

Ethical issues in eHealth

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Tamankag Paul Nji Master of Health promotion Thesis, 2013 Laurea University of Applied Sciences Laurea Otaniemi Master of Health promotion **Abstract**

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EHealth refers to the use of information and communication technologies to improve or enable health and healthcare. In a broader sense, it characterizes not only 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 by using information and communication technology (Eysenbach, 2001).

EHealth involves new forms of patient-physician interaction as opposed to the traditional face to face contact and poses new challenges and threats to ethical issues; Fundamental values at stake in eHealth include: candour and honesty, quality of products, services and information, respect for individuals, right to give informed consent, privacy and confidentiality. Also at stake is good professionalism and good business practice.

The purpose of this study is to establish what ethical code of ethics is considered in the development and implementation of eHealth services and how it is enforced. Qualitative research method was used in which major stakeholders in eHealth activities such as Entrepreneurs (Medixine), Espoo city, and Healthcare educators (Laurea University of Applied Sciences) were interviewed and the data collected was analyzed using deductive content analysis. The findings will shed more light on the phenomenon ethical issues in eHealth and make possible recommendations.

This study examines some of the potential ethical concerns and carefully looks into what and how major players in eHealth services incorporate safeguards/ethical protocols in the development and implementation of eHealth services. The findings suggest that ethical codes have been considered in the development of eHealth services; a lot still has to be done to build trust in society considering that this is a relatively new phenomenon.

Key Words: eHealth, Ethical issues, Information and communication technology (ICT)

Table of Contents

1. Int	troduction	5
2. Th	neoretical Framework	6
2.1.	eHealth	14
2.2.	Ethical Issues	16
3. Pu	urpose and Research questions	18
3.1.	Research Questions	18
4. Me	ethodology	18
4.1.	Data Collection	21
4.2.	Data Analysis	23
5. Fir	ndings	25
6. Dis	scussion	29
6.1.	Ethical Considerations	31
6.2.	Validity	33
6.3.	Recommendations	34
Referer	nces	35
Figures	;	38
Append	dix	39
Appe	endix 1. Consent letter	39

1. Introduction

EHealth is the transfer of health resources and healthcare via electronic medium. It involves health information delivery, using IT and e-commerce to improve health services and the management of health systems using e-commerce and e-business practices. EHealth mediums include mobile health, telehealth, internet health, and websites (WHO 2012).

E-health has been in use since 1999 but nobody has been able to come up with a comprehensive definition of the term. It's virtually anything related to computer and medicine. It's a term more used in the business world related to e-commerce, e-business, and e-solutions. Internet has created new possibilities and challenges to the healthcare system; the term eHealth is defined how it's used for is dynamic and constantly changing (Eysenbach 2001).

"eHealth 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, it characterizes not only 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 by using information and communication technology". EHealth involves new forms of patient-physician interaction and poses new challenges and threats to ethical issues such as online professional practice, informed consent, privacy and equity (Eysenbach 2001).

Ethics deals with right and wrong conduct, with what we ought to do and what we should refrain from doing. Medical ethics concerns how to handle moral problems arising out of the care of patients; often clinical decisions must consider more than just the patient's medical condition. (Uottawa 2004)

"Ethical issues arise when not all values can be respected. The values in conflict must then be prioritized and the essence of 'doing ethics' is to justify breaching the values that are not respected" (Uottawa 2004).

2. Theoretical Framework

Questions of ethics and its relationship to human consciousness have been the focus of philosophical consideration for thousands of years and can be understood as encapsulating "traditions of belief that have evolved in societies concerning right and wrong behavior" (Hopkins 1997).

Code of Ethics: Why Now?

There is Critical mass and exponential growth, new"/"non-health" participants, questionable practices, Bad press and Legislation/regulation concerns. Also, 66% of online health seekers are concerned about privacy, only 21% of health seekers willing to trade privacy for personalization. Online medical record keeping perceived as greatest threat, Seals of approval have no impact on attitude and government and medical associations most trusted sources (Mack 2000).



Figure 1. Four Pillars of quality management of health information on the web (Gunther 2000).

First, consumers need to be educated on how to "filter" information, i.e. how to discriminate trustworthy information from less trustworthy information. The second pillar is self-rating of information providers, i.e. publishing of meta-information, which allows users to locate and filter information automatically; however without a third-party evaluation and enforcement this ethical code is a toothless tiger. An action plan was adopted by the EU in 1998 (http://www2.echo.lu/iap/) to ensure the implementation of the various initiatives on how to deal with undesirable content on the Internet and designed to support non-regulatory initiatives for promoting safer use of the Internet" (Gunther 2000).

Health promotion is about empowerment, education and creating the right environment for the individuals and communities to take responsibility for their health and make better and informed choices; a culture of wellbeing for people of all ages. Advantages of eHealth services such as interactivity, use of active learning methods, multimedia presentations, temporal flexibility, relative ease and tailoring and low costs can greatly enhance health more so if ethical dilemmas are appropriately resolved, build confidence and increase public willingness to use internet as a tool for health (Nutbeam 2006).

Ethics has become a fashionable field of study. There has been a remarkable rise of interest in ethics particularly in the more developed countries over the last two decades or so. For instance, in the United States alone, the Congress was reported as having created an Ethics Commission to correct and defend certain trends of conduct. It is done because there is that inner quest which urges human beings to seek those things that will satisfy their need for happiness and harmonious living. (Christine 2013)

The ethical rules of conduct are firmly grounded in moral theory. *Teleological ethics* also known as consequentialism, moral conduct is assessed by its effects and consequences. Utilitarianism as an expression of consequentialism focused on affecting the greatest good and a minimum harm. In *Deontological ethics*, the nature of conduct is assessed using established universal standards for behavior such as religious commandments, professional ethical codes, and rules of civil and criminal law. In this case, an actor follows rules not on the consequences. *Deonutility ethics* combines both rules and consequences to produce good principles and guidelines (Ron 1998).

Modern professions incorporate the idea of ethics into practice by developing specialized codes of ethics to apply order and guide professional decision-making in conjunction with Deontological ethics (Dolgoff, Loewenberg, & Harrington 2005).

The Code of Ethics' is a set of core values and the principles and standards developed on the basis of those values are designed to inform ethical decision-making. However, the *Code of Ethics* does not provide universal prescriptions for behavior, nor does it specify a hierarchy of values, ethical principles, or standards. This is likely due to the complex, context-bound nature of the process of ethical decision-making (NASW 1999).

Studies suggest that the *Code of Ethics* does not serve as the primary basis for ethical decision-making but that practice wisdom, personal values (Dolgoff & Skolnik 1996), and supervision (Landau 1999b) are key resources that inform decision-making.

The philosophical foundation of the e-Health Code is the principle of respect for persons; that is, the ethical obligation to treat each individual as having dignity and moral worth him- or herself, and never simply as a means to someone else's purposes. The principle of respect requires that we treat individuals as independent decision makers and allow them to make choices about what products to buy, what services to use, what is most important in living a good life based on their own values (Crigger 2001).

The Internet offers real potential to improve well-being by offering unprecedented access to health information, products, and services. At the same time, it also makes possible forms of communication and kinds of practice that raise ethical, social, and legal concerns. We are only beginning to develop a clear, shared understanding of how to participate in the virtual environment of the health Internet and only beginning to think carefully about what opportunities we can take advantage of and what opportunities may be technically possible but are ones that we should not pursue in the new world of e-health (Crigger 2001).

The importance of Code of ethics in e-health cannot be over emphasized. It provides the appropriate environment to harness the potential of internet in improving the well-being of people around the world be they patients, healthcare professionals, website sponsors, application developers and other internet users. Fundamental values at stake in e-health includes, candour and honesty, quality of products, services and information, respect for individuals, right to give informed consent, privacy and confidentiality. Also at stake is good professionalism and good business (Crigger 2001).

Fundamental to e-health is trust because clients have to share their personal info, use medication and buy products to receive the care they need. In the virtual world, trust is difficult to sustain because anyone anywhere connected to the internet can set up health services and sell health products regardless of their qualifications and anyone can be a patient. Compared to traditional methods of healthcare, eHealth has no limitations geographically or politically hence clients can seek services or sell services across international and local borders. Laws on medical licences, client privacy, advertisement &

marketing of services, vary in different places, therefore a law that is internationally applicable is a subject of debate and deliberation (Mack 2000).

As the area of online, interactive healthcare communications continues to expand, healthcare organizations must be concerned about securing individual privacy and fostering strong ethical behavior. What are the ethical principles relevant to e-health? How should healthcare organizations develop and promote ethics guidelines and codes of conduct for websites and electronic patient information? (Mack 2000)

There is inequality in the access to the benefits of ICT which are divided along Socioeconomic, geographic gender, age and ethno-racial lines (Brodie et al., 2000). Access cost also presents a potential barrier to engaging with health resources. Another critical issue related to access is content and web-based information itself. Those with low literacy rate are biased because they cannot effectively use the information and resources available on the internet to meet their health needs infringing on equality and equity enshrined in ethics (Norman 2004).

According to the Ottawa Charter (WHO, 1986), there is need for a healthy public policy, create supportive environments, strengthen community action, develop personal skills and reorient health services.

Ethical considerations pervade all levels of decision-making in the social welfare and health care sector. Particular attention should be paid to conflicts between ethics and economy. Legislation enacted and ethical values and principles observed in other areas of society must support the efforts of the social welfare and health care sector to achieve better health and wellbeing for citizens. (Ethical grounds for the social and health care field, 2008-2011)

In May 2005, the World Health Assembly in their 58th meeting adopted a resolution on eHealth focused on the use of ICT and its implication on health security, health services delivery and the transformation of health systems worldwide. The implications for public health include quality of information, data security and privacy, the promotion and sales of medical products and services (WHO 2013).

In the 66th World Health Assembly, it was also established that the global nature of the internet makes it difficult for national laws to be enforced. The lack of an overarching international legal framework hinders an effective response to crime and fraud, quality seals and voluntary codes of conduct are still ineffective after a decade of use. Efforts to educate consumers are insufficient and government action/schemes have had limited impact globally (WHO 2013).

In the 66th World Health Assembly it was also recognized that it is essential to ensure secure online management of health data and to increase trust in eHealth tools and health services as a whole. It was also emphasized that health-related global names should operate in a way that protects public health by preventing development of illicit markets of medicines, medical devices and unauthorized health products and services (WHO 2013).

Ethics is a very important factor in marketing especially in eHealth services considering the very many ethical dilemmas it poses to consumers such as privacy, safety, respect and honesty, quality and good professionalism or practices. Customer choice and participation in eHealth activities is influenced greatly by the above mentioned values. Consumers of eHealth services tend to look at the pros and cons of consuming eHealth services and research have shown that a large percentage is not willing to sacrifice privacy and safety for easier and faster accessibility to eHealth services (Mack 2000).

The purpose of this study is to establish what code of ethics is considered in the development and implementation of eHealth services and how it is enforced. Some of the key themes of ethics from literature include:

Respect for persons

It is the ethical obligation to treat each individual as having dignity and moral worth him- or herself, and never simply as a means to someone else's purposes. The principle of respect requires that we treat individuals as independent decision makers and allow them to make choices about what kind of services to use to improve their health based on their own values. Individuals should be given enough information, provided with the right environment and be allowed to make informed choices about their health even though it might not necessarily be the right decision. The principle of self-determination must be at all-time be respected in eHealth processes (Crigger 2001).

eHealth as perceived by consumers today has the top bottom approach in which the consumers have little or no influence what so ever on the development, production and implementation of eHealth services or products. The actors involved in the eHealth processes more or less are the decision makers and decides the needs of the consumers. More recently there has been a new wave of discussion on co-creation in which the consumer is part of the process and also client centered processes in which the consumers decide their own needs. This whole new approach is still more at the theoretical level than in practice in the eHealth domain because the product developers and entrepreneurs don't consider them in their practices.

As a result of the above mentioned issues, society gets what they are provided not what they would want. The decisions about people's life are being made by others and people just have to accept those decisions made for them. A solution to the status quo will be to involve society/people in the decision making process so as to take their wishes and also give them the opportunity to decide about their lives. There seems not to be a dialogue between the decision makers and those the decisions are made for (Crigger 2001).

Service providers should treat consumers as beings that have choices and desires not just as objects to our own ends. Old people have the right to be listened to and their point of view taken seriously in decision making about their care. Also their health status should be given proper consideration to make sure the best kind of help is sought and the right decision made. Kantians talk of respect for users' rights, Utilitarian's talk of promotion of users' welfare, and the Radicals talk of empowerment (Sarah 2001).

Trust & Honesty

Trust and honesty are very important concepts in this new health care environment. As the philosopher (Annette Baier, 1994) has noted, trust is like the air we breathe — "we take it for granted and only notice it when it is polluted or violated". Most of the time, we assume that we can trust people or institutions, and do so until we learn something that causes us to question whether we should. As Baier further notes, "reasonable trust" requires "good grounds for confidence in another's good will, or at least the absence of good grounds for expecting another's ill will or indifference." The eHealth Code specifies in the broadest sense what count as "good grounds" for confidence (Crigger 2001).

Consumers tend not to trust the society both public and private because most eHealth initiatives are profit driven than consumer driven; the economics of the world is moving more towards a capitalist system in which profit is the driving force. This approach overlooks the risk consumers are exposed to so long as it's profitable; therefore consumers tend not to trust the eHealth products and services more so because they are not part of the processes and therefore will no influence on the outcomes. Consumers feel they should be provided with enough information and ways to verify the information especially on websites where there is no possibility for interaction or censorship in order to make informed choices about their health; "To treat us with respect, they must not withhold information that a reasonable person would want to know, for example, about risks involved in using their products or services and they must be truthful and not deceptive in their claims, for example, about the benefits of their products or services".

To treat someone with respect, and as an autonomous decision maker, requires that we be forthcoming and truthful with him or her. The ethical obligation of health-related websites is not specifically to assure that individuals always make the "right" decision, but to assure that they have the information they need to reach considered decisions (Crigger 2001).

Informed Consent

Informed consent is one of the cornerstones of contemporary medical ethics, and is as binding in the eHealth environment as it is in face-to-face health care. Respect for persons as autonomous decision makers requires that we acknowledge individuals' right to decide what will be done to their bodies and to determine what we may do with their personal information. Given the technical ability of websites (or even third parties) to collect personal data without users' knowledge, informed consent becomes a particularly important condition for a trustworthy health Internet (Crigger 2001).

Customers share personal data online to enable service providers tailor services they receive according to their needs. Most often if not always the service providers use the information for other purposes like marketing and share this information also with third parties without consent from the customers. Customers feel they are not well informed of the consequences of not sharing personal data in order to use e-service sites and sometimes feel the cost of giving personal data outweighs the benefits; they are therefore reluctant to take advantage of this new trend in healthcare. Customers of eHealth services should be in control of their personal data such that service providers cannot without their consent use or share their personal information with third parties. Service providers have the obligation to allow customers themselves to decide for themselves whether they will permit such uses of their information, by explicitly seeking customers' informed consent for specific data-gathering and data-sharing activities (Crigger 2001).

Privacy & Data Security

Privacy is generally understood to be an instrumental value: It makes good things possible, and/or helps us to avoid harms. Privacy enhances our ability to form and sustain the kinds of intimate relationships important to our flourishing as human beings. Like informed consent, privacy and confidentiality are widely seen as essential to health care. To receive needed care, patients perforce must often reveal information about themselves that is highly sensitive. They must be able to trust that their personal health information will be kept confidential and will not be inappropriately disclosed or used in ways that could harm them. The harms that can follow when confidentiality is breached range from the affront of receiving unwanted communications, to material losses when personal information is used to discriminate against individuals in employment, housing, health or life insurance, and other areas (Crigger 2001).

Privacy, as we have come to understand it, involves a bundle of rights: to physical privacy, to prevent unwanted or unwelcome intrusions on our bodies and minds; to decisional privacy, to forestall intrusions on our capacity to make choices for ourselves based on our individual values and understanding of what is in our best interest; and to informational privacy, to control how we are known in the world. When others collect and share information about us, especially when they do so without our knowledge, our control of how we are known — and by whom — is thwarted. Our dignity as persons is violated (Crigger 2001).

Customers perceive information theft and misuse as very recurrent in eHealth services because they are not aware of a security protocols or mechanisms in place to prevent that from happening. Like mention earlier customers don't trust society both public and private first of all because they are not part of their processes but also because they have no control of the personal data they feed into their systems. Public and private actors in eHealth services are perceived by customers as profit oriented than customers safety and privacy especially more recently it was made known that major ICT companies collect personal data for Government security agencies.

Customers have to be well informed of the type of data protection protocols or mechanism in place to ensure that their personal data will not end up in the wrong hands or places and possibly a system that guarantees anonymity in the virtual world. It's the obligation of service providers to inform the customers of possible risks involved in the virtual world that they cannot control so as to help them make informed decisions. "This reduction of "me" to an impoverished data set bought and sold for ends that are not my own is an assault on dignity. It is, in the end, a violation of the principle of respect and the obligation to treat persons always as ends in themselves, never as means merely" (Crigger 2001).

Professionalism

The health Internet can pose new challenges for physicians, nurses, and other health care professionals. Offline providers, for example, may find that they spend a great deal of time explaining information that patients have found on the Web. Or that their practices must change to accommodate new forms of electronic record keeping, communication, and information sharing — with patients, insurance plans, other caregivers, laboratories, and others. Moreover, emerging technologies that enable providers to give personal medical care or advice online raise a further set of challenges. In particular, health care professionals who practice on the Internet must help consumers understand the limitations of online healthcare (Crigger 2001).

In eHealth, there are a lot questionable practices by health care professionals and those that engage in eHealth products. In the virtual it's difficult to verify who is a real physician or healthcare professional and also to verify the quality and safety of products customers purchase online to improve their health. The laws across international boundaries apply differently and therefore put customers at a cross when legal issues occur in eHealth processes. There is no established international protocol yet in the virtual world to protect consumers and also to hold responsible those engage in unethical activities though great effort has been made to improve things.

The public consultation commissioned by the EU Member states in 2009 was launched on 31 March 2011 and closed on 30 May 2011 with the following objectives: Increase awareness of the benefits and opportunities of eHealth, and empower citizens, patients and healthcare professionals. Address issues currently impeding eHealth interoperability and to improve legal certainty for eHealth. EC should encourage professional associations, scientific societies and, civil society representatives to promote best practices through the development of guidelines and/or codes of conduct for eHealth services; these includes issues of data protection, cross-border data transfer, and provider liability and ethics issues (EC Report on eHealth Action Plan 2012-2020).

2.1. eHealth

"E-health is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (Eysenbach 2001, adapted by Pagliari et al 2005).

Though current technological developments are essentially limited to developed countries, e-Health is now a global topic. It was discussed at the United Nations World Summit on the Information Society in December 2003 and at the World Health Assembly in May 2005. The World Health Organization has established various eHealth initiatives, such as the WHO Global Observatory for eHealth (GOe) in 2005 which aims "to provide Member States with strategic information and guidance on effective practices, policies and standards in eHealth" (Silber 2003).

The World Summit on the Information Society (WSIS), held with the participation of 175 countries (second phase, 16-18 November 2005, Tunis), affirmed its commitment to

"improving access to the world's health knowledge and telemedicine services, in particular in areas such as global cooperation in emergency response, access to and networking among health professionals to help improve quality of life and environmental conditions". In Europe, e-Health forms a major part of the European Commission eEurope action plan.

The EU has set out ambitious plans for its member states envisaging the definition of health data interoperability standards by the end of 2006, the implementation of health information networks by 2008 and "online services such as teleconsultation (second medical opinion), e-prescription, e-referral, telemonitoring and telecare" by the end of 2008 (Silber 2003).

The public consultation commissioned by the EU Member states in 2009 was launched on 31 March 2011 and closed on 30 May 2011 with the following objectives

- Increase awareness of the benefits and opportunities of eHealth, and empower citizens, patients and healthcare professionals.
- Address issues currently impeding eHealth interoperability
- Improve legal certainty for eHealth
- Support research and innovation in eHealth and development of a competitive European market (EC Report on eHealth Action Plan 2012-2020).

239 participants contributed to the consultation representing different stakeholders including non-governmental organisations, academia, enterprises, health and social care providers and public authorities from many Member States. Regarding specific actions for every objective, the majority of respondents believed that the main instrument to increase patients' awareness and trust on eHealth is the information campaign.

Regarding legal issues, most of the participants thought encouraging professional associations, scientific societies and civil society representatives to promote the best practices through the development of guidelines and/or codes of conduct for eHealth services is an important action for the EC. Data protection and liability are the areas to focus on. Some respondents considered that most of the barriers are interconnected, i.e. the lack of patients' awareness would be interconnected with the lack of users' involvement in the research process (EC Report on eHealth Action Plan 2012-2020).

It is worth noting that security and safety guarantees will reassure citizens and encourage greater participation. Also providing a legal frame-work for eHealth is a good way to secure its use and adoption. eHealth services should meet the needs of patients. Educating policy makers and healthcare managers to become informed decision makers on eHealth problems and solutions and involving health care stakeholders in multidisciplinary projects are considered possible ways of addressing barriers.

73.8% of the participants thought it important that the EC should encourage professional associations, scientific societies and, civil society representatives to promote best practices through the development of guidelines and/or codes of conduct for eHealth services; these includes issues of data protection, cross-border data transfer, and provider liability and ethics issues (EC Report on eHealth Action Plan 2012-2020).

2.2. Ethical Issues

Health care professionals are special status professionals. There are no other endeavors on earth in which people in their most vulnerable physical, emotional, spiritual and mental state place their lives in the hands of others. Caring for others is a sacred calling and health professionals owe their highest duty to patients under their care and must be of high moral standing (Ron 1998).

The base for ethical conduct is Morals which refers to beliefs, principles and values about what is right and what is wrong. Morals can be grounded in religion or philosophic theories about right and wrong. Morals can also be cultured based and cultured driven. It is worth highlighting that there are only a few universal or near universal morals including prohibition against murder, rape, incest. People and cultures are different therefore variety in the perception of morals (Ron 1998).

Basic concepts of ethics include "Morality" which is an individual's personal conceptions of good and bad, right and wrong. "Ethics" a self-chosen morality and individual is conscious of and is committed to follow, a reflected systematic conceptualization of the good and right. "Professional ethics" which is the shared reflected viewpoint on ethical issues among the professionals, often expressed through ethical codes of profession. "Value" a preference, an aim or priority, general conception of belief about good. "Norm" tells what to do in a practical situation. (Juujärvi 2013)

The biggest concern at the general level is the erosion of the code of ethics in Healthcare as well as Social Welfare by the ensuing economic woes and the extensive use of Information and Communication Technology (ICT). People's right to self-determination and other values are being compromised to save cost. Especially in the Healthcare sector, ICT is vigorously introduced to cope with rising cost of care and as such fundamental values are at stake in creating conditions for trust in the health Internet: candor and honesty; quality of information, products, and services; respect for individuals' right to give informed consent; and respect for privacy and protection of confidential information. The principles identify as well the essential features of good professional and business practices that instantiate those values (Crigger 2001).

Communication across national borders is a commonplace today, principally thanks to information and communication technologies. The movements of goods, services, capital and labour are now deregulated, and this is reflected in the social welfare and health care sector in many ways. Indeed, services may now be sought in another country, and this may give rise to tricky questions of interpretation: How should ethical guidelines be applied when the two countries involved apply different principles?

To understand the importance of ethics, one should first of all understand what it is not. It is not a single bundle of knowledge of what is wrong or right because the world is more intricate and ambiguous. The purpose of ethical reflection is to help answer questions on how to act; therefore the scope of ethical concern is infinitely varied. Ethics in general sense refers to the deliberation about how best to conduct one's self generally (Seedhouse 2009).

It is also worth highlighting that moral persons acknowledges the fact that rules and principles are necessary and often conflicting; therefore edicts and principles should be contextual with the range of alternative actions made apparent and their pros and cons assessed (Seedhouse 2009).

The e-Health Code of Ethics is an important part of the effort to make it possible for the Internet to realize its potential to enhance people's health status and well-being worldwide. The goal of the code of ethics is to help create a trustworthy environment for all users, whether they are patients, health care professionals, website sponsors, people who develop health applications and content for the Web or individuals who turn to the Internet to help them stay well (Crigger 2001).

First and foremost, taken together the principles of the e-Health Code identify the fundamental values at stake in creating conditions for trust in the health Internet: candor and honesty; quality of information, products, and services; respect for individuals' right to give informed consent; and respect for privacy and protection of confidential information. The principles identify as well the essential features of good professional and business practices that instantiate those values (Crigger 2001).

Everyone has the right to receive the treatment and services they need. The core principles of treatment and services include doing good and not doing harm. Engaging in activities that support the needs, expectations and goals of the human individual in need of care and treatment: provide reliable and safe care, actions based on evidence based knowledge and show professionalism. Ensure that action taken must be such that its benefits outweigh its disadvantages; services are provided fairly and equally to everyone on the same principles. The treatment and services must be of good quality and available to all. Good treatment and

services include treating clients and patients as humans and as individuals; tolerance; a comprehensive consideration of the health and wellbeing of clients and patients; and taking into account their linguistic and religious or ethical background. (Ethical grounds for the social and health care field, 2011)

The goal of the "e-Health Code of Ethics" is to ensure that all people worldwide can confidently and without risk, realize the full benefits of the Internet to improve their health (Mack 2000).

3. Purpose and Research questions

"eHealth 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. EHealth involves new forms of patient-physician interaction and poses new challenges and threats to ethical issues such as online professional practice, informed consent, privacy and equity (Eysenbach 2001).

 The purpose of this study is to establish what code of ethics is considered in the development and implementation of eHealth services and how it is enforced.

3.1. Research Questions

- What code of ethics is being considered in the development and implementation of eHealth services?
- How is the code of ethics enforced in the development and implementation of eHealth services?

4. Methodology

Research is a systematic inquiry that uses discipline methods to answer questions and solve problems with the ultimate goal to develop, refine and expand a body of knowledge. Nursing research is a systematic inquiry designed to develop trustworthy evidence about issues of importance to the nursing profession (Polit & Beck 2008).

Paradigms for nursing research include positivist or logical positivism and Naturalistic or constructivist. Positivism is a reflection or broader cultural/natural phenomenon that emphasizes the rational and scientific. Positivist paradigm believes that reality exist independent of human observation that can be studied and known. Post positivism paradigm

that emerged from strict positivism see objectivity as a goal and strive to be as neutral as possible and more widely used research method in nursing research (Polit & Beck 2008).

According to the naturalistic paradigm, reality is not a fixed entity but rather a construction of the participants in the research; reality exists within a context and many constructions are possible. The interpretations of those under study and subjective interactions between the inquirer and the participants are crucial in understanding the phenomenon (Polit & Beck 2008).

It is difficult to define precisely qualitative methodology which is considered outside of the traditional scientific approach. However, (Parahoo, 2006) argues that, this type of research involves a phenomenological perspective whereby researchers aim to understand report and evaluate the meaning of events for people in particular situations, that is, how their social world is structured by the participants in it. The focus of qualitative methodologies is the way in which participants (rather than the researcher) interpret their experiences and construct reality. Some examples are an unstructured interview, focus group, open-ended questionnaire and participant observation (Risjord et al 2001).

Qualitative research is characterized by its aims which relate to understanding some aspect of social life, and its methods which (in general) generate words, rather than numbers, as data for analysis. Qualitative methods generally aim to understand the experiences and attitudes of people and the community. These methods aim to answer questions about the 'what, how or why of a phenomenon rather than 'how many or how much which are answered by quantitative method (Patton & Cochran 2000).

Phenomenology as an approach, intends to explore in depth of peoples' experiences of a phenomenon; the phenomenon is explored, described, communicated and possibly interpreted. In this research the phenomenon is what and how code of ethics is being considered in the development and implementation of eHealth services (Grbich 2013).

The participants included a representative of the City of Espoo who has very rich background in eHealth activities and has been a board member of the ethics committee of the city of Espoo for many years. The second participant a representative of Laurea University of Applied Sciences also have a background in International law, long experience in leadership as well as eHealth activities. This participant has also been collaborating with a lot of local and international partners on eHealth activities. The third participant representing ICT developers and entrepreneurs from Medixine have been in the business for over a decade and have a very deep understanding of the phenomenon working with other partners as well as consumers of eHealth services.

The researcher in collaboration with the participants find out what and how code of ethics has been considered in the development and implementation of eHealth services. Participants will include service providers like Espoo city, entrepreneurs, Educators and ICT developers. The researcher will use interviews to collect data and based on analysis of data collected, recommendations will be made on ethical considerations in the development and implementation of eHealth services.

In this study, semi-structured interview was used for data collection. This involves the researcher and the interviewee in a one-to-one situation and may take at least 1,5hours. The interviewees will be chosen based on their eHealth related activities and relevance to the purpose of the research. The researcher interviewed three participants at different times using the same research question. The data was transcribed, reviewed and then analyzed using deductive content analysis.

4.1. Data Collection

Three major data collection methods have been used most frequently in nursing research. Self-reports in which participants respond to questions posed by researcher as in interviews, Observations of people's behaviors, characteristics and circumstances, and Bio-physiologic measures to assess important clinical variables (Polit & Beck 2008).

Furthermore, qualitative research or more specifically nursing research have implored three traditional approaches namely "Ethnography" research which is primarily observation and interviews, plus artifacts, documents, photographs mainly in a cultural system or context. The second approach implored is "Phenomenology" which is primarily in-depth interviews, sometimes diaries and other written materials with main unit of data collection individuals. The third approach implore is "Grounded Theory" which is primarily individual interviews, sometimes group interviews, observations, participants diaries, documents. Main unit of data collection is also individuals. Nowadays, Action research is gaining momentum and is widely used is social research (Polit & Beck 2008).

Qualitative self-reports usually obtained through interviews tend to be conversational. In unstructured interviews, respondents are encouraged to define the important issues of the phenomenon and to elaborate on what is relevant to them and not guided by the researcher. In semi-structured interviews, the researcher has a list questions that must be addressed, encourages the participants to talk freely about all the topics; the researcher guides the process and ensure that all the questions are covered in the process (Polit & Beck 2008).

In this study, qualitative research method has been used in which semi-structure interviews is used as a method of data collection in which there were lists of broad questions that were answered or addressed by participants. Inform consent and sample questions were sent to participants beforehand to prepare for the interviews. The participants were encouraged and guided to talk freely on the topic in question. Interview time was one session of about 1-1.5/h. and place of participants' convenience. The whole session was audio recorded. There were three participants involved including service providers like Espoo city, entrepreneurs and ICT developers from Medixine, Educators from Laurea University of Applied Sciences

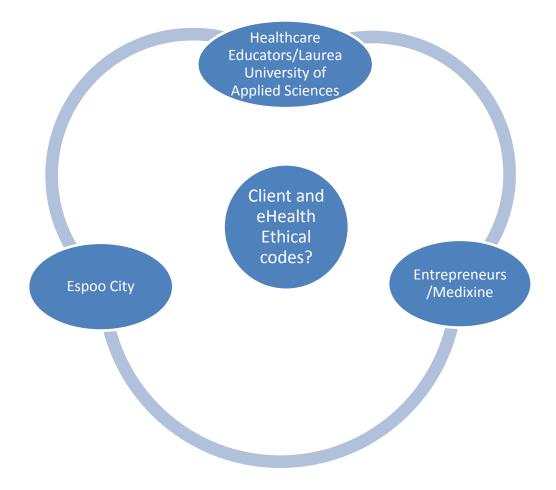


Figure 2. Actors in eHealth services in the study

The above figure is a representation of the actors in eHealth services from which the participants involved in this research are representing. The above mentioned actors if not always, often collaborate in the development and implementation of eHealth services. The new comers in the domain of health raise ethical questions or are faced with ethical dilemmas. As shown in the figure, the client is at the center of eHealth activities and reason why ethical codes are very relevant to guarantee Safety, security respect, good quality and good professionalism or practices.

4.2. Data Analysis

There are two much used but distinctively different types of empirical materials in qualitative research namely interviews and naturally occurring materials. Interviews consist of accounts given to the researcher about the phenomenon in question. By using interviews, the researcher can reach areas of reality that would otherwise remain inaccessible such as subjective experiences and attitudes (Denzin & Lincoln 2011)

Qualitative data are derived from narratives such as transcriptions from interviews, participant observer notes or personal diaries (Denis & Cheryl, 2008). In this research as mentioned above, data will be derived from transcripts from interviews and analyzed using deductive content analyses.

Morse and Field (1995) noted that, qualitative analysis is a process of fitting data together, making the invisible obvious, of linking and attributing consequences to antecedents. It is also a process of conjuncture and verification, of correction and modification, of suggestion and defence (Polit & Beck 2008).

In this study, deductive content analysis method was used to organize, provide structure and elicit meaning from the data. According to Crabtree and Miller (1999), thematic analysis method search for meaningful segments and units; segments were used to develop a category scheme and corresponding codes that was used to sort and organise the data. The researcher also seeks to establish interconnections between the categories (Polit & Beck 2008).

Themes have often been referred to as: groupings, outcomes of coding/conceptualizing, abstract construct, and analytic patterns. Gery Ryan and Russell Bernard (2003) have detailed the potential sources of themes as: repetition= themes, indigenous typologies = meaningful terms from data, Metaphors; KWIC - key words in context, comparison, and contextual explanations (Grbich 2013).

Themes were derived from the literature and earlier studies; themes that reflected ethics in eHealth such as Privacy, security, respect, good professionalism, and quality service. Collected data was analysed based on the mentioned themes and result serve as answer to the research questions.

According to (Lester 1999), the 'problem' for many researchers with phenomenological research is that it generates a large quantity of interview notes, tape recordings, jottings or other records all of which have to be analysed. Analysis is also necessarily messy, as data doesn't tend to fall into neat categories and there can be many ways of linking between different parts of discussions or observations.

The researcher listened to the recorded interviews and read through interview transcripts carefully; identifying key themes and issues in each text. The resulting list is used as a set of points to interrogate the texts and structure and summarise them ("what is this participant saying about:"). The themes reflected what ethical codes are used in eHealth processes and also themes that reflect how these ethical codes are enforced or implemented.

After reading and rereading the recorded interview, the important section that was relevant to the research was coded into two main categories which answered the research questions. The first category was those that answered what ethical codes are considered in the development and implementation of eHealth services and the second category addresses the issue of how these codes are enforced in these eHealth processes. The participants in the research were codes as, P1 representing the educators, P2 representing the city of Espoo and P3 the entrepreneurs. Key phrases and words were identified as expressed by the different participants on the phenomenon in question. These key phrases and key words were further grouped under different themes related to eHealth code of ethics.

Key themes related to ethical codes where derived from the literature namely Security, Privacy, Respect, good quality service, and good professionalism. These themes are very crucial issues in ethical codes irrespective of the profession and constitute most of the ethical dilemmas in eHealth services. The coded data was then assigned under the different themes as indicated in figure 4 and figure 5 below. Most of the safety protocols used in eHealth services as described by the participants is to ensure security and privacy as enlisted in figure 4. The implementation and enforcement of these protocols are ensured by different enforcement committees, legislation and other methods as indicated in figure 5.

Interviews were audio taped

Data transcription (data written into word document)



Data enterogated and coded according to research questions

Themes were identified from literature



Coded data was assigned under the different themes

Results discussed and recommendations made

Figure 3. Data analysis process

5. Findings

The purpose of this study was to establish what code of ethics is considered in the development and implementation of eHealth services and how it is enforced. Based on the interviews conducted, and the analysis made, the findings showed that ethical codes or protocols have been used in the development and implementation of eHealth services as reflected in figure 4. The educators and Espoo city as collaborators in eHealth initiatives referred to secured platforms such as TALTIONI, SITRA a social insurance fund for the support of security and safety issues in eHealth and also the use of VETUMA in eHealth processes to ensure privacy and security. Legislation (Data protection Law) was also highlighted by all participants as a tool to ensure both safety and security.

On the other hand, the entrepreneurs use these secured platforms as well but in addition they use other internal protocols like CE safety standards, ISO 901, External inspectors, certificate 13485 to ensure safety and security. The entrepreneurs often deal directly with the customers not necessarily through secured platforms and therefore needs some form of internal protection systems on like the city of Espoo and Educators who uses mostly secured platforms for eHealth activities. Also Entrepreneurs in eHealth activities form regional consortiums where common standards are forged to improve safety and security and also to improve interoperability and legal certainty for eHealth in eHealth activities. R&D processes within the organisations of the key players in eHealth activities puts the current safety and security codes under scrutiny to make sure they are updated progressively

On the issue of enforcement of these different protocols not only to ensure safety and security but also to ensure respect for consumers, good quality services and good professionalism, the participants mentioned different ways as indicated in figure 5. Different committees and professional societies exist that overlook the activities of stakeholders in eHealth activities to ensure good practices and respect for legislation. Most of the committees and professional societies are public institutions that work in collaboration with the private sector to enforce legislation and other agreed protocols. Espoo city is one of the major stakeholders and consumers of eHealth services and therefore ensures that other stakeholders respect ethical protocols and legislation, support user-driven activities thereby protecting consumers and ensuring good business practices. The National consumer association in Finland also overlooks bad practices and in collaboration with the police handle ethical issues when they arise in eHealth processes.

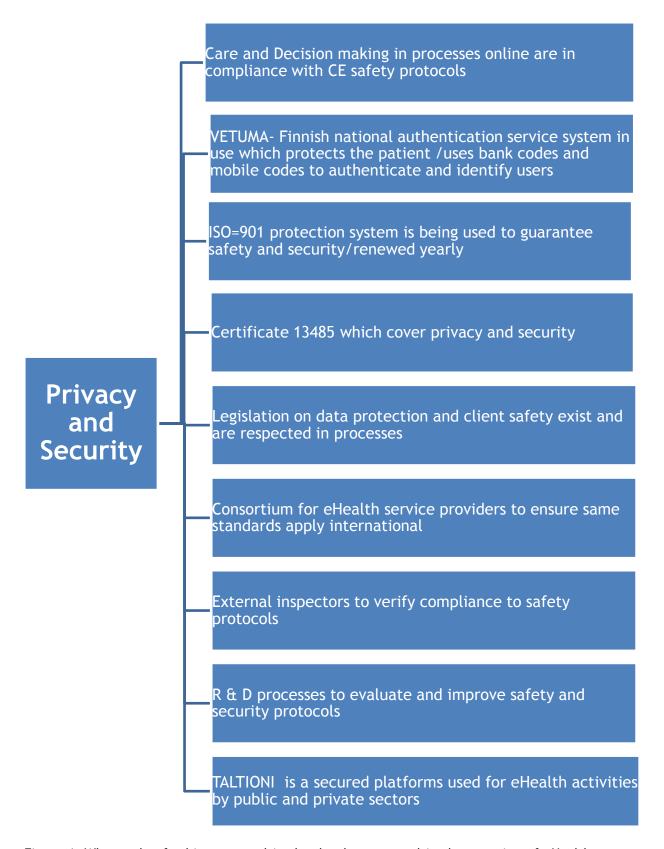


Figure 4. What code of ethics are used in the development and implementation of eHealth services

Social service and health ethical committee/handle complains or dilemmas Medical scientific society /non-commercial; ensures good healthcare practices Espoo City support Customer driven not money driven initiatives that comply with ethical codes Espoo city has the responsibility to overlook eHealth related services /Legislation National consumer association overlooks bad business or behavior Different actors in eHealth services have own ethical committee to enforce good practice In-born and in-build moral standings through own career education Collaborative/multi-disciplinary including health professionals and user driven service approach Police cooperation in case safety and security issues arise IT capacity of patients taken in to consideration in processes/tailor made services Co-working with healthcare professionals in implementation of eHealth services guarantees respect for ethical codes Patient empowerment and self-care No recommendation to clients by Espoo city if eservice does not fulfill safety and privacy standard System configuration to match legislation requirements

Figure 5. How the code of ethics are enforced in the development and implementation of eHealth services

Respect, Service

quality/Trust, Good professionalism,

Inform consent

All the participants acknowledged the ethical worries of consumers of eHealth services considering how difficult it is to control the virtual world. That notwithstanding, major actors in eHealth have put in place measures to ensure privacy, safety, respect, quality services, professionalism and good practices. All participants said "a bad reputation is bad business and no company is willing to risk that". No company can survive without customers and customers make choices based on reputation and trust, and adherence to certain ethical codes or principles. Entrepreneurs have put in place very pro-active methods to deal with privacy and safety issues such as external security and safety inspectors, R&D processes to evaluate and improve security protocols, established certain pathways to deal with ethical issues when they arise. The City of Espoo also has an ethical board whose responsibility is to follow-up and makes sure eHealth activities involving Espoo city are in accordance with ethical protocols and in collaboration with Medical scientific society of Finland which is non-commercial ensures good healthcare practices.

Furthermore, participants also indicated that though new comers into health such as entrepreneurs and ICT developers, most eHealth activities or processes has health professionals involved such Doctors, Nurses, Physiotherapists, Managers who are versed with the healthcare code of ethics. These healthcare professionals overlook and ensure that these processes are in accordance with ethical protocols.

According to participants, there was also a dimension of in-born/natural ethical behavior which implies that people are born and raised to do the right things and to avoid doing harm to other intentionally; it's further re-enforced or developed through career education. Most professionals in the process of their education irrespective of trade have some form of ethical code education to help them make decisions that would not intentionally harm other people and also a way to take responsibility for their actions. This in-born and learned capacity helps actors in eHealth activities make moral decisions and put the best interest of the client first.

EHealth is a global phenomenon and demands global solutions to address issues currently impeding eHealth interoperability and to improve legal certainty for eHealth, data protection and cross-border data transfer. Considering that this a relatively new phenomenon, differences in laws and cultures, the participants in this study agreed that there is no international binding protocol or code of ethics covering eHealth activities but great effort is being made to establish some kind of working document at the level of the WHO as well as EU. Local governments have very limited control over cross-border eHealth activities and therefore consumers are exposed to different kinds of risks which could be safety, privacy, bad quality services and products as well as deceit.

6. Discussion

EHealth involves new forms of patient-physician interaction as opposed to the traditional face to face contact and poses new challenges and threats to ethical issues; Fundamental values at stake in eHealth include: candour and honesty, quality of products, services and information, respect for individuals, right to give informed consent, privacy and confidentiality. Also at stake is good professionalism and good business practice. The purpose of this study was to establish what kind of ethical codes are being considered in the development and implementation of eHealth services and how thesis ethical codes are enforced. Some of the major actors in eHealth activities where interviewed and data analyzed by deductive content analysis.

This study has not only proven that ethical codes are considered in the development and implementation of eHealth services and that a lot of effort is being made both by the public and private sector to improve on the ethical dilemmas involved in eHealth but has also proven how little society understands the phenomenon. "We are only beginning to develop a clear, shared understanding of how to participate in the virtual environment of the health Internet and only beginning to think carefully about what opportunities we can take advantage of and what opportunities may be technically possible but are ones that we should not pursue in the new world of eHealth" (Crigger 2001).

It has also been proven through this study that there is a public reluctance to take advantage of the opportunities provided by this new trend to improve upon their health due to the ethical dilemmas or issues like safety, privacy, quality, good professionalism or questionable practices, compatibility and legal issues across boarders and also because they are not aware of the safety protocols in place. Customer choice and participation in eHealth activities is influenced greatly by the above mentioned values. Consumers of eHealth services tend to look at the pros and cons of consuming eHealth services and research have shown that a large percentage is not willing to sacrifice privacy and safety for easier and faster accessibility to eHealth services (Mack 2000).

Considering the importance of eHealth and the many benefits to society, it has been a subject of discussion at the macro and micro level of society by different regional and international organizations and also governments to find ways to address the ethical issues to enhance the use of eHealth. In May 2005, the World Health Assembly in their 58th meeting adopted a resolution on eHealth focused on the use of ICT and its implication on health security, health services delivery and the transformation of health systems worldwide.

In the 66th World Health Assembly, it was also established that the global nature of the internet makes difficult for national laws to be enforced; it was also recognized that it is essential to ensure secure online management of health data and to increase trust in eHealth tools and health services as a whole. The importance of eHealth and the relevance to address ethical issues is very much discussed in the EC Report on eHealth Action Plan 2012-2020.

Major stakeholders in eHealth activities who were participants in this research don't only realize the importance and urgency to provide the right environment for society to take advantage of eHealth to improve their health but also recognizes the consequences if nothing is done. The resources have been depleted and there is an aging population which puts more constrains on the already ineffective status quo making eHealth a viable alternative. Ethical issues are a very complex phenomenon as one participant puts it "there is no silver bullet to address ethical issues in eHealth" but tremendous effort is being made both at the macro level and micro level to address them as indicated in figure 4 and 5.

As one participant said, "In the virtual world there is no such thing as 100% safety and security, the ethical codes only helps to reduce the risk considerably and make people accountable for their actions. One participant also said "it is the moral responsibility of the state to provide health care to society and will be even more ethically wrong to sit and do nothing to the present inefficient system and let it grind to a halt where people are left without services".

It's imperative that society be involved as much as possible in this new trend of healthcare and also be well informed on the security measures in place to guarantee a safe use in order to build public confidence and trust. Consumers need to be educated on how to "filter" information, i.e. how to discriminate trustworthy information from less trustworthy information. The second pillar is self-rating of information providers, i.e. publishing of meta-information, which allows users to locate and filter information automatically; however without third-party evaluation and enforcement this ethical code is a toothless tiger (Doyle, Miller, & Mirza 2000).

It is worth noting that security and safety guarantees will reassure citizens and encourage greater participation. Also providing a legal frame-work for eHealth is a good way to secure its use and adoption. EHealth services should meet the needs of patients. Educating policy makers and healthcare managers to become informed decision makers on eHealth problems and solutions and involving healthcare stakeholders in multidisciplinary projects are considered possible ways of addressing barriers.

6.1. Ethical Considerations

The difficulties inherent in qualitative research can be alleviated by awareness and use of well-established ethical principles, specifically autonomy, beneficence, and justice. It's also worth mentioning that ethical issues are present in any kind of research. Ethics is about doing good and avoiding harm. Harm can be prevented or reduced through the application of appropriate ethical principles; thereby protecting participants. Ethics in health research includes appropriateness of the research design, the methodological design as well as behaviors in reporting data (Orb, Eisenhauer, & Wynaden 2001).

In qualitative studies, researchers rely heavily on collecting data through interviews, observations, written materials, and audiovisual material. Unanticipated Ethical dilemmas most often occur during the early stages of data collection and continue with analysis, interpretation and publication of results. When preparing research protocols, researchers should consider the potential ethical issues that can be anticipated in the study, such as informed consent, confidentiality, data generation and analysis, researcher/participant relationships, and reporting of final outcomes (Orb, Eisenhauer, & Wynaden 2001).

The purpose of qualitative studies is to describe a phenomenon from the participants' points of view through interviews and observations. The intention of the researcher is to listen to the voice of participants or observe them in their natural environments. A balanced research relationship will encourage disclosure, trust, and awareness of potential ethical issues. An interview is usually equated with confidentiality, informed consent, and privacy, but also by recurrence of "old wounds" and sharing of secrets (Doyle, Miller, & Mirza 2001).

There are a diverse range of research methods and research contexts potentially available and each carries its own specific ethical considerations, which makes it difficult to provide one global set of ethical issues. It would be impossible to construct a composite list of all potential problems. There are broad ethical areas that need to be considered in a research such as voluntary participation, informed consent, confidentiality and anonymity, the potential for harm (Smith and Quelch 1992).

Taking into consideration ethical issues, participants in this study were well informed of the purpose of the study, procedures, and right to participate voluntarily. It also allows the individual to terminate participation without penalty or loss of benefits if any. Ethical standards require non-maleficence whose principle is that researchers not put participants in a situation where they might be at risk of harm as a result of their participation. Overseeing the potential consequences of revealing participants' identities is a moral obligation; pseudonyms will be used to guarantee anonymity. Another ethical standard that is applied in order to help protect the privacy of research participants is confidentiality. This essentially means that the participant will remain anonymous throughout the study i.e. data collection, analysis and publication of report (Katherine 2008).

In this study, the participants were well informed of the purpose of the study, procedures, and right to participate voluntarily. Participants consented to participate by signing a consent form beforehand, the contents and the forum where the interviews took place in no way put the participants at risk be it emotional, psychological or physical; the forum for the interview was unanimously agreed between researcher and interviewee. They were assured that identifying information will not be made available to anyone who is not directly involved in the study such as audio tapes made during the interviews as well as their identities.

6.2. Validity

Without rigor, research is worthless, becomes fiction, and loses its utility. Therefore a lot of importance is given to reliability and validity in all research methods. A number of leading qualitative researchers argued that reliability and validity were terms pertaining to the quantitative paradigm and not considered important to not to qualitative inquiry (Altheide & Johnson, 1998; Leininger, 1994). Validity, as any other concept in the social sciences, is a contested term; it means different things to different observers and there is more than one type of validity. According to (Lincoln & Guba, 1985) validity and trustworthiness comprises of four aspects: credibility, transferability, dependability, and confirmability; (Morse, Barrett, Mayan, Olson, & Spiers 2002).

According to (Hammersley, 1992; Kuzel & Engel, 2001; Yin, 1994), the broad and abstract concepts of reliability and validity can be applied to all research because the goal of finding plausible and credible outcome explanations is central to all research (Morse, Barrett, Mayan, Olson, & Spiers 2002).

In qualitative content analysis, validity and trustworthiness must be considered. The results will be congruent with data; findings must be presented openly and honestly (Beauchamp and Childress 1994).

According to (Talbot 1995), the concept of trustworthiness in qualitative research includes credibility, transferability, dependability and conformability. The participants in this research were carefully chosen such that they have a long experience in the phenomenon in question i.e. eHealth activities which ensure credibility because data collected can be trusted. Semi structured interview as a method of data collection in this study also gave the participants the opportunity to talk freely and broadly ensuring that the phenomenon in question is fully examined.

The method used in this study conforms to research standards and procedures; the research purpose was clearly defined, research questions congruent with the purpose and topic, participants were carefully chosen such that they had long experience in eHealth activities and are major actors in the development and implementation of eHealth services.

Inform consent and sample questions were sent to participants beforehand to prepare for the interviews; that gave them time to reflect on the phenomenon in questions and put their thoughts together. The researcher has clearly presented the steps in the analysis process making the process dependable and transferable. The findings and conclusions and recommendations are supported by data.

6.3. Recommendations

Education of consumers on the importance of eHealth and also on the security and safety guarantees that are in place very crucial to establish confidence and trust. During the study, all participants acknowledged the fact that there is very little effort made to inform the public about the phenomenon in question and about the ethical codes that are in place to ensure safety and privacy. Educate new comers into health on the ethical code in healthcare through seminars or working groups and how it should be incorporated in their processes. Legislation is slower than eHealth development and as such, a cross section of the population can't take advantage of the opportunities of eHealth to improve their health. Legislation on minors does not consider how they can participate and take advantage of eHealth because they need consent from parents/ big percentage of society are <18 and therefore left out. Educational institutions should lead the way in encouraging society participation by encouraging students to research on this very important phenomenon. Find out people's concerns and seek solutions that will encourage them to participate and trust more the system. Enforcement requires feedback channels for worried consumers, procedures for evaluating complaints, and the possibility of appropriate measures such as labeling (blacklisting) of information providers who, for example, seriously violate ethical or legal standards; which may lead to the re-evaluation of a site and retraction of a rating/certification.

References

- Abu T. M., Tavallaei M., 2010. A general perspective on Role of theory in Qualitative Research. The journal of international Social Research Vol 3/11
- Basic Concepts in Medical Ethics, Society, the Individual and Medicine.
 Updated March 14, 2012
 www.med.uottawa.ca/sim/data/Ethics_e.htm
- Bekhert A. K., Zauszniewski J. A., 2012. Methodological triangulation: an approach to understanding data. Nurse Reseacher. 20, 2, 40-43.
- Beuchamp T. & Childress J., 1994: Principles of biomedical ethics. 4th edition. London, Oxford University press.
- Clissett P., 2008. Journal of orthopedic Nursing, 99-105. Continuing professional Education. Evaluating qualitative research.
- Coughlan P., & Coghlan D., International Journal of operations and Production Management. AR for operations management.
- Crigger B-J., 2006. The Hastings Center Foundations of the <u>eHealth Code of</u> Ethics
- Crigger B-J., 2001. Foundations of the e-health Code of Ethics
- Creswell J. W. & Plano Clark V. L., 2007. Designing and Conducting Mixed Methods Research.
- Denzin N. K., Lincoln Y. S., 2011; Collecting and Interpreting Qualitative Materials, 4th Edition.
- Doyle O. Z., Miller S. E., Mirza F. Y., 2009. Journal of Social Work Values and Ethics, Volume 6, Number 1 (2009) Ethical Decision-Making in Social Work: Exploring Personal and Professional Values http://www.socialworker.com/jswve/content/view/113/67/
- Ethical grounds for the social and health care field, 2008-2011.
 http://www.etene.fi/c/document_library/get_file?folderId=190083&name=DLFE-3107.pdf
- European Commission eHealth Action Plan 2012-2020 public consultation results report
- Eysenbach G., 2001. What is e-health? J Med Internet Res; 3(2):e20 Gabel D., 1995., an Introduction to AR
- Grbich C., 2013. Qualitative Data Analysis, an Introduction. 2nd Edition.

- Eysenbach G., 2000. Journal of Medical Internet Research; Towards ethical guidelines for e-health: JMIR Theme Issue on eHealth Ethics. Jan-Mar; 2(1): e7. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1761845/
- Huxham C., 2003. AR as a methodology for theory development, polices and politics vol. 31
- Juujärvi S., 2013. Theories of ethics, Health care and welfare ethics https://optima.discendum.com/learning/id74/bin/user?rand=2144
- Lester, S (1999) 'An introduction to phenomenological research,' Taunton UK, Stan Lester Developments (www.sld.demon.co.uk/resmethy.pdf, accessed [8.10.13])
- Mack J., 2000. Ethical Issues for Internet Healthcare: The eHealth Code of Ethics. The First National HIPAA Summit, October 15-17, 2000
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002).
 Verificationstrategies for establishing reliability and validity in qualitative research. International Journal of Qualitative Methods 1 (2), Article 2. 28.10.13, from http://www.ualberta.ca/~ijqm/
- Nutbeam D., 2006, Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century.
- Omachonu v. k., & Einspruch N. G., 2010. Innovation in Healthcare Delivery Systems - A conceptual Framework The innovation journal: The public sector innovation journal, vol. 15(1), Article 2
- Orb A., Eisenhauer L., Wynaden D., 2001. Journal of Nursing Scholarship First Quarter 2001
- Patton M. Q., & Cochran M., 2002; A Guide to Using Qualitative Research Methodology http://fieldresearch.msf.org/msf/bitstream/10144/84230/1/Qualitative%20research%20methodology.pdf
- Polit D. F., Beck C. T., 2008. Essentials of Nursing Research, Appraising Evidence for Nursing Practice. 7th Edition
- Reason P., & Bradbury H., The Sage Handbook of Action Research, Participative inquiry and Practice 2nd Edition
- Ron W. S., 1998. Professional Ethics: A guide for Rehabilitation Professionals
- Seedhouse D., 2009. Ethics the Heart of Health Care. 3rd Edition
- Smith, N. C., & Quelch J. A., 1992. Ethics in Marketing. Homewood, IL: Irwin

- Stroetmann K. A., Tom J., Dobrev A., Stroetmann V. N., 2006; the economic benefits of implemented e-health solutions at ten EU sites www.ehealth-impact.org
- Talbot L., 1995. Principles and practices of nursing research. Mosby St Louis.
- Whitehead J., AR (2009; 7; 85) Generating living theory and understanding in AR studies http://arj.sagepub.com/cgi/content/abstract/7/1/85
- WHO, eHealth and health Internet domain names, 66th World Health Assembly 14th May 2013
 www.who.int/ehealth/programmes/governance/en/
- WHO | E-Health World Health Organization
 http://www.who.int/trade/glossary/story021/en/index.html

Figures

Figure 1. Four Pillars of quality management of health information on the web (Gunther, 2000)
Figure 2. Actors in eHealth services in the study2
Figure 3. Data analysis process
Figure 4. What code of ethics are used in the development and implementation of eHealt services
Figure 5. How the code of ethics are enforced in the development and implementation of eHealth services

Appendix

Appendix 1. Consent letter

CONSENT LETTER

29/4/2013

Dear Mr/Mrs/Miss

My name is Paul Nji Tamankag, a graduate student in Laurea University of Applied Sciences, Otaniemi. I am studying health promotion and interested in eHealth. I am conducting a research as part of my thesis work.

• The purpose of this research is to establish what and how code of ethics is considered in the development and implemented of eHealth services.

You are being asked to participate in this research study, if you agree please kindly fill in the Background information form attached below and return it to me via my email.

It is possible that some of the questions may make you feel uncomfortable, but you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded and kept in locked files at all times. Only study personnel will have access to the files. Individual results will not be shared with personnel of your company.

While there will be no direct benefit to you from participating in this study, the anticipated benefit of this study is a better understanding if and how code of ethics is considered in the development and implementation of eHealth services.

There will be no costs to you as a result of taking part in this study, nor will you be reimbursed for your participation in this study.

If you have questions about the research, you may contact me at +358409608224. If you have further questions about the study, you may contact Laurea University of Applied Sciences, which is concerned with protection of volunteers in research projects. You may reach the Laurea University of Applied Science at +358400541479.

Participation in this research is voluntary. You are free to decline to be in this study, or to withdraw from it at any point.

Interview time will be one session of about 1-1.5/h. and place will be any place of your convenience. The whole session will be audio recorded. Below are sample questions just to give an idea of the nature of the interview. Thank you for your attention.

Sincerely,
Paul Tamankag
Masters Student
Laurea University of Applied Sciences

Sample questions

- Do you consider code of ethics in the development and implementation of eHealth services?
- How is code of ethics enforced in the development and implementation of eHealth services in your organization?
- What are the ethical principles relevant to eHealth?
- How should healthcare organizations develop and promote ethical guidelines and codes of conduct for websites and electronic patient information?

I have read the above information and give my consent to participate in the research.

Signature				
Names				
Email				
Telephone				
Position in organisation/Company				
Other Information				