

# **Inflammatory bowel disease customers' experience survey for domestic long-distance transportation**

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<p>The purpose of this thesis is to research the issues that people with an inflammatory bowel disease (IBD) might have to face when travelling domestic long-distance journeys with buses, trains and airplanes. Currently the number of people diagnosed with an IBD in Finland is almost 50 000 and 2000 new diagnoses are made every year. As the main symptoms of the diseases are related to the sometimes urgent need to use a toilet and the right dietary options, the main focus is on the provided foodservices and quality and number of the toilets provided by the public transportation companies. The commissioner of the thesis is Crohn ja Colitis ry (Crohn and Colitis Association of Finland), which is an IBD association that aims to provide support for people with IBD and raise awareness.</p> <p>The research was conducted by creating a quantitative questionnaire in the form of a survey. The survey included questions about the satisfaction and perceived importance and issues of the above-mentioned aspects. It was sent to the members of Crohn ja Colitis ry by email and the answers were gathered during the international IBD awareness week on December 2018.</p> <p>The results show that there is a need of improvement of the provided services as 54% of the respondents prefer their own vehicle over public transportation means. The collected data shows there was a vast difference between the satisfaction on the current services and the perceived importance of them. The main reasons for this were the low number and poor hygiene level of the toilets and the lack of food options provided. In addition, the lack of knowledge about the diseases amongst people, especially employees of the companies, had an impact on the choices made by the respondents. This thesis provides suggestions for the companies on how to improve their services to assure an enjoyable journey for everyone, including people suffering from inflammatory bowel diseases and other conditions with similar issues.</p>	
<b>Keywords</b> Inflammatory bowel disease, public transportation, accessibility, quality of service, customer experience	

## Table of contents

1	Introduction .....	1
2	Inflammatory bowel disease .....	1
2.1	Chron's disease.....	2
2.2	Ulcerative colitis .....	3
2.3	Cause of the disease.....	4
2.4	Surgery.....	6
2.5	Challenges living with IBD.....	8
2.6	Stigmatization.....	8
3	Passenger Traffic and accessibility .....	9
3.1	Passenger traffic in Finland.....	10
3.2	Accessibility.....	11
3.3	Disabilities .....	12
3.4	Accessibility for people with IBD .....	12
4	Research on travelling experiences.....	15
4.1	Commissioning company Crohn ja Colitis ry.....	15
4.2	Quantitative research as a method .....	15
4.3	Survey .....	16
4.4	Results .....	19
4.4.1	Effects of the disease to long-distance travelling .....	20
4.4.2	Preference and frequency of transportation means .....	21
4.4.3	Level of satisfaction and perceived importance of provided services .....	23
4.4.4	Toilet card .....	25
4.4.5	Differences between respondent groups .....	26
4.4.6	Summary of results .....	27
5	Discussion and conclusion .....	28
5.1	Improvement suggestions .....	32
5.2	Evaluation of own work .....	33
5.3	Conclusion.....	34
	References .....	35
	Appendices.....	39

# 1 Introduction

This is a research orientated thesis that has been conducted by creating a quantitative questionnaire in the form of a survey. The purpose of the work is to create a better understanding of the possible problems that people with IBD face when travelling on public transportation means such as busses, airplanes and trains. The research findings can be used by companies working in the travel industry to take them into better consideration.

As there are almost 50 000 people suffering from an IBD in Finland, and 2000 new diagnoses made every year, the issues that these people have, need to be addressed (Finnish Medicines Agency Fimea and Social Insurance Institution 2016, 130). The thesis explains the basic information of inflammatory bowel diseases and the symptoms and possible harms that come along with it. It also goes through concepts such as accessibility and disabilities and their relation to inflammatory bowel diseases. In addition, public transportation and passenger traffic information are discussed, and people suffering from an IBD as customers.

The main objective is to research the possible difficulties that people suffering from Inflammatory bowel diseases face when using public transportation. This includes factors such as number, quality and accessibility of the toilets and the provided food options, whether they provide a suitable option or not. As inflammatory bowel diseases are still quite unknown in Finland, a lot of companies working in the transportation field are not familiar with them. Concepts such as the Toilet card have been created to help the everyday life of people with IBD, but they are hardly recognized by others and especially the companies.

The commissioner of this thesis is Crohn ja Colitis ry. The association aims to provide many different types of peer support for people with IBD and to raise IBD awareness among those affected, as well as health professionals, decision makers and the general public. (Crohn ja Colitis ry 2018.) The association has provided help with distributing the questionnaire.

## 2 Inflammatory bowel disease

Inflammatory bowel disease, or IBD, is an umbrella term for two chronic bowel diseases, ulcerative colitis and Crohn's disease. Both diseases have a nature of relapsing and remitting, and the complex set of symptoms and overlapping signs can lead to lifelong compli-

cations. (Ananthakrishnan 2015, 1.) Generally classified they are autoimmune diseases. An autoimmune disease affects the immune system so that when it would normally fight infections, it is attacking the intestines causing ulcers and sores inside them, which leads to the symptoms the diseases are known for. (Chandrasekar & Venu 2015, 15.)

These two diseases mainly affect the large and small intestine. A common characteristic for both Crohn's disease and ulcerative colitis is inflammation in the intestine, which can be active or stay quiet also known as a state of remission. A clear reason as to why and how the disease develops on people has yet to be discovered, even though several possible reasons have been suggested. (Ananthakrishnan 2015, 1.) The incidence of inflammatory bowel diseases is considerably bigger in developed countries compared to developing countries. It is less common in countries with low living standards and becomes more usual as the living standards raise and urbanization evolves. It is most common in Northern Europe and Canada. (Färkkilä 2018, 504.)

In addition to Crohn's disease and ulcerative colitis, approximately 10-15% of all IBD cases are faced with difficulties in distinguishing the symptoms from the two diseases. In these situations, the patient will be diagnosed with indeterminate colitis. However, most patients with this diagnose will evolve to a definite diagnosis of either Crohn's disease or ulcerative colitis on later follow ups. (Guindi & Riddel 2004, 1233.)

In Finland the incidence of ulcerative colitis is almost threefold more than Crohn's disease, and ulcerative colitis is more common with men than women, especially men over 35-years old. With Crohn's disease there is no stated gender difference. It seems that the number of new diagnoses of ulcerative colitis is growing, as with Crohn's disease it seems to be steady. The most common age to be diagnosed with Crohn's disease or ulcerative colitis is between the ages 20 to 35-years. (Färkkilä 2018, 504.) However, it is possible for a younger individual to fall ill with an IBD. Family history with IBD increases the likelihood of an early onset disease. (Baldassano, Mamula & Markowitz 2013, 9.)

According to a report co-released by Kela and Fimea (Finnish Medicines Agency Fimea and Social Insurance Institution 2016, 130) in 2016, there were over 46 000 people in Finland eligible for the compensation of the medication, from which it is possible to say the number of people with either Crohn's disease or ulcerative colitis. From these people roughly 24 000 are male and a 22 000 are female.

## **2.1 Chron's disease**

Crohn's disease is an inflammatory bowel disease, which is generally known as an autoimmune disease. It is a condition in which the lining of the gastrointestinal tract becomes inflamed, causing severe diarrhoea, constipation, vomiting, weight loss or weight gain and abdominal pain. Some of the possible complications caused by the disease are skin rashes, arthritis, and inflammation of the eye. (Reddy 2017, 921; Cadwallar 2008.)

Unlike ulcerative colitis, the disease may affect all parts of the gastrointestinal tract from mouth to anus but will most commonly affect the ileum and colon. Because of the wide reach on the bowel, the symptoms differ with people who are afflicted. (Cadwaller 2008.) The most common age to be diagnosed with Crohn's disease is between the ages 20 to 35-years. There is no known gender difference amongst patients. (Färkkilä 2018, 504.) According to Danesse & Fiocchi (2011, 1713) the worldwide incidence of Crohn's disease is 0.03 to 15.6 cases per 100,000 persons per year.

While the cause of Crohn's disease is not discovered yet, it is believed to be genetically linked. The highest relative risk occurs in siblings, and studies with identical twins show a concordance of 50%. (Goldin, Orchard, Tekkis & Williams 2011, 3.) Another major influence is smoking, which significantly increases the risk of recurrence, whereas quitting reduces the postoperative recurrence rate. Smokers are three times more likely to get Crohn's disease. (Cadwaller 2008.) Crohn's disease has a nature of causing greater disability than ulcerative colitis. Only 75% of patients are fully capable of work within the first year of their diagnosis and 15% are unable to work after 5-10 years of having the disease. (Carter & al. 2004, 53.)

Different from ulcerative colitis, there is yet to be discovered a drug based or surgical cure for Crohn's disease. Options for treating the disease are limited to controlling symptoms, reaching and keeping a state of remission and preventing relapse. Most patients will eventually require surgery at some stage of their disease. However, it cannot cure the disease. Nonetheless, surgery is inevitable in 80% of patients with ileal Crohn's disease after 10 years of progressive disease. The aim of surgery for Crohn's disease is to relieve clinical symptoms that won't respond to medications or to help with complications such as perforation, bowel obstruction, abscess, fistula or bleeding. (Cadwaller 2008.)

## **2.2 Ulcerative colitis**

Ulcerative colitis, as explained by the basic medical facts, is an autoimmune disease or a non-specific inflammatory condition of the mucous membrane of the large bowel and rectum. It is also known as an inflammatory bowel disease, or IBD. (Kelly 2003, 1.) It usually appears with young adults aged 20 to 35 and its more common with men, especially over the age of 35-years (Färkkilä 2018, 504). In Finland it stated to be almost three times more common than Crohn's disease (Färkkilä, Jussila, Kautiainen, Nieminen, Rekiaro & Virta 2011, 557). According to Danesse & Fiocchi (2011, 1713) the worldwide incidence of ulcerative colitis is 1.2 to 20.3 cases per 100,000 persons per year.

The causes of ulcerative colitis are yet to be discovered, but the pathology is well known. The main symptoms are diarrhoea with passage of blood, mucus, abdominal pain, loss of energy and weight, and raised temperature. It often follows a relapsing and remitting course and about 50% of patients with ulcerative colitis have a relapse in any year. (Kelly

2003, 2; Carter & al. 2004, 53.) A medical cure has not been discovered yet for the disease, however, there are surgical cures, and about 20 to 30% of patients require surgical treatment (Carter & al. 2004, 53). The most frequently used one involves the complete removal of the colon, anus and rectum. With this operation the patient's ileum will be operated through the skin in order to produce a new artificial anus called an ileostomy. As the opening has no muscular control, the patient will not have any control of the faeces. A plastic or a rubber bag that collects the digestive waste matter will be attached to the opening. (Kelly 2003, 2.)

After the surgical operation is done and there have been no malignant complications, it leaves the patient free of disease. However, they will have to get used to and live with the pouch attached to the opening for the rest of their life, which for a lot of people will shake up their own body image and self-esteem. Even without having to go through surgical procedures, the disease can severely undermine the ability to function socially. Unpredictable diarrhoea can affect life at any time from eating, sleeping to so sexual activities. For patients with either ulcerative colitis or Crohn's disease, life can sometimes be revolving around going to the toilet, or at least knowing where the nearest toilet facilities are. As these symptoms are not usually considered being normal for young people, it can cause extreme embarrassment. (Kelly 2003, 2.)

### **2.3 Cause of the disease**

Even though the cause of the diseases is still unknown, growing evidence proposes that the environmental factors play a role in it, and that the conditions involve immune-mediated tissue damage caused by genetic susceptibility factors. (Rampton & Shanahan 2008, 7). Some of the possible environmental factors researched include for instance smoking, stress, way of childbirth and breastfeeding, nutrition, infections and medication. (Färkkilä 2018, 504).

#### **Smoking**

Smoking increases the risk of getting Crohn's disease and weakens the effect of most of the medications used to treat it. It also increases the periods of active illness, the need for surgical operation, and supports complications to advance. Yet smoking seems to lower the risk to get ulcerative colitis and reduces the times of relapses. (Färkkilä 2018, 504.) There is a possibility that the effects that come from smoking are not disease, but organ related. This means that even if smoking is harmful for small intestinal mucosa, it could be protective to the large intestinal mucosa. Research shows that from patients with ulcerative colitis only about 10% smoke, whereas the percentage for people with Crohn's disease is as high as 40%. (Rampton & Shanahan 2008, 12.)

#### **Dietary factors and nutrition**

Some dietary factors have also been proposed as possible exacerbators. Patients with ulcerative colitis can benefit from avoiding cow's milk, as up to 5% has improved their condition by doing so. Unfortunately, milk is the only potential pathogenetic dietary factor known so far. When it comes to Crohn's disease, no particular foods have been identified of being universally harmful for the patient's symptoms. However, Crohn's disease patients with an active phase may improve if their usual food is replaced by a liquid formula diet. After this, the patients may be affected negatively when introduced to specific foods. (Rampton & Shanahan 2008, 13.)

The food we eat has a direct and a modifying affect to the bowels microbiota. Thus, the risk of falling ill with an inflammatory bowel disease can be increased by our eating habits. Research shows that heavy consumption of foods that contain linoleic acids, which are fatty acids found from vegetable oils, nuts, seeds and animal products, increases the risk of ulcerative colitis approximately 2,5 times. The rise in consumption of linoleic acid is presented to explain one third of the risks from falling ill with ulcerative colitis. (Färkkilä 2018, 504.)

Heavy consumption of animal proteins increases the risk of colitis ulcerosa, but sweets and sugar on the other hand increase the risk of Crohn's disease. A diet which is heavy on fruits and fibers lowers the risk of getting an inflammatory bowel disease. Low levels of vitamin D can be a risk factor for relapses with Crohn's disease. (Färkkilä 2018, 504.)

### **Appendectomy**

Appendectomy done by the age of 30 may lower the risk of coming ill with ulcerative colitis, but not at an older age. Preliminary research indicates that appendectomy might settle a chronically active ulcerative colitis that is not responding to other treatment. With Crohn's disease the affect would be the opposite, meaning it would worsen the course of the disease and increase the risk of forming an intestinal stricture. (Färkkilä 2018, 504.)

### **Medicine**

Antimicrobial drugs, such as antibiotics, have been stated to correlate with the incidence of chronical inflammatory bowel diseases. The childhood usage of antimicrobial drugs increases the risk of becoming ill with an inflammatory bowel disease. The use of antimicrobial drugs increases the risk by possibly adding to the penetrability of the intestinal mucus. The contraceptive pill has been noticed to increase the risk of especially Crohn's disease. (Färkkilä 2018, 504.)

### **Stress**

The illness can also cause psychological stress due to its unpleasant, chronic and intractable nature. It is common in those with IBD, especially with Crohn's disease (Rampton & Shanahan 2008, 14). According to recent studies chronic stress, depression, and adverse



life events can cause relapse in patients with ulcerative colitis and Crohn's disease. Stress on gut motility and fluid secretion can worsen the symptoms of IBD. (Mawdsley & Rampton 2005, 1488.)

### **Infections**

Regardless of the two diseases similarities to infective diarrhea, it has not been proven that neither Crohn's disease nor ulcerative colitis would be due to a specific infection. There is no research supporting that neither of the diseases would be caused by transmissible pathogenic infection.

However, a virulent form of E. coli, also known as Escherichia coli, has been identified in patients with Crohn's disease (Rampton & Shanahan 2008, 14). E. coli, as described by the U.S. Centers for disease control and prevention (2018) are mostly harmless, but large and diverse group of bacteria. Some strains of E. coli can make people sick, but most are non-dangerous. They are also used as markers as to when water is contaminated, even though E. coli itself are as said, mostly harmless. According to Rampton & Shanahan (2018, 14) it is not clear if the bacteria further advances Crohn's disease or if it is caused by the disease itself.

### **Childbirth and breastfeeding**

Gut flora is formed after birth and soon stabilizes within the first year and it can be affected by the childbirth technique and breastfeeding. Caesarean section does not seem to add to the risk of getting an inflammatory bowel disease. Breastfeeding for longer than six months has been stated to protect from the disease from developing. (Färkkilä 2018, 504.)

### **Genetic factors**

Although the cause of inflammatory bowel diseases remains unknown, many hypotheses have been presented as to what the pathogenesis of it are. Genetics are presented as a possible cause along with the environmental factors. There is some evidence that having a first-degree relative with and IBD will increase risk of disease between two and ten times. From patients with the disease, approximately 10-20 % report having a family history of IBD in a first-degree relative. Studies with monozygotic twins, commonly known as identical twins, show a concordance of 50 % with Crohn's disease, but lower with ulcerative colitis. (Goldin, Orchard, Tekkis & Williams 2011, 3.)

## **2.4 Surgery**

Medical therapy related to IBD has gone through steady advances, however, in some cases of both Crohn's disease and ulcerative colitis, surgery is still a necessity. The signs for a need of surgery along with the performed operations differ between the two chronic diseases. The area of the bowel affected may also have an impact on the results. (Goldin

& al. 2011, 101.) Approximately 20% of people with ulcerative colitis and 80% of people with Crohn's disease will require surgery during their lifetime (Carter, Lobo & Travis 2004, 53).

The role of surgery and the circumstances in which it is necessary differ with Crohn's disease and ulcerative colitis. Surgery might be considered as an option with ulcerative colitis if the patient has an acute severe condition, the chronic active disease with substantially hostile effects on quality of life, or if signs of damages or carcinoma are found during colonoscopy. (Goldin & al. 2011, 101.)

As the chances of recurrence in the remaining bowel are quite high, all surgeries for ulcerative colitis involve colectomy, which means removing all or part of the colon. As a result of the surgery, the patient will either get ileostomy or an ileal-pouch anal anastomosis, commonly known as a J-pouch. (Goldin & al. 2011, 102.) With the J-pouch the whole colon, or large intestine, and rectum are re-moved and an internal pouch or reservoir, is fashioned using the small intestine to store stools which is connected to the anus. The pouch resembles the letter J, thus the name J-pouch. (Fazio & Joyce 2009, 115.) With this result the patient is capable of using the toilet in normal fashion, but most patients have to use the toilet 5-8 times a day. However, in this case the frequency has nothing to do with the difficult characteristics of the disease. (Goldin & al. 2011, 102.)

As for Crohn's disease, surgery plays a different role, partly as the disease almost always returns after it. Because of this, extensive resections are usually tried to be avoided, to not run into problems due to a short gut. Surgery might be considered for several reasons; If as with ulcerative colitis, the active disease forces the patient to suffer from hostile effects on quality of life, if there is fibrous stricture causing disruptive symptoms that medical therapy is not helping with, or a fistulizing disease. (Goldin & al. 2011, 106.) Ileocolic resection, mostly performed because of obstruction, is the most frequently performed surgical procedure for patients with Crohn's disease. A less common operation is stricturoplasty, which is chosen for patients with small bowel strictures. (Biancone & Sica 2013, 2445.)

Life after the surgery can take time for the patient to get accustomed to. Living with an ileostomy does not only come with having to learn how to manage it, but also with a changed physical appearance. The stoma, the opening in the stomach, is not publicly visible, unless the person with it is without a shirt. Theoretically, if the ileostomy is functioning properly it should not be a major handicap. In the case of ulcerative colitis, the surgery is also a cure to the disease. (Kelly 2003, 73.) When it comes to surgery for Crohn's disease, the fact is that the surgery is not permanent cure, and the risk of relapse exists. However, as long as the patient stays in remission, a high quality of life can be sustained. (Fichera & Mukta 2015, 294.)

## **2.5 Challenges living with IBD**

Once the diagnose has been given and a reason for the ongoing symptoms have been explained, actual life with the chronic disease begins. This means accepting having to live with the disease and the symptoms and getting accustomed to new routines that come with it. These routines can affect eating habits, family, social, work and school life, among others. When the urge to use the toilet can come at any time, especially in an active phase, the effects to one's life are undeniable. For some this might lead to taking a sick leave, but many continue working with the symptoms. With some patients the symptoms are there but not as visible to others, yet others might have a dramatic downfall where it is obvious to others that there is something wrong. (Kelly 2003, 32.)

Patients might have to make changes to their life and habits, such as quitting smoking, changing their eating habits and starting medication (Cohen, Micic, & Sakuraba 2015, 60). The changes in daily routines show especially with people who have gone through surgery and have a stoma. With the operation comes an ostomy bag where the patient's feces will go, and it needs to be emptied several times a day. (Kelly 2003, 75.) The disease can also be stressful because of the constant threat of symptoms. A considerable amount of evidence has been collected in the recent years supporting the statement that psychological stress does contribute to the risk of relapse. (Mawdsley & Rampton 2005, 1488.) Patients have also stated feelings of anger, loneliness, sadness and even depression (Kelly 2003, 109).

Dietary restrictions might affect the patient's life by having to control what they eat and to hope that there are suitable options available. Guidelines differ between Crohn's disease and ulcerative colitis. There are no specific guidelines to what to eat and what not, rather than some suggestions to what might help. For example, avoiding cow's milk and fibre supplementation might help some patients with ulcerative colitis. With Crohn's disease the recommendations vary from the patient's condition and the bowel area of inflammation. Patients with stricturing small-bowel Crohn's disease as an example should avoid high-residue foods such as uncooked vegetables, nuts and citrus fruit. However, these differ with individuals and for many need to be tested by themselves. (Rampton & Shanahan 2008, 84, 102.)

## **2.6 Stigmatization**

Inflammatory bowel diseases do not only include physical harm, but also the psychological distress that might come along with the symptoms. A noticeable issue for people with chronic illnesses such as Crohn's disease and ulcerative colitis is social stigma, which can be described as identification of negative features that differentiate a person from the normative group and make the person worthy of separation. It might often lead to loss of status and discrimination. (Link & Phelan 2001, 363.) Social stigma consist of the way stigma is perceived, self-stigmatization which means internalization of the negative attitudes of others and passed stigma behaviours from others. Psychological distress related

to perceived stigma may relate to increased suffering that could further damage the patient's health. (Ramakrishna, Somma & Weiss 2006, 279.)

The symptoms that are common for IBD such as abdominal pain and bloating, sometimes constant need to use the toilet, and fatigue, might support the six illness dimensions that increase the likelihood of stigmatization. These dimensions are: concealability, disease course, disruptiveness, aesthetic qualities, origin and level of danger associated with the illness. (Artz, Bratten, Jones, Keefer & Taft 2011, 1392.) Research studies conducted by Artz & al. (2011, 1396) state that IBD patients with longer disease duration perceive less stigma. The perceived stigma can be harmful especially with young adults. Kelly (2003, 2) points out how many of the issues that come with the symptoms, such as soiling yourself, are not considered normal for people who are supposedly in the prime of their life. For infants and the elderly, it might be more acceptable, not normally for adults. The disease can undermine the control of one of the most basic human functions, bowel control. All of this can lead to the patient's loss of adult social status. (Kelly 2003, 2.) The feeling of shame or fear of soiling or embarrassing yourself might complicate activities that are considered normal parts of one's life such as taking a bus or a train with other people.

### **3 Passenger Traffic and accessibility**

Inflammatory bowel diseases are often not visible for other people unless the person with the disease has an ongoing relapse or the symptoms are extremely bad. The goal of medical or other therapies is not only to control the symptoms, but also prevent structural bowel damage and even disability. (Ali 2015, 36.) Even without having to go through surgery or being severely disabled, the disease can affect the patient's daily routines quite drastically. The impairments that make a person disabled are not alone the factors that disable them and for this it is important to include the role that is played by the environment and the society in which they live. It is argued that the issues faced by people with disabilities are a direct consequence of people's attitudes and the way the problems are dealt with in society. (European Conference of Ministers of Transport 2004, 5.) This chap-

ter will go through the terms disabilities, accessibility, and how they are related to inflammatory bowel diseases.

### 3.1 Passenger traffic in Finland

The public transport performance statistics report of 2015 of released by The Finnish Transport Agency (2017) gives some detail to the public transportation means that Finnish people use the most. In 2015 there were 23,5 million people travelling domestic long-distance journeys with public transportation from which 12,3 million were by train, 8,7 million by bus and 2,5 million by flying. The percentages of the passenger number can be found below in figure 1. (Finnish Transport Agency 2017.)

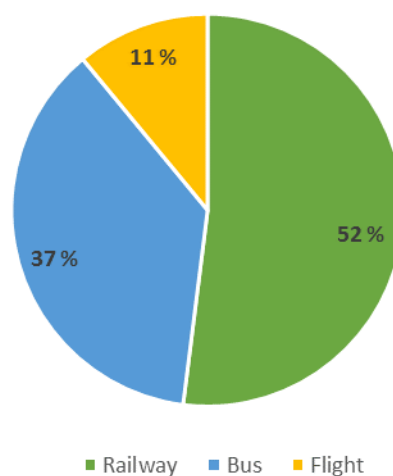


Figure 1. Finland's domestic long-distance public transportation passenger statistics 2015 (Finnish Transport Agency 2017)

The most kilometres per person were travelled by train with 2927 kilometres. As opposed to the number of people, flying had the second most kilometres per person with 1355,8 kilometres, leaving busses third with 946,7 kilometres per person. (Finnish Transport Agency 2017.) Due to the lack of information on long-distance travelling done by private vehicles in Finland, it is difficult to compare it with public transportation. However, according to an annual report released by VR Group (VR Group 2017) private transport covered 84% of all of Finland's passenger travel in 2015, whereas busses only covered 7%, trains 5%, flights 2% and other transportation means 2%. These numbers include all passenger traffic in Finland, which is why it can't directly be compared with the long-distance statistics.

By looking at the internet pages of some of the biggest public transport companies in Finland it possible to see how they acknowledge and handle the possible difficulties of accessibility and other issues for people with disabilities. Finnair (2018), which is the largest airline in Finland, has covered disabilities and special request regarding food and animal

allergies and medical conditions quite comprehensively. On their internet page they offer information on aspects such as how to get special assistance and how they help with special dietary requests. Accessibility to the toilets during flights is mentioned on the “Tips for the elderly” page.

VR (2018), which is the only operating railway company in Finland, also seems to cover the disability and accessibility issue quite comprehensively information wise. The company provides a seemingly wide variation of foods on their long-distance trains, assistance for wheelchair users for instance is offered, and multiple toilets are offered on their trains. Their internet page also shows the stations around Finland that offer toilets for the customers. Onnibus, which is one of the most popular bus companies in Finland (Talouselämä 2017) offers options for people with disabilities as well. In case the passenger has a wheelchair, the company can offer a place for it and a free ticket for a personal care assistant. All their busses have two floors, offer one toilet and do not offer food services. All the companies mentioned offer different amounts of information and assistance for people with special needs, but many of the issues are covered on their pages. None of them mention inflammatory bowel diseases, but many of the issues and solutions to them are covered in different sections.

### **3.2 Accessibility**

Accessibility as a problem can sometimes be thought of only impacting people with sight, mobility or hearing disabilities, which is not the case. An example provided by the European Conference of Ministers of Transport (2004, 5) questions the problem by asking the following: “if a wheelchair-user cannot get into a building, is it because of their disability, or rather that the principles of universal design have not been considered in designing the building?”. The same might apply to people with IBD when thinking of the access, quality, and number of toilets. For instance, it is stated that many patients with ulcerative colitis limit their lifestyles because of the constant need to be near a toilet (Bala & al. 2007, 1135).

The United Nations has set guidelines for accessibility for the States Parties, which are the countries that have adhered to the Convention on the rights of persons with disabilities, on accessibility for everyone. The aim is to provide accessibility for everyone and everywhere, thus enabling persons with disabilities to live independently and be able to participate in all aspects of life. These guidelines cover physical environment, transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, not only in urban but also in rural areas. (The United Nations 2018.)

The provided measures are aimed to identify and eliminate obstacles and barriers to accessibility with the following: buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces. It also covers information, communications and other services, including electronic services and emer-

gency services. The United Nations also require the States Parties to take appropriate measures on such aspects as developing and monitoring the implementation of the guidelines, to ensure that private and public entities that offer facilities and services to the public take the accessibility aspect into account, and to make sure that there is access to information for everyone, and assistance if needed. (The United Nations 2018.)

### **3.3 Disabilities**

According to the World Health Organization (2018) disabilities as a term covers the following three aspects: impairments, which is a problem in body function or structure, activity limitations, meaning a difficulty faced by an individual when executing a task or an action, and participation restrictions which can be problems experienced by an individual's involvement in life situations. Therefore, disability is not just a health problem. It is more of a complex phenomenon, reflecting the interaction between one's bodily features and the society which they live in. To overcome the difficulties that disabled people must face on daily basis, it is necessary that the environmental and social barriers are removed, and changes are made. (WHO 2018.)

Having an inflammatory bowel disease can take over one's life quite dramatically as the urge to use the toilet can be unpredictable, and so the ability to function socially can be severely undermined (Kelly 2003, 1). Because of this the existence of a toilet somewhere nearby might affect the decision of going to certain places, thus limiting the actions of the person.

### **3.4 Accessibility for people with IBD**

Accessibility for people with an inflammatory bowel disease often means having access to a bathroom and having suitable food options. To help with these issues, associations such as Crohn ja Colitis ry in Finland offer a Toilet card that gives access to toilets that would otherwise be accessible only for employees, by paying a fee toilets or toilets for disabled people (Crohn ja Colitis ry 2018).

Some associations related to inflammatory bowel diseases also offer advices on how to travel with the disease. The Crohn's & Colitis Foundation in the USA have written a page of advices that include advices on how to prepare for the upcoming trip, how to manage with personal medication and what to prepare for. (Crohn's & Colitis Foundation 2018.)

#### **Toilet card**

Toilet card, or Vessapassi as it is known in Finnish, is started and patented in Finland by Crohn ja Colitis ry. It is a part of the benefits that members of the following associations get: Crohn ja Colitis ry, Finnish Neuro Society, Colores ry, Endometriosisyhdistys and different cancer associations. The main purpose of it is to make it more accessible for people with special conditions to use the toilet when the urge comes. These special conditions

include people suffering from chronic diseases such as inflammatory bowel disease, intestinal cancer, endometriosis, neurological diseases, gynaecological cancer, bladder cancer and neuroendocrine tumours. (Crohn ja Colitis ry 2018.)

The idea of the card is that companies participating would have a sticker visible to inform people with the card that their toilet facilities are accessible for them. This might mean the toilets that are usually only for staff members, disabled people or pay toilets. The mission is to enlarge the range of living space for the people with an illness and thus, to better their quality of life. The sticker can also be used to inform others that people with the Toilet card might have an urgent need to use the toilet because of an illness. (Crohn ja Colitis ry 2018.)

In addition to the Finnish Toilet card, the same concept exists in other countries such as the United Kingdom and Australia. In these two countries it is known as the Can't Wait Card. In the United Kingdom more than 39 000 people have it and it is offered in 30 different languages for travelling purposes. (Crohn's & Colitis UK 2018; Crohn's & Colitis Australia 2018.)





## **4 Research on travelling experiences**

The main objective of this thesis is to research the possible difficulties that people suffering from Inflammatory bowel diseases face when using public transportation means such as busses, airplanes and trains. This may include factors such as accessibility, the quality of the toilets and the provided food options, whether they provide a suitable option or not. The results can be used by public transportation companies to acknowledge and improve their services to better serve this group of people.

To be able to find out what the real issues are, the answers had to come from actual people suffering from them. A survey aligning with the quantitative approach was conducted to get a wholesome view of the challenges and sent solely to people with an IBD. This chapter will explain the research methods and tools used for it and clarify the findings.

### **4.1 Commissioning company Crohn ja Colitis ry**

The commissioner of this thesis is Crohn ja Colitis ry. As described on their internet page, "the association aims to provide many different types of peer support for people with IBD and to raise IBD awareness among those affected, as well as health professionals, decision makers and the general public." (Crohn ja Colitis ry 2018.)

The association was established in 1984 and has since grown its number of members to almost 8000 people. It is financially supported by the Finnish Ministry of Social Affairs and Health from the profits that come from Veikkaus, the Finnish government-owned betting agency. Their mission is to improve the well-being and quality of life for those ill with an IBD and for their close ones. The association's vision is to offer up-to-date information and support in different ways. Their goal is to further advance the availability of equal treatment by working with and influencing other parties. (Crohn ja Colitis ry 2018.) The association has provided help with this thesis by distributing the questionnaire to their members through their email lists.

### **4.2 Quantitative research as a method**

Quantitative research is a technique which can also be considered as a hypothesis-testing research. Studies with this approach usually begin with theoretical statements from which the research hypotheses come from. The aim of quantitative research is to explain the phenomena by variables, which are measured while controlling for the effects of selected independent variables. This method is suitable when the aim is to get a large group of respondents and it's possible to make some assumptions. It is important that the subjects chosen for the study are selected at random to reduce error to cancel bias. (Benz & Newman 1998, 18.)

After the data has been collected, it requires processing and analyzing so that the findings can be turned into information and explained. This can be assisted by taking the results

which usually include numerical data and transforming them into statistics and graphs. These tables and graphs are easier to understand rather than the raw data and can show aspects such as frequency of occurrence and comparisons between the results. This will help to answer the research questions and to meet the objectives. (Lewis, Saunders & Thornhill 2016, 496.)

### **4.3 Survey**

To reach as many people with an IBD as possible, a questionnaire proved to be the most effective tool to do so. According to Lewis & al. (2016, 439-440) questionnaires are commonly used for descriptive or explanatory research. By analyzing the data collected with a questionnaire, it will make it possible to identify and describe the variability in different phenomena.

The process of creating the survey (Appendix 1) started by fashioning a frame that would support the questions. From an early stage it was clear that the transportation means had to be narrowed down to trains, busses and airplanes. This was because these options place the customer in a situation where it is not possible to leave from, thus magnifying the importance of the services provided on the journey. As an example, busses in Finland usually provide only one toilet, which makes the quality of it even more important.

The next decision was to narrow it down to long-distance travelling, instead of all public transportations regardless the distance. The longer the journey is, the more importance the services provided bring. This is especially true to many people suffering from symptoms that force them to use the toilet multiple times a day. Besides this, the local short-distance busses don't offer toilets, which is why the services couldn't be evaluated.

As mentioned earlier, Crohn ja Colitis ry as the commissioner helped to spread the survey to the right people by sending it to the members of the association via email. As it's a Finnish association, the language used in the survey was Finnish.

The final question was what the major themes would be. As explained in chapter 2, probably the biggest concerns that people with IBD have about their symptoms are the need of a toilet and the possible food restrictions. The three major themes were; quality of toilets, accessibility of toilets and provided food options.

#### **Accessibility of the toilets**

As for many living with an inflammatory bowel disease, especially the ones with an active disease, the need of a toilet can arise quite unexpectedly. For many people their daily routines, activities and decisions can be immensely affected by the need of a toilet somewhere near (Kelly 2003, 1). For this reason, the accessibility factor was chosen as one of the key aspects of the survey. Not only does it cover the question of how easy it is to ac-

cess the toilets, but also how many toilets there are in a train, bus or an airplane, and how long one might have to wait to use one.

### **Quality of toilets**

When the need of a toilet is constant, people start to pay even more attention to the quality of the service. This does not only concern people with a chronic bowel disease, but any customer who might have to use the toilets. However, when it comes to inflammatory bowel diseases, people often have less of an option to not use the toilets as the symptoms are not always possible to simply be ignored.

Some people might also have special need related to their disease, such as having a possibility to clean up using water or having enough space to empty a J-pouch from feces. Simply not providing clean facilities or necessities such as toilet paper, can ruin the travel experience for many and make them choose not to use the same company again. This was chosen to get a clearer view on how much it actually affects the decision making of the transportation mean.

### **Food options**

One aspect that can have a major impact on the day of a person with an IBD are the provided food options. There is no specific diet that works for everyone with the diseases, thus many must learn it by trying different food and diets out for themselves. Some people might not be able to eat food with gluten, some people try to avoid greasy food and other require vegan food. (Rampton & Shanahan 2008, 13.) Especially when the journey lasts more than two hours, the options might be to prepare and buy your own food before the journey, go without eating or hope that the service provider has taken different diets into consideration with their selection. These options might have extra value for people with an IBD, thus it was chosen as one of the themes of the survey.

### **Survey questions**

The survey (Appendix 1) begins with a brief introduction explaining who the respondents are it is made for, what is the aim of it and how will the results be used. In addition, the e-mail in which the link to the survey was in, had a brief introduction of the author, contact information and where the thesis can be found once it is finished. The questions used for the survey were planned to go along with the predetermined themes. The survey consisted of nineteen questions and an additional optional feedback question. Only one of the nineteen questions was open, however, nine had an open option for the respondent to leave their own answer.

The questions consisted of five information related questions of the respondent, twelve service related questions, three questions related to the Toilet card, which Crohn ja Colitis ry offers, and the earlier mentioned feedback question. The survey started with the infor-

mation related questions, the first question being the respondent's gender. This question was chosen to be able to see if there are any significant differences between the different genders related to the answers of the upcoming questions. The second question was about the respondents age, for comparing the differences of opinion between the age groups. The third question was about the specific inflammatory bowel disease that the respondent had. As the diseases differ from each other, this question helps to see what issues concern, and how much so, people with these two different conditions. The fourth question was about the state of the disease. This question was added for comparison reasons and to see if people with a newer diagnose have different opinions and experiences about the asked questions in comparison to the people who have had the disease for a longer period. The fifth question was about the status of the disease. People living with a disease in remission, active phase or with an ileostomy may have different needs regarding services, which is why it was added. This question had an option to be able to select multiple options, since people with Crohn's disease can experience an active phase even after surgery and ileostomy, meaning that none of the options by themselves would be accurate.

In question six, the respondent is asked if their disease affects their choice of transportation with long-distance travelling. The aim was simply to clarify how many people feel that their disease affects their choice of transport. Question number seven, "How much do the following aspects affect your choice of transportation mean?" offered four predetermined options and three open options. The scale was from one to five, with one being not at all and five being drastically. The predetermined options were: duration of journey, provided foodservices and the number and quality of the toilets. These were chosen according to the three themes mentioned earlier. Question eight, "Which transportation mean do you prefer on long-distance journeys?", was selected to see if there is a commonly more favorable option. The options provided were: bus, train, airplane, own vehicle and "doesn't matter". Question nine, "How often do you travel with the following transportation means?", was intentioned to follow question eight with a more specific result. The six options ranged from "at least once a week" to "never". Question ten, "What services would you improve in long-distance travelling?", was an open question meant to give the respondent more freedom on their answer, and to see if there were aspects that were left out by the author.

Question eleven, "Have you experienced difficulties with the following facts?" offered the respondent the following options to choose from: not enough toilets, poor quality of toilets, difficult location of toilets, lack of food options, and two voluntary open options. These were aspects that were considered as possible difficulties by the author because of the symptoms. The aim was to get a basic idea if people with an IBD perceive these factors as issues. Questions twelve, thirteen and fourteen, ask the same questions separately related to trains, airplanes and busses. The question, "How satisfied are you with the following services offered currently in..", was answered on a scale from one to five, one being "not satisfied at all" and five being "very satisfied". The options followed the three themes with quality and accessibility of the toilets and the provided food options. As there

are big differences with the three-mentioned transportation means, the questions aim was to clarify the opinions towards them. Food options as an aspect was left out from the question fourteen related to busses, since it is not common for bus companies in Finland to offer them at all. This was also mentioned in the survey. Questions fifteen, sixteen and seventeen, “How important are the following aspects to you when travelling with...”, also asked the same question in relation to the three-different transportation means. The options were scaled from one to five like the previous questions. The intention of the question was to provide important suggestions for improvement and to clarify what the most central aspects are.

As the last three questions were related to the Toilet card, a brief information about it was written before this section of the survey. Question eighteen, “Are you familiar with the Toilet card”, aims to clarify the awareness of it. Question nineteen simply asks if the respondent owns a Toilet card, to see how many do own it. Question twenty is a follow up question for question nineteen, asking if the respondent finds the Toilet card useful. With the option “No” comes a voluntary open option to answer why they do not feel that it is. This data can be used by Crohn ja Colitis ry to improve this service. Question twenty-one is more for open feedback. Here the respondent could leave feedback and comments of anything related to the survey.

#### 4.4 Results

With the help of the commissioning party, Crohn ja Colitis ry, the survey was sent to associations members through their email list. The survey was sent on the 3<sup>rd</sup> of December 2018 during the international IBD Awareness week and kept open for seven days.

Through the email list it went out to 4733 people, from which 1398 (30%) opened it and 811 (17%) finished the survey and sent their answers. This means that 587 (12%) of the people who received it, opened the survey but decided not to finish it. As can be seen in table 1, the majority by 489 (60%) of the respondents had ulcerative colitis, 296 (37%) had Crohn’s disease and the remaining 26 (3%) had indeterminate colitis.

Table 1. Diagnoses of the respondents (n=811)

Disease	Number of people	Percentage
<b>Crohn’s disease</b>	296	37%
<b>Ulcerative colitis</b>	489	60%
<b>Indeterminate colitis</b>	26	3%

The three biggest age groups within the respondents were 51-64 (26%), 31-40 (22%) and 41-50 (21%). The lowest numbers were with the age groups under 18 (2%), over 65 (12%) and 18-30 (17%). But as can be seen from table 2 below, the age distribution overall was quite diverse.

Table 2. Age demographics of the respondents (n=811)

Age	Number of Answers	Percentage
<b>Under 18</b>	17	2 %
<b>18-30</b>	138	17 %
<b>31-40</b>	178	22 %
<b>41-50</b>	169	21 %
<b>51-64</b>	210	26 %
<b>Over 65</b>	99	12 %

An interesting aspect to how people with an IBD perceive the symptoms and possible difficulties that come along with the disease, is how long they have been diagnosed for. The majority, 401 (49%), of the 811 respondents had already had the diagnose for over 10 years. Second biggest group, 232 (29%), were people who had had the diagnose for one to five years. After this came people with a diagnose between six to ten years, 149 (18%), and the smallest group were people who'd had the diagnose for less than a year, 29 (4%).

Question four asked the respondents about their current state of the disease. Because with Crohn's disease the ileostomy does not always cure the disease, it was made possible to answer to more than one of the options. The options were: remission, active and ileostomy. The total number of selections made were 877, which is 66 more than the total number of the respondents. Table 3 shows that from all the answers, 602 (74%) were currently in remission which means they had a state where their symptoms were either in decrease or even non-existent. 245 (30%) had an ongoing active disease phase, and 30 people (4%) answered ileostomy.

Table 3. Current state of the disease (n=877)

State of the disease	Number of answers	Percentage
<b>Remission</b>	602	74%
<b>Active</b>	245	30%
<b>Ileostomy</b>	30	4%

#### 4.4.1 Effects of the disease to long-distance travelling

When asked if the disease affects the respondents long-distance travelling, 59% answered yes and 41% no. When compared, the answers between people with Crohn's disease and ulcerative colitis are quite similar. 61% of the respondents with Crohn's disease answered yes compared to the 57% of the respondents with ulcerative colitis. A majority of 69% of respondents with indeterminate colitis answered yes. However, this group had only 26 respondents, 3% of the total number of respondents, which makes it a rather small sample.

In question seven the respondents were asked what are the factors that affect their choice of transportation mean when travelling long-distance journeys, and how much do they

affect on a scale from one to five. The predetermined options were; duration, provided foodservices, number of toilets and quality of toilets. Table 4 shows that the most important in average rate and in order according to the replies were the number of toilets (3,66) and the quality of toilets (3,56), duration of the journey (3,23) and provided foodservices (2,51).

Table 4. Affecting factors to long-distance travelling (n=811)

Aspect	Average rating
Number of toilets	3,66
Quality of toilets	3,56
Duration	3,23
Provided foodservices	2,51

In addition, the respondents could add up to three of their own options. In total there were 156 self-written answers, from which the three most commonly repeated were the need of a bidet shower, the current status of the disease and the time of the day when travelling, as especially mornings are difficult according to the respondents. Other aspects mentioned included getting to be located near a toilet while travelling, using their own vehicle if possible, the possibility to walk around and stretch, and the difference of the journey being direct or having to change transportation.

#### 4.4.2 Preference and frequency of transportation means

When asked about the preferred mean of transportation, an overwhelming 54% of the respondents chose their own vehicle (figure 2). From the three provided public transportation means the most popular options in order were train (20%), airplane (16%), and bus (2%). For the remaining 7%, the transportation means, public or private, made no significant difference.

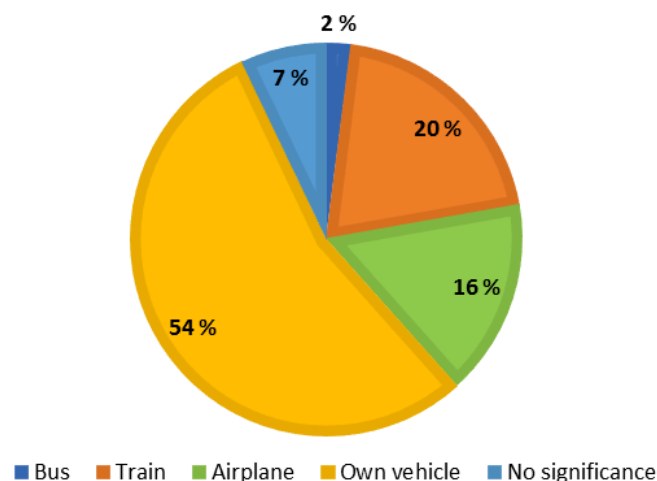


Figure 2. Preferred means of transport by percentage (n=811)



In question nine the respondents were asked how frequently they use each transportation mean. As this question was mandatory to answer, all the options had a total of 811 responses scaling the frequency of use of each transportation mean. Own vehicle, meaning a car for most people, was the most used option on a weekly basis by 289 replies which was 36% of the total number of responses. It also got the lowest amount of selections on the option Never by 25 (3%) selections, meaning it was the most popular choice for frequent use.

As can be seen from figure 3, all of the public transportation means received low numbers on weekly basis with bus being the lowest from the three with only 24 selections (3%). Most people replied to only use busses, trains and airplanes mainly two to three times in six months, once a year, or less than once a year. The most selected option for bus and airplane was less than once a year with 250 selections (31%) for bus and 302 selections (37%) for airplane. For train it was between two to three times in six months by 244 selections (30%).

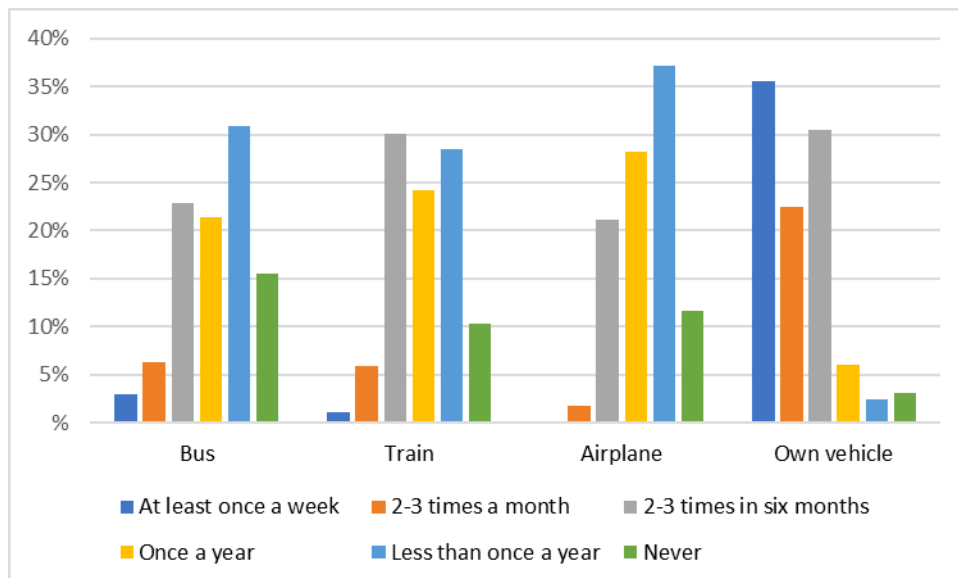


Figure 3. Frequency of travel per transportation means (n=811)

In question ten the respondents were asked about services by the transportation companies that they would want to be improved. It was an open question that was not required to answer to, and 304 people wrote an answer to it. The main issues that came out related to travelling with IBD were:

- tidiness, size and number of toilets
- bidet shower
- possibility to wash hands
- provided information about the availability of toilets
- toilets not available at stations
- possibility to book a seat close to the toilets

- lack of knowledge regarding the Toilet card by staff members and overall understanding of the situation

The respondents were also asked about the issues faced when travelling long-distance journeys with public transportation, and the following predetermined options provided: low number of toilets, low quality of toilets, difficult location of toilets and lack of food options. From the total 811 respondents, 631 people (78%) said they have faced issues with the quality of toilets, 483 (60%) have had issues with the low number of toilets, 308 (38%) stated having issues with the difficult location of the toilets and 201 (25%) had faced difficulties with the lack of food options provided. Two open options were added, to which people had stated mostly issues such as mentioned earlier for question ten.

#### **4.4.3 Level of satisfaction and perceived importance of provided services**

Questions twelve, thirteen and fourteen were in relation to the level of satisfaction experienced of the current services provided by the airlines, bus and train companies. The options were to be scaled from one to five and had three predetermined options and two open choices for other services to be written by the respondents. The three predetermined options were number of toilets, quality of toilets and offered food services. As most Finnish bus companies do not offer food services at all, this option was not included when asked about the services provided by bus companies.

In questions fifteen, sixteen and seventeen the respondents were asked to give a rating about the importance of the quality of toilets, accessibility and number of toilets and the diversity of provided foods. The rating was given on a scale from one to five. Similar to the previous questions, open options were provided for the respondent to fill in their own aspects. All the predetermined options, except the diversity of provided foods, were ranked as really important at a rating of over 4.

The lowest ratings of satisfaction related to the number (2,49) and quality (2,43) of toilets were for busses, which can be seen in figure 4 and figure 5. The open section explained it a bit, with comments about the small size of the toilets, no running water or soap provided, and over all unsanitary facilities. Most busses usually offer only one toilet, and some of the respondents had been in a situation where the toilet was uninformedly out of use. The average ratings of perceived importance of the services in busses were 4,11 for quality of toilets and 4,14 for accessibility and number of toilets. One of the comments mentioned in the open section was the hope of a possibility to use toilets free of charge at bus stations.

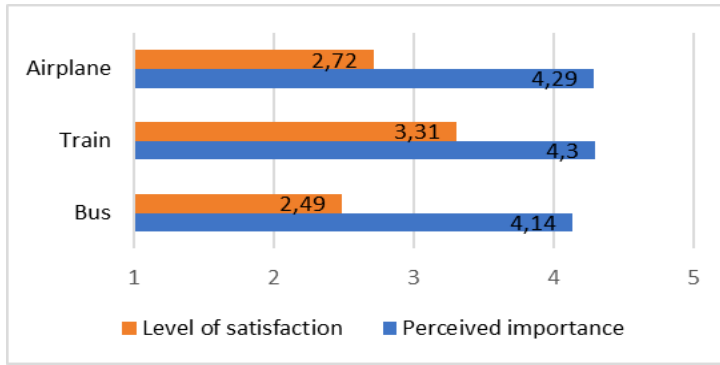


Figure 4. Comparison between the perceived importance and current satisfaction of number of the toilets (n=811)

Trains received an average satisfaction rate of 3,31 for number of toilets (figure 4), 2,82 for the quality of toilets (figure 5) and 3 for the provided foodservices (figure 6). The issues mentioned in the open section were similarly to busses related to the size and hygiene level of the toilets. The lack of knowledge about the Toilet card and low number of handi-cap toilets were also mentioned alongside with the toilet locking system that fails to work from time to time. The fact that many train toilets have a bidet shower was mentioned as a positive aspect. The average ratings of perceived importance of the services in trains were 4,18 for quality of toilets (figure 5), 4,30 for accessibility and number of toilets and 3,01 (figure 4). Mentioned in the open comment section were the possibilities to be able to book a seat near the toilet and have larger seats for comfortability, for reasons such as joint pain.

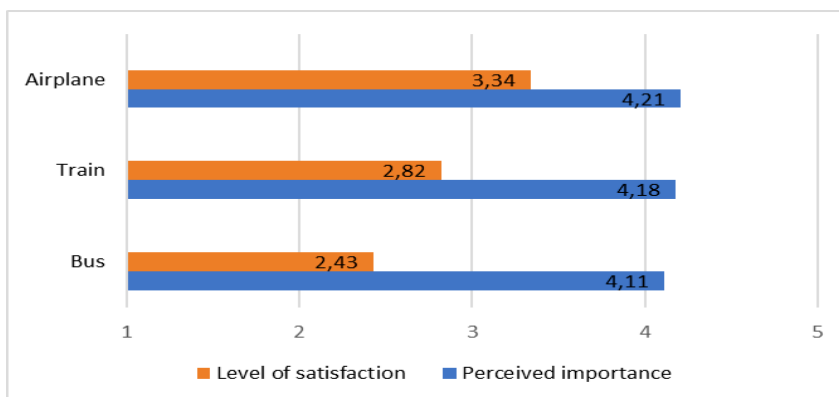


Figure 5. Comparison between the perceived importance and current satisfaction of quality of the toilets (n=811)

Airplanes average satisfaction rating for number of toilets was 2,72, which was lower than trains but higher than busses. Also mentioned in the open section were how many air-planes only have a few toilets for the entire aircraft. Quality of toilets received an average rating of 3,34, which was the highest from all three transportation means. Similarly, to the comments left for the other transportation means, the common topics were the small size, poor hygiene and lack of a bidet shower. Also mentioned was the difficult access to the toilets because of the narrow aisles and having to have to wait in an urgent need to use

the toilet. Provided foodservices average rating was 2,91, which was lower than for trains. The lack of gluten and lactose free options were mentioned for some of the reasons.

The average ratings of perceived importance of the services in airplanes were 4,21 for quality of toilets (figure 5), 4,29 for accessibility and number of toilets and 3,34 (figure 4). Foodservices were rated more important on airplanes than in trains by a difference of 0,33 (figure 6). For airplanes and the other transportation means, the lack of knowledge about the Toilet card was mentioned.

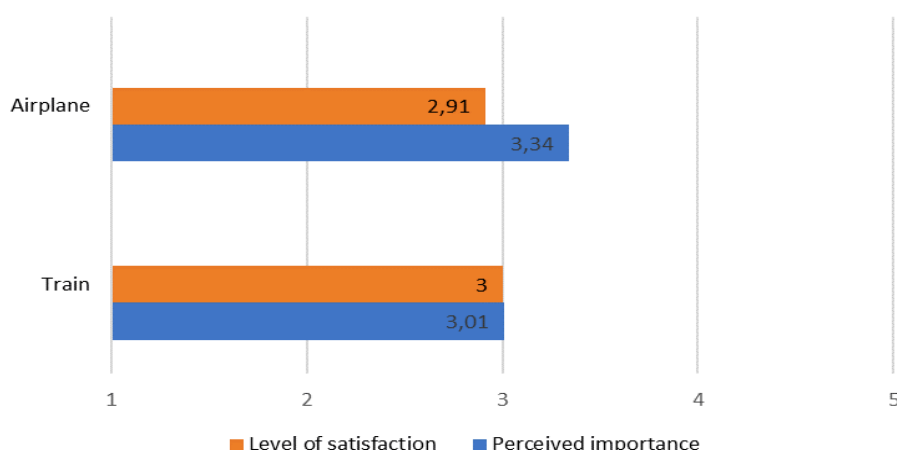


Figure 6. Comparison between the perceived importance and current satisfaction of provided foodservices (n=811)

In almost all the aspects rated by the respondents, there is a vast difference between the average rate of perceived importance and level of satisfaction on the current services. The biggest differences can be seen in the quality of toilets, with bus having a difference of 1,68. The smallest differences were with foodservices where with trains the difference was almost nonexistent, and with bus only 0,43.

#### 4.4.4 Toilet card

The last three questions of the survey were about the Toilet card. The respondents were asked if they know about the concept, to which 799 (99%) answered yes and the remaining 12 (1%) answered no. This can be explained by the fact that all the Crohn ja Colitis ry associations members get it automatically when joining. The following question asked if the respondent owns a Toilet card, which also for this reason was mostly answered with yes. 754 (93%) replied they have it, 42 (5%) replied they don't have it and 15 (2%) replied that they don't have it, but they will get it later.

The final question related to the Toilet card was voluntary and aimed for the people who replied yes to the previous question about owning one. It was simply asking if the pass holder has found it useful or not, and if not, why so. 433 people (57%) replied that they

had found it useful, and 325 (43%) replied no. For the people that answered no, there was an option to explain the reason, to which 249 people wrote one. Some of the most common answers were that they didn't feel a need to use the card because of their current condition but will most likely use it if the situation changes. Many answers concerned the fact that the Toilet card is not commonly known by others and especially employees of the transportation companies, and because of this it wasn't as useful as it could be. Another aspect was that people do not want to have to explain their condition for example in a situation where there are other people queuing too. The fear of embarrassment was brought up in many of the answers.

### **Section for open feedback and comments**

In the end of the survey the respondents were given an opportunity to leave feedback and comments on an open section. This section was optional, and 134 people ended up leaving feedback or comments. The themes of these replies were mainly the same as for previous open questions and had to do with the issues faced with toilets and the Toilet card, and improvement suggestions for companies. One that was not stated in the answers for the previous questions was the mental comfort brought by simply knowing that there is a toilet in use. Some comments were related to the thesis itself, with positive and constructive feedback.

#### **4.4.5 Differences between respondent groups**

An interesting point of view of the results is comparing different respondent groups. Chosen groups for this are the ones related to the diseases which are the respondent's disease, the number of years from the diagnose and the current status of the disease.

Differences with average ratings related to the services between respondents with Crohn's disease, ulcerative colitis and indeterminate colitis were quite small. Questions with a one to five scale answers had only minor differences between Chron's disease an ulcerative colitis, highest differences with average rating being approximately 0,2. Indeterminate colitis showed bigger differences between the averages, however, this group only had 26 respondents. Thus, it might not be considered as trustworthy as the other groups with 296 respondents with ulcerative colitis and 489 with Crohn's disease.

The number of years that the respondent had been diagnosed for showed the biggest difference when asked about certain aspects affecting the choice of transportation mean. There was a clear pattern showing that the most importance given to almost all the aspects were the people who had been diagnosed for a shorter period of time. The only exception was when asked about the importance of the number of the toilets. This question the respondents who have had the diagnose for over 10 years gave it the most im-

portance, different from all the other aspects where this group gave the lowest importance rating. With all the other questions there was no pattern with the four different groups, yet there were average differences up to 0,4.

The current status of the disease shows quite well in differences with the answers. Respondents with remission are the most satisfied with provided services and less bothered about the challenges in almost every question. This can of course be explained with the simple fact that the symptoms are much more in control when in remission. 47 % of the people in remission say that the disease does not affect their choice in public transportation mean in long-distance travelling, whereas from respondents with an active disease only 24% say the same and 23% from respondents with an ileostomy. The biggest average rating difference with respondents with remission and respondents with an active phase or ileostomy is up to 0,85 when asked how much the duration of the journey matters in a scale from one to five. The average rating for most questions is quite similar between people with an ileostomy and an active phase, with average rating difference around 0,2.

#### **4.4.6 Summary of results**

From the respondents a majority of 74% were in remission and the biggest age group was 51-64 years by 26%. The biggest disease group was ulcerative colitis with 60% of the respondents, 37% had Crohn's disease and 3% indeterminate colitis. From all the 811 respondents, 59% stated that their disease affects their long-distance travelling. 54% answered that they prefer using their own vehicle. From public transportation means train was the most popular option with 20% of the answers, airplane received 16% of the answers, and the lowest option was bus with only 2%. When asked about the satisfaction level of the services bus as an option received the lowest averages on both quality and number of toilets. When asked about the importance of services, there were no major differences between the transportation means. As train was the most popular option (20%) when asking about the preferred transportation mean, it also received the highest satisfaction average on services with only quality of toilets being lower than airplanes.

99% of the respondents were familiar with the Toilet card and 93% had their own card. 57% of the people who had it, found it useful. On the open section it was explained that some did not find it useful because they simply didn't need to use it at the time being, and many commented on the lack of knowledge related to the Toilet card.

## 5 Discussion and conclusion

The main objective of this thesis was to research the possible difficulties that people suffering from an IBD have to face when travelling long-distance journeys with public transportation means such as busses, trains and airplanes. As 59% of the survey respondents stated that their disease affects their long-distance travelling, it emphasises the need of the companies to provide quality services so that all customers can have a pleasant journey. It also shows that the respondents do indeed face difficulties related to their disease when travelling. The survey results show that most people with an inflammatory bowel disease are not satisfied with some of the services provided by public transport companies. It is quite clear that the services that have a close impact on the disease can have a bigger impact on the travel experience of those with an IBD or conditions with other similar symptoms or restrictions. These services are mainly related to the toilets and provided foods. Even in the open sections of different questions the same themes of issues were repeated.

As seen in chapter 4.4 60% of the respondents have ulcerative colitis, whereas only 37% have Crohn's disease and 3% indeterminate colitis. This correlates with the statements made by Färkkilä (2018, 504) saying ulcerative colitis is almost threefold more common in Finland than Crohn's disease. According to Guindi & Riddel (2004, 1233) roughly 10-15% of all IBD cases are diagnosed as indeterminate colitis and, in most cases, later diagnosed again with either Crohn's disease or ulcerative colitis. This explains the low number of respondents with indeterminate colitis.

A majority of 74% of the respondents had a remissive state of the disease. Remission according to Ananthakrishnan (2015, 1) means that the symptoms are less disruptive or non-existent. This might have also had an impact on the survey results, as the majority were presumably suffering less disruptive symptoms as they would have had with an active phase. However, 30% of the respondents did have an ongoing active phase and 4% had an ileostomy, which comes with certain difficulties such as emptying the faeces from the possible J-pouch. Also worth mentioning is the fact that 49% of the respondents had already had the diagnose for over 10 years. The results showed this respondent group rated the importance of all the aspects, except the number of toilets, the lowest. This respondent group can be assumed being more accustomed to the disease and its symp-

toms, which might have had an impact on the results such as the mentioned low importance of the services. According to Artz & al. (2011, 1396) IBD patients who have had the diagnose for longer perceive less stigma.

The difference between the perceived importance of the services and current satisfaction can be best seen with the answers to questions twelve to seventeen. In a scale from one to five, the importance of the number and accessibility and quality of toilets were rated higher than 4 for all the transportation means, with the averages ranging from 4,11 to 4,3. Average ratings for questions asked with the same services as options, but measuring the current satisfaction, were a lot lower. The averages ranged from 2,43 to 3,34 and had a minimum difference of 0,99 to the perceived importance. When asked about the factors that affect the choice of transportation on a scale from one to five, the two highest average rates were for the number of toilets (3,66) and the quality of toilets (3,56). This already shows that the respondents feel there is a lot to improve.

Average importance ratings for foodservices were not as high. The average rates both for perceived importance and current satisfaction were circling around 3, with the biggest difference being 0,43, with the current satisfaction being rated 2,91 and perceived importance 3,34. For trains the difference was only 0,01, with current satisfaction average being 3 and perceived importance 3,01. Some explanation to the low importance of foodservices might be the factors written in the open comment section. Commented was that the diversity of the provided foods was not wide enough, but at the same time some stated just not eating before a long journey or packing their own foods to avoid problems. In other words, some people dealt with this problem by themselves and thus didn't feel it was in that big of an importance to them.

### **Transportation means**

The respondents were asked about their preferred transportation mean, and the majority of 54% chose their own vehicle. It was also the most frequently used mean of transport with 36% of the respondents stating using it at least once a week. This was possibly mentioned as the preferred option whenever it was possible, because of the freedom that comes with it. By freedom is meant the option to stop whenever and where ever. This way it is possible to have as many toilet breaks as pleased and to have them in places which more likely have high quality and free of charge toilet facilities. By choosing yourself where to stop, it is also possible to do so in places where there are more suitable food options. One comment left mentioned that just by knowing there is a possibility to use a working toilet reduces the stress of facing issues as the stress itself can also cause problems with the stomach. This can be supported by Mawdsley & Rampton (2005, 1488), as according to them stress can worsen the symptoms of IBD.

As can be seen in chapter 4.4 in figure 2, from the public transportation means train was the most popular option with 20%, airplane second by 16% and bus the least popular by only 2%. Even the option "no significance" was more popular than bus, with 7% of the



answers. Bus as an option also received probably the most negative feedback in the open sections of the questions and 31% said they only used it less than once a year. 16% even stated to never using busses in long-distance travelling. The respondents hoped for more and longer toilet breaks and better toilets in aspects such as size, tidiness, hygiene level and lighting. Mentioned by the respondents were experiences of a situation where the busses toilet, as there usually is only one provided toilet, was not working and it was not informed about beforehand. As mentioned earlier, this can cause uneasiness and stress, which can worsen the symptoms (Mawdsley & Rampton 2005, 1488). According to Kelly (2003, 1) the disease can take over one's life drastically as the urge to use the toilet can be unpredictable. Because of this, access to a toilet is extremely important.

When comparing the survey results to the statistics made by the Finnish Transport Agency (2017), it can be seen that the most kilometres travelled per person correlate with them. The same statistics show that most kilometres were travelled by train, followed by airplane and then bus. According to VR Group (2017) private transport covered 84% of all Finland passenger travel in 2015 which would also correlate with the survey results, where 54% chose their own vehicle. However, VR Groups statistics included all passenger traffic in Finland including short-distance travelling, which might not make it so accurate for long-distance travelling.

Some of the reasons for train being the most popular transport mean amongst the respondents can be explained by the number of toilets. Long-distance trains usually offer multiple toilets, which makes it easier for the customer to find one and not have to queue for too long. Trains also offer foodservices, which busses do not, and have a better possibility for the customer to walk around and stretch. 30% of the respondents stated using trains between two and three times in six months. However, some of the improvement suggestions left by the respondents were the lack of tidiness and hygiene in the toilets mentioning that soap was not always offered.

Many people, especially with an ileostomy, had a common request to get to use a bidet shower, and for train there were positive feedback related to it being provided. Even though trains offer more toilets, the low number of disabled toilets and the lack of knowledge about the Toilet card by the employees were hoped to be improved. As mentioned in chapter 3.3 WHO (2018) states that the term disability also covers problems in body function and activity limits, which can be case for some people with an IBD. According to the European Conference of Ministers of Transport (2004, 5) it can be argued that the challenges disabled people have to face are a direct consequence of people's attitudes and the way problems are dealt with in society. Thus, by understanding the challenges of the disease, it can be easier to understand the comments left by the respondents concerning the lack of understanding and the access to use a disabled toilet.

Airplanes didn't get as much feedback as the other transportation means. One reason for this can be seen in Figure 3 which shows the frequency of use of each transportation mean. 37% answered flying less than once a year, 28% only once a year and 22% an-

swered two to three times a year. 12% stated that they never fly. The open feedback that it did receive concerned the low number, small size and bad smells and hygiene of the toilets. The foodservices and provided options were also criticised of not being diverse enough. As an example, according to Rampton & Shanahan (2008, 13) approximately 5% of patients with ulcerative colitis improved their condition by avoiding cow's milk. If the service provider can't offer an option according to the customers restriction, it has a direct impact on their travel experience.

### **Main issues according to the respondents**

In questions seven, and eleven to seventeen the respondents were offered an option to write their own option to the question. Question ten was also an open question, question twenty had an open question related to the Toilet card, and question twenty-one was meant for open comments and feedback. The main themes of the responses were quite repetitive which shows that there are certain issues that the respondents share. The themes were mainly within the themes of the thesis, concerning the number and quality of the toilets, the Toilet card and the food services. Multiple times mentioned was the possibility to use a bidet shower in the toilet. As stated by Kelly (2003, 2) in the case of an ileostomy, a plastic or a rubber bag collects the digestive waste matter. This bag will have to be emptied and can be messy, thus the need of bidet shower makes it a lot more convenient. It can be more convenient also for a person with an IBD who is in a condition where they have to use the toilet multiple times a day.

One of the comments repeated in the open sections concerned the Toilet card. The lack of knowledge amongst especially staff members was upsetting for many. When people don't understand the urgency and need of a toilet for some, it might lead to awkward and embarrassing moments for the card holder. Some of the open comments in the feedback in fact mentioned this as a reason for not using it. In chapter 2.6 it is mentioned that an IBD can lead to social stigma which can differentiate a person from a normative group and make the person worthy of separation (Link & Phelan 2001, 363). This is something that Crohn ja Colitis ry will have to work on to get the knowledge about the card to the people and companies of Finland. Other commonly mentioned issues had to do with the quality and number of toilets and the provided foodservices, that have already been mentioned in analyzing the results.

### **Reliability and validity**

As Joppe (Golafshani 2003, 598) points out that for a research to be considered reliable, the results must give an accurate illustration of the entire population studied. These results must also be possible to repeat by using a similar methodology as before. In other words, the observations or results must be able to replicate. Validity determines how accurate the research results are in concordance with the set research object (Golafshani 2003, 599).

The conducted survey had 811 replies, which was 17% of the number of people it was sent to. The age demographics were quite evenly spread from under 18 to over 65. Both the number of respondents and the diverse age differences can be considered to support the reliability of the survey. The number of respondents with ulcerative colitis was almost twofold to the number of Crohn's disease, which might give a bigger representation for that specific group. This was an aspect that could not be affected as the research was for people with all inflammatory bowel diseases, but it might give an unequal illustration of both. However, as mentioned in chapter 2, colitis ulcerosa is almost threefold more common (Färkkilä 2018, 504), which can explain the difference.

The structure of the survey and the understandability of the questions were made in a clear fashion. However, there were factors that could've made some of the questions understood in different ways by different individuals. In the survey the term "long-distance" was not clarified which might have led to different interpretations. In addition, there were some other minor setbacks that were pointed out by the receivers. Three different respondents sent an informative feedback about the options provided in question five about the current status of the disease. The options provided were: remission, active and ileostomy. As pointed out in the feedback many of the people suffering from ulcerative colitis who go through surgery, will have a so-called J-pouch, but as a temporal solution. In this case the respondents felt that none of the provided options were suitable for them, thus leaving some respondents to not finish the survey.

Another problematic failure of function was the mobile platform. Many of the questions offered the respondent an option where they could write their own option, making it an open question. Unfortunately, this function was not supported on the mobile platform, making it impossible to answer on the specific parts of those questions. As many people today have their email connected to their phones and are likely to use them instead of their computers, this was a possible reason for some people not finishing the survey. Despite the following setbacks, I feel that the large number and variety of participants provides the survey the reliability and validity that it need to be used by companies in the field to improve their services.

## **5.1 Improvement suggestions**

The following recommendations are written by the author for the companies operating on the public transportation field. By acknowledging the issues and recommendation propositions mentioned in this thesis, the companies can improve their services to better serve customers suffering from inflammatory bowel diseases and other customers with similar difficulties. These recommendations are based on the literature combined with the survey results.

As can be seen from the results, people with inflammatory bowel diseases do feel that there is a lot to improve. Improvement requests such as the size and number of toilets can be difficult to fulfil, as for example busses do not have much space where to place new

facilities, and so the enlarging of the toilets can be difficult. The same applies for trains and airplanes. However, there are many other aspects that can be improved. The main emphasis being on the quality and number of the toilets as these were rated important and thus in need of an improvement. For all the mentioned means of transportation the average rating of the importance of the quality and number of toilets was over 4. Yet the perceived satisfaction was ranging from as low as 2,43 up to 3,34.

Bus as an option got especially low average ratings with only 2,49 for the number of toilets and 2,43 for the quality of toilets and only 2% of the respondent choosing it as their preferred mean of transport. Reasons for the low averages and possible areas of improvement were especially the poor quality of toilets. As busses usually offer only one toilet, the importance of the quality is even more important. Mentioned issues included the poor level of hygiene and overall tidiness, lack of a bidet shower or running water, soap and toilet paper. All these aspects should be taken care of by the company. If there is a situation of the toilet being out of work, it should be informed beforehand so that the customers can prepare for this. Another issue to improve are the toilets at the stations. If they are not offered free for everyone, the Toiler card should at least be taken into use and the concept explained to the employees. This way the card holders can have access to the toilets at the stations too, without having to pay in a possibly urgent need of one.

All the above-mentioned areas of improvement also apply to trains and airplanes. The lack of free accessible toilets might not apply to airports, but the knowledge about the Toilet card is important. As stated by Kela and Fimea (Finnish Medicines Agency Fimea and Social Insurance Institution 2016, 130) in Finland there are close to 50 000 people suffering from the disease and 2000 more every year. These people need to be recognized and taking the Toilet card as a part of their organization, it would already help. Another improvement to be made by VR Group and airlines is to diversify their selection of offered foods. The companies do seem to already offer foods for special dietaries but there is always room for improvement. As for people with different inflammatory bowel diseases dietary restrictions might differ from person to person but offering vegan options and gluten and dairy free products makes a difference. The survey results show that the average rating for perceived importance of foodservices was 3,34 for airplanes and 3,01 for trains. The average ratings of satisfaction for current services were 2,91 for airplanes and 3 for trains. There were no major differences between the two, as compared to the ratings for quality and number of toilets. Airplane foodservices had a difference of 0,43 which means there is room for improvements.

## **5.2 Evaluation of own work**

As the workload for a thesis was quite a lot more than a regular school report, it took some adjusting of working and writing habits. The work also included many new tasks for the author that took some time to learn. The actual process of writing the thesis started between September and October 2018 and lasted for roughly three and half months, which was within the personal desired schedule. Overall the process went quite efficiently, the

biggest issues were more perceived and perhaps over thought, as everything did end up going along the hoped amount of time. One of the difficulties was simply to start the work and divide the workload rather than thinking about the big picture and the total amount of work. As the writer's day job was restricted to less than ten shifts per month, it offered the opportunity to put more hours on the thesis itself and not have to rush through it.

In the beginning the finding of sources of information was a bit difficult, but that changed once the right channels were found. As inflammatory bowel diseases are getting more common around the world, the literature about it is easier to find. Research on the topic has been worked on for decades and thus there was plenty of it. Recent and new sources were also quite easy to find, which was not as easy when searching for information for chapter 3, Passenger traffic and accessibility. The biggest surprise was with the number of respondents for the survey. As the commissioning party Crohn ja Colitis ry offered to help with the distribution, within the first day there were almost 500 respondents. This did not only give a bigger reliability for the results, but also speeded up the time that the survey had to be open. As the original planned time was two weeks, now the survey could already be closed in one week and start the analyzing of the results. What could have been done better with the survey was to test it not only on a computer, but also on a mobile platform before sending it. Because of this, there were some errors as mentioned before.

All in all, the work process went well. It could have been done faster with the amount of time available, but knowing one's own working methods and capabilities, it was better to be done with a more relaxed schedule to gain a better-quality outcome. The same aspect also provided a better opportunity to learn about the process and the information related to it. The author has learned a lot about the topics of the thesis and the working methods.

### **5.3 Conclusion**

The survey results clearly show that people suffering from inflammatory bowel diseases do face issues when travelling in public transportation means. 54% of the respondents prefer using their own vehicle, but companies operating in this field can change this. If the services are improved, it can have a major effect on the customers journey and chosen transportation mean. The biggest issues were seen with the quality and number of the toilets, especially with busses. With the recommendations written for the companies, it is possible to improve and take people with an IBD in to better consideration as customers.

Some of the main issues with the toilets were the level of hygiene and over all tidiness of the toilets and the lack of running water or a bidet shower. The lack of information of a toilet being out of use was perceived as a problem which is especially important with buses as they usually only provide one toilet. One of the biggest improvement suggestions for all the companies was taking the Toilet card into use and informing all the employees of it. This especially at stations could prevent uncomfortable situations for the users of it.

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# Appendices

## Appendix, 1. Survey on long-distance travelling with IBD.

IBD:n kanssa pitkien matkojen matkustaminen junalla, bussi tai lentokoneella.

Tämä kysely on suunnattu tulehduksellista suolistosairautta (Crohnin tauti, haavainen paksusuolentulehdus) sairastaville henkilöille. Kysely tehdään osana Haaga-Helian opinnäytetyötä. Kyselyn tarkoitus on selvittää kuinka pitkien matkojen matkustaminen junalla, bussilla tai lentokoneella koetaan, minkälaisia haasteita siitä seuraa sekä miten palveluita voitaisiin parantaa.

Vastaaminen kyselyyn vie noin 10-15 minuuttia. Kiitos ajastasi!

### 1. Sukupuoli \*

- Nainen
- Mies
- Muu
- En halua sanoa

### 2. Mihin seuraavista ikäryhmistä kuulut? \*

- Alle 18
- 18-30
- 31-40
- 41-50
- 51-64
- yli 65

### 3. Sairaus \*

- Crohnin tauti
- Colitis Ulcerosa (haavainen paksusuolentulehdus)
- Välimuotoinen koliitti

### 4. Kuinka monta vuotta sairauden diagnoosista on? \*

- Alle vuosi
- 1-5 vuotta
- 6-10 vuotta
- Yli 10 vuotta

### 5. Sairauden nykystatus (voit valita useamman vaihtoehdon) \*

- Oireeton (remissio)
- Aktiivinen (akuutti)
- Avanne

(Sivu 1 / 6)

Huom! Kaikki kysymykset koskevat kaukoliikennettä.

## 6. Vaikuttaako sairaus pitkien matkojen kulkuvälineen valintaan? \*

- Kyllä
- Ei

## 7. Kuinka paljon seuraavat asiat vaikuttavat kulkuvälineen valintaan pitkillä matkoilla?

1 = Ei vaikuta ollenkaan, 2 = Vaikuttaa jonkin verran, 3 = En osaa sanoa, 4 = Vaikuttaa paljon, 5 = Vaikuttaa todella paljon

	1	2	3	4	5
Matkan kesto *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tarjotut ruokapalvelut *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vessojen määrä *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muu, mikä? <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muu, mikä? <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muu, mikä? <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 8. Mitä kulkuvälinettä suosit pitkillä matkoilla? \*

- Bussi
- Juna
- Lentokone
- Oma kulkuväline, esim. auto
- Ei merkitystä

## 9. Kuinka usein matkustat pitkiä matkoja seuraavilla kulkuvälineillä? \*

	Vähintään kerran viikossa	2-3 kertaa kuukaudessa	2-3 kertaa puolessa vuodessa	Kerran vuodessa	Harvemmin kuin kerran vuodessa	Ei koskaan
Bussi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Juna	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lentokone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oma kulkuväline, esim. auto	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 10. Mitä asioita parantaisit kaukoliikenteen palveluissa?

### 11. Oletko kohdannut haasteita seuraavien tekijöiden kanssa? \*

- Liian vähän vessoja
- Heikko vessojen laatu, esim. likaista, ei vessapaperia
- Vessojen vaikea sijainti
- Ruokatarjonnassa puutteita
- Muu, mikä?
- Muu, mikä?

Huom! Kaikki kysymykset koskevat kaukoliikennettä.

### 12. Kuinka tyytyväinen olet junien nykyisiin palveluihin?

1 = Todella tyytymätön, 2 = Jokseenkin tyytymätön, 3 = En osaa sanoa, 4 = Jokseenkin tyytyväinen, 5 = Todella tyytyväinen

	1	2	3	4	5
Vessojen määrä *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ruokatarjonta *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 13. Kuinka tyytyväinen olet lentokoneiden nykyisiin palveluihin?

1 = Todella tyytymätön, 2 = Jokseenkin tyytymätön, 3 = En osaa sanoa, 4 = Jokseenkin tyytyväinen, 5 = Todella tyytyväinen

	1	2	3	4	5
Vessojen määrä *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ruokatarjonta *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Muu, mikä?

#### 14. Kuinka tyytyväinen olet bussien nykyisiin palveluihin?

1 = Todella tyytymätön, 2 = Jokseenkin tyytymätön, 3 = En osaa sanoa, 4 = Jokseenkin tyytyväinen, 5 = Todella tyytyväinen. Ruokatarjoilu ei ole yleistä busseista, josta johtuen sitä ei arvioida bussien kohdalla.

	1	2	3	4	5
Vessojen määrä *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Huom! Kaikki kysymykset koskevat kaukoliikennettä.

#### 15. Kuinka tärkeäksi koet seuraavat asiat matkustaessasi junalla?

1 = En ollenkaan tärkeäksi, 2 = Jokseenkin tärkeäksi, 3 = En osaa sanoa, 4 = Tärkeäksi, 5 = Todella tärkeäksi

	1	2	3	4	5
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vessojen saavutettavuus sekä määrä *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ruokatarjonnan monipuolisuus *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 16. Kuinka tärkeäksi koet seuraavat asiat matkustaessasi lentokoneella?

1 = En ollenkaan tärkeäksi, 2 = Jokseenkin tärkeäksi, 3 = En osaa sanoa, 4 = Tärkeäksi, 5 = Todella tärkeäksi

	1	2	3	4	5
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vessojen saavutettavuus sekä määrä *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ruokatarjonnan monipuolisuus *	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muu, mikä? <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 17. Kuinka tärkeäksi koet seuraavat asiat matkustaessasi bussilla?

1 = En ollenkaan tärkeäksi, 2 = Jokseenkin tärkeäksi, 3 = En osaa sanoa, 4 = Tärkeäksi, 5 = Todella tärkeäksi.  
Ruokatarjoilu ei ole yleistä busseista, josta johtuen sitä ei arvioida bussien kohdalla.

	1	2	3	4	5
Vessojen laatu, esim. siisteys, onko vessapaperia *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vessojen saavutettavuus sekä määrä *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muu, mikä? <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muu, mikä? <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Seuraavaksi hieman tietoa Vessapassista, jonka jälkeen seuraa muutama kysymys.

Vessapassin tarkoituksena on helpottaa suolistosairauksia, endometriosia, suolistosyöpää, neurosairauksia, eturauhassyöpää, gynekologisia syöpiä, rakkosyöpää ja neuroendokriinisiä kasvaimia sairastavien mahdollisuutta päästä välittömästi lähimpään vessaan. Tavoitteena on laajentaa sairastavien elinpiiriä ja parantaa heidän elämänlaatuaan.

Mukana olevat yritykset asettavat Vessapassi-tarran näkyville, josta Vessapassin haltija näkee voivansa päästä esimerkiksi inva-WCH:hen, henkilökunnan WC:hen tai maksulliseen asiakas-WC:hen kortin avulla. Tarralla yleisessä vessassa viestii myös muille vessankäyttäjille, että kortilla näytävällä henkilöllä on nopea WC:hen pääsy edellyttävä sairaus.

Vessapassi kuuluu Crohn ja Colitis ry:n, Endometriosisyhdistys ry:n, Colores ry:n, Neuroliiton, ja Syöpäjärjestöjen jäsenetuihin. Se on yhdistyksen jäsenkortin kääntöpuolella ja sen saa liittymällä yhdistyksen jäseneksi.

### 18. Onko Vessapassi sinulle entuudestaan tuttu? \*

- Kyllä
- Ei

### 19. Onko sinulla Vessapassi? \*

- Kyllä
- Ei
- Ei, mutta aion hankkia

### 20. Jos vastasit kyllä, oletko kokenut Vessapassin hyödylliseksi?

- Kyllä
- En, syy (vapaaehtoinen)

### 21. Palautetta

Halutessasi voit kirjoittaa tähän kehitysideoita kaukoliikenteen toimijoiden palveluiden parantamiseksi tai muuta palautetta.

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