Liis Piirsoo

# Development of a framework for collecting patient experience data in Haapsalu Neurological Rehabilitation Centre

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| Author | Liis Piirsoo |
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The purpose of this study was to develop a framework for collecting patient experience data in Haapsalu Neurological Rehabilitation Centre (HNRC) located in Estonia. This developmental project aimed to create a questionnaire and a framework that addresses key aspects of care from a patients' perspective for everyday use in HNRC.

In this development project, qualitative descriptive method was used. 11 employees of HNRC were individually interviewed to understand which aspects of patients' experiences should be included in a questionnaire. After the data analysis with inductive content analysis model, a preliminary version of the questionnaire and a framework was formed. Additionally, a focus group of four members from HNRC was conceived, that developed the final version of the questionnaire and a framework.

From the analysis of the data gathered from the interviews, four big picture categories emerged about the aspects important for patients related to HNRC and their care in HNRC: factors related to personnel, services, living conditions, and leisure time opportunities. Based on the data, a questionnaire that consisted of 22 questions was formed. There were some room left after every question to add a qualitative element to the questionnaire. Also, some demographic features were added, and suggestions to make the form available online, collect near-time data, answering to be anonymous, and to collect feedback from all inpatients.

This work is unique in Estonian medical field, as there is little research done in the patient experience area. Other medical facilities in Estonia are using patient satisfaction questionnaires, there is no known other medical facility planning to start using a framework of collecting feedback that considers patient experiences. This work was the first phase of a larger developmental project, that aims to create and implement the system of collecting, analysing and presenting the patient experience feedback in HNRC. As a result of this work, a framework to collect patient experience data in HRNC was proposed. The next phases of the project should be: inclusion of patients to enhance the validity of the questionnaire; creating an IT-solution for the questionnaire; developing of a system to analyse and present the data gathered; implementation of the full system.

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| Keywords | Patient experience, neurological patient experience, inpatient rehabilitation, questionnaire, inductive content analysis |

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# 1 Introduction

Patient experiences, care quality, and effectiveness are increasingly important and strongly related aspects of modern health care. Western countries are using patient experience data extensively to measure the quality of health care, clinical quality, safety, and effectiveness. Patient experience data is considered as a key component of quality of care, thus gathering this information is in the interest of policy makers, health care facilities, as well as patients. Literature supports the fact that there are many positive associations linked to a better patient experience – increased clinical health outcomes, self-assessed physical and mental health status, adherence to recommendations, and safety of care. (Ahmed, Burt & Roland 2014: 236, 239; Anhang Price et al. 2014: 11; Anhang Price et al. 2014: 5; Doyle, Lennox & Bell 2013: 1, 4; Feng et al. 2020: 2.)

Patient experiences or feedback could be collected in many forms, all of them have advantages and disadvantages when used in real life and on a regular basis. The focus in patient experience measurements is on what happened with the patient during hospitalization or service provision. Also, measurements should focus on key aspects of care that are important for patients, and to gather meaningful patient experiences, collecting real- or near-time data is considered to be the most effective. (Beattie, Murphy, Atherton & Lauder 2015: 2; Edwards, Walker & Duff 2015: 82; Gibbons, Hewitson, Morley, Jenkinson & Fitzpatrick 2015: 180.)

Although gathering patient experience data has a potential to bring out solutions and opportunities for quality improvements, it is seen that much of the data collected is not used in a meaningful way. Barriers seen from an organization point of view are the time and resources available from staff, not having a priority to gather and analyse the data for a longer period of time, lack of plans to use the data, not including employees, and lacking of skills to understand the data. (Gleeson et al. 2016: 2; Sheard, Peacock, Marsh & Lawton 2019: 49.)

Haapsalu Neurological Rehabilitation Centre (HNRC), a modern neurorehabilitation centre in Estonia, sets patient-centred approach as a priority in their care. Hospital gathers patient feedback in a regular basis from all inpatients. Currently used patient feedback system is used as a management tool, and measures mostly patient satisfaction. Developed countries are moving to a direction of gathering patient experiences instead of collecting patient satisfaction data – patient experiences are expected to view aspects of care in a deeper level, and encompass the care from a wider perspective. To support HNRC's core values and strategic objectives, there is a need to take a step further in gathering feedback from patients, so the feedback system would create a comprehensive picture of patient experiences related to HNRC, and show aspects that are important for patients about their care in HNRC. (HNRK 2019: 4; Wolf 2017: 7.)

According to the evidence found, and in line with HNRC's values and strategic objectives, a framework for collecting the data and a tool that measures patient experiences, is the purpose of this Master's Thesis. This thesis aims to create an instrument for HNRC for everyday use, that addresses key aspects of care from a patients' perspective.

# 2 Background information

## 2.1 Patient experience

The Beryl Institute, a global leader in improving patient experience in health care, defines patient experience as "the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care" (The Beryl Institute 2023). This definition aggregates four concepts: interactions, culture, cross-continuum view, and perceptions. Interactions can be further seen as touchpoints of people, processes, policies, communications, and environment. This part highlights that experience of health care happens in different places, mainly between people. Culture could be viewed as values an organisation has, and people in it. Patients' experiences are strongly related to the culture an organisation has – patients might be able to derivate organisation's values according to the service they receive, and an attitude personnel has. A cross continuum of care shows that the experience does not start or end at admission and discharge, acknowledges that experience is not hospital centric, and both direct and indirect interaction could be associated with the organisation. Lastly, but the most critical part of the definition is perceptions: "… experience remains beholden to one test: It is only as true as the perceptions of those having the experience." (Wolf 2017: 5–6.)

Patient perceptions could be further looked as things recognised, understood and remembered by patients and their support people. Thus, the term patient experience refers to the process that is observed by patients: key aspects of care are measured from a patients’ perspective. These processes can be either subjective or objective experiences of patients, or patients’ observations of staff behaviour. Per example, patient experience includes elements related to setting an appointment, cleanliness, waiting times, provided information, and communication with employees. (Ahmed et al. 2014: 236–7; Anhang Price et al. 2014: 5; Gualandi, Masella, Viglione & Tartaglini 2019: 2; Wolf 2017: 6.)

There are many positive associations found to be linked to a better patient experience. Positive associations have been found for both objective measures of health outcomes, as well as self-assessed physical and mental health status. Better clinical health outcomes related to better patients’ experiences have been found particularly in inpatient setting. Evidence strongly supports the link between higher levels of adherence to recommendations and positive patient experience, highlighting the importance of clinician-patient communication. Positive associations have been found between better patient experience and safety of care.  In technical quality of care, a systematic review by Doyle and colleagues (2013) found mixed evidence about associations between patient experiences and technical aspects of care. Adding to that, gathering patient experience data is a viable resource to improve health care services. All these aspects combined, better patient experience is related to less health care utilisation, meaning lower health care cost for the society. (Anhang Price et al. 2014: 11; Doyle et al. 2013: 4; Feng et al. 2020: 2; Gibbons et al. 2015: 179.)

## 2.2 Patient experience vs patient satisfaction

In the literature, there is a debate in how the terms “patient experience” and “patient satisfaction” are in connection with one another, and what is the nature and directions of their relationship. Although it has been brought out that some authors use them interchangeably, most authors distinguish the two terms. (Ahmed et al. 2014: 236.) The term ”patient experience” was described in previous subchapter. Patient satisfaction could be viewed as the gap between patient expectations and experience. Satisfaction is often overrated, therefore the validity and usefulness of the satisfaction data is debated, leading to the trend and direction of collecting more and more patient experience data about the quality of care. (Beattie et al. 2015: 2.)

Wolf (2017) argues in his article that the concept of patient experience is much wider and encompasses more. While satisfaction captures perceptions at points in time, experience is the lasting story that patients carry with them. Moreover, patient experience colours the lens through which an organisation is seen in the present and future, and influences what patents tell others about the organisation. Thus, Wolf (2017) lists patient satisfaction as a part of patient experience, while other authors see patient experience as a part of patient satisfaction. Ahmed and colleagues (2014) add that the conceptual view might be dependent on the level at which feedback from patients is studied.

While patient satisfaction and experience might seem similar in nature, it is seen from different authors' work that most of them view these as different concepts. It is an important distinction to acknowledge, as it gives an idea about how wide aspects the collected data covers, and how deep information could be expected. In the context of rehabilitation, the concept of patient experience is unquestionably important, as in many cases the patient has a long-term and recurring relationship with the health care and rehabilitation system, and in many cases might have prolonged connection with one facility. Thus, gathering patient experience data might give more understanding about patient preferences, and the story behind those. (Ahmed et al. 2014: 236; Wolf 2017: 7.)

## 2.3 Collecting patient experience data

There are various ways and methods how patient experience data could be collected, all of them have their advantages and disadvantages that will be discussed in more details below. Specific attributes could be pointed out from the literature, that could make the data collection more beneficial, for example which kind of questions are asked, how long the data collection instrument is, and when the data is collected. Other important aspect to consider when collecting patient experience data is, what happens to the data, how, when, and who is going to use it. (Beattie et al. 2015: 2; Edwards et al. 2015: 82; Gibbons et al. 2015: 180.)

### 2.3.1 Different data collection methods

In general, collecting patient experience data could be viewed as quantitative/qualitative, or hospital-initiated/patient-initiated. As this work concentrates on hospital-initiated forms of gathering patient experience data, patient-initiated methods are discussed briefly. Marsh, Peacock, Sheard, Hughes & Lawton (2019: 323) list categories in which way patient experiences can be collected: hospital-initiated quantitative surveys, hospital-initiated qualitative feedback, and patient-initiated qualitative feedback

Hospital-initiated quantitative surveys are the most common in clinical settings. Quantitative methods are popular due to their relatively simple analysis, possibility to generalise, and compare. They come in a form of questionnaires that can be filled in paper, online, hand-held devices or kiosks. It has been brought out that questionnaires tend to cover issues important for organisations about their service delivery. Adding to that, it is brought out that surveys can show general level of satisfaction with the service but offer little understanding about why patients are satisfied or not. Many questionnaires used are relatively long, and as most quantitative data, aim to generalise and compare between organisations or over time. Effort has been made with make shorter versions of some surveys, without losing their core ideas. Although being the most common form of collecting patient experiences, quantitative methods are criticised in providing overly positive results, not reflecting the actual situation, not being able to cover all aspects of patient experiences, and being slow in giving feedback to staff. (Ahmed et al. 2014: 237; Beattie et al. 2015: 2; Edwards et al. 2015: 82; Gleeson et al 2016: 2; Gualandi et al. 2019: 2; Jenkinson, Coulter & Bruster 2002: 256–7; Marsh et al. 2019: 319-321.)

In hospital-initiated qualitative feedback category, qualitative methods are used to collect patient experiences. These include patient interviews, focus groups, patient journey mapping, diaries, observation, shadowing. Qualitative types of feedback are expected to analyse patient experiences more in-depth, and look at patient concerns more closely, thus content is being determined, what is important for patients. Although patient interviews are the most common form in this category, the importance of using unstructured diaries completed by patients is highlighted. On the other hand, it is shown how real-life experiences can change in time, and how high-emotional situations may not be covered adequately. Also, it is emphasized that patient shadowing may give valuable information about real-time experiences, and cover the whole picture. However, there are ethical aspects of shadowing that need to be thought trough, as well as how to limit subjectivity of the shadower. Although it has been shown that qualitative ways of collecting patient experience data is more likely to bring out negative experiences of care, it is mostly used for research purposes due to its time expenditure and cost of collecting and analysing such data, and difficultness to interpret such data without bias. On the other side, it has been shown that clinicians and ward staff prefer the qualitative data over numerical data, that is mostly collected via questionnaires and surveys. (Gleeson et al. 2016: 4; Gualandi et al. 2019: 2; Marsh et al. 2019: 318, 321.)

Patient-initiated qualitative feedback could be seen as unofficial patients’ feedback. In controversy to the second category, this type of qualitative feedback is initiated by patients, is created whenever they choose to, and in most cases, is available to organisations quickly or in real-time. Methods vary greatly - feedback from patients about their experiences could be retrieved via complaints and compliments they give to the medical staff, thank you cards, online systems that collect feedback, and external webpages (Ahmed et al. 2014: 237; Marsh et al. 2019: 320).

According to Beattie et al. (2015) quantitative methods as surveys and questionnaires will probably stay as a core method of measuring patient experience in clinical practice and when used as regular processes, but they do highlight the need for combining different, quantitative and qualitative, methods to gather comprehensive information, create compelling evidence, and a whole picture of patient experiences. Experiences cannot be evaluated by using only standard questions, nor analysed by solely focusing on individual aspects of the experience. Qualitative patient experience data provides not only supporting but additional insights necessary to understanding some aspects of patient experiences not possible to see through quantitative methods. (Edwards et al. 2015: 80; Marsh et al. 2019: 318.)

### 2.3.2 Attributes of patient experience data collection methods

Beattie et al. (2015) emphasise how instruments used for collecting patient experience data need to be thought through in where they are used and what kind of information for who is needed, so they would have high utility in real-life practice. The focus in patient experience data is on “What happens to patients?” and “How they describe this experience?”, thus it describes “How patients feel about their care?”. Therefore, questions asked in patient experience measurements are designed around what happened during hospitalisation or service provision, and asking questions starting with whether or not, or how often they experienced certain processes. In these measurements it is considered that the experience is not only the time a patient spends in an hospital. The experience is much wider, including elements of direct and indirect interaction. Other feature to consider when designing the questions is, how questions are phrased. It has been found that, in neurological population, positive statements are easier to understand than negative statements. (Ahmed et al. 2014: 236–7; Beattie et al. 2015: 2; Kneebone, Hull, McGurk & Cropley 2012: 835; Wolf 2017: 7.)

Gibbons et al. (2015) bring out that some health questionnaires have grown extensively in length and diversity, as feedback from patients could be collected about many aspects of care. The authors highlight the need for questionnaires to focus on key aspects of care that are important for patients. Thus, a burden for a patient as a respondent would be minimal. That would potentially make the questionnaire more acceptable for patients.

Edwards et al. (2015) highlight that to capture meaningful patient experiences, collecting real- or near-time data is the most effective. This means that the data is collected either while patient is still in the hospital or immediately after discharge. The authors bring out that there are ethical and validity concerns when collecting real-time data, as patient might tend to give out more positive feedback for fear of jeopardising treatment. In controversy to that, health care staff see timely and fresh information as having a greater validity.

### 2.3.3 Results of collecting patient experience data

Patient experience measurements can highlight potential solutions and opportunities to improve the quality of care. Although it has been brought up in many sources that collecting patient experience data has a potential to bring upon quality improvements, it is argued how much of the data is used in a meaningful way. (Ahmed et al. 2014: 239; Beattie et al. 2015: 2; Gleeson et al. 2016: 2; Sheard et al 2019: 47.)

A qualitative study by Sheard et al. (2019) among ward staff found that much of the data seems to be collected to “tick the box” of collecting patient experience data, rather than figure out ways, how the feedback could be used for improvements. Barriers around the organisation’s ability to use the data collected include time and resources available for collecting and analysing data, setting up the collecting of the data, making analysing of the data a priority for a longer period, lacking of clear plans to use the results for quality improvements, and employees’ inclusion in setting directions for changes. There is also evidence that employees may lack skills to effectively use the data to identify the areas for improvement and implement changes. (Gleeson et al. 2016: 2; Sheard et al. 2019: 49.)

# 3 Development work setting

## 3.1 Estonia

Estonia is a Baltic country located in North-East Europe. Population of Estonia is around 1,3 million. Historically Estonia has been under different countries' occupation, independence was regained in 1991. Since then, country has undergone major reforms, health care system included. After regaining independence, main policy objective has been an integration with international organizations and unions – Estonia is a member of European Union (EU) and Eurozone, National Atlantic Treaty Organization (NATO), Organisation of Economic Cooperation and Development (OECD), World Trade Organisation (WTO). Economically, conservative fiscal policy combined with liberal economic policy, and simple taxation system, have created a stable economic environment and growth. Joining EU in 2004 had a significant additional impact in county's economy and Estonia is considered as a high-income country since then. (Habicht et al. 2018: 2, 4.)

Reforms in early 1990s completely changed the health care system's financing, organisation, and planning. The goal of these major turnaround was to ensure the funds for health care, to enhance system efficiency, and to improve responses to the needs of the Estonian population. In the centre of the reforms was the establishment of a social health insurance model, so funds were collected through earmarked tax instead of financing health care from the state budget. Additionally, provider network was completely restructured, universal access to family physician services was established, reimbursement system for pharmaceuticals was developed, and system shifted to prevention of non-communicable diseases and health promotion. (Habicht et al. 2018: 19-20.)

## 3.2 Estonian health care system

The health care system is managed by Ministry of Social Affairs and its agencies. Financing of the system is mostly organised through independent Estonian Health Insurance Fund. Reforms conducted in early 1990s moved the centrally funded and managed model to a decentralised model. The system is mostly publicly funded, 2/3 of total health care expenditure comes from solidarity-based mandatory health insurance contributions in a form of an earmarked social payroll tax. (Habicht et al 2018: 16, 52.)

Primary care is provided by independent family doctors working in solo or group practices. Family doctors serve clients based on a practice list, and are the first contact with the health care system. To see most specialists or to be admitted to the hospital, patients need a referral from their family doctor. Secondary level health care services are provided via publicly or privately-owned providers (hospitals or outpatient clinics), sector is dominated by public hospitals that are mostly owned by the state, local governments, or public legal bodies. Hospitals operate under private law as joint-stock companies or foundations. (Habicht et al 2018: 28, 119, 126.)

In 2003, government approved Hospital Network Development Plan, that forms the main tool for hospital governance. The decree lists of 19 hospitals, that form the base of Estonian health care system, and guarantee equable service provision in all areas. Hospitals are divided into five categories: regional, central, general, local, and rehabilitation hospitals. (Haiglavõrgu arengukava 105/2003.)

Health care providers and Estonian Health Insurance Fund are connected via contracts that set the terms of funding of health care services: quality, access, and detailed cost- and volume-based financial appendices. Although the contracts cover conditions for five years, financial appendices are negotiated every year, and can be adjusted semi-annually. Capped cost and volume contracts are negotiated between Estonian Health Insurance Fund and each service provider at the beginning of each year. Negotiations determine the volume of services as well as the average price per speciality. Both public and private providers can be contracted by Estonian Health Insurance Fund. Hospitals that are included in the Hospital Network Development Plan are favoured in contract negotiations with Estonian Health Insurance Fund, and are major recipients of most investments. (Habicht et al 2018: 71-73, 110, 127.)

### 3.2.1 Rehabilitation system in Estonia

Estonian rehabilitation system is fragmented. The system consists of three main parts. Medical rehabilitation is provided by the health care system, and aims to restore impaired and preserve restored functions. Social rehabilitation is provided by the welfare system, and aims to achieve or restore social participation. Vocational rehabilitation is provided by the employment system, and aims to prepare people with special needs for work, support their search for jobs, and help maintain their ability to work. (Habicht et al 2018: 136.)

Medical rehabilitation is provided by the health care providers. Access to the rehabilitation services requires a referral, there is no formal procedure for referring patients to rehabilitation, the decision is made by a physician. The number of services and duration of rehabilitation Estonian Health Insurance Fund covers is limited, there is a system that assigns the volume of services, and for inpatient rehabilitation, how many hospital days the patient gets according to diagnosis and condition. Social and vocational rehabilitation operates separately from the health care system. In those systems, the need for services is assessed and decided by the team working for the Social Insurance Board or the Unemployment Insurance Fund. Overall, rehabilitation system in Estonia uses team-focused approach. Different specialist that are usually included to the team are: doctor, social worker, nurse, carer, physiotherapist, occupational therapist, speech therapist, psychologist, and other specialists. In varies greatly how many and which specialists are working in which service provider. (Habicht et al 2018: 136-137; Lai et al 2015: 29.)

Estonian rehabilitation system is criticised for not being able to assess people’s comprehensive needs. The main reason for that lays in the fragmented system, confusing pathways, and a few links between different systems that have been described above. At the national level there are several initiatives to improve the system:  integrate different systems, increase the overall quality of rehabilitative services, modify system to be more needs-based and goal oriented, and guide the services to be more community-based. Since 2000’s, several steps have been taken to increase access to rehabilitation services. The steps to increase the importance of these services include improved legislation, additional funding, and promoting bigger role for mid-level health care professionals. Nevertheless, according to World Bank Group Analysis, limitations in rehabilitation capacity and accessibility result in high level of unmet needs, and the deterioration of patients’ conditions, that leads to higher levels of care. It is also brought out that the barrier for service provision is mostly due to lack of staff. Moreover, it is seen that the system lacks clear pathways of care, cooperation and continuity between health and social systems. (Habicht et al 2018: 16, 110; 166-167; Lai et al. 2015: 29.)

### 3.2.2 Patient feedback in Estonian health care

Estonian Health Insurance Fund emphasizes in their quality of care development plan 2018-2021 the importance of asking feedback from patients, and patient feedback analysis by the hospitals regularly. The decree sets the requirements for service providers to ensure the quality of health care services, and to measure patient satisfaction is one part of the quality system. Health care service providers are required to at least once a year to analyse and conclude patient satisfaction and complaints. Results have to be made publicly available. (Eesti Haigekassa; Tervishoiuteenuse kvaliteedi tagamise nõuded 128/2004.)

Largest health care service providers in Estonia have a similar system for collecting patient feedback. Once a year, a study is conducted in 6 of Estonian biggest hospitals. The hospitals can choose the details, but form and method are the same. It usually lasts about 1 month and during that time, selection of patients is chosen to answer a set of questions about satisfaction of care provided. In 2021 the form consisted of 30 questions. Additionally, all biggest hospitals have a form available in websites where feedback can be given all the time, structure of the form varies depending on a hospital. It is required for hospitals to present the results on their websites but in some cases it is not easily findable, and the content about what is included in reports varies greatly. The author of this work was not able to find published and freely accessible information considering gathering patient experience data in Estonian health care. (Ida-Tallinna Keskhaigla 2022; Ida-Viru Keskhaigla 2022; Lääne-Tallinna Keskhaigla 2022; Pärnu Haigla 2022; Regionaalhaigla 2022; Tartu Ülikooli Kliinikum 2022.)

## 3.3 Haapsalu Neurological Rehabilitation Centre

### 3.3.1 Overall information about Haapsalu Neurological Rehabilitation Centre

Haapsalu Neurological Rehabilitation Centre (HNRC) is a public hospital in Estonia that is focused on neurological rehabilitation for adults and children (HNRK 2022). HNRC is a part of Hospital Network Development Plan since 2018, and is the only hospital included in the network that is focused on one speciality, rehabilitation (Haiglavõrgu arengukava 105/2003.) Hospital offers inpatient services in 102 beds, thus being the biggest service provider for inpatient rehabilitation services in Estonia. HNRC provides rehabilitation services from early intensive inpatient rehabilitation to outpatient services.

In 2021 there was almost 2200 inpatient, 1450 outpatient, and 70 day-care cases. Inpatient services were conducted in more than 27 000 bed days. Main funder of services is Estonian Health Insurance Fund, that covered around 85% of services conducted in 2021. As a competence centre for neurological rehabilitation in Estonia, HNRC offers services for people all over Estonia. Inpatient services are conducted proportionally to a population in different counties, outpatient services are targeted to people from western Estonia. (HNRK 2019: 5; HNRK 2021: 3, 11, 17).

HNRC’s core values are quality, patient-centeredness, professionalism, innovation, cooperation, and honesty and consideration. The hospital values person-centred and inclusive approach, and is focused in supporting people according to their impairments to help them participate fully in their roles: to study, work, spend leisure time etc. There are around 160 employees in HNRC. Everyday work is organized in three departments: neurorehabilitation unit, spinal rehabilitation unit, paediatric and musculoskeletal rehabilitation unit. Each department divides into two sub departments: nursing and therapy. In the therapy part, physiotherapy, occupational therapy, speech therapy, psycho-social services, and other supportive therapies are provided. Care is organized in diagnose-based departments, and regular planned meetings are conducted to enhance team-based approach. (HNRK 2019: 12; HNRK 2021: 5, 11.)

### 3.3.2 Current patient feedback system

HNRC has two official ways to collect feedback from patients: written questionnaire and compliments/complaints/proposals form. Both forms are available in Estonian and Russian languages. Questionnaire is in paper format. The questionnaire has nine questions all together from which one question has 14 sub questions. First five questions are related to patients’ attributes (per example age, main way of mobility etc). A question that is divided into 14 parts asks about satisfaction with different services: physiotherapy, nursing services, living conditions, aid centre etc. These sub questions are ranked in 4-point scale (very satisfied, satisfied, not satisfied, not satisfied at all), there is also a box available if a certain service was not used by patient. A small comment area is added at the end of each question. Next two questions ask about what is valued most about HNRC and what could be changed. These questions only have comment area. Last question is related to the recommendations given from HNRC, and whether patient plans to follow them. This question has five different options: definitely yes, rather yes, rather no, definitely no, have not got recommendations. (Paesüld 2022.)

From the description, it could be seen that HNRC’s current system combines aspects of quantitative and qualitative methods, as suggested by Beattie et al. (2015) to be the most efficient way in collecting patient feedback. The feedback concentrates in asking questions about the satisfaction of different services, and household. The current questionnaire is not designed to ask questions about patient experiences, thus the data gathered might not capture the comprehensive picture of patient care, nor cover aspects not directly related to care. (Beattie et al. 2015: 2; Englas 2022.)

Questionnaires are handed out all year long, and given to every inpatient by a head nurse. Questionnaires are department based but consist of same questions. In the paediatric department, parent or accompanying person can fill out the form. Officially it is expected that questionnaires are handed in the last hospital day, but in reality, one department hands out questionnaires in the arrival day. Gathering information form patients in their last hospital day, is considered as most efficient way to capture meaningful patient experiences. Filling out the questionnaire is voluntary and anonymous. (Edwards et al. 2015: 82; Paesüld 2022.)

Filled questionnaires are collected, inserted, and analysed by the quality specialist. Over the years, satisfaction with HNRC according to results from questionnaires has been high. In 2021, overall satisfaction with services was 3,61 in 4-point scale. This is in correlation with the literature, as quantitative methods tend to provide overly positive results. In 2021, 44% of all patients gave feedback. This percentage has been relatively the same throughout recent years. (Ahmed et al. 2014: 237; HNRK 2021: 12.)

Answers from questionnaires and comments are inserted and typed manually into the Microsoft Access system. The Power BI system automatically takes answers from the Access system and analyses them. In the Power BI, visual representations from results are also formed. Conclusions from patient feedback questionnaires are department-based, and are formed quarterly. Heads of the departments receive their departments’ conclusion, and share the information with the rest of the departments’ employees. All feedback is presented and discussed by the executive board. Quality specialist presents constructive proposals made by patients, and they are discussed by the board who decides what proposals could be taken into work. A current patient feedback collection questionnaire is mostly a management tool used to enhance service quality. It was developed by an expert group from the hospital around 15 years ago, and has been modified according to the need on an ongoing basis. (Englas 2022; Paesüld 2022.)

Compliments/complaints/proposals form consist of a field that its' related to, and area to describe the content. Compliments/complaints/proposals form is freely available in each department, and it can be taken and filled as wanted by patients. There is a possibility to submit the form anonymously or add your contacts. If contacts are added, patient will receive an answer to their compliment/complain/proposal. The forms are entered to the hospital's inner information system immediately after collecting, and the forwarded to the related department. In 2021, 44 compliments, 8 complaints, and 5 proposals were submitted via written form. Although, compliments/complaints/proposals form is a way to gather real-time feedback, suggested to be the most effective way, it could be seen that not many patients choose to submit the form, and the vast majority of patients express gratitude this way, not complaints or proposals. Also, collecting the forms might not always be as fast as needed, and patient might leave the hospital before submitted form is collected and analysed. Once a year, information about overall patient satisfaction is added into HNRC's website. Additionally, information about patients' proposals is included, with the list of proposals taken into action or done by the hospital. (Edwards et al. 2015: 82; Keskustelu 2021: 7; Paesüld 2022.)

According to the quality specialist, there are some actions that could be taken regarding current patient feedback system. The form could be electronically filled to ease data collection and analysis. The numerical values of the questions do not give valuable information, and not much is done with these values, or the data received from there. This finding is supported by Beattie et al. (2015) who bring out the importance of thinking through methods and how the data is used, so it would have high utility in real-life. Mostly, comments included by patients are used for proposals, but few patients include these. (Paesüld 2022.)

In the past few years, two qualitative studies have been conducted in HNRC to measure patient experiences and satisfaction: “Determinants of patient satisfaction among patients with central nervous system damage in inpatient neurological rehabilitation setting” by Ööpik-Loks (2019), and “Qualitative satisfaction survey among parents of children in inpatient treatment of Haapsalu Neurological Rehabilitation Centre” by Zeinalova (2021). Both of these studies are a part of Master Theses. The fact that qualitative methods are mostly used for research purposes is brought out in the literature as well (Gleeson et al. 2016: 4).

# 4 Purpose and aim of the thesis

The purpose of this Master's thesis is to develop a tool and a framework for collecting patients' experience data in a long-term inpatient rehabilitation setting (HNRC). This Master's thesis aims to create an instrument that addresses key aspects of care from a patients' perspective for everyday use in HNRC.

# 5 Methodology

For this developmental project, qualitative descriptive approach was used. Qualitative descriptive approaches are a common practice in examining health-care related phenomena, especially suitable for developmental projects, such as this Master's Thesis. There are several features that describe qualitative descriptive methods. First, naturalistic perspective is used, and phenomena is examined in its' natural state. Secondly, qualitative descriptive methods are considered not to have many theoretical touchpoints, creating a flexibility for a researcher. Third, data collection typically involves focus groups and/or individual interviews, with minimal or semi-structured interview guide. Fourthly, purposeful sampling strategies are usually used to ensure broad insights and rich data. Fifth, content analysis is the method mostly used for data analysis. Finally, representation of the study findings is expected to be straight-forward, include descriptive summaries, and accurate details of the data. (Kim, Sefcik & Bradway 2017: 1-2.)

## 5.1 Data collection

A purposive sampling strategy was used to include employees from different specialities and departments, and those who might have a valuable information and opinion relevant to research questions (Avis & Reardon 2008: 9). To achieve the aim of this thesis, the employees of HNRC who are in contact with patients were interviewed to understand which aspects of patients' experiences need to be included in an instrument. Also, people responsible for quality in HNRC were interviewed to create a comprehensive picture about the views of the hospital. Diversity of employees were included in the sample to ensure versatile data about the areas important for patients. Professions of employees who were included consisted of nurses, care workers, different therapists, and people from the quality department.  On one hand, people working in close contact with the patients on a regular basis, and on the other hand, people working with the patient experience data and decisions regarding collecting feedback from patients were interviewed to ensure richness of the data.

Head of the clinical departments were asked to provide the list of the employees, who might have a valuable information regarding research questions, and might be willing to participate in the study. Author contacted all of the employees who were listed via e-mail. Participation was entirely voluntary. 13 employees answered to the author, and agreed to participate but due to timely order, and one participant getting sick before the pre-arranged interview, 11 individual interviews were conducted. By then, data saturation was achieved so there was no need to continue looking for additional participants. Interviews lasted about 30-55 minutes. Interviews were conducted in person in HNRC in a private cabinet.

Interviews were semi-structured, that has proven to be versatile and flexible data collection method in qualitative research, that allows reciprocity between participants and interviewer, improvisation based on participants' responses, and enables individual verbal expressions (Kallio, Pietilä, Johnson & Kangasniemi 2016: 2). Based in the author's knowledge about the organisation, an interview guide was developed (Appendix 5). Pilot testing of the interview guide was done on an HNRC's employee not participating in the study prior to the interviews.

All the participants received an invitation to the study (Appendix 6) and information sheet about the study prior to the interviews (Participant's Information Sheet in Estonian Appendix 4) via e-mail. As the requirements from the Research Ethics Committee of the University of Tartu and from the Metropolia University of Applied Sciences were different regarding information listed in Participant Information Sheet, the documents in Estonian (Appendix 4) and in English (Appendix 3) are not direct translations but follow the instructions from both institutes.

Before the interview started, study related information was talked through orally and Participant Consent Form (Participant Consent Form in Estonian Appendix 2) was signed in two exemplars with each participant. Considering the differences in requirements explained in previous section, Participant Consent From was also composed in English (Appendix 1), and two versions are not direct translations of each other.

The interviews focused on the factors that employees think or have seen that are important to inpatients about their experience and care in HNRC. The author used previously formed interview guide (Appendix 5). Interviews' guide helped to stay on the topic, and ensured that similar topics were covered with all of the interviewees. During the interviews, open questions relevant to the topic were asked, and guidance was provided when needed.

Interviews were recorded with a phone. Recordings were kept in a phone that was secured with a password that only an author had access to. Interviews were transcribed to a written format as soon as possible, mostly following in next couple of days after the interviews. Recordings were deleted from the phone as soon as the interviews were transcribed. Transcribed text was kept in HNRC's server in a secured drive to ensure data protection.

## 5.2 Data analysis

To analyse the information gathered from individual interviews and make conclusions, inductive content analysis was used. Recorded interviews were transcribed by the author who conducted the interviews into a written form. Codes were used instead of names, to ensure confidentiality and pseudonymity of the participants. The text was analysed with an open mind to identify meaningful subjects, combine new information into theories, present data in words to interpret the results. Thus, an analysis process aimed to provide an understanding of the content of the data set.  In an inductive coding process, codes are developed during the coding process, and they tend to emerge from the data. Inductive content analysis is a common data analysis technique in developmental processes, especially when the plan is to apply the findings into a new concept. (Bengtsson 2016: 9–10; Vears & Gillam 2022: 112-6.)

### 5.2.1 Inductive content analysis process

For the transcription process, Vears & Gillam’s suggestions about inductive content analysis were used. The authors descriptions of the inductive content analysis process should be particularly suitable for the researchers new to qualitative study, thus suitable and relevant for the author of this Master’s Thesis. (Vears & Gillam 2022: 112.)

During inductive content analysis process, a 5-step approach suggested by the authors was followed (Vears & Gillam 2022: 117-125):

1. Read and familiarise. The data (transcribed texts) was read through multiple times to get to know the data thoroughly, and to become very familiar with the context.

2. First round coding – identifying big-picture meaning units. In this step, big chunks of texts in transcriptions were highlighted to organise the data in big-picture terms – a broad category of content that is relevant to the research questions. During this phase an identifying of units of meaning begins, and at the end of the first round of coding, a first version of the coding schema was produced with preliminary list of big-picture categories.

3. Second round coding – developing subcategories and fine-grained codes. During second round of coding, a closer look in the big-picture categories was taken. Each big-picture category and all the text listed in each category was looked through again to produce new codes that describe the content precisely. By the end of this phase, subcategories were formed for the big-picture categories.

4. Refining the fine-grained categories. In this phase, comparing and refining the subcategories formed in the previous phase was done. Some subcategories had very similar content so they were emerged into one, some subcategories suited better to another big picture category, and some subcategories were too broad and needed to be broken up into more smaller ones. The aim of this phase is to bring out the richness and complexity of the data, without being repetitious or lose some of the collected data. By the end of these four phases, a coding schema was formed.

5. Synthesis and interpretation. In the last phase of the analysis, the goal was to create an explanation of the phenomena under investigation. An interpretation of the data was created that answers the research questions - aspects important for inpatients about HNRC and their stay in HNRC were mapped.

## 5.3 Development of an instrument

There were some requests from the hospital requiring framework to be developed. First, it had to be based on the research, but as well be suitable and adapted especially for HNRC. Second, a tool had to be suitable and usable in all clinical departments. Thirdly, the tool should be comfortable for patients to fill, and easy for the quality department to analyse. (Paesüld 2022.)

Based on the research in the field, the most prevalent way to gather patient experience data in a clinical setting on a regular basis, is via quantitative questionnaires. As the plan is to gather patient experience data on a regular basis from all inpatients in HRNC, it was decided that a questionnaire is the best way to do that. It is brought out in the research, how important it is for the questionnaires to be focused on the key aspects of patients' experiences, so the burden for the respondents would be minimised. Thus, considering how to combine different themes into questions without the important aspects being lost, as well as how to make the questionnaire as short as possible, has to be taken into account. (Beattie et al. 2015: 2; Gibbons et al. 2015: 180; Oltedal et al 2007: 541; Sjetne, Bjertnaes, Olsen, Iversen & Bukholm 2011: 2; Wong et al 2015: 2).

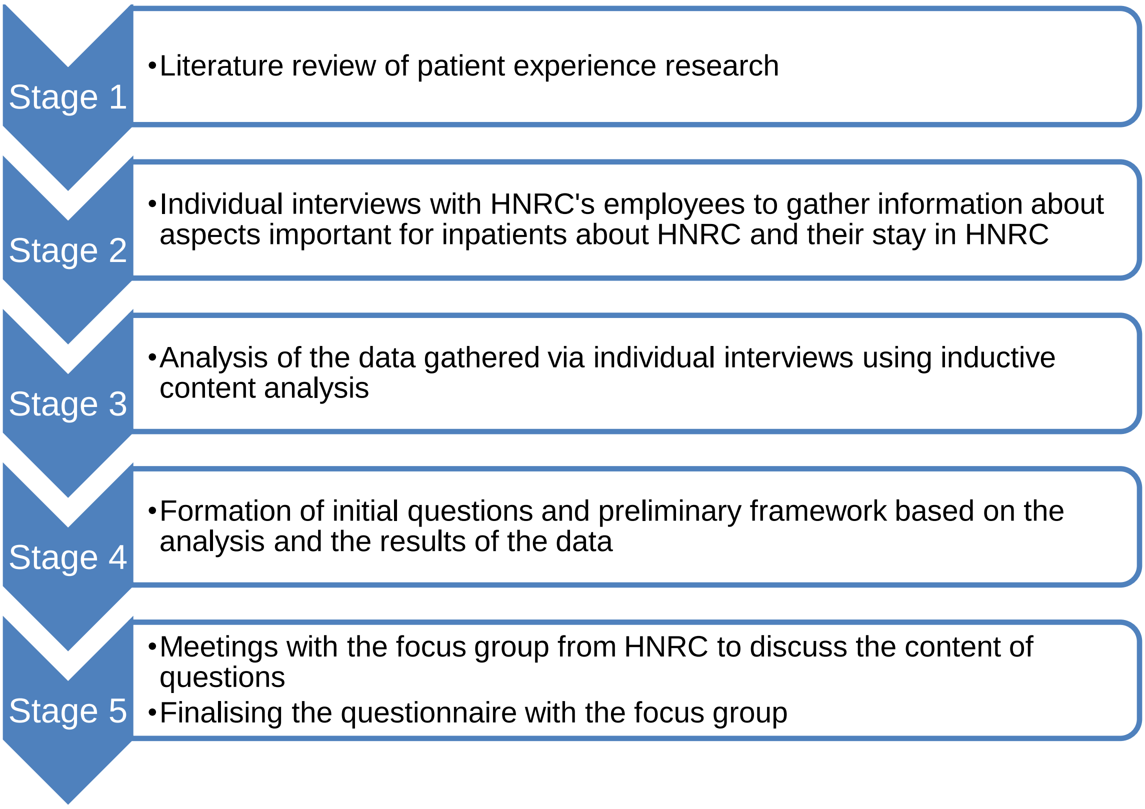
The development of an instrument and a framework consisted of two phases: in the first phase, an author composed a preliminary questionnaire and framework, based on the previous research and the data gathered from the interviews. After that, a focus group consisting on four members from HNRC, who are familiar with the topic, was formed. A focus group discussed the findings from preliminary framework and questionnaire, and formed the final version.

## 5.4 Model description

The aim of this study was to create a framework for collecting patient experience data from inpatients in a long-term neurorehabilitation setting. Chart 1 shows the steps that were taken in order to create a framework. The development of the questionnaire and a framework for collecting patients' experience data consisted of five stages.

In the first stage, an author of this work familiarised herself with the previous findings and the theory of patient experience research by doing an extensive search in databases. In the next stage, individual interviews with the employees of HNRC were conducted to explore the aspects important for inpatients about HRNC and their care in HRNC. In the third stage, data analysis process was done by using inductive content analysis. In the next stage, based on the data analysis, results from the interviews, and a theoretical background, a preliminary version of the questionnaire and a framework was conducted by the main author. In the final phase, a focus group from HNRC, was created. A focus group discussed the features included in a preliminary version, and formed the final version of the questionnaire and a framework.

Chart 1. Development of a framework for collecting patient experience data in HNRC.



Stage 1
- Literature review of patient experience research

Stage 2
- Individual interviews with HNRC's employees to gather information about aspects important for inpatients about HNRC and their stay in HNRC

Stage 3
- Analysis of the data gathered via individual interviews using inductive content analysis

Stage 4
- Formation of initial questions and preliminary framework based on the analysis and the results of the data

Stage 5
- Meetings with the focus group from HNRC to discuss the content of questions
- Finalising the questionnaire with the focus group

## 5.5 Ethical questions

Invitation to participate in the study was e-mailed to the employees suitable to participate in the study via e-mail. In the e-mail, the employees were asked to take contact with the author if they would like to participate in the study. An information about the study was included in participation information sheet additionally via e-mail (Appendix 4). Right before the interviews, study related information was talked through again with the participants. Written informed consent (Participant Consent Form in Appendix 2) with all the subjects participating in the study was signed before the interviews. Signed Participant's Consent Forms were scanned and saved to HNRC's server, and encrypted with a password. Only the author had an access to the password. Originals were destroyed right after scanning. Participation in the study was entirely voluntary. Subjects had the right to step out from the study at any moment.

Interviews were carried out in person in HNRC in a private cabinet. Door was closed to ensure privacy and avoid disturbance during interviews. The interviews were recorded with a phone. The recordings were stored in a phone that was secured with a password that only an author had access to. Recordings were transcribed as soon as possible to a written format, and transcriptions were kept in HNRC's server in a secured drive. Recordings were deleted from the phone after the transcription. In transcripts, codes instead of names were used to ensure confidentiality and pseudonymity of the participants. Code key was saved to HNRC's server and encrypted with a password. Signed Informed Consent Forms were scanned and saved to HNRC's server and encrypted with a password. Only an author had an access to the secured drive on a server where the files were kept.

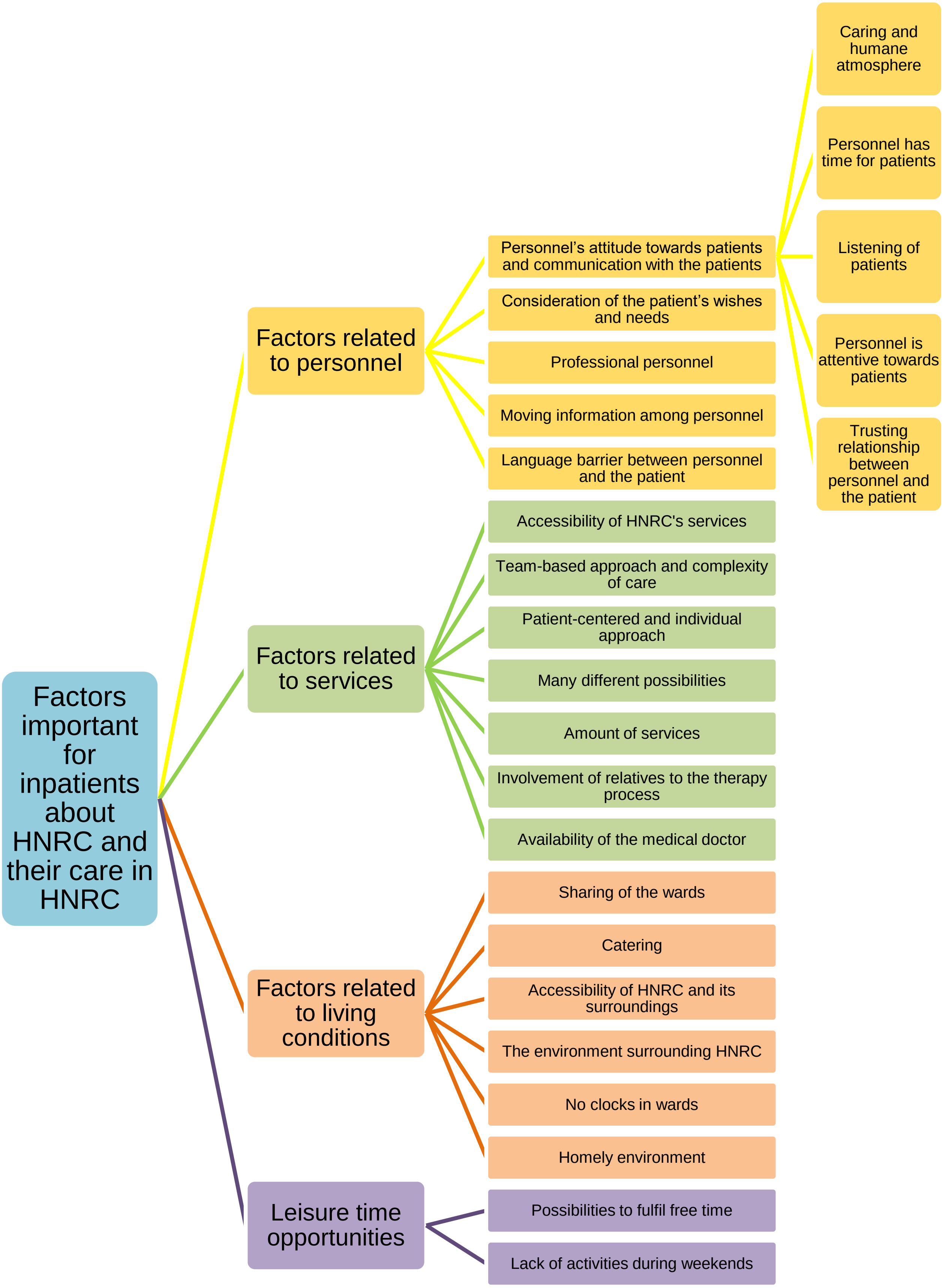
Participant Consent Forms and code key are going to be deleted after the end of the study (July 2023). Transcribed text and results are going to be kept in HNRC's server for possible use of the data in coded form for future analysis. University of Tartu Research Ethics Committee has granted a permit (permit number 317/T-17 in Appendix 7) to conduct this study, and to keep the data in a coded form for future analysis. Conclusions from the analysis were given to all the participants to read to ensure the credibility of the data.

# 6 Results

The data gathered from 11 individual interviews with the employees of HRNC, and the analysis of the data brought out four big picture categories and 20 subcategories about aspects important for inpatients about HNRC, and their care and experiences in HNRC. It is important to note that as interviews were done with the employees not directly to patients, all information listed in next subchapters is considered as aspects important to patients through the eyes and views of the employees.

First and most broad category is “Factors related to personnel” that consists of all the things related patients’ experiences that are connected to HNRC’s employees. Second category, “Factors related to services”, includes aspects related to different services patients receive during their stay in HNRC. Thirdly, “Factors related to living conditions”, lists aspects important for patients about their stay in HNRC, and considering different arrangements about living in HNRC. Fourth big picture category that came up was “Leisure time opportunities” that included different possibilities and concerns about how to spend time outside from therapies. In the next subchapter, categories are explained in more details. Chart 2 in the next page shows the coding schema that emerged from the analysis of the data gathered from the interviews.

Chart 2. Coding schema



## 6.1 Results from the individual interviews

### 6.1.1 Factors related to personnel

During the interviews, factors related to HNRC's personnel were the most broadly included big picture category. This means that factors that include people who work in HNRC, and are in close contact with patients during their stay in HNRC, might have a great impact in how patients view their experience.

One of the main features in this big picture category was "Personnel's attitude towards patients and communication with patients". Considering how much the overall attitude and communication with patients was mentioned during the interviews, it might be one of the most important aspect influencing patients' experiences during their inpatient stay. The overall atmosphere in HNRC seems to be seen as positive and friendly. Employees are cheerful and smiling, they are polite with each other and with patients. This overall attitude and communication make patients feel that they are expected and welcomed in HNRC.

> Participant 125321: It's the whole personnel's' attitude – that's the most important.
>
> Participant 133303: They like that we all smile, are friendly, and help them. --- I think they feel good, homely, freely and welcomed. I am pretty sure they feel as they are welcomed here.

This subcategory about personnel's attitude and communication divides into five smaller categories. From the patients who have experiences in other hospitals or institutions, the feedback has been, that there is a caring atmosphere in HNRC. It was mentioned several times that the personnel is very humane towards patients, and patients are treated with respect. It was mentioned during the interviews as well that patients feel that they can always ask or call somebody for help.

> Participant 142715: They have said that it [communication with patients] is respectful. It's not as treating an object but treating and handling a human being. Patients have brought out that… they dare to ask help in here. I think this describes well how patient is feeling or being here.
>
> Participant 084438 adds: I have been told that there is such a good and warm environment. Among employees and in the department. More among patients who come from care homes. In one or couple of days

> they are crying that, god you are so humane. It is so surprising - how can you work with people if you are cruel or doesn't care? I don't know (snorts) – that would be out of question.

Two smaller categories, that are related to each other, are that personnel have time for patients, and they are listening to what patients have to say. Although it was brought out that sometimes the time is limited and patients would want more attention from nurses, care assistants or different therapists, but in general patients feel that they are noticed and personnel has time for each patient.  Additionally to having time for patients, personnel is willing to and wants to listen to what patients have to say. Patients feel that they get a lot of support when somebody listens to them. Both of these features were brought out from both sides – from the employees working in the department, and by therapists as well who are meeting patients in individual or group therapies.

> Participant 110921: Not only nurses but care assistants have time as well. This is really important for them. There are some moments where you have to rush, but you have an opportunity to say that I am coming back to you when I have a moment, and we can talk more about this theme.

> Participant 110921: I have never received a better service than here. I am so heard that I am almost tired of talking.

> Participant 095004: shows the combination of those two categories: And another thing is what we ask – very personal questions. How it is at home, what is hard. And we listen to them. ---- Yes, we have time for that.

It was mentioned in the interviews that HNRC's employees are attentive towards patients. Patients get a lot of attention during their stay in HNRC – from care assistants, nurses, but as well from different therapists. It presents itself through small things as saying hello to patients or asking about their day, but on the other hand, asking more deeper questions related to their overall well-being or coping with their situation.

> Participant 142715: Patient gets this attention in here – whole teams' attention, dedication and intervention. I think this is not that way in many places.

It can be seen that all those smaller categories listed under the subcategory of personnel's attitude and communication, form a trusting relationship between employees and patients. Trusting relationship between patients and employees is created mostly via communication, honesty and confidentiality. Good relationship between patients and employees is considered to be really important, and influence the outcome of patients' treatment.

> Participant 094438: They are really trusting, at least for me. During these 12 years I have never betrayed their trust. It certainly is with patients, that as a care assistant when you promise them something, then you can't say that I'm not going to do that. They really start to trust you and they will rely on you. It doesn't matter whether they want you to bring them a pack of cigarettes or a pack of razors – they will trust you. Or you are bringing them a cup of water. They will wait for it.

Next subcategory listed under this big picture category is consideration of patient wishes and needs. It was mentioned that patients have a say about timing and things included or not included in their schedules, and accommodation possibilities up to a certain limit. Although mainly it was pointed out that employees try to consider patient's wishes and needs as much as they can, it is not always possible to take under consideration everything. In the paediatrics department in was mentioned the most how much personnel tries to consider parent's wishes and child's needs – per example take into consideration children's sleeping times.

> Participant 140225: We take into consideration patient's needs. Patient is still also a human, not just patient. We help, we will find a solution.
>
> Participant 133303 describes the situation in the paediatrics department: Then they can tell us the time when they get here, what time the child wakes up, sleeps and eats. We can take that under consideration as much as possible. At the parent's request, we can cancel services, when they really don't want to go to pool. --- I think it is really important for parents, after all nothing comes out during nap time. It would be pointless if they have physiotherapy, and all days it is during their nap time. As a matter of fact, in terms of children, it is really important that we are considering it. --- I have understood that they are satisfied that they are considered – they are getting therapies at the time that suits for them.

HNRC's personnel is considered as professional, and the quality of services they are offering is high. It was mentioned both from the department side (care assistants, nurses, doctors) as well as from the therapy point of view. Patients are satisfied with the quality of services the personnel is offering, and information or recommendations given by the employees are taken seriously by patients. In HNRC, highly educated personnel is working, the hospital values additional trainings, and employees are learning from each other as well.

> Participant 125215: All therapists are learning and developing. This is natural, it has to be that way. But care assistants as well – that they know how to handle patients. --- Our care assistants are well trained.

> Participant 133303: But I feel like the level of our therapist is highly valued. It is seen that there are highly educated people working here who know what and how to do. In Estonian sense, it is considered as a place with level.

When all subcategories mentioned above in this big picture category have a positive note, there was some critique brought out from the patients as well. Firstly, it was mentioned that sometimes an information about patients does not move as it should, and some employees handling the patient might not have all important information. This could bring possible discomfort to the patient, or misunderstanding among employees or between employees and a patient.

> Participant 140225: I feel that I lack information. As I understand, physiotherapist don't always have 100% overview what do I do now. Somehow this information gets stuck in here.

Secondly, there has been some problems with language barrier between employees and patients. On one side, HRNC is known in Estonian medical field to hire foreigner specialists. On the other side, there is a wide Russian speaking population in Estonia, and as many young specialists are not fluent in Russian, thus might be unable to communicate well with patients in their preferred language. Biggest concern for patients about language barrier seems to be that the therapists does not understand their problems, nor can explain well about how to do certain activities during the therapies.

> Participant 095327: …when something negative, then that we have foreigner therapist. That they don't understand. They say that the therapist does not understand their concerns. --- Younger therapist do not speak Russian…

### 6.1.2 Factors related to services

Second big picture category that emerged from data analysis is “Factors related to services”. In this category, factors related to different services HNRC is offering, their accessibility and amount is discussed. Information about different services HNRC is offering, is listed in paragraph 2.6.1 Overall information about HNRC.

First, it was discussed during the interviews how patients have different experiences in how easy or hard it was to receive a treatment in HNRC. More prevalent was the answer that it was hard for the patients to gain access to the therapy period in HNRC, because of the difficulty of the system about referrals or due to long waiting lists. It was brought out how it seems to be an easier process for children compared to adult patients.

> Participant 142712: It's like a "promised land" that you'll eventually get to at one point. Many patients bring out that it's very difficult to get here.

HNRC values patient-centred and individual approach, and this came out form the interviews with the employees as well, as being an important factor influencing patients' experiences. Patients feel as they personally and their concerns are important in HNRC. In was brought out that in comparison with other similar facilities in Estonia, patients feel that HNRC's personnel is a lot more focused on a patient. In the interviews, this feature was mentioned both from the departments side, as well as from the therapy point of view.

> Participant 094438: I think I mentioned that before that therapists treat them personally. It is done according to them. Not everything is generalisable. It cannot be that way. One stroke is one way and another is different. Or car accidents – they are not the same for people. This is the biggest thing that has been said – therapists take one-on-one.

Another subcategory that came out from the interviews, is team-based approach and complexity of care. It was mentioned, that a possibility to get many services from the same building is very convenient for the patient. Additionally, care is more effective when there is a whole team, who is in contact with each other, is handling the patient. From the interviews it was brought out that in HNRC, patient is able to get answers to their questions in different fields – there are many different specialists who are able to give advice in multiple areas.

> Participant 133303 concludes: I think they value our complex service. In other words, we have all the specialists in one building. --- Probably because a person is a whole. If we only make patient's leg better, patient's general well-being might not be better. In other words, when you get everything from one place with as little travelling- and time cost, and those people communicate with each other, so they are doing one thing, then it is more effective. It really is that way.

> Participant 110137 adds: I think this team is really important. Physiotherapist cannot speak for everybody, occupational therapist as well. The person in charge of each field can give more specific instructions.

Additionally, it was mentioned how there are many different possibilities in HRNC regarding therapies. It was brought out that there are variety of instruments that therapists are able to use during the therapies. Moreover, that there is a possibility to try and use different robotic devices during their therapies: using different robotic devices is seen as interesting and effective by many patients.  Also, the rooms where therapies are held, are convenient for patients, and paediatric therapy rooms look very child-friendly. It was mentioned a lot how beneficial it is for patients that there is a possibility to try different aids in HNRC. There are aids available in the therapy rooms, as well as there is aid centre located in the same building, where patients can try and purchase the aids they need. From the negative side, it was mentioned a couple of times some aspects about pool therapies: the pool itself and the room where the pool is located, is considered as small, moving around in the room is not comfortable for the patients, and everything in there is overall outdated.

> Participant 125321 brings out different possibilities: Maybe this whole environment is really an important factor. --- Therapy tools per example. And the whole therapy room. How it looks. Children's' therapy room is very child-friendly. Adults as always, but in general there are those large rooms. That it's not packed.

> Participant 133303 discusses about robotic devices: Additionally to that, a huge plus is of course these high-tech devices. I think this is one huge plus why people come here – to try these.

> Participant 125214 explains benefits of aids centre: We have this aid centre. We can try orthoses. They are so expensive and you only get a discount only every two years. When a patient buys something blindly and it doesn't work, then it's a shame. Here we can just take and try what works and what doesn't – it's a huge plus.

There were various features listed under the subcategory “Amount of services”. There seems to be a controversy that generally there seems to be quite a lot of complains from patients about the lack of therapies, especially when employees get sick or are away from work for other reasons, but also patients get stressed when there is a lot of therapies in the schedule, and the schedule is tight.  It was brought out in the interviews as well, that patients always want to have more therapies but sometimes they are not able to adequality evaluate their state and understand their limits. There seems to be a variation in different clinical departments. In some departments patients seem to care less about the amount of therapies in their schedule, whereas in other departments it seems to matter more to patients. Also, it came out from the interviews how times vary considering employees. There might be lack of staff in one department or people away from work at one point, and other times when the team is fully present. This makes a difference whether the patient sees their experience as positive or negative. Overall, it seems important for the patients that they have a lot of therapies listed in their schedule, as they feel the therapy period is more effective that way.

> Participant 142715 concludes this controversy: What is interesting is that, when a patient has too little therapies or procedures in a day – then it's bad. When there is too much and the day is packed – then it's also bad.
>
> Participant 133303 adds the reason why the amount of therapies might be important for patients: I presume they think that this therapy period is not as effective, that they don't get the same thing for the same money, that they get less. That's their concern.

It was brought out in the interviews, how Covid-19 pandemic has changed the factor that used to be important for patients – "Involvement of relatives to the therapy process". It was mentioned, how it used to be important for the patients that relatives were able to visit them, and be in the therapies to see what and how is done to the patients. Now, with the limitations and restrictions a worldwide pandemic has brought for couple of years, its' influence has decreased.

> Participant 147215: Relatives can come here. Now less, considering different restrictions, but it used to be really important for patients that their relatives could come here, and for the relative as well. --- So, they see what is done with the patients, and how to continue at home. Those who have had this consultation, have always been really grateful as it has been highly needed. Situation has changed. A lot…

A negative feature in this big picture category is "Availability of the medical doctor". There seems to be a wish from many patients to have more access or more frequent contact with the doctor during their stay in HNRC. Patients feel like the doctor has an information about their health, and want to ask things related to their health from them. Also, there seems to be more trust in doctor, and patients wish to ask questions regarding their stay, therapies, or what to expect from the doctor. During the interviews it was also mentioned, how doctors generally have little time for patients, and it's sometimes hard to access them.

> Participant 094438 expresses patient’s concerns: Am I not going to see the doctor today? I see the doctor so little. So those are the things, that who are coming, who are new. I don’t see the doctor. Maybe he/she sees the doctor the next day. These things have been on patient’s mind. He/she wants to talk to the doctor straight away.

> Participant 095327 adds: From negative side – doctors have little time for patients. They want that doctors have reception times. --- They want the doctor to be available, at least to some extent.

### 6.1.3 Factors related to living conditions

Third big picture category identified during the interviews was “Factors related to living conditions”. During the interviews, questions were asked about inpatients, so those patients, who come to HNRC for different amount of days, and stay there for the whole time of their therapy period. It varies how long a patient stays in HNRC consecutively – from 5 days to 42 days (or sometimes even longer). So, considering the quite long periods in some cases, living conditions can be an important factor influencing the overall experience.

During the interviews, the theme that was discussed the most under living conditions, was about sharing the wards. On one hand, wards are small, and as there are 2-4 people staying in one room, they can be quite packed. On the other hand, when rooms are shared, communication and consideration of a companion is really important, but sometimes ward neighbours might not fit together nicely. Both these features seem to influence the experiences of those staying in the paediatric department the most, as there are usually four people staying in one room (two children and the person accompanying them), and requests are higher regarding sleeping conditions per example.

> Participant 125321 concludes: Wards are small. Often when they have to be together… There are two children is one room and often both of them have a parent with them. It depends with who you’ll be in the same ward, how the communication is going to be. It all influences them. A lot has been brought out that there should be single wards. Of course, it influences.

Another widely discussed feature was catering. In this subcategory, there were both positive and negative factors mentioned. It was brought out the most, how patients praise the overall food quality that is offered in the hospital. Moreover, that there is a possibility to offer special menu when needed, as HNRC has their own kitchen. It was brought out both as negative and positive that food portions are big. Other feature that was widely mentioned from a negative side, was eating in the wards. Usually patients are having their meals in dining rooms, but due to Covid-19 restrictions and attempts to limit patients contacts, it was changed to eating in wards. Wards are not specially designed or furnished for eating so it is uncomfortable for patients. As well, sometimes the food is cold as transportation to wards is more complicated, and with children it gets messy when they eat in the ward.

> Participant 125215 concludes several features listed under catering: They praise the food. The meals are good but sometimes portions are too big. Now the food issue is, that the food has cooled down because due to Covid, they are eating in wards now.

It came out from the interviews that patients value the accessibility of HNRC and its' surroundings. Many patients, who get their treatment in HNRC, are using wheelchair, walking aids, or have difficulties moving around. Under this subcategory, patients have expressed to employees, how comfortable they are in HNRC as they are able to access the whole building, including toilets and bathroom. Moreover, that patients are able to go outside, and the surrounding of HNRC is accessible to them. There were several positive comments about the park next to HNRC, where wheelchair skills can be learned, outdoor gym, and wheelchair accessible playground for children is located.

> Participant 125215: They have the possibility to go outside. Especially patients who are using a wheelchair, and who live in an apartment building. Maybe it's once a year when they can go freely. --- That the whole building is accessible, that you can go outside, and move around freely in the surrounding area – this is definitely really important.

From a different perspective about the surroundings of HNRC, it was mentioned how the general environment that is surrounding HNRC has benefits for patients during their stay in HNRC. From the interviews it came out that for many patients, the fact that HNRC is located next to the sea, views form the windows are beautiful, and the overall location is really nice, has a supportive effect for the recovery and rehabilitation.

> Participant 142715: But otherwise this physical environment – they feel that it supports their recovery.

A smaller topic that came out from the interviews, was how patients would like to have clocks in the wards. The presence of clocks is important for them so they could look at the time when they have therapies, and would not be late for their appointments.

> Participant 110216: There should be a clock in the ward. --- [They wish to have clocks] to look at the time they have to go to the therapy.

Generally, patients feel that the environment in HNRC is cosy and homely. Many people come here on a regular basis several times a year, they feel that this is their second home, and there has been some comments that they don't want to leave. Even when they have to share rooms, and the rooms are packed, they are still looking forward to the time they are coming to HNRC.

> Participant 110137: Other thing is that I have heard as a feedback that they have been afraid to come here. The word "hospital". And when they have arrived and spent per example a week in here, then most have admitted that it is really homely, cosy in here. And they feared much worse.

### 6.1.4 Leisure time opportunities

Two topics emerged under the big picture category "Leisure time opportunities" – possibilities to fulfil free time, and lack of activities during weekends. Paragraph 5.2 Factors related to services discussed the time when patients have arranged therapies and appointments, which is usually from 8AM to 4PM, considering the working hours of the therapists. There is still some time after the therapies until bedtime that could be considered as leisure time, as well as weekends where there are only some official activities available for patients.

In the subcategory "Possibilities to fulfil free time" there were both positive and negative aspects mentioned from patients' perspective. There were more comments about lack of opportunities to fill the evenings: patients would want more guidance or organised events to spend the time outside of therapies. The examples that came up were social circles, movie nights, playing board games, group activities, using the gym independently. Some employees brought out that there have been times, when there have been more organized events for the patients in the evenings, and patients have been satisfied with them, but currently due to Covid-19 restrictions and attempts to limit patient contacts, most of them have been cancelled. From the positive side, it was brought out that there are theatre performances for children every other week, and there is a possibility to use the fully-accessible playground located outside next to the building.

> Participant 147215: Many have said that there could be more joint activities. We used to do group activities… --- People like to come to together

> and do together, especially when it’s a nice environment and atmosphere. I think a lot of people miss this.

Under the subcategory “Lack of activities during weekend” it was brought out how patients feel there is nothing to do during weekends. There are usually some therapies in Saturday mornings, but most of the weekend there are no official activities provided. It was pointed out that the hospital has provided some activities like inside health track, board games and pool table, but they don’t really seem to be used that much. It was also brought out that while some patients would like to have more therapies or trainings during weekends, some would just want to have something to do. Additionally, it was mentioned that some adult patients are taking the weekend as resting days but with children, it is hard to find activities for the whole weekend. One participant explained that due to Covid-19 restrictions, there are restrictions for patients to go to public places, and that currently limits their possibilities to fulfil their weekends as well.

> Participant 125215: What the patients bring out themselves is, that there are no activities during the weekends. They are bored, there is nothing for them to do in here. Although there is a lot offered – inside health track has been made, we have board games, pool table. I guess they are really not used that much. Everybody wants to work out.

> Participant 095004: I think they do wish that there are some activities on Saturday and Sunday. They say that they are bored on Saturdays and Sundays. It might not be therapy. Is there would be a walk outside or I don’t know… Drawing or colouring… Something that they can do.

According to the data gathered from HNRC’s employees about the important factors influencing patients’ experiences in HNRC, there are various factors that seem to matter for the patients. Most broadly mentioned, and the category that included most subcategories, was about personnel. This means that patients’ experiences seem to be influenced the most about things related to HNRC’s personnel and the general atmosphere people who work there are creating. Most of the features brought out in this big picture category have a positive note. Although there were both negative and positive elements listed in the big picture category about services, patients seem generally satisfied about the services they receive in HNRC, how they are built, and what they include. While the most widely mentioned category in the big picture category about living conditions was negative, this does not seem to influence the overall experience patients have with HNRC, as there seem to be more important factors in other big picture categories that have more effect for patients about their stay in HNRC. Also, in the fourth big picture category about leisure time possibilities, there were mostly negative aspects brought out, but these as well does not seem to influence that much the overall satisfaction most patients express about their stay and care in HNRC.

## 6.2 Results from the framework and instrument development

The development of the framework and an instrument for collecting patient experience data in HNRC consisted of two phases. Initially, an author composed a preliminary questionnaire and framework, based on the previous research and the data gathered from the interviews. After that, a focus group with four members from HNRC was formed. Members from the focus group were familiar with the topic, and the inclusion of them further enhanced the validity of the study.

During the individual interviews with the employees of HNRC, a question about how patients would like or prefer to give feedback about their experiences related to HNRC, was asked. The feedback was, that questions should be simple and easily understandable. Other important aspect that was pointed out – the questionnaire could be filled out online, as it is more comfortable for the patients, they can choose the time for filling, and in online, it could be filled by the patients unable to hold a pen or pencil. It was mentioned as well that there should be a room available after every question for patients to comment on their answer or add additional features. Having some room to write comments, adds a qualitative component to the questionnaire. It has been suggested in the literature that combining quantitative and qualitative methods to gather patient experiences, might provide additional insights in understanding the data. (Marsh et al 2019: 318.)

Initial questions for the questionnaire were composed by the author based on the analysed data. In the initial version, there were 18 questions. The questions were designed as positive statements, as negative statements could be harder to understand and might provide inconsistent results in neurological population. (Kneebone et al. 2012: 835.) There were room left after every question, as suggested during the interviews, and to add a qualitative component.

The author proposed to add some demographic features as sex, age, education, nationality, previous or current profession, and a reason for rehabilitation to the questionnaire. There is evidence that the results of this kind of questionnaires are influenced by the person who completes it, thus demographic data should enable better analysis and interpretation of the data in the future. (Kneebone et al. 2012: 835.)

It has been shown in the literature that the structure of the response categories can strongly influence data quality, thus number of categories and how categories are labelled can influence the results. Although there has been a debate in the field of surveys more generally about using neutral or middle response, the evidence supports the use of five-point scale in gathering patient experience data in the medical field. The possible responses proposed were: “not at all”, “to a small extent”, “to a moderate extent”, “to a large extent”, “to a very large extent / always”. (Garratt, Helgeland & Gulbrandsen 2011: 205; Oltedal et al. 2015: 542; Sjetne et al 2011: 4.)

Based on the literature research about patient experience questionnaires and data gathered during the interviews with HNRC’s employees about HRNC’s patients’ preferences considering giving feedback, a preliminary framework for collecting patients’ experience data in HNRC was developed. There should be a possibility for the questionnaire to be filled out online – suggested by patients as a convenient way for them to give feedback. As proposed by Edwards et al. (2015: 82), patients’ experience data should be collected near-time, thus immediately after discharge to capture real events. Filling in the questionnaire and giving feedback should be anonymous to capture adequate feedback about patients’ concerns. Patients might be afraid that by giving negative feedback, it might alter their future care in the hospital. (Kneebone et al. 2012: 835.) As HNRC has previously gathered feedback from all inpatients, it was suggested to continue this practice.

After forming preliminary questions and composing a framework, a focus group was convened. A focus group consisted of four HNRC’s employees familiar with the topic. Before the meetings, members of the focus group were asked to familiarise with the results of the analysed data, preliminary questions and framework. In two meetings (one in HNRC, one online) questions and framework proposed by the author was discussed in HNRC’s context.

During the first focus group meeting, it was discussed, that some questions had two different questions included in one, thus possibly making it harder for patients to answer. Thus, at the end of the meetings, the questionnaire was extended to 22 questions. In most of the questions, the wording was changed so the questions would be easier to understand. It was agreed that there should be approximately two lines after each question, and around five lines after the last question. In possible responses, the wording was changed in one option: “to a very large extent / always” was changed “to a full extent” (Questionnaire in Appendix 8). The form is currently in a basic format. In the later phases of the project, the form is going to be designed. It is planned that the questionnaire will be available in an electronic format, and located in the secured platform to ensure the anonymity of the people answering.

From the structure point of view, it was agreed that demographic features should be included. It was argued how much of the demographic data is useful to include. At the end, it was agreed that these features will be included: age, sex, who answered the questions (myself, relative, HNRC’s personnel), department, length of the therapy period, and what services were received. It was also agreed that filling out the questionnaire should stay anonymous, patient data should be collected near-time, there should be a possibility to fill out the questionnaire online, and the feedback should be collected from all inpatients.

# 7 Discussion

Patient’s experiences and aspects important for them about their care, are important features in modern health care and quality of care. When considering patient’s experiences, hospital care is looked and considered from patients’ perspective, and the way they have felt or seen their care. This Master’s Thesis aimed to create a framework for collecting patients’ experience data in a long-term inpatient rehabilitation setting (HNRC). The development of a framework consisted of five stages, including literature research, individual interviews with the employees of HNRC, and the analysis of the interviews, developing preliminary framework, and finalizing the questionnaire and a framework with the focus group. This work is a first step of a larger developmental project with a purpose to create and implement the system of collection and analysis of patients’ experience data in HNRC on a regular basis.

This work is unique in Estonian medical field, as there is little research done in the patient experience area. Other medical facilities in Estonia are using patient satisfaction questionnaires, there is no known other medical facility planning to start using a framework of collecting feedback that considers patient experiences. The views of patients about care differs greatly among countries, cultures, and different health-care systems.

Also, it is highlighted, how sensitive patient experience measurements are, and how important it is to assess specific clients' group perceptions for health care. Considering these facts, a framework developed especially for HNRC might show the aspects important for inpatients better than standardised questionnaires. (Wain, Kneebone & Billings 2008: 1367; Wong et al 2013: 10.)

There were some requests from the hospital requiring framework to be developed: based on the research, but suitable and adapted especially for HNRC; suitable and usable in all clinical departments; comfortable for patients to fill, and easy for the quality department to analyse. From the literature, it is brought out as well, how important it is for the questionnaires to be focused on the key aspects of patients' experiences, so the burden for the respondents would be minimised (Gibbons et al. 2015: 180; Sjetne et al 2011: 2; Oltedal et al 2007: 541; Wong et al 2015: 2.)

In order to map the aspects important for patients about their inpatient stay and care in HNRC, individual interviews with the employees of HNRC were conducted. Although in the development of similar tools, mostly interviews with patients have been used as a data collection method, due to ethical and organisational features, patients could not be included at this stage (Sjetne et al 2011: 2; Kneebone et al 2012: 835-6; Wong et al 2013: 3; Cleary et al 1991: 255; Larsson & Larsson 2002: 682-3). There is some supportive evidence about employees or other experts included in the development of such questionnaires (Oltedal et al 2007: 541; Wong et al 2015: 2). The reason that employees of HNRC were asked to give feedback about patients' experiences, might have an impact about the content of the data gathered, as their views about how patients might see HNRC and their care in HNRC might be biased and influenced by their own views, and interpretation of the information patients have given to them. In order to enhance the validity of a questionnaire developed, the next phase should be to test the questionnaire with patients, and to get their feedback about the aspects and questions included.

Purposive sampling strategy was chosen for recruiting the participants to the study to ensure variety of professions from different clinical departments to be included. The information about possible participants was received from the heads of the departments, and it was asked from them to list the employees who have enough experience with the patients, as well as who would possibly be willing to speak to the author, and might have valuable information about the theme. Although there were various professions included from all clinical departments, not all professions in contact with the patients were represented, for example there was no doctor, psychologist, speech therapist, or supportive personnel included. Thus, the choice of purposive sampling strategy might have influenced the data received via individual interviews, as not all professions in contact with the patients were presented in the sample.

From the individual interviews, four big picture categories emerged: factors related to HNRC's personnel, services, living conditions, and leisure time opportunities. Those four big picture categories were divided into 20 subcategories. It was interesting to see, that many of the factors listed in the results as aspects important for patients about HNRC and their care in HNRC, are listed as HNRC's core values: quality, patient-centeredness, professionalism, innovation, co-operation, and honesty and consideration. This shows that the core values are actually seen by the patients in the hospital, as well as the employees of HNRC express these values.

## 7.1 Comparison with previous studies

In correlation with the previous study by Ööpik-Loks (2019), that explored patient experiences in HNRC via focus groups with the patients from two departments, this Master's Thesis found as well how patients value the overall attitude personnel has towards patients: patients are treated with respect and as individuals, and their requests and wishes are mostly considered. This finding, that came out in both studies done in HNRC, is in correlation with two important concepts from the definition of patient experience. Patient experiences are shaped by the interactions between people, and a culture that is formed by an organisational values, and the people in it. Experiences are strongly related to the culture of an organisation and an attitude its' personnel has. (Wolf 2017: 6; Ööpik-Loks 2019: 22-23.)

There were similarities in this Master's Thesis and Ööpik-Loks' study in the category about services, where it came out in both, how some patients find it difficult to access the therapy period in HNRC, how there is some dissatisfaction about the amount of services they are having during their stay in HNRC, problems with the lack of staff, and poor accessibility of the doctor. This shows that there are some features about service provision that seem to be important for patients, but are continuing to make the experience negative, as they have not been solved fully in the eyes of the patients. (Ööpik-Loks 2019: 19-21.)

Considering living conditions, the matter of sharing wards came out in this Master's Thesis and Ööpik-Loks' study (2019). While in this Master's Thesis, it did not come out that sharing the wards or having a roommate has some positive features, it was mentioned in Ööpik-Loks' study, how it is sometimes positive to share a room with somebody, and some people find it supportive. Both also found that patients see that there is not much to do during free time, and how using different high-tech devices during therapies, is seen as a positive feature in HNRC. (Ööpik-Loks 2019: 22-25.)

Wain et al. (2008) qualitative study explored patients experiences in a neurological setting as well. Similar to this Master's Thesis, authors found that person-centeredness was an important factor for the patients. It was interesting that even similar wording was used in both while describing the key theme – patients feel like they are valued and taken as individuals. While Wong and colleagues investigated patents' experiences in an acute and rehabilitation hospitals, they did see as well how it was important for patients to be felt respected. (Wain et al 2008: 1368; Wong et al 2013: 7.)

Another key theme included in Wain's et al. (2008) study, was holistic approach. These authors found that holistic approach for patients included the whole experience – therapies with different specialists, free time activities, communication with the employees, as well as with other patients. In this Master's Thesis, it came out similarly that patients value multidisciplinary approach, but only in the sense of having different specialists working with them. Another similarity in both studies was the overall relaxing atmosphere that is created by employees, and surroundings that supported their rehabilitation.

This Master's Thesis and Wong et al. (2013) both found, how important it was for patients to have the employees available for them, and that the staff has time for patients. While Wong et al. (2013) found that were more complaints in this area, this Master's Thesis had more positive responses regarding employees' availability to patients. Although in Wong and colleagues' study (2013), it came out that there were many negative comments about the availability of staff, the employees nevertheless made an effort to take care of the needs of the patients. This theme correlates with the current Master's Thesis' findings, that it is important for patients that their wishes and need are considered.

There were some similarities in this Master's Thesis and Wong et al. (2013) study regarding the big picture category listed in this study as "Factors related to living conditions". Both studies found, how important privacy is in supporting recovery. As well, in both studies, the subtheme about food was mentioned. Unfortunately, is was not described in Wong's et al. study  (2013) whether all comments were mostly negative about the food, but the phrase taken from the interviews explained the amount of food being too little, and the bad quality of the food. While in this Master's Thesis, comments about the food and the amount were completely positive, but the negative aspect regarding catering was the uncomfortableness that was related to eating in wards due to Covid-19 restrictions.

## 7.2 Trustworthiness

To evaluate trustworthiness of the qualitative study, credibility, dependability, transferability, and confirmability are analysed, as suggested in Yilmaz article (2013: 319–21). The concept of credibility in qualitative study corresponds to internal validity in quantitative studies, and means that study findings are accurate and true from the viewpoint of the participants, and the readers (Yilmaz 2013: 319). During the interviews, interviewer had an open conversation with the participants. The interviewer is a long-term employee in HNRC with much background information about the setting. Employees participating in the study were mostly familiar with her, thus possibly creating more relaxed and trusting environment for participants to express their true feelings, so the data gathered is expected to be abundant and rich. The interviewer has been away from active work over a year by the time of planned interviews, and might have a fresh eye in analysing the findings.

This was the first time for the author to conduct interviews in a study related context. The pilot interview with one employee was done prior to the interviews, feedback given by this employee was considered when preparing the interviews. Although the feedback given by people interviewed was positive, the inexperience of the author might have influenced the context of the data received via interviews.

Inductive content analysis is considered as good analysis method for researchers new to qualitative study. Using inductive content for the analysis of the data gathered via individual interviews, was a new practice for the author, thus possibly influencing the content included in the results. (Vears & Gillam 2022: 113.) To enhance the validity of the study, a focus group from HNRC was included in the last phase of the development of an instrument. The focus group familiarised themselves with the results of this Master's Thesis, and preliminary framework, and was included in the formation of the last version of the framework and the questionnaire.

Confirmability shows that findings are based on the analysis of the collected data, and auditor confirms that findings are logical and clear (Yilmaz 2013: 320). To create more credibility and confirmability to the Master's Thesis, results were sent to all participants who participated in the individual interviews to read and confirm. When looking at the analysis of the data and results found from chapter 6, direct quotes from the interviews could be found to further enhance the credibility and transparency of the study. To further enhance the credibility of a questionnaire, an expert group was formed from HNRC's employees to combine the data gathered from the interviews to a questionnaire.

Dependability in qualitative study is similar to reliability in quantitative study. To ensure dependability of the study, selecting, justifying, and applying research strategies, procedures, and methods are clearly explained, as well as confirmed by the auditor. (Yilmaz 2013: 319-20.) This study has two auditors – one from Metropolia and one from HNRC who looked through selected strategies, procedures, and methods. Also, local ethical committee has approved this Master's Thesis.

External validity in quantitative studies corresponds to transferability in qualitative studies. This means that study findings are transferable to other similar settings. Transferability could be achieved via thorough description of the setting, context, people, actions, and events. (Yilmaz 2013: 320.) Description of the background, and methods chosen could be found in chapters 3 and 5.

# 8 Conclusion

Patient experiences are an important part of modern health care. By gathering the experiences patients have while receiving a care in health care facility, it is possible to enhance the quality of care. While there are many ways to collect feedback from patients, research supports methods that gather patients' experiences rather than collecting feedback and asking about satisfaction with the services received, and the combination of quantitative and qualitative methods. Collecting patient experiences are expected to cover much wider aspects of patient care, and might give an understanding about patients' preferences and the meaning behind those.

HNRC is a modern neurorehabilitation centre in Estonia, that has a unique place in Estonian health care. The hospital is gathering feedback from all inpatients in a regular basis, via questionnaire that mostly evaluates patient satisfaction with different services. As patient-centred and evidenced-based care are core values of HNRC, the hospital has set a goal to take the collecting of patient feedback to the next level.

The purpose of this work was to develop a tool and a framework for collecting patients' experience data in a long-term inpatient rehabilitation setting (HNRC). This Master's Thesis aimed to create an instrument that addresses key aspects of care form a patients' perspective for everyday use in HNRC. In order to achieve this aim, a qualitative study was composed. The development of the questionnaire and a framework for collecting patients' experience data consisted of five stages. In the first stage, an author of this work familiarised herself with the previous findings and the theory of patient experience research by doing an extensive search in databases. In the next stage, individual interviews with the employees of HNRC were conducted, to explore the aspects important for inpatients about HRNC, and their care in HRNC. In the third stage, data analysis process was done using inductive content analysis. From the analysis of the data gathered via individual interviews, four big picture categories emerged:  factors related to personnel, services, living conditions, and leisure time opportunities. In the next stage, based on the data analysis, results from the interviews, and a theoretical background, a preliminary version of the questionnaire and a framework was conducted by the author of this Master's Thesis. In the final phase, a focus group consisting of 4 members from HNRC, was created. A focus group discussed the features included in a preliminary version, and formed the final version of the questionnaire and a framework.

As a result of this work, a questionnaire and a framework for collecting patient experience data in HNRC was proposed. Questionnaire consists of 22 questions. In the possible answers, five-point scale was used. The possible responses are: "not at all", "to a small extent", "to a moderate extent", "to a large extent", "to a full extent". There is two lines after each question, and fve lines after the last question. The lines after the questions create a qualitative component to the questionnaire, by providing a possibility to explain the answers. Some demographic features were included: age, sex, who answered the questions (myself, relative, HNRC's personnel), department, length of the therapy period, and what services were received. Filling out the questionnaire should be anonymous, patient data should be collected near-time, there should be a possibility to fill out the questionnaire online, and the feedback should be collected from all inpatients.

This work was the first phase of a larger developmental project, that aims to create and implement the system of collecting, analysing and presenting the patient feedback in HNRC. In the current study's data collection phase, the employees of HNRC were included. To further enhance the validity of the study, patients of HNRC should be included in the next phase. They could look at the questionnaire composed, answer the questions, and give feedback in a qualitative form (focus groups or individual interviews) about their findings about the content of the questions, aspects included, and framework created.  Also, it needs to be decided, whether the questionnaire is going to be available both in paper and online, or only in an online platform. Further, a secured IT-solution with a designed questionnaire has to be developed. Depending on which solution is going to be used, a system for analysis and presentation of the collected data could be created. When the questionnaire is validated by the patients, and a solution is created for collecting, analysing and presenting of the data, an implementation phase of a new system can begin.

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# Appendices

## Participant Consent Form (English)

**Title of the study:** Development of a framework for collecting patients' experience data in a long-term inpatient rehabilitation setting (HNRC).
**Location of the study:** Haapsalu Neurological Rehabilitation Centre.
Researcher conducting the study:
Liis Piirsoo; tel: [redacted] e-mail: [redacted]
Supervisor:
Heini Maisala-McDonnell; tel: [redacted], e-mail: [redacted]
[redacted]

I                                         have been invited to participate in the above research study. The purpose of the research is to develop a framework for collecting patients' experience data in HNRC. The study aims to create an instrument that addresses key aspects of care form a patients' perspective for everyday use in HNRC.

I have read and understood the written participant information sheet. The information sheet has provided me sufficient information about above study, the purpose and execution of the study, about my rights as well as about the benefits and risks involved in it. I have had the opportunity to ask questions about the study and have had these answered satisfactorily.

I have had sufficient information of the collection, processing, and transfer/disclosure of my personal data during the study and the Privacy Notice has been available.

I have not been pressurized or persuaded into participation.

I have had enough time to consider my participation in the study.

I understand that my participation is entirely voluntary and that I am free to withdraw my consent at any time, without giving any reason. I am aware that if I withdraw from the study or withdraw my consent, any data collected from me before my withdrawal can be included as part of the research data.

**By signing this form, I confirm that I voluntarily consent to participate in this study.**

**If the legal basis of processing personal data within this study is a consent granted by the data subject, by signing I grant the consent for process my personal data. I have right to withdraw the consent regarding processing of personal data as described in the Privacy Notice.**

**Date**

____________________________________________

Signature of Participant

The original consent signed by the participant and a copy of the participant information sheet will be kept in the records of the researcher. Participant information sheet, privacy notice and a copy of the signed consent will be given to the participant.

## Participant Consent Form (Estonian)

### Uuritava teadliku nõusoleku leht

**Uuringu nimi**: Patsiendi kogemuspõhise tagasiside raamistiku loomine pikaajalise statsionaarse taastusravi kontekstis

Mind, ..........................................................................................................., on informeeritud ülalmainitud uuringust. Ma olen teadlik läbiviidava uurimistöö eesmärgist, uuringu metoodikast ning uuringuga kaasnevas.
Kinnitan oma nõusolekut uuringus osalemiseks.
Kinnitan oma nõusolekut oma isikuandmete töötlemiseks.
Tean, et uuringu käigus tekkivate küsimuste kohta annab mulle täiendavat informatsiooni:

Uuringu läbiviija: Liis Piirsoo
Tel: [redacted]
Email: [redacted]

Uuritava allkiri: ............................................
Kuupäev, kuu, aasta ......................................

Uuritavale informatsiooni andnud isiku nimi: Liis Piirsoo
Uuritavale informatsiooni andnud isiku allkiri ……………………………
Kuupäev, kuu, aasta ……………………

## Participant Information Sheet (English)

**Study title:** Development of a framework for collecting patients' experience data in a long-term inpatient rehabilitation setting (HNRC).

### Invitation to participate in a research study

We would like You to take part in our research study, where we are developing a framework for collecting patients' experience data in HNRC. The study aims to create an instrument that addresses key aspects of care form a patients' perspective for everyday use in HNRC. In order to achieve this aim, employees of HNRC who are in contact with patients are interviewed to understand which aspects of patients' experiences need to be included in a questionnaire. Also, people responsible for quality in HNRC are interviewed to create a comprehensive picture about aspects of care important for the hospital. A focus group from HNRC forms the conclusions from the data to a questionnaire.

This information sheet describes the study and Your role in it. Before you decide, it is important that You understand why the research is being done and what it would involve for You. Please take time to read this information and discuss it with others if You wish. If there is anything that is not clear, or if You would like more information, please ask us. After that we will ask You to sign a consent form to participate in the study.

### Voluntary nature of participation

The participation in this study is entirely voluntary. You can withdraw from the study at any time without giving any reason and without there being any negative consequences. If You withdraw from the study or withdraw Your consent, any data collected from You before the withdrawal can be included as part of the research data.

### Purpose of the study

Patient experiences, care quality, and effectiveness are increasingly important and strongly related aspects of modern health care. Western countries are using patient experience data extensively to measure the quality of health care, clinical quality, safety, and effectiveness. A framework for collecting, analysing, and presenting the data is the purpose of this qualitative study. This study aims to create a tool for HNRC for everyday use that addresses key aspects of care from a patients' perspective.

### Who is organising and funding the research?

This research is organized by HNRC. Liis Piirsoo is the researcher of this study, and she is conducting the interviews. This study is a part of Liis Piirsoo's Master's Thesis in Metropolia University of Applied Sciences. Person in charge of the study is Heini Maisala-McDonnell.

### What will the participation involve?

To create a comprehensive picture of aspects important for patients receiving inpatient care in HNRC, employees, who are in close contact on a regular basis with patients receiving inpatient care, are interviewed. Also, employees of HNRC, who are responsible for quality aspects in HNRC, are interviewed to receive an information about aspects of care important for HNRC.

One individual interview will be held with each of the participants, interviews are conducted in a private cabinet in HNRC. An interview will last approximately 45-60 minutes. Interviews are recorded with a phone. Phone is secured with a password, that only researcher of this study has access to. Interview concentrates in different aspects of inpatient care in HNRC. During the interviews, interviewer asks open questions relevant to the theme.

### Possible benefits of taking part

Your contribution to this study helps to develop a modern framework of collecting patient experience data and possibly enhance the quality of care HNRC is offering to their patients.

### Possible disadvantages and risks of taking part

There are no known possible disadvantages for You participating in this study.

### Financial information

Participation in this study will involve no cost to You. You will receive no payment for Your participation.

### Informing about the research results

Conclusions from the data gathered from the interviews are made available for all the participants via e-mail.

In conclusions, codes are used instead of names to ensure the anonymity of the participants.

### Termination of the study

The researcher(s) conducting the study can also terminate the study due to serious unexpected personal reasons.

### Further information

Further information related to the study can be requested from the researcher / person in charge of the study.

### Contact details of the researchers

Researcher / Student
Name: Liis Piirsoo
Tel. number: [redacted]
Email: [redacted]

Person in charge of the study / Supervisor
Name: Heini Maisala-McDonnell

Helsinki Metropolia University of Applied Sciences / Rehabilitation
Tel. number: [redacted]
Email: [redacted]

## Appendix to the Participant Information Sheet: A Privacy Notice for Scientific Research

Within this study, Your personal data will be processed according to the European Union General Data Protection Regulation (679/2016) and current national regulation. The processing of personal data will be described in the following items.

**Data controller of the study**
Liis Piirsoo
Metropolia University of Applied Sciences
MSc in Health Business Management
PO BOX 4000, FI-00079 Metropolia, Finland

**Contact person for matters related to the processing of personal data**
Name: Liis Piirsoo
Tel. number: [redacted]
Email: [redacted]

**Types of personal data that will be collected**
The personal data that will be collected in this project is anonymous voice material of the individual interviews.

There is no statutory or contractual requirement to provide Your personal data, participation is entirely voluntary.

**Personal data protection principles**

Interviews are recorded with the phone Voice recording application. The information systems used are a password protected for the interview recordings and a password protected for transcribing the recordings. The only person to have the passwords is the data controller. The transcriptions are kept in a researcher's computer that is secured with a password only known to the data controller. Additionally, files are encrypted with a password to ensure additional safety.

The data that is to be processed in the information systems has been protected using the following:
☐ user ID X password ☐ user registration ☐ access control (physical location)
☐ other methods, please specify:

**For what purpose will personal data be processed?**
A framework for collecting, analysing, and presenting the data is the purpose of this qualitative study. This study aims to create a tool for HNRC

for everyday use that addresses key aspects of care from a patients' perspective. Data from the interviews is used to create a comprehensive picture about aspects of care important for patients.

**Legal basis of processing personal data**
The legal basis of processing personal data is a consent granted by the data subject. You have the right to withdraw the consent at any time as described in this Privacy Notice.

**Nature and duration of the research (how long will the personal data be processed):**

☒ One-time research ☐ Follow-up research

The research is one-time research, no follow-up research is scheduled.

Duration of the research: December 2022 – December 2023.

The data will be collected during December 2022 and January 2023 and analysed during February 2023 – March 2023. The thesis will be published at the latest by July 2023. Additional 9 months are reserved for possible reclamations about the research results and time needed to respond to them.

**What happens to the personal data after the research has ended?**
How the personal data will be processed after the research has ended:
X Any research materials containing personal data will be destroyed
☐ Any research materials containing personal data will be archived
 ☐ without identifiers
 ☐ with identifiers

No personal information is collected during the research. The project interviews are anonymous. The interviews will be performed in person and will be recorded with participants' permission. A password secured phone is used for the recording. Transcriptions are stored in a data controller's computer, secured with a password. Passwords are only known to a data controller. Transcriptions will not include any sensitive personal information. All data is destroyed after the end of the study.

**Your rights as a data subject**
Because Your personal data will be used in this study, You will be registered to study registry. Your rights as a data subject are the following

You can exercise your rights by contacting the data controller of the study.

- Right to obtain information on the processing of personal data
- Right of access
- Right to rectification
- Right to erasure (right to be forgotten)
- Right to withdraw the consent regarding processing of personal data

- Right to restriction of processing
- Notification obligation regarding rectification or erasure of personal data or restriction of processing
- Right to data portability
- The data subject can allow automated decision-making (including profiling) with his or her specific consent
- Right to notify the Data Protection Ombudsman if you suspect that an organization or individual is processing personal data in violation of data protection regulations.

If the purposes for which a controller processes personal data do not or do no longer require the identification of a data subject by the controller, the controller shall not be obliged to maintain, acquire or process additional information in order to identify the data subject for the sole purpose of complying with this Regulation. If the controller cannot identify the data subject the rights of access, rectification, erasure, notification obligation and data portability shall not apply except if the data subject provides additional information enabling his or her identification.

**Personal data collected in this study will not be used for automated decision-making**
In scientific research, the processing of personal data is never used in any decisions concerning the participants of the research.

**Pseudonymisation and anonymisation**
All information collected from you will be handled confidentially and according to the legislation. Individual participants will be given a code, and the data will be stored in a coded form in the research files. Results will be analyzed and presented in a coded, aggregate form. Individuals can not be identified without a code key. A code key, which can be used to identify individual research participants and their responses, will be stored by Liis Piirsoo and the data will not be given to people outside the research group. The final research results will be reported in aggregate form and it will be impossible to identify individual participants. Research registry will be stored in a researcher’s computer that is secured with as password for 1 years, after which it will be destroyed by deleting the files permanently from the computer.

## Participant Information Sheet (Estonian)

### Uuritava informeerimise vorm

**Uuringu nimi**: Patsiendi kogemuspõhise tagasiside raamistiku loomine pikaajalise statsionaarse taastusravi kontekstis

**Hea Haapsalu Neuroloogilise Rehabilitatsioonikeskuse töötaja!**

Kutsume Teid osalema uuringus, mille eesmärgiks on arendada patsiendi kogemuspõhise tagasiside kogumise raamistik Haapsalu Neuroloogilises Rehabilitatsioonikeskuses (HNRK-s). Uuringu tulemusel loome igapäevaselt kasutatava instrumendi, mis hindab ravi põhiaspekte patsiendi vaatenurgast. Patsiendi kogemused, ravi kvaliteet ja efektiivsus on kaasaaegse tervishoiu olulised ja omavahel tugevalt seotud aspektid. Arenenud riigid liiguvad patsiendi tagasiside kogumises enam patsiendi kogemuste kogumise poole – arvatakse, et patsientide kogemuste kogumine analüüsib raviga seotud aspekte sügavalt ja hõlmab laiemat perspektiivi. Toetamaks HNRK põhiväärtusi ja strateegilisi eesmärke, on vaja teha samm edasi patsientidelt tagasiside kogumise süsteemis, et see looks kõikehõlmava pildi patsiendi kogemustest HNRK-ga seoses ja hõlmaks ravi aspekte, mis on patsientide meelest olulised.

Käesolev infoleht kirjeldab uuringut ja Teie rolli uuringus. Enne, kui otsustate uuringus osaleda, on oluline, et mõistate uuringu sisu ja mis sellega Teie jaoks kaasneb. Lisainformatsiooni või täpsustusi on võimalik küsida uuringu läbiviijalt, kelle kontaktid leiate altpoolt. Uuringus osalemiseks palume Teil allkirjastata nõusoleku lehe, millega kinnitate, et olete uuringut kirjeldava infolehega tutvunud.

### Uuringu sisu

Uuringu käigus viiakse iga uuritavaga läbi üks individuaalne intervjuu. Intervjuus käsitletakse HNRK-s statsionaarsel ravil viibivate patsientidega seonduvat, et kaardistada patsientide jaoks olulised aspektid HNRK-ga seoses. Intervjueerija küsib avatud teemakohaseid küsimusi patsientidega või patsientidelt tagasiside kogumisega seoses. Intervjuu kestvus on umbes 45-60 minutit. Intervjuu salvestatakse telefoni rakendusega.

Intervjuude käigus saadavad andmed analüüsitakse ja analüüsi kokkuvõte põhjal koostab 3-5 HNRK töötajast moodustatud fookusgrupp patsientide kogemuspõhise tagasiside kogumise instrumendi. Analüüsi kokkuvõte ja loodav instrument ei sisalda isikuandmeid.

Osalemine uuringus on täielikult vabatahtlik. Teil on võimalus igal hetkel uuringus osalemisest loobuda, ilma et sellega kaasneks negatiivseid tagajärgi.

**Potentsiaalne kasu/kahju uuritavale**

Teie panus uurimustöösse aitab luua modernse raamistiku patsiendi kogemuspõhise tagasiside kogumiseks.

Uuringus osalemisega kaasneb Teie jaoks ajakulu intervjuu läbi viimisel – 45-60 minutit.

Uuringus osalemisega ei kaasne Teie jaoks mingeid kulusid. Te ei saa uuringus osalemise eest tasu.

**Uuringu läbiviija**

Uuringut viib läbi HNRK. Liis Piirsoo on käesoleva uuringu ja intervjuude läbiviija. Uurimustöö on osa Liis Piirsoo magistritööst Metropolia Rakenduskõrgkkoolis. Uurimustöö juhendajad on Heini Maisala-McDonnell ja Toomas Danneberg.

**Isikuandmete töötlemine**

Uuringu jaoks salvestatakse individuaalse intervjuu käigus uuringus osaleja häält. Intervjuud salvestatakse telefoni rakendusega. Salvestatud intervjuud transkribeeritakse uurimustöö läbiviija poolt kirjalikku vormi. Nimede asemel kasutatakse koode, et tagada osalejate konfidentsiaalsus ja pseudonüümsus.

Salvestatud intervjuud transkribeeritakse esimesel võimalusel pärast intervjuu toimumist ning andmed kustutatakse telefonist koheselt pärast transkribeerimist ja asutuse serverisse salvestamist. Telefoni parool on teada ainult uuringu läbi viijale, seega ainult temal on ligipääs salvestatud intervjuudele. Transkribeeritud intervjuud hoitakse asutuse serveris ning krüpteeritakse parooliga. Uuritava teadliku nõusoleku vormid ja koodivõti skaneeritakse ja salvestatakse asutuse serverisse, originaalid hävitatakse koheselt pärast skaneerimist. Ainult uuringu läbiviijal on ligipääs serverisse salvestatud andmetele.

Uuritava teadliku nõusoleku vormid ja koodivõti säilitatakse asutuse serveris kuni uuringu lõpuni (juuli 2023). Pärast uuringu lõppu kustutatakse Uuritava teadliku nõusoleku vormid ja koodivõti asutuse serverist. Transkribeeritud tekst ja kokkuvõtted säilitatakse, et vajadusel kodeeritud kujul andmeid edaspidises arendustöös kasutada.

### Tulemustest teavitamine

Intervjuude käigus kogutava info kokkuvõte edastatakse kõikidele uuringus osalenutele e-maili teel.

### Uuringu läbiviijate kontaktid

Lisainfot uuringus osalemise kohta võib küsida uuringu läbiviijatelt igal ajal.

Kontaktid:

Uuringu läbiviija:
Nimi: Liis Piirsoo
Tel: [redacted]
Email: [redacted]

Vastutav uurija:
Nimi: Heini Maisala-McDonnell
Metropolia Rakenduskõrgkkool
Tel: [redacted]
Email: [redacted]

Kui Teil tekib küsimusi seoses uuritava õigustega, siis palun pöörduda eetikakomitee poole – nimetatud uuringu läbi viimiseks on andnud loa Tartu Ülikooli inimuuringute eetikakomitee (taotlus nr 371/T-17). Andmekaitseliste küsimuste korral palun pöörduda Andmekaitse Inspektsiooni poole.

**Tartu Ülikooli inimuuringute eetikakomitee**
Tel: +372 737 6215
E-mail: eetikakomitee@ut.ee

**Andmekaitse Inspektsioon**

Tel: +372 627 4135

E-mail: info@aki.ee

## Interview guide

**Please described the overall image HNRC has.**

### Relationship between HNRC and inpatient

How would You describe the relationship between HNRC and an inpatient?

- What activities an inpatient relates to in connection with HNRC?
- What activities happen before, during and after receiving inpatient care in HNRC?

### Themes inpatients talk to You about

Which are the themes related to HNRC or care in HNRC that inpatients talk to You about?

- What aspects/activities/parts seem to be important / less important for an inpatient?
- What inpatients bring out as positive / negative experiences in connection with HNRC?

### Patient feedback

- What feedback inpatients give you about HNRC?
- Has a patient given feedback to You about in which form or how they would like to give feedback about HNRC?

**Invitation to the Study**

**Hea Haapsalu Neuroloogilise Rehabilitatsioonikeskuse töötaja!**

Kutsume Teid osalema uuringus **„Patsiendi kogemuspõhise tagasiside raamistiku loomine pikaajalise statsionaarse taastusravi kontekstis“**, mille eesmärgiks on arendada patsiendi kogemuspõhise tagasiside kogumise raamistik Haapsalu Neuroloogilises Rehabilitatsioonikeskuses (HNRK-s). Uuringu tulemusel loome igapäevaselt kasutatava instrumendi, mis hindab ravi põhiaspekte patsiendi vaatenurgast.

Patsiendi kogemused, ravi kvaliteet ja efektiivsus on kaasaaegse tervishoiu olulised ja omavahel tugevalt seotud aspektid. Arenenud riigid liiguvad patsiendi tagasiside kogumises enam patsiendi kogemuste kogumise poole – arvatakse, et patsientide kogemuste kogumine analüüsib raviga seotud aspekte sügavalt ja hõlmab laiemat perspektiivi. Toetamaks HNRK põhiväärtusi ja strateegilisi eesmärke, on vaja teha samm edasi patsientidelt tagasiside kogumise süsteemis, et see looks kõikehõlmava pildi patsiendi kogemustest HNRK-ga seoses ja hõlmaks ravi aspekte, mis on patsientide meelest olulised.

Uuringu käigus viib uuringu läbiviija Liis Piirsoo andmete kogumiseks iga uuritavaga läbi ühe individuaalse intervjuu. Intervjuus käsitletakse HNRK-s statsionaarsel ravil viibivate patsientidega seonduvat, et kaardistada patsientide jaoks olulised aspektid HNRK-ga seoses. Intervjueerija küsib avatud teemakohaseid küsimusi patsientidega või patsientidelt tagasiside kogumisega seoses. Intervjuu kestvus on umbes 45-60 minutit. Intervjuud toimuvad HNRK-s detsembris ja jaanuaris. Intervjuu salvestatakse telefoni rakendusega. Andmete analüüsimisel kasutatakse koode nimede asemel, analüüsi kokkuvõte ja loodav instrument ei sisalda isikuandmeid ja Teie isik ei ole tuvastatav.

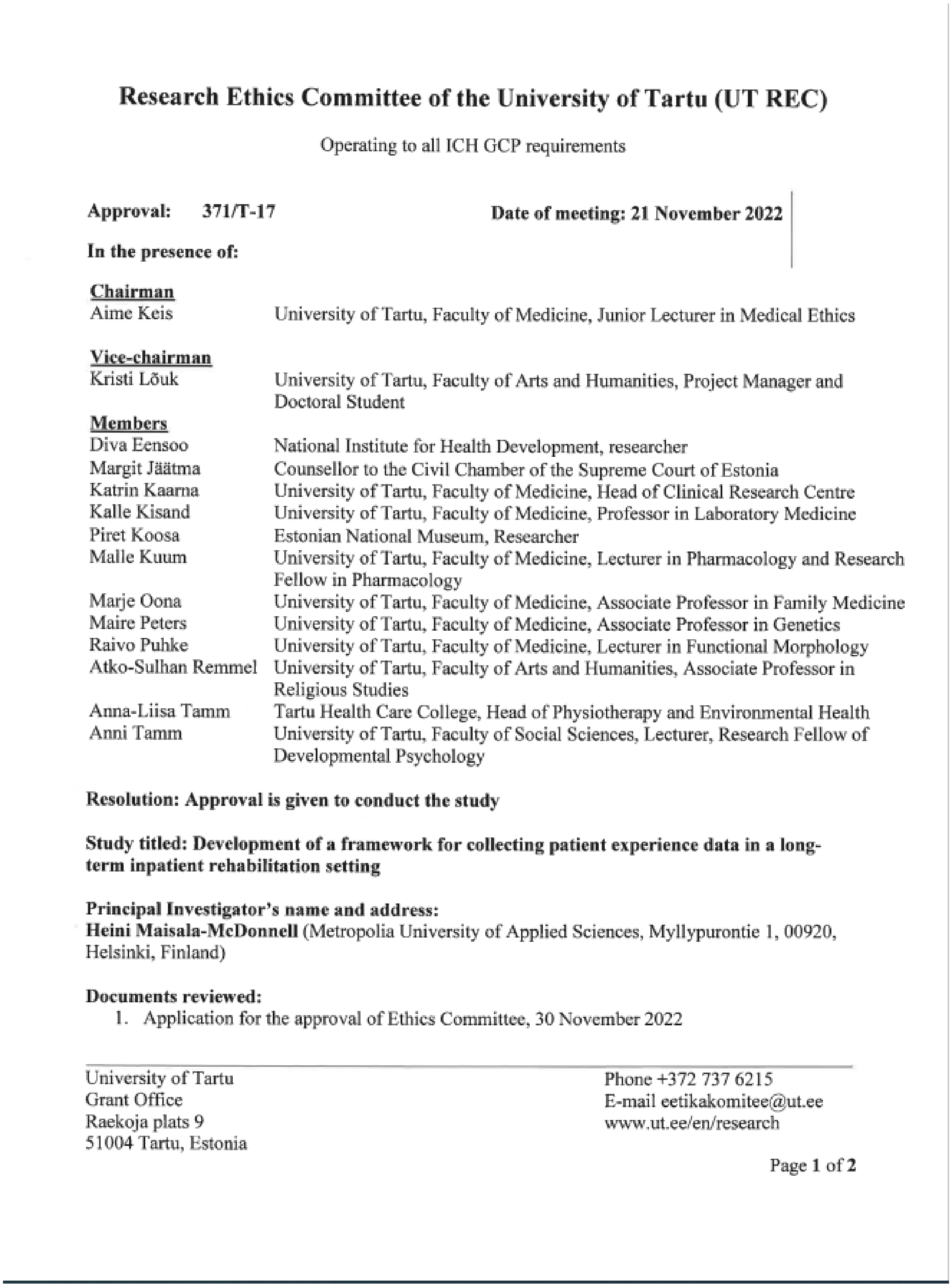
Uuringu teostamise on kooskõlastanud Tartu Ülikooli inimuuringute eetikakomitee (taotlus nr 371/T-17).

**Lisainfo saamiseks ja uuringus osalemiseks, võtke palun ühendust uuringu läbiviijaga:**

Liis Piirsoo
E-mail:[redacted]
Tel:[redacted]

Appendix 7

## Approval from the ethics committee



### Research Ethics Committee of the University of Tartu (UT REC)

Operating to all ICH GCP requirements

**Approval: 371/T-17** **Date of meeting: 21 November 2022**

**In the presence of:**

| | |
|---|---|
| **Chairman** | |
| Aime Keis | University of Tartu, Faculty of Medicine, Junior Lecturer in Medical Ethics |
| **Vice-chairman** | |
| Kristi Lõuk | University of Tartu, Faculty of Arts and Humanities, Project Manager and Doctoral Student |
| **Members** | |
| Diva Eensoo | National Institute for Health Development, researcher |
| Margit Jäätma | Counsellor to the Civil Chamber of the Supreme Court of Estonia |
| Katrin Kaarna | University of Tartu, Faculty of Medicine, Head of Clinical Research Centre |
| Kalle Kisand | University of Tartu, Faculty of Medicine, Professor in Laboratory Medicine |
| Piret Koosa | Estonian National Museum, Researcher |
| Malle Kuum | University of Tartu, Faculty of Medicine, Lecturer in Pharmacology and Research Fellow in Pharmacology |
| Marje Oona | University of Tartu, Faculty of Medicine, Associate Professor in Family Medicine |
| Maire Peters | University of Tartu, Faculty of Medicine, Associate Professor in Genetics |
| Raivo Puhke | University of Tartu, Faculty of Medicine, Lecturer in Functional Morphology |
| Atko-Sulhan Remmel | University of Tartu, Faculty of Arts and Humanities, Associate Professor in Religious Studies |
| Anna-Liisa Tamm | Tartu Health Care College, Head of Physiotherapy and Environmental Health |
| Anni Tamm | University of Tartu, Faculty of Social Sciences, Lecturer, Research Fellow of Developmental Psychology |

**Resolution: Approval is given to conduct the study**

**Study titled: Development of a framework for collecting patient experience data in a long-term inpatient rehabilitation setting**

**Principal Investigator's name and address:**
**Heini Maisala-McDonnell** (Metropolia University of Applied Sciences, Myllypurontie 1, 00920, Helsinki, Finland)

**Documents reviewed:**

1. Application for the approval of Ethics Committee, 30 November 2022

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University of Tartu
Grant Office
Raekoja plats 9
51004 Tartu, Estonia

Phone +372 737 6215
E-mail eetikakomitee@ut.ee
www.ut.ee/en/research

2. Approval of the Principal Investigator and approval of the Metropolia University of Applied Sciences.
3. Informed Consent Form, 30 November 2022
4. Study Invitation, 30 November 2022
5. Plan of the semi-structured interview
6. CVs of the investigators (H. Maisala-McDonnell, L. Piirsoo)

**End of the clinical trial: July 2023**

**Chairman of UT REC:** Aime Keis

**Secretary of UT REC:** Kaire Kallak

**Date of issue in Estonian: date of the latest digital signature 02 December 2022**
**Date of issue in English: 14 December 2022**

## Patient Experience Questionnaire in HNRC

Demographic features
Age:
Sex:
Who answered the questions? Myself / relative / Personnel of HNRC
Department:
Length of the rehabilitation period:
What services you received during the period?

Questionnaire

Please choose the most correct answer from the list. It is important for us, that you leave your comment, so we could better understand your answers.

1. The process of coming to HNRC for treatment was an easy process for me
2. When arriving to HNRC, personnel explained the house rules to me
3. Personnel explained the rehabilitation period to me
4. Personnel treated me with respect and courtesy
5. My wishes and needs were considered
6. I received enough attention from the personnel
7. Personnel had time for me
8. The doctor was available to me to the extent I wanted
9. Personnel communicated to me in an understandable manner
10. Personnel is professional
11. My schedule of services was suitable for me
12. My problems were approached personally
13. I was included in making decisions about treatment to the desired extent
14. The team working with me cooperated with each other
15. Living conditions supported my recovery
16. Catering was suitable for me
17. The possibilities to organize time outside therapy supported my recovery
18. I know, what are the next steps for my recovery
19. Relatives were included to my rehabilitation to the desired extent
20. I was satisfied with the rehabilitation period

   - Answer possibilities to all questions above:
     not at all, to a small extent, to a moderate extent, to a large extent, to a full extent
   - Two lines after each question to leave comments.

21. Would you recommend HNRC to your friends and family?
    Yes / No
22. I would like to add:
    - 5 lines after this question to leave comments.