

Need for eHealth Ethics

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Abstract. The healthcare is an area where ethics has justifiably gained a central position, and this fact has acted as a safeguard for people and society. However, the increasing use of information technology has brought forth new kind of situations that the traditional medical ethics approach has not faced before. There is need for a new approach of eHealth ethics that covers the needs for modern healthcare to ensure that the ethicality will be ensured today and future likewise. We argue that a fruitful approach for this is the synthesis of traditional medical ethics and IS-ethics. In this article we look the four principles of medical ethics together with IS-ethics approaches by Moor and Brey to see what kind of values should be protected and what are the needs for justified use of information technology in healthcare.

Keywords: eHealth · Ethics · Values · New approach

1 Introduction

Information systems are an inseparable part of modern healthcare. Electronic medical records, electronic health records and other electronic information systems have changed the way that healthcare functions and is moderated. Despite the major impact of information technology (IT) on the healthcare this relationships seems to be poorly understood [1–3]. Since healthcare strongly relies on technology, the potential risks with technology are also potential risks for successful healthcare [4, 5].

Technology causes change in the social system to which is implemented and this change can be unpredictable as well. When an information system is changed or implemented it will change the organisation as well [6–9]. Technological products, such as information systems, influence their social context by either through affordances or through constrains, enabling or discouraging certain behaviour or use [10]. Thus, the way that the information system is designed also plays an important role in this unpredictable interaction. As information systems are always designed by human beings that are trying to fulfil certain goals, information systems are never value free [11–13].

Values are abstract ideals of what is important in life, that people strive to realise in the real world and thus, often act upon their values. [10, 14] Thus, values that are held in importance while making decisions about information systems affect the inbuilt values of a system. For instance, if efficiency of the system is a value that is held by the people developing the information system, the value of efficiency is probably going to be build in that system. However, this value might not be valued by other people that

are going to be using or are otherwise in interaction with the system. Thus, we should aim to find the values that are beneficial to all human beings affected by the information system that is designed. However, we have to be able to justify why specific values are preferred instead of others and then the ethics comes forward.

The field of IT-ethics has attempted to find the ethically justified way to make systems for the people [10]. However, we argue that there is a special need for eHealth ethics, since modern healthcare is in many ways different from the traditional organisation. First, healthcare has strong background in ethics [15, 16]. Second, healthcare is depended on the healthcare information systems and in case of malfunction the negative consequences can be irreversible [17]. Third, current development trend brings individuals closer to practitioners with eHealth solutions and makes the modern healthcare even more complex socio-technical system [18].

Thus, in this paper we consider some aspects of eHealth ethics and represent some values that could be a part of its basis. Since ethics without action is not going to make a change, we also consider how eHealth ethics could be applied in practice when developing and assessing health related information systems. The aim of this paper is to spark a discussion about the need and content eHealth ethics. Thus, we do not argue that our description of eHealth ethics or its application is the only way of making ethically justified health related information systems, but rather present it as one proposal for a more ethical approach on eHealth.

In the next section we describe the background of eHealth and explain why eHealth ethics as a new way of viewing healthcare information systems is required. In the section three we discuss different kinds of applied ethics that are in relation to eHealth ethics and describe what eHealth ethics is. In the section four we consider ways that could be used to apply eHealth ethics in practice. Finally, we conclude in section five.

2 Background

As a topic eHealth is widely discussed in conferences, in the literature, and in the media. Despite the frequent use of the term there is no consensus about the definition of eHealth. Many definitions have been proposed and used to describe broad range of technology in various different settings. [19–21]

According to Shaw et al. [21] the most popular definition with most citations is Eysenbach's [22] high-level definition of eHealth:

"e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterises not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology"

Despite that this definition is more like an idea of eHealth than clear definition, it fits our purposes well. However, we can no-longer state that the field of eHealth is emerging. Also we use the term healthcare informatics to describe the intersection of

medical informatics, public health and business. Thus, our definition for eHealth in this paper is "*eHealth is a sub-field of healthcare informatics, referring to health services and information delivered or enhanced through the Internet and related technologies*".

Healthcare informatics can also be described as an interdisciplinary field in the cross-roads of information systems and healthcare. Information systems science as a field has its roots in the managerial aspects of the computer assisted organisations even there are also other paradigms, such as the Scandinavian participatory approach [23]. Thus, the paradigms of the field have been shifting towards wider consideration of the nature of an information system, that acknowledges also the social aspects in relation to the technical ISs [24]. This shift can be seen also in the field of health informatics, as example there is an increasing interest towards customer-centric information systems such as personal health records [25–27].

Also the field of healthcare is going through a paradigm shift from sickness centrality towards more preventive healthcare [28]. Simultaneously, the expert driven nature of healthcare is shifting, as the customers of healthcare are more interested in health issues and due to technological changes more capable of getting more information, thus breaking the long standing information monopoly of the healthcare professionals [29]. Thus, healthcare informatics are amid of the paradigm turmoil.

Technology has played a major role in the paradigm shifts of healthcare as White [30] noted a decade ago. Now healthcare systems globally are facing the problem of ageing population and thus, are in pressure to become more efficient [18, 28]. Once again technology is playing an important role in this change. However, the change is no longer happening only within the healthcare institutions but also in the customer side. Technologies which endorse patient engagement and self-care are gaining more and more popularity, and changing the healthcare systems. [18]

It is apparent that these changes will change the nature of healthcare drastically. Healthcare is no longer all about practitioners healing sick patients, but rather a complex cooperation between professionals and people with the help of technology. Due to this tectonic shift, we can no longer view healthcare information systems solely from the perspective of healthcare. We have to take into account also the individuals who are taking care of their selves with technological systems connected to healthcare. Thus, new ways of viewing healthcare information systems are needed.

Healthcare and medicine have a long history that is interrelated with ethics for millennia. Ethical values have guided the practitioners as well as the development of the field in general [15, 16]. We still need to understand the ethical aspects and consequences in relation to healthcare and technology. Thus, ethics should be embraced as a basis for the modern eHealth now and in the future.

However, due to the evolving and complex state of the healthcare we can no longer rely merely on the ethical basis of the healthcare. We also need to consider ethical values of the individuals that are becoming more active actors in the complex socio-technical system of modern healthcare. Besides understanding the values of practitioner and individuals, we also need to understand values that are incorporated in healthcare information systems (HISs), since information systems are never value free [11–13].

A good example of a value that is built in information technology is the value of efficiency that often seems to be the goal of the healthcare development. Efficiency is

based on the speed of computers likewise its advanced freedom from limitation of space and location. Efficiency itself is not a bad value — from utilitarian point it is also ethical as it enables the production of more good — but if it is the core value we may have situation where anything inefficient is seen as bad which obviously is not true. Also, if efficiency is seen as the most important value, surpassing all others, such as quality of care and compassion, it will inevitably create problems. Therefore, without noticing these kind of embedded values and ethical issues following those values underneath the outcome can be unpredictable and in many cases undesirable.

We should clearly question efficiency as a core value of healthcare and medicine based on this short analysis. But which values could be considered to be the basis of modern healthcare and thus, also as a value base for technology used in it? To analyse this, we need to understand ethics of both healthcare and technology. To make a real change, we also need a way to pass this understanding to the developers and stakeholders of HISs. For these purposes we propose a new form of applied ethics that we have here named as eHealth ethics, which combines healthcare ethics and computer ethics.

3 eHealth Ethics

3.1 Healthcare Ethics

As stated earlier healthcare, medicine, and ethics have a long history [15, 16]. Likewise, from the beginning of nursing, the ethical nature of the work of the profession has been emphasized [15]. Ethical codes define the duties of nurses, give guidelines for ethical actions, express the virtues of nurses and provide nurses with core values and standards [31]. Thus, it is obvious that ethics cannot be overridden by efficiency.

Thus, ethical reflexivity towards the work process has a major role in the field of healthcare and is – or at least should be – the standard position in the field [16]. Thus, as ethics is an inseparable part of healthcare and when developing or implementing a HIS, we should understand the underlying values that have manifested through ethical principles (here the four principles of medical ethics) in action.

Thus, in this current situation we can turn towards the four principles of medical ethics which have been the basis of medical ethics: respect for autonomy, beneficence, non-maleficence, and justice. [32–34] Information systems developed for the healthcare should thus fulfil these principles to incorporate the values of healthcare.

Autonomy

Principle of autonomy is aimed at securing the rights of individual to be treated without forced paternalistic manners. Leino-kilpi [35] stated that there are four points for autonomy of patient.

First, human rights and values has to be respected [35]. We need to understand the value of people as themselves. This is very Kantian approach — people should always seen as ends in themselves, not merely as means [36]. Thus, when designing an information system, one should respect the people that are affected by the system.

Secondly, patient needs information about health services and they need to have access to their own information [35]. The current trend is to give patients access to their health information [37]. This right for patients to their own information from ethical

perspective is also underlined by Koskinen [38]. However, the information in many cases is not easy to understand by layman and there is obvious need for improving how the information system are developed. Those should also serve the needs of patients if we want to achieve autonomy of patients instead of supporting paternalistic structures with information systems.

Thirdly, informed consent is needed for a patient to be autonomous [35]. If a patient cannot give consent that is based on their own judgement, they do not have autonomy. Informed consent can be fulfilled only if the information needs of patients are fulfilled. Even if there are systems that support giving and making consents — like Omakanta in Finland — it does not be enough if there is no information available to make decisions, yet alone informed ones.

Fourthly, the privacy and confidentiality must be respected [35]. If there are risks of losing privacy, patients possibility to be open and have trustworthy relationship with healthcare (professionals) is endangered. Thus, the security issues in HISs should be taken seriously if we want to secure the trust towards healthcare.

Beneficence and Non-maleficence

Beneficence and non-maleficence are principles which have to be analysed together in healthcare as there are many cases where some harm must be done to achieve the created good. In practise, there should always be substantial beneficence for patient to be ethically justified practise. [39]. For HISs this means that they may not cause harm but always be beneficial. There is clear advantages of using HIS that works well - increased effectiveness, more information for medical decision making etc.

The problem is, that in many cases the promises that are put in HIS, are not met. There have been even life-endangering situations that information systems has been caused in healthcare [40, 41]. Thus, there exist and ethical demand to ensure that new HISs create more beneficence for patients than previous system. This should be taken care when designing and implementing new systems.

Justice

Justice – it is not easy to say what kind of healthcare would be just. Campbell et al. [39] announce that for treating people without consideration of their worth, the need should probably be the basis for delivering care. It is obvious that there usually are needs in excess of the resources of healthcare and we need to find solution to use resources ethically. Equal and fair treatment of people when they are in need of help justifies the existence of healthcare. People should have access to care which they need and which healthcare can arrange with allocation of its limited resources [42].

We need to use information technology to improve our healthcare but such way that we are not violating the other principles. Technology — likewise efficiency — has instrumental value in healthcare but not instrinsic and thus it must serve the good for society not be the main goal.

The four principles have received some criticism but they are still used in practise and research despite of limitations they have [43, 44]. Thus, these principles should be considered as a simplification of the codes of ethics – as a necessary but not as a sufficient condition to be taken care in context of HISs too.

3.2 Computer Ethics

Computer ethics(also known as IS ethics) is a branch of ethics concerning the unique ethical issues that wouldn't exist without computers (or other information technology) [45]. One of the breakthrough articles was written by James Moor in 1985 [46], and after that researchers have continued to examine modern ethical dilemmas from this unique perspective. Just as Environmental Ethics has emerged as a field of ethics relating to the moral relationship between humans and the environment, Computer Ethics concerns the moral questions of what *should* and *shouldn't* be done in situations that involve IS [47].

While the uniqueness of Computer Ethics has been a source of some debate and its legitimacy as a unique field has been challenged [48], there are many examples of unique cases where it is difficult or impossible to use everyday analogues to situations concerning information technology. While simply involving a computer is not enough for an ethical issue to be considered computer ethics, some cases are unique enough to warrant a special category of examination. In such instances, it is imperative to clear up all related concepts. For example, copying a file is not analogous to borrowing or reproducing or stealing a physical object, but a distinct act of its own. As such, the morality of copying files in different situations is nearly impossible to analyze without incorporating the technological perspective of Computer Ethics. [46, 49, 10, 47]

This type of new acts and situations often create what Moor calls policy vacuums, which computer ethicists attempt to fill [47]. A policy vacuum is created by fast technological development that makes it hard or even impossible to adjust laws and policies fast enough to fit the current situation. Examples of such vacuums exist, for example, in regards to cyborgs, nanotechnology and AI. [50–52] Here we attempt to, at least partially, bridge such a gap in eHealth.

3.3 eHealth Ethics as a Framework

As technological development has made and will continue to change how our healthcare will evolve, we need to be able to combine the ethical knowledge from the fields of healthcare and technology. There has been proposal that the four principles of medical ethics could serve as common language between the medical and IS professionals [13].

However, it seems that ethical guidelines or codes —such as the four principles — of healthcare are not used or widely known by developers of HIS's even though IS field has developed the ethical codes of their own [53]. If ethical principles for healthcare and medicine are not followed/understood in the development or procurement of HIS the outcome hardly is fulfilling the demands of those principles. The developed system necessarily creates ethical consequences to the whole healthcare system as it dynamically changes the whole system instead of being mere isolated static technological implementation [6–9, 54]

When designing systems for healthcare the ethics of the medical profession, values of patients and society must be reflected in the system; if they are not, the system does not (or at least may not) answer to the needs of the field, and thus we get systems which do not answer to the needs of the healthcare or society. Of course there may be need for

rethinking and revising those ethical principles but there is need to have something to base on today and we leave the revision of those principles out of scope of this paper.

Why these ethical principles are seen as important for IS professionals that develop systems? Why it is not enough that healthcare as buyer of HIS makes sure that systems are in line with values and regulation in the healthcare? Koskinen et al. [13] stated that these principles could be common ethical ground for both healthcare professional and developers of information systems. The common ethical language would help the developers to understand values that must be respected in healthcare. Likewise, the need for healthcare professionals to see how technology is affecting organisation would be more easily to be shown, when risks could be stated with language that shows the ethical consequences. Thus, there is need for strong participatory approach in eHealth ethics.

However, we see that before we have possibility to participatory actions we need for more detailed view for the ethics of eHealth, that should be focused by researchers. We claim that even the four principles may be a good, simplified tool for practitioners, the more detailed codes should be also looked to meet the needs of varied ethical issues that emerges with technology.

Our aim is to develop the synthesis of IS-ethics (based on Moor [46] and Brey [10]) There is lot of other IS-ethical theories and directions but in this paper we look only the those above mentioned ones. Moor can be seen as one of founders in IS-ethics approach (called computer ethics by Moor) who did make the problems of computerisation visible. Thus, we chose to use it as it points the relevance of IS focus in ethics.

If Moor is one of the founders of IS-ethics, Brey is an advocate of more modern research and is focusing on wider aspects of technology in level of society and what are the fundamentals that technology should supported in good society. These together with the four principles are basis of our first draft for eHealth ethics that should be evaluated by public discourse and real life problems faced in healthcare. Thus our approach is somewhat similar — but not same — as RRI (responsible research and innovation) that is seen to be more fruitful than mere philosophical-theoretical approach by offering the more practical way of looking ethical issues concerning ISs [55].

It must be noted that even Stahl et al. [55] see that although RRI has its advantages there is still need for computer ethics as such. We see that our approach is the between of those views by relying heavily on ethical theories but looking towards the participatory approach at the same time.

4 eHealth Ethics in Practice

Moor [46] shows we need to consider the ethical consequences of information technology and see that legislation cannot be seen as sufficient safeguard. A complementing regulative approach for legislation is soft law that includes professional guidelines and codes of ethics.

Soft law means varied, rule of law kinds of norms that do not fulfil the characteristic of the legislation as soft laws are created different way than laws are. Government authority may formulate those to support specific legislation and its application. Soft laws can be also created by co-operation of governmental official and private actors to

work as norms that should be followed. Likewise specific branches of industry or professional groups may enforce norms that they should comply with (example standards of accounting). [56] Soft laws (here ethical codes) are important as they guide toward actions that are in line with values of society.

The four principles are an example of soft law, in a sense that they guide the work of medical professionals. However, medical professionals and organisations are bound to follow also other ethical codes and standards when treating people [57, 58]. If the public intent is to keep the healthcare systems ethically justified, it is mandatory to extend this thinking also to the development of HISs in more extended rate than it appears to be currently. Thus, the eHealth ethics — not seen only as medical ethics — as a field should cover not only the healthcare professionals, but also the developers of HISs and the public authorities behind the resolutions on behalf of the society.

However, this has not been the situation in the previous and current way in procurement, development and implementation of HIS [59–61]. The HISs are tools for achieving improved health and quality of life for citizens and as with any other healthcare tools, it must function in the maximum quality achievable within reasonable limits. If — and when — these systems are created without the aid of ethical analysis and guidelines, the whole purpose of the dependant field, i. e. healthcare, is compromised.

The four principles of medical ethics is a promising ethical basis for HIS development because of its universal and yet case-by-case adaptable nature. They are theoretically simple, generalisable, well established in the field of healthcare and when more deeply inspected, yet still cover quite well the needs of HISs as well as healthcare as a field. As every philosophical theory, it does not solve all possible problems; rather its strength is that it can be used as a common ethical basis to be used for both healthcare and HIS development.

Hence, different professionals can derive and sharpen their own, more specific ethical codes and rules and still have a common ethical basis for discussions and analysis of actions. To summarise, the usage of the four principles in context of technology does not remove all the problems, but it allows different participants to use a common language in development of modern healthcare. Used in this way it would be a major improvement compared to current procurement, development and implementation of HISs.

However, we need more research and analysis about the values that the eHealth ethics is based on. Although the four principles provide a good basis from the perspective of healthcare, also more general values should be examined to guarantee the respect of patients and citizens. Also due to fast development of technology and policy vacuums that it easily creates, we are not suggesting that eHealth ethics should be a static but rather an always evolving framework that has inbuilt the participatory approach. Thus, in future we hope to develop this framework further by considering a wider spectrum of values than the four principles of medical ethics from perspective of Healthcare side and also other IS-ethical theories should be evaluated and pondered for creating sustainable and ethically justified soft laws and codes in context of eHealth.

5 Conclusions

This paper has three main contributions. First, it views the change of the eHealth from perspective practitioners and individuals that are taking more active role in the healthcare with help of the fast developing technology. Although, individual paradigm changes have been noted before, there is very little consideration on how we can manage this change as a whole. Second, this paper introduces eHealth ethics - a possible way of managing this change by developing ethically justified healthcare information systems. Third, the contribution is not limited to a theoretical framework, but this paper also introduces codes as possible practical implementation to eHealth ethics.

However, as noted before, this paper is just a first draft and introduction of eHealth ethics in hopefully long and fruitful discussion about the topic. Thus, further analysis is needed and welcomed. Also, participatory approach should be brought to this discourse of ethical issues in healthcare to ensure that the core values of whole society could be founded and implemented as code of eHealth ethics. Otherwise there is risk that we come up with codes that are not internalised by society. We as researchers can offer new ideas and view for wider discussion and this is the point of this paper; offer one proposal for ethical guidelines for modern healthcare to be evaluated by open discourse — first by researchers but hopefully by larger audience too if our idea seen promising one.

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