



Journal of Medical Internet Research

Journal Impact Factor (JIF) (2022): 7.4
Volume 3 (2001), Issue 2 ISSN 1438-8871 Editor in Chief: Gunther Eysenbach, MD, MPH

Contents

Editorials

What is e-health? (e20)
G Eysenbach. 3

What is e-Health (2): The death of telemedicine? (e22)
Vincenzo Della Mea. 5

Review

Ethical Challenges of Medicine and Health on the Internet: A Review (e23)
Kirsti Dyer. 7

Short Paper

Factors Associated with Intended Use of a Web Site Among Family Practice Patients (e17)
Peggy Smith-Barbaro, John Licciardone, Howard Clarke, Samuel Coleridge. 23

Original Papers

A Framework for an Institutional High Level Security Policy for the Processing of Medical Data and their
Transmission through the Internet (e14)
Christos Ilioudis, George Pangalos. 29

Comparing Web and Touch Screen Transaction Log Files (e18)
David Nicholas, Paul Huntington, Peter Williams. 53

Virtual Sonography Through the Internet: Volume Compression Issues (e21)
Olga Ferrer-Roca, Joseba Vilarchao-Cavia, Juan-Mario Troyano-Luque, Matilde Clavijo. 64

A Web-Based Distance Education Course in Nutrition in Public Health: Case study (e16)
Dirce Sigulem, Tania Morais, Lilian Cuppari, Sylvia Franceschini, Silvia Priore, Kátia Camargo, Reinaldo Gimenez, Viviane Bernardo, Daniel
Sigulem. 81

Viewpoints

Evidence-based Patient Choice and Consumer health informatics in the Internet age (e19)	
Gunther Eysenbach, Alejandro Jadad.....	36
The Patient-Physician Relationship in the Internet Age: Future Prospects and the Research Agenda (e15)	
Ben Gerber, Arnold Eiser.....	47

Editorial

What is e-health?

G Eysenbach

(J Med Internet Res 2001;3(2):e20) doi:[10.2196/jmir.3.2.e20](https://doi.org/10.2196/jmir.3.2.e20)Introduction

Everybody talks about e-health these days, but few people have come up with a clear definition of this comparatively new term. Barely in use before 1999, this term now seems to serve as a general "buzzword," used to characterize not only "Internet medicine", but also virtually everything related to computers and medicine. The term was apparently first used by industry leaders and marketing people rather than academics. They created and used this term in line with other "e-words" such as e-commerce, e-business, e-solutions, and so on, in an attempt to convey the promises, principles, excitement (and hype) around e-commerce (electronic commerce) to the health arena, and to give an account of the new possibilities the Internet is opening up to the area of health care. Intel, for example, referred to e-health as "a concerted effort undertaken by leaders in health care and hi-tech industries to fully harness the benefits available through convergence of the Internet and health care." Because the Internet created new opportunities and challenges to the traditional health care information technology industry, the use of a new term to address these issues seemed appropriate. These "new" challenges for the health care information technology industry were mainly (1) the capability of consumers to interact with their systems online (B2C = "business to consumer"); (2) improved possibilities for institution-to-institution transmissions of data (B2B = "business to business"); (3) new possibilities for peer-to-peer communication of consumers (C2C = "consumer to consumer").

So, how can we define e-health in the academic environment? One JMIR Editorial Board member feels that the term should remain in the realm of the business and marketing sector and should be avoided in scientific medical literature and discourse. However, the term has already entered the scientific literature (today, 76 Medline-indexed articles contain the term "e-health" in the title or abstract). What remains to be done is - in good scholarly tradition - to define as well as possible what we are talking about. However, as another member of the Editorial Board noted, "stamping a definition on something like e-health is somewhat like stamping a definition on 'the Internet': It is defined how it is used - the definition cannot be pinned down, as it is a dynamic environment, constantly moving."

It seems quite clear that e-health encompasses more than a mere technological development. I would define the term and concept as follows:

e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term

characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.

This definition hopefully is broad enough to apply to a dynamic environment such as the Internet and at the same time acknowledges that e-health encompasses more than just "Internet and Medicine".

As such, the "e" in e-health does not only stand for "electronic," but implies a number of other "e's," which together perhaps best characterize what e-health is all about (or what it *should* be). Last, but not least, all of these have been (or will be) issues addressed in articles published in the Journal of Medical Internet Research.

The 10 e's in "e-health"

1. **Efficiency** - one of the promises of e-health is to increase efficiency in health care, thereby decreasing costs. One possible way of decreasing costs would be by avoiding duplicative or unnecessary diagnostic or therapeutic interventions, through enhanced communication possibilities between health care establishments, and through patient involvement.
2. **Enhancing quality** of care - increasing efficiency involves not only reducing costs, but at the same time improving quality. E-health may enhance the quality of health care for example by allowing comparisons between different providers, involving consumers as additional power for quality assurance, and directing patient streams to the best quality providers.
3. **Evidence based** - e-health interventions should be evidence-based in a sense that their effectiveness and efficiency should not be assumed but proven by rigorous scientific evaluation. Much work still has to be done in this area.
4. **Empowerment** of consumers and patients - by making the knowledge bases of medicine and personal electronic records accessible to consumers over the Internet, e-health opens new avenues for patient-centered medicine, and enables evidence-based patient choice.
5. **Encouragement** of a new relationship between the patient and health professional, towards a true partnership, where decisions are made in a shared manner.
6. **Education** of physicians through online sources (continuing medical education) and consumers (health education, tailored preventive information for consumers)

7. **Enabling** information exchange and communication in a standardized way between health care establishments.
8. **Extending** the scope of health care beyond its conventional boundaries. This is meant in both a geographical sense as well as in a conceptual sense. e-health enables consumers to easily obtain health services online from global providers. These services can range from simple advice to more complex interventions or products such as pharmaceuticals.
9. **Ethics** - e-health involves new forms of patient-physician interaction and poses new challenges and threats to ethical issues such as online professional practice, informed consent, privacy and equity issues.
10. **Equity** - to make health care more equitable is one of the promises of e-health, but at the same time there is a considerable threat that e-health may deepen the gap between the "haves" and "have-nots". People, who do not have the money, skills, and access to computers and networks, cannot use computers effectively. As a result, these patient populations (which would actually benefit the most from health information) are those who are the least

likely to benefit from advances in information technology, unless political measures ensure equitable access for all. The digital divide currently runs between rural vs. urban populations, rich vs. poor, young vs. old, male vs. female people, and between neglected/rare vs. common diseases.

In addition to these 10 essential e's, e-health should also be

- easy-to-use,
- entertaining (no-one will use something that is boring!) and
- exciting

- and it should definitely exist!

We invite other views on the definition of e-health and hope that over time the journal will be filled with articles which together elucidate the realm of e-health.

Gunther Eysenbach

Editor,

Journal of Medical Internet Research

Acknowledgments

Based on the author's speech delivered at UNESCO (Paris), June 2001, Conference of the International Council for Global Health Progress: Global health equity - Medical progress & quality of life in the XXIst century.

The article was partly stimulated by the question "what is ehealth?" asked by A. Risk on various mailing lists and in Health Informatics Europe <http://hi-europe.co.uk/files/2001/9996.htm>.

Conflicts of Interest

None declared.

Submitted 22.12.00; this is a non-peer-reviewed article; accepted 18.06.01; published 18.06.01.

Please cite as:

Eysenbach G

What is e-health?

J Med Internet Res 2001;3(2):e20

URL: <http://www.jmir.org/2001/2/e20/>

doi: [10.2196/jmir.3.2.e20](https://doi.org/10.2196/jmir.3.2.e20)

PMID: [11720962](https://pubmed.ncbi.nlm.nih.gov/11720962/)

© G Eysenbach. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 18.6.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Editorial

What is e-Health (2): The death of telemedicine?

Vincenzo Della Mea

(J Med Internet Res 2001;3(2):e22) doi:[10.2196/jmir.3.2.e22](https://doi.org/10.2196/jmir.3.2.e22)

The first time I heard the term "e-health" I was at the 7th International Congress on Telemedicine and Telecare in London, at the end of November 1999. John Mitchell from Sidney, Australia, spoke about a national government study whose main result was the recognition that "cost-effectiveness of telemedicine and telehealth improves considerably when they are part of an integrated use of telecommunications and information technology in the health sector." [1]. This led to the identification of "e-health" as an umbrella term, with definitions such as "a new term needed to describe the combined use of electronic communication and information technology in the health sector... the use in the health sector of digital data - transmitted, stored and retrieved electronically - for clinical, educational and administrative purposes, both at the local site and at distance" [2].

In this talk, e-health was introduced as the death of telemedicine, because - in the context of a broad availability of medical information systems that can interconnect and communicate - telemedicine will no longer exist as a specific field. The same could also be said for any other traditional field in medical informatics, including information systems and electronic patient records. e-health presents itself as a common name for all such technological fields.

Mitchell also pointed out that "e-health can be considered to be the health industry's equivalent of e-commerce," and this could be one key for understanding the sense of e-health: just medical informatics and telematics on the shop shelves, a fashionable name for something already existing but otherwise difficult to sell.

Without arguing anything about the consequentiality of the facts, in December 1999 the subtitle of *Telemedicine Today*- a non-peer-reviewed journal - changed from "Where healthcare + telecommunications converge" to "The eHealth Newsmagazine," and just some months later, even the *Telemedicine Journal*- a scientific, peer-reviewed journal - added an "and eHealth" to its title. Nice name? Fear of being left out of a possibly-new field? The Ace Allen editorial that introduces the change in the subtitle of *Telemedicine Today* [3] sounds slightly bitter: during the time the telemedicine market exploded, *Telemedicine Today's* name suddenly changed, perhaps to satisfy the hundreds of healthcare-related dotcoms looking for a buzzword.

Shortly after the above changes, E. Rosen [4] rationally explained some differences related to the use of the words "telemedicine" and "e-health." Investors look for investments that can produce high returns even after several years. From this point of view, the specific term of telemedicine seems inadequate, as it identifies a market niche, while e-health, as any "e-thing", seems more open and promising (just like anything without a clear meaning). Rosen also points out the hardware-centric aspects of telemedicine, which is based on the traditional equipment sales model, while e-health is apparently oriented to service delivery, which is more interesting on the business side. The final remark of Rosen is that almost all "e-things" will again become simply things as soon as we become acquainted with the novelty of the Internet; after all, we all know that e-commerce is just commerce...

Allen, in a further editorial [5], discovered a new difference: telemedicine remains linked to medical professionals, while e-health is driven by non-professionals, namely patients (or, in the e-health jargon, consumers) that with their interests drive new services even in the healthcare field-mostly for their empowerment through access to information and knowledge .

Interestingly enough, even after the name change, *Telemedicine Journal and eHealth* did not publish any paper directly mentioning e-health; also, the other major scientific journal related to telemedicine, the *Journal of Telemedicine and Telecare*, seems not to care much about e-health. This could be related to the business role the term e-health seems to have: when researchers describe their work, the classical categories of, for example, Medical Informatics, Telemedicine, and Electronic Patient Records are more meaningful than the generic term e-health.

As a researcher, I can see some sense in the term e-health; coming from the integration perspective it suggests: integrated-healthcare-systems' properties, possibilities, and consequences that are (in a holistic approach) more than the sum of the single-component outcomes. However, even these aspects are already studied in some computer science fields - for example Artificial Intelligence (at least inside the multi-agent paradigm), Information Economics, and Dynamic Systems; thus, there is nothing new again, except for the specific interest in healthcare.

Vincenzo Della Mea

*Institute of Pathology, University of Udine, Italy***Conflicts of Interest**

None declared.

References

1. Mitchell J. Increasing the cost-effectiveness of telemedicine by embracing e-health. *J Telemed Telecare* 2000;6 Suppl 1(6 Suppl 1):S16-S19. [Medline: [20254430](#)] [doi: [10.1258/1357633001934500](#)]
2. Mitchell J. From telehealth to e-health: the unstoppable rise of e-health. Canberra, Australia: National Office for the Information Technology; 1999. URL: http://www.noie.gov.au/projects/ecommerce/ehealth/rise_of_ehealth/unstoppable_rise.htm
3. Allen A. Editor's note: when the ship.com comes in. *Telemed Today* 1999;7(6):7.
4. Rosen E. The death of telemedicine? *Telemed Today* 2000;8(1):14-17.
5. Allen A. Morphing Telemedicine - Telecare - Telehealth - eHealth. *Telemed Today*, Special issue: 2000 Buyer's Guide and Directory 2000(1):43.

Submitted 20.06.01; this is a non-peer-reviewed article; accepted 22.06.01; published 22.06.01.

Please cite as:

Della Mea V

What is e-Health (2): The death of telemedicine?

J Med Internet Res 2001;3(2):e22

URL: <http://www.jmir.org/2001/2/e22/>

doi: [10.2196/jmir.3.2.e22](https://doi.org/10.2196/jmir.3.2.e22)

PMID: [11720964](https://pubmed.ncbi.nlm.nih.gov/11720964/)

© Vincenzo Della Mea. Originally published in the *Journal of Medical Internet Research* (<http://www.jmir.org>), 22.6.2001. Except where otherwise noted, articles published in the *Journal of Medical Internet Research* are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Review

Ethical Challenges of Medicine and Health on the Internet: A Review

Kirsti A Dyer, MD, MS, FAAETS

Corresponding Author:

Kirsti A Dyer, MD, MS, FAAETSPhysician

Graduate Student, Oregon Health Sciences University, Distance Learning Program in Medical Informatics

Kaiser Permanente

Lafayette CA 94549

USA

Email: griefdoc@kirstimd.com

URI: <http://www.journeyofhearts.org>

Abstract

Knowledge and capabilities, particularly of a new technology or in a new area of study, frequently develop faster than the guidelines and principles needed for practitioners to practice ethically in the new arena; this is particularly true in medicine. The blending of medicine and healthcare with e-commerce and the Internet raises many questions involving what sort of ethical conduct should be expected by practitioners and developers of the medical Internet. Some of the early pioneers in medical and healthcare Web sites pushed the ethical boundaries with questionable, even unethical, practices. Many involved with the medical Internet are now working to reestablish patient and consumer trust by establishing guidelines to determine how the fundamentals of the medical code of ethical conduct can best be adapted for the medical/healthcare Internet. Ultimately, all those involved in the creation, maintenance, and marketing of medical and healthcare Web sites should be required to adhere to a strict code of ethical conduct, one that has been fairly determined by an impartial international organization with reasonable power to regulate the code. This code could also serve as a desirable, recognizable label-of-distinction for ethical Web sites within the medical and healthcare Internet community. One challenge for those involved with the medical and healthcare Internet will be to determine what constitutes "Medical Internet Ethics" or "Healthcare Internet Ethics," since the definition of medical ethics can vary from country to country. Therefore, the emerging field of Medical/ Healthcare Internet Ethics will require careful thought and insights from an international collection of ethicists in many contributing areas. This paper is a review of the current status of the evolving field of Medical/Healthcare Internet Ethics, including proposed definitions and identification of many diverse areas that may ultimately contribute to this multidisciplinary field. The current role that medicine and health play in the growing area of Internet communication and commerce and many of the ethical challenges raised by the Internet for the medical community are explored and some possible ways to address these ethical challenges are postulated.

(*J Med Internet Res* 2001;3(2):e23) doi:[10.2196/jmir.3.2.e23](https://doi.org/10.2196/jmir.3.2.e23)

KEYWORDS

Internet; Ethics, Medical; Ethics, Professional; Ethics, Informatics; Physician-Patient Relation; Code of Ethics; Research Ethics; Medical Informatics Ethics

Introduction

The practice of medicine is rooted in a covenant of trust among patients, physicians, and society.

The ethic of medicine must seek to balance the physician's responsibility to each patient and the professional, collective obligation to all who need medical care.

The Council of Medical Specialty Societies, 2000 [1]

Ethics can be viewed as a prerequisite for the success of medical practice, much the same way that safety is a prerequisite for the success of airline travel. In both cases, if the prerequisites are

not in place to ensure trust in the product or services provided, consumers will not utilize the product or service. In the case of the medical field, the public trusts the medical profession to regulate its own practices [2]. Knowledge and capabilities of new technology or an area of study often develop faster than the guidelines and principles needed for practitioners to practice ethically in the new arena. One area of rapid technological and economic expansion is that of the Internet, in particular how quickly the Internet is impacting and changing the practice of medicine in the 21st century. We hope, for the success of medical practice, even with the rapid changes in technology and the medical field, that practitioners involved with the Medical Internet will continue to behave ethically. This paper will review

the ethical challenges raised by the Internet for the medical community, explore the role that medicine and health play in the growing area of Internet communication and commerce, and postulate some possible solutions for addressing these new challenges.

Methods

Available, published and related articles were located with an Ovid MEDLINE search for "Internet" and "Ethics, Medical," "Internet" and "Ethics, Professional." The Internet was searched for "medical and ethics," "Internet and ethics," "science and ethics," and "research and ethics" using the Google search engine (www.google.com). Additional articles and information were located by hand searching pertinent online medical journals, related organization Web sites, and relevant medical LISTSERVs: MWM-L (Medical Web Masters List), ISMHO (International Society of Mental Health Online), and AIR-L (Association of Online Researchers, AoIR).

Results

Background: The Integration of the Internet into Daily Life

For many of us the Internet has been integrated into our daily lives, with e-mail use becoming as commonplace as talking on the telephone. This modern method of communication has been the fastest-growing medium in the world, reaching 50 million users in only 4 years, compared to radio, which existed for 38 years before reaching 50 million listeners, and television, which took 13 years to reach the same level of use [3]. Although it is difficult to determine the exact number of people online, a reasonable estimate from Nua Internet Surveys in November 2000 was 407.1 million people worldwide, with 167.1 million in the US and Canada and 113.14 million in Europe [4].

Background: The Integration of the Internet into Medicine

The Internet has the potential to substantially alter the way medicine is practiced, from simple e-mail communication to routine billing, distant consultations, and routine patient care. There are more than 20,000 Web sites online devoted to medicine and healthcare [5] originating from diverse sources-medical, health, personal, and commercial. Online health consumers (also known as patients) can access: Web sites related to health, on-line support groups, chatrooms and Web sites devoted to a specific disease, pharmaceutical sites, alternative-health sites, information on medical products, and online practitioners or consultants. By recent estimates, 52 million American adults, or 55% of those with Internet access, have used the Web to obtain health or medical information [6]. The number of adults using the Internet for health information, shopping for health products, and communicating with payers and their providers is anticipated to reach 88.5 million by 2005 and is projected to grow at approximately twice the rate of the overall online population [7].

The number of people surfing the Internet in search of health and medical information has not gone unnoticed by the business

sector. The merger of medicine and healthcare with e-commerce has resulted in a number of online business models: selling services or healthcare products, creating high-profile health or medical portals, and providing online services to physicians and healthcare providers. Even with the recent decline in "dotcoms," there is still great projected monetary potential for those involved with medical and healthcare sites. Business-to-consumer (B2C) healthcare commerce is expected to become a \$70 billion industry by 2003, while business-to-business (B2B) healthcare commerce is expected to grow into a \$170 billion industry [8]. Although a recent survey conducted by Medem showed that half of all physician practices surveyed indicated that they already had or planned to build a Web site for their practice [9], there is a realistic concern that if medical and health practitioners, insurance companies, and hospitals do not provide the services demanded by their patients, then the online healthcare consumers may turn to seek online services from unlicensed, unqualified, or unprofessional providers - or disreputable sources [10].

An important challenge for the new class of ethicists - those studying the Medical Internet - will be determining the boundaries of "Medical/Healthcare Internet Ethics." Some of the boundaries needing to be defined include establishing the type of ethical conduct that could be expected from practitioners in this new medium, determining which of the existing codes of conduct could be adapted for use, and deciding which areas unique to the Internet will require the development of new ethical guidelines.

Medical Ethics

Some physicians regard the decision to enter medicine as "a calling," similar to that seen in the clergy or in public service. This commitment to help and serve others has traditionally taken precedence over economic interests [11]. Medicine's code of ethics is considered to be far more stringent than the law. Most physicians are governed by their own internal code of ethics and more-formalized codes have been developed by professional organizations to advocate that their members behave ethically. The American Medical Association (AMA), one of the major medical organizations in the United States, established the Code of Medical Ethics for members, which has served as an ethical guideline since the mid 1840's. This code reinforces that "the primary goal of the medical profession to render service to humanity" while emphasizing that "reward or financial gain is a subordinate consideration and under no circumstance may physicians place their own financial interests above the welfare of their patients." [12] Additionally, in the AMA's 1995 Patient-Physician Covenant, physicians are reminded that "Physicians, as physicians, are not, and must never be, commercial entrepreneurs, gateclosers, or agents of fiscal policy that runs counter to our trust." [13] The Council of Medical Specialty Societies published their consensus statement in 1997 on the ethic of medicine, reminding physicians that "the practice of medicine is rooted in a covenant of trust among patients, physicians, and society. The ethic of medicine must seek to balance the physician's responsibility to each patient and the professional, collective obligation to all who need medical care." [1] However, codes of ethical conduct rely on self-regulation for enforcement.

Most medical and healthcare professional organizations have a code of ethical conduct established for their members, but many have not yet addressed the ethical issues of medicine, health, and the Internet. These organizations will need to adopt or establish ethical standards to guide their members in ethical conduct, in the areas of research, development, commerce, and practice on the Internet.

With the exponential expansion of the Internet, online entrepreneurs, business and medical, are trying to cash in on the projected potential of Internet commerce with healthcare services and products. Financial interests are sometimes placed above the welfare of visitors to the Web site. Depending on how one regards online site visitors - as visitors, clients, healthcare consumers, or patients - these actions can be seen to be in direct conflict with the AMA's Principles of Medical Ethics and other professional codes of conduct. Some may regard the paid-physician consultants to medical e-commerce sites as having a clear conflict of interest; others may not see it as an ethical issue. If one redefines the physician-patient relationship to be merely a provider-consumer one, then without "patients" there is no conflict of interest. However, if medical leaders do not introduce rigorous and credible conflict-of-interest rules, they risk eroding the public's trust in the profession to self-regulate [2]. Some of the early medical and healthcare Web site leaders pushed the boundaries of traditional medical ethics, so that many regarded their business practices as unethical. Ethical boundaries were stretched, even broken, in disregard for their Web site visitors, often in the name of profit. The medical profession, in the tradition of regulating its own, is striving to reestablish the public trust, by determining how traditional medical ethics can best be translated as codes of conduct for the medical and healthcare Internet.

Medicine and Healthcare on the Internet

Medical websites, more than any other type of site on the Internet, should ensure visitors' personal privacy and prevent personal medical information, including patterns of use and interests, from being sold, purchased, or inadvertently entering the hands of marketers, employers, and insurers.

Principles Governing AMA Web Sites [14]

In stark contrast to typical e-commerce sites, intended for sales of products or services to visitors, medical and healthcare Web sites differ because the sites are frequently dedicated primarily to educating their Web site visitors. Also, with the medical or healthcare Internet the focus is on medical and healthcare interactions, transactions, and research that occur over the Internet. Another difference is the type of content obtained at a medical or healthcare site. This information is often of a very private nature and may result in life-altering and, in some situations, life-and-death decisions.

Business and computer professionals have typically not been held to the same ethical code of behavior as medical and healthcare professionals. With the merger of medicine and e-commerce, business, computer, medical and healthcare professionals are working side by side in developing online Web sites. Non-medical professionals involved in providing online medical services may be unaware of the unique standards

they must adhere to when dealing with online healthcare consumers and may need to be educated about the obligation not to exploit patients or clients and to respect issues of privacy and confidentiality. Those who develop, maintain, and sell healthcare computing systems and components, including Web sites, have an ethical obligation to make patient care a primary concern [15].

Studies have shown that most adult Internet users are unaware their movements are being tracked and are also not aware of the personal information gathered about them when visiting a Web site [16]. Many Internet users believe they can visit a site anonymously and obtain information about controversial subjects such as AIDS, herpes, or suicide without anyone else ever knowing. Many may also believe that once their e-mail is deleted it is gone forever. In reality, e-mail is forever; messages are backed up and recoverable. Therefore, medical and healthcare Web sites should be following strict security measures to ensure that their site-users' personal medical information remains private and does not involuntarily enter the hands of marketers, employers, and insurers [14].

Communication technology is evolving. New technology - such as mobile phones, hand-held computers, personal device assistants (PDAs), and even wearable computer devices - is being developed. The ethical guidelines being developed for the Internet will need to have the flexibility to adapt and include future forms of telecommunication as they appear.

Merging Fields of Study: Medicine, Ethics, Science, Computers, E-commerce...

Medical Internet Ethics includes several existing areas of study. How it is defined depends on who is viewing or experiencing the field. Describing Medical Internet Ethics is much like the parable of "The Blind Men and The Elephant" only with more people involved. In the parable, 6 blind men are asked to describe an elephant. Their descriptions of the elephant differ depending on which part of the animal was touched: side, tusk, knee, ear, trunk, or tail. Each man becomes convinced his experience and subsequent description is the only correct one. The updated fable occurs in countries around the world. People from different professions - physician, Web site designer, information technologist, marketing personnel, computer programmer, researcher, patient, consumer, ethicist, healthcare practitioner, hospital administrator, lawyer, and policy maker - are all asked to describe their ideal medical or health Web site. They are also asked to include what they would consider to be acceptable professional or business practices for the people involved with developing and creating the Web site. Their descriptions of the Web site and an acceptable code of conduct would be highly variable and strongly influenced by their professional viewpoint and motivating factors eg, financial, patient care, research, rules, and regulations.

Insights from professionals in the following diverse groups from countries around the world, should be included when defining this new interdisciplinary domain:

1. Healthcare delivery: physicians, nurses, pharmacists, healthcare professionals, and other healthcare personnel

2. Applied computing: systems developers, database managers, medical software developers, and Web administrators
3. Science and research
4. Government agencies: public-health and regulatory agencies
5. Healthcare services and e-commerce: providers of healthcare transactions conducted over the Internet
6. End users: healthcare consumers and patients
7. Healthcare organizations: insurance companies, management organizations, and societies
8. Administration and healthcare management
9. Medical ethics
10. Law

Those involved professionally with the medical or healthcare Internet have very different, and at times conflicting, motivation. Different professions and different professionals may have very different views on ethical practices. Furthermore, these views can be highly variable from country to country. It will be a challenge for Medical Internet Ethicists to reach a consensus on what constitutes "ethics" and which areas should be included in defining the field of Medical Internet Ethics. The remainder of this paper will explore some of these issues.

Defining Medicine, Health, and Ethics on the Internet

In determining the ethics of the medical and health Internet, it is important to establish a common vocabulary. For the context of this paper, the use of the term "medical" is intended to cover the range of healthcare professions. The term "medical" or "medicine" is often used interchangeably with "health" or "healthcare." [17]

Medical Internet Ethics is the field existing at the intersection of medicine, ethics, and computers, but is conducted, occurs, or practiced in the new arena of the Internet. Therefore, a definition can be stated as:

Medical Internet Ethics is an emerging interdisciplinary field that considers the implications of medical knowledge utilized via the Internet, and attempts to determine the ethical guidelines under which ethical participants will practice online medicine or therapy, conduct online research, engage in medical e-commerce, and contribute to medical websites.

Healthcare Ethics is the term used in the description of Medical Ethics, in Encyclopedia of Ethics, to distinguish ethical principles that apply to healthcare providers - including nurses - other than physicians [18]. Thus, **Healthcare Internet Ethics** would involve the ethical principles that apply to nurses and other healthcare providers, however, in the context of this discussion, we are using "healthcare" interchangeably with "medicine" or "medical" when referring to Internet ethics.

e-health and e-healthcare are other terms being touted for use by the "dotcom" and e-commerce circles. Electronic health or e-health refers to all forms of electronic healthcare delivered over the Internet; these range from informational, educational, and commercial "products" to direct services offered by professionals, non-professionals, businesses, or consumers [19].

For better or for worse, the "e-health" terminology coined by the dotcom and e-commerce companies is being promoted to become the preferred term for healthcare services available through the Internet [19]. This formulated vocabulary tries to create an aura of specialized, technical, insider knowledge, one that requires high-priced consultants to help others decipher and apply, rather than using recognizable, understandable terms. If the e-commerce terminology becomes the standard for medical and health sites, there is a real concern that the primary interest is economic and commercial gain not patient care.

Ethics and Self-regulation versus the Law and Enforced-regulation

The basis for the public's trust in a profession to self-regulate is the profession's fundamental responsibility to be concerned first and foremost with the public good.

Jerome P. Kassirer, MD [2]

When considering ethics one must also distinguish between what is considered "ethical" and what is considered "the law," since in many instances there is a fine line separating the two. Legal principles are often derived from ethical ones.

Ethics attempt to determine what is good or meritorious and which behaviors are desirable or correct in accordance with higher principles. It offers conceptual tools for evaluating and guiding moral decision making [15].

Ethics has been defined by Webster's as "the discipline dealing with what is good and bad, and with moral duty and obligation." [20] By comparison, laws instruct people directly on how to behave (or not to behave) under various specific circumstances. Furthermore, there are prescribed remedies or punishments for individuals who do not comply with the law.

Law is defined by Webster's as "a binding custom or practice of a community: a rule of conduct or action prescribed or formally recognized as binding or enforced by a controlling authority." [20]

Legal principles emphasize the practical regulation of morality, or behaviors and activities, whereas ethical principles deal with moral decisions. Many legal principles deal with the inadequacies and imperfections in human nature, compared with ethics, which looks to establish the ideal behaviors of individuals or groups. Legal practices also tend to be more affected by historical precedent, matters of definition, issues related to detectability and enforceability, and evolution of new circumstances than are ethical ones [15].

Dr. George Lundberg, editor-in-chief of Medscape, is one of the medical leaders working to define online medical ethics. He believes "the essence of professionalism is self-governance," and that the leaders of the e-health information enterprise should be the ones setting common standards for ethical behavior, not governments [21]. Self-regulation relies upon professionals upholding their personal and professional code of ethics; there are limited means of enforcing the ethical guidelines. During the early dotcom bonanza days of the Internet, there were few real standards of accountability and ethical behavior for medicine and healthcare on the Internet. Web sites and the

organizations supporting them were left to regulate their own ethical behavior. In many instances esteemed medical leaders, professional organizations, and medical institutions proved to be less than exemplary ethical role models.

In a recent article, Dr. Jerome Kassirer, with Tufts University School of Medicine, examined the problem of "pseudoaccountability" where weak regulations give the appearance of setting and enforcing high standards [2]. His insights are equally applicable to the problems facing medicine and the Internet. There is concern that many of the existing codes of ethics are in actuality promoting pseudoaccountability; they are lengthy codes of conduct crafted with technical or obfuscating language to give the impression of setting high standards, but are in reality non-enforceable. Dr. Kassirer and others do not believe that self-regulation guidelines for medical Web sites are enforceable [2]. Dr. Glenn McGee, a professor in bioethics at the University of Pennsylvania School of Medicine, described some of the early efforts as being self-inclusive and lacking objectivity, reminding us that "real peer review means thinking about and making rules with regard to conflict of interest." He believes these early efforts fell short of providing well-regulated, enforceable ethical codes [22]. There is a realistic concern that without mechanisms of enforcing ethical codes and rigorous, credible conflict-of-interest rules, the medical profession risks further eroding society's trust in their abilities [2]. One way of encouraging ethical conduct would be with a unifying ethical pledge-for all those professions involved with the Medical or Healthcare Internet, from designers, programmers, and developers to consultants, financiers, and managers-to promote internal ethical conduct.

An Oath for Medical/Healthcare Internet Professionals?

Under the ancient tenets of the Hippocratic oath, physicians pledge to uphold the injunction *primum non nocere* (first do no harm). For physicians, nurses, and psychologists, ethical issues are often among the greatest challenges in practice. Long after their training, students in training tend to remember-and may even be influenced more by-experiences rather than factual knowledge. It is important that all professions involved in the development of the medical Internet understand, respect, and uphold the uniqueness of the physician-patient, practitioner-patient, or therapist-patient relationship. Goodman and Miller maintain that the Hippocratic injunction should apply to all those involved in Web site development as well as to the practitioners [17]. Placing patients/consumers first can be in direct conflict with the business model of generating profits for shareholders, but not placing patient's needs before profits can have serious consequences.

Recently there has been an interest in developing a Hippocratic-Oath-equivalent for scientists, computer scientists, engineers, and executives. Supporters of an Oath for scientists promote its great symbolic value to reaffirm the importance of scientist to behave ethically. A survey by the American Association for the Advancement of Science (AAAS) identified an estimated 15 to 16 oaths for scientists or engineers proposed or currently in use [23,24]. Many support the pledge initiated by the Student Pugwash Group in the United States [25].

Another oath promoted by the Institute for Social Inventions is a modified version of the Hippocratic Oath. Thus far, over a hundred eminent signatories, including 40 Nobel Prize winners and University Vice Chancellors are supporting this Hippocratic Oath equivalent for scientists, engineers, and executives [26].

As with the medical profession, the main value of an oath would be symbolic, but supporters believe it would also stimulate young scientists and professionals to reflect on the wider consequences of their field of study before embarking on a career in academia or industry [25]. Proponents believe the oath would encourage a deeper reflection by scientists and engineers on the conduct and impact of their work and create a greater sense of accountability [24]. The long-term goal is for ethics to be included in the scientific curriculum and that an ethical oath would become part of the graduation ceremony for scientists, engineers, and executives.

Why be concerned about online ethical principles? The Not-so-Legitimate Internet Practitioners

Complicating the situation, in addition to all of the legitimate online practitioners abiding by the current ethical principles, there are also the unethical, voyeuristic people functioning outside of the traditional boundaries of medical and healthcare Internet ethics. These individuals often push the limits of Internet laws and existing Web site code of ethics, even blatantly ignoring one of the fundamentals of medical ethics whereby patients trust their physician or provider to maintain confidentiality of their personal medical information. For these unscrupulous individuals looking to make easy money on the Internet before they get caught, self-regulation may not be enough to protect healthcare consumers. The risk of losing out to the competition causes many to compromise their ethics, bending, even breaking the rules, believing that if they do not their competitors will win their market share.

Unfortunately, additional ethical guidelines would have little impact on the not-so-legitimate computer and Internet practitioners; this is where upholding internal moral-belief systems and codes of conduct may have to give way to enforceable laws. The groups outlined below - the crackers; virus and worm writers; e-paparazzi; e-stalkerazzi; online information brokers, industrial spies and unlicensed, unqualified online information providers, or online charlatans - are not bound by internal or medical Internet ethics to adhere to patient confidentiality or ensure that their Web site visitors come to no harm.

Some of The Not-So Legitimate Practitioners:

Cracker: malicious meddler who tries to discover sensitive information by poking around. One who breaks security on a system. Coined ca. 1985 by hackers in defense against journalistic misuse of the term "hacker," which more properly refers to the highly skilled computer programmers who enthusiastically enjoy programming and sharing their expertise [27,28].

Virus writer: Writer of a cracker program that searches out other programs and 'infects' them by embedding a copy of itself in them, so that they become Trojan horses (a malicious, security-breaking program that is disguised as something

benign). When these programs are executed, the embedded virus is executed too, thus invisibly propagating the 'infection.' Unlike a worm, a virus cannot infect other computers without assistance [29].

Worm writer: writer of program that propagates itself over a network, reproducing itself as it goes. A worm can infect other computers without assistance. The term has taken on negative connotations, since it is assumed, nowadays, that only crackers write worms [30].

e-paparazzi, e-stalkerazzi: The Invasion of Privacy: Paparazzi bill [31] would have made it illegal to harass a person of media interest for commercial purposes including photographing, videotaping, or recording. "Cyberstalking" [32] refers to the stalker engaging in a pattern of conduct intended to follow, alarm, or harass, or making a credible threat or violating a restraining order. "Credible threat" includes threats made by means of an electronic communication device. In this context, e-paparazzi and e-stalkerazzi refers to journalists or crackers electronically gaining access to confidential information or harassing people via the Internet.

Online information brokers: This type of information broker is one who sells or exchanges specific information gathered on users to a Web site-often done without the users explicit knowledge. Permission is 'granted' somewhere within the fine print of the privacy policy for a Web site. These lists of specific user's demographics and preferences can be invaluable to a marketing person for targeted advertising, eg, online or mail.

Industrial Spies: So far, this has been primarily a part of high tech industrial espionage, in which the industrial "secret agents" obtain access to other companies' computer databases looking for company secrets to utilize or share.

Unlicensed, Unqualified Online Information Providers, or Online Charlatans : These non-professionals and Web entrepreneurs have flooded the Internet, offering "mentoring" or "counseling" services, "miracle cures" or other life-enhancing products. Many are working outside the ethical and legal boundaries on the Internet hawking their "life lesson" expertise, selling services or products that may constitute health fraud.

These unlicensed, unqualified online information providers are not professionals so there are no overseeing professional regulatory organizations to which they can be reported for professional misconduct. One potential solution in the United States is to report Internet fraud, to the Internet Fraud Complaint Center (IFCC), a government agency that addresses issues of fraud committed over the Internet including both criminal and civil violations [33]. The online charlatans can also be reported directly online to the Federal Trade Commission, [34] which along with the Food and Drug Administration is waging war against Internet health fraud under "Operation Cure.All." [35]

Cybercrimes and the Medical Internet

The Internet has provided a new arena for the criminal element as well. In the US the Criminal Division's Computer Crime and Intellectual Property Section (CCIPS) was established as a separate section of the Department of Justice. Their staffs focus exclusively on the issues raised by computer and intellectual

property crime, encryption, electronic privacy laws, search and seizure of computers, e-commerce, cracker investigations, and intellectual property crimes [36].

With the growth of the Internet and the increase in cybercrime, it is easy to see why protection of privacy is an issue of great concern particularly among Internet users seeking health information [37]. In August 2000, it was made public that the Kaiser Permanente Health Care System had the confidentiality of 858 members breached; this security issue was actually an internal problem due to human error, not from external hackers [38]. In January 2001, the University of Washington Medical Center affirmed that a hacker had infiltrated its computer system in December 2000. The 25-year-old hacker gained access to administrative databases containing confidential records of at least 5,000 patients. Representatives from the University of Washington have since admitted that their databases were not secure [39]. The potential for further breaches is enormous. In a March 12, 2001 survey released by the Computer Security Institute and the FBI's (Federal Bureau of Investigation's) San Francisco Computer Crime Squad, they reported that 85% percent of respondents (primarily large corporations and government agencies) had detected computer security breaches within the last 12 months and 40% had detected system penetration from the outside [40]. It may only be a matter of time before the medical and healthcare professions are more affected.

One can imagine potential disastrous scenarios, both personal and professional, that could occur if medical information or a person's personal seemingly "anonymous" online health surfing habits, e-mail messages, or confidential medical records were made public. Insurance companies could hire online medical information brokers to obtain medical information on policyholders and use this information to deny coverage or claims. Potential employers could use information brokers to obtain health information and health-Web-site (eg, cancer, AIDS, herpes, suicide, alcohol, and depression Web sites) surfing habits on current or potential employees and use this information to fire or not employ a person. Online marketers are already using private information to design targeted e-mail advertising that fills our e-mail boxes. The potential risks for celebrities and others in the public eye may be even higher. With the premium attached to getting "unauthorized" photographs of public figures to satisfy an ever-more voyeuristic society, it is easy to imagine scenarios in which the e-paparazzi and e-stalkerazzi could be looking for, or even be paid to search for, confidential medical information on celebrities, politicians, athletes, and other prominent public figures that could be published in print and/or online media.

Other Examples of Questionable Online Conduct

Cyberplagiarism

Other issues of unethical online conduct were brought to the attention of the medical and research professions by the Journal of Medical Internet Research - that of online plagiarism or cyberplagiarism. It is easy to copy and paste bits and pieces from different articles or graphics on different Web sites to "write" a paper. Cyberplagiarism occurs when a scientist or researcher "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." Eysenbach cautions that the only sure, reliable way of avoiding plagiarism charges is to "cite the source properly, even if it is 'only' an electronic document." Because JMIR editors were impacted personally by incidents of cyberplagiarism, the Journal of Medical Internet Research became the first scholarly journal worldwide to institute an anti-cyberplagiarism policy whereby every submitted manuscript is now electronically scanned for plagiarism [41].

Copyright infringement

Contrary to popular belief, just because something is available on the Internet, it does not mean anyone can use it. This applies to all of the various media forms- including text, images, and music. One has to carefully look at copyright issues, especially at what constitutes a copyrighted work, what constitutes copyright violation, and what constitutes "fair use."

The principle of "fair use" is often cited when materials found on the Internet are incorporated into lectures, scientific reviews, or education-based Web sites. Fair use of a copyrighted work can be cited when using works for the purposes of criticism, comment, news reporting, teaching, scholarship, and research. If a work falls into the category of fair use, it is exempted from normal copyright laws, and using the material is not considered an infringement of copyright. Copyright owners are required by law to consent to fair use of their works by others. Most lectures that incorporate slides or video clips into their presentations would probably fall under the category of "fair use" if the sources were being used for the purposes of "teaching, criticism, or scholarship"; however credit should be given to the source. The copyright laws are not clear as to whether using a cartoon for humor or using a music or video clip as an entertainment break in the lecture qualifies as fair use [42,43].

The Internet allows users to access information from the Web across national boundaries; this creates problems when the existing laws only apply to a particular country. There is no "international copyright" that automatically protects works on the World Wide Web. Most countries do offer protection to foreign works under certain conditions specified by international copyright treaties and conventions. An international consensus will need to be reached about how these conditions apply to the Internet so that online works will be protected against unauthorized use [42].

One novel way of dealing with copyright infringement and cyberplagiarism, particularly in the scientific and research realm, is to make articles and resources freely available on the Internet and avoid copyright concerns altogether. This approach will be adopted by Massachusetts Institute of Technology with the creation of their OpenCourseWare Web site which will be available in 2002 [44] and is already in use at the University of Pittsburgh's Department of Public Health with their Supercourse [45].

Major Areas of Medical Internet Ethics

In this emerging field of Medical/Healthcare Internet Ethics, there are at least 6 identified areas that will require codes of ethical conduct to be established. The following lists major

areas and the subsequent discussion will undoubtedly stimulate thought for additional areas to include [46].

- Doctor-patient, provider-patient, therapist-client relationships
- Online medicine, online therapy
- Online research
- Quality of information on medical and healthcare Web sites
- Ethical conduct of medical and healthcare Web sites
- Privacy and security

Defining the Essence of the Doctor-Patient, Provider-Patient, Therapist-Client Relationships

Growing numbers of patients are going online and becoming savvy healthcare consumers desiring more online contact with their physicians. Concern about the liabilities of practicing online has been a driving force to try and clearly define the online physician-patient relationship.

Online physicians and therapists are innovators, exploring the types of interactions and services that can be provided over the Internet. Thus far, a consensus has yet to be reached regarding what ethical responsibility exists, if any, between the physician or therapist and Web site visitor. One of the early pioneers in health Web sites, Dr. C. Everett Koop, felt no professional ethical obligation towards visitors to his Web site, because they were not "his patients." [47] Key questions still need to be answered to define the online relationship: Does a patient have to be seen, examined or spoken to, to have a relationship with their physician? Does a physician consultant to a Web site have an ethical obligation to visitors? Is it dependent on the type of services or contact offered to users at a Web site or the consultant's position with the Web site? What are the boundaries for an online therapist? Can traditional therapy be translated to the Internet, or is it primarily a new form-e-therapy? At what point is there a patient-provider relationship? Case law has not determined at what point, if any, the physician-patient or therapist-client relationship begins, when the only contact is between them is online.

The eRisk Working Group in Healthcare (comprised of the leading medical malpractice insurers, Medem, and medical societies) is working on determining the issues and liabilities associated with online physician-patient interactions. The AMA Council on Judicial and Ethical Affairs (CEJA) is also working to determine what constitutes the essential elements of physician-patient relationships and how this may be translated to the Internet [22]. These issues are still ill defined since there have been few legal cases challenging online physician-patient communication and cybermedicine [9]. Once these basic components of the relationship are defined, then determining guidelines for online medicine and therapy can proceed.

Establishing Guidelines and Regulations for Practicing Online Medicine and Online Therapy

In addition to defining what constitutes an online relationship, the types of services and products that can and should be provided over the Internet will need to be clearly determined along with standards of professional online conduct.

The mental health community has been leading the efforts to define and determine the therapeutic benefits of online relationships. Seeman and Seeman have examined e-psychiatry, how the patient-psychiatrist relationship is practiced in the electronic age [48]. In January 2000 the International Society for Mental Health On-line (ISMHO), and the Psychiatric Society for Informatics (PSI) endorsed "Principles for the Online Provision of Mental Health Services" defining the online client-therapist relationship and what constitutes providing online mental health services [49]. The National Board of Certified Counselors (NBCC) has established standards for their counselors that define what constitutes an ethical practice of Web counseling [50]. Organizations in the medical community are exploring the nature of the physician-patient relationship [9,22,51].

Professionals-physicians, psychologists, psychiatrists, and social workers-are licensed by their respective professional agencies and therefore required to follow a certain professional code of conduct established by their professional boards. But what sort of training or license should be required, if any, to practice online? The logistics of who is traveling through cyberspace to meet whom is the first issue that needs to be determined. With telemedicine, many states already require licensure in their state before an out-of-state physician can electronically provide services to patients [52]. With the Internet, it needs to be decided if it is the patient or the provider traveling to meet the other through cyberspace. If the patient is traveling to meet the provider, the consensus reached in e-psychiatry, [48] then the provider is already licensed in the state where he/she practices and would not need a license. However, if the provider is the one traveling to meet the patient, following the telemedicine statutes, then the provider would need to be licensed in the state the patient was residing, severely limiting the practice of cybermedicine, e-psychiatry, or e-therapy.

How the practice of online medicine and therapy will be conducted is yet another issue. Several approaches have been proposed for credentialing practitioners of online medicine and therapy. These include: self-regulation through abiding by ethical guidelines, advanced training for "e-providers," or requiring a special license. However, self-regulation will only work if there exist some enforceable penalties for violators, otherwise the unscrupulous will push the limits hoping to make their fortune before they are caught. Additionally, special training programs for healthcare providers who want to become "e-providers" and practice online medicine or online therapy could be instituted. These programs could educate potential online providers about online ethical obligations, essentials of the provider-healthcare consumer relationship, e-commerce, privacy and security issues, and Internet legalities [46]. A more comprehensive approach would be the establishment of an independent, international body to assess "cyberdocs," issue a special license to practice in cyberspace, and then monitor their practice [53].

Establishing Ethical Standards for Internet Research

The new forms of communication available on the Internet - chatrooms, message boards, and LISTSERVs - have created a researcher's paradise of new online arenas to utilize and study.

A wide range of research tools - including online experimental studies, surveys, interviews, field observations and participant observations - are being put to use to determining how online individuals and groups are utilizing and behaving in this new media [54]. Internet users can participate in unique pilot programs such as the National Cancer Institute's LiveHelp, that provide real-time site guidance with an information specialist who will answer questions and provide direction to helpful information on the site [55].

Real-time chatrooms are a new unique method of communicating unlike any previous form of communication. This new form of communication blurs the distinction between what is "private" and what is "public" in online communities. Researchers have tried using the analogy of a "public square" to describe a chatroom, but chatrooms are unusual; they are part telephone party line, part instant journaling, part random anonymous phone calls, and part permanent "recording" of Internet chat in the form of e-mail messages. Many researchers have already conducted studies to monitor discussion groups collecting research data surreptitiously as "lurkers," believing that this behavior is acceptable as long as they do not identify subjects in research projects. But is it ethical? Are researchers obligated to disclose their presence if they are collecting data by "observing" in chatrooms, knowing their presence may alter participant's behavior? Is it ethical for researchers to gather information for research projects under the guise of "naturalistic observations" from chatrooms without participants being aware they are part of a study? Does merely participating in public forums imply informed consent? Offline research projects are required to adhere to clearly delineated ethical guidelines when dealing with research participants [56]. It is essential that Internet researchers demonstrate clear ethical judgment and follow clear ethical guidelines to protect chatroom participants' privacy.

Not everything improves when moved onto the Internet. Many of the traditional research techniques do not adapt well in this new media. The anonymity of the Internet makes it difficult to get a truly randomized, unbiased study population for an online survey; anonymity and the ease of use of pseudonyms blurs key demographic details normally important to research studies such as age, gender, ethnicity, and country of origin. Online researchers face the challenge of determining which parts of the traditional research methods can be adopted or adapted for use on the Internet and which will need to be discarded as non-adaptable [46].

Several organizations have worked or are working to establish ethical standards for research and expanding them to include research on the Internet. In November 1997, the American Psychological Association (APA) issued a statement for their members to provide guidelines for dealing with services provided by telephone, teleconferencing, and the Internet [57]. The Association of Internet Researchers (AoIR) is currently working to establish guidelines for conducting online research. The American Medical Informatics Association (AMIA) is also exploring various aspects of research and informatics through their working groups - Clinical Trials and the Ethical, Legal and Social Issues (ELSI) [58,59]. The determinations of these organizations will help determine the ethical guidelines for

conducting online research, which can then be combined into a cohesive set of guidelines.

Determining Guidelines for Quality Medical and Healthcare Information on the Internet

For patients to feel confident about the medical and health information they obtain at a Web site, a standard set of ethical guidelines needs to be adopted and enforced. Many different organizations are using varied approaches to try to determine ethical guidelines for the Internet [60].

The predominant Internet - industry and public - policy approach to addressing these concerns is to encourage voluntary codes of conduct and industry self-regulation or self-governance [61]. The Health on the Net Foundation (HON) developed one of the first codes of conduct set of principles, the Net Code of Conduct [62]. The British Healthcare Internet Association has published Quality Standards for Medical Publishing on the Web [63] and an Internet Bill of Rights for Access to Health Information on the Net [64]. Editors of the Journal of the American Medical Association proposed guidelines for "assessing, controlling, and assuring the quality of medical information on the Internet." [65] Dr. George Lundberg expanded the definition of Medical Internet Ethics to include medical ethics, journalism ethics, business ethics, and the ethics of medical editing [21]. In addition to medicine, if one expands the definition and includes business and journalism ethics, other professional organizations and their codes include: the Society of Professional Journalists' Code of Ethics [66] the American Health Information Management Association's (AHIMA) recommendations to ensure privacy and quality of personal health information on the Internet, [67] and the International Committee of Medical Journal Editors' (ICMJE) policy statement about publishing on the Web [68]. The major limitation to this approach is that self-regulation does not deter the unscrupulous, who most need to have their ethical standards raised.

A second approach relies upon healthcare consumers to evaluate Web sites for quality using a checklist or rating tool. Different rating tools are available to consumers - if they know where to find them. The Health Summit Working Group of the Health Information Technology Institute of Mitretek Systems developed a Web-based, interactive Information Quality (IQ) tool for use in assessing the quality of health information on the Internet [69]. DISCERN is a brief online questionnaire, developed by the University of Oxford's Division of Public Health and Primary Health Care, at the Institute of Health Sciences. This questionnaire provides Internet users with a valid and reliable way of assessing the quality of consumer health information [70]. The Quick Web site tool, developed by the Health Education Authority and the Centre for Health Information Quality, is designed to be used as a teaching aid for children in an educational setting [71]. However, the checklist approach requires the consumer to be motivated enough to seek out, understand, and then use the rating tools.

A third approach utilizes third-party reviewers - physicians, academicians, nurses, librarians, and other experts - to evaluate health information and write reviews or create useful lists of sites, so that users, patient or physician, can determine the quality of information at these sites [60]. Review sites can be

libraries such as NOAH (New York Online access to Health) [72] or MedWeb; [73] university-based or university-sponsored such as Netwellness [74], InteliHealth, [75] or MayoClinic.com [76]; or non-profit-based such as Medical Matrix [77]. The reviewer approach is very labor intensive and dependent on the frequency that reviewed materials are updated, and requires frequent updates.

Fee-based rating or "accreditation" systems for medical and health Web sites are also being established. In May 2001, URAC ("American Accreditation HealthCare Commission," see www.urac.org, to explain the discrepancy in their name [78]) and Hi-Ethics announced that they would be collaborating on the URAC Health Website Accreditation program as a way for health Web sites to demonstrate their compliance with ethical standards. URAC is in the final stages of developing and testing its accreditation standards for health Web sites with implementation of the fee-based program scheduled to begin in August 2001. This accreditation program will involve an onsite review and analysis of Web site documentation and operations [79]. One concern with implementing fee-based accreditation systems is that this system favors the larger, well-funded organizations. URAC's proposed fee structure may exceed the yearly operating budget for many of the medical and health information Web sites. There is concern that the presence of seals of approval and certifications may provide a false sense of security and mislead consumers unless there is a system of enforcement and rigorous verification [61].

A next-generation approach is being developed by MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net). This project is developing a self-rating and third-party rating system enabling individuals, organizations, associations, societies, and others to filter health information and identify and select high-quality information. The MedCERTAIN consortium will also establish an international trustmark for health information by creating different levels of certification for those who publish health information on the Internet. Web sites wanting the MedCERTAIN certification will have to commit themselves to the eHealth Code of Ethics [80].

Requiring Ethical Conduct for Medical and Healthcare Web sites

Online ethics of commercial medical Web sites and the ability of the online healthcare industry to effectively self-regulate grabbed the limelight in the fall of 1999 after several prominent medical and health Web sites showed questionable ethical behavior. Among the complaints were that the distinction between objective information and advertising or promotional content was hazy and that business ties were not properly disclosed [47]. Other questionable practices included non-disclosure of business partnerships, [81] cookies tracking unsuspecting visitors, [82] and blatant conflicts of interest, with officers profiting from insider stock trading [83]. Since then, efforts to create codes of ethics for Web-based medical and healthcare activities have intensified.

One of the first codes of conduct for health and medical Web sites was developed by the HON in 1996 [62]. The following year the APA's Ethics Committee created guidelines for their

members for dealing with services provided by telephone, teleconferencing, and the Internet [57]. In September 1999, Medscape published their advertising and sponsorship policy, "The Ethics of the Medical Internet." [21] During 2000, the AMA published guidelines for their medical and health information sites on the Internet to follow, [14] the Internet Healthcare Coalition's (IHC) eHealth Ethics Initiative published an International Code of Ethics, [84] the MedCERTAIN consortium published a statement of purpose and the Consensus Recommendations on Trustmarks, [85] and Health Internet Ethics' (Hi-Ethics) published Ethical Principles for the Health Internet [86]. Many of the most-trafficked health Web sites (America Online, Discoveryhealth.com, drkoop.com, Healthon/WebMD, InteliHealth, Mediconsult/Physician's Online, and Medscape) agreed to be compliant with the Hi-ethics principles [87].

Baur and Doering of the US Department of Health and Human Services tried to make some sense of the different frameworks. They reviewed the four main private-sector proposals-HON, AMA, IHC, and Hi-ethics-and compiled a side-by-side comparison of the key elements for improving the quality of health Web sites. They found that the various codes may have different audiences and different purposes, with different motivations for developing the framework, yet all are being promoted to the general public as ways of improving quality [61].

The current framework situation is thus a bit chaotic, with many redundant, overlapping, and competing organizations. Each organization has spent a great deal of time, resources, and money to become the definitive ethical standard setting association [61]. With over 60 different instruments for rating Web sites found by Jadad and Gagliardi, [88] and a variety of proposals and ethical codes having been drafted by various profit, non-profit, and e-health organizations, it may prove to be difficult to provide Internet users with one quality rating system. Reaching a consensus does not necessarily mean merging all frameworks into one, but it does mean forging an agreement on what Web site developers and users need to do, how the information will be described, and how the guidelines will be enforced [61]. There is still no single, unifying consensus for determining quality of Web sites and establishing medical Internet ethical principles, but there is movement in the right direction, ie, movement to consolidate efforts. One can be optimistic that the agreement reached by several organizations at recent meetings and conferences is an indication of integrating efforts towards finally adopting *one* common, cohesive Medical/Healthcare Internet Code of Ethics, guaranteed by a trusted third party, that all online medical and healthcare Web sites can finally agree upon, implement, and enforce.

Ensuring Internet Users Privacy and Security

In this age of expanding access to information, a critical ethical responsibility is recognizing the right to privacy. A considerable challenge arises from trying to balance the desire to make information freely available to users of the Internet, while at the same time protecting people's privacy and confidentiality [14]. Additionally, personal information is being transmitted to different medical and health organizations via the Internet and

should be protected from intentionally or unintentionally reaching unsecured or unauthorized users. Understandably, protection of privacy is an issue of great concern among Internet users seeking health information [37].

There is an obvious need for secure Web sites, to ensure visitors' personal privacy and prevent personal medical information, including patterns of use and interests, from being sold, purchased, or inadvertently entering the hands of marketers, employers, and insurers [14]. Former US President Bill Clinton noted that "Nothing is more private than someone's medical or psychiatric records. And, therefore, if we are to make freedom fully meaningful in the Information Age, when most of our stuff is on some computer somewhere, we have to protect the privacy of individual health records." [89]

The United States has several governmental agencies responsible for certain regulatory efforts on the Internet. The Department of Health and Human Services will work to protect the confidentiality of medical records and ensure online privacy under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, now scheduled to be implemented over the next few years. HIPAA will govern the privacy of medical records and protection of digital information about patients, and will require providers, claims clearing houses, and health plans to implement administrative and technical steps to protect the confidentiality of electronic health records [39]. The final law may still be amended from the original. One could envision an expanded role for the Criminal Division's Computer Crime and Intellectual Property Section to aid in the prevention of cybercrimes within the medical field. In regards to medical data, the anti-paparazzi law [31] could be extended to allow victims to sue for damages that occur from a reporter (or online information broker) obtaining personal medical information. The cyberstalking laws [32] could be expanded to include obtaining medical information via the Internet. If adapted, both laws would go a long way toward preventing private medical information from getting into the wrong hands [61]. However, even if more U.S. regulations are enacted, they are only enforceable in the US. What will happen when problems occur in the international Web community? Ultimately, online activities and behaviors may require an impartial, unifying, international regulatory body to enact and enforce international ethical regulations, and codify medical/healthcare Internet conduct.

Discussion

A Field in Evolution

The rapid technologic development of the Internet has opened communication and commerce to the wired world, to people and professionals in different countries with different customs, beliefs, and definitions of ethics. The Internet is also changing how medicine will be practiced in the 21st century. The Internet raises many new ethical challenges for the medical community, especially when trying to consolidate different views from different countries on medical ethical practices.

Medical/Healthcare Internet Ethics is an emerging multidisciplinary field at the intersection of medicine, ethics,

and the Internet. In this paper 10 diverse areas were identified that will be melded to produce the new field. These include: healthcare delivery; applied computing; science and research; government agencies; healthcare services; end users: consumers and patients; healthcare organizations: insurance companies, management organizations, and societies; healthcare management organizations; administration and healthcare management; medical Ethics; and law. Other areas will most likely be added later. In this paper Medical/Healthcare Internet Ethics was defined as "an emerging interdisciplinary field that considers the implications of medical knowledge utilized via the Internet, and attempts to determine the ethical guidelines under which ethical participants will practice online medicine or therapy, conduct online research, engage in medical e-commerce and contribute to medical Web sites."

Medical/Healthcare Internet Ethicists will be looking to current views of medical ethics and codes of professional conduct from participating countries to establish the ideal behaviors and ethical conduct for all the professions involved with the medical Internet. The areas identified for further examination and study in this paper include:

- How visitors' privacy, security, and confidentiality should be ensured when visiting a Web site or conducting transactions over the Internet.
- How Web-site visitors can determine the quality of information at a Web site.
- How the doctor-patient, patient-provider, and therapist-client relationships should be translated into practicing online medicine and online therapy.
- How Web site designers, developers, managers, and sponsors should develop and maintain ethical medical and healthcare Web sites.
- How online medical and healthcare businesses should be ethically conducted.
- How online research should be ethically conducted.
- How all the professions involved in the medical or healthcare Internet should ethically comport themselves.

The field of medicine has traditionally relied upon self-regulation of its members, especially in the area of medical ethics. However, unethical conduct by some of the early medical and health Web pioneers left both the public and medical ethicists wondering about the effectiveness of self-regulation. Although the essence of medical professionalism is self-governance, there is no way of enforcing standards if practitioners choose not to follow professional ethical guidelines, or if non-professionals have no professional guidelines to follow. There is concern that many of the existing codes of ethics developed for the Internet are in actuality promoting pseudoaccountability, with lengthy codes of conduct crafted in technical language that convey the impression of setting high standards, but in reality are non-enforceable.

Several challenges await the practitioners, scientists, researchers, developers, programmers, patients, administrators, governments, e-commerce marketers, managers, and ethicists involved in this emerging field. An early challenge will be blending the varied definitions of "medical ethics" from many different countries into a cohesive consensus. Another will be determining which

components of the existing medical, scientific, computer, management, and economic areas, among others, should contribute to defining the field of Medical Internet Ethics. How to credential practitioners interested in online medicine or online therapy - whether requiring additional training, certification, or even a special license - is yet another challenge. One key challenge will be in fully restoring the public's trust in medical and healthcare Web sites. This challenge may be solved with a cohesive code of ethics and Web site guidelines to effectively regulate the medical/health Internet industry.

Unfortunately, the Internet has many unscrupulous people and professions functioning outside of the traditional realm of medical ethics, often pushing the limits of the existing Web site codes of ethics and the Internet laws. Additional ethical guidelines would have little impact on these not-so-legitimate computer and Internet practitioners. In order to protect healthcare consumers' privacy and confidentiality, the self-regulation of ethical codes of conduct may have to evolve into enforceable laws. Without some international agreements, national regulatory efforts are only enforceable within the country that has passed the law. The worldwide availability of online locations makes it easy for unethical medical and healthcare entrepreneurs to establish their Internet company in the most permissive jurisdiction they can find, moving if necessary to another online locale to continue their Internet misconduct. Ultimately all those professionals involved in the creation, maintenance, and marketing of medical and healthcare Web sites should be required to adhere to a strict code of ethical conduct, one that has been fairly determined by an impartial international organization with reasonable power to regulate the code.

Contributing to this issue is the projected changing demographic profile of the Internet. Much of the discussion on Medical Internet Ethics has been initiated by organizations and companies from the United States or the EU (European Union). With tremendous growth of Internet use in Asia, China, and Japan, it is predicted that by 2002 the majority of Internet users will be non-English speaking [90]. This changing face of the Internet further underscores the need for an international approach when developing a medical Internet regulatory organization.

Many of the international organizations - the United Nations (UN), particularly UNESCO (United Nations Educational, Scientific, and Cultural Organization), the World Health Organization (WHO), the World Trade Organization and the International Telecommunications Union - have been in the forefront of determining ethical and regulatory questions relating to: quality of information on the Internet, telemedicine, and e-commerce [91]. The past successes of the WHO and UNESCO suggest these two organizations may be well suited to unify the many disparate initiatives in Medical/Healthcare Internet Ethics. For example, the adoption of the UN-sponsored ebXML Internet communications standard confirmed that the United Nations can be an effective catalyst for standard-setting in the crucial area of Internet development [92]. The United Nations, with its specialized agencies and nonaligned consensus groups is uniquely qualified to lead discussions on Medical Internet Ethics, and perhaps establish something like a UN Commission

for the Medical Internet. Such a body would be ideally suited for establishing, and most importantly, regulating, a single code of Medical Internet Ethics that would include advertising, health fraud detection, and ensuring consumer privacy [91]. The prestige afforded the United Nations would provide the authority to regulate; the prospect of being "blacklisted" by a UN Commission as an unethical medical or healthcare Web site would be a powerful deterrent to any would-be charlatan, organization, or company, when trust and public opinion is critical to a Web site's success. Additionally, UN authorities would be in the best position to gain the attention of the necessary national authorities if it became necessary to press for action against Internet-based medical or healthcare activities that endangered the health of individuals.

Many organizations from the fields of medicine, informatics, counseling, journalism, business, research, and management are already carefully deliberating to establish guidelines for their members in ethical conduct - including ethical research

and ethical online practice - and translating or adapting many of the traditional codes of ethics to the Internet. Non-medical professionals involved in providing online medical services (designers, writers, backers, programmers, promoters, and executives of medical and healthcare Web sites) must be educated as ancillary healthcare professionals, so as not to exploit online patients or clients. These organizations involved in medicine and healthcare on the Internet will need to establish strong internal protection, privacy, and security measures, to ensure the safety of stored personal data and the confidentiality of transmitted information over the Internet.

In this paper, several of the key challenges have been presented and explored to stimulate more thought by the medical Internet community. The greatest challenge for all concerned with Medical Internet Ethics will be to catch up to the explosion in Internet technology and determine the most effective use of new technology in medicine and healthcare, while not compromising the fundamentals of medical ethics.

Acknowledgments

An earlier review of this topic "The Ethical Challenges of Translating the Doctor-Patient Relationship to the Internet" was written for the Summer 2000 MINF 510, Medical Informatics at Oregon Health Sciences University. The topic was further examined within the Winter 2001 MINF 528 course Web resource "Medicine, Ethics, & Medical Informatics." [93] A shorter paper on "Medical Internet Ethics: A Field in Evolution" has been accepted for presentation at Medinfo 2001 in London this September [46].

Conflicts of Interest

None declared.

Multimedia Appendix

Downloadable slides of the presentation "Medical Internet Ethics: A Field in Evolution", presented at Medinfo'01, Sept 2001, London [46] [[PowerPoint ppt file, 191 kB - jmir_v3i2e23_app1.ppt](#)]]



References

1. Charles SC, Lazarus JA. Reframing the professional ethic: the Council of Medical Specialty Societies consensus statement on the ethic of medicine. *West J Med* 2000 Sep;173(3):198-201 [[FREE Full text](#)] [Medline: [20444544](#)] [doi: [10.1136/ewjm.173.3.198](#)]
2. Kassirer JP. Pseudoaccountability. *Ann Intern Med* 2001 Apr 3;134(7):587-590 [[FREE Full text](#)] [Medline: [21178448](#)]
3. ; US Department of Commerce. The emerging digital economy, Chap 1: The digital revolution. 1998 Apr. URL: <http://www.ecommerce.gov/emerging.htm> [accessed 2001 Apr 17]
4. ; Nua Internet Surveys. How many online?. 2000 Nov. URL: http://www.nua.ie/surveys/how_many_online/index.html [accessed 2001 Apr 17]
5. Guadagnino C. Using medical information on the Internet. *Physician's News Digest*. 2000 Jul. URL: <http://www.physiciansnews.com/spotlight/700.html> [accessed 2001 Apr 17]
6. ; The Pew Internet and American Life Project. The online health care revolution: How the Web helps Americans take better care of themselves, Summary of findings: The Internet's powerful influence on "health seekers." 2000 Nov 26. URL: <http://www.pewinternet.org/reports/toc.asp?Report=26> [accessed 2001 Jun 24]
7. ; Cyber Dialogue. Online health information seekers growing twice as fast as online population [press release]. 2000 May 23. URL: <http://www.cyberdialogue.com/news/releases/2000/05-23-cch-future.html> [accessed 2001 Apr 17]
8. Goldman J, Hudson Z, Smith RM. Privacy: Report on the privacy policies and practices of health Web sites. California HealthCare Foundation. 2000 Jan. URL: <http://ehealth.chcf.org/view.cfm?section=Privacy&itemID=1750> [accessed 2001 Apr 18]

9. ; Medem Inc. eRisk for providers: Understanding and mitigating provider risk associated with online patient interaction. 2001 Mar. URL: <http://www.medem.com/erisk> [accessed 2001 Apr 13]
10. Childress CA. Ethical issues in providing online psychotherapeutic interventions. *J Med Internet Res* 2000 Mar 31;2(1):e5 [FREE Full text] [Medline: 21577989] [doi: 10.2196/jmir.2.1.e5]
11. Halvorsen JG. Professionalism reconsidered. Priorities for physicians. *Arch Fam Med* 1999 Apr;8(2):173-176 [FREE Full text] [Medline: 99202218] [doi: 10.1001/archfami.8.2.173]
12. ; American Medical Association Council on Ethical and Judicial Affairs. Code of Medical Ethics: Current Opinions with Annotations 2002-2003. Chicago, IL: American Medical Association; Jul 15, 2002:105.
13. Crawshaw R, Rogers DE, Pellegrino ED, Bulger RJ, Lundberg GD, Bristow LR, et al. Patient-physician covenant. *JAMA* 1995 May 17;273(19):1553. [Medline: 95257437] [doi: 10.1001/jama.273.19.1553]
14. Winker MA, Flanagan A, Chi-lum B, White J, Andrews K, Kennett RL, et al. Guidelines for medical and health information sites on the internet: principles governing AMA web sites. American Medical Association. *JAMA* 2000;283(12):1600-1606 [FREE Full text] [Medline: 20197445] [doi: 10.1001/jama.283.12.1600]
15. Goodman KW, Miller RA. Ethics and Health Informatics: Users, Standards, and Outcomes. In: Shortliffe EH, Perreault LE, editors. *Medical Informatics: Computer Applications in Health Care and Biomedicine*. New York: Springer-Verlag; 2000:Chap. 7.
16. ; Internet Healthcare Coalition. New Survey shows disparity between Web developers and consumers over Health Internet [press release]. 2000 Oct 4. URL: http://www.ihealthcoalition.org/about/ihc_pr8.html [accessed 2001 Apr 17]
17. Goodman K. Bioethics and Health Informatics: An Introduction. In: Goodman K, editor. *Ethics, Computing, and Medicine*. Cambridge: Cambridge University Press; Jan 15, 1998:1-31.
18. Ruddick W. Medical Ethics. In: Becker LC, Becker CB, editors. *Encyclopedia of Ethics*, 2nd edition: Garland Publishing; 1998. URL: <http://www.nyu.edu/gsas/dept/philo/faculty/ruddick/papers/medethics.html> [accessed 2001 Feb 12]
19. Maheu MM. Delivering Behavioral Telehealth via the Internet: eHealth. 2000 Feb 1. URL: <http://telehealth.net/articles/deliver.html> [accessed 2001 Jun 17]
20. Merriam W. *Websters Ninth New Collegiate Dictionary*. Springfield, Mass: Merriam-webster+ Inc; 1984.
21. Lundberg GD. The Ethics of the Medical Internet: Medscape's Advertising Policy. *MedGenMed* 1999 Sep 10:e25 [FREE Full text] [Medline: 11104427]
22. Foubister V. Developing rules for the Web. *American Medical News* 2000 Jul 31;43:11-12 [FREE Full text]
23. Rotblat J. A Hippocratic Oath for scientists. *Science* 1999 Nov 19;286(5444):1475 [FREE Full text] [Medline: 20058720] [doi: 10.1126/science.286.5444.1475]
24. ; American Association for the Advancement of Science. Science and society, To pledge or not to ledge: An oath for scientists?. 2001 Feb 19. URL: <http://www.aaas.org/meetings/2001/6048.00.htm> [accessed 2001 February 17]
25. ; Student Pugwash USA. About the pledge. 2000 Sep 22. URL: <http://www.igc.org/pugwash/pledge> [accessed 2001 Mar 1]
26. Alberty N. Hippocratic Oath for Scientists. URL: <http://www.globalideasbank.org/BOV/BV-381.HTML> [accessed 2001 Mar 1]
27. ; Jargon File 4.2.3. Cracker definition. 2000 Nov 23. URL: <http://www.tuxedo.org/~esr/jargon/html/entry/cracker.html> [accessed 2001 Apr 29]
28. ; Jargon File 4.2.3. Hacker definition. 2000 Nov 23. URL: <http://www.tuxedo.org/~esr/jargon/html/entry/hacker.html> [accessed 2001 Apr 29]
29. ; Jargon File 4.2.3. Virus definition. 2000 Nov 23. URL: <http://www.tuxedo.org/~esr/jargon/html/entry/virus.html> [accessed 2001 Apr 29]
30. ; Jargon File 4.2.3. Worm definition. Nov 23. URL: <http://www.tuxedo.org/~esr/jargon/html/entry/worm.html> [accessed 2001 Apr 29]
31. ; California Department of Consumer Affairs. 1998 Legislative Digest SB 1379. Invasion of Privacy: Paparazzi (Civ C SECT 1708.8). URL: <http://www.dca.ca.gov/legis/sb1379.htm> [accessed 2001 Apr 29]
32. ; California Department of Consumer Affairs. 1998 Legislative Digest SB 1796. Stalking: Cyberstalking (Civ C SECT 1708.7 and Pen C SECT 422, 646.9 & 653). URL: <http://www.dca.ca.gov/legis/sb1796.htm> [accessed 2001 Apr 29]
33. Internet Fraud Complaint Center (IFCC). URL: <https://www.ifccfbi.gov/> [accessed 2001 May 14]
34. Federal Trade Commission. URL: <http://www.ftc.gov> [accessed 2001 May 14]
35. ; Federal Trade Commission. "Operation Cure.All" wages new battle in ongoing war against Internet health fraud [press release]. 2001 Jun 14. URL: <http://www.ftc.gov/opa/2001/06/cureall.htm> [accessed 2001 Jun 19]
36. Computer Crime and Intellectual Property Section (CCIPS) of the Criminal Division of the US Department of Justice. URL: <http://www.cybercrime.gov/> [accessed 2001 Mar 4]
37. ; California HealthCare Foundation. Ethics survey of consumer attitudes about health Web sites. Conducted by Cyber Dialogue and the Institute for the Future. 2000 Sep. URL: <http://ehealth.chcf.org/view.cfm?section=Consumer&itemID=1740> [accessed 2001 Jun 24]
38. Galewitz P. 858 Kaiser e-mails go to wrong patients. *Contra Costa Times* 2000 Aug 10.

39. Chin T. Security breach: Hacker gets medical records. American Medical News. 2001 Jan 29. URL: http://www.ama-assn.org/sci-pubs/amnews/pick_01/tesa0129.htm [accessed 2001 Mar 4]
40. ; Computer Security Institute. Financial losses due to Internet intrusions, trade secret theft and other cyber crimes soar. 2001 Mar 12. URL: http://www.gocsi.com/prelea_000321.htm [accessed 2001 Mar 12]
41. Eysenbach G. Report of a case of cyberplagiarism--and reflections on detecting and preventing academic misconduct using the Internet. J Med Internet Res 2000 Mar 31;2(1):e4 [FREE Full text] [Medline: 21577988] [doi: 10.2196/jmir.2.1.e4]
42. ; US Copyright Office, Library of Congress. Copyright basics. 2000 Dec. URL: <http://www.loc.gov/copyright/circs/circ1.html> [accessed 2001 May 10]
43. Brinson JD, Radcliffe MF. Multimedia law and business handbook. Chap 2: Copyright Law. URL: <http://www.laderapress.com/laderapress/copyrightlaw1.html> [accessed 2001 May 4]
44. ; MIT. MIT to make nearly all course materials available free on the World Wide Web: Unprecedented step challenges 'privatization of knowledge' [press release]. 2001 Apr 4. URL: <http://web.mit.edu/newsoffice/nr/2001/ocw.html> [accessed 2001 Apr 10]
45. Supercourse: Epidemiology, the Internet and global health. 2000 Apr 1. URL: <http://www.pitt.edu/~super1> [accessed 2001 May 5]
46. Dyer K, Thompson C. Medical Internet ethics: A field in evolution. Medinfo 2001 [in press].
47. Noble H. Hailed as a Surgeon General, Koop is faulted on Web ethics. New York Times 1999 Sep 5.
48. Seeman MV. E-psychiatry: the patient-psychiatrist relationship in the electronic age. CMAJ 1999 Nov 2;161(9):1147-1149 [FREE Full text] [Medline: 20035589]
49. ; ISMHO/PSI (International Society for Mental Health Online/Psychiatric Society for Informatics). Suggested principles for the online provision of mental health services [version 3.11]. 2000 Jan 9. URL: <http://www.ismho.org/suggestions.html> [accessed 2001 Mar 4]
50. ; National Board for Certified Counselors, Inc. Standards for the ethical practice of WebCounseling. 1999 Sep 30. URL: <http://www.nbcc.org/ethics/wcstandards.htm> [accessed 2001 Mar 4]
51. Gerber BS, Eiser AR. The patient physician relationship in the Internet age: future prospects and the research agenda. J Med Internet Res 2001 Apr 9;3(2):e15 [FREE Full text] [Medline: 21578022] [doi: 10.2196/jmir.3.2.e15]
52. Spielberg AR. On call and online: sociohistorical, legal, and ethical implications of e-mail for the patient-physician relationship. JAMA 1998 Oct 21;280(15):1353-1359. [Medline: 99008448] [doi: 10.1001/jama.280.15.1353]
53. Eysenbach G. Consumer health informatics. BMJ 2000 Jun 24;320(7251):1713-1716 [FREE Full text] [Medline: 20323060] [doi: 10.1136/bmj.320.7251.1713]
54. Suler J. Ethics in cyberspace research: Consent, privacy and contribution. Psychology of cyberspace. 2000 Feb. URL: <http://www.rider.edu/users/suler/psycyber/ethics.html> [accessed 2001 March 9]
55. ; CancerNet. Help: LiveHelp Cancer.gov. URL: <http://cancernet.nci.nih.gov/help.html#LH> [accessed 2001 May 12]
56. Roberts P. Protecting the participant in the contested private/public terrain of Internet research: Can computer ethics make a difference?. Presented at: AiCE 2000, 2nd Australian Institute of Computer Ethics Conference URL: <http://www.aice.swin.edu.au/events/AICE2000/papers/rob.pdf> [accessed 2001 Mar 11]
57. ; Ethics Committee of the American Psychological Association. APA statement on services by telephone, teleconferencing, and Internet. 1997 Nov 5. URL: <http://www.apa.org/ethics/stmnt01.html> [accessed 2001 May 3]
58. ; American Medical Informatics Association. Clinical trials working group. URL: <http://www.amia.org/working/ct.html> [accessed 2001 Mar 9] URL: <http://wgct-amia.crc.cuse.usherb.ca/> [accessed 2001 Mar 9]
59. ; American Medical Informatics Association. Ethical, legal, and social issues working group. URL: <http://www.amia.org/working/elsi.html> [accessed 2001 Mar 9]
60. Price SL, Hersh WR. Filtering Web pages for quality indicators: an empirical approach to finding high quality consumer health information on the World Wide Web. Proc AMIA Symp 1999:911-915 [FREE Full text] [Medline: 20033003]
61. Baur C, Deering MJ. Proposed frameworks to improve the quality of health web sites: review. MedGenMed 2000 Sep 26;2(3):e35 [FREE Full text] [Medline: 20556719]
62. ; Health on the Net Foundation (HON). HON code of conduct (HONcode) for medical and health Web sites: Principles. URL: <http://www.hon.ch/HONcode/Conduct.html> [accessed 2001 March 5]
63. ; British Healthcare Internet Association. Quality standards for medical publishing on the Web. 1996. URL: http://bhia.org/reference/documents/recommend_webquality.htm [accessed 2001 May 5]
64. ; British Healthcare Internet Association. A Bill of Rights for the Internet. 1997. URL: http://bhia.org/reference/documents/press_19971107.htm [accessed 2001 May 5]
65. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor--Let the reader and viewer beware. JAMA 1997 Apr 16;277(15):1244-1245. [Medline: 97256510] [doi: 10.1001/jama.277.15.1244]
66. ; Society of Professional Journalists. Society of Professional Journalists, Code of Ethics. 1996 Sep. URL: <http://spj.org/ethics> [accessed 2001 May 5]

67. ; American Health Information Management Association (AHIMA). AHIMA's recommendations to ensure privacy and quality of personal health information on the Internet. 2000 Aug. URL: <http://www.ahima.org/infocenter/guidelines/tenets.html> [accessed 2001 May 5]
68. ; International Committee of Medical Journal Editors. Policies for posting biomedical journal information on the Internet. 2000 May. URL: <http://www.icmje.org/index.html#internet> [accessed 2001 May 13]
69. ; Health Summit Working Group. Information quality tool. 2000 Jun 23. URL: <http://HitiWeb.mitretrek.org/iq/default.asp> [accessed 2001 May 5]
70. DISCERN. URL: <http://www.discern.org.uk> [accessed 2001 May 5]
71. The quality information checklist. 2000 May 15. URL: <http://www.quick.org.uk> [accessed 2001 May 5]
72. New York Online Access to Health (NOAH). URL: <http://www.noah-health.org> [accessed 2001 May 5]
73. Robert W. Woodruff Health Sciences Center Library of Emory University. MedWeb. URL: <http://www.medweb.emory.edu/MedWeb> [accessed 2001 May 5]
74. Netwellness University of Cincinnati. URL: <http://www.netwellness.org> [accessed 2001 May 5]
75. ; IntelliHealth. Harvard Medical School's consumer health information. URL: <http://www.intelihealth.com> [accessed 2001 May 5]
76. ; Mayo Foundation for Medical Education and Research. MayoClinic.com. URL: <http://www.mayohealth.org> [accessed 2001 May 5]
77. ; Medical Matrix L.L.C. Medical matrix. URL: <http://www.medmatrix.org/index.asp> [accessed 2001 May 5]
78. ; URAC (American Accreditation HealthCare Commission). Answers to frequently asked questions: What is the cost of accreditation?. URL: <http://www.urac.org/webfaq.htm> [accessed 2001 Jun 19]
79. ; URAC (American Accreditation HealthCare Commission). URAC and Hi-Ethics collaborate on health Web site accreditation [press release]. 2001 May 21. URL: <http://www.urac.org/010521Hi-EthicsURAC.htm> [accessed 2001 Jun 19]
80. Eysenbach G, Yihune G, Lampe K, Cross P, Brickley D. MedCERTAIN: quality management, certification and rating of health information on the Net. Proc AMIA Symp 2000:230-234 [FREE Full text] [Medline: [21027353](#)]
81. Sherrid P. What's up, Dr. Koop? The health care Web site comes under fire. U.S. News. 1999 Sep 20. URL: <http://www.usnews.com/usnews/issue/990920/koop.htm> [accessed 2001 May 5]
82. ; The Associated Press. Sealing the cookie jar: Citing privacy, drkoop.com ditches cookies. 2000 Feb 12. URL: <http://abcnews.go.com/sections/tech/DailyNews/drkoop000212.html> [accessed 2001 May 5]
83. Calacanis C. Drkoop.com's troubles continue: Class-action suits abound. IhealthcareWeekly.com. 2000 Aug 8. URL: <http://www.ihealthcareweekly.com/issues/ihcw08082000.html> [accessed 2001 Mar 5]
84. Rippen H, Risk A. for the e-Health Ethics Initiative. e-Health Code of Ethics. J Med Internet Res 2000;2(2):e9 [FREE Full text] [doi: [10.2196/jmir.2.2.e9](#)]
85. ; MedCERTAIN. Consensus workshop, Quality criteria for health related websites: A foundation for rating and filtering health information. 2000 Aug 2. URL: http://www.medcertain.org/English/About_us/Consensus_Workshop/consensus_workshop.htm [accessed 2001 May 5]
86. ; Hi-Ethics, Inc. Health Internet ethics: Ethical principles for offering Internet health services to consumers. URL: <http://www.hiethics.org/Principles/index.asp> [accessed 2001 Mar 5]
87. ; Hi-Ethics, Inc. Hi-Ethics releases ethical principles for the health Internet: top health Web sites agree on rules to earn public trust. 2000 May 7. URL: <http://www.hiethics.org/Press/Releases/000507.asp> [accessed 2001 May 5]
88. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? JAMA 1998 Feb 25;279(8):611-614. [Medline: [98146162](#)] [doi: [10.1001/jama.279.8.611](#)]
89. ; Department of Health and Human Services. Remarks by the President on medical privacy [press release]. 2000 Dec 20. URL: <http://www.hipaadvisory.com/news/clinton1220.htm> [accessed 2001 Mar 4]
90. Dillon N. Web should prepare for a non-English majority. 1999 Jun 14. URL: <http://www.cnn.com/TECH/computing/9906/14/nonenglish.idg> [accessed 2001 Jun 15]
91. Rodrigues RJ. Ethical and Legal Issues in Interactive Health Communications: A Call for International Cooperation. J Med Internet Res 2000;2(1):e8 [FREE Full text] [doi: [10.2196/jmir.2.1.e8](#)]
92. ebXML Website. URL: <http://www.ebxml.org> [accessed 2001 May 12]
93. Medicine, Ethics, & Medical Informatics. URL: http://www.kirstimd.com/MINF_528 [accessed 2001 June 24]

Abbreviations

- AAAS:** American Association for the Advancement of Science
- AMA:** American Medical Association
- AMIA:** American Medical Informatics Association
- AoIR:** Association of Internet Researchers
- APA:** American Psychological Association
- CCIPS:** Criminal Division's Computer Crime and Intellectual Property Section
- CEJA:** Council on Judicial and Ethical Affairs of the AMA

ELSI: Ethical, Legal and Social Issues working group of the AMIA
EU: European Union
FBI: Federal Bureau of Investigation
HIPAA: Health Insurance Portability and Accountability Act
HON: Health on the Net Foundation
IFCC: Internet Fraud Complaint Center
IHC: Internet Healthcare Coalition's
ISMHO: International Society for Mental Health On-line
MedCERTAIN: MedPICS Certification and Rating of Trustworthy Health Information on the Net
NBCC: National Board of Certified Counselors
NOAH: New York Online access to Health
PDA: personal device assistant
PSI: Psychiatric Society for Informatics
UN: United Nations
UNESCO: United Nations Educational, Scientific, and Cultural Organization
URAC: American Accreditation HealthCare Commission
WHO: World Health Organization

submitted 21.05.01; peer-reviewed by KW Goodman, R Rodrigues, A Risk, J Mack; comments to author 12.06.01; revised version received 22.06.01; accepted 23.06.01; published 28.06.01.

Please cite as:

Dyer KA

Ethical Challenges of Medicine and Health on the Internet: A Review

J Med Internet Res 2001;3(2):e23

URL: <http://www.jmir.org/2001/2/e23/>

doi: [10.2196/jmir.3.2.e23](https://doi.org/10.2196/jmir.3.2.e23)

PMID: [11720965](https://pubmed.ncbi.nlm.nih.gov/11720965/)

© Kirsti A Dyer. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 28.6.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Short Paper

Factors Associated with Intended Use of a Web Site Among Family Practice Patients

Peggy A Smith-Barbaro¹, PhD; John C Licciardone¹, DO; Howard F Clarke¹, P.A.-C.; Samuel T Coleridge¹, DO

Department of Family Medicine, Texas College of Osteopathic Medicine, University of North Texas Health Science Center at Fort Worth, USA

Corresponding Author:

Peggy A Smith-Barbaro, PhD Assistant Professor

Director of Education and Research

University of North Texas

Health Science Center at Fort Worth

Department of Family Medicine

3500 Camp Bowie Boulevard

Fort Worth TX 76107

USA

Phone: +1 817 735 2405

Fax: +1 817 735 5089

Email: pbarbaro@hsc.unt.edu

Abstract

Background: The World Wide Web has become a widely utilized source of health information. Although the frequency of health related queries is impressive, the demographics associated with patients making queries has not been clearly delineated.

Objective: This study's objective was to determine health related Internet usage patterns of family medicine patients.

Methods: Internet use among 824 eligible patients 18 years or older attending seven university based family practice clinics during a two week period in November of 1999 was studied. The survey instrument included 10 items and was designed to collect data in less than five minutes using a paper and pencil format. Statistical significance associated with intended Web site use was computed using a multiple logistic regression model.

Results: A response rate of 72.2% was observed with 63.1% being females and 36.9% being males. The mean and median age were 44.0 and 45.7 years, respectively. A steady decline in intended Web site use was observed with advancing age with significant differences observed above 65 years (OR = 0.30; 95% CI = 0.14 - 0.64; $p < .002$). Other significant findings associated with intended use of a Web site by clinic based patients included having a home computer (OR = 1.99; 95%, CI = 1.05 - 3.76; $p < 0.03$) and having Internet access at home (OR=5.6, 95%, CI = 2.83-11.18; $p < .001$). A lack of association between intended Web site use and health insurance status was observed.

Conclusions: Results from this study suggest that Web sites are not likely to be alternative sources of health information for the uninsured or elderly in the near future.

(*J Med Internet Res* 2001;3(2):e17) doi:[10.2196/jmir.3.2.e17](https://doi.org/10.2196/jmir.3.2.e17)

KEYWORDS

Internet/utilization; Questionnaires; Surveys; Patients/statistics; numerical data; Attitude to Computers; Socioeconomic Factors; Age Factors; Health Education/methods; Health Behavior; Family Practice; Logistic Models; Odds Ratio; Digital Divide

Introduction

Sophisticated consumer health information systems, supported by emerging technologies, are expected to become integral components of future medical practice [1]. Online resources have created not only the potential for health care providers to complement their usual delivery of services, but also to fundamentally alter how they deliver health care [2]. Increasingly, health information and consultations are being

sought online, [3,4] with little evidence of international barriers [5]. In fact, it is postulated that online health communications may replace a substantial amount of health care now delivered in person [6].

Nevertheless, questions have been raised regarding access to and the quality of online health information [7]. Among the potential barriers to this emerging resource are cost, location, illiteracy, and disability [8]. Demand for online health information appears to be enormous, with allegedly 25% of

search engine queries on the World Wide Web involving health issues [9]. However, it has also been shown that the majority of Medline searches via free Web access are still made by health care professionals and researchers rather than members of the general public or students [10]. In fact, 5% of outpatients at an urban medical center used the Internet to access health information and only 20% reported access to the Internet [11]. Further, a systematic review of computerized educational interventions found that they appear to be a valuable supplement to, but not a substitute for, face-to-face time with physicians [12,13]. To further study the potential of providing online health information in family practice, we conducted a survey of patients attending a network of university clinics.

Methods

Patients at seven family practice clinics affiliated with the University of North Texas Health Science Center at Fort Worth

Textbox 1. Survey Instrument

1. Age ____
2. Sex female male
3. Are you: single married other
4. Do you have children yes no
5. If you answered YES please list their age(s) _____
6. Are you privately insured a member of an HMO/PPO uninsured Medicaid/Medicare
7. Do you have a computer at home? yes no
8. Do you have access to the internet? At home: yes no At work: yes no
9. If you answered YES, how much time do you spend on the internet? daily _____ weekly _____
10. Would you use a free health information web site provided by the University of North Texas Health Science Center at Fort Worth? use frequently use occasionally Not use

Survey results were summarized using standard descriptive statistics. The main outcome measure was response to the following survey item: "Would you use a free health information Web site provided by the University of North Texas Health Science Center at Fort Worth." Responses to this item

were surveyed. Six of the seven clinics were located in the Fort Worth/Tarrant County metropolitan area. The seventh clinic was located in a rural, health professional shortage area of an adjacent county. The number of surveys allocated to each clinic was in proportion to its patient population. The survey instrument included 10 items and was designed to collect self-reported data in less than five minutes using a paper and pencil format (Textbox 1). Clinic personnel were trained in survey administration and collection. Eligible patients included those 18 years of age or older who attended one of the participating clinics during a two-week period in November 1999. The survey sought information on patient sociodemographic characteristics, home computer availability, and Internet access. There were no financial incentives for survey participation.

included "use frequently," "use occasionally," or "not use." A multiple logistic regression model was used to compute odds ratios (ORs) and 95% confidence intervals (CIs) associated with intended use of the clinic-based Web site for each of seven variables while simultaneously adjusting for the other variables.

The dependent variable in this model was dichotomized as intended Web site use (either frequent or occasional) vs. no use. Analyses were conducted using the SYSTAT 7.0 for Windows software (SPSS Inc., Chicago, IL). All hypotheses were tested at the .05 level of statistical significance.

Results

A total of 595 (72.2%) of the 824 eligible patients provided survey information. Patient responses are summarized in [Table 1](#). There was an adequate representation of all age groups among the respondents. A total of 226 (39.0%) respondents had a home computer and 179 (32.1%) also had Internet access at home. There were 242 (48.1%) respondents who stated they would use the clinic-based Web site to acquire health information.

Table 1. Sociodemographic characteristics of survey respondents

Variable	No	%
Age, yr		
< 35	204	34.7
36-50	153	26.0
51-65	115	19.6
> 65	116	19.7
Gender		
Female	370	63.1
Male	216	36.9
Marital Status		
Single	251	43.7
Married	307	53.4
Other	17	3.0
Have Children		
No	151	26.1
Yes	427	73.9
Health Insurance		
None	31	5.4
Private	89	15.6
Health Maintenance Organization /Preferred Provider Organization	355	62.4
Medicare or Medicaid	141	24.8
Have Home Computer		
No	354	61.0
Yes	226	39.0
Have Internet Access at Home		
No	378	67.9
Yes	179	32.1
Intended to Use the Clinic-Based Web Site		
No	261	51.9
Occasionally	166	33.0
Frequently	76	15.1

The multivariate factors associated with intended use of the clinic-based Web site are presented in [Table 2](#). A majority of younger respondents would use the Web site; however, there was a steady decline in intended Web site use with advancing age. Respondents greater than 65 years of age were less likely

than young adults to report intended Web site use, even after adjusting for potential confounders such as having a home computer and Internet access (OR=0.30, 95% CI=0.14-0.64; P=.002). Other factors such as gender, marital status, having children, and having health insurance were not significantly

associated with intended Web site use. A total of 569 patients responded to the item on health insurance; 47 patients reported multiple insurance types. Almost three-fourths of respondents with a home computer would use the Web site. Having a home computer almost doubled the likelihood of using the Web site

(OR=1.99, 95% CI=1.05-3.76; P=.03). Not surprisingly, however, having Internet access at home considerably enhanced the likelihood of using the Web site (OR=5.62, 95% CI=2.83-11.18; P<.001).

Table 2. Factors associated with intended use of a Web site by family practice clinic patients

	No. of Users	Total No	% Users	Odds Ratio	95% Confidence Interval	P
Age, yr						
< 35*	102	180	56.7	1.00		
36-50	72	132	54.5	0.91	0.51, 1.63	.76
51-65	47	97	48.5	0.69	0.36, 1.33	.27
> 65	19	88	21.6	0.30	0.14, 0.64	.002
Gender						
Female*	153	314	48.7	1.00		
Male	86	185	46.5	1.11	0.68, 1.81	.67
Marital Status						
Single*	107	220	48.6	1.00		
Married	126	258	48.8	0.88	0.54, 1.45	.62
Other	3	12	25.0	0.76	0.15, 3.85	.74
Have Children						
No*	70	128	54.7	1.00		
Yes	167	363	46.0	1.34	0.75, 2.40	.33
Have Health Insurance						
No*	11	28	39.3	1.00		
Yes	227	459	49.5	1.19	0.48, 2.96	.71
Have Home Computer						
No*	85	282	30.1	1.00		
Yes	155	214	72.4	1.99	1.05, 3.76	.03
Have Internet Access at Home						
No*	91	306	29.7	1.00		
Yes	139	171	81.3	5.62	2.83, 11.18	<.001

Discussion

This study indicates that less than 40% of family practice patients attending a network of university clinics have a home computer and less than one-third have Internet access at home. At most, about one-half of this patient population would use a clinic-based Web site to acquire health information. Slightly higher results were previously reported in a study of primary caregivers of pediatric patients or patients aged 16 years or older. Results from this study showed that 58.9% of study participants reported having a computer or some type of Internet connection [14].

By far, the strongest independent factor associated with intended Web site use was having Internet access at home. (Table 2) We observed that 32.1% of survey respondents have Internet access at home (Table 1). This figure is within the range of previously

reported results from a 1999 study of Internet access of genitourinary patients (range 31% - 52%) [15].

Simply having a home computer was not as strongly associated with intended Web site use as having home Internet access. These results suggest that Internet access outside the home, such as at the workplace or at public libraries, may not be conducive to accessing health information, although a variable explicitly representing such access was not actually included in the model. One possible explanation for this phenomenon is that Web site users may prefer the privacy of their own homes and computers in accessing potentially sensitive health information. Almost half of genitourinary patients reported difficulty accessing Internet sites with privacy [15]. This may reflect real or perceived intrusions such as viewing a user's computer display screen or even the possibility of electronic monitoring of a user's trail of Web sites accessed in cyberspace [16,17].

Patients greater than 65 years of age were less likely to report intended Web site use, even after adjusting for such factors as having a home computer and Internet access. (Table 2) This finding indicates that older patients may be more resistant to non-traditional modes of receiving health information and care, or perhaps less educated or interested in computer usage. It is also possible that diseases and functional impairments in the elderly may limit their ability to access and view Web-based health information [18]. This may represent an important barrier in making online health communication an integral part of future health care delivery for chronic, debilitating conditions.

Characteristics such as gender, marital status, and having children were not associated with intended Web site use. These findings, particularly with regard to marital status and children, suggest that intended Web site users may be more interested in acquiring information about personal health matters rather than those of spouses or children. The lack of an association between intended Web site use and health insurance status suggests that Web sites are not currently an important alternative source of health information for those not having health insurance.

There are several limitations of the present study that should be noted. Although the possibility of selection bias among

respondents cannot be dismissed, the relatively high response rate achieved in the survey helps minimize its likelihood. However, our results should be extrapolated to other clinic populations with caution because it is unlikely that our survey respondents are representative of the general population, or even of family practice patients in other health care settings. There are also limitations attributable to the survey instrument. For example, data were self-reported and not verified in any manner. Further, there is additional uncertainty because we asked about intended use of a hypothetical Web site rather than current or past use of an existing Web site. Finally, to minimize potential barriers to survey response, we elected not to collect potentially sensitive information such as race/ethnicity, educational level, and income.

It has been noted that the focus of traditional medical informatics is shifting from health professionals to patients, a trend which coincides with the desire of most patients to assume greater responsibility for their health, with the emphasis on public health and prevention [18]. The results of this study indicate that more pervasive Internet access at home is needed to facilitate the public health approach to health information and that barriers to using the Web among older patients must be overcome if they are to become more proactive partners in family practice.

Acknowledgments

We would like to thank Carol Pruet, Senior Administrative Assistant, for her support with the survey and data management.

Conflicts of Interest

None declared.

References

1. Blumenthal D. The future of quality measurement and management in a transforming health care system. *JAMA* 1997 Nov 19;278(19):1622-1625. [Medline: [98036278](#)] [doi: [10.1001/jama.278.19.1622](#)]
2. Johnston C. Psychiatrist says counselling via e-mail may be yet another medical use for Internet. *CMAJ* 1996 Dec 1;155(11):1606-1607. [Medline: [97115440](#)]
3. Borowitz SM, Wyatt JC. The origin, content, and workload of e-mail consultations. *JAMA* 1998 Oct 21;280(15):1321-1324. [Medline: [99008441](#)] [doi: [10.1001/jama.280.15.1321](#)]
4. Eysenbach G, Diepgen TL. Responses to unsolicited patient e-mail requests for medical advice on the World Wide Web. *JAMA* 1998 Oct 21;280(15):1333-1335. [Medline: [99008444](#)] [doi: [10.1001/jama.280.15.1333](#)]
5. Licciardone JC, Herron KM, Clark AJ, Squires D. Clinic-based health information Web site for international travelers. *JAMA* 1998 Oct 21;280(15):1310. [Medline: [99008438](#)] [doi: [10.1001/jama.280.15.1310](#)]
6. Kassirer JP. The next transformation in the delivery of health care. *N Engl J Med* 1995 Jan 5;332(1):52-54 [FREE Full text] [Medline: [95082840](#)] [doi: [10.1056/NEJM199501053320110](#)]
7. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: a public highway or a private road? *JAMA* 1998 Oct 21;280(15):1371-1375. [Medline: [99008453](#)] [doi: [10.1001/jama.280.15.1371](#)]
8. Agbamu DA, Sim E. Public health information on World Wide Web is hard to find. *BMJ* 1997 Nov 29;315(7120):1469. [Medline: [98079317](#)]
9. Ferguson T. Health online and the empowered medical consumer. *Jt Comm J Qual Improv* 1997 May;23(5):251-257. [Medline: [97323227](#)]
10. Lindberg DA, Humphreys BL. Medicine and health on the Internet: the good, the bad, and the ugly. *JAMA* 1998 Oct 21;280(15):1303-1304. [Medline: [99008430](#)] [doi: [10.1001/jama.280.15.1303](#)]
11. Robinson C, Flowers CW, Alperson BL, Norris KC. Internet access and use among disadvantaged inner-city patients. *JAMA* 1999 Mar 17;281(11):988-989. [Medline: [99184236](#)] [doi: [10.1001/jama.281.11.988-a](#)]
12. Krishna S, Balas EA, Spencer DC, Griffin JZ, Boren SA. Clinical trials of interactive computerized patient education: implications for family practice. *J Fam Pract* 1997 Jul;45(1):25-33. [Medline: [97372855](#)]

13. Lewis D. Computer-based approaches to patient education: a review of the literature. *J Am Med Inform Assoc* 1999;6(4):272-282. [PMC: [10428001](#)] [Medline: [99354955](#)]
14. Mandl KD, Feit S, Peña BM, Kohane IS. Growth and determinants of access in patient e-mail and Internet use. *Arch Pediatr Adolesc Med* 2000 May;154(5):508-511. [Medline: [20265584](#)]
15. Ross J, Chapman C, Murray C, Stevenson M, Natin D, Rogstad K. How much interest is the Internet to patients? *Sex Transm Infect* 2000 Oct;76(5):393-394 [[FREE Full text](#)] [Medline: [21022634](#)] [doi: [10.1136/sti.76.5.393](#)]
16. Frisse ME. What is the Internet learning about you while you are learning about the Internet? *Acad Med* 1996 Oct;71(10):1064-1067. [Medline: [97320908](#)]
17. Larkin M. Web gears up for people with disabilities. *Lancet* 2000 Jul 8;356(9224):142. [Medline: [20417246](#)] [doi: [10.1016/S0140-6736\(05\)73158-5](#)]
18. Eysenbach G. Consumer health informatics. *BMJ* 2000 Jun 24;320(7251):1713-1716 [[FREE Full text](#)] [Medline: [20323060](#)] [doi: [10.1136/bmj.320.7251.1713](#)]

submitted 18.04.01; peer-reviewed by G Eysenbach, H van der Slikke; revised version received 14.05.01; accepted 15.05.01; published 17.05.01.

Please cite as:

Smith-Barbaro PA, Licciardone JC, Clarke HF, Coleridge ST
Factors Associated with Intended Use of a Web Site Among Family Practice Patients
J Med Internet Res 2001;3(2):e17
URL: <http://www.jmir.org/2001/2/e17/>
doi: [10.2196/jmir.3.2.e17](#)
PMID: [11720959](#)

© Peggy A Smith-Barbaro, John C Licciardone, Howard F Clarke, Samuel T Coleridge. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 17.5.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Original Paper

A Framework for an Institutional High Level Security Policy for the Processing of Medical Data and their Transmission through the Internet

Christos Ilioudis¹; George Pangalos¹

Aristotle University of Thessaloniki, Thessaloniki, Greece

Corresponding Author:

Christos Ilioudis

Abstract

Background: The Internet provides many advantages when used for interaction and data sharing among health care providers, patients, and researchers. However, the advantages provided by the Internet come with a significantly greater element of risk to the confidentiality, integrity, and availability of information. It is therefore essential that Health Care Establishments processing and exchanging medical data use an appropriate security policy.

Objective: To develop a High Level Security Policy for the processing of medical data and their transmission through the Internet, which is a set of high-level statements intended to guide Health Care Establishment personnel who process and manage sensitive health care information.

Methods: We developed the policy based on a detailed study of the existing framework in the EU countries, USA, and Canada, and on consultations with users in the context of the Intranet Health Clinic project. More specifically, this paper has taken into account the major directives, technical reports, law, and recommendations that are related to the protection of individuals with regard to the processing of personal data, and the protection of privacy and medical data on the Internet.

Results: We present a High Level Security Policy for Health Care Establishments, which includes a set of 7 principles and 45 guidelines detailed in this paper. The proposed principles and guidelines have been made as generic and open to specific implementations as possible, to provide for maximum flexibility and adaptability to local environments. The High Level Security Policy establishes the basic security requirements that must be addressed to use the Internet to safely transmit patient and other sensitive health care information.

Conclusions: The High Level Security Policy is primarily intended for large Health Care Establishments in Europe, USA, and Canada. It is clear however that the general framework presented here can only serve as reference material for developing an appropriate High Level Security Policy in a specific implementation environment. When implemented in specific environments, these principles and guidelines must also be complemented by measures, which are more specific. Even when a High Level Security Policy already exists in an institution, it is advisable that the management of the Health Care Establishment periodically revisits it to see whether it should be modified or augmented.

(*J Med Internet Res* 2001;3(2):e14) doi:[10.2196/jmir.3.2.e14](https://doi.org/10.2196/jmir.3.2.e14)

KEYWORDS

High Level Security Policies, Internet Security, Security of Health Care Information

Introduction

A High Level Security Policy (HLSP) is a set of high-level statements intended to guide Health Care Establishment (HCE) personnel who are involved in the processing and management of sensitive health care information. It provides a set of mandatory regulations to ensure adequate security of personal health information processed by health information systems. "High level" in this context means that the HLSP states *what* should be done to implement security efficiently; however, it does not provide technical details on *how* to do this.

We have previously reported in detail the set of acceptable technical measures that are needed to implement an Internet security policy and we have classified them into categories, such as: encryption approaches, Web server usage, mail usage, and protection from virus and interactive software [1]. This paper defines a suitable HLSP for Health Care Establishments and establishes the basic security requirements that must be addressed in order to use the Internet to safely transmit patient and other sensitive health care information.

The Internet provides unprecedented opportunities for interaction and data sharing among health care providers,

patients, and researchers. However, the advantages provided by the Internet come with a significantly greater element of risk to the confidentiality and integrity of information [2]. It is therefore essential that the Health Care Establishments develop and implement an appropriate HLSP for processing medical data and transmitting this data through the Internet.

The HLSP should be used as a reference for a wide variety of information security and privacy activities, including establishing user access privileges, and investigating security and privacy threats. The HLSP refers primarily to the people involved (including patients, doctors, administrators, and health care authorities) and the data objects that should be protected (including medical records and communication data). The HLSP should be fully adopted to be effective; in addition, conformance to its regulations should be made mandatory for all members of staff.

This work has taken place in the context of the Intranet Health Clinic (IHC) project, which is an international project involving EU (European Union) member countries and Canada. The IHC concerns a deployment of a secure Internet-based application for patient care using Internet-based advanced multimedia techniques. The aim is to offer users of health services high-quality care over inexpensive communication pathways, using Internet-based, interactive communication tools. IHC addresses patients' needs in three key health domains (oncology, respiratory diseases, and obstetrics/gynecology), along with Canadian rheumatic-disease patients, as they seek health services in a complex regional environment of large tertiary-level hospitals, secondary-level hospitals, remote primary-level health care centers, and homes. The IHC is intended to help patients discharged from a tertiary-level health care organization (eg a highly specialized hospital) who must be effectively followed-up by the primary-level physician in a geographically remote area like the many small isolated islands of Greece.

The IHC services involve image and audio transmission, Web-based education, and Intranet-multimedia patient records. The users of the application are patients and their family members, and health professionals at all levels of health care delivery (primary, secondary, and tertiary care).

Methods

Security in health care automated information systems can be conceptually viewed at four distinct levels of abstraction: *generic principles* (that are society-dependent and culture-dependent); *principles* (that are administration-dependent); *guidelines* (that are technology-dependent) and *measures* (that are installation-dependent). The HLSP addresses the two middle levels of abstraction: *principles* and *guidelines*. Thus, an HLSP depends on generic principles and must be complemented by measures [3].

The HLSP in this document provides a set of mandatory regulations to ensure adequate security of personal information processed by the health care information systems. We developed the proposed HLSP by a top-down approach. More specifically, *principles* were first derived as a result of: considering what the functional model of a secure Health Care Establishment should

be; analyzing and adapting relevant similar efforts of international bodies from the EU, USA, and Canada; and consulting with Health Care Establishment users in the context of the IHC project mentioned above [2]. Then, *guidelines* were developed, by detailing principles.

In addition to our own work and experience [2,3,4,5], the proposed HLSP has also been based on a detailed study of the related recommendations from various significant security and standard groups, mainly from the EU countries, USA, and Canada. More specifically, this paper has also taken into account major directives, technical reports, recommendations, and specific descriptions that are related to the protection of individuals with regard to the processing of personal data, the protection of medical data, and the protection of privacy and medical data on the Internet [6,7,8,9,10,11,12,13,14,15,16,17,18,19].

The proposed principles and guidelines have been made as generic and open to specific implementations as possible, to provide for maximum flexibility and adaptability to local environments. It is clear however that these principles and guidelines can only serve as reference material for developing an appropriate HLSP in a specific implementation environment. When implemented in specific environments, these principles and guidelines must also be complemented, as seen earlier, by the appropriate measures, which are installation dependent.

Results

The result is the proposal of a suitable HLSP for Health Care Establishments. The proposed HLSP includes a set of 7 principles and 45 guidelines, which are presented below.

1. Limited Data Circulation Principle

P1. All personal health data are considered sensitive and should be protected with care. Circulation of personal health data should be according to the regulations set out in the Health Care Establishment.

Related Security Guidelines

G1.1. Purpose

The circulation of personal health data should take place only for Health Care Establishment purposes.

G1.2. Informed consent

The explicit and informed consent, written or recorded, of the data subject is mandatory for the disclosure of named data about this patient.

G1.3. Data release for research purposes

The release of health data for research purposes should be non-identifiable with a patient.

G1.3. Data confidentiality

All Health Care Establishment users should ensure that, in any dealings with the media, the patient's right to data confidentiality is fully safeguarded and that the patient's free and informed consent is always obtained prior to any release of the data to the media.

G1.4. Personal health data transmission

Personal health data transmission should be provided only when necessary and only for purposes of the Health Care Establishment.

G1.5. Health data storage limitation

Personal health data should be kept in a form that permits identification of the patient concerned for no longer than is necessary for the purpose for which the data are stored; when the purpose no longer exists, the data should be erased.

G1.6. Data release for educational purposes

The release of health data for educational purposes should be non-identifiable with a patient.

2. Security Regulations Principle

P2. Appropriate measures should be taken for the security of health data and for the protection of the privacy of the patients, aiming at preventing:

- denial of the services of the system,
- accidental or deliberate destruction of data,
- unauthorized access to, or disclosure of, data,
- accidental or deliberate alteration of data,
- unauthorized creation of data.

These measures comprise technical, organizational, personnel management (procedural), and physical security measures.

Related Security Guidelines

G2.1. Data categorization

Personal health data should be characterized within general categories, according to the security requirements of the data.

G2.2. Identifiable users

Each Health Care Establishment user needs to be recognized and identified by the user's name and function so that any patient receiving hospital care and all users of the health care information system can recognize the person to whom they transmit data, or from whom they receive data, or to whom they pass control of information systems.

G2.3. Health data integrity

Technical experts should ensure the integrity of personal health data. The use of integrity mechanisms, such as checksums, can guarantee that data have not been altered or destroyed in an unauthorized manner.

G2.4. Organizational issues

The regulations should include articles applicable to the organization and staff, such as:

- the obligation for computer staff to comply with their professional code of conduct and with the sanctions applicable in the event of non-compliance,
- designation or appointment of one person for each Health Care Establishment, with responsibility for the application of the data security principles and guidelines,
- appointment of a person responsible for data security in operations, programming, communication, filing, and

similar areas (this person is not necessarily different from the one mentioned in the previous item in this list).

G2.5. Staff reminders

The security regulations should remind staff of patient's rights regarding the circulation of personal health data.

G2.6. Separable data

The medical records must be designed to enable the separation of data according to their nature (identifiers, administrative data, medical data, and demographic data), in a logical fashion.

G2.7. Secure transmission

Methods ensuring an appropriate level of security should be chosen for the transmission of personal health data within the Health Care Establishment Intranet.

G2.8. Access-rights limitation

The basic principles governing access to personal health data are the need-to-know requirements.

G2.9. Limited access

The number of user categories, in the Health Care Establishment information system, having access to personal health data should be limited to the minimum.

G2.10. Time-limited and place-limited operations

For each access profile there should be specified the associated operations that are possible (including validation, visual display, printing, copying, and statistical processing), the location within which certain of the associated operations may be carried out, and the period within which or deadline before which certain of the associated operations may be carried out.

G2.11. Access-rights procedure

Procedures providing for restrictions on access in time and space should exist. If the means for implementing these restrictions is an access-rights table of the Health Care Establishment user categories, then this should be established according to the specialty, function, job domain, hierarchy position, and intent of each user category, in connection with the category of data that is intended to be accessed.

G2.12. Monitoring facility

Computerized health information systems should record each access to the Health Care Establishment information system and have an appropriate facility to monitor details of, for example: user, date, time and place of access, operation, and nature of information.

G2.13. Improvement of regulations

The security regulations should include procedures for following-up, monitoring, and improving them.

G2.14. Encouraging security improvement

Trials of technology, software, and applications for protecting security and privacy should be supported.

G2.15 Documented security measures

A detailed description covering all the technical aspects of security of the Health Care Establishment information systems, both from a physical and a logical point of view, and all existing security procedures in force, should be documented in detail and made available to the Health Care Establishment sites.

G2.16. Security policy

A health-data technical security policy should be adopted by each Health Care Establishment site. The policy should be concerned with confidentiality, integrity, and availability of the data, as well as with accuracy, reliability, performance, and functional correctness of the information system.

G2.17. Definition of the ultimate purpose

The regulations should include the ultimate purpose of any information system that functions within the Health Care Establishment, and the type of data that it contains.

G2.18. Database security

For storing personal health data in database environments, a database-specific security policy should be established. This policy should state which kind of communication channels between users can be established, requirements for the availability of certain facilities of these channels, and requirements for the separation and non-interference of these channels.

G2.19. Teleconference Service Security

This policy should state which kinds of data are permitted to travel through teleconference services. In addition, the requirements of confidentiality and of user identification must be satisfied.

3. Patient's Rights Principle

P3. Information systems in the health care field exist and operate to serve patients according to human rights and freedoms and according to constitutional provisions pertaining to civil rights. These rights are consistent with national law, but may be additional to rights embodied in it.

Related Security Guidelines

G3.1. Purpose

All regulations, policies, and measures about the preservation of security of personal health data should respect human rights and freedoms, and the pertinent constitutional provisions. In no case may these rights be neglected while enforcing any security-related function.

G3.2. Knowledge of stored health data

The patient has the right to obtain, at reasonable intervals and without excessive delay or expense, confirmation of whether that patient's personal health data are stored in a file. The patient has the right to be given such data in a form that is intelligible to the patient.

G3.3. Knowledge of a processing operation

The patient has the right to know of the existence of a processing operation, its purposes, the categories of data concerned, and

any third parties or categories of third parties to whom the data are to be disclosed.

G3.4. Processing of health data

The processing of personal health data should be, in principle, viewed and treated as an exceptional means to obtain information. Whoever asks for such data should be obliged to explain the need for the data: why and to what extent particular purposes cannot be fulfilled by using other information.

4. Health Care Service Providers' Obligations Principle

P4. Service providers in Health Care Establishments exist, operate, and have responsibilities according to the law and according to the regulatory security framework.

Related Security Guidelines

G4.1. Proper use of data

Health Care Establishment providers are responsible for proper use of data. They should declare: the kind of data they collect, process, and store; and the way of and purpose for collecting, processing, and storing the data. In addition, the introductory page of the data must have a clear statement about privacy policy.

G4.2. Technical and organizational measures

Health Care Establishment providers must take the appropriate technical and organizational measures to protect personal data against accidental or illegal destruction, accidental loss, and any form of unauthorized processing (including access, alteration, and communication).

Such measures shall ensure an appropriate level of security taking account, on the one hand, of the technical state of the art and, on the other hand, of the sensitive nature of medical data and the evaluation of potential risks.

These measures shall be reviewed periodically.

G4.3. Data separation

In order to develop effective security policy, the information produced or processed by an Health Care Establishment must be separated into: identifiers and data relating to the identity of individuals, administrative data, medical data, and demographic data.

5. Quality of Health Data Principle

P5. Personal health data should be processed in a way that ensures a high quality of integrity and accuracy.

Related Security Guidelines

G5.1. Accuracy

Personal health data should be accurate and, where necessary, kept up to date; every step must be taken to ensure that data that are inaccurate or incomplete, for the purposes for which they were collected, are erased or corrected.

G5.2. Protection responsibility

The Health Care Establishment is responsible for maintaining the integrity and correctness of personal health data so that it is free from both accidental and malicious errors.

G5.3. Quality evaluation

Measures should be specified to ensure the regular evaluation by Health Care Establishment staff of the quality of the software used.

6. Medical and Epidemiological Research Principle

P6. Requests for health data identifiable with a person - and for a purpose previously unspecified - can be addressed, if the informed and freely-given consent of the person concerned has been obtained and if the person has been informed of rights of refusal, access, and correction.

Related Security Guidelines

G6.1. Purpose

Medical and epidemiological research promotes human knowledge, thereby improving the quality of health care; therefore, epidemiological research should be encouraged, stimulated, and promoted as strongly as possible. However, preservation of confidentiality and respect for patient's rights should take precedence over any scientific purpose. Thus, release or disclosure of personal health data should be made only when specific predetermined regulations are observed.

G6.2. Erasure of research data

The patient has the right to obtain correction of inaccurate or incomplete personal health data, or the erasure or blocking of such data.

G6.3. Anonymity

Personal health data to be used for research purposes should be anonymous.

G6.4. Communication of research data

Personal health data processed for a medical or an epidemiological research project should neither be used nor disclosed for another research project or for other purposes.

7. Transmission of Sensitive Health Care Data over Internet Principle

P7. Sensitive Health Care Establishment information sent through the Internet must be accessed only by authorized people. The Internet can be used for the transmission of sensitive health care data, provided that: a suitable Internet Security Policy is in place, an acceptable method of encryption is utilized to provide for confidentiality and integrity of this data, and suitable authentication or identification procedures are employed to assure that both the sender and recipient of the data are known to each other and are authorized to receive and decrypt such information.

Related Security Guidelines

G7.1. Acceptable technologies

To make the Internet adequately safe for Health Care Establishments (that is, to ensure that data travel safely through

the Internet, are only disclosed to authorized parties, and are not inappropriately disclosed or modified) technologies must be used that allow users to prove they are who they say they are (identification and authentication) and allow the organized scrambling of data (encryption).

G7.2. Encryption

To make the Internet adequately safe for Health Care Establishments, a complete Internet communications implementation must include adequate encryption. Encryption must be at a sufficient level of security to protect against the cipher being readily broken and the data compromised. The length of the key (a secret value used to encrypt and decrypt messages) and the quality of the encryption framework and algorithm must be increased over time, as new weaknesses are discovered and as processing power increases.

G7.3. Authentication and Identification

To make the Internet adequately safe for Health Care Establishments, a complete Internet communications implementation must employ authentication or identification of communications partners. Public key certificates can facilitate authentication and identification services through the Internet.

G7.4. Integrity

To make the Internet adequately safe for Health Care Establishments, they should be required to be able to provide corroboration that data have not been altered or destroyed during transmission through the Internet.

G7.5. Availability

To make the Internet adequately safe for Health Care Establishments, a complete Internet communications implementation must include adequate security measures to improve availability of Internet services. Information should be available when needed at appropriate places and Health Care Establishment information systems have to be protected from denial-of-service attacks.

G7.6. Non repudiation

To make the Internet adequately safe for Health Care Establishments, a complete Internet communications implementation must include adequate security measures to improve non-repudiation, so that responsibility for actions cannot be denied. These measures support the provision of evidence that will prevent a participant in an action from convincingly denying responsibility for the action.

Discussion

This paper defines a suitable High Level Security Policy (HLSP) for Health Care Establishments and proposes the basic security requirements that must be addressed to use the Internet to safely transmit patient and other sensitive health care information. It has been based on a detailed study of the related recommendations from the more-significant security and standard groups, mainly from the EU countries, USA, and Canada. These recommendations are related to: the protection of individuals with regard to the processing of personal data,

the protection of medical data, and the protection of privacy and medical data on the Internet. Therefore, the proposed HLSP satisfies the security requirements that originate from European Law and from other international recommendations. During the development of the proposed HLSP, we considered draft laws and prestandards, to achieve a state-of-the-art security policy.

There are two different security frameworks from the EU and Canada. Since these two regions have different legal frameworks, technological developments, and levels of users' concern about the security of medical data transmitted through the Internet, the proposed HLSP has an advantage. Works corresponding to the proposed HLSP include ISHTAR and Health Level Seven (HL7) security policy.

The HLSP is primarily intended for large Health Care Establishments in Europe, USA, and Canada. It should be fully adopted to be effective and conformance to its principles and guidelines should be made mandatory for all members of staff. Even when an HLSP already exists, it is advisable that the management of the Health Care Establishment periodically revisits the HLSP to see whether it should be modified or augmented.

Currently, there is no specific national law on the protection of privacy and medical data on the Internet. We expect that in the future there will be important laws and recommendations that will affect the protection of medical data transmitted through the Internet.

Acknowledgments

This work was partially supported by the Intranet Health Clinic project (HC- 4012), Telematics Applications Programme, Health Care sector.

Conflicts of Interest

None declared

References

- Ilioudis C, Pangalos G. Development of an Internet Security Policy for health care establishments. *Med Inform Internet Med* 2000;25(4):265-273 [FREE Full text] [Medline: 21039959] [doi: 10.1080/146392300455567]
- Pangalos G; Intranet Health Clinic project. Intranet Health Clinic project, WP6 deliverable: Security, Aristotle University of Thessaloniki - Greece. 1999. URL: <http://www.biomed.ntua.gr/Intraclinic> [accessed 2001 Apr 3]
- Pangalos G. Security of Medical Database Systems for Health Care IT and Security Personnel. In: , editor; The SEISMED ConsortiumThe SEISMED Consortium. *Data Security for Health Care*. Amsterdam: IOS Press; Jan 1, 1996, Vol. 2.
- Pangalos G. Health Care Security and Privacy in the Information Society, EU, ISIS programme, MEDSEC project Deliverable D14. Thessaloniki, Greece: Aristotle University of Thessaloniki; 1998.
- Ilioudis C, Pangalos G. Security issues for Web based Electronic Health Care Record. Presented at: Third European Conference On Electronic Health Records (EuroRec'99); Seville, Spain.
- Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. 1995 Nov 23. URL: http://europa.eu.int/comm/internal_market/en/media/dataprot/law/index.htm [accessed 2001 Apr 3]
- ; Council of Europe. Recommendation No R (95) 4 and Explanatory Memorandum of the Protection Of Personal Data in the Area of Telecommunication Services, with Particular Reference to Telephone Services. 1995 Feb 7. URL: [http://www.coe.fr/dataprotection/rec/r\(95\)4e.htm](http://www.coe.fr/dataprotection/rec/r(95)4e.htm) [accessed 2001 Apr 3]
- ; Council of Europe. Recommendation No R (97) 5 and Explanatory Memorandum of the Committee of Ministers to Member States on the Protection of Medical Data. 1997 Feb 13. URL: [http://www.coe.fr/dataprotection/rec/r\(97\)5e.htm](http://www.coe.fr/dataprotection/rec/r(97)5e.htm) [accessed 2001 Apr 3]
- ; Council of Europe. Recommendation No. R (99) 5 of the Committee of Ministers to Member States for the Protection of Privacy on the Internet. 1999 Feb 23. URL: <http://www.coe.fr/dataprotection/rec/elignes.htm> [accessed 2001 Apr 3]
- ; European Committee for Standardization, Technical Committee for Health Informatics, (CEN/TC251). Document N98-110, Health Informatics - Framework for security protection of health care communication, Draft CEN Report. 1998. URL: <http://www.cen251.org/TCMeet/Doclist/doclist1998.htm> [accessed 2001 Apr 3]
- ; European Committee for Standardization, Technical Committee for Health Informatics, (CEN/TC251). Security for healthcare communication, documents N99-046, N99-047, and N99-048. 1999. URL: <http://www.cen251.org/TCMeet/Doclist/doclist1999.htm> [accessed 2001 Apr 3]
- ; Canadian Standards Association. Model Code for the Protection of Personal Information. 1996 Apr. URL: <http://www.privacyexchange.org/buscodes/standard/CanadianStandards.html> [accessed 2001 Apr 3]
- ; Canadian Organization for the Advancement of Computers in Health (COACH). Security and Privacy Guidelines for Health Information Systems. Edmonton, Canada: Healthcare Computing & Communications Canada Inc; 1995.
- Pangalos G. Examination of the Implications of the EU Data Protection Directive to a TrustHealth Information system, EU, INFOSEC/trustHealth project, Deliverable D6.2. Thessaloniki, Greece: Aristotle University of Thessaloniki; 1996.
- ; US Department of Health and Human Services. Security and electronic signature standard. *Fed Regist* 1998 Aug 12;63(155).

16. ; US Health Care Financing Administration, Security And Standards Group, Department of Health and Human Services. HCFA Internet Security Policy. 1998 Nov 24. URL: <http://www.hcfa.gov/security/iseclply.htm> [accessed 2001 Apr 3]
17. ; Department of Health and Wellness of Alberta, Canada. Report and Recommendations from the Provincial Steering Committee on the Health Information Protection Act. 1998 Jun 30. URL: <http://www.health.gov.ab.ca/public/document/hipa/index.htm> [accessed 2001 Apr 3]
18. ; Government of Alberta, Canada. Freedom of Information and Protection of Privacy (FOIP) Act: Policy and Practices. 1998.
19. ; US Department of Health and Human Services. Health Insurance Portability and Accountability Act of 1996. 1996 Aug 21. URL: <http://aspe.os.dhhs.gov/admsimp/pl104191.htm> [accessed 2001 Apr 3]

Abbreviations

EU: European Union

HCE: Health Care Establishment. An establishment where medical services are provided or health education, research, medical-training or prevention activities are conducted.

HLSP: High Level Security Policy. A set of high-level statements intended to guide those members of the Health Care Establishment personnel who are involved in the processing and management of sensitive health care information.

IHC: Intranet Health Clinic project. A deployment of a secure Internet-based application for patient care, using Internet-based advanced multimedia techniques.

submitted 26.09.00; peer-reviewed by V Della Mea; comments to author 22.02.01; accepted 22.03.01; published 06.04.01.

Please cite as:

Ilioudis C, Pangalos G

A Framework for an Institutional High Level Security Policy for the Processing of Medical Data and their Transmission through the Internet

J Med Internet Res 2001;3(2):e14

URL: <http://www.jmir.org/2001/2/e14/>

doi: [10.2196/jmir.3.2.e14](https://doi.org/10.2196/jmir.3.2.e14)

PMID: [11720956](https://pubmed.ncbi.nlm.nih.gov/11720956/)

© Christos Ilioudis, George Pangalos. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 6.4.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Viewpoint

Evidence-based Patient Choice and Consumer health informatics in the Internet age

Gunther Eysenbach, MD; Alejandro R Jadad, MD DPhil FRCPC

Corresponding Authors:

Gunther Eysenbach, MDHead
Research Unit for Cybermedicine and eHealth
Department of Clinical Social Medicine
University of Heidelberg
Heidelberg 69115
Germany
Email: ey@yi.com

Alejandro R Jadad, MD DPhil FRCPCDirector
Rose Family Chair in Supportive Care
Professor, Department of Health Administration and Anesthesiology
Program in eHealth Innovation
University Health Network
University of Toronto
Toronto ON
Canada
Email: ajadad@uhnres.utoronto.ca

Abstract

In this paper we explore current access to and barriers to health information for consumers. We discuss how computers and other developments in information technology are ushering in the era of consumer health informatics, and the potential that lies ahead. It is clear that we witness a period in which the public will have unprecedented ability to access information and to participate actively in evidence-based health care. We propose that consumer health informatics be regarded as a whole new academic discipline, one that should be devoted to the exploration of the new possibilities that informatics is creating for consumers in relation to health and health care issues.

(*J Med Internet Res* 2001;3(2):e19) doi:[10.2196/jmir.3.2.e19](https://doi.org/10.2196/jmir.3.2.e19)

KEYWORDS

Consumer Health Informatics; Evidence-based medicine; Patient Education; Patient Participation; Physician-Patient Relations; Internet; Decision-Making

Introduction

For the past 100,000 years, people have been able to produce, distribute, and process information in a synchronized manner. About 500 years ago, the situation started to change rapidly. With the advent of the mobile typepress, our ability to produce and distribute information started to accelerate, outpacing our capacity to process information. During the past 10 years, we have witnessed how the Internet and the World Wide Web have led to a hyper-production and hyper-distribution of information, which have clearly overwhelmed our capacity to process it.

In this article we will explore current access to and barriers to further information for consumers. We will discuss how computers and other developments in information technology are ushering in the *era of consumer health informatics*, and the

potential that lies ahead. It is clear that this will be a period in which the public will have unprecedented ability to access information and to participate actively in evidence-based health care.

We propose that consumer health informatics be regarded as a whole new academic discipline, one that should be devoted to the exploration of the new possibilities that informatics is creating for consumers in relation to health and health care issues. In its broadest sense, consumer health informatics should involve the following [1]:

- analysing, formalizing, and modelling consumer preferences and information needs;
- developing methods to integrate these into information management in health promotion, clinical, educational, and research activities;

- investigating the effectiveness and efficiency of computerized information, (tele)communication, and network systems for consumers in relation to their participation in health- and health care-related activities;
- studying the effects of these systems on public health, the patient-professional relationship, and society.

We will discuss the responses that are required of the health care professions and individual practitioners. There are also potentially helpful checks and balances on the nature of information now available to consumers. We will outline some of these and explore how all these developments may come together. None of these developments in information occur in isolation. They must be seen within the context of other changes, particularly the shifting emphasis away from the traditional paternalistic model of health care. These other changes are addressed more fully in other chapters of this book so will not be discussed in detail here. We will describe the development in information availability, but want the reader to place these issues in the broader context of moves towards greater informed choice for consumers in their health care decisions.

Current access to information by consumers: the gap between the ideal and the real

Ideally (as long as they wish), all consumers should be able to access valid and relevant information about their health status. They should be able to judge the advantages and disadvantages of all possible courses of action, according to their values, beliefs, preferences, and their personal circumstances (for example, their perceived state of health, their socio-economic status).

In reality, we are far from this ideal state, as many barriers prevent consumers from accessing the information they need, when they need it, where they need it, and in the amount and format in which they need it. The following is a brief description of some of the most prominent barriers. We do not pretend to include an exhaustive list, but a selection of those that, in our opinion, are preventing consumers from participating meaningfully in evidence-based decision making. We have separated the barriers depending on whether they relate to providers, to the consumers *per se*, to the information available, to the health care system, and to information technology. As a theme in the titles of the following sections we will draw an analogy from the supply of water.

Barriers related to providers: keeping the consumer thirsty

Despite a strong international trend to shift towards a shared decision making model, many consumers in both developed and developing countries still find themselves interacting with providers who favour the 'classical', authoritarian, paternalistic, asymmetrical model of consumer-provider interaction. In these situations, consumer access to information is prevented by health care providers who adopt the role of main purveyors of knowledge. The professional acts not only as the sole holder of the consumer's data but also as the filter for other types of

information needed by the consumer to participate in decisions about their health and health care. In other cases, consumers face providers who prefer an 'informed choice' decision making model, in which they give consumers as much information as they think they need to make a decision, but the professionals do not participate directly in the decision. A shared decision making approach goes beyond this, placing consumers and providers as active participants in the decision making process, with two-way exchange of information and working as partners.

Even if providers wish to shift from the authoritarian or informed models to a shared one, however, many remain unable to do it because of inadequate communication skills, lack of time, or lack of financial incentives. A combination of the above factors may explain why many providers do not even think that consumers could benefit from the Internet. A survey from the US shows striking figures: only 39% of all professionals see the Internet as a valuable health information source for consumers. This sharply contrasts with the value consumers give to web-education: 70% of consumers retrieving health information on the Internet agree that 'the Internet empowers me to make better choices in my life' (*source*: cyberdialogue/findsvp survey, reproduced in Reents and Miller [2]).

Various factors probably contribute to the low esteem in which professionals hold the Internet as an educational tool. These include the (partly justified) concerns about the quality of Internet information and discomfort about having to deal with a consumer who is perhaps better informed than oneself. The Wilson study [3] illustrates the extent of this: an amazing 65% of the family doctors said that the information presented by consumers was new to them (see Table 1).

Barriers related to consumers: a rocky road, few shoes and no maps to find the wells

Lack of easy-to-access sources of high-quality relevant information

Until very recently, databases such as Medline were available only to experts (sometimes not even to them). Although consumers were always 'passively' exposed to health information in the mass media, the possibilities to actively perform targeted literature searches were limited. Not only did consumers have limited insights into and access to the whole body of medical knowledge, but usually they also had virtually no access to their own medical records.

To date, it has been the 'traditional' responsibility of the professional to integrate all types of information in the personal interaction with the consumer. Thus they would give consumers details about their conditions and distil and present the relevant external information on the available options. Increasingly, however, the traditional professional - filter and sole provider of information - is being bypassed by consumers, who now have direct access to both the external evidence and their personal health record (Figure 1). This process is likely to accelerate and evolve quickly, thanks to powerful forces which are shaping health and health care, of which the Internet is perhaps the most prominent [4]. These changes are already facing resistance from the provider community. Many professionals are concerned that consumers may misinterpret information and will not arrive at

the information that is relevant to them (intersection of Figure 1) but get lost in a stew of irrelevant and low-quality information. Vignettes of how the influence of information affects the models of care are illustrated in Figure 2.

Figure 1. Consumer data and external evidence are the two categories of information that need to be integrated by the professional and consumer to arrive at a health care decision. Increasingly, consumers can bypass the professional as a filter (and moderator) and have direct access to parts of this information. This may be problematic, if the consumer accesses not only information that is relevant for their informed decision process, but also low-quality and irrelevant information. At the same time this is also an opportunity for evidence-based health care, as consumers are now able to question the evidence-base of professionals

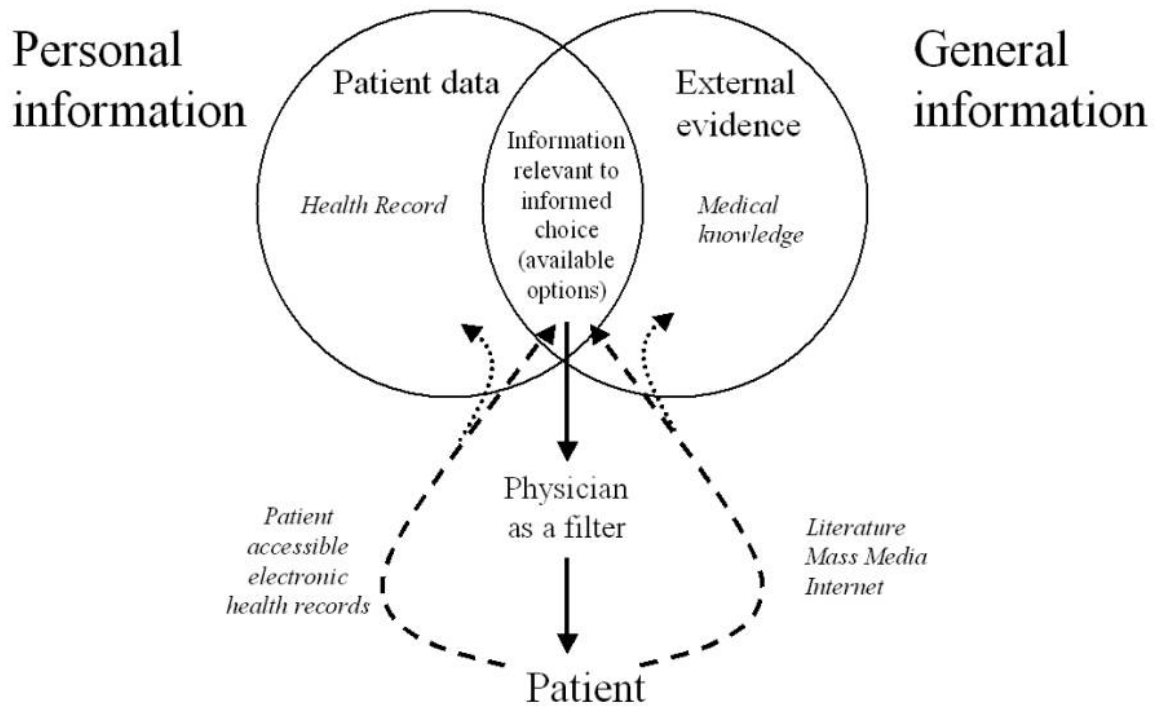


Figure 2. Different models of the consumer-professional relationship: a) paternalistic, b) educational, c) Internet-age, and d) consumer-as-partner

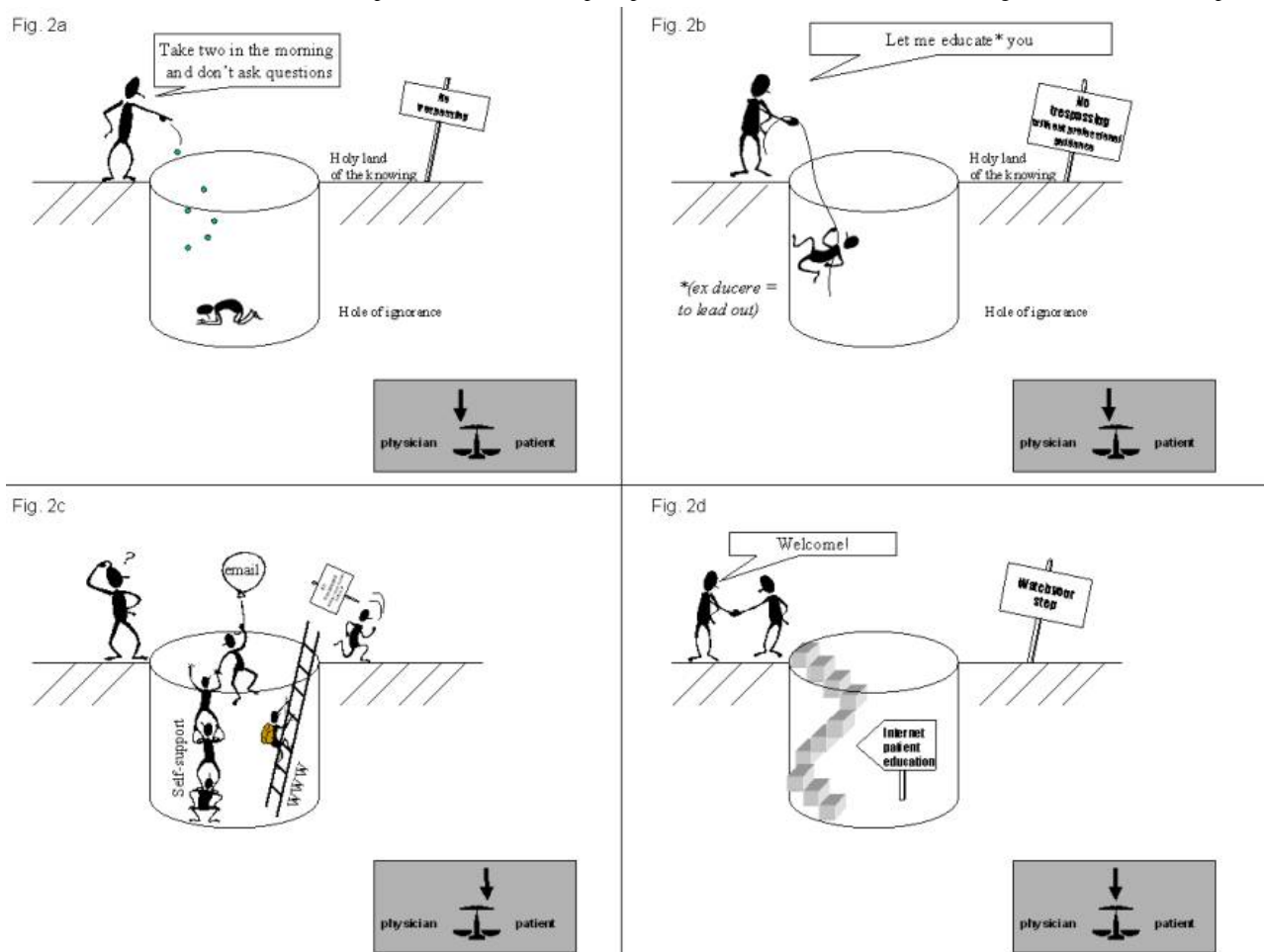


Table 1. Survey among family doctors and practice nurses about consultations with consumers holding Internet health care information

	Family doctor No. of Staff (%)	Practice Nurse No. of Staff (%)
The consumer participates more actively in his/her treatment	65 (78.3%)	26 (83.9%)
The consumer has higher expectations	75 (85.2%)	26 (78.8%)
The information is accurate	59 (73.8%)	24 (75%)
The length of consultation is increased	68 (77.3%)	24 (72.7%)
This type of consumer is a welcome challenge	46 (55.4%)	24 (72.7%)
The consultation is more interactive than usual	43 (50.6%)	22 (68.8%)
The consumer correctly interpreted information	38 (44.7%)	19 (59.4%)
The consumer is more demanding	50 (58.8%)	14 (42.4%)

The problem of low health literacy

Low health literacy frequently impairs consumers' understanding of health messages and limits their ability to care for their health problems [5]. This is a problem especially prevalent among the elderly [6]. Consumers with inadequate health literacy have a complex array of communications difficulties, which may lead to poor health outcomes. Individuals judged to be 'functionally illiterate' (estimated to include 30 to 50% of the adult population in the US and Canada) have been shown to report worse health status and have increased risk of hospitalization [7]. To compound this, much consumer education material has been produced which is at a higher reading level than the estimated

average reading level of the American public [8] and most patient information on the WWW is written at even higher reading levels [9]. Unsurprisingly such material may fail to communicate the basic information intended.

Twentyfive years ago Tudor Hart [10] described the inverse care law, stating that 'the availability of good medical care tends to vary inversely with the need for it in the population served'. In analogy, we may postulate an 'inverse information law' [1] stating that access to appropriate information varies inversely with the need for it. In other words, it is likely that access to high-quality relevant information is particularly difficult for those who would need it most. At present, people with low

health literacy do not benefit from advances in consumer health informatics and cybermedicine, as they lack access to or understanding of these technologies. A sequence can be envisaged in which low health literacy leads to poor health, poor health leads to low income, and low income limits access to modern information technology. Thus, one fundamental problem of telemedicine and using the Internet for health education is that those who are at highest risk of preventable or treatable health problems have the greatest need for information and are the least likely to have access to such technologies [11].

Public policies are needed to actively fight this pervasive inequality. It is also important to realize that there needs to be greater awareness about the problem of health literacy. The American Medical Association's Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs concluded that 'professional and public awareness of the health literacy issue must be increased, beginning with education of medical students and professionals and improved consumer-professional communication skills' [5]. In addition to efforts to increase awareness, we also need to develop better methods of screening consumers to identify those with poor health literacy, more effective health education techniques, and more research on outcomes and costs associated with poor health literacy, and the causal pathway of how poor health literacy influences health.

Limited access to the Internet

Even if there were resources that provided high-quality information easily on the Internet, regardless of their literacy levels, a major barrier that would still need to be overcome is the broader barrier of access, described in detail below ('Barriers related to technology'). Thus, the inverse information law is true both on the macrolevel - the poorest countries have the worst access to information and communication [12] - and on the individual level (microlevel), with disadvantaged individuals within a society having the poorest health, inferior health literacy, and the worst access to information.

Barriers related to the information: hydrants with muddy water

Unlimited access to poorly organized information

In the past, health professionals had to cope with information overload, while consumers had to cope with information deficit. Today, consumers have many opportunities to access information in abundance, through mass media, self-support groups, and particularly the Internet (Figure 2c). The directed, intentional process of active 'health education' (Figure 2b) is now being counteracted by an anarchical process of uncontrolled information retrieval by the consumer.

For the first time in the history of medicine, consumers have equal access to the knowledge bases of medicine - and those 'connected' are making heavy use of this. An example of this is the fact that the number of Medline searches performed by directly accessing the database at the National Library of Medicine increased from 7 million in 1996 to 120 million in 1997, when free public access was opened. The new searches are attributed primarily to 'non-professionals' [13]. It has been argued that 'a driving force behind demand for online health information is the shortage of information easily obtained from

traditional channels' [2]. With the duration of an average consultation still only seven minutes in the UK (and twelve minutes in the US) it comes as little surprise that professionals routinely fail to address the information needs of consumers [4]. While most professionals do not understand or have access to these modern information technologies, or simply lack sufficient time to familiarize themselves with the Internet, consumers have all the time in the world to search the Internet for relevant information.

This new 'reversed' information asymmetry creates new conflicts - the fact that consumers are taking the initiative to look out for the latest research results 'stands on its head the tradition in which a doctor gives orders and the consumer obeys', as an article in the *New York Times* put it. 'And that makes some doctors nervous' [14]. Some of the concern is well founded. It is likely, for instance, that health professionals may find themselves in the middle of unnecessary conflicts if consumers find information on the Internet that is unknown to the professional, contradicts their recommendations, or that suggests the use of an effective intervention that is unavailable.

In a postal questionnaire survey among 160 family doctors and 96 practice nurses in Scotland [3], 58% of doctors and 34% of nurses stated that they have been approached by consumers with Internet health care information. Only 39% of the doctors and 31% of the nurses felt 'positive' about these consumers, the remainder were 'indifferent', 'uncomfortable', or 'not sure'. About half of the respondents were concerned about the reliability of Internet information and a similar percentage were concerned that consumers did not interpret information correctly [3]. On the positive side, the majority of health professionals feel that when consumers bring information they participate more actively in their treatment, that the consultation is more interactive, and that overall 'this type of consumer is a welcome challenge' (see Table 1).

The almost unlimited access to information offered by the Internet also creates other potential problems. Seeking desired information on the Internet is often time-consuming. Consumers often experience confusion and anxiety caused by the virtually unlimited amount of information available, which is poorly organized and has quite variable quality and relevance.

Few mechanisms to control the quality of the information

Currently there is no agreed mechanism for ensuring the accuracy, currency, or completeness of the information presented to consumers [15]. A quality control process, both when preparing information and when accessing it, has been demanded from different sides. A recent review of 54 consumer information materials concluded that 'current information materials for consumers omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties; moreover, many information materials adopt a patronizing tone - few actively promote a participative approach to decision making' [16].

On the Internet, there have been numerous studies evaluating the quality of information given on different venues such as websites [17], newsgroups [18] and email-consultations [19,20].

While the Internet offers a huge amount of health information, many of the authors are not trained in medicine or even health education. In many situations, the intention of information provision is not to educate, but to sell something.

The lack of reliability is a particular concern. In addition to this, the Internet poses special problems for consumers, which have been summarized as 'lack of context' [21], meaning that the Internet poses additional problems for consumers and health professionals to assess and apply the material, compared to critical appraisal of traditional information. This is due to the following characteristics of the Internet [22]:

- There are no clear markers such as traditional publishing which allow consumers to recognize:
 1. the target group of a document (consumers/professionals)
 2. the intention (advertisement or objective information);
- The anonymity (of authors) makes it difficult to appraise information based on the credentials of the authors;
- Internationality: information valid in foreign health care systems may not be applicable locally [23].

These characteristics of the Internet may explain why consumers have difficulties finding information that relates to them and why the majority of physicians say that the consumer has difficulties interpreting information correctly [3]. While it has been pointed out that we still know very little about the impact of the Internet on public health [24], there are many ways that Internet information could do harm [25]:

- Misinformation can lead consumers with life-threatening conditions to lose trust in their provider, and take actions that undermine the effectiveness of their treatment (such as by taking substances that interact in a negative way with prescribed medications).
- Consumers may use their limited time with their health care provider unproductively, or in ways that ultimately increase costs of care, and even abandon a provider delivering high-quality care to pursue ineffective therapies.
- Vulnerable people may also be victimized by biased or incomplete information from those with a financial interest in the information they provide.

Such risks are present in most media, but on the WWW this problem reaches a new dimension.

Barriers related to technology: few pipes, few glasses, and complex taps

If consumers are to take full advantage of the Internet, access to it should be easy, affordable, and available in all settings. This is still far from reality. Despite an unprecedented rate of penetration in developed countries, the majority of people in the world remain without access to computers and the Internet. The Internet is still available to less than 50% of people in North America, the region with the highest proportion of users in the world. In developing countries, the main barriers are the high cost of computers and poor telecommunications infrastructure. In both developed and developing countries, many consumers still perceive computer-based systems as difficult to use.

The end result is that rather than levelling the playing field, the rapid development of the Internet is contributing to widening

inequalities across the world [26]. Even in developed countries, there is some evidence of a similar widening gap across groups with different socio-economic and demographic profiles [12]. There is a clear digital divide between the information rich (such as Whites, Asians/Pacific Islanders, those with higher incomes, those more educated, and dual-parent households) and the information poor (such as those who are younger, those with lower incomes and education levels, certain minorities, and those in rural areas or central cities) [27]. The levels of access appear to be increasing rapidly in other parts of the world, particularly in Western Europe and in the developed countries of Australasia. Although the data are very poor, it seems that the developing world is lagging behind, creating an increasingly wide access gap.

While the information society offers tremendous potential for reducing the knowledge gap between professionals and patients, it also brings a risk of a widening of the gap between those who have access to new technology and those who have been excluded. Therefore the field must not be left to market forces alone and active policy is required to push information technology to those who are underserved [1].

Striving for the ideal: bridging the gaps through information technology

Developing advanced approaches to knowledge representation

So far, most (if not all) of the Internet-based applications to promote transfer of knowledge to consumers are a mere transition from paper-based to electronic-based means to process and distribute information in text form. The true 'revolution' (in the sense of going full circle), however, is likely to come from ongoing and future increases in bandwidth that will enable all people to communicate through the Internet more effectively. The next generation Internet (see www.ngi.gov) will operate at speeds up to a thousand times faster than today. Sight, sound, and even touch will be integrated through powerful computers, displays, and networks. With these developments we will be able to go beyond text to more 'natural' or primal ways of representing and exchanging knowledge. Soon we will be able to put together and deliver relevant and valid information, of different types, using more engaging ways to package the messages and multisensory modes of communication. The effectiveness and efficiency of these new modalities to organize information will be optimized through inexpensive Internet appliances (such as fridges and microwave ovens with Internet access), personal portable or wearable computers, and wireless access to the Internet [28].

Another trend will lead to a 'quality leap': the perspective of 'machine understandable information'. Key to this development is the widespread use of metadata. Recent developments and Internet standards, such as the eXtensible Markup Language (XML), Dublin Core metadata [29], MedPICS [21,22], and RDF (Resource Description Framework), will make relations between information pieces 'understandable' for computers, allowing software for example to perform intelligent searches, filter information automatically, or to tailor information to the

individual. The Web would evolve into a global medical knowledge base that is easily navigable and searchable across languages and continents [30].

Promoting team work

It is time for health professionals 'to embrace the concept of informed consumers and use their web-surfing skills' [31] (see also Table 2) rather than seeing them as threatening intruders trespassing into a forbidden zone. For the providers, this requires the acquisition of skills in the use of the Internet, familiarization with sources of high-quality information [32], and confidence with the use of aids and tools to engage in shared decision making. On a public health level, 'stairways' for the consumer should be built, guiding consumers to high-quality information,

as illustrated in Figure 2d. Examples include 'Healthfinder', a government-sponsored health portal in the US (www.healthfinder.gov) or the National electronic Library for Health (NeLH) in the UK. The latter's mission is 'to improve health and health care, consumer choice, and clinical practice', and it includes NHS Direct Online, a service to provide consumers with information such as 'How can I stay healthy, feel better, and reduce the risk of disease?', 'Do I need to see a doctor for this problem?', and 'How can I learn more about my condition, contribute to my care, and make the best use of health services?' [33]. Clearly, the demand for such information is vast, as can be seen in the large number of patient requests doctors on the Internet receive via email [34,19,35].

Table 2. Suggestions for providers to interact with Internet-literate consumers

Do
<ul style="list-style-type: none">• Try to react in positive manner to information from the Internet• Warn about the variability in the quality and reliability of material from the Internet• Warn about time constraints that may limit your ability to address all the information found on the Internet• Develop a strategy for dealing with Internet information before the encounter (e.g. get consumers to email summary of issues before consultations)• Accept consumer contributions as valuable• Accept that they may find relevant and valid information previously unknown to you.
Don't
<ul style="list-style-type: none">• Be dismissive or paternalistic• Be derogatory of comments made by others on the Internet• Refuse to accept information found on the Internet• Feel threatened

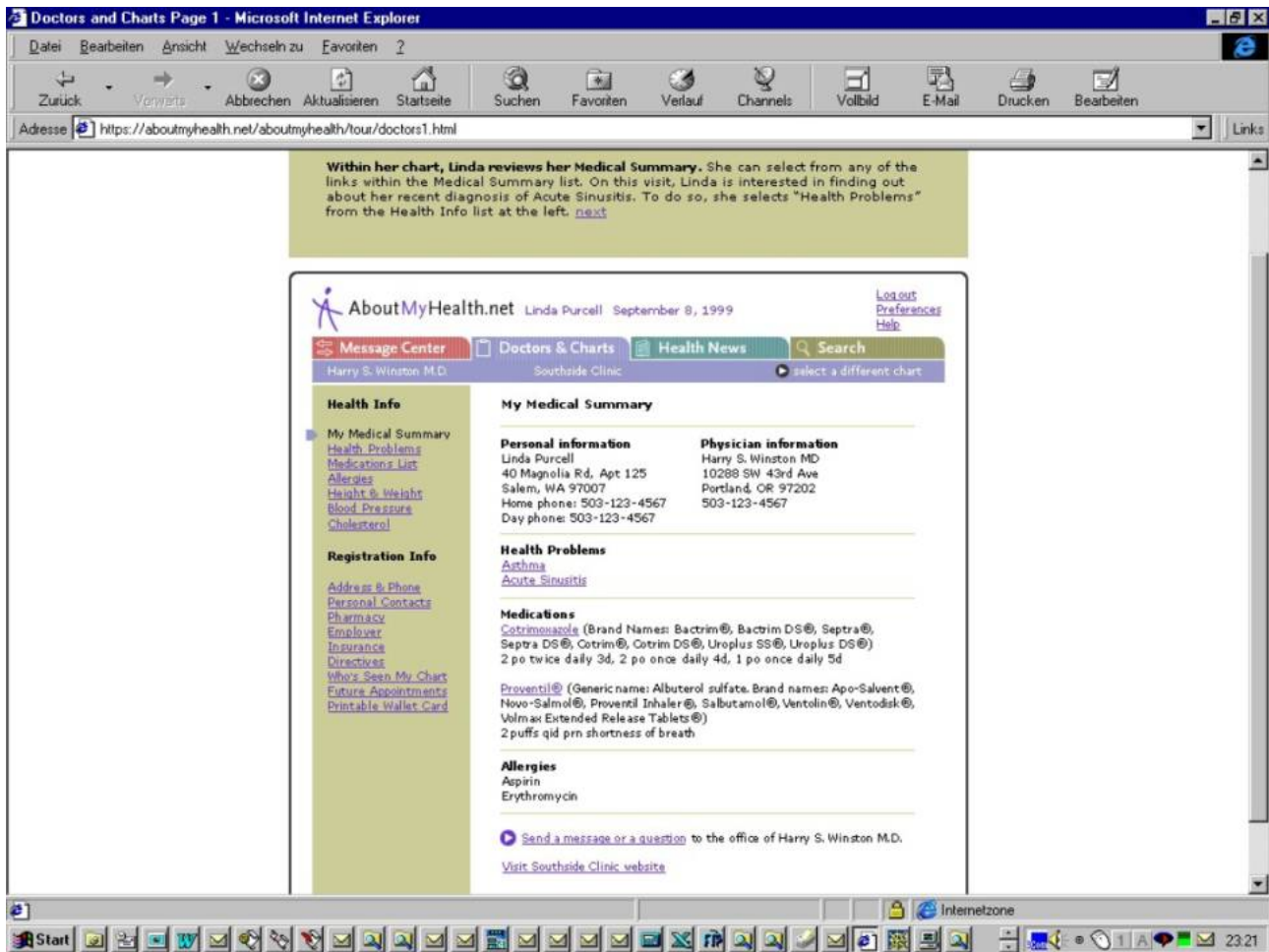
Giving consumers control over their own information

One of the most radical steps towards consumer empowerment will involve making the electronic health records (at least parts of them) available to consumers on the Internet. Once this occurs, consumers will be able to do 'online-doctoring', just as they do 'online-banking' and 'online-shopping' today [1].

To put the records into the hands of consumers is not a new idea. More than 25 years ago it was already advocated that 'patients' should be able to take their records home [36]. Baldry [37] conducted an early experiment with giving consumers in the waiting room their medical records to read. The international trend is to allow consumers to inspect their records and to allow them to make copies there of [38]. The European Union Data Directive (applicable October 1998) required all member countries to enact legislation enabling subject access to medical records, if not already enacted.

Consumer health informatics developments offer further opportunities for this process, with the potential to grant consumers access to information which is relevant to them and to integrate their personal data with explanatory information. For example, a system called SeniorMed allows elderly consumers access to their electronic medication lists via the WWW. Such systems may be integrated with drug information [39]. MedicalLogic, a company based in the US, is also testing a concept called 'Internet Health Record', a service that lets consumers privately access information from their real medical records over the Internet. The information is embedded in a system that lets them research health conditions, refill prescriptions, and communicate with their professional's office. Consumer records could be linked with glossaries, and be linked to information on the Internet (for example, if the problem list contains 'smoking', links could refer to 'how-to-quit-smoking' health promotion sites or to Medline). Consumers could also change or comment on certain entries (http://www.medicallogic.com/services/about_98point6.html).

Figure 3. Internet accessible consumer health record



Ensuring better quality control

In the field of Internet publishing, many instruments to evaluate health information exist, but none of them have been validated. In addition, it is unclear whether they should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm [40].

The Swiss Health on the Net foundation has compiled some consensus ethical principles for publishers of health information, the so-called HON Code of Conduct (<http://www.hon.ch/HONcode/>). Information providers who agree to implement these ethical principles display the HON logo on their websites. However, there are no mechanisms for controlling or enforcing the adoption of such principles. As a result, it is not clear how many of the several thousand sites displaying the logo have actually implemented the principles. The HON Code is often misinterpreted (also in the peer-reviewed literature!) as an award-system, rating system, or as 'quality criterion' which allows consumers to appraise the quality of a website. It is however not possible for a third party (that is, the user of a website) to verify for example that a principle such as 'privacy and confidentiality' or 'honesty in disclosing sources of funding' is observed.

A systematic review on different quality criteria used to assess information on the Internet has been published recently [41]. Consumers may for example use indirect quality criteria such

as popularity, expressed as number of visitors or 'webcitations' [21,42]. There are now several tools available on the Internet for use by consumers which help users to assess the quality themselves (<http://hitiweb.mitretek.org/iq/default.asp>, <http://www.discern.org.uk>, <http://www.quick.org.uk>).

DISCERN is a standardized index to judge the quality of health information. This instrument is targeted at producers, health professionals, and consumers to appraise written information on treatment choices. Crucial in the development was the determination of inter-rater agreement among different user groups. Questions with insufficient inter-rater agreement, such as those concerning design or reading level ('the information is easy to understand'), were eliminated from the final instrument. However, the validity of DISCERN in terms of the relationship between a DISCERN score and impact of the information on consumer outcomes have not yet been determined. It should also be noted that the inter-rater reliability for DISCERN was rather low when it was used by consumers. Thus it is not yet clear whether DISCERN is a truly useful instrument for consumers to distinguish good from bad information. In the near future, an international system of accreditation or 'quality seals' (evaluative meta-information assigned by trusted raters) may help consumers to identify high-quality information on the Internet. A European Union (EU) funded project, 'G7 ENABLE', has described 'Barriers To A Global Information Society For Health'. It made the following observations to the EU Commission: 'A great deal of health-related information on the

Web is poor, misleading and much positively harmful. This substantially diminishes the benefits that the Internet could potentially deliver'.

What is required is an internationally-recognized scheme whereby the public can identify, and search for, high-quality Internet health information. These should carry the authority of clinical bodies, which are recognized as having the clinical standing to be trusted. Such a filtering and rating system is currently being implemented in a new EU project called MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net, <http://www.medcertain.org>), funded under the EU Action Plan for safer use of the Internet [43]. The aim of this project is to establish trust and improve the quality of health information on the Internet by the 'four E's' [44]:

- *Educating* the public (teaching critical appraisal skills to consumers);
- *Encouraging* self-governance, for example encouraging health information providers to obey ethical codes for health [44] and promoting self-labelling (disclosure of important information such as authorship and sponsors, also with metadata);
- *Evaluation* and certification of information (offer a framework for third party rating, so that interested medical societies and bodies can assign 'quality seals' to trustworthy information)
- *Enforcement*(Network of Hotlines for consumers)

The international MedCERTAIN trustmark will be established in close collaboration with all interested agencies and relevant

national organizations which pursue similar aims. These would include, for example, bodies such as OMNI (Organizing Medical Networked Information, <http://www.omni.ac.uk/>) or the UK Centre for Health Information Quality. A basic principle is inter-operability of existing rating services and the creation of metadata exchange standards.

The future

The vast potential of the Internet to promote health information and to foster consumer-professional communication is far from being realized. The Internet has both the clientele (consumers who really want to learn something about their health) and the technical prerequisites (the reach of a mass-medium, combined with the possibility for interactivity to tailor information specific to the individual) to be an ideal medium to promote consumer education and decision support. An interesting future perspective is the linkage of the personal online-accessible health record with general health information from evidence-based resources. The convergence of technology and knowledge will be greatly enhanced by the use of multimedia and artificial intelligence. Further contributions will come from the advent of low cost portable and wearable computers. These will allow access to knowledge at the right time and in the right place through ubiquitous computer networks and wireless connections to the Internet. Among other challenges [45], development and proper evaluation of these tools and making them accessible to those who need them most will be the main themes of consumer health informatics in the information age.

Acknowledgments

This article is based on a book-chapter written for the book "Evidence-Based Patient Choice", edited by by Adrian Edwards and Glyn Elwyn, published by Oxford University Press (ISBN 0192631942) [Further information about the book from the publisher].

Reproduced in JMIR with kind permission of Oxford University Press.

Conflicts of Interest

None declared.

References

1. Eysenbach G. Consumer health informatics. *BMJ* 2000 Jun 24;320(7251):1713-1716 [FREE Full text] [Medline: 20323060] [doi: [10.1136/bmj.320.7251.1713](https://doi.org/10.1136/bmj.320.7251.1713)]
2. Reents S, Miller TE. The health care industry in transition - the online mandate to change. *Cyber Dialogue*. 1998. URL: http://www.cyberdialogue.com/free_data/white_papers/intel_health_day.html
3. Wilson SM. Impact of the internet on primary care staff in Glasgow. *J Med Internet Res* 1999 Nov 19;1(2):e7 [FREE Full text] [Medline: 21577981] [doi: [10.2196/jmir.1.2.e7](https://doi.org/10.2196/jmir.1.2.e7)]
4. Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. *JAMA* 1999;282(24):2313-2320. [Medline: 20077565] [doi: [10.1001/jama.282.24.2313](https://doi.org/10.1001/jama.282.24.2313)]
5. ; Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *JAMA* 1999 Feb 10;281(6):552-557. [Medline: 99144710] [doi: [10.1001/jama.281.6.552](https://doi.org/10.1001/jama.281.6.552)]
6. Gazmararian JA, Baker DW, Williams MV, Parker RM, Scott TL, Green DC, et al. Health literacy among Medicare enrollees in a managed care organization. *JAMA* 1999 Feb 10;281(6):545-551. [Medline: 10022111] [doi: [10.1001/jama.281.6.545](https://doi.org/10.1001/jama.281.6.545)]
7. Baker DW, Parker RM, Williams MV, Clark WS, Nurss J. The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health* 1997 Jun;87(6):1027-1030. [Medline: 97367487]
8. Vivian AS, Robertson EJ. Readability of patient education materials. *Clin Ther* 1980;3(2):129-136. [Medline: 81088301]

9. Graber MA, Roller CM, Kaeble B. Readability levels of patient education material on the World Wide Web. *J Fam Pract* 1999 Jan;48(1):58-61. [Medline: [99133148](#)]
10. Hart JT. The inverse care law. *Lancet* 1971 Feb 27;1(7696):405-412. [Medline: [71133209](#)]
11. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: a public highway or a private road? *JAMA* 1998 Oct 21;280(15):1371-1375. [Medline: [99008453](#)] [doi: [10.1001/jama.280.15.1371](#)]
12. ; UNDP. Human development report 1999. Oxford: Oxford University Press URL: <http://www.undp.org/hdro/report.html>
13. Sieving PC. Factors driving the increase in medical information on the web--one American perspective. *J Med Internet Res* 1999 Aug 11;1(1):e3 [FREE Full text] [Medline: [21577977](#)] [doi: [10.2196/jmir.1.1.e3](#)]
14. Hafner K. Can the Internet cure the common cold? *The NY-Times*; Sect Technology. 1998 Jul 9. URL: <http://www.corporateserver.com/qiodemo/nyt.htm>
15. Hersey JC, Matheson J, Lohr KN. Consumer Health Informatics and Patient Decision making (Report nr AHCPR; Publication No.98-N001). Rockville, MD: Agency for Health Care Policy and Research; 1997 Oct. URL: <http://www.ahcpr.gov/research/rtisumm.htm>
16. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999 Jan 30;318(7179):318-322 [FREE Full text] [Medline: [99122887](#)]
17. Impicciatore P, Pandolfini C, Casella N, Bonati M. Reliability of health information for the public on the World Wide Web: systematic survey of advice on managing fever in children at home. *BMJ* 1997 Jun 28;314(7098):1875-1879 [FREE Full text] [Medline: [97367429](#)]
18. Culver JD, Gerr F, Frumkin H. Medical information on the Internet: a study of an electronic bulletin board. *J Gen Intern Med* 1997 Aug;12(8):466-470. [Medline: [97420666](#)] [doi: [10.1046/j.1525-1497.1997.00084.x](#)]
19. Eysenbach G, Diepgen TL. Responses to unsolicited patient e-mail requests for medical advice on the World Wide Web. *JAMA* 1998 Oct 21;280(15):1333-1335. [Medline: [99008444](#)] [doi: [10.1001/jama.280.15.1333](#)]
20. Eysenbach G, Diepgen TL. Evaluation of cyberdocs. *Lancet* 1998 Nov 7;352(9139):1526. [Medline: [99036198](#)] [doi: [10.1016/S0140-6736\(05\)60334-0](#)]
21. Eysenbach G, Diepgen TL. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. *BMJ* 1998 Nov 28;317(7171):1496-1500 [FREE Full text] [Medline: [99051215](#)]
22. Eysenbach G, Diepgen TL. Labeling and filtering of medical information on the Internet. *Methods Inf Med* 1999 Jun;38(2):80-88. [Medline: [99360180](#)]
23. Coiera E. The Internet's challenge to health care provision. *BMJ* 1996 Jan 6;312(7022):3-4 [FREE Full text] [Medline: [96135901](#)]
24. Coiera E. Information epidemics, economics, and immunity on the internet. We still know so little about the effect of information on public health. *BMJ* 1998 Nov 28;317(7171):1469-1470. [Medline: [99051204](#)]
25. ; Science Panel on Interactive Communication and Health. *Wired for health and well-being; the emergence of interactive health communication*. Washington, DC: US Department of Health and Human Services, US Government Printing Office; Apr 1999.
26. ; UNDP. Human development report 2000. Oxford: Oxford University Press URL: <http://www.undp.org/hdr2000/english/HDR2000.html>
27. Irving L, Klegar-levy K, Everette DW, Reynolds T, Lader W. Falling through the Net: defining the digital divide. A report on the telecommunications and information technology gap in America. 1999 Jul. URL: <http://www.ntia.doc.gov/ntiahome/ftn99/contents.html> URL: <http://www.ntia.doc.gov/ntiahome/ftn99/FTTN.pdf>
28. Jadad AR, Haynes RB, Hunt D, Browman GP. The Internet and evidence-based decision-making: a needed synergy for efficient knowledge management in health care. *CMAJ* 2000 Feb 8;162(3):362-365 [FREE Full text] [Medline: [20157984](#)]
29. Malet G, Munoz F, Appleyard R, Hersh W. A model for enhancing Internet medical document retrieval with "medical core metadata". *J Am Med Inform Assoc* 1999;6(2):163-172. [PMC: [10094069](#)] [Medline: [99191857](#)]
30. Eysenbach G, Sa ER, Diepgen TL. Cybermedicine. Interview by Clare Thompson. *BMJ* 1999 Nov 13;319(7220):1294 [FREE Full text] [Medline: [20025693](#)]
31. Pemberton PJ, Goldblatt J. The Internet and the changing roles of doctors, patients and families. *Med J Aust* 1998;169(11-12):594-595 [FREE Full text] [Medline: [99104850](#)]
32. Shepperd S, Charnock D, Gann B. Helping patients access high quality health information. *BMJ* 1999 Sep 18;319(7212):764-766 [FREE Full text] [Medline: [99418920](#)]
33. Muir Gray JA, De Lusignan S. National electronic Library for Health (NeLH). *BMJ* 1999 Dec 4;319(7223):1476-1479 [FREE Full text] [Medline: [20050394](#)]
34. Widman LE, Tong DA. Requests for medical advice from patients and families to health care providers who publish on the World Wide Web. *Arch Intern Med* 1997 Jan 27;157(2):209-212. [Medline: [97163143](#)] [doi: [10.1001/archinte.157.2.209](#)]
35. Eysenbach G, Diepgen TL. Patients looking for information on the Internet and seeking teleadvice: motivation, expectations, and misconceptions as expressed in e-mails sent to physicians. *Arch Dermatol* 1999 Feb;135(2):151-156. [Medline: [99159764](#)]
36. Coleman V. Why patients should keep their own records. *J Med Ethics* 1984 Mar;10(1):27-28. [Medline: [84164804](#)]

37. Baldry M, Cheal C, Fisher B, Gillett M, Huet V. Giving patients their own records in general practice: experience of patients and staff. *Br Med J (Clin Res Ed)* 1986 Mar 1;292(6520):596-598. [Medline: [86132533](#)]
38. Mcquoid-mason D. Medical records and access thereto. *Med Law* 1996;15(3):499-517. [Medline: [97162627](#)]
39. Rind DM, Kim JH, Sturges EA. SeniorMed: Connecting patients to their medication records. *Proc AMIA Symp* 1999(1-2):1147.
40. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? *JAMA* 1998 Feb 25;279(8):611-614. [Medline: [98146162](#)] [doi: [10.1001/jama.279.8.611](#)]
41. Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related web sites: review. *BMJ* 1999 Mar 6;318(7184):647-649 [FREE Full text] [PMC: [10066209](#)] [Medline: [99165691](#)]
42. Hernández-borges AA, Macías-cervi P, Gaspar-guardado MA, Torres-Álvarez De Arcaya ML, Ruiz-rabaza A, Jiménez-sosa A. Can examination of WWW usage statistics and other indirect quality indicators help to distinguish the relative quality of medical websites. *J Med Internet Res* 1999;1(1):e1 [FREE Full text] [doi: [10.2196/jmir.1.1.e1](#)]
43. Eysenbach G, Yihune G, Lampe K, Cross P, Brickley D. MedCERTAIN: quality management, certification and rating of health information on the Net. *Proc AMIA Symp*. 2000. p. 230-234 URL: <http://www.amia.org/pubs/symposia/D200285.PDF> [Medline: [11079879](#)]
44. Eysenbach G. Towards ethical guidelines for e-health: JMIR theme issue on eHealth ethics. *J Med Internet Res* 2000 Mar 31;2(1):e7 [FREE Full text] [Medline: [21577991](#)] [doi: [10.2196/jmir.2.1.e7](#)]
45. Jadad AR. Promoting partnerships: challenges for the internet age. *BMJ* 1999 Sep 18;319(7212):761-764 [FREE Full text] [Medline: [99418919](#)]

peer-reviewed by A Edwards, G Elwyn; published 07.06.01.

Please cite as:

Eysenbach G, Jadad AR

Evidence-based Patient Choice and Consumer health informatics in the Internet age

J Med Internet Res 2001;3(2):e19

URL: <http://www.jmir.org/2001/2/e19/>

doi: [10.2196/jmir.3.2.e19](#)

PMID: [11720961](#)

© Gunther Eysenbach, Alejandro R Jadad. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 7.6.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Viewpoint

The Patient-Physician Relationship in the Internet Age: Future Prospects and the Research Agenda

Ben S Gerber, MD; Arnold R Eiser, MD

¹Section of General Internal Medicine, College of Medicine, University of Illinois, Chicago, USA

Corresponding Author:

Ben S Gerber, MD
General Internal Medicine (M/C 787)
University of Illinois at Chicago
840 South Wood Street
Chicago IL 60612
USA
Phone: +1 312 413 0312
Email: bgerber@uic.edu

Abstract

In the "Internet Age," physicians and patients have unique technological resources available to improve the patient-physician relationship. How they both utilize online medical information will influence the course of their relationship and possibly influence health outcomes. The decision-making process may improve if efforts are made to share the burden of responsibility for knowledge. Further benefits may arise from physicians who assist patients in the information-gathering process. However, further research is necessary to understand these differences in the patient-physician relationship along with their corresponding effects on patient and physician satisfaction as well as clinical outcomes.

(*J Med Internet Res* 2001;3(2):e15) doi:[10.2196/jmir.3.2.e15](https://doi.org/10.2196/jmir.3.2.e15)

KEYWORDS

Physician-Patient Relations; Internet; Decision-Making; Patient Education; Medical Informatics

Introduction

Increasingly, individuals around the world are turning to the Internet for health-related knowledge [1]. In the United States, more than 52 million adults have searched the World Wide Web for health and medical information [2]. An increasing number of health-related Web sites are now becoming available for up-to-date answers to medical questions. In response to this information-seeking activity, physicians have expressed concern regarding access to misinformation and patients' interpretation of available online content [3-9]. Many doctors believe that only qualified medical professionals may adequately assess and interpret external sources of information. Defensive attitudes may arise from the Internet having a "leveling effect" on access to information and, subsequently, on the patient-physician relationship [10,11]. This situation contrasts with physicians' sole possession of medical knowledge, as was the case for most of the 20th century. Today, there is greater acceptance of more informed and educated patients. Healthcare providers can take advantage of this unique opportunity to create, support, reference, and promote awareness of quality electronic sources of medical information. Still, practitioners may differ according

to the extent they embrace this technological revolution and make it part of the patient-physician relationship.

In this commentary, we explore the effects of information obtained through the World Wide Web on the patient-physician relationship. The impact of the Web affects decision-making processes and offers new possibilities for physician-to-patient recommendations. However, there remains much uncertainty about what effect the Web has on public health outcomes [12]. Similarly, uncertainty surrounds individual reactions to using Internet information for making medical decisions. With these points in mind, we propose a research agenda for further investigation of online information and its effects on the patient-physician relationship.

Patient Personality/Information Types in Medical Decision-Making

One of the newest sources of knowledge for patients comes from visiting health-related Web sites. The greatest impact on medical decision-making may come from this increase in knowledge prior to the clinical encounter. Until recently, in the clinical visit the physician had the sole responsibility for medical knowledge, whereas the patient was only accountable for his

or her own preferences. Now, by more easily obtaining medical information prior to seeing their doctors, patients potentially have a different position in the decision-making process; possessing both preferences and knowledge prior to any physician contact. Another probable advantage comes from having the opportunity to reflect on and reconsider preferences prior to discussions with health professionals. People are likely to redefine their desires and intentions over time because they frequently are uncertain [13].

Paradoxically, a patient's interest in knowledge may not always accompany an interest in the medical decision-making process. According to studies of patient-physician relationships, although patients typically express a high degree of interest in learning about their illnesses and treatment, their preference for actual participation in treatment decision-making is highly variable [14,15]. Patients may investigate information about their medical conditions without interest in taking responsibility for making decisions about treatment. Given this variability, two kinds of patient-physician encounters may result, based on differential interest in medical decision-making. For each situation, additional knowledge obtained from the Internet offers potential benefit yet may influence decision-making and outcomes in different ways. However, in both of these scenarios the advantages realized assume accuracy in the health information obtained.

Physician and the Informed Decision-Maker

In one scenario, a patient may be motivated to become involved in the decision-making process and have access to additional sources of information about a particular illness as well as the treatments available (the *informed decision-maker*). Such a patient could be at an additional advantage by having accessed related information via the Internet prior to meeting with a physician. Instead of utilizing scheduled time to provide the patient with basic knowledge, the physician may devote extra time to refining what the patient has learned and offering greater depth on treatment options (assuming the information obtained is accurate). Theoretically, more time could be spent on discussions necessary to arrive at a clinical decision. However, physicians must be prepared to address alternative possibilities that the patient has learned about from external sources. Instead of saving time, this scenario may require extra discussion when untested approaches need to be debunked (as in the case of some complementary and holistic medicine practices). The concept of efficient use of clinical time is of greater importance when the restrictive pressures of managed care and business economics enter the equation. Still, it is yet uncertain whether efficiency improves or declines when patient-acquired Internet information is brought into the decision-making process. This subject warrants further investigation.

The "deliberative" or "participatory" decision-making model is recommended as the preferred model of treatment decision-making in the clinical encounter [14,16,17]. One necessary requirement for this decision-making process is that both parties take steps to participate in the process of treatment decision-making. In this model, the patient takes a newly found responsibility for disclosing preferences, obtaining information, and weighing treatment alternatives. Someone who is willing

to accept such responsibility will be at an advantage through consulting the Internet for information. The patient brings to the table technical knowledge in addition to that offered by the physician. This is more likely the case if the information was obtained through a qualified Web site certified by an evaluating organization for accuracy. Eventually, informed consent may become more a reality than a theoretical concept.

The physician's role in shared decision-making has several requirements. Physicians must ensure that the information a patient wishes to use in making a decision is founded in fact and not misconception or falsehood. In addition, proposed treatment options must be weighed with assistance from physicians. To accomplish these tasks, physicians must be prepared to address alternative therapies that may not have been suggested if the patient had not learned about them from external sources.

Health providers must avoid frustration about having their role as the sole source of information challenged, or possibly risk losing patients. In one survey of different specialty and general medicine practices, one third of the patients who felt their relationship with their physicians was low in participatory decision-making changed providers within a year [16]. In addition, because higher volume practices were rated as "less participatory," efficiency becomes an important factor to consider. Thus, physicians must be open to those highly motivated patients who are active participants in their healthcare.

Shared decision-making includes the ideal that both parties need to agree on a treatment option, even if both do not agree that it is the best possible treatment to implement [14]. Certain types of physicians are probably more likely to subscribe to this model than others. Some doctors may not be willing to relinquish the authoritative role. Research suggests that physicians vary widely in the extent to which they feel comfortable in facilitating patient participation in decision-making [16]. In one survey of 1276 Norwegian physicians, 3 out of 4 doctors had experiences with patients bringing Internet information to the consultation setting [18]. Although most found this experience unobtrusive, some believed it had a negative effect on the patient-physician relationship, and others found it to be a positive challenge.

Physician and the Knowledge-Acquirer

Physicians need to be aware that patients who are interested in obtaining additional knowledge may not be motivated to participate in actual decision-making. This circumstance may reflect less assertive personality traits on the part of some patients. Consequently, the patient-physician relationship may more likely resemble the "physician-as-agent" model [13-14]. In this case, the patient (the *knowledge-acquirer*) provides some personal values to the physician. By possessing the medical knowledge and learning about the patient's values and beliefs, the physician may then be the formulator of the final decision. Though the patient may not actively pursue outside sources of information prior to the clinical visit, there still may be interest in learning more about the medical condition or treatment decided on by the physician. This case was found to be particularly true after relatively long patient-physician encounters [19].

This type of patient may benefit from obtaining information on the Web after the clinic visit. This supplemental information may allow the individual to feel more comfortable or satisfied with a treatment decision, even though there is no involvement in the actual decision-making process. For example, when behavioral interventions are addressed, prior interactions with a physician may have a "priming effect" - improving the behavioral response to reading materials encountered subsequently [20]. This outcome may be a potentially important benefit not realized by physicians who mistakenly feel that "no interest in making decisions" translates into "no interest in medical knowledge." Physicians who recommend Web sites may further benefit patients who acquire medical knowledge via the Internet.

Physicians Recommending Web Sites to Patients: The Internet Prescription

A physician-recommended Web site could be thought of as an *Internet prescription*. For example, a young woman presents to her physician's office with an interest in starting an exercise regimen, but she is concerned about developing athletic injuries. The Internet-savvy physician "prescribes" a specific Web page on stretching exercises [21]. At home, the patient initially views the recommended information, including images, animation, or video [22]. Subsequently, she also searches the Internet for alternative information and ends up reading about the dangers of traditional stretching exercises [23]. The physician may not have intended her to read this information; though it may be of interest to the open-minded patient. Although healthcare providers may suggest to patients that they acquire information from specific sources, patients will likely obtain a "second opinion" on the Internet. In this case, the potential benefit of the Internet prescription may arise from a patient viewing suggested information first and giving it preference because his or her physician provided it.

Furthermore, patients who find additional sources of information on the Internet have the option of obtaining another opinion through their physicians. In this case, the woman in our example could provide her physician with the Web address (or printed information) that addresses the dangers of traditional exercises. This step may promote discussion between her and her physician about its interpretation. Whereas it is difficult to teach "evidence-based medicine" to the layperson, it is more feasible to discuss articles with patients using related concepts that physicians have learned.

There is great concern about the accuracy and validity of medical information found on the Internet [3-5]. For the physician prescribing Web sites, there is the persistent challenge of ensuring quality in online content. Both physician and patient must become aware of what information is available, the source of information, and the intended audience [24]. Online information that differs significantly from that prescribed by the physician may result in unanticipated consequences. The additional strength and reinforcement of referenced consumer information requires the physician to carefully review what patients will read and to recognize that such information may be periodically updated. In the instance of a major medical

illness, some sites may soothe an individual's anxiety whereas others may raise false hopes [25]. The physician's traditional reluctance to offer more information than is necessary may be well intended. However, with the Internet, patients may opt to pursue stories and anecdotal literature evoking strong emotions (for an example, see ConquerCancer.com [26]).

To combat online misinformation, healthcare providers must positively influence patient selection of online materials. The presentation of awards on medical Web pages may not have a significant impact on patients' assessment of credibility [27]. However, approximately 3 out of 4 Internet users seeking health information feel that a doctor recommendation would make them more likely to trust a health Web site [28]. Unfortunately, less than 5% say they currently use doctor recommendations to find the sites visited on the Internet. Physicians need to take an active role in this regard. For example, physicians can link their own Web sites to various known Web sites that provide quality content. This idea appears to be increasing in popularity as physician practice Web sites continue to grow in number. In one corporate survey of over 700 physicians, the percentage of pediatrician practices with Web sites increased from 24% in August 1999 to 46% in October 2000 [29]. As an alternative, medical journals and professional health organizations may represent even more valuable sources, for they offer assessment and dissemination of the best evidence for clinical problems.

Referenced Web sites may be explicitly recommended to patients during clinical encounters or by electronic mail. It then becomes important for physicians to know where high caliber information is located in cyberspace rather than merely know what the specific information is itself [24]. Given how difficult it is for health professionals to keep track of the ever-changing Web, it becomes equally important to know about quality repositories of medical links. The "healthfinder" Web site selects links to health information from sources that include government agencies, nonprofit and professional organizations serving the public interest, universities and other educational institutions, libraries, and so on [30]. This site was developed by the US Department of Health and Human Services to provide up-to-date resources beyond what physicians have time to prepare on their own. The National Library of Medicine has created MEDLINE *plus*, which allows the provider or consumer to search quality Web sites for health information [31]. Physicians may feel more comfortable recommending information from MEDLINE *plus* rather than a "dot-com" source of medical information, which often endorses products or companies.

Despite the existence of quality repositories of health information, there is still significant resistance to online physician activity. In a survey of 1084 physicians by the American Medical Association, only 11% of respondents felt the Internet was useful in providing patient education [32]. This aversion may be related to factors including start-up time, computer/network finances, time spent verifying the accuracy of information on Web sites, and liability issues. Many have a "fight or flight" response to these technical communicative innovations, creating a challenge in implementation [33].

The Research Agenda

Though there have been previous studies analyzing the patient-physician relationship, research must be directed toward evaluating the impact of electronically obtained knowledge on this relationship. Further analysis of the current models for the patient-physician relationship may reveal that new, emerging trends are taking place. Efficiency, patient satisfaction, and clinical encounter time may vary when Internet-acquired information is considered in decision-making. Variability in patient types and in physician personalities compounds the dynamics of decision-making analysis. Additional focus must be placed on studies that include the impact of electronically obtained knowledge on the patient-physician relationship.

Another issue that should be addressed is the extent of responsibility that a patient is willing to accept. In one pilot study, individuals have been given access to their medical records and have been provided with online communication with their physicians (derived from Web-based methods of sharing clinical content) [34]. Patient interest, as well as physician acceptance, has been evaluated. In another pilot project, patients are being provided with consumer health information in waiting and exam rooms [35]. The resulting patient-physician communication and level of satisfaction will be measured.

When patients assume a greater role in acquiring medical knowledge, there must be a corresponding change in the physician's role as treatment decision-maker. Additional dynamics are likely to result from different physician behaviors, including embracing, avoiding, or disregarding Internet-derived information. To better define this variable, surveys and observational studies are needed that will elicit physician attitudes toward Internet health information and their corresponding patient-physician relationships. In addition, research is needed to evaluate the barriers to physician implementation of information technology. In Canada, researchers have administered a new survey instrument to stratify primary care physicians into different levels of information technology usage [36]. This approach may allow for specifically tailored strategies to be used in implementation.

Although many individuals have the potential to gain medical knowledge easily through on-line information, others do not. Few studies have examined the benefit of computers in patient education within economically depressed urban areas [37]. There is also little evidence that describes how individuals lacking the latest technology (including high-speed Internet Service Providers) cannot access resource-intensive Web sites, including those requiring audio or video streaming. The long-term effects and potential benefits of computer technology for vulnerable populations have yet to be determined. Although there is a considerable amount of data that demonstrate limited access, there still is overwhelming interest in computer education by all segments of the public. Additional research is necessary to define how patients of different cultural or socio-economic backgrounds utilize computers and the Internet for information, and how this has an impact on their relationship with healthcare providers.

Most patients using a home computer have access to medical information on the Internet. This circumstance will likely reflect a select, educated patient population with income levels that support the equipment. In an inner-city medical center in Los Angeles, California, 18% of surveyed minority patients with low levels of income and educational background had Internet access - considerably less than the corresponding national estimate of 37% to 45% [38]. Yet there was significant interest expressed in on-line health information. If minority patient populations are to become active participants in the Internet age, it is necessary to continue to devote greater resources to improving easy access of electronic information. There is a definite need for interventions that empower ethnic minority patients and help them become informed and active healthcare consumers [39].

Patients with poor literacy skills are less likely to take advantage of the Internet in order to acquire additional medical knowledge, whether they have access or not. Unfortunately, because these individuals are more likely to have worse health, their needs for health education are greater, especially for those with chronic illnesses [40]. This issue affects their relationship with physicians; studies have shown that patients' acceptance of diagnoses and treatment plans depends on education [41]. Hence, additional efforts are required to assist persons with lower literacy skills. With adaptive technologies supplying touch-screen input and audio output, kiosks can be made available for patients motivated to learn, independent of their literacy or education level [42,43]. Physician offices with health information kiosks may be an alternative method for browsing health-related information, being temporally linked to clinician interactions. However, additional issues, such as cost, complexity of use, and potential for misinformation, then arise [44]. Still, additional research is necessary to determine the possible benefits and effects on the patient-physician relationship.

In sum, the research agenda on on-line information and the patient-physician relationship includes: (1) an assessment of Internet medical information usage by patients on patient outcomes, satisfaction, and willingness to share decision-making responsibility; (2) determination of changes in physician efficiency, satisfaction, and willingness to share decision-making responsibility; and (3) studies of methods to increase access to computer-based information for patients with low computer and print literacy, which assess process and outcomes measures.

Conclusions

The Internet Age is altering the patient-physician relationship. If physicians actively assist patients in the information-gathering process, an improved relationship may result. Through the understanding of evolving professional roles, the decision-making process between physicians and patients may improve with efforts to share the burden of responsibility for knowledge. This change could usher in a new era of the patient-physician relationship, with a potential gain for all collaborative parties. However, there is no assurance that implementation will occur smoothly or in a desirable fashion. Thus, there is a compelling need for prospective research in this

area. Methods of bridging the Digital Divide are also important considerations for future research, for this disparity in technology use still exists today [45]. It is essential that large segments of the population not be left behind as strides are made in information technology and healthcare decision-making.

Acknowledgments

We are indebted to Paul Heckerling, M.D., for his useful comments in the development of this manuscript.

Conflicts of Interest

None declared

References

1. ; Health On the Net Foundation. HON's Fifth Survey on the Use of the Internet for Medical & Health Purposes. URL: http://www.hon.ch/Survey/ResultsSummary_oct_nov99.html [accessed 2001 Mar 20]
2. The Pew Internet and American Life Project. URL: <http://www.pewinternet.org/> [accessed 2001 Feb 1]
3. Eysenbach G, Diepgen TL. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. *BMJ* 1998 Nov 28;317(7171):1496-1500 [FREE Full text] [Medline: 99051215]
4. Robinson TN, Patrick K, Eng TR, Gustafson D. An evidence-based approach to interactive health communication: a challenge to medicine in the information age. Science Panel on Interactive Communication and Health. *JAMA* 1998 Oct 14;280(14):1264-1269. [Medline: 99000344] [doi: 10.1001/jama.280.14.1264]
5. Kassirer JP. The next transformation in the delivery of health care. *N Engl J Med* 1995 Jan 5;332(1):52-54 [FREE Full text] [Medline: 95082840] [doi: 10.1056/NEJM199501053320110]
6. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? *JAMA* 1998 Feb 25;279(8):611-614. [Medline: 98146162] [doi: 10.1001/jama.279.8.611]
7. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor--Let the reader and viewer beware. *JAMA* 1997 Apr 16;277(15):1244-1245. [Medline: 97256510] [doi: 10.1001/jama.277.15.1244]
8. Moore AS. How to Help Patients Sift Through Junk On The Internet. *RN* 1999;62:67.
9. Anderson JG. Health Information on the Internet: Let the Viewer Beware (Caveat Viewer). *MD Computing* 2000 Jul:19-21.
10. Podolsky DK. Patients, gastroenterologists, and the World Wide Web. *Gastroenterology* 1998 Jan;114(1):5. [Medline: 98089811]
11. Mclellan F. "Like hunger, like thirst": patients, journals, and the internet. *Lancet* 1998;352(2S):39-43. [doi: 10.1016/S0140-6736(98)90301-4]
12. Wyatt JC. Commentary: measuring quality and impact of the World Wide Web. *BMJ* 1997 Jun 28;314(7098):1879-1881. [Medline: 97367430]
13. Emanuel EJ. Four models of the physician-patient relationship. *JAMA* 1992 Apr;267(16):2221-2226. [Medline: 92211788] [doi: 10.1001/jama.267.16.2221]
14. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997 Mar;44(5):681-692. [Medline: 97185094] [doi: 10.1016/S0277-9536(96)00221-3]
15. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989 Feb;4(1):23-30. [Medline: 89125103]
16. Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med* 1996 Mar 1;124(5):497-504 [FREE Full text] [Medline: 96169949]
17. Ballard-Reisch DS. A Model of Participative Decision Making for Physician-Patient Interaction. *Health Communication* 1990;2:91-104.
18. Hjortdahl P, Nylenna M, Aasland OG. [Internet and the physician-patient relationship--from "thank you" to "why"?]. *Tidsskr Nor Laegeforen* 1999 Nov 30;119(29):4339-4341. [Medline: 20131785]
19. Beisecker AE. Patient information-seeking behaviors when communicating with doctors. *Med Care* 1990 Jan;28(1):19-28. [Medline: 90113341]
20. Kreuter MW, Chheda SG, Bull FC. How does physician advice influence patient behavior? Evidence for a priming effect. *Arch Fam Med* 2000 May;9(5):426-433 [FREE Full text] [Medline: 20269084] [doi: 10.1001/archfami.9.5.426]
21. MayoClinic.com. URL: <http://www.mayohealth.org/> [accessed 2001 Mar 30]
22. ; About.com. About: Health/Fitness: Sports Medicine. URL: <http://www.sportsmedicine.about.com/health/sportsmedicine/cs/flexibility/> [accessed 2001 Feb 1]
23. Gold L. Beyond Stretching. URL: <http://www.somatics.com/stretch.htm> [accessed 2000 Nov 23]
24. Bader SA, Braude RM. "Patient informatics": creating new partnerships in medical decision making. *Acad Med* 1998 Apr;73(4):408-411. [Medline: 98241819]
25. Prevost L. "Healme.com.". In: *Civilization* 1999:101-103.

26. ConquerCancer.com. URL: <http://www.conquercancer.com/main/guest.htm> [accessed 2001 Mar 30]
27. Shon J, Marshall J, Musen MA. The impact of displayed awards on the credibility and retention of Web site information. Proc AMIA Symp 2000:794-798 [FREE Full text] [Medline: [21027467](#)]
28. ; CyberDialog. Impacts of the Internet on the Doctor-Patient Relationship. URL: <http://www.cyberdialog.com/> [accessed 2001 Mar 30]
29. Medem. URL: <http://www.medem.com/> [accessed 2001 Mar 29]
30. Healthfinder. URL: <http://www.healthfinder.gov/> [accessed 2000 Dec 10]
31. MedlinePlus. URL: <http://www.nlm.nih.gov/medlineplus> [accessed 2000 Dec 10]
32. ; The Forrester Report. Why Doctors Hate the Net. URL: <http://www.forrester.com/ER/Research/Report/0,1338,9114,FF.html> [accessed 2001 Mar 15]
33. Lorenzi NM, Riley RT, Blyth AJ, Southon G, Dixon BJ. Antecedents of the people and organizational aspects of medical informatics: review of the literature. J Am Med Inform Assoc 1997;4(2):79-93. [PMC: [9067874](#)] [Medline: [97220712](#)]
34. Middleton B, Anderson J, Fletcher J, Masarie FE, Leavitt MK. Use of the WWW for distributed knowledge engineering for an EMR: the KnowledgeBank concept. Proc AMIA Symp 1998:126-130. [Medline: [99123100](#)]
35. Rice F, Ward DH, Patrick TB, Sievert M, Hodge R, Kemp ED. Calming the Waters: Helping Patients Find Healthcare Resources in the Sea of Information. Proc AMIA Symp 1999:1144.
36. Dixon DR, Stewart M. Exploring information technology adoption by family physicians: survey instrument valuation. Proc AMIA Symp 2000:185-189 [FREE Full text] [Medline: [21027344](#)]
37. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: a public highway or a private road? JAMA 1998 Oct 21;280(15):1371-1375. [Medline: [99008453](#)] [doi: [10.1001/jama.280.15.1371](#)]
38. Robinson C, Flowers CW, Alperson BL, Norris KC. Internet access and use among disadvantaged inner-city patients. JAMA 1999 Mar 17;281(11):988-989. [Medline: [99184236](#)] [doi: [10.1001/jama.281.11.988-a](#)]
39. Cooper-patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR, Nelson C, et al. Race, gender, and partnership in the patient-physician relationship. JAMA 1999 Aug 11;282(6):583-589. [Medline: [99377932](#)] [doi: [10.1001/jama.282.6.583](#)]
40. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. Arch Intern Med 1998 Jan 26;158(2):166-172. [Medline: [98110005](#)] [doi: [10.1001/archinte.158.2.166](#)]
41. Grueninger UJ. Arterial hypertension: lessons from patient education. Patient Educ Couns 1995 Sep;26(1-3):37-55. [Medline: [96037463](#)] [doi: [10.1016/0738-3991\(95\)00750-T](#)]
42. Pearson J, Jones R, Cawsey A, Mcgregor S, Barrett A, Gilmour H, et al. The accessibility of information systems for patients: use of touchscreen information systems by 345 patients with cancer in Scotland. Proc AMIA Symp 1999:594-598 [FREE Full text] [Medline: [20032938](#)]
43. Patyk M, Gaynor S, Kelly J, Ott V. Touch-Screen Computerized Education for Patients with Brain Injuries. Rehab Nursing 1998;23:84-87.
44. Glasgow RE, Mckay HG, Boles SM, Vogt TM. Interactive computer technology, behavioral science, and family practice. J Fam Pract 1999 Jun;48(6):464-470. [Medline: [99313062](#)]
45. Falling Through the Net: Toward Digital Inclusion. URL: <http://www.ntia.doc.gov/ntiahome/ftn00/contents00.html> [accessed 2001 Apr 2]

submitted 23.02.01; peer-reviewed by McLellan, Little, Adelhard; comments to author 16.03.01; revised version received 03.04.01; accepted 03.04.01; published 09.04.01.

Please cite as:

Gerber BS, Eiser AR

The Patient-Physician Relationship in the Internet Age: Future Prospects and the Research Agenda

J Med Internet Res 2001;3(2):e15

URL: <http://www.jmir.org/2001/2/e15/>

doi: [10.2196/jmir.3.2.e15](#)

PMID: [11720957](#)

© Ben S Gerber, Arnold R Eiser. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 9.4.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Original Paper

Comparing Web and Touch Screen Transaction Log Files

David Nicholas¹; Paul Huntington¹; Peter Williams¹

The Internet Studies Research Group, Department of Information Science, City University, London, UK

Corresponding Author:

David Nicholas

Department of Information Science

City University

London EC1V 0HB

UK

Email: nicky@soi.city.ac.ukURI: <http://www-digitalhealth.soi.city.ac.uk/isrg/doh.htm>

Abstract

Background: Digital health information is available on a wide variety of platforms including PC-access of the Internet, Wireless Application Protocol phones, CD-ROMs, and touch screen public kiosks. All these platforms record details of user sessions in transaction log files, and there is a growing body of research into the evaluation of this data. However, there is very little research that has examined the problems of comparing the transaction log files of kiosks and the Internet.

Objectives: To provide a first step towards examining the problems of comparing the transaction log files of kiosks and the Internet.

Methods: We studied two platforms: touch screen kiosks and a comparable Web site. For both of these platforms, we examined the menu structure (which affects transaction log file data), the log-file structure, and the metrics derived from log-file records.

Results: We found substantial differences between the generated metrics.

Conclusions: None of the metrics discussed can be regarded as an effective way of comparing the use of kiosks and Web sites. Two metrics stand out as potentially comparable and valuable: the number of user sessions per hour and user penetration of pages.

(*J Med Internet Res* 2001;3(2):e18) doi:[10.2196/jmir.3.2.e18](https://doi.org/10.2196/jmir.3.2.e18)

KEYWORDS

Metrics; access log files; Internet; health; Web site; touch screen kiosks; robust measures; caching

Introduction

There are an increasing number of formats by which digital health information can be disseminated. The media that have been employed to disseminate health information since the "digital revolution" include the Internet, CD-ROMs, WAP (Wireless Application Protocol) phones, touch screen public kiosks, videoconferencing, and cable television. One-half of all American homes now have access to the Internet. Britain is said to be leading the European "race" to get online [1]. Accompanying (and fuelling) this online boom is the growing demand to provide the public with informed choices. To give one example, less than one year after Medline became freely available on the Web, the number of searches increased tenfold, with no less than 30% of users being members of the general public [2]. Cyber Dialogue [3] claims that in the United States alone, nearly 41 million Internet users consult the Web for health care information.

While many people have been eagerly watching for the latest Internet development, touch screen digital health information kiosks (and their hybrid forms) have quietly spread around Britain. There are probably more than 200 of them altogether, in surgeries, hospitals, health centers, and shopping centers and even in airports and railway stations. It has been predicted that the number is likely to double over the next couple of years. Kiosks can produce comprehensive and in-depth information and can appeal to people that do not have Internet access at home—for example, the elderly and the poor. Little research has been done, however, to test the public's receptivity to this new medium.

Use is clearly an important characteristic in assessing the popularity of a touch screen kiosk and in making comparisons between Web sites and kiosks. The source of most use data is the digital logs that record user activity on a continuous and real-time basis. The logs provide data on what people have done, not on what people might do or remember having done—this gives the logs their strength, and differentiates them from other

data-capture methods, like questionnaires and interviews. There is much demand from sponsors, Web site and kiosk owners, and marketing departments for this information. To meet the demand, a range of metrics has been introduced: pages viewed, time on-line, page view time, and number of users (visitors). These metrics are much bandied about by the press. Terms like hits and visitors have entered our everyday vocabulary.

Surprisingly then, generating kiosk-use metrics from log files has not been well researched, despite the fact that it is important to undertake such studies for a number of reasons.

Firstly, such analyses give information-providers data on, for example, which pages, pieces of information, or subjects are being accessed and to what extent. This data can be cross-tabulated by age and gender. From this information policy decisions can be made regarding increasing, changing, or reducing the information provided, depending on who is targeted to receive the information. To give one example, if a document posted on a kiosk dealing with some aspect of drug abuse was shown to be accessed by few of the target age group (eg, 18-25 year olds), but by many more 40-50 year olds the information provider would be armed with information indicating that it is the older age group (possibly parents of teenagers) who read pages on this topic. The page could thus be modified either to provide more information that may be relevant to parents, or to repackage the information in another attempt to reach the original intended target.

Secondly, commercial interests come into play in gauging usage-advertising space on web sites is sold on the basis of readership. Still on this theme, if commercial providers (such as newspapers) have a clearer idea of who is looking at their product they can tailor it to capture a larger readership. On discovering, for example, that a large proportion of its readers were coming in from the United States, The Independent newspaper has begun to emphasize news items that cater to this market.

Looking at the minimal research that has been undertaken, Jones et al [4] estimated use of a medical kiosk by questionnaire only and did not analyze log files. A later study of Healthpoint kiosks by Naven et al [5] did analyze logs of a limited number of users and showed that although only 65 search "episodes" were logged, CCTV (Closed Circuit Television) video showed that the system was actually used by a total of 116 users. The discrepancy was due to users taking over the kiosk before it timed out, thus appearing on the log file to be a continuation of the previous searcher. Also, Jones et al [6] in a comparative study of information technology delivery systems for patients, used log statistics to estimate session times, although the methodological problems associated with this metric were not discussed.

Much of the analysis and development of metrics associated with logs comes from the study of Internet-access (Web site) log files [7,8,9] and OPAC (Online Public Access Catalog) log files [10]. Typically, metrics reported include the number of pages viewed, page view time, number of pages per session, and session length. Early research on Web metrics [11] looked at how to standardize metrics and terminology for the advertising industry. Pitkow [12] noted inconsistencies in terminology and

revisited the idea of what terms should be employed to describe the metrics. Neither included an analysis of the problems or an estimate of metric statistics. Chun et al [13] investigated search behavior in a small sample (32 users) by questionnaire and by tracking client machine log files; they identified what they termed search "episodes" but did not clarify the definition of an episode or estimate an episode time. Williamson [14], among others, points to the frustrations posed by logs: "it's a marketer's dream--and worst nightmare: Being able to watch your customers' every move, but possessing only limited tools to influence them." Much of the literature is concerned with the problems and pitfalls associated with Web site log analysis. Zawitz [15] makes the very important point that server logs and their measures were designed originally to measure and manage server traffic and not to analyze the use/effectiveness of Web sites. As a result measures are often misquoted or misunderstood.

Aims and objectives of The Digital Health Information Project

The Digital Health information project is a far-reaching UK Department of Health funded study into the developing use of digital consumer-health-information services, which is being undertaken by City University in cooperation with Intouch with Health, a leading UK consumer health-information company. Intouch with Health has been responsible for deploying 70 health-information touch screen kiosks around the country, and has a comparable health Web site SurgeryDoor (www.surgerydoor.co.uk). Intouch with Health has made transaction log data from both kiosks and the SurgeryDoor Web site available as a national test-bed against which to benchmark the progress and impact of digital information provision.

The aims of the Digital Health information project are to develop a context-specific understanding of the extent to which and way in which the public interact with the digital delivery of health care information and to examine the wider issues involved: eg, impact of information and communication technologies (ICTs) on the health care profession in general, implications for training needs, and health-inequalities issues.

The paper presented here is part of the Digital Health information project and compares metrics derived from the access logs of the SurgeryDoor Web site with metrics derived from four of Intouch with Health's kiosks. The kiosk sites involved in this study are: the Harpenden general practice surgery, the Edinburgh Royal Infirmary, the Wakefield walk-in health center, and the Esk medical center based in Scotland. Comparisons were made on the basis of data collected for July 2000. During this period the four kiosks recorded an approximate page use of 30,062, and the Web logs recorded an approximate page use of 118,350.

Methods

As previously mentioned two "platforms," or information-delivery systems, were studied, both the product of the digital health information company Intouch with Health. These were the publicly-accessible Web site SurgeryDoor and a touch screen kiosk.

The purpose of both platforms is to provide the general public (rather than medical professionals) with information about all aspects of health and medical care. This includes advice for people facing a surgical operation, attempting to give up smoking, or simply desirous of leading a healthier lifestyle. For much of the information the text is the same on the two platforms. However, the Web site is more comprehensive in

terms of scope of content. It includes, for example, such features as a health-consumer magazine and the latest health news.

Both systems are menu-based. The Web site (Figure 1) has menus on both the left and the right of an information page and offers direct access to submenus, with the menu hierarchy listed fully.

Figure 1. Home page of SurgeryDoor Web site showing menu-hierarchy structure

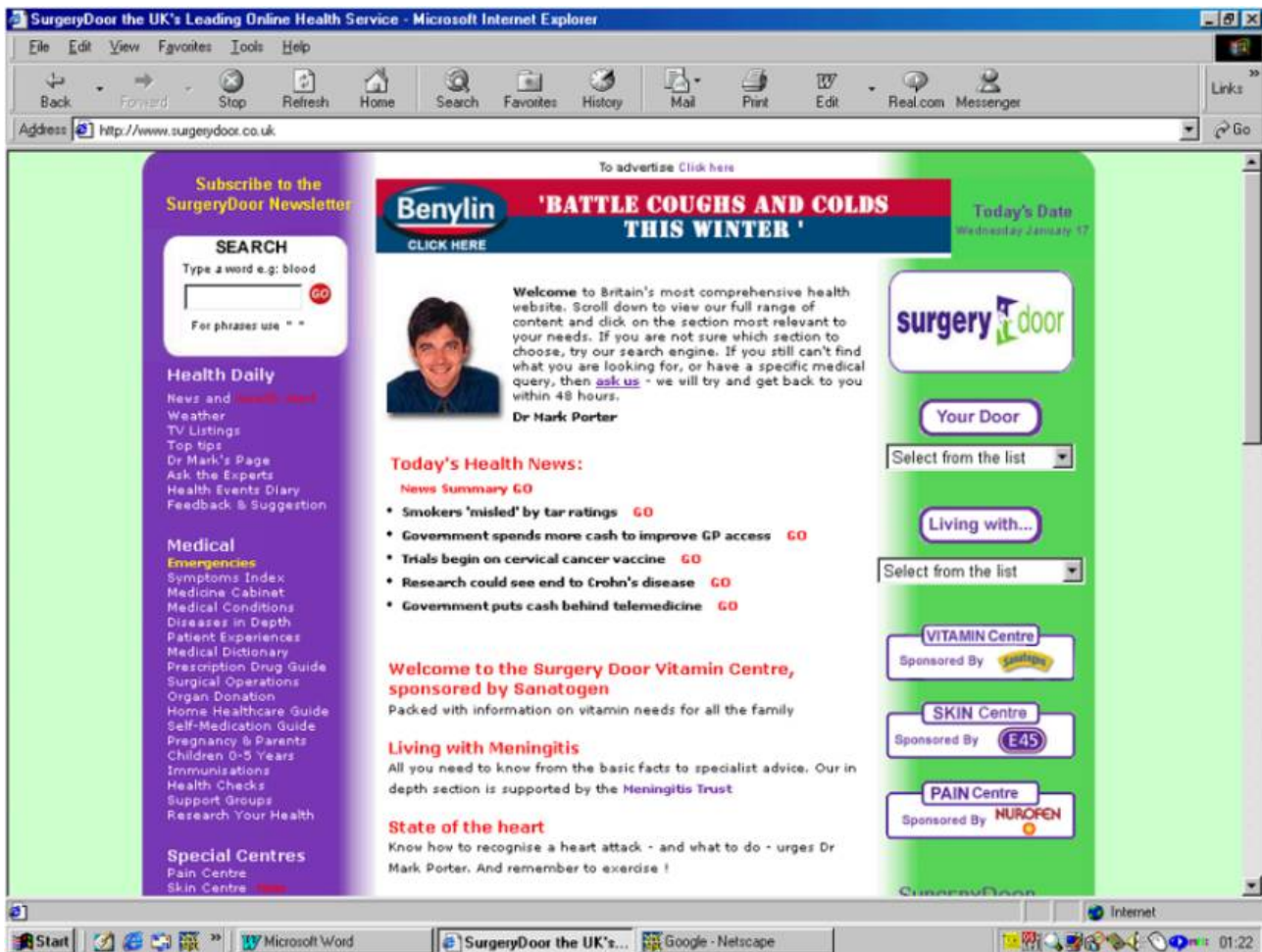


Figure 2. One of two "home page" screens from an Intouch with Health kiosk



Kiosks (Figure 2) have a screen for a set of menus that lead to an information page. The kiosk "home page" consists of eight menu buttons distributed between 2 screens. Accessing all 8 menu-buttons requires "toggling" (switching) between 2 screens. The menu buttons lead to submenu pages.

The menu options for the two platforms are different, but there is some overlap. Both platforms have a Healthy Living menu item and both include sections on the National Health Service (NHS): called NHS & benefits on the Web site, and A-Z of the NHS on the kiosk. The Web site has entries that are not on the kiosk: Community & Fun, Complementary Medicine, and Shopping.

When comparing the platforms, it is important to distinguish between differences in content and differences in structure. Differences in content of the two platforms: there is material on the Web site that is not on the kiosk. Differences in structure of the two platforms: differences concerned with, for example, Medical Conditions and Surgical Operations are principally differences in structure.

The structural differences between the two platforms can be illustrated by the example of Surgical Operations. Although Surgical Operations is not a main heading on the Web site, unlike on the kiosk, it is nevertheless an entry, subsumed under the main heading of Medical. Selecting the Surgical Operations submenu link on the Web site or the Surgical Operations link

on the kiosk, gives access to virtually the same content, but via different routes.

- **Web site**
the Surgical Operations submenu link leads to a page displaying each letter of the alphabet. Selecting a letter-link leads to a list of medical conditions that start with the selected letter. Selecting a medical condition leads to information on the selected condition.
- **Kiosk**
selecting the Surgical Operations option leads to a main-menu page listing options, eg, Blood vessel systems, Bones, Joints and tendons, Breast, and Children's operations. Selecting an option leads to a comprehensive scrollable alphabetical list of conditions and then to information on the conditions.

However, importantly, the list of conditions on the Web site appears to be identical to the list of conditions on the kiosk and the information for a condition on the Web site appears to be identical to the information for the same condition on the kiosk (on both platforms, the information is under the headings: What is it?, The Operation, Any Alternatives, Before the operation, After - In Hospital, After - At Home, Possible Complications, and General Advice).

Another difference between the two platforms is that the Web site does not collect personal information. The Web site does not ask for age or gender information. Cookies (files or parts

of files stored on a Web-site-user's computer, created and subsequently read by a Web site server, containing personal information such as an identification code) could have been used to collect some user information but they were not used on this Web site. The kiosk, however, did prompt users to give their age and gender.

What are log files?

Log files are machine-generated records of user activity. Both kiosk logs and Internet-access (Web site) logs record user page requests.

Kiosk log files

Table 1 shows an example of information from a log file of a kiosk user session.

Table 1. Example of Information from a Log File of a Kiosk User Session

H	10-Jan-1999	Sun	15:14:17	0000	_Male_ 1 under 15
D	10-Jan-1999	Sun	15:14:18	0001	1#####001#XXX
D	10-Jan-1999	Sun	15:14:26	0008	#6#####002#XXX
D	10-Jan-1999	Sun	15:14:32	0014	#6a0#####00001#####003#XXX
D	10-Jan-1999	Sun	15:14:50	0032	#6a2#####00001#####004#XXX
D	10-Jan-1999	Sun	15:15:10	0052	#3-#####600001###005#XXX
D	10-Jan-1999	Sun	15:15:14	0056	#3--####0015#####600001###006#XXX
D	10-Jan-1999	Sun	15:15:21	0064	#3--a###0015#00090#600001###007#XXX
T	10-Jan-1999	Sun	15:15:43	0085	

- **First column**
codes page information: H indicates a beginning of a session, D a successful page view, and T a termination sequence generated by the user.
- **Next three columns**
record the date, day, and time.
- **Column starting 0000**
records the seconds from the start of a session; this system does not record the time taken by the user to fill in age and gender details; recording of time starts when the user selects "continue" from the age-and-gender page. In the second row, 0001 is the time taken to download the first menu page. This user spent 7 seconds negotiating the first menu page. As shown in the last row, this user session lasted 85 seconds. The longest page view was 21 seconds (calculated by subtracting 64 from 85) and the shortest was 4 seconds (calculated by subtracting 52 from 56). Information in this column will be affected by the kiosk's automatic termination of a session after two minutes of inactivity.
- **Last column**
records gender and age, in the first row, and page information, in other rows. In the first row, the "1" to the right of Male is the age grouping and repeats (codes) the "under 15" information. In other rows, the numbers and hash signs (#s) relate to page identification codes. The 001 near the end of the line in the second row is a page counter; each line of a log refers to a page viewed by the user. The counter does not record the opening dialogue page where the user records age and gender.

Web log files

Web log files record a range of information similar to the information in a kiosk log file, but the information collected will depend on the software used and how the server was configured. A Web site page is made up of one or more graphic/text files that are delivered separately and then combined on the client's machine. The SurgeryDoor Web site used Microsoft Internet Information Server 4.0 software that was configured to record requests of files rather than requests of pages.

Table 2 shows an example of information from the SurgeryDoor Web site log.

- **First and second columns**
record the date and time.
- **"IP number" column**
records the user's identifying IP (Internet Protocol) number.
- **"Request" column**
records the user's request.
- **"File request" column**
records the name and directory of the file downloaded; in the first line, the file requested is "chickenpox.htm" and in the second line the file requested is a graphic file "tv_surgery.jpg."
- **Next two columns**
record the status of the delivery and the browser compatibility (information on the type of browser software used to access the Web site).
- **Last column**
records the Web page the user came from.

Table 2. Example of Information from a Web Log File

Date	Time	IP number	Request	File request	Delivery Status	Browser compatibility	
2000-04-02	07:58:43	62.252.100.17	GET	/homehealth-careguide/chicken-pox.htm	200	Mozilla/4.0+(compatible;+MSIE+4.01;+Windows+95;+VNIE4)	http://www.surgery-door.co.uk/frame/search.asp?Search-Where=ALL
2000-04-02	07:58:46	62.252.100.17	GET	/homehealth-careguide/tv_surgery.jpg	304	Mozilla/4.0+(compatible;+MSIE+4.01;+Windows+95;+VNIE4)	-
2000-04-02	07:58:46	212.140.119.160	GET	/images/middle.jpg	200	Mozilla/4.0+(compatible;+MSIE+5.0;+Windows+95;+DigExt)	http://www.surgery-door.co.uk/frame/topleft.htm

Differences between kiosk and Web log files

There are a number of important differences between the kiosk and Web log files.

- **User identification**

Kiosk logs do not provide a user identification number. Web logs provide an IP number. The IP number cannot be traced back to an individual, only to a machine. The extensive use of proxy servers and Point-to-Point Protocol (PPP) connections mean that the IP address might not relate to a specific machine (since the IP address might have been temporarily allocated to that machine) and might relate to a group of users (rather than to an individual). Cookies, which sit on the client's machine, can be employed to help overcome these problems. However Web users may be sensitive to having cookies placed on their machines. Still, Web providers can, and many do, place cookies on client machines, since most browsers are installed by default with cookie acceptance turned on and the average user probably does not turn cookie acceptance off. Cookies were not used on the SurgeryDoor Web site.

- **Multiple users**

While only one user can use a kiosk at a time, many users can be logged on to a Web site at the same time. Kiosk logs record the consecutive pages viewed by one user. For Web logs, however, the server may have a large number of remote clients logged on simultaneously. The server records a time sequence of file downloads from these clients (that is, the sequence is ordered by the time a file is sent, not by client IP number), so sequences within individual user sessions are identifiable only after the file has been sorted by IP number and, within IP number, by time.

- **Data record**

Kiosk logs record pages viewed, while Web logs generally record files requested, though the software can be configured to record pages only. As a result it is not uncommon to discard 85% of Web log lines, relating to images downloaded, in a multistage process to estimate pages viewed. Furthermore, as HTML has developed identifying files to reject has become more and more complicated.

- **Time measurement**

Kiosk logs record the log-off time of the user, either as a result of a user-generated termination request or the automatic log off that happens after two minutes of inactivity. In most cases as far as Web site logs are concerned people do not log off from the Web, they depart anonymously. Typically, a log off or session end is assumed to occur after a specified time of inactivity. The industry (for example, Zawitz [15]) normally assumes a 30-minute inactivity as a termination signal. A 30-minute time out signal is probably too generous (and inaccurate) given a typical page reading time of a minute.

Table 3 shows the metrics that can be generated solely from Internet and kiosk log files. Metrics common to both include: number of pages viewed, number of user sessions, length of session, page view time, number of pages viewed in a session, and subject viewed. Time-based Internet variables have to be calculated on the basis of the lapse in time between the downloading of one page and the downloading of the next page or on the change of a session (as demonstrated by a change in IP address). Individuals may be tracked on the kiosk only if they were asked to log in using an identification name-and this was not the case in our study.

Table 3. Metrics that can be generated solely from Internet and kiosk log files

	Internet	Kiosk
Number of pages viewed	&	&
Number of users	&	
Number of user sessions	&	&
Length of session	&	&
Page view time	&	&
Number of pages viewed in a session	&	&
Amount of use per user	&	
Returnees	&	
Geographical location	&	
User gender		&
Subject viewed	&	&
User age		&

Problems comparing kiosk and Web log files

Comparing "hits" or page impressions (the number of times a Web page has been accessed) between on-line systems poses many problems. The most severe problem is caching of pages when using the Web. Caching of files takes place as the files are downloaded to the client's machine; a file may be cached by the client's machine, the client's provider, or by a user wishing to cache the contents of a Web site to display elsewhere.

Local caching to the client's machine occurs once a page is viewed. Files related to that page are stored on the client's computer; further views of that page are made from this cache and are not recorded in the Web log files. Local caching may be switched off by the client but rarely is, because caching speeds up the reading and access of pages. Hence Internet log files will underreport pages viewed by the number of pages extracted from the cache. Fieber [16] compared videotaped user sessions with the data recorded in the log and found that, depending on the length of the session, between 32% and 55% of transactions were cached and as a result were not recorded by the Web log. This is not an issue with kiosks as their logs record every page viewed by the user. Hence, although estimates of page impressions can be derived for both Internet and kiosk information retrieval systems, the estimates are not strictly comparable. Internet metrics assume the presence of caching and an adjustment cannot easily be made to estimates of page impressions or even to the number of pages used in a session. Browsers can be configured to check for cached pages; however this is unlikely to happen as this slows the delivery of pages-and page-delivery times are a key performance measure for most Web sites.

It sometimes happens that a user will cache the contents of a Web site to deliver the content to a third party or to a population of users; this eases data transfer problems, because information can be delivered locally. The initial and subsequent caching is recorded in the logs of the originating information holder, but page use and hits recorded against the caching server are not. Internet statistics underreport usage because of this.

Robots are another feature of the Internet environment that create havoc with the Internet metrics but are not a feature of kiosk use. Robots are electronic agents used by search engines and organizations to put information about Web page addresses and content in databases. Robot activity is recorded in the log file. Gutzman [9] states that it is estimated that as much as a third of all Web site traffic is made up of robots and spiders (a term that often means robots, as defined in this paper, but which may also mean programs looking for e-mail addresses). Robot use should be excluded from the count of page impressions and many of the software packages available for analyzing log files have an option to exclude robots. Robots can be identified by analyzing IP addresses or by seeing which users visit the "robot.txt" file. This file resides on the host Web server and is accessed by robots. However robots can be set up to not visit the robot.txt file and may have an address that may not be resolved to a domain name server (a domain name server has a database of host computers and their IP addresses). These undeclared robots will be difficult to exclude from the count of page impressions. This makes comparisons between a kiosk and the Internet based on a page-count metric unreliable.

Results

Page view time comparison

Page view time appears on the surface to be a metric that can be used to compare kiosk and Internet use. Arguably, view time can be taken as a measure of user satisfaction. Table 4 compares estimates of page view time obtained from kiosk and Internet. Both the frequency distribution of kiosk page view time and Internet page view time were found not to be normally distributed but to be skewed (nonsymmetrical). This is indicated in Table 4 by the differences between the arithmetic mean and the median. The arithmetic mean will be biased and cannot be relied upon if the underlying distribution departs from the normal distribution. To accommodate the departure from the normal distribution the robust estimators (estimators that are not very sensitive to the presence of anomalous values in the sample) the 5% trimmed mean and Huber's M-estimator were

generated. Both give estimates of the mean that are not sensitive to the underlying frequency distribution and give unbiased estimates of the mean. The 5% trimmed mean does this by discarding the lowest and highest 2.5% of the values and then

computing the mean of the remaining values, Huber's M-estimator is a weighted mean estimate where extreme values are given less weight.

Table 4. Page view time in seconds: Kiosk and Internet

	Estimate of kiosk page view time	Estimate of Internet page view time
Mean	27.66	1137.30
Median	10.00	59.00
5% trimmed mean*	17.91	283.82
Huber's M-estimator*	11.19	68.99

* Estimators of the mean that are not very sensitive to the presence of anomalous values in the sample.

Kiosk page view time is less than that recorded for the Web. Given the severity of the departure, as indicated by the difference between the arithmetic mean and the median, from the normal distribution it was decided to use Huber's M-estimator. The mean view time of a kiosk page was approximately 11 seconds and this compares to a mean view time of approximately 69 seconds of an Internet page. Thus, Internet page view time is estimated to be about 6 times that of kiosk page view time—a large difference. There are a number of factors that might explain this, the three most important being:

- **Load up time**
Internet users are subject to a download waiting time while the server delivers the page to and displays the page on the client's computer. Load up time is likely to be increased by increased use of graphics.
- **Information density**
The density of information may affect delivery time, and it may be expected that increasing the density of information on the screen will increase the download time.
- **Caching**

Internet page view time will include the viewing of cached pages. Page view time is the difference between time stamps. However, since logs do not record access to locally-cached pages the time difference will include views of cached pages, thus extending page view time significantly.

Caching is the most influential of the 3 factors since depending on how the Web site is constructed more than half the pages viewed may be from the client's cache. Clearly the more pages that are cached the longer the between-page download time recorded by the server will be. Further, even cached pages are subject to a delay in appearing on the screen.

Session view time

Session view time also appears to be a worthy metric for comparisons. Longer sessions might indicate greater user satisfaction. Table 5 compares estimates of kiosk and Internet session time. An Internet session end signal was recorded if the user remained on a page for longer than 300 seconds. Session time distributions were skewed and robust estimators were again generated.

Table 5. Session view time in seconds: Kiosk and Internet

	Estimate of kiosk Session view time	Estimate of Internet session view time
Mean	201.72	3472.37
Median	123	495
5% trimmed mean	162.87	1936.90
Huber's M-estimator	133.52	586.23

Again Huber's M-estimator is used because of the severity of the departure from the normal distribution. The estimated length of a session at the Web site is approximately 4 times that of a kiosk session—slightly less than 10 minutes for the Web site compared to slightly more than 2 minutes for the kiosk. Load up time will again be a major reason for this difference. Another factor might be Web site design.

Number of sessions

The number of sessions conducted is a metric common to both kiosks and the Internet. The total number of Internet sessions for July 2000 was estimated to be 34,243. The four kiosks recorded an estimated 2,689 user sessions. To enhance the metric it was decided to estimate the average number of sessions per hour. By using a rate per hour the metric is not sensitive to kiosk opening-hour differences. The overall estimates of user sessions per hour are shown in Table 6.

Table 6. Average Number of Sessions Per Hour: Kiosk and Internet

	Estimate of Kiosk sessions per hour	Estimate of Internet sessions per hour
Mean	1.67	46.02
Median	1.65	59.91
5% trimmed mean	1.57	46.07
Huber's M-Estimate	1.48	51.53

The average number of sessions per hour for the kiosks was estimated at about 1.67 (for the kiosk data there is little difference between the mean and median so the mean is used here). The average number of sessions per hour for the Internet is about 51 (for the Internet data there is a difference between the mean and the median so the Huber's M-estimator is used here). Using number of user sessions per hour as a metric we can argue that the Web site provides approximately the same information service as about 30 kiosks. However, as a metric, number of user sessions per hour is only of limited value. The metric gives only a basic comparison and no estimate of user satisfaction or any indication that the user has made use of the information.

Use per session

In an attempt to make more meaningful statements about the extent to which people use a system, we classified users according to whether they reached only menu (navigation) pages or whether they penetrated to (reached) a page with actual information (non-navigation) content. For what we consider actual use to have occurred, the information seeker has to navigate beyond the collection of initial menu screens and reach the actual information pages. This type of classification is especially important in menu-based systems where the user has to navigate through a number of menu screens to arrive at an information page. This idea can be developed into a manageable and versatile metric by grouping users by the number of pages

they have viewed. However, the number of pages that a user has to navigate before reaching an information page is different for the Web and the kiosk, and will be affected by the caching of pages.

- **Web site**
users recording a single page download were classified as not penetrating to an information page. This classification is based on the Web site as of July 2000. In July 2000, content pages were single HTML pages containing information on a number of topics with a menu of internal links at the top of the page. There were up to 2 higher-level menus. Also, there were a variety of links from the opening page that went directly to an information page. Depending on how users entered the Web site it was highly likely that they would have cached a multiple-topic information page and a menu page by downloading just two pages. The user could then read about related topics by accessing the cached information and menu pages; during this access the server would not record any more hits or page downloads.
- **Kiosk**
users viewing 4 (or fewer) screens were classified as not having penetrated to an information page. This classification is based on the need to navigate 4 menu screens (see Methods, above) to reach an information page.

Table 7 shows the result of these classifications.

Table 7. Percentage of Users Penetrating to Information Pages

User classification*	Kiosk users %	Internet users %
Not penetrating to (reaching) an information page	28.9	34.5
Penetrating to (reaching) an information page	71.1	65.5

* Kiosk users viewing 4 (or fewer) screens were classified as not having penetrated to an information page. Web site users recording a single page download were classified as not penetrating to an information page.

From Table 7 there appears to be slightly more penetration of pages on a kiosk compared to the Internet. Approximately 71% of kiosk users reached an information-rich page compared to an estimated 65.5% on the Internet. This is a metric needing further research; in particular, more research is needed on how users navigate to an Internet information-content page.

Discussion

None of the metrics examined can be regarded as an effective way of comparing the use of the two different platforms. The

most reliable measure, the number of user sessions per hour, is the weakest in terms of understanding obtained. The measure of page penetration, while more informative, needs much more work done on it. Session length is also a promising metric although in regard to the Internet it needs to be adjusted for download time and Web site design if this should prove to be factor. Measures based on the amount of page use and page view time are not comparable as Internet based measures include a significant but non-quantifiable cached element. Internet logs are not easily comparable to kiosk logs.

Acknowledgments

The paper emanates from research on digital health consumer information services conducted for the Department of Health, UK: The Web, the kiosk, digital TV and the changing face of consumer health information provision: a national impact study. April 2000 - January 2002. We are thankful to the JMIR reviewer who pointed out that information density might account for page view time differences.

Conflicts of Interest

None declared.

References

1. Jameson R. Britain Leads EU Internet Race. NOP Research Group Internet Survey. 2000 Apr 23. URL: <http://www.nopres.co.uk/> [accessed 2001 Apr 8]
2. Lindberg DAB. Fiscal Year 1999 President's Budget Request for the National Library of Medicine, Department of Health and Human Services: Statement by Dr. Donald A.B. Lindberg Director, National Library of Medicine. 1998 Mar 18. URL: <http://www.nlm.nih.gov/pubs/staffpubs/od/budget99.html> [accessed 2000 Apr 8]
3. ; Cyber Dialogue. Cyber Dialogue Releases Cybercitizen Health 2000. 2000 Aug 22. URL: <http://www.cyberdialogue.com/news/releases/2000/08-22-cch-launch.html> [accessed 2000 Apr 24]
4. Jones R, McLachlan K, Bell G. HEALTHPOINT: a Public-access Health Information system. In: Deglanville H, Roberts J, editors. Current perspectives in Health Computing. Weybridge, England: BJHC Books; 1990:65-69.
5. Naven L, Jones R, Kohli H, Crawford J. How Should we Evaluate a Public-access Health Information System. In: Richards B, editor. Healthcare Computing. Weybridge, England: BJHC Books; 1996:557-562.
6. Jones R, Labajo R, Soler LM, Sanz JJ, Alonso P, Claveria LE. Evaluation Of a Scottish Touch-screen Health Information System in Rural Spain. In: Bryant J, editor. Healthcare Computing 2000. Weybridge, England: BJHC Books. [in press].
7. Stout R. Web Site Stats: Tracking Hits and Analyzing Web Traffic. Berkeley, Calif: McGraw-Hill Osborne Media; Dec 1, 1996.
8. Williams D. Data Plays Key Role in Net Success. URL: <http://www.adage.com/interactive/articles/19990802/article3.html> [accessed 1999 Oct 17]
9. Gutzman A. Analyzing Traffic on Your E-commerce Site. URL: http://ecommerce.internet.com/solutions/tech_advisor/article/0,,9561_186011,00.html [accessed 2001 May 2]
10. Nicholas D, Huntington P, Williams P, Lievesley N, Withey R. Developing and Testing Methods to Determine the Use of Web Sites: Case Study Newspapers. Aslib Proceedings 1999;51(5):144-154.
11. Novak TP, Hoffman DL. New Metrics for New Media: Towards the Development of Web Measurement Standards. 1996 Sep 26. URL: http://www2000.ogsm.vanderbilt.edu/novak/web_standards/webstand.html [accessed 2000 May 22]
12. Pitkow J. In Search of Reliable Usage Data on the WWW. URL: <http://www.scope.gmd.de/info/www6/technical/paper126/paper126.html> [accessed 2000 May 19]
13. Choo CW, Detlor B, Turnbull D. Information Seeking on the Web: An Integrated Model of Browsing and Searching. First Monday [serial online]. 2000 Feb. (2) URL: http://www.firstmonday.dk/issues/issue5_2/choo/ [accessed 2000 Jul 17]
14. Williamson D. Data Plays Key Role in Net Success. 1999 Aug. URL: <http://www.adage.com/interactive/articles/19990802/article3.html> [accessed 1999 Oct 17]
15. Zawitz M. Web Statistics -- Measuring User Activity. 1998 May. URL: <http://www.ojp.usdoj.gov/bjs/pub/ascii/wsmua.txt> [accessed 1999 Oct 9]
16. Fieber J. Browser Caching and Web Log Analysis. 1999 May 25. URL: <http://ella.slis.indiana.edu/~jfieber/papers/bcwla/bcwla.html> [accessed 1999 Sept 9]

Abbreviations

CCTV: Closed Circuit Television
ICT: Information and Communication Technology
IP: Internet Protocol
NHS: National Health Service
OPAC: Online Public Access Catalog
PPP: Point-to-Point Protocol
WAP: Wireless Application Protocol

submitted 05.09.00; peer-reviewed by R Appleyard; comments to author 29.11.00; revised version received 21.02.01; accepted 22.04.01; published 23.05.01.

Please cite as:

Nicholas D, Huntington P, Williams P

Comparing Web and Touch Screen Transaction Log Files

J Med Internet Res 2001;3(2):e18

URL: <http://www.jmir.org/2001/2/e18/>

doi: [10.2196/jmir.3.2.e18](https://doi.org/10.2196/jmir.3.2.e18)

PMID: [11720960](https://pubmed.ncbi.nlm.nih.gov/11720960/)

© David Nicholas, Paul Huntington, Peter Williams. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 23.5.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Original Paper

Virtual Sonography Through the Internet: Volume Compression Issues

Olga Ferrer-Roca¹, MD, PhD; Joseba Vilarchao-Cavia²; Juan-Mario Troyano-Luque³, MD; Matilde Clavijo⁴, MD

¹Chair of Pathology and UNESCO Chair of Telemedicine, University of La Laguna, Spain

²Fellow at the UNESCO Chair of Telemedicine, Spain

³Chief of the Gynecology Ultrasound Unit. Clinic Hospital, Tenerife, Spain

⁴Assistant doctor at the Ultrasound Unit. Clinic Hospital, Tenerife, Spain

Corresponding Author:

Olga Ferrer-Roca, MD, PhD

University of La Laguna

38071 Tenerife, Canary Islands

Spain

Phone: +34 922 319321

Fax: +34 922 641855

Email: catai@teide.net

URI: <http://www.teide.net/catai>

Abstract

Background: Three-dimensional ultrasound images allow virtual sonography even at a distance. However, the size of final 3-D files limits their transmission through slow networks such as the Internet.

Objective: To analyze compression techniques that transform ultrasound images into small 3-D volumes that can be transmitted through the Internet without loss of relevant medical information.

Methods: Samples were selected from ultrasound examinations performed during, 1999-2000, in the Obstetrics and Gynecology Department at the University Hospital in La Laguna, Canary Islands, Spain. The conventional ultrasound video output was recorded at 25 fps (frames per second) on a PC, producing 100- to 120-MB files (for from 500 to 550 frames). Processing to obtain 3-D images progressively reduced file size.

Results: The original frames passed through different compression stages: selecting the region of interest, rendering techniques, and compression for storage. Final 3-D volumes reached 1:25 compression rates (1.5- to 2-MB files). Those volumes need 7 to 8 minutes to be transmitted through the Internet at a mean data throughput of 6.6 Kbytes per second. At the receiving site, virtual sonography is possible using orthogonal projections or oblique cuts.

Conclusions: Modern volume-rendering techniques allowed distant virtual sonography through the Internet. This is the result of their efficient data compression that maintains its attractiveness as a main criterion for distant diagnosis.

(*J Med Internet Res* 2001;3(2):e21) doi:[10.2196/jmir.3.2.e21](https://doi.org/10.2196/jmir.3.2.e21)

KEYWORDS

Virtual sonography, telemedicine, 3D-ultrasound, 3-D ultrasound, obstetrics, volume rendering

Introduction

Image-communication systems for medical images have bandwidth (data-transfer capacity) and image-size constraints that result in time-consuming connections for uncompressed raw-image data. Image compression is a key factor to improving transmission speed and storage, but it risks losing relevant medical information.

The radiology standard DICOM3 (Digital Imaging and Communications in Medicine, Version 3.0) [1] provides rules

for compression using lossless JPEG (Joint Photographic Expert Group) methods. However, there are no rules for acceptance of lossy compression in medical imaging—it is an extremely subjective decision. Acceptable levels of compression should never sacrifice diagnostic information.

Ultrasonography has always been envisaged as one of the easiest telemedicine applications due to the small size of images with a dynamic range of 8 bits [2]. A new era of daily patient-care, even at a remote site, is expected using volume-rendering techniques for 3-D reconstruction of noisy ultrasound (ultrasound) images.

The three most common radiology reconstruction techniques are: shaded surface display, maximum intensity projection for x-ray simulation [3], and 3-D volume rendering for solid 3-D reconstruction [4]. In 3-D volume rendering, volume data management includes special techniques for acquisition (in our case moving the ultrasound probe by hand), re-sampling (particularly detailed because of the compression it achieved) and editing the data set by "flying-through", "flying around", multiple-view display, obscured structure and shading depth cues, or kinetic and stereo depth cues [5].

In 3-D reconstructions, the original ultrasound "moving frames" are composed of 500 to 550 single frames of 512-pixel x 512-pixel-spatial resolution, and the size of the final image (100- to 120-MB) is too large to be sent through the Internet. This paper presents the experience of our team on 3-D ultrasound, focusing on data-reduction techniques that allow teleconsultation through the Internet.

Methods

This trial used ultrasound examinations carried out in the ultrasound unit in the Obstetrics and Gynecology Department at the University Hospital in La Laguna, Tenerife, Canary Islands, Spain in 1999 and 2000.

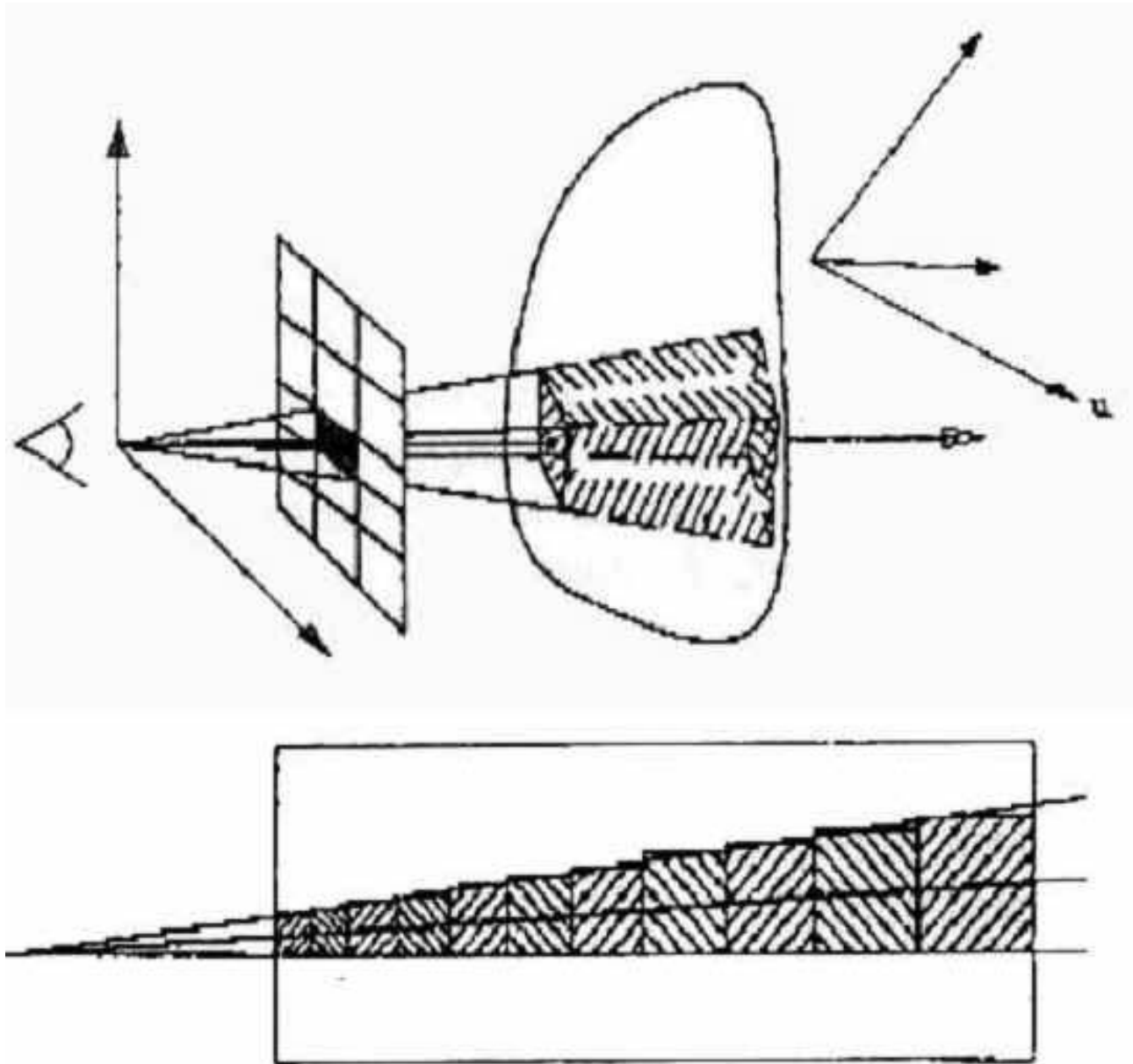
The ultrasound equipment used was an Aloka-SSD 680 ultrasound device connected to a PC. Acquisition was carried out by moving the ultrasound probe by hand. The probe was a 5-MHz curvilinear abdominal probe transducer, attached to a magnetic-field positioning device. The probe position, with 6 degrees of freedom, was transmitted to the computer by an ISA (Industry Standard Architecture) PC-Bird board,. A Falcon digitizing board captured frames with 8-bit dynamic range.

Our PC (Personal Computer) was a 450-MHz dual Pentium II computer, with 256-MB RAM using a Windows NT operating system.

Volume rendering and display were carried out with the TeleInVivo™ volume visualization software (Fraunhofer Center for Research in Computer Graphics, Darmstadt, Germany) commercialized by MedCom™. Three builds of version 3.3 of the software were tested: build 1400, build 1500, and build 1510.

The PC was connected to the Internet through a standard 100bT (also known as a 100BaseT) LAN (Local Area Network) board. Images were transmitted using TCP/IP (Transmission Control Protocol/Internet Protocol) through the Internet, either to other countries (eg, Coimbra in Portugal) or to smaller islands (eg, La Palma, Canary Islands).

Figure 1. Detail of the pyramid casting technique. The vertex is the eye-view. The rendering allows distance sampling to be expressed as resolution (algorithm 1, top drawing) or the volume size of the final voxel (algorithm 2, bottom drawing). For algorithm 1 the voxel volume is 100%. Image taken with permission of the author G. Sakas [8] and of the editor of The Visual Computer



The acquired original moving frames with 8-bit dynamic range were resampled and then converted into a volume data set that combined frames together with their position and orientation into a single 3-D image, with a system accuracy less than 1 mm.

Resampling is a geometrical transformation of the ultrasound-pixels into the 3-D-voxel (volume element) spaces based on the tracking measurements. Resampling transforms the 2-D sequential images into a single volume data set and is carried out in the TeleInVivo™ software using the pyramid-casting technique [6,7]. The pyramid-casting technique is a modification of ray-casting that improves rendering speed by reducing distance sampling and averaging pyramidal voxels (Figure 1, from [7]) to produce "cloud" representation of the 3-D ultrasound image.

Data editing used the well-known maximum-intensity and minimum-intensity projections, x-ray absorption, and surface

visualization by gradient or cloud applied in the pyramid-casting algorithm. The "flying around" technique, which can be recorded with video, is currently used for display. The TeleInVivo™ software package allowed us to see 2-D orthogonal cuts of the 3-D reconstructed volume and allowed us to obtain oblique cuts from the volume, allowing virtual sonography, which is available after transmission-even at a remote site.

To illustrate the image quality and compression techniques obtained by the software, we chose 505 digitized frames (slices) of a fetus with an encephalocele. In Results we show 4 sets of an orthogonal plane (slice 86, equivalent to a 2-D-ultrasound image view) together with a 3-D volume reconstruction. The volume was displayed with the maximum intensity projection algorithm. Selected parameters were: a contrast of -0.34 and an intensity of 1.03; surface mixing of 45% with a semitransparent surface algorithm having a mean gray value of 157 and a tolerance of 169; depth weight of 0; contrast of -0.36; and

intensity of 1.13. The surface was displayed with high quality and medium smoothing.

Results

The moving frames, recorded with the ultrasound device, have an original size of 100 to 120 MB (from 500 to 550 single frames). This size must be drastically reduced. The size-reduction process is shown in [Figure 2](#), together with intermediate file sizes obtained using an example with an original size of 126 MB before storage and 106 MB after storage.

First Step: ROI (Region of Interest) selection

The parts of the moving frame with no relevant clinical information such as background and/or non-interesting parts are deleted. In this step original images of 106 MB and 505 frames were reduced to 40 MB (62% reduction).

Second Step: volume rendering (Resolution/Sampling portion of [figure 2](#))

Volume rendering transforms the original data into a collection of visible primitives (basic shapes) from the 3-D object, which

can be viewed from any direction in space. Resampling was carried out with a pyramid casting technique that selects the resolution and the degree of interpolation required for visualization based on the sampling quality.

Resolution can be chosen by means of 2 algorithms:

- Algorithm 1 takes into account the memory space of the geometry buffer and selects the "distance sampling" required for it, resulting in data sets of 16 MB (about 256^3), 4 MB (about 160^3), and 2 MB (about 128^3).
- Algorithm 2 considers the size of the voxel that is averaged, using a "pyramidal volume" method for sampling. At 100% resolution, the size reached the system resolution (1 mm^3); lower percentages give rise to bigger voxels introducing gaps on the orthogonal plane images that were not visible on the volume data. A detail of a gap using a 75% voxel size is shown in [Figure 3](#) and [Figure 4](#). The size and frequency of these gaps increased when lower percentages were chosen, resulting in orthogonal images that did not produce a proper diagnosis.

Figure 2. Compression scheme of the TeleInVivo software. MB data indicates file size

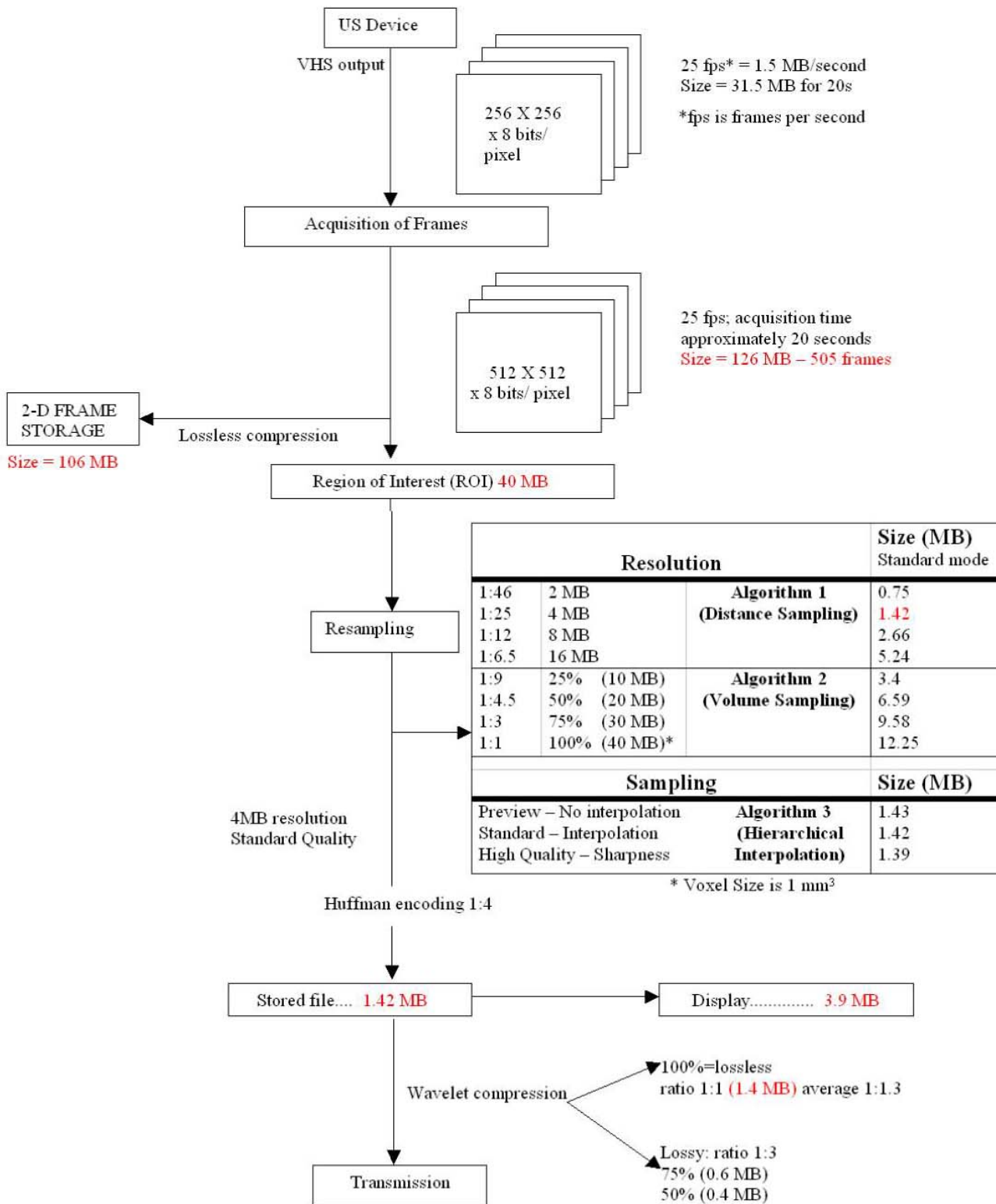


Figure 3. Image generated with algorithm 2 at 75% resolution and high-quality sampling. File size is 30 MB at display and 9.63 MB stored. Top image: orthogonal plane slice 86s. Notice the gaps on the left. Bottom image: 3-D image

Figure 4. Image generated with algorithm 2 at 75% resolution and preview sampling. File size is 30 MB at display and 9.25 MB stored. Top image: orthogonal plane slice 86s. Notice the gap on the right. Bottom image: 3-D image

Algorithm 2 produces a larger final-file-size and a lower-quality image (Figure 3, Figure 4), due to the voxel averaging technique.

Algorithm 1 produces a smaller final-file-size and a higher-quality image (Figure 5, Figure 6, Figure 7, Figure 8).

Figure 5. Image at 4-MB resolution with preview sampling. File size is 3.9 MB at display and 1.43 MB stored. Top image: orthogonal plane slice 86. Bottom image: 3-D image

Figure 6. Image at 4-MB resolution with high-quality sampling. File size is 3.9 MB at display and 1.39 MB stored. Top image: orthogonal plane slice 86. Bottom image: 3-D image

Figure 7. Image at 4-MB resolution with standard- sampling. File size is 3.9 MB at display and 1.42 MB stored. Top image: orthogonal plane slice 86. Bottom image: 3D image

Figure 8. Image at 16-MB resolution with standard sampling. File size is 15.8 MB at display and 5.24 MB stored. Top image: orthogonal plane slice 86. Bottom image: 3D image

Sampling quality is based on degree of interpolation and sharpness provided by algorithm 3. It produces a visual representation by hierarchical interpolation of the sampled data obtained with Algorithms 1 and 2, resulting in no interpolation with preview sampling (Figure 4 and Figure 5) and higher-sharpness with high-quality sampling (Figure 3 and Figure 6).

Third Step: Huffman encoding

When volume data is stored, it is compressed with a Huffman-encoding technique, which is lossless, of about 1:3 compression ratio (Table 1). The size of displayed images and the final size of stored images used for teleconsultation are shown in Table 1. All possible combinations provided by the available rendering algorithms are listed. The compression ratio can vary from image to image; in Figure 2 the compression ratio is 1:4.

Table 1. Sizes of displayed and stored images using TeleInVivoTM rendering algorithms. Image quality (attractiveness) can be seen in the Figures listed in the last column

Algorithms	Memory Display, MB	Stored File, MB	Huffman compression ratio for Transmission	Figure
2 MB-High quality	2.0	0.73	1: 2.7	
2 MB-Standard	2.0 MB	0.75	1: 2.6	
2 MB- Preview	2.0	0.76	1: 2.6	
4 MB-High quality	3.9	1.39	1: 2.4	Figure 6
4 MB-Standard	3.9	1.42	1: 2.8	Figure 7
4 MB-Preview	3.9	1.43	1: 2.7	Figure 5
8 MB-High quality	7.8	2.63	1: 3	
8 MB-Standard	7.8	2.66	1: 2.9	
8 MB- Preview	7.8	2.67	1: 2.9	
16 MB-High quality	15.8	5.22	1: 3	
16 MB-Standard	15.8	5.24	1: 3	Figure 8
16 MB-Preview	15.8	5.18	1: 3	
25%-High quality	9.9	3.36	1: 3	
25%-Standard	9.9	3.40	1: 2.9	
25%-Preview	9.9	3.40	1: 2.9	
50%-High quality	20	6.57	1: 3	
50%-Standard	20	6.59	1: 3	
50%-Preview	20	6.44	1: 3.1	
75%-High quality	30	9.63	1: 3.1	Figure 3
75%-Standard	30	9.58	1: 3.1	
75%-Preview	30	9.25	1: 3.2	Figure 4
100%-High quality	39.7	12.38	1: 3.2	
100%-Standard	39.7	12.25	1: 3.2	
100%-Preview	39.7	11.79	1: 3.4	

Fourth Step: Compression before transmission

Before transmitting the image, two compression techniques were used. The lossy wavelet algorithm produced, in the final file, a 1:3 compression without a significant loss of the visual image quality. Nevertheless image transmission in the present trial was carried out with a lossless technique. Compression achieved in this phase was negligible for 4-MB resolution images (Figure 2). For 16-MB images compression in this phase was 1:2.

To compare lossless compression provided by the software we used with regular lossless compression techniques (such as WinZip compression) a lossless JPEG algorithm was applied to the original frame images. Compression ratios were 1:4 to 1:5.

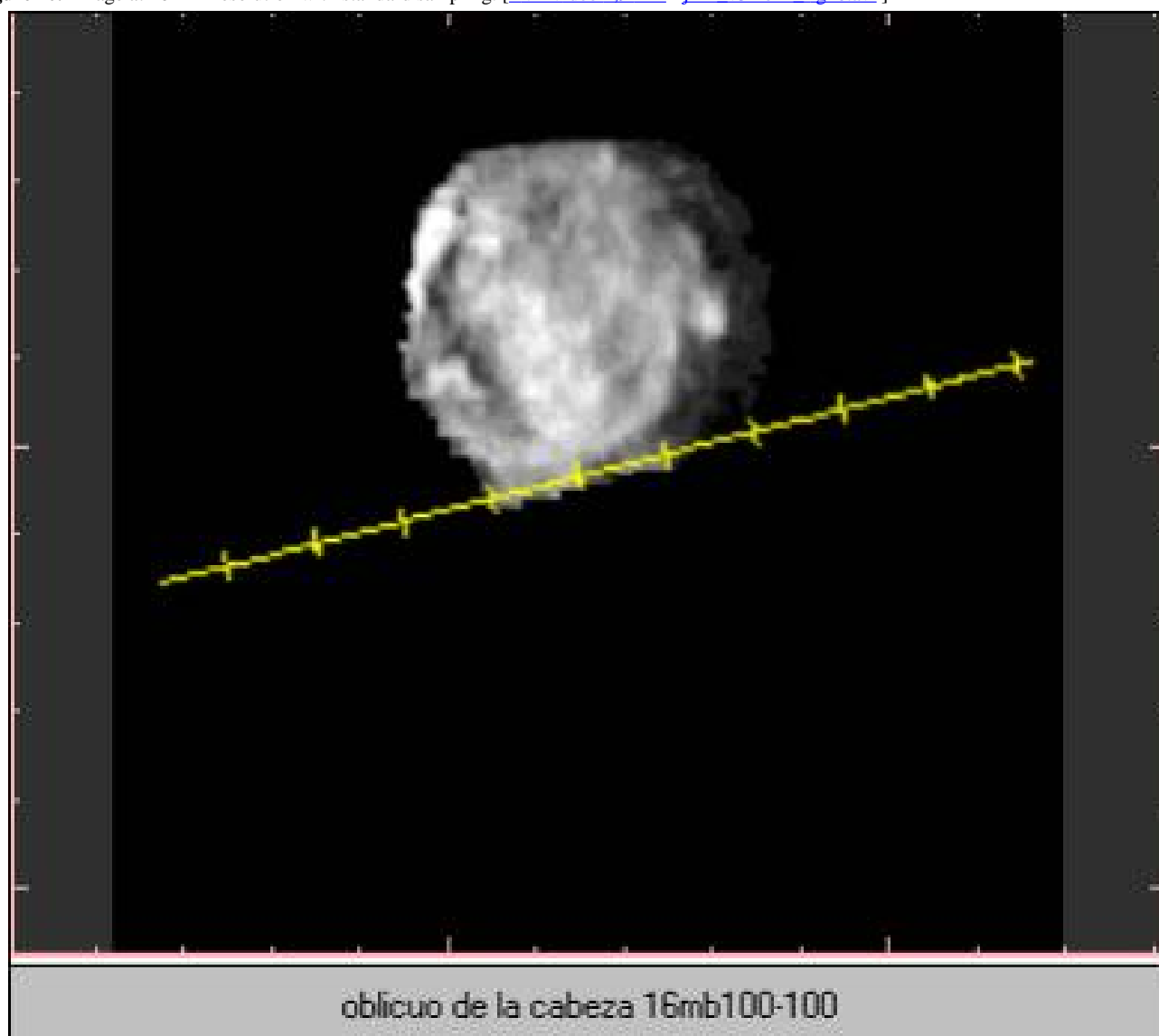
There were 101 cases that used consultation through the Internet. Only 3 of these cases were resampled at 16-MB resolution. The remaining cases were resampled at 4-MB resolution with algorithm 1. This was done because visual image quality did not show subjective differences (Figure 7 and Figure 8).

During consultations the telecommunication line broke down 17 minutes, with an average data throughput of 6.6 Kbytes per 17 times. The mean transmission time per image was 6.8 second.

Figure 9. Image at 4-MB resolution with standard sampling. Sine Loop video-image. [[AVI-Video 7.1 MB](#) - [jmir_v3i2e21_fig9.avi](#)]



Figure 10. Image at 16-MB resolution with standard sampling. [AVI-Video 1.9 MB - [jmir_v3i2e21_fig10.avi](#)]



Distant diagnosis was possible on 94 out of 101 transmitted images. The transmitted images that did not allow distant diagnosis were bad-quality images, due to acquisition difficulties related to moving the probe by hand [9].

The volume-rendering technique makes it possible to cut the volumetric image in all directions. This technique allows "offline" virtual sonography, both locally and at distance, that does not require the patient's presence. Software facilities allow recording volume movement in short videos that help visualization (Figure 9 and Figure 10).

The 2-D orthogonal planes were the ones used by the doctors for diagnostic purposes. The oblique cuts were helpful in only 2 of the 101 cases: a case of an ectopic pregnancy in a rudimentary uterine corn, and an abdominal implant of a pinealoblastoma of the brain that was drained, for treatment purposes, into the abdominal cavity.

Discussion

The present work summarizes one-year's experience with 3-D-ultrasound image acquisition and processing, using a device

that can provide virtual sonography and teleconsultation at distance. This was done with an external add-on system in an existing 2-D ultrasound device, at the sonography unit of the Obstetrics and Gynecology Department, University Hospital of Tenerife, Canary Islands, Spain.

The clinical expectations offered by inexpensive 3-D acquisition systems such as the one presented here are high, particularly because they can be used in "noisy" images, such as sonographic images, and also because they provide teleconsultation facilities. Furthermore, the capability to cut volume data in all spatial directions, producing distant and local virtual sonography [8] improves diagnostic procedures. In the present trial, teleconsultation was possible due to the small size of final 3-D files obtained by volume-rendering techniques.

Our results showed that the essential compression processes were related to the volume-rendering technique and were so efficient that further compression (such as compression before transmission) was unnecessary.

Although final 4-MB files provided an adequate medical visual quality for diagnosis, they did not contain individual pixel data

anymore; instead they have "volume primitives" obtained during the pyramid-casting rendering technique at specific sampling frequency. This file is therefore highly optimized for redundancies (that is, due to the type of stored data it is not possible to have any redundant values).

We used compression-before-transmission values as high as 1:2 only for 16-MB-quality images, but those images did not substantially improve the visual perception and had the disadvantage of increased file-size.

These results have two main consequences:

- The degree of compression achieved was very high (1:25 with 4-MB resolution), allowing Internet teleconsultation with 3-D-ultrasound reconstructed images.
- The exact compression technique applied to the medical image was obscure, making it difficult to evaluate, from the medical point of view, whether or not relevant information was lost. Neither the technical manuals from MedCom™ nor the publications of the research team [6,7,9] clarified how the compression achieved by volume rendering using the pyramid-casting technique affects an individual medical image.

According to our previous results [8], the resampling provided by algorithm 1 allowed ultrasound diagnosis at a distance because reconstructed images had the "attractiveness attribute," so that doctors feel comfortable with the esthetic component of the images [2].

Resampling provided by algorithm 2 that caused gaps in the 2-D orthogonal planes, the essential images for diagnosis (since 3-D reconstruction was only used in 2 of the 101 teleconsulted cases), did not have the attractiveness attribute. Although the 100% voxel sampling provided good-quality images, the size of the resulting final volumes was too big for efficient teleconsultation.

Additional problems are: finding out: if algorithm-1 images fulfilled the remaining attributes, such as fidelity and informativeness (an image attribute based on visibility and detectability) [2] for original ultrasound images that are noisy by definition and determining how rendering lossy-compression modifies the visibility and detectability of a specific pathology.

In the present experience, the relatively small size of the final files (1.5 to 2 MB) facilitated the 3-D-ultrasound teleconsultations, even through low-bandwidth networks such as the Internet. Constraints linked to distant reception of static volumes [3] were overcome by virtual sonography, which allowed 2-D cuts in all spatial directions and "sine loop" moving video files.

In summary, volume-rendering techniques applied to ultrasound freehand image acquisition achieved a degree of compression such that teleconsultation through the Internet is possible, but it is still not clear if the rendering techniques could modify visibility and detectability of specific pathologies.

Acknowledgments

We give thanks for the support provided in the HC4021 EC project on technical aspects by Eng. Dr. G. Sakas and S. Walter in the IGD (Institute for Computer Graphics), Fraunhofer, Darmstadt and the distant consultation team of Dr. L. Teixeira and Dr. P. Avidago at the Coimbra University Hospital.

The work was done as part of the HC4021 TeleInvivo Project. 4th Framework. Telematics applications. DG-XIII [10] and was cofinanced by the FIS 99/1278E of the Spanish government.

Conflicts of Interest

None declared

References

1. ; ACR/NEMA. Digital Imaging and Communications in Medicine (DICOM) Version 3.0 Standard. Vol. 1 to Vol. 13. Washington, DC: NEMA; 1994.
2. Ferrer-Roca O, Sosa-Iudicissa M, et al. Handbook of Telemedicine. Amsterdam: IOS-Press; 1998:65-70.
3. Macedonia CR, Littlefield RJ, Coleman J, Satava RM, Cramer T, Mogel G, et al. Three-dimensional ultrasonographic telepresence. J Telemed Telecare 1998;4(4):224-230. [Medline: [99434984](#)] [doi: [10.1258/1357633981932280](#)]
4. Levoy M. Display of Surfaces from Volume Data. IEEE Comp Graph App 1988;8(3):29-37. [doi: [10.1109/38.511](#)]
5. Drebin RA, Carpenter L, Hanrahan P. Volume Rendering. Comp Graph 1988;22(4):65-74.
6. Calhoun PS, Kuszyk BS, Heath DG, Carley JC, Fishman EK. Three-dimensional volume rendering of spiral CT data: theory and method. Radiographics 1999;19(3):745-764 [FREE Full text] [Medline: [99267243](#)]
7. Sakas G, Walter S, Grimm M, Richtscheid M. [Free hand acquisition, reconstruction and visualization of 3D and 4D ultrasound]. Radiologe 2000 Mar;40(3):295-303. [Medline: [20249606](#)] [doi: [10.1007/s001170050672](#)]
8. Sakas G. Interactive volume rendering of large fields. Visual Comp 1993;9(8):425-438.
9. Sakas G, Hartig J. Interactive Visualization of Large Scalar Voxel Fields. IEEE Visualization'92 Conference Boston, MA: IEEE; 1992 Oct 19:29-36.
10. TeleInvivo Project Web site. URL: <http://www.igd.fhg.de/teleinvivo>

Abbreviations

ACR/NEMA: American College of Radiology/National Electrical Manufacturers Association

CATAI: Center of Advanced Technology in Image Analysis

DICOM3: Digital Imaging and Communication in Medicine, Version 3.0

EC: European Community

FIS: Fondo de Investigaciones Sanitario

fps: frames per second

IGD: Institut Graphische Datenverarbeitung

IP: Interconnection Protocol

ISA: Industry Standard Architecture

JPEG: Joint Photographic expert group

LAN: Local Area Network

MB: Megabyte

MHz: Megahertz

PC: Personal Computer

RAM: Random Access Memory

ROI: Region of Interest

TCP: Transfer Control Protocol

TCP/IP: Transmission Control Protocol/Internet Protocol

UNESCO: United Nations Educational, Scientific, and Cultural Organization

US: Ultrasound

submitted 23.08.00; peer-reviewed by S Keevil, VD Mea, G Mogel; comments to author 20.09.00; revised version received 10.11.00; accepted 10.05.01; published 22.06.01.

Please cite as:

Ferrer-Roca O, Vilarchao-Cavia J, Troyano-Luque JM, Clavijo M

Virtual Sonography Through the Internet: Volume Compression Issues

J Med Internet Res 2001;3(2):e21

URL: <http://www.jmir.org/2001/2/e21/>

doi: [10.2196/jmir.3.2.e21](https://doi.org/10.2196/jmir.3.2.e21)

PMID: [11720963](https://pubmed.ncbi.nlm.nih.gov/11720963/)

© Olga Ferrer-Roca, Joseba Vilarchao-Cavia, Juan-Mario Troyano-Luque, Matilde Clavijo. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 22.6.2001. Except where otherwise noted, articles published in the Journal of Medical Internet Research are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

Original Paper

A Web-Based Distance Education Course in Nutrition in Public Health: Case study

Dirce M Sigulem¹, PhD; Tania B Morais¹, PhD; Lilian Cuppari¹, PhD; Sylvia C.C Franceschini², PhD; Silvia E Priore², PhD; Kátia G Camargo³, MSc; Reinaldo Gimenez³, MSc; Viviane Bernardo³, MSc; Daniel Sigulem³, PhD

¹Post-graduate Course in Nutrition, Federal University of São Paulo Medical School, Brazil

²Department of Nutrition and Health, Federal University of Viçosa, Brazil

³Department of Health Informatics, Federal University of São Paulo Medical School, Brazil

Corresponding Author:

Dirce M Sigulem, PhD

630 CEP 04020

060 São Paulo, SP

Brazil

Email: dirsigulem.pnut@epm.br

Abstract

Background: Strict work timetables, personal and professional duties or an inability to be absent from home or work can all represent major constraints for those wishing to improve their professional skills. Within this context, the World Wide Web can allow people to conveniently follow distance courses from their homes.

Objective: To present an experience in the use of the Web in the continuing education of healthcare professionals in Brazil.

Methods: A Web-based distance education course in nutrition in public health was developed. The methodology was an adaptation of both problem-based and task-based learning. At the end of the course an evaluation questionnaire which covered the course's contents, the educational methodology and resources, the duration and schedule, and the use of the Web as a tool for distance education was given to the students.

Results: There were 83 on line registrations from 13 states, 73 of the applicants were female, 62 had a degree in nutrition and 18 were physicians. From these; eleven students from ten states were chosen: nine female nutritionists, two female physicians, and one male physician. Seven students completed the course, took and passed the final exam. Of the other four students, two failed to follow the schedule, one had health problems, and one did not obtain the minimal score for sitting the final exam. The students had a mean age of 35, and a mean of ten years in practice. They all stated that they were unable to attend a regular course, even though they felt that they needed to improve their professional skills. Most of them studied seven days a week for between two and four hours a day. The students also felt that their professional skills had improved and each reported having made changes in their practice as a result of their participation. The students approved of the course's contents, methodology and resources, however they were divided about its duration. The Web as a tool in distance education was approved by the students. If it was not for the Web they could not have taken part in a continuing education program. All students said they would attend another virtual course, if available. Even though most of them did not have difficulty adapting to the virtual environment, they did feel that an adaptation period would be of value.

Conclusions: A Web-based course may be more effective than other distance education methodologies because it is more interactive and dynamic. On-line material can be constantly reviewed and updated, and the students can have the opportunity to submit commentaries or questions directly to the teaching staff. A Web-based course also allows the students to go beyond the course content as they learn how to search and take advantage of the huge resources of information available on the Internet.

(*J Med Internet Res* 2001;3(2):e16) doi:[10.2196/jmir.3.2.e16](https://doi.org/10.2196/jmir.3.2.e16)

KEYWORDS

Internet; Curriculum; Nutrition; Education, Distance; Education, Medical, Continuing; Questionnaires; Program Evaluation

Introduction

Continuous education is vital in the health sciences field due to the huge amounts of new data generated by the rapid growth of

knowledge in the area. This gives rise to new challenges, not only for graduate professionals, but also for universities, which have to extend their role to continuous education and not be

restricted solely to the instruction of undergraduate and postgraduate students.

Evidence indicates that traditional college environments deprive a large group of people from the opportunity to enhance their professional skills. In order to accommodate this group, universities have established a wide range of alternative options such as evening courses, correspondence courses, cassette/videotape learning packages and tele-courses. However, the needs of people already practicing in their fields are so unique that they are barely met, even by these educational methods. Strict work timetables, personal and professional duties or an inability to be absent from home or work can all represent major constraints for those wishing to improve their professional skills.

Within this context, the World Wide Web, as a relatively low cost tool for the democratization and dissemination of knowledge [1], can play a revolutionary role by allowing students to conveniently follow distance courses from their homes.

In Brazil, the potential usefulness of the Web is accentuated by the country's size and the uneven geographical distribution of the universities, which are mainly concentrated within the most developed regions. Furthermore, regional economic dissimilarities have led to a shortage of human resources within the less developed regions, heightening the importance of measures that favor the development of the few professionals who are working in these areas.

Aware of this situation, the Federal University of São Paulo Medical School developed and produced a distance course in Nutrition in Public Health using the World Wide Web.

The main goals of this project were:

- to provide professionals in various regions of Brazil with the latest knowledge in the field of Nutrition in Public Health;
- to qualify the professionals to adequately diagnose and solve the major problems related to Nutrition in Public Health in Brazil; and
- to familiarize the professionals with the main computing resources available to assist them in this learning process.

In this article, an educational model of Web-based learning and its resources is described. The positive aspects and the restrictions of the model as well as our personal experiences with the implementation of a distance education course are discussed.

Methods

In 1997, the Postgraduate Program in Nutrition and the Department of Health Informatics developed a distance course, to be delivered via the Internet, for specialization in Nutrition in Public Health.

In Brazil, one must pursue a postgraduate degree in order to specialize within a specific field. Pursuing a postgraduate degree is more demanding than partaking in other continuing education courses because it aims to improve the performance of its

graduates in professional activity in a specific field that requires particular skills. Specialization also facilitates promotion for government employees and is a prerequisite for entry into a Master's degree program. Specialization courses are regulated by the Ministry of Education and can only be offered by universities accredited by it. This was the first project for a distance Web-based course in the health sciences field submitted to, and approved by, the Ministry. The project covered the course format, the goals, the schedule, the number of credits, the number of hours, and the students' evaluation and final exam. The course was also evaluated and approved by the Federal University of São Paulo which issued a degree certificate on completion of the course.

After the course had received these approvals, a link was placed on the University's web site (www.epm.br) to the Virtual Course of Nutrition in Public Health (www.virtual.epm.br/cursos/nutrica.htm). A range of information about the course is available on this page including a registration form which can be completed and submitted electronically. The course is free of charge and is currently run biannually.

There have been three editions of the course with ten places available in each one. The first edition, intended for nutritionists only, started in August 1997 and ended in December 1997. The second and third, which were intended for both nutritionists and doctors, ran from April to December 1998 and from March to July 2000, respectively. The course is delivered in Portuguese, although some of the documents used are in English or Spanish.

The Courseware Development Model

The Educational Model: Problem-based and task-based learning

In 1997, it was necessary to develop an original methodology for the course as there was a shortage of educational models for use on the Web. A partnership between the faculty of University's Postgraduate Course in Nutrition, and the Education team of the Department of Health Informatics resulted in a computer and Web based learning design.

The faculty consisted of one experienced pediatrician (DMS) who was working on malnutrition and anemia in children, two nutritionists who were working on the nutritional status of pregnant women (SCCF) and adolescents (SEP), one nutritionist with clinical experience in nephrology (LC) and one graduate in biomedical sciences (TBM) with experience in food quality control.

The aims of the course guided the choice of the methodology, which was an adaptation of both problem-based and task-based learning [2,3,4]. Problem-based learning is one of the most appropriate methodologies for community-oriented instruction in health. Students are required to combine their knowledge of a range of areas and also to bring into consideration psychosocial elements which encourages them to take a wider and more critical view of the issues related to the health of the community [2]. One characteristic of this type of methodology is the stimulation of an active search for knowledge [2], which was in perfect accordance with one of the aims of the course.

The faculty selected the seven main subjects which were to be developed during the course (Figure 1). For each of these subjects, a variable number of problems and tasks, of differing degrees of complexity, were prepared based on real day-to-day situations experienced by the teachers.

The number of credits given for each subject took into account its difficulty and ranged from 2 to 6 with a total of 30 credits in all. The structure of the course calendar also brought into consideration the difficulty of the tasks and the different periods allowed for their resolution (Figure 1).

Figure 1. Course screenshot with course schedule

Period	Subjects	Length (days)	Credits
Mar/13 to Mar/26	1. Health Status Measures	14	4
Mar/26	Deadline for sending the assignment		
Mar/27 to Apr/9	2. Primary Health Care	14	4
Apr/9	Deadline for sending the assignment		
Apr/10 to May/7	3. Nutritional Assessment	28	6
May/7	Deadline for sending the assignment		
May/8 to May/21	4. Nutritional Requirements and Recommendations	14	4
May/21	Deadline for sending the assignment		
May/22 to Jun/11	5. Nutrient Deficiencies and Community Nutrition Programs	21	6
Jun/11	Deadline for sending the assignment		
Jun/12 to Jun/25	6. Nutritional Aspects in Chronic Degenerative Diseases	14	4
Jun/25	Deadline for sending the assignment		
Jun/26 to Jul/02	7. Food Quality Assurance	7	2
Jul/02	Deadline for sending the assignment		
Jul/06 and Jul/07	Final Exam	2	-
	Subjects and Final Exam	114	30

Computer and Web resources

Taking into account that the students might not have easy access to libraries, as much information as possible was made available through the Web. This created an atmosphere of enjoyable, interactive learning.

For each problem there were direct links to references, sites of interest on the Internet, supplementary texts and links to BIREME (the Pan American Health Organization and World

Health Organization health sciences information center for the Latin American and Caribbean area) (Figure 2).

Hyperlinks direct the students to various other resources such as a glossary, an image data bank of techniques and equipment (Figure 3), institutional material published by the Brazilian Ministry of Health (Figure 4), documents published by the World Health Organization (Changes in nutritional status, WHO, Belgium, 1983, which uses the tables of the National Center

for Health Statistics, see [Figure 5](#)), as well as to other sites of interest ([Figure 6](#)) and supporting texts ([Figure 7](#)).

The pages and links were created using the software Namo Web Editor® 2.0. The image data bank, the institutional materials

and the additional texts were created by first scanning and then editing the images using the software Aldus® Photo Styler® 2.0.

Figure 2. Course screenshot with a primary health care problem

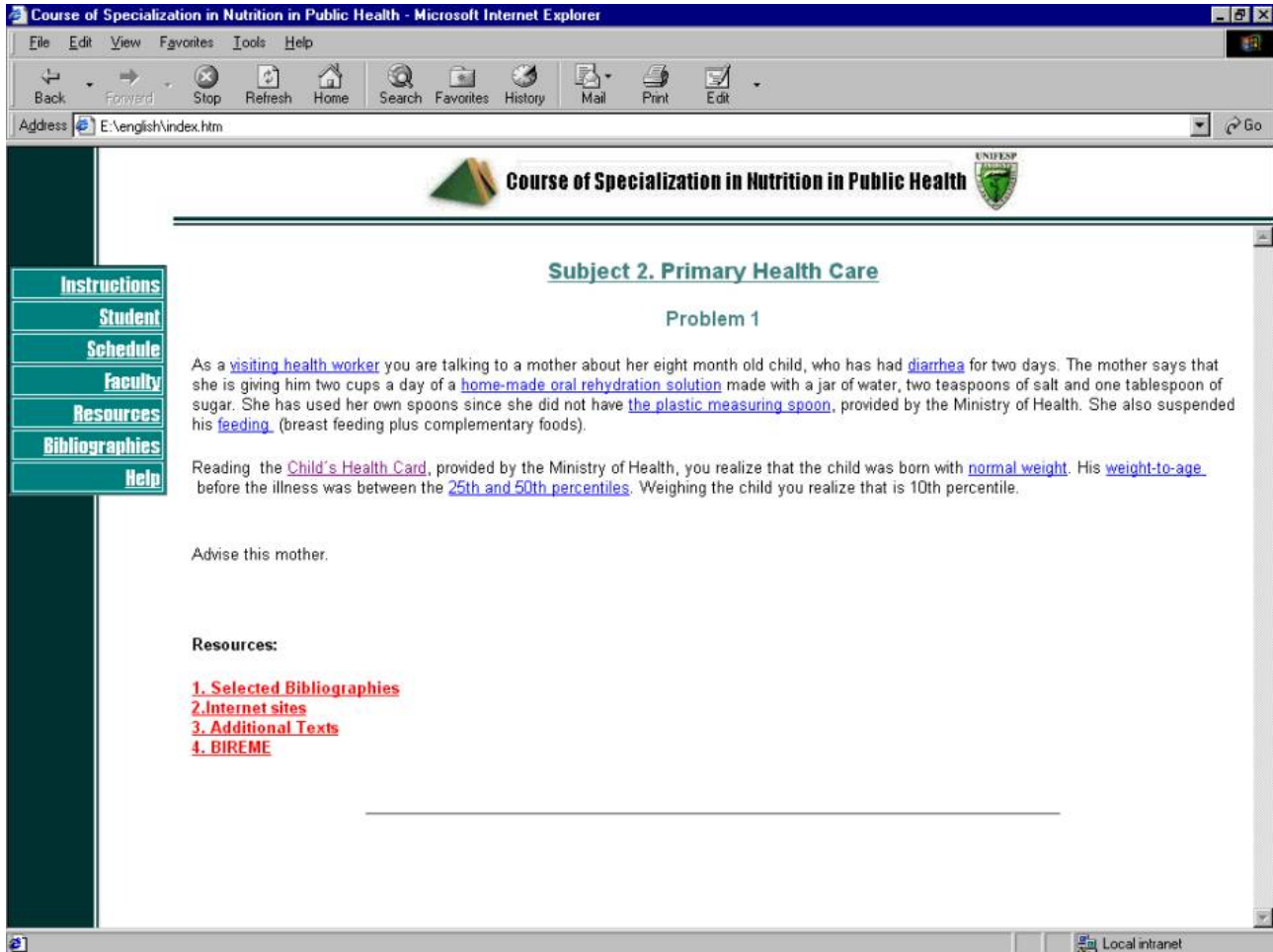


Figure 3. Course screenshot with an illustration from the image data bank of techniques and equipment

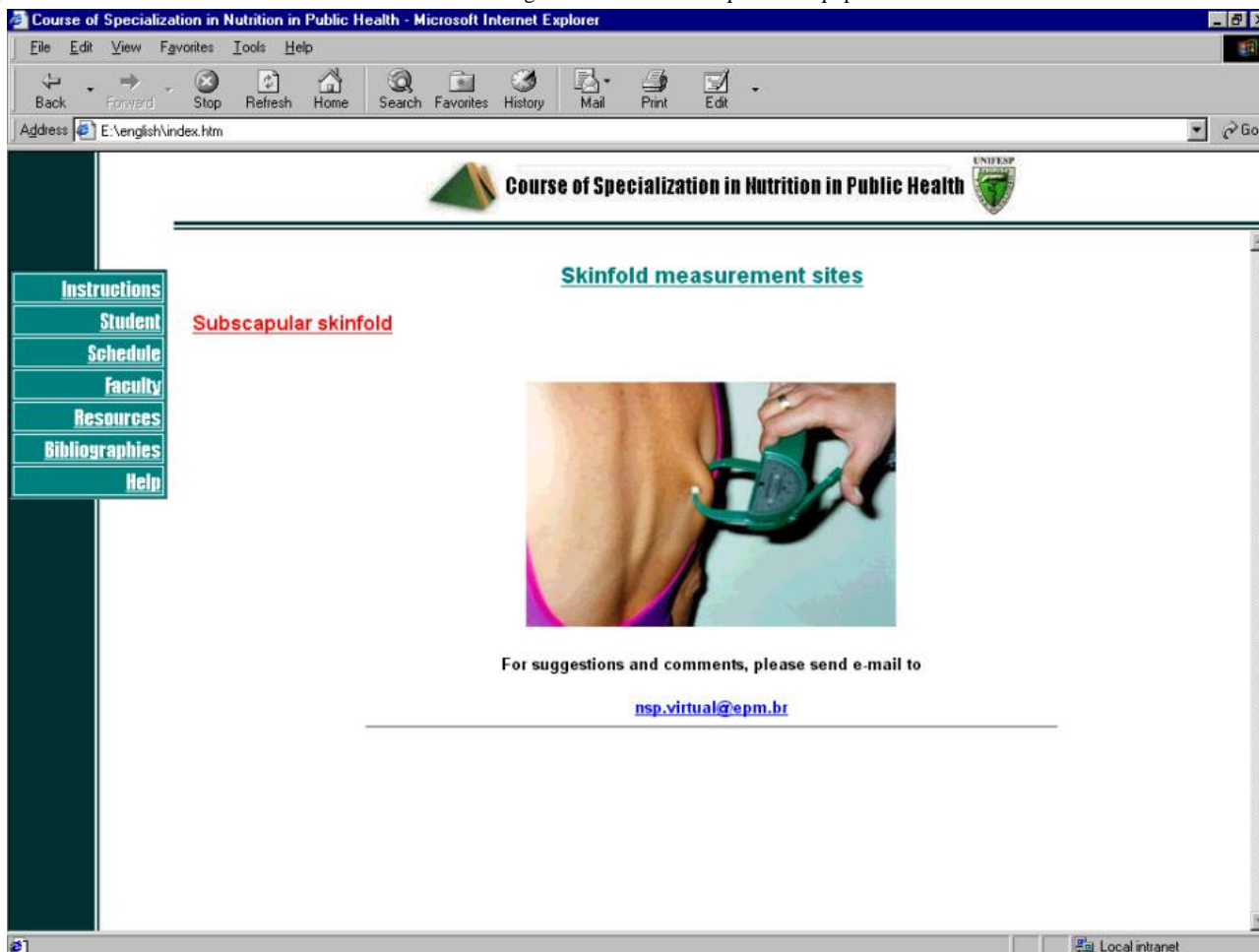


Figure 4. Course screenshot with Child Health Card

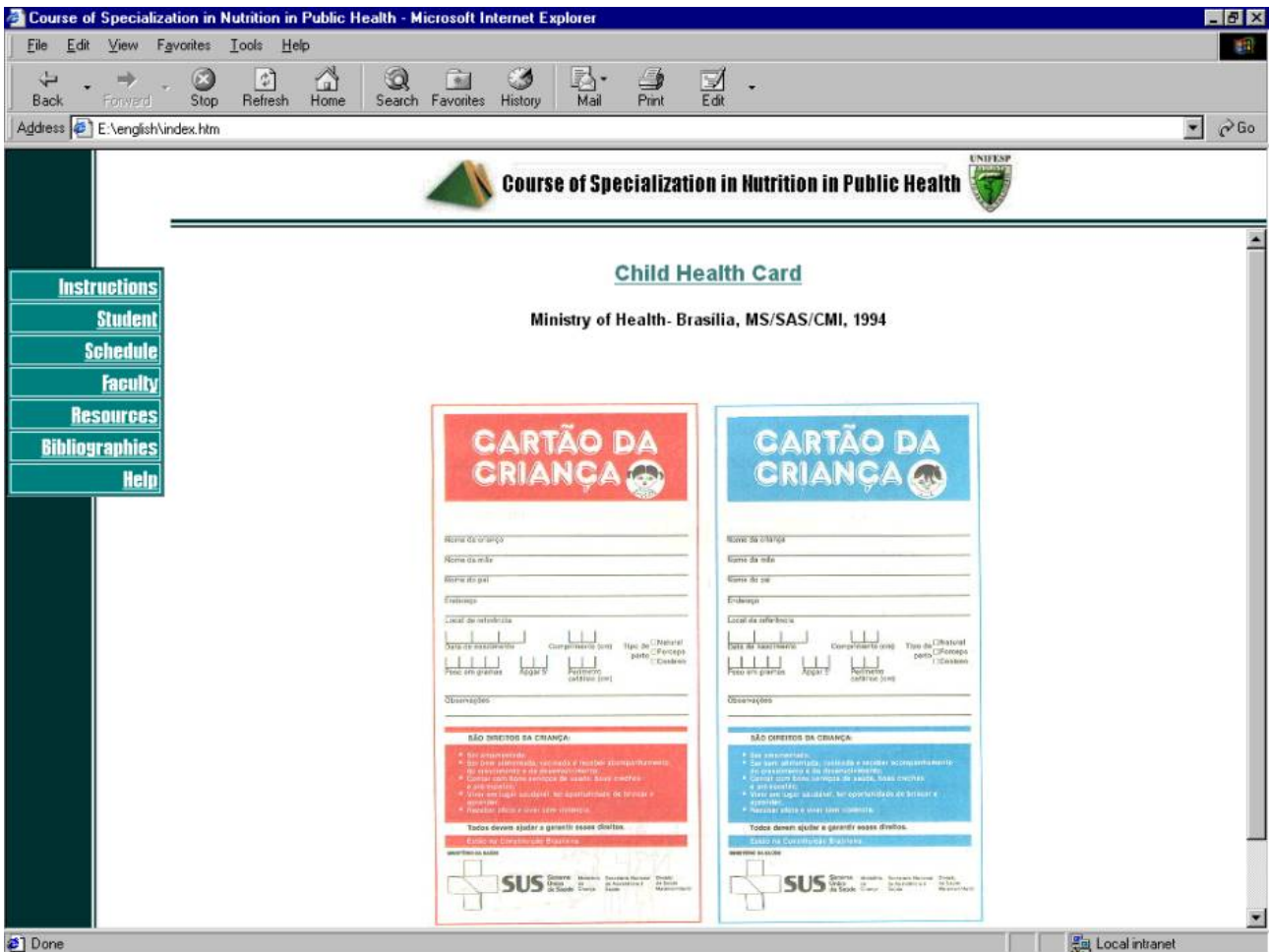
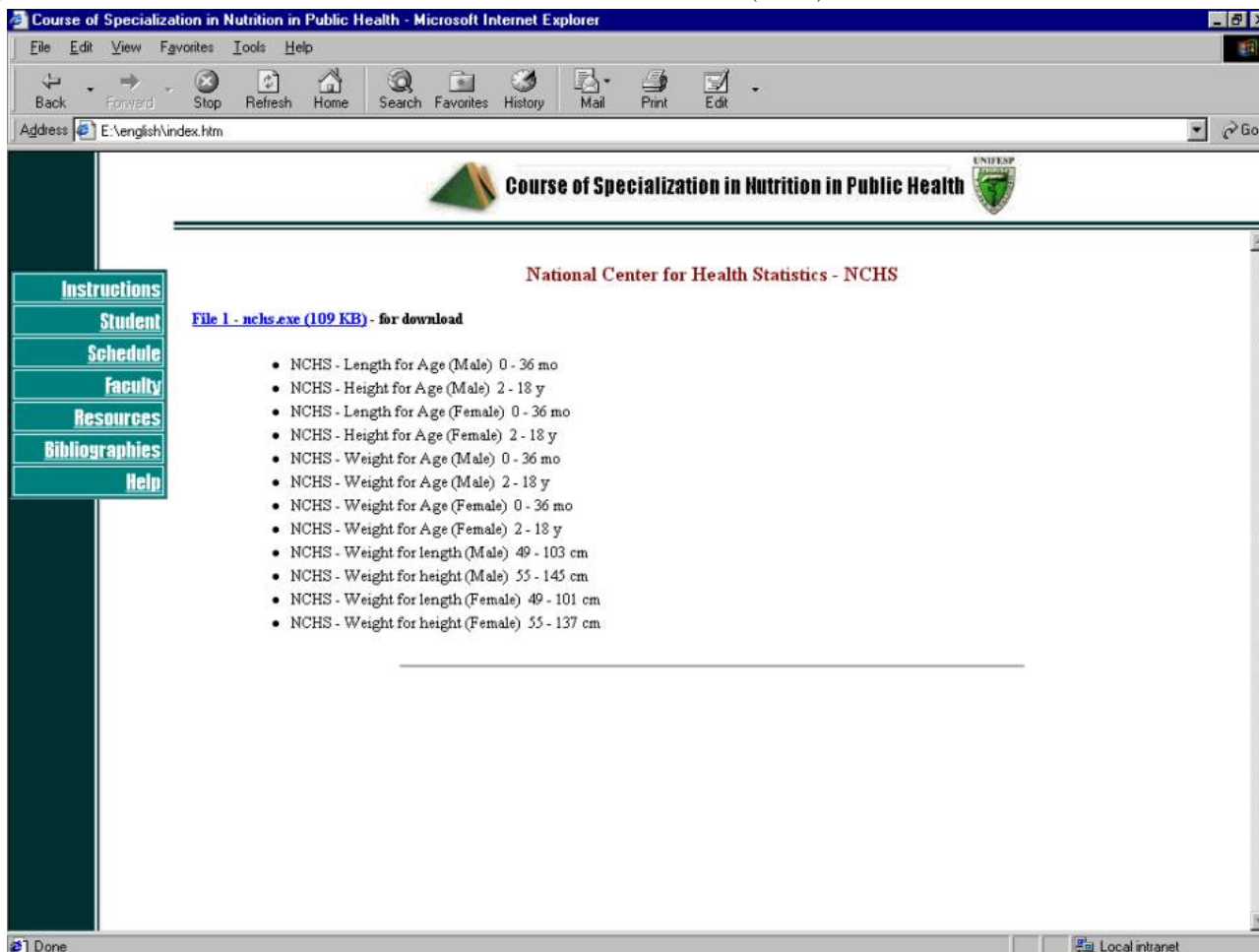


Figure 5. Course screenshot with tables from the National Center for Health Statistics (NCHS)



National Center for Health Statistics - NCHS

[File 1 - nchs.exe \(109 KB\) - for download](#)

- NCHS - Length for Age (Male) 0 - 36 mo
- NCHS - Height for Age (Male) 2 - 18 y
- NCHS - Length for Age (Female) 0 - 36 mo
- NCHS - Height for Age (Female) 2 - 18 y
- NCHS - Weight for Age (Male) 0 - 36 mo
- NCHS - Weight for Age (Male) 2 - 18 y
- NCHS - Weight for Age (Female) 0 - 36 mo
- NCHS - Weight for Age (Female) 2 - 18 y
- NCHS - Weight for length (Male) 49 - 103 cm
- NCHS - Weight for height (Male) 55 - 145 cm
- NCHS - Weight for length (Female) 49 - 101 cm
- NCHS - Weight for height (Female) 55 - 137 cm

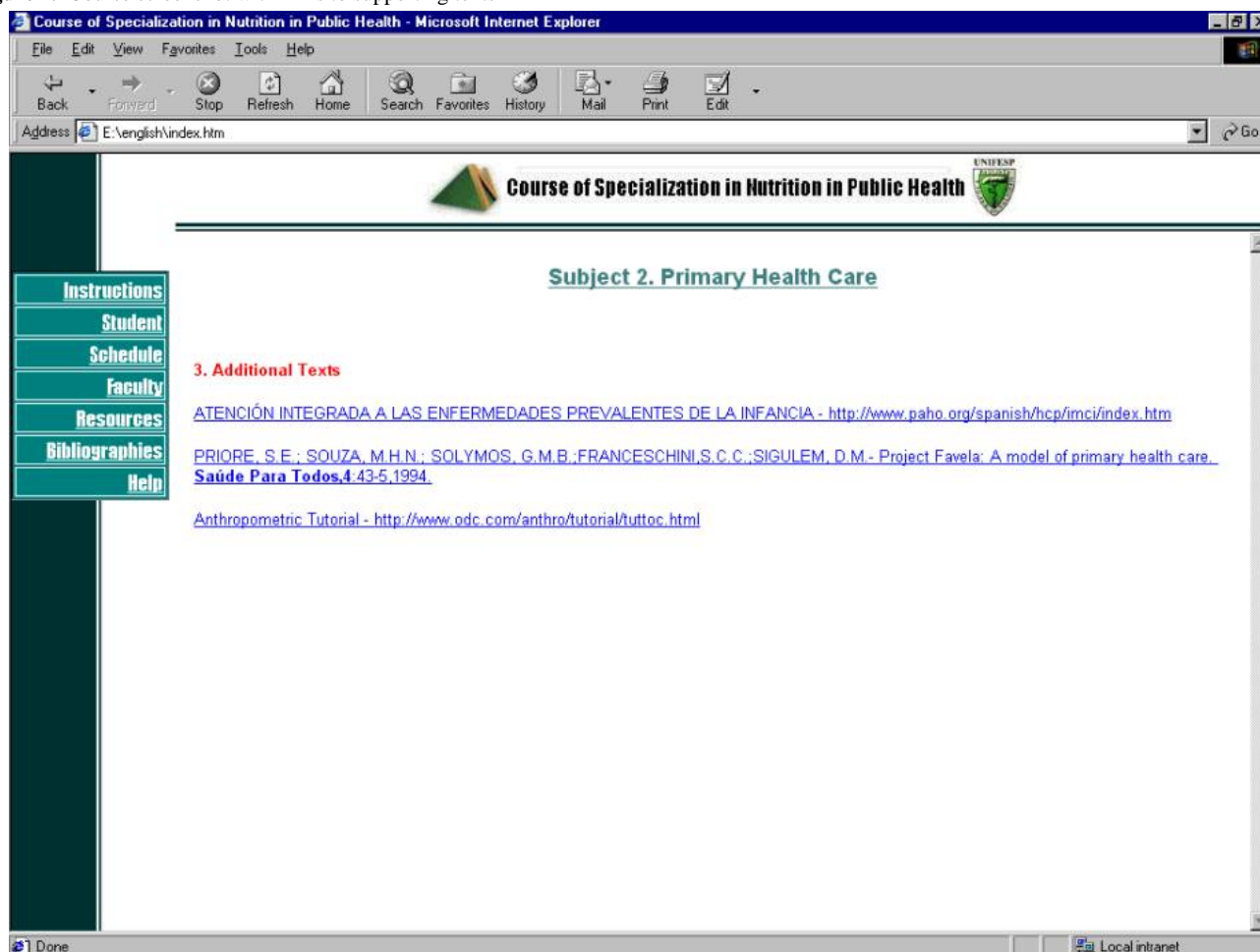
Figure 6. Course screenshot with external links

The screenshot shows a web browser window titled "Course of Specialization in Nutrition in Public Health - Microsoft Internet Explorer". The address bar displays "E:\english\index.htm". The page content includes a header with the course title and a UNESP logo. A left sidebar contains navigation links: Instructions, Student, Schedule, Faculty, Resources, Bibliographies, and Help. The main content area is titled "Subject 2. Primary Health Care" and lists "2. Internet sites" with the following links:

- Ministry of Health- Mortality Data - <http://www.datasus.gov.br/cgi/sim/dxmap.htm>
- World Health Organization - Child Health and Development - <http://www.who.int/chd>
- World Health Organization Office of World Health Reporting - <http://www.who.int/whr>
- World Health Organization - <http://www.who.int/wer>
- The WHO Statistical Information System - <http://www.who.int/whosis>
- Pan American Health Organization - <http://www.paho.org>
- UNICEF - <http://www.unicef.org>

The browser status bar at the bottom shows "Done" and "Local intranet".

Figure 7. Course screenshot with links to supporting texts



The Implementation of the Course

Course structure

Following the Web-based registration of students interested in the course, the teaching staff selected the applicants who would take part. The aims of the course determined the most important selection criteria, which were the applicant's professional activity in Public Health and their geographical location, with preference being given to those applicants working in the less developed regions of Brazil. The applicants' curriculum vitae and a letter they had written justifying their interest in the course were also brought into consideration.

The selected students were given an electronic password which gave them access to the course at any time via a specially set-up web site. This web site also contained a list of the participants together with their photographs and e-mails.

The students worked individually on the solutions to the problems, although they could exchange information with each other, and with the teachers, by e-mail. The assignments were submitted electronically via e-mail using an attached file. The students were also supplied with a specific e-mail address at the Department of Health Informatics where they could seek assistance with any computer related problems.

Evaluation of the students

The students were evaluated through reports they wrote in response to the problems and tasks in each subject. In some subjects they also had to create posters, pamphlets and booklets to be used in health education. These materials were also considered for evaluation.

As the model used did not include pre-established, single answers for the tasks, grading was performed by all the instructors and the final grades were reached through a consensus. At the end of each subject, the teaching body wrote "Final Comments" in which a summary of the most important points and a correction of general concepts were made.

For each subject the students were awarded a mark in the range A to E. To calculate a score for the subject these marks were converted to values of 4 to 0, respectively, and this value was multiplied by the number of credits given for the subject. The scores in each subject were then summed to give an overall score, with a maximum of 120. A supervised final exam was taken at the University by those students with an overall score of at least 60 (50%). An accredited certificate was awarded to the students who passed the exam.

Methods of evaluation of the course

The first two courses were treated as preliminary experiences in the development of the proposed Web-based model. For these two courses a total of 60 on-line registrations were received,

from which 20 students were chosen. Of these 20 students, a final total of 7 completed the courses and were approved. The main problem in the first course was the poor quality of Internet service which was available in Brazil in 1997, while in the second course there was a high dropout rate which was attributed to the course's long duration and the fact that many of the students did not work in the public health service and therefore did not feel that the course was relevant.

Through these experiences a satisfactory format for the course was developed. At the end of the third course a paper-based evaluation questionnaire was given to the students as they sat for the final exam. This questionnaire covered the course's contents, the educational methodology and resources, the course duration and schedule, the use of the Web as a tool for distance education, and the informatics support.

The dropout rate, the students' evolution throughout the course, and the changes in their practices were also brought into consideration in the overall course evaluation.

Results

For the third course there were 83 on-line registrations from 13 states. Eighty-eight per cent (73/83) of the applicants were

female. 75% (62/83) had a degree in nutrition and 22% (18/83) were physicians; the remaining three applicants had degrees in dentistry, biology and pharmacy. From these 83 registrations, eleven students from ten states were chosen: nine female nutritionists, two female physicians, and one male physician. The students who were not chosen either did not work in the public health system or lived in developed areas of the country. All the chosen students were government employees as this is the only class of employee that works in the public health service.

Seven students (64%) completed the course and took and passed the final exam. Of the other four students, two failed to follow the schedule (were not able to send the assignments in on the fixed day - see [Figure 1](#)), one had health problems, and one did not reach the minimal score for sitting the final exam. The characteristics of the students who completed the course are shown in [Table 1](#). [Table 2](#) shows the students' self-reported study habits and [Table 3](#) shows their evaluation of the course after the exam. The students' opinions of the Web as a tool for distance education are given in [Table 4](#).

Table 1. Characteristics of the participants who passed the final exam

Sex	Female: 6 Male: 1
Degree	Nutrition: 6 Medicine: 1
Mean age (years):	35 (min.26-max.55)
Mean years of Practice (years):	10
GovernmentEmployees:	7

Table 2. Self-reported students study habits

Time at which study started	7:00 P.M. - 9:00 P.M. : 4 10:00 P.M. - 12:00 P.M. : 3
Number of hours of study per day	2 hours: 3 3 hours: 2 4 hours: 2
Number of days of study per week	seven days: 4 six days: 3
Resources searched other than course resources	other web sites: 5 books: 5 library: 1
Methods used to save the course contents	printed all the pages:2 just read on screen: 0 printed just the relevant pages: 3 saved to hard drive or diskettes: 2

Table 3. Course evaluation

Contents	good: 7 average: 0 bad: 0
Methodology	good: 7 average: 0 bad: 0
Resources	good: 6 average: 1 bad: 0
Duration	sufficient: 3 insufficient: 4
Improvement of professional skills	yes: 7 no: 0
Practice changes; ("Have you changed your professional practice as you learned new information during the course?")	yes: 7 no: 0

Table 4. Responses to the post-course survey among successful participants of the program

Why did you attend a distance course on the Web?	impossible to attend a regular course: 7 need to improve my professional skills: 7 lack of a college in my city: 6
Did you have difficulty adapting to the virtual environment?	yes: 1 no: 6
Should the course have an initial period for adaptation to the virtual environment ?	yes: 4 no: 3
Would you attend another virtual course?	yes: 7 no: 0

Discussion

Although the use of the Web in continuing education is a relatively new practice [5,6,7], the high number of on-line applications that we received (a total of 143 in the three courses already delivered) showed the high demand for this kind of educational methodology. Indeed, many students applied for the course even though they didn't have the required profile. Nevertheless, as the course was very demanding both for the students and the faculty, only ten places per edition were made available, although less demanding courses could accommodate higher numbers of students.

For us, the most successful aspect of the course was the fact that it demonstrated that it is possible to reach professionals through the Web who would otherwise have been unable to take part in a continuing education program. The students were adults, with a mean age of 35, and were all experienced professionals with a mean of ten years in practice. They all stated that they were unable to attend a regular course, even though they felt that they needed to improve their professional skills. For most of them there was neither a college in their city nor an available library.

Possibly due to feelings of isolation, the students valued the opportunity the course gave them and demonstrated an

extraordinary motivation. Working very hard; most of them studied seven days a week for between two and four hours a day. The methodology was found to be very satisfactory and the teaching staff was able to observe the positive evolution of the students as they developed their critical thinking and independent learning skills. The students also felt that their professional skills had improved and all of them reported having made changes in their practice as a result of their participation. This supports the idea that a model of continuing education that allows students to participate actively in the learning process, and that targets a need or deficiency perceived by them in their everyday practices, can result in better performance in examinations and an overall improvement in patient care outcomes [8]. Furthermore, as all the students were government employees, it can be expected that this had a beneficial effect on the public health care in the regions where they worked.

The students approved of the course's contents, methodology and resources, however they were divided on its duration. Four students thought that it was insufficient, although, from the eleven students who started the course, two were unable to follow the schedule. This issue of course duration is a controversial point and our previous experience has shown that a duration of more than four months increases the dropout rate. The faculty's feeling on this point was that the student's commitment to the course was more important than its duration.

It is worth emphasizing that the model used demanded a lot of work from the teaching staff and the amount of time spent in planning and delivery was greater than expected; a similar experience was reported by Chan et al [7]. One aspect that was especially time consuming was searching and evaluating external web sites. Furthermore, at the start of each course a complete revision of all the material was required as the external web sites often changed their structure, necessitating revision of all the links to them.

It is interesting to note that two of the teaching staff were based at another university about 700 kilometers away and were therefore also working at a distance. This further demonstrates the possibilities created by the Web for people in different locations to work on a common project including a distributed faculty for a training course.

The Web as a tool in distance education was enthusiastically approved by the students, all of who stated that they would attend another virtual course, if available. Indeed, if it were not for the Web none of the students would have been able to take part in a continuing education program.

Most of the students did not have difficulty adapting to the virtual environment, although they did feel that an adaptation period would be of value.

The main problems that were observed were related to such things as students' computers not meeting the minimum hardware or software requirements, students' lack of computer skills, low access speed to Internet service providers, and even

temporary interruption of service. Also, some of the students had not expected to spend an average of 10 - 15 hours a week on the course-work, and were therefore unable to follow the course. A further restriction was that the didactic material used was necessarily limited to that which was not copyright, or was available for free on the Internet, or for which the author's permission for use was obtained.

Despite these limitations, the Web was shown to be a useful tool for distance education and should play an important role in the future of education, particularly in large countries with marked regional economic differences and unevenly distributed universities, like Brazil.

Our experience raised two issues that merit attention. The first is that it is important to define a precise profile of the target audience. The second is that a Web-based course may be more effective than other distance education methodologies because it is more interactive and dynamic. On-line material can be constantly reviewed and updated, and the students can have the opportunity to submit commentaries or questions directly to the teaching staff. A Web-based course also allows the students to go beyond the course content as they learn how to search and take advantage of the huge resources of information available on the Internet.

This educational model is already being reproduced by other departments at the Federal University of São Paulo including Dermatology, Ophthalmology and Orthopedics, and Traumatology.

Acknowledgments

The authors wish to thank the Brazilian Ministry of Health and the World Health Organization, which allowed the reproduction of their materials, and also the authors who kindly gave permission for reproduction of their work.

Conflicts of Interest

None declared

Multimedia Appendix

Downloadable Screenshots of the course [[PowerPoint ppt file, 2.5 MB - jmir_v3i2e16_app1.ppt](#)]



References

1. Mooney GA, Bligh JG. Information technology in medical education: current and future applications. *Postgrad Med J* 1997 Nov;73(865):701-704. [Medline: [98179705](#)]
2. Bligh J. Problem-based learning in medicine: an introduction. *Postgrad Med J* 1995 Jun;71(836):323-326. [Medline: [95372254](#)]
3. Bresnitz EA. Computer-based learning in PBL. *Acad Med* 1996 May;71(5):540. [Medline: [20140688](#)]
4. Harden RM, Laidlaw JM, Ker JS, Mitchell HE. Task-based learning: an educational strategy for undergraduate, postgraduate and continuing medical education. Part 1. *Med Teach* 1996;18:7-13.
5. Horn KD, Sholehvar D, Nine J, Gilbertson J, Hatton C, Richert C, et al. Continuing medical education on the World Wide Web (WWW). Interactive pathology case studies on the Internet. *Arch Pathol Lab Med* 1997 Jun;121(6):641-645. [Medline: [97342988](#)]
6. Séka LP, Duvaferrier R, Fresnel A, Le Beux P. A virtual university Web system for a medical school. *Medinfo* 1998;9 Pt 2(Pt2):772-776. [Medline: [99312560](#)]

7. Chan DH, Leclair K, Kaczorowski J. Problem-based small-group learning via the Internet among community family physicians: a randomized controlled trial. *MD Comput* 1999;16(3):54-58. [Medline: [99368458](#)]
8. Wentz DK. Continuing medical education at a crossroads. *JAMA* 1990 Nov 14;264(18):2425-2426. [Medline: [2232002](#)] [doi: [10.1001/jama.264.1.18](#)]

submitted 16.02.01; peer-reviewed by JP Aparicio, RJ Rodrigues; revised version received 03.04.01; accepted 03.04.01; published 19.04.01.

Please cite as:

Sigulem DM, Morais TB, Cuppari L, Franceschini SC, Priore SE, Camargo KG, Gimenez R, Bernardo V, Sigulem D

A Web-Based Distance Education Course in Nutrition in Public Health: Case study

J Med Internet Res 2001;3(2):e16

URL: <http://www.jmir.org/2001/2/e16/>

doi: [10.2196/jmir.3.2.e16](#)

PMID: [11720958](#)

© Dirce M Sigulem, Tania B Morais, Lilian Cuppari, Sylvia C.C Franceschini, Silvia E Priore, Kátia G Camargo, Reinaldo Gimenez, Viviane Bernardo, Daniel Sigulem. Originally published in the *Journal of Medical Internet Research* (<http://www.jmir.org>), 19.4.2001. Except where otherwise noted, articles published in the *Journal of Medical Internet Research* are distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited, including full bibliographic details and the URL (see "please cite as" above), and this statement is included.

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

<https://www.jmirpublications.com/>