PATIENT ACCESS TO HEALTH INFORMATION ON INTERNET: AWARENESS AND INFLUENCE BASED ON THE INVESTIGATION OF WOMEN WHO USED ON-LINE ACCESS DURING THE PREGNANCY

Master’s thesis

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PATSIENDI LIGIPÄÄS TERVISEANDMETELE INTERNETIS: TEADLIKKUS JA MÕJUD NAISTE UURINGU ALUSEL, KES KASUTASID VEEBIPÕHIST TERVISEANDMETE LIGIPÄÄSU RASEDUSE AJAL

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INTRODUCTION

Over the past decades internet and development of information and communication technology has had a huge impact on healthcare. Not only it has given people opportunities to access health information more easily and empowers patients to be more involved in treatment processes by changing the classical doctor-patient relationship, but also it has influenced healthcare processes, helping healthcare to increase its quality and become more effective, using new technological opportunities like telemedicine, information systems, patient portals etc. Internet is a very popular tool for searching health related data and its impact has been growing every year (Eesti Haigekassa et al., 2010; Eesti Haigekassa et al., 2011; Eesti Haigekassa et al., 2013).

Estonia created electronic health information system in 2008. As the information system being very unique on global scale, covering the whole population, the finding of new solutions to utilize its potential is very important (Sepper et al., 2011).

Estonian people have several opportunities to make life easier with the e-health applications – digital prescriptions, patient portals and opportunities to see personal health data and additionally make official statements without even leaving home. But the use of these opportunities is not widely researched (in Estonia as well as in other countries) and there is not enough information about the people’s awareness and usage of e-health solutions, specifically patient portals, and how people use information retrieved from the internet, how information from patient portals influences people.
The aim of this thesis is to research health information accessibility and use in internet, based on example of iPatsient portal in East Tallinn Central Hospital.

A questionnaire was developed specially for this study and the survey was conducted, using internet forums and social network, among women who delivered their child(ren) or monitored their pregnancy in East Tallinn Central Hospital to determine their awareness of iPatient and its opportunities, usage and satisfaction with the system. Also to find out if and how women used the information that they got from the internet.
1. USING INTERNET FOR FINDING HEALTH-RELATED INFORMATION

1.1. History of using the internet

A hundred years ago no one probably imagined that today, on the 21st century, information is quickly accessible with unlimited data and all you need is a computer and internet. Internet is a system of computer networks worldwide that are connected to each other and according to McGraw-Hill encyclopedia (Venkatesh, 2007) it is „a product of the convergence of media, computers and telecommunications. It is not merely a technological development but the product of social and political processes as well, involving both the academic world and the government“ (Venkatesh, 2007).

The history of internet dates back to the 1960s, when U.S. Department of Defence created ARPANET (Advanced Research Projects Agency Network) as a network of computers in 1969. First connection was set with 4 computers and that was a start of a new era, from where internet started its development. Although internet has had a great impact on economics and social order, it took almost 30 years to become really global (internet’s impact was truly understood in 1995) and widely used as it is today (Leiner et al., (n.d.); Venkatesh, 2007).

In terms of health, internet is a popular source of knowledge among people but also for doctors, who’s professional interests are probably associated mostly with scientific articles that can easily be accessed in the internet. People’s health information use in internet involves searching health information and support (i.e. specific diseases, healthy nutrition, fitness, specialized support groups etc.) but also using e-mail to
communicate with healthcare professionals and using electronic health record. Healthcare information systems enable patients to see the individual health data and from doctor’s side, it can be a huge time saver. One of the main purposes why people search for health related information is a feeling of being prepared and to be able to take part in treatment process. It also gives a sense of being in control (Cohen et al., 2010; Yaşin et al., 2011).

1.2. Basic internet users and factors that influence internet use

According to Statistics Estonia, in the first quarter of 2005 the percentage of internet users aged 16-74 was 59.2% and in 2012 the same percentage was already 78.4% (in EU the average was 54% in 2005 and in 2012 75%). But if we compare with nordic countries near Estonia, then we still have a long way to go – for example in Norway the percentage is 95%, in Sweden 94% and in Finland 91%. In Baltic region Estonia has the highest percentage of internet users. Latvia follows with 74% and Lithuania with 68% (Statistics Estonia, 2012; Eurostat, 2013).

Factors that influence internet use may be different – from personal factors to economical. There are certain groups, who do not use internet as widely as others – for example older people (Randver, 2005).

From figure 1 you can see that only one in four people in age group 65-74 use internet (Statistics Estonia, 2012). This may be because of financial issues, that older people just can not afford this luxury but also interpersonal factors play a role here – new technology frightens and elderly just do not know how to use it. (Randver, 2005)

Differences in internet using between men and women in Estonia are not big – 79.2% of men and 77.7% of women were using internet in the first quarter of 2012
(Statistics Estonia, 2012). If we look by the age groups (figure 1), then highest percentages of internet users were in the age groups 16-44.

![Bar chart showing internet usage by age group](image)

**Figure 1. Percentage of internet users in different age groups in 2012 I quarter (Statistics Estonia, 2012).**

Statistics Estonia has gathered information about the purpose of internet usage and that also involves data about searching health-related information (i.e. trauma, nutrition, illnesses etc.). In 2005 the percentage of internet users who searched health-related information was 27.7% and in 2011 it was already 44.1%. In 2012 19.7% of people aged 16-74 used different patient portals in Estonia and digital prescription was used by 62.1% of internet users (Statistics Estonia, 2012).

Estonian Health Insurance Fund together with the Ministry of Social Affairs is performing a survey every year to collect data about citizens assessment to health and healthcare and that has also included data about sources from where people get health-related information.
In 2010 data showed that people preferred to get urgent health information from television (44% of respondents) and internet was the next source of information with 42%. In 2011 results had already changed and internet was the most popular source for health information (45%) and in 2012 it was already 49% (Eesti Haigekassa et al., 2010; Eesti Haigekassa et al., 2011; Eesti Haigekassa et al., 2013).

Also in 2011 survey asked how many people use internet portals to search health information and only 21% had done that (from search engine google, www.kliinik.ee and www.arst.ee mostly). Results about the year 2012 showed that already 30% had used internet portals to search health information. In Estonia most commonly the person who searches health information from the internet is with university degree, aged 20-49 and mostly women but unfortunately there is no more exact data in this area (Eesti Haigekassa et al., 2011; Eesti Haigekassa et al., 2013).

Other sources also bring out that women are more likely than men to search for health information from the internet as they are more concerned about their and their family member’s health, also younger people, people with higher income and education more likely use internet for health information search (Fox et al., 2013).

National Health Interview Survey in U.S. in 2009 determined that among adults aged 18–64, women were looking more health information on the internet than men (women 58.0%, men 43.4%) and were also more likely to use online chat groups for health topics (women 4.1%, men 2.5%) (Cohen et al., 2010).

Internet statistics in U.S. also show that internet, besides doctor’s visit, is the most popular source for finding medical information, reading about others’ experiences and tracking a personalized health data. 81% of adults use internet (men 80% and women 82%) and in the past year, 72% of internet users looked online for health information. Almost 8 out of 10 started their search from a search engine (google, bing etc.) (Fox et al., 2013).
2. INFLUENCES OF HEALTH INFORMATION AVAILABILITY AND USE IN INTERNET

2.1. Health literacy

„Health literacy is the capacity of individuals to access, understand and use health information to make informed and appropriate health-related decisions“ (Ishikawa et al., 2009).

It is a concept that is mostly used in health promotion and is connected with health education area. Patients with adequate health literacy are able to read, understand, and use health information correctly. Expanded definition of health literacy includes „a working knowledge of disease processes, self-efficacy, and motivation for political action regarding health issues“ (Berkman et al., 2004).

Research (HLS-EU Consortium, 2012) shows that in Europe, 47% of respondents in the survey had inadequate general health literacy or problematic health literacy, which shows that this area needs attention and could possibly cause serious problems in healthcare, because people with poor health literacy have bad self-management skills, they do not understand the information that is given by doctors (but it is important to mark out, that doctor’s communication skills also play an important role in this matter), the risk for hospitalization or poor treatment outcome is higher due to poor health literacy etc. (Weiss, 2007; HLS-EU Consortium, 2012).
The research also showed that within Europe, there are huge differences between countries and that needs to be considered when planning policies to promote health literacy (HLS-EU Consortium, 2012).

Good knowledge of health literacy means understanding health determinants, which will help person to change attitudes and motivation to make right choices in terms of health and healthy behaviour (Ishikawa et al., 2009).

Nutbeam (Nutbeam, 2000) has categorized health literacy into 3 groups:

- Basic/functional – a person is able to read and write basic health information and functions effectively in everyday life;
- Critical – the person has advanced cognitive skills and is able to evaluate health information critically and use it in everyday life. People with higher critical health literacy are more likely to provide psychosocial information to doctors, to check credibility of information obtained from other sources;
- Communicative/interactive – the person has more advanced health literacy skills and is able to apply the information into everyday life, even when circumstances are changing. Also people with higher communicative/interactive health literacy are more likely to ask questions from doctors (Nutbeam, 2000).

In 2005, Alexa T. McCray wrote: „Addressing health literacy – the ability to understand and act on health information – is one of the most pressing issues in our health care system today. Perhaps one of the most significant challenges we face is to make health information accessible to everyone, regardless of background, education, or literacy level“ (McCray, 2005).
The need for good health literacy is greater than ever, because medical care is getting more complex and the volume of information is growing every day. As internet is a valuable source of health information and it is crucial that people have good health literacy skills then in the other hand the quality of information is also very important – it should be trustworthy, easy to find and understand, as it may affect people’s decisions and can potentially harm their health (Weiss, 2007).

If you search term „health“ in google, then in 0.26 seconds the search resulted with exactly 3 470 000 000 results (16.04.2013) and finding right sources from this kind of volume, is not an easy task for anyone.

Professionals usually use subscription-based sites because they provide peer-reviewed and evidence-based materials. Patients are more free sites users that offer more general information. This leads to concerns about the quality of health information that is in the internet (Benigeri et al., 2003; Pourmand et al., 2011).

2.2. Impact of health information accessibility on patients

Web environment enables us to find health information in different topics (diseases, symptoms, alternative medicine etc.). We have access to scientific evidence, educational materials and we see personalized health data from patient portals (i.e. test results, information about diseases diagnosed, information about medications etc.) (Yaşin et al., 2011).

Also we can use interactive programs for health promotion and information – for example smoking cessation programs (an example from U.S.: http://utah.quitnet.com) or other online counseling services, weight-loss tools or programs (in Estonia http://tap.nutridata.ee, www.kaaluabi.ee etc.), share experiences
and get support in specialized online groups (www.diabetes.ee, www.kasvaja.net) or in different online forums (i.e. www.perekool.ee, www.fitness.ee). These are just a few examples.

Health-related websites have a powerful influence on the attitudes and behaviour of people and online information affects people’s decisions about health, but health literacy skills are also a factor. For example, people with lower health literacy have higher health risk behaviours. Online support groups can additionally be good for emotional support, which can motivate people to make better decisions in terms of better health (Esquivel et al., 2006; Korp, 2006; Ybarra et al., 2006; Easton et al., 2010).

Ybarra (Ybarra et al., 2006) brought out in their article that different research has discovered online health information to have many positive effects on people’s behaviour. For example, reliable information about a disease reduces anxiety, self-efficacy improves and people can better take care of themselves. Health information on internet may motivate people to seek professional help or decrease ambulatory care use, because of higher awareness. Good access to quality health information also gives good base for empowerment (ability to control and take action for better health) and improves people’s ability to more effectively communicate with health professionals. All this supports better health outcomes. (Ybarra et al., 2006; Korp, 2006; Kasmel et al, 2007; Sun et al., 2013).

From negative side health information in internet widens the equity gap in health, because for people who already have knowledge and information skills, it gives additional resources (empowerment) but people in the other side, with less knowledge, skills and opportunities, are disempowered (Korp, 2006).
2.3. Impact of health information accessibility on doctor-patient relationship

„Health on the internet might, in the long term, affect the doctor-patient relationship, moving power and initiative from the former to the latter“ (Korp, 2006). Medical records and other accessible health information has potential to improve medical care, especially by enhancing communication between doctors and patients and this enables to improve quality of healthcare and avoid errors (Ross et al., 2003).

Good communication between patients and doctors is essential and a very powerful tool for healthcare professionals for providing quality healthcare. Traditionally the communication has taken place with face to face encounters or in telephone. But now, with advanced technology, there are more opportunities – communication by email, telemedicine options, digital registration systems and health information systems enable us to see test results, book doctor appointments etc. – and that is changing doctor-patient relationship to a more patient-centered approach and patient participation in healthcare process is a key to successful disease management. As today’s patients are more active and participate in decision making process by educating themselves about available interventions, new drugs, new information about treatments and diseases etc. They are sharing their knowledge with doctors, changing the classic doctor-patient relationship (Hassol et al., 2004; Weiner et al., 2006; Weiss 2007; Ishikawa et al., 2009).

From patient’s point of view e-mail is considered more efficient for patient-physician communication than using the telephone. And patients who want to communicate about sensitive issues, such as for example substance use, computer-based communication is preferred, as it offers anonymous communication and takes pressure off from the patient (Weiner et al., 2006).

But there is often a mismatch between a clinician’s level of communication and a patient’s level of understanding because patients often misinterpret or do not
understand the information given, because of poor health literacy skills and/or
doctor’s bad communication – for instance the use of complicated vocabulary and
discussing physiological concepts which people, who do not have medical education,
are not able to understand. That can lead to medication errors, adverse medical
outcomes, and even malpractice lawsuits (Weiss, 2007).

Effective communication with patients has a beneficial effect on medical outcomes –
lower rate of anxiety, psychological distress, pain and better results in treatment. In
terms of reduction of utilisation of health services, patients who perceived that their
visits were patient-centered received fewer diagnostic tests and referrals in the
subsequent months (Wong et al., 2006; Weiss, 2007).

2.4. Health information in internet and use among pregnant women

In certain situations people are more concerned about their health – for example
during pregnancy. Internet offers pregnant women information and also enables
communication, sharing of experiences, support. Most common information that
pregnant women are searching or exchange their experience in social groups is about
nutrition, general healthy lifestyle, different symptoms during pregnancy, child
development, childbirth etc. Different research has shown that mothers use internet
for health information more than non-parents, especially during pregnancy, for
parenting information and health information (Romano, 2007; Bouche et al., 2008;
Sparud-Lundin et al., 2011).

Swedish researcher Larsson (2009) conducted a study among pregnant women who
visited 11 antenatal clinics in a county in mid-Sweden. The results of the study
showed that 91% of women had internet access and 84% of them used internet for
searching health-related information, especially in the early stage of pregnancy.
“Most (70%) of the women did not discuss the information they had retrieved from the Internet with their midwife, but more than half of them (55%) searched for information on topics brought up by the midwife“ (Larsson, 2009).

Another survey by Lagan (Lagan et al., 2010) among pregnant women from 24 countries showed that 97% of women used search engines (google at most) and social networking for finding health information related to pregnancy and almost 94% of respondents used internet for additional information after getting information from health professionals. Also this research brought out the problem that almost half of the women were not satisfied with information they got from health professionals and problem is their lack of time to ask questions – that is the main reason pregnant women use internet as informational source (Lagan et al., 2010).

Sparud-Lundin (Sparud-Lundin et al., 2011) researched internet use, communication and information search among pregnant women with type I diabetes. According to this research 22% of respondents never used internet to search for information concerning pregnancy, childbirth and parenthood. 12% searched for information every day, 29% one or more times a week, and 38% one or more times a month. 48% of the women said that they are active users of general websites of pregnancy and childcare, which also offer communication options. In this case we have to keep in mind that diabetic pregnant woman need different approach and support and are not entirely comparable with healthy pregnant women’s information needs (Sparud-Lundin et al., 2011).

Pregnant women’s behaviour on internet is related with two theories – social support theory and social comparsion theory (Szwajcer et al., 2005). The first theory gives a sense of belonging, with sharing experiences with other women and opportunity to get guidance (i.e. how to deal with morning sickness or more practical things – what kind of clothes to buy etc). Social comparison theory is associated with self-evaluation and comparing with others in similar situation to see if what they are
doing is right. Pregnant women prefer to talk with women who are pregnant or who have been pregnant. There are also behavioural differences between women expecting their first child and women who already have been pregnant – first group is using more internet for information and the second group mainly rely on their previous experience, their midwife or books (Szwajcer et al., 2005).
3. DIGITAL HEALTH INFORMATION SYSTEMS

3.1. Estonian health information system and electronic health record

Before health information systems were developed, everything was documented on paper and every patient had their own file where all information and patient history was collected. Nowadays we use computers and electronic systems for these actions and patient information is stored in electronic health record.

Estonian Health Information System (EHIS) was created in 2008 and is a part of state information system. The processor of the Estonian National Health Information System by law is the Ministry of Social Affairs and the authorized processor is the Estonian eHealth Foundation (Sepper et al., 2011).

„The health care related data is processed in this database in order to conclude and execute the health care services provision contract, ensure patients’ rights, protect public health and quality of health care services, to maintain the registers of health conditions as well as to manage health care.” (Health Services Organisation Act, §59¹ section 1).

Estonian electronic health record (EHR) is a part of health information system and is built around the X-road, which is a connection between different information systems, from both public and private sector. The system enables data exchange between different databases - electronic health record has access through X-road to data from population register, e-prescription system etc. It integrates data from healthcare providers, who may use different systems but present their data in a standardized format, for creating a common record for each patient, which doctors
can access and read test results, patient information (blood group, medications, allergies) and even see images from x-ray. EHR in Estonia is very unique from global point of view as it covers the whole population. Healthcare professionals can access the EHR by authentication with ID card and every entry leaves a mark for security reasons. Patients can access their data from Patient’s Portal the same way (Sepper et al., 2011; Estonian Information…, 2013; E-Estonia (n.d.)).

By the February 2013 Estonian health information system already had data about more than one million persons and through Patient Portal more than 50 000 patients had viewed their health information and they had done almost 2 million inquiries (Ross, 2013).

Despite the fact that law mandates doctors and healthcare institutions to send health record to the Estonian health information system, many of them are not doing it. As a consequence many patients are only seeing partial data about themselves or do not have any data to view (Ross, 2013).

3.2. Patient Portal

Estonian Patient Portal is an online application where patient can view their health related data (previous doctor visits, prescriptions, previous diagnoses etc.) but also their children’s health data. It is possible to appoint people who can buy out their prescriptions or make a statement for organ donation after death. People have an opportunity to restrict access to their individual health data and in this case doctors are not able to see the patient’s data (Sepper et al., 2011; Eesti Haigekassa (n.d.); E-Estonia (n.d.)).

Everyone who has viewed the information leaves an electronical „footprint“ for security reasons and patient can see who has viewed their health data. This security
measure should prevent misuse of data by health professionals. Patient Portal in Estonia is accessible with authentication by ID card through www.digilugu.ee and www.e-tervis.ee websites (Sepper et al., 2011; Eesti Haigekassa (n.d.); E-Estonia (n.d.)).
4. SPECIFIC AIM

The aim of this master thesis was to research health information accessibility and use in internet by pregnant woman, based on example of iPatsient portal in East Tallinn Central Hospital.

Sub aims of the study were:

- To give an overview of health information use in internet and its influence in terms of healthcare;
- Based on the example of patient portal iPatient, find out women’s awareness of iPatient;
- Find out the percentage of women who used iPatient portal;
- Investigate women’s satisfaction with iPatient portal and its opportunities.
5. MATERIALS AND METHOD

The research is based on literature review and questionnaire designed specially for this thesis. Respondents were asked about the awareness and usage of iPatient portal and the dissemination of the questionnaire were done in the internet. More detailed overview and description is available below.

5.1. Questionnaire

The questionnaire was developed in January 2013 and consisted of 11 questions. Questions were about respondents’ age, education, awareness, usage and satisfaction of iPatient portal in East Tallinn Central Hospital.

Target group of this questionnaire was women who had delivered their baby or monitored their pregnancy in East Tallinn Central Hospital in the time period of December 2007 – December 2012. The questionnaire was uploaded to www.ankeet.ee website and dissemination was done in three different internet environments:

- [http://www.perekool.ee](http://www.perekool.ee) – a public internet forum very popular among pregnant women and parents. Request to answer the questionnaire was made in sections of delivery, babies (0-1 year), children (1-6 years) and multiples;
\begin{itemize}
\item \url{http://naistekas.delfi.ee} forum – another public and quite popular forum where request to answer the questionnaire was disseminated in sections birth stories, babies and children.
\item \url{http://www.facebook.com} – questionnaire in Facebook was shared in two different ways. First sharing to friends and friends sharing it forward to their friends. Secondly in a Facebook community „Autumn babies 2010“ (Sügislapsed 2010). Unfortunately this kind of Facebook communities are not open to public, which is the reason why only this group was used for dissemination of the questionnaire, as the author of this thesis is a member in that group. This group currently involves 459 women.
\end{itemize}

Questionnaire was reachable in the internet from 29th of January 2013 – 29th of March 2013.

\section*{5.2. Description of examined group}

The questionnaire was addressed to women who had in the period of December 2007 to December 2012 given birth and/or had monitored their pregnancy in East Tallinn Central Hospital. In the introduction it was brought out that questionnaire is for women who had delivered their baby or monitored their pregnancy in East Tallinn Central Hospital. And just to be sure to get answers from the right group, the first question asked whether the respondent had given birth or monitored their pregnancy in East Tallinn Central Hospital or not and if the answer was „no“, then the questionnaire automatically moved to the end.
5.3. Description of iPatient

iPatient was East Tallinn Central Hospital’s e-service that was launched at the end of November in 2007 and was closed in December 2012 for developing a new eHealth portal that should be more advanced and comfortable to use. In 2007 iPatient was a new innovational solution for patients and it was developed for different reasons – patients’ feedback, that they would prefer online access to health record and online registration, but also quicker and better access to patient information for general practitioners. It was as if the hospital comes to the patient not the other way around as it traditionally has been (arst.ee, 2008; Podošvilev et al., 2009).

iPatient enabled patients to get quick and secure access to their patient records from any location and if necessary, share their information with other healthcare professionals. Access to iPatient was the same as to the patient portal – using ID card for secure identification. It was possible to view test results, even some images (ultrasound for example), pay for visits etc. Portal offered a comfortable way for booking doctor’s appointments or cancelling the appointments, also it was possible to get appointment reminder by e-mail or SMS (arst.ee, 2008; Podošvilev et al., 2009).

Data about the usage of iPatient in first two years showed that in average monthly 1150 people used the portal and that the main users were younger women and parents who viewed medical data about their newborn, but also elderly people. Main interest was the medical data (Podošvilev et al., 2009).
6. RESULTS

In total 235 questionnaires were answered, but since the questionnaires’ focus was on women who delivered their baby or monitored their pregnancy in East Tallinn Central Hospital then the first question, did the respondent deliver their baby or monitored pregnancy in East Tallinn Central Hospital, was with the purpose to rule out women who were not in this thesis’ focus.

32 (13,6%) respondents answered „no“ to this question and 203 (86,4%) answered „yes“. Only the 203 questionnaires are analyzed from this point on, since they matched the criteria.

For comparison 3811 babies were delivered in East Tallinn Central Hospital in 2012 (Ida-Tallinna Keskaigla, 2012).

6.1. Age of the respondents

Two people had not answered about the age and one had written her age to be 1 year, which will not be counted. 200 women who had answered about their age, minimum age was 17 and maximum 45 years. Average age was 30,51 years. Respondents’ age distribution is shown in figure 2.
6.2. Education of the respondents

From 203 respondents 128 (63%) had higher education, 69 (34%) had secondary education and 4 (2%) had basic education. 2 respondents did not answer this question.

6.3. Number of delivery

For the majority of respondents (figure 3) it was their first delivery (for 131 women), 59 women answered that it was their second and for 13 women it was their third delivery.
6.4. Awareness about iPatient

115 (55%) women knew about iPatient and that they could see their health data from there, 94 (45%) did not know about this possibility.

6.5. iPatient usage among respondents

From 115 women who knew about the possibilities of iPatient, 97 (84.3%) used iPatient to view their data, 18 (15.7%) did not. Those who did not, were asked about the reasons why they did not use iPatient. In this case they were able to choose multiple answers and 12 answers said that it was because they were not interested and 13 answers were that they could not get access to iPatient.
Although respondents had an opportunity to write their own option why they did not use iPatient, no one used this option.

6.6. Helpfulness of information accessible in iPatient

Majority of respondents, 73 (75.3%) out of 97, who used iPatient said that it was helpful information for them. 11 (11.3%) stated that it was not helpful information for them in any way and 12 (12.4%) could not say.

Also there was a question for the respondents who stated that the information was helpful, whether they would like to specify their experience, but none of the respondents did not want to do that.

6.7. iPatient’s user friendliness

From 97 women who used iPatient, 70 (72.2%) answered that it was comfortable and 27 (27.8%) answered that it was not comfortable to use.

6.8. Reasons why iPatient was not comfortable to use

In the questionnaire there were 2 options given (finding information took too much time and getting in to iPatient took too long). The third option was open for respondents to write themselves. Also it was possible to choose multiple answers. 21 respondents said that finding information took too much time and 23 respondents said that getting in to iPatient took too long. No respondent used the opportunity to write their own reasons.
7. DISCUSSION

The purpose of the questionnaire was to examine if people, in this case women/mothers, were aware that their health information was available on iPatient portal and also find out if it was useful for them and comfortable to use. Based on different sources, women are more likely to search health information from internet as they are more concerned about the health and wellbeing of their family and themselves and women are usually the caregivers in the family. (Cohen et al., 2010; Eesti Haigekassa et al., 2010; Eesti Haigekassa et al., 2011; Eesti Haigekassa et al., 2013; Fox et al., 2013)

This specific target group was chosen for the reasons that overall iPatient users are very hard to reach, especially since iPatient was closed at the end of 2012 and new eHealth portal is in development. But women who are now mothers can be reached in internet in many ways and as being pregnant normally means periodical check-ups and analysis, also ultrasounds, then they were presumably connected with the hospital for certain period of time.

iPatient usage data from East Tallinn Central Hospital about the first two years showed that main users were younger women and parents who viewed medical data about their newborn (Podošvilev et al., 2009). That was also one of the incentives to investigate this target group in the survey.
7.1. General information

From general information only age and education was asked in the questionnaire. Nationality data and data about the region were excluded as the questionnaire was in Estonian language and it was distributed only in Estonian internet environments, then presumption was that most of the women are Estonians. And as East Tallinn Central Hospital is situated in Tallinn, then most of the respondents are most likely from Tallinn and Harjumaa area and even if there were women from other regions then it would not affect the results.

Also in terms of questionnaire, it was important that it is short and easy to answer as the target group involves mothers, who’s babies could now be only a few months old (taking into account the time period that was included in this study – December 2007 – December 2012), then to get enough responses, answering questionnaire could not take too much time.

The age range of respondents was 17-45 years old. Data from national health statistics database from Estonian Medical Birth Registry and Estonian Abortion Registry shows for example that in 2011 there were 14 503 childbirths and the distribution by the mothers age on childbirth is shown on figure 4, where we can see that nationally most of the women (60%) who gave birth were in the age of 25 – 34 years (Tervisestatistika ja…, 2012).
When dividing target group researched in this thesis into same age groups, then rough estimate would be that most of the women (69%) in this study were also 25 – 34 years old. But it is important to mark out that it is not possible to compare the data one on one as national data is about mother’s age in the childbirth but data from this thesis’ questionnaire presents the age on the time of answering the questionnaire.

Education data showed that most of the women (63%) in this study had higher education, 34% had secondary education and 2% had basic education. 1% of the respondents did not answer this question. Comparing this data with Estonian Medical Birth Registry and Estonian Abortion Registry’s data retrieved from health statistics database then the situation is a little different. National data show that in year 2011 40% of women that gave birth had higher education, 46% of women had secondary education and 14% had basic education or less (Tervisestatistika ja…, 2012).

The proportions are different as most of iPatient users have higher education and only few had basic education. There may be several factors that have influenced this difference. First of all, the number of the respondents – national data is based on data
of 14,503 women (Tervisestatistika ja..., 2012) which leaves more opportunities to divide in different groups, but this thesis only had 203 respondents.

Secondly, collection of data – national data is collected from hospitals’ official documents and all women who gave birth in specific time period were included in the sample and analyzed. But questionnaire in this thesis was only answered by women who got the information about the survey either from facebook or from forums, who were interested and also who had time and opportunities to answer (computer and internet access).

Another factor that could influence people’s activity in answering surveys is the differences in socio-economic status of people – this means differences in education, income, occupation. The presumption based on this questionnaires result is that people with higher socio-economic status are more likely to take part in this kind of surveys.

The presumption was influenced by health promotion field, as research has shown that socio-economic status influences people’s behaviour. People with higher education and income are making better choices in life and live longer, happier and healthier life (Kasmel et al., 2007). For example people who have higher education smoke less – in 2012 only 12% of people with higher education were daily smokers but the same value among people with basic education was almost 37% (Tekkel et al., 2013).

Another parallel could be drawn in terms of voting and civic engagement – some sources say that people with higher socio-economic status are more likely to vote and take part in civic activities than people with lower status (Foster-Bey, 2008; Brown et al., 2009).

As the surveys of Estonian Health Insurance Fund and Ministry of Social Affairs have shown that most commonly people who search for health related information
from internet are with higher education and mostly women, then it supports the result that more than half of women in this thesis’s research were with higher education (Eesti Haigekassa et al., 2010; Eesti Haigekassa et al., 2011; Eesti Haigekassa et al., 2013).

7.2. iPatient awareness and usage

55% of women knew about iPatient and its opportunities. It is very hard to analyze the awareness of this focus group since there is no detailed data to compare it with as research done for this thesis dealt with quite unique group of people that have not been analyzed. Question is – why almost half of the women who answered to this questionnaire, were not aware of iPatient and its possibilities for individual health information?

We can only presume that iPatient marketing was perhaps too modest or healthcare workers did not introduce iPatient opportunities to the women. Maybe women themselves did not pay attention to information that was available in the hospital and hospital’s webpage. Since there is not enough data about patient portals then it is hard to analyze women’s awareness as we have no good comparison.

Looking at the data that we have in this study from another point of view then situation is a little bit different. For example comparing iPatient awareness using education as a factor, then among respondents who had higher education, the iPatient awareness was a bit higher than the overall result was – 62.5% of respondents with higher education knew about iPatient and its opportunities. Among women with secondary education, the awareness rate is 40.6%. Among women with basic education, 3 out of 4 knew about iPatient, but it is not possible to make any conclusions based on this result because of the small sample size. But higher education and secondary education comparison result was expected as people with
higher education usually are more aware, no matter if it is concerning health determinants or health information search.

If looking the data about using iPatient then 84.3% of respondents who knew about the possibilities, used iPatient to view their health data. This is quite high percentage. For example one study that researched disparities in enrollment and use of electronic patient portal, showed that 69% of the patients, who were introduced with the opportunity and invited to use patient portal, enrolled in the patient portal (Goel et al., 2011).

Another study that researched electronic patient portal use among disadvantaged populations (socioeconomic and clinical characteristics) showed that 60% of patients who received an access code to patient portal, activated the account and almost half of the patients who received that code, used patient portal two or more times (Ancker et al., 2011).

When looking at iPatient usage data again from another point of view, using education as a factor, then from women who had higher education, 53% used iPatient portal. Among women with secondary education, the rate was 36%. Again this confirms the fact that people with higher education are using more opportunities for health information.

When talking about iPatient awareness and usage, then according to literature review also the number of delivery had an important role. Previous overview pointed out that internet is more a source of health information among women who are having their first child. Those women who already are mothers, they are acting more based on their previous experiences (Szwajcer et al., 2005).

But this overview was about overall information search in internet. Information about patient portal use among this group could not be found and this area definitely needs more research.
This questionnaire’s results show that for 65% of the all respondents it was their first delivery. Almost 59% of all women for whom this was the first delivery were aware of iPatient opportunities and among women who were aware of the opportunity, 82% used iPatient. Among women with second delivery these numbers were not much different (accordingly almost 58% were aware and 85% of them used iPatient). Women who had their third delivery, 54% were aware and all of them used iPatient. Based on this data, it is not possible to say that first time mothers are looking more information from internet than these women who already are mothers.

7.3. Information use and user-friendliness

Majority of respondents (75,3%) said information that they got from iPatient was helpful for them and for the rest of respondents, information was not helpful in any way or they could not say whether it was useful or not. Unfortunately no-one specified how this information was helpful for them.

If talking about internet use for health information then nowadays it is very common (not only among pregnant women and mothers) and there are even implications that for example attendance in childbirth classes is on the decline. Fortunately internet is still a supplement information source and has not entirely replaced healthcare professionals’ advice but it has definitely changed the situation and relationships between patients and healthcare professionals (Hassol et al., 2004; Weiner et al., 2006; Romano, 2007).

According to a survey done in four years apart, participation in childbirth classes among mothers who had their first child dropped from 70% to 56% and among experienced mothers from 19% to 9%. The same survey estimated that basically 3 out of 4 women use internet as a source of information as it is quick, easily
accessible at any time and any place and also considered quite reliable. 16% of first-time mothers and 13% of experienced mothers indicated internet as most important source for health information (Romano, 2007; Bouche et al., 2008).

Using this knowledge from literature we can assume that for this questionnaire’s respondents who found the health information in iPatient to be useful, it meant better overview and perhaps more prepared communication with midwives and/or doctors. Secure access to health records can give an opportunity to learn and understand the health risks and determine what kind of measures to use in order to decrease those risks (Ross, 2013).

But as this research did not give an answer to the question where pregnant women and mothers get information and how they use information that they get from patient portal, then this could be a good topic for further research (not only among pregnant women and mothers) as we don’t have any good data about health information use.

The questionnaire also asked about the usage convenience of iPatient. For more than 70% of users iPatient was comfortable to use. The questionnaire also asked the reasons why iPatient use was not comfortable. There were two choices given (finding information took too much time and getting in to iPatient took too long) and third option was open and respondents had an opportunity to write their own reason. As it was possible to choose multiple options then majority of people for whom iPatient was uncomfortable, both answers were chosen and no one took the time to write their own reason. It is possible that respondents were not using iPatient so frequently or used it a long time ago (as first respondents could be from the end of 2007 already) and could not specifically remember what problems may have occurred while using the portal. For better results the question should have been asked in a different way as this presentation of the question did not get any considerable result.

East Tallinn Central Hospital has registered patients’ complaints regarding to iPatient portal in 2009. According to this data, problems were more associated with technical
issues. Total of 162 complaints were registered and almost 39% of complaints were about technical issues such as problems with ID-card certificates, pop-ups not allowed etc. Almost 31% of complaints were about the problems with booking the appointments and rescheduling. The rest of the problems were with payments, not finding a desired doctor, problems with test results (i.e. could not find results) and not understanding performed procedures and diagnoses. Only 8% indicated that improvements in the system should be done or data should be changed. (Ida-Tallinna Keskhaigla, 2009)
8. CONCLUDING REMARKS

Health information use and its influence

The literature review showed that internet is a very important source of health information. This has changed doctor-patient relationships, because patients are more prepared and empowered, healthcare has moved into more patient-centered approach and in the future the impact of internet will be even bigger. Estonian data showed that internet has also risen to a very important channel in terms of health.

Data about health information systems and patient portals is harder to find and there is not enough good reasearch done in this area. In other countries some sources implicated that health information systems and patient portals are not widely used by patients. The few data that Estonia had, showed quite good results compared to other countries, but still the proportion of people using health information system to review personal health data is quite low.

Awareness and percentage of women who used iPatient

More than half of women who answered the questionnaire developed for this thesis were aware of iPatient and its opportunites. Most of the respondents were with higher education.
The percentage of women who used iPatient was quite high among these respondents who were aware of the opportunity – almost 9 women out of 10 who knew about iPatient used it for reviewing health related information.

**Satisfaction with iPatient**

Most of the respondents (70%) were satisfied with the iPatient and found the information to be useful. Unfortunately the survey did not give good results on how respondents used information that they got from patient portal and women who were not satisfied with iPatient, what were the reasons why it was uncomfortable to use.

**Further research is needed**

The study in this thesis focused on a quite unique group of health information users – mothers. East Tallinn Central Hospital has some statistics about iPatient users but there is a lack of data on specific user groups and especially, how people use the information that they get from patient portals. This is definitely a topic that needs further research alongside with the use of overall information people retrieve from other sources in internet.
The development of internet has been extremely fast and in about twenty years internet has become an important and popular source for information. Most of all because it is reachable 24 hours a day and enables us to find information very fast.

The whole development of technology has of course influenced healthcare. Technology helps to increase quality of healthcare and improve accessibility but of course this has had impact on classic doctor-patient relationship – in the past doctor was the first source of information but now internet has taken this role and given patient different position. Healthcare has moved more on to patient-centered approach where patient has more power and opportunities to take part in the treatment process. Another positive side is that e-services make our lives more convinient.

The purpose of this master’s thesis was to research health information accessibility and use in internet, based on example of iPatsient portal in East Tallinn Central Hospital. To achieve this goal a questionnaire was developed and study carried out in the internet among women who in the time period of December 2007 – December 2012 had delivered their baby or monitored their pregnancy in East Tallinn Central Hospital. In addition to questionnaire, literature review gave an overview on how popular is searching health related information from internet.

Besides general information (age, education, number of deliveries), the questionnaire researched women’s awareness of iPatient and its opportunities, percentage of users, how respondents are using the information that they receive from patient portal and
satisfaction with iPatient. Dissemination of the questionnaire was done in different internet forums and in facebook. 203 women matched the criteria and formed the sample of thesis’ research.

Literature overview showed that internet is quite common source for health related information and most commonly women and people with higher education are searching health information from the internet. Also mothers and pregnant women have higher need for information, especially with first pregnancy/child.

The awareness of iPatient was good but relatively many women had not heard about iPatient and its opportunities. However those who were aware, most of them had used iPatient and most of the users assessed the retrieved information to be useful. Unfortunately none of the respondents specified, how they used information that they got from the patient portal. Satisfaction with iPatient was mostly good. Those who were not satisfied, had chosen answers given in the questionnaire (information was not to be found quick enough, getting the information took too long) and none of the respondents brought out any additional reasons.

It is definitely necessary to do further studies in this area since Estonia does not have enough data about patient portals. Research is needed about patient portals and overall health information search from internet, for example the aspect, how people use the information that they get from the internet and how it influences different user groups.
RESÜMEE

Interneti areng on olnud ülimalt kiire ning paarikümne aasta jooksul on internetist saanud oluline ja küllaltki levinud informatsiooni allikas, eelkõige sellepärast, et see on kättesaadav ööpäevaringselt ning informatsiooni on võimalik leida väga kiirelt.

Kogu tehnoloogia areng on muidugi mõjutanud ka tervishoiu valdkonda, kus tänva tehnoloogiale on võimalik tervishoiukvaliteeti tõsta ning parandada selle kättesaadavust, aga kõik need protsessid on mõju avaldanud ka klassikalisele arsti-patsiendi suhtele – kui varem oli esmane tervisealase info allikas arst, siis nüüd on suures osas internet selle rolli enda peale võtnud, mis on andnud patsientidele teise positsiooni ning tervishoid on liikunud rohkem patsiendikeskse lähenemise suunas, kus patsiendil on vörreldes varasemaga rohkem võimalusi kaasa rääkida. Lisaks info paremale kättesaadavusele võimaldavad e-teenused ka mugavamalt asju ajada.


Küsimustikus uuriti lisaks üldisele taustale (vanus, haridustase, sünnituste arv) naiste teadlikkust patiendiportaalist ja selle võimalustest, kasutajate osakaalu, saadud informatsiooni kasutamist ning iPatsiendi kasutamismugavust. Küsimustiku levitati erinevates foorumites ja kasutades facebooki jagamisvõimalusi. Küsimustikule vastajaid, kes vastasid esitatud kriteeriumitele, oli kokku 203 naist.
Kirjanduse ülevaate põhjal selgus, et internet on küllaltki levinud tervisealase info otsimise allikaks ning peamisteks terviseinfo otsijateks internetis on eelkõige naised ning kõrgharidusega inimesed. Ka rasedate naiste ning emade info otsimise vajadus on kõrgem, eriti esimese raseduse/lapse puhul.


Edasised uuringud on kindlasti vajalikud, kuna Eestis patsiendiportaalide kohta ei leidu eriti andmeid ning vaja oleks patsiendiportaalidega ja üleüldse internetist tervisealase info otsimisega seoses uurida, näiteks seda aspekti, mismoodi internetist saadud informatsiooni kasutatakse ja kuidas see mõjutab erinevaid kasutajagruppe.
EXPRESSION OF GRATITUDE

My greatest gratitude is to my supervisor Peeter Ross, for taking the time to put my ideas into focus and guiding me during the writing of this thesis.

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BIBLIOGRAPHY


APPENDIXES

Appendix 1 – Questionnaire

Tere!


Küsitlusele vastamine vôtab Teie ajast mõned minutid. Lõpus ärge unustage vajutada lingile „edasta vastused“.

Ette tänades,
Kristel Ojala

1. Kas sünnitasite ja/või jälgisite oma rasedust Ida-Tallinna Keskaiglas?
   a) Jah
   b) Ei

2. Kas Ida-Tallinna Keskaiglas sünnitanud ja/või rasedust jälginud Ida-Tallinna Keskaiglas?
   a) Esimene sünnitus
   b) Teine sünnitus
c) Kolmas sünnitus
d) …… ?

3. Kas teadsite, et kogu Teiega kaasnevat terviseinfot (k.a. rasedusega seotud UH pildid, mis samas haiglas teostatud) oli võimalik vaadata iPatsiendi portaalist?
a) Jah
b) Ei

4. Kas kasutasite seda võimalust ning vaatasite oma andmeid iPatsiendi portaalist?
a) Jah
b) Ei

5. Juhul, kui Te ei vaadanud oma andmeid iPatsiendi portaalist, siis mis põhjusel?
a) Ei huvitanud
b) Ei pääsenud ligi
c) Muu (nimetage palun)

6. Kui kasutasite iPatsienti, siis kas see info oli teile kuidagi ka abiks?
a) Jah
b) Ei
c) Ei oska öelda
7. Kui iPatsiendist saadud info oli teile abiks, siis kas soovite saadud kogemust täpsustada
   a) ...
   b) Ei

8. Kas iPatsienti kasutada oli Teie jaoks mugav?
   a) Jah
   b) Ei

9. Juhul, kui iPatsiendi kasutamine oli Teie jaoks ebamugav, siis miks?
   a) Info polnud kiirelt leitav
   b) Info kättesaamine võttis liiga palju aega
   c) Muu (nimetage palun)

10. Teie vanus?
    ......

11. Milline on Teie haridustase?
    a) Põhiharidus
    b) Keskharidus/keskeriharidus
    c) Kõrgharidus