

AirCare



Final Master Project Kyara Fasen
Enhancing HNIV patient compliance

COFLON

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ABSTRACT

This report showcases the research and design process for the Final Master Project 'AirCare'.

During this semester I worked on the challenge: Enhancing COPD patient compliance for at home non-invasive ventilation (HNIV) through user empowerment.

A user-centered design approach has been taken, involving multiple other stakeholders throughout the process. Used design methods include: Focus group sessions, interviews, annotated portfolio's, and more. Read with me as I gain more knowledge about HNIV, behavior change theories, data physicalizations, and sound design. Resulting in my final design 'AirCare'.

'AirCare' is a pleasing feedback mechanism using data physicalization to showcase how long the ventilator is used today. Making invisible progress visible, while motivating them to complete their daily goals. The design stimulates reflection-in-action as well as reflection-on-action by giving the patient a new way to interact with their data and sparking conversations about health within families.

The artwork is connected to an app where one can ask questions, compare results, and connect to others.

SAMENVATTING

Dit verslag toont het onderzoeks- en ontwerpproces voor het Final Master Project 'AirCare'.

Tijdens dit semester heb ik gewerkt aan de uitdaging: het verbeteren van de naleving door COPD-patiënten voor niet-invasieve beademing thuis (HNIV) door middel van empowerment van gebruikers.

Er is gekozen voor een gebruikersgerichte ontwerpaanpak, waarbij gedurende het hele proces meerdere belanghebbenden zijn betrokken. Gebruikte ontwerpmethoden zijn onder meer: focusgroepsessies, interviews, geannoteerde portfolio's en meer. Lees met mij mee naarmate ik meer kennis opdoe over HNIV, gedragsveranderingstheorieën, data fysicisatie en geluidsontwerp. Met als resultaat mijn uiteindelijke ontwerp 'AirCare'.

'AirCare' is een feedbackmechanisme dat gebruikmaakt van data fysicisatie om te laten zien hoe lang het beademingsapparaat al is gebruikt. Zo maakt het onzichtbare vooruitgang zichtbaar en tegelijkertijd motiveert het patiënten om hun dagelijkse doelen te behalen. Het ontwerp stimuleert reflectie-in-actie en reflectie-op-actie door de patiënt een nieuwe manier te geven om met hun gegevens om te gaan en gesprekken over gezondheid binnen gezinnen aan te wakkeren.

Het kunstwerk is verbonden met een app waar men vragen kan stellen, resultaten kan vergelijken en verbinding kan maken met anderen.

ETHICAL CONSIDERATIONS

The studies in this report are approved by the Ethical Review board of the Eindhoven university of Technology and conducted in conformity with the Netherlands Code of Conduct for Research Integrity. All the participants' names in this report are removed or pseudonyms to ensure anonymity.

The Netherlands Code of Conduct for Research Integrity and the derived Code of Ethics of Eindhoven University states that for both students and staff: "In their research and design, they adhere to the ethical codes for activities in which human subjects and animals are involved." [1].

DESIGN PROCESS

In the visual presented on the next page I showcase my process based on the paper 'Natural Science and Design: A Framework for Triangulation Across Disciplines' [2].

A theoretical foundation can be useful, but only if the end-user requirements are adequately understood. I want to demonstrate this in my visual by showing how the different methodologies of learning and evaluating supported my central design process.

To give a grasp of the relationships between them, and show how the scientific and design disciplines are related to/benefit from one another.

In the visual you can recognize 5 circles, these represent the different chapters in this report.

1. Explore
2. Ideate
3. Focus
4. Refine
5. Realize

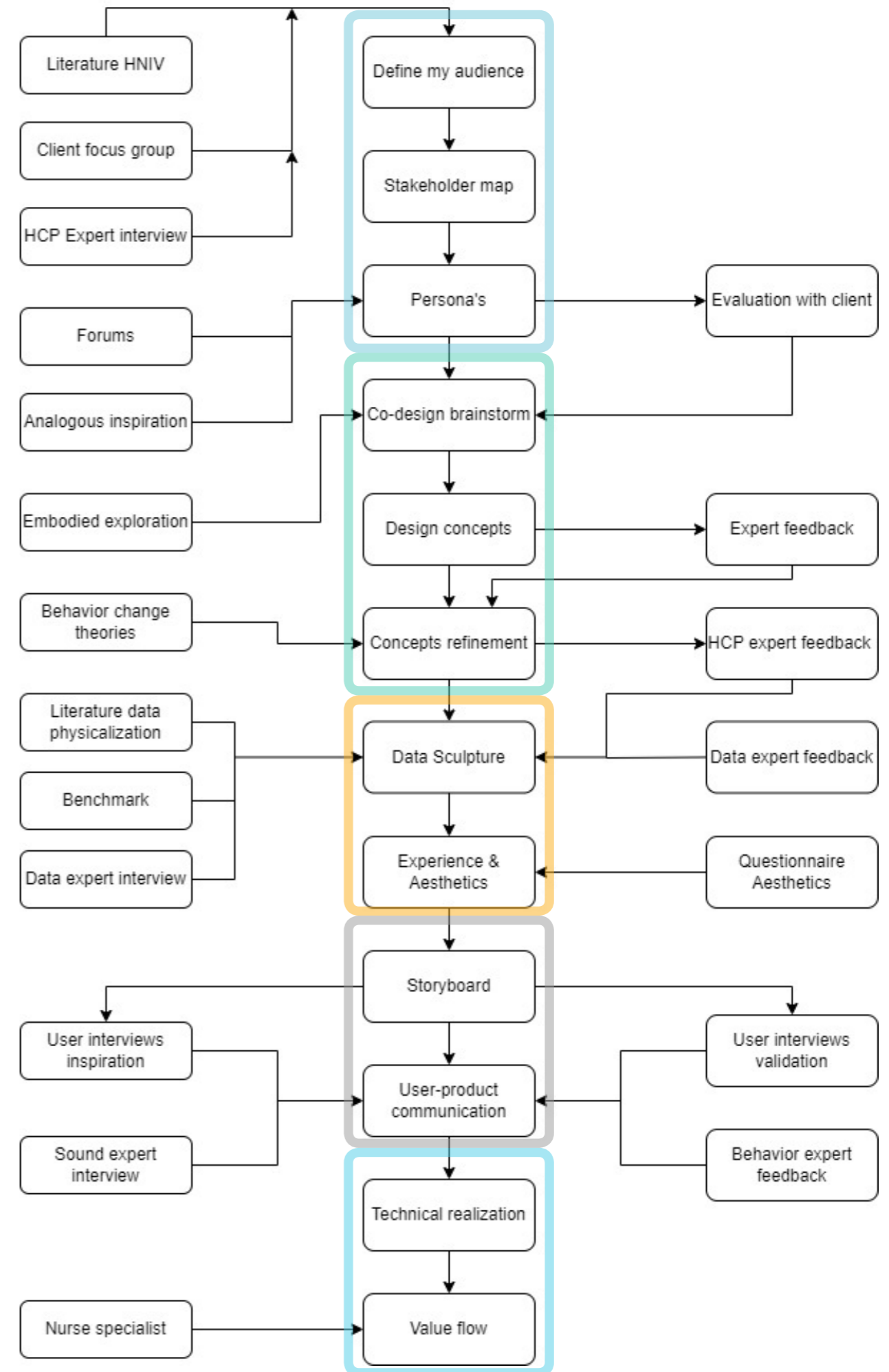


Figure 1: Visualization of the process based on the paper 'Natural Science and Design: A Framework for Triangulation Across Disciplines'

INTRODUCTION

In my work, I aim to empower and socially integrate people who are affected by (mental) health issues and as a result restricted to participate in everyday life. I believe design should focus on creating equality and empowerment for its users. Especially for Individuals with special needs. Design has the wonderful ability to support independence and self-worth within people. It can enhance a person's quality of life and help them to live healthier and more fulfilled lives by enriching daily experiences.

In this report I work for patients with Chronic Obstructive Pulmonary Disease (COPD).

COPD is a chronic condition in which a patient's lungs are damaged. People living with COPD have less oxygen and breathing is more difficult. This gives a patient less energy. Normal things like climbing stairs and running errands can become difficult, impacting their quality of life [3].

More severe COPD patients can receive non-invasive ventilation treatment at home (HNIV). This treatment can help relieve symptoms, give patients more energy, and avoid re-hospitalization. However despite being shown to improve quality of life in stable COPD patients, wearing the ventilation mask for the recommended amount of hours during the day proved to still be difficult for patients [4].

This lack of patient compliance can result from multiple different areas, HNIV gives more energy but of course being connected to a ventilator also makes an impact on a patients daily routine and social life in itself.

In this project I explored what causes the lack of patient compliance through desk and field research. Eventually creating a design concept that brings patients empowerment back and will improve their quality of life with HNIV treatment. The direction I focus on is giving patients back their sense of control of their own disease management. The final design solution 'AirCare' will give patients more overview over their daily goals and promote feelings of pride over their behavior. Playing into the underlying issues that cause the lack of patient compliance, as well as using several behavior change techniques that are recommended to improve user motivation.

I believe work in this area is not only important for COPD patients using HNIV but can also shed light on a broader research gap between hospital care and home care. Using the power of design to help people restricted to participate in everyday life to live healthier and more fulfilled lives by enriching daily experiences.

DESIGN OPPORTUNITY

The main challenge of this project is the stimulation of HNIV treatment adherence. To improve medical care for this condition and long term chronic disease treatment. Adding to close the research gap between NIV hospital experience and home treatment.

In relation to my vision as a designer I want to tackle this issue through user empowerment. Providing the patient with tools to receive a higher mental vitality, and improving their HNIV experience.

I've been introduced to this topic by Xinying Zhao from Philips research who took on the role as client for this project. Zhao and the research team she works with started their own research trajectory around this same design challenge earlier this year. My project will be of benefit to them by using the explorative nature of it as an exploration of the design space for their own research. They believe that innovations should not be limited, especially at the beginning stage, and are open-minded for any insightful ideas in the field of COPD patient engagement.

PREVIOUS PROJECT

During my M2.1 project, I mapped what influences a patient's trust during home monitoring of their chronic disease. I explored ways patients can improve trust in their own competence when it comes to self management. But also how to create an accurate sense of trust in the system. I did this through developing design guidelines that I revisited in this semester. During the M2.1 project, I gained a deep understanding of the user issues and design takeaways of moving chronic disease treatment from the hospital to the home setting, to prepare for my Final Master Project.

LITERATURE REVIEW

What is Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is the name of a progressive deterioration of a patient's lung function that causes breathlessness (initially with exertion) and predisposes to exacerbations and serious illness [5]. COPD is a large contributor to the global burden of disease. As it is also an excessive health resource consumption and associated with high health costs worldwide [6].

According to the Global Burden of Disease Study, there were 251 million cases of COPD worldwide in 2016. In 2015, the disease is estimated to have killed 3.17 million people worldwide. Which makes COPD responsible for 5 percent of all deaths globally in that year [7].

Exposure to tobacco smoke, either through active smoking or secondhand smoke, is the leading cause of COPD. Some of the other main risk factors are exposure to indoor and outdoor air pollution, as well as occupational dusts and fumes [7].

People who have the symptoms of breathlessness, chronic cough, and sputum (mucous) production are likely to have chronic obstructive pulmonary disease. This can be validated with a breathing test called "spirometry," which evaluates how much and how rapidly a person can forcibly exhale air [7].

COPD is incurable. Available medical and physical treatments, on the other hand, can help alleviate symptoms, enhance exercise capacity and quality of life, and lower the risk of death [7].

Non-invasive ventilation

Non-invasive ventilation (NIV) for patients with acute exacerbation of COPD and with respiratory failure is a well-documented treatment that is used internationally [11,12].

Some of the main goals of NIV include correction of severe hypoxaemia and hypercapnia, minimizing a patient's laborious breathing and associated breathlessness, and respiratory muscle rest [10]. The device is adjusted in such a way that the lungs receive sufficient air and oxygen with the least possible effort from the patient [9].

NIV treatment is administered through a mask that fits tightly over the patient's nose and mouth. Because of the mask and the machine's noise, communication is difficult during NIV treatment. The patient's acute condition, which is commonly marked by panic, and a feeling of suffocation, also makes communication challenging and the experience unpleasant [13,14].

The treatment of COPD with NIV often takes place at the later or end stages of the disease treatment [15,16].

The start of a high-intensity NIV is a delicate process of providing adequate ventilation while keeping patients comfortable and avoiding negative side effects [8].

In most countries NIV treatment is started in the hospital, especially when it comes to COPD patients who require high-intensity NIV [8]. In the paper 'Home initiation of chronic non-invasive ventilation in COPD patients with chronic hypercapnic respiratory failure: a randomized controlled trial' the authors showed that Home non-invasive ventilation (HNIV) is feasible at home through telemedicine-based monitoring. Patients are able to take more time at home, resulting in a more relaxed approach to getting used to the high pressures required to achieve the goals, namely improved gas exchange, respiratory muscle unloading, comfort, and patient compliance [8].

Previous research on NIV treatment for COPD patients has found that additional research is needed into the patients' and their relatives' experiences with and attitudes regarding NIV treatment, both in the hospital and at home [17-19].

The amount of time a patient will have to wear the mask during the day is personal. The policy for this time is determined on the basis of various factors [9]. Like the oxygen level in the blood, the respiratory rate and other values measured by a professional. The oxygen level in the blood is measured by finger pricks or blood samples from the IV or the wrist. The initial aim is to have the patient wear the mask only at night. However, if the patient's condition does not allow this, the patient will also wear the mask for several hours during the day, this does not have to be one continuous session [9].

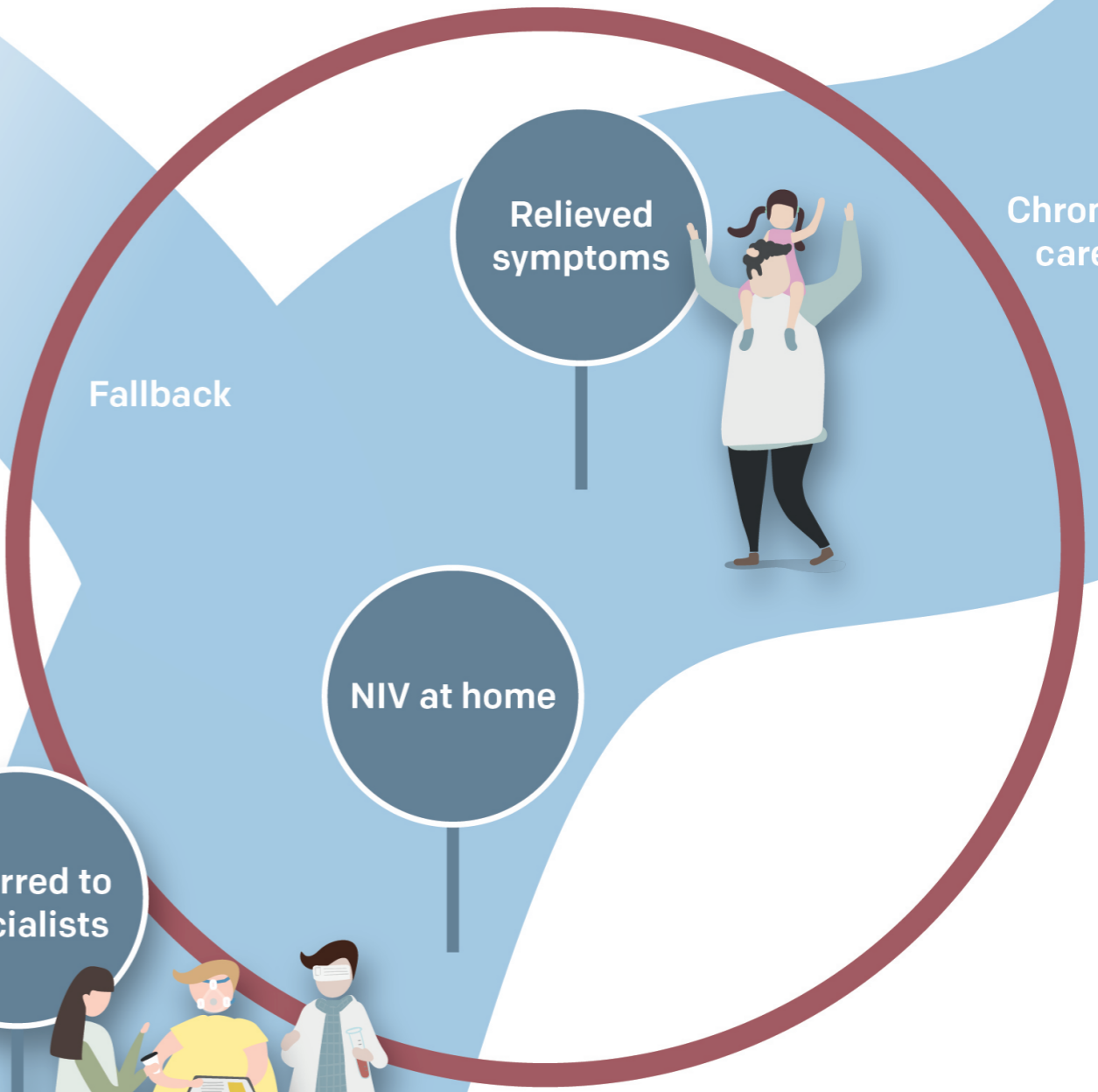
Hospitalization

Introduced to NIV



NIV treatment is working

Referred to specialists



Fallback

NIV at home

Relieved symptoms



Chronic care

PATIENT JOURNEY: DESIGN SPACE

Figure 2: user journey with circle around the design space for this project [20]

LITERATURE REVIEW

PATIENT EXPERIENCE WITH HNIV

Before I reached out to experts in this topic I reviewed literature to learn more about the user experience and already explore potential design opportunities to improve HNIV adherence. Stated below are 3 interesting directions.

Introduction to NIV and education

It is important for patient adherence that patients have a good understanding of how ventilation works and what its benefits are. Patients are namely more quick to doubt if NIV is worthwhile if they do not understand the principles of ventilation [23].

Conventional methods currently used for patient introduction like info leaflets turned out to be insufficient in outlining technical solutions to patients, since their content was barely remembered [21]. Optimizing the process of adaptation could be achieved by improving this introduction of NIV by Health Care Professionals (HCP). Considering broader ways of explaining the process and generating more patient-centered data on the benefits of different forms [21].

It is important to not immediately overwhelm a patient and include explanation of potential problems and who to contact in what situation in this education, this way a patient will feel more secure when a problem arises [22].

Anxiety

Emotional vitality is a second area where a lot of progress for patient empowerment can be made. Patients currently can feel out of control in their own disease management [23]. This can occur when patients have to depend more on their ventilator during the day, due to loss of autonomy over their day planning [22]. It is however important for ventilator users to use effective approaches to manage this anxiety and depressive symptoms. Emotional distress and spiritual emptiness can exacerbate physical pain [25].

Lack of self acceptance is a common cause of psychological struggles when patients face the reality of their medical condition [22]. However as soon as patients experienced progress in symptoms/coping they found it easier to cope with the side effects of ventilation [24]. Also helping patients in recognizing and creating new familiar routines was a wellbeing strategy that gave patients the feeling of being capable of retaining or gaining control over their situation [23].

Social stigma

It is common for patients to experience a stigma around using a ventilator in the company of others [22]. Patients can fall victim to shame and anxiety surrounding using HNIV in public, leading to avoidance [23].

This while having a good social support system is of great importance. While poor support of friends and family led to concerns for patient compliance. Patients with supportive families often had the best treatment outcomes [21]. Adaption to NIV is not an individual experience but extends also to the families of patients [21].

Loneliness is a significant challenge for ventilator users who lack a support system. Patients need to be encouraged to learn constructive strategies for expressing feelings and seeking support for better treatment outcomes [26]. Support can also be found in fellow patients. Interactive communities between patients turn out to be a great source of support for a HNIV patient [22]. When patients who are struggling with using HNIV in their daily life, see fellow patients succeeding in this, it helps reduce feelings of loneliness and gives hope [22].

Patients often felt that the burden of adaptation was theirs and did not discuss issues with their HCP [21]. Reducing the stigma around discussing struggles with HNIV compliance, can in the end benefit compliance.

Here I identified the design opportunities for:

Tackling the negative self image patients have, offer a support network, giving patients some autonomy back and more control over their disease management, make invisible progress visible, and improve education about HNIV.

DEFINE MY AUDIENCE

EXPERT INTERVIEW

Another way to learn more about my audience, their daily life with HNIV, and hurdles in their treatment is through discussing this with experts who work with my user group. I had a **focus group** with my client Xinying Zhao and colleagues from Philips Research, and I also spoke with pulmonologist Dr. R. Sprooten from MUMC.

During these conversations I learned that using the NIV mask during the daytime is for more severe COPD patients, usually a patient will start with only wearing the mask at night, but if their condition further develops they will also have to start using the HNIV for certain hours during the day. My client Zhao recommended me to focus on the average wearing time of 5 to 6 hours during a day, patients do not have to use the ventilator continuously but can spread these hours throughout their day. However patients who use their ventilator distributed during the day often do not have a good sense of how long they have actually worn the mask today.

Sprooten also explained that although a large portion of patients in this target group are above the age of 50, there are also children and young adults being treated with HNIV. There are between 200-300 people in his center being treated for COPD with ventilation.

COPD patients who have to follow HNIV treatment are seriously ill. *"You're talking about the end stage of lung disease. Patients can only walk several 100 meters, before needing a break. They can do some things indoors, but their world is quite small. Luckily with treatment patients can improve their energy level during the day, and improve their QoL,"* states Sprooten. However despite this improved QoL Sprooten still notices the challenge it is for patients to wear their mask according to the recommended amount of hours each day.

When wearing the mask a patient only has limited movement space, they can walk, but it is not recommended since they would also have to move the ventilator and don't want the mask to shift and cause air leakages. Speaking with the mask is difficult, however a patient can still see and hear clearly. The ventilator records data as 'the amount of time used' however does not communicate this to the patient.

During her own research Xinying already discovered 3 problem areas that can cause people to not wear the NIV mask for the recommended amount of hours each day. Namely:

- Resistance towards NIV treatment (Lack of knowledge: purpose, benefits, principle)
- Physical discomfort (Tight mask, noise)
- Experience of anxiety (Need for human closeness, panic, and loss of control due to tech dependency and difficulty to communicate)

Here I determined my design scope to be:
make a design to improve the adherence of a COPD patient who has to wear the mask 5 to 6 hours during the day.

I identified the design opportunities for:
Helping people in "reading" their device as well as home not just during checkups (make the invisible progress visible).
A physical interaction with a potential design should require minimal energy.



Figure 3: Target user

ANALOGOUS INSPIRATION

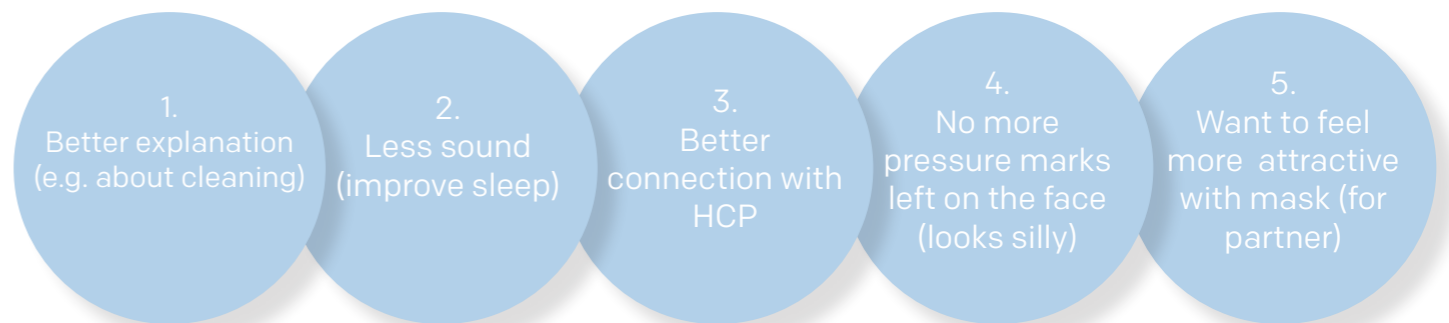
Goal

To get a fresh perspective on my topic, I shifted my focus to get inspiration from a new yet similar context. The method analogous inspiration from 'The Field Guide to Human-Centered Design' can assist a designer in isolating elements of an experience, interaction, or product and apply them to whatever design challenge they're tackling [32]. Going out of my office and into a different scenario is often a good approach to spark new ideas.

I decided to visit and talk to patients with sleep apnea who use HNIV at night since they can also tell me a lot about their experience with wearing a mask.

Method & Analysis

The 3 semi-structured interviews with patients, each about 20 minutes in length conducted over Microsoft Teams, were audio-recorded and later transcribed after the participants gave explicit permission for this through signing a consent form (see appendix B). These transcripts and field notes were analyzed by doing a thematic analysis in which I printed all the transcripts and cut loose all the quotes. Afterwards the quotes were clustered according to their meaning. The most relevant clusters were 'Positive experiences with HNIV' and 'Negative experiences with HNIV'. Within these bigger themes I identified smaller sub-themes such as 'attractiveness', 'support', and 'physical complaints' amongst others. I also asked participants to rank the 5 areas of their experience with HNIV open to improvement that were mentioned during the interviews from most to least important to them (card sort method) [33]. The average top 5:



However it was noticeable that for sleep apnea patients, HNIV patient adherence is not a problem. Since all participants were noticeably very happy with their ventilator and would no longer want to sleep a night without it.

So noted one of the participants: "I benefit a lot from the device. I don't think I could live without it anymore, I sleep so comfortably with it on."

And another: "I don't mind putting the mask on at night at all. I have used it every day from day one. I am very excited about it and would recommend it to everyone!"

Here I learned that:

I learned that the mask itself is not the main issue. Patients with sleep apnea love using their mask (being it after a short transition period). This shows me that for my target group, COPD HNIV users, it is more important to focus on psychological hurdles one runs into during the day that are avoided at night (e.g. social stigma), than the physical annoyances that come with having to wear a mask.

STAKEHOLDER MAP

After defining my target group I would like to get a better overview of who the stakeholders in the design process are for improved HNIV treatment adherence. This is why I decided to create a stakeholder map. Based on online orientation and my conversation with pulmonologist Dr. R. Sprooten.

Sprooten explained that the patients he works with reach the center for home ventilation after referral by a fellow pulmonologist. Usually in a stable situation after acute hospital admission due to a lung attack. If it is not possible to stop ventilator usage in the hospital, home ventilation is a continuation of this care in the hospital. *"Or if a patient has already been admitted to the hospital several times in need of a ventilator, we say okay, we are now going to focus on the possibilities for a home ventilator, to avoid rehospitalization,"* explains Sprooten.

Also at home patients are not alone. *"We have a whole home respiration team, nurses who come to people's homes. These home care nurses, helping patients with daily tasks are all instructed by us. They receive courses from us, so they know what to look out for regarding this specific user group,"* explains Sprooten. Besides healthcare professionals (HCP) providing care at home, patients often also have informal carers (acquaintances).

There are five 'Knowledge Centers Complex Chronic Lung Disorders' in the Netherlands that offer integrated treatment to people with complex chronic lung disorders [27-31].



Image 1, Location of the five 'Knowledge Centers Complex Chronic Lung Disorders' in the Netherlands from <https://kenniscentraccl.nl/>

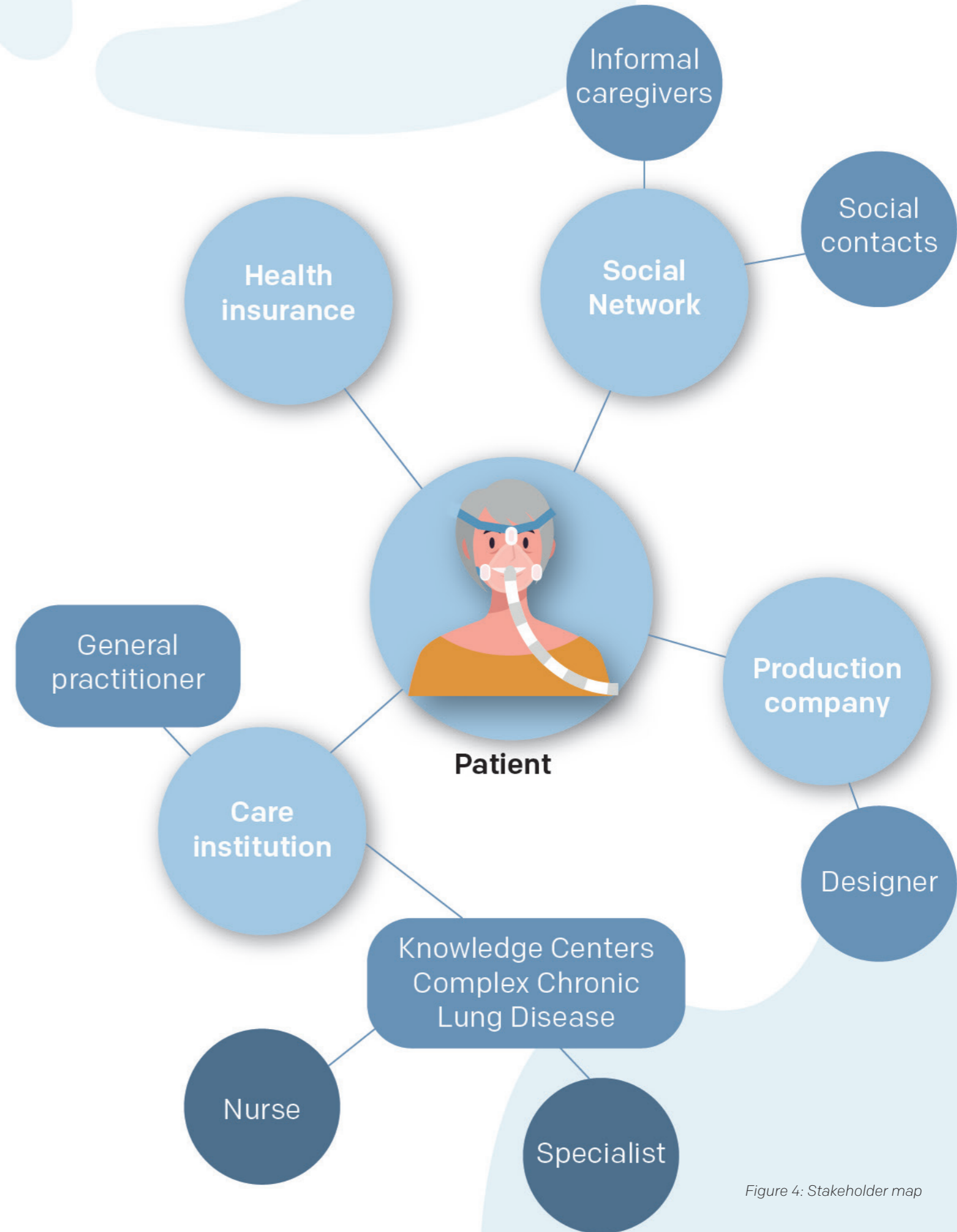


Figure 4: Stakeholder map

ONLINE FORUMS

To learn more about the topics that concern my user group from my target users themselves, I took a look at several online forums for COPD patients who use HNIV [34-37]. Through this activity I learned about several tools or gadgets patients currently use to improve their HNIV treatment (see image 2,3), especially tools to help communication seem to be common. On the forums people share helpful instruction videos, ask each other questions about management of the equipment, and express their support to each other. On the forum patients express their delight to talk with people with similar experiences as their own.



Image 2: Reddyport elbow with microphone from <https://www.reddyport.com/reddyport-microphone>



Image 3: EZ talk connector from <https://sleepsense.com/shop/accessories-bands-and-adapter-cables/ez-talk-connector/>

Gadgets like the Reddyport elbow with microphone or EZ talk connector are examples of products on the market to improve communication possibilities for the patient while wearing the mask. This resembles their bigger underlying need for connectedness and inclusion. Other tools, such as handmade soft sleeves for the ventilator cord or colored headbands were also promoted to improve appearance of the ventilator, seem to all be related to improving the appearance of their device. Giving it a more homely and less “hospital” atmosphere.

Here I learned that

While there are tools available to improve aesthetics or make it easier to communicate, these tools individually only tackle very small parts of larger underlying needs of the patient I discovered earlier (e.g. talking, to meet need for connectedness, to achieve social support). Also tools to help in other areas such as ‘control over their disease management’ and ‘making invisible progress visible’ seemed to still be missing. The need for education is partly met through peer advice on the platforms, however since these platforms are so decentralized and big (large numbers of participants) I make the assumption patients would appreciate to have a central point to turn to with questions for correct information as well as a place to find social support through real personal connections.



Image 4: self exploration with mask

PERSONA'S


Through literature research, interviews, and using methods like acting out I have gained insights into challenges and possibilities for designing for people with chronic COPD. Based on these insights, a design that promotes user adherence should give an answer to one or more of the following questions:

- How can users gain more control over their disease management?
- How can the social stigma patients feel around NIV be relieved?
- How can the support network of a patient be improved?
- How can a patient receive better education about NIV usage?

I decided to create persona's based on these results to better understand my users' needs, behaviors, experiences and goals. It helped me to empathize with the users I'm designing for by stepping out of myself. (See appendix C for enlarged image)

The different persona's personalize these issues:

- Mom mia resembles social frustrations (feeling cut off from outside world, social stigma, reduced sense of agency & autonomy)
- Elderly Ed resembles fear due to loss of control (anxiety tech dependency, trouble with daily routine)
- Wife Wendy resembles the informal carer role (Wants what is best for her husband but lacks education about HNIV, and edures side effects of husbands treatment)



Mom Mia
55 y/o

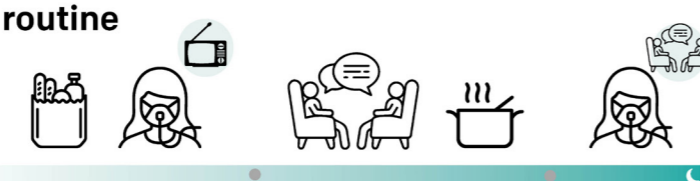
**Caring
Sensitive
Low Energy**

Wants to still be seen as her cheerful normal self

"I don't want to sit there like a sack of potatoes, I'll come to the living room when I can be my normal chatty self."

Mia is the mom of 3 young adults, living at home. With her youngest son being 15 and her oldest daughter being 21. Mia has recently started using HNIV in the hope to get more energy during the day and prevent hospitalization. With such a busy household she often isolates herself during her treatment to find some peace and to feel less awkward. However it's a big loss to her she can't be as social as she used to be.

Daily routine




GOALS:

- Feel part of the family life
- Partake in social activities
- Maintain social relationships

FRUSTRATIONS:

- Has to wear the mask for long amounts of time
- Low energy
- Can't speak with mask on



Elderly Ed
82 y/o


**Distrust technology
Self-reliant**

Dislikes wearing the mask

"Oh dear I'm not sure how long I've worn it already today, but I'm fairly certain its been a few hours already. Must be enough for today."

Ed is living alone in his apartment since his partner passed away. Since two years he has to use NIV during the day and at night at home. But he isn't a big fan. Not only is wearing the mask uncomfortable, he also finds it a scary realization to be so reliant on a piece of technology. Using it when he is home alone is also scary, cause it triggers feelings of claustrophobia. He therefor likes to go to the common room of the apartment building with the machine and sit there.

Daily routine



GOALS:

- Stay healthy
- Have confidence in health plan

FRUSTRATIONS:

- Mask is uncomfortable
- Scared to depend on technology he doesn't understand
- Bad time estimation



Wife Wendy
66 y/o

**Caring
Empathic
Active**

Wants to enjoy life with her husband

"Look I also prefer to be close to my husband without the device in between us, but I'm sure the device is at least doing some good for his health otherwise they wouldn't have given us right?"

Wendy has been married to her husband Mark for 32 years now. After his hospitalization for his COPD 6 years ago, he has been using HNIV. The time Mark spend in the hospital was very hard for Wendy and she wants her husband to take this HNIV treatment serious to prevent future hospitalization. But her husband much rather has his mouth free to kiss Wendy when they crawl into bed at night, and also Wendy can't deny she prefers sleeping with Mark without the noise of the HNIV device.

Daily routine



GOALS:

- Keep her husband healthy
- Enjoy the time they have together
- Wants to kiss her husband

FRUSTRATIONS:

- Scared for her husband's health
- Not sure what the benefits of HNIV treatment are
- Has to endure side effects of husbands treatment (noise)

BRAINSTORM SESSIONS

Based on the persona's that resemble my users' needs I organized 3 design sessions. For each session 2 industrial design students or graduates were invited. After an introduction I introduced them to one of the persona's, and would set a timer for 15 minutes to come up with 100 ideas that could help them in their situation. This was repeated for all 3 persona's. After completion of the 3 brainstorms we would reflect together on all the ideas generated and give arguments for our personal favorites.

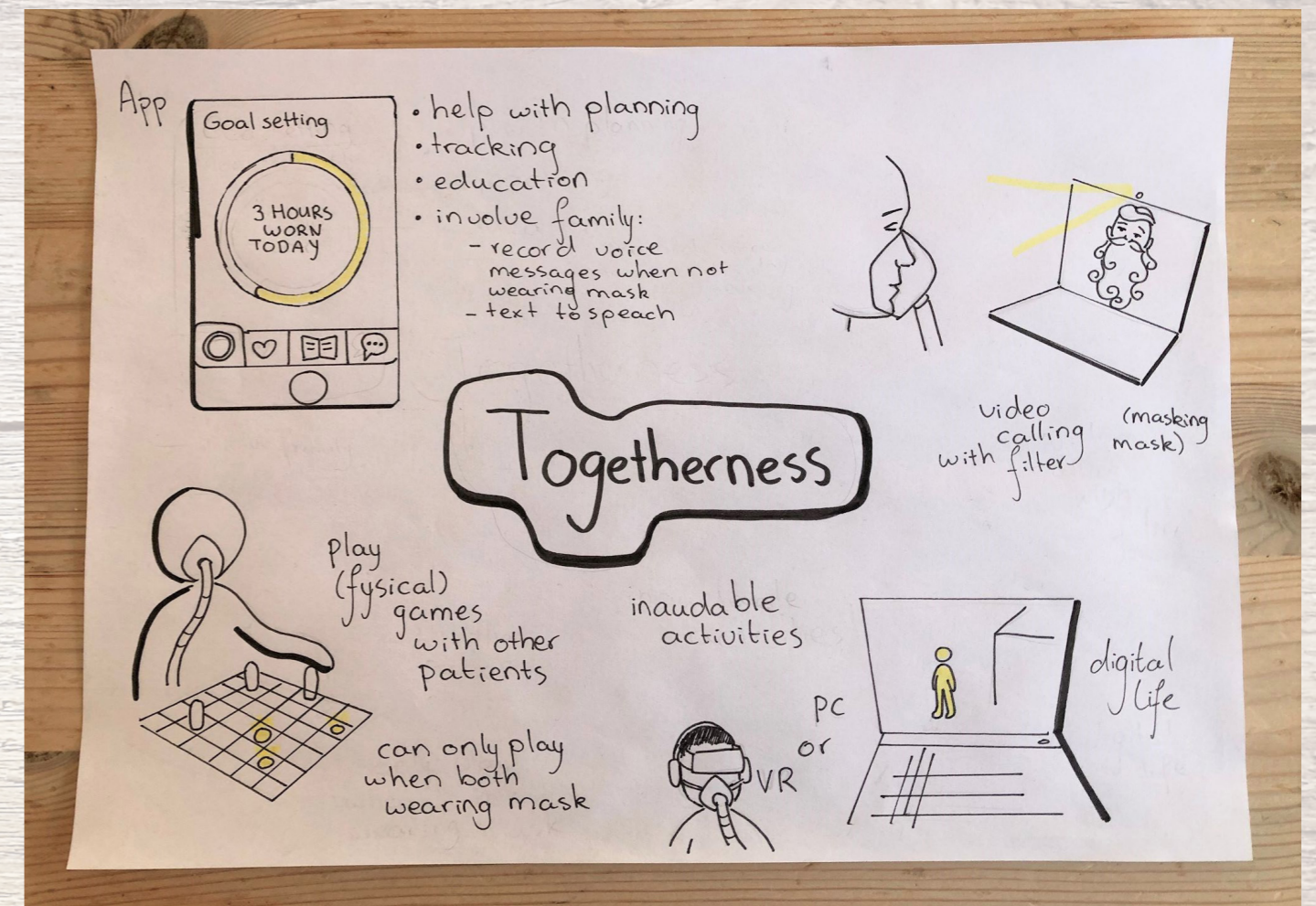
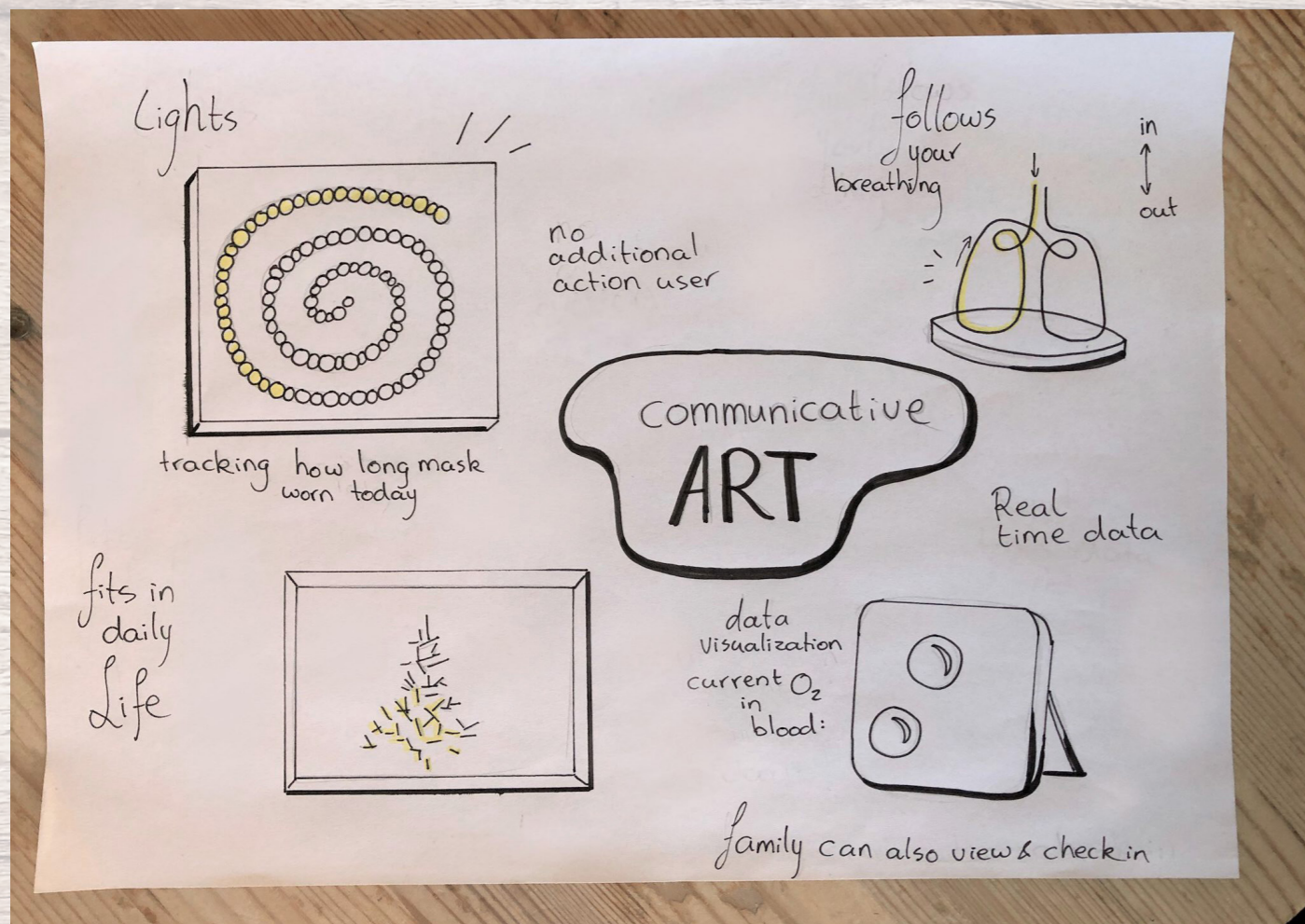
Later I clustered all the reasonable ideas into 4 themes: Data communication (communicative art), Togetherness, Playful tangible interaction (cover for the hose), and Education. And worked the idea's out further in the sketches represented on the next page. The 4 themes and sketches were evaluated by my client.

In addition **behavior change theories** were also used to review which ideas have sufficient theoretical backbone and thus the highest potential to change user behavior.



Image 5: Brainstorm





“Do people want this in their homes?”
Client

“How can a user look back at progress on other days?” Client

Make a public testimony [39]:
visual to all if not wearing enough

Conscious motivation affects performance and job satisfaction [42]

Create favorable social norms [38]:
socially good if family sees you completed goal!

For goals to be effective, people need summary feedback that reveals progress [42]

Use no punishment/ not too controlling [41]: Only uses positive motivation

Final insight:
Has potential! But I need to explore the right aesthetics. If patients do not want this in their home all else fails.

“How can it actively involve family?” Client

“Will the same game over and over get boring?” Client

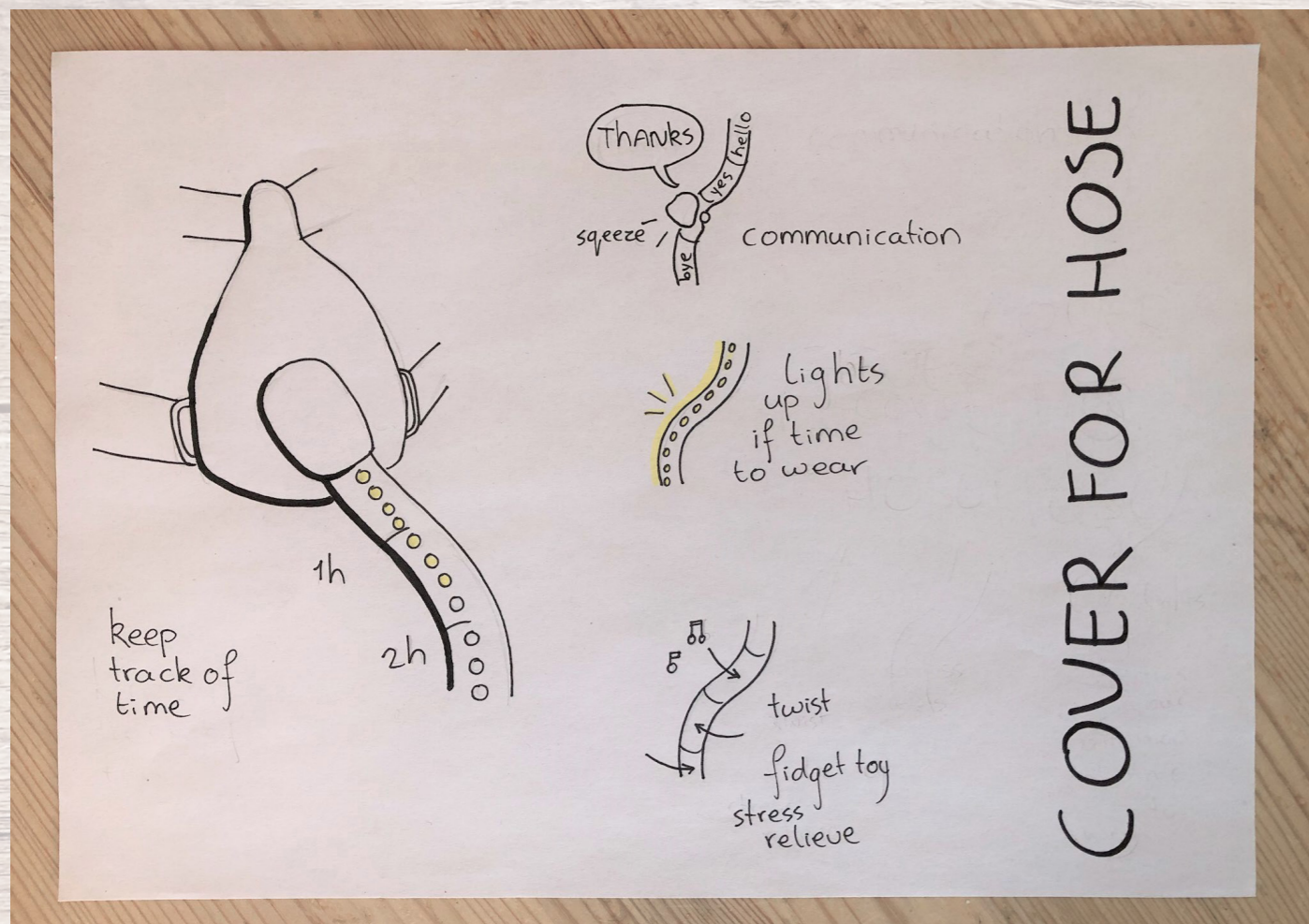
Substitute behavior & environmental re-engineering [39]: talk to friends online instead of in real life (engage in social life online instead of irl)

Create a social environment where users see they are not the only one doing this (improve: would others do it?) [38]

improves togetherness and autonomy by being able to live your own life again (online) [41]

helping relationships [39]: arrangements with fellow patients to do it together (buddy system)

Final insight:
Togetherness is important, but can perhaps be integrated in another concept instead of being a stand alone concept. Strengthening togetherness outside of “wearing time” might be more powerful than creating alternatives to social situations during wearing time.



"Can patients see their own hose properly?" Client

"Nice that this design seems to tackle multiple painpoints" Client

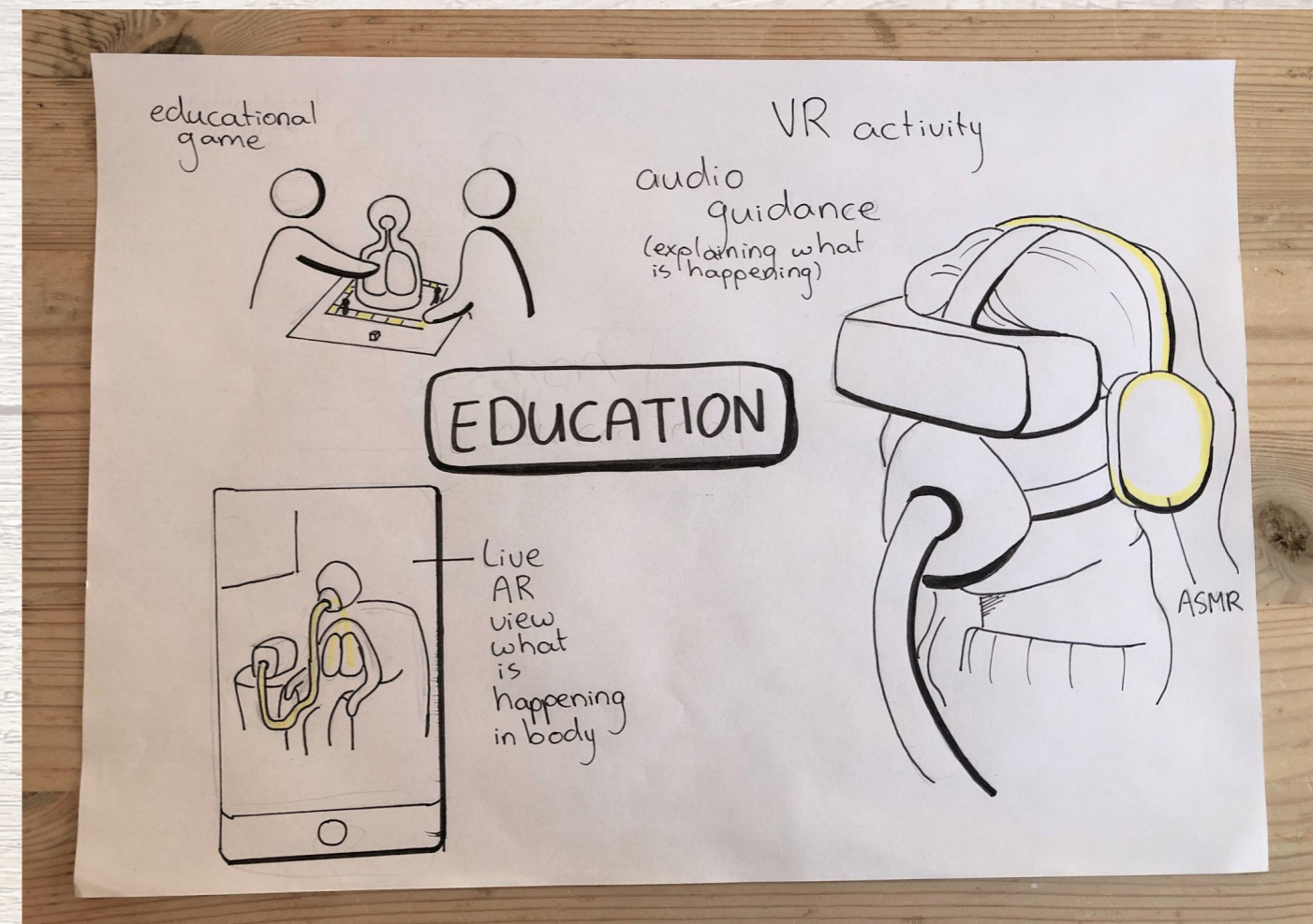
Improve autonomy[41]: be able to call out for family again

Make behavior more enjoyable [38]:
Improve communication and make wearing playful

For goals to be effective, people need summary feedback that reveals progress [42]

Final insight:

Has potential! Nice that more directions can come together in one concept. But need to explore what interactions with a sleeve are comfortable and realizable, taking into account this is healthcare equipment.



"Only use at the beginning? Is it even worth the investment?" Client

"VR is scary, AR has potential although not fitting to a large part of the user group (elders), however their informal carers (kids) can use it!" Client

Consciousness raising [39]: feedback and confrontation when being thought about the consequences of their actions

Self-reevaluation [39]: With game.. have to realize they are losing (losers) if they dont wear mask enough

Improves user confidence they know what is happening and know they can do it [38]

Dramatic relief [39]: Initially produces increased emotional experiences. followed by reduced affect or anticipated relief if appropriate action is taken. (game playing)

Final insight

Methods used in this stage of behavior change, such as dramatic relief where you basically make the user scared of what will happen if they don't change their behavior, like is often done with smoking [39]. It may not be the most ethical approach. Also immersive informative methods such as AR and VR might not be suitable to the target group need, who are majorly elderly. This makes me realize education is probably not the best direction, however still important. Can potentially be combined with other design directions.

BEHAVIOR CHANGE

As can be seen in the previous pages I used **behavior change theories** to review which ideas have sufficient theoretical backbone and thus the highest potential to change user behavior. It has been shown that basing behavior change interventions on theory can be more effective. The theories in the papers (on which I based my design insights used in the reflection) primarily deals with changing behavior, but also with attitude change as the two are closely related. I used 5 well known theories of behavior change:

- Theory of planned behavior [38]
- Self Determination Theory [41]
- Trans Theoretical Model / Stages of change model [39]
- Elaboration Likelihood Model [40]
- Goal Setting Theory [42]

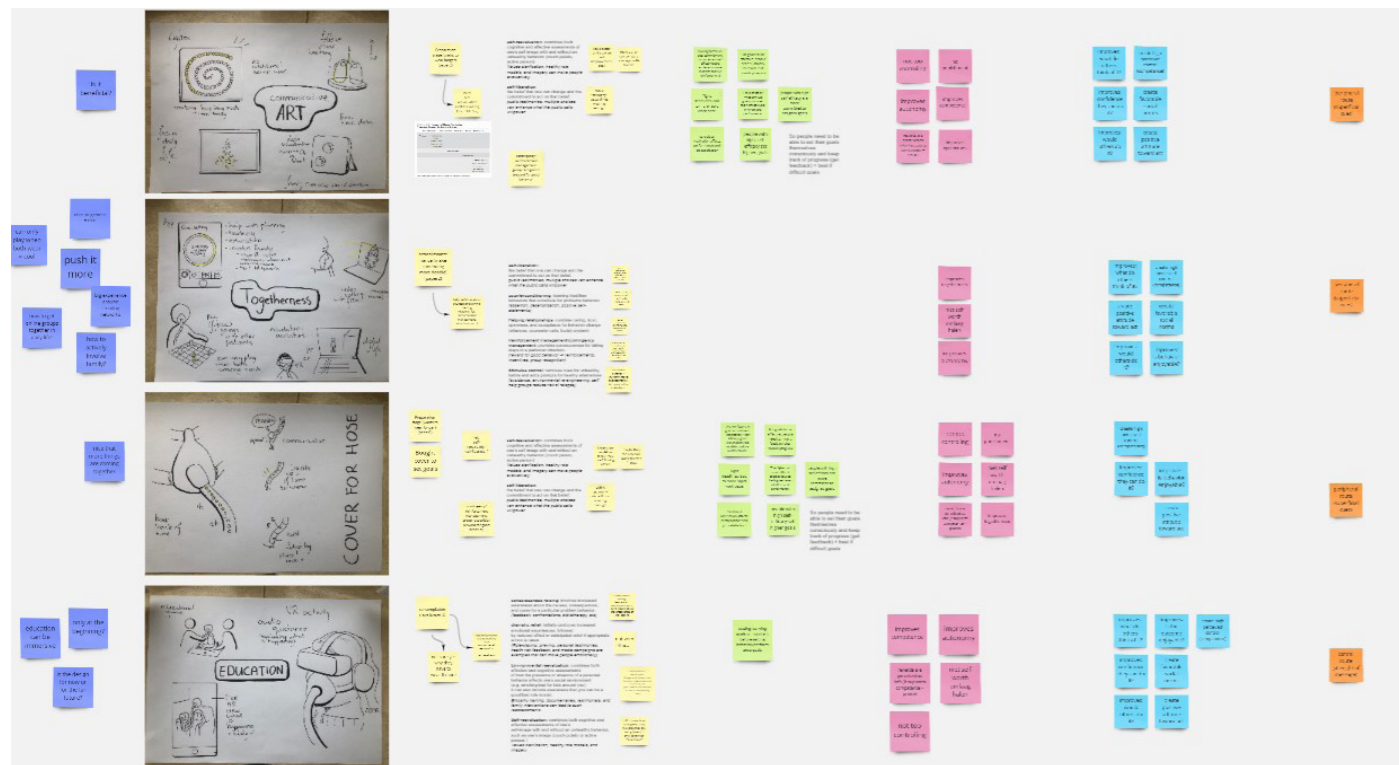


Image 6: link theory insights to design concepts

Ethics of behavior change

Design for behavioral change is a form of persuasive design. Persuasion is of all times, and is always all around us (radio, books, friends). However this does not mean we as designers should implement it without care. Design for Behavioral Change is the attempt to change a person's attitude or behavior through planned effects of a design intervention. If persuasion is successful it results in a change to a person's behavior, attitudes, or beliefs.

To ensure this project stays ethical I identified and avoided potential value conflicts between stakeholders (read more about this in chapter 5). I also believe it is important to communicate clearly with my user group. The final design concept is a device that will actively try to help them change their behavior, so they can make a conscious decision.

Reflection & Refinement

I used the behavior change theories and literature to reflect on my concept ideas, in order to narrow my focus down to one final concept I refined some of the most promising ideas further. So did the design concepts in the directions 'education' and 'togetherness' not make the cut. While these themes are important, the ideas in those directions were not very strong. However I do think combining these 2 directions with the remaining two 'data physicalization' and 'wearable' can create much stronger concepts.

I used rapid prototyping to try and explore more detailed design concepts with fabrics and paper mockups. In the area of 'data physicalization' I expanded the idea from only showing progress in the daily goal, to being able to track your goals in an app. This application will also be used to create an online environment to meet other patients and set goals together. Combining the strengths of 'data physicalization' and 'togetherness'.

For the area of 'wearable: Cover for the hose' I explored interactions possibilities with the hose and added an online environment to the concept as well. Here users can record voice prompts before wearing the mask to also be able to initiate conversation or call for help whilst wearing the mask. Improving their peace of mind.



Image 7: communicative art (base image used for alteration from <https://daphnemenheere.nl/>)

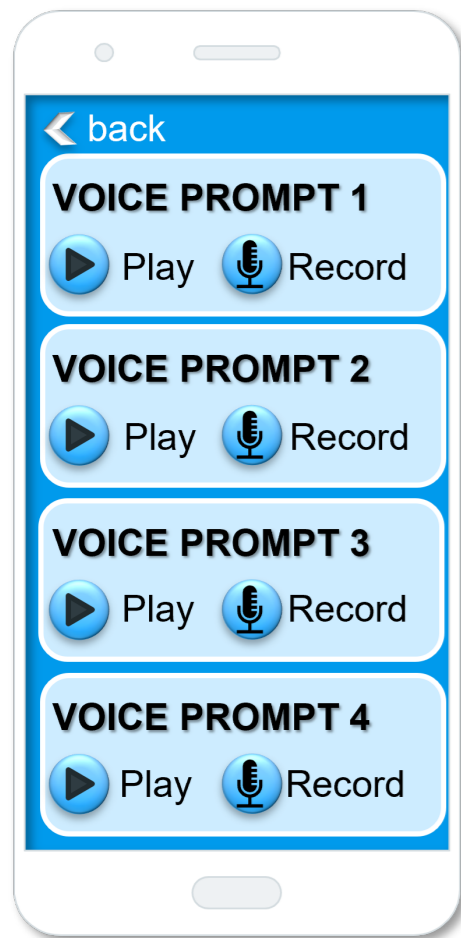
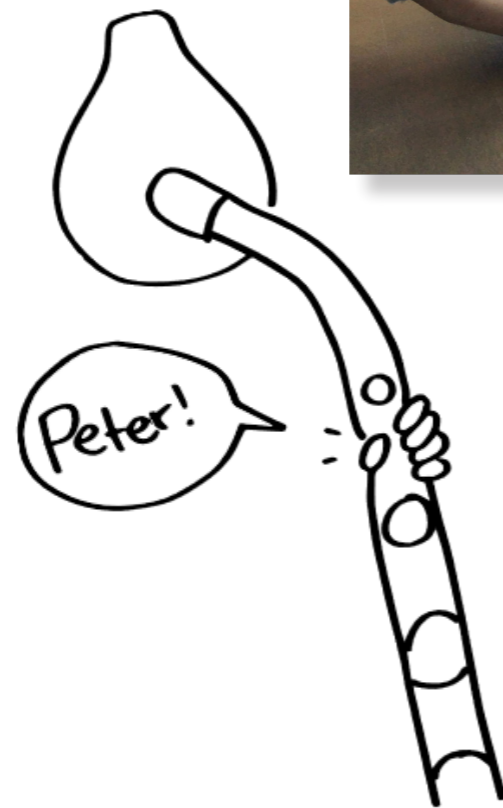
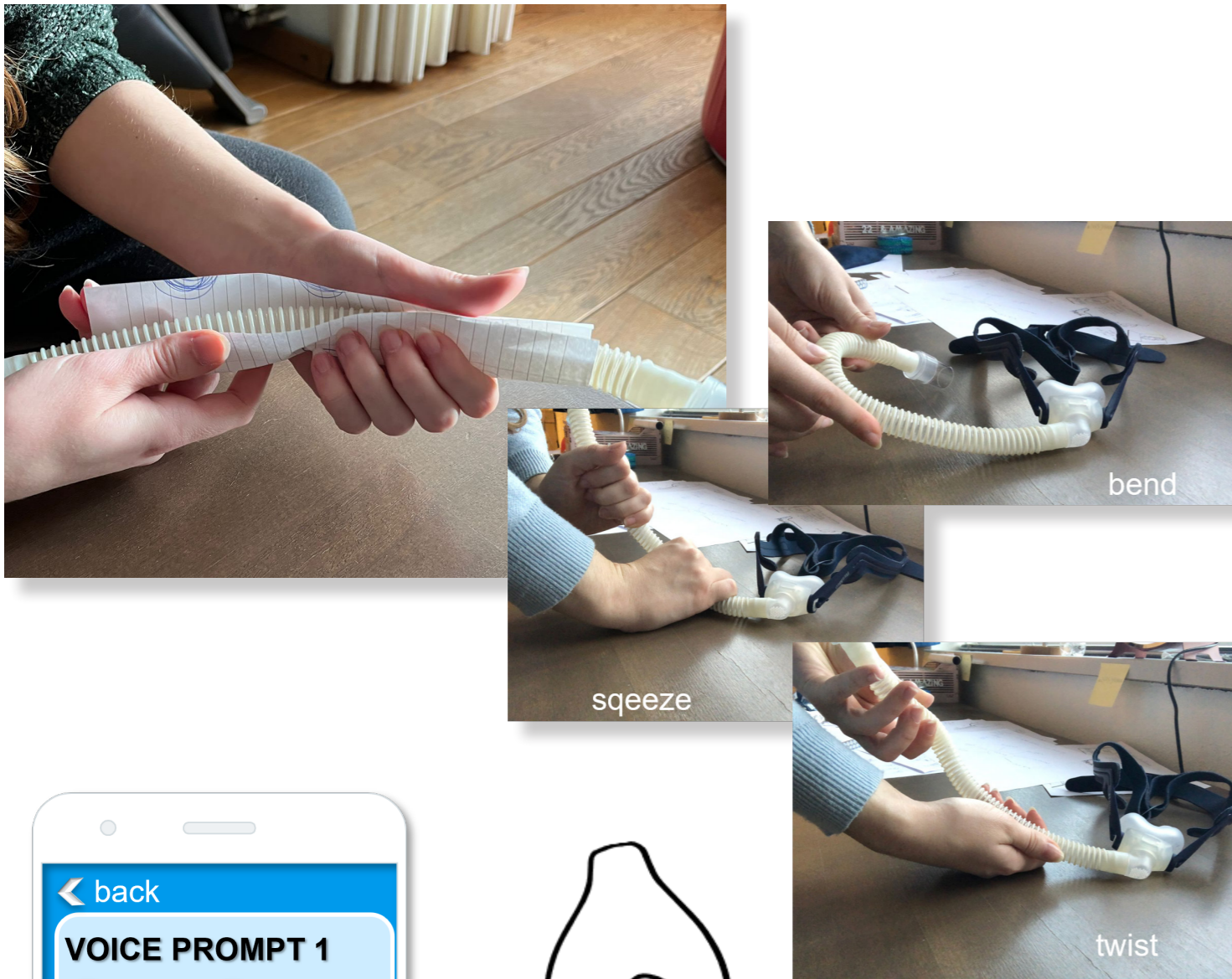


Image 8: (Exploration for) Interactive cover for the hose

EXPERT FEEDBACK

To make a well informed final decision I spoke with the research team of my client in China, as well as with HNIV expert pulmonologist Dr. R. Sprooten. They expressed their opinions on the concepts and gave me recommendations for developing their preferred concept further moving forward. This preferred direction namely unanimously turned out to be 'data physicalization'. The research team from Philips was excited about this concept because "It is art! It doesn't make the patient feel ill! While it can still be a nice subtle way to get the family more involved in the smaller goals of the patient as well."

Sprooten had a similar positive reaction to the data physicalization, but warned me that when it came to the app I should be careful to steer away from gamification. "These people are ill. They don't want to play games, nor will they care about high score lists. They want their condition to be taken seriously," expressed Sprooten. However the app was a welcome addition to the concept. Sprooten shared that he thought the online environment would be great for the user to actively reflect on their goals, as well as a clear visual way to share these goals with family members. The researchers from Philips shared that it would be nice to include more general education about HNIV in this online platform as well, while expressing the importance for patients to feel competent in their treatment. About the wearable however, they were not so much to speak "It's a fun idea, however I think healthcare devices and play should stay separate. We do not want the life saving equipment to be damaged due to play," shared one of the researchers.

What I learned here

Based on both my reflection with the behavior change design guidelines and the expert feedback I decided to continue in the direction of 'Communicative art', also known as 'Data physicalization'. However I will be implementing aspects of other directions in the final design where fitting.

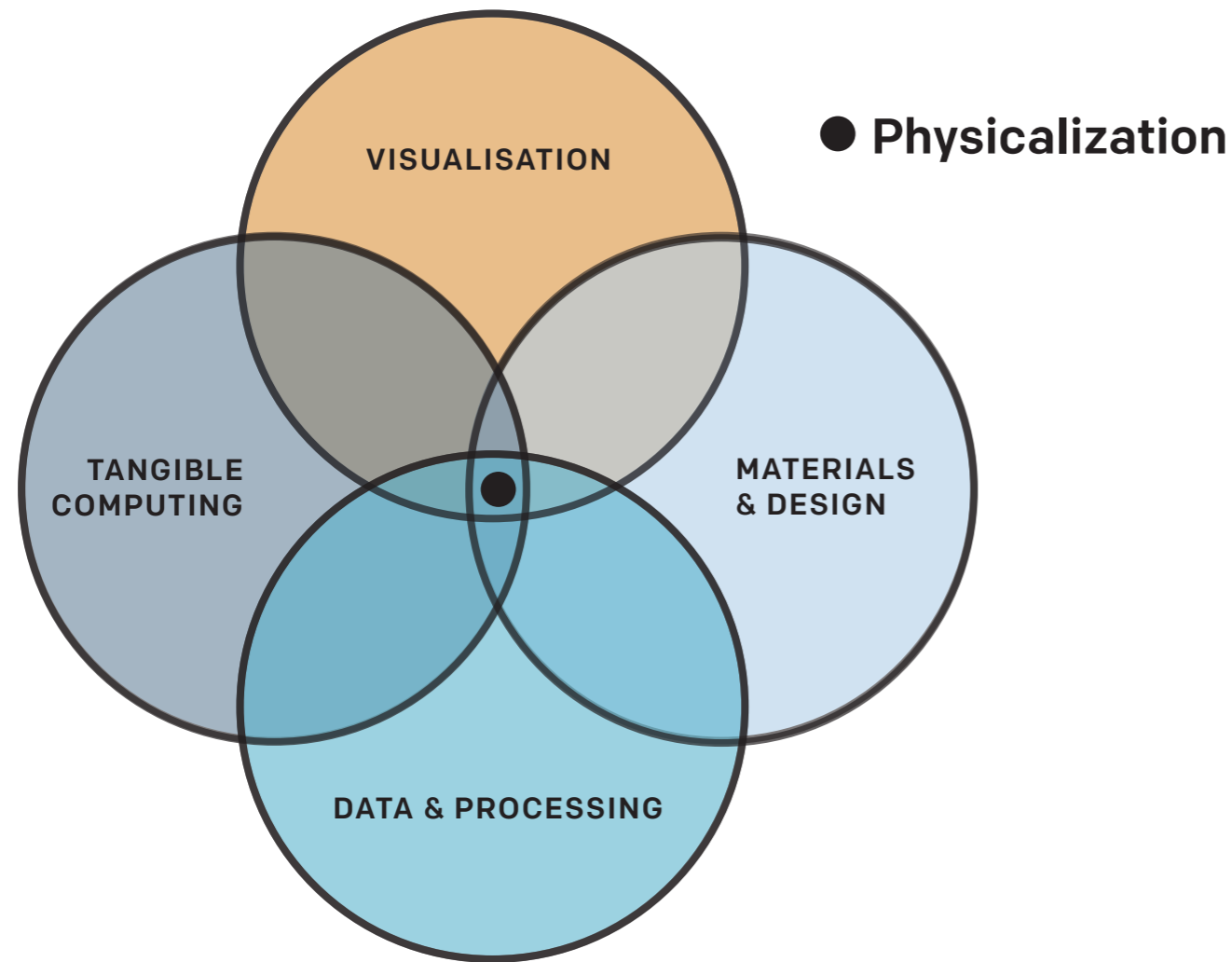


Figure 5: what is data physicalization?

What actually is data physicalization? And how can I best use it for my goal? These are all questions that arose from reflecting on the previous iteration. Since I have no previous experience with data physicalization I reached towards literature, online lectures, and interviewed data physicalization expert Steven Houben at the Technical University of Eindhoven to learn more about this topic and find the answers to my questions.

What is data physicalization?

Data physicalization is an emerging research area with the purpose to convey meaningful information through physical shapes or materiality [43]. It designates “a physical artifact whose geometry or material properties encode data.” [44, p.3228]. These physical representations are intended to help people explore, share, and comprehend external or self-quantified data. Data physicalizations also operate as ambient data displays [44], which are always “on” and can be placed anywhere, unlike on-screen visualizations.

Why is it fitting to my goal?

Data physicalizations, through their physical presence, have the potential to make data accessible not just to the direct user (e.g., hidden in a screen or activity tracker), but also to others in the environment, stimulating discussions [45]. Data physicalizations, among other things, enable for better use of active perception abilities and can thus be easily explored from different perspectives [46]. These data physicalizations provide users with a new tool for better understanding themselves and make positive changes in their lives [47]. These data-driven types of self-reflection can lead to self-improvement thoughts or acts [48], as well as digital epiphanies such as accepting or changing one’s own behavior [49].

What types of data physicalizations are there?

- Data Physicalization: Individual data points mapped directly to an object (physical bar charts)
- Ambient Physicalization: Ambient communication of data (e.g. through light, vibration)
- Data Sculptures: Artistic symbolic perspectives on data
- Composite/Constructive Physicalization: Design of a toolkit with interactive/exploratory mapping inviting to move the data points around
- Data Installation: Malleable installation inviting to experiment with data

What type is fitting for me

Of Course there are also hybrid data physicalizations possible but I explored the different strengths of each option in regards to my design goal.

A clear limitation of certain physicalizations can be that they are static, and cannot be updated [50]. Users are also unlikely to keep such individual representation objects for extended amounts of time, it would cause clutter in their home as more and more of them would appear [50].

Shape-changing interfaces may be able to solve this issue! They can provide the same type of feedback as static data physicalization while overcoming these drawbacks. It may allow for the physicalization of dynamic data as well as long-term and dynamic user interactions with data [44, 51, 52].

However being able to physically engage with the design has to still be possible. Being able to physically engage with the design lets users feel more connected to their data [43]. Touch adds a new perspective to data reflection. And especially as opposed to digital interfaces, can bodily engagement have a beneficial effect on personal pride, connectedness, and reflection [53].

So a data sculpture seemed to be the best fit with my topic and my current concept. Data Physicalization expert Steven Houben walked me through the most important aspects of a data sculpture:

1. “Firstly it is important that you ensure the data communication is clear, but that you also take privacy into account. Strangers walking by shouldn’t be able to make sense of the personal data, however once the user makes the decision to disclose its meaning, they should be able to easily understand”. This means it is important to find that boundary between what is abstract but can still be clearly and easily read if you know what it means.
2. “Secondly you have the social element. Data sculptures often have a watercooler effect, a place where people come together to discuss. Having a data sculpture in your house will be a conversation starter for the other residents”
3. “Lastly, within that data sculpture it is important to give a clear frame of reference. You should not compare personal data from a healthy person with the data from a chronically ill patient. Look per user how the sculpture should react to certain values”.

How 3D should this physicalization sculpture be?

I learned through different sources that the examination and manipulation of physical objects can promote reflection, understanding and learning [54, 55]. However data sculptures are typically not meant to be interacted with. A study by Cockburn and McKenzie [56] shows it is noteworthy that the 3D object performed worse on memorability than 2D overall, but a physical 2D data representation also still outperformed the screen-based implementation [56]. But also 2D there are many options for shape changing physicalizations. Rasmussen et al. [57] identified eight types of deformations supporting information and meaning, namely changes in orientation, form, volume, texture, viscosity, spatiality, adding/subtracting, or permeability.

Lastly it is also noteworthy that more abstract representations appear to benefit task performance and reflection (linked to my goal!), but more playful data representations are better able to “engage” people, an effect that can be amplified by emotional commitment triggering [50].

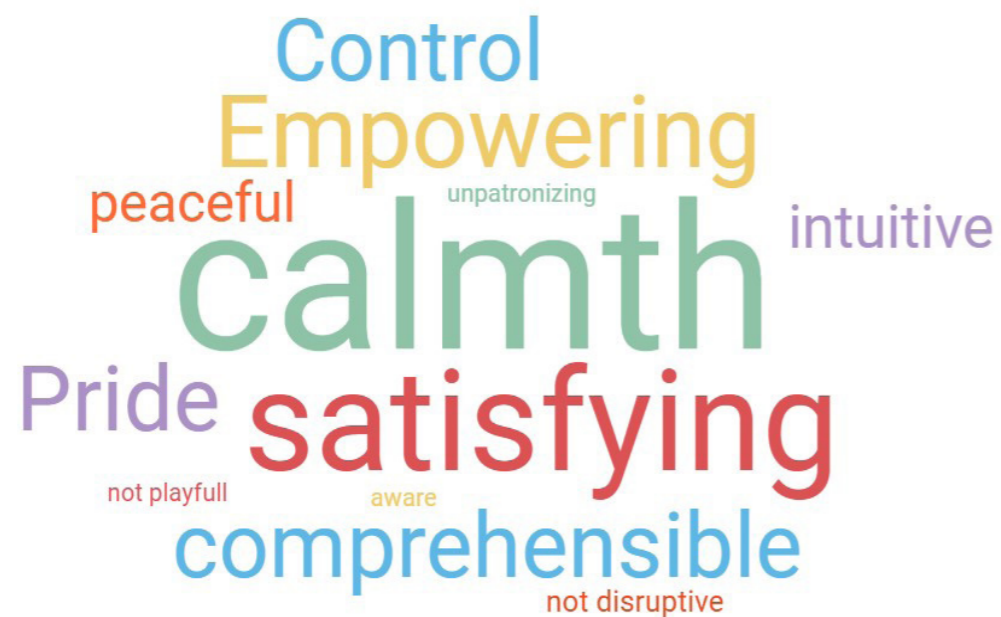
What I took from this experience

Make the final design a data sculpture. Include tangible interaction with the sculpture to encourage reflection. Make sure the sculpture shape changing, but keep it flat.

EXPERIENCE

What is the experience I want to create with my data physicalization?

Before going into details regarding the aesthetics of the design the intended experience needed to be defined, this will be the base for later design decisions. For this I made use of the product reaction cards [61]. Product reaction cards were developed by Microsoft as part of a “desirability toolkit” created to understand the illusive, intangible aspect of desirability resulting from a user’s experience with a product. It is a list of 118 words to check or define an experience.



The words selected to describe the intended experience are based on a combination of my vision as a designer, the design brief, and the needs and values of my target audience (which I gathered through my client, an HNIV expert interview, and personal stories on online forums).

BENCHMARK

To get inspired by the different ways data representations are being physicalized in my own project I made a **moodboard** with ‘physical data’ images from the visual discovery engine website Pinterest and looked at websites as <http://dataphys.org/list/> [58, 59]. The website named above is maintained by Pierre Dragicevic and Yvonne Jansen and was perfect to benchmark data physicalizations as it contains a chronological list, with currently 370 entries, of physical data visualizations and related artifacts.

Especially when looking at some of the published data sculptures, I paid attention to see how the design and aesthetic choices were made to support the experience. Even though aesthetic beauty choices are important to make the sculpture a wanted item in a user’s home, that fits with the interior. It is also important to realize how the aesthetics and aesthetics of interaction align with the intended user experience. I want to highlight the paper ‘Capturing, Representing, and Interacting with Laughter’ here data sculptures represent the laughter of loved ones in the form of 3D printed chocolates [60]. Chocolate has a connotation of being a social gift, also they trigger more modalities than only visual. From this I learned that the usage of metaphors in the data physicalization can be a useful tool.

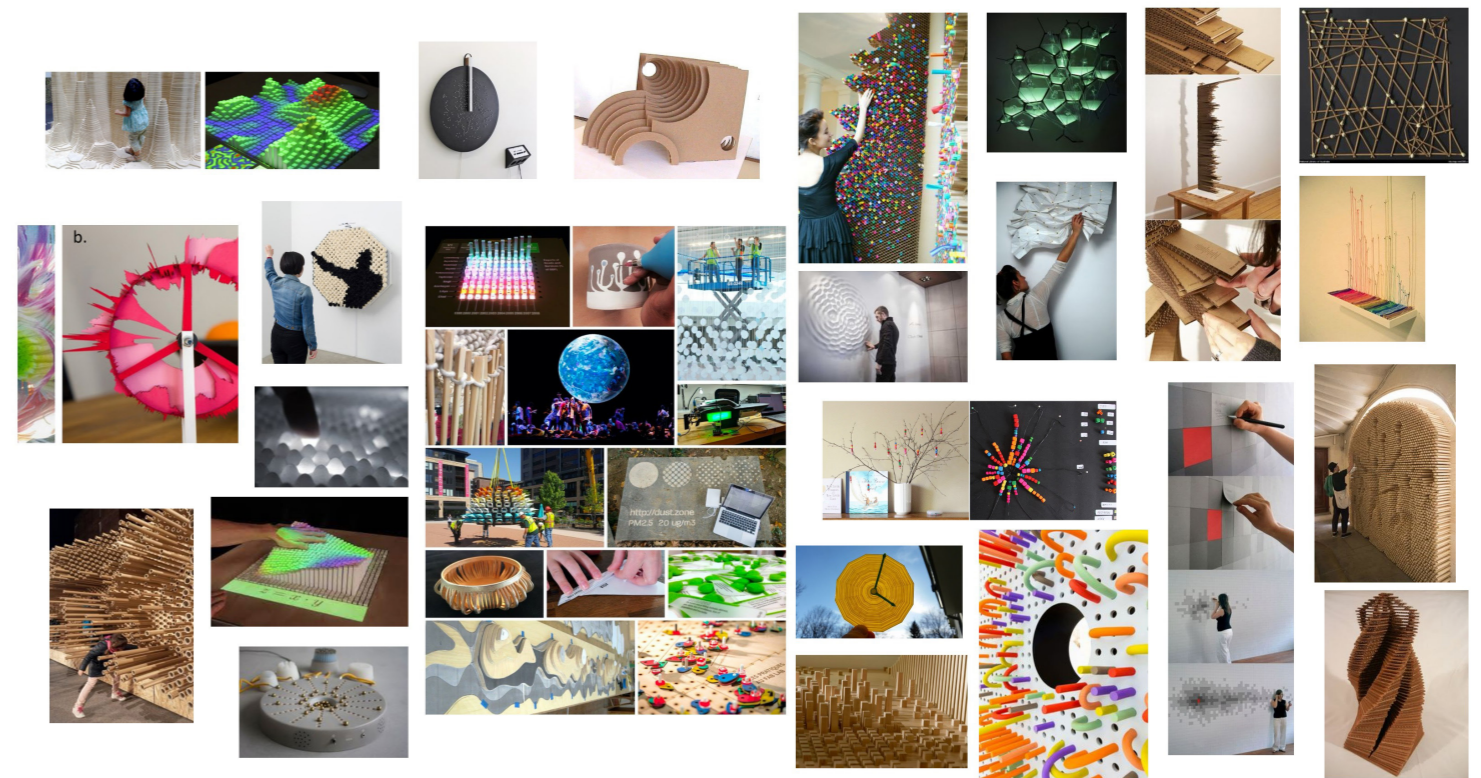
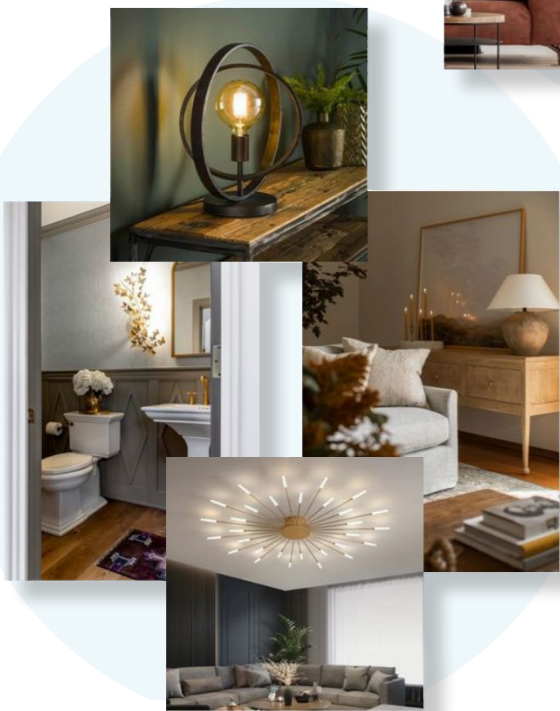
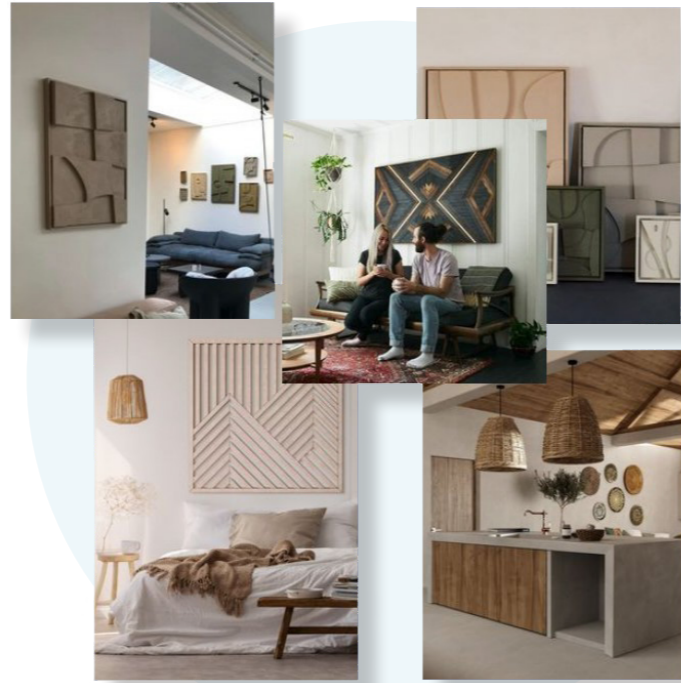


Image 9: moodboard with images from the platform Pinterest.com



AESTHETICS

When designing a piece that is intended to be placed in a central spot in the home, it is of great importance this design is aesthetically pleasing.

HNIV specialist Sprooten already stated in the earlier mentioned interview, that solely the medical look of the ventilator with mask can already be a hurdle to people's willingness to use the device in the semi-public setting of their living room.

To tackle this challenge ahead I created 5 different mood boards displaying several interior design themes (see image 10). The 5 themes represent 5 directions I had in mind for the data sculpture, namely data communication through light art, wooden shapes, colorful design, abstract patterns, and shapes resembling real world objects.

Through convenience sampling I asked a group of 30 adults between the ages 43 and 81 and up to rank the 5 mood boards, from most appealing home decor to least. The moodboard rated most appealing would receive 5 points, the least appealing moodboard only 1. This is called the Card Sort method [33]. I later counted these points to determine the overall preferred style. The participants were selected because they resemble the age range of my target user group. The participants did not have to use HNIV to be able to participate in this test, since COPD does not alter a person's interior design taste. Meaning healthy adults can also give sufficient insight in the interior design taste of my target group.

The mood board that received the highest score was wood! Abstract patterns and shapes resembling real world objects made a close second and third place. While light art and colorful design were clearly not wanted by this participant group.

What I took from this experience

Since my previous concept for the data physicalization included the shape of a tree that would light up as the user gets closer to the realization of their goal, I realized the design of this concept needed to change. Since both real world objects, as lights, scored poorly. Based on these moodboards I decided to use wood for the final concept.

SHAPE AND MATERIAL EXPLORATION

Whilst exploring different potential ways to display wearing time data on a wooden surface I kept the key words selected for the intended experience in mind. Namely calm, comprehensive, and satisfying. Through experience I want to let the patient feel competent and in control.

After exploring different shapes and movements through **low-fi prototypes** made using laser cutting, cardboard modeling, and hand stitching. In addition to working on my **annotated exploration portfolio** [62]. I ended up selecting a round wooden design from which a black shape retracts to communicate how close a patient is to reaching their wearing time goal. This design was selected because of the organic and visually enjoyable movement of the data representing abstract shape. The design is minimalistic to keep a sense of calmth, and portray luxury. The shape will showcase live data to the user, making the invisible passing of time and clearance of the lungs visible. This design has a high glanceability since a user can see in one second how far removed they still are from their daily goal, but protects a users privacy since to the unknown beholder the shape means nothing.



Image 10: Shape Exploration

METAPHORS IN DESIGN

Because the data sculpture will resemble the passing of time, the association with a clock is quickly made. I chose a final design that will make use of the same placement of a clock, as well as a similar shape, to strengthen this association.

I made the choice to use a black stretchy fabric that retracts over time to showcase this passing of time. The shape will retract back faster in the areas that match the current time on a clock (e.g. when wearing the mask at 6pm the black shape will retract faster on the bottom, than in other areas). Through this I was to visualize patterns in wearing time, and help users understand their daily routine.

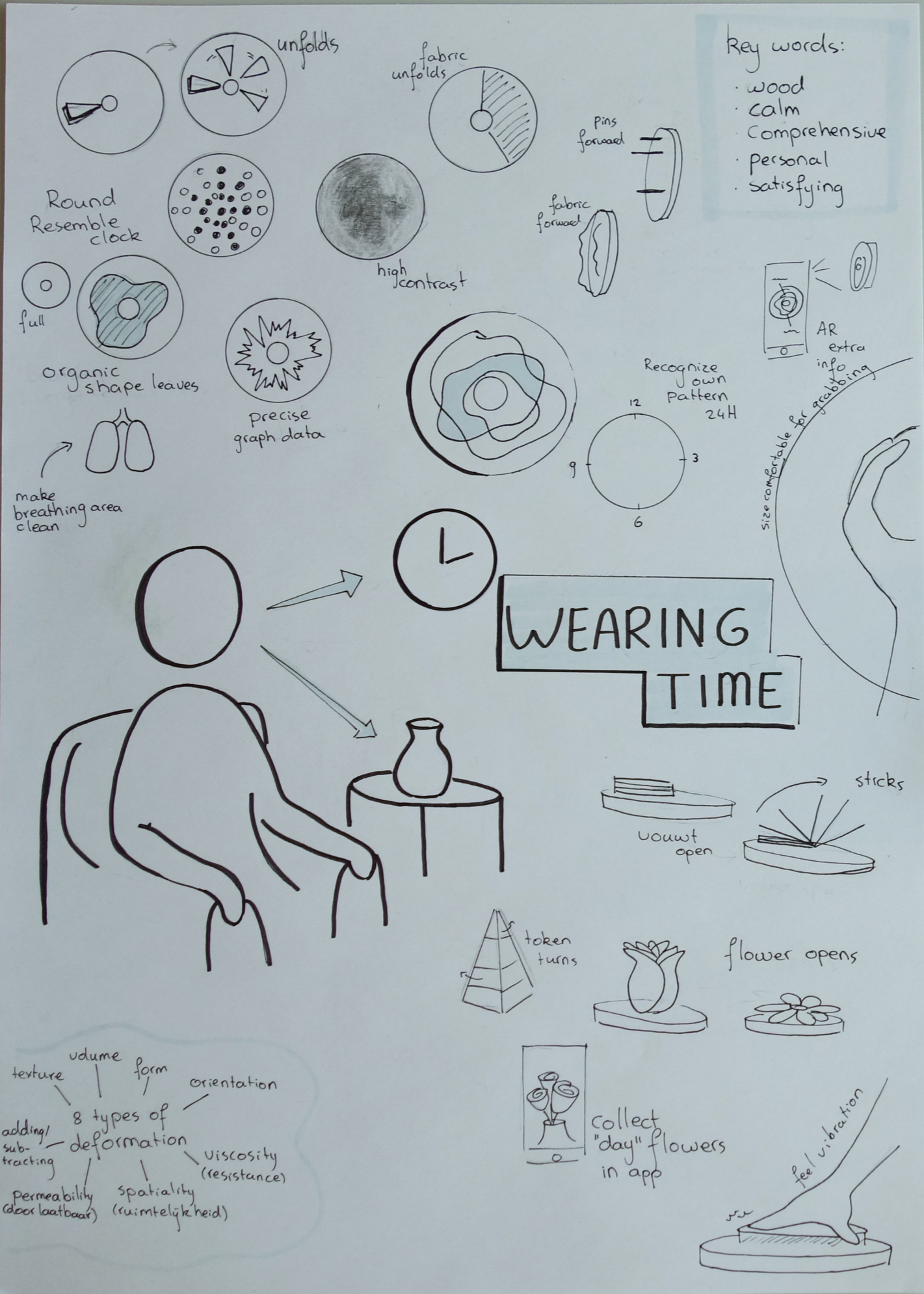
With the retraction of the black shape I want to resemble the clearance of the lungs. As the black color leaves it creates more room.

IMPLEMENTATION TANGIBILITY

I learned earlier that including tangibility in my data sculpture is beneficial to stimulate active reflection. And that examination and manipulation of physical objects can promote understanding and learning [54, 55]. Since bodily engagement encouraged connectedness, pride and reflection I was very interested in this [43]. Because let this be exactly the experience I want to create.

The adaptive qualities of the shape-changing interface I selected as a final design can be used to enhance this users' examination and manipulation. The moment where I want my user to reflect on their daily goal the most, is at the end of the day, before the artwork would unfold again to start a new day. I decided to make this moment of unfolding more meaningful by giving the user the option to be more actively involved in this moment. At the end of the day the patient can choose to physically turn the top knob to reset the artwork for a new day to come. By physically unfolding the artwork the patient can feel and see the effort they put in. Creating a satisfying moment that stimulates reflection-on-action.





APP

In addition to the data sculpture, users can download an app on their smartphone that makes it possible for them to compare their current shape, to for example the shape they had at this moment in time yesterday. The app can also be used for insight into more precise data or progress (under the 'Analysis' tab), connecting to other patients from the buddy system (under the 'Connect' tab), and finding answers to questions they run into (under the 'Education' tab).

The NIV track app prototype that I created in Figma, is largely based on the results of my M1.2 research project 'How to support (Long Term) Motivation in Cardiac Telerehabilitation Patients: Design guidelines' as well as insights from behavior change theories.

An example of one of these guidelines is:

- "Have the opportunity for personalization.
It should be possible for patients in collaboration with their healthcare provider to regulate how much data points are communicated back to the patient in the online environment."

While some enjoy exploring their data, others will perhaps feel overwhelmed when flooded with much information. This comes back in my idea for the NIV app through the opportunity to personalize which tabs they want to use in the app. If a patient for example does not want to join an online support group, they can dismantle this tab in settings. It will stop being visible on the app's home page. If they later change their mind they can add it back again in settings. This way patients can also have a transition period. Where they start with a simple version of the app, and keep adding functionalities when they feel ready.

Also the insights I gained from reviewing the different behavior change theories earlier come back in the functionalities of the app. An example of this is the implementation of tips from the Goal Setting Theory. The Goal Setting Theory namely explained that two key factors in goal commitment are: Importance and self efficacy.

Factors that can be achieved through things such as educational info to teach one about importance, as well as role models and visible progress to improve self efficacy [42]. People with high self-efficacy are more committed to their assigned goals. Seeing other patients live fulfilled lives under the 'connect' tab causes self-reevaluation [42]. It combines both cognitive and affective assessments of one's self image with and without the unhealthy behavior [39]. Not only seeing but also connecting to these other patients through the support groups/buddy systems the app provides creates helping relationships [39]. Reducing the feeling of loneliness and hopelessness patients with chronic illness can experience.





1) Comment by informal carer



2) Enjoying open conversation



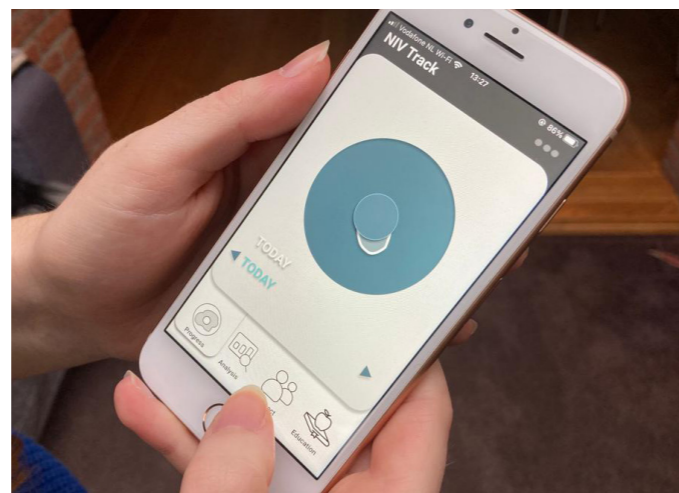
3) Patient reflection



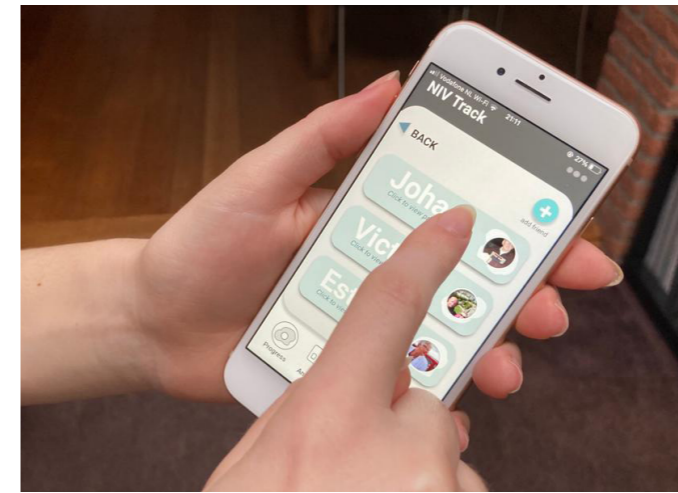
4) Wearing time



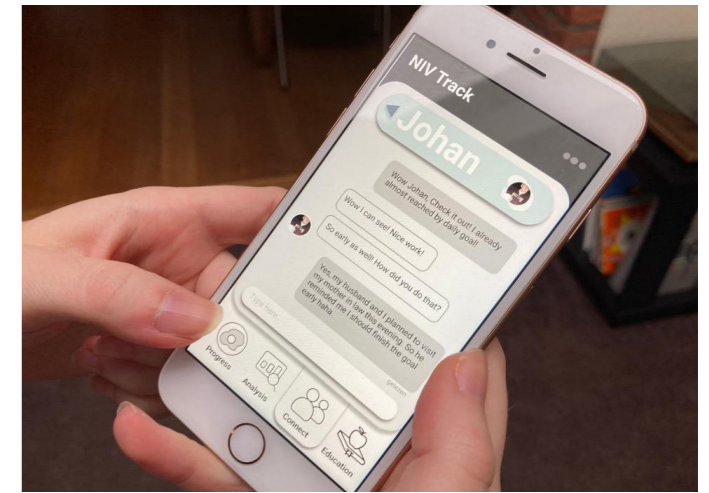
5) Noticing progress



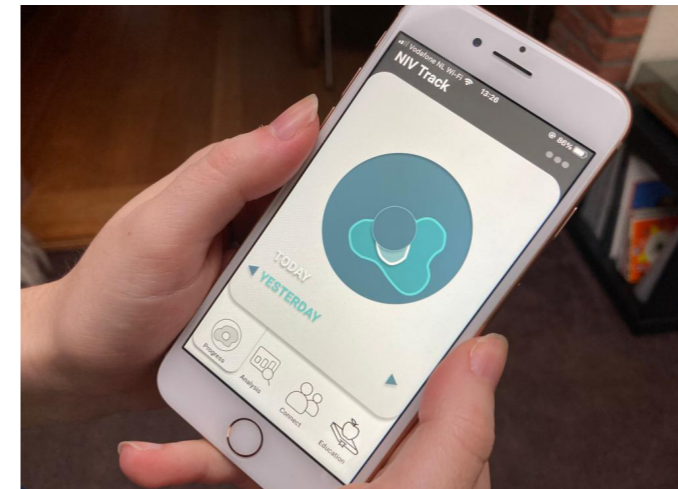
6) Opening app



7) Reaching out to buddy



8) Celebrate small victories



9) Compare with other dates



10) End of the day unfolding

USE SCENARIO

In the storyboard a scenario of use for the design concept can be seen. Here a user discusses her daily goal progress with her husband, this conversation motivates her to wear the mask in the afternoon (perhaps her husband reminded her of evening plans). After seeing how well she has progressed in her daily goal after a while, she excitedly opens her NIV track app to share this early completion of her daily goal with a fellow patient from her (online) support group, celebrating small victories. She also reflects back at how much closer she is already to reaching her daily goal today, in comparison to yesterday. At the end of the day the user physically unfolds the shape and has a moment of connection and reflection. If the user were to forget or does not want to participate in this reflection activity (today) the shape will automatically unfold again at midnight.

USER INTERVIEWS

Design Probe & Evaluation

Goal

The goal of the interviews was to both validate the concept and use it as a design probe to gain insights for concept improvement. I wanted to test my assumption that the data sculpture I introduced as 'AirCare' is a tool people would like to have in their house to explore their data and give them a sense of control. I used the interviews to validate the design and learn more about how effective 'AirCare' is in physicalizing the data through talking to users about e.g. their understanding of proportions, their ability to navigate through the app, etc.

Next to using these semi-structured interviews as concept validation, I also used the prototype as a design probe to start the conversation and learn more about how people would use 'AirCare', and their opinion on topics as "amount of data visualized", "privacy of physicalized data", and "what they expect to get out of the app".

Now validating long term behavior change is tricky. In the paper 'How to evaluate technologies for health behavior change in HCI research' researchers explain that demonstrating behavior change is often impossible but also unnecessary for making a meaningful contribution to HCI research. Especially when developing new technologies or in the early stages of design [63]. Instead, they propose that HCI contributions focus on efficacy evaluations that are tailored to the specific behavior-change intervention strategies (e.g. does it make a patient reflect on their actions? Does it spark conversations? etc) embodied in the system, as well as studying people's experiences with the technology.

Participants

I spoke with 5 participants about the data sculpture 'AirCare'. These participants were selected because of their similarity to my target users (COPD Patients using HNIV). The 5 participants were people between the ages of 40 and 65, that were following a strict diet at the 'Power Slim'. HNIV Patients are a hard to reach and vulnerable group, because I want to showcase the prototype I also want to visit the participants at home. However in the current covid-19 situation visiting this user group of severely ill lung patients is not responsible.

Because the questions I would like to have answered through this interview are more about the general principle of using the data sculpture to track daily goals, I did not have to burden this group to get the answers I want.

The participants following this very strict dietary restrictions are namely similar to my target users since they too have to set and keep up with daily goals (e.g. number of carbohydrates intake), they too go through this challenging process for their health alone (e.g. family and friends do not understand the daily struggles they run into), and can also feel social stigma since they are held back from participating in any social events centering around food (e.g. going out for dinner).

In the following segment the participants will be labeled as P1-5. The quotes have been translated to English since they were originally in Dutch.

Method & Analysis

The semi-structured interviews, each about 45 minutes in length, were audio-recorded and later transcribed after the participants gave explicit permission for this through signing the offered consent form (see appendix B). Next to audio-recording I took field notes about the behavior responses to interaction with the prototypes (data sculpture and app). These transcripts and field notes were analyzed by doing a thematic analysis in MAXQDA. During this analysis I clustered quotes according to their meaning. Then within these overarching clusters I defined sub-themes. The clusters were summarized and interpreted. Particularly significant quotes were translated, and pieces of text where I suspected there could be a difference between this user group and my target audience were marked.

The 6 overarching themes defined were: Motivation, Tracking, Understanding, Privacy, Social, and Reflection

Motivation

The main takeaways I got from this theme is that users **enjoy being able to see the impact of their behavior**. "I find it wonderful and satisfying to get rid of that black! so it feels like I'm doing something useful. It's also nice to be able to compare yourself every now and then!" (P1). The confrontation of their progress during the day is not seen as something negative as participants note that: "Being confronted with it is nice, I really want to work on it. Can see easily now, don't have to look up in app." (P3).

The fact that only a daily goal is physicalized is appreciated, "I like working with day goals because it's demotivating when I see that I've ruined my month goal already" (P3).

Design opportunity

However, a design opportunity arose when participants noted that because of the quite large daily goal, the black shape on the physicalization is also moving very slowly. "I have little patience, I want to see things happen, this fabric moves so slow" (P4).

Tracking:

The main takeaway in this theme was that participants want to track their behavior to get a better overview of how they are doing. However people are "lazy" and do not want to put too much effort in tracking.

"It would be wonderful to have such a device as a guideline, saves my space in my head. I know I can currently also write [the data I track] down but that is just too much effort. I just try to keep up with the numbers approximately in my head.." (P5).

Design opportunity

Make sure the patient can always recall old collected data when in conversation with a HCP. "I don't always track my daily data, but I try to do it as much as possible because it is nice to be able to look back on this when speaking to my health coach." (P1).

Theme's from analysis	Subthemes
Motivation	Confrontation <ul style="list-style-type: none">• Location
	Visible progress
	Joy
Tracking	maintenance
	Self-tracking <ul style="list-style-type: none">• precision
	Guideline
	Data input
Understanding	Benefits
	Milestones
	Notifications <ul style="list-style-type: none">• Timing• Sound• Light
	Precision data
Privacy	Illness
	Abstraction
	Location
Social	Lotgenoten/fellow patients
	Loneliness
Reflection	Family
	Active reflecting
	Goals

Figure 6: Identified themes

Understanding:

Within this theme I came to a similar design opportunity as in the 'motivation' theme. Participants understand the parameters easily and know in a glance what is happening. However they would appreciate more feedback from 'AirCare'. "I think this model would be nice for me, so I don't get fixated on exact numbers.. however it would be nice to get some encouragement for 'milestones' like a halfway point along the way" (P2).

Design opportunity

Improve moments of feedback, potentially work with notifications. "I would want to be notified of milestones like when I passed the halfway point! Then I would have a better sense of time and progress." (P2).

Privacy:

I spoke with participants about privacy of data through asking them at the start of the interview what they thought the function of this sculpture was. Guesses ranged from 'representing my current health' to 'alerting me of behavior by suddenly changing shape'. However none of them were correct. Afterwards I explained to them in the context in which it would be used (tracking a daily goal), now the design suddenly made sense.

"Nice that strangers don't see what it means. That means I can share what it is with certain people when I'm ready and willing to share this with them.

I don't want everyone who comes in to see that I'm sick. But I don't associate this with being sick or anything negative." (P1).

Design opportunity

Make sure the data represented stays private if perceived by a stranger. Also make sure the device keeps its artistic style and does not associate to medical equipment.

Social:

The main takeaways from this theme were that participants were very eager to get in contact with people in the same situation (lotgenoten), as well as being willing to share personal stories with them. "I really enjoy contact with fellow sufferers. motivates me when I see that others are doing well. can exchange tips among themselves. I am certainly willing to meet new people and share them with them." (P1). "Nice to share small proud moments that not fellow sufferers do not understand. It's harder to persevere if I can't talk about it, then I feel less alone in my problems." (P4).

Participants recognised that discussing their daily health goals with family members can be difficult since they don't want to be a burden. However they are willing to start that conversation. "A burden is lifted off your shoulders when family can help. Even if you don't dare to ask. With AirCare' you are "forced" to share more with others, talking is difficult but nice." (P5).

Design opportunity

Allow for patient-patient friendships to form through the app. People can keep up with each other and share small victories.

Reflection:

The main takeaway in this theme is that participants think that actively reflecting on your daily goals is nice, however it might not be something for every day. "This [reflection moment] sounds very nice! I do enjoy some mindfulness and personally unfolding at the end of the day seems like a meaningful reflective experience to me. I would prefer to do it myself than automatic." (P1). In opposition to: "I have a busy household and already know I will not remember to unfold the shape every evening." (P2).

Design opportunity

Offer options for personalization! Also make sure there is always the option to fall back on automatic unfolding at the end of the day, so the device can always continue to function at the start of a new day.

FEEDBACK & NOTIFICATIONS

How does the digital world make itself known to us if smart objects become an inherent part of our everyday environment? What can it say to us? How does it act such that we can recognize its intentions or how we can tap into the possibilities it has to offer to us?

Through the interviews I learned that some users would like to receive more information through the data sculpture then it is currently communicating. "The black shape moves very slowly over those 5 hours, how do I even know if it is activated when I just put my mask on?" (P3). I want to improve the feedback & feedforward 'AirCare' gives to tackle this issue, and improve user-product communication.

Based on the user interviews I determined 6 different occasions a notification can be used to improve the users experience. Which are visible in figure 7.

When considering different options for this communication of notifications I took the insight into account to not disturb the calm and praised exterior of the data sculpture. "I don't like the idea of getting visible notifications on the beautiful sculpture, then you can better just send them to my phone.. instead of me having to read some text on the wooden plate." (P3).

Sound

Using sound is a great way to communicate with the user without disrupting the calm and minimalistic look of the design. After all, sound does not need to be seen to be heard. It can be in the background, but when necessary also move into the focus of the user's attention. It can be continuous, discrete, directional, or more.

Through a conversation with Bart Hengeveld an expert from Eindhoven University of Technology in Sound Design. I gained more understanding of techniques that show how sound can be used to communicate with my users, in a more meaningful sense than a beep on a cellphone.

The sound design I created for 'AirCare' doesn't make use of spoken word because of the lack of interest in this that was expressed during the interviews "I don't like the idea of communication through spoken words, it is still my private info and I want to keep the power myself to determine who I will explain the meaning of the sculpture to and who not." (P4). However this can surely be an option for a more elderly audience, or an audience who solely uses the data sculpture without the app (because they might not possess a smartphone). The sound design was recorded on a keyboard and edited in Audacity.

Light

To create a visual notification without disturbance of the minimalistic feel of the data sculpture I wanted to work with surround lighting. Light signals from behind the wooden base plate will be visible on the wall. Through exploration with different codes on an addressable LED strip I programmed light signals to fit or (if the user prefers) replace the sound design. A video displaying the different sound and light effects can be seen on my portfolio website: kyarafasen.com

On/Off

Function: Communicate the start and end of tracking wearing time.

Sound: Full tune using call & response.

Light: The lighting flashes to signal the (de) activation of the data sculpture, the white light follows a gradual transition from off to bright to off again. Both the tune and the light signal last 5 seconds.

Grab attention

Function: An option based on the comment "If my mom would use this sculpture, I would have to manage the app on a distance since she doesn't have a smartphone. When I see in the she hasn't worn the mask today I want to be able to send her a notification to say HEY! time to put that mask on" (P1). Additionally the data sculpture can also recognize patterns in wearing time. If a patient is not wearing the mask at a time where they usually would, 'AirCare' can send them a "Grab attention" notification to alert the patient of this.

Sound: Call tune. Same tune as the call & response tune connected to the action "on/off", only now just the call part is playing. The call & response tune will be completed if the user activates the ventilator.

Light: A white light will blink for 5 seconds with approximately 1 blink per second.

Prideful reflection

Function: Make the experience of physically unfolding the shape and the end of the day and reflecting on your progress very enjoyable.

Sound: the principle of tension & release will be used here to build up to a satisfying moment of release when the complete shape is unfolded.

Light: Again the light will portray a joyful and playful mood by different bright colors fading into each other creating a rainbow effect that will play for the duration of the unfolding as well as 3 seconds after completion.

Progress

Function: Communicate the passing of an hour. Help motivate patients with smaller milestones in between their daily goal whilst offering them more insight in their progress.

"I like the abstract shape but I also would like to know when I'm halfway done and that is currently hard to tell." (P2).

Sound: A short uplifting tune will be played for 2 seconds

Light: A white light will go on, and stay on for 5 seconds before turning off again

Goal achieved

Function: Communicate the realization of the daily goal.

Sound: An elongated version of the progress tune will be played.

Lights: The light will portray a joyful and playful mood by different bright colors fading into each other creating a rainbow effect that will play for 5 seconds.

Buddy goal achieved

Function: communicate when a buddy contact of the user in the app has finished their daily goal. *"I would love to see how my buddies are doing during the day as well, it would make me feel less alone during my own day, knowing that they are out there doing the same." (P4).*

Sound: the same elongated version of the progress tune will be played as during the action "goal achieved" only this time the tune will be played in a different tone. Making use of a motif. If a user has multiple buddies, multiple different tones for the same tune can be used to resemble the different buddies.

Light: Faded low intensity rainbow effect will play for 5 seconds

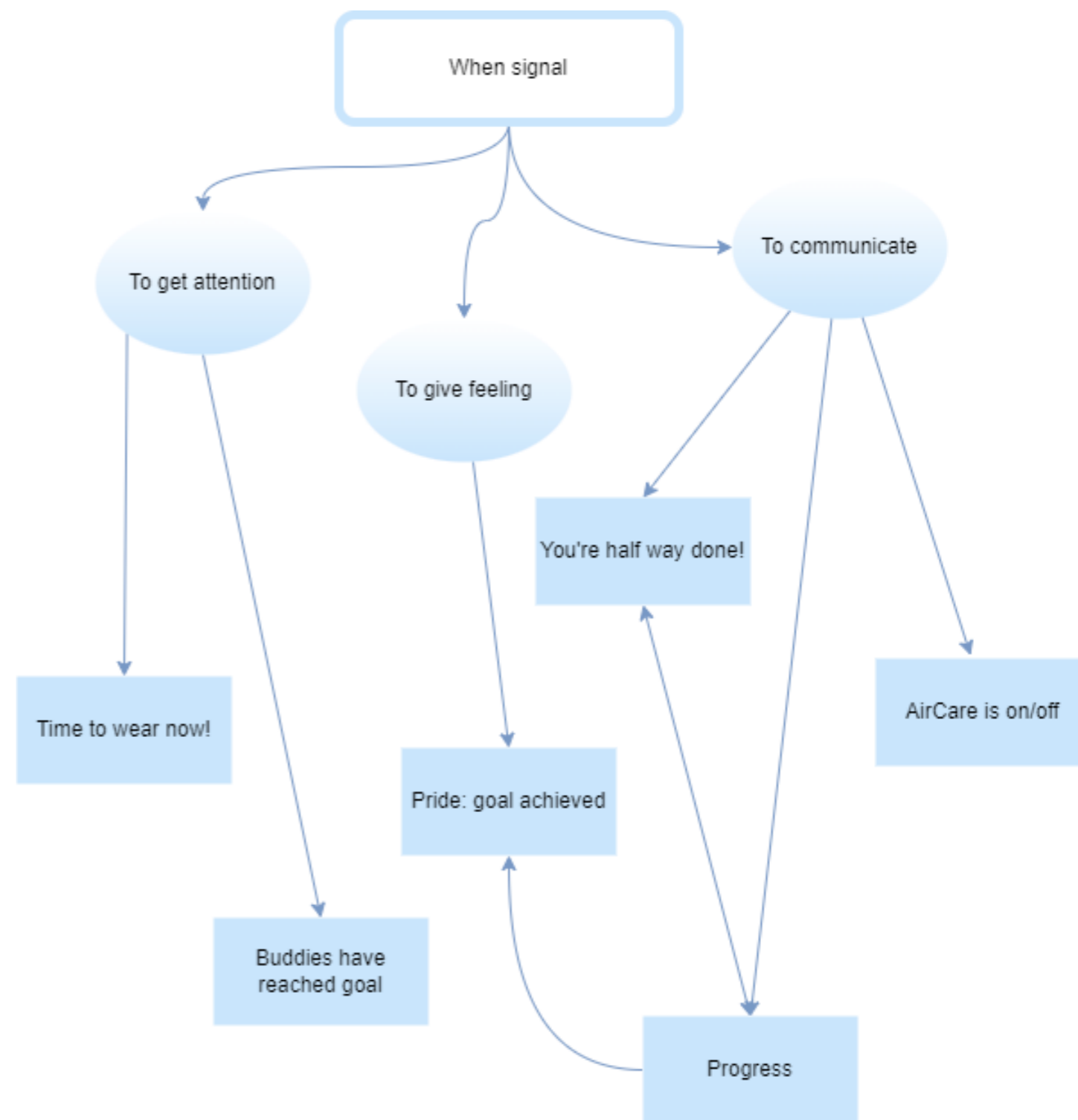


Figure 7: Types of signals

PERSONALIZATION

The interviews showed that wishes varied between people! Where some people did not want the data sculpture to give light signals, others loved this idea.

In the app people should be able to determine for themselves when they would like to receive notifications and through which medium (sound, light, both, none)

Personalization can also be achieved through offering different colors of wood and fabric.

EVALUATE WITH EXPERTS

To evaluate my refined concept I conducted expert interviews. I spoke with behavior change expert Panos Markopoulos and HNIV expert pulmonologist Dr. R. Sprooten. The main insights were: Validation and enthusiasm about the amount of data represented in the data sculpture, and tips for improvement of HCP involvement in the app.

Behavior change expert Panos Markopoulos from the Technical University of Eindhoven validated that behavior change techniques I gained from literature were correctly implemented in the design *"It is motivating to users when they get a tangible moment of reflection. Because examination and manipulation of physical objects can promote understanding and learning,"* explained Markopoulos. He also remarks how using a data physicalization is a nice way to have a proactive conversation starter while still respecting privacy, saying its unobtrusive but still easily perceived. Lastly he emphasizes the importance of the design having high aesthetic value, since *"if people don't want this in their living room. All else fails."*

With HCP Dr. R. Sprooten I spoke about the app and how he as a professional would like to be involved in this online platform opening up to the patient. Sprooten let me know that he is pleased by the idea of giving patients more handles to reflect on their goals and their progress within them. *"Before we start HNIV treatment we will always set goals with a patient what we want to work towards. From being able to walk longer distances, to feeling more awake during the day. However it is common for patients to forget these goals as time passes,"* noted Sprooten.

Sprooten expresses interest in being involved in this patient platform as a HCP as well. However there should be clear boundaries as to what patients can expect from HCP through the platform, to not create a false sense of overtrust thinking the HCP will always be aware of their current health status. *"I think I can speak for all healthcare personnel if I say we don't want to see all the data from every patient come in 24/7. That is overkill and only causes chaos,"* says Sprooten. Also for patients seeing too much information can cause chaos, *"Because they may all see things happening that they don't want to see or want to know at all. The more information you show patients. The more questions it raises. That is also why I think only communicating the number of hours of ventilation in the sculpture is the right move to create a sense of calmth."*

Design opportunity

Make it possible for patients to easily plan a video call session with a HCP through the app if they have a question. However, have the patient go through a questionnaire before this appointment is made to filter out questions that can already be answered by directing the patient to info under the 'education' tab in the app. This will make correct info easy to find in the app for patients, and saves HCP time.



TECHNICAL REALIZATION

ELECTRONICS

To determine how the concept can be realized I mapped out all the electronics that are involved in creating the data sculpture in a reliable and affordable way.

To create the retract and extend motion of the fabric, linear actuators can be used. For the prototype I would use 8 of them placed in a circular pattern on the bottom of the hollowed-out wooden base plate out of sight from the user. Attached to the moving part of this motor is a magnet. In the fabric, on the visible sight of the wooden base plate, there will also be magnets placed, aligning with the linear actuators.

Thus creating the seamless movement of the fabric, when the linear actuators move either inwards or outwards on the bottom of the plate. This same motion can be created by making slots in the wooden base plate through which the moving part of the linear actuators can move up and down, directly attached to the fabric. However, I have chosen to use magnets to not ruin the clean look of the baseplate with slots. This also promotes the idea of an organic movement, instead of having visual movement lines. The choice for the linear actuators is made to be able to create the organic asymmetric movement of the fabric black shape. I also looked at beautiful (un)folding shape options like the NASA solar power origami shape, however origami shapes are not a good fit to this prototype because of the irregularity of the (un)folding shape [64].

To keep the 8 linear actuators running, 4 motor drives need to be installed. This is because only 2 actuators can be connected to 1 motor drive. An Arduino Uno will be used to control the components.

If you are using the Arduino Uno a wifi/bluetooth shield will be needed to receive the wearing time data from the ventilator, since it does not have a built-in wifi receptor. The data received through this shield will be translated through the code installed in the Arduino to the movement of the actuators.

The unfolding motion of the fabric however is not solely triggered by the data received from the ventilator, but also by the user physically turning the middle knob, making the unfolding a reflection moment at the end of the day. A Potentiometer notices this turning movement and will in turn also trigger the linear actuators to move outwards, in a speed fitting to the turning motion.

Besides the organic movement of the fabric the data sculpture also communicates with its user through audio and light signals. Behind the base plate that is visible for the user, and on the bottom where the named components so far are placed, is the back plate of the prototype. This back plate can be easily attached to a wall by placing its hook over a screw in the wall. The sides of this back plate are lined with an addressable LED strip. This LED strip is also connected to the Arduino and can be programmed to give various light signals, depending on the data it receives from the wifi/Bluetooth shield. The same holds up for the speaker (MP3 Module) that is placed on the insight of the back plate. This speaker produces various audio cues, depending on the incoming data.

Lastly, the components used need to have a power supply. I recommend using external power sources, so the prototype does not need to be placed close to a wall outlet.

See appendix D for a more elaborate technical drawing and links to the materials mentioned in this paragraph.

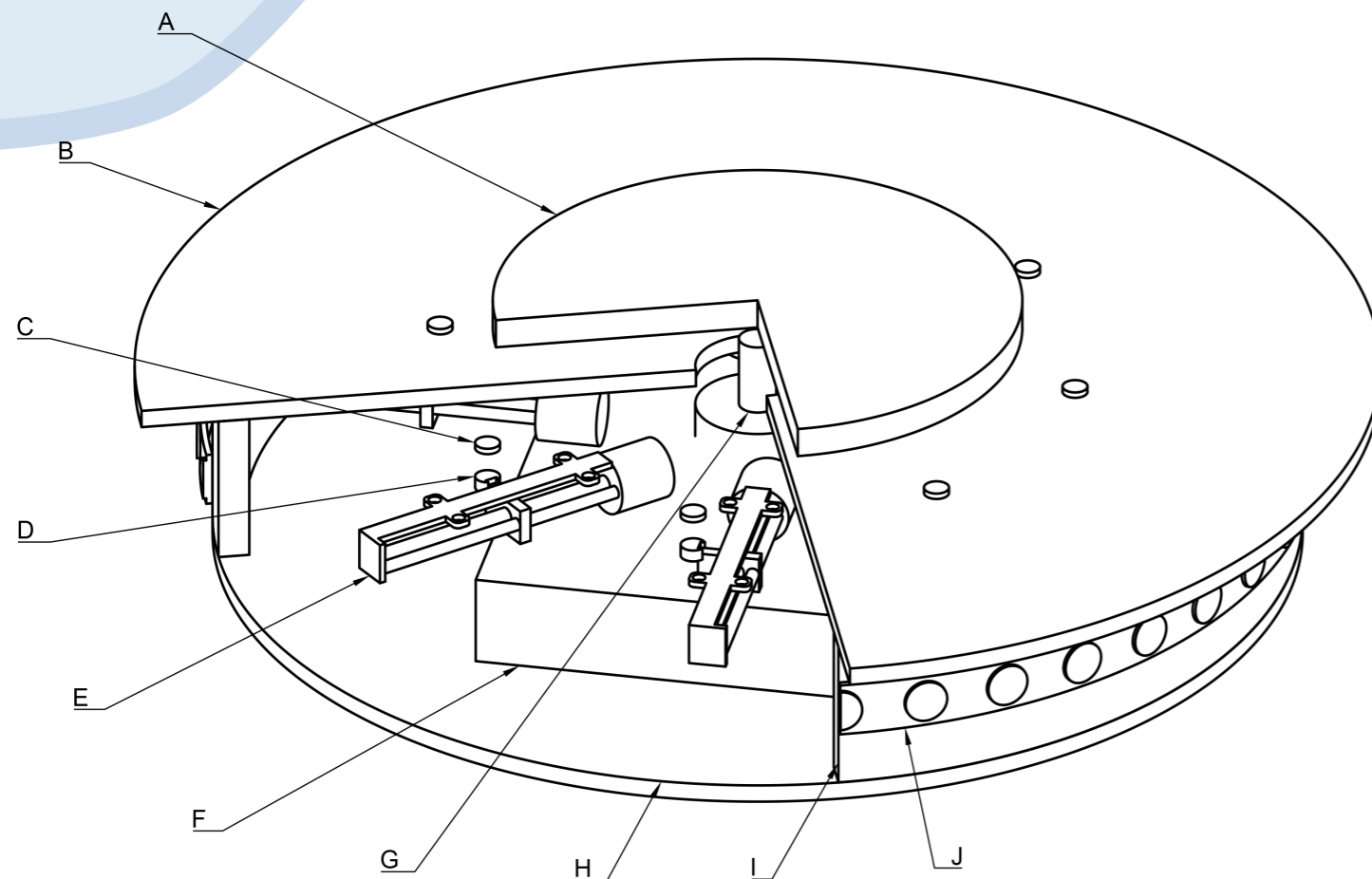


Figure 8:

- A)** Turn knob wood
- B)** Top plate wood
- C)** Top magnet (attached to fabric)
- D)** Bottom magnet (attached to linear actuator)
- E)** Linear actuator
- F)** Electronics housing
- G)** Potentiometer
- H)** Bottom plate
- I)** Side housing prototype
- J)** LED strip

MATERIALS

The data sculpture 'AirCare' can be constructed in several ways:

- *Plastic* has a low weight and is cheap to produce. However, the material is less durable and has a lower quality appearance as an eye-catcher in the living room;
- *Metal* such as aluminum also has a low weight, is particularly strong and easy to work with. However, it is less durable, expensive and more difficult to machine;
- *Wood* (with sufficient strength) has a higher weight, and requires more attention when processing. However, it is a very durable product, which with a beautiful and high-quality appearance is well suited to most interiors.

Because of these material characteristics and the insights I gained earlier from my interior design style card sort, I chose a wooden construction for 'AirCare'.

I used stretchy fabric to make the movement of the levers look like an organic shape. Fabric is one of the few materials with which making stretching and declining organic shapes possible. Another advantage of fabric is that it does not make sound as it moves and swirls over the wooden plate. As an alternative solution, I considered an LCD display (or digital screen). This offers even more possibilities for projecting all possible shapes, and allows easy color change. However, a screen also has important disadvantages;

- It is expensive (especially in a round shape);
- It does not give the impression of a qualitative element in the interior. Rather, it draws disproportionate attention as a "monitor" or "TV screen"

Sustainability

The construction of the AirCare consists largely of wood. This is a natural product where only the processing causes a low CO2 footprint. The turn knob and the top plate are made of sustainable European wood such as oak or beech. This provides a qualitative and luxurious look, that fits the users interior design wishes. For personal preferences these wooden plates can be shaded in different tones.

A choice for plastic (plastic) would lead to lower production costs, but would also take away from the quality of the appearance of 'AirCare' in the interior, and would lead to a higher CO2 load during production.

The fabric is made of durable elastic cotton and can, if the user would like to determine themselves, be supplied in various colors. Wood and fabric together provide a natural look with a material that fits well into any interior. These materials can also be produced responsibly.

The Arduino, linear actuators, motors and LED strip have a low energy consumption. This makes it possible to provide the energy with a battery. This allows the 'AirCare' to be placed wirelessly anywhere on a wall. A power supply with a battery is, however, less durable. If future work showcases that the wirelessness of 'AirCare' is not necessary for users, it can be decided to switch for battery usage to mains voltage. Mains voltage can be generated sustainably with wind energy or PV-panels.

VALUE FLOW MODEL

I create a Value Flow Model (figure 9) on the basis of a talk with a nurse specialist to depict specific network interactions and to provide a perspective on value-creating roles and relationships, as well as a dynamic view of how financial and non-financial assets are converted into value.

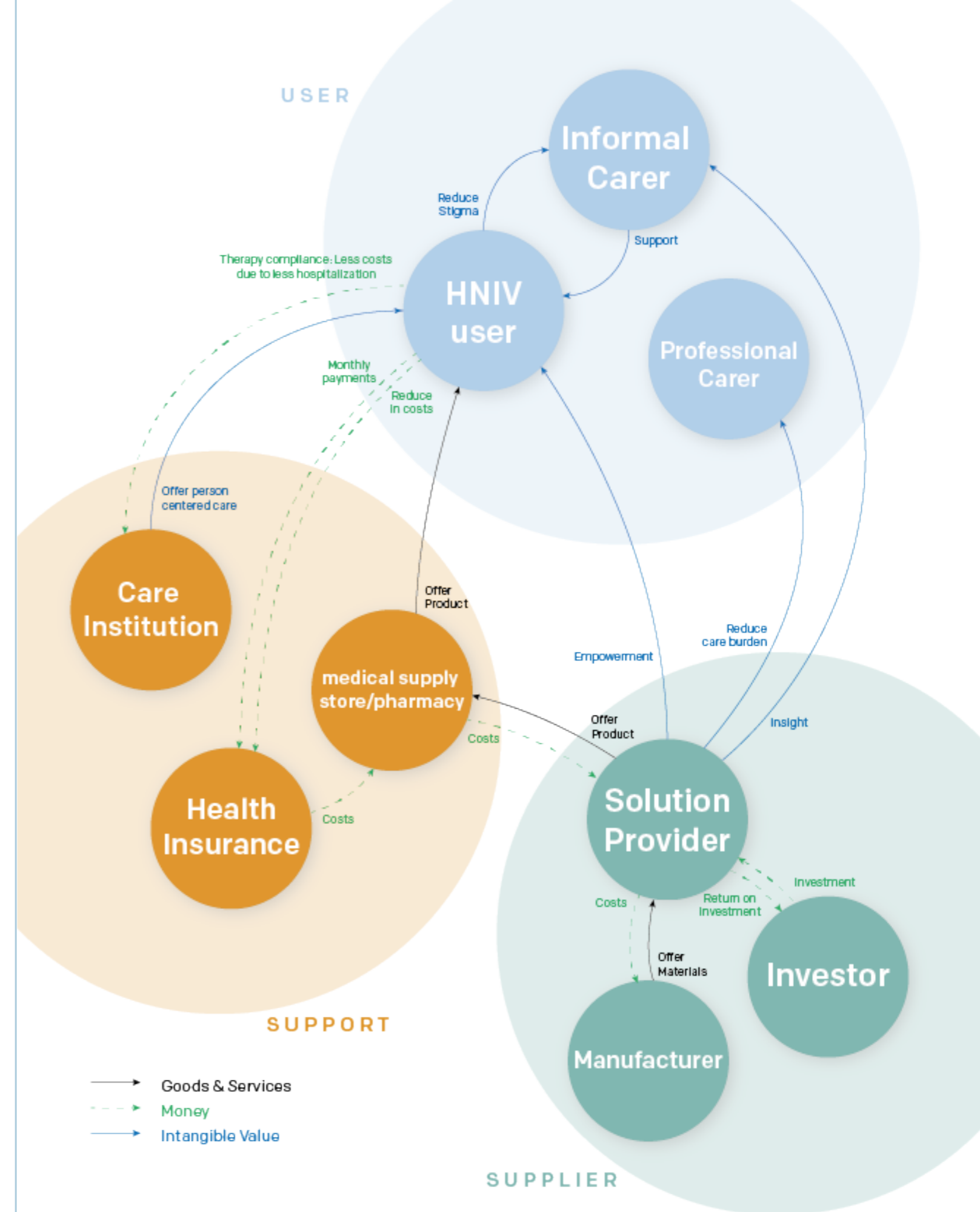


Figure 9: Value flow model



FINAL DESIGN

AirCare

To enhance COPD patient compliance for HNIV treatment I want to make the treatment more bearable. By giving the patient more confidence in their disease management and empowering them, I motivate the patient to reach daily personal goals. AirCare helps patients to get an improved sense of control and pride when it comes to their healthcare. The different aspects of AirCare play into these keywords in different ways.

The final design of AirCare is based on literature reviews, concept iterations and user/expert evaluations. It is a high quality prototype, suitable for evaluation in context with potential end users and stakeholders.

CONCEPT DESCRIPTION

'AirCare' is a pleasing feedback mechanism that gives users insight into their daily routines and the feeling of progress while assisting them in following HNIV treatment correctly. It is a data sculpture, aimed at making self-management easier, that visualizes how close users are to their daily goal of ventilation time. When the organic black shape has folded itself completely inwards, the goal has been achieved. The shape of the black fabric is thus an abstract representation of the users' data, communicating it to a public area, while still reserving their privacy. Because to the unknown beholder the shape will mean nothing. The abstract shape will also make sure users don't get fixated on the specific numbers, but rather give them the feeling of seeing their airways being "refreshed" again.

The design of 'AirCare' is based on insights from behavior change techniques and aims to motivate COPD patients each day. It does this first and foremost through creating moments of reflection, making invisible progress visible, and increasing performance satisfaction.

In addition 'AirCare' aims to relieve the stigma that is felt around talking about HNIV care, through sparking conversations about HNIV usage (goals) within families.

The final design of 'AirCare' consists of three important aspects. The physicalization of the wearing data, the tactile interaction and reflection, and the digital application.



TANGIBLE DESIGN & FUNCTIONALITIES

'AirCare' has a wooden base plate with an organically moving black fabric on top. The form of the data physicalization is based on styles participants rated the highest out of a series of interior art mood boards. The retraction of this fabric resembles the amount of time a user has already worn their mask today and how close they thus are to reaching their daily goal. It is noticeable that the shape however does not contract evenly, it namely retracts faster at the point of the hour of the current time (e.g. using AirCare at 3pm will result in the right side of the shape retracting faster, as this is the placement of 3pm on a normal clock). The shape gives the user insight into their daily wearing habits and routine.

These physical representations aim to help users explore and understand their data. Opposed to on-screen visualizations, data physicalizations can act as ambient data displays: which are always "on" and placed anywhere. Because they are physically placed in the house they also make the collected data visible to more people in the environment. Creating involvement of the family in the user's care. Loved ones can now more easily check in and stimulate discussions. Hanging a piece of art like this in your room thus serves as a public testimony to your willingness to change your behavior and allows the user to get feedback on this behavior. Now users no longer have to keep track of how long they've worn the mask today themselves.

At the end of the day the patient can choose to physically turn the wooden top knob to reset and unfold the artwork for a new day to come. Creating a moment of tactile interaction and reflection. The soft rounded edges of the knob invite the user to touch. By physically unfolding the artwork the patient can feel the effort they put in which is encouraged since bodily engagement can improve connectedness, pride, and reflection. Simulating not only reflection-in-action but also reflection-on-action.

The physical presence of the data is likely to trigger more moments to remind oneself of the progress of wearing through positive feedback. The art emits a homely atmosphere and avoids negative feelings patients may have towards medical equipment in their house. 'AirCare' communicates with its users through subtle light and sound signals, without disrupting the calm and satisfying exterior of the device.

DIGITAL APPLICATION

In addition to the data sculpture, users of AirCare can use an application on their smartphone to enrich the user's experience with AirCare.

The app makes it possible for users to compare their current shape, to for example the shape they had at this moment in time yesterday. The app can also be used for insight into more precise data or progress (under the 'Analysis' tab), connecting to other patients from the buddy system (under the 'Connect' tab), and finding answers to questions they run into (under the 'Education' tab).

In settings the user can personalize the app as well as the data sculpture. If the user does not want to work with certain app functionalities (e.g. more precise data under the 'Analysis' tab, because this might be overwhelming), they can disable this tab. It will no longer be visible on their home page, but can always be added again in settings. The same holds for personalization of the data sculpture, if a user wants to adjust their daily goal, or change the notification style, this can be done in the app. This function is added based on user interviews and the guidelines created in my M2.1 project.

The app is connected to AirCare but owning AirCare is not obligated to make use of the app. The application as an e-health portal works with or without using the data sculpture. Users not interested in the data sculpture can still make use of the functionalities of the app (e.g. tracking their daily goal) making it possible for all patients to have a central go-to portal for information.

This app can be managed by the patient or if necessary by an informal or professional caregiver. All designed screens for the app can be found in appendix C.



DISCUSSION & IMPROVEMENT

Throughout the process I have been in contact with several experts as well as potential users, who come close to my target group. However the only people who can really judge the effectiveness and useability of 'AirCare' are COPD patients who struggle with their usage of HNIV.

Due to the lack of COPD patients in my personal circles, hesitation to not involve patients unless absolutely necessary from HCP, extra suspicion due to covid-19, and the lack of replies on my social media posts it was in this time period impossible for me to talk with a patient directly about their personal situation. The sample of participants that do not match my target users one-on-one may have led to less accurate results. Still the results from the tests with the selected user group were assumed to hold for the target group as well because of the generality of the questions, but the accuracy of this still needs to be tested. Having a larger test pool with COPD patients will help to spot patterns and trends and might help improve the design of 'AirCare'.

Secondly, as can be read in chapter two, there are many directions a project addressing this design challenge could lead. I chose to work the data physicalization option out further because with my current understanding of the topic I believed this direction yielded the most valuable outcome. However one may wonder, is bringing data into our physical world forward thinking? Or is thinking backwards? In a future world where people live more and more online, perhaps physical objects will become outdated, and artificial reality was a more fruitful direction to go when designing for future care. Future work will have to determine the most likely future course of events through trend research and recognizing development patterns.

In addition one may also argue that the connected time of the internet we live in now, is not beneficial for the human psyche. Do we really want to flood ourselves with information constantly? By manipulating our physical world this flow of information can no longer be stopped by turning off your phone. Also this future work will have to determine what a future world is people want to live in. I personally predict this will depend on the importance of the information. Users in my interviews expressed they would want to be "bothered" by the constant presence of their goal progress, because they actively want to work on it for their health. However I think things like Facebook timelines have no place in the physical world.

FUTURE WORK

RESEARCH POSSIBILITIES

Longitudinal study

Enhancing patient compliance in chronic care is a process that can only be measured over a long period of time. In this design process I could not test on a long-term basis. Therefore my focus in this project mainly laid on the usability and aesthetic value of the tool. Nevertheless it is interesting for researchers to look into whether the usage of the tool will influence patient compliance positively, neutral, or negatively over time.

The current prototype is not yet suitable for a longitudinal study as the different components are not yet programmed to respond to each other. The audio, light, and movement is manipulated by me.

Involvement Family

Social connectedness has proven to be a very important theme within COPD patient compliance. However no family members have currently been involved in the interviews as I only spoke with/about direct users. I think it would be very interesting to also discuss with family members how they want to be involved in the chronic care of their loved one and how they experience the social stigma.

Hospital room of the future

In a more exploratory continuation of this project it would be interesting to consider redesigning the hospital room of the future. Users as well as experts expressed their delight over the aesthetic value of 'AirCare' noting that it "made you not feel ill". Does the aesthetic quality of a healthcare device have a positive effect on a patient's mood? And what would this mean for the aesthetic qualities of other healthcare devices currently being used/in development? Also is this a wish patients only have at home, or could the interior of the classic hospital room also be improved?

DESIGN POSSIBILITIES

There are four main aspects that possibly add value to the concept to be taken into account regarding future design possibilities.

App (E-health)

The main focus of the project layed on the development of the data sculpture and the general functions that should be available in an application, however the usability of this application still has a lot of room for further development. Since also the pulmonologist I interviewed expressed such interest in the development of an e-health platform, it can make a very interesting design project to develop the functionalities of this app further.

Social Connection

During the user interviews a participant suggested the following; "It may also be nice if I can celebrate the completion of the daily goal at the end of the day together with my buddies from the buddy system! The data sculpture could say something like: congrats! you all made it today!" They explained that this seemed nice to them because being happy for others is easier than being happy for yourself. But I can also imagine a shared goal can be beneficial for user motivation as well, as a user perhaps might not want to let the rest of the group down, and therefore completes their goals. All in all it would surely be interesting to explore how the buddy system can play a more prominent role in the design of 'AirCare'.

Data in the physical world

Our daily lives are becoming increasingly entangled in data, which can range from physical activity logs, to social media archives. These data points provide a new source of information that may be used to better understand ourselves and make positive changes in our life. It is interesting to explore further how healthcare data can be communicated to patients through their environment. How can physical data help patients to better understand their condition? And for what patient groups would this be beneficial?

The pulmonologist I interviewed also expressed his interest in exploring how designs like 'AirCare' could help patients also beyond the group of COPD HNIV.

Culture

Cultural aspects were not yet taken into account in our design process, such as the meaning of colors, the way of reading time, materials and shapes in different communities.

CONCLUSION

The goal of this project was to design a tool to enhance COPD patient compliance for HNIV treatment through user empowerment.

As an individual final master student, in cooperation with the Maastricht University medical Centrum (MUMC) and XinYing Zhao from Philips research, I developed 'AirCare'.

'AirCare' is a pleasing feedback mechanism that gives users more control in their disease management while assisting them in using the HNIV correctly, motivating them to reach (daily) goals and connecting patients to a support network.

Chronic Obstructive Pulmonary Disease (COPD) is the name of a progressive deterioration of a patient's lung function that causes breathlessness. COPD is a large contributor to the global burden of disease. As it is also an excessive health resource consumption and associated with high health costs worldwide.

COPD is incurable. Available treatments like Home Non-Invasive Ventilation (HNIV), on the other hand, can help relieve symptoms and avoid re-hospitalization. However through interviews and literature research I learned that following treatment guidelines (especially making the recommended amount of hours a day on the ventilator) can be difficult due to the loss of autonomy, the social stigma, and lack of knowledge. Patients find it difficult to combine healthcare and their daily life as they get easily swept up in day to day life and might also feel alone due to a perceived negative stigma around having to wear the mask in the company of others. Not properly understanding the importance of NIV or not recognizing their own progress is also part of the problem.

'AirCare' is the tool I created for this design opportunity of stimulating patient adherence. Aimed to empower patients through helping them gain an improved sense of control and pride when it comes to their healthcare management.

Does this mean the goal is met? A longitudinal study would be needed, as well as a larger test pool of COPD patients, to prove the effectiveness of 'AirCare' on user adherence over a longer period of time. However I do have proof collected in interviews that there is interest in the device and that my client and target users recognize it's potential.

This leads to me believing this device shows potential in helping these users to feel more competent in their disease management and improve user adherence. Where the interviewed pulmonologist currently notes that patients can feel lost in their daily care in between appointments, and can face a negative self image. Implementation of the device could make a large difference in giving the patient tools to feel more empowered and in control.

So yes, my goal is met. However there is always room for enhancement, you can read more about this in the discussion.

The development of 'AirCare' is of significance as there is not only a lack of a central place for patients to take back control over their disease management. But also a lack of non-digital supportive tools for this (not always digitally inclined) user group. Besides offering insight and control, 'AirCare' also open up the conversation around health care and replace feelings of stigma with pride.

With a global issue such as this one the concept holds a lot of potential and could possibly end up helping many people around the globe.





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I would like to take a moment to thank the coaches, and fellow students from the 3th floor of Atlas for their support, guidance, and inspiration. In particular I want to thank my graduation mentor Daniel Tetteroo for his valuable feedback throughout my process. Thank you for your flexibility, inspiring words, and encouragement.

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I also want to thank the different participants who participated in my interviews, questionnaires, and brainstorms. Your stories allowed me to get a better understanding of the real experience of living with chronic care, or showed me how lonely it can be to go through such a difficult process for your health on your own. Thank you for constantly reminding me why working on topics like these is important.

Without the (mental) support of the Graduation Group organized by V. Kuppens, I would surely not be standing here today. Thank you for all your encouragement for me to keep my spirit up even when things got dark. I look forward to spreading the things I learned here to the students I coach.

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APPENDIX

K.R. Fasen – FMP M2.2

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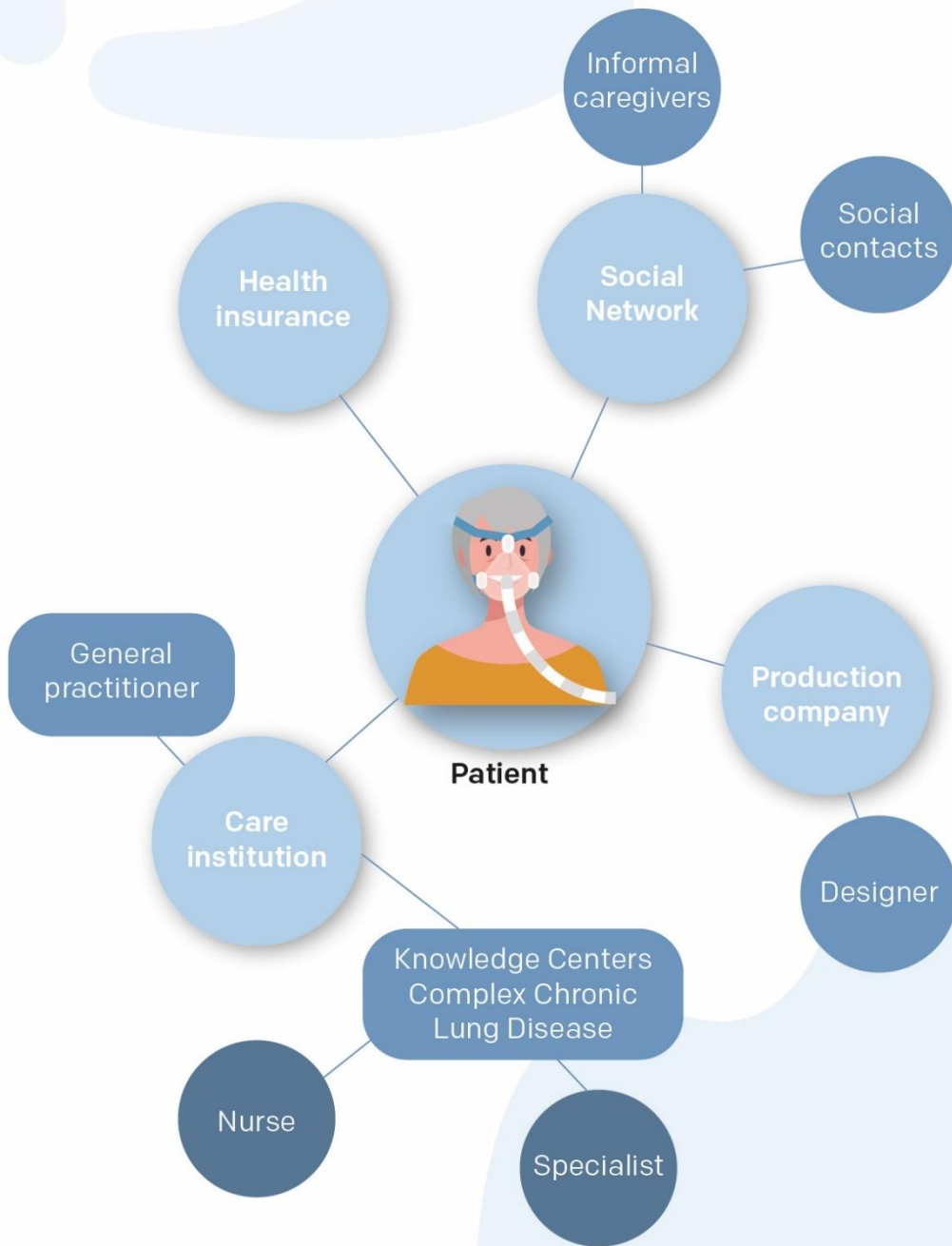
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APPENDIX A

FIGURES & VISUALS



TARGET USER



HOME NIV PATIENT ADHERANCE

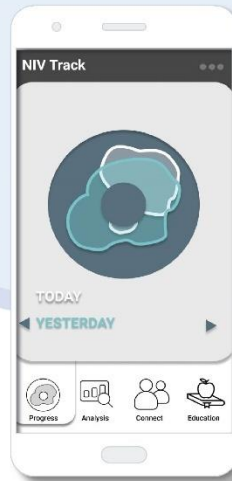
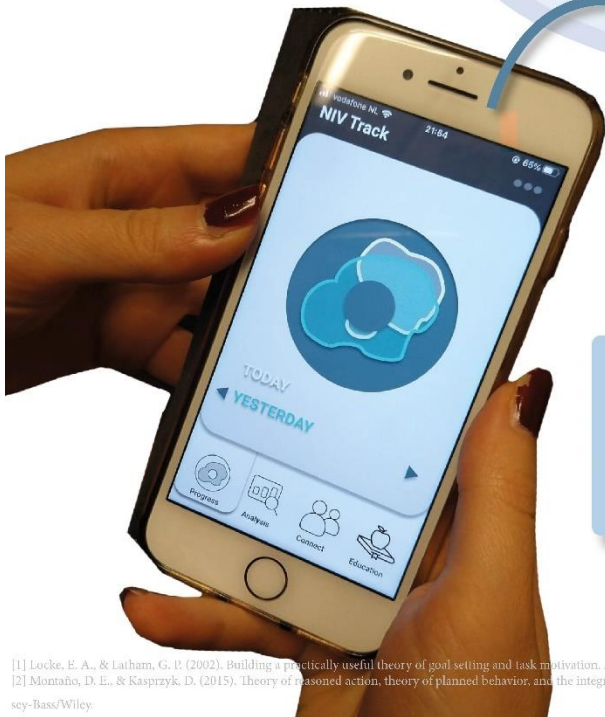


image reference: Man using NIV. Vita Laire, 15 December 2021,
<https://www.vitalaire.com.sa/ventilation/non-invasive-ventilation>

Conscious motivation affects performance positively and increases job satisfaction [1]

For goals to be effective, people need summary feedback that reveals progress in relation to their goals. [1]

Open discussions about wearing NIV within ones social circle and seeing others performing the same behavior creates favorable social norms, which work motivating [2]



[1] Locke, E. A., & Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. *The American psychologist*, 57(9), 705-717. <https://doi.org/10.1037//0003-066x.57.9.705>

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Bodily engagement can encourage connectedness, pride, and reflection [1]

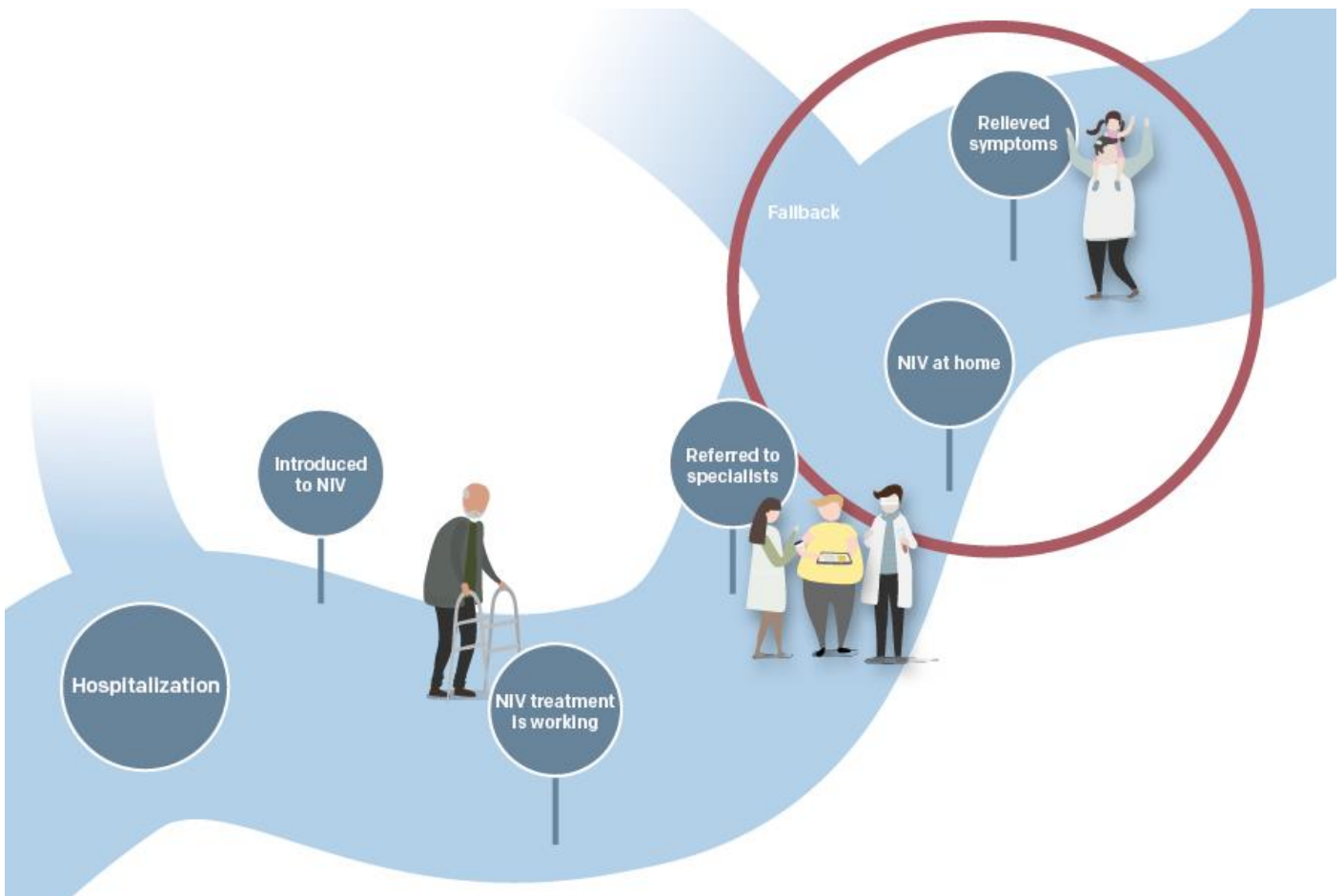
people feel more connected to their data if touched [1]

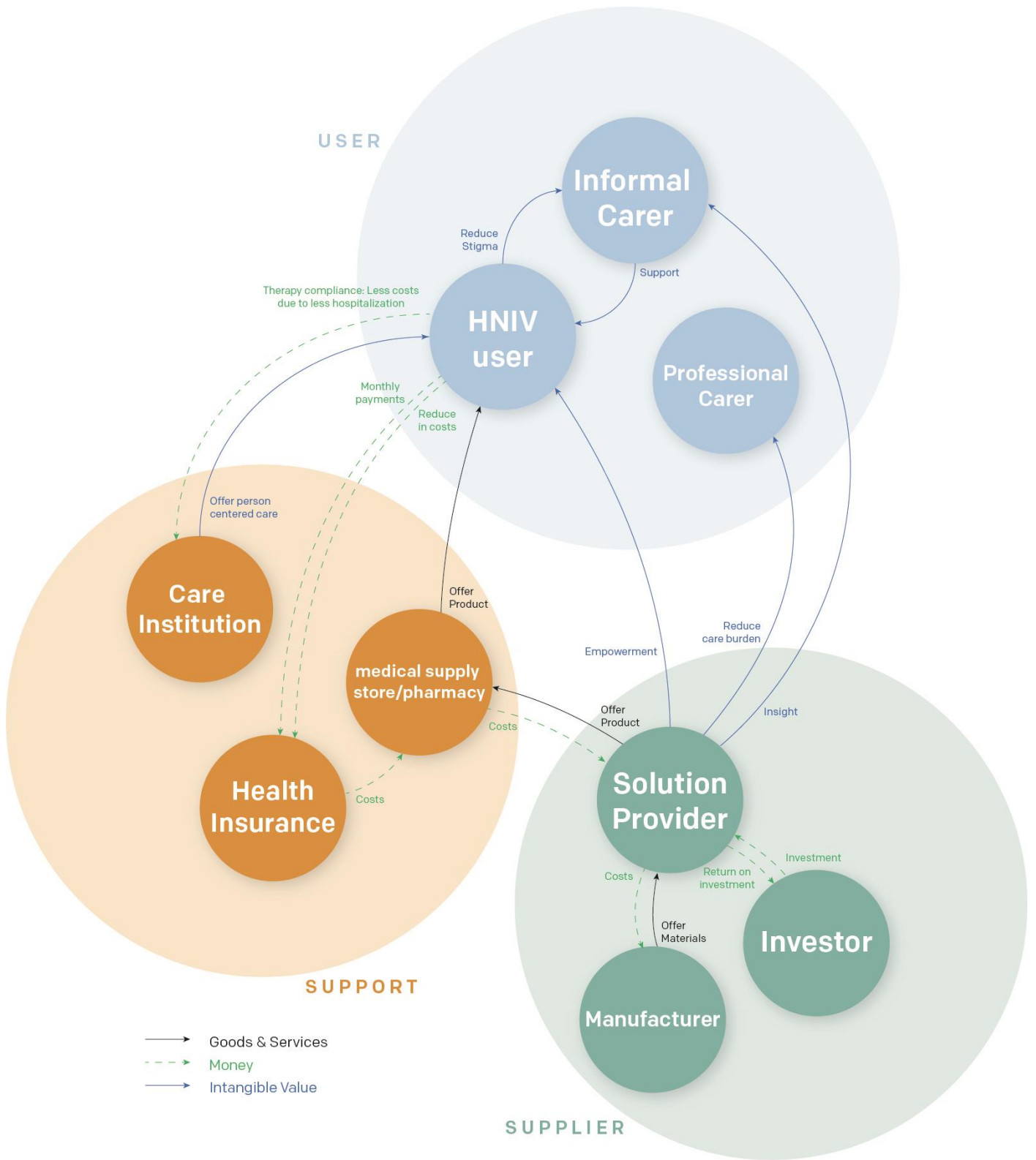
TURN KNOB TO RESET FOR NEW DAY

Physically feel the pressure you put in during the day



[1] Menheere, D., Van Hartingsveldt, E., Birkebaek, M., Vos, S., & Lallemand, C. (2021). Latina: Dynamic Data Physicalization for Slow Exercising Feedback. In *CHI 2021 - Proceedings of the 2021 ACM Designing Interactive Systems Conference: Nowhere and Everywhere* (pp. 1015-1030). Association for Computing Machinery, Inc. <https://doi.org/10.1145/3461778.3461841>





APPENDIX B

CONSENT FORMS

Informatie voor deelname aan wetenschappelijk onderzoek

Enhancing chronic obstructive pulmonary disease (COPD) patient compliance for home non-invasive ventilation (HNIV) treatment through user empowerment

Officiële Nederlandse titel:

Verbetering van de therapietrouw van patiënten met chronische obstructieve longziekte (COPD) voor niet-invasieve thuis beademing (HNIV) door middel van empowerment van gebruikers

Inleiding

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een wetenschappelijk onderzoek.

Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker om uitleg als u vragen heeft. U kunt er ook over praten met uw partner, vrienden of familie.

1. Algemene informatie

Situatie	Voorbeeld passage
Dit onderzoek is opgezet als een student project op de Technische Universiteit Eindhoven	Dit onderzoek is opgezet door Kyara Fasen en haar coach Daniel Tetteroo. Dit project wordt gedaan door Kyara Fasen als onderzoeksproject binnen haar master studie op Technische Universiteit van Eindhoven. Philips zal inzicht krijgen in de resultaten van dit onderzoek. Er is geen budget voor dit onderzoek vanuit de universiteit of Philips.

Voor deze fase van het onderzoek zijn deelnemers uit verschillen sectoren nodig die ervaring hebben met niet-invasieve thuis beademing (HNIV). Kyara Fasen zal kijken naar gebruikerservaringen om meer te weten te komen over de ervaringen en meningen van de gebruikersgroep door middel van kwalitatieve onderzoeksmethodes zoals interviews en focus groepen. Naar verwachting zullen 15 deelnemers meedoen.

2. Doel van het onderzoek

Het doel van dit onderzoek is de gezondheidszorg voor COPD patiënten te verbeteren.

Door meer te leren over de gebruikers ervaring van HNIV kan Kyara Fasen tijdens dit project een ontwerp maken dat deze gebruikers ervaring kan verbeteren. Door feedback op dit design concept te krijgen kan Kyara dit ontwerp optimaliseren voor de gebruikersgroep.

3. Wat meedoen inhoudt

Tijdens het onderzoek zal het volgende gebeuren:

- Kyara Fasen zal met u in gesprek gaan over HNIV.
- Hierin zullen onderwerpen zoals de ervaring van uw patiënten met HNIV en uw mening over mogelijke ideeën die Kyara heeft om deze gebruikers ervaring te verbeteren aan bod komen.
- Dit gesprek zal opgenomen worden, zodat Kyara de opname later kan terug luisteren en aantekeningen van inzichten kan maken.
- De inzichten uit dit gesprek zullen verwerkt worden in het onderzoeksverslag van Kyara Fasen.
- Als u toestemming geeft zullen er mogelijk foto's worden gemaakt. (Wel of niet toestemming geven is niet van invloed op deelname)
- Quotes van u (anoniem) kunnen terechtkomen in verslag.

Het interview zal naar inschatting 30 minuten duren.

4. Wat wordt er van u verwacht

Om het onderzoek goed te laten verlopen is het belangrijk dat u open antwoord geeft op de vragen en uw ervaringen en kennis deelt.

Het is belangrijk dat u contact opneemt met de onderzoeker:

- als u niet meer wilt meedoen aan het onderzoek.

5. Potentiële risico's en ongemakken

Er zijn geen fysieke, juridische of economische risico's verbonden aan uw deelname aan deze studie. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig. Dit betekent dat u uw deelname op elk gewenst moment mag stoppen door dit te melden bij de onderzoeker. U hoeft niet uit te leggen waarom u wilt stoppen met deelname aan het onderzoek.

6. Als u niet wilt meedoen of wilt stoppen met het onderzoek

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft niet te zeggen waarom u stopt. Wel moet u dit direct melden aan de onderzoeker.

De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

7. Einde van het onderzoek

Uw deelname aan het onderzoek stopt als

- u zelf kiest om te stoppen
- aan het einde van het interview
- de onderzoeker het beter voor u vindt om te stoppen

Het hele onderzoek is afgelopen als alle deelnemers klaar zijn.

8. Gebruik en bewaren van uw gegevens

Voor dit onderzoek worden enkele van uw persoonsgegevens gebruikt en bewaard. Het gaat om gegevens zoals uw naam, functie en contactgegevens. Maar ook een audio opnamen die gemaakt wordt tijdens het gesprek. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden. Wij vragen voor het gebruik van uw gegevens uw toestemming. Deze gegevens zullen na afronding van het onderzoek weer verwijderd worden.

Vertrouwelijkheid van uw gegevens

Wij doen er alles aan uw privacy zo goed mogelijk te beschermen. De onderzoeksresultaten die gepubliceerd worden zullen op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u bevatten waardoor iemand u kan herkennen. Tenzij u in ons toestemmingsformulier expliciet toestemming heeft gegeven voor het vermelden van uw naam, bijvoorbeeld bij een quote.

De persoonsgegevens die verzameld zijn via bijvoorbeeld audio-opnamen, formulieren en andere documenten in het kader van deze studie, worden opgeslagen op een beveiligde locatie bij de Technische Universiteit Eindhoven zoals Sharepoint en op de storage solutions die aangeboden worden door de afdeling IMS van de TU/e.

Toegang tot uw gegevens voor controle

Sommige personen kunnen op de onderzoek locatie toegang krijgen tot alle gegevens. Dit is nodig om te kunnen controleren of het onderzoek goed en betrouwbaar is uitgevoerd. Personen die ter controle inzage krijgen in uw gegevens zijn Kyara Fasen en haar project coach Daniel Tetteroo in naam van de universiteit. Zij houden uw gegevens geheim. Wij vragen u voor deze inzage toestemming te geven.

Bewaartermijn gegevens

Na succesvolle afronding van het onderzoeksproject zullen uw gegevens verwijderd worden.

Intrekken toestemming

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens

Dit onderzoek wordt uitgevoerd vanuit de Technische Universiteit Eindhoven en is de verwerkingsverantwoordelijke in de zin van de AVG. Indien u specifieke vragen hebt over de omgang met persoonsgegevens kun u deze ook richten aan de functionaris gegevensbescherming van de TU/e door een mail te sturen naar functionarisgegevensbescherming@tue.nl. U hebt daarnaast het recht om een klacht in te dienen bij de Autoriteit Persoonsgegevens.

Tot slot heeft u het recht een verzoek tot inzage, wijziging, verwijdering of aanpassing van uw gegevens te doen. Ga voor meer informatie naar <https://www.tue.nl/storage/privacy/>. Dien uw verzoek daartoe in via privacy@tue.nl.

9. Heeft u vragen?

Bij vragen kunt u contact opnemen met Kyara Fasen.

Indien u klachten heeft over het onderzoek, kunt u dit bespreken met de onderzoeker. Wilt u dit liever niet, dan kunt u zich wenden tot haar supervisor Daniel Tetteroo of een dataprotection officer.

Alle gegevens vindt u in **bijlage A**: Contactgegevens.

10. Ondertekening toestemmingsformulier

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek.

Het handtekeningenblad wordt door de onderzoeker bewaard. Zowel uzelf als de onderzoeker ontvangen een getekende versie van deze toestemmingsverklaring.

Dank voor uw aandacht.

Bijlage A: Contactgegevens

Investigator

Name: Kyara Fasen

Phone: +31 (0)623443719

Email: k.r.fasen@student.tue.nl

Department: Industrial Design

Section: Master student

Address:

Technische Universiteit Eindhoven

P.O. Box 513

5600 MB EINDHOVEN

Complaints

Name: dr.ir. D. Tetteroo

Email: D.Tetteroo@tue.nl

Data Protection Officer of the institution

B.J.A. Schellekens LL.M.

Data protection officer

dataprotectionofficer@tue.nl

+31 (0)40 247 3809

Bijlage B: toestemmingsformulier deelnemer

Verbetering van de therapietrouw van patiënten met chronische obstructieve longziekte (COPD) voor niet-invasieve thuis beademing (HNIV) door middel van empowerment van gebruikers

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het gebruiken van mijn opmerkingen tijdens het interview voor de beantwoording van de onderzoeksvraag in dit onderzoek
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn gegevens kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor die inzage door deze personen.

- Ik geef
 - wel**
 - geen**toestemming om de persoonsgegevens die gedurende het onderzoek bij mij worden verzameld te verwerken zoals is opgenomen in het bijgevoegde informatieblad.

- Ik geef
 - wel**
 - geen**toestemming om mijn antwoorden te gebruiken voor quotes in de onderzoekspublicaties

- Ik geef
 - wel**
 - geen**toestemming dat Kyara Fasen een audio opname mag maken van het tijdens het interview en mijn antwoorden uit mag werken in een transcript. En weet dat deze verwijderd zal worden na afsluiting van het onderzoek.

- Ik geef
 - wel**
 - geen**toestemming om mijn naam en werkgever te delen in de onderzoekspublicaties

- Ik wil meedoen aan dit onderzoek.

Naam deelnemer:

Handtekening:

Datum : __ / __ / __

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: __ / __ / __

De deelnemer krijgt een volledige informatiebrief mee, samen met een versie van het getekende toestemmingsformulier.

Informatie voor deelname aan wetenschappelijk onderzoek

Enhancing chronic obstructive pulmonary disease (COPD) patient compliance for home non-invasive ventilation (HNIV) treatment through user empowerment

Officiële Nederlandse titel:

Verbetering van de therapietrouw van patiënten met chronische obstructieve longziekte (COPD) voor niet-invasieve thuis beademing (HNIV) door middel van empowerment van gebruikers

Inleiding

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een wetenschappelijk onderzoek.

Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker om uitleg als u vragen heeft. U kunt er ook over praten met uw partner, vrienden of familie.

11. Algemene informatie

Situatie	Voorbeeld passage
Dit onderzoek is opgezet als een student project op de Technische Universiteit Eindhoven	Dit onderzoek is opgezet door Kyara Fasen en haar coach Daniel Tetteroo. Dit project wordt gedaan door Kyara Fasen als onderzoeksproject binnen haar master studie op Technische Universiteit van Eindhoven. Philips zal inzicht krijgen in de resultaten van dit onderzoek. Er is geen budget voor dit onderzoek vanuit de universiteit of Philips.

Voor deze fase van het onderzoek zijn deelnemers uit verschillen sectoren nodig die ervaring hebben met niet-invasieve thuis beademing (HNIV). Kyara Fasen zal kijken naar gebruikerservaringen om meer te weten te komen over de ervaringen en meningen van de gebruikersgroep door middel van kwalitatieve onderzoeksmethodes zoals interviews en focus groepen. Naar verwachting zullen 15 deelnemers meedoen.

12. Doel van het onderzoek

Het doel van dit onderzoek is de gezondheidszorg voor COPD patiënten te verbeteren.

Door meer te leren over de gebruikers ervaring van HNIV kan Kyara Fasen tijdens dit project een ontwerp maken dat deze gebruikers ervaring kan verbeteren. Door feedback op dit design concept te krijgen kan Kyara dit ontwerp optimaliseren voor de gebruikersgroep.

13. Wat meedoen inhoudt

Tijdens het onderzoek zal het volgende gebeuren:

- Kyara Fasen zal met u in gesprek gaan over HNIV.
- Hierin zullen onderwerpen zoals uw ervaring met HNIV en uw mening over mogelijke ideeën die Kyara heeft om deze gebruikers ervaring te verbeteren aan bod komen.
- Dit gesprek zal opgenomen worden, zodat Kyara de opname later kan terug luisteren en aantekeningen van inzichten kan maken.
- De inzichten uit dit gesprek zullen verwerkt worden in het onderzoeksverslag van Kyara Fasen.
- Als u toestemming geeft zullen er mogelijk foto's worden gemaakt. (Wel of niet toestemming geven is niet van invloed op deelname)
- quotes van u (anoniem) kunnen terechtkomen in verslag.

Het interview zal naar inschatting 30 minuten duren.

14. Wat wordt er van u verwacht

Om het onderzoek goed te laten verlopen is het belangrijk dat u open antwoord geeft op de vragen en uw ervaringen en kennis deelt.

Het is belangrijk dat u contact opneemt met de onderzoeker:

- als u niet meer wilt meedoen aan het onderzoek.

15. Potentiële risico's en ongemakken

Er zijn geen fysieke, juridische of economische risico's verbonden aan uw deelname aan deze studie. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig. Dit betekent dat u uw deelname op elk gewenst moment mag stoppen door dit te melden bij de onderzoeker. U hoeft niet uit te leggen waarom u wilt stoppen met deelname aan het onderzoek.

16. Als u niet wilt meedoen of wilt stoppen met het onderzoek

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft niet te zeggen waarom u stopt. Wel moet u dit direct melden aan de onderzoeker.

De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

17. Einde van het onderzoek

Uw deelname aan het onderzoek stopt als

- u zelf kiest om te stoppen
- aan het einde van het interview
- de onderzoeker het beter voor u vindt om te stoppen

Het hele onderzoek is afgelopen als alle deelnemers klaar zijn.

18. Gebruik en bewaren van uw gegevens

Voor dit onderzoek worden enkele van uw persoonsgegevens gebruikt en bewaard. Het gaat om gegevens zoals uw naam en contactgegevens, maar ook een audio opnamen die gemaakt wordt tijdens het gesprek. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden. Wij vragen voor het gebruik van uw gegevens uw toestemming. Deze gegevens zullen na afronding van het onderzoek weer verwijderd worden.

Vertrouwelijkheid van uw gegevens

Wij doen er alles aan uw privacy zo goed mogelijk te beschermen. De onderzoeksresultaten die gepubliceerd worden zullen op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u bevatten waardoor iemand u kan herkennen. , tenzij u in ons toestemmingsformulier expliciet toestemming heeft gegeven voor het vermelden van uw naam, bijvoorbeeld bij een quote.

De persoonsgegevens die verzameld zijn via bijvoorbeeld audio-opnamen, formulieren en andere documenten in het kader van deze studie, worden opgeslagen op een beveiligde locatie bij de Technische Universiteit Eindhoven zoals Sharepoint en op de storage solutions die aangeboden worden door de afdeling IMS van de TU/e.

Toegang tot uw gegevens voor controle

Sommige personen kunnen op de onderzoek locatie toegang krijgen tot alle gegevens. Dit is nodig om te kunnen controleren of het onderzoek goed en betrouwbaar is uitgevoerd. Personen die ter controle inzage krijgen in uw gegevens zijn Kyara Fasen en haar project coach Daniel Tetteroo in naam van de universiteit. Zij houden uw gegevens geheim. Wij vragen u voor deze inzage toestemming te geven.

Bewaartermijn gegevens

Na succesvolle afronding van het onderzoeksproject zullen uw gegevens verwijderd worden.

Intrekken toestemming

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens

Dit onderzoek wordt uitgevoerd vanuit de Technische Universiteit Eindhoven en is de verwerkingsverantwoordelijke in de zin van de AVG. Indien u specifieke vragen hebt over de omgang met persoonsgegevens kun u deze ook richten aan de functionaris gegevensbescherming van de TU/e door een mail te sturen naar functionarisgegevensbescherming@tue.nl. U hebt daarnaast het recht om een klacht in te dienen bij de Autoriteit Persoonsgegevens.

Tot slot heeft u het recht een verzoek tot inzage, wijziging, verwijdering of aanpassing van uw gegevens te doen. Ga voor meer informatie naar <https://www.tue.nl/storage/privacy/>. Dien uw verzoek daartoe in via privacy@tue.nl.

19. Heeft u vragen?

Bij vragen kunt u contact opnemen met Kyara Fasen.

Indien u klachten heeft over het onderzoek, kunt u dit bespreken met de onderzoeker. Wilt u dit liever niet, dan kunt u zich wenden tot haar supervisor Daniel Tetteroo of een dataprotection officer.

Alle gegevens vindt u in **bijlage A**: Contactgegevens.

20. Ondertekening toestemmingsformulier

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen. Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek.

Het handtekeningblad wordt door de onderzoeker bewaard. Zowel uzelf als de onderzoeker ontvangen een getekende versie van deze toestemmingsverklaring. Dank voor uw aandacht.

Bijlage A: Contactgegevens

Investigator

Name: Kyara Fasen

Phone: +31 (0)623443719

Email: k.r.fasen@student.tue.nl

Department: Industrial Design

Section: Master student

Address:

Technische Universiteit Eindhoven

P.O. Box 513

5600 MB EINDHOVEN

Complaints

Name: dr.ir. D. Tetteroo

Email: D.Tetteroo@tue.nl

Data Protection Officer of the institution

B.J.A. Schellekens LL.M.

Data protection officer

dataprotectionofficer@tue.nl

+31 (0)40 247 3809

Bijlage B: toestemmingsformulier deelnemer

Verbetering van de therapietrouw van patiënten met chronische obstructieve longziekte (COPD) voor niet-invasieve thuis beademing (HNIV) door middel van empowerment van gebruikers

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het gebruiken van mijn opmerkingen tijdens het interview voor de beantwoording van de onderzoeksvraag in dit onderzoek
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn gegevens kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor die inzage door deze personen.

- Ik geef
 - wel**
 - geen**toestemming om de persoonsgegevens die gedurende het onderzoek bij mij worden verzameld te verwerken zoals is opgenomen in het bijgevoegde informatieblad.

- Ik geef
 - wel**
 - geen**toestemming dat Kyara Fasen foto's mag maken tijdens het interview. En deze mag gebruiken in haar rapportage.

- Ik geef
 - wel**
 - geen**toestemming dat Kyara Fasen een audio opname mag maken van het tijdens het interview en mijn antwoorden uit mag werken in een transcript. En weet dat deze verwijderd zal worden na afsluiting van het onderzoek.

- Ik geef
 - wel**
 - geen**toestemming om mijn antwoorden te gebruiken voor quotes in de onderzoekspublicaties – zonder dat daarbij mijn naam wordt gepubliceerd.

- Ik wil meedoen aan dit onderzoek.

Naam deelnemer:

Handtekening:

Datum : __ / __ / __

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: __ / __ / __

De deelnemer krijgt een volledige informatiebrief mee, samen met een versie van het getekende toestemmingsformulier.

APPENDIX C

PROCESS



Mom Mia

55 y/o

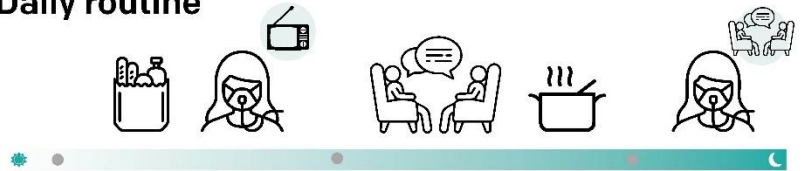
Caring
Sensitive
Low Energy

Wants to still be seen as her cheerful normal self

"I don't want to sit there like a sack of potatoes, I'll come to the living room when I can be my normal chatty self."

Mia is the mom of 3 young adults, living at home. With her youngest son being 15 and her oldest daughter being 21. Mia has recently started using HNIV in the hope to get more energy during the day and prevent hospitalization. With such a busy household she often isolates herself during her treatment to find some peace and to feel less awkward. However it's a big loss to her she can't be as social as she used to be.

Daily routine

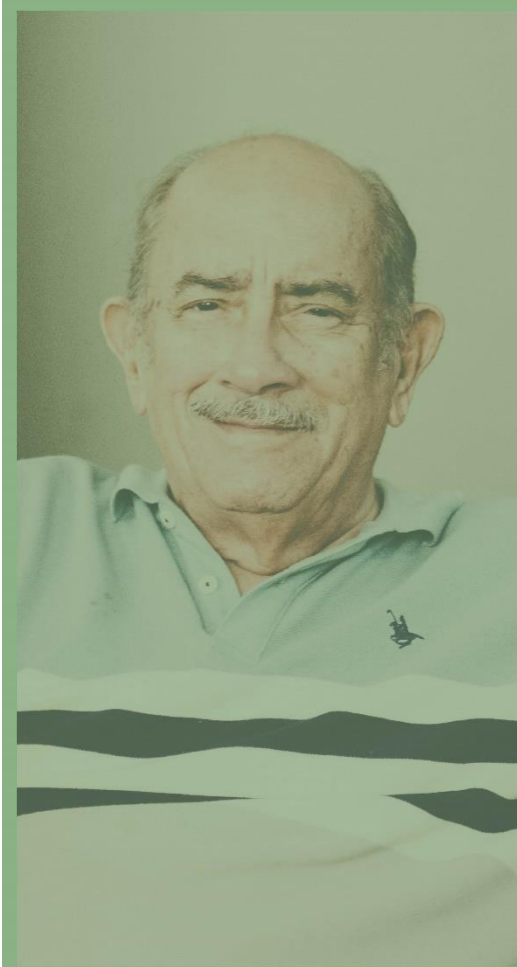


GOALS:

- Feel part of the family life
- Partake in social activities
- Maintain social relationships

FRUSTRATIONS:

- Has to wear the mask for long amounts of time
- Low energy
- Can't speak with mask on



Elderly Ed

82 y/o

Distrust technology
Self-reliant

Dislikes wearing the mask

"Oh dear I'm not sure how long I've worn it already today, but I'm fairly certain its been a few hours already. Must be enough for today."

Ed is living alone in his apartment since his partner passed away. Since two years he has to use NIV during the day and at night at home. But he isn't a big fan. Not only is wearing the mask uncomfortable, he also finds it a scary realization to be so reliant on a piece of technology. Using it when he is home alone is also scary, cause it triggers feelings of claustrophobia. He therefor likes to go to the common room of the apartment building with the machine and sit there.

Daily routine

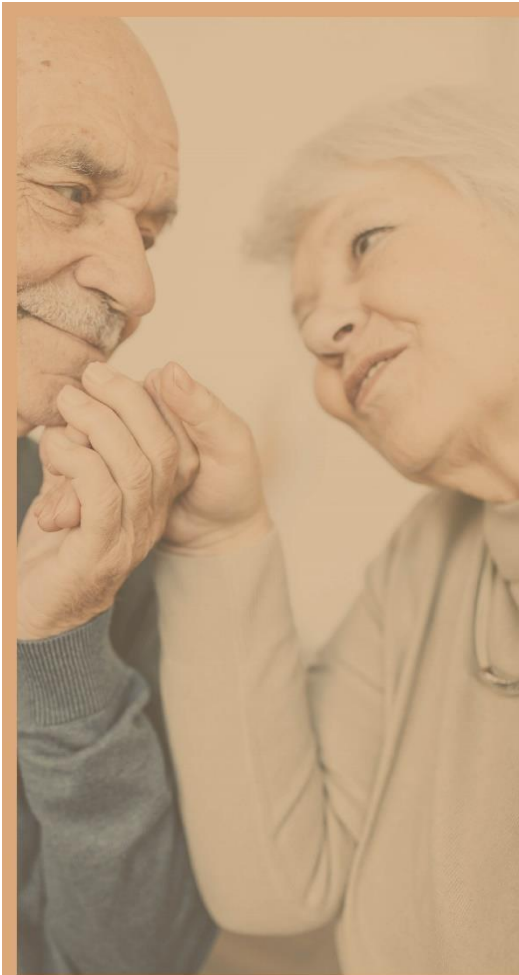


GOALS:

- Stay healthy
- Have confidence in health plan

FRUSTRATIONS:

- Mask is uncomfortable
- Scared to depend on technology he doesn't understand
- Bad time estimation



Wife Wendy

66 y/o

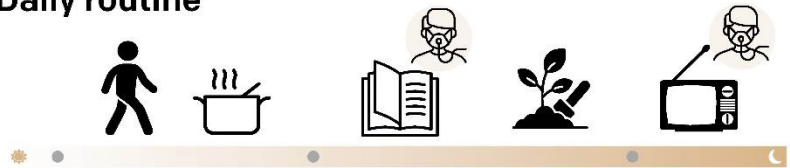
Caring
Empathic
Active

Wants to enjoy life with her husband

"Look I also prefer to be close to my husband without the device in between us, but I'm sure the device is at least doing some good for his health otherwise they wouldn't have given us right?"

Wendy has been married to her husband Mark for 32 years now. After his hospitalization for his COPD 6 years ago, he has been using HNIV. The time Mark spend in the hospital was very hard for Wendy and she wants her husband to take this HNIV treatment serious to prevent future hospitalization. But her husband much rather has his mouth free to kiss Wendy when they crawl into bed at night, and also Wendy can't deny she prefers sleeping with Mark without the noise of the HNIV device.

Daily routine



GOALS:

- Keep her husband healthy
- Enjoy the time they have together
- Wants to kiss her husband

FRUSTRATIONS:

- Scared for her husband's health
- Not sure what the benefits of HNIV treatment are
- Has to endure side effects of husbands treatment (noise)

Paper 1: Theory of reasoned action, theory of planned behavior, and the integrated behavioral model

Daniel E. Montaño and Danuta Kasprzyk, Chapter 4: Theory of reasoned action, theory of planned behavior, and the integrated behavioral model, in Karen Glanz Barbara K. Rimer K. Viswanath (Eds) Health behavior and health education: Theory, Research, and Practice, 4th edition, 2008.

TPB theory predicts that

1. positive attitude toward act (person believes act makes a positive contribution to their life)
2. favorable social norms (subjective norm = what do others think)
3. high perceived control (how easy is it to perform)

are the BEST predictors for forming behavioral intention & thus performing the behavior

The Theory of Reasoned Action (TRA) and the Theory of Planned Behavior (TPB)

focus on theoretical constructs concerned with individual motivational factors as determinants

of the likelihood of performing a specific behavior. TRA and TPB both

assume **the best predictor of a behavior is behavioral intention**, which in turn is **determined**

by attitude toward the behavior and social normative perceptions regarding it.

Although TRA and TPB have been criticized, many published intervention study reports show that changing TRA or TPB constructs leads to subsequent change in behavior.

TRA: developed to better understand relations between attitudes, intentions and behaviors.

(asserts that the most important determinant of behavior is behavioral intention)

TRA only works if behavior is under volitional control (person has control over their behavior)

attitude is determined by:

- the individual's beliefs about outcomes or attributes of performing the behavior (behavioral beliefs)

a person's subjective norm is determined by:

- his or her normative beliefs, that is, whether important referent individuals approve or disapprove of performing the behavior

Perceived control: added from TPB

So we look at:

is behavior enjoyable? (behavioral beliefs > attitude)

is outcome enjoyable? (evaluations of behavioral outcomes > attitude)

What do others think of it? (normative beliefs > perceived norm)

Would others do it? (normative beliefs > perceived norm)

Confidence they can do it? (personal agency (perceived power/ self-efficacy belief)

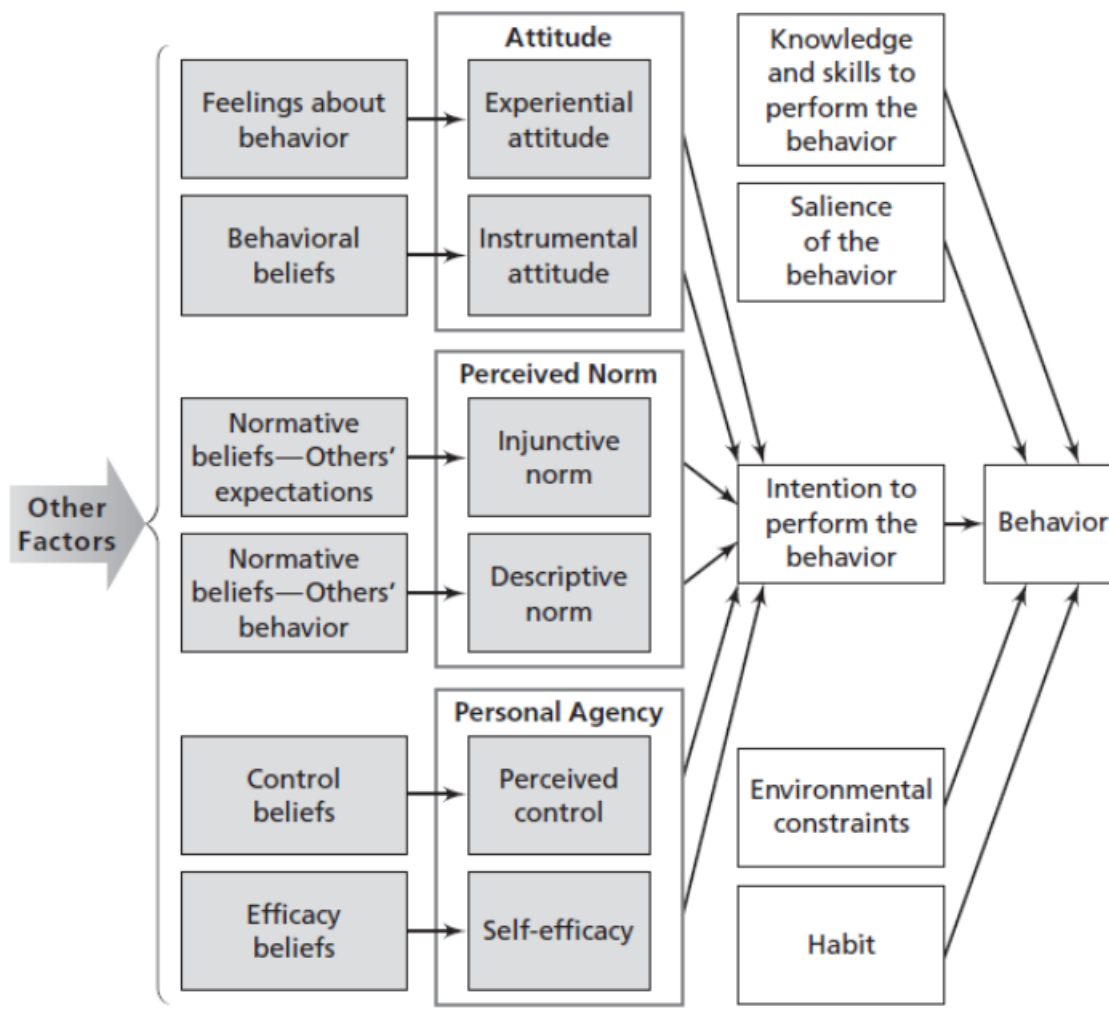


FIGURE 4.2. Integrated Behavior Model.

Paper 2: The transtheoretical model and stages of change

James O. Prochaska, Colleen A. Redding and Kerry E. Evers, Chapter 5 The transtheoretical model and stages of change, in Karen Glanz Barbara K. Rimer K. Viswanath (Eds) Health behavior and health education: Theory, Research, and Practice, 4th edition, 2008.

difference of approach: in early stages, people apply cognitive, affective, and evaluative processes to progress through stages. in later stages people rely more on commitments, conditioning, contingencies, environmental control, and support for progress toward maintenance or termination.

To move to the next stage pro's of good behavior should get higher or con's should get lower

The best strategy to promote retention is to match interventions to stage of change.

Paper 3: Elaboration likelihood model

Petty and Cacciopo. The Elaboration Likelihood Model. In *Advances in Experimental Psychology*, 19(1), 1986.

persuasion = process by which attitudes are changed through communication

we process this communication in 2 different basic ways (dual process model)

1. central route (when ppl think critically about the topic -> persuaded by strength of the message)
2. peripheral route (when ppl do NOT think critically about a message, but are persuaded by superficial cues -> reputation, handsome speaker)

Paper 4: Self-determination theory

Gagné, M., & Deci, E. L. (2005). Self-determination theory and work motivation. *Journal of Organizational Behavior*, 26(4), 331–362. <https://doi.org/10.1002/job.322>

Basic psychological needs according to Self Determination Theory:

competence, connection, and autonomy

(3 needs are universal > all cultures)

competence and autonomy underlie intrinsic motivation

intrinsic motivation = people want to do it and enjoy it

- controlled motivation: reward and punishment
- moderately controlled motivation: self-worth contingent on performance (ego involvement)
- moderately autonomous motivation: importance of goals, values and regulations
- autonomous motivation: coherence among goals, values, and regulations

supporting the 3 needs can move someone up the scale (from external to integrated regulation)

reward doesn't work if they are too controlling (yo lose intrinsic motivation when reducing autonomy)

if rewards are perceived as information it supports competence! (praise)

Paper 5: Goal-setting considerations for persuasive technologies that encourage physical activity

Sunny Consolvo, Predrag Klasnja, David W. McDonald, and James A. Landay. 2009. Goal-setting considerations for persuasive technologies that encourage physical activity. In *Proceedings of the 4th International Conference on Persuasive Technology (Persuasive '09)*. ACM, New York, NY, USA.

Goals increase productivity because:

- goals keep you focused
- goals make you more persistent
- goals help you rise to the challenge

characteristics of motivating goals are:

- Clear (S.M.A.R.T.)
- Challenging
- Commitment to goal
- Feedback (constructive)
- Task complexity (feel competent + break down big goals)

A goal is the object or aim of an action, for example, to attain a specific standard of proficiency, usually within a specified time limit.

The **highest or most difficult goals produced the highest levels of effort and performance.**

We found that specific, difficult goals consistently led to higher performance than urging people to do their best.

The concept of self-efficacy is important in goal-setting theory in several ways. When goals are selfset, **people with high self-efficacy set higher goals** than do people with lower self-efficacy.

They also are **more committed to assigned goals**, find and use better task strategies to attain the goals, and respond more positively to negative feedback than do people with low self-efficacy.

Tight deadlines lead to more rapid work pace than loose deadlines in lab and the field

two key factors in goal commitment: **importance + self efficacy** (good explanation/role models/ positive reinforcement)

For goals to be effective, people need summary **feedback** that reveals progress in relation to their goals.

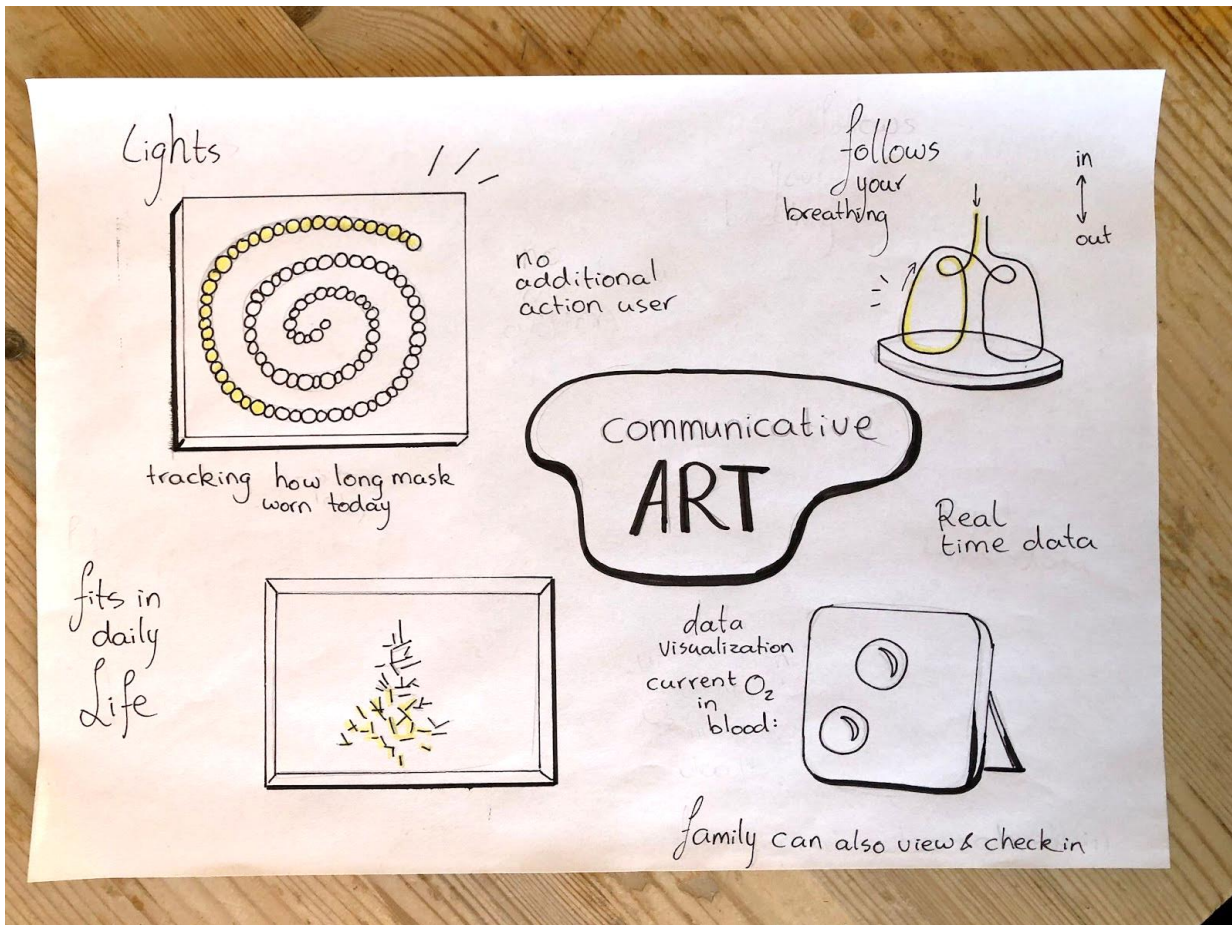
Goals are an object or outcome to aim for and a standard for judging satisfaction. Thus goals serve as the reference standard for satisfaction vs dissatisfaction.

Goal setting theory states that, no matter the subconscious, **conscious motivation affects performance and job satisfaction.** (again self efficacy, people have the power to control their lives)

Common mistakes: Failures to replicate them are usually due to errors, such as not matching the goal to the performance measure,

- not providing feedback,
- not getting goal commitment,
- not measuring the person's personal (self-set) goals,
- not conveying task knowledge,
- setting a performance goal when a specific high-learning goal is required,
- not setting proximal goals when the environment is characterized by uncertainty, or not including a sufficient range of goal difficulty levels

(see Locke & Latham, 1990, chapter 2).



Preparation stage (wants to wear longer) (paper2)

help: self-reevaluation (self-liberation) (see table 5.2)

self-reevaluation: combines both cognitive and affective assessments of one's self image with and without an unhealthy behavior (couch potato, active person)
Values clarification, healthy role models, and imagery can move people evaluatively

see a better and a worse self (improvement/goal)

maybe they can compare averages with friends

self-liberation: the belief that one can change and the commitment to act on that belief.
public testimonies, multiple choices van enhance what the public calls willpower

public testimony: visual if not wearing enough

TABLE 5.2. Processes of Change That Mediate Progression Between the Stages of Change.

	Precontemplation	Contemplation	Preparation	Action	Maintenance
Processes	Consciousness raising Dramatic relief Environmental reevaluation				
	Self-reevaluation				
			Self-liberation		
					Counterconditioning Helping relationships Reinforcement management Stimulus control

Note: Social liberation was omitted due to its unclear relationship to the stages.

contingency/reinforcement management: group recognition (reward for good behavior)

two key factors in goal commitment: importance + self efficacy (good explanation/role models/ positive reinforcement)

For goals to be effective, people need summary feedback that reveals progress

Tight deadlines lead to more rapid work pace

The highest or most difficult goals produced the highest levels of effort and performance.

people with high self-efficacy are more committed to assigned goals

conscious motivation affects performance and job satisfaction

people with high self-efficacy set higher goals

So people need to be able to set their goals themselves consciously and keep track of progress (get feedback) + best if difficult goals

not too controlling

no punishment

improves autonomy

improves competence

rewards are perceived as info (it supports competence = praise)

improves togetherness

improves: what do others think of it?

create high perceived control (competence)

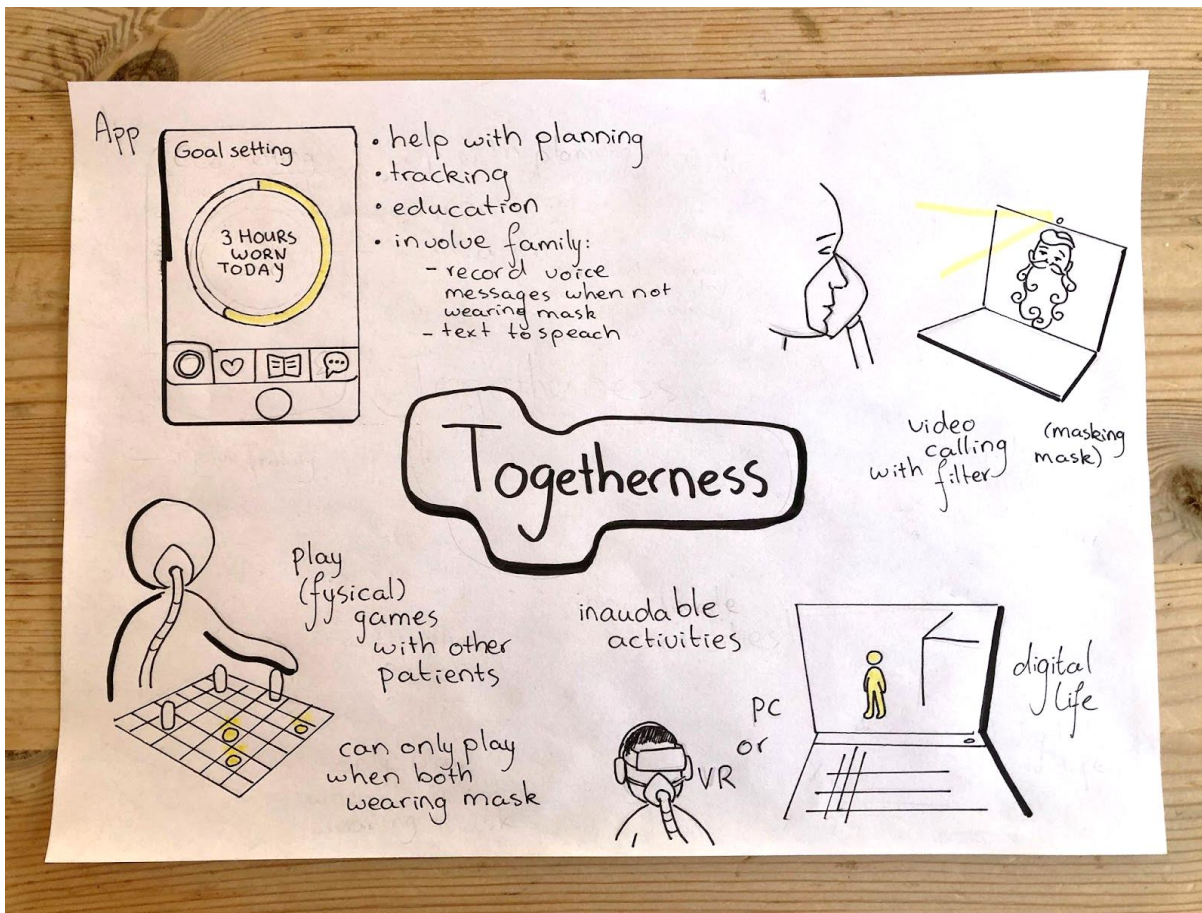
improves: confidence they can do it?

create favorable social norms

improves: would others do it?

create positive attitude toward act

peripheral route (superficial cues)



action/maintenance (make continuing more doable) (paper2)

help: self-liberation, counterconditioning, helping relationships, reinforcement management, stimulus control

self-liberation: the belief that one can change and the commitment to act on that belief. *public testimonies, multiple choices van enhance what the public calls willpower*

counterconditioning: learning healthier behaviors that substitute for problems behavior (*assertion, desensitization, positive self-statements*)

Helping relationships: combine caring, trust, openness, and acceptance for behavior change (*alliances, counselor calls, buddy system*)

Reinforcement management/contingency management: provides consequences for taking steps in a particular direction. (*reward for good behavior -> reinforcements, incentives, group recognition*)

Stimulus control: removes cues for unhealthy habits and adds prompts for healthy alternatives (*avoidance, environmental re-engineering, self help groups reduce risk of relapse*)

public testimonies: arrangements with fellow patients to do it together

substitute behavior: talk to friends online instead of IRL

helping relationships: arrangements with fellow patients to do it together (buddy systems)

reinforcements: wearing the mask now actually STRENGTHENS social relationships + get rewards in the app?

substitute behavior + environmental re-engineering: talk to friends online instead of IRL

improves
togetherness

niet self
worth
omlaag
halen

improves
autonomy

improves:
what do
others
think of it?

create
positive
attitude
toward act

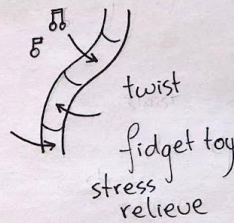
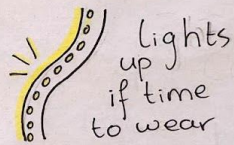
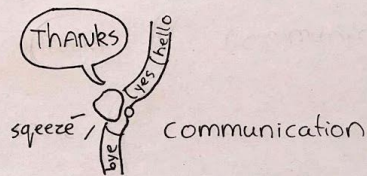
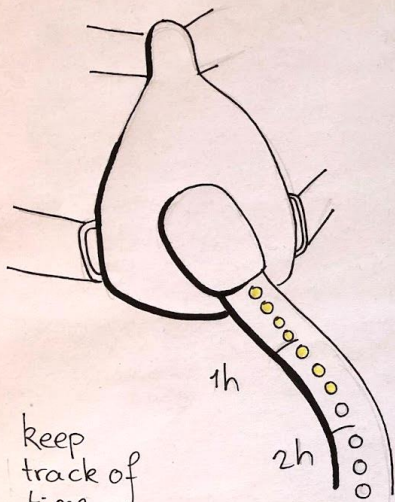
improves:
would
others do
it?

create high
perceived
control
(competence)

create
favorable
social
norms

improves:
is behavior
enjoyable?

peripheral
route
(superficial
cues)



COVER FOR HOSE

Preparation stage (wants to wear longer) (paper2)

Bought cover to set goals

help: self-reevaluation (self-liberation)

self-reevaluation: combines both cognitive and affective assessments of one's self image with and without an unhealthy behavior (couch potato, active person)
Values clarification, healthy role models, and imagery can move people evaluatively

healthy role model: to family, they are following advice

maybe they can compare averages with friends

contingency/reinforcement management: group recognition (reward for good behavior)

self-liberation: the belief that one can change and the commitment to act on that belief.
public testimonies, multiple choices can enhance what the public calls willpower

public testimony: visual if not wearing enough

two key factors in goal commitment: importance + self efficacy (good explanation/role models/ positive reinforcement)

For goals to be effective, people need summary feedback that reveals progress

not too controlling

no punishment

Tight deadlines lead to more rapid work pace

The highest or most difficult goals produced the highest levels of effort and performance.

people with high self-efficacy are more committed to assigned goals

improves autonomy

niet self worth omlaag halen

conscious motivation affects performance and job satisfaction

people with high self-efficacy set higher goals

So people need to be able to set their goals themselves consciously and keep track of progress (get feedback) + best if difficult goals

rewards are perceived as info (it supports competence = praise)

improves togetherness

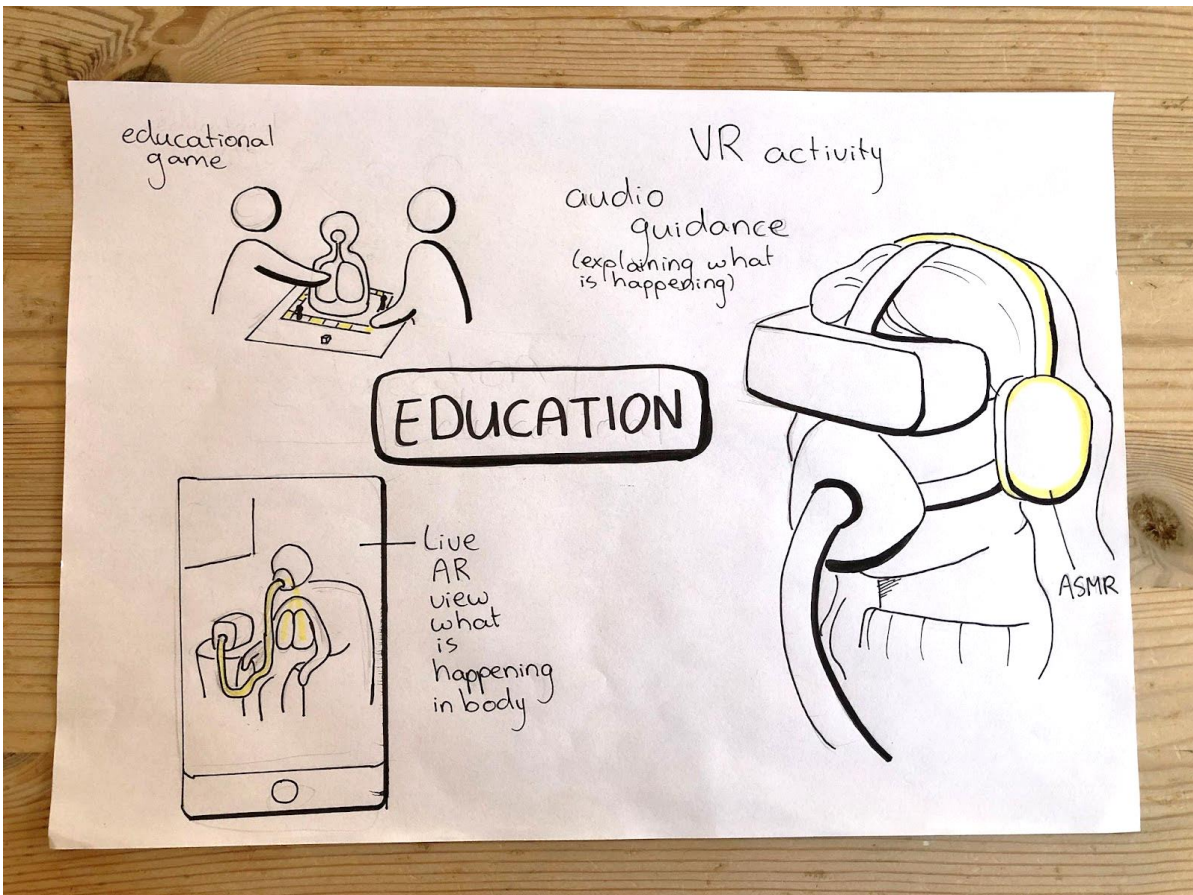
create high perceived control (competence)

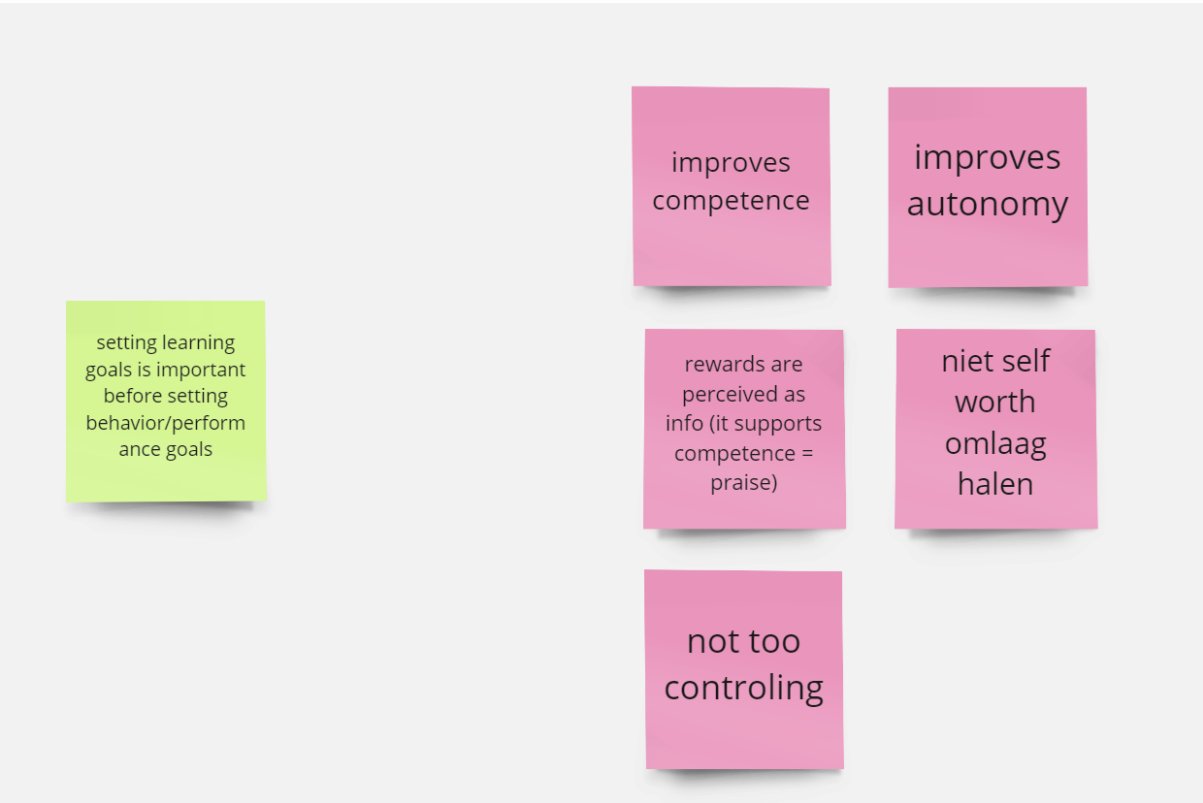
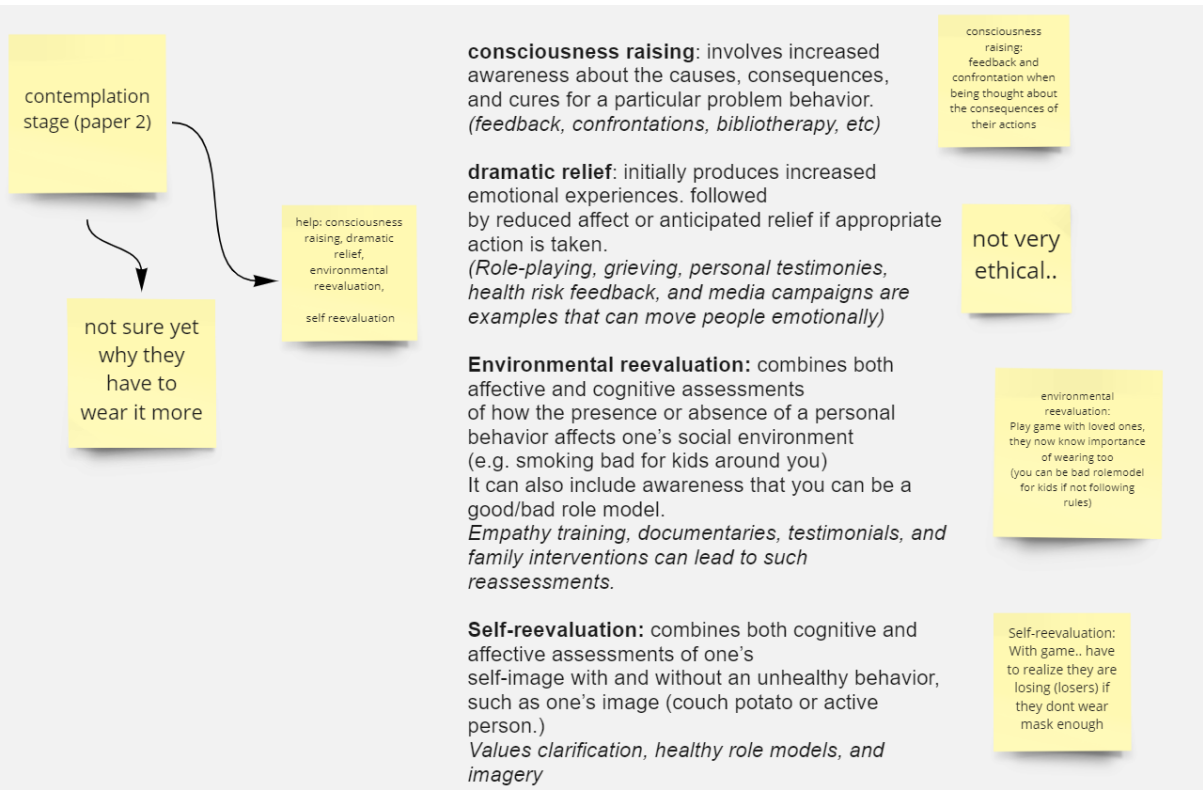
improves: confidence they can do it?

improves: is behavior enjoyable?

create positive attitude toward act

peripheral route (superficial cues)





improves:
what do
others
think of it?

improves:
is the
outcome
enjoyable?

create high
perceived
control
(competence)

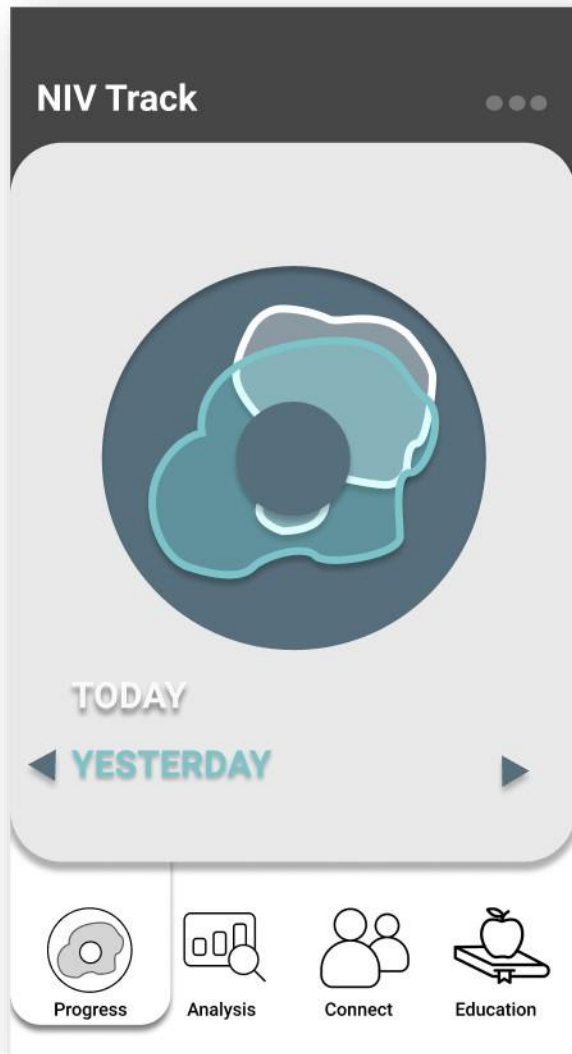
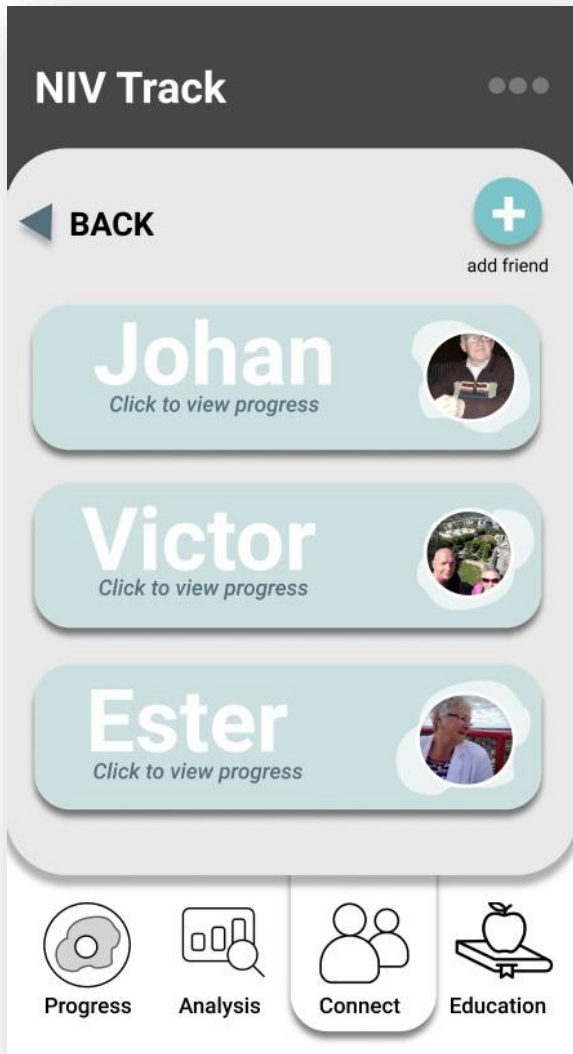
improves:
confidence
they can do
it?

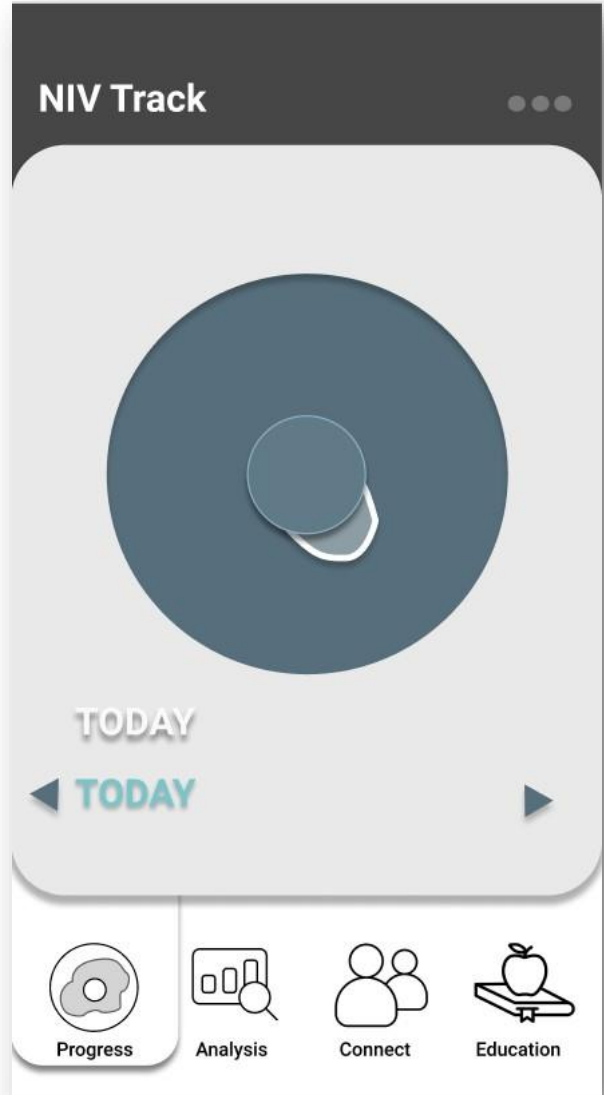
create
favorable
social
norms

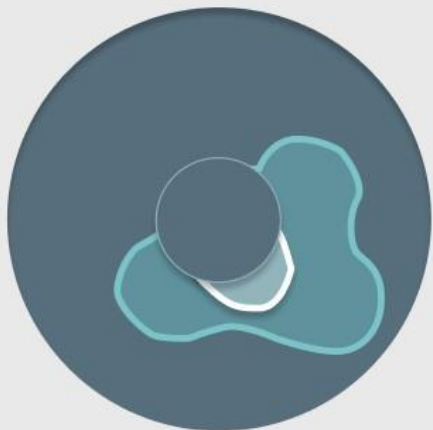
central
route
(strength of
message)

improves:
would
others do
it?

create
positive
attitude
toward act







TODAY

◀ YESTERDAY ▶



Progress



Analysis



Connect

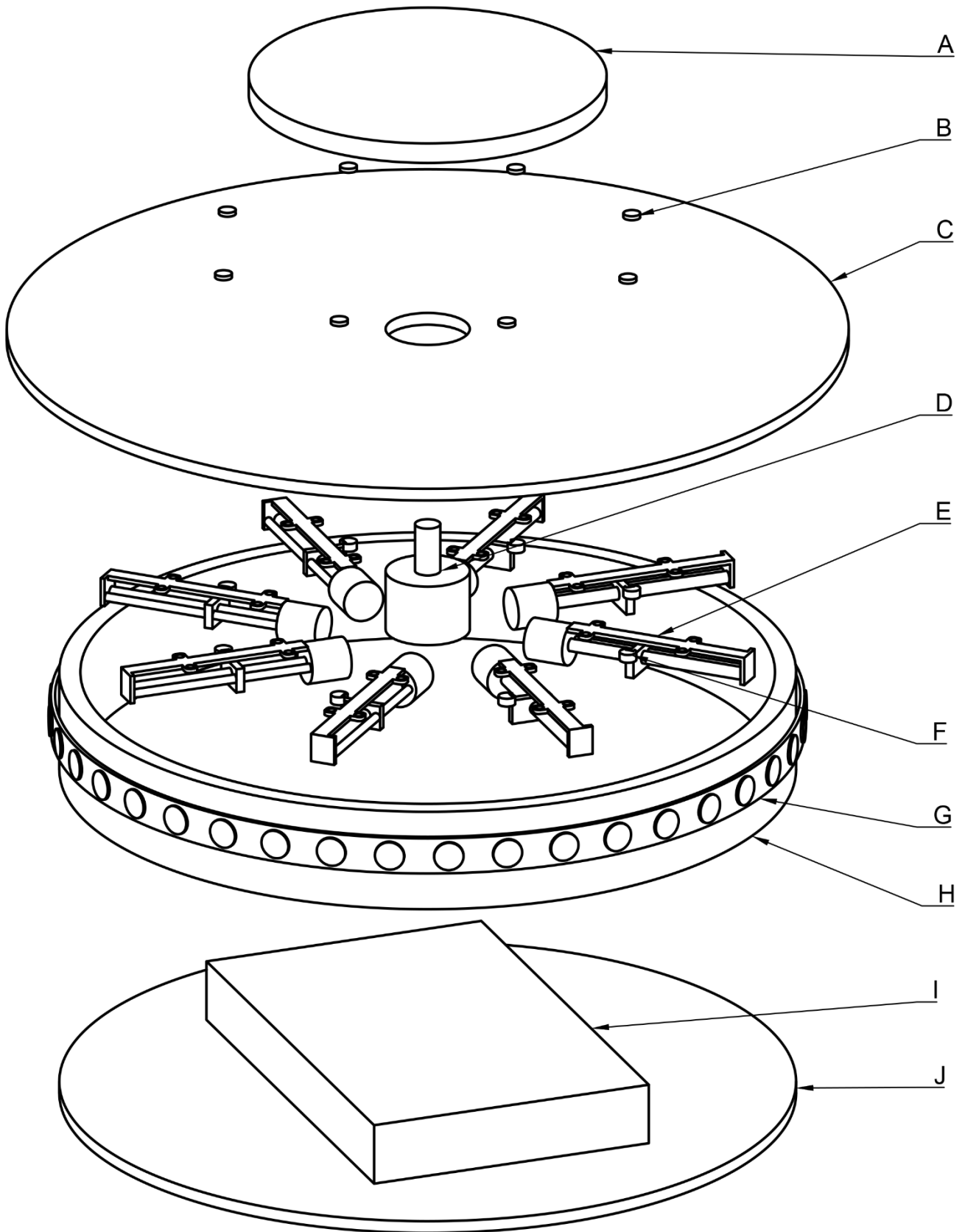


Education

APPENDIX D

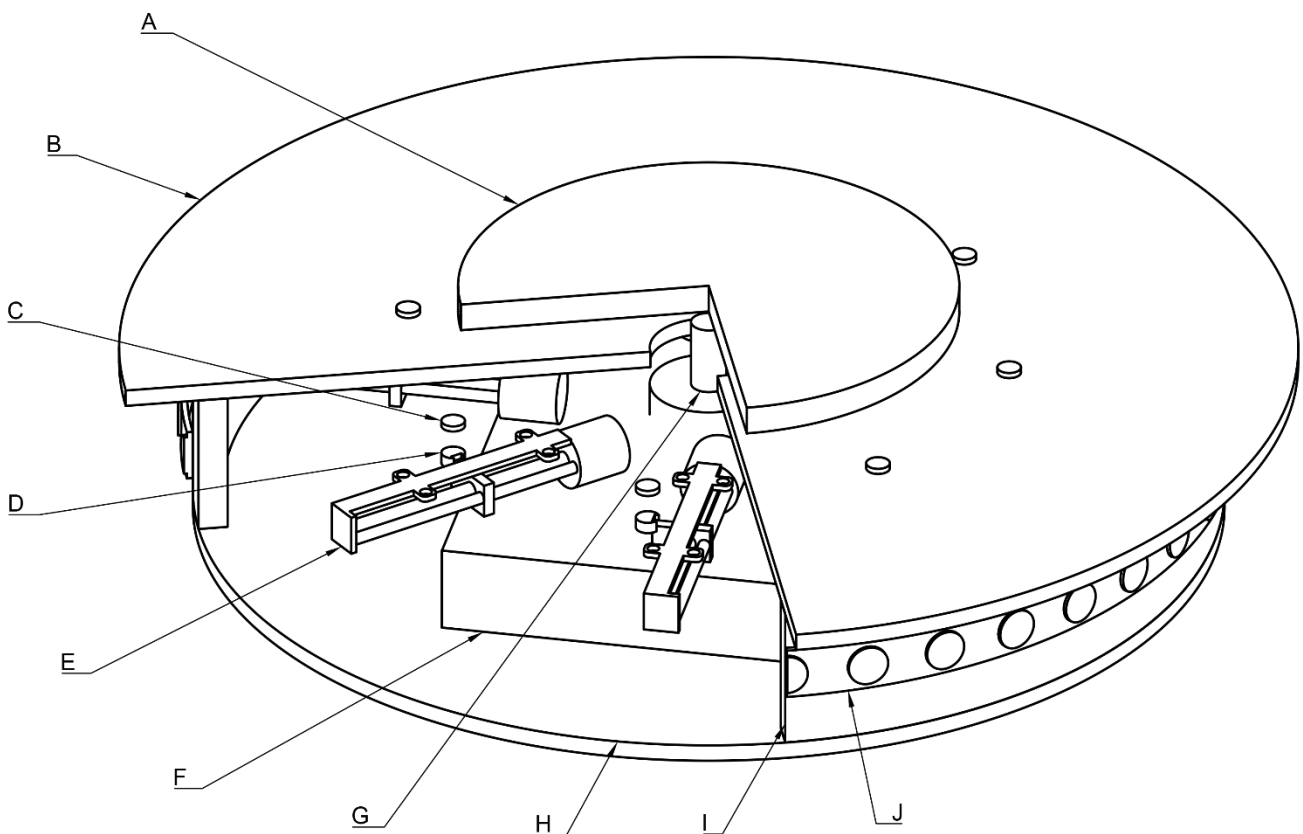
REALIZATION

Image 1:



- A. Turn knob
- B. Top magnet (attached to fabric)
- C. Top plate
- D. Potentiometer
- E. Linear actuator
- F. Bottom magnet (attached to linear actuator)
- G. LED strip
- H. Side
- I. Electronics housing
- J. Bottom plate

Image 2:



- A. Turn knob
- B. Top plate
- C. Top magnet (attached to fabric)
- D. Bottom magnet (attached to linear actuator)
- E. Linear actuator
- F. Electronics housing
- G. Potentiometer
- H. Bottom plate
- I. Side
- J. Led strip