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ONCOLOGISTS' EXPERIENCES AND PERSPECTIVE ON THE USAGE OF ELECTRONIC PATIENT-REPORTED OUTCOMES IN ROUTINE ONCOLOGY CARE IN ESTONIA

Masters' Thesis

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ONKOLOOGIDE KOGEMUSED JA VÄLJAVAATED PATSIENDI ENDA HINNATAVATE TERVISETULEMITE KASUTAMISEL RUTIINSES ONKOLOOGILISES RAVIS EESTIS

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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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09/05/2022

Abstract

Background: With digitalisation and increased use of Information and Communication Technology [ICT] tools, patient-generated data could potentially create value in the delivery of healthcare by tailoring to individual needs. Electronic patient reported outcome [ePRO] is part of patient-generated data. Existing literature has shown that the usage of ePROs in routine care benefit patients, including those who require oncology care. Despite the evidence, it is not known why ePROs are yet to be implemented in routine oncology care across Estonia. **The aim of this thesis** is to explore the baseline experience of Estonian oncologists in the usage of ePROs in their current delivery of oncology care, along with their perceived barriers and benefits if ePROs were potentially to be used routinely. **Methods:** A qualitative research approach was used to identify oncologists' experience, benefits, and barriers when using ePROs in routine oncology care. Oncologists' perspectives constitute a part of experts' opinion within the field of oncology care. A combination of deductive and inductive approach was taken to analyse the qualitative data collected through a structured interview guide. **The results** were categorised into three parts: participants' experiences in using ePROs, barriers, and benefits in the potential implementation in routine care. Participants' experiences in the use of ePROs yielded several sources of encounter, while the perceived barriers and benefits were analysed and coded into several themes, with the ease of using ePROs being perceived differently among the participants. **Conclusions:** Oncologists were found to have varied experiences in the usage of ePROs. These experiences could further tailor knowledge and translated to other oncologists to improve success of implementation. Benefits and barriers did not differ with pre-existing literature despite the participants' familiarity in use of digital tools. Future studies could consider a wider group of healthcare professionals and stakeholders who are beneficiaries of the increased value of healthcare delivery using ePROs, to create a comprehensive implementation strategy.

This thesis is written in English and is 58 pages long, including 6 chapters and 2 figures.

Annotatsioon

Onkoloogide kogemused ja väljavaated patsiendi enda hinnatavate tervisetulemite kasutamisel rutiinses onkoloogilises ravis Eestis

Taust: Seoses digitaliseerimisega ning info- ja kommunikatsioonitehnoloogia vahendite suurenenud kasutamisega võivad patsientide loodud andmed, kohandades neid vastavalt individuaalsetele vajadustele luua väärtust tervishoiuteenuste osutamisel. Elektroonilised patsiendi enda hinnatavad tervisetulemid on osa patsiendi loodud andmetest. Olemasolev kirjandus on näidanud, et nende kasutamine patsientide ravis on kasulik patsientidele endile, sealhulgas onkoloogilist ravi vajavatele. Vaatamata olemasolevatele tõenditele jääb selgusetuks, miks patsiendi enda hinnatavaid tervisetulemeid Eestis veel tavapärases onkoloogia ravis ei rakendata. **Selle lõputöö eesmärk on** uurida Eesti onkoloogide baaskogemust patsiendi enda hinnatavate tervisetulemite kasutamisel ravitöös ning nende võimaliku rutiinse kasutamise takistusi ja eeliseid. **Meetodika**: onkoloogide kogemuste, võimalike takistuste ja eeliste tuvastamiseks patsiendi enda hinnatavate tervisetulemite kasutamisel rutiinses onkoloogilises ravis kasutati kvalitatiivset uurimismeetodit. Arvestades, et onkoloogid on onkoloogilise ravi ühed valdkonnaeksperdid, moodustavad nende seisukohad onkoloogilise ravi ekspertarvamuse osa. Struktureeritud intervjuu kaudu kogutud kvalitatiivsete andmete analüüsimiseks kasutati deduktiivse ja induktiivse lähenemisviisi kombinatsiooni. **Tulemused jaotati kolme osasse**: osalejate kogemused, võimalikud takistused ja eelised patsiendi enda hinnatavate tervisetulemite rakendamisel rutiinses raviprotsessis. Osalejate kogemused väljendusid erinevat viisi kokkupuudetel, võimalikud takistused ja eelised aga analüüsiti ning kodeeriti, mille tulemusena tekkisid mitmed kategooriad. Kusjuures patsiendi enda hinnatavate tervisetulemite kasutusmugavust tajuti osalejate seas erinevalt. **Järeldused**: Leiti, et onkoloogide kogemused patsiendi enda hinnatavate tervisetulemite kasutamisel varieerusid. Neid kogemusi saab kasutada teadmiste kohandamiseks ja üle kandmiseks teistele onkoloogidele, et tõsta implementatsiooni edukust. Hoolimata osalejate varasemast kokkupuutest digitaalsete tööriistadega, ei erinenud võimalikud eelised ja takistused olemasolevast teaduskirjandusest,. Selleks, et luua laiaulatuslik implementatsiooni strateegia võiksid tulevased uuringud kaasata suurema hulga tervishoiutöötajaid ja sidusrühmi, kes saaksid samuti kasu patsiendi enda

hinnatavate tervisetulemite kasutamisest.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 58 leheküljel, 6 peatükki, 2 joonist.

List of abbreviations and terms

CPD	Continued Professional Development
EBP	Evidence-Based Practice
EPDS	Edinburgh Postnatal Depression Scale
ePRO	Electronic Patient Reported Outcome
ePROM	Electronic Patient Reported Outcome Measure
ICHOM	International Consortium for Health Outcome Measurement
ICT	Information and Communication Technology
IPOS	Integrated Palliative care Outcome Scale
ITK	East Tallinn Central Hospital (Ida-Tallinn Keskhaigla)
IS	Implementation Science
KTA	Knowledge-To-Action
PEHR	North Estonia Regional Hospital (Põhja-Eesti Regionaalhaigla)
PRO	Patient Reported Outcome
PROMIS	Patient-Reported Outcomes Measurement Information Systems
PSSQ	Psychosomatic Screening Questionnaire
QoL	Quality of Life
TAIEK	Ethics Committee for Human Research of the Institute for Health Development (Tervise Arengu Instituudi inimuuringute eetikakomitee)
TÜK	Tartu University Hospital (Tartu Ülikooli Kliinikum)
WHO	World Health Organisation

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1 Introduction

Data in healthcare has become more digitalized with the advancement of Information and Communication Technology (ICT) [1]. The World Health Organisation (WHO) has drawn up a global strategy to advance digital health globally, using digital health technologies towards empowering patients and the vision of health for all [2]. The strategy also encourages international collaboration and support countries towards improving health care service delivery and promoting research and development [2]. Therefore, Estonia has partnered with other Nordic countries to establish NORDeHEALTH, an NordForsk-funded project, aiming to identify challenges and opportunities in digitalisation of health services to deliver better healthcare by harnessing the power of digitalisation and ICT [3]. One approach that NORDeHEALTH proposed taking is by using patient-generated data to explore factors in the co-design of innovative projects which provides personalised healthcare services [3]. Potentially, using patient-generated data can provide a wide range of value to both patients and clinicians. The importance of value creation in healthcare settings has also been echoed by the Expert Panel on effective ways of investing in Health for the European Commission [4] and the European Institute of Innovation & Technology [5] in future usage.

A suggestion in value creation by applying patient-generated data is through measuring appropriate outcomes for every patient in the line of care [6]. These outcomes are globally known as patient-reported outcomes (PRO). It is defined as "*directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment*" [7]. PROs have been implemented in different aspects of clinical care, especially when externally observable outcomes are unavailable or in health-related patient experience [7]. By including the use of ICT tools in the collection pathways, these outcomes have been collectively digitalised as electronic PRO (ePRO), which is a term used to describe the digitalised format of PRO. ePROs have been implemented in multiple specialised areas to improve the delivery of patient care, particularly in the field of oncology. Previous randomised-controlled trials and systematic reviews have also

involved the use of ePROs in the provision of oncology care [8]–[15]. ePROs have several advantages in creating additional value through digitalisation, by having better data quality, decrease cost and facilitation of faster clinical decision making [16].

In Estonia, the usage of ePROs in routine oncology care has not yet been standardised across different oncology centres. Oncologists are known to have prior experience in collecting data on patients in clinical trials using electronic case report forms [17] and in some instances taken the initiative to chart ePROs outside of routine medical care. However, to the best of the author's knowledge there has been no studies done regarding the knowledge and experience of Estonian oncologists and their perceived opinions to ePROs routine usage in Estonia.

Problem statement: Usage of ePROs in oncology care can benefit patients by providing value and patient-centred care, yet it has not been used in routine oncological care in Estonia. There is an information gap regarding the baseline knowledge of oncologists about the use of ePROs routinely in Estonia. Additionally, the potential barriers and benefits from the perspectives of oncologists have yet to be explored if ePROs were to be routinely implemented in Estonia's healthcare system.

The aim of the research is to explore the baseline experience, including knowledge of working oncologists of the use of ePROs in oncology care, their perceived barriers and benefits in ePROs usage, if it was to be implemented routinely in oncology care within Estonia.

Research questions

1. What is oncologists' experience in the usage of ePROs in oncology care for patients in Estonia?

2. What are oncologists' perceived barriers and benefits for the usage of ePROs in routine oncology care?

2 Theoretical Framework

This chapter will describe the science behind the basis of the investigation of the research question – implementation science (IS) together with the theoretical framework that will be applied for the thesis, the Knowledge-To-Action (KTA) process. Additionally, the usage of ePROs, their application in the field of oncology care and the use in Estonia are outlined as they are relevant background information. Lastly, current literature on the identified barriers to routine ePROs usage will be elaborated as part of the theoretical framework.

2.1 Knowledge to Action Process

Using ePROs as part of routine clinical care stems from the concept of translating evidence-based practices (EBP) to real-life usage. To investigate if implementing an EBP can be successful, it involves research in implementation science (IS), which is defined as "*the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services*" [18]. The usage of theories, models, and frameworks involved in IS have also provided better explanation, identification and predicting factors of success that contributes to formulating implementation strategies [19]–[21]. In the context of using ePROs in medical care, various models have been previously used to explain how they are successfully applied into routine care. These models include the Knowledge-To-Action (KTA) process [22], Normalization Process Theory (NPT) [23] and integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS) framework [24]. Specific to this thesis, the Knowledge to Action (KTA) process (Figure 1) is chosen for the theoretical basis for this thesis.

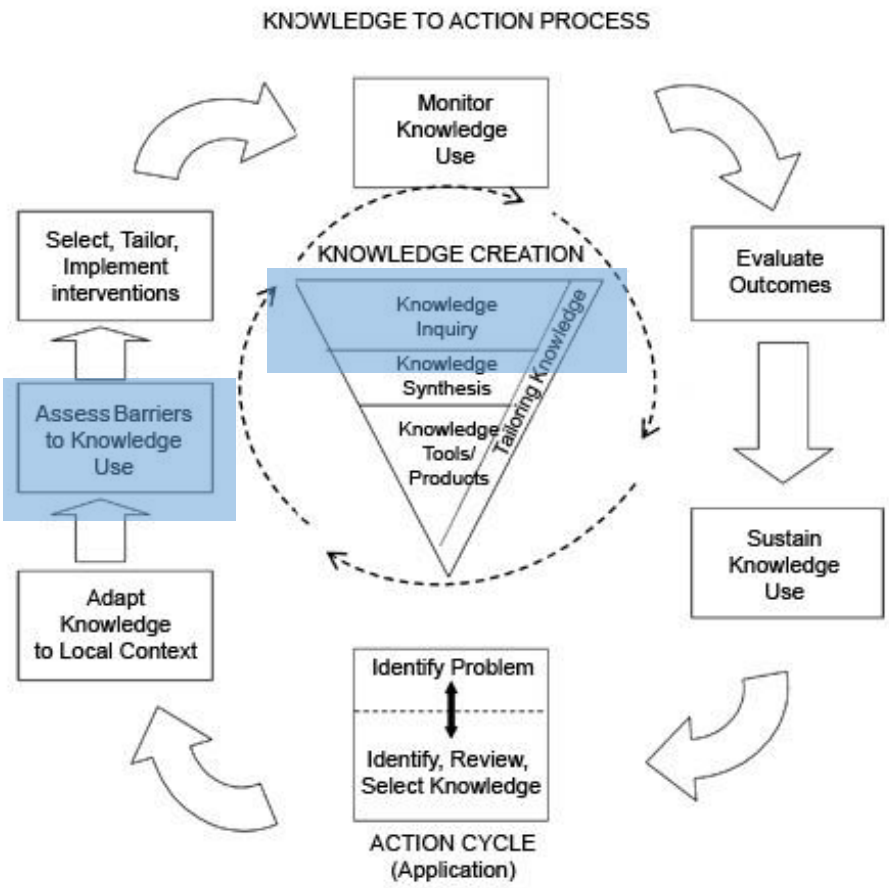

Figure 1. Knowledge to Action Process [22], modified

The aims of the thesis serve to establish the stakeholders' experiences and evaluate their perceived barriers and benefits in the implementation of ePROs, which has been widely used in clinical research but not commonplace in routine practice. Different experiences and knowledge could contribute to factors that either hinder or facilitate the implementation. These factors could be identified, thereafter an implementation strategy can be formulated and periodically reviewed which could then improve the overall success rate of implementation. This has been reflected in the KTA process, where it has been described as a process with practical steps to translate research into practice [22]. The two main parts of the KTA process, which are the inverted funnel 'Knowledge Creation' and the iterative 'Action Cycle' reveals that knowledge plays a significant role towards the application process, further requiring a cycle of evaluation to measure success. The application of the KTA process gave a rationale to the formulation of the aims in this thesis.

The scope of this thesis covers the planning stage in the implementation of ePROs into routine oncology care. As such, only parts of the KTA process will be applicable to form the basis of investigation in the thesis. These parts are highlighted in Figure 1, which are 'knowledge inquiry' and 'assess barriers to knowledge use'. Despite only applying parts of the theoretical framework, it is relevant for exploring factors in successful implementation.

To establish a baseline of ePROs usage in oncology care in Estonia, it involves the opinions of stakeholders and experts in the field before actual implementation of ePROs in routine oncology care. Therefore, in the 'knowledge inquiry' phase, the authors of the KTA process mentioned that *"at each phase of knowledge creation, knowledge producers can tailor their activities to the needs of potential users"* [22]. Considering that there is currently an information gap regarding oncologists' experiences and knowledge on ePROs in Estonia, knowledge inquiry on the use of ePROs is initiated, before giving results to identify the factors that could affect implementation. From the results, it could *"tailor or customise the message for the different intended users"* [22]. Therefore, other stakeholders who are involved in the implementation process of ePROs, such as department chiefs, hospital managers and policy makers, could make use of the opinions of oncologists to identify factors that could potentially contribute to a successful implementation.

Secondly, factors that could contribute to the success of implementation have not been identified, hence only a limited aspect of the entire 'Action Cycle' falls within the scope of this research thesis. In the application of 'assess barriers to knowledge use', benefits and facilitators during the KTA process are advantageous to be assessed simultaneously [22]. In addition, both barriers and facilitators are consistently known to be important elements that should be considered in the study of knowledge implementation [25]. Therefore, interviewed participants were inquired on their perceived barriers as well as benefits towards the use of ePROs as part of the aims of the thesis.

Lastly, the KTA process has shown its applicability in continued education in healthcare setting [22]. The gap between implementing an EBP and real-life practice lies within knowledge translation. As healthcare professionals partake in continued professional development (CPD) throughout their years of professional practice, by providing tailored

education that plugs the gap is both practical and relevant. In this context, to successfully implement ePROs, which has been established in literature as a tool to benefit patient care, the use of CPD can be used as an implementation strategy to improve the rate of success in its uptake.

Utilising the KTA process provides an understanding of how the current experience of a practicing oncologist in the usage of ePROs and their perceived benefits and barriers in potential usage could be related. This would provide practical insights on what gaps could be addressed and improvements made, therefore contributing to the expansion of successful implementation of ePROs in routine care to other centres, or an opportunity for a national-wide rollout.

2.2 Background in the implementation of ePROs

2.2.1 Initial usage of ePROs in clinical care

EPROs are initially developed for use in clinical trials and in research. Their purpose is to aggregate score for group comparison and determine best outcomes from variations [26]. However, when ePROs are applied in routine clinical care, patients would be able to input outcomes of their functions and quality of life (QoL) directly to clinicians [27], where QoL is understood as quantitative measures to assess levels of wellness in patients using a psychometric approach [28]. A common extension of ePRO, electronic patient reported outcome measure (ePROM) performs in a similar manner. Instead of using absolute terms, ePROMs are reliable and validated electronic tools or instruments that measure various domains of health [29]. ePROMs can either be broad-based or disease specific and utilised within an assessment pathway, similar to ePROs. Clinicians can utilise these inputs, together with clinical information such as physical assessments, laboratory values and imaging, allowing better communication to make informed treatment decisions [16].

2.2.2 EPROs in Oncology Care

Patients suffering from oncological conditions experience a plethora of symptoms beyond the clinical progression of their illness. Oncology treatment strategies include surgeries, chemotherapies, radiotherapies, or a combination of those. Post-treatment, patients may experience post-surgical impairments or varying levels of acute toxicity during aggressive

oncology treatment [30]. These symptoms can have substantial impact on their day-to-day lives, and in some instances may affect QoL. Improving patients' QoL has been a major objective to meet in oncology care [31], [32], thus the use of ePROs becomes relevant for use.

Published systematic reviews regarding the use of ePROs in oncology has established various benefits in patient care [8], [13]–[15]. Utilization of ePROs has been shown to improve communication of symptoms and symptom control [13], produce better patient-to-health provider communication where health providers can raise and review specific and sensitive issues [14], [33] and to prompt discussion around symptoms that affect patients' daily functions [15]. Routine use of ePROs have shown to facilitate outcome monitoring and detection of unrecognized problems [8], [15]. Given the possibility that symptoms may manifest latently and continue to affect the well-being of cancer survivors, data from ePROs can facilitate discussion on providing supportive care in cancer advancement [10] or palliative needs [9]. Other benefits gathered from randomized-controlled trials in the use of ePROs have shown decreased emergency clinic visits [34], [35], improvement in overall survival for younger patients with advanced cancers [36] and addressing issues with mental health [37].

2.2.3 Current usage of ePROs in Estonia

To the author's knowledge, usage of ePROs in Estonia is in its preliminary stages. Efforts were made to translate ePROMs, such as the integrated palliative care outcome scale (IPOS) [38], Edinburgh Postnatal Depression Scale (EPDS) and the Postpartum Social Support Questionnaire (PSSQ) [39] to Estonian language for cultural adaptation for future implementation. There are also ongoing projects, which utilize ePROs pertaining to stroke rehabilitation. However, the manner of collecting and collating ePROs has not been streamlined in routine oncology care within Estonia's healthcare system. In addition, requesting access to specific data points on patients suffering from oncological conditions can be a challenge for policy makers or healthcare administrators, given that there is no fixed structure in data collection or the use of a dedicated ePRO software. This is set to change, as other interested stakeholders such as pharmaceutical companies are forming working partnerships with oncology centres in Estonia, using commercially available software such as KAIKU Health [40], to collect ePROs. Some pilots have been initiated

by some oncological centres, but data collection pertaining to ePROs are neither standardized nor part of routine clinical care among patients with oncological conditions.

2.2.4 EPROs implementation internationally and on commercial platforms

Various international organizations have established ways to ease the implementation of ePROs for specific conditions or measurements of QoL domains. The International Consortium for Health Outcome Measurement (ICHOM) is a non-for-profit organization which was founded in 2011 and has been publishing standard sets of relevant PROs for various medical conditions [41]. The Patient-Reported Outcomes Measurement Information Systems (PROMIS) is a program funded by the National Institute of Health in the United States, which addresses the standardization of PROs and measurement of multiple QoL domains, and it is available in different languages for usage without any need for licensing [42].

In the commercial market, innovative eHealth technology and digital tools not only provide oncological support care to patients but also incorporates the use of ePROs. Within the European consumer market, examples of digital tools that makes use of ePROs includes the previously mentioned KAIKU health and others such as Oncokompas, Moovcare and LuCApp, to name a few.

2.2.5 Barriers to implementation of ePROs in routine usage

Barriers to routine use of ePROs have also been identified in systematic reviews [13]–[15], [43], [44]. There were concerns regarding time required for user training, with the possibility of increase in workload if ePROs were not fully integrated into clinical workflow or existing information technology infrastructures [15], [44]. Healthcare professionals' negative attitudes towards using ePROs were seen as a barrier to use, examples include the lack of time to meaningfully interpret the data [44] and without having clear and strong evidence of significant clinical importance or improvement of care [15], [44]. Moreover, without guidelines to guide clinicians' response to patients' input, additional support is needed to address uncertainties that patients may bring up about in their ePROs [13]. Challenges towards patients' adaptability of use were also indicated [14], [43], [44], considering differing levels of patients' digital literacy, which would compromise compliance and adherence to usage [14], [15], affecting their

effectiveness. With the above-mentioned barriers, ePROs implementation was perceived to decrease rather than increase the value of delivering healthcare to patients.

3 Methodology

This chapter will explain the study design of the research and further elaboration on how the data was collected, the methods used in the recruitment of participants and how the data was analysed. Ethical consideration, approval and data protection are also outlined in this chapter.

3.1 Study Design

A qualitative research approach was taken to explore oncologists working in Estonia, on their experiences in the usage of ePROs, alongside the benefits and barriers in usage during routine oncology care. Qualitative research seeks to *"identify, analyse and understand patterned behaviours and social processes"* [45]. It is ideal in fulfilling the aims of the thesis given that it could develop contextual understanding of interactions between experts who will be making use of the digital tool [46]. Structured interview format was used to direct participants towards appropriate context, with little opportunity to introduce new topics [45]. Using structured interview would also provide an explicit agenda with a tentative hypothesis and ensuring all participants were given equal opportunities to provide their opinion [45]. In exploring opinions in the usage of ePROs, there had been previous studies undertaken on their benefits and barriers, thereby having a structured interview format could provide further elaboration regarding the hypothesis.

In the context of implementation science research, engaging experts' views enables transparent communication, which can be effective in achieving the goals, design, and process of implementation of the innovation [47]. Given that oncologists are the experts in oncology care, they form the main user group that would utilise ePROs to guide clinical judgements. Furthermore, engaging experts' opinions would facilitate trust and feedback, fostering better partnership and identify potential barriers at the planning stage [48]. The process to factor in views of oncologists' opinion in this context could potentially enhance the successful uptake of a new digital tool into routine oncology care.

To craft the questions for the structured interview, they were developed based on the insights that the author had gained from research literature and background research from other stakeholders who have interest in the pilot implementation of ePROs, such as

hospital managers and the departmental lead of an oncological centre. These questions were further refined with two researchers of the NORDeHEALTH team, and finally evaluated with the thesis supervisors. No further changes were found to be necessary after the final evaluation. A copy of the interview guide can be found in the Appendix 2

As described in Chapter 2.2.1, the KTA process was selected to be the theoretical basis of the study design. The first part consisted of the knowledge inquiry phase, where participants' experiences on ePROs were explored based on day-to-day work or in educational settings, including clinical trials or medical conferences. For the next part, participants were asked on their perceived thoughts on barriers of using ePROs and lastly their thoughts on the benefits, including ePROs potential usefulness and ease of use in routine oncology care. Before commencement on the opinions regarding barriers and benefits, participants were supplied with an information sheet on ePROs implementation regardless of each participant's prior experience and knowledge. This was to ensure that participants had similar understanding on ePROs. It was also to establish that the usage of ePROs in routine care had not yet implemented in their routine care but only as a proposed idea in gathering their opinions for the thesis. The information sheet included an infographic model of how an ePRO assessment system worked, with a commonly used questionnaire in oncology care EORTC QLQ-CR30. An example of this information sheet can be found in Appendix 3.

3.2 Data Collection

As a no-visitor rule was still in place in Estonian hospitals during the study period due to the COVID-19 pandemic, interviews were conducted virtually on Microsoft Teams platform using video conferencing. This was done to facilitate a similar experience as a real-life interview, so participants could feel more comfortable and voice their opinion more honestly. The interviews were also audio recorded with permission and transcribed using a speech-to-text feature that is available on Microsoft Teams. It was further verified by manual checks before the text was further analysed. A total of 5 interviews were conducted, which lasted between 25 to 51 minutes. Sociodemographic information of the participants, including their age, current workplace, and the number of years that they have been practising medicine were also collected. Participants' answers were clarified during the interviews therefore no repeated interviews were required. An email would be

sent to participants, together with parts of the transcripts to seek clarification in the event where any further clarification would be required. However, no participants were contacted to seek any clarification based on the content of the interviews conducted.

3.3 Participant eligibility and recruitment

The eligibility criteria for participant for the thesis includes oncologists who are actively involved in the care and treatment of patients. To recruit the required participants for the study, the sampling technique used consisted of a mix of convenience and snowball sampling. There was no publicly available registry which contained the contact details of all possible available participants (i.e actively working oncologists). Hence, a convenience sampling approach was used, where information about the study was sent out to at least one working oncologist in Estonia in each oncology centre, whose contact was available by a search on their websites or through currently available contacts with thesis supervisor and the lecturers in Tallinn University of Technology. A copy of the recruitment information can also be found in Appendix 4.

The snowball method was used to further recruit eligible participants. The snowball method is relatively efficient for locating hard-to-find individuals, by utilising the existing interaction of participants to further locate eligible participants, with an additional advantage of being low cost [49]. In Estonia, there are only three oncological centres, within the North Estonian Medical Centre (PERH), Ida-Tallinn hospital (ITK) and Tartu University Hospital (TÜK). Therefore, after the completion of an interview with a participant from an oncology centre, a request was made to disseminate the study information to their colleagues for voluntary participation in the study, given that participants have work interactions with other eligible participants in their respective oncology centres.

Among 11 participants who were contacted via email, 6 people responded and agreed to participate in the study. 5 of the respondents were eligible, and 1 oncology nurse was excluded. All the eligible respondents (n=5) provided verbal informed consent for the study by agreeing to be interviewed and for their interviews to be recorded.

3.4 Data Analysis

A combination of deductive and inductive approaches was utilised to analyse the data based on the transcribed interview texts that were collected from the structured interview. To determine participants' experiences, perceived barriers and benefits, a deductive approach was taken using structured interview questions which fitted their answers into the respective topics. Following that, an inductive approach was taken to determine the themes in each topic. Analytic memos were written based on the short excerpt that participants had mentioned in their perceived benefits and barriers respectively. Two cycles of coding were used, where the first coding cycle will employ structural coding by grouping the analytic memos of the similar concepts together and the second coding will generate the themes from the first cycle coding. The data categorisation based on the codes and themes generated are shown in Figure 2. The inductive approach was taken to achieve a broader understanding of the participants' thoughts towards the main topics asked in the interview.

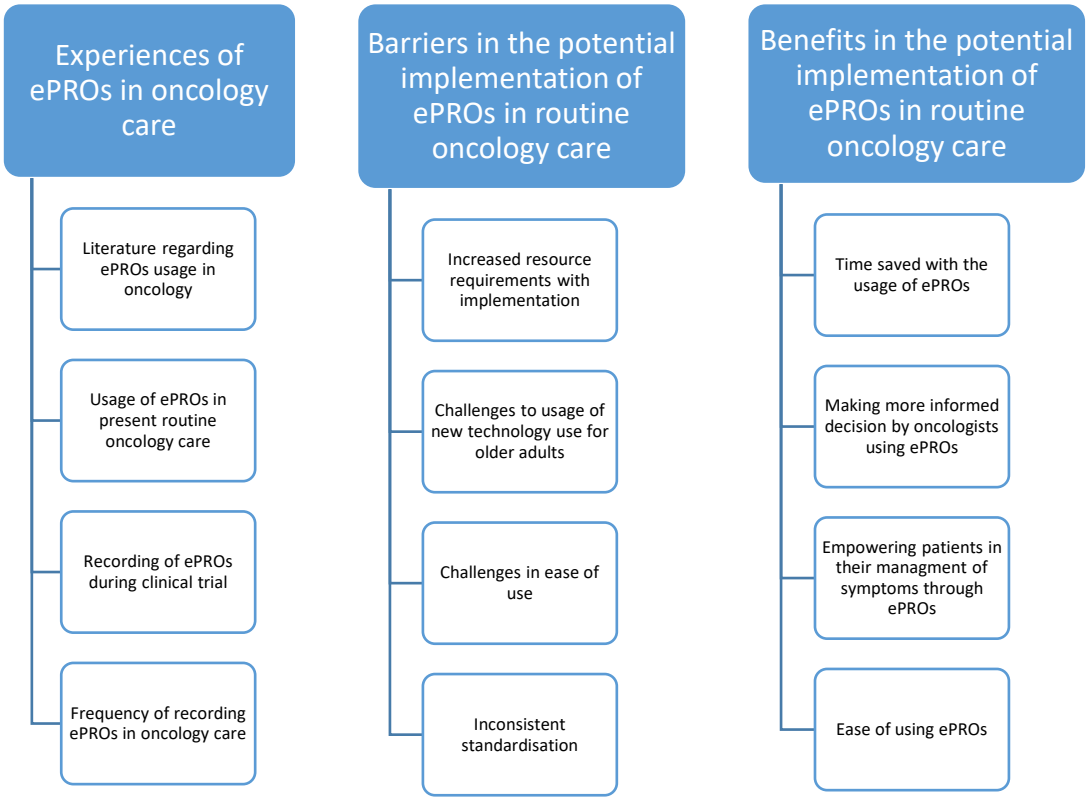

Figure 2. Themes derived from the coding

3.5 Ethical considerations and Data protection

The thesis is part of the research project "NORDeHEALTH – Nordic eHealth for Patients: Benchmarking and Developing for the Future. Approval for this research has been provided by Ethics Committee for Human Research of the Institute for Health Development (TAIEK) in Estonia and it was granted on 17.02.2022. Decision nr 1048, research nr 2391.

3.5.1 Ethical Concerns regarding Implementation Science research

Increased recognition in IS research has led to the development of Ethics in Implementation Research Toolkit publication of research toolkit by the Word Health Organisation (WHO) [50]. For this study, ethical concerns which are relevant in the implementation of digital tools were brought up. Firstly, there was a need for a clear distinction between what is done is normal circumstances and what was proposed to fulfil the aims of this study [50]. Therefore, during the process of conducting the interview, participants were first questioned on their routine care and then further informed regarding the hypothetical scenario of an implementation of ePROs in routine care. This was explained in the study design in Chapter 3.1.

Secondly, ensuring the privacy, confidentiality and anonymity of participants has been brought up as an important component of research ethics [50]. In this study, participants were informed that their participation were not anonymous, but the socio-demographic details collected were kept private and confidential. Therefore, to quote the views of each participant in the thesis, they were given an assigned code based on the chronological framework when the participants completed the interview. The first participant will be coded as *1-P*, second participant will be coded *2-P* and so on, to ensure that that no details on the participants were revealed without explicit permission.

3.5.2 Aspects regarding Data protection

To ensure data collected from participants in the form of video recordings were adequately protected, they were only made accessible to the author and the thesis' supervisors. Any other access to the video recordings and transcription could only be made possible with the author's permission. Furthermore, they were stored securely in a

password-protected folder under the cloud server which was provided by TalTech. The video recordings, together with transcription and analysed data, would be permanently deleted after the defence of the thesis. In the event that there is a potential of an article publication, the recordings would be stored for a period of 6 months (till Nov 2022) and subsequently deleted.

4 Results

This chapter will explore and outline the interviews provided by the participants, who are experts in oncology care, on their views on the usage of ePROs. The experts' interviews are divided into three parts. Firstly, they would provide their experiences in their use of ePROs in current care process. It will be followed by opinions regarding the barriers of potential ePROs implementation in routine oncology care, and lastly the benefits regarding the same topic of implementation.

4.1 Demographics

Representation from each of the 3 oncology centre in Estonia (PERH, ITK, TÜK) was between 20% to 40%. There were 4 female participants and 1 male participant. The age of the participants ranges between 32 to 56 years old. All the participants identified themselves as either a resident in oncology care or medical oncologists with a specialty field. The years of experience in clinical care that each participants had, including their residency period, ranged from 5 to 25 years individually.

4.2 Experiences on use of ePROs

Experiences regarding the use of ePROs by oncologists were categorised based on four components, which are – literature regarding ePROs usage in oncology, usage of ePROs in present routine oncology care, recording of ePROs during clinical trials and the frequency of using ePROs in oncology care.

4.2.1 Literature regarding ePROs usage in oncology

Interviewed participants indicated varied sources of literature regarding their knowledge of ePROs usage in oncology. For example, it was mentioned knowledge of ePROs came from *"conferences, papers, journals"* (1-P) which were academic in nature. One participant specifically mentioned a study that concerned the use of ePROs.

> *I know some of them. I have heard of a lot about this ePRO, which was (from a) randomized study when we first know about the ePROs outcomes.* (4-P)

Another participant mentioned having *"regularly receive all sorts of news, so there's a lot of ePRO available data and the patient reported outcomes and it's coming more and more in practice."* (1-P). Based on this response, the knowledge of the use of ePROs had been drawn from data which was accessible. The same participant further mentioned *"I know that interest is much bigger because nowadays more and more quality related issues are coming to oncology. So, we're not expecting to see not so much overall survival benefit or progression free survival benefit, but also the patient quality of life indicators that are necessary in order to provide care"* (1-P) suggesting that these accessible data collected through ePROs were used to measure metrics such as QoL, which was in line with trending evidence regarding the provision of oncology care.

In conclusion, participants had information regarding the usage of ePROs from academic studies, including the trends of usage, their purposes and the benefits that had been mentioned in research papers.

4.2.2 Usage of ePROs in present routine oncology care

There were differences among participants regarding the usage of ePROs in current routine clinical care. Among participants, two of them mentioned having actual hands-on usage while others indicated that they did not have any. One participant mentioned *"for example in lung cancer, right now we use the KAIKU program"* (2-P). This indicated that the participant had already started to use a specific software that records ePROs during the course of clinical work. Another participant mentioned working with the relevant agencies to assist the implementation of ePROs.

> *"We are in a process in our clinic, actually in the final phase with our ethical committee and sick fund to start a trial in our clinic to implement the ePRO to all of our cancer patients"* (4-P).

The same participant also indicated *"practical time I spent on just to get know about that platform (KAIKU), it was an hour, an hour and half"* (4-P). Although this participant specifically quantified the amount of time spend on learning the ePRO software (KAIKU), it was mentioned that "*mostly I know theoretical base of that, but I do not have practical experience yet".* (4-P). This suggests that despite making use of the tool, it was seen to be used as part of a trial but felt that it was not classified to be a clinical experience in using ePROs in the delivery of oncology care.

Other participants expressed not having used any ePROs tools in their current oncology practice, however, did have knowledge of ongoing pilots that had been implemented in routine oncology practice. When asked about the use of ePROs, one participant mentioned *"I have no experience"* (1-P) but stated that *"there should be a pilot going on in one hospital"* (1-P). This was also mentioned by another participant who mentioned that *"personally I haven't had any practical experience. So, I haven't used those on my patients /.../ I've heard about them (ePROs), and I know that there are many different programs which have been developed already. And they're also used in many countries and in many hospitals. And I also know that we have projects going on with that type of devices (ePROs)"* (5-P).

Another participant shared that he did not experience the use of ePROs presently in his routine oncology care but had experienced them solely in clinical trials.

> *"No. Well, in those trials, yes. But in everyday life, it is more like you just ask the patient how it's being, for example side effects or complaints or something like else. But there is no like program or specific tool to evaluate it. You just ask and you just report it in your medical history and then you generate this overall opinion, is it good or bad or how it's going? We can say that in Estonia we don't use those (ePROs) other than in a clinical trial"* (3-P)

The participant revealed the experience of using ePROs in clinical trials, which would be further elaborated in the next section 4.2.3. It was shared that there had been no similar tool, like those in clinical trials, that could help in charting symptoms in normal circumstances, therefore did not have any experience in usage for routine oncology care. In summary, ePROs usage in present oncology care greatly differs among participants, with these variations ranging from not using any ePROs to usage in current day-to-day practice in Estonia oncology clinic.

4.2.3 Recording of ePROs during clinical trials

As previously mentioned in chapter 2.2, the usage of ePROs had initially been utilised in clinical trials. Two participants mentioned they had experience in recording ePROs during their participation in clinical trials, while others either did not mention about their involvement in clinical trials or indicated that they had knowledge of use but had not been personally involved.

Participants shared that that ePROs was applied in the use of clinical trials. An example was given on how the collection was done.

> *"They will give us a special tablet, where (there) is only that program... you give it to the patient (and) patient will answer those questions. And this information is stored in the server of the clinical study team"* (3-P).

This suggests despite the usage of ePROs, the collection of ePROs was controlled through device supplied by the investigation study teams. It was further mentioned that the information was held by the investigating team and unclear if participating oncologist have access to the ePROs collected at any given time. Another participant also mentioned that having been involved in clinical trials but did not use ePROs despite having knowledge of them. As quoted *"I'm participating in clinical trials as an investigator. But in those we haven't had those ePROs"* (5-P), additionally suggests that oncologists' participation in clinical trials does not necessarily mean that ePROs will be utilised in the duration of the trials.

In summary, despite oncologists recording of ePROs during clinical trials, they did not have full control to access these data. Furthermore, the use of ePROs in clinical trials should be further clarified with oncologists and not assumed to be the default in participation of trials.

4.2.4 Frequency of recording ePROs in oncology care

One participant who already had the experience of making use of a specific software (KAIKU) in routine oncology care mentioned that the recording of ePROs was automated.

> *"From my study nurse… she says that our patients who are registered in our KAIKU program, they get a weekly reminder from the program to their email that they need to insert their symptoms."* (2-P)

As suggested by the quote, oncologists do not know the frequency in charting ePROs as they were not the person to make the decision. Participants who had used ePROs clinical

trials stated that the frequency of use was dependent on the trial protocol, with one participant stating, "*it depends, what the clinical trial protocol will say"* (3-P). Therefore, regardless of their experience using ePROs within or outside of clinical trials, oncologists themselves do not have the authority to determine how frequent recording of ePROs would take place, but instead pre-determined by the software or protocols set within clinical trials.

4.3 Barriers of using ePROs in routine oncology care

4.3.1 Increased resource requirements with implementation

Participants brought up issues regarding the need of additional resources in the implementation. One participant mentioned *"someone has to teach the patient as well, how to use these things. So maybe the logistics about who is responsible of showing and demonstrating and everything"* (2-P), suggesting that there was additional responsibility was required in the implementation of ePROs. The participant also shared the possibility of collecting ePROs as part standardised routine care for all patients.

> *"if we were to implement these to all cancer patients, we probably will have problem with the personnel working with these alerts, and if something will need to be done with the patient /…/ And someone has to check the symptoms. Ask the patient how he is doing or refer to the physician or ask the physician. So we need probably more personnel who is able to conduct all this thing"* (2-P).

This suggest that the use ePROs as a routine would add additional manpower to manage alerts of the system. This view was also affirmed by another participant.

> *"With the home ePROs like you have shown, I understand that there are like possibility that there is a nurse who is calling. In reality, unfortunately, it's hard to find those nurses. We even have problems to find nurses to everyday normal clinical life"* (5-P).

The perceived requirement for additional manpower, combined with the perceived inability to acquire it was seen to be a barrier towards the use of ePROs.

Besides additional manpower, concerns regarding monetary cost in utilisation and integration of ePROs were also shared as a barrier to usage. Many participants shared

their concerns regarding funding and the cost of using the ePROs platform. As quoted by one participant, *"barriers which we (have) met so far, in the debate with our sick fund, of course it's money. Because those platform (have) costs"* (4-P). Other participants shared similar views on inadequate funding as a barrier to implementation, in the case *"if there is no money behind those programs (ePROs), then it will not be implemented"* (3-P). It was further compared with other digital tools that also required funding but were not implemented due to cost.

> *"Some of the hospitals have not been starting using to use the electronic health system that we have, (as) in a lot of hospitals is because of monetary issues. So I'm thinking money would maybe be one"* (2-P).

In conclusion, the participants brought up the need for additional resources in the form of manpower and monetary means, and the challenges to acquire these resources, were perceived to be a barrier to ePROs implementation.

4.3.2 Challenges to usage of new technology use for older adults

Challenges in the ability of using newer technological tool like ePROs were brought up as barriers to use by all the participants.

> *"Most of the cancer patients are elderly. And it's just difficult for them to use this digital solution"* (2-P)

This suggest that most oncology patients that were seen in by the participants were older adults and they face problem to utilise new technological tools like ePROs. It was shared by another participant that challenges to technology persist in this particular group, but mentioned it constitute *"10%... mostly they're very fragile, very elderly patient, patient, all whom do not (understand) Wi-Fi or different reasons"* (4-P), which suggest that the presence of the problem but did affect a significant number of patients.

Besides the ability to use, preferences of older adults and the availability of hardware to use the tool were also brought up as barriers to use. A quote from a participant explained the barriers that older adults faced with new technology usage.

> *"Obstacles are, like, the technology part. Not everybody, especially older people have the correct appliance to use or fill it in. I think that they feel much more comfortable to use it like with pen and paper. Or if they have something, put in (their) hands, like, if it's like in the outpatient setting, that we have our own tablets there, then they probably use it. I think it's more like the hardware part."* (1-P)

Such similar sentiments were also gathered from other participants where they felt both the ability of using newer digital tools and the skills in manipulation newer hardware were lacking in the older adult population which were perceived as a barrier to implementing ePROs. Given that older adults form a majority of the patient group in oncology care, participants perceived this as a significant barrier in the usage of ePROs.

4.3.3 Challenges in ease of use

Challenges faced in the ease of use of ePROs were perceived as a barrier. One participant suggested *"it is simple when it all comes together in that same one patient diary /../ you don't want to go to another system or another program to log in and watch the patient data in there. You want to see it all in one place"* (3-P), where it was suggested that compilation of information should be at one location, or it would be a challenge to use.

The possibility of putting in extra effort in the use of ePROs was shared by another participant

> *"Of course, they(ePROs) give you, like, more work. But at the same time, it should be that way that it's (work) as little as possible"* (5-P).

This perception of extra load was shared by another participant who felt *"the extra time required for the patients to inform them how to fill in the blank, explain(ing) why we are collecting their data, what difference does it make for them."* (1-P), which contributes to more time required to review patients and not help ease the time pressures that oncologists are already experiencing.

One participant felt that the challenging usage was reliant on how well the IT team's implementation process and how people could adopt to the new work process

> *"I think when the IT part works well then. There is no obstacle from that side, but I think yes, like the people behind it/…/ It can be an obstacle or so especially when*

it's something which should be in our hospital program somehow. So how to implement it that it's because all new things." (5-P).

To summarise, the additional challenges of use due to the complexity of systems, requiring additional time and the IT implementation process, was perceived as a barrier to implementing ePROs.

4.3.4 Inconsistent standardisation

Lastly, the perceived barriers to use identified were the inconsistent standardisations about ePROs usage. One participant brought out how *"different guidelines, providing different questionnaires to about psychological health, about sexuality, about cardiac health, for example. /../ I think that the hospital needs to, or the professionals working there need to agree on things that are or are useful to ask"* (1-P). This suggest that there had yet been a consensus on the kind of ePROs that should be used in to measure different domains of QoL presently.

Another participant further explained how the terminologies used in questions could be interpreted in various manners if no one was present to clarify it in-person. It was quoted, *"what's the diarrhea for him like? Is it like loose stool? Is it like porridge or is it like water that runs through a patient like 10 times a day. So it's something that when people are filling up papers or answering questions, they sometimes get stuck into those really tiny details that actually don't cross others minds"* (1-P). This suggest that the terminologies used in ePROs could be misrepresented if there was no one present at that point to seek clarification, and that the contents of the questions in ePROs may not be consistent to different interpretation and therefore perceived to be a barrier to usage.

One participant mentioned how the poorly co-ordinated usage of ePROs in Estonia, despite its small population, hinders the usage of ePROs.

> *"In Estonia, everybody here is doing their own business. They have nice ideas, a lot of nice, really nice ideas but they want to do it themselves. So I think that the ePROs should be like really standardised"* (1-P),

This suggests the participant viewed that implementation of such digital tools were fragmented across Estonia despite the small number of oncology centres, and without a streamlined effort it would be a barrier in the usage of ePROs.

Overall, the inconsistent standardisation, in terminologies, guidelines, implementation of usage of ePROs and co-ordination the implementation with other oncology centres, was perceived as a barrier for usage of ePROs.

4.4 Benefits of using ePROs in routine oncology care

4.4.1 Time saved with the usage of ePROs

Participants mentioned about the potential time saved if ePROs was used. The functionality of the ePROs that gives oncologists' the ability to view patient outcomes for their appointments was seen to be beneficial.

> *"What kind of complaints, how serious or not serious they are. The picture is under me already. I don't have to ask additional questions. And I can just scroll quite quickly through the main problems (the) patient have had during their treatment course"* (4-P).

Time could potentially be saved by looking at the outcomes that were organised by the ePROs and need not repeat questions that have been answered by the prompts of ePROs. Another potential benefit of using ePROs was in the approach of sensitive topics through questioning.

> *"Question like, 'Did you worry' or 'Do you feel depressed?' Because if you start asking those questions in person, it's kind of a feeling of an attack or something like (that). And it requires a lot of time, like a lot of time, to go through the questions face-to-face. So I think that they (patients) would be more comfortable answering that on paper"* (1-P).

The quote suggest that it was time-consuming to start conversations on certain topics, but the use ePROs could make it easier for clinicians trying to elicit replies to challenging questions.

Another way that participants perceived time could be saved, is through deploying the input of ePROs during idle waiting time.

> *"I think the patient, when they're in the clinic, they always have to wait there. So I think it's also like a good time they can you know do something and it doesn't take so much time, but at the same time they have something to do"* (5-P).

Potentially, the time while waiting for laboratory results could be used to fill in ePROs, to maximise the time that patients spent in the clinic. Another participant shared in detail on how the whole journey of filling ePROs during patient's visit to the clinic could fit into her current workflow.

> *"When the patients comes to hospital, he or she first goes to nurses. And they (nurses) set the IV line and take blood tests. And during the waiting time, in order to receive the test results, they have like an hour (or) an hour and a half time. A window when they (nurses/patients) can fill in the blanks, so that's usable"* (1-P).

Lastly, time could be saved by having quicker access to medical service when ePROs are being used. One participant mentioned how the use of ePROs *"is one way for patients' to be monitored and to give them (the) possibility to tell about their symptoms (or) complaints twenty-four seven"* (4-P). This meant that patients' symptoms could be charted in real-time, without having to wait for an appointment prior. Another participant shared how a specific function in the use of ePROs could help determine patient to achieve quicker access to emergency service.

> *"(Patients) don't know when the situation is already serious, and they should call the ambulance or go to the emergency room. Then maybe this device (ePROs) also helps better that they (patients) can make up their minds more quickly"* (5-P).

Another function which was mentioned by one participant state that *"it also sends patients, if it's necessary, to the ER or call your doctor or call ambulance"* (4-P), where specific protocols in the software could automate services which could save the time in getting emergency services or other referrals, rather than waiting for another appointment by visiting an oncologist.

Overall, participants find certain specific functionality in the use of ePROs could help save time in access to healthcare service and administrative time, therefore perceived them as a beneficial.

4.4.2 Making more informed decision by oncologists using ePROs

The use of ePROs was perceived by one participant for patients to *"mostly report more symptoms with the PROMs than they tell to the doctor actually. So, they're being more honest"* (2-P). Using ePROs was seen to be a way to elicit detailed and honest answers, which could lead to better clinical judgement by oncologist. Another participant also mentioned *"(in) those clinical studies if the patient answers those questions before they come to the doctor visit, they (patients) will answer more. Maybe in the doctor visit, very often the patient don't want to complain"* (3-P). This suggest that the participant felt the use of ePROs would allow patients to mention more findings that could potentially be of benefit to the oncologists.

Other areas which another participant mentioned was how *"ePROs would allow us to, I think, to remember the data, to keep the data and to consistently monitored the data, how is it evolving in time"* (1-P). This coincides with how another participant perceived the ability of trending ePROs could benefit their care to patients which could assist the oncologist to make informed decision.

> *"If we can see a trend, for example, that's getting worse, or something we can tackle the possible side effects and problems beforehand when they get out of out of hand"* (2-P).

One participant mentioned ePROs *"gives like a quick and good overview I think, to also better clinical work."* (5-P), suggesting how these uses of ePROs would be beneficial in decision-making by the oncologist through better presentation of information. Besides having the presentation format that help better informed decisions, the ability for ePROs to be filled at home gives patients access to real-time charting and more time to ponder about their symptoms was also perceived as a benefit.

> *"I could see the patient, like, complaints and overall problems more quickly/.../ maybe they thought a little bit more truly about those problems and answer correctly, very often if they come to your appointment, they will forget what problem they have at home"* (3-P).

In explaining the above functionality of ePROs, it was suggested that ePROs could provide an overview and a more comprehensive assessment from patient to clinician,

therefore leading to better clinical care. Patient groups, particularly oncological patients who are in remission, were seen to benefit through the trending of data, where *"patients (who) are at more high risk to get (cancer) recurrence and then I see a definite benefit for using the ePROs because we may see something already beforehand"* (2-P). This suggests that for some cancer survivors, the use of ePROs could trend outcomes that would be beneficial for oncologist to make well-informed decisions if changes were detected.

Finally, references were made by participants to studies that involved ePROs suggested that their usage of ePROs could positively impact the survival of patients.

> *"Many studies already which have shown that if we document those ePROs, patient-reported outcome then even like the survival of the patients can be better"* (5-P).

Data that were collected from ePROs could be *"used… to publish something or have an overview in general how patients are doing... the main problems patients have you know to analyse our work and our data"* (5-P). This could potentially be a contribution to future research for oncologist, as a way to improve the reliability in making informed decision.

In conclusion, participants acknowledged that the data generated from ePROs could aid in their decision-making, and it was perceived that ePROs provided opportunities for patients to share their symptoms truthfully as well as the ability to look at data trends.

4.4.3 Empowering patients in their management of symptoms through ePROs

Participants perceived the potential usage of ePROs to empower patients through reflecting on their symptoms by looking through questions that was shown concurrently when they filled up ePROs.

> *"Those questions, like feeling tired or feeling anxious or feeling depressed are already in the list of all the symptoms, that patient (can) relate to. If the questions are about the appetite or the weight loss and diarrhoea or vomiting, and then the same Q (questionnaire) there also question about feeling depressed or not. They (patients) start just to see that it's so common that it is actually relevant. I think it's nice for them to get used to the fact that actually psychological health is*

important as or physiological side effects. And maybe they then start to fill (in) the questions as well" (1-P).

From the quote, the participants felt that by exposing patients to questions pertaining to topics such as depression, it could help normalise certain conditions which were not seen to be common for patients, thus patients could be more aware of these symptoms and be used to them, empowering them to self-manage.

One participant also shared that how ePROs allowed more time for patients to reflect on their symptoms better.

> *"They are sitting down; they are thinking about (their symptoms) and they are not rushed. I mean the patient has the ability of time to think about their symptoms. Write down everything, they have to think through their symptoms. And maybe when they think about these things, they can find quicker solutions and not miss very potentially a disastrous situation"* (2-P),

The perceived ability of ePROs to give more time for patients to ponder over questions was seen to not only allows patients to find an ideal solution but also to react to their symptoms sooner, which helps empower patient in management of their condition.

To sum it up, participants perceived that the use of ePROs could empower patients in normalising symptoms that they are not familiar with and allowing them to take charge in managing symptoms that may be associated with their condition.

4.4.4 Ease of using ePROs

Despite the differences in opinions about the ease in the use of ePROs, where it was previously mentioned as challenging, in this case some participants did not find it a challenge. It was brought up by one participant on a clinical study about how easy ePROs was being used.

> *"If the study showed that 90% of patients were available to use it, and they did, it means it's easy to use. And I use it myself, I was able to try it. It's really easy to use."* (4-P)

Another participant also finds the use of ePROs would be easy, assuming that *"things when they've been implemented and when people are being schooled. Then after that I think they're not difficult to use"* (2-P). It was further mentioned that the acceptance from other colleagues in the usage of ePROs would make it easy as *"I am quite positive about our clinicians because we do (know) what to expect from the data and from this platform"* (4-P).

Hence, participants felt that there were benefits in using of ePROs as it was not only shown to be easy by studies, but also the perceived ease due to the participant's own experience. Moreover, it was supported that with proper education, ePROs will not be difficult to be used.

5 Discussion

This chapter provides an analysis of the results that were gathered to fulfil the aims of the thesis. It includes participants' experiences in the usage of ePROs as an expert in the field of oncological care. Perceived benefits and barriers that were brought by the participants in the potential usage of ePROs in routine oncology care were compared with current literature. Lastly, limitations of the study and the further research using the results would be discussed.

5.1 Oncologist's experience in the usage of ePROs

There has been no prior published literature regarding oncologists' experience and knowledge of using ePROs within Estonia. Therefore, this thesis is the first to explore and outlines participants' knowledge and experience that makes use of patient-generated data and usage of ePRO in Estonia. Themes that were generated from the participant interviews indicated that oncologists in Estonia have knowledge of ePRO from a variety of sources. One of the sources include knowledge through medical conference or research literature, and this was not unexpected considering the large number of studies in the provision of oncology care with ePROs in recent years [8]–[15].

Other sources of experience in ePROs usage included participants' involvement in clinical trials during their career span. More details emerged on the process and frequency of collection, together with the level of access regarding these patient-generated data, where participants indicated that they did not have much control. This gave some insights on how oncologists were unable to harness the use of the data despite their participation in collection for clinical trials. Another source of ePROs usage came from ongoing pilot studies in their workplaces, with ePROs software such as KAIKU health being implemented. The momentum in the use of ePROs in routine oncology care is relatively new considering that these running pilot studies have only rolled out in some, but not all the oncology centres and in recent times as well.

Current exploration to seek the baseline experiences could be explained by the KTA process, where knowledge inquiry is first undertaken before research can be made into practice through knowledge translation [22]. Through understanding the different

experiences and knowledge of individual oncologists, the results could be used to facilitate the creation of knowledge and translation as part of healthcare workers' CPD.

In summary, oncologists working in Estonia possessed varied level of experiences in the use of ePROs, gained from theoretical knowledge to actual hands-on usage. These variations in experiences could be identified factors that can be applied in tailoring of knowledge to improve the success of implementing ePROs.

5.2 Perceived Barriers in relation to current literature

The findings from this study builds on existing literature and qualitative research that examines doctors' perspectives on the use of ePROs in routine care. The value of this study adds onto the contextual evidence that is related to Estonia, where it has been described to be an IT-mature society, with a health system that has been digitalised for more than a decade [51]. As such, oncologist working in Estonia possessed the unique perception of having more experiences in utilisation of digital tools. They are likely to be more self-efficient in using new technological tools and would face less anxiety with digital tools usage, as compared to doctors in other countries whose health systems are not as matured in digitalisation.

However, the perceived barriers of usage of ePROs mentioned by the participants in the study were comparable to the findings from various RCTs and systematic reviews that were done in other countries. Issues such as additional workload [15], [44] were equally seen to be a barrier, despite Estonia having establish a health system that uses digital tools a decade before. This indicates that the presence of resistance in the introduction of a new digital tool even though there was a climate of use previously. Other barriers such as challenges to use in certain groups in society with poor digital literacy were also brought up, but this has been a challenge that was well-acknowledged despite the prolific use of ICT in healthcare systems [51].

There were differing opinions regarding the ease in usage of ePROs. Although some felt that it could be a barrier, other participants felt otherwise. The contrast in the ease of use among participants suggest that there may be more underlying reasons that accounts for the difference. It had been understood that education alone may not be sufficient to enable

the use of ePROs in clinicians and requires a more-theory driven approach especially with in the use of ePROs that involves QoL [52].

Despite having more exposure in the use of digital tools by oncologists working in Estonia [51], the perceived barriers in using ePROs does not appear to differ much from existing literature. This could mean that perceived barriers in ePROs usage are independent of the familiarity of digital tools encountered by oncologists.

5.3 Perceived Benefits in relation to current literature

Benefits which have been mentioned by the participants provide additional value in existing literature on ePROs. Specifically, understanding how Estonian oncologists perceived benefits in the usage of a digital tool in routine oncology care provides essential views from a unique group of people who have been utilising digital tools in the delivery of care in their day-to-day work.

Benefits of using ePROs in previous literature mentioned higher quality of data and responses [14], positive impact in patient-clinician communication [8], [15] and improve frequency of discussion of symptoms during consultations [13]. This has been reflected from the perspective of participants, who felt that they could make better informed clinical decision and empowering patients in the use of ePROs. Additionally, participants also mentioned time that could be saved using ePRO, especially in the discussion of tough topics. Given that the use of digital tools has been ongoing in Estonia, the perspective of time saving could have been experienced from prevalent usage of other electronic tools for delivery of healthcare or digital tools in managing patients.

One prominent difference in the perceived benefit gathered from participants was regarding the ease of using ePROs. In this aspect, it had also been brought up as a barrier through the analysis of participants' perceptions. However, there had been no explicit factor identified for explaining the differences of opinion, likely due to the small number of participants. Other possible reasons include having the prior knowledge in the use of ePROs through spending time to test the digital tool or applying the use of ePROs in an actual live clinical scenario that could account for the difference.

All in all, the perceived benefits of participants were similar to those brought up by the existing literature. While several of the participants had been involved in the use of ePROs in their current line of work, they might perceive more benefits due to the actualisation of the benefits through daily usage in the care of patients. The co-relation in the variation on participants' experiences could also suggest the differences in their perceived barriers and benefits with the potential implementation of ePROs in routine oncology care.

5.4 Limitations of the study

There were several limitations to the study. Firstly, only a small number of participants agreed to be part of the expert interview for this study. Several attempts have been made to recruit participants from convenience or snowball sampling, but they have been unsuccessful. In view of the time frame given to complete the study for the presentation of the thesis, only a small number of participants participated, therefore the overall findings did not reach data saturation. In such a case, there may be more emergent themes regarding the oncologists' experiences and perceptions on the usage of ePROs which had not been identified. Despite not reaching data saturation in the thesis, the findings still provide relevance to have a basic understanding regarding the baseline of oncologists in all the oncological centres in Estonia.

Another limitation of the study was that only one stakeholder perception was taken into consideration. In the provision of oncology care, oncologists may be the leading expert, but other healthcare professionals such as oncology nurses and specialists such as psychologists, physiotherapists are also deeply involved in the provision of oncology care. It has also been mentioned by participants that oncology nurses were the primary respondents to manage ePROs alerts, rather than the oncologists. Therefore, the implementation of ePROs should consider others who may be gatekeepers in management of the data, rather than only those who utilises the data to lead decisions. During the recruitment process, one oncology nurse responded to the recruitment of participants and agreed to the interview, however her input was not included in the findings. By including the viewpoint of other experts who are also involved in the field of oncology care, it could possibly give a broader and comprehensive perspective regarding the usage of ePROs in routine oncology care.

Despite the above limitations mentioned, the results have provided some value in establishing a baseline of oncologists' experience and perspectives regarding ePROs usage in Estonia.

5.5 Future research

By establishing a baseline for the experiences and perspective on Estonian oncologists on the potential usage of ePROs, future research could make use of the themes identified in the thesis to create a framework for quantitative studies in the future. Having a higher number of participants in future studies would also improve the quality of the results. As more oncology centres starts to roll out pilots in the usage of ePROs, future studies can be designed to compare utilisation rates after establishing the baseline knowledge of participants. Another point of contention would be the perceived ease of using ePROs, where opinions were divided regarding this area. Future work could also undercover in-depth factors which could contribute to these divisive opinions. More importantly, future research could engage the opinions of a wider range of experts in the field of oncology care, such as oncology nurses, psychologists, and physiotherapists, in the implementation process of ePROs. The opinions of other stakeholders who may be involved in the implementation of ePROs, including hospital administrative managers, IT managers and patients are also driving forces in successful implementation and should be explored as well. To summarise, future studies could explore the perspectives from other experts and important stakeholders who are involve in provision of oncology care, and by consolidating these views it could produce a comprehensive implementation strategy.

5.6 Conclusions

This study drew several conclusions. Firstly, experiences in the usage of ePROs by oncologists who work in Estonia varies between conferences, research literature, usage in clinical trials and in current ongoing pilots in Estonia. Despite participants having experience in the use of digital tools previously, the barriers and benefits expressed towards the implementation of ePROs in routine oncology care does not appear to differ vastly. A difference in the ease of use of ePROs was shown in the participants, where some perceived it as barrier but not others. Although there were a small number of participants, the contributions made by the oncologists in this thesis is still valuable

towards the implementation of ePROs in routine oncology care, by facilitating implementation strategies in knowledge translation to increase the success of implementation. Future research on the implementation could gather viewpoints of other experts in the provision oncology care to patients and other stakeholders who will benefit from the use of ePROs as a personalised health service.

6 Summary

This study aims to benchmark the experience of oncologists working in Estonia in the usage of ePROs, which makes uses of patient-generated data to improve the value of healthcare to patient. It also aims to seek out the perceived barriers and benefits in oncologist in the use of ePROs.

Results in the experience of usage of ePROs pointed to several sources, with academic literature and conferences as the main source of knowledge. While ePROs usage has been established in clinical trials, clinicians do not have control in accessing the data. There are ongoing pilots in the use of specific ePROs software within different oncology centres and a small number of oncologists have experienced usage during their routine oncology care.

Themes that have emerged from the participants' perceived barriers in the use of ePROs includes increased resource requirement with implementation, challenges to usage of new technology use for older adults, challenges in ease of use and inconsistent standardisation. In the perceived benefits, themes that were generated by participants were time saved with the usage of ePROs, making more better-informed decision, empowering patients in their management of symptoms and the ease of using ePROs. These themes have overlaps in both the barriers and benefits faced by clinicians in existing randomised-control trials and systematic reviews and does not have deviate much from oncologists working in Estonia, who may have a better grasp of using digital tools.

Overall results from the study could be utilised in as a baseline in the use for future implementation strategies in establishing ePROs during routine oncology care. As this study only covers the oncologists' views, future research could seek the views of other healthcare professions involved in oncology care, policymakers from organisations or taken from patients' perspective.

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Appendix 2 – Interview Guide

PART 1

TABLE 1: Background of Clinicians – (Knowledge + Experience)

Questions	Other Prompting Questions	Purpose
1. Demographics a. Year of birth b. Years of working experience (including residency)	• Re-confirming their location of work	Demographical information
2. How much do you know about electronic Patient Reported Outcomes (ePROs)?	• If extensively heard, please elaborate and continue on to question 2 • If not much heard or if with other clinicians, probe if they personally have heard in conferences, research papers etc., go on to question 2	Differentiate different clinician based on knowledge
3. What is your experience in the use of ePROs?	• Using them in specific areas (e.g. clinical trials, case report forms, clinical care, collection by other disciplines) • Probe if they have collected PROs using paper and pen, then transcribed to digital platforms	Differentiate different clinician based on experience Traditional way of using PROs VS Not using them
4. Based on your experience, how frequent is it being used in oncology care?	• Special circumstances – e.g. Use of trial medicine, Use during new treatment • Routinely (every consultation)	Baseline in frequency of use - Hospital-wide implemention - Self-use

PART 2

TABLE 2: Barriers

Question	Other Prompting Questions	Purpose
Based on participant's knowledge and experience		
5. How do you feel if ePROs are implemented in **routine oncology care before your consultation?**	Rephasing: 'What do you think of the idea for patient to fill in their reported outcome status electronically before every session?'	To gauge their thoughts and lead on to their perceived barriers and opportunities.
6. What are the barriers/ obstacles expected if ePROs are implemented routinely? OR Are there problems you might foresee when ePROs are implemented routinely?	If responses are minimal, prompt them with secondary questions, based on domains - Data Integration, Clinical Integration (clinical care, multidisciplinary) - Accessibility (viewing and analysis) OR prompting words – acceptable for patients, skills level, training, increased time, costly etc. OR comparing from their experiences based on what they have described.	Perspective in barriers in the use of ePROs based on the scenario or their own prior experiences **<u>For Analysis</u>** Thematic Analysis - Patient level, Clinician level, Service/Infrastructure level

PART 3

Table 3: Benefits

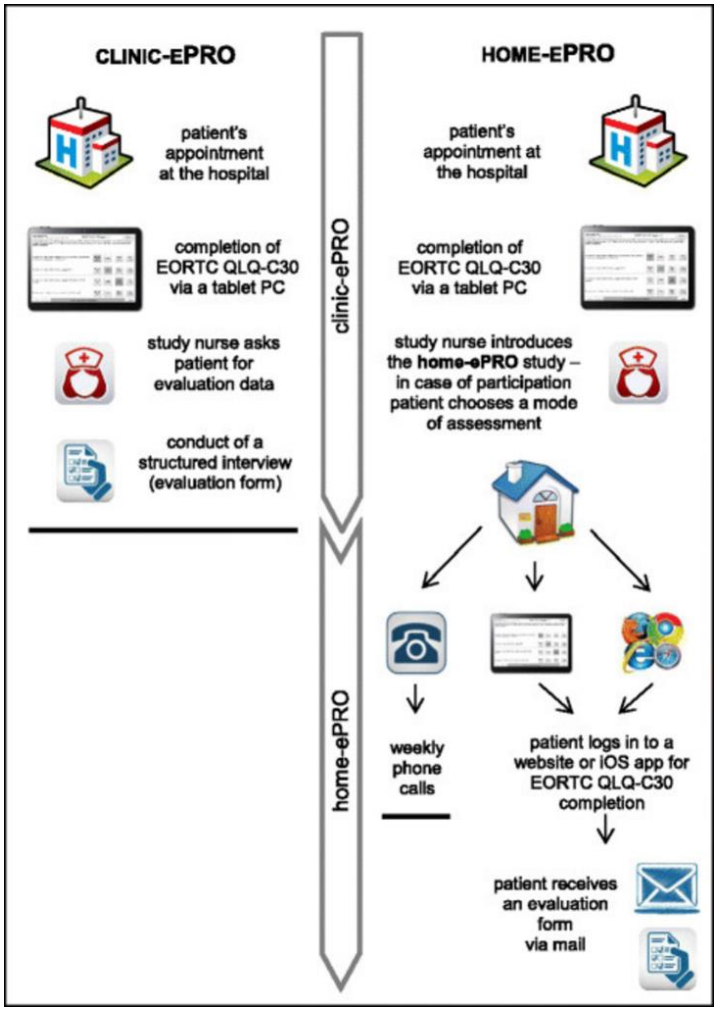
Question	Other Prompting Questions	Purpose
Based on participant's knowledge and experience		
7. Any there any benefits in using ePROs in routine oncology care?	Suggested scenarios as above • Patient level, Clinician level, Service/Infrastructure level	**<u>For Analysis</u>** Thematic Analysis
8. In your opinion, do you think ePROs is useful for routine clinical use presently? 9. In your opinion, do you think it is easy to use is useful for routine clinical use presently?	For these questions: YES/NO Elaborate more on their opinions and consolidate them	

Appendix 3 – Information Sheet on ePROs

What is Electronic Patient Reported Outcomes (ePROs)?

Defined by *Cochrane Handbook for Systematic Reviews of Interventions*, PRO are outcomes directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment.

The outcomes may be measured in absolute terms, such as a patient's rating of the severity of pain and or through tools or instruments (Patient Reported Outcome Measures or PROMs) which can be either broad-based or disease specific.
An electronic PRO (ePRO) is the electronic version of PROs, and the assessment system involves capturing these outcomes electronically, using tablets, touchscreen devices, text messages or even voice response technology. An example of ePRO assessment system is shown (infographic) using an attached copy of EORTC QLQ-C30, which is commonly used in oncology care.



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ⌊_⌋⌊_⌋⌊_⌋⌊_⌋

Your birthdate (Day, Month, Year): ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋

Today's date (Day, Month, Year): 31 ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

Appendix 4 – Information for recruiting participants

Hello!

I am a student of TalTech University, enrolled in the Masters' Degree in Digital Health. I am also currently an intern at NORDeHEALTH, where the project aims to identify challenges and opportunities in digitalization of health services within the Nordic countries. I am current doing my research thesis regarding the use of Electronic Patient Reported Outcome (ePROs), specifically in oncology care. The main aim is to explore the experience of clinicians in usage of ePROs, the barriers and future opportunities. The ethics committee has given their approval in conducting this study and my supervisor for this thesis is Dr Kerli Luks (MD). For any more information, you can reach me at tenkoh@ttu.ee

If you are currently involved in the routine care of oncology patients in your clinic, your input will be greatly useful in shaping the future use of ePROs in routine oncology care. It will take place in a form of a 25-minutes interview and can be done via an online platform. All opinions and information provided in the interview will be kept strictly private and confidential, no personal identifiers will be collected.
I look forward to your participation and thank you for your time.

Teng Han

Tere!

Olen TalTechi Ülikooli üliõpilane, magistriõppes digitaalse tervise alal. Samuti olen hetkel praktikal ettevõttes NORDeHEALTH, kus projekti eesmärk on välja selgitada väljakutsed ja võimalused tervishoiuteenuste digitaliseerimisel Põhjamaades.
Teen praegu oma uurimistööd, mis käsitleb elektroonilise patsiendi teatatud tulemuste (ePRO) kasutamist, eriti onkoloogias. Peamine eesmärk on uurida arstide kogemusi ePRO-de kasutamisel, takistusi ja tulevikuvõimalusi. Eetikakomitee on andnud oma nõusoleku selle uuringu läbiviimiseks ja minu selle lõputöö juhendaja on dr Kerli Luks (MD). Täpsema info saamiseks võite minuga ühendust võtta aadressil tenkoh@ttu.ee

Kui tegelete praegu oma kliinikus onkoloogiliste patsientide rutiinraviga, on teie panusest palju kasu ePRO-de edaspidise kasutuse kujundamisel rutiinses onkoloogilises ravis. See toimub 25-minutilise intervjuu vormis ja seda saab teha veebiplatvormi kaudu. Kõik intervjuul esitatud arvamused ja teave hoitakse rangelt privaatsena ja konfidentsiaalsena, isikuandmeid ei koguta. Ootan teie osalemist ja tänan teid aja eest.

Teng Han