ADEMGENOOT

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An asthma self-management app

Master Thesis
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Design for Interaction

Ademgenoot

Asthma self-management app

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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 taken 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 graduate 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.

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01

INTRODUCTION

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.

Partners

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 is prescribed to be taken daily to achieve the best outcomes. 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 health care 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-use data. Figure 2 shows 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.

1/3 of Dutch asthma patients do not follow their treatment as prescribed
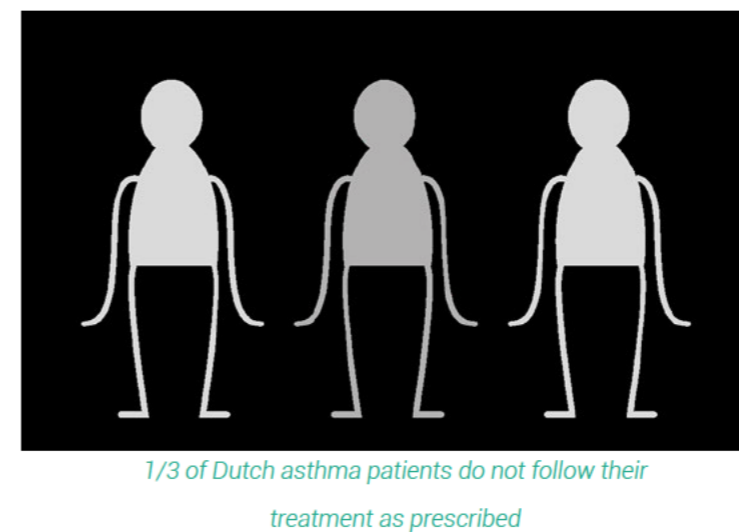
From a healthcare professional's perspective

Patients need daily maintenance medication
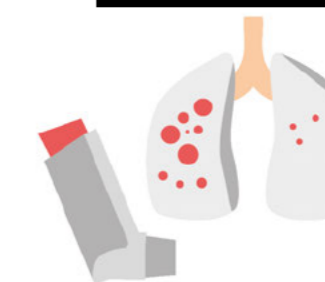
The maintenance medication reduces the inflammation in the airways
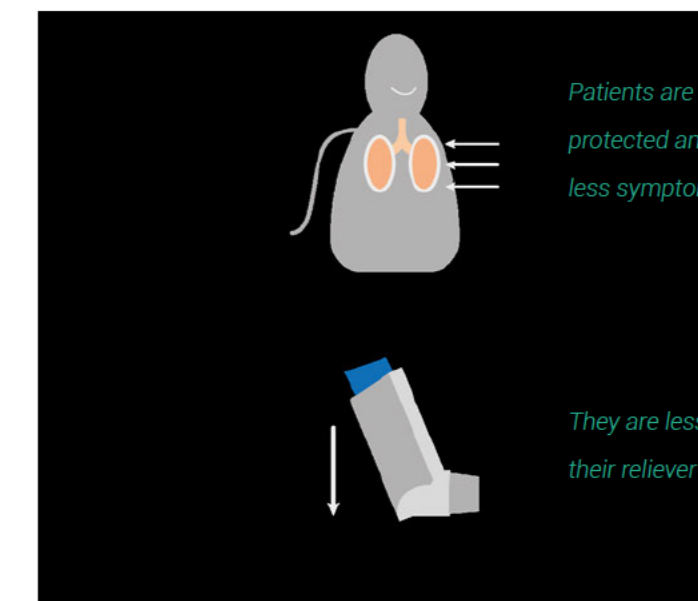
Patients are better protected and experience less symptoms

They are less in need for their reliever medication

Figure 1. Why patients should use their daily maintenance medication
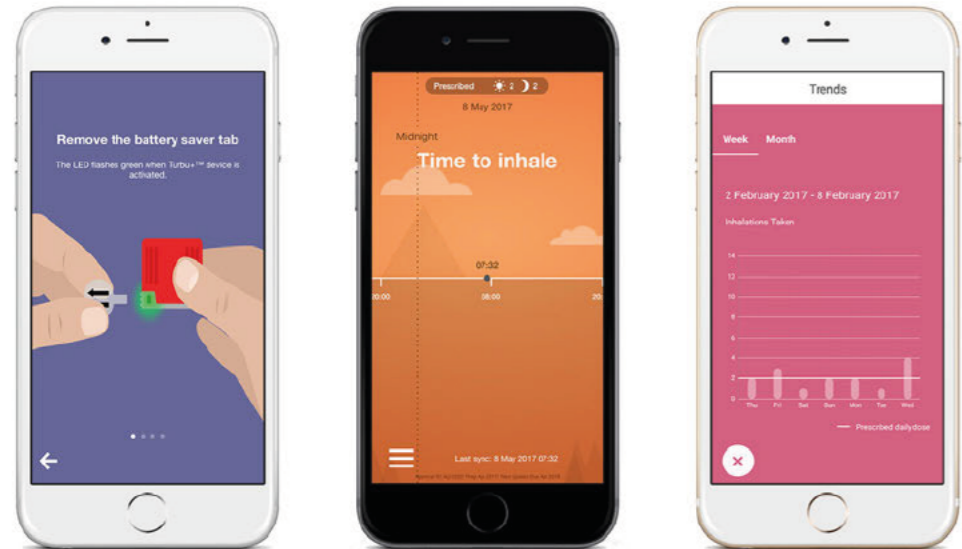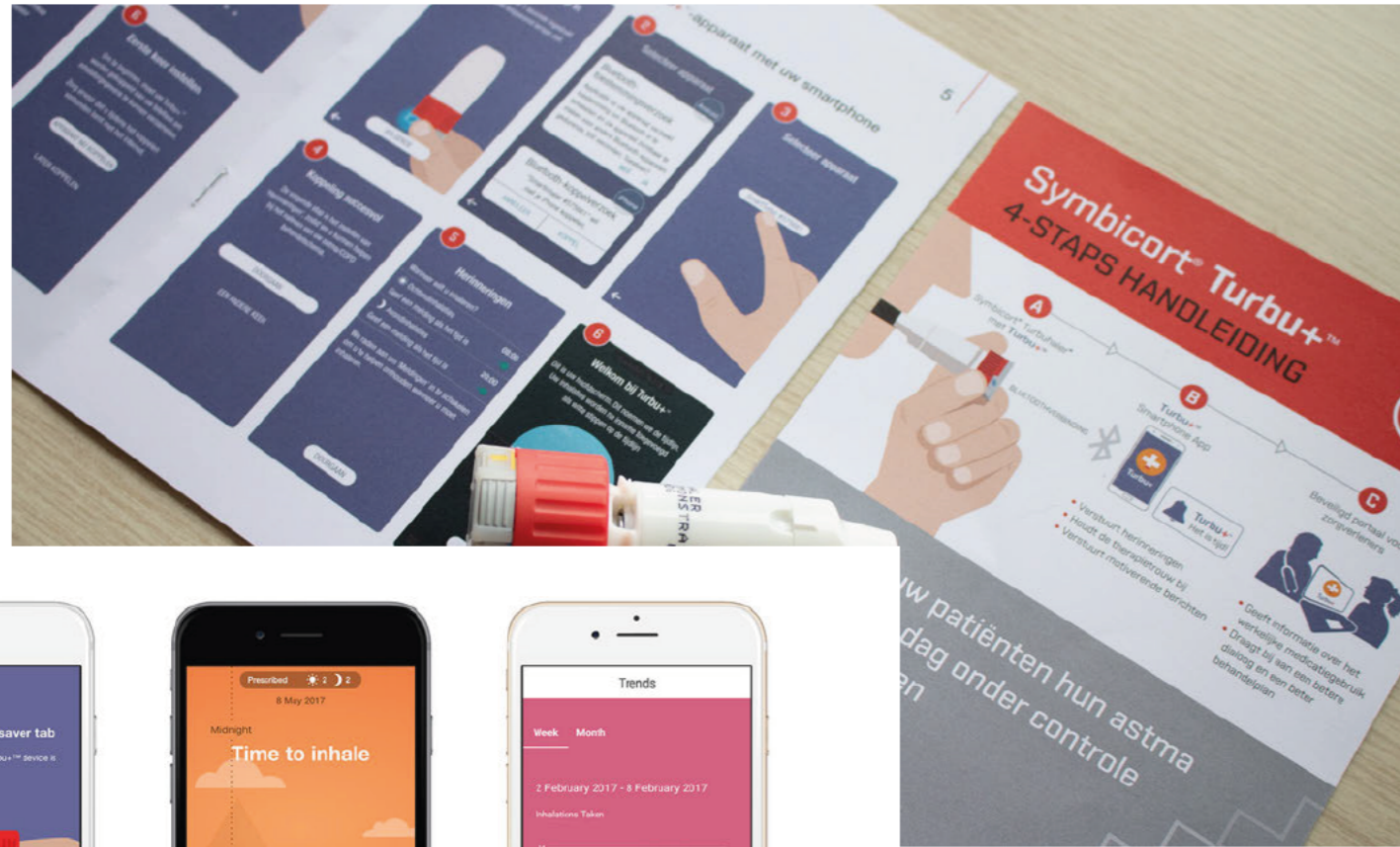
Figure 2. The Turbu + application shows the patient's medication intake on a timeline and in a statistic overview. This data is automatically gathered from the smart inhaler.

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.

Project approach

The project consisted of four phases inspired by the Design Council's (2005) 'Double Diamond Design process': 'Discover', 'Define', 'Develop' (rather: 'Design') 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.

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.

Figure 3. Double Diamond Design Process
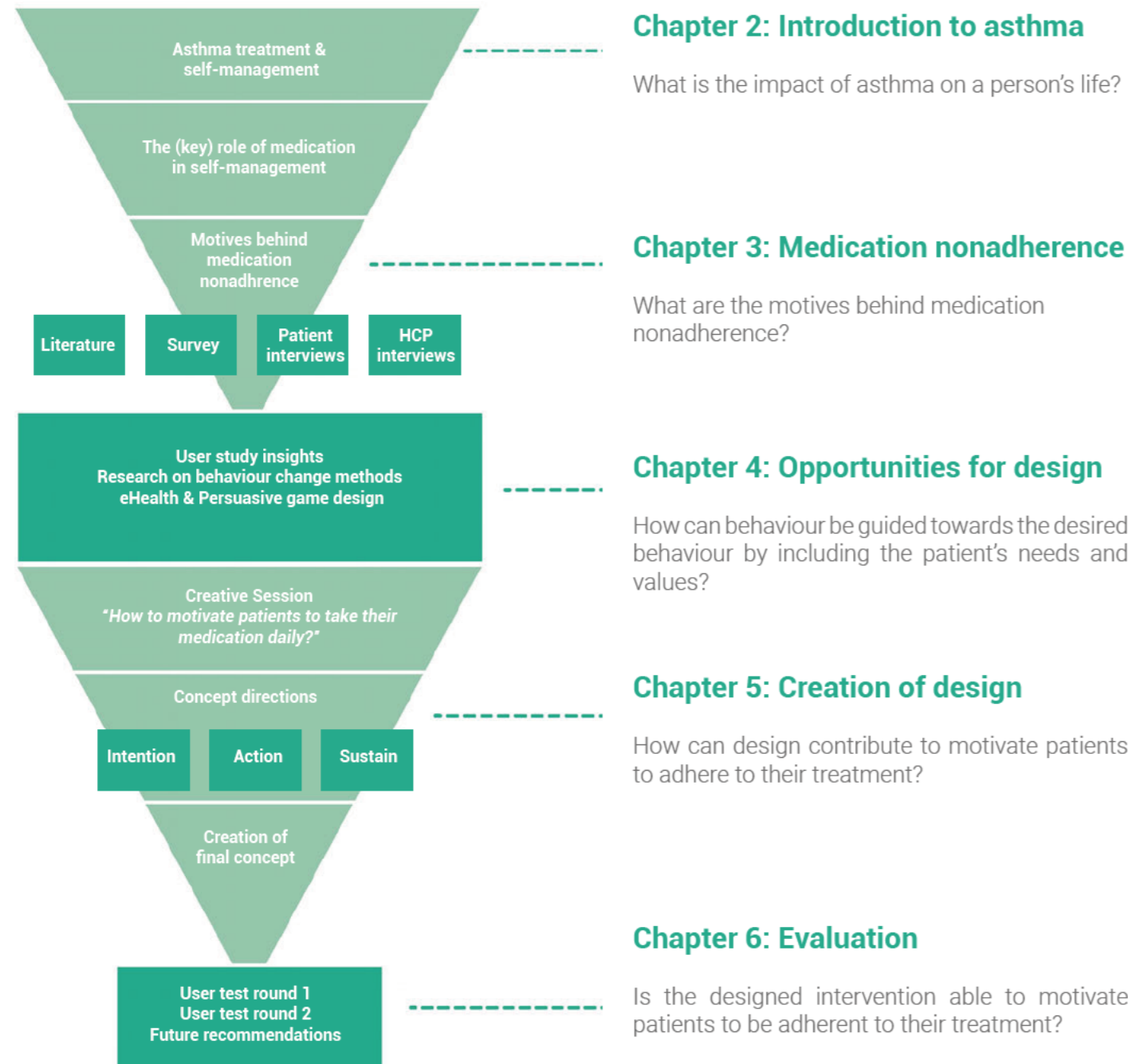
Figure 4. Project's structure

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?

02

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

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; Rennard & Farmer, 2004).
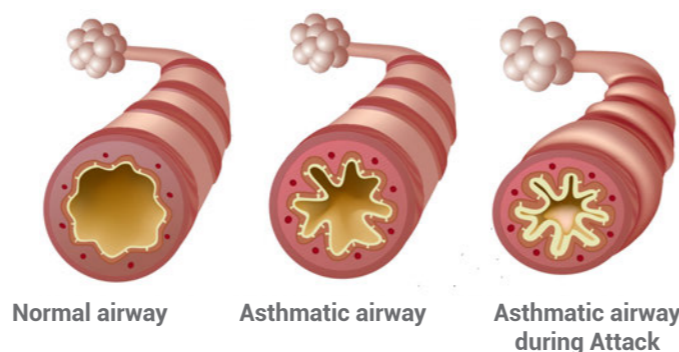

Normal airway   **Asthmatic airway**   **Asthmatic airway during Attack**

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

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.

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.

Figure 6. Lung (Pulmonary) function can be used to diagnose asthma

2.2.2 TREATMENT & MEDICATION

There are two main types of pharmacological asthma treatment: maintenance medication (often provided in a red-coloured inhaler) and reliever medication (often provided in a blue-coloured inhaler).

The daily maintenance medication treats the inflammation and has shown to effectively control asthma symptoms, improve lung function, decrease exacerbations and reduce hospitalization and asthma-related morality rates. In addition, when patients adhere to their daily maintenance medication, they are less likely to need their reliever medication (Byer & Myers, 2000).

The reliever is often prescribed if needed. The reliever opens the airways when patients experience a worsening of symptoms or an asthma attack, but does not treat the cause of the patient's experienced symptoms. Figure 8 provides an explanantion of the different medications in use.

A key driver for asthma treatment success is the extent to which patients adhere to their prescribed pharmacological regimen, also called 'medication adherence', which is defined as follows:

The degree to which the person's behaviour corresponds with the agreed recommendations from a health care provider

- World Health Organization (2003)

In the Netherlands, the majority of asthma care is provided by first-line care – namely, general practitioners. They adhere to the guidelines from the Huisartsen Genootschap (NHG), which uses a stepwise four-stage framework for managing patients with asthma (Figure 7 is based on information retreived from www.nhg.org). The guidelines include 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.
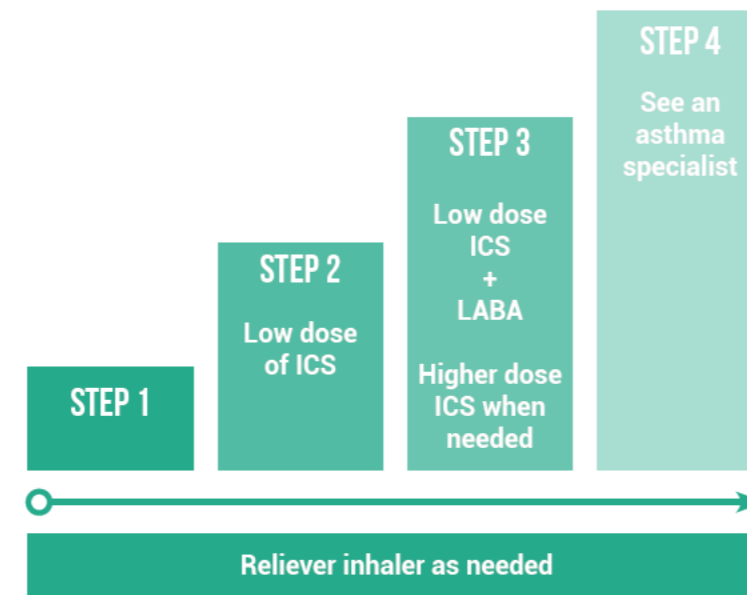


Figure 7. Four-stage framework used by NHG

One third of Dutch asthma patients show poor adherence

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 show 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 seem to rely more on their reliever medication, since this provides them of 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 remains 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 adhere 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.
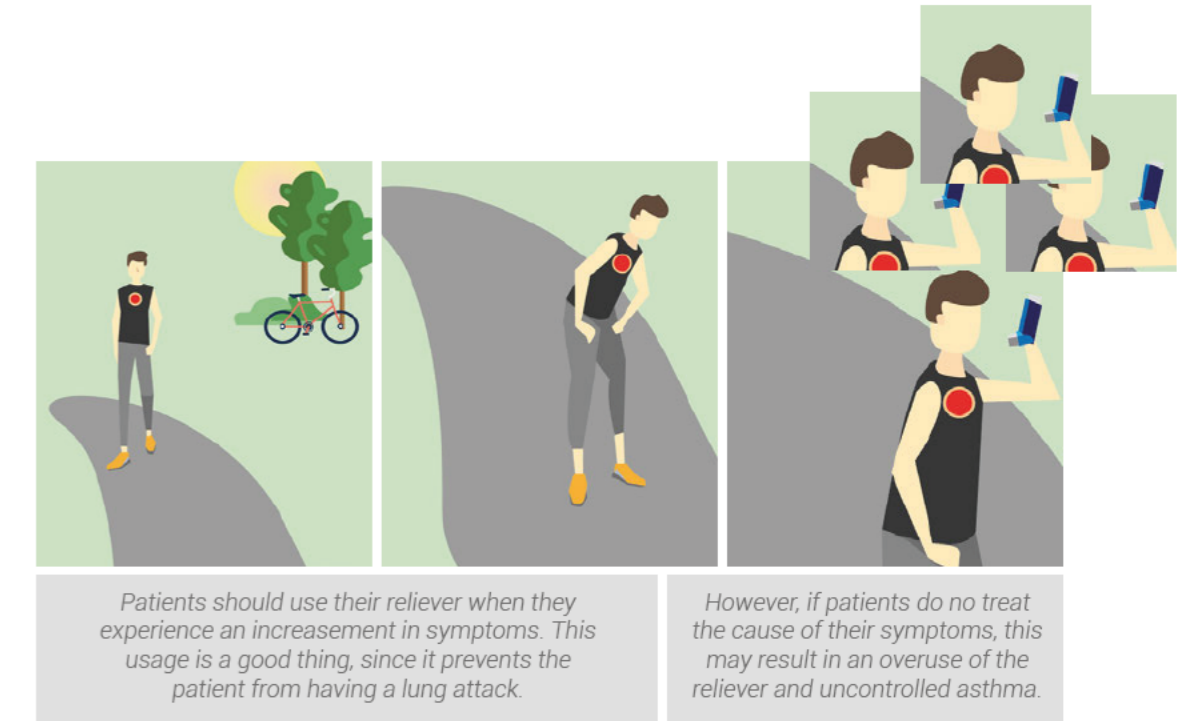
Patients should use their reliever when they experience an increasement in symptoms. This usage is a good thing, since it prevents the patient from having a lung attack.

However, if patients do no treat the cause of their symptoms, this may result in an overuse of the reliever and uncontrolled asthma.

The daily maintenance medication treats the inflammations. This reduces symptoms and risks of lung attacks. Therefore, it is likely that patients need their reliever medication less.

Figure 8. The different use of reliever and maintenance medication illustrated in a storyboard

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 thesis refers to the maintenance medication, the anti-inflammatory preventer medication is meant.

Preventers: Work slowly, effect 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 the inflammation and swelling of the airways, the cause of patient's symptom experiences. In the context of this project, it is important to note that it can take weeks for ICS to reduce inflammation in the airways and consistency of intake is key. 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. It may be that patients experience thrush and hoarseness. However, rinsing the mouth and gargling after using the inhaler, can help prevent these side effects. In this regard, a general practitioner was approached regarding his view, and he confirmed that a low dose of daily ICS does not do any harm.

> *If persons experience some burden due to their asthma, the advantages always outweigh the disadvantages of the medication*
> - P.H. (general practitioner)

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 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 antagonists (SABA), which are prescribed as a reliever medication.

Reliever medication
Relievers

Relievers: Used when needed for rapid relief of symptoms - Open the airways by relaxing the tight muscles – Work quickly, within a few minutes for 2-4 hours

People with asthma are advised to carry a reliever medication (or rescue medication), which consists of short-acting beta antagonists (SABA)s. 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, headache, 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.

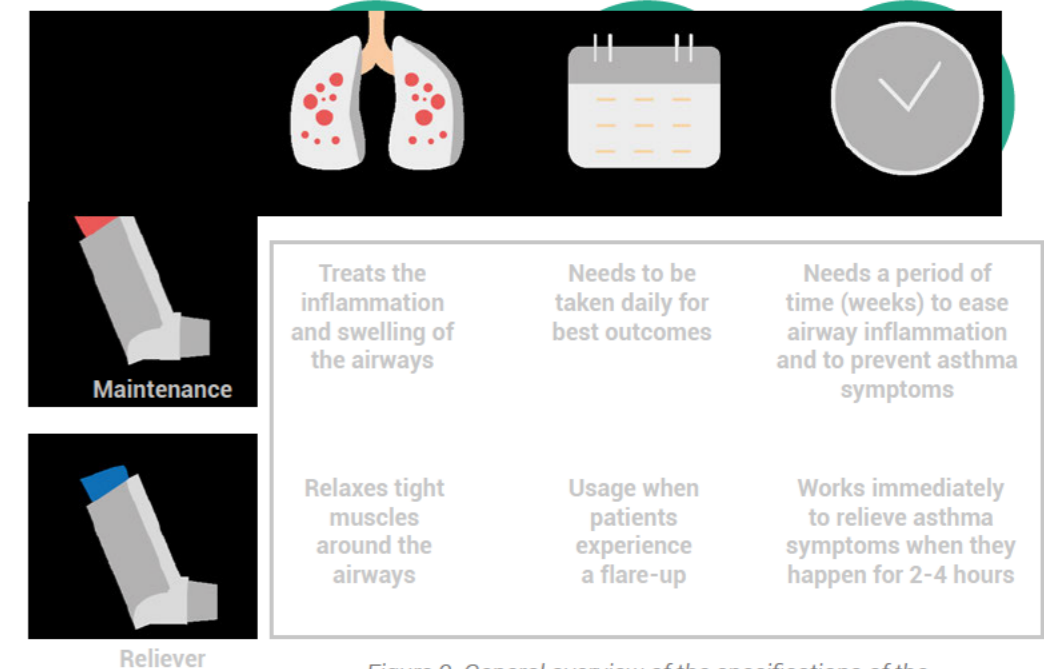| Maintenance		
Treats the inflammation and swelling of the airways	Needs to be taken daily for best outcomes	Needs a period of time (weeks) to ease airway inflammation and to prevent asthma symptoms
Reliever		
Relaxes tight muscles around the airways	Usage when patients experience a flare-up	Works immediately to relieve asthma symptoms when they happen for 2-4 hours

Figure 9. General overview of the specifications of the maintenance medication and reliever medication

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 addition, poor sleep and symptoms such as shortness of breath can negatively impact people's social and work life

– indicating that asthma may take a psychological toll on a person's life as well. At the same time, people have to adjust 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*
- S.D.

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*

- Battersby & 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*

- Gruham & 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 know how to recognize triggers, to understand the different roles of medication and to know how to manage exacerbations, patients' attitudes towards their asthma have a great influence on their self-managing practices (Wigal et al., 1993; Chiu et al., 2014). For example, patients' decision to not follow their medication treatment may be highly influenced by their attitude concerning their disease and treatment. For instance, patients may not adhere to their treatment if they believe it is not necessary to take medication in their situation or if they have concerns about side effects. In addition, patients can feel embarrassed about their asthma, which may result in them not using their inhaler in public spaces and not being transparent about their condition with others.
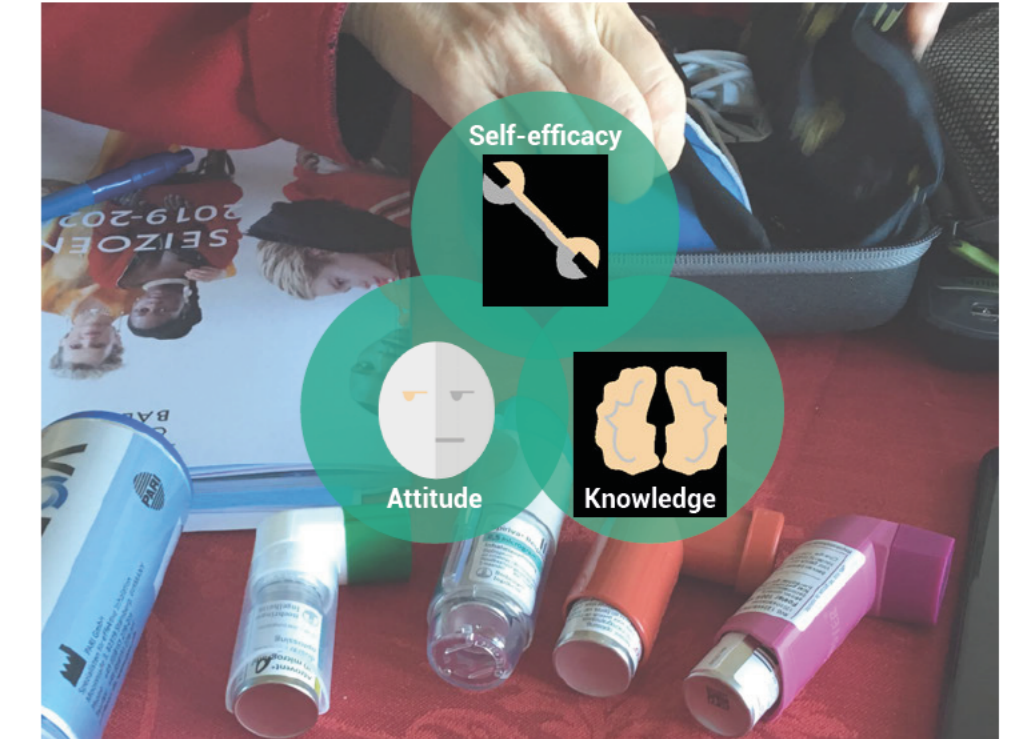

Figure 10. Influences on asthma self-management

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 execute the behaviour necessary to complete a task successfully (Bandura, 1982). In general, self-efficacy refers to a stable sense of personal competence in different 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 (Náfrádi, Nakamoto & Schulz, 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.

2.3.2 SELF-MANAGEMENT & EHEALTH

After having gained a better understanding of field of asthma treatment and self-management, research was done to find out what eHealth is and what its advantages and disadvantages are. eHealth is considered to be a healthcare practice where ICT is used to provide care and can be described as:

The use of health information systems and communication tools to improve management and delivery of healthcare, by making electronic medical records remotely accessible

- Alkhaldi, Sahama, Huxley & Gajanayake (2014)

Opportunity for tailored interventions that offer control

In recent years, the number of people with a chronic disease has rapidly increased (Raghupathi & Raghupathi, 2018). This has resulted in a growing burden on modern health care systems, as HCPs struggle in finding sufficient time to manage the range of chronic conditions. Since asthma requires ongoing treatment throughout patients' lives and patients need to be involved in different self-management behaviours, eHealth seems to be a perfect fit to support asthma patients in their self-management and improve the efficiency of the treatment.

In addition, eHealth has the potential to improve disease control and adherence to treatment in asthmatic patients. This potential is especially promising when considering the fact that data can be obtained through a mobile phone connected to a smart inhaler, such as the Turbuhaler shown

in Figure 11. This connection offers the opportunity to deliver tailored self-management interventions based on individual smart-inhaler use and thus increase each intervention's efficacy (Bonini, 2018; Merchant, Inamdar & Quade, 2016).

Figure 11. The Turbuhaler uses reomote sensors to detect medication intake

mHealth is a sub-segment of eHealth covering health practices that are connected to smart phones and tablets. In this project, mHealth is considered to be a healthcare practice in which a patient's phone is used to support the needs of both patients and HCPs.

With nearly everyone in possession of a mobile phone, apps in particular could enable effective low-cost interventions, especially when taking into account the unlimited scalability and availability of applications (Wu, 2016). Additionally, mHealth enables patients to store and monitor their own health data. Furthermore, they can access electronic health records on their personal mobile devices anytime and anywhere.

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, 20014). 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.

key takeaways chapter 2

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

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

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

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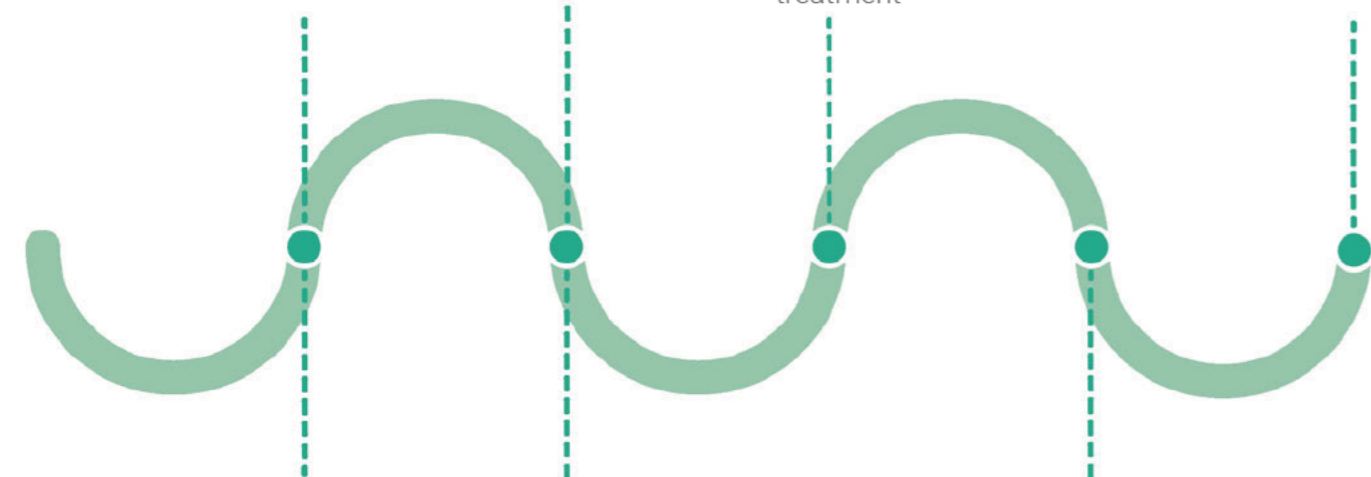
Medication plays a key role in how well ashtma is controlled

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

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

03

MEDICATION NONADHERENCE

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

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.

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!

Unwitting   **Intelligent**   **Erratic**

Figure 12. The different types of medication nonadherence

Intentional nonadherence takes place when patients decide to not 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 patient's 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):

- Causal beliefs (genetic vs. environmental)
- Consequences beliefs (social and/or financial costs)
- Timeline beliefs (acute vs chronic vs sporadic)
- Control beliefs (medication vs lifestyle change)
- Identify 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 (Horne, 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 nonadherent 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.
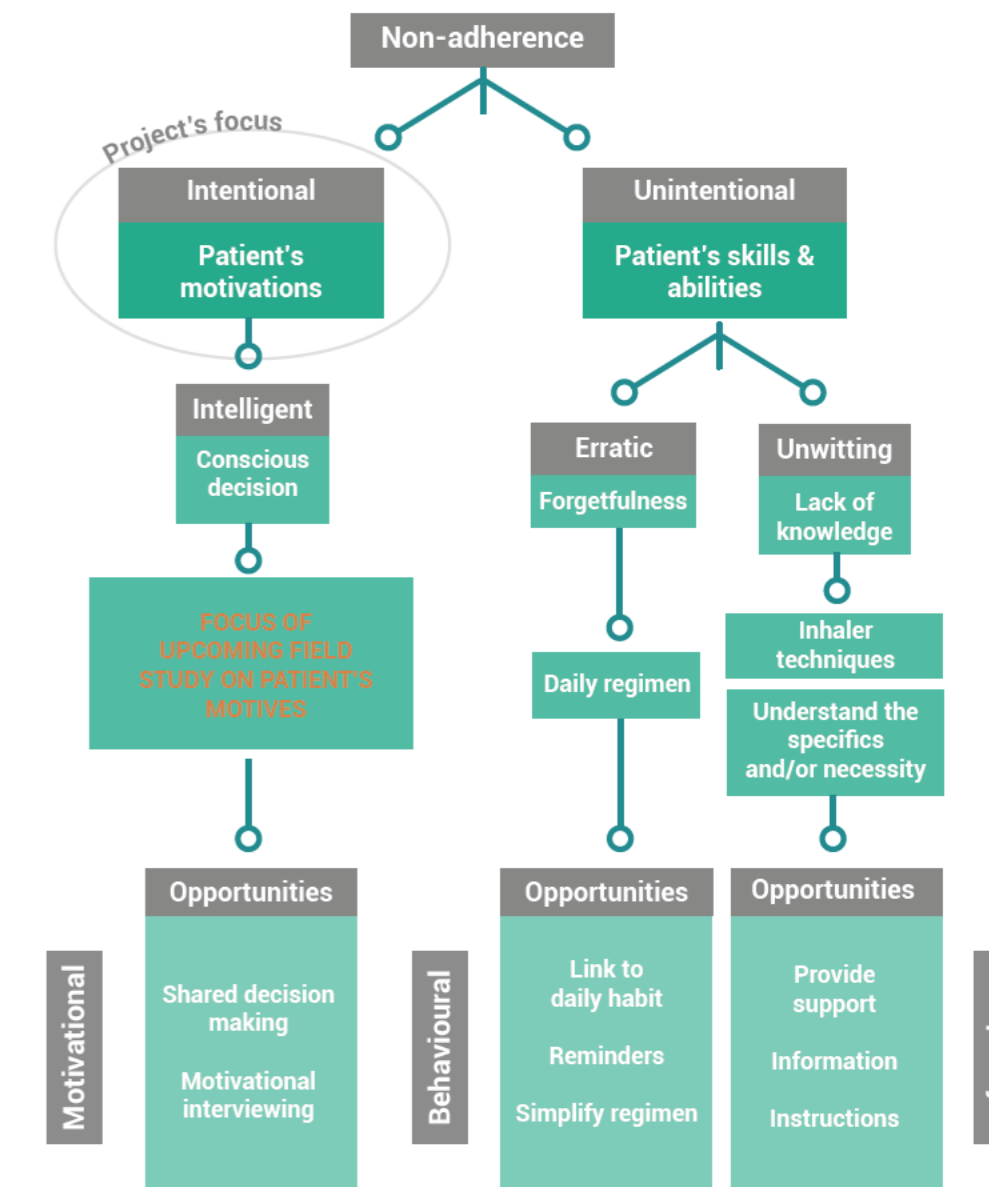

Figure 13. Combined research on intentional and unintentional nonadherence

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.
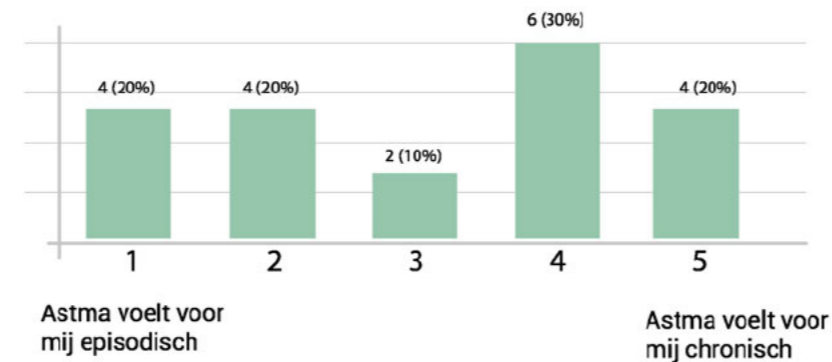

Figure 14.   Answers on the survey question 'asthma feels sporadic or chronic'

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.

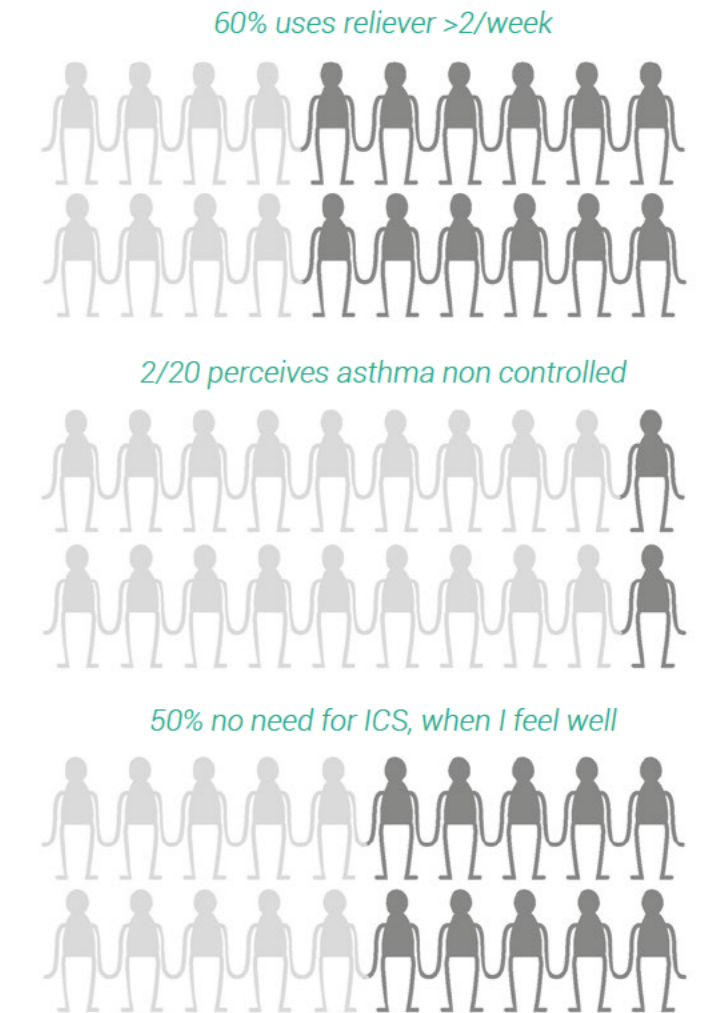- Ten out of 20 people indicated needing more knowledge about their medication

Figure 15. Visualisations of some of the results from the survey

3.2.2 PATIENT INTERVIEWS

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 use reliever medication more than twice a week. At the same time, only two out of the 20 respondents responded negatively to the question regarding whether they have their asthma under control. This could indicate that they do not feel the urge to adhere or to adapt to their treatment, since they believe their asthma is controlled.

In addition, half of the respondents do not feel the need to take medication when they feel well, and more than 20% even perceive taking their daily medication as overuse. This could be caused by the fact that they experience asthma as a sporadic disease instead of as a chronic disease, which was confirmed by eight patients responding that their asthma feels episodic.

Additionally, this belief could reinforced by a lack of knowledge, since half of the respondents indicated a need for more knowledge about their prescribed medication (10/20). However, almost all respondents did indicate that they understood the need for anti-inflammatory medication. Nevertheless, since almost half of the respondents do not feel the need to take daily medication when they feel well, there seems to be a negative attitude towards using medication on a daily basis.

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.

It became clear, that some patients easily say that they just forget to take the medication, but that there are often multiple personal motives to not take the medication as prescribed.

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
- S.B.

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
- F.D.

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.

Perceived necessity depends on the severity of symptoms

The two patients who suffer from uncontrolled severe asthma clearly expressed that not taking their daily medication was not an option because of the consequences:

If I do not use my medication, I notice it. I have to take Foster three times a day, which is a combination of anti-inflammatory medication and reliever medication. I can not afford to not do it... and that is why I manage to take it again
- A.L.

This attitude is in contrast with the students who have mild to moderate asthma. Some students mentioned that they did not feel the need to take their medication if they did not experience symptoms or that they saw their medication as a last resort. Furthermore, it also became clear that people do not always link their experienced symptoms to their disease.

Lack of experienced effect of the maintenance medication

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:

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.

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 became clear in one of the other interviews.

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 in communicating with an 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 the 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 mediation does not seem to them to be a logical response. Instead, the use of their reliever medication appears to be more convenient. This mindset seems to be amplified by a lack of knowledge of the exact specifics of the different medications and a lack of experienced effect of the maintenance medication on their lungs. Especially on days they feel good, they perceive it as not necessary to take the daily medication.

In light of the above, it is not surprising that patients may choose to not change their daily routine by incorporating the maintenance medication. If they believe that they function well enough without the medication and are not experiencing the effect of the medication on their health and daily living, they see no reason to change.
As a result, it is important to make patients aware of the positive effects that the medication could have in their

situation. Additionally, patients should experience the fact that incorporating the daily medication into their life will not limit them but rather that doing so will help them to get more out of life – showing them that they will not be limited because their inflammations decrease and that taking care of their health now will pay off in the future.

Furthermore, the interviews indicate that it could be useful to make the disease process visual for patients and to incorporate personal events to stimulate patients to adhere to their treatment.

I do not Need daily maintenance medication

...s episodic.
...l, I do not
...n

Reliever medication works because I 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

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

Figure 17. Shows the different perspectives between patient and HCP

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

Figure 18. Interview with practice nurse on nonadherent patients

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]

– 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 for 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 their 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 airways 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, HCPs mentioned that it is important to not quarrel with patients' beliefs but instead to clearly state the consequences

This often results in an underuse of the maintenance medication, followed by an overuse of the reliever medication
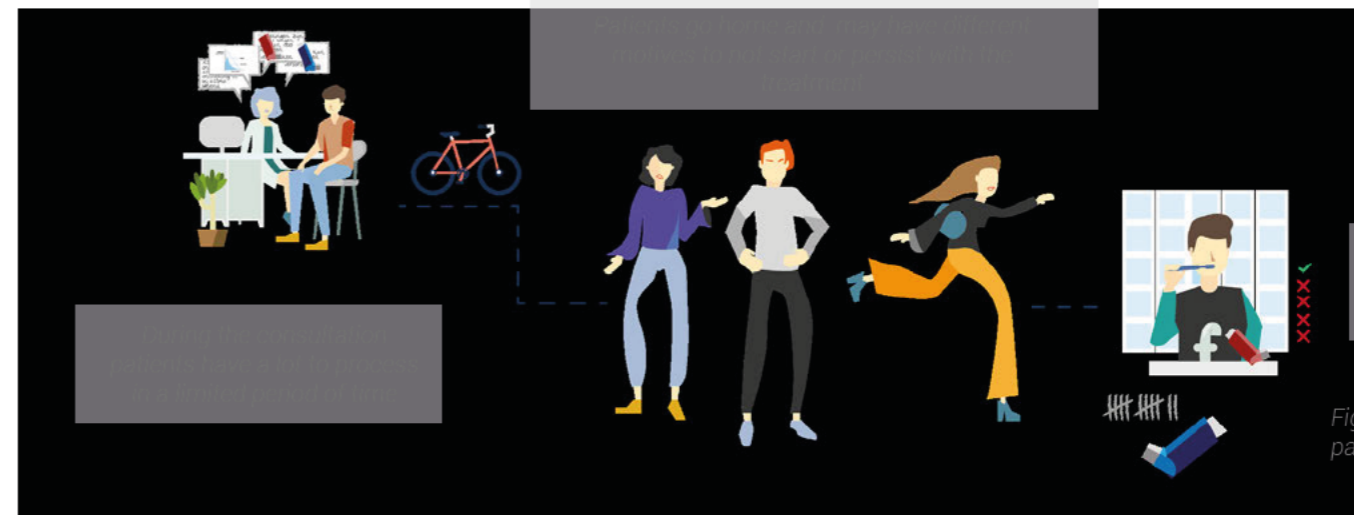
Figure 19. HCPs are not always aware of the patient's motives to not follow the treatment

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 import 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 most frequently recurring themes were combined to provide a clear picture of the target group to which the intervention must relate.

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 take their reliever medication more often when their asthma worsen 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 may 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)
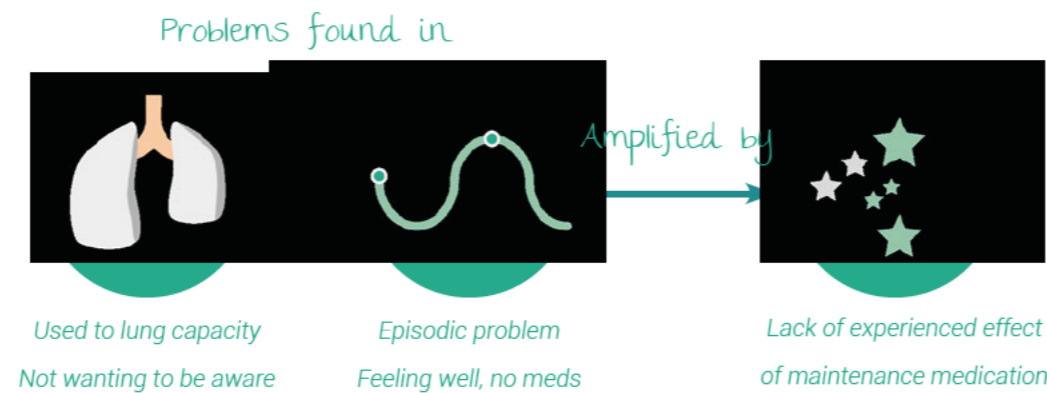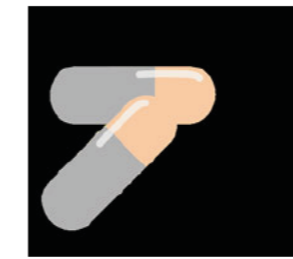

Problems found in

Amplified by

Used to lung capacity
Not wanting to be aware

Episodic problem
Feeling well, no meds

Lack of experienced effect
of maintenance medication

Figure 20. Key findings

Medication beliefs
*"There is prednisone in ICS, you know that"*

- 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
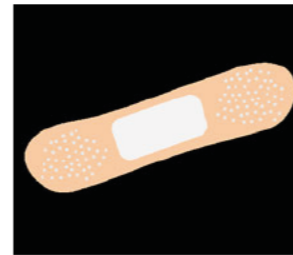
Illness representation
"Some inconvenience from time to time"

- Asthma feels episodic
- When feeling well, no medication*
- Misperceptions 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
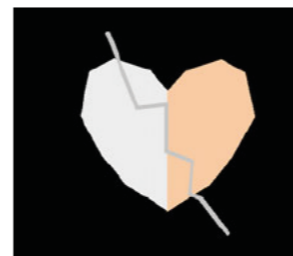
Emotional Resistance
"I get more out of life, when not thinking of it"

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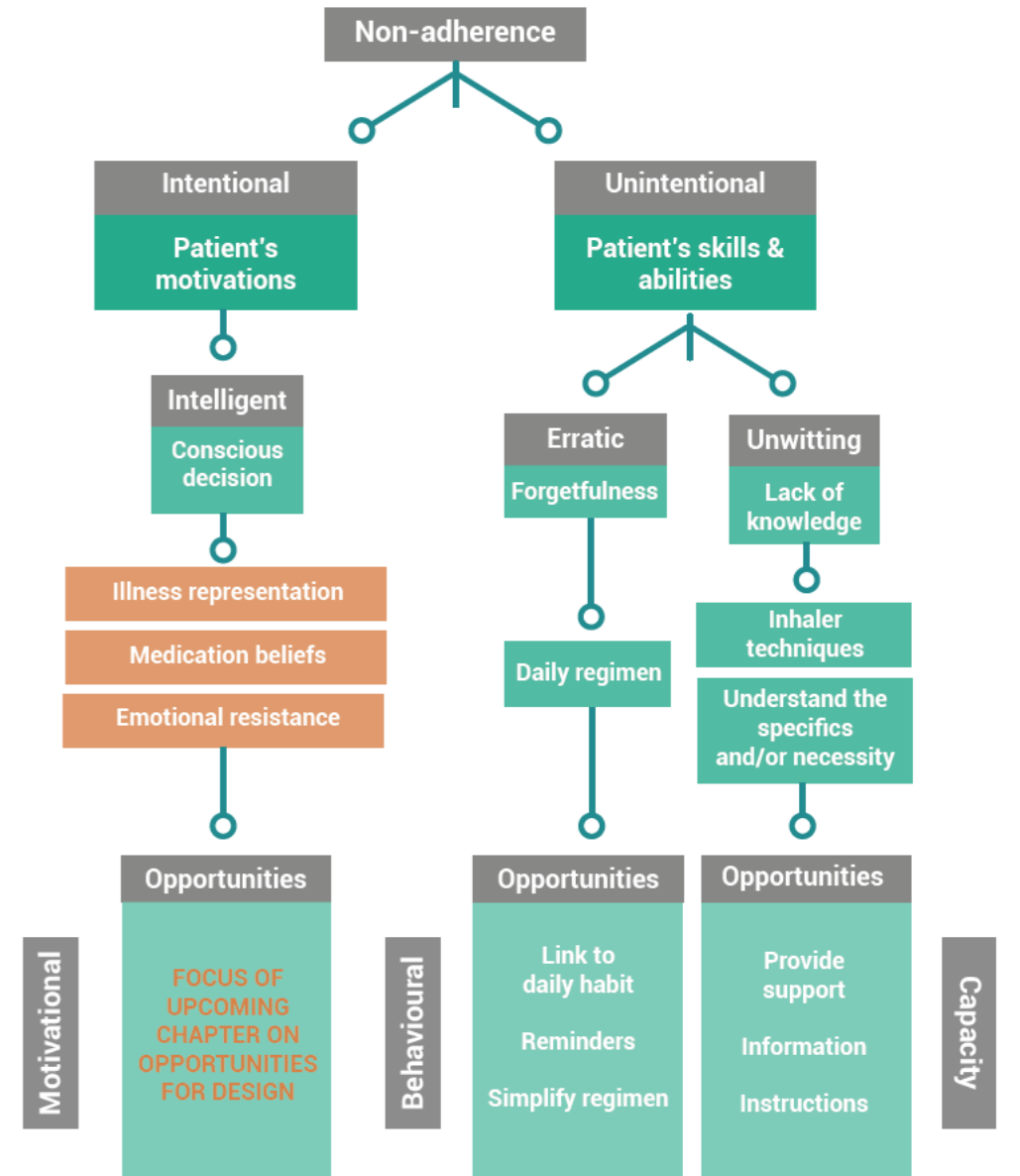- Interference daily life

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

MYRTHE (27)

Asthma level: Mild persistent

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.

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

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

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

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.

Some patients expressed to experience a lack of direct feedback of the maintenance medication in contrast with the reliever medication.

Patients seem to be unaware of the positive influence the maintenance medication can have on their daily activities and health

Intentional nonadherence: Patient's personal beliefs and motivation
Unintentional nonadherence: Patient's skills and ability

Patients want to live in the here and now, where taking care of asthma is not a priority

Patients who perceive asthma as a sporadic disease with low consequences are more likely to show poor adherence to the treatment

Patients do not seem to see a problem:
• Use of reliever medication more often
• Learned to deal / got used to limited lung capacity

04

OPPORTUNITIES FOR DESIGN

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 behaviour 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.
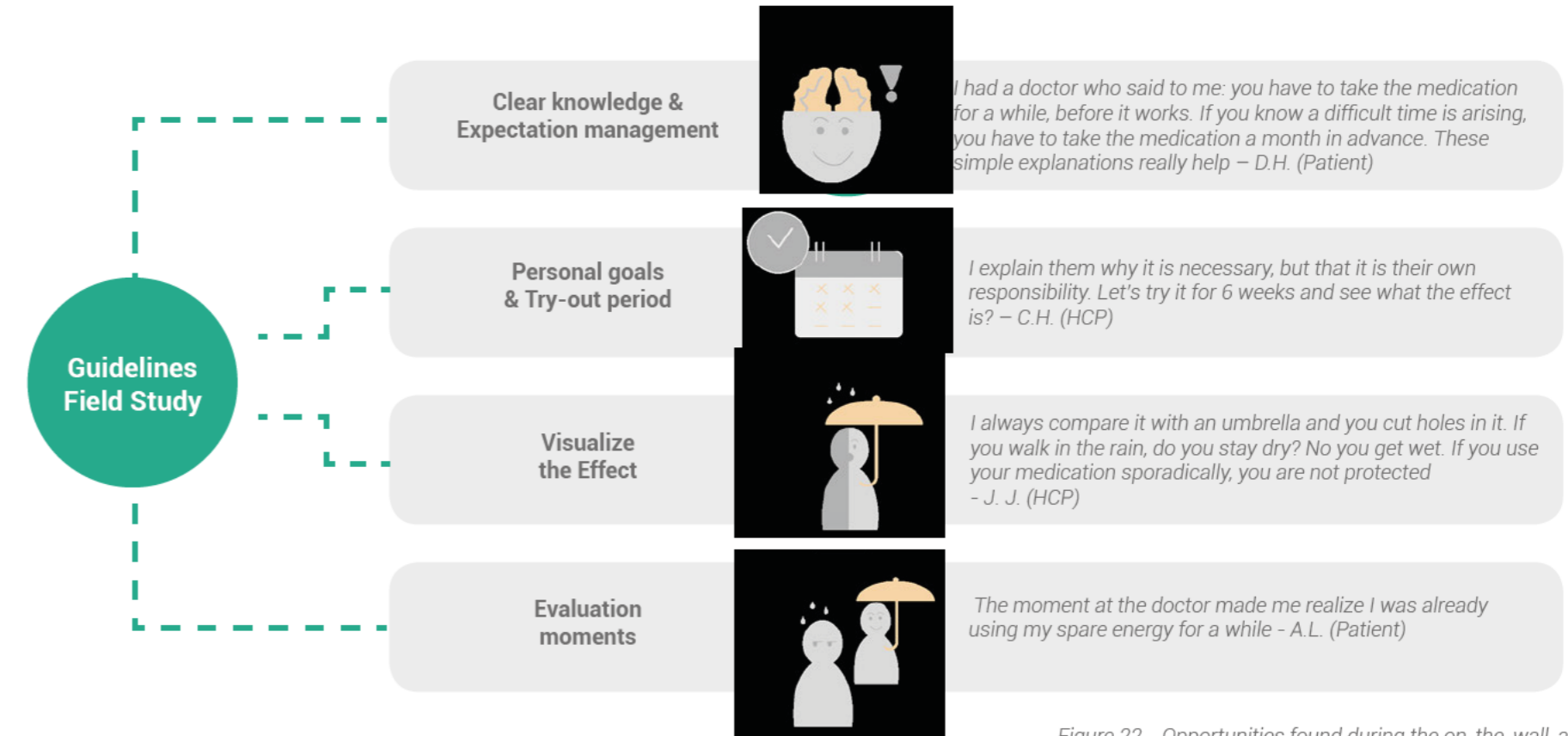
Figure 22. Opportunities found during the on-the-wall-analysis

Text boxes in figure:

Clear knowledge & Expectation management — *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 arising, you have to take the medication a month in advance. These simple explanations really help – D.H. (Patient)*

Personal goals & Try-out period — *I explain them why it is necessary, but that it is their own responsibility. Let's try it for 6 weeks and see what the effect is? – C.H. (HCP)*

Visualize the Effect — *I always compare it with an umbrella and you cut holes in it. If you walk in the rain, do you stay dry? No you get wet. If you use your medication sporadically, you are not protected - J. J. (HCP)*

Evaluation moments — *The moment at the doctor made me realize I was already using my spare energy for a while - A.L. (Patient)*

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 the lungs for them. Different HCPs expressed that the use 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 symptoms, may remain unnoticed, or patients may not link those results to their improved medication adherence.
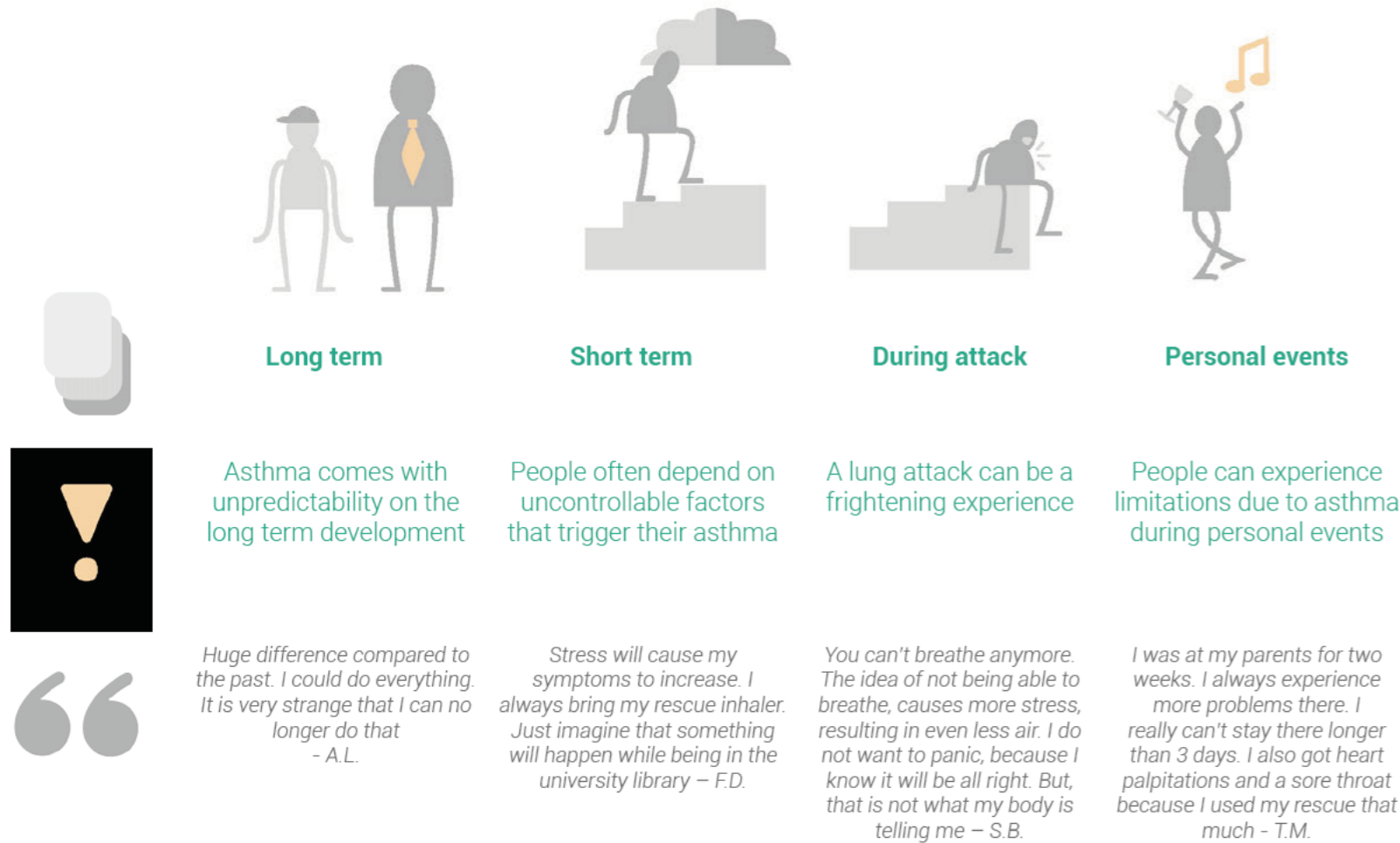
Reduce uncertainty and offer a feeling of control

Long term

Asthma comes with unpredictability on the long term development

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

Short term

People often depend on uncontrollable factors that trigger their asthma

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.

During attack

A lung 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.

Personal events

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.

Figure 23.   Different uncertainty touchpoints

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 identified 523 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 patient's 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.

Figure 24. Requirements of app to improve self-management

Guide or change behaviour

Active element that supports user

Motivate user to deliver active ingredients

Acceptable quality

- The paper shows that reminders and feedback were implemented in almost all apps, however other gamification components (such as rewards, challenges and time pressure) were seldom implemented. Which is remarkable as elements such as point systems and achievements are easily to integrate.
- The paper investigated the integration of behaviour change techniques and motivational interviewing was not implemented at all. This is remarkable as people's personal beliefs play an important role in non-adherence.
- In addition, the researchers found that engagement scored worst. Which may result in the problem that individuals will use an app for a relatively short time period (Cook, Modena & Simon 2016). Therefore it will be important to provide the user of an engaging experience.

These findings were included in the following research on motivation and behaviour change methods.

4.3 BEHAVIOUR CHANGE

Patients are required to take their maintenance medication twice daily, every morning and evening. Consequently, a shift needs to take place in patients' belief that daily medication is not needed in their situation, towards incorporating the medication two times a day into their routine. Radical behaviour changes in which people are expected to deviate from their beliefs and implement new behaviours have a larger chance of not being successful: Such shifts require effort and conscious deliberation, and people can easily return to their previous behaviour (Kahneman, 2002).

In order to understand the current state of research with regard to behaviour change, research was done in the field 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 need 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 nonadherence shows that 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 towards 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 return to 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.
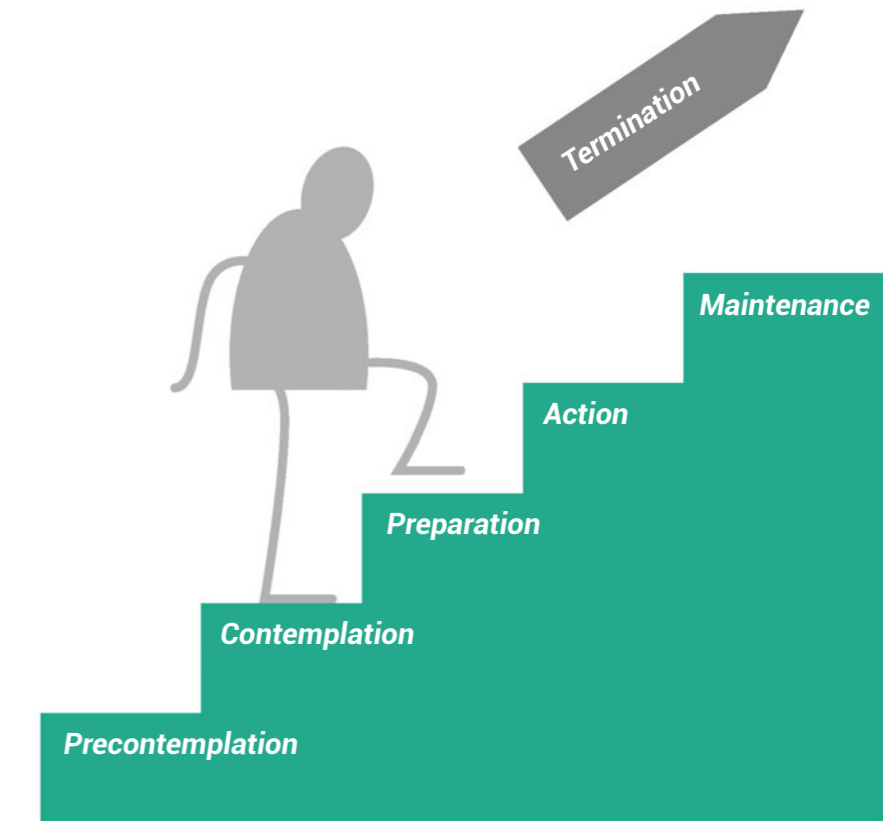

Figure 25.   Different uncertainty touchpoints

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. 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 and a person's perceived self-efficacy. Moreover, HAPA emphasizes that the process of behaviour change is often not linear. Therefore, HAPA can be seen as a stage model but also as a continuum model, in contrast with TTM.

Figure 26 shows the different steps of the health action process approach.
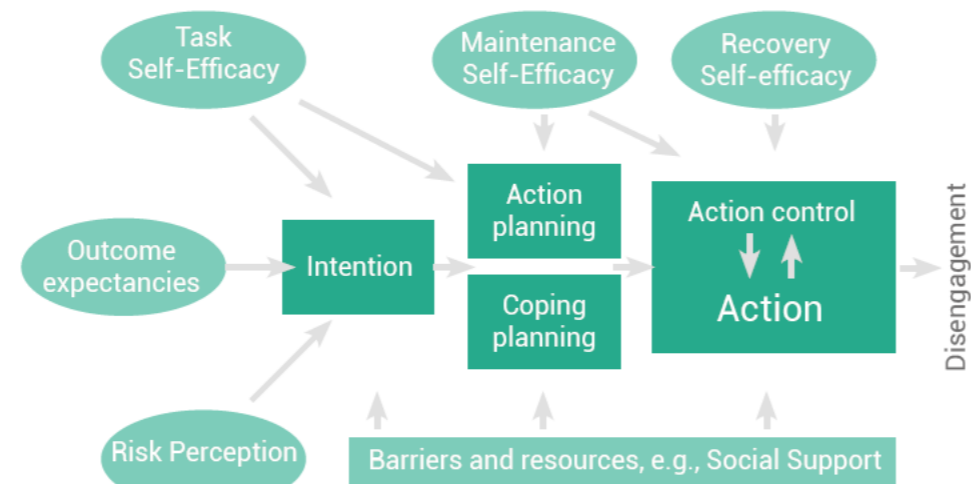
Figure 26. Health Action Process Approach

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 to understand a patient's reasons for changing or not changing before setting out a plan of action. The role of the HCP is more one of listening than intervening. 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 the medication as prescribed, HCPs often seek to identify specific personal goal(s) that will benefit from the patient' change in behaviour. If, 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 (Stuzer, 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 cause of their exacerbations, their asthma becomes worse. However, this confrontation should quickly be followed by solutions (Prochaska & DiClemente, 1983). In asthma treatment, this includes the intake of the maintenance medication (including on days patients feel better) and avoiding triggers when possible.

When the patients' decisional balance of potential advantages and disadvantages is tipped, individuals may move to the action stage.

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, especially 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 (Siriaraya, Visch, Vermeeren, Bas, 2018). This closely relates to the concept of serious games: Both aim to facilitate a transfer effect, which does not have entertainment as a primary goal. However, the difference between serious games and PGD is that the former are designed for educational purposes and the latter aim to persuade users to change their beliefs and views or to influence their behaviour.

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. In 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. 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
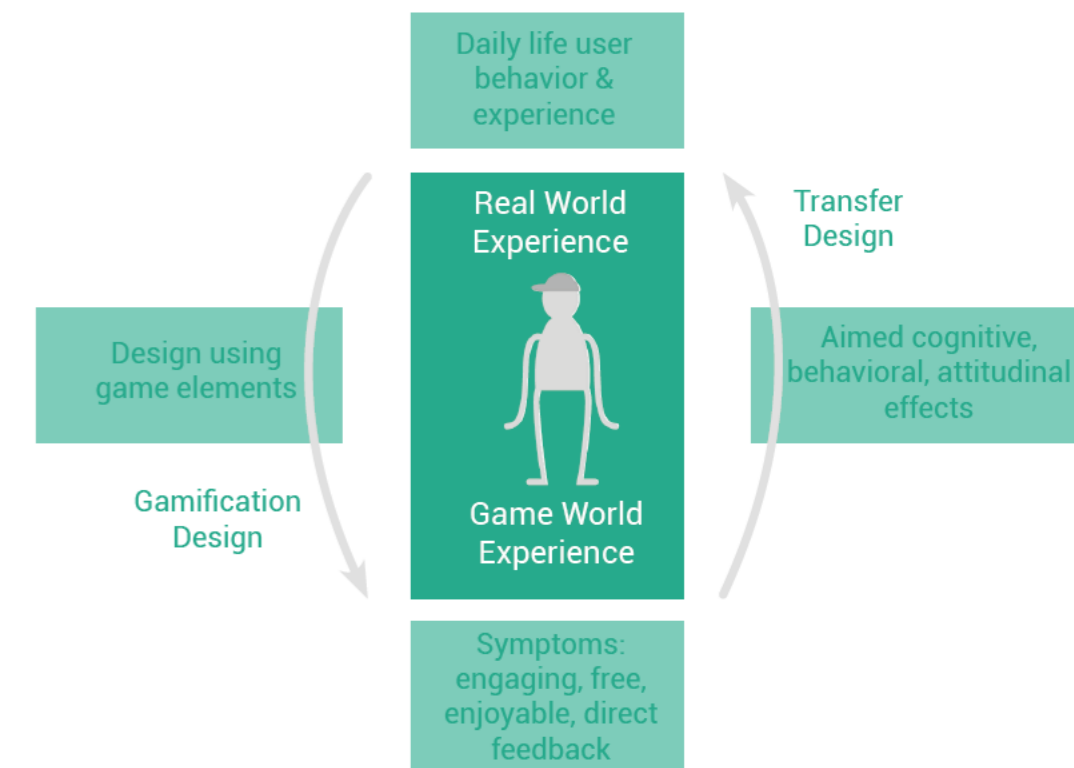

Figure 27. Building the PGD Model

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 (Lu, Baranowski, Thompsom & 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 patients often experience a lack of feedback. The intake of the medication could directly be reflected in a positive outcome in the game 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

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.

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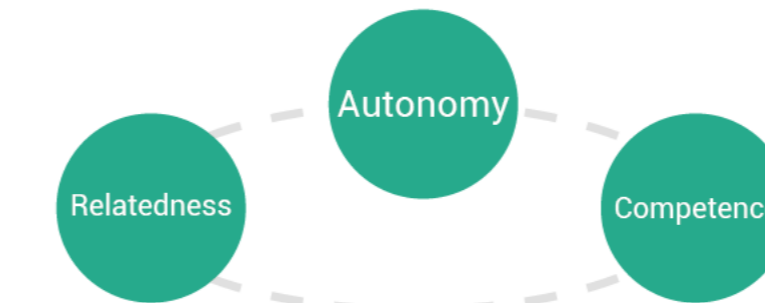 over their life. Self-determination theory defines autonomy as synonymous with behaving with a sense of willingness and choice. This need was selected as the main motivator in this project.

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).
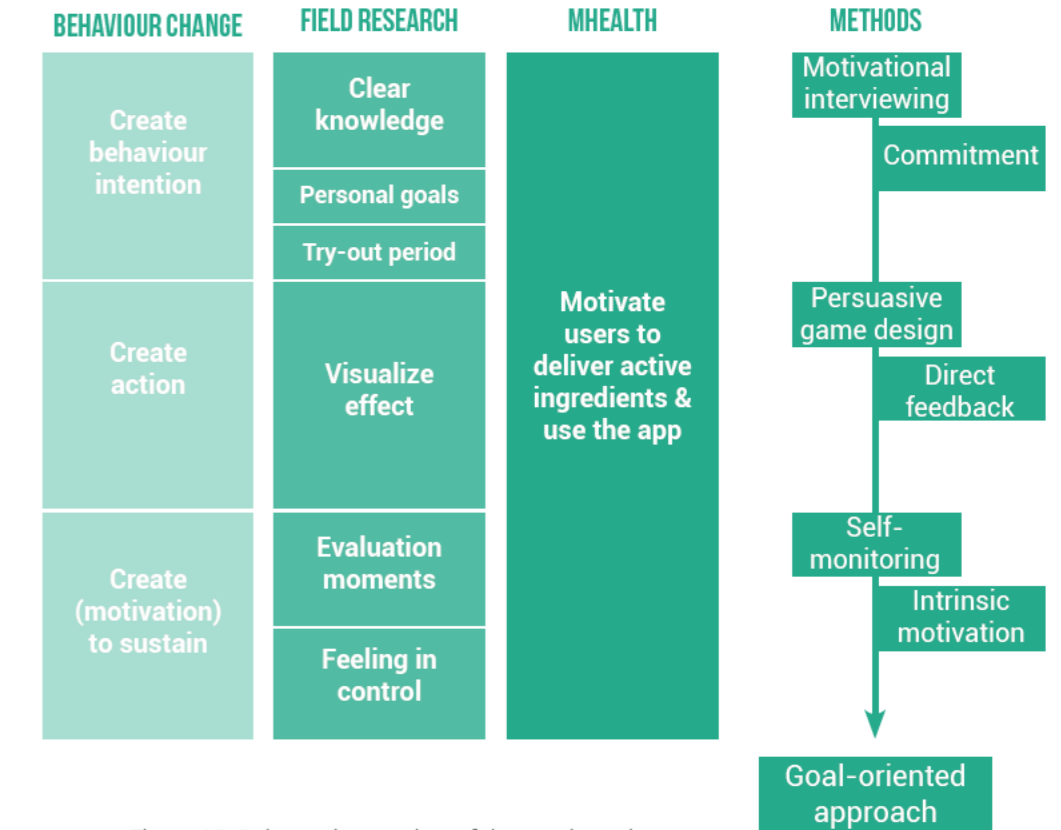

Figure 28. The psychological needs defined by self-determination theory

Figure 29. Schematic overview of the conducted research for design opportunities & methods

Figure 29 shows a schematic overview of important insights resulting from the field study, study on mHealth and study on behaviour change. This overview will be used in the ideation phase of this project, described in the next chapter.

Key takeaways chapter 4

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

The application needs to
increase patients awareness of
autonomy

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

A narrative can work as an
analogy of a real world setting
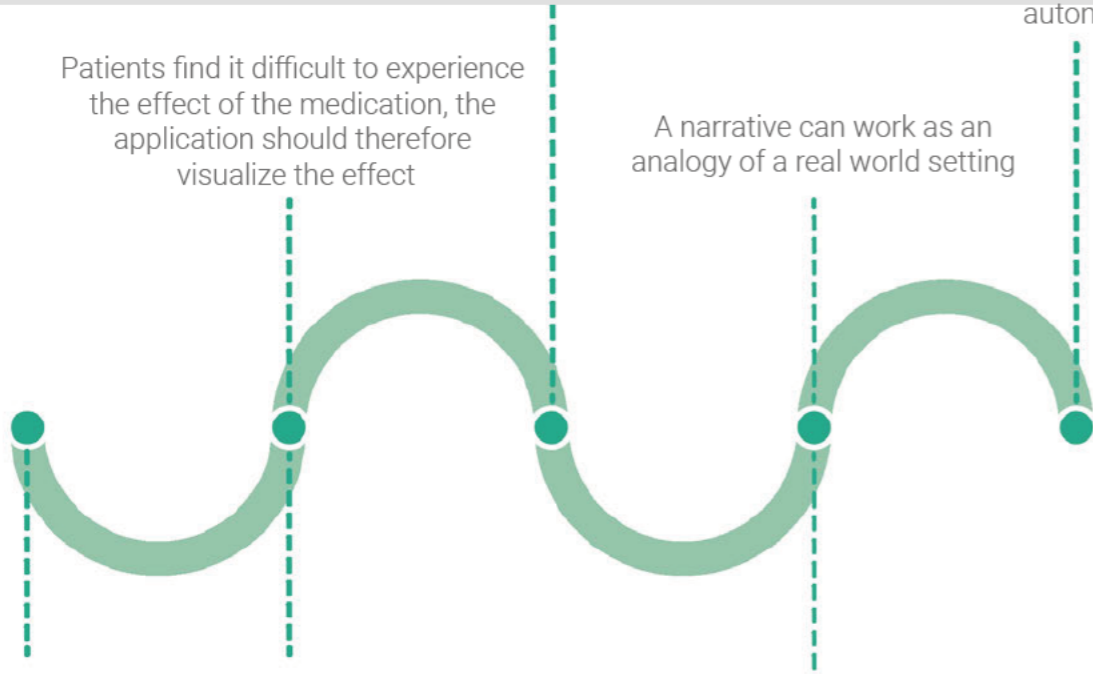
In order to show patients the
advantage of taking the daily
medication, they could be
offered a try-out period of six
weeks

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

05

CREATION OF DESIGN

The creation of the concept is the focus of this phase. 0The
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.
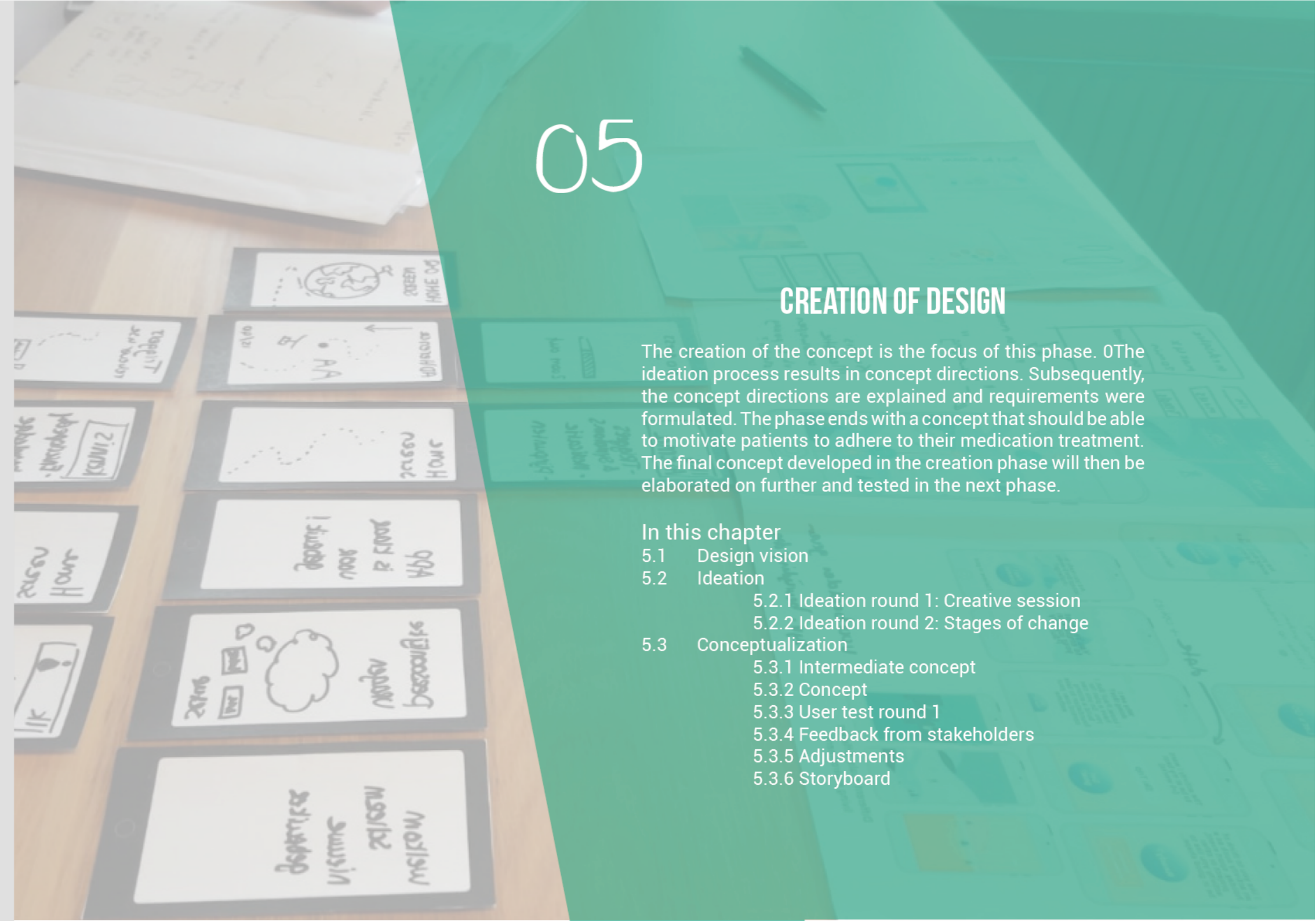
5.1. DESIGN VISION

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.

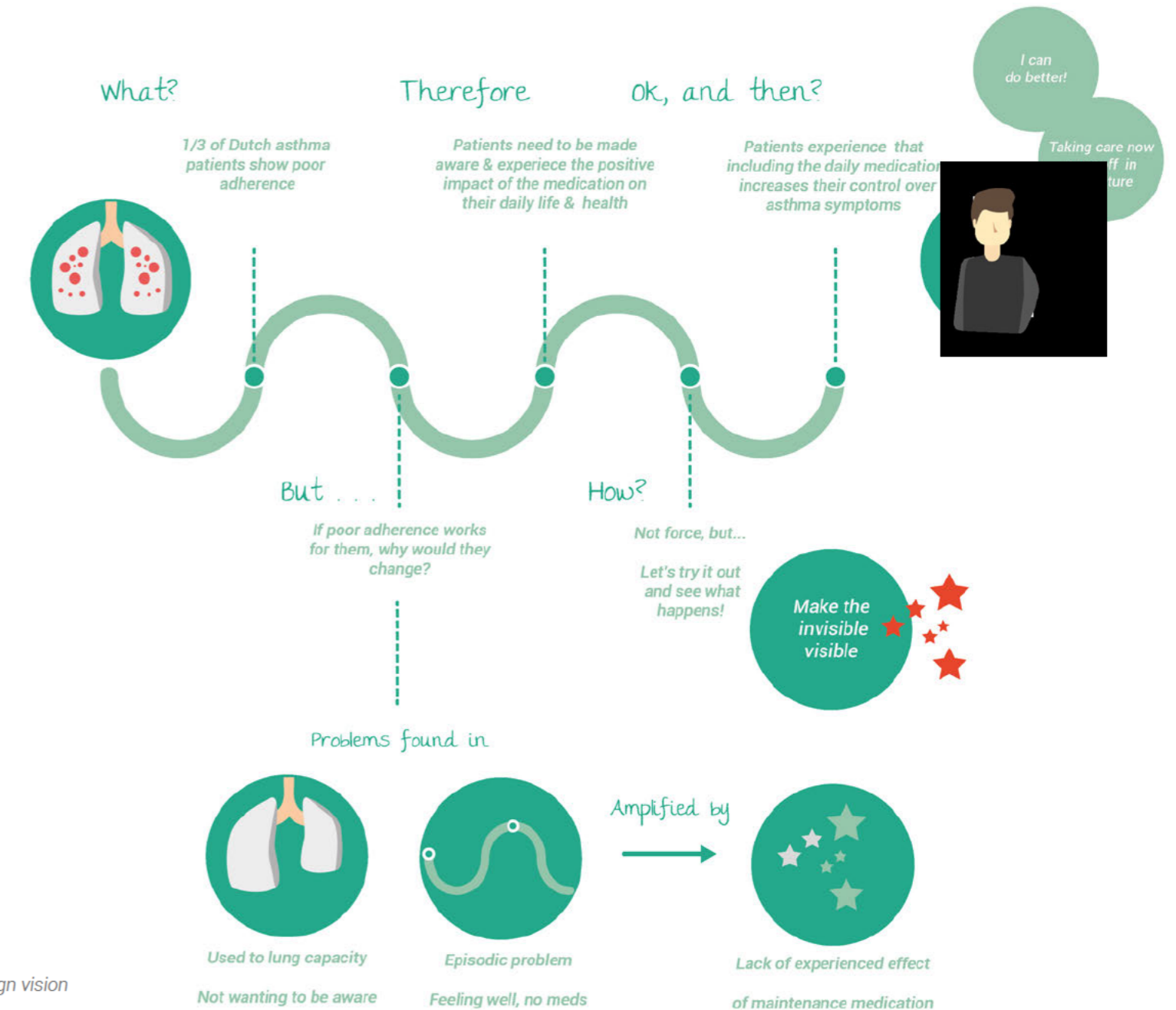Figure 30 shows a visual overview of the design vision.

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?' T¬¬his 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 provi¬ding 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 less 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, in the next step, 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.

Patients are provided contrasting statements such as 'not taking my medication on a daily basis' versus 'lowering my

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?'

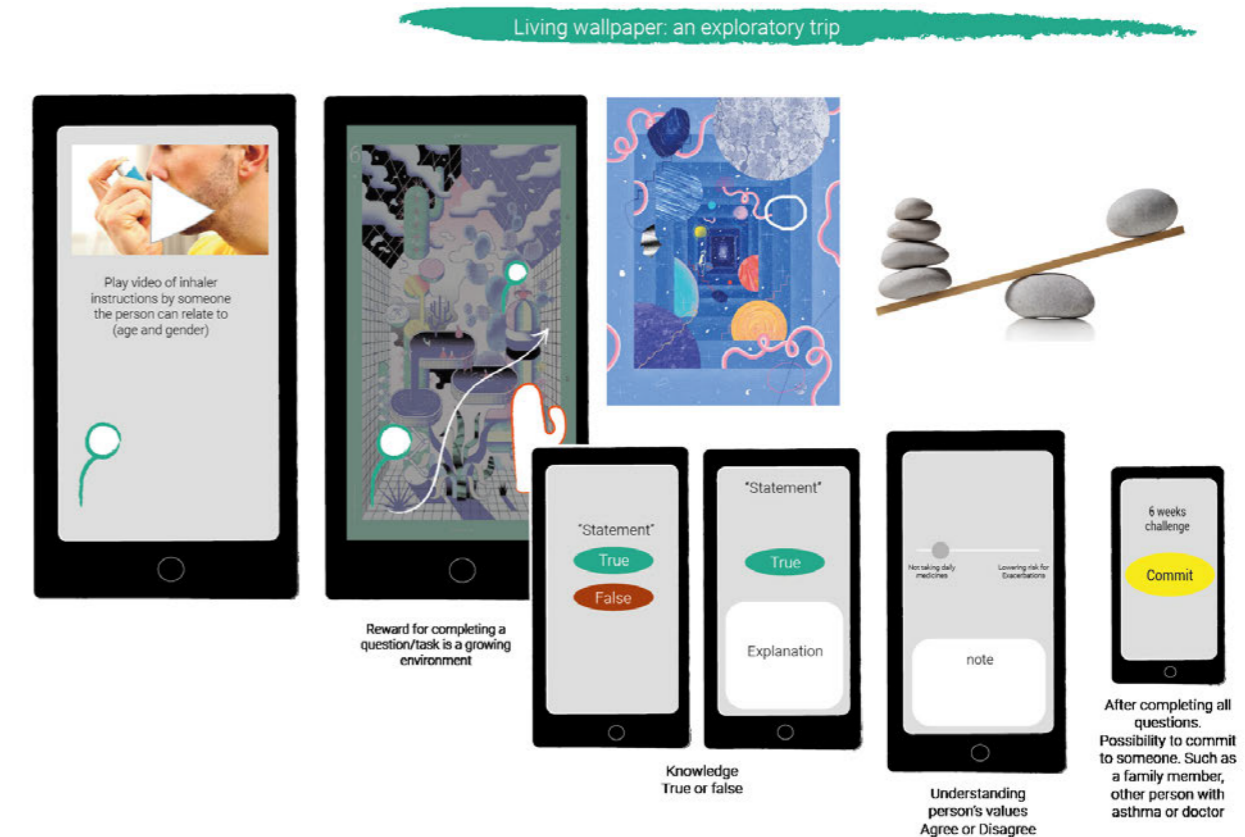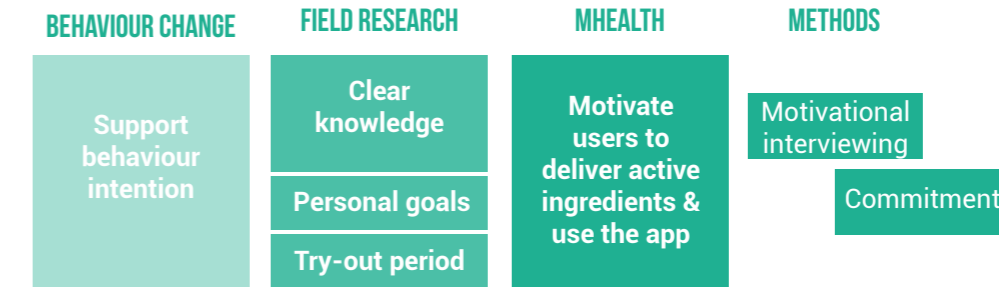Figure 32 shows the results of the ideation on supporting the intention to uptake the daily medication.

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.

BEHAVIOUR CHANGE — Support behaviour action

FIELD RESEARCH — Visualize effect

MHEALTH — Motivate users to deliver active ingredients & use the app

METHODS — Persuasive game design / Direct feedback

Take control: Fill your lungs

Calm breathing movement grows when usage of inhaler is detected

Going from bad towards good weather when using inhaler

Changing environment

Activate part Reminder on telephone

Goal-oriented approach

Figure 33. Action: 'Gain control'

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 around 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.
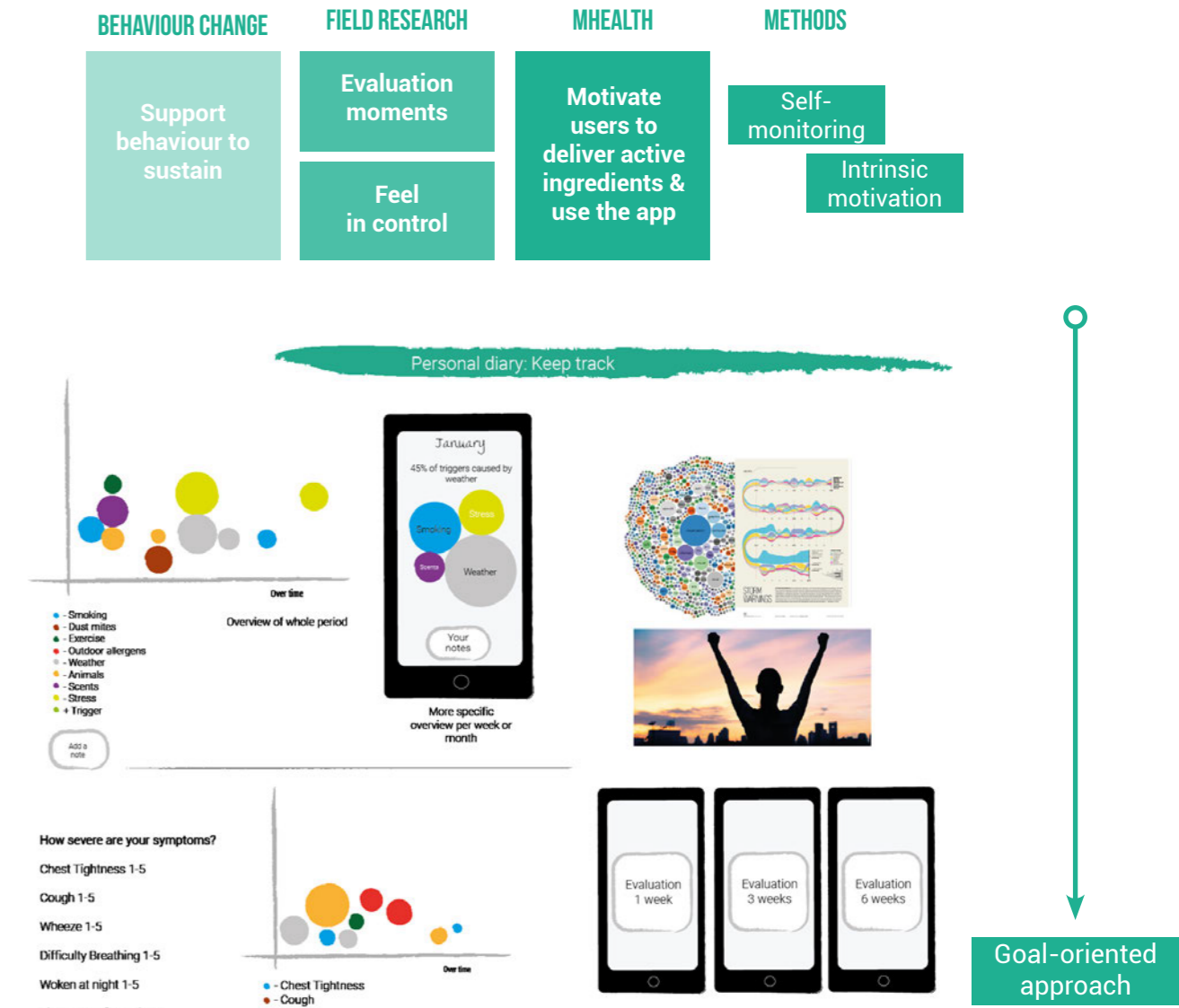

BEHAVIOUR CHANGE — Support behaviour to sustain

FIELD RESEARCH — Evaluation moments / Feel in control

MHEALTH — Motivate users to deliver active ingredients & use the app

METHODS — Self-monitoring / Intrinsic motivation

Personal diary: Keep track

- Smoking
- Dust mites
- Exercise
- Outdoor allergens
- Weather
- Animals
- Scents
- Stress
- + Trigger

Overview of whole period

45% of triggers caused by weather

More specific overview per week or month

How severe are your symptoms?
Chest Tightness 1-5
Cough 1-5
Wheeze 1-5
Difficulty Breathing 1-5
Woken at night 1-5

- Chest Tightness
- Cough

Evaluation 1 week / Evaluation 3 weeks / Evaluation 6 weeks

Goal-oriented approach

Figure 34. Sustain: 'My diary'

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's 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.

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

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

1&2: Set-up	3: Maintenance meds	4: Reliever meds	5: Trends on Reliever & Maintenance
Different personal goals, different 'living' environments	*User builds environment by being adherent. After 3 (hat-trick) days' of daily maintenace medication, a new visual element is added in the environment*	*When the reliever medication is detected, and the user opens the app, the user is asked to provide feedback on the experienced trigger event*	*The insights on medication intake and triggers are blurred. This to make the user curious and stimulate the user to fill in the feedback.* *Trends will be revealed later. When maintenance medication has had time to work*

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 use of themes linked to a personal goal was rejected because of the above mentioned.

Integrating the reliever to make the long-term effect of the maintenance medication clear was included in the final concept.
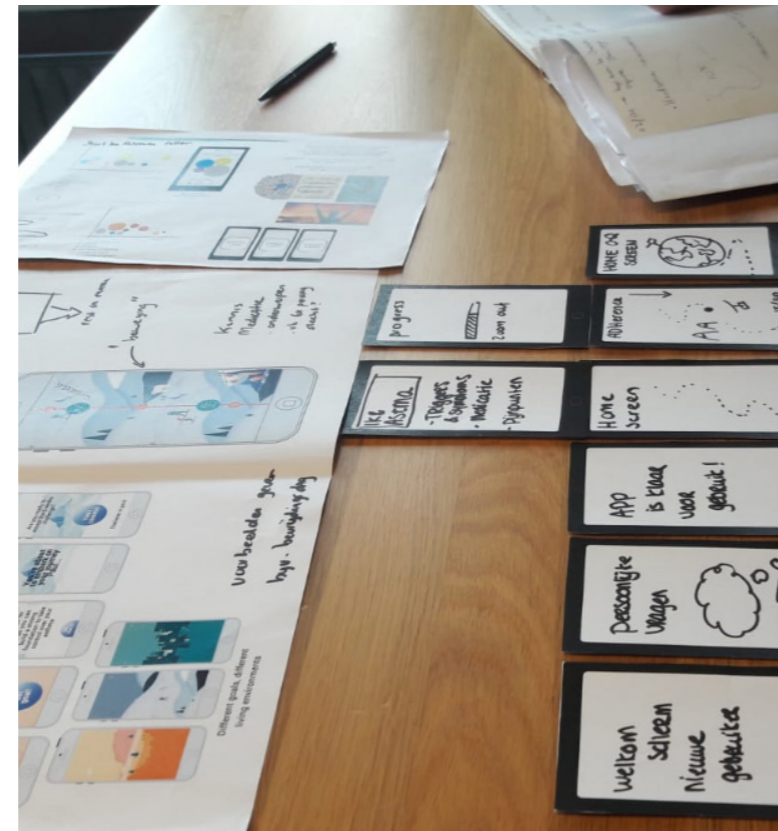
Figure 37. Discussions about the different elements used in the intermediate concept took place

5.3.2 CONCEPT

The intermediate concept made it clear that a suitable metaphor had to be found. That metaphor needed to have a strong link with the disease experience and to communicate the negative effects of not using the maintenance medication as well. Next to this, the concept should include more game elements.

In the intermediate concept of the app, the emphasis was on the personal goal. In the following concept, the need for self-care by taking the maintenance medication is the focus of the game to reach the personal goal.
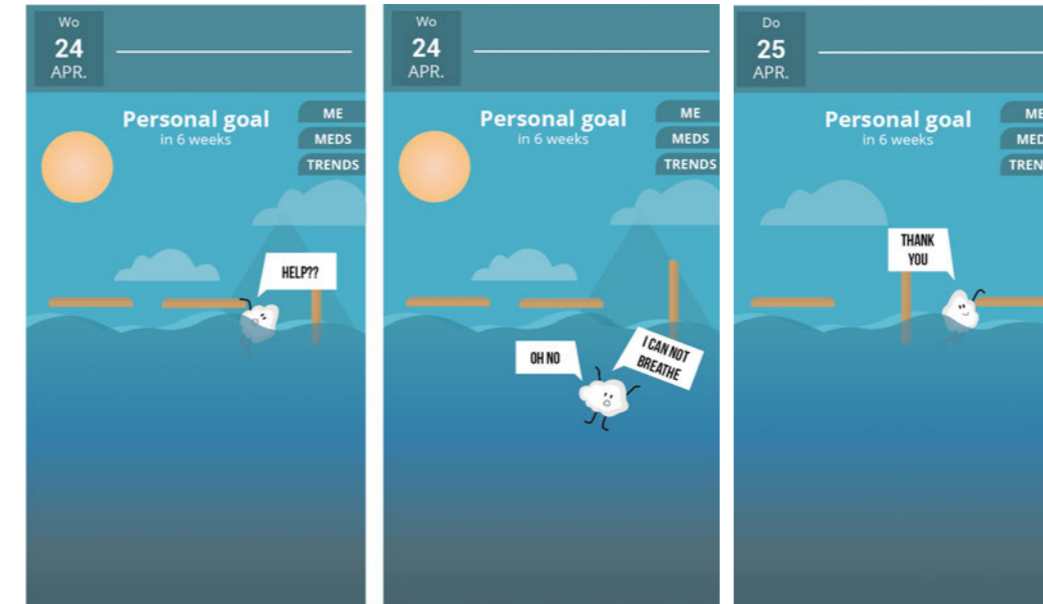
Figure 38. Narrative is inspired by the feeling of not being able to breathe

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. On the other hand, being adherent positively influences the weather and environment in the app, and this in turn has a positive influence on Brad, who becomes stronger. 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 piranha/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.
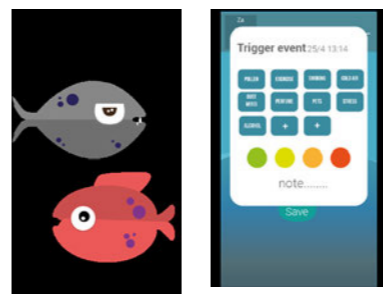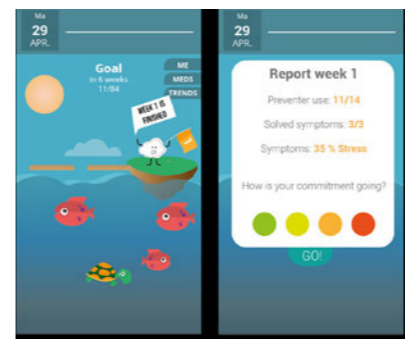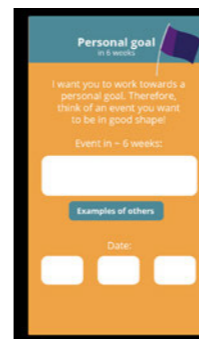
The challenge

Set up: Personal goal & Commitment

Methaphor: Interactive timeline with the metaphor of breath and water. The environment and character Brad represent how the person is doing.

**Character:** 'Brad' cloud moves towards goal is 6 weeks. Every week a report is provided with the process.

Maintenance medication: *Bridge* towards goal when being used. Otherwise character *falls* into the water

Reliever medication: *Threat* if user does not pay attention to the feedback, otherwise *friend.*

Nonadherence: Not protected/weak & bad weather

Adherence: Well protected/strong & good weather

Statistics: Evaluation moment
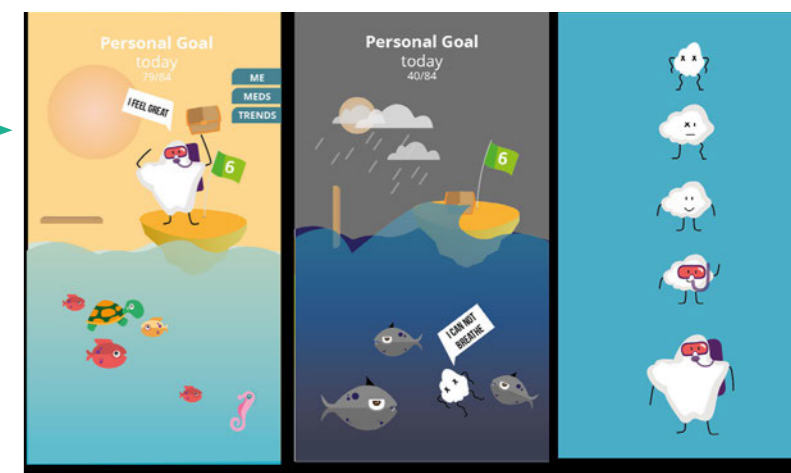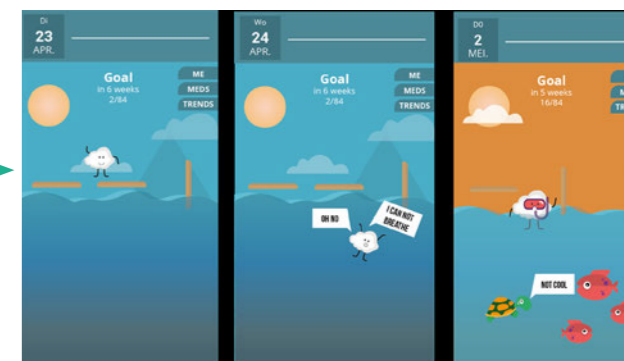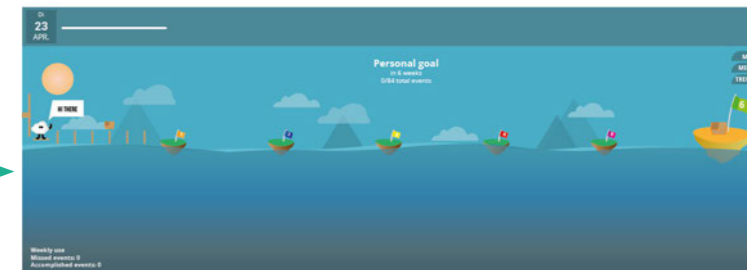
First change in game world
takes place in weather
(real world: lungs are affected)
Second change in game world
takes place in character
(real world: performance of person
is affected) etc.

First changes take place earlier than
later in the process, to make person
aware of consequences straight away

Maximum for negative change,
otherwise person is not able to turn
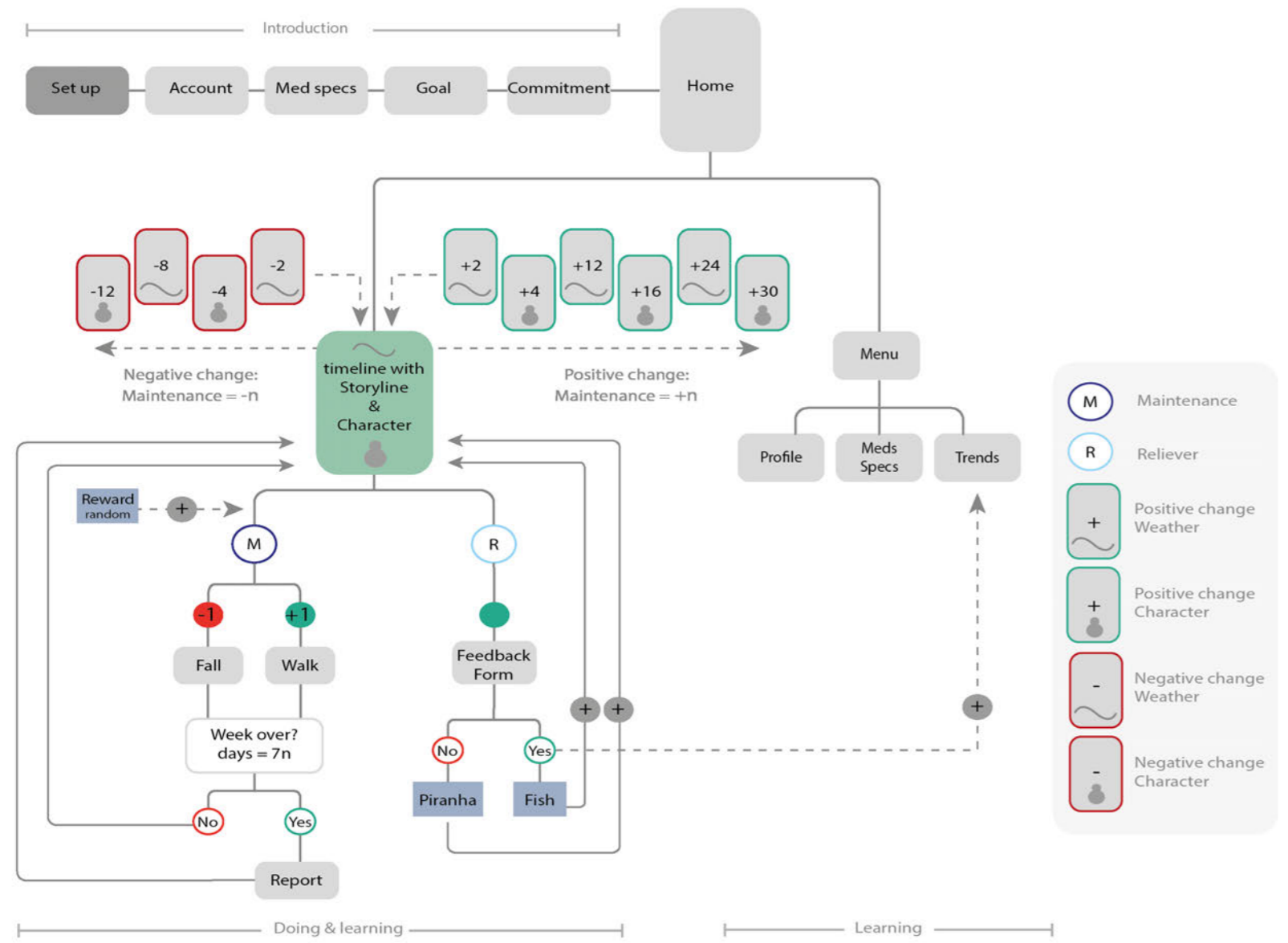back into positive, which works
demotivating

Figure 39. A schematic overview of the flow of the different steps of the applications

5.3.3 USERTEST 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.

• 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.

Conclusions

One of the participants mentioned that it would be more logical to see the whole week overview, instead of three days. A weekly overview is indeed more clear than a 3 days overview. Participants are able to see the island they need to reach and it will give participants a better impression of how their medication intake goes. This will therefore be changed in the concept.

The visualisation of the character appears to be a matter of taste, but the character should not negatively affect the experience. Therefore, it was decided that people should have two options (and maybe more in the future).

The weekly report now consist 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 of 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.

One person 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 to not frame the personal goal as an event that will happen in 6 weeks, but that this could 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

5.3.4 FEEDBACK FROM STAKEHOLDERS

The concept was presented to two persons of AstraZeneca (digital health functionary and the head of intelligent of pharmaceuticals). They liked the idea of the six weeks challenge and the interactive story. AstraZeneca expressed to see the concept fit 40-55 age people as well. They did express that the communication about the visualisation of the piranha/friendly fish should be made very clear, since this may discourage the use of the reliever medication too much. In addition, they would like to see the concept tested with a wide range of people, to make sure that medical data will not be misinterpreted.

That the concept would fit a wider target group also became clear when the concept was presented to three people from the Longpanel. They do not fit the scope of this project, since they are all three adherent to their prescribed medication. However, they expressed to like to use the concept in managing their medication. They liked the visualisations of the medication use, including the character, which was not perceived as childish.

Additionally the paper prototype was demonstrated to a practice nurse. She expressed to be enthusiastic about the concept. Furthermore she pointed out that the app cannot promise people that they will experience less symptoms or use their reliever less, however there will be a high likelihood. Expectation management at the start and uptake in the end about the results will be important. The HCP should be aware if the patient does not experience any improvements.
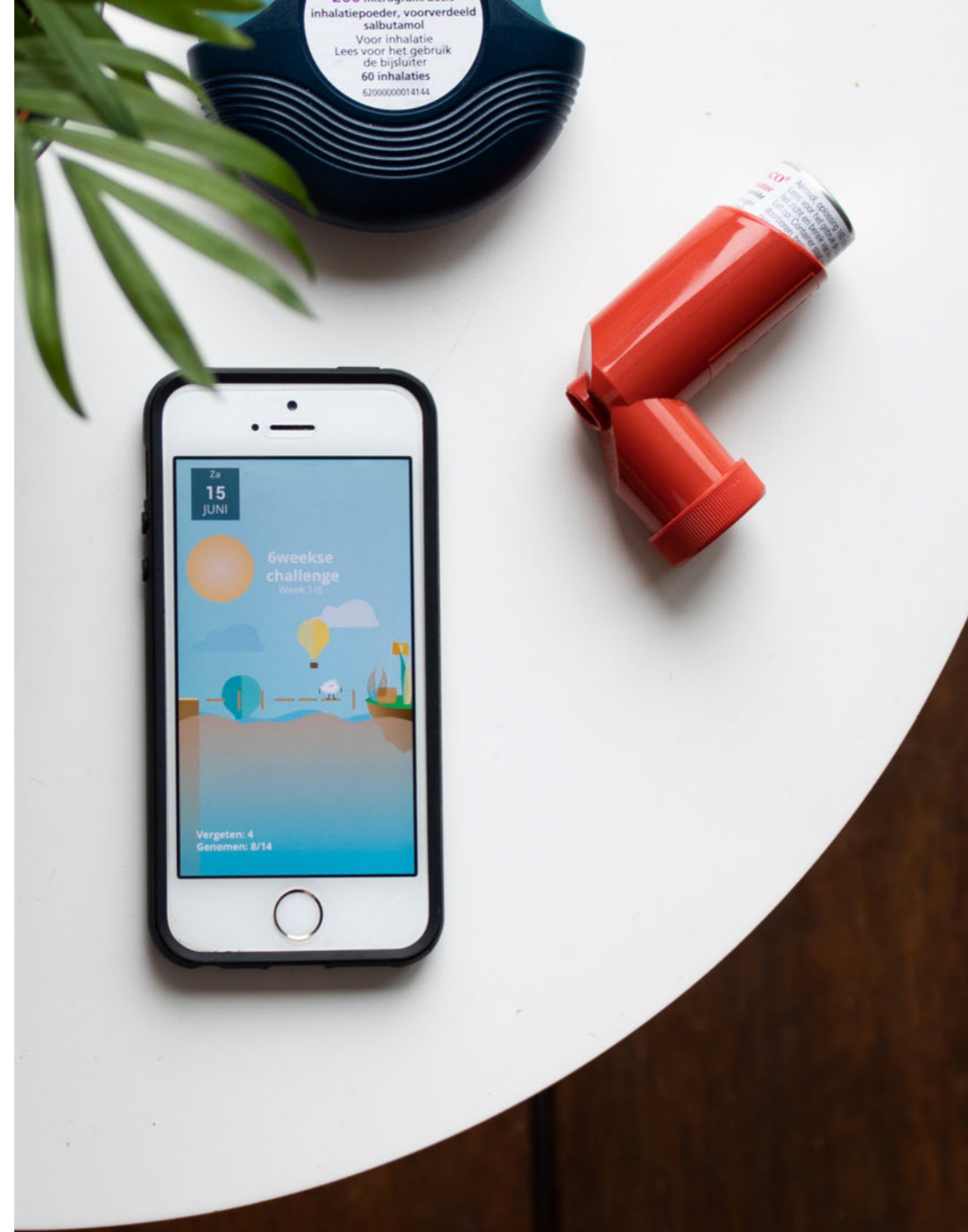
Figure 42. The visual overview was changed into a weekly overview and the colour scheme was adjusted
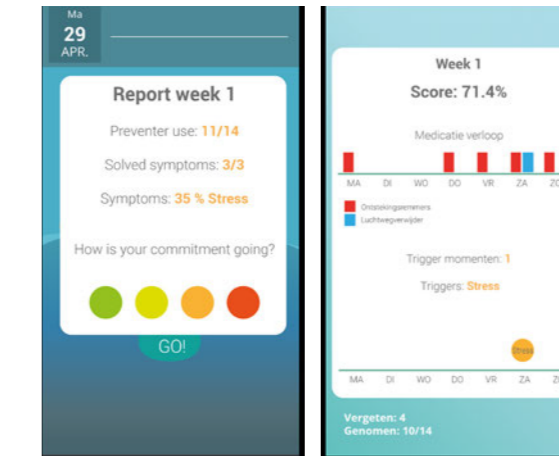
Figure 43. The redesign of the weekly report

Figure 44. A second character was developed

5.3.5 ADJUSTMENTS

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

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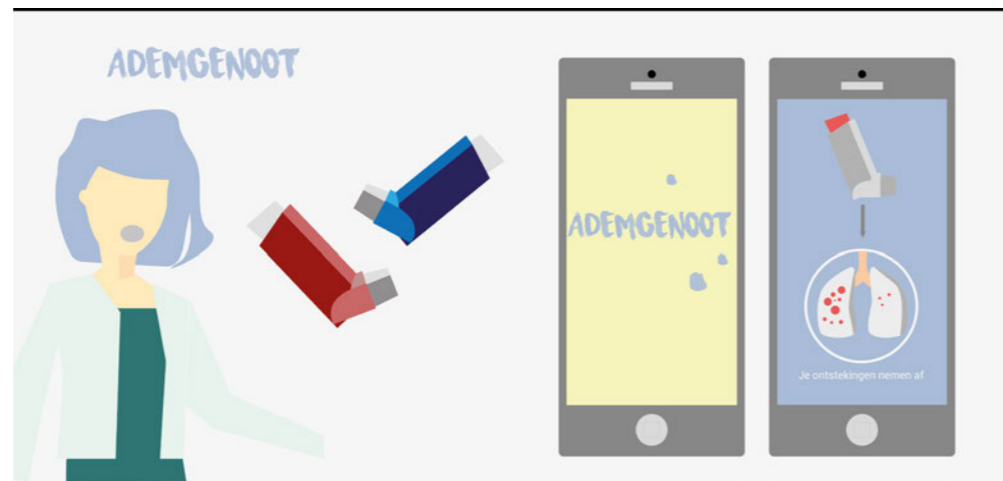
Next to this, the weekly reports conclude a more statistic overview of the medication intake (Figure 43) . Finally, the personal goal does not have to be a personal event that is linked to the 6 weeks period.

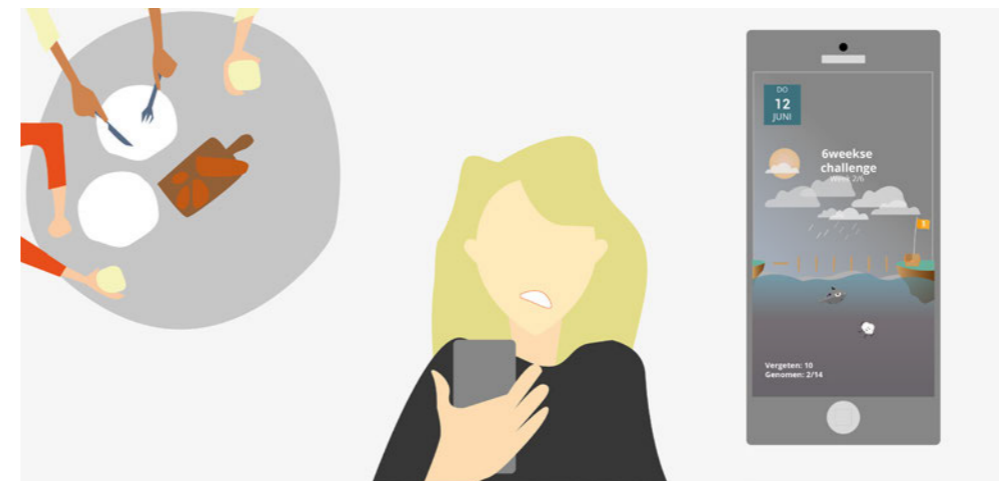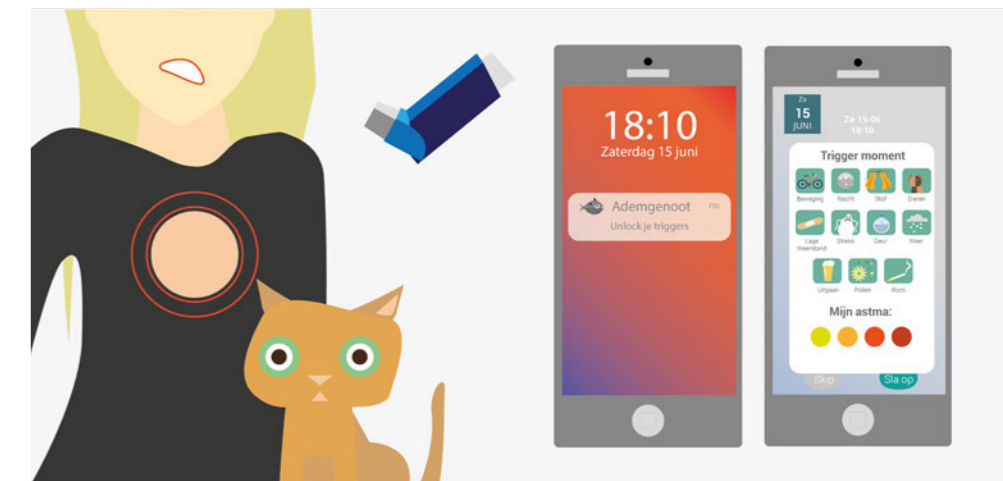The storyboard on the next page shows the final concept: Ademgenoot.
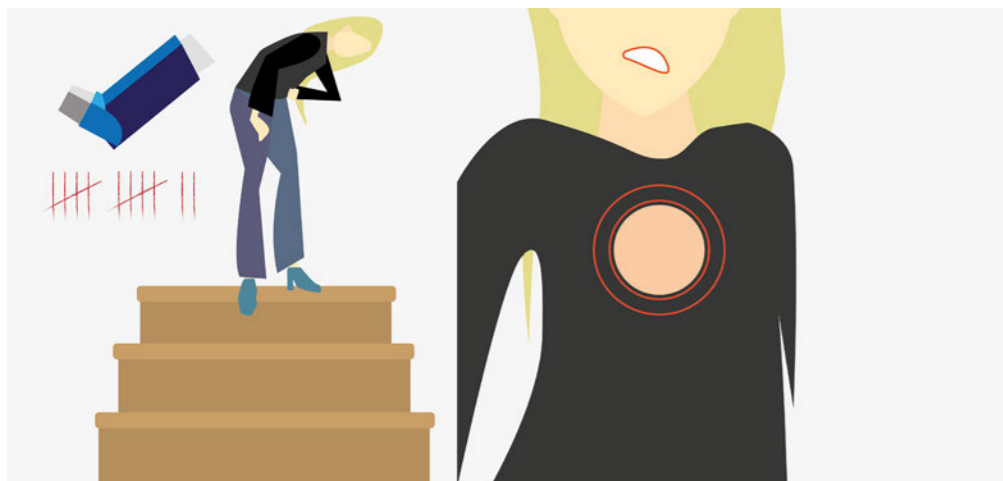
(1) Myrthe is used to her limited lung capacity and uses her reliever often
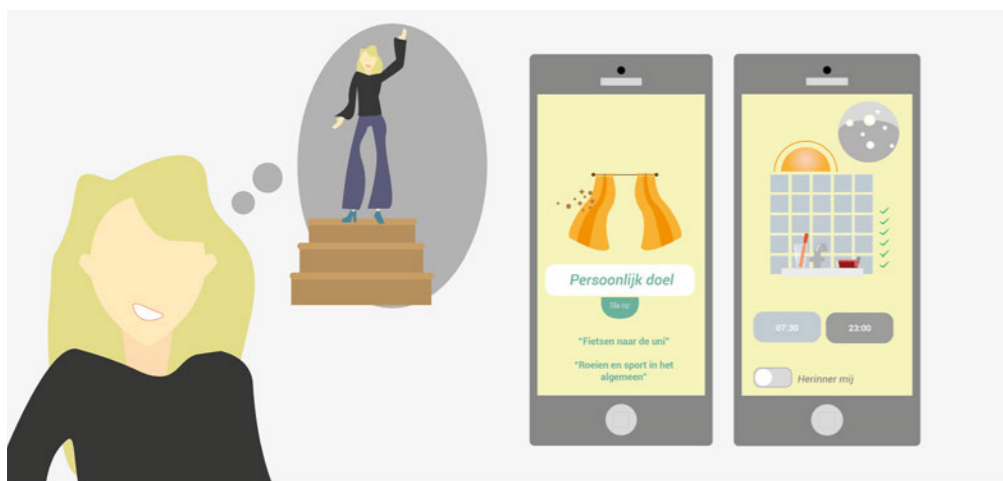
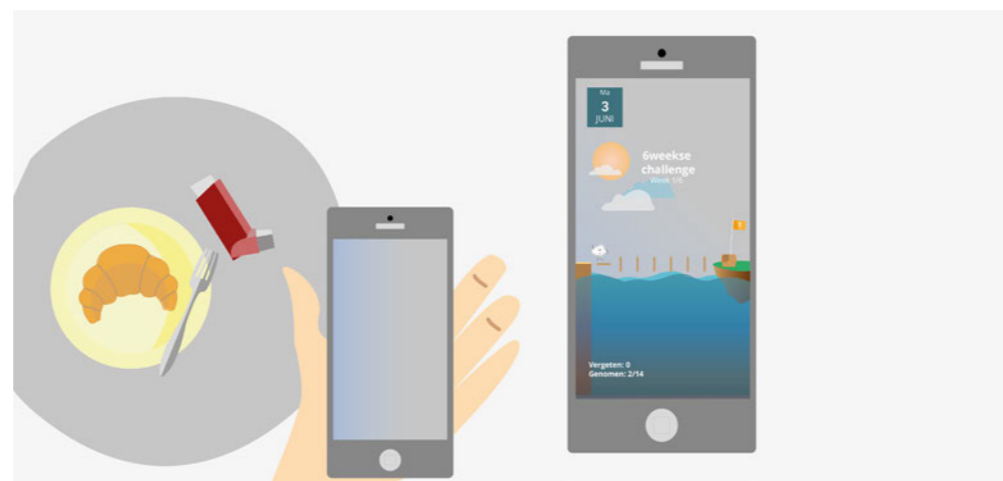(2) The doctor says 'Give the Ademgenoot 6 weeks challenge a try'

(5) But, during a fun week with friends, Myrthe forgets........ She is motivated to uptake the daily medication again, because of Brad.
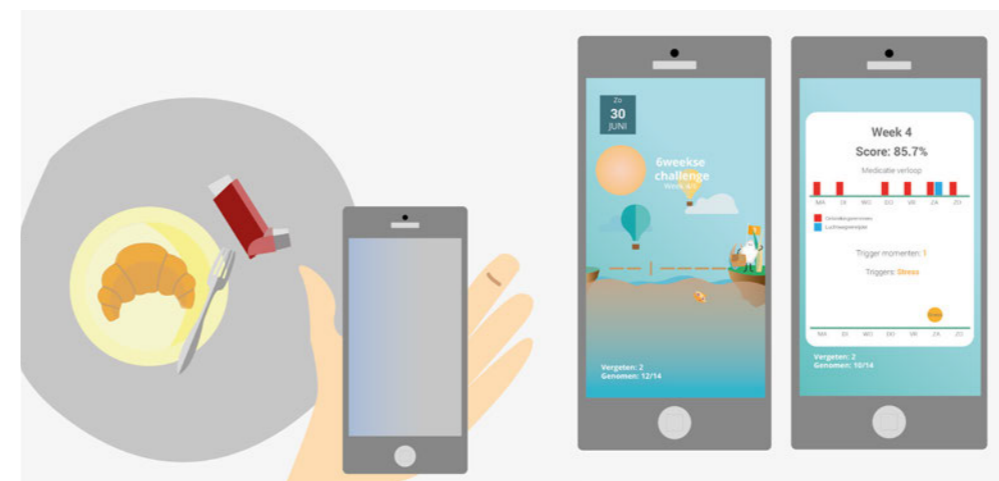
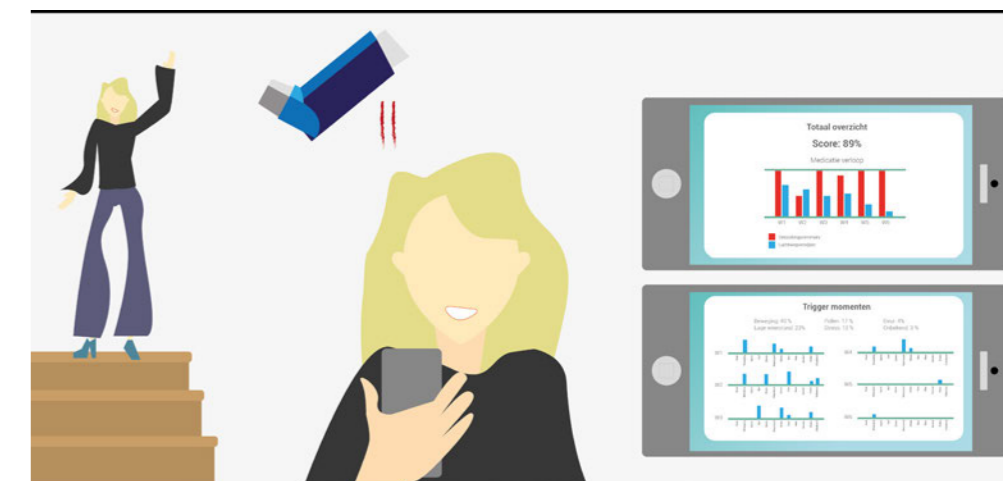(6) Myrthe uses her reliever and is asked to provide feedback

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

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

(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

06

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.

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 WhatsApp:

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:
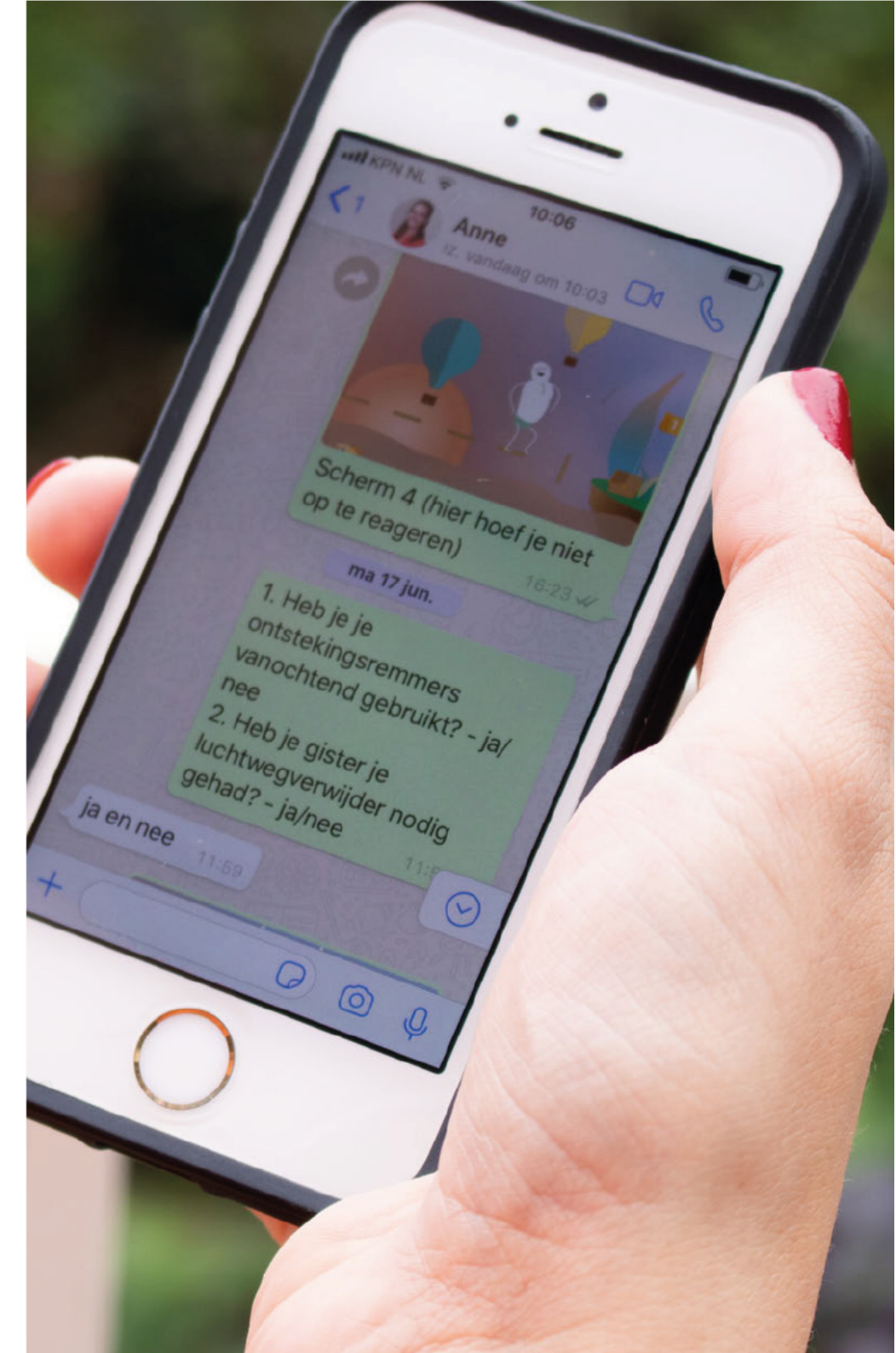
1. Maintenance medication: Screen included character falling in the water (answer = no) or character walking towards the island (answer = yes). Next to this, small changes in the weather or character took place every other day (good or bad changes).
2. Reliever medication: If participants used their 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.

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

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, and they found this easy to understand. They thought 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.

> *I thought it was great that I was working on it. I was normally not busy with it. I am now aware that I am more tired and more stuffy*
> *– A.B.*

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.

If I get such a pop-up in my screen, I open it and tap it. Easy.
- T.M.

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.S.

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 at 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.

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 5days 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

Figure 45. Interviews about the 5days challenge and concept of Ademgenoot with the participants took place

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.

Metaphor and Character: The participants were asked whether the six-week challenge would also work with an abstract visualization (as in the report) of medication use and reminders. All four participants indicated that the story and character would motivate them to use the app more often. Two thought the story and character were important for motivating them to take the medication daily. The other two indicated that they thought that a static overview and challenge would probably be enough but that this would make the experience more boring.

The report is an extra check and overview. The images for me were more the motivation to take medication. If I only had a schedule, I wouldn't do it
- T.S.

As mentionend before, one of the participants received dark screens with a character that floated farther and farther away on four out of the five days. Surprisingly, she said that the use of colour and character made the screens motivating for her. The visualizations made her aware that she was not doing well and had to take better care of herself. Because of this she used her medication in the evening, but she still forgot the next morning. She indicated that without the images she would probably have not taken any medication all week (see Figure 46 for her screens).

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. They were asked if they would find it demotivating if they opened the app and saw the character lying in the water with dark weather. 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 if faithfully taking their medication made 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. One of the participants indicated that this could be done, for example, by indicating on a scale what her 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
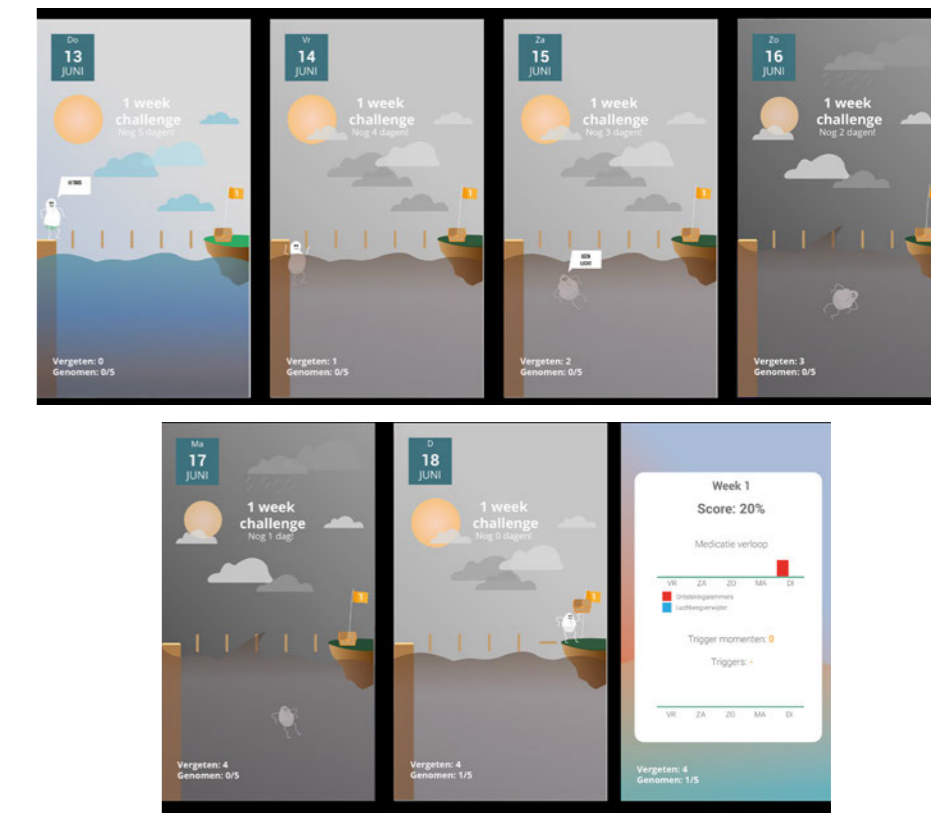*- A.B.*

Figure 46. Overview of screens of participant T.S.

From the researcher's perspective: "I felt very guilty to send black and depressive screens on a daily base to the participant"

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 control 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.

" *Because there is pressure behind it and because someone is watching – that's why you think about it. Are you already working on it? For me, personally getting a message every day was what worked the most.*
- L.J.

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.

Schematic overviews and reminders: The schematic overviews – the weekly report and the final report – were seen as an important element because they provided a sense of control over the use of medication. This, combined with the automatic registration of the medication, provides a clear picture of how often they have taken the medication and whether they have forgotten this.

In addition, the four participants indicated that setting reminders was an important part of not forgetting the medication. One participant indicated that she would like it if the frequency of reminders were to decrease over the weeks, because she would then be challenged to do this more and more herself.

Conclusion

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,
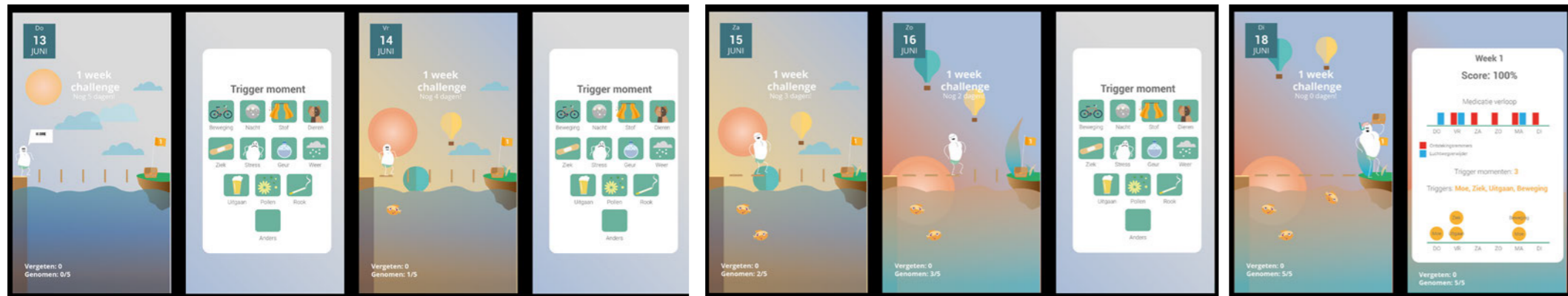

Figure 47. An overview of the screens of one of the participants via WhatsApp

and the automatic registration of the medication, mentioned by all four participants, contributes to this on the longer run.

Metaphor & character

The elements used in the storyline of 'Ademgenoot' to make people aware of the effect of their daily medication on their wellbeing, seem to work. Participants expressed to like the overall impression. Participants claimed that they did not pay a lot of attention to details and they liked to have a direct insight into their health and medication intake when using their phone. According to the participants, the character and overall colour use provided them of a clear representation of this.

In addition, all participants claimed that the app was not boring and has an active users interface. One of the participants proposed the use different themes per week and pointed out the importance of subtle surprise elements in the environment. In addition, another participant mentioned that it was a shame that experiencing less trigger events, results in an emptier sea. This is something to take into account, since less use of the reliever medication should be experienced as something positive.

Motivation & habit creation

The user test showed that the WhatsApp prototype was able to motivate people to be more adherent to their treatment. Three out of four participants claimed to take their medication more during the 5days WhatsApp challenge.

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 the biggest motivators during the 5days challenge was reaching the goal of the island.

For two out of four participants the story of 'Ademgenoot' was perceived necessary in motivating them to take their daily medication. Both experienced increased symptoms for a while now and the storyline with the possibility to sink and to receive a black screen especially supported them to get started with incorporating the daily intake in their lives. They need an nudge in the right direction and 'Ademgenoot' is useful for this. In addition, they stated that the six week period would help them to create a habit out of the daily intake. Since the app aims to motivate people to sustain the behaviour, this is a very important advantage.

The other two participants thought that the challenge and statistics could provide sufficient motivation, but that they would be less motivated to use the app. This shows that Ademgenoot consist of different elements that appeal to different kind of people. The combination of the challenge and storyline appears to be a good combination to motivate people to uptake the daily medication.

In addition, all four 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 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.

Perceived control

The participants indicated that the app would increase the control over their medication use, because of the automatic registering, the overview of their mediation 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 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, two out of four participants were very interested in their trigger events, and thought that the app could support them in recognizing those moments.

Effect of the medication on the patients' daily wellbeing

At this stage, the app works with the reliever medication, 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 patients' daily wellbeing.

On the other hand, one of the participants also mentioned that using the app would already make her more aware of her symptom experiences. If she would notice 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 to log those moments in the app, to make sure that the user is aware of those positive changes and to experience these 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 the daily intake affects 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 patients' 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 concepts 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 you 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

should be able to give additional feedback throughout the process that is focused more on how they feel than only on their experienced triggers. However, because previous research also shows that patients do not want to pay a lot of time to filling in questions, it will be important that this is very easy to do or a lot of fun.

Important role of HCP
In addition, the role of the HCP was seen very important. The HCP should evaluate with the patients the outcomes of the medication intake. If patients do not experience any improvements this may indicate that the treatment should be adjusted. In addition, the app was seen useful in the communication between patient and HCP. Since the app shows patients' experienced triggers in relation with the their medication intake over time.

Indeed, it will be very important to communicate in the app that if patients do not experience any improvement, that they should contact their HCP. Otherwise, patients may be demotivated to take their daily medication, since they do not experience results. However, it could be that they are prescribed to the wrong treatment and that adjustments in the treatment are needed. Or as described in the earlier conducted research, other factors may influence the lack of result. People may use their inhaler wrong or live in a house full of animals, while they are allergic. Therefore the role of the HCP remains very important.

Figure 48. A powerpoint was used to show the concept

6.2 FUTURE RECOMMENDATIONS

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 relieve 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.

Pay attention to the abstract visualisations of the gathered data

Patients indicated the bar charts are important to have a good overview of their medication intake and trigger events besides the visual overview.

This 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 medication use and triggers were mainly designed to provide the patients of an impression of how the statistics on this data could look like. The patients expressed to understand the statistic overviews during the end user test, however the patients only saw those visualisations for a short amount of time and these visualisations were not worked out in detail. For example, the patients were asked to provide feedback on their experienced triggers and intensity within the feedback form (with the use of a color). This intensity is not visualised in the statistic overview of trigger events at the end of the six week period. The overview of triggers could include more data than the quantity of trigger events only. Therefore it is recommended to look into the data visualisation of the trigger events and how to effectively communicate the data gathered from the patients' provided feedback over time.

Trigger the curiosity of the user

The user tests showed that the storyline of 'Ademgenoot' was well received. The participants expressed to especially like the look and feel that was incorporated in the story, this provided them of an immediate impression of progress. In addition all participants expressed to like the metaphor and character and the storyline was not perceived as boring. However, since the participants 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.

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 and keep the user engaged 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 water could be changed to keep the user curious and to prevent disengagement. However, it is important to keep this minimalistic, since different participants mentioned that they liked how the weather and character were the main points of attention in the application and they expressed not to like the use of too many details.

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 AstraZeneca 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. Or to include random sea life that stops by, to keep the user curious to open the app.

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 will be important to include evaluation moments between HCP and patient. Especially when patients do not experience any improvements after the six week period, it is important to look together with the HCP into potential causes. Either It could be that the patient treatment should be adjusted. Or the absence of improvement could be caused by other factors such as incorrect inhaler technique or extreme circumstances such as the pollen season. When the overviews show 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 used 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 time of use 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.

Keeping in mind that in the current user-tests the participants only received images for five days in a row via WhatsApp, the next step is to start building a working prototype of the application that can be tested over a longer period of time. Therefore the application should be linked to the patients' phone and inhaler.

Furthermore the working prototype should be tested with a wider variety of asthma patients. At this moment the application was mostly tested with female students and young urban professionals. However, while discussing 'Ademgenoot' with different professionals and patients, different ages and target groups were mentioned to potentially benefit from 'Ademgenoot'. Moreover, AstraZenca expressed that their largest group of users is between 40-55 age and they did see potential of the concept for this group of patients as well.

To conclude, a working prototype should be installed on the phones of a more representative group of patients (different age groups and a good balance between male/female users), to test motivation over a longer period of time and to discover whether medical data can be misinterpreted because of the way the data is visualized.

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 acknowledge 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 functionally 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.

07

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08

APPENDICES

DESIGN FOR our future

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

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.

① 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.

STUDENT DATA & MASTER PROGRAMME
Save this form according 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 !

family name		Your master programme (only select the options that apply to you):
initials	given name	IDE master(s): ◯ IPD ★ DfI ◯ SPD
student number		2nd non-IDE master:
street & no.		Individual programme: _____ (give date of approval)
zipcode & city		honours programme: ◯ Honours Programme Master
country		specialisation / annotation: ◯ Medisign
phone		◯ Tech. in Sustainable Design
email		◯ Entrepeneurship

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

** chair	Valentijn Visch	dept. / section:	ID - DA	
** mentor	Lyè Goto	dept. / section:	ID - AED	
2nd mentor	Astrid Bontenbal			
	organisation:	LUMC		
	city:	Leiden	country:	Netherlands

comments (optional)

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

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

① Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Personal Project Brief - IDE Master Graduation

Meer grip op astma — project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date **08 - 02 - 2019**   **07 - 07 - 2019** end date

**INTRODUCTION **
Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money, …), technology, …).

Asthma is a chronic disease of the airways (figure 1). Asthma is characterized by various symptoms such as wheeze, shortness of breath, chest tightness and/or cough. Factors such as exercise, allergens or irritant exposure and change in weather are often a trigger but this differs per person. The three classifications used to indicate asthma severity as defined by the Global Initiative for Asthma (GINA) (1) are mild, moderate and severe asthma.

Asthma is a disease that has no cure. The goal of asthma treatment is to control the disease. Asthma is treated with two types of medicines: long-term control and quick-relief medicines. Preventive, long-term control medications reduce the inflammation in the airways that leads to asthma. Quick-relief inhalers quickly open swollen airways that are limiting breathing. Reducing and, ideally, eliminating the need for reliever treatment is both an important goal in asthma management and a measure of the success of the treatment (1).

Adherence to medication is an important factor in effective self-management. Self-management includes asthma information, correct inhaler usage, adherence to medication, a written asthma action plan, self-monitoring of symptoms or peak flow and regular review by a health care provider (2).

Effective self-management has resulted in improved quality of life and reduced healthcare utilisation, reduced days absent from work or school and less night-time asthma. However promotion, uptake and use of self-management based interventions among patients and health-care professionals remain low (2).

Opportunities might be found in the direction of paying more attention to the psychological side of living with asthma. The Nederlands Instituut voor Onderzoek van Gezondheidszorg (NIVEL) describes how currently, healthcare professionals' preference is to improve physical treatment results and do not pay enough attention to the psychological side of living with asthma. Which is important as asthma can cause psychological problems, such as depression, anxiety, loneliness and feelings of embarrassment. (3)

The Leids Universitair Medisch Centrum (LUMC) and Astrazeneca (a pharmaceutical and biopharmaceutical company, are working on the project 'meer grip op astma' (4) to develop an innovative self-management application. The research is being conducted in the National eHealth Living Lab (NeLL). Currently they are evaluating patients' experiences that they have collected through sensitizing booklets and interviews which I will use as a starting point for my graduation project. I will further investigate how to increase motivation for self-management, to improve medication adherence through eHealth.

space available for images / figures on next page

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Initials & Name   J.H.   de Boer   Student number 4297210
Title of Project   Meer grip op astma

Personal Project Brief - IDE Master Graduation

**PROBLEM DEFINITION **
Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

Poor medication adherence is a problem among asthma patients. Most people underuse their controller medication which is used for regular maintenance and treatment, and overuse relievers medication that treats asthma attacks. One of the reasons for non-adherence, is that people do not experience the full benefit of their treatment instantly when taking controller medication. Further motives will be researched (5).

Another problem is found in the fact that healthcare professionals prefer to base asthma control on improving measurable physical treatment, lacking the attention to the psychological and social side of the person with asthma. Acceptance of the disease and the image of the person's illness for instance, often determine the way patients deal with their disease (3).

I will take a human-centered design perspective in researching how an eHealth design can increase motivation for self-management to improve medication adherence. This project is in line with the Medisign track I am trying to obtain and my master direction Design for Interaction.

**ASSIGNMENT **
State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, … . In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Design an eHealth solution that facilitates in improving motivation for self-management to increase long-term controller medication and decrease reliever medication. The aimed deliverable will be a proof of concept of an e-Health solution, usable in the daily at home context.

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Title of Project   Meer grip op astma

Personal Project Brief - IDE Master Graduation

**PLANNING AND APPROACH **
Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date **8 - 2 - 2019**   **7 - 7 - 2019** end date
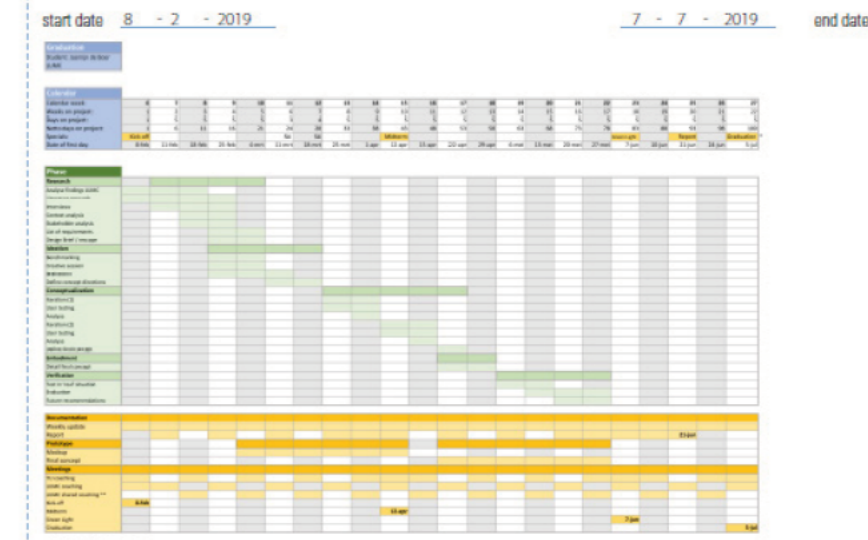
In the Gantt Chart is shown that the total amount of working days is limited to 100. The planning is divided in the following 5 main phases: Research, Ideation, Conceptualization, Embodiment and Verification. Each phase will take approximately 4 weeks, but are overlapping. Meanwhile the phases Documentation, Prototype and Meetings/Deliverables are stretched over the full project. One week of holiday in between is calculated.

Throughout an extensive user study, including interviews, user testing and engaging multiple experts, a concept will be developed. LUMC & NeLL have different expert contacts within this field, such as lung specialists and an expert on medication adherence, Job van Boven, I have access to. Furthermore NeLL is in contact with multiple asthma patients (Longfonds panel), I will contact for my graduation project. I already started analysing the conversations NeLL has had with patients recently and I am contacting the persons with asthma they were not able to speak to. Furthermore my own social network will be contacted. The focus will be on adults, with moderate asthma. This research will be conducted on how to increase motivation in combination with profiles of non-adherence (potential solutions per non-adherence phenotypes are described by Boven et al. (2017)) (6) and how this is done in related subjects. Opportunities may be found in using persuasive game design methods combined with theories on intrinsic motivation. The aim is to test the final concept with a minimum of 3 participants for at least one week.

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Personal Project Brief - IDE Master Graduation

TUDelft

MOTIVATION AND PERSONAL AMBITIONS
Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

For this graduation there are multiple reasons why I am motivated to execute this assignment:

- Experience hospital context --> is this a context I would like to work in?
- Conceptualisation of medical tool
- User centered design process
- Building bridges between different disciplines (Me (Industrial Design), NeLL (eHealth), AstraZeneca (pharmaceutical company) , LUMC (Medical Center)and persons with asthma)
- Learn to contribute to research by design engineering

The personal learning ambitions I have during this graduation:

- Ability to become an expert in a specific medical subject, in a short period of time
- Use quick prototyping for the iteration phases, but still generate a suitable test
- Graphical skills for communication
- Learn and experiment with new theories & methods (Persuasive Design)
- Take into account different values of stakeholders
- Decisiveness in process

FINAL COMMENTS
In case your project brief needs final comments, please add any information you think is relevant.

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AGE:
18-25: 12p
26-35: 7p
>45: 1p

In welke mate had je het gevoel dat je de afgelopen maand door astma beperkt werd bij activiteiten (20p)?

- Helemaal niet
- Nauwelijk beperkt
- Een beetje beperkt
- Tamelijk beperkt
- Erg beperkt
- Heel erg beperkt
- Volledig beperkt
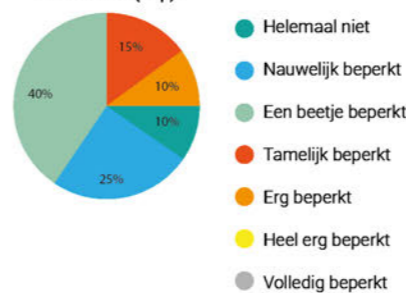
Mijn aantal pufs/inhalaties van de kortwerkende luchtwegverwijder gemiddeld per week:

- 0 pufs/week
- 1-2 pufs/week
- 3-4 pufs/week
- 5-8 pufs/week
- >9 pufs/week

Astma voelt voor mij episodisch — Astma voelt voor mij chronisch
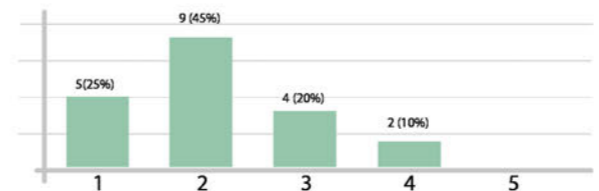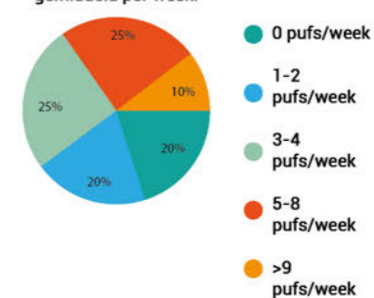
Ik heb mijn astma goed onder controle — Ik heb mijn astma niet onder controle

Het nemen van ontstekingsremmers, vind ik niet nodig als ik mij goed voel — Het nemen van ontstekingsremmers vind ik nodig, ook als ik mij goed voel
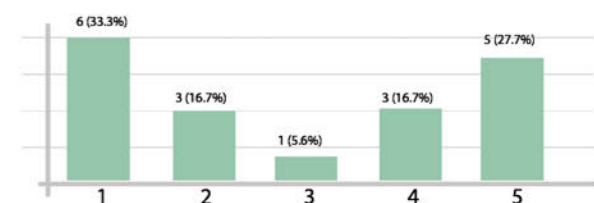

Ik vind het vervelend om mijn inhalator in de buurt van anderen te gebruiken — Ik heb er geen problemen mee om mijn inhalaotr in de buurt van anderen te gebruiken
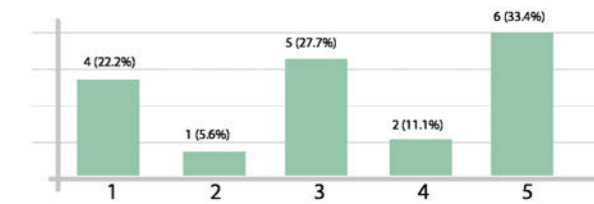

Het nemen van dagelijkse ontstekingsremmers voelt als overmatig gebruik van medicatie — Het nemen van dagelijkse ontstekingsremmers voelt alsof ik mijn longen goed onderhoud

Ik heb geen behoefte aan meer kennis over de precieze werking van mijn medicatie — Ik heb behoefte aan meer keennis over de percieze werking van mijn medicatie
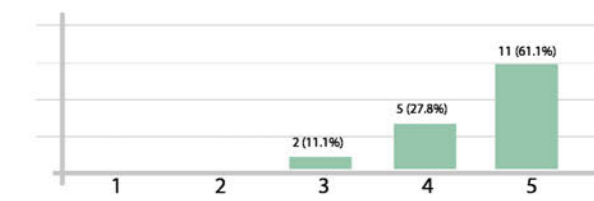

Ik zie het belang van ontstekingsremmers niet in — Ik zie het belang van ontstekingsremmers in

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 juist al heel veel keelpijn had, dacht ik, ik wacht daarmee. Dat wilde ik er toen niet bij hebben. Daarna geen nieuwe meer gehaald. (T)"

•"Ik heb ook die oranje disk en die moet ik wel dagelijks gebruiken, als die zou moeten werken. Maar ik heb er geen last van en ben niet medicatietrouw. (E)"

•"Ja maar met de hitte heeft iedereen het warm (E)".

•"Is het nu mijn conditie of mijn ademhaling, dat weet ik dan ook niet zo goed. Alleen vraag ik mij ook af, omdat ik een slechte conditie heb, of het daar niet gewoon aan ligt. Soms vind ik het ook een beetje slap van mezelf. Ik kan wel zeggen, ik heb astma, maar het is ook niet dat ik mega veel sport (E)."

•"Ik denk ook als ik niet meer student ben, ik er veiliger mee om zou gaan. Omdat je dan meer regelmaat hebt. Dat is het een dagelijks ritueel, bij het tandenpoetsen ofzo. Niet de ene keer om 9 uur of 11 uur 's ochtends. (E)

•"Ik heb wel het voornemen het wel te doen, maar het is lastig. Zeker bij de onderhoudsmedicatie. Als daar corticosteroïden inzitten. Dan moet je eten en drinken daarvoor. Dat zit niet in mijn ritme (S)"

•"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 (S)."

•"Ik vind het lastig om effect te voelen, drie jaar geleden gingen die testen bij de longarts veel beter, maar ik had dat niet gemerkt (S)"

•"Dan doe ik het twee weken, en dag gaat het weer goed en stop ik weer. Dan denk je dat je het niet meer nodig hebt (E)"

•"Ik heb daar geen wantrouwen tegen. Maar ik heb weleens dat ik er gewoon geen zin in heb. Dan is er wel weerstand. Maar ik heb dan gewoon geen zin in al die pillen. Echt geen zin. (A)"

•"Mensen zijn eigenwijs. Die denken, ik doe het al tien jaar. Het is wel goed zo. Maar dat is het dus niet. (A)"

•"Ik slaap weleens heel slecht. Dus je hoofd is moe en je lichaam is moe, en dan vergeet je dingen. Maar ik merk dat meteen. (D)"

"Ja toch wel een soort van taboe in het openbaar. Toch toegeven dat je iets niet kan. (A)"

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
Geen controle (lange termijn)
Quotes

•"Mijn vader heeft ook astma, maar die is er overheen gegroeid (T)."

•"Extreem verschil met vroeger, vroeger kon ik alles. Heel bizar dat ik dat niet meer kan (A)."

•"Het is al beter geworden, sinds dat ik 15 was (F)."

•"Het gaat bij mij meer achteruit. Ik ben pas gediagnostiseerd met astma toen ik 25 was. Ik het hyperreactief astma en dat is met de huidige medicatie moeilijk te behandelen (D)."

Astma ontwikkeld zich op verschillende manieren door de tijd heen, het is niet constant.

Dit zou ervoor kunnen zorgen dat de ziekte sporadisch voelt in plaats van chronisch.

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 ook niks zeggen. Dus andere mensen raken ook in paniek. Maar, in mijn hoofd weet ik dat het goed komt. Ik heb het een keer heel erg gehad. Toen moest er een ambulance komen. Ik begon te hyperventileren en te verkrampen (F)."

•"Ik zit dan helemaal dicht en krijg geen lucht meer. Het idee van geen lucht meer krijgen, zorgt voor meer stress. En dan krijg je nog minder lucht. Ik moet me dan focussen ipv in paniek raken. Ik heb geen paniek, want ik weet dat het goed komt. Maar dat gevoel zit in je lichaam. (S)"

•"Dat is best eng, want je kent het gevoel (longaanval). Maar uit enthousiasme voor de sport wil je door gaan. (S)"

Een astma aanval kan een hele nare ervaring zijn, omdat de persoon controle verliest over zijn ademhaling. Wat ervoor kan zorgen dat de persoon in paniek raakt.

Categorie
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 zwerven door het huis (A)"

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

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

•"Maar het gaat soms ook gewoon echt niet goed. Dan heb ik een nacht en is het echt afgrijselijk (A)."

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

"Wij hebben een vakantiehuisje in Friesland. Hier heb ik heel veel last, lig ik de eerste dag als een vis op de bank. Heel veel puffen, maar daar word je misselijk van. En alles heel goed poetsen, dat doet mijn moeder dan. De gordijnen wassen. (S)."

"Laatst was ik voor twee weken bij mijn ouders, anders maar een paar dagen… daar heb ik er altijd veel meer last van. Ik kreeg toen ook hartkloppingen en keelpijn omdat ik mijn puffer zoveel gebruikte. (T)."

"Een keer heb ik vijf keer een aanval op een festival gehad (S)"

"En die moeheid is wel een beperkende factor, dat ik niet even ergens heen kan fietsen. Dat is lastig. Het gaat heen en weer. Er zijn momenten dat ik daar heel boos over ben (A)."

"Met de dispuut driedaagse ging ik heel slecht, toen was het warm en had ik stress. Toen ging het ook mis. Als ik veel aan mijn hoofd heb, luister ik ook niet goed naar mijn prikkels (F)"

•"Door stress krijg ik het sneller benauwd. Ik heb altijd mijn puffer mee. Stel je voor dat er iets gebeurd (F)"

"Niet perse stress, maar lichamelijke stress. Sommige mensen krijgen rugpijn of worden ziek, ik krijg meer last van mijn astma. Dat is het moment dat mijn lichaam zegt. Nu is het genoeg (S)"

Bij astma ben je vaak afhankelijk van factoren buiten je macht om. Het is niet te voorspellen of je een aanval krijgt. Dit kan voor een bepaalde onzekerheid bij personen zorgen.

Stress blijkt hierin een veelvoorkomende factor

Astma kan de persoon overvallen of limiteren tijdens persoonlijke evenementen: vakanties, sociale evenementen, zoals een festival of uiteten gaan, of sport.

Categorie
Leven in het hier en nu
Quotes

"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 rook al af en toe sinds mijn 17e. In de zomer ook weleens elke dag. Als ik op een feestje 5 sigaretten rook, voel ik dat nog minstens een week aan mijn ademhaling. Dan stop ik weer en dan begin ik weer (S)."

"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)"

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.

Categorie
Meten
Quotes

"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 mijn gevoel zei 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 vermoeid was. Ik was daaraan gewend, in je hoofd zit dat niet meer, maar in je lichaam wel. Daar hebben ze toen goed op gereageerd met Relvar. (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.

Categorie

Belang HCP bij medicatiegebruik

Quotes

"Toen zei hij ook, het belangrijkste is rust, rein en regelmaat. Maar dat ga je toch niet doen. Dus zorg dat je je medicatie dan altijd neemt. Dat je die altijd bij je hebt en er zo een beetje rekening mee houdt (S)."

"Nee niet direct. Toen ik bij de huisarts een longfunctietest moest doen. Vraagt hij of ik gerookt heb. Nee want je moeder zit ernaast (E)."

"Bijvoorbeeld motivational interviewing is een techniek waarin je dat boven tafel kan krijgen. Het is een patroon managen. Je maakt afspraken, maar iemand checkt vervolgens niet of je eruit komt. En niemand vraagt mij: Dominique lukt het jou om met al deze medicatie een redelijke dag te maken? (D)"

"Toen ik ook de eerste keer gediagnostiseerd werd, dacht ik ook. Moet ik dit elke dag nemen, wat een onzin. Maar langzamerhand ging ik steeds meer achteruit en toen had ik een huisarts die zei: Dominique je moet de tijd nemen voordat het werkt. Als je weet dat er een slechtere dag aankomt dan moet je het een maand van te voren gaan nemen. Dat zijn simpele uitleggen om het te gaan doen. (D)"

"Als het maar werkt voor jou, zei de dokter (F)."

"Bij mij is het irritant dat het nog steeds niet stabiel is. Maar als ik het niet doe, het steeds slechter gaat. Jarenlang hebben ze gezegd dat als je medicatie neemt, ik er vanaf ben. Dat is gewoon niet waar. Het is verwachtingsmanagement. (D)"

"Wij reflecteren daar samen op, dat hij jaar daar de tijd voor neemt is super. Toen kwamen we ook allebei tot de conclusie, daar ik daar zelf nog niet aan toe was. (A)"

Categorie

Persoonlijke doelen

Quotes

"Ja sport is echt mijn doel. Ik heb nu twee keer de ringvaart geroeid en dan is het ook een maand niet drinken en een maand niet roken. Ook echt bewuster mijn medicatie nemen. Ik heb daar hard voor gewerkt en wil niet dat dat mij nekt (S)."

"Ik ga volgend jaar senaat doen. Ik heb ook tegen mijn longarts gezegd, dat als ik dat volgend jaar ga doen, dat ik wel vaker langs kom. Ook met de gedachte dat het volgend jaar lastiger wordt en dat ik er zo fit mogelijk in moet gaan (S)."

"In mijn systeem gaat het veel meer over hoeveel energie ik heb. En of iets fysieks is of dat ik het rustig aan de keukentafel kan doen. Hoe gaat het nu? En dat lijstje pak ik. En dan ook lekker afstrepen, dat vind ik heerlijk (A)"

"Met wintersport neem ik het wel altijd, en met zaalhockey vooral (E)."

Goed contact met de HCP is ontzettend belangrijk en bepaald ook voor een groot deel of iemand therapietrouw is. Maar aan de andere kant zijn mensen niet altijd eerlijk tegen hun arts.

Verwachtingsmanagement over de medicatie is belangrijk

Het zetten van doelen die belangrijk zijn voor mensen in hun persoonlijke leven kan een stimulans zijn bewust(er) met astma om te gaan.

Ergens naartoe werken geeft houvast en iets afstrepen voldoening.

Categorie

eHealth

Quotes

"Ik denk dat het heel handig is als je je huisarts niet zo vaak ziet. Dat als ik hem na 8 weken zie en op dat moment het goed gaat, ik kan laten zien, kijk hier ging het niet zo goed (A)"

"Ik denk dat het heel goed zou zijn. Omdat ik mijn huisarts niet altijd kan vertellen, hoe ik me voel en hoe het gaat. Natuurlijk heeft de arts er inzicht in, maar ik kan moeilijk definiëren, hoe dit gaat. Nu zeg ik het gaat minder, wat is dat? Wat is nou het ijkpunt. Terwijl de afgelopen drie weken ik er wel heel erg last van had: kijk maar, zoveel meer last. Maar als je in een comment kan zeggen, waarom het minder gaat. Ik had bijvoorbeeld een hele zware training (S)"

"Ik denk eigenlijk dat een goede begeleiding door longarts of verpleegkundige meer effect heeft. eHealth kan daar wel een opvolging voor zijn (D)"

Dat je trends kan zien en verbanden. Ja dat vind ik altijd leuk. Ik vind het leuk om dingen te meten en inzichtelijk te maken (A)"

"Ik zou er dol op zijn. Zover ik ze nog niet kan (prikkels). Bijvoorbeeld dat ik een patroon in tijd zie, woensdag om 3 uur, dan komt je moeder langs die net gerookt heeft (D)"

"Ik ben er zelf niet achter, wat het verschil maakt, behalve de hitte (F)"

Bij mij werkt mijn horloge, omdat het trilt. Heb ik 's nachts ook altijd om. (Anne)"

"Ja handig en iets meer van deze tijd, zeker voor mijn leeftijd. Als je hier een melding van krijgt dagelijks en denkt, oh ja! (E)"

"Verder weet ik niet hoeveel pushberichten iemand aan kan (S)"

"En reminders worden snel vervelend. Misschien kun je het aan iets anders koppelen (T)"

"Ik vind kennis wel fijn. Ik had bijvoorbeeld de blauwe bij mijn ouders 6 keer gebruikt op een dag en ik kreeg hardkloppingen. Want je mag het niet zo vaak gebruiken. Wel fijn als dit zou worden aangegeven in een app. Hij weet welke medicatie je gebruikt. En dan per onderwerp informatie, ik heb het meest aan praktische info (T)"

"Zelf zou ik nog wel iets meer willen weten ook, over wat ik precies voor medicatie gebruik. Ik weet daar eigenlijk heel weinig over. Niet echt een duidelijk overzicht. (E)"

Het bezoek bij de HCP is een momentopname. Als het op dat moment goed gaat, vinden mensen het lastig om te communiceren over de periode ervoor. Hier kan eHealth inspringen. Maar geen vervanging.

Om de ziekte inzichtelijk te maken en prikkels bij te houden.

Handig voor reminders, maar dit kan ook erg vervelend zijn.

Nuttig in het geven van precieze specificatie over medicatie

Categorie
Wanneer ICS
Quotes

" Ontsteking is de basis van je benauwdheid. Deze kan ontstaan door prikkels of allergieën. Maar die ontstekingsremmer is voor alle astma patiënten van belang. Behalve degene die heel incidenteel hun pufje soms nodig hebben. Maar dan moet je heel goed monitoren of die ze echt maar zo weinig gebruiken. Als ze die meer dan 2 keer per week gebruiken, heb je onderhoudsmedicatie nodig. Dat is lastig want in de eerste stap van NHG onderhoudsplan in de eerste stap staat die reliever. (C)"

" Dan wil je in ieder geval weten... Als iemand nog net zo beroerd is, wil je hem niet langer door laten lopen. Ik houd dat zelf wel aan, week of 6, gaat het alweer beter? En heb je je reliever al minder nodig. En soms is dat ook niet zo. Maar dat ze wel beter slapen en minder moe zijn en klachten minder worden. (C)"

" Als jij 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)"

" Licht echt aan de ernst van het astma. Er is een enorme groep mensen met mild astma die vrijwel nooit last hebben. Dan zou ik zelf ook niet standaard een medicijn nemen, alleen als het slechter gaat. Als je echter op wat voor manier dan ook beperkt wordt door het astma, zou ik altijd ICS nemen, want dan wegen de bijwerkingen eigenlijk niet op tegen de te verwachten winst. (P)"

"Algemeen gezegd, ik ben erg blij dat er ICS is. Als ik zou moeten schatten (data zijn er niet), zou ik denken dat 10-20% van de astmaten met alleen salbutamol wel uitkomt.

Dagelijkse ontstekingsremmers is voor het grootste deel van de astma patiënten van belang, omdat het de oorzaak aanpakt (>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

Categorie
Waarom ICS
Quotes

" 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)"

" Na zo'n aanval duurt het 6/8 weken voor het weer goed is. Maar in die tijd ben je wel weer gevoeliger omdat alles openligt. Je hebt eerder kans dat je terugvalt. Als je heel veel slechte controle hebt, kan het zijn dat het niet meer reversibel is en dat je van astma naar COPD gaat. (C)"

" Je krijgt continu weer die inflammatie, die ontstekingen van je luchtwegen. Hoe vaker het gebeurd, hoe slechter dit voor je longen is. Je kan daar zelfs, zeker als je ernstigere astma hebt, je komt in de ene exacerbatie naar de ander. Omdat je in de goede periode denkt dat je het niet nodig hebt en twee maanden later ga je weer onderuit. Want dan gaat het goed en komt er een pol voorbij en dan is het opeens weer mis. (C)"

ICS pakt de ontstekingen aan en daarom minder kans op aanvallen.

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

Therapieontrouw

Quotes

"Het is eigenlijk de mensen, die mooi onder controle zijn. Bijvoorbeeld zo'n symbicort. De laagste dosering 's ochtends en 's avonds en in principe als ze dat de rest van hun leven zouden doen, zouden ze heel weinig klachten hebben. Alleen die hebben niet de motivatie om dat te doen, omdat ze weinig klachten hebben. (M)"

"En je kan het nog zo vaak uitleggen, maar mensen willen het ook niet horen. Sommige mensen snappen echt wat je zegt. Dat verhaal van die mevrouw die dan niet haar medicatie neemt, terwijl ze wel het effect zag. Zij is hoogopgeleid, maar zegt ook van zichzelf: 'ik wil gewoon zo min mogelijk medicatie. (M)"

"Medicatie niet in het openbaar gebruiken hoor ik heel vaak. Helemaal met voorzetkamer. (M)"

"Waarschijnlijk als het goed gaat, willen ze er niet mee bezig zijn. En elke keer als ze die puffer nemen, is het weer een moment van bewust zijn, oh ja. (M)"

" Licht astmatisch en juist met een lage dosering, heel goed onder controle. Maar dan denken ze juist, dan kan ik het beter niet gebruiken, want ik heb toch niet zoveel klachten. Mensen met lichte astma zien het nut er niet in. (M)"

"Mensen beslissen vanuit hun probleem. Daarom is het lastig om onderhoudsmedicatie te gebruiken. Want ze zien geen probleem. (J)"

"Als mensen niet bewust de afweging maken, door vaak drukte en onregelmatig leven. Heb ik het nu wel of heb ik het nou niet genomen. Dus een terugkoppelingssysteem zou ontzettend mooi zijn. Dat mensen zien, ik heb geïnhaleerd. Een signaaltje of een notificatie. Als ik die app openmaak, dat ik kan zien, oh ja ik heb gebruikt. (J)"

"Dus waarschijnlijk puft deze meneer heerlijk. Dat is ook een stuk perceptie, salbutamol werkt. Flixotide, ik merk er niets van. Alleen ik zie het wel in zijn aanvallen en zijn spirometrie. Zo werkt het voor ons. Dit is inzichtelijk voor ons, maar niet voor de patient en dat stuk wat jullie aan willen pakken. (J)

"Jij noemde al dat mensen er soms bewust voor kiezen. Dat heeft ook te maken met hoe een mens in elkaar zit. Als je iets hebt wil je best medicatie slikken, maar als je je goed voelt, wil je geen medicatie slikken. Want medicatie, heeft bijwerkingen. (J)"

"Antroposofische medicatie... allemaal op de natuurlijke manier doen. Dat merk je wel. Meer lezen op internet. Mensen die hier wonen zijn toch wel hoger opgeleid (M)"

- Als patiënten zich goed voelen, vinden ze het niet nodig om medicatie te slikken
- Mensen met een lichte vorm van astma, zien geen probleem. Zij hebben niet zoveel klachten en daardoor geen motivatie (maar juist deze mensen zouden perfect onder controle kunnen zijn).
- Medicatie is slecht: zo weinig mogelijk medicatie willen slikken.
- Het moment van de puffer gebruiken, is een moment dat personen zich patiënt voelen. Geen fijne bewustwording.
- Effect van de luchtwegverwijder voelen, maar het effect van de onderhoudsmedicatie niet voelen en daarom werkt de onderhoudsmedicatie 'niet'. Directe feedback ontrbreekt.
- Onregelmatig of druk leven

Intentie: Kennis & Motivational Interviewing

Quotes

"Ik bespreek dat altijd met ze. Dat is het grote verschil tussen een reliever en een onderhouds. Reliever voel je gelijk, bij ICS dan behandel je de oorzaak van de benauwdheid en voorkom je eigenlijk dat je benauwd wordt. Ik leg dat altijd aan patiënten uit. Hier voel je vrij weinig van, maar het zorgt ervoor dat je minder benauwd bent en die reliever veel minder nodig hebt (C)

"Niet alleen kennis, maar voorlichting en inzichten. Een keus maken, niet op grond van ideeën: de buurvrouw zegt... mijn broer zegt wat anders. Maar gewoon goede informatie. Wel aangeboden o.a. aan mensen die niet taalvaardig zijn. En dan kun je voor groepen die wel taalvaardig zijn ook hun eigen info geven. Die kunnen niets met info voor mensen die niet taalvaardig zijn. (J)"

"Het is heel vervelend dat je het hebt en ik vertel ook altijd dat ik het zelf ook heb. Dat helpt. (Cynthia – POH)"

"Dan zie ik in het dossier, die heeft al heel lang zijn puffer niet gebruikt. Dus dan vraag ik hoe vaak gebruik je hem? Jaja wel twee keer per dag. Dan zeg ik, wat goed, had je dan veel voorraad? Ik moet hem bijna voor je bestellen? Nee, ik heb nog. Oh, wat knap. Had je voorraad gehaald? Dan zie je het. We schrijven het voor met een bepaalde bedoeling, maar als jij een reden hebt om daar vanaf te wijken... laten we daarover praten. (C)"

" Uitleggen waarom het nodig is. Maar ik wijs mensen wel het is je eigen verantwoordelijkheid. Laten we het dan 6 weken proberen, kijk wat het effect is? Zodat ze gaan zien wat het effect is. Soms lukt dat wel en soms lukt dat niet. (C)"

"Met astma ga ik meer de dialoog aan. Je probeert erachter te komen, waarom gebruikt iemand niet? Hoe denkt iemand over astma? Wat weet iemand? Dan kan ik daar wel sturend in zijn. Ik wil gewoon uitleggen wat eraan de hand is. Wat voor keuze iemand dan maakt... Ik zeg ook, ik ga er niet bijstaan of je het wel of niet doet. Dat moet jezelf weten. Maar ik wil wel dat je weet hoe het werkt en waarom we het voorschrijven. Er is geen goed en kwaad. Als jij het niet wilt gebruiken, maar wees op de hoogte van de consequenties (C)"

"Als je iemand beter leert kennen, dan weet je ook wat de motieven zijn en waar ze tegenaan lopen (M)"

"Mensen maken niet een bewuste afweging, maar laten zich leiden door hun onderbuikgevoel en zijn ze onvoldoende op de hoogte van hun consequenties van het niet gebruiken of het onregelmatig gebruiken. Dat is heel belangrijk dat mensen dat weten. Toegang tot een stuk voorlichting. (J)"

Heel eigenwijs en ook heel moeilijk te beïnvloeden. Daar heb je hele speciale gesprekstechnieken nodig om mensen aan het denken te zetten. Bijvoorbeeld over de onderhoudsmedicatie, dat is slecht voor je, wist je dat? Prednison zit erin. Dat moet je niet gebruiken. En ga dan maar uitleggen hoe en wat. Ik beaam dat, en zeg inderdaad. Er hangt een prijskaartje aan. Maar mag ik u vertellen wat het risico is als u het niet gebruikt. Da ga ik er echt op in, nu heeft u informatie van het ene en het ander en het is aan u om de balans te maken en wat is belangrijk voor u? Wilt u daar over nadenken? (J)"

Tijdens een consult is het belangrijk kennis over de medicatie over te brengen op een manier die de patiënt begrijpt en misverstanden aan te kaarten.

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 duidelijk de consequenties mee te geven.

Achter beweegredenen komen kan lastig zijn, omdat patiënten niet altijd eerlijk zijn.

Een uitprobeerperiode kan een oplossing zijn

Categorie

Effect: Gebruik van metaforen & beeld

Quotes

"En ik vergelijk het met dingen uit het dagelijks leven, dat is herkenbaar. Als je een snelweg hebt met vier banen en het is door je astma geïrriteerd en de buitenste twee banen zijn afgesloten. Dus dan sta je in de file. Dan kun je een reliever nemen en staat het even op, maar daarna slipt het weer dicht. Terwijl als je continu je ICS neemt, dan blijven de rijbanen open en heb je geen filevorming. (C)"

"Daar gebruik ik voorbeelden uit van dingen die mensen kunnen voorstellen. Dan wordt het inzichtelijk. Longen die je niet ziet. Ik heb ook modellen van normaal en een stukje dat verdikt is. Kijk als je lichaam geïrriteerd is, omdat er prikkeling is. Wat voor prikkel dan ook. Dan gaat daar vocht naar toe. Als je enkel dik is, komt daar vocht. Dat weet iedereen. Maar bij je voet zit je bot aan de binnenkant, dat kan uitzetten. Je schoen zit niet meer zo lekker. Bij bronchiën zitten de kraakbeenringen aan de buitenkant. Dus als het gaat zwellen, het kan niet 'dit' doen. Dat is wat je voelt. (C)"

"Nee, ik vergelijk het altijd met een paraplu en je hebt daar gaten in geknipt. Je loopt in de regen, zal je droog blijven? Nee je wordt nog steeds nat. Dat is als je er af en toe je onderhoudsmedicijnen gebruikt, dan heb je geen volledige bescherming. Je hebt te maken met de tijd waarop het werkt en de tijd die die medicatie nodig heeft om de beschermlaag te maken. Dat leg ik vaak uit aan de hand van deze dingen (pakt uitvergrootte longblaasjes erbij). Deze zijn simpel, maar heel duidelijk. (J)"

"Sommigen vinden het heel interessant. En soms helpt het als je het visueel doet, dus dan moet je het brandje uitblussen. (M)"

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.

Categorie

Bewustwording: stilstaan & meten

Quotes

"Het is niet dat ze dan altijd een longfunctie hoeven te blazen. Zeker bij astma heb je een normale longfunctie, dus waarom zou je? Maar wat je wel wilt weten is, hoe gaat het met je medicatie? Hoe gaat het met je prikkels? Omdat mensen zichzelf heel vaak overschatten. En dan vraag je door en dan beseffen ze dat het helemaal niet zo goed gaat. (C)"

" Misschien niet meer behoefte. Maar je merkt dat als ze hier zijn, dat ze even stil staan bij hun ziekte. Je dagelijks leven gaat door, je werkt en je doet en als het goed gaat, dan komt die astma op de achtergrond. Als ze hier komen, reflecteren. (M)"

"Maar dan kwam ze nu een halfjaar later en omdat het zo goed ging, is ze dan ook weer gaan minderen. Die gebruikt ze dan ook alleen maar af en toe. Dat visuele is dan wel heel belangrijk, dat bewustwordingsmomentje. Ook als ze dan hier komen, zeggen ze hard op hun klachten. 'Ik heb toch wel weer meer last dan ik dacht' en we hebben ook ACQ en MRC. Zijn ook een paar goede standaardvragen, die je weer kan vergelijken met de vorige keer. (M)"

"Mensen leven heel erg toe naar longfunctie test. Maar je vaart het meest op de klachten die mensen hebben, soms is de longfunctietest hartstikke goed, maar is iemand wel heel benauwd. Als iemand stabiel is, hoeft die longfunctietest ook maar 1 keer in de 2 jaar te gebeuren. Patiënten willen die longfunctietest doen, omdat ze de cijfers willen zien. Daar hebben ze wel behoefte aan. (M)"

"En ze is dan ook wel redelijk onder controle. Je moet dit en je moet dat, dat werkt dan niet. Maar ik zeg dan wel, mijn advies is wel echt om het dagelijks te gebruiken. Want je ziet het op die longfunctietest, dan is het wel heel fijn om iets visueels erbij te pakken. Dan pak ik die longtest erbij. Of de ACQ kan je vergelijken met de vorige keer. En zo'n app die dan bijhoudt, wanneer ging het goed en wanneer ging het slecht, werkt dan wel. (M)"

"Soms is het wel grappig, maar ja... Nee. In principe met astma, heb je een normale longfunctie. Je wilt alleen weten dat als het minder goed gaat en je hebt hem nodig als een stukje bevestiging en diagnostiek. Maar dan is het niet alleen de spiro maar de hele analyse eromheen. Want als jij net op dat moment goed bent, dan heb jij gewoon een normale longfunctie. (C)"

Een moment bij de HCP, is voor patiënten vaak een moment dat ze even stil staan bij hun klachten. In hun dagelijks leven gaan mensen vaak gewoon door, zonder zich bewust van hun astma te zijn.

Metingen maken de patiënt bewust van hun astma, Hierin is het ook fijn om resultaten van verschillende momenten met elkaar te kunnen vergelijken. Dit zet kracht bij het advies van de arts, mensen willen cijfers zient.

Longfunctietest werkt niet bij iedereen, mensen astma kunnen prima een normale longfunctie hebben.

JOHAN - SKEPTICAL DENIER
F rst see, then be eve - Externa excuses - D strust

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 wil 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 - Act ve - Not want ng 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

RICHARD - TIMID LONER
Ashamed - Not want ng to be a burden - Avo d ng conf ct

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 undergoes the discomfort without addressing his asthma. When someone lights a cigarettes, 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.

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

ANNA - CONFIDENT GOAL PURSUER
Transparent – Cur ous – Exper ence 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 mantenance medication and uses her reliever medication without a problem in public.

I used to find it difficult to stand up for myself, not anymore

I have no problem to use my inhaler in the train, it should be normal

JUDY - INNOCENT VICTIM
Asthma as save haven – Excuses –
Stubborn

For Judy her diagnoses felt like a relieve. Asthma has become her security blanket in a way. It makes it easy for her to explain why she feels the way she feels. However, sometimes Judy finds it hard to push her boundaries and easily says no to activities she is actually able to do, for example doing some exercises. Her asthma is sometimes a pitfall to become too passive.

Medication: Judy sometimes takes more medicines than her doctor's prescription, because she is afraid for an exacerbation. She is very anxious to cut down on her treatment, even when her doctor says so.

It can't get any better than this

Working-out is not something I am able to do anymore, because of my asthma

include others

Exclude others
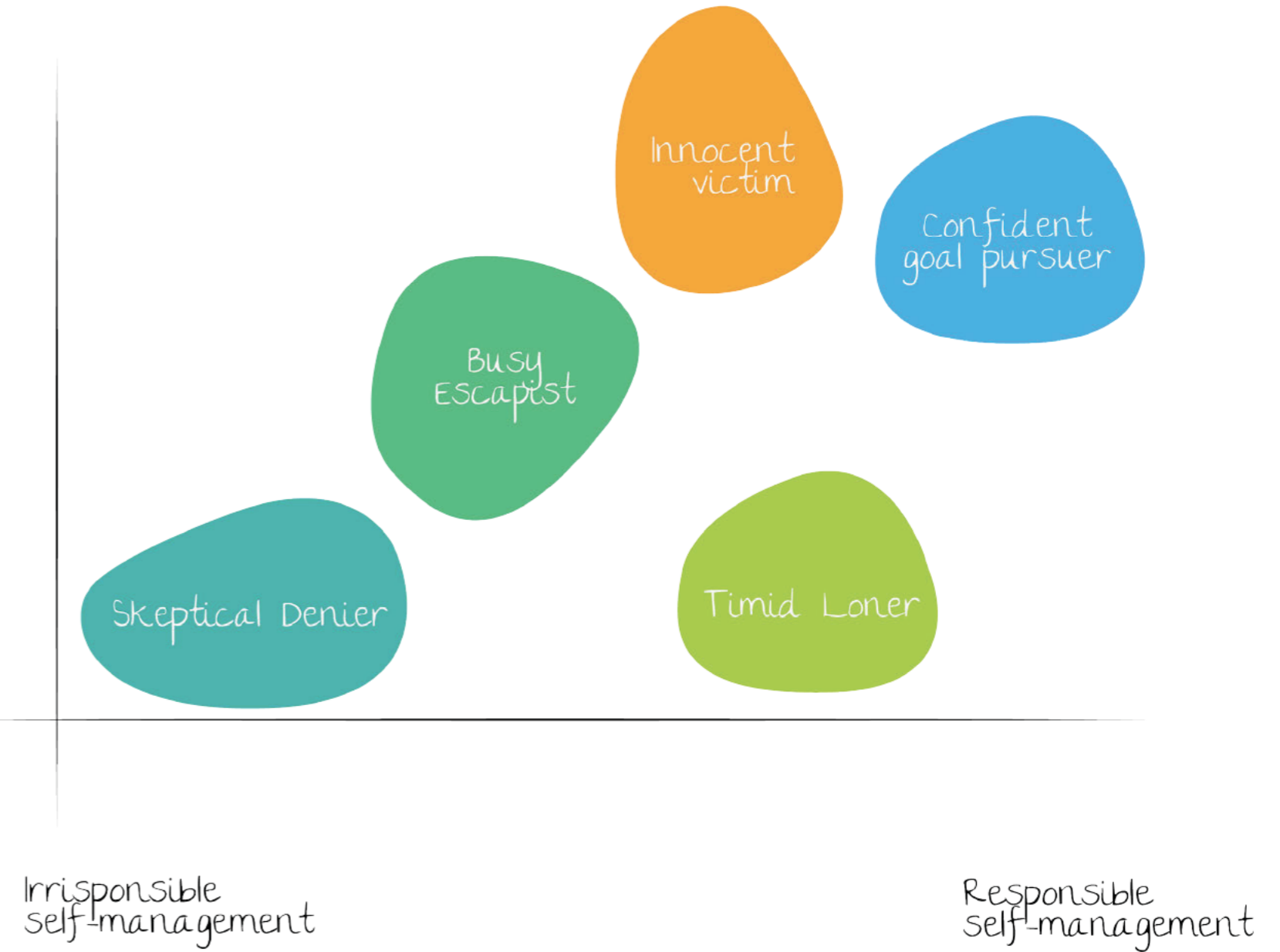
Irrisponsible self-management

Responsible self-management

Innocent victim

Confident goal pursuer

Busy Escapist

Skeptical Denier

Timid Loner

I ked the graph cs and mages (aesthet c appea)

Strong y d sagree — Strong y agree

The exper ence was fun (fe t nvo vement)

Strong y d sagree — Strong y agree

The content encouraged my cur os ty (Nove ty & Cur os ty)

Strong y d sagree — Strong y agree

I fe t empathy for the character (Character empathy)

Strong y d sagree — Strong y agree

I wou d find the app usefu n manag ng my meds (usefu ness)

Strong y d sagree — Strong y agree

Participant
E.C.

Participant
F.B

Participant
T.M.

Participant
Z.K.

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 vooraf?

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. Hoe ervaarde je het dat je medicatiegebruik gevisualiseerd werd?

4. Wat vond je van het verhaal van de Ademgenoot?

5. Was je nieuwsgierig naar je volgende scherm? Gebeurde er genoeg of te weinig?

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 report achteraf dat je ontving?

Dagelijks ontvangen

1. Heb je de afgelopen dagen je medicatie meer genomen? Waarom wel of niet?

2. Hoe vond je het om elke dag een afbeelding te ontvangen op je telefoon?

3. Hielp het ontvangen van schermen in het niet vergeten van je medicatie?

4. Voelde je je meer gemotiveerd om je medicatie te nemen? Waarom wel of niet?

5. Hoe vond je het om de afgelopen dagen op deze manier met astma bezig te zijn?

6. Kosten het je moeite?

7. In hoeverre denk je dat het moeten doorgeven van de medicatie je ervaring heeft beïnvloed.
a. Appjes van mij (voelde je hierdoor meer verplicht je medicatie te nemen)?
b. Het niet automatisch registreren?

Onderdeel 2: Motivatie 'game' ervaring (na Powerpoint)

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

1. Zou je de 6weekse challenge aangaan?
2. Zou Ademgenoot je kunnen motiveren om je medicatie zoals voorgeschreven te nemen?
3. Welke elementen dragen hier aan 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?

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 astma controleert? En je vertrouwen hierover?
4. Heeft de app Ademgenoot iets veranderd in je gevoel over hoe goed je geïnformeerd bent over astma?

Onderdeel 4: algemeen
1. Is de app makkelijk te begrijpen?
2. Zou je de app vaker en voor een langere periode willen gebruiken?
3. Zou de app als een inbreuk op je dagelijks leven kunnen voelen? (Bijv. patiënt)
4. Hoe nuttig vind je het gebruik van Ademgenoot vergeleken met een behandeling zonder het gebruik van de app?
5. Positieve punten, negatieve punten en aanbevelingen

Participant
T.S.

Participant
A.B.

Participant
T.M.

Participant
L.J.

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 kunnen gebruiken en welke functies mis 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 aanraden aan iemand die de noodzaak van dagelijkse medicatie niet inziet of het lastig vindt dit in zijn/haar dagelijks leven in te bouwen?

Hang de verschillende elementen uitgeprint op. Wat motiveert en wat niet?
Invullen van een aantal waardes 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

Participant M.M. (left form)

Plezierig							Onplezierig
Makkelijk, maar wanneer dagelijks moeten stilstaan kan demotiverend werken	☐	☑	☐	☐	☐	☐	
Begrijpelijk							Onbegrijpelijk
Spreekt voor zich	☑	☐	☐	☐	☐	☐	
Creatief							Saai
ja, maar te weinig fases, tussen motivatie	☐	☐	☐	☐	☑	☐	
Waardevol							Inferieur
geeft duidelijke informatie. werkt als dagboek.	☑	☐	☐	☐	☐	☐	
Motiverend							Demotiverend
kan motiverend werken met meer tussenstadia en meer persoonlijk	☐	☐	☑	☐	☐	☐	
Interessant							Oninteressant
kan leuke kennis opleveren over je zelf.	☑	☐	☐	☐	☐	☐	

Participant J.O. (right form)

Plezierig							Onplezierig
voor 90% — poppetje —> weer — eigen toevoegingen.	☐	☑	☐	☐	☐	☐	
Begrijpelijk							Onbegrijpelijk
heel begrijpelijk	☑	☐	☐	☐	☐	☐	
Creatief — poppetje — weer	☐	☑	☐	☐	☐	☐	Saai
Waardevol							Inferieur
zeker voor starters wel evaluatie moment	☐	☑	☐	☐	☐	☐	
Motiverend							Demotiverend
zeker mits dat infectie of lage dosis je je niet goed laat voelen en poppetje knolletje	☐	☑	☐	☐	☐	☐	
Interessant							Oninteressant
zeer interessant idee	☑	☑	☐	☐	☐	☐	

bij arts / longarts nurse practitioner etc

na 3 weken controle of via video / telefoon etc.

rode / gele vlaggen —>

aangeeft dat je je "studend" moet voelen omdat je 't zo trouw inneemt.

Thank you!