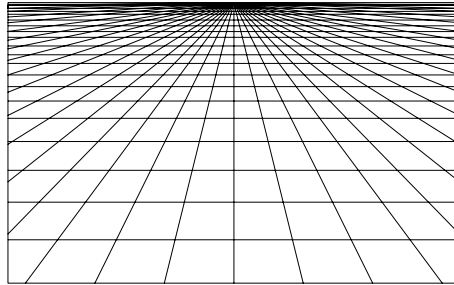




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Health information on the Internet: The case of BarniMagen.com

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Health Information on the Internet: the case of



Dissertation for MA in Society, Science and Technology in Europe.

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## **Chapter 1: Introduction**

Throughout history features have been assigned to stretches of time in order to distinguish them from one another. These features have pointed to several different parts of life, although a lot of focus has been centred on the work life of the human. From pointing to the materials available to work with for humans, like iron or bronze, to structures of work, Fordism and Industrialism, theories have abounded. On many of these distinctions academics disagree, and there are vast numbers of theories and literature on why a period of time should be termed after one or another aspect of it. One of the theories receiving a lot of support and criticism that focuses on the present time is that we are in an Information Society, or an Information Age. Within those who agree on this term, there are different methods in which they attempt to show that society can indeed be shown to distinguish itself from what has come before it through information's place within it. Although there are numerous aspects of these theories that are disagreed upon, few critics, be they academics or otherwise, will disagree with the statement that the access to large quantities of information and services has increased in the years since the Internet surfaced. Particularly in the last 3-4 years the use of the Internet has spread, and through this use the access to information has increased for many people. Academics enter into dialogues to ascertain what this means for society, and at other levels policies are discussed for the same reasons. The information and services to be accessed on the Internet lie within various areas, illegal and legal, but one of the areas with a lot of growth is the area of health. Both health information and services are showing constant increases and the implications of this are not yet fully clear. Specifically what are people using the health information from the Internet for, which services do they use and why? How is this use affecting their relationships with their health care professionals? These and many others are questions academics as well as policy-makers must consider.

This dissertation will attempt to look at the present debates on the role of information in the present society, both at an academic and a policy level, as well as the more specific debates on health information and its affects on the relationships between health care professionals and patients. As well as this, a case study of a midwifery website will be done to illustrate the last question: Whether the health information online is considered by users to be a substitute or a supplement to regular consultative services with health care professionals.

## **Chapter 2: The Information Society: Fact or Fiction?**

For one reason or another it has always been necessary for people to be able to label the society that encompasses them. This has often lead to the use of a so-called “ism”, ranging from feudalism to totalitarianism (Webster, 1995). These expressions allow us to discuss and point out the features that identify our society, setting it apart from others. In the last years, there has been an increasing focus on using “information” as the defining feature in the modern, western society (Webster, 1995). There is talk of an “information age” and “information society” is a label given to many countries such as the United States and others that have similar ways of life (Webster, 1995).

*“...(information has)...become so important today as to merit treatment as a symbol for the very age in which we live.” (Martin, 1988, pp. 303)*

Although it seems as though many academics agree on the fact that there is indeed something special about “information” in this era, there doesn’t seem to be any sort of convergence on the form this “information” takes, where it comes from, why it is so important to the present system, and how, if at all, it is changing social, economic and political relationships (Webster, 1995). This divergence has lead to a number of different theories and arguments for and against the “information society” and this chapter will look at several of them; some that consider this “information society” to be an entirely new sort of society, as well as those who consider the society today to be a continuation of pre-established relationships (Webster, 1995).

There are several different methods that have been used to define the “information society”, but they can roughly be divided into five main groups. These different groups, titled



economic, spatial, occupational, cultural and technological, focus on the sectors in the titles and how the changes in those sectors has lead to an “information society” (Webster, 1995). As an example it can be useful to look at the technological perspective, where the main theorem is that breakthroughs in technology, more specifically the use of information technologies in all areas of the society, have lead society to become based on information (Webster, 1995). In these theories technology is very present, new technology holding a vital place and being the distinguishing feature of society. However, many of the authors are vague about technology itself, mentioning it in broad sweeping terms, not providing any usable measure of it. Without using anything testable it is argued that information technology is everywhere, as well as nowhere, leading to several questions, two of which are the questions of how to measure technological diffusion and when a society ceases to be “industrial”, going over to being “informational”. Neither of these questions seem to have a clear answer, as most of the literature on this argument seems in many ways to be technologically deterministic, stating that a new technology is invented, *then* impacts on society, forcing people to adjust; placing technology as the prime social dynamo.

*“People shape technology to fill their own needs (...)” (Castells, 1996, pp. 363)*

This technological theory does not take into account the social, economic and political processes that go into technological change and innovation, all the factors that can lead one innovation, instead of another, to be invented (Webster, 1995). Consequently this argument also has flaws that make it difficult to apply to a theory of an emerging “information society”, although is quite clear, and relatively uncontested, that technology has a vital role in whatever kind of society we are in today.

The technological argument for an “information society” shows flaws, and arguments against it abound, as is the case with the other four groups of theories. However, all the groups have one main flaw in common, namely the problem of quantifying information. Simplistically it is possible to say that some of the most basic problems with these arguments can be boiled down to the clear distinction between qualitative and quantitative measures. Quantitative measurements of information are often used before qualitative measures, a curious predilection, as it seems strange to think that the simple presence of more information is enough to break the present society from all previous systems. However, if a change in quality of information could be shown, no matter how small, the difference could seriously question whether a shift in society had not taken place (Webster, 1995). To argue that the presence of more information, the quantity of information, is transforming the quality of social life is a theorem that simply does not hold up under scrutiny (Roszak, 1986). The idea that it is merely how much information circulating within a society, not the quality of that information, that can transform it into an “information society” does not seem to encompass the complexities of the changes in society, whether they are revolutionary or evolutionary. The content of the information seems equally, if not more, important in this sense. Roszak goes on to argue that before the quantity of information increases and leads to a new quality of society there are so called “master ideas” that are central to, and underpin society as a whole, examples of such are “live and let live” and “all men are created equal”. These “master ideas” are not necessarily correct but they, and their qualities, come before the quantity increases when it comes to effect on society (Roszak, 1986).

Looking at information in general, many attempts have been made at defining it, some succeeding better than others.

*“Information exists. It does not need to be perceived to exist. It does not need to be understood to exist. It requires no intelligence to interpret it. It does not have to have meaning to exist. It exists.” (Stonier, 1990, pp. 21).*

Information looked at this way is simply anything that can be coded for transmission, regardless what happens to it after transmission. This allows for quantification of information, but no quality assessments of the information is allowed under this definition. However, to define information in non-social terms, saying it simply exists, as opposed to being created or produced by someone or something, and then follow that statement with one saying that the information must be adjusted to, that it’s social consequences must be followed, is not an adequate method of explaining social change (Woolgar, 1985). A focus on the quantity of information leads to an assumption that an increase in information leads to a more informed society. This may be assuming too much. Simply the presence of more information seems unlikely to suddenly enable people to sift through, evaluate and absorb the appropriate information. It does not seem likely that the ability to assess information will increase merely as a function of more information. An increase in quantity does not immediately lead to an instant ability to assess the quality of the information, something people are likely to continue relying on experts for. Interestingly, it is this focus on the quantification of information that has led many academics to become devotees of the “information society” theories just as where quantification is questioned, and the quality of the information is focused on, suspicion and reluctance have proliferated (Webster, 1995).

Another way of looking at the “information society” is to focus on the whole process of change. Almost all technologies have been a result of some sort of evolution, seldom popping up from nothing, but shown to have been the outcomes of evolutionary advances (Kranzberg,

1989). In order to call the Industrial Revolution a revolution a series of fundamental changes in distribution and production of goods had to take place, as well as a series of social and cultural changes. The same applies to an “information revolution” or “information society”. Keeping in mind that the mere introduction of new technology does not mean the demise of the old, the revolutionary advances in storage, manipulation and retrieval of information that have resulted in improvement in computers, by this argument, entitle the future to be known as the “information age” (Kranzberg, 1989). The computer has become a ubiquitous household item, but the question remains whether this “information age”, even if it has revolutionised the technological sector, has revolutionised the social sector.

There have been several economic changes in society; economies have become more globalised and decentralised, the dispersion of information making it impossible for complete, centralised, control (Kranzberg, 1989). In this argument as well, a decline in employment in traditional industries is alleged, and an enlarged service sector implied, although it goes on to point out that the thought that all work will, in the future, be done from home is seen as highly unlikely, pointing out that humans are social animals, appreciating intellectual stimulus and gaining social satisfaction from interaction (Kranzberg, 1989). However, it is argued that although employment might be changing sectors, old industries are not dying out, new technology is simply being superimposed onto them. As well as some changes in the economic and political arenas, made possible with for example increased communication, there are also some changes in some social processes. Machine technology has created an industrial sector where brute force is no longer a special asset, allowing women more equality. This advancing technology is said to mean that racial and gender discrimination scarcely matter in the production process in the same way they did previously. Even though the distinctions still persist in places, it is argued that we are in the middle of a social

revolution, a sexual revolution, at least through technical, if not social or wage, equality (Kranzberg, 1989). There is also a matter of a cultural lag, that is, that although technology may be allowing us to perform in new ways, that we will perform in new ways is not a given, an example of which is nationalism, a technically obsolete concept, though still very much in evidence.

According to this theory, although the “information age” might be *evolutionary*, appearing over time, it will be *revolutionary* in its effects on society (Kranzberg, 1989). This argument is more persuasive than many of the previous ones in that it does not advocate a sudden division between a new and an old society, nor a clear distinction between the two, focusing on how the changes are more evolutionary, even though they may, in retrospect, prove to have changed society dramatically.

The ongoing nature of the developments in society are also stressed by Schiller, who, although acknowledging the increased impact of information on society argues that this will have a gradual effect on society, not a sudden one (Schiller, 1984). Schiller has developed a theory of a “political economy” that looks behind the information at the structural features behind for instance newspapers, where a structural feature would be ownership, arguing that these structural features profoundly influence the content of the information (Webster, 1995). Furthermore, a systemic analysis of information and communication is said to be necessary, looking at the technology in the context of the functioning of the entire socio-economic system, a very holistic approach. The starting point in this theory is very similar to that of those who argue for an entirely new economy, in that it is argued that more information is being generated than previously, as well as the proliferation of new machinery that can disseminate this information (Webster, 1995). However, Schiller then goes on to say that

capitalism has not been transcended, there are clear features that the market economy is still as determinant as ever in the transformations in technology and information sectors. The argument takes a Marxian perspective saying that although changes have taken place, capitalism is still constant and primary, leading the focus to the role of power, control and interest (Webster, 1995). There are three major elements to the argument. The first states that there are certain market criteria present; the pressures of buying, selling and trading all in order to make a profit influence information, leading to an impulse towards the commodification of information. Added to this is the presence of class inequalities, where social class determines who is entitled information and who is not, creating winners and losers in this “information revolution”. The third element focuses on corporate capitalism and the way in which corporate priorities are important in the informational realm, where information and information technologies will be developed for private, not public ends, the focus being on profit (Webster, 1995). All these elements are clear markers of capitalism, that is, capitalism’s long established features are these key elements in the “information society”. The crux of this argument is then that if this so-called “information age” breaks with the past, creating an entirely new society, how is that possible when its traits are so clearly taken from capitalism? The suggestion that this “information society” is capable of superseding its creator is hard to believe, leading to the point that this society is a reflection of capitalistic imperatives, not an entirely new society breaking with all that is past (Webster, 1995).

From the arguments outlined above it is quite appropriate to say that the views from academia on the topic of the “information society” differ widely. Large quantities of work are being done on the issue, and new theories and points of view are surfacing constantly. In policy papers, the views differ as well, although the existence, or emergence of an “information society” is not doubted to the same extent as in academic publications. The policy view is,

like the academic view, not uniform, and as it varies widely it is not possible to outline all point of view. Therefore, the focus here will be on documents from the European Union as well as those from the Norwegian Government, as these pertain to the case study that will be outlined later on in the thesis.

In policy documents from the European Union it seems that no one theory on its own is used about the “information society”, on the contrary, several of the point of view are used concurrently. The “information society” is mentioned as making changes that will rival the Industrial Revolution, as a result of the development of information and communication technologies (ICTs), a technology based point of view (Delors-report, 1994). ICTs are here said to be transforming many aspects of economic and social life, leading to the emergence of an “information society”. It is stated that this forging of a link between technological innovation and social and economic organisation is unprecedented in its significance, elaborating with the thought that a multitude of innovations are combining to bring about a major upheaval in the organisation of activities and relationships in society. This is leading to a new “information society” where services provided by ICTs underpin human activities (Delors, 1994, Ch. 5). When describing this new society, technology, the increased use of ICTs in particular, is given a crucial role.

*“(...) the enabling technologies are the foundations of the information society” (CORDIS, 2000).*

These technologies are said to provide a means of creating, processing, accessing and transferring information that is radically changing organisations as well as relationships

*“(technology is)...changing the way we work together and the way we live together.”*

*(Bangemann-report, 1994, Ch. 1).*

New forms of economic and social organisation are surfacing where geographical location is no longer a constraint. This same report then goes on to say that this “information society” will have networks present at a number of different levels, comparing the networks to motorways (Delors-report, 1994). What is termed in the paper as the “new Industrial Revolution” (Delors-report, 1994, pp.3), is leading to an economy that is increasingly knowledge-based, with a growing services sector. In this way, the policy fluctuate between the different groups of arguments for an “information society”. However, it does not seem as if there is ever a real question of whether or not such a society is in fact emerging or present. It seems that the policy papers take the “information society” for granted, although the thought of what it means is not universal. However, there does not seem to be a single method of approaching the topic of an “information society”. In some instances it is argued that this new kind of society is one that must be chosen to enter into, or join, although not joining will lead to a disaster economically and employment wise (Bangemann-report, 1994). Then, only a few paragraphs away, this same society is no longer something existing and waiting to be joined, but something that must be created.

*”Europe must play an active role in the development of a more equitable information society” (eEurope, 2000).*

As suddenly, talk of the arrival of the “information society” appears implying something with it’s own momentum (Bangemann-report, 1994). Underlying these arguments is the thought that the technology is changing society as we know it, a technological deterministic idea. In



some of the papers technology is spoken of as a force of extreme power, appearing out of nowhere to suddenly radically change everything around us. It is interesting then to note that projections from some of these reports have not come to pass, and were in fact somewhat optimistic in their predictions (Bangemann-report, 1994), something that may suggest that what is happening, although it may be a radical change, is not a revolution at all.

A similar problem is seen with policy papers and publicised material from the Norwegian government and their Ministry of Trade and Industry. Although Norway is at present not a member of the European Union, the government has stated clearly that Norway must set goals that are as ambitious, if not more ambitious, than the EU, leading to policies and plans similar to that of the EU (eNorway 1.0, 2000). The view is that there is a global “information society” that Norway must be a part of, and the government feels that in order to encourage this participation, policy must be in place to among other things facilitate, encourage and simplify the use of ICTs in both business and public settings (Norwegian Government policy for E-Commerce). When looking at the Norwegian policy point of view, it is clear that here as well the general view is a technological one, with the introduction of ICTs and other new technologies, the main source of change. The increased use of ICTs in particular is argued to lead to a knowledge-based society.

*“Information technology is the driving force in globalisation,” (Grete Knudsen, Norwegian Minister for Trade and Industry, as quoted in Johnsen, 2000)*

Technologies are argued to be changing society, influencing where people live, family structures, organisational structures, even national structures (Knudsen, 2000). It has been stated that Norway, and the rest of the world, is traversing from a society based on industry

and oil to a knowledge-based society (Knudsen in eNorway 1.0, 2000). A date is even put on this phenomenon, January 17<sup>th</sup> 1992, the day Microsoft stocks exceeded General Motors stocks in value, illustrating the change from machines and raw labour (GM) to knowledge and creativity (M) (Peters, as quoted in Knudsen, 2000). This is happening through technological advances and globalisation, and is changing society (eNorway 1.0, 2000).

The concept of “information society” is almost seen as a given, and the government goes on to state that it means that everyone must have, or must acquire, the access, the skills and the trust to take advantage of these ICTs, and it is the government’s duty to help (eNorway 1.0, 2000). However, at times, the opinion also seems to go to broader concepts, including economic and social issues as playing a role as well (Norwegian Government policy for E-Commerce, 1999). Furthermore, the government itself is seen as having an active role in the changing of society. Through political decision the government desires to be an active accomplice to the changes made by technology (Knudsen, 2000). If the “information society” is seen by the Norwegian government, like the EU, to be a given, the problem of how to approach this society is also encountered in policy and other literature from the Norwegian Ministry of Trade and Industry. In one instance the verb surf is argued to be very appropriate not only when discussing navigating the Internet, but also when speaking about Information Technology policy, as the growth in technology is forcing the government, and people in general, to realise that they *cannot control* the waves of the “information society”, they can only attempt to steer the board with style and elegance (Norwegian Government Policy for E-Commerce, 1999). This implies the same lack of control seen in some of the terminology used in EU publications going on to say:

*“No nation or state can steer the development of technology (...)” (Norwegian Government Policy for E-Commerce, 1999, introduction).*

This approach is deterministic in insinuating that technology is created out of nothing, suddenly appearing and impacting upon society, something that seems irrational when one considers that there are people developing the technology and that they are constantly being influenced by an enormous number of things. Following on from this it must be questioned whether society does not first influence the creators of the technology, the people, before the new technology influences anyone, making it seem as though the “information society” argument is taking technology out of its context in the world and endowing it with more power than it intrinsically has.

*“The developments will run us over unless we take command and put ourselves in the driver’s seat” (Norwegian Minister of Trade and Industry Grete Knudsen in Knudsen, 2000).*

There is a constant sense of urgency in the publications given out by both the EU and the Norwegian government, repeating that if this “information society” isn’t joined or created as soon as possible, Europe, and Norway, will be doomed to be left behind the rest of the world on its mission to become a knowledge-based society. Although this may be a tool to illustrate the necessity of innovation and research, it also contributes to giving a somewhat slanted version of today’s society, and technology. It is hard to believe that it is quite so cut and dry, that technology appears and changes society, revolutionising it every so often, creating something entirely new and different. Allowing technologies, ICTs etc., to keep their place in the hierarchy of society, for instance acknowledging that they themselves are created, may allow the public to regard them with less reverence, perhaps leading to a more realistic view

of their uses and limitations. If the ultimate goal is to encourage widespread use of these new technologies, it could be more helpful to approach the topic in this way as opposed to a method that seems to imply lack of control and that may instil fear in people. A rhetoric that focuses on the revolutionary change technology will have on society will inevitably give technology a role and reputation that is not necessarily beneficial. Looking at technology, and ICTs, as huge, life changing concepts will not make them any less daunting and is unlikely to encourage professionals to use them. There is no doubt that ICTs for instance can restructure and streamline many areas, serving a definite purpose and being beneficial to an entire professional sector, like the health sector. However, with this “revolutionary” rhetoric, the introduction of technology, ICTs and Internet use in this case, seems like a vast, as well as time consuming undertaking. Perhaps changing the focus away from superlatives about the life changing capabilities of technology, focusing on their potential as tools for humans, would encourage more people to attempt to use them, something which is surely one of the aims of the entire discourse.

As it is, there is as yet no clear way of measuring whether the change in society really is as revolutionary as some would argue, therefore it seems curious to insist on such broad generalising terms in policies and publications. It could be a more successful tactic to make people look upon the new technologies as new tools for them to utilise in different areas of their lives, instead of something that will change their entire way of life forever, something we, as yet, are not even able to be certain about.

## **Chapter 3: Health Information and the Internet**

### **3.1: The Internet:**

Measuring the size of the Internet is difficult in itself with all calculations being approximations, and estimates ranging from 250 million to 500 million pages (IT-analysis.com, 2000). A study on the size of the indexable web done on figures from 1997 estimates a lower bound of 320 million pages (Lawrence & Giles, 1999), and that the Internet is vast is an uncontested fact. Furthermore, there is also a general agreement that it is constantly expanding, the latest numbers predicting that the number of web pages will exceed the world's population by 2002 (Lake, 2000). Figures of how many people are online in the world are as approximate, with data from March 2000 showing that roughly 300 million people worldwide are online, approximately 80 million of them in Europe, 140 million in the United States and Canada (NUA Internet surveys, 2000).

This difficulty of measurement and extreme growth also applies to health information on the Internet. There are at least 100 000 medical websites and numerous other health related websites, many legitimate and some less so (Eysenbach, Sa & Diepgen, 1999). Surveys conducted in the United States indicated that up to 65% of consumers had searched for health information at least once, and up to 45% of all searches on the Internet were health related (Gruen, 1999). Another survey indicated that 27% of female Internet users and 15% of male users accessed health information at least once a week (Eysenbach et al., 1999). A survey conducted by AOL, an American online service, showed that almost 6 % of their users reported that the site's health forum helped them avoid at least one unnecessary emergency room visit. The same survey showed that 26 % said it had helped them avoid an unnecessary consultation with their physician and 51 % reported that the health site had increased their confidence when interacting with their health care professionals (Gilbert, 1996). Websites like that of the National Library of Medicine in the United States; Medline, receives 1 million

visits a day, not an unusual occurrence for some of the large online health resources (Stoltberg, 2000).

### 3.2: Health Information on the Internet: A policy view.

*“...the public will someday become as comfortable with online medicine as they are using an ATM<sup>1</sup>” (former Speaker of the House, Newt Gingrich, as quoted in Breslau, 2000).*

The growth in health information on the Internet has not escaped notice among policy makers both in Europe and Norway. When discussing the “information society” electronic health services are pointed to as an important area where substantial growth is seen (eEurope, 2000). Several challenges are seen to health information online, one of them being that at present the European citizen does not have enough resources with which to assess the quality of the information on the Internet as well as pointing to the necessity for data protection and legality issues (eEurope, 2000). This area was focused on in the Delors-report as well, where it was acknowledged that services, like health, where the public authorities have traditionally played a large role, could in the future and with the help of the Internet be provided more widely, rapidly and effectively (Delors-report, 1993). The report argues that the new society will include service areas that will increasingly be dictated by the needs of users, whether they be companies or, as in this case, consumers; patients (Delors-report, 1993). When it comes to implementing reforms within the field of health and the use of ICTs the EU leaves a great deal up to each member state, making it difficult to generalise. Therefore it can be helpful to focus on one of the member states in the EU as an example, though other member states may differ.

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<sup>1</sup> ATM: Automatic Teller Machine

In the UK a National Health Service (NHS) exists and is responsible for the area of health throughout the country. The NHS state that it will be increasingly necessary to focus on enabling people to care for themselves and their families by providing good advice and information (The New NHS, 1997). The NHS aims to focus on the needs of the patient, putting them at the centre of the care process, involving the patients in developing a Health Improvement Programme (The New NHS, 1997). In order to meet the public's need the NHS argues that information about health and health services must be available to them, recognising that patients need information about their problems as well as treatment options and potential outcomes (NHS Executive, 1998). One method of providing the patient with health information is through an information gateway named NHS Direct. At present this is a phone line serving parts of the country, that enables the public to speak to a nurse about health related issues. Although the goal was to make this service available nation-wide by the year 2000 (The New NHS, 1997), this has yet to happen, though a website by the same name has been created to support the telephone help line (NHS Executive, 1998). At present NHS Direct covers two thirds of the population in England. A caller speaks to a call handler who is capable of answering any general questions about the NHS, if, however, the caller is enquiring about specific symptoms, they are transferred to a nurse. The nurse uses a computer package with guidelines on a range of different conditions to question the caller in order to assess what advice to give (Mayor, 2000). The help line, and the website, hope to enable people to more easily treat common health problems at home, encouraging appropriate use of the NHS and advise the public on how best to use their local health care professionals (Gann, 1999). Implied in the publications and publicity material on NHS Direct is the idea that through the use of these services, the help line and the website, the public will be more able to find reliable health information, ultimately leading to less use of face to face consultations



with health care professionals. Through the use of interactive services the public will be less inclined to physically consult with a health care professional, leading to a different structure in the health system. Research done on NHS Direct has shown that in the first year of implementation this shift has not been seen. NHS Direct has not reduced the pressure on the immediate health services, with the only apparent change present in the slight decrease in demand on general practitioners' out of hours services (Munro et al, 2000).

Some of the initial thoughts expressed by the NHS are supported by the publications and policies of the Norwegian Ministry of Health and Social Affairs (NMHSA). The NMHSA goes so far as to state that the most central aspect of any health service concerns information, both procuring it from patients and providing it to them (NMHSA, 1996). Here as well focus is put on empowering the patient by providing them with high quality information, as well as stating that increased use of ICTs for patient journals and the like will free up the health care professionals' time, allowing them more time with the patient (NMHSA, 1996). The main emphasis is on the way in which the health service wishes to be in a partnership with the patient through increasing the patients' knowledge, awareness, and control in the area of health. An electronic patient journal is seen as the central piece in the new, interactive health sector, making information available to the health care professionals, the patient, and to a certain extent, their families. Most of these ideas mentioned are ones that the NHS and the NMHSA have in common. However, they seem to disagree on one aspect. Where the NHS points out that through use of ICTs the public will have *an alternative* to seeking face to face consultations with health care professionals, the NMHSA points out that ICTs are merely *a tool* to better the existing health services, in particular by freeing the health care professionals from hours spent doing paperwork enabling them to spend more time with patients (NMHSA, 1996). Consistently, ICTs and interactive services are regarded by the NMHSA to be devices

to improve the services offered by them. It is thought that the health service will become more efficient through information sharing and the use of both regional and national health networks, something projected to be in place within the next three years (eNorway 1.0, 2000). Although the NHS is more optimistic than the NMHSA when considering the impact of the use of ICTs and interactive health services, both consider these technologies as having a profound influence on the health system in their country. This view is one that is supported and expanded on by a number of academic sources.

### 3.3: Health Information on the Internet: an academic view.

Physicians have always been faced with a constantly expanding and evolving information base, forcing them to spend considerable time in the attempt to keep themselves up to date. The health care industry is an information intensive industry that depends on the development and interpretation of specialised knowledge (Tyson, 2000).

*“I thought of the airline pilot who was thoroughly familiar with the instruments in the cockpit yet still had to go through a checklist before takeoff and landing. And as a passenger, I was reassured by the process. I decided that I would want my doctor to look things up. (...) the computer could be of help to doctors and patients in the future of medicine.” (Slack, 1997, pp. xiii).*

The future mentioned in the quote above is no longer the future but the present, and the growth in both the amount and use of health information on the Internet has led to the definition of a new academic field within medicine, namely cybermedicine. A hybrid of medical informatics and public health, cybermedicine focuses on the use of the Internet in the

field of medicine, its impact and limitations, as well as the opportunities and challenges for health care (Eysenbach, 1999). This field is seen as important, because among other topics it looks at how the Internet is, at an unprecedented rate, providing opportunities for better access to information, something that could seriously affect the health care sector. Although this could become apparent on many different levels in the health sector, many of the initial effects seem to be linked in some way to the relationship between health care professionals and patients. This section will seek to focus on some of the aspects receiving the most attention. However, first it must be pointed out that the Internet and health information on the Internet are often looked upon as a single large issue and treated very generally. While studying health information on the Internet it has become clear that it is important to realise that it is not a simple issue, quite the contrary, it is a complex, multifaceted issue. Different sites on the Internet serve vastly different purposes for the users, making generalisations treating all health information on the Internet as the same entirely inappropriate. Furthermore, when tackling large issues such as those bellow it is important to keep this in mind and remember the dangers of overgeneralization.

The case study detailed later on in this dissertation will help to illustrate more clearly how health information on the Internet is really too broad a term, and that questions regarding these issues should, as questions regarding any aspect of the Internet, be looked at within the context of the specific website. In the following sections four issues considered to be central in the academic research on health information on the Internet are explored. These same issues will be addressed through the case study. However, these four issues are not treated as equal. The overriding issue addressed is whether health information on the Internet is a supplement or substitute for contact with health care professional. The three other issues are each a facet of that discussion, showing the complexity of the question. In discussing whether

health information is a supplement or substitute, democratisation, the participating patient and the quality of the information on the Internet are issues that are often brought up and are central to arguments. It is hoped that the academic discourse introduced and the case study will be able to show why the supplement argument is a sounder one, as well as raising other interesting questions about the future of the patient—health care professional relationship.

### *3.3.1: Supplement or Substitute?*

In order for patients to feel able to question their health care professionals about their health, they must feel at ease with them. Findings that patients often append their real concerns to questions initiated by their physicians or only imply them, instead of clearly stating them due to a fear of ridicule or embarrassment, lead to worries that patients may feel unable to pose questions about their own health in consultation with their health care professionals (Lang, 2000). Armed with information from the Internet patients may feel more confident approaching their health care professionals, and therefore be more able to engage in informed dialogue in order to decide on the care of their own bodies and minds (Weed & Weed, 1999). The quality of the information allowing the patients to feel empowered can almost be considered irrelevant, as the importance lies in the ability to feel more included and confident in the interaction with their health care professional. Studies show that computer-based patient education supports the communication that takes place between health care professional and patient (Lewis, 1999). However, in order to act upon the information gathered, it must be evaluated, something the health care professionals are much better suited for than the patients. Recognising that this role for the health care professional, though perhaps inevitable, could prove more time consuming than is reasonable, this must be communicated to the patient. In order to collaborate fully, perhaps the patient must bear most

of the information gathering burden, sifting through the information and summarising it in a consultation with the health care professional. The health care professional's role will become more advisory, more analytical and interventionist.

*"...(the role of doctors will change from)...unquestioned guru to a partner or collaborator."*  
(Ferguson, in Geraci & Swierczynski, 1997).

Health care professionals will need to be experts in assessing information from diverse sources, a new role to take on, but a necessary one (Yellowlees & Brooks, 1999). In order to accommodate this role, changes in health care professional training may need to occur, tailoring responses to different models. For example in a medical crisis the health care professional, the physician in particular, would need to communicate competence and provide direction and guidance, while in most other situations, including those requiring long-term interventions, training in the language and skills of collaboration as well as avoidance of paternalism would be more important skills (Lang, 2000). Health care professionals could also, as some have already realised, gain further insight into how their patients feel by visiting online support groups and other health related chat groups (Ferguson, as cited in Gilbert, 1996).

The relationships are shifting so that in the future health system it is the patient that decides what information is delivered to them, not the authors or professional experts. Already there exists proof of this, a study showed that half the online users of an American health site said they would be interested in using a website operated by their physician's office, and 29 % of them said they would change physicians in order to do so (Cyberdialogue, 1999). By allowing the patient to take on more and more responsibility for their own treatment, for instance

through the use of the Internet, physicians can free themselves from some of the responsibility of unwise decisions or outcomes. A decision shared with a patient is a way of dealing with the uncertainty of medicine, an uncertainty that may be more willingly acknowledged by both health care professionals and patients (Laine & Davidoff, 1996). However, it is important to remember that irrespective of how good it is, online information *cannot* replace the vital personal relationship between health care professionals and patients, although it *can* make them more knowledgeable, and better able to work together as a team (HON, 1999).

*“...any doctor who could be replaced by a computer deserves to be.” (Dr. W. Slack, in Slack, 1997, pp. 82)*

### *3.3.1.a: Democratisation of Health: The patient as a consumer.*

It was the dependence on the evaluation of specialised knowledge, among other things, that lead the medical profession to become relatively paternalistic, making paternalism almost an essential component for care. The power balance was far from even, the self-reliance of patients low, and the mantra “the doctor knows best” became common (Slack, 1997). The turning point for medical publications came in 1946 with a book by Dr. Benjamin Spock titled *Baby and Child Care*. Although criticised by the American Medical Association, specifically for being too permissive, the book obviously filled a niche, encouraging parents to trust themselves when caring for their children and giving advice to allow them to feel more secure in their roles as parents, empowering them (Slack, 1997). The book could be kept close at hand and consulted for quick reference whenever people wanted, it was accessible from home, convenient and comfortable to use, criteria that are now being met by computers and the Internet as well.

At the moment, the health sector is moving gradually away from episodic treatment to more continuity of care, the focus being shifted towards wellness promotion, away from a singular focus on illness treatment (Yellowlees & Brooks, 1999). The patients are more and more often being looked upon as consumers of a service, the health service, and through that a central theme has become to supply the client (patient) with information (Hardey, 1999). This is spurred by the fact that with increased information, the patient is increasing his/her participation in his/her own health. Through this, it is claimed that the health care professional-patient relationship is set to change and become more intensively run by the patients themselves (Yellowlees & Brooks, 1999), who are increasingly meeting their health care professionals armed with Internet printouts (Baker, 1999).

*“Suddenly, for the first time in the human history, patients have virtually the same access to the same information that doctors have.” (Dobson, 1999, pp. 1).*

This statement is one that is repeated in different forms in different fora, and points out that due to the Internet in particular, patients are increasingly able to access the same information bases their health care professionals use. The Internet is a medium that allows anyone with a computer and a modem to have access to expert knowledge (Hardey, 1999). The views on the effect that this increased access to information will have on medicine as a field differ enormously. Some feel that an educated patient, with the access to the same information as the health care professionals, will lead to a higher quality of health care, where the patient will be able to challenge the health care professionals and keep them up to date (Thompson, 1999). In this argument, the Internet provides a pool of resources available to both health care professionals and patients, allowing for more patient involvement in decision making, and

encouraging health care professionals to deliver high quality health services (Eysenbach et al., 1999). With a more patient-centred approach to medicine, the focus in the relationship between the health care professional and the patient shifts from compliance to participation (Laine & Davidoff, 1996). The Internet is here seen as an extremely positive addition to the health sector.

*“The Internet has transformed the relationship between the patient and the physician, much in the way parents’ relationships change with their children once they become adults.” (Ferguson, quoted in Albert, 1999, pp. 1).*

Active participation from the patients makes their relationship with health care professionals more of an equal partnership, providing that the health care professional is supportive to the participation (Ferguson, as quoted in Albert, 1999). Health information can transform the patient from passive recipient to active participant in their own health care (Laine & Davidoff, 1996). This is the key to the democratisation process in this field. Here, the patient has, through greater access to health information, reached a certain level of equality with the health care professional. This equality is something the patient feels deeply and appreciates. Also, as a result of the greater access to information, the patient has been able to claim a larger part of the responsibility for their own health care. This claiming of responsibility has created the so-called participating patient, and more favourable treatment outcomes have been seen in certain cases as a result of it (Greenfield, Kaplan & Ware, 1985). The informed patient is often seen to have better treatment compliance and better treatment outcomes (Miles, as quoted in Stoltberg, 2000), and numerous studies have been done in order to understand the possible reasons for use of the Internet in this way.



### *3.3.1.b: The Participating Patient*

A study looking for possible reasons why this purported new breed of patients use the Internet rather than, or as well as, questioning their own health care professional found several possible explanations (Eysenbach & Diepgen, 1999). The patient's possible feeling of helplessness in the face of a diagnosis was one of the explanations found, where information seeking behaviour was done to compensate for these feelings. Another possible reason for use of the Internet was the anonymity it provides its users with, allowing them to pose "stupid" questions or enquire about more intimate matters. In some cases the information asked for is not for themselves but about diseases friends or relatives are suffering from, or it might simply be that a patient has a question s/he has forgotten to ask their health care professional during a consultation (Eysenbach & Diepgen, 1999). In yet other cases, especially those in which a certain method of treatment has failed, patients no longer trust their own physician and hope to find something new on the Internet. Although this group is not necessarily in majority, health care professionals often seem to be under the impression that they are, leading that thought to guide their feelings on informed patients in general. The view is that the informed patients have become distrustful of health care professionals, wanting to arm themselves with information from other sources before consulting with them (Stoltberg, 2000). The increased amount of information available has left health care professionals and patients uncertain about whether the limitations they experience in medicine are inherent or a reflection of deficits in the health care professional's expertise (Quill & Brody, 1996). Scepticism in health care professionals in the lay population has increased as a demystification of medical expertise has taken place (Hardey, 1999). Patients are less willing to trust the health care professional's opinions, something that can be seen in cases involving disputes over care (Dobson, 2000). For some patients it is no longer enough to know only

their diagnoses, they also want patho-physiological details, all possible treatment options and prognoses. Furthermore, patients are more readily inclined to challenge their diagnoses, demanding information that has previously only been within the health care professionals' reach (Laine & Davidoff, 1996). If the information the patient has found on the Internet does not agree with or is unknown to their health care professional, a serious conflict can arise, as well as the cases where information of an effective treatment method is found when that treatment is not available to the patient (Jadad, 1998). This type of behaviour by patients has been dubbed Internet Print Out syndrome (IPO), because the health care professional is met with exactly that, a patient with a stack of printouts they want them to look at (Brown, 2000). The health care professionals' reaction to this type of behaviours can vary greatly, ranging from irritation, hostility, fear or dismissiveness, the most common one being fear (Brown, 2000). The health care professional may feel that s/he is being forced to spend a lot of time dealing with this information, as well as feeling threatened by the implication that their diagnosis or management is being questioned. The feeling of fear often stems from the thought that the patient knows more than the health care professional, and has gained an upper hand by presenting information the health care professional may not be aware of (Brown, 2000). Any and all of these situations can lead to an urge to treat the information dismissively. Studies that have been done on these types of situations have lead to conclusions urging the health care professionals to take these patients seriously (Pemberton & Goldblatt, 1998). Although health care professionals may feel threatened by the use of online resources, that type of attitude may undermine their relationship with the patients and in some cases lead to the patient seeking advice elsewhere, perhaps in disadvantageous environments. This type of behaviour is not really very unusual, as people will often aggressively seek out information to help them understand and cope with medical conditions they or their loved ones have been diagnosed with, especially if the condition is rare (Pemberton & Goldblatt,

1998). Recognising that reviewing printouts may take up valuable consultation time, it is suggested that it would be useful for the patients to send their findings to their health care professional in advance, whether by e-mail, fax or post. These studies urge the health care professionals to recognise the patients, or their families, as useful research assistants able to hunt for information in a way the health care professional may not have time for. When it comes to the assessment of the information however, it becomes apparent that even the “participating patient” cannot replace a health care professional.

### *3.3.1.c: The Quality of Health Information on the Internet.*

Though the patient may have more time and possibility to access information on the Internet, the balance in the relationship with their health care professionals is not difficult to maintain, due to the fact that the health care professional is more qualified to assess the *quality and relevance* of the information accessed (Brown, 2000). This is a critical point in the discussion of health information on the Internet and the health care professional- patient relationship. Perhaps one of the main reasons for scepticism and mistrust in the shift in the relationship, especially from the health care professional’s point of view, is due to the extremely variable quality of the information available on the Internet. Even though Mark Twain was remarking books on health and not the Internet, no doubt many health care professionals would agree with him when he warned:

*“You may die of a misprint.” (Twain, as quoted in Foley, 2000, pp.1).*

Although the Internet is many things; a shopping mall, a library, a museum, a university, a health information provider as well as an entertainment vehicle, it also has the ability to create

an environment of chaos and information overload, completely overwhelming users, no matter what their level of expertise (Eysenbach, 1999). There is a vast amount of information on the Internet, on all topics, but not all the information is of the same quality. When searching for information on a health question, sites can range from those of the pharmaceutical companies giving one point of view, sites from different groups of health care professionals, as well as sites from followers of alternative medicine and homepages of individuals suffering from a condition. Each of these websites are influenced by a number of different issues, constructed by a number of social factors, including founders and sponsors to name a few. Even the most fervent Internet enthusiast will agree that the information there, on any topic, can be far from valid, partly due to the ease with which something can be posted on a site. When faced with this plethora of choices it can prove near impossible for a user of the Internet to decide what information to trust and what to doubt; what to discard and what to keep. Mere common sense does not always guide the user to the correct information, especially if their common sense is coloured by worry and hope for information their health care professional is unaware of. Many sites are unclear as to where the information they display comes from. The material accessed through hyperlinks may seem to the user to come from the site that presents that frame, and they may move between different countries and even continents without being aware of even having left the site they first accessed (Hardey, 1999). Where health information is concerned this can be especially damaging, providing information which is invalid in the home country of the user. The way in which all information on the Internet is shown in an equal manner allows the user to make assumptions about the expertise behind the information, effectively dissolving the expertise upon which the medical profession have derived much of their power (Hardey, 1999). This may benefit the less orthodox medical sites, giving them the symbols of power and authority they have previously lacked by presenting them side by side with orthodox sites (Saks, 1992). Although

health information is no longer the exclusive field of health care professionals (Coiera, 1996), there have been cases where sites run by physicians have received complaints due to their obvious blurring of the line between objective information and advertising and promotional content (Charatan on DrKoop.com, 1999).

Several studies have been done on the quality of the content of health websites with interesting results. One, done through a search for information on home management of feverish children, retrieved 41 web pages, finding that only 4 of them adhered closely to the main recommendations in medical guidelines (Impicciatore et al., 1997). A study at the University of Michigan found that one website reported a mortality rate for a type of bone cancer to be 5 %, while in reality the mortality rate is closer to 75 % (study quoted in Gottlieb, 2000). These as well as other, similar results have led to a focus on informing the users on aspects to look for in order to better judge the reliability of the information on a website. Although there is a vast quantity of information on the Internet, not enough attention has been paid to how the information is being delivered to the users (Shaughnessy & Slawson, 1999). This problem is gaining more and more attention, and guidelines to follow when looking for information on the Internet are to be found a number of places.

Almost all lists of guidelines mention that it must be clear who is posting the information, what their credentials and affiliations are, as well as possible conflicts of interest (Modica, 1998). Knowledge about an affiliation to a pharmaceutical company for instance can cast a very different light on the information provided on a site, as it is, these affiliations are sometimes hidden and take a lot of digging to unearth (Charatan, 1999). The currency of the information, judged through disclosing when the site was last updated, is also important, allowing the user to make a decision on the probability of outdatedness (Shepperd, Charnock

& Gann, 1999). These three: authorship, disclosure and currency of the information, as well as attributing the information clearly to research sources where appropriate, are considered minimum standards for health information on the Internet (Silberg, Lundberg & Musacchio, 1997). However, it has become clear that issuing users with guidelines is not sufficient, and a number of non-profit organisations have surfaced to help the user assess websites, one example being Mitretek (Hardey, 1999). Through its Health Information Technology Institute and Health Summit Working Group, Mitretek has developed a set of criteria to use in assessing the quality of health information on the Internet, publishing a policy paper outlining these (Mitretek, 1999). Similarly, in the United Kingdom a project named DISCERN has emerged, funded by the British Library and the National Health Service and run by the University of Oxford Divisions of Public Health and Primary Health Care, the Help for Health Trust, and the Buckinghamshire Health Authority. DISCERN was developed to provide consumers with a tool to judge the quality of health information, and although the focus was written health information, an online version of DISCERN is being developed, having started with a DISCERN website (Charnock & Shepperd, 1999). This tool hopes to play a key role in ensuring that consumers are able to take a more active role in their healthcare (Charnock & Shepperd, 1999). A third option for users is the Health On the Net Foundation (HON), another non-profit organisation based in Geneva. HON publish guidelines (the HON Code of Conduct), user-friendly search engines, as well as providing users with a portal through which they can access websites that have been vetted by HON (HON, 1999). There are also websites that focus solely on outlining and explaining faulty reasoning or dubious links, like Quackwatch<sup>2</sup>. This site is run by a group of volunteer health care professionals concerned by the quality of the information on the Internet (Coburn, 2000). It is necessary to keep in mind that users may never notice, or if they do notice, may choose to

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<sup>2</sup> <http://www.quackwatch.com>

ignore, evidence for or against the benefits of the evaluation of the information on the Internet, just as they often do with paper-based information (Jadad & Gagliardi, 1998). It is here, according to studies, the health care professionals come in. Although patients have the same access to information as the health care professionals, the health care professionals have the expertise to evaluate that information.

*“...physicians have a duty to guide patients through the information jungle...” (Eysenbach, 1999, pp. 385).*

## **Chapter 4: Midwifery Information on the Internet: the case of BarniMagen.com**

Having already pointed out the vast quantities of information on the Internet, and the quantity of health related information on the Internet, it is not hard to believe that a website or webpage can be found on almost any ailment, both real and imaginary. In order to find an example of how operators and users of such a website view the place and purpose of online health information a specific site for a case study was selected. Due to the vastness of the Internet, it was regarded as necessary to select a specific topic within health, and the choice fell on midwifery.

When a search on the Internet was performed, using a reputable search engine, a total of over 1 million hits were found using the search words pregnancy, childbirth and midwife (AltaVista, 2000). The services offered and the scope of the sites varies tremendously, even if only looking at a handful of them. Some offer herbal remedies and alternative advice such as ideas of what to do with the afterbirth as well as suggestions for baby names, while others are set up by midwives to outline what they do and offer their services and expertise. Yet other sites are set up by parents to help others who are looking for the answers to questions they themselves struggled with, and quite a few large, general health websites offer pages dedicated to pregnancy and childbirth. Companies that are focused on babies or healthcare often also have pages that are dedicated to pregnancy as well as promoting their products<sup>3</sup>. Some of the information on these different websites is supplied by lay-people, with varying degrees of accuracy and credibility, while others provide information from health care



professionals. The target audiences vary as greatly as the contents of these sites, some of the sites are entirely unofficial, targeting parents and stating clearly that no health care professionals are present on the site, while others are meant for both health care professionals' and patients' use.

The website selected for the case study here is a Norwegian midwifery website called *BarniMagen.com*<sup>4</sup> that was started in February 1999. This particular website was chosen for a number of reasons, one of them being the recency of its launch which, paired with the previous experiences of both the users and the providers of the information, would allow for some comparative comments about off- and online experiences, however subjective. Another reason was the immediate and somewhat surprising success of this website in Norway, where user numbers boomed at an unprecedented rate within a very short period of time after the launch, leading to questions of the site's appeal to users and its place within the health sector.

#### 4.1: Introducing BarniMagen.com:

BarniMagen.com (<http://www.barnimagen.com>) was launched through an article in one of the broadsheets with the widest distribution in Norway, Aftenposten, under the title "The Virtual Female Society: Online with Midwife Siri" (Borud, 2000). The article was published on February 5<sup>th</sup> 2000, introducing the website, its midwife founder, Siri von Krogh, and the services BarniMagen.com offered. Although the site offers a number of different services, the one focused on in the launch article was the fact that pregnant women and their partners, as well as anyone else concerned with pregnancy, could, after registering with the site, send in questions on any related topic and Siri von Krogh would answer them within 24 hours. In the

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<sup>3</sup> Some websites are listed at the end of the references.

first week the first question after registration was free, the following ones costing 49 NKR (approximately £3.50). The initial offer resulted in 50 e-mails a day, and with about four e-mails taking an hour to answer the offer was difficult to sustain over time, forcing von Krogh to stop this free offer. Everyone who knew anyone who was pregnant was contacting the site asking questions on just about any topic. Now that each question costs the users 49 NKR, the site receives between 5 and 10 questions a day, something von Krogh can easily handle herself. However, even though the site receives fewer questions than the first week, the number of users is ever increasing, and it has been remarked that in order to maximise a profit a lot of the information on the site should be less accessible than it is, charging for access to that as well. In answer to that von Krogh can only shake her head, saying that in her opinion that is vital to the site, that the information there is readily accessible to anyone who wants it, that there is an obvious abundance of information available to the users.

This view proved a hit with users as shown by BarniMagen.com's first week online with over 600 registered users, over 230 000 hits and an average of 10 minutes spent on the site by each user (Verdens Gang, 2000). The enormous popularity of the site lead von Krogh to hire on a second midwife, Trine Lise Bakstad<sup>5</sup>, to help answer the many questions. A month after its launch the site could boast over 1500 registered users (Unnersaker, 2000) and two weeks later 10% of Norway's pregnant women who had access to the Internet, over 2250 women, were registered users of BarniMagen.com (BarniMagen.com, 2000)<sup>6</sup>. By this time Siri von Krogh had assembled a panel of experts to answer any questions not strictly within the midwifery field, including a gynaecologist, Åsle-Marit Ullern, an acupuncturist, homeopath and doctor, Bernt Rognlien, a paediatrician and specialist in children's diseases, Jon Steen-Johnsen, a

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<sup>4</sup> Roughly translated this is a colloquial expression meaning "baby in the tummy".

<sup>5</sup> Bakstad no longer works with the BarniMagen.

psychologist, Knut Halfdan Svendsen, as well as a third midwife, Jorunn Kverndalen Frisch<sup>7</sup>. It is von Krogh's job to decide which questions she answers herself and assess which questions to send to different members in their expert panel, be that the gynaecologist or the acupuncturist and homeopath. Questions are sent on when they are on topics she feels she lacks training in, often highly technical medical questions requiring specialist knowledge. Von Krogh sends these questions on the moment she receives them, and the user is told that their question requires more specialist knowledge, has been sent on, and may take longer than the 24hrs a midwife question takes to answer.

To focus only on the fact that it is possible to have questions answered from health care professionals via the site, does not do it justice. It seems wrong to assume, as is often done about the Internet in general, that this website only offers its users one type of service. BarniMagen.com includes a number of different services targeting different aspects of pregnancy and serving different needs in an expecting couple. This is also a reason why focusing on a single website is beneficial in that through a comprehensive understanding of one website it is possible to understand the complexities existing in most websites, the complexity of the Internet. Having done this it is possible to recognise that BarniMagen.com is not one single thing to its users, but several things at once; it is an information channel, a shopping mall, a doorway to other sites, and a mode of communication to name but a few. Therefore, in order to better understand BarniMagen.com the site will be described in detail below.

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<sup>6</sup> Numbers from June show a record of half a million hits as well as over 3700 registered members of BarniMagen.

<sup>7</sup> Kverndalen Frisch will be increasing her participation starting summer 2000.

When accessing the website at <http://www.BarniMagen.com> the site's home page<sup>8</sup> is reached where some recent news reports can be seen as well as any news about the site in general and the information it offers. The home page is updated every few days to incorporate new additions to the site and news from other media. Here, there are two different menus giving access to the different services BarniMagen.com offers, most of which can be accessed without registering with the site. Running vertically along the right side of the page is a strip of adverts, something that is repeated on all the different pages of the site, as well as a banner of advertising along the top of the page that flashes different adverts. The two menus on the home page, one running horizontally and the other vertically, offer different types of services for the users; the horizontal one focusing on the interactive services, some of which require registration, and the vertical menu offering more general informative pages.

#### *4.1.1: Information services.*

On the vertical menu the first option for users is a page called "From week to week" that allows them to follow their pregnancy from week to week, detailing what stage the foetus is at and giving tips appropriate for that particular stage in the pregnancy. Next there is a page, "Kjerringråd"<sup>9</sup>, offering tips from user to user and from the site to the users. These tips are not necessarily scientifically proven, based more on experiences from others and old wives tales, including tips on how to avoid neck pains and methods on handling morning sickness. Following this, there is the page labelled "News", where articles taken from newspapers, magazines and other publications concerning pregnancy and childbirth are summarised giving everything from statistical information on baby names to economic tips for expecting parents

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<sup>8</sup> See appendix for example of home page

as well as articles published about the site itself. The next section on the site is entitled "Topics" where more central questions are explored with lengthy articles incorporating tips and information. Here a smaller number of topics are looked at in depth as well as providing links for specific areas of information on for example twin/triplet-births and ultrasound exams. In early May 2000 two sociology students from the University of Oslo wrote a paper on BarniMagen.com and this paper in its entirety is also available from this page (Bråten & Solsvik, 2000).

A section entitled "My story", where users can share positive and negative experiences in their pregnancies with others, follows the "Topic" section. This is followed by a section called "Birthplace", where details of the different areas of Norway and the places where users can have their babies delivered are outlined. From 2001 a law will stipulate that people are free to choose where they want to deliver their baby within the region they belong to. Already many regions are allowing people this choice, and on this page each hospital is shown with information about the treatment available there. The information includes average births per year, the length of stay allowed, the types of pain relief available (Epidural to acupuncture), whether there is a midwife assigned to each patient and visiting information for fathers and siblings. BarniMagen.com has the support of the Union of Professional Midwives in Norway, making the information on this page very accurate. Following this, there is a page that acts as an online dictionary, "From A to Å"<sup>10</sup>, which details the meanings of words and terms connected to pregnancy, often medical in their origin.

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<sup>9</sup> Roughly translated, this means "old women's remedies", however the term in Norwegian encompasses more than remedies in that it includes information ranging from tips to wisdom on everything from weather to medicine, often with historical references, and often based on tradition.

<sup>10</sup> "Å" being the last of the 29 letters in the Norwegian alphabet.

When BarniMagen.com was opened, Siri von Krogh pledged to give the first 100 "BarniMagen-babies" their own webpage on the site, and that is what the next page details. Here at "New-born" pictures of the babies born to users of the site can be seen with links to their webpages. Next, the panel of experts used by the site is introduced in "Expert panel", including pictures and detailing each of the members' academic and professional background as well as speciality areas. The last two pages on this menu give more specific information about BarniMagen.com, starting with "Our sponsors", where, as the name suggests, the corporate sponsors of the site are introduced.

There are four main sponsors, including an online bookstore, Bokkilden, a patisserie, Kristines, an online store for baby and toddler equipment, Jacadi, and one of the largest pharmaceutical companies in Norway, Nycomed. Each of the sponsors offers in co-operation with BarniMagen.com information and services specifically aimed at expecting parents. The final page titled "About BarniMagen.com", is exactly that, a page about the mission behind the site, the people who started it and those who run it.

#### *4.1.2: Interactive services*

The menu running horizontally along the top of the main page at BarniMagen.com offers access to, as has been mentioned, the more interactive services BarniMagen.com has. The first of these is the users' "own page", protected with a username and password, where a registered user of the site can write a day to day personal diary, allowing them to see their own progression through the pregnancy. The next option is the one that has been focused on by the media, the offer to pose the midwife a question. Any question can be posed, the user is billed for each question and an answer can be expected within 24 hours. However, if the

question is technically or medically complex, needing to be forwarded to the gynaecologist or the paediatrician for example, it may take a day or two longer, something the user is informed about within the first day. The users are billed to their own addresses, information the users are urged to send from their secure “own page”.

Following this is a page dedicated to telling the users about a telephone line the website has recently opened. Here the users are able to communicate directly with the midwives, reverting to e-mail if the number is overloaded. The next page offered to users is the discussion page run by the site. This page allows users to talk to each other about any topic they are interested in, ranging from talks about miscarriages and stillbirths to expecting twins, or being pregnant in foreign countries. This provides the users with the opportunity of helping each other with whatever they are concerned about and also allows them to be completely anonymous if they so choose. Through this page there are also links to the pages dedicated to due dates in specific months, allowing the users to have contact with other users with due dates close to their own. The last two options concern themselves with the Internet more specifically, the first being a collection of links for the users. Through these links, the user can explore website in the United States, as well as other Scandinavian sites and British sites. The final option offers a guide of the website, detailing the content of each of the other pages and how best to use them.

#### *4.1.3: Future plans*

The present services offered by BarniMagen.com seem to be only the beginning of what von Krogh hopes to offer users in the future. There is talk of publishing a book with the most frequently asked questions from the site as well as endorsing pregnancy related products. The

site has recently made it possible for users to call a phone service in order to ask their questions “live”. If the call cannot be answered, it will be diverted to e-mail and the answer will be delivered in the same way. This brings up an interesting point when thinking about the development of technology. This example illustrates how the development is not always linear, that “old” technologies are not necessarily abandoned for new ones. In fact it is quite the contrary in this case, here, a service based on a new technology is “reverting” to another, older, technology, a development worth noting.

There is a new site due to be opened by one of the television companies in Norway, focusing on health<sup>11</sup>, where there is talk of BarniMagen.com representing the pregnancy and birth part of the site. The new site would act as a portal to BarniMagen.com, its opening coinciding with BarniMagen.com’s planned expansion to include 0-18 month old babies, with a nurse present on BarniMagen.com to answer questions. There is already a psychologist specialising in children with behavioural problems present on the site whose involvement will increase, as well as the possible inclusion of another psychologist, one with experience from grief groups, to offer help in some of the more difficult situations experienced by expectant and new parents.

The site is in the process of being translated, first to the other Northern European languages; Danish, Swedish and Finnish, then to English. Local midwives in the countries of origin will run each of these new sites. With the opening of an SMS<sup>12</sup> service as well, providing the users with different tips and pieces of information throughout the week, von Krogh does not seem to be short on ideas of how to evolve the site, something that paired with an unending enthusiasm bodes well for BarniMagen.com.

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<sup>11</sup> TV2 “God Helse”



## **Chapter 5: The Case Study**

### **5.1: Methodology**

In order to fully understand BarniMagen.com and its background, the founder, as well as two other health care professionals involved in the site, were contacted. Interviews were conducted with the founder, Siri von Krogh, a paediatrician consulting on the site, Jon Steen-Johnsen, and a gynaecologist, also consulting on the site, Åsle-Marit Ullern. The meetings all took place in Oslo, with Siri von Krogh on June the 6<sup>th</sup> 2000, Jon Steen-Johnsen June the 7<sup>th</sup> 2000, and Åsle-Marit Ullern June the 9<sup>th</sup> 2000.

As well as interviews with health care professionals involved with BarniMagen.com, von Krogh was contacted and asked to post a short message on the site detailing the research and asking users of the site for their help, something she agreed to. The finished message made it, thanks to the team at BarniMagen.com, very simple for users to get into contact leading to a number of very enthusiastic volunteers for the research. A questionnaire was made to ask those who had volunteered about themselves, their use of the Internet, and their use of BarniMagen.com<sup>13</sup>.

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<sup>12</sup> Short Message Service: text messages on mobile phones.

<sup>13</sup> See Appendix

Keeping in mind that all the participants volunteered their help, that they self selected themselves, there are questions about how representative they are of the entire user group at BarniMagen.com. However, the answers given seem to imply that most of these women are in contact with several other users of the site and have considered and thought about the different implications of each question before answering it. As well as this, their answers have not been looked at as truths and unquestioned facts, for that they are too little a percentage of the entire user group, but as indications of how users of the site might think about midwifery information and the Internet. It is understood that simply by using an Internet site for information places these women in a group that would be more likely to praise that type of information over traditional sources, and perhaps be eager to replace some of the traditional methods with the Internet.

The users who participated in the study were assured of anonymity and were told that they were free to leave questions blank if they did not feel comfortable answering them. The questionnaire was piloted and found to be satisfactory, it was then sent to roughly 30 women via e-mail, 26 of whom responded. The information gathered from the interviews and the questionnaires is presented in the form of text and quotes. All the interviews were recorded on tape in the interest of accuracy<sup>14</sup>. Both the questions posed to the health care professionals and the questions on the user questionnaire focused on the four subheadings corresponding to the main topic areas introduced in chapter 3: Supplement or Substitute?, Democratisation of Health: The patient as a consumer, The Participating Patient and The Quality of Health Information on the Internet. Although information was gathered on all these topics, the main area of concern here is the question Supplement or Substitute?. Therefore this area is given more attention.

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<sup>14</sup> All the quotes have been translated by the author.

After a section detailing the respondents, and a short history of BarniMagen.com as told by von Krogh, the information given by the 26 participants in their answers, as well as the information given by the health care professionals involved in the site in the interviews, has here been collated and will be presented under the subheadings detailed earlier.

## 5.2: Respondent biographies:

### *5.2.1: The Founder:*

The midwife founder of BarniMagen.com, Siri von Krogh (38), is herself the mother of two children, a two year old and a seven year old. The family lives in Oslo, and von Krogh works from their home. She has been a midwife for ten years, working at the Central Hospital in Akershus<sup>15</sup> where she still practises on a part time basis, although most of her time is spent at home, on BarniMagen.com. On the question of how long she has been using the Internet, von Krogh laughs, saying that it has only been some months, since October (1999). This is, she went on to say, in spite of the fact that her husband has been in a job requiring use of the Internet for a while and they have had access to it through a home computer for at least a couple of years. Starting BarniMagen.com has been her reason to start using the Internet, and she now spends about seven or eight hours a day online, mostly searching for information for her own site.

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<sup>15</sup> Sentral Sykehuset i Akershus, SIA.

### *5.2.2: The Experts*

When Siri von Krogh found that some of the questions and topics discussed on BarniMagen.com were outside her specific field of expertise, she created the expert panel described earlier in the thesis. Two of the doctors on this panel were asked, and agreed, to be interviewed, Jon Steen-Johnsen, a paediatrician, and Åsle-Marit Ullern, a gynaecologist.

Jon Steen-Johnsen is Siri von Krogh's father-in-law and has been involved in the site since it started, answering questions focusing on his specific area. Steen-Johnsen has been a paediatrician since 1966 working in a number of different hospitals, as well as spending some time in Korea, and is now at the Central Hospital in Telemark. He has had access to the Internet more or less since it was readily available and considers himself relatively computer and Internet literate.

Åsle-Marit Ullern has also been involved in BarniMagen.com more or less since the site opened in February. Ullern has been a gynaecologist for roughly ten years and is currently at the Central Hospital in Akershus, where von Krogh also worked full time until recently. Ullern has much the same reaction as von Krogh on her own use of the Internet, saying that it is the work at BarniMagen.com that has started her use of it. If a question is outside of von Krogh's medical expertise when it comes to gynaecology, it is sent to Ullern, therefore most of the questions she answers are highly technical medical questions, a somewhat narrower field than what her face-to-face patients tend to ask her about.

### 5.2.3: *The Users*

The user-participants in the study, all of whom had volunteered to fill out the questionnaire, were 26 Norwegian women with a mean age of 29 years, ranging from 20 to 38. The table below (Table 1) details their occupations, Table 2 showing their pregnancy histories.

Table 1: Occupation

Occupation:	Academic	IT/Media	Office environment	Health care professional	Homemaker
	5	7	9	4	1

The fact that the majority worked in IT/Media or in an office environment could have some bearing on their own use and their attitudes toward use of the Internet in general. This proportion of the users could be very comfortable using computers in their professional life and therefore not necessarily be representative of all the users of BarniMagen.com. It is also possible to say that these users would have, due to their jobs and their reliance on computers, a possibly uncommonly positive attitude toward the use of computers as substitutes for face-to-face interaction. As the results will show, that is not the case, possibly making an even stronger point. Nonetheless, it is important to keep the presence of this occupational group in mind when looking at the results, in order to keep from overgeneralising.

Table 2: Pregnancy

Pregnant/at home with: first child	16 (5 at home with newborn)
: second child	7
: third child	2
: fourth child	1

From Table 2 it is clear that there was an overriding majority of first pregnancies and new parents participation in the study. From what has been gathered from the founder and what the users commented themselves, it seems as though there may be a general majority of first time parents using BarniMagen.com, at least at the time the study was conducted. This does not seem altogether unusual as it seems to make sense that first time parents may have more general questions and doubts while those with children may rely on experience and previous networks more heavily to provide them with information. This majority of first time parents could lead to over enthusiasm for BarniMagen.com, as they are less likely to have a large basis for comparison and are unlikely to have experience with pregnancies without the access to it. Just as with the occupational data, it is necessary to keep this division in the participants in mind when looking at the results in order to put them into the correct context.

All the participants had some access to the Internet, almost all of them from both home and work. They had used the Internet for a time period ranging from three months to eight years, with a mean of seven years. Keeping in mind that these were estimates and the Internet not readily available before 1994, it is thought that most of the participants would have gained access shortly after that. When asked about the extent of their use of the Internet 17 of the

participants said that they used it on a daily basis, the remaining nine ranging in use from three hours a week to accessing the Internet roughly every three days.

The participants were asked to place themselves in one of three user groups identified in the questionnaire. The three groups to choose between were: Internet enthusiast (surf a great deal, enjoy it for its own sake etc.), Internet pragmatist (use it for very specific pre-defined reasons) and Internet sceptic (unsure of its merits over other media). Of the 26 participants only one identified with the last group, stating that she only used BarniMagen.com and e-mail. Fifteen participants placed themselves in the pragmatist group and the remaining nine termed themselves Internet enthusiasts. However, though the majority of the participants said that they used the Internet quite a lot, five of them stated that BarniMagen.com was the only health related website they used. Overall, the 26 women stated that they found approximately 45 % of the information concerning their pregnancies on the Internet, ranging from those who found only 5 % to those claiming to find 99 %. Most of them supplemented the information from the Internet with books and magazines, some using videos as well.

When asked specifically about their use of BarniMagen.com it was found that 18 of the participants had used the site since it opened in February, the remaining eight had used the site for period ranging from ten weeks to three months. 12 of the participants had found out about the site from newspaper or magazine articles, the largest group after that had come upon the site through an Internet search.

Table 3: Use of BarniMagen.com

Use:	Daily	2-3 times a week	Twice a month
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Number of participants:	7	16	3
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Table 2 shows the participants use of BarniMagen.com, and when asked about the duration of their visits to the site the participants reported that they as a rule stayed on the site for an average of 20-30 minutes, from just a few minutes to several hours, depending on what they needed the site for at the time. Asked about the type of services on BarniMagen.com they most used, most of the women replied that the pages that were personal to them, their "own page" and "From week to week" were the ones they most frequented. As well as this most of them mentioned the discussion forum and all of them mentioned browsing the main page for articles concerning something they were interested in.

### 5.3: A History of BarniMagen.com

When asked to give a short history of the site the founder, Siri von Krogh begins by saying that they (she and her husband, Ivar Steen-Johnsen) started thinking about the idea in August (1999). They agreed that both of their jobs were difficult to combine with the care for their children, and the idea surfaced that she could consider going online as a midwife. Because her husband's job includes extensive use of the Internet, he had become aware of the growing need for specific niche sites, and they agreed that this was a perfect development of her training as well as his skills. They contacted some programmers who were offered stakes in the company as payment for their work, and the programmers thought it was an interesting idea, creating a program that is so easy to use that von Krogh can post information, as well as edit it and add links. The information on the site is a product of von Krogh's training as well as searches on the Internet. She says that the users of the site are very involved in the site



already, even though it has only existed 6 months, sending her tips and ideas of areas of information they are interested in. The information on the opening page of the site is changed approximately every other day, and it is apparent from statistical programs they run, that the users notice if the information has stayed the same too long. These statistical programs are run every day in order to give von Krogh an idea of her user base, and she says it's a great feeling to go to bed at 2 am knowing that there are 13 users logged on to the site.

## 5.4: Findings

### *5.4.1: Supplement or Substitute?*

Von Krogh has clear thoughts about what BarniMagen.com's purpose is, and what its position in the health sector is. She says that the overriding objective of the site is to provide as much information about pregnancy and birth as possible, enabling users to make informed decisions based on that information. This is one area where she feels that the national health system in Norway is lacking, where women feel that consultations are too short and the publications provided not sufficient to cover their needs.

*"I went to see the doctor in my 6<sup>th</sup> week (for 15 minutes!), and I'm going for an ultrasound exam when I'm almost 5 months gone. In the meantime I have no doctor or midwife appointments, because even though you're meant to have a consultation both in the 12<sup>th</sup> and the 16<sup>th</sup> week, my doctor feels that it's unnecessary with more consultations until after the ultrasound, and the number of midwives where I live is too low, so I don't have an appointment with a midwife until I'm 6 months pregnant. That's why BarniMagen.com is perfect for me."*

This appreciation of the accessibility of BarniMagen.com is echoed by other users:

*"What's great is that I can access BarniMagen.com any time I want."*

*"There is no time limit on BarniMagen.com."*

*"You might forget to ask something in the face to face consultation, then you can ask the question from home to BarniMagen.com."*

Von Krogh goes on to say that in order to take advantage of the consultations with health care professionals the women, and their partners, need to be very organised and ask specific questions, something that is not necessarily easy, as they often get carried away with the topic the midwife or doctor is targeting. Perhaps there is a specific area the health care professional feels it necessary to cover, because of where in the pregnancy the woman is, and the situation often arises where there are a number of questions that are left unanswered at the end of a consultation, due to time constraints or that the questions get forgotten, only to resurface later on. When this happens, there may be a month to wait until the next consultation and for expecting mothers, first time mothers in particular, this can be really hard, and that is what BarniMagen.com is here for, von Krogh says.

When the participants were asked to reply to a question asking them whether they felt that it was necessary, or whether they merely wished that they had face to face consultations with a health care professional more often, of the 25 who answered the question 15 did not feel the need for more frequent consultations with health care professionals. The remaining ten

women would have liked to have more frequent consultations, nine of them with a midwife and the last with a doctor.

*"More face to face consultations would make me feel more comfortable with the health care professionals before the birth."*

These comments often came from first time parents who seemed to feel neglected by the health system and insecure, turning to BarniMagen.com to learn more about pregnancy.

*"...the body changes so much during a pregnancy and it isn't easy to know which changes are natural and which ones aren't..."*

Von Krogh recognises the site's limitations as well, saying that the only thing she can do is try to provide all the available facts, so that the women and their partners are better equipped to make decisions. Sometimes she feels that in answering the questions of the users they want her to make decisions for them, something she cannot do. In situations like that it is frustrating not being able to fully answer the users question, however, von Krogh believes that there are certain important value judgements people have to make for themselves. She has often discussed this issue with other midwives, concluding that as a midwife it is only possible to inform the patient as extensively as possible and then support them in the decisions they make, irrespective of personal views, a method she feels it is important to use on the site as well. The Internet is allowing her to use ideas and plans she has thought about before but that have never been followed through due to economic constraints in the health system. Von Krogh says that the Internet is in a way laying the world at her feet, and instead of economic constraints, only the imagination is limiting the possibilities.

Another issue that must be looked at when addressing the supplement/substitute issue is whether the Internet is providing people with a new community in which to interact with people, creating new networks between them. Von Krogh has found that as well as providing information to the users, it is important to her that the users have a forum in which to share their knowledge with each other and provide support for each other. The site is in a way providing a new type of community feeling for the pregnant women and their partners, and von Krogh says she can see, when she reads the discussions and sees the kind of advice they give each other, that they approach the site with an incredible degree of openness and care for each other. She marvels at the fact that separate mailing lists have been created by groups of users who initially met on the site and some of them meet face-to-face almost every week, some still pregnant and some with new-borns. The way in which they support each other, and

how important it is for them to keep in touch, is a sign that the site must be doing something right in von Krogh's view.

The users clearly appreciate this aspect of BarniMagen.com:

*"(...) I've used BarniMagen.com as a social supplement to the regular pregnancy services at my local midwife (...)."*

*"(When you use the site) you get a community feeling with other pregnant women."*

*"Pregnant women are getting a bigger social network (through BarniMagen.com). A lot of the old networks (wise grandmothers and local midwives) have disappeared in the modern society (...) at the same time the need to talk to others about your pregnancy has not lessened in modern society (...) BarniMagen.com, the way I see it, is rebuilding some of this type of social network. When we've established reliable contact with someone on the site, we might choose to meet them face-to-face and laugh and talk over a cup of coffee and a bun in a cafe. I've done that myself."*

Users are using the site to share their grief:

*"(...) I don't feel so alone. This would be completely different without the Internet. I haven't been in direct contact with others that have experienced a loss (miscarriage), but it's enough for me to read others' stories."*

and exchange other experiences:

*"Groups with special challenges and needs get in touch with each other more easily already during the pregnancy. Parents expecting multiple children, parents of children with handicaps, single mothers (...) many live places in the country where they are the only ones in their situation (...) with Internet these (people) get direct contact with each other irrespective of geographic and social restraints (...)."*

*"I can talk to other pregnant women in similar situations and similar areas – that are experiencing the same things."*

The users are able to relate to each other on different terms than when they interact with health care professionals:

*"Often the things I wonder about are trivial, and it's nicer to get answers from other pregnant women than a "that's normal" from a health care professional."*

*"Nothing is stupid and you get all the necessary information by accessing different topics, you're honest and say what you feel and at the same time you feel a sense of belonging."*

BarniMagen.com is, through providing its users with these new communities and networks, supplying them with something a health care professional cannot. The health system and health care professional have not been able to uphold the networks and communities to the extent they used to exist. BarniMagen.com is enabling its users to get in touch with people, creating networks that are vital for them, something they greatly appreciate. This service could argue for the substitution of health care professionals by health information on the

Internet. However, it is a service unique not to health information on the Internet but to the Internet in general, and therefore not in direct “competition” with the face to face contact with health care professionals.

These networks are created partly due to the method of communication on the Internet, a question that is important and has different sides. When asked whether her approach to answering the questions posed on BarniMagen.com and those posed in face-to-face consultations differs, von Krogh answers negatively. However, though her approach to the questions is the same, she remarks that she does not feel that she can always answer the questions in the same way she would were it a face to face consultation. She feels she needs to change her method of communication, expressing herself much more clearly and concisely, while still not being too forceful. She uses publications and medical books extensively to help her, as well as sometimes replying to the user asking for further information in order to answer more thoroughly. In a face-to-face consultation, she says, she uses her body language as well as a patient’s body language to guide a conversation, something she is deprived of with BarniMagen.com. Nevertheless, von Krogh feels that this same deprivation can sometimes work to her, and the users, advantage. She points out that for the user it can help them think more clearly about what they want to ask, with a written question it forces more thought on specificity and requires the user to consider what it is they want answered. Von Krogh says the same applies to her and that she feels she thinks more clearly when she writes, making it easier for her to answer exactly the question posed, without deviating from the topic, something which easily happens in a face to face consultation. As well as this, she feels she is exempt from holding a mask of professionalism when she is in front of a computer. When told of a miscarriage or delivering a stillbirth it is her job as a midwife to support the parents and give them comfort in any way that she can. On BarniMagen.com in the same

situation she can allow herself more freedom, crying if she wants to, or even, in other situations, shouting in frustration at the unimpressive health service in a rural area.

The users had many thoughts on what they perceived to be communication differences between face-to-face consultations and questions posed on BarniMagen.com, either to the midwife or to other pregnant women on the discussion lists. One of the first questions enquired whether they felt that the types of questions they asked online were different in any way from those posed in face-to-face situations. Here, of the 25 that answered, 15 of the participants felt that there was no difference, the remainder feeling that there was. Most of the differences mentioned were also answers to a later question, where the role of anonymity was enquired on.

Here, asked whether the anonymity the Internet provided them with affected their method of communication on the Internet, of the 25 that answered, 15 replied that the fact that they could be anonymous had no bearing on their style, the remainder felt that it did make a difference.

Some of the users were concerned about their health care professional's impression of them:

*"Online is less censored—you aren't worried about how you appear to the health care professional."*

*"You can ask more intimate questions or questions doctors may think are stupid."*

*"It's easier to ask questions you're worried might put you in a bad light (hypochondriac, hysterical etc.)."*



*"There's no need to attempt to use "doctor language" the way you feel you have to in order to get through to health care professionals."*

Other users commented on how interacting through a computer made them better able to share sensitive information:

*"You can ask deep/profound emotional questions (online)."*

*"I would never have asked questions about depression if I couldn't be anonymous, and I don't have to pretend to be ecstatic if I'm not."*

*"This is a forum where it is easy to pose non-medical, practical questions about the organisation of everyday life and family life. (...) I think the anonymity allows many people to have the nerve to ask questions that are more emotional and of a more personal nature than they would ask their regular health care professionals face to face. It is easier to air your frustrations (...)."*

Commenting on communication over the Internet Ullern said, that when she first started answering questions on BarniMagen.com, she was surprised at how difficult she felt it was to reply to the questions. She has always been interested in language and communication and found it very difficult to communicate the same answers over e-mail as in face-to-face situations, deprived of non-verbal communication. Ullern was very aware of the fact that her answers could frighten people unless worded correctly, as a lot of the material she was communicating was of a serious medical nature. She points out that this may be a

disadvantage of BarniMagen.com, that because it is there in black and white, the answers can seem cold or unfeeling, if they are very direct. An advantage, in her view, is the way in which it seems to be easier for the users of the site to ask questions about intimate issues, the computer creating a distance that in that sense is put to positive use, allowing the user the freedom to ask any questions they want. As well as this, the users take the site seriously, asking serious questions and expecting serious answers from competent health care professionals, making her experience with health on the Internet a mostly positive one.

The question of communication seems to have many different levels. On the one hand it seems that the health care professionals feel that they would be better able to answer many questions in a face-to-face setting, benefiting from for example non-verbal communication. This speaks in favour of the supplement argument. On the other hand the health care professionals feel more able to genuinely react to the information from the patient when communicating through the Internet, perhaps leading a deeper, more honest, interaction on their part. This supports a substitution argument and is, to a certain extent, supported by the users who appreciate the anonymity the Internet can provide them with. Nevertheless, it seems that the lack of non-verbal communication and direct contact with the health care professional is more important to the users in the long run, explaining why they appreciate the new way of communicating and the intimate contact they establish with their peers the most.

Therefore, from the users' point of view, BarniMagen.com as a substitute for face-to-face consultations is seen as ridiculous, the closeness and personal feeling experienced in face-to-face consultations both emotionally and with regards to the information received being a vital difference between the two.

*"(...) in consultation I get to hear the baby's heartbeat (...) it's irreplaceable."*

*"I get better answers about my own health (in a face to face consultation)."*

*"One question easily triggers another so a theme is more thoroughly explored (in a face to face consultation)."*

*"The health care professional should be able to point out questions and issues I haven't thought about."*

*"The answers I get from my doctor are more clear and direct."*

*"BarniMagen.com is a supplement to face to face consultations for me (...) I can get some questions answered and share information with others in similar situations (on the Internet) (...) the serious academic issues I approach with my health care professional."*

*"(...) face to face consultations are much more personal – BarniMagen.com is an encyclopaedia more than anything."*

*"A face to face consultation can't be compared to using an Internet site. On the Internet it is not possible to get the same type of consultation, as personal and comforting as face to face."*

*"Sometimes you need to hear some well chosen and comforting words face-to-face."*

*"(...) the personal contact with a doctor or a midwife is irreplaceable."*

*"The net can (luckily) never replace the personal contact."*

Generally speaking, Steen-Johnsen agrees with the users, saying that because finding information is important to the patient, a balance is necessary between the Internet and face-to-face contact with health care professionals. Although the Internet, and BarniMagen.com, cannot replace face-to-face contact with health care professionals, he thinks that this type of information can lead to asking more thorough questions in a consultation and therefore also a better understanding of ones own health, as well as an improved, more equal relationship with the health care professional. Ullern agrees, saying that a new type of consultation with the health care professional is emerging, both on the Internet and face-to-face. She feels that health care professionals are going to need to work with more preventative medicine in the future, spending more time with their patients both on and offline.

Von Krogh's point of view in the general subject of supplement substitute is quite clear:

*"(BarniMagen.com is a) supplement to face to face consultations, full stop!"*

A service such as this site could never replace consultations with health care professionals largely because there are such clear restraints on how thorough the site is able to be, she says. Von Krogh states that there are so many aspects that must be collated if people are sick, or need a check up, aspects such as skin tone as well as many other observations and tests that come together to create an accurate medical impression of the patient. The medical opinion she feels she makes in a face-to-face consultations goes a lot deeper than the one she makes on the Internet, she says, making her experience in face-to-face consultations invaluable for

her work online. She says that her ambition would never be to even attempt to replace face-to-face contact, as if even the thought is ridiculous.

From this it seems safe to say that the Internet is not taking the place of the health care professional. Although it is clear that websites can provide users with important services, they cannot replace the face-to-face contact with a qualified health care professional. The following topics will continue to illustrate this argument from different point of view.

#### *5.4.1.a: Democratisation of Health: The patient as a consumer.*

In von Krogh's view there exists a paradox in the health system today; while people must place their lives in the hands of health care professionals they must also learn to make demands of them. BarniMagen.com, as von Krogh sees it, is enabling users to make demands on the health system, demands they are entitled to make. She points to examples of women who have had terrible births, saying that some of the stories she has heard, even accounting for exaggeration, are truly gruesome, and that these women have then been assured that because of this their next birth will most likely be a caesarean section. When the women then return to the health care professional with a new pregnancy their concern that the birth will again be difficult is brushed aside and the promise of a c-section withdrawn. In von Krogh's opinion it is in situations such as these that the women need to know their rights and the extent of the treatments they are entitled to demand.

From Steen-Johnsen's point of view, the question is more about recognising that there is an extreme need for information that is not met by the present health system, reasoning that there is little time for doctors to familiarise themselves with the Internet. The need for an increased focus on the patient as a consumer is important, but in Steen-Johnsen's opinion it is not something that can be done over night. Ullern goes deeper, saying that the advantages with the Internet, and sites like BarniMagen.com, are that this type of information gathering is done on the patients own terms, allowing them to ask questions when they want and receive answers soon after, allowing the patients to feel more in control of their own health care. This is repeated by the users in the answers to the questionnaire:

*"You don't need to rush when you're on the net, there's no one waiting in the corridor to come in to see the doctor or midwife, you can take your time and look for the answers you need, when you need them. I like finding the answers straight away instead of having to wait for four weeks (the next face to face consultation) – then the question might seem stupid – or I've forgotten it."*

*"I can choose the information I'm interested in (on the site)."*

The users also point out that it is not merely being able to access the information *when* they want, but it is also being able to access *what* information they want:

*"There's more information about alternative options to standard medicine – that's taboo in face to face consultations."*

In 2001 legislation will be introduced making it possible for pregnant couples to decide at which hospital within their region to give birth, increasing the couples' autonomy and in many ways empowering them. This legislature is already being introduced in some parts of the country, and when asked, 14 of the participants stated that they had chosen their hospital themselves. Most of them stated that the proximity to the hospital led to their choice, although some added that the facilities also influenced their decisions. Of those who had not chosen the hospitals themselves, keeping in mind that one of the participants was opting for a homebirth, all of them had experienced that the decision was made *for* them by a health care professional, something seen as the health care professional imposing his/her views and wishes onto the patient. However, although it is implied through this that the users of BarniMagen.com want to be considered consumers, it seems that there are aspects of consumerism they would rather not experience. An example is the issue of having to pay in order to have a question answered by the midwife at BarniMagen.com. 14 of the 26 women stated that they had no objections to having to pay for this service saying that because it was a service it should be paid for, three of them going so far as to say that paying for an answer was an assurance of the quality of the information they received. One of the participants reacted very negatively to having a fee payable for questions, while another said that having to pay was at least preferable to having more sponsors or advertising on the site. Nine participants replied that the fee lead them to avoid using the service asking other users of the site for advice or using alternative sites that offer the same service for free.

*" (about Doktoronline.no), there you can ask the midwife questions without it costing anything."*

It seems that although some of the users recognise that paying for a service is a marker of consumerism, not all of them approve of it, creating a contradiction. The users seem to recognise the need for a more consumer driven health care system, where services can improve through competition, even though some of them disapprove of some of the markers of consumerism. Although democratisation is something the health care professionals can agree with, they warn of attempting to change the health care system too quickly. A balance must be found between health care professionals and patients when it comes to division of responsibility, participation and authority. Allowing patients to take a more active role in their own health care will put more of the responsibility onto them, something that will lead to even more participation on their part.

#### *5.4.1.b: The Participating Patient*

Pregnant women and their partners may be a group of people that wish to participate to an extreme extent in their own health situation. In von Krogh's opinion, what may set pregnant women apart from others who use health related websites is that the majority of them are generally healthy, clued up people in the prime of their lives not necessarily suffering any ailments, but nonetheless exhibiting extreme information seeking behaviour. This is also one of the chief goals of the site, according to von Krogh, namely that people get better at thinking for themselves. It is important that people, women in particular where BarniMagen.com is concerned, take control over their own lives and their own health situation. They need to move on from thinking that the health system is some kind of guru and start thinking for themselves, participating in their own health care more actively. When the topic turns to whether she feels that the questions she receives on BarniMagen.com in any



way differ from those she receives in face to face consultations; that the way in which the “participating patient” interacts with health care professionals differ, she replies no. There are of course a certain number of people who rely heavily on the fact that they don’t need to be in a face-to-face situation, some have experienced rape or sexual abuse and feel more comfortable communicating through a computer. However, the majority of patients pose questions in a similar way to what von Krogh has experienced in face to face consultations, something she says may be due to the situations in which the meetings with a midwife take place. She explains that as a midwife you tend to meet people in a very special way, there is extreme honesty, they are in a situation in their lives where they are very open, and as a midwife a lot of positive feedback is experienced.

For Steen-Johnsen, it is only recently that he has experienced the necessity of health information on the Internet, encountering the “participating patient” in his work. There have been situations where patients of his have been suffering difficult illnesses, where in order to best inform the patient he has found that although the illness is extremely rare, there is a lot of information on the Internet as well as family support groups and the like. It is Ullern’s opinion that this is one of BarniMagen.com’s most important services as well, because it allows the users to be interactive, both in relating to von Krogh and in relating to each other, encouraging more active participation in their health care. She feels that increasingly the doctor patient relationship will include contact via e-mail, because people are demanding more and more different types of information and increased participation in their own health situation, something she looks upon as a mostly positive development.

Here it is made clear that the coming of a more informed, more participating patient is considered inevitable. Patients feel more entitled to information about their health and are to a

greater extent demanding it from health care professionals and using tools such as the Internet to find it for themselves. This increased participation is looked upon as a positive development by the health care professionals interviewed here, although opinions are more divided on the subject elsewhere.

#### *5.4.1.c: The Quality of Health Information on the Internet*

Assessing the quality of information on the Internet is generally difficult, and BarniMagen.com is no exception. Steen-Johnsen points out that when using information on the Internet with patients, the quality of the information differs greatly. Due to this he himself performs the searches and then presents the links to the patients and families concerned, working as a sort of filter for the patient, in order to ensure quality.

When asked about what role she has on the site, von Krogh says she also feels that a filter would be an accurate description. The information included on BarniMagen.com is researched thoroughly, mostly by herself, as well as being clearly marked so that it is possible for the users to know whether the information is from a research journal, a newspaper article or a statement from a health care professional. This is also important to von Krogh when it comes to the discussion forum. Here, the users are free to discuss anything they want within the different topic areas existing. Von Krogh says that one of the most important issues for her and a vital point for the site is that there is a clear division between official material and information the users post themselves. Expanding on the topic of quality and security on the Internet, von Krogh says it is clear that people should never post anything on the Internet that is of such a personal nature that they would not want anyone else to know about it, due to general security concerns. These concerns are not specific to the site, as BarniMagen.com has

done much to use password protection to make the personalised areas of the site as secure as possible, but general opinions about the Internet and the abilities of hackers. She says that it seems that most of her users are aware of the security risks, and she has yet to experience receiving information that is that sensitive. However, she feels it is important for someone on the BarniMagen.com team to monitor the debates that take place on the discussion pages of the site, ensuring that no one is abusing the site. Apart from that what goes on there is not the site's responsibility.

Interestingly enough, all the participants reported that they were generally happy with the quality of the information they encountered on the Internet. When asked how they assessed the information they accessed online, it seemed that they generally tended to trust their own judgements.

*"I don't double check the information (on the Internet) if it sounds reasonable."*

*"...common sense helps a great deal..."*

*"I look at what different sites say about a topic."*

*"Personally I think that the receiver of all information from all mediums must have an awareness of the quality of the information."*

*"...if you only read about your health/pregnancy on the Internet, you could fall into some traps (...) I sometimes ask my midwife to confirm or dispel what I've learned."*

*"I still trust face to face consultations more (than the Internet)".*

All of the participants expressed that they found the information on BarniMagen.com to have generally high quality though there were a range of different types of comments.

*"...BarniMagen.com refers to a lot of research etc. (...) very few things are presented as indisputable truths, that shows reliability."*

*"BarniMagen.com has been mentioned in midwifery magazines and newspapers and that shows that it is trustworthy."*

Questions on the quality of the information on the Internet almost inevitably lead to questions about the sponsorships and endorsements existing in the sector. When asked about the financing of the site, von Krogh points out that there are several different parts to financing, stressing that these different parts are necessary, pointing to the dangers of relying on only one source of income. In theory, the 49 NKr the users pay to have their questions answered should represent von Krogh's wages, but the site is not quite "there" yet. At present, the site has an agreement with the online bookstore, Bokkilden, whereby a percentage of the profit from the books and videos sold goes to BarniMagen.com. Nycomed, a pharmaceutical company, pays to have a microweb on the site, where they provide information about vitamins and other products they consider to be of interest to pregnant women. Nycomed is responsible for the content of this microweb, and von Krogh stresses the importance of clearly marking that BarniMagen.com is not involved in the microweb, nor does it take responsibility for any of the information posted there.

The participants were also, in conjuncture with the questions about the quality of the information on the site, asked their opinions on whether the presence of sponsors affected their opinions of the quality of the information on BarniMagen.com. Of the 25 that answered this questions only three were uneasy about the sponsors on the site, although those three were adamant.

*"I'm generally against advertising so I don't like this very much. They could have had pages specifically for advertising only. I don't like the fact that chemically manufactured vitamins and other pharmaceuticals are advertised for."*

*"I don't read any of the information about the vitamins because it's all written by Nycomed<sup>16</sup>!"*

At the other end of the spectrum were those who felt there should be more sponsors.

*"...they (BarniMagen.com) should get in more sponsors and offer to answer the questions (posed to the midwife) for free."*

Both the health care professional and the users are confident of their own abilities to assess the information they find on the Internet. For both groups it seems this is done by cross-referencing and double-checking the information, as well as looking for the source of the information. The sources of the information are important to both groups, although the users are divided on the topic. Attitudes range from a confidence in taking information sponsored by companies with a pinch of salt to aggressive dislike for even the presence of sponsors.

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<sup>16</sup> A Norwegian pharmaceutical company, and one of BarniMagen.com's main sponsors.

However, no easy solutions are suggested, and websites depend on funds coming in from somewhere.

It seems that the issue of quality speaks in favour of the supplement argument. Although the users have great faith in themselves when it comes to being able to assess the information they access on the Internet, they recognise the dangers of blindly trusting it, some saying that they double check the information with a health care professional. The same can be said for the presence of sponsors on sites on the Internet. The users feel that they can be more sure that the health care professional will not be guided by profits when treating them, something they do not trust the Internet to be. At present these quality issues are some of the strongest arguments for the supplementary nature of health information on the Internet. As one of the corner stones of the Internet is the way in which anyone can post nearly anything on it, it is unlikely that a secure way of controlling the quality of the information present will appear in the near future, supporting the argument that this may lead the health care professional—patient relationship to change, but is unlikely to substitute face to face interaction.

## **Chapter 6: Conclusion**

In this dissertation several claims concerning the “information society” were made. It was argued that whether or not this society existed, it is clear that the increased use of technology is impacting on society in some way, one of which is the increase in information available to consumers. It was claimed that this increase in information is contributing to a democratisation, allowing consumers to have more equal relationships with the suppliers of services and to participate more actively in taking advantage of these services. This same emergence of more equal relationships was argued to influence the balance of responsibility,

allowing the consumer to shoulder more of it. These claims, when translated into the specific field of health, and even more specifically, that of health information on the Internet, became more precise.

Arguments that the increase in information was leading to a democratisation within the health sector, leading to a more equal relationship between health care professionals and patients, were outlined. As well as that, claims that this democratisation was leading to a new breed of consumer within the health sector seen as the “participating patient”, a patient more eager to take responsibility for their own health care, were put forward. Both the democratisation and the participation were introduced as arguments in favour of the use of health information on the Internet as a supplement to the face-to-face contact with health care professionals. This was also the case for the quality issues raised in conjunction with health information on the Internet, a strong argument against substituting the health care professional. The policy view that health information on the Internet would grow to act as a substitute for face-to-face contact with health care professional was contested, as were similar claims from the academic literature.

These arguments were all addressed through a case study of a midwifery website, BarniMagen.com, after first having turned them into questions intended for health care professionals involved in the site, and a group of its users. These questions were intended to illustrate the claims made and were divided into four areas.

When the claims of the impossibility of the substitution of interaction with health care professionals with health information on the Internet were investigated through the case study, they were supported. Both the health care professionals and the users agreed that



although health information on the Internet had an important purpose, it could not replace the face-to-face contact with health care professionals. Several aspects of face-to-face interactions were pointed to as irreplaceable while at the same time health information on the Internet was shown as having its own advantages. It seems that both the users and the health care professionals looked upon the two as addressing very different needs and therefore one could not be a substitute for the other.

Looking at the results obtained for the claim of democratisation and a more consumer driven health sector, the case confirmed the arguments made. The users' comments showed that they did feel empowered to a certain extent through the use of BarniMagen.com, because it allowed them to access the information they wanted when they wanted it, without having to depend on a health care professional for it. The opinions of the health care professionals were the same in that they agreed on the necessity for the health system to treat the patients more like consumers, recognising that one way of aiding this development is to increase the patients' access to health information. However, although the users appreciated being treated as consumers, taking more control of their own health care, certain markers of consumerism were looked upon negatively. Paying for health information, such as answers from the midwife on BarniMagen.com, was seen as an unattractive feature of consumerism. The same reaction was seen in some of the users when asked about the necessity for sponsors on sites with health information, showing that although generally agreeing on the shift in the health sector to a more consumer driven sector, the users saw definite drawbacks to this shift as well as advantages. The claims made of the emergence, through this democratisation, of a "participating patient" willing to shoulder more of the responsibility for their health care were also upheld. The health care professionals agreed that not only was it their experience through their own work, but also in their opinions an inevitability, that this type of patient was

increasing, something they looked upon as a positive development, though this may not be the general opinions in other medical circles.

The question of the quality of health information on the Internet as an argument for the supplementary nature of such information received the expected reaction from the health care professionals. They vehemently agreed in the claim that the differing quality of the information on the Internet was a strong argument for why the patients would still require interaction with them, in order to assess the information accessed. The users, although very confident in their own abilities to assess the information they accessed, ultimately agreed, saying that they still felt more comfortable receiving information from a consultation with a health care professional.

From this it is possible to say that the initial, overarching claim; that health information on the Internet should be seen as a tool, a supplement to interaction with health care professionals, was supported by both the health care professional interviewed and the users who participated in the study. The increased access to information is making a more consumer driven health system, and to a certain extent a new breed of patients is emerging. Though there are some negative opinions on these points in some medical and policy circles, continuing with this focus on Internet use in the health system as the exploitation of a powerful tool as opposed to a possible competitor, could lead health institutions and health care professionals to appreciate and use it more. This would no doubt benefit both the organisations, those working in them, and the patients. However, it is important to look upon this as a development, not an all or nothing, sudden changeover. Increased use of the Internet and related technologies in the health sector is something receiving more and more attention, and through further research the optimum methods of use can be found. Research with larger user groups could

more clearly show the consumers' point of view on this, as could research of users from multiple websites. Research on the use of the Internet in national health organisations, and the opinions of those working in them could also give a fuller picture of the present situation, as well as theories on how to better integrate the use of ICTs and the Internet in national health systems. This is a field where there are many questions left to ask, and many possibilities left to investigate, making for an interesting future.

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2. <http://www.europa.eu.int>
3. <http://www.ispo.cec.be>
4. <http://www.odin.dep.no/nhd>
5. <http://www.nhsdirect.nhs.uk>

### Medical Journals :

1. <http://www.ama-assn.org/derm>
2. <http://www.archfami.ama-assn.org>
3. <http://www.bmj.com>
4. <http://www.jama.com>
5. <http://www.jamia.org>
6. <http://www.mja.com.au>

### Midwifery and Parenting:

1. <http://www.barnimagen.com>
2. <http://www.bestfed.com>
3. <http://www.boots.co.uk>
4. <http://www.doktoronline.no/pub/pregnancy>
5. <http://www.gentlebirth.com>
6. <http://www.libero.no>
7. [http://www.nettdoktor.no/graviditet\\_foedsel](http://www.nettdoktor.no/graviditet_foedsel)
8. <http://www.obgyn.net>
9. <http://www.pampers.com>
10. <http://www.thebabyregistry.co.uk>
11. <http://www.virtualbirth.com>
12. <http://www.yourbabysname.com>

## Appendices

a.1|: User questionnaire

a.2: Sample questions for the health care professionals

a.3: Questions for the founder of BarniMagen.com, Siri von Krogh

a.4: Sample of home page of BarniMagen.com

## a.1: User Questionnaire

### Online questionnaire for users of BarniMagen.com

Thank you for taking the time to fill out this questionnaire about your use of online health services and BarniMagen in particular. Some of the questions only require short answers while others open for more lengthy answers, feel free to add any information you feel is necessary. Your answers will be anonymised in the text of the dissertation, but if there are any questions you would rather not answer, simply write that on the questionnaire instead of an answer. Thanks again for your participation!

Personal details:

1. Age:
2. What is your occupation?
3. How many children do you have, and how old are they?
4. At the moment are you: pregnant/home with a new baby/other(please specify)?
5. Have/will you take/n maternity leave? Yes No
6. If you plan to take maternity leave how long will you be on leave?

As you may be aware new laws will make it possible for you have more choice in the matter of where you give birth within your area. This section focuses on this topic:

1. What hospital will you give birth at?
2. Did you choose this hospital yourself? Yes No
  - \* If no, who chose the hospital?
  - \* If yes, what were your reasons for choosing this hospital?
3. If you have other children, were they born at the same hospital? Yes No
4. Do you have a midwife assigned to you at the hospital? Yes No
5. Where have you found information about the different hospitals and birthing options available to you?

Interaction with Health Care Professionals in the context of this/your most recent pregnancy:



1. How often do you have face to face consultations with health care professionals (specify: midwife, obgyn, nurse, other)?
  2. What takes place in these consultations?
  3. Would you like to have more frequent consultations with health care professionals?    Yes  
No
- \* If yes, can you name reasons for this?
  - \* Who would you want to see more often (specify: midwife, obgyn, nurse, other)?

Internet access:

1. How long have you had Internet access?
2. Where did you first gain access to Internet?
3. Where do you access it now?
4. Approximately how often do you access the Internet?
5. What category of user would you put yourself in?
  - \* Internet enthusiast (surf a great deal, enjoy it for its own sake etc.)
  - \* Internet pragmatist (use it for very specific pre-defined reasons)
  - \* Internet sceptic (unsure of its merits over other media)
6. What type of sites do you visit the most on the Internet?
7. Do you use the Internet for e-mail?    Yes    No

Health Information on the Internet:

1. Do you visit other pregnancy and birth-related website other than BarniMagen?
  - \* If yes, which ones?
  - \* Do the other websites offer something BarniMagen does not? Yes No
  - \* If yes, please specify:
2. If you have other children, did you use the Internet to access health information during that/those pregnancy/ies? Yes No
  - \* If yes, could you specify which sites you used?
3. What other sources of pregnancy and birth-related information do you use (books, TV, magazines)?
4. Roughly what proportion of all of pregnancy and birth-related information you gather is:
  - \* from the Internet?
  - \* from BarniMagen?

Quality of information on the Internet:

1. What is your opinion on the quality of health information on the Internet?
2. Do you feel that the regulation of the quality of health information on the Internet is good enough? Yes No
  - \* Could you say why?
3. How do you discern good information from bad information?

BarniMagen.com:

User Information:

1. Where did you first learn about BarniMagen?
2. How long have you used BarniMagen?
3. How often do you visit BarniMagen?
4. On average how long do you stay online when you use BarniMagen?
5. What do you use BarniMagen for?

Content Information:

1. What is it you like the most about BarniMagen?
2. If you could change anything about BarniMagen what would that be?
3. Are the questions you can ask online different from those you ask in a face to face consultation?      Yes      No
  - \* If yes, can you try to explain how?
4. Does the anonymity you can have online affect the questions you ask? Yes      No
  - \* If yes, can you name some examples of this?
5. Are there any aspects you feel you get from a face to face consultation that you don't get from BarniMagen? Yes      No
  - \* If yes, can you name some examples?
6. Are there any aspects you feel you get from BarniMagen that you don't get from a face to face consultation? Yes      No
  - \* If yes, can you name some examples?

7. What is the most important difference between a face to face consultation and BarniMagen?
8. If you were to compare a face to face consultation with BarniMagen where do you feel you:
  - \* have more time
  - \* are more relaxed?
  - \* get the most information about your health?
  - \* get the best emotional support?

Quality of information on BarniMagen:

1. In your opinion how is the quality of the information at BarniMagen?
2. Does the presence of sponsors on the site affect your opinion of the quality of information there?    Yes    No
  - \* If yes, can you explain how?
3. How do you feel about having to pay for each question you ask?

Thank you very much for your participation in this questionnaire! If you think there is anyone you know who is an ex-user of BarniMagen, who tried the site and was unhappy with it or who has any reservations about using the Internet for health information, it would be very helpful if you could encourage them to get into contact with me as they would bring a different perspective to the project.

Finally, if you have any comments on the content or layout of this questionnaire, or any other feedback, it would be much appreciated!

Thanks again!

To respond to this questionnaire you can either: press forward and put in [benedicteb@hotmail.com](mailto:benedicteb@hotmail.com) as the address, fill in your answers, and e-mail the questionnaire

back to me, or you can print it out and send it to: Benedicte Bjørnstad

Bernhard Herres vei 16

0376 Oslo

## a.2: Sample questions for the health care professionals

Questions for Health Care Personnel: Semi-structured Interview setting.

### Personal Information:

1. Age:

2. Occupation:
3. How long have you been in this occupation?

Internet access:

1. How long have you had Internet access?
2. Where did you first gain access to Internet?
3. Where do you access it now?
4. How often do you access the Internet?
5. What type of sites do you visit the most on the Internet ?
6. Can you name a few of your regular sites?
7. Do you use health related sites on the Internet, which ones?
8. Do you use the Internet for e-mail?

BarniMagen.com:

1. What is your role at BarniMagen (pt/ft etc.)?
2. How long have you worked for BarniMagen ?
3. What made you start at BarniMagen?

The following questions will focus on BarniMagen and its content:

1. What, in your opinion, does BarniMagen offer its users?
2. What do you think is the reason for BarniMagen's, and other health websites', success and appeal to users?
3. What is the need for sites like BarniMagen, where do they fit into the health sector?
4. In your opinion, does BarniMagen have any competitors, can you name them?

Comparing face to face consultations and BarniMagen:

1. If you were to compare a face to face consultation with a health care professional and using BarniMagen what are the advantages and disadvantages for the patient and HCP in the use of each?
2. What, if any, are the differences between the questions posed online and those posed in a real-time consultation?
3. Are there situations where the questions posed by the users would be better answered in a consultation? (why/why not)
4. Do you employ different approaches when answering a question online versus off-line?
5. How much time do you, on average, spend in a F2F consultation with a patient compared with how much time you spend answering single questions online?
6. Do you think users feel they have more with time an HCP online?
7. Would you encourage your patients to use the Internet as a substitute for F2F contact with HCP? (why/why not)
8. How can the Internet complement F2F consultations with HCP?
9. How important do you think anonymity is for the users of the site?
10. What part does anonymity play for the way in which you answer the questions?

11. Do you think that users feel more comfortable asking certain types of questions online, can you think of any examples, do you feel more comfortable answering certain types of questions online?
12. Are the users showing any ability to discern the quality of information, or are they assuming generally high quality?
13. What is your opinion on the role of sponsors on the site?

The extent to which people and users are more informed:

1. You may/may not be aware of this, but the media is focusing on the aspect that people are becoming more informed in general, is this your experience too?
2. When thinking about users and non-users of the Internet, do you find that the users of, for example BarniMagen, are more informed than non-users?
3. Do you find that the questions posed are more pointed/specific?
4. Could this be due to a wider access to information?



### a.3: Questions for the founder of BarniMagen.com, Siri von Krogh

#### Interview questions for founder : Siri von Krogh

##### Personal Information:

1. Age:
2. Family:
3. Occupation:
4. How long have you been in this occupation?

Internet access:

1. How long have you had Internet access?
2. Where did you first gain access to Internet?
3. Where do you access it now?
4. How often do you access the Internet?
5. What type of sites do you visit the most on the Internet ?
6. Can you name a few of your regular sites?
7. Do you use health related sites on the Internet, which ones?
8. Do you use the Internet for e-mail?

BarniMagen.com:

1. When did it open?
2. What is your role, filter for questions as well as main responder?
3. When did you get the idea for the site?
4. Where did the idea and concept come from?
5. What was your motivation when you started BarniMagen?
6. How was content decided upon?
7. How is the information to post selected, how often is it changed/revised?
8. What kind of quality control is done on the information posted?
9. How was the design of the site decided upon?

The team:

1. When was it decided to take on board more HCPs?
2. What are the roles of the other HCPs?

The following questions will focus on BarniMagen and its content:

1. What, in your opinion, does BarniMagen offer its users?
2. What do you think is the reason for BarniMagen's, and other health websites', success and appeal to users?
3. What is the need for sites like BarniMagen, where do they fit into the health sector?
4. In your opinion, does BarniMagen have any competitors, can you name them?

Comparing face to face consultations and BarniMagen:

1. If you were to compare a face to face consultation with a health care professional and using BarniMagen what are the advantages and disadvantages for the patient and HCP in the use of each?
2. What, if any, are the differences between the questions posed online and those posed in a real-time consultation?
3. Are there situations where the questions posed by the users would be better answered in a consultation? (why/why not)

4. Do you employ different approaches when answering a question online versus off-line?
5. How much time do you, on average, spend in a F2F consultation with a patient compared with how much time you spend answering single questions online?
6. Do you think users feel they have more with time an HCP online?
7. Would you encourage your patients to use the Internet as a substitute for F2F contact with HCP? (why/why not)
8. How can the Internet complement F2F consultations with HCP?
9. How important do you think anonymity is for the users of the site?
10. What part does anonymity play for the way in which you answer the questions?
11. Do you think that users feel more comfortable asking certain types of questions online, can you think of any examples, do you feel more comfortable answering certain types of questions online?
12. Are the users showing any ability to discern the quality of information, or are they assuming generally high quality?
13. What is your opinion on the role of sponsors on the site?

The extent to which people and users are more informed:

1. You may/may not be aware of this, but the media is focusing on the aspect that people are becoming more informed in general, is this your experience too?
2. When thinking about users and non-users of the Internet, do you find that the users of, for example BarniMagen, are more informed than non-users?
3. Do you find that the questions posed are more pointed/specific?
4. Could this be due to a wider access to information?

Sponsors:

1. Who are the sponsors?
2. How were the sponsors found, where any sponsors rejected?
3. What are the sponsors' involvement in the running and layout, content etc. of the site?
4. Why do you think the site has become so popular?

Future plans?

a.4: Sample of home page of BarniMagen.com

<http://www.barnimagen.com/>