FINAL BACHELOR PROJECT REPORT

DESIGN FOR SLEEP PARALYSIS

PROJECT SLEEP

DAAN MATTHIJSSE
S138998
STUDENT INFORMATION

NAME: DAAN MATTHIJSSE
S-NUMBER: S138998
BLOCK: B3.2
EMAIL: D.MATTHIJSSE@STUDENT.TUE.NL
PHONE NUMBER: +31 (0) 6 38 336 129
SQUAD: SLEEP

INVOLVED EXPERTS

dr. J. (Jun) Hu - PDEng MEng
prof. dr. P. (Panos) Markopoulos
dr. S. (Sebastiaan) Overeem
L. (Linkai) Tao
J.M.S. (Jan) de Wit - MSc
# Table of Content

## Introduction
- 4

## Executive Summary
- 5

## Project Description
- 6

## Process Description
- 7

## Research
- 8
  - Research
  - Interviews
  - Symposium Kempenhaeghe
  - Research conclusions
    - Narcolepsy
    - Sleepparalysis

## Iterations | Ideas & Concepts
- 10
  - Ideas & concepts
    - Adaptingagendma
    - Adviceapp
    - Communitytree
    - Freezingcataplexysuit
    - Narcolepsyloggingwristband
    - Narcolepsysleeptimewatch
    - Sleepcyclealarmclock
    - Growingsleeptree
    - Combined feedback session

## First Iteration | Logging Wristband
- 12
  - Loggingwristband
  - Meeting Jande Wit
  - Meeting Sebastiaan Overeem
  - Interactions
  - Conclusion and change of concept

## Second Iteration | Sleep Paralysis Sensor
- 14
  - Persona
  - Sleepparalysis sensor
    - Midterm modemday
  - Prototyping

## Final Concept | Sleep Paralysis Sensor
- 31
  - Final concept
    - Thesensor
    - Howtowakethepersonup?
    - Afterwakingup
    - Logging
    - Thesleepparalysisapp
      - Functions of the app
      - More technical structure
    - Moretechnicalstructure

## Final Concept | Prototyping
- 38
  - Prototyping
    - Wakingthepersonup
    - Thewristband
    - Thelamp
    - Afterwakingthepersonup
    - Moretechnicalstructure

## Future Plans
- 42
  - How could this idea be realized?

## Reflection
- 44
  - Reflection

## Appendices
- 47
  - Appendix A: Summary Hans
  - Appendix B: Summary Liza
  - Appendix C: Summary Maxime
  - Appendix D: Summary Puck
  - Appendix E: Wiring lamp module
  - Appendix F: Wiring transmitter module
  - Appendix G: Schematic wristband
  - Appendix H: Interview concent form
  - Appendix I: Process overview
  - Appendix J: Project description SLEEP
  - Appendix K: Demo Day posters

## References
- 62
INTRODUCTION

During my Final Bachelor Project I’ve been working on the topic of Narcolepsy in the Sleep squad. A difficult topic because the symptoms of this sleeping disorder vary a lot from person to person and the disorder is still quite unknown. This made the project more challenging but I was ready to take on the challenge. There was not a specific design case so I had to come up with a design case myself. Talking with patients helped me to find one and to kick start my project.

Half way the project I decided to go into another direction, deviating a little from the topic of Narcolepsy. I decided to focus on one of the symptoms of Narcolepsy; Sleep Paralysis. Why I decided to go into this direction will be discussed later in this report.

In this report I’ll guide you through the design process and explain the final concept of the Sleep Paralysis Sensor. The problems, choices, learning points, meetings and everything else will also be discussed in this report.
EXECUTIVE SUMMARY

The Sleep Paralysis Sensor helps people to cope with the negative effects of a sleep paralysis. By measuring the heart rate which increases because of the terrifying experience, a sleep paralysis episode can be detected only short after it occurred and the person can be wakened. By waking the person up only short after an episode has occurred the impact of this experience can be reduced.

This report shows the development of the Sleep Paralysis Sensor concept, a concept which will improve the quality of life of people suffering from sleep paralysis.
PROJECT DESCRIPTION

The name of the project is called SLEEP, which is an umbrella name for several projects related to sleep. “Health and vitality are among the most important application domains of ID at TU/e. Sleep is an essential component of health and ID wants to strengthen its expertise on sleep, sleep disorders, sleep diagnosis and therapy, in order to create intelligent systems, products and related services improving sleep. This goal will be achieved by the new squad SLEEP.”

“We combine wearables (in-bed and on-body) together with social computing (what can social-media behavior tell us about sleep hygiene, for example)” (Project Case Description)

I was allocated to the topic of Narcolepsy. One of the possible design cases was to support the design and evaluating of the Narcolepsy App. “An app for monitoring Narcolepsy related symptoms.” The other option was to explore the topic of Narcolepsy and to come up with a design challenge myself, and that’s what I did.
PROCESS DESCRIPTION
RESEARCH
RESEARCH

The project started by doing research to the topic of Narcolepsy. After getting a basic understanding about the sleeping disorder itself I started reading personal experiences. I learned that, especially in this case, it is the most valuable to read personal experiences because what actually matters the most is how people feel about and live with the disorder, rather than knowing what the disorder actually is.

Because I wanted to know more about the personal experiences, I subscribed to some Narcolepsy Facebook groups. Through these groups I could ask questions and go more into depth. It was a very nice way to quickly get some valuable information and opinions from people who are suffering from Narcolepsy. The groups were very active and some nice discussions evolved from it. To go even more into depth, I did some interviews with people suffering from Narcolepsy. The results of these interviews will be discussed on the next page.

Links to the Facebook groups:
Narcolepsy Support Group: https://www.facebook.com/groups/NarcolepsySupportGroup/?ref=ts&fref=ts
Narcolepsie België en Nederlands: https://www.facebook.com/groups/479490968788669/?fref=ts
Narcolepsy Network: https://www.facebook.com/groups/narcolepsynetwork/?fref=ts

Figure 1: Narcolepsy word web.
Together with Lean van den Dikkenberg, another student working on the topic of Narcolepsy, I did 4 interviews with people suffering from Narcolepsy. Our goals of the interviews was to just have a normal conversation and to let the interviewee just tell their story. We prepared some open ended questions which we used as a guideline through the interview. People also had to fill in a consent form so they knew what we were going to do with the data. (see appendices)

The interviews were all very interesting and it gave us a lot of new insights. I also realized that not everything which is written on the internet is true, at least not for everybody. For me, this confirmed the importance of having personal meetings with “patients” and experts. We also discovered that everybody experiences Narcolepsy differently and that the symptoms are different for everybody. This made it hard to design something which is suitable for everybody.

After the 4 interviews I made a summary for each interview to filter out the most important aspects and I made a word web of these aspects. I tried to group the symptoms by dividing them over 2 axes, psycho-social vs everyday life activities and environment/relatives vs individual/personal. The goal of this word web was to get an idea about in which area there were the most problems. It seemed to be that the most problems were personal and psychological/social (bottom right). Working on a design in this area would probably affect the most people and also the most problems. I used a different color for every person and if symptoms were double, I wrote down a “+” behind the symptom.

The summaries of the interviews can be found in the appendices.
I’ve also been to the Sleep Symposium at Kempenheaghe to get an update of what is going on in the field of sleep and technology and to learn more about sleep itself.

The talks of different researchers and designers were interesting although many of them were pretty statistic and focused on the results of their research. I used the results of their research as an inspiration for new ideas, measurement methods and new technology. The talks also made me realize that accurately measuring the sleep phases is quite difficult. This has also influenced me in the exploration phase of the process.
Narcolepsy is a chronical neurological sleeping disorder which is characterized by many symptoms. Some of the most common symptoms are excessive daytime sleepiness (EDS), cataplexy attacks (loss in muscle tone) and sleep paralysis, which often comes with hypnagogic hallucinations (Raffaele Ferri, 2005).

People with Narcolepsy have an 85%–95% reduction in the number of Hypocretin neurons (Thomas C. Thannickal, 2000). This neuron controls the sleep/wake cycle and the REM sleep. Without Hypocretin, the sleep/wake cycle becomes confused and the REM sleep is increased.

People recover in their deep sleep, however people with Narcolepsy do not come into deep sleep as much as normal people do. During their sleep, they recover a lot less than people without Narcolepsy. This is one of the biggest reasons why People with Narcolepsy are always tired during the day. If people with Narcolepsy need to explain others how they feel during the day, they’ll tell you that you have to compare it to being awake for 72 hours, coming straight out of a warm bath and sitting in bed with a warm cup of tea. People with Narcolepsy can fall asleep any time of the day. During these “sleep attacks” they pass directly into the REM sleep, unlike healthy people, who always go through a period of non-REM sleep first. The figure below shows the sleep pattern of a normal person vs. the sleep pattern of a person with Narcolepsy.

Figure 4: Distribution of sleep phases over 24 hours.
Sleep Paralysis is a neurologic phenomenon which can be described as the inability to move and speak on awakening during the REM (Rapid Eye Movement) sleep, while being fully conscious (Randolph W. Evans, 2008). During REM Sleep, the muscles of the body are completely paralyzed. Scientists say this is to prevent the dreamer from physically acting out their dreams (Alison Abbott, 2005). Psychophysiological studies have shown that sleep paralysis episodes are particularly likely to occur if a person enters REM sleep short after going to bed, bypassing the stages of NREM sleep (Randolph W. Evans, 2008). Normal people have about 60-120 minutes of NREM sleep stages before going into REM sleep (Raffaele Ferri, 2005)(Gary S. Richardson, 1978). That is the reason why PWN are more likely to get a Sleep Paralysis episode. Sleep Paralysis normally occurs when lying on your back. That is why an episode can also occur when taking a nap on the couch and not only in bed.

Sleep Paralysis is often accompanied by vivid and terrifying hallucinations (G. Browne Goode, 1962). These hallucinations are also called Sleep Terror; dreams (nightmares) that happen earlier in the sleep, during a REM sleep. During these hallucinations people experience shadows, demons, ghosts, witches, scary sounds or other paranormal events and sensations as feelings of being dragged out of bed, falling or flying. Many people also feel a pressure on their chest and have a difficulty breathing (Randolph W. Evans, 2008). These hallucinations can result in a panic attack which comes with a significant increase in heart rate (Barr Taylor, 1986) (Jack M. Gorman, 2000).

The duration of the paralysis can last from a few seconds up to minutes. An episode of sleep paralysis is often accompanied by fear and anxiety causing a pounding heart rate and sweating (Sleep Health Foundation, 2011) (Randolph W. Evans, 2008). 10-25% Of the people with Narcolepsy (National Institute of Neurological Disorders and Stroke, 2005) and around 5-8% of the total population suffers from Sleep Paralysis more often while 20-60% has experienced it at least once (Victoria M Indivero, 2011) (Randolph W. Evans, 2008). The frequency of Sleep Paralysis episodes differs from person to person. Research done by J.A. Cheyne (2005) reports the following data.

<table>
<thead>
<tr>
<th>SP frequency</th>
<th>Age onset</th>
<th></th>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Females</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>23.19</td>
<td>10.22</td>
<td>25.83</td>
<td>9.52</td>
</tr>
<tr>
<td>Several</td>
<td>18.46</td>
<td>8.74</td>
<td>30.57</td>
<td>10.40</td>
</tr>
<tr>
<td>Several/year</td>
<td>17.09</td>
<td>8.33</td>
<td>30.01</td>
<td>10.08</td>
</tr>
<tr>
<td>Monthly</td>
<td>15.85</td>
<td>7.81</td>
<td>26.71</td>
<td>8.71</td>
</tr>
<tr>
<td>Weekly</td>
<td>16.06</td>
<td>7.65</td>
<td>25.98</td>
<td>8.88</td>
</tr>
<tr>
<td>Several/week</td>
<td>16.21</td>
<td>8.80</td>
<td>27.53</td>
<td>10.34</td>
</tr>
<tr>
<td>Males</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>22.12</td>
<td>9.47</td>
<td>24.17</td>
<td>9.03</td>
</tr>
<tr>
<td>Several</td>
<td>18.71</td>
<td>8.76</td>
<td>28.15</td>
<td>10.01</td>
</tr>
<tr>
<td>Several/year</td>
<td>16.75</td>
<td>7.91</td>
<td>30.01</td>
<td>10.12</td>
</tr>
<tr>
<td>Monthly</td>
<td>15.19</td>
<td>6.78</td>
<td>27.39</td>
<td>9.22</td>
</tr>
<tr>
<td>Weekly</td>
<td>15.33</td>
<td>6.91</td>
<td>26.15</td>
<td>8.45</td>
</tr>
<tr>
<td>Several/week</td>
<td>15.60</td>
<td>7.87</td>
<td>26.16</td>
<td>9.25</td>
</tr>
</tbody>
</table>

Figure 5: Frequency of sleep paralysis episodes
ITERATIONS
IDEAS & CONCEPTS
IDEAS & CONCEPTS

After doing the research to Narcolepsy on the internet I came up with a few ideas which I presented at the combined feedback session. In this phase of the project I was still focusing on the topic of Narcolepsy and not yet focused on Sleep Paralysis. In this part of the report, the ideas will be shortly described.

ADAPTING AGENDA
Combined with a sensor, a Narcolepsy attack could be detected and the agenda could be rescheduled if someone would have fallen asleep. The agenda could also notify the user for an upcoming agenda item by vibrations in the sensor.

Reflection
Although planning is quit a big problem for people with Narcolepsy, the user needs to be very organized and put everything in the agenda, also the smallest things. Besides this, accurately detecting a sleep attack would have been quite difficult. I've done some research to existing techniques to accurately detect a sleep attack but no successful design could be found.
ADVICE APP
The application will give you advice on what to do depending on the time of the day and the amount of hours you’ve already slept. This way people will probably sleep better during the night and be more relaxed and/or rested during the day.

Reflection
The idea was too superficial and would not really work because everybody has his/her own planning so it would be hard to always follow the advice of the app. Besides that, it is hard for an app to assess the user’s energy level because this is really personal. An option could have been that people would score their energy level to help the app to more accurately assess the energy level of the user.

COMMUNITYTREE
This idea would encourage people to fill in their Narcolepsy logs. After creating small communities, these communities could earn rewards after everybody has filled in their log. People within the community would encourage each other because they all want to earn the rewards. This would result in more logs being filled in and more information for the experts. There would also be a chatroom where they could talk with each other and share their experiences. A kind of Narcolepsy social media platform.

Reflection
The community and social support aspect of this ideas were really interesting but the application was not interesting enough. Eventually I used the aspects of creating smaller community groups and social support in my final concept.
FREEZING CATAPLEXY SUIT
This “suit” would freeze as a person with Narcolepsy would get a cataplexy attack and prevent the person from collapsing. The cataplexy attack could be detected by measuring the loss in muscle tone.

Reflection
The particular idea of a suit would not work because the person would fall down like a board because of the muscle tone loss in their feet too. The overall idea of designing fall protection for people with Narcolepsy was interesting though. These protection products would possibly attract some attention, but because people with Narcolepsy do not want to be “linked” to this disorder, this would not be a great idea. Also, people with Narcolepsy often did not hurt themselves that much that they would need a product like this.
NARCOLEPSY LOGGING WRISTBAND
This actually could have supported the Narcolepsy App. It would automatically detect a Narcolepsy attack and log this in the app. It could detect the attack by measuring the heart rate, muscle tone and movements. The user could also log caffeine, alcohol or physical exercise themselves.

Reflection
I really liked this idea. I’ve done some research to this and also tried to make a prototype but I realized that this idea was too complex and most likely not feasible for me as an Industrial Designer. Detecting a Narcolepsy (sleeping) and Cataplexy attack was too difficult for me. More about this concept will be discussed in the next chapter.

NARCOLEPSY SLEEP TIME WATCH
This watch could calculate the amount of hours you’ve already slept and determine the hours you still have to sleep to reach a sufficient amount of sleeping hours over the day.

Reflection
The amount of hours which a normal person has to sleep are not equal to the hours people with Narcolepsy have to sleep. People with Narcolepsy sleep less deep and so they recover less in their sleep. Their energy level has nothing to do with the amount of hours they’ve slept during the day but more about how well they recovered.
**SLEEP CYCLE ALARM CLOCK**
This clock visualizes the sleep cycle and also functions as an alarm clock. This way you would have an abstract visualization of your sleep cycle over the week.

**Reflection**
It does not really have a clear function, rather than being an alarm clock. For this reason it did not fit into my vision as a designer.

---

**GROWING SLEEP TREE**
The overall idea behind the Growing Sleep Tree was to turn something negative (sleeping in the case for people with Narcolepsy) into something more positive. In this case, the user would earn something (e.g. a tree would grow) while the user was asleep.

**Reflection**
The idea to turn something negative into something positive would help people with Narcolepsy to accept their disorder more easily. Although, when using the sleep time as the input, the user would not really experience the concept because the user is asleep while "the tree is growing". The experience of the user would not be good enough to help in the acceptance of the disorder.
During the combined feedback session I presented my ideas. I experienced that my way of presenting using the printouts of my Illustrator visuals of my ideas worked out well. It was an easy way to present my ideas and the visualizations made it a lot more clear than just using words to explain the ideas. Also in the discussing afterwards, where I just put all the ideas on the table, it created a nice overview and the printouts could be easily picked up and be discussed. During the feedback moment after my presentation we discussed the pros and cons of the ideas and brainstormed about possibilities.

The ideas which were the simplest were also perceived as the best. The Freezing Cataplexy Suit and the Narcolepsy Logging Wristband were the favorites of the people attending this combined feedback session.

I decided to continue with the Narcolepsy Logging Wristband because in my opinion this was the most interesting idea and it was still much related to the project description and the Narcolepsy App, which was initially the aim of the project.

**Combined feedback sessions overall**

Overall, the combined feedback sessions were a good way to receive feedback on your concept(s) and process and to gain new input for your project. Especially when experts joined the session, the feedback became more valuable and this guided me in the right directions.
FIRST ITERATION
LOGGING WRISTBAND
continued with the Narcolepsy Logging Wristband because this would help both the person with Narcolepsy as well as the doctors. Until now the user had to fill in a sleep log by hand. This was unclear and it took quite some time to fill this in.

The wristband would make the logging a lot easier and faster and because it could also automatically detect a Narcolepsy or Cataplexy attack. The user would not have to guess the times he/she fell asleep and woke up anymore. The data would become more accurate, reliable and valuable.

**MEETING JAN DE WIT**

I had a meeting with one of the designers of the Narcolepsy App, Jan de Wit. My goal of this meeting was to gain more information about which aspects need to be/are logged and which of these I could incorporate in the Logging Wristband I wanted to design.

Jan liked the idea of the wristband and thought that it was a good tool to support the logging via the Narcolepsy App. Also the fact that you could log more quantitative aspects with the wristband next to more qualitative/subjective aspects with the app was a good addition to the logging as a whole.

Also logging lifestyle and sleep hygiene such as drinking coffee or alcohol was something he really liked because this was not yet touched upon with the app. Another advantage of logging these aspects is that these can also be used for other sleep related problems, which would broaden the user group.

The advantage of using the wristband is that it is more accessible and less demanding and time consuming than the app. The wristband could also function to give notifications to the user by using vibrations. This could be used to motivate them to use the app for example.

Jan also suggested a small screen, but from a previous meeting with Jun Hu, I learned that people would go and ask the user “what’s that new Smart Watch you’re wearing?”. Then people will have to explain that it is for Narcolepsy. But people with Narcolepsy don’t always want to be linked to Narcolepsy and the fact that they have a disorder. For this reason, the wristband needs to be as a jewelry, something subtle.
MEETING SEBASTIAAN OVEREEM
I also planned a meeting with Sebastiaan Overeem because he is a doctor at the Kempenhaeghe Sleepcenter and I wanted to know more about the importance of logging the different symptoms of Narcolepsy. He is also one of the developers of the NarcolepsyApp.

Initially I thought that quantitative logging of symptoms such as Cataplexy would also be useful for doctors/experts. Sebastiaan however told me that every symptom is personal; one person would not bother 4-5 Cataplexy attacks a day, another person will experience 1-2 attacks as terrible. The subjective aspect is more important for doctors because they base the advice and medication on how the patient experiences the disorder. I personally thought that both qualitative (subjective) and quantitative data are important. It might also have been good to link these two to each other to get a qualitative measurement about each symptom.

The meeting with Sebastiaan gave me more insight in the importance of logging the subjective part of different symptoms. Something which I did not really take into account yet. I also learned that every symptom is experienced in a personal way, and not every symptom is as relevant for everybody.

A challenge for me could have been to come up with an interaction to quickly log different symptoms, quantitative but also qualitative (subjective), taking into account how many times a day/week/month every symptom needs to be logged. But also to design the interface is such a way that the user can get a clear overview of the symptoms or that the user can simply choose the symptom he/she wants to log.

Figure 16: Sebastiaan Overeem
INTERACTIONS
After these meetings I started brainstorming about different interactions to subjectively log the symptoms. One of the challenges was to design an interface which would be simple and intuitive, without too many buttons. Another challenge was to give the user an overview of the symptoms which could be logged and to create an interaction to quickly choose the symptom you want to log at that particular moment, but without making it too high-tech (e.g. with a screen) Below you can find some visualizations of logging wristbands.
realized that it was pretty hard to make a wristband with as few buttons as possible and a simple intuitive interaction while still keeping it organized. In my opinion the concept of the Logging Wristband also conflicted too much with ongoing research project of the Narcolepsy App and in my opinion the wristband would not be able to improve the user interaction enough to continue with this idea.

I was also not feeling comfortable about the project because it was not very close to my vision as I like to design something directly for the people with a disorder, and I was having the feeling that in this case I was more designing for the expert/doctor. If the doctor or expert would have been my user group, then it would have been different, but in this case I really wanted to design something directly for the user (people with Narcolepsy).

Although this conclusion was quite late in the semester, I thought it would still be no problem to change my concept. In the planning I made in the beginning of the semester I planned this week to decide with which project to continue. I learned that making a planning keeps your process more organized and helps you to make decisions at the right moments.

I discussed this change with my coach Jun Hu and also with Sebastiaan Overeem. Sebastiaan said that in his opinion, it was impossible to design something directly for the user instead of a detour via experts or doctors. I did not agree with him, because at our department we almost do nothing else than designing directly for a user, even if this user is disabled and partly dependent on the doctor’s advice. I followed my own vision.
SECOND ITERATION
SLEEP PARALYSIS SENSOR
Every person with Sleep Paralysis experiences it differently. Some only experience an episode once or twice a year, some multiple times a week. This concept focuses on people who experience SP multiple times a week because for these people it is probably a bigger problem than for those who rarely experience it. After a meeting with Linkai Tao (PhD) we came to the conclusion that it would be a good idea to create a persona to focus the design on. John has been created to describe a member of this more specific user group.

Meet John
John is 32 years old and he lives together with his wife in a cute little house in the Netherlands. John has been diagnosed with Narcolepsy since he was 17 and also suffers from Sleep Paralysis. The SP occurs 2-3 times a week and it also comes with hypnagogic hallucinations which are very vivid and scary. John can’t get out of the SP himself, sometimes, when his wife is still awake she notices the strange breathing of John and she can wake him up, but most of the time his wife is already asleep and she doesn’t notice when John gets an attack.
AFTER brainstorming, reading back the interviews, looking at the word webs and reading on the internet again I came up with a new design challenge. It seemed to be that many people with Narcolepsy also suffered from Sleep Paralysis, a neurological phenomenon which can be described as the inability to move and speak on awakening during the REM sleep, while being fully conscious. This seemed to be a terrifying experience and I saw some opportunities to help people with this problem. One of the biggest problems was that they could hardly get out of this paralysis themselves, so my goal was to detect the Sleep Paralysis and to get the person out of it as soon as possible.

2 Days after this change of concept was the Midterm Demo Day, so I immediately made a video to present my new concept during the midterm Demo Day.

MIDTERM DEMO DAY
Even though I had to make this video in only little time, I was quite satisfied with the result. Reflecting on this video, I had to put in more background information about Sleep Paralysis because the problem was not clear for the viewer. Background information in the beginning of the video would have made the video and the concept stronger.

I was not yet able to show anything during the “exhibition” after the video presentations so I used this moment to get more input about research and ideas. This resulted in some new ideas to measure heart rate during sleep, but also interesting discussions about the next steps in my process. How was I going to wake the person up? What was I going to do after the person woke up? etc.

PROTOTYPING
My goal was to make a reliable Sleep Paralysis sensor which would be able to detect a Sleep Paralysis episode by measuring the heart rate of the user. This could be made more accurate by also measuring the movements of the user with an accelerometer to see if the person was actually paralyzed. The first prototype consisted out of a heart rate sensor to detect the Sleep Paralysis episode.

Figure 19: Finger heart rate sensor
I tried out different heart rate sensors and I tried to make a more reliable algorithm by filtering out sudden peaks and impossible values. I tested the sensor myself by wearing it during the night and keeping a log file on an SD card. Unfortunately, the (relatively) cheap sensors were not accurate enough to make a reliable Sleep Paralysis Sensor. The sensor had to be placed on an exact good spot and was not allowed to move much during the night. Also body movements during the night influenced the data. Of course I could not check the outputs during the night and adjust the placement of the sensor so the sensor was not reliable enough for this application.

In the graph below you can see the outcomes of the heart rate measurements. 'BPM' is the raw heart rate, 'BPM Average' is the average heart rate over 10 seconds and the 'Long Average' is the average heart rate over 60 seconds. You can see that the heart rate differs very much, it sometimes jumped from 100 to 200+. I filtered these sudden peaks out by the algorithm I made in the code but still the sensor was not accurate enough.

Figure 20: Heart rate sensor.

Figure 21: Results of heart rate measurement over a night.
A new heart rate sensor had pot meters which could be adjusted to change the strength of the signal. One time, while testing the sensor during the day, I was able to adjust them almost perfect for that moment and the measurements were really good. But I was not allowed to move and the heart rate sensor had to stay at the exact same place in order to get these measurements. During the night it is almost impossible to not move and to make sure that the sensor stays at the exact same place.

Figure 22: Easy Pulse V1.1 heart rate sensor.

Figure 23: Results of heart rate measurement with adjusted pot meters on the Easy Pulse V1.1.

After discussing this with Linkai Tao, we came to the conclusion that making such a sensor would be more something for the faculty of Electrical Engineering, rather than Industrial Design. It would be great if I could manage to make such a sensor but it was a bit above my level.

I decided to assume that the heart rate could be measured accurately and to focus on 2 other phases after detecting the sleep paralysis; 1) waking the user up and 2) what to do after the user woke up. These steps would make the concept more complete.
FINAL CONCEPT
SLEEP PARALYSIS SENSOR
Sleep Paralysis often comes with vivid and terrifying hallucinations which can have a big social and emotional impact on people's life. People suffering from Sleep Paralysis often can't get out of the paralysis themselves. By taking people out of the sleep paralysis only short after it occurred, the experience will make less impact and people will be less emotionally affected.

A sleep paralysis episode can cause a panic attack which results in a rapidly increasing heart rate. The paralysis will be detected by measuring the heart rate of the person by using a simple sensor. By using vibrations and light the person could be waked and taken out of the Sleep Paralysis.

On the long term, this concept can “train” the people to recognize the paralysis earlier and to be aware of the fact that the hallucinations were part of the paralysis.

The concept consists out of 3 phases; detecting the Sleep Paralysis, waking the person up from the paralysis and the third phase; comforting and processing and accepting the experience.

**THE SENSOR**
The sensor will be used to detect the Sleep Paralysis episode. This will be a simple and comfortable wearable, a wristband. The reason to not use an in-bed heart rate sensor is because Sleep Paralysis also often occurs when people are taking a nap on the couch. In these cases, people also need to be woken from the paralysis. A wearable could detect a Sleep Paralysis episode any time. The wristband would include a heart rate sensor, vibration unit, rechargeable battery, Bluetooth and a microcontroller. To ensure accurate measurements, the material of the wristband must have grip on the wrist so that it can’t easily rotate, but it still needs to be comfortable to wear. A soft silicone material would be a good choice.
HOW WAKE THE PERSON UP?
The person will be woken by a vibration on the wrist. The reason for this is that this kind of alarm will not wake up their partner if they don’t want to. The users can decide whether they want to wake up their partner to share the experiences or not.

A light will also be linked to the wristband. As soon as a Sleep Paralysis episode is detected, the light will go on. Waking up from a scary dream with a light on makes it a lot more comfortable and less scary. The color of the light is a warm relaxing color. The light will slowly change in brightness on the rhythm of a normal breathing to help the person calm down and get their breathing under control.

The light will be switched on by wireless Bluetooth communication between the wristband and the light. The light in the bedroom will not switch on when the user gets an episode while taking a nap on the couch because then the user is too far away from the lamp.

AFTER WAKING UP
The person can’t immediately go back to sleep because then it is more likely that they get back in the sleep paralysis again. For that reason the user needs to get some distraction before going back to sleep. As soon as an Sleep Paralysis Episode is detected by the wristband and the user is waked, the Sleep Paralysis App will pop-up a notification, which will light up the screen of the phone to attract the user’s attention. The user can then spend some time to log his/her experience in the app, which will prevent them from falling back to sleep immediately after waking up from an episode. The user can also choose to later, or not log the episode at all.

LOGGING
The wristband combined with an app will automatically log the date and time of the sleep paralysis and a notification will pop up when an attack has occurred. The user can choose to also keep a log/diary of the episodes and to keep these experience logs for themselves or to share it with the community. There is also the option to reject the assumption of the app that a sleep paralysis episode has occurred in case of a false alarm.

One of the advantages of logging the sleep paralysis episodes is to see if there are patterns and/or relations to certain activities. Logging can also help them to process their experiences and it might be useful for sleep experts and doctors.
THE SLEEP PARALYSIS APP

After a sleep paralysis attack, the date and time will be logged automatically via the Bluetooth communication between the wristband and the app. It is up to the user if he/she wants to fill in the experience log. Some might find it interesting to keep a kind of diary of their experiences so they can read it back or to see if there are any patterns.

The user can also choose to share the logged experience with the community. By using tags, more specific community groups are formed with people who experienced kind of the same. If they choose to share the experience with the community, it will be send to the users from the specific community group. Then users can support each other, which means that they know what they are going through and they let the other know that they are not alone. By a soft vibration on the wristband, feedback about the support is given to the user. The amount of supporters per logged experience is also visualized in the app.

The 10 “best” supporters will appear in the user’s own community “world” within the app. Within this world you can read other’s experiences and have a chat with your supporters to share some more specific experiences, tips or just to talk to someone who experiences the same as you do.

This worldwide Social Support can help people to cope with the negative effects of Sleep Paralysis. Research has shown that social support reduces people’s scores on depression and perceived stress and thus it will help people to stay more positive about the disorder (Andrew JWInzelberg, 2003).

FUNCTIONS OF THE APP
- Overview of Sleep Paralysis episodes
- Logging experiences and reading back experiences
- Sharing experiences with community
- Worldwide social support

- Overview of your worldwide supporters
- Chat with people from your community
- Own profile
More technical structure

How the community groups are formed

Identification is one of the aspects of Social Support, for that reason, the community groups are formed based on the experiences people had. This will be achieved by filtering the people based on the tags they use when filling in their experience log. The people who are the most related to each other, based on their tags, will be in the same community group. Since you can choose different tags every time, this community group can change over time, it is dynamic. This way you will always be in a group with people who are the most related to you. People you already had contact with will stay in your “chat” box.

Example: Let’s say that the numbers in figure 28 stand for different words describing an experience (e.g. #shadow). Dark Grey uses hashtags 1-5, Blue Grey 1-10 and Light Grey 6-10. Then Blue Grey can be in Dark Grey’s world as well as in Light Greys’s world, but because Dark Grey and Light Grey have no common hashtags, they are not in each other’s world. Over time, if Dark Grey is going to use hashtags 6-10 more, then he can end up in both Blue Grey and Light Grey’s world. In the image below you can see what happens if Dark Grey starts using hashtags 6-10 more over time.
Sharing the experiences
The experiences will be shared with people within the community groups, which are larger than the "community world", which only consists out of the 10 best supporters. The size of the community group may not be too large, because then you possibly receive tens of “supports” per day, on the other hand, if the groups are too small, there is a chance that you will not receive any support. There is a way to prevent this from happening, for example, if nobody has supported within 10 minutes, the experience will be send to 10 extra other users, which may be a bit less related to you (less common hashtags). This goes on until support has been given. This way you’ll get at least 1 supporter every time after you’ve had an episode.

Supporting
As soon as the experience is shared with the community, this experience will be received by all kinds of users all around the world. People who are still awake (probably at the other side of the world), will be able to read and support immediately. The user will receive feedback about this support by a soft vibration on the wristband. Hard enough to feel it, but soft enough so it won’t wake you up when you’re asleep. This will give the user the feeling that he/she is not alone and that people support him/her. The support is also visualized in the app.
SLEEP PARALYSIS APP DESIGN

SLEEP PARALYSIS APP
Hi John, it seems that you’ve just had a sleep paralysis episode.
Would you like to log this episode?
Yes, open the app
No thanks
Remind me later

WEDNESDAY, APRIL 20
00:31
CAN YOU DESCRIBE WHAT YOU JUST EXPERIENCED?
Type here
WHAT DID YOU DO BEFORE GOING TO BED?
Type here
WHAT DID YOU DO AFTER THE PARALYSIS?
Type here

CHOOSE TAGS RELATED TO YOUR EXPERIENCE
#blackshadow #falling #shaking #faintmove
Add other tags.

SAVE
SHARE

DATE
WEDNESDAY, APRIL 20, 2016
LAST SLEEP PARALYSIS
YESTERDAY, APRIL 19

M T W T F S S
28
29 30 31 1 2 3
4 5 6 7 8 9 10
11 12 13 14 15 16 17
18 19 20 21 22 23 24
25 26 27 28 29 30 1

Hi! I've been reading all your experiences and they are really interesting and close to mine. Wanna have a chat?

DATE
16-04-2016
EXPERIENCE
I saw a black shadow at the end of my bed and it also felt like I was being pulled into the mattress. Luckily enough, I woke up quickly because of the sensor.

DATE
17-06-2016
EXPERIENCE
I forgot to put on the sensor! What a hell! I saw the same black shadow as always but now he tried to pull me out of the bed! I could not do anything but just wait for it to go over but then I woke up scared. I woke up all sweaty and my heart was pounding! I will never forget to wear that sensor again!
FINAL CONCEPT
PROTOTYPING
One of the problems I encountered was that I was not able to make a reliable heart rate sensor for the prototype of the Sleep Paralysis Sensor. Because the sensor is the trigger for the rest of the aspects of the concept, I had to find a way to “fake” this. I decided to assume that that the heart rate could be detected accurately by a sensor (like already existing sensors such as used in the FitBit, Sony Smart Band 2 etc.) and to focus on the phases after detecting the Sleep Paralysis episode; waking the person up and what to do after waking up.

The wristband will eventually look like the Sony Smartband 2, which includes a heart rate monitor, vibration unit, Bluetooth 4.0, a battery and LED’s (Sony Mobile Communication, 2016). A corporation with Sony could be established to realize this concept. More about this can be found in the chapter “Future plans”.

**WAKING THE PERSON UP**

**The Wristband**

The user will be woken by vibrations on the wrist. The prototype is a wristband with a vibration motor and a button in it, just as the final product would have. (except that the final product would also include a small microcontroller, a Bluetooth module and a battery). I first tested the vibration motor circuit on a bread board, connected to the Arduino. After testing I moved the components to a prototyping board and arranged them in such a way that the small board would fit into the wristband of the Sony Smartband. The schematic can be found in the appendices. Later I put the board in the wristband and poured polyurethane in it to make a small solid block which would fit exactly into the wristband of the Sony Smartband. I chose to make it small but not wireless because this way it would fit into the wristband, which made it look like the final product a lot more. The wires are connected to an Arduino with an RF transmitter module which can send signals to the lamp.

I’ve chosen to use a wristband for the heart rate measurement and waking because of multiple reasons. Firstly, the wrist is a good spot to accurately measure the heart rate (Juha Karvonen MD, Jolanta Chwalbinska-Moneta MD & Seppo Saynajakangas, 2016) Secondly, by waking the person up by using vibrations on the wrist, their partner won’t be waked if they don’t want to. Waking the user up using sound would definitely wake the partner up. I could have chosen to use soft sounds in the pillow for example but I like to keep my designs more simple and straight to the point. The goal is to wake the person up as soon as possible after a sleep paralysis episode, not to wake the person up with a very aesthetic interaction. I also want to keep the designs as low cost as possible and this is one of the simplest and cheapest ways to achieve my goal.
The Lamp
The lamp will have the function to wake the person up but also to comfort the user when the user wakes up. The lamp module consists out of an RF Receiver, NeoPixel ring, an Arduino and a distance sensor. The schematic can be found in the appendices. I first tested the RF modules with a simple code to see if they worked. I choose the RF modules because they were only 1,95 euro per set and XBees are way more expensive (around 70 euro per set). The RF modules were perfect for this application and it kept the prototype cheap.

In the beginning I used a small Neopixel ring with only 8 LED’s but the light intensity was not high enough to light up the lamp shade. I bought a new Neopixel ring and used 40 LED’s of it, which was sufficient to light up the lamp shade. An external power source was needed to be able to power this Neopixel ring.

I programmed the Neopixel in such a way that it would represent a slow breathing to help the user relax and get their breathing under control.
AFTER WAKING THE PERSON UP
The Sleep Paralysis App
I made the design of the app in illustrator and changed it into an interactive webapp in Adobe Muse so I could show to potential users how it looks like on a phone and how it would work. Making an interactive web app/website is a lot easier than developing a complete app so it was a good way to prototype the Sleep Paralysis application.

Developing an actual app would have cost me a lot of time. Since this is just an addition of my concept, a web app prototype was good enough to show the design and functionality of the app.

I first sketched out some of my ideas before working them out in Illustrator and Muse. You can find some of the sketches and different iterations in the images on the right. I used already existing apps as an inspiration for my own app. I had never designed an app before so it was a new experience for me. I learned more about which aspects need to be in the app and also think about the structure/navigation within the app.
FUTURE PLANS
As a designer I need to have an idea how my concept could be realized. In this case I think this concept could be realized quite easily. The technique of the wristband already exists. The Sony Smart Band 2 includes a heart rate monitor, vibration unit, Bluetooth 4.0, a battery and LED’s. This is actually everything I need in the Sleep Paralysis Sensor.

A collaboration with Sony could be established to realize the concept. New software will need to be written, but the wristband will not have to be designed and produced, which will significantly lower the development costs. Besides Sony there are more companies who already produced a wristband with the same functions. If Sony is not interested in a collaboration, these other companies could also be addressed.

The design of the app will be done by myself, together with app developers which will do the coding for me. I will need to design the structure of the app so the developers will know how I want the app work. I already made a web app prototype which I can use to show how the app will look like and how it will work.

For the lamp there are multiple options. One of the options is to use the Philips Hue lamps which can be controlled wirelessly. The Philips Hue lamps can also be placed in your own night-lamp, so you can buy any night-lamp you want and still be able to use the light function of the concept of Design for Sleep Paralysis. Another option is to design a completely new lamp which can be controlled wirelessly via Bluetooth, but this will increase the development costs.
REFLECTION
REFLECTION

Project goal
I am always trying to improve the quality of life of people with a disability. A sleeping disorder can also be seen as a disability. I was attracted to this project because I saw possibilities to improve the sleep quality and the quality of life of people with a sleeping disorder. My goal was to design a user-focused concept which would make the life of those people easier and more comfortable.

Process
I was allocated to the topic of Narcolepsy which, initially, was not my first choice. But this is also how it works in real life, you can’t always choose the project you want to do.

Already early in the process I came to the conclusion that Narcolepsy was a difficult topic. After doing research and having interviews with people suffering from Narcolepsy I found out that everybody experiences the disorder differently and this made it hard to design something which was suitable for everybody.

My process included many different iterations. For a few weeks I’d been working on the Narcolepsy Logging Wristband. A wristband which would support the logging and evaluating of the symptoms of Narcolepsy. This wristband would be the most suitable for quantitative logging of the symptoms. However, after discussing my concept with Sebastiaan Overeem, I came to the conclusion that qualitative/subjective logging is way more valuable for both the doctors as well as the patients.

However, I was not feeling comfortable with this concept because I didn’t believe that a wearable could improve the user interaction of qualitatively logging the symptoms of Narcolepsy enough to continue with this project. I also felt that the concept of the Logging Wristband conflicted too much with ongoing research project of the Narcolepsy App. Besides that I was not feeling comfortable about the project because it was not very close to my vision. I think it is important to look at vision and to design something you’re passionate about.

Change of concept
Halfway the semester I decided to change my concept to something which was more related to my vision. For me, this was a very good choice. I became more enthusiastic and motivated again and was looking forward to finish this project. I was now focusing on Sleep Paralysis, one of the symptoms of Narcolepsy. Finding test users was hard because my user group was quite small. Facebook groups with members all over the world helped me to quickly gain some more knowledge and gather personal experiences without having to travel for hours.

Concept
I am satisfied with the outcomes of my concept. I have done proper research and I think I achieved my goal to design something which improves the quality of life of people with a sleeping disorder, in this case people suffering from Sleep Paralysis. Although I’ve received positive reactions to my project, also from people suffering from Sleep Paralysis, my concept still needs to be validated. Unfortunately, I can only get “opinions” of people, and not a real validation because the prototype is not completely working. I am planning to share the concept with the members of the Facebook groups and to gather as many opinions as possible to “validate” my concept.
Prototype
One of my goals for this semester was to make a fully working prototype. I was eager to make a good prototype but the accuracy of the sensors let me down. Not having a fully working prototype also made user testing a lot more difficult. Eventually I made a prototype which could be “experienced”. It required some imagination of the user, but this was the best way to do it.

Conclusion
Unfortunately, my Final Bachelor project has not been my favorite project because it was a difficult topic and I’ve had some struggles finding a good design case. Nevertheless, I am satisfied with the results and throughout the process and due to the struggles I’ve learned a lot. The overall concept is complete and worked out well. Despite that I was not able to do a proper user test, I have been able to support my findings and design decisions with documentation and experience experts.

I’ve learned to focus on what you as a designer want to achieve and to pursue this goal. Sometimes you do not have to listen to experts but follow your own opinion.
APPENDICES
APPENDIX A
SUMMARY HANS

- Narcolepsy since he was 2-3
- Diagnosed at 30
- Parents never recognized this as Narcolepsy
- Before diagnose
  - Often sick and tired
  - Could not follow classes, not finished school
  - Missed bus stop because fell asleep (public transport not possible)
  - Hallucinations
  - Started working at young age
  - Made a lot of mistakes because of tiredness
  - Sleep paralysis
  - Locked knees to keep standing straight (cataplexy)
  - Naps during the day
  - Described as lazy guy
- Hided illness for partner and relatives > not long at parties
- Became very ill because exhausted his body > caused examination > diagnose
- After diagnose
  - Many things fell on their place
  - Depressive period
- People always see him when it’s going well, you can’t see anything from outside
- Psycho social attack
- People accept it, but do not understand the impact of it
- Has an energy package which he has to divide over whole day
  - Activities depending on energy level
  - As long as it is fun > ok
- No need for contact with other narcotics
- As partner
  - Happy with diagnose
  - New job (money, taking care of kids)
  - Feels like taxi driver all the time
  - Family life dominated by narcolepsy
  - Sacrifice a lot
  - Wake up in middle of night > medication
  - Travel abroad impossible > GHB (medication)
  - Not to “away” games of kids
- Had to change day rhythm and write down weekly planning
- Rides a scooter
- Takes naps 3 times a day (2x 15 min couch, 1x 45 minutes bed) + at least 5 times unconscious
- Eat a lot (better sleeping full stomach + gets energy from eating)
- Positive
  - A lot of spare time and time with kids
- Does not look to the future
- Forgetful
- Would have been nice if diagnosed earlier (could have learned a profession)
- Doctors still too little knowledge
Before medicines cataplexy up to 7 times per hour
- With emotions, jolt and laugh
- During medication almost no cataplexy
- After medication 10 times a day
- Feels very strange to feel your muscles stop
- Stopped with Xyrem because of very heavy side effects (psychoses, emotions)

Tricks
- To restrain cataplexy > squeeze toes
- For nightmares > watch “feel good” movies, makes her dream about those movies. First imagined nice stories to herself
- When feels coming, sit down or hold on to something

First symptoms
- Sleeping while TV, dinner, school, biking
- Discovered through “bonus mother” who was translating a paper about it
- While diagnosed scared from injection > cataplexy
- No self-confidence and gained 15 kg of weight
- Bullied a lot, parents thought that + stress was reason of gaining weight
- Fell asleep within 30 seconds at sleep center diagnose
- Did not want to go to special school, but realized it was better. Now at Kempenheaghe
- She has accepted it is how it is...
  - With medication strong emotions, irritated etc.
  - Became mentally very strong because the side effects are gone, now easier to live with
  - Feels more grown up
  - Can sleep everywhere
- Kids are hard against each other, grownups understand better
- She only tells it if narcolepsy occurs, or if people ask, sometimes too sensitive to tell, especially when telling to peers which are “normal”, she wants to be the same
- Does not look to the future, but from day to day (maybe week)
  - Positive things ok, negative makes her sad and disappointed

Dreams a lot
- Feeling during day influences dreams during the night

What keeps her awake?
- Series > adrenaline
- Parties > fun, temporary
- Coffee > caffeine
- After this extra tired, but sometimes worth it
- Gained 15 kg because of Narcolepsy
  - Parents thought was because of bullying, stress and no sleep
- Forgetful, especially smaller things and conversations
- Meetings with other narcs are interesting, to talk with other people and their experiences
- As parents
  - Disaster, feel sorry for your kid. You can’t help it
  - Annoying that there is so little knowledge about Narcolepsy
  - When she feels ok, parents feel ok
  - Mainly emphasize the positive things in life, things she CAN do
- Stopped thinking about future, makes her mad
- Humor helps to accept it

Feeling during day:
- Feels ok in between naps
- After exercising she feels very tired
Diagnose
- Often slept afterschool
- Sleep paralysis and nightmares/hallucinations
- Fell on the ground when laughing
- Mother searched symptoms and found out
- Sleep survey, (4x 20 minutes sleeping)
- After 18 effects became worse

- A lot of medicines
- Forgetful, mostly small things
- Changed after diagnose
  - She was always very happy, energetic, going out, not anymore
  - Does not work
    - Also not motivated because of many rejections
  - People tell her she can’t or isn’t allowed to do things
    - Very frustrating and hard
  - Has the idea she can do more than she is allowed
  - Spontaneous actions not possible
- Friends take her illness into account
- Does not look at the future > day to day
- Only tells people if they really want to know
  - For others seems worse than actually is
- Has the feeling people understand her, especially relatives
- Advantage: A lot of spare time, not really an advantage in her opinion
- Facebook page mostly negative posts > she is optimistic
- Good that doctors can search for info on such a forum
- Exercising > shaking legs, sweating, extreme heart rate > medicines
- Feels healthy, but body is tired, makes her mentally tired too
- Would like that work would take illness into account
- Feels cataplexy attack coming very shortly before
- Avoids scary movies > hallucinations
- Does not avoid cabaret
- Watching movie/series sitting up straight is ok
- Can fall asleep during conversation
- Consciously avoids long conversations
APPENDIX D
SUMMARY PUCK

- During a normal day always feeling tired, but she is used to it
- When enough stimulants can stay awake
- Does not like to always tell everybody
- Does not take medicines, side effects to heavy and effect decreased over time
- Kids don’t know how it is different, used to it
- After 2 days of no sleep during day, really tired and needs days to recover
- Tight sleeping schedule works better for her
- Staying awake for social/rewarding things is worth it
- Adrenaline + fun + active is good stimulant
- During youth a disaster, missed lot of classes and could not finish school
- Diagnose is needed, better if quickly, normally years
- Acceptance is a process, takes years. Every time new experience you got to live with
- Planned naps 15-20 minutes, “attacks” sometimes only 2 minutes
- Carefully deal with energy, divide by touch
- Extra rewarding after longer, energetic activities
- She feels sorry for her kids
- Not overweight because she stays active because of kids
- Motivation: I’ll have to!
  - Physical exercise: At the moment more energy, after exhausted and tired
  - Shopping with no naps > feeling of sleep-walking
  - Very scary and realistic hallucinations combined with sleep paralysis
  - “sleeps” from 23:00 till 07:00, but wakes up up to 20 times a night
  - Advantage: can sleep everywhere
  - Would be nice if she could go out more and socialize with people. Sometimes hard to find connection
  - Really likes facebookpage
  - Talking with narcotics is nice, but you still need to have a click to stay friends
  - People find it hard to grasp, so also hard to explain. This is frustrating.
- Energy level is unpredictable at beginning of day
APPENDIX E
WIRING LAMP MODULE

DISTANCE SENSOR

NEOPIXEL

DI  SV  GND  DO

ARDUINO

D7 | D6 | D5 | D4 | D3 | D2 | D1 | D0

RF RECEIVER

GND | DATA | DATA | VCC

SV | GND | GND | Vinn

5V | 5V | 5V | 5V | 5V | 5V | 5V
APPENDIX F
WIRINGTRANSMITTERMODULE
APPENDIX G
SCHEMATIC WRISTBAND
Informed Consent Agreement

Please read this consent agreement carefully before you decide to participate in the study.

**Purpose of the research study:** The purpose of the study is to gather data about personal experiences of people with Narcolepsy. This data will be used as inspiration and foundation for the designing of products or services for people with Narcolepsy.

**What you will do in the study:** In this study, an interview will be conducted with a person with Narcolepsy and if agreed also with their relatives. The data will consist out of an audio recording and if agreed a video recording. The participant is always allowed to skip questions which makes them uncomfortable, to pause the interview or to stop the interview at any time. The participant can always ask us to stop recording the video as well as the audio.

**Time required:** The study will require about 1 hours of your time.

**Risks:** The risk is that you name will be published on the showcase (website) and report of the students. Please read “confidentially” for more information.

**Benefits:** There are no direct benefits to you for participating in this research study. The study may help us understand people with Narcolepsy better and to design products or services which fulfil the needs of people with Narcolepsy.

**Confidentiality:** The data will only be used by the students Daan Matthijsse and Lean van den Dikkenberg. The data could be published on the showcase of the students as evidence of the interview. The showcase will be viewed by the assessors of the students, but is also open for other people. The data can also be used in the project report of the students. The participant may choose how the data will be published. Please cross one of the boxes below.

- None of the data may be published on the showcase (internet)
- Only audio
- Do not mention my name and age
- Audio and Video
- Only quotes
- Everything
- You can mention my name and age
- Only mention my age

**Voluntary participation:** Your participation in the study is completely voluntary.

**Right to withdraw from the study:** You have the right to withdraw from the study at any time without penalty. If you decide to withdraw from the study, the audio and video tapes will be deleted from all devices.

**How to withdraw from the study:**

If you want to withdraw from the study, please tell the interviewer to stop the interview. To withdraw from the study after the interview has already taken place, send the interviewer (students) a message through either email or Facebook. There is no penalty for withdrawing
Project Title: Interview Narcolepsy

Payment: You will receive no payment for participating in the study

If you have questions about the study, contact:
Daan Matthijsse
Student Industrial Design
University of Technology Eindhoven
Telephone: 0031 (6) 38 336 129
Email address: d.matthijsse@student.tue.nl

Lean van den Dikkenberg
Student Industrial Design
University of Technology Eindhoven
Telephone: 0031 (6) 83 149 742
Email address: l.j.v.d.dikkenberg@student.tue.nl

Student coach:
J. (Jun) Hu
Faculty Industrial Design
University Of Technology Eindhoven
Email address: J.Hu@tue.nl

Agreement:
I agree to participate in the research study described above.

Signature: ___________________________ Date: ______________

You will receive a copy of this form for your records.
INTRODUCTION
Health and vitality are among the most important application domains of ID at TU/e. Sleep is an essential component of health and ID wants to strengthen its expertise on sleep, sleep disorders, sleep diagnosis and therapy, in order to create intelligent systems, products and related services improving sleep. This goal will be achieved by the new squad SLEEP.

We combine wearables (in-bed and on-body) together with social computing (what can social-media behavior tell us about sleep hygiene, for example). There are currently three PhD students working on topics such as Cognitive Behavior Therapy for Insomnia, and Subjective Sleep Monitoring. We have excellent connections with Philips Design, Philips Research and Kempenhaeghe. Sebastiaan Overeem is a medical sleep expert (and researcher in DI) who is well-known for his research on sleep disorders like narcolepsy, and sleep disturbances in Parkinson’s Disease. One master student works at Koninklijke Auping. We shall also explore the relation between sports and sleep, tapping into the Sports Valley initiative.

DESIGN CHALLENGES
Smart subjective sleep monitoring. Explore interactive solutions that will support people with sleep complaints in monitoring their sleep quality and sleep related behavior over time, in an unobtrusive manner, i.e., with low effort, with respect to a person’s privacy, lifestyle, aesthetics, and values.

Design interventions for insomnia using technology
Many patients with sleep disorders follow Cognitive Behavioral Therapy. Digital Cognitive Behavioral Therapy (DCBT) where interactive applications support patients in this process promises to reduce this workload and allow also a wider population of people with sleep problems to benefit from them. We also look into other interventions beyond CBT, for example Mindfulness-based interventions.

Night “watch”
Design the physical casing for a form to measure sleep related signals during the night: what we wear in the day is not necessarily what we wear in bed. It should be comfortable, and comforting, and it should look appropriate, and its interaction should be calming. Philips have created the technology to measure heart rate variability and movement, which can be applied for sleep monitoring.

Disappearing arm band
Health monitoring smart arm bands, tend to look very cheap and tacky. Could we make this watch physically and cognitively disappear by using different technologies? Or could we design it so nice that it becomes a jewel and a means of personal expression.

Self-Monitoring Experience
This project will evaluate the user experience of self-monitoring health related behaviors using wearables and apps. Does monitoring influence the behavior itself? And how?

Narcolepsy App
App gradually shows its power in many areas, and our way of life has been influenced in many aspects. This project aims to support the design and evaluating of an application for monitoring narcolepsy related symptoms. It raises interesting questions: how mobile and social computing technologies could be utilized to support data collection and self-management for patients and data visualization for doctors?; how would self-logging would influence sleep quality, perceived sleep quality and change of sleep behavior?
Longitudinal sleep quality assessment
Evaluating the usefulness of internight sleep quality reports in assessing sleep quality. This project is going into some depth in empirical research methods relating to evaluating the sleep experience. It will contribute to a running research project, asking the same research question that we asked for healthy sleepers to a population of people with some sleep disorder.
APPENDIX K
DEMO DAY POSTERS

B3.2 Final Bachelor
SLEEP

SLEEP PARALYSIS SENSOR

The Sleep Paralysis Sensor helps people to cope with the negative effects of a sleep paralysis. By measuring the heart rate which increases because of the terrifying experience, a sleep paralysis episode can be detected only short after it occurred and the person can be wakened. By waking the person up only short after an episode has occurred the impact of this experience can be reduced.

The person will be woken using vibrations on the wrist and a special light which also represents a slow breathing to help the user to get his/her breathing under control after a sleep paralysis episode.

World wide social support is offered through the Sleep Paralysis App. Within this app, people can share their experiences and support each other. Research has shown that social support reduces people’s scores on depression and perceived stress so it will help people to cope with the negative effects of sleep paralysis. [1]

Student(s): Daan Matthijsse
Coach: Jun Hu
Expert(s): Linkai Tao

John goes to bed and falls asleep

The sensor measures the HR and starts vibration to wake the person up

John logs his episode in the app and shares it with the community

Sleep paralysis occurs, including hypnagogic hallucinations

John wakes up from the paralysis. The light is automatically switched on to make him feel more comfortable. And the Sleep Paralysis App notification pops up.

The world-wide community can support John, which will make John feel more comfortable and not alone anymore.

The heart rate increases significantly as a result of the anxiety and/or panic.

John can go back to sleep. The support John receives through the app makes him feel a lot better.

John stops the vibration by pressing on the button. This automatically logs the sleep paralysis.
REFERENCES
REFERENCES

DBP001 - Sleep


Sleep Health Foundation (2011), “Nightmares”

National Institute of Neurological Disorders and Stroke (2015), “Narcolepsy Fact Sheet”


G. Browne Goode (1962), “Sleep Paralysis”

Raffaele Ferri et. al. (2005), “NREM sleep alterations in narcolepsy/cataplexy”

Gary S. Richardson et. al. (1978), “Excessive Daytime Sleepiness In Man: Multiple Sleep Latency Measurement In Narcoleptic And Control Subjects”

Anastasios Bonakis (2008), “Narcolepsy presenting as REM sleep behaviour disorder”

Nicholas P. Spanos et. al. (1995), “The Frequency and Correlates of Sleep Paralysis in a University Sample”
Retrieved from: http://ac.els-cdn.com/S0092656685710173/1-s2.0-S0092656685710173-maind?_cache_=2e7e42b0-fa47-1e5-b982-00000aacb362&acdnat=1459762113_83b0b8ae8cf2078d9d8961901c768bf9

J.A. Cheyne (2005), “Sleep paralysis episode frequency and number, types and structure of associated hallucinations”
Alison Abbott (2005), “While you were sleeping”,
Barr Taylor et al. (1986), “Ambulatory Heart Rate Changes in Patients with Panic Attacks”

Jack M. Gorman et al. (2000), “Heart rate variability in depressive and anxiety disorders”
Retrieved from: http://ac.els-cdn.com/S0002870300160053/1-s2.0-S0002870300160053-main.pdf?tid=2cf40-06d0-11e6-92e7-00000aacb35e&acdnat=1461140659_57199f003262bcfd181b06b875045346

Thomas C. Thannickal et al. (2000), “Reduced Number of Hypocretin Clinical Study Neurons in Human Narcolepsy”


REFERENCES IMAGES

Page 11: Kempenhaeghe logo
http://www.brabantzorg.net/brabantzorg/organisaties/Kempenhaeghe/

Page 12: Sleep cycles Narcolepsy
http://thebrain.mcgill.ca/flash/a/a_11/a_11_p/a_11_p_cyc/a_11_p_cyc.html
http://ellewales.com/narcolepsy-infographics/

Page 22: Jan de Wit
http://www.uxcamp.nl/img/people/jan.png

Page 23: Sebastiaan Overeem
https://media.licdn.com/mpr/mpr/shrinknp_200_200/p/2/000/077/327/1848f0b.jpg

Page 29: Pulse Sensor
https://chioszrobots.files.wordpress.com/2014/08/pulse-sensor-heart-chiosz-robots-5.jpg

Page 30: Easy Pulse
Page 39: Sony Smart Band 2

Page 43: Sony Logo
https://mir-s3-cdn-cf.behance.net/project_modules/disp/f6fbb311005713.560ef847bb0c7.jpg