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CHATBOT FOR ASSISTING PARENTS OF CHILDREN WITH CHRONIC LONG-TERM ILLNESS

Master's Thesis

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CHATBOT KROONILISE PIKAAJALISE HAIGUSEGA LASTE VANEMATE ABISTAMISEKS

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

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Abstract

With the exponential growth of the IT industry, massive health-related services such as different web applications, mobile applications and chatbots are being offered to the patients. However, most of these systems lack the ability to understanding the caretaker's and parents' needs and difficulties while taking care of the patient. Currently, in Estonia, there are numerous services offered by the government to children with chronic diseases. However, due to the non-centralised setup, lack of coordination and a fragmented information system, it becomes difficult for the parents to make use of these facilities.

On the other hand, the availability of source of information about these services could greatly help the parents by reducing their burden thus leading to a more relaxed life.

The main goal of this thesis is to find a solution to help the parents of chronically ill children with the problems mentioned. A chatbot is an innovative tool that would help parents in managing the condition of their children by gathering information from different portals and presenting them on a user-friendly platform. The main research question of this work is "How could a Chatbot benefit the parents of chronically ill children?". To answer this question, the author conducted a series of interviews with some of the major stakeholders of the application including doctors/experts and parents of chronically ill children and designed a prototype to determine how the features of the proposed "*Lapsevanemad Chatbot*" could be helpful for parents of children with complex needs. For that, interviews were conducted with different stakeholders to understand the needs of the parents and a prototype of the chatbot was designed and validated.

Keywords: chatbot for parents, chronic diseases, caretaker stress, health care system

This thesis is written in English and is 64 pages long, including 6 chapters, 16 figures and 15 tables.

Annotatsioon

CHATBOT KROONILISE PIKAAJALISE HAIGUSEGA LASTE VANEMATE ABISTAMISEKS

Infotehnoloogia üha kiireneva kasvuga kaasnevalt pakutakse patsientidele palju erinevaid tervisega seotud teenuseid, nagu näiteks erinevad veebirakendused, mobiilirakendused ja *chatbot*'id.

Siiski puudub enamikul nendest süsteemidest aspekt, mis saaks spetsiifiliselt aru lapsevanemate vajadustest ja raskustest patsiendi (lapse) eest hoolitsemisel.

Hetkel on Eestis arvukalt teenuseid, mida valitsus pakub krooniliste haigustega lastele.

Kuid mitte-tsentraliseeritud ülesehituse, koordineerimise puudumise ja killustatud infosüsteemi tõttu, on lapsevanematel raske neid vahendeid kasutada.

Samas võib hästi määratletud andmebaasi kättesaadavus nende teenuste kohta oluliselt lapsevanemaid aidata, vähendades nende hoolduskoormust ja luues pingevabamat elu.

Selle magistritöö põhieesmärk on leida lahendus mainitud probleemidele, et aidata krooniliselt haigete laste vanemaid.

Chatbot on uuenduslik lahendus, mis aitaks lapsevanematel oma laste seisundit hallata, kogudes infot erinevatest portaalidest ja esitledes neid kasutajasõbralikul platvormil.

Selle töö peamine uurimisküsimus on "Kuidas võiks *Chatbot* olla kasulik krooniliselt haigete laste vanematele?".

Sellele küsimusele vastamiseks viis magistritöö autor läbi mitmeid intervjuusid rakenduse olulisemate huvigruppidega, sealhulgas arstid/eksperdid ja krooniliselt haigete laste vanemad ning kujundas prototüübi, et teha kindlaks, kuidas väljapakutud „Lapsevanemate *Chatbot*" funktsioonid võiksid olla abiks erivajadustega laste vanematele.

Märksõnad: vestlusrobot lapsevanematele, krooniline haigus, hoolduskoormus, tervishoiusüsteem

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 64 leheküljel, 6 peatükki, 16 joonist, 15 tabelit.

List of abbreviations and terms

WHO	World Health Organization
GDP	Gross Domestic Product
ICBT	Internet-delivered cognitive behavioural therapy
MCCs	Multiple chronic conditions
CA	Conversational Agents
EU	European Union
DALYs	Disability-adjusted life-years
SHCN	Special health care needs
ID	Intellectual disability
ICTs	Information and Communication Technologies
EHIF	Estonian Health Insurance Fund
FD	Family Doctor
GP	General Physician
CMC	Children with medical complexity
AI	Artificial Intelligence
DOI	Diffusion of Innovation
IS	Information Systems
U&G	Uses and Gratification
TAM	Technology Acceptance Model
PU	Perceived usefulness
PEU	Perceived ease-of-use
AU	Actual Use
BI	Behavioural intent
DSR	Design Science Research
DSRM	Design Science Research Methodology
UI	User Interface

Table of contents

List of figures

List of tables

1 Introduction

According to a report by the World Health Organization (WHO), the main reason for the mortality and morbidity in Europe are chronic diseases, and research suggests these complex conditions are going to impose more burden on the healthcare system in the future [1]. The WHO defines chronic disease management as the “ongoing management of conditions over a period of years or decades" [1]. Earlier chronic diseases were considered to be a problem of the rich and elderly population as the research was mostly focused on the distribution of diseases between different countries but it is well known today that it does affect the poor as well as young and middle-aged people [2]. Chronic diseases have a negative impact on gross domestic product (GDP) because these reduce wages, income, workforce participation and productivity and thus have major implications on the economy [1]. Patients with chronic conditions have complex and extensive health and social care needs for which there must be someone always available to assist [3]. Once a disease is diagnosed in a child, the parents start falling into difficult situations as their child needs professional consultation and help [4]. Such diseases need long-term and continuous intervention [1].

There is a significant interest in utilizing eHealth solutions to improve the quality and safety of health care [5]. Healthcare systems need significant advancement for medical accessibility like other domains of travel and food [6]. Producing an internet-based application in the form of a chatbot could be important for parents having a need for obtaining the maximum diagnostic information about similar chronic diseases [7]. Chatbots are software applications designed to conduct a natural conversation with users via speech or text by using an algorithm. The programs in chatbots are built to simulate real-time conversations. Replacing human-based information assets, these applications could prove worthy [8].

The main aim of this research is to provide help to the parents of chronically ill children in various difficult situations during diagnosis, observation, and treatments of the disease by assisting them by designing a health chatbot (*Lapsevanemad Chatbot*).

"*Lapsevanemad*" is an Estonian word meaning 'parents' since the author got the idea to make this chatbot in Estonia. Therefore, the goal of the master's thesis is to find how such problems can be solved using technology. The chatbot will have the features enabling parents to get the information required by them in different instances and will assist them by providing the data about various services by the government and other organisations for disabled children. The parents would not need to manually look for the information for their children which is spread across different websites and platforms rather this chatbot will present all the necessary information on one screen.

1.1 Purpose of thesis

Across Europe, the expenses of dealing with treatment and prevention of chronic diseases are huge as these require a long-term and complex response. Being an important issue, policymakers and researchers are constantly inquiring about the plans and the strategies to manage chronic diseases [1]. An enlightened and healthier life has already been attained by the use of information and communication technologies (ICT) in every field and in particular in the health sector. For example, Internet-delivered cognitive behavioural therapy (ICBT) is considered to be an effective and efficient method for mental health care [4].

This research focuses on designing a chatbot to support the parents having children with some chronic diseases. Not all parents having children with chronic ailments including genetic diseases are experienced and hence they do face difficulties in satisfying the child's hygiene, hydration, and nutritional needs thereby experience higher levels of stress [9] [10]. Internet-based channels in the form of a chatbot could be useful for the parents by providing quick responses to the queries. Chatbot corresponds with its users through an algorithm by making a decision map without humans being involved. This could be a solution for various treatments and simultaneously for follow-ups during their treatments and so would save a lot of time contributing to the care and health of different patients. Parents of patients could get information and advice by generating an active conversation either by text or voice describing the symptoms [9]. There is already literature on Internet-delivered applications which have been demonstrated to be an effective and efficient method of health care delivery [4].

This research aims to explore how chatbots could benefit parents of children with chronic diseases in European countries and in general around the world. Many chronic diseases like cardiovascular diseases, diabetes, chronic respiratory and genetic diseases are the main cause of functional impairment and mortality in many countries, with 85% of related deaths in Europe. Furthermore, in the European region, about 70-80% of healthcare funds are spent on chronic diseases, of which 97% on treatment and only 3% on prevention. A huge number of people (about 50 million) are also suffering from multiple chronic conditions (MCCs) [11]. Designing a chatbot having the features to provide immediate help and information to avoid the critical situations of the children could reduce the number of deaths in Europe. The author started investigating the problems faced by the parents in Estonia and designed the prototype as per the information gathered there, however, the problems will be quite similar to the parents living in other parts of Europe and thus can be introduced there later.

1.2 Research Questions

This research will depict the needs of the caretakers of the children when it comes to dealing with their children daily. What needs do they have? What kind of information do they require continuously and what kind of assistance is required in emergency situations? The thesis will figure out the functional requirements of the chatbot and design it and validate it in the later stage.

The main research question is:

How could a Chatbot benefit the parents of chronically ill children?

The question is divided into three sub research questions as follows:

Sub RQ1: What are the existing services available for parents having children with chronic diseases and problems with those systems?

The research question aims to find the need of designing '*Lapsevanemad chatbot'* by analysing other similar existing services.

Sub RQ2: What would be the minimum functionalities of the chatbot?

The research question aims to find the main functionalities of the chatbot which can be obtained by the interviews conducted with the doctors and the parents.

Sub RQ3: What additional functionalities would parents want?

The aim of the research question is to understand the needs of the parents dealing with ill children.

The questions are important as the chatbot could help such parents by providing assistance anytime 24x7 from anywhere. The service could be fast by conducting a natural conversation via text or speech. Patients could get information and advice quickly by describing the symptoms which would save time, avoid delays, and would save lives. In particular, the caretakers would feel less burden and would be able to work with the child more effectively.

1.3 Thesis Outline

The thesis has been divided into 6 chapters. A short description of each chapter is given below.

Chapter 1 provides an introduction of the thesis i.e., the impact of chronic diseases on Europe and a possible solution to minimize it and gives a brief description of the objective of the research followed by the research questions and their goals.

Chapter 2 will present an overview of the literature about the chatbots, particularly in health sector and their acceptance, in parallel chronic diseases, needs in chronic diseases, the stress of the caretaker and digital interventions will be discussed. An overview of the of the theoretical background where different theories in information systems related to this research and their implementation for this research will be discussed in the following section.

Chapter 3 presents the methodology used for the research.

Chapter 4 the initial prototype designing phase is explained in this chapter and it presents the key findings and analysis from the interviews conducted by the author. The chapter also presents system architecture for the chatbot. followed by the section on the function and non-functional requirements of the chatbot and presents a modified prototype for the chatbot based on the analysis.

Chapter 5 represents the evaluation results with a brief description obtained from the participants followed by a section on discussion.

Chapter 6 concludes the thesis, followed by the answers to the research questions, limitations of the research and future work where recommendations for further research is given. At last, the interview questions asked to the doctors and parents for designing and validating prototype are represented in the **appendices**.

2 State of the Art

The preceding section provides an overview of the existing body of knowledge. The figure below gives a graphical overview of this section.

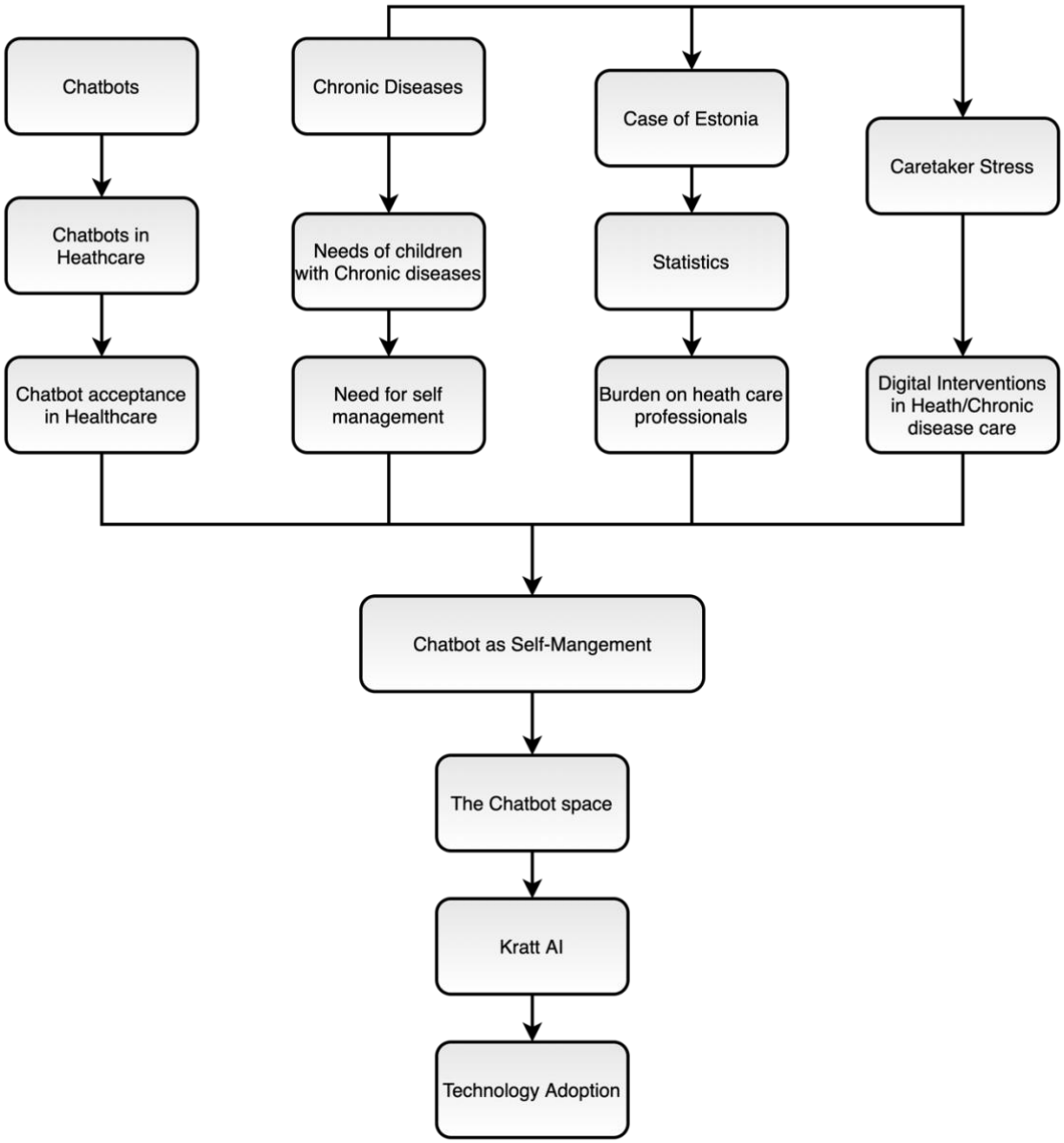

Figure 1 State of the Art

2.1 Chatbots

Chatbots are software applications designed to conduct a natural conversation with users via speech or text by using an algorithm. The programs in chatbots are built to simulate real-time conversations. Replacing human-based information assets, these applications could prove worthy [8]. Originally, chatbots were developed for passing Turing tests or for fun, such as conducting psychology interviews but over time, with the rapid advancement in machine learning and development of social media, service chatbots were designed as per the needs of the humans to be able to provide easily accessible services 24/7 in specific domains [12]. The development of building chatbots with data-driven approaches was quick because of the accumulation of human conversations by the services of social networks like Twitter, Weibo etc [8].

Chatbots are classified based on their purpose (i.e., assistant or conversation) and mode of communication (i.e., text or voice). While assistant chatbots are programmed to assist users in their daily activities to provide short, structured, and simple responses helping in getting information from the internet or scheduling an appointment and so on, the conversation chatbots are built for more extended responses engaging in human-like conversations [13]. According to the mode of communication, chatbots are either voice-enabled or text-based. Voice chatbots interact with users via auditory means whereas text-based ones can read and respond to typed messages and requests [14]. In mobile applications such as Lyra Virtual Assistant latest chatbots combine both text and voice as a mode of communication [13].

2.1.1 Chatbots in healthcare

Vik, a chatbot designed by Wefight, helps patients with cancers or chronic diseases through personalized text messages by suggesting treatments and their side effects [15]. HealthTap, a chatbot are miniature doctors that collect symptoms and provide potential causes in dialogue-based interactions [16]. Another healthcare Chabot Melody schedules an appointment for the patient with the doctor by communicating with the medical staff. Similarly, a chatbot Oscar estimates the health-insurance of its customers via Facebook-Messenger-based chatbot. The Molly chatbot service is a virtual-nurse platform that monitors the patients using the patient's real-time health data and thereby saves the time

of medical staff by 20% [17]. Pharmabot, a paediatric generic medicine consultant is designed for the prescription and suggestion of medicine for children. In the Netherlands, Chatbot Erica is developed for a dental practice [18]. Some of the chatbot health-platform services that could be used daily have been released by Google and Microsoft [17]. In recent times, the investigation on integration of some services is also conducted by chatbots like Dure which was a digital innovation developed to fight the COVID-19 outbreak [8].

2.1.2 Chatbot acceptance in healthcare

The use of technology in public health services depends on its easy accessibility. Making technology easily available to the people makes its acceptance and adoption fast [19]. The interviews conducted in one of the studies [20] showed that the intention to adopt a Conversational Agents (CA) for disease diagnosis depends on how a faster or better diagnosis is obtained from it. The better (worse) the performance expectancy, effort expectancy, the facilitating conditions, the higher (lower) the intention to adopt or the actual use of conversational agents for disease diagnosis [20]. Chatbot adoption in healthcare could serve as a great tool for collecting data from the patients and making quick the diagnosis [8].

Some researchers like Lucal et al [21] show that for some people it is more comfortable to share their personal information with a chatbot than humans whom they consider to be judgemental. This gives a clear picture of the patients and would not lead to serious complications because patients respond quite honestly without fear and overthinking about their impression [21]. These applications thus could prove themselves worthy of replacing human-based information acquisition because of their ability to understand the emotions and hence prediction of attitudes of users [8].

2.2 Chronic diseases

The leading cause of deaths globally is chronic diseases including cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes. In 2004 60% of deaths of 58.8 million deaths were attributed to chronic diseases and by 2030 the number of deaths caused by chronic diseases is estimated to increase dramatically [22].

In the US 12.6 million children require health or other related services beyond that of normal children due to a chronic physical, developmental, behavioural, or emotional condition [23]. In most European countries, more than 97% of health expenses are spent on treatment and only <3% are invested in disease prevention [24]. In 2009–10, in the EU15 morbidity in children was dominated by non-communicable chronic diseases, accounting for 79% of disability-adjusted life-years lost [25]. Prevention, early diagnosis and treatment of common non-communicable diseases in children has become a priority for the EU's public health policy of the Polish Presidency of the Council of the European Union (EU) [26]. The figure below gives a proportion of disability-adjusted life-years assigned to diseases in children aged 0–14 years in western Europe in the year 2004.

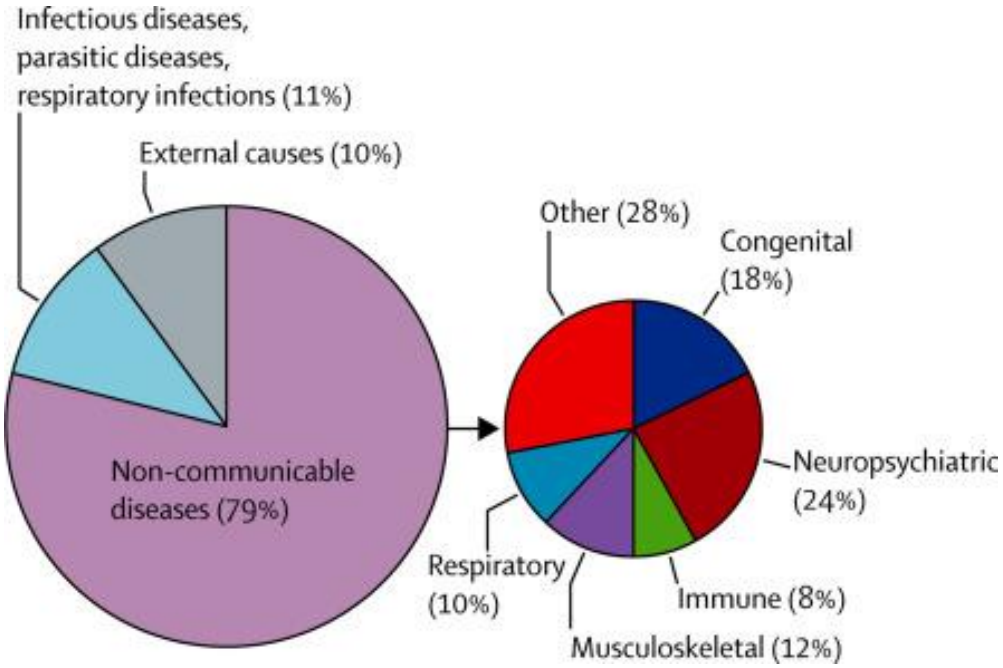

Figure 2 DALYs in children aged 0–14 years in western Europe, 2004 [14]

Preventing and curing infectious diseases has become easier while the paediatric sector has been dominated by non-communicable diseases. As a result of the variations in the diseases and social factors affecting the children of Europe, the health care needs change. However, the services in the health sector fail to deliver high-quality care as the changes have not been adapted well. European health systems need to develop better systems to meet children's current and evolving health needs for which there is a need to reconfigure the services across the interfaces between hospitals, primary care, and public health [25]. Below is the graph (Fig 3) showing trends in mortality in children aged 0–14 years in 11 European Union countries, from the year 1980–2010.

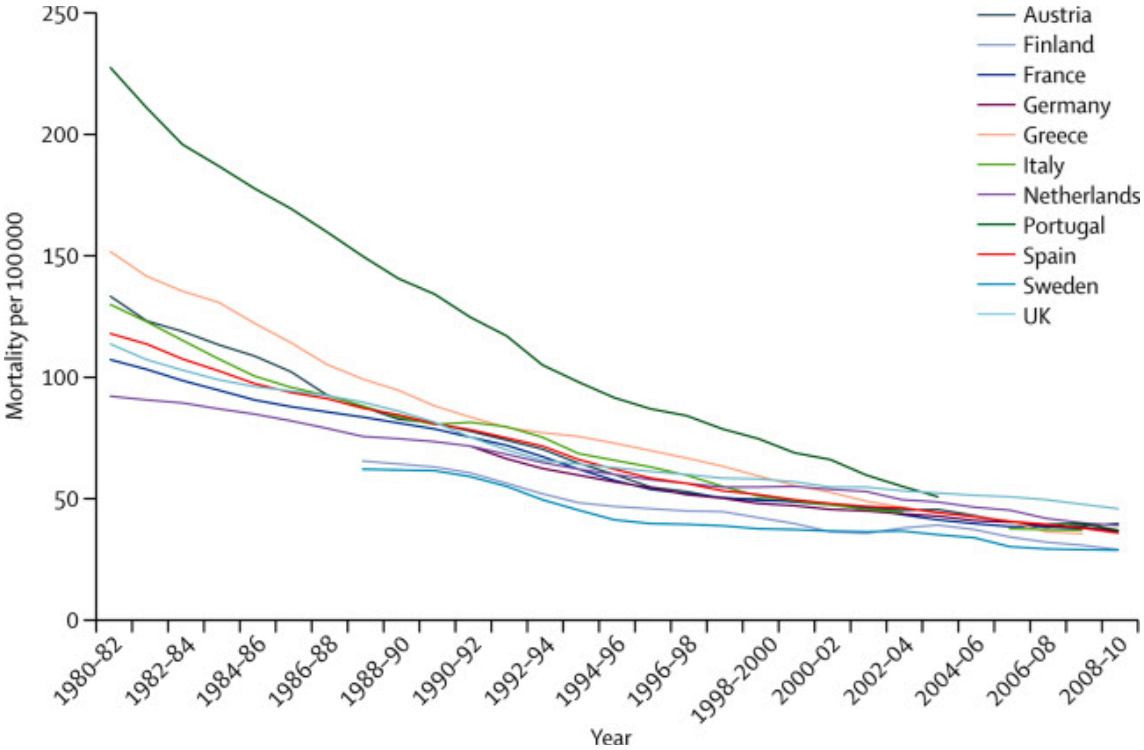

Figure 3 Trends in mortality in children aged 0–14 years in 11 European Union countries, 1980–2010 [25]

2.2.1 Needs of the Children with chronic conditions

Children with Special Health Care Needs (SHCN) require health care services more than other normal children do as they are at high risk for a chronic physical, developmental, behavioural or emotional condition [27]. These children have severe chronic conditions, require greater health resources and use substantial health services [28]. A study conducted by Farmer et al conducted [29] estimated about ninety-three per cent of mothers find the needs like information about services for their children and ways to promote their health and development insufficient. In addition, over half reported financial crisis and a need for some services for the support of caregivers [29].

2.2.2 Need for Self-management

Self-management support means a set of services for persons with chronic illness and their families that is a collaboration between the patient, family, and health care providers to facilitate self-management. It includes a set of common tasks like medication adherence, symptom or biometric monitoring, nutrition, physical activity, skill-building, the use of an action plan, sleep, and stress reduction aimed at the well-being of the individual with a chronic condition [30]. Promoting self-management in the care of paediatric chronic conditions is important because of the evidence proving that self-

management improves chronic illness outcomes [30]. Self-management in some chronic diseases such as Asthma has reduced health care expenditures and hospitalisations as well as visits to emergency departments [31].

2.3 Caretakers Stress

The birth of a child brings tremendous happiness to a family however, sometimes the joy can turn into feelings of distress if the child is associated with any disability due to chronic diseases. Parents of chronically ill children may experience higher stress levels and difficulties in accepting the health condition of their children. Not all parents are experienced and hence go through feelings of sadness and anger due to their inability of dealing with the diseases [10]. Parents of chronically ill children having long term illness experience extreme burden and physical and mental health morbidities [11]. Family or caregivers of people with ill children also experience poorer mental health because of continuous anxiety and severe depression. Often the mothers of those with congenital anomalies may have a greater risk of cardiovascular disease and mortality than parents of normal children [22]. Besides, the caring burden on parents of ill children, their financial and social challenges, physical and psychological morbidities adversely affecting them has well been established [11]. One of the studies has also reported depressive symptoms among caregivers with a chronic illness because of the increased burden [37]. Research on paediatric caregivers has reported that parents of chronically ill children experience the poorer health-related quality of life, worse sleep due to high levels of stress which might negatively affect the emotional health and development of children [38]. Parenting children with developmental disabilities is associated with the sense of devaluation and blame and also impaired physical functioning, tiredness or exhaustion in them [39]. One of the researchers examined the families of children with intellectual disability (ID) and reported families supporting a child with ID were significantly economically disadvantaged and the difficulties of their children resulted in a greater social and psychological impact on them. This has led to their unhealthy family functioning [40]. A study conducted by Farmer et al [29] has reported negative influence of the child's illness on family members' social interactions both within and outside of the family, and personal strain characterized by the subjective distress and psychological strain experienced by the parent as a result of caring for a child with a chronic illness [29]. Chronic illness and disability put a lot of pressure on the economic resources, social capital and personal

strength of the ill children and their families and may strain their resilience, economic resources, and social capital [30].

2.3.1 Digital interventions in health/chronic disease care

With the application of Information and Communication Technologies (ICTs) in the healthcare system, new integrated care services can be provided to patients with chronic conditions especially for providing care at distance [11]. Medical services have begun to shift from treatment to prevention and management of health. Remote medical treatment services have expanded as the interest of the individuals in their proper healthcare has increased. The need to monitor health daily has further led to the expansion of e-Health services [17]. E-health solutions have the potential to support patients and their caregivers by offering better quality services efficiently and effectively [11]. Self-service channels and digital health intervention could support patients in improving their health conditions and connect them or the caregivers to the medical staff for continuous assistance through smart devices [9]. E-Health tools can potentially be used for obtaining continuous health and social services by the patients to increase their safety and health quality. These tools could be used for looking into new opportunities for treatment and healthier lifestyles and overall for improvising the well-being of patients and their associated families [11]. Internet-based applications like chatbots are important for parents who need to obtain the maximum diagnostic information about the chronic diseases of their children. Mobile phones which are already being used to improve communication between patients and nurses to monitor health outcomes can also be of great use in the management of chronic diseases. These applications are also expected to increase over time for the management of various diseases like cancer, heart disease, asthma, and diabetes [6]. E-Health interventions make care delivery accessible and approachable. Web interventions aim to provide knowledge, self-efficacy, caregiving appraisal to the family carers however, their well-being has not been explored but these reduce health mortalities globally. There is good evidence suggesting that carers get benefitted from psychosocial interventions, delivered to individuals [11].

2.4 Case of Estonia

This section gives a brief overview of Estonian healthcare system.

2.4.1 Statistics on children in Estonia

As the methodology for compiling the statistics published by the Health Board is not public, it was not possible to assess the current statistics on chronic diseases. However, from the work of Mariane Koplimaa, the number of disabled citizens in 2012 was 130 000 which account for about 10% of the population. These people were mostly old and retired, 59% of all are more than 63 years old, 35% are of working age. The number of disabled children aged 0 to 17 was around 8000 (6%) and 1600 (6%) in Estonia and Tallinn respectively [32].

Table 1 presents the number of persons who received services with the corresponding basic diagnosis and the amount paid by the EHIF between the year 2015-2019 [33].

Table 1 Funds released for different diseases associated with children [33].

	2015		2016		2017		2018		2019	
	Amount	Persons	Amount	Persons	Amount	Persons	Amount	Persons	Amount	Persons
J00-J99 Respiratory diseases	2716475	327944	3030932	328738	3385194	327756	3778149	336296	3821058	310045
O00-O99 Pregnancy, childbirth and the postpartum period	5482	1380	6951	1465	8755	1493	9871	1596	11206	1649
P00-P96 Certain conditions occur during perinatal birth	2591	697	3360	728	3800	714	4238	752	5219	771
Q00-Q99 Congenital malformations, deformities and chromosomal abnormalities	27780	4192	32736	4370	38470	4362	44774	4332	48056	4352

The table above shows the funds spent on the various diseases between 2015-2019 in Estonia.

A study conducted by Sirli Tamm analysed the medical bills submitted to the Estonian Health Insurance Fund (EHIF) by family doctors, specialists and dentists for all children born in 2010 in the period 2010–2017. The study showed the cases of treatment involving family medical care accounted for 63% of cases of treatment involving children of preschool age having 61 % cases of skin diseases. Another major cause was respiratory disease (J00- J99) with the highest cases involving children aged 2 and 3 years. Specialists dealt with 23 percent of respiratory disease-related treatment cases throughout children's

pre-school life. Out of these, 28% were associated with chronic diseases of oral and neoplasm, 13% with inflammation of the nose, 12% with asthma, 10% with bronchitis and 9% with multiple and unspecified local infections of the upper respiratory tract.

Conditions occurring during the birth period (P00-P96; i.e. neonatal age-specific diseases and conditions that mostly cover all groups in this period) occurred in about four children, with congenital problems (Q00-Q99) occurring in about 18% of children. His study excluded the group (O00-O99) but it is clear that the group includes children. Table 2 shows maximum treatment cases of the children between the year 2010-2017.

Table 2 maximum treatment cases per children in Estonia [34].

Disease code	Number of children	Proportion of children born in 2010 (n = 15825)	Proportion of children in the dataset (n = 16417)	Maximum treatment cases per child
J00-J99 (Respiratory diseases)	15694	99.2%	95.6%	92
P00-P96 (Certain conditions occur during perinatal birth)	3956	25%	24.1%	20
Q00-Q99 (Congenital malformations, deformities and chromosomal abnormalities)	2936	18.6%	17.9%	90

The table above is a part of Sirli's work [34].where she had analysed the medical bills submitted to EHIF associated with children's disease. It is understood that in children with serious and acute chronic health problems health checks are important. However, preventive measures can help overcome difficult situations. The most important and major challenge of modern primary health care is prevention and counselling among parents, which would help children from an early age to intervene in the development of chronic diseases that have arisen from unhealthy social and physical environments and unhealthy lifestyle choices. Effective prevention and parental care can also help to reduce children's mental health problems.

This work also showed that not all vaccinations were provided to the children as per the immunisation plan. Only 40% of children under 7 years of age were able to safely claim that they were given all the vaccines provided for in the immunisation plan [34].

2.4.2 Burden on the health care professionals

The management of chronic diseases has increased the burden of healthcare professionals. The self-reports by the Family Doctors (FDs) suggest that patients with chronic conditions like heart problems, diabetes, and obesity seek their advice more often than patients with depression [35]

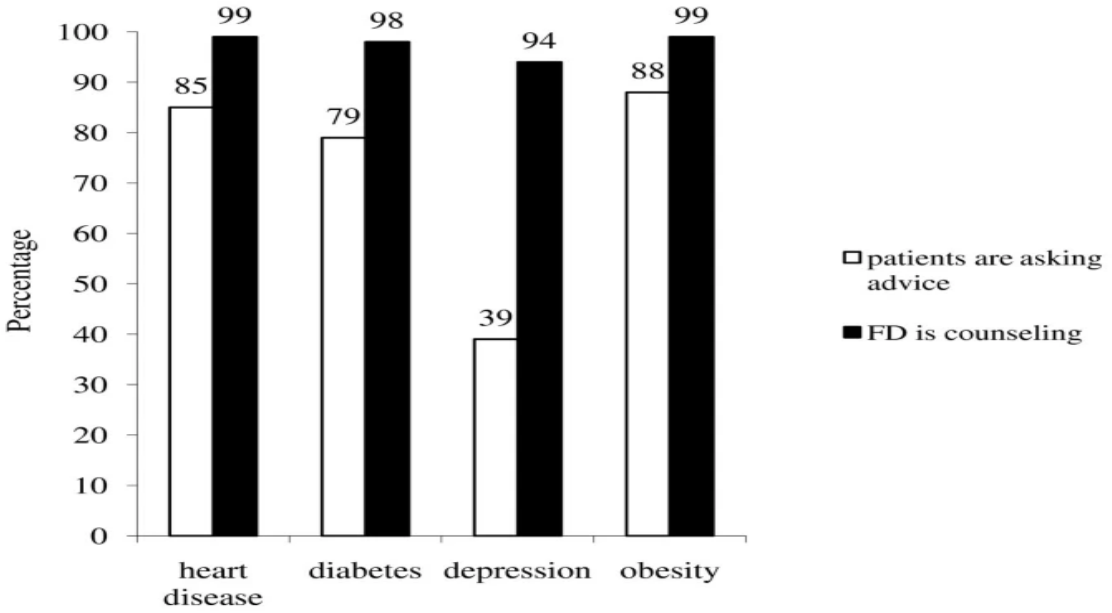

Figure 4 shows how frequently patients with chronic diseases visit and seek advice from FD [35].

2.4.3 Insufficient number of healthcare professionals

The number of doctors and nurses in Estonia is lower than the EU average. There are 3.5 per 1000 doctors and 6.2 per 1000 nurses in the population. The ratio of nurses to doctors is 1.8 which is also below the EU average (2.3). The low number of nurses is exacerbated by the low number of other skilled health professionals, including nutritionists and physiotherapists, thereby reducing the options for task shifting [36].

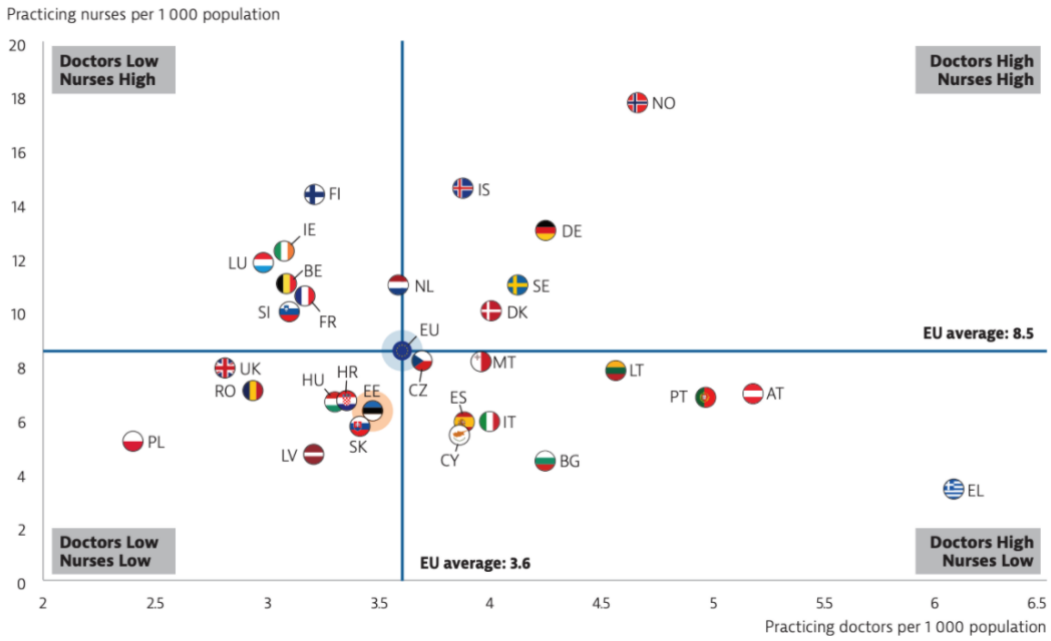

Figure 5 shows the number of doctors and nurses in Estonia is below EU averages [36].

2.4.4 Accessibility

The health system in Estonia is unable to solve the problem of long waiting lists due to which the country has the highest level of unmet needs in the EU. The waiting times for different types of care, including acute primary care, non-acute primary care, specialised outpatient care, day surgery and inpatient care is set by EHIF [36].

For chronic diseases like asthma and chronic obstructive pulmonary disease (COPD) avoidable hospital admissions in Estonia are lowest among other member states of Europe, however, an assessment done by the government indicated that nearly half (49 %) of patients could have received care from their FDs instead of seeking emergency care [36].

2.4.5 Key findings

- Need of Technology adoption and investments in the health sector especially in primary health care.
- Importance of implementation of e-health interventions to reduce the burden on health care professionals.
- Need to put further efforts to prevent hospital admissions and to increase the coordination of care.

2.5 Chatbot as a framework for self-management

While identifying frameworks that might be used to address these challenges in self-management in paediatrics, having a chatbot could potentially help parents in organizing and managing conditions in their children with complex chronic conditions. Chatbots could diagnose or identify chronic condition, look into needs, distinguish severe or manageable conditions and offer health care.

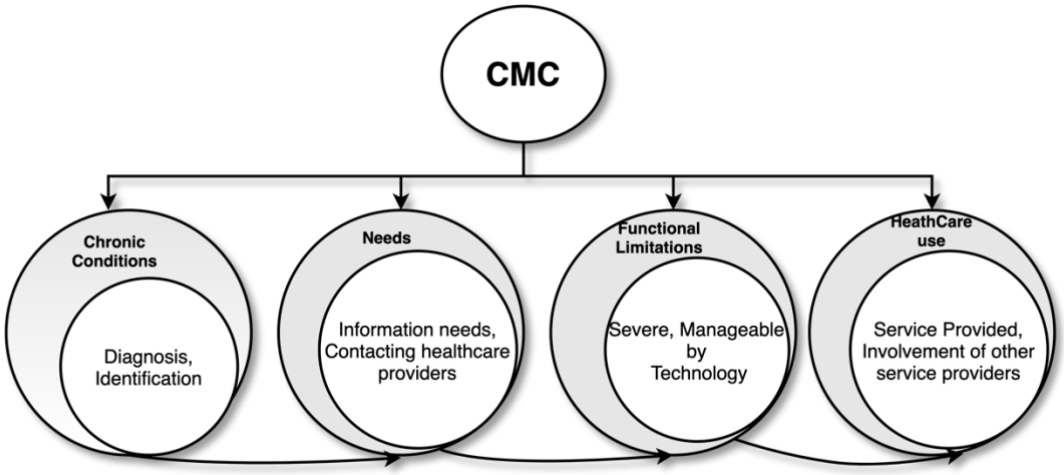

Figure 6 Modified Definitional framework for children with medical complexity (CMC) among other definitions of chronic conditions of childhood [41]

Chronic conditions: sufficient knowledge, understanding, and decision-making support from the chatbot by two-way communication.

Needs: Chatbot could act as a family-centred system of care that provides accessible health care services as well as information to families in self-management.

Functional limitations: ensuring the availability of supports for the family by providing information anywhere 24/7.

Health care use: a care-delivery system that prioritizes high-quality and efficient care through Artificial Intelligence (AI tools) [41]

2.6 The chatbot space

The proposed work is different from the earlier work in the sense that the target audience is the parents/caregivers of chronically ill children rather than the patients themselves or the clinicians. The interest in this study began from observing the stress felt while handling a child with a chronic disease in the parenting population.

Chatbots can provide help in decision making to the parents of chronically ill children by giving chat-based feedback through tracking different activities [42] of their children like heart rhythm, blood pressure, body temperature, facial expressions. Chatbots can assist the parents by counselling about healthy eating behaviour [14] [43] by promoting healthy habits and physical exercises along with delivering positive psychology and mental well-being techniques [44]. Chatbots can also make the parents aware of depression episodes in some diseases and improve their adherence to therapy treatment [45] or help in the diagnosis of rare diseases [46]. Proposing a health care environment based on chatbot would make treatment fast as AI systems can predict emergencies especially for patients with chronic diseases. A chatbot could propose ways for the improvement of patients' conditions by identifying them properly through conversation [17].

2.7 Kratt AI

Estonia has a strong base in Information Technology, is one of the most digitally advanced countries in the world and is considered a pioneer in e-governance. The government is planning to build implement AI in various fields in both the private and public sector to advance the take-up of AI. According to the current strategy of Estonia, the government will invest at least 10 million Euros in 2019-2021 for the implementation of AI strategy in its different directions [47]. Estonian experts assessed how the private and public sectors could engage more with AI in the 2019 Kratt report [48]. The word “Kratt” comes from Estonian mythology that the government of Estonia uses as a synonym for narrow AI applications. The general aim of Kratt AI is to have around 50 use-cases of AI in the public sector by the year 2020, some of which already exists [49]. Ott Velsberg, Government Chief Data Officer of Estonia is on a mission to bring AI into every public service of the country, from healthcare to education and job centres. While explaining about the implementation of AI in various fields, he suggested that AI would solve more complex problems, such as making an appointment with the doctors automated. The Estonian government is seeking help from the private sector to develop a solution for doctors to make appointments for check-ups with the patients automated that would require scanning of healthcare records. For example, some patients with disabilities or suffering from heart diseases may need to visit the doctor much more frequently, almost every month, while others having diabetes and no other problems need to visit after every six months. The solution utilising AI tool would help doctors to

manage their patient lists and time more effectively [50]. Consequently, the government of Estonia could develop a *Lapsevanemad* chatbot for parents of chronically ill children as an initiative in the healthcare services under Kratt AI.

2.8 Theoretical background

With the exponential increase in technology, health care has also revolutionized. One of the techniques that may be useful is the use of novel chatbots that would act as an interface between the caretakers, health service providers, and the other stakeholders.

A precisely defined technology adoption model will help us to understand how much the chatbot will be useful to the stakeholders. The main component of the technology adoption model is to find whether the users think the application will be useful or not. This can be analysed by having thorough interactive sessions with the parents, caretakers, and doctors involved.

2.8.1 Technology adoption

How fast users accept a Technology depends on various factors like its needs, convenience, and availability to use. To understand it better, we need to know the different types of adoption or acceptance models that have been developed.

2.8.2 Diffusion of Innovation (DOI) Theory

To adopt new technology in any field is challenging. Diffusion of Innovation (DOI) Theory is also an important adoption model used in the research of Information Systems (IS). DOI is mainly based on technological characteristics and users' perceptions of the innovation. According to DOI the adoption of innovation depends on five key factors, relative advantage, compatibility, complexity, trialability, and observability.

1. Relative advantage: this is perceived as productivity or efficiency of the technology adopted.

2. Compatibility: it is perceived as the needs of the potential users

3. Complexity: it is perceived as the ease to use innovation.

4. Trialability: it is perceived as the quick adoption of the innovation which depends on the count of its use.

5. Observability: perceived as the performance and productivity of the adopted technology [51].

2.8.3 Uses and Gratification (U&G) Theory

Uses and Gratification theory explains how and why people adopt certain technology to fulfil their specific needs. It assumes that the activeness of using a medium by the user depends on whether it suits his purpose or not. Precisely, uses and gratifications refer to the motivation and satisfaction obtained by using a particular medium. Chatbots, being a new technology could fit the purpose of the users with different needs than the rest of the population [52]. This theory has been applied in traditional media research such as television, internet research etc by scholars. With advancements in new technologies, scholars extended this theory in the context of podcasts, Facebook and other social websites on mobile devices [53]. The focus of U&G theory is on active users for explaining and understanding the choice of media use for their satisfaction.

There are two key dimensions of gratification i.e., utilitarian and hedonic factors.

Utilitarian is related to the practicability and usability of the media use.

Hedonic is related to the experience of media use [54].

Taking the U & G theory framework for the use of chatbots, the efficiency of chatbot to assist can be an important reason for its usage. The efficiency of the chatbot is closely related to its convenience in use. Thus, it can be assumed that people would use a chatbot for healthcare because they will be gratified by having queries answered promptly.

2.8.4 Technology Acceptance Model (TAM)

Technology Acceptance Model (TAM) was developed by Fred Davis in 1989 [55]. According to the TAM, two key factors that influence users' decisions about how and when they use it are.

a. **Perceived usefulness (PU)** – a degree to which the user thinks that the technology will enhance their performance.

b. **Perceived ease-of-use (PEU)** – the degree to which the user believes that using a particular technology will be easy to use.

The core concept of TAM is that users will use the system (AU) if they show Behavioural Intent (BI) to use the proposed system. BI will depend on the perceived usefulness (PU) of the system and the perceived ease of use (PEU). Out of the two factors, perceived use has more influence on behaviour intent than perceived ease of use which means that if the user finds the technology useful then they are more inclined to use it even if they have to make some extra effort to use it [55].

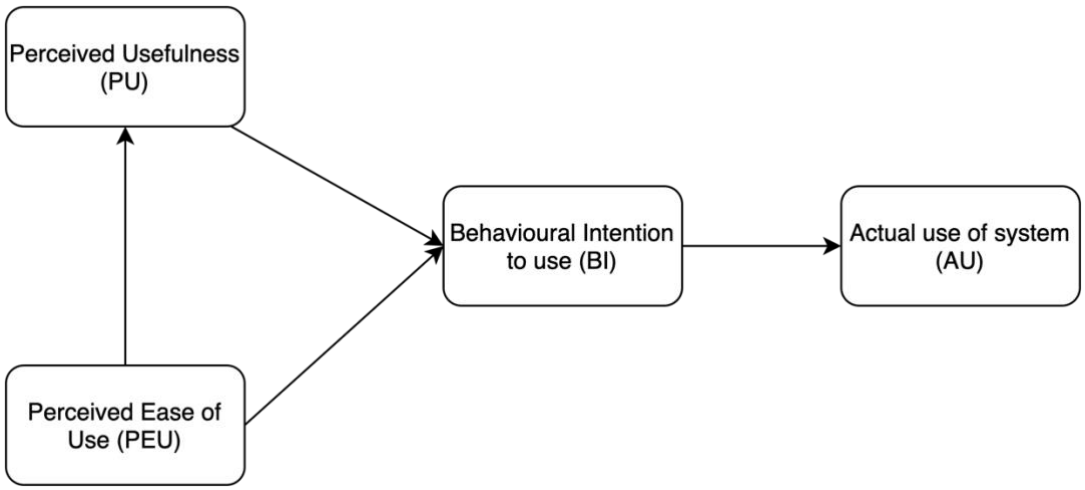

Figure 7 TAM framework elements

Over time, there have been many extensions to TAM e.g. TAM2, TAM3 which took into consideration individual differences, system characteristics, etc which are the determinants of the perceived usefulness and perceived ease of use and as such the concept remains still the same [56] [57]. TAM has been mostly used for quantitative research with a large number of users and by conducting surveys and using the Likert Scale however it can also be used for qualitative research [58].

TAM is the main theoretical framework for this research as it helped us to understand which components need to be included while designing the prototype of the chatbot. The extent to which the chatbot would be useful and easy to use will determine whether the end-users i.e., the caretakers of the children will use the chatbot or not. Translating this model to chatbots, we assume that the perceived ease-of-use and usefulness of the technology within its application area can predict its acceptance and adoption.

The operational definitions of each variable in the study framework are as follows:

1. Perceived usefulness – caretakers believe that the chatbot will provide instant answers to their queries and therefore reduce their stress.
2. Perceived ease of use - caretakers believe that they can easily use chatbots for immediate queries.
3. Behaviour intent - caretakers are willing to use and promote chatbots for the management of a chronic disease.

We can formulate the following hypotheses based on TAM
H1: Perceived usefulness increases Behavioural intent.
H2: Perceived ease of use increases Behavioural Intent.
H3: Behavioural intention increases Actual use.

2.8.4.1 Implementation of TAM

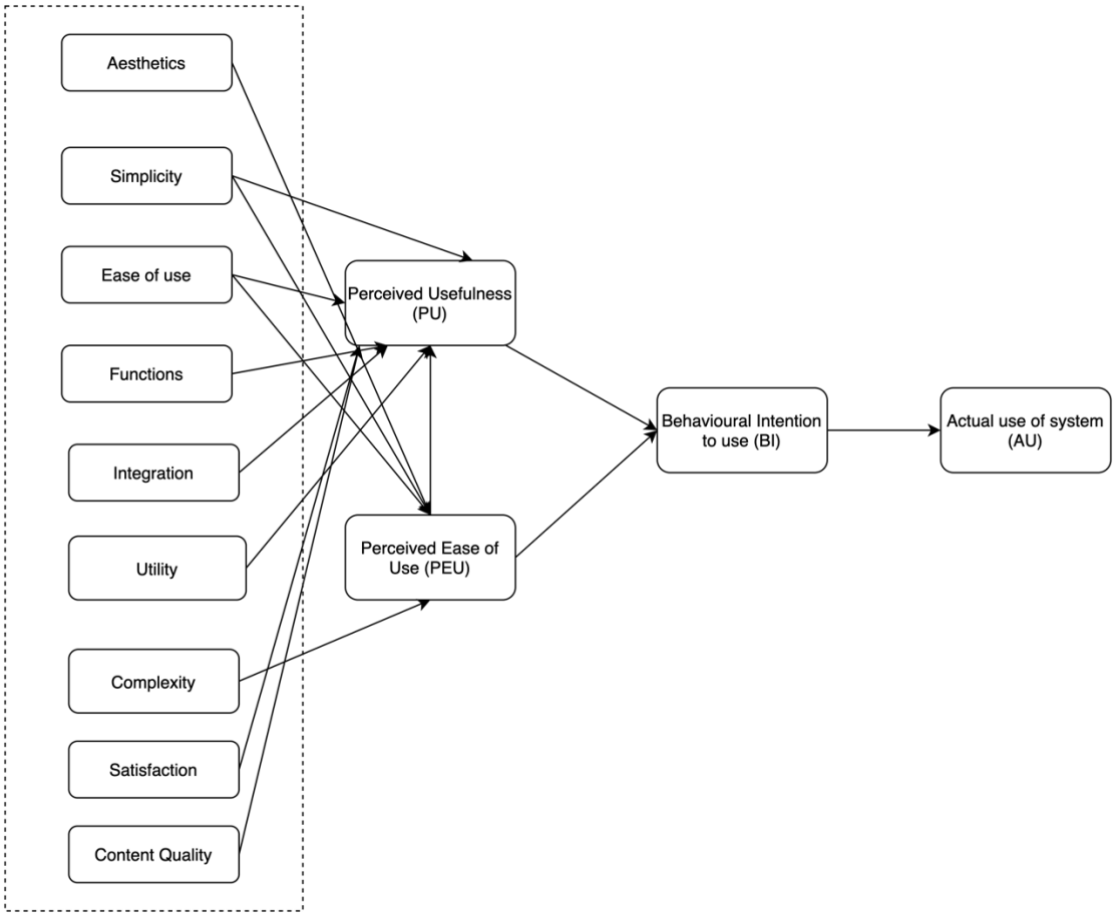

Figure 8 TAM3 for this research [57].

As discussed above, the core concept of TAM is that users will use the system (AU) if they show Behavioural Intent (BI) to use the proposed system. BI will depend on the perceived usefulness (PU) of the system and the perceived ease of use (PEU). The extensions to TAM e.g., TAM2, TAM3 took into consideration individual differences, system characteristics, etc which are the determinants of the perceived usefulness and perceived ease of use.

Table 3 show the adopted determinants of PU and PEU and propositions against each criterion.

Table 3 The determinants of PU and PEU

Constructs	**Propositions**
Aesthetics	P1: Visual Design (VD) has a direct positive influence on users PEU of Chatbot.
Simplicity	P2: Simplicity has a direct positive influence on users PEU of Chatbot. P3: Simplicity has a direct positive influence on users PU of Chatbot.
Ease of use	P4: Systems which are easy to use has a direct positive influence on users PEU of Chatbot. P5: Systems which are easy to use has a direct positive influence on users PU of Chatbot.
Functions	P6: More the functions of the system, the more is its positive influence on PU.
Integration	P7: the integrity in the functions of the application has a direct positive influence on PU.
Utility	P8: The more information about the services in the application, the more positive influence on PU. P9: more the utility of the system, more is its positive influence on PU
Complexity	P10: the less complex the system is, the more is PEU.
Satisfaction	P11: the satisfaction of the users with the functions of the application, the direct positive influence on PU.
Content Quality (Functional Requirements)	P12: The quality of the content has a direct positive influence on PU.

Based on the proposition discussed in above table, we can formulate the following hypotheses based on TAM:

H4: Perceived usefulness has a direct positive impact on BI for chatbot.

H5: Perceived ease of use has a direct positive impact on BI for chatbot.

H6: Behavioural intention increases Actual use of chatbot.

3 Research methodology

This section presents research questions and the objectives in section 3.1. In section 3.2 methodology for conducting research is discussed.

3.1 Design Science Research Methodology (DSRM)

This thesis uses Design Science Research (DSR) methodology which is an outcome based research methodology for solving problems in Information Systems [59].

DSR must produce a design artifact. A design artifact can be in the form of a construct, a mode, method or an instantiation [59].

Table 4 Types of design artifacts

Type of design artifact	**Description**
Constructs	Symbols and vocabulary
Methods	Algorithms and practices
Models	Abstractions and representations
Instantiations	Prototypes and implemented systems

Hanver et al (2004) gave seven guidelines that should help in building and evaluation process of DSR (see table).

Table 5 Guidelines for DSR [59]

Guideline	**Description**
Guideline 1: Design as an artifact	DSR must produce a viable artifact in the form of a construct, a mode, a method, or an instantiation.
Guideline 2: Problem Relevance	The objective of DSR is to develop technology-based solutions to important and relevant business problems.
Guideline 3: Design Evaluation	The utility, quality, and efficacy of a design artifact must be rigorously demonstrated via well-executed evaluation methods.

Guideline 4: Research Contributions	Effective DSR must provide clear and verifiable contributions in the areas of the design artifact, design foundations, and/or design methodologies.
Guideline 5: Research Rigor	DSR relies upon the application of rigorous methods in both the construction and evaluation of the design artifact.
Guideline 6: Design as a Search Process	The search for an effective artifact requires utilizing available means to reach desired ends while satisfying laws in the problem environment.
Guideline 7: Communication of Research	DSR must be presented effectively both to technology-oriented as well as management-oriented audiences.

3.2 Design science process elements

In this section the design science process elements (Table 6) related to this research are explained. The research was carried out in three steps: Problem identification, Solution design and Evaluation [60].

Table 6 DS Process Elements from IS for a DSRM

	Design process elements	**Process**
Problem identification	1. Identification of the problem 2. Objectives of a Solution	• Identify problem • Literature research • Designed first prototype • Expert interviews
Solution design	1. Design & Development	• Analysed the interview results • Designed a System Architecture • Redesigned the prototype of the system
Evaluation	1. Demonstration 2. Evaluation	• Expert survey • Analysed the feedback & Evaluated the System

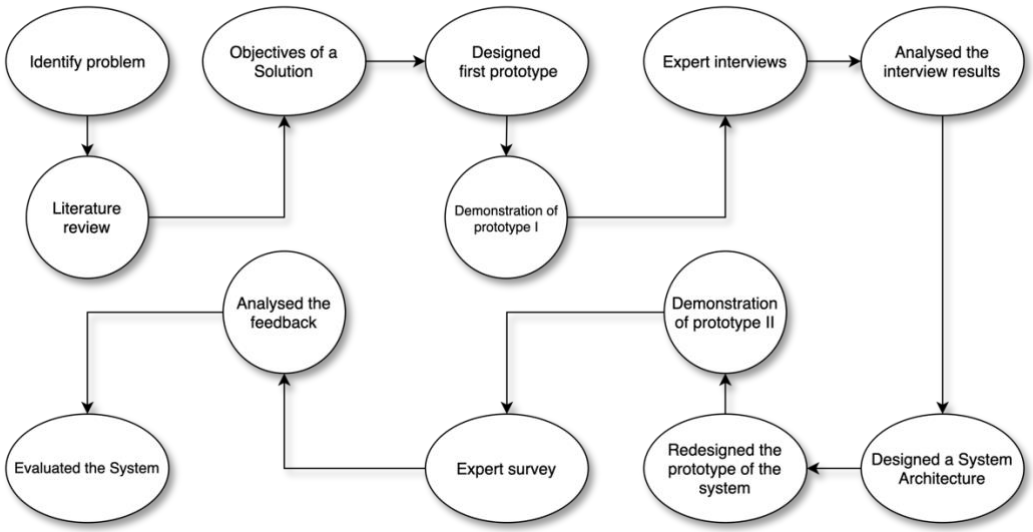

Figure 9 Flowchart of process of research based on DSRM

3.2.1 Problem identification

Children with chronic diseases have conditions that are kept under control by their medications, but their better health is likely to be dependent upon access to medical care and appropriate medication. Appropriate medical care and medication on time would avoid developing more complex needs and poorer health status [61]. For that the ability to access information frequently and quickly by AI tools would provide answers to a broad domain of queries beyond human ability to do so and thus could target and improve health conditions of children with complex health care needs [60].

3.2.2 Defining the objective of the solution

A chatbot could be the best solution because it can handle simple questions and frequently asked questions (FAQs). It has the ability to provide practically instant and up-to-date answers to almost every question a user could ask and could engage a huge number of users simultaneously by providing two-way communication [60].

3.2.3 Design and development phase I and II

The main idea of prototyping is to create something that resembles the final product. It is used to demonstrate a real image of the system and evaluate patterns and style guides [62]. After understanding the need of developing a chatbot for parents assisting them in managing the condition of their chronically ill children, a preliminary literature review was conducted. From literature, looking into similar work, the basic problems associated

with the chronic diseases, needs of the parents were understood and the initial prototype of the chatbot containing the basic functionalities was designed.

The initial prototype designed was presented before the interviewees to make the purpose of chatbot clear. The interview was conducted with the doctors and the parents of the chronically ill children. During the interview a certain number of questions were asked to the doctors and some other to the parents. The questions asked to the doctors were different from those asked to the parents except for one or two questions in common. Most of the interviews were conducted online, one face to face, one by phone and one via email. The interviews were transcribed to obtain the requirements effectively.

For designing the architecture and prototype of the chatbot interviews were conducted interviews with the doctors and the parents of chronically ill children. All the information gathered was used to understand the functional and non-functional requirements of the chatbot.

3.2.3.1 Interview methodology

A semi-structured interview was conducted to reflect the feelings and viewpoints of the stakeholders. The idea of presenting the initial prototype during the interviews was to get feedback on the ideas of the interviewer towards the solution of the problem and to get recommendations from the interviews. The interview questions were structured to get answers to all the research questions discussed in section 1.2 and to get all the functionalities for designing the chatbot. In semi-structured interviews, two-way communication takes place allowing for a discussion with the interviewee rather than a straightforward question to discuss different angles of the topic.

3.2.3.2 Tools used during designing

For designing the prototype of the chatbot a software Figma was used. Figma [63] is a designing tool with several interface controls connecting where users or designers get a realistic view of the application designed by immediately testing it.

3.2.4 Demonstration

The initial prototype and the final prototype both were demonstrated before the interviewees after designed in phase I and II. After the first phase of designing the link to the clickable prototype was provided to the interviewees to see the functionalities of the

chatbot. During the evaluation process, a link to the final prototype in Figma and a link to the YouTube video of the chatbot was given on the expert survey response sheet.

3.2.5 Evaluation

For evaluating the designed product, a survey on the designed prototype was conducted. The link to the final prototype was attached to the survey feedback form to the interviewees and evaluated based on the comments obtained by the interviewed doctors and parents.

3.2.5.1 Validity procedure

For carrying out the validation of the proposed solution in the form of a designed prototype of the chatbot, design science validation methods were used. Design science validities are applicable to research which involve either designing or implementing or evaluating of artifacts. Design science validities are defined as formalized procedures that justify arguments and conclusions of a research study involving the design, development to solve identified problems [64].

For validation of the prototype two validity groups were chosen:

1. Internal design validities: It is defined as the extent to which the internal components of an IT artifact are consistent, transparent, and explainable.

2. Requirement's validities: It is defined as the extent to which a particular IT artifact satisfies physical or functional needs.

Internal design validities:	The interviewees were asked to fill in the feedback form with questions on the user experience using the Likert scale. They were asked to add additional comments against each question asked to evaluate the criteria presented in Table 7 under UI

Requirement's validities:	The interviewees were asked to fill in the feedback form with questions on the functionalities of the chatbot using the Likert scale. They were asked to mark the level of need for features on the prototype and to add additional comments against each question to evaluate the criteria presented in Table 7 under functional requirements

3.2.5.2 Evaluation criteria

For evaluating the prototype of the chatbot, interviewees were asked about two properties user interface and functional requirements. These properties were evaluated by some criteria to capture the utility of the proposed solution using a 1-5 Likert scale, with one being strongly disagreed and five being strongly agreed.

Table 7 Evaluation Criteria, Likert scale

Property	Criteria	Distribution				
		1	2	3	4	5
User-interface (UI)	1. Aesthetics					
	2. Simplicity					
	3. Ease of use					
	4. Functions					
	5. Integration					
	6. Complexity of system					
	7. Utility					
	8. Satisfaction					
Functional Requirements	1. Answer to general queries					
	2. Redirecting to emergencies					
	3. Redirecting to medical specialists					
	4. Reminders					
	5. Parent to parent conversation					
	6. Information about governmental services					
	7. Information about other services					

1 strongly disagree 2 disagree 3 neutral 4 agree 5 strongly agree

4 Design and analysis

This section aims to answer RQ2: What would be the minimum functionalities of the chatbot?

The minimum features of the chatbot were obtained from the knowledge obtained from literature review as explained in the sections 2.2.2, 2.5 and 2.6. Table 8 lists the minimum functional requirements for the chatbot.

Table 8 Minimum requirements of the chatbot

Requirement	**Description**
As a parent, I can log in to the chatbot application	As medical data is private and sensitive only authorized users should be able to log in
As a parent, I should be able to get basic advice from the chatbot	Here basic advice would include information about the illness, queries about diet, growth (weight check) etc
As a parent, I should be able to get notifications about my child medication	Notifications and reminders about medications, exercise etc should be included

4.1 First phase of designing

In the first phase of designing, a prototype of the chatbot was designed from understanding the basic needs of the parents having children with chronic diseases. The prototype was designed in the Figma software and the prototype is presented below.

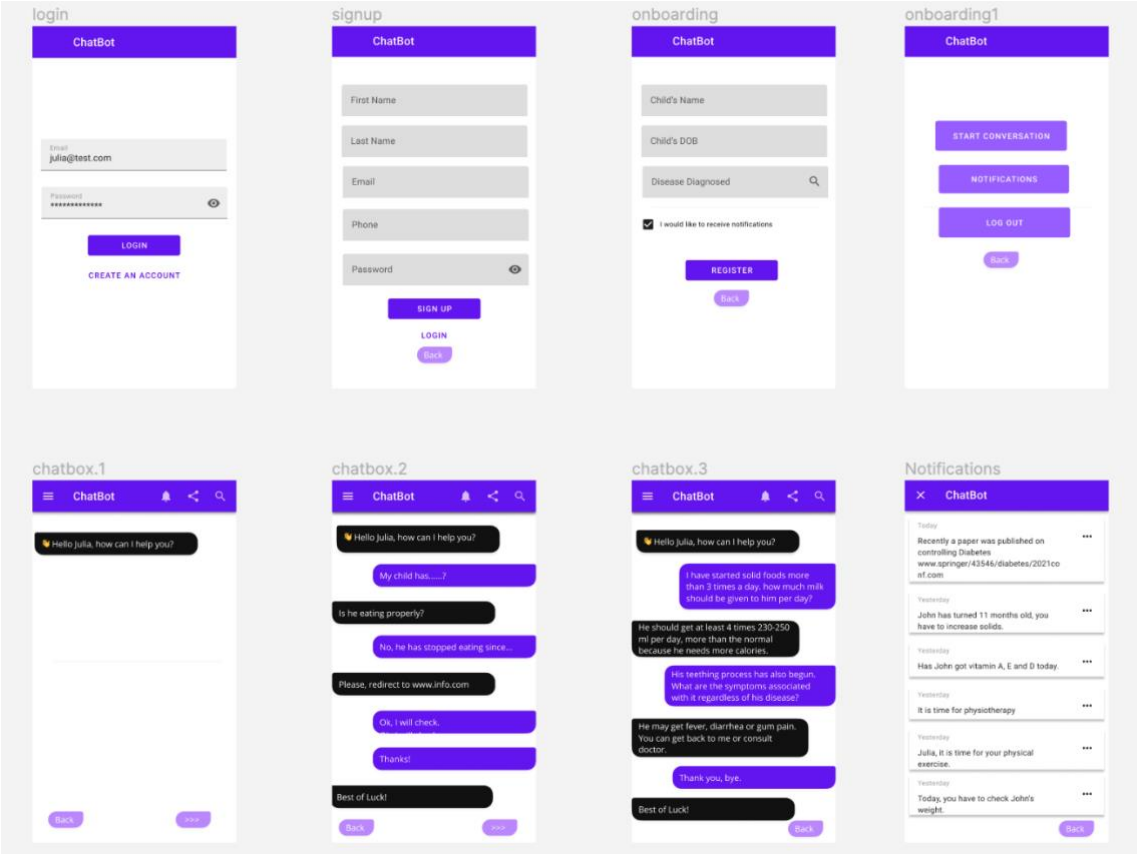

Figure 10 Initial Prototype designed

Table 9 shows screens 1-8 of the initial prototype

Screen	**Screen Title**	**Purpose**
Screen 1	Login	New users can sign up by creating account via email
Screen 2	Sign up	On this screen, the user must fill in personal details for signing up
Screen 3	Onboarding	The screen has fields to fill the information related to the child
Screen 4	Onboarding1	This screen enables the user to start a conversation with the bot, look for notifications or log out from the system
Screen 5,6,7	Conversation	These screens show the samples of conversation between the user and the bot
Screen 8	Notifications	The screen shows the reminders provided by the bot in the form of notifications

But to get a clear picture of the required additional functionalities of the chatbot the author conducted interviews with few doctors and some parents of children with chronic diseases.

The interviews were conducted online via MS Teams. The already designed prototype was presented before the interviewees to get some feedback and additional necessary information to design the other functionalities of the chatbot. The system architecture of the chatbot was then developed. After redesigning the chatbot, the modified prototype was again presented before interviewees and evaluated from the comments and feedback obtained from them.

4.2 Interview results

This chapter presents the analysis of the interview results which will give a broader overview of the problems faced by the parents of chronically ill children and their needs to manage their children easily without being stressed. The objective of the chapter is also to answer RQ1: "What are the existing services available for parents having children with chronic diseases and problems with those systems"?

4.2.1 Interview introduction

Interviews were conducted during the month of March and April 2021, to get some feedback on the previous prototype designed and to get the required functionalities for improving the design by adding the additional functionalities discussed during the interviews. During the interviews, many questions were asked to the parents for their needs and opinion about the chatbot, functions that a chatbot could have to help them manage their children without getting stressed, the information that the parents need daily. From the doctors, some other aspects were discussed to know the needs from their side, their experience of dealing with chronically ill children and their parents. In total, eight people, four doctors/experts, one nurse and three parents of chronically ill children were interviewed. The author has amended the transcripts collected from the interviews to be grammatically correct and to summarise what was discussed during the interviews without damaging the integrity of the interviewee's statement. The questions asked to the interviewees are presented in appendices of this thesis.

4.2.2 Description of the interviewees

This section gives a description of the participants in the interview. The aim was to include parents of chronically ill children where main information was gathered as they represent main stakeholders as users for the chatbot. Besides, the doctors who deal with chronically ill children explained quite a lot of things from their side. The list of interviewees in more detail can be viewed in Table 10 below:

Table 10 List of Interviewees

Interviewee	**Type**	**Job Title**	**Time and Duration of the interview**
Interviewee A	HP	Paediatrician, department of Allergy, Tallinn Children's Hospital	26.03.2021, 30 mins
Interviewee B	P	Parent of a chronically ill child	30.03.2021, 23 mins 48 secs
Interviewee C	P	Parent of a chronically ill child	31.03.2021, 53 mins 55 secs
Interviewee D	HP	Family doctor	01.04.2021, 31 mins, 45 secs
Interviewee E	P	Parent of a chronically ill child	07.04.2021, 24 mins 58 secs
Interviewee F	HP	Family doctor	09.04.2021, 40 mins 26 secs
Interviewee G	HP	Family doctor	13.04.2021, 33 mins 48 secs
Interviewee H	HP	Nurse of the Allergology-Pulmonology, Tallinn Children's Hospital	16.04.2021, contacted via email
*HP – Health Professional *P – Parent of chronic child			

Table 11 Current situation and challenges faced by the parents

Code	***Description by Interviewees***
Common problems in chronic diseases	1. Patients have allergic diseases, asthma, allergic rhinitis, some skin allergies, food allergies, etc. (Interviewee A) 2. The children who suffer from chronic illnesses are quite varied starting from type one diabetes (Interviewee F) 3. The objective findings are different like new rashes, or new breathing problems (Interviewee G)
Observation needed	1. The treatment depends on the type of disease a child has, for asthma, we check the lung function and with skin problems, we check the skin and do allergy tests (Interviewee A)

	2. In our listing, the children who suffer from chronic illnesses are quite varied and need different monitoring. Children with diabetes need daily monitoring by the parents for which they usually do blood sugar tests every day, actually many times per day to understand to amount of insulin and medication needed after every meal (Interviewee F) 3. The patients need continuous monitoring of treatment regimens and following the physiotherapy procedures/exercises (inhalations, Creon treatment, gymnastics). (Interviewee H)
Reaching out to doctors/experts	1. Email reply by doctors take time sometimes for example when it is Friday then it takes 2-3 days (Interviewee E) 2. I prefer writing an email to the doctors as calling is more difficult because they're not in the office all the time. So, writing an email is one good way of getting quite a fast reply (Interviewee C) 3. We do have a policy that all letters have to be answered within five working days. A question that doesn't need acute answering or that doesn't need immediate attention is more likely to be shifted to be answered for the next day, because we do a triage from all the letters as well so things that are more imminent and need quicker answers will be answered first (Interviewee F)
Psychological Stress	1. I do believe and know that parents experience mental pressure, but as a nurse I can't directly deal with those kind of problems (Interviewee H) 2. It took us three months to get the exact diagnosis while doctors and we were wondering what is wrong with my child (Interviewee B) 3. My son had multiple diagnoses, one of which was identified after six months, one after one year and one when he was already two years old. It is not ok; it is so stressful (Interviewee E) 4. The condition of my child does disturb me and my husband got depression two years ago when he started to think about the child's condition (Interviewee C)
Lack of Psychologists	1. The parents are provided with psychologists when they spend a lot of time in the hospital with their children but not if the children go only to see a paediatrician because unfortunately there are not many psychologists (Interviewee G)

	2. It's quite a big problem in Estonia, that we don't have so many psychologists that we meet our needs. There are countries where psychologists are part of the department of chronic diseases but in our hospital, they are so busy with children who have some mental problems that they just don't have the resources to deal with parents who need psychological help (Interviewee A) 3. Parents need psychological support and in the GP's office we can organize sometimes, but it's not always possible, so I feel that is one part that is left unchecked quite often (Interviewee F) 4. Unfortunately, our health care system offers them very little. There should be either psychologist visits or psychiatrist appointments offered to them (Interviewee H)
Importance of Psychologists	1. I do personally feel that many parents would benefit from psychological support as well. The illness of the child leads to anxiety which could be just a manifestation of the depression problem and we do see that often that's why I do feel that there should be some psychological counselling before it happens and before these things tend to escalate (Interviewee F) 2. Very often, parents just need somebody to listen to them and their problems, to see that someone cares for them and that they are not alone in their journey. This is very important like for mental health they need a nurse who can do counselling. A family doctor doesn't have the time to go deep into the problems of the parents (Interviewee G)
	1. I don't know if the chatbot can give me advice, especially when I have so specific disease for my child, because when a child throws up for example five times a day so if it would have been useful to know it as this was normal in her condition, but for a child who is not sick this can be a big problem, then it is really tricky to get information for this kind of medical advice from the chatbot (Interviewee C) 2. It's communication between parent and doctor which helps reduce the burden on both because inviting a patient to an appointment, just because they have few questions, is a waste of both the doctor's time and the patient's time (Interviewee G)
Groups or Associations	1. There is a closed Facebook group where all the conversations take place in the Estonian language. There are not many people, but only Estonian

	patients who are adults, some parents, and their family members. Usually, we get answers if they're available for example during the daytime but if it's like night, then they're not available (Interviewee B) 2. There is an international Facebook group for the disease of my child where people ask about different problems, happy and sad news and share their journey of life. It is quite supportive and useful (Interviewee C)
Information about Social Services/Benefits	1. I have to say the system is very fragmented. Fragmentation is a very huge problem of medical social systems in Estonia because we have quite a lot of services solving one small part of the problems and we don't have a good system to deal with the issues of very complex problems. So, you have to go to different departments to do a single thing and it's a complete mess. Some of the help is provided by primary care, some by social workers, counsellors from the specialist care. Some are obtained at the local government level, some at the state level (Interviewee D) 2. There are definitely numerous things that parents don't have access to, and I don't have access to either. I feel that the systems are very separate from each other, no really good database that would take all of the information and put it together. Parents are helped by different government programs like by providing access to rehabilitation, physiotherapy, etc. but accessing information, which is specific, starting with the process, filling out all the paperwork is really difficult at some points and it's the biggest problem that there are support groups as well, but they are very well hidden (Interviewee F) 3. When you get to know that your child is disabled, then your world basically collapses, so you may not think realistically. You're really shocked, you're not eager to solve the problem or start to investigate where to get this support with my child needs, you're more like sitting in your bubble and even if the information is available in the Internet or through some specialists, then you don't get this in your head to start to look, or you don't know from where to look for this information (Interviewee C) 4. When a child gets a chronic disease diagnosed, it's of course a shock to the parents as well as to the child. So even if they might have had a deeper consultation regarding the matter, some information just doesn't stick because they are in a state of worry and astonishment, and so usually what

	happens is that we have to do a consultation again regarding just the state of what kind of a chronic illness it is, what kind of outcomes it has just because it's totally normal for people not to remember everything they have been told, especially if the information is a lot to take in at first (Interviewee F)
Opinion about chatbot	1. There is a need to have something in the form of a chatbot to give information for all the needs my child has. A chatbot could act as a source to provide all the information of the services from the government for disabled children (Interviewee C) 2. A chatbot could act as means of quick communication between parent and doctor to avoid the worst or critical situation of a child's health. I think chatbot is effective as I think it's a much easier version of my email. Most of the problems can easily be solved just by calming down the parent by a quick message through a chatbot (Interviewee G) 3. Reminders can be useful when my child remains away from home for example in grandparents' home. It can remind about morning vitamins, inhalations, and antibiotics and in the evening for exercising and all (Interviewee B) 4. Children with chronic conditions have to be on regular medications, therapies, so reminders are really important especially with diseases where people are feeling quite drained (Interviewee A) 5. In the future there should be a page for psychologists, physiotherapists, food experts, different specialists, etc. may be on the chatbot and even the contacts of the other parents (Interviewee G)

4.2.3 Key findings

1. The symptoms of chronic diseases depend on the nature and type of disease a patient has.
2. Most chronically ill children need everyday medication, they can be kept under control with everyday medication and do not need constant supervision or testing.
3. For contacting doctors, the parents either call or send an email. The phone calls are not always answered as doctors and nurses may remain away or busy with other consultations. Once a parent sends an email to the doctor the parent gets the answer within 3-4 hours or the next day and sometimes it takes 3 days if the email sent day

follows a weekend. The doctors usually answer as per the priority of the importance to provide the answer to the parent.

4. From the interview it came out clearly, it does take a lot of time for the diagnosis of the diseases especially when the chronic disease is genetic in nature which leads to stress.
5. There are not enough psychologists available to talk to parents. A parent can talk to the psychologist during the time his/her child is hospitalized. Once discharged it is difficult to get information from the psychologists available. The parents are quite stressed, and they feel alone during this journey.
6. Parents need some specialists to get counselling that can help them overcome stress felt due to the chronic illness of their children.
7. Once a child is diagnosed with a chronic disease, the child is provided with every possible medical assistance by the concerned department of the hospital. The parents of the child are informed of the necessary information by the doctors and other medical staff in the hospital. The problem that the parents face after the child diagnosis is the small queries related to the disease for which they have to turn to the hospitals always rather than getting the small piece of information from home.
8. There are certain Facebook groups for a particular disease that are meant to get information and advice if needed. However, this service is from the activeness of the parents, not the healthcare system. The problem in these groups is either the language barrier or not being so quick responsive.
9. From the interview, it came out that the healthcare system in Estonia is fragmented and information is distributed among various organizations which most of the time creates confusion rather the parents of chronically ill children are unable to use the services provided by the government because of lack of knowledge about it and information is fragmented.
10. The parents are overburdened with the 24/7 care of the child as such most of the parents do not have time to look at the services provided by the government for chronically ill children.
11. In the discussion with the interviewees, it was pointed out that there is a need to collect information from all the databases and the services provided by the government and other external organizations be presented at one place which could solve the problem of the parents as well as the doctors.

4.3 Stages of chronic illness and information needs

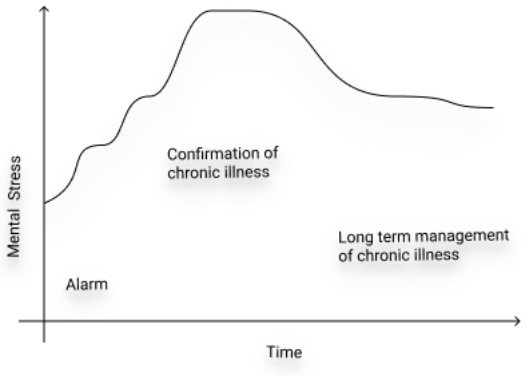

Figure 11 Graphical representation of stress using the knowledge from the interviews

Figure 11 represents the graphical view of the psychological stress experienced by the parents of chronic children from before and after the diagnosis of a disease. The graph was drawn using the details obtained from the interviewees during the discussion. The graph is divided into 3 parts:

1. Alarm: This is the initial stage when the parents or medics observe something is wrong in the child, like frequent infections, weight loss or child not growing well, a child not eating properly, vomiting often, etc. These changes in the behaviour of the child lead to frequent visits to the family doctor or need some observation at the hospital. At the hospital, multiple analysis is done, and a parent gets confused about what is happening and what is wrong. This leads to deep thinking and makes them stressed at every instance of time. In this stage, the expertise of the doctor matters and the time to identify it depends on the rareness of the disease. A chatbot would not be helpful to the parent at this stage however, it could help the health professionals to reduce the time of diagnosis from the database of the chatbot especially if data will be gathered outside Estonia. Estonia is a small country with a population being only 1.3 million and data gathered from chronic diseases in Estonia only will not be enough for the quick diagnosis of the disease.

2. Confirmation of illness: Depending on the type of illness a child has; it can take hours to years for the diagnosis of the disease. Once the disease is confirmed by the experts, parents are informed about it. Initially, it becomes difficult for a parent to accept the condition of his/her child leading to higher levels of stress. With the

beginning of the treatment, the new schedules, medication, and all other different activities related to the treatment processes make a parent more anxious. Doctors discuss most of the things with the parents but being in a state of shock a lot of this information gets over their heads and they do not remember everything. This is the stage where a chatbot can help a parent the most. A parent can get all kind of information needed for managing his child. The chatbot can help a parent getting contact with different service providers helping his child for example social services, benefits, physiotherapies, rehabilitation, etc. The burden on the parents could be reduced by some of the features of the chatbot like reminders on medications, inhalations, FDs visits, expert check-ups etc. The parents could get benefited from the counselling of the psychologists as well by making them feel positive and motivated about things happening in their lives.

3. Long term management of chronic illness: Once a parent starts accepting that his/her child has a chronic disease and needs continuous treatment or observation. He/she gets used to certain schedules and most of the treatments necessary for his/her child. At this stage, parents would not need reminders for medications or other treatments as they would have got used to it. But they would need reminders in the form of notifications for events happening once a year for example getting their children vaccinated, renewing some documents for some services e.g., disability applications and certificates, etc. It would be also useful for getting information for long term and continuous treatments like physiotherapies, special nutrition, rehabilitation, etc.

4.4 Conclusion of the key findings

This section answers Sub RQ1: What are the existing services available for parents having children with chronic diseases and problems with those systems?

From the interviews, it was clear that there is no good system because the healthcare system in Estonia is fragmented and information is spread among different organisations. The parents of chronically ill children are unable to use the services provided by the government because of a lack of knowledge about it as most of the parents are overburdened with the 24x7 care of the child and do not have time to look at the services

provided by the government for chronically ill children. There are no additional facilities available for the medical assistance of their children, they rather have the same medical services which is provided to other normal children. They frequently visit doctors or specialists. Parents need some specialists to get counselling that can help them overcome stress felt due to the chronic illness of their children. There are not enough psychologists available to talk to parents. The problem that the parents face after the child diagnosis is the small queries related to the disease for which they must turn to the hospitals always rather than getting the small piece of information from home. There are certain Facebook groups for a particular disease that are meant to get information and advice if needed. However, this service is from the activeness of the parents, not the healthcare system. The response of the groups is not so quick.

4.5 Functional and Non-Functional Requirements

The purpose of the section is to state the functional and non-functional requirements which a chatbot would need to be useful for the target group of parents and caretakers as defined by the stakeholders.

To achieve organisational goals in software development, requirements are classified as functional requirements and non-functional requirements. Functional requirements describe the system functionality specifying its features and capabilities. Non-functional properties of software describe system properties, characteristics and quality constraints (e.g., security, performance, usability) that a software product must demonstrate [65] [66].

This section will answer RQ3: What additional functionalities would parents want?

The additional functionalities of the chatbot are to gather and place the information about the services related to children with a chronic condition in one place. The functions that the chatbot should have are described in section 4.5.1. These functional requirements were used to redesign the prototype.

4.5.1 Functional Requirements

Functional requirements are an important category of the requirement engineering. Functional requirements describe a behaviour that a system should exhibit under specific conditions [67]. Functional requirements describe what functions the system or software must perform. These functions determine the capability provided by the components of a

system. Functional requirements are sometimes termed as behavioural or operational requirements [68]. The functional requirements described in Table 12 describe the top-level requirements of the chatbot based on the author's analysis.

The requirements have been prioritise based on the MoSCoW schema which stand for four possible priority classifications for the requirements in a set [69] described as:

"Must: The requirement must be satisfied for the solution to be considered a success.

Should: The requirement is important and should be included in the solution if possible, but it's not mandatory to success.

Could: It's a desirable capability, but one that could be deferred or eliminated. Implement it only if time and resources permit.

Won't: This indicates a requirement that will not be implemented at this time but could be included in a future release" [69].

MoSCoW is one of the methods of prioritisation recommended by International Institute of Business Analysis [69].

Table 12 Functional Requirements of the chatbot

ID	**Priority**	**User Story**	**Description**
US001	M	As a parent, I can log in to the chatbot application	As medical data is private and sensitive only authorized users should be able to log in
US002	M	As a parent, I should be able to get notifications about my child medication	Notifications and reminders about medications, exercise etc should be included
US003	S	As a parent, I should be able to chat with another parent	Based on interviews both doctors and parents want the bot to have the ability for parents to interact with each other

US004	M	As a parent, I should be able to get basic advice from the chatbot	Here basic advice would include information about the illness, queries about diet, growth (weight check) etc
US005	S	As a parent, I should be able to get information about Social support	Based on the interview's parents find the social support information scattered all over different governmental organizations. A chatbot should be able to provide this information in a simple form in a single location
US006	M	As a parent, I should be able to get information about different specialists	Parents should be able to see information about nearest rehabilitation centres, physiotherapists, psychologists, dieticians.
US007	S	As a parent, I should be able to get information about schools/kindergartens that support my child's needs	Parents should be able to see information about nearest schools and kindergartens that can provide all the required assistance for their child

4.5.2 Non- Functional Requirements

Non-functional requirements describe a property or characteristic that a system must exhibit or a constraint that it must respect [67]. Non-functional requirements specify system properties, such as reliability and safety [68]. The requirements have been prioritised as:

Critical priority: Requirements that are both important and urgent.

High priority: Requirements that are important but are not urgent.

Low priority: Requirement that is not important and system has capability to perform without it.

Table 13 Non-functional Requirements of the chatbot

Type	Priority	Description	Purpose
Usability	High	Every user should be able to use the chatbot easily	To avoid the major risks of the acceptability of the chatbot it should be easy to use as this will be a new approach for them to manage their children
Reusability	High	The features should be easily reconfigured to make any change or implement it in any other country	One of the main goals of the project is to implement it across Europe to reduce the number of deaths in children due to chronic illnesses
Reliability	High	The platform should be able to function without interruptions. All the data should be saved at separate places, so when an error occurs or the platform gets interrupted, all previous data should get restored automatically. All information must be provided in an accurate and detailed form	To help gain the trust of the users, the platform must be dependable by ensuring accurate information is provided, uninterrupted availability of the platform anywhere and anytime. Also, the platform must easily be recovered from any interruption for continued use by all the users
Maintainability	High	The application should be updated regularly	Updating system frequently for adding new features
Performance	High	The application should be accessible 24/7. If there is any problem or scheduled fixing users should get notification about maintenance	Users' satisfaction
Performance	High	The platform is a real-time system. The new questions asked by the users must be saved and appear for the future references	The platform must remain updated with reliable information as per the requirements of the users
Performance	High	The application accessing and responding time should be short	To reduce load time of UI to increase users' satisfaction
Performance	High	The application should be responsive to the users' inquiries	Users' satisfaction
Efficiency	High	The response time between input and output request must be short. The platform must be able to handle the high-capacity request with little response time or delay	The users are concerned with how fast the system can function since it has a high level of information that needs to be accessed at any time
Efficiency	High	The storage capacity should also be high as this platform assumes a lot of data from each user and for long-term storage	Also, the storage capacity is of concern too as it needs to keep data saved for many users and this data could be accessed easily irrespective of the time it was uploaded

Supportability	High	The system should be scalable, easy to maintain and understand	As this platform could also be used by users outside Estonia as well, the bugs should be easily fixed, and the overall system should be easily understandable
Security	Critical	The application should validate the users' login. The system should be securely connected to networks/servers to avoid security or privacy issues surrounding the use of the product or the protection of data	To make our platform to be accepted by the users without security issues
Safety	Critical	No treatment in the form of medicine should be recommended to ensure the safety of patients	To make the system safer and motivate more users
Other constraints	High	The system must be built according to database requirements (specified in technical requirements document), legal requirements or international requirements	To reuse objectives for the project and attract more users to take part. And to support all the above requirements

The non-functional requirements above were derived by triangulating data from documents, legislation, and interviews.

4.5.3 System Architecture

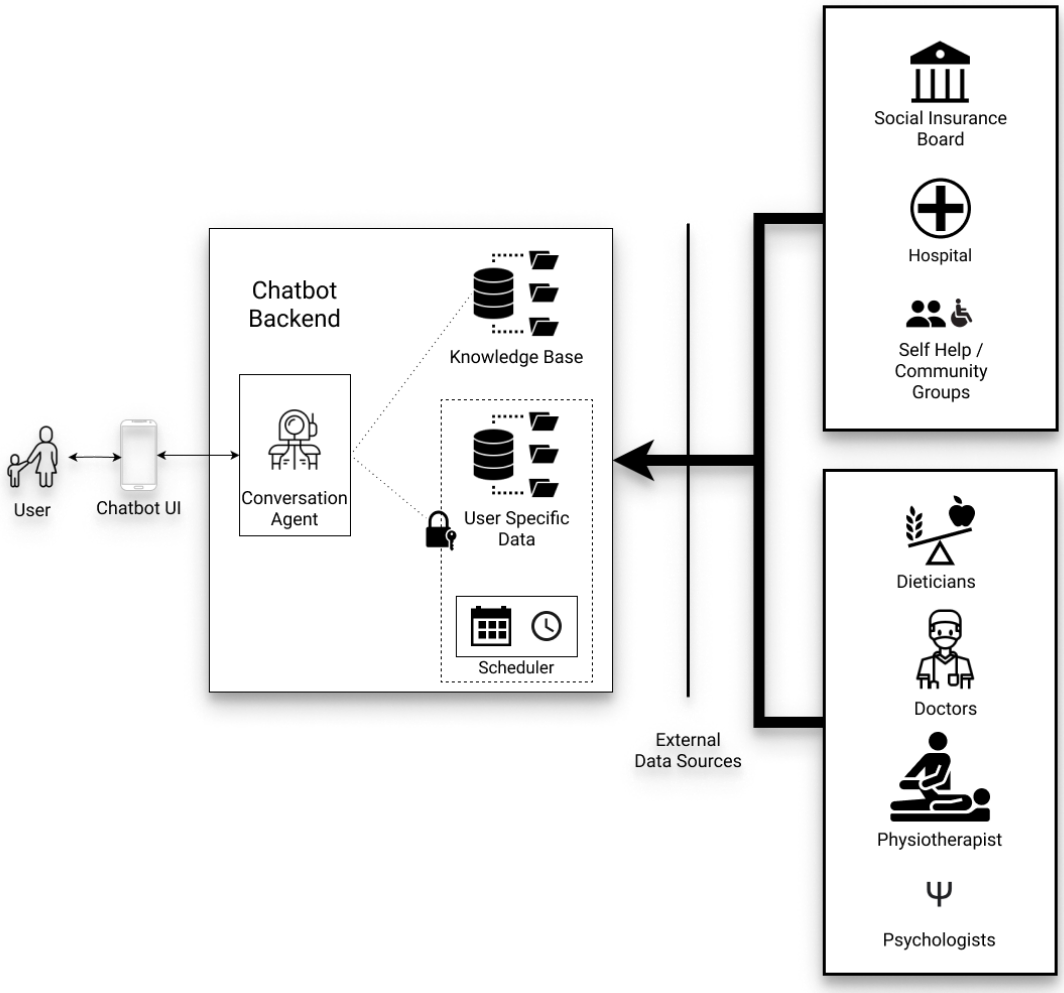

Figure 12 System Architecture

Components of chatbot architecture:

1. User: The users of the chatbot would be the parents and caregivers of children with complex conditions. The users would be doctors or experts as well for suggesting in case the bot is unable to answer the caregiver.

2. Chatbot UI: Mobile or web application. The chatbot could be used both as a mobile and web application. For using this application, the user must install and sign up for the platform.

3. Chatbot Backend: Web server interacting with the application.

a. Conversational Agent: Natural Processing Language (NLP) based conversational agent responsible for interpreting user intent and composing the appropriate reply.

b. Knowledge Base: This will be the database of all the medical information required by the users for example symptoms, treatments etc for different chronic diseases. The information about different social services provided by the government etc.

c. User-Specific Data: Database for storage user profile, medical history, conversation history, etc.

d. Scheduler: User-specific temporal events like notification for different activities to be performed.

4. External Knowledge Sources: These are the sources for data to build the knowledge base of the chatbot. The sources can be:

    a. Organisations: These can be different governmental and private organisations like the National social insurance board, rehabilitation centres, hospitals etc.

Specialist: These will provide data for medical information like diet-related information by dieticians, therapy-related information by physiotherapies, counselling by psychologists, etc.

4.5.4 Designing 'Lapsevanemad' Chatbot

After gathering all the requirements, the prototype was redesigned, and the modified clickable prototype is presented below.

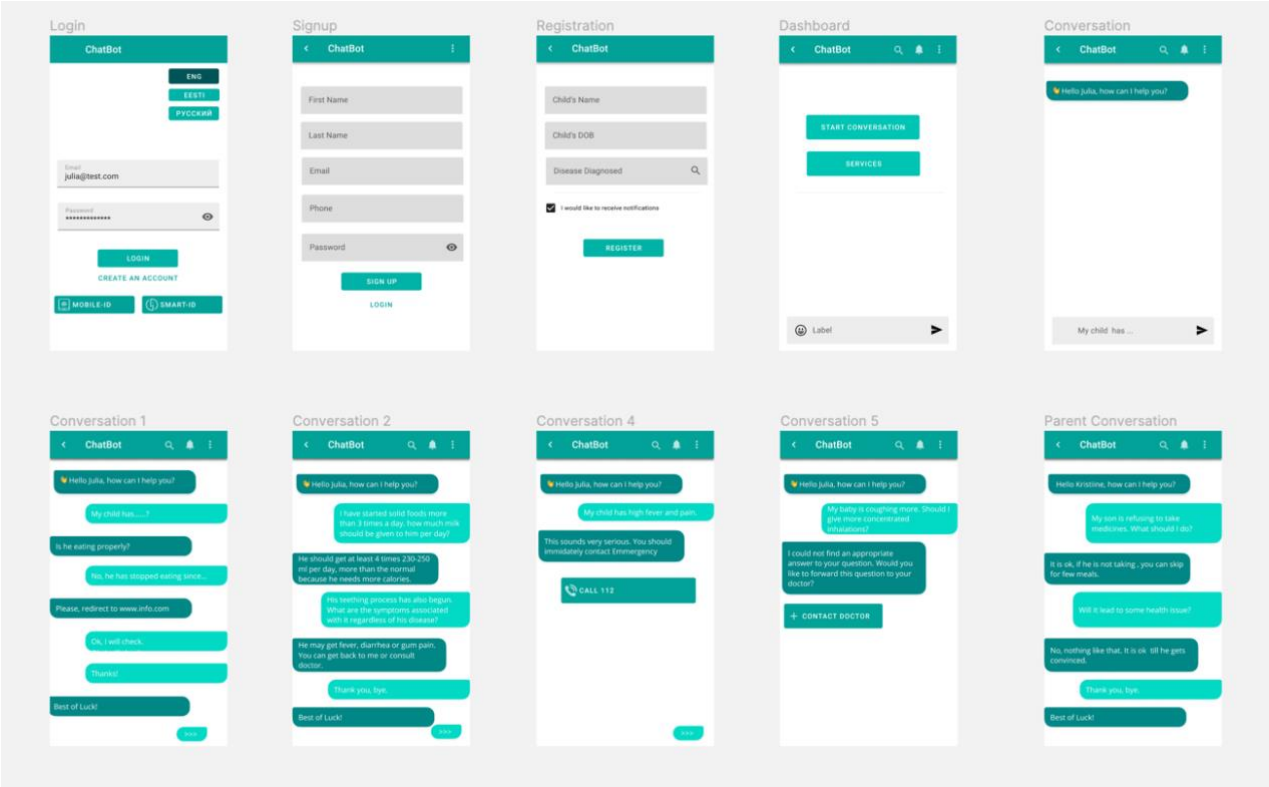

Figure 13 shows screens 1-10 of modified prototype

Table 14 represent screens of prototype and their purpose

Screen	**Screen Title**	**Purpose**
Screen 1	Login	New users can sign up and the different icons on the screen will enable the user to log in securely
Screen 2	Sign up	On this screen, the user must fill in personal details for signing up
Screen 3	Registration	The screen has fields to fill the information related to the child
Screen 4	Dashboard	This screen enables the user to start a conversation with the bot or ask for other services provided by the bot
Screen 5,6,7	Conversation	These screens show the samples of conversation between the user and the bot
Screen 8	Conversation 4	The screen shows a conversation when the bot suggests the user call the emergency
Screen 9	Conversation 5	The screen shows a conversation where the bot does not have an answer and suggested contacting a doctor for getting an exact reply
Screen 10	Parent conversation	The screen shows parent to parent conversation

Screen 11	Services	The screen shows different kinds of help provided by the bot to the users
Screen 12	Other services	The screen shows the information about the other necessary services provided by the bot
Screen 13	Notifications	The screen shows the reminders provided by the bot in the form of notifications
Screen 14	Rehabilitation centres	The link on the screen provides the information of the rehabilitation centres available
Screen 15	Social benefits	The screen has a link for the information on the benefits provided by the government
Screen 16	Special services	The screen provides the link redirecting to the information about special services provided by the government

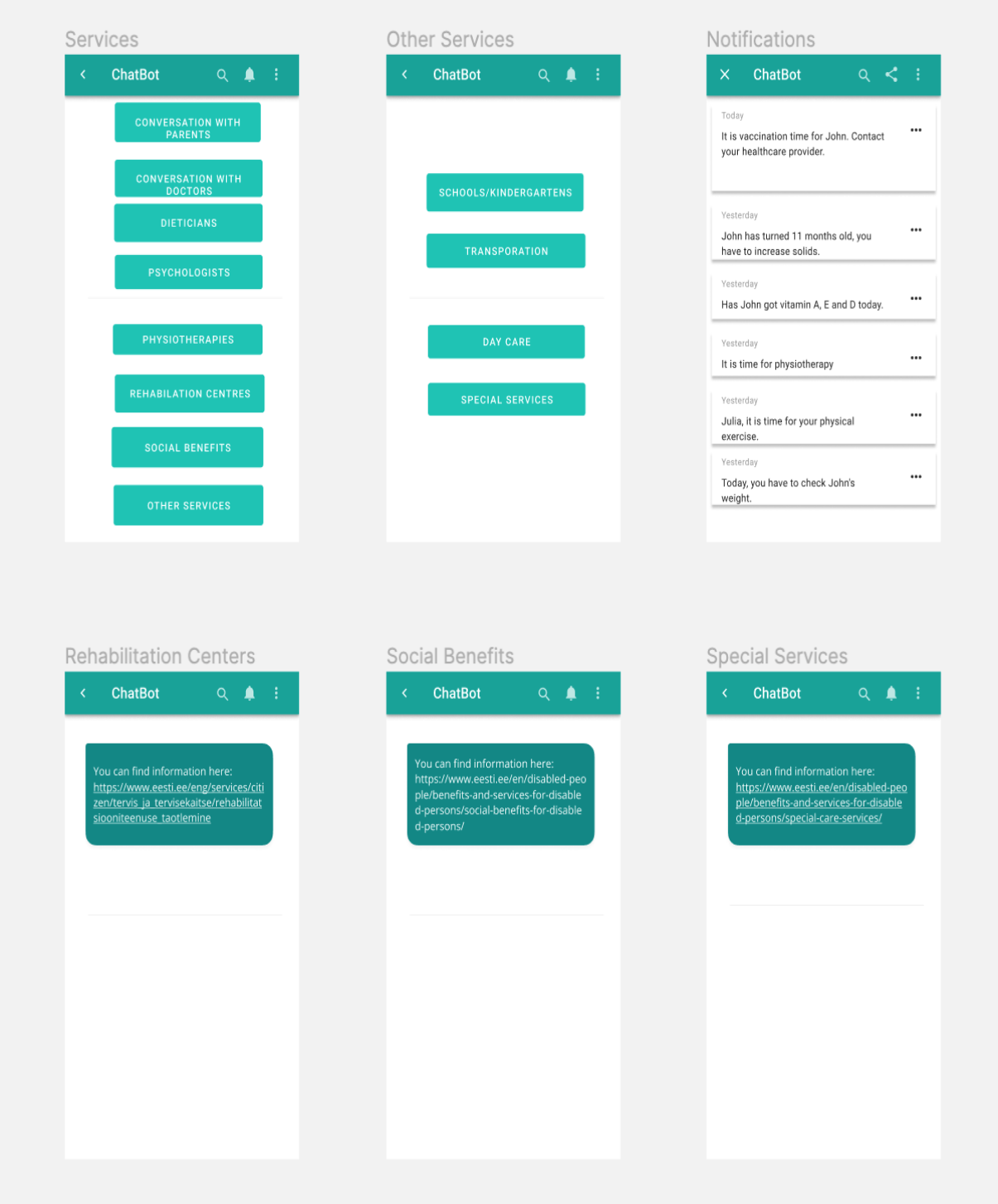

Figure 14 shows screens 11-16 of modified prototype

5 Results and discussion

This section presents the results obtained from the feedback for the redesigned clickable prototype from the parents and the doctors. The section is divided into three parts, Section 5.1 presents the evaluation feedback from interviewees responses to the Likert Scale survey, section 5.2 presents the results followed by section 5.3 on result discussion.

5.1 Validation

From the technology adoption theories discussed in the section Technology Acceptance Model (TAM) the intention to adopt a technology depends on the two factors Perceived Usability (PU) and Perceived Ease of Use (PEU). PEU increases PU and both, in turn, increases BI and hence AU.

5.1.1 Evaluation feedback

All the interviewees who were interviewed were asked to assess user-experience variables on a five-point Likert scale. Only six interviewees participated in the survey on feedback and the responses to the Likert Scale survey are presented in Table 15.

Table 15 Evaluation Results

Property	Criteria	Distribution				
		1	2	3	4	5
User-interface (UI)	1. Aesthetics			1	4	1
	2. Simplicity			1	2	3
	3. Ease of use				1	5
	4. Functions			3	3	
	5. Integration				5	1
	6. Complexity of system	4	2			
	7. Utility				2	4
	8. Satisfaction			1	4	1
Functional Requirements	1. Answer to general queries					5
	2. Redirecting to emergencies			1	2	3
	3. Redirecting to medical specialists	1			1	4

	4. Reminders				2	4
	5. Parent to parent conversation		1		1	4
	6. Information about governmental services					6
	7. Information about other services					6
1 strongly disagree 2 disagree 3 neutral 4 agree 5 strongly agree						

5.2 Results

5.2.1 User-Interface:

All the participants were satisfied with most of the features of the UI of the designed prototype. The average score on Likert scale for different criteria is presented in Figure 15 followed by complete description.

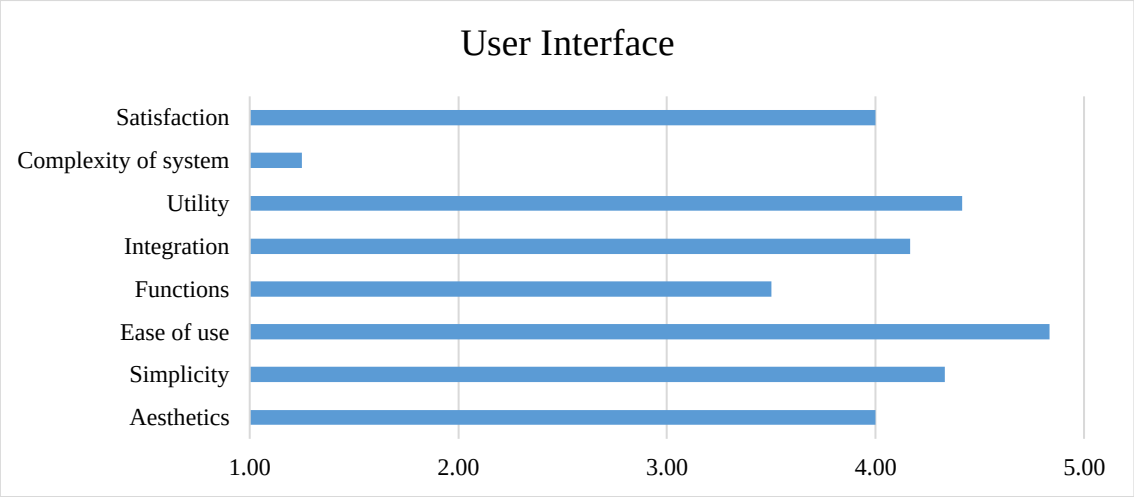

Figure 15 Average Likert scale score for UI

- Aesthetics

As described in the section Implementation of TAM, a proposition about Aesthetics P1: Visual Design (VD) has a direct positive influence on users PEU of Chatbot. From the results, 66.7% of participants felt that the interface of the prototype is pleasant and understandable hence validating P1. On the VD, one of the participants commented:

"*Looks professional"*

- Simplicity

A proposition about Simplicity P2: Simplicity has a direct positive influence on users PEU of Chatbot.

P3: Simplicity has a direct positive influence on users PU of Chatbot.

From the results, 50% of participants strongly agreed and 33.3% agreed that the design of the prototype is simple and easy to use hence validating P2 and P3. One of the participants commented:

"It seems very nice and smooth to use"

- Ease of use

A proposition about Ease-of-use P4: Systems which are easy to use has a direct positive influence on users PEU of Chatbot.

P5: Systems which are easy to use has a direct positive influence on users PU of Chatbot. From the results, 83.3% of participants strongly agreed and 16.7% agreed that they would imagine that most people would learn to use the system very quickly. 5 out of 6 participants strongly disagreed and 1 disagreed that they would need the support of a technical person to use the system hence validating P4 and P5.

- Functions

A proposition about functions P6: More the functions of the system, the more is its positive influence on PU.

Half of the participants agreed that the system has all the functions and capabilities they expect it to have as commented by one of the participants.

"*Chat with other parents or with a doctor in some cases would be great to have through this Chatbot*"

The other half responded neutral on the Likert scale. 2 out of 3 who marked neutral were health professionals and commented as:

"I don't have a complete overview of the chatbot yet"

"The functions depend on user's expectation and expectations could be different"

The comments were general, and no negative comment was obtained for the prototype. Besides, the caretakers agreed and hence validates P6.

- Integration

P7: the integrity in the functions of the application has a direct positive influence on PU. 5 out 6 agreed and 1 strongly agreed that the various functions in the system are well integrated and hence validates P6.

- Utility

P8: The more information about the services in the application, the more positive influence on PU.

From the results, 50% strongly agreed, 16.7% agreed and 33.3% marked neutral that they would the application to get the information necessary to them.

P9: more the utility of the system, more is its positive influence on PU

All the participant either strongly agreed or agreed that they could understand the purpose of the application, hence validates P8 and P9. The following comments were provided by the participants:

"Yes, it is designed to make the life of sick kids easier in the situation they are"

"*If all the info about my child is presented from one place, then of course"*

- Complexity

P10: the less complex the system is, the more is PEU.

None of the participants agreed that they find the system unnecessary complex, hence validates P10. On complexity, the following comments were obtained:

"*The system is understandable and simple"*

"If it makes a parent's life easier then I'm completely positive"

- Satisfaction:

P11: the satisfaction of the users with the functions of the application, the direct positive influence on PU.

From the results, 16.7 % strongly agreed, 66.7 % agreed and none disagreed that they are satisfied with the functionalities of the prototype of the chatbot. Hence P11 gets validated.

All the propositions get validated which means all the participants felt that system has PEU and PU. Thus, the behavioural intent of adoption of the chatbot can be perceived and hence its actual use can be perceived.

5.2.2 Functional Requirements:

All the interviewees were satisfied with most of the functional requirements of the designed prototype.

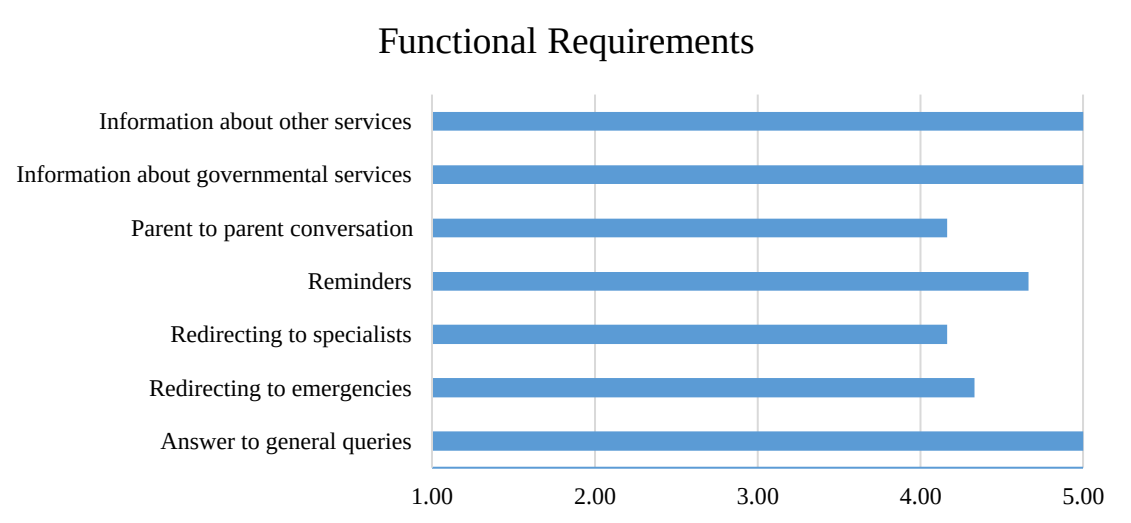

Figure 16 Average Likert scale score for FRs

A proposition on functional requirements P12: The quality of the content has a direct positive influence on PU.

All the participants strongly agreed that the chatbot should be able to answer basic questions keeping in context the illness, age, and other factors of the child should provide information about different governmental support systems and information about different organisations supporting children with complex needs like rehabilitation centres, psychologists, etc. The following comments by participants reflect their opinion:

"This is very important as the information is so scattered it is very difficult to orientate it otherwise"

"Chatbot can answer based on the average patient. There always stay some interindividual differences what you can`t know"

50% of participants strongly agreed, 33.3 % agreed and one responded neutrally for the chatbot to redirect the user to emergencies.

4 out of 6 strongly agreed, 1 agreed and 1 strongly disagreed that chatbot should forward queries to the specialists to find an appropriate answer. The participant who disagreed with the functionality is a health professional and commented:
"*Then there should be doctors who have enough free time to answer questions"*

From the results, 66.7% strongly agreed that chatbot should enable a parent to parent conversation. 1 out of 6 participants responded neutral and 1 disagreed with the feature. Some of the comments obtained:

"*This could be really useful. Reliable platform for families in similar situation"*

Since all the participants either strongly agreed or agreed that the content placed in the prototype of the chatbot is important. Figure 16 suggests that the average Likert scale for the functionalities of the chatbot is either 5 or more than 4 which validates P12.

Hence, all the participants felt that the quality of content is very good and as a result system has PU. Thus, the behavioural intent of adoption of the chatbot can be perceived and hence its actual use can be perceived.

5.3 Discussion

The results from the validation of the prototype were positive. Some of the useful features as commented by the participants are discussed below.

The login option with mobile/smart ID would validate the data as commented by one of the participants:

"*After logging in with mobile/smart id, the system should recognize the name and data of the disabled child info automatically or at least proposes, if this data is correct*"

Half of the participants felt that the system has all the function and capabilities that they expected to have and none of them disagreed with it. Having an option to get recommendations from the expert was felt very useful as one of the participants commented:

"*Chat with other parents or with a doctor in some cases would be great to have through this Chatbot*"

Most of the participants agreed that the chatbot should be able to forward questions to a medical specialist like a doctor, a dietician etc in case it cannot find an appropriate answer. They feel that the users are more confident in case a suggestion or recommendation is provided by a specialist. They also feel that it is better to get advice on time from the experts rather than waiting for a long time till things get out of control.

"This would give users more confidence if they could also talk to a doctor or some other specialist"

"*And perfect would be 24/7 "customer support" because usually, people wait until the evening to see how the situation is and then there is the night to live through without any advice. So yes, if one can ask advice any moment of the day/night, would be perfect"*

However, one of the participants disagreed and felt that doctors do not have free time to answer all the time.

"*Then there should be doctors who have enough free time to answer questions"*

And of the participant suggested that for avoiding workload on the health professionals it is better to recommend asking questions from the specialists rather than forwarding queries directly.

"It should recommend asking the question from a specialist, but not forward the questions itself - this will increase medical staff's workload immensely as it creates a very easy route to ask about everything, even, if the question should be asked elsewhere"

The medical professionals were concerned with the function that the chatbot forwards a query to them it will add to their already overburdened workload as it might become a "ask me anything" tool. This concern can however be resolved by a better AI-based tool

in chatbot so that most of the queries get answered by the chatbot itself without getting forwarded to the specialists. As the number of users will increase, the accuracy of the bot will also increase thereby reduce the number of queries forwarded to the medical professionals. The conversations between users and chatbot would need parodic review to ensure the quality of recommendations. It would make sense to get regular feedback from the users.

All the participants agreed that the chatbot should notify about different events like medication, vaccination time, etc. They want to have reminders for prescriptions as well.

"*Yes! This is very useful. Also, perhaps could notify if there is a new prescription needed or if some medicine is running out (could be connected to prescription and pharmacy system -the system knows, when I bought the medicine, how much I give per day and when the package will finish"*

Most of the parents agreed that the chatbot should enable a parent-to-parent conversation. They felt that parents having children with complex needs can help each other by sharing their experience.

"Yes. This could be useful. A reliable platform for families in a similar situation"

One of the participants commented:

"There are Facebook groups where I can chat with parents"

However, based on the interview discussion with the parents, the Facebook group responses are not so quick as could be a chatbot. and these Facebook groups often remain hidden from the users.

Most of the participants agreed the chatbot should redirect a user to emergency in case of questions requiring immediate medical attention and one of the participants expressed how important is to redirect to the emergencies to avoid a critical situation for the child.

"*Sometimes people are afraid to call 112 and they think the situation is not so bad. But I believe, it's better to turn to 112 or emergency room before the situation is too complicated"*

However, one of the participants suggested that the chatbot should avoid suggesting contacting an emergency and instead should suggest the user contact the Family doctor as it could unnecessarily increase their workload if non-emergency cases are pointed to Emergency Services. Family doctors should be enough in most cases.

"*The line of needing an emergency service called is very difficult to establish - I would rather prefer if the bot would say something in the lines of "contact your GP as soon as possible, if it seems to be a medical emergency, call 112" - otherwise it would be a great liability for you if some keyword would not be recognized as an "emergency" and you probably can't exclude that from happening*"

Most of the participants found that getting information about different services is very useful. A chatbot would be able to provide information scattered all over different governmental organizations in a simple form in a single location. Parents should be able to see information about nearest rehabilitation centres, physiotherapists, psychologists, dieticians. Parents would be able to see information about nearest schools and kindergartens that can provide all the required assistance for their child. The comments obtained from the participants on the feedback form provided for the redesigned prototype suggest that the chatbot should not only provide information about different services but must propose applying or confirming the application process of some services/benefits from the government. They want to have this chatbot linked to governmental organisations where every application could be filled and submitted via this chatbot as commented by some of the participants:

"*If I could dream, I would like the system to propose filling and submitting your application as by logging in besides showing from where to find additional information (about benefits), the system should recognise me, my child's needs based on the supports/health databases*"

"*It would be perfect if the system would already propose applying or confirming some benefits/services instead of a link from where to read more information*"

"*If it is a government service provided with all the local governments and health systems then it is really helpful for parents who have sick kids and are lost in the world of disabilities. Reading long texts and trying to understand what to do is more complicated in this situation. It's not a hobby that makes people excited about some topic. It's a real*

struggle for the life of the kid and parents and siblings to remain healthy physically and mentally. This kind of chatbot is a big step forward to help the parents, doctors and in return, also the whole country"

The initial proposal could be the development of this chatbot with the features designed. A chatbot could be a big step forward to help the parents for getting governmental services provided by the local government and health systems and in turn for the healthcare professionals by reducing their burden.

The requirements needed to make it fully a public service is beyond the scope of this thesis. The current system of the different application processes for children with the complex need to be investigated which would have helped for getting further requirements by the parents for the chatbot.
However, the government of Estonia is planning to build implement AI in various fields in both the private and public sector to advance the take-up of AI. Ott Velsberg, Government Chief Data Officer of Estonia while explaining the implementation of AI in various fields, suggested that AI would solve more complex problems, such as making an appointment with the doctors automated. The Estonian government is seeking help from the private sector to develop a solution for doctors to make appointments for check-ups with the patients automated that would require scanning of healthcare records. For example, some patients with disabilities or suffering from heart diseases may need to visit the doctor much more frequently, almost every month, while others having diabetes and no other problems need to visit after every six months. The solution utilising AI tool would help doctors to manage their patient lists and time more effectively [50]. Consequently, the government of Estonia could develop a *Lapsevanemad* chatbot for parents of chronically ill children as an initiative in the healthcare services under Kratt AI. The recommendations by the participants could be taken in the second phase of its development. To make this chatbot efficient big data is required for which the data need to be outsourced.

The participants suggested that there is a need to see the other aspects of the application besides the technical part as commented by one of the participants

"The idea and technical solution of this application is good, but the medical side needs more replenishment and communication with specialists"

This issue could be resolved as the chatbot should be well integrated with the Estonian e-health system which integrates healthcare data of all healthcare providers and provides health records of every resident. Better communication would be ensured by X-Road, which is the main component for interoperability in the country, providing a unified, secure platform for organizations between public-public, public-private, private-private to exchange data and communicate [70].

The main research question of the thesis is: How could a Chatbot benefit the parents of chronically ill children?

The solution to the problems faced by the parents of children with complex needs could be a one-clickable service i.e., a chatbot. The chatbot would gather all the information from all the databases and present it on one screen. The chatbot would not only provide medical assistance but would help parents to know about all the data that a parent need. A parent would not need to search for the information on different websites, but he/she would get all the required information on the chatbot. By having all the identified features to help parents, the chatbot can help and reduce their burden, motivate them, make them feel positive and would have a normal life with less stress.

6 Conclusion and Further Work

Chapter 6 concludes this thesis by providing an overview of the research. Section 6.1 contains general conclusions of this thesis and proceeds Section 6.2 reflects upon the research limitations and Section 6.3 describes the future work needed.

6.1 Conclusion

This research is concerned with designing a virtual tool that could help the parents and caretakers of chronically ill children. The tool is a chatbot named *Lapsevanemad* which could provide medical assistance to the parents and would give the necessary information about different services offered by the government and different organisations. This thesis gives an overview of the challenges that parents of children with complex needs have. The parents experience stress, burden, loneliness, anxiety and sometimes depression during their journey of managing a chronic child. The solution to all the problems can be a one-clickable service in the form of a chatbot. After understanding all the needs and the conditions in chronic disease from literature review and interviews with the parents and the experts, a prototype of the chatbot was designed. The design was presented before the interviewees and feedback were obtained. The chatbot can gather all the information from different databases and present it on one screen. The chatbot would not only provide medical assistance but would help parents to get information about various policies, financial aids, services etc. A parent does not need to search for the information on different websites, but he/she would get all the required information on the chatbot. The solution will not only reduce the burden on the parents but overall, on the healthcare system of Estonia.

Consequently, the thesis provides a well-designed prototype of the chatbot that would bridge the gap between the caretakers and the various information sources. It also states some ways that the chatbot could be integrated into current Estonian services. The thesis proposes an idea for easing the difficulties of parents and then designed a prototype that was validated by stakeholders.

6.2 Research Limitations

The research has a few limitations. Firstly, to get the answers in a generalised /globally accepted language, the interviews were conducted in English however this limited the number of people who could be interviewed as most of the stakeholders were non-English speaking. Secondly, the interviewees were all located in Tallinn, the capital of Estonia, which has better medical facilities as compared to the other parts of the country. There would be more requirements from the parents and doctors who did not speak English or were in the countryside or smaller towns. The current system of the different application processes for children with complex needs remained un-investigated which would have helped for getting further requirements by the parents for the chatbot.

Finally, to make this chatbot efficient big data is required for which the data need to be outsourced because Estonia is a small country with a population of 1.3 million only. The percentage of chronic children as compared to the population is quite small, the data from Estonia is not enough to answer all the queries made by the parents.

6.3 Future Work

For future work, many items should be done to determine the effectiveness and potential issues with the concept of a chatbot to help aid parents of children with complex needs. The design should be refined as per the requirements of the parents of the whole country, not a part of it as mentioned in the limitations. The experience with the current system of services must be investigated like the filling of different applications under different organisations. This is very important to solve the problem of building an actual chatbot in the future. As suggested by the interviewees, the chatbot should have an integration with existing systems like the patient's portal (digilugu.ee). It is of interest to have a data collection for the knowledge base from reliable sources. The data must be outsourced to have big data for the efficiency of the chatbot. Implementation of this must be kept under Kratt AI to make its adoption for the people of Estonia quick and easy.

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Appendix 2 – Interviewee Questions

Doctors /Expert Interview:

Q1: Do you have a certain number of chronically ill children who need continuous treatment or observation? What kind of observation do they need?
Q2: How do you manage such parents in COVID like situations? Has this pandemic disturbed their treatment anyhow? Are they provided with any other form of assistance?
Q3: According to your experience, what are the common problems which such parents encounter on daily basis?
Q4: Do you think some parents among them experience mental pressure? Has it led to any kind of severe depression or health issues?
Q5: Have you ever tried using any kind of chatbot? What is your experience with it? What is your opinion on using a chatbot for health-related queries?
Q6: If the child needs continuous medication, therapies or diet-related kind of things, what kind of assistance you think can be helpful to reduce the burden on the medical professionals and parents?
Q7: What ways have been useful for children with special needs to keep them in proper health? What according to you must be added in the assistance to avoid any worse or critical situations of such children?
Q8: Apart from such children, what things you or your health care system provides to their parents in terms of reducing their stress?
Q9: What are the problems with getting information today which might be important for parents to help managing their children?
Q10: Do you think it is important for a parent to know the latest research for the type of disease his child has? How can it be helpful for the doctors or the health care system?
Q11: Taking virtual assistance like chatbot into account what feature you would like to add to reduce the burden on the parents as well as on the healthcare system?

Parents Interview:

Q1: How did you come to know about the disease of your child? How long it took to get an exact diagnosis for your child? Did you want to have quick assistance for his diagnosis? In what respect would have it helped or had not helped at all?

Q2: What platforms/applications do you have to use to manage your child's health condition which is different from those having a child without any disability?

Q3: Have you ever encountered situations when you needed immediate help especially when medical assistance had been difficult? What mediums have you used in that case?

Q4: How do you manage things in COVID like situation? Are you able to reach out to the medical care properly for your child? Does it somehow make you wish to have an alternative than visiting the hospital?

Q5: If you need assistance to help you deal with the condition of your child. How would it look like to you? What features you would like to see in it?

Q6: Have you ever tried using any kind of chatbot? How is your experience with it? What is your opinion on using a chatbot for health-related queries?

Q7: How often do you google when you have queries related to any problem or treatment? What sources do you use? Do you have to visit multiple websites to find answers? How difficult it becomes for you to exact and accurate information?

Q8: Do you trust what you find in the sources. How often have you applied the information you have got from these sources? Can you give an example?

Q9: Please tell me a specific instance in which you needed to look online to get information? What was the situation? How did you find your answer?

Q10: Did you have followed up with a doctor afterwards? How was the information gathered online helpful in discussing things with the doctor?

Q11: Does your child need your continuous attention whether it is medication, therapies, or diet-related things. Have you experienced mental stress on you do in dealing with your child?

Q12: In that case what kind of assistance would you like to have? What things would you like it to do for you which will reduce your burden?

Q13: Is there anything else you would like to add that virtual assistance like chatbot should have to help a parent like you or the health care system in general?

Appendix 3 – Questions for Evaluation of design of prototype

Please answer on a scale of 1-5, with one being the lowest and 5 being the highest:

1 strongly disagree, 2 agree, 3 neutral, 4 agree, 5 strongly agree

Evaluation of UI (User-Interface)

1. I like the user interface of the system as I found the interface pleasant.
2. I think it is simple and easy to use.
3. I would imagine that most people would learn to use the system very quickly.
4. The system has all the functions and capabilities I expect it to have.
5. I found the various functions in the system are well integrated.
6. I would be able to use this application to get the information necessary to me.
7. I find the system unnecessary complex.
8. I think that I would need the support of a technical person to be able to use the system.
9. I could understand the purpose of the application.
10. Overall, I am satisfied with the functionalities of this system.

Evaluation of Functionalities

1. The chatbot should be able to answer basic questions keeping in context the illness, age, and other factors of the child.
2. The chatbot should redirect users to emergencies in case of questions requiring immediate medical attention.
3. The chatbot should be able to forward questions to a medical specialist like a doctor, a dietician etc in case it cannot find an appropriate answer.
4. The chatbot should notify about different events like medication, vaccination time, etc.
5. The chatbot should enable parent to parent conversation.
6. The chatbot should provide information about different governmental support systems for disabled children.
7. The chatbot should provide information about different organisations supporting children with complex needs like rehabilitation centres, psychologists, etc.