Design of an exoskeleton maturing with boys with Duchenne Muscular Dystrophy

Master thesis by
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Fig. 1 *My "research wall"*

Preface from the designer

Working on this thesis has been an emotional rollercoaster. It was fun, rewarding, difficult, confronting and amazing, all at the same time. I look back on it with a lot of new insights and a result, which you are about to read, which I am truly proud of. However, I could not have achieved this result without the following people.

I would like to first of all thank my chair, Marijke, and my mentor, Gonny, for giving me all the feedback, both professional and personal, I needed to make this project into a success. Thank you, Laura, for your enthusiasm and energetic personality in general, and for always standing by to help me and give me the right advice and perspectives when I needed it. Also thank you to Paulien and the others at Yumen for the freedom you gave me to work on this project in my own way, while giving helpful tips and feedback at the right moments.

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I would like to thank my parents for their endless support and believe in me. Lastly, my dear boyfriend Kyle, for always supporting me and being there fore me. You have the talent of giving me exactly the right words and perspectives when my emotions get the best of me and you always manage to make me laugh.

Executive summary

Boys with Duchenne Muscular Dystrophy have a different life from most children. As they grow up, their muscles lose strength progressively. Around the age of 10, they lose their ability to walk, in their teens they slowly lose their arm function, in their twenties they often need respiratory support and their life expectancy is usually between 30 and 40 years old.

To support Duchenne boys' physical functioning and contribute to their independence, a passive exoskeleton has been developed to support their arm function. The exoskeleton is designed to be physically most beneficial for boys with Duchenne between 10 and 17 years old, which is therefore defined as the target group. It is expected that, as the boys in this target group mature, both their physical and emotional needs regarding medical aids, such as exoskeletons, will change. However, the exoskeleton is not yet able to mature with the user, to accommodate for those changing needs. The design goal of this project is therefore to redesign the exoskeleton to increase its ability to mature, both physically and emotionally, with Duchenne boys from 10 to 17 years old. In order to understand the requirements needed to meet the design goal, both physical and emotional needs of Duchenne boys are researched through a literature study and user research.

Literature shows that the boys can physically benefit from the exoskeleton from the moment of wheelchair confinement (around the age of 10), but do not usually use arm supports until a much later age, or not at all, indicating a lack of perceived relevance for the target group. It also shows that there is a high variety in disease progression, so it cannot be predicted when the exoskeleton needs to be altered to fit and support the user physically.

User research shows that there are three phases of growing up with Duchenne (Naïve Playful Kid (10-12 years old), Anxious Self-Conscious Teen (12-15 years old) and Constrained Reluctant Adolescent (15-17 years old)), who differ on topics such as confidence level, attitude towards their disease, responsibility, social life, relation with their parents, and relation towards healthcare products. Products can have a positive influence on emotional development if they can improve independence and individual functioning. Products can have a negative influence if they feel like an imposition, if the user has no control or choice over them, and if the introduction or alteration of the products confirm further muscle decline.

For the exoskeleton to fit with the physical and emotional maturing process, it should therefore achieve the following design goals. The use of the exoskeleton should be made more relevant for each of the three emotional phases of growing up; the user should be able to focus on positive progress and anticipate on negative decline; the exoskeleton should accommodate for an increasing responsibility and independency of the user; and the user should feel like he has a sufficient amount of control and choice over the exoskeleton.

For the exoskeleton to achieve these goals, a new concept is proposed, which consists of three components. Firstly, the exoskeleton is given an added functionality of controlling devices in the user's house, by making movements. Secondly, an interface containing a coding platform enables the user to decide which devices are controlled with which movements, and through a communication platform he can ask questions and share experience. Thirdly, a service in which an expert regularly checks the exoskeleton's hardware (physical fit and support) and software (controlling functionality).

The concept increases the ability of the exoskeleton to mature with its user, because it ensures the exoskeleton fits well with the needs of all different ages in the target group and because the target group expects the concept to remain interesting for a longer period of time. They expect this because of the amount of possibilities and adaptabilities the interface provides, but also because of the combination of fun and extra independence the extra controlling function provides directly when using the concept. Furthermore, the expert service ensures the physical fit and support of the exoskeleton is regularly checked and updated, without confronting the target group negatively regarding their physical decline. By implementing the concept, the exoskeleton is expected to continue to be relevant for boys with Duchenne and give them a more positive experience as they mature from children to adults.

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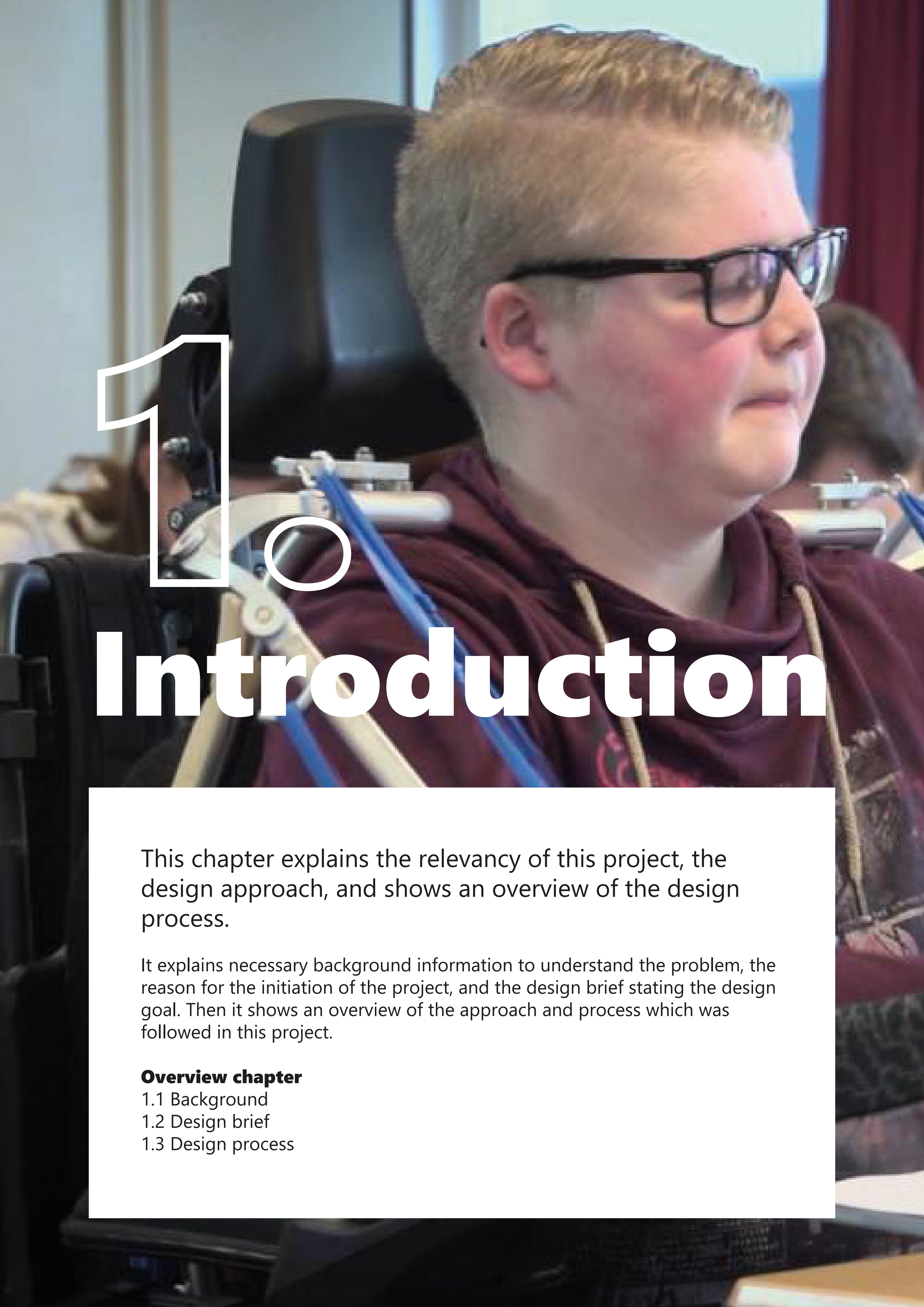


1. Introduction

This chapter explains the relevancy of this project, the design approach, and shows an overview of the design process.

It explains necessary background information to understand the problem, the reason for the initiation of the project, and the design brief stating the design goal. Then it shows an overview of the approach and process which was followed in this project.

Overview chapter

1.1 Background
1.2 Design brief
1.3 Design process

Fig. 2 *Flextenstion A-gear prototype*

1.1 Background

Children with Duchenne Muscular Dystrophy (DMD) have a different life from most children. As they grow up, their muscles lose strength progressively. Around the age of 10, they lose their ability to walk, in their teens they slowly lose their arm function, in their twenties they often need respiratory support and their life expectancy is usually between 30 and 40 years old (Kohler et al., 2009).

Because Duchenne is caused by a mutated dystrophin gene on the X chromosome, only boys have symptoms of the disease, and females are carriers with a 50% chance of transferring the gene to their child (Mendell and Lloyd-Puryear, 2013). The target group is extremely small: only 650 boys/men in the Netherlands have DMD (Van den Bergen et al., 2014). Besides practical problems such as not being able to walk or do simple tasks (like eating independently, scratching their head or hugging a friend), Duchenne can also cause emotional and psychological difficulties in boys' lives, such as affecting their ability to participate in social activities (Hendriksen et al., 2011). Also, as they constantly need specialized help, usually provided by their parents, it is challenging to become autonomous and build their own future.

Boys with Duchenne are still just normal children and teenagers growing up and wanting to function and be independent as any other. Although the wheelchair fosters this by coping with the loss of leg function, there are little suitable aids developed for the loss of arm function, which happens mostly in their teenage years. Since life expectancy has increased tremendously in the last years (Eagle et al., 2002) (Kohler et al., 2009), and Duchenne boys and men nowadays have to live without arm function for a significant part of their adolescent and adult life, the relevancy of this problem has increased.

In order to accommodate for the lack of suitable arm supports, Yumen Bionics was founded to develop a passive exoskeleton which supports the arm function of Duchenne boys. It was founded based on the A-gear, an outcome of the Flextension research project (figure 3) (Kooren et al., 2015). "Passive" means the exoskeleton has a supportive function for the muscles of the wearer, but is not driven by an external force such as a motor. By making use of a balancing system, the exoskeleton carries the weight of the boys' arms, so they can use all their strength to move their arms in the way they want (Lin et al., 2013). This can positively influence their functioning and independence in their everyday lives. It also helps training their arm muscles, so the weakening process is slowed down and they can use their arms more effectively over a longer period of time. The exoskeleton is expected to be physically most beneficial for boys with Duchenne between 10 and 17 years old, who are therefore defined as the target group.

Fig. 3 *The A-gear (Flextension): first prototype of a passive exoskeleton for Duchenne boys*

1.2 Design brief

Although the functionality and mechanics of the exoskeleton, as described in chapter 1.1, are far developed, it is not yet designed specifically for boys of different ages within the target group. The exoskeleton can, to a certain extent, be adjusted in size to fit to the user, but thus far little attention is put into whether it is the right type of solution for all ages within the target group.

It is expected that as boys with Duchenne Muscular Dystrophy grow up between 10 and 17 years old, their physical and emotional needs regarding medical aids, such as exoskeletons, will change. However, the exoskeleton is not yet able to mature with the user, to accommodate for those changing needs. The design goal of this project is therefore to redesign the Yumen exoskeleton to increase its ability to mature, both physically and emotionally, with the intended user.

However, little research is done into the process of Duchenne boys maturing, physically and emotionally, so it is unclear what is needed for the exoskeleton to fit within this maturing process. In order to achieve the design goal, this thesis therefore aims to research the physical and emotional needs of boys with Duchenne between 10 and 17 years old, in order to get a deeper understanding of what is needed for the exoskeleton to mature with them. Subsequently, the outcome of this research will be used as input for the redesign of the exoskeleton.

The original Project Brief of this graduation assignment, which was agreed upon with all supervisors before the start of the project, is included in appendix A. Furthermore, appendix B shows a mindmap containing initial exploration of research questions related to the design goal.

Design goal:

To redesign the exoskeleton to increase its ability to mature with Duchenne boys from 10 to 17 years old

1.3 Design process

2

Product analysis to understand the current technology and interactions of the Yumen exoskeleton

3

Literature study to map the physical needs and maturing of boys with Duchenne between 10 and 17 years old

4

User research to map the emotional needs and maturing of boys with Duchenne between 10 and 17 years old

5

Define **focus** (design vision and design guidelines) based on the combined insights gathered in all research

6-7

Design phase with the ideation, development and evaluation of different concepts, leading to a final design

8

Validation, to test to what extent the design accommodates the initial design goal of increasing the ability of the exoskeleton to mature with the user

9

Recommendations, containing recommendations for further development and steps to improve and implement the concept

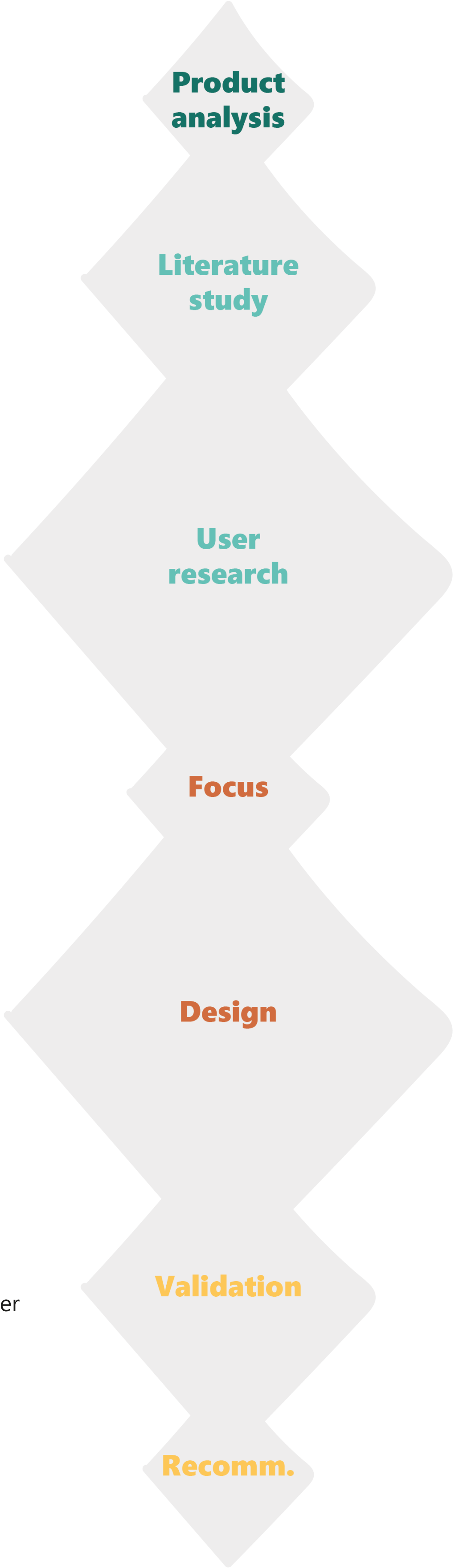


Fig. 4 *Design process*

__Fig. 5__ Methods and tools used during the design process

2.

Product analysis

This chapter contains an analysis of the functioning of and interactions with the exoskeleton

In order to redesign the product, it must first be understood and anlysed thoroughly. Therefore, this chapter analyses how the product works and how the interactions with the product are currently, in order to understand and define opportunities for growth and maturing.

Overview chapter

2.1 Approach
2.2 Product functioning
2.3 Product interactions
2.4 Key insights

Fig. 6 *A prototype of the exoskeleton*

2.1 Approach

In order to find opportunities to redesign the exoskeleton, to increase its ability to mature with the user, the exoskeleton must first be analysed. The insights gained from the analysis serve as a clear starting point for further research (chapter 3 and 4), and eventually for the redesign (chapter 5, 6 and 7).

The following **research questions** were formulated:

- How does the exoskeleton function and which parts does it consist of?
- How are the interactions with the exoskeleton, currently?
- How is the exoskeleton currently designed for adjustments?

To answer the research questions, the product was analysed by observation and by interviewing an engineer from Yumen Bionics. Chapter 2.2 describes the product functionality and chapter 2.3 analyses the interactions with the product and the user, daily helper and professional. In chapter 2.4, key insights from the anlysis are summarised.

Fig. 7 *The passive exoskeleton gives Duchenne boys the ability to move their arms how they want to*

2.2 Product functioning

2.2.1. Exoskeleton parts and functions

The exoskeleton's objective is to help boys with Duchenne to move their arms in the way they want to (see figure 7). In figure 8 (page 18-19), the most recent prototype of the exoskeleton can be seen. The exoskeleton supports the arm function by balancing part of the weight of the arms using the Lin-principle (Lin et al., 2013). Using elastic springs with the appropriate strength for the user's arm weight and remaining muscle strength, part of the weight of the arms is 'lifted' or 'weightless'. Because the arm weight is taken away, the boys can use their remaining muscle strength to move their arms.

Figure 8 shows the design of the exoskeleton and indicates the separate parts and their main functions. From this overview and previous research, the following conclusions can be made.

The exoskeleton and all its parts are currently designed with the main objective of functioning, which is done successfully. In a recent pilot study performed with three DMD boys and three boys with Spinal Muscular Atrofy (SMA), the ability to perform ADL's (Acitivities of Daily Life) increased with 11.6% on average (variation 2.7-23.2% for individual test participants) by using this prototype (Janssen and de Groot, unpublished). This means the exoskeleton supports the arms effectively.

In this project, the objective will not be to redesign the basic functioning. However, **there is room to add functionality to the exoskeleton, if that would enhance the ability of the exoskeleton to mature with the boys.**

Besides functionality, other criteria are considered important for acceptance of the exoskeleton. A questionnaire filled in by 350 people with Duchenne worldwide has shown that only 8.5% uses some form of arm support (Janssen et al., 2014). Other studies have shown that the most important factors besides functionality for the users are inconspicuousness, intuitive use, easy donning and doffing and comfort (Rahman et al., 2000) (van der Heide et al., 2015). These criteria are considered important for the final design of the exoskeleton, but were of secondary importance for the current prototype. This project will focus on these factors, if they appear to be an important factor for a maturing exoskeleton as well (which is further researched in chapter 3 and 4).

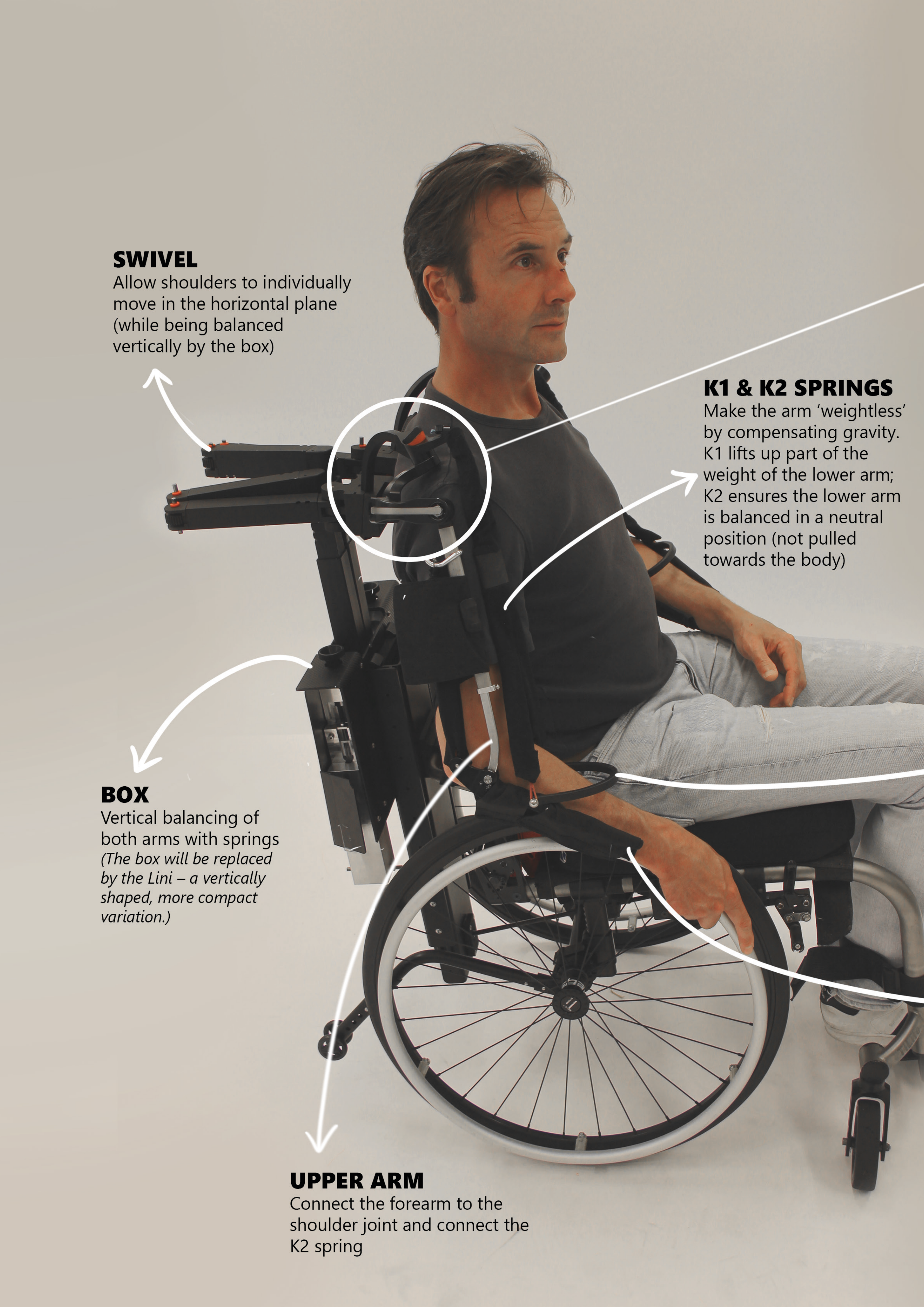
The exoskeleton design is a prototype which is still under development. The design is fluid; parts are updated and redesigned regularly. This means **there is a lot of room for changes and updates within this project.**

2.2.2. Possible adjustments

Some parts of the exoskeleton, in its current form, can be adjusted and some cannot. An overview of possible adjustments is shown in appendix C (information obtained from Yumen Bionics directly).

Although the exoskeleton can be adjusted to the size and muscle strength of the user, it is cumbersome to make these adjustments and they can only be done by an installer (only the length of the upper arm can easily be re-adjusted). Also, the frequency with which these adjustments need to be redone during one user's lifetime is unknown. Besides, there is no research done into what impact the adjustments can have on the boys; how will the experience of the adjusting be for them and what impact does this have on the overall perceived use? **It is needed to explore how frequent these adjustments need to be done, how the adjustments can be less cumbersome, and what impact these adjustments can have on the boys' lives.**

All possible adjustments over time are about size and needed support. **There are no changes in the use of the exoskeleton itself.** This is logical, because it is unknown if and what needs to change about the exoskeleton to keep it relevant and attractive to use for Duchenne boys of different ages. Therefore, thorough research is needed into how Duchenne boys mature over the years (both physically and emotionally) and what those developments imply for the design of the exoskeleton.

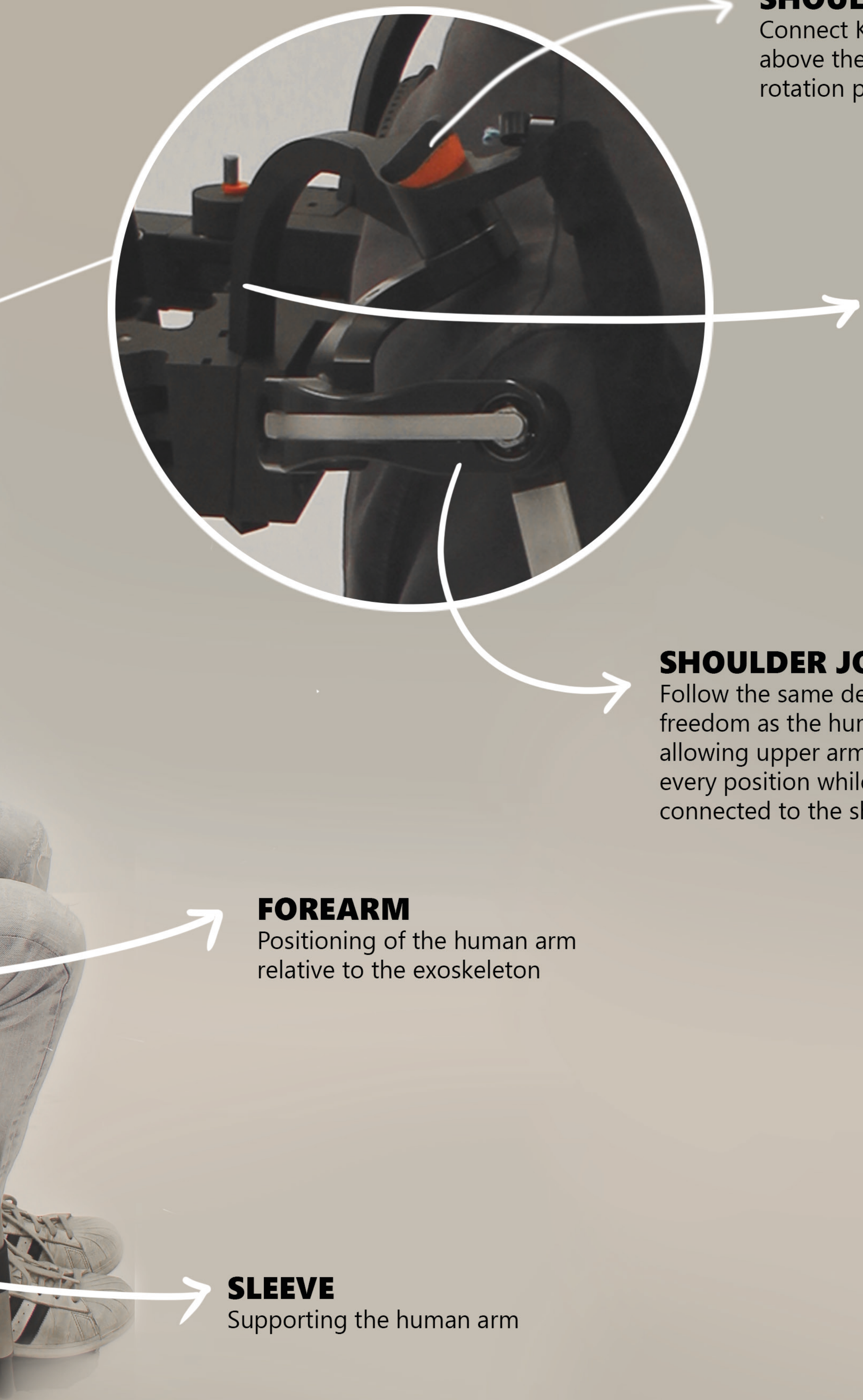


SWIVEL
Allow shoulders to individually move in the horizontal plane (while being balanced vertically by the box)

K1 & K2 SPRINGS
Make the arm 'weightless' by compensating gravity. K1 lifts up part of the weight of the lower arm; K2 ensures the lower arm is balanced in a neutral position (not pulled towards the body)

BOX
Vertical balancing of both arms with springs
(The box will be replaced by the Lini – a vertically shaped, more compact variation.)

UPPER ARM
Connect the forearm to the shoulder joint and connect the K2 spring



SHOULDER ADAPTER
Connect K1 spring exactly above the virtual shoulder rotation point

BACK CONNECTOR
Keep the shoulder adapters on a fixed width to each other without rotation of the shoulder adapters

SHOULDER JOINT
Follow the same degrees of freedom as the human shoulder; allowing upper arm to move in every position while being connected to the shoulder adapter

FOREARM
Positioning of the human arm relative to the exoskeleton

SLEEVE
Supporting the human arm

Fig. 8 *The exoskeleton - parts and functions*

2.3 Product interactions

Fig. 9 *Daily interactions are done by daily helpers (parents) - not by the boys*

Appendix C shows an overview of the interactions of each part with the user, daily helper and installer (information obtained from Yumen Bionics). The following conclusions can be made from this overview.

- **The only parts that the user directly interacts with through touch are the back pad of the back connector and the sleeve.** Besides, the only parts the user can see daily, are the sleeve, forearm and upper arm of the exoskeleton (the other parts are visible for everyone else in his surrounding).
- **The user has no role in donning and doffing of the exoskeleton, while this happens daily.** It might be interesting to see if and how it is desired for the user to have a bigger role in this.
- **The user has no role in installation, short-term or long-term changes on the exoskeleton.** It is interesting to explore if and how it is desired to involve the user more in this process.
- **The most important interactions of the daily helper (usually the parents) are the daily handling, donning and doffing of the exoskeleton.** It is interesting to explore how these daily routines might change over time (because the parent-son relationship might change) and what influence this can have on the user experience of the boys.
- **Interactions of the installer are all about adjusting the size and amount of support, to fit the user.** Currently, these interactions are cumbersome and can only be done by an installer, to ensure the safety and functionality of the exoskeleton. It is interesting to gain insight into the frequency and repetition of these installations, to see if and how these interactions need redesigning.

2.4 Key insights

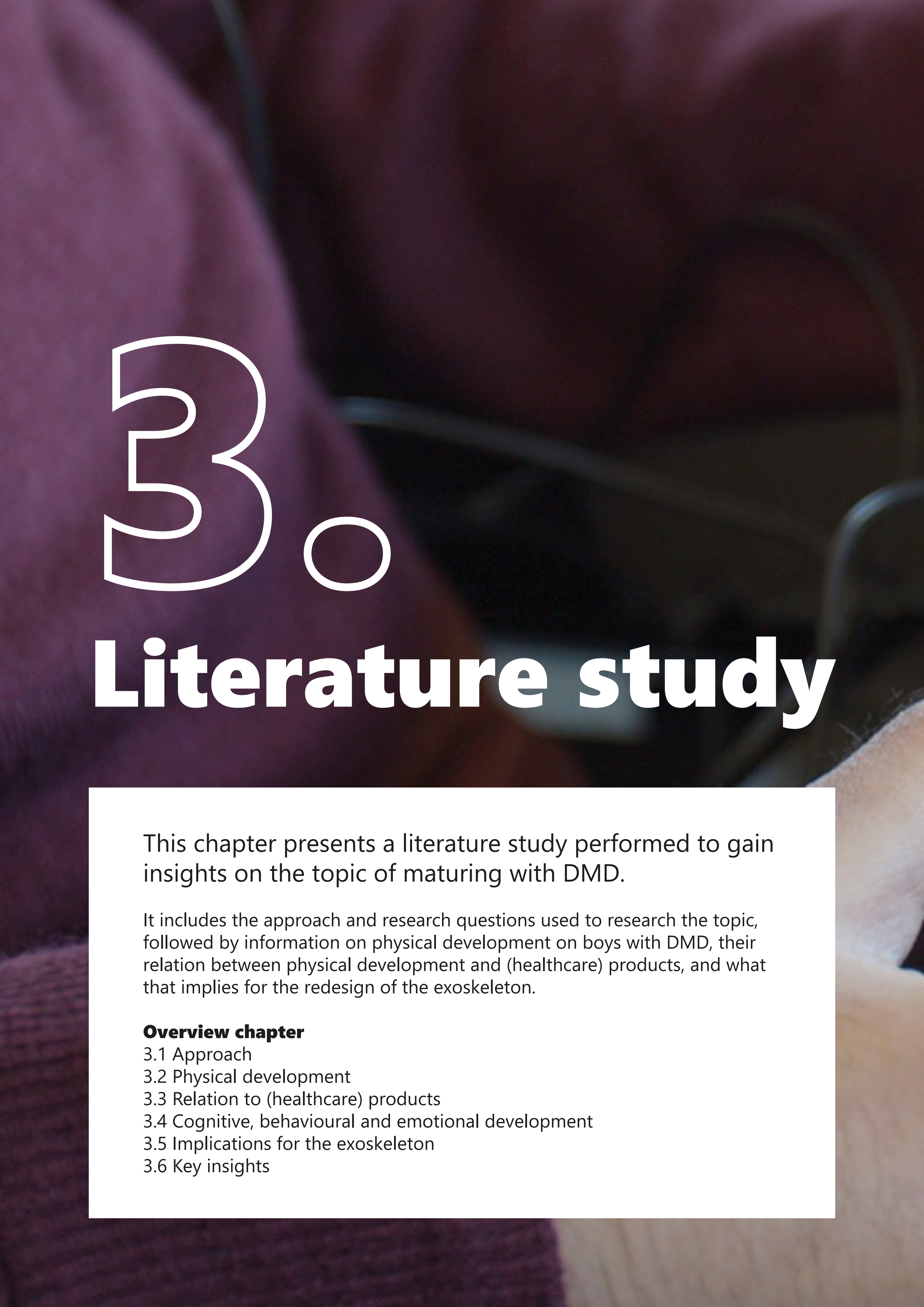
- The exoskeleton is designed to **support** the arm function of boys with Duchenne, so they can perform Activities of Daily Life more independently for a longer time. This is done by making part of the arms weightless, so remaining muscle strength can be used to move the arms.

- The objective of this project is not about changing the basic functioning principle of the exoskeleton (supporting the arms) – this is already done successfully. **The objective is to redesign the use of the exoskeleton, so it stays relevant for the user over the years.** There is room to add functionality if this facilitates maturing of the exoskeleton better.

- It needs to be explored how **Duchenne boys can have a bigger role in daily interactions, short-term changes and long-term adjustments** in the exoskeleton, and if it is desired for the boys to make more decisions over these interactions and adjustments.

- Possible changes or adjustments in the exoskeleton are currently only physical, and are **cumbersome and difficult to perform** (can only be done by installer). There are no changes in the use of the exoskeleton itself – interesting to explore possibilities.

- Before the exoskeleton can be redesigned to be maturing with Duchenne boys, **more insights on how they mature over time** are needed.



3.

Literature study

This chapter presents a literature study performed to gain insights on the topic of maturing with DMD.

It includes the approach and research questions used to research the topic, followed by information on physical development on boys with DMD, their relation between physical development and (healthcare) products, and what that implies for the redesign of the exoskeleton.

Overview chapter

3.1 Approach
3.2 Physical development
3.3 Relation to (healthcare) products
3.4 Cognitive, behavioural and emotional development
3.5 Implications for the exoskeleton
3.6 Key insights

Fig. 10 *Contractures in hands due to product use*

3.1 Research approach

In order to understand how a product can mature with a user, the maturing of the user himself must first be understood. As stated in the design brief (chapter 1), maturing can be looked at in two different ways; physical development (growth), and emotional development (growing up). In this chapter, the physical development is analysed by performing a literature study, complemented with an interview with expert Mariska Janssen, researcher and expert on Upper Extremity function in DMD. Since the exoskeleton is meant to support the arms and shoulders, this chapter focusses, next to general physical development, especially on the Upper Extremity functionality. Literature about emotional development is also studied, however since literature on this topic appears to be limited, it is researched further by performing user research - this is further explained in chapter 4.

The following research questions were formulated:

- How do boys with Duchenne develop physically from 10-17 years old?
- How can (healthcare) products influence the physical development?
- What does the physical development imply for the design of the exoskeleton?

Chapter 3.2 focusses on physical development of boys with Duchenne, whereas chapter 3.3 focusses on the influence of products on this development. Chapter 3.4 explores the topic of cognitive and psychosocial development (which is what is available in literature studies and comes closest to emotional development). Finally, chapter 3.5 shows implications for a maturing exoskeleton. In 3.6, key insights are presented.

3.2 Physical development

3.2.1 Disease stages

Bushby et al. (2010) defined four disease stages Duchenne boys go through while growing up, namely early ambulatory, late ambulatory, early non-ambulatory and late non-ambulatory (ambulatory referring to their ability to walk). Early ambulatory is the stage where the boys start to show symptoms, but are still able to walk and climb stairs. Late ambulatory means they are still able to walk, but not to climb stairs or get up from the floor independently. The early non-ambulatory stage refers to when they are not able to walk anymore and have become wheelchair-dependent, but their Upper Extremity (arm) function is not very limited yet. In the late non-ambulatory stage, the boys also experience serious limitation in UE function.

To study more about upper extremity limitations in each stage, Janssen et al. (2014) distributed a survey amongst 344 Duchenne patients, aged 1.5-35.2, which were subdivided into the four stages based on functionality questions. The median age of the four stages were respectively 7.2, 11.6, 13.5 and 19.9 (figure 11), but there was a high variety of age within each stage, so it cannot be predicted at which age a boy with DMD would reach a certain stage and with which pace the disease develops. Therefore, it cannot be predicted at which points the exoskeleton should be adapted to support further muscle function loss. This calls for a highly individualized approach per user.

Since the exoskeleton is designed to be mounted to the user’s wheelchair (see chapter 2: Product analysis), the earliest it can be introduced would be in the early non-ambulatory stage.

Fig. 11 *Disease stages and average ages (high variety)*

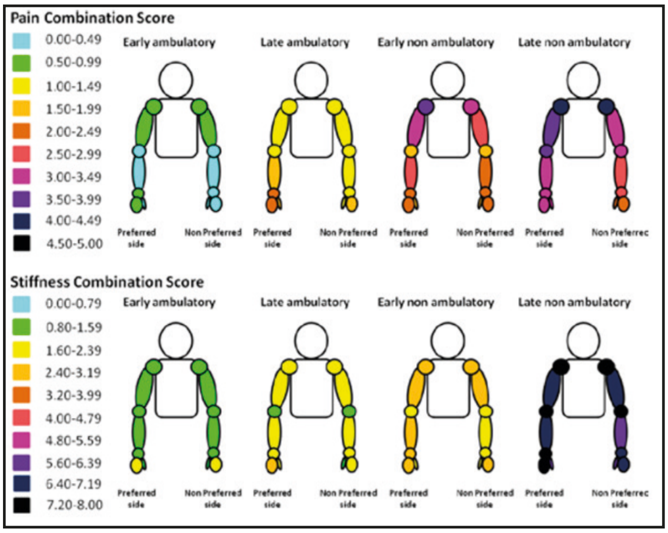


Fig. 12 *Average UE pain and stiffness scores per disease stage per body segment (Janssen et al., 2014)*

> **“Although the muscles in their arms decline gradually, losing a function can happen suddenly”**
>
> Mariska Janssen, researcher
> Upper Extremity function of Duchenne

3.2.2 Upper extremity function

Janssen et al. (2014) have studied the Upper Extremity (UE) pain, stiffness and activity limitations and have concluded that all three evolve which each disease stage. Furthermore, they have concluded the following decline patterns.

This study showed that UE activity limitations already start in the first (early ambulatory) stage, long before the boys end up in a wheelchair. Social participation, for instance, is already limited in this stage due to UE impairments (Janssen et al., 2014). This implies that interventions (such as using an arm support/ exoskeleton to retain UE function) should start way before DMD boys become wheelchair confined. Since the current design of the exoskeleton does not allow this (wheelchair mounted solution), it should at least be encouraged to start using directly when they have reached the early non-ambulatory stage.

Besides, Janssen et al. (2014) researched the pain and stiffness evolvement of DMD boys in every disease stage. In figure 12 (Janssen et al., 2014), pain and stiffness combination scores of boys with DMD for each stage can be seen. It shows that pain increases rather gradually, while stiffness suddenly increases in the last disease stage. Stiffness can happen when contractures occur, which can greatly influence the ability to perform UE activities. To retain UE function, “preventing contractures is of utmost importance” (Janssen et al., 2017). Since the exoskeleton can keep joints flexible and keeps the range of joint movements big, it can help to prevent contractures. Therefore, it is important to introduce the exoskeleton in the boys’ lives before contractures start to occur, so before the last (late non-ambulatory) stage.

Although the muscle deterioration evolves gradually, the loss of a function is more stepwise and often feels sudden for boys with DMD (Janssen, 2020). In their experience, one day they can do something and the next day they cannot anymore. The exoskeleton should take this ‘sudden’ loss of function into account and should therefore be easily adaptable in the amount of support to accommodate for stepwise function loss.

Another pattern in UE limitation, which has been proven multiple times in literature and was confirmed once again, is the order of decline, which is from proximal to distal (Janssen et al., 2014). This means that muscle deterioration first occurs in the shoulders, then upper arms, elbows, lower arms, wrists and finally hands. For an optimal training effect, the muscles that first get weak (proximal) should first be supported, and distal muscles should be supported later. In this way, DMD boys use their muscle capacity to their optimal ability (Janssen, 2020).

Janssen et al. (2017) has presented a model of functional decline in DMD (see figure 13). This model gives great insights into the overall physical development of boys with DMD, which is why it is presented it in this report as well.

From this model it can be concluded that, before the boys notice a decline, UE task performance is already declined and before that, UE muscle capacity already shows a difference from healthy boys. Besides, UE function decline already starts before losing ambulation, although boys with DMD do not notice it yet. From this model it can be concluded that Duchenne boys will not notice in time when an arm support (such as an exoskeleton) is needed and that an early introduction of the exoskeleton in their lives should be encouraged.

Although there is a clear general pattern of progression in Upper Extremity function, there is a great variability of how and when the function and limitations progress (Janssen et al., 2014). Therefore, it cannot be predicted beforehand which UE support is needed at which specific moment for an individual. The exoskeleton design should therefore allow for a highly individualized approach, and be adaptable for each individual patient over time. As mentioned in chapter 2, these adaptions currently need to be done by an expert to ensure the safety and functionality of the exoskeleton.

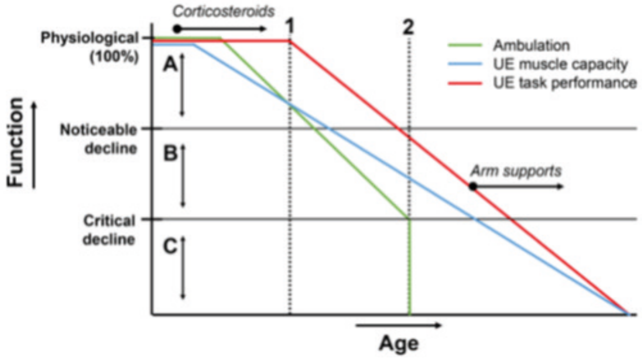


Fig. 13 *Model of functional decline in DMD, by Janssen et al. (2017),*
A: natural reserve, B: compensatory phase, C: loss of function. 1: loss of muscle function precedes functional decline, 2: UE function decline starts already before losing ambulation

3.2.3 Anthropometry

Anthropometric data on DMD boys is scarce; it is only known they have a shorter statue compared to healthy boys, which is exacerbated by the use of corticosteroids (Sarrazin et al., 2014). Unfortunately, there is no anthropometric data published of DMD compared to healthy subjects on specific measurements correlated with the arms. Although it is important for an accurate design of a maturing exoskeleton to form such a database, this is out of the scope of this project due to time limitations. From general knowledge, it can be concluded that the size of the exoskeleton must change or be adjusted over time to accommodate to the boys' physical growth, but it cannot be predicted with which frequency this must happen. Therefore, the design and service around it should allow for a highly individualized approach.

3.2.4 Weight increase- and fluctuation

Although there is little data available on the physical growth of DMD boys compared to healthy subjects, it is known that DMD patients generally have a higher BMI (Sarrazin et al., 2014). They are already overweight since infancy and without the use of medication. However, the use of corticosteroids, which is proven in several studies to help retain muscle function for a longer period of time (e.g. Biggar et al., 2006), often causes more increase in BMI (Sarrazin et al., 2014). Besides, since corticosteroids are often used on an on-off-schedule to moderate side effects (Connolly et al., 2002), the weight can fluctuate, although the frequency is unknown, and it is highly variable per patient. Also, external factors, like confinement to a wheelchair, can cause a rather sudden weight increase (Richardson and Frank, 2008). Weight increase and -fluctuation might have a negative emotional effect on teenage boys with DMD (more about this in chapter 4). The design of the exoskeleton should take possible sudden weight increase and weight fluctuation with high variety into account.

3.2.5 Effects of disuse vs. training

Bergsma et al. (2017) compared the characteristics of four neuromuscular diseases (NMD). He concluded that DMD is typically related to inactivity and underuse of muscles (not using them to their full capacity). DMD patients experience relatively little pain compared to other NMD patients, but relatively many activity limitations. Since they have a high risk of disuse, strategies should revolve around making them move more (Bergsma et al., 2017). The exoskeleton can have precisely this effect; even though they can still perform a function with their own muscle capacity, wearing the exoskeleton would result in performing that function more frequently (Janssen, 2020).

Boys with DMD often end up in the vicious cycle of disuse; their arms are too tired to perform a function frequently, the function declines further, meaning it is even more difficult to perform, eventually resulting in the loss of the function all together (Jansen et al., 2013).

However, disuse can be prevented by regular physical training. Jansen et al. (2013) found that a low-resistance (arm) bicycle training, which is feasible and safe for boys with DMD even in later disease stages, can be beneficial to retain muscle function for a longer time. It showed that the more often and regular boys perform a training, the better their muscle function is retained. This implies that the use of the exoskeleton should be daily and frequent, to reach this same training effect. Also, using a dynamic arm support as assistance to perform a training which otherwise would not be possible can improve or retain muscle function that would otherwise be lost to disuse (Jansen et al., 2015). Since the exoskeleton is essentially a dynamic arm support, it can have the same effect. However, if this training is initiated too late, when too much function has already been lost, a training might not have any beneficial effect anymore (Jansen et al., 2015). This again underlines the importance of starting the use of the exoskeleton as early as possible.

Fig. 14 *Motivating Duchenne boys to keep moving*

Fig. 15 *Regular physical training prevents disuse*

3.2.6 Physical developments timeline

Figure 16 shows a visual timeline of the physical developments of boys with DMD from 10 to 17 years old, which were presented in this chapter.

- The blocks represent the disease stages – wheelchair confinement defines the start of the early non-ambulatory phase. This moment also defines the start of (possible) exoskeleton use, since it is installed on the wheelchair.
- The green line represents physical growth; although little data is available on this, from general knowledge it can be concluded physical growth will occur in the boy's teenage years. A growth spurt is not uncommon for teenage boys. Physical growth and growth spurts can imply a necessary physical change in the exoskeleton's size.
- The purple line represents weight fluctuation; it is known wheelchair confinement can cause a weight increase, which can later fluctuate due to medication use and (possibly) dieting. Again, this differs per individual. Weight fluctuation can imply a necessary physical change in the exoskeleton's size.
- The light blue line represents UE muscle decline. Although with a different pace for each Duchenne boy, the pattern of gradual muscle weakening is generally the same. Muscle weakening implies more support from the exoskeleton is needed over time, meaning the elastic spring strength needs to be increased.
- The dark blue line represents UE functional decline, meaning the functional tasks DMD boys can perform with their remaining muscle strength. This line declines more stepwise, because loss of function happens rather suddenly in the boy's experience. A sudden functional loss implies a change in the amount of support the exoskeleton gives, so the function can be regained again.

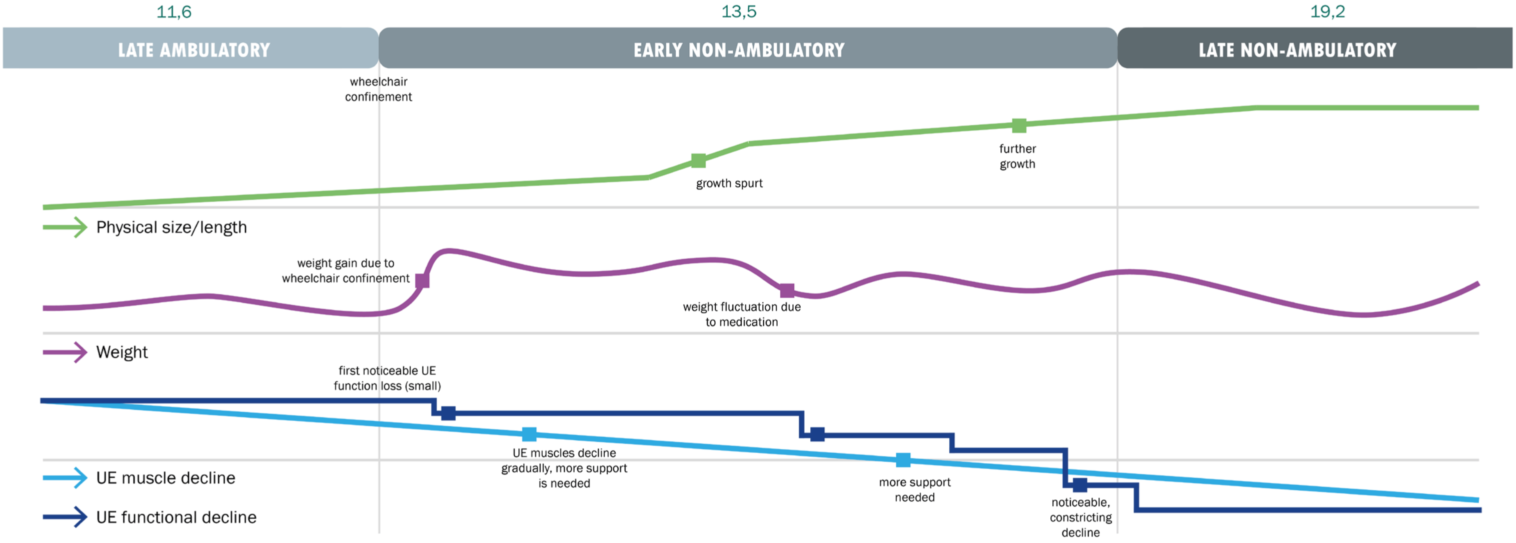


Fig. 16 Physical developments timeline

3.3 Relation physical development and products

3.3.1 Wheelchair, top blade and game controller

Usually, products with the goal of improving or retaining functioning in daily life are introduced when boys are starting to lose, or have already lost a function (Janssen, 2020). For instance, the wheelchair is introduced when a boy is not able to walk anymore. However, although introducing a product can help to perform daily activities and live as independently as possible, it can also cause an accelerated decline in muscle function. For example, using a wheelchair with a top blade results in the user only moving in within the limits which the wheelchair allows (Jansen et al., 2015). This can result in not using muscles to their full capacity, which further increases the risk of disuse. Richardson and Frank (2008) have also found a negative effect of wheelchair use on posture, pain and deformity.

Generally speaking, if a product puts the user in a certain position, he will only move within the limits of this position. He will train these movements, but also lose the possibility to do other movements (Janssen, 2020). The game controller (figure 17) is another example; although with frequent use the fingers will be trained, the posture of the hands and body might result in contractures in the wrists and shoulders (Janssen, 2020).

3.3.2 Dynamic arm supports and exoskeleton

The use of a dynamic arm support, such as the exoskeleton, can have a positive effect; it can increase the use of muscles that would otherwise be underused, enlarge the range in which the user can move and make movements more dynamic and frequent, which in its turn prevents disuse and contractures (van der Heide et al., 2015), (Janssen, 2020). It can also be used to train the arms dynamically to retain arm function (Jansen et al., 2015).

As mentioned in chapter 2 (product analysis), despite the functional advantages the dynamic arm support can give to its users, and its potential to improve their quality of life (Bergsma et al., 2016), the actual use in daily life seems to be extremely low (Maciejasz, 2014), (Janssen, 2014). This suggests that more than functionality alone is important for boys with Duchenne to start using a dynamic arm support (van der Heide et al., 2015). With the A-gear project, prior to the development of the Yumen exoskeleton, this problem was already addressed by attempting to make the use of the exoskeleton as natural and the looks as inconspicuous as possible (Kooren et al., 2015). Chapter 4 further explores what is needed for boys to accept wearing an exoskeleton in their daily lives.

Fig. 17 *Holding the joints in the same position because of a product can cause contractures*

3.4 Cognitive, behavioural and emotional development

3.4.1 Cognitive development

It is known that boys with DMD have a low average IQ, but with a high variation (Hendriksen et al., 2011). Therefore, just like with physical functioning, it calls for a highly individualised approach; whether a boy with DMD has problems with learning in school, for example, should be carefully examined per individual. Contrary to the physical functioning of boys with DMD, their cognitive functioning does not decrease over time (Hendriksen et al., 2011).

Learning disorders (dyslexia and dyscalculia) occur more frequently in boys with DMD. However, with the right support, they usually are able to keep up with their peers in normal education (Hendriksen et al., 2011). In some cases, special education is needed.

3.4.2 Behavioural development and psychosocial adjustment

Behavioural disorders are more common in boys with Duchenne Muscular Dystrophy, but only a small percentage is affected by it (Hendriksen et al., 2011). Furthermore, every child who has a disability has to, to some extent, adapt to the consequences of that disability, which is called psychosocial adjustment. A study by Hendriksen et al. (2008) showed that overall psychosocial adjustment was not significantly different in DMD compared to males with other chronic medical conditions. Besides, it was positively associated with increases in age, indicating that boys mentally adjust better to their disease as they grow older.

This development is interesting for the design of the exoskeleton; it might be that older boys will accept wearing the exoskeleton more easily, because they have become more used to accepting the consequences of their disease.

3.4.3 Emotional well-being

Hendriksen et al. (2011) state that the quality of life of boys with DMD can be equal to, if not better than, the quality of life of healthy people. They mention that boys with Duchenne have a good chance of having a full adult life with higher education and employment. In order to achieve a good quality of life, it is important for parents to treat them equal to their siblings and other healthy children (Hendriksen et al., 2011). A Health Related Quality of Life (HQRoL) study of Houwen – van Opstal et al. (2014) has shown that boys with Duchenne rate their own quality of life similar to their healthy peers, with exception of physical abilities. Parents, however, scored their sons much lower on the domains “Self perception” “Moods and emotions”, and “Bullying” than the boys themselves. Bray et al. (2010) has found similar results: parents and boys had a moderate to poor agreement on health-related quality of life measures, with parents reporting lower overall health-related quality of life when compared with their sons. According to how Duchenne boys rate their own quality of life, it can be expected that their overall emotional well-being is of an average level. However, since parents rate their own son’s quality of life lower, they might be more careful or overly protective with their son. This might have indications for the exoskeleton use; for example, they might experience difficulty with letting their son wear the exoskeleton, fearing they might get bullied in school. This interesting dynamic in the relation between parents and DMD boys is further explored in chapter 4.

There was no literature found which gives specific knowledge on the emotional development of boys with Duchenne focussed on adolescence (aged 10 to 17). Although it is known that generally, boys with DMD do not rate their quality of life lower than their healthy peers, it is unclear how emotional needs develop and change over time during adolescence exactly. Besides, it is not yet researched how products, for example for healthcare, can influence their emotional well-being while they mature. This knowledge, however, is important in order to understand how an exoskeleton can be designed to influence Duchenne boys’ emotional well-being in a positive way. Therefore, chapter 4 aims to qualitatively research emotional needs and development of Duchenne boys from 10 to 17 years old.

3.5 Implications for exoskeleton

From the findings in this chapter, the following implications for the design of a (physically) maturing exoskeleton were defined.

Firstly, we should **encourage an early introduction of the exoskeleton**, since UE impairments already start in the earliest disease stage (early ambulatory) and the sooner the intervention with the exoskeleton (with the right support), the better UE function can be retained. However, since the exoskeleton can only function when mounted to the wheelchair, the earliest introduction possibility would be at the start of the non-ambulatory phase. Also, it should be carefully considered what the needs of the user are in this phase, since products are usually only introduced when a function is lost. The user is not used to an early introduction of a product and acceptance therefore might be difficult. This is further explored in chapter 4 (user research).

The exoskeleton should be used daily and with a high frequency (as much as possible), since this can cause a training effect which can result in a longer retainment of UE function. Besides, this will prevent disuse (the quick muscle functionality loss due to not using the muscles to their full capacity). Also, the more the exoskeleton is used, the more the joints are kept flexible, preventing joint contractures.

For an optimal training effect, **the exoskeleton should first support the muscles that first get weak** (proximal, shoulders) and support stronger muscles (distal, hands) later.

The exoskeleton should be **highly individualized and adaptable over the years** to accommodate for Duchenne boys' needs. Although there is a clear development pattern, every Duchenne boy is different, and the size and amount of support should be precisely right. Also, the amount of necessary support will change over time for each boy as their muscles deteriorate further and they reach the next disease stages.

Checks and measurements need to be done regularly by experts to ensure the right fit and to prevent injuries, overuse and underuse of the muscles. Although it might be possible to make small adjustments at home, these checks cannot be avoided all together. The frequency with which the checks need to be done is, however, still unknown.

The design of the exoskeleton should take weight gain and weight fluctuation into account. Since it is experienced as negative and cannot be influenced by the boys, weight gain should never be a restriction for wearing the exoskeleton.

The exoskeleton should take a "sudden" loss of function into account. Although the muscle capacity deteriorates gradually, functions are lost from one day to the other, which is often experienced as shocking for the boys. If the exoskeleton could support a lost function directly, this would be beneficial.

3.6 Key insights

- Duchenne boys go through four disease stages: early ambulatory, late ambulatory, early non-ambulatory and late non-ambulatory. There is a high variety in disease progression, so i**t cannot be predicted at which age a DMD boy reaches a certain stage.** The exoskeleton can and should be used from the beginning of wheelchair confinement (start of early non-ambulatory stage).

- Over time, Duchenne boys grow in length (unknown how much or how fast), fluctuate in weight (due to wheelchair confinement, diets and medication use) and their Upper Extremity muscle strength will decline gradually, although their UE muscle function loss will be experienced as more stepwise. These physical developments again occur at a different pace and at different moments in time, **calling for a highly individualized approach per user.**

- Products can have a negative, disuse effect if they confine the boys to a certain position (like the wheelchair or game controller). **Products can have a positive effect on the muscle development if they increase the movement range, encourage muscle use and keep the joints flexible** (like the exoskeleton) – this causes a dynamic training effect and prevents disuse and contractures.

- The insights on the physical development of Duchenne boys has the following **implications for the design and use of the exoskeleton**:
    - Encourage an early introduction of exoskeleton
    - Encourage daily use and high frequency use to have a training effect
    - First support the muscles that first get weak (proximal), support stronger muscles (distal) later
    - Design it to be highly individualized and adaptable over the years (in size and amount of support)
    - Regular checks and measurements by experts are necessary to ensure safety and functionality
    - Take weight gain and -fluctuation into account; wearing the exoskeleton should not emphasize it (further explored in chapter 4)
    - Take "sudden" loss of function into account; take away negative shock

- Despite its advantages, the use of dynamic arm supports in practise is extremely low. Also, literature on emotional development of Duchenne teenagers is limited. Chapter 4 therefore further explores the emotional development of Duchenne boys from 10-17 years old, in order to understand what is needed for boys to accept wearing the exoskeleton in their daily lives.

4.

User research

This chapter presents the user research performed to gain insights on the topic of maturing with DMD.

It includes an explanation of the research methods used (including a self-invented co-creation tool), followed by results, a presentation of three personas and conclusions on the topic of emotional maturing with Duchenne, the relation between emotional maturing and (healthcare) products, and implications for the exoskeleton.

Overview chapter

4.1 Research approach
4.2 Results
4.3 Personas: phases of growing up with Duchenne
4.4 Emotional development
4.5 Relation emotional development and products
4.6 Implications for the exoskeleton
4.7 Key insights

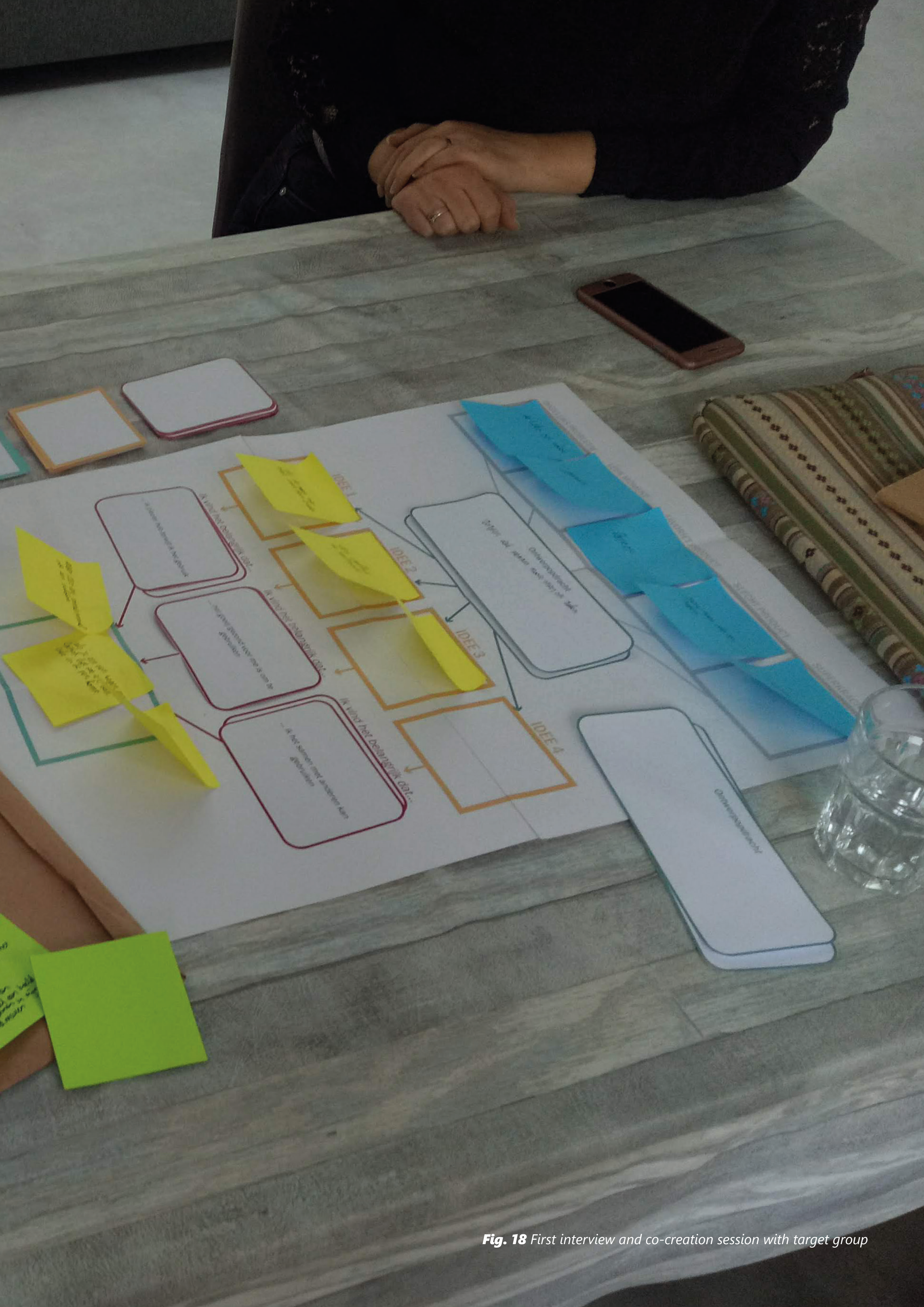


Fig. 18 *First interview and co-creation session with target group*

4.1 Research approach

Besides Duchenne boys maturing physically from 10 to 17 years old, their emotional wants and needs will inevitably change as well. These emotional developments in Duchenne boys are interesting and important to understand and explore further for an exoskeleton to stay relevant. As the knowledge on emtional development in literature is limited (see chapter 3), this chapter shows the user research conducted to gain more insights into the emotional maturing of boys with Duchenne Muscular Dystrophy.

The following research questions were formulated:

- How do boys with Duchenne develop emotionally from 10-17 years old?
- How can (healthcare) products influence the emotional development?
- What does the emotional development imply for the design of the exoskeleton?

Chapter 4.1 describes the methods used to perform user research. In chapter 4.2, the results are described, leading to three phases of growing up (chapter 4.3). Different emotional developments according to these phases are presented in chapter 4.4. Chapter 4.5 describes the relation between (healthcare) products and the emotional development and well-being, giving insights into potential effects of the exoskeleton. All findings resulted in implications for what is important in the design of the exoskeleton, which are presented in chapter 4.6. Chapter 4.7 contains key insights.

Participant name*	Age	Gender (m/f)
Lucas	11	m
Sam	13	m
Mitchel	17	m
Thomas	17	m

Table 1 *Participants recruited for generative research*

** The names are fictional to protect participants' privacy*

4.1.1 Method: Contextmapping

To research Duchenne boys' needs, context and emotional development over time, a generative research method called Contextmapping was used. Contextmapping is a qualitative research method, which is designed to inform the designer with rich insights into the targeted context, uncover tacit and latent knowledge, and inspire the designer for ideation. Users are considered the experts of their own experiences, needs and dreams. Uncovered information is qualitative and supported by quotes (Sanders and Stappers, 2012).

Since the design brief is about a maturing exoskeleton, needs and development over a long period of time needed to be researched. Contextmapping was considered a suitable method, because it cannot only provide insights into user's present and past, but also uncover possible dreams and futures. Also, answers of participants of different ages in different periods of their lives could be compared to discover patterns of growing up.

Although the method usually requires all participants joining in a creative session together, this was difficult due to practical reasons (wheelchair-bound kids with special needs). Instead, interviews were conducted at their homes, which also provided additional insights into their daily lives.

4.1.2 Participants

Four to six participants of various ages was considered a sufficient amount to get rich insights within the time limit and scope of the project. Table 1 shows an overview of research participants (the names are fictional to protect participants' privacy). Recruitment was done targeted with the help of the Duchenne Parent Project organisation, because the target group is small and hard to reach, and boys with Duchenne are already asked often to participate in research, resulting in aversion to participate in another (according to representatives of DPP). A flyer (appendix D) was posted on private Facebook groups and sent to private e-mail addresses, to approach teenage boys with Duchenne directly. Boys of various ages were targeted specifically.

4.1.3 Sensitizing

The participants were probed before the interviews with sensitizing materials. Boys were asked to fill in a booklet, so they had the opportunity to already consider topics discussed in the interview, and so the interviews had a clear starting point: discussing what they filled in and why. Parents were given their own booklet, so their perspectives could be research, but also so they would not be interfering with their sons' answers.

The booklet contains five assignments:

1. Introduction: questions about themselves, school and hobbies, family and friends
2. A day in my life: a timeline, to complete with daily activities, emotions felt during those activities (with emoticon stickers) and reasons for these emotions
3. Products: three positive and two negative products, a positive/negative word describing the product, and the reason why the product was chosen
4. Superpower: what superpower they would like to have and why
5. Future: what they would like to be when they grow up, and their biggest dream

The assignments were chosen based on what other generative research method examples, assumptions of important topics around growing up, and previous research of Yumen Bionics. Parents' booklets differed on the third and fifth assignments (a positive and negative memory with the family, and an advice for other parents of Duchenne boys). Appendix E shows all pages with assignments of both booklets. The booklets and extra materials for the assignments were sent to participants' homes in a sensitizing package (figure 19).

Beste Mees.

Super leuk en fijn dat je mee wil doen aan mijn onderzoek! Succes met het invullen van het boekje. Als je vragen hebt kun je mij altijd bereiken via l.m.vermeer@student.tudelft.nl of bellen/appen naar 0610762377.

Tot maandag 2 december!
Lindsey

Fig. 19 *Sensitizing package sent to participants*

4.1.4 Interview and co-designing: the Product Design Game

During the interviews, the participants were first questioned on their answers in the sensitizing booklets. The answers formed the beginning of a creative co-design assignment: to design a product for themselves, by playing a game. This form of interviewing was chosen to keep the participants involved and entertained, but also to gain richer insights; creation gives more (tacit and latent) knowledge than conversation (Sanders and Stappers, 2012).

The Product Design Game contains five steps:

1. Input for the design game, coming from the output of the booklets (daily problem, fun moment of the day, favourite product, bad product and superpower) (fill in with post-its)
2. Forming a design assignment
3. Coming up with ideas (fill in with post-its)
4. Deciding on criteria to choose idea
5. Reflect on chosen idea

The Product Design Game board is shown in figure 23. Step 1 represents the connection between the booklets and the game – while discussing the booklets, the boxes of the first step are filled in, to give the participants a purpose and focus. Step 2 was to transform one of the boxes to a design assignment, with help of the interviewer. For step 3, idea cards with inspiring questions (figure 20) could be used to come up with more ideas. For step 4, boys could either choose criteria from a pile of cards (figure 21) or come up with criteria themselves. **Step 4 was most important, because it could provide direct criteria important for boys in any product designed for them, including the exoskeleton.** For step 5, cards with reflective questions (figure 22) needed to be answered. All cards of the design game can be found in appendix F. The full interview script can be found in appendix G.

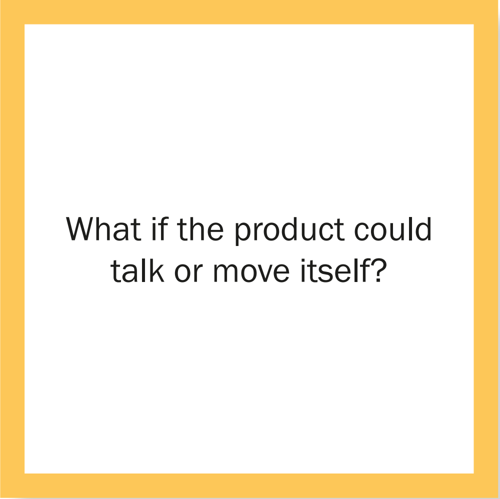

What if the product could talk or move itself?

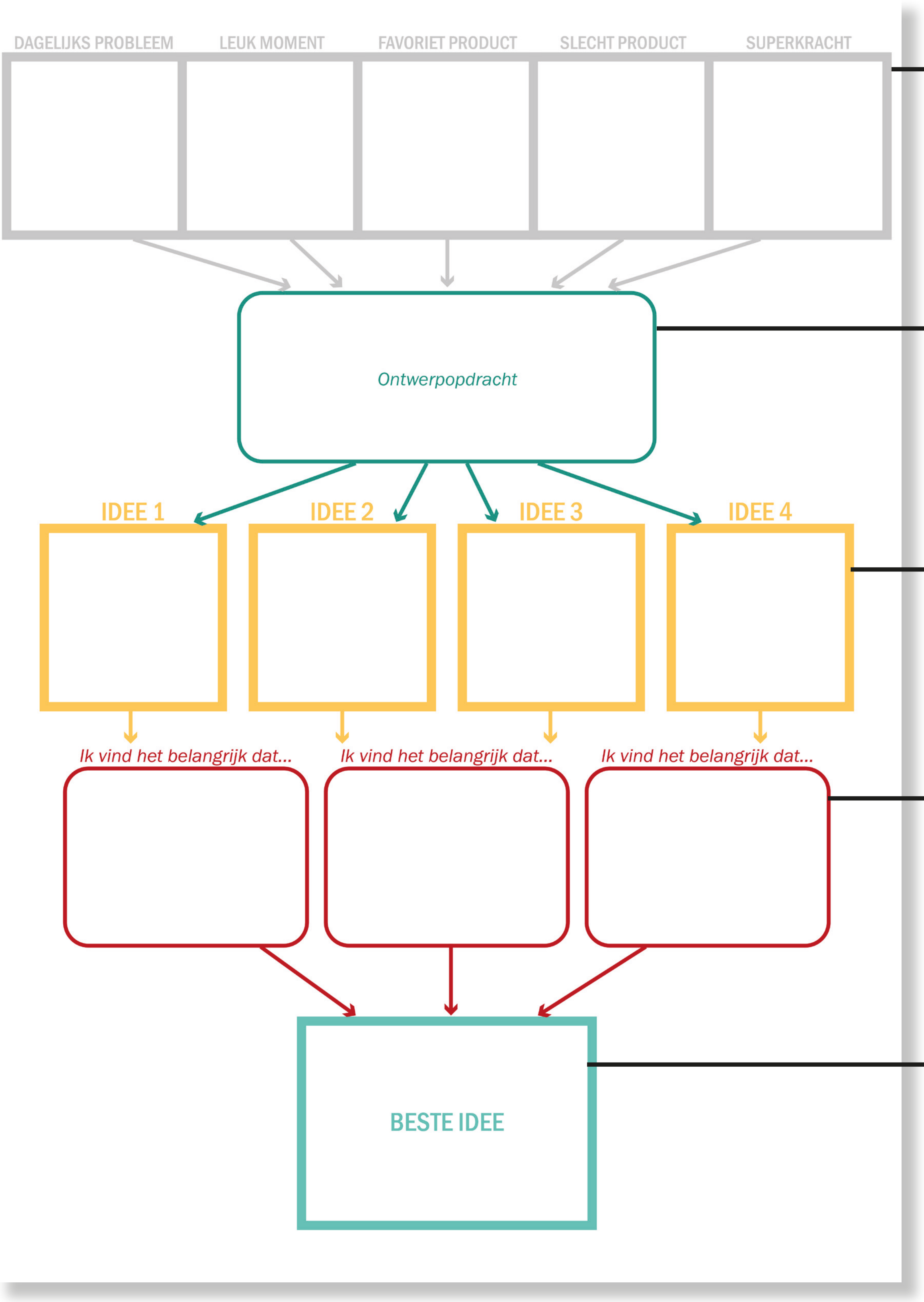
Fig. 20 *Example idea card*


... it makes me more independent

Fig. 21 *Example criteria card*


What would your friends and classmates think if you would use this product?

Fig. 22 *Example reflection card*



Step 1
Pick one of your topics written on post-its (followed from booklets/ interview)

Step 2
Form a design assignment (with help of interviewer)

Step 3
Put four ideas on post-its (use idea cards for inspiration)

Step 4
Choose your most important criteria from criteria cards

Step 5
Reflect on your chosen best idea with reflection cards

Fig. 23 *The Product Design Game*

> **“That I can use the product without help… that’s always the case, so not important for me!”**
>
> Rowin, 13 year old healthy boy

Fig. 24 *Pilot test of the Product Design Game*

4.1.5 Pilot

A pilot (figure 24) was conducted with a healthy boy of 13 years old for four reasons:

1. To check if the design game was interesting and fun enough for the target group
2. To test the length of the game
3. To optimise the questions on the game cards
4. To later compare answers of healthy and Duchenne boys for additional insights

Conclusions from the pilot:

- He thought **the game was fun and interesting and the length was just right**. He did not lose attention and said he would gladly play it again. “I feel like every time you play this game it will have a different outcome!” “This is different from school, because you can really think of ideas for yourself, to solve your own problems.”
- **Mom was interfering a lot**, without consciously noticing, mostly out of curiosity and enthusiasm. How to approach parents is a delicate balance; she was interfering, but also encouraging when the boy got stuck. It is important to keep in mind to focus on the boys during the interviews, but to not leave out the parents. Therefore, it was explicitly mentioned before the interviews that the boy would be interviewed first, before the mom (interfering might still happen but less so).
- **Many criteria were not interesting for him**, although I do still consider them interesting for Duchenne boys: “…that I can use the product myself without help… well, that’s always the case, so not important for me!” (healthy 13 year old boy)
- He considered the **most important criteria, for any product, that he could use it together with others**.
- The the first go-to answer to a ‘why’-question was “I don’t know” or very short, but after continuously asking questions, **talking became easier and more comfortable**. Inventing his own ideas also increased confidence – now the game was something of his own.
- Some of the descriptions on the criteria cards were changed (without changing the meaning) since the **wording was sometimes difficult or misunderstood**.

4.2 Results

"I think you have to keep moving as much as you can."

Lucas, 11 year old boy
with Duchenne

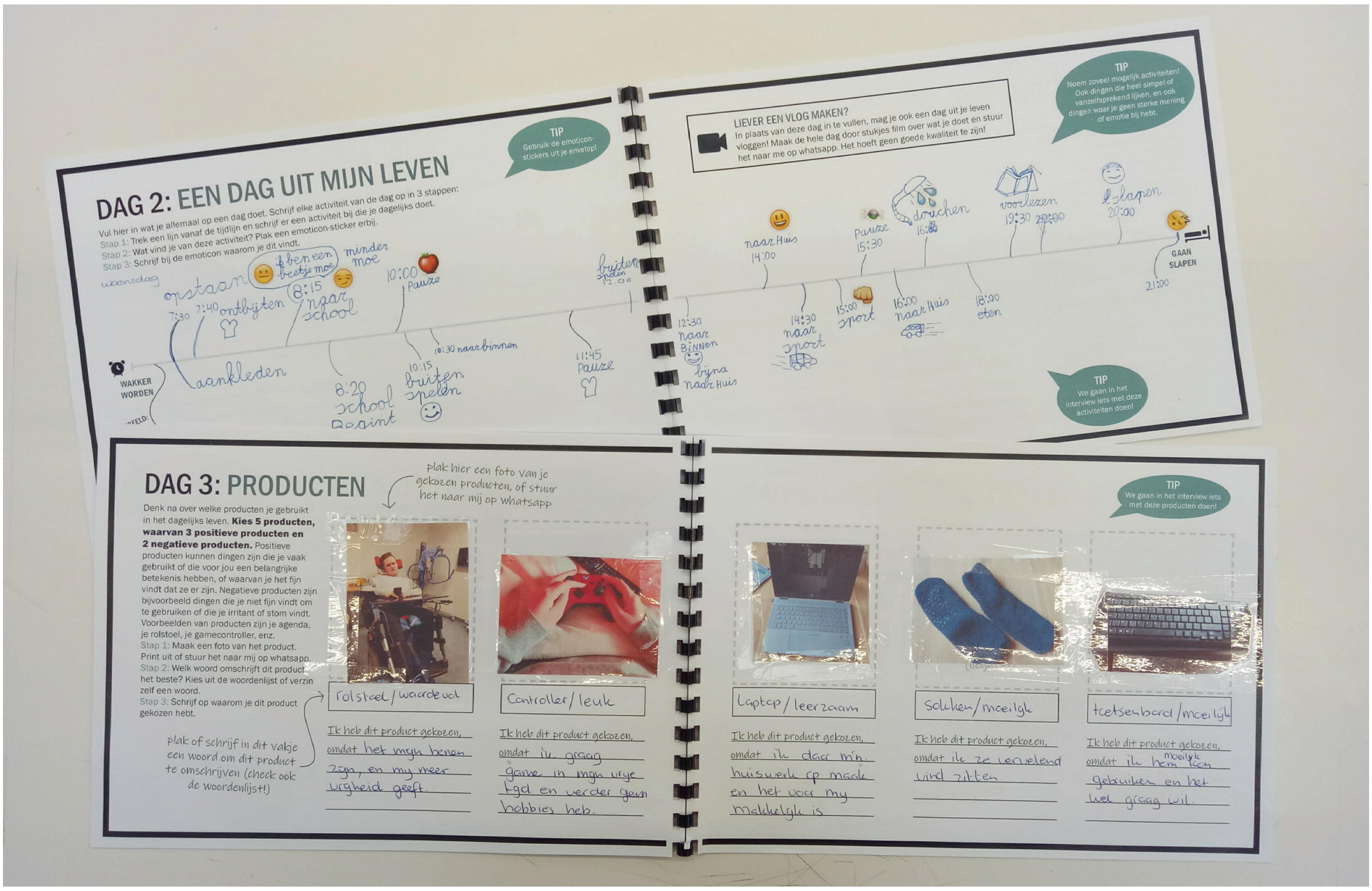
Figure 25 and figure 27 show pictures of the participants after completing the design game (written permission was given to show their faces, the names under the quotes are fictional). The interviews and design games went well and gave many insights into the daily lives and needs of teenage boys with Duchenne Muscular Dystrophy. As a nice extra, positive reactions about the design game came from both boys and their moms (who were all at home with their sons during the interviews). Sam (13) mentioned: "This was actually really fun to do! Researches are usually stupid. This was also research, but good!"

In general, the positive attitude of all four boys was remarkable. They were all proud of themselves, of how positive they were and how much they could push through difficulties in life. They did not complain, and all said "you just have to try to make the most out of it".

"You have to admit to it, if you can't do something anymore. But that is difficult."

Sam, 13 year old boy
with Duchenne

Fig. 25 *Participant (13) and his completed Design Game*



DAG 2: EEN DAG UIT MIJN LEVEN

Vul hier in wat je allemaal op een dag doet. Schrijf elke activiteit van de dag op in 3 stappen:
Stap 1: Trek een lijn vanaf de tijdlijn en schrijf er een activiteit bij die je dagelijks doet.
Stap 2: Wat vind je van deze activiteit? Plak een emoticon-sticker erbij.
Stap 3: Schrijf bij de emoticon waarom je dit vindt.

TIP
Gebruik de emoticon-stickers uit je envelop!

LIEVER EEN VLOG MAKEN?
In plaats van deze dag in te vullen, mag je ook een dag uit je leven vloggen! Maak de hele dag door stukjes film over wat je doet en stuur het naar me op whatsapp. Het hoeft geen goede kwaliteit te zijn!

TIP
Noem zoveel mogelijk activiteiten! Ook dingen die heel simpel of vanzelfsprekend lijken, en ook dingen waar je geen sterke mening of emotie bij hebt.

woensdag
WAKKER WORDEN
7:30 opstaan
ik ben een beetje moe
minder moe
aankleden
7:40 ontbijten
8:15 naar school
8:20 school begint
10:00 Pauze
10:15 buiten spelen
10:30 naar binnen
11:45 Pauze
buiten spelen 12:00
12:30 naar BiNNen
bijna naar Huis
naar Huis 14:00
14:30 naar sport
Pauze 15:30
15:00 sport
16:00 naar Huis
douchen 16:30
18:00 eten
voorlezen 19:30 ~~20:00~~
slapen 20:00
21:00
GAAN SLAPEN

TIP
We gaan in het interview iets met deze activiteiten doen!

DAG 3: PRODUCTEN

Denk na over welke producten je gebruikt in het dagelijks leven. **Kies 5 producten, waarvan 3 positieve producten en 2 negatieve producten.** Positieve producten kunnen dingen zijn die je vaak gebruikt of die voor jou een belangrijke betekenis hebben, of waarvan je het fijn vindt dat ze er zijn. Negatieve producten zijn bijvoorbeeld dingen die je niet fijn vindt om te gebruiken of die je irritant of stom vindt. Voorbeelden van producten zijn je agenda, je rolstoel, je gamecontroller, enz.
Stap 1: Maak een foto van het product. Print uit of stuur het naar mij op whatsapp.
Stap 2: Welk woord omschrijft dit product het beste? Kies uit de woordenlijst of verzin zelf een woord.
Stap 3: Schrijf op waarom je dit product gekozen hebt.

plak hier een foto van je gekozen producten, of stuur het naar mij op whatsapp

plak of schrijf in dit vakje een woord om dit product te omschrijven (check ook de woordenlijst!)

TIP
We gaan in het interview iets met deze producten doen!

rolstoel/waardevol
Ik heb dit product gekozen, omdat het mijn benen zijn, en mij meer vrijheid geeft.

Controller/leuk
Ik heb dit product gekozen, omdat ik graag game in mijn vrije tijd en verder geen hobbies heb.

Laptop/leerzaam
Ik heb dit product gekozen, omdat ik daar m'n huiswerk op maak en het voor mij makkelijk is

sokken/moeilijk
Ik heb dit product gekozen, omdat ik ze vervelend vind zitten

toetsenbord/moeilijk
Ik heb dit product gekozen, omdat ik hem moeilijk kan gebruiken en het wel graag wil.

Fig. 26 *Completed sensitizing booklets*

4.2.1 Results sensitizing booklets

- Some booklets were filled in by mom, because boys could not write properly anymore – they assured me they only filled it in at their son's instructions. It did show the **close personal-caring connection between mother and son** straight away – but also a lack of privacy.
- **Gaming was a recurrent theme** for all four boys; as their favourite hobby, game controller as a favourite product. Lucas (11) and Sam (13) hung out with friends and had hobbies outside of the house, while Thomas (17) and Mitchel (17) rather stayed inside as much as possible.
- Although their daily lives (assignment 2) seemed fairly average, although they all seemed aware of their own strict schedule, which usually included getting up extra early and some form of exercise or physical therapy (because they had to). However, **they did not put emphasis on anything that was different from usual because of their disease**.
- 3 out of 4 boys mentioned the **wheelchair as a positive product**, because it gives them a feeling of freedom and independence; because of it, they can choose where to go at which moment. However, Sam (13) mentioned the wheelchair twice – also as a negative product, because it made him feel different from his friends.
- For both Sam (13) and Mitchel (17) **the airstacker was a negative product**, because it is annoying to use, and confirms that their disease worsens (breathing support is a 'step back').
- Superpowers varied from turning into animals (Lucas, 11, most imagination), to being able to heal others (Sam, 13), to being able to walk (Thomas, 17) to being able to teleport (Mitchel, 17). Although the fantasy level differed, **all superpowers had to do with making life easier and more convenient** – although one focussed on making other's lives better rather than his own.
- About the future: Lucas (11) was absolutely certain of what he wanted to do, although he did not know why or how. Sam (13) had no idea because he was insecure about his abilities. Thomas (17) had already chosen a career path so was more realistic about his future.
- All boys filled in as their **biggest dream that Duchenne would be healed**.

Figure 26 shows some pages of the filled in sensitizing booklets. All completed sensitizing booklets (of both boys and parents) can be found in appendix H.

4.2.1 Results Design Game

- Design assignments chosen were moving better (11), making the wheelchair more fun (13), making teleporting possible (17) and making the moment of getting in the wheelchair better (17).
- Two criteria-cards were chosen by almost all of them: "...that it makes me more independent" and "...that I have fun using it." So, **independency and fun are important themes for the design of a product.**
- **Only the 13-year-old chose criteria focussed on other people's opinions:** "...that I make a good impression with it" and "...that it looks good".
- The product designs the boys came up with were: an exoskeleton for the whole body that could turn you into animals (11), a formula-1 steering wheel on the wheelchair (13), a teleporting-watch (17) and a built-in speaker on the wheelchair (17). All product ideas were focussed on having fun or being useful now, rather than in the future.

All completed Design Game Boards can be found in appendix I.

> **"You just have to try to make the best of it. Always keep smiling!"**
>
> Thomas, 17 year old boy with Duchenne

Fig. 27 *Participant (17) and his mom after the interview*

Fig. 28 *Statement cards divided in clusters; thorough analysis of similarities and differences between participants*

4.2.3 Analysis approach

The results of the generative research were analysed with statements cards of each participant, which were clustered (figure 28) into recurring themes in the interviews. The statement cards contain personal interpretations of literal quotes from the boys during the interviews. Quotes of different participants (different ages) within one topic were compared, to find patterns, similarities and differences. An important question asked was: does their emotion, attitude or opinion on this topic change over time? Or is it the same for every age? In this way, patterns of growing up and maturing were discovered. Transcriptions of all interviews can be made available on request; all statement cards used are included in appendix J.

4.3 Personas: phases of growing up with Duchenne

From thoroughly analysing the results (chapter 4.2), three fundamental phases of growing up with Duchenne were defined. Each phase is represented by a persona, which are shown and described in detail in figure 29. As he matures, a boy with Duchenne gradually transitions from one phase into the next. In chapter 4.4 and 4.5, the phases' takes on different topics (parents, disease, healthcare) are elaborated upon.

Two notes on the phases of growing up:

- Although in this model, each phase transitions linearly into the next, in reality one boy of course can have different trades of multiple personas, or might be somewhere in-between phases.
- These three phases are based on the experiences of only four participants. Although this is around 0.6% of the Dutch Duchenne population, the data is qualitative, and it includes some personal interpretations that should be further confirmed with multiple participants in follow-up research.

see next page for the three phases of growing up ---->

NAÏVE
PLAYFUL KID

Characteristics

- Age: 10-12 (primary school)
- Enjoys life by the day and is mostly living in the moment
- Unaware of the larger context of his life

ANXIOUS
SELF-CONSCIOUS TEEN

Characteristics

- Age: 12-15 (middle school)
- Very insecure, cares a lot about what others think of him
- Does not trust his own judgement to make important decisions

CONSTRAINED
RELUCTANT ADOLESCENT

Characteristics

- Age: 15-17 (high school)
- Wants to become more independent and make his own choices, but still has to figure out how to do that
- Simultaneously still wants to have fun and avoid responsibilities and difficult decisions

With Duchenne

- His disease is not very restricting yet, although he gets tired soon and has some doing all the things his friends can do when they play outside together
- He is unaware of the future consequences of his disease and might still believe in ‘fairy tales’.

“I would say that you have to move as much as you can. Maybe, the disease will be cured because you are moving so well.”

11 year old boy
with Duchenne

With Duchenne

- His disease makes him different from others, which makes him even more insecure
- He does not make any decisions about his healthcare – he trusts his parents’ and doctors’ advice
- He is aware of his future and consequences of his disease in big lines, but cannot oversee yet all small setbacks that will come.

“I did not want that top blade on my wheelchair, because I was afraid of what others would think. It looks so handicapped.”

13 year old boy
with Duchenne

With Duchenne

- His disease makes him restricted and increasingly dependent on caretaking, which is frustrating.
- He feels like he is continuously watched.
- He has already had many small setbacks and problems from his disease, so he is down-to-earth about the future.

“I was kind of done with that special school after a while. Everyone was always watching me.”

17 year old boy
with Duchenne

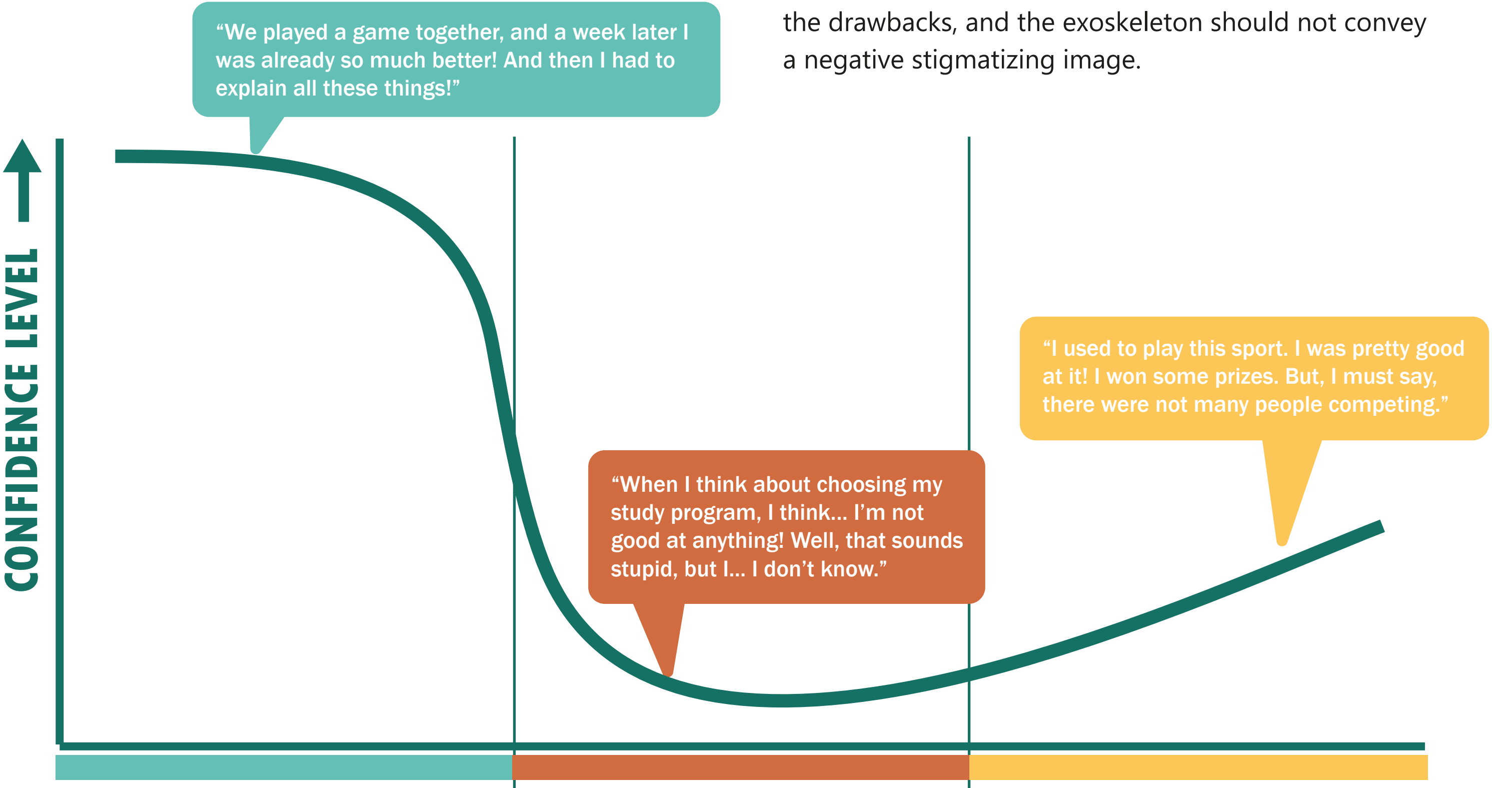
Fig. 29 *Phases of growing up with Duchenne*

4.4 Emotional development

With the results and analysis (chapter 4.2), several themes of emotional development for Duchenne boys were discovered. Going through each of the phases described in chapter 4.3, the attitude of a boy with Duchenne within these themes changes. In this chatper, each theme is explained based on the three phases of growing up. Also, all figures and statements are supported with illustrations and literal quotes from the participants from the interviews.

4.4.1 Confidence level

As shown in figure 30, the confidence level of the boys changes over time. They start with high confidence, just as any other kid. Then, a drop in the middle phase is expected because of puberty. Later it slowly climbs up again and they become more confident, but also more realistic in their abilities. This transition is important for the use and design of the exoskeleton. Since the Anxious Self-conscious teens worry a lot about other people's opinions, they might reject a product which was earlier fine to wear. This calls for a change in the appearance and use of the product when the transition to this phase happens (this cannot be predicted – the boys should be able to indicate when they want this change). It is important to design the exoskeleton so that this phase accepts it; the benefits should outweigh the drawbacks, and the exoskeleton should not convey a negative stigmatizing image.



- Confidence level at first is just like any other kid. He knows he is good at things and is not afraid to say it.
- Asking for help is quite easy.

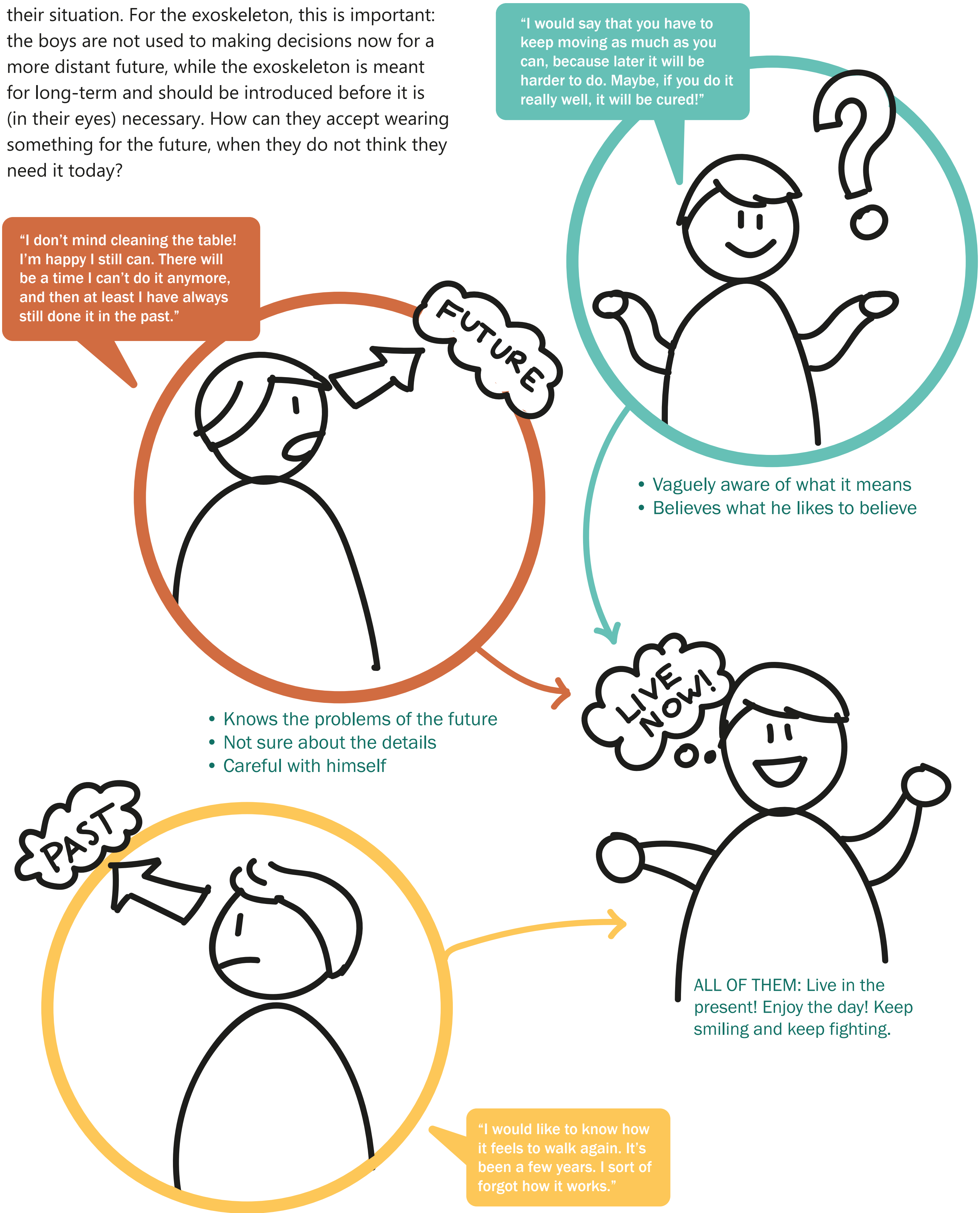
- When the boy goes through puberty, he is very self-conscious and Duchenne makes it worse.
- He has difficulty asking for help from people he does not know very well.

- After a while he has learned to stop caring about others, it is what it is.
- He is more realistic about his talents and skills.
- Asking for help is easier, because he knows better how to express what he needs.

Fig. 30 *Confidence level*

4.4.2 Attitude towards disease

Although the attitude towards the disease changes over time (figure 31), and boys become more down-to-earth and realistic, it always results in a positive attitude towards life. They 'live in the now' and try not to focus on the (more difficult) future, because it does not help their situation. For the exoskeleton, this is important: the boys are not used to making decisions now for a more distant future, while the exoskeleton is meant for long-term and should be introduced before it is (in their eyes) necessary. How can they accept wearing something for the future, when they do not think they need it today?



"I would say that you have to keep moving as much as you can, because later it will be harder to do. Maybe, if you do it really well, it will be cured!"

- Vaguely aware of what it means
- Believes what he likes to believe

"I don't mind cleaning the table! I'm happy I still can. There will be a time I can't do it anymore, and then at least I have always still done it in the past."

- Knows the problems of the future
- Not sure about the details
- Careful with himself

ALL OF THEM: Live in the present! Enjoy the day! Keep smiling and keep fighting.

"I would like to know how it feels to walk again. It's been a few years. I sort of forgot how it works."

- Looks back at what he can't do anymore
- Many obstacles and problems overcome
- More down-to-earth about disease

Fig. 31 *Attitude towards disease*

4.4.3 Social life & comfort zone

As they grow up, boys retract more and more into their comfort zone (figure 32), which is usually gaming at home. When they are younger, they go outside (even when it is difficult with their wheelchair). In this situation, the exoskeleton has a risk of being in the way when they are trying to play. As they grow up, they do not go out, lose interest in hobbies that become too difficult and avoid social situations. It is seen as 'too much effort'. The social life they have shifts from physical to digital. It might be interesting to explore how the exoskeleton can be integrated with their digital world.

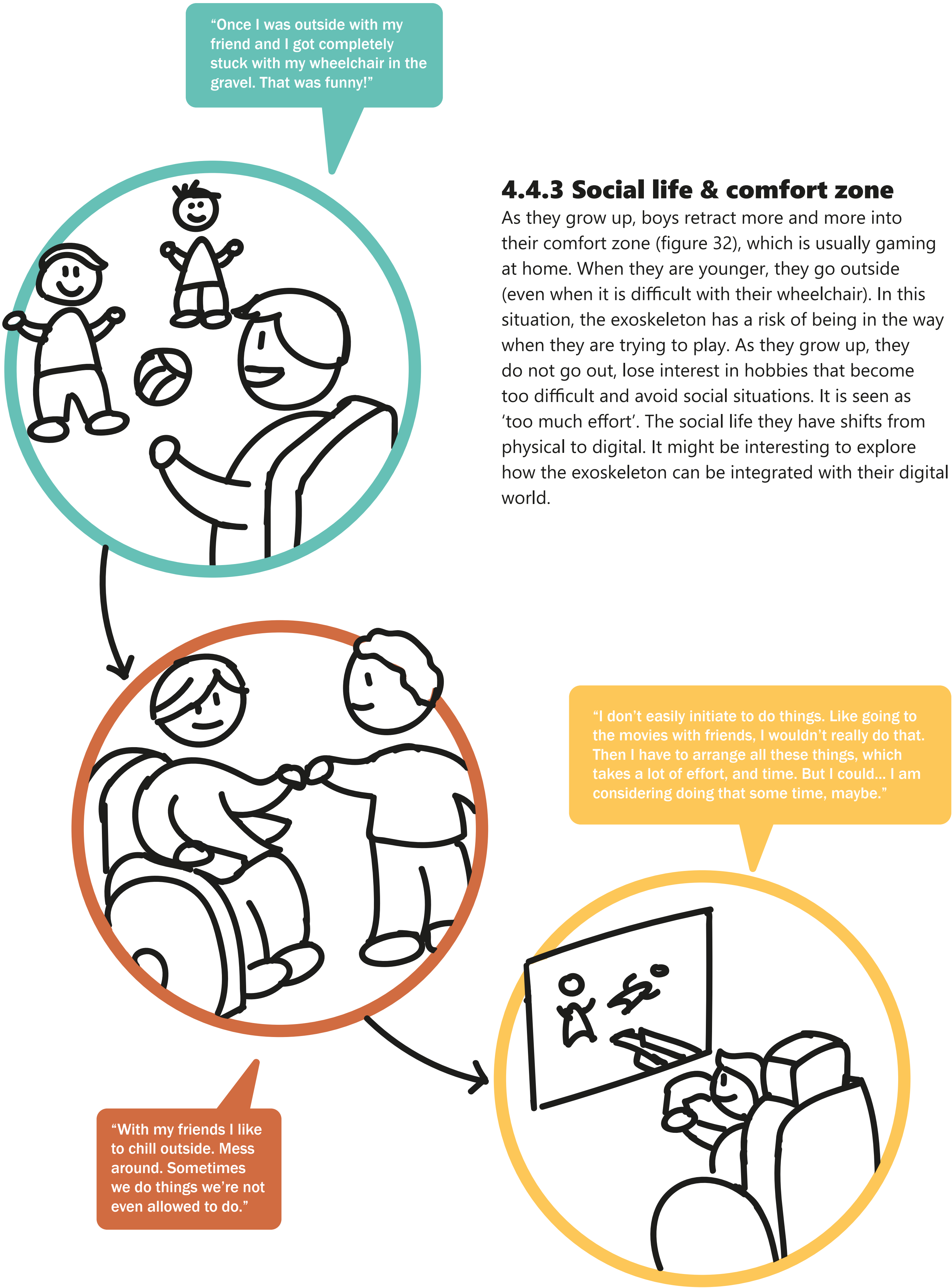


Fig. 32 *Social life & Comfort zone*

4.4.4 Responsibility vs. fun

Duchenne asks boys (and their parents) to plan their life more carefully than usual; exercising, medication, dieting, doctors, appointments. There is a constant battle in the back of their head: they must think about their future, but also just want to enjoy daily life and have fun (figure 33). As they grow up, they develop a bigger feeling of responsibility than their peers, but it also puts extra pressure on their shoulders. For the use of an exoskeleton, it is important not to increase this pressure, but to realise they can handle an increasing amount of responsibility over time.

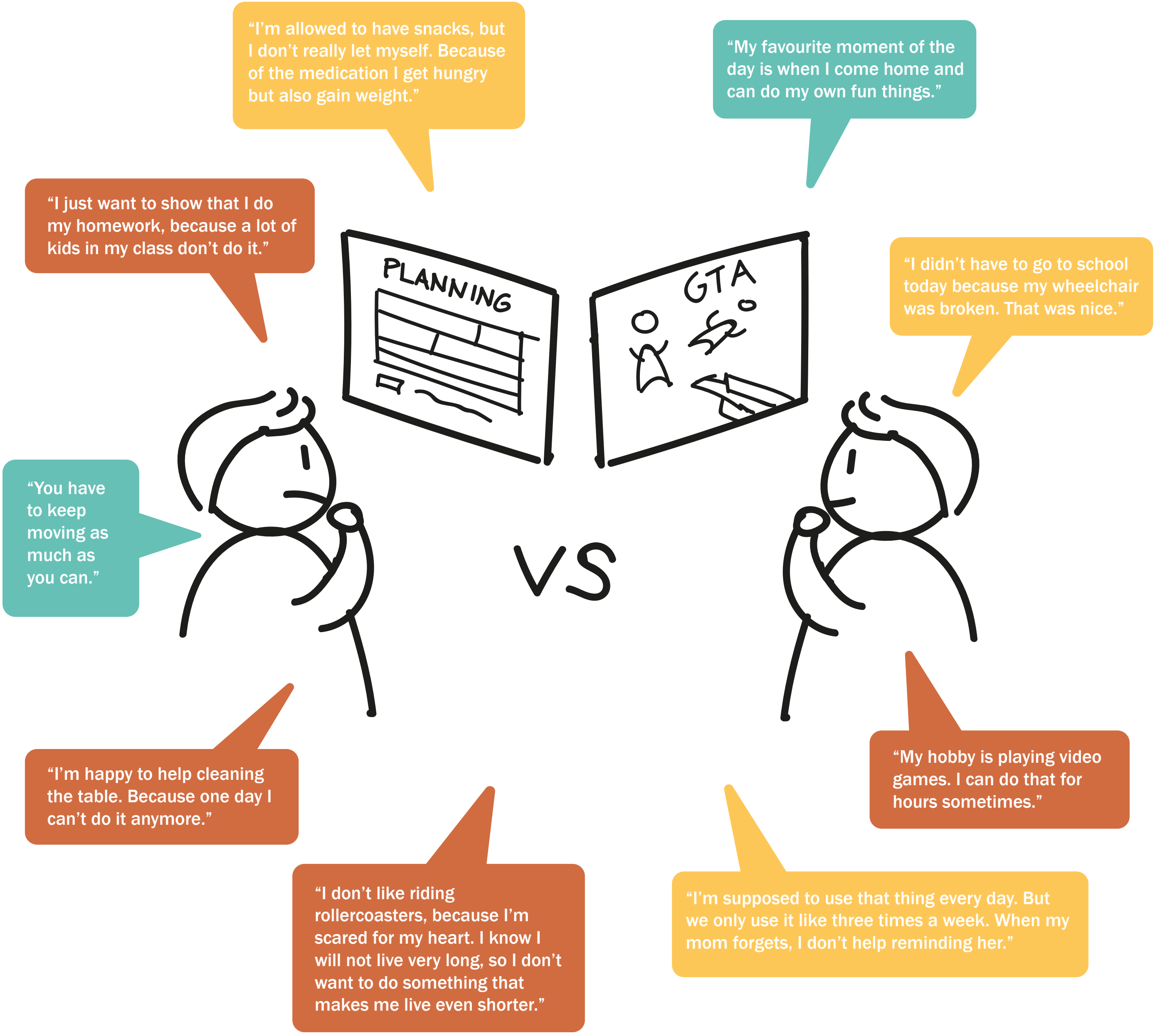
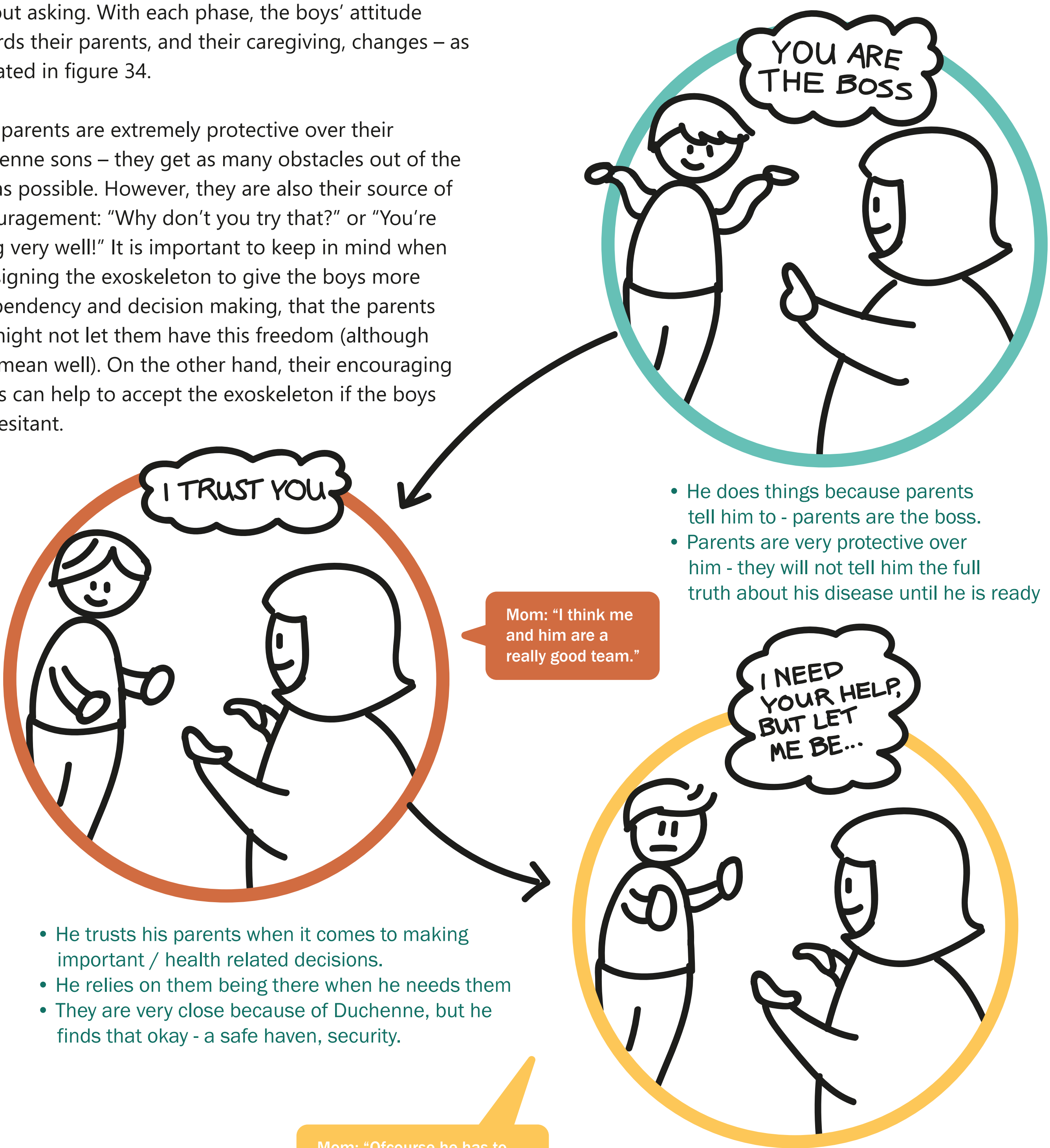


FIg. 33 *Responsibility vs. Fun*

4.4.5 Relation to parents

Since parents are extremely protective, they need to be able to trust the exoskeleton completely. Since having a son with Duchenne is often a full-time job, the exoskeleton should not give them an extra worry or a lot of extra organizational tasks.
Duchenne boys are closer with their parents than usual, because they rely on their caretaking. The parents are extremely specialised in helping the boys – they know exactly what they need and when, so help is given without asking. With each phase, the boys' attitude towards their parents, and their caregiving, changes – as indicated in figure 34.

Also, parents are extremely protective over their Duchenne sons – they get as many obstacles out of the way as possible. However, they are also their source of encouragement: "Why don't you try that?" or "You're doing very well!" It is important to keep in mind when redesigning the exoskeleton to give the boys more independency and decision making, that the parents still might not let them have this freedom (although they mean well). On the other hand, their encouraging words can help to accept the exoskeleton if the boys are hesitant.



Mom: "He is not very aware of his future. And I would like to keep it that way. Everything in its own time."

- He does things because parents tell him to - parents are the boss.
- Parents are very protective over him - they will not tell him the full truth about his disease until he is ready

Mom: "I think me and him are a really good team."

- He trusts his parents when it comes to making important / health related decisions.
- He relies on them being there when he needs them
- They are very close because of Duchenne, but he finds that okay - a safe haven, security.

Mom: "Ofcourse he has to give permission."
Boy: "Not really..."

- He wants to make decisions without parents, but he is extremely dependent on their caretaking.
- It can be annoying if they do things for him without asking - he feels like he is continuously watched
- Because he was always automatically helped, he does not know how to undertake action on his own

Fig. 34 *Relation to parents*

4.4.6 Emotional developments timeline

Figure 35 shows a visual timeline of (some of) the emotional developments of boys with DMD from 10 to 17 years old, which were presented in this chapter.

- The blocks represent the three phases of growing up with Duchenne – the Naïve Playful Kid, the Anxious Self-Conscious Teen, and the Constrained Reluctant Adolescent (chapter 4.3). Each phase represents a different attitude and different behaviour towards confidence, disease, social life, responsibility, parents, and relation to (healthcare) products – as described in chapter 4.4 and 4.5.
- The red line represents the confidence level; when boys enter the anxious self-conscious phase, their confidence level might drop and they might worry a lot more about opinions from their peers and others. This could result in rejecting the exoskeleton, because it could worsen their perceived difference from others. It is important something about the exoskeleton can change in this phase, when they want to. Later their confidence slowly increases again, because normal functioning and independence becomes more important than other people's opinions.
- The orange line represents the desired independence from parents. Although boys become physically more dependent on their parents, as they grow up they want more independence and responsibility. In the last phase, this feeling increases more. It is important that the design of the exoskeleton allows for this growth; decision making over (parts of) the exoskeleton should gradually shift from parents to boys.

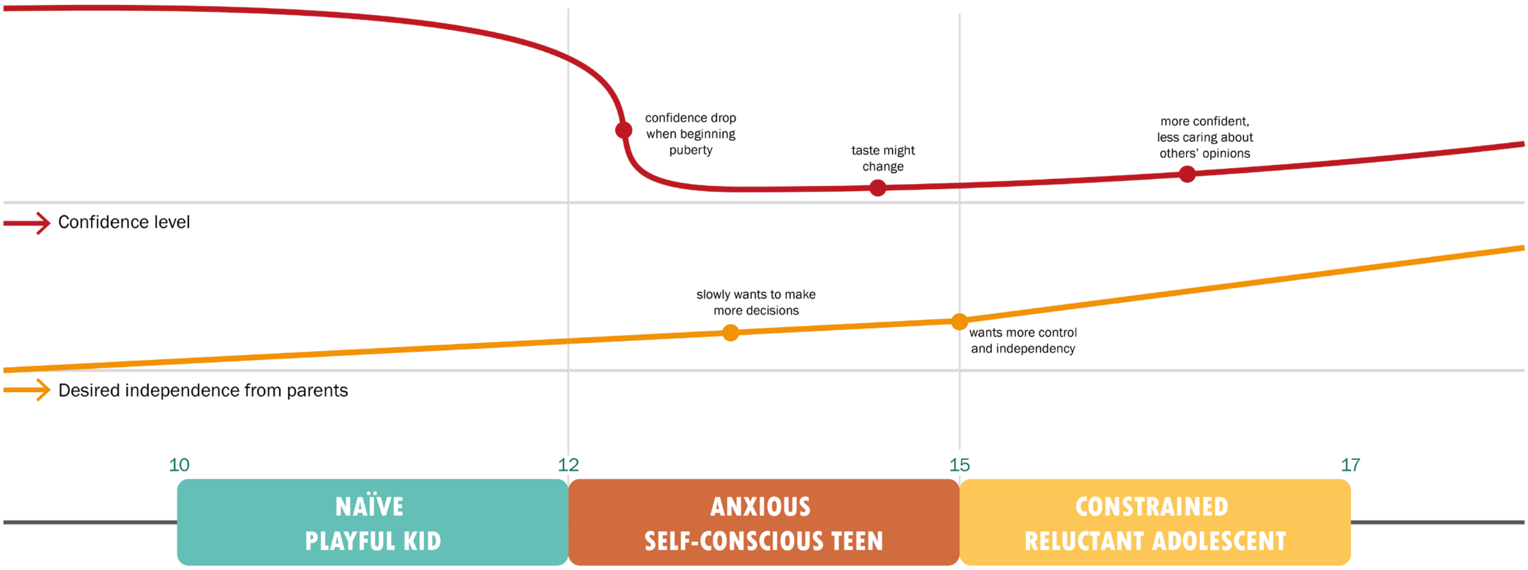
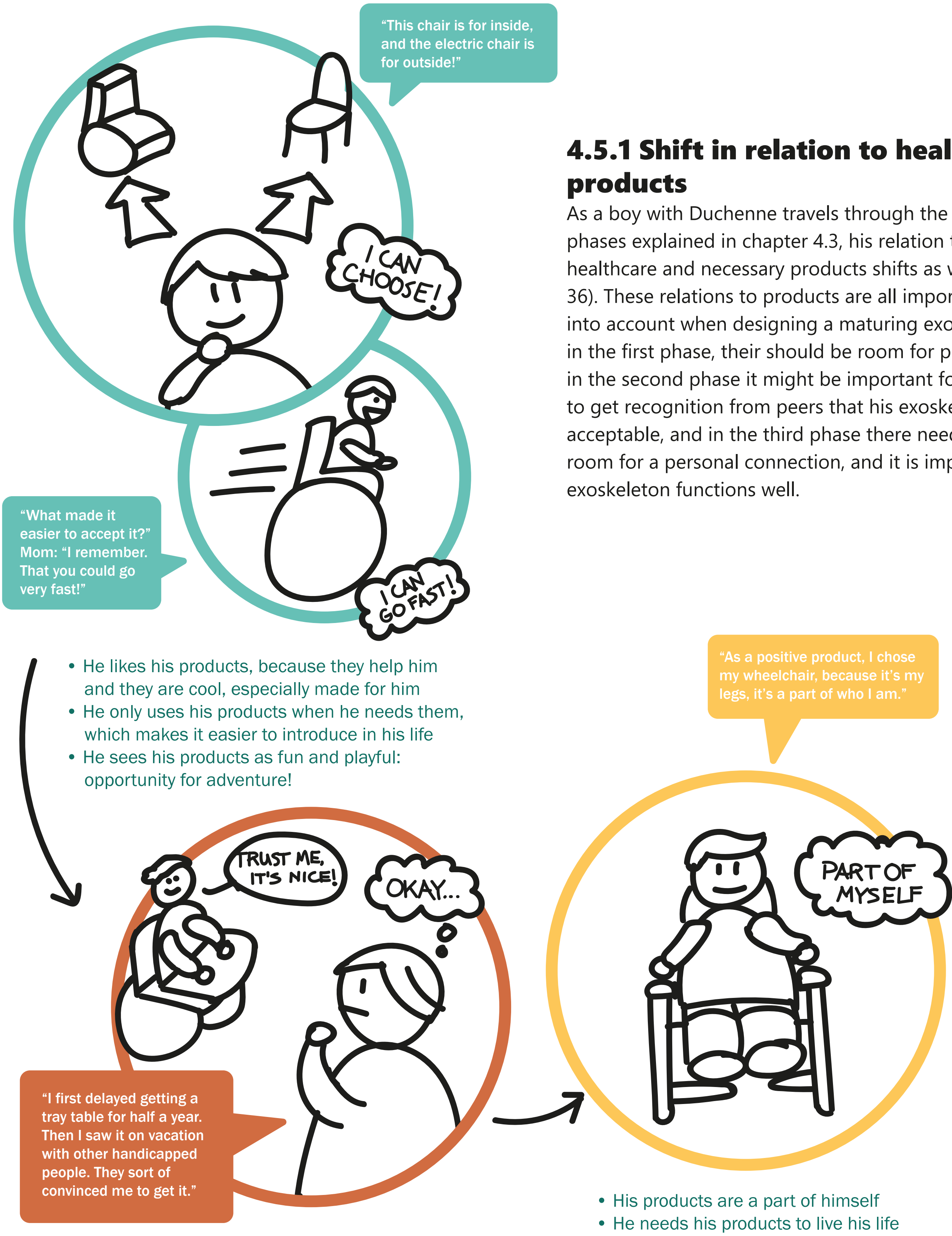


Fig. 35 *Emotional developments timeline*

4.5 Relation emotional development and products

4.5.1 Shift in relation to healthcare products

As a boy with Duchenne travels through the different phases explained in chapter 4.3, his relation towards healthcare and necessary products shifts as well (figure 36). These relations to products are all important to take into account when designing a maturing exoskeleton; in the first phase, their should be room for playfulness, in the second phase it might be important for the boy to get recognition from peers that his exoskeleton is acceptable, and in the third phase there needs to be room for a personal connection, and it is important the exoskeleton functions well.



"This chair is for inside, and the electric chair is for outside!"

"What made it easier to accept it?" Mom: "I remember. That you could go very fast!"

- He likes his products, because they help him and they are cool, especially made for him
- He only uses his products when he needs them, which makes it easier to introduce in his life
- He sees his products as fun and playful: opportunity for adventure!

"As a positive product, I chose my wheelchair, because it's my legs, it's a part of who I am."

"I first delayed getting a tray table for half a year. Then I saw it on vacation with other handicapped people. They sort of convinced me to get it."

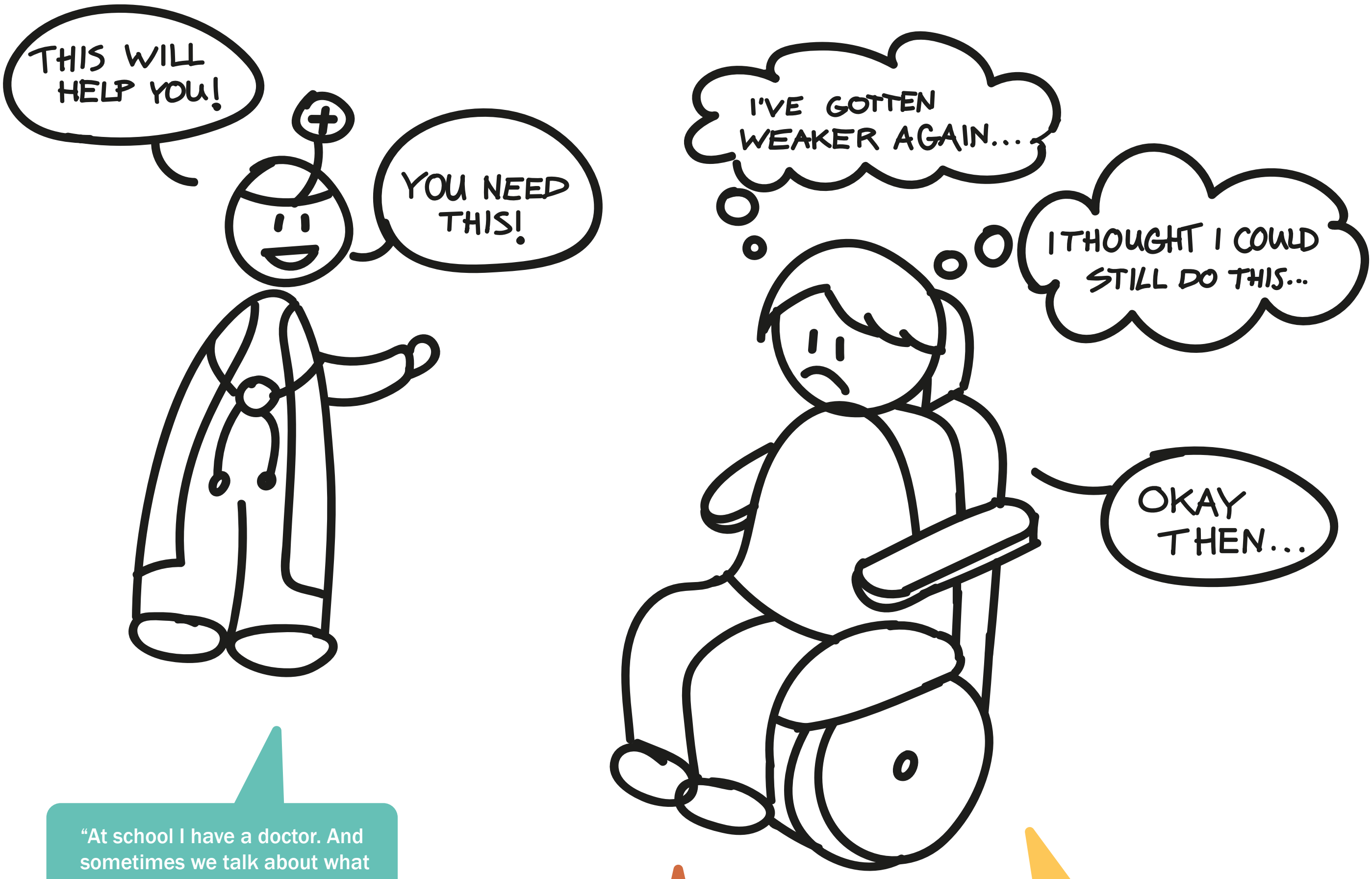
- He does not like his products, because they make him feel different from others
- He does appreciate the help the products provide; it makes him function like normal
- Acceptance is easier when seen with peers

- His products are a part of himself
- He needs his products to live his life and do what he wants to do
- When something is wrong, it is extremely annoying and life-disrupting

Fig. 36 *Shift in relation to healthcare products*

4.5.2 Healthcare: no choice, no control

Decline of muscle strength happens gradually, but products are introduced in Duchenne boys' lives suddenly. Every new product the boys need for their disease is negative: it makes their decline tangible and visible and confirms a step backwards. They have no control or choice over this process and just have to accept it, which is difficult (figure 37). Only once they start using the product, they start noticing the benefits. The exoskeleton has a double risk; the first introduction can come across as a step backwards, and physical changes on the exoskeleton can confirm this once again. Therefore, the focus should be on a positive transition, and the boys should feel like they are more in control over the process of acceptance and change.



"At school I have a doctor. And sometimes we talk about what is needed for me. And sometimes he tells me: maybe this is smart to do. At first I didn't accept it, I thought I was not that bad yet."

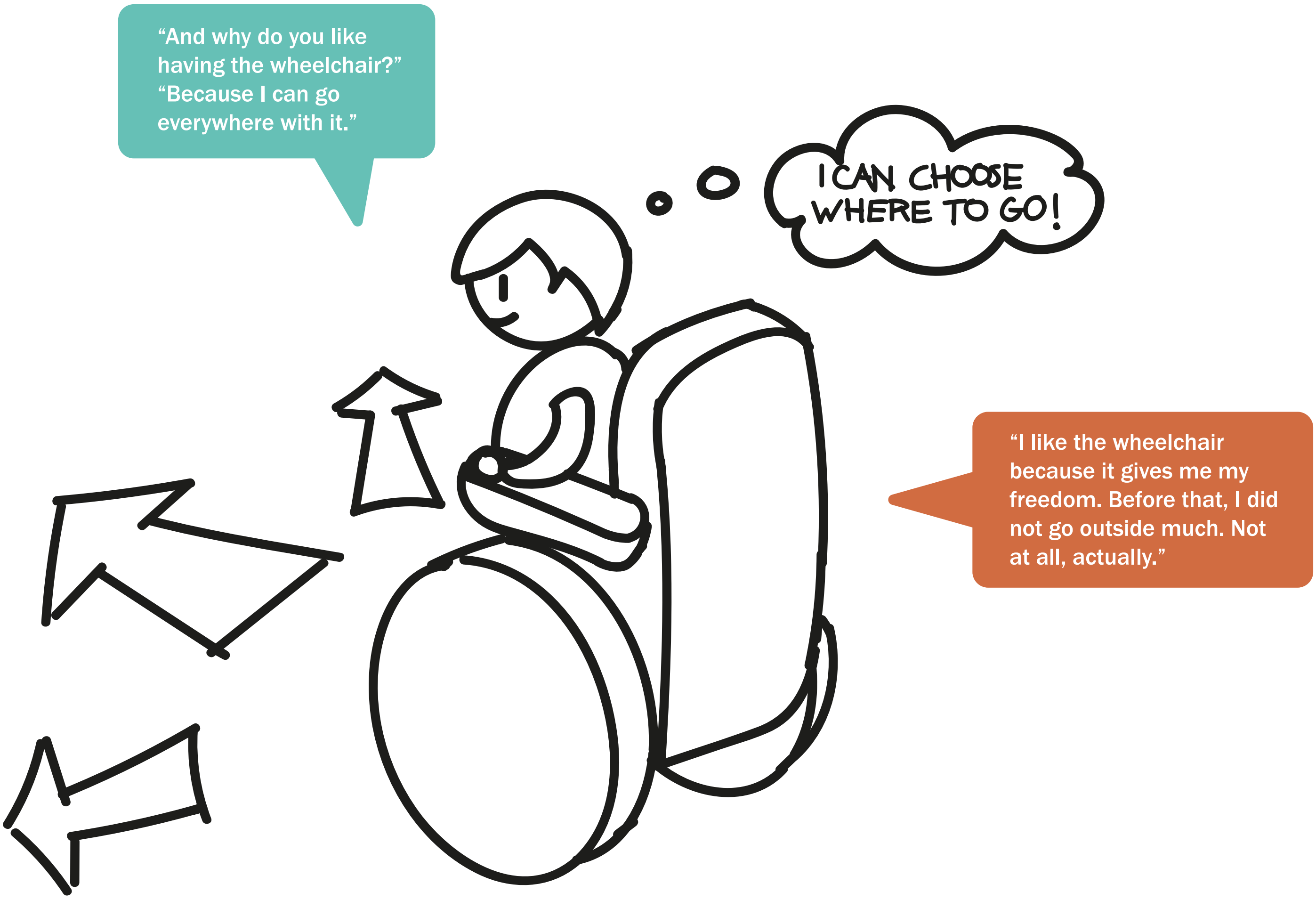
"This product is not nice. It is a breathing support, and you don't want that. And it's also a step backwards, so my lungs have appearently weakened. So that is difficult."

"Maybe I want to design something that would make the moment of getting in the wheelchair less bad. First I dreaded that moment. But then I started to accept it. It is what it is."

Fig. 37 *Healthcare: No choice, no control*

4.5.3 Freedom and independence

In the interviews with Duchenne boys of all different ages, they all mentioned that they liked their wheelchair, because it gives them a feeling of freedom and independence (figure 38). Because of the wheelchair, they can decide again where to want to go at which moment. The exoskeleton has the potential to have the same effect; because they wear it, they can decide again what to do with their arms. However, this effect might not yet be reached in the first phase, because then boys do not notice big restrictions in arm function yet.



"And why do you like having the wheelchair?" "Because I can go everywhere with it."

"I like the wheelchair because it gives me my freedom. Before that, I did not go outside much. Not at all, actually."

Fig. 38 *Freedom and independence from wheelchair*

4.6 Implications for exoskeleton

The exoskeleton should be redesigned to be more relevant to each of the three phases. From the research to their daily lives and the impact of products, it is expected each phase has different reasons why the exoskeleton would, or would not, be accepted by them. Figure 39 shows expected statements that boys from each phase could make over the exoskeleton (these are NOT literal quotes).

Products should not feel like an imposition that Duchenne boys do not want, because they are not ready for it or because it does not fit in with their lives. When they feel like they need it, or when they feel like they need something different, they should have the ability and control to make a change. Therefore, **the exoskeleton should be able to transition or change (during or between phases) at moments of the boys' choosing.**

Boys with Duchenne have to constantly struggle between being responsible with their disease (planning, dieting, training), and having fun and relaxing. Parents often have a fulltime job taking care of their child, with a lot of organizational and care tasks in the medical world. Therefore, **the exoskeleton should not cause extra worries on the boys' or parents' minds.**

The extra responsibility the disease causes also gives the boys an extra strength; they are capable of handling some responsibility. Besides, as they get older they want to be more independent and treated as an adult. Also, parents might have a difficult time giving their sons more space. Therefore, **control and responsibility over (parts of) the exoskeleton should slowly shift from parents towards boys,** without being too sudden, scary or worrying.

Introduction of new products related to the boys' disease often confirm a step backwards. It usually means their muscle capabilities have declined further. Although it is introduced as a help and with good intentions, boys do not see it that way. Also, they feel like using the product is not their choice, it is more an imposition that is out of their control. Introducing the exoskeleton can have the same effect. Besides, an exoskeleton that changes over time has the risk to repeat these 'confirmation of decline' moments again and again. Therefore, **the introduction and transitions of the exoskeleton should never be a confirmation of decline.**

Introduction of new products related to boys' disease usually happen when there is 'no other choice'. When the boys are about to lose, or have already lost, a function, a product is introduced to compensate for this function. However, as seen in chapter 3, the exoskeleton is meant to be introduced to the boys long before a function is lost, when the Upper Extremity muscle strength is already declining but this is not restricting yet in daily life. The boys are not used to this idea, which might complicate acceptance. Therefore, **the exoskeleton should be designed to be accepted long before a physical function is lost.**

Expected statements from each persona on the exoskeleton

(not literal quotes)

Naïve Playful Kid

"Why would I wear the exoskeleton? **I do not really need it.** Maybe only if I'm tired, but not for the whole day.

It should not be in the way when I'm trying to play with my friends."

Anxious Self-Conscious Teen

"I don't want to wear the exoskeleton because **it makes me feel different from others.** I'm afraid of what people might think of me, I don't want to look more handicapped.

I know it can help my muscles a little bit, but I can also still do most things with my arms myself. So it's not worth it."

Constrained Reluctant Adolescent

"I can see why the exoskeleton can help me. **It can make me more independent.** I care more about that, than others' opinions.

I would like to make my own decisions over how to use it and what happens with it... but my parents or doctors usually do that for me."

Fig. 39 *Expected statements from each persona on the exoskeleton (NOT literal quotes)*

4.7 Key insights

- **Three phases of growing up with Duchenne Muscular Dystrophy were defined**: the Naïve Playful Kid, the Anxious Self-Conscious Teen, and the Constrained Reluctant Adolescent.

- Different attitudes or behaviours between phases were indications for emotional development. **Differences were found on the topics of confidence, attitude towards their disease, social life, responsibility, and the relation to parents.**

- Between the three phases, **a different relation towards (healthcare) products** was also found. These relations can indicate what is (not) desired for the use of the exoskeleton in different phases.

- Products can have a **positive influence** on the emotional development of Duchenne boys if they can **improve their independence and individual functioning**. The exoskeleton has the potential to do this.

- Products can have a **negative influence when they feel like an imposition, when the boys have no control or choice over it, and when they confirm further muscle decline** and negative progress. These moments should be avoided throughout the years of using the exoskeleton.

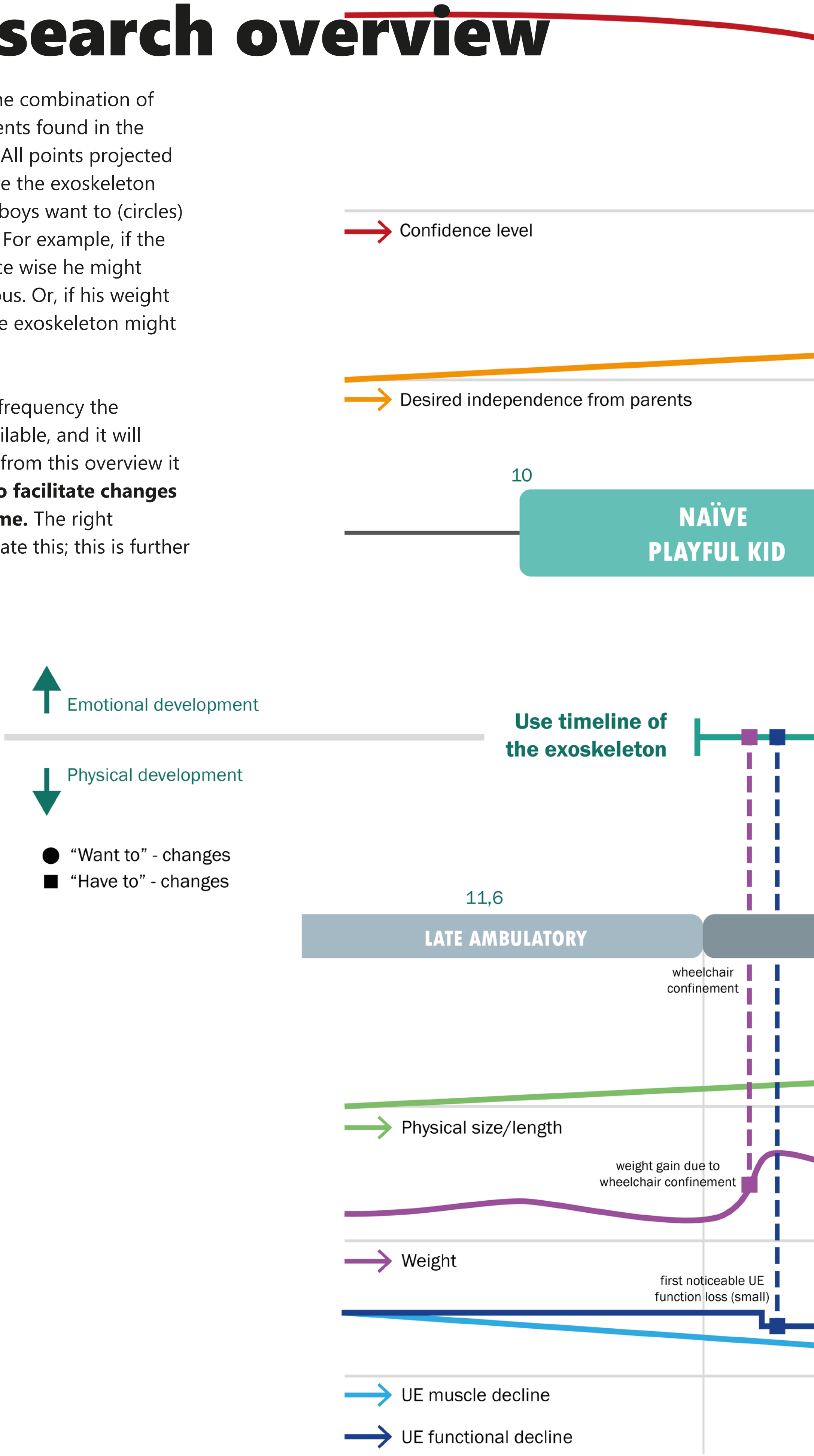
- Going through each of the three phases, boys would have different reasons why they would (not) accept the exoskeleton. The design of a maturing exoskeleton needs to make sure the use is **relevant for and accepted by each phase.**

- The results on emotional development have the following **implications for the exoskeleton**
  - The exoskeleton should be redesigned to be more relevant for all three phases
  - The exoskeleton should be able to transition or change (during or between phases), at moments of the boys' choosing (when they desire/are ready for a change)
  - The exoskeleton should not give extra worries to boys or parents; they both have enough on their mind
  - Over time, control and responsibility should carefully shift from parents towards boys
  - The introduction or transition of the exoskeleton should never be a confirmation of declined muscle strength
  - The exoskeleton should be designed to be accepted long before a physical function is lost (the boys are not used to this idea)

Visual research overview

The overview of figure 40 shows the combination of physical and emotional developments found in the literature study and user research. All points projected on the timeline are moments where the exoskeleton has to change; either because the boys want to (circles) or because they have to (squares). For example, if the boy's confidence drops, appearance wise he might want something more inconspicuous. Or, if his weight fluctuates, the forearm width of the exoskeleton might not fit him anymore.

It cannot be predicted with which frequency the changes happen – little data is available, and it will defer highly per person. However, from this overview it can be seen that **it is important to facilitate changes at the right place, at the right time.** The right product – service design can facilitate this; this is further explored in chapter 5, 6 and 7.



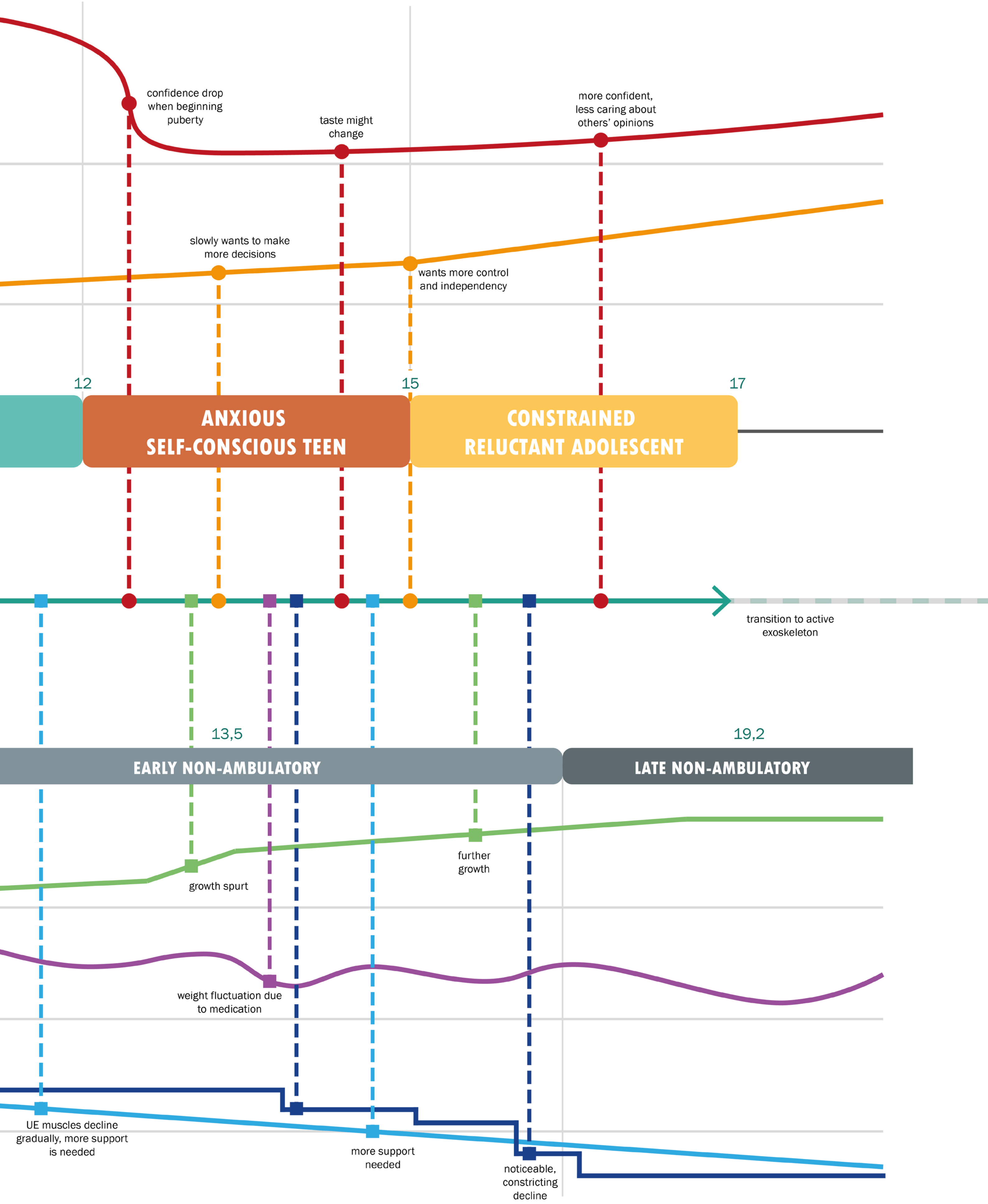


Fig. 40 *Overview timeline of all developments found in literature study and user research*

5.

Focus

This chapter presents the design guidelines and design vision used to achieve the design goal of the project.

The chapter includes an explanation and substantiation of the designer's vision, based on conclusions from research in chapter 3 and 4. To be able to follow the design goal, four design guidelines were formulated and substantiated. These guidelines recur in the rest of the report to support design choices. The guidelines were combined in one coherent vision.

Overview chapter

5.1 Design Guidelines
5.2 Design Vision

Fig. 41 *A boy with Duchenne playing a game, his wheelchair on the side*

5.1 Design Guidelines

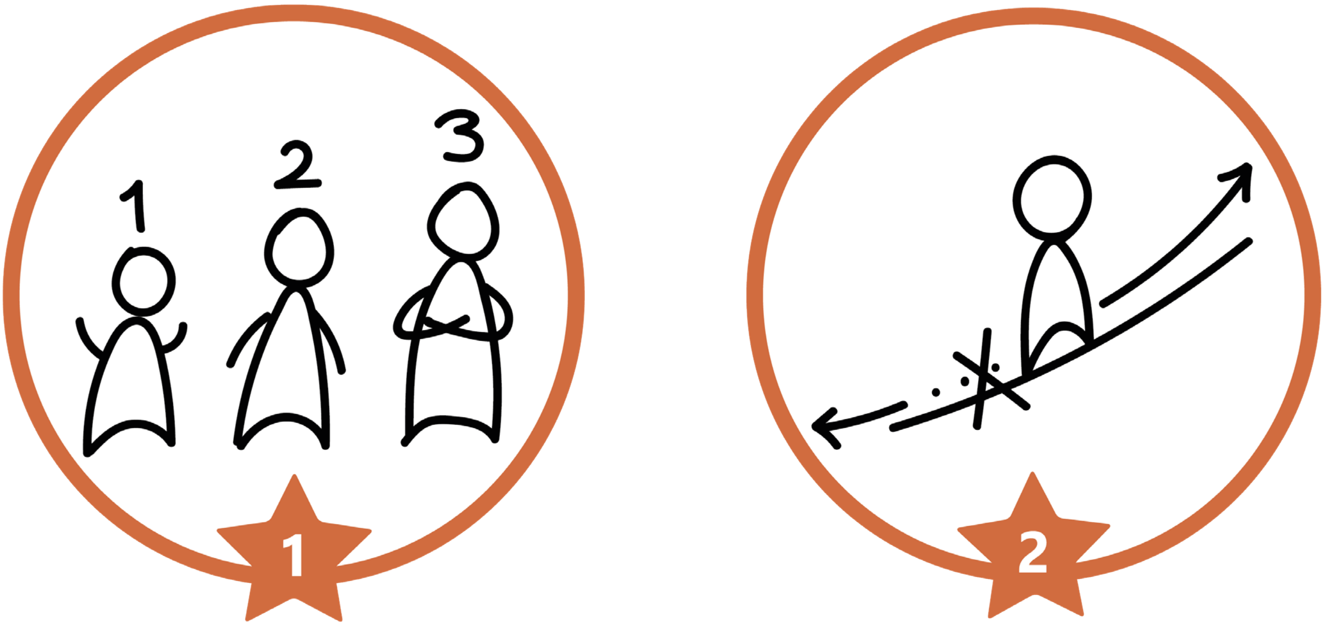
In chapter 3 and 4, insights were gained on the physical and emotional development of boys with DMD, from 10 to 17 years old. For the exoskeleton to fit with this maturing process, this chapter defines a focus by stating four design guidelines. Each design guideline is visualised in figure 42.

1. **The use of the exoskeleton should be made more relevant for each of the three emotional phases of growing up** (Naïve Playful Kid (10-12 years old), Anxious Self-Conscious Teen (12-15 years old) and Constrained Reluctant Adolescent (15-17 years old)).
   Especially for the first phase, the relevancy of the exoskeleton is not very clear. Boys in this phase do not think they need it physically since they can perform most tasks themselves, neither does it bring direct emotional benefits. For the second phase, the relevancy is somewhat higher, but the physical benefits of the product are still not expected to overcome the emotional drawbacks, like feeling different from peers. For the third phase, the exoskeleton already has more relevancy in its current form; however, when redesigning the exoskeleton this relevancy should not be lost. Boys with Duchenne from all three phases each have different social lives, attitudes towards their disease, relation with their parents and relation with their healthcare products. The exoskeleton should be designed for these differences.

2. **The user should be able to focus on positive progress and anticipate on negative decline.**
   As shown in chapter 3.2, the loss of physical functions happens stepwise and therefore can often feel sudden. The introduction or alterations of healthcare products usually confirm this decline for the boys even further, which can have a negative impact on their emotional well-being (chapter 4.5). When the exoskeleton goes through a change to mature, it should avoid being that extra confirmation of decline. Besides, in response to the negative physical disease progression, for the exoskeleton to mature with the user it should focus on positive progress instead; some element about it should develop with the user in a positive way.

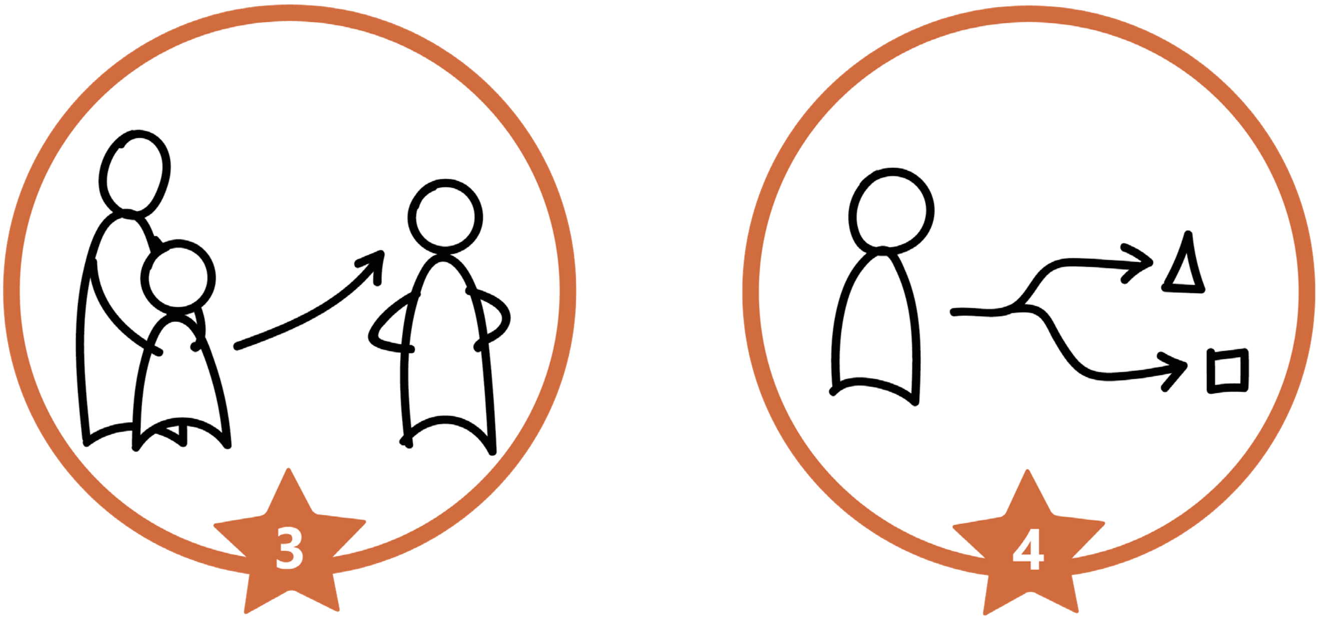
3. **The exoskeleton should accommodate for an increasing amount of responsibility and independency for the user.**
   As boys mature from children to adults, they want to become more independent and they learn to be more responsible with their choices. Having Duchenne makes it impossible to be physically independent, but also affects the emotional feeling of independency. Duchenne boys' parents are often overly protective over their children (see chapter 3.4 and 4.4), making the risk of not becoming (emotionally) independent even greater. To fit with the typical Duchenne parent-son relationship, the responsibility over the exoskeleton should gradually shift from parents to boys.

4. **The user should feel like he has a sufficient amount of control and choice over the exoskeleton.**
   The negative disease progression of Duchenne boys happens without them feeling like they have any control or choice over it (see chapter 4.5). Also, products are experienced as negative if they feel like an imposition in Duchenne boys' lives, rather than a choice. They just have to learn to accept the situation as it is. In the current use of the exoskeleton, many interactions need to be done by (informal) caregivers and installers/professionals (see chapter 2). There is a risk of the user not making any decisions and the exoskeleton feeling like an imposition as well. Using the exoskeleton should therefore give the boys the feeling that they do have some form of control over the situation.



Relevant for all three emotional phases

Focus on positive progress, anticipate on negative decline



Increasing responsibility & independency

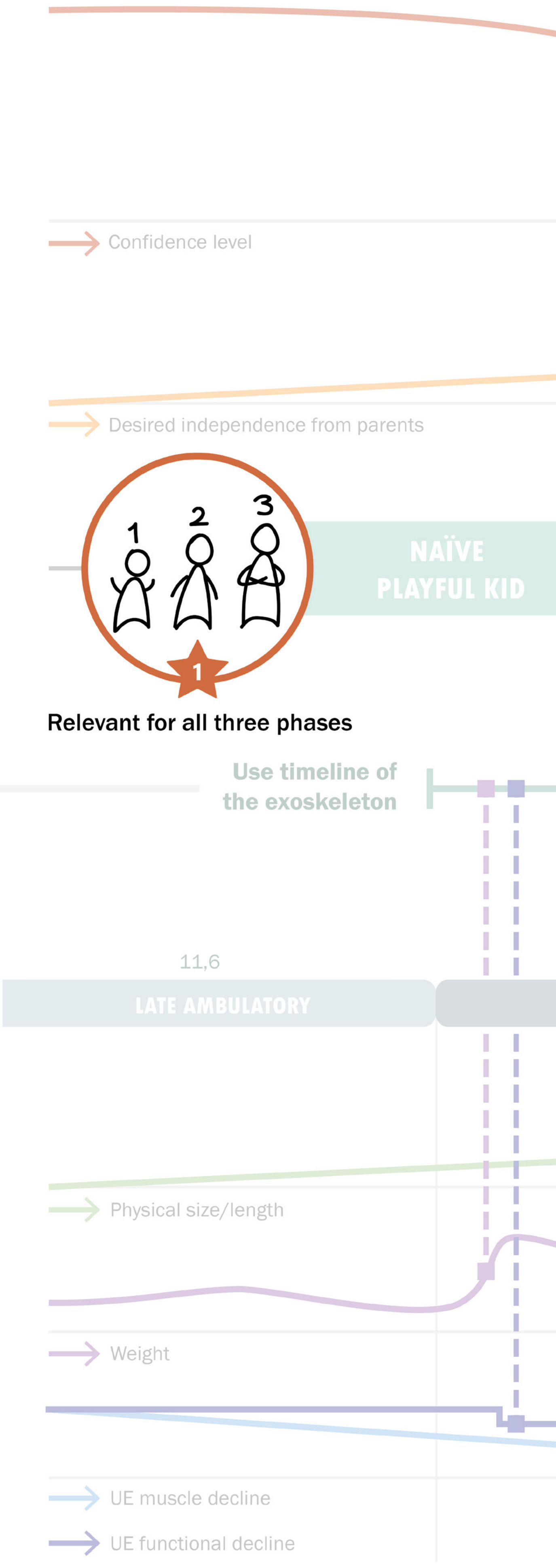
Feeling of choice & control

Fig. 42 *Design Guidelines*

In figure 43, each design guideline is placed on the research overview (which was originally presented on page 60-61), to show how all guidelines can be related back directly to the conclusions from both the literature study and user research of chapter 3 and 4.

1. “**Relevant for all three phases**” is placed at the beginning of the timeline of the three emotional phases, because the relevancy of the exoskeleton was demonstrated to be especially low for the Naïve Playful Kid and to become higher towards the Constrained Reluctant Adolescent.
2. “**Focus on positive progress, anticipate on negative decline**” is placed on the physical timeline of Upper Extremity functionality, because the physical development only declines negatively, and a confirmation of that decline due to product introduction or alteration was indicated to impact Duchenne boys’ emotional well-being as well.
3. “**Growing responsibility and independency**” is placed at the end of the emotional timeline of the desired independence from parents, since the desire to make own decisions was shown to be especially high with the Constrained Reluctant Adolescent.
4. “**Feeling of choice and control**” is placed at the confidence drop of the Anxious Self-Conscious Teen, because at moments like these the boys are expected to want the possibility to make a change on the exoskeleton.

The design guidelines described in this chapter are used to gain insights and make design choices in chapter 6: Design Exploration. These insights and choices can be recognized visually; the four visualisations of the guidelines in this chapter are recurring in chapter 6 as well.



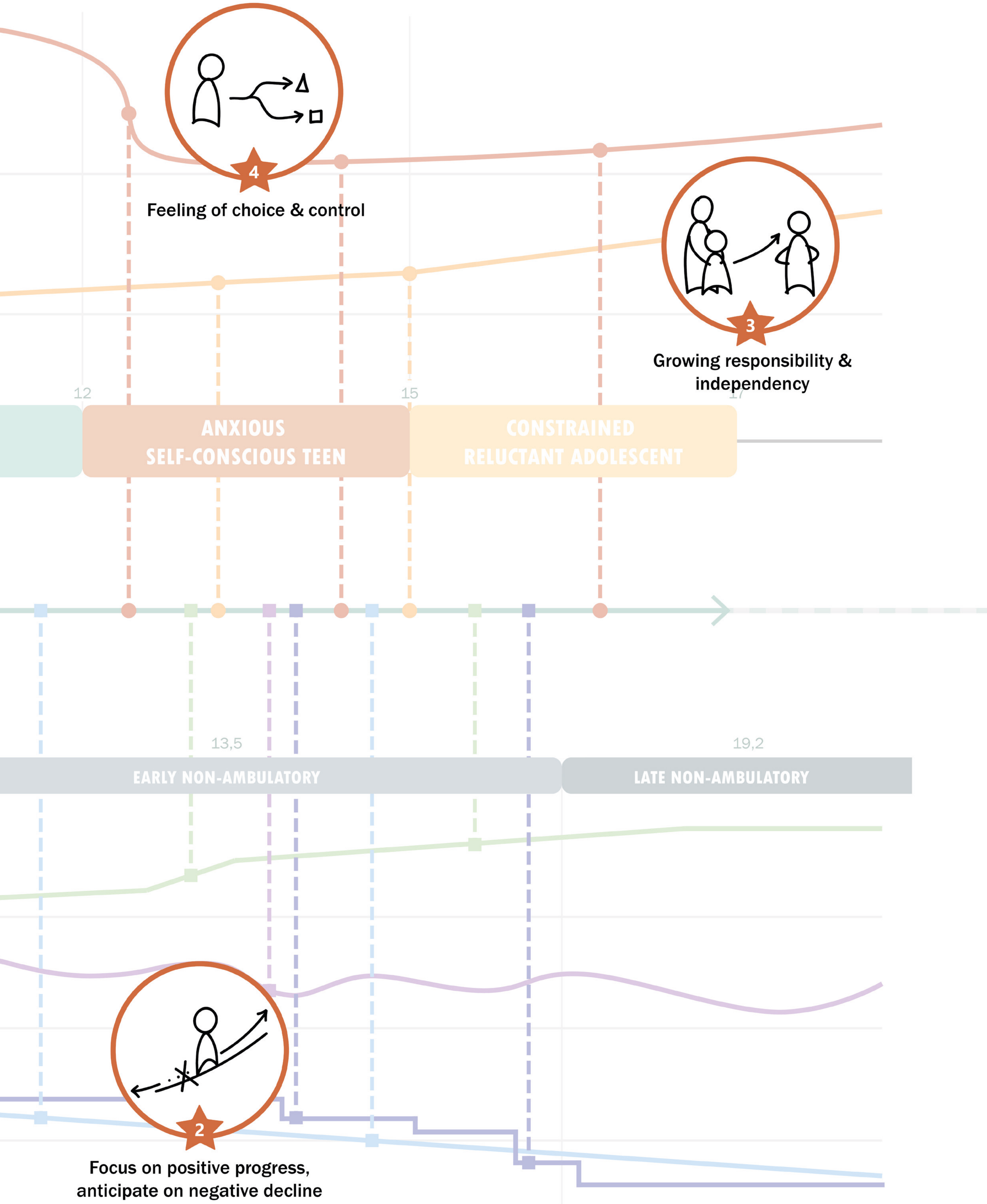


Fig. 43 *Design Guidelines placed on research overview*

5.2 Design Vision

All design guidelines were combined to form one design vision (figure 44): "A maturing exoskeleton needs to be able to develop positively, when the user is ready to make a change". The "maturing exoskeleton" refers to the relevancy for all three emotional phases, "develop positively" refers to the focus on positive progress and anticipation on negative decline, "when the user is ready" refers to the user taking on an increasing amount of responsibility, and "to make a change" refers to the user feeling in control and making the choice to change something if he wants to. The design vision serves as a summary of the design guidelines and a general reminder of the goals needed to accomplish during further development.

Design vision:

A maturing exoskeleton needs to be able to develop positively, when the user is ready to make a change

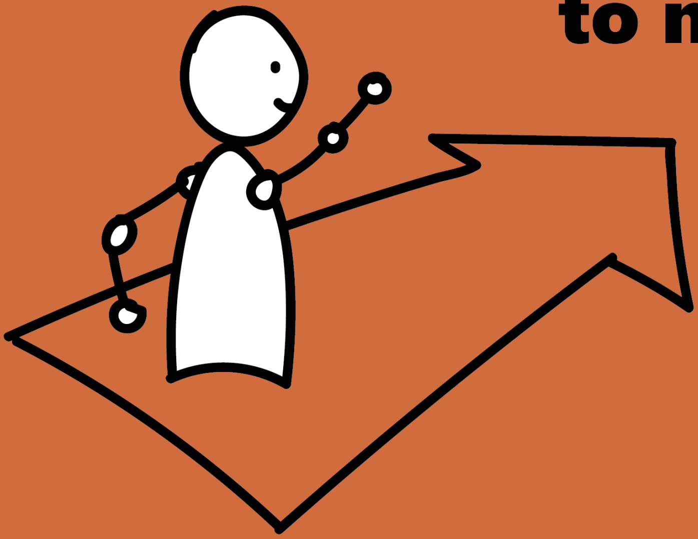


Fig. 44 *Design Vision*

6.

Design explorations

This chapter presents design activities done to form ideas for a maturing exoskeleton, and the design and evaluation of two concepts.

The chapter includes an overview of the different design activities done and creativity techniques used, followed by a description and scenario of two concepts. Both concepts were evaluated with the design vision and target group, and one concept was chosen for detailing.

Overview chapter

6.1 Design activities
6.2 Concepts
6.3 Concept evaluation & choice

Fig. 45 *Brainstorm wall for ideation*

6.1 Design activities

This chapter contains design activities done in this project to broaden the scope and come up with innovative, creative ideas and concepts. Design activities, next to general brainstorming and sketching, consist of a creative session with design students (chapter 6.1.1) and using analogies and metaphors (chapter 6.1.2). Key insights from both activities are summarized in chapter 6.1.3.

6.1.1 Creative session with design students

A creative session with design students was done to explore the design space and start off with fresh perspective ideas to provide additional insights. Figure 46 shows the creative session plan, which was composed with creativity techniques from two books: Integrated Problem Solving (Buijs and van der Meer, 2013) and the Delft Design Guide (Boeijen et al., 2013).

The session was executed with four participants:

- Two master students Integrated Product Design
- Two master students Strategic Product Design

The goal of the session was to explore ideas for all three phases of growing up (first design guideline), and later combine them into integrated concepts. Additionally, insights were gained on the other three design guidelines as well.

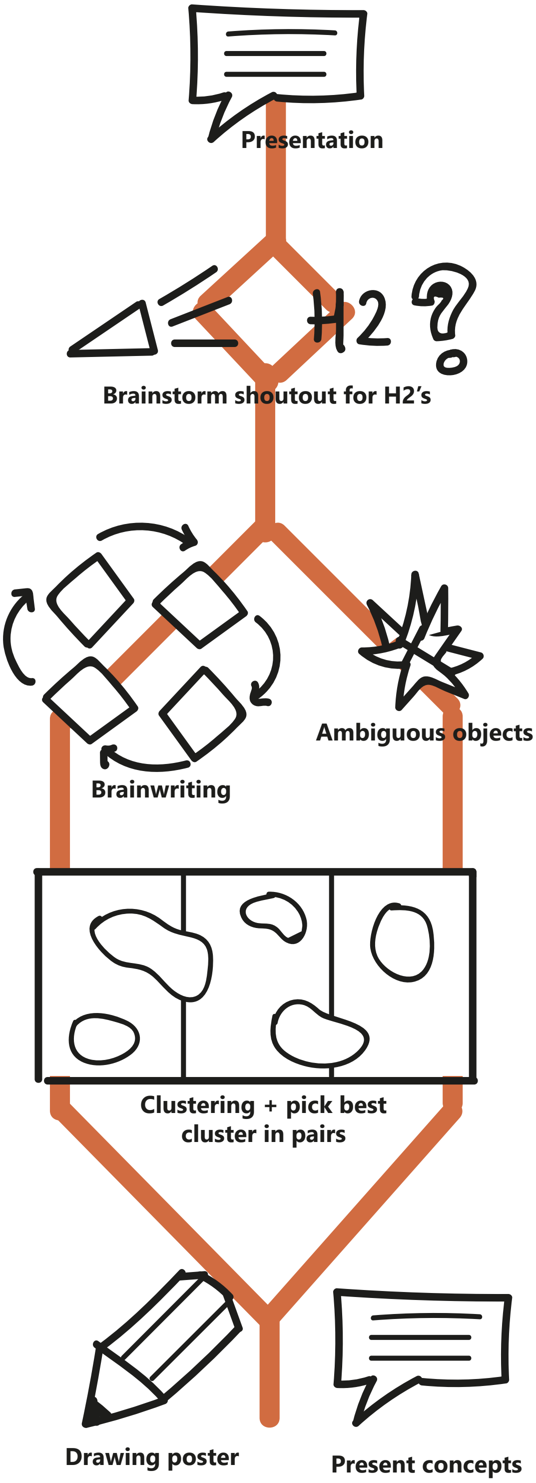


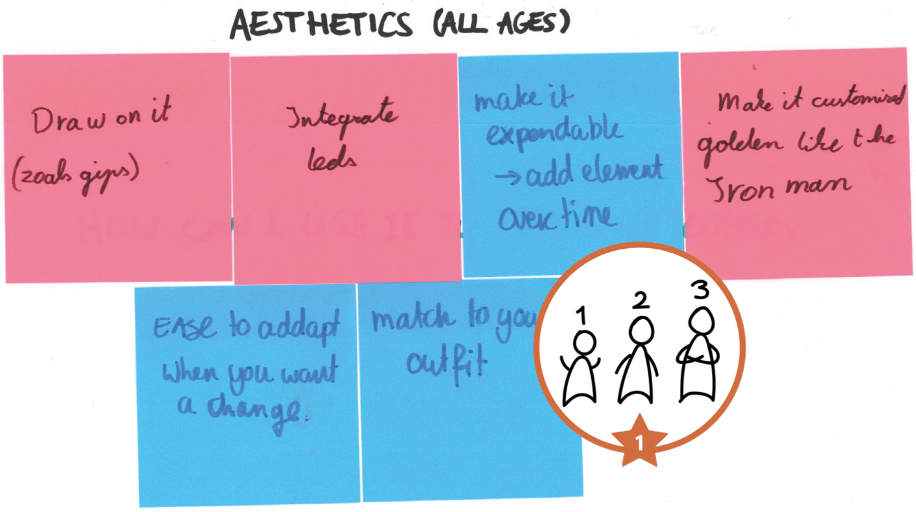
Fig. 46 Creative session set-up

Figure 47 shows a picture from the session. In figure 48, some ideas the students came up with are presented, including an explanation of how they lead to insights. The stickers show to which design guideline (chapter 5.1) the insights mostly belong. Other results from the session are presented in appendix K.

The following insights were most important for further development:

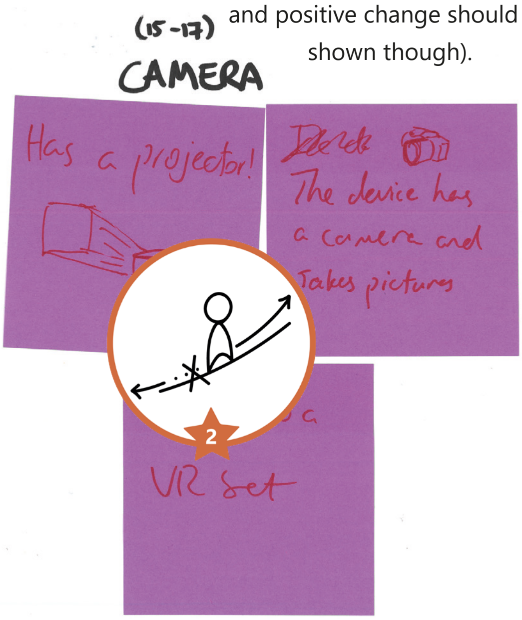
- Lots of games were thought of, and might be interesting at first for the youngest target group (10-12 years old), but are not expected to stay interesting in the long term.
- Visual customisation and appearance in general was an important recurring theme, especially for the middle target group (12-15).
- Giving the user an extra power by wearing or moving the exoskeleton was a promising idea to increase acceptance for the younger phases (10-12 and 12-15 years old) who do not think the exoskeleton is physically necessary yet.
- Several interesting ideas were about personal attachment to the product, like storing memories, so the user would not want to part from it as he matures.
- Setting goals can be interesting to stay involved in the long term, and can work motivational, but also have a risk of confirming muscle decline. Therefore, goals should always be related to positive progress. They could be focussed on things that are not directly related to physical functioning, like learning a new skill.
- The boys should be given control, but not too much responsibility, as to where a wrong or irresponsible choice can affect their well-being.

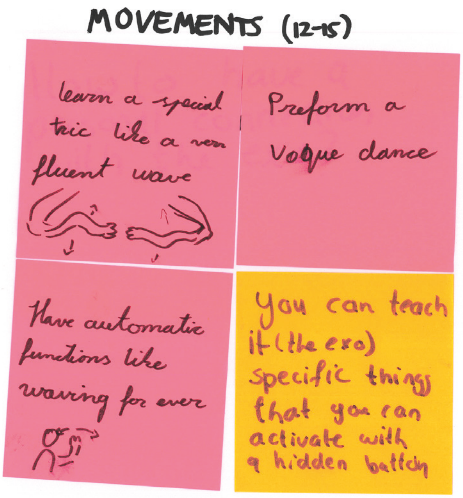
***Fig. 47** Creative session with design students*



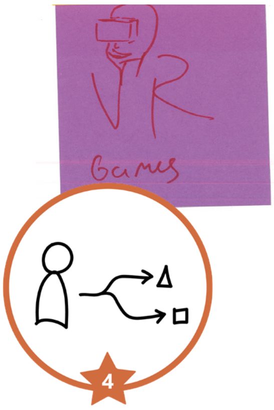
Idea: Add self-chosen features to the device (Nike ID) / match to your outfit / make it customized
Insight: Since the exoskeleton will be visually standing out, and since each teenager has a different taste, and since taste will change over time, visual personalisation seems important and logical to have.

Idea: The device has a camera and takes pictures
Insight: Storing memories into the exoskeleton can increase the boy's attachment to it. Although it will change over time, it can be valuable to remember what it used to be (only good memories and positive change should be shown though).

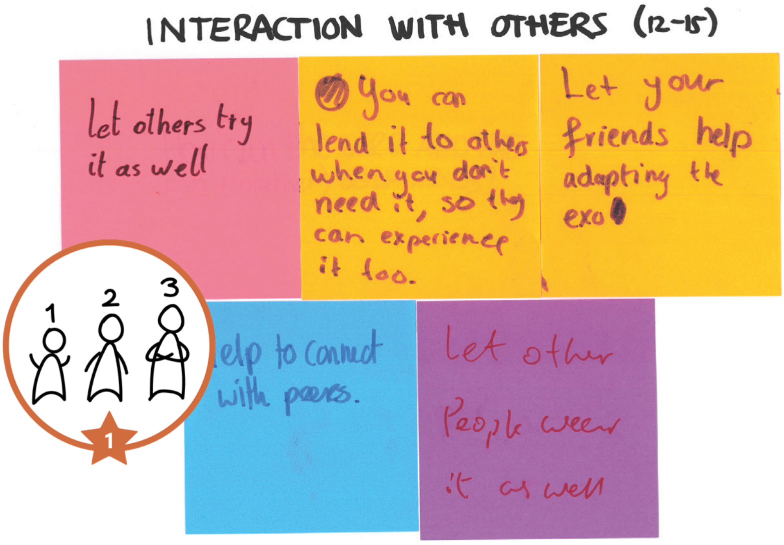




Idea: Integrated games/game controller
Insight: Although games can make an exoskeleton fun at first, especially for the first phase, no game will stay interesting for the use of seven years. However, a gradual switch from a playful function towards a more serious function might still be interesting.



Idea: Integrated VR game set
Insight: By moving the exoskeleton you create an extra function --> interesting interaction, because it stimulates movement and gives a direct reward. You have a direct control over something by moving.



INTERACTION WITH OTHERS (12-15)

let others try it as well

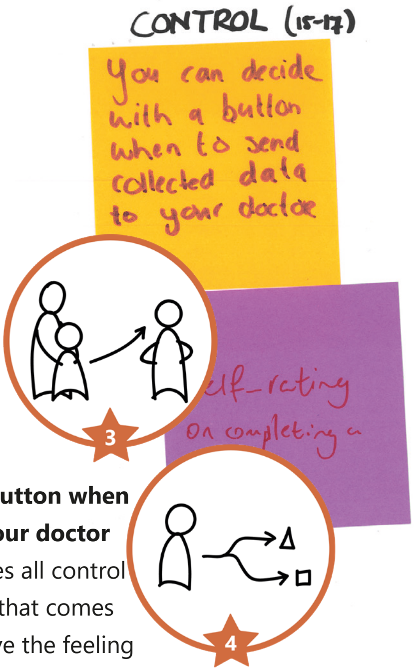
You can lend it to others when you don't need it, so they can experience it too.

Let your friends help adapting the exo

elp to connect with peers.

Let other people wear it as well

Idea: Let your friends try it as well
Insight: The second phase (anxious self-conscious teen) needs confirmation from others that he is not weird. Although literally letting others wear the exoskeleton might be dangerous/risky, involving friends or maybe connect other boys with Duchenne might increase acceptance.

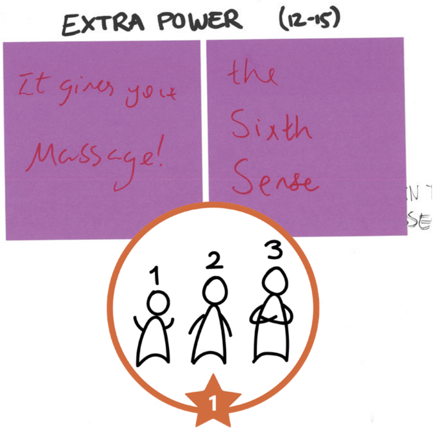


CONTROL (15-17)

You can decide with a button when to send collected data to your doctor

elf-rating on completing a

Idea: You can decide with a button when to send collected data to your doctor
Insight: Although this idea gives all control to the boy, the responsibility that comes with it is too big. He should have the feeling of control, without being able to avoid important obligations.

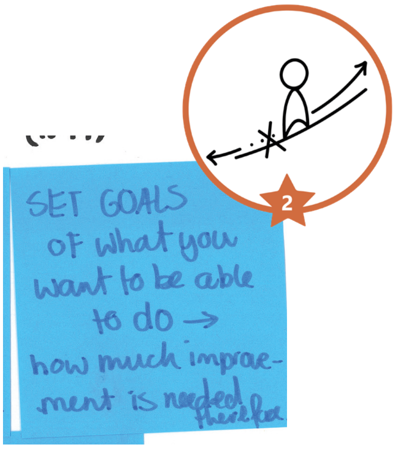


EXTRA POWER (12-15)

It gives you massage!

the Sixth Sense

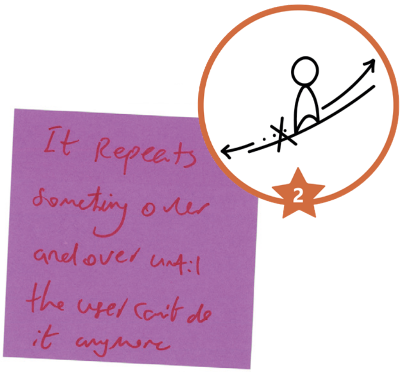
Idea: Let the exoskeleton have superpowers / the "sixth sense"
Insight: It can be really valuable, especially to the youngest phase, that the exoskeleton gives them something more than just 'normal functioning' (since for the youngest phase wearing the exoskeleton doesn't seem necessary for physical functioning)



SET GOALS of what you want to be able to do → how much improvement is needed therefore

Idea: Set goals on what you want to be able to do
Insight: Goal setting is a way to motivate yourself and to focus on positive improvement. BUT the goals set should be about something else than physical improvement (not reachable for DMD boys), which can develop positively, like learning a skill.

Idea: It repeats something over and over until the user can't do it anymore
Insight: Storing 'movement memories' in your exo makes it your own personal device. This is a very smooth, gradual transition from using yourself towards an active supporting exoskeleton, without having the conformation of decline.



It Repeats something over and over until the user can't do it anymore

Fig. 48 *Ideas & insights from creative session*

6.1.2 Analogies and metaphors

To find inspiration for new solutions from more distant domains, analogies and metaphors were used. This method is considered especially helpful during ideation generation, because it can support the creation and exploration of novel solutions (Boeijen et al., 2013). On this page, one analogy for each guideline of the design vision is shown (figure 49-52) and completed with a description of the most important insights.

Fig. 49 *Superhero arm*

Metaphor: Superman/ Iron man
Insight: By putting on the exoskeleton, the boy gets an extra (secret) power that others do not have – this can increase acceptance in the early stage, where the muscle strength loss is not as big yet.

Fig. 50 *Opticien, picking a model of glasses*

Metaphor: Optician, choosing a model of glasses
Insight: Your eyes need to be measured ('handicap', might be confronting) but you get to pick a model and style for glasses which suit you. You can even get advice from a stylist if you are not sure what looks good. The boys should also feel like they have options when (re-) fitting the exoskeleton. Also, since it is such a personal product that is worn every day, they should be able to personalise/customise.

Fig. 51 *Visiting the orthodontist*

Metaphor: Brace colours at orthodontist
Insight: Although going to you orthodontist appointment is not fun and even painful, eventually you do it to get nicer teeth (positive progress). You also get an immediate reward: you get to pick a colour of elastic bands that you like. This is a question only you can answer (not your ortho or parents). It can even be something to look forward to. For the boys to feel like they have a choice, they should be offered a question only they can answer.

Fig. 52 *Parents teaching kids to handle money*

Metaphor: Parents teaching kids how to handle money (from cash allowance to own bank account)
Insight: Responsibility should be increased in small steps, so boys feel like they are in a safe space where they can make mistakes and learn from it. Also, they learn by doing, not by someone telling them. Responsibility and decision making should also increase in small steps. Boys should feel like they are given enough independence for their knowledge and skills (they should feel prepared for a next step).

6.1.3 Key insights

- ... on designing something relevant for all three phases:
  - For the youngest phase (Naïve Playful Kid), wearing the exoskeleton should feel like an **extra benefit or superpower**, since 'only' long-term physical benefits will not be interesting enough for them. Playfulness can easily be integrated, but not sure if it stays interesting in the long term.
  - For the second phase (Anxious Self-Conscious Teen), it should be possible to **personalise or convey their own style,** and to change that style over time. Also, they need **confirmation from others,** which can be obtained by including (subtle) interaction with peers in the concept.
  - For the third phase (Constrained Reluctant Adolescent), the exoskeleton should make them **feel independent and they should feel in control** (see also other key insight on control/choice)

- ... on focus on positive progress
  - **Learning a new skill** by using the exoskeleton
  - Letting the boys **set goals** for themselves can be a good motivator
  - Focussing on the positive also includes **taking attention away from negative progress.** Goal setting should not be about doing things the boys will never be capable of doing with their disease.
  - 'Shocking' negative steps backwards can be prevented by doing **regular check-ups**.

- ... on growing responsibility & independency
  - **Responsibility and independency should be given to the boys in small steps.** They should not feel overwhelmed and therefore discouraged. But they should be treated to what they are capable of.

- ... on feeling of choice & control
  - Although boys will not be able to control every decision, **there should always be a question that only they can answer.**
  - Feeling in control can range from choosing one feature, to getting and interpreting your own movement data. There should be a delicate balance; **too much information or choice can lead to losing control**.

- Since the exoskeleton is used over a long time period, it is challenging to cover all needs with one simple product idea. **The design of a product-service combination which includes multiple touchpoints with the user and a user scenario is more suitable for the purpose of maturing.** Therefore, the two concepts described in chapter 6.2 are a combination of multiple ideas and are presented as a scenario.

6.2 Concepts

In this chapter, two concepts are presented as user scenarios. First, it is explained and visualised how certain insights formed to spark to come up with a new concept. Then, the concept scenario is explained, followed by the substantiation of how they follow the different guidelines and therefore aim to fulfil the design vision.

6.2.1 From insights to concepts

The insights "the boys should be able to personalise or convey their own style" and "give the boys a question only they can answer" were seen as a valuable combination, because it gave a vision of the user 'shopping' for an exoskeleton as if it was being sold in a normal store. The combination led to concept 1, which is described in chapter 6.2.2.

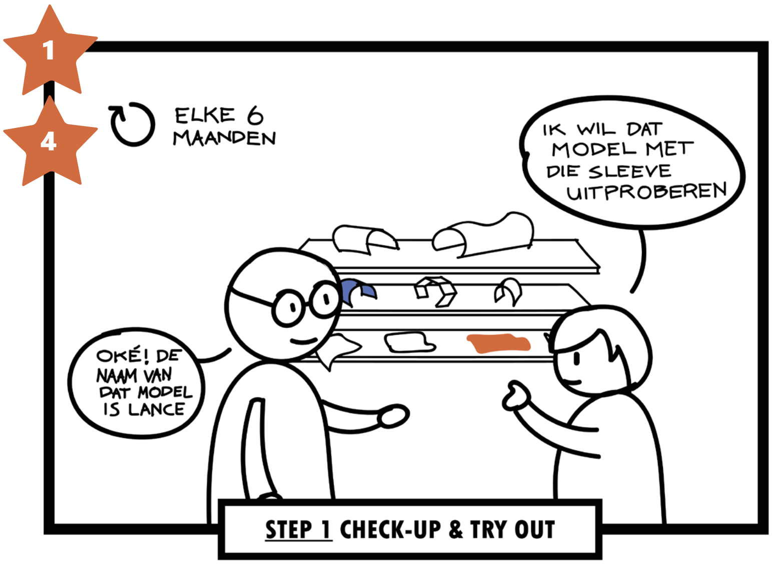
The insights "wearing the exoskeleton should give the user an extra benefit or superpower" and "learning a new skill by using the exoskeleton" sparked the idea to take the focus of the exoskeleton away from the physical use and into a new world. The combination led to concept 2, which is described in chapter 6.2.3.

From the initial insights which lead to the ideas, both concepts were further detailed into user scenarios to comply with all design guidelines.

Fig. 53 *Brainstorm wall to link ideas and insights into complete concepts*

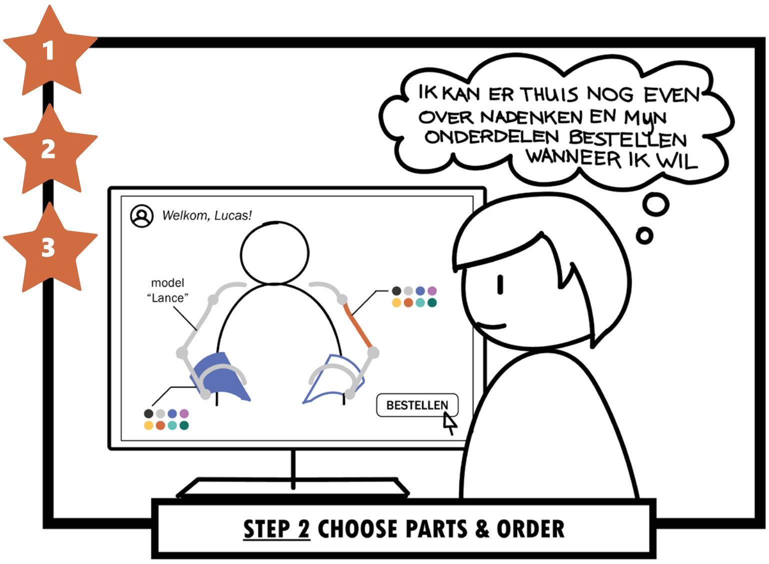
6.2.2 Concept 1: Build Your Exo

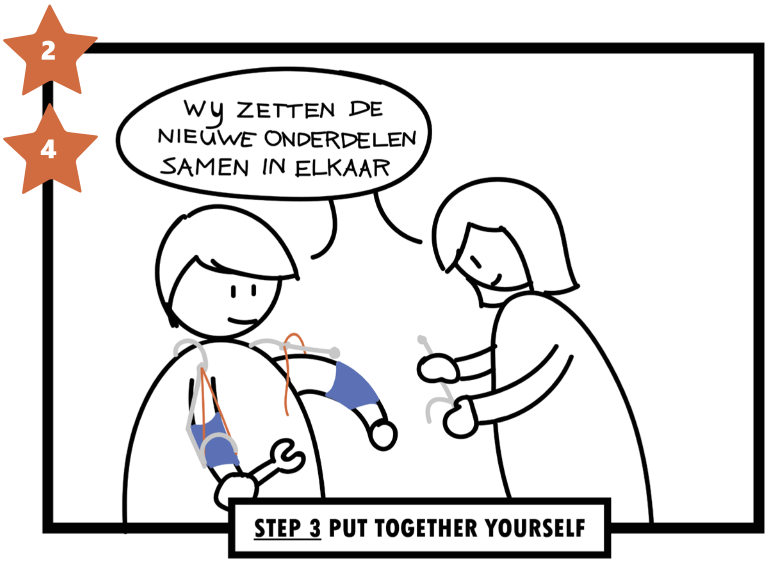
Concept 1 changes the ordering and replacing process of visual parts of the exoskeleton. The idea is that the boys can check out different visual options of parts in a store, try out what model they like, order those parts online and finally (re-)build their Exo by assembling ordered parts together (maybe with help of parents). They can change outfits per day if they have multiple models/colours/prints. The online platform is also a place to ask questions to experts, check out instruction videos for building, and share experiences with other exoskeleton wearers.



Step 1: Check-up & try out
The boy visits a store where he can check out the latest models. He tries out different shapes, colours and prints of the most visual parts of the exoskeleton that he interacts with (lower arm, sleeve and elastic bands). An expert advises him on what he needs and gives him the name of the model (NOT a numbered size), so he knows what to order later. This moment is also an opportunity for the expert to check and adjust the size and settings of the exoskeleton – but it is not emphasized. The check-up repeats every 6 months.

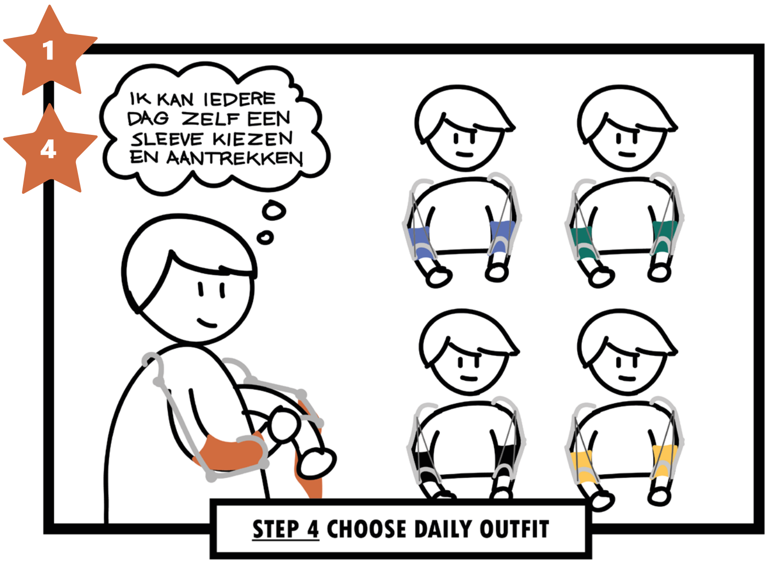
Step 2: Choose parts & order
The boy has time to think it over at home and look at his options again. He can log in with his own account to 'build his exoskeleton online' and save his favourites. When he is ready, he orders his new parts. He gives a code to his parents which they can use to pay.

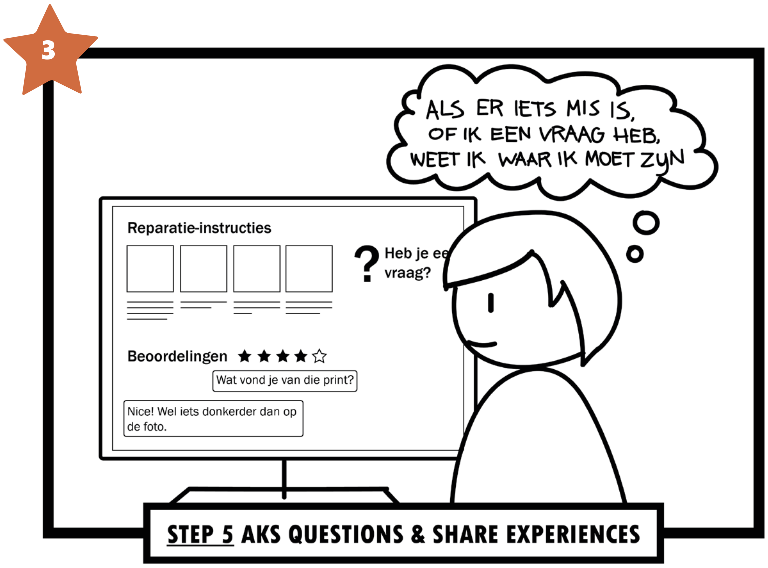




Step 3: Put together yourself
The parts are delivered at home and can be easily be assembled with help of his parents. This activity teaches them both how the exoskeleton works. Some building activities he can do himself, for some he needs help. The website provides instructional videos. (Note: he does not put together the entire exoskeleton himself, he only replaces the lower arm, sleeve and elastic bands).

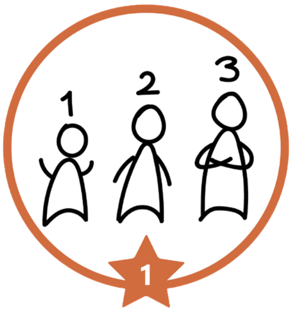
Step 4: Choose daily outfit
The boy puts on his exoskeleton daily with help of his parents. He can change his sleeve himself daily to match his outfit or style. He can own multiple parts and switch between them. His old parts can still be saved for memory. He can always order extra parts if he wants to, or if something breaks.





Step 5: Ask questions & share experiences
The website where parts were ordered can be used to ask questions to experts and check out building- and repair instructions. He can leave reviews and share experiences with other exoskeleton wearers. Whenever the boy is ready for a change, he can order new parts and the process starts again.

Substantiation: How is concept 1...



... relevant for all three phases?

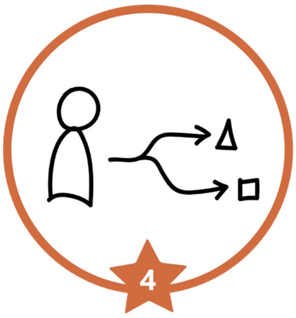
- Naïve Playful Kid: It is fun and interesting during the check-ups to learn how the exoskeleton works and how it is made. Building the exoskeleton himself is a fun activity and makes him proud of wearing it: he made it himself so is eager to show it off.
- Anxious Self-Conscious Teen: The store and online sharing of experiences makes it feel more normal to have an exoskeleton. Possibility to change outfits gives him the opportunity to convey his own style, which will likely change in this phase. Seeing simple options next to flashy colourful options might make the simple options more attractive, because it looks less noticeable.
- Constrained Reluctant Adolescent: He has become an expert over the exoskeleton because he has gained experience with checking out parts and building it himself. He has clear preferences and can order his own things online independently (possibly even with his own money).

... focussing on positive progress?

Every time the exoskeleton needs to be checked, it is an opportunity for renewal. It focusses on growth and developing your style and yourself as an individual. Old parts can be saved to look back; not on how strong he used to be, but on how his preference has developed.

... accommodating a growing responsibility?

Boys pick out what they like themselves, and when they feel ready, they can order parts themselves as well. Although parents have to give permission and pay, boys have their own account and create a paying code. As they grow up, they can start paying themselves, maybe even from their own earned money. Also, making appointments can shift from parents' to boys' job, because they can easily make them through the platform.

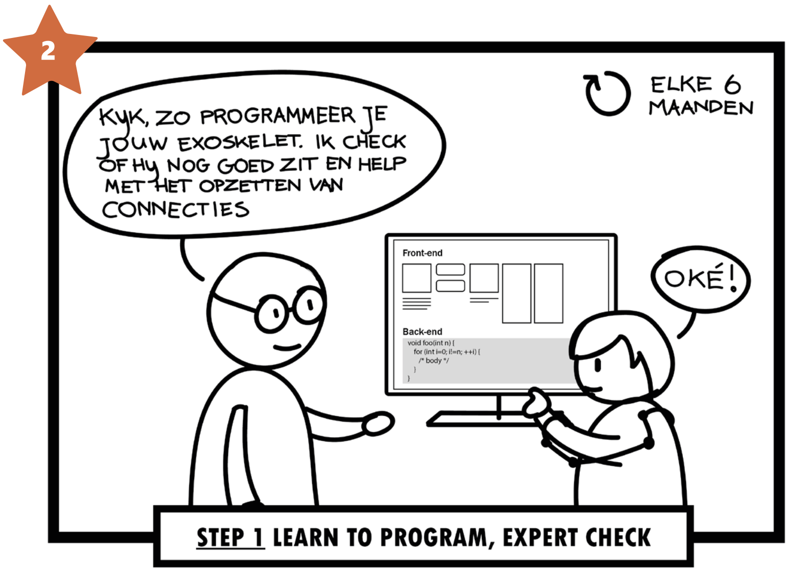


... giving a feeling of choice and control?

The boys can clearly make a choice, because they can choose their preferences each time when a new part is needed. Every time there is a check, there will be a question answered that only they can answer.

6.2.3 Concept 2: Program Your Exo

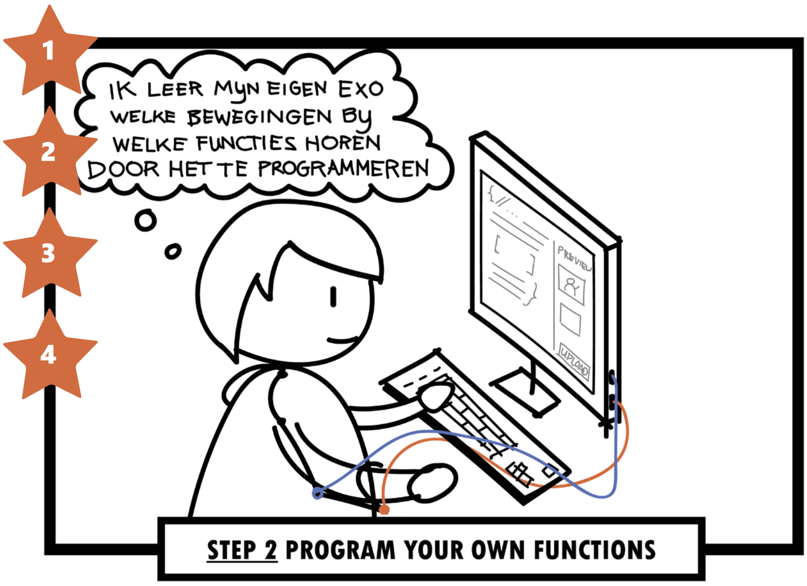
Concept 2 adds function to the exoskeleton itself. The idea is that, by making specific movements with your exoskeleton, specific functions and devices in your house can be controlled (e.g. turning on lights, opening doors, turning up music). Which functions are controlled by which movements, can be programmed by yourself. As you grow up, you learn more advanced programming to control more devices and tweak it more to your preferences. Expert checks are meant for checking your 'hardware' (does the exoskeleton fit and support well) and 'software' (help to update and install devices).

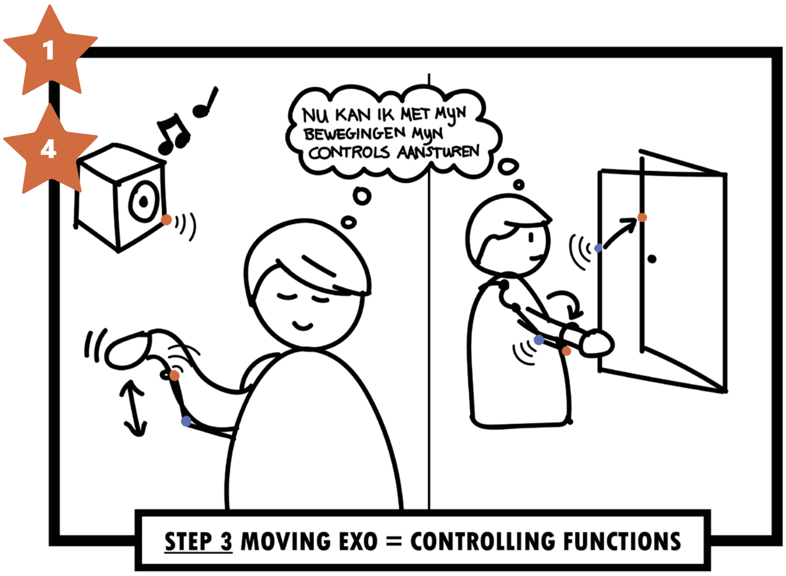


```
void foo(int n) {
   for (int i=0; i!=n; ++i) {
      /* body */
   }
}
```

Step 1: Learn to program, expert check
An expert visits the boy at home. The expert helps setting up his exoskeleton and devices in his house and teaches him how the programming interface works. Together they set up their first function(s). The expert also checks his hardware, check if the exoskeleton fits and supports enough. This check-up repeats every 6 months.

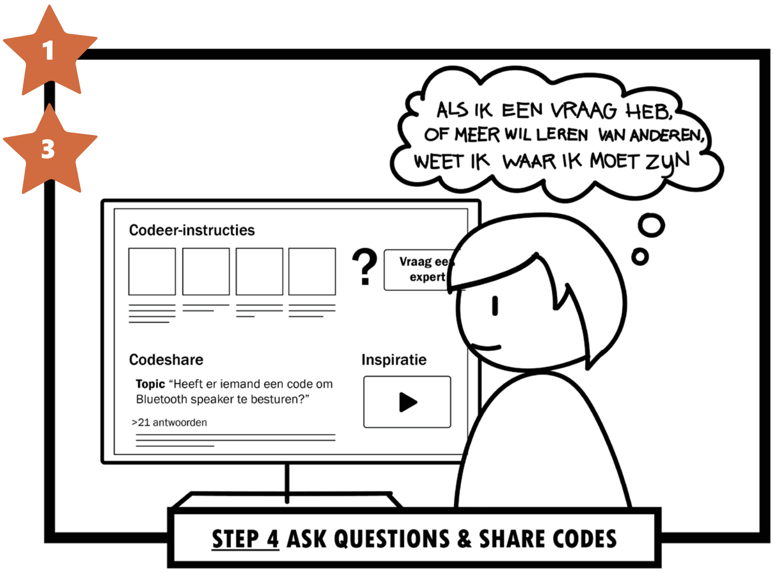
Step 2: Program your own functions
The boy can (re-)program his own functions at home, when he wants to. He programs through an understandable interface which has different levels (from linking easy pre-programmed movements and functions to programming your own specific coordination) and a login account. Over time he can learn more and improve his programming skills.





Step 3: Moving exo = controlling functions
By making specific (programmed) movements with the exoskeleton, the boy can control functions in his own house. These functions can vary from playful (gaming, sound effects, music) to serious (controlling lights and devices). The boy can also wear the exoskeleton to school; even here extra functions could be useful or fun. He can choose when his extra powers are turned on or off through his phone.

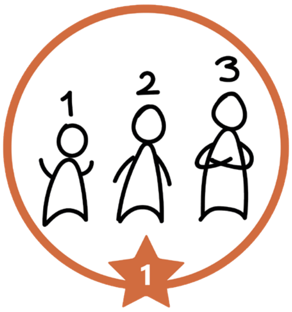
Step 4: Ask questions & share codes
Until the expert visits again, the boy can ask questions and look up instructions through a platform (same website as programming space, same login account). Here, he can also watch inspirational videos on what is possible with his exoskeleton, and share codes and tips with other exo-users.



Topic "Heeft er iemand een code om Bluetooth speaker te besturen?"

>21 antwoorden

Substantiation: How is concept 2...



... relevant for all three phases?

- Naïve Playful Kid: He can use the new function to play with devices and toys in the house. He has a cool secret superpower and he is eager to show it off to his friends.
- Anxious Self-Conscious Teen: The concept creates an online community between Duchenne boys, without putting emphasis on the disease. The community can help him to see he is not the only one, and it is actually cool what can be done with his exoskeleton. If he wants to be unnoticeable while wearing it to school, he can 'just' use the exoskeleton like normal, without extra function.
- Constrained Reluctant Adolescent: He has full control and expertise over his exoskeleton and extra functions. Over the years he has gained experience in programming his exoskeleton and choosing exactly what he likes. Functions in house can be used for more serious things that are actually needed, like turning on lights (but the transition towards these serious functions can be done in small steps without a shock-factor).

... focussing on positive progress?

Over time, boys learn a skill. They become better and more advanced at programming and teach their own exoskeleton more and more functions, which they can earn over time. During check-ups, focus lies on 'updating software' and helping the boys develop new functions. Therefore, attention is taken away from negative muscle decline. If they cannot do a movement anymore, they can just reprogram their function to another movement.

... accommodating a growing responsibility?

Programming is something the boys get to do, where the parents cannot interfere. It is something of their own. Making appointments is first done by the parents, but in the programming interface, the platform is also directed towards the boys learning how to make appointments.

... giving a feeling of choice and control?

Boys get quite literal control over devices, but are also in control over which movement does which function, because they learn how to program it themselves.

6.2.4 Concept Overview

Table 2 shows a short overview of all different components of the two concepts Build Your Exo and Program Your Exo, compared on different levels: day-to-day use, continuous service, and occasional check-ups.

	Concept 1: Build Your Exo 	**Concept 2: Program Your Exo** 
Day-to-day use	Boy can choose a different sleeve/cover daily.	Boy can control devices by making movements.
Continuous service	Parts can be ordered online and assembled at home. The boy has his own login account where he assembles the exoskeleton digitally beforehand and saves favourites.	Functions to control devices can be programmed. The boy has his own login account where he sees his programmed exoskeleton in a digital environment.
Occasional check-ups (to check if exoskeleton needs adjusting)	During the check-ups, boy can try out options for sleeves, covers and models in the store. He can learn how the exoskeleton works and see how it's made.	The expert visits the boy at home to check and set up 'software' and 'hardware'. The boy learns how to program and can get inspiration from what others have programmed.

Table 2 *Overview two concepts*

6.3 Concept Evaluation

6.3.1 Evaluation approach

To gain feedback on both concepts, and to gain insights into how much both concepts comply with the design vision in order to make a substantiated decision on which concept to further develop, a concept evaluation was done. In addition, feedback was deemed useful for improvement of both concepts, regardless of the final decision.

Both concepts were evaluated with two parties:

- With the target group: interview with Chris, 15-year-old boy with Duchenne (name is fictional)
- With several people from Yumen Bionics, with different areas of expertise (technical, business, interaction)

Both evaluations were done with the following steps:

1. Explain the context/exoskeleton
2. Explain concept 1 and concept 2 by showing the scenario steps
3. Let them evaluate each step of concept 1 and concept 2 by choosing one of three cards: positive, doubt/doesn't matter, or negative (see figure 54)
4. Ask to write suggestions for improvement on each step of both concepts on a post-it (see figure 54)
5. Ask to compare the concepts: which one would they prefer and why?

Mind that the opinions of all parties were taken to gain insights, not to 'blindly' follow others' preferences.

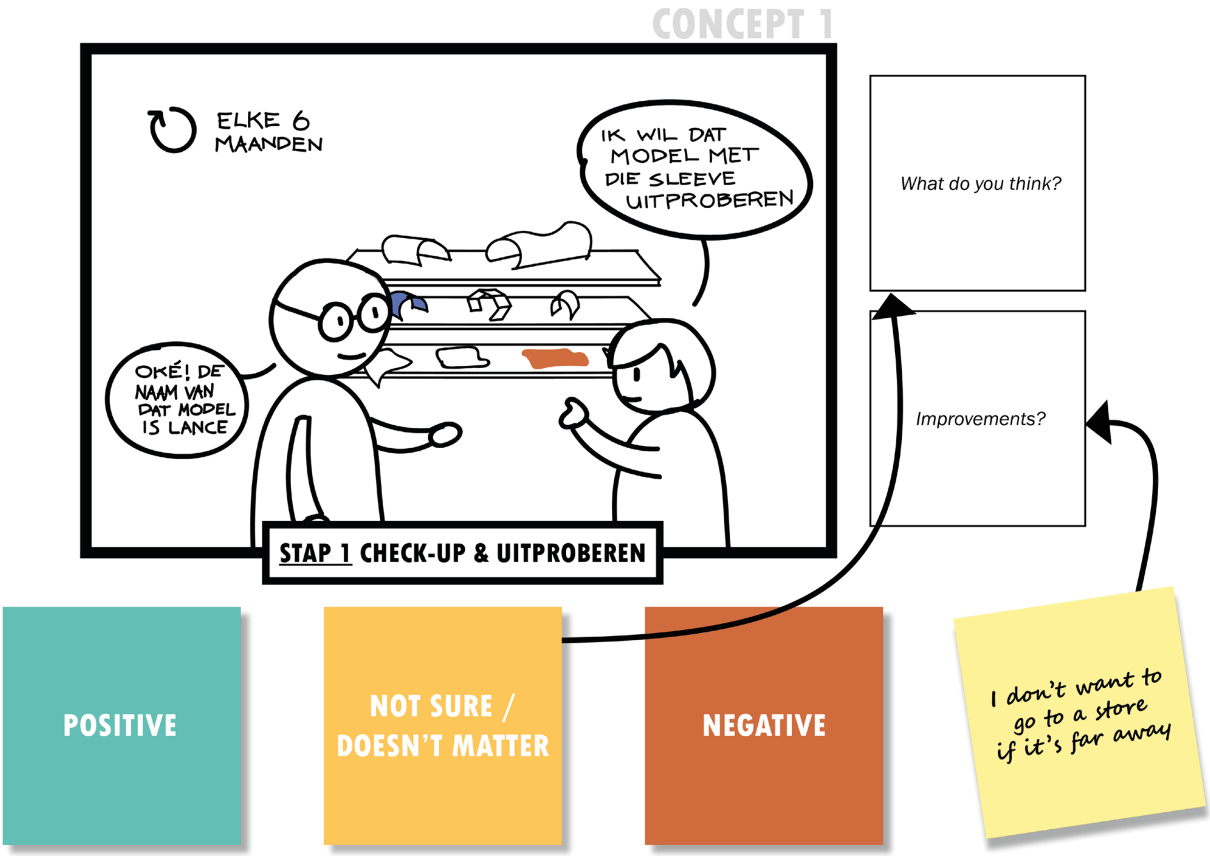


Fig. 54 *Evaluation method for each step of both concepts*

6.3.2 Evaluation results

The results and summary of findings of the interview with Chris can be found in appendix L. A summary of comments from people from several expertise areas from Yumen Bionics is in appendix M. In this chapter, the most important results comparing the two concepts are listed.

Chris evaluated nearly every scenario step of both concepts as "positive", which shows they were both interesting for him. However, two steps of concept 1 were evaluated as "not sure": step 1 "try out in the store", because it would be dependent for him how far away the store was ("it should be as close to home as possible"), and step 4 "change outfits daily" because although it was not necessarily a bad option, he did not think he would use it personally.

For both concepts, the expert service seemed useful, but should be elaborated on further. For example, Chris did not understand why the expert needed to come by every 6 months, instead of just calling him when he needs him.

Both concepts were evaluated equally on the social platforms. For both concepts, the possibility of asking questions and sharing experiences through a platform was "just good to have" according to Chris. Yumen Bionics agreed that the platform was interesting, and wondered how it would be put into practise in terms of maintenance. Regardless of the concept decision (chapter 6.3.3), this part will therefore be further developed.

Chris would prefer concept 2, since he saw an added value of getting more functionality compared to concept 1 ("It seems like fun. But also, it seems better. I like that you actually can do more. That it does more than just supporting your arms."). However, he did not see why both concepts could not be combined; since the expert service and social platform were similar, the purchasing and customisation process of concept 1 could exist next to the extra controlling function of concept 2.

Yumen Bionics saw the service part of concept 1 (combination of digital and physical purchasing process) as valuable and even necessary in the short term, because it fits well with the exoskeleton ("This combination of digital and physical interaction with seeing, imagining and then trying out, fits really well with the exoskeleton as a product."). However, the building interaction of concept 1 seemed too risky for them to execute - an engineer from Yumen said that he would rather not let any functionality depend on the hands of the user, meaning that the level of building would need to be extremely simple ("like lego bricks") and the current prototype is not close to that stage of development yet. **The extra functionality added to the exoskeleton in concept 2 (controlling devices from a distance) was more interesting for Yumen for longer term development** (part of a larger vision).

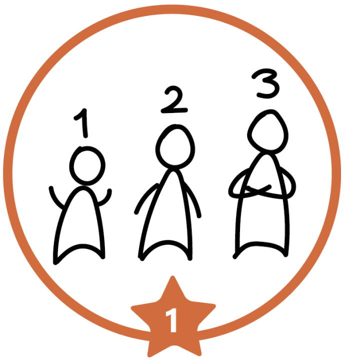
The home location-based service of concept 2 was more interesting and suitable than the store-location based service of concept 1, since travelling times were seen as a burden by Chris and since Yumen mentioned a store could not be kept open all year because of the small target group. **Regardless of the concept decision, the expert service should therefore eventually be centred around the user's house.** In addition, using the product in the comfortable environment of his home (which concept 2 focusses on) seemed more attractive to Chris; he mentioned he would use the exoskeleton in school, but only for physical support and not to draw attention to himself.

Feedback from Chris was helpful to understand that **concept 2 fitted very well with his needs and with the target group** ("this is just perfect"). He also mentioned it could "prevent unnecessary burdens", indicating how interesting it is especially for Duchenne boys in terms of independence and convenience in the house. **For concept 1 on the other hand, this was questionable.** For example, the customisation options and regular outfit changes were designed to fit well to the middle target group (12-15 years old) but was not evaluated as interesting or necessary by Chris.

Concept 1 gives the user a feeling of control by giving him the possibility of choosing his exoskeleton appearance (which Chris would like to choose in "as much detail as possible") and concept 2 by giving the user the possibility of coding his own exoskeleton functionality (which Chris would really like to be able to learn). However, **Yumen Bionics pointed out that it should be looked into further how different people experience the level of control in a product in a different way.** For concept 1, giving the user the idea that he has a lot of choice is different from actually letting him make 'engineering decisions', for example. For concept 2, giving a user many coding options could also feel overwhelming.

Concept 1 **Concept 2**

Yumen:
"Letting the user assemble parts is just too risky. It would need to be extremely simple, and we're not close to that level yet."



Chris (15):
"This is just perfect. It is fun, and it can prevent unnecessary burdens."

Chris (15):
"Although I would like to decide in detail what it looks like, I would not want to change that daily or weekly."

Chris (15):
"I like that you can actually do more. That it does more than just supporting your arms."

Chris (15):
"I think, for both concepts, instead of every 6 months, I should be able to make my own check-up appointments when it's necessary."

Chris (15):
"I think, for both concepts, instead of every 6 months, I should be able to make my own check-up appointments when it's necessary."

Chris (15):
"I like that I can choose the appearance in as much detail as possible."

Chris (15):
"I like that I am able to program it myself for sure."

Yumen:
"Different people experience different levels of control, while using the same product."

Fig. 55 *Evaluation of both concepts on design guidelines, after feedback*

6.3.3 Conclusion: concept choice

To make a decision between the two concepts*, they are compared on their ability to comply with the different design guidelines (chapter 5.2), based on the evaluation with both the target group (Chris) and Yumen Bionics. Figure 55 shows an overview of the evaluation on the design guidelines for both concepts, including quotes used to substantiate the final decision.

Fitting to the three phases (Naïve Playful Kid, Anxious Self-Conscious Teen, Constrained Reluctant Adolescent)

If concept 1 would be chosen, it would have to focus on only combining the digital and physical purchasing process. It would not include the actual building-at-home interaction, since Yumen saw this interaction as risky for functionality ("it would have to be extremely simple") and Chris wanted an additional option of having it assembled beforehand ("in case you don't like it or don't understand it"). Since the building interaction was designed for the concept to fit to the youngest target group (10-12 years old), this target group might not be interested in the concept anymore if that interaction is lost. Concept 2 therefore has, after this evaluation, more potential to be interesting for the youngest target group. Since the exoskeleton use is currently not physically necessary in the minds of boys in this target group (see chapter 4.6), it is important to find a concept which fits well with their needs. Further feedback of Chris also indicated that concept 2 was more interesting for the target group overall. Therefore, in terms of the first design guideline of fitting well to the three phases, concept 2 seems like a better choice.

Focus on positive progress

In order to let the user focus on positive progress over a longer period of time, both concepts contain changing elements which can positively benefit the user. However, one comment from Chris made it clear that concept 2 has more potential to focus on positive progress: "I like that it can actually do more than just supporting your arms." This shows that over time, concept 2 can give the user more functionality which is valuable. Concept 1 on the other hand contained the changing element of choosing your own appearance and changing it regularly. This was, however, not valued as interesting by Chris ("I would not really use it"). Therefore, in terms of focussing on positive progress, concept 2 is preferred.

Growing responsibility and independency

Since the expert service was evaluated as equally interesting and important for both concepts, it will be included in the final concept as well – with necessary adjustments for the service to make more sense to the user in terms of taking responsibility. However, the concept decision does not depend on it.

Feeling of choice and control

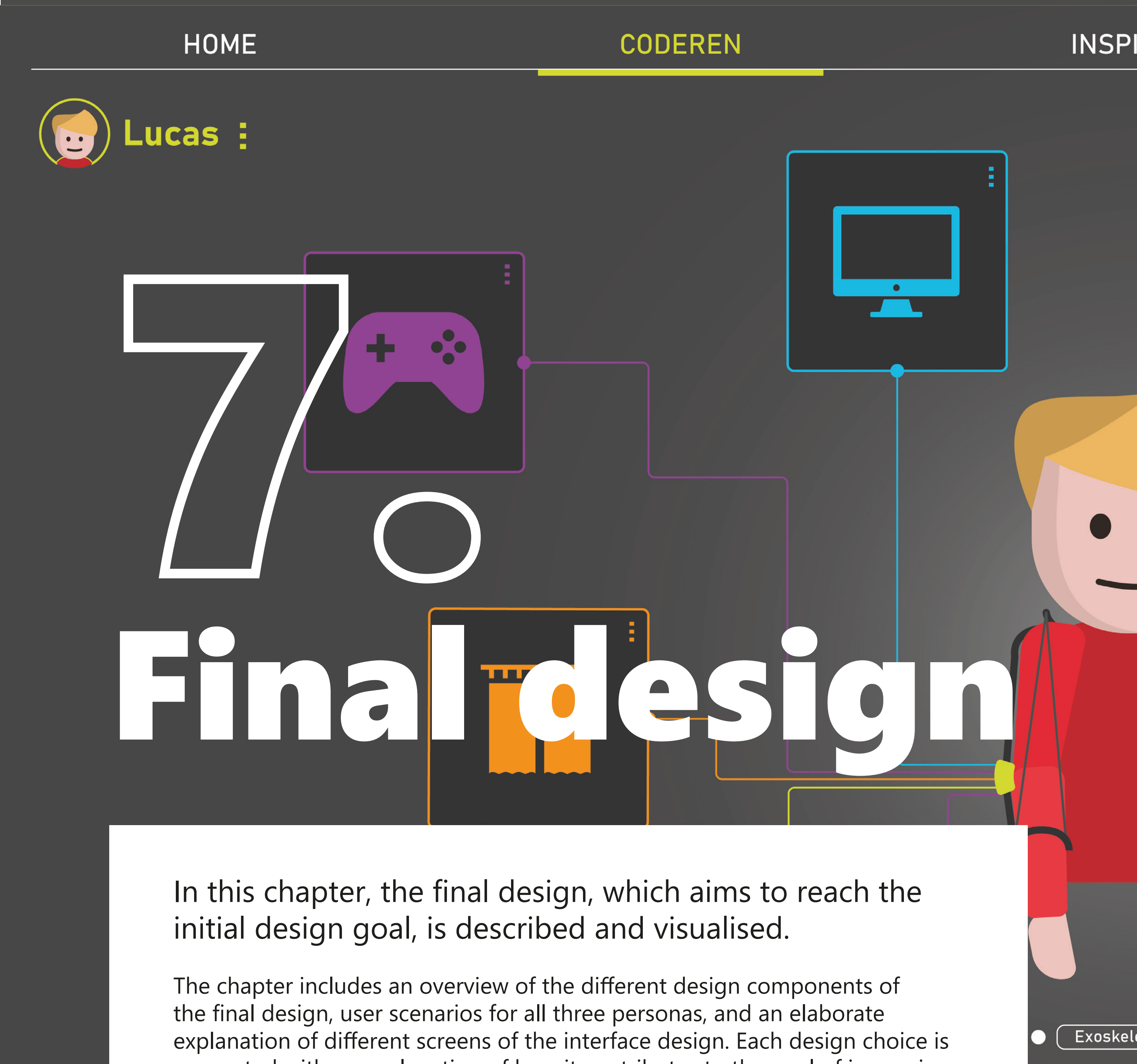
Both concepts have aspects which give the user a certain feeling of control or choice in different ways, which are both evaluated as valuable (concept 1 by letting the user choose the appearance in detail, concept 2 by letting the user program his own functions). However, regardless of the concept decision, it should be further investigated how different users can experience different levels of control with the same product.

Personal preference

The personal preference of the designer between the two concepts lies with concept 2. Not only because it seems more fun in general, but also because it seemed to spark more reaction and enthusiasm when it was evaluated with the target group.

Given all the considerations mentioned above, **concept 2: Program Your Exo is chosen to continue with and detail into a final design,** which is further described and illustrated in chapter 7.

*Even though both concepts were evaluated as interesting by both Chris and Yumen Bionics, and Chris saw a possibility of combining both concepts, only one concept is chosen to detail into a final design. Since the nature of follow-up design activities is so different (designing a suitable and adaptable product appearance versus a coding platform suitable for beginners to code their own product), combining them would be too time intensive within the scope of this project.



7.

Final design

In this chapter, the final design, which aims to reach the initial design goal, is described and visualised.

The chapter includes an overview of the different design components of the final design, user scenarios for all three personas, and an elaborate explanation of different screens of the interface design. Each design choice is supported with an explanation of how it contributes to the goal of increasing the ability of the exoskeleton to mature with its user.

Overview chapter

7.1 Final design components
7.2 User scenarios
7.3 Interface design
7.4 Technology
7.5 Final design overview

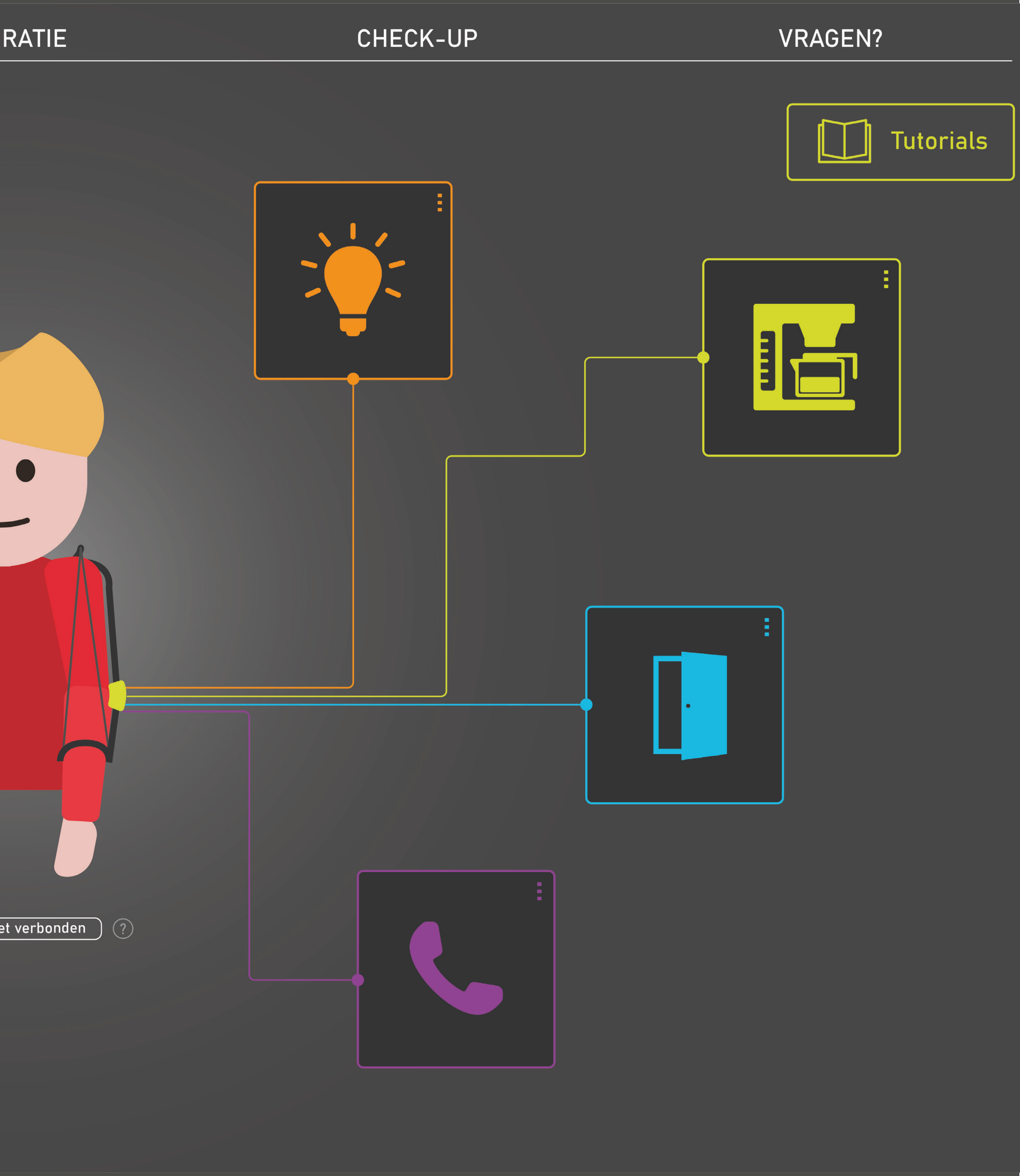


Fig. 56 *Page of final interface design*

7.1 Final design components

The final design consists of three components: the exoskeleton with motion sensing technology, the interface consisting of a coding and communication platform, and a service with an expert checking the product regularly (figure 57). Furthermore, the system can control Bluetooth devices, which can be purchased separately.

The **exoskeleton with motion sensing technology** senses the exact movements of the arms of the wearer. The movements are interpreted to control devices from a distance. This is only done when the user first makes an initiation movement – like shrugging the shoulders – to not control devices by accident. The system also tracks how (much) the wearer has moved over the years. The exoskeleton is physically the same as described in chapter 2 (product analysis) – although the appearance should eventually be redesigned as well to fit the target group (see chapter 9 – recommendations). With this design, two motion sensors are added to the product, one to each elbow. Yumen Bionics has already developed a sensor specifically for the purpose of measuring the movements of the arm. This sensor can directly be applied for the purpose of the final concept (see chapter 7.4).

The **interface** consists of a coding and communication platform. The coding platform is designed for the boys to "code" which movement controls which function on which device. Although it is called "coding" to fit better with the suspected interests of the target group, they are merely configurating the system. The communication platform is designed to ask questions to experts and share knowledge with other exoskeleton wearers. Both the coding- and communication platform are combined in one interface design, which is configurable and can change over the years. How each component of the interface design increases the ability of the product to mature with its user, is further explained in chapter 7.3.

The **expert service** is designed with the main purpose of checking and, if necessary, adapting the size, fit and support of the exoskeleton. This is to ensure the exoskeleton physically grows with the user, and to ensure it supports the wearer in the right way and the muscles are not under- or overused. It is expected this check-up is necessary roughly every six months. However, since these alteration moments were expected to feel like a negative confirmation of decline (see chapter 4.5), the check-ups also include checking and adding controlling functions, and are presented as a moment where the boys can ask questions and indicate their preferences. This is to make them feel more in control over the situation, and to take away the attention from the weakening of the muscles. Besides, after every check-up (in combination with using the exoskeleton enough), the boys unlock a new control; this makes them associate check-ups with positive moments.

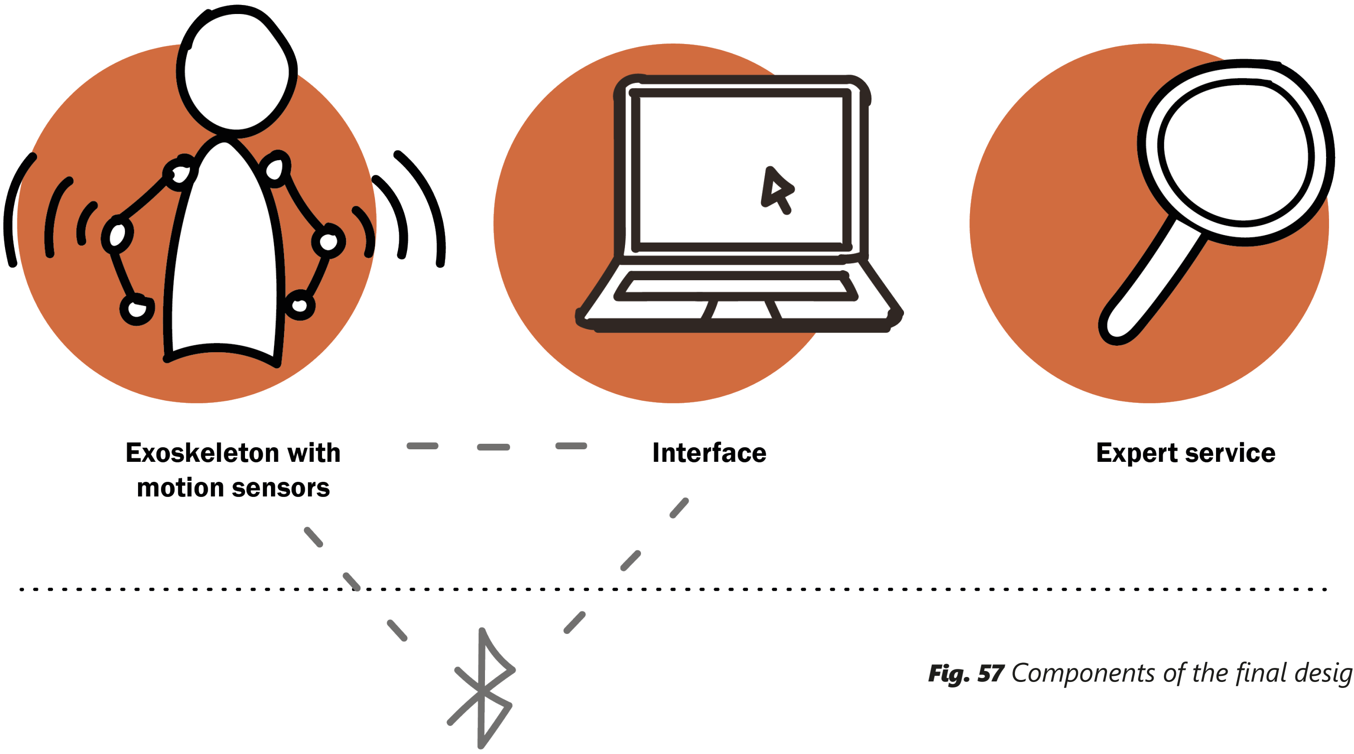


Fig. 57 *Components of the final design*

7.2 User scenarios

The user scenario for each persona (Naïve Playful Kid, Anxious Self-Conscious Teen and Constrained Reluctant Adolescent) is explained and illustrated in chapter 7.2.1, 7.2.2 and 7.2.3 respectively. Each scenario consists of the following five steps:

1. Plan & prepare for check-up
2. Check-up with expert
3. Program & upload functions
4. Use controls in house
5. Share & ask questions

Although each persona experiences the same five scenario steps, the user scenarios differ slightly, since the different personas are expected to have different needs and interactions with the same product and expert. The design of the concept aims to meet the expected needs of all three personas, with one solution. How this is realized, and how each component increases the ability of the product to mature with its user, is further explained in the user scenarios, and in chapter 7.3.

see next page for the three user scenarios ---->

7.2.1 User scenario Naïve Playful Kid (10-12 years old)

1. PLAN & PREPARE FOR CHECK-UP

- Parents get reminder about the next check-up is coming up and make the check-up appointment
- Boy can login to his own website, which is clearly designed for him, where he can prepare for the check-up by watching an explanatory video and write down questions he has for the expert

2. CHECK-UP WITH EXPERT

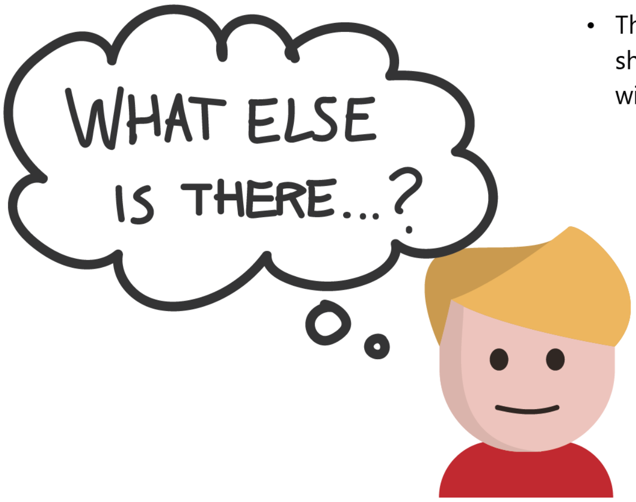
- The expert helps to set up the boy's first controls.
- The expert checks if the exoskeleton fits and supports right, while the boy is distracted playing with his first controls.
- The expert focusses on the boy: he shows him how the programming works, and gets him excited and confident in his abilities. The expert keeps parents involved and informed in the background as well.

3. PROGRAM & UPLOAD FUNCTIONS

- The boy codes his first few functions. The coding interface has an easy-to-understand first level. Pre-programmed movements can be dragged-and-dropped to functions.
- The coding interface shows there are more functions to unlock later.

4. USE CONTROLS IN HOUSE

- The boy first chooses controls which he can use for fun. For example, to control toys or race cars, to play (video) games.
- The boy likes his cool new superpower and shows it off to his friends. He can use it to play with them, as well.

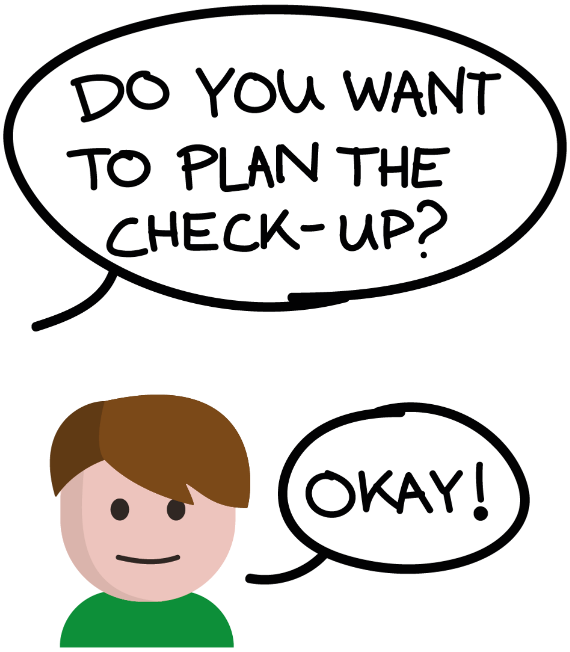


5. SHARE & ASK QUESTIONS

- Although the step-in coding level is easy, the boy tries out more difficult levels. He comes across questions, which he can ask through a platform with a chat function.
- The boy starts to wonder what else is possible with his exoskeleton. Therefore, he checks out what older boys have coded with their exoskeleton. This makes him more excited for what's to come, although he does have to some have patience until the next check-ups.

Fig. 58 *Typical user scenario of the Naïve Playful Kid*

7.2.2 User scenario Anxious Self-Conscious Teen (12-15 years old)



1. PLAN & PREPARE FOR CHECK-UP

- Both the boy and his parents get a reminder that the next check-up is coming up. They can decide together who makes the appointment. Making the appointment can now also be done through the platform in an easy, user-friendly way.
- The boy can prepare for his check-up by writing down questions, and send his wishes of which devices he would like to install next.

2. CHECK-UP WITH EXPERT

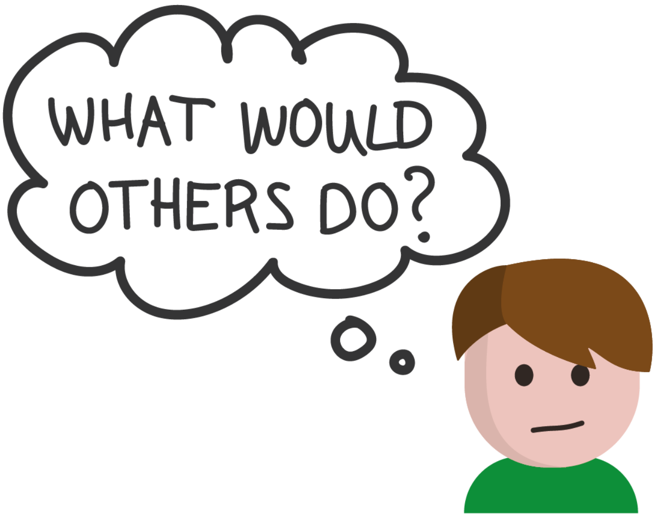
- The expert communicates more openly to the boy what he is doing during the check-up.
- The boy feels comfortable to ask the expert what he wants to know. However, if he feels put on the spot, he can also ask those questions in advance or afterwards in a chat (low threshold).

3. PROGRAM & UPLOAD FUNCTIONS

- The boy tries out more advanced levels of programming, since he starts to notice what his preferences are regarding movements and likes to tweak them.
- The boy unlocks more devices which he can program, because he has moved with the exoskeleton enough, and because he has had a few check-ups now.
- The boy can easily change movements if they do not feel comfortable or if they are physically not possible for him anymore, in a discrete way.

4. USE CONTROLS IN HOUSE

- The boy (subconsciously or consciously) shifts some controls from fun towards more useful. For example, he can open doors or turn on lights with his movements. These controls give him more independence in his house. However, some fun controls, like gaming, are still kept.
- At school, the exoskeleton is ‘just’ a physical support; the boy does not want to grab attention here. At home, the boy has a secret power. He may show it to his friends, but only when he feels comfortable.



5. SHARE & ASK QUESTIONS

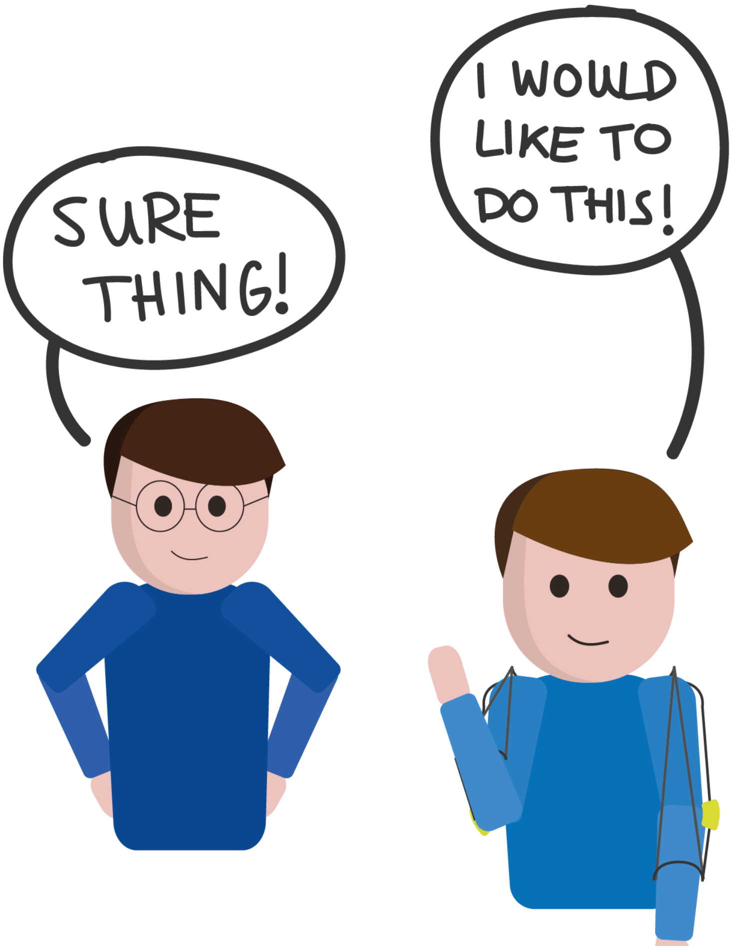
- The boy can ask questions to an expert in a safe, easy and low-threshold way, through a chat.
- Because the boy sees what other exoskeleton users have coded, and he can share what he has done, he knows he is not alone, and he feels like wearing an exoskeleton is more normal.

Fig. 59 *Typical user scenario of the Anxious Self-Conscious Teen*

7.2.3 User scenario Constrained Reluctant Adolescent (15-17 years old)

1. PLAN & PREPARE FOR CHECK-UP

- The boy knows when check-ups need to happen and takes the responsibility to plan his own check-ups through a calendar.
- The boy can indicate exactly what needs to happen at his next check-up. He sends problems to solve and personal wishes to the expert in advance.

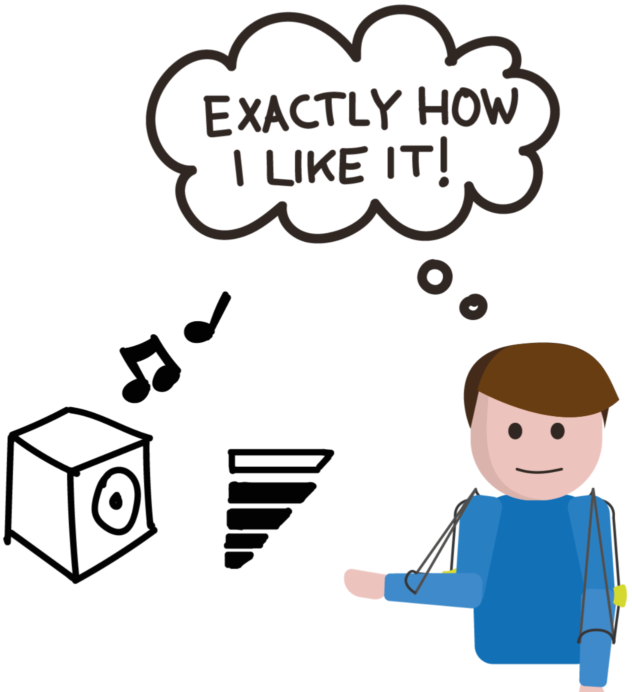


2. CHECK-UP WITH EXPERT

- The expert approaches the boy more as an adult and talks to him on a more even level. He communicates what he is doing during the check-up and why, both the digital and physical aspects.
- The boy can indicate more precisely what he prefers when using his exoskeleton, since he has used it for a long time.

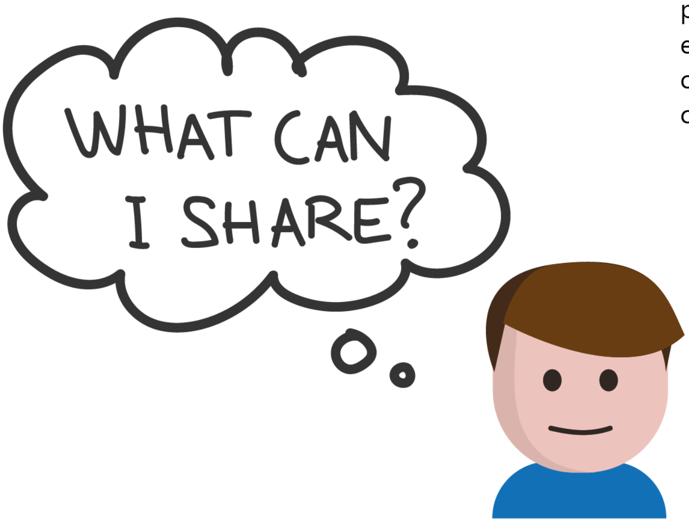
3. PROGRAM & UPLOAD FUNCTIONS

- The boy has programmed many functions now, most of them at the highest level. He has become an expert over the coding platform and can code the functions exactly how he wants to.
- The boy now also knows how to install new Bluetooth devices, which he possibly buys with his own pocket money.



4. USE CONTROLS IN HOUSE

- The boy now has almost full control over many functions in the house.
- The controls are all useful controls which he needs to function as independently from his parents as possible while he is at home. For example: opening doors and curtains, switching on and off every light, making coffee, opening closets and kitchen cabinets.



5. SHARE & ASK QUESTIONS

- The boy asks less questions, because he has become more of an expert his own. However, he still appreciates having the option.
- The boy mostly uses the sharing platform to share his own findings with younger Duchenne boys, and to show off a little bit.

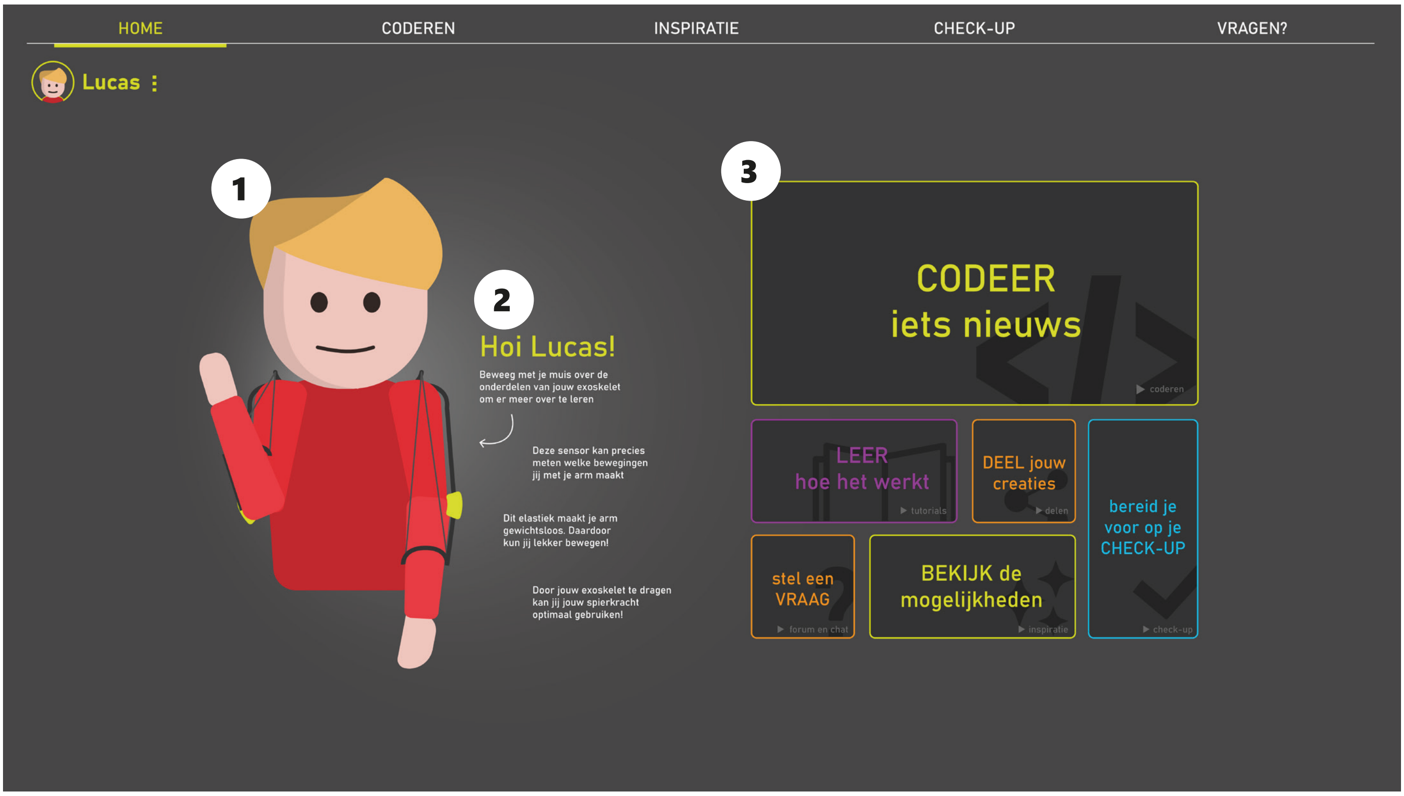
Fig. 60 *Typical user scenario of the Constrained Reluctant Adolescent*

7.3 Interface design

7.3.1 Home page

The purpose of the home page (figure 61-63) is to give some updated information and spark an interest, since it is the first page that the boys see when they log in. The home screen contains the following elements: a self-chosen avatar of the boy (who is logged in to the program) wearing the exoskeleton (1), information about his exoskeleton when his mouse is hovered over different parts of the avatar's exoskeleton (2), and buttons in block shapes leading to other pages on the platform (3).

- The avatar (1) is customised/self-chosen because it is expected to help in feeling more attached to the program. Besides, it can be changed to the boys liking whenever they want to, so if their preference or appearance changes as they grow up, they can adapt it. The avatar is wearing the exoskeleton to instantly make a clear connection between the real and virtual world, and to normalize the idea of wearing an exoskeleton through the platform.
- The information about the exoskeleton (2) changes over time, depending on how much the user has moved and how many check-ups he has had (which indicates how long he has been using the exoskeleton). In the beginning, the information is "fun facts" about the exoskeleton which teach the boy how it works and why the different parts of the exoskeleton are necessary. As he moves more with the exoskeleton, the information is about how many times he has done a certain movement with it ("you have opened the door 32 times!"). This is to focus on positive progress around movement; although their physical abilities will decline, these numbers will not go away and only add up.
- The block buttons (3) lead to other pages on the platform. They change in size automatically, depending on which pages are visited the most, and therefore have a dynamic nature over the years. This is a casual way of making the use of the interface fit to the boy, no matter his age.



Hoi Lucas!

Beweeg met je muis over de onderdelen van jouw exoskelet om er meer over te leren

Deze sensor kan precies meten welke bewegingen jij met je arm maakt

Dit elastiek maakt je arm gewichtsloos. Daardoor kun jij lekker bewegen!

Door jouw exoskelet te dragen kan jij jouw spierkracht optimaal gebruiken!

Fig. 61 *Typical home page of the Naïve Playful Kid*

Hoi Sam!

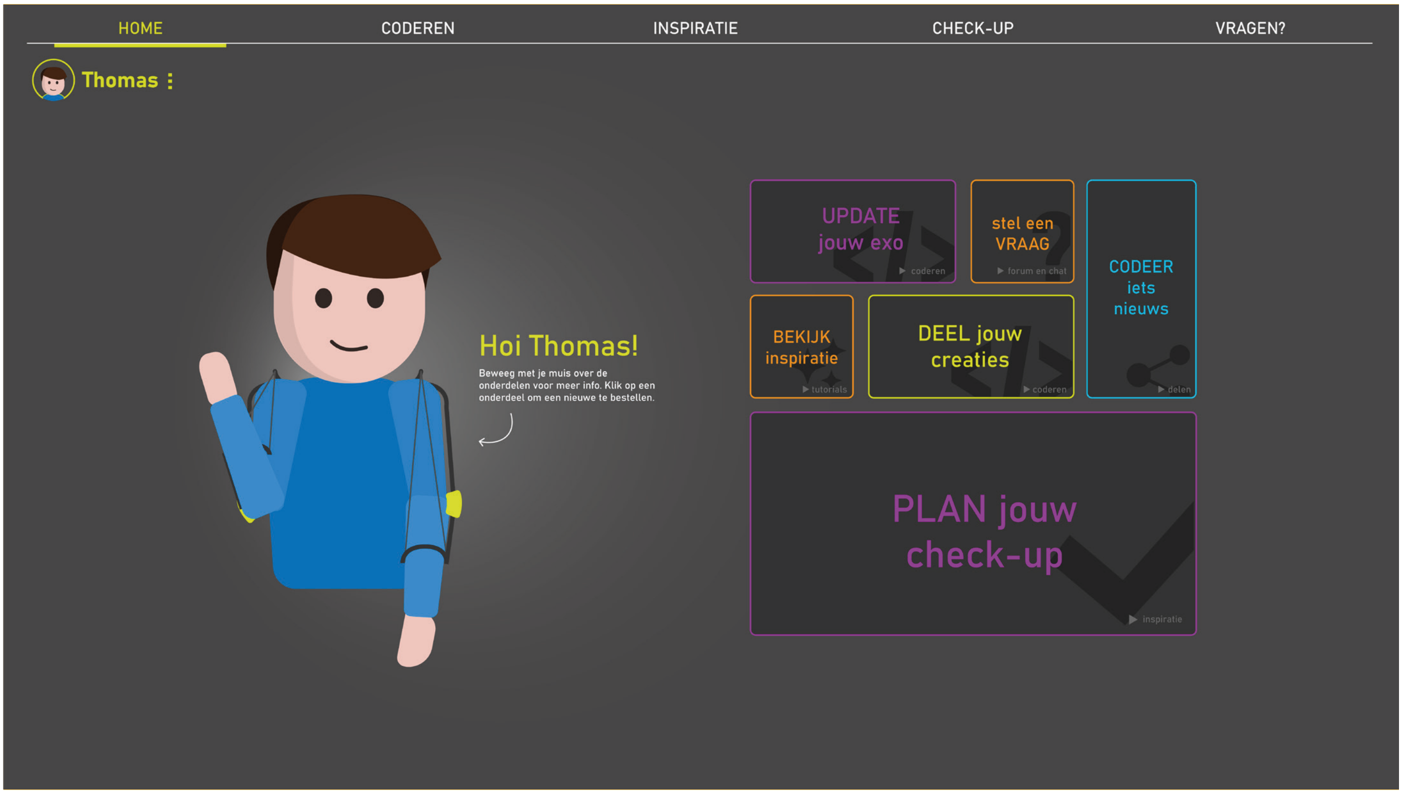
Beweeg met je muis over de onderdelen van jouw exoskelet voor meer info over jouw gebruik

Jij hebt met deze sensor al 32 keer de deur opengemaakt! Lekker bezig!

In de maand november heb jij de meeste controls gebruikt

Zijn jouw elastieken versleten omdat je veel bewogen hebt? Geef het aan bij de expert vóór de volgende check-up!

Fig. 62 *Typical home page of the Anxious Self-Conscious Teen*



Hoi Thomas!

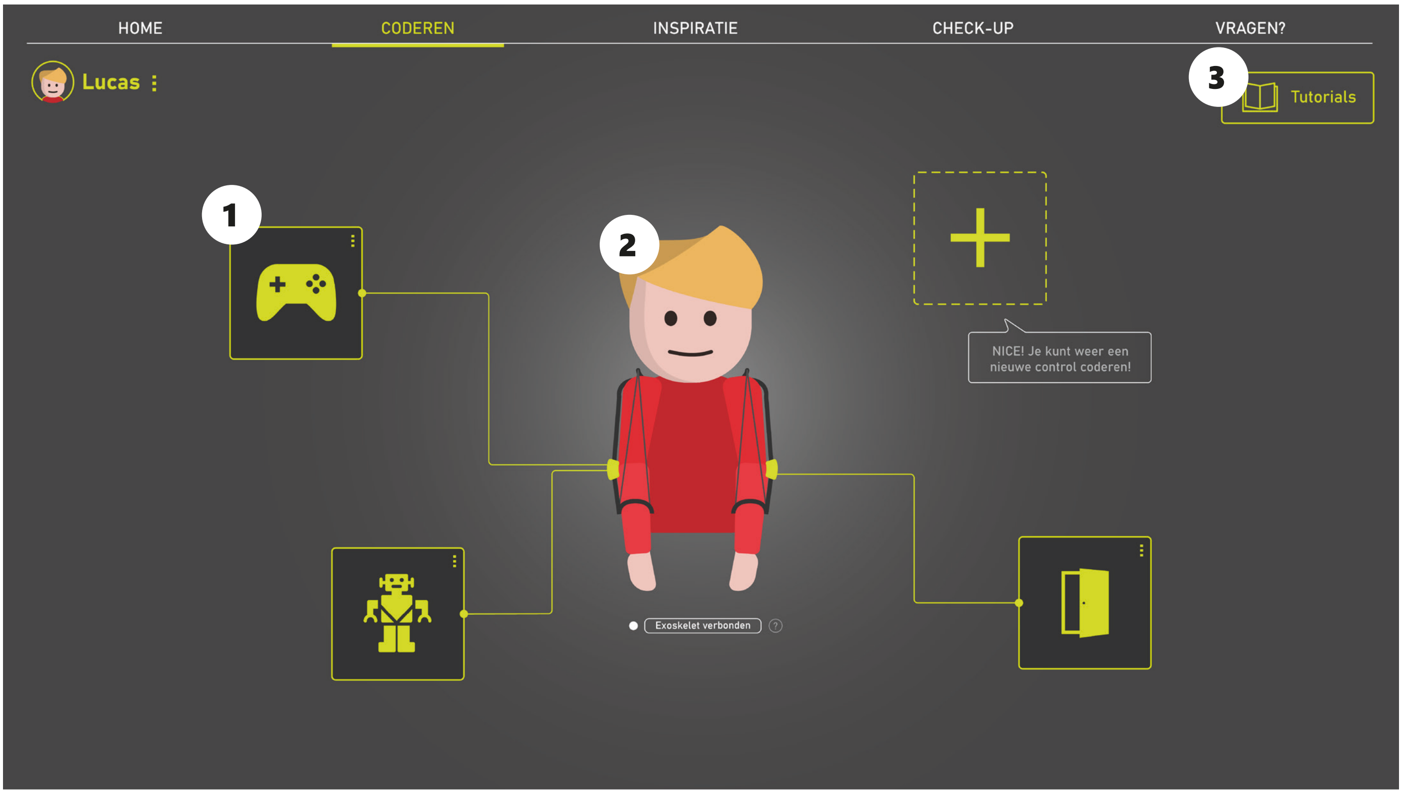
Beweeg met je muis over de onderdelen voor meer info. Klik op een onderdeel om een nieuwe te bestellen.

Fig. 63 *Typical home page of the Constrained Reluctant Adolescent*

7.3.2 Coding page

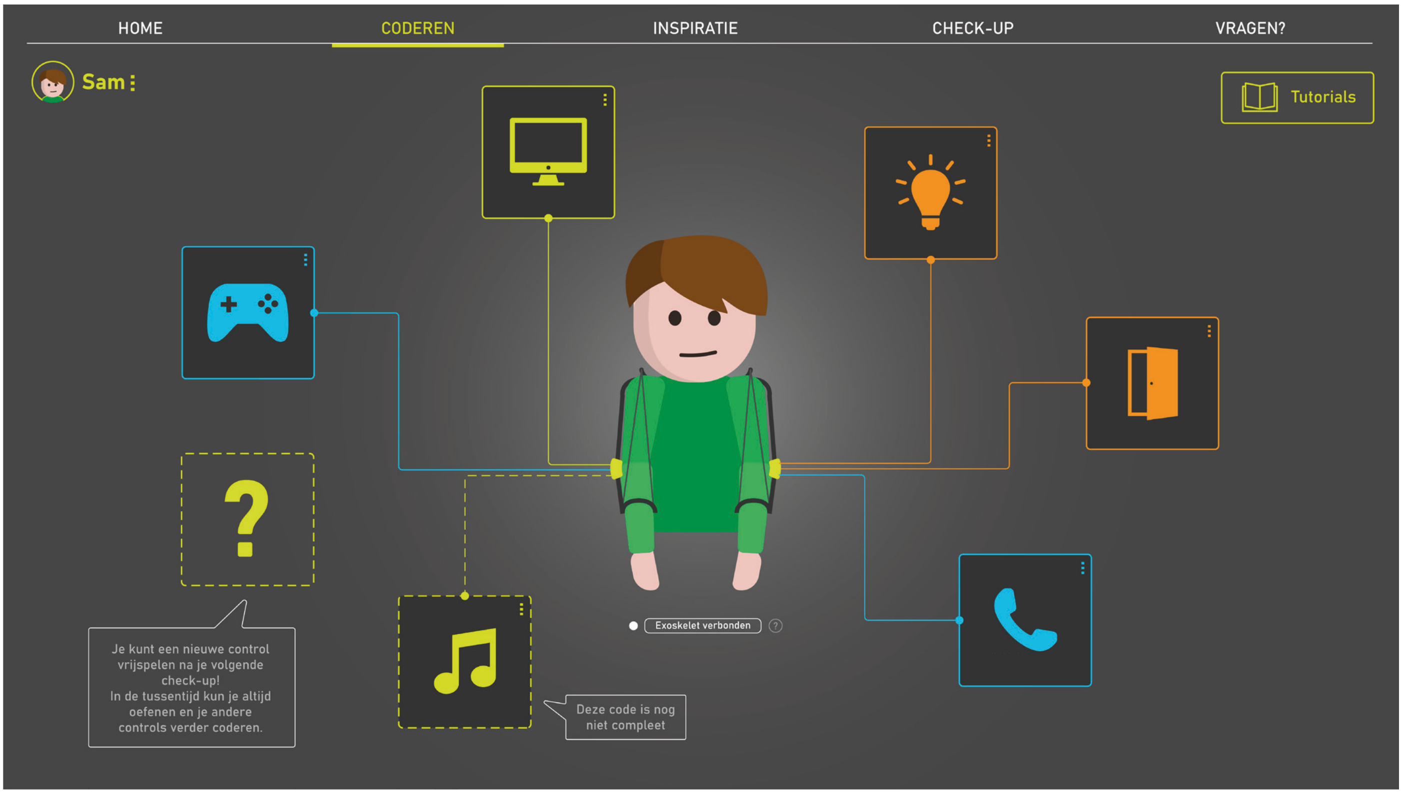
The coding page (figure 64-71) is the environment where the boys can configure which movements control which functions of which devices. It contains the following elements: an overview of the devices coded with the exoskeleton which are visually linked to the exoskeleton (with a line) (1), a central avatar which makes some of the coded movements (2), tutorials (3), a coding pop-up with four different levels (4), and a calibration interaction (5).

- The overview of the devices (1) is designed to be visually appealing, to give the user a clear structure, and to easily make changes to already coded devices. Each device has a tile with a self-chosen logo (which could also be replaced by own pictures). The number of tiles instantly represent how much the user has used the exoskeleton already, because a new tile can be programmed after every check-up (and when the user has moved enough). The tile's colour represents the colour of the level the device was coded in. Therefore, it is directly visible at what level of difficulty the user has coded his exoskeleton. The number of tiles will grow over the years and its colours will change, making the product maturing with the boys as they grow up. Although the amount of functions is dependent on time, the level of coding and recoding is completely dependent on the user himself. He can choose a higher level when he is ready.
- When the boy hovers his mouse over the different device elements on the page, the avatar in the centre of the page (2) makes the movements which is paired with the device. This is done to easily remember what was already coded over a longer period of time, but also to make the interaction on screen more fun and directly related to the real-life product use.
- The tutorials (3) are mostly meant for new users who are just getting to know the program, but can always be consulted later on as well. There will be different tutorials offered for different levels, so when the user feels ready for the next level, he can watch it whenever he wants to.



NICE! Je kunt weer een nieuwe control coderen!

Fig. 64 *Typical coding page of the Naïve Playful Kid*



Je kunt een nieuwe control vrijspelen na je volgende check-up!
In de tussentijd kun je altijd oefenen en je andere controls verder coderen.

Deze code is nog niet compleet

Fig. 65 *Typical coding page of the Anxious Self-Conscious Teen*

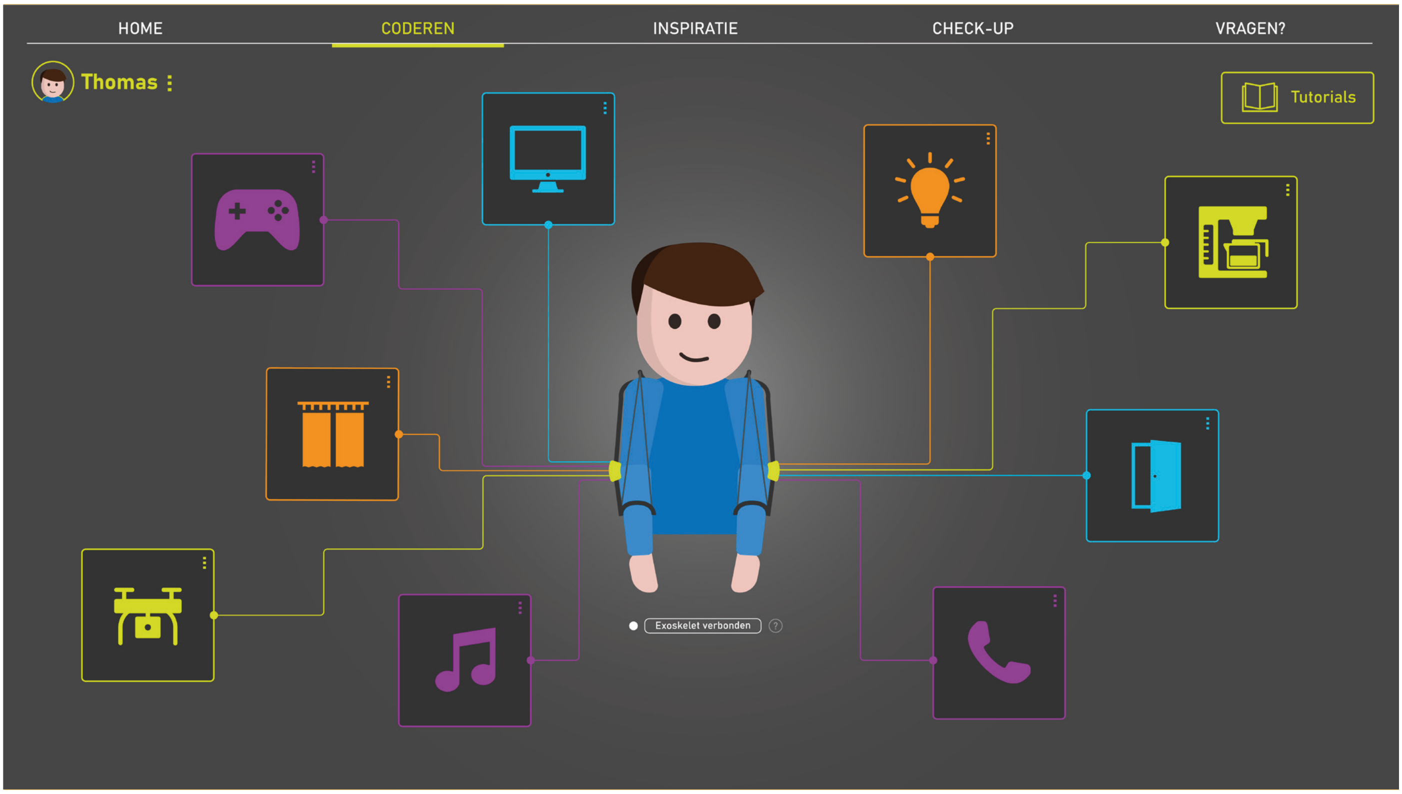


Fig. 66 *Typical coding page of the Constrained Reluctant Adolescent*

- The coding pop-up (4) has four different levels. Level 1 requires the user to choose pre-programmed movements which he can drag and drop onto the functions the device has (for most devices this will be on and off – see chapter 7.4). Level 2 contains blocks which tweak the movements chosen in level 1 by dragging them under them (repeating, faster, slower and reverse). Level 3 contains pre-programmed movements as well, but only to combine with the basic movements chosen in level 1. The movement to control the device therefore becomes a combination of movements, which will be more complex. These movements can also be tweaked with blocks from level 2. Level 4 allows the user to create an entirely new movement, by 'recording' a movement he makes with his exoskeleton and inventing a name for it. The interaction of dragging blocks was inpired by an openly available coding platform for children called 'Scratch' (scratch.mit.edu).

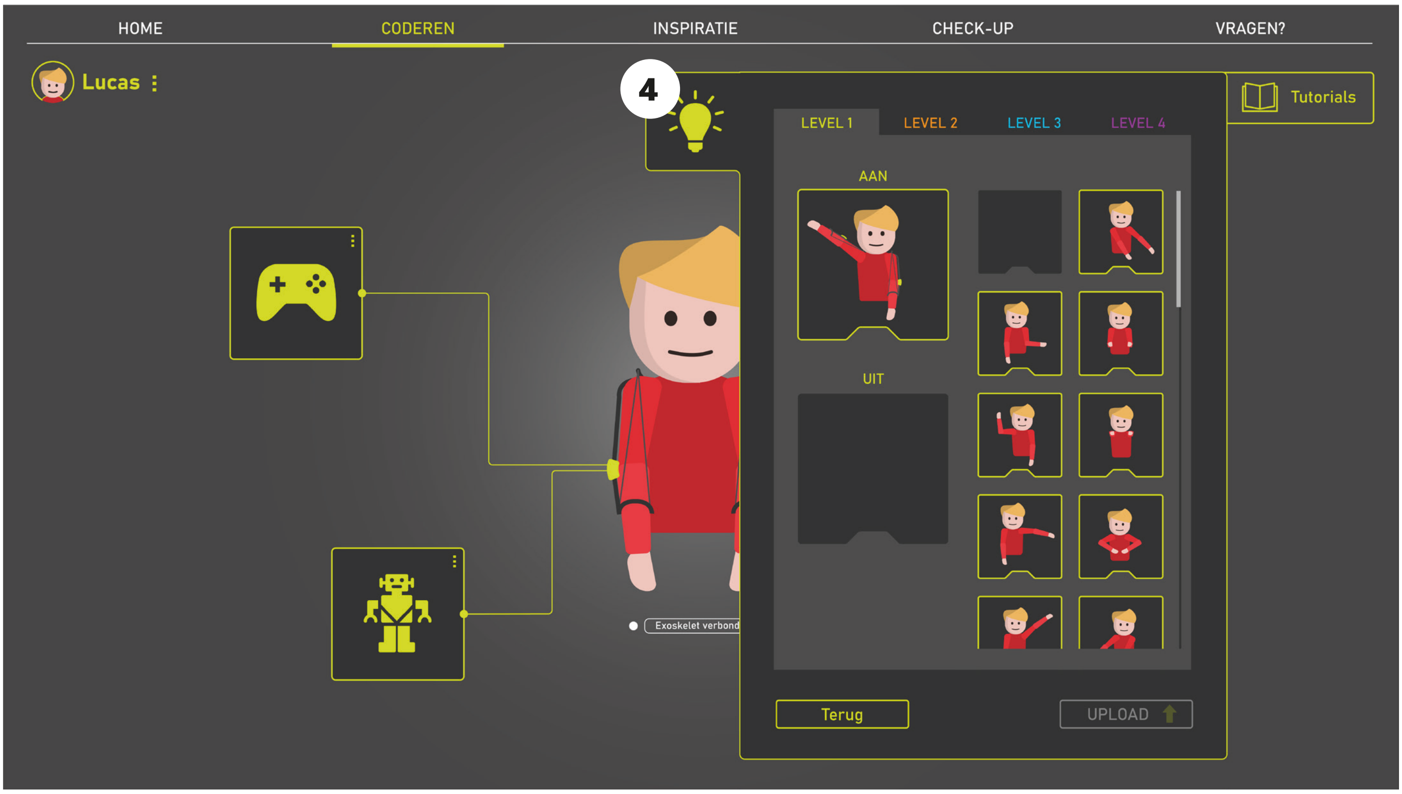


Fig. 67 *Coding page level 1*

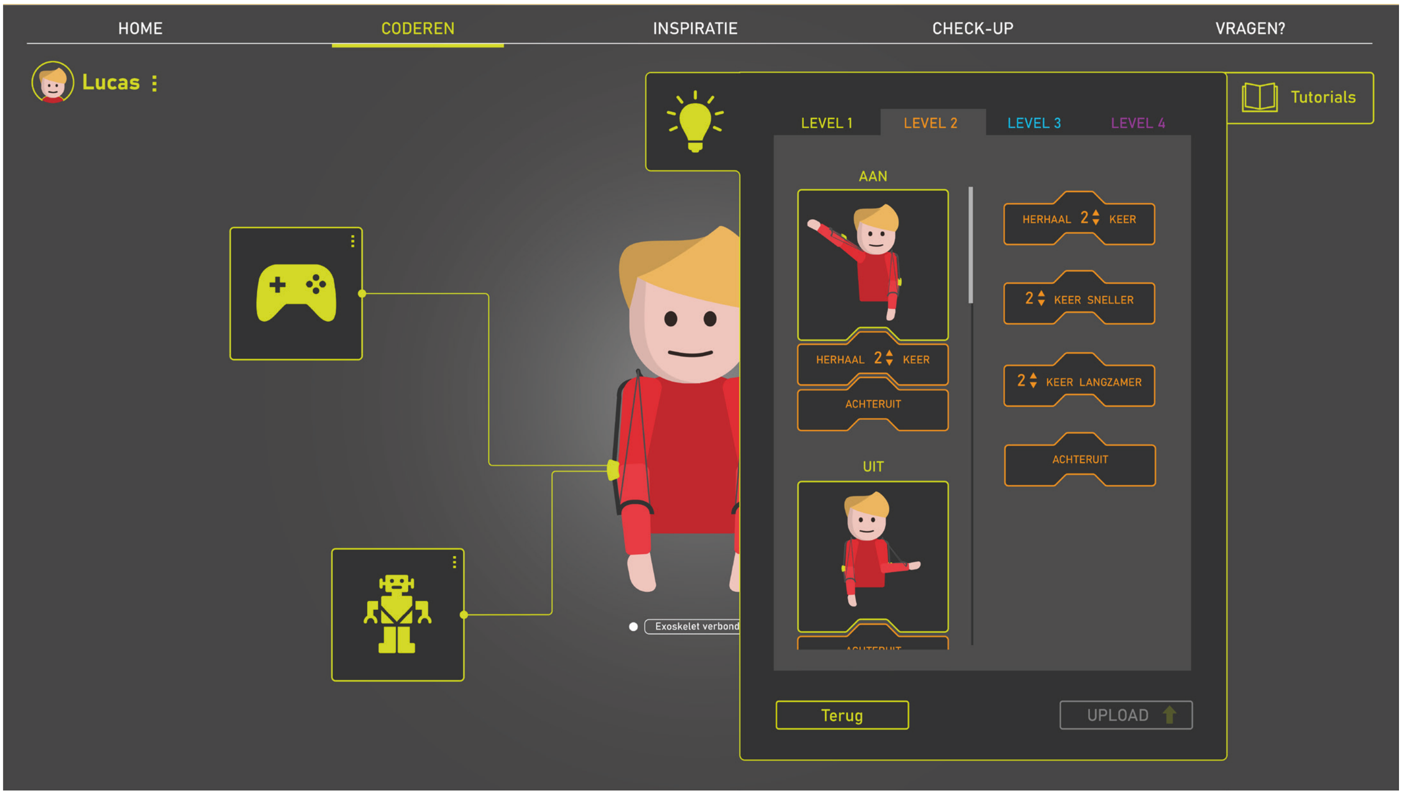


Fig. 68 *Coding page level 2*

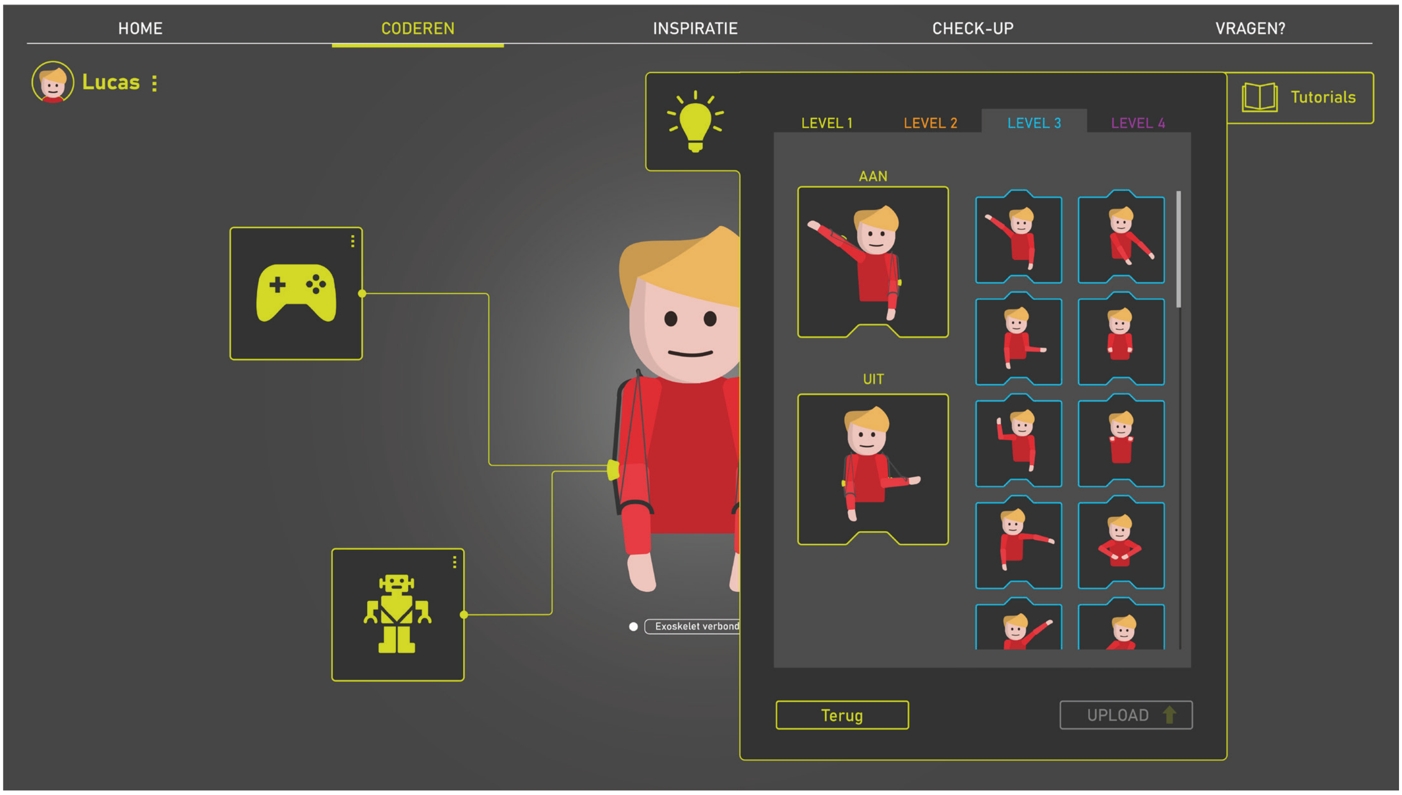
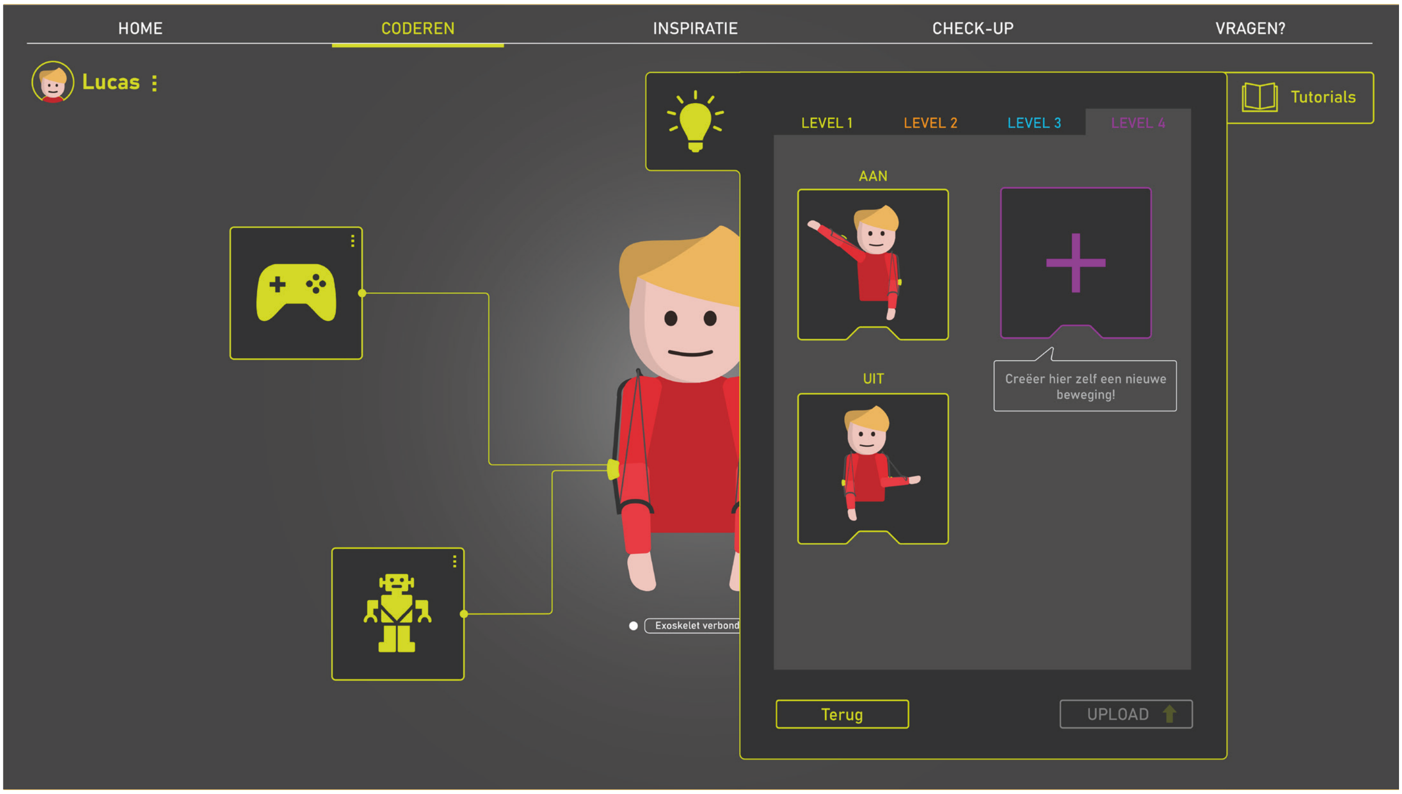


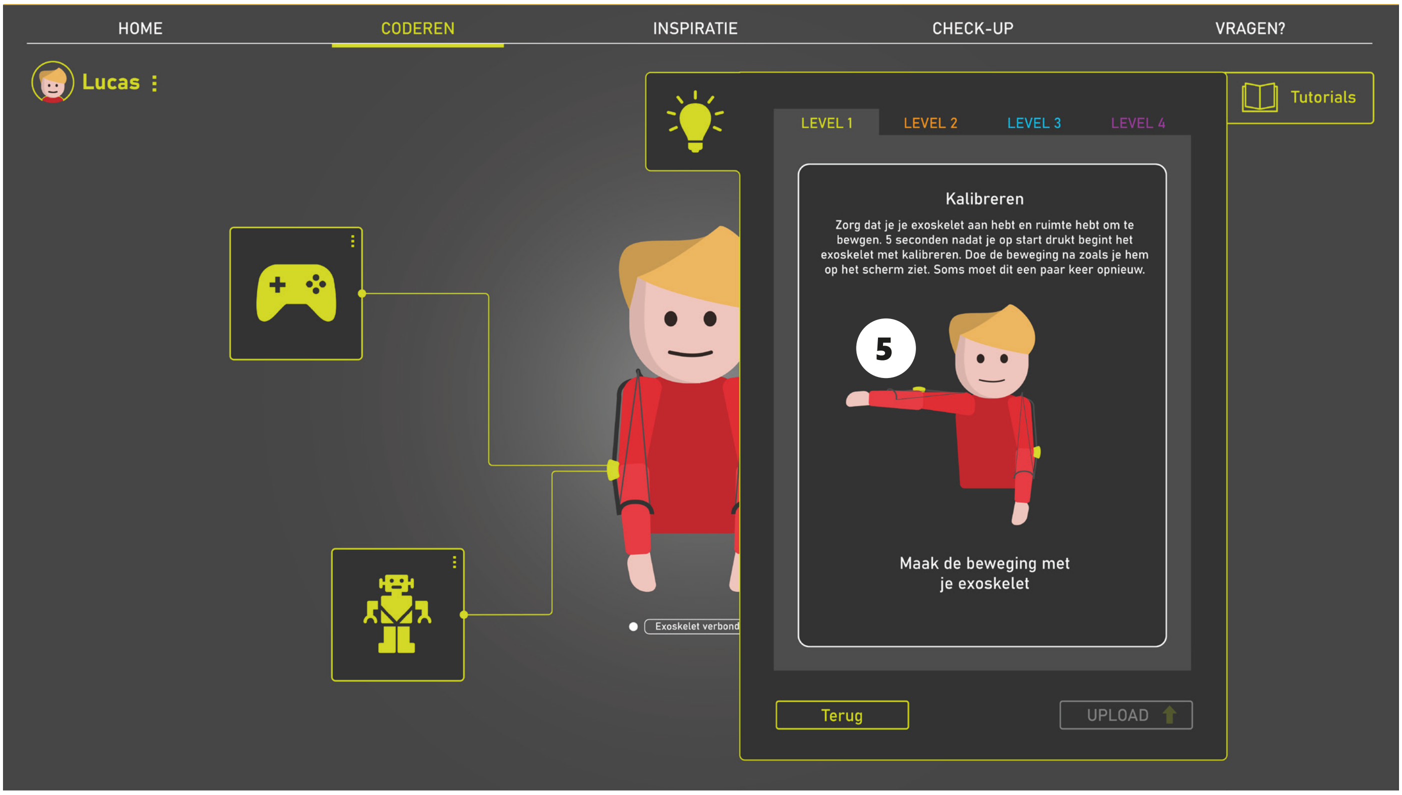
Fig. 69 *Coding page level 3*



Creëer hier zelf een nieuwe beweging!

Fig. 70 *Coding page level 4*

- When the user chooses a new movement, he must calibrate (5) it first with his exoskeleton. He is wearing the exoskeleton while he is coding, and it is wirelessly connected to the program (under the avatar the status of the connection is shown). When he chooses the movement, he has to copy the movement the avatar is making on the screen in real life. In that way, the system learns how he in particular makes this movement. The calibration action will also be repeated once in a while over the years. For the boy, this seems like a technical necessity, but it is actually a discrete solution for physical muscle decline. Since the boys will not be able to make the movement as well after a while, devices will still respond to it after it is re-calibrated.



Kalibreren

Zorg dat je je exoskelet aan hebt en ruimte hebt om te bewgen. 5 seconden nadat je op start drukt begint het exoskelet met kalibreren. Doe de beweging na zoals je hem op het scherm ziet. Soms moet dit een paar keer opnieuw.

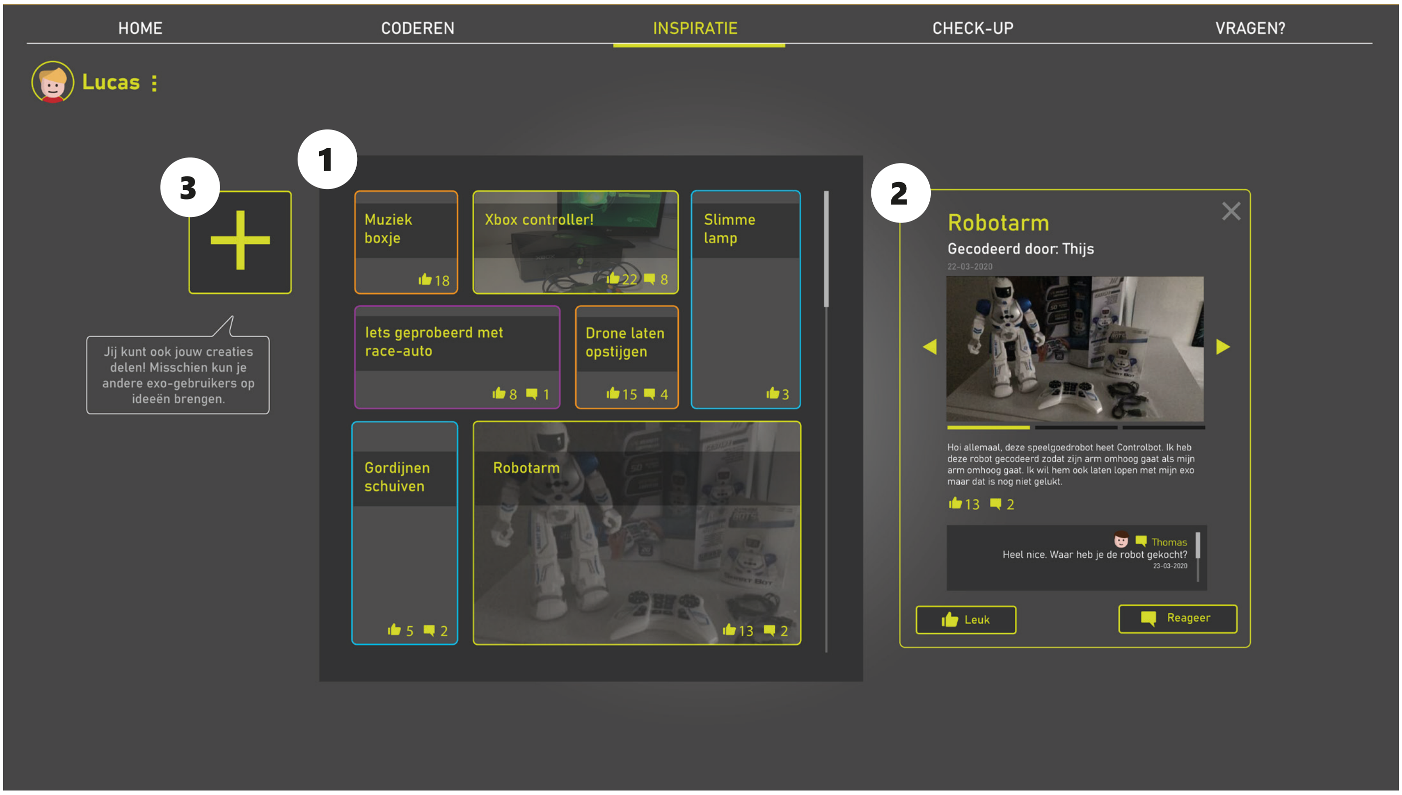
Maak de beweging met je exoskelet

Fig. 71 *Calibration interaction, where user copies movement seen on screen in real life with his exoskeleton*

7.3.3 Inspiration page

The inspiration page (figure 72) is a platform where users can share which devices they have coded with which movements. The page can also contain some inspirational examples made by the company distributing the product. The inspiration page contains an overview of everything that has been shared by users (1), a pop-up with more information once a topic is clicked (2), and a button to share your own movements (3). This idea for this page is derived from social media, and is mostly designed for the Anxious Self-conscious Teen phase; it serves as a confirmation that he is 'normal' using an exoskeleton, and that there are more people out there doing the same. However, it can also serve as an inspiration for younger or older boys.

- The overview (1) is designed so the user can easily browse through ideas and choose things he finds interesting. This might differ per user – so different users can choose to look at different topics.
- The pop-up (2) contains more pictures of the device/interaction and a description made by the person who uploaded it. In the pop-up, other users can like or respond to the idea.
- The content will automatically be updated over the years as the exoskeleton users create new content (3). So even though the elements stay the same, the product matures over the years with the user.



Jij kunt ook jouw creaties delen! Misschien kun je andere exo-gebruikers op ideeën brengen.

Hoi allemaal, deze speelgoedrobot heet Controlbot. Ik heb deze robot gecodeerd zodat zijn arm omhoog gaat als mijn arm omhoog gaat. Ik wil hem ook laten lopen met mijn exo maar dat is nog niet gelukt.

Heel nice. Waar heb je de robot gekocht?

Fig. 72 *Inspiration page*

7.3.4 Check-up page

The check-up page (figure 73-75) is designed especially for the boys to be able to prepare themselves for their next check-up, on different levels. It contains a countdown (1) with how many days are left until the next check-up, a checklist (2) with what to do to be prepared for the check-up, a video (3) explaining what happens during a check-up, an area where the boys can write down questions and wishes (4) for their check-up, save them, and send them to the expert, and a 'plan your check-up' button (5) with a calendar (6). The elements sometimes change, depending on the number of check-ups the boys have already had. In this way, they can slowly get used to the idea of taking more responsibility over the (healthcare) processes needed around the product, as opposed to other healthcare solutions in which their parents take care of and have control over this process.

- The countdown (1) indicates that the check-up is something to look forward to, but also to prepare for. This element stays the same for all ages, unless no check-up is planned yet ánd the boy is old enough (16 years old) to plan his own check-up. Then, the number of days is replaced with a button to plan your own check-up.
- The checklist (2) with preparing steps changes as the boys have had more check-ups. The steps are in essence the same, but the explanation given for each step is more elaborate and more directed towards the boys' responsibility.
- The video (3) explains what boys can expect from a check-up. In the beginning of using the exoskeleton, this element is big and present, since it is necessary to watch it. After two check-ups the video can still be watched, but it is under a smaller button, as the user has now experienced it himself and watching the video is not necessary anymore.
- The room to fill in questions and wishes for the check-up (4) will change as the user fills in more information. Also, when the video becomes a smaller button, this area becomes bigger instead, as it is expected the wishes and questions will become more specific and elaborate.
- The check-up calendar planner (6) is designed to be easy and straight-forward: choosing a date from a calendar and a time from a drop-down menu, and your check-up is planned. The button to go to the calendar pop-up is always there, however, there is an age limit to be able to use it. If the user is under 16, he sees a pop-up saying he has to wait until he is 16 to plan his own check-up, and to consult his parents. In this way, he has some more responsibility to look forward to in the future.

Sorry! Je mag pas zelf een nieuwe check-up plannen als je 16 bent. Overleg de planning even met je ouders. Je kunt je ondertussen wel voorbereiden door je vragen en wensen aan de expert door te geven.

Jouw check-up checklist

8 dagen tot je volgende check-up

Heb je...

✓ ... de video over de check-up bekeken?

✓ ... je vragen voor de expert opgeschreven?
(je kunt ook vragen stellen in de chat en in het forum)

✓ ... je wensen voor controls doorgegeven?
(zie ook inspiratie voor de mogelijkheden)

Dan ben je klaar voor de check-up!

Een check-up: hoe gaat dat eigenlijk?

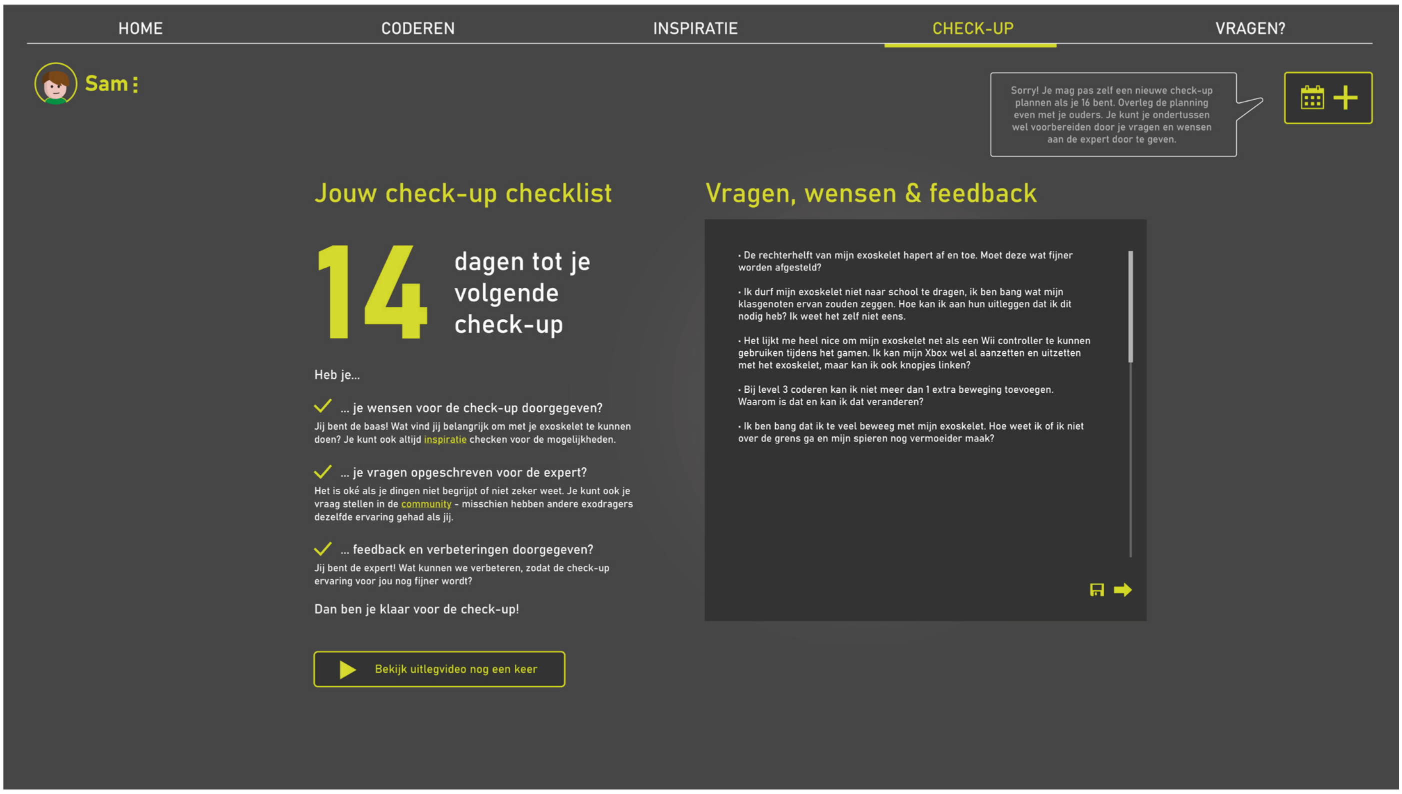
Bekijk deze video met uitleg over de check-up. Als je nog meer vragen hebt, kan je die altijd stellen op het forum, in de chat, of tijdens de check-up zelf.

Vragen & wensen

an ik de deur in mijn slaapkamer openen met mijn exoskelet?

· Waarom luistert mijn exoskelet niet naar een bepaalde beweging?

Fig. 73 *Typical check-up page of the Naïve Playful Kid*



Sorry! Je mag pas zelf een nieuwe check-up plannen als je 16 bent. Overleg de planning even met je ouders. Je kunt je ondertussen wel voorbereiden door je vragen en wensen aan de expert door te geven.

Jouw check-up checklist

14 dagen tot je volgende check-up

Heb je...

✓ ... je wensen voor de check-up doorgegeven?
Jij bent de baas! Wat vind jij belangrijk om met je exoskelet te kunnen doen? Je kunt ook altijd inspiratie checken voor de mogelijkheden.

✓ ... je vragen opgeschreven voor de expert?
Het is oké als je dingen niet begrijpt of niet zeker weet. Je kunt ook je vraag stellen in de community - misschien hebben andere exodragers dezelfde ervaring gehad als jij.

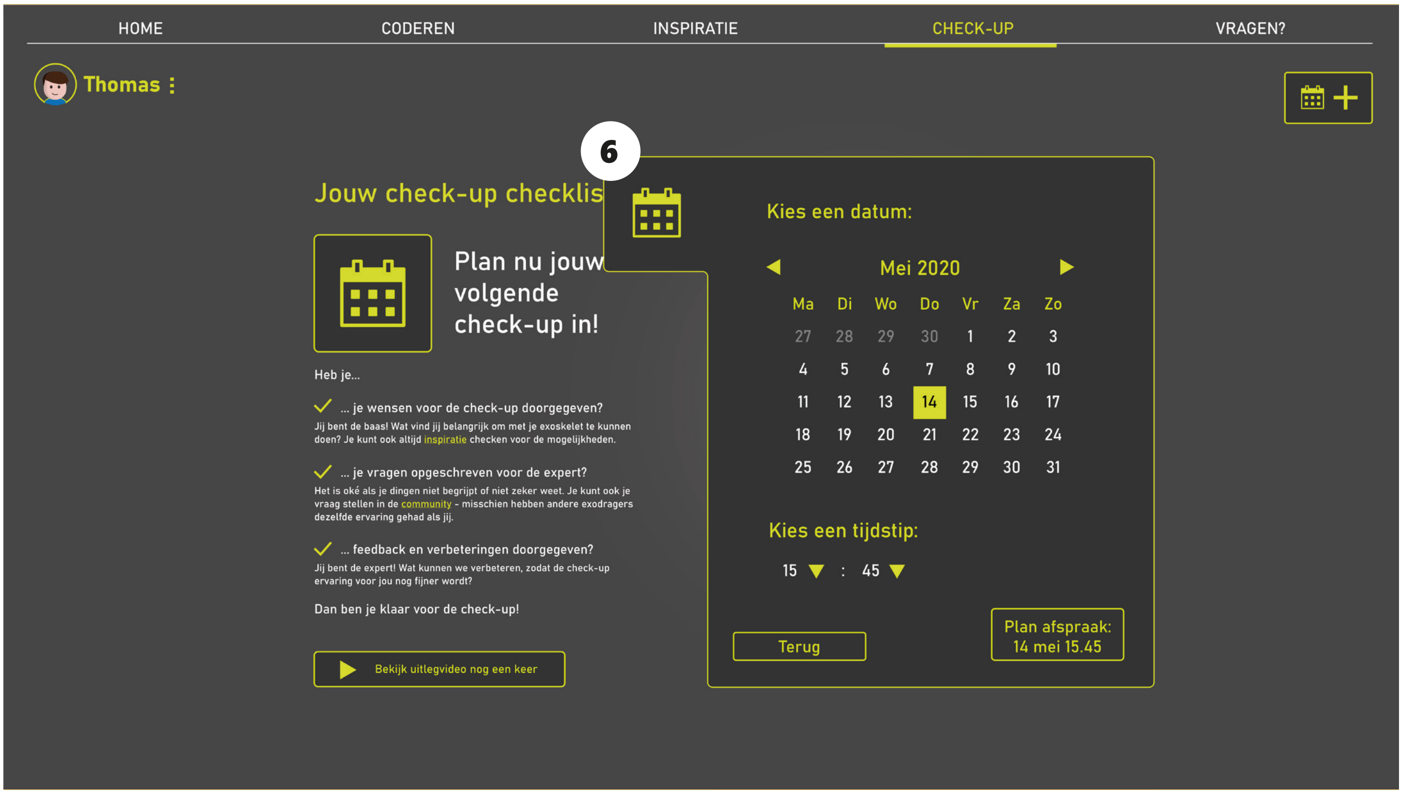
✓ ... feedback en verbeteringen doorgegeven?
Jij bent de expert! Wat kunnen we verbeteren, zodat de check-up ervaring voor jou nog fijner wordt?

Dan ben je klaar voor de check-up!

Vragen, wensen & feedback

- De rechterhelft van mijn exoskelet hapert af en toe. Moet deze wat fijner worden afgesteld?
- Ik durf mijn exoskelet niet naar school te dragen, ik ben bang wat mijn klasgenoten ervan zouden zeggen. Hoe kan ik aan hun uitleggen dat ik dit nodig heb? Ik weet het zelf niet eens.
- Het lijkt me heel nice om mijn exoskelet net als een Wii controller te kunnen gebruiken tijdens het gamen. Ik kan mijn Xbox wel al aanzetten en uitzetten met het exoskelet, maar kan ik ook knopjes linken?
- Bij level 3 coderen kan ik niet meer dan 1 extra beweging toevoegen. Waarom is dat en kan ik dat veranderen?
- Ik ben bang dat ik te veel beweeg met mijn exoskelet. Hoe weet ik of ik niet over de grens ga en mijn spieren nog vermoeider maak?

Fig. 74 *Typical check-up page of the Anxious Self-Conscious Teen*



Jouw check-up checklis

Plan nu jouw volgende check-up in!

Heb je...

✓ ... je wensen voor de check-up doorgegeven?
Jij bent de baas! Wat vind jij belangrijk om met je exoskelet te kunnen doen? Je kunt ook altijd inspiratie checken voor de mogelijkheden.

✓ ... je vragen opgeschreven voor de expert?
Het is oké als je dingen niet begrijpt of niet zeker weet. Je kunt ook je vraag stellen in de community - misschien hebben andere exodragers dezelfde ervaring gehad als jij.

✓ ... feedback en verbeteringen doorgegeven?
Jij bent de expert! Wat kunnen we verbeteren, zodat de check-up ervaring voor jou nog fijner wordt?

Dan ben je klaar voor de check-up!

Kies een datum:

◀ Mei 2020 ▶

Ma	Di	Wo	Do	Vr	Za	Zo
27	28	29	30	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	31

Kies een tijdstip:

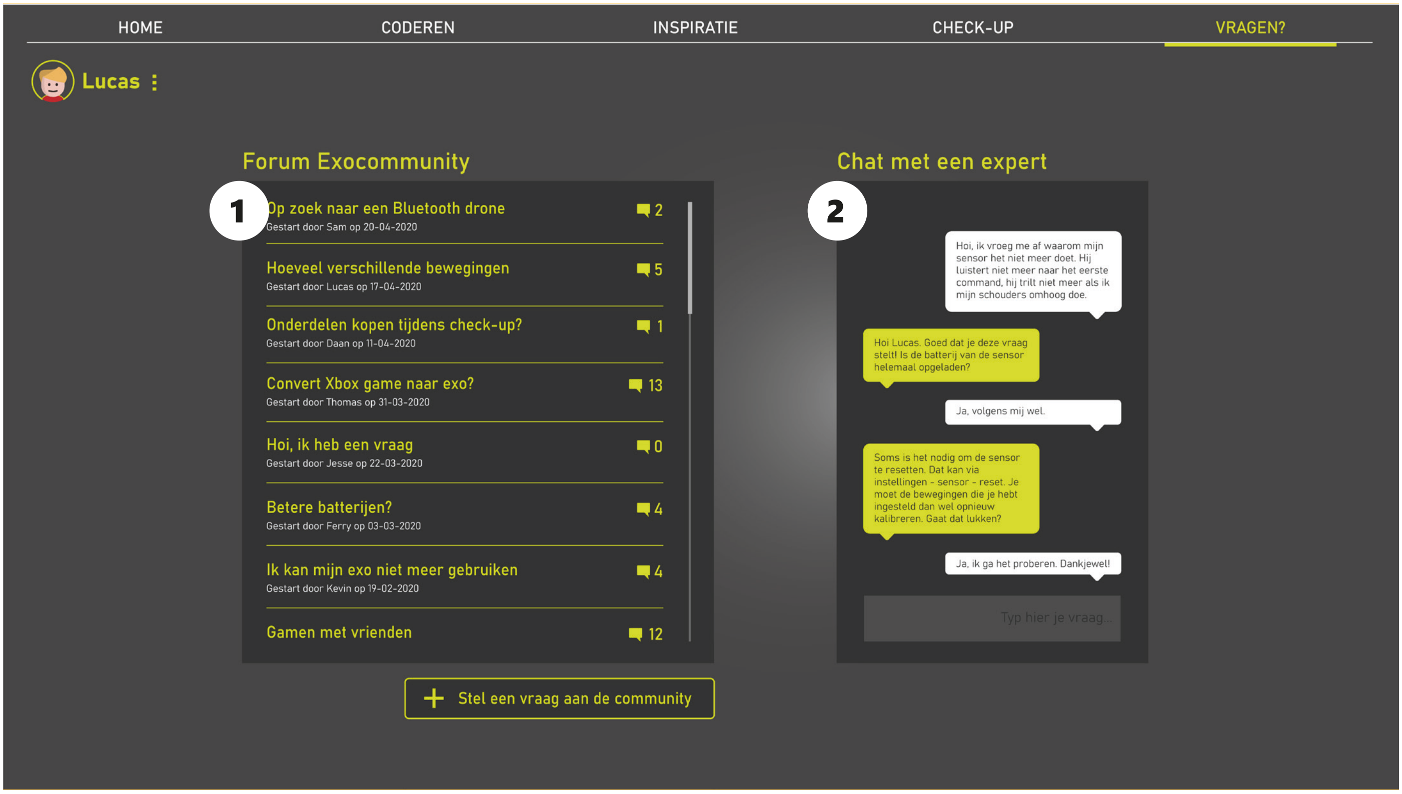
15 ▼ : 45 ▼

Fig. 75 *Typical check-up page of the Constrained Reluctant Adolescent*

7.3.5 Questions page

The goal of the questions page (figure 76) is to offer the boy a safe, low threshold environment to ask questions. The page contains two elements: a forum (1), where questions can be asked to the community of people using an exoskeleton, and a chat (2), where questions can be asked to an expert. The two different options are there because it is expected that the nature of the questions might be different. The elements do not change over time, but the content of the elements automatically matures as the community asks more questions, and the chat becomes more elaborate as the user asks more questions.

- The forum (1) is meant for casual questions, for instance about exploring different coding options. The forum will mature over the years as more users add and respond to topics. A nice extra advantage: because of the forum (together with the inspirations page), a community between boys with Duchenne emerges, where the focus is not on their disease. This might provide them with the support they need from each other, without feeling ‘weird’ or ‘different’.
- The chat function (2) is designed to be a low threshold place to ask questions. This is expected to be especially necessary for boys between 12 and 15 years old (Anxious Self-Conscious Teen persona), because they might feel scared or insecure to call or e-mail someone they do not know with a lot of knowledge. However, younger and older boys are also expected to have questions, and the chat-format is expected to be suitable for them too.



Op zoek naar een Bluetooth drone 2
Gestart door Sam op 20-04-2020

Hoeveel verschillende bewegingen 5
Gestart door Lucas op 17-04-2020

Onderdelen kopen tijdens check-up? 1
Gestart door Daan op 11-04-2020

Convert Xbox game naar exo? 13
Gestart door Thomas op 31-03-2020

Hoi, ik heb een vraag 0
Gestart door Jesse op 22-03-2020

Betere batterijen? 4
Gestart door Ferry op 03-03-2020

Ik kan mijn exo niet meer gebruiken 4
Gestart door Kevin op 19-02-2020

Gamen met vrienden 12

Hoi, ik vroeg me af waarom mijn sensor het niet meer doet. Hij luistert niet meer naar het eerste command, hij trilt niet meer als ik mijn schouders omhoog doe.

Hoi Lucas. Goed dat je deze vraag stelt! Is de batterij van de sensor helemaal opgeladen?

Ja, volgens mij wel.

Soms is het nodig om de sensor te resetten. Dat kan via instellingen - sensor - reset. Je moet de bewegingen die je hebt ingesteld dan wel opnieuw kalibreren. Gaat dat lukken?

Ja, ik ga het proberen. Dankjewel!

Fig. 76 *Questions page*

7.4 Technology

7.4.1 Motion sensor

Yumen Bionics has recently developed a motion sensor which is especially developed to measure exact motions of the upper- and lower arm. Although initially developed for other purposes, the developer of the sensor ensured it is applicable for this purpose with minor modifications. The sensor is located on the elbow and can measure the movements of one arm. Therefore, two sensors (one for each arm) are required in the design.

For confidentiality reasons, not all details of the functioning of the sensor can be explained in this thesis. However, important information is that the input needed is the arm length of the wearer – which is likely to change over time for maturing boys. To ensure the precision of the measurements, it is therefore necessary to regularly re-measure the arm length. This can easily be done by the expert during the check-up. Besides, the sensor needs a computer to interpret and communicate the data it measures. For this purpose, the developer suggested a phone, since nearly every user will always carry one with him.

7.4.2 Connection to devices

For the product to communicate with devices on a distance, it requires a wireless technology (figure 77). Bluetooth Low Energy (BLE) was selected for this purpose for several reasons. Firstly, it is a short-range wireless connection device (10 m), which is suitable for an in-house application where products are only controlled when in sight or close by. Secondly, it has a relatively low energy use compared to other wireless short-range solutions, so the product could work for days without charging (Elkhodr et al., 2016). Thirdly, Bluetooth products are commercially widely available and expected to be known with both the boys and their parents. The solution is therefore expected to be more easily accepted and trusted than a different wireless connection solution.

Nowadays, there are already many smart home solutions which are commercially available. This product has an advantage compared to those solutions for boys with Duchenne, because it does not only control devices in the house, it also stimulates movement with Duchenne boys. This has many physical advantages: it can extend their muscle strength and physical abilities and slow down the decreasing process (see chapter 3.2.5). It is, however, interesting for Yumen Bionics to look at third parties who are specialised in smart homes to cooperate with in order to realise this concept, since they already have the knowledge of how to set up functioning and user-friendly solutions.

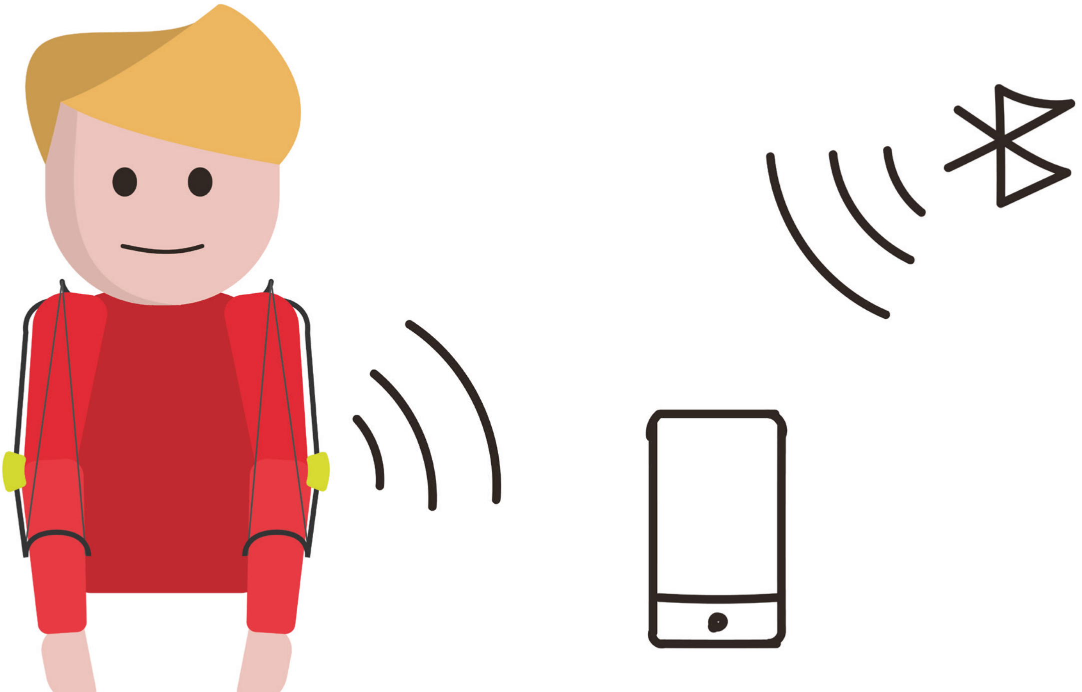


Fig. 77 *The sensor connects with Bluetooth Low Energy (BLE) devices*

8.

Validation

In this chapter, the final design is validated through a user test, and the results are analyzed to form a final conclusion

It explains which research questions were asked to validate the idea, the user test set-up and components, interesting results and quotes from participants, and a final conclusion as to what extent the concept fulfills the design goal.

Overview chapter

8.1 Research questions
8.2 User test method
8.3 Results
8.4 Conclusion

Fig. 78 *A boy with Duchenne enjoying the wind*

8.1 Research questions

To validate the final concept, a user test was conducted with three boys with Duchenne Muscular Dystrophy. The user test was conducted to see to what extent the proposed concept was successful in fulfilling the design goal stated in chapter 1.2: to redesign the exoskeleton to increase its ability to mature with Duchenne boys from 10 to 17 years old. The main- and sub research questions answered in this chapter are stated on this page.

Main research question:

To what extent does the concept increase the ability of the exoskeleton to mature with its user?

Sub research questions:

- To what extent is the concept suitable for all different ages in the target group (10-17)?
- Which parts of the concept are most interesting for which ages in the target group (10-17)?
- To what extent does this concept remain valuable/ interesting over a longer time period?
- To what extent does the concept fulfil the design guidelines, as formulated in chapter 5.2?
  - Does it fit to the three phases: Naïve Playful Kid, Anxious Self-Conscious Teen, Constrained Reluctant Adolescent?
  - Does it focus on positive progress and does it anticipate on negative decline?
  - Does it accommodate for an increase in responsibility and independence of the user?
  - Does it give the user sufficient feeling of choice and control?
- To what extent does using the concept add value to the exoskeleton, compared to using the exoskeleton alone?

8.2 User test method

The user test consisted of three parts (see figure 79). Firstly, a **video** explaining the concept was shown. Since the concept has many new aspects (exoskeleton, extra function, platform) that the participants were not introduced to before, they were expected to need some time to grasp and understand the full concept. Therefore, a video explaining the concept in a short and concise manner was sent to the participants a few days beforehand. In addition, this would ensure an equal comparison of the concept between the participants. The video included an explanation of the context (Duchenne boys), working principle and physical effect of the exoskeleton, explanation of the added controlling function, a show of the interactive coding interface and all other parts of the platform, and an explanation of the check-ups with the expert. It concluded with a suggestion of how more controlling functions can be unlocked over time, indicating a long-term benefit of using the concept.

Secondly, an **interactive prototype** of the interface was tested. The prototype was made to give participants insight in how the coding interaction would work and what the level of difficulty would be, but also to discuss more in-depth parts of all different pages of the platform with them one by one. The testing was done over Skype; the prototype was sent to the participants, who were asked to share their screen, so the interactions on the interface could be observed and recorded step by step.

Thirdly, an **interview** was conducted to discuss the video and the prototype. The intention was to do the interviews in person, since this was expected to provide a comfortable environment where participants would feel free to speak their minds, and parents could easily be included in the conversation if necessary. However, due to circumstances, the interviews were conducted using a video-call program. This called for interviewing in a short and concise way, since their digital attention span was expected to be shorter than their physical attention span. The interview script can be found in appendix N.

The user test was conducted with three test participants of different ages within the target group, because the comparison of answers of different aged boys was expected to give insights into the maturing abilities of the concept. To link the user test outcome to the initial user research, the same test participants were used.

Video **Interactive Prototype** **Interview**

Fig. 79 *Components of final user test*

8.3 Results

Figure 80-84 show pictures of the pariticpants during the user test (written permission was given to show their faces, names in the description of results are fictional). The results of the user tests are summarized in different themes. These were either themes directly related to the research questions formulated in chapter 8.1 or emerged in the interviews itself. The summary of the user test of each separate participant, including comments of their parents, can be found in appendix O.

Positive reactions

- In general, the concept was very positively received by all participants. They all said they would like to have the product themselves if it was available.
- Lucas (11) said he liked it mostly because he could constantly adapt the controlling functions to his liking.
- Sam (13) said he was very enthusiastic and thought the concept was very cool, and could provide a lot of benefit for many Duchenne boys including himself.
- Thomas (17) was impressed by the advanced technology within the concept, and would like to use it himself in everyday life, and later in his job as well.

Fit with different ages

- Lucas (11) said he could imagine himself using the exoskeleton, including extra functions, in school as well. He thought his friends would also like to have exoskeletons, but it might be expensive. His little brother (9), who does not have DMD, asked repeatedly if he could also have an exoskeleton – indicating how interesting the concept is for kids in the younger age category, regardless of whether the exoskeleton is needed as a physical aid.
- Sam (13) said the interaction was "cool" and something his friends would be impressed by because no one has such a thing (in a good way).
- Thomas (17) could imagine himself using this concept later in his life and even in a job setting.

Applications of the controller function

- All participants were very interested in the ideas of opening and closing doors and turning lights on and off, because they all experienced trouble with these tasks in their house. Lucas (11) mentioned shoes were often in front of the door, causing him not to reach it. Sam (13) said he could not reach the doorknobs or light switches because of the tray table on his wheelchair.
- Additional controlling functions mentioned were turning on the tv ("then I do not have to ask for the remote control"), using the exoskeleton in school (Lucas (11)) and using it later in his job (Thomas (17)).
- Playful interactions were mentioned as well. It was suggested by Lucas (11) to let his wheelchair drive towards him without him in it ("like a dog"). Sam (13) said how he would like to use the exoskeleton as a game controller because he loves gaming.
- Parents mentioned a few extra useful applications of the controller function. For example, flushing the toilet, calling an emergency number, calling a toilet help or another caretaker in a discrete way in school, and opening kitchen cabinets and the fridge to help cooking. Also, it was asked if some functionality could be preserved in a night setting, even though the exoskeleton could not be worn to bed.

Fig. 80 *Participant (17) thinking about the applications he could use the concept for*

> **“I would like to have it, because then I can easily do things myself!”**
>
> 11-year-old with Duchenne

Fun and useful

- Both Lucas (11) and Sam (13) usually mentioned ”because it’s more fun” as a first reason why aspects of the concept were good.
- However, when asked further, they both mentioned it was useful and helpful in everyday life as well and could improve their independence. Lucas (11) said he could “easily do things himself” and Sam (13) said he “wouldn’t have to ask for help as much”.
- Thomas (17) was both impressed by the advanced technology, and noticed how it could help him in everyday life (“it would give me more freedom”).
- Besides, all parents of the participants saw the concept as something useful, which could prevent burdens, make their sons move more, and give them back more independence.

Interesting for the long term

- Lucas (11) said the concept would remain interesting for a long time, because he can adapt what he controls with which movements as much as he wants. He appreciated this, as he expected that some movements would become heavier in the future.
- Sam (13) found the concept interesting over a longer period of time because “you can keep adding features”. Also, he imagined himself using the product for the rest of his life, because his arms would get weaker (he had the misbelief that he would not need the physical support until his arms were too weak to perform tasks himself and that the exoskeleton would eventually give an active support).
- Thomas (17) saw himself using the product in the long term, because it is especially useful to control devices that are hard to use without the product (referring to the controlling function). He also thought he would have found the concept even more spectacular when he was younger.
- Lucas’s father asked the possibility of different sizes or growth of the product. This shows he expects the product to be interesting for long-term use. He was impressed by the idea that the product was adaptable in size and would be adapted at every check-up when necessary.

Motivation to move

- Sam (13) mentioned Duchenne boys, including himself, have the tendency to become lazy. He expects the possibility of getting a reward for using the exoskeleton, in combination with seeing how much he moved, to be a motivator to keep moving and prevent laziness.
- The mom of one of the participants mentioned she thinks the extra benefit of this concept is that it promotes independence by motivating the boys to move more. This is, according to her, the most important added value the product can provide.

Negative decline in a discrete way

- Lucas (11) mentioned he liked the ability to change movements over time, because “they might get heavy”.
- Thomas (17) mentioned “some people can do movements better than others”, including himself, so he liked having the different options given.
- Calibrating was seen as logical and technically necessary; none of the boys suspected this had to do with their declining arm function.

> **“The biggest advantage of this concept is, that you actually promote extra movement with Duchenne boys.”**
>
> Mom of 11-year-old with Duchenne

Responsibility and expert check-up

- Lucas (11) did not know if he would like to plan the check-ups himself, but did not seem to mind it was meant for an older age. He thought of the check-up page as the least interesting, because it would not be necessary to look at it often.
- Sam (13) would like to plan his own check-ups. Usually his parents arrange doctors appointments and product repairments, but he said he liked this idea better, where he can arrange it himself and ask his own questions.
- Thomas (17) said he would rather have the expert coming over regularly, than having to plan it himself, because he was bad at planning. This is different from what was expected from the oldest participant and the oldest age group in general.
- All participants did not see the expert check-up as a bad or controlling moment; they mainly thought of it as useful as long as it was not happening too often or in vain.

Customisability and choice

- Lucas (11) liked how he could constantly determine to make changes to his program whenever he wanted to. His mom also mentioned his interest in this.
- Sam (13) thought the amount of choice is enough and the options are presented in a clear, structured way.
- Thomas (17) was slightly overwhelmed with the amount of choice, but is happy to be able to make the product "his own" and likes the challenge of exploring his options.

Comparison of different platform pages

- All participants considered the coding page as the most interesting part of the platform, because it is the most dynamic element that will be changed the most.
- However, Sam (13) expected the coding platform to be used the most in the beginning, but replaced by the inspiration- and questions platform later on, which shows the maturing nature of the concept.
- The check-up page was not as interesting and the perceived use was not often for all boys, because although the check-up itself was appreciated, the preparing page was mostly giving information (which was not read) and little interaction. It was suggested to use a pop-up function if a check-up appointment would be approaching.

Fig. 81 *Participant (13) explains how he thought making movements was cool*

"The coding platform has many options. This can form a challenge, but a fun one to take."

17-year-old with Duchenne

Intuitiveness of prototype

- In general, observations showed that all participants found the interface intuitive enough. They clicked on the right buttons without much explanation and even tried to move functionalities which were not prototyped but designed to be moving elements.
- Sam (13) mentioned the programming page was clear and structured, which he found pleasant.
- Thomas (17) did not directly understand the blocks could be dragged
- All participants did not read big pieces of text (explanation text for calibration, check-up page text).

Practical comments

- Sam (13) mentioned as a negative aspect that the Bluetooth connection could get lost, causing it not to work. This would not be a disaster, but a little bit annoying.
- Both parents of Lucas (11) and Sam (13) asked how easy it was to take it on and off, since they could imagine if it would be difficult, the product would be more annoying than beneficial.
- Father of Lucas (11) was wondering if this concept could also be used in a night setting, to turn on lights, set the bed up right or call someone from the bed. So it was unpractical the exoskeleton could not be worn at night.

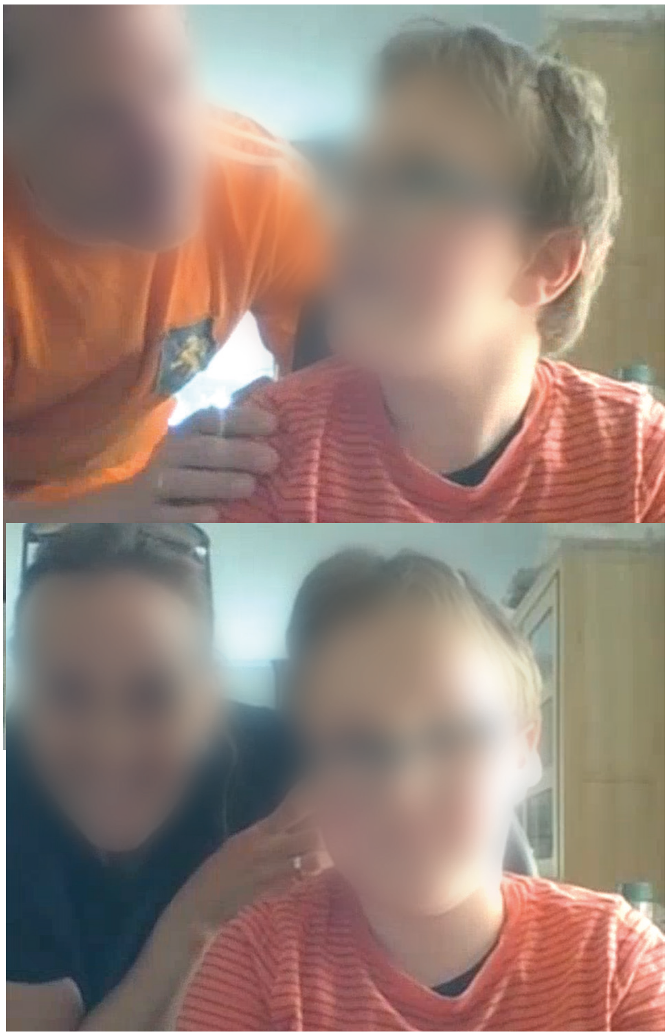


Fig. 82 *Mom and dad of participant (11) regularly came to ask practical questions and give suggestions*

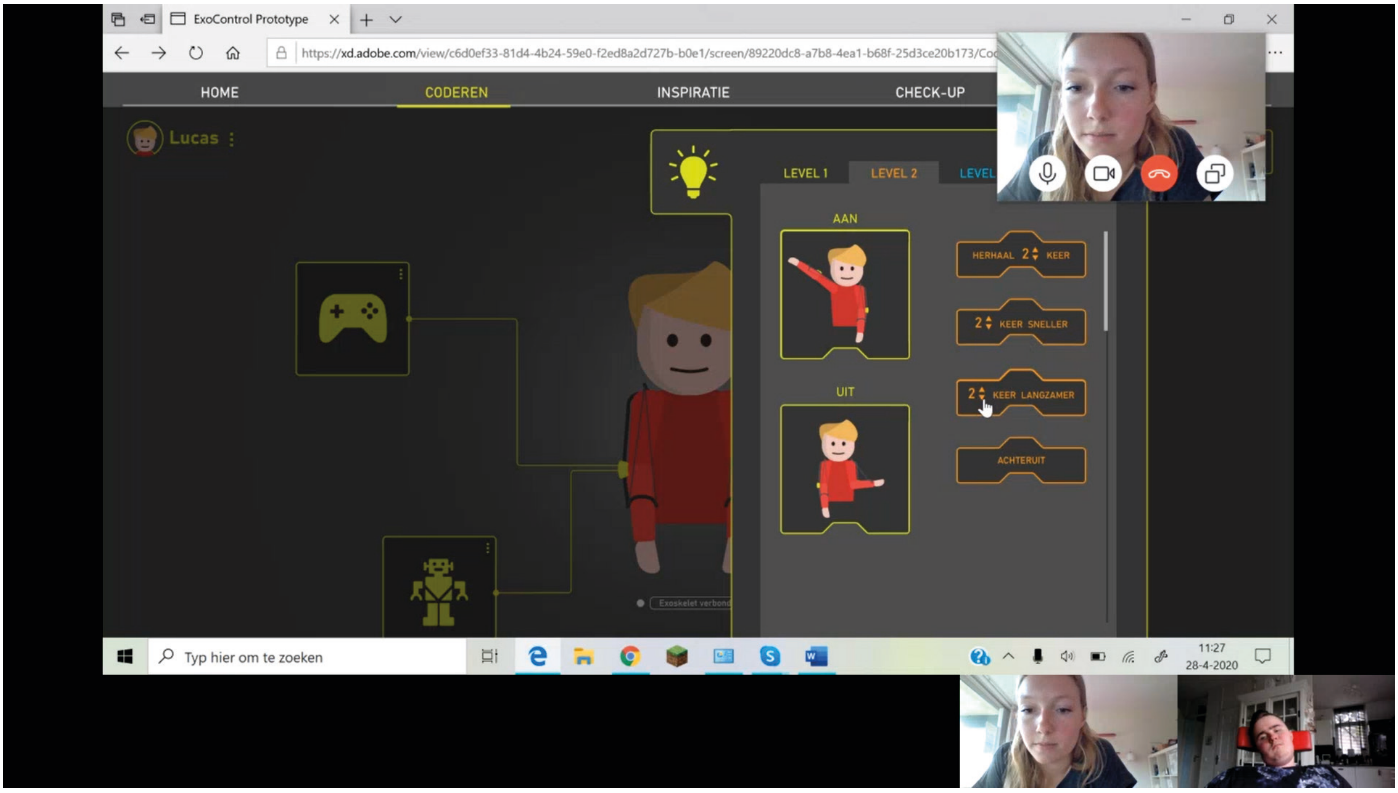


Fig. 83 *Participant (17) trying out the interface – confused about whether to click or drag the blocks*

Added value of concept compared to exoskeleton alone

- Lucas (11) said that without the added function of controlling devices, “other people would still have to control those devices for me”, indicating the importance of the added value it gives him. Also, the suggestion of having buttons instead of a moving interaction was responded to with “that would be less fun”.
- Sam (13) thought the added value of the controlling function was that the interaction would be more fun. Besides, the added function could give him more independence, because he would not have to ask for help as much. His mom agreed with this: he would directly become more self-reliant because he would get back functions that he had already lost (while his arm function was in this moment still quite good).
- Thomas (17) said that the concept added value, because it gave him more freedom. When asked to elaborate on what that meant, he could not explain it. Furthermore, he was not expecting to use the coding platform often, however he did like the option of personalising the concept to make it more “his own”.

“I think this concept is super cool and fun, and I think many boys with Duchenne can benefit from it, including myself.”

13-year-old with Duchenne

“Can I also have an exoskeleton?”

9-year-old brother, who does not have Duchenne

“This immediately gives him some independence back. And when I see how enthusiastic he is about it... can we get this tomorrow?”

Mom of 13-year-old with Duchenne

8.4 Conclusion

From the results of the user test described in chapter 8.3, the following conclusions can be made.

The concept fits well with the different ages of the target group.

- For the youngest age group (10-12 years old) experiences the concept mostly as fun, but also expects it to continue to be useful as they grow up.
- For the middle age group (12-15 years old), the interaction is seen as “cool” and gives a direct benefit, whereas the exoskeleton alone is not perceived as necessary until later in life when the arm function is significantly weakened. Therefore, the added control function has the potential to encourage an earlier use of the exoskeleton.
- For the oldest age group (15-17), the exoskeleton alone is already seen as a great improvement of independence, because they already experience more limitations in their arm function. The extra controlling function is seen as an extra dimension which gives the user even more freedom and independence.

The concept offers a good balance between fun and usefulness. Boys mostly see the concept as fun but can also see how it can be useful and give them more independence in everyday life. Parents mostly see the concept as useful, because it directly increases independence of their sons, and are happy to see the enthusiastic reactions of their sons.

The concept is perceived by the target group as interesting over a longer period of time, because functions can continuously be adapted by the boys when they want to, according to their own preferences and physical capabilities. Also, the possibility of adding more features over time makes it increasingly interesting. Besides, the concept is not only perceived as fun now, but is also expected to be useful in later life. Lastly, the platform gives a lot of new possibilities and it is expected to take a long time before all possibilities are explored.

The concept meets the design guidelines as described in chapter 5.2, for the most part.

- The concept gives the user room for positive improvement, because releasing functions over time as the user moves more is seen as a good motivator. This effect can be further explored and tested.
- The concept anticipates on negative decline, because the boys can choose and adapt movements that they feel comfortable with. When they want to change movements because their muscle function has declined, they can do this in a discrete way when they feel ready, without losing the controlling function linked to the movement.
- There is a lot of difference in the amount of responsibility boys like to take over their check-up appointments; this seems to be more personality-related than age-related. The age limit for planning their own check-up should therefore be lower, as long as consultation with parents is always done in the background. The check-ups are seen as useful but should not happen too often or when it does not seem necessary, for practical reasons.
- The concept gives the boys enough feeling of choice, because the programming interface and platform pages provide them with a sufficient amount of options.

The concept adds value to the exoskeleton compared to using the exoskeleton alone, because it stimulates the boys to move more (physical benefit), because it makes the user interaction more fun (emotional benefit), and because it directly adds an extra level of independence (emotional benefit), besides the physical independence that is provided by the exoskeleton itself through improving arm function (which was perceived as not needed yet by the youngest two participants). This added value can ensure the use of the exoskeleton is initiated earlier (which is physically beneficial as well), the experience is directly better and more interesting, and the product remains more interesting in the long term.

The interface design is a good start in terms of intuitiveness and appearance, but could be improved further. The level of coding is easy and clear to start with, while there are also expected to be enough options for elaboration on that first level, although these options should be tested in a longer-term test setting. Small improvements to enhance intuitiveness can be made directly.

Some practical issues are expected to emerge when developing the product. The concept is well received, but practical problems are expected to emerge while the product is being tested over a longer period of time, following the usual experience of introducing new aids in Duchenne boys' lives. Some practical problems mentioned were donning and doffing of the exoskeleton (should be easy and quick) and losing the Bluetooth connection (would be annoying).

In conclusion, the concept increases the ability of the exoskeleton to mature with its user, because it ensures the exoskeleton fits well with the needs of the different ages in the target group, and because the target group expects the concept to remain interesting for a longer period of time. They expect this because of the amount of possibilities and adaptabilities the interface provides, but also because of the combination of fun and extra independence the extra controlling function provides directly when using the concept. Furthermore, the expert service ensures the physical fit and support of the exoskeleton is regularly checked and updated, without confronting the target group negatively regarding their physical decline.

9. Recommendations

In this chapter, recommendations for further development are listed

It includes recommendations about further development and implementation of the concept, and additional recommendations about product development for boys with Duchenne Muscular Dystrophy.

Overview chapter
9.1 Concept recommendations
9.2 Other recommendations

Fig. 84 *A family with two boys with Duchenne*

9.1 Concept recommendations

9.1.1 About concept improvement

- **The concept should be further evaluated with other stakeholders** besides boys with Duchenne, such as parents, caretakers, researchers and health insurance companies. During the user test, some parents already made comments, which turned out to be valuable for evaluation and improvement of the concept. Additional evaluations are expected to improve and enrich the design further.
- **A functioning prototype of the concept should be made,** to test the concept in use for a longer time period, and to improve the usability of the product overall. One practical usability issue, for example, can be how often the product should be charged to be functional and how the charging would work. Some parents already mentioned some additional practical issues during the final user test but were expecting to find more if the product would be tested in practise.
- The concept stimulates movement, which is positive. **Which movements it stimulates, and to what extent, can be further utilised and evaluated with experts** (for example human movement scientists or physiotherapists). What is exactly 'enough' movement for a user to earn his next device control, and which movements should be trained, might even differ per user and will likely change over time as well (since Duchenne is a progressive muscular disease) – this should be further evaluated and tested.
- **The interface can be further designed and evaluated to enhance intuitiveness and solve minor problems.** The style and appearance do seem to match with the target group. Also, the tutorials for the interface should be developed, to ensure an easy start of use and guide the user to try out more difficult levels over time.
- **The person to fulfil the role of the expert during check-ups should be further considered.** For example, every check-up might need a combination of two professionals, one to check the physical features of the exoskeleton (an occupational therapist) and one to check the software and help with installing devices (a software developer or a trained professional from Yumen Bionics). If multiple professionals are necessary, it would be advisable to align those appointments as much as possible, to make sure Duchenne boys always associate these check-ups with positive changes.
- **The housing of the sensor should be designed** to fit with the concept, be recognizable, and be in line with the appearance of the sensor in the interface. This is to ensure the user directly understands the connection between the physical product and the digital interface, which is expected to make the coding and calibration interactions more intuitive.

9.1.2 About concept implementation

- To realize the concept, it might be interesting for Yumen Bionics to **investigate collaborations with third parties who are specialised in smart home solutions** and technology, since they already have the knowledge on how to set up functioning and user-friendly solutions.
- After a certain age (expected around 18), the passive exoskeleton will not be suitable for Duchenne boys to use anymore, since their own physical abilities will be too weak to move their arms, even with the support the exoskeleton provides. There might be a possibility to transition to an active exoskeleton, but the development of that exoskeleton is not as far as the passive one. **It should be investigated how, even though the user loses the physical exoskeleton, the digital functionality (controlling devices in the house) can still be preserved.** This functionality has proven to give a great advantage regarding independence and would have a big negative impact if it would be lost together with the physical exoskeleton. Instead of making movements, the interface could for instance provide buttons, or the user might control devices by making his avatar make movements on his phone screen. During the user test, the participants expected a button interaction to be less fun; however, it would be better than losing the function of controlling devices all together.
- **Once the concept is implemented, it is important to continuously evaluate the concept with the user over a long period of time.** Although this concept is designed to mature with the user, is well received and is expected to remain interesting for the entire intended use, evaluating the use over multiple years will further confirm its ability to mature with and stay relevant to the user.

9.2 Other recommendations

- The first concept "Build Your Exo", as described in chapter 6.2, was positively received by both the target group (Chris) and Yumen Bionics. Chris thought both concepts in chapter 6.2 should be combined and implemented together. Due to time constraints, this concept was not further elaborated on in this thesis. However, **the process of purchasing and replacing physical parts of the exoskeleton while still providing a feeling of choice for the user should be further designed and investigated.** It might be interesting to implement the option of purchasing new parts in the interface of the current concept, or even earn new physical parts over time, next to earning new digital functionalities.
- **The product appearance should be designed to match the maturing target group.** It should be further investigated how the product appearance should mature over time and what impact that can have on the user.
- Two of the test participants' parents mentioned donning and doffing of the exoskeleton as an important practical issue. They expected that if putting the exoskeleton on and taking it off for simple tasks (like going to the bathroom or putting on a coat) would take a long time, the product would do more harm than good. **Donning and doffing of the exoskeleton should therefore be easy and quick, performable by one person, and should be understandable for laymen.** Although this physical product interaction was outside of the scope of this thesis, it should be considered as a high priority.

> **"Once you put the product in our hands, practical problems are bound to come up"**
>
> Mom of 13-year-old with Duchenne

> **"I see no reason why you can't combine the two concepts"**
>
> Chris, 15-year-old with Duchenne, about the concepts described in chapter 6.2

- One of the participants mentioned that the concept might motivate him to move more. **This motivational effect is interesting to explore and utilise further.** It should especially be researched if this motivational effect can last the time of the intended use, or if it will cease earlier, since Duchenne boys will not be able to physically improve over time (which might harm their motivation). To what extent the motivational effect exists with the user is also expected to be personality dependent.
- Regardless of whether the concept presented in this thesis will be implemented, **the outcomes of the literature study and user research, as presented in the overview of page 60-61, can be used as inspiration and source for further product development** for boys with Duchenne between the ages of 10 and 17. How they mature and how their physical and emotional needs will change over time, should always be considered when designing a product for them.

Personal reflection

At the start of this thesis, my mentor asked me: "When will you see this project as successful?" I answered that I was going to be happy if I could look back on it with joy, and if I had the feeling that someone was helped because of my work. Well, I can honestly say that both of these goals were achieved.

The one thing in this project that gave me most joy was the interviews I did with boys with Duchenne. It was amazing to dive into their world, and to learn from their positive attitude in life, despite their condition. It was also great to see how they experienced the interviews themselves; they gave me so much positive feedback. "I like your positive approach" was a great compliment one of the boys gave me at the end of a co-creation session. Another boy told me "Usually research is stupid. But this was actually fun to do!" These comments gave me enough energy to keep working and doing my very best until the end. In addition, getting the acknowledgement at the end, when seeing how enthusiastic the boys were about the concept I had developed, was extremely rewarding. The conversations I had with these boys will stay with me for a long time.

"I like your positive approach"

Thomas, 17 year old boy
with Duchenne

Besides, talking to their parents gave me whole new perspectives as well. They expressed so much gratitude to the fact that I was giving all my energy and attention to help their sons, that I knew I was doing the right thing and using my energy and design skills for the right purpose.

Of course, every project is accompanied with some setbacks. When I hit a wall, I was forced to re-learn when to take a step back, take some rest and recognize when enough is enough. I have learned to trust more in my own abilities, and how to deal better with the emotional rollercoaster I go through when working on projects on my own – even though I still have some work to do in this area. Also, I have learned that it helps sometimes to stop overthinking and just start doing – it will all land on its feet in the end.

Fig. 85 *My face when seeing the boy's enthusiasm during the final user test*

I felt like within this project I could really use a combination of my interests and strengths. I have learned what qualities I have in projects like these and how they can work to my advantage. In addition – although not intentional - it was nice to discover a secret talent for developing creative research methods, which is something I am hoping to continue doing in my future design career.

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