

Applied Ethics in Internet Research

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Ethical questions related to the development of telemedicine

Introduction

Are telecommunications and the Internet contributing to the development of far-ranging standards for ethics and behavior? Charles Ess (2002) discusses questions that explore Marshall McLuhan's concept of the "electronic global village." One ideal in Western society is that we can foster societal development, democracy, individualism, equality, free speech and consequently, economic prosperity, as a result of computer-mediated communication (CMC) and the Internet. In this utopian world, ethnocentric conflicts based on local cultural values are subordinate and a unified world based on Western values should result. Ess argues that two philosophical assumptions are fundamental to the concept of "the global village." The first is that technologies are value-neutral, and that they are "tools", wherein their value derives from their use. Ess refers to this assumption as *technological instrumentalism*. The second underlying assumption, *technological determinism*, holds that technologies are the primary sources of social change in the world's peoples and cultures. This perspective implies that the consequences of the technology are *pre-determined*. Are the decisions people make regardless of technology, or are they informed by the technology, or are they actually driven by the knowledge and power of the technology? Which ethical questions are implicit in each of these positions?

In this essay I shall draw on my experience in the fields of both education and telemedicine in order to discuss ethical issues relating to the design and implementation of telemedical information and communication technology (ICT).

Those of us who followed technological developments closely in the 1990s, and who have been working for years to develop applications and tech-

nological solutions -- driven partly by a naïve optimism about technology, and curious to see what technology could accomplish -- can confirm that technology per se is not value-neutral. There are always people with different values, attitudes, competence and knowledge who govern the technology's development and hence its potential uses. When I worked at a major publishing house in Oslo in the 1990s as a project leader for educational software development, I thought that technology would deeply influence the science of education and the approaches used for both individual and social learning processes in Norwegian primary and secondary schools. What I have realized, however, is that technology itself does not cause educational sciences to develop or change. Human beings in the society must actively influence that development. We can use technology as one of many different scaffolds to support pupils in educational settings. In my paper "A Web of Discourses," I discuss the interplay of these issues, such as societal relations and human activity in different social contexts, which influence educational software development (Gilstad 2001a). Politicians, teacher and student organizations, IT-staff, education professionals, pupils and teachers all contribute to the underlying forces that lead to educational change within the school system. Learning does not improve simply by introducing technology in the classroom. I have not yet seen a computer application that is completely value-neutral and that improves teaching, unless there is a meaningful change in the learning environment for which it is intended.

Ess (2002) defines two fundamental questions: "First, can we craft an ethic that will shape the design, implementation, and use of CMC-technologies so that individuals and peoples both communicate with one another globally through these media, and thereby move towards at least a modest realisation of the old ideals of a cosmopolis and a global community marked by less rather than more authoritarian values - but without, at the same time, overriding local cultural identities through a "computer-mediated colonization", i.e. the relentless imposition of a specific set of cultural values and preferences? In doing so, secondly: can such an ethic be crafted so that it is indeed universally valid i.e. so that it derives from and reinforces ethical sensibilities commonly shared among peoples and cultures of the world – so that endorsing it avoids the initial ethnocentrism and limited validity of the vision of an 'electronic global village', a vision that, despite the presumed universal validity, in fact initially rested on distinctively Western values (democracy, equality, freedom of expression for the individual, etc.) rather than universally-shared values?"

These questions are not easy to answer, and I am aware that I am moving into a fundamental philosophical discussion that I will not be able to address thoroughly in this essay. In this essay, however, I will try to sort out some of

the ethical aspects in the complexity implicit in the development of telemedicine. It is with this caveat that I will consider which ethical questions one should potentially consider when dealing with telemedicine, whether concerning the development, use or evaluation of the technology's role in communication about medical issues and activities.

Development of telemedicine

The main subject of this essay will be the ethical questions that result from the development of telemedicine solutions. With Ess' discussion above as a point of departure, it is relevant to examine this question:

Is it possible to propose an ethic for the development of telemedicine solutions that can both maintain the need for geographically-independent communication and, at the same time, reflect complex professional and cultural identities and interests?

To begin to answer this question requires an understanding of telemedicine applications and making some analytical distinctions. I will therefore discuss the following:

- What are ethics?
- What is telemedicine?
- What are the overriding reasons for developing telemedicine, and what are the ethical implications?
- How can we preserve both major and the subordinate ethical questions during the development of telemedicine?
- Which medical ethical guidelines have implications for telemedicine, and what new questions must be raised when dealing with this new technology?
- How should cultural and linguistic issues be weighed in the development of telemedicine?

To explore these issues I will use examples from the field of fetal diagnosis. Examples from other medical fields are equally relevant, but I have selected fetal diagnosis because I am especially interested in this field. Ethical questions related to fetal medicine as a field of research, however, will not be discussed in this essay.

What are ethics?

Let us start by clarifying the concept of ethics. Wyller (1999, 3. ed) uses the words 'morals' and 'ethics' interchangeably, and describes both as "the individual's way to live their life and the relationship between human beings in a

society." The focus in ethics is on the individual's activities and on more general norms of activity in a social context. Several parameters determine whether an action can be interpreted as ethical or not. Relevant aspects of deontology and consequentialism will be discussed in the course of this essay while examining the motivations to develop telemedicine.

What is telemedicine?

Telemedicine is defined by the Standing Committee of European Doctors (CPME) as "the practice of medicine over a distance. In telemedicine interventions, diagnostic and treatment decisions and recommendations are based on data, documents and other information transmitted through telecommunication systems."¹

In everyday language, telemedicine is used relatively widely to describe all kinds of technology-mediated medical communication, ranging from simple websites with medical information, to advanced synchronous telecommunication used during surgery with the expertise of doctors and medical experts who can be across town or across the globe. Some examples are:

- Synchronous or asynchronous communication on Internet-based solutions
- Communication through video-based telecommunication equipment and satellite
- Computers used to log patient symptoms, both in general internal medicine and in specialized medical fields.

With the understanding that we can comprehend theoretical perspectives more clearly through empirical examples, I will briefly describe four telemedicine situations:

Telemedicine 1. Both in Norway and internationally there are static websites offering information about relatively uncomplicated conditions like flu, gnat bites, etc. These solutions have usually very limited functionality. One-way communication is often the norm, and interactivity is limited to search functions and sometimes a FAQ (frequently asked questions) that is updated weekly.

Telemedicine 2. Communication technology is often used in the relationship between the medical personnel and the patient. In a traditional face-to-face consultation with a general practitioner, technology is commonly used to document the patient's diagnosis and treatment. Treatment can also be virtual, where the patient or the doctor describes symptoms via e-mail, and the doctor or the specialist returns a diagnosis via e-mail within a certain time period.

¹ http://www.cpme.be/Telemedecine_2002.pdf

Telemedicine 3. In educational situations, where students and teachers are geographically separated, teleconferencing with synchronous video is quite common. In these settings participants can project their images, hold discussions and exchange experiences. Teleconferencing makes it easier to keep distant participants up-to-date with the latest techniques and diagnoses. Problems have been reported, however, with the two-way-communication aspect of teleconferencing.

Telemedicine 4. Laparoscopic surgery and virtual operations.

In this essay I will primarily use the concept of telemedicine to describe medical communication through Internet- and satellite-based solutions.

What is the major motivation for developing telemedicine, and what are the ethical implications?

Some organizations develop Internet-based solutions to secure prestigious projects that demonstrate that they are on the cutting edge of information technology. This might supply a temporary feeling of comfort for the organization's leaders, who can present the organization as technologically updated. During the so-called dot-com period in the late 1990s, small and large firms, organizations and institutions often felt they should have a website. Many did not necessarily know what kind of information the website ought to include, or why, but the unstated feeling was that a website was an important way to demonstrate to clients the company's competence and activity. Consequently, a website was thought to be a critical component of the company's success and hence an assurance of working conditions and income of the employees.

Alternatively, motivation can be linked to the possible benefits of the technology, such as improved working conditions for health personnel and in communication with patients.

Several perspectives can function as a point of departure to interpret ethical intentions and actions. In the first example, we can sense a utilitarian perspective, while in the second there seems to be a more deontologic, sense-of-duty motivation for the act. Utilitarianism is a kind of consequentialism (Wyller 1999). A consequentialist would consider the value of the act from the consequences. The moral value of the act is independent of whether it is done out of duty or not. An ethicist who considers duty, or a deontologist ('deon' means duty), does not focus on the consequences of the activity, but rather emphasizes the moral attitudes behind the act. Although organizations may develop telemedicine for the associated prestige, the technology simultaneously brings great value to the users. On the other hand, there are no guarantees that tele-

medicine will be used in a reasonable way by health personnel, in spite of the best intentions of those who developed the technology.

The purpose of the examples I have presented is to show that there is more than one way of evaluating whether or not the motives for developing a technology are ethical and that a variety of motives might be ethical, depending upon the perspective we take as we examine motivation. This does not mean that I subscribe to *ethical relativism* (AOIR ethics committee. 2001); instead, I recognize that a variety of motives are acceptable, and can be considered ethically justifiable. On the other hand, I do not want to lock myself into a full endorsement of *ethical dogmatism* (ibid), by saying that only one motive is sufficient to decide if an act is ethical or not.

As with Ess (2002), I would rather focus on *methods* that assure ethical aspects are weighed in the development of telemedical solutions. In fact, having one sort of motive does not necessarily exclude others. There is nothing that implies that one motive is more ethical than another. Either we can link a motive to consequentialism or deontology. Both forces might be at work at the same time, acting together to help overcome the difficulties involved in creating a technology as complex as telemedicine.

How can we preserve both major and the subordinate ethical questions during the development of telemedicine?

Iterative development

The development of Internet-based solutions is a rather complicated process. In an earlier paper, I have argued for the importance of conducting regular evaluations of a site's usability, content organization and choice of technology, and the potential for communication during the developmental process to assure that users' preferences and needs are maintained, and to assure that the solution is of the highest quality (Gilstad 2001b). Thus, the developmental process becomes an iterative one, in which results of initial evaluations influence subsequent development.

Ethics should also be evaluated iteratively throughout in considering the relationship with the user, communication, content and technology. A conscious understanding of the reason for the project and its need to be Internet-based are important, both with respect to societal interests and the impact the project will potentially have on individuals. With this in mind, we can note the link between the deontological perspective and the developmental process, because it is necessary to relate decisions to both the preparations and the intentions behind the act.

If the motive for the technology is inspired by McLuhan's "global electronic village" concept, and the wish is to create a solution that can represent a model for ethical normativity, the concrete aspects of the proposal, for example, content organization and user-integrity, should be examined to determine if they correspond with the motive behind the technology's development. Let me illustrate with an example: We are going to develop telemedicine technology for ultrasound and fetal diagnosis. The technology is intended for health worker education worldwide, for those who specialize in fetal diagnosis. Health care professionals might need to contact a professional forum where they can address questions related to fetal diagnosis, such as for example, fetal anomalies. We develop a thorough project plan and discuss all relevant aspects, such as administrative affairs (human resources, time, economics), technological solutions, design, user-groups, and the technology's content as well as its organization. We try to project how the solution will look and operate and how it will be used. There is, however, no guarantee that the technology will work as intended in the social and cultural contexts in which it is actually used. There might, for example, be different ethical standards when it comes to the visual presentation of pathologies in different professional and/or ethnic cultures that also might include religious convictions that differ from the developers'.

To determine if proposed solutions are working, we need feedback from the users during the developmental process so that the technology can be adjusted during development -- not after the work is final and complete. The costs of making adjustments based on iterative queries of users during the technology's development are minor compared to the economic costs of making adjustments to the final product. In other words, it is possible to derive, evaluate and improve ethical norms and questions when conducting regular evaluations during the iterative developmental process. It is strongly recommended to evaluate all aspects, including ethical ones, to assure the highest quality product.

Informed consent

Such an approach can raise ethical questions of its own. When evaluating how a user will respond to a new technology such as telemedicine, should observations be conducted without the knowledge of the informant, or should a researcher ask for informed consent before conducting evaluations or research?

Evaluation of telemedicine, however, must of necessity be conducted with informed consent, for ethical as well as practical reasons. From a practical perspective, we have to ask people to use a pilot-version or the beta-

version of the technology, since there is no final version commonly available. Consequently, users must be informed beforehand. However, this has some methodological implications that I will mention briefly. If the informant is aware of being a participant in a research project, their activity might be influenced by that knowledge and the outcome may not represent the informant's actual response when facing the problem in a normal, unstructured situation. What is the value of the research if it is not representative? On the other hand, when will the study of human behavior be 100 per cent representative? Human beings are not robots; their actions change from situation to situation. Context (other participants, environmental factors, etc.) also determines to a large degree how we behave in the actual situations. Even an individual's state will vary from one day to the next; one day we might be highly motivated to learn and explore, another day we may not be motivated and not have time to explore. These and many other aspects will influence behavior. Informed consent is, however, important to consider when conducting research on human behavior.

Which ethical guidelines in the medical field have implications for telemedicine, and what questions should be raised when dealing with this new technology?

Telecommunication is subject to the same ethical rules as other medical communication (Den Norske Lægeforening, 1997-1999). In Norway, those who work with the development of telemedicine consult the Ethical Council for medical affairs with respect to maintaining patient *anonymity* in the use of technology-mediated material. No other ethical questions related to the development of telemedicine are considered in Norway (with reference to a conversation to the leader of one of the major companies).

Some initiatives have been undertaken internationally to set ethical norms and standards. The Internet Health Coalition² has developed the *eHealth Code of Ethics* which is an important contribution to the understanding of ethics in eHealth and telemedicine. The goal of the *eHealth Code of Ethics* is to:

help create a trustworthy environment for *all* users, whether they are patients, health care professionals, website sponsors, people who develop health applications and content for the Web, or individuals who turn to the Internet to help them stay well.³

² <http://www.ihealthcoalition.org/index.html>

³ <http://www.ihealthcoalition.org/ethics/code-foundations.html>

A communication from the Commission of the European Communities which focuses on the “Quality Criteria for Health related Websites” was released in December 2002 with the aim to:

draw up a commonly agreed set of simple quality criteria on which the Member States, as well as public and private bodies, may draw in the development of quality initiatives for health related websites.⁴

This document briefly touches on some general aspects related to health-related websites, and can serve as a point of departure for more detailed discussions.

I have not yet found any standard-setting initiatives that treat ethical questions related to the *developmental process*, or proposals on how to implement ethical questions in detail.

What are relevant new research questions when dealing with medicine and technology?

The answer is that it depends on how telemedicine is to be used and who the users are. There are many aspects of telemedical technology and they all have different ethical and technological implications.

Risks

Chris Mann (2002) refers to potential risks when using the Internet as a research tool. Developers of telemedicine might and should discuss these risks from an ethical perspective, because people are entitled to protection when they are operating in these new communication forums. Mann focuses mainly on three areas: technical risks, legal risks and personal risks.

Technical risks fall in two categories: lack of security and lack of privacy. Users often do not have the competence, the access or the ability to control what happens to information that is transmitted via computer and the Internet.

Technology-mediated material might be used, abused, reduced -- or it might even disappear without the user's knowing, or being able to control it. There are no guarantees that the technology has been created in conformance with technological or ethical responsibilities.

The American Medical Association (JAMA, 2002) has developed "Guidelines for Medical and Health Information Sites on the Internet." These guidelines reference a survey of Internet medical service use where protection of confidentiality was rated as the most important component of any techno-

⁴ http://europa.eu.int/information_society/eeurope/ehealth/doc/communication_acte_en_fin.pdf

logical offering. Another study showed that most telemedical services inform users about protocols to protect privacy, but most do not follow these protocols.⁵

With respect to legal issues, Mann (2002) emphasizes the lack of awareness of legal ramifications related to using the Internet. Even though many users believe (in accordance with the idea of the electronic global village) that the Internet is uncensored, global anarchy; the reality is different. Local or national laws can apply in the case of legal violations. So far, there are no detailed, overarching legal rules or regulations that apply across cultures, and which transcend local laws or rules. There are initiatives to develop such rules, however. In one such instance, the EU committee is considering challenges related to life sciences and biotechnology. Authors of a recent report made an appeal to European society to take the lead in setting standards for this new knowledge and technology:

Europe is currently at a crossroads: we need to actively develop responsible policies in a forward-looking and global perspective, or we will be confronted by policies shaped by others, in Europe and globally. The technology and its applications are developing rapidly - the Commission believes that Europe's policy choice is, therefore, not whether, but how to deal with the challenges posed by the new knowledge and its applications (Commission of the European Communities 2002).

There is a need to guide societal development in a direction that maintains social and cultural relationships. An international commission like the EU is in a position to make rules and set standards for ethical questions related to new technologies.

When describing the third risk, Mann (2002) focuses on the personal risks for the users. She describes the following risks from a research perspective: lack of protection against harassment, misuse or fraud, a lack of communication between the researchers and the users after the study that would help the user understand the material (for example, an evaluation of procedures), lack of protection from exposure as well as a lack of knowledge about the potential of being exposed, and the lack of protection for society's most vulnerable groups. Developers should force themselves to devise solutions that maintain personal protection for users at all levels. They also must present this information in a convincing manner. The demands of maintaining personal integrity can be met during the iterative developmental process by evaluation of potential problems at different stages of the process.

With the introduction of ICT in medicine, it is also important to ask if technology will, directly or indirectly, reduce human contact between health

⁵ <http://jama.ama-assn.org/issues/v283n12/ffull/jsc00054.html>

care professionals and patients, and if this will result in negative long-term consequences from the perspectives of both society at large, and the medical community. The report of the Standing Committee of European Doctors (1997) discusses the doctor-patient relationship, and emphasizes that the use of technology should not influence the fundamental nature of this relationship:

Preferably, all patients seeking medical advice should see a doctor in a face-to-face consultation, and telemedicine should be restricted to situations in which a doctor can not be physically present within an acceptable time. The major application of telemedicine is the situation in which the treating doctor seeks another doctor's opinion or advice, at the request of or with the permission of the patient (Standing Committee of European Doctors, 2002).

The physical care that health care professionals provide give patients a sense of security and comfort during the diagnosis and treatment of disease. This is difficult to maintain with the use of telemedicine. Patients should be informed of this before telemedicine is introduced as an option.

How should cultural and linguistic issues be weighed in the development of telemedicine?

How should cultural and linguistic issues be weighed when deciding how content will be communicated, so that telemedical applications can transcend geographical biases and professional interests and identities? The concepts *culture* and *context* are interpreted in various ways in scientific disciplines. The underlying understanding of these concepts, when mentioning them below, is related to socio-contextual perspectives on communication. Socio-contextual perspectives on communication emphasise the dialogic nature of human communication and human existence (Cole 1988, Vygotsky 1978). Every individual is actively conditioning and is being conditioned by the previous, present and future activities in the social contexts and in the various discourses taking place in the society. However, the social aspects of human existence do not exclude the individual characteristics of the human being. We make meaning and interpret communication based on our previous experiences and our previous knowledge about the world in an active interplay with other human beings in the contexts. It is important to notice that the dialogic nature of human communication and human existence is not limited to the present life of the individual person, but implicates both historical and future aspects which directly and indirectly affect and are being affected by human beings in society.

The basis for the construction of meaning in a context, in a society and in a culture is that the communicators apply a reciprocally interpretable code or

language. The applied code or language can be verbal or non-verbal, visual, audible or tactile. In other words, the code or language must be perceivable by the communicators in the context.

With the Internet, communication is visual, with written texts, pictures, videos, slide shows, icons, pictograms, colours, fonts, etc. Some solutions also include transmission of synchronous and asynchronous sound. We might borrow the concept of *sign* from semiotics (Berge et al. 1999) as a collective concept for all these elements. All signs have different potential interpretations depending on the reader's perspective. However, the different signs are not value-neutral or independent of cultural norms and identities. What we read into the signs depends on our cultural and social background. The designer's biases and goals for communication also affect the sign in an Internet application.

With the perspective of value-dependence as a point of departure I suspect that the "electronic global village" of McLuhan is an impossible achievement. A utopian unified world can not be based on Western values and be a democratic world at the same time.

Does the fact that all signs have a value-dependent research potential mean that there are no universally valid signs? This question clearly can be the basis of an extended discussion, which is not the point of this essay. However, the issue does illustrate the problems that result from efforts to create a global style.

Content should, however, be presented in a language that is available to and understood by the largest number of individuals worldwide. Today, English is the language that fills this demand. However, a language is not value-neutral. Language and identity are inseparable. The complex web of values and norms becomes evident in the way we use language, and distinguishes between native and non-native speakers.

A certain level of understanding is needed to make sense of telemedicine, in the same way that specific knowledge is required to read and understand a book about a medical speciality. Telemedicine will thus not be meaningful to all the users who might encounter it. Some people will be better prepared to make use of the information than others. A general-practice physician would have better qualifications than a layperson, but less ability than a specialist, in understanding telemedical information dealing with fetal diagnosis. A South African specialist in fetal medicine would be better able to understand a specialist presentation than a Norwegian general practitioner, even if the information has been developed by Norwegians to serve in diagnosing medical conditions in Norwegian fetuses. In other words, culture is not the only factor in determining comprehension.

The challenge of how to communicate information about medical issues is discussed in the American Medical Association's (AMA) guidelines, and the following is emphasized:

...the guidelines' fundamental principles: authorship, attribution, and disclosure must always be clearly provided; editorial content must be current and the way in which quality is ensured explicitly stated; advertising and commercial sponsorship must not influence any editorial content, and advertising must be easily discernible from editorial content; privacy and confidentiality policies must be explicit and adhered to, ensuring that individuals' rights to privacy and confidentiality are preserved; and e-commerce must function efficiently and securely. Adherence to these fundamental principles will facilitate acquisition and application of medical information by patients, the public, physicians, and other health care professionals (JAMA 2000).

This is the main focus of the "Guidelines of Medical and Health Care information sites on the Internet." The guidelines emphasize the importance of publishing-related questions, with respect to assuring content quality, publicity and sponsorships, protection of confidentiality and principles for electronic commerce. This demonstrates the importance of having an editorial group working with content and publishing, and to assure that ethical demands related to content and organization are considered.

The role of the doctor and the medical field

According to the Report from the Norwegian Doctors Organisation to the Value Commission (Den Norske Lægeforening, 1998-1999), doctors have professional and moral obligations as an underlying requirement of their profession. As professionals, doctors must have specialized knowledge about the human body, illnesses and treatments. The moral obligation includes a life-long duty to serve others without concern for the self, and in pledging to uphold the Hippocratic oath, to do no harm. A doctor must use his/her knowledge and provide care and resources to improve the health of his/her patients, whether that patient suffers from chronic or acute problems. Patients expect a doctor to have the ability to heal and most of us assume that all health problems can be cured.

The doctor's role is evolving with the introduction of new technology. The computer has become an "actor" in the doctor-patient relationship, both in face-to-face and virtual communication. Doctors will practice medicine independent of the presence or absence of technology. Further, medicine is not one professional field but many, consisting of a plethora of specialities, such as cardiology, obstetrics, gynecology, oncology, etc. Each speciality has its own

set of standards, norms and practices. These principles all derive from common ethical norms and standards, but each field has both opportunities and restrictions for specialized medical practices. Different cultures also have standards and rules for human activity and ways of making meaning in society.

An understanding of research ethics is important both generally and when implementing and using new technological solutions. In the education of health care professionals it is important to focus on the ethical implications of the use of technology in the treatment of patients. A question of particular importance is how the doctor-patient relationship will evolve when communication is virtual, or when the doctor uses a computer for consultation in patient treatment.

Conclusion

Specialists who develop telemedicine have a certain awareness that ethical questions must be considered. Descriptions about projects are sent to the Ethical Council for advice or approval according to established medical procedures and standards. The principal focus in these cases is patient confidentiality and anonymity. But should we provoke more discussion about ethical questions related to telemedicine or are existing rules adequate?

My opinion is that it is important to have discussions about ethical questions in the earliest phases of project development. Developing a web-based solution should be an iterative process in which evaluations are conducted throughout the project to assure optimal quality of all aspects. In order to preserve user preferences, integrity and ability to interact with the technology, patients should be consulted as the project develops.

From the preceding discussion, it is possible to deduce ethical guidelines for the development of telemedicine applications:

- Define the overriding ethical reasons for developing the specific application, since those reasons will set the parameters for decision-making during the process.
- Ensure the application is crafted with regular, iterative evaluations that assure all aspects, including ethical ones, are considered and, if necessary, changed if the application does not conform to ethical parameters.
- Develop the application according to general rules of medical communication, and
- Discuss the following ethical issues: technology (security and privacy), law, protection of confidentiality and privacy, and the effects on the doctor-patient relationship.

- Be aware of the effects of linguistic elements and content choices.
- Use a professional editorial committee to assure content quality, with specific emphasis on ethical questions.
- Update content regularly
- Make clear distinctions between content and publicity
- Make certain users have an explicit understanding of how the application protects the individual, as well as their privacy and confidentiality.
- Consider possible ramifications that the application might have for both professionals and researchers.
- Consider education in the research field.
- Discuss the role technology should have in the doctor-patient relationship.
- Make explicit any ethical guidelines for use of the material.
- Consider to what degree it is possible to define global ethical standards for the presentation of content, and develop content in such a way that it will not be interpreted as offending or unethical according to international standards.
- Make ethical guidelines for research available, both in situations with and without technology.

Whether these ethical guidelines are adequate will only become clear after specific telemedicine applications have been in use for some time, and after those applications have been tested by a heterogeneous group of users.

Bibliography

- Aoir ethics working committee (2001): a preliminary report
(<http://www.aoir.org/reports/ethics.html>, August 2002)
- Berge, Coppock, Magerø (1998): *Å skape mening med språk*, Oslo, Norway : Landslaget for norskundervisning (LNU) and Cappelen Akademisk Forlag.
- Cole, M. (1988): "The zone of proximal development: Where culture and cognition create each other" in (ed.) I.J.V Wertsch: *Culture, communication, and cognition: Vygotskyan perspectives*, pp.146-161. Cambridge, New York: Cambridge University Press
- Commission of the European Communities (2002): Communication from the Commission to the Council, The European Parliament, The Economic and social committee and the committee of the regions: Life Sciences and biotechnology - A Strategy for Europe
Commission of the European Communities (December 2002): "Quality Criteria for Health related Websites"
(http://europa.eu.int/information_society/europe/ehealth/doc/communication_acte_en_fin.pdf)

- Den Norske Lægeforening (1998-1999): "Fra legekunst til medisinsk teknologi. Hva gjør de helsepolitiske reformene med lege-pasientforholdet?" Notat til Verdikommisjonen fra Den Norske Lægeforening (<http://www.legeforeningen.no/index.db?id=304>, feb. 2003)
- Den Norske Lægeforening (1997-1999): "Reglementet for Rådet for legeetikk og avdelingens utvalg for legeetikk" (<http://www.legeforeningen.no/index.db?id=298>, feb. 2002)
- Ess, Charles (2002): "Electronic Global Village or McWorld? The Paradoxes of Computer-mediated Cosmopolitanism and the Quest for Universal Values" in Rolf Elberfeld, Johann Kreuzer, John Minford, and Günter Wohlfart (eds.), *Ethik: Ost und West [Ethics: East and West]*, München: Wilhelm Fink Verlag
- Gilstad (2001a): En vev av diskurser, Paper til diskurs- konferansen, Stockholm, Sweden.
- Gilstad (2001b): Evaluering av det nettbaserte undervisningsopplegget i italiensk, Rapport 1, SOFF/Romansk Institutt, NTNU.
- Internet Health Coalition (2002): *eHealth Code of Ethics* (<http://www.ihealthcoalition.org/ethics/code-foundations.html> , Dec 2002)
- JAMA (2000): Guidelines for Medical and Health Information sites on the Internet, Principles Governing AMA Web Sites (<http://jama.ama-assn.org/issues/v283n12/ffull/jsc00054.html>, August 2002)
- Mann, Chris (2002), "Risks in Internet Research", Handout on seminar "Internet and Ethics", Program for Applied Ethics, Dragvoll, Norway.
- Mann, Chris, Stewart, Fiona (2000): *Internet Communication and Qualitative Research, A Handbook for Researching Online*, London, England: Sage Publications.
- National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) (2001): Guidelines for research ethics in the social sciences, law and humanities (<http://www.etikkom.no/NESH/guidelines.html>, August 2002)
- Standing Committee of European Doctors (CPME) (2002): CPME guidelines for telemedicine (http://www.cpme.be/Telemedecine_2002.pdf) page 16, feb. 2003)
- Vygotsky, L.S. (1978): *Mind in Society: the Development of higher Psychological Processes*, London: Harward University Press.
- World Medical Association (1999): World Medical Association Statement on Accountability, Responsibilities and Ethical Guidelines in the Practice of telemedicine (<http://www.nil.org.pl/nsl/wwmatelemed1.htm>, August 2002)
- WHO (1997): A Health Telematics Policy, Report of the WHO Group Consultation on Health Telematics, 11-16 December, Geneva, Switzerland.
- Wyller, Truls (1999 3.ed.): *Etikkens historie*, Oslo, Norway: Cappelens Akademisk Forlag.

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