PART III

Social limitations in the everyday life for asthmatic children
A study on the way in which a new asthma centre in Rotterdam can improve this childhood life

Lisa Deighton
Student number: 4011511
E-mail: lisa_d91@live.nl
Msc 3 The architecture of the interior: the healthy environment. Spring 2015
Irene Cieraad Research Seminar AR3Ai 055
21 may 2015
1. Introduction

Asthma is a very common disease in the Netherlands and amongst children the most common one. Over 0.5 million people in the Netherlands suffer from this disease and whereof 119,000 are children. This comes down to 2 to 3 children in each school class, who will have to deal with their asthma on a everyday base. In the larger cities, including Rotterdam, the numbers are even worse, 1 of every 6 children.¹

Not everyone of these children will visit an asthma centre and most of them will go for check-ups to the hospital or visit the general practitioner a few times a year. In addition, most of the asthma centres in the Netherlands are inpatient rehabilitation clinics, where a child will have to stay for a few weeks or even months, such as Heideheuvel in Hilversum. There are some outpatient asthma centres within the Netherlands, but these mostly focus on adults. These inpatient clinics are meant for children (or adults), that suffer from severe and uncontrollable asthma. This means, that only when the medication is not successful and both the asthmatic child and his or her parents can’t control the home situation any longer, the child will be referred to such a centre.²

In other words, the majority of asthmatic children and their families just deal with the possible difficulties of asthma within their everyday life. Several scientific articles acknowledge the significance of these limitations and indicate the need for research on it.

“[...], for example having to be ‘at the back’ and therefore ‘not with my friends’ when walking up a hill in school. One boy said that his friends didn’t understand the way in which he had to limit his participation in football.”³

In order, for my centre, to improve the life of asthmatic children and support them within this struggle, I needed to find out what these limitations are. I especially wondered how this disease

¹ www.longfonds.nl
² www.merem.nl/heideheuvel/
³ Rudestam, Brown, Zarcadoolas & Mansell 2004: 426
⁴ Nichol, Thompson & Shaw 2013: 420
effects the social life of a child. A normal childhood consists of playing with friends, going on imagery adventures, sports, climbing and playing outside, as I found out during my interview with Emma. From this emerged the following research question:

*In which ways can an outpatient asthma centre in Rotterdam improve the everyday life of asthmatic children?*

This question will be answered with the help of two very important sub questions:

*What are the social limitations for children with asthma within their everyday life?*
*What is the relationship between ethnicity and asthma and asthma limitations?*
*What are the qualities and flaws of existing outpatient asthma centres for children?*

To be able to answer these questions, I used different research methods:

1. **Interview**: I’ve interviewed five adults who have had asthma since their childhood. I choose to interview adults, as they are able to reflect on this childhood as well as relating it to their current situations. A child is only able to name their current limitations as for example on the lovely postcards from het Longfonds (former Astmafonds). The results will be compared to one another.

2. **Literature**: In order to place my results from the interviews in a larger framework, I’ve read different articles on social limitations of asthmatic children. As a great amount of the children in Rotterdam have another ethnicity, I wondered if asthma has a different effect on their social lives. Therefore I particularly tried to find articles on this relation between cultural background and asthma.

3. **Case study and observation**: I’ve visited one of the very few outpatient asthma centres that offers treatments for children, Salem in Ermelo. My goal for this visit was to find out the qualities and the flaws of Salem and therefore, which qualities my outpatient asthma centre should possess. Salem is situated in Ermelo and focusses on the region of this village. Children are able to incorporate the treatment easily in their lives as the treatment is only a few times a week and the centre is nearby. I tried to discover the vision of the centre and how they envision it as a part of a child’s life. On a more practical note, I observed the different functions, there placement within the facility and the types of therapies they offer.

In the conclusion I will summarize my findings and relate them to measurements I should implement in my own design. The result of this research should be a clear image of the social limitations asthmatic children encounter in their everyday life, due to their illness, treatment and environmental aspects. These results should lead to a plan of action for the design of the asthma centre, with tools that will improve the user experience.

---

5 This was the interview assignment earlier in this course with a healthy represent of the target group
2. Interviews about the everyday life as a child with asthma

In order to investigate what’s like for a child to deal with asthma in the everyday life, I’ve interviewed five adults who suffered from asthma throughout their childhood. Among these interviewees are friends and relatives of friends. Some of them also suffer from other diseases or allergies such as hay fever or eczema or even certain types of nutrition.

To be able to relate the answers and the stories of the different interviewees to one another, I’ve summarized them with the help of so-called focus points. These points are subjects that kept on reappearing in the conversations and therefore could elucidate the struggles an asthmatic child may have to face. The meaning of each focus point within the everyday life of an asthmatic person, is illustrated by quotes from the different interviews. On some occasions I will relate the findings on these subjects to my own experiences, because I have had to deal with asthma from a young age too.

2.1 Focus point 1: General practitioner and hospital experience

During the interviews I’ve asked them about their experiences, regarding visits to doctors and hospital visits. Most of the interviewees didn’t mind a visit to the general practitioner as it was for a good cause.

“As far as I know I went to the doctor for checks every year. This, I have never experienced as annoying, it was no problem for me to just go there. Eventually, it is for a good cause.”

“I have regularly visited the general practitioner, regarding symptoms as coughing and shortness of breath. However, nothing was done about these symptoms. I didn’t mind visiting the doctor. It was a nice doctor and there were always toys to play with.”
However, a visit to the emergency room or even hospitalization was described as scary and unpleasant. One can imagine that it can be very frightening for a child to undergo many test with different medical equipment in a sterile surrounding. After being hospitalized at a young age, I was truly afraid every time I had to enter that building again for a long time. On a more positive note, reflecting on such experiences, they can also be pleasing afterwards, as Stephanie describes. It can be the moment that the child is diagnosed with asthma and the treatment can start.

“I was hospitalized in 1998, due to a bacterial infection. It was scary at the time, but pleasing afterwards, because at that moment my asthma was diagnosed. From 2004, I had to go to the pulmonologist for checks 3 to 4 times a year. This was unpleasant, because of the many tests.”

2.2 Focus point 2: Parents
To my surprise, I found out that parents are an extremely important subject in the case of to what extend a child is able to live a ‘normal’ life. By ‘normal’ I mean, a life not disturbed by asthma symptoms or related issues. From the interviews, three different ways of parenting when having an asthmatic child, emerged.

First, some parents are simply unaware. They don’t know what asthma is, what the symptoms are of what can trigger an attack. This became clear during my conversation with Machiel.

“My mother didn’t know about asthma, so she waited until she really saw that something was wrong before she took me to the general practitioner. There I got medication, which became my own responsibility.

We always had pets, first a cat and later a dog. But my mom wasn’t aware that these triggered my asthma. [...] I was glad when I could move out and breathe. [...] Unfortunately, she just bought a cat again.”

Sometimes, the contrary is the case. Parents can become (over)protective when their child is diagnosed with asthma. They try to keep their child safe at all times and try to eliminate all potential triggers. For example, by redecorating the entire house with asthma-friendly materials, such as special flooring and bed linen, always having the medication on stand by and avoiding smoke and animals.

“They used special methods to build-up my immune system. For example, washing my chest and back with cold water and then dry them with a warm towel.

In my bedroom, slippery tiles were placed, I got special blankets and a hypoallergenic pillow. I was only allowed to have a poodle, because of its hair. [...] No more smoking in the home and in the car.”
Thirdly, there are parents with a much more rational attitude towards dealing with asthma. They don’t emphasize it and will support you in learning how to deal with it, as exampled by Laura.

“My parents never magnified the disease, so neither did I. My mother always took me outside when I felt cramped inside a store and then said she also noticed the stuffiness in the store.

[...] They have always supported me and were never overprotective. For that matter they have ensured that I have never begun to feel or act as an asthma patient.”

2.3 Focus point 3: Misunderstanding

When I asked the interviewees, in what way they felt obstructed by their asthma as a child, most of them replied that they felt misunderstood by others. For asthma is an invisible disease. A differentiation can be made between the way asthmatic children can feel misunderstood by other children or the way they feel misunderstood by other adults than their parents.

Feeling misunderstood by other children is often related to not be able to keep up with them during gym classes or other activities.

“I felt misunderstood by classmates during gym, as I often had to stand along the side of the hall. They will see you as an exaggerator.”

“I felt ashamed, because I couldn’t keep up with my classmates during gym.”

“I felt indoor pools were uncomfortable, because I found these spaces oppressive. Others couldn’t understand this.”

Misunderstanding by other adults, especially during gym classes, is regularly related to not having proper awareness of what an asthmatic child is and isn’t capable of doing. I know all about this issue, as at some point I stopped participating the gym lessons at school, because I wasn’t allowed to take a pause for breath by the teachers on multiple occasions.

“I was glad, when adults understood my asthma and would take it into account.

For example: every year I had to be certified by a sports doctor. One time I was “rejected” by a young sports doctor; I was not allowed by him to exercise. Luckily my general practitioner disagreed and I was able to sport and participate in competitions again.”
“I often had failing grades, if I did not make a certain distance at tests, such as the Cooper test and the shuttle run. I also fainted once [...] I still received an insufficient grade.”

2.4 **Focus point 4: Contact with other asthmatic children**

Surprisingly, five out of five interviewees didn’t feel the need for knowing or meeting other asthmatic children during their childhood. The comparison with other asthmatic children or the emphasis on having a disease, would only make them feel less and less normal.

“I don’t feel ashamed and I don’t see my asthma as a handicap. [...] I found having asthma not peculiar or annoying. So, for me it did not matter that I didn’t know any other children with asthma.”

“I didn’t know any other children with asthma. I have never felt a need for it. Then I would have start to compare myself with them and maybe I would also behave differently if those children would suffer more from asthma than I do.”

“It could have been nice to know other children with asthma, but it wasn’t really necessary within my childhood. It’s not something that you really talk about, you just deal with it on your own.”

2.5 **Focus point 5a: Sports**

Sports was the most reoccurring subject during the interviews, as for all of the interviewees the biggest limitations in their everyday life were related to this. In particular, it not being able to sport or exercise the way they would have liked to do. Symptoms as shortness of breath, irregular medication and not having enough information are to blame for this. Though, sports can really improve life with asthma, as Jannie stated. Regrettably, a lot of parents are not aware of what’s possible for asthmatic children.

“I had to quit swimming and while cycling I repeatedly needed time to catch my breath.

Now I cycle and I used to row. I’m also thinking about to start swimming again.”

“I have sported as a child and that usually went fine along with the appropriate medication.

I have taken my medication irregular for a while, because I thought it was not necessary. But then I found myself short-winded even after a short cycle.”
As my first report was about designing a garden for asthmatic children, who often also suffer from hay fever, I was curious to find out if asthma had an effect on the amount of time the interviewees spent playing outside. Almost all of them played outside very regularly.

“Being outside was nice most of the time. However, cold or dry air can really trigger my asthma.”

“I used to play outside as much as possible, but with that I did not experience many barriers in my opinion.”

“I was outside a lot, to play. I didn’t find any particular obstacles.”

“As a child, I played a lot outside. Then we played hide and seek or we built huts. In both games, you do not have to run that much.”

“As a child I played a lot outside. In wet weather and fog I was short of breath, and if it was very cold then I had to wear a scarf over my mouth to warm the cold air.”

2.6 Focus point 5b: Playing outside

“I was particularly quickly out of breath often. I played soccer, and that has had a positive impact on my asthma, because by exercising I less rapidly suffered from shortness of breath.”

“I used to dance and I rode horses. In these sports, I barely had problems with my asthma. Especially with gym and especially with running, I was very short-winded and I was light-headed.

I would have liked to have more information about that. I used to think, I would never be able to run. Certainly not for fun.”

“I grew up in a sporting family. I know that others did not sport that often. Even now I often find that parents and pupils are not always aware of what children can and can’t do if you have asthma. [...] Students that sport often have fewer problems with their asthma.”
2.7 Ideas and tips

At the end of each interview I asked them, what they thought an asthma centre should offer and what it should look like if it was up to them. In return I got same great tips and ideas:

- Create awareness at schools (m.b. Jannie)
- Use a lot of ‘happy’ colours (m.b. Berber, Laura, Stephanie and Jannie)
- Offer education for parents (m.b. Machiel, Jannie)
- Treat each child as an individual (m.b. Laura)
- Don’t fill up outdoor spaces with plants and trees, show space to breath (m.b. Stephanie)
- Don’t disadvantage children with hay fever (m.b. Laura)
- Use proper materials and a make use of a climate control system (m.b. Machiel, Jannie)
- An understanding sports instructor (m.b. Jannie)
- Enough space to play indoors and outdoors (m.b. Laura)

“Offer outside play areas with games, for children that mostly play indoors.”

“Offer music lessons: wind instruments are good for asthma patients.”

“It is also important that there is space for personal things as photos, to hang on the wall. Rails, shelves or nails are convenient.”
3. Childhood asthma and cultural background

Many different ethnicities are to be found among children in Rotterdam, as mentioned in my second report.

![Diagram 3.1 Ethnicity children (4-19 years) in Rotterdam]

Ethnicity is, by itself, an important indicator in health, as some of them are known to have higher rates in certain ailments. It has been known, from literature, that the mortality rates of Moroccans are higher, due to among others infections and genetic disorders. In other countries, such as the United States, many research has been done on this relationship between ethnicity and diseases. In particular, the relationship to pulmonary diseases, including asthma. The results of these researches indicate a higher prevalence of asthma among immigrant children than native children and this applies also for the most part to the Netherlands (table 3.2). Often, these researches point towards a difference in social-economic status as a cause for this higher prevalence. Although these differences are not as large in the Netherlands as in many other countries, this status still influences the way in which these ethnic groups handle their asthma.

<table>
<thead>
<tr>
<th></th>
<th>Dutch</th>
<th>Turks</th>
<th>Moroccans</th>
<th>Surinamese</th>
<th>Antilleans</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>25,9</td>
<td>24,9</td>
<td>34,6*</td>
<td>42,9*</td>
<td>34,9*</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>24,0</td>
<td>28,8</td>
<td>36,7*</td>
<td>45,5*</td>
<td>39,4*</td>
</tr>
<tr>
<td>Women</td>
<td>27,7</td>
<td>20,8</td>
<td>32,4</td>
<td>40,8*</td>
<td>30,9</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-4</td>
<td>55,6</td>
<td>67,9</td>
<td>81,3</td>
<td>78,3</td>
<td>49,7</td>
</tr>
<tr>
<td>5-17</td>
<td>36,6</td>
<td>30,1</td>
<td>47,2</td>
<td>43,8</td>
<td>35,4</td>
</tr>
</tbody>
</table>

* p<.05 in comparison to Dutch

**Table 3.2 Prevalence of asthma (R96) per 1000 patients a year**

Likewise, van Dellen mentions this status as a cause for this higher prevalence of asthma, as factors as culture differences, poor housing, lower education and income level of parents can all contribute

---

6 Information in diagram from table in: Gemeente Rotterdam 2014: 4
7 Bouw huis 2002: 11-12
8 Information in table from table in: Zantinge, Devillé & Heijmans 2006: 39
to this. However, she indicates other factors that could be appointed as possible causes of these differences among various ethnicities. Firstly, the social-economic status is closely related to the quality of life, in other words, how children evaluate their lives. Another factor that influences this quality, is the amount in which an asthmatic child has control over his or her asthma (Table 3.3 & 3.4). The lack of control of their asthma can be caused by not consistently taking their medication, not using the right medication or triggers in the living environment, such as woollen blankets. In relation to the proper use of medication, can be stated that is extremely important to incorporate the parents of the child within the treatment, as they have a great influence on the treatment adherence of the child. However, among other ethnicities, the lack of control can also be ascribed to a not sufficient understanding of the Dutch language by the child and/or the parents. Moroccan or Turkish parents, who have difficulties with the language, are less likely to visit the paediatrician. Despite of having poor asthma control, these ethnic children make use of health care services to the same extend as Dutch children.\textsuperscript{9} For a patient or a family to feel in control over asthma, much more is needed than just avoiding triggers. The living conditions should be improved through for example environmental activism and more education should be given and more awareness should be created about asthma. Schools have an important role to play within this, as they should less focus on solely giving health education in a theoretical way and focus more on offering tools for children. With these tools children will be able to make more decisions about their own health and at the same time they will feel empowered. This could even be helpful for non-asthmatic children.\textsuperscript{10}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{diagram3.3.png}
\caption{Diagram 3.3 Asthma control of children per ethnic group (in %)}
\end{figure}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{diagram3.4.png}
\caption{Diagram 3.4 Results of a Paediatric Asthma Quality of Life Questionnaire}\textsuperscript{11}
\end{figure}

In addition, the diagnosis of asthma in children regularly results in anxiety and insecurity with parents, about the symptoms, consequences for the everyday life and the treatment. This is not directly related to the ethnicity, but it can be increased through poor communication between patient and family and the doctor. Stress in both parents and patient in relation to handling asthma can also be assigned to a lack of knowledge.\textsuperscript{12} On top of this, research has shown that all ethnic groups, mentioned in table 3.2, experience less social support than Dutch families. In particular, Moroccan and Turkish families with asthma mentioned a lack of people in their surroundings, who can offer support or understand their difficulties.\textsuperscript{13} Social network and social support are closely related to psychical and psychological health. Therefore improving this feeling of support could lead to an increase in confidence and combined with more knowledge this could lead to better asthma control and less limitations.\textsuperscript{14}

\begin{footnotesize}
\begin{enumerate}
\item Van Dellen 2007: 115-118
\item Rudestam, Brown, Zarcadoolas, & Mansell 2004: 439
\item Both diagrams originate from: Van Dellen 2007: 24, 45
\item Van Dellen 2007: 115-118
\item Zantinge, Devillé & Heijmans 2006: 53-54
\item Rudestam, Brown, Zarcadoolas & Mansell 2004: 426, 439
\end{enumerate}
\end{footnotesize}
4. Treatment centre Salem

Salem is a very small centre in Ermelo, situated in the northwest of the Veluwe. It is surrounded by a very green environment and is one of many other healthcare institutions in this village. This centre is one of the few independent centres that provides an outpatient treatment for asthmatic children. I have visited this centre on the 7th of May, on a very sunny day, in the hope to find out why this centre focusses on outpatient treatment and to find inspiration for my own design. I was met by pulmonary nurse Helene Elema, who gave me a lot of information during our conversation and during the tour she gave me of the centre. This offered me not only an insight in the role such a centre plays in the everyday life of an asthmatic child, but also a lot of practical information about how such a centre functions. The following information is a summary of this conversation.

4.1 History of the centre

The village of Ermelo has always been closely connected to healthcare. Over forty years ago, a paediatrician of the former hospital Salem, doctor Kale, decided to realize a clinic for children with asthmatic or psychosomatic conditions. The clinic was constructed around 1968 in a former doctors house from the late twenties. It was designed as an intern centre, distributed over different pavilions, with a strong focus on movement therapy. Children from all over the Netherlands could get treatment here, if needed. Almost ten years later the centre was closed, due to financial and legal conditions, and the asthma and psychosomatic care was handed over to the hospital Salem. A few years later this hospital, also situated in Ermelo, was incorporated into the larger regional hospital st. Jansdal in Harderwijk. However, this meant that there was no longer place for the movement therapy as given in the centre of Kale. Thanks to motivated parents and a strong management, an independent asthma centre could be established again on the same location. The new centre led a uncertain existence for a long time, up to 1996, and was to the utmost extent voluntary based. This uncertainty originated from the fact that the centre was not recognized as a health care institution. Especially the movement therapy was not seen as a true medical treatment. This lack of acknowledgment resulted in very little revenue. Due to all this uncertainty, a clinical treatment was no longer possible. The centre became an outpatient clinic and the children were treated after school up to three times a week. With the help of a scientific research in Nijmegen on movement therapy and a successful fusion with asthma centre Heideheuvel in Hilversum, Salem finally got its scientific medical support and was able to build on its treatment provision. This resulted in an extension of provision with a treatment programme for adults with asthma and COPD in 1999, which led the number of treatments up to 7500 a year. In 2005 the fusion with Heideheuvel was repealed and the centre became once again part of the hospital st. Jansdal. Recently, the centre was completely remodelled and also provides an oncological aftercare programme called ‘herstel en balans’.  

4.2 Goals of the centre

Healthcare is undergoing major changes which form a significant treat for small treatment centres such as Salem. Asthma centres such as Salem, were founded at a time when there was no proper medication available yet and the importance of exercise was not recognized as it is today. Asthma medication has improved a lot since then and the need for independent centres, like Salem, is up for discussion. The treatments are less and less reimbursed by the insurer and this makes it difficult to maintain these centres. The government is planning on bringing back this asthma treatment to the responsibility of the general practitioner. However, Helene Elema states that this could be a potential disaster. The power of Salem lies not in finding the right medication for asthma patients, but in offering the patient a change of lifestyle. The children as well as the adults are redirected to

---

15 Information is based on the conversation with Helene Elema and some additional information found on: https://archive.is/tbZKa
this centre after they are done with the medicinal treatment. Asthma treatment is more than just finding the right medication, she tells me. Salem makes use of a holistic approach, this means that the patient is treated as a whole. People that solely suffer from asthma, don’t need to be here, they can take care of themselves. So the severeness of the asthma is not the point of measurement in this centre. Often there is more to it, for example after going in and out of the hospital, the internal balance of a patient can be disturbed. These stressful periods or other psychological problems can have a negative outcome on the normal life of an asthmatic patient. One can suffer from asthmatic attacks, even with the right medication, as stress can form a trigger for asthma. Beside psychological problems, many asthmatic patients also suffer from other diseases such as eczema, food allergies or hay fever, which can also form great obstacles in the everyday life. By insufficient knowledge or social pressure related to this, asthma patients continuously cross their own boundaries. This is the point when Salem comes in, and together with the patient (and in the case of children, their parents) we start a treatment to turn the tide.

Salem offers a multidisciplinary approach, from psychologist to dietician, adapted to the individual. If this treatment is brought back to the general practitioner, it would become impossible to achieve the same level of cohesion between the different disciplines as inside such a centre. Every treatment would take place on different days and different locations with the general practitioner as a mediator. Inside Salem, the different disciplines can strengthen each other advices as the different specialist can easily address one another during a coffee break and discuss treatment plans. Another benefit of this multidisciplinary design is that the barriers are lowered for example, going to a psychologist. When asthmatic patients are advised by the hospital to see a psychologist, some of them will respond with: “Why, I’m not crazy!” When they enter Salem, they don’t have a choice as the treatment is offered as an all in one package. Afterwards, the psychological therapy is often highly appreciated by the patients. Later on, Helene mentions another example of lowering the barriers for entering other treatment next to the medicinal one. The treatment within Salem takes about half a year for adults and one year for children. This long duration of treatment scares people off, especially parents. That’s why the centre offers them first a treatment period of 3 months and then extends this treatment after every period up to a year. The child will visit the centre 1 or 2 times a week in this period. Parents are an important issue in the treatment of children. As a child becomes cramped by an asthma attack, it can be very frightening for the parents. If one of the parents starts to panic, it can increase the attack, resulting in a vicious circle. Therefore, it is important to give parents confidence, when it comes to how to deal with an asthmatic child. Both on the asthma clinic inside the hospital and in Salem, parents receive instructions on this subject by a psychologist or a pulmonary nurse. These instructions vary greatly per stage of life. Salem attempts to involve parents as much as possible in the treatment of their child, including through parent-child courses.

4.3 Tour of the centre

At the beginning of the tour Helene tells me that the remodelling of the centre was designed by an architect, who had never designed a sport facility before. Ermelo has always been a care village. Around the care park, where Salem is located, are also other health care facilities situated, such as a dental clinic and a hospice. The ground is managed by a foundation that has determined that only care functions should be built on this location. Hereby, one architect is designated to design these different care facilities, namely D.J. Veen. However, the centre Salem consist largely of sport functions and as a result, many things needed to be adapted after the completion of the remodelling. She showed me some examples of the changes later on in the tour.

First, Helene shows me the part where the professionals have their room. These rooms are situated on the ground floor of the former doctors house. In between these rooms, an instruction room is situated with a beamer. This space is used a lot, because it is multifunctional and can be used for meetings as well as courses. It is even rented out for meetings of other organizations. In the hallway
Pictures of the tour (o.i.), (f.l.t.r.):
1. Hallway with examination rooms
2. Staff meeting room
3. Staff changing room
4. Sofa in the hallway that functions as waiting area
5. Examination room of the pulmonary doctor with the child friendly logo of the centre, a giraffe
6. Other side of the examination room of the pulmonary doctor
7. Kitchen next to the coffee corner
stands a sofa. Proudly, Helene tells me that she has put it there, as it used to be an empty spot. The sofa would be thrown out first, but now that she has put it in the hallway, it functions as a small waiting room. A benefit of this is, that the professionals have a clear overview of the patient that are waiting for them. The staffrooms are on the first floor, consisting out of two meeting rooms (one for the professionals addressing the adults and one for children), a changing room, toilets and a small kitchen. The meeting rooms were multifunctional as well, as the professionals have little workspaces within these rooms. Walking through the building, I began to wonder where all the equipment was. Helene explained that every medical test takes place in the hospital and not inside Salem. Salem offers the patient a positive experience, while adapting a new improved lifestyle. Therefore it is very important that the building exudes a different atmosphere than a hospital. The centre is decorated with soft colours and is very light. Helene contributes to this in her own way. Although it is mandatory to wear white clothes within the centre, as it is a part of the hospital st. Jansdal, she refuses to do this. A visit to this centre should feel informal and a clinical white outfit does not contribute to that, she explains. There are some uniforms, for example for the sport therapists, but these are blue and look like sport outfits. This centre is truly experienced differently than a hospital environment. Many patients and especially children say that the centre feels like a large holiday house.

When we walk towards the entrance, she tells me that she really likes this space. The reception is centrally located and the receptionist has a clear overview of different rooms. All therapy sessions take place in groups. So it is convenient that the hall is spacious, when they go outside as a group. Across the reception, there is a small coffee corner, that also functions as a waiting room, with a kitchen next to it. This waiting room is unfortunately not that clearly visible for the professionals. From the entrance, a wide hallway with glass on the left side leads to the sport section of the centre. On the left of this hallway lies the outdoor pool and on the right are the other sport functions situated. On one side of the hallways hangs an artwork with pictures of the professionals, which is made from a part of an old window of the former doctors house, that functions as a ‘smoelenboek’ for the patients. According to Helene, this part of the building has been subject to many changes after the remodelling. Here, it became visible that the architect did not have much knowledge of asthma or these kind of centres. For example, only the first part of the hallway used to be closed off. The second part was opened to the outside. This meant that the patients, while wet from the pool, had to walk a long way through the outside air to the toilet. These patients are very vulnerable and can quickly catch a cold, so this open hallway just wouldn’t work. The second idea was to fill up this part by making the changing rooms larger. Helene tells me, that she strongly opposed to that idea and suggested to just close the hallway. This way, the hallway is very practical and offers clarity to both patient and professional. The patient now only have to take a short walk to the changing rooms. I asked her why they had chosen for an outside pool. She explains that a great advantage of an outside pool is that the chlorine vapour disappears. This vapour normally can cause distress for asthmatic patients in an inside pool. The pool is heated up to 32 degrees Celsius and when it’s colder than 15 degrees outside, the patients wear bathing caps. This way they won’t catch a cold. After every therapy group, the pool is covered with a cloth and the different values, such as chlorine, are gauged 2 or 3 times a day. Salem rents out this pool also to other physiotherapists.

A short note: During my visit, I could really see the profit of this pool within the therapy. There was this woman, floating around the pool in the sunshine, and she seemed so completely relaxed. As stress can be a trigger for asthma, I can very well imagine that this kind of relaxation can have a positive impact within dealing with asthma in the everyday life.

Across from the pool, 2 dry and 2 wet changing rooms are situated between two hallways. One hallway leads from the pool, alongside the changing rooms, to the showers and the other hallway leads to the sports hall and the fitness room. These hallways should be wider, Helene states, as there
Pictures of the tour (o.i.), (f.l.t.r.):
8. Coffee corner at the entrance
9. Spacious hall
10. Corner with information leaflets
11. Hallway next to the pool
12. End of the hallway with lockers and doors to the changing rooms
13. Small canopy at the side of the pool
14. View on the pool from the hallway. The artwork functions as a ‘smoelenboek’ of the professionals
Pictures of the tour (o.i.), (f.l.t.r.):
15. Hallway leading to the fitness and sports hall
16. Covered windows in one of the hallways
17. Sound plates on the walls and ceiling in the sports hall
18. The sports hall
19. Storage of sports supply
20. Examination room of the physiotherapist next to the sports hall
should be enough space for a stretcher. Besides that, the privacy of the patients should have been taken into greater consideration. Although the centre is situated in a quiet and wooded area, large windows still will make the patients feel like they’re being watched by passers. That’s why some parts of the windows are covered with translucent material.

The sports hall is the second place, were the design of the architect does not fully comply. Helene shows me the sound plates that they have put on the walls and ceiling, in order to improve the acoustics and make the instructors understandably. Also, the space is difficult to keep dust free, due to the small windows, the many edges and the beams. In addition, the ventilation is not optimal and forms a difficult subject in the design of an asthma centre. Patients cannot tolerate air-conditioning and openable windows are easier to burgle and can lead to draft. In the ideal situation there would be a climate control system, but for now they have just put in some air vents. One positive aspect of the sports hall, is the examination room for the physiotherapist that is located next to it. This way the physiotherapist can first discuss the treatment with the patient before executing it in the hall. However, the room is very cramped and there is no window. Helene would also like to add blinds to the sport hall, as the hall can become very hot, especially during the summer. The sport hall is also used for other kinds of therapy than sports, such as psychosomatic therapy. In this kind of therapy it is not necessarily about moving, but about the way you move and how this can illustrate psychological issues. The fitness room, next to the sport hall, deals with similar problems as the sports hall. This room gets even more cramped as it is smaller. Children start the fitness treatment from 12 years old.

4.4 Tour of the care park
Salem shares a care park with some other medical institutions. When we enter the park, Helene point to some buildings in the back and explains that that used to be the barracks, where the children slept in the asthma centre of dr. Kale. Nowadays, people with disabilities live in them and they maintain the park. There is not a lot of playground equipment, only one set for children and one for adults. Next to this equipment, there is a storage for stuff to play outside and a small sport multifunctional court. The park is very green, with lots of trees and even flowers. Surprised, I ask Helene how this park could function for asthmatic children, as many of them also suffer from hay fever. She explains that an important goal of the centre is to learn patient to cope with the conditions as they are. In the end, every child needs to go back to their everyday living environment, so why put them in a glass bubble. You can create a perfect world for asthmatic children and their asthma will improve, but if they don’t learn to cope with ‘normal’ circumstances they will be back in the centre in no time. This is also one of the reasons why this is an outpatient centre. The adults visit the centre in the morning and the children after school. They learn to anticipate on circumstances and to stand up for themselves. If many pollen are in the air, the children will just stay inside. Of course, it would be clever to avoid the use of plants that are known for their pollen distribution, such as a birch. On any other occasion the centre really tries to motivate the children to go outside. An example, umbrellas are available at the reception, so if it rains, everyone can borrow one. For the patients, it is nice that they can come here and go home afterwards, but there are always exceptions to this approach. Sometimes it is necessary to take a child out of the situation or vicious circle. These are the more extreme cases, such as one girl who suffered strongly from eczema and had difficulties with drugs, related to the family atmosphere. In such cases, the patient should be put in a stimulus-free environment.

The park often forms a part of the therapies. The long pathways are used for running or Nordic walking and the little hill is used for the children to run up and down. It can also function as a place for relaxation, as many of the employees of the different care institutions have lunch here.

4.5 Comments and possible improvements
At the end of the tour I asked Helene what her thoughts were about this centre, what improvements
Pictures of the care park (o.i.), (f.i.t.r.):
21. Playground equipment
22. Pathway from the centre towards the park
23. View on the care park
24. Small sports court in the park
25. Grass hill
26. View on the centre from the park
27. View on the entrance from outside: on the left the former doctors house and on the right the new part of the building
she would like to made and if she had any tips for me.

Children are referred to this centre by st. Jansdal and therefore the centre focusses on the same region as the hospital. Per half day, 40 patients visit the centre. It is one of the few centres that also focuses on the treatment of children. The centre is multi-usable and is suitable for any chronic disease, such as heart and lung diseases or diabetes. It is also very suitable for the treatment of obesity as it focuses on a change in lifestyle. It illustrates and educates the importance of exercise and proper nutrition to the patient. The centre teaches how to avoid triggers in the everyday life, as simple as that, in combination with a change in behaviour. Many people are simply stubborn. By starting the treatments at a young age, many problems in the future can be avoided. Think of the impending obesity epidemic. In March, the centre had a successful obesity programme, but it was stopped because it became too expensive for the centre. Hence, the problem in this case is not so much the target groups, but the costs. This kind of care is less accessible as it is less compensated by the insurer. To make such a centre profitable, it should become more commercial and focus even more on shared use. This means that the centre should be larger, for example an extra sports hall, and that is should be possible to rent out different parts of the building by the use of separate locks. This also offers more privacy for the different institutions that will make use of such a building. The building is highly appreciated by the different visitors, due to its warm atmosphere, Helene tells me. Even employees from the hospital come here for their work meetings, to get away from the hospital environment.

Helene states that, the treatment of lung diseases like asthma still remains difficult, as the diseases are invisible. In the everyday life, many patients try to keep their difficulties to themselves or stay at home, when they are not feeling well. Mostly, because they feel misunderstood. The experience of feeling cramped or having an asthma attack is very difficult to explain to another person. This is also why within Salem the patient are treated in groups. In groups they learn to talk about the difficulties they face in their social lives and learn how to stand up for themselves. Among their companions, the patient dare to admit the things, with which they struggle. For children, the therapy is also based on this psychological factor. Through games they learn to identify their emotions and to articulate what they are feeling. This playfulness is a better method than just telling them a story. They learn what air is and what lungs are by placing a little block on their chest or blowing away a feather through a straw. Parents are strongly involved and participate in these exercises as well. Another example of improving the notion of lung diseases, are the so-called Long Punten, organised by volunteers of het Longfonds. One of these events was held inside Salem. Such a lung point consists of workshops, education and movies about lung diseases. Everybody is welcome and patients can bring other people to take part in these activities. When someone, without for example asthma, participates I an activity such as moving while breathing through a straw, then it will hit them and he or she will start to comprehend what such a disease entails. To generate a greater understanding of children with asthma, het Longfonds (then Astmafonds), launched the ‘Luchtbus’ in 2001. Any school could hire this bus and inside the bus children could climb through parts of the lung, such as wind pipes, and experience the way asthmatic children breathe by breathing through a straw. Unfortunately she says, this bus no longer exists.
5. Conclusion and points of action

By answering the sub questions, that were formulated at the beginning of this report, the findings will be summarized and conclusions will be drawn from this information. Subsequently, the main research question will be answered by relating these conclusion to my design project. From this, points of action will be drawn, that need to be implemented within my design in order for my asthma centre to be successful.

5.1 What are the social limitations for children with asthma within their everyday life?

The interviews resulted in 5 focus points, that all point toward a different subjects on which the interviewees experienced obstacles related to asthma within their everyday life as a child.

Focus point 1: General practitioner and hospital experience
Hospital and emergency room experiences are more likely to be traumatising than regular visits to the G.P., due to the many tests with different medical equipment a child will have to undergo in these facilities.

Focus point 2: Parents
Parents are a very important topic in the everyday life of an asthmatic child. The way parents deal with the asthma of their child, influences largely how the child not only copes with asthma, but also affects the way they perceive their asthma as a handicap. Three types can be distinguished:
- Unaware parents, are unaware due to lack of knowledge of asthma.
- (Over) protective parents, making the environment as trigger free as possible. Could result in overprotectiveness by fear of something happening to the child.
- Rational parents, they don’t emphasize the disease and try to support the child in their own responsibility to deal with the disease.

Focus point 3: Misunderstanding
Misunderstanding is mostly related to the school environment, especially gymnastics (While this could form an important part of the treatment).
- The feeling of being misunderstood by other children, arises from not being able to keep up with friends or classmates during activities, such as sports.
- Misunderstanding by other adults, especially during gym classes, is regularly related to not having proper awareness of what an asthmatic child is and isn’t capable of doing.

Focus point 4: Contact with other asthmatic children
There is no real need to meet other asthmatic children, as it could emphasize the disease, instead of let children feel normal.

Focus point 5a: sports
Most of the social limitations are related to not being able to sport or participate at gym at school in the way they would like to. This is caused by asthmatic symptoms, such as shortness of breath and lack of knowledge of what they can and can’t do.

Focus point 5b: playing outside
Most asthmatic children, as seems from the interviews, like to be and play outside (if the weather is not to disturbing). Inside areas such as an indoor pool or shops are experienced as oppressive.

5.2 What is the relationship between ethnicity and asthma and asthma limitations?
Asthma has a higher prevalence among children from other ethnicities and these children also experience their asthma as more limiting. This can be subscribe to different causes:
- Socio-economic status of the child and family: culture differences, poor housing, lower education and income level of parents
- Less asthma control, due to triggers in the environment and lack of treatment adherence.
- Lack of knowledge, due to not sufficient understanding of the Dutch language by child and/or parents
- This not properly understanding can lead to an increase of insecurity in parents.
- Not enough social support for both child as parents.

Elements on a large scale that could decrease these limitations are: better living conditions, education and creating awareness about asthma and empowerment of children according to handling their own health.

5.3 What are the qualities and flaws of existing outpatient asthma centres for children?

The answer on this question is based on my observations at the treatment centre Salem in Ermelo and my conversations with Helene Elema, a pulmonary nurse at this centre.

Qualities:
- Children aren’t pulled out of their normal living environment, but can go home after every treatment session.
- Focus on region, rather than the whole country.
- Offering a change in lifestyle, rather than just treatments based on finding the proper medication. Learning a child how to deal with everyday circumstances.
- Multidisciplinary approach: the different disciplines strengthen each other advices and boundaries for a visit for example at the psychologist are lowered.
- Parents are involved through parent-child courses.
- Offering knowledge to children and parents in a playful way, by games.
- Shared use, by renting out rooms and parts of the centre when they’re not needed, as asthma treatments are only 1 or 2 times a week.
- The usual negative healthcare experience is prevented, as all medical test and examinations take place at the hospital and not inside the centre.
- A warm atmosphere, very different from the clinical hospital environment: warm, soft colours, lots of light, spacious and no doctor uniforms.
- Both active as relaxing functions as part of treatments: outdoor pool, sports and park.
- Offering a safe environment to explore personal boundaries in relation to sport.
- Centres are suitable for treatments of other chronic diseases.
- Offering as space for sharing experiences in a subtle way in the form of group treatments.
- Creating awareness and spreading knowledge through events such as Long Punten.

Flaws:
- The architect has not always taken in account the needs of the patients: the need for remodelling the pool part, placing sound plates, need for better climate control.
- The architect has not always taken in account the privacy of the patients: large windows, that needed to be covered.
- The small scale: This kind of care is less accessible as it is less compensated by the insurer. To make such a centre profitable, it should become more commercial and focus even more on shared use.

5.4 Points of action: In which ways can an outpatient asthma centre in Rotterdam improve the everyday life of asthmatic children?

This answer can be seen as a checklist for my design and is based on the previous conclusions of all
three sub questions.

1. Spread knowledge and create awareness
   - My design should offer room for education. This doesn’t mean that it should necessarily be a classroom. Teaching children about their asthma should be playful, as in Salem, and take place in a sports hall, in a kitchen setting to learn about nutrition or maybe even a place in a garden (vegetable gardens for example).
   - Not only the children, but also the parents are in need for more knowledge. They can participate in the playful learning activities as mentioned before.
   - Besides that, I want to offer these parents a place to meet other parents of asthmatic children, as I found out that other ethnicities experience a lack of social support. A fixed Long Punt, designed as a living room or cozy coffee house, could offer this place. In contrast to the Long Punten, organized by het Longfonds, that are events that take place on a different location each time they are held. Especially Moroccan and Turkish parents have difficulties with the language and in this way they can meet other Moroccan or Turkish parents and share experiences and learn from each other (at the same time building a social support system).
   - This insufficient understanding of the language forms a great obstacles within coping with asthma for children and parents of other ethnicities. Therefore, the education should not solely focus on a proper lifestyle with asthma, but the centre should also offer language lessons and an interpreter during therapies. Next to this, in the evening some rooms can be rented out for language lessons not related to asthma.
   - It is important for the professionals in this centre to have some cultural knowledge about the many different ethnicities in Rotterdam. So even the professionals should participate in courses, which could be about norms and values in different countries.
   - Asthmatic children are in need for more awareness at schools and in particular amongst gym teachers. Therefore, my centre should offer educational courses for them, about what asthma is and what an asthmatic child can and can’t do.
   - Awareness amongst children can be created in a much more fun way. A function of my centre should be an Asthma Experience Centre. This is similar to the Luchtbus, mentioned by Helene, that went by different schools. However, this centre will have a fixed placed and can best be compared to Corpus, as a travel through the human body, but with a strong focus on asthma. It should be a separate building from the actually asthma centre, to make it easily accessible and should function on its own. At the same time this could offer a great place for school trips.16
   - To be able to spread knowledge, a library would be perfect. This library should not only offer books and information regarding asthma, but this information should be available in different languages. This way the children and parents of different ethnicities can educate themselves and this could possibly take away parts of their stress and anxiety about the life of a child with asthma.

2. Offer a positive experience
   - The centre should offer a positive experience to the children, by keeping the tests and medical equipment inside the hospitals and offer outpatient treatment. This way the centre could easily become a part of their everyday life.
   - The centre should not look like an institution, but should make you feel as you can walk around freely through it.

16 Showing other children what it’s like to have asthma, was also mentioned by Wessel Steenhuis as a tip for my design, during the presentations on 29 April 2015.
- The centre should exude light and space, as a true space where these children feel like they can breathe. It should be decorated with happy and warm colours.
- Offer room for personalization, make them feel at home. This could be walls where children can hang pictures of drawings for example.
- The centre should be practical and clear designed. The entrance should be clearly visible and spacious.

3. Treat the whole family not just the child
   - As mentioned before, the parents are a great influence on the way a child copes with asthma and should therefore also participate in the different courses a child will attend. This will also give the child a feeling of safety, to have his/her parents with him/her

4. Offer a change in lifestyle in a safe environment
   - Offer a multidisciplinary approach: the asthma will be addressed from different disciplines, with can strengthen one another mutually.
   - Teach the children how to avoid triggers, how to handle their emotions and the importance of the right nutrition. Teach the children how to sport and be active with asthma.
   - Not only the sports hall, but the whole centre should feel as a safe place and offer the asthmatic children an environment in which they can discover what their limitations are. If something would go wrong, professionals and the Erasmus MC are always nearby.

5. Let the children feel as normal as possible
   - Keep the connection with ‘healthy’ children: renting out certain facilities as the sports hall to the nearby schools, the Asthma Experience Centre and involving non-asthmatic children as well in information meetings.
   - Don’t emphasize the disease, as this would make the children feel less normal. Call treatment spaces differently: wellness or sport club

6. Offer both active and relaxing indoor and outdoor spaces
   - Combine sports with the outdoors: outside sport courts, long paths for running, a hill for climbing and an outdoor pool.
   - Make playgrounds interesting and challenging to activate the children naturally.
   - Offer different activities for children that are not used to play outside or sport on a daily base, such as (outdoor) board games, music lessons or just places to sit, relax and read a book.
   - Don’t fill up the squares or gardens with plants and trees, show (literally) space to breath.

7. Commercialize and share use
   - The centre should consist out of multiple smaller buildings, this way parts of the centre can be easily rent out to schools or for meetings by staff from the nearby Erasmus MC. At the same time every part can be individually be closed off by different keys, which makes the centre safer and guarantees privacy of the different user groups.
   - The insures are less and less willing to compensate these centres. In order to make the centre accessible for as many asthmatic children as possible in the surroundings of Rotterdam, the centre should become more profitable than Salem. This can be accomplished by the Asthma Experience Centre, renting out different facilities as the sports hall and the fitness and the implementation of a restaurant.
   - On top of these functions, the centre could offer small vacation homes especially adapted for asthmatic patients, as the centre is located on a very nice location, nearby the museum park. This can be compared to the Ronald Mc Donald House on top of Groot Klimmendaal.¹⁷

¹⁷ Groot Klimmendaal is a rehabilitation centre in Arnhem www.kinderfonds.nl
6. References

6.1 Literature

Bouwhuis, C.  

Gemeente Rotterdam  

Nichol, J., Thompson, E. & A. Shaw  

Rudestam, K., Brown, P., Zarcadoolas, C. & C. Mansell  

Van Dellen, Q.  
2007 *Asthma care in children from different ethnic origins: A study among children from Moroccan, Turkish, Surinamese and Dutch origin with asthma living in Amsterdam, the Netherlands* (Doctoral dissertation). Amsterdam: University of Amsterdam.

Zantinge, E., Devillé, W. & M. Heijmans  
2006 *Allochtonen met astma, COPD of hooikoorts in Nederland: wat is er bekend?* Utrecht: Nivel

6.2 Internet sources

https://archive.is/tbZKa (12-5-2015)
https://www.longfonds.nl/astma/alles-over-astma/wat-is-astma (26-4-2015)

6.3 Illustrations

Page 2:  
Fig. 1 https://www.facebook.com/longfonds/photos_stream (28-4-2015)

Page 3-8:  
Symbol of a person adapted version of original from: http://iconmonstr.com/user-icon/ (28-4-2015)

Page 8:  
Fig. 1 https://www.pinterest.com/larsboom/cura%C3%A7ao/ (28-4-2015)  
Fig. 2 https://www.pinterest.com/ldebel/kosteloos-materiaal/ (28-4-2015)  
Fig. 3 http://www.muzieklesdeventer.nl/ (28-4-2015)
Page 13:
Fig. 1-7 Own illustration

Page 15:
Fig. 1-7 Own illustration

Page 16:
Fig. 1-6 Own illustration

Page 18:
Fig. 1-7 Own illustration

Page 19:
Fig. 1-3 http://www.brabantscentrum.nl/oud_archief_2003/nieuws/0323_astmabus.htm (16-5-2015)