

THESIS ON MECHANICAL ENGINEERING E70

**Access Rights and Organizational
Management in Implementation of
Estonian Electronic Health Record System**

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Declaration:

Hereby I declare that this doctoral thesis, my original investigation and achievement, submitted for the doctoral degree at Tallinn University of Technology has not been submitted for any academic degree

/Madis Tiik/

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MEHCHANOTEHNIKA E70

Päasuõiguste ja organisatsiooniliste meetmete rakendamine Eesti tervise infosüsteemi näitel

MADIS TIIK

Contents

LIST OF ORIGINAL PUBLICATIONS	7
ABBREVIATIONS, TERMS AND SYMBOLS	8
PREFACE	9
ACKNOWLEDGEMENTS	10
1. INTRODUCTION.....	11
1.1. The factors influencing implementation of the electronic health records (EHR)	13
1.1.1. National leadership to promote health IT adoption.....	13
1.1.2. Health care system organization and financing.....	15
1.1.3. Size of a country’s population.....	16
1.1.4. Common health IT infrastructure.....	17
1.1.5. Robust standards to support health IT.....	17
1.2. Patient identifiers, privacy and access right	18
1.2.1. Use of unique patient identifiers	18
1.2.2. Privacy issues related to health IT systems.....	19
1.2.3. Access rights	20
1.3. Patient empowerment.....	21
1.4. Secondary usage of medical data of EHRs	22
1.5. Evaluation and indicators for measuring success of nationwide data sharing	23
1.6. Acceptance by the end-users – doctors and nurses	25
1.7. Aims of the study	26
2. SUBJECTS AND METHODS.....	27
2.1. Theoretical methods used during the research	27

2.2. Describing the process of the preparatory phase.....	30
2.2.1. Access rights	30
2.2.2. Methods used in standardization process.....	31
2.2.3. Piloting and monitoring the actual implementation of EHR by the HCO-s activities	33
3. RESULTS AND DISCUSSION	35
3.1. Access rights	35
3.2. Establishing Estonian eHealth Foundation	40
3.3. Standardisation	42
3.4. Results of the implementation of EHR	43
3.5. Future developments	45
4. CONCLUSIONS.....	48
5. REFERENCES.....	50
6. SUMMARY IN ESTONIAN.....	59
7. SUMMARY IN ENGLISH.....	62
8. PUBLICATIONS.....	67

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following original publications referred to in the text by Roman numerals.

- I. Tiik, M. 2010. Rules and access rights of the Estonian integrated e-Health system. *Medical and Care Compunetics*, 6, pp. 245–256.
The author participated in the workgroups which compiled the documents on access rights and was the main person responsible for analyzing the process and writing the manuscript.
- II. Tiik, M. Ross, P. 2010. Patient opportunities in the Estonian Electronic Health Record System. *Medical and Care Compunetics*, 6, pp.171–177.
The author participated in the process of describing services and functionalities of Electronic Health Record, was responsible for implementing services and was the main person responsible for writing the manuscript.
- III. Sepper, R, Ross, P, Tiik, M. 2011. Nationwide Health Data Management System: a novel approach for integrating biomarker measurements with comprehensive health records in large populations studies. *Journal of Proteome Research*, 10(1), pp. 97–100.
The author participated in the process of describing services and functionalities of EHR, developed a concept of secondary use of data and contributed to the manuscript.

ABBREVIATIONS, TERMS AND SYMBOLS

AR – Action Research
EEHF – Estonian eHealth Foundation
EHIF – Estonian Health Insurance Fund
EHR – Electronic Health Record
EMR – Electronic medical records
ETSA – Eesti eTervise Sihtasutus
GP – General practitioner
HCO – Health care organization
HIE – Health Information Exchange
HIT – Health information technology
ICT – Information Communication Technology
IT – Information technology
PHR – Personal health record
SA – System analysis

PREFACE

“eHealth means Information and Communication Technology (ICT) tools and services for health. eHealth covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals. Examples include health information networks, electronic health records, telemedicine services, wearable and portable systems which communicate, health portals, and many other ICT-based tools assisting disease prevention, diagnosis, treatment, health monitoring and lifestyle management.”
(European Commission)

The first signs of the use of information technology in Estonian healthcare took place in the last decade of the last century. Family doctors' centers and hospitals began to build a digital database in order to submit medical claims to the Estonian Health Insurance Fund (EHIF) and share patient administration information. Assets of the respective software functionality are constantly being upgraded, and now computers have become a commonplace tool for doctors.

Telemedicine is one of those areas in health care that can offer many valuable opportunities and work tools for doctors. In Estonia, the first telemedicine pilot project, named Bitnet, took place in the turn of the century 1999–2001. During the Bitnet project, telemedicine consultations were held between primary health center in Kuressaare and Tartu University Hospital to determine the suitability of consultations with remote areas in various disciplines and issues of patients' health problems. In addition, regular distance training sessions were held between family physicians at the island of Saaremaa and the University of Tartu, using the video conference equipment and communication channels of the project (Maaroos et al., 2001).

In the coming years next projects followed. For instance, Estonia participated in the Baltic eHealth Project and R-Bay that were teleradiology projects with several countries to set up primary reading and second opinion services for radiological images (Ross et al., 2010).

Family doctors advice telephone launched in 2004 was Estonia's first telemedicine service to be included in the official price list of the EHIF. Before starting the project, in 2003, a comprehensive survey of family physicians and residents in Estonia was carried out to study the willingness to give and receive medical advice by phone (Baltcom, 2004). Results of the survey gave the assurance that there is a need for such services recognized by citizens. Within the next two years the author of the dissertation developed a concept on how to start a state-financed nationwide telephone advice service (Tiik et al., 2007). Family doctors advice service was launched in summer 2004.

The Estonian Society of Family Doctors has been supportive to e-health as an innovative approach to health care system development. As a representative of Estonian Society of Family Doctors, the author of this dissertation was involved in all e-health activities in Estonia. This has been an excellent starting point for studying different aspects and prerequisites of e-health implementation as well as analyzing their impact on the healthcare system.

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1. INTRODUCTION

The guiding document for the development of the information society in Estonia, *the Estonian Information Policy*, was approved by the Parliament of Estonia in 1998. As the value of using Information and Communication Technology (ICT) solutions in health care had become increasingly evident, the government support followed. In 2006, the Estonian government initiated the development process of a comprehensive nationwide Electronic Health Record System (EHR system) as a part of the *Estonian Information Society Strategy 2013* (Ministry of Economic Affairs and Communications, 2006).

In designing such a multifaceted system, not only the technological but also the legal, organizational and ethical aspects of the healthcare service process needed to be taken into account.

The vast opportunity of using ICT in health care is well captured by Robert D. Atkinson who has said in his book *Digital Quality of Life*: “*Most of the things that can be developed have already been developed, but we have only begun to scratch the surface when it comes to making the world alive with information.*”

The potential benefits of implementing the Estonian EHR system were introduced as follows:

- More efficient use of health care labor resources (doctors, nurses, pharmacists).
There will be a need for fewer specialists to carry out the same amount of work and they will be able to provide better quality services in less time. Thanks to utilizing modern IT solutions, specialists can complete the bureaucratic paperwork faster and have more time for patients.
- Significantly reduces paper consumption and space requirements for paper document archives in health care. Therefore, it also has a positive environmental impact.
- Reduced postage cost and the use of patient as an information-carrier.
- Reduces the costs of security measures for the protection of confidential data.
- Efficient use of radiology equipment. Radiology equipment amortization and personnel costs are usually the biggest cost of radiology service. EHR will result in cost reduction as the efficiency of the service availability improves, and since the images are digital the queues and cost of radiology supplies and materials will be reduced (Ministry of Social Affairs, 2007).

It was predicted that handling sick-leave documentation electronically will give us the following positive results:

- By using electronic transmission of data citizens can get their reimbursements quicker, i.e. in fewer days.
- Employers save on postal and handling cost of sick-leaves and it will take less time.
- Health care organisations don't have to print sick-leave documents.
- Estonian Health Insurance fund (EHIF) is saving on handling costs and it is also easier to analyse sick-leave patterns (Ministry of Social Affairs, 2007).

The research upon which this thesis work is based on arose from the personal involvement in several nationwide ICT projects in Estonia. My personal participation, starting with software development for the family doctors in early nineties, followed by telemedicine and eHealth projects, led me to realize that I want to delve into the academic world, and to explore the assumptions that must be met in order to maximize the benefits of eHealth projects.

1.1. The factors influencing implementation of the electronic health records (EHR)

1.1.1. National leadership to promote health IT adoption

Perhaps no factor is more influential in explaining why some countries lead in health IT adoption than strong national-level leadership. Implementing health IT involves a complex set of relationships among individuals and organizations with competing goals and priorities. Following are some examples of health IT adoption approaches from different countries.

In 2001, the Danish Regions together brought the public partners running the healthcare sector in Denmark and jointly established a non-profit organization, the Danish National e-Health Portal – Sundhed.dk. In 2003 agreement between the government and county hospital owners resulted in the five new hospital regions adopting the standard of “one patient – one EHR” within each region. Furthermore, many Danish hospitals are carrying out development in relation to electronic medical records (EMR). In the beginning there will be a shared EMR for each hospital, but this is also a basis for providing an interconnected EMR system for the entire hospital network and in the long term for the Danish healthcare services as a whole (Doupi et al., 2006).

The eHealth portal is run by a political board with members from the Danish Regions, the Ministry of Health, Association of Danish Municipalities, and the Association of Pharmacies. Although these early efforts in Denmark resulted in substantial progress, in June 2006, Denmark’s Ministry of Health, the Danish Regions, and the municipality association came together to form a new, cross-governmental organization – *Connected Digital Health in Denmark* (Connected Digital Health in Denmark, 2007). Its role was to coordinate health IT initiatives between different government organizations and ensure that the nation follows a clear and consistent national health IT strategy (Nøhr et al., 2005; Bhagat et al., 2010). The current Danish roadmap for eHealth is the “National Strategy for Digitalization of the Danish Healthcare Service” from 2008. The strategy’s goal is to support the reorganization of tasks and the adaptation of healthcare structures caused by digitalization. Digitalization is to be an integral element of all future healthcare initiatives. The implementation of the strategy is described in a number of action plans. Each action plan defines many different aspects, such as development, testing, implementation, application, operation, maintenance, monitoring and efficiency measurement (Doupi et al., 2006).

Finland’s eHealth Roadmap from 2007 is a follow-up to the *Strategy for utilizing information technology in the field of social welfare and healthcare in Finland*, which was launched in 1996. Its underlying principle is the development of seamless service chains, which requires the introduction of

new technology, new types of information system architectures, and better compatibility between information systems (Doupi et al., 2010).

Denmark and Finland stand out for having the foresight to establish a national vision for health IT adoption well before other countries reached the same conclusion, but their higher level of adoption of health IT is not necessarily just the result of their having a head start. Much of the success of Denmark and Finland in health IT can be credited to the clear goals they established. The formal institutions they created to pursue these goals, and the commitments they have made to regularly revisit and renew their national eHealth strategies behind Sweden, the Netherlands, and the United Kingdom (Hämäläinen et al., 2007).

Sweden has established an early lead in applying IT to health care through coordination at the national level (National Strategy for eHealth: Sweden, 2006). The work to be jointly undertaken is grouped into six action areas. The first three areas are concerned with establishing better basic conditions for ICT in health and elderly care. The last three are about improving eHealth solutions and adapting these to patient needs. Education, training, and research initiatives are crucial to all six areas. These are legislation and regulations, common information and technical infrastructure, interoperability, access to information and services for citizens.

In Australia, three parallel streams of activity are planned – a set of activities to enable the enhancement of relevant software; activities to build implementation program capacity; and another set of activities to build implementation readiness in the early adopters and subsequently the fast followers. This will produce a state of readiness for early adoption, the outputs of which will initially be uptake of the identifiers – allocation of the identifiers to the in-scope practices, providers and their patients – and better identity management within practices. National personally controlled electronic health record system for all Australians was launched in 2011, by the National E-Health Transition Authority. It was done in collaboration with health sector leaders, is seeking to drive the adoption of a range of new and improved healthcare capabilities enabled by advances in information and communications technologies, and the development of national information infrastructure (National E-Health Transition Authority, 2010). In Canada, an independent not-for-profit corporation Infoway was created by Canada's First Ministers in 2001 to foster and accelerate the development and adoption of EHR systems with compatible standards and communications technologies. Funded by the Government of Canada, Infoway works with the country's ten provinces and three territories to implement private, secure EHR systems, enabling best practices and successful projects in one region to be shared or replicated in other regions (Canada Health Infoway, 2011).

There are convincing evidence that central governance and top-down approach with strong cooperation with professional societies and foremost stakeholders have been successful in many countries like Sweden, Denmark, Canada and

Australia. In the other hand, too centralized approach with less flexibility and local choice in electronic health record systems and their delivery has contributed to deployment delays and frustrations (Robertson, A et al., 2010; Protti, 2008).

1.1.2. Health care system organization and financing

The organization of a country's health care system and health care financing can have a significant impact on health IT adoption. Countries like Denmark, Finland, and Sweden with single-payer health care systems, the costs and benefits of investing in health, IT systems are better aligned than they are in countries such as the United States, where multiple governmental and non-governmental entities pay for health care. Moreover, in these nations governments can afford to take a longer term view and make investments that might not pay off fully in the short term. More government involvement in health care also leads to more accountability.

Finland's national government has been the primary source of funding for health IT initiatives in that country. Between 2004 and 2007, Finland's Ministry of Social Affairs and Health allocated €30 million per year for health IT projects, with a third of the money distributed through the county councils and the rest distributed directly through the ministry (Doupi et al., 2008).

United Kingdom is another example of a single-payer health care system, where the government has made a large investment in health IT. In the United Kingdom, most doctors and hospitals are paid directly by the government, and an estimated 90 percent of acute hospital beds are in public hospitals (Smee, 2000). The country's National Health Service is one of the world's largest employers with over 1.3 million individuals on its payroll (National Health Service Information Centre, 2010). As a result, government can more directly enact broad changes in the health care system while also receiving many of the cost savings benefits of health IT investments. Not surprisingly, the National Health Service Program for IT is one of the most ambitious and most expensive eHealth programs in the world with a budget of £12.4 billion over 10 years (Anderson et al., 2006).

In Australia as part of the 2010/11 federal budget, the Government announced a \$466.7 million investment over two years for a national personally controlled electronic health record system for all Australians who choose to register online, from 2012-13 (Personally Controlled Electronic Health Record, 2011).

Researchers consistently identify the high initial cost of EHR systems as a barrier to more widespread health IT adoption. Financial incentives for health IT adoption by health care providers, therefore, can be an effective policy tool. This has been used effectively in Australia, Denmark, the Netherlands, and the United Kingdom, among others, to spur the use of health IT (NEHTA, 2011;

Anderson et al., 2006; Doupi et al., 2008; Infoway, 2011; United States Congress, 2009; Schoen et al., 2006).

American Recovery and Reinvestment Act (United States Congress, 2009) directs a significant \$19.2 billion to health information technology, which the US government estimates will lead over time to better quality of care, better care coordination, less duplication of services, fewer medical errors, and, ultimately, more cost savings. As some have noted, the funds available for EHR systems may be insufficient to spur the needed change by some providers. In addition, the total cost of implementing health IT exceeds the level funding in the stimulus package: Global research and development corporation RAND predicts that implementation of EHRs by all medical practices would cost approximately \$8 billion per year over 15 years. The biggest chunk of money – \$17 billion – will come in the form of Medicare and Medicaid incentives to entice physicians and hospitals to adopt EHRs. Besides carrots, the government also has penalties for non-adopters. Beginning in 2015, physicians who have not adopted health IT will be subject to decreasing Medicare payments, up to a 3% reduction by 2017 and beyond (Guglielmo, 2009, Girosi et al., 2005; Anderson et al., 2006; Doupi et al., 2008).

Many countries use government mandates to achieve universal health IT adoption. Governments can mandate either the use of specific functionality or the use of specific technology. Denmark and Norway, for example, have achieved high rates of e-prescribing by making e-prescribing mandatory for primary care providers (Protti et al., 2006; Protti, 2007).

1.1.3. Size of a country's population

Large countries with a diverse group of stakeholders appear to be at a disadvantage when deploying health IT. Arguments can be made for both a positive and a negative correlation between a country's population size and health IT adoption. On the one hand, economies of scale would suggest that deploying health IT in larger countries would be cheaper and thus larger countries would be more likely to have higher rates of health IT adoption. Conversely, smaller countries may be more likely to lead to health IT adoption because their smaller size allows easier coordination between various stakeholders.

European experience shows that national EHR systems tend to fail in the larger countries, with habitants more than 10 million people. There is more evidence of decentralised healthcare systems with a focus on interoperability and connectivity in the regions (Stroetmann et al., 2011). Indeed, a significant challenge with health IT is the difficulty of coordinating and bringing various stakeholders together to work towards a shared vision and overcome obstacles such as interoperability. Coordination is often easier

in smaller countries in part because the ability to collaborate is closely related to the number of competing stakeholders, such as the number of health IT vendors. Some mid-sized nations, like the United Kingdom, have also been able to achieve a level of success coordinating the deployment of health IT because they have a more centralized health care system (Castro, 2009).

1.1.4. Common health IT infrastructure

Building shared IT infrastructure – that is, technology that can be used by multiple health care providers, helps lower costs and increase interoperability by creating a shared platform for health care organizations to use. Examples of common health IT infrastructure include shared EHR systems, online authentication services, electronic billing systems, secure email, online portals, and health data networks.

For example, in Denmark there are secure intranets established across regions, local authorities and other organizations, linked by an Internet-based healthcare data network through VPN connections. In addition, more than 4 million standardized medical documents are sent as Electronic Data Interchange per month, representing 80% of all communications in the primary healthcare sector. Since 1996, the Danish organization MedCom has developed Electronic Data Interchange standards based on the EDIFACT syntax and these standards have also been developed in an XML format version for future hospital communications (Kushniruk, 2009).

The Canadian approach has focused on Infoway, a national effort to provide vision and strategy to increase the national adoption of EHRs. On the health information exchange front, Infoway promotes the interchange of a wide array of clinical data, including laboratory, pharmacy, and hospital information (Ausford, 2005; Adler-Milstein, 2007).

Sweden has developed Sjunet, a national broadband network for the secure exchange of health information connecting all hospitals, primary care centres, and many other health centres. Sjunet is an IP-based broadband network, connecting all Swedish hospitals, primary care centres and many other health services. Sjunet is used for multiple clinical and administrative purposes in Sweden, including video-conferencing, teleradiology, secure e-mail, electronic data interchange, and e-learning in medical education (Malmqvist et al., 2004).

1.1.5. Robust standards to support health IT

Robust standards are critical to the effective application of health IT and play a crucial role in spurring the use of new technology. To facilitate the standard-setting process, many governments actively engage with all stakeholders,

including those from the private sector, to coordinate the development of standards. In Denmark, for example, MedCom, the Danish health care organization, responsible for setting standards for health IT systems, acts as a coordinating body to bring health care providers, laboratories, vendors, and others together to develop interoperable standards (MedCom, 2010).

The basis for EHRs quality is – apart from the methodological, structural, and organizational aspects – the collection and definition of EHR-specific requirements. These requirements are of a different nature and origin, and differ from country to country. The heterogeneity renders an inter-organizational or even cross-country selection and coordination of such requirements difficult (Hoerbst et al., 2010).

1.2. Patient identifiers, privacy and access right

1.2.1. Use of unique patient identifiers

Unique patient identifiers help facilitate data sharing between different health care organizations and benefits of their use include reduced risk of medical errors, improved efficiency, and better privacy protection for patients. The use of unique patient identifiers is common in many of the global leaders in health IT, including Denmark, Finland and Sweden (Protti, 2008).

Notably, the United States has not adopted a system of unique patient identifiers – in large part because of unwarranted fears about a loss of privacy – a fact that has been identified as being a hindrance to using data from EHRs for research (Quantin et al., 2007).

There has been some implementation of (Health Information Exchange) HIE in both Australia and New Zealand, in both nations, hospitals are increasingly sending discharge summaries electronically to general practitioners (GPs), who in turn are sending referrals and other communications to hospitals and specialists electronically. Some experts suggest that the lack of a single national identifier code has hindered health information exchange in Australia to a substantial degree. New Zealand, which does have a single consumer health identifier, may have an easier time creating a national health information exchange program (Jha, 2008).

The Finnish personal identity code or Finnish Unique Identifier is issued by the Population Register Centre and it is mapped to the Social Security Identity Number, which functions as a unique identifier for Finnish citizens and permanent residents to eGovernment services. The personal identity code is needed in order to be able to apply for pensions and other benefits. It is also needed for the payment of wages, salaries and fees. The code is also essential in bank transactions, and the banks require it when one is opening an account (Ruotsalainen et al., 2007).

An identity and authentication solution based on smart card technology currently provides a best of breed foundation for improving EHRs in secure, private and sensitive way. Many governments worldwide are currently making efforts for technological modernization and innovation. Countries like Portugal (Falcao-Reis et al., 2010), Spain (Protti, 2007), Finland (Doupi et al., 2010), and Belgium (Sembritzki, 2004) are already implementing such systems.

Using their digital signature, citizens of Denmark can log on their personal web space in order to book appointments, order medications and renew prescriptions, review their own medication and health care data and communicate with healthcare authorities (Protti 2008).

As another option for secure identification inside hospital settings, to reduce errors when administering drugs to hospitalized patients (e.g., when a nurse gives the medication to a patient), hospitals use bar coding or radio frequency identification wrist bands at medication administration and electronic medication administration records. Studies have found that using bar-coding at medication administration can reduce errors by 65 to 85 per cent (Cohraine et al., 2007).

1.2.2. Privacy issues related to health IT systems

Although there are policies existing in healthcare organizations (HCOs), they are not capable of protecting privacy in electronic healthcare. "Having extensive privacy policies on an enterprise does not directly ensure privacy protection if there is no effective means of consistent policy enforcement across multiple applications and across enterprise boundaries" (Reed, 2005). Enforcement of the privacy policy is essential to ensure that personal information is accessed, used and disclosed in accordance with ethical norms, so privacy policies should be represented electronically and be managed through software tools capable of detecting the underlying hidden errors. This approach will enable HCOs to enforce a policy while sharing information with other HCOs (Mizani et al., 2007).

The key issue when creating databases for collecting and managing the entire population data is building the trust in society and its members. Trust is a two-way relationship that requires constant effort for creating and maintaining it. In addition, trust is extremely relevant to many different levels and relationships existing in healthcare system, i.e. doctor-patient, doctor-doctor, doctor-healthcare system, patient-healthcare system. It is clear that digital health information system will fundamentally change the current doctor-patient relationship and the relationship between doctors and doctors' relationship with the healthcare system (Sutrop, 2006).

The study carried out in the central Hampshire, UK, shows that process of widespread dissemination of information and seeking explicit consent

whenever possible seems to have caused little concern among the residents. Usage of the helpline and website was low compared with the numbers of leaflets dispatched, and the volume of feedback was also low. It might be expected that those who were concerned about patient confidentiality would make more effort to express their opinion; feedback was mostly positive (Adams et al., 2004).

In Denmark, for example, patients have access to health information through the official Danish e-health portal Sundhed.dk and can control many privacy functions through this portal, including monitoring who has accessed or modified their personal medical records. As a result, privacy advocates generally supported efforts to implement health IT (The Danish National eHealth Portal, 2007).

1.2.3. Access rights

The EHR systems are becoming more and more sophisticated and include nowadays numerous applications, which are not only accessed by medical professionals, but also by accounting and administrative personnel. This could represent a problem concerning basic rights such as privacy and confidentiality. Granting access to an EHR should be dependent upon the owner of the record; the patient: he must be entitled to define who is allowed to access his EHRs, besides the access control scheme each HCO may have implemented. In this way, it's not only up to health professionals to decide who have access to what, but the patient himself. Implementing such a policy is walking towards patient empowerment which society should encourage and governments should promote (Falcao-Reis, 2008).

Most of the eHealth experts agree that access to the EHR is a fundamental patient right and that the implementation of personally accessible electronic health records should not be delayed. The question is how much information should be provided and whether access should be given only to the "relevant" content in the EHR. Ideally, this clinical information should be coupled with tailored educational materials to help people meet their information needs. The second approach is to provide full access to all information contained within the EHR and allow the patient decide what information they consider to be relevant. In this approach, educational information could also be linked to a fully accessible personally accessible electronic health records (Wiljer, 2008).

In modern, electronic-based HCOs, individuals from diverse professional backgrounds work collaboratively in decision making processes concerning patients' health, and patients have the right to influence these processes. Winkler states that an organization-wide policy that covers all individuals in an HCO and deals with both standard and morally controversial medical practices ensures autonomy, quality, fairness and efficiency of decision-making processes. The privacy policies of many developing countries, which

mainly assume a traditional physician–patient decision-making approach, fall short of fulfilling such goals (Winkler, 2005).

1.3. Patient empowerment

Ever since Hippocrates developed an oath for doctors the model of health care has been one where the doctor had the information and the patient received it. However, this model was always flawed because it failed to make patients active participants in their care and treatment. One of the reasons why some individuals are not more actively involved in managing their own health is that they have bought into the idea of the doctor as the expert, believing that “the doctor always knows best” (Atkinson et al., 2008).

Personal health record (PHR) has recently been published as one of the means to support patient empowerment and patient control over their personal health record. The functionality of such a PHR may vary from a simple web-based interface for interactive data entry and data review up to a much more powerful system additionally supporting electronic data / document communication between clinical information systems of primary care practitioners or hospitals and even reminder based support for the empowered citizen, to actively take care of his health, based on relevant disease management programs. Since storage and communication of data in a PHR comprises sensible personal health data, each of those functions need specific security and access management requirements to be considered and implemented (Ückert et al., 2002).

In the US, a study of 1421 users of an EHR that provides web messaging and online access to medical records found that attitudes about the use of these features were mostly positive (Hassol et al., 2004). The majority of patients were satisfied that the medical information contained in their EHR was complete and accurate, and most patients were not concerned about the confidentiality/privacy of their medical information or about learning of test results before discussing them with their providers. Patients and physicians differed substantially in their preferred means of communication, with patients preferring e-mail communication for most interactions followed by in-person communication, whereas physicians preferred in-person communication followed by telephone communication. As healthcare continues to be more patient-centered, patient’s expectations will be a driving force for change in healthcare communication (Couchman et al., 2001, Kane et al., 1998).

Creating secure and easy Internet access to patients’ health data will increase patients’ awareness of their health. Citizens can get an overview of their recent doctor’s appointments, laboratory tests, and medical reports, etc. This allows patients to make more informed decisions about their health behaviour or prepare more thoroughly for the appointment with the health care professional. Citizens can also record their expressions of will (e.g., donation

of organs, permit blood transfusion) or choose preferences which increases their involvement in decision making process related to their health condition.

In Sweden, it was studied if patients' are satisfied with e-prescription. The vast majority of the respondents were satisfied with e-prescribing and storing of prescriptions electronically (Hammar et al., 2011).

EHIF has carried out annual surveys on patient satisfaction related to different aspects of eHealth services. One of those studies indicated that 95% of the patients who had purchased prescription medicines during last year were satisfied with e-prescriptions, and 85% answered that EHR is highly valuable or valuable and it will make data exchange easier between HCOs (Estonian Health Insurance Fund, 2011).

Patient and physicians survey in US indicated 15% primary noncompliance among patients with e-prescriptions. The top 2 reasons for this were perception of lack of efficacy and concern about side effects. High cost and absence of symptoms ranked next. Only 34% of all patients felt that e-prescriptions improve medication safety significantly, and many of them were not aware of e-prescriptions use by their physicians. The satisfaction with e-prescriptions among physicians was 83% (Hakim, 2010).

A white paper from the American Association of Medical Informatics outlined the potential barriers to and benefits for the adoption of PHRs not only for patients, but also for health care organizations. Those barriers are privacy and security issues, change management issues, and the lack of basic infrastructure such as EHRs (Tang et al., 2006). At the same time, several potential benefits for patients include better access to health information, increased ability to self-manage chronic health conditions, increased medication tracking and safer prescription renewals and improved connections for patients and providers are named. Increased patient satisfaction, continuity of care and improved processes standardization of care are the benefits for HCO (Tang et al., 2006; Ball et al., 2007).

From July 2012, all Australians who want can register for a personally controlled electronic health record. As the personally controlled electronic health record system matures, Australians who use personally controlled electronic records will be able to see their important health information in one consolidated view. They will be able to share this information with trusted healthcare practitioners, who in turn will be able to access their patient's personally controlled electronic health record to support the delivery of high quality healthcare regardless of where and when it is needed (Personally controlled electronic health record 2011).

1.4. Secondary usage of medical data of EHRs

Secondary use of health data applies personal health information for uses outside of direct health care delivery. It includes such activities as analysis,

research, quality and safety measurement, public health, payment, provider certification or accreditation, marketing, and other business applications, including strictly commercial activities. Secondary use of health data can enhance health care experiences for individuals, expand knowledge about disease and appropriate treatments, strengthen understanding about effectiveness and efficiency of health care systems, support public health and security goals, and aid businesses in meeting customers' needs (Safran et al 2007).

An interesting study was carried out in Canada, Ontario, where patients in family practices were interviewed regarding their preferences on method of consent for the use of information from EHRs for research. The results of the study showed that patients are willing to allow information from their medical records to be used for research, but most prefer to be asked for consent either verbally or in writing (Willison et al., 2006).

The Kaiser Permanente device registries leverage their integrated health care system's administrative databases and electronic health records system, collecting important information about patient safety, quality improvement, cost-effectiveness, and research (Paxton et al., 2012).

1.5. Evaluation and indicators for measuring success of nationwide data sharing

After two years of implementing electronic health records in Colorado and Northwest regions of Kaiser Permanente, rates of office visits fell by 9% in both regions. Primary care visits decreased by 11% in both regions and specialty care visits decreased by 5% in Colorado and 6% in the Northwest (Garrido et al., 2005). In the Northwest, scheduled telephone contact increased from a baseline of 1.26 per member per year to 2.09 after two years. Use of clinical laboratory and radiology services did not change conclusively. Intermediate measures of quality of health care remained unchanged or improved slightly. This study showed that readily available, comprehensive, integrated clinical information reduced the use of ambulatory care while maintaining quality and allowed doctors to replace some office visits with telephone contacts. Shifting patterns of use suggest reduced numbers of ambulatory care visits that are inappropriate or marginally productive (Garrido et al., 2005).

The provision of around-the-clock care to critically ill patients in intensive care units by physicians who specialize in their care (intensivists) is considered key to improving outcomes for critically ill patients, but some hospitals cannot provide such care because of a shortage of intensivists. Recently, some hospitals have used telemedicine to improve care for critically

ill patients via remote electronic intensive care units. Remote electronic intensive care units allow a team of intensivists to monitor critically ill patients in the hospital continuously using streaming video, EHRs, and remote sensors, so that they can coordinate care with the physicians and nurses who are caring for these patients in the hospital. A health system in Kansas City, for example, implemented an electronic intensive care unit to leverage its limited intensivists and standardize clinical practices and processes in its seven hospitals. Researchers found that this initiative reduced the health system's intensive care units and hospital mortality rates (Howell et al., 2007). In addition, it reduced the length of stay for patients in the intensive care units and hospital, a factor that strongly influences hospital costs.

A study of the first major electronic intensive care units installation similarly found that the hospital reduced mortality by 27 per cent and reduced the costs per intensive care units case by 25 per cent. In the United States, hospital adoption of electronic intensive care units is still low – fewer than 50 hospitals had implemented electronic intensive care units by late 2007 (Kowalczyk, 2007).

In the systematic review of the literature by Poissant (Poissant et al., 2005) to examine the impact of EHRs on documentation time of physicians and nurses came out that the use of bedside terminals and central station desktops saved nurses, respectively, 24.5% and 23.5% of their overall time spent documenting during a shift. But the results were opposite for doctors, using bedside or point-of-care systems increased documentation time of physicians by 17.5%. This review highlighted that a goal of decreased documentation time in an EHR project is not likely to be realized. It also identified that documentation time for the two main user groups, physicians and nurses can be different.

Richard Hillestad and colleagues suggest that the EHR could produce efficiency and safety savings of \$142 billion in US physician offices and \$371 billion in US hospitals over the next fifteen years (Hillestad et al., 2005).

Systematic review of the literature of 256 studies made by Shekelle (Shekelle et al., 2006), show that health information technology (HIT) has the potential to enable a dramatic transformation in the delivery of health care, making it safer, more effective, and more efficient. Some organizations have already realized major gains through the implementation of multifunctional, interoperable health IT systems built around an EHR.

Systematic review of the literature (Black et al., 2011) found that empirical evidence for the beneficial impact of most eHealth technologies is often absent or, at best, only modest. While absence of evidence does not equate with evidence of ineffectiveness, reports of negative consequences indicate that evaluation of risks – anticipated or otherwise – is essential.

1.6. Acceptance by the end-users – doctors and nurses

Doctors and nurses are the primary end users of EHR and related health IT systems. They use health IT on a daily basis and should their facility decide to implement EHR, it will become integral to all their work. As such, they are a critical group to consider in any discussion on the field of health IT.

According to systematic review of literature by Victor Castillo from Mexico, six critical adoption factors have been described: end-user attitude towards information systems, workflow impact, interoperability, technical support, communication among users, and expert support. The main limitation of the adoption factors of electronic health records reported are type of practice, setting, or attention level (Castillo et al., 2010).

Physicians stand to gain an enormous amount from the use of health IT. If an effective, standardized EHR system were implemented, doctors could retrieve important patient information and share it with those who need it. Easier and quicker retrieval of important information would lead to higher quality of care.

Paperless electronic records contain significantly more words and abbreviations. They are more legible and easier to understand. The results of the study carried out in three counties in the UK indicate that they contain more diagnoses, details of referrals and medication. (Cox et al., 2003).

In addition, doctors would not have to run duplicate tests on patients, as all of a patient's test results would be conveniently available. A well-designed system could grant all these benefits and reduce errors in patient treatment and help avoid malpractice suits (Goldschmidt, 2005).

In 2008, half a year before launching the nationwide EHR system, a telephone survey on awareness and perceptions of the nationwide EHR system was done among Estonian doctors. There were 350 doctors who participated in this study. Altogether, 97% of the participants were aware of the nationwide EHR system and its services and 77% had positive perceptions of the EHR system (Emor, 2008).

In the multi-site case study of evaluation of the implementation of summary care records in England show that two out of seven influences were related to doctors concerns (especially about workload and the ethicality of sharing “confidential” information on an implied consent model). The second influence was interpersonal influence (for example, opinion leaders, champions, facilitators) (Greenhalgh et al., 2008).

In the systematic literature review, based on research papers from 1998 to 2009, concerning barriers to the acceptance of EMRs by physicians, eight main categories of barriers, including a total of 31 sub-categories, were identified. These eight categories are: A) Financial, B) Technical, C) Time, D) Psychological, E) Social, F) Legal, G) Organizational, and H) Change Process. All these categories are interrelated with each other. In particular,

Categories G (Organizational) and H (Change Process) seem to be mediating factors on other barriers (Boonstra, 2010).

The risks for physicians in implementing health IT systems are not nearly as obvious as the gains. Doctors find a number of practical problems in EHR systems. First, doctors must spend large amounts of time and effort to get used to the systems, meaning their workflow is less efficient – sometimes for months. Poorly designed systems can also inhibit their work (Sprague, 2004). Because of the lack of interoperability between many health IT systems, smaller offices often have trouble implementing them since they have to work with many other institutions (Anderson, 2007).

Physicians, especially those unfamiliar to computers, also worry that the computer systems will diminish their relationship with their patients – a critical part of their profession. For example, if a physician is speaking with a patient, their communication may be interrupted if the physician is trying to use a computer at the same time to access an EHR system. This may lead to less perceived face time with a patient, and consequently a poorer relationship. In addition, if a provider is trying to pay attention to a patient while using a computer, they are more prone to make errors in using the system (Gaffey 2009).

The nurses from the study (Whittaker et al., 2009) experienced many of these problems with their newly-implemented EHR system. Many of their complaints about the system were related to the computers being slow or inconvenient to use. They also cited the amount of training needed and their lack of proficiency with computers as major issues.

1.7. Aims of the study

The aim of this research is to investigate the main factors and preconditions necessary for successful implementation of the nationwide EHR system. The concrete aims of the study were:

- To analyse different preconditions to the EHR implementation and find factors which are crucial for success.
- To define leaders of governance process and operators of implementation of the EHR system
- Development of agreement in defining access rights and privacy and security of the data usage for HCO, doctors and patients. Creating the concept of the attending doctor
- To define specialist and their role and interest in the development of EHR system.
- Describe the process of standardization of medical documents.
- To follow up use and acceptance of EHR system after launching.

2. SUBJECTS AND METHODS

The research upon which this thesis work is based arose from the author's personal involvement in several nationwide ICT projects in Estonia (BitNet, 1999–2001; National telephone advice line, 2003–2004; Developing nationwide EHR system, 2005–2012).

2.1. Theoretical methods used during the research

During the process the author collected and analysed information compiled reports and took part in meetings with different experts. As a CEO of the Estonian eHealth Foundation (EEHF) the author of the thesis was also personally responsible for creating conditions for successful implementation of the nation-wide EHR system.

The selected research approach for analysing different preconditions and the process of change can be classified as Action Research (AR).

Action research – By the definition of Rapoport the AR is defined as: “*Action research aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework*” (Rapoport, 1970).

AR is an interactive inquiry process that balances problem solving actions implemented in a collaborative context with data-driven collaborative analysis or research to understand underlying causes enabling future predictions about personal and organizational change (Reason et al., 2008). AR challenges traditional social science by moving beyond reflective knowledge created by outside experts sampling variables, to an active moment-to-moment theorizing, data collecting, and inquiry occurring in the midst of emergent structure. “Knowledge is always gained through action and for action. From this starting point, to question the validity of social knowledge is to question, not how to develop a reflective science about action, but how to develop genuinely well-informed action – how to conduct an action science” (Torbert, 2004). In this sense, performing action research is the same as performing an experiment, thus it is an empirical process.

In AR the researcher takes unique role – “helping role, to solve the practical problems and in the same time, increase scientific knowledge.” In other research methods, the researcher does not change the process; only

examine the process and organisation (Checkland, 1991; Baskerville et al., 1996; Baskerville et al., 2004).

Lewin's description of the process of change involves three steps (Lewin, 1958):

Unfreezing: Faced with a dilemma or disconfirmation, the individual or group becomes aware of a need to changing.

Changing: The situation is diagnosed and new models of behavior are explored and tested.

Refreezing: Application of new behavior is evaluated, and if reinforcing, adopted.

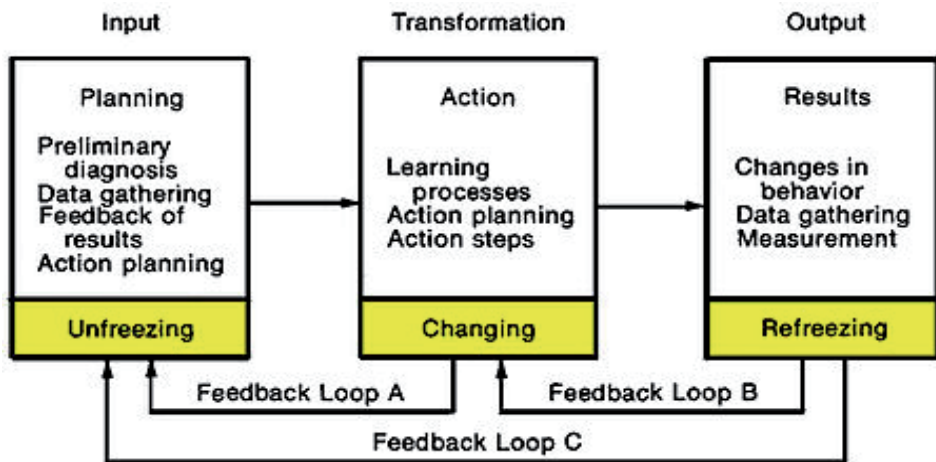


Figure 1. Systems Model of Action-Research Process (Lewin, 1958)

Figure 1 summarizes the steps and processes involved in planned change through action research. Action research is depicted as a cyclical process of change.

The cycle begins with a series of planning actions initiated by the client and the change agent working together. The principal elements of this stage include a preliminary diagnosis, data gathering, feedback of results, and joint action planning. In the language of systems theory, this is the input phase, in which the client system becomes aware of problems as yet unidentified, realizes it may need outside help to effect changes, and shares with the consultant the process of problem diagnosis.

The second stage of action research is the action, or transformation, phase. This stage includes actions relating to learning processes and to planning and executing behavioral changes in the organization. As shown in Figure 1, feedback at this stage would move via Feedback Loop A and would have the effect of altering previous planning to bring the learning activities of the client

system into better alignment with change objectives. Included in this stage is action-planning activity carried out jointly by the consultant and members of the client system. Following the workshop or learning sessions, these action steps are carried out on the job as part of the transformation stage.

The third stage of action research is the output or results phase. This stage includes actual changes in behavior (if any) resulting from corrective action steps taken following the second stage. Data are again gathered from the client system so that progress can be determined and necessary adjustments in learning activities can be made. Minor adjustments of this nature can be made in learning activities via Feedback Loop B (see *Figure 1*). The action-research model shown in *Figure 1* closely follows Lewin's repetitive cycle of planning, action, and measuring results. It also illustrates other aspects of Lewin's general model of change. As indicated in the diagram, the planning stage is a period of unfreezing, or problem awareness (Lewin, 1958).

The process of implementation always relied on analysis of the impact of the change and the feedback received was used to correct further plans of change. As the author of the thesis was participating in the process, analysis relay also on personal experiences previously collected in different projects.

The AR is claimed to be an especially appropriate in the field of ICT (Rapoport, 1970).

System analysis – Systems analysis (SA) is the dissection of a system into its component pieces to study how those component pieces interact and work (Lorents, 2006). SA is (1) the survey and planning of the system and project, (2) the study and analysis of the existing business and information system, and (3) the definition of business requirements and priorities for a new or improved system. Traditionally, SA is associated with application development projects, that is, projects that produce information systems and their associated computer applications. But SA methods can be applied to projects with different goals and scope. In addition to single information systems and computer applications, SA techniques can be applied to strategic information systems planning and to the redesign of business processes. There are also many strategies or techniques for performing systems analysis. They include modern structured analysis, information engineering, prototyping, and object-oriented analysis. In this research object – oriented analysis and modern structured analysis was used in standardization process, in creating managing processes, in the business process design and in the building up organizational processes of the EEHF.

Focus group interviews – A focus group is a form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs, and attitudes towards a product, service, concept, advertisement, idea, or

packaging. Group discussion produces data and insights that would be less accessible without interaction found in a group setting – listening to others’ verbalized experiences stimulates memories, ideas, and experiences in participants. This is also known as the group effect where group members engage in “a kind of ‘chaining’ or ‘cascading’ effect; tap links to, or tumbles out of, the topics and expressions preceding it” (Lindlof et al., 2002).

2.2. Describing the process of the preparatory phase

Several working groups were established during the preparatory phase. These workgroups were legal experts group to prepare the legislative acts, workgroup of ethicist to find balance in privacy and security of the data usage and using data for secondary purposes, workgroup of access rights to describe access rights to data and give input for creations of different roles in system, and workgroup of economic impacts of the EHR system implementation. Part of the preparations was establishing special juridical body to guide change through the projects. As a CEO of the EEHF the author actively attended with all processes concerning EHR system. Building up a standardization process of the medical documents was a task of the EEHF. Author was personally involved in the two workgroups: access rights and economic impact of the EHR and in the work of standardization of medical documents.

2.2.1. Access rights

In order to study different preconditions for the implementation of EHR, group interviews were carried out with professional groups about access rights and privacy issues in the different specialties (internal medicine; gynaecology; psychiatry; infections disease, general practitioner; dental care). Each professional group was interviewed once. Interviews were made with representatives named by medical professional societies. Each group (3-5 doctors) described needs of their speciality and limitations of using data they had collected. Altogether 8 group interviews were transcribed and analysed, after which interviewers (project team from EEHF) wrote analytical report that included an overview of necessary access roles and description of role limitations. By the model of Lewis (see *Figure 1*) this can be described as Input phase of the cycle. This paper was sent back to doctors with a request to clarify questions that had surfaced during interviews (Feedback loop A, in the *Figure 1*).

Between specialties there were large disparities regarding using delicate data outside their speciality: psychiatry, gynaecology and infectious diseases were

the most delicate groups as they wanted to keep their own documentation. Finally, after receiving feedback from all specialities, all reports were submitted to one single document named “Access rights” and the results were discussed at a focus group discussion. Focus group was organised to provide a discussion forum to representatives of all specialties (general practitioners, gynaecologists, psychiatrists, infectionists, internal medicine doctors, dentists and surgeons) to find a suitable balance between specialties. This is the second phase of the cycle Transformation (see *Figure 1*).

After having all necessary input and requirements of different professionals, the next step was to discuss disparities and limitations of data usage. In this step the workgroup of ethicists’ presented their work and the concept of attending doctor.

The finalization of the “Access rights” document (Access rights, 2007) was task of EEHF and this third phase “Output” of the cycle (see *Figure 1*) was delivered to the workgroup of legislation for preparation the necessary changes in legislation and it was also input to the role description for the software.

2.2.2. Methods used in standardization process

Approach of the system analysis was used. In this method researcher can be also named as a system analyst. The responsibility of creating the standardization process was task of the EEHF together with external experts from hospitals.

Research



Collecting information about the present system works

Observation – This involves the researcher walking around the organization or business, watching how things work with his/her own eyes. Observation allows gather first-hand, unbiased information.

Interviews -The researcher can interview key people within the system to find out how it works. Interviews allow lots of very detailed information to be gathered, but they take a long time to do, so are not possible if large groups of people are involved.

Questionnaires – With large groups of people, a questionnaire is a quick and simple way to gather information. However the information gathered is limited by the questions set by the researcher (people could have a lot of

useful information in their heads, but if the questionnaire doesn't ask the right questions, they will not be able to pass it on)

Collecting Documents – Most businesses and organizations use documents to record information, or to communicate information (forms get filled in and passed to other offices, etc.) The researcher needs to collect examples of the documents used to get an understanding of the type and quantity of data that flows through the business or organization. Having collected as much information about the present system as possible, the systems analyst now looks though it all to understand how the system works, and to try and identify problems that need to be fixed.

Analysis



Examining out how the present system works and identifying problems with it.

Identifying the Inputs, Outputs and Processes – for example who use the document and to whom this document is sent or what are the use cases with the document

Identifying Problems – after collecting different documents used by the HCO, it came out that there is lot of overlapping data in the documents.

New System Requirements Specification – the problems with present system are understood and standardization team can begin to plan how the new system will fix those problems. New content to the documents was created and optimization of the data was applied.

The content of documents was also input for the legislative acts.

Design



In this stage external experts were used to create data models and technical documents. An HL7 CD document with necessary documentation was created.

Production



Technical documentation, explanatory material and classificatory was published in the web of EEHF – the official published of the standards. The EHR system central services were created to support the gathering new types of documentation.

Testing



Healthcare providers software developers started to test new standard documentation and communication with EHR system.

Documentation



Creating documents that describe how to use the new systems, and how documents should be transferred.

Implementation



The EHR system services were launched and HCO started to send documents.

Evaluation

Monthly reports about documents arrived to the EHR system.

2.2.3. Piloting and monitoring the actual implementation of EHR by the HCO-s activities

Piloting the EHR system in 3 major hospitals: North Estonia Regional Hospital, East Tallinn Central Hospital and Tartu University Clinic and in one

primary healthcare centre – Järveotsa Family Doctors Centre. This centre was selected as they used the most popular software solution for family doctors, and they had motivated doctors to test EHR services. During the piloting phase the major work was done by the IT personnel of the hospitals. The IT specialists sent test messages to the EHR test environment and created secure access for doctors and nurses inside the hospital. Piloting took place during the last quarter of the 2008, just before launching the nationwide EHR in the 16.12.2008. All three hospitals had different software and internal processes. Each software solution of HCO had to pass acceptance test before getting access to the working environment of EHR.

In order to monitor the actual implementation of the EHR by HCOs the following aspects were observed:

- Monthly reports from EEHF and EHIF
- EEHF database regarding messages sent and retrieved from the EHR
 - Number of different documents sent to EHR
 - Number of enquiries sent to EHR
- EHIF database regarding prescription activities
 - Number of prescriptions issued by doctors
 - Number of purchased prescriptions in pharmacies

3. RESULTS AND DISCUSSION

3.1. Access rights

The most important prerequisite for realizing the Estonian EHR system was to establish the rules for the usage of patients' health data. The finalization of the "Access rights" document was task of EEHF and was delivered to the workgroup of legislation for preparation the necessary changes in legislation and it was also input to the role description for the software.

The access rights workgroup described the principles of system of access rights and the system of rights related to handling patient's health data from the following aspects (Paper I):

- Purpose of data usage
- Roles of health care system's employees
- Patient's will
- Specific situations
- Recommendations for legislative and technical implementation of the EHR:
 - All health care providers must send mutually agreed data to EHR (as prescribed in legislation – the Health Services Organization Act and Associated Acts Amendment Act, Health Services Act 2007)
 - All access rights and data use is regulated by law (Health Information System Statute)
 - Access only enabled to licensed medical professionals
 - A patient's data can only be viewed by their attending physician, i.e. the person currently associated with the patient's treatment and who is a health care employee registered with the Health Care Board under the Ministry of Social Affairs
- EHR authorization system. Because security reasons don't allow password based authentication, complex authentication is recommended:
 - ID cards are used to authenticate and provide digital signatures
- Access rights for citizens
 - Citizens can access their data through the Patient's Portal, where they can also declare their intentions and preferences regarding certain subjects. More specifically, patients have the right to set access restrictions on documents, cases of illness and all personal information in EHR. In short, access restrictions can be set on one specific document or applied to the complete set of data in EHR. Patients can see how and why information is used (logging data) in EHR. This enables citizens to monitor every incidence of access to their personal medical records. By ensuring that people are able to determine the sources of retrieval of their personal information at any time, it is possible

to detect any undesired action. As each log-in is registered, patients can immediately inform the Estonian eHealth Foundation (authorized processor of the EHR) or the Estonian Data Protection Inspectorate when an unjustified log-in is identified.

Comparing our experience with other researchers, it has become evident that concerns about medical privacy should not be used to impede the adoption of health IT. Deploying EHR systems with robust technical controls, including encryption, electronic identification, and audit logs can improve the privacy and security of personal medical data (Falcao-Reis et al., 2010; Ruotsalainen et al., 2007; Mizani et al., 2007; Sutrop, 2006).

In Denmark (Doupi et al., 2006), for example, patients have access to health information through the official Danish eHealth portal Sundhed.dk and can control many privacy functions through this portal, including monitoring who has accessed or modified their personal medical records. As a result, privacy advocates generally supported efforts to implement health IT. In Estonia, by using Patient Portal and ID card for authentication, patients have full access to the EHR.

In the United States (Reed, 2005), health privacy advocates have often opposed efforts to implement health IT and have succeeded in advocating for overly restrictive laws and rules that have limited implementation of health IT. In general, privacy regulations are most effective when they strike a balance by reassuring citizens that their privacy is being protected while not implementing restrictive measures that reduce data sharing and result in lower quality care.

In Estonia, an enormous effort was made to design the most appropriate and comprehensive security solutions for the EHR system to prevent any adverse events. Complex authentication methods have to be applied in order to correctly identify a specific EHR user. To fulfill this requirement, the Estonian ID card was considered to be the most secure method to establish the highest security and trust needed.

From the discussions following principles of secondary usage of the data were formulated. There are three main objectives for the health information usage in EHR:

- Personal usage
- Social utilization
- Medical registries

The term *personal usage* of health information refers to using health information for personal treatment interests and realization of rights of data subject. In addition, the term *social utilization* of health information is used in association with promoting public health, including the development of health and health care policy, stewardship of health system, quality management in health care, health research and statistics, but also using health information by

other authorities to perform their public protection tasks (e.g. weapons permits, driving licenses etc.). As social importance dominates over personal utilization, then sustainable financing of EHR should be part of public financing. The preparatory as well as the implementation phase was fully financed from the State budget. Since 2012, one third of the maintenance costs are budgeted through the EHIF, who allocates the resources for the contracts' with HCO-s.

Collection and exchange of patient information in EHR creates new threats to privacy and can increase the risk of patient data misuse. Therefore, it is very important to strengthen the patient autonomy with patient's one-time informed consent ("opt-in") or right of patients' to limit using their personal data in treatment process, but also right to add data or make statements of intent. Exchange of patient information should be limited to medical professionals functionally connected to the patient treatment process, e.g. concept of attending physician. Access to the data should be equal to all professional groups to support effective treatment processes (e.g. holistic view of patient does not recognize interdisciplinary limits in treatment process). Prosecution and punishment functions create an environment of mistrust in health system. Instead of that, there is a need to strengthen the patient-health professional relationship by using appropriate requirements for patient counselling and informed consent applications.

IT is fostering a radical transformation of health care by enabling patients to be much more empowered, both about the kinds of treatments that are available to them and about the quality of the health care providers they choose. By providing patients with access to more and better information, IT empowers them to make more informed healthcare decisions. By increasing patients' access to their own medical records and to a plethora of information to help patients make better decisions, IT has the potential to improve health care. When patients have access to their personal medical records, they can take a more active role in their health care and routinely monitor their symptoms and treatment. Access to personal health records helps give patients a stronger sense that they have control of and responsibility for their own care (Atkinson et al., 2008).

The author agrees with Andreson who indicates that education plays an important role in patient empowerment (Andreson, 1995). Therefore, it is relevant to continuously increase patients' computer and Internet skills and inform them about their many opportunities related to Personal Health Records.

The question is to which degree the patient should have the right to decide on her/his health data collection and utilization (Wiljer, 2008). There are different opportunities, which range in wide scale from strong autonomy (patient has full control over personal health data) to strong paternalism (other institutions or persons decide over management of personal data on behalf of patient). However, the intermediary versions are possible too, such as soft

paternalism, where patient has the right to know, who has viewed her/his health data, and patient is able to limit the access to data (e.g. closing data, refusing to use personal data in the treatment process). The latter is due to public interest and social utilization of health data, which require limitation of patient autonomy and solidarity takes precedence over autonomy. Therefore, paternalism would be a better choice, because the patient autonomy is limited in her/his own interest: also, these patients who are more interested in their data limitations, at the same time hope for higher safety (curbing the spread of infection diseases) and expect the development of health system and clinical services (for better treatment) (Tang et al., 2006; Ball et al., 2007).

Informed consent pros:

- It increases patient autonomy, which is based on adequate information and understanding.
- It fulfils the legal obligation of individual counselling.
- It deepens the trust in patient-doctor and patient-health system relationships, as a prerequisite for efficient performance of health system.
- It enhances patient self-contribution and responsibility for her/his own health and health interventions.
- It also helps to alleviate impaired communication and misunderstandings between patients and health professionals.
- It helps to increase patients' awareness about the importance of health system's quality and the need for measures or research to ensure that quality.

Informed consent cons:

- It takes time and efforts from health professionals and requires financial resources from health system.
- The maximum public benefit and effect (safety, wellness) will not be reached if EHR does not include complete health data. Hence, it wouldn't be possible to promote wellness or develop optimal health system or perform health statistics. Nevertheless, in other countries, it has been found that only a very small proportion of citizens are not willing to send their health information to EHR.
- The formal consent does not fulfil the above mentioned objectives.
- It can't protect a person from harming themselves. Indeed, not all individuals think and behave rationally and they might have irrational distrust against the health system or professionals. Therefore, they might refuse to accept the opportunities offered by the EHR and they may end up causing harm to themselves.
- Throughout centuries the only possible solution accepted worldwide has been making data available for health professionals so they can use this information in patient's best interest, unless patient limits access to her/his data. However, in EHR, the limitations should be visible. That principle leads us to the idea, that health data accessibility should not be connected to the specialty, but to the relationship with patient during her/his treatment process.

This needs to be widened to all areas of medicine and should be based on new concept of "attending physician".

In Estonia, the concept of attending physician was established by the ethical working group. "Attending physician" is an institution with long traditions (Atkinson, 2008), which is accepted by health professionals as well as by patients (my doctor – my patient). The doctor is patient's confidant and he/she trusts information given by patient. The doctor acts also like a mediator between patient and health system regarding to the disease management. Attending physician plans diagnostic activities represents patients' and safeguards their rights to get treatment. However, at the same time the doctor is also responsible for the medical results. Therefore, the doctor should have the right to grant access to patient data to other specialists and consultants, e.g. radiologists etc. The status of "attending physician" is applied, when patient visits the doctor in outpatient or inpatient ward. Becoming an "attending physician" means full access to patient data including also the medical history. In the future, the EHR fulfils this current gap of medical history data. Today, it often occurs, that patient has forgotten or does not understand the importance of previous diseases or health problems. Also, at the present time, the patient data is spread between many institutions (e.g. family doctor, outpatient specialist etc.) or even missing after regular cleaning up of document registries. Therefore, the implementation of the EHR will considerably improve the situation.

Introduction of "attending physician" concept also increases the autonomy and safety of patient, for the data is available only for a doctor or nurse. Also, the doctors in charge of the ward or clinic should have access to patient data as they are responsible for the medical processes. The same applies to the doctors on duty (night shift, etc.) who need to follow patients' health situation during out-of-hours period. These doctors become automatically "attending doctors", if they admit patients to hospital because of emergencies, as they start diagnostic and treatment procedures. In addition, all emergency care physicians, intensive care unit doctors and traumatologists need to have the rights of "attending physician" already in first contact with patients.

Establishing rules for nationwide data sharing in different working groups of Estonian EHR was a complicated process, where different stakeholders had different views and different expectations. Between specialties there were large disparities regarding using delicate data outside their specialty: psychiatry, gynaecology and infectious diseases were the most delicate groups that wanted to keep their own documentation. The final version of the "Access Rights" document was discussed in a focus group discussions and consensus agreement between the specialties was established. After that, the "Access Rights" document was confirmed and ready to use.

The reason why one of the most important tasks of the workgroups was to complete the "Access Rights" was the importance to both health care

providers and patients. The studies from other countries show that for the healthcare providers the main concern was that during the EHR implementation their workflow increased and they had less time for patients (Anderson, 2007; Gaffey, 2009). From one side, the society expects better overview and transparency of healthcare processes. At the other hand, from the side of patients, the main expectation is to get better access to their medical data and to be an equal partner in the decision making process (Hassol et al., 2004, Couchman et al., 2001, Kane et al., 1998; Atkinson, 2008).

3.2. Establishing Estonian eHealth Foundation

In 2005, the Estonian Ministry of Social Affairs, as a recipient of structural aid, launched a new e-health concept by phasing in four eHealth projects: the Electronic Health Record, Digital Image, Digital Registration and Digital Prescription. In order to effectively manage the process of developing these projects, the ministry initiated the establishment of a separate administrative body, the Estonian eHealth Foundation (EEHF), see Figure 2. This was founded in 2005 by the three largest hospitals in Estonia, the Ministry of Social Affairs, the Estonian Society of Family Doctors, the Estonian Hospital Union and the Association of Ambulance Doctors. In short, it unified various stakeholders in Estonian health care to ensure compliance and cooperation in developing the four projects. EEHF was responsible of project management, development of services, maintenance of the EHR system and creating standards for data exchange. This has been one of the main key factors for successful implementation of EHR (Doupi et al., 2006; Nøhr et al., 2005; Bhagat et al., 2010).

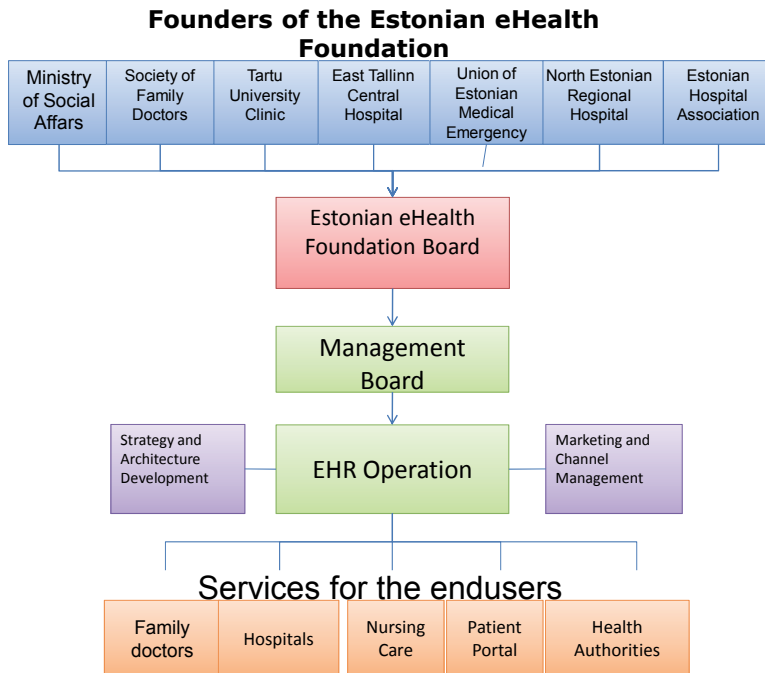


Figure 2. Governance structure of Estonian eHealth

Currently, the division of roles is similar to the initial phase in 2005. The Ministry of Social Affairs is responsible for the policy, while the Estonian E-Health Foundation manages the operating system. To elaborate, the Estonian E-Health Foundation is responsible for the standardization and development of digital medical documents, maintenance of EHR, international and scientific cooperation with universities and development of new services for citizens and doctors.

As the services have been developed in association with a broad range of stakeholders, EHR was structured in accordance with the best practice of service orientation. Interaction with end users works via alternative channels, as there are various information systems that connect to central EHR messaging services. Health care institutions, specialist health care registries and others have made use of the possibility to connect to EHR for message exchange. The development of new services took place in subsequent phases. First, all stakeholders and associated parties were linked through the standardization of the information exchange function. As a result, each health care provider was able to send and receive data to and from the central database. This, in turn, enables the continuation of the development of intelligent services, which is an ongoing process and ensures the sustainability

of EHR. The standards that form the basis of the joint services have been published on the website of the Estonian eHealth Foundation. Experiences the author of this thesis collected during the last ten years also demonstrate that national government policies can play an important role in shaping and facilitating a country's health IT adoption and use. The most important prerequisites to establish a nationwide data sharing platform is finding a good solution for access rights to find balance between autonomy of the patient, the personal use of data of the patient and the benefits for society.

Although, there is no one-size-fits-all set of rules for achieving widespread health IT adoption, government policymakers can learn many lessons from other countries about how to inspire progress in modernizing their health care systems.

As discussed in this paper, strong national leadership is needed to coordinate the actions of these various health care stakeholders, either from a government agency or a public-private partnership, responsible for setting goals, measuring progress and overcoming barriers to adoption. For example, with regards to privacy and security, policymakers should establish clear functional requirements to protect patient data and the appropriate legal safeguards to prevent the misuse of private patient information in the event of disclosure, but at the same time allow for appropriate data sharing.

3.3. Standardisation

Collection and analysing of existing documents – ministerial decrees about obligatory medical documentation, different types of existing medical documents of HCOs, analysing the content of existing medical documents. The ministerial decree describing formats and content of medical documents included 16 documents. However, due to the lack of standardization there was a large variety of documents used by HCOs overlapping information and similarities were identified between different documents during the analysis process. The content was discussed with the experts (hospital statisticians, scientists, IT analysts, nurses and doctors).

Describing the existing system of data collection and roles, i.e. who and where adds data, who are the users of the data.

The help of the experts and interviewers was used to describe new processes of sharing medical data between healthcare organizations and citizens according to attending doctor concept, to formulate access rights statements for EHR, and to work on legislation and guidelines. Experts were selected from among the doctors who were able to describe the business process of the

healthcare system. Author of the thesis was one of the experts, representing (Estonian Society of Family Doctors) ESFD.

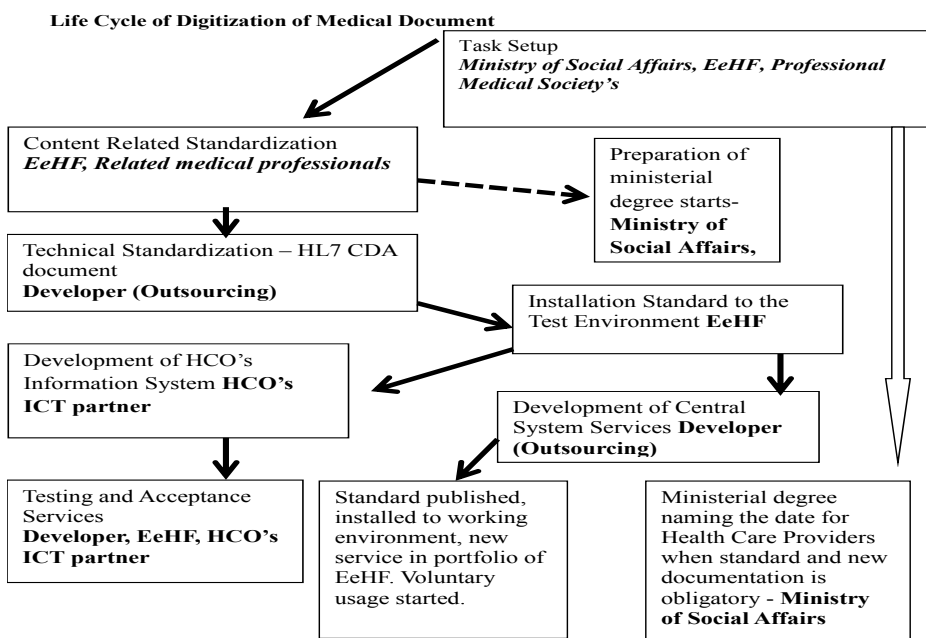


Figure 3. Process of standardization of medical documents

There are 20 different types of standardized documents. Most popular documents are:

- Ambulatory consultation notes 2 311 506
- Hospital discharge letters 897 944
- Image address links 1 139 790
- Consultation notes/image reports 1 508 306
- Immunization notes 50 590

3.4. Results of the implementation of EHR

The practical result of the work was the implementation of the EHR system and its services from 1st of January 2009. The system implementation was realized under the strong leadership of the Estonian E-Health Foundation, through the good preparatory work done by the workgroups and setting up the

rules. The author of the thesis was the key person responsible for the implementation of the EHR (Paper II).

The development of a nationwide framework that uses different digitalized medical documents has enabled to facilitate the exchange of health information. Through EHR it is now possible to share information that was previously only available in local databases and information systems unable to communicate with one another.

During three years more than 989338 citizens has digital documents in the EHR system; this is more than 75% of population. 555 healthcare providers have joined the system and have begun to send medical documents prescribed by law. 3879 doctors in Estonia have used the system either by sending data or making enquiries about their patients' data. (Figure 4).

Another example of electronic data exchange usage is e-prescriptions. By the end of 2012 (nov.2012) around 94% of prescriptions were digital.

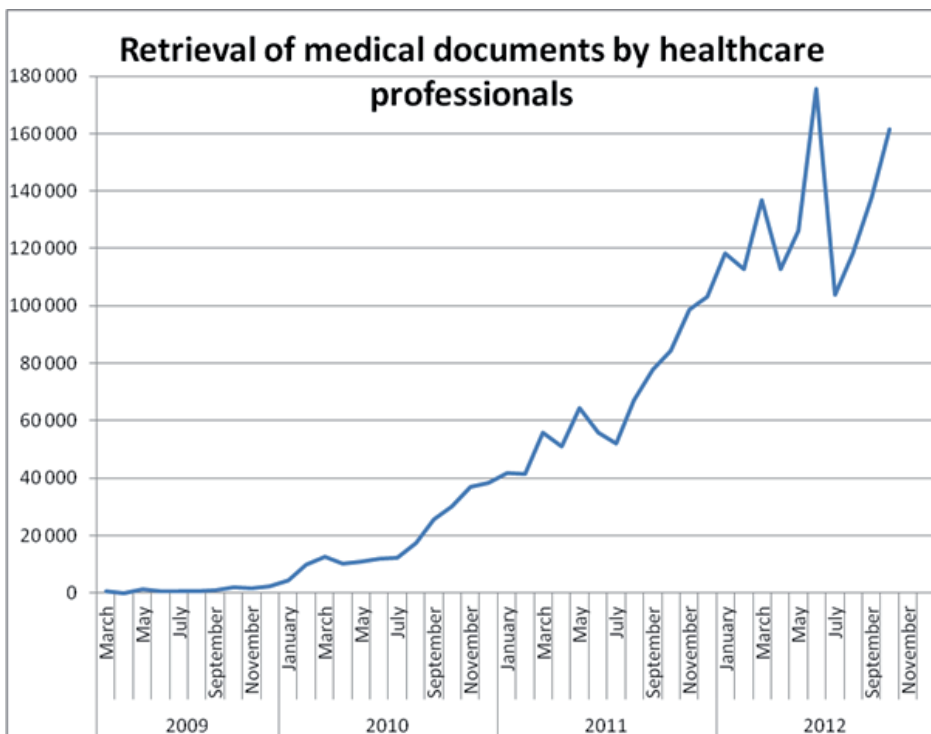


Figure 4. Retrieval of medical documents by health care professional (data from EEHF)

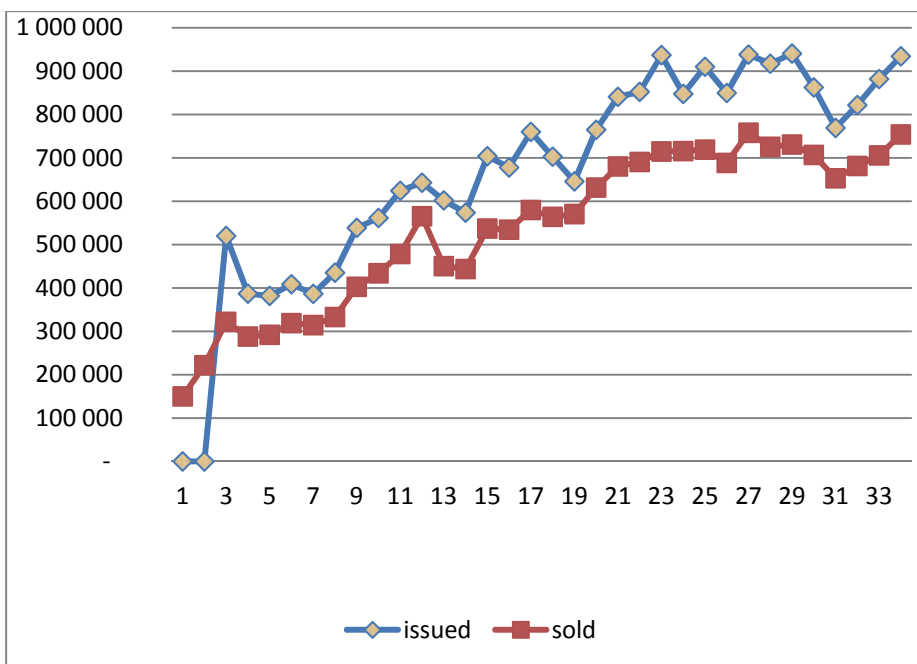


Figure 5. Implementation of e-prescriptions in Estonia (1-34 months) (data from EHIF)

3.5. Future developments

The EHR can also create a number of different services using decision support engine, existing medical documents, and information added by citizens. As an example, certificate for driver's license could be one of those. Another possible new intelligent service is a reminder service, which means sending an automatic SMS or e-mail reminder about the next visit to the doctor or to the lab to give a blood sample (Paper III).

There are numerous opportunities for the secondary usage of medical data in EHRs. For instance, self-serve computer kiosks can be used by hospitals to automate a number of patient interactions. They can be used to facilitate patient management activities such as patient admission, discharge, transfer, but also collecting data from patients about complains and symptoms. Kiosks can also be used to process co-payments, receive patient consent forms, collect demographic data, perform clinical pre-screening, and perform satisfaction surveys. Another common application of kiosks in hospitals is for way-finding (i.e., patients getting directions to their appointments). Finally, kiosks can offer all of these services in multiple languages and can be accessed through web. Kiosks benefit hospitals by freeing nurses and hospital staff from routine activities and allowing them to work more efficiently. Patients benefit from

kiosks by experiencing shorter waiting times, more convenience, and more privacy (Rhoads et al., 2009).

In further development the EHR can also provide data from the Estonian Genome Centre. However, several new services should be created to enable this. Firstly, a consent on person's willingness to know their gene data should be established. Secondly, a consent which allows the Genome Centre to send data to the EHR is also needed. The third possible service in this area could be updating personal health data for gene donors.

All these services with full access to the EHR give citizens more reliable information about their health status, and provide opportunities for an adequate care process. However, it also means more responsibility and commitments for citizens.

Due to the complexity of the nationwide project, the components of the EHR are being launched on a different time scale. It is currently projected that the development of the system will continue until 2013.

The experience of implementation of EHR in Estonia has shown that technically and organisationally the task is achievable in a relatively short period. However, realising concrete benefits for patients, health care personnel, and society depend on the completeness and quality of the data in the central system. In our experience this is achievable only in the case the common standards are used, and the majority of health care institutions connect to the EHR in a relatively short period. In Estonia the health care providers were obligated to interface with the EHR because of the recent amendments to the Health Services Organization Act. Despite this fact, there has been a considerable amount of reluctance among the health care providers to interface with the EHR. According to the feedback from the health care managers, it was mainly because interfacing with the EHR demanded additional information technology investments from GPs and hospitals. Unfortunately, the benefit of this investment is not realised in a short term, and thus hardly acceptable from an economical point of view.

The implementation of the EHR has increased the use of information technology in health care institutions. To overcome the potential problems caused by the inefficient knowledge of computer skills among the personnel, several training programs for the health care professionals were carried out during the first year. Programs included training in computer skills, gave an overview of security regulations, and taught participants how to use the EHR. However, there still seems to be a quite large number of health professionals who are not fully satisfied with the design and functionality of the EHR.

The number of citizens who have used the Patient's Portal to view their own health data during the first two years is relatively low. This is not surprising, because the launch of this new service was not accompanied by wide public campaign. The same results are shown by Andreson (Andreson,

1995). The information about the Patient's Portal is given to citizens by health care professionals. The reason for discreet introduction of the Patient's Portal is the unawareness of the influence of this service to patient behaviour and physician-patient relation. Also, there are different opinions among the health care professionals about the usefulness of sharing the health data openly with patients. However, the first experience is that citizens are accepting the Web-based access to their health data, and there have been no remarkable drawbacks.

Indeed, for the near future, the most promising advances will relate to the ability to use information more effectively. The digital information revolution is enabling the creation of a rapid learning network to enable global healthcare system to quickly find out what treatments work best and which don't (Atkinson et al., 2008; Khosla, 2012).

EHRs and e-Prescribing bring about considerable strategic gains for healthcare and should be approached as a clinical venture, not as an ICT project. Using EHRs and e-Prescribing as part of successful change in clinical and working practices is an essential component of improving health services delivery, quality and performance (Dobrev et al., 2009; Steinschaden et al., 2009; Adler, 2003; Corley, 2003).

Some of the factors that influence health IT, including organizational challenges, technical hurdles, societal issues and standardization are more amenable to change by national policy (Robertson et al., 2010; Protti, 2008; Gastro, 2009).

Electronic access to the shared health database increases the role of patient in the diagnostic and treatment processes (Guadagnoli, 1998). Health care providers should become more responsive to patients' needs and preferences and deliver better quality of care (Falcao-Reis, 2008). Patients', having more adequate and comprehensive information about their health, can participate in the health care in many new ways. This includes communicating directly with healthcare professionals by using information on health and health care through internet channels, mobile devices, etc. This might lead to a situation where patients start taking more control over their illnesses and treatments where possible. Patients are given information in the belief that this will enable informed choices.

It is assumed that information technologies will not only lay the foundations for completely new products and services in health care, but also that it will create new ways of providing and managing services (Garrido et al., 2005). This will result in changes to the way that work and business is organized, and the rules that govern how organizations operate are already changing – as has already been the case in banking, the media and trade. At the same time, we have to gradually change the way we look at things; the new generation is certain to embrace the new approach (Catwell et al., 2009).

It is important to look at the provision of health care services and system improvement through ICT from three perspectives: those of the service provider, the patient and society. It is also important to accept that different parties see the same thing from different angles. Releasing the data will force change because it will facilitate more informed choices by patients and affect resource allocation because funding follows the patient. Another opportunity for e-health is linking patients to peers for information sharing.

It is very important to continuously monitor and evaluate the development of the system over the years.

4. CONCLUSIONS

- An important prerequisite for implementing Estonian EHR System was clear governance where the Ministry of Social Affairs together with the Estonian E-Health Foundation played a leading role in the implementation process. This top-down approach appeared to be successful due to the small size of the country and very centralized healthcare policy structure. Strategic decision making is done by the Supervisory Board of EEHF that is comprised of representatives of main stakeholders in the healthcare.

- It is essential that in the earliest phases of implementing the nationwide EHR it is agreed how to find balance in access rights to the data, privacy and security of the data usage and using data for secondary purposes. The concept of attending physician was established by the ethical working group and it was accepted during discussions in focus groups of doctors. Role “attending doctor” was taken also basic for the legislative act and designing access rights to access in to the EHR system.

- The fundamental balance is not only the mixture of patient autonomy and social benefits, but also the agreements on the security measures, culture of the HCOs and attitudes and belief system of doctors. In order to develop principles of EHR system, it is extremely important to involve different specialists, such as medical doctors, IT architects, ethicists, lawyers, public relations specialists, politicians and many others.

Many of those issues were already solved in Estonia through appropriate legislation, sufficient IT infrastructure and existing e-services environment (x-road, ID card, public acceptance of e-services, etc.).

- Standardization is one of the most critical conditions for fluent data exchange between HCOs. Involving affected professional groups in the early

stage of the content standardization is critical factor for later acceptance among those specialties which will start use those documents.

- Continuous evaluation of the EHR is crucial to demonstrate the potential areas where the benefits can be found. Creating a methodology for evaluation of the nationwide EHR system enables us to use the same approach for different modules and structures of the system in the future, and to study impact of the change planned. Special indicators can be developed, after knowing where the benefits can be found in. Although, the potential benefits can be achieved only after full deployment of the EHR, with its services and functionalities. Regular check-ups of the implementation are needed to make changes in the policies.

Estonia has taken a big step enabling nationwide data exchange and has the potential to become the first country where patient is the main driving force of their personal health issues. Hopefully this will lead to a more healthy behavior of citizens and decrease cost of healthcare in the country.

After three years of launching the EHR, the exponential growth of the messages can be seen. This means acceptance by healthcare professionals and will result in implementation to the daily treatment process. Acceptance of the e-prescriptions has been even more rapid. After two year almost 95% of all prescriptions are digital.

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6. SUMMARY IN ESTONIAN

Käesolevas töös vaadeldakse peamisi tervise infosüsteemi käivitamiseks vajalikke eeldusi, nende loomist ja kirjeldatakse tegureid, mis on olulised üleriigilise süsteemi juurutamisel. Telemeditsiini ja eTervise kogemused Eestis on saanud läbi mitmete rahvusvaheliste koostööprojektide, nagu BitNet (Maaroos *et al.*, 2001), Baltic eHealth Project (Ross *et al.*, 2010). Heaks kogemuseks telemeditsiini teenuse loomisel ja juurutamisel oli ka autori poolt läbi viidud perearstide telefonikasutuse uuring (Tiik *et al.*, 2007) ning perearsti nõuandetelefoni kontseptsiooni väljatöötamine ja eeluuringute tegemine.

Uurimistöö eesmärk oli:

1. Analüüsida erinevaid eeltingimusi kogu riiki hõlmava tervise infosüsteemi loomiseks ja juurutamiseks ning pääsuõiguste, privaatsuse, turvalisuse ja andmete teisese kasutamise seotud aspekte.
2. Juhtimisstruktuuri juurutamise ja standardiseerimise protsessi analüüs.

Metoodika

Käesolevat uurimistööd võib nimetada aktiivseks uurimistööks, kuna autor osales vahetult mitmete tervise infosüsteemi loomiseks vajalike eelduste väljatöötamisel. Töö käigus analüüsiti terviseandmete kogumist, liikumist ja eri osapoolte rolle, samuti tehnilisi võimalusi uuenduste läbiviimiseks. Peamine eeltingimus kogu riiki hõlmava terviseandmete vahetamise keskkonna loomisel on pääsuõiguste reeglistiku loomine. Pääsuõigustega määratletakse süsteemis osalejate õigused, kohustused ja piirangud. Pääsuõiguste kaudu realiseeritakse mitmeid infosüsteemide omadusi, nagu autoriseerimine, turvalisus, andmete vaatamine ja sulgemine. Pääsuõiguste loomisele eelnesid laiapõhjalised arutelud arstlike erialade kaasamisega ning samaaegselt ellu kutsutud eetika töögrupi töö tulemuste kasutamiseega.

Pääsuõiguste kaudu antakse lähteülesanded tehniliseks teostamiseks ja õigusruumi kujundamiseks.

Tulemused

Töö tulemusena loodi pääsuõiguste süsteem, mis võttis arvesse eetika töögrupi ettepanekud ning mõtestas lahti raviarsti kontseptsiooni ning andis suunised privaatsuse ja turvalisuse tagamiseks. Samuti mõtestas lahti andmete teisese kasutamise olulisuse.

Praktiliseks tulemuseks on tervise infosüsteemi käivitumine ja aktiivne kasutamine. Esimese kolme aasta jooksul on kõik arstid aktiivselt asunud tervise infosüsteemi kasutama ning terviseandmeid on kogutud 70% elanike

kohta. Eriti hästi on vastu võetud digiretsepti teenus, koguni 94% retseptidest on digitaalsed.

Diskussioon

Tervise infosüsteemi loomine on olnud suurimaid muudatusi, mida Eesti tervishoius on kunagi ette võetud. Tegemist ei ole infotehnoloogilise revolutsiooniga, vaid revolutsiooniga meditsiinikorralduses ja arstlikus mõtlemises.

Informatsiooni kättesaadavus ja õige kasutamine annavad võimaluse uute teenuste ja lahenduste loomiseks. Luues samaaegselt teenuseid kodanikele, andes neile rohkem informatsiooni nende tervisest, toimub võimu liikumine tervishoiuteenuse osutaja juurest patsiendi juurde. 21. sajandi tervishoiumudel on patsiendikeskne, mitte raviasutusekeskne.

Kolme aasta jooksul, kui tervise infosüsteem on töös olnud, oleme näinud olulist muutust terviseinfo kasutamise osas. Üha rohkem on neid arste, kes regulaarselt vaatavad tervise infosüsteemi vahendusel patsiendi varasemaid terviseandmeid ja üha rohkem on kodanikke, kes oma terviseandmete vastu huvi tunnevad ja seeläbi on valmis rohkem vastutust võtma oma tervise eest.

Järeldused

- E-tervise lahenduste rakendamise oluliseks eelduseks Eestis oli selge juhtimine, milles Sotsiaalministeerium koostöös Eesti eTervise Sihtasutusega (ETSA) olid vastutavas rollis üleriigilise elektroonilise terviseinfosüsteemi rakendamisel. See ülalt alla lähenemine on olnud edukas tänu riigi väiksusele ja väga tsentraliseeritud tervishoiupoliitilisele struktuurile. Operatiivsed otsused tehakse ETSA nõukogus, kuhu kuuluvad peamiste tervishoiu huvigruppide esindajad.
- Elektroonilise terviseinfosüsteemi põhimõtete välja töötamiseks on äärmiselt oluline kaasata eri spetsialiste, näiteks arste, IT arhitekte, eetikuid, juriste, avalike suhete spetsialiste, poliitikuid ja paljude teiste erialade esindajaid.
- Üleriigilise tervise infosüsteemi rakendamise varases faasis on oluline kokku leppida, kuidas leida tasakaal andmete juurdepääsuõiguste, eraelu puutumatuse, andmete kasutamise turvalisuse ja sekundaarsete eesmärkide vahel. Põhiline tasakaal ei hõlma üksnes patsiendi autonoomiat ja sotsiaalset kasu, vaid ka kokkuleppeid turvameetmete, tervishoiuasutuste kultuuri ning arstide hoiakute ja veendumuste süsteemi osas. Paljud neist teemadest on Eestis juba lahendatud asjakohaste õigusaktide, piisava IT infrastruktuuri ja olemasolevate e-teenuste keskkonna (x-tee, ID-kaart, e-teenuste avaliku tunnustamise jne) abil.
- Eesti on astunud suure sammu, võimaldades üleriigilist andmevahetust ning Eestist võib saada esimene riik maailmas, kus patsiendil on võimalus saada

ülevaade oma tervisega seotud andmete kasutamisest. Loodetavasti parandab see elanike tervislikku käitumist ning vähendab tervishoiuteenuste riiklikku kulu.

- Kolm aastat pärast tervise infosüsteemi käivitamist on ilmnunud sõnumivahetuse eksponentsiaalne kasv. See tähendab, et tervishoiutöötajad on süsteemi heaks kiitnud ning seda rakendatakse igapäevases raviprotsessis. E-retseptide tunnustamine on olnud veelgi kiirem. Kahe aasta möödumisel on ligi 95% kõigist retseptidest digitaalsed.

7. SUMMARY IN ENGLISH

In this work main preconditions and processes are described and analysed for successful implementation of nation-wide EHR systems.

First signs of the use of information technology in Estonian health care took place in the last decade of the last century. Family doctors' centers and hospitals began to build a digital database in order to submit medical claims to the Estonian Health Insurance Fund (EHIF) and share patient administration information. Assets of the respective software functionality are constantly being upgraded, and now computers have become a commonplace tool for doctors.

Telemedicine is one of those areas in health care that can offer many valuable opportunities and work tools for doctors. In Estonia, the first telemedicine pilot project, named Bitnet, took place in the turn of the century 1999–2001. During the Bitnet project, telemedicine consultations were held between primary health center in Kuressaare and Tartu University Hospital to determine the suitability of consultations with remote areas in various disciplines and issues of patients' health problems.

The Estonian Society of Family Doctors has been supportive to eHealth as an innovative approach to health care system development. As a representative of Estonian Society of Family Doctors, the author of this dissertation was involved in all eHealth activities in Estonia. This has been an excellent starting point for studying different aspects and prerequisites of eHealth implementation as well as analyzing their impact on the healthcare system.

Introduction

The guiding document for the development of the information society in Estonia, *the Estonian Information Policy*, was approved by the Parliament of Estonia in 1998. As the value of using Information and Communication Technology (ICT) solutions in health care had become increasingly evident, the government support followed. In 2006, the Estonian government initiated the development process of a comprehensive nationwide Electronic Health Record System (EHR system) as a part of the *Estonian Information Society Strategy 2013* (Ministry of Economic Affairs and Communications, 2006).

In designing such a multifaceted system, not only the technological, but also the legal, organizational and ethical aspects of the health care service process needed to be taken into account.

Subjects and methods

The selected research approach for analysing different preconditions and the process of change can be classified as Action Research – AR is an interactive inquiry process that balances problem solving actions implemented in a collaborative context with data-driven collaborative analysis or research to understand underlying causes enabling future predictions about personal and organizational change. AR challenges traditional social science by moving beyond reflective knowledge created by outside experts sampling variables, to an active moment-to-moment theorizing, data collecting, and inquiry occurring in the midst of emergent structure. In AR the researcher takes unique role – helping role, to solve the practical problems and in this sense, performing action research is the same as performing an experiment, thus it is an empirical process.

Also, system analysis for document research and focus group interviews were used as a methods collecting data and analysing it, during decision making.

During the process the author collected and analysed information compiled reports and took part in meetings with different experts. As a CEO of the Estonian eHealth Foundation (EEHF) the author of the thesis was also personally responsible for creating conditions for successful implementation of the nation-wide EHR system.

Results

The most important prerequisite for realizing the Estonian EHR system was to establish the rules for the usage of patients' health data. The “Access rights” document was prepared and was delivered to the workgroup of legislation for preparation the necessary changes in legislation and it was also input to the role description for the software.

In order to effectively manage the process of developing these projects, the ministry initiated the establishment of a separate administrative body, the Estonian eHealth Foundation. This was founded in 2005 by the three largest hospitals in Estonia, the Ministry of Social Affairs, the Estonian Society of Family Doctors, the Estonian Hospital Union and the Association of Ambulance Doctors. EEHF was responsible of project management, development of services, maintenance of the EHR system and creating standards for data exchange. This has been one of the main key factors for successful implementation of her.

The practical result of the work was the implementation of the EHR system and its services from 1st of January 2009. The development of a nationwide framework that uses different digitalized medical documents has enabled to facilitate the exchange of health information. Through EHR it is now possible to share information that was previously only available in local databases and information systems unable to communicate with one another.

Discussion

IT is fostering a radical transformation of health care by enabling patients to be much more empowered, both about the kinds of treatments that are available to them and about the quality of the health care providers they choose. By providing patients with access to more and better information, IT empowers them to make more informed healthcare decisions. By increasing patients' access to their own medical records and to a plethora of information to help patients make better decisions, IT has the potential to improve health care. When patients have access to their personal medical records, they can take a more active role in their health care and routinely monitor their symptoms and treatment.

Establishing rules for nationwide data sharing in different working groups of Estonian EHR was a complicated process, where different stakeholders had different views and different expectations.

The most important prerequisites to establish a nationwide data sharing platform is finding a good solution for access rights to find balance between autonomy of the patient, the personal use of data of the patient and the benefits for society.

Although, there is no one-size-fits-all set of rules for achieving widespread health IT adoption, government policymakers can learn many lessons from other countries about how to inspire progress in modernizing their health care systems.

As discussed in this paper, strong national leadership is needed to coordinate the actions of these various health care stakeholders, either from a government agency or a public-private partnership, responsible for setting goals, measuring progress and overcoming barriers to adoption. For example, with regards to privacy and security, policymakers should establish clear functional requirements to protect patient data and the appropriate legal safeguards to prevent the misuse of private patient information in the event of disclosure, but at the same time allow for appropriate data sharing.

Conclusions

An important prerequisite for implementing Estonian EHR System was clear governance where the Ministry of Social Affairs together with the Estonian E-Health Foundation played a leading role in the implementation process.

It is essential that in the earliest phases of implementing the nationwide EHR it is agreed how to find balance in access rights to the data, privacy and security of the data usage and using data for secondary purposes. The concept of attending physician was established by the ethical working group and it was accepted during discussions in focus groups of doctors. Role “attending doctor” was taken also basic for the legislative act and designing access rights to access in to the EHR system. Introduction of "attending physician" concept also increases the autonomy and safety of patient, for the data is available only for a doctor or nurse.

Standardization is one of the most critical conditions for fluent data exchange between HCOs. Involving affected professional groups in the early stage of the content standardization is critical factor for later acceptances among those specialties which will start use those documents.

Regular check-ups of the implementation are needed to make changes in the policies. Although, the potential benefits can be achieved only after full deployment of the EHR, with its services and functionalities.

After three years of launching the EHR, the exponential growth of the messages can be seen. This means acceptance by healthcare professionals and will result in implementation to the daily treatment process. Acceptance of the e-prescriptions has been even more rapid. After two year almost 95% of all prescriptions are digital.

8. PUBLICATIONS

Paper I

Tiik, M. 2010. Rules and access rights of the Estonian integrated e-Health system. *Medical and Care Compunetics*, 6, pp. 245–256.

Rules and Access Rights of the Estonian Integrated e-Health System

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Abstract. There should be a clear understanding that when implementing an electronic health record system (EHR), one of the hardest problems we have to solve is the access rights. In Estonia this process lasted for three years and involved all stakeholders of the healthcare sector. Special ethical committee was established to advise the decision makers and doctors to help them understand the ethical dilemmas from the patient's and society's point of view. In this article you will find a short overview of the access rights of the system, roles of the healthcare systems' employees. Descriptions of some specific situations like underage patients and representation of patient with restricted active legal capacity.

Keywords. Access rights, integrated EHR, patient's rights, legislation.

Introduction

The prerequisite for realising the health information system and the Electronic Health Record (hereafter EHR) is to establish the rules for the usage of patient's health data. The purpose of this article is to analyse the principles of the system of access rights and the system of rights related to handling patient's health data from the following aspects:

- Purpose of data usage
- Roles of health care system's employees
- Patient's will
- Specific situation

This article contains descriptions of:

- Data stored in the EHR information system
- Rules of accessing patient's health data

The EHR data usage rules were created by the Estonian eHealth Foundation and it was finished on 18.03.2008. The Health Services Organization Act and Associated Acts Amendment Act² approved by the Estonian Parliament „Riigikogu” on 20.12.2007 has also been considered.

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² Health Services Organization Act and Associated Acts Amendment Act (Tervishoiuteenuste korraldamise seadus ja sellega seonduvate seaduste muutmise seadus), available only in Estonian, <https://www.riigiteataja.ee/ert/act.jsp?id=12909773>

The Minister of Social Affairs has issued a regulation that establishes a list of documents necessary to prove the provision of health care services, and these documents have to be forwarded to the EHR system as electronic documents. From 01.01.2009 all healthcare providers are obligated to send agreed numbers of medical documents to the central database. The responsibility of the Estonian E-Health Foundations is to provide necessary services to patients and healthcare providers and secure the operation of the system.

1. Definitions used to describe the roles

1. An underage patient – individual aged 0-18 whose data is being processed in the EHR, who can carry out different types of activities in the EHR, and who has a legal representative.
2. Guardian – legal representative. Person who is making transactions and activities on behalf of patient. In the EHR system this person is considered to have a role of a representative who has maximum rights. The data of the guardian is enquired from the Population Register via online processing.
3. Information Service – data issued from the EHR information system over the X-tee standard interface (including enquiries and electronic documents).
4. Patient – person whose data is processed in the EHR information system.
5. Patient's health data – sensitive personal data containing information about patient's health condition.
6. Patient's general personal data – non-sensitive information about patient, such as address, etc.
7. Patient with restricted active legal capacity – Person who has no rights to carry out any activities or transactions in the EHR information system because their active legal capacity has been restricted by court.
8. Attending physician – health care service providers, who are treating a patient and who are registered with the Health Care Board. Midwives and medical assistants providing independent services are deemed as sub-categories, and they have the same rights as an attending physician.
9. Attending physician's assistant – employee who is assisting attending physician and who is not registered in the register of the Health Care Board. For example, attending physician's secretary.
10. Treatment setting – treatment, advising, and documenting of patient's complaints by the health care service employee registered at the Health Care Board.
11. Employee at the registry office – person who is carrying out the activities of the registry but is not an attending physician.
12. Legal representative – legal representative and guardian are the same person, i.e. legal representative has the rights of a guardian, and guardian has the rights of a legal representative.
13. Representative – person appointed by patient who has the right to carry out activities and transactions in the EHR information system. There can be representatives of two different levels of rights. Representative who has full rights is identical to patient and can proceed with all activities and transactions (including expressions of will) on behalf of patient. Representative with limited rights can view patient's data in the EHR information system but has

no other rights. The extent of the rights of a representative is determined by the authorization (expression of will) made by patient. In terms of the EHR information system legal representative is a patient's representative who has full rights. Person under guardianship can't appoint representatives – representatives are appointed on his/her behalf by guardian.

2. Data in the Electronic Health Record

Patient's health information will be submitted to the EHR by health care service providers in form of electronic documents as listed below:

- Electronic information notes
- Electronic medical documents

The electronic documents are formalised as standard HL7 CDA documents that will be stored in central database (i.e. archived electronically). The person compiling the medical document has to be identifiable: documents containing medical information or a physician's decision must have the physician's digital signature or be date-stamped by health care service provider's information system. The confirmation of the sender's information system is sufficient if the document only contains information related to the administrative or technical process (i.e. appointment confirmation).

There will be additional information associated with patient's person and health sent to the EHR:

- Orally submitted information from patient and patient's representative
 - Contact information
 - Representatives
 - Patient's expressions of will regarding their preferences of health services
 - Refusal from blood transfusion
 - Refusal from organ transplantation
 - Consent for organ donation
 - Refusal from resuscitation (treatment related will)
 - In the event of death, consent to donate a body for research and educational assignments.

2.1. Data Required for Using the Electronic Health Record Information System

The EHR information system needs and uses data:

- to authorize an attending physician
- to authorize a patient and a representative
- to enable patient to get information about their health data
- to enable physician to fill out the personal data section in documents
- to support physician in the process of medical decision making
- as an additional information source gathering/taking anamnesis

- to automatically create notes by the EHR system (the EHR information service)
- to carry out assessments related to treatment quality and health care administration

Data not submitted either by health care provider or by patient will be enquired through online processing from the organisations or administrative domains, and this data will be used to carry out a specific automated procedure. Therefore, the end-user (physician and patient) does not set access rules for this data. Each enquiry of data or storage of data in the EHR information system will be determined according to the mission-critical and informational-logistical considerations.

The data necessary for authorizing attending physicians is mission-critical since without this data no physician will be able to use the services of the EHR. Therefore, certain tables from the registers of the Health Care Board have to be duplicated and renewed after regular intervals (for instance once in every 24 hours) in the EHR information system.

2.2. Electronic documents

The electronic documents differ from the documents listed in the regulation of documents proving the provision of health care services, because electronic documents contain comprehensive information representing a specific fixed time gathered by one person.

(e.g. emergency medical care card is filled out by several physicians, and entries on this document are derived from and represent different moments in time. HL7 messages are created separately per each entry. However, because the HL7 message is comprehensive it can be decided upon this message which patient and incident is being referring to, i.e. which messages together form the total content of the emergency medical card; health care service provider can forward the electronic documents either together at one time at the end of the case or after each treatment episode. According to a general principle, the electronic documents are forwarded to the EHR information system when the patient leaves the doctor's office or health care institution that provided the treatment).

Electronic document includes additional information added by default by the health care institution's information system (*e.g. directory code used in the document for each field described by the directory, i.e. OID, value of the directory's element in coding determined by OID if the output form of the document has a name of formatting legible only to the human eye, unique identifier of a case in health care providers information system, etc.*).

Documents are marked in the EHR information system to indicate if the first time reviewing of a document has to be done together with a physician. This specific mark will be added by the physician creating the document before he/she forwards it to the EHR information system.

Types of EHR Documents Pursuant to Access to Documents

1. Documents visible to the patient and attending physician without any restrictions

2. Documents closed by the attending physician (the physician compiling the document will add a specific mark banning access to the document by patient or attending physician)
 - a. Documents visible to the attending physician but visible to patient only after the first review (the attending physician will introduce the document to patient)
 - b. Documents visible to the attending physician but not available for the patient to enquire from the EHR information system
 - c. Documents not visible to the attending physician but what can be enquired by patient from the EHR information system
3. Documents closed by patient
 - a. Documents not visible to the attending physician but visible to the patient (and representatives acting in patient's rights)
 - b. Documents not visible to the representative/legal representative but are visible to the attending physician

Correcting Incorrect Data in Documents

The attending physician can invalidate a document if he/she discovers that a document with incorrect information has been forwarded to the EHR information system (attending physician will send a message to the EHR information system to inform that the status of the document has been changed). The attending physician can send a new updated version of the document to the EHR information system after the initial document has been invalidated.

If a document containing incorrect information is discovered either by patient or an attending physician, the organization responsible for creating the document has to be contacted. The document will be corrected by the organization that created the document in the first place, and the corrected version of the document will be forwarded to the EHR information system.

3. Rules on Accessing Patient's Health Data

3.1. General Principles

This chapter describes the attending physician's job in regular and emergency care situations. Information created during treatment will be first stored in health care service provider's information system, and the attending physician uses the information contained in local system. Documents forwarded to the EHR will be electronically signed by the attending physician or date-stamped by health care service provider.

Only the health care employee (the attending physician) currently associated with patient's treatment has the right to make enquiries about patient's data, i.e. the patient's attending physician or a medical assistant. Making enquires about patient's health data outside of treatment process is not allowed.

Health data will be issued to health care employees registered with Health Care Board and who are marked as the attending physician

During the first visit, the health care service provider's information system will enquire about patient's personal data

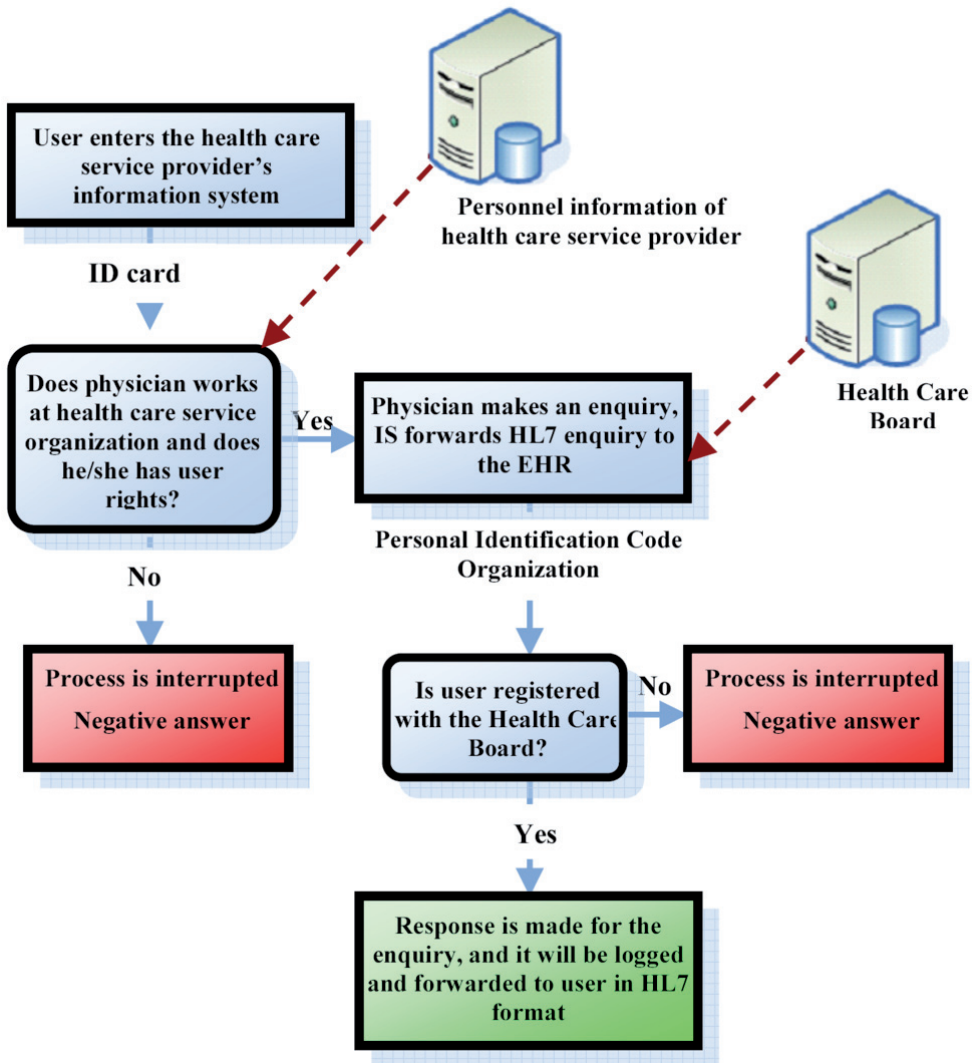


Figure 1. Authorization of health data enquiry.

- Pre-filled document's header will be compiled if possible, and the physician will orally verify the continued validity of data if necessary

Following the data usage rules provided in this document, the attending physician may choose to enquire other documents or information related to patient as the treatment process progresses. This necessity is determined by the attending physician, and he/she must be able to justify to patient the purpose of using the data in relation to providing a specific service.

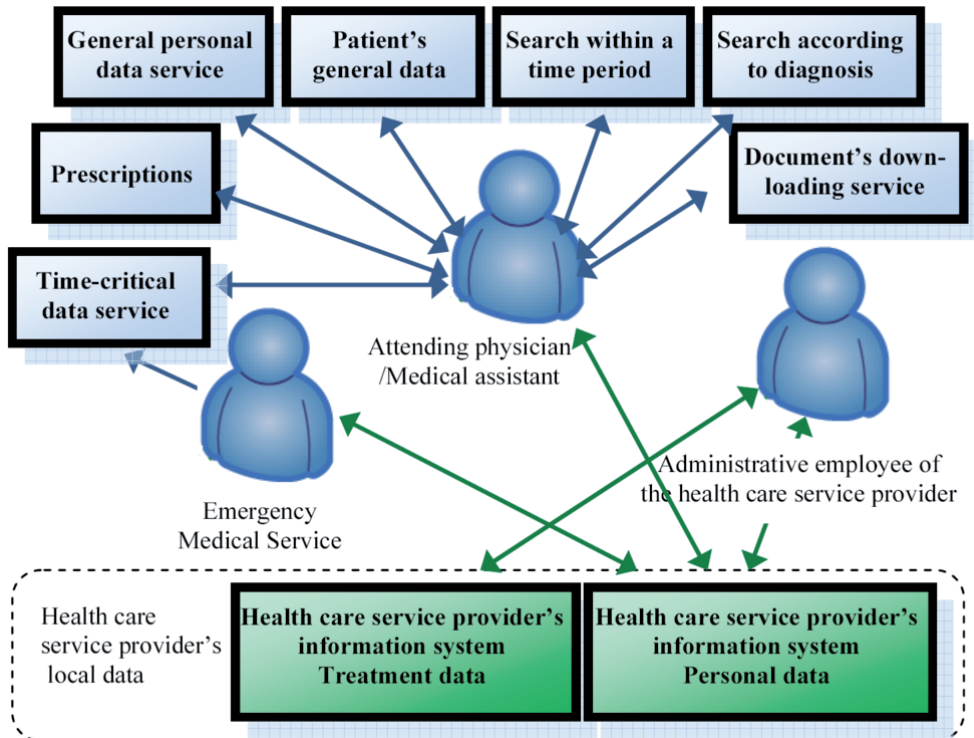


Figure 2. Services and their users.

3.2. Roles of Data Users

- Physician (health care service providers associated with patient's treatment and registered at the Health Care Board)
- Patient
- Patient's guardian (a legal representative)
- Patient with restricted active legal capacity
- Representatives – persons associated with patient
 - o Representative with complete rights
 - o Representative with restricted rights (can only view data)

Attending Physician

An attending physician is a health care employee registered with the Health Care Board who is currently associated with patient's treatment. A family physician is the attending physician on permanent basis to all patients in his/her practice list. The attending physician may hold different positions related to specific case (replacement physician, on-call physician, consulting physician, etc.), and regardless of the position the physician is still considered to be the attending physician. Patient's data can be enquired from the EHR information system by patient's attending physicians and assistants (excluding the enquiry about the referrals list which can also be enquired by register office's employees). The assistants will participate in treatment together with

the physician or they will work as medical assistants who see patients during independent appointment times.

Acting as the patient's attending physician refers to treating a patient during a set time period beginning with the initial appointment and ending when the case of illness is resolved (excluding family physician and pathologist). Documenting the treatment process is regulated by legislation and the summary of each case of illness (ambulatory visits, duration of in-patient medical treatment, day care surgery and procedures) must be sent to the EHR information system.

Family Physician's Rights

A family physician is the attending physician on permanent basis to all patients in his/her practice list. The family physician may enquire from the EHR the electronic documents and personal data of patients listed in his/her practice list.

It is not possible to make enquires about documents to which patient has set access restrictions.

Specialty Physician's Rights

The specialty physician is entitled to enquire about patient's documents and data in the EHR if he/she is patient's attending physician.

The organisation's information system must ensure that attending physicians can be correctly established and authorized in organisation's information system and that other users could not make enquiries without proper authorization. More specifically, it has to be made sure that physicians, assistants and other employees of the organisation could not carry out any activities by using name and password of another physician or assistant.

Differences of Gaining Access for Pathologists and Forensic Medical Physicians

Pathologists and forensic medical physicians have access to patient's medical information in the EHR after patient's death (excluding documents patient has banned access to) if patient is brought for autopsy.

Pharmacist's Rights

Pharmacists have the right to make enquiries to the prescription centre about prescriptions prescribed to patients as well as prescriptions not bought out. The pharmacist can't make enquiries from the EHR.

If patient wishes, the attending physician will add names of representatives to the prescription who will have the right to buy it out from the pharmacy. The names of representatives are available in the e-prescription centre, and patient can determine his/her representatives at the time the prescription is issued. The patient can determine if a certain prescription can be bought out by a certain person, by patient himself or by anyone.

Resident's Rights

Resident is a general practitioner who in the event of patient's treatment is patient's attending physician.

School Health Care Employee's Rights

A school's health care employee is not involved in treatment process but carries out the prophylactic exams of school children. On some occasions, the school health care employee has a role of the attending physician, and in this case he/she has rights in the EHR information system equal to the rights of the attending physician.

The physician and a medical assistant both are active in school health care system, and both of them have the right to make independent referrals (physician directly to specialty physician, assistant to family physician). The decisions of other health care employees that have occurred based on these referrals will be reflected in the EHR and must be available to school's health care employee.

3.3. Restrictions

Patient's Right to Set Restrictions

The patient has a right to set access restrictions to documents, cases of illness and to all his/her information in the EHR. The access ban can be set one specific document or applied to complete data in the EHR. In the event patient has set access restrictions, users will not be able to enquire patient's documents or any data from restricted documents. There will be an indication generated dynamically in patient's general personal data sent as a response to enquiry if patient has set any restrictions to his/her data. Access to data necessary for the interoperability of different information systems can't be banned. For instance, health information system must still be able to exchange information with medical registers regardless of the fact that access to data has been closed. Therefore, the closing will only close access to the attending physician providing health care services.

The patient will be informed by information system at the time of setting the restriction that it is dangerous to patient's life and health to provide health care services based on insufficient information.

Example: If patient has set an access restriction to epicrisis then this restriction will also extend to the index of and diagnosis in the epicrisis as well as to prescribed medications, etc. Therefore, when making an enquiry to get a patient's comprehensive list of epicrisis compiled throughout their medical history, the epicrisis with restricted access will be omitted. Also, the medication indicated on this epicrisis will not be visible under the list of medications being taken by patient.

Patients with restricted active legal capacity or who have been assigned a guardian by court don't have a right to set restrictions. In case of guardianship, patient's rights will be executed by the guardian (defined by the EHR information system as a representative who has complete rights).

Ignoring the Access Restriction

The access restrictions to patient's health data in the EHR information system can't be ignored. There will be no access allowed to initial documents even in the emergency situation and the patient will take full responsibility regarding possible consequences that may arise from banning access to data.

Patient's Right to Enquire the Electronic Health Record Documents

The patient has a right to enquire all documents relating to him/her from the EHR information system that physician has not set any restrictions on.

In the event of an examination the physician ordering the examination will indicate on referral if the initial viewing of the results of the examination has to take place accompanied by the physician or if patient may view the results independently. If patient wished to see the results of the exam before the summary is created then he/she can do so at the institution where the physician who ordered the examination works, and this is where the attending physician will introduce the appropriate documents to patient.

Information deemed unnecessary at the time of creating the summary will not be forwarded to the EHR information system, and patient may examine this information at health care organisation if necessary.

The patient has a right to enquire information from the EHR information system on how his/her data has been used by attending physicians.

Rights of a Patient's Representative

The patient's representative of full rights is by default patient's legal representative (guardian for an underage patient and persons with restricted active legal capacity). The EHR information system makes enquiries via online processing about legal representatives from the Population Register. Representative with full rights has a complete authorization to act on behalf of patient.

The patient doesn't have a right to change the level of authorization of legal representative.

In addition, the patient can assign representatives authorized to make transactions on behalf of patient in the EHR information system. The authorization can be partial or comprehensive. Partially authorized representative can only view patient's data and is not allowed to make any transactions on behalf of patient. Representative with full rights:

- can get health information related to the patient from the EHR information system or from health care service provider
 - o will be informed in emergency situations
 - o gets information after patient dies
- executes patient's rights
 - o sets or removes access restrictions on documents
 - o makes expressions of will
 - o assigns other representatives

The patient (excluding patients with restricted active legal capacity) has a right to change or let go of a representative (excluding legal representative). Only an adult of active legal capacity can be authorized as a representative. A representative can be the patient's attending physician who will execute patient's rights in the EHR information system according to the agreement with the patient.

Rights of an Underage Patient

The underage patient has a right to set restrictions to documents and cases of illness, i.e. his/her legal representatives and representatives can't enquire these documents or cases of illness.

The attending physician must be convinced that the underage patient is capable of responsibly assessing the pro- and con-arguments related to the provision of health care services³. If the underage patient is capable of such assessment, then he/she is capable of giving consent. This means that if the underage patient came to see the physician independently, then the documents associated with this particular case can only be enquired by the patient. The attending physician must ask the patient if he/she wants to disclose information to his/her legal representative. Information will not be disclosed by default. The physician has a right to disclose information to legal representative if patient or other persons would be put in danger if information is not disclosed⁴.

Rights of a Person Whose Active Legal Capacity is Restricted by Court

Persons whose active legal capacity has been restricted by court do not have a right to administer their data in the EHR. The rights of a person whose active legal capacity has been restricted by court will be executed by his/her legal representative.

Patient's Right to Request Correction of Data

If patient discovers a document in the EHR information system that according to his/her assessment has incorrect information, the patient has a right to request from health care provider the forwarding of a corrected document to the EHR. Patient must turn to health care service provider in order for the document to be corrected.

3.4. Other Health Care Employees

Administrative Personnel

Administrative employees can't enquire patient's data from the EHR information system. Administrative employees will use data contained in the health care service provider's information system. Health care service provider's information system may enquire patient's non-sensitive general data from the EHR, and this information will be used by administrative personnel through their information system.

Registry office's employees can use patient's non-sensitive general data in the extent necessary to set up appointment times and prepare documents. Registry office's employee has a right to view data on referral in the extent necessary for sending the patient to an appropriate physician and to prepare documents given to the physician, and for this purpose registry office's employee can make an enquiry on referrals to the EHR information system.

Accountants can't enquire data from the EHR information system. Accountants will be created access to the organization's internal data in the extent necessary to create reports and invoices for treatment.

Since administrative employees do not have an independent right to make enquiries in the EHR information system, there will be no data enquiry access rules established for them. Administrative employees are employed on contractual basis and the organization's information system must ensure that data will be used as minimally as possible, and that the employees will only have access to data without which they

³ Law of Obligations Act § 766 section 4, <http://www.legaltext.ee/et/andmebaas/ava.asp?m=022>

⁴ Law of Obligations Act § 768 section 2, <http://www.legaltext.ee/et/andmebaas/ava.asp?m=022>

could not complete their work. The fulfilling of the minimal requirement will be verified by the Data Protection Inspectorate at the time of issuing the data use license.

Physicians of Defence Forces

If Defence Forces physicians are registered at the register of the Health Care Board, they will be enabled access to patient's health data through information system interfaced with the EHR. The physicians of Defence Forces are attending physicians to their patients.

Rights of a Prison Physician

If prison physicians are registered at the register of the Health Care Board, they will be enabled access to patient's health data through information system interfaced with the EHR. The prison physicians are attending physicians to their patients.

4. Summary

Implementing a nationwide integrated EHR has been one of the largest and most complex projects in the Estonian healthcare sector. During the process several parallel processes were carried out: establishing and developing responsible body – Estonian E-Health Foundation; creating a legal system; establishing access rights and rules for participants; creating integrated EHR with service oriented architecture and maintenance for the system .

Creating the rules and access rights, you must find a right balance between personal rights and social expectations for delicate data usage.

Estonia is a first country in the EU that has done it, but we still need to make a lot of efforts to receive full acceptance from medical professionals and citizens.

Paper II

Tiik, M. Ross, P. 2010. Patient opportunities in the Estonian Electronic Health Record System. *Medical and Care Compunetics*, 6, pp.171–177.

Patient Opportunities in the Estonian Electronic Health Record System

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Abstract. Estonia is the first country which has implemented a nationwide electronic health record system and gives full access to its citizens. This provides new opportunities to citizens, healthcare providers and e-health developers. Combining health data, citizens' self added health and welfare data, decision support and possibilities of service oriented architecture of the Estonian Electronic Health Record System – a new era of e-health services can begin.

Keywords. Nationwide electronic health record system, access rights, integrated EHR, patient's rights, health portal, patient's portal, patient empowerment.

Introduction

The Estonian Electronic Health Record System (hereafter EHR) is a globally unique EHR system as it encompasses the whole country, registers virtually all residents' medical history from birth to death, and is based on the comprehensive state-developed basic IT infrastructure [1,2,3]. The Estonian nationwide EHR was launched on 17th of December 2008. Since 1st of January 2009 all healthcare providers have an obligation to send agreed number of standardized medical documents to the EHR. The content of the information stored centrally is indicated by the legislation. Electronic documents are formalized as standard HL7 CDA documents that are stored in a central database (i.e. archived electronically). The person compiling the medical document has to be identifiable: documents containing medical information or a physician's decision must have the physician's digital signature, or it must be date-stamped by health care service provider's information system. Regardless of more than ten years history of digital collection of medical data by doctors, the medical data collected prior to 1st of January 2009 was not transferred to the EHR due to its poor quality and insufficient standardization.

The purpose of this article is to give an overview of the Estonian EHR system, and based on the first year's experience of full deployment of the system analyse the initial results for citizens.

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1. Materials and Methods

1.1. EHR– Overview of the System

The EHR is a database that is a part of the state information system. 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 [4].

To secure the access to the EHR, the Estonian countrywide data exchange platform X-Road is used [5]. X-Road is based on a principle of using one integral set of user interfaces for organizing communication with databases (see Figure 1). The system ensures sufficient security for the treatment of inquiries made to databases and responses received. It is suitable for managing a dialogue between the consumer (citizen, civil servant and entrepreneur) and numerous databases as well as for realizing cooperation between application programs and databases. The technical solution of the project does not lie in the transition of all databases to some larger data management system, but in the creation of unified user interfaces for different databases. Citizens and institutions can join and use the X-Road free of charge. Identification of the person is based on the compulsory ID-card issued by the state. ID-card is used both for identification of the user and for digital signing of documents, e.g. discharge letters, radiology reports, etc. According to the Health Information System Statute, the processor of the EHR is the Ministry of Social Affairs, and the authorized processor of the EHR is the Estonian eHealth Foundation [4].

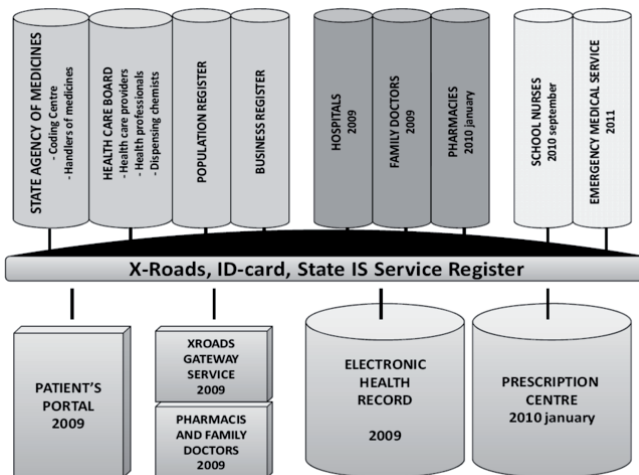


Figure 1. EHR partners and integration through secure data layer X-Road

1.2. Access Rights

- All healthcare providers must send agreed data to EHR.
- All access rights and data usage is regulated by the law.
- ID-card for authentication and digital signature for both, doctors and citizens.
- Access is enabled only to licensed medical professionals.
- The attending doctor concept – an attending physician is a health care employee currently associated with patient's treatment and registered with the Health Care Board.
- Citizens can access their own data through Patient's Portal, where they can also declare their intentions and preferences. Patient has a right to set access restrictions to documents, cases of illness, and to all his/her information in the EHR. The access ban can be set to one specific document or applied to the complete data in the EHR.
- The EHR will record information about when, how, and why the data was used (logging information), enabling citizens to monitor who has viewed their health data.

1.3. Services of EHR

The EHR is built according to the best practices of Service Orientation. Services of the system are based on standards that Estonian eHealth Foundation publishes openly on its website.

Interaction with end users is established via alternative channels. Also, there are portals that are served by the Estonian eHealth Foundation (e.g., Patient's Portal). There are also various information systems that are connected to the central EHR messaging services. The messaging standard is openly available for healthcare institutions, specialized healthcare registries and others, and they have taken advantage of this possibility to connect to EHR for message exchange.

The EHR processes messages according to regulated validation and security requirements.

Authorized messaging client of the EHR can benefit from the following services (Figure 2):

- Health event service enables to browse and search for health related events of patient treatment history. Health related events are for example diagnosis, visit, prescription, operation, diagnostic image, etc.
- Health status service enables to fetch information about certain health related parameters of a patient. These parameters are for example blood type, pregnancy, allergy, height, weight, smoking, etc.
- Booking service enables healthcare service providers to publish information about their healthcare services and available resources, so that doctors of other institutions and patients can book for appointments at these providers. Booking service keeps track of referrals and appointments.
- Reporting service provides users with prebuilt reports about patient health status. Here one can find so-called Time Critical Report that summarizes information about patient's health events and health status in a way most useful for emergency treatment.

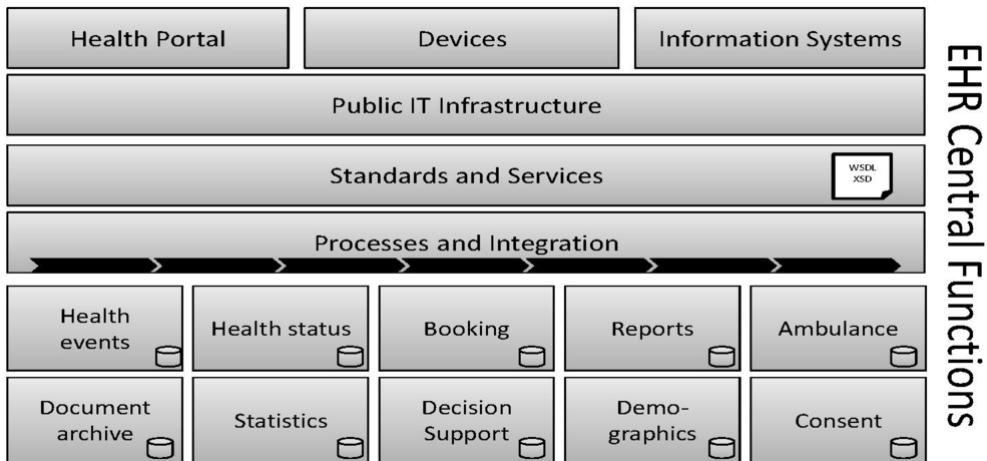


Figure 2. Functional Architecture of EHR

- Document archive service organizes all digital documents that are submitted to the central system. One can fetch a document by ID from a document archive.
- Statistics service reorganizes facts from patient health related documents for further statistical processing.
- Demographics service collects and reports general information about patient identity, locations, and relationships. The information is based on the data of the Estonian Population Registry, registration documents from healthcare institutions, and information submitted via Patient's Portal.
- Consent service maintains data about patients' will expressed in digital documents. Currently there are trustee access rights, healthcare service options, and health record access rights related consents implemented.

Patient's Portal (Figure 3) allows patient representatives (adult patient, parent of an underage, legal representative, trustee) to browse patient's health record, download documents, submit consents, update demographics data, book an appointment, and review patient health record usage logs via Web.

2. Results

More than 350 000 medical documents, including about 10% of patient summaries, were sent to the EHR during 2009. Altogether 953 general practitioners (GP), private health care specialists, and hospitals have connected to EHR during the first year, and this number represents 90% of all health care institutions in Estonia. By the end of 2009, 143360 citizens had a medical document in the EHR. As of January 1st of 2010, this number has rapidly increased with additional 114 012 citizens due to the launch of the digital prescription. The population of Estonia is 1,304,021, meaning that by the

Citizens view to the EHR

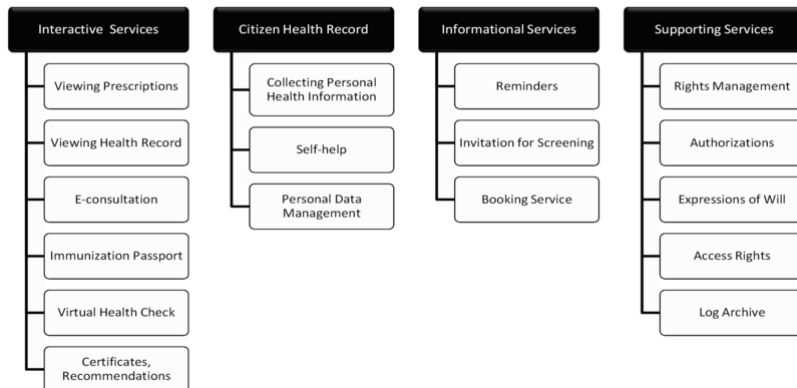


Figure 3. Health Portal functionalities.

end of January 2010 twenty percent of citizens had some type of medical record in the EHR [6].

According to the law, all citizens have full access to data collected in the EHR [4]. For that function a Web-based Patient's Portal was launched on October 26 of 2009. During the first five months the portal was visited by 12993 citizens. This accounts for 1% of the Estonian population as of January 1st of 2010. There has not been any public campaign for citizens on how to use the Patient's Portal, and so far the information has been given by the doctors.

3. Discussion

Creating secure and easy internet access to patients' health data will increase patients' awareness of their health. Citizens can get an overview of their recent doctor's appointments, laboratory tests, and medical reports, etc. This allows patients to make more informed decisions about their health behaviour or prepare more thoroughly for the appointment with the health care professional. Citizens can also record their expressions of will (e.g., donation of organs, permit blood transfusion) or choose preferences which increases their involvement in decision making process related to their health condition.

The experience of implementation of EHR in Estonia has shown that technically and organisationally the task is achievable in a relatively short period. However, realising concrete benefits for patients, health care personnel, and society depend on the completeness and quality of the data in the central system. In our experience this is achievable only in the case when the common standards are used, and the majority of health care institutions connect to the EHR in a relatively short period. In Estonia the health care providers were obligated to interface with the EHR because of the recent amendments to the Health Services Organization Act. Despite this fact, there has been a considerable amount of reluctance among the health care providers to interface with the EHR. According to the feedback from the health care managers, it was mainly

because interfacing with the EHR demanded additional information technology investments from GP's and hospitals. Unfortunately, the benefit of this investment is not realised in a short term, and thus hardly acceptable from an economical point of view.

The implementation of the EHR has increased the use of information technology in health care institutions. To overcome the potential problems caused by the inefficacious knowledge of computer skills among the personnel, several training programs for the health care professionals were carried out during the first year. Programs included training in computer skills, gave an overview of security regulations, and taught participants how to use the EHR. However, there still seems to be a quite large number of health professionals who are not fully satisfied with the design and functionality of the EHR.

The number of citizens who have used the Patient's Portal to view their own health data during the first four months is relatively low. This is not surprising, because the launch of this new service was not accompanied by wide public campaign. The information about the Patient's Portal is given to citizens by health care professionals. The reason for discreet introduction of the Patient's Portal is the unawareness of the influence of this service to patient behaviour and physician-patient relation. Also, there are different opinions among the health care professionals about the usefulness of sharing the health data openly with patients. However, the first experience is that citizens are accepting the Web-based access to their health data, and there have been no remarkable drawbacks.

The EHR can also provide a number of different services using decision support engine, existing medical documents, and citizen's added information. As an example, certificate for driver's license could be one of those. Another possible new intelligent service is a reminder service, which means sending an automatic SMS or e-mail remainder about the next visit to the doctor or to the lab to give a blood sample.

In further development the EHR can also provide data from the Estonian Genome Centre [7]. However, for that we need several new services. Firstly, consent on person's willingness to know their gene data. Secondly, we need a consent which allows the Genome Centre to send data to the EHR. The third possible service in this area could be an updating of personal health data for gene donors.

All these services with full access to the EHR give citizens more reliable information about their health status, and provide possibilities for an adequate care process. However, it also means more responsibility and commitments for citizens.

4. Conclusion

Electronic access to the shared health database increases the role of patient in the diagnostic and treatment processes. Health care providers should become more responsive to patients' needs and preferences and deliver better quality of care. Patients', having more adequate and related information about their health, can participate in the health care in many new ways. This includes communicating directly to healthcare professionals by using information on health and health care through internet channels, mobile devices, etc.

This might lead to a situation where patients start taking more control over their illnesses and treatments where possible.

Patients are given information in the belief that this will enable informed choices. Finally, this will lead to healthy behaviour and decrease cost of healthcare in the country.

Estonia has taken a big step in this direction and has potential to be the first country where patient is the main driving force of their personal health issues.

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Paper III

Sepper, R, Ross, P, Tiik, M. 2011. Nationwide Health Data Management System: a novel approach for integrating biomarker measurements with comprehensive health records in large populations studies. *Journal of Proteome Research*, 10(1), pp. 97–100.

Nationwide Health Data Management System: A Novel Approach for Integrating Biomarker Measurements with Comprehensive Health Records in Large Populations Studies

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The nation-wide electronic health record database acts as an interoperable repository of health data obtained throughout citizen contacts with health care providers. This system improves accessibility for citizens and researchers to health data with the ability to assign context to disease development. In that system, individual patients who are members of the large population-based health database can be assessed as individuals or as a population in prospective studies of prospective diseases.

Keywords: Health Information System • National Electronic Health Record • COPD • Lung Cohort Study • Protein Biomarkers • eHealth • X-Road

Introduction

The study of health and disease in large populations is an important global endeavor that demands large-scale resource investment into infrastructure, surveillance programs, and education and training activities within various levels of society. Most often, even when sponsored on a national scale, such types of health evaluation are conducted at a local level, at individual health care centers that may not be at all aligned with similar activities at other local health care centers. At the level of care, assessment and treatment of individual patients, and quite often the historical data of clinical management, are fragmented between many different health care facilities that have come in contact with individual cases. Clinical assessment requires access to both laboratory and clinical measurements such as computed tomography (CT) scans, lung function, and clinical chemistry evaluations. The rising costs of health care could be partially addressed by systems that allow clinical data to be collected and shared centrally by health care providers irrespective of the location of the data acquisition. Such systems could act as repositories of all important clinical measurements taken throughout an evaluation and treatment period. An important aspect of this system would be to classify disease using standardized scales of nomenclature that could most accurately describe the form and stage of the disease being assessed as well as reference to previous disease or comorbidities of disease. Chronologically following the response to treatment and thus further enabling strategies for clinical decision support could attain a further clinical advantage.

Why then would such an electronic data management system be of interest to the clinical proteomics community or to clinicians? This question is most often posed as either “What

value do protein biomarkers have in clinical management?” or “What forms of clinical presentation are associated with specific markers?” There are currently global activities addressing these important questions that will require testing and validation in large population-based studies to establish the usefulness of protein marker measurements in routine clinical practice. However, the actual importance of individual measurements (both quantitative and qualitative) of protein biomarkers, as prognostic indicators can only be evaluated by first establishing ranges of normal values, in population based studies. Then, these normal scores can align with contexts of disease presentation, other clinical measurements that address structural and functional abnormalities, and with eventual clinical outcome. At this point, the true value of a digital health database begins to be appreciated as a valuable resource in not only clinical research but, first of all, as an essential clinical measurement tool. Why again? Through its ability to assign context to disease development in individual patients who are members of large population based on data sets that can be assessed as individuals or as populations.

Estonian Countrywide Health Information System. Preparation for Estonian e-health system started in 2002 with the assigned purpose to develop a nationwide framework (database) that encompasses different medical documents in the digital format to facilitate the exchange of diffuse health information. In 2005, the Estonian Ministry of Social Affairs launched a new e-health concept by phasing in four projects: *Electronic Health Record (EHR)*, *Digital Images*, *Digital Registration*, and *Digital Prescription*, forming the National Electronic Health Record (EHR) with the gradual development until 2013. The Health Services Organisation Act and Associated Acts Amendment Act, accepted by the Parliament on 20th December in 2007, provides that as of September 1st of 2008 the health care service providers are obligated to forward medical data to the EHR. EHR is a database that is part of the Estonian State Information System (www.ria.ee), the data associated with the

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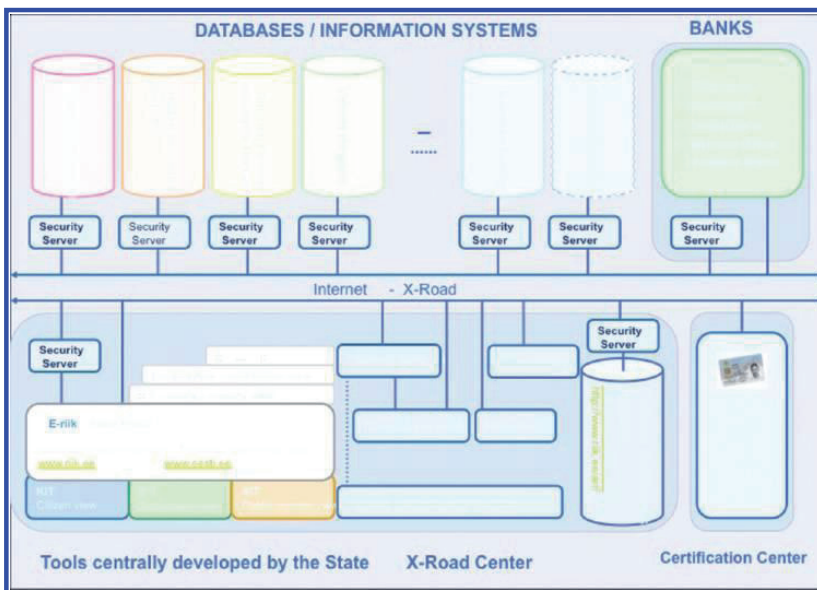


Figure 1. Databases and information systems.

health care field is processed in this database to conclude and execute the contract for providing health care services, to ensure patients rights and to protect public health and the quality of health care services, including maintaining the registers reflecting health conditions and managing health care. According to the Health Information System Statute, the processor of the EHR is the Ministry of Social Affairs and the authorized processor of the EHR is the Estonian e-Health Foundation (www.e-tervis.ee) (Figure 1).

Estonian Electronic Health Record System. The Estonian EHR is globally unique because it engages the whole country (population ~1.34 million inhabitants), registers virtually all residents' medical history from birth to death, and is based on the comprehensive state-developed basic IT infrastructure. The three largest Estonian hospitals, Ministry of Social affairs, The Estonian Society of Family doctors, The Estonian Hospital Union and The Association of Ambulance Doctors were the founders of Estonian e-Health Foundation. The operating principle of health information system is to reuse as much as possible of the existing components of public ICT (Figure 2). To collect and process all of the necessary data in the EHR, all healthcare providers are connected to the X-Road. X-Road applies a number of standard tools that have been developed for the eServices, capable of simultaneously integrating and interoperating data derived from different databases. These services enable reading and writing data and to perform most common data processing operations. Proceeding from this principle, several extensions have been developed for the X-Road: writing operations to databases, transmission of large data sets between information systems, successive search operations of data in different data sheets, and the ability to provide services via web portals, etc. (www.ria.ee/index.php?id27309).

EHR in Practice. Entry into the EHR is obtained for citizens and entitled health care personnel through the use of a chip card, the Estonian ID card, which are issued by The Citizenship and Migration Board. Estonian ID cards are issued to all

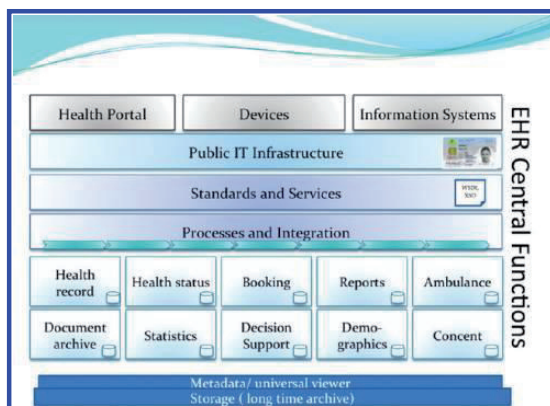


Figure 2. EHR central functions.

Estonian citizens as well as foreigners who reside in Estonia on the basis of a residence permit. Over one million cards have been issued, which marks the biggest ID card rollout in Europe. The ID card is used for securing authentication off and for digital signature of the person. These digital signatures have the same legal consequences as a hand-written signature. The ID card is a mandatory document for all Estonian residents from the age of 15. The card is valid for 10 years and can be used as an identification and travel document within EU.

Each card is embedded with an electronic tamper-proof chip that contains a personal data file, certificate for authentication, and certificate for digital signature. The ID card is used as a common key to access different services, and it performs automated checks from the Estonian Population Registry. Data processing and storage in the EHR has been developed in a way that patients' personal data in connection with the medical data is visible only to legally authorized parties. To date, permission to carry out certain clinical trial from local ethical committee is mandatory. Access right to EHR is allowed to

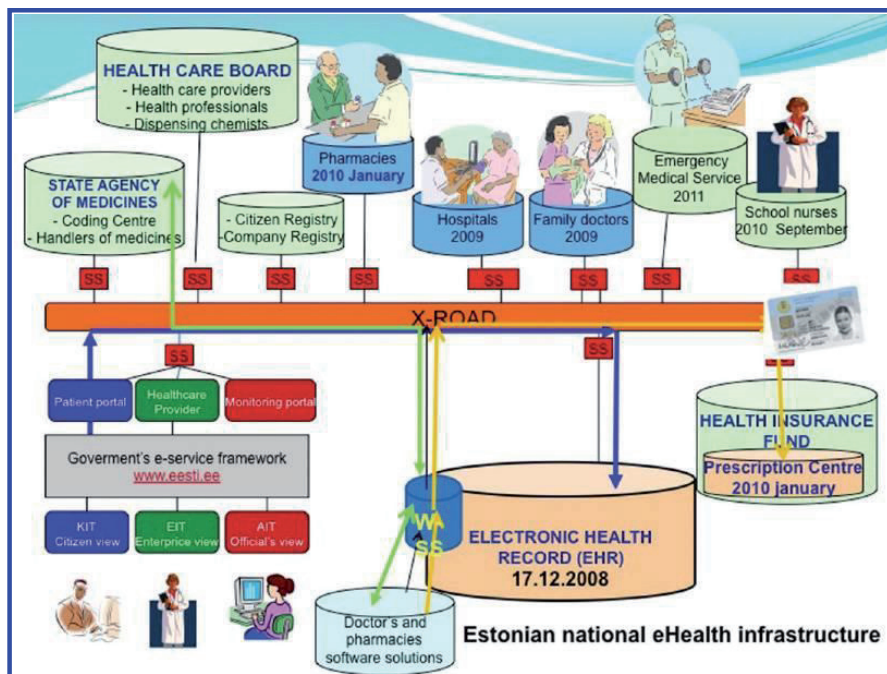


Figure 3. Estonian national eHealth infrastructure.

medical professionals; there are no differences between specialties. Authentication is allowed only with ID card; all logs are stored and monitored. By law, access to patient data is legal only if there is a current relation between the health care professional and patient. An attending physician is a health care employee registered with the Health Care Board who is currently associated with patient's treatment. A family physician is the attending physician on permanent basis to all patients in his/her practice list. The attending physician may hold different positions related to specific case (replacement physician, on-call physician, consulting physician, etc.), and regardless of the position, the physician is still considered to be the attending physician. Citizens can access their own data through Patient's Portal, where they can also declare their intentions and preferences. The patient has a right to set access restrictions to documents, cases of illness and to all his/her information in the EHR. The access ban can be set to one specific document or applied to complete data in the EHR. The EHR system will record information about how and why the data was used (logging audit trail information) enabling citizens to monitor visits to the EHR (Figure 3).

Standardization. To support interoperability and to build an open architecture for future interdisciplinary integration, mostly all input medical data is coded and classified based upon international standard protocols of defined nomenclature that must be used when entering patient data into EHR. Medical history, disease history, and clinical status are in certain extent coded using SNOMED-CT (www.ihtsdo.org); diagnoses are coded using ICD-10 (www.who.int/classifications/icd/en); laboratory tests are coded using Loinc (www.loinc.org); and prescriptions are coded using ATC (www.whocc.no). Integration as well as mutual usage of medical data based on state-central health information system provided by Estonian eHealth Foundation is supported based on XML based HL7 CDA v3 standard

message transactions. Implementation of standards provided by HL7 (HL7 and its members provide a framework and related standards) for the exchange, integration, sharing, and retrieval of electronic health information. v3.x of the standards, which supports clinical practice and the management, delivery, and evaluation of health services, are most commonly used in the world. The priority of the Estonian Electronic Health Record project has increased on the national level, and the number of medical documents that will be digitized has also increased during the project. A large volume of additional documents will be added throughout the following phases of the Electronic Health Record (EHR) project, and this will set high requirements for standardization of medical documents, for interfacing organisations business processes and adaptation of their information systems, as well as for the development of the EHR central system.

Utility of Health Information System in Population Based Studies: Prospective Studies of Prospective Diseases. Cigarette smoking is the most important risk factor in the development of a number of major life threatening diseases including cancer, COPD, coronary heart disease, and stroke. To date, smoking prevalence in Estonia in adults in 2005 was 28% (42% in male, 21% in female) and in youth 24% (boys 30% and girls 18% from age 15–18).¹ Quite often smokers develop clinical complaints related to smoking long after pathological damage has begun.² Diseases related to smoking are heterogeneous within individual patients with a wide variety of comorbidity involving any and all of the above-mentioned disorders. The time frame required for disease development also differs between individuals by smoking history, age, gender, diet, genetic background, and environmental exposure. The staging of disease is most often determined by clinical symptoms using a variety of measurement devices.

Chronic obstructive pulmonary disease (COPD) is a major concern worldwide (www.goldcopd.com). Clinical COPD patients experience breathlessness, productive cough, shortage in many life functions especially those associated with constitutional capability.³ The diagnostic tools currently address structural (CT lung density scan, CT airway wall thickness) and functional abnormalities (spirometry for expiratory flow, residual volume, total lung capacity, forced residual capacity). Although some technological modalities, for example, body plethysmography, measuring static lung volumes instead of dynamic can provide additional information to functional disability of smokers without COPD complaints,^{4–6} these diagnostic approaches are valid in the more advanced COPD leaving; however, the early onset of lung functions decline in chronic smokers who are destined to, but have not yet, developed irreversible changes in lung structure and function. The development of new protein biomarker assays that could diagnose early ongoing diseases are a great assistance and add context to and complement the existing diagnostic tools. The CT scans that are typically used in lung density measurements in smokers will provide information on the distribution of emphysema but will not differentiate between older inactive emphysema lesions and early active areas of current parenchyma destruction. Protein measurements capable of providing quantitative information on current ongoing lung tissue matrix destruction would be invaluable assets in monitoring progression of disease in the context of the CT scans, measuring emphysema and the functional tests. The validity of these associations could never be established in small case-controlled studies. This level of power can only be achieved in large cohort studies that are logistically not in place in most instances for these applications. The country-wide digital health information database provides the means to form virtual large cohort studies by combining subjects from throughout the registry. Stored retrospective samples could be collected and queried in biomarker assays, and these measurement values could be correlated with clinical measurements as mentioned above. The power of such population studies could be used to test the hypotheses that equilibrate marker measurements with disease development and eventual outcome.

Identifying Diseases in Early Phase of Onset. An even further advantage of the digital health information database would be to identify and treat subjects with symptom-free early disease among the at the risk groups in the population. There are currently no laboratory tests that can detect the smokers' susceptibility toward the deleterious effects of smoking on lung function. Smoking cessation is still the only proven tool to stop lung function decline and, as several studies have shown, that it is especially beneficial in early quitters. At the most basic level, the digital health information database can identify smokers at a relatively early age, and these smokers could be counselled with smoking cessation programs to reduce risk

factors. The database could also be used to form epidemiological cohorts from younger smokers with no complaints that continue to smoke despite counselling to follow certain disease development and early entry into treatment and therapy to reduce potential disease burden. The overall benefit is not only to the individual patient but also to the society by limiting the costs of long-term hospital care necessitated by advanced disease as well as achieving higher levels of quality of life for both symptom-free and clinically burdened subjects.

Conclusion

The interoperable digital health information system improves accessibility for citizens and researchers to health data. Public and private sectors, clinical care providers, and researchers all benefit from the accelerated delivery of comprehensive health data.

Summary

Studies of health or disease in a large population demand large-scale resource investments. Estonian National Electronic Health Record (EHR) was established with the assigned purpose to develop a comprehensive framework that encompasses different medical data in the digital format to exchange health information. EHR system acts as repository of health data obtained throughout citizen contacts with health care providers. EHR system can be of interest to the clinical proteomics community. The interoperable digital health information system improves accessibility for citizens and researchers to health data, with the ability to assign context to disease development in individual patients who are members of large population-based health database that can be assessed as individuals or as a population in prospective studies of prospective diseases. Public and private sectors, clinical care providers, and researchers all benefit from the accelerated delivery of comprehensive health data.

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Tartu Ülikool	1996	Arst
Tallinna 2. Keskkool	1996	Keskharidus

Keeleoskus

Keel	Tase
Eesti	Emakeel
Inglise	Kõrgtase
Soome	Kõrgtase
Vene	Keskmine tase

Teenistuskäik

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2012–	Finnish Innovation Fund	Vanemkonsultant
2011–	Tallinna Tehnikaülikool Kliinilise Meditsiini Instituut	Projektijuht
2007–2011	Eesti eTervise SA	Juhatuse liige
2005–2007	Eesti eTervise SA	Nõukogu liige
2001–2006	Kuressaare Gümnaasiumi SA	Nõukogu esimees
2000–2004	Kuressaare Haigla SA	Nõukogu liige
1999–2012	Eesti Perearstide Selts	Juhatuse liige
1998–	Terviseagentuur OÜ	Juhatuse liige, Perearst
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Eesti Perearstide Selts

Finish Society of Telemedicine and Ehealth

Teadustöö

Põhiline teadustöö valdkond on olnud perearsti töö korraldus ja infotehnoloogia kasutamine perearsti töös, samuti infotehnoloogia laiem kasutamine tervishoius, vajalike eeltingimuste ja juurutamisraskuste uurimine.

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Education:

Institution	Date: from (m/y) to (m/y)	Degree(s) or Diploma(s) obtained
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Nordic School of Public Health	5/1994 to 6/2003	Diploma in Public Health
Tartu University	9/1997 to 8/1999	Family doctor specialisation

Tartu University	9/1986 to 6/1996	Medical doctor, <i>MD</i>
Secondary School nr 2 Tallinn	9/1975 to 6/1986	

Language competence/skills (fluent; average, basic skills)

Language	Level
Estonian	Mother tongue
English	Fluent
Finnish	Fluent
Russian	Average

Professional Employment

Period	Organisation	Position
2012–	Finnish Innovation Fund	Senior adviser
2011–	Institute of Clinical Medicine Tallinn University of Technology	Lecturer, project manager
2007–2011	Estonian eHealth Foundation	CEO
2005–2007	Estonian eHealth Foundation	Member of the supervisory board
2001–2006	Kuressaare Gymnasium Foundation	Chairman of the supervisory board

2000–2004	Kuressaare Hospital Foundation	Member of the supervisory board
1999–2012	Estonian Society of Family doctors	Member of the board
1998–	Terviseagentuur Ltd.	Family doctor, CEO
1996–1997	Kuressaare Hospital	Internship

Membership of professional bodies:

The Estonian Society of Family Doctors

Finish Society of Telemedicine and Ehealth

Scientific work

Main areas of interest are: clinical and managerial contents of family doctors work

Using ICT in healthcare

Main areas of scientific work/Current research topics

Data sharing among healthcare and with the citizen

Process reengineering in healthcare

Telemedicine services for the patients

Personal health record services and patient motivation

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