Research Ethics in Health Informatics – Why Bother?

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Abstract

Research ethics is an obvious part of every researcher's life. For some areas like health informatics, the multi- and interdisciplinarity of the field make it necessary to pay attention to ethical guidelines, acts/laws, and principles from medicine, health science, science, technology, social sciences and humanities.

If you know where to look and what to look for, it is easy to find relevant information about research ethics. However, studies have indicated that we cannot take this knowledge for granted. If you do clinical trials in Norway, you have to apply to the Regional Committees for Medical and Health Research Ethics (REC) for approval. If you do studies with patients that do not imply any treatment or improvement of medical procedures, i.e., are not covered by the Health Research Act, you need to contact the "personvernombudet" (patient data protection ombudsman) to get approval for involving patients in your study. But for many research projects in health informatics, these kinds of approvals are not necessary. Some PhD students take part in large project with an existing approval by REC. This means that they probably have not been involved in writing the research protocol and applying for REC approval. As a consequence, the do not know this process very well nor the implications of this process.

For most researchers, ethical guidelines are not something they have good knowledge of. A small inquiry among PhD students in science and technology at the University of Tromsø – The Arctic University of Norway showed that ethical guidelines were vaguely known. This paper gives an overview of what kind of ethical guidelines, acts and ethical principles a researcher in a multi- and interdisciplinary field as health informatics needs to know and pay attention to. Norwegian laws and regulations ae used to illustrate what kind of information that is needed.

Keywords:

Ethical guidelines, research ethics, health informatics.

Introduction

Health Informatics is *"the interdisciplinary study of the design, development, adoption and application of IT-based innovations in healthcare services delivery, management and planning"* [1]. The multi- and interdisciplinarity of health informatics implies that a range of research methods and approaches might need to be applied in order to solve the research problems addressed, which again makes it necessary to pay attention to ethical guidelines, acts/laws, and principles from both medicine and health science, science and technology, and social sciences and humanities.

Researchers in health informatics often have their education and research training from one of these disciplines. E.g., researchers with a background in computer science often lack formal training in medicine, health science, social science and humanities, researchers in medicine are not familiar with experimental research in computer science and technology, etc. Compliance with ethical guidelines for research is an obvious part of doing research in a field. Also, for ethical guidelines, there are differences between the fields. And, as for research training, ethical guidelines vary a lot between different fields. If you do research in, e.g., computer science, it is sufficient to know the content of and follow ethical guidelines for science and technology. The same goes for other disciplines – researchers in that particular area have to adhere to the guidelines for that specific area. But, as indicated above, researchers in health informatics often have to deal with ethical guidelines and principles from many areas.

For many researchers, it is a challenge to know the ethical guidelines for a single area. A few years ago, Hartvigsen [2] conducted a survey among doctoral students at the Faculty of Science and Technology, University of Tromsø – The Arctic University of Norway (UiT). In this study, PhD students where asked whether they knew about ethical guidelines, and if they did, if they could name one of the guidelines. The result was rather discouraging; no one passed the test – the knowledge of research ethics was almost non-existing. The only positive result was that all respondents thought research ethics was important for their research.

But it is perhaps not surprising that Norwegian doctoral students fail to reproduce one of the guidelines: the document that presents the current ethical guidelines in science and technology spans nearly 20 pages [3]. Each of the 24 guidelines is presented with a detailed explanation. Similarly, ethical guidelines for social sciences, humanities, law and theology, consist of 47 different guidelines described in a 40-page document [4]. (Both sets of guidelines will be revised in 2016, but the length will be approximately the same.) These guidelines cover all relevant aspects of research ethics that a

researcher might touch upon during his/her career. Today's guidelines are consequently not designed in such a way that researchers should walk around and remember them, but designed to educate scientists in scientific practice and to be a useful tool for in-depth discussions about research ethics.

In addition to the ethical guidelines, we have a separate law in Norway, the Research Ethics Act [5], which shall, as stated in §1, *"contribute to research in public and private sector made in accordance with recognized ethical standards."* (It is strange that the law does not use the term "ethical norms". The law is also being revised in 2016.)

In medicine and health science, we have a separate law, the Health Research Act [6], which together with a regulation on the organization of medical and health research, regulate research in this area. §1 of the Health Research Act states that: *"The purpose of the Act is to promote good and ethically sound medical and health research."* The Act also regulates medical research involving human subjects related to the Helsinki Declaration [7] prepared by the World Medical Association.

Different research societies have their own ethical norms developed jointly. These can be defined as a research community's generally accepted standards of good research practices. (A discussion of research ethical norms is, e.g., given in [8].) We can say that the national research ethics guidelines represent a summary of ethical norms formed internally in the research community supplemented with norms that occurred in a broader societal context.

In addition to a fairly extensive selection of literature on research ethics available from The National Research Ethics Committees' (FEK) Research Ethics library (FBIB) [9], there is a lot of relevant literature available from other nations and supranational bodies, including the "European Textbook on Ethics in Research", which can be downloaded from the European Commission's Website [10].

As pointed out, for the researcher, there is actually no lack of relevant ethical guidelines. The problem is that ethical guidelines, regulations and acts, are unknown. Or, if the researcher knows about their existence, the knowledge is superfluous. For researchers in health informatics, the situation is even more complex since their research often covers several fields that are regulated with separate ethical guidelines. We cannot assume that we for this group, in particular for researchers in science and technology or social sciences and humanities, will find a much higher percentage of people that know all relevant ethical guidelines.

There are, in general, two different approaches to this problem: (1) Don't bother (we do our research as the rest of the crowd), and (2) please teach me (all what a researcher in health informatics should know about research ethics). (The first alternative cannot be chosen if the project is regulated by the Health Research Act.) For the second alternative, the main question is: *how can we teach our researchers about the existence of ethical guidelines and their content and meaning?*

This paper gives an overview of ethical guidelines, regulations and acts that regulate our research fields. In addition, the paper presents an example of a simple set of ethical guidelines, the ten commandments of research ethics, which can be used when discussing and teaching ethical guidelines in health informatics. The paper is based on the situation in Norway, but most of the paper is relevant for other countries as well. Except for ethical guidelines in medicine, which, by the way, is well regulated internationally and available in may different languages, all Norwegian guidelines and regulations are available in English.

Research Ethics Guidelines Used in Norway

As mentioned above, quite a few research ethics guidelines exist. They vary in length and contents, depending on purpose, field and research society. In this paper, the Norwegian rules and regulations are used to illustrate what is going on in research ethics guidelines.

In Norway, we have three National Research Ethics Committees in: (1) medicine and health science, (2) social science and the humanities, and, (3) science and technology. Below, we summarize the committees' most important guidelines and recommendations for research ethics.

Medical and Health Science Research

The Norwegian National Research Ethics Committee for medical and health research (NEM) deals with ethical questions related to medicine and health science research. Since medical research is concerned with human beings directly of indirectly, and treatment of humans, guidelines for research ethics in medicine and health science research is regulated by quite a few ethical guidelines, regulations and acts.

The primary ethical guidelines relevant to medical and health science research are:

- Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects [7]
- The Vancouver Protocol [11]
- Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. CETS No. 164. Oviedo, 4.IV.1997. [12]

In addition, NEM has published the following relevant documents:

- Guidance for research ethics and scientific evaluation of qualitative research in medicine and health sciences. ("Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative forskningsprosjekt innen medisin og helsefag.") [13]
- Payment to participants in medical or health research. ("Betaling til deltakere i medisinsk eller helsefaglig forskning.") [14]
- Guidelines for the inclusion of women in medical research. ("Retningslinjer for inklusjon av kvinner i medisinsk forskning.") [15]

- Clinical trials of medicinal products. Guidelines for ethical evaluation of post-marketing studies. ("Klinisk utprøving av legemidler. Retningslinjer for vurdering av post-marketing studier.") [16]
- Guidelines for research on persons with impaired informed consent capacity. ("Redusert samtykkekompetanse i helsefaglig forskning. Retningslinjer for inklusjon av voksne personer med manglende eller redusert samtykkekompetanse i helsefaglig forskning.") [17]

All five reports are available in Norwegian only. (NEM has not developed its own ethical guidelines.)

Finally, we have the Norwegian Health Research Act:

- Lov om medisinsk og helsefaglig forskning. (ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act)) [6]

In medicine, clinical trials are regulated by the Regional Committees for Medical and Health Research Ethics (REC) [18]. These "shall provide advance approval for: (1) Medical and health research projects, (2) General and thematic research biobanks, and (3) Dispensation from professional secrecy requirements for other types of research."

Clinical projects also have to register their clinical trials at ClinicalTrials.gov. *"ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world."* [19]

Science and Technology

The National Committee for Research Ethics in Science and Technology (NENT) has its own guidelines:

- Guidelines for research ethics in science and technology [3]

Social Sciences and the Humanities

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) has published two ethical guidelines:

- Guidelines for research ethics in the social sciences, law and the humanities [4]
- Ethical guidelines for Internet research. ("Etiske retningslinjer for forskning på Internett") [20]

How to Proceed with Research Ethics in Health Informatics

The National Research Ethics Committees deal with issues regarding research ethics in their respective fields. Several of the committees have made their own ethical guidelines that can be downloaded from their web-page [18].

Medical and health research projects are managed by The National Committee for Medical and Health Research Ethics (NEM) and The Regional Committees for Medical and Health Research Ethics (REC). The REC is contacted directly through their web-page [18]. General enquiries must be addressed to the REC in the researcher's own geographical region.

NEM is an advisory and coordinating body for the seven regional committees for medical and health research. NEM is also appellate body for research projects discussed in REC.

The National Committee for Research Ethics in Science and Technology (NENT) *"is an advisory body for research ethics in its subject areas and provides advice and recommendations for specific projects submitted to the committee. Obtaining advice prior to a research project is not mandatory, but researchers are encouraged to contact the committee if the project is considered to present challenges in terms of research ethics. You can also obtain assessments on matters of research ethics that go beyond the framework of a single research project."* [21]

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) *"is an advisory body for research ethics in its subject areas and provides advice and recommendations for specific projects submitted to the committee."* As for NENT, it is not mandatory to get approval or obtain advice prior to a research project. Likewise, *"researchers are encouraged to contact the committee if the project is considered to present challenges in terms of research ethics."*

Discussion and Recommendations for Health Informatics

As indicated above, for a student in health informatics with a different background than health science, research ethics may appear as complex and comprehensive. To improve this situation, this section presents some possible starting points for discussion of ethical guidelines for research.

Ethical Guidelines in Short

There are no specific ethical guidelines for research in health informatics. As argued above, health informatics is both a multidisciplinary and interdisciplinary field, which might involve ethical guidelines, acts/laws, and principles from both medicine and health science, science and technology, and social sciences and humanities. This creates a dilemma for research groups in this area – should they allocate sufficient time to discuss all ethical guidelines in minute details or discuss major ethical principals and let each member study the details on their own? In accordance with this author's own experiences, a presentation of overall principles receives much more attention and initiate real discussions, while a presentation of ethical principles in full almost has the opposite effect – no one cares. This has led us to look for shorter and more general ethical principles that can be addressed during research group meetings and supervision of students.

Research ethical commandments

To be sure that doctoral students have a mature relationship to research ethics, we have made 10 research ethics

commandments in which we have tried to summarize what we believe for them (as doctoral students and researchers) are the most important research ethics guidelines. (We presuppose that a presentation of national research ethics guidelines is included as part of the compulsory courses that they must follow during the doctoral program.) Our 10 research ethics commandments are:

1. You shall conduct research in accordance with good research practice.
2. You shall always be honest.
3. You shall not copy other researchers' research.
4. You shall recognize contributions of other researchers.
5. You should make your results available to other researchers.
6. You shall act as a responsible citizen.
7. You shall comply with all laws, rules, regulations and guidelines that apply to your research.
8. You shall report serious breaches of ethics.
9. You shall be able both to explain and defend all publications where you are co-author.
10. You shall when you evaluate other researchers' research unasked declare all relationships, positive and negative, to he/she/them you evaluate.

One of the benefits of this short form is that it is suitable to be debated during supervision and in research group meetings. Several commandments have also been changed following discussions in our research group. For example, the commandment "You shall tell the truth" changed to "You shall always be honest" as a result of a discussion on truth versus honest ("truthful"). The discussion of what is the most important commandment led what is now commandment No. 1 to the top.

An important issue that is not explicitly pointed out in these short commandments is that the law comes first. If a research project is regulated by The Health Research Act, ethical guidelines come second.

The commandments directly address the responsibility of each individual researcher. Hopefully this will help to ensure that these guidelines both will be remembered and followed. They are also suitable for being published in social media. The review of the commandments may advantageously be followed up with examples, both real and constructed.

Other ethical guidelines for research in short form

The National Research Ethics Committees launched in 2014 "General guidelines on research ethics" [22]. These consist of 14 guidelines, which all fit on an A4 page. These are based on the four principles [22]:

- *"Respect.* People who participate in research, as informants or otherwise, shall be treated with respect.
- *Good consequences.* Researchers shall seek to ensure that their activities produce good consequences and that any adverse consequences are within the limits of acceptability.
- *Fairness.* All research projects shall be designed and implemented fairly.
- *Integrity.* Researchers shall comply with recognized norms and to behave responsibly, openly and honestly towards their colleagues and the public."

The board of the University of Oslo (UiO) passed in 2007 "UiOs 10 bud for for god forskningsetikk" / "Guidelines for ethical practice in research: UiO's 10 Commandments" [23]. UiO's commandments also include the use of research funding and responsibility to stay current in a research field. UiO's 10 commandments are substantially longer than the commandments that we have put together. UiO's commandments do not affect the researcher's responsibility or duty to report serious breaches of ethical guidelines. At the University of Bergen (UiB), the university board in 2006 acknowledged "10 Code of Ethics for the University of Bergen" [24]. Since each of the rules is elaborated and explained, UiB's ethical rules are somewhat more extensive than UiO's rules. (UiB's ethical rules are available in Norwegian only.)

There are numerous examples of "rules" or "principles of research ethics" available online. These are often tailored to specific disciplines. One of the more famous ethical guidelines for research in short form (10 rules), is the "Nuremberg Code" of 1947 [25], designed in conjunction with the trials of German doctors who had participated in cruel experiments on humans during WWII.

Relevant Ethical Guidelines

Every researcher in health informatics should know which ethical guidelines are relevant for their research. As argued in the above section about "Research Ethics Guidelines Used in Norway", Norwegian researchers in health informatics need to know about current ethics guidelines, principles, laws, regulations, etc. in several disciplines. The question is, however, to what extent these guidelines etc. should be discussed in research group meetings.

The Advisory and Management Responsibilities

Every supervisor should regularly discuss research ethical issues with his/her students. At UiT, we have since 2004 had ethical guidelines for supervision [26]. These are available both in Norwegian [27] and English [28]. The guidelines, presented over two pages, say nothing about whether the supervisor has the responsibility to inform the student about research ethical guidelines or to discuss these during supervision meetings. At the Department of Computer Science, no common methodology courses for master's degree students exist, despite the fact that students submit a research-based thesis. As a consequence, ethical guidelines remain unknown for many students.

But what about the ethical guidelines for supervision? This author believes that if we carry out the same exercise as the one referred to in the introduction to this article (and presented in [2]) with other faculty members, it would hardly be many

who would have been able to render one or more of the ethical guidelines for supervision at UiT.

Evolutionary Development of Ethical Guidelines

Ethical guidelines are not static or developed in a vacuum. On the contrary, such guidelines are a result of a specific field's characteristics and must be adjusted in accordance to the development of the field. In a guest editorial in Cambridge Quarterly of Healthcare Ethics (CQ), Goodman [29] argues that:

> *"The global bioethics community is, collectively and generally, a quick study. The literature rapidly incorporates, analyzes, and otherwise metabolizes the latest scientific developments as they relate to health-care and pose new ethical issues. Genetics and genomics shaped a new subspecialty in bioethics; neuroethics arose quickly as brain research evolved and matured; and nanoethics blossomed as nano-technology and nanoscience posed new challenges ranging from personal tracking to human enhancement.*
>
> *Strikingly, however, the community of bioethics scholars and educators has been comparatively slow to grasp, let alone analyze, the significant transfor-mations and challenges caused and elicited by the use of health information technology (or biomedical informatics, e-health, or information and communi-cation technology)." (p. 252)*

In order to meet the rapid development within this area, the CQ has introduced a special section on "Bioethics and Information Technology" that *"aims to address this short-coming and fill this lacuna"*. Goodman [29] illustrates his points by stating:

> *"Countries around the world are spending billions of dollars, euros, and pounds to promote the use of electronic health records, which are transforming the clinician-patient relationship. Intelligent machines render diagnoses and prognoses more accurately than human experts, challenging traditional notions of professional practice. The analysis of big (and not-so-big) data fosters and identifies conundrums about the limits of privacy and the scope of informed consent. Indeed, every aspect of clinical practice, hospital operations, and biomedical research is touched by the use of computers, by information technology." (p. 252)*

Even though not every research project in health informatics has to deal with similar problems, we have to make all researchers in our field aware of what is going on. These kind of problems should have a natural place on every health informatics research group's meeting agenda.

Violation of Ethical Guidelines

To this author's knowledge, there are none "famous" cases of scientific misconduct in health informatics / medical informatics. There are some blogs that mentions cases, e.g., the blog by Gunter Eysenbach, who, among others, discusses a case about plagiarism in a medical informatics journal [30]. The tools for detecting scientific misconduct are becoming better and better. Sox [31] argues that: *"Plagiarism in the digital age is easier to commit but much easier to detect. On balance, we're making progress."* Hartvigsen [32] claims that committing plagiarism probably is the stupidest thing you can do as a researcher.

Teaching Ethical Guidelines in Health Informatics Research Groups

Even though teaching of research ethics and ethical guidelines and principles is a mandatory part of research education (i.e., PhD program), ethical guidelines should also be on every health informatics research group's agenda. This paper argues that this kind of discussion should take place on both research group and individual (supervision) level. Topics that should be discussed include:

- Ethical guidelines in short
- Relevant ethical guidelines
- The advisory and management responsibilities
- Evolutionary development of ethical guidelines
- Violation of ethical guidelines

How much time that should be spent on each of these topics will vary in accordance with the group members' knowledge of these issues.

Final Remarks

This paper has presented "10 research ethics commandments" that have been established through discussions in a health informatics research group. The objective of preparing a digest of research ethical guidelines has been to be able to discuss the topic in research team meetings and supervision sessions. Researchers and students are also encouraged to go ahead and consult the website of The National Research Ethics Committees (FEK) (www.etikkom.no). Students are encouraged to download FEK's poster with "General guidelines for research ethics" ("Generelle forskningsetiske retningslinjer") [22] and make it visible in their workplace. For those who want to get started with teaching in ethics, FEK's "Short Guide to teaching" ("Miniguide til undervisningsopplegg") [33] and RREE (Resources for Research Ethics Education) [34] are good starting points.

International sources for research ethics can be found at UNESCO and its Global Ethics Observatory (GEObs) [35]. According to their web-page: "The observatory is a *system of databases with worldwide coverage* in bioethics and other areas of applied ethics in science and technology such as environmental ethics, science ethics, and technology ethics." GEObs contains among others comprehensive databases of "related legislations and guidelines" and of "codes of conduct". UNESCO has published several books and reports of ethics, including "Ethics of Science and Technology at UNESCO" [36].

CODEX, the Swedish Centre for Research Ethics & Bioethics presents a comprehensive list of "Rules and Guidelines" on

their web-page [37]. Their web-page is a very good starting point if you want to get overview of what is going on in research ethics in the world.

This paper has only scratched the surface of ethical guidelines. The goal has been to present the minimum knowledge needed in this field for researchers in health informatics. The paper has not addressed the value of the specific guidelines, e.g., as discussed by Eriksson et al. [38]. In their paper, they question *"the premise that laws and ethical guidelines are as useful for ethical decisionmaking as is often assumed."* (p. 15)

We have to suppose that perceptions about how many and whether it is possible to identify a range of key ethical guidelines vary between disciplines, research groups and individual researchers, and that this topic in itself is a good starting point for a debate. And perhaps it is precisely a debate which is the basis of commitment and compliance with ethical guidelines for research?

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References

1. *Procter, R. Dr. (Editor, Health Informatics Journal, Edinburgh, United Kingdom). Definition of health informatics [Internet]. Message to: Virginia Van Horne (Content Manager, HSR Information Central, Bethesda, MD). 2009 Aug 16 [cited 2009 Sept 21]. [1 paragraph]*. Available from: https://www.nlm.nih.gov/.
2. Hartvigsen, G., *Rekk opp hånden alle som kjenner til forskningsetiske retningslinjer. ("Raise your hand all who are familiar with research ethics guidelines")*. Forskningsetikk 2013. **13**(3): p. 22.
3. NENT, *Guidelines for research ethics in science and technology*. 2007, De nasjonale forskningsetiske komiteer: Oslo.
4. NESH, *Guidelines for research ethics in the social sciences, law and the humanities*. 2006, Oslo: De nasjonale forskningsetiske komiteer.
5. Kunnskapsdepartementet, *"Lov om behandling av etikk og redelighet i forskning." ("Act on ethics and integrity in research") Act of 30 June 2006 No. 56.*
6. Helse- og omsorgsdepartementet, *"Lov om medisinsk og helsefaglig forskning (helseforskningsloven)." (ACT 2008-06-20 no. 44: "Act on medical and health research (the Health Research Act)") Norwegian Act of 1.7.2009.*
7. WMA. *WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects*. 2013; Available from: http://www.wma.net/en/30publications/10policies/b3/index.html.
8. Kunnskapsdepartementet, *Ot.prp. nr. 58 (2005-2006) "Om lov om behandling av etikk og redelighet i forskning" (White paper no. 58 (2005-2006) "On the Act on ethics and integrity in research")*. M.o.E.a. Research, Editor. 2006: Oslo.
9. De nasjonale forskningsetiske komiteene. *Forskningsetisk bibliotek*. [cited 1.2.2016; Av. from: https://www.etikkom.no/FBIB/.
10. European Commision, *European Textbook on Ethics in Research*. Vol. EUR 24452 EN. 2010, Brussels, Belgium: European Commision, Directorate-General for Research.
11. ICMJE. *Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals*. 2015; Available from: http://www.icmje.org/icmje-recommendations.pdf.
12. Oviedo. *Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. CETS No. 164. Oviedo, 4.IV.1997*. 1997 1.2.2016; Available from: http://www.coe.int/nb/web/conventions/full-list/-/conventions/treaty/164.
13. NEM, *Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative forskningsprosjekt innen medisin og helsefag. Laget av Den nasjonale forskningsetiske komité for medisin og helsefag (NEM), 2009*. 2010, Oslo: De nasjonale forskningsetiske komiteer.
14. NEM, *Payment for research participants in medical and health research. ("Betaling til deltakere i medisinsk eller helsefaglig forskning.")*, in *En veiledning laget av Den nasjonale forskningsetiske komité for medisin og helsefag (NEM)*. 2009, De nasjonale forskningsetiske komiteer: Oslo.
15. NEM, *Guidelines for the inclusion of women in medical research. ("Retningslinjer for inklusjon av kvinner i medisinsk forskning.")* in *Laget av Den nasjonale forskningsetiske komité for medisin og helsefag (NEM)*. 2001, De nasjonale forskningsetiske komiteer: Oslo.
16. NEM, *Clinical trials of medicinal products. Guidelines for ethical evaluation og post-marketing studies. ("Klinisk utprøving av legemidler. Retningslinjer for vurdering av post-marketing studier.")*, in *Utarbeidet av Den nasjonale forskningsetiske komité for medisin*. 2005, De nasjonale forskningsetiske komiteer: Oslo.
17. NEM, *Guidelines for research on persons with impaired informed consent capacity. ("Redusert samtykkekompetanse i helsefaglig forskning. Retningslinjer for inklusjon av voksne personer med manglende eller redusert samtykkekompetanse i helsefaglig forskning")* in *Utarbeidet av Den nasjonale forskningsetiske komité for medisin (NEM)*. 2005, De nasjonale forskningsetiske komiteer: Oslo.
18. REC. *Regional Committees for Medical and Health Research Ethics (REC)*. [cited 1.2.2016; Av from: https://helseforskning.etikkom.no/.
19. U.S. National Institutes of Health. *ClinicalTrials.gov*. [cited 1.2.2016; Available from: https://clinicaltrials.gov/.
20. NESH, *Ethical guidelines for Internet research. ("Etiske retningslinjer for forskning på Internett")* in *The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH)*. 2014, De nasjonale forskningsetiske komiteer: Oslo.
21. The Norwegian National Research Ethics Committees. *Am I obligated to submit my research project to a committee for research ethics?* [cited 2016 1.2.2016]; Available from: https://www.etikkom.no/en/our-work/frequently-asked-questions/am-i-obligated-to-submit-my-research-project-to-a-committee-for-research-ethics/.
22. The Norwegian National Research Ethics Committees. *General guidelines for research ethics*. 2014 [cited 1,2,2016; Available from: https://www.etikkom.no/en/ethical-guidelines-for-research/general-guidelines-for-research-ethics/.

23. University of Oslo. *Guidelines for ethical practice in research: UiO's 10 Commandments*. 2007 [cited 1.2.2016; Available from: http://www.uio.no/forskning/om-forskningen/etikk/10-bud-for-for-god-forskningsetikk.html.

24. University of Bergen. *10 etiske regler for Universitetet i Bergen*. 2006 [cited 1.2.2016; Available from: https://regler.app.uib.no/regler/Del-2-Forskning-utdanning-og-formidling/2.1-Forskning/2.1.4-Etikk-og-personvern-i-forskning/Reglement-og-retningslinjer-fastsatt-av-universitetsstyret/10-etiske-regler-for-Universitetet-i-Bergen.

25. Nuernberg Military Tribunals, *Trials of War Criminals before the Nuernberg Military Tribunals under Control Council Law No. 10*. 1949, U.S. Government Printing Office: Washington, D.C. p. 181-182.

26. University of Tromsø - The Arctic University of Norway. *Etiske retningslinjer for veiledning - Ethical Guidelines Supervision*. 2011 [cited 1.2.2016; Available from: https://uit.no/om/enhet/artikkel?p_document_id=200332&p_dimension_id=88199&men=42429.

27. University of Tromsø - The Arctic University of Norway. *Etiske retningslinjer for veiledning ved Universitetet i Tromsø*. 2004 [cited 1.2.2016; Available from: https://uit.no/Content/171815/Etiske retningslinjer for veiledere - 200305499-15.pdf.

28. University of Tromsø - The Arctic University of Norway. *Ethical guidelines for supervision at the University of Tromsø*. 2004 [cited 1.2.2016; Available from: https://uit.no/Content/171816/Etiske retningslinjer for veiledere - engelsk.pdf.

29. Goodman, K.W., *Addressing Ethical Issues in Health Information Technology.* Cambridge Quarterly of Healthcare Ethics, 2015. **24**(3): p. 252-254.

30. Eysenbach, G. *Another plagiarist bites the dust (anatomy of a plagiarizing paper)*. 2008 Posted 10th March 2008 [cited 1.2.2016; Available from: http://gunther-eysenbach.blogspot.no/2008/03/another-plagiarist-bites-dust-anatomy.html.

31. Sox, H., *Plagiarism in the Digital Age.* Office of Research Integrity Newsletter, 2012. **20**(3): p. 1, 6.

32. Hartvigsen, G., *Plagiering – det dummeste du kan gjøre som forsker? ("Plagiarism - the stupidest thing you can do as a researcher?")* Forskningsetikk, 2012. **12**(2-3): p. 26.

33. Fossheim, H.J. and H. Ingierd. *Miniguide til undervisningsopplegg*. 2014 [cited 1.2.2016; Available from: https://www.etikkom.no/FBIB/Ressurser/Miniguide-til-undervisningsopplegg-/.

34. RREE. *Resources for Research Ethics Education*. Research Ethics Program 2013 [cited 1.2.2016; Available from: http://research-ethics.net/.

35. UNESCO. *Global Ethics Observatory (GEObs)*. 2016 [cited 1.2.2016; Available from: http://www.unesco.org/new/en/social-and-human-sciences/themes/global-ethics-observatory/access-geobs/.

36. UNESCO, *Ethics of Science and Technology at UNESCO*. 2008, Division of Ethics of Science and Technology Sector for Social and Human Sciences United Nations Educational, Scientific and Cultural Organization (UNESCO): Paris, France. p. 20.

37. CODEX. *Rules & guidelines for research*. [cited 1.2.2016; Available from: http://www.codex.vr.se/en/regler.shtml.

38. Eriksson, S., A.T. Höglund, and G. Helgesson, *Do Ethical Guidelines Give Guidance? A Critical Examination of Eight Ethics Regulations.* Cambridge Quarterly of Healthcare Ethics, 2008. **17**(1): p. 15-29.

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