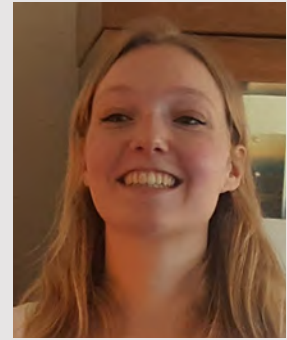


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Research question (design goal)

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 (Kohler et al., 2009).

To support Duchenne boys' physical functioning and contribute to their independence, a passive exoskeleton has been developed by Yumen Bionics, to support their arm function (figure 1) (Kooren et al., 2015). The exoskeleton's target group is boys with Duchenne between 10 and 17 years old. It is expected that these boys' physical and emotional needs regarding medical aids such as exoskeletons will change as they mature. However, the exoskeleton

cannot yet accommodate these changing needs. The design goal of this project is to redesign the exoskeleton's ability to mature, both physically and emotionally, with Duchenne boys from 10 to 17 years old.

Methods

To understand the design goals' requirements, both the physical and emotional needs and development of the target group were researched. Physical development was studied in literature, whereas emotional development was studied through user research. The user research was based on the Contextmapping Method (Sanders and Stappers, 2012) and complemented with a self-invented co-creation research method. Four boys with Duchenne of different ages (11, 13, 17, 17) participated. They were asked to fill in sensitizing booklets before the interviews and play a game during the interviews in which they



Figure 1. The A-gear (Flextension), first prototype of a passive exoskeleton for Duchenne boys, which is being developed further by Yumen Bionics



Figure 2. Interview and co-creation session with the target group, in which the participant designs a product for himself

designed a product for themselves (figure 2). The insights resulting from the interviews led to a proposal for a new exoskeleton concept, which was then evaluated with three boys of different ages (11, 14 and 17) with Duchenne, by showing a video explaining the concept, testing an interactive interface and interviewing them about their experience.

Results

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:

1. Naïve Playful Kid (10-12 years old);
 2. Anxious Self-Conscious Teen (12-15 years old) and;
 3. Constrained Reluctant Adolescent (15-17 years old)).
- These groups 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 and if they provide entertainment. 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 follow the following design guidelines:

- the exoskeleton's use 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 negative decline;
- the exoskeleton should accommodate increasing responsibility and independency of the user, and;
- the user should feel like he has control over the exoskeleton and choices in using it.

By following these guidelines, 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 (figure 3). Through a communication platform he can ask questions and share experiences.

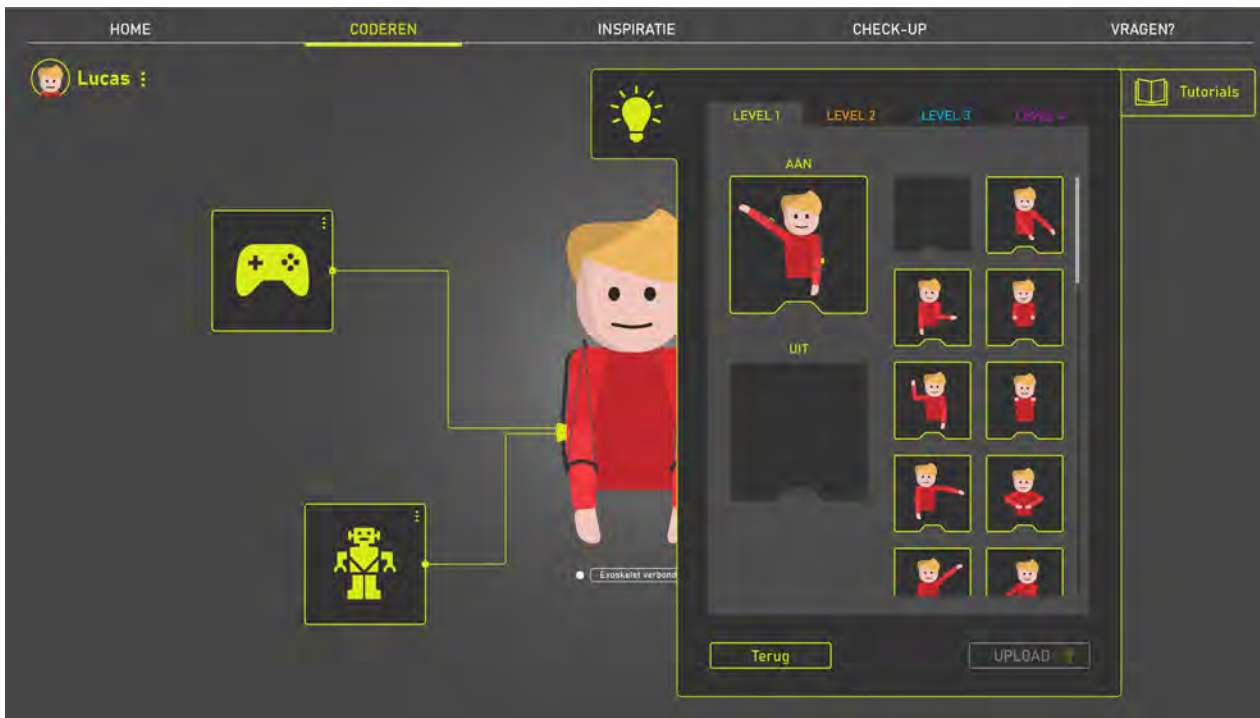


Figure 3. Interface design in which the user can 'code' which devices in his house are controlled with which movements of his exoskeleton

Thirdly, a service in which an expert regularly checks the exoskeleton's hardware (physical fit and support) and software (controlling functionality) is introduced. The evaluation of the concept resulted in positive reactions from all participants, indicating a relevance for the entire target group. Furthermore, a balanced amount of comments on both fun and usefulness were made, and all participants expected the exoskeleton to be interesting for a long period of time for varying reasons. Parents of the boys mentioned how the concept could give their sons an increased level of independence and how it has the potential to stimulate extra movement with Duchenne boys.

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 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.

Personal impression

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. Positive feedback and gratitude from both boys and parents on the interviews and final design were extremely rewarding. I constantly knew I was using my energy and design skills for the right purpose. In my experience I could use a combination of my interests and strengths within this project. I have learned about my qualities 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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