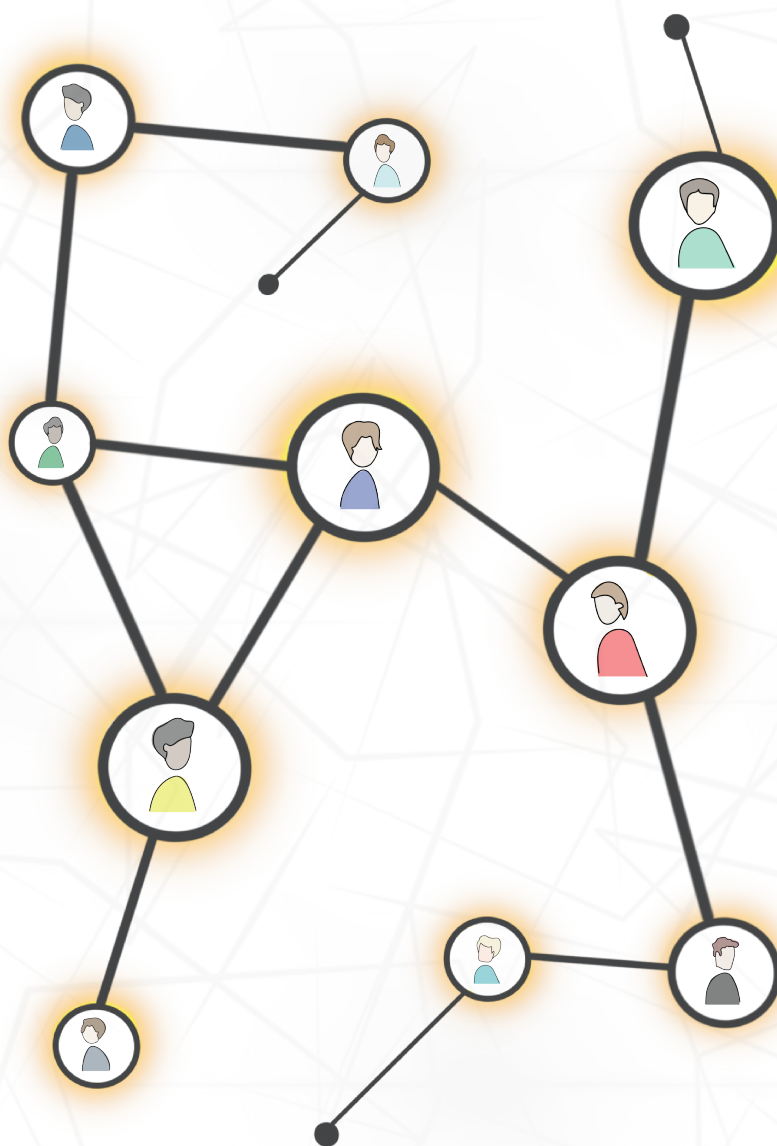


Designing Motivational Data for Males with Duchenne Muscular Dystrophy

APPENDICES



Milla Zlatanova

October 2021

Designing Motivational Data for Males with Duchenne Muscular Dystrophy

APPENDICES

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October 2021

MSc Design for Interaction
Faculty of Industrial Design Engineering
Delft University of Technology



Abbreviations

DMD: Duchenne Muscular Dystrophy

YB: Yumen Bionics

RtD: Research through Design

DT: Digital Twin

SG: Serious Game

UI: User Interface

SDT: Self-Determination Theory

App: Mobile application

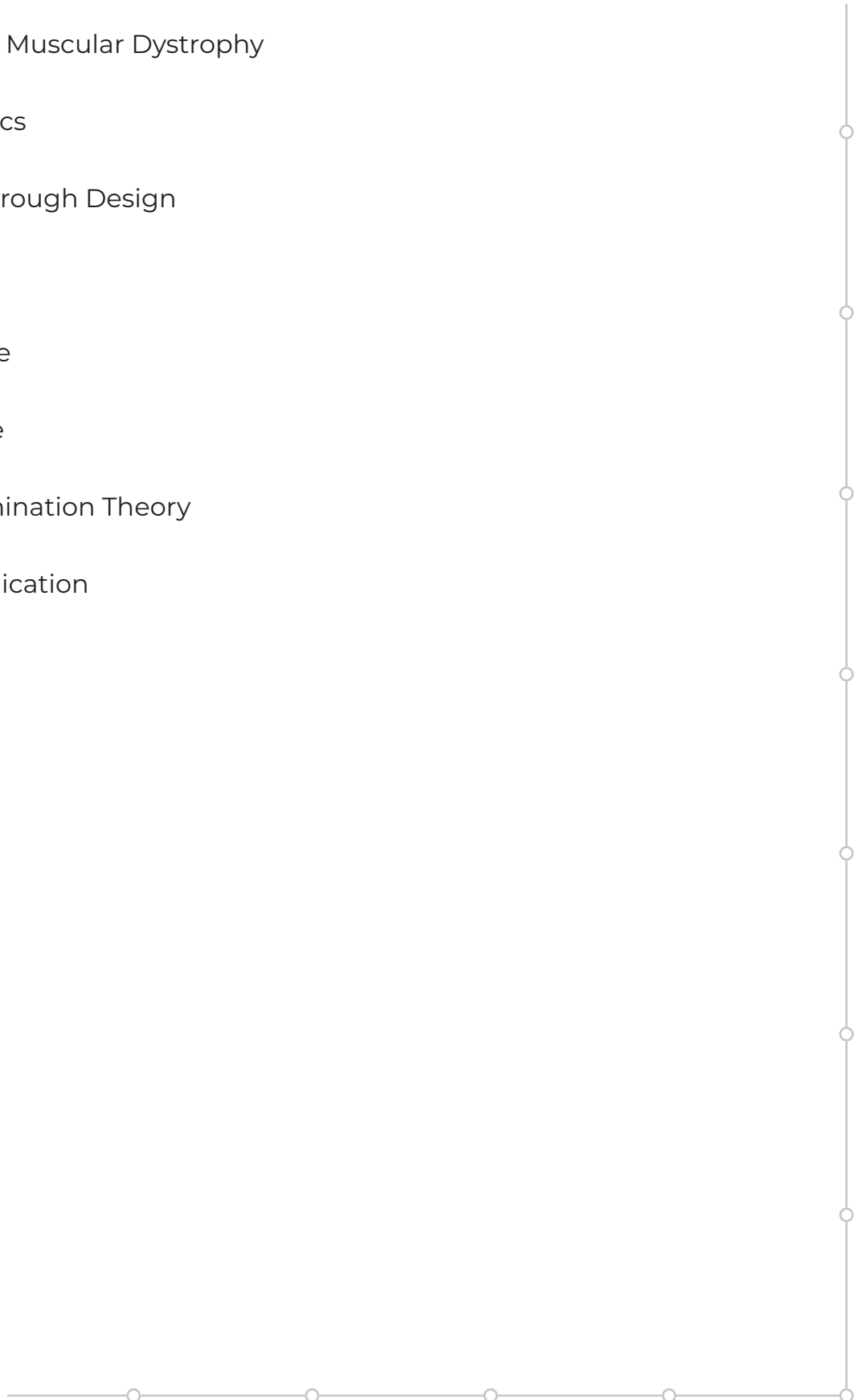


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Appendix 1: Project Brief

DESIGN
FOR OUR
future

4993



IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

! USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT
Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy". Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 ! !

<p>family name <u>Zlatanova</u></p> <p>initials _____ given name <u>Milla</u></p> <p>student number _____</p> <p>street & no. _____</p> <p>zipcode & city _____</p> <p>country _____</p> <p>phone _____</p> <p>email _____</p>	<p>Your master programme (only select the options that apply to you):</p> <p>IDE master(s): <input type="radio"/> IPD <input checked="" type="radio"/> Dfl <input type="radio"/> SPD</p> <p>2nd non-IDE master: _____</p> <p>individual programme: _____ (give date of approval)</p> <p>honours programme: <input type="radio"/> Honours Programme Master</p> <p>specialisation / annotation: <input type="radio"/> Medisign</p> <p><input type="radio"/> Tech. in Sustainable Design</p> <p><input type="radio"/> Entrepreneurship</p>
--	--

SUPERVISORY TEAM **

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

<p>** chair _____ dept. / section: _____</p> <p>** mentor _____ dept. / section: _____</p> <p>2nd mentor _____</p> <p>organisation: _____</p> <p>city: _____ country: _____</p> <p>comments (optional) : : :</p>	<p>Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..</p> <p>! Second mentor only applies in case the assignment is hosted by an external organisation.</p> <p>! Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.</p>
---	--

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair Stella Boess date 20 - 05 - 2021 signature _____

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair. The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: 25 EC

Of which, taking the conditional requirements into account, can be part of the exam programme 25 EC

List of electives obtained before the third semester without approval of the BoE

YES all 1st year master courses passed

NO missing 1st year master courses are:

name J. J. de Bruin date 25-5-2021 signature JdB

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **. Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: APPROVED NOT APPROVED

Procedure: APPROVED NOT APPROVED

comments

name Monique von Morgen date 8/6/2021 signature MvM

Designing Motivational Data for Males with Duchenne Muscular Dystrophy

Designing Motivational Data for Males with DMD

project title

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

start date 07 - 05 - 2021

19 - 10 - 2021

end date

INTRODUCTION **

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

Duchenne muscular dystrophy (DMD) is a serious hereditary muscle disease that almost only occurs in boys and men. Duchenne causes the muscles to become weak, damaged, and worse over time. This process is usually visible at a very early age and gradually increases. Duchenne muscular dystrophy cannot be cured yet, but with good treatment (e.g. general exercises) they can combat several symptoms and greatly improve both quality of life and delay the progression of symptoms [1]. Yumen Bionics (a MedTech start-up located in Amsterdam) is developing a wearable/exoskeleton for children with progressive muscle diseases. The wearable supports their arm movements and collects data. This data could be translated as feedback regarding the right amount and type of movement that is best for them. The goal is to eventually have the children wear the wearable all day, every day.

Previous user research regarding the exoskeleton has shown that there are "three phases of growing up with DMD, who differ on topics such as confidence level, attitude towards their disease, responsibility, social life, relation with their parents, and relation towards healthcare products" [2]. The outcomes of this research can be used as inspiration and source for further product development for males with DMD between the ages of 10 and 17 -- however, further research needs to be done for a daily at-home context for males with DMD and their personal motivations to exercise, in addition to understanding how the Self-Determination Theory can be applied in order to better understand and foster the males' motivation. The goal of exercising is to obtain and maintain an active lifestyle so that secondary physical deterioration due to disuse is prevented and patients can function as independently as possible for as long as possible; this indicates that "doing something" is better than "doing nothing" [3]. Currently, the wearable that has been developed collects information of the exact positions of both arms over time. The project goal is to develop a concept design that will be seen as an improvement of the current 'user interface (UI)' (Figure 1) and will give meaningful data feedback to the following main stakeholders (Figure 2):

- 1.) The 10-20 year old male with DMD: How can we give feedback and keep them motivated to move just enough? How can data connect/address both the health goals (to exercise enough) and the child's personal goals?
- 2.) The parents/any other informal caregiver: In what ways can we best comfort and reassure the caregiver? What data are they interested in seeing?
- 3.) For the healthcare specialist and researcher: How can we best support them? What data is needed and in what ways should it be provided so it can optimally support specialists' practices? What data is needed/expected by researchers in order to run their investigations?

The entirety of the project will be in a partnership with Yumen Bionics, and the stakeholders will mostly likely come from the Duchenne Parent Project. A great opportunity would be to work with the males and their families/physical therapists in the setting of a home. This will allow me to build rapport, and conduct observations/contextmapping activities/user tests better. However, I realize that due to COVID-19's ever-changing restrictions, I may need to adjust my plans accordingly. Regardless of how these meetings will be held, I hope to gain a better understanding of the males' behavior patterns (both in daily life and in terms of exercising), motivations, and conduct multiple interventions/test types of data interaction scenarios in order to design a useful, usable, and motivational concept.

References: 1.) Bird, E. (2020, September 17). Potential treatment strategy found for muscular dystrophy. Retrieved from <https://www.medicalnewstoday.com/articles/potential-treatment-strategy-found-for-muscular-dystrophy>
 2.) Vermeer, L. (2020, May 14). Design of an exoskeleton maturing with boys with duchenne muscular dystrophy (Master's thesis). Retrieved April 2, 2021, from <https://repository.tudelft.nl/islandora/object/uuid%3A24187be8-b65f-4e4c-80f8-f192ec807a36?collection=education>

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Personal Project Brief - IDE Master Graduation

introduction (continued): space for images

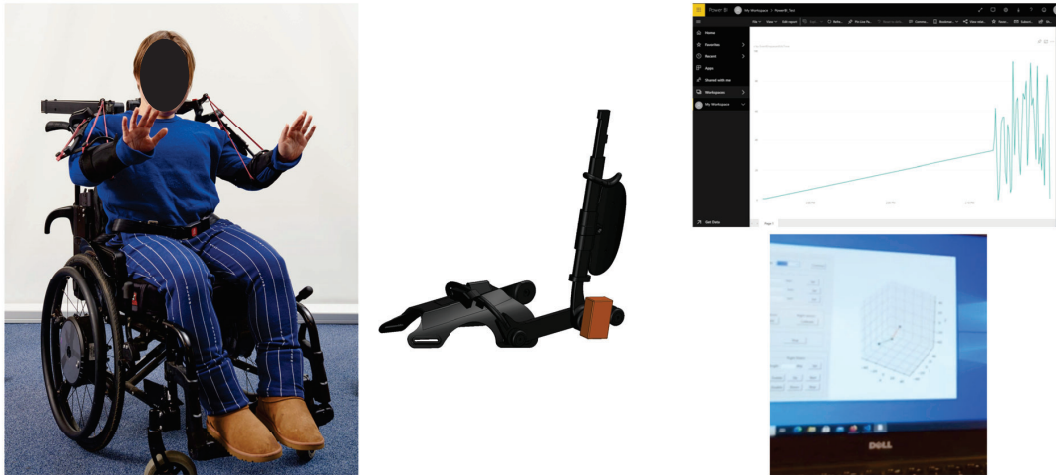


image / figure 1: The exoskeleton and current 'user interface'/data visualization

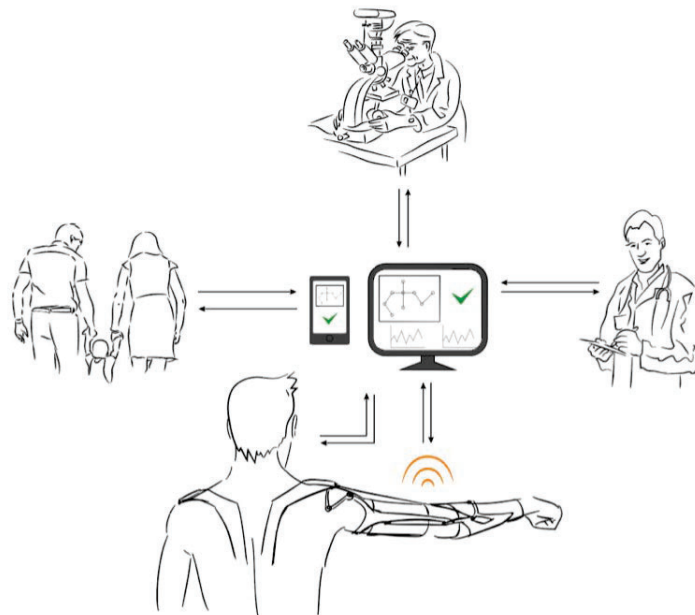


image / figure 2: The movement data that is tracked by the wearable -- and distributed amongst certain stakeholders

PROBLEM DEFINITION **

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

This project aims to discover and test which data interaction scenarios could increase a DMD males' quality of life by helping them and their network manage their health condition. The scenarios will explore relevant data collection and engaging interactions for different contexts. E-Health solutions embrace a variety of online communities and health services with the aim to facilitate connectivity between a patient (i.e. the DMD male) and other stakeholders (i.e. other patients, the parents, healthcare specialists, and researchers). In some technologies, there is often a mismatch of goals (e.g. life and health). Health goals should integrate with life goals -- therefore homecare technologies should consider patients' personal experiences and social context as crucial aspects when providing care support [1]. To dive deeper into e-Health care, and begin exploring different data interaction scenarios, it would also be interesting to look into two specific ways of visualizing patient/medical data: through the use of Digital Twins and Serious Games. Due to the current development stage in which the wearable is in and the scope/length of the project, actual measurements of the movements and appropriate data visualization feedback will not be available. However, it will be possible to simulate the data visualizations and interactions. Also, further research by experts (e.g. physiotherapists, YB researchers and developers, etc.) will be needed in order to answer what is exactly 'enough' movement for a user and which movements/to what extent they should be exercised. This will inevitably differ per user and will likely change over time as well -- meaning that the design concept should aim to deliver tailored care for each individual male. Although the concept will be tested to a certain extent (e.g. unmoderated usability test), in the future it would be ideal to program, test, and validate if the male's long-term motivation and behavior has been affected.

References: 1.) Garcia, J. J., Romero, N., Keyson, D., & Havinga, P. (2014). An Integrated Patient-Centric Approach for Situated Research on Total Hip Replacement: ESTHER. Pervasive Health Human-Computer Interaction Series, 343-365. doi:10.1007/978-1-4471-6413-5_14

ASSIGNMENT **

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

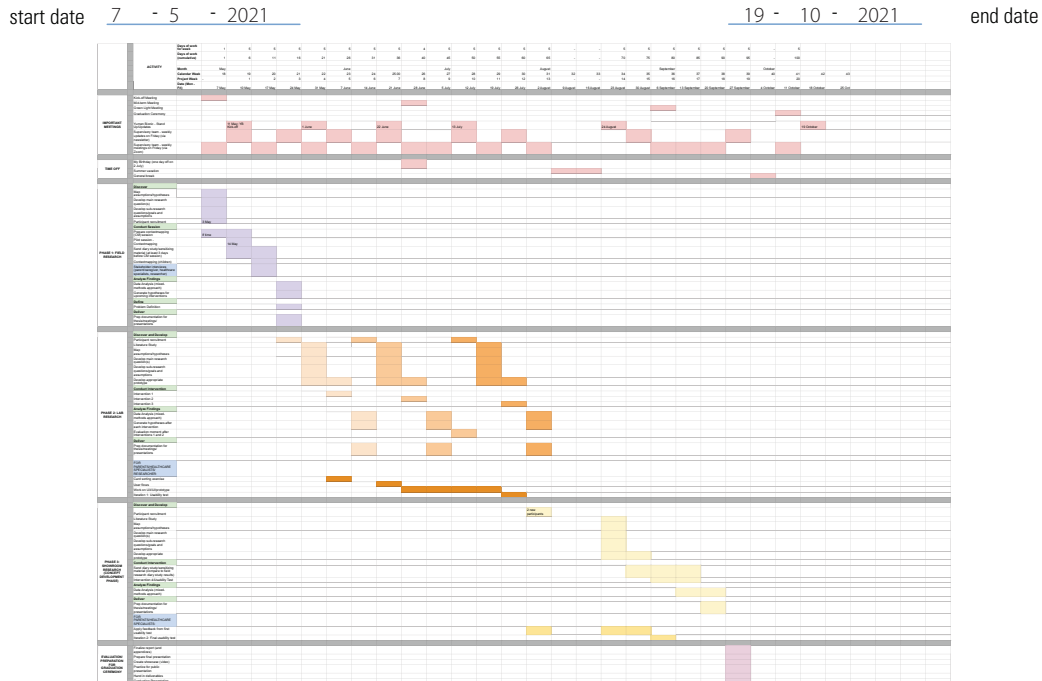
Using a "Research through Design" approach, I plan to test multiple data interaction scenarios/prototypes in order to discover which influence(s) and engage(s) 10-20 year old males with DMD -- and in turn motivate(s) them to move just enough. The project will be divided into 3 main phases: field, lab, and showroom research.

We want the male with DMD to play a central role in how they view their own (meaningful) medical data. This project aims to mainly apply a Research through Design (RtD) and patient-centric approach, since it is planned to create a "series of prototypes in finding out knowledge about the research problem." [1] All the prototypes will aim to investigate how 10-20 year old males with DMD can best engage with their own medical data and, in turn, become more motivated to 'move just enough'. From an inclusive design standpoint, the project will also look into "the experience of situations and how to support a person's needs, rather than mainly on the development of products to compensate for specific disabilities." [2] Given the knowledge gained via multiple interventions, a 'final' design concept (most likely in a digital form) will emerge. Due to foreseeable time constraints/stakeholder availability/project scope, a User-Centered Design (or rather, a Stakeholder-Centered Design) approach will be applied in order to take the parents' and healthcare specialists' perspectives and needs into consideration. I aim to deliver a comprehensive and centralized digital service that can be seen as a valuable addition to the physical wearable. This service will include the following:

- A motivational data interaction scenario for the male with DMD (i.e. an intuitive way to understand and interpret the wearable data)
- A digital space (most likely a mobile application) for the parents and healthcare specialists to look into the child's data

PLANNING AND APPROACH **

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



The project timeline has been structured in a way that will allow me to conduct four main interventions using a RtD approach. In phase 1, I plan to use contextmapping (a form of participatory design) as a technique to uncover current exercises done with physical therapists/behaviors/motivations/values/goals/etc. In phase 2, I plan to hold three different interventions: the first aims to test the effectiveness of a "Digital Twin" (a virtual version of the male which looks, behaves, and reacts like the real male, and could help them receive proper treatment in the right time, in the right way). The second aims to test the effectiveness of a "Serious Game" (or an "exergame", to be specific). They are interactive games which require physical activity and have been found to have promising effects). Both these interventions are using the prototype as a 'physical hypothesis' to prove (or disprove) the feasibility of a proposition. [1]

Based on qualitative and quantitative data, the insights gained from the first two prototypes should give a direction for the third intervention. The goal will then will be to either iterate on (one of) these concepts, or to continue exploring other possibilities. In phase 3, the fourth intervention will test the effectiveness of the 'final' concept design via an unmoderated usability test.

References:

- 1.) Stappers, P., & Giaccardi, E. (n.d.). Research through Design. Retrieved from <https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/research-through-design>
- 2.) Boess, S. (2018). Design for Self-inclusion: Supporting emotional capability. DRS2018: Catalyst. doi:10.21606/drs.2018.628

MOTIVATION AND PERSONAL AMBITIONS

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

Coming from a non-design background, I would like to briefly reflect on how I got to where I am today. One memorable activity I did during my bachelor years was being a part of the ASSIST (Assistive Sociotechnical Solutions for Individuals with Special needs using Technology) research lab, where one of the projects was to co-create a speech therapy game for children born with orofacial cleft. Assistive technology, participatory design, and design thinking genuinely fascinated me, which led me to the decide that I would like to further my education.

I knew I wanted to gain a deeper understanding of products, perspectives, design processes, theories, and methodologies, so I decided to go on a journey to learn more while attending TU Delft and pursuing a master's degree in "Design for Interaction". For this graduation project, I can surely see myself applying knowledge from courses like "eHealth", "Context and Conceptualization", "UXAD", and my internship as a "Product Design" intern, for starters. From learning about contextmapping to redesigning a Trophy Mobile Scooter's interface for the elderly, the courses I have taken have been incredibly valuable towards my development as a designer.

During my internship, I learned the importance of and gained some skills in the following areas: collaborating between multiple teams and end users, user research, data analysis, and a bit of digital prototyping and UI design. I also learned how to adapt quickly, work in a fast-paced environment, and prioritize tasks. Through this internship experience, I found out how passionate I am about UX Research, and how much I would like to continue to expand my knowledge regarding different research methods and approaches.

Since I began attending TU Delft in September 2019, I have remained true to my values and interests. My sister that is disabled has inspired me over the years, and I am continually determined to find ways to interact, help, and include people with a range of abilities and perspectives when designing. When searching for a graduation project, I seemed to be drawn towards Yumen Bionics' design challenge the most since it resonated and aligned so well with my interests. Additionally, I enjoyed working with a tight-knit team/in a start-up environment at my internship, which is another reason why I decided to develop a partnership with Yumen Bionics.

Given my experience, it seems that my strengths lie in qualitative (and some quantitative) research. Now, I would like to challenge myself and try a research approach I have not yet had the chance to experiment with: Research through Design. Overall, this project gives me the opportunity to:

- work with multiple stakeholders and understand how can we best translate their needs/values into a solution
- test and improve upon my prototyping skills; be able to prototype iteratively
- hone my data analysis and visualization skills, and how I present information/results (to Yumen Bionics, supervisory team, and beyond)
- learn how we can best portray data in a meaningful way for males with DMD (and how to not place emphasis on their disability, but rather on their abilities and personal goals)

I am excited to see how this graduation project will guide and support my growth as a young designer.

FINAL COMMENTS

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

References:

3.) Richtlijndatabase. (n.d.). Retrieved from https://richtlijndatabase.nl/richtlijn/duchenne_spierdystrofie_dmd/fysieke_training_bij_dmd.html

User Research: Appendices

Appendix 2: Sensitizing Materials

Using an audio diary (voice messages sent in WhatsApp), participants can respond to the following daily exercises:

Day 1, 10 min: Intro to a male's hobbies

- What are your hobbies? Tell me why you like them.
- Can you please send a picture of you doing that hobby -- (artifact photos regarding the male himself)

Day 2, 10 min: Intro to a male's daily life and their network

- What does a 'day in your life' look like? From the moment you wake up to the moment you go to sleep, how do you spend most of your time?
- Please tell me 3 things you like to do with your friends and family -- and try to be specific. Who is there? What are you all doing?
- If you'd like, take or send some of your favorite pictures that you would like to share with me... these can be with your friends or family ... or the activities you like to do with them... anything that you would like to share! (artifact photos regarding parts of male's network)

Day 3, 10 min: Intro to their physical activities and data interactions

- What physical activity did you do today? Were you motivated to do it?
- What are your three favorite mobile applications, websites, or games? (They could be anything ... here are some examples: there's Snapchat Fortnite ... the weather app... Ooo! and live score apps that help you keep track of your favorite football team! What do you usually use and like the most?) Please tell me the name of each.

<https://bit.ly/AudioDiary>

(Example of Day 2, Question 1 Audio Diary Prompt)

Appendix 3: Contextmapping Plan/Guide, Interview Guides, and Presentation Slides

Contextmapping Plan/Guide

(English + Dutch)

What is it like to be a male with DMD and what concerns, feelings, drivers, and attitudes do they have towards physical activities?

1. Overview

Contextmapping Plan		
Time	Action	Explanation/Checklist
5 min	Introduction/Ice breaker	Opportunity to get to know each other Explain set up of session, goal, and that they are the experts of their own experiences -- start recording if there is written and verbal consent (refer back to consent forms)
20 min	Activity 1: Looking into RQ 1, 2, and 3 "Make" "Do"	Using a storyline toolkit, let the participant map out a "day in their life" on a timeline
15 min	"Say"	Present timeline/ask follow-up questions Gain a better understanding of their daily activities and their challenges regarding physical activities
5 - 10 min	BREAK	Give the participant a chance to recharge
15 min	Activity 2: Looking into RQ 4 and 5 "Say"	Using photos to elicit emotions, I hope to gain a deep understanding of their current data interactions via products
5 min	Activity 3: Looking into RQ 6 "Say"	Show a short video of exoskeleton Keeping it in mind, what is the future vision the participants have regarding how they can best be

		motivated to engage with their own medical data?
~ 2 min	Closing	Any last discussions. Thank them for their time.
Interview the parent once this session finishes?		

2. Intro/icebreaker

- a. Hello! My name is _____ and I am a _____ student at TU Delft that's currently working with Yumen Bionics for a project _____. Today we will be doing some activities together that will help me understand what will help you feel motivated to physically continue to move your muscles. As you may already know, it's super important for you to keep moving. So with that said, I'll be asking you a couple of questions here and there and doing some activities with you.
- b. **(slide 1) Welcome slide (slide 1)**
- c. *Introduce yourself: your hobby, and what makes you want to continue to do it*
 - i. **(slide 2) *add pic of researcher with hobby (slide 1)**
 - ii. **(slide 3) *add pic of participants hobby, given sensitizing material response (slide 2)**
 1. What makes you want to continue to do it?

Hallo! Mijn naam is _____ en ik ben een _____ student aan de TU Delft die momenteel samenwerkt met Yumen Bionics voor een project _____. Vandaag zullen we samen een aantal activiteiten doen die me zullen helpen begrijpen wat u zal helpen om gemotiveerd te blijven om uw spieren fysiek te blijven bewegen. Zoals je misschien al weet, is het super belangrijk dat je in beweging blijft. Dus met dat gezegd, zal ik je hier en daar een paar vragen stellen en wat activiteiten met je doen.

(dia 1) Welkomstdia (dia 1)

Stel jezelf voor: je hobby, en waarom wil je dat blijven doen?

(dia 2) * voeg foto van onderzoeker met hobby toe (dia 1)

(dia 3) * voeg een foto toe van de hobby van de deelnemers, gezien de reactie van sensibiliserend materiaal (dia 2)

Waarom wil je het blijven doen?

2. Activity 1: Life/Movement

- a. So -- given this past week's voice messages, you told me what a "day in your life" looked like.
- i. On the left, you will see pictures that may or may not relate to you and your day. Let's put what a "day in your life" looks like on this timeline!
 - ii. **(slide 4) *DO* (make the timeline in Miro) (slide 3)**
 1. Give them about ~20 min to make the timeline
 2. Then have them briefly go through it without interrupting them.
 - v. What kind of physical activity do you do by yourself?
 1. Can you tell me more about this (hobby, activity)?
 2. What do you like?
 3. What is challenging?
 - vi. **(slide 5)** I see you like to _____ ... on the other hand, what specific activities do you need help with from an adult (ex: friends/family [sibling])?
 1. Do you like receiving help? Why or why not?
 2. How independent do you feel? **(scale of 1-7) (slide 5)**
 3. How independent do you want to feel? **(scale of 1-7) (slide 5)**

- a. Dus - gezien de spraakberichten van de afgelopen week, vertelde je me hoe een "dag in je leven" eruit zag.
- i. Aan de linkerkant ziet u afbeeldingen die al dan niet betrekking hebben op u en uw dag. Laten we op deze tijdlijn zetten hoe een "dag in je leven" eruitziet!
 - ii. **(dia 4) * DO *** (maak de tijdlijn in Miro) (dia 3)
 1. Geef ze ongeveer 20 minuten om de tijdlijn te maken
 2. Laat ze er dan kort doorheen gaan zonder ze te onderbreken.
 - iii. Wat voor soort fysieke activiteit doet u zelf?
 1. Kun je me hier meer over vertellen (hobby, activiteit)?
 2. Waar hou je van?
 3. Wat is uitdagend?
 - iv. **(dia 5)** Ik zie dat je het leuk vindt om _____ ... aan de andere kant, bij welke specifieke activiteiten heb je hulp nodig van een volwassene (bijv. vrienden / familie [broer of zus])?
 1. Vind je het leuk om hulp te krijgen? Waarom of waarom niet?
 2. Hoe onafhankelijk voel je je? (schaal van 1-7) (dia 5)

3. Hoe onafhankelijk wil je je voelen? (schaal van 1-7) (dia 5)

vii. **(slide 6)** Now ... imagine your physical therapist comes over to your home to do certain physical activities with you that will help move your muscles. What kind of physical movements do you do with your physical therapist? Can you please show me... or explain? **(OBSERVE) (slide 6)**

1. What do you like about these activities?
2. What is challenging/do you have any concerns?

viii. **(dia 6)** Nu... stel je voor dat je fysiotherapeut bij je thuis komt om bepaalde fysieke activiteiten met je te doen die je helpen je spieren te bewegen. Wat voor soort fysieke bewegingen doet u met uw fysiotherapeut? Kunt u mij alstublieft laten zien ... of uitleggen?

(OBSERVE) (dia 6)

1. Wat vind je leuk aan deze activiteiten?
2. Wat is een uitdaging / maakt u zich zorgen?

viii. On average, in a week, how often do you physically move by yourself?
(ex: 30 minutes per day)

1. Are you satisfied with how much you move? Why or why not?
2. *If yes:* Do you see yourself improving anything?
3. *If no:* If you would like to change something... what would you like to change?

ii. Hoe vaak beweegt u zich gemiddeld in een week alleen? (bijv. 30 minuten per dag)

1. Ben je tevreden met hoeveel je beweegt? Waarom of waarom niet?
2. *Zo ja:* zie je jezelf iets verbeteren?
3. *Zo nee:* als u iets zou willen veranderen ... wat zou u dan willen veranderen?

(slide 8) ----- 5 MIN BREAK ----- (slide 8)

3. Activity 2: Data

- a. **(slide 9) SHOW PICS OF 1 FAVORITE APP (slide 9)**
- b. I noticed you like to use _____.....
 - i. Let's say I'm someone that has never used this app/product before. How would you describe to me what this app does?
- c. Can you tell me a little more about why you like this app/game/website?
- d. If we dive deeper, what features or parts in the app do you like and usually look into? ... or think are important?

a. (dia 9) FOTO'S VAN 1 FAV-APP TONEN (dia 9)

- b. Ik heb gemerkt dat je _____ graag gebruikt
 - i. Laten we zeggen dat ik iemand ben die deze app / dit product nog nooit eerder heeft gebruikt. Hoe zou je voor mij omschrijven wat deze app doet?
- c. Kun je me iets meer vertellen over waarom je deze app / game / website leuk vindt?
- d. Als we dieper duiken, welke functies vind je dan leuk en kijk je er meestal naar? ... of denk dat zijn belangrijk?

Before showing slide 11, explain that they will be doing a 5-second test

- g. **(slide 10) * 5-second test (pics 1,2,3): Show some pictures and see which picture (data visualization) catches their eye (slide 10)**
- h. **(slide 11) * 5-second test (Serious Game/DT): Show some pictures and see which picture (data visualization) catches their eye (slide 11)**
- a. **(dia 10) * 5 seconden test (foto's 1,2,3): laat enkele foto's zien en kijk welke foto (datavisualisatie) hun aandacht trekt (dia 10)**

- b.
- c. **(dia 11) * 5 seconden test (Serious Game / DT):** laat enkele foto's zien en kijk welke foto (datavisualisatie) hun aandacht trekt **(dia 11)**

4. Activity 3: Future

- a. **(slide 14) Show short video of exoskeleton purpose to give an idea of what the product is (slide 14)**
- b. As a first impression, do you want to use this? Why?
 - i. The exoskeleton can track your arm movements and then visually display some information. What kind of information are you curious about knowing?
 - ii. What kind of information do you not want to see?
 - ii. **(slide 12)** How much would you like your parent/caregiver to be involved in helping you keep track of how much you're moving? **(scale of 1-7, 7 meaning very involved) (slide 12)**
 - iii. Where would you like to see this information? *(manually, via phone, laptop)*
 - iv. **(slide 13)** How do you want to feel when using the exoskeleton and seeing the information that has been collected by it? **(see word list)** If you had to pick three words of how you want to feel, what would they be? **(slide 13)**
 - 1. How would you NOT want to feel? Again, pick 3 words.
- d. Generally speaking, when do you feel most proud of yourself?
- e. Wil je hier als eerste indruk gebruik van maken? Waarom?
 - i. Het exoskelet kan uw armbeweging volgen en vervolgens visueel wat informatie weergeven. Naar wat voor soort informatie ben je nieuwsgierig?
 - ii. Wat voor soort informatie wil je echt niet zien?

- iii. **(dia 12)** In hoeverre zou u willen dat uw ouder / verzorger betrokken is bij het bijhouden van hoeveel u beweegt? (schaal van 1-7, 7 betekent zeer betrokken) **(dia 12)**
- iv. Waar zou je deze informatie willen zien? (handmatig, via telefoon, laptop)
- v. **(dia 13)** Hoe wil je je voelen als je het exoskelet gebruikt en de informatie ziet die erdoor is verzameld? (zie woordenlijst) Als je drie woorden zou moeten kiezen van hoe je je wilt voelen, wat zouden dat dan zijn? **(dia 13)**
 - 1. Hoe zou je je NIET willen voelen? Kies opnieuw 3 woorden
- f. Wanneer ben je in het algemeen het meest trots op jezelf?

5. Closing

- a. **(slide 14)** Thank you! Any last comments/questions/concerns? **(slide 14)**
- b. *Last discussion points and anything they would like to bring up*
- c. Thank them for their time, and ask if they are interested in participating in future interventions
- d. **(dia 14)** Bedankt! Eventuele laatste opmerkingen / vragen / opmerkingen **(dia 14)**
- e. *Laatste discussiepunten en alles wat ze zouden willen noemen*
- f. Bedank hen voor hun tijd en vraag of ze geïnteresseerd zijn in deelname aan toekomstige interventies

Parent Interview Guide

The parents/caregivers have deep and prolonged observations and knowledge regarding their child's life and can give meaningful input as well. How can we best comfort and reassure them?

Overview:

Interview Plan		
Time	Action	Explanation/Checklist
A couple of weeks/days before the interviews	Recruitment	Invite interviewee through the males' contact ... or recruit via DPP
Day of interview: 5 min	Introduction	Explain what the goal of the interview is and introduce the exoskeleton/project goal
Day of interview: ~35 min	Conduct interviews	Gain qualitative input on the key topics discussed: Their role/expertise, their child/patient, and their views on physical activities and data
Day of interview: +-10 min	Discussion	If they have any other additions

INTRO:

Hello! My name is _____ and I am a _____ student at TU Delft that's currently working with Yumen Bionics for a project _____. Today I will be interviewing you for about 30 minutes so that you can help me understand a couple of key topics. Those topics include what role you play in your son's life, how you perceive your son's life in general (in terms of daily life and moving habits), and your current interactions with data products.

RQ 1: INTRO PARENT; How do the parents view their involvement in their child's life?

- **Sub-RQ 1.1:** What is your daily schedule? Are you able to spend all day long with your child or specific periods in time during the day?

- **Sub-RQ 1.2:** On a scale of 1-7 how independent do you think your child is?
 - (see how much they may or may not micromanage)
- **Sub-RQ 1.2:** On a scale of 1-7 how independent do you think your child wants to be?

RQ 2: INTRO TO THEIR SON; How do parents perceive their own child's life in terms of daily activities, environments, emotions, motivations, and network?

- **Sub-RQ 2.1:** What does a 'day in the life' look like for your child? (*ask this question if they weren't involved in the contextmapping session ... and then cross-check if their 'journey' matches the males'*)
 - Any activities they do on a daily basis?
 - likes/dislikes/challenges?
 - What assistive technologies do they use?
 - Any frustrations so far with those technologies?
- **Sub-RQ 2.2:** Regarding environments/settings, where does your child spend most of their time? (*e.g. in their room? Car? school? [this gives more info on the child's usual context]*)
 - What context/setting/environment do they feel most comfortable in?
- **Sub-RQ 2.3:** How does your son prefer to spend their time? (*e.g. with friends? Or alone?*)
 - Do they like meeting new people? Or being surrounded by the same circle of people?
- **Sub-RQ 2.4:** When does he feel most proud of himself?
- **Sub-RQ 2.5:** What are some moments in life that particularly frustrate him?

RQ 3: PHYSICAL MOVEMENTS; What are the physical movement habits/constraints a child has that are perceived by the parents?

- **Sub-RQ 3.1:** How do you currently moderate or make sure that your son physically moves (enough)?
- **Sub-RQ 3.2:** How do you and your family currently encourage your son to continue to move his muscles?
- **Sub-RQ 3.3:** Is there anything in particular that helps motivate your child to “keep going”/“keep moving”? (ex: *extrinsic rewards such as stickers, can watch more TV afterward, etc.*)

RQ 4: DATA; What are the parents’ desires when viewing/being involved with their child’s medical data?

- **Sub-RQ 4.1:** Outside of your usual work, what kind of data, regularly do you use/like to look into? (ex: *Apple Watch App, checking to see what the football scores are, checking the weather app, etc.*)
 - Why?
 - If we dive deeper, what features do you like and usually look into? ... or think are important?
 - What makes you want to look back at the *product/application* or use it again?
- **ACTIVITY 4.12: SHOW VIDEO OF EXOSKELETON -- explain also the overall goal of my project (designing motivational data)**
- **Sub-RQ 4.2:** As a parent, (and having in mind the capabilities of the exoskeleton), what kind of information are you interested in knowing about?
 - How much of it would you want to know?
 - How would this information be recorded? (*manually, via phone, laptop*)
 - **(slide 15)** How do you want your child to feel when using the exoskeleton and seeing the information that has been collected by it? (**see word list**) If you had to pick three words of how you would like them to feel, what would they be? (**slide 15**)
- **Sub-RQ 4.3:** To what extent do you want to be involved in managing your son’s health? (scale of 1-7, 7 meaning very involved)

ASK ANY REMAINING QUESTIONS GIVEN CONTEXTMAPPING SESSION WITH MALE

Closing

Thank you! Any last comments/questions/concerns

Last discussion points and anything they would like to bring up

Thank them for their time, and ask if they are interested in participating in future interventions



HS/R

Interview Guide

How can we optimally support the specialists' practices and the researchers' investigations?

Overview:

Interview Plan		
Time	Action	Explanation/Checklist
A couple of weeks/days before the interviews	Recruitment	Invite interviewee through the males' contact ... or email directly
Day of interview: 5 min	Introduction	Explain what the goal of the interview is and introduce the exoskeleton/project goal
Day of interview: ~35 min	Conduct interviews	Gain qualitative input on the key topics discussed: Their role/expertise, their child/patient, and their views on physical activities and data
Day of interview: +-10 min	Discussion	If they have any other additions

INTRO:

Hello! My name is _____ and I am a _____ student at TU Delft that's currently working with Yumen Bionics for a project _____. Today I will be interviewing you for about 30 minutes so that you can help me understand a couple of key topics. Those topics include what role you play in your patient's/male with DMD's life, how you perceive their life in general (in terms of daily life and moving habits), and your current interactions with any data products.

RQ 1: INTRO HEALTHCARE SPECIALIST/RESEARCHER (HS/R); How do the (HS/R) view their involvement in the males' life?

- As a _____ **insert expertise/current experience here** _____.... Can you tell me a little bit more about that? ... ('day in the life')

RQ 2: INTRO TO THEIR PATIENT; How do HS/R perceive their own patient's life in terms of emotions and motivations?

- **Sub-RQ 2.1:** What are some moments in life you know of, from experience, that makes the male feel proud of himself?
- **Sub-RQ 2.2:** What are some moments in life you know of, from experience, that particularly frustrates a male with DMD?
- **Sub-RQ 2.3:** On a scale of 1-7 how independent do you think males with DMD are (I know it depends on which stage they are in, but maybe how much in each)?
 - *Early ambulatory, late ambulatory, early non-ambulatory, late non-ambulatory*

RQ 3: PHYSICAL MOVEMENTS; What are the physical movement habits/constraints a child has that are perceived by the HS/R?

- **Sub-RQ 3.1:** How do you make sure that your patient moves (enough)? (*e.g. send encouraging texts Ask the parents to stay involved and encourage the child Keep in touch with the parents weekly.... etc.*)
- **Sub-RQ 3.2:** On estimate, how much should a boy move every day (to make sure that he is moving 'just enough')? (*ex: 15 min a day.... 5/7 days*)
- **Sub-RQ 3.3:** Any specific physical activities you think would be good for the boys to do?
- ****** ask further questions related to papers they have published/their expertise and experience**

RQ 4: DATA; What are the HS/R's desires when viewing/being involved with the male's medical data?

- **Sub-RQ 4.2:** Outside of your usual work, what kind of data, regularly do you use/like to look into? (*ex: Apple Watch App, checking to see what the football scores are, checking the weather app, etc.*)
 - Why?
 - If we dive deeper, what features do you like and usually look into? ... or think are important?
 - What makes you want to look back at the *product/application* or use it again?
- **ACTIVITY 4.22: SHOW VIDEO OF EXOSKELETON -- explain also the overall goal of my project (designing motivational data)**
- **Sub-RQ 4.3:** As a _____, and having in mind the capabilities of the exoskeleton, what kind of information are **you** interested in knowing about?
 - How much of it would you want to know?
 - How would this information be recorded? (manually, via phone, laptop)
 - **(slide 15)** How do you want your patient to feel when using the exoskeleton and seeing the information that has been collected by it? (**see word list**) If you had to pick three words of how you would like them to feel, what would they be? (**slide 15**)
- **Sub-RQ 4.4:** As a _____, if you had access to a male's health data, to what extent would you like to be involved in managing/viewing it? (*scale of 1-7, 7 meaning very involved*)
- **Sub-RQ 4.5:** Do you have any final advice or things I should take into consideration when designing a concept that will assist all stages of this disease?

Closing

Thank you! Any last comments/questions/concerns

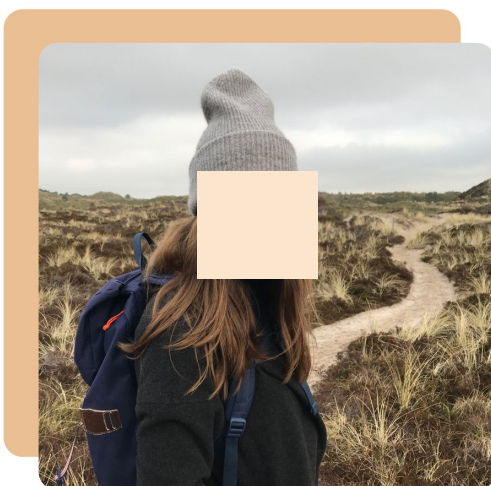
Last discussion points and anything they would like to bring up


Thank them for their time, and ask if they are interested in participating in future interventions

Welkom



Intro

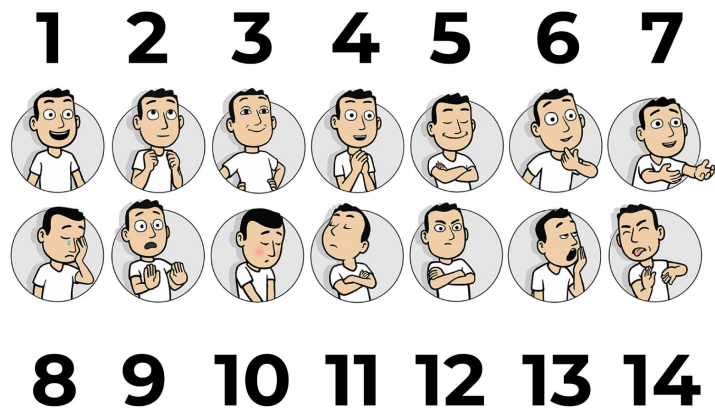


Hoi! Ik ben 
Ik hou van **dansen/**
wandelen.

Activity 1

Kun je me uitleggen?

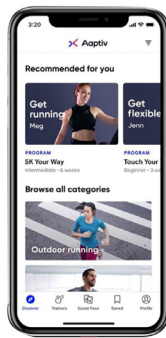
Activity 1



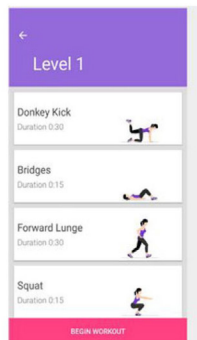
Activity 2



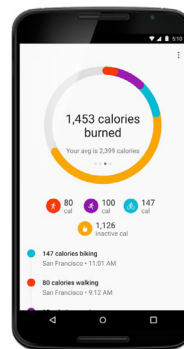
Activity 2



1

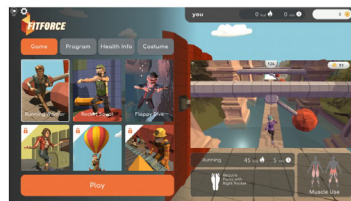


2



3

Activity 2



1



2

Activity 3



Activity 3

In balans	Schamen	Angstig	<i>Verbonden</i>	
	Gezond	Overweldigend	<i>Blij</i>	LEERGIERIG
LVI	Gefrustreerd	Zelfverzekerd	Eenzaam	Jammer
	Nieuwsgierig	Ontwijken	ACTIEF	Veilig
Gestrest	Aangemoedigd	Gewoonte	Jaloers	Teleurgesteld



BEDANKT!

Presentation Slides - For Other Stakeholders

Designing Motivational Data for Males with Duchenne Muscular Dystrophy

Interview - Intro Slides



Hello! ... and welcome

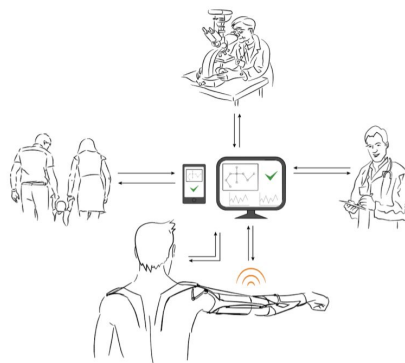


Main Project Topic

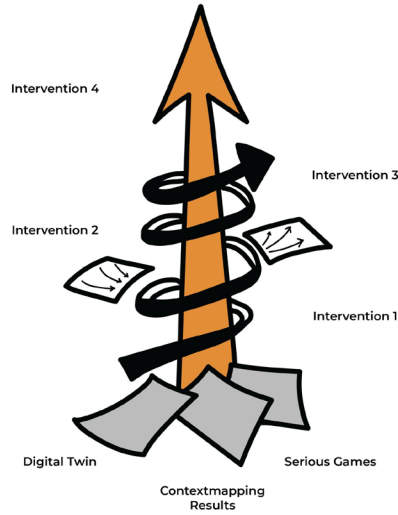
- Discover and test which data interaction scenario/visualization could **increase the quality of life of a** (10-20 year old) male with DMD
 - How can the scenario be intuitive and informative?
 - How can the scenario be motivational and engaging?
- How we can best encourage a male with Duchenne Muscular Dystrophy to engage with their medical data and motivate them to physically move “just enough”?



The Stakeholders



Turn arm movement data into a meaningful, motivational, and informative data interaction scenario



5

How you can help!

- What role you play in the male's life
- How you perceive the male's life in general (in terms of daily life and moving habits)
- Your current interactions with any data products

Any questions so far?

7

Balanced	Embarrassed	Fearful	<i>Connected</i>	
	Healthy	Overwhelmed	<i>Happy</i>	COMMITTED
LAZY	Frustrated	Confident	Lonely	Pity
	Curious	Avoid	ACTIVE	Safe
Stressed	Encouraged	Habit	Jealous	Disappointed

Appendix 4:

Consent Forms



Consent for Participation in Research Project

Hello!

I heard you're interested in helping out with my project! That's great -- I'm so excited to meet and talk with you online. Before we get started, please read some statements below:

1. I understand that during this project, Milla will explore how I can feel more motivated to physically continue to move my muscles.
2. In a couple of days, I will allow Milla to photograph, video, and/or audio-record our online meeting.
3. I will allow Milla to use photos and videos for her project reports and presentations. The photos will be blurred and your name will be stated differently; therefore, you will remain anonymous. These will only be used during her project.
4. The online meeting should last between 40 minutes - 1 hour.
5. I understand that my contribution to Milla's project is voluntary and I will mention immediately if I don't feel comfortable answering questions or if I have objections to answer a certain question. Also, I can stop the interview any time I want without any explanation.
6. I have read and understood the statements that are written above.
7. I will be given a copy of this consent form.

_____ My Signature _____ My Printed Name

_____ Date _____ Signature of the Researcher

For further information or questions, please contact: Milla Zlatanova (by email: ----- or by phone: -----) or Laura Koot (-----).

Thank you! Looking forward to working with you.

Toestemming deelname onderzoeksproject Milla Zlatanova

Hallo! Bedankt dat je mee wilt doen aan mijn project. Ik heb heel veel zin om je online te ontmoeten binnenkort. Daarvoor wil ik je vragen de volgende punten aandachtig te lezen:

1. Ik snap dat, gedurende dit project, Milla onderzoek doet naar de vraag: Wat motiveert jongens en mannen met de spierziekte van Duchenne om te bewegen en in beweging te blijven?
2. Tijdens het interview geef ik toestemming om het interview (video en/of audio) op te nemen. Deze opnames zullen alleen gebruikt worden voor Milla haar afstudeeronderzoek.
3. Ik geef toestemming dat Milla video's en foto's kan gebruiken voor haar rapport waar ik in onherkenbaar ben (gezicht zal vervaagd worden en een fictieve naam zal gebruikt worden)
4. Het interview duurt tussen de 40-60 minuten.
5. Ik begrijp dat mijn deelname vrijwillig is en ik zal onmiddellijk melden als ik bezwaren voel. Ik weet dat ik mag weigeren te antwoorden op een vraag en het interview zonder opgave van rede op elk moment mag stoppen.
6. Ik heb alle bovenstaande punten gelezen en begrepen.
7. Ik krijg een kopie van dit toestemmingsformulier.

_____ Mijn handtekening _____ Mijn gedrukte naam

_____ Datum _____ Handtekening van de onderzoeker

Voor meer informatie of vragen kunt u contact opnemen met: Milla Zlatanova (per e-mail: ----- of telefonisch: -----) of Laura Koot (-----).

Bedankt! Ik kijk er naar uit om met je te werken.



Consent for Child’s Participation in Research Project

Dear parent/guardian/caregiver,

Hello! Recently, your child has shown interest in participating in a research project conducted by Milla Zlatanova from TU Delft. She has partnered with Yumen Bionics for this project and is focusing on exploring how we can best encourage your child to engage with their medical data and motivate them to physically move “just enough”.

In this study, I will involve your child in “interesting interviews”, and hopefully further sessions/interventions that are planned to be held (if they are interested). Regarding the “interesting interviews”, I plan to host an online session that should last between 40 minutes - 1 hour. During the 1 hour, there will be a variety of creative design activities that will help me gain a better understanding of their daily life and their perceptions towards physical movement and information gathering (medical data).

Of course, if the child would like to end the interview at any time or earlier, they may do so. It is of utmost importance that they feel comfortable during the session. After the session finishes, the child will be asked if they would like to continue to work with me throughout the duration of my project.

The session will be photographed, video recorded, and audio taped; the pictures and videos will be used for Milla’s graduation project only. The photos will be blurred, and their names will be different in the report/presentations; therefore, your child will remain anonymous. If you consent to this workshop occurring and having your child participate in it, please fill out the following:

_____ My child’s name (Printed)

_____ My Signature _____ My Printed Name

_____ Date _____ Signature of the Researcher

For further information or questions, please contact: Milla Zlatanova (-----) or Laura Koot (-----). Thank you!

Toestemming voor deelname van kinderen aan onderzoeksproject

Beste ouder/verzorger/verzorger,

Hallo! Onlangs heeft uw kind interesse getoond om deel te nemen aan een onderzoeksproject van Milla Zlatanova van de TU Delft. Ze werkt voor dit project samen met Yumen Bionics en richt zich op het onderzoeken hoe we uw kind het beste kunnen aanmoedigen om met hun medische gegevens om te gaan en hen te motiveren om "net genoeg" fysiek te bewegen.

In dit onderzoek zal ik uw kind betrekken bij "interessante interviews", en hopelijk verdere sessies/interventies die gepland staan (indien ze geïnteresseerd zijn). Wat betreft de "interessante interviews", ben ik van plan een online sessie te organiseren die tussen de 40 minuten en 1 uur duurt. Gedurende het 1 uur zullen er verschillende creatieve ontwerpactiviteiten zijn die me zullen helpen een beter begrip te krijgen van hun dagelijks leven en hun perceptie van fysieke beweging en het verzamelen van informatie (medische gegevens).

Als het kind het interview op een bepaald moment of eerder wil beëindigen, kan dat natuurlijk. Het is van het grootste belang dat ze zich op hun gemak voelen tijdens de sessie. Na afloop van de sessie wordt het kind gevraagd of het met mij wil blijven werken gedurende de duur van mijn project.

De sessie wordt gefotografeerd, op video opgenomen en op geluidsband opgenomen; de foto's en video's worden alleen gebruikt voor onderzoeksdoeleinden. Als u ermee instemt dat deze workshop plaatsvindt en uw kind hieraan deelneemt, vul dan het volgende in:

_____ De naam van mijn kind (gedrukt)

_____ Mijn handtekening _____ Mijn gedrukte naam

_____ Datum _____ Handtekening van de onderzoeker

Voor meer informatie of vragen kun je contact opnemen met: Milla Zlatanova (-----) of Laura Koot (-----). Bedankt!

Toestemming voor deelname aan interviewonderzoek

Ik heb vrijwillig deelgenomen aan een onderzoeksproject van Milla Zlatanova van de TU Delft. Ik begrijp dat ze voor dit project samenwerkt met Yumen Bionics en zich concentreert op het onderzoeken hoe we een man met Duchenne spierdystrofie het beste kunnen aanmoedigen om met hun medische gegevens om te gaan en hen te motiveren om "net genoeg" te bewegen. In dit onderzoek zul je betrokken worden bij een interview, en hopelijk verdere sessies/interventies die gepland staan (als je geïnteresseerd bent). Lees het volgende:

1. Mijn deelname aan dit project is vrijwillig. Ik kan de deelname op elk moment zonder boete intrekken en beëindigen. Dat kan door contact op te nemen met Milla Zlatanova per e-mail (-----) of telefonisch (-----)
2. Ik begrijp dat als ik me op wat voor manier dan ook ongemakkelijk voel tijdens de interviewsessie, ik het recht heb om te weigeren een vraag te beantwoorden of het interview te beëindigen.
3. Het interview (online/videogesprek) duurt ongeveer 45 minuten. Tijdens het gesprek worden aantekeningen gemaakt. Een geluidsband en video-opname van het interview zal later door Milla worden gemaakt en geanalyseerd. Als ik niet opgenomen wil worden, laat ik Milla dat vooraf weten. Zij zal ook vlak voor aanvang van het gesprek om uw mondelinge toestemming vragen.
4. Ik begrijp dat de informatie die ik verstrek en de opgenomen beelden zullen worden gebruikt voor rapporten, publicaties, websites en documentatie en ook voor interne communicatie met het onderzoeks- / Yumen Bionics-team. U kunt ook met Milla bespreken of u wilt dat bepaalde informatie die uit dit interview is verkregen vertrouwelijk is -- of als u tijdens de documentatie anoniem wilt blijven..
5. Ik begrijp dat ik Milla mogelijk kan blijven helpen door mijn feedback te geven in toekomstige vergaderingen. Milla zal vragen of je hierin geïnteresseerd bent.
6. Ik heb de bovenstaande uitleg die aan mij is verstrekt, gelezen en begrepen. Ik heb al mijn vragen naar tevredenheid beantwoord en ik stem nog steeds vrijwillig in met deelname aan dit onderzoek.
7. Ik krijg een kopie van dit toestemmingsformulier.

_____ Mijn handtekening _____ Mijn gedrukte naam
_____ Datum _____ Handtekening van de onderzoeker

Voor meer informatie of vragen kun je contact opnemen met: Milla Zlatanova (-----) of Laura Koot (-----). Dank u! Ik kijk er naar uit om met je te werken.

Appendix 5: Recruitment Flyer

Ben je een jongen van 10-20 jaar of een ouder van een jongen van 10-20 jaar?

Wat **motiveert** jou om te bewegen en om in beweging te blijven?



Wat voor soort **lichamelijke activiteit** doe jij gewoonlijk (alleen en met een fysiotherapeut)? Wat vind je **wel en niet leuk** aan beweging?



Ben je geïnteresseerd in het **volgen van je dagelijkse activiteiten** ?



Hallo, ik ben Milla, en ik studeer Industrieel Ontwerpen aan de TU Delft. Dit zijn het soort vragen die ik graag samen met jou zou willen beantwoorden voor mijn afstudeerproject. Ik ben erg **benieuwd wat je motiveert om te bewegen ...** en wat je motiveert om in **beweging te blijven** .



Ik werk samen met Yumen Bionics aan mijn project; deze startup maakt momenteel een **wearable / exoskelet** dat armbewegingen ondersteunt en kan gegevens verzamelen van armbewegingen. Met jouw hulp hoop ik te ontdekken **hoe we die data het beste kunnen weergeven aan jou!**



Ik hoop een aantal van de bovenstaande vragen te beantwoorden door middel van **online activiteiten** die bestaan uit een **interview** en **kleine dagboek-oefeningen** .

- **3 kleine, dagelijkse dagboek-oefeningen** die je moet doen voor het leuke interview'. Dit duurt niet langer dan 10 minuten per oefening.
- **Een interview van 1-1,5 uur** zodat we samen de onderwerpen kunnen verkennen.



Als je geïnteresseerd bent om deel te nemen, neem dan contact op met Laura Koot: laura.koot@yumenbionics.com (**Nederlands**) of mij, Milla: milla.zlatanova@yumenbionics.com (**English**)

Engels is de voorkeurstaal voor de gesprekken, maar mocht u hier niet comfortabel mee zijn, kan het ook in het Nederlands.

Dankjewel! Ik kijk ernaar uit om met jou/u/jullie in contact te komen.



Appendix 6:

Remaining Stakeholder Findings

A. PARENT

a. ACTIONABLE INSIGHTS/REMINDERS

- i. 2/2 would like to know if their child is moving too much or too little
 - 1. “What you don’t want to know, but what is important is if something stops or goes worse or is not possible anymore ... if they have used it too much or too little” - Parent of 17 year old
- ii. “The kind of movement that is enough for his age to be healthy.” - Parent of 11-year-old

b. OVERVIEW SUBFEATURES

- i. times/amount moved throughout the day
- ii. the specific movements made

c. SUBJECTIVE DATA

- i. 2/4 would like to have some sort of “sentiment analysis”
 - 1. “For us, it’s more, ‘Is he happy? Can he do what he can do? Is it helping him? Or is it more frustrating him?’” - Parent of 17 year old

d. CONNECTING:

- i. P - being able to connect with healthcare specialists and ask for advice

B. HEALTHCARE SPECIALIST

a. ACTIONABLE INSIGHTS/REMINDERS

- i. ⅔ would like to know if their patients are moving too much or too little

b. OVERVIEW SUBFEATURES

- i. ⅔ would like to know joint mobility and muscle strength
 - 1. “I would love to know what kind of angles the joints will reach every day and how often, because we believe that they develop contractures. We believe that because these Duchenne boys don’t have enough power and they don’t

reach their end range of motion, that they will become contracted.” - Pediatric physiotherapist

- ii. $\frac{2}{3}$ would like to see the extensions and range of motion
 - 1. “So if it can measure on a daily basis, how often an arm is moved between what kind of ranges... and what the end ranges are? That would be really interesting... that could help explain why contractions may develop.” - pediatric rehabilitation doctor
 - 2. “I would like to know something because you're always afraid of, of developing contractures... especially in the elbow. It's always the elbow that limits the boys also in their performances.” - pediatric rehabilitation doctor
 - iii. $\frac{3}{3}$ would like to know the times and amount moved throughout the day
 - iv. The specific movements made / how the level of their arms is changing
- c. SUBJECTIVE DATA
- i. “We should find out WHY they are not active.” - pediatric rehabilitation doctor
- d. CONNECTING:
- i. Ability to advise physiotherapist and parent

C. RESEARCHER

- a. ACTIONABLE INSIGHTS/REMINDERS
 - i. $\frac{2}{4}$ would like to know if the males are moving too much or too little
- b. OVERVIEW SUBFEATURES
 - i. R - times/amount moved throughout the day/how often is it used
 - ii. the specific movements made / activities done (where they use it)

- iii. raw joint angles
 - iv. how the level of their arms is changing
 - v. Exo Specifics, as noted by Yumen Bionics' sensor/electronics engineer
 - 1. if sensors are functioning properly/correctly (which device it is)
 - 2. who the exoskeleton belongs to
 - 3. error codes and understanding what part of the exoskeleton needs fixing, if need be
 - 4. damage to springs/elastics
 - 5. see at what points muscles are getting weaker so that stronger elastics may be recommended to the user
 - 6. see if the left and right sides of the exoskeleton are functioning well
- c. CONNECTING, COMPARING, AND OPTIMIZING FEEDBACK AND COMMUNICATION:
- i. 2/4 would like to keep in touch with the user to
 - 1. "I think it's also really necessary for a two-way communication so that the user can say, 'I'm experiencing this and that'" - YB design engineer
 - ii. Measure and compare patients in different stages of the disease, and compare to healthy controls and DMD patients
 - 1. "It'd be interesting to see if they do indeed do less physical activity, or maybe they even do more with their arms because they are in a wheelchair... who knows." - post-doc researcher
- d. SUBJECTIVE DATA
- i. 2/4 would like to have some sort of "sentiment analysis"
 - 1. "It's not only the measurable data but also the experience."
 - 2. ¼ was particularly interested in a "how are you feeling score"/pain or stiffness score
 - 3. ¼ would like to know when the males feel fatigued.
 - a. "Collect subjective scores on experienced fatigue, so you can relate the amount of activity to how people are feeling and in terms of fatigue get a sense of

when they are doing too much and when they could
have done a little more.” - post-doc researcher

Intervention 1: Appendices

Appendix 7:

Interview Guide and Presentation Slides

RESEARCH GOALS:

- 1.) Gain insight regarding which medical data visualization(s) (Serious Game vs Digital Twin) provokes the most interest and why.
- 2.) Understand how they feel while looking through the potential data scenarios -- and how they WANT to feel while using it.
- 3.) Foster a participatory design session after sharing 7 potential concepts.
- 4.) Confirm which user requirements are crucial and pinpoint any additional requirements that were not mentioned during the contextmapping session.
- 5.) Understand user expectations regarding some UI elements

PARTICIPANTS:

- 3 males with DMD (15, 17, and 30 years old)
- 1 teenage girl (17 years old)

GENERAL SET-UP:

- Method: User Test and Participatory Design Session
- Each participant:
 - Gets an idea of what each of the seven concepts entailed
 - With each participant, the order of concepts shown was alternated to avoid "order effects"
- After experiencing each concept:
 - Identify within both DT and SG categories which concepts were most intriguing

- Wrap-up/data collection
 - Qualitative comparison of all 7 concepts/final discussion and thoughts
-

Activity 1 - What I've learned from them/intro:

- **A quick intro to researcher**
- **SLIDE 2: Have them read through a consent form and verbally consent/'sign'**
- **Record session**

SLIDE 3: Remember when we met a couple of weeks ago? ... and we made this? **show original CM timeline*

Well, I met with you and some other people and learned that you have health-related movements that you do and personal-related movements that you do. Can you explain to me what you think I mean by that?

understand if they differentiate between the two

SLIDE 4: *Explain difference*

So... it seems like you have some personal-related movements you already do _____*INSERT PR MOVEMENTS FOUND IN CM SESSION ...* _____

- Participant1: eating breakfast by himself, play the Super Smash Brothers game... go outside ... writing your exam
- Participant2: getting a good coffee in town, playing with your dog, gaming, creating with Legos
- Participant3: swimming, laser cutting, working with your laptop a lot as a designer
- Participant4: watch videos on Youtube, listen to music, eat, drink

SLIDE 5: On the other hand, health-related movements are...

SLIDE 6: Both of these types of movements are super important for you to do and continue to do so that your muscles remain strong! Now, we will try to also focus on supporting you to do more health-related movements by yourself.

SLIDE 7: Given what I have learned from you and others, and to summarize what my project is all about, I would like to see how the exoskeleton + a mobile application can support you in doing both these two types of movements more every day.

Remember, there are no right or wrong answers during this session -- please be as honest as possible once I do start showing you some designs.

Activity 2 - Serious Game:

SLIDE 8: The exoskeleton can collect when you move your arms and the mobile application can help show this information to you.

SLIDE 9: Here is a timeline of what your day might look like once we create the visualization.

The first possible way of visualizing your arm movement and your progress can be done with a game. Now I will show you an example timeline during your daily life where you can possibly fit in the game and take some time to play it.

**GO THROUGH TIMELINE*

SLIDE 10: What are your thoughts about this potential schedule?

SLIDE 11: Now, I have prepared three examples of how the game could look like.

The first concept is this

.... One thing I'd like to add is that the final app design will NOT look exactly like this. These are just examples of what it could look like.

- What do you think this icon means? (top right settings)
- What do you expect to see when you click on this first bottom left icon? Middle? Right?
- What do you think H and P stand for?

SLIDE 12: The second concept is this

SLIDE 13: The third concept is this

SLIDE 14: Here are all the concepts again. Now, can you please rate them from your most favorite to your least favorite?

SLIDE 15: Why is this one your most favorite? Least?

SLIDE 16:

- How do you feel when looking at these concepts?
 - How do you want to feel?
-

Activity 3 - Digital Twin:

SLIDE 17:

Now I will show you some other ways in which we can visualize your arm movement data -- and an example timeline during your daily life where you can possibly fit it in and use it

SLIDE 18: What are your thoughts about this potential schedule?

SLIDE 19: Now, I have prepared three concepts of how this visualization could look like:

The first concept is this

SLIDE 20: The second concept is this

SLIDE 21: The third concept is this

SLIDE 22: Here are all the concepts again. Now, can you please rate them from your most favorite to your least favorite?

SLIDE 23: Why is this one your most favorite? Least?

SLIDE 24:

- How do you feel when looking at these concepts?
 - How do you want to feel?
-

Activity 4 - Comparative Analysis/Participatory Design Session

SLIDE 25:

- PICK TOP 3:
 - Looking at all of these once again, which one would motivate you the most to make sure you do both your personal and health-related movements daily?
 - Can you please explain why again?
- Do you have any other recommendations or anything else you know you would like to see in the app?

Presentation Slides - For Males

WELCOME

!!



Consent for Participation in Intervention

- 1.) I understand that during this project, Milla will explore how I can feel more motivated to physically continue to move my muscles.
- 2.) I will allow Milla to photograph, video, and/or audio-record our online meeting.
- 3.) I will allow Milla to use photos and videos for her project reports and presentations. The photos will be blurred and your name will be stated differently; therefore, you will remain anonymous. These will only be used during her project.
- 4.) The (online) meeting should last between 40 minutes - 1 hour.
- 5.) I understand that my contribution to Milla's project is voluntary and I will mention immediately if I don't feel comfortable answering questions or if I have objections to answer a certain question. Also, I can stop the interview any time I want without any explanation.
- 6.) I have read and understood the statements that are written above.
- 7.) If I consent to help with this project, then I will give Milla a verbal confirmation (for example, you may say, "I agree with these statements, Milla.")

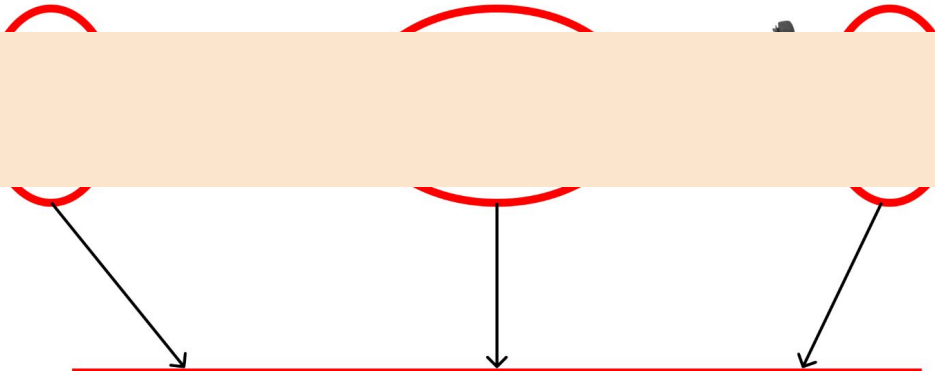
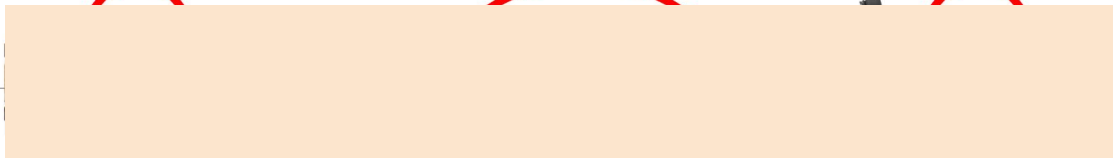
Activity 1: What I Learned From You!



* personalized timeline goes here *

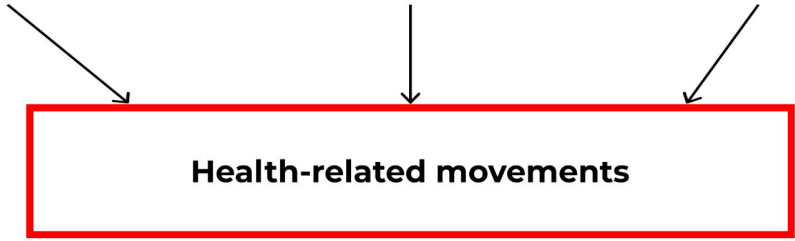


Activity 1: What I Learned From You!

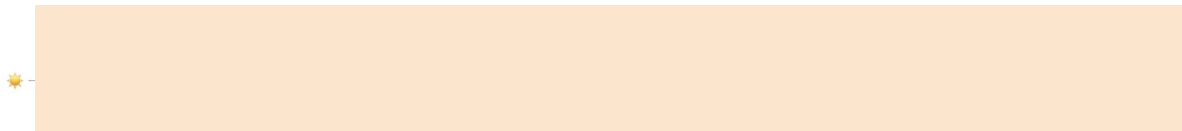


Personal-related movements

Activity 1: What I Learned From You!

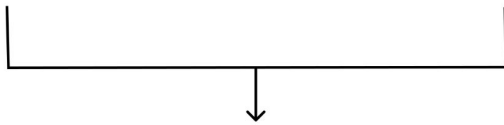


Activity 1: What I Learned From You!



Personal-related movements

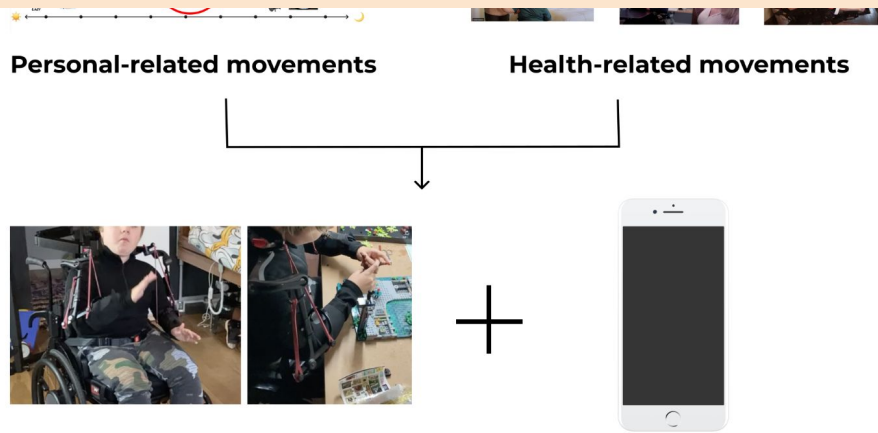
Health-related movements



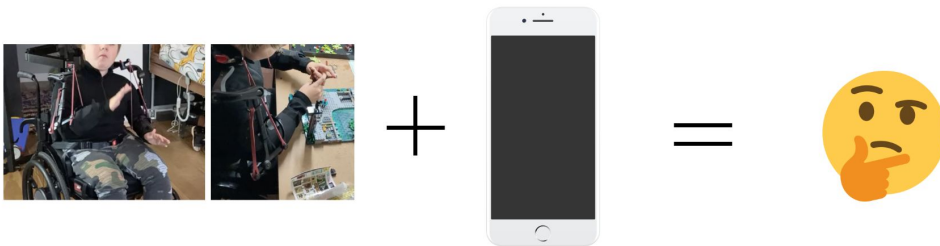
Both are important! 😊



Activity 1: The Goal of My Project



Activity 2: Goal



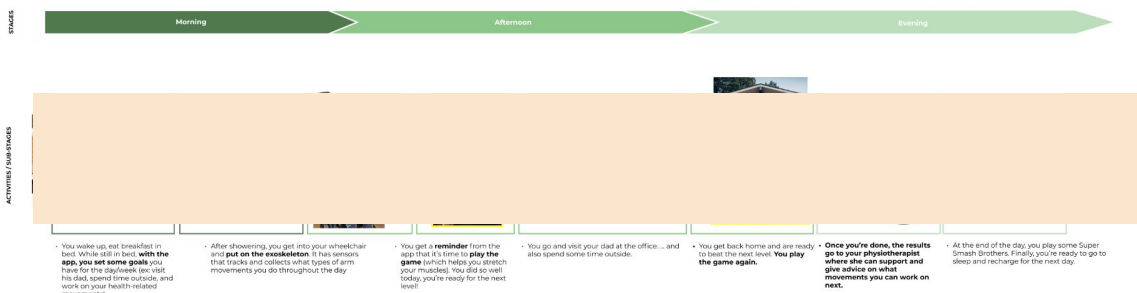
Activity 2: A Game/Timeline

A Day in the Life of [] - Playing the Game - Interaction Scenario



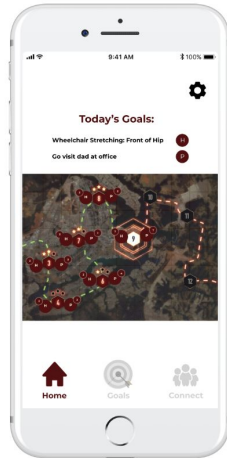
Activity 2: A Game/Timeline

A Day in the Life of [] - Playing the Game - Interaction Scenario



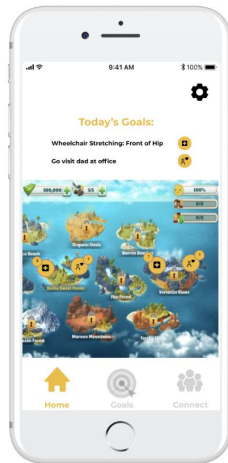
What are your thoughts about this potential daily schedule?

Activity 2: The Road, Concept 1



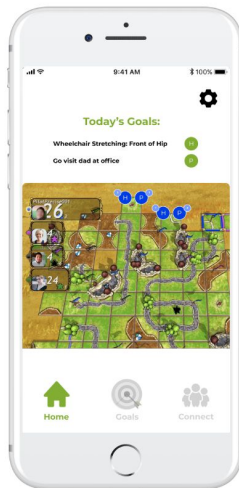
- **unlock** new levels the more you do personal and health-related movements
- go **“up the mountain”**
- **challenge your friends and family** to also move!

Activity 2: The Islands, Concept 2



- **unlock** new levels the more you do personal and health-related movements
- **travel around** different islands/countries, **build** something on the island
- earn **in-game currency**

Activity 2: The Tiles, Concept 3



- **unlock** new levels the more you do personal and health-related movements
- **look at other peoples' scores**
- earn **points**

Activity 2: The Game, All Concepts



- **unlock** new levels
- go **"up the mountain"**
- **challenge your friends and family** to also move!



- **unlock** new levels
- **travel around** different islands/countries, **build** something on the island
- earn **in-game currency**



- **unlock** new levels
- **look at other peoples' scores**
- earn **points**

1.) Rate these concepts from your most favorite (1) to your least favorite (3)

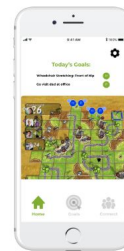
Activity 2: The Game, All Concepts



- **unlock** new levels
- go **"up the mountain"**
- **challenge your friends and family** to also move!



- **unlock** new levels
- **travel around** different islands/countries, **build** something on the island
- earn **in-game** currency



- **unlock** new levels
- **look at other peoples' scores**
- earn **points**

2.) Why?

3.) Any other ideas you might have in mind?



Activity 2: The Game, All Concepts

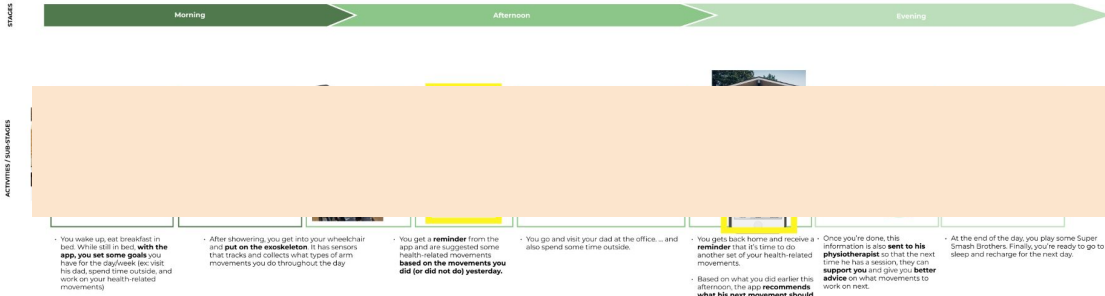


1	2	3	4	5	6	7
8	9	10	11	12	13	14



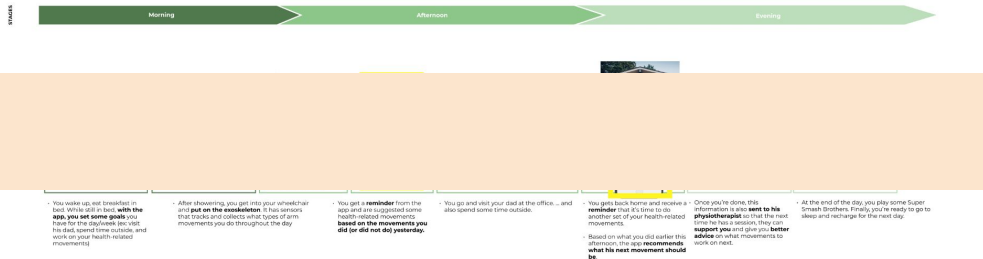
Activity 3: The Twin/Timeline

A Day in the Life of [] - Playing the Game - Interaction Scenario



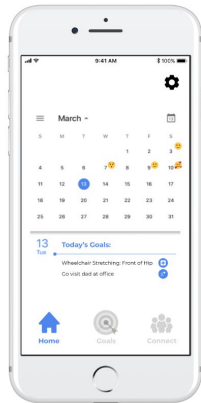
Activity 3: The Twin/Timeline

A Day in the Life of [] - Playing the Game - Interaction Scenario



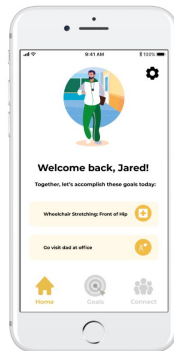
What are your thoughts about this potential daily schedule?

Activity 3: The Overview, Concept 1



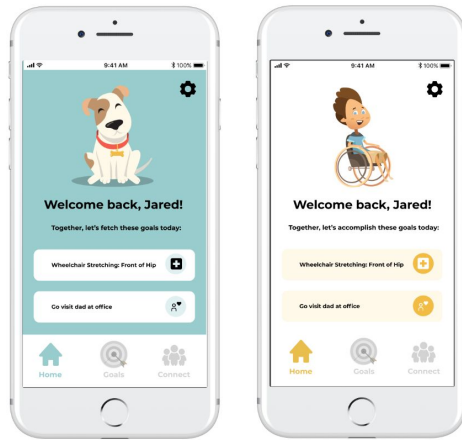
- **track your progress** when you do personal and health-related movements
- have a **calendar overview**
- instantly view how you were **feeling** on a specific day

Activity 3: The Coach, Concept 2



- **track your progress** when you do personal and health-related movements
- have a **personal coach** to support you when doing the movements
- instantly view your **agenda** for the day

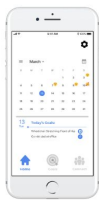
Activity 3: The Pal, Concept 3



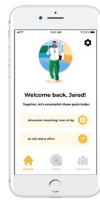
- **track your progress** when you do personal and health-related movements
- have a pal (**animal or character**) to support you when doing the movements
- instantly view your **agenda** for the day



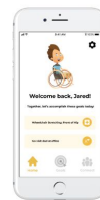
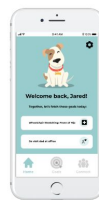
Activity 3: The Twin, All Concepts



- **track your progress**
- have a **calendar overview**
- instantly view how you were **feeling** on a specific day



- **track your progress**
- have a **personal coach** to support you when doing the movements
- instantly view your **agenda** for the day

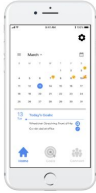


- **track your progress**
- have a pal (**animal or human**) to support you when doing the movements
- instantly view your **agenda** for the day

1.) Rate these concepts from your most favorite (1) to your least favorite (3)



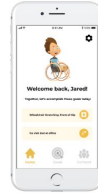
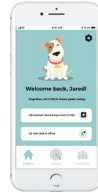
Activity 3: The Twin, All Concepts



- track your progress
- have a calendar overview
- instantly view how you were feeling on a specific day



- track your progress
- have a personal coach to support you when doing the movements
- instantly view your agenda for the day



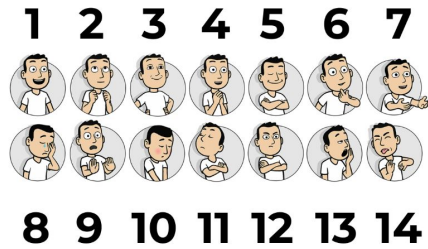
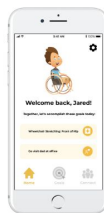
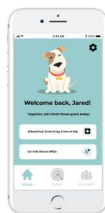
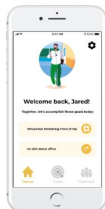
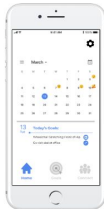
- track your progress
- have a pal (animal or human) to support you when doing the movements
- instantly view your agenda for the day

2.) Why?

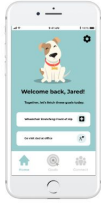
3.) Any other ideas you might have in mind?



Activity 3: The Twin, All Concepts



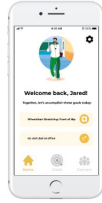
Activity 4: Conclusion



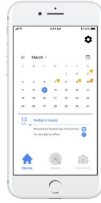
1



2



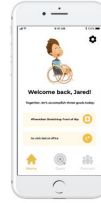
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4



5



6



7

Thank you for your help!



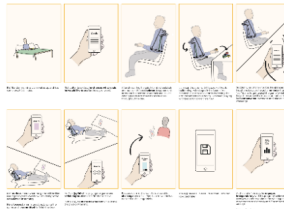
Intervention 2: Appendices

Appendix 8: Brainstorm

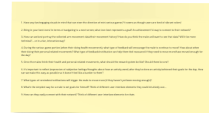
SUB-FUNCTIONS

Fun/Engaging Visuals	Have any fun/engaging visuals in mind that can steer the direction of mini-serious games? It seems as though users are fond of vibrant colors!
Menu Navigation	Bring in your best icons! In terms of navigating to a next screen, what icon best represents a goal? An achievement? A way to connect to their network?
Informative Overview/ Movement History	How can we best portray the collected arm movement data/their movement history? How do you think the males will want to see that data? Will it be more technical?... or in a fun, interactive way?
Receiving Feedback	During the serious game portion (when they're doing health movements), what type of feedback will encourage the male to continue to move? How about when they're doing their personal-related movements? What type of feedback/notification can help them feel reassured if they need to move more/have moved enough for the day?
Reward System	Once the males finish their health and personal-related movements, what should the reward system be like? Should there be one?
Supporting a Reflection Moment	It's important to reflect (expression of subjective feelings/thoughts about how an activity went) after they've done an activity/achieved their goals for the day. How can we make this easy as possible so it doesn't feel like a burden to them?
Receiving Reminders	What types of reminders/notifications will trigger the male to move more (if they haven't yet been moving enough)?
Setting Goals	What's the simplest way for a male to set goals for himself? Think of different user interface elements they could intuitively use...
Connecting with Others	How can they easily connect with their network? Think of different user interface elements for chats

I want to help males with Duchenne Muscular Dystrophy between ages 10-20 increase their sense of autonomy and feel more motivated to engage with their everyday personal life and health movement activity data (especially when doing at home stretches).



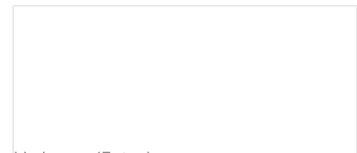
MAIN QUESTIONS/CATEGORIES



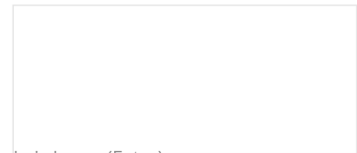
Morphological Chart - Original



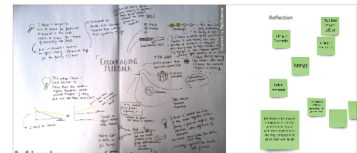
A's Inspo (Extra)



L's Inspo (Extra)



Lo's Inspo (Extra)



M's Inspo (Extra)



Extra Brainstorm Ideas (Team)



SUB-FUNCTIONS

		POTENTIAL SOLUTIONS							
Fun/Engaging Visuals	Have any fun/engaging visuals in mind that can steer the direction of this system game? (Seems as though users are fond of abstract colors)								
Menu Navigation	Bring in your best icons in terms of navigating to a next screen, what can best represent a goal? An achievement? A way to connect to their network?								
Informative Overview/ Movement History	How can we best portray the collected arm movement data/their movement history? How do you think the layout will need to be that ideal? (It'll be more technical... or in a fun, interactive way?)								
Receiving Feedback	Being in your game panel when their step counts movements showed? (How can we represent a reward moment? What type of feedback can we have when they reach their goal? How can we represent it?)								
Reward System	Once the users finish their health and personal-related movements, what should the reward system be like? Should there be one?								
Supporting a Reflection Moment	It's important to reflect on progress of subjective feedback/insights about how an activity went after they've done an activity/achieved their goals for the day. How can we make this easy or possible or doesn't feel like a burden to them?								
Receiving Reminders	What types of reminders/notifications will trigger the user to move more if they haven't yet been moving enough?								
Setting Goals	What's the simplest way for a user to set goals for himself? Think of different user interface elements they could interact with...								
Connecting with Others	How can they easily connect with their network? Think of different user interface elements for chats								

SUB-FUNCTIONS

		POTENTIAL SOLUTIONS							
Fun/Engaging Visuals	Have any fun/engaging visuals in mind that can steer the direction of this system game? (Seems as though users are fond of abstract colors)								
Menu Navigation	Bring in your best icons in terms of navigating to a next screen, what can best represent a goal? An achievement? A way to connect to their network?								
Informative Overview/ Movement History	How can we best portray the collected arm movement data/their movement history? How do you think the layout will need to be that ideal? (It'll be more technical... or in a fun, interactive way?)								
Receiving Feedback	Being in your game panel when their step counts movements showed? (How can we represent a reward moment? What type of feedback can we have when they reach their goal? How can we represent it?)								
Reward System	Once the users finish their health and personal-related movements, what should the reward system be like? Should there be one?								
Supporting a Reflection Moment	It's important to reflect on progress of subjective feedback/insights about how an activity went after they've done an activity/achieved their goals for the day. How can we make this easy or possible or doesn't feel like a burden to them?								
Receiving Reminders	What types of reminders/notifications will trigger the user to move more if they haven't yet been moving enough?								
Setting Goals	What's the simplest way for a user to set goals for himself? Think of different user interface elements they could interact with...								
Connecting with Others	How can they easily connect with their network? Think of different user interface elements for chats								

Concept 1 - Buddy the Dog

- emphasizes on informational and motivational affordances

Concept 2 - ActiFriends

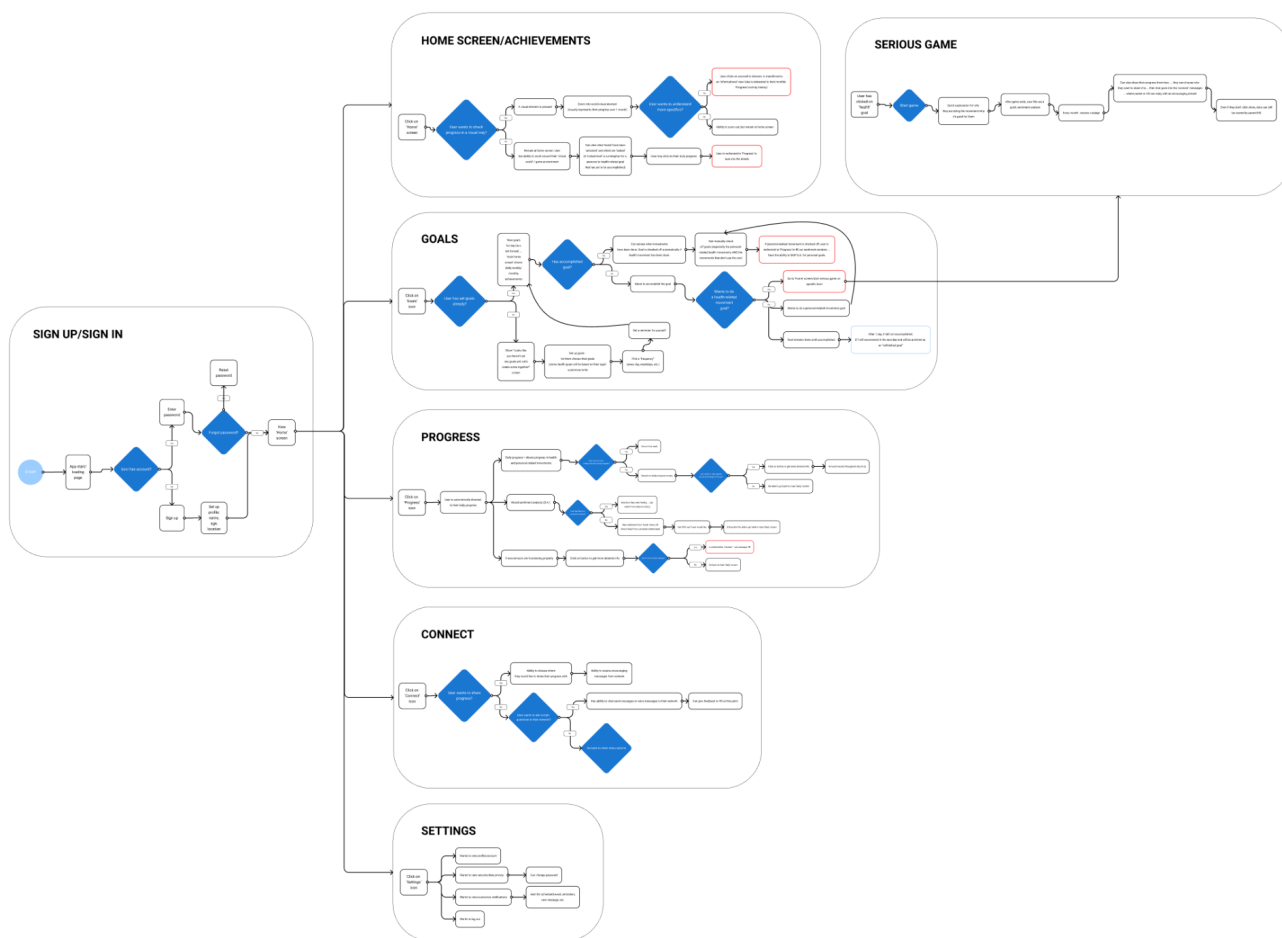
- emphasizes on informational and social elements/ motivational affordances

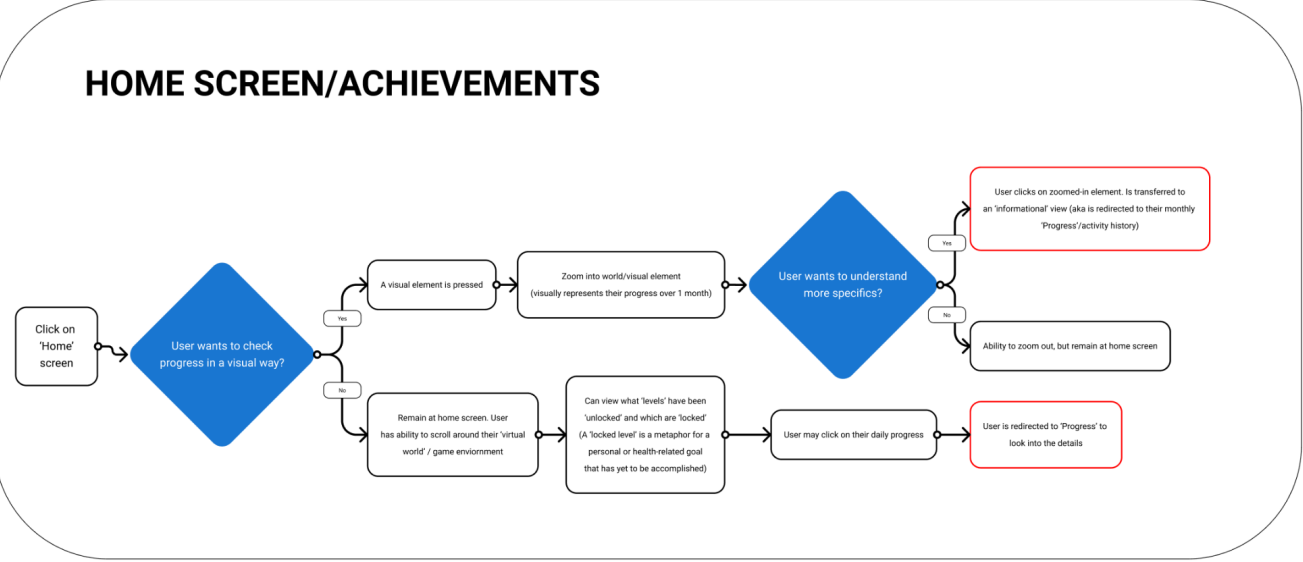
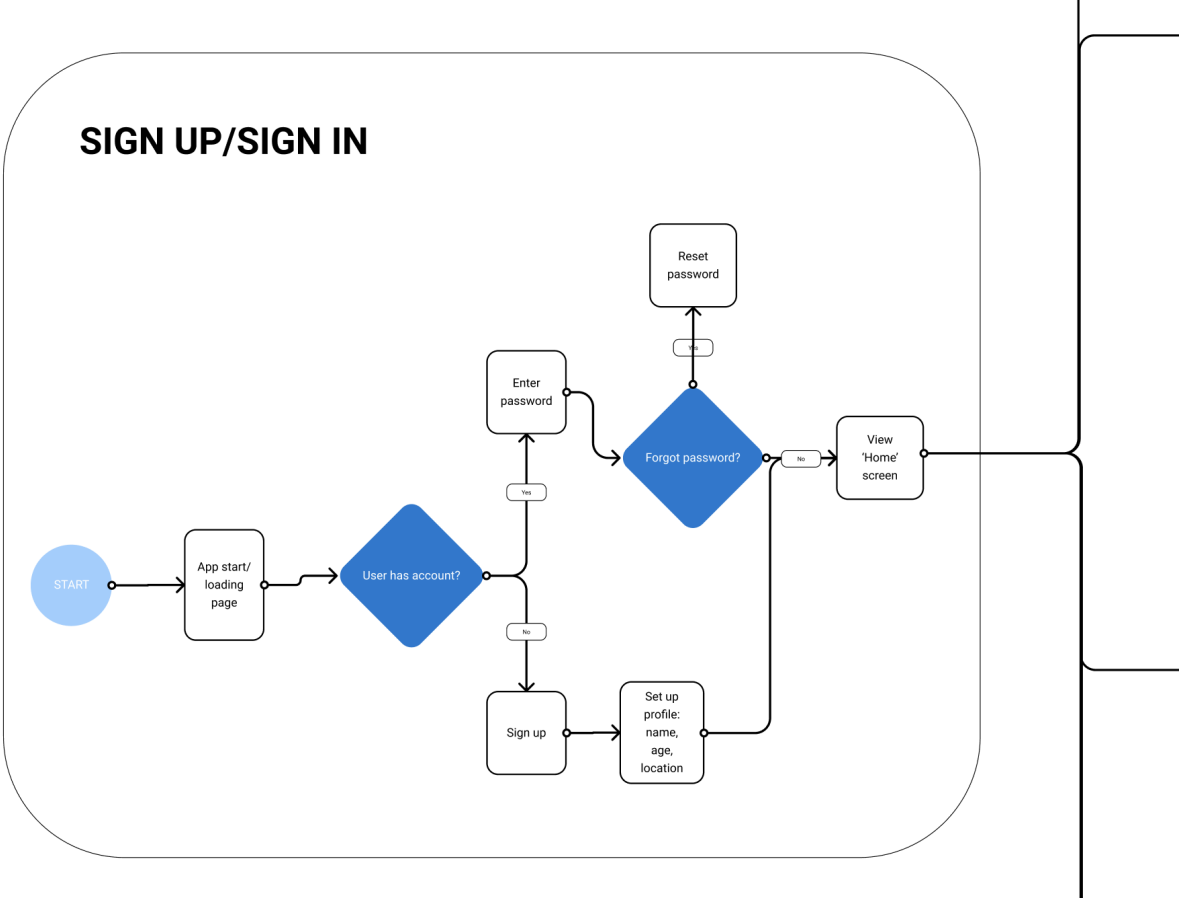
Concept 3 - Peter the Pal

- emphasizes on informational and playful interactions/more engagement with the DT (motivational affordance)

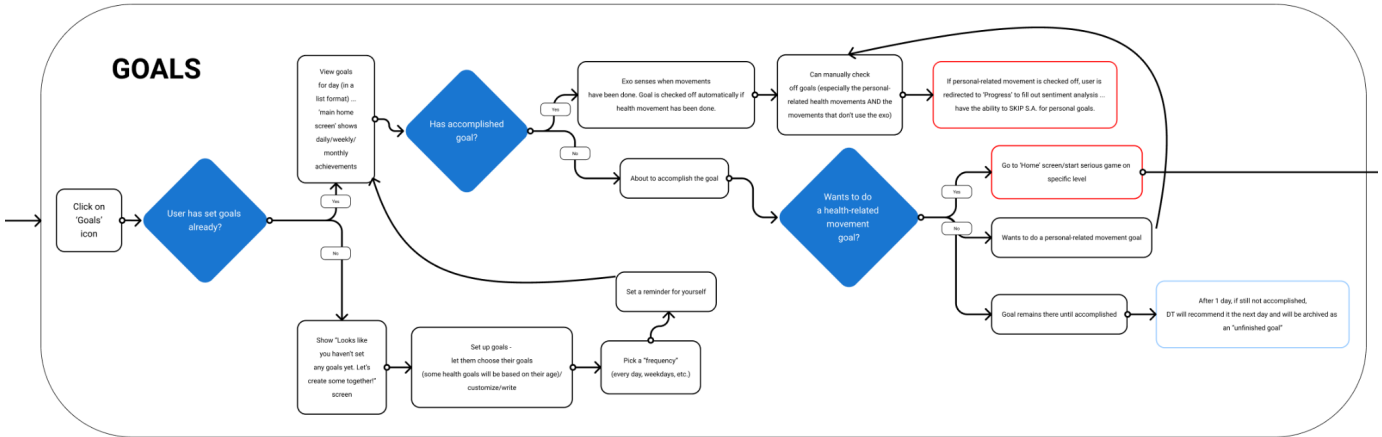
All Concepts

Appendix 9: User Flows

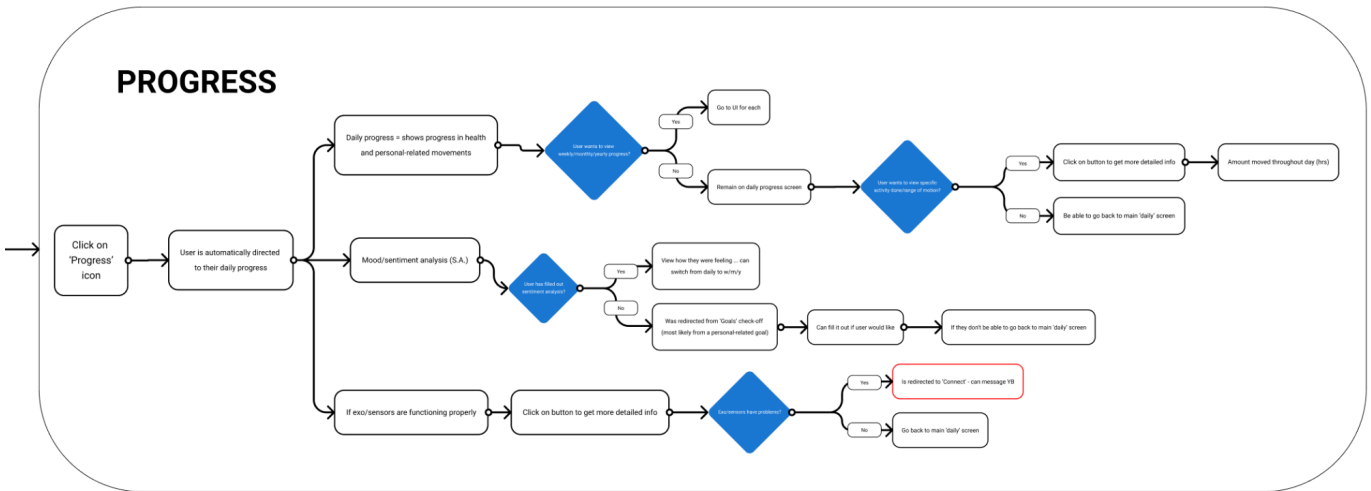




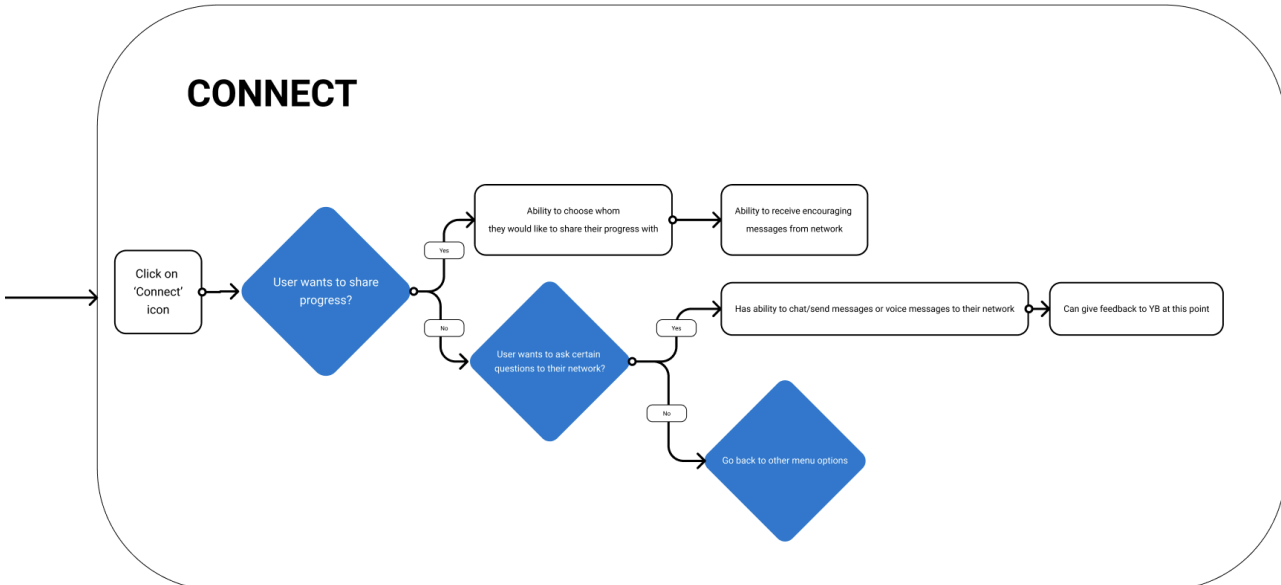
GOALS



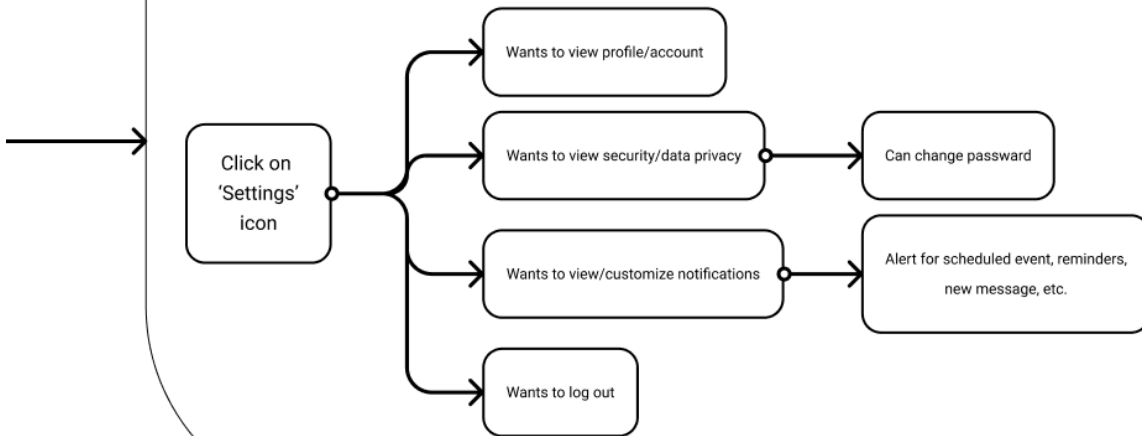
PROGRESS



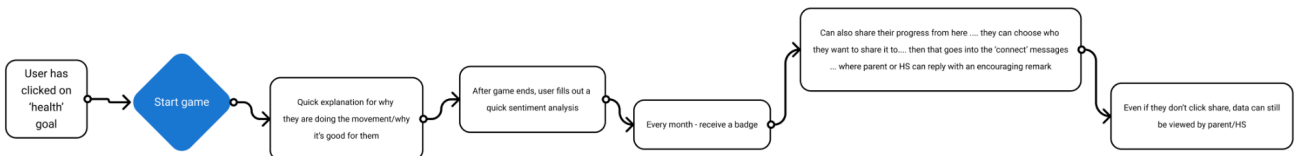
CONNECT



SETTINGS



SERIOUS GAME



Appendix 10:

Test Scenarios, Interview Guide, and Presentation Slides

RESEARCH GOALS/QUESTIONS:

- Obtain an understanding of the participant's experience when using the prototype and how it may (or may not) connect to the Design Goal and Interaction Vision.
 - Is the intended effect close to being reached?
- Test overall layout, look and feel, and **intuitiveness/interactivity** of prototypes and identify any interface issues that need optimizing
 - This will help understand if they can autonomously use the product
- What kind of **presence/character of the data** supports the feelings of **autonomy** the most?
- What kind of presence/character of the data seem to **motivate** them?
 - What UI elements/ideas are the most "memorable"?
- What (data/interface elements) are they missing?

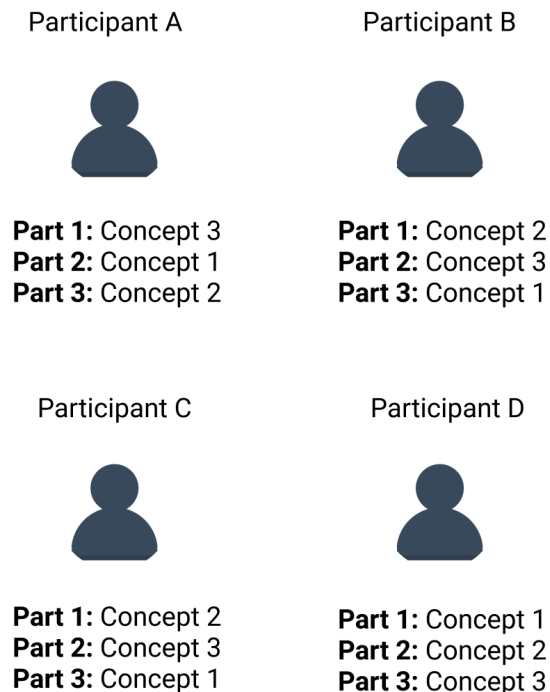
PARTICIPANTS:

- 2 designers (1 YB designer did not do the test, only gave initial feedback. Another did the test and has previously worked with males with DMD)
- 2 males with DMD
- 1 teenage boy

GENERAL SET-UP:

- Method: Qualitative comparative usability test
- Tasks: *see below*
- Participants will be encouraged to **think aloud** when performing the tasks
 - The tasks are situated within a short scenario. So, not just ordering "do X" but providing a bit of explanation and context for *why* the user is "doing X."

- Each participant:
 - Will test the **3 concepts**, each time doing the same **7 task scenarios**
 - With each participant, the order of concepts shown will be alternated to **avoid “order effects”**



- After experiencing each concept:
 - Identify what data elements were most **memorable**
 - Fill out a short **UX questionnaire**
- Wrap-up/data collection
 - **Qualitative comparison** of all 3/final discussion and thoughts

INTRO:

- Intro to project once more and that there are 3 designs we will be looking at today
- “Last time, we talked about personal and health-related movements. Do you remember what the difference was?”
- Go over personalized interaction scenario with them

Part 1, 2, 3:

- “Now, I will show you the first concept. I will give you some tasks to do and, using the app, you can show me how you’d go about doing the task. Please note that not all the functions on the app work... so don’t worry if you click on something and it doesn’t work.
- Lastly, if you can, please think aloud as you go through the tasks. There are no right or wrong answers, just let me know what’s on your mind (for example, if you think something is too difficult to find, if you would rather click here than there, if you like/dislike something, etc.).
- As always, if you would like to end this meeting at any time, you may do so. Just let me know how you’re feeling!”
- Record meeting

Part A, B, C apply to concepts 1-3

Part A:

- You’ve just woken up and are ready to start your day.
- **TASK A1:** Plan your day!
 - *Schedule/reminder*
- **TASK A2:** Set a new goal

Part B:

- Now, imagine you continue with your day and you’re ready to check back in with the app. Where would you go to...
- **TASK B1:** ... check off your personal-related goal?
- **TASK B2:** ... to “do” your health movement?
 - “This game will help you do some movements from your home! Since you picked a health-related goal, you could play this game to help guide you do your movements. Keep clicking to see the type of feedback you’d receive while you are playing.”
- **TASK B3:** Reflect

Part C:

- Lastly, imagine it's the end of the day. You've achieved all your goals for the day and want to look back at some of your progress.
 - **TASK C1:** You would like to check the total moods that you experienced throughout the day today. How would you do that?
 - **TASK C2:** You also want to check something from last month. What movements did you do on July 5th, 2021?

EVALUATION OF INTENDED EFFECT:

- *Only after last test:* PREMO - current feelings going through the apps
- *After each test:* Brief chat on overall experience/specific experiences observed during usability test
 - "What was most memorable about this app?"
- *After each test:* Fill out a short UX questionnaire
 - <https://docs.google.com/forms/d/e/1FAIpQLSf7ZuFUSwUWwLWkK22j9N6aD9aFCP7kPpDT4ZIH9UgHvfOosw/viewform>

Part 4:

COMPARATIVE ANALYSIS

Some of these questions may or may not have been covered during the "talk aloud" moments in Parts 1-3. From the following questions, you may ask the questions that have not been answered yet... or have them go a little more in depth.

General questions:

- Which prototype makes you feel extra curious?
- When going through the prototypes, which one made you feel most confident? (*competence*)

- Were there any parts in any of the apps where you think you would need help in figuring out how to use it? (*tests ease of use/overall understanding of product/autonomy levels*)
- Was there anything you were missing? ... or any other information you'd be interested in seeing?

Specific questions:

Questions (PICKING/SETTING GOALS):

- What are your thoughts on specifying whether or not it's a health/personal-related goal? (c2 vs c3)

Questions (CHECKING OFF GOALS/DOING THE GAME/REWARD SYSTEM):

- Can you tell me more about what you see on the home screen?
- What are your thoughts on a dog vs a "buddy system" vs a digital friend?
- What do you think of the rewards? (*badges vs points*)

Questions (CHECKING PROGRESS):

- What do you understand from this graph?
 - Graph 1:
 - Graph 2:
 - Graph 3:



Presentation Slides - For Males

WELCOME [REDACTED] !!

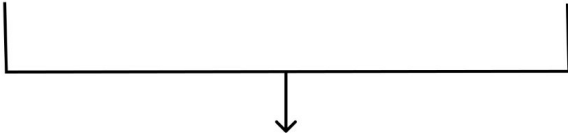


Consent for Participation in Intervention

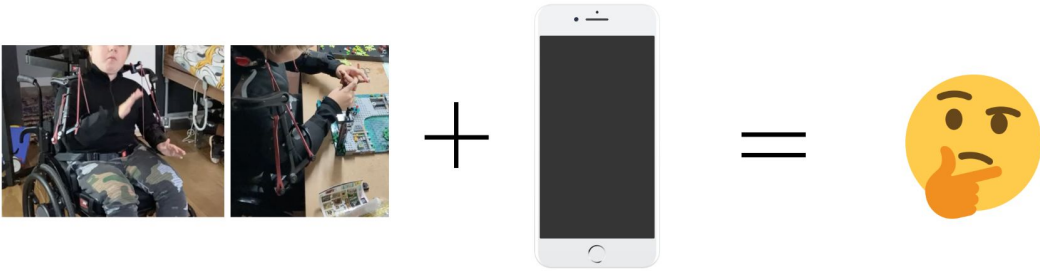
- 1.) I understand that during this project, Milla will explore how I can feel more motivated to physically continue to move my muscles.
- 2.) I will allow Milla to photograph, video, and/or audio-record our online meeting.
- 3.) I will allow Milla to use photos and videos for her project reports and presentations. The photos will be blurred and your name will be stated differently; therefore, you will remain anonymous. These will only be used during her project.
- 4.) The (online) meeting should last between 40 minutes - 1 hour.
- 5.) I understand that my contribution to Milla's project is voluntary and I will mention immediately if I don't feel comfortable answering questions or if I have objections to answer a certain question. Also, I can stop the interview any time I want without any explanation.
- 6.) I have read and understood the statements that are written above.
- 7.) If I consent to help with this project, then I will give Milla a verbal confirmation (for example, you may say, "I agree with these statements, Milla."

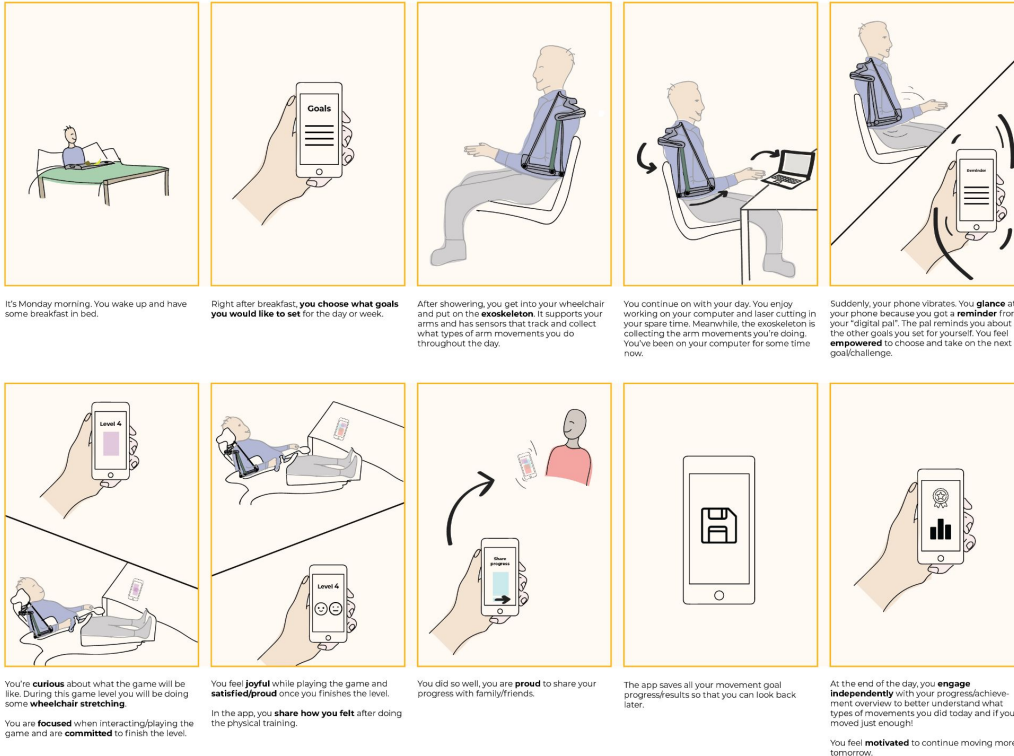
Personal-related movements

Health-related movements



Both are important! 😊





Part 1:

Overall experience?

Part 2:

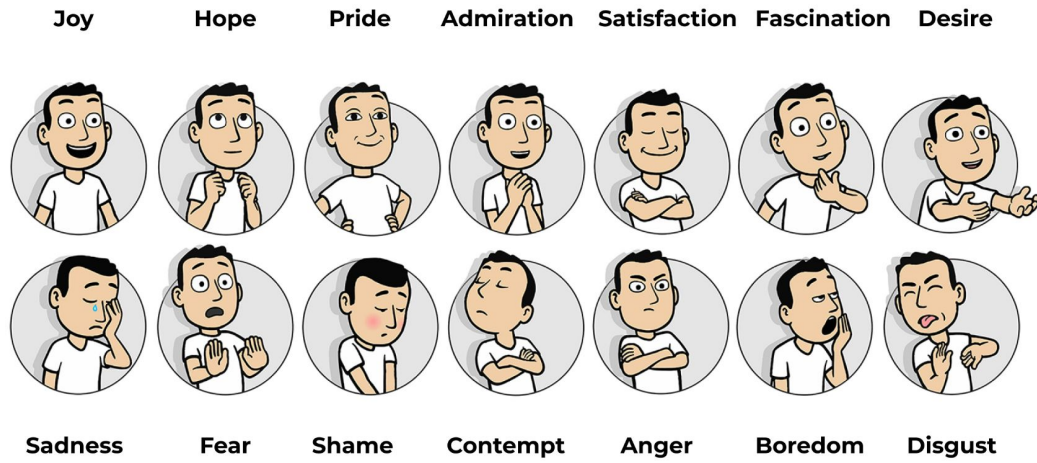
Overall experience?

Part 3:

Overall experience?

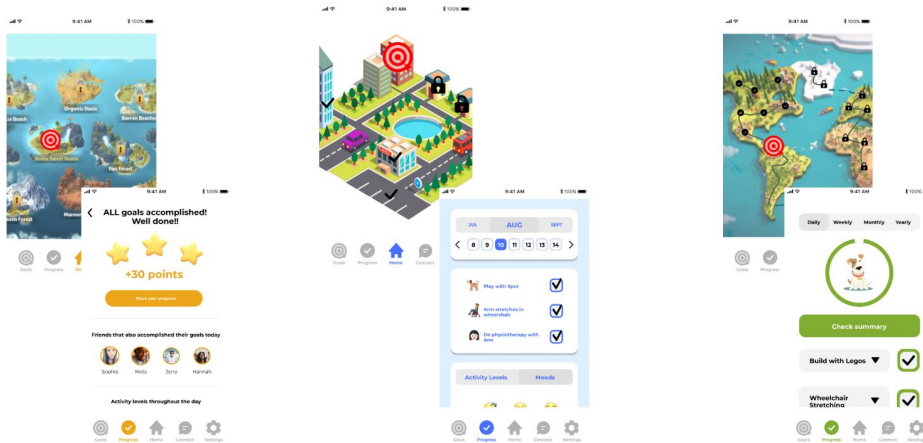


Part 3:



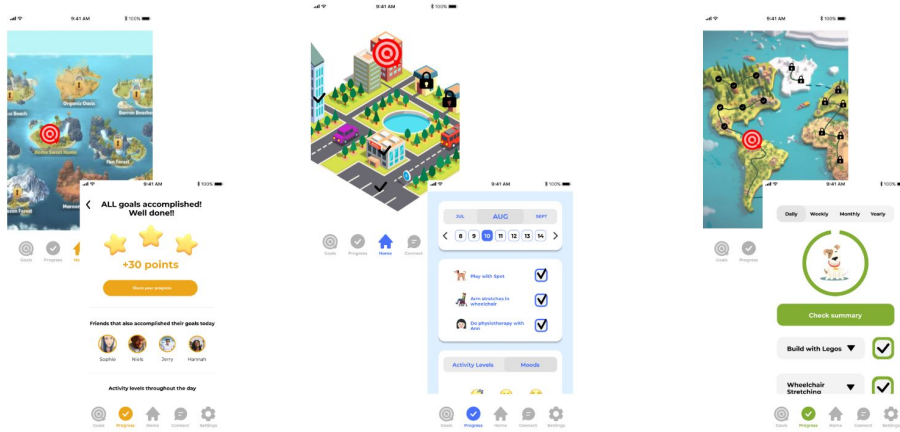
Part 4:

Which prototype makes you feel extra **curious**?



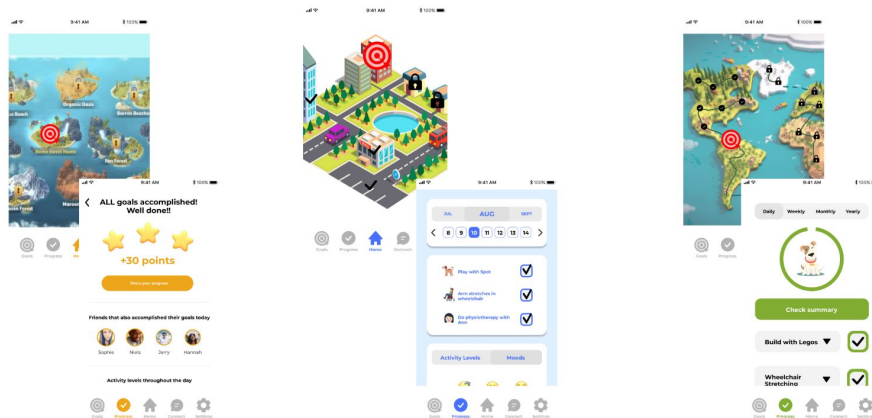
Part 4:

When going through the prototypes, which one made you feel most **confident**?



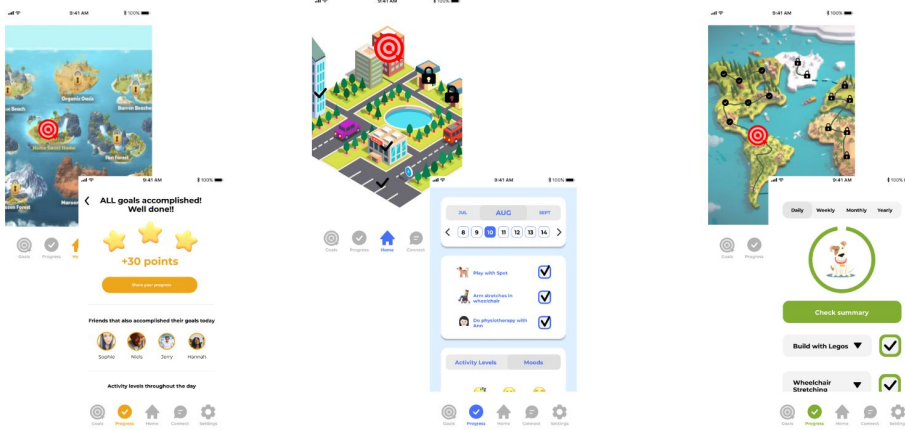
Part 4:

Were there any parts in any of the apps where you think you would need help in figuring out how to use it?



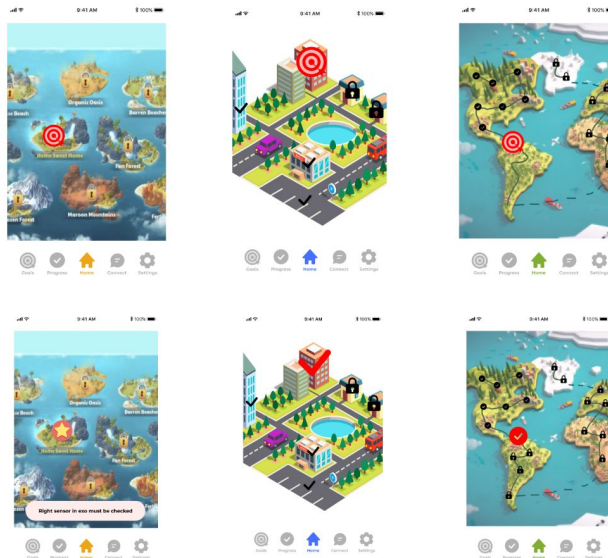
Part 4:

Was there anything you were missing? ... or any other information you'd be interested in seeing?



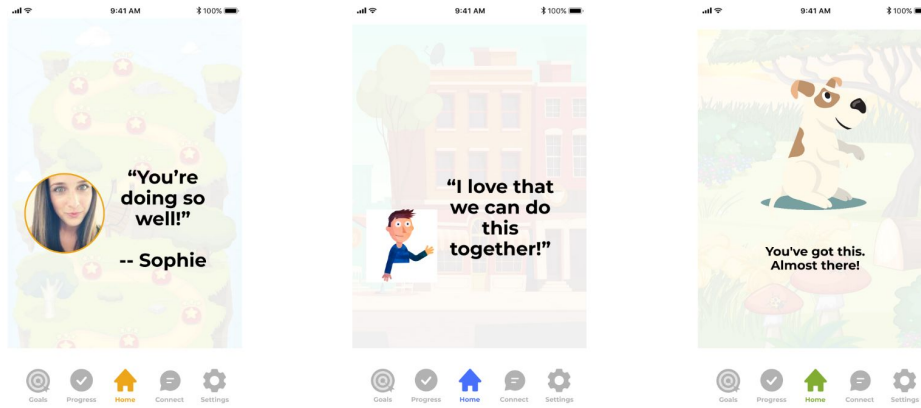
Part 4

Can you tell me more about what you see on the home screen?



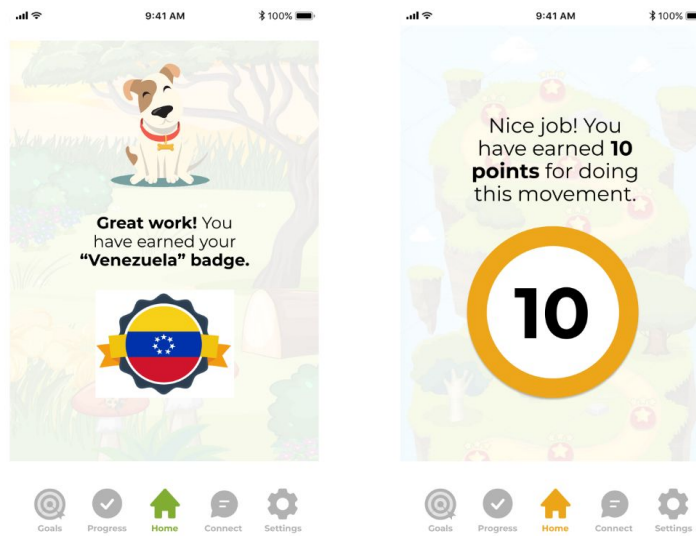
Part 4

What are your thoughts on a “buddy system” vs a digital friend vs a dog?



Part 4

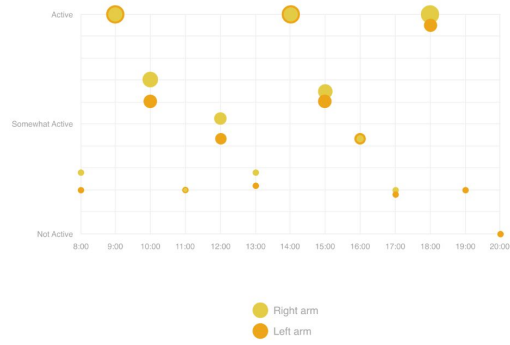
What do you think of the rewards? (*badges vs points*)



Part 4

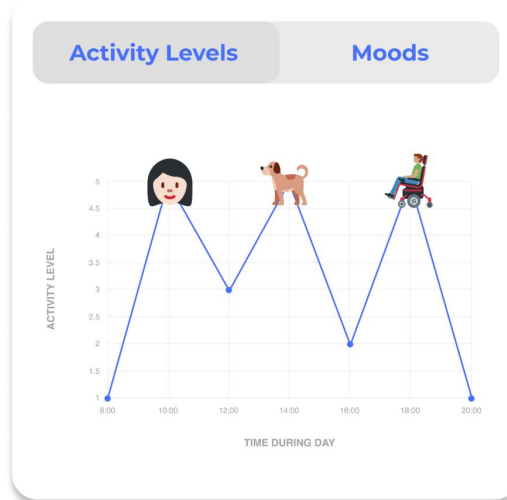
Activity levels throughout the day

What do you understand from this graph?



Part 4

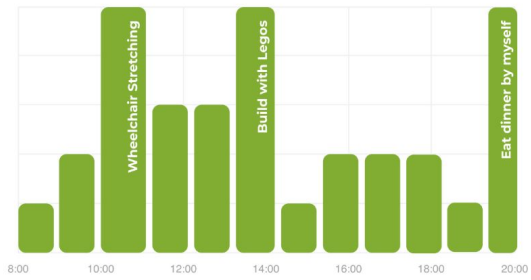
What do you understand from this graph?



Part 4

Activity levels throughout the day

What do you understand from this graph?



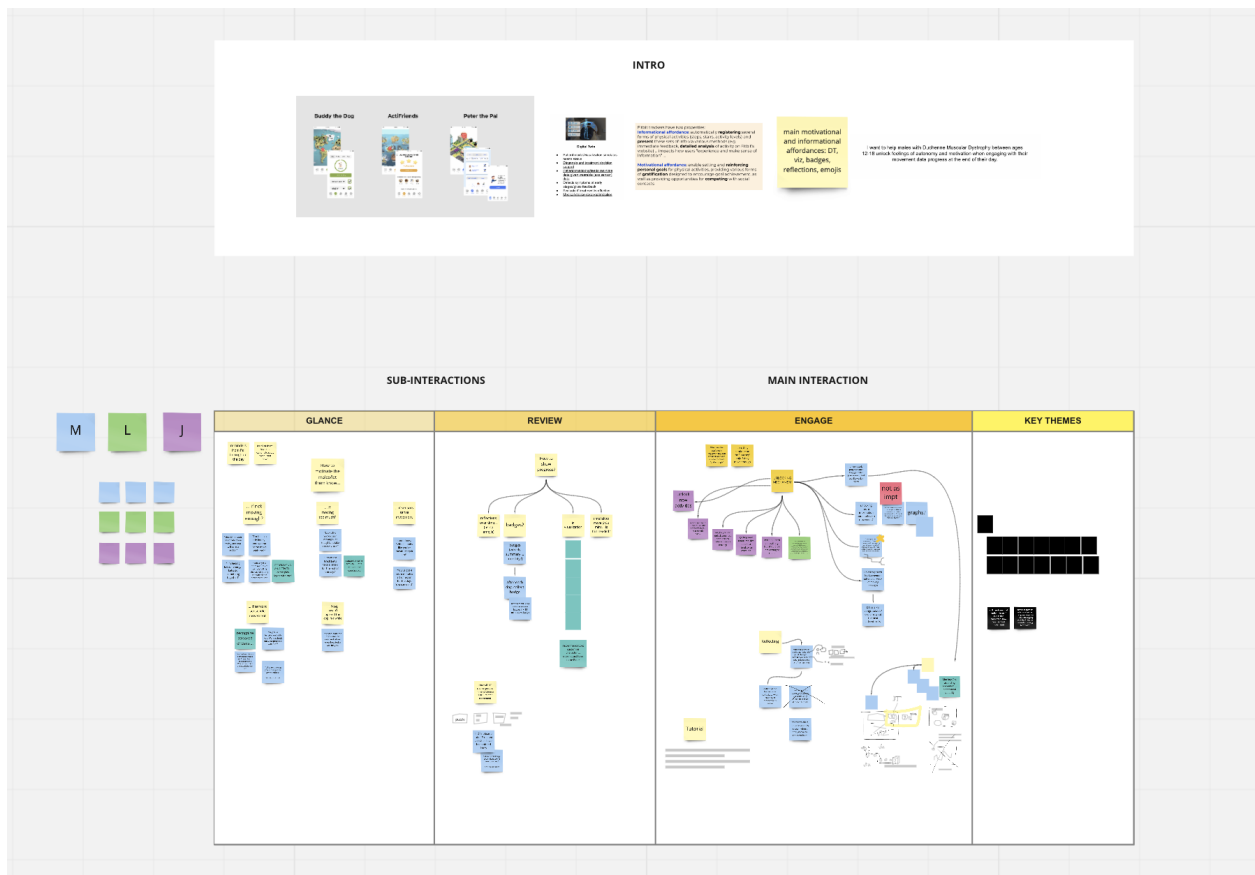
Thank you for your help!



Intervention 3: Appendices

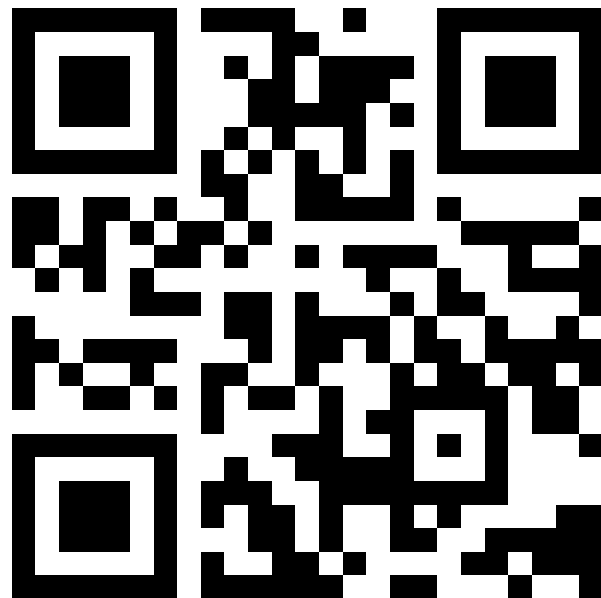
Appendix 11: Brainstorm

- A brief intro to the engineers:
 - Intervention 2 Recap/main findings
 - The main technology being used (DT)
 - Design Goal
- Brainstorm:
 - “Engage” sessions first (5 minutes)
 - Discuss/do a group brainstorm
 - Brainstorm “review” and “glance” interactions together
- Closing comments/discussions/ideas
- You may find the brainstorm here: https://miro.com/app/board/o9J_lz7IZYQ=



Appendix 12: Final Concept - Figma Link

https://bit.ly/Exo-Pal_App



EX  **-PAL**



Appendix 13: Video - Showcase

https://bit.ly/Exo-Pal_Demo



A screenshot of a YouTube video player. The video content shows a smartphone screen with a colorful app interface. The app displays a progress indicator '3/30 minutes moving' and a cartoon character. The background of the app is a green field with a blue pond, a white fence, and a brown house. The YouTube player interface includes a search bar at the top, a play button, a progress bar at 1:24 / 5:03, and a subtitle 'and reaches the 30-minute goal for those days.' The video title is 'Exo-Pal' and it is unlisted. The video has 5 views and was uploaded on Sep 27, 2021. The player also shows like, dislike, share, and save icons.

Appendix 14:

Interview Guides

RESEARCH GOALS/QUESTIONS:

- Goal 1: Identify to what extent the Exo-Pal is able to increase the male's curiosity, motivation, and sense of autonomy. (Design Goal, Interaction Vision, and SDT relevance)
- Goal 2: Determine what data element(s) in Exo-Pal seemed to be of most interest for 12-20-year-old males
- Goal 3: Understand how males view the concept in the longer term.
- Goal 4: Understand if the males view the Exo-Pal as something that provides an added value to the exoskeleton
- Goal 5: Identify any interface issues that may need optimizing
- Goal 6: Discover how other stakeholders view the concept as a whole

PARTICIPANTS:

- 2 researchers
- 1 physiotherapist
- 3 designers
- 2 teenagers
- 1 male with DMD

GENERAL SET-UP:

- Method: Conducting a Product Concept Evaluation
- Send an interaction scenario of how the Exo-Pal might be used a day before meeting with participants
- During the day of the test, watch the video that presents the Exo-Pal's purpose
- Conduct an interview and use a self-invented evaluation method called "S.I.D"
 - This evaluation method includes creating visuals that represent the following: (not) liking something, (not feeling a sense of) curiosity, (not) feeling in control of the app, and a (not) clear understanding.
 - Some main user interface screens will be posted. The user will be given Zoom mouse control and will then drag the visual(s) onto the user interface to specify the exact data element that made them feel a certain way.
 - This can help quantitatively and qualitatively analyze parts of the user

interface(s) and can lead to optimizing them in future design iterations.

Interview questions for the males and teenager:

- Do you have any questions about the video?
- What did you think of the Exo-Pal in general?
- How did you feel when hearing what Exo-Pal is all about?
 - Use *PREMO* - current feelings

(Using the S.I.D. eval method)

- Which parts in the app did you like or dislike?
 - 2 pics: like, dislike
- Which parts in the app did not make you feel curious? ... Or were there parts that made you feel curious? (*IV, understanding of motivational affordances*)
 - 2 pics: indifferent, curious
- If you were to use the app, which parts do you think would help you feel in control or feel like you have a choice? ... Or are there parts that would make you feel like you do not have control of the app?
 - 2 pics: in control, not in control (*DG/SDT/autonomy levels/overall understanding of product*)
- Which parts in the app did you find confusing to understand? ... or clear?
 - 2 pics: confusing, clear (*DG/SDT/competence, understanding of informational affordances and some motivational affordances*)
- *Have them fill out a UX Questionnaire*
 - annoying/enjoyable, creative/dull, practical/impractical, clear/confusing, demotivating/motivating, meets expectations/does not meet expectations, boring/exciting
 - <https://forms.gle/jJhzQQ1cK56dfRnC8>

- Were there any parts in Exo-Pal that you think you would not use?
- Would you like to have Exo-Pal for yourself? Why or why not?
- How do you see Exo-Pal in the long term? Do you see yourself using it for more than one year? Why or why not? (*tests to see if they see themselves being committed to the product and a more active lifestyle*)
- On a scale of 0 to 10, 10 being very likely, how likely are you to recommend Exo-Pal to a friend? Why?
- Let's pretend you only have the exoskeleton and no Exo-Pal. How would you feel then?
- Do you have any last thoughts or recommendations that can improve Exo-Pal?

Interview questions for other stakeholders:

- Do you have any questions about the video?
- What did you think of Exo-Pal in general?

(Using the S.I.D. eval method)

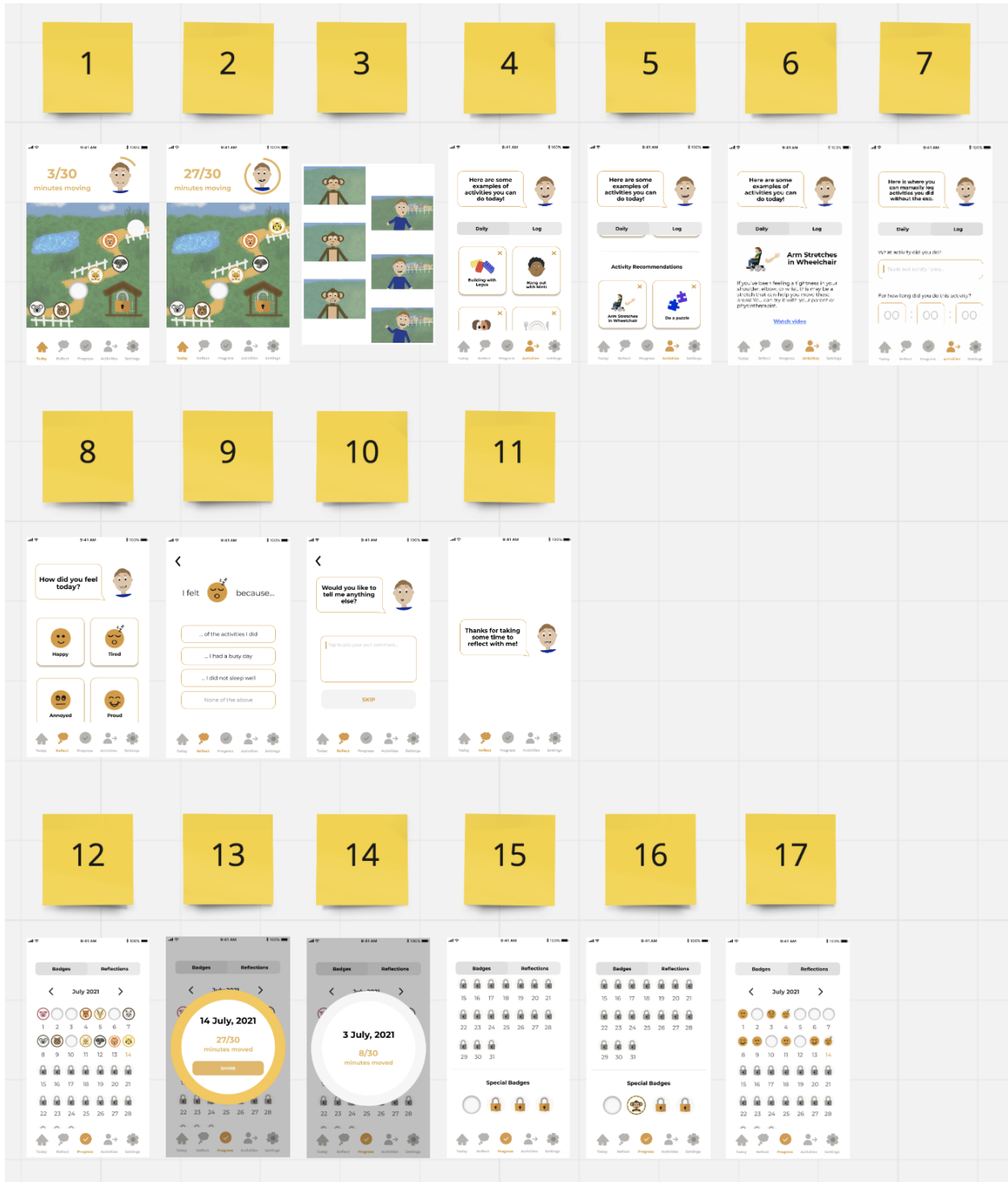
- Which parts in the app did you like or dislike?
 - 2 pics: like, dislike
- Which parts in the app did not make you feel curious? ... Or were there parts that made you feel curious? (*IV, understanding of motivational affordances*)
 - 2 pics: indifferent, curious
 - What do the badges mean to you?
 - Unlocking?
 - After a long day of physiotherapy and being at your dad's office... or aunt's place Do you see yourself reflecting at the end of the day?
- If you were to use the app, which parts do you think would help you feel in control or feel like you have a choice? ... Or are there parts that would make you feel like you do not have control of the app?
 - 2 pics: in control, not in control (*DG/SDT/autonomy levels/overall understanding of product*)

- Which parts in the app did you find confusing to understand? ... or clear?
 - 2 pics: confusing, clear (*DG/SDT/competence, understanding of informational affordances and some motivational affordances*)

- *Have them fill out a UX Questionnaire*
 - annoying/enjoyable, creative/dull, practical/impractical, clear/confusing, demotivating/motivating, meets expectations/does not meet expectations, boring/exciting
 - <https://forms.gle/jHzQQ1cK56dfRnC8>

- How do you see Exo-Pal in the long term? ... Do you see your child/patient/a male using it for more than one year? Why or why not?
- On a scale of 0 to 10, 10 being very likely, how likely are you to recommend Exo-Pal to a male/another parent/healthcare specialist/researcher? Why?
- Let's pretend you only have the exoskeleton and no Exo-Pal. How would you feel then?
- Do you have any last thoughts or recommendations that can improve Exo-Pal?

Appendix 15: More Quotes from Evaluation Sessions



Like/dislike:

- (1) LIKE: "I really like the zoo -- it's interesting because it has a theme." - IPD/Dfl m
- (4) LIKE: "I really liked this! Can they see the activities they have done before? Like, 'I did this on Monday, I really enjoyed it, let's do it again.'" - IPD f
- (6) LIKE: "I think the explanation is nice, especially as they get older they'll want to understand more... but when they're 12, maybe not as much." - IPD f
- (12, 16) LIKE: "I like that they can see why they are getting badges, and why they're not. I think being able to see the pros and cons of what you're doing is good. I also liked the special badges, it's a little extra something. I like how in the map, the special badge is locked up because users will want to get it unlocked and it's a great way to keep them going." - IPD f
- (1) LIKE: "I like this screen in general. It makes sense for me. Maybe it makes more sense to have the special badge at the end of the route. Other than that, it's a nice page and shows what it has to show." - IPD/Dfl f
- (4) LIKE: "I really like this page, I think it's very useful... like having suggestions for activities." - IPD/Dfl f
- (1) LIKE: "That's really fun that it changes [every month], because maybe you don't like the zoo, but then next month you have something you do like." - 17 y.o. f
- () LIKE: "Actually, there wasn't one that I didn't like." - 17 y.o. f
- (3) NEUTRAL: "I think the video is really cool, because it feels like you have an extra interaction. But then it kind of feels like you have that scene and then it disappears." - IPD m

- ACTION POINTS:

- Create more dynamic interactions with the special badge. (16) "I really like the idea of having special badges, in addition to what you're normally doing, only they don't feel that special... maybe have them glimmer ... or have it as a GIF." - IPD/Dfl m
- (17) Add a "share" button to reflections
 - It is a form of consent (from the boys' perspective)
 - They can choose what they would like to share (maybe just the emoji and suggestions, but not the explanation)

Curious/not curious:

- (8) CURIOUS: "I think it's nice. My only worry is if they would fill it out at the end of the day. I love the self-check-in though, and seeing how you personally feel." - IPD f
- (12) CURIOUS: "I like badges. I like to see when I'm not doing well and then it makes me feel like I need to keep going. This is based off of my personal experiences ... that I liked to see if I've achieved my goal for the day. That's important for me." - IPD f
- (4) CURIOUS: "I like this part a lot. ... It might also be nice if other app users have their own activities added that these will also be showed in an anonymous way. So having application suggestions and suggestions from peers." - IPD/Dfl f
- (1) CURIOUS : "This is definitely interesting; it has missing pieces and there's a scenario [theme] in there and you want to know what it means and explore." - IPD/Dfl m
- (12) CURIOUS: "I'm curious what's behind the locks" - YB designer
- (16) CURIOUS: "If it changes every month, ... is every year the same theme? [*researcher explains that it's different every month, every year*] ... Oh, I like that! That it's different every month." - 17 y.o. m

- (13) NOT CURIOUS: "I think sharing for me, it's nice but it's not something I would personally use. It's not my thing. I like to keep it to myself." - IPD f
- (8) NOT CURIOUS: "I can imagine you're not really willing to give information. Maybe there's some other way to communicate the information." - YB designer

Control/not in control:

- (2) CONTROL: "People can control how they influence this number directly." - post-doc researcher
- (4, 7) CONTROL: "I really feel like I'm in control when customizing my activities. ... and when I put my own activities in there." - IPD/Dfl m
- (1) CONTROL: "You're in charge of your own progress." - IPD f
- (4) CONTROL: "This gave me a lot of control." - IPD/Dfl f
- (4) CONTROL: "You can choose things, you have options." - YB designer

Clear/confusing:

- (1) CLEAR: "I think the most clear would be the home screen." - post-doc researcher
- (4) CLEAR: "I think overall this is very clear." - IPD/Dfl m

- () CLEAR: "Everything was very, very clear." - IPD f
- (13) CONFUSING: "For me, it's confusing if you get 27/30 minutes that you would still receive a badge. I do get that if you get 29/30 minutes it's quite a pity you don't get a badge, but at the same time if I would get to know that, I would just look at it and say, 'Oh, no worries, I'll get a badge.'" - IPD/Dfl f

