Examining Ethical Issues of IT in Health Care
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# TABLE OF CONTENTS

## INTRODUCTION

- Introduction to Ethical Theories ................................................................. 5
- Introduction into Ethical Theories .............................................................. 7
- About Ethics .................................................................................................. 7
- Feminist Critique ......................................................................................... 9
- Empirical Ethics .......................................................................................... 9
- Applied Ethics and Technology in Health Care ............................................ 9
- Information Technology, Health Care and Ethics ....................................... 10

## LITERATURE SURVEY: ETHICS, IT AND HEALTH CARE

- About the Scope and Limits of the Literature Review ............................... 11
- Clinical Ethics and E-Medicine: What It Is the Place of Ethics? ................. 12
- Why Privacy Matters and What to Do About It? ..................................... 13
- Privacy as a Shield ..................................................................................... 15
- The IT Professionals' View: Privacy as an Instrumental Value .................. 16
- Issues in the Doctor-Patient Relationship and Use of ICT: A Philosophically Argued View ................................................................. 16
- Guidelines for Professionals to Protect Electronic Health Care Data ....... 18
- Participation of Practitioners in Development of Integrated Health Care Record Service: Concerns of Clinicians ........................................... 19
- Active Role of Patients in Design and Implementation: Empowerment and Control? .......................................................... 20

## HOW TO STUDY ETHICAL ISSUES

- The 'Narrative Ethics' Approach ................................................................. 22
- Ethical Case Deliberation .......................................................................... 23
- The Art of Constructing 'Vignettes' ............................................................ 25
- How to Use Vignettes as a Research Tool .................................................. 26

## THE SURVEY

- The Survey ................................................................................................ 28

## ETHICAL ISSUES: PRELIMINARY OBSERVATIONS AND CONCERNS

- Monitoring and Surveillance: For What Purpose? .................................... 32
- Health Data Management Outside the National Boarders ....................... 33
- Access to Health Information: Retrieval and Results .............................. 33
  - Regulation of access to bytechnology and/or standards .......................... 34
- Literacy Considerations and Discrimination ............................................. 35
- Access and Discrimination ....................................................................... 36
- Using ICT for Overcoming Prejudice and Isolation .................................. 36
- Using ICT for Solving Shortages in Medical Care .................................... 37
- ICT Offers to Give Youth More Attention ............................................... 37
INTRODUCTION

The health care system has always been a place for and target of debate and controversy. Bringing computer-support into the health care system reinforces this debate. It is shaped by a diversity of perspectives and interests and by the conflicts between them. The development of Information and Communication Technologies (ICT) reflects the changing nature of health care. The modern health institution is dense with medical specialties, technologies, organizational rules, safety measures, fiscal accounting and monitoring systems. Organizing diagnostic and therapeutic action is a complex task and health organizations are places of multiple work sites - "places where different kinds of work are going on, where different resources (space, skill, ratios of labour force, equipment, drugs, supplies, and the like) are required to carry out that work, where the divisions of labour are amazingly different, though all of this is in the direct or indirect service of managing patients' illnesses" (Strauss et al. 1985, p.6)

Computerization is one of the answers to the complexity of health work and adds its own momentum. It is driven by a multiplicity of actors. The resulting systems reflect a complex web of occupational hierarchies, work practices, professional perspectives and priorities. Apart from the health care professions themselves, each representing specific substantive and social domains, health administrators, insurers and legislators has a dominant voice. Computers are inseparable from their preoccupation with exploding costs, and many systems in use today reflect the idea to establish management criteria in the heart of the health professions (Feldberg 1990). In response to these developments, there is a growing international market for healthcare systems. With this an entirely different set of actors - computer companies, systems developers, vendors, Internet providers - enter the scene.

Embedding ICT systems and applications in complex work activities and relationships may give rise to value conflicts. Some of these conflicts are to do with the nature of health work. Other conflicts are connected to the scarcity of resources, the exigencies of a modern health administration, and the growing importance of health care as an economic activity. Among the ethical aspects of technology/IT use which have been identified in the research literature are:

- Issues of transparency (Are users provided with a valid and simple model of what the system does; are they made aware when their activity has an effect on the system?) and agency (principle of responsibility)
- Issues of standardization with respect with tolerance for variation (Are the standards that are introduced through e.g. EPR disruptive of local work practices? Does this affect the quality of the work? Are 'profiles' conducive to thinking in simple measures such as 'averages' and does this reduce the tolerance for discrepancy and variation?)
- Issues of work ethics (Do ICT systems and applications augment health care professionals' workloads at the expense of care? Are certain doctor-nurse order-sequences built into an EPR and does this reify hierarchical relations on the shop floor?)
- Issues of privacy and confidentiality (Can ICT systems be used for surveillance of employees? What limits should be placed on electronic patient record information sharing?)
- Issues regarding intellectual property – What intellectual property issues could arise with health information websites and the maintenance of health information databases?
• Issues of liability (Can patient/physician reliance on on-line health information lead to liability of the provider? Are telemedicine practitioners more likely to be sued, and for what?)

• Issues dealing with equitable allocation of resources (Must online access to health information be made available to all, or only to those who can pay?)

• Issues of literacy (Is health information presented in ways that help citizens to understand their problems and to make choices?)

One of the first steps of the ethics team was to send out a questionnaire to all Action for Health projects asking which of these issues they anticipate encountering, or have already encountered. In addition, interviews were carried out with all projects, discussing the ethics perspectives and research strategies with individual project teams. In parallel we conducted a literature survey with a focus on the contributions of philosophy, moral theory and medical ethics to understanding ethical issues on the one hand, specific studies with a perspective on ethical issues of IT in health care on the other hand. Finally, the ethics team looked into data collection methods, examining different approaches to studying ethical issues, in particular the method of ethical case deliberation.

The report documents these activities, in five steps:

• We will give a short introduction into ethical theories

• Provide a literature survey with a focus on applied ethics and technology in health care

• Describe how to study the ethics of everyday practices, using (ethnographic) fieldwork, making a case for ‘narrative ethics’

• Specify the ‘vignette’ method for both, presenting ethical case material and for generating data – stimulating additional and novel insights into ethics-in-practice

• Present the results from the survey and individual interviews.
INTRODUCTION INTO ETHICAL THEORIES

About ethics

The subject matter of ethics, or moral philosophy, has to do with questions relating to how we should live to live the good life (what is the good life?), what kind of society we should have (how to distribute goods and burdens?), how we should treat others. Typically ethical issues deal somehow with the well being and interests of others but duties can also be self-regarding. Typical ethical terminology includes the notions of right and wrong, good, bad and evil, rights and duties, and responsibility. Normative ethical theories seek for answers regarding the standards of moral right and wrong, grounds for what would be the right thing to do, in other words, what would be our duty in a given situation. A broad distinction can be made between theories representing an absolutist or relativist view of morality: the absolutist view holds that the grounds for judging human conduct are always the same, independent of people involved, time and place, while the proponents of the relativist view claim that the grounds vary with social and individual needs, customs and historical evolution (see, for example, Abelson & Friquegnon 1995).

One of the major problems of ethics has to do with the logic of reasoning that is used in moral deliberation and moral justification. Moral reasoning that agents resort to when weighing the alternatives available to them in morally perplexing situation is called deliberation. When agents provide reasons for acts that they have already committed, they are involved in moral justification. Much of traditional ethical theorizing then has dealt with the logic of moral reasoning: trying to establish whether there is something like an intersubjectively valid method of reasoning in ethics, and secondly, specifying the principles of the logic of moral reasoning. The history of ethics has witnessed a variety of responses to the problem of moral reasoning and many theories have been presented for a general method for solving particular moral problems.

Valid moral reasoning and sources of our duties have been seen as resting either on single principles such as the greatest happiness principle proposed by the utilitarian philosopher J.S. Mill or the categorical imperative (in its different versions) formulated by the German thinker Immanuel Kant or on pluralistic theories. (see, for example, Taylor 1967; McNaughton 1988.) Mill and Kant's views on the rightness or wrongness of an act depend either on the consequences of the act (Mill) or on its correspondence with a duty (Kant). Bearing intrinsic value in these two theories are then a good states of affairs and right action respectively. For the utilitarian, testing the rightness of an act would mean a kind of evaluation of the state of the affairs produced by the act: if the intrinsic good to be maximized is happiness, then an act that produces the greatest happiness to those involved is the right one and deserving of moral praise. Sometimes what makes an action appear right is a fact regarding its consequences but often this is not the case, instead rightness of an act is determined by respect for others' rights or other obligations that agents may have (Williams 1995). For Kantian, or deontologist theories the latter would be an appropriate measure of moral rightness. Kant proposed a very strict view: he believed that an act is morally praiseworthy only if it is done neither for self-interested reasons nor as a result of natural disposition. Moral praise is reserved only for acts done out of respect for moral duty. (See, for example, Beauchamp & Walters 1994). Practical moral recommendations of these two different kinds of theories will of course differ. For example,
whereas lying might sometimes be justified for the utilitarian, or at least figure in as an option in a deliberation, it would never be permissible for the Kantian.

Virtue theory, a third type of approach to ethics places value on the cultivation of the character of persons. Plato and Aristotle, for example, conceived of ethics in terms of virtues instead of terms of right and obligatory (see, for example, Frankena 1973). Strictly speaking, virtue theory is not an ethical theory like the single-principle approaches above because it does not offer an alternative standard to right action or guidance to decision making. A virtuous person acts right as a result of having cultivated certain character traits that are relevant for recognizing what the right thing to do is and then acts accordingly. Conversely it can be said that no matter what kind of a moral toolkit a person with a bad character is provided, this person will often fail to act right. The goal of moral education is then to help young people develop themselves in accordance with relevant virtues. Moral judgment would not rely on the language of right and wrong as much it would take the shape of sentences like - "her act was courageous" – depending on the virtues that would be seen as worth cultivating. According to proponents of this approach, the main task of ethical theory is to distinguish the virtues that make up a good moral character and resolve any conflicts between them. (See, for example, Abelson & Friquegnon 1995.)

Moral theory need not be based on one single principle as a standard for right conduct. This has indeed been the solution that has been most presented in bioethics.

The so-called common morality pluralist views on ethics present the possibility of many principles. This has been a particularly popular approach in the field of health care ethics. Possibly the single best known piece of literature in biomedical ethics written by Beauchamp & Childress Principles of Biomedical Ethics (for example 4th ed, 1994) introduces such a pluralistic common morality approach for analyzing ethical problems in the health care setting. The authors defend a four-principles approach to biomedical ethics. The principles – autonomy, justice, beneficence, and non-maleficence – derive from considered judgments in the common morality and medical tradition, their centrality to biomedical ethics is a conclusion the authors have reached by the search for considered judgments and coherence, not a position that they will give an argued defense. The view presented by Beauchamp & Childress dominated much of the bioethical discussion during the 1980s and 1990s. Practitioners in medicine and nursing found it understandable and applicable to their fields. However, a common critique against the common morality system presented by Beauchamp & Childress is that there is no way to order the principles within the theory itself: should two principles clash, the theory does not provide means to solve the conflict as there is no ordering of the principles available.

Professional codes of conduct and guidelines are also typically constructed around commonly accepted ethical principles, duties and even virtues. Numerous such codes have been written by professional organizations, universities and companies, over the past decade in response to ethical problems in computing technology. "The ACM Code of Ethics" (see, for example, Anderson, Johnson, Gotterbarn & Perrolle 1993) and “the E-health Coalition Code of Ethics” (EHealth Ethics Initiative 2000) are two examples of attempts to create a shared understanding of ethical conduct in the area of informatics. Directly addressing the health informatics professionals is the code of professional ethics sketched by Kluge (1998) that is based solely in the nature of the profession and the activities in which it engages.
Feminist critique

Despite the fact that a great deal of moral theorizing has been done in the tradition of the three main approaches to ethics, interesting alternatives do exist. Related to virtue ethics, the ethics of care, which originally emerged as a feminist critique to traditional theorizing, focuses especially on personal relationships and character traits that are valued in them: sympathy, compassion, love and friendship. Absent in ethics of care are abstract rules and impartial calculations typical of mainstream theories. Whereas traditional moral theories build on the ideas of autonomous choice between free and equal agents, the proponent of ethics of care argue for rethinking of the moral universe: much of social cooperation especially in the context of families and relationships experienced particularly of women is rather to be described, as Anette Baier has done, as "unchosen, intimate and among unequals" (Beauchamp & Walters 1994; Baier 1995). Moral theory should address and reflect these realities.

Theorists like Baier have opened new perspectives in moral inquiry by introducing new, previously neglected and even ignored concepts into the moral discourse. One of them is the notion of trust. (Baier 1995.) Feminist ethics has paid much attention to real contexts where moral decision-making takes place. Feminist ethicists have also argued for the need for moral theories that actually give, in the words of Virginia Held (1993), "guidance in confronting the problems of actual life in the highly imperfect societies that we live in." The proponents of ethics of care have also paid attention to contexts which have moral relevance but which have not been considered to have ethical relevance before. It is in this way that entirely new contexts have been opened up to ethical discussion, for example, that of mothering and raising children in general (see, for example, Held 1993).

Empirical ethics

A relatively recent development in the field of practical ethics is known as empirical ethics. Typical for empirical ethics are the following: striving at being both descriptive and normative, giving special attention to the context in understanding and analyzing ethical problems, and supplementing ethical theorizing with empirical, social scientific study. (Musschenga forthcoming). The importance of context can be seen in the work of empirically oriented ethicists in two ways: either context sensitivity is stressed, or the context can even be regarded as a source of moral rules (and moral expertise). In general, empirical ethicists take a critical view on moral expertise that could be in the possession of a given profession, especially the so-called bioethicists.

Much of work of biomedical ethicists has consisted of consulting practices with regard to ethical issues. One of the critiques of introducing ethical principles to a particular context of work is that the new norms often conflict with the already existing principles. For this reason, understanding of the particular context and its internal rules is essential. In general, more empirically oriented approaches to ethics - including feminist theory and hermeneutic ethics - draw attention to the fact that morality itself is formed and transformed by practices, not by theories (Verkerk 1999).

Applied Ethics and Technology in Health Care

When it comes to the development of academic ethics during the past 40 years, the most notable feature is probably the revival of an interest in ethical issues that arise in ordinary social contexts, that is, an interest in applied ethics (see, for example, Singer 1986). The fact that there
is more attention paid by philosophers to applied ethics can be partially attributed to the
development of new technologies (Almond 1987; 1995). This connection between the rapid
advance of new technologies and an increase in ethical debate is certainly the case when it
comes to ethics in health care, or, the so-called biomedical ethics. Biomedical ethics has
emerged as an academic discipline in the past 30 years and has responded particularly to
advances in reproduction technology and problematic questions regarding the limits of care and
end of life (Ibid.). The standard textbooks in health care ethics typically address issues regarding
just allocation of scarce health care resources.

The technologies the use of which spurred ethics-related discussions in the health care context
three decades ago are not necessarily the same as the ones that are found problematic today.
But the core ethical questions are likely to remain. The health care domain is characterized by
mutually competing values and ethical problems and debates are practically unavoidable. On the
level of health care provision, a scarcity of resources prevails and the system is expected to be
efficient and just to all citizens (in its allocation of services) at the same time. In an effort to
make more efficient care provision systems relying on ICT, issues of ownership of health records
and control over one’s property, become a problem. How to appropriately deal, for example, with
the claims derived of the principles of autonomy, promoting good, avoiding harm, allocation of
benefits and burdens continues to be a relevant question whether the “new” technology adopted
relates to transplanting hearts or transferring electronic records of transplant patients.

The interest of academic ethicists in the medical field has generated a mass of literature
published in books and professional journals of medical ethics (in 0.41 seconds, a Google
search with the words “medical ethics” yields 15,900,000 results), new ethics-related educational
needs and courses for professionals. Besides displaying a thriving publishing activity, the field of
bioethics has shown some signs of institutionalization, specialization, and professionalization. In
the European Union, for example, the building up of a common system for co-operative
biomedical research and necessary ethical control systems has been given a high priority in
recent years’ European politics backed up by agreements such as the Convention of Human
Rights and Biomedicine in 1997 (Riis 1998). New national and international committees and
advisory boards (see, for example, http://www.etene.org/e/index.shtml;
http://europa.eu.int/comm/european_group_ethics/index_en.htm), as well as standards and
practices for evaluating ethical aspects of scientific research have been established. At the
same time, completely new professional descriptions such as those of the medical ethicist,
clinical ethicist, and bioethicist have been added to lists of experts closely involved in the field
health of care and research related to it.

Information Technology, health care and ethics

The intersection of the fields of information technology, health care (medicine) and ethics has
developed rather recently. In general, technology and ethics is a field of study that has evolved
rather late. Ropohl (1998) mentions that in Germany, for example, technology and ethics as a
field of study did not exist until 1970. Some authors have expressed their dissatisfaction with the
unsystematic way that ethical questions in technology have been addressed. Despite a late
start, the intersection of information technology, health care (medicine) and ethics has been
presented as one capable of offering issues and practical problems on which bioethics can test
its theoretical-ethical approaches (Verkerk's 1999 review of Goodman 1998). For example, it is
possible to test against real issues emerging in health informatics whether a principle-based
approach or virtue theory is more adequate in addressing problems in this field. Practical
problems in the field can serve as test cases and thereby help development of ethical theory in
general (Ibid.). Additionally, bioethics has been seen as providing guidance in identifying issues
and in finding or inventing optimal solutions in the area of health informatics (Ibid.). But perhaps
a providing a testing ground for moral theories is not quite sufficient? Verkerk (304) points out to
a theoretically interesting point: If practices are shaped through the introduction of new
technologies innovations and our values are thereby challenged, will the relevance and meaning
of some ethical concepts also not be changed?

Verkerk point out to a weakness that is obviously not so well developed, or perhaps not even
identifiable, by the research tradition of bioethics and it is probably legitimate to ask whether
bioethics does not stop a little short of its potential tasks here.

**LITERATURE SURVEY: ETHICS, IT AND HEALTH CARE**

*About the scope and limits of the literature review*

This literature review with regard to ethical issues related to the use of information technology in
the health sector has been prepared to provide a background document for the ethical aspects
in the Act for Health project. It is not intended to be a systematic and comprehensive review of
literature written in this area. Instead it looks at the issues that have been widely discussed when
it comes to ethics and health care informatics.

For this paper, principally two kinds of documents have been reviewed:

- Articles addressing ethical issues identified in the area of health care informatics by
  professionals working in that area;
- Articles on ethics and information technology in health care written by clinical ethicists or
  ethicists working with questions on health care informatics.

This approach to the literature review serves the point of identifying the main problems that
professionals working in the field of health care informatics find relevant from the point of view of
ethics as well as those topics that ethicists working in the health care area have identified as
important. This makes sense especially from the point of view empirical ethics the proponents of
which emphasize the role of context in assessing practices. Paying due attention to context can
for example mean that

Two primary sources available through the electronic databases of the Vienna University of
Technology library were used for locating literature: *The Digital Library of the Association for
Computer Machinery (ACM)* and the *International Journal of Medical Informatics*. Additionally,

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1 In the ACM Digital Library, a straight-forward search-string consisting of the words “information
technology, ethics, health care” produced a search result of 190 articles that were rated second highest on
a 5-point relevance scale. Despite the high rating, most of the articles proved irrelevant for this literature
review as they had no reference to ethics in health care or ICT and ethics. After reviewing the titles,
keywords, and abstracts of the 190 articles, another exclusion criterion was adopted: articles published
prior to the year 1990 were not included in the review. Altogether 30 articles were included in this review
from the search in the ACM database. The inquiries with the terms “ethical issues” and
“ethics” produced 5 and 11 results respectively in the case of the International Journal of Medical
Informatics. Three (3) of the articles were included in both search results, 13 remaining from this search
for the review.
two academic journals, the *Journal of Medical Internet Research*, an open-access and peer-reviewed transdisciplinary journal on health and health care and *Ethics and Information Technology* were included as sources in this review.

Previously familiar resources based on the author’s previous experience were added to provide additional background. The ACM Digital Library is a vast collection of citations and full texts from ACM journal and newsletter articles and conference proceedings. The International Journal of Medical Informatics is the official journal of the European Federation of Medical Informatics (EFMI) and its scope includes, for example, information systems, hospital information systems, departmental and/or physician’s office systems, document handling systems, electronic medical record systems, standardization systems integration; organizational, economic, social, ethical and cost-benefit aspects of IT applications in health care

Other articles and Internet sites outside of the scope of the two main sources were included based on previous experience and their relevancy to the topic at hand.

**Clinical ethics and e-medicine: what it is the place of ethics?**

The rapid development of e-medicine poses important ethical challenges for health professionals but also for providers of clinical ethics support. As examples, Parker and Muir (Parker & Muir 2001) mention three ethical challenges related to the Internet and health care practice: 1) access to information, 2) access to treatment, and 3) commercialization. The authors see the role of clinical ethics support as continuing to be important, however, clinical ethics support needs to offer health professionals ways of responding to the challenges of the Internet both electronically and face-to-face and thereby show themselves to be an “indispensable part of good quality health provision” (Ibid.). Because access to information is itself insufficient for good judgment, the key challenge for the future will be finding ways for consumers and health professional alike to tell the difference between good and bad information. Not only the quality, but also the source of information can be an issue. Parker and Muir suggest that much of the information available to the public and health professionals will be provided by pharmaceutical companies or those, for example, patient support groups, who attempt to exert pressure in order to bring a drug to the market. (Ibid.)

With regard to access to treatments, the Internet removes traditional barriers to care and medication. Parker and Muir pose the question: who will be liable for misuse of mis-selling of a drug if both the clinical advice and the drug originate in a distant country (Ibid). Another set of issues may emerge from the closer relationship of clinical practice and research: increasing information being available to the public on on-going drug tests, people may demand to be able to participate in order to get access to new treatments.

Relating to commercialization, Parker and Muir voice a concern regarding the increasingly unmediated relationship between pharmaceutical companies and the public. As an advantage, companies may become more responsive to public demand. But the information available is likely to be biased or limited in scope. The ethical challenge is then: who will take on responsibility for the provision of quality-evaluated health information and information about the ethical implications of developments in medicine and medical science?

Clinical ethicists need to act more efficiently and flexibly to better respond to physicians’ daily ethical challenges. The ethics support will itself have to use the Internet more. Using the web can also enhance communication between committees. Finally, the Internet also offers
possibilities of developing innovative forms of ethics education and training for members of ethics committees and health professionals.

Why privacy matters and what to do about it?

Not surprisingly, privacy, confidentiality, and security related issues dominate the list of ethical topics addressed by the health informatics professionals and philosophically oriented authors working in the area of health informatics in this survey. This makes sense, as after all, the basis for a trusting physician-patient relationship lies on the notions of privacy and confidentiality. Privacy can be defined as the right and desire of a person to control the disclosure of personal (health) information (Rindfleisch 1997). Security has to do with issues relating to effective implementation of privacy and confidentiality policies (see, for example, O’Brien, Yasroff 1999). Confidentiality is a basic term prescribing the physician-patient relationship. Applied to the health care informatics setting, Barber (1998), for example, has claimed that: “[I]t derives directly from the professional code of ethics of all health professionals it has provided a basic underpinning for discussions between clinicians and informaticians in their development of all computer based systems holding personal health information.” By confidentiality Rindfleisch refers to the controlled release of personal health information to a care provider or information custodian under an agreement that limits the extent and conditions under which that information may be used or released further.

In philosophy, privacy has often been given three different definitions: privacy as a claim, right or entitlement, privacy as control, and privacy as limited access to a person (Walters 2001). Especially in the texts reviewed, privacy has been addressed in terms of its value to individuals and approaches to protection of privacy of medical records (see, Wagner DeCew 1999 below) but also in more practically, in terms of identifications of risks and possibilities to contain risks to privacy especially with the help of technological interventions (see Rindfleisch 1997 below). IT professionals recognize on one hand the great opportunities for their profession and industry in the development of health informatics, on the other hand they feel the responsibility of making reliable systems. Without reliability, the health providers and patients are likely to reject the products (see Raghupathi below) and systems like the electronic health record will fail (Rindfleisch). In the texts reviewed here, privacy appears to have both intrinsic and instrumental value, something appreciated and valued for itself but also for those important goods that it makes possible.

In his article “Privacy, Information Technology and Health Care” (1997), Thomas C. Rindfleisch takes a systems view of privacy and information security in health care. Outlined in this article are, the benefits and the risks of electronic patient records, the concepts that are involved in protecting health care information - privacy, confidentiality, and security -, the kind of threats that exist to confidentiality of health care information, and the technical interventions available for protecting sensitive health care information. Rindfleisch reminds the reader about the reasons why patient privacy is so pertinent. While patient records contain much mundane information (weight and height readings, information about broken bones, etc.), the same records can also contain the most sensitive information about who and what we are: records about mental (health) about topics such as fertility and abortions, emotional problems and psychiatric care, sexual behaviors, sexually transmitted diseases, HIV status, substance abuse, physical abuse, genetic predispositions to diseases, and so on. “Access to this information must be controlled because disclosure can harm us. It may cause social embarrassment or prejudice, or affect our insurability, or limit our ability to get and hold a job,” Rindfleisch writes (Ibid. 94). It is the finality...
of damage resulting of accidental disclosure of private medical information that makes privacy so important: "Once sensitive information about an individual is exposed and the resulting damage is done to that person, the information cannot be withdrawn and made secret again (Ibid. 100)."

A broad confidence in medical privacy is necessary because without it the patients may avoid needed health care and physicians may not enter all information into patient records. The system, then, depends on the trust of patients and physicians.

The primary threats to privacy, according to Rindfleisch, arise from various kinds of disclosures by members of the health care provider community themselves, and from uncontrolled use of information among secondary users, consisting of insurers, pharmaceutical payers, some employers, and other players in the emerging health information services industry. The threats can take the form of accidental disclosure, insider curiosity, and insider subornation in the case of threats originating within a patient care institution. Threats that originate within secondary user settings include uncontrolled secondary usage and outsider intrusion into medical information systems, as in the case of unauthorized access. A particularly serious kind of disclosure has to do with an individual’s genetic information. Rindfleisch refers to a study reporting over 200 cases of direct discrimination in employment and insurance from unauthorized use of genetic-test information. (Ibid.)

For Rindfleisch, privacy and security of health care information is a "people problem": "Technology can help to ensure that only health care personnel access information they have a right and need to know, and that information gets from one place to another accurately and securely. But technology can do very little to ensure the person receiving the information will handle it according to confidentiality standards. That depends of ethics and effective supervisory and legal structure that provides sanctions against detected misuse (Ibid. 99)." Deterrents such as reminders, alerts and education of users; obstacles limited access to appropriate users; and system management precautions backed up with an explicit policy defining the appropriate and inappropriate use of information can help protect privacy of patients. Deterrents and obstacles, however, do not play a role in controlling exploitation of patient information by secondary users. Rindfleisch considers blocking outsider intrusions a major problem and long-term threat where special diligence is needed for health care systems to ensure state-of-the art protections. The fact remains that real-life information systems will always be vulnerable and security measures in medicine must be chosen in the light of this fact. Security interventions must be evaluated in terms of their functional benefits for protecting the patient, provider, and institutional privacy and in terms of their costs.

Protection of privacy of patients is important, however, it is only one aspect of a broad calculation of risks and benefits in the future of health care. In this calculation, individual persons may have a lot to lose. Rindfleisch writes: "The significant advantages of facile information access for improved medical care, enhanced research, and more cost-efficient management of medical institutions have to be traded off with the privacy consequences. In cold business terms, this comes down to assessing the value of health care information, the magnitude of risks of improper disclosure, the costs of an improper disclosure incident, and the costs of preventative measures. However, whereas financial enterprises such as banks and credit card systems can absorb the costs of abuse over the user community, without undue hardship on individuals, medical enterprises cannot. (Ibid. 100)."

In an analytically interesting article, Wagner DeCew (1999) has addressed privacy from a more philosophical point of view by discussing the value of privacy and examining alternative
approaches to protection of medical records. These alternatives are: 1) reliance on governmental guidelines, 2) the use of corporate self-regulation, and 3) a hybrid view of her own on "how to maintain a presumption in favor of privacy with respect to medical information, safeguarding privacy as vigorously and comprehensively as possible, without sacrificing the benefits of new information technology in medicine. (Ibid. 249)."

**Privacy as a shield**

Privacy protection poses a dramatic challenge in an age of advancing technology, with the switch from paper medical files to massive computer databases. Wagner DeCew summarizes the development and threats as follows: "Given high speed computer and Internet capabilities as well as other advanced communications technologies, the collection, storage, errors, improper access, exploitation, unauthorized disclosure and secondary use, and aggregation of data are all far easier, faster, less expensive, and thus more threatening and beyond an individual's control than ever before (Ibid. 249.)"

The value of privacy, according to Wagner DeCew, lies in the freedom and independence that it provides individuals. Privacy acts as a shield that protects us in various ways: from scrutiny, prejudice, coercion, pressure to confirm, and the judgment of others. "Loss of privacy leaves us vulnerable and threatened (Ibid. 249)." In the context of medical information, the possibilities to aggregating, exploiting or misusing genetic testing results, drug test data, mental health records, information about pregnancy or HIV status are, according to Wagner DeCew, just some examples that make it obvious how important it is to preserve the privacy for individuals.

Governmental guidelines can be effective in protecting medical health data. In Sweden, Germany, and the European Union, there is an initial *presumption* that privacy protection is important and that guidelines are important. Centralizing of sensitive information might be a problem, however, as it places too much power in one single public agency. Wagner DeCew writes that, "[A]lthough a constitutional right to see one's files can place a check on government, having access to information does not guarantee *control* over the information. Thus it is still necessary to have procedures for those who find erroneous information or want data eliminated from their record. Finally, even with the addition of careful guidelines for protecting privacy, other concerns include questions about who or what group would oversee enforcement of the guidelines and how effective such enforcement would be. (Ibid. 251)."

Corporate self-regulation is an alternative considered in the United States. Privacy guidelines in the Clinton era took the form of empowering people to protect themselves. On this view, privacy guidelines should be led by industry and the private sector, should be market-driven and not regulated, and should allow and maximize consumer choice as well as governmental restraint. In the field of medicine, this would mean that hospitals, health management organizations and insurance companies would be basically left to regulate themselves in their handling of patient medical records. Individual control in such a system is minimal. Personal medical files can be viewed by a large number of actors, even outside the immediate medical realm. (Ibid. 251.)

Wagner DeCew's own approach to protecting privacy of medical records is based on the idea of dynamic negotiation. Much like in the system of caller identification where protection of privacy (the caller's name and telephone number) is the default value, and a release of the caller's number happens by choice, the same principle could work in the case of patient records. The negotiation is dynamic because the receiver of the phone call can decide whether or not to pick up calls that are not identified (and of course, similarly screen of identified calls). Applied to the
field of health care, dynamic negotiation would require (federal) guidelines mandating the priority of privacy, meaning that collection, storage, and use of medical records would require maximal privacy protection as the default. Privacy guidelines would extend to primary users of medical records to secondary users. Dynamic negotiation goes further than the process of informed consent to information disclosure. It invites "health care providers and secondary users to have an ongoing conversation with patients to gain access to their data. That is, the goal is to educate patients so that they understand the benefits of the release of their data, not only for themselves, but for medical research for example, that they make the choice about how much or little they wish to withhold, that they release information voluntarily, and so on. The goal is to allow patients to retain control over their health records. (Ibid. 253.)"

Wagner DeCew presents a strong case for protecting patient privacy from the point of view of the patient. IT professionals are also interested in privacy, but from a somewhat different point of view.

The IT professionals' view: privacy as an instrumental value

"These are exciting times for the health are industry and IT. The integration of the two disciplines will revolutionize health care delivery in the decades ahead," writes W. Raghupathi (1997) in an editorial in the Communications of the ACM. The rapid development of health care information systems stands for challenges and opportunities for computer professionals. Raghupathi writes that computer professionals are concerned simultaneously how this development affects them as facilitators of IT applications and as consumers of health care. In the former role, issues of concern include design and development of applications, acceptance testing, integration with existing technology, and standards are relevant, while in the latter they include confidentiality, ethics, privacy, security, and user-friendly interfaces. (Ibid.) With regard to the electronic patient record, Raghupathi mentions that its "adoption has been slow because of practical issues such as complexity, cost, security, confidentiality and lack of standards". The author is optimistic with regard to the future adoption of the system, admitting however that the prospect of storing health information in electronic form raises concerns about patient privacy and data security. A technological fix to the issue of limiting access to confidential information is foreseen but such a solution will also has its weakness: while IT enables the use of technology to limit access to confidential information, it also introduces some vulnerabilities. "Unless proper controls and procedures are in place, these kinds of applications also invite unauthorized users to tap into the data." The importance of trust in the system surfaces although the author does not directly refer to it. Raghupathi issues the warning that that if concerns are not sufficiently addressed, the health care industry might be discouraged from exploiting IT and the health care consumers might be hesitant to share information. Raghupathi concludes: "therefore, IT application development and use must be done in the midst of maintaining confidentiality, privacy and security. Ethical issues must also be addressed (Ibid. 82)."

Issues in the doctor-patient relationship and use of ICT: a philosophically argued view

Much of the traditional physician-patient relationship was based on personal encounters and face-to-face communication between the patient and a doctor. Whatever data was collected was stored in the physician's paper or electronic files. A topic of ethical interest centers upon the
ways the physician-patient relationship may be affected by the adoption of the electronic health record or reliance on ICT in facilitating communication between a physician and a patient.

In a recent article on cyber medicine and the moral integrity of the physician-patient relationship Keith Bauer (2004) discusses in a philosophically interesting way the nature and quality of electronically mediated encounters between doctors and patients and whether they are conducive to good patient care and meet the standards of medicine. Although the article reads somewhat exaggerated, the reader getting the view that in the times of cyber medicine physicians mostly deal with their patients in a technologically mediated manner, the dangers of too much detachment between physician and patient to the goals of medicine - promotion of patient health and well-being - are well presented. Consequently, the case for not viewing cyber medicine as an ethically neutral set of technologies, but as a possible threat to the moral integrity of the physician-patient relationship, is well made.

Bauer’s starting point is that one aspect of cyber medicine, namely that of how mediated interactions and disembodied telepresence alter the moral integrity of the physician-patient relationship is poorly understood, although it is basic to an ethical evaluation.

By cyber medicine, Bauer means primarily ICT (computers and Internet) that are used to mediate physician-patient interactions and to deliver healthcare services (e.g., email, interactive video, and online chat rooms). But he also includes the electronic patient record system and information management and the use of the ICT - such as the telephone - to mediate physician-patient communications (Ibid.) For Bauer, effective communication and compassion are necessary ingredients for a trusting physician-patient relationship. Trust - perhaps the most critical component of a therapeutic relationship - in turn is necessary for the construction of a healing physician-patient relationship. Trust is facilitated by effective communication, which in Bauer's view is affected by cyber medicine. "In cyber medicine, physician-patient interactions are now disembodied and telepresent." The kind of virtual presence, almost being present but not quite, possible through the telephone, for example, has ethically significant implications to the participants in a doctor-patient relationship.

Bauer’s argumentation involves Merleau-Ponty's notion of human embodiment and disembodiment. According to Merleau-Ponty, our minds are embodied, and our embodied selves are embedded in the world. Our ability to navigate in the world is not only dependent on our embodiment, but we are by nature geared to be directly present to world, ourselves, and others. Cyber medicine alters our sense of embodiment and our intersubjective connections to other persons. Bauer also refers to Don Ihde (2002) in using analogies of a blind man’s cane and a hammer to show how a tool can extend one’s sense and touch, and even the person. But however useful the cane and hammer are and while capable of extending some bodily perceptions, they reduce, exclude and distort others. Based on this analogy Bauer claims that cyber medicine not only simply disembodies “physician-patient interactions, but rather alters how these interactions are embodied by extending and reducing different bodily perceptions (Bauer 86).” In this light cyber medicine is a poor substitute for face-to-face physician-patient interactions. Bauer sees cyber medicine as reducing the level of interconnectedness between doctors and patients. The quality of the mediated interaction falls short of the quality of face-to-face interaction, for example, when it comes to recognition of emotions, having eye contact and communicating other non-verbal cues.

In closing, Bauer qualifies his remarks somewhat. The ethical issues are more complex when cyber medicine is used in the complete absence of a pre-existing physician-relationship. He
admits that there could also be some positive distributive justice implications such as augmented access to physicians and improved continuity of care. Bauer also calls for physicians’ responsibilities in protecting the physician-patient relationship: "As the Internet revolution changes the way medicine is practiced, physicians will need to, and ought to, play a greater role in protecting and defining the moral sphere of the physician-patient relationship within cyber medicine." If physician do not take care of their professional obligation, the responsibilities will fall on information technologists and specialists who do not necessarily share the goals and values of the medical profession. "If this happens, it will be technologic efficiency and cost-effectiveness...that will have the greatest influence on the moral integrity of the physician-patient relationship", Bauer concludes.

**Guidelines for professionals to protect electronic health care data**

Many organizations are struggling to develop principles addressing the privacy, confidentiality, and security of health information as a response to the information needs in the health care systems and a heightened public awareness of information privacy. Many guidelines exist already, but their contents vary. (See, for example, Buckovich, Rippen, Rozen 1999). Common to all codes of ethics and professional guidelines is, however, that they are voluntary standards adopted by organizations, professions or entire industries that set expectations for how all participants will behave (Crigger 2001).

Ethics encompasses more than the law, law constituting a minimum standard for conduct and interaction with others. One problem with professional guidelines is that they are often drafted for a national setting. As has been seen (see Parker & Muir above 2001), some of the important issues with regard to ICT and health care, however, have to do with the fact that they no longer are "national" problems. The ways in which many professional ethical guidelines have been formulated appear to confuse the relationship between law and ethics (Kluge 2000). A case in point are guidelines for the protection of electronic health care data that stipulate that national laws should be followed commit according to Kluge the fallacy of nationality (Ibid. 85). Elsewhere, Kluge (1998) has formulated a code of professional ethics for health informatics professionals that is solely rooted in the nature of the profession and the activities in which it engages. This is in line with Kluge’s (2000) view that appropriately constructed ethical guidelines for the protection of electronic health care data must focus solely on fundamental ethical principles.

The model code of ethics for health information professionals consists of a preamble, principles and duties (Kluge 1998, 107). The preamble describes the nature of electronic patient records, and the central role of the health informatics professionals. The principles consist of 11 principles relevant for the health informatics field. They are: principles of autonomy; equality and justice; beneficence; impossibility; information-privacy and disposition; openness; access; legitimate infringement; least intrusive alternative; accountability; and security. Finally, the duties consist of subject-centered duties, duties toward health care professionals, duties toward society, self-regarding duties, and duties to the profession. (Ibid. 107-110.)

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2 As this principle may be somewhat less self-explanatory, the definition of Kluge (1998, 107) may be helpful: "all rights and duties hold subject to the condition that it is possible to meet them under the circumstances that obtain". In philosophical literature the same principle is expressed in the words "ought implies can"; whatever cannot be done, cannot be a duty.
While Kluge's model guidelines are intended for the health informatics professionals, another set of guidelines in the area called the "eHealth Code of Ethics" by the eHealth Ethics Initiative (2000) is intended for all users of the Internet for health-related purposes: patients, health care professionals, researchers, those who create or sell health products or services, and other stakeholders who all must "join together to create a safe environment and enhance the value of the Internet for meting health care needs (eHealth Initiative 2000)."

The eHealth Code of Ethics consists of a vision statement, introduction, definitions, and principles, introduced by a statement of right of users: "Anyone who uses the Internet for health-related reasons has a right to expect that organizations and individuals who provide health information, products or services online will uphold the following guiding principle (Ibid. 2)." The principles are: candor; honesty; quality; informed consent; privacy; professionalism in online health care; responsible partnering; and accountability. (Ibid. 2-8)

**Participation of practitioners in development of integrated health care record service: concerns of clinicians**

The role of clinicians in developing an integrated health care record service sharing patient information electronically throughout the British National Health Service (NHS) has been criticized as having been insufficient. Booth (2003) argues that few clinicians have played any part in planning the "health information spine" where patient summary information will be published for use of all NHS staff involved in the care of individuals. Booth's concern is that populating such a system with appropriate and accurate clinical data will not be straightforward. Booth lists several problem areas: risks to both clinician and patient if confidential identifiable data fall into the hands of people who have no right to see it, problems resulting from inaccuracy, misinterpretation and omission of information. Furthermore, there are problems related to dissolving responsibility: who is responsible for the integrity, veracity, attribution and distribution of information that moves beyond one organization to a wider "shared health space"? (Ibid.)

In discussing the populating of the spine with information, Booth calls attention to a study of patients in English general practice according to which up 40 % of the summary information derived from the current computer records was inaccurate. The only way, Booth write, patient information can be acceptable in a shared information source will be if summarized records have attested accuracy, agreed by patient and general practitioner together. Another issue has to do with updating: some events should trigger automatically transactions to update the information spine.

When it comes to patient acceptance and views about sharing health data, Booth mentions two aspects of ethical relevance for the system: "designing effective mechanisms for patients to exercise rights to withhold elements of their health record will be challenging, but trust in the new information service is fundamental to its success (Booth 2001 114)." Trust being of such importance access to shared information should (emergencies aside) be available only to clinicians concerned in the care of that patient. Booth concludes that without trust the system will end underused and a failure. Additionally, involvement of front line clinicians in the development of their workplace information systems is essential. (Ibid.)

Ethically rooted concerns continued to be a topic for the British Medical Association. In an article published in *Computing* magazine, Arnott (2004) reported that the National Program for NHS (National Health Service) IT was objected to by the physicians based on questions on patient consent and trust and lack of clinician involvement. According to the *Computing* magazine
general practitioners had threatened not to cooperate with the National Programme for NHS IT if concerns about patient consent were not clearly answered. The British Medical Association (BMA) GP IT committee passed a motion that the GPs “should not engage with” the Care Records Service (CRS) (Arnott 2004). The clinicians objected to allowing patient data from their systems to be used to populate the so-called spine, which was being developed as the core of the national system. The chair of the BMA GP IT committee said the clinicians were concerned about patient trust. According to the chair, the clinicians had not been informed what data would be taken where, under what circumstances and for how long, and that patients would want to know that. He said that patients had not been asked whether their data could be transferred to the central spine or not.

Nikula, Elberg & Svedberg (2000) also address an involvement issue with regard to electronic patient records. They emphasize the importance of clinicians being sufficiently informed and prepared for the EP (145). The authors claim that often clinicians are not sufficiently informed about the advantages and disadvantages of EPR over paper-based patient records. Clinicians have a different understanding of the existing systems depending on their profession, professional experience and experience with IT. “Nevertheless, EPRs are promoted by comparing the possibilities of existing paper-base paper records (PPR) and newly developed EPR applications, or EPRs existing only on the vendor's blueprint.” In general, corners seem to be cut in promoting EPRs and expressions such as “improved, increased, better, faster, easier” frequently appear where advantages of the EPR are compared with the disadvantages of the PPR. (Ibid. 142.) The authors propose the notion of ‘price to pay’ to illustrate that it takes human effort to create better health care and that clinicians play a very important role in implementing EPR systems. The price to pay in making EPR more advantageous than PPR relates to: structured data entry, common terminology, maintenance of guidelines, and data entry by clinicians. Although the authors do not directly state it, they imply through their example of the difficulties in reaching consensus on common terminology between nurses and doctors that participation in the creation EPR of all relevant actors early on in the development process is likely to be conducive to technology acceptance by the users.

Active role of patients in design and implementation: empowerment and control?

The traditional health-care model, based on a highly structured and hierarchical delivery system dominated by physicians and with patients as mere receivers of health services has been challenged in the past couple of decades through patient rights documents and in some cases even legislation as in the case of the Finnish Act on the Right and Status of Patients (http://www.finlex.fi/fi/laki/kaannokset/1992/en19920785.pdf).

The new paradigm that stresses the ideas of patient-centered care and seamless health care processes requires the full involvement of citizens in all aspects of their health and during all aspects of their health care value chain. (See, for example, Stroetmann, Pieper & Stroetmann 2003.)

In times when the patient organizations are demanding a more significant role in the management of patients’ own health and health care, the electronic healthcare record has been regarded as an opportunity for enhancing patient empowerment. For example, the Dutch Federation of Patient and Consumer Organizations (NPCF), as reported by (Beun 2003), is working to achieve demand-driven care, which is based on solidarity, freedom of choice and retention of personal autonomy. The patient perspective is stressed and the electronic health
record is seen as an important instrument for improving care and strengthening the position of
the patient. For the electronic patient record to be empowering for the patients, patients and their
organizations have to play an active role in designing and implementation of an ICT
infrastructure. Beun lists changes in the patient care provider relationship that can be expected
as a result of the implementation of ICT applications in health care: the patient can take more
control of his own care and take more responsibility for the optimization of his own health. In
addition to addressing the question (addressed in many other articles) of who has access to
which elements of an electronic patient health record, the Dutch patient movement argues for a
principle of use according to which the patient should be the one who determines who has
access to which information contained in his EPR. (Ibid.) This claim represents a strong right for
self-determination for the patient with regard to his/her self-regarding and private health
information.

There is an important issue of informed consent relating to the sharing of electronic patient data.
Not all patients appear to be ready to accept wholesale consent to automatically sharing of their
health record. Booth (2003) refers to a study by the NHS Information Authority in conjunction
with the Consumer Association, which showed that while some patients already expect a certain
degree of sharing of information, others want to be asked for their consent whenever new health
information is to be shared. ³
HOW TO STUDY ETHICAL ISSUES

The ‘narrative ethics’ approach

Practical or empirical ethics looks at moral reasoning as part of people’s everyday practice. A widespread model of moral action has been developed by Rest (1979, 1994). It describes four components of the ethical reasoning process: Ethical sensitivity initiates this process through the identification of an ethical dilemma. Once the dilemma has been identified (on the level of conflicting principles that come to bear on the situation), prescriptive reasoning evaluates the dilemma and arrives at a prescriptive judgment of what ought to be done. The next step of deliberative reasoning involves assessing the ‘ethical choice’ with respect to other decision alternatives. The process results in ethical action that Rest, following cognitive-developmental theory (Kohlberg 1969, 1976) sees as being shaped by personal characteristics, such as ego strength and locus of control.

As we already argued, researchers criticize the principled philosophical approach to ethics-in-practice, arguing “there is a vast gulf between their philosophical models of moral reasoning and detailed anthropological accounts of practical moral reasoning in particular settings” (Turner 2003, p. 112). One major point of objection is that the principled approach assumes common moral intuitions, failing to recognize the existence of multiple cultural and religious traditions. Turner points at considerable cross-cultural variation in understandings of what constitutes morally acceptable social practices. She refers to ‘comparative bioethics’, an approach that can be found in Fox and Swazey’s (1984) study of ethical decision making in cases of terminal diagnosis in China and North America. Studies such as these reveal marked differences in how individual suffering was interpreted, and hence how truth telling, information disclosure and informed consent were handled. In view if this and other studies Turner introduces the concept of ‘local moral worlds’ as meaningful for understanding different modes of moral reasoning. In a similar vein, Thorne and Saunders (2002) highlight the influence of culture on an individual’s reasoning, using the dimensions of culture Hofstede (1991) and Hampden-Turner and Trompenaars (1993) identified for describing how the value structures of individuals may vary cross-culturally.

Another point of criticism is that clinical/medical ethics has not only been couched in general and abstract terms but that it focuses on dilemma-type issues. Guillemin and Gillam (2004) argue that when it comes to looking at the day-to-day ethical issues, these can rarely be phrased in the form of a dilemma. They take an example from research – a woman informant disclosing that her husband has been sexually abusing her daughter. This can be interpreted as a classical ethical dilemma of whether to breach confidentiality or prevent harm. However, there are also more immediate ethical concerns, like if and how to take up what the woman disclosed, in which words, what tone, whether to switch off the tape recorder, abandon the interview, and offer help. These practical but ethically highly relevant concerns cannot be framed as dilemmas. Guillemin and Gillam (2004) talk about ‘ethically important moments’, moments of response where wrong can be done. They refer to ‘microethics’, a term coined by Komesaroff (1995) to address the complex dynamics which unfolds in everyday situations between actors, such as doctor and patient, nurse and management, clinical personnel and technical support/vendor. Microethics sharpens our sensitivity towards small ethically relevant events; reflexivity helps us deal with
them without prescribing particular morally justified action. Guillemin and Gillam’s issue is more how to sensitize to ethical tensions and through this enable ethical action than prescribe specific types of responses.

Hall has proposed an interesting approach in her study of different types of medical decision-making. She bases her arguments on the work of Johnson (1994) who sees in the ‘moral imagination’ the basis for our moral sensitivity: “What the human mind actually does when faced with an ethical challenge is not to immediately decide from a selection of rules to follow; but rather, it imagines various narrative extensions to see how the story we are living might proceed, depending on which course of action we may choose” (Berne 2004). Hall distinguishes three types of decision-making:

- Applying rules with the belief that there are only few (if any) decision options
- Using a plurality of reasons, balanced, weighed and sifted with each other, paying attention to the particulars of the case, also accommodating a greater degree of uncertainty
- Taking an ‘ethical stance’ or position (based on emotion, empathy, stereotypes, notions of justice, previous experience and so forth) – this is how participants typically ‘crafted’ their other types of reasoning through ethical imagination and interpretation.

Hall stresses that narrative ethics and arguing on the basis of rules and principles are not mutually exclusive but can complement each other.

Hall’s notion of narrative ethics puts imagination and interpretation at the center of ethical decision-making. Narrative ethics includes constructing and telling one’s own story and comprehending the story of the other. This may include decisions such as: What is my story? What is important to relate? How best to express what I consider to be the ethically most relevant material? Narratively crafting our understanding allows us enter a decision-making process which includes contextual elements. The imaginative capacity is revealed in the images, metaphors, and symbolisms, the narrator uses, as well as in the small details s/he fills in.

**Ethical case deliberation**

Ethical case deliberation has a tradition in the clinical field. There it is mainly used for evaluating clinical cases. It has also been used in studies assessing an individual’s moral reasoning (e.g. by Kohlberg and Gilligan). Case-based reasoning is also widely used in teaching ethics and/or biomedical ethics. For example Anderson (2004) uses the case of a hospital introducing a decision-support system called ‘beside assistant’ as an illustration of how to teach ethics. In this case the engineers developing the system have major concerns about its safety. Just to mention a few: Anderson suggests a six-step procedure, from data collection to identifying ethical issues and appropriate action, exploring practical alternatives, and evaluating the process and outcome. Benbunan-Finch (1998) proposes a similar procedure for teaching computer ethics. Howard et al. (2004) work with a case of youth reporting suicidal ideation to work with public health students.

Steinkamp and Gordijn (2003) compare different methods of ethical case deliberation:

**Clinical pragmatism**: Clinical pragmatism “aims to integrate guidance of judgment with guidance of process” (p. 236). ‘Pragmatism’ refers to the process being shaped by American pragmatism. It assumes that there is no agreed upon order of moral values and norms that can be simply applied and that “it is accepted to be impossible to anticipate a sound solution in a moral conflict
without elaborate actual deliberation” (p. 236). Ethical principles are understood in analogy to scientific hypotheses, as providing a tentative orientation rather than a solution. The ethics consultation is to be guided by an expert ethicist. The process should start with carefully analyzing the clinical details of a case, taking into account its ambiguity and complexity. In accordance to Dewey (1991), the quality of such an analysis rests on open, democratic deliberation and suspended judgment. The protocol is based on a structural analogy between clinical judgment and the structure of ethical reflection. It requires ‘contextual factors’ to be taken into account in “concentric circles. Implying first and foremost the perspectives of the other professional groups as well as their contributions to care giving” (p. 237). Narrative elements, representing moral intuitions and stories are to be included. Institutional policies have to be examined. Finally, classical casuistry is to be practiced, making comparisons to other, similar cases. Clinical pragmatism accounts for the fact that moral problems do not typically take on the shape of moral conflicts.

The Nijmegen method: Here the model is that health care providers themselves are supported in deliberating about the moral problems they encounter. At the beginning of the process is a clear moral question. Sometimes the clear-cut moral question is only found during the course of the deliberation itself. As moral problems in institutional health care delivery occur in a complex professional environment, various tools of analysis, interpretation, mediation, and ethical argumentation are combined. In comparison to clinical pragmatism, the Nijmegen method more clearly stresses the difference between facts (and their interpretation) and values. Also ethical principles play a somewhat different role. An assumption is that moral questions are accessible on an intuitive level prior to an elaborate ethical argumentation. At the same time specific moral obligations, which (according to Ross 1930) are valid _prima facie_ provide a well-defined realm of ethical content. Taking this mid-level principle approach makes it possible to develop a more distinct judgment, which also is more clearly definable as ethical. Equal emphasis is laid upon the process of argumentation with the objective to generate coherent, acceptable ethical reasons. Although stressing the ability of all involved to argue coherently about ethics, moderation of the process by an expert is pivotal for the quality of the process.

The hermeneutic method: Here the focus is more on exploring the interaction between a phenomenon (or case) and its broader context, aiming a mutual explanation of the two sides. The idea is that how we perceive ethical issues may be shaped by organizational, technical and even larger societal issues. The hermeneutic method is primarily interpretive, seeking to achieve a deeper understanding of a moral problem, rather than to come to a judgment. Typical of hermeneutics is (which is applied to literary texts, works of art, and human action more generally) is that it proceeds in cycles, with the interpreter starting with primary assumptions and questions to the ‘text’ that ‘talks back’ thereby shaping (refining, modifying, deepening) the interpreter’s understanding. Accordingly, the inquiry starts with a primary intuition rather then a clear moral issue and explicitly takes account of moral uneasiness, moral remorse, and moral residue. Narratives play a large role, since the approach builds on the assumption that moral intuitions are embedded in narratives. The objective is to achieve a more rational and at the same time more ‘contextualized’ understanding of these intuitions. Normative conclusions are only secondary to the analysis of narratives.

Socratic dialogue: This is a method for deliberating about philosophical questions in a group, based on the assumption that truth is not universal and that access to truth is not reserved for those specifically trained in philosophy. Finding the truth is not dependent on ‘pure reason’ but on getting involved in communication. The dialogue usually starts with a specific question (based
on a closed case, which lies in the past), seeking to find a general answer, which ultimately can be formulated in terms of rules and principles. All participants are expected to speak only from their own experience and insight. Having found a judgment for the specific question (e.g. ‘In decisions concerning end life care, should patient autonomy always prevail?’), they gradually move to more abstract levels of reflection to formulate a philosophical insight in what Badura (2002) calls ‘regressive abstraction’. Practitioners of the Socratic method developed rules of process (e.g. being reserved, non-directive and impartial, working in direction of a consensus) and rules of behavior. The method requires more time and abstraction as compared to the others.

The art of constructing ‘vignettes’

The quality of ethical case deliberation not only depends on the quality of the process. All four methods see moral intuitions embedded in narratives. Hence, participants are encouraged to bring forward/argue through stories and or organizers of a deliberation process are required to provide suitable case descriptions. Throughout the literature we find the term ‘vignette’ for such descriptions.

Vignettes are short, narrative accounts of a ‘case’ from the field that illustrates one or more ethical-legal issues. They are constructed on the basis of extensive practical experience in the field or of fieldwork material produced through research. Hence, they may be real cases or hypothetical ones that are based on experience. Wilks, for example, defines vignettes as “simulations of real events depicting hypothetical situations” (2004, p. 80). When simulated, a vignette can be constructed so as to look at the same situation from different perspectives or contain one manipulated variable (e.g. the gender or the race of one of the people in the scenario). When based on field work, a vignette can describe a real-life dilemma as it occurred, with the advantage that all contextual information necessary to understand and analyze the issues at stake are at hand; and with the other advantage that the situation it describes is sufficiently complex and enriched with relevant detail.

A third approach to constructing vignettes is connected to a technique used by Wang and Redwood-Jones (2001) as part of a participatory health promotion strategy. ‘Photovoice’ is a photographic technique that encourages people to use cameras to document their health and work realities. The idea is “to bring new or seldom heard ideas, images, conversations, and voices into the public forum” (2001, p. 561). Collecting image material around ethically relevant situations from the perspectives of different participants (including patients) could be used in combination with fieldwork material (produced by researchers) to arrive at multi-faceted, dense descriptions. Wang and Redwood-Jones include an elaborate discussion of “image ethics” – ethical issues connected to using images of people – in their description of the ‘photovoice’ method.

Ideally, a vignette should be written so as to make readers understand the context (of people, tasks, IT support, organization, cultured practices, history, etc.) in which ethical issues arise and they should have a clear focus on describing the issues. Video material, cartoons and other techniques have been used for producing lively accounts. Wilks points to the characteristics of a ‘good’ vignette, which he defines as an account that has “great hermeneutic power in its capacity to enhance our understanding of behavior,” (p. 83). One is ambiguity, which leaves space for participants to define the situation in their own terms. Another important feature is narrativity, which introduces specificity and detail, helping to understand the context in which an ethical
issue arises. Both encourage and enable reflexivity and discourse. Wilks points to the fact that
discursive activity is more and more seen as crucial in ethical case deliberation, arguing: “Real
decision-making is socially situated and we ignore the linguistic repertoires of those involved in
the resolution of dilemmas at our peril” (p. 85). This leads us back to the argument put forward
by Hall that “narrative ethics allows the mental activities of imagination and interpretation to be
central to the discussion “(2002, p. 67).

How to use vignettes as a research tool

Vignettes have been used in quantitative as well as qualitative research designs to study
attitudes, beliefs and norms. They are typically employed as “elicitation tools facilitating an
exploration of subjects’ responses to hypothetical situations” (Wilks 2004, p. 80). When used in
quantitative research, subjects are typically exposed to a series of short vignettes together with a
set of predetermined responses. Walden et al. (1990) used short accounts of ethical dilemmas in
social work in combination with four possible courses of action in response to each of (twelve)
vignettes. A Lickert scale may be used, enabling respondents to rate a particular response.
Some researchers (e.g. Dobrin 1989) used vignette-bases standard moral reasoning scales.
Vignettes may look at the same situation from different perspectives or contain a manipulated
variable. Wilks sums up the advantages of quantitative vignette approaches as follows: “The
vignette is seen as having the potential to aid the study of potentially difficult topics of enquiry as
they can help to desensitize aspects of these for participants (…). It is non personal and
therefore less threatening” (p. 81f.)

We are more interested in using vignettes as part of qualitative research and in vignette writing
as based in fieldwork. This ensures that a vignette genuinely represents phenomena that occur
in real world settings and that they reflect the complexity of an area being studied. Moreover,
“the ethical decision-making in such a situation has a narrative context, in which competing
moral stories containing strongly rhetorical elements present themselves” (Wilks 2004, p. 84).
Vignettes can be used as part of semi-standardized or completely open-ended interviews with
different participants in real world settings. One strategy here can be to expose different
stakeholders (e.g. nurses, physicians, patients, vendors, IT support staff, etc.) with one and the
same vignette trying to capture their different perspectives on one and the same situation. The
vignette can also be modified in response to emergent issues. The objective is to unravel the
complexity of ethically relevant situations, looking at them from different points of view, rather
than to identify ‘one right answer’. Several legitimate interpretations of the situation and
alternative courses of action may emerge.

Another fruitful way of using vignettes is as part of a focus group. Focus group research involves
organised discussion with a selected group of individuals to gain information about their views
and experiences of a topic. It is particularly suited for obtaining several perspectives about the
same topic. Interaction in a group enables participants to ask questions of each other and to
reconsider their own understanding (Gibbs 1997). The potential benefits of focus group research
are many. They are often used to involve participants in a particular social setting to
cooperatively develop solutions to problems thereby empowering them to actively contribute. For
our purpose the opportunity to elicit multiple understandings of an ethically relevant situation and
to have a group jointly explore solutions can be of great value.

The recommended number of people per group is usually six to ten. There are different
possibilities of composing a group, depending on the problem to discuss and the aims of the
research. One option is to include different stakeholders in the group, for example mixing medical personnel and nurses with IT professionals and/or policy-makers. Another option is a more homogeneous group, such as for example policy-makers on different levels. Focus group sessions usually last from one to two hours. The role of the moderator is very significant. The moderator “has to allow participants to talk to each other, ask questions and express doubts and opinions, while having very little control over the interaction other than generally keeping participants focused on the topic. By its nature focus group research is open ended and cannot be entirely predetermined” (Gibbs 1997).
THE SURVEY

The projects of the Action for Health Program concentrate on two main research themes. Projects of theme I investigate the role of information technology in the public consumption of health information, projects of theme II explore the effects of electronic patient records, computerized information systems and other forms of information technology in the health sector work environments.

During summer 2004 a questionnaire (see Appendix) sent to individual projects asked researchers which ethical-legal issues they expected to encounter or had already. Table 1 gives a review of the projects participating in the Action for Health Program and their status quo at the time the questionnaires were filled in.

Tab 1.: Projects, status quo (February 2005) and survey participation

<table>
<thead>
<tr>
<th>Theme</th>
<th>Projects</th>
<th>Status Quo</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>(P1) Rural Women’s Health Information Seeking: Matching E-Health Initiatives with Consumer Realities</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>I</td>
<td>(P2) Macomorran Community Centre: Exploring Public Internet Use, Access, Equity and its Relationship to the Goals of the Health Sector</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>I</td>
<td>(P3) The Role of Internet Lay User Consumption of Cancer Related Information</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>I</td>
<td>(P4) HIV/AIDS Treatment Information Network Study</td>
<td>Beginning – funding has to be clarified</td>
</tr>
<tr>
<td>I</td>
<td>(P5) A Survey of Users of One Government Sponsored Health Web Site</td>
<td>Ongoing – data collection</td>
</tr>
<tr>
<td>I</td>
<td>(P6) Analysing a Government Sponsored Health Information Web Site</td>
<td>Finished in June 2004</td>
</tr>
<tr>
<td>I</td>
<td>(P7) Assessing Different Methods of Communication Impact upon Farsi-Speaking Immigrants perception toward an Intention to Use a Government Sponsored Health Information Programme</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>I</td>
<td>(P8) Information Websites: Usability, Transparency and Redundancy</td>
<td>Ongoing</td>
</tr>
<tr>
<td>I</td>
<td>(P9) The Impact of a Nurse Intermediary in E-Health Support for Rural Youth</td>
<td>Beginning – funding has to be clarified</td>
</tr>
<tr>
<td>I</td>
<td>(P10) The Vancouver Library Study</td>
<td>Ongoing</td>
</tr>
<tr>
<td>II</td>
<td>(P11) Impacts of technology on Palliative Care</td>
<td>Ongoing – data analysis</td>
</tr>
<tr>
<td>II</td>
<td>(P12) Mid Main meets EMR: Vancouver EMR Case Study</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>II</td>
<td>(P13) Mid Main meets EMR: Patients Experiences of WOLF</td>
<td>Ongoing – start of data collection</td>
</tr>
<tr>
<td>II</td>
<td>(P14) Introduction of a Standardized EMR System in five Viennese Oncology Departments</td>
<td>Ongoing – start of data collection</td>
</tr>
</tbody>
</table>
Until January 2005, 14 questionnaires were returned: Ten were filled in by researchers of theme I projects and four by theme II projects. At that time, nine projects had been in an initial phase, dealing with matters of funding, negotiating with research ethics boards or organizing data collection. Only five projects had already collected ethnographic data, such as observation protocols or interviews, in the field. So in the majority of the cases, the researcher’s imagination and experience base was challenged to anticipate possible encountered ethical issues. Due to the lack of practical experience at that time, the answers provided in the questionnaires were rather general and often took the form of questions. Only a few researchers were able to describe examples from their fieldwork.

For data clearing examples and questions given in the questionnaires were reviewed. It was checked if the ethical or legal aspects mentioned referred to the researcher’s project and fitted into the chosen ethical category. Wrong mappings were corrected. Some entries contained aspects matching more than one ethical category; in these cases, multiple assignments were made (see Appendix). Contributions without any connection to the researcher’s project and/or relation to ethical/legal aspects were excluded as well as entries exclusively dealing with ethical aspects of the project’s research design or the research ethics board.

Tab. 2: Named ethical categories per project

<table>
<thead>
<tr>
<th>Nr.</th>
<th>Name of the Project</th>
<th>Theme allocation of resources</th>
<th>Ethical Aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rural Women’s Health Information Seeking: Matching e-health initiatives with consumer realities.</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>2</td>
<td>Macomorran Community Centre: Exploring Public Internet Use, Access, Equity and its Relationship to the Goals of the of the Health Sector</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>3</td>
<td>The Role of the Internet in Lay User Consumption of Cancer-Related Information</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>HIV/AIDS Treatment Information Networks Study</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>5</td>
<td>A Survey of Users of One Government-Sponsored Health Information Web Site.</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>6</td>
<td>Analysis of Government-Sponsored Health Information Web Sites</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>7</td>
<td>Assessing Different Methods of Communication Impact upon Farsi Speaking Immigrants Perception toward an Intention to Use a Government Sponsored Health Information Programme.</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>8</td>
<td>Information Web Sites: Usability, transparency and redundancy</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>9</td>
<td>The Impact of a Nurse Intermediary in E-Health Support For Rural Youth.</td>
<td>I</td>
<td>x</td>
</tr>
<tr>
<td>10</td>
<td>The Vancouver Library Study</td>
<td>I</td>
<td></td>
</tr>
</tbody>
</table>

Number of theme I projects responding: 9, 7, 5, 3, 4, 2

Number of theme II projects responding: 3, 3, 4, 4, 3, 4

Number of theme I and theme II projects responding: 12, 10, 9, 7, 7, 6

As can be seen in Table 2, the majority of the participating projects stated issues dealing with equitable allocation of resources (12), literacy (10) and standardization (9). Every second project
named issues of privacy and confidentiality as well as transparency and 6 projects mentioned issues of work ethics.

**THE INTERVIEWS**

During the annual Action for Health Meeting (Feb 28th – March 4th, 2005) 12 interviews were conducted with participating researchers. Five interviews dealt with theme I projects, one with theme I and II and four with theme II projects. Two interviews were excluded because of the early status of their projects.

Tab.3: Interviewees and their projects

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Theme</th>
<th>Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roma Harris, Nadine Wathen</td>
<td>I</td>
<td>Rural Women’s Health Information Seeking: Matching E-Health Initiatives with Consumer Realities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HIV/AIDS Treatment Information Network Study (Ontario)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information Websites: Usability, Transparency and Redundancy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Critical Perspectives on Empowerment in Health Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The Impact of a Nurse Intermediary in E-Health Support for Rural Youth</td>
</tr>
<tr>
<td>Leslie Bella</td>
<td>I</td>
<td>Macomorran Community Centre: Exploring Public Internet Use, Access, Equity and its Relationship to the Goals of the Health Sector</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rural HIV/AIDS Information Networks Study (Newfoundland)</td>
</tr>
<tr>
<td>Bev Holmes, Guenther Krueger</td>
<td>I</td>
<td>The Role of Internet Lay User Consumption of Cancer Related Information</td>
</tr>
<tr>
<td>Irving Rootman, Judith Krajnak</td>
<td>I</td>
<td>A Survey of Users of One Government Sponsored Health Web Site</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Analysing a Government Sponsored Health Information Web Site</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assessing Different Methods of Communication Impact upon Farsi-Speaking Immigrants perception toward an Intention to Use a Government Sponsored Health Information Programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rural HIV/AIDS Information Networks Study (BC)</td>
</tr>
<tr>
<td>Karen Smith</td>
<td>I</td>
<td>The Vancouver Library Study</td>
</tr>
<tr>
<td>Nina Boulus</td>
<td>I</td>
<td>Mid Main Clinic - Implementation of EMRs - Patients Perspectives/Expectations</td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>The Use of Internet Terminals in Patient Waiting Rooms for Getting Health Information</td>
</tr>
<tr>
<td></td>
<td>II</td>
<td>Mid Main Clinic - Implementation of EMRs - Experiences of Professional Users</td>
</tr>
<tr>
<td>Craig Kuziemsky, Francis Lau</td>
<td>II</td>
<td>Impacts of Technology on Palliative Care</td>
</tr>
<tr>
<td>Patrick Feng</td>
<td>II</td>
<td>The Development of Electronic Health Records in Canada</td>
</tr>
<tr>
<td>Eilen Balka, Casper Jensen</td>
<td>II</td>
<td>Vancouver Costal Health Case Study: Implementing the Wireless Nurse Call System</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Database Ethnography: Cohort of Health Care Workers Study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The Social Life of an Indicator</td>
</tr>
<tr>
<td>Karen Messing, Kate Laxer</td>
<td>II</td>
<td>The Social Life of an Indicator</td>
</tr>
</tbody>
</table>

The interviews covered the following topics:

- To achieve of a deeper understanding of the different projects
• To discuss possibly relevant ethical issues
• To introduce the vignette methodology to be used for identifying ethical issues
• To provide answers to questions concerning the ethical perspective and next steps to take.

The interviews were taped and transcribed. Here we give an overview of ethical aspects brought forward as part of the questionnaires and interviews.

ETHICAL ISSUES: PRELIMINARY OBSERVATIONS AND CONCERNS

Monitoring, surveillance, and data sharing: Under what terms?

With regard to monitoring, surveillance and data sharing respondents raised numerous questions of a 'privacy and confidentiality' nature. Citizens using public Internet access for the retrieval of sensitive health information in community centres might be bothered by surveillance cameras causing a feeling of being observed (P2). Lay users looking for online health information at the Vancouver library are concerned “... if other people are able to see what they are looking up, what information they are looking on...” (Karen Smith).

While lay users seem to fear to be watched by people around them, the researchers themselves voice concerns with regard to the more hidden opportunities for surveillance connected with ICT systems or devices (cameras) and/or invisible ICT users. It is for instance suspected that web based health education systems initiated by e-health initiatives might not only aim at providing access to health information for adolescents but also allow monitoring their activities (P9).

Lay users might make monitoring easy because they often pay little attention to data-protection when entering and transmitting sensitive health information: "If you are dealing with sensitive topics in an online focus group, it is a technological headache. In fact there are a lot of ethical issues with the technology, which are a headache. E.g. encrypting e-mail can be done but nobody bothers. E-mail is not particularly secure." (Guenther Krueger) Users are corresponding about health problems via e-mail or discussing them in online discussion groups without being aware how the information will flow, who will have access and what is going to happen with it (P3).

It is also suspected that health care professionals are “... not always well informed about their activities and the implications of that on the system”. (P12) An example given in the questionnaire refers to a “... system that connects pharmacists and physicians ...” and “... some concerns of physicians who feel that they are being monitored”. (P12)

To be able to protect one’s privacy, keep data confidential or act responsibly when using ICT users have to gain a certain degree of ICT-literacy. ICT skills are necessary to be able e.g. to find a “... suitable technique to preserve that (privacy and confidentiality), like for instance the use of factor authentication, encryption of information, etc. (P12) or to decide which assessments can be left to the ICT-system and which should be done by a care giver: “The question is does the use of a paper based record require greater intentionality on the part of practitioners in comparison to electronic records (where what is shared may reflect algorithms programmed into the system, rather than conscious choices made by an individual who has to decide which parts of the record to share) ...” (P13). One of the researchers states “... transparency and education of all components of the system and the capabilities of the system
at different intervals after implementation is recommended”. (P13) On the other hand experience often shows that “… people are generally only interested in the portion of the system that meets their requirements”. (P13) But even fairly developed ICT-literacy does not always help, since there are cases when the ICT-system or device does not meet higher demands on the user’s ICT knowledge.

Patients often seem to be overstrained by the demands of these new information technologies. They express concerns e.g. if the information stored in their Electronic Medical Record (EMR) will be kept in confidence. It is unclear “… who should have access to which parts of information”. (P12) How can different levels of accessibility be defined, so that only authorized users have access? “Can the patients be given the choice?” (P12) Should he/she place access limitations, as it is his/her information that is stored in the record? Is the patient the owner of this information? But independent from that isn’t it asked too much to leave this decision to the patient?

**Monitoring and surveillance: For what purpose?**

Besides storing data about patients and sharing them with different health professionals EMRs or electronic assessment tools can also be used: “… for surveillance of all those who enter information into the record (clinical staff, administrative staff, physicians, etc.) … Surveillance of employees could be undertaken for a number of different purposes, including monitoring the performance of an individual, of how a medical practitioner handles a particular type of diagnosis, etc.” (P13) EMRs may also be used for monitoring certain data entries done by caregivers.

On the one hand the purpose of monitoring could be to improve the quality of care on the other hand employees could also interpret it as a sign of distrust in their work performance or an observation impinging upon their right of privacy. An example provided by a participating research team describes the irritation created by a newly implemented assessment tool in a palliative care ward: “One of the assessments they (the nurses) collect is how physically active is the patient. It goes from 100 to 0 and 0 is dead. They noticed in the database a few patients with a functional level of 0 what means that they are dead. They brought that to the nurse’s attention that they did an entry mistake. There are a couple of code miners who took quite a bit offence that – you know, like: ‘We do not appreciate people checking up on our work. We are doing our best.’ They felt it was intruding on their care delivery and they felt they have been monitored.” (Craig Kuziemsky)

Monitoring may contribute to a change of workflow and a change of values by drawing attention to particular activities. An example is the monitoring of timelines for data entry. Given high workload and constrained resources data entry may be done at the expense of taking care of patient needs. So “… perhaps the issue is what types of monitoring and surveillance might be acceptable. And which would in all likelihood always be unacceptable.” (P13)

What contributes to make monitoring, surveillance or data sharing problematic is lack of transparency caused by insufficient information about their purpose and insufficient involvement of people affected by it: “They (the nurses) were probably taken by surprise. Suddenly the head nurse comes up: ‘I noticed you made two charting mistakes yesterday’. It was out of the blue … one phrase my colleague used was the hidden hen – (a project) which starts out as a research project now becomes a hidden way of monitoring what people do.” (Craig Kuziemsky)
In another case the health authorities spare no effort to inform care givers about the purpose of data sharing by using certain software: “The authorities have many training sections and seminars … for the health care professionals. Most of the seminars are focused around the issue of who will have access to which part of the information. It is a very sensitive issue.” (Nina Boulos) The stated aims behind the software are: “They are supporting evidence-based medicine, and say that they want to collect all this information in order to allow the doctors to compare themselves between each other so that they work more effectively.” (Nina Boulos) Although these aims are transparent and health professionals have opportunities to participate, the authorities experience resistance: “… The authorities stand there and sell these ideas (the use of their software) and you have all these doctors there protesting, saying: ‘What would it help me to compare myself to another doctor?’ or ‘Why should I send you information about my patients’.” (Nina Boulos) Using the software may help improve work performance and support doctors in cooperating with each other. At the same time there is the fear of having invited a ‘Trojan horse’ which behind the back establishes economic motives into health care: “Effectiveness, decreasing in costs, standardization – standardized solutions for medical practice.” (Nina Boulos).

Many anxieties were connected to possible and imagined implications of the new software. Health professionals did not trust the arguments given by the health authorities. The fear is that using the software and working with the results of the monitored data may confront health professionals with unexpected demands and force them to change workflow and working routines. This might cause stress because of lack of resources or nebulous responsibilities.

**Health data management outside the national boarders**

In case that the health authorities themselves or a public institution do not have the capacity to manage nationally collected health care data, private companies have to be found for this task. It may be a problem to find a suitable company within the state. Then the solution is outsourcing the management of health data to a company outside the national borders. While national health professionals are obliged to seek the consent of their patients for transmitting their health data to the national health authorities, it is feared that the authorities might transmit these data over the country’s border without seeking consent. As a result the data may be accessible to institutions or companies without the patients knowing and having consented to: “The authorities … ask various clinics in the primary health care sector to send them information about how many patients are being treated and details about chronic diseases. They say that it is for research reasons … it applies that the clinic has to share information with the authorities (information about the patient, demographic information – this has nothing to do with the economical part where they send information about the patient to bill the authorities) by using a toolkit (special software). … So they ask the patient to sign on a sheet, where they express their consent and allow the clinic to send the information to the authorities … Now the issue here in BC is that there was this talk about contracting out the medical data bases to a company in the US. So the patients and the clinics started to think: “Okay, first we give the information to the authorities and soon they will be in the hands of the Americans … “ (Nina Boulos).

**Access to health information: Retrieval and results**

The role of information intermediaries becomes more and more important as the availability of health information in the web increases. Even for professionals who are used to handle large
amounts of information it might be challenging to have “…access to something like pub-med being able to get articles of medical journals from virtually any place where there is an Internet terminal. It may be a new experience for librarians that they have to sift through this new massive pool of information that they may not have had as much exposure to before”. (Karen Smith)

The selection of appropriate information is not easy especially when it comes to health information. Online sources providing documentations of medical research present complex contents which are often seen as hardly understandable for lay users: “I do not think that lay users have a good enough understanding how medical research occurs, how that content comes to exist in databases they are accessing. Centuries of centuries of medical information get compiled into a database. I do not think that is an overly transparent process”. (Karen Smith)

**Regulation of access to by technology and/or standards**

Besides using the support of information intermediaries a variety of regulation modes have been developed to assist lay users in finding appropriate online health information. Some of them are technology based like search engines (e.g. google) or ‘spy software’ programs (e.g. Net Nanny). They help users to navigate through the information overflow or block the access to websites with offensive content (pornography, violence, etc.).

The use of search engines is common when retrieving information from the Internet. But how do these engines work? How do they select their results and how reliable are these results? As on participating researcher puts it: “Every time you google you may get a different list of returns”. (Karen Smith)

Another example is the use of ‘spy software’ like Net Nanny on the computers, which prevents children and/or adolescence from access to pornographic sites. But this could also mean, “…that it also prevents people from accessing sites on safer sex, HIV-Aids, etc.” (Leslie Bella)

Lay users often have a difficult time assessing the trustworthiness of online health information. A possible solution to that may be the introduction of “…certification modes for health information web sites …” standing for certain “…criteria (that) must be fulfilled to meet the requirements.” (P6) Transparency about the defined criteria is seen as vital otherwise the certification can not be interpreted: “I myself have seen disclaimers that doctors or pharmacists have reviewed the information but I do not know what kind of criteria have been involved in those reviews. So I would assume that lay users would have a similar experience.” (Karen Smith)

Developing criteria, guidelines or standards concerning online health information may help ensure the reliability of the content but maybe also restrict its richness and variety.

One of the research projects aims at assessing the quality of answers provided by online health websites on questions about common medical conditions. Therefore: “…research assistants entered websites with general health questions, like: ‘My husband was recently diagnosed with prostate cancer, I would like to know more about treatment options’, or: ‘I am confused about hormone replacement therapy’.” (Nadine Wathen)

Depending on the degree of standardization of health websites different websites may either provide different answers to a problem, then “…obviously some of that information will not be accurate or credible” (Nadine Wathen) or people may find exactly the same answer in different
websites. In this situation “... questions might be asked about the investment of public resources in redundant services” (P8), which “… is not a very ethical use of resources.” (Roma Harris)

The question is who is defining these standards? Especially when online health information is addressed to children and/or adolescents, parents might not agree with the standards used by providers: “… unique sensitivities around health information for examples may object to having all this information available to teenagers. The education system should actually promote these websites to give the students information but then parents may say that is inappropriate”. (Irv Rootman).

The regulation of access to information through money is seen as an unsuitable instrument which would increase inequality: “Those who can pay may turn out to be those with the best access i.e. this may be a circular argument where those with good information retrieval resources also are able to further obtain the best services. (P3) The regional differences are another interesting issue that adds complexity to presenting online information. I believe that access to health information should not be a privilege provided only to those who can pay, but should rather be the right of every citizen. (P12)

Finally regulation modes will directly influence the offer of information as well as its accessibility and quality by controlling the selection and the content.

**Literacy considerations and discrimination**

The demands on the **readability** of health information offered in publicly supported health information web sites and online services or EMR are very high. It has to be understandable to a variety of users. It has to accommodate different levels of literacy, language skills, cultural backgrounds, disabilities, etc. to inhibit discrimination.

The below mentioned aspects might cause an inappropriate presentation excluding certain population groups from access to health information needed:

- The reading level is too high (P5, P6) - “Governments are putting up health information websites they assume the general public are using. … The literacy was extremely high.” (Judith Krajnak)
- The information is not available in different languages (only English) (P3, P5, P6, P12) - “A very important issue in a multicultural country like Canada. Due to the fact that there are two official languages in Canada, the information should be available both in English and in French. In addition, the growing cultural diversity in Canada implies that information should also be translated to various languages so that recent immigrants, for instance, will have equal access to information”. (P12)
- Cultural sensitivity is missing (P6, P9) - “Canada is a multicultural country - the information from a North American standard might be seen as insensitive to other cultures. How do governments and school systems promote that”? (Irv Rootmann)
- No disability friendly format is used (P3, P5, P6).

Our respondents raised several questions:

“If e-health initiatives are introduced e.g. web supported services to provide health information in rural communities, what are the literacy considerations, necessary to make them effective?” (P1)
“What language skills, style, format and content are appropriate in web based e-health interventions to support PHAs (people suffering from HIV/AIDS) and their families in rural communities?” (P4).

Access and discrimination

Besides literacy, access to necessary infrastructure, computer equipment and/or know how for online health information retrieval is necessary. Participating researchers see the reasons for unequal or even non existing access to online health information and health information services in conditions like:

- Being poor and/or illiterate - access to online information is also regulated by the necessity to protect computer equipment open to the public. So is a valid ID needed to get access to a computer terminal at e.g. the Vancouver library. “... people who are homeless could have difficulties (to get access), also new immigrants, who do not have ID documents”. (Karen Smith)
- Having difficulties in using the English language
- Living in a rural area or a low income community and/or
- Suffering from a (stigmatised) disease
- And, even worse, combinations of those characteristics.

They assume that discrepancies occur between currently offered and needed online health information services for the subsequently named population groups:

- Women living in rural communities (P1, P4),
- Youth living in rural communities (P9),
- People living in a low income community (P2),
- Minority groups (P6),
- People suffering from a certain disease or disability (P3, P4, P5, P6, etc.)

The following questions were raised:

"How big has a target group to be to qualify for equal access? (P1)

"Presenting materials in a language appropriate to a particular cultural group (Farsi speakers) an ethical issue might be why this particular group was chosen as opposed to some other groups. (P7)

" What are the obligations of communities to make health information accessible to non English speaking itinerant farm workers? (P1)

Using ICT for overcoming prejudice and isolation

It is unclear to what extent e-health initiatives can compensate for lack of access to health services or information. A positive impact might be that especially in rural areas online health services could make information declared scared and forbidden anonymously accessible. Thereby these offers could protect affected people’s privacy and could help to overcome existing barriers and their consequences like "isolation in terms of social support" (Roma Harris) or
difficulties in finding information on treatment and services urgently needed: "One of the big dilemmas for people with HIV/Aids is confidentiality. In rural communities that is a big issue. Part of the isolation comes out of it. In some rural communities people really deny that this problem exists. In fact they exclusively describe it as a big city problem. (Roma Harris) The research team is planning to design a sort of net-based intervention to see whether or not it will be helpful.

**Using ICT for solving shortages in medical care**

It is feared that the motivations behind the promotion of e-health initiatives offering online consumer health information services could be to fill gaps in access to publicly funded health care existing in certain areas or for certain population groups. The offer of online health information services might imply a hidden agenda enhancing a shift of responsibility in the provision of health care from the public to the individual: “Some people in the general public thought - this is a way for the government to give us information but it relieves the government of responsibility - in a way it is providing us less care.” (Judith Krajnak) Or: “It appears that a lot of the designed systems that are technological aided like telephone nurse advice services or the website maintained by the government are motivated not so much because there is an obvious need to provide information in that sense but that people in the province were we come from are very upset that they do not have access to medical services because there are not enough family physicians for everybody.” (Roma Harris).

**Access to health care professionals** is seen as vital for the interpretation of health information. The experience shows that patients use “… the different information sources … for retrieving advices or additional information, rather than … as a tool for making decisions/choices. … Patients still have a large reliability to physicians (or other clinical staff) than to online sources.” (P12)

Besides access to information and professional advice people struggling with health concerns are often in need of emotional support and care: "If they cannot get it because they do not have access to a person who comes from the funded public health system then they go and look … for health information from sources outside the formal health system, e.g. they look at health food stores, their books at home, etc. (Roma Harris). As a result individuals who are already hit by a lack of access to the health care system will take on a greater burden of responsibility for their own health care. This might be overstraining and dangerous, when it leads to hazardous self-treatment: "Sometimes … they (lay users) start keeping things that are really bad for them. I suppose there are some legal liability implications. They start to do things that are not indicated.” (Nadine Wathen). The human factor plays an important role in health care and cannot be replaced by online consumer health information services.

It is unclear to what extent e-health initiatives might compensate lack of access to medical care for disadvantaged persons like e.g. rural residents? (P4) It seems that “… the creation of these systems at least in the interviewed population does not seem to have addressed their health concerns … A question that is of interest … is: ‘What is the purpose of an investment in an infrastructure that seems to bear so little relationship to what people actually want and need’. (Roma Harris)

**ICT offers to give youth more attention**

The idea of providing online health information access quickly arises when health authorities encounter health concerns of population groups which are not so easy to target or have been
neglected, e.g. youth: “The people of the public health unit in the area have identified in focus groups with youth that they have several health concerns that include things like bullying, homophobia and eating disorders.” (Nadine Wathen)

Introducing ICT may be considered a cheap solution and readily available to an unresolved problem: “The health unit wants to respond because there is not a lot in the county for the youth.”(Nadine Wathen) and: “They do not have a lot of resources”. (Roma Harris) The ICT solution offers itself as there are already existing information packages and infrastructure, and a research project that may help them use these resources: “They have access to a public school system through a website that was developed by another county or school board that has that type of information.”(Nadine Wathen) They want our research project to assist them to honour a commitment that they made.”(Roma Harris)

The health unit does not exclusively trust in providing access to online health information but also wants the researchers to find out if the offer can be improved by the employment of information intermediaries: “The health unit also wants to know if adding a nurse – a real life expert – to the website helps the youth get the information, interpret it and use it – we are still working on the range of outcomes we could look at – whether making it attractive, having somebody to respond either in real-time or synchronically through the board service – this sort of thing will enhance that service and better provide answers for these kids. (Nadine Wathen)

Whose standards and why?

International, national and regional standards: Establishment and compliance

Data sharing in the health sector requires a certain level of standardization. The shaping of these standards is a complex and difficult process, due to the variety of stakeholders to involve on the international, national, provincial, and regional level. They have to find a consensus on questions like e.g.: “… national versus international autonomy, … about the responsibilities of all concerned organisations, … in what ways do they take cues from the public and are they accountable to the public? …” (Patrick Feng). Which stakeholder groups will dominate the discussions and will enforce their standards with what consequences?

Additionally these standards have to be strict enough to provide a basic framework and at the same time they have to be flexible enough to fit to local practice to be accepted and used: “Basic regulatory frameworks should be set at a national level since EMRs are part of the Pan Canadian Health-Info-Way, which is a national initiative. These should then be adjusted at the level of local practice to comply to local regulatory frameworks.” (P 13) Or: “Basic (general) system standards should be set at a provincial level and those areas specific to a specialized practice should be given the flexibility to localize.” (P 13) It is stated that: “When it comes to standardization, it is important to have an active participation and transfer the responsibilities to the health authorities level, regional or national.”(P12)

Standardization: Improvement, ease of work or thoughtlessness?

In general the possibility of data sharing between different health professionals is seen as a helpful instrument. It is expected that standardization can support the improvement of quality of care and treatment by stimulating and facilitating interdisciplinary cooperation and research:
“One of the raisons d’etre of the electronic record is to make information more easily accessible to a wider range of practitioners.” (P 12) Or: “The sharing of patient information could facilitate interdisciplinary talks between physicians” (P14).

Standardization is also seen as an instrument that helps to increase efficiency: “It is also possible that it (the new system) diminishes the workload. … Now they often do the medical history for a patient more than once, as the already existing data is not available when the patient comes to the hospital again. With the computer system they should be able to access the data anytime”. (P 14) Or: “Sometimes it is difficult to find the information for a patient (when needed), this could be improved by the computer system”. (P14)

It can make data entry easier and more secure: “… catalogues of diagnoses and predefined protocols are going to be set up. The system will also suggest a dosage of medication and give a warning if a certain level is exceeded.” (P 14)

But it might also encourage thoughtlessness: “The question is, does the use of a paper based record require greater intentionality on the part of practitioners than the ease with electronic records (where what is shared may reflect algorithms programmed into the system, rather then conscious choices made by an individual who has to decide which parts of the record to share).” (P13), and thereby diminish the quality of treatment.

Implementation of new standards

Insufficient financing, insufficient human resources

Scarce resources in the health care system might result in giving the order to the cheapest vendor, who might be from a different country and therefore not familiar with the national standards used in the region of the ordering party. The implementation of standards that are not “sensitive to the (national, in this case) Canadian context” (P5) might lead to a variety of problems, for instance the system could use other units of measurement as those commonly used in Canada.

Insufficient funds might result in the implementation of incomplete ICT solutions that augment health care professionals’ work loads: “After the implementation of the electronic medical record (more specifically, the billing and scheduling modules) the health care personnel at the primary care clinic has to enter the same information into two different sources. The information is first registered on the paper-based registry and then entered to an electronic database (in order to register the information in the Ministry of Health registry). The information is being registered twice due to the lack of a built in application (in the EMR) which is supposed to transfer the registry to the Ministry” (P12).

Another possibility might be that invisible shortages become visible as soon as a new standardized documentation device is implemented: “At the moment they (physicians) do not document everything in the required detail because they do not have enough time/personnel. For example it is not always noted who did specific interventions. So it is possible that with the IT system they are no longer able to skip this documenting.” (P14)

Insufficient communication and participation, lack of transparency

The implementation of new standards makes demands on the adaptation of established working routines. They are often disruptive of local work practice. They go hand in hand with: “...
additional work tasks, rigid routines, entering overlapping information, etc. ... The disruptions are often faced during this transition period." (P 12) Or: “The IT system augments work loads for the nurses and doctors. Especially in the beginning it is possible that they have to document some things twice (using the old documentation practices as well as the new system).” (P 14)

Therefore it is seen as important that caregivers are informed about the reasons standing behind the implementation of new standards. They should be given an active role in the implementation process. Using this new standard has to make sense to them. There must be good reasons why they should integrate them into the daily working routine. So for instance: “If information sharing is indeed related to patient care then the increase in their workload can be construed as part of care”. (P 13)

If there are not enough resources to deal with the consequences of the implementation this might lead to a negative attitude. In a professional setting this could result e.g. in unreliable documentation practices, resistance in adapting new standards into the working routines or even rejection: “Provisional solutions may be a good reason to document later ...” (P 11), “Standards that are not perceived as useful may lead to workarounds or other ways of circumventing the system ...” (P 3) or “… Workaround or gateway practice (those that attempt to incorporate previous paper-based or older systems) ... People may gravitate back to the way they did things prior to the introduction of the system; there may be resistance or even sabotage.” (P 13)

**Insufficient consideration of work flow and/or patients needs**

Changes of working routines caused by the implementation of new standards might result in changes of the division of work between different professional groups. In the following example the installation of a new wireless alarm system alters the occupational tasks of nurses and PCAs resulting in an unequal and problematic shift of workload from the PCAs to the nurses: “The thing they wanted to achieve is, to cut down on the time PCAs start run around after nurses or nurses run around after other nurses. The phone should make sure that when you pull a string and it starts ringing it rings directly to the nurse. That is a great idea it goes to the nurse for 30 sec. then to a back up nurse covering the same room and then to the PCA. Everybody agreed that was a great idea. But then when people started to think more about it, nurses were saying: “Does that mean that PCAs are not going to turn the alarm off? ...” So they were very unhappy with that and started to say: “Well, actually most of the calls are no nurse calls” and “I do not want to take all those calls”. So it turns out that the PCA actually has an important role as sort of a gatekeeper for the nurses almost like a secretary for the doctor, making sure that everything goes through.” (Casper Bruun Jensen).

If the implementation is done without reflecting its effects there is a risk that it will be interpreted as unchangeable by the staff: “Because when they code this way of doing it into the telephone nobody will think that it is possible to change it any longer. They cannot do it by themselves. They have to go back to the vendor.” (Casper Bruun Jensen)

In another case the development of a pain assessment tool by collecting data through personal digital assistants (PDAs) in a palliative care ward created irritation: “The purpose of the research was to determine (a pain) assessment tools ... it was also a standard of how frequently you should measure this pain. One way they started was in fact measure quite frequently and then carry the frequency down to what is the optimum ... this was a disruption of work flow ... Researchers can say: 'We measure 10 times a day”, ... This is just one measurement. But the frontline workers have got so many things in their head - which is part of their standard practice,
which is research, which is quality improvement.” (Craig Kuziemsky, Francis Lau). The frequencies of pain measurement were conflicting with the everyday working routines of the nurses. They also courted patients’ resentment and the nurses had to feel their anger. They “…complained that the patients were getting annoyed: ‘I just told you my pain two hours ago and now you are asking me again’,” As a result the PDAs were refused by the nurses: “In fact I think that causes problems in the sense that people were upset with the PDA because they had to measure so frequently - in fact it was not the PDA it was because they wanted to measure frequently, it could have been by hand…” (Craig Kuziemsky, Francis Lau).

The research requirements for the development of the pain measurements through PDAs were contradictory with the requirements of palliative care: “The patients are at their end of life and they (the nurses) may give them a little more … than in a regular keep in hospital. They may know e.g. Mr. Smith, he does not like to be woken up before 9:00 and they do not do that out of their considerate to the patient. But if you do a research project ... Do you not do it because this patient does not like to be woken up? Or do you wake him up? It brings dilemmas like that. Who is the nurse responsible to?” (Craig Kuziemsky, Francis Lau). In this case nurses felt more responsible to the patients than to the research requirements. Patients’ wellbeing outweighed the collection of data for research purpose.

An important question is if the nurses who had to use the PDAs and do the measurements were informed about the research and its impact on their work? Was there a possibility to consider objections raised by the nurses?

On the other hand the nurses’ support of the development of the pain assessment tool could improve pain management and provide acceptable standards of measurement to the benefit of patients and nurses.

**Indicators: Products of standardization**

Indicators come in to being in the course of multiple standardization processes. These processes comprise complex technology based standardization as well as complex science based standardization. At last the result, a single number, represents a complex social context.

Indicators are seen as powerful instruments that can “… very easily be used for policy (or management) purposes. … They seem to be very neutral.” (Casper Bruun Jensen) Mostly they are “… presented as a straight forward true representation of a complex matter e.g. incidence rate, how many and how often are people sick, mortality rates and so on”. (Casper Bruun Jensen) Often their significance is accepted unquestioningly without knowing a lot about their ‘manufacturing’.

That is way indicators inhere two contradictory qualities: On the one hand they are “… extraordinarily transparent. Anybody can compare two indicators …”, on the other hand they are opaque and as one researcher puts it: “If you have no idea how that number came to be, you miss a lot of stuff” and actually “… you do not know what you are comparing”. (Casper Bruun Jensen)

The emergence of indicators often lacks transparency. Therefore documenting the attendant circumstances of their construction process is seen as crucial for their interpretation. For instance when merging data sets the historically grown data management infrastructure will influence the quality of data used to create an indicator: “We have a situation were we have all these different hospitals that used to all be separate and used to make all of their own IT
decisions. Now they are part of one large administrative unit and the systems partly dictate what data is collected and when those data is collected and practices are different from one hospital to the other.” (Ellen Balka) The reflection of these diversities in collection and interpretation of their effects on the indicator is necessary to decide: “… to what extent can you even merge those data and maintain the integrity of those data”. (Ellen Balka).

Misinterpretations of indicators may be based on missing background information about their construction: “When dealing with it, I found out that the people from OASA have been misinterpreting data from that database. Obviously it was unintentional but it has to do with how far down in the data you drill and at what level you disaggregate the data what you see”. (Ellen Balka) Besides considering the limitations occurring from the ‘manufacturing process’ these sorts of numbers have a complex underlying methodological basis. Users have to be trained to be able to apply indicators correctly and act responsible. This is not always the case even when the user is supposed to be an expert in this field: “I work in the health authority with people who have a very limited understanding of the limitations inherited to the use of data”. (Ellen Balka)

REFERENCES


Parker, Michael; Muir Gray, JA (2001). What is the role clinical ethics support in the era of e-medicine?. *Journal of Medical Ethics*, 27, suppl I:i33-i35.


APPENDIX

ACT for Health Questionnaire: Identification of Ethical-Legal Issues

<table>
<thead>
<tr>
<th>Information regarding your project</th>
<th>Please provide your answers below</th>
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<tbody>
<tr>
<td>a. Name of your project</td>
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<tr>
<td>b. Name of contact person</td>
<td></td>
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<tr>
<td>c. E-mail address of contact person</td>
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<tr>
<td>d. Date of filling out the questionnaire (dd/MM/yyyy)</td>
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<tr>
<td>e. Please describe briefly the status of your project at the time of filling out this questionnaire (beginning, on-going, finishing)</td>
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</table>

Do you anticipate encountering, or have you already encountered, ethical-legal issues in your project? Below is a sampling of a few of the issues of technology/ICT use that you may be anticipating will arise in the course of your research. For further details of potential legal issues, please consult the draft memorandum dated March 16, 2004 and circulated by Elaine Gibson at the meeting (if you would like another copy, contact me at elaine.gibson@dal.ca). An additional memorandum is available on jurisdictional legal issues.

Please provide preliminary examples of ethical-legal issues that you anticipate encountering in your own project. Even if you cannot answer everything, please respond to the questions you can relate to.

Please fill out separately for each project/data collection context.

**Ethical-legal aspects of technology/ICT use**

Among the ethical-legal aspects of technology/ICT use which have been identified in the research literature are:

<table>
<thead>
<tr>
<th>Ethical-legal aspects of technology/ICT use</th>
<th>Please check box where applicable</th>
<th>Please provide preliminary examples below</th>
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</thead>
<tbody>
<tr>
<td>a. Issues of privacy and confidentiality – Can ICT systems be used for surveillance of employees? What limits should be placed on electronic patient record information sharing?</td>
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<tr>
<td>b. Issues regarding intellectual property – What intellectual property issues could arise with health information websites and the maintenance of health information databases? Possible issues may include those arising in relation to website design, contents, the use of links and frames. Who owns copyright in electronic patient records?</td>
<td>[ ]</td>
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<tr>
<td>c. Issues of literacy – Is health information presented in ways that help citizens to understand their problems and to make choices? Is the support of health professionals for reading and evaluating health information provided where this is necessary?</td>
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</table>
**Ethical-legal aspects of technology/ICT use**

Among the ethical-legal aspects of technology/ICT use which have been identified in the research literature are:

<table>
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<tr>
<th>d. Issues dealing with <strong>equitable allocation of resources</strong> – What does the Charter of Rights and Freedoms require in the provision of health information online – e.g. translation into other languages? Disability-friendly format? Must online access to health information be made available to all, or only to those who can pay?</th>
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<tbody>
<tr>
<td>e. Issues of <strong>liability</strong> – Can patient/physician reliance on on-line health information lead to liability of the provider? Are telemedicine practitioners more likely to be sued, and for what?</td>
</tr>
<tr>
<td>f. <strong>Jurisdictional Issues</strong> – Electronic information flows readily across borders. Which laws apply? Which licensing/regulatory bodies are responsible?</td>
</tr>
<tr>
<td>g. <strong>Issues of transparency</strong> - Are users provided with a valid and simple model of what the system does; are they made aware when their activity has an effect on the system? (For example, a system that connects general physicians and pharmacists, allows for dose control of the patient's medication behaviour, yet it does so by building in all kinds of control mechanisms behind the patient's back.)</td>
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<tr>
<td>h. <strong>Issues of standardization</strong> – Are the standards that are introduced through e.g. EPR (communication protocols, classifications systems, standardized reporting procedures, clinical protocols, indicators, etc.) disruptive of local work practices? Does this affect the quality of the work? For example, do clinical protocols reduce the scope of what health professionals actually care to observe and document? Are 'profiles' (e.g. patterns of symptoms) conducive to thinking in simple measures such as 'averages' and does this reduce the tolerance for discrepancy and variation?</td>
</tr>
<tr>
<td>i. <strong>Issues of work ethics</strong> – Do ICT systems and applications augment health care professionals' work loads at the expense of care? For example, do EPR require documentation in the interest of secondary users, drug dispensing machinery requiring additional work? Are certain doctor-nurse order-sequences built into an EPR and does this reify hierarchical relations on the shop floor?</td>
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<tr>
<td>j. Issues relating to research ethics.</td>
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<tr>
<td>k. <strong>Other issues.</strong></td>
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</table>
3. For some of the ethical-legal issues, it would be beneficial to collect data. There are several methods potentially available for collection. Which of the following methods of data collection would suit your project's approach and ways of working? Please look into the descriptions of the methods of data collection and indicate the suitable method(s) by checking the appropriate box.

<table>
<thead>
<tr>
<th>Methods of collecting data about ethical-legal issues</th>
<th>Please check where applicable</th>
<th>Please specify below your ideas about how to proceed with regard to this method.</th>
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<tbody>
<tr>
<td>a. Unlikely to require data collection – academic research is likely to suffice</td>
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<tr>
<td>b. Identify issues from observation and ethnographic fieldwork material – here the idea is to look for incidents/episodes that reveal and illustrate such an ethical issue and to provide rich descriptions that can be analyzed.</td>
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<tr>
<td>b. Conduct focused interviews with informants (system designers, physicians, nurses, patients, etc.) which are constructed around already defined ethical/legal issues in their field of work, asking them about examples from their own practice (is this something they encounter, in which context) and how they solve these issues or what prevents them from responding to them adequately.</td>
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<tr>
<td>c. Expose informants to so-called 'ethical dilemmas' – fictitious situations which elicit an ethical choice - recording and analyzing informants' reasoning (this is a method that has been used in research on individuals' moral development; Kohlberg, Gilligan).</td>
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<tr>
<td>d. Other. Preferred methods of data collection include others than listed above. Please describe.</td>
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<td>Please describe method(s) here</td>
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<table>
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<tr>
<th>Does your project rely on some ethical guidelines?</th>
<th>Yes</th>
<th>No</th>
<th>Please list guidelines here</th>
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<tbody>
<tr>
<td>Has ethics approval been sought?</td>
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<td>Received?</td>
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<tr>
<th>Tasks and/or work packages with ethical-legal issues</th>
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<tbody>
<tr>
<td>a. Are there specific tasks and/or work packages in your project in which you expect to explore ethical-legal issues in more depth?</td>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>b. If you checked “yes”, please describe the tasks and/or work packages briefly, along with tentative dates, and attach a preliminary work plan on exploration of ethical/legal issues.</td>
<td>Please describe tasks and/or workpackages here</td>
<td></td>
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</tbody>
</table>

Please save the document and your answers, and send it as an E-mail attachment to mrauhala@pop.tuwien.ac.at or iwagner@pop.tuwien.ac.at. If you would like to discuss further any questions that arise as a result of this, please contact Ina Wagner at +43 1 58801 18711 or Elaine Gibson at 902-494-6882 (Canada) or elaine.gibson@dal.ca.

Thank you for your cooperation!
Results of the ethical/legal-questionnaire (theme I)

List of participating theme I projects:

<table>
<thead>
<tr>
<th>Project No.</th>
<th>Project Title/Researcher/s (Status: February 2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rural Women's Health Information Seeking: Matching E-Health Initiatives with Consumer Realities (Roma Harris, Nadine Wathen, Jana Fear)</td>
</tr>
<tr>
<td>2</td>
<td>Macomorran Community Centre: Exploring Public Internet Use, Access, Equity and its Relationship to the Goals of the Health Sector (Leslie Bella)</td>
</tr>
<tr>
<td>3</td>
<td>The Role of Internet Lay User Consumption of Cancer Related Information (Bev Holmes, Guenther Krueger)</td>
</tr>
<tr>
<td>4</td>
<td>HIV/AIDS Treatment Information Network Study (Roma Harris, Tiffany Veinot, Jana Fear)</td>
</tr>
<tr>
<td>5</td>
<td>A Survey of Users of One Government Sponsored Health Web Site (Irving Rootman, Judith Krajnak)</td>
</tr>
<tr>
<td>6</td>
<td>Analysing a Government Sponsored Health Information Web Site (Irving Rootman, Judith Krajnak)</td>
</tr>
<tr>
<td>7</td>
<td>Assessing Different Methods of Communication Impact upon Farsi-Speaking Immigrants perception toward an Intention to Use a Government Sponsored Health Information Programme (Irving Rootman, Judith Krajnak, Iraj Poureslam)</td>
</tr>
<tr>
<td>8</td>
<td>Information Websites: Usability, Transparency and Redundancy (Roma Harris, Nadine Wathen, Jana Fear)</td>
</tr>
<tr>
<td>9</td>
<td>The Impact of a Nurse Intermediary in E-Health Support for Rural Youth (Roma Harris, Nadine Wathen, Jana Fear)</td>
</tr>
<tr>
<td>10</td>
<td>The Vancouver Library Study (Karen Smith, Ellen Balka)</td>
</tr>
</tbody>
</table>

Project No. a) Issues of privacy and confidentiality

2 (Also mentioned in “transparency”): Surveillance cameras in the computer room, in order to address theft. This also reduces privacy for people using the computers.

3 (Also mentioned in “transparency”): Not all users may be aware that e-mail can easily be stored and archived. Patients are probably not as aware of how information about them will flow and who has access to it.

9 (Also mentioned in “transparency”): Do web-based e-health initiatives for youth expose them to surveillance by health systems/education systems?

Project No. c) Issues of literacy

1 How well do current health information systems/networks in rural communities serve the needs of women?

If e-health initiatives are introduced e.g. web supported services to provide health information in rural communities, what are the literacy considerations, necessary to make them effective?

3 Information must be presented to people in an appropriate manner.

4 What language skills, style, format and content are appropriate in web based e-health interventions to support PHAs and their families in rural communities?

(former mentioned at “issues of work ethics”):
How well do current health information systems/networks in rural communities serve the needs of women?

(former mentioned at “issues of work ethics”):
If e-health initiatives are introduced, e.g. web supported services to provide health information in rural communities, what are literacy considerations necessary to make effective?
<table>
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<tr>
<th>Project No.</th>
<th>c) Issues of literacy</th>
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<tbody>
<tr>
<td>5</td>
<td>What is the reading level of the information? (extremely high reading level)</td>
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<tr>
<td>6</td>
<td>What is the reading level of the information?</td>
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<tr>
<td></td>
<td>Is the information tailored to particular groups (i.e. Aboriginals, gay/lesbian/ transgender)?</td>
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<td></td>
<td>Is the site culturally sensitive to minority groups?</td>
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<tr>
<td>8</td>
<td>(also mentioned at “issues equitable allocation of resources”):</td>
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<tr>
<td></td>
<td>How accessible is the information provided to lay users on publicly-supported health information websites?</td>
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<td></td>
<td>(also mentioned at “issues equitable allocation of resources” and “issues of liability”):</td>
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<tr>
<td></td>
<td>Our analysis will assess the degree of difficulty lay users may encounter in pursuing, to a useable conclusion, information about common medical conditions</td>
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<tr>
<td>9</td>
<td>(also mentioned at “issues equitable allocation of resources”):</td>
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<tr>
<td></td>
<td>How can health information relevant to youth be made accessible through web-supported e-health initiatives?</td>
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<td></td>
<td>Language skills, as well as sensitivities to youth culture should be considered.</td>
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<tr>
<th>Project No.</th>
<th>e) Issues dealing with equitable allocation of resources</th>
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<tr>
<td>1</td>
<td>(former mentioned in “issues of work ethics, also mentioned in “issues of liability”, “issues of transparency”):</td>
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<tr>
<td></td>
<td>Do web based health information initiatives direct the lay public obviate need for formal services? In other words, to what extent do consumer health information services on the web assume that individuals will take on a greater burden of responsibility for their own health care and with what consequences?</td>
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<tr>
<td></td>
<td>How big has a target group to be to qualify for equal access?</td>
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<tr>
<td></td>
<td>What are the obligations of communities to make health information accessible to non English speaking itinerant farm workers?</td>
</tr>
<tr>
<td>2</td>
<td>This project focuses on access to computer resources and their use in a low income community which is also likely to be challenged by literacy issues.</td>
</tr>
<tr>
<td>3</td>
<td>Access to online services</td>
</tr>
<tr>
<td></td>
<td>Translation issues: Those who can pay may turn out to be those with the best access i.e. this may be a circular argument where those with good information retrieval resources also are able to further obtain the best services.</td>
</tr>
<tr>
<td></td>
<td>Those with disabilities are often able to exploit technology to help themselves (synthetic voices for email, large fonts size, etc.)</td>
</tr>
<tr>
<td>4</td>
<td>Do people living with HIV/AIDS enjoy the same access to health care as their urban counterparts?</td>
</tr>
<tr>
<td></td>
<td>To what extent do e-health initiatives compensate rural residents for lack of access?</td>
</tr>
<tr>
<td>5/6</td>
<td>What languages are the site translated into?</td>
</tr>
<tr>
<td></td>
<td>Is a disability format used?</td>
</tr>
<tr>
<td>7</td>
<td>(former mentioned in “issues of literacy”): Presenting materials in a language appropriate to a particular cultural group (Farsi speakers) an ethical issue might be why this particular group was chosen as opposed to some other groups.</td>
</tr>
<tr>
<td>8</td>
<td>(former mentioned in “issues of literacy”): How accessible is the information provided to lay users on publicly-supported health information websites?</td>
</tr>
<tr>
<td></td>
<td>(former mentioned in “issues of literacy”): Our analysis will assess the degree of difficulty lay users may encounter in pursuing, to a useable conclusion, information about common medical conditions.</td>
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</tbody>
</table>
### e) Issues dealing with equitable allocation of resources

<table>
<thead>
<tr>
<th>Project No.</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>How can health information relevant to youth be made accessible through web-supported e-health initiatives? To what extent do young people living in rural communities enjoy similar access to health services as their urban counterparts? Do e-health information initiatives compensate for any differences that may exist in access?</td>
</tr>
</tbody>
</table>

### h) Issues of transparency

<table>
<thead>
<tr>
<th>Project No.</th>
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<tbody>
<tr>
<td>1</td>
<td>Do web-based health information initiatives direct the lay public obviate need for formal services? In other words, to what extent do consumer health information services on the web assume that individuals will take on a greater burden of responsibility for their own health care and with what consequences?</td>
</tr>
<tr>
<td>2</td>
<td>Surveillance cameras in the computer room, in order to address theft. This also reduces privacy for people using the computers.</td>
</tr>
<tr>
<td>3</td>
<td>Not all users may be aware that e-mail can easily be stored and archived. Patients are probably not as aware of how information about them will flow and who has access to it.</td>
</tr>
<tr>
<td>9</td>
<td>Do web-based e-health initiatives for youth expose them to surveillance by health systems/education systems?</td>
</tr>
</tbody>
</table>

### i) Issues of standardization

<table>
<thead>
<tr>
<th>Project No.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To what extent do people, living in rural communities enjoy similar levels of access to health care as their rural counterparts? Do e-health initiatives, such as web based consumer health information web sites, provide an adequate response to individuals’ rights to accessibility?</td>
</tr>
<tr>
<td>3</td>
<td>Standards that are not perceived as useful may lead to workarounds or other ways of circumventing the system.</td>
</tr>
<tr>
<td>5</td>
<td>Are there any certification modes for health information web sites? Which criteria must be fulfilled to meet the requirements of certification modes for health information web sites?</td>
</tr>
<tr>
<td>6</td>
<td>(former mentioned in “issues of literacy also mentioned at “issues of liability”): Is the information sensitive to the Canadian context (as the provider is a US base company)? -&gt; legal issues: different measurements for blood sugar -&gt; SW -&gt; ... algorithms based on different models</td>
</tr>
<tr>
<td>8</td>
<td>If lay users are led to different answers in response to queries about common medical conditions, what does it say about the quality of public supported health information websites? Alternatively, if users are led to the same answers, questions might be asked about the investment of public resources in redundant services.</td>
</tr>
</tbody>
</table>
Results of the ethical/legal-questionnaire (theme II)

List of participating theme II projects:

<table>
<thead>
<tr>
<th>Project No.</th>
<th>Project Title/Researcher/s (Status: February 2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Impacts of technology on Palliative Care (Craig Kuziemsky, Francis Lau)</td>
</tr>
<tr>
<td>12</td>
<td>Mid Main meets EMR: Vancouver EMR Case Study (Nicki Kahnamoui, Ellen Balka)</td>
</tr>
<tr>
<td>13</td>
<td>Mid Main meets EMR: Patients Experiences of WOLF (Nina Boulos, Ellen Balka)</td>
</tr>
<tr>
<td>14</td>
<td>Introduction of a Standardized EMR System in Five Viennese Oncology Departments (Marianne Tolar, Ina Wagner)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Project No.</th>
<th>a) Issues of privacy and confidentiality</th>
</tr>
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<tbody>
<tr>
<td>11</td>
<td>By developing electronic assessment tools caregivers, such as nurses or physicians could be monitored as to whether symptom assessment or medication data are entered at the proper times.</td>
</tr>
<tr>
<td>12</td>
<td>(Also mentioned in “jurisdictional issues”): ICT Systems can easily be used for surveillance of employees. One of the main important benefits of going to electronic patient records is the ability to rapidly access updated information from patient records. Therefore information sharing between the various health institutions (including community practice, acute, and primary health care) is vital. However, this should be controlled and limited to various degrees depending on the situation. In other words, access permissions should be regulated according to the type of users and business needs. Privacy and confidentiality are critical in these settings, and it is important to find the suitable technique to preserve that, like for instance: the use of factor authentication, encryption of information, etc. ... Within the transition to EMRs, many of the concerns which were brought up by the patients had to do with confidentiality of information, and who should have access to which parts of the information ...</td>
</tr>
<tr>
<td>13</td>
<td>(Also mentioned in “issues of transparency” and “jurisdictional issues”): The limits to be placed on the sharing of information through electronic records should be up to the patient. Can the patients be given the choice? After all, it is their information. Information should also be accessible to authorized users and different levels of accessibility should be defined. (Also mentioned in “issues of standardization” and “issues of work ethics”): One of the raisons d'etre of the electronic record is to make information more easily accessible to a wider range of practitioners. The question is does the use of a paper based record require greater intentionality on the part of practitioners than the ease with electronic records (where what is shared may reflect algorithms programmed into the system, rather than conscious choices made by an individual who has to decide which parts of the record to share).</td>
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</table>
### Project No. 13

#### a) Issues of privacy and confidentiality

(also mentioned at "issues of work ethics"): EMR’s could be used for surveillance of all those who enter information into the record (clinical staff, administrative staff, physicians, etc.). Surveillance of employees could be undertaken to a number of different purposes, including monitoring the performance of an individual, of how medical practice handles a type of diagnosis, etc. Some types of surveillance might be acceptable (e.g., comparing characteristics of patient loads for the purposes of assignment of more equitable loads or to develop equitable billing practice), while surveillance for other reasons (e.g., monitoring work speed) might be unacceptable. So perhaps the issue is what types of monitoring and surveillance might be acceptable. And which would in all likelihood always be unacceptable.

(also mentioned at "issues of work ethics"): EMR can be used to monitor physician’s diagnosis by their colleagues. And as problematic as that might be, isn’t the whole purpose of EMR the sharing of information? The trade off in this sharing is matter of privacy in physician’s methods of practice.

### Project No. 13

#### a) Issues of privacy and confidentiality

(also mentioned in “issues of work ethics”, “issues of liability” and “jurisdictional issues”): Having everyone who enters information within the record have their name assigned to the piece of information holds the person accountable, and that is no different than filling out paper based records. The only difference is that the sharing of information is not widespread and sometimes the difficulty in reading the handwriting of the practitioner prevents one from knowing their identity when records are paper based. With electronic records the legibility of handwriting is no longer a problem.

(also mentioned in “issues of standardization” and “issues of transparency”): One of the planned uses of the EMR is for it to interface with a chronic disease management system, run by the province. … Once the data goes from the clinic in which it was collected to the province, it is not entirely clear who owns it or how it can be used. … So the Province can report back to clinics on the health of their patient population (… on a broader pool of patients with the same chronic disease).

### Project No. 13

#### a) Issues of privacy and confidentiality

(also mentioned in “issues of work ethics” and “issues of transparency”): In our case study they are not using the new ICT system now. It is possible that the system is going to be used for surveillance of employees. The system could be used to report on who did how much of the work.

(Also mentioned in “issues of transparency”, “issues of privacy and confidentiality”): Statistical analyses are going to be implemented into the computer system. It is not clear who is going to have access to this data for what aim.

### Project No. 12

#### c) Issues of literacy

(Also mentioned in “issues dealing with equitable allocation of resources”): There are various sources of literacy available on health information, both paper based and electronic based information. However, from my understanding, the different information sources are being used by patients for retrieving advices or additional information, rather than being used as a tool for making decisions/choices. I think that patients still have a large reliability to physicians (or other clinical staff), than to online sources. According to my impression online information is being used for issues such as: retrieving overview of the available medical sources etc.

### Project No. 13

#### c) Issues of literacy

(Also mentioned in “issues dealing with equitable allocation of resources”): This is a topic we would like to further explore in our third case study of Mid Main, where we will be observing patients use their records. … If all this data sharing is supposed to be of benefit to the patient, should not the patient have access to her/his data, both physically and intellectually? Obligation to describe information sources that patient understand it.
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<tr>
<td>14</td>
<td>(Also mentioned in “issues dealing with equitable allocation of resources”): There are plans at the hospital (that are independent of the introduction of the computer system) to give all the information gathered to the patient to store it. There is also the idea to integrate pictures in the patient letter which could help patients to “visualise” their disease.</td>
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<td>(Also mentioned in “issues of literacy”): There are various sources of literacy available on health information, both paper based and electronic based information. However, from my understanding, the different information sources are being used by patients for retrieving advices or additional information, rather than being used as a tool for making decisions/choices. I think that patients still have a large reliability to physicians (or other clinical staff), than to online sources. According to my impression online information is being used for issues such as: retrieving overview of the available medical sources etc. A very important issue in a multicultural country like Canada. Due to the fact that there are two official languages in Canada, the information should be available both in English and in French. In addition, the growing cultural diversity in Canada implies that information should also be translated to various languages so that recent immigrants, for instance, will have equal access to information. The regional differences are another interesting issue that adds complexity to presenting online information. I believe that access to health information should not be a privilege provided only to those who can pay, but should rather be the right of every citizen.</td>
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<td>13</td>
<td>(Also mentioned in “issues of literacy”): This is a topic we would like to further explore in our third case study of Mid Main, where we will be observing patients use their records. ... If all this data sharing is supposed to be of benefit to the patient, should not the patient have access to his data, both physically and intellectually? Obligation to describe information sources that patient understand it. Online forum is supposedly public space and as such be made available to everyone and not only to those who can pay.</td>
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<tr>
<td>12</td>
<td>I am not familiar with such system which connects pharmacists and physicians together, but I read some concerns of physicians who feel that they are being monitored. Based on my previous research experience. I suspect that users are not always well informed about their activities and the implications of that on the system. Therefore, I find it an important issue which needs enhancement. (Also mentioned in “privacy and confidentiality” and “jurisdictional issues”): One of the main important benefits of going to electronic patient records is the ability to rapidly access updated information from patient records. Therefore information sharing between the various health institutions (including community practice, acute, and primary health care) is vital. However, this should be controlled and limited to various degrees depending on the situation. In other words, access permissions should be regulated according to the type of users and business needs. Privacy and confidentiality are critical in these settings, and it is important to find the suitable technique to preserve that, like for instance: the use of factor authentication, encryption of information, etc.</td>
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### g) Issues of transparency

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<tr>
<td>Not necessarily, people are generally only interested in the portion of the system that meets their requirements. However, transparency and education of all components of the system and the capabilities of the system at different intervals after implementation is recommended.</td>
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<tr>
<td>Users need to be informed of the reasoning behind the utilization of EMRs.</td>
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<tr>
<td>(Also mentioned “privacy and confidentiality” and “jurisdictional issues”): The limits to be placed on the sharing of information through electronic records should be up to the patient. Can the patients be given the choice? After all, it is their information. Information should also be accessible to authorized users and different levels of accessibility should be defined.</td>
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<tbody>
<tr>
<td>Transparency of the system could become an issue, depends on the implementation of the system.</td>
<td></td>
</tr>
<tr>
<td>(Also mentioned in “issues of transparency”, “issues of privacy and confidentiality”): Statistical analyses are going to be implemented into the computer system. It is not clear who is going to have access to this data for what aim.</td>
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### h) Issues of standardization

<table>
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<tr>
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<tr>
<td>One area of research we are interested in is how technology impacts care delivery. One aspect of our study is evaluation of a previous introduction of handheld computers in palliative care that was not successful partially due to disruptions in workflow and impacts to caregiver-patient relationships. In the second phase of our study it is our hope that our extended grounded theory approach will help us overcome issues of workflow or patient care disruptions that can arise from introduction of technology.</td>
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<tr>
<td>(Former mentioned at “issues of privacy and confidentiality, also mentioned at liability): In Norway, for instance, the different hospitals cannot share electronic information. Therefore, when a patient is being transferred from one hospital to another, copies of parts of the electronic paper record are being taken and sent with him. However, if the hospital could share information prior to the arrival of the patient, then they would have had a better overview of the patient’s trajectories and examinations that should be conducted.</td>
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<tr>
<td>Standards are disruptive, to some degree, to the local work practice. Often the local practice must be changed in order to adapt to the standards. This might result in additional work tasks, rigid routines, entering overlapping information, etc. However, it is important to remember that when a new standard is being implemented, there is a transition period where work practices must be changed and adapted to the standard. The disruptions are often faced during this transition period. When it comes to standardization, it is important to have an active participation and transfer the responsibilities to the health authorities level, regional or national.</td>
<td></td>
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<tr>
<td>(Also mentioned in “privacy and confidentiality” and “issues of work ethics”): One of the raisons d’etre of the electronic record is to make information more easily accessible to a wider range of practitioners. The question is does the use of a paper based record require greater intentionality on the part of practitioners than the ease with electronic records (where what is shared may reflect algorithms programmed into the system, rather then conscious choices made by an individual who has to decide which parts of the record to share).</td>
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<tr>
<td>As much as they have the potential to be disruptive, they also allow for data sharing. Again, it is trade off. Basic (general) system standards should be set at a provincial level and those areas specific to a specialized practice should be given the flexibility to localize.</td>
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</tr>
</tbody>
</table>
### h) Issues of standardization

(Also mentioned in "jurisdictional issues"): Isn’t it similar to asking about standards? Whose standards and why? Basic regulatory frameworks should be set at a national level, since EMR are part of the Pan Canadian Health Infoway, which is a national initiative. These should then be adjusted at the level of local practice to comply to local regulatory frameworks.

14 (Also mentioned in "issues of literacy", "issues of work ethics", "issues dealing with equitable allocation of resources"): There are plans at the hospital (that are independent of the introduction of the computer system) to give all the information gathered to the patient to store it. There is also the idea to integrate pictures in the patient letter which could help patients to "visualise" their disease.

(Also mentioned in "issues of work ethics"): Standards are going to be implemented with the system. Catalogues of diagnoses and predefined protocols are going to be set up. The system will also suggest a dosage of medication and give a warning if a certain level is exceeded. It is to be seen if this interferes with established work practices.

### i) Issues of work ethics

11 (former mentioned at "issues of privacy and confidentiality", also mentioned at "issues of liability"): Provisional solutions may be a good reason to document later.

12 There are some applications that augment health care professionals’ work loads. An example of that is: after the implementation of the electronic medical record (more specifically, the billing and scheduling modules) the health care personal at the primary care clinic has to enter the same information into two different sources. The information is first registered on the paper-based registry and then entered to an electronic database (in order to register the information in the Ministry of Health registry). The information is being registered twice due to the lack of a built in application (in the EMR) which is supposed to transfer the registry to the Ministry.

13 (Also mentioned in "issues of standardization" and "privacy and confidentiality"): One of the raisons d’etre of the electronic record is to make information more easily accessible to a wider range of practitioners. The question is does the use of a paper based record require greater intentionality on the part of practitioners than the ease with electronic records (where what is shared may reflect algorithms programmed into the system, rather then conscious choices made by an individual who has to decide which parts of the record to share).

(Also mentioned at “issues of privacy and confidentiality"): EMR’s could be used for surveillance of all those who enter information into the record (clinical staff, administrative staff, physicians, etc.) … Surveillance of employees could be under taken to a number of different purposes, including monitoring the performance of an individual, of how medical practice handles a type of diagnosis, etc. Some types of surveillance might be acceptable (e.g. comparing characteristics of patient loads for the purposes of assignment of more equitable loads or to develop equitable billing practice), while surveillance for other reasons (e.g.: monitoring work speed) might be unacceptable. So perhaps the issue is what types of monitoring and surveillance might be acceptable. And which would in all likelihood always be unacceptable.

### i) Issues of work ethics

(Also mentioned at “issues of privacy and confidentiality"): EMR can be used to monitor physician’s diagnosis by their colleagues. And as problematic as that might be, isn’t the whole purpose of EMR the sharing of information? The trade off in this sharing is matter of privacy in physician’s methods of practice.
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<td>13</td>
<td>(also mentioned at “issues of privacy and confidentiality”): EMR can be used to monitor physician's diagnosis by their colleagues. And as problematic as that might be, isn't the whole purpose of EMR the sharing of information? The trade off in this sharing is matter of privacy in physician's methods of practice. Depends on the system, the implementation, the culture of the practice, the individual user. … If information sharing is indeed related to patient care, then the increase in their workload can be construed as part of care. (Also mentioned in “issues of liability” and “jurisdictional issues”): Workaround or gateway practice (those that attempt to incorporate previous paper-based or older systems) may lead to ethical issues. People may gravitate back to the way they did things prior to the introduction of the system; there may be resistance or even sabotage.</td>
</tr>
<tr>
<td>14</td>
<td>Also mentioned in “issues of standardization”: Standards are going to be implemented with the system. Catalogues of diagnoses and predefined protocols are going to be set up. The system will also suggest a dosage of medication and give a warning if a certain level is exceeded. It is to be seen if this interferes with established work practices. (former mentioned in “issues of privacy and confidentiality”): The sharing of patient information could facilitate interdisciplinary talks between physicians. This is what the target hospital is very proud of; they have a lot of such talks where they present interesting or difficult cases of patients. But sometimes it is difficult to find the information for a patient when they need it, this could be improved by the computer system. It is possible that the IT system augments work loads for the nurses and doctors. Especially in the beginning it is possible that they have to document some things twice (using the old documentation practices as well as the new system). At the moment they do not document everything in the required detail because they do not have enough time/personnel. For example it is not always noted who did specific interventions. So it is possible that with the IT system they are no longer able to skip this documenting. However it is also possible that the workload diminishes. Now they often do the medical history for a patient more than once as the already existing data is not available when the patient comes to the hospital again. With the computer system they should be able to access the data anytime. (also mentioned in “issues of literacy”, “issues dealing with equitable allocation of resources”, “issues of standardization”): There are plans at the hospital (that are independent of the introduction of the computer system) to give all the information gathered to the patient to store it. There is also the idea to integrate pictures in the patient letter which could help patients to “visualise” their disease.</td>
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