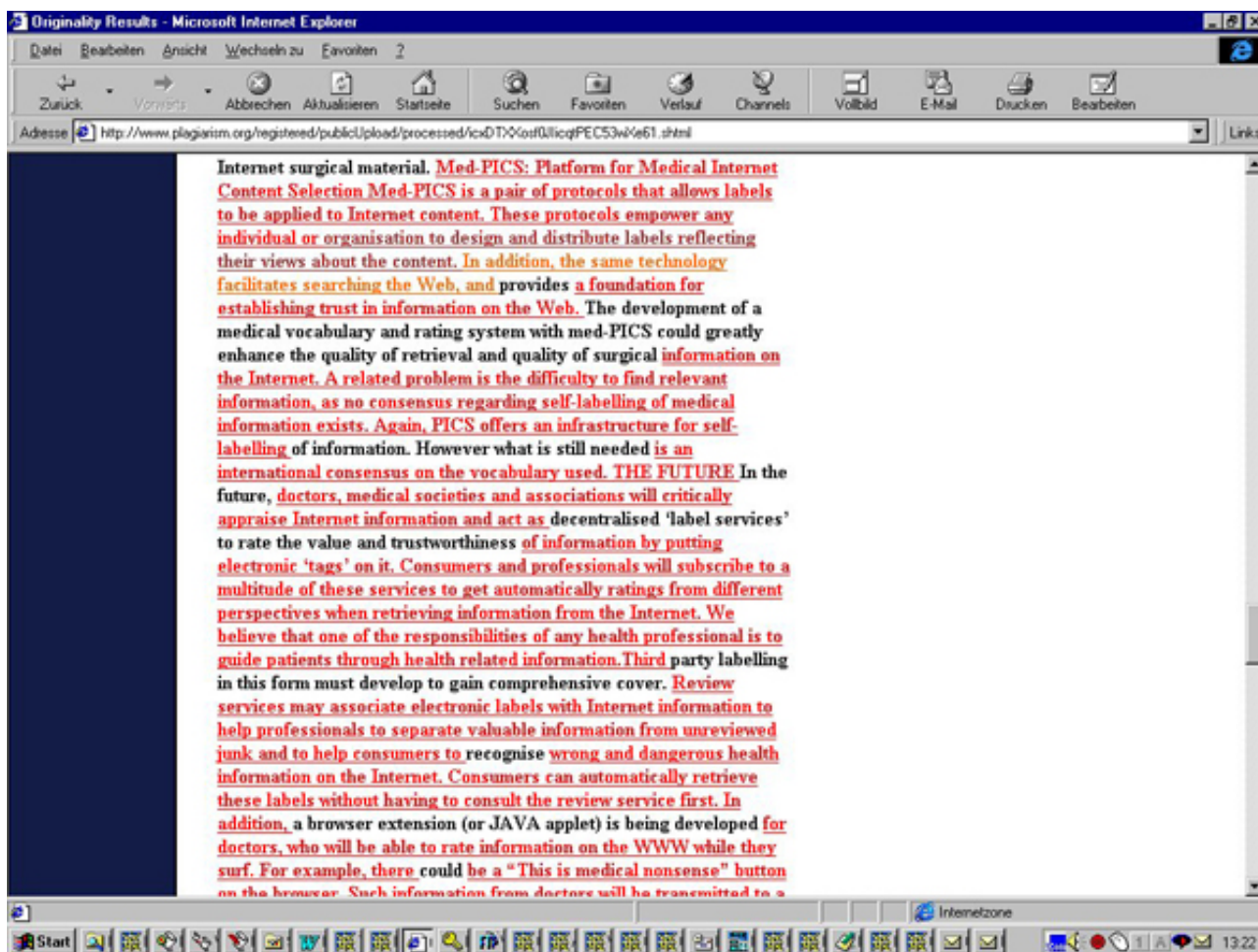


Figure 3b. Fig. 3a+b. The words which are underlined and highlighted red in the plagiarism.org report (a) were lifted from the website medpics.org (b)

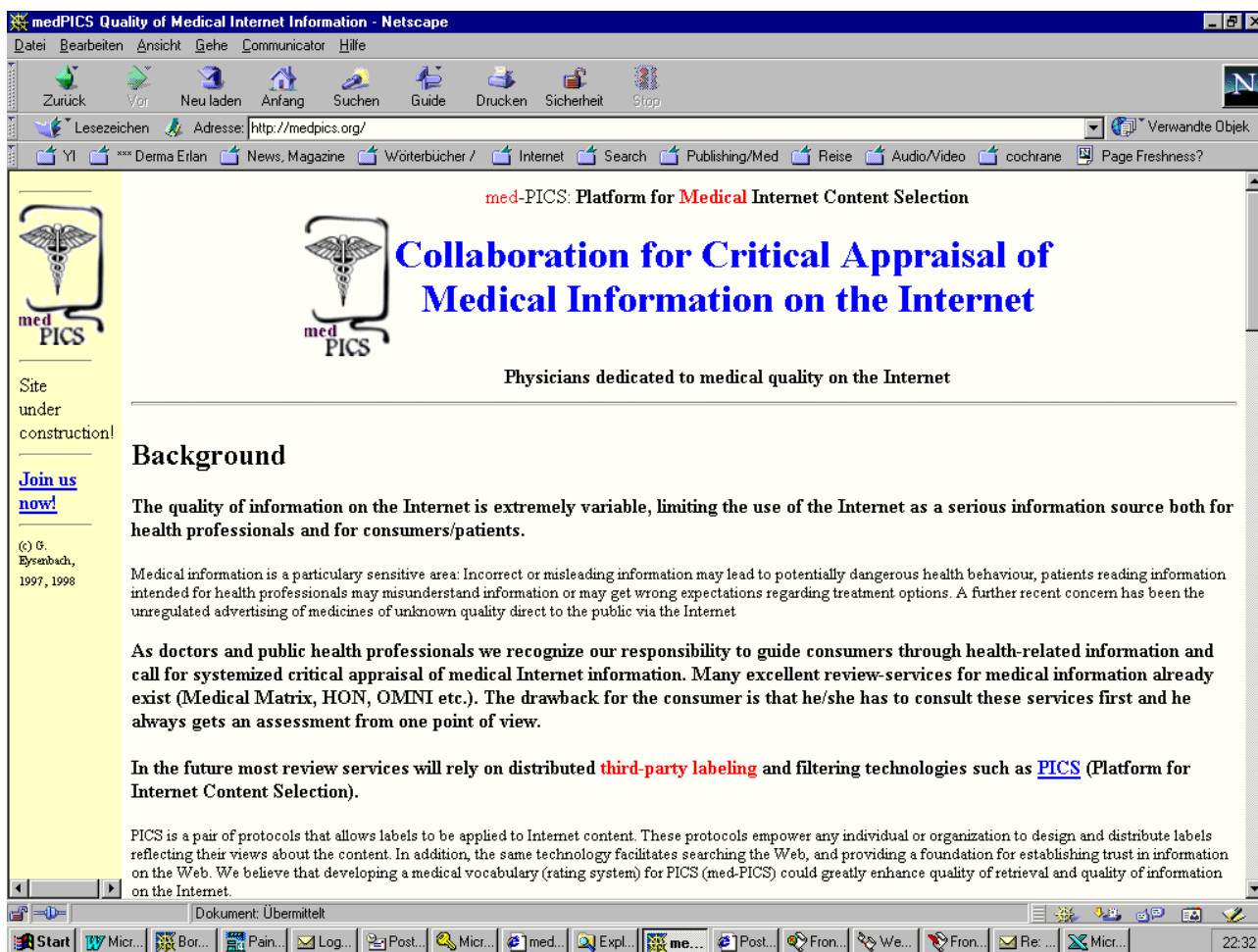


Figure 4a. Fig. 4 a+b. The words which are underlined and highlighted green in the plagiarism.org report (a) were lifted from the Dublin Core metadata website (b)

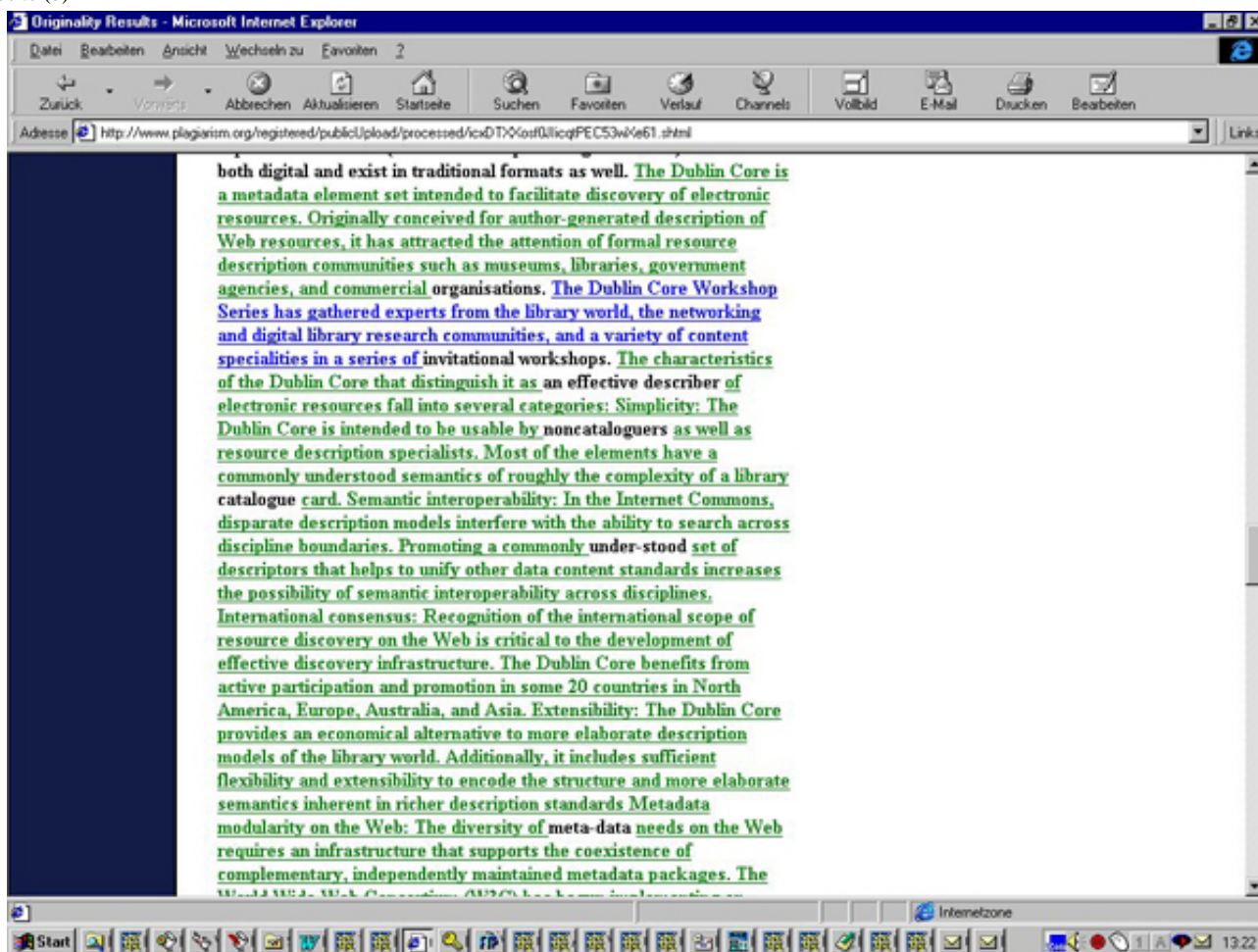
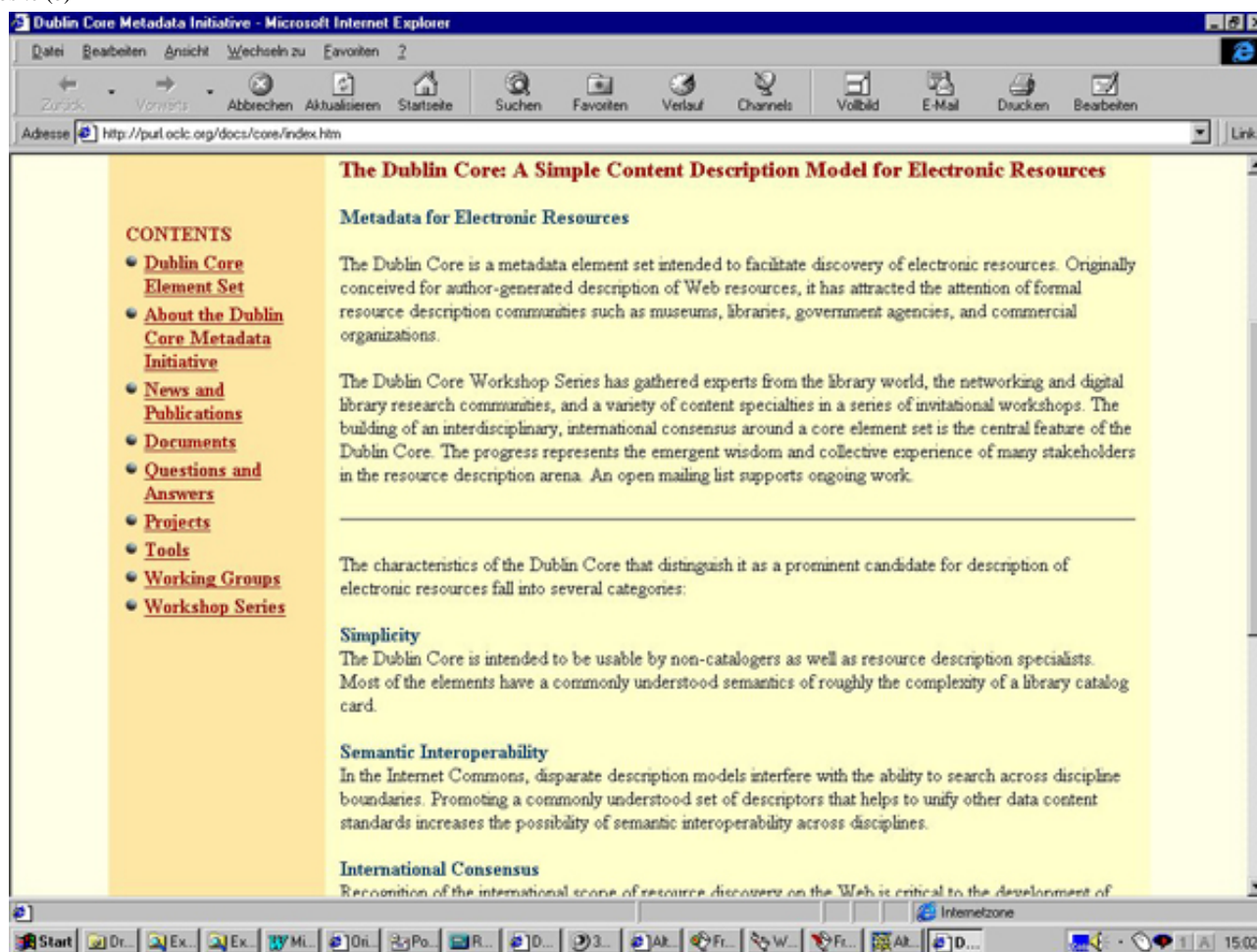


Figure 4b. Fig. 4 a+b. The words which are underlined and highlighted green in the plagiarism.org report (a) were lifted from the Dublin Core metadata website (b)



As an aside it should be noted that the plagiarism.org tool proved to be very sensitive, in that it also retrieved several websites which cited the same or a similar set of publications. Thus, a tool like plagiarism.org could also be used to identify similar publications on the Web which deal with related topics; thus it may serve a similar function as the "Related Articles" button in PubMed [7].

Prospective monitoring

Other scenarios could be imagined, but are not yet available. For example, one possible future development could be that Web authors would be able to use special search engines to monitor the Web (or full text databases) prospectively and continuously to receive alerts when there have been parts of their documents "webnapped," i.e. published on other websites or lifted into articles. This would require that the authors submit whole published manuscripts or register the URL at a special search engine, together with their email address. The search engine would then not only crawl and index webpages like a normal search engine, but also automatically notify Web authors if a "similar" page shows up somewhere on the Web, or if a similar article appears in a dynamic database such as PubMed Central, Medline, in e-print servers, or other databases containing full text articles or abstracts. In fact, such software agents would not only be useful in detecting plagiarism, but

could also be used to alert authors of similar new articles in their field being published on the Web or in the literature.

Detecting duplicate publication

Plagiarism comes in many different varieties. When authors "plagiarize" themselves this is called "redundant" or "duplicate publication." According to Charles Babbage, from his book *Reflections on the Decline of Science in England* (cited in Lock [8], p 161), this belongs to the category of "Trimmin and Cooking" (while plagiarism is classified as "fraud"). The Uniform Requirements For Manuscripts Submitted To Biomedical Journals of the International Committee of Medical Journal Editors (ICMJE) [9] state that:

Readers of primary source periodicals deserve to be able to trust that what they are reading is original, unless there is a clear statement that the article is being republished by the choice of the author and editor. The bases of this position are international copyright laws, ethical conduct, and cost-effective use of resources.

Duplicate publication is another kind of misconduct which could be detected by the use of modern information technology: Stephen Lock already noted that "duplicate publication might be disclosed more often if journal offices were to routinely search the databases" [8, p 162]. Never before has it been easier to compare each submitted article against the Internet and

databases such as PubMed Central and MEDLINE to detect cases of duplicate publication.

An example: Redundant publication of a "letter to the editor"

Interestingly, a case of duplicate publication occurred in the very same issue of the very same journal, conducted by the very same person as described in the case above: On page 278 of JRCSEd, C.O. published a letter "How to cope with unsolicited Email from the general public seeking medical advice" [10], which was nearly identical to a letter submitted to BMJ by the same author, entitled "Automatic replies can be sent to unsolicited email from general public," published on 27 November 1999 [11]. The titles of the letters are different, as they are usually changed by the editorial staff - the original letter submitted to BMJ as a rapid reply did have the same title as the letter submitted to JRCSEd. (As an aside it should be mentioned that, interestingly, the authors are not exactly the same - the JRCSEd piece lists one more author. A case of gift authorship?) As in neither of the journals did a note appear pointing to the fact that the letter also appeared in another journal, this meets the definition of duplicate publication, which is, according to the international guidelines of ICMJE cited above, considered unethical. According to an informal survey among editors of the World Association of Medical Editors (WAME), there is consensus among editors that the same rules apply for letters as apply for articles: Duplicate publication should be disclosed to editors.

Without discussing this case further at this point, it should only be mentioned that intelligent software agents could be developed to alert journal editors about possible cases of redundant publication and copyright violations by automatically comparing publications with each other - for example within and between PubMed Central, Medline, in e-print servers and the web - and alert publishers if similarities are found. As both JRCSEd and BMJ have online versions of their journals, an intelligent software agent could have detected this case of duplicate publication. Once again, the effect of installing and applying such systems would be primarily an educational one: If such measures were in existence and their use known, this would probably discourage authors from submitting redundant articles and committing plagiarism.

Software that analyzes writing styles

It should be noted that other informatics techniques for detecting plagiarism exist. The Glatt Plagiarism Screening Program is a computer program especially targeted for teachers who want to prove the guilt or innocence of a student. The program detects plagiarism by analysing the writing style within a document. The software developers say that each person has an individual style of writing which is as unique as fingerprints. The procedure is described as follows: "The Glatt Plagiarism Screening Program eliminates every fifth word of the suspected student's paper and replaces the words with a standard size blank. The student is asked to supply the missing words" [12]. Thus, basically this is a test of memory for the student's own writing style - it is assumed that authors know and can remember their own writing better than anyone else. The number of correct responses, the amount of time intervening, and various other

factors are considered in assessing the final Plagiarism Probability Score. The authors claim that the program has a specificity of 100% ("no student has been wrongly accused"). The description of this approach makes clear that this program is less suitable for screening and comparing large amounts of documents, but more appropriate to proving plagiarism in an individual case.

Tools to detect software plagiarism

As an aside, it should also be briefly mentioned that in the field of software development and informatics education, several tools are available which can test the similarity of software to protect computer codes from being lifted; examples include the software similarity tester SIM [13] and software named "MOSS" (Measure Of Software Similarity), which looks for similar or identical lines of code sprinkled throughout a program, then creates a web page where the instructor can see the top 40 matches [14].

Metainformation and hidden watermarks

The future may bring even more possibilities, especially helping authors avoid inadvertent plagiarism. One option would be to expand the concept of "copy & paste" towards "copy & paste & attribute (=give credit to the source)." Future versions of word processors could be designed which allow authors to clearly identify which parts of the document have been inserted by copy & paste and where they come from. For example, authors could be able to click on the text and the word processor would show in a comment field from what website (or other application) this "copied & pasted" part originated from.

Other developments may include techniques to assign invisible metainformation to electronic information, which could identify the author and which cannot be stripped. Such invisible "watermarks" are already in use for digital images, but future operating systems may also support metainformation assigned to text, so that the author of a given paragraph could be identified, even if the text is "copied and pasted" from one application into another.

On a different level, the company Xerox is also active in developing products which make redistribution of digital content impossible. The Digital Property Rights Language (DPRL) is a computer-interpretable language, developed at the Xerox Palo Alto Research Center, which "describes distinct categories of uses for digital works in terms of rights, including rights to copy a digital work, or to print it out, or to loan it, or to use portions of it in derivative works" [15]. DPRL is not a document protection technology. Protection of content integrity and the persistent control of digital property rights is accomplished through the use of The Xerox Self Protecting Document (SPD) [16]. "SPD contains the encrypted content, rights associated with it, watermarks, usage policies and a set of controls that travel along with the document in the form of Java applets. Proven cryptographic algorithms ensure complete protection during rendering by converting a document to the rendered form in various stages; thus, intercepting the document at any stage will not yield a usable form of the document."

Another form of academic misconduct: Underreporting of research

Not only plagiarism and duplicate publication ("overreporting of research") can be a problem in medical science; ", i.e. not publishing the results of a randomised controlled trial, has also been called scientific misconduct [17]. The reason for this is that the biggest threat of a systematic review and meta-analysis is publication bias. Reviewers and policy makers need a complete picture of the results of all randomised controlled trials conducted, and not only of positive or interesting trials, which have been published by researchers. We have recently shown that the Internet is useful in identifying unpublished and ongoing trials, and suggested specialised search engines and software agents that collect information about ongoing trials on the Internet [18]. In addition to prospective trial registers [19], such a search engine could help to detect the digital traces most researchers leave today on the Internet when they conduct a study, such as hints to grant proposals or webpages for recruitment of participants. This would aid reviewers in locating unpublished studies and at the same time - if sanctions for this kind of scientific misconduct are in place - discourage researchers from leaving clinical studies unpublished.

Reasons for and Prevalence of Plagiarism

Many authors seem to be encouraged to copy from the web as electronic publications are seen as "inferior" in quality and worthiness of protection, and are seen as more volatile than "real" publications on paper. While the majority of authors would refrain from copying whole paragraphs from printed articles, the barrier to do the same from web publications seems to be lower, as information on the web would disappear sooner or later, making the proof of plagiarism apparently impossible, while the printed journal would remain in the library as a durable witness of plagiarism waiting to be discovered and used as evidence. However, plagiarists should be warned that material

on the Internet is not as volatile as they may think, and that future historians will well be able to reconstruct online-plagiarism, as there are online-archives of the Internet such as <http://www.archive.org> [20].

Insufficient familiarity with English [21], the pressure to publish much and fast [8], and sometimes also sloppiness and forgetfulness are probably the main reasons for cyberplagiarism. An interesting question is how common plagiarism, especially "cyberplagiarism," actually is. Interestingly, questioned about the case described above, C.O. was quoted in Nature as saying: "If you ran [this system] on every article [in the medical literature] that comes out, you would find this happening all over the place" [22].

Jeremy Wyatt, a respected medical informatics researcher from London and an editorial board member of the Journal of Medical Internet Research, also says that he has "seen paragraphs of my work copied in other people's papers without acknowledgement at least three times now (in obscure conference papers and medical informatics journals) but have never kept a note of it; after the initial anger, I dismissed it as a case of 'imitation is the sincerest form of flattery'." Future studies applying tools such as plagiarism.org in editorial offices may establish estimates on how widespread this phenomenon is.

JMIR the first scholarly journal to screen submitted manuscripts for plagiarism

In the future, the Journal of Medical Internet Research will routinely check accepted manuscripts for plagiarism, using the automatic plagiarism detector at plagiarism.org. We are the first scholarly journal worldwide to adopt such a plagiarism screening policy, but we hope (and expect) that other biomedical journals will follow. Authors should remember that there is only one easy and reliable way to avoid plagiarism charges: that is to cite the source properly, even if it is "only" an electronic document [23].

Conflicts of Interest

The author of this article is also author of the partly-plagiarized website medpics.org and editor of the Journal of Medical Internet Research.

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submitted 03.03.00; peer-reviewed by H van der Slikke; comments to author 13.03.00; revised version received 29.03.00; accepted 29.03.00; published 31.03.00.

Please cite as:

Eysenbach G

Report of a case of cyberplagiarism - and reflections on detecting and preventing academic misconduct using the Internet

J Med Internet Res 2000;2(1):e4

URL: <http://www.jmir.org/2000/1/e4/>

doi: [10.2196/jmir.2.1.e4](#)

PMID: [11720923](#)

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Commentary

The Internet Healthcare Coalition

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(*J Med Internet Res* 2000;2(1):e3) doi:[10.2196/jmir.2.1.e3](https://doi.org/10.2196/jmir.2.1.e3)

KEYWORDS

Internet; Ethics; Quality of Health Care

About the Internet Healthcare Coalition

As individuals take a larger role in managing their own healthcare, more consumers are independently seeking out health information via the Internet. Health professionals are also turning to the Internet to keep informed and interact with their patients. Given the vast amount of healthcare data available on the Internet, the Internet Healthcare Coalition was created to promote quality health resources online and to ensure that consumers and professionals are able to find reliable, quality information online.

The Coalition is an international, non-partisan, non-profit organization dedicated to promoting quality healthcare resources on the Internet. Founded in 1997, the Coalition's membership represents every sector of the Internet health space, including consumers, patient advocates, commercial developers of health information, health professionals, medical librarians, government officials, and pharmaceutical manufacturers. The goal of the Coalition is to educate healthcare consumers, health professionals, and others about the evolving issues relating to the quality of Internet health resources and information.

The Coalition is dedicated to:

- Educating healthcare consumers, professionals, educators, marketers, and both healthcare and mainstream media, as well as public policymakers on the full range of uses of the Internet - current and potential - to deliver high-quality healthcare information and services.
- Furnishing clear models, not only of good and bad sources of online healthcare information and services, but of the potentially disparate methods of evaluating disparate sources of information - from product- or disease-information sites developed by regulated

manufacturers, to peer-reviewed electronic publications and patient support groups.

- Publicizing and promoting the use of currently available resources and developing new resources that exemplify ethical, innovative, and high-quality uses of the Internet to deliver healthcare information and services.
- Acting as a representative of our constituencies in areas of mutual concern before public policymakers and with the media.

The Coalition consults with various government agencies including the World Health Organization (WHO), the US Food and Drug Administration (FDA), and the US Federal Trade Commission (FTC) on broader-based efforts to promote credible healthcare information and combat health fraud online. To that end the Coalition formed an Internet Health Fraud Resources Working Group which will work with the FTC to develop, coordinate, and promote a global online health-fraud reporting web site, which will link to authorities with jurisdiction over illegal or fraudulent online healthcare activities. Using this resource, consumers and healthcare professionals anywhere in the world can be sure that their complaints are transmitted to the appropriate authorities for action.

The Coalition holds an annual conference, "Quality Healthcare Information on the Net," each year in October or November for key thought leaders in the healthcare industry and government representatives to exchange their thoughts and opinions about the problems associated with and solutions to healthcare and the Internet. In October 1999, responding to calls from within the Internet Health community, the Coalition launched its ongoing "eHealth Ethics Initiative" to provide a forum for the development of a universal set of ethical principles for health-related Web sites.

The Coalition can be found at <http://www.ihealthcoalition.org>

###Reviewer names will be inserted here### published 05.03.00.

Please cite as:

Mack J

The Internet Healthcare Coalition

J Med Internet Res 2000;2(1):e3

URL: <http://www.jmir.org/2000/1/e3/>

doi: [10.2196/jmir.2.1.e3](https://doi.org/10.2196/jmir.2.1.e3)

PMID: [11720922](https://pubmed.ncbi.nlm.nih.gov/11720922/)

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Commentary

Digital plagiarism - The web giveth and the web shall taketh

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Abstract

Publishing students' and researchers' papers on the World Wide Web (WWW) facilitates the sharing of information within and between academic communities. However, the ease of copying and transporting digital information leaves these authors' ideas open to plagiarism. Using tools such as the Plagiarism.org database, which compares submissions to reports and papers available on the Internet, could discover instances of plagiarism, revolutionize the peer review process, and raise the quality of published research everywhere.

(J Med Internet Res 2000;2(1):e6) doi:[10.2196/jmir.2.1.e6](https://doi.org/10.2196/jmir.2.1.e6)**KEYWORDS**

Ethics; Manuscript; Internet; World Wide Web

After obtaining information regarding a 1996 finding that Polish authors had plagiarized the work of Danish researcher Jan Fallingborg, Marek Wronski (a cancer researcher from New York's Staten Island University Hospital) conducted a Medline search which revealed 30 additional manuscripts that contained passages allegedly taken from prior publications of other researchers [1]. This could have been just another exposure of a plagiarizing scientist [2,3] except that it was uncovered by the use of new, Internet-based technology. Fallingborg and Wronski both used a simple search function to sift through the massive amount of information contained within Medline (a database of biomedical references and abstracts) to locate acts of gross plagiarism that may never have been discovered otherwise. The ability to utilize powerful computers to mine large electronic databases for instances of plagiarism could revolutionize the peer review process and raise the quality of published research everywhere. As with most technologies, there are also some glaring negatives, in that digital information is easily copied and transported, and thus more available to plagiarize.

Medline is just one example of an Internet tool that facilitates previously unheard of levels of information dissemination. The large Internet search and navigational guides such as Yahoo!, Altavista, and Excite [4] convey Internet-based information to enormous audiences. For example, each month about 25 million

users of the World Wide Web (WWW, one modality of the Internet) access information from Yahoo! at an average rate of 50 million web pages of information viewed per day, or 1.5 billion pages viewed per month [5]. This is a larger audience than magazines such as Newsweek, Time, and Life. These navigational guides also direct a subpopulation of the electronic community to numerous Internet locations that provide free access to very large databases containing thousands of academic term papers. Evil House of Cheat, Cheater.com, and School Sucks [6] are just a few locations which offer term papers to be used as "reference materials, research guides, or as educational resources."

The proliferation of sites specializing in the electronic commerce of academic papers is based on the simple truth that there is a sufficient demand for such work. Evil House of Cheat receives several thousand visits per day [7] and claims that over 11,000 students have benefited from their services [6]. Cheater.com claims to have over 30,000 members and adds approximately 100 new essays to its database each week [6]. School Sucks has received almost 1.6 million visits since its inception in the summer of 1996 [6]. Notwithstanding the warnings against plagiarism that greet their clientele, these web entities are supplying term papers to a student population that could choose to ignore such advice.

In a 1991 study of 15,904 students taken from 31 top U.S. universities, Rutgers University professor Donald McCabe found that 66% cheated at least once and that 12% were regular cheaters (four or more times) [8]. A study in Psychological Record found that 36% of the undergraduate participants had plagiarized written material and a significant number of the participants could not even determine what plagiarism was [9]. Nor are graduate and post-doctoral students immune to plagiarism, especially when it serves the purpose of obtaining funding or publishing a manuscript [10].

The problem concerning free Internet access to student term papers is not nearly so simple because it is not limited to dedicated Internet paper databases. Before the existence of Internet term paper providers, we confronted this very problem. In the 18 October 1996 issue of Science we reported on our model for utilizing the World Wide Web as an adjunct to education in a neurochemistry class (at that time 123 students; currently 320 students) at the University of California at Berkeley [11]. The final course project required that each student submit a 10-page manuscript through our Web site. Every manuscript was anonymously posted to the Internet, electronically peer-reviewed by two other students, and the reviews were then anonymously placed on the Web site alongside each paper. From our largely Internet-naïve student population there was a 98.4% completion rate for this assignment, indicating that the use of Internet technology was not problematic. What was potentially problematic concerned the placement of high-quality term papers onto the WWW, where any person could view and copy a manuscript at will. Our temporary solution to the dilemma of free access versus plagiarism potential was to password-protect the manuscript domain of the course web site so that only students from that class could read their peers' papers. Password protection may seem antithetical to the idea of sharing information within and

between academic communities, but the alternative is an Internet link from sites advertising free student term papers to the university web sites containing such papers and other academic essays [12].

Current solutions available for instructors include guidelines for spotting plagiarism, searching the Internet for similar papers, and attempting to instill a firm sense of ethics in their students. These solutions are incomplete when applied to the modern advancements in the technology of information dissemination. Our proposed solution has been to construct an archive of manuscripts (from previous classes and gathered from the Internet) that allows for a computer-based, digital check of originality for all newly submitted manuscripts. This experiment resulted in no manuscript being recycled from previous science courses, and yielded increased term paper quality levels. What it didn't address is the real possibility that a course manuscript could be used for a different class. We have now addressed this problem with the creation of Plagiarism.org. This Internet service allows any instructor or student to check our database for cases of gross term paper plagiarism by tracking and "finger-printing" those term papers already in the public domain and from other classes. Manuscript "finger-prints" are statistically compared and degrees of originality are computed.

We have successfully utilized the power of the WWW to allow students to share information and ideas at levels not previously achievable in the classroom. Now we have harnessed that power to insure that reference materials from Internet paper databases and from other university classes are used appropriately. The WWW has increased in size by 480% in the 18 months between October 1996 and April 1998 [13], and our three-year experiment checking term papers has necessarily gone from an experiment to a reality. This technology gives us a glimpse of the direction that education is evolving in the digital age.

Conflicts of Interest

The authors are developers of the plagiarism.org web site, described in this article.

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submitted 08.02.00; peer-reviewed by G Eysenbach; comments to author 22.02.00; accepted 27.03.00; published 31.03.00.

Please cite as:

Barrie JM, Presti DE

Digital plagiarism - The web giveth and the web shall taketh

J Med Internet Res 2000;2(1):e6

URL: <http://www.jmir.org/2000/1/e6/>

doi: [10.2196/jmir.2.1.e6](https://doi.org/10.2196/jmir.2.1.e6)

PMID: [11720925](https://pubmed.ncbi.nlm.nih.gov/11720925/)

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Green Paper

Towards ethical guidelines for dealing with unsolicited patient emails and giving teleadvice in the absence of a pre-existing patient-physician relationship — systematic review and expert survey

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Abstract

Background: Many health information providers on the Internet and doctors with email accounts are confronted with the phenomenon of receiving unsolicited emails from patients asking for medical advice. Also, a growing number of websites offer "ask-the-doctor" services, where patients can ask questions to health professionals via email or other means of telecommunication. It is unclear whether these types of interactions constitute medical practice, and whether physicians have the ethical obligation to respond to unsolicited patient emails.

Objective: To improve the quality of online communication between patients and health professionals (physicians, experts) in the absence of a pre-existing patient-physician relationship or face-to-face communication, by preparing a set of guiding ethical principles applicable to this kind of interaction.

Methods: Systematic review of the literature, professional, and ethical codes; and consultation with experts.

Results: Two different types of patient-physician encounters have to be distinguished. "Traditional" clinical encounters or telemedicine applications are called "Type B" interactions here (Bona fide relationship). In comparison, online interactions lack many of the characteristics of bona fide interactions; most notably there is no pre-existing relationship and the information available to the physician is limited if, for example, a physician responds to the email of a patient who he has never seen before. I call these "Type A" consultations (Absence of pre-existing patient-physician relationship). While guidelines for Type B interactions on the Internet exist (Kane, 1998), this is not the case for Type A interactions. The following principles are suggested: Physicians responding to patients' requests on the Internet should act within the limitations of telecommunication services and keep the global nature of the Internet in mind; not every aspect of medicine requires face-to-face communication; requests for help, including unsolicited patient questions, should not be ignored, but dealt with in some appropriate manner; informed consent requires fair and honest labeling; health professionals and information providers must maintain confidentiality; health professionals should define internal procedures and perform quality control measures.

Conclusions: Different media are appropriate at each point on the continuum between dispensing general health information and handling patient problems that would require the practice of medicine to solve. For example, email is a sufficiently capable medium for giving out general health information, while diagnosis and treatment usually requires at least advanced telemedical technology. Patients have to be educated that it is unethical to diagnose and treat over the Internet in the absence of a pre-existing patient-physician relationship, and if the interaction is limited to a single email. More research is needed to establish more evidence regarding situations in which teleadvice is beneficial and efficient.

(*J Med Internet Res* 2000;2(1):e1) doi:[10.2196/jmir.2.1.e1](https://doi.org/10.2196/jmir.2.1.e1)

KEYWORDS

Internet; Ethics; Quality of Health Care; Referral and Consultation; Remote Consultation; Physician-Patient Relations; Professional-Patient Relations; Medical History Taking; Teleadvice; Electronic Mail; Chat; Newsgroup

The green paper set forth below concerns ways to improve the quality of online communication between patients and health professionals (physicians, experts) in the absence of a pre-existing patient-physician relationship or face-to-face communication, and takes a first step towards proposing a set of ethical standards for this kind of interaction. These principles are preliminary, and were drawn up as a result of a systematic review of the literature; consultation with professional organizations, associations and bodies; and a workshop at the AMIA Fall Conference in 1998; and with input by an international expert panel of the Internet Healthcare Coalition (IHC), Society of Internet in Medicine (SIM) and the American Medical Informatics Association (AMIA). In order to provide input into a more general set of guidelines, the Code of e-Health Ethics currently being set up by the e-Health community, this paper was also circulated among the participants of the e-Health Ethics Summit, organized by the Internet Healthcare Coalition in Washington D.C., January 31 - February 2, 2000. Aspects of this paper were subsequently included in the "provision of medical practice on the Internet" section of the Code.

The author will accept comments on the paper starting today until March 31, 2000. Comments may be sent via electronic mail to ey@yi.com. All comments received will be considered in the context of issuing a final white paper, and if the comments are substantial, the author of the comment will become a co-author of the final paper. The green paper has been published in the Journal of Medical Internet Research solely as a means to facilitate the public's access to this document, and to provide an additional means of notifying the public of the solicitation of public comment on the proposed White Paper, which is scheduled to be submitted for publication in April 2000.

Introduction

While telemedicine services and physician telephone services have been around for several decades, the unprecedented popularity of the Internet has greatly facilitated patients' access to physicians and led to a new form of communication between patient and health care professional - "text-only" communication in emails and other venues, in the absence of a pre-existing relationship (in this paper called "Type A" communication). Every physician who has published his email address or who runs a medical website receives unsolicited emails from patients he or she has never seen before. Patients use email to ask medical questions to physicians unknown to them, or sometimes even describe their symptoms and expect a remote diagnosis. Health portal sites and specialized services responded to this consumer demand for "virtual interaction" with physicians, and have set up "ask-the-expert" services and "cyberdoctor" services, which offer such advice for free or for a charge.

The intent of this paper is to prepare a consensus on a set of guidelines for health professionals on dealing with unsolicited patient emails, and for physicians and nurses working for medical "ask-the-doc" or "ask-the-expert" services on the Internet.

Terminology and definition of the issues: Type A and Type B interactions

The digital revolution and the Internet have opened new ways for health providers and consumers to interact. Aside from the fact that the Internet allows transmission of high-level, high-bandwidth telemedicine applications, it also allows simple exchange of electronic, written messages between patient and health professional, which can be seen as a form of "low-level," "low-tech," "low-cost" telemedicine. Other terms used for this kind of interaction are "teleconsultation" or "teledvice."

Table 1. Differences in Type A and Type B relations

	Type A encounters (online interaction between patient and health professional in the absence of pre-existing relationship)	Type B encounters (bona fide relationship; encompasses traditional clinical encounters and telemedicine)
Contractual relationship before the encounter	No pre-existing relationship	Mostly pre-existing contractual relationship
Responsibility	Physician has not taken explicit responsibility for the patient	Physician has taken explicit responsibility for the patient
Contact initiation	Contact usually initiated by the patient	Contact scheduled or initiated by physician, or by patient
Transmission of information	Usually only text (e-mail consultations and chats)	Face-to-face, sound, video, images
Access to information	Information limited to what the patient provides	Physician has access to health record or other channels to obtain more information
Patient's knowledge of the physician	Patient doesn't know the physician in advance	Patient usually knows the physician or has a referral
Physician's knowledge of the patient	Physician doesn't know the patient	Physician usually knows the patient
Physician's preparation to receive requests from patients	Physician is not prepared to get requests from patients*	Physician explicitly offers advice

* Does not apply to "ask-the-expert" services

Different technologies may be used for teledvice:

- electronic mail (email), allowing "private" exchange of messages
- newsgroups, allowing "public" discussions
- chatrooms, allowing direct written communication via keyboard

All these venues for "cybermedicine" may cater to patient-physician interactions that are fundamentally different from classical telemedicine applications in a number of ways (see Table 1).

In "traditional" clinical encounters or telemedicine applications, there is either a pre-existing patient-physician relationship or, if the patient comes to the practice for the first time, the professional at least has access to the patient's electronic health record, or can consult with the referring physician. For the purpose of this paper, I call these traditional interactions "Type B" interactions (**B**ona fide relationship).

On the contrary, online interactions lack many of the characteristics of bona fide interactions; most notably there is no pre-existing relationship. I call these "Type A" consultations (**A**bsence of pre-existing patient-physician relationship). Note

that Tom Ferguson calls the latter Type I and the former Type II interactions, "Type I because this developed first" [Ferguson T, personal communication].

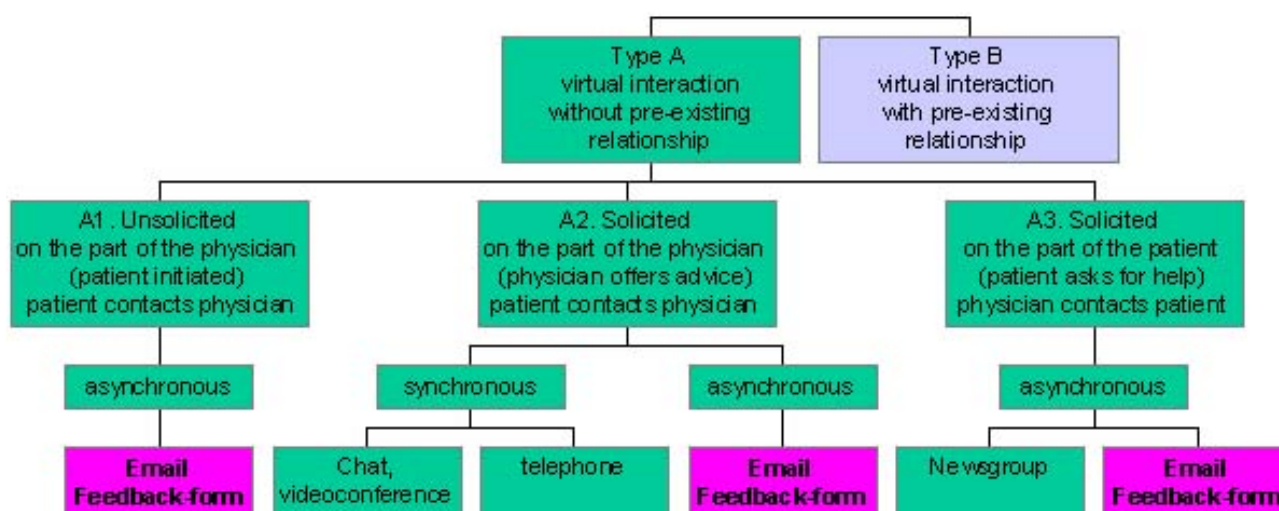
Subgroups of Type A encounters

Examples for (and subgroups of) these "atypical" telemedicine encounters are:

- a patient sending an "unsolicited" email to a physician (A1)
- "ask-the-expert" services on the Internet, where consumers are invited to ask medical questions which are forwarded to medical experts (A2)
- a patient soliciting help from a physician by posting a public request for help on a newsgroup or website, to which a physician replies (A3)

These interactions differ from each other because the physician has taken different levels of action (and perhaps responsibility) - in the first case, unsolicited patient email (A1), only the patient has taken action; in the second case, (A2), the physician is part of a team that volunteered and explicitly offered to answer patient questions; and in the third case, (A3), the physician replies to a patient request (see Figure 1).

Figure 1. Subgroups of Type A interactions



In all of these cases, the relationship between patient and physician is less well-defined and more prone to misunderstandings than in traditional Type B patient-physician encounters. For example, in Type B encounters the patient is used to receiving a reply, which may not be the case in Type A encounters. Similarly, the situation is difficult for the physician, as he or she may not be sure about the ethical duties and the legal consequences of his or her actions. Guidelines may help to better define such contacts to avoid misunderstandings [1,2]. There have also been concerns that what we call Type A encounters here may "disturb delicate balances in the patient-physician relationship, widen social disparities in health outcomes, and create barriers to access" [3]. In the context of newsgroup-like interactive communication and information listservers, where patients can ask questions to experts, Spielberg criticized that such a system "bypasses existing patient-physician relationships, since it does not facilitate communication within them" [4].

What is different on the Internet?

It should be noted that Type A consultations may also occur outside of cyberspace, in the form of patients calling or writing letters to physicians. However, in comparison with these interactions, there are differences in Internet-enabled consultations; for example:

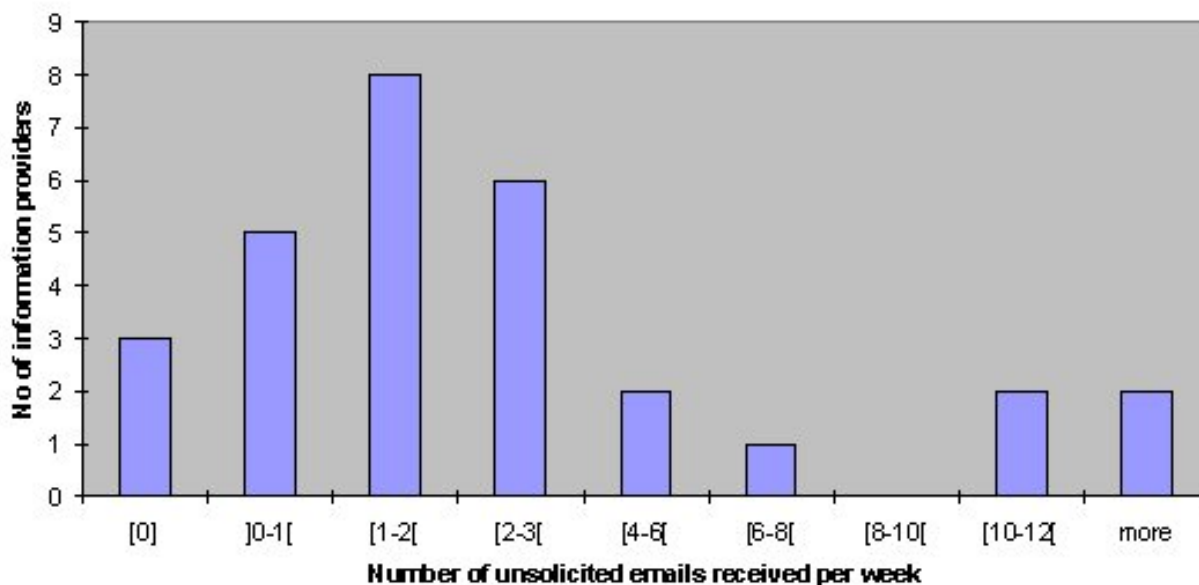
- communication is nearly anonymous, thus more impersonal
- communication is more informal
- communication is global
- access to physicians on the Internet is easier than in the real world

All of these factors, especially that the Internet allows near-anonymous communication and lowers the barrier for consumers to interact with providers, contribute to the fact that the demand for Type A interactions has reached an unprecedented level in the history of medicine. Every doctor or medical information provider who runs a medical website which

provides his or her email address will sooner or later be faced with the problem of getting unsolicited emails from patients asking him or her for medical information or advice. In a survey of 23 Internet health information providers (mostly doctors also acting as webmasters), participants were asked, "How many unsolicited patient emails do you get per week?" The numbers

given ranged between 0 and 50 emails, with a mean value of 4.4 (STD 9.47) and a median of 1 email per week (see Figure 2). In the same survey, 62% of the information providers said that "unsolicited emails from patients represents a significant unresolved problem on the Internet" [1].

Figure 2. Number of unsolicited emails received per week, according to a survey of 23 health information providers



There are further differences between Type A email-teleadvice compared to Type B telemedicine, which primarily concern privacy and security concerns inherent to email and other insecure venues on the Internet. Aspects of these concerns have been explored elsewhere [5].

Existing guidelines

The most important guideline in the context of "virtual" patient-physician interactions on the Internet is the guideline published by the AMIA Internet Working Group, which however explicitly focuses on "computer-based communication between clinicians and patients within a contractual relationship in which the health care provider has taken on an explicit measure of responsibility for the client's care" (emphasis added by the author) [5], thus applying only to Type B interactions. Although many of the principles of email communication in the clinical context also apply to email communication in Type A interactions, the more ill-defined Type A interactions between providers and consumers in which no contractual relationship exists require additional exploration. It was not before several papers published in the *Journal of the American Medical Association (JAMA)* [5-8] drew attention to the fact that these kinds of interactions exist that the need to develop guidelines for Type A interactions was acknowledged. In the same issue, Spielberg pointed out that "email communications are not merely virtual approximations of medical practice, they are very real exchanges of information, advice and emotions. (...) Electronic communication, as a novel technology, is neither inherently unethical nor readily acceptable for medical practice. Rather, the emergence of electronic communication launches a

reexamination of the necessary values for good communication in the patient-physician relationship" [8].

Aim of this paper

This paper tries to analyze and synthesize issues arising from Type A interactions and intends to summarize existing evidence, opinions, and ethical codes relevant to the issues. A set of principles will also be proposed.

Methods

Database Searches

I tried to primarily identify publications describing empirical data or legal and ethical standards on patient-physician interaction on the Internet (in email, chat, and newsgroups). MEDLINE was searched from 1966-1999 with the PubMed search strategy:

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(( "remote consultation"[majr] OR "Referral and Consultation"[majr] OR "Physician-Patient Relations" OR "Professional-Patient Relations" OR "teleadvice" OR "advice" OR "unsolicited email*" ) AND ( internet OR "email*" OR "e-mail*" OR "electronic mail*" OR "chat" OR "newsgroup*" OR "usenet" ) )
```

A total of 200 publications were found and screened on the basis of the abstract and the title. Most of these publications dealt with physician-to-physician telemedicine applications or physician-patient interactions in the framework of a pre-existing

patient-physician relationship and were therefore only of marginal interest for this review.

Review of ethical and professional codes

The professional and ethical codes of the following organizations (countries) were reviewed: American Medical Association (USA); Bundesärztekammer and Landesärztekammern (Germany); Ethical guidelines for telemedicine adopted by the Standing Committee of European Doctors; Swiss Medical Federation FMH (Switzerland); General Medical Council (UK); World Medical Association (WMA).

Contacts to experts

A wide range of experts was consulted to elucidate the issues. A workshop entitled "Unsolicited emails from patients to health information providers and doctors on the WWW asking for medical advice - how to handle them?" was organized by the author at the AMIA Fall Symposium, Orlando(Florida), Nov 7, 1998. Letters were written to legal experts at professional medical bodies. Requests for comments were posted on various mailing lists and a panel of experts (listed under Acknowledgements) identified themselves and provided input.

Results

Available Evidence

What are patients asking online?

Three studies exist in the medical literature that have analyzed the nature and content of patient requests:

- Widman & Tong [9] analyzed 70 unsolicited emails sent by patients over a period of 12 months. The inquiries (mostly concerning cardiac arrhythmias, as they were sent in response to a website focusing on this topic) were questions about diagnosis (15), therapy (48), prognosis (1), and patient education (6).
- Eysenbach & Diepgen [2] provided a more thorough analysis of 209 emails sent to a university department of dermatology in a four-month period between April and August 1997. Forty percent of all emails could have been answered by a librarian, 28% of all emails were suitable to be answered by a physician via email alone, and in 27% of the cases any kind of consultation would not have been possible without seeing the patient. In 34% of the cases, patients wanted to have general information about a condition, and three-quarters of the messages (75%) contained 1 or more specific questions, mostly about therapy (30%) or requests for information about a "specialist" to treat a given condition (15%). Eleven percent gave a list of symptoms and wanted to hear a diagnosis.
- Borowitz & Wyatt [7] analyzed 1,001 requests from patients sent between November 1995 and June 1998 to the Division of Pediatric Gastroenterology at a children's medical center. Contrary to the previous two studies, these appear to be solicited requests. In 69% of the requests, there was a specific question about the cause of a particular child's symptoms, diagnostic tests, and/or therapeutic interventions. In 112 of the requests (9%), the requester sought a second opinion about diagnosis or treatment for a particular child,

and 272 consultations (22%) requested general information concerning a disorder, treatment, or medication without reference to a particular child.

In summary, it can be learned from these studies that the spectrum of questions ranges from very general questions to questions that would involve medical decision-making. The latter constitute about 27% in one study [2]. It can also be learned that patients are not always able to distinguish between questions that are suitable to be answered via email and those that aren't.

What are physicians doing on the Internet?

Very little is known about what physicians are actually doing on the Internet and to what degree this constitutes medical practice.

- Culver and colleagues [10] analyzed 1,658 consecutive messages on a particular online discussion group during a 5-month period. Of all messages, 55.9% (927) addressed a medical topic. Of these, 79% (732) provided medical information, of which 5.1% (37) were authored by trained health professionals. Personal experience was the basis of information provided in 13.5% of the professionals' messages, while no source was given as the basis of information provided in 29.8% of the nonprofessionals' messages and 67.6% of the professionals' messages. A published source was cited in 9.2% of the nonprofessionals' and 18.9% of the professionals' messages.
- Eysenbach and Diepgen [1] sent an unsolicited email in December 1997 and January 1998 from a fictitious patient describing an acute dermatological problem to 58 physicians and webmasters to explore the response rate and the types of responses in terms of amount of information given. Fifty percent responded to the fictitious patient request; of those who responded, 31% refused to give advice without having seen the lesion, 59% explicitly mentioned the correct "diagnosis" in their reply, and 17% gave detailed treatment advice. Ninety-three percent recommended that the patient see a physician. Two different arguments were brought forward in the replies: the impossibility of making a diagnosis via email without an examination ("The diagnosis is unclear because we cannot look at your exanthema."), and/or lack of resources and/or mandate to "reply to all the enquiries of this kind that we receive." Some of these responses were probably standard replies.
- A similar email from a fictitious patient was also sent to commercial "cyberdocs" who explicitly offered medical advice on the Internet [11]. Ten free and 7 charging cyberdocs were contacted. Ten cyberdocs responded. Three declined to give advice because dermatology was not their area of expertise. Seven cyberdocs provided advice (2 for free, 5 for a charge). The advice given by 5 cyberdocs was accurate, and the "correct" diagnosis herpes zoster was mentioned. In the remaining 2 cases the advice was highly questionable: one cyberdoc recommended a homeopathic medicine, the other unusual methods such as drinking rain water and eating red clover and dandelion.
- Sandvik [12] repeated these studies by sending an email from a fictitious incontinent woman to 75 websites

providing information on this topic. Sixty-six percent of the sites responded to the email request for advice. Messages were also sent to two newsgroups, but the results are not reported.

In summary, it can be stated that a significant number of physicians on the Internet do not confine their interactions with patients to giving general advice, but also make diagnoses and give therapeutic hints.

What constitutes medical practice - and can a patient-physician relationship be established online?

Although the a large part of the daily practice of medicine encompasses giving health information, providing emotional support, and coordinating care, legislation defines "practicing medicine" much more narrowly, by focusing on diagnosis and treatment.

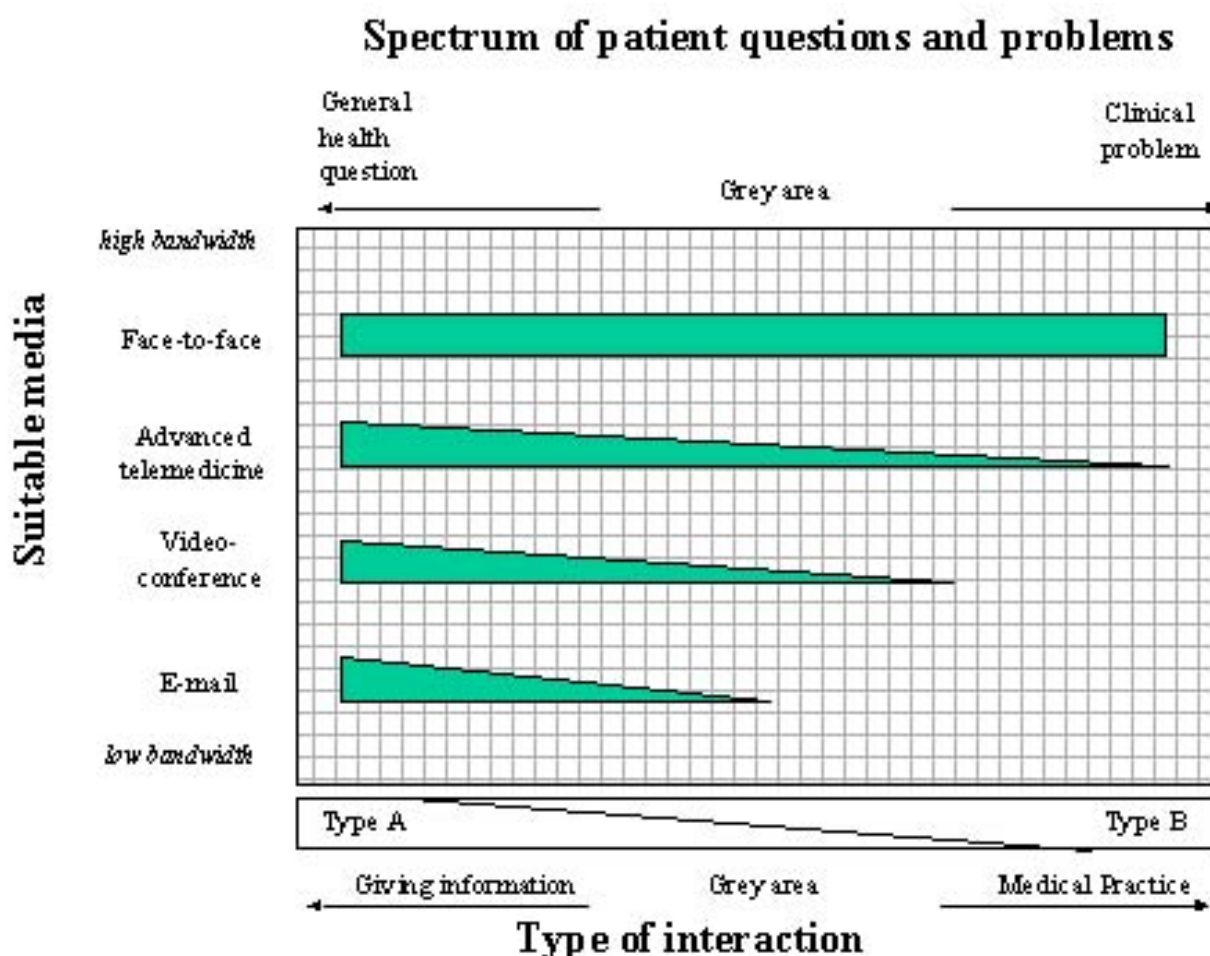
For example, the US State of New Hampshire defines the practice of medicine as follows:

Any person shall be regarded as practicing medicine under the meaning of this chapter who shall diagnose, operate on, treat, perform surgery, or prescribe for

or otherwise treat any disease or human ailment, whether physical or mental. "Surgery" means any procedure, including but not limited to laser, in which human tissue is cut, shaped, burned, vaporized, or otherwise structurally altered, except that this section shall not apply to any person to whom authority is given by any other statute to perform acts which might otherwise be deemed the practice of medicine. "Laser" means light amplification by stimulated emission of radiation. [[State of New Hampshire, RSA 329:1, amended June 18, 1997. Available from: <http://www.state.nh.us/gencourt/bills/chaptered/97chapters/0214-hb0718.htm>]]

That lawyers focus on the concepts of diagnosis and treatment has its justification, as many other people also give health information, and provide emotional support or health advice, without being physicians and having a medical license; for example, journalists, webmasters of health websites, librarians, priests, or hair stylists. While there seems to be consensus that giving general health information is not "practicing medicine," and that the process of diagnosing and treating clearly constitutes practicing medicine, there is a large grey area between these two extremes (see Figure 3).

Figure 3. Different media are appropriate at each point on the continuum between dispensing general health information and handling patients' problems which would require the practice of medicine to solve. For example, email is a sufficiently capable medium for giving out general health information, while diagnosis and treatment usually requires at least advanced telemedical technology. Likewise, when dispensing general health information, a Type A relationship between the patient and the physician is sufficient; for practicing medicine, a Type B relationship is desirable. The difficulty is that there is no clear-cut line between the two extremes - and it is in this grey area that the majority of patient-physician interactions on the Internet take place



A significant part of patient-physician interactions on the Internet takes place in this grey area. Part of the problem is that "treatment" is another ill-defined concept - do we "treat" someone, if we give him or her advice related to his other health? Physicians would say yes, as many medical conditions can in fact be treated simply by giving advice. Journalists would perhaps say no, as otherwise they would practice medicine if they publish health stories. What is the difference between health advice given by a physician and health advice given by a journalist? One difference is that the former is usually given face-to-face, while the latter is given via a medium. In the age of telemedicine, however, face-to-face interaction cannot be a suitable criterion to define medical practice - especially not on the Internet, where everything we do is through a medium. Another difference is that the physician listens to our problem and then gives tailored advice hoping that the patient will act upon it, while the journalist only listens to the "collective voice" of his target group and gives more general advice without knowing who acts on this information. Thus, the feedback loop of listening to an individual and reacting specifically to his needs could be a guiding principle to define medical practice: The more health information is personalized and tailored to the individual, and the more it encourages the receiver to act upon the advice, the more we are moving within the continuum from giving general health advice towards attempting to treat, and therefore practicing medicine. This would also imply that expert systems and dynamic web pages providing tailored information on the basis of feedback forms filled in by users may well be considered as practicing medicine. Still, there remains a huge grey area. For example, telephone advice services such as the British NHS Direct, where health professionals advise patients whether their condition justify a doctor visit, certainly provide personalized information on which the receiver acts directly, without being necessarily considered as practicing medicine. Thus, different standards for different kinds of advice given may apply. Much of the confusion, controversy and debate about the legitimacy of giving medical teleadvice has also to do with the fact that different people have different thoughts on what exactly is meant by teleadvice; for example, giving general health information, giving personalized health information, or even diagnosis or treat.

On many medical websites, particularly on "ask-the-expert" services, health information providers publish disclaimers which aim to reduce the risk of misunderstandings on the nature of such advice. It has been noted that the legal ramifications of such disclaimers are unclear: "Statements claiming that medical advice or second opinions rendered via the Internet do not constitute the practice of medicine have yet to be tested for legal effect, though such disclaimers rarely insulate practitioners from the prevailing standards of care" [8].

Thus, disclaimers may well help patients to become aware on the limitations of telecommunication services, but they are unlikely to liberate physicians from liability claims.

In a letter to JAMA, R. Neill pointed to the fact that: "In the United States, a patient-physician relationship is established when a physician exercises independent medical judgment on the patient's behalf, whether explicitly or implicitly. One legal test of the relationship is embodied in the question of reliance:

did the patient reasonably rely on the physician's judgment [13]? Keeping in mind these precepts, physicians clearly have the capacity to establish patient-physician relationships using e-mail" [14].

Not all advice can be treated equally, as there is a spectrum of patient questions and physician replies (as shown above) that ranges from "general information" to "clinical issues." It is necessary to make a distinction between such general responses and clinical advice. M. Howard mentioned in another article that: "A physician offering advice by email will be liable for unfavorable results of that advice if a reasonable person would have understood the physician to be offering therapy. A general response to a vague question will probably not be sufficient to establish a physician-patient relationship with a person not already a patient of the practice" [15].

Thus, there seems to be consensus that physicians can indeed establish a patient-physician relationship online, and that it depends on their reply and their actions whether the interaction can be considered to be an act of medical practice or just an act of "information brokerage." However, there will always be a grey area, and it is the responsibility of the physician to act according to where on the continuum (Figure 3) the patient's problem is located, and according to which "media" of interaction are available. Moreover, it is essential to clearly state the nature of the interaction to the patient.

Ethical and professional codes

A number of ethical and professional codes were reviewed concerning giving advice by telecommunication.

World Medical Association

The World Medical Association (WMA) is currently consulting its National Medical Association members around the world with a view to drawing up new ethical guidelines on telemedicine.

Standing Committee of European Doctors

Ethical guidelines for telemedicine adopted by the Standing Committee of European Doctors demand that: "Where a direct telemedicine consultation is sought by the patient, it should normally only take place when the doctor has an existing professional relationship with the patient, or has adequate knowledge of the presenting problem. (...) Preferably, all patients seeking medical advice should see a doctor in a face to face consultation, and telemedicine should be restricted to situations in which a doctor can not be physically present within acceptable time" [16].

Both are rarely the case on the Internet in Type A interactions - neither is there, by definition, an existing professional relationship, nor are remoteness or physical disabilities the main reasons for consulting Internet doctors [2].

Germany

German physicians who give individual advice to patients by mail or email would clearly violate their professional code, which explicitly provides that:

...no physician may give individual medical treatment, including medical advice, neither exclusively by mail

. . . nor exclusively over communication media or computer communication networks.

(B.II. §7, Par. 3; German Model Regulations for the Professional Code)

A spokesperson from a German physician association recently insisted that "any medical advice must be given face-to-face. This has been always like this, and it will remain like this" [17].

Switzerland

In Switzerland the professional code [18] says:

The regular treatment solely on the basis of written, by phone or electronically transmitted information or reports from third parties is incompatible with a genuine conduct of the profession.

(Standesordnung FMH, 12 Dec 1996; Article 7)

Note that the word "regular" is used, which does not exclude an initial or occasional contact. Recognizing that advice via telecommunication is part of medical reality, and that there is a demand on the patients' side for Internet teleadvice services, Swiss legal experts have taken steps to define a framework for teleadvice services. A main requirement for such services is that they define their offer thoroughly in terms of:

- Defining of reply times
- Defining whether each question will be answered, or whether there is a selection
- Defining whether only requests from Swiss citizens are answered, or also international requests

- A disclaimer saying that not all questions can be answered by email, and that the patients may have to see a doctor

If there is no pre-existing patient-physician relationship, physicians can charge patients only on a private basis; coverage by the social security health insurance is not possible.

HON-Code

The Swiss Health On the Net Foundation (HON) does not, in its HON Code of Conduct, provide any specific principles for giving advice via email; but referring to information on medical websites, it is stated as one of the principles that: "Information should be designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician" [19].

United States

The Ethics Committee of the American Medical Association (AMA) has drawn up recommendations for "Physician Advisory or Referral Services by Telecommunications" [20]. These acknowledge that teleadvice services can be useful for the public and are, compared to the other professional codes listed above, much more clear as to what can be considered reasonable and what is ethically critical (diagnosis and especially therapy). Also relevant is the policy statement on phone counseling (which could also be applied to "ask-the-expert" services on the Internet) and - in terms of quality management of such services - the policy on "disease management and demand management" (all given below).

Textbox 2. AMA Current Opinions of the Council on Ethical and Judicial Affairs***E-5.025 Physician Advisory or Referral Services by Telecommunications***

Telecommunication advisory services, by way of phone, fax, or computer, distinct from an existing physician-patient relationship can be a helpful source of medical information for the public. Often, people are not sure where to turn for information of a general medical nature or do not have easy access to other sources of information. Individuals also may be embarrassed about directly bringing up certain questions with their physicians. Although telecommunication advisory services can only provide limited medical services, they can be a useful complement to more comprehensive services, if used properly.

Any telecommunication advisory service should employ certain safeguards to prevent misuse. For example, the physician responding to the call should not make a clinical diagnosis. Diagnosis by telecommunication is done without the benefit of a physician examination or even a face-to-face meeting with the caller. Critical medical data may be unavailable to the physician. Physicians who respond to callers should therefore act within the limitations of telecommunication services and ensure that callers understand the limitations of the services. Under no circumstances should medications be prescribed.

Physicians who respond to the calls should elicit all necessary information from the callers. When callers are charged by the minute, they may try to hurry their calls to limit their costs. As a result, important information may not be disclosed to the physician. Physicians should also ensure that callers do not incur large bills inadvertently or without understanding the billing system.

Physician referral services can also offer important information to the public. Referral services are often provided by medical societies, hospitals and for-profit entities. To ensure that the service bases its recommendation on medically legitimate considerations rather than the likelihood of being paid by the physician, when the service charges physicians a fee to participate, physicians should not pay the service per referral. Also, callers should be told how the list is created. For example, callers should be informed whether the list includes physicians who pay a flat fee to be listed, members of a particular hospital staff or medical society, or physicians who meet some general quality-based criteria.

While these safeguards are described as applying primarily to telephone services, they should be considered equally applicable to any other communication media, such as radio, or television, in which the physician and patient do not meet face-to-face. Issued June 1994; Updated June 1996. (I, IV, VI)

Policies of the AMA House of Delegates***H-160.935 Policy on Phone Counseling***

The AMA recommends the following statements on phone counseling: (1) Medical phone counseling services must appoint a physician director. Such services are not absolved of that responsibility by a disclaimer to the callers. A physician director must be ultimately responsible for the telephone triaging of patients in a given system. (2) A physician director must be responsible for: (a) Providing and updating protocols and algorithms for phone counseling by non-physicians. (b) Identifying high-risk patients who must be directly and immediately referred to physicians at all times. (c) Supervision and review of second-level triage provided by advanced nurse practitioners and physician assistants. (d) Ensuring permanent records of all calls received. (e) Maintaining accountability for the patient until a referral has been effected with an accepting physician. (3) Urges quality assurance programs be developed by national accrediting agencies that address issues raised by phone counseling centers. (BOT Rep. 2, A-97)

H-285.944 Disease Management And Demand Management

.... phone counseling and triage centers should routinely compile outcome information on all calls handled, and should modify their operating policies and referral protocols as needed to enhance the effectiveness of the service.

(14) Telephone triage centers should routinely inform primary or principal care physicians of the disposition of all calls received from their patients.

(15) Telephone counseling and triage should be performed by health professionals with a level of knowledge and training no less than that of a registered nurse.

(16) Qualified physicians should be readily accessible for consultation and second-level triage to the nurses or other health professionals providing telephone counseling or triage.

(17) Physicians performing second level triage for telephone triage centers should be compensated for such services by the center or sponsoring health plan.

(18) Compensation for individuals performing telephone counseling and triage should not be based on the number or the disposition of calls handled.

(19) Organizations that provide telephone triage services should provide such services 24 hours a day on a year-round basis and calls should be handled as expeditiously as possible. (CMS Rep. 3, I-97; Reaffirmed by Sub. Res. 707, A-98)

Great Britain

Following reports in the literature on "cyberdoctors" [11], the General Medical Council (GMC) has drafted a note on "Providing advice and medical service on-line or by telephone",

which is reprinted below. It is noteworthy that it does not strictly preclude any email advice (such as in the German professional code), but leaves the responsibility and the decision to the judgment of the individual physician.

Textbox 1. GMC-General Medical Council (UK) "Good Medical Practice"***Providing advice and medical services on-line or by telephone (November 1998)***

Giving advice by telephone is part of many doctors' day-to-day relationship with their patients. In some circumstances providing advice by telephone or computer link may be essential, for example, where patients are geographically isolated from their doctor.

However the use of phone or e-mail should not diminish the quality of care patients receive. Consultations and prescribing by phone or e-mail may seriously compromise standards of care where:

- The patient is not previously known to the doctor, and
- No examination can be provided, and
- There is little or no provision for appropriate monitoring of the patient or follow-up care.

Doctors who wish to provide telephone or on-line services should consider carefully whether such a service will serve their patients' interests, and if necessary, seek advice from their professional association or medical defence society.

Discussion and Recommendations

Most current professional codes and ethical guidelines for telemedicine explicitly discourage - sometimes even forbid - giving or offering any concrete medical advice via telecommunication and computer communication networks in the absence of a pre-existing patient-physician relationship. Against this background we have previously argued that: "Given the enormous patient demand for 'teleadvice' such restrictive guidelines should be reconsidered, as otherwise unqualified 'cyberquacks' offering dubious advice on a commercial basis [11] may take over. Thus, restrictive national provisions should perhaps be replaced by more liberal, less paternalistic international guidelines that do not prohibit any patient-physician interaction by e-mail but set international standards on proper teleadvice" [21].

As there is no clear-cut line between giving general information and practicing medicine on the Internet, ideally professional codes should not flatly forbid any teleadvice. Rather, physicians should have the responsibility to decide according to their ability and judgment on which point of the continuum the question is located, and how much and which information can be given to a patient given the constraints of the data available, the medium used, and the relationship established (Figure 3).

Based on the review of the literature and consultation with numerous experts, the following six principles for Type A teleadvice and teleconsultation are suggested.

Six suggested principles for giving Type A teleadvice on the Internet

1. Physicians responding to patients' requests on the Internet should act within the limitations of telecommunication services and keep the global nature of the Internet in mind.
2. Not every aspect of medicine requires face-to-face communication or physical examination, thus teleadvice may be legitimate in some cases.
3. Requests for help, including unsolicited patient questions, should not be ignored, but dealt with in some manner.
4. Informed consent requires fair and honest labeling (disclaimers and disclosure).
5. Health professionals and information providers must maintain confidentiality.

6. Health professionals should define internal procedures and perform quality control measures.

Principle 1: Physicians responding to patients' requests on the Internet should act within the limitations of telecommunication services and keep the global nature of the Internet in mind.

As there is currently not enough evidence on the effects and effectiveness of teleadvice given to patients that contains information on diagnoses or treatment, physicians should not propose or attempt to diagnose or treat online.

Don'ts:

- Don't make a specific diagnosis. If you do mention possible diagnoses, always provide a disclaimer that this is only one of several possibilities, and that the final diagnosis can only be established by the treating physician.
- Don't prescribe medicines.
- Don't judge the appropriateness of therapeutic interventions or challenge the diagnosis given by other physicians without knowing the case in detail.
- Don't send out general information in the guise of individualized information. (For example, avoid "personalizing" general information by including the name of the sender automatically in the text.)
- Don't mention suspicions, especially those that could have severe consequences (e.g. possible diagnoses such as cancer). Keep the emotional impact of your advice in mind.
- Don't give detailed advice if you are not sure about the nationality or cultural background of the sender.

Principle 2: Not every aspect of medicine requires face-to-face communication.

While diagnosis and treatment should not be attempted online, there is much that online health professionals can legitimately do; for example, answering questions about the side effects of medicines and about whether certain symptoms need to be investigated.

Drug information is a good example. In several countries, for example at the United Kingdom's Trent Drug Information Centre, Leicester Royal Infirmary [22], there are already telephone help lines which provide information and advice on all aspects of drug treatment directly to the public via telephone. Such services may also be provided on the Internet.

Other questions that could be answered mainly fall under the field of preventive medicine such as lifestyle counseling, nutrition advice, primary injury and disease prevention, and questions regarding screening and health risk assessment including genetic counseling and tertiary prevention.

Things to do:

- Encourage patients to see a doctor if you feel the patient should, and if the patient seems to be reluctant for some irrational reason.
- Provide addresses of self-support groups and other organizations which may provide help and support.
- Provide addresses of specialists and hospitals.
- Answer general questions on side effects of medicines.
- Answer general questions on the compatibility of certain drugs and identify combinations of drugs which may pose problems.
- Give your opinion on whether certain symptoms need to be investigated.
- Answer questions on prevention of diseases and injuries.
- Recommend simple measures which may alleviate the problem.
- Try to identify questions the patient should ask himself to decide whether or not to see a doctor.
- Provide emotional support.
- Provide general information, e.g. disease fact sheets, the latest research results, and information on ongoing trials; but make clear that this is general information which may not apply to the patient's individual case and should be discussed with the treating physician.
- Refer to areas of uncertainties.

Principle 3: Requests for help, including unsolicited patient questions, should not be ignored, but dealt with in some appropriate manner.

Whether or not (and how) to react to an email largely depends in the content: "So how one deals with e-mail questions often depends on the content. Particularly inappropriate questions may be simply deleted, quickly disposed of without further thought" [23].

However, an interesting question is whether physicians have the ethical duty at least to try to help the patient to find more appropriate ways to answer his/her question. Currently, most physicians will actually simply delete the message without any attempts to help. In letter to the editor of the Archives of Dermatology a physician wrote in response to our call to establish guidelines [2]: "The appropriate resolution for the majority of unsolicited mail is the same as for unsolicited email: the wastebasket/delete button. Do not offer advice to someone you personally have not seen physically, touched and examined in real time" [24].

The letter writer brought forward the Hippocratic principle of "first do no harm" (*primum nil nocere*) to justify his position.

However, we think that physicians have an ethical obligation not only to do no harm, but - if possible - to do good and to protect the patient, as has been pointed out in the following letter reply [25]:

While we are well aware of all the problems and pitfalls associated with giving advice under conditions of extremely limited information [11] and the problems of quality information on the Internet at large [26], we think that to react to these questions by simply discarding them is probably the worst of all possible alternatives. To delete them without having replied or even read the e-mail is not only disrespectful patients and rude, it also signifies an ignorance toward patients' concerns and is a slap in the face to those who argue that patients should be informed, educated, and encouraged to take responsibility for their own health. Already, patients are largely turning to the Internet because they think that physicians do not take enough time for their concerns [27].

Physicians (increasingly!) have an ethical responsibility to educate patients and consumers. To "respond" to patients' questions by deleting them seems much more unethical to us than giving a professional and courteous reply or forwarding the e-mail to a third party who can deal with the patient's concerns or questions. In any case, hitting the delete button is the opposite of what we would consider to act "for the good of my patients according to my ability and by judgment" (Hippocratic Oath).

Thus, physicians do have an ethical responsibility to read their email and to reply by helping the sender to find someone who can respond to their need. While this may not be always possible in practice, every effort should be made to minimize misunderstanding on the part of the patient, raising false hopes or causing potential harm by, for example, replying with a standard message saying that it is impossible to reply to every email.

The ethical duty to help may also be resolved by forwarding the email to an institution who is prepared to handle such requests (a "clearance center" for unsolicited emails has been proposed [21,25]). It is however essential that - if the email request is forwarded to a third party - the sender must give his or her consent. Alternately, the receiver may post on his website near his email address his policy of forwarding unsolicited patient emails to a third party.

Standard replies may for example contain URLs of useful and quality-assessed websites, addresses of self-support groups and professional organizations, or book titles and articles which contain further information (see Box 3).

Textbox 3. Example standard reply, used by HealthSCOUT (courtesy of Dr. Renner)

Hello, _____. Thank you for your recent request to HealthSCOUT. I receive many e-mails each week and will do my best to respond appropriately.

It's not right legally or ethically to practice medicine over the Internet. That may change in the future, but right now, the best advice you're going to get is from a face-to-face consultation with a physician.

Nevertheless, there are some distinct advantages to using the Internet for consumer health research, and HealthSCOUT is a very good place to do it.

If you do a key word search for _____, you'll probably find a number of HealthSCOUT items. In your case, for example, here is one of a number of articles found there _____. You can print out this and share it with your doctor.

Generally reliable Information about your question may be found elsewhere on the Internet on the following URL: www._____.

Healthfinder____, Stars list____, medline____, others_____.

If you want to really polish your skills at finding health information on the Internet look at www._____. Please make sure the information really applies to your specific condition by sharing it with your doctor.

If you are unable to find appropriate answers this way and you need further assistance, please call me at _____.

If you get voice mail, leave your name, number and brief message, I will call you back.

Sincerely,

John H. Renner M.D. Chief Medical Officer, HealthSCOUT

Standard replies should be made clearly recognizable as standard replies. Under no circumstances should standard replies be made to appear to be individual replies.

Standard replies may be sent manually or automatically. If standard replies are sent manually, it should not take longer than 24 hours to respond.

If the patient gives a list of symptoms and asks for possible diagnoses, a standard reply could be sent, which points out that it is impossible to make a remote diagnosis without a complete medical history and examination. In some cases, standard replies are inappropriate and should be replaced by a more sensible personal email. A patient who received a standard reply (which contained the standard phrase to see a real doctor) replied angrily with the following email:

Dear Person, how insulting to have you tell me to seek a "real" doctor's advice. Obviously you did not read my e-mail. My sister has been given this diagnosis by a "real" doctor who told her she has to live with it!!!! I do not believe there is any condition one has "to live with", there is always help and hope in nature. That you choose not to offer any help or advice on where to find help is unfortunate. We merely want to find out more about this skin condition!

(Response from a patient to a standard reply of G.E.)

Principle 4: Informed consent requires fair and honest labeling.

Patients should at all times understand the nature and limitations of email consultations. In the context of "ask-the-doctor" services, terms and phrases labeling this service as "medical advice," or even "virtual hospital," may mislead (as they evoke certain associations leading to the impression that these services could replace a doctor visit) and should be avoided.

Disclaimers and full disclosure of all relevant information as specified below are crucial for informed consent and informed choice.

4.1. Disclaimers and informed consent

Patients cannot always be expected to understand the nature and limitations of Internet consultations. Spielberg has pointed out that patient-initiated email does not automatically imply consent: "Simply because patients use email informally in other contexts does not mean that they understand the implications of communicating about sensitive medical topics" [4]. Thus, every effort should be taken to ensure that patients understand and explicitly consent to the implications of communicating with the physician, for example on issues such as:

- Storage and handling (in particular forwarding) of messages
- Security issues: Any sites that offer email addresses should contain a written statement regarding email security risks [8]

4.2. Disclosure and informed choice

At a minimum, the following should be disclosed:

- The identities of those who will (have) read the patient's emails, and who will (have) answer(ed) them. If the physician delegates office staff to triage all incoming email, this should be disclosed on the website. If the physician uses a third-party service provider (e.g. a web site which handles back-end office tasks), that relationship should be made clear along with the potential for privacy and security violations related to third party.
- The qualifications of the responder
- Financial dependence / sponsoring
- Before the patient sends the request, he should be clear about all procedural aspects (e.g. are the emails forwarded, published, collected, etc.) and whether or not any costs will incur.

Principle 5: Health professionals and information providers must maintain confidentiality.

No medical interaction of any sort should generate the remotest possibility that an outside person or organization of any kind should be able to detect that the medical interaction had taken place.

If an "ask-the-doctor" service plans to publish users' questions, he or she should disclose this fact. Never should questions be published that could lead to identification of the sender without his or her explicit consent (in this case a general statement that questions may be published is not sufficient, but the individual must be contacted directly). Patients need to be informed about privacy issues and should know who reads his or her email if it is any person other than the doctor or addressee (see also Disclosure).

The physician should never communicate to a group of patients by email in such a way that all recipients are visible to one another (e.g. by using the carbon copy function [cc]).

Principle 6: Health professionals should define internal procedures and perform quality control measures.

Health professionals should define responsibilities within the institution and define procedures for triaging messages from

unknown patients. Performing quality assessments assures that patients are receiving the correct and proper information.

Conclusion

While the Internet offers huge opportunities for patients to educate themselves and to take responsibility for their own health, it also provides new challenges. One of these challenges is that patients and doctors alike still have to learn how to communicate with each other. Patients have to be educated that it is unethical to diagnose and treat over the Internet in the absence of a pre-existing patient-physician relationship, and if the interaction is limited to a single email. Likewise, physicians also sometimes break from the normal standards of care, and are tempted to make a diagnosis or even give therapeutic advice in the context of extremely limited information [1]. More research is needed to establish more evidence regarding situations in which teleadvice is beneficial and efficient.

Acknowledgments

Members of the panel who provided input, ideas, and advice for this paper were Donna M. D'Alessandro, James E. Levin, John H. Renner, Tom Ferguson, Badal Pal, Jari Forsstrom, R. Neill, Stanberry Benedict, Robert Hsiung, R. Johnson, Virginia R. Hetrick, Helga E. Rippen, John Mack, Kenneth W. Goodman, Theo Arvanitis, Jens Doerup and Hans v.d. Slikke. The American Medical Informatics Association (AMIA) provided space and the framework for a workshop on "unsolicited patient emails" on their Fall Symposium, Orlando/Florida, Nov 7, 1998.

The Internet Healthcare Coalition (IHC) provided the framework for the e-Health ethics summit in Washington DC, Jan 31 - Feb 2, 2000, on which the topic of practicing medicine on the Internet (and this paper as a subset of the issue) has been discussed. Members of this workgroup were Jaak Aru (Doctus); Allan Bruckheim (Market Data Corp., Med Scan); Gunther Eysenbach (Cybermedicine Research Group, University of Heidelberg); Ruth Faden (The Bioethics Institute, Baltimore); Jim Harris (CIGNA Healthcare of California); Tom Houston (Johns Hopkins University); Sybil Ingram-Muhammad (Enlightened Inc.); Murray Kopelow (US Accreditation Council for Continuing Medical Education), Alex Langermann (Northwestern University), George Lundberg (Medscape); Blackford Middleton (Medicalogic); Roberto Rodrigues (WHO/PAHO); Mike Squires (Medscape); David B. Vance (Glaxo-Wellcome). The results of these discussions will be fed into the forthcoming white paper.

Conflicts of Interest

The author acts as a paid consultant, editor, and author for a number of health websites.

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###Reviewer names will be inserted here### published 24.02.00.

Please cite as:

Eysenbach G

Towards ethical guidelines for dealing with unsolicited patient emails and giving teleadvice in the absence of a pre-existing patient-physician relationship — systematic review and expert survey

J Med Internet Res 2000;2(1):e1

URL: <http://www.jmir.org/2000/1/e1/>

doi: [10.2196/jmir.2.1.e1](#)

PMID: [11720920](#)

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Policy Proposal

e-Health Ethics Draft Code (Feb 18)

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Abstract

The Internet is changing how people receive health information and health care. All who use the Internet for health-related purposes must join together to create an environment of trusted relationships to assure high quality information and services; protect privacy; and enhance the value of the Internet for both consumers and providers of health information, products, and services. The goal of the "e-Health Code of Ethics" is to ensure that all people worldwide can confidently, and without risk, realize the full benefits of the Internet to improve their health. The draft code, presented in this paper, has been prepared as a result of the "eHealth Ethics Summit," which convened in Washington DC on 31 January 2000 - 2 February 2000, organized by the Internet Healthcare Coalition and hosted by the World Health Organisation/Pan-American Health Organisation (WHO/PAHO), and attended by a panel of about 50 invited experts from all over the world. It sets forth guiding principles under five main headings: candor and trustworthiness; quality; informed consent, privacy, and confidentiality; best commercial practices; and best practices for provision of health care on the Internet by health care professionals.

(*J Med Internet Res* 2000;2(1):e2) doi:[10.2196/jmir.2.1.e2](https://doi.org/10.2196/jmir.2.1.e2)

KEYWORDS

Internet; Ethics; Quality of Health Care

Please note: This is a discussion paper. Feedback on this proposal may be given until April 14, 2000. (Please use the feedback form at http://mednetics.org/ethics/ehes_feedback.htm)

*Note added on May 24, 2000: This draft is now obsolete. The **final version** of this article has been published in the Journal of Medical Internet Research 2000;2(2):e9.*

Vision Statement

The Internet is changing how people receive health information and health care. All who use the Internet for health-related purposes must join together to create an environment of trusted relationships to assure high quality information and services, protect privacy, and enhance the value of the Internet for both consumers and providers of health information, products, and services. The goal of the "e-Health Code of Ethics" is to ensure that all people worldwide can confidently, and without risk, realize the full benefits of the Internet to improve their health.

Introduction

Health information has the potential both to improve health and to do harm. All people who use the Internet for health-related purposes must be able to trust that the sites they visit adhere to the highest ethical standards and that the information provided is credible.

Because health and health care are critically important to people, the organizations and individuals that provide health information on the Internet have special, strong obligations to be trustworthy, provide high quality content, protect users' privacy, and adhere to standards of best practices for online commerce and online professional services in health care.

Guiding Principles

1. Candor & Trustworthiness

Guiding Principle:

Organizations and individuals providing health information, products, or services on the Internet have an obligation to candidly disclose

- (A) those factors that could influence content*
- (B) the potential risks of providing personal information on the Internet*

2. Quality

Guiding Principle:

Organizations and individuals offering health information, products, or services on the Internet have an obligation to

- (A) provide high quality information, products, or services*
- (B) provide means for users to evaluate the quality of health information*

3. Informed Consent, Privacy & Confidentiality

Guiding Principle:

Organizations and individuals providing health information, products, or services on the Internet have an obligation to

- (A) safeguard users' privacy*
- (B) obtain users' informed consent when gathering personal information*

4. Best Commercial Practices

Guiding Principle:

Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to

- (A) disclose any information a reasonable person would believe might influence his or her decision to purchase or use products or services*
- (B) be truthful and not deceptive*
- (C) engage in responsible business relationships and affiliations*
- (D) guarantee editorial independence*
- (E) disclose the site's privacy policy and terms of use*

5. Best Practices for Provision of Health Care on the Internet by Health Care Professionals

Guiding Principle:

Health care professionals and organizations who provide health information, products, or services on the Internet have an obligation to

- (A) adhere to the highest standards of professional practice*
- (B) help patients to understand how the Internet affects the relationship between professional and patient while adapting the highest professional standards to the evolving interactions made possible by the Internet*

Definitions

Health Information

Health information includes information for staying well, preventing and managing disease, and making other decisions related to health and health care.

It includes information for making decisions about health products and health services.

It may be in the form of data, text, audio, and/or video.

It may be subject to frequent changes due to the updating of websites or user-provider interactivity

1. Candor & Trustworthiness

Guiding Principle: Organizations and individuals providing health information, products, or services on the Internet have an obligation to candidly disclose

- (A) those factors that could influence content*
- (B) the potential risks of users providing personal information on the Internet*

Principle Part (A): Content

People who use the Internet for health-related purposes must have sufficient information to make fully informed decisions about the integrity of content and the potential for bias. Thus

Organizations and individuals offering health information, products, or services on the Internet have an obligation to

- (1) prominently, clearly, and accurately indicate*
- (2) clearly distinguish advertising from educational or scientific content*

Principle Part (B): Risk

People may not realize that personal information may be collected when they use the Internet. And they may not understand that declining to provide personal data may affect the information or services they receive. Thus

Organizations and individuals offering health information, products, or services on the Internet have an obligation to

- (1) alert users to the potential risks to the privacy of personal information on the Internet (for example, that third parties may be collecting information without the site's knowledge)*
- (2) provide clear, complete, and accurate information regarding*
- (4) clearly disclose the consequences, if any, of refusing to provide personal information*
- (5) clearly describe the accountability mechanism used by the organization or site and how to contact the responsible party*

2. Quality

Guiding Principle: Organizations and individuals offering health information, products, or services on the Internet have an obligation to

- (A) provide high quality information, products, or services*

(B) provide means for users to evaluate the quality of health information

Principle Part (A): Quality

People who use the Internet for health-related purposes need credible, well-supported information in order to make prudent decisions. Thus

Organizations and individuals offering health information, products, or services on the Internet have an obligation to provide information that is

- (1) culturally appropriate and easy to use*
- (2) accurate and unbiased*
- (3) up to date*

Further explanation of Part (A)

- (1) High quality health information*
- (2) High quality health information should*
- (3) High quality health information should clearly display*

Principle Part (B): User Evaluation

People who use the Internet for health-related purposes need to be able to judge the credibility of content. Thus

Organizations and individuals offering health information, products, or services on the Internet have an obligation to

- (1) clearly and accurately*
- (2) provide tools for feedback from users about the quality of content and usability of the site*

3. Informed Consent, Privacy & Confidentiality

Guiding Principle: Organizations and individuals providing health information, products, or services on the Internet have an obligation to

- (A) safeguard users' privacy*
- (B) obtain users' informed consent when gathering personal information*

Principle Part (A): Informed Consent

To make prudent decisions about whether to provide personal information online, especially information about their health status, people need to know what information is being gathered and why. Thus

Organizations and individuals providing health information, products, or services on the Internet have an obligation to

- (1) prominently and clearly describe*
- (2) verify that users have given their voluntary informed consent to collect and use personal information in the ways described*

Principle Part (B): Privacy and Confidentiality

The personal information that may be gathered by a health-related site is often intimate and highly sensitive. People must be able to trust that any personal information they provide will be kept confidential and secure. Thus

Organizations and individuals providing health information, products, or services on the Internet have an obligation to

- (1) prevent unauthorized access to personal information*
- (2) assure users' access to their personal information*
- (3) assure users' rights to review personal information and to amend it as appropriate or necessary*
- (4) provide mechanisms for tracing use of personal information (for example, audit trails)*

4. Best Commercial Practices

Guiding Principle: Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to

- (A) disclose any information a reasonable person would believe might influence his or her decision to purchase or use products or services*
- (B) be truthful and not deceptive*
- (C) engage in responsible business relationships and affiliations*
- (D) guarantee editorial independence*
- (E) disclose the site's privacy policy and terms of use*

Principle Part (A): Transparency

People who use the Internet for health-related purposes need to be assured that commercial health or medical sites are trustworthy. They have a right to expect that material presented as scientific or educational in nature is accurate, timely, and objective, and to be assured that they will be able to choose, consent, and control when and how they actively engage in a commercial relationship. Thus

Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to

- (1) prominently, clearly, and accurately identify the business and/or site sponsors*
- (2) clearly distinguish content intended to promote or sell a product, service, or organization from educational or scientific content*
- (3) clearly disclose any financial or other incentives for providers who develop or present content*

Principle Part (B): Truthfulness

People using the Internet for health-related purposes need to know that products or services are described truthfully and that information is accurate and reliable. Thus

Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to

- (1) Tell the truth; tell the whole truth; make sure it is the truth. Thus they must [gk]*

Principle Part (C): Business Relationships & Affiliations

People who use the Internet for health-related purposes must be confident that commercial sites select partners who adhere to the highest ethical standards. Thus

Organizations and individuals who sponsor, promote, or sell health information, products, or services on the Internet have an obligation to

- (1) make reasonable efforts to ensure that linked and partner sites comply with applicable law and uphold the same ethical standards as the site itself*
- (2) encourage users who believe that a site's commercial partners or affiliates may violate law or ethical principles to notify the site's webmaster*

Principle Part (D): Editorial Independence

People who use the Internet for health-related purposes must be able to clearly distinguish editorial content from content intended to promote or sell health products or services. Thus

Health-related sites supported by advertising or other commercial sponsorship have an obligation to

- (1) clearly separate advertising from editorial process and*
- (2) assure that the site's editors have full authority for determining editorial content*
- (3) assure that the site's editors have sole discretion to determine the type of advertising that will be accepted and full authority to reject advertising of any kind*
- (4) assure that current or potential sponsors do not influence the way search results for specific information on key words or topics are displayed.*

Principle Part (E): Privacy

See 3. Privacy, above.

5. Best Practices for Provision of Health Care on the Internet by Health Care Professionals

Guiding Principle: Health care professionals and organizations who provide health information, products, or services on the Internet have an obligation to

- (A) adhere to the highest standards of professional practice*
- (B) help patients to understand how the Internet affects the relationship between professional and patient while adapting the highest professional standards to the evolving interactions made possible by the Internet*

Principle Part (A): Professional Standards

Health care professionals have fundamental ethical obligations to patients. Thus

Physicians, nurses, pharmacists, therapists, and all other health care professionals who provide information, products, or services pertaining to an individual's health care on the Internet have an obligation to

- (1) serve patients' best interests*
- (2) protect patients' confidentiality (by adhering to the principle of privacy discussed above)*
- (3) conscientiously assess patients' needs and local resources in order to recommend or provide appropriate health information or services*
- (4) abide by the ethical codes governing their professions as practitioners in face-to-face relationships*
- (5) obey the laws and regulations of the relevant jurisdiction*

Principle Part (B): The Professional-Patient Relationship

The Internet can be a powerful tool for helping to meet patients' health care needs, but it also has limitations. Thus

Health care professionals who practice on the Internet have an obligation to

- (1) clearly and accurately describe the nature of the online relationship*
- (2) clearly and accurately describe the constraints of online diagnosis and treatment recommendations (for example, that the professional cannot prescribe certain medications online)*
- (3) describe the nature of information being provided (for example, whether based on expert consensus, personal professional judgment, or other sources of evidence)*
- (4) help "e-patients" understand that although not every aspect of health care requires a face-to-face interaction, online consultation should not take the place of an ongoing relationship with a health care provider in every situation [bc]*
- (5) clearly disclose any sponsorships, financial incentives, or other information that might affect the professional's role or the services offered*
- (6) clearly disclose how payment for services is to be made*

Acknowledgments

The Internet Healthcare Coalition (IHC) provided the framework for the e-Health ethics summit in Washington DC, Jan 31 - Feb 2, 2000, chaired by Helga Rippen and Ahmad Risk.

The following people were participants in the summit:

Jaak Aru; Wendy Borow-Johnson; Mark Boulding; Allan Bruckheim; Mary Cain; Lynn Cates; Richard Cleland; Stefan J. Darmoni; Mary Jo Deering; Markus Dey; Donna Doneski; Gunther Eysenbach; Ruth Faden; Giles Frydman; Bruce Grant; Bruce Grobe;

Jon Grohol; James Harris; John Hoben; Tom Houston; Sam Karp; Paul Keckly; Don Kemper; Murray Kopelow; Alex Langermann; Harry A. Levy; George Lundberg; John Mack; Blackford Middleton; Sandi Mitchell; Sybil Ingram Muhammad; Thomas Murray; Beth Nash; Tim Nater; David Nickelson; John Renner; Roberto Rodrigues; Mark Samuels; Michael H. Samuelson; Michael D. Scott; Denise Silber; Bill Silberg; Loretta Skucas; S. Stuart Spector; Mike Squires; Harry Sweeney; David B. Vance; C. Peter Waegemann

Group Facilitators were Kathy Alison, Laura Guyer Miller, Maria Nagorski and Maureen Ponte.

Submitted 18.02.00; ###Reviewer names will be inserted here### published 29.02.00.

Please cite as:

Rippen H, Risk A

e-Health Ethics Draft Code (Feb 18)

J Med Internet Res 2000;2(1):e2

URL: <http://www.jmir.org/2000/1/e2/>

doi: [10.2196/jmir.2.1.e2](https://doi.org/10.2196/jmir.2.1.e2)

PMID: [11720921](https://pubmed.ncbi.nlm.nih.gov/11720921/)

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Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
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