



Determinants of patient satisfaction among patients with central nervous system damage in inpatient neurological rehabilitation setting

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The purpose of the study was to explore the experiences of adult patients with stroke, brain trauma or spinal cord injury in Haapsalu Neurological Rehabilitation Centre (HNRC), Estonia and to identify the factors that determine patient satisfaction.

The patient experiences were studied through conducting four focus group interviews, which were analysed using the principles of inductive content analysis. Each focus group consisted of five participants and the groups were diagnose-based. Half of the participants were recruited from the Department of Neurorehabilitation and the other half from the Department of Spinal Rehabilitation.

Five intertwined themes emerged from the analysis: “Striving for independence”, “The therapist as the key partner in goal setting and patient involvement”, “Obstacles on the road”, “Daily life at the hospital” and “The past, the present, the future of HNRC”.

The independence of the patients of HNRC is limited due to their condition, and with therapists as their main partners, they strive for greater autonomy. Physiotherapists provide support in goal setting that was admitted to be challenging by the participants and are the most important partners for discussing their condition and giving feedback.

The patients value respectful and considerate communication, accessibility of the specialists and expect clear information on their condition, test results and further options.

Problems are encountered on the level of health care system, as well as service provision of HNRC, especially in terms of occupational therapy. The main suggestion for improvement by the participants was to have access to gym or other therapy room in the evenings as many reported boredom in their free time.

The results are in accordance with other research in the field that show the importance of respectful communication and adequate, timely information. Additionally, there is a tendency for younger patients to be more critical despite the general reluctance of the patients to criticise. These findings are also supported in the literature.

Some recommendations for improving the patient experience in HNRC could be made, specifically regarding educating staff in communication skills, organized free time activities, provision of occupational therapy and information exchange.

Further research is required in order to cover other patient groups of HNRC in the future.

Keywords: patient satisfaction, patient experience, neurological patient experience, focus group interview, inductive content analysis

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1 Introduction

Patient satisfaction has gained increased attention worldwide as an aspect of quality of healthcare service that in some countries has been tied to financial incentives.

Haapsalu Neurological rehabilitation Centre (HNRC) has been collecting patient satisfaction data for over a decade, using a self-designed questionnaire. The results are traditionally positive, but literature shows that since the data collection methods themselves affect the results, these positive outcomes of such surveys may be deceiving. A combination of quantitative and qualitative methods for gathering patient feedback has been suggested as more informative and actionable method.

This study was designed with the aim of collecting additional information on patient satisfaction and experience through interviews as described in the action plan of HNRC for 2019 as a part of the organizational improvement activities.

2 The importance of patient satisfaction and experience

Patient satisfaction is one aspect of healthcare service quality and used as an outcome indicator (Wilson, Yepuri & Moses 2016). Kelly (2007), with references to Donabedian's work (1980), describes the two main components of healthcare quality - technical quality and service quality. The first is understood as clinical competency and knowledge of the staff while the latter encompasses their interpersonal skills and the extent to which patient expectations are met. In terms of satisfaction, the technical quality is usually presumed by the patients, but it is the service quality that the patients base their experience on and which therefore needs special attention and conscious effort. (Kelly 2007; Crawford 2018).

It has been argued in the past that patients, due to their lack of medical education, cannot, in reality; assess the quality of care. However the evidence shows that although the patient may not be in the position of assessing whether the prescribed treatment was optimal for his condition, higher satisfaction levels with cleanliness and probability of recommending the care provider to others are associated with lower infection and re-admittance rates of these hospitals. (Johnson, Russell & White 2016).

Higher patient satisfaction has been shown to be strongly linked to increased guideline adherence and therefore improved outcomes of treatment (Doyle, Lennox & Bell 2013; Bahari & Noor 2015; Johnson et al. 2016; Ng & Luk 2018) and, from the viewpoint of service providers, it is important to note that higher patient satisfaction is related to increased probability of recommending the hospital to others as well as patient loyalty (Ng & Luk 2018).

In the United States, since 2010 due to the Affordable Care Act, patient satisfaction and patient experience have become the centre of discussion as the results of the mandatory pa-

tient surveys are public, allowing patients to make decisions on which care provider to choose and insurance companies increasingly use them for reimbursement decisions, although this practice has met strong criticism (Farley, Enguidanos, Coletti, Honigman, Mazzeo, Pinson, Reed & Wiler 2014). The same applies to the UK, where it is mandatory in the National Health Service to monitor patient experience and the service providers' financing partially depends on the results of this domain (Doyle et al. 2013).

2.1 Patient satisfaction and patient experience - problems with definitions

In literature, the terms patient satisfaction and patient experience are often used as synonyms along with other terms such as perceived service quality, patient perspective and patient perception, which is confusing and flawed (Gill & White 2009; Ahmed, Burt & Roland 2014; Berkowitz 2016; Wolf 2017). All of these are separate concepts, but their borders and essence is still under debate.

Wolf (2017) defines satisfaction as perceptions at points of time, and explains experience as the lasting story consumers carry with them. The more recent texts (Gill & White 2009; Ahmed, Burt & Roland 2014; Berkowitz 2016; Wolf 2017) underline that patient experience does not equal patient satisfaction, but there does not seem to be a universal understanding of the relationship between these distinct concepts. Some authors view patient experience as a determinant of patient satisfaction while others have exactly the opposite approach (Ahmed et al. 2014) while yet others seem to believe that we should move past patient satisfaction and focus on patient experience only as it is a broader concept (Wolf 2017).

There are a handful of studies where patient experience has been demonstrated to predict satisfaction. Bjertnaes, Sjetne and Iversen (2012) showed in their study on patient-reported experiences and fulfilment of expectations that both of these are strong predictors of overall patient satisfaction and at the same time that although related to satisfaction, they are still separate concepts.

2.2 Measuring patient satisfaction and patient experience

Patient satisfaction is most commonly measured using questionnaires handed out or mailed to the patients but web-based solutions are becoming more and more widespread in addition to other technological options such as dedicated tablets or kiosks where responses can be collected immediately after the service provision (Ahmed et al. 2014).

There has been a lot of criticism over the questionnaires as a variety of them have been used over many years but the discussion over their validity and psychometric parameters only started about a decade ago (Gill & White 2009). However, according to Manary, Boulding, Staelin and Glickman (2013), when designed and carried out correctly, they do measure quality and provide valid information that can be used for organizational change.

Crawford (2018) illustrates the difference between patient satisfaction and patient experience surveys by the following examples: a question in a satisfaction survey would ask the patient to assess on a scale 1 to 10 the level of friendliness of the therapist while patient experience assessment would require the patient to answer the question how often he was greeted by name by the therapist or how well the patient understood instructions for home at discharge.

As Golda, Beeson, Kohli and Merrill (2018) note, a proper patient experience measurement is a frequency analysis (how often the patient experienced one or other behaviour from the staff, for example) and the results are more actionable for the service provider as opposed to satisfaction survey responses which are more prone to emotional fluctuations of the patients. After all, the aim of the data collection is reliable information that can be used for real improvements in patient experience.

It is important to note that the data collection methods themselves affect the results. For example it is known from literature that questionnaire-based satisfaction surveys tend to provide results of high satisfaction levels but in reality overshadow some aspects of services that patients are actually critical about. It is argued that this phenomenon appears due to the fact that the questionnaires have been created from the viewpoint of the service provider and enquire about topics that the service provider believes are important to the patients while their actual experiences and real values may not emerge. (Wain, Kneebone & Billings 2008; Lees 2011; Medina-Mirapeix, Jimeno-Serrano, Escolar-Reina & Bano-Aledo 2012; Ahmed et al. 2014; Ng & Luk 2018).

In comparison, qualitative methods, such as focus group interviews and patient stories or narratives have shown to emerge more negative accounts on healthcare services than surveys because people tend to express their negative experiences more willingly in a group setting (Green & Thorogood 2009, 131; Lees 2011; Ahmed et al. 2014). The benefit of the interviews is also that they allow the rise of topics that have not been directly asked about. Therefore, it has been suggested that a mixed method of enquiry, combining qualitative and quantitative information, would be the most successful in exploring patient experience (Lees 2011), although the qualitative methods require considerably more work and time.

The background variables of the survey/interview participants also affect the results. Various groups of patients (based on age, sex, ethnicity, education, socioeconomic status) may have tendencies towards rating some aspects of care either more negatively or more positively than others due to differences in expectations. For example there is abundant evidence that older patients tend to report higher satisfaction levels (Ahmed et al. 2014; Russell, Johnson & White 2015; Snelgrove-Clarke 2015; Chumbler, Otani, Desai, Herrmann & Kurz 2016).

In terms of gender, the data is inconsistent. According to Russell et al. (2015), gender does not have any impact on overall satisfaction, but Chen, Li, Wang, Xue, Ding, Nong, Lin and Zhang (2016) found that men do rate several care domains higher than women, resulting in greater overall satisfaction scores. However, men and women place different emphasis on various aspects of their care, for example communication with doctors is more important for older men while older women consider communication with nurses more important (Chumbler et al. 2016).

It is also clear that the healthcare system itself as well as the cultural background of the patients affect satisfaction. Ahmed et al. (2016) mention for example that similar waiting time is perceived differently by Asian and White patients as the former are more sensitive to waiting than the latter.

The abovementioned patient-level characteristics are unmodifiable and the service providers in countries where the patient satisfaction scores are tied to reimbursement decisions have used this as an argument in their criticism (Chen, Beal, Okunrintemi, Cerier, Paredes, Sun, Olsen & Pawlik 2018).

2.3 Qualitative research on patient satisfaction in neurological rehabilitation setting

When narrowing the patient satisfaction studies down to qualitative methods and neurological rehabilitation setting, the information is not as abundant. One of the reasons could be the abovementioned problem with qualitative satisfaction studies, they require more time and effort and it seems that the great majority of satisfaction research is quantitative.

Neurological rehabilitation setting itself differs from many other fields of healthcare. First of all, most of the patients need these services over a long period of time since the disorders and traumas to the central nervous system (either brain or spinal cord) affect a person greatly, recovery is often only partial and in many cases the patient has to learn to live with a disability that in turn requires learning to use the wheelchair and/or relearning lost skills. Also, such conditions affect the family members of the patient, who may have to learn skills to assist the patient at home. These aspects make the neurological rehabilitation unique, often the patients come to the same rehabilitation facility over an extended period of time (years) and most probably this has an effect on their satisfaction, too.

Mangset, Dahl, Førde and Wyller (2008) interviewed elderly stroke patients in order to determine factors that affect their satisfaction with rehabilitation services. The results showed that the patients' most prevalent expectation was that they would be treated with dignity and respect and the level of nursing/caregiving activities of daily living played an important role in general satisfaction. For the participants of this study, dignity was related to satisfaction more than their inclusion in decision-making, but at the same time it did not mean that

they were not be interested in information regarding their health status and treatment. In conclusion, the authors found that the common approach in rehabilitation, concentration solely on functional improvement, should be broader and include the patients' own perspective as well.

Wain, Kneebone and Billings (2008) found in their study with neurological patients that the most important factor for the participants was person-centeredness and four sub-topics: personal value, holistic approach, ownership and therapy environment. When one of the categories was not fulfilled or satisfactory, the experience of rehabilitation was perceived as less positive by the patients.

A study among spinal cord injured patients that looked at the process of decision-making and participation in treatment decisions during the initial rehabilitation period, showed that the patients were most annoyed by lack of information. They would have preferred to be more informed about changes in medication schemes, plans for medical examinations and further treatment, but also about the roles and responsibilities between team members (Scheel-Sailer, Post, Michel, Weidmann-Hügler & Baumann Hölzle 2017). The importance of holistic approach and access to information was also underlined in another study among spinal cord injured patients in Italy, where these topics emerged as the leading themes (Garrino, Curto, Decorte, Felisi, Matta, Gregorino, Actis, Marchisio & Carone 2011).

Gill, Dunning, McKinnon, Cook and Bourke (2014) qualitatively studied the experiences of patients (including stroke survivors) and their relatives with inpatient rehabilitation services and also found that the attitude and behaviour of the staff had a remarkable effect on the experience with care.

These studies support the numerous findings from other areas of healthcare which show that patient satisfaction is much more strongly determined by the communication skills of the personnel and thus the patients' interaction with the medical team than technical and clinical competency or waiting time (Bjertnaes et al. 2012; Berkowitz 2016; Wilson et al 2016; Chumbler et al. 2016; Waters, Edmondston, Yates & Gucciardi 2016).

2.4 Patient satisfaction survey at Haapsalu Neurological Rehabilitation Centre

Haapsalu Neurological Rehabilitation Centre (HNRC) is a modern hospital with 102 beds on the Western coast of Estonia. HNRC provides inpatient and outpatient rehabilitation services for adults and children with various neurological conditions such as stroke, traumatic brain injury (TBI), spinal cord injury (SCI) and paediatric pathologies.

Patient satisfaction has been monitored for over ten years, using a self-developed satisfaction survey which consists of 13 rating questions about the services on the scale 0-4 and some space for free handwriting to add comments. Due to their impairments, some patients are

unable to fill in the forms and in this case nurses provide them with assistance. It is likely that these patients are not completely honest in their responses due to the lack of anonymity. Feedback to the staff is provided with quarterly reports.

In accordance with the previously cited sources, the survey usually yields highly positive results with a few occasional fluctuations and the obtained information could be more actionable.

2.5 Conclusions and justification for research

Based on the literature it is clear that patient satisfaction, but even more so, patient experience, is a solid quality indicator in health care. Service providers should be interested in collecting valid data on patient experience in order to be able to use it for service development.

As suggested by Lees (2011), combining quantitative and qualitative methods could be the best way to obtain information on patient experience. This study serves as the first qualitative attempt to gain more meaningful insight of the experiences of the patients of HNRC.

3 Goals and aims of the study

The goal of the study is to explore the patient experiences of adult patients with stroke, brain trauma or spinal cord injury in HNRC.

The aims are to identify the factors that determine patient satisfaction; to assess the patient-centeredness of the services and make suggestions for further improvement.

4 Method

The experiences of inpatient neurological rehabilitation patients were studied through conducting four focus group interviews which were analysed on principles of inductive content analysis (Bengtsson 2016; Graneheim & Lundman 2004).

In order to increase trustworthiness of the study, a checklist suggested by Elo, Kääriäinen, Kanste, Pölkki, Utriainen and Kyngäs (2014) was used during the different phases of the research.

The application form and necessary documents were prepared in November and December 2018 and the study was approved on January 17th 2019 by Tallinn Medical Research Ethics Committee, approval no 2604 (Appendix 1).

4.1 Participants

The participants were patients of HNRC who were receiving inpatient rehabilitation services at the time of the interviews.

The inclusion/exclusion criteria were as follows:

- adults, SCI and TBI/stroke diagnose
- fluent in Estonian
- absence of cognitive issues that prohibit participation
- able to physically participate (sitting position min 60 min)
- has completed at least 1 therapy period at HNRC prior to the current one

The patients were recruited by the heads of departments who themselves are actively working physiotherapists. The Participant Information Sheet (Appendix 1) was introduced to possible participants and initial agreement of participation was obtained. Among SCI patients, the Participant Consent Form (Appendix 2) was signed immediately prior to the focus group interviews, among TBI/stroke patients the form was signed upon agreement of participation and was orally confirmed immediately prior to the interviews.

20 patients were recruited, half of whom had a SCI diagnosis and the other half had been diagnosed with stroke or TBI. As expected, finding patients who met the inclusion criteria was easier in the spinal rehabilitation department (SCI patients) and took more time in the neuro-rehabilitation department (stroke and TBI patients) mainly due to the cognitive issues and speech impairments arising from their diagnose. However, there was one patient who eventually could not participate fully in the group interview setting due to the hearing impairment, and that patient came from the spinal rehabilitation department. Table 1 presents the background information of the participants.

Focus groups	4
Number	20
Sex	Female 11 Male 9
Mean age	52.3
Range of age	20-88
Mean age in SCI groups	40.7
Range of age in SCI groups	20-70
Mean age in stroke/TBI groups	63.9
Range of age in stroke/TBI groups	23-88

Table 1: Background information of the participants

It is worth pointing out the big age difference between the SCI and stroke/TBI groups. The age difference was expected because stroke more commonly affects older people while spinal cord injury is more prevalent among younger males (Singh, Tetreault, Kalsi-Ryan, Nouri &

Fehlings 2014). However, the tendency of older people to state higher satisfaction, has been shown by many authors and it is one of the patient-level parameters that the data is very consistent on.

4.2 Focus groups and interview setting

The focus groups were formed from patients of the same department, each group consisting of 5 participants. The interviews took place in the library of HNRK after their therapies and after the working hours of the staff to avoid interruptions. The interviews were carried out from February to April 2019. The working language of the groups was Estonian.

Prior to the discussion, the aim of the research was introduced again to the participants and small talk between the participants was encouraged in an attempt to create a friendly and relaxed atmosphere. All four group interviews were recorded with a dictaphone.

Each discussion started with an opening question from the researcher: "Please recall your current therapy period, what would you bring out as a positive experience? What would you bring out as a negative one?" In some cases the time frame had to be expanded as the patients had commenced their therapy period on the previous day. In some cases it was also evident from the answers that the participants did not limit themselves to the current period. This was not corrected by the researcher unless experiences described were from years ago.

No defined sequence of the further questions was followed because sometimes the discussion naturally led to the topics. The complete set of pre-determined questions used to guide the focus groups is given in the Appendix 3.

The researcher's impressions on the groups can be found in Appendix 4.

4.3 Analysis of data

The data analysis commenced once all of the four interviews had been carried out and transcribed verbatim. The first interview produced 26 pages, the second 27, the third 23 and the fourth 27 pages with line spacing 1 and font size 11. In transcriptions, the symbol "//" marks irrelevant text that has been removed, for example repetitive stammering by the participant due to speech impairment or jumping to another thought in between that is not related to the main topic. The symbol "..." marks vague endings of sentences and small pauses.

Based on the recommendations by Graneheim and Lundman (2004), the full transcript of a focus group interview was chosen as the unit of analysis for this study.

The process of inductive content analysis was based on the suggestions of Bengtsson (2016) and consisted of four stages: decontextualisation (open coding process) - recontextualisation - categorisation- compilation.

In decontextualisation phase, the researcher initially familiarized herself with the transcripts and each text was read several times in order to get the best idea of it. Meaning units were marked and then condensed into shorter forms without losing the original content. The question asked from the text to reach the meaning units was “How is it, to be the patient of HNRC?” The meaning units and their condensed forms from interviews were printed out on coloured paper, each source interview marked with a different colour. This facilitated the process of coding as the codes were created inductively and also allowed to note possible differences between the diagnose groups.

In recontextualisation phase, the text was once again checked to ensure that all aspects related to the aim had been covered and all relevant information had been included.

This was followed by categorisation of codes and eventually dividing the categories into themes. Again, the coloured meaning units and codes were helpful as they could be moved freely around during the thought process.

Once the researcher had reached the themes, the compilation phase: analysis and writing process began. To achieve trustworthiness, the interview transcripts and the codes, categories and themes were shared for feedback with a colleague who as the head of department of neurorehabilitation had also assisted in finding suitable participants for the stroke/TBI group (Elo et al.2014; Bengtsson 2016).

For a detailed overview of the analysis process, tables complete with coloured meaning units, codes and categories by theme, are presented in Appendices 6 to 10. Blue and yellow represent the first and the second group of SCI patients and the third and fourth group (stroke/TBI) are marked with green and red respectively.

5 Results

Five intertwined themes rose from the analysis of the four focus group interviews that depict the reality of the patients of HNRC and their opinion of it. Tables 2 to 6 under each subchapter give an overview of the codes and categories that formed the theme, as suggested by Bengtsson (2016).

1. Striving for independence

The neurological problems and functional limitations arising from these problems affect the independence of the patients negatively. This theme brings together the aspects of personal responsibility and importance of respect of the individual as well as patient’s opinion on the involvement of the immediate circle in their rehabilitation.

2. The therapist as the key partner in goal setting and patient involvement

Based on the information the participants provided, therapists, but especially physiotherapists are their most important partners on the path to greater independence. The participants feel that the therapists are accessible, provide the main support in goal setting and motivation.

3. Obstacles on the road

This theme sums the problems the patients encounter on their road to independence: either issues with service provision at HNRC or on the level of the health care system in general.

4. Daily life at the hospital

The wellbeing of the patients at the hospital seems to depend mainly on two things: the quality of interactions with the staff members, especially the caregivers, and the peer patients, most importantly the roommate.

5. The past, the present, the future of HNRC

As the patients told their stories, often references were made to the old building of HNRC or to other facilities where they had been to. This theme also sums up their suggestions for future improvements in the services of HNRC.

5.1 Striving for independence

The participants expressed their desire for independence directly and indirectly and that on the level of autonomous decision-making as well as physical abilities. Three categories emerged: "Patient's own role in the recovery", "Personal value" and "The involvement of the immediate circle", as shown in Table 2.

Code	Category	Theme
Personal responsibility	Patient's own role in the recovery	Striving for independence
Slow recovery		
Recovery requires effort		
My opinion matters	Personal value	
Individual approach		
Independence/Dependence		
Immediate circle involved by the patient	The involvement of the immediate circle	
Immediate circle involved by HNRC		
Family involvement and independence		

Table 2: Striving for independence

One patient described a situation at the nursing home where he lives:

At this nursing home where I am now, there is... once... that was a long time ago, but once, when there was an argument... we feed you, you must follow our rules... excuse me, but this is death to me. (P 3, I 4)

The same person further states:

My main goal is that I want to manage my life on my own.

The participants also acknowledge their own role in their rehabilitation process, but it is clear that it is not easy for them and the results take time and effort.

... if you are lazy yourself, nothing will come out... of this goal. (P 3, I 2)

Well, here I have doubts, whether I will be able to. But you have to try of course. (P 2, I 1)

Mmm, well, those knees of mine are so worn and you know those exercises are hard, it makes my head wet, but you have to... you have to do it and then I put such a... thought to my mind that you have to be able to, and then this little knee pain does nothing... most important that the hand and the leg would move. (P 5, I 3)

Expressions like “torturous”, “top sports”, “showing no mercy” were used by several patients when talking about their experience of the therapeutic activities, but always in a positive way, implicating that they actually value the challenge.

Researcher: If you have been supported, how is it explicit for you?

P 4, I 4: Better services for example.

Researcher: But what is a better service for you?

P 4, I 4: When I get a lot of exercises and they show no mercy

The patients talked positively about their involvement in decision-making and they value the individual approach in therapies as well as in communication. When they felt that they were not treated with respect to their distinguished needs, it resulted in a negative account.

Something like ... with him and him I am doing it like this, why with you then...// I cannot do it the same way... that // with the other patient I do it like that... then I say that, does this other // patient walk around or what? Some things have to be done a little differently. (P 2, I 2)

Generally, the patients still felt that they are treated as individuals and there was a general feeling that their opinion is taken into account or would be taken into account in case they had a clear idea about something regarding their rehabilitation.

Everything you want to achieve is tackled right away and... every time you open your mouth, you say something then they will tackle it. It is not postponed. (P 1, I 1)

If I had some kind of a goal in my mind and what would be necessary to suggest, they definitely would take that into account. (P 3, I 1)

The idea of a more organized involvement of the immediate circle (presented as family, friends, employer or school) seemed to be new to the patients. This is something that HNRC is planning to work on in the near future, to involve the family members more in the rehabilitation process of the patients, so these reactions were not surprising as it has not been consciously done until now.

It was also not surprising that most of the accounts on involvement were about how the patient himself has involved the family members in the process or where the family members were actively involved upon their own initiative. There were only a few accounts where the patients described some kind of an involvement from the side of HNRC.

I have involved them myself, that me, when I first came here, the activities were not enough and then I arranged it so that every evening someone came here so that I could walk outside for an hour and this is really nice... (P 2, I 3)

When discussing whether a more organized family involvement would be necessary, the patients remained hesitant. This topic was intertwined with issues of personal responsibility and independence.

... but they will not come here to work out for you so to say... you have to do it yourself. (P 4, I 3)

It also depends on the injury of the person, and I have a minor, well, relatively minor problem compared to these people. It does depend on how serious the injury is that is being treated. (P 2, I 1)

The participants described how in their cases the family had been more involved in the initial stages of their recovery, but as they grew more independent, they took matters more to their own hands. Therefore, they argued, a more organized involvement would be more important for new patients and their families.

In the beginning yes, now it is the same that you have a mouth and brains like... now that if there is really a big problem, they turn to me... (P 1, I 2)

Maybe the fresh ones, let's say, who come, maybe they have then... how to manage with them, or how... they see it for the first time... maybe for them. (P 2, I 2)

5.2 The therapist as the key partner in goal setting and patient involvement

The most surprising finding for the researcher from the whole research was the extent of the role of the physiotherapist in the patient's rehabilitation process as a whole and in areas like goal setting and motivation. The only reason why the theme is titled as "The therapist..." is that in some cases the patients were not explicit that the therapist they talked about was indeed the physiotherapist, however it could still be guessed from the context of the discussion.

It is possible that due to the inclusion criteria and specifics of the diagnose (for example SCI groups), the participants had less severe speech impairments, if any, and had relatively high cognitive abilities thus reducing the importance of psychosocial services for them and increasing the variety of physiotherapy services provided to them resulting in increased contact with physiotherapists.

Regarding the variety of services, physiotherapy is also the most prevalent in HNRC, this group of services includes individual and group physiotherapy, gym, aquatic therapy, robotics. In comparison, occupational therapy is offered as a group or individual service and speech and language therapy as well as psychologist services are individual therapies. Physiotherapy is also offered on a daily basis - at least one service from this group per day, while the rest of the services are usually scheduled a couple of times a week, not daily.

The two categories that emerged from the discussions were "The therapist as a partner" and "Goal setting". The codes and categories that formed the theme are presented in Table 3.

Code	Category	Theme
Discussing therapy with the therapist	The therapist as a partner	The therapist as the key partner in goal setting and patient involvement
Discussing condition with the therapist		
Trust in specialists		
Therapist's role in therapy		
Difficulty in formulating goals	Goal setting	
Goal setting by the therapist/team		
Goal setting together		
Goal setting		
Personal goals		
Expectations		

Table 3: The therapist as the key partner in goal setting and patient involvement

The patients see the therapists as partners on their road to independence, with whom to discuss their condition and also aspects of the content of the therapy.

I talked to the physiotherapist, I already knew that I will be back for ten days // So I did ask that if I will be working with you again // I will check your improvement, what are you doing better, this is how we can discuss between us, when I will be back. (P 1, I 3)

They also expressed trust in the specialists and their professional competency.

In my opinion they are all educated people, they know, I don't know anything. I know what is wrong with me, but... (P 1, I 4)

They probably know that this exists and if they would have the chance here, they would do it to us, yes... what is there to ask then... (P 1, I 2)

Many patients expressed difficulties in formulating their rehabilitation goals. The goals that were inadvertently stated in discussions were very general indeed and often physiotherapy-related. A few patients admitted not having a clear goal.

Well, for me it is always difficult to think about goals, I don't know how to formulate them. (P 1, I 2)

That the patient himself wants something big, but to get there, maybe he doesn't know how to formulate that so well. (P 5, I 1)

It appears that sometimes the goals in this situation are actually set by the therapist or the team while there are also goals that are set together and worked towards as partners. In any case, the patients need the support from the specialists in goal setting.

She is quite good, she sets such goals for me and I in turn also set some... she may create this... come on, I cannot do it... but this stubbornness that comes, but why, she set this kind of a goal on purpose, so the motivation increases quite a lot. (P 1, I 2)

Some patients also stated how over time, they have started to participate more in goal-setting.

I think that there is the difference that if you are here for an umpteenth time, you already know what to ask for, that I would like to do this or that, I would want that, I need to develop this and then in cooperation with... (P 2, I 3)

Right now I put the goal down so to say, earlier I couldn't understand what I had to do. (P 4, I 4)

The practice of goal-setting has been a topic among the specialists of HNRC for quite some time already. A good quality goal would be based on SMART-principle: specific, measurable, attainable, relevant and timely (Siegert & Levack, 2015, p. 106). However, patients themselves state general goals and admit struggling with them, as already demonstrated.

In addition, sometimes the most meaningful goals have to do with the patient's life outside of the rehabilitation centre, making the assessment of success very difficult, which may also explain why even the therapists set goals with limitations.

Two examples of goals from interviews:

The goal is to do all of your workouts to the maximum or... then we will see what comes out... (P 3, I 2)

Well, as a goal, the easiest, to get well in general, right, but such like a 10-day certain goal, I don't have... (P 4, I 3)

The therapist's own motivation and attitude in the therapy has a big impact on patient involvement and motivation and can either "make it or break it".

It is important to know why you are doing something, for what... If you just do, then someone like me doesn't really get it, but if I know that the result is like this or I can achieve that, well then doing it is completely different. (P 2, I 3)

Another patient describes her experience as her therapist suddenly changed:

It was like quite stable before, she wasn't bad but, well, it was like I didn't feel I was doing anything special, but now I feel myself that I am doing something and I think it maybe has to do with the therapist. (P 1, I 2)

The same participant talks about her current physiotherapist:

Exactly, I see that she wants to do it, which creates a kind of... also creates a stubbornness, that I also want to do it with her, I kind of like it very much.

5.3 Obstacles on the road

The problems the patients encounter in their rehabilitation process appear on two levels: at the level of health care system in general and at the level of the service provision of HNRC. Prevalent in both is the lack of information. The formation of the theme through codes and categories is presented in Table 4.

Code	Category	Theme
Problems with health care system	Problems with health care system	Obstacles on the road
The therapy period is too short		
Waiting list for services	Problems with service provision at HNRC	
Lack of staff		
Wish for more services		
The doctor is hard to find		
Lack of information	Lack of information	

Table 4: Obstacles on the road

The patients note that the information is a problem since the moment they get their trauma or stroke.

I wanted to say exactly this that actually getting the information already in the very beginning is... fragmented. Already when the disease gets you, already then it is... The people at home they don't know what to do or where to start,

what is allowed to do and what not and how much and what... already there is a gap. (P 2, I 3)

However, even during their rehabilitation period, they do not necessarily feel informed about their condition or further plans. Satisfaction with the information about their condition was stated mainly by patients who upon further investigation had not had any analyses taken.

And I don't know when I will again... get treatment. P 1, I 4)

Here it was... they took me to the hospital and took a picture of my head and did and... and... as much as I heard from the doctor, it was sent to Tallinn, that you will find out from there, the result. I got out of here, asked... as long as I was here for the ten days, I didn't find out anything from here and they said that you will get the result from the family doctor, but... // I went to the family doctor... no I don't know anything, I have no time for you. (P 3, I 3)

For me today or last night one pill was added, but why and what kind of a pill... in the evening I didn't ask anyone anymore, I ate it and guessed what... for what it... well... what it cures. I realized when I tasted what pill it was // the analysis was taken a week earlier. (P 3, I 2)

Me for example, I am not informed, my doctor is such, who... they take all kinds of samples and analyses, but I absolutely don't get to know about the results. She comes and tells me that, oh, yes they are... and oh, what is the result... and then at this moment she either cannot recall or hasn't written down. And she promises that she will find me during the same day, but doesn't and eventually two weeks have passed and then she comes like, hey, your results were such... so either she comes several weeks later herself or I have to and find her, to say, hey you were supposed to say whether there is something // Already last week we had the same problem actually... // It is very hard to get information sometimes,, sometimes she surprises and comes and tells me as soon as they arrive, but this is a very rare occasion. (P 1, I 2)

Several times the patients used the expression "having to chase the doctor" because they felt that she was not available. This may be a problem with a certain person, though, as one participant explains:

Yes, a lot depends on the doctor; I used to have another one before and then too... I had to wait for her behind her door or run after her, chase her, but when the doctor changed, I am very satisfied with the current one (P 4, I 2)

And there is such a frequent communication with the doctor of our floor that this accessibility of information has been arranged well. (P 5, I 1)

Although known to the researcher, the magnitude of obstacles the patients encountered in HNRC were somewhat surprising as the participants from all groups stated problems with service provision in terms of waiting lists, lack of staff and lack of information. Especially prevalent was the problem with occupational therapy and that also in groups that gave their interviews over a month apart, meaning that the problem was not apparent only at a certain point of time - a specialist temporarily on a sick leave or holiday etc.

It is so that I have been here almost half of the time and I haven't got the electrotherapy, it will be next week. There is also the public holiday in between, maybe I will only get 2-3 times, if that. Simply cannot make it. This hasn't been the nice side that simply I got the question that they take the house so full that they themselves get in trouble with this, that people cannot get all of the procedures, simply all of the patients don't fit on that one service. (P 2, I 4)

They could have mentioned something to them, or... they do know that my hand is ill as well and... hand robot was prescribed, quite a lot. (P 1, I 3)

P 1, I 4: No, everything is OK, only that I don't have the doctor this week, it is almost empty.

Researcher: Empty in which sense?

P 1, I 4: My... doctor is on holiday.

Researcher: But in terms of services?

P 1, I 4: Well, a few, I sit mostly outside, sunbathe.

The main complaint the patients have about their therapy period is that it is too short, but this depends on the regulations of the Estonian Health Insurance Fund.

In case of stroke, for example, the initial therapy period is 21 days for more severely affected patients which can be extended to 42 days with the decision of the rehabilitation team. The less affected patients get 14 days, also with a possibility of extension. In some cases, both of these options are used, however this is only possible during the first six months post-stroke (Estonian Health Insurance Fund 2019).

In case of traumatic brain or spinal cord injury, the allowance is three times that much and it can be used up to 18 months post-trauma. Once the patient is considered chronic, the Estonian Health Insurance Fund pays for 80% of the expenses of a 10-day period, with the patient having to cover the 20% (Estonian Health Insurance Fund 2019)

In a way those patients whose brain or spinal cord injury occurs in a vehicle accident (and unless they have been under the influence of alcohol or drugs) are lucky, because they are covered by the insurance and in this case the amount of rehabilitation services they get is incomparably higher, often reaching several 2-3 week periods per year, for years.

5.4 Daily life at the hospital

The codes and categories that formed the theme are presented in Table 5.

Code	Category	Theme
Familiarity	The patient and the staff	Daily life at the hospital
Helpful staff		
Positive interactions with staff members		
Negative experiences with staff members		
Reluctance to criticise		
Socializing with peers	The patient among patients	
Peer support		
Disturbing behaviour by the room mate		
The role of the roommate		
There is nothing to do in free time	Nothing to do in free time	

Table 5: Daily life at the hospital

While results depend on the patient himself and the rehabilitation team's efforts, the wellbeing at the hospital is dependent on the caregiving/nursing staff and peer patients, most notably the immediate roommate.

Well, since I come here to... to work out and get my... well... walking or something else fixed, then it is... there has to be a time for rest, has to be this kind of calm. (P 2, I 3)

The same participant describes a situation she experienced:

I lived like in a latrine, because my roommate, whatever came she did it in the bed and smeared everything (making a gesture to illustrate smearing the walls with faeces) and then, well said that... I really did live like in a latrine and then I... had my clothes taken away in the meanwhile, because I didn't want to go home with such stinky clothes... So I am saying that this is very important.

At the same time, there are positive examples as well.

I happened to have such a nice roommate and we got... well along and we both liked that the windows were open, such very cool, fresh air. And then when we had been here our time, well, somehow we matched so well that... but you could order a new therapy period from the doctor, and then we asked that... we calculated that well... half a year in between, so in April sometime. (P 2, I 4)

The match or non-match between room-mates is unfortunately something that is nearly impossible to control by HNRC and remains mostly up to luck.

When discussing socializing with peers in general, the opinions were divided, some patients look forward to their therapy period so that they could communicate, others don't value it.

Let's say for me yes, my being here is... more, yes that I put the emphasis on my, this, wellbeing and physique and more, that at home the two are together, the social side and then... workouts and things. (P 1, I 2)

Exactly, alone, well, when you are here for the first time then it is relatively bad alone, but... Of course you do look forward to it, maybe to get new acquaintances or old ones. It is more fun and time passes faster, for example. For example this time in the evening when there is nothing to do really. (P 3, I 1)

The topic of inactivity during free time was brought up by several patients and it constitutes the basis for the most prevalent suggestion for improvement (in theme "The past, the present, the future"), that the gym would be accessible during the evenings and weekends as well.

Actually during the day it is also that you are waiting for workouts and those and here it is that in the evening hours especially if you don't communicate with anyone really, you don't have acquaintances, then there is actually nothing to do. You are either lying in bed or you just ride around. In the evenings there is nothing to do. (P 3, I 1)

In summer at least outside... you go and walk here in Haapsalu sometimes if you have a chance. But in winter, there is nothing, you only look at the pile of snow or this frozen bay there and... (P 3, I 3)

When speaking about their interactions with staff members, the vast majority of the patients stated satisfaction and that the staff is friendly and helpful.

Friendly, as I said already... if there is a problem or... you can always talk, it will be solved, not like, giving orders, that we will do it like that and end of story. We find... look and find a compromise or a solution. (P 3, I 4)

At first I was thinking if... I will not manage here, but no, everyone is assisting and supporting and then I feel that I... that there is still hope, that I can get to my feet a little bit too. (P 5, I 3)

Very pleasantly, they are the pros of their field I can say. In the sense that they are schooled // They know to make you feel so well here that you don't get any problems (P 2, I 4)

Besides the positive encounters, the patients also brought up occasions where the behaviour of the staff had been less than satisfactory, but in general, they are very reluctant to criticize, often saying that the problem had already been solved or that they themselves played a part in it, or just giving hints that something had happened, but not revealing the full story. In some cases they also found justifications for one or the other behaviour. For example, one participant describes her experience:

Some kind of conflicts with the caregivers. Then to a certain extent it was so that... that I sensed that if you are weaker then they treat you a bit disdainfully. (P 5, I 1)

And immediately says: Yes, yes, the caregivers. But this is also the hardest job, so...

Another participant on the doctor's behaviour:

Maybe they can be understood as well, they have to tip page by page of all kinds of stuff into this //computer, machine yes. (P 3, I 2)

The same patient a bit later: She has some additional tasks nowadays, I guess, this is why they communicate less with the patients, they don't have time.

As quite a few of the participants were long-term patients of HNRC, they mentioned the feeling of being welcome and seeing familiar faces around, as well as expressed feeling of safety in HNRC.

For me everything has been so positive since I came back here. Everyone already was asking and expecting as if they had expected me, they called me by my name and those caregivers and all... was very positive. (P 5, I 3)

In general we feel quite like home here. (P 1, I 3)

I don't leave the phone completely freely around, I put it a bit aside, but it is still in a visible spot from the door and until now has not gone missing. But where can it go? Everyone is familiar here. (P 1, I 1)

5.5 The past, the present, the future of HNRC

In their stories, participants often compared HNRC now and in the past, the old building. HNRC moved to the new premises in 2001 and this shows how long time some of the patients have been coming to HNRC.

They also compared HNRC to the other facilities they have been to or go additionally. In both cases, the majority of them concluded that they prefer HNRC and that for various reasons it is better here. One of those reasons that was mentioned by some patients, is the technical equipment of HNRC.

Well, for me it would be that since I have to drive here from another town, to be closer to home, well, maybe I would be somewhere else, but then again in my home place there are not those.. (P 1, I 2)

Opportunities... (P 2, I 2)

... there is no Lokomat and those machines... or the same gym that helps so much, so then it is yes... not happening (P 1, I 2)

As many patients reported boredom and having too much free time after the therapies that they would rather use more purposefully, their main suggestion was that the gym would be accessible in the evenings and weekends. This has often been suggested in the satisfaction surveys that are carried out regularly at HNRC, as well. However, the primary obstacle is that as patients understand themselves too, the risk of someone hurting themselves or overexerting.

But I have thought about this that in the evening, after the lunch there is...a lot of spare time remains, couldn't we use the gym more, I do understand that

there has to be a person again, but still, well, already this strength, this gives us something extra already. (P 2, I 3)

That he can enter /the gym/ with the card and also can use the equipment and who cannot without the instructor or is not allowed without the instructor, this is decided by the doctor, they cannot go. (P 2, I 1)

Unfortunately, while it is possible to give the entrance card only to eligible patients, it is impossible to avoid those who are already in, letting in others who have not been authorised.

In addition, since the gym group therapies that are scheduled for patients, are also billed to the Estonian Health Insurance Fund and insurance companies, this would create a situation where some services are billed and others not. Furthermore, the current system where the gym is only accessible during the scheduled therapies gives the patients the incentive to attend those groups on the scheduled time. Otherwise it is easy to imagine that they would at least occasionally skip a scheduled group if it is on an inconvenient time, and go on their own in the evening hours.

Table 6 summarises the codes and categories that form the theme.

Code	Category	Theme
Improvement of staff behaviour over time	Progress at HNRC	The past, the present, the future of HNRC
Improvement of services over time		
Positive experiences with high tech devices	High tech devices	
Wish to use high tech devices in therapy		
High tech devices as the unique feature of HNRC		
Positive comparison with other facilities	HNRC vs other rehabilitation facilities	
Negative comparison with other facilities		
Suggestions for additional services	Ideas for improvement	
Living conditions		
Access to gym in free time		

Table 6: The past, the present, the future of HNRC

6 Discussion

6.1 Comparison of results with prior studies

The results of this study once again highlight the numerous findings that age is correlated to higher satisfaction levels among patients (Ahmed et al. 2014; Russell et al. 2015; Snelgrove-Clarke 2015; Chumbler et al. 2016). The age gap between the two diagnose-based patient groups was 23.2 years in this study and it is evident from the patients' accounts, that the

younger (SCI) groups were more critical about the staff as well as the living conditions in the hospital.

At the same time, the stroke/TBI groups reported more problems with the health care system, but this can be explained by the different funding principles that apply to different diagnoses and circumstances of acquiring the injury. Despite the differences in criticism, the general reluctance to criticise the staff was common across all patient groups, which is similar to the findings of Mangset et al. (2008).

Independence and the limitations of it due to their condition as well as respect of the patient as a person were the core of the talks, even if in a latent form, with the participants and many other areas were directly or indirectly related to this. For example, the patients' wish to use the gym in free time did not mean that they simply wanted more therapies, but they rather wanted to be able to decide on their own, whether and when to do it. Also, the negative accounts the participants presented were related to situations where they perceived themselves to be in the hands of the caregivers, dependent on them or not being treated as an individual, or where they felt that their specific needs were not considered.

These results are in accordance again with the study on elderly stroke patients' satisfaction with rehabilitation by Mangset et al. (2008), where the findings were very similar: "To be treated with respect and dignity" was the main theme, while the five sub-categories included "Being acknowledged as individuals" and "Having their autonomy respected". Another, albeit small, study on spinal cord injured patients (Lindberg, Kreuter, Taft & Person 2013) reached to almost identical conclusions - being treated with respect by staff was one of the central themes.

Similarly to the findings of Lindberg et al. 2013, the patients in the current study remained hesitant about the family involvement, which implies that the preferences vary by individuals and this should be taken into account when planning the services directed towards the family members.

The two abovementioned studies share another common finding with the current one: the importance of sharing adequate and timely information. Here there is definitely room for improvement within HNRC, but also on the level of health care system. HNRC can contribute to this by actively participating in relevant discussions with other stakeholders and policy-makers.

The participants complained about the large amount of free time and suggested free access to the gym as a compensation. It has been shown in literature that patients for example in stroke rehabilitation units spend about $\frac{3}{4}$ and even more of the day sedentary and that their activity levels in these units are actually not higher than in acute care (Åstrand, Saxin,

Sjöholm, Skarin, Linden, Stoker, Roshandel, Dederling, Halvorsen, Bernhardt & Cumming 2016; Sjöholm, Skarin, Churilov, Nilsson, Bernhardt & Lindén 2014; West & Bernhardt 2012).

HNRC is dedicated to provide at least three hours of active services (physiotherapy, occupational therapy, speech and language therapy, psychologist's services) per day per patient, but according to the Australian Clinical Guidelines for Stroke Management 2017, in case of stroke patients, "rehabilitation should be structured to provide as much scheduled therapy (occupational therapy and physiotherapy) as possible" and "stroke survivors should be encouraged to continue with active task practice outside of scheduled therapy sessions".

It seems that the participants of this study were more motivated or perhaps more aware of the benefits of extra workout than some other qualitative studies have shown. For example Peiris, Taylor and Shields (2012) found that rehabilitation patients valued interactions with their physiotherapists more than the amount or content of therapy. However, also in their study, once the patients did receive services on Saturdays, they felt that weekends could also be dedicated for recovery, not simply rest.

At HNRC physiotherapy services, individual sessions and gym groups, are provided also on Saturdays but not to all of the patients because on Saturdays only a few specialists are present and their schedule is shorter than on ordinary workdays. Patient selection depends on the availability of time, on the condition of the patient and the length of their therapy period. In this case usually patients on shorter period (meaning chronic phase) are preferred as otherwise they would have two out of ten days without any services during their time at HNRC.

Despite of all the above, keeping patients more active during the evening hours has been discussed in HNRC for some time already. As it often is, finding resources is problematic therefore one of the possibilities is involving volunteers in an organised manner to fill this gap. Volunteers have been shown to improve the quality of long stays in rehabilitation units (Barbieri, Maffoni, Negro, Maddalena, Bosone & Tronconi 2017), but in Estonia it would be a novel practice.

Goal setting was admitted by several patients to be challenging. Similarly to other findings (van Seben, Smorenburg, & Buurman 2019; Plant, Tyson, Kirk, & Parsons 2016), the goals that the patients stated themselves differed from those of the specialists, as they described how the team members suggested lower level or stage by stage goals to start with. The goals were perceived to be realistic as a result of this process. Still, most of the goals that the patients expressed themselves were broad, general and related to "getting well".

Besides the role of the therapists in goal setting, the participants positively talked about inspiring and challenging exercises and the importance of explanations for their motivation.

Indeed, the therapists' manner, level of support and involvement as perceived by the patient, has been shown to have an impact on patient engagement in their rehabilitation (MacDonald, Kayes & Bright 2013).

6.2 Suggestions

1. Educating staff in communication skills

As Gill et al. (2014) state, assuming that by choosing to work in the field of health care the staff members naturally present excellent communication skills will most probably not result in a consistent high standard of communication across the organization. They recommend conscious, systematic efforts to support staff education in this area as well as communicating clear expectations and creating accountability pathways to guarantee participation.

2. Activities of free time

In addition to considering the possibility of fulfilling the participants' wish to have access to the gym in free time, providing other ways to spend free time in a more structured way, could be an option. It has been shown that structured leisure time activities improve experience with care and could promote continuation of activities after discharge (Sartori, Marelli, Garavaglia, Castelli, Busin & Delle Fave 2014). There is also evidence that these activities could be provided by volunteers with good results in terms of improving the quality of stay in rehabilitation units (Barbieri et al. 2017).

3. Efforts for occupational therapy provision

If efforts in increasing the number of occupational therapists are unsuccessful, another option would be to create more group therapies in this field. Similar suggestions have been made in terms of physiotherapy, where a circuit training setting has been recommended to increase therapy time for patients (English, Bernhardt, Crotty, Esterman, Segal, & Hillier 2015).

4. Improving information exchange

One of the findings of this study was the importance and desire for independence and at the same time several patients complained about lack of information regarding their test results, condition and further options. Interestingly, lack of information has been shown to inhibit patient's independence, autonomy and the motivation to participate in rehabilitation (MacDonald et al. 2013). Therefore, it is especially important to improve the information exchange within HNRC as it may improve patient experience both directly and indirectly through supporting their autonomy.

7 Limitations of the study

This is the first attempt to gather qualitative information about patient experience and satisfaction of the patients of HNRC.

The participants were Estonian-speaking and their physical as well as cognitive status was such that they were able to participate. Thus the results are limited as patients in more severe conditions were not included, nor those who communicate in Russian (or some other language) only. The other two big groups that were excluded were the paediatric patients and their caregivers/parents as well as the patients who receive outpatient treatment. It is possible that a similar study will be conducted with these groups in the future.

It was also the first attempt for the researcher to conduct a qualitative study. Many lessons were learnt, especially about interviewing and managing the group discussions but also about the participant selection.

The main challenge for the researcher was to ask open-ended questions and not to offer answers to the participants herself, but there was improvement during the course of the study. In addition, the skill to notice and encourage less active group members grew in the process.

However, based on the information gathered, some suggestions for improving the experience of the patients of HNRC could still be made.

8 Conclusion

In conclusion, based on the results of this study, patient satisfaction is mainly determined by the quality of communication between the patient and the surrounding specialists and other hospital staff, but also the peer patients.

The participants of this study expressed their wish to be treated respectfully as individuals and they expect support from the specialists, especially the physiotherapists, in their striving for greater independence. Therapists, who give feedback, discuss with the patient, consider the specific needs of the person and support them in goal setting, increase the motivation of the patient.

The extent of communication with peer patients is individual, but a patient's experience of the therapy period can be affected by the behaviour of the immediate roommate.

A problem area in communication appeared in terms of informing the patients of the results of their analyses and following changes in medications. Having to "chase" the doctor or receiving information that is unclear or late negatively affects satisfaction.

Another problem that was observed, was access to services, mainly that of the stroke/TBI patients. Many of them were disappointed that they did not receive the services that had been prescribed by their doctor and what they actually needed. The most problematic is occupational therapy, but also speech and language therapy and electrotherapy were mentioned.

A common issue that was reported by patients from different diagnose groups was the big amount of free time and boredom, that they themselves would see as alleviated if the gym or at least a special therapy room would be accessible after the regular working hours and during weekends. One possible solution is involving volunteers, a practice that has not been tested in HNRC yet.

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Appendix 1: Tallinn Medical Research Ethics Committee, approval no 2604.

Tallinn Medical Research Ethics Committee

Decision no 2604

Tallinn Medical Research Ethics Committee (TMEC) in composition: Kristi Rüütel, Jaak Põlluste, Avo-Rein Tereping, Adik Levin, Vahur Valvere, Jaanus Kerge, Marje Liibek, Kaire Innos, Kadi Lubi, Anne Kull discussed during their meeting on January 17th 2019 and decided to approve the following research project: „**Determinants of patient satisfaction among patients with central nervous system damage in inpatient neurological rehabilitation setting**“. The main researcher is Master student **Mari-Liis Ööpik-Loks**, her supervisor (responsible researcher) is **Teija-Kaisa Aholaakko** (Finland), the research is carried out based on the data of Haapsalu Neurological Rehabilitation Centre.

Application no 1942, TMEC meeting protocol no 236.

K.Rüütel
Chairman of TMEC

M.Liibek
Secretary of TMEC

Appendix 2: Participant Information Sheet.

Participant Information Sheet

I would like to invite you to participate in my study! Before you take any decisions about participation I am asking you to take time and read through the following information. It is important that you understand why the research is done and what it would involve for you. If anything remains unclear, please ask me about that.

The main aim of the study is to understand how patients of Haapsalu Neurological Rehabilitation Centre (HNRC) experience their therapy period and to find out what determines their satisfaction or dissatisfaction with the whole experience.

Participation criteria.

You are invited to participate because you are currently a patient of HNRC and thought to be able to provide interesting information about your experience here. Unfortunately you are not able to participate if:

- you feel uncomfortable sharing your views in a small group (5 members) of peer patients
- don't speak and understand Estonian
- your medical diagnose is other than stroke, traumatic brain injury or spinal cord injury
- you are less than 18 years old

The participation is fully voluntary. It is up to you to decide whether you want to participate or not. You can withdraw yourself from the research at any time without giving reasons.

Actions if participating.

If you decide to take part in the research you are kindly asked to do the following steps: read through the current information sheet and take informed decision about participation.

Fill in and sign the consent form.

Participate in one focus group discussion. The focus groups are about 60 minute discussions among no more than five other patients with similar diagnoses who are currently on their rehabilitation period in HNRC. The discussion is facilitated by the researcher. The discussions will be recorded with a dictaphone for analysis.

You and other participants are asked to discuss about topics related to your experience as a patient of HNRC. The discussion is triggered by the researcher's questions.

Possible distress.

During the study the information is collected through interviews in small groups of peer patients. It might happen that some distress is caused during the interviews, although no one is required to reveal any information they don't feel comfortable to. If this happens the discussion will be stopped and „time-out“ is provided for the whole group. Private moment and support from the researcher is offered for the distressed participant. If this is insufficient, possibility to withdraw is offered. You can withdraw yourself from the research at any time point without giving reasons.

Possible benefits.

The interviews will be held at HNRC, therefore you will have no spending connected to the research.

You will not benefit from the study directly but the results of the study will possibly help to improve the patient experience and satisfaction in HNRC. Participation also gives you an opportunity to get to know your peer patients who share similar experience with you and to hear their thoughts. You will not receive financial or any other benefits.

Anonymity and confidentiality.

Your anonymity and confidentiality will be guaranteed. The data will be collected, transcribed and analysed anonymously, which means that your name is not recorded or written down. From the very beginning the pseudonyms will be used. No visual images of you will be taken or presented. Hand-written data will be kept in a locked filing cabinet and destroyed

when the project is completed. Audio- and computer-written data will be saved to a separate external data holder within a password-protected folder and also deleted upon completion of the study.

No data is given to third parties at any point of the study or later in the future.

Presentation of the results.

The research is aimed to be ready no later than May 2019. The results are shared with you and other participants as well as the employees of HNRC. No participant can be identified in any report or publication. Only anonymised quotes will be used.

Any complaints you might have during the study will be addressed by contacting my supervisors. The contacts are at the bottom of the information sheet.

The research has been approved by the Tallinn Medical Research Ethics Committee, approval no 2604. If you have any questions, please don't hesitate to ask me or my supervisor.

Mari-Liis Ööpik-Loks

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Appendix 3: Participant Consent Form.

Laurea University of Applied Sciences

Master Programme: Global Development and Management in Health Care

Participant Consent Form

Title of the study: „Statsionaarse neuroloogilise taastusraviga rahulolu määravad tegurid kesknärvisüsteemi kahjustusega patsientidel.“

„Determinants of patient satisfaction among patients with central nervous system damage in inpatient neurological rehabilitation setting.“

Name of the researcher: Mari-Liis Ööpik-Loks

I confirm that I have read and understand the information sheet dated for the above study.

I have had the opportunity to consider the information and ask questions, which have been answered to my satisfaction

I confirm that my decision to participate within the research has been fully voluntary

I have not received any pressure of other influence

I know that I can withdraw from the research at any point in time without giving reasons

I permit that my talk about my experiences and opinions is used for the purpose of analysis within the research and anonymous quotations may be used within the presentation of the research

I participate without any payment, gift or other benefits

I agree to and want to participate in the research project about patient experiences and satisfaction in HNRC carried out by Mari-Liis Ööpik-Loks

Name and signature of the participant

Date of the signature

Name and signature of the researcher

Date of the signature

Appendix 4: Questions and topics guiding the focus group interviews.

Introductory question:

1. Please recall your current therapy period. What would you bring out as a positive experience? What would you bring out as a negative one?
 - 1.1. What did you like about this situation? What annoyed you in this situation?

Safety and courtesy:

2. Do you feel safe in HNRC - materially, physically, mentally?
 - 2.1. How does the staff treat you? Are you being treated with respect and courtesy?
 - 2.2. How is your relationship with peer patients?

Involvement and person-centeredness:

3. What were your expectations prior to the therapy period? Have these expectations been met?
4. Have you been asked what you would like to change in your life with rehabilitation?
 - 4.1. While being here, do you feel supported in achieving your personal goals? Have you achieved them? If not, why in your opinion?
 - 4.2. Have there been situations where you would have liked to discuss your goals but you were not enquired about them?
 - 4.3. Is there anything you wish that would be dealt with, but it has not been done?
5. Do you feel that you are involved in the services provided to you - can you discuss, think and express your opinion?
6. Is your family, friends, school, employer involved in the services provided to you? Should they be? How?

Satisfaction and proposals in terms of services:

7. Are you satisfied with the information about your situation and self-management?
8. Is there anything you would like to change about the services you receive?
 - 8.1. Which additional services could HNRC offer?
9. Please try to bring out three things you would change about HNRC if that was possible?

Appendix 5: Researcher's impressions on the focus groups.

Group 1 - SCI patients	<p>One member barely participated. This was the only group that stated issues with living conditions.</p> <p>The first group for the researcher, there were difficulties in supporting a smooth discussion.</p>
Group 2 - SCI patients	<p>One group member was hearing-impaired which affected the whole discussion. Probably a one-to-one discussion would not have been a problem but it was hard for this patient to participate in the group. Therefore, parts of the text cannot be used since it is not clear whether the researcher and the participant understood each other completely.</p> <p>Suprisingly, this group stated the biggest difficulties with goal formulation and generally left an impression of a more passive attitude towards their rehabilitation.</p>
Group 3 - stroke/TBI patients	<p>This group had the most positive atmosphere and willingness to talk.</p>
Group 4 - stroke/TBI patients	<p>The longest discussion, due to the speech impairments of the participants - they were almost all speaking very slowly. One participant was dominating over the rest. Two participants were the oldest across all groups.</p>

Appendix 6: Striving for independence.

Personal responsibility		Patient's own role in the recovery	Striving for independence
PT3:// if you are lazy yourself, nothing will come out... of this goal	If you are lazy yourself, there will be no result		
PT1: I have been thinking about it the whole time, but oftentimes when I see how many people are there and especially if the majority are like, needing help, then it is like.. running from one side to the other.. well... well, I will not start in the meanwhile that, hey, am I doing it correctly, it is more like, I have taken it on me, I know how I should do it, so that..	I don't want to disturb the therapist if there are many patients who need help at the gym, so it is my responsibility to do exercises correctly		
PT2: Not as intensively as here, but... well, but... as the tools and devices have been bought then.. it is not like dots in the ceiling, counting until next time... not like that	The workout intensity is not the same, but I am not only resting at home		
PT1: Then it is upon yourself, either you do it or not	It is your responsibility to follow the recommendations		
PT2: it is rather your own fault then.. ML: Aha, how has this happened then? PT2: Well, you avoid something, or, or, or.. you don't want to go or something.. ML: But why is it so, that you don't want to go? PT2: You work your way around.. I don't know really, it is.. like, like it is currently, so that.. they want to make me cook in that kitchen.. I don't feel like this so you work your way... ML: So you are not in the mood, or? PT2: Yes, rather, yes.. ML: Such a temporary thing PT2: It is lazyness.. that too, I'd rather call it this	Avoiding therapy when the activities are not appealing		
PT1: //only here I started to see everything, to look into things and I am curious myself, too.. If I need something, if I want it, I have to get it	After coming here I started to ask about things		
PT4: Yes, of course they are with me or, well, with me in their thoughts or.. right, but this remains individually up to everyone themselves	Recovery is everyone's individual responsibility		
PT1: // I am active myself as well, sticking my nose everywhere to see how to do it better	I am interested in my therapy		
PT4: //but they will not come here to work out for you, so to say.. you have to do it yourself	The family members are remotely involved, they cannot practice for me		
PT2: Well, here I have doubts, whether I will be able to. But you have to try of course..	Although I have doubts, I have to try to achieve the goal		
PT2: Well, I cant afford this to myself. You have to motivate yourself. But will I be able to by the time the deadline comes...	I have to motivate myself despite the doubts I have about the probability of achieving the goal		
PT5: Yes, no I got it already before coming here... then I worked so hard that I got out of the wheelchair and then I started limping around on my own feet	I worked hard to get rid of the wheelchair		
PT3: if the person himself does not want to, then you can break your head, you cant do anything with him.. but if the person wants, then they will help and get excited. Sometimes someone is so weak, I can't do it (makes a whining voice)... but you can do it! Set yourself goals and...	In order to achieve anything, the person must want it himself		
Slow recovery			
PT3: Well yes when the therapy period is finished yes, or during the therapy period there comes such movements, well I am a difficult trauma, for me it is very slowly.. anything comes, but,.. yes	The movements recover very slowly		

PT4: It is coming very slowly, right, actually, but all of this is step by step to this improvement //	The recovery is slow		
PT4: // in the sense that step by step so to say at once, you cannot jump over your shadow, so to say... I am not even thinking that... exactly as I said that you are.. in ten days you are running, right... it is coming little by little... but very..	Step by step improvements, but you cannot jump over your shadow		
PT2: Well, it showed at home. What was done to me here, it appeared at home, this achievement that I tried.	The results of the treatment appeared at home		
PT5: There are some wishes maybe, but allegedly they come with time, so I just have to wait	It takes time for some results to show		
PT3: well, I feel that... // but I have developed more and I feel in comparison what I .. well not ten, but five years ago, in comparison to that, I have improved a lot	I feel that I have improved a lot over time		
PT5: Yes, that the hand, the little hand, that the fingers would work, because my hand was off, I had a stroke //and then yes.. these fingers and... I was here once, but I thought that maybe,, but there is nothing.. well, numb, I cannot work	I want my hand to function again but it hasn't happened yet		
PT2: I would like my hand to start moving, but I do realize that my hand will not start to move. Initially they told me, well if there was a stroke and you are so deeply paralyzed, at first.. at first the big muscles will start moving and all the time go to the smaller muscles and those joints.. And it is, at first the hip and legs started, but those little ones... say.. the shoulder joint eventually now, but the elbow joint is not working... and fingers	I would like my hand to function but the progress is very slow		
PT3: Yes, to put it short, such an example, when I came here for the first time, I was in the wheelchair and I had epicysto.. and it was far from walking... I dreamed about it... but the the third or the fourth time I came here, I made the first steps... independently (laughs) and tease me or not, I had tears in my eyes. Over four years I couldn't walk... this felt really good.. and then I understood that I have the victory and now, thank God that this kind of a hospital, if I may say so, or centre, like HNRK, exists	I made the first steps after 4years of coming to HNRC and this made me cry of happiness		
Recovery requires effort			
PT3: There is no spare time, if you have spare time then I spend this one hour in the bed, well.. (laughing), this injury... I cannot be in the wheelchair from the morning to the evening	I need rest in between the therapies due to my condition		
PT2: Because the daily schedule is so tight, well you take the maximum of it	Taking the maximum of the tight schedule		
PT3: I lost hope completely, lost my balance.. already for the second year I don't have it	Losing hope due to the condition		
PT5: mmm, well, those knees of mine are so worn and you know those exercises are hard, it makes my head wet, but you have to... you have to do it and then I put such a.. thought to my mind that you have to be able to, you have to be able to and then this little knee pain does nothing.. most important that the hand and the leg would move	Despite of the hard exercises and painful knees, I must make an effort		
PT2: .. and you should not tell them that it is easy, then they increase the load so much that I am dead some-times Laughter	The workout load can be intense		

PT2: This is how it is in top sports, you have to put up with pain	Rehabilitation is top sports where you have to put up with pain		
PT2: I would also go happily, when you have been tortured in the therapy here and you bones hurt, I would go and rest in between (laughing).	The therapies are intensive and I would happily rest in between		
ML: What about the therapies? What goes on in the therapy PT2: They are torturous (everyone is laughing)	The therapies are torturous		
PT5: They are taking you forward, they are hard, but taking you forward	The therapies are hard but they give results		
PT5: And they scared me that the workout load will be even worse (laughter).	I was told that the workout load will increase even more		
PT3: It is two sided thing, yes, that from the physical side some workouts are really tiresome, but when looking at it later, then there are also results. That you can see the reason why they tortured you a bit	The therapies can be demanding but the results show that it was necessary		
PT2: ... how I cried, the first time I went out, I hated that Lii as much as I could, I came.. over ten years later I came back, then I thanked that Lii. That she was so consistent with me. I remember how she dragged me from bed.. threw me on the mat... now you crawl 4 times	I am thankful to the physio-therapist who didn't show mercy		
ML: If you have been supported // how is it explicit for you? PT4: Better services for example ML: But what is a better service for you? PT4: When I get a lot of exercises and they show no mercy	Better service for me means a lot of exercises and showing no mercy		
PT4: At first for a very long time, I thought this is just a hospital. At first I was such a long time... I couldn't get home and this made me feel disgusted	The long therapy period was difficult to put up with		
PT4: .. I know that I am very critical about myself and when they ask afterwards in the end, how are you satisfied with this or that, that result, then I am just (makes a gesture).. I am not satisfied	I am critical about my achievements		
PT2: when I was here the first time, the last time I came here, you know I had such a feeling that I am at some kind of a training camp for olympic team top athletes (laughing). Four procedures per day, half of them gymnastics..	The training load was as of a top athlete's		
My opinion matters		Personal value	
PT1: // They are forthcoming, it is like... if you don't feel well or, really, it really is lazyness, not in the mood, you work your way around it somehow.. they are forthcoming like.. they do a bit easier or milder tasks or its like..if you express a wish that you would like something.. to do something more intense or something more rough then they also think of something, so.. this is yes..	The therapeutic activities are modified according to the patients' wishes		
PT2: Mmm, when with some things.. a little carelessly.. very easily like cutting corners.. if you have said, well, asked, that please do it like.. well, but she does it still her way, and then...	I don't like when my wishes are not taken into account		
PT1: Everything you want to achieve, is tackled right away and.. every time you open your mouth, you say something, then they will tackle it. It is not postponed.	Whatever you want to achieve, the specialists help without delays		
PT3: If I had some kind of a goal in my mind and what would be necessary to suggest, they definitely would take that into account.	My opinion would be considered if I had some kind of a certain goal on my mind		
PT3: In general.. this attitude with	I feel that I am necessary and		

you and... well // in general there is this situation that... //you are not simply thrown to the street... you are necessary, you are important	important here		
PT2: Yes, the doctor, as soon as I got here, then what do you... what procedures helped you the last time and what do you wish now? // That in this sense, they discuss with the patient, what suits you and what doesn't suit you	The doctor discussed with me what is the most suitable treatment for me		
PT2: They take it into account a lot if I ask something, well not demand, but imply that it is not alright	My opinion is taken into account		
PT2: Yes, sure. I said that this time I told that the last time I overdid it.. now I.. the doctor immediately considered this and now that I told her that the electrotherapy had a good effect, but I don't have it this time, she immediately said that yes and looked it up, why I didn't have electrotherapy, so in this sense	The doctor considered my previous experience in determining the current therapy load		
PT2: yes, that no one allows you there, so to say, over your abilities that I do there with tears in my eyes, that I have to get it done, that they say, you see, you have to complete this.. that you do it then. No, it is very pleasant in the sense that exactly... your time is up, yes, you can leave if you cannot.. Every time she asks if you can or do you want to rest	They consider my opinion in the therapeutic activities		
PT4: Yes, I have always said what I want ML: And is it taken into account? PT4: Yes, it is always taken into account,	What I say, is taken into account		
Individual approach			
PT2: Something like... with him and him I am doing it like this, why with you then.. // I cannot do it the same way... that //with the other patient I do it like that.. then I say that, does this other// patient walk around or what? Some things have to be done a little differently	Personalized approach is necessary for each patient, not everyone is the same		
PT1: // I used to have a room mate who was a vegetariand and // she had mentioned it, but still when she went for food, there was either some kind of a.. well... cutlet on the plate or some meat stuff was still there.. //it is definitely an important thing to pay attention to	The personal needs of patients should be taken seriously		
PT4: There is stair walking and everything is individual in this sense that it is not so that we are now all the same, I don't know, the programme foresees it like that.. they take into account, well, they take into account the personal need	The individual needs are taken into account during the therapies		
PT1: Well, in my case the doctor saw that I needed more, therefore she prescribed more for the hand	The doctor noticed the necessity for therapy		
PT1: Since I live on the second floor, then they taught me how to move up and down the stairs. Which is not very logical in case of a wheelchair, but it is doable. Achievable.	I was taught to use the stairs with my wheelchair due to my living conditions		
PT1: ... that if you want to learn to knit then the goal is to teach you to knit, right. Or cooking or dishwashing.	Your personal preferences are considered in goal-setting		
PT2: She remembers, despite of having many patients and at the same time it is so pleasant that she remembers you immediately, passes you, smiles and asks if you have had any problems during the few days, what else would you like, and..	I like that despite of having many patients, my doctor remembers me		
PT2: I like that this young doctor I	I like that my doctor enquires		

have, she is Latvian.. for example she meets me on the stairs.. How is it going? Is everything alright, do you have any wishes or problems? She always asks if there is anything...	about me when we meet		
Independence/Dependence			
PT1: // in terms of coffee drinking, that this... this machine down there is very nice but // I can't properly hold this thin plastic cup, well.. I can prepare the coffee there, but how do I get it from there, this is // a bit thoughtless that.. //	I can't use the coffee machine independently		
PT1: // Asking for help, it is never like.. it is about yourself that you don't want to ask for help, I will manage myself, but no.. when you ask for help, they do come, they don't start like.. what, you can't do it or.. no there is no such thing, it is proper..	Avoiding asking for help, but if necessary, the staff helps		
PT1: // I am so strong that I will manage on my own	I am strong so I can manage on my own		
PT1: //.. I dont want to, I must manage on my own, I manage on my own, I am so stubborn that...	I need to manage on my own		
PT5: // Right now I am still completely... completely... But well, an elderly person, it takes some time, to be able to manage a little... even a little on my own... and there is still hope that it will get better	It takes time for an older person to become more independent		
PT3: Otherwise it is set in the plan, that I have to go there at a certain time. In the evening it is for example so that the day has been busier, you rest a bit, do your other stuff and then you look that the time is almost seven o'clock... that there is nothing to do right no, that I could go. But if it is in the plan, then it is like.. you have to go at that certain time	The gym could be open so that I can go anytime I wish, not following a schedule		
PT1: It is good to be back, that I can move actively. Otherwise I am fed up with sitting at home	I can be more active in HNRC than at home		
PT3: Even the massage specialist comes, makes space for me, lifts the wheelchair away, but puts it back herself.. At the moment for me it is good, I am able to reach it myself exactly, but when I am in the other room, they put it in the corner and I would stay here waiting...	The specialist moves the wheelchair away but doesn't put it back and I am stuck waiting for someone to come		
PT1: Of course you can play snooker, you can play cards, table tennis, whatever, options are there, but you always have to find the other person too, with whom you will play and unfortunately we are not going to play it with another person who is in the wheelchair, because the ball can fall on the floor and we stay there getting the ball	The free time activities depend on finding a suitable partner		
PT1: I can't explain it.. I could not... close my right hand like this (shows)... I have... I started the ball... already at the hospital, I just have to.. I am.. I live alone, so... I don't go anywhere but I have to manage on my own	I am doing exercises on my own because I have to manage on my own		
PT1: I have to manage on my own, I live on my own.. I want to go, I go shopping and all... more or less what is close... close by. But I want to walk a longer distance.. now I just practice, walking... but my feet hurt.	I live on my own and I need to be able to manage independently, so I practice by myself		
PT3: my main goal is that I want to manage my life on my own	I want to manage my life on my own		
PT1: I will not.. I cannot cause trouble. They have their own life. They are already old people in their own right. I am.. I am also old. What is there for me to want. I do what I can. That's it.	My sons have their own life and I am doing what I can myself		

PT3: at this nursing home where I am now, there is... once.. that was a long time ago, but once, when there was an argument.. we feed you, you must follow our rules.. excuse me, but this is death to me..	At the nursing home they give orders and I hate it		
PT2: I came in and the doctor very pleasantly asked if I have all of my medications that I take // She said, don't call, I can prepare the digital prescription and you can get it from here. So it is, I just haven't had the chance to go to the town, the distance seems so long to me and by bus... I haven't gotten myself together to take the bus downtown	It is difficult to go downtown to buy my medications		
PT3: well the main thing is that my goal is that I can, I would, manage on my own in my life. And this is why I am coming here that I could walk better, move better and this is why I want occupational therapy, that there they teach you to independent... that you manage independently.	I am coming here so that I could manage on my own in my life		
Immediate circle involved by the patient		The involvement of the immediate circle	
PT2: Friends... certain..certain... I mean stretches or those, they will not bother, or hurt me, they could do something wrong, but this kind of recovery stretches, these.. when they come or when I visit them, then yes..	The friends help with exercises at home		
PT2: Family maybe more than friends for me, you are together with family every day, so with them it is like.. you want to stand up or something and they then kind of help, but friends maybe yes not so much, they don't really know what I do or how I do.. so	The family assists more than friends in home activities		
PT3: They have talked to my husband, or he has talked or with the doctor over the phone or.. these periods that I am here.. made arrangements or.. such things... and my husband often comes to visit me, my son does and some kind of friends also have been ML: But do you feel the initiative from HNRC? PT3: Well, more.. no.. how do I say it,, more from us, from ourselves ,	The husband is making arrangements for therapy periods, friends and son visit		
PT3: In a way, yes, sure, who is closer and...but those who are further away, they cannot make it like this.. only talk to you on the phone PT5: The same with me, I can only talk to my children over the phone	The family members are involved over the phone by the patient		
PT2: I have involved them myself, that me, when I first came here, the activities here were not enough and then I arranged it so that every evening someone came here, so that I could walk outside for an hour and this is really nice... //	I arranged family and friends to come for a walk and talk every evening		
PT4: Well, in this sense my wife has always picked me up, the last.. /// that the last, so to say, communication with the doctor has been together with everyone, that this is not some kind of a tete-a-tete, but there are more eyes there, so to say	The wife usually attends the last meeting with the doctor		
PT5: My daughters they also talk to the doctor and then also with those.. well.. those who do the workouts, with all of them they have talked already..	The daughters communicate with the team members on their own initiative		
PT2: Well, at home my wife is now officially my caregiver and then she has to do these things for me at home that the caregivers and nurses do here - meals, washing. Now I am capable myself of course, but well, these things. This is direct and active participation in my such being	My wife is involved in my rehabilitation as my caregiver at home		

PT5: I don't know really, for example my family members are informed about my therapy plan, my partner asks me every day how has it been, what are the developments	My family members know my therapy plan and improvements		
PT3: Yes, to this extent the family got to know. But they have not been involved more, I guess. The rest has been directly from me. They suggest to me and I pass it on. I don't know about direct involvement.	The family involvement has only been by me		
PT2: She keeps an eye on me at home so that I wouldn't get lazy with... well, the workout that she sets me there	My wife urges me to work out at home too		
PT5: In the beginning maybe more the family. But I would rather say that it is from them, their initiative	Initially the family was involved on their own initiative		
PT4: For the exam for example I don't write with the pen, but they give me more time on the computer	At the university they make exceptions to support my studies		
PT4: // now after the accident I do live with a parent. And I am really lucky in this sense that my mother always puts a note in the fridge for example, where I have to go at what time, because I cannot remember well	My mother supports my memory with notes on the fridge		
PT4: For example one professor asked if I am capable of graduating my university. That if I am capable for that. Physically and mentally.	The university professor asked me whether I am capable of graduating		
PT5: Well she is the a and x who helps me and brings me and takes me where I need to and who cares for me and..	My daughter takes care of me and makes arrangements		
PT2: Yes, my husband.. // I was thinking, how will I go again for ten days again.. to put it short the husband's load will be like double... // he paid for the contribution for the treatment he gave me spending money to take with me //	My husband supports me by taking over the tasks at home and by paying for my treatment		
Immediate circle involved by HNRC			
PT3: It is a burden for the facility, if so to say, relatives, family also all the time...	Family involvement would be a burden for HNRC		
PT5: // the therapist sent all the workout exercises and those to my daughters, that when I was at home then I have to work out following those samples, this... therapist contacted my daughters, still	The therapist sent home exercises to the daughters		
PT4: For example that come earlier, they called my wife that maybe I could, this exact time right now, that maybe I could... i guess it was three weeks earlier or two... well, two for sure, that come earlier, that there is a chance, but life had been arranged in such a way that I did not come earlier, the answer was negative, that I cannot, right	The arrival arrangements were discussed with the wife		
PT2: I don't know, when they asked me... was it the psychologist, I guess... that whether she can call my husband, I don't know if she called, I don't know if or what they talked about, I said that of course you can	The specialist asked for permission to call the husband		
PT4: Well, for me it was a bit different, at first for example my mother came here very often and then during the therapy the doctor or nurse or someone from the caregivers talked to her, that she was told.	My mother was informed by specialists on her visits to HNRC		
Family involvement and independence			
PT2: Maybe the fresh ones, let's say, who come, maybe they have then.. how to manage with them, or how.. they see it for the first time... maybe for them	The involvement of the immediate circle and family is more important for new patients		
PT2: Yes, in the beginning if you are weaker yourself... then it was like, yes.. occupational therapist or then	The relatives were more involved in the early stages of rehabilitation, but not any		

they like talked to the relatives.. that this or that or... this yes that in the beginning years.. they gave those leaflets or had printouts on what exercises to do at home, yes, then it was and.. But now that you are a bit better, no need to keep an eye on all the time, then this has disappeared	more		
PT1: In the beginning yes.. now it is the same that you have a mouth and brains like... now that if there is really a big problem, they turn to me, but...	As I have recovered, things are discussed with me, not with the immediate circle		
PT1: I was at home here, improved on my own, no one asked how am I doing.. nothing	Recovering alone at home, no one asked how am I doing		
PT2: . It also depends on the injury of the person, and I have a minor, well, relatively minor problem compared to these people. It does depend on how serious the injury is that ise being treated.	The family involvement depends on the seriousness of the injury		
PT4: Sometimes I just didn't tell what or how is happening here. Now they only listen to me, what is going on and so forth. This is how it is for me	As I recover, the family is less involved		
PT4: Because the person is connected to this for the first time and he doesn't know anything and no one tells him in any other way but when he comes here then the social worker or the psychologist or someone else should tell him	Someone from the specialists should talk to the family members as it is their first experience with something like that		

Appendix 7: The therapist as the key partner in goal setting and patient involvement.

Discussing therapy with the therapist		The therapist as a partner	The therapist as the key partner in goal setting and patient involvement
PT1: Lets say yes that not exactly a workout plan or such has not been given, but orally they mention that you could work on that at home, or try this or like three times a week or whatever... well orally they let you know what you could do	The home activities are discussed orally		
PT2: Yes, in physiotherapy or.. we discuss that do this or at home if.. how much you do at home and how do you do it, yes.. this is discussed	We discuss home activities with the physiotherapist		
PT2: //we always discuss, well, there is no such thing that.. lifting the same.. the same thing.. the same.. no there is no such thing. We do.. whatever you wish to try, they always agree to..	The content of the therapy is discussed with me and my wishes are taken into account		
PT1: // I talked to the physiotherapist, I already knew that I will be coming back for 10 days // So I did ask that if I will be working with you again, and that it would be good // I will check your improvement, that you are doing better, this is how we can discuss between us, when I will back//	I discussed the future cooperation with the physiotherapist		
PT1: // at first you have to discuss, whether this is appropriate at all, if this is good for my hand if this is good for my leg... everything should be discussed at least ML: And this is done? PT1: Yes, sure	The therapeutic activities are discussed with the patient		
PT5: Yes-yes, they do tell me, because I have... those knees are so sick, this is why they ask all the time, how it is and how it is and can I do it today and what we will do today and everything is discussed, that, well.. we could do everything a bit better	The patients current condition is discussed during the therapy		
PT1: I would say for example that me with the physiotherapist... well the one who worked on my hand, or well, generally with my ability to move, that we had a very positive cooperation between us // we discussed, what is like more painful and what would be better, how does this affect me, things like that. How it would be better and how was it the next day, how I generally feel	Good cooperation with the physiotherapist means discussing the patient 's condition		
PT3: For me here, the first time I came here and started going home, then all the therapy instructors they came and talked what I should do and what movements or so I could do with my legs	I was instructed by the therapists on home activities when I went home for the first time		
Discussing condition with the therapist			
PT4: // I was a bit scared off, like, what am I now.. what can I explain or what are we going to do	The foreign therapist scared me at first		
PT2: In terms of physiotherapists, they do give feedback all the time	The physiotherapists give feedback		
PT1: // to be honest, for me	It is important to have the		

the most important is whether my former helpers are still here, so when I talk about my troubles, how they could help me, then we can think about it together	same specialists with whom to discuss		
PT5: // with those, who is doing these workouts with me, with those all the time we can... they ask all the time that how and if you get tired then they let me rest and then we go again, start	The therapists ask about my condition and consider it in therapy		
T5: Yes, the same for me, they do say that how.. oh today went better, but last night it was bad..	The physiotherapists give feedback		
PT1: But, honestly, where would I get the information, as much as the therapists have said about me or those physiotherapists, as much as we communicate, discuss, I expect this, she helps with that, that's it	The information comes from the discussions with the therapist		
PT1: With all others - I can go anytime and talk to the physiotherapist, I can step into the room anytime with the occupational therapist, to discuss everything	The specialists in general are easy to access and I can discuss everything		
PT3: Yes... not like... this is a question of communication, I think. That they do ask, not like, giving order that do this and that and the third thing. But Can you do it? Are you so tired that you cannot do it anymore? They do take me into account. But not like in the prison.	They take me into account and don't give orders		
Trust in specialists			
PT3: They probably know that this exists and if they would have the chance here, they would do it to us, yes... what is there to ask then..	The specialists are aware of the treatment options and they would provide them if they existed here		
PT3: Well, here the opportunities are what they are and tools are what they are and yes.. maybe somewhere else there are better tools, here are these..	It is what it is in terms of opportunities and equipment		
PT1: If you don't know to ask, then they will tell you	If you don't know to ask, they will tell you		
PT3: They deal with their own things, what is in the limits of their abilities, you cannot deal with everything. Or deal with or like guarantee everything	The specialists help as much as they can but not everything is possible		
PT2: If you got under Lii, then... you will.. Lii, she will get you to your feet.	You will get results with this physiotherapist		
PT1: In my opinion they are all educated people, they know, I don't know anything.. I know what is wrong with me, but..	The specialist know better than me		
ML: Do I understand correctly that you rather think that the specialist should say what you are doing? PT1: Of course, I don't know ML: But let's say if there is a choice between two activities, is there? PT1: No, I don't... I never impose myself.. in this sense	I think that the specialists should say what has to be done, I don't want to impose myself		
PT1: yes, it is, but I don't know to tell them, I think that the specialists are completely at their right place	I trust the specialists' expert opinion		
PT5: if no one has asked, then	If no one has asked, then I will		

I will not ask either	not ask either		
PT2: you don't know what to ask PT5: Yes, you don't, this is well said, you don't know to ask what is the best or...	I don't know what to ask, what is the best		
Therapist's role in therapy			
PT1: Exactly, I see that she wants to do it, which creates a kind of.. also creates a stubbornness, that I also want to do it with her, I kind of like it very much	The PT's motivation arouses a wish to cooperate		
PT4: I like that the therapist changes occasionally.. so that is not all the same all the time, so.. not that it becomes tedious, but like everyone is doing different exercises	Occasional exchange of therapists is welcome because they give different exercises		
PT1: I can immediately say that in physio... when my therapist is like thinking.. somehow innovatively or so, an exercise I haven't done before and never thought of like oh, we could do something like, I don't know, my legs in the air and doing something, abdominals or whatever, I like this very much, thinking outside the box, it is not your typical.. I don't know, just sit or wheel the chair or something...that some interesting elements are added, it's always...	The new physiotherapist (PT) thinks innovatively and gives interesting exercises		
PT4: I am a bit annoyed that the language barrier.. that the therapist communicates in English.. I haven't studied English at school, but we managed somehow	The language barrier with a foreign therapist is annoying		
PT1: Let's say yes, I wouldn't have thought or foreseen this, that I would like a change, because I was like very satisfied and..and.. we had like a good cooperation and a good relationship, but somehow yes, when.. I think they accidentally changed it so that she simply didn't have any appointments available and.. and somehow it came out that with this new one it worked even better, this thing.. so for me it has been suitable, this change, yes	Collaboration with the accidentally changed therapist was even better		
PT1: It was like quite stable before, she wasn't bad but, well, it was like I didn't feel I was doing anything special, but now I feel myself that I am doing something and I think it maybe has to do with the therapist	There was no feeling of doing anything special with the previous PT		
PT2: // But I should say that the interns are very nice, those that you have here. They are very active somehow and since I have been coming here many times, then I feel like new wind when the interns are here, they are very nice.	Interns bring new ideas and therapies are more active		
PT2: It is important to know why you are doing something, for what... If you just do, then someone like me doesn't really get it, but if I know that the result is like this or I can achieve that, well then doing it is completely different	It is motivating to know why something is done		

PT2: During the physiotherapy he is beside you, during this time you can have a conversation, to communicate	The physiotherapist is available for discussion during the therapy		
PT2: Me.. exactly because this service that... I got interested, that without asking me... why do you walk wrong, that they determined it themselves, they referred me themselves, that.. not that I should have gone to look for help from somewhere, but they.. in the sense that.. let's find out now, why are you walking wrong.... thatt go there, there is something wrong about your stepping. They could have turned a blind eye, because I do walk, I can manage with my life, that I walk.. but..	I like that the therapists didn't turn a blind eye and worked on a problem I was not aware of		
PT2: Yes, the physiotherapists take it like this that even if you... they work with you so that whether you want or not, we have to get you on your feet, we have to get you to work.. exactly this.. they work with you with eagerness, as if they were ill and not me	The physiotherapists work with eagerness and make effort		
PT4: actually I am happy when I fulfill the goal somewhere and even I am happy, but the therapist is happy with me, about me	The therapist is happy with me when I succeed		
PT2: // She is doing exercises, I am saying that it hurts and this hand doesn't grasp, she said, it will, let's do this exercise and then eventually it will. A few days later.. they pass, and I already feel that aha, the hand is already soft and warm, otherwise it is such spastic and stiff all the time. So this stretching and working out here it helps	The therapist's approach works		
Difficulty in formulating goals			
PT1: Well, for me it is always difficult to think about goals, I don't know how to formulate them	I don't know how to word my goals		Goal setting
PT1: You can prepare, but when the question/ <i>about goals/</i> comes, then...	I don't know what to say when I am asked about goals		
PT1: There are very many things I would like to do and where to get, but if they ask me so suddenly, like, so, what would your goal be, then everything is gone..	There are plenty of things I want to do and achieve, but when asked, I don't know what to answer		
PT1: I don't know really, every time they ask what would you like to do, but I myself don't really know what to say. I do my things and get by so to say.	I don't know what to say when they ask me about goals		
PT3: In my case, mostly it is so that I cannot think like this, what I need exactly and then the therapists and everyone suggest what could be or what that way and towards what to strive. It has been beneficial	It is hard for me to formulate what I need exactly and the therapists suggestions have been beneficial		
PT5: That the patient himself wants something big, but to get there, maybe he doesn't know how to formulate that so well	The patient may have difficulties in formulating realistic goals		
PT4: Right now I put the goal down, so to say, earlier I couldn't understand what I had to do	In the early stages I didn't understand goal setting		

Goal setting by the therapist/team	
PT1: She is quite good, she sets such goals for me and I in turn also set some.. she may create this.. come on..I cannot do it, but... but this stubbornness that comes, but why, she set this kind of a goal on purpose, so the motivation increases quite a lot	The PT sets goals which increase motivation
PT1: Well, this is what for the psychologist and all of us sit there together, the doctor and.. all of us there discuss everything.. they look at what is more or less wrong with me, what to prescribe more or less, what could and.. //	The goals are discussed with the team who decides how much and what is needed
PT3: If they think that this is too big, then to start somewhere quietly, but if it is nothing difficult, to add something, like some pieces to have something to make effort to, not that you go to the first therapy, you do it and its done	The therapists help to adjust the goals
PT3: Maybe it is as this girl said that they set lower /goals/, but you strive towards this that when you achieve that then you know that you are capable and you try to show more that you are capable for more and then you exceed them manyfold or so..	The realistic goals set by the team motivate you as you achieve them and then you strive even further
PT5: Well, here it is so that the patient himself maybe finds it hard to see those stages. That rather the goals are coming from the outside. That they come step by step.	The team suggests gradual goals that the patient may find hard to determine
PT2: But now the team set... well now I got scared, the team set the goal that I will start going to the therapies without adaptive devices.	The team set an ambitious goal to walk indoors without adaptive devices
PT5: They put everything down themselves, what they gave me and no, I had nothing else to say, I don't know what is the best	The goals were set by the specialists, I don't know what is the best
Goal setting together	
PT2: When you come in they ask, physiotherapist, that what are your goals //	Physiotherapist enquires about the goals
PT4: You are more aware, well, you know exactly so to say, but there is this proverb that if you haven't had it you don't know to want it, if you think about it..	Experience makes you more knowledgeable
PT2: I think that there is the difference that if you are here for an umpteenth time, you already know what to ask for, that I would like to do this or that, I would want that, I need to develop this and then in cooperation with...	As an experienced patient I know what to want
PT1: We all sat together and the goal was that I would be able to carry my walking stick with my ill hand	The goal was set together with the team
PT2: In my case they have taken into account what I set myself as a goal and then the team works towards this.	My wishes in terms of goals are taken into account by the team
PT3: ... and they start suggesting to move quietly towards there, not the big goal right away, but like those lower level goals, that would help	The specialists help in splitting the big goal into smaller ones

along to this, the goal I suggested myself			
PT1: With the team those things are set that are achievable.	The team helps to set realistic goals		
PT2: This is within the team meeting, there it has been asked, in this process	The team enquired about my goals		
PT3: It is rather that everyone together is striving towards this /the goals/	The team is striving together towards the goals		
PT3: Lii, this physiotherapist of ours, she asked, what do you want. .	My physiotherapist asked me about my goals		
PT4: We always discuss first what the goals are and they talk what you wish for example and what is your goal.	The goals are discussed with me and my opinion is considered		
Goal setting			
PT3: It is such a modern question, there were no such questions in the older days	Talking about goals is a modern thing		
PT1: Let 's say in my opinion asking about the goal, that every time you come, in some way is good, well, haven 't seen for a long time, that maybe there have been some changes inside yourself, that when hey ask, then constantly during this therapy period you have the aim in front of your eyes, they know where to try to reach and what to do for this so that yes, maybe if they didn 't ask, it would be.. well.. I don 't know.. you work on something, you go your way, right.. then you meet again, but what has happened in the meanwhile, you don 't know anything, one side doesn 't know and so doesn 't theother and then... well... maybe you are working on the completely wrong thing, so in this case asking about the goals is good.. it could be annoying, that everyone asks in a row, but it is good... I understand why this is done	Enquiring about the goals is annoying, but necessary		
PT2: You come several times a year, then it is like.. the main question in the beginning, is that what are your... it already tires me this question	Enquiries about the goals several times a year is annoying		
PT2: // in the beginning my goals were much higher that I achieved, now I have come with my feet to the ground	The goals have become more realistic		
PT1: The goals are set according to what is possible	The goals are realistic		
PT5: There is no such thing /goals that have not been achieved/ rather the goals have been exceeded manyfold	The goals have been exceeded manyfold		
PT5: Mhmh, this sounded so weird in the beginning, you knew that this should come easily. But then the next therapy period you understood that it makes sense to set such goals. That if you start moving towards there, it doesn 't come SO easily	The goals may seem easy to achieve but in reality may not be		
PT1: This goal setting is more like everyday work, that here you get new ideas every day and new things and then you strive towards them. And then the thing that was written down, this will come naturally	I get new ideas and goals constantly and while striving for them, I achieve the main goal as well.		

eventually, you have to do that as well.			
PT3: If it were the same /the goals/, there would be no motivation either, otherwise they would become too monotonous	The goals keep the motivation up		
Personal goals			
PT2: //goal is not to get shittier	The goal is not to get worse		
PT3: The goal is to do all of your workouts to the maximum or .. then we will see what comes out..//	The goal is to complete all of the trainings well		
PT2: Goals.. it is like.. you try to do the same, either the same way as you did the last time or.. or a bit better, so to..//	The goal is to maintain the same physical status		
PT2: // let 's say in my case with walking, we do the round that we do, walk up the stairs and down the other, we make this circle, so to try not to remain too far.. too far from this record.. or the same	Stair walking round is a landmark for physical status		
PT1: But why am I coming here anyway, it is logical that I want to get well	The goal is to get well		
PT4: Well, as a goal, the easiest, to get well in general, right, but such like a 10-day certain goal, I don 't have//	The goal is to recover in general		
PT2: Let 's say in my case initially it was to get up from the bed to get moving, I was also a bedridden patient. I had one goal, that I could get my private hygiene things done on my own foot, to the toilet. And this was the first goal that has been achieved. And to walk the stairs. But this was all what I wanted myself.	The goals that were set and that I have achieved, were all what I wanted myself		
PT1: the third time it is simply balance exercises, this time there were no big goals, I can 't say that I will do squats tomorrow, you can 't predict such a thing	This time there is no big goal, simply balance exercises		
PT1: Me also, I have been here three times and the first goal was to get out of the bed, then I was lying down..	The first goal was to get out of bed		
PT1: The second goal was going up and down the stairs, well, just in case.	The second goal was stair walking		
PT2: To improve my quality of life due to the disability of my illness	I want to improve my quality of life due to the disability of my illness		
Expectations			
PT1: I came like into an empty hole, I didn 't know at all what is done here	There were no expectations prior to the therapy period		
PT4: For me it was all somehow step by step, it goes as it goes. I will go as it will go, I didn 't have such a thing.	I had no expectations, it goes as it goes		
PT5: I did, I still have the hope to go home almost as a healthy person at some point.	I hope to go home almost like a healthy person		
PT1: No, I didn 't /have any expectations/ because I have nothing much to learn from here. For me this physical balance is better, that I can move and be.	I don 't have expectations, I enjoy that I have more freedom to move here		
PT2: I had this expectation that I will go away from here in 2-3 weeks as a healthy person.	I had a hope for a quick recovery		

<p>PT2: I had such an expectation, it is a bit tragicomic, I have another diagnose, the thyreoid gland diagnose was added and the body mass started to increase, I thought that well, I will go to Haapsalu, I will start there... I will work out like crazy and lose my weight..</p>	<p>I hoped to lose weight in HNRC</p>		
<p>PT2: Of course the expectations are big that now when those insoles come that go in the... that my.. that the quality of my gait will improve, that I imagine that I will start running, I guess... Of course the disappointment.. that you shouldn't expect too much, then the disappointment is bigger accordingly, that maybe eventually they will not justify themselves, but I hope that it will get better...</p>	<p>I have big expectations for the new individually made insoles</p>		

Appendix 8: Obstacles on the road.

Problems with health care system		Problems with health care system	Obstacles on the road
PT3: The GP asks, what do you want, we only prescribe medications, we have not time, the prescription takes three days..	The GP is not helpful		
PT3: No matter in which hospital you are, it's still those 10 days, no matter which hospital it is // National Health Fund, don't even talk about it, when they... when you go and as something or there is something, then no, we don't know anything, we don't want to know, we are not interested in this..	The therapy period is short everywhere and NHF is not helpful when needed		
PT3: Later on you hear if somewhere.. from GP, that documents have arrived and you hear from there that this and this kind of a thing has been with you and this and that and.. it stays there with the GP, you cannot hear anything	I cant get the information from my GP		
PT1: For example I didn't even have a GP now in this big... there Vinni and Laekvere were joined. In Laekvere (the GP) left and then I went... to the social worker of Vinni, that she can give me a referral, but she... the doctor doesn't even know what I have, as much as I was there, she checked me and sent me here	After the reform the GP left and the new one is not familiar with my problem		
PT3: ... but you have to wait, to get here again, you have to wait for a year or over a year or so..	Long waiting between therapy periods		
PT2: // And then this friend ended up in Denmark // and started brain cell transplantations. I understand that in our Estonia the medicine has not developed that far, our country doesn't have that much money. And now the last time she called me last year, she said that she has had 4 cell transplants, she said she is running on 6 cm heels already. //	My friend abroad has better results thanks to the more advanced medical treatment		
PT3: this is again only my opinion that I don't like at the nursing home.. that I go to the rehabilitation... me myself... they told me that you have no benefit there..	The nursing home staff does not support my rehabilitation		
The therapy period is too short			
PT4: //even the hedgehog can understand that one won't run in ten days, you can't get into that top sports	10 days are not enough for achieving anything		
PT4: yes, sure and this 10 days // as if it is cut off, right... there could be more, I don't know.. maybe 12 or 15 or say 15, a little bit longer...	10 days for therapy period is too short		
PT3: When this therapy period is coming to an end, you would need another four-five days... to completely, well, get well or I don't know, there is still.. well.. about 10 cm short	The therapy period is too short		
PT4: I also think that the ten days are too short, you have this kind of a feeling that it gets going.. // it is getting somewhere, right, and then it is over, right,	The therapy period is too short		

it could be more, even a little bit			
PT3: It is understandable that 10 days is little, but if possible, I use this	10 days is too short		
PT2: About this.. well, of course I would like that this treatment here... 10 days is generally a short time for something to work, it could be longer, but I understand that others also want to be here, that I cant come to lie around here alone	10 days is a short time for treatment		
PT2: I wish I could be here longer sometimes.	The therapy period is short		
Waiting list for services			
PT3: There is so to say a waiting list for Lokomat, so, well... the first week I did not get there, but this week is the second one and...	There is a waiting list for Lokomat, it is available from the second week		
PT1: They could have mentioned something to them, or.... they do know that my hand is ill as well and.. hand robot was prescribed, quite a lot	Although prescribed, the service has not commenced yet		
PT1: Either they don't have available appointments or I don't know, I talked to herself, she said that you haven't been scheduled for me yet, maybe next week	Maybe there is no time available, maybe I will get OT next week		
PT1: // at first I had this problem that I had issues with my stomach when I came and then I said I needed to stand, right, to stand with the bed or something, but they were - no you can't, the doctor has not prescribed it, you cannot. It took two days to argue with this // the doctor had prescribed it, but on the third day, but I needed it immediately //	The treatment that I needed was prescribed for later and it took time before the problem was solved		
PT1: Well, the doctor prescribed it the first day, but It hadn't been scheduled in the therapy plan yet. That this thing took three days.	The prescribed therapy wasn't scheduled until three days later		
PT3: Well, speech and language therapist I don't know for what reason, but the occupational therapist is.. the doctor said so that there are so many people, such a long queue that no... at least this is what the doctor told me	There is a long waiting list for occupational therapy		
PT2: //But I saw that the days go by and they bring new those schedules, but there is no electrotherapy. // so I guess they have so many people simply that they cannot find the queue, they simply cannot find an appointment to this electrotherapy//	Days passed but I didn't get electrotherapy due to the long waiting list		
PT2: I think yes that they have taken patients over their abilities, that the line is so big that the person cannot get his services	I think that the hospital is too full, hence the waiting list		
PT2: It is so that I have been here almost half of the time and I haven't got the electrotherapy, it will be next week. There is also the public holiday in between, maybe I will only get it 2-3 times if that. Simply cannot make it. This hasn't been the nice side that simply I	I will only get a few electrotherapy sessions because the hospital is full of patients and there are not enough services for everyone		
		Problems with service provision at HNRC	

got the question that they take the house so full that they themselves get in trouble with this, that people cannot get all of the procedures, simply all of the patients don't fit on that one service			
Lack of staff			
PT3: // here actually there are too few of those therapists	There are not enough OT-s		
PT2: Since there are only a few occupational therapists and this service is not offered much right now, then they told me from this department that this is only prescribed for men, that women cannot get it//	There are not enough OT-s and the service is limited		
PT2: I especially went, before I came here the last time, I went to them, to talk to them and ask and then they told me that no, we don't have people	No OT service in the schedule, I was told there are not enough people		
PT1: I did. I want... I can't speak properly even now... I would like to speak, but the speech and language therapist... I am not lucky because the speech and language therapist is on holiday and I haven't got to the speech and language therapist not once.. haven't got... and... took over.. but she is ill as well and the doctor is ill as well...	The specialists are on a sick leave and I don't get the service that I need		
PT3: Yes and... this.. occupational therapist is only one in this facility... maybe... this is also the reason	There is only one occupational therapist		
PT2: My room mate has the same issue, no speech and language therapist .	No specialist available for the condition		
Wish for more services			
PT3: what could be here, would be that my kind could get to the water.. but it is not here // I don't feel the lower, yes.. but according to my knowledge, this kind go into the water as well somewhere..	As far as I know, aquatic therapy is possible also in my condition, I wish I could get it		
PT1: // that in the gym for example, if you do something // I would like to know somehow, that I am doing it correctly.. //an additional supervisor or somehow, who only looks at that, // with some for example it is like that that I feel that I am doing it completely wrong, but since no one is checking, I don't know it and eventually I can hurt myself more..	I would like an additional therapist to supervise the exercise techniques at the gym		
PT2: I don't have occupational therapy appointment, yes, as much as.. eee... the physiotherapist is doing, she is doing, and...	Not enough OT services		
PT1: Yes, I would like that, with my hand, but it is not up to me, I mean right now in physiotherapy we do this, push the shopping carts with my hand and do exercises for the hand as well	I wish I had more therapy (OT) for my hand, but I can't help it		
PT3: But I wonder how this will work at home, what it was... there was supposed to be a new service, the National Health Fund was supposed to support it, that when I go home, then...// PT3: ... to carry on the activity...	I wonder how to home therapy service will function to continue at the rehabilitation at home		

PT4: Well, women have had it at least once as I understand, I haven't got any this time, so you beat me by one	I haven't had any OT this time		
PT1: It is the only thing that maybe could make me tired. I would do not one round as prescribed in the plan but then I would do two rounds in my free time there at the gym	The gym would increase my workload		
PT1: It doesn't give as much physical load as needed. I am a very active person in the sense that... also earlier, my jobs and things were such.. very active that for me this programme is so to say too light, that if one person gets tired then I say, well, yes, five minutes break and lets continue. Let's start again	For me the workload here is not enough		
PT1: Well, it is prescribed three times a week, it would be an improvement if it would be 5 times a week. That would be an improvement, sure	It would be better if the gym group would be in the schedule daily		
PT5: Well, to put it short, some kind of sensory restoration for example, I don't know, that both sides would feel cold and warmth equally for example. And it seems that there could be something that would do it, but allegedly only time. But this has all been discussed with the doctor and everything has been done what is possible	I wish to do something about my sensory functions but allegedly only time helps		
PT1: It would be... it would be nice... everyone there.. many have swimming here as well, but it hasn't happened to me, I would like that	I would like to have pool therapy		
PT1: No... everything is OK, only that I don't have the doctor this week, it is almost empty ML: Empty in which sense? PT1: My... doctor is on holiday ML: But in terms of services? PT1: Well, a few, I sit mostly outside, sunbathe	I don't have a doctor this week and my schedule is empty of services		
PT3: I have something in my mind, yes, but lets say that I am damn... not disappointed, but well... well.. to put it short, it is not meeting my expectation, I want occupational therapy and speech... the same with the speech and language therapist... but I can't.. they are not available	I am disappointed that I didn't get occupational therapy and speech and language therapy		
PT3: Maybe this that.. well.. for example I would like.. to make my hand work... I talked to Lii, she said so that at first we will make you walk nicely and then we will see about the hand.. well.. maybe, I am not competent in this, maybe she is right	I would like to work on my hand more in therapy		
The doctor is hard to find			
PT4: Yes, a lot depends on the doctor, I used to have another one before and then too... I had to wait for her behind her door or run after her, chase her, but when the doctor changed, I am very satisfied with the current one	I am satisfied with my current doctor, I had to chase the former doctor in order to get information		
PT4: // we so to say met with the doctor in the hallway, // that I am saying goodbye	I said good bye in advance because I might not be able to find the doctor tomorrow		

<p>already now, not to look for you tomorrow somewhere and not to find you at the right time when you are not in the office</p>			
<p>PT2: I think in the sense that if they take any analyses, it should be.. not like I have to chase her several days myself, that I am about to go home, what the results were.. that the doctor or the nurse comes and tells, hey, see.. this kind of results</p>	<p>The test results should be offered without the patient having to chase the doctor</p>		
<p>PT2: I know that my husband is chasing the doctor all the time, asking the doctor for information</p>	<p>The need to chase the doctor for information</p>		
<p>PT5: My docu..well, those results of the tests were sent to my GP, I asked there and then the GP told me, that the results were fine // I didn't get from here, yes, because I left and then I didn't... didn't get to talk to the doctor, I don't know where to find her either and... And she doesn't know, maybe she sent them to the GP to Kurssaare, from the GP..</p>	<p>I didn't know where to find the doctor before going home, but he test results were available from the GP</p>		
Lack of information		Lack of information	
<p>PT3: For me today or last night one pill was added, but why and what kind of a pill... In the evening I didn't ask anyone anymore, I ate it and guessed what... for what it ... well.. what it cures.. I realized when I tasted what pill it was //</p>	<p>A new medication was prescribed and provided but without any information about it</p>		
<p>PT1: Me for example, I am not informed, my doctor is such, who.. they take all kinds of samples and analyses but I absolutely don't get to know about the results.. she comes and tells me that, oh, yes they are.. and oh, what is the result and then at this moment she either cannot recall or hasn't written down. And she promises that she will find me during the same day, but doesn't and eventually two weeks have passed and then she comes like, hey, your results were such... so either she comes several weeks later herself or I have to and find her, to say, hey you were supposed to say whether there is something // already last week we had the same problem actually...// it is very hard to get information sometimes...sometimes she surprises and comes and tells me as soon as they arrive, but it is a very rare occasion</p>	<p>The doctor's feedback about test results is not consistent, oftentimes it is necessary to go find her and remind her about the results.</p>		
<p>PT3: Here it was.. they took me to the hospital and took a picture of my head and did and... and.. as much as I heard from the doctor, it was sent to Tallinn, that you will find out from there, the result. I got out of here, asked... as long as I was here for the 10 days, I didnt find out anything from here and they said that you will get the result from the GP, but... // I went to the GP... no</p>	<p>During the therapy period there was no information about the results and also not from the GP</p>		

I don't know anything, I have no time for you			
PT3: No, I can't get all of the information	I can't get all of the information		
PT2: I wanted to say exactly this that actually getting the information already in the very beginning is.. fragmented. Already when the disease gets you, already then it is.. The people at home they don't know what to do or where to start, what is allowed to do and what not and how much and what.. already there there is a gap	The information is fragmented from the moment I became ill		
PT1: I came here, the fingers on both of my hands „died“... then the stroke came and took this hand away completely, // but now this hand also starts to „die“, is there something that starts to connect them like before.. but now it would be good to get some agreement... or information..medications, whatever... but there is no one to ask	There is no one to ask about the change in condition		
PT1: No, she.. she is aware but doesn't know what to tell me.. //	The doctor is aware but doesn't say anything		
PT2: It has sometimes occurred to me that could there be a, say, neurologist, with whom to communicate and talk about this disease, to get some kind of a background, how the end result would be better	The wish to get more information about probable outcomes		
PT1: well, yes, from HNRC this communication could be more relaxed or so. I understand the principle, why it is so confidential, these matters of information and... How to solve it, I don't see it myself. So for some it is problematic. It should be helped a bit somehow.	I don't know the solution but the communication could be easier		
PT1: Well, to a very limited extent, in the sense that if the family members want to know something, then everything is very confidential and it is like a closed system, they don't give out information just like that. Then you have to make an appointment and come here at a certain time. In this sense yes. Some things could be simpler, some kind of an information phone line, that you want to ask something, how to solve it quick and easy so that I wouldn't have to book a doctor's appointment and come especially here. We all live in different parts of Estonia. We don't live next to here	Getting information is difficult over the phone for family members, an appointment is expected, but they don't live nearby		
PT1: For us this is a first time situation, we have no previous contact, no such acquaintances, I don't know how to find her /the specialist from Unemployment Fund/. There are problems already in finding her	The specialist from the Unemployment fund is hard to find		
PT1: And I don't know when I will again... get treatment	I am worried if I will get treatment again		
PT2: Here, let's say they are the specialists, they should contact or somehow in a written form, should give a letter to me to my partner. That he would understand why I am so slow	I wish my condition was explained more to my partner		

Appendix 9: Daily life at the hospital.

Familiarity		The patient and the staff	Daily life at the hospital
PT1: In general we feel quite at home here	Feeling quite like at home		
PT1: To be honest, for me they were all good, I will not bring anyone especially out. Everything was good and nice... From a distance hello and good-bye and	All of the staff members have been nice, greeting from a distance		
PT3: Already during this time I have acquired so many acquaintances... have been.. I know everyone's face already	Familiar faces among staff		
PT1: They know you by name	They know me by name		
PT5: For me everything has been so positive since I came back here. Everyone already was asking and expecting, as if they had expected me, they called me by my name and those caregivers and all.. was very positive.//	The feeling of having been expected		
PT4: I would say that you get this impression that you have been expected, not that you have come and, hey, I came now, do something with me, right, or do something. You get this opinion or impression, really, that you are welcome here, this is why it is good to come here and be here. //	A feeling of having been expected		
PT2: // And of course, what was for me at first... well, was unacceptable was that you changed rooms. Since I barely just had overcome the disease and thought a little bit, that you are here and then you are transferred to the other room, together with others, the first time for me was a complete shock. But now it hasn't happened anymore, I am coming so often, that I always come to the same, I am always in the same room... this is...	Exchange of rooms was a shock, but now I am always in the same room		
PT1: I don't leave the phone completely freely around, I put it a bit aside, but it is still in a visible spot from the door and until now has not gone missing. But where can it go? Everyone is familiar here	I am not worried that my phone would be stolen, everyone is familiar here		
PT2: But it is like this here that you can't understand what it is. It is not a hospital in this traditional sense, it is some kind of a centre, like something in between a holiday home and a hospital, you can't really nail it, what it actually is (laughing).	HNRC is something in between a hospital and a holiday home		
PT2: It is a safe town and you know that you are disabled, but you will not be in danger even in this town for example, the town is so used to this HNRC and those disabled people	I feel safe in Haapsalu because the people are used to seeing people with disabilities		
PT2: But then again, let's say about this building, yes, it is a mammoth hospital, I understand that it is a hospital, that I am not in a holiday home, although you get this feeling of a holiday home	There is a feeling of a holiday home		
PT2: I can compare to what the old house was. I liked it	I liked the cosy feeling in the old building of HNRC		

more there// It was such a small and compact, it was like home. //I had the impression that there were only 10 rooms for the whole building. And it was all like a big family			
Helpful staff			
PT5: I had such a fear that I will not cope here. But when I got here then they help you to everywhere and assist everywhere and so..	I can manage here thanks to the staff 's help		
PT5: I have had no problems at all with the staff // they come as soon as I pull the red cord	The staff is is helpful		
PT5: // At first I was thinking if... I will not manage here, but no, everyone is assisting and supporting and then I feel that I... that there is still hope, that I can get to my feet a little bit too. //	The assistance and support from the staff gives hope		
PT4: No, there is positive, not negative, positive in the sense that.. exactly in relation to the pool that the time table was so busy that.. // I wouldn't have made it to the breakfast in the morning //, I said that, hey, I will get.. // out of the pool at that time, that come five minutes later that I will get washed already, come and help me get dressed // and they helped me exactly as we had agreed, that // she was there so to say and helped of course //	The caregiver assisted as asked at the pool		
PT1: The staff manages very well, here some single situations or, well, something that I would like to get immediately, this doesn't happen every time, maybe. But otherwise it is very polite and helpful and they manage. Sometimes this postponing is annoying, but maybe it is natural, I don't know	Despite of some single issues, the staff is professional and helpful		
PT4: That I needed a lot of help earlier, now I need a little help and even if I ask a simple thing, to make a ponytail, then I always ask for help and they come and help	The staff helps also with little details		
Positive interactions with staff members			
ML: Mmm, I would ask, how are you being treated here? PT3: Well. PT2: As equal	Behaviour by the staff is equal		
PT5: And the attitude has been so positive, towards me	Positive attitude towards the patient		
ML:// I would ask now, how does the staff behave with you? PT1: I am very satisfied PT2: Nicely PT3: I can't complain PT4: Satisfied, yes	Satisfaction with staff behaviour		
PT1: //if there will be more problems I will go and ask room 308, I can talk to her and discuss... she told me that if you have any questions..	The doctor told me to come and discuss if I have questions		
PT1: Always a smiling face, a merry spirit, always cheering each other, well, how did you do today and... such simple things	Smiling face and positive mood		
PT1: Communication, this is the most important, positive	Positive communication is most important		

communicaton for sure			
ML: // then I would ask that how do the employees treat you? PT3: Extremely friendly PT5: Very well PT3: Everyone is very helpful, friendly PT5: Supportive	The employees are friendly, helpful and supportive		
PT1: I am very happy about the doctor. She knows how to guide very well, how to help very well and she is doing everything very quickly. She is very quick.	I am satisfied with my doctor who is quick		
PT5: They notice the improvements, cheer. Yes, support and encouragement	The staff is supportive and attentive		
PT5: And there is such a frequent communication with the doctor of our floor that this accessibility of information has been arranged well	The communication with the doctor of our floor is frequent and information is accessible		
PT2: Here the feeling is such that the client is the king	I feel that the client is king here		
PT2: The staff is very educated	The staff is educated		
PT3: I will tell my opinion.. he is not like a king but he is taken care of	The patient is taken care of		
PT5: yes, taken care of and very well.... polite and such, I don't know how to say it, you get this, pleasant feeling inside, you feel that, something.... is different	The care and politeness of the staff makes me feel very pleasant		
PT3: // the attitude of people and communication with a smile, well, this makes me change my own opinion as well	The staff's friendly communication affects me positively		
PT3: //here.. on the second floor and all this staff and the doctors and nurses and caregivers are friendly, they know to help and if there... if there is a misunderstanding then... mmm.. try... we try and and they try to solve it, not like that, not like giving orders and so it must be... right	Any misunderstandings are solved friendly by the staff, without giving orders		
PT3: Friendly, as I said already.. if there is a problem or.. you can always talk, it will be solved, not like, giving order, that we will do it like that and end of story. We find.. look and find a compromise or a solution	Any problems can be solved friendly and without giving orders		
PT2: But it came, a few days passed, they gave me, practically there is one day difference. // I liked exactly this that, to put it short, they timed us so that we even got back to the same room // Exactly this that they were forthcoming, that they could time those periods	I like that my wish to come at a certain time was granted without problems		
PT4: For example that they were forthcoming that I had to come in March... I couldn't come and they joined the two periods to one.	My therapy periods were summed helpfully		
PT2: Very pleasantly, they are the pros of their field I can say. In the sense that they are schooled // They know to make you feel so well here that you don't get any problems	The staff is professional and they make me feel so good that I don't get any problems		
PT4: For example I am a blabbermouth and sometimes I just.. I need to go and chat,	When I need to chat I talk to the caregivers and nurses		

then I go to the nurses post for example or where the caregivers are and simply start talking			
PT2: Yes, sure.. the last time there was a psychologist, he was such a fun young guy.. // We couldn't do else but we sat for an hour across the table, I told him anecdotes, he told me his funny stories, we only laughed and giggled and this time they did not prescribe the psychologist. //	I had a positive meeting with the psychologist the last time		
Negative experiences with staff members			
PT3: Well, I dont know, I guess it is the content then.. the three quarters of the hour goes by like.. well, there is some kind of a delay in the beginning, then something is done, then there is... well..	There is a delay in the beginning of therapy, then something is done		
PT1: // the caregivers they came all the time to say that oh, how I have gained weight and gotten bigger again.. to put it short, my body was this kind of constant topic for talking and it was very.. well, it was disgusting that... well, if you have problems with this anyway, then it is not necessary to come to tell me this //	Feeling of disgust because the care-givers constantly discussed my body		
PT1: the caregiving personnel was worried so to say.. that I am some kind of an anorexic and whatever they said, that.. well, I don't eat because, I have.. I either have my own food with me or I actually don't want to eat... then it was yes a big deal that.. somehow I found out from far that there are stories going around that, oh, see, she doesn't eat this and she is not OK with that and she is so picky and then I thought..	My eating habits were commented by the caregiving personnel		
PT1: // these caregivers don't work here anymore, but one came to me to tell me like.. oh my God, you know, I went running and my knees hurt so much.. I listen there and think that well... what a nice problem because.. well, no, I have nothing against it, for the sake of God, tell, but well.. I think you have other caregivers somewhere, tell them this, you don't have to come to my free moment and tell me how you went running there and how... how your toe hurts so much that you can't do anything, well, I am sorry, but this... this is not ok	It is not OK for the caregiver to complain about knee pain after running /to a patient in the wheelchair/		
PT2: I went, the first time I went to the pool, she reprimanded me that I don't know how to stand, I don't know how to sit and oh, what are you doing under the water, oh, you peed into the water! Did you really come here for this? And me myself I was still.. the disease just had got me and it made me cry so badly and of course I did not owe her and I told them that I will not come to the pool anymore and thats it, you can do it yourself and immediately told others of course and thankfully that	I was reprimanded at the pool by the caregiver and it made me cry, but I solved the problem		

person.. later on we agreed nicely, she said that she got a bit upset..			
PT1: It is said for a reason that one Estonian eats the other...	There is a reason for the proverb that one Estonian eats the other		
PT1: To us, the patients, everyone is nice, or.. or.. well.. those who do the therapies.. but between themselves, it is still like... you hear it.. sometimes they should go behind the door for this..	Overhearing the staff quarrel- ing		
PT1: Well, this you have to check all the time yourself yes, that they wouldn't... they move the things and then leave them and then they wonder, why you ring the bell PT3: ... and ask them back, they just came from there..	The caregivers leave things around and are surprised when they are called back		
PT5: Yes there was this, for a certain extent, that if you were already a little bit better but still able to move with the wheelchair, then the wheelchair was forgotten somewhere far for example. There was this forgetting, yes	The staff members forget to put the wheelchair close enough		
PT5: Some kind of conflicts with the caregivers. Then to a certain extent it was so that.. that I sensed that if you are weaker then they treat you a bit disdainfully	Conflicts with caregivers who treat you disdainfully because you are weaker		
PT1: Maybe yes, that if they forget and I ring the bell, to improve your attitude... The mistake is yours	If they make a mistake, the attitude could be better		
PT1: Let's say yes, about caregiving staff, this communication part. I mean exactly with those more quiet people, who are not active or who don't speak or who don't demand that much. That they would come, ask, look, enquire, that they wouldn't forget them to stand on the bed for a few hours really. When they make you stand, then you don't have access to any remote or anything. Then you stay there alone	I wish that the caregiving staff would pay more attention to patients who are quiet and less independent		
PT1: Well, it is not exactly directly like that, but still, those who are more active, they are talked to more, there is more communication, they get more, well, it seems logical	The more active patients get more attention		
PT4: And you needed to go somewhere quickly, you have to explain them how it has to be done and some are such who listen, with them you can manage nice and quick. But who doesn't listen and starts to argue with you a little bit, that what are you explaining to me, I do it as I want to do it, then it takes time and you are late to a procedure. Well, this is what happens more.	Some caregivers were arguing which led to being late for procedures		
Reluctance to criticize			
PT2: Well, this... bad side.. everyone makes mistakes, it is...	Everyone makes mistakes		
PT2: I have this stupid habit myself, that if someone pokes something, then.. well.. I will	I myself have a bad habit of snapping back if something is said, but in the end we have		

not owe them and you can very painfully and wrongly as well... there have been sayings and... but well, by the end of the day we all make up and..	made up		
PT1: // let 's say yes that this kind of delays, they are... understandable, well, five minutes, well, it has taken longer somewhere or.. well.. there is a meeting, this is natural, but I can 't say anything concrete like this about therapies.. anything like bad..	Short delays are understandable		
ML: Mm, question of dignity, when you need help, do you feel that this is offered without compromising your dignity or have there been any situations regarding this? PT3: I have strong nerves, so, well..	I have strong nerves		
PT1: Well, yes.. it is exactly that during the years, it is the same that.. the skin is thicker.. //	During the years, my skin has grown thicker		
PT3: Maybe they can be understood as well, they have to tip page by page of all kinds of stuff into this.. // computer, machine, yes	The doctors have a lot of computer work		
PT3: She has some additional tasks nowadays, I guess, this is why they communicate less with the patients, they don't have time	The doctor has less time for patients due to extra tasks		
PT1: Well, everyone has their good days and their bad days	Everyone has their bad moments		
PT2: And I am this type that if someone says something nasty to me, I immediately tell that person, I am not keeping it to myself. I tell at that moment and later I forget ML: Has this been necessary? PT2: A couple of times, yes ML: Maybe you can describe the situation, what happened? PT2: But we clarified this between us..	It has been necessary to defend myself a few times, but the problem has been solved		
ML: Has anyone said anything bad to you? PT1: You know, not directly, because I take everything with humor	I take things with humor		
PT5: yes, yes, the caregiving staff. But this is also the hardest job, so...	The caregiving job is the hardest so this may explain their behaviour		
PT1: The attitude is ok, you understand that everyone has better and worse days	The attitude is ok, you understand that everyone has better and worse days		
PT1: The attitude is ok. This, that they push the wheelchairs away, we can't hold against them, this is not such a...	We can't hold the small mistakes against them <i>/caregivers/</i>		
PT3: No.. well... it happened once, a long time ago, was it the second time or... it was my.. I don't want to talk about it, it is my mistake	I had a situation in the past here but it was my fault and I don't want to talk about it		
Socializing with peers			
PT2: No in this way I don't look forward to it, to get to communicate... Communication.. I am not in the need of communication	Communication with peer patients is not important to me	Patient among patients	
PT3: I communicate with my room mate or say hello to those I know for longer here, or.. but I don't want to talk much, for me it is not.. well.. easy.. speaking or such	Communication is difficult for me due to my injury		

PT4: I do look forward because then I can communicate	I am expecting the therapy period because I can communicate with others		
PT1: Let 's say for me yes, my being here is.. more, yes that I put the emphasis on my, this, wellbeing and physique and more, that at home the two are together, the social side and then.. workouts and things	While being here I concentrate on my rehabilitation, not socializing		
PT3: Sometimes we do communicate over the phone, when will you come and can you come or.. exactly about this coming here... I can come, yes, but I can come in a month, later..	Talking with peer patients over the phone prior to therapy period		
PT2: On Wednesdays, this quiz is very nice, but this alone is not enough. Something like, let 's say a club day, that today we will do this-this, to meet each other, to talk, already this socializing...	There could be a pre-determined day for organized activities that would promote socializing		
PT3: Right now for example we sit downstairs and play cards sometime, so we busy ourselves, but who doesn 't have interest in cards, then I don 't even know...	I socialize with peer patients		
PT1: Sure! I couldn 't imagine having to be here alone	I cannot imagine being here alone		
PT3: Exactly, alone, well, when you are here for the first time then it is relatively bad alone, but.. Of course, you do look forward to it, maybe to get new acquaintances or old ones. It is more fun and time passes faster, for example. For example this time in the evening where there is nothing to do, really	It is more fun when there is communication with other patients		
PT2: Here it feels a bit like a mammoth hospital, so that you can 't even follow all of the patients from your floor and get to know them, who is who.	I don 't get to know other patients because of the size of the hospital		
Peer support			
PT1: Well, yes, there are people who cannot speak, I am trying to understand her when the caregiver doesn 't happen to be there at that moment or anyone, of course I help, right, it is not hard for me, sometimes it is good if you can... if we can 't do it, then we call the caregiver	Trying to understand and help a room mate with speech impairment		
PT1: Yes, sure, it is actually very good if someone is a bit troubled, then you can support the other, to be positive, this is very important... difficult of course	Supporting peer patients		
PT4: So it is the same for you that you keep looking for it.. It will come /to the other patient/	The results will come in time		
PT2: I started the same, the years have gone by, I was the same then, 20 years have passed, but I have got up and walking. So don 't despair, it will take time, you are also young, I was also only 30 when I fell off like that	Supporting younger patients that recovery will happen, although slowly		
Disturbing behaviour by the room mate			
PT4: //if one of the room mates is afraid of wind... and doesn 't let the door to be	It is difficult to share the room with people who have different preferences for temperature		

open, then it is.. difficult	etc		
PT5: Otherwise it was nice, but yes, the room mate, in the beginning she was yes.. this kind of nervous, she was sick of course too and therefore she was nervous but otherwise with caregivers, I was very satisfied with them, actually	Everything was nice and satisfactory apart from the room mate's behaviour		
PT4: // For example, I didn't like at the first time when I was... // that at 12 o'clock at night he goes to have a shower... and not only this, he turns the light on, well... // The next night it is at 2 AM, then it is 4 AM. Well, every night he takes a shower, well, and the light is on, he himself is having a shower. //	The room mate had showers at night		
PT4: //the TV should be that if there is a curfew, then it is a curfew, exactly the same with this shower, that it should be, // followed so to say that there wouldn't be such a situation, because from his point of view, even if to talk to him or to tell him, I ... which I did, right, well because it annoyed me, right and said... there are so many justifications.. this is wrong I think, this behaviour is wrong but he thinks it is right and finds lots of excuses for himself..	The room mate had lots of justifications for his behaviour		
PT2: //I lived like in a latrine, because my room mate, whatever came she did it in the bed and smeared everything (<i>making a gesture to illustrate smearing the walls with feces</i>) and then, well, said that... I really did live like in a latrine and then I... had my clothes taken away in the meanwhile, because I don't want to go home with such stinky clothes... So I am saying that this is very important. //	The room mate put faeces on the walls, I lived like in a latrine		
PT5: My first experience was such that I had a patient... well, she did not hear very well and then she put the phone.. the TV so loud that I said that it is going through my head//she was swearing so much, called that TV names that it doesn't give a good signal, but she had such a serious problem with her ears...// the remote was hidden, they gave it to me and how can I... she is constantly asking and I have it on my table, how can I say that I will not give it to you and then it was very difficult the first time to be here.. //	The first room mate was hard to put up with		
The role of the roommate			
PT1: Not really, it depends with whom you happen to be in the room, definitely you need to find... something like was mentioned here, that someone maybe wants hot and someone wants cold, to find some kind of.. PT2: Compromise PT1: ..Yes, some kind of a middle road that because the room is meant for two or three, so that both could live..	Compromises are needed when several patients share the room		

PT4: .. you are right that a lot depends on the company, with whom you share the room. About personnel, I can only say plus, so to say, but this company doesn't depend on the personnel or yourself, right, we all come and want to get something	The room mate plays an important role in the general comfort		
PT2: It is actually very important, with whom you share the room	The room mate is important		
PT2: Well, since I come here to... to work out and get my.. well,.. walking or something else fixed, then it is... there has to be a time for rest, has to be this kind of calm. It can't be that you happen to be in the same room with someone who is snoring through the whole night or is doing other kind of tricks //	The room mate is important, because of the need to rest after therapies		
PT1: People are different, how the disease affects you, someone may be more demanding, she has to have her pillow there, me here, you cannot always dance to everyone's tune	The roommate may be demanding		
PT2: // I happened to have such a nice room mate and we got... well along and we both liked that the windows were open, such very cool, fresh air. And then when we had been here our time, well, somehow we matched so well that... but you could order a new therapy period from the doctor, //and then we asked that.. we calculated that well... half a year in between, so in April sometime.	I had such a good contact with my room mate that we decided to come back at the same time again		
There is nothing to do in free time			
PT1: For example open on Saturday and Sunday, then we have nothing to do	Over the weekends there is nothing to do		
PT3: In summer at least outside.. you go and walk here in Haapsalu sometimes if you have a chance. But in winter, there is nothing, you only look at the pile of snow or this frozen bay here and...	In summer there are more possibilities to spend free time than in winter		
PT1: There is too much free time, there could be more activity//	Too much free time, there could be more activity		
PT3: // they do this one hour during the day, but the rest of the 4-5 hours he is with his feet up in the bed, who is watching TV, who is reading literature...	There are many hours of inactivity		
PT3: Instead of free time there should be some kind of additional service	Free time could be filled with some kind of an additional service		
PT1: I have four workouts in the morning altogether, or five. I start at 8.15 in the morning, by lunchtime I have done them all - what will I do for the rest of the day? Then these options could be there as well.	There could be some extra options during the free time		
PT3: Actually during the day it is also that you are waiting for workouts and those and here it is that in the evening hours, especially if you don't com-	In the evenings there is nothing to do		

municate with anyone really, you don't have acquaintances, then there is actually nothing to do. You are either lying in bed or you just ride around. In the evenings there is nothing to do.			
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Appendix 10: The past, the present, the future of HNRC.

Improvement of staff behaviour over time		Progress at HNRC	The past, the present, the future of HNRC
PT3: Yes, there is no one like this here now	There are no staff members with questionable behaviour anymore		
PT1: If anything has been said, then it has been done so delicately that I haven't understood.. no, there is not such a problem any more, it remained yes.. in the early years and I hope it will never come back, so..	The staff behaviour has improved over time		
PT2: Well, it was in the old building where we were..	The problem was in the old building		
PT1: Let's say, concretely from my aspect, it has improved, I had quite.. when I came here in the beginning then.. well.. I don't know how... I don't know how to put it politely, well basically they came.. //	The staff behaviour has improved over time		
PT2: // I had such a situation that // one boy of the caregivers, he came to this room mate of mine and he said that you can do it yourself. I said, how are you talking to her, you are the caregiver, if there was no us, you would not get paid. And now this boy is so good, he is coming on his own, I am not even calling for him and he is coming and asking if he should put the shoes or slippers on me or... //	Reprimanding the caregiver changed his attitude		
Improvement of services over time			
PT2: Well, in my case.. in occupational therapy when I... when this building was open, well it wasn't like... the old kind of came... old habits came along so to say, but when those Siiris and those who came then, the new generation came of occupational therapists well and then it was kind of started... teaching dressing and well... cooking in the kitchen and such..	Over time the OT services have improved		
PT5: Yes, there has been some kind of a development in these terms, that now the cooperation is even more close, I think	The cooperation has improved over time		
PT4: The staff, there were caregivers for example, some were completely new and they completely did not know what to do.	The new staff members were incompetent		
PT2: Exactly these exercise... gyms. There was no gym in the old building. I like it a lot.. // But there was no gym in the old building. That in this sense it is good, yes, there has been development.	There is development in terms of the new gym that did not exist in the old building		
Positive experiences with high tech devices		High tech devices	
PT2: Well this... Lokomat let's say, it kind of released me like... of bigger tensions, so that I can walk better at home, without the chair and this actually... made me... easier	Lokomat therapy released tension and it is easier to walk		
PT1: Especially that the computer is used, there how it is.... You try to get a grasp of this game, although an older	Using computers in therapy is exciting		

person, but still exciting			
PT1: Well, here this physiotherapy, I would say.. and the gym is the best	The physiotherapy and the gym are the best		
Wish to use high tech devices in therapy			
PT2: I already let them know that I will be coming and then they put me to the waiting list	Making arrangements prior to the therapy period to get Lokomat therapy		
PT2: It is rather that they have used me... used me as a sample, invited me there so that you can get more	Possibility to get extra Lokomat therapy as a demo patient		
PT3: During the first week Erigo was this kind of mechanical mover so to say; it had been scheduled three times so I am not complaining... complaining about anything... yes	Lokomat was replaced with Erigo for the first week, no complaints		
High tech devices as the unique feature of HNRC			
PT4: I have been to two different places apart from Haapsalu, I like it here the most ML: But for what reasons? PT4: There are more machines	The technical equipment is what makes me prefer HNRC		
PT1: Well, for me it would be that since I have to drive here from another town, to be closer to home, well, maybe I would be somewhere else, but then again in my homeplace there are not those.. PT2: Opportunities.. PT1: .. there is no Lokomat and those machines.. or the same gym that helps so much, so then it is yes... not happening	Maybe otherwise would attend another facility but due to the technical equipment, I prefer HNRC		
PT1: I have heard once and then they said that here it is better. Here it is that the gait robots, things.. the technology	It is better in HNRC due to the technology		
PT3: The technology is high level, yes	The technology at HNRC is high level		
Positive comparison with other facilities		HNRC vs other rehabilitation facilities	
PT2: I... not in relation with this place, but I have also been in several places and there it is so that they forgot me on the tilt.. tilt table or, or well, 3-4 hours later the cleaning lady discovered	In other facilities the patient was forgotten on the tilt table		
PT3: As much as you hear there, about Haapsalu, no, you have to go to Haapsalu, it is the best there	HNRC was recommended		
PT3: // I have been to several places.. I have been to Magdaleena, some other places.. If I only could get away from here, to Haapsalu, then maybe there is still hope for this therapy, whatever	Compared to other facilities, the hope lies on HNRC		
PT2: But one nurse from the caregiving staff, //she said that it would be very good if you could go through Haapsalu.	HNRC was recommended at another hospital		
PT2: Well I cannot recall anything right now. Bad. I can talk about the time before I was brought here, from there there is...	There were negative experiences in the previous facility		
PT2: Exactly the reputation of this hospital was underlined very much in Tallinn	The reputation of HNRC was underlined in another facility		
ML: This is quite a tough story. Do you have anything similar to compare here? That you are reprimanded for something?	At HNRC the things are different in a good sense		

PT3: Here the things are different PT2: Here things are far from this			
PT4: But I don't like, I didn't like that although I didn't understand at all, now I can compare thanks to this to Tallinn and I can honestly say that this hospital, this centre is a good place, the best place.	In comparison to Tallinn, HNRC is the best place		
Negative comparison with other facilities			
PT5: Well, I would say for example that the so to say caregiving part was better at PERH. The attitude.	The caregiver's attitude is better at PERH		
PT3: I am here during so to say breaks, I am at another place where there are therapies and when I now went to that other place from here, when I went from here the last time, I think it was like that, yes.. and talk to them, then there those occupational therapists said about my hands that they had turned to the worse here.. now that I came back from there now, then they told me here that my hands are better than usually, so.. the occupational therapists are good at the other place, there is also a physiotherapist	The OT services in the other facility are better		
Suggestions for additional services			
PT2: .. dry needling.. dry needling could be here, because a lot of patients.. a lot of patients they go to.. well, God knows to whom, it may not always be beneficial, it is rather... rather not good	HNRC could offer dry needling	Ideas for improvement	
PT1: They could bring back the cafeteria // It was a very important part	The cafeteria should be opened again		
PT3: But there has to be one present all the time.. the last time we were here and the room mate, well, he pushed himself so to say and later he was taken away by the ambulance, he overexerted	The self guided activities should be under surveillance by a therapist		
ML: Have you thought about some kind of a thing in addition to the gym, that could also be? PT2: I have thought about it, yes, that somehow.. a little bit of a club like activity PT1: This is exactly what I just thought.. to get together like this..	There could be some kind of an opportunity for socializing		
PT2: Not taking the treatment into account, then me, let's say... maybe it is possible, I have used it myself, that there would be such a service, that with limited mobility, that it would be possible to use transport. For example to the supermarket since there is no burger spot downstairs anymore either, then some kind of transportation to go to the pharmacy or supermarket or wherever here in Haapsalu town I mean. Not to go home but to get to the shop shortly, to buy what is necessary. This kind of a service..	There could be a means of transportation for patients of HNRC to go to downtown to the pharmacy or shops		
PT2: I could do it now as well,	The means of transportation		

if I started arranging it with someone here. That it would be such an official option. I wish, it doesn't have to be according to my time table, but that I would be told that you can go on Wednesday at 12. If I have asked for it. Not that they should set up a bus line or something, but that it would be possible	could be available at a certain time		
PT1: Well, this transport service is definitely one part and then the system of getting to work could be better, like... this programme of courses, that the person from Unemployment Fund currently comes once a month, but she could be like a social worker who knows, can and does guide.	There could be a more complete service about returning to work		
PT1: It doesn't have to be mandatory, but it could be like a psychologist service that you go and talk to the person, talk, right and she guides, then I can go back to her the whole day. But right now there is no such person. This month, this week there is, but at the end of the month she is not any more.	The person from the Unemployment Fund should be accessible all the time		
PT4: or you have no time.. You can't eat during the lunchtime, then you do all of your stuff. You know you have this cafeteria downstairs, for example it used to work until 4PM. You go, for example, you have free time from half past two to four and you eat	Cafeteria would be good in case there is no time to eat during the day		
PT4: What could be maybe not about the services but for example when people come to me and they have nowhere to park really... some parking opportunity for example	Visitors have problems with parking		
PT2: There could be a small transport van from the hospital, I am sure there would be a group during the day, who would like to go to the shop downtown.	There could be a means of transportation for patients of HNRC		
PT2: Well, yes, if down here there is the newspaper booth and what else.. the orthopedic.. why couldn't there be a small pharmacy.. they will open the cafeteria	There could be a pharmacy at HNRC		
PT2: Look, I said the pharmacy is missing, the paraffin is missing and the mud treatment is missing, that I would like to get.	I would also like to get mud and paraffin treatment in addition to pharmacy		
Living conditions			
PT4: There is a lot of pasta	There is a lot of pasta		
PT3: The soup is the same all the time, you come here then you know what the soup is like, what kind of cubes are there..	The soup is always the same		
PT3: The meals to be better PT2: (exhaling) Ahh, yes this is monotonous	The food is monotonous		
PT1: Somehow yes, I don't feel like eating, but sometimes when you do, it is the same that.. either some kind of rice has been cooked into porridge as much as possible, so that.. you simply can't any	I am the wrong person to ask about food, but there have been occasions were it is not well made		

more.. well.. simply drops off my fork as well and... you can't anymore.. but yes.. I cannot.. about food.. about food I am the wrong person to ask			
PT2: Well.. you can make.. you can make it also.. the same stew you can make it tastier, you don't have to make it into such a damn mess, or.. it is impossible to..	The food could be tastier		
PT2: Cold air is blowing on you yes.. in some rooms directly down	In some rooms the airconditioning is blowing above the beds		
PT1: There should be a better WIFI connection, the one that is, is.. PT2: This is yes, such a.. nuisance	The WIFI should be better		
PT4: In the three-person room there is too hot again, although the radiator is turned to zero, it is still sultry//	The room is sultry even with the heat turned off		
PT5: Well, nothing too big, but I would lose those bathrooms that are shared between two rooms PT2: Ah, with this I agree, yes PT5: This is rather uncomfortable PT2: With this, I agree, yes	The shared bathrooms are uncomfortable		
PT2: I think that it is more this that if all of those four would be in the same room then I have control over that who is away, who is where, I know that I can go, but right now, they storm it from the other side when I go. I now learned it that I watch the light. You didn't know if there is anyone in there and sometimes when you are in a hurry...	The shared bathroom is a problem because it is hard to control whether it is occupied or not		
PT1://Of course the bathrooms and toilets could use a little renovation	The bathrooms and toilets need renovation		
PT2: Some kind of ants live there, yes ML: Some kind of insects live there? PT2: Yes, at night there are triangular bedbugs, they run around the floor, some are flying as well	Insects in the bathroom		
PT4: With food everything is very well right now	Food is good		
PT2: TV, what else. The programme is poor, only those Estonian ones and you don't watch much else there. There could be more sports programmes, I mean, it costs of course, but that could be one way to pass the time, to show something more content-rich	There could be better TV programmes to pass the time		
PT3: And for example right now there is no this.. call button either, where you can call the caregiver. It is not within my reach really.	I don't have a call button within my reach		
PT1: The staff actually exists here, who could put that little cord anywhere. The clips, little screws and stuff is sold... actually these things should be arranged	The call button could be brought closer to the patient		
PT2: I also had this during the first session, yes. Then it was somehow poorly attached, so that I pulled it off the wall, from this button.	I broke the call button as it was poorly attached		
PT3: In my toilet it really is so	The toilet is too small		

that the toilet is here and the small shower is exactly down there. It is exactly so that as soon as you move a little bit, the hand touches it and the water is running. That this is just a place where you have to sit, you can't move anything and you shouldn't breathe either. As soon as you move a bit, the water is open and running			
PT3: And the warm water should come immediately, not that you wait for half the day and then you can start washing	The warm water takes time to come in the shower		
PT1: It is really so that one person goes, about 15 minutes on the hot water, then the next one goes, then maybe in 15 minutes the warm water starts running	Problems with warm water in the shower		
PT2: the dishes are so good, then I started saying that please only put me half the portion only, but such good food, how can you say no	The food is very good		
Access to gym in free time			
PT2: But I have thought about this that in the evening, after the lunch there is... a lot of spare time remains, couldn't we use the gym more, I do understand that there has to be a person again, but still, well, already this strength, this gives us something extra already	Too much free time, the gym should be open with surveillance		
PT4: I quite agree that the gym could be open, yes.. and of course it is not like.. depends on the patient anyway, but if he is very sick, then he will not go there, but who can and wants and knows to be there, I think there is not much to break	The gym could be open for those who are able to use it		
PT4: Some kind of a room should be open as well, it doesn't have to be this so to say big physiotherapy room, but a smaller one could be the same, a smaller room so to say, that you go..	There could be a small therapy room open for patients		
PT4: You go and twist yourself there here and there to, well... more than lying in bed	Self-guided activities instead of lying in bed		
PT1: //if the others /therapy rooms/ are closed, maybe we ourselves could do somewhere...	There should be a possibility for independent workout		
PT1: Actually there is one thing that I would like to get - the use of the gym. I understand, why it is forbidden - who can't do it, who may fall, who is a dangerous patient or whatever, but it could be so that a selected group.. well, this person gets the permission and the card or whatever	The gym could be open to selected patients		
PT2: That he can enter /the gym/ with the card and also can use the equipment and who can not without the instructor or is not allowed without the instructor, this is decided by the doctor, they cannot go	The gym should be open to those who can work out independently		
PT3: And in the evening the nurse has the card for example. To get a group together	The patients could use the gym either as a group or individually		

and take some card and then you can go to the gym or for example, if no one wishes to go, then alone, for example. Those who can manage. The gym could be used in this way, the opportunity to use those..			
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