An asthma self-management app

Master Thesis

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Design for Interaction
Ademgenoot
Asthma self-management app
by Jasmijn de Beer

To obtain the degree of Master of Science in Industrial Design Engineering - Design for Interaction with the Medisign specialisation at the Delft University of Technology, to be defended publicly on Friday July 12 2019, at 10:45.

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Preface

Change is often difficult and can make people feel insecure. I believe that products and services are needed to guide and support people in this. The end result of this graduation project supports my vision to empower people in difficult changes and to turn their insecurities into confidence again, thereby making them happier and healthier in their social environment.

In front of you is the final deliverable of my graduation project for the Design for Interaction master’s program at Delft University of Technology. This five-month project was done in collaboration with the Leids University Medical Centre, the National eHealth Living Lab and the pharmaceutical company AstraZeneca.

This graduation project, including its combination of a user-centred approach with a medical and design engineering perspective, comprises the final chapter of my career as a student at TU Delft. This thesis describes the research I carried out to explore possibilities for electronic health (eHealth) interventions to motivate asthma patients to follow their prescribed medication treatment. I found it challenging to design for this topic, since I could emphasize with the users reluctance of taking medication daily. However, this also made it very interesting! Throughout this project, I have become an expert in the topic of asthma self-management in a short amount of time and gained new knowledge on the challenge of motivating people to change their behaviour. In addition, this project has shown me the rewarding nature of eHealth.

I want to express my gratitude to everyone that supported me over the past months – firstly, to Valentijn Visch and Lyè Goto, who supervised the project. Valentijn, I want to thank you for your pleasant and positive feedback and for keeping me focused when needed. I have learned much from you regarding persuasive game design, and after every meeting, I felt inspired to start implementing your advice in practice. Lyè, thank you for offering a listening ear and your advice. I always felt comfortable during our meetings, and I could talk to you about the different facets of the graduate-student life, including its peaks and valleys.

In addition, I want to thank both my coaches from my graduation internship: Astrid Bontenbal and Charlotte Poot. Astrid, I enjoyed our collaboration a lot; our sessions helped me find a focus during the start of my project. Charlotte, thank you for your enthusiasm and for believing in me. I could always go to you with questions, and you were immediately ready. I really appreciate this!

I offer a special thanks to all people who participated in the interviews and in the different user tests of this project. I could not have done this project without them. Lastly, I would like to express my gratitude to my family and friends for supporting me each in their own way during this project!

Jasmijn de Boer
July, 2019
Summary

Asthma is a chronic disease and is characterized by inflammations of the airways. Since there is no cure available yet, asthma treatment is aimed at asthma control, to minimize patients’ symptom experiences and to prevent patients of having exacerbations (lung attacks). A key driver in this is the extent to which patients adhere to their prescribed medication treatment, also called ‘medication adherence’. It has been found that one third of Dutch asthma patients show poor adherence to their treatment.

The client of this project, the pharmaceutical company AstraZeneca, has developed a smart inhaler in combination with an application. This technology makes it possible to measure medication adherence and present the adherence data to patients and healthcare providers. However, if the motivation of patients remains low to take their medication as prescribed, such interventions will likely not succeed because patients may ignore the reminders sent. Therefore, the aim of this graduation project is to develop a proof of concept for a self-management eHealth intervention that motivates patients to adhere to their medication treatment.

This thesis describes the development of Ademgenoot, an asthma self-management application connected to a smart inhaler. Ademgenoot uses narrative game-elements to motivate asthma patients to adhere to their prescribed medication treatment. In this, Ademgenoot focuses on the positive outcomes of taking the daily maintenance medication. Moreover, the application gives the patients the opportunity to try-out the daily intake of the medication, by offering them a six weeks challenge linked to a personal goal. During this period Ademgenoot visualizes the process of the medication intake in a playful way to make the effect of the medication visible and to prevent disengagement. At the end of the challenge, patients should have gained insights on the effect of the intake of the daily medication and their improved symptom control within their daily lives.

The design process from investigating the user’s needs and values to various idea directions towards the final design will be discussed. In addition, this thesis includes the different research that was conducted to gain a better understanding behind patients’ motives to not follow their treatment, the conducted research on the difficult step of motivating people to change their behaviour and the different user tests that were set up.

A WhatsApp prototype was built to test the concept of Ademgenoot in practice. Patients received screens responding to their medication use for a couple of days via WhatsApp. The end user test delivered the proof of principle that the concept of Ademgenoot has the ability to motivate patients to adhere to their prescribed treatment. In addition, participants expressed to be enthusiastic about the concept and stated that they would like to use the application in their daily life. A positive side-effect appeared to be that some participants mentioned that it would help in the creation of a habit.

Follow-up studies are recommended on finding additional ways to track the development of the patients’ daily wellbeing within the application. This and other recommendations are presented in the final part of this thesis.
In the introduction, the topic of the graduation thesis and the collaboration partners, Leids University Medical Centre (LUMC), the National eHealth Living Lab and AstraZeneca, are introduced. In addition, the problem statement and project approach are shortly discussed. Finally, a schematic overview of the different chapters and discussed topics of the project are provided.
This graduation assignment was founded on a research collaboration between the Leids University Medical Centre (LUMC), the National eHealth Living Lab and the pharmaceutical company AstraZeneca. AstraZeneca is currently evaluating the effectiveness of their ‘smart inhaler’, the Turbu+. A user-centred design research Meer Grip op Astma, is executed at the LUMC and NeLL, which investigates the needs and wishes of asthma patients regarding this technology and to find opportunities how this technology could be implemented to improve self-management among asthma patients. In this regard, this graduation project was born.

Introduction to the project
This assignment revolves around asthma. Asthma is characterized by chronic inflammation of the airways. Since there is no cure available yet, the goal of the treatment is to control the disease to enable patients to live as active and healthy a life as possible with as few symptomatic experiences and exacerbations (lung attacks). A key driver in this is the extent to which patients adhere to their prescribed medication treatment, also called ‘medication adherence’. The two main types of medication used to treat asthma are the reliever medication (often a blue-coloured inhaler) and the maintenance medication (often a red coloured inhaler). The reliever medication, which is used when patients experience asthma symptoms opens the airways within minutes, but it does not treat the cause of the patients’ asthma symptoms. Therefore, patients should also take the maintenance medication (anti-inflammatory drugs), which treats the inflammation of the airways. Treating the inflammation results in less symptoms experiences and lung attacks, and therefore also the reliever medication is less needed. The maintenance medication, Figure 1 shows the aimed for results of the daily medication intake.

Research shows that poor adherence is a problem for one third of Dutch asthma patients (Waverijn, Spreeuwenberg & Heijmans, 2014). Poor adherence can arise from patients’ unintentional and intentional motives. Unintentional nonadherence follows from patients’ lack of skill in incorporating the treatment in their daily life. For example, patients sometimes forget to take their medication or fail to understand the instructions given by the healthcare providers (HCPs). On the other hand, patients may decide to not follow their treatment because of personal motivations and beliefs. For those patients, the disadvantages (e.g. taking medication every day) outweigh the advantages (e.g. less symptom experiences). In addition, they seek to balance their perceived necessity and concerns, resulting in minimising their use of prescribed medicines (Horne, 2006).

AstraZeneca has developed a ‘smart inhaler’ and an accompanying Turbu+ programme, enabling real-time monitoring of medication adherence. In this programme, the Symbicort inhaler (anti-inflammatory drugs), developed by AstraZeneca, uses Bluetooth to automatically detect (from remote sensors) inhaler use. That data is sent to users’ phones to support them in adhering to their prescribed treatment. The app saves and shows the users’ medication intake, provides the ability to log triggers and symptoms and provides medication reminders. Via an online portal, HCPs also can access that inhaler is prescribed to be the Symbicort inhaler with the provided application. This research should shed light on possible design directions that are important to take into account regarding the implantation of the Turbu+. This graduation project will focus on the intentional nonadherent patients and how an eHealth intervention could motivate them to uptake their daily treatment.

Figure 1. Why patients should use their daily maintenance medication

From a healthcare professional’s perspective
Patients need daily maintenance medication
The maintenance medication reduces the inflammation in the airways
Patients are better protected and experience less symptoms
They are less in need for their reliever medication

1/3 of Dutch asthma patients do not follow their treatment as prescribed
Project approach

The project consisted of four phases inspired by the Design Council’s (2005) ‘Double Diamond Design process’: ‘Discover’, ‘Define’, ‘Design’ (rather: ‘Define’) and ‘Deliver’ (see Figure 3).

In order to create a meaningful and implementable design for the user’s daily context, the user was placed in the centre of this design process. Experts’ perspectives and patients’ experiences and needs were integrated throughout the whole design process.

Therefore, the aim of this graduation project is to develop a proof of concept for an asthma self-management eHealth intervention that motivates patients to adhere to their medication treatment. Thus, this thesis focuses on the motives behind nonadherence, the possibility of guiding patients’ behaviour towards the desired behaviour and the possibility of design increasing patients’ motivation to follow their treatment as prescribed.

Problem Statement

eHealth-based design solutions, such as a smart inhaler with an accompanying patient support programme, offer the opportunity to deliver tailored self-management interventions and to improve adherence to treatment. However, if the motivation of patients remains low to take their medication as prescribed, such interventions will likely not succeed because patients may just ignore the reminders sent.

Therefore, the aim of this graduation project is to develop a proof of concept for an asthma self-management eHealth intervention that motivates patients to adhere to their medication treatment. Thus, this thesis focuses on the motives behind nonadherence, the possibility of guiding patients’ behaviour towards the desired behaviour and the possibility of design increasing patients’ motivation to follow their treatment as prescribed.

Research Questions

How can an eHealth intervention motivate asthma patients to adhere to their prescribed treatment?

a. What is the impact of asthma on a person’s life?

b. What are the motives behind medication nonadherence?

c. How can behaviour be guided towards the desired behaviour by including the patient’s needs and values?

d. How can design contribute to motivate patients to adhere to their treatment?

e. Is the designed intervention able to motivate patients to be adherent to their treatment?

Figure 4 shows how those questions are integrated in the project structure.
Introduction to asthma

A literature is performed to understand the meaning of living with asthma in order to create a feasible design. The first step was to understand what asthma is, what the impact of asthma is on a person’s life and how asthma is treated. Furthermore, an introduction is given to asthma self-management and eHealth.

In this chapter

2.1 Asthma characteristics
2.2 Asthma treatment
2.2.1 Treatment and goals
2.2.2 Treatment and medication
2.3 Asthma self-management
2.3.1 Self-management and daily life
2.3.2 Self-management and eHealth

Chapter 2: Introduction to asthma

What is the impact of asthma on a person’s life?

Chapter 3: Medication nonadherence

What are the motives behind medication nonadherence?

Chapter 4: Opportunities for design

How can behaviour be guided towards the desired behaviour by including the patient’s needs and values?

Chapter 5: Creation of design

How can design contribute to motivate patients to adhere to their treatment?

Chapter 6: Evaluation

Is the designed intervention able to motivate patients to be adherent to their treatment?
2.2 Asthma treatment

2.2.1 Treatment & Goal

Because asthma is not curable, treatment is aimed at minimizing symptoms and preventing exacerbations to enable patients to live an active and normal life. In other words, asthma symptoms should not negatively influence patients' activities.

The main goal of treatment is asthma control, which describes the degree to which the goals of therapy are met and which includes the relation between patients' current control of symptoms and the future risk of exacerbations (Global Strategy for Asthma Management and Prevention, 2018). Patients therefore should be able to keep their symptoms under control with medication and avoid triggers when possible.

Asthma control is incorporated into any definition of asthma severity, a term which describes the intrinsic intensity of the disease processes. The severity of a person's asthma is ideally determined before initiating therapy in order to assess the level of medication treatment required to control symptoms and exacerbations. In order to do so, HCPs ask patients questions about their symptoms. Furthermore, such a diagnosis includes a physical exam, and patients often take a lung function test to detect how well they exhale air from the lungs (Figure 6). The classifications for asthma severity are intermittent, mild persistent, moderate persistent and severe persistent.

A common misconception is that controlled asthma is equal to mild asthma and that uncontrolled asthma equates to severe asthma. However, it is important to distinguish between asthma control and asthma severity, since uncontrolled asthma is more common for persistent symptoms and exacerbations and may be easily improved (Cockcroft, 1996). That is to say, patients with poorly controlled asthma, regularly experience exacerbations, may be easy to treat with small amounts of daily maintenance medication. This project therefore focuses only on asthma control. The types of medication used to treat asthma are described in the next section.

2.1 Asthma characteristics

Around 300 million people of all ages are affected with asthma worldwide. This number is expected to reach 400 million by 2025 (Braido, 2013). In the Netherlands, 641,000 people have asthma (Volksgezondheid en zorg, 2017), and it is the most common chronic disease among children. While research has demonstrated that asthma is a result of heredity and environmental factors, how those factors interact with each other and how they are associated with the development of asthma is not fully understood.

Asthma is a chronic disease

Asthma is a long-term lung condition characterized by chronic inflammation of the airways – that is, the inside walls of the airways, known as bronchial tubes, become swollen and inflamed. Figure 5 shows an illustration of asthmatic airways and normal airways. Because of this inflammations, the airways become extremely sensitive to triggers. When this increased sensitivity leads to a reaction, the muscles tighten, and the airway becomes further narrowed. Additionally, an overproduction of mucus occurs, clogging the bronchial tubes. When this happens, a person experiences an attack also known as an exacerbation.

Exacerbations are episodes characterized by a progressive increase of symptoms and a temporary decrease of lung function. When asthma symptoms are not treated, it can result in repeated attacks. Severe or persistent asthma attacks may eventually lead to irreversible damage to the lungs and permanently worsened airflow (Bousquet et al., 2010; Hernandez & Farmer, 2004).

Symptoms & triggers differ per person

The symptoms of asthma manifest themselves in episodes of wheezing, chest tightness, shortness of breath and coughing. Symptoms often occur at night, early in the morning or during activity. An asthma trigger is anything that brings on the symptoms of asthma in a person with asthma, and such symptoms and triggers differ for different people. Moreover, symptoms may increase as a result of an allergic reaction caused by allergens, such as pollen and dust mites, or by nonallergenic triggers, such as strong emotions and cold air. When symptoms are only experienced with physical effort, this is often called exercise-induced asthma.

In addition, symptoms vary over time and in intensity, but even when symptoms may be absent for weeks or months at time, some degree of the inflammation is usually present.

Figure 5. Comparison of the normal airway and asthmatic airway (untitled from www.asthmafriendly.ca)

Figure 6. Lung (Pulmonary) function can be used to diagnose asthma
In the Netherlands, the majority of asthma care is provided by first-line care – namely, general practitioners (GPs). They adhere to the guidelines of the Huisartsen Genootschap (NGG), which uses a stepwise four-stage framework for managing patients with asthma (Figure 7 is based on information retrieved from www.ngg.org). The guidelines indicate that before increasing pharmacological treatment, the doctor should always check for common problems, such as incorrect inhaler technique, poor adherence to the treatment, and environmental exposures. Incorrect inhaler technique lowers drug deposition to the lungs, and may lead to poor control. On the other hand, poor control can be a result of the patient’s environmental exposures. If someone with allergic asthma appears to keep two cats at home, this should be addressed first.

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The degree to which the person’s behaviour corresponds with the agreed recommendations from a healthcare provider World Health Organization (2003).

A report of the Netherlands Institute for Health Services Research (NIVEL) revealed that nonadherence occurs in one third of the people with asthma in the Netherlands (Waverijn, Spreeuwenberg & Heijmans, 2014). Nonadherence is often characterized by an underuse of maintenance medication and an overuse of reliever medication. That poor adherence to the maintenance medication often includes an overuse of reliever medication is indicated in the results from the Dutch respondents from the European Recognise Asthma and Link to Symptom Experience (REALISE) survey. This survey showed that over 60% of Dutch asthma patients (n = 817) reported using reliever medication more than two times a week, which is associated with high exacerbation frequency and which may indicate that their asthma is uncontrolled (Baron et al., 2019).

Patients may rely more on their reliever medication, since this provides them with quick relief when they are in need, than to use their daily maintenance medication. Which may result in patients who do not treat the underlying inflammation, and their asthma may be uncontrolled (Janson, Earnest, Wong & Blanc, 2008; Ulrik et al., 2006; Partridge, Molen, Myrseth, Busse, 2006). This is already one of the causes of nonadherence, as the motives for not adhering to daily medication play are of great influence in this project, this and other motives will be described in more detail in chapter 3.

The different medications used to treat asthma are described in more detail on the next page, since they play an important role in this project. Understanding the medication types and their pharmacological effects also clarifies the correlation with nonadherence and helps to define the problem statement.

One third of Dutch asthma patients show poor adherence

In the Netherlands, the majority of asthma care is provided by first-line care – namely, general practitioners (GPs). They adhere to the guidelines of the Huisartsen Genootschap (NGG), which uses a stepwise four-stage framework for managing patients with asthma (Figure 7 is based on information retrieved from www.ngg.org). The guidelines indicate that before increasing pharmacological treatment, the doctor should always check for common problems, such as incorrect inhaler technique, poor adherence to the treatment, and environmental exposures. Incorrect inhaler technique lowers drug deposition to the lungs, and may lead to poor control. On the other hand, poor control can be a result of the patient’s environmental exposures. If someone with allergic asthma appears to keep two cats at home, this should be addressed first.

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Maintenance medication

Preventers and controllers

Maintenance medication consists of preventer medication, which are anti-inflammatory drugs and include inhaled corticosteroids (ICS). When symptoms are not adequately controlled with ICS, the treatment may be complemented with controller medication, which includes long-acting β2-agonists (LABAs). When this relates to the maintenance medication, the anti-inflammatory preventer medication is used.

Preventers: Work slowly effective noticeable after couple of weeks – reduce the swelling and mucus in the airways – Must be taken every day as directed to work properly

All asthma patients are prescribed preventer medication unless they have mild intermittent asthma (step 1 in Figure 7). Such preventer medication includes ICS, which treat inflammation and swelling of the airways, the cause of patient’s symptom experiences. Because this project includes ICS as a daily treatment, it was important to be aware of their possible side-effects. In this regard, LABAs relax tight muscles and open the airways. For the best outcomes, the medication should be taken two times a day (every morning and evening), regardless of how a person’s daily asthma symptoms are (Figure 9).

Because this project includes ICS as a daily treatment, it was important to be aware of their possible side-effects. Inhaled steroids have few side-effects, especially at lower doses. However, rinsing the mouth and gargling after using the inhaler, can help prevent these side effects. In this regard, a low dose of daily ICS does not do any harm.

However, an important side effect may occur when a high dose of daily ICS is needed – namely, adrenal suppression may occur whereby the adrenal gland can become ‘lazy’. This may cause vague symptoms of fatigue and potentially acute adrenal crisis. Since this project does not focus on the group of people that need a high dose of daily ICS, this side-effect will not occur.

Controllers: Long acting medications to relieve symptoms of asthma - Work by opening the airways and keeping them open for 12 hours - Used in conjunction with preventers

Controllers include Long acting β2-agonists (LABAs) and can be an important part of the maintenance treatment when symptoms are not adequately controlled with ICS alone. In this regard, LABAs relax tight muscles and open the airways. Meant to be taken twice a day, they open the airways for 12 hours or more. It is important to note that the LABAs should never be used without ICS. Therefore, they are often used in a single ICS/LABA combination inhaler. Patients who are prescribed separate ICS and LABA inhalers could potentially have poor adherence to their ICS.

Furthermore, LABAs may be prescribed to use every day to control asthma, in contrast with short-acting beta agonists (SABA), which are prescribed as a reliever medication.

If persons experience some burden due to their asthma, the advantages always outweigh the disadvantages of the medication.

- P. H. (general practitioner)

People with asthma are advised to carry a reliever medication (or rescue medication), which consists of short-acting beta agonists (SABAs). Such SABAs are prescribed as needed and are the first choice for quick relief of asthma symptoms. They are used when patients experience a flare-up, during which the reliever medication relaxes tight muscles around the airways and improves airflow. However, SABAs do not treat the underlying inflammation that causes the flare-up (Figure 9).

The effect of SABAs on the lungs starts within minutes after inhalation and lasts for two to four hours. Moreover, SABAs are also used by some patients before exercise to prevent exercise-induced asthma. The side effects of SABAs can include increased heart rate, nervousness and shaking hands. This may occur when a higher dose of the medicine is taken. The side effects of SABAs and LABAs are similar, as the two drugs share the same mechanisms of action.

Reducing, and ideally eliminating, the need for reliever treatment is an important goal and measure of the success of an asthma treatment (GINA, 2018), as overuse of a reliever is often a sign of uncontrolled asthma. The use of the reliever >2/week may indicate that a patient’s asthma is uncontrolled.
2.3 ASTHMA SELF-MANAGEMENT

In order to create a self-management intervention for patients with asthma as part of this research, it was important to determine the impact of asthma on a person's life and how self-management plays a role in this impact. In addition, more research was done on the potential of eHealth to support patients in adequately self-managing their asthma.

2.3.1 SELF-MANAGEMENT & DAILY LIFE

Prior to this project, researchers from the Department of Public Health and Primary care at LUMC conducted and recorded several focus group discussions with asthma patients, and a range of topics were discussed. Themes derived from those discussions that were relevant for this project include energy management and lifestyle changes. The recordings (n = 4) of those discussions were played back and used for the pre-exploratory phase of this project.

These interviews soon made clear that the impact of asthma on daily life varies for different people. Some patients may experience some inconvenience from time to time, and for others asthma is a major problem that interferes continuously with their daily activities, which can even result in not being able to work anymore. Asthma may limit people in their physical activities, such as playing sports and taking the stairs, or it can cause difficulties in sleeping through the night. In order to create a self-management intervention for patients in adequately self-managing their asthma.

2.3.2 Asthma self-management

Self-management involves active involvement in decision making, coping with signs and symptoms of disease, making lifestyle changes and managing the impact of the disease on the person's life.

- indicating that asthma may take a psychological toll on a person's life as well. At the same time, people have to adjust to their lifestyle to deal with asthma, and such adjustments may result in small or major changes that are necessary for adequately self-managing their asthma. Indeed, they have to remember to take daily medication and learn to cope with the unpredictability of asthma and its impact on their life.

** I was arriving in Utrecht. I had to inflate my tire there, and that was unexpected. Pumping up such a tire... Then it went wrong. Those are the small things. But, yes, I can hardly figure out the whole day by myself.

In light of this picture regarding how asthma can have an impact on a person's life, more specific literature research was conducted on asthma self-management. Self-management, in the context of a chronic disease, can be described as follows:

- ** A set of tasks and processes that are used by a patient to maintain wellness in the presence of an ongoing illness
  - Batterly & Schoo (2010)

- ** Which involves active involvement in decision making, coping with signs and symptoms of disease, making lifestyle changes and managing the impact of the disease on the person's life
  - Gruchem & Von Koff (1996)

In the case of asthma self-management, patients need to be actively engaged in multiple self-management behaviours: self-monitoring symptoms, avoiding triggers where possible, using a written asthma action plan (most patients are not in possession of such a plan), scheduling regular reviews, adhering to prescribed medication and using the appropriate inhaler technique. When patients adhere to these self-management behaviours, asthma can be effectively controlled (Gamble, Sevenson & Heaney, 2011). Moreover, effective self-management results in symptom reduction, improved lung function, improved quality of life, reduced need for healthcare and a decrease in absence from school or work (Gibson Peter et al., 2003).

The role of knowledge, attitude & self-efficacy in self-management

Knowledge about asthma is an important factor in effective self-management. However, knowledge alone is not enough. In addition to patients' knowledge and attitudes, an important aspect of effective self-management is self-efficacy, which refers to an individual's belief in his or her capacity to follow a prescribed medical regimen in challenging situations.

In addition to patients' knowledge and attitudes, an important aspect of effective self-management is self-efficacy, which refers to an individual's belief in his or her capacity to follow a prescribed medical regimen in challenging situations. Self-efficacy in asthma treatment includes patients' confidence in being able to avoid triggers, recognizing worsening of symptoms, applying the written action plan and taking their medication as prescribed. Moreover, medication adherence self-efficacy refers to patients' belief in their capacity to follow the prescribed medical regimen, including in challenging situations (Nafzaki, Nakamotos & Schub, 2017). Feeling confident in managing asthma, therefore, may depend less on formal education or instructions and more on people's perceived ability to control their asthma.

Figure 10: Influences on asthma self-management

In addition to patients' knowledge and attitudes, an important aspect of effective self-management is self-efficacy, which refers to an individual's belief in his or her capacity to follow a prescribed medical regimen in challenging situations. Self-efficacy in asthma treatment includes patients' confidence in being able to avoid triggers, recognizing worsening of symptoms, applying the written action plan and taking their medication as prescribed. Moreover, medication adherence self-efficacy refers to patients' belief in their capacity to follow the prescribed medical regimen, including in challenging situations (Nafzaki, Nakamotos & Schub, 2017). Feeling confident in managing asthma, therefore, may depend less on formal education or instructions and more on people's perceived ability to control their asthma.
Consequently, eHealth allows for more control by the patients and supports proactive patient participation. Therefore, eHealth has the potential to empower patients by allowing them to take an active role in their treatment, to gain a deeper understanding of their conditions and how to effectively manage them. This is a big advantage since patients who believe that they are in control of their own health (a facet of high empowerment) often have greater adherence to their treatment plan (Náfrádi, Nakamoto & Schulz, 2017).

Empowered patients have control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being (Alkhaldi, Sahama, Huxley & Gajanayake, 2014).

Some of the disadvantages

eHealth also has some disadvantages, such as potential privacy and security issues, which could lead to the leakage of sensitive data. Moreover, patients may become frightened as a result of misinterpreting their medical data. Additionally, eHealth will likely be challenging for some population groups – in particular, people with low health literacy, which plays a key role in people’s ability to benefit from applications. Health literacy refers to the ability to obtain, process and act appropriately on health information (Mackert, Champlin, Holton, Muñoz & Demásia, 2014). In order to meet the needs of people with low health literacy, a different approach is needed, as such people struggle to follow medication instructions and to understand information. Furthermore, the elderly often lack the skills and experience necessary to use applications on their mobile phones, so mHealth will likely be difficult to implement. The elderly’s attitude towards using mHealth is often less positive. However, as this project does not focus on the elderly or on people with low health literacy, the use of eHealth is not seen as a barrier.
A key element to designing solutions to nonadherence is to understand patients' worlds and their perspectives on asthma and treatment. Poor adherence is a complex issue and why this is often influenced by patient's personal beliefs and/or practical barriers is explained in this chapter. In order to do so, a literature study was first conducted, after which a field study was set up to gain more in-depth insights in the patient's personal motives to not follow their treatment as prescribed.

3.1 Types of nonadherence
3.2 Field study on nonadherence
  3.2.1 Survey
  3.2.2 Patient interviews
  3.2.3 HCP interviews
3.3 Conclusion
3.4 Creation of persona

Key takeaways chapter 2

Asthma treatment & self-management focus on asthma control
Medication plays a key role in how well asthma is controlled

Knowledge, self-efficacy and attitude play an important role in how well patients self-manage their asthma. Including the use of their daily treatment

The maintenance medication treats the cause of the patient's experienced symptoms and asks for consistency, also on days the patient feels well

A smart inhaler in combination with an app has the potential to improve adherence by providing tailored interventions and to empower patients by allowing them to take an active role in their treatment

1/3 of Dutch asthma patients show poor adherence to their maintenance treatment. In addition, people tend to rely more on their reliever medication

The reliever medication opens the airways when the patient is in need, but does not treat the inflammations

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1/3 of Dutch asthma patients show poor adherence to their maintenance treatment. In addition, people tend to rely more on their reliever medication

A smart inhaler in combination with an app has the potential to improve adherence by providing tailored interventions and to empower patients by allowing them to take an active role in their treatment

Knowledge, self-efficacy and attitude play an important role in how well patients self-manage their asthma. Including the use of their daily treatment

The maintenance medication treats the cause of the patient’s experienced symptoms and asks for consistency, also on days the patient feels well

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Knowledge, self-efficacy and attitude play an important role in how well patients self-manage their asthma. Including the use of their daily treatment
3.1 Types of Nonadherence

This project takes the same approach described by Horne et al. (2005), whose understanding of nonadherence acknowledges patients’ personal beliefs and their active decision-making in not following their treatment as prescribed as well as practical barriers that reduce their ability to take their medicines as prescribed. Nonadherence is therefore seen as a behaviour that can include intentional (motivation and beliefs) and unintentional (skills and abilities) causes.

Additionally, the World Health Organization (WHO) (2003) defined three types of nonadherence: erratic nonadherence, intelligent nonadherence and unwitting nonadherence (shown in Figure 12). These definitions are integrated in the description of unintentional and intentional nonadherence below.

Unintentional nonadherence

Skills and abilities - practical

Unintentional nonadherence occurs when patients do not take medicines as prescribed as a result of factors beyond their control, such as these:

- Forgetfulness
- Poor understanding of the drug regime
- Language barriers
- Poor inhaler technique
- Poor recall of the consultation

The WHO defined two types of unintentional nonadherence – namely, erratic nonadherence and unwitting nonadherence. Erratic nonadherence is often referred to as forgetfulness; patients have the intention to be adherent, but they simply fail to build the medication regimen into their daily life. For example, they may have changing work schedules or a chaotic lifestyle.

On the other hand, unwitting nonadherence is the failure to understand the specifics and/or necessity of adherence. It is not in patients’ intention to be nonadherent, but they frequently forget instructions given by HCPs, and they may misunderstand the differences between the maintenance and reliever medications. This often has to do with a lack of knowledge. Unwitting nonadherence includes poor inhaler technique as well.

Intentional nonadherence

Motivation and beliefs - perceptual

As described before, patients’ attitude towards their illness and treatment often determines how they deal with their prescribed treatment. This is largely reflected in intentional nonadherence, which arises from the beliefs, attitudes and expectations that influence patients’ motivation to begin and persist with a treatment regimen. This type of nonadherence is described by the WHO as intelligent nonadherence.

Figure 12. The different types of medication nonadherence

I find it hard to understand the specifications of my meds.

I don’t want to take medication when I feel well.

I am so busy!
Intentional nonadherence takes place when patients decide not to take their medication or to take it in a way that differs from their doctor’s prescription. Therefore, intentional nonadherence reflects a reasoned choice. Although these ideas most often conflict with medical reality, they are often a logical response to the patients’ illness and treatment— that is, a logical response from the patients’ perspective.

In general, patients often seek to balance their perceived necessity and concerns and thus minimize their use of prescribed medicines. Patients may decide that they do not need a daily medication if the perceived disadvantages of doing so (e.g., concerns about potential side effects) outweigh the advantages (e.g., less need for reliever medication). However, such perceptions may change over time as patients evaluate the effects of their medication (Horne et al., 2004).

In addition, the daily maintenance medication requires consistency. Research shows that patients who feel better may decide that they no longer need to take their medications (Horne et al., 2005). Illness representation and symptom experience are important factors in this phenomenon. Illness representation refers to patients’ belief or perception regarding their illness. Five categories can be discussed with regard to patients’ illness representation (Diefenback, 2008):

1. Causal beliefs (genetic vs. environmental)
2. Consequences beliefs (social and/or financial costs)
3. Timeline beliefs (acute vs chronic vs sporadic)
4. Control beliefs (medication vs lifestyle change)
5. Identifying beliefs (symptoms that are and are not related to the illness)

Moreover, patients who perceive asthma as a chronic disease with potentially serious consequences are more likely to take their daily ICS, as they understand that their asthma is still present when they do not experience symptoms. In contrast, patients who link their asthma to their symptoms often take ICS sporadically, as they experience asthma as an episodic problem (Home, 2006).

**Tailor Interventions**

Van Boven (2015) explains that is necessary to identify the phenotype of nonadherence in order to offer a tailored solution that fits the type of nonadherence and that targets its underlying cause(s). Interventions should therefore be clearly tailored to the specific needs and beliefs of the patient to solve nonadherence behaviour.

Attempts to solve intentional nonadherence should be more focused on influencing motivation by changing knowledge, beliefs and attitudes. In contrast with interventions that aim to reduce practical barriers to tackle unintentional nonadherence, these should focus on influencing specific patient behaviour—for example, by giving reminders or by building skills.

In other words, erratic nonadherence could be helped with interventions such as reminders or linking the intake to a daily habit, and unwitting patients are expected to be helped with extra education and support. In contrast, patients with intelligent nonadherence are more likely to benefit from a process of shared decision-making and motivational interviewing, and they do not benefit from reminders. The approach of motivational interviewing is described in more detail in the next section of this thesis.

However, it is also important to note that the different types of nonadherence can occur alongside each other and that there is often a degree of overlap between them. In addition, van Boven (2015) found that current interventions often fail to take into account the interaction between different forms of nonadherence. For example, people might be less likely to forget their medication when the treatment seems more important.

Figure 13 shows a graphical depiction that was created of the conducted research. To further scope the project, an interesting design challenge was found in patients who have the skills and ability to take their medication as prescribed but who lack the motivation to do so. As a result, a field study was set up to gain a more in-depth understanding of patients' personal motives to not adhere to their treatment.

![Figure 13. Combined research on intentional and unintentional nonadherence](image-url)
3.2 FIELD STUDY ON NONADHERENCE

In order to be able to design an intervention supporting patients in adhering to their daily medication, a field study was conducted to gain more insight into people's motives for nonadherence as well as their integrated needs and values in their nonadherence. In addition, this field research was conducted to find design opportunities for the design phase later in this project.

The field research consisted of three activities:

- An online survey (n = 20), to gather data on medication beliefs from a larger group of patients.
- Face-to-face interviews with patients (n = 6), to gain a more in-depth understanding of patients' motives in not adhering to their treatment.
- Face-to-face interviews with HCPs (n = 4) in order to become aware of experts' perspective on onadherent behaviour and to understand their strategies to adress nonadherence.

3.2.1 SURVEY

Method

To gain a better understanding of patients' medication use and their attitude towards their treatment, an online survey was sent out in order to collect data from a large number of patients. The survey was distributed within the network of the researcher. People who visited a doctor for their asthma were invited to fill in the survey.

The three-part survey consisted of several multiple choice questions. The first part concerned questions about people's medication use in general (e.g. which medications they are prescribed and how often they use them). The second part concerned contrasting statements about illness representation with a 5-point response scale (e.g. Asthma feels episodic versus Asthma feels chronic). The third part concerned contrasting statements about the use of daily medication with a 5-point response scale (e.g. Taking daily medication feels like overuse versus Taking daily medication feels like taking care of my lungs). The results of the survey can be found in Appendix B.

Results

In total, 20 respondents filled in the survey. Two respondents did not have maintenance medication prescribed and therefore only filled in the questions about their treatment and the statements about illness representation. Therefore the third part was filled in by 18 respondents instead of 20.

- 40% of the respondents use their reliever medication two times per week or less. 25% of the respondents use their reliever medication more than two times per week, and 35% use it more than five times per week.
- Only two out of 20 respondents responded negatively to the question regarding whether their asthma was well controlled.
- Half of the respondents did not feel the need to take daily medication when they feel well.
- Almost half of the respondents perceived asthma as a sporadic instead of a chronic disease (Figure 14).
- For more than 20% (5/18) of the respondents, daily medication feels like overuse.
- Sixteen out of 18 respondents indicated seeing the need for anti-inflammatory medication.
- Ten out of 20 people indicated needing more knowledge about their medication.

Figure 14. Answers on the survey question ‘asthma feels sporadic or chronic’

Figure 15. Visualisations of some of the results from the survey
3.2.2 Patient Interviews

Method
To gain a more in-depth understanding of why patients may decide to not take their medication as prescribed, semi-structured face-to-face interviews were conducted. Topics discussed included patients’ medication treatment, their attitude towards their treatment, their strategies for dealing with lower energy levels caused by asthma and their opinion regarding opportunities for the integration of eHealth. Each interview was recorded and used as an input for an on-the-wall analysis phase, which included all data sources. The transcripts were reviewed, and interesting quotes were selected and clustered into themes. The clustered themes and corresponding quotes can be found in Appendix C.

Results
In total, six interviews were performed. Four students with mild to moderate asthma and two women with uncontrolled severe asthma were interviewed (Figure 17). The interviews took around 45 minutes each, and all took place at the interviewees’ homes. Analysis of the interviews led to the identification of several themes.

Conclusion
While it has been debated that use of the reliever medication more than twice a week could indicate that asthma in uncontrolled, it seems that this is not how respondents experience it. 60% of the respondents indicate that they prefer to have a bad day as a result of living their life than to take responsibility for their condition. Some interviewees expressed wanting to ‘live in the here and now’ and that taking care of their asthma was not a priority for them. One of the interviewees, a student, stated that this included not wanting to pay attention to her disease:

‘I don’t have a steady rhythm. I am a student. I don’t want to pay attention to it. I smoke occasionally, sometimes every day when it is summer, and I will feel my lungs for at least one week’

Living in the here and now
Some interviewees indicated that they preferred to have a bad day as a result of living their life than to take responsibility for their condition. Some interviewees expressed wanting to ‘live in the here and now’ and that taking care of their asthma was not a priority for them. One of the interviewees, a student, stated that this included not wanting to pay attention to her disease:

‘I don’t have a steady rhythm. I am a student. I don’t want to pay attention to it. I smoke occasionally, sometimes every day when it is summer, and I will feel my lungs for at least one week’

Unpredictability and dealing with the discomfort
The interviews made it clear that asthma brings uncertainty to people’s lives. The interviewees mentioned that they often depend on uncontrollable factors, such as the weather or emotional triggers:

‘Stress will cause my symptoms to increase. I always bring my reliever, just imagining that something will happen while being in the university library’

In addition, all six interviewees mentioned personal events in which they felt asthma limited their performance – for example, visiting a restaurant, going on a ski holiday and playing sports. In addition to this, two of the interviewees expressed that the loss of control they felt, since they are not able to breath during an asthma attack can be a frightening experience.

However, the maintenance medication did not seem to be a logical response to the students’ experienced asthma symptoms. Even when their condition worsened, they mentioned using reliever medication more often to avoid the situation or to deal with the discomfort. For example, one of the participants mentioned using his reliever medication in certain periods more than six times a day, which resulted in heart palpitations. On the contrary, two of the interviewees did not change the frequency with which they used their inhaler; instead, they simply expressed becoming accustomed to their limited lung capacity.

‘I don’t have a steady rhythm. I am a student. I don’t want to pay attention to it. I smoke occasionally, sometimes every day when it is summer, and I will feel my lungs for at least one week’

‘Stress will cause my symptoms to increase. I always bring my reliever, just imagining that something will happen while being in the university library’
Personal goals as a motivator

On the other hand, one of the interviewees mentioned that a personal event motivated him to take his medication as prescribed. Additionally, the importance of clear and personalized advice to motivate the intake of daily medication was not an option because of the consequences:

"I find it hard to feel the effect of the medication. I do notice when I feel bad, but I don’t notice it when it goes well – S.B.

"I find it hard to feel the effect of the medication, I do notice it when I feel bad, but I don’t notice it when it goes well – L.H.

During indoor field hockey, I experience a lot of symptoms, in those periods I take my daily medication more often – E.C.

When I was diagnosed for the first time, I did not believe I had to take the medication daily. What nonsense. But my asthma deteriorated more and more, and at that moment, I had a doctor who said to me: “You have to take the medication for a while before it works. If you know a difficult time is coming, you have to take the medication a month in advance.” These simple explanations really help – D.H.

Measurements and eHealth

EHealth was especially seen as useful in setting reminders to take medication, in keeping track of the development of the disease and communicating with their HCP. Some interviewees expressed to experiencing difficulties in communicating their disease progress with their HCP. They often do not remember how they felt weeks before the appointment. To keep track of their progress, some interviewees said that they would fill in data about their asthma if they did not feel well but that would forget to do so (or not want to do so) when they felt well. In this regard, recording their progress would make them feel like patients:

"Of course, if it goes well, you tend to not fill in questions. But if it goes well, I don’t want to pay attention to it as well – A.L.

Additionally, different interviewees mentioned the importance of measurements such as the lung function test at the HCP and filling in the Asthma Control Questionnaire (ACQ). They reported that such tools made them aware of the severity and development of their disease. One of the interviewees mentioned that for another study on eHealth, she had to fill in the ACQ multiple times, which made her realise that her asthma was actually never under control.

Conclusion

The two women who reported experiencing the full consequences of not taking their medication expressed that they did take their medication as prescribed. For them, the effect of the medication on their health and daily activities was clear. This clear effect was a strong motivator for them to take their medication, and they said that they felt no choice in this.

For the other four interviewees, it seems that the consequences of not taking daily medication were not influential enough. While their asthma may bother them, they have learned to live with their limited lung capacity or to deal with the discomfort in other ways. Even when their asthma worsens, taking the maintenance medication does not seem to them to be a last resort. Furthermore, it also became clear that people do not always link their experienced symptoms to their disease.

In addition, some of the interviewees expressed not being aware of the exact specifications of the different medications, but the interviews also indicated that the effect of the maintenance medication was not always visible to the patient.

The two patients who suffer from uncontrolled severe asthma always felt the effect of the medication, but that would forget to do so (or not want to do so) when they felt well. In this regard, recording their progress would make them feel like patients.

"I find it hard to feel the effect of the medication. I do notice it when I feel bad, but I don’t notice it when it goes well – S.B.

But if it goes well, I don’t want to pay attention to it as well – A.L.

Additional information on the importance of the disease is coming, you have to take the medication a month in advance.’ These simple explanations really help – D.H.

**Figure 16. Interviews with asthma patients on living with asthma and their medication treatment**
3.2.3 HCP interviews

Method

To gain more knowledge of how HCPs view medication nonadherence and to gain insights into their approaches to address poor adherence, interviews with HCPs were conducted as part of this research. A semi-structured interview method was used, guided by an interview topic guide. The main questions included the following: Why is it important that patients adhere to their treatment? Which motives for nonadherence appear in practice? How do HCPs deal with patients who show poor adherence to treatment? In addition, the insights gained from the different strategies for addressing poor adherence were used later in the project to inspire the design phase. The clustered themes and corresponding quotes can be found in Appendix D.

The interviews were recorded and used as an input for an on-the-wall analysis phase. The transcripts were reviewed, and interesting quotes were selected and clustered into themes.

Results

In total, four face-to-face interviews were held with HCPs. Interviews ranging from half an hour to one hour took place with three practice nurses and one doctor at their offices.

Patients’ motives to not follow the treatment

All HCPs were convinced of the importance of the maintenance medication in a patient’s treatment. One of the practice nurses pointed out that a lung attack can take six to eight weeks to fully recover and that this more harmful than the use of ICS. However, the interviewees pointed to a wide range of reasons for patients to not follow their prescribed treatment. The HCPs mentioned that some patients believe that when they feel well, no medication is needed. Furthermore, the HCPs said patients seem to rely more on their reliever medication because this provides them with direct feedback in contrast to their maintenance medication, which takes time to build a protection layer:

"This man used his reliever four times a day, which is really a lot. This has something to do with his perception: Salbutamol [the reliever] works. But I do not notice the effect of Flixotide [the maintenance]."

Figure 18. Interview with practice nurse on nonadherent patients

- J.J.

From a healthcare professional’s perspective

Patients need daily maintenance medication

The maintenance medication reduces the inflammation in the airways

Patients are better protected and experience less symptoms

They are less in need for their reliever medication

From a patient’s perspective

I do not need daily maintenance medication

My asthma feels episodic

When I feel well: I do not need medication

Reliever medication works because it experience effect right away & the intake when I experience symptoms feels right

I find it difficult to feel the effect of the maintenance medication & the intake on days I feel well feels wrong

I have got used to my limited lung capacity and I do not want to be aware of my asthma

Figure 17. Shows the different perspectives between patient and HCP

Figure 18. Interview with practice nurse on nonadherent patients

From a patient’s perspective

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When I feel well: I do not need medication

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"This man used his reliever four times a day, which is really a lot. This has something to do with his perception: Salbutamol [the reliever] works. But I do not notice the effect of Flixotide [the maintenance]."

- J.J.
In addition, the HCPs mentioned a number of motives for nonadherence, including patients wanting to take as little medication as possible, being afraid of side-effects, not wanting to feel like a patient and lacking the knowledge or ability to incorporate the regimen into their irregular and/or busy lifestyle.

And you can explain it multiple times, but sometimes people just do not want to hear it. That story of the lady who does not take her medication. . . . She is highly educated but also says, ‘I want as little medication as possible’.   - M.A.

Strategies of HCPs During the conversations with the HCPs it became clear that patients often consider their symptoms and reflect on their asthma at their doctor’s appointments. In their daily lives, patients tend to be unaware of their disease. Conversely, at their appointment with the HCP, patients are asked to reflect on their disease and are educated about the use of the medication and the specifications of their treatment. However, the HCPs also mentioned that patients are not always honest and that HCPs have to deal with time constraints.

Knowledge and expectation management: All HCPs mentioned the importance of providing clear and understandable knowledge about the medication to patients. In addition, two of the HCPs mentioned the importance of expectation management: Patients should be aware that the maintenance medication takes some weeks to work and that the medication should be taken consistently, including when patients feel better.

Visualizations and metaphors: It can be difficult for patients to imagine the effects of the medication on the lungs since the lungs are hidden. Therefore, the HCPs use metaphors or other comparisons that are recognizable for patients. For example, one of the HCPs said she kept enlarged models of normal and asthmatic airways on her desk (Figure 18). In addition, she said that she used to compare the daily intake of medication with the use of an umbrella to keep the patient protected. Not taking the medication as prescribed could be compared to walking in the rain with an umbrella with holes.

Measurements: In addition, the interviews indicated that the lung function test often helps HCPs make patients aware of their condition and may act as a wake-up call to take action. In this, HCPs find it useful to compare different measurement moments. However, the lung function test is not always able to indicate asthma because the results of some asthma patients may indicate normal lung function.

Motivational Interviewing: Different HCPs mentioned the use of motivational interviewing, in which it is seen important to place patients at the centre of the conversation and to determine their reasons for nonadherence. Furthermore, the HCPs mentioned that it is important not to quarrel with patients’ beliefs but instead to clearly state the consequences of their nonadherent behaviour. Moreover, in motivational interviewing, the HCPs said they try to align patients’ personal goals with taking the medication as prescribed. Additionally, one of the HCPs mentioned that she sometimes proposes a try-out period to motivate the patient to get started. After a couple of weeks, she evaluates the effect of the medication together with the patient: ‘I explain why the medication is necessary, and I tell people that it is their own responsibility. ‘Let’s try it out for six weeks and see what the effect is’.   - C.H.

Conclusion The interviews with the HCPs demonstrate that HCPs play an important role in encouraging patients to adhere to their treatment. However, it also became clear that patients are not always honest with their doctor and that the HCPs have to communicate a wide range of information about the disease and treatment to the patient within a limited timeslot. These limitations could result in misconceptions about the medication and could cause motives to not take the medication as prescribed to remain undiscovered (Figure 19).

On the other hand, appointments with HCPs appear to be a moment when patients can reflect on the development of their disease and when the importance of the maintenance medication on the patients’ health and daily activities is made clear.

The interviews provided many insights regarding how to motivate patients to adhere to their treatment, such as the use of metaphors and motivational interviewing.
3.3 CONCLUSION

The different motives for nonadherence found during the interviews were clustered into three categories: medication beliefs, illness representation and emotional resistance. The different motives per category are shown in Figure 21.

The survey and interviews with HCPs and patients confirmed that different patients do not feel the need to take their medication when they feel well. This could be because people may experience asthma as a sporadic disease instead of as a chronic disease, which is in line with past research on illness representation as a predictor for nonadherence. Indeed, eight out of 20 patients confirmed in the survey that their asthma feels like an episodic, sporadic problem.

Although asthma may feel like an episodic problem, the face-to-face interviews also indicate that some patients have learned to deal with the discomfort of shortness of breath or limited lung capacity – resulting in their perception of the low necessity to take the daily treatment.

In addition, the literature study, interviews with patients and HCPs show that different patients tend to take their reliever medication more often when their asthma worsens instead of responding to the experienced symptoms with increased use of their maintenance medication. This behaviour seems to be amplified by not knowing what effect taking the maintenance medication would have on them as well as lacking knowledge of the specifics of the different medications. Additionally, the survey conducted during the field research indicates that patients do not relate high reliever use to uncontrolled asthma. This may cause them to not take the maintenance medication, since they believe their asthma is controlled.

Who: Patients who perceive their asthma as a sporadic problem. As a result of that perception, their reliever medication seems to be more convenient, since it offers them quick relief when they experience symptoms.

Amplified by: Unawareness of the exact specifications of the different medications and the lack of experienced effect of the maintenance medication.

Problem: Patients have learned to deal with the discomfort asthma brings and become accustomed to their limited lung capacity. They are unaware (or want to be unaware) of the fact they can do better and of the positive influence taking maintenance medication can have on their situation. (See Figure 20)

Figure 21. Combined research on intentional and unintentional nonadherence with new insights gained from the field study

**Medication beliefs**

- Fear of short- or long-term side effects
- Fear for addiction & dependence
- Too much medication “toxic”
- Medication works if it provides clear feedback on the body
- Medication is last case scenario

**Illness representation**

- Asthma feels episodic
- When feeling well medication*
- Misinterpretations about the severity of the disease
- Used to limited lung capacity
- No link between symptoms and disease
- Could also be covered by “issues around medication”, but this behaviour was seen as a result of someone’s illness representation

* Could also be covered by “issues around medication”, but this behaviour was seen as a result of someone’s illness representation

**Emotional resistance**

- Health is enjoying life
- Costs feel higher than the benefits
- Not wanting to feel like a patient
- Embarrassment
- Interference daily life

Figure 20. Key findings

procedures found in...

- Not wanting to be aware
- Feeling well, no meds
- Lack of experienced effect of maintenance medication

Amplified by...

- Used to lung capacity
- Not wanting to be aware
- Feeling well, no meds
- Lack of experienced effect of maintenance medication

Figure 21. Combined research on intentional and unintentional nonadherence with new insights gained from the field study.
3.4 CREATION OF PERSONA

The just described insights on nonadherent behaviour were further translated into one representative persona – Myrthe. Myrthe represents the future user’s behaviour, values and needs. The elaborated persona, Myrthe, inspired the design phase of this project.

Myrthe is an elaborated version of one of the five personas who were created at the start of this project. The five personas embodied different types of asthma patients, specifically based on how they deal with asthma and their treatment in their daily lives. After the additional literature and field research on nonadherence, Myrthe was selected and elaborated with regard to her motives for nonadherence, illness representation and medication beliefs. A full description of the other personas can be found in Appendix E. The different personas were discussed with a practice nurse to validate the profiles created, and the nurse expressed clearly recognizing the profile of Myrthe.

Meet Myrthe!

“Very recognizable! I know someone who even looks like her, so to speak. She is a nurse student and knows how it works. I also explained it to her. But she does not use her maintenance medication. She only uses Ventolin (reliever). I am not sure why... This persona is actually applicable to people who have a busy lifestyle in general – people who are mildly asthmatic and who could control their asthma well with a low dose of ICS but who do not feel the desire to do so.”

* M.A.

**MYRTHE - BUSY ESCAPIST**

Here & Now - Active - Not wanting to be aware

Myrthe wants to pay as little as possible attention to her asthma. She rather has a bad day after a day full of activities, than taking asthma into account and pay attention to her symptoms. She thinks her asthma is under control when there is still plenty of terrain to gain.

In addition, Myrthe often forgets to take her maintenance medication because of her busy lifestyle. However, the main reason for her nonadherence is that her disease feels sporadic instead of chronic and therefore her reliever medication feels more convenient to use.

“I get more out of life, when not thinking of it. It means more fun.”

Very recognizable! I know someone who even looks like her, so to speak. She is a nurse student and knows how it works. I also explained it to her. But she does not use her maintenance medication. She only uses Ventolin (reliever). I am not sure why... This persona is actually applicable to people who have a busy lifestyle in general – people who are mildly asthmatic and who could control their asthma well with a low dose of ICS but who do not feel the desire to do so.”

* M.A.
Nonpatient
For Myrthe the interaction with the inhaler sometimes makes her feel like a patient, which in her opinion, she is not. She believes it would be nice if it could be a more subtle interaction, something as easy as taking a pill:

I am not ashamed, but I don’t like the interaction with the inhaler either.

Lack of direct feedback
Myrthe may easily say that she just forgets to take her medication, but this forgetfulness is strengthened by the absence of a perceived necessity to take her medicines. She is young, and she enjoys living in the moment. If she functions fine without, she wonders why she should take medicine. But also in periods when her symptoms worsen, she uses her reliever inhaler frequently or deals with the discomfort.

In addition to this, she finds it difficult to feel the effect of her maintenance medication on her lungs, in contrast with her reliever, which gives quick relief of her asthma symptoms when she experiences a flare-up.

I find it hard to experience a result when using the maintenance medication.

Trigger events
Myrthe notices her symptoms are triggered in periods of stress, especially when she does not pay enough attention to her asthma. Last year, she participated in a couple of intensive projects at her work, and during this period, her asthma worsened, causing her to experience constant shortness of breath. This also happens with cold weather and dust mites.

If I have a lot on my mind, I don’t listen to my symptoms.

Fear of no control
It is frightening for Myrthe when she has a serious asthma attack and when she has the feeling that she is running out of air. The idea of not getting any air causes stress, which makes her breathe faster, causing her to get less air. She knows she will be all right, but this is not what her body tells her. The feeling in her body makes her panic. Myrthe recently had a severe asthma attack when she visited a festival with her friends. Few people can help her when this happens. In fact, other people may start to panic too.

Of course, I know I am not going to die, but that is not what my body tells me then.

Opportunities for Myrthe:
To motivate Myrthe it is important to show her that she can get more out of her activities when taking her daily medication into account.

The moment of intake should feel as if she takes good care of her lungs instead of ‘medication moment’ that makes her feel like a patient. Just as brushing her teeth daily.

In addition, Myrthe has a busy lifestyle and therefore the intervention should not be too time consuming, but also should not become invisible.

Tone of voice:
• Goal oriented
• Well-founded story
• Don’t patronize

Goals
Myrthe wants to be physically active and to exercise frequently. She would like to reduce the frequency of her asthma symptoms and to lead a stress-free life without being afraid of exacerbations, such as during festivals in the summer.

I want to be up on my feet and to not think about what I can or can’t do.

Busy Escapist
Myrthe just finished her studies and has worked at a small consulting firm for two months. Myrthe is open about her asthma; people who are close to her know she has asthma, and she feels no shame about it. At the same time, she wants to pay as little attention as possible to it. She has a busy lifestyle filled with work and friends. She would rather have a bad day after a day full of activities than take her asthma into account. She believes this is not a big deal, and she has dealt with her asthma since she was a child. Thus, she is used to her limited lung capacity, except in sports. She loves to row two times a week, and she feels her asthma limits her in her results. This sucks.

Myrthe notices her symptoms are triggered in periods of stress, especially when she does not pay enough attention to her asthma. Last year, she participated in a couple of intensive projects at her work, and during this period, her asthma worsened, causing her to experience constant shortness of breath. This also happens with cold weather and dust mites.

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I want to be up on my feet and to not think about what I can or can’t do.
After a broader understanding of the motives behind nonadherence was developed, the next step in this research was to determine how design could motivate patients to adhere to their treatment.

Based on the insights gained from the field study, different design guidelines were created. In order to identify key factors and possibilities when designing for eHealth, some literature research was conducted on eHealth design.

To understand how to complete the difficult step of motivating people to change their behavior, to more effectively develop the design, a literature study was done into the history of behavior and behaviour-change theories.

In this chapter

4.1 Guidelines emerging from field study
4.2 mHealth design
4.3 Methods on behaviour change
4.3.1 Behaviour change stages
4.3.2 Behaviour change methods
4.1 GUIDELINES EMERGING FROM FIELD STUDY

During the analysis of the interviews with asthma patients, it became clear that asthma can bring uncertainty into people’s lives. The disease’s intensity changes over time, patients often depend on uncontrollable factors that trigger their symptoms and they experience a loss of control during asthma attacks. However, patients seem to be unaware of the fact that they are adjusting their lifestyle in a suboptimal way by dealing with the unpredictability that asthma brings into their life instead of improving their situation by treating the cause with the daily maintenance medication.

Therefore, the intervention should show people that incorporating daily medication will not limit them but instead will reduce or remove the uncertainty they experience, thus giving them control over their health and personal activities (Figure 23). To establish this, insights gained from the field study were combined into different guidelines for the design of the intervention (Figure 22).

Provide clear knowledge & include expectation management

During the conversations with HCPs and patients, it became clear that patients are not always aware of the specifications of their medication and may not take their medications because of misconceptions. When designing for nonadherence, it will be important to provide clear and understandable information about the different medications as well as to include expectation management in so doing. Moreover, patients need to be aware that the maintenance medication takes some weeks to work and the importance of consistent intake, including in periods when patients feel better. On the other hand, the intervention cannot ensure that patients’ symptoms will disappear when taking the daily medication, since extreme circumstances (such as the pollen season) may still trigger their asthma symptoms. However, there will be a high probability that patients will experience fewer symptoms, since they are better protected.

The use of personal goals and a try-out period

The perceived necessity of taking the daily medication appears to be low for some patients. However, the interviews with patients and HCPs show that incorporating personal goals increases patients’ perception of the importance of the daily medication, since this makes patients aware of what the daily medication intake will bring them.

As a result, in order to show patients the advantage of taking the daily medication (and because the effect of the medication becomes visible after some weeks), patients could be offered a try-out period of six weeks. Such a period would give patients an opportunity to try out the behaviour, motivated by their personal goal, and to reflect on the outcomes throughout the try-out period afterwards. Moreover, this approach would show patients that taking care of their health in the present has positive effects in the future. In fact, one of the practice nurses mentioned that she already incorporated the approach of a try-out period in practice.

Visualize the effect of the medication

Visual: Patients appear to find it difficult to imagine the effect of the maintenance medication on their lungs. It is important that the design visualizes the effect of the maintenance medication intake on their lungs for them. Different HCPs expressed that the use of metaphors effectively communicates the effect of the medication on the lungs.

Tangible: Additionally, the field study shows that patients experience difficulties in experiencing the effect of the medication and recalling how they felt weeks in the past. Therefore, it is useful for them to visualize the development of their asthma symptoms over time.

Establish evaluation moments

In addition to visualizing the effect and course of the medication, it is important to incorporate evaluation moments. The interviews with HCPs and patients made clear that patients often go on, without paying attention to their disease development. Therefore, patients should consider the progression of their asthma symptoms and medication use. Otherwise, positive outcomes, such as reduced medication use, may remain unnoticed, or patients may not link those results to their improved medication adherence.
Stress will cause my symptoms to increase. I always bring my rescue inhaler. Just imagine that something will happen while being in the university library – F.D.

Long term
Short term
During attack

I was at my parents for two weeks. I always experience more problems there. I really can’t stay there longer than 3 days. I also got heart palpitations and a sore throat because I used my rescue that much – T.M.

Huge difference compared to the past. I could do everything. It is very strange that I can no longer do that – A.L.

Asthma comes with unpredictability on the long term development

People often depend on uncontrollable factors that trigger their asthma

A long attack can be a frightening experience

You can’t breathe anymore. The idea of not being able to breathe causes more stress, resulting in even less air. I do not want to panic because I know it will be all right. But, that is not what my body is telling me – S.B.

Asthma comes with unpredictability on the short term development

People can experience limitations due to asthma during personal events

I was at my parents for two weeks. I always experience more problems there. I really can’t stay there longer than 3 days. I also got heart palpitations and a sore throat because I used my rescue that much – T.M.

4.2 mHEALTH DESIGN

To find specific design opportunities for mHealth and asthma, the study of Tinschert, Jakob, Barata, Kramer and Kawatsch (2017) “The potential of mobile apps for improving asthma self-management: a review of publicly available and well-adopted asthma apps” was used.

The paper describes the potential of mobile apps for improving self-management and identifies 526 asthma application. This study reviewed 38 apps in detail. The study suggest that even without scientific proof for efficacy, some of the applications have the potential to improve asthma self-management based on four requirements (see Figure 24):

1. App is able to change or guide behaviour for effective self-management (e.g. follow prescribed treatment)
2. App has to contain some kind of active element: Functions that support the person in managing his or her disease (e.g. medication tracking and notes)
3. App should motivate the user to use the app and to deliver the active ingredients (e.g. medication intake and patients feedback)
4. App should be of acceptable quality (e.g. functionality and aesthetic appeal)

This study shows that the intervention should be able to change or guide the behaviour of the user towards taking the daily medication. This corresponds to the field study, that discovered different personal motives that play an important role in not taking the medication as prescribed.

The technology of automatically saving will be useful in supporting the patient to deliver the active ingredients the daily medication intake. It is a big advantage that users do not have to report this themselves in the application. However, since previous conducted research shows that the motivation of patients is low to uptake the daily intake, the application should motivate the user to deliver the intake of the medication and to use the application (referring to point three). The created guidelines resulting from the field study indicate the importance of visualizing the effect of the medication in this and to make people aware of what the daily intake will bring them. However, how to motivate the user through the use of an application has not yet been studied for this project. Tinschert et al. provide some insights that could be particularly interesting to motivate the user to deliver the active ingredients (the daily use of the inhaler) with the use of an app. These are described on the next page.
In order to understand the current state of research with previous behaviour (Kahneman, 2002).

conscious deliberation, and people can easily return to their chance of not being successful: Such shifts require effort and from their beliefs and implement new behaviours have a larger behaviour changes in which people are expected to deviate the medication two times a day into their routine. Radical is not needed in their situation, towards incorporating needs to take place in patients’ belief that daily medication twice daily, every morning and evening. Consequently, a shift Patients are required to take their maintenance medication on how to motivate people to change their behaviour. This chapter includes how different methods and strategies are able to contribute to this project.

4.3.1 BEHAVIOUR CHANGE STAGES

Change is rarely easy and often requires a gradual progression of small steps towards a larger goal. Two well-known behaviour change models, with the goal of using this knowledge for the design, will be described in more detail in this section.

The transtheoretical model of behaviour change

The transtheoretical model of behaviour change (TTM), developed in the 1980s by Prochaska and DiClemente, is commonly used in research and clinical practices. Its use has shown that behaviour change is a process that requires people to go through several steps or stages of change. Movement between different stages is driven by two key factors: self-efficacy and decisional balance (the outcome of an individual’s assessment between the advantages and disadvantages of a behaviour) (Wagner, Burg & Sirois, 2004). In addition, relapse (falling back to previous stages) is common. The different stages of change are described in more detail below (Figure 25).

1. Precontemplation: The person has no desire to change and is not ready to perform the new behaviour. In this stage, individuals are unaware of the problem. The previous research on motives behind non-adherence shows patients may experience asthma as a sporadic problem

with low consequences, which eliminates their motivation to persist with the treatment as prescribed. Such patients often underestimate the advantages of taking their medication and place strong emphasis on the disadvantages, such as interference with their daily schedule and the inconvenience of taking the medication in periods they feel well.

2. Contemplation: The person is getting ready to explore alternatives. If patients become more aware of the positive impact the maintenance medication could have on their daily life or are aware of the negative consequences nonadherence behaviour may bring, a more thoughtful consideration of the advantages and disadvantages will take place. However, patients may still feel ambivalent about taking the maintenance medication on a daily basis.

3. Preparation: The person formulates intentions and is ready to take action. In this stage, patients are ready to take action. For example by integrating personal goals, as described in the field research, asthma patients believe changing their behaviour can lead to a healthier and/or more active life.

4. Action: The person performs the new behaviour. During the action phase, asthma patients have recently changed their behaviour and intend to keep taking their daily medication in the future.

5. Maintenance: The person has sustained the new behaviour. In this stage, patients have sustained the behaviour of taking their medication every morning and evening for a given period of time (in this study, over the last 6 months), and they work to prevent relapse to earlier stages.

6. Termination: The person has no desire to return to the old behaviour and is certain to not relapse. In this last phase, patients have no desire to re-take their previous behaviour of not integrating the maintenance medication into their lives and are certain to not fall back on their old behaviour. This stage is rarely reached, and patients tend to stay in the maintenance stage.
Health Action Process Approach

Another widely used approach is the health action process approach (HAPA), which includes two phases: one leading to a behaviour intention and the other to the actual behaviour. Thus, this consists of a motivation phase and a volition phase (Schwarzer, 2008).

During the motivation phase, individuals form an intention to adopt the behaviour. This phase is strongly influenced by outcome expectations (expected benefits and disadvantages). Outcome expectations can be positive (advantages, e.g., ‘taking my medication will lower my asthma symptoms during my hockey season’) or negative (disadvantages, e.g., ‘taking my daily medication will make me feel like a patient, which I am not’). The volition phase, or action phase, describes the amount of effort people put into trying to perform a behaviour and how long they persist. This phase also includes relapse prevention skills. Patients should be prepared for particularly high risk situations, such as holidays, where they have irregular schedules and are more likely to not take their medication.

Both the motivation phase and volition phase are influenced by barriers and facilitators, such as (a lack of) social support. Moreover, HAPA is influenced by barriers and facilitators, such as (a lack of) social support. Furthermore, HAPA emphasizes that the process of behaviour change is often not linear. Therefore, HAPA can be seen as a stage model but not linear. Thus, this consists of a motivation phase and a volition phase.

Figure 26 shows the different steps of the health action process approach.

The stages of change of the intervention developed for this research

Following those insights on intentional motives, on the importance of guiding behaviour and on the stages of behavioural change, the following stages for the intervention were identified:

1. Support the behaviour intention to take daily medication
2. Support the action to take daily medication
3. Support motivation to sustain the behaviour

Since patients have different motives for not starting or persisting with the treatment, the intention first needs to be created to adopt the daily behaviour. Secondly, patients should be motivated to actually perform the behaviour of using the maintenance medication for a period of time, and afterwards patients need to feel motivated to sustain the new behaviour of taking the maintenance medication.

It was chosen to not focus on the maintenance phase as the timespan of this project does not allow for a well conducted, valid test. However, it should be kept in mind that the user should feel motivated to sustain the behaviour.

After deciding on the stages the intervention should include, research was performed on which methods would be useful to support the behaviour intention, to support the action and to stimulate the person to sustain the behaviour. Some of those methods overlap with the previous methods used by HCPs but are described in more detail in the next section.

4.3.2 Behaviour change methods

Support behaviour intention

It is important for patients to develop the intention to start their treatment as prescribed and to discover personal motives that could be used to encourage the intake of taking the medication. In addition, at this phase, patients may not have the motivation to change.

Motivational interviewing

Motivational interviewing, an effective behaviour-change strategy, was applied by different practice nurses interviewed in the field research.

Patients may not be ready to commit to the change of taking daily medication, but motivational interviewing can help them to find their motivation (Miller & Rollnick, 2012). The key issue for behaviour to change is this question: ‘What will be the benefit of this new behaviour for me?’ In this regard, HCPs explore and seek patient reasons for changing or not changing before setting out a plan of action. The role of the HCP is more one of listening than interpreting. In so doing, it is important that HCPs do not push back against the resistance they experience from patients.

To strengthen the patient’s personal motivation to commit to taking their medication as prescribed, HCPs often seek to identify specific personal goal(s) that will benefit from the patient’s change in behaviour. For example, a patient appears to be a fan of skiing and if cold air triggers that patient’s symptoms, this could be used to motivate the patient to start the treatment.

Goal-setting

Intention to work towards a goal have proven to be a major source of motivations. The goal-setting theory shows that goals must have specificity, commitment, challenge and feedback (Locke & Latham, 1994). This means that in order to reach a goal (for example, to experience fewer symptoms during an upcoming ski trip by taking daily medication), patients should know how, when and why taking the maintenance medication daily benefits them.
Additionally, this goal-oriented approach could be easily linked to the above-described opportunity of offering patients a try-out period of six weeks, since the effect of the medication only becomes visible after some weeks and this is a clear timespan for the patient to work towards.

In addition to the specificity of the goal, patients should make a commitment towards the goal of being adherent, since this constitutes an active decision and can thus create consistent behaviour in the future (Sluizer, 2011). In addition, a goal is meant to present a challenge to the individual but should still be attainable. Finally, patients should be provided with ongoing feedback to be aware of progression or regression so that they can make adjustments to their behaviour if needed.

**Consciousness raising**

As described above, a key aspect of fostering motivation to change behaviour is to show patients what the benefit of the behaviour will be for them. This aspect may also include confrontation regarding the causes of the problem behaviour. In the context of nonadherence, this means that patients should be made aware of the fact that asthma can cause damage to their airways. Moreover, if they do not treat the asthma appropriately, it will cause their exacerbations, their asthma becomes worse. Patients may easily regress to their old behaviour because they will not feel the effect of the medication on their lungs for the first couple of weeks.

Additionally, previous research on self-management asthma apps shows that existing applications score low on engagement and therefore that opportunities may be found in implementing elements of gamification to keep patients motivated to continue the daily intake.

Hence, a change in behaviour needs to take place, and the intervention has to keep the patient engaged to take the medication daily. The following section explores the use of persuasive game design (PGD) as a method for designing the intervention.

**Persuasive game design**

Persuasive game design creates the experience of a game world to change users’ behaviour in the real world (Siniyava, Vosch, Vermeiren, Bals, 2018). This closely related to the concept of serious games: Both aim to facilitate a transfer effect. After defining the transfer effect, attention should therefore be given to the game design. Game elements and mechanics are motivational elements common to game design. These elements are often rule-based in his book, Home Ludens, Johan Huizinga (1938) describes how games are characterized by rules and how the rules create a game. The game world falls to pieces, once the rules are broken. Game elements are, for example, virtual rewards and points, and game mechanics include achievement, competition and exploration.

The power of a narrative

Another way to teach and change behaviour is through storytelling. Narrative components, such as storylines, metaphors, and characters, are useful for provoking awareness about specific issues and have been used in other design studies on behaviour change. Engaging narratives can help patients to suspend disbelief and reduce their counterarguments. Research shows that narrative in addition, PGD typically shifts users’ experience from a real-world experience to a game-world experience. In other words, users experience the real world, but when they start playing a game, this experience is changed into a game world experience. However, this change is never complete, and users always experience a mixture of both worlds. An enjoyable and immersive game world can motivate users to behave differently in the real world. PGD, the intended real-world change resulting from gameplay is referred to as the transfer effect (Figure 27 shows the PGD Model).

**Transfer effect**

The transfer effect can be achieved through a game world specifically designed to motivate the user towards this transfer effect. After defining the transfer effect, attention should therefore be given to the game design. Game elements and mechanics are motivational elements common to game design. Game elements are, for example, virtual rewards and points, and game mechanics include achievement, competition and exploration.

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**Support action**

When patients decide to adopt the new behaviour of incorporating the intake of medication into their daily life, it is important to keep them motivated to perform the action. Patients may easily regress to their old behaviour because they will not feel the effect of the medication on their lungs for the first couple of weeks.

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games featuring an attractive character with a plot – a beginning, middle and end – allow patients to experience the character’s happiness in his or her journey towards adopting a health behaviour more directly than instructions alone (Li, Baranowski, Thompson & Buday, 2012). On the other hand a narrative can act as analogies of real-world settings, which can enrich boring, unstimulating context, and inspire and motivate players by adding a narrative ‘overlay’ (e.g. being hunted by zombies while going for a run) (Sailer, Hence, Mayr & Mandl, 2017). Which is also applicable for the usage of the inhaler two times a day.

Additionally, the use of a narrative could be an interesting approach to make patients aware of the effect of the medication. Some of the HCPs already mentioned to use metaphors in practice. In this regard, the narrative could create a sense of the intake of the medication. Since asthma patients often experience a lack of feedback. The intake of the medication could be reflected in an outcome of the game’s world’s narrative, and not taking the medication could be reflected into a negative outcome. Which on the other hand, may be helpful in providing users ongoing feedback with regard to their progression or regression of their medication intake over time.

Support behaviour to sustain autonomy as synonymous with behaving with a sense of willingness and choice. This need was selected as the main motivator in this project.

Intrinsic Motivation: One of the most influential theories of motivation is self-determination theory (SDT), which was developed by psychologists Richard Ryan and Edward Deci (2000). The theory describes two types of motivation: extrinsic motivation and intrinsic motivation. When a person tends to do a task or activity mainly because it yields some kind of reward or benefit upon completion, this is called extrinsic motivation. Conversely, intrinsic motivation occurs when people act without any obvious external rewards. According to SDT, there are three innate psychological needs that drive intrinsic motivation, also known as self-motivation: the need for competence, the need for relatedness and the need for autonomy (Figure 28).

The need for competence describes how people need to develop skills and abilities and to develop mastery over tasks that are important to them. Next to this, the need for relatedness refers to how people need to feel a sense of belonging and connectedness with others.

The need for autonomy describes how people need to feel that they are masters of their own destiny and have (some) control over their life. Self-determination theory defines

![Figure 28. The psychological needs defined by self-determination theory](image)

A change in a person’s behaviour from poor adherence to medication adherence involves an increase in that person’s autonomy. Indeed, the uncertainty and limitation asthma has on a person’s daily life and activities will likely decrease when patients experience fewer symptoms and need their reliever medication less often.

The intervention should make patients aware of this increased autonomy. It is important to help patients see this impact. Therefore, it is important to receive data pertaining to the patients’ experience of their symptoms in order to compare results over time. Self-monitoring of symptoms and triggers could be used to receive patients’ data. Self-monitoring was originally developed as a tool that allows psychologists to gather information from patients regarding behaviours, feelings or thoughts in order to evaluate the effectiveness of interventions (Kanfer, 1970).

In the end, patients need to feel motivated to sustain the behaviour of taking their medication daily. Therefore it will be important that patients see the added value of their daily medication on their life, such as fewer symptoms and/or less need for the reliever medications.

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Creation of Design

The creation of the concept is the focus of this phase. The ideation process results in concept directions. Subsequently, the concept directions are explained and requirements were formulated. The phase ends with a concept that should be able to motivate patients to adhere to their medication treatment. The final concept developed in the creation phase will then be elaborated on further and tested in the next phase.

In this chapter
5.1 Design vision
5.2 Ideation
  5.2.1 Ideation round 1: Creative session
  5.2.2 Ideation round 2: Stages of change
5.3 Conceptualization
  5.3.1 Intermediate concept
  5.3.2 Concept
  5.3.3 User test round 1
  5.3.4 Feedback from stakeholders
  5.3.5 Adjustments
  5.3.6 Storyboard

Key takeaways chapter 4

Patients find it difficult to experience the effect of the medication, the application should therefore visualize the effect.

In order to show patients the advantage of taking the daily medication, they could be offered a try-out period of six weeks.

Change is difficult and often requires a gradual progression of small steps towards a larger goal.

People need to feel that they are masters of their own destiny.

Therefore three stages were identified to be included in the intervention: Intention • Action • Sustain.

A narrative can work as an analogy of a real world setting.

The application needs to increase patients awareness of autonomy.
5.1. DESIGN VISION

The literature and user research shows that patients may experience their asthma as an episodic problem and that they don’t feel the need to take medication when they feel well. Therefore their reliever medication feels more convenient, since this helps them when they experience symptoms. On the contrary, patients expressed to get used to their limited lung capacity, which results in a low motivation to uptake the daily intake of the maintenance medication, since they learned to live with the discomfort. This is amplified by a lack of experienced effect of the maintenance medication, the medication needs a couple of weeks to work and asks for consistency.

Therefore the most important questions remains; if poor adherence works for the patients, why would they change?

The user study shows that asthma brings a certain uncertainty into the patients’ lives on the long and short run. The intensity of the disease changes over time and patients depend on uncontrollable factors that trigger their symptoms to increase, such as the weather and strong emotions. In addition, different patients expressed that the loss of control during an asthma attack, whereas they feel that they cannot get enough air, is a scary experience.

The goal of the intervention is to motivate patients to be adherent to their treatment by making patients aware of the positive impact of the daily medication and by this improve the perceived control the patients have over their asthma symptoms. Hence, it is highly important that the intervention shows the patients what the new behaviour of incorporating daily medication will bring them. In addition, it important that patients take the medication consistent for at least a couple of weeks, since the medication needs time to work. In those weeks, the intervention should provide the patients of an engaging experience and visualise the effect of the medication, to prevent disengagement. And because, people may easily fall back on their old behaviour, especially considering the lack of experienced effect in the first couple of weeks.

After a couple of weeks, the intervention should establish the patients to reflect on the outcome of the medication on their daily wellbeing.

If patients decide not to continue, the intervention has at least contributed to a fair consideration. However, the aimed for outcome is that patients become aware that being adherent positively contributes to their daily activities, and that they feel intrinsically motivated to continue their treatment as prescribed.

Figure 30 shows a visual overview of the design vision.

Figure 30: Visual of design vision
5.2 IDEATION

5.2.1 IDEATION ROUND 1: CREATIVE SESSION

During the research phase, a creative session was organized with industrial design students. The conclusions from the research phase had not yet been drawn, and students were asked to use their own imagination and common sense.

Method
A creative facilitation session took place with six industrial design students. During the session, the students brainstormed this question: How can asthma patients be motivated to use their maintenance medication daily?

This session was used to get the inspiration flowing, and the participants were told to speak freely and to distinguish themselves from existing ideas.

Participants generated ideas with the method of absurd questioning, whereby three different parts of the sentence of the problem statement are replaced with three totally different words. For example, ‘asthma patients’ is replaced with ‘Micky Mouse’. ‘Use’ is replaced with another verb such as ‘sing’ and ‘daily medication’ is replaced with, for example, the word ‘car’: ‘How can Mickey Mouse by motivated to sing in the car daily?’

Results
Multiple brainstorming rounds on different absurd questions took place, and ideas were written down on post-its. The post-its created by the use of absurd questioning were eventually translated back to the actual problem statement, and in the end three concepts were presented (Figure 31).

The first concept focuses on relatedness, the second on visualizing the effect of the medication and the third on making the intake as easy as possible.

Stef Stuntpiloot: ‘Pass on the puff’

This concept is focused on making the interaction of the daily intake fun. Ideas were generated by applying principles from Russian roulette to changing the patient’s passwords every day and only providing the password of Netflix after the usage of the inhaler. Eventually, the Russian roulette post-it was combined with a post-it relating to peer pressure, which resulted in the game application: ‘pass on the puff’.

Concept: A group of asthma patients is formed within an app, and each patient is able to use his or her inhaler only when the previous patient has used his or her medication. After this, it is the next patient’s turn to ‘pass on the puff’. Because of this principle, different asthma patients depend on each other: When one patient does not use the medication, the patients after him or her are not able to use their medication.

By using game elements, integrating social control and making patients responsible for each other’s medication use, patients should feel motivated to take their medication on a daily basis.

Fantasy inhaler: ‘Flame your asthma’

The second concept is focused on provoking the patient a feeling of empowerment. Post-its pertaining to making the intake ‘tasty’ and ‘glitter smoke’ were combined into a breath-changing inhaler.

Concept: Since it is hard for patients to notice the effect of the medication, the effect is made visible in a far-fetched way. When the patient has used the maintenance inhaler and exhales, his or her breath is coloured and sparkled (i.e. the flame). This to communicate a message: ‘using the maintenance inhaler empowers the patient. To change someone’s breath would be difficult, but the idea of visualizing the effect to make the patient feel stronger is powerful.’

Keychain inhaler: ‘Puff & Go’

The third direction is focused on making inhaler use an easy daily habit. Post-its of a ‘daily ritual’ and using the inhaler as an ‘implant in a human’s body were combined.

Concept: In this concept, a mobile phone detects the patient’s routine or notices when the patient is waiting – for example, when the patient makes coffee at 07:00. In such cases, the inhaler’s alarm goes off to remind the patient to take the medication. Because this concept takes the form of a key chain, the user will always have it nearby, including when not at home. This prevents the user from not taking the medication because of an irregular lifestyle.

Figure 31: Pictures taken during the creative session
5.2.2 Ideation Round 2: Stages of Change

The inspiration from the creative session provided many different ideas on how to create a fun experience, how to communicate the clear effect of the medication and how to make the daily intake loss of an effort. The different ideas were used as inspiration for the next round of ideation.

While the creative session was set up without input from any research data, the conclusions from the research phase were implemented. This was a relatively short phase and was used to generate as many ideas as possible to use in the final concept. The insights from Figure 29 have been translated into three concept directions.

Intention: ‘An exploratory trip’

When patients are diagnosed with asthma, their HCP advises them to download this app. Since patients have a lot to process during their appointment with the HCP, they may not be aware of the exact specification of the medication afterwards; therefore, this direction explores patients’ motives to take the medication and provides them knowledge about their treatment.

Risk for exacerbations’, and patients then rate their preference on that scale. This is done to explore the potential facilitators and barriers to taking the medication as prescribed. In addition, patients are asked about personal goals that could motivate them to take the daily medication.

In addition, patients are provided statements pertaining to the specifications of their treatment – for example, ‘the reliever medication treats the chronic inflammation of my asthma’. Patients are asked to respond to these statements with ‘true’ or ‘false’, and they then receive the right answer with information on each question.

By completing different tasks, the app environment grows, creating a living wallpaper in a theme chosen by the patient. After completing all the questions, the patient is asked the final question: ‘Do you commit to the six-week challenge?’ Figure 32 shows the results of the ideation on supporting the intention to uptake the daily medication.

Figure 32. Intention: ‘An exploratory trip’
**Action: ‘Gain control’**

After the patients’ personal motives for change are explored, this direction is focused on motivating them to perform the action. In this stage, patients work towards personal goals that they filled in earlier (e.g., taking city trips with less asthma symptoms).

The patient works towards this goal for the following six weeks. During this process, the development of the effect of the medication is made visible – for example, by using a metaphor (bad/good weather), by presenting a visualisation of how the lungs change or by collecting points to stimulate the daily intake. At the moment the patient uses the inhaler, the game world changes. This offers the patient a sense of direct experience and feedback on his or her progression towards the personal goal. The changes in the game world are linked to the automatic registration of the patient’s maintenance medication use.

Figure 33 shows the results of the ideation on supporting the action of taking the daily medication.

**Sustain: ‘My diary’**

This direction is focused on making patients aware of the positive effect the daily medication can have on their life and involves asking the question: ‘What’s in it for me?’

For a period of 6 weeks, patients have to record the symptoms and triggers they experience. That data is represented in a way that gives patients a clear overview of their triggers and the development of their symptoms over time. At three different moments, the patients are asked to provide the app with elaborate feedback on how they feel (i.e., after 1, 3 and 6 weeks).

By keeping track of the triggers and symptoms experienced over time, patients can (hopefully) become aware that the maintenance medication helps them to feel and perform better after some weeks – that they experience fewer symptoms and that their need to use the reliever medication decreases. Moreover, the logging of symptoms and triggers will also provide the patients with new insights regarding their asthma.

In the end, the increase of the medication intake in combination with the decrease of experienced symptoms should motivate patients to proceed with the treatment in the future.

Figure 34 shows the results of the ideation on supporting the patient to sustain the behaviour of taking the daily medication.
5.3 CONCEPTUALIZATION

This section describes how the various insights from the research phase and the ideation phase were integrated into one concept.

In order to deal with the complexity of integrating all insights, the following points were developed as requirements with which the concept had to comply.

Requirements

1) Support intention – Motivational interviewing
   a. Education about different medications to clarify misconceptions
   b. Personal goal setting to show the patient what’s in it for the patient
   c. Six-week try-out period because the maintenance medication needs time

2) Support action – The game world
   a. The game must be rewarding if the desired behaviour is carried out and punitive if the desired behaviour is not carried out
   b. The game must make it possible to visualize the effect of the medication use
   c. The game must work as a memory aid. The daily intake must be clearly visible on a timeline (e.g. ‘Did I take my medication today or not?’)
   d. The game must contain elements that makes it fun to use the app.

3) Support to sustain – Evaluation moment
   The app must visually represent two important processes:
   a. The intake of daily medication
   b. The long-term effect on daily well-being
   If the user uses the app for six weeks, there must be insight that there is a clear link between a and b. This should increase the intrinsic motivation of the patient.

5.3.1 INTERMEDIATE CONCEPT

In light of these requirements, an intermediate concept was developed and discussed with different people. The discussions of this concept have led to new insights that were used to shape the final concept. See Figure 36.

The intermediate concept was designed in the following way:

1. The patient indicates a personal goal to work towards in the coming six weeks and commits to the 6 weeks challenge.
2. The environment of the app is linked to that personal goal. There are a number of themes: seasons/sports/cities.
3. The maintenance medication is linked to app (through Bluetooth and remote sensors), and the environment becomes richer as they consistently take their medication. In addition, the character in the app gets closer to the ultimate goal.
4. The reliever is linked (through Bluetooth and remote sensors) to the moment the person is asked to give feedback on triggers and symptoms.
5. A graph gives a clear overview of medication use and trigger events over time.

A challenge was to communicate the effect of maintenance medication. One of the most important

Figure 35. Discussion with Sander Hermsen (expert on behaviour change) about the 3 different concept directions and important take-aways for the creation of the concept.

Figure 36. Explanation of the intermediate concept.
solutions in this concept is to link the feedback moment on triggers and symptoms to the use of the reliever. This has two important aspects: it is a clear moment when people experience triggers and symptoms, and the use of the reliever will become less necessary after a few weeks, which clearly demonstrates the effect of daily medication. In other words, the requirements of point 3: the intake of daily medication and the long-term effect on daily well-being are both included in this concept.

**Evaluation intermediate concept:**
However, when the concept was evaluated with students and professionals, it appeared that the concept had a number of requirements that were not met:

- The person is rewarded for taking medication but is not confronted with the negative consequences of not taking the medication. Immediate feedback of not taking is missing (requirement 2a).
- One of the most important shortcomings was that the app did not contribute enough to the awareness process. The app did not show that the changing landscape is directly related to the quality of the user’s lungs (2b).
- There are not enough game elements: if the users do not use their medication for a few days, nothing changes in the environment of the app. Because this does not really have consequences, there is only stagnation; the person can easily lose interest, and the goal is not achieved. (requirement 2d)

In addition, the reliever medication use was not integrated in the storyline.

The new concept uses the metaphor of breath and water, using a character named Brad, who can get into trouble by falling into the water. By taking the medication properly, the patient immediately takes care of Brad. If medication is not used, Brad will run out of breath (see Figure 38).

As described in the previous section, to provide feedback on triggers through the use of the reliever was included in the storyline.

The various elements of the app are explained in more detail on the next pages.

**Explanation of different elements used**

The different elements are described according to the requirements described in the introduction of this chapter (5.3).

**Support intention – Motivational interviewing**

The different medications will be explained in the set-up. After the necessity and positive impact of the daily intake are explained, patients are offered a six-week challenge of adherence, which is linked to a personal goal. After accepting the challenge, they enter the game world.

**Support action – The game world**

The breath-cloud character, Brad, moves automatically towards the goal of being adherent for six weeks. As the time proceeds, he moves closer, regardless of whether the patient is adherent or not. However, the patient is in control of how the character (and indirectly the patient) reaches this goal.
Confrontation with negative and positive consequences:
The automatic logging of the maintenance medication acts as a bridge to the goal: Brad is able to walk when the medication is used. However, when the patient does not take the prescribed medication, Brad falls into the water.

Visualize the effect of the medication use: Missing the medication once is not catastrophic: Brad hangs on, halfway in the water. However, if the person’s medication intake remains negative, this has a negative impact on the game world. Brad sinks deeper into the water, and the weather and environment becomes worse, which has an impact on Brad, who becomes weaker. See figure 39 for the interval times.

Clear overview of medication intake: Since every day is connected to a stick, the daily intake of patients’ medication is clearly visible. Every week, Brad stops by an island, where the patient receives a weekly report that provides the medication use in a descriptive way.

Game elements to make it fun: The storyline includes progression and regression, and sometimes a random reward is waiting in the game, as an extra incentive. In addition, when the app is closed, Brad virtually continues living in the app. The patient remains responsible for the well-being of Brad. In addition, a fish/piranha enters the water if the reliever medication is detected.

Support to sustain – Evaluation
The intake of the daily medication: See Visualization effect of medication use described at the action stage.

The long-term effect on daily well-being: When the reliever medication is detected, the person is asked to provide feedback on the trigger event. If the person does not fill in the feedback, a piranha enters the water. If the person fills in the feedback, a friendly fish replaces the piranha. The presence of a piranha, a threat, reflects that the person is bothered by asthma symptoms in the real world. However, when the patient pays attention to this moment, this feedback can be used to provide the person with personalized trends and becomes a friendly fish. Towards the end of the six weeks, and when the patient uses the daily maintenance medication, the number of piranhas/fishes will probably decrease and a bright environment appears with a strong character. Or the other way around; if people did not take their medication, this will reflect in a weak character and bad weather, with a lot of trigger events.

In the end of six weeks, the users are provided with statistics regarding their maintenance and reliever use (these are automatically saved), and the user is provided with an overview of the experienced trigger events. Which has probably decreased over time, if the user has increased his use of the daily medication. This overview is used as evidence to support the benefits of the daily intake of the medication use on a person’s life.
5.3.3 Usertests Round 1

Method

A paper prototype was created for all the different screens that appear in the app. The education on the reliever and maintenance medication was not worked out but instead was provided on a paper sheet and verbally communicated to the participants.

A step-by-step scenario was used to let people walk through all the different elements of the concept. The participants were asked to think out loud. The elements used in the app were not explained to the participants beforehand in order to determine if the visualisations were understandable and intuitive. Figure 40 shows a couple of the created cards.

The paper prototype consisted out the following elements:

- Personal-goal setting
- Character walks and falls a couple of times
- Changes in weather and character
- Feedback form for trigger moment
- Weekly report
- Random rewards
- End report

Afterwards, subjective measures with a five-point Likert-type scale on satisfaction and usefulness took place, and an open conversation was held concerning likes, dislikes and recommendations. The outcomes of the closed questions on satisfaction and usability are provided in Appendix F.

Results

A user test took place with four patients with asthma (20–25 years old), who were all prescribed ICS. The tests took place with one individual at a time and lasted around one hour (Figure 41).

Positive

- Participants liked the challenge of adhering for six weeks. Working towards something, instead of being on an endless journey, was perceived as positive.
- The storyline that reflects the user’s behaviour and effect of the medication was clear and perceived as fun – especially in combination with the statistics, which made the progress more concrete.
- In addition, two people did not know the exact specification of their medication, and the explanation of the differences in medication prior to the test was seen useful.
- All participants expressed that they would like to use the application to manage their medication.

Most important points of attention

- Three participants found it difficult to identify a personal event linked to the duration of six weeks. They thought the commitment to the goal of being adherent for six weeks would already provide enough motivation.
- Additionally, the cloud character was perceived a bit childish by two participants. However, all four expressed enjoying the use of the character.
Conclusions

One participant mentioned that it would make more sense to provide the overview of a week instead of three days. Some of the participants expressed that they would like to have more static data of their medication use alongside the visual overview.

The weekly report now consists of a lot of texts. Participants explained that they liked the statistics in the end since it provides a clear overview of their intake. Therefore the weekly report will be adjusted to provide the user with an abstract version of their medication use and trigger development as well.

Persons expressed to find it hard to come up with an event that is linked to six weeks. However when talking about personal moments, they were able to come up with different situations they would like to experience less symptoms. However this is not always a specific event (such as an upcoming holiday trip), but can also be more intertwined in their daily life.

Persons expressed that he would like to experience less symptoms when visiting his parents or when arriving at the university after cycling. Therefore it should be possible to not frame the personal goal as an event that will happen in 6 weeks, but that this can also be a more general daily situation, where people would like to work on.

Figure 40. Part of the different screens created for the user test

Figure 41. The concept was tested with a paper prototype on four students with asthma
5.3.5 Adjustments

After the user test and feedback of different stakeholders, some adjustments were made to the concept.

The timeline of three days was changed into a weekly overview (Figure 42). Next to a cloud character a more ‘human’ like figure that becomes stronger, filling his longs, was created (this to provide the users of a different option). Also the colour scheme was adjusted, to make the overall look of the app a more grown-up (Figure 44). Additionally, the trigger feedback form was adjusted and the text was replaced with icons. Prior to this test, this was not yet been worked out.

Next to this, the weekly reports conclude a more statistic overview of the medication intake (Figure 43). Finally, the personal goal does not have to be a personal event that is linked to the 6 weeks period.

The storyboard on the next page shows the final concept: Ademgenoot.
(1) Myrthe is used to her limited lung capacity and uses her reliever often.

(2) The doctor says ‘Give the Ademgenoot 6 weeks challenge a try’.

(3) Myrthe sets a personal goal and a daily alarm.

(4) Myrthe starts to take the daily medication with good cheer.

(5) But, during a fun week with friends, Myrthe forgets...... She is motivated to uptake the daily medication again, because of Brad.

(6) Myrthe uses her reliever and is asked to provide feedback.

(7) Ademgenoot reflects that she is on track again with her daily medication and is doing a good job.

(8) After six weeks, she sees and experiences that she has more control over her symptoms.
EVALUATION

This chapter describes the user study that was done to find out whether the intervention would be able to motivate patients to adhere to their treatment in its current form, and in what way the effectiveness of the design can be improved.

In this chapter
- 6.1 User test round 2
- 6.1.1 Prototype
- 6.1.2 User test 1
- 6.1.3 User test 2
- 6.2 Future recommendations

6.1 USER TEST ROUND 2

6.1.1 Prototype

The main objective was to discover if the designed concept could motivate patients to adhere to their prescribed medication and to determine how the design could be improved.

In order to provide good feedback on whether the concept could motivate users to use their medication, it was important that participants also use the concept for a few days. In order to make this possible, a WhatsApp prototype (without the need of a working application and a smart inhaler) was created, as described below.

Explanation of prototype

A five-day challenge was set up, and every day at 12:00, the participants were sent these questions through VPhatApp:

1. Did you use your maintenance medication this morning (yes/no)?
2. Did you use your reliever medication yesterday (yes/no)?

Each day, the participants also received a personalized image of a screen reflecting their medication use over WhatsApp.
Procedure
Participants received a message daily through WhatsApp with the question if they used medication. In result of the answers of the participants, they received a personalized image of the screen that resembled the screen they would see if they used the app.

At the end of the five days a face-to-face interview took place with each participant. This interview consisted of the following parts (The questions can be found in Appendix H):

1. A discussion about the experience of receiving the screens the last couple of days, on understandability, motivation and impact on the participant’s daily life.
2. After discussing the experience of receiving the screens, the whole concept was walked through with the participants. Because not all parts of the app were included in the WhatsApp prototype. Several additional questions were asked on the following subjects:
   a. Motivation & “gaming” experience
   b. Perceived control over asthma
   c. Usefulness

Results
Ease of use
Easy to use: All four participants indicated that the app was easy to understand. When they received the screens, two participants had not linked the ‘days’ to the ‘sticks’. They only saw that the character progressed when they took their medication. During the final review of the received screens, this immediately became clear to them. They understood that if they actually would use the app on their phone, this would also be clearer than receiving images on WhatsApp. Furthermore, all elements of the app were experienced as clear.

No negative feelings: Participants indicated that they had not experienced it as a nuisance to pass on their use of medication and to open visualizations for five days. In addition, all four participants said that they thought it was helpful to be more aware of their asthma for a while because they often forget to pay attention to it. Furthermore, one participant mentioned that this was related to the fact that the app had no medical appearance. They thought this would also apply to the intended use of the app for six weeks. The four participants also said that because most of the app’s features happen automatically, the participants would experience its use as easy. Next to this, all participants indicated that they wanted to use the app for a longer period of time.

1. Maintenance medication: Screen included character falling in the water (answer = no) or character walking towards the island (answer = yes). Next to this, small changes in the weather or character took place every other day (good or bad changes).
2. Reliever medication: If participants used their reliever medication (answer = yes), they received an additional screen asking about their trigger event. If participants did not use reliever medication (answer = no), no additional screen was sent.
3. On the last day, participants received a report with a schematic overview of their medication use and triggers in addition to the visual overview.

Benefits
In this way, the participants are able to experience the following:
• Daily visualizations of their medication use on their phone
• The use of the application in their everyday context
• The setting of a challenge

Drawbacks
• Lacks the experience of automatically recording medication use and therefore asks for more effort of the participants
• Extra control of researcher; this can influence the experience and motivation of the participants to take their daily medication.

6.1.2 User test 1
Method
The user test took 5 days. An interview (duration: 1.5h) took place at the end of the 5 days period.

Participants
A poster was created to recruit participants and it was placed on different channels (see Appendix G). Two participants were selected who indicated that they were not at all adherent to their medication and 2 participants were selected who indicated that they sometimes forgot to take the medication, but that they did recognize themselves in the statements of the poster (I find it hard to feel effect/I don’t need medication when I feel well/I am very busy).

Material
Prior to the test, the participants received a document on their mail with a short explanation of the different medication, a brief introduction of the concept and the explanation about the communication of their medication use in the upcoming days. The participants used their own telephone to communicate their medication use and to receive images from the researcher via WhatsApp. The interview that took place later was recorded. Furthermore, the personal images of the different screens the participants had received were print out to discuss during the test and a Powerpoint was used, which included all the different steps of the concept.

1. I thought it was great that I was working on it. I am normally not very busy with it. I am not aware that I am more tired and more stuffy - A.B.
I didn’t really look at the pictures. I mainly want to make it every day. I would find it annoying if one of those wooden sticks was up. That just has to be all straight - T.M.

Motivation and medication use

One-week and six-week challenge: Three participants said that they had taken their medication more in recent days than they did before. One indicated that she only occasionally forgets to take her medication and that her intake stayed the same.

One of the participants stated that the extra control of the researcher was the biggest influence in this. In contrast with one of the participants that expressed to feel most triggered by the story. She responded negative on almost all the messages of the researcher (four out of five), but the grey images of the character sinking in the water, made her realize to take better care of herself and motivated her to take her medication in the evening. The other two participants indicated that reaching the goal of the island and to not miss a day were the biggest motivators during the 5-days challenge.

All four participants clearly expressed that they would accept the six-week challenge. Three indicated that they would take up the challenge to improve their use of medication. Two said that they were not taking their medication at all but that they were quite bothered by their asthma. They said they wanted to take their medication but that they found it difficult to actually take the step. A challenge would be a good motivation for them to start taking their medication. The participants

Opportunity for quick feedback: Participants liked that feedback on triggers could be provided in an easy way. They liked the idea of a pop-up appearing on their phone and of only having to click on icons, which could be done quickly and easily.

Metaphor & Character

Look and feel: All participants liked that the visualisations gave a quick impression and feeling regarding their medication use. Participants indicated that they did not pay much attention to the details but that the colour, weather and character walking or lying in the water gave a clear and quick overview of how the person was doing. The style of the app was much appreciated.

I thought it was nice. You can see which day it is. It is a nice layout, and I thought it was nice to use a character because it appealed to you personally - T.C.

In addition to the daily screens, participants responded positively to the visual overview of the six weeks afterwards. However, one participant mentioned that it was unfortunate that fish decrease if they use less of the reliever medication, pointing out that fewer trigger moments is a good thing but that the user of the app gets nothing in return in the game environment.

Fish decrease if you take less medication – that’s a shame. You will be punished if you do not use an reliever or something. That whole element of the reliever is less for me. But I want some fish - L.J.

Curiosity: All participants indicated that the app was not boring and that enough was happening. The changes in the environment and character were experienced as pleasant. One of the participants indicated that it was important that small surprises occurred in the environment or that different themes appeared each week. Three participants were curious about what their next screen would be during the five day test.

It’s nice to get pictures that you don’t know. For example, it was surprising that my character had grown. Difference in colour and surprising elements in the area, but that it is minimal - A.B.

One participant said that she did not pay much attention to the image she received. She first looked to the bottom left corner at the forgotten/taken sign. She found it particularly important that it was visible whether or not she had taken medication and that she did not miss a day. When asked if this was because she did not find the story interesting enough, she said that the story is less important to her. She mainly wanted to achieve the goal and not miss a day, so how this was visually represented did not matter to her as much. However, she still considered it important that some kind of visualisation be used.

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"It was surprising that my character had grown. Difference in colour and surprising elements in the area, but that it is minimal." - A.B.

"I thought it was nice. You can see which day it is. It is a nice layout, and I thought it was nice to use a character because it appealed to you personally." - T.C.

"One participant said that she did not pay much attention to the image she received. She first looked to the bottom left corner at the forgotten/taken sign. She found it particularly important that it was visible whether or not she had taken medication and that she did not miss a day. When asked if this was because she did not find the story interesting enough, she said that the story is less important to her. She mainly wanted to achieve the goal and not miss a day, so how this was visually represented did not matter to her as much. However, she still considered it important that some kind of visualisation be used." - T.C.

"I didn’t really look at the pictures. I mainly want to make it every day. I would find it annoying if one of those wooden sticks was up. That just has to be all straight." - T.M.
said that the one-week challenge had already helped them with this. In addition to motivating them to start, these two participants also indicated that the six-week period would help them to make daily uptake of their medication a habit. One of the participants indicated that she had deliberately put her medication beside her bed last week so that she did not forget.

Yes I would. Because I’ve wanted to try for a long time, because I want to see if it works and I find it hard to motivate myself. The past week has already helped in this. I want to try such an app anyway - L.J.

One of the participants said she would take on the challenge with regard to keeping track of her triggers. She indicated that she almost always took her medication and that that element of the app was less interesting for her. However, she was curious about insights into her trigger moments.

The confrontation of the screen worked for me. I’m doing a bad job. I really have to do something. I am very sensitive to colour; I like that, that grey sky with the character I received. I started with sunshine and beautiful sky - T.S.

The other participants did not receive any negative screens, so the negative consequences only became clear to them when the entire app was discussed during the interview. The participants indicated that this would rather motivate them to get the character back on track. Two participants indicated that it was important that the character be immediately on shore again and does not float up in steps.

Effect of maintenance medication: Three of the four participants were particularly curious and unknowledgeable about what the effect of the medication actually is. Gaining that knowledge was the greatest motivation for them to use the app. They wanted to see faithfully taking their medication make a difference.

I now have more symptoms, and I want to try to see if it helps. I have not used it for so long now and am learning to live a little with that. I am short of breath. If I use it for a longer period, do I notice it? I am very curious about that. - A.B.

Two participants indicated that the use of the reliever would not be a good benchmark for them to measure whether things are going better. They reported almost never using their reliever. Both indicated that they could suffer from shortness of breath for periods of time but that they still do not use their reliever. They said they would therefore like to measure the effect of the medication in a different way. The other participants indicated that this could be done, for example, by rating on a scale how their lung content feels like or to use her personal goal for this. She mentioned that the user could be rewarded for this with a fish in the water (instead of linking this to the reliever).

I don’t take the reliever for all the times that I have trigger moments. Better if it is requested per week. Otherwise, it is not entirely correct - T.S.

Or a percentage. How my asthma is feeling. If I had to fill in now how my asthma is doing, I would be less comfortable at the moment. Now more in the red direction, and hopefully at the end I’m more towards the green - A.B.
Influence of researcher: The participants were also asked what the impact of the app contact with the researcher was on their behaviour. One person indicated that the app contact with the researcher was the main motivator for taking her medication, as this felt like an extra check. The other three participants indicated that the extra contact did not result in extra motivation. Instead, the challenge for them was to not miss a day, and the metaphor was their strongest motivator. Nevertheless, being aware of it and having app contact did work as a reminder.

Perceived control Insights regarding trigger events and development: Three participants indicated that if the app helped them to take the medication and thus to experience fewer symptoms or trigger moments, this would give them more sense of control over their symptoms. Participants indicated that it would be nice if this would appear in the overview, but two participants also indicated that this could be achieved by using their personal goal as a benchmark. One participant said, for example, that she would like to arrive at meetings with less breathlessness, which she is ashamed of. If she noticed that this was decreasing because she had taken her medication faithfully for a few weeks, this would strengthen her sense of control over her asthma.

If I would notice that I am able to give a presentation for a longer period of time. When I can talk for a long time, without getting out of breath. And if I notice that I need my blue inhaler less.

A.B.

All four participants also indicated that using the app would give them more insight into their asthma by helping them become more aware of their trigger moments. Thus, they reported that it would be useful to keep track of their triggers for a period of time with the app so that they could respond better to such moments.

Ease of use The participants indicated that the app was user-friendly. However, misinterpretation of the used elements by the participants should be further investigated. The participants only received images at this stage, the details were not explained to them. Therefore two of the participants did not pay attention to the sticks that indicate the days. On the other hand they stated that paying a bit more attention to the images would make the connection between the inhaler and application more clear.

In addition, it is important that the app does not evoke a feeling of being patient among the participants, this does not seem to be the case. All participants indicated that the five-day use did not elicit negative feelings and that being more aware of asthma was experienced as positive. The non-clinical appearance of the app, mentioned by one participant,
One of the participants stated that the extra control of the medication use during the 5 days WhatsApp challenge would work for a longer period of time and would accept the six week period of taking their medication as prescribed.

The other two participants indicated that the biggest motivators during the 5 days challenge was reaching the goal of the island and the automatic registration of the medication, mentioned by all four participants, contributes to this on the longer run.

One of the participants expressed that they would like to use the app for a longer period of time and would accept the six week period of taking their medication as prescribed. Three out of four participants were most curious if the daily intake would make a difference on their lives. One of the participants expressed that she almost never forgets her daily medication and also did not increase the use of her medication the past five days (she did take the medication all five days). She therefore did not really match the target group ‘Ademgenoot’. However, she expressed to still like to use the app, because she is interested in keeping track of her triggers for a period of time. This shows that the app has features that are useful for people who do take their daily medication as well.

The participants pointed out the importance of subtle surprise elements in the storyline of ‘Ademgenoot’ to make people aware of the effect of their daily medication on their daily life. They would like to use the application to see if the daily intake would make a difference on their lives. One of the participants mentioned that this would not work for them, because they often do not use their reliever medication when they experience symptoms. Therefore the app will not show them the impact of the medication on their daily wellbeing. Both mentioned that they would like to have an additional way of measuring symptom experiences. One of the participants gave the example to score her experienced symptoms based on her personal goal, taking the stairs to her apartment or to express the volume of her lungs in percentages. Therefore, it will be important that the application provides additional ways to measure the patient’s daily wellbeing.

The other two participants thought that the challenge and storyline appears to be a good combination to motivate people to uptake the daily medication. Three out of four participants were most curious if the daily intake would make a difference on their lives. One of the participants expressed that she never forgets her daily medication and also did not increase the use of her medication the past five days (she did take the medication all five days). She therefore did not really match the target group ‘Ademgenoot’. However, she expressed to still like to use the app, because she is interested in keeping track of her triggers for a period of time. This shows that the app has features that are useful for people who do take their daily medication as well.

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The participants indicated that the app would increase the control over their medication use, because of the automatic registration of their medication and of the accepted challenge, which will less likely make them to forget to take the medication.

In addition, three participants expressed to find it difficult to experience the effect of the medication and they that they are very interested in the results of the intake of the daily medication on their daily life. They would like to use the application to see if the daily intake would make a difference in their symptom experiences. They expressed that if they would experience less symptoms because of the maintenance medication, this would provide them a feeling of control over their symptoms. In addition, three out of four participants were very interested in their trigger events, and thought that the app could support them in recognizing those moments.

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Effect of the medication on the patients’ daily wellbeing

At this stage, the app works with the self-recognition, which saves the number of trigger events experienced. Two of the participants mentioned that this would not work for them, because they often do not use their reliever medication when they experience symptoms. Therefore the app will not show them the impact of the medication on their daily wellbeing. Both mentioned that they would like to have an additional way of measuring symptom experiences. One of the participants gave the example to score her experienced symptoms based on her personal goal, taking the stairs to her apartment or to express the volume of her lungs in percentages. Therefore, it will be important that the application provides additional ways to measure the patient’s daily wellbeing.

The other two participants mentioned that using the app would already make her more aware of her symptom experiences. She noticed that she would be able to give presentations for a longer period of time, this would be a motivator for her to continue with the daily intake. However, it will still be useful as a tool in their daily life. One of the participants also mentioned that using the app, to make sure that the user is aware of those positive changes and to experience those moments consciously.
6.1.3 USER TEST 2

Method

One additional feedback session took place to gain more insights on the potential and drawbacks of the concept with patients that expressed to be very adherent to their treatment. A lot can be learned from those patients, since they know how daily interventions affect their life and are experts in self-managing their condition.

The participants were walked through the concept by the use of a PowerPoint and afterwards a discussion took place (see Figure 48). First the participants were able to express their first thoughts about the concept, after this a discussion took place on if they thought the concept would be able to motivate people to take their prescribed medication. In the end the topics ease of use, usefulness and if the intervention could lead to an undesired effect on patient life were discussed.

The questions can be found in Appendix I, also the answers given on ease of use, attractiveness and satisfaction, that were used during the discussion can be found here.

Results

Two women with asthma and both prescribed to ICS provided feedback on the concept. One of the participants mentioned that she would find it important that people would be able to pick their own character, the character of a breath cloud (the more human-like figure was not shown in the PowerPoint), would be too childish for her. However, if she could personalize the character, she would see the concept fit adults as well.

Both participants expressed that they thought the concept would be easy to use and was perceived very understandable. One of the participants mentioned that she would see the concept work for starters (people who just had the diagnose of asthma) and children. Next to this, she expressed to be curious how people with low health literacy would react on the concept. Since the concept makes the disease development and daily intake very visual.

Both participants liked the visual style and story of the application. They especially liked the statistics of the medication use in combination with the game elements. The combination of both was seen strong and they thought this could motivate patients to take their daily medication. However, they did mention that it will be important to incorporate more evaluation moments.

The feedback form on trigger moments alone was not seen enough. People may daily take their medication and feel horrible, and the app shows them a shining environment with a strong character.

**If the application indicates that you must feel amazing, bright and all... because you take your medication every day. But you feel terrible - J.O.

Therefore, both expressed that patients should be able to provide more feedback on how they feel. They thought that the frequency of triggers and logging experienced triggers does not reflect this enough.

They also saw an important role of the caregiver, when people use the application. They would like to see that patients evaluate the intake of the daily medication with the HCP after three weeks and at the end of the six weeks period. In addition to the previous mentioned, people may take their daily medication as prescribed, but do not see improvements. This could be the result of not being prescribed to the right doses of medication and may ask for adjustments in the treatment.

They indicated that the concept could make the communication between HCP and patient easy, since the app shows the experienced triggers and medication use of the patients over a period of time. In addition, the app makes it possible to reflect on patients’ behaviour. If patients experienced a lot of symptoms, but also did not take the medication, this is clearly visible in the app.

Conclusion

The app is easy to understand and useful.

Both participants thought the concept would be easy to understand. The combination of the storyline with game elements and the statistics was perceived strong. Both participants expressed that they would see the concept work (in motivating patients to take the prescribed medication), especially because of this combination.

Other target groups

According to one participant, two other target groups, namely children and people with low health literacy, could be interesting to focus on as well. To test if the concept would be applicable for those patient groups, additional user studies should take place.

The two most important insights gained from this feedback session are the importance of including evaluation moments in the app based on how the patient feels and the importance of involving the HCP in the six weeks period.

Provide a different way for feedback on wellbeing

The app shows the patients a shining environment with a strong character, because patients take their daily medication. But if patients feel terrible, this may be frustrating. Providing feedback on triggers was not seen enough, since this lacks to reflect the actual feeling of the patients. Therefore patients
The final part of this thesis presents the recommendations followed from the gained insights during the evaluation of ‘Ademgenoot’ with users and experts.

Look into additional ways to measure the effect of the medication on the daily wellbeing

The main recommendation of this project is to investigate in additional ways to track the patients’ daily wellbeing in the application. The end user tests showed that the use of feedback on the reliever medication usage (to measure the frequency of symptom experiences and to indicate different trigger events) is not relevant for all patients. Not all patients use their reliever medication when they are bothered by symptoms and therefore will not receive a feedback form. In addition, patients may open the app environment without any trigger moments (since they did not use the reliever medication), but at the same time still feel terrible.

On the other hand, some patients did find it useful to provide feedback on their reliever. It helped them to gain insights in their asthma and disease development. Hence, it is advisable to keep this feature in the end design. However, research should also be performed to find alternatives that could be used to capture patients’ wellbeing. Two alternatives are proposed based on the field study and user tests.

One alternative could be to incorporate the ACQ6, a validated questionnaire used to measure asthma control. HCPs mentioned to use the ACQ6 to identify how well the asthma of their patients is controlled and to track how the asthma develops over time. The questionnaire addresses the following topics over a patients’ past week: waking up due to asthma, severity of symptoms, limitation in activities, shortness of breath, wheeze and frequency of reliever use.

Another alternative could be to use personal (smaller) goals based on the everyday limitations of asthma. Some patients clearly identified daily activities where they would like to reduce their symptom experience (e.g. taking the stairs, giving a presentation or cycling to university). These moments were used multiple times during the user test as the personal goal to start the daily treatment. Hence these could be convenient moments to measure the effect of the medication on the patients’ daily wellbeing, since patients indicate the importance of these moments.

From a patients’ point of view it is recommendable, that it would be most effective to combine the ACQ with a patients’ own personal experiences. More research is needed to accomplish this kind of combination.

From a patients’ point of view it is recommendable, that it would be most effective to combine the ACQ with a patients’ own personal experiences.
Patients indicated the bar charts are important to have a statistic overview during the end user test, however the patients only received images for five days in a row (the app should be used for a six week period), it is not validated that the storyline will be interesting enough for a longer period of time. The design cannot replace the HCP, therefore evaluation moments with the HCP will stay necessary. Following evaluation of the concept with a practice nurse and the feedback session with two patients, it became clear that it is important to look together with the HCP into potential causes. Either it could be that the patient’s wellbeing is not improved, it is recommended that the application communicates the importance of discussing the outcomes of the medication intake with the patients’ HCP. Patients and HCPs mentioned this could be considered a strength of the application as well. Since, patients often find it difficult to communicate their disease development towards their HCP. Therefore the application can be beneficial to offer the patients a tool to communicate their medication use in combination with the frequency of triggers during the appointment with their HCP. Thereby facilitating the HCP in giving more personalized feedback.

Future testing of Ademgenoot

A couple of important limitations of this project should be taken into account when evaluating the application. First, the tested period of time was short, the long term motivation to use the application and to take the medication as prescribed has not been tested. Secondly, the intermediate test included two men and two female, but the end test group included only female. Finally, the medication was not automatically connected to the application, therefore the influence of the researcher cannot be ignored. This could have resulted in patients who better adhere to their treatment, this was confirmed by one participant. During the interviews, one of the participants already mentioned the importance of surprising elements and the opportunity to use different themes per week. To retain the element of surprise it is recommended to include this in the design and to include enough randomness of small things happening in the environment. Also, the islands, bridges and elements appearing in the background and weather could be changed to keep the user curious and prevent disengagement. However, it is important to keep this minimalistic, since different participants mentioned that they had problems interpreting the weather and character were the main points of attention in the application and they expressed not to like the shortcut weather and character.

Moreover, one of the participants mentioned that it was a pity that when she uses her reliever less, the sea becomes more empty. Less piranhas is something positive, however less fishes is not. This remark could be addressed by filling the sea when the use of the reliever medication is decreasing. However, HCPs and Asthazenza also pointed out that patients should not be punished when they use their reliever medication, since the reliever medication prevents them of having a lung attack. Another option could therefore be found in earning ‘sea life’ by providing more continuous feedback on wellbeing mentioned in point one: when the weather and sea life that stops by, to keep the user curious to open the app.

The project focused on the communication of data with the use of narrative game-elements to motivate patients to adhere to their daily treatment. The abstract overviews of the gathered data were designed to provide the patients of an impression of how the statistics on this medication use in combination with the frequency of triggers during the appointment with their HCP. Therefore the application can be beneficial to offer the patients a tool to communicate their medication use in combination with the frequency of triggers during the appointment with their HCP. Therefore facilitating the HCP in giving more personalized feedback. The design cannot replace the HCP, therefore evaluation moments with the HCP will stay necessary.

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In the longer term, future opportunities may be found in testing the concept with people with low health literacy, because of its visual way of communicating medical data and children. Especially the latter target group was mentioned a couple of times during the development of ‘Ademgenoot’. When children are just diagnosed with asthma and have to learn to integrate the intake in their daily life, the use of ‘Ademgenoot’ including its metaphor and game elements, could be a good tool to motivate children to start their treatment.

Look into other diseases & medication intake

‘Ademgenoot’ is designed to increase patients motivation to take their medication as prescribed via amongst others a goal-oriented approach. Medication nonadherence caused by a lack of motivation, perceived benefit of the medication is however not unique for asthma, but has been acknowledged as a complex health problem for other patient groups as well. Hence, other patients that need daily medication may benefit from ‘Ademgenoot’ as well. Especially when considering that ‘Ademgenoot’ provides the medication intake over a timeline and combines practicality with playfulness. One important functionality of the concept for asthma patients is the automatic registration of inhaler/medication usage via of Bluetooth sensors. This is something to take into consideration, when applying the principles of this app on a solution for other patient groups. In the nearby future, there will be new opportunities for this, since automatic dose dispensers are developed and provided at the moment.

Organization Consultation on Severe Asthma. Journal of Allergy and Clinical Immunology, 126(5), 926-938.


Appendix A: Project brief

IDE Master Graduation
Project team, Procedural checks and personal Project brief

STUDENT DATA & MASTER PROGRAMME

Save this form according to the format “IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy”.

Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1!

** chair dept. / section:
** mentor dept. / section:

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right!

Ensure a heterogeneous team.

In case you wish to include two team members from the same section, please explain why.

2nd mentor Second mentor only applies in case the assignment is hosted by an external organisation.

IDE master(s):

2nd non-IDE master:

Your master programme (only select the options that apply to you):

Medisign
Tech. in Sustainable Design
Entrepreneurship

Honours Programme Master

individual programme: (give date of approval)

specialisation / annotation:

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

This document contains the agreements made between student and supervisory team about the student’s IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

• The student defines the team, what he/she is going to do/deliver and how that will come about.
• SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student’s registration and study progress.
• IDE’s Board of Examiners confirms if the student is allowed to start the Graduation Project.

comments (optional)
Appendix B: Online Survey (n=20)
Als mensen zich niet te belemmerd voelen in hun dagelijks leven, zijn ze vaker slordig met hun medicatie. Mensen die ernstig astma hebben, kunnen zich dit niet veroorloven. Maar ook zij vergeten het weleens.

Factoren:
- Onregelmatig leven & vergeten
- Misverstanden
- Gewenning beperkte longinhoud
- Geen effect voelen
- Bijwerkingen
- Soms ook gewoon geen zin in hebben
- Symptomen niet aan ziekte koppelen
- Als het een periode goed gaat weer stoppen
- Geen symptomen, geen medicatie
- Schaamte

Categorie
Therapieontrouw

Quotes

• “Ik ben heel therapietrouw, maar ik ben wel heel goed in dingen vergeten (A).”

• “Ik had heel veel van mijn astma en hardkloppingen en keelpijn (gebruik luchtwegverwijder). Toen ben ik naar de dokter gegaan, maar toen zei ze dat ik ontstekingsremmers ook voor keelpijn zouden zorgen. Maar omdat ik toen al aan het naar behoren, dacht ik, ik wacht daarmee. Dat volde er en toen niet tot de dokter. Daarom is er geen nieuwe meer gehaald.”

• “Ik heb ook die oranje disk en die moet ik wel dagelijks gebruiken, als die zou moeten werken. Maar ik heb er geen zin in, omdat die symptomen moeten. Maar ik heb er geen idee van, omdat je ziek moet zijn.”

• “Is het nu mijn conditie of mijn ademhaling, dat weet ik niet goed. Alleen vraag ik mij ook af, omdat het een soort controle is. Dan ben ik daar niet doorgaand voor.”

• “En als ik niet meer student ben, denk ik dat er meer regelmaat zal komen. Zeker bij het tandenpoetsen.”

• “Ik heb astma sinds mijn zesde en je went aan je longcapaciteit. Eigenlijk kwam ik er drie jaar geleden achter dat het heel slecht was. Ik merk het wel als het slecht gaat, maar anders niet.”

• “Ik vind het lastig om effect te voelen, drie jaar geleden gingen die testen bij de longarts veel beter, maar ik had het niet gemerkt.”

• “Doe dan ook wat je weet, en dan gaat het weer goed en stop ik weer. Dan denk ik dat je het niet meer nodig hebt.”

• “Ik heb altijd geen antwoord van de dokter. Maar ik heb wel iedereen die ik kende gewoon geen zin in hebben. Dan is er weleens een reden.”

• “Iedereen is erg mede, denken dat ik het kan halen. Het is heel geweldig. Maar ik heb het dus niet.”

• “Ik slap weleens heel slecht. Dus je hoofd is moe en je lichaam is mee, en dan vergeet je dingen. Maar ik weet dat dat moet.”

• “Zoals wel elke manier van latere in het openbaar. Toch toegerust dat iedereen niet kan.”

Categorie
Geen controle (lange termijn)

Quotes

• “Altijd hard werken met astma, maar je moet er overheen gekomen (A).”

• “Extreem verschil met vroeger, verkeer was ik alweer. En heel hard dat je dat niet meer kan (A).”

• “Het is al even geworden, maar als ik 15 jaar geleden.”

• “Ik ben bij mij weer achteraf. Ik ben pas gedaagd met astma toen ik 25 was. Ik had het hypnozoeastma en dat is met de huidige medicatie moeilijk te behandelen.”

Categorie
Geen controle (tijdens aanval)

Quotes

• “Heel veel mensen hebben ook geen idee wat ze moeten doen, tijdens zo'n aanval. Ik wil dan niet huilen, maar door mijn ademhaling kan ik niks zeggen. Dus andere mensen nemen ook in paniek. Maar ik heb al les over hoe het gaat. Ik heb het een keer heel goed gehaald. Toen moest er een ambulance komen. Ik begon het weer te verstikken en te verklamperen.”

• “Ik zit dan helemaal dicht en krijg geen lucht meer. Heel veel mensen hebben ook geen idee wat ze moeten doen, tijdens zo'n aanval. Ik wil dan niet huilen, maar door mijn ademhaling kan ik niks zeggen. Dus andere mensen nemen ook in paniek. Maar ik heb al les over hoe het gaat. Ik heb het een keer heel goed gehaald. Toen moest er een ambulance komen. Ik begon het weer te verstikken en te verklamperen.”

• “Dat is best erg, want je kent het gevoel (langgerekend). Maar uit enthousiasme voor de sport wil je door gaan (A).”
Mensen willen liever geen aanpassingen doen of met hun astma bezig zijn. De toekomst is nog ver weg. Op dit moment heeft astma managen geen prioriteit.

**Quotes**

**Leven in het hier en nu**

"Dat je niet alleen maar bezig bent met de ziekte (D)"

"Of op de vereniging als ik in et rokershok heb gestaan, dan heb ik er last. En in de periodes dat ik veel dronk, toen had ik er wel echt last van (E)."

"Nee ik heb geen goed ritme, ik ben student. Ik ben er niet mee bezig. Alcohol is niet goed voor je, roken is niet goed voor je, roken is niet goed voor je en ik is al of al je dunne mond (F)."

"Ik denk dat ik mijn medicatie vaak te laat neem, dus bij een aanval. Dan denk ik het gaat wel goed (F)."

"Ik rook zelf niet, maar dan sta ik bij het rokershok. Ik heb ook tegen mijn vriendinnetjes gezegd, zodra ik begin te hoesten, stuur me weg (F)."

"Mijn medicatie is al een halfjaar op. Ik heb zelf geen actie ondernomen omdat het wel prima ging. Maar nu gaat het wel echt niet zo goed. Nu moet ik het recept ophalen, dat duurt allemaal langer. (S)"

"Nee met mijn ernst ben ik niet beperkt en zo wil ik mij ook niet voelen (S)"

Meten kan fijn zijn omdat het de ziekte tastbaar maakt en iemand bewust kan maken van de ernst. Dit kan ook confronterend zijn. Maar metingen zeggen niet altijd iets.

**Quotes**

**Meten**

"Zo’n longfunctietest vind ik een beetje shocking eigenlijk. Dit is normaal en jij zit hier (E)"

"En mijn hartslag als die omhoog gaat, zegt het ook wel wat (A)."

"Bij peakflow is het hard uitblazen. Dat gaat bij mij altijd goed. Dus dat zegt niks. Die spieren zijn bij mij enorm getraind. Ik heb een saturatiemeter en dat zegt meer. Als ik onder de 95 zak, dan moet ik wel gaan bellen (A)"

"Toen kwam ik er niet zo goed uit. Ben ik naar de huisarts geweest, maar mijn zuurstofsaturatie was goed, ik zag er normaal uit en ging op de fiets. Maar ik was daar mijn gevoel dat ik te weinig lucht kreeg. Alleen de metingen zagen dat niet. Toen konden ze niks voor mij doen en dat is heel frustrerend (S)"

"Toen ben ik naar een longarts gegaan en had ik nog maar een 60/70 longcapaciteit en dat mijn lichaam ermee vermoedelijk vrede. Ik was daar geen zin in, ik zag dat niet meteen, maar toch lichaam wil. Daar hebben ze toen goed op gereageerd met Relvar. (S)"

"Zijn longfunctietest is ook een beetje shockend eigenlijk. Dit is normaal en jij zit hier (E)"

"En mijn hartslag als die omhoog gaat, zegt het ook wel wat (A)."

"Bij peakflow is het hard uitblazen. Dat gaat bij mij altijd goed. Dus dat zegt niks. De spieren zijn bij mij enorm getraind. Ik heb een saturatiemeter en dat zegt meer. Als ik onder de 95 zak, dan moet ik wel gaan bellen (A)"

"Toen kwam ik er niet zo goed uit. Ben ik naar de huisarts geweest, maar mijn zuurstofsaturatie was goed, ik zag er normaal uit en ging op de fiets. Maar ik was daar mijn gevoel dat ik te weinig lucht kreeg. Alleen de metingen zagen dat niet. Toen konden ze niks voor mij doen en dat is heel frustrerend (S)"

"Toen ben ik naar een longarts gegaan en had ik nog maar een 60/70 longcapaciteit en dat mijn lichaam ermee vermoedelijk vrede. Ik was daar geen zin in, ik zag dat niet meteen, maar toch lichaam wil. Daar hebben ze toen goed op gereageerd met Relvar. (S)"

**Geen controle (korte termijn)**

**Quotes**

"Als ik acht kilometer ga rennen en op vier kilometer krijg ik een aanval, dan kom ik niet meer thuis en dat is heel vervelend (S)"

"Pufjes heb ik altijd bij me. Alle tassen en jaszakken, ze werven door het huis (S)"

"Ik merk dat ik er meer last van met hockeyen (E)"

"Maar het gaat soms ook gewoon niet goed. Dan zie ik dat niet (A)."

"Ik denk wel dat astma mij limiteert in mijn sport en resultaten (S)"

"En die moeheid is wel een beperkende factor, dat ik niet even ergens kan fietsen. Dat is lastig, het gaat hier en hier. En er zijn momenten dat ik dat heel boos over ben (A)"

"De tijd die ik dan nodig heb om van het huis naar de vereniging te komen, is bijna anderhalve uren (A)"

"Ik word ook beperkt doordat mijn longen reageren op van alles en nog wat. Op prikkels. Naar een restaurant gaat goed mis lukken. Omdat er dan een openkeuken is (A)"

"Ik heb een mexicaanse vader en een Nederlandse moeder. Ik heb geen enkel principe. Maar allemaal goed plezier, dat staat mij moeder van de ongeloof (A)"

"Ik heb een vatbekkenbehandeling in Nederland. Het heeft heel veel last, bij de eerste dag als een steen op de bank. Ik heb veel pufjes, maar daar wordt niks van gemaakt. En alle hard proberen, dat staat mij moeder van de ongeloof. En die vissesoopjes (A)"

"Ik ga ervan uit dat we van een week iets nieuws zijn, maar dan ook veel pufjes doen. Door het hebben van een nieuwe generatie pufjes (A)"

"Dat ben ik blij met. Ik ben een rokershok en daar wordt het veel ingekleurd. Daar zijn veel mensen die daar blijven, en dat is nog steeds niet goed voor je (E)"

"Mensen willen liever geen aanpassingen doen of met hun astma bezig zijn. De toekomst is nog ver weg. Op dit moment heeft astma managen geen prioriteit.

Stress blijkt hierin een veelvoorkomende factor.

Astma kan de persoon overvallen of limiteren tijdens persoonlijke evenementen, vakanties, sociale evenementen, zowel binnen als buiten de lucht. De toekomst is nog ver weg. Op dit moment heeft astma managen geen prioriteit.

**Leven in het hier en nu**

"Dat je niet alleen maar bezig bent met de ziekte (D)"

"Of op de vereniging als ik in et rokershok heb gestaan, dan heb ik er last. En in de periodes dat ik veel dronk, toen had ik er wel echt last van (E)."

"Nee ik heb geen goed ritme, ik ben student. Ik ben er niet mee bezig. Alcohol is niet goed voor je, roken is niet goed voor je en ik is al of al je dunne mond (F)."

"Ik denk dat ik mijn medicatie vaak te laat neem, dus bij een aanval. Dan denk ik het gaat wel goed (F)."

"Ik rook zelf niet, maar dan sta ik bij het rokershok. Ik heb ook tegen mijn vriendinnetjes gezegd, zodra ik begin te hoesten, stuur me weg (F)."

"Mijn medicatie is al een halfjaar op. Ik heb zelf geen actie ondernomen omdat het wel prima ging. Maar nu gaat het wel echt niet zo goed. Nu moet ik het recept ophalen, dat duurt allemaal langer. (S)"

"Nee met mijn ernst ben ik niet beperkt en zo wil ik mij ook niet voelen (S)"

Meten kan fijn zijn omdat het de ziekte tastbaar maakt en iemand bewust kan maken van de ernst. Dit kan ook confronterend zijn. Maar metingen zeggen niet altijd iets.

**Geen controle (korte termijn)**

**Quotes**

"Als ik acht kilometer ga rennen en op vier kilometer krijg ik een aanval, dan kom ik niet meer thuis en dat is heel vervelend (S)"

"Pufjes heb ik altijd bij me. Alle tassen en jaszakken, ze werven door het huis (S)"

"Ik merk dat ik er meer last van met hockeyen (E)"

"Maar het gaat soms ook gewoon niet goed. Dan zie ik dat niet (A)."

"Ik denk wel dat astma mij limiteert in mijn sport en resultaten (S)"

"En die moeheid is wel een beperkende factor, dat ik niet even ergens kan fietsen. Dat is lastig, het gaat hier en hier. En er zijn momenten dat ik dat heel boos over ben (A)"

"De tijd die ik dan nodig heb om van het huis naar de vereniging te komen, is bijna anderhalve uren (A)"

"Ik heb een vatbekkenbehandeling in Nederland. Het heeft heel veel last, bij de eerste dag als een steen op de bank. Ik heb veel pufjes, maar daar wordt niks van gemaakt. En alle hard proberen, dat staat mij moeder van de ongeloof. En die vissesoopjes (A)"

"Ik heb een mexicaanse vader en een Nederlandse moeder. Ik heb geen enkel principe. Maar allemaal goed plezier, dat staat mij moeder van de ongeloof. Daar zijn veel mensen die daar blijven, en dat is nog steeds niet goed voor je (E)"

"Mensen willen liever geen aanpassingen doen of met hun astma bezig zijn. De toekomst is nog ver weg. Op dit moment heeft astma managen geen prioriteit.

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**Leven in het hier en nu**

"Dat je niet alleen maar bezig bent met de ziekte (D)"

"Of op de vereniging als ik in et rokershok heb gestaan, dan heb ik er last. En in de periodes dat ik veel dronk, toen had ik er wel echt last van (E)."

"Nee ik heb geen goed ritme, ik ben student. Ik ben er niet mee bezig. Alcohol is niet goed voor je, roken is niet goed voor je en ik is al of al je dunne mond (F)."

"Ik denk dat ik mijn medicatie vaak te laat neem, dus bij een aanval. Dan denk ik het gaat wel goed (F)."

"Ik rook zelf niet, maar dan sta ik bij het rokershok. Ik heb ook tegen mijn vriendinnetjes gezegd, zodra ik begin te hoesten, stuur me weg (F)."

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"Nee met mijn ernst ben ik niet beperkt en zo wil ik mij ook niet voelen (S)"

Meten kan fijn zijn omdat het de ziekte tastbaar maakt en iemand bewust kan maken van de ernst. Dit kan ook confronterend zijn. Maar metingen zeggen niet altijd iets.
Deze zitting kon ik niet natuurlijk maken, want ik ben volgend jaar senaat. Ik heb ook tegen mijn longarts gezegd, dat als ik dat volgend jaar ga doen, en wil niet dat dat mij nekt. Als ik mijn huisarts niet altijd kan vertrouwen, hoe vaak moet ik dan het hoegezondheid zijn? Natuurlijk heeft de arts er rechts in, maar ik kan nu reeds de ogen sluiten, hoewel ik het grotendeels, maar niet kan voorkomen, want die medicatie gaat het. En dan ook echt bewuster mijn medicatie. Ik heb daar hard voor gewerkt.
### Dagelijkse ontstekingsremmers

Dagelijkse ontstekingsremmers is voor het grootste deel van de astma patiënten van belang, omdat het de oorzaak aangaat (>2 reliever per week gebruik, ICS erbij).

Een lage dosering ICS kan totaal geen kwaad en de voordelen wegen dan niet op tegen de nadelen (vanuit het perspectief van de behandelaar).

Sommige artsen vinden het geen probleem als mensen met mild astma, niet standaard hun medicatie nemen. Onderhoudsmedicatie duurt ongeveer 6 weken voor het effect heeft

<table>
<thead>
<tr>
<th>Categorie</th>
<th>Quotes</th>
</tr>
</thead>
</table>
| Wanneer ICS | "Ontsteking is de basis van je benauwdheid. Deze kan ontstaan door prikkel of alergieën. Maar die ontstekingsremmer is voor alle astma patiënten van belang. Behalve degene die heel incidenteel hun pufje nodig hebben. Maar dan moet je heel goed monitoren of die zo echt maar zo weinig gebruiken. Als je die meer dan 2 keer per week gebruikt, heb je onderhoudsmedicatie nodig. Dan ben je vast in de eerste stap van NHG onderhoudskans in de eerste stap staat de reliever. (C)"

| Waarom ICS | "Als je meer dan 2x per week je reliever nodig hebt, dan heb je gewoon onderhoudsmedicatie nodig. Dan kun je met een hele lage dosering ICS, wat totaal geen kwaad kan verder. Behalve wat irritaties in je mond als je niet oplet. (C)"

<table>
<thead>
<tr>
<th>Categorie</th>
<th>Quotes</th>
</tr>
</thead>
</table>
| Wanneer ICS | "Als je een longaanval hebt, geeft dit veel meer schade toe aan je longen. Dat is wel de afweging, dat je die onderhoudsmedicatie moet gebruiken. In plaats van af en toe. (M)"

| Waarom ICS | "Als je veel vaker gaat, komt het er dan op dat je de inflammatie van je luchtwegen. Hoe vaker het gebeurd, hoe meer je het risico op een reductie in de longen. Als er vaak aanvallen zijn, kan dit reversibel worden. (C)"

---

**ICS pakt de ontstekingen aan en daarom minder kans op astmakoorts.**

Een aanval op je longen duurt 6-8 weken om te herstellen. Hoe vaker dit gebeurt, hoe slechter voor je longen. Als er vaak aanvallen zijn kan dit reversibel worden.
Categorie: Therapieontrouw

Quotes

- "Als patiënten zich goed voelen, vinden ze het niet nodig om medicatie te slikken."
- "Mensen met een lichte vorm van astma zien het nut niet in."

Categorie: Intentie: Kennis & Motivational Interviewing

Quotes

- "Ik begrijp dat altijd met de patiënt omgaan. Het is belangrijk om achter de beweegredenen om geen medicatie te nemen te komen en de persoon centraal te zetten. Hierin niet tegen de patiënt in te gaan, maar wel een oplossing bieden die de patiënt integreert in zijn eigen verantwoordelijkheden."
Het is lastig voor patiënten om het effect op de longen voor te stellen, omdat ze verstopt zitten. Hiervoor gebruiken behandelaars andere voor de persoon herkenbare vergelijkingen of visualisaties van de longen.

Het is niet nodig dat ze de uitkomsten van hun longfunctietesten boven de tafel leggen. Zeker bij astma heeft een normale longfunctie, dus waarom zou dat nodig zijn? Maar wel kan het goed zijn om te vragen hoe het met je medicatie? Hoe gaat het met je bloeddruk? Omdat mensen zich vaak te weinig waarderen. En een vluchtige praatje kan dat veranderen.


Het is lastig voor patiënten om het effect op de longen voor te stellen, omdat ze verstopt zitten. Hiervoor gebruiken behandelaars andere voor de persoon herkenbare vergelijkingen of visualisaties van de longen.

Het is lastig voor patiënten om het effect op de longen voor te stellen, omdat ze verstopt zitten. Hiervoor gebruiken behandelaars andere voor de persoon herkenbare vergelijkingen of visualisaties van de longen.
JOHAN - SKEPTICAL DENIER
First see, then believe − External excuses − Distrust
Johan does not recognize his/her asthma. He will get off easy with jokes or nonchalant remarks: “Oh, it’s nothing!” He ignores complaints and tries to conceal and normalize the symptoms for himself and the outside world. He has no confidence in specialists, due to some bad experiences in the past. Johan feels no need to visit HCPs, and avoids such contact moments completely.
Medication: Johan does not trust his doctor and the medicines he has prescribed. He does not follow his treatment and will not tell this to his doctor.

It’s just a flu, probably
I don’t have a disease, just some inconvenience from time to time

MYRTHE - BUSY ESCapist
Here & Now − Active − Not wanting to be aware
Myrthe wants to pay as little as possible attention to her asthma. She rather has a bad day after a day full of activities, than taking asthma into account and pay attention to her symptoms. She thinks her asthma is under control when there is still plenty of terrain to gain. Myrthe does not realize that she actually can get more out of life when taking her asthma more into account.
Medication: Because of her busy lifestyle Myrthe often forgets to take her maintenance medication. However, the main reason for her non-adherence is that her disease feels sporadic instead of chronic and therefore her reliever medication feels more convenient to use.

Because of my busy life I forget
I get more out of life, when not thinking of it
I feel ashamed when leaving my niece’s party out of the blue, because of my asthma. At home they did not pay any attention to my asthma.

I feel ashamed when leaving my niece’s party out of the blue, because of my asthma.

Richard - Timid Loner
Ashamed - Not wanting to be a burden - Avoiding conflict

Richard sees asthma as his problem. He does not even tell other people around him he is asthmatic because he is embarrassed. Richard rather avoids critical circumstances at all or undertakes the discomfort without addressing his asthma. When someone lights a cigarette, he will leave without mentioning the actual reason. Richard does take his asthma into account and tries to avoid triggers, but does not want to bother others with this.

Medication: Richard takes his maintenance medication as prescribed. He even set an alarm on his telephone, to not forget. However he would like to take less medication and is interested in more alternative curative solutions. In contrast to his maintenance medication, Richard does not like to use his reliever in public.

Anna - Confident Goal Pursuer
Transparent – Curious – Experience expert

Anna is very open about her asthma. She has been burned a couple times too much, and sets boundaries and goals clearly for herself. Anna indicates her limits and assumes others will understand this because of her transparency. She will address a complaint when experiencing one. Anna has no problem to use her medication in public and believes this is important, to break down taboos. This is a real difference with her past.

Medication: Anna has a very good relationship with her doctor. They regularly discuss her treatment. Anna is very adherent to her prescribed maintenance medication and uses her reliever medication without a problem in public.
Working-out is not something I am able to do anymore, because of my asthma.
Appendix F: User Test Round 1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Experience</th>
<th>Aesthetic Appeal</th>
<th>Involvement</th>
<th>Curiosity</th>
<th>Empathy</th>
<th>Usefulness</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.C.</td>
<td>Strongly Disagree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
<td>Strongly Agree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>F.B.</td>
<td>Strongly Disagree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
<td>Strongly Agree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>T.M.</td>
<td>Strongly Disagree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
<td>Strongly Agree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>Z.K.</td>
<td>Strongly Disagree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
<td>Strongly Agree</td>
<td>Strongly Disagree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

Appendix G: Poster for User Tests

![Poster for user tests](image-url)
Appendix H: user test 1 round 2

Onderdeel 1: bespreken afgelopen dagen / ‘gebruik’ ervaring

1. Hoe heb je de afgelopen dagen ervaren?
2. Waren er dingen onduidelijk?
3. Had je nog iets aan de uitleg over de medicatie vooral?

De schermen

Ik heb hier de schermen die je de afgelopen dagen ontvangen hebt.

1. Kun je beschrijven wat je ziet? Wat denk je dat de verschillende elementen betekenen?
2. Vond je het scherm makkelijk te begrijpen?
3. Wat was je reactie naar je volgende scherm?
4. Vond je het verhaal van de Ademgenoot betekenisvol?
5. Was je nieuwsgierig naar je volgende scherm?
6. Zat er een verschil in de eerste keer dat je het scherm opende en latere schermen?
7. Hoe vond je het om je prikkels door te geven?
8. Wat vond je van het rapport afgelopen dag je medicatie meer genomen? Waarom wel of niet?
9. Hoe vond je het om elke dag een afbeelding te ontvangen op je telefoon?
10. Hielp het ontvangen van schermen in het niet vergeten van je medicatie?
11. Voelde je je meer gemotiveerd om je medicatie te nemen? Waarom wel of niet?
12. Hoe vond je het om de afgelopen dagen op deze manier met astma bezig te zijn?
13. Zou je de 6weekse challenge aanpakken?
14. Zou Ademgenoot je kunnen motiveren om je medicatie zoals voorgeschreven te nemen?
15. Welke elementen dagen hier aan bij en welke niet?

Dagelijks ontvangen

1. Zou je de app makkelijk te begrijpen?
2. Zouje de app vaker en voor een langere periode willen gebruiken?
3. Zou de app als een inbreuk op je dagelijkse leven kunnen vóelen? (bijv. patiënt)
4. Hoe nuttig vond je het gebruik van Ademgenoot vergeleken met een behandeling zonder het gebruik van de app?
5. Positieve punten, negatieve punten en aanbevelingen

Onderdeel 2: Motivatie ‘game’ ervaring (na Powerpoint)

Motivatie nemen van de medicatie & Motivatie voor interactie met de app

1. Zou je jezelf een challenger aangaan?
2. Zou Ademgenoot je kunnen motiveren om je medicatie zoals voorgeschreven te nemen?
3. Welke elementen dragen erbij bij en welke niet?

Verhaal en Karakter

1. Zou het verhaal en karakter bijdragen aan het sneller/openen gebruiken van de app?
2. Zou het verhaal en karakter bijdragen in je motivatie om de medicatie te nemen?
3. Vind je de visualisaties een toegevoegde waarde hebben naast de statistieken?
4. Zou je Ademgenoot nuttig vinden in het managen van je medicatie?
5. Zou de app bijdragen in het vertrouwen van het juist nemen van de voorgeschreven medicatie en het niet vergeten?
6. Zou de app kunnen bijdragen in hoe je je astma controleert? En je vertrouwen Nemen?
7. Heeft de app Ademgenoot iets veranderd in je gevoel over hoe goed je geïnformeerd bent over astma?

Grip op astma

1. Zou je Ademgenoot nuttig vinden in het managen van je medicatie?
2. Zou de app bijdragen in het vertrouwen van het juist nemen van de voorgeschreven medicatie en het niet vergeten?
3. Zou de app kunnen bijdragen in hoe je je astma controleert? En je vertrouwen Nemen?
4. Heeft de app Ademgenoot iets veranderd in je gevoel over hoe goed je geïnformeerd bent over astma?
De app wordt gedemonstreerd aan de deelnemers

1. Uitleg: Het is een prototype, en het gaat om de ervaring. De app is gericht op het managen van medicatiegebruik, voor mensen die hier weinig motivatie voor hebben of de noodzaak hier niet van inzien.

2. De medicatie is via bluetooth aan een applicatie gelinkt en het gebruik van de inhalatoren wordt automatisch opgeslagen. Zowel van de ontstekingsremmers, als de luchtwegverwijder.

3. Ik wil dat je denkt aan een periode dat je niet je medicatie nam zoals je dit moest nemen. Dit kan nu zijn, toen je net gediagnostiseerd was of een ander moment.

4. Je dokter of praktijk ondersteuner heeft je aangeraden om eens de app Ademgenoot uit te proberen.

5. Je neemt je medicatie nog niet zoals voorgeschreven, hebt je inhalatoren via bluetooth aan de app Ademgenoot gelinkt en opent nu de app.

Vragen achteraf:

1. De participanten kunnen nu eerst hun eerste gedachtes kwijt.
   • Is alles duidelijk? Wat is onduidelijk?
   • Wat vinden jullie van het concept?
   • Wat vinden jullie van de visualisaties?
   • Vonden jullie de app makkelijk te begrijpen?

2. Eigen situatie:
   • We hebben net de app doorlopen en wat denken jullie als personen die aangeven therapietrouw te zijn, zouden jullie iets aan deze app kunnen hebben?
   • Wat voor functies zou je gebruiken en welke functies miss je in dit geval?
   • Zou je de app willen gebruiken? Waarvoor zou je de app wel of niet willen gebruiken?

3. Elementen voor niet therapietrouw:
   • Denken jullie dat het concept zou kunnen bijdragen in het motiveren van het gebruik van dagelijkse medicatie? En in astma zelfmanagement? Waarom wel of niet?
   • Zou je de app aarzelen aan iemand die de noodzaak van dagelijkse medicatie niet inziet of het lastig vindt dit in zijn dagelijks leven in te bouwen?

Hang de verschillende elementen uitgezet op. Wat motiveert en wat niet?

Insuline van een aantal waarden van UEQ (1-7)

4. Gebruik in het algemeen:
   • De medicatie wordt automatisch opgeslagen, maar het kost natuurlijk wel tijd de app te gebruiken. Zou je de app gebruiken?
   • Zou het een gevoel van inbreuk kunnen geven op je dagelijks leven?
   • Positieve gevoelens of roept het negatieve gevoelens op?
   • Positieve punten, punten van verbetering & aanbevelingen

Appendix I: user test 2 round 2
<table>
<thead>
<tr>
<th>Participant</th>
<th>M.M.</th>
<th>Participant</th>
<th>J.O.</th>
</tr>
</thead>
</table>

| Planning | | | |
| Memory | | | |
| Motivation | | | |
| Attention | | | |
| Creativity | | | |
| Emotional | | | |
| Behavioral | | | |
| Motoric | | | |
| Intellectual | | | |

| Planning | | |
| Memory | | |
| Motivation | | |
| Creativity | | |
| Emotional | | |
| Behavioral | | |
| Motoric | | |
| Intellectual | | |

Note: The table above contains the results of the planning, memory, motivation, creativity, emotional, behavioral, motoric, and intellectual aspects for both participants, M.M. and J.O.
2.2 Living with asthma

In order to create a self-management application for patients with asthma, it was important to find out what the impact of asthma may be on a person's life and how self-management plays a role in this.

Researchers from the department of Public Health and Primary care, LUMC conducted and recorded several interviews with asthma patients in the light of 'Meer grip op Astma' project (prior to this project). Most interviews were organized in group sessions. These interviews were listened back and used for the pre-explorative phase of this project: to gain a better understanding of patients' context. The interviews were discussed together with the researchers who carried out the interviews, Astrid Bontenbal and Charlotte Poot. A range of topics were discussed within these interviews. Amongst others, the participants were asked to describe one good day and one bad day when having asthma.

Physical & psychological barriers

From these interviews, themes such as energy management and acceptance of the disease contributed to a rich understanding of the context of people with asthma. For most participants, their decreased energy level, both resulting in physical and social limitations, remains the hardest part of coping with asthma and is experienced as a process of trial and error. This corresponds to the Netherlands Institute for Health Services (NIVEL) research on the impact of asthma, where 30% of asthma patients expressed to have to deal with limited energy daily due to their asthma (Waverijn, Spreeuwenberg & Heijmans, 2014).

Additionally, the interviews made clear that the impact of asthma on a person's daily life differs a lot per person. People may experience some inconvenience from time to time and for others, asthma is a major problem that interferes continuously with their daily activities, which can even result in not being able to work anymore.

In general, people may need to remember to take daily medication, to learn to cope with the unpredictability of asthma and the impact this has on their life. Asthma may limit people in their physical activities, such as sport and taking the stairs or can cause difficulties in getting a good night's sleep. In addition, poor sleep and symptoms experience such as shortness of breath, can negatively impact people's social and work life. Which illustrates that asthma may take a psychological toll on a person's life as well. This is reinforced by a perceived social stigma on inhaler use, which caused embarrassment at times. Participants expressed that the perceived social stigma can play a role in not using the inhaler in public, to not be transparent about the disease and the feeling of not being taken seriously. At the same time, persons have to adjust their lifestyle to deal with asthma, resulting in small or major changes to adequately self-manage their asthma.

Thank you!