

Toward a Comprehensive Model of eHealth Literacy

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Abstract. A common understanding of the notion “eHealth literacy” is that it concerns the individual ability to use and understand the content of interactive health information technologies. The paper discusses the competencies and knowledge embedded in being an eHealth literate, and suggests a comprehensive, new model, and a new definition, of eHealth literacy.

1 Introduction

eHealth solutions are becoming essential in modern healthcare. It is widely assumed that interactive health information systems can help to improve the quality, capacity, efficiency and access to the health care system [1]. A Norwegian survey reported that 78% of the informants had searched health information on the web [2]. However, while there are many identified advantages to offering eHealth solutions for authorities, healthcare professionals and citizens, there are concerns that the systems may create disparities by being accessible and understandable only to people with greater resources [3]. Questions have been raised about the degree of inclusiveness of content for minority groups, since mainstream online health resources tend to reproduce taken for granted notions about nationality, gender and race [4]. Borits and Hartvigen [5] observed that although there are many advantages in using telecare for elderly, there are organizational, ethical, legal, design usability challenges that need to be resolved before a successful implementation can occur.

The use of eHealth solutions, be they Internet based health information systems or welfare technologies, requires eHealth literacy. eHealth literacy is in general terms the capacity to use and understand the content of interactive health information technologies. Stellefson et al. [6] define eHealth literacy as: “the ability to seek, find, understand and appraise health information from electronic resources and apply such knowledge to addressing or solving a health problem”. As we shall see, eHealth literacy is even more complex than suggested above. In order to maintain ethical and relational aspects for human beings in an increasingly more complex healthcare system, it is necessary to shed light on the implications of what it means to be an eHealth literate, and to take into consideration the implications in the development and implementation of eHealth.

The objective of this paper is to elaborate on the notion *eHealth Literacy*. The following research questions are discussed: What kind of competencies and

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knowledge are embedded in the practice of being an eHealth literate? Which analytic notions must be taken into consideration in an eHealth literacy model?

2 Methods

The paper offers an analytic discussion of the notion eHealth literacy. The method applied is explorative, based on an eclectic review of relevant interdisciplinary literature from technology studies, human- and social sciences and healthcare studies. Recurrent concepts in the literature are derived, and applied as point of departure for the discussion. New concepts are suggested based on insights from ethnographic studies on health communication and discourse analysis. A database search of the concepts relevant to “eHealth literacy” was performed in Google Scholar.

3 The Competencies and Knowledge Embedded in the Practice of Being an eHealth Literate

Practice knowledge involves different kinds of knowledge and competencies. A fundamental distinction is between propositional knowledge and procedural knowledge [7]. Propositional knowledge is the knowledge of facts derived from for example lectures, theories and research, while procedural knowledge refers to the physical and experiential knowledge of performing a task. Moreover, practice knowledge is manifest on different proficiency levels. Inspired by the philosopher Merleau-Ponty and his notion of bodily adaption to situational requirements, Dreyfus and Dreyfus [8] distinguished between competence levels: *novice*, *competence*, *proficiency*, *expertise* and *mastery*. Knowledge acquisition is a dynamic process. On an individual level we go through a process from being completely unfamiliar with the subject, the practices and the communication relevant to the subject, to developing a level of competence within the subject in interaction with the relevant community of practice [9]. Competence level depends upon on the nature of the task. A person may be an excellent mechanic but unfamiliar with iPads and vice versa. Likewise, a person may be a poor reader of books, but an expert in gaming in visual virtual environments.

3.1 The Lily-model

Several distinct competencies and knowledge are embedded in the practice of being an eHealth literate. In their eHealth literacy Lily model in a paper in the Journal of Medical Informatics, Norman and Skinner [10] suggest six components of eHealth literacy: *traditional literacy and numeracy*, *computer literacy*, *information literacy*, *health literacy*, *media literacy* and *science literacy*.

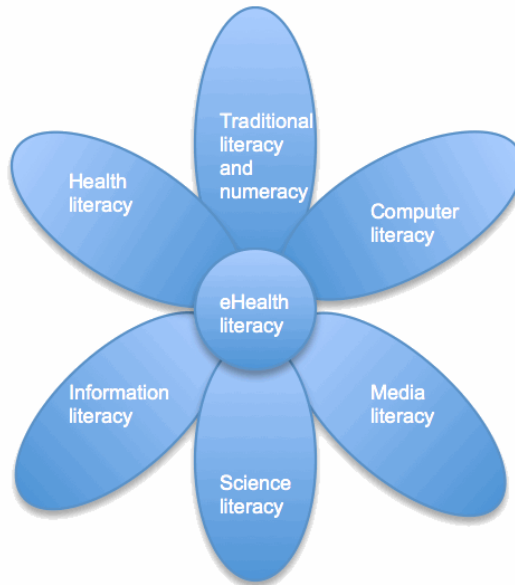


Fig. 1: The Lily model, Norman and Skinner (2006)

Although the Lily model, and the accompanying method for measuring eHealth literacy, eHEALS, have been criticized [11] and revised [12], the components offer insights that are useful as point of departure for discussing the complexity of eHealth literacy.

Traditional literacy and numeracy concerns reading and understanding written text as well as the ability to communicate and write coherently. It involves quantitative skills, and the ability to interpret information artefacts such as graphs, scales and forms. The level of literacy and numeracy varies significantly in the population. The OECD study “Survey of Adult Skills (PIAAC)[13] showed that although Norway scored relatively high on literacy and numeracy, there are still groups in society that have lower literacy proficiency than the OECD average. Norwegian youth between 16 and 24, and elderly people between 60 and 65, score lower on the literacy and numeracy test than the average of the Norwegian population. People with lower education have a lower score than people with higher education. Unemployed persons score lower than average. Not surprisingly (since the tests are carried out in Norwegian), immigrants’ score lower than average on reading and numeracy tests in Norwegian.

Computer literacy concerns the different skills from basic knowledge of using the computer to participating in for example social media. *Information literacy* concerns skills related to defining information needs, locating, evaluating and using the information for knowledge production. The combination of computer literacy and information literacy can be compared to problem solving in technology-rich environments from the OECD-study mentioned above. The study distinguished between levels of skills in problem solving in technology-rich ICT environments. The

lowest level were persons not knowing how to handle a mouse let alone scroll the webpage and who took the test on paper instead. On highest Level 3, use of both generic and specific applications was required. Navigation between webpages and applications was necessary to solve the problem, and tools and functions had to be used. The problem solver had to define the goal, and the criteria were not clearly defined. In addition, she had to make assessments and evaluations, and challenges, such as surprising results occurred which meant that she had to critically consider the information as reliable and relevant. The results of the tests of problem solving in technology-rich environments in the adult population showed that the average Norwegian was on Level 2, and totally 45% scored on Level 2 or Level 3. Persons between 25 and 29 had most scores on Level 3. In comparison, among persons over 60 years, only 1 % was on Level 3. Immigrants had lower scores on the same test, which again was not surprising since the test was in Norwegian. 24% of the immigrants were on Level 2 or 3.

Media literacy concerns the ability to select, interpret, evaluate, contextualize and create meaning of visual and auditive information. According to the Center for Media Literacy [31], “media Literacy is a 21st century approach to education. It provides a framework to access, analyze, evaluate, create and participate with messages in a variety of forms — from print to video to the Internet. Media literacy builds an understanding of the role of media in society as well as essential skills of inquiry and self-expression necessary for citizens of a democracy”. Different types of interactive health information systems require different kinds of competences and knowledge. The competences and skills related to the reading a web-based information site are different than the competences required for welfare technologies. A media literate has the ability to critically assess and pose questions to the media she has at hand, be that questions about content or use. Teaching and training of using the relevant technological tool is decisive for the development of knowledge level.

Science literacy concerns the familiarity with basic biological concepts and the scientific method, as well as the ability to understand, evaluate and interpret health research findings using appropriate scientific reasoning [1]. Science literacy is required for personal decision-making, and for being a participant in the democratic society. The citizen needs scientific literacy to make qualified decisions and to give valid informed consent when facing questions about personal health and treatments of diseases. According to Gross [14] only 17% of Americans are considered able to understand basic science [1] which means that the rest may lack the knowledge of how to interpret scientific publications, scientific methods and reasoning and scientific terminology. The role of the healthcare professionals as interpreters of science for patients is thus essential.

Health literacy concerns acquisition, evaluation and appropriate application of relevant health information for communication about health, making health decisions and using health services for maintaining good health [15][16]. According to Nutbeam [17], health literacy involves knowledge and skills on three levels: *functional health literacy*, which is reading, writing and basic knowledge of the body necessary to understand simple health advices, *interactive or communicative health literacy* which are communicative skills that helps maintaining own health in interaction with professional healthcare workers. This involves knowing what

institutions to communicate with and how to use them, and *critical health literacy*, which is the ability to critically evaluate the available health information.

The eHealth literacies above represent competencies needed for citizens when dealing with modern healthcare. A primary focus in the components mentioned above is on the propositional knowledge, while procedural knowledge is basically linked to the use of the computer. Each of the literacy components suggest that being an eHealth literate requires complex knowledge and competencies, and this may create even more differences between certain groups in society. Moreover, we have seen that to be an eHealth literate is not only understanding received information, but also actively communicating relevant information to healthcare professionals. In addition, the functions and purposes of the technology condition the interpretation and use. Finally, the role of the healthcare professional as interpreter and communication partner when making decisions about health is significant for the understanding of the patient.

3.2 Toward a New Model and Definition of eHealth Literacy

The second research question of this paper concerns the analytic notions that must be taken into consideration in a comprehensive eHealth literacy model. Although pointing out important components of eHealth literacy, the Lily-model of Norman and Skinner lack a focus on important competences, such as acknowledgement of *the bodily experience* of a health challenge, the *procedural literacy* of handling the tools and technologies, the *contextual and the cultural literacy* and *the communicative expertise*. These notions are subsequently presented and discussed, and implemented in a new model of eHealth literacy.

The bodily experience of a phenomenon is subjective. Merleau-Ponty [18] suggests the notion cenesthesia to describe the mass of sensations that the subject experiences of the state of her different organs and different bodily functions. A person can recognize her own bodily experiences, but is not able to feel the bodily experiences of others. The ability to identify a subjective health problem, and to convey this critically into a type of health question is a fundamental element of being an eHealth literate.

The *procedural literacy* is essential for being able to make use and sense of handling the tools and technologies. Procedural knowledge is the knowledge of how to act upon and how to do things, or what Sarangi [19] calls the “how”-dimension of knowledge. This is closely linked to the experience of performing tasks. Handling welfare technology requires procedural literacy. The aging population is expected to increase in the near future, and since the workforce will not increase respectively, welfare technology is considered a solution to overcome some of the challenges in society. Several solutions may help elderly to live at home longer [20]. Future health care at home will presumably include simple or complex versions of smart houses, where monitoring of medical data, sensor technology, video based technologies, alarms, warnings, call for personal help, tracing of persons, control of light, personal robots, technologies for hygienic and nutrition activities are integrated. In order for the welfare technologies to be useful, the users must know how to handle them. Extensive teaching and training of the users is needed. The teaching and training will

also depend on the capabilities of the users. While some users may need help with basic eHealth challenges, such as activating the sensor for turning on the light, others may have need to more extensive medical training in self measuring of blood sugar or blood pressure.

Contextual and cultural literacy is essential to cope in society. Goffman [21] emphasized the importance of studying the interaction order and argued that the participants in the social situation actively produce the social structure in the communication. Moreover, aspects not happening here and now condition the communication in the social situation, for example norms, values, rules and regulations in the contextual or the cultural context. Hirsch [22] referred to the idea that reading comprehension requires not just formal decoding skills but also wide-ranging cultural background knowledge as *cultural literacy*. An eHealth solution is not developed in a social vacuum, but has to be adapted to the user's health information needs in the contextual and cultural context. The information must be understandable and considered relevant by the actual users in their everyday lives. Solomon [23] discussed the experiences from an electronic personal health record, called MiVia [24], and tailored for migrants and seasonal farm workers who access many different clinics and health care systems from San Diego to Alaska on the West coast of the United States. The target group includes Spanish-speaking persons, several of whom do not speak English well enough to make themselves understood. MiVia offers a Spanish version of the system. MiVia is linked to other health information resources in the regions, and offers many features. In addition to having health registration of personal info and emergency contacts, the person and the clinician can register medical office visits, dental office visits, healthcare providers, pain and symptoms diary, medications, allergies, immunizations, family medical history, hospitalizations and injuries, scanned documents and lab tests. There are also possibilities for saving reports of various kinds and administrative issues. MiVia also offers a service wheel that identifies recourses by population or region, for example information about employment, transportation, housing, community services, health services and legal assistance. Solomon emphasises the importance of considering cultural aspects in the solution: "resources should be made available to assist organizations in accessing, measuring, and deploying health content that is relevant and respectful of cultural differences." Society has a responsibility for providing health information solutions adapted to all groups.

Finally, *communicative expertise* is essential for conveying personal health issues and health matters of family members and other relations to healthcare professionals. Communicative expertise entails the communicative and interactional competencies necessary for maintaining the patients ethically and relationally [25][26][27]. Communication with healthcare professionals, be that verbally on the phone, in face-to-face encounters or written texts, is fundamental for creating trust and human relationships, for exchanging information about symptoms, previous health conditions, treatments, services, handling of medications and for following up the prescribed treatment regimes. To be an eHealth literate is consequently to be an actively communicating and assessing citizen.

In the previous discussion, competencies and knowledge have been used interchangeably to explain the different literacies. Subsequently, the notion literacy

will be used as the term that includes knowledge, skills, competencies and similar concepts concerning literacy.

Figure 1 below illustrates an elaboration of the Lily-model from Norman and Skinner [10], with an inclusion of overall literacies such as cultural, contextual and communicative literacies and a distinction between propositional and procedural literacies.

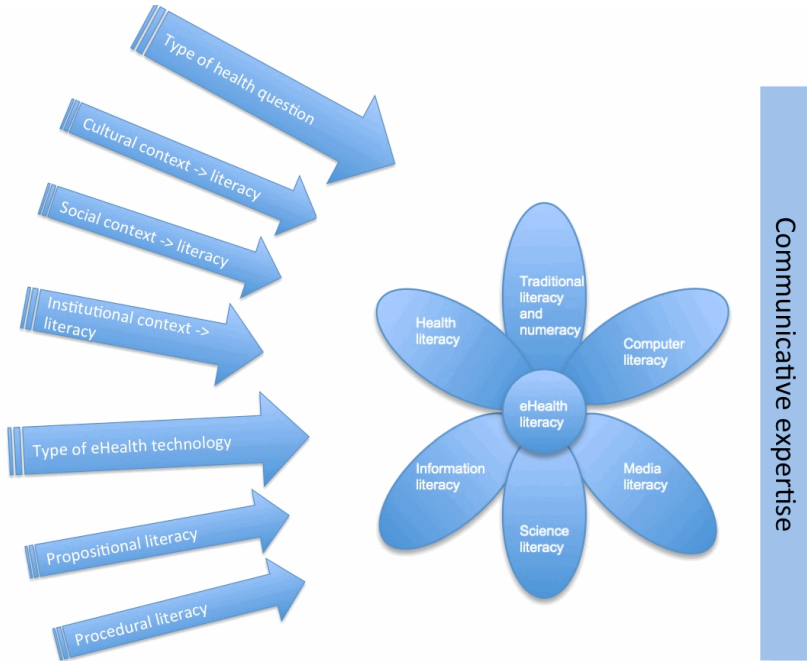


Fig. 2: eHealth literacy-model (Gilstad 2014)

Cultural literacy, contextual literacy and communicative expertise are overall literacies that are manifesting in the situated activity. Cultural literacy is fundamental for making sense of and for orienting in the world, and includes for example knowledge of norms, identities, habits and expectations. This ability to perceive the cultural framework is the basis for making sense also on a contextual and situational level. The contextual literacy discussed in this paper concerns orienting in modern healthcare, including the situational level or the “here-and now”-activity. Communication and interaction occur in the actual situation, and the realization of the eHealth literacy is perceivable and measurable in the situation in which the technology is being applied.

The conceptualization of eHealth Literacy illustrated in the model above calls for a redefinition of eHealth literacy:

eHealth literacy is the ability to identify and define a health problem, to communicate, seek, understand, appraise and apply eHealth information and welfare technologies in the cultural, social and situational frame and to use the knowledge critically in order to solve the health problem.

This definition includes the fundamental chronology of being an eHealth literate from identifying a health problem and applying available resources to solving the problem. The definition may be used as a point of departure for discussing, measuring and monitoring eHealth literacy.

4 Discussion

Good health does not only concern being a person in need of healthcare services, but it means being a whole person with various needs. The integration of the eHealth solution with public services such as organizations, libraries, housing and language courses enables the person to find help to sort out fundamental needs for a good life. The experiences with MiVia showed that an eHealth solution needs promoters in the communities, i.e. persons that can create trust and inform about the value of the solution, and that can train people in using it.

Teaching and training is crucial for overcoming poor eHealth literacy. Moreover, the content must be presented in media types and in formats that people can relate to and make sense of, be that linguistically or content wise. The designer's biases and goals for communication affects the content of the application. Furthermore, signs, such as written text, pictures, videos, slide shows, icons, pictograms, colors and fonts, are not value neutral or independent of cultural norms and identities, and understanding them depend on the cultural and social background of the individual [28]. Although there are good examples of eHealth solutions that take the necessity for multiple media presentations that include texts, video, audio and drawings [29], there is a major unrevealed potential to develop this further.

MiVia is an eHealth solution tailored for a particular group. Many have argued for the necessity to tailor eHealth solutions for the particular needs of the patients or citizens. However, this is not without challenges. As Das and Svanæs [30] observes, the characteristics of the different illnesses and patient groups are diverse, and consequently patient-centred solutions need to be developed with considerations to their particularities. Moreover, the development of eHealth solutions must pay attention to the disease-management process as suggested and supported by healthcare professionals.

From the perspective of the patient, several eHealth literacies are required for handling a tailored electronic patient record or welfare technology. The interaction with a system like MiVia requires that the person is familiar with the computer and mouse, and can handle this to navigate on the screen (procedural, computer and media literacy), and that she can read and make basic sense of the content on the screen (traditional literacy and numeracy). The user must define goals for the use of the information, and be able to assess its relevance on a basic level (information literacy) and hopefully also on an advanced level (scientific literacy). Her understanding of the health information she finds must be adequate for communicating about it with health personnel and for making decisions about treatment (health literacy).

The eHealth literacies required for welfare technologies are somewhat different than the ones required for computer, iPad and smartphone, although there is overlap.

In order to handle elements in a smart house, for example remote control for light or an alarm when the door opens or when the patient has to take her medication, the person needs to understand the purpose of and the reason for using the technology (media literacy) and she needs the competence in how to handle it (procedural literacy). She needs to understand and assess the information to be found in or derived from the technology and act upon it (information literacy and science literacy), for example an alarm or results from self-monitoring. Additionally, she must be able to relate the information to own condition and to communicate this to caregivers or health personnel (health information). Each welfare technological tool requires particular training concerning eHealth literacies.

Several deductions may be drawn from the discussion above. Firstly, eHealth solutions should be tailored for the intended user group, and representatives of the group should be consulted in the development. This may seem obvious in 2014, after 20 years of focus on user inclusion, but unfortunately, there is still a way to go. Secondly, the eHealth solution should use several media types in order to make the information easily understandable to groups with various eHealth literacy levels. Thirdly, teaching and training programs, preferably with promoters' in the user group, helps users trust and feel confident about the use. This includes training of propositional and procedural on different levels. Demonstration smart houses and smart rooms can be used in the training activity. In order for individual training to work, the relevant interest organizations in the community should be included in the process. Inclusion of target citizens as well as healthcare professionals is mandatory on all stages, from idea to realization of the project.

6 Conclusion

The objective of this paper was to discuss the notion of eHealth literacy, and the analytic notions that must be taken into consideration in an eHealth literacy model. An eHealth literate must be able to read and write, interpret and communicate health information relevant for her in the given situation and given cultural context. Moreover, she must be able to apply the accessible technological tools. Society must facilitate for promoting eHealth literacy for all citizens.

References

1. Hernandez (2009) Health literacy, eHealth, and communication putting the consumer first. Workshop summary roundtable on health literacy board on population health and public health practice, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C, www.nap.edu
2. Sørensen T, Andreassen HK, Wangberg SC. (2014): E-helse i Norge 2013 Prosjektrapport, NST-rapport
3. IOM (2002) in Hernandez, Lyla M (2009) Health Literacy, eHealth and Communication: Putting the consumer first: workshop summary. The National Academies (www.nap.edu/catalog/12474.html)
4. Kvasny, L, Chong, J., & Payton, F. C. (2006) [Minority women and ehealth: Social inclusion in online HIV/AIDS information](#). Electronic poster presentation at International Conference on

- Information Processing (IFIP) Working Group 8.2 Conference, Limerick, Ireland, July 13-15, 2006
5. Borits and Hartvigsen (2008) Current status and future perspectives in telecare for elderly people suffering from chronic diseases, *Journal of Telemedicine and Telecare*, SAGE Journal
 6. Stellefson, Hanik, Chaney, Chaney, Tennant, Chavarria. (2011) eHealth Literacy Among College Students: A Systematic Review With Implications for eHealth Education. *J Med Internet Res*
 7. de Cossart, L. & Fish, D. (2005) *Cultivating a thinking surgeon. New perspectives on clinical teaching, learning and assessment*. Shrewsbury, UK: TFM Publishing Ltd.
 8. Dreyfus, H. L. & Dreyfus, S. E. (1986) *Mind over machine: the power of human intuition and expertise in the era of the computer*. New York: Free Press.
 9. Lave, Jean; Wenger, Etienne (1991) *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.
 10. Norman and Skinner (2006): eHealth Literacy: Essential Skills for Consumer Health in a Networked World, *Journal of Medical Internet Research*.
 11. Chan CV, Kaufman DR (2011) A Framework for Characterizing eHealth Literacy Demands and Barriers. *J Med Internet Res*.
 12. Norman, C (2011) eHealth Literacy 2.0: Problems and Opportunities With an Evolving Concept, *Journal of Medical Internet Research*.
 13. Bjørkeng (2013) Ferdigheter i voksenbefolkningen. Resultater fra den internasjonale undersøkelsen om lese- og tallforståelse (PIAAC).
 14. Gross (2006) in Hernandez, Lyla M (2009) Health Literacy, eHealth and Communication: Putting the consumer first: workshop summary. The National Academies (www.nap.edu/catalog/12474.html)
 15. Finbråten HS, og Pettersen, S (2009) Kunnskap er egenmakt. *Tidsskriftet Sykepleien*
 16. World Health Organization (2013): Health Literacy. The Solid Facts. Ed. Kickbusch, Pelikan, Apfel& Tsouros. http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf
 17. Nutbeam, D (2009) Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*
 18. Merleau-Ponty, M (2005); The child's relations with others, *Childhood: in ed. Jenks C. Critical Concepts in Sociology, Volume 3*, Routledge.
 19. Sarangi, S. (2005) Social interaction, social theory and work-related activities. *Calidoscopio 3*
 20. Hofmann B (2010) Ethical challenges with welfare technology, Nasjonalt kunnskapssenter for helsetjenesten.
 21. Goffman, E. (1974) *Frame analysis: an essay on the organization of experience*. Lebanon, NH: University Press of New England.
 22. Hirsch, E. D, Jr. (1987) *Cultural Literacy: What Every American Needs to Know*. Boston: Houghton Mifflin
 23. Solomon, C (2009) in Hernandez (2009): Health literacy, eHealth, and communication putting the consumer first. Workshop summary roundtable on health literacy board on population health and public health practice, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C, www.nap.edu
 24. MiVia, <https://www.mivia.org/> (26.03.2014)
 25. Gilstad, H (2012) Obstetric ultrasound expertise as manifest in encounters between midwives and pregnant women. A case study from KwaZulu-Natal. Trondheim: NTNU 2012 (ISBN 978-82-471-3468-9) ;Volum 96.310 s. Doktoravhandling ved NTNU(96)
 26. Gilstad, H (2013) Health Communication Expertise in Encounters Involving Medical Technologies. *CEUR Workshop Proceedings 2013* ;Volum 984.(7) s. 75-83
 27. Sarangi, S, Gilstad, H (2014) Nurse midwives' communicative expertise in obstetric ultrasound encounters. I: *The Routledge Handbook of Language and Health Communication*. Routledge 2014 ISBN 978-0-415-67043-2. s. 539-557
 28. Gilstad, H (2003) Ethical questions related to the development of telemedicine. *Publication series = Skriftserie 2003* (Pub Series no1) s. 109-124, NTNU
 29. Mine behandlingsvalg, <https://minebehandlingsvalg.unn.no/> (26.03.2014)
 30. Das, A. Svanæs, D (2013) Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment, *International journal of medical informatics 82*, Elsevier.
 31. The Center for Media Literacy <http://www.medialit.org/> (26.03.2014)