

UNIVERSITY OF TWENTE.

**Faculty of Electrical Engineering,
Mathematics & Computer Science**

Gamified musical breathing exercises for children affected by Duchenne Muscular Dystrophy

Alessandro Capra
M.Sc. Thesis
July 2018

Supervisors:

dr. Dennis Reidsma
dr. Robby van Delden
Marijke Groothuis, MMTh
(ARTEz University of Arts)

Human Media Interaction Group
Faculty of Electrical Engineering,
Mathematics and Computer Science
University of Twente
P.O. Box 217
7500 AE Enschede

Acknowledgements

As my academic career comes to its end with this thesis work, it is also worth to look back and see how I came this far. I have many people to thank, since without their support I probably could not have made it until this point. First of all, a big hug and thank to my family, which has always supported me in my journey and pushed me to never stop exploring: without them, you would not be reading these lines. I would also mention the importance of my lifetime friends in Italy, which have known me since forever and are always following me in my personal growth. Another important thank goes to all the beautiful friends I made in my time in Finland and in the Netherlands: they are so many that I feel pointing out names is not the best way to go, you know I am talking about you right? They had such a big impact on my strength to pursue my studies and gave me beautiful memories that will stick with me for a long time. On the professional side, I definitely would like to thank Mika and Hakan for the support received while studying in Finland, as well as recommendations on where to point for my future. More specifically, regarding the thesis work, my supervisors Dennis, Marijke and Robby have guided me through this hard and tedious process. Last, but not least, thanks to the amazing people at the Roessingh Revalidatie Centrum for their amazing collaboration and availability: Allard, Gerben and all the children that have been intrigued by this project.

Allow me a final, more general thought: during the past two years of my double-degree master, I have been challenging myself to get out of the comfort zone of a safe job and lifetime friends to get a better sense of what it entails to be a citizen of the world. Indeed, both in Finland and in the Netherlands I had the first approach to totally different cultures coming from across the whole globe. The initial sense of awkwardness, the misunderstandings coming from using different expressions and tones of voice (Italians

always shout, that is indeed a fact), learning to swear in other languages, tasting new food and moments of total laughter and joy. All of these factors, and many more, are part of the beautiful exchange that happens whenever individuals with different backgrounds get together. And although there many difficult situations can arise, the important aspect that always makes these issues vanish is to keep listening and talking. Being open to criticism and ideas that go against one's deepest beliefs is the key to allow a multicultural setting to work, allowing to accept others for who they are and leading to a true integration, which has become one of this century's substantial issues. To conclude, I would like to cite an advert of a British telecommunication company which featured a powerful message, with Stephen Hawking as voiceover:

For millions of years, mankind lived just like the animals. Then something happened which unleashed the power of our imagination. We learned to talk. And we learned to listen. Speech has allowed the communication of ideas, enabling human beings to work together... Mankind's greatest achievements have come about by talking. And its greatest failures by not talking... All we need to do is make sure we keep talking.

Abstract

DUCHENNE Muscular Dystrophy (DMD) is the second most common gene disorder that affects predominantly male subjects. The most recent statistics report that, coupled with the Becker muscular dystrophy, it affects 1 out of 7250 male children aged between 5 and 24 years [30]. The disease consists in a progressive degeneration of muscle functionality, usually starting from the lower limbs and followed by the upper ones. Eventually, it affects the respiratory and cardiac muscles leading to a premature death in the late teen or early twenties of the subjects. To postpone the late stage respiratory decline, which eventually forces the children to be subjected to invasive operations such as tracheotomy or dependent on different kinds of electronic equipment for ventilation and coughing assistance, a constant training in the early stage of the disease has proven to improve the life quality and prolong the life expectancy of the subjects [38]. The therapy usually consists in a series of breathing exercises that aim at maintaining the respiratory muscles functionality. However, without the inclusion of an engaging factor there is a significant chance of abandonment of the therapy when the children will move to a different school, as reported by one of the physiotherapists that has been interviewed. The current project aims to tackle this issue by making the system more engaging thanks to the addition of gamification and musical therapy elements. Thanks to different interviews with the stakeholders of the project, many insights were collected and informed the final design. The finished implementation includes a hardware prototype, which senses the breathing pattern of a person (direction, strength and duration) and sends it to a central server, which in turn communicates this data to the game client. Thanks to such architecture the implementation of a multiplayer game, which was mentioned as a desirable feature from physiotherapists, children and parents, is made possible. As for

the game itself, it consists in a runner game in which the player needs to collect as many coins as possible to achieve a high-score. It incorporates a leaderboard as a gamification component and an audio track is used as a hint system, suggesting the player when to carry out actions based on the dynamics and the beat of the music. However, the broader vision of the project sees a system which allows a set of devices, each one addressing a specific rehabilitation exercise as controller of the game, to be connected to a central unit. The game could then be played by multiple players, although using a different way to control the main character. The evaluation phase of the current implementation involved children affected by DMD, and the results of this qualitative test suggested that the system has potential, especially thanks to the incorporation of the gamification aspects since they promote competitiveness and re-play. However, the role of music should be better integrated with a careful design of the levels, avoiding to fit many actions in a limited span of time since it makes it difficult to breathe properly for patients with respiratory problems. Nonetheless, it seems to be a first step in the right direction and additional research should be carried out to confirm the potential and explore additional possibilities.

Contents

1	Introduction	1
2	Methodology	5
2.1	The UCD iterative cycle	5
2.1.1	Analysis	6
2.2	Design	8
2.2.1	Evaluation	10
2.2.2	Implementation	11
3	Context analysis	13
3.1	Classic therapy and exercises in the treatment of Duchenne Muscular Dys- trophy (DMD)	13
3.2	Music therapy	15
3.3	Gamification	16
3.4	Related work	20
3.4.1	Hardware solutions	20
3.4.2	Software implementations	23
3.5	User research	31
3.5.1	Observations of a music therapy session	31
3.5.2	Interviews	33
3.6	Personas	37
4	Conceptual Design	43
4.1	Generalized input mapping	43
4.2	Inclusion of therapeutic aspects	44
4.3	Game concepts and music as hinting system	45
4.4	Online multiplayer for social gaming	48
4.5	Gamification components	48
4.6	Internet connection as fundamental requisite	49
4.7	Determination of focus areas for implementation	49
5	Technical design and implementation	53
5.1	General overview	53
5.2	Hardware	54
5.2.1	Desired measurements of breathing patterns	54

5.2.2	Final hardware prototype	55
5.2.3	Physical casing for the hardware prototype	59
5.3	Software	61
5.3.1	General architecture	61
5.3.2	Javascript as the main programming language of the project	61
5.3.3	Server	62
5.3.4	Database	63
5.3.5	Clients	63
5.3.6	Hosting platform	66
5.3.7	Music	67
5.4	Level design	68
5.5	Limitations	70
6	Evaluation	71
6.1	Approach	71
6.2	Background & Goals	72
6.3	Context	73
6.4	Participants	73
6.5	Risk analysis	74
6.6	Schedule	74
6.7	Script	74
7	Results	77
7.1	Approach	78
7.2	Differences in children's cognitive abilities and consequences on the game-play	78
7.3	Interface usability issues	79
7.4	Level design, proximity of breathing actions and prototype structure	80
7.5	Gamification elements as a necessary tool for motivation and engagement	81
7.6	Music therapy component's issues	81
7.7	Game design issues and feature requests	82
8	Conclusions	83
8.1	Research goals	83
9	Discussion and future work	87
9.1	Performance improvement	87
9.2	Level design and music therapy	87
9.3	Interface improvements	89
9.4	Physical prototype	90
9.5	Desirable features	90
9.6	The vision and meaning of the project	91

A	Appendix	93
A.1	Forms	93
A.1.1	Information brochure	93
A.1.2	Consent for interview with parents	95
A.1.3	Consent for testing with children	96
A.2	Interview questions / therapist	96
A.3	Thematic analysis / physiotherapists	98
A.4	Interview questions / parents	101
A.5	Thematic analysis parent's interview	103
A.6	Thematic analysis of evaluation session	105
A.6.1	General	105
A.6.2	Persona	105
A.6.3	Signup	106
A.6.4	Welcome	106
A.6.5	Settings	106
A.6.6	Calibration	106
A.6.7	Training / Game	107
A.7	Game screens	110

Chapter 1

Introduction

THE research on the treatment of the Duchenne Muscular Dystrophy (DMD) has seen an interesting development over the course of the last century, thanks to technological development, which led to better tools to analyse muscle tissues and consequently get a more thorough understanding of the disease, and the inclusion of different treatments that were not usually employed in therapy, such as gamification and music therapy. DMD seems to have been affecting humans since thousands of years. Indeed, it is possible to find the first depictions that closely describe the disease symptoms in Ancient Egypt. Indeed, an analysis of Figure 1.1 shows a probable case of lumbar lordosis, with a potential case of calf enlargement [7]. However, the first official medically recorded cases dates back around 1850; these records show a degeneration in muscle functions, eventually leading to a premature death. Since then, there have been many notable researchers that devoted their lives to get a better understanding of these symptoms and eventually find a cure. The most notable scientists that analyzed and further defined this particular disease are Edward Meryon and Duchenne de Boulogne, who outlined a thorough analysis on symptoms such as progressive weakness of movement, which affects first the lower limbs and the upper limbs in the next stage; a gradual increase in the size of the affected muscles and an increase of interstitial connective tissue in the affected muscles [7]. Moreover, Duchenne had the intuition that the disease was of a genetic nature and affected mostly male subjects [6].

DMD is for about one third caused by a new genetic mutation, while in two thirds of the cases is genetically inherited from one of the parents. The issue resides in a mutation of the gene of the dystrophin protein, which leads to muscle tissue weakness. The

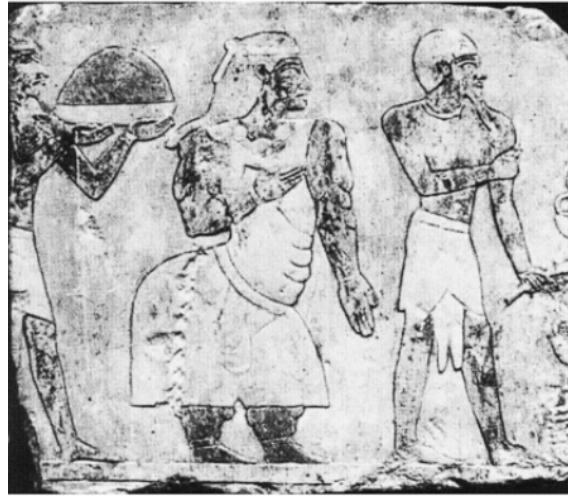


Figure 1.1: a potential depiction of a subject affected by muscular dystrophy [7].

reason why it affects mainly the male population resides in the disorder being X-linked recessive: this means that the information of the lack of dystrophin is linked to the X chromosome, of which female have two (XX) while the male have one (XY). Therefore, it is more rare that a female will be affected by DMD, since the other X chromosome will remain functional, while man have a much higher probability of developing the disorder [26]. As briefly explained in the abstract of this paper, the initial symptoms of the disease manifest on average around 5 years of age, subsequently leading to muscle weakness in the lower limbs and also in their spine, which forces the children to be wheelchair-bound on average around 8-10 years of age. In the latest stage of the disease, the weakness spreads also through the other muscles of the body, eventually leading to serious respiratory (diaphragm muscle) and cardiac (heart) complications [7]. The decrease in functionality of these muscles is the leading cause of death, with an estimation between 55%-90% of death by pulmonary complications due to respiratory muscle weakness between age 16.2 and 19 on average [11]. A study found also that 90% of pneumonia episodes were largely caused by the ineffective coughing [1]. Efforts have been undertaken to properly train these muscles, in order to prolong the lifespan of the patients. This approach has been proven successful, with an average prolonged life expectancy thanks to specific trainings that start already in the early stage of the disease, when the subjects have recently been wheelchair-bound and have a moderate lung functionality [38]. For instance,

the exercises incorporated into therapy include deep breathing, coughing with or without assistance and forced expiration [13]. However, it has been reported that although physical rehabilitation has several advantages, patients feel that it is sometimes hard to fully engage in the exercises due to different causes including pain, anxiety or lack of motivation [22]. Indeed, during an interview with a music therapist of the Roessingh Revalidatie Centrum, one of his main concerns is about the children sticking to the therapy after they change school and move to another part of the country. To counter these consequences, researchers have investigated the possibility to embed elements of music and gamification to improve engagement and motivation. On the one hand, music has been proved to be an useful element of distraction that allows the patient to focus less on the exercise and more on a purposeful, pleasant experience while doing exercises [21]. On the other hand, gamification seems to be effective especially in the hands-off therapy approach (i.e. doing exercises independently, without the therapists assistance), since this procedure has a lower long-term lasting effect compared to the hands-on one. Therefore, with the addition of elements aiming for higher attractiveness and engagement, there is a potential increase in therapy involvement and an improvement of the intensity of the training [14].

In this project I designed a game, which has been used to answer the following research questions:

1. What is the added value of adding gamification and musical elements to the classic breathing therapy exercises?
 - Do they stimulate different breathing behaviour patterns during exercises?
 - Do they provide more motivation and engagement towards the therapy?
2. Do users understand the game mechanics and perform actions correctly?
3. Can the therapist have control over the settings of the game in a way that contributes to the therapy?

Chapter 2

Methodology

THIS chapter will provide the framework that will be used for the design and development processes of the project. The techniques discussed here are part of the classic User-Centred Design (UCD) methods usually adopted for the design of services and/or products that take into account the experiences that are provided to the final user, assessing iteratively the usability and ease of use of the final system.

This part was already included in the previous Research Topics assignment carried out by the author of this Master's thesis. Whenever new information is added, it will be explicitly pointed out as such.

2.1 The UCD iterative cycle

The design of a product or service requires engineers to take several decisions on its implementation, for instance regarding its available functionalities or how it is going to be used by people from different backgrounds and cultures. The problem with this approach is that designers/engineers and users have different mindsets and way to approach a new system and interface to it. Therefore, to avoid this pitfall during this Masters thesis work the researcher will use the classic UCD approach depicted in figure 2.1. This iterative cycle starts with gathering enough information about the users, through several methods that will be explained in detail in the following chapters. When the designer has a sufficient overview of the users, the design phase will start and prototypes will be created and evaluated iteratively with the users, trying to get constructive feedback to further improve the system. After few iterations, the product/service will be

ready for an high-fidelity implementation that can be released and additionally refined to achieve the maximal user experience given the available resources.

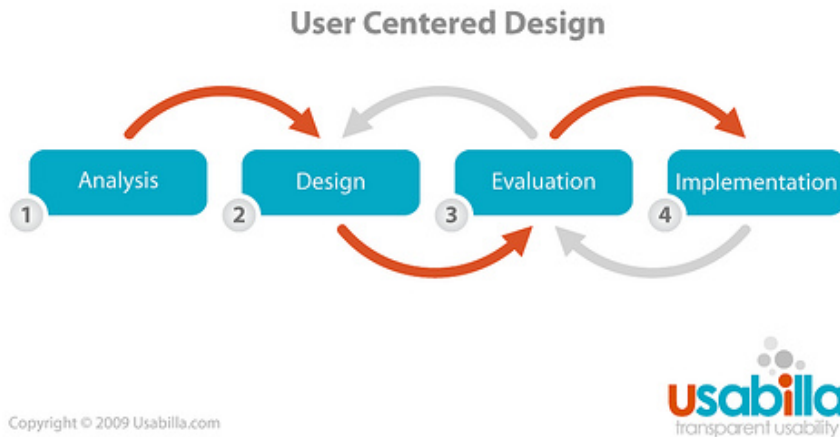


Figure 2.1: the general process of UCD (taken from Usabilla blog).

2.1.1 Analysis

In the first phase of the UCD iterative cycle, it is important to gather information to understand the context of use of the final product. Here context must be seen in a broad context, encompassing for instance who the users are, their experience with technology, the relationships between them — such as, in the DMD case, the physiotherapists, children and parents — and the environment in which the interaction with the product take place to better understand the user behaviour [37]. There are many methods available to the researcher in order to collect and analyse this data, which will be discussed in the following sections.

Interviews

To get a better understanding of the context surrounding the children affected by DMD, interviews will be carried out targeting the different people they get in contact with — such as physiotherapists, volunteers and family members. The format will be mainly of a semi-structured nature, meaning that a pre-defined set of questions will be prepared

but the researcher will be allowed to diverge and follow paths that he deems interesting to inform the design of the project [27]. The richness of the qualitative data collected in this phase will allow a thorough understanding of the users, which could inform an additional collection of quantitative data through surveys in a future research. While interviews support the collection of qualitative data, there might be a need to generalize assumptions to a greater sample. In this case, it is advisable to use surveys that can be administered through the Internet and therefore easily reaching more participants.

Observations

Another technique that allows to get a more thorough understanding of the context and activities the users perform consists in observations. They are run usually by silently standing in the same room where the activities under study are performed, giving the designer the chance to investigate and get insight on aspects that might be not considered of interest by users, but that could later on inform the design of the prototype. Although they rely mostly of silent observation, a designer can decide to ask a question to the users in order to clarify an aspect that he/she deems of particular importance. In the specific case of this project, observations will be carried out mainly during the music therapy sessions or whenever breathing exercises are conducted by the professional therapist. Moreover, they can be employed in the evaluation session while the users are trying out the final system.

Thematic analysis

As an addition to the Research Topics work, it is important to mention thematic analysis as a method to analyse the large amount of qualitative data that will be gathered through the interview process. It basically consists in finding and analysing patterns, which are also called themes, in the data previously collected [3]. It will be employed both in the analysis of the interviews and to examine the outcomes of the evaluation session.

Personas

Once enough data to give a sufficient overview on the users is gathered, it must be analysed. A common tool to employ to summarize the analysis on the stakeholders of a system (which include users as well as other people eventually affected by the system) is the creation of personas. Personas, as reported by Garrett [8], are fictional characters that are constructed from the gathered data to represent a whole range of real users. The reason behind their use is that when a lot of data becomes available to designers, it is easy to feel overwhelmed by it and lose the connection to what it is describing. Therefore, summarizing the available data into one fictional representation of a group archetype makes it easier to keep the users need as the main focus for the entire design team. In the scope of this project, potential personas could be created for the children (even several personas to reflect differences amongst the patients), family members and therapists.

Scenarios

Unlike reported in the previous Research Topics work, the scenarios were eventually not deemed a fundamental addition to the requirements described in the form of personas, therefore they were not included in this thesis.

2.2 Design

In this second phase of the UCD iterative cycle, the information gathered in the previous phase is used to build a prototype that resembles the final desired product. To have a resource-effective design process, the design phase usually sees two different kinds of prototypes: low-fidelity and high-fidelity.

Low-fidelity prototyping

Especially in the first cycles of the UCD process, working on a prototype consist in briefly laying out the concept of the interface to quickly and inexpensively test assumptions on the real users. To do so, paper prototypes are usually employed to roughly sketch the

interaction and visualization elements of the interface: users will try to navigate through the system by touching the elements drawn on paper, with the designer facilitating the change of screens. However, digital applications such as POP (Prototyping On Paper)¹ let the designer take pictures of the sketches and select which of the drawn elements are interactive and to which subsequent screen they can lead to. Navigation design is also an important aspect to take into consideration when laying out an initial prototype, in order to enhance the ease of use in exploring the interface and empowering the users to easily find the information they are looking for. To achieve this, wireframes are usually employed. They consist in an essential visual depiction of the elements composing the interface, without the use of colors or unnecessary details². By testing these screens with real users, it becomes possible to discover potential issues and inexpensively fix them before committing to a higher-fidelity version of the prototype, in which a considerable amount of resources has already been invested. Regarding the thesis work, wireframes have been used to layout the screens composing the app, which have been subsequently tested with some non-representative users to quickly check the information architecture. Unlike what was reported in the Research Topics assignment, no Wizard-of-Oz testing was used since the finalized system was tested eventually.

High-fidelity prototyping

After a few iteration cycles, the designer could be satisfied with the results gathered from the evaluation phases of the low-fidelity prototypes. In this case, the following steps consists in adding more details to the interface, in order to simulate the final product as much as possible. Therefore, the latest version of the prototype will be translated to a higher definition, specifying more precisely the interface colors, fonts etc. For the project of this masters thesis, the high-fidelity prototype will consist in a online prototype built with web technologies such as HTML, CSS and Javascript, which are further described in chapter 5.

¹<https://marvelapp.com/pop/>

² <https://www.usability.gov/how-to-and-tools/methods/wireframing.html>

2.2.1 Evaluation

The evaluation phase occurs many times during the UCD cycles, since the feedback of the users has to be taken into account to further improve and refine the prototype to reach the final desired outcome. There are many techniques available to the designer at this point, either involving users or usability experts. Nielsen [24] offers a broad overview of these methods, which will be further explained in the following paragraphs.

There are two main options when choosing which kind of evaluation to carry out: either involving the users in the process or have experts analyse the design. The most widely used technique which involves users is called usability testing. It consists in evaluating a system in a controlled laboratory setting (see figure 2.2), to precisely measure aspects such as tasks completion times and number of errors made by the user. The planning of the test includes also the creation of a scenario, which gives a real life context to the user being tested, and a series of specific tasks listed on paper that the participant should follow to try to accomplish the goal of the test. While the test is ongoing, the researchers will observe the user and take notes, possibly recording the user interactions if he/she previously agreed upon it. Another common technique consists in administering at the end of the testing session also questionnaires, such as the System Usability Scale (SUS), to gather further feedback on the pain points occurred during the interaction with the system.

However, due to real-world constraints, it is not always possible to directly involve the users into the testing process. However, several techniques have been designed to pinpoint the interface issues that commonly occur in the design of systems. For instance, heuristic evaluation is described in Nielsen [24] as having usability experts to assess whether the interface elements follow standard rules, called heuristics. This method has proven to be more efficient when 3 to 5 experts explore the interface individually, subsequently meeting to discuss their findings: this setting has proved to uncover on average 75% of the interface problems [25]. See figure 2.3 for an overview of such heuristics. Another method that can be employed to evaluate an interface without the participation of the final users is the cognitive walkthrough. This technique consists in having an expert evaluator which has a deep knowledge and empathy towards the real user, therefore be-



Figure 2.2: a typical setting for usability testing.

ing able to assume how the latter would behave in completing a series of tasks taking into account for instance aspects as technology literacy, memory load and goals to be achieved.

For the specific case of this Masters thesis, the availability of real users for the testing was preferred over the methods not involving them. A more detailed description of the process can be found in chapter 6.

2.2.2 Implementation

The implementation phase comes after possibly many cycles of design and evaluation, either when the resources for the project are scarce or the designer feels to have gathered enough feedback to proceed with the final step of creating the product. However, the feedback collection should continue, since the final system might still need some tweaking or new features could be requested by the final users. Regarding this Masters thesis, the implementation part built upon the high-fidelity prototype that was gradually developed over time.

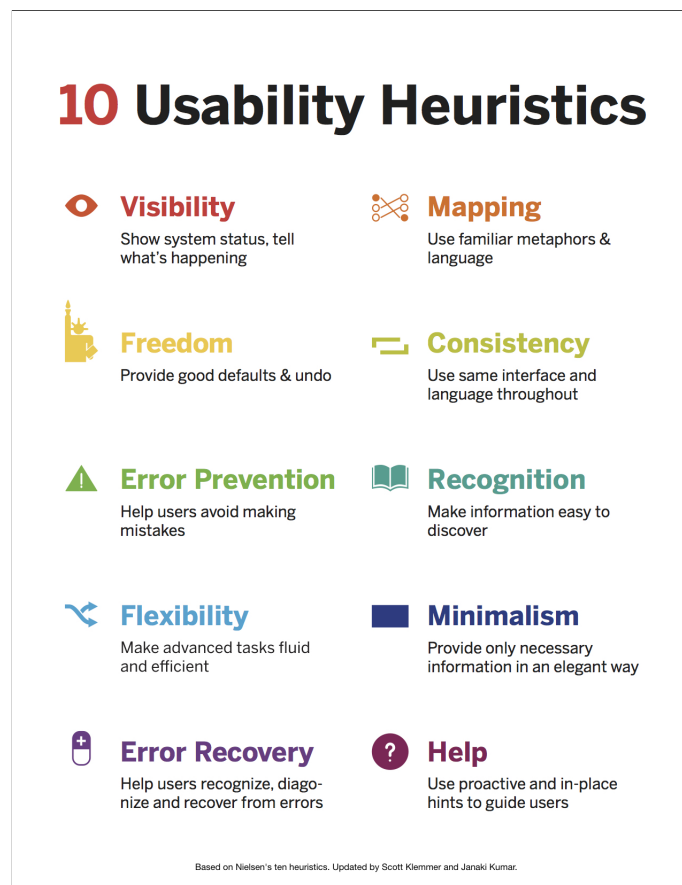


Figure 2.3: the 10 usability heuristics defined by Nielsen (1994).

Chapter 3

Context analysis

THIS chapter will be divided into 5 different parts, each one focusing on specific topics related to the overall research. First, specific exercises regarding the rehabilitation process of Duchenne Muscular Dystrophy (DMD) disorder will be discussed. The second part focuses on gaining insights about music therapy through the available literature. In the third section, the gamification implications for the current project will be outlined. The fourth part will offer an analysis of the existing related work. Lastly, the outcomes of the user research that has been carried out to get a better overview of the stakeholders involved in the project will be discussed. The chapter ends with a thematic analysis of the outcomes, and a description of 4 personas, that together summarize the requirements informing how the final system should fit in its context of use.

The work contained in this section, except for the user research part, has been already presented by the same researcher as a background research for the current Master's thesis in the Research Topics assignment. New information, not present in the previous report, will be explicitly pointed out as such.

3.1 Classic therapy and exercises in the treatment of Duchenne Muscular Dystrophy (DMD)

Since the symptoms of DMD have been already outlined in the Introduction, this section will provide the most common measures that are used to assess the patients respiratory functions, additionally giving an overview on the exercises routine that has been proven to be effective in delaying the weakness of respiratory muscles. Before starting any kind

of therapy, it is instrumental to assess the current lung functionality of the patient. The rationale for this measurement consists in balancing how intensive the exercises should be for the child, since using a standard threshold could potentially harm the subject. Houser & Johnson [13] provide a set of measurements that allows the therapist to get an overview of the lung functionality of the patient:

- Forced Vital Capacity (FVC): the maximum amount of gas that can be forcefully expelled from the lungs after a deep inspiration.
- Maximal Voluntary Ventilation (MVV): the largest amount of air moved through inspiration and expiration in a specific timeframe.
- Forced Expiratory Flow (FEF): The average flow rate during expiration, considered between 25% and 75% of the FVC.
- Peak Expiratory Flow Rate (PEFR): the highest flow rate, lasting at least ten milliseconds, during a single forced expiration.

Regarding the final prototype of the game, FVC could be used for calibration purposes since it was considered to be the best pulmonary reserve indicator by Houser & Johnson [13] (thanks to the interviews carried out with the physiotherapists, which can be found in section 3.5, it has been clarified that the two factors considered for calibration purposes in practical terms are maximal expiration and inspiration rate). After these measurements are recorded, a set of exercises is administered to the children for a total of approximately 20 minutes per day. The importance of such recurring routine resides also in possibly avoiding more invasive methods, such as tracheostomy. Indeed, both the family and the patients frequently reported that the non-invasive methods allows to avoid some consequences of more radical solutions, therefore improving safety, convenience, verbal communication, sleep, swallowing, appearance, comfort and general acceptability [11].

3.2 Music therapy

Music therapy, as reported by the American Music Therapy Association, is “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program”. Following this definition, the goal of music therapy is to be an additional aid to traditional therapies with the aim to improve a patients physical and/or mental health. Indeed, many musical therapy interventions are included in rehabilitation programs to encourage the patient to perform the self-care activities that are part of the daily life. Indubitably, physical rehabilitation has several advantages on the patients quality of life; however, patients frequently report that it is sometimes hard to fully participate due to pain, anxiety or lack of motivation [22]. These feelings often emerge in patients due to the inability to control their environment, since they are dependent on others to perform even the most basic tasks in the daily routine; this results in a feeling of powerlessness of control over their own life. When music is added to a traditional therapy program, the subjects feel they are in control of the environment through the creation of sounds that are powerful and expressive [17] [28]. Additionally, it has been proven that music, in combination with a rehabilitation therapy, allows to improve the success rate of motoric, cognitive and communication [18] [35]. As observed in the research by Purdie & Baldwin, the use of auditory stimuli with rhythm during a therapy involving upper limbs use helped in achieving a smoother and more therapeutically favorable result rather than the control group, which was not exposed to these additional stimuli. However, it is important to note that In the specific case of DMD, unfortunately the advancement of the disease does not make it possible to get a successful rehabilitation, therefore the aim shifts towards the training of the muscles to delay the further decline in their functionality. Moreover, as previously stated, interventions to delay the muscles deterioration have the effect to improve the current quality of life and postpone the need for more invasive methods such as tracheotomy. Since the inception of music therapy there have been numerous studies that attempted to investigate whether embedding music into exercises has a positive effect on the subjects performance. The results are overall positive, with reports of an improved performance by 400% in healthy sub-

jects thanks to the use of rhythmically synchronous cues [36]. On the cognitive side, it has been observed that the repetition of the combination of exercises and music can lead to form new neural connections, which can be trained by repetition and form a strong neural connection over time [14]. Moreover, the repetition of rhythmic sounds have been observed to synchronize with motor neural activity when performing a task based on rhythm [35]. However, it is important to observe that music is not generically beneficial per se and it needs to be carefully chosen to fit the specific set of exercises forming the rehabilitation therapy. For instance, the beat and tempo of the music should be chosen to match the same pace at which the exercise is performed [32]. Moreover, given the engaging nature of music that might push the patient to perform over his/her safety threshold, the respiratory and cardiac rates should be measured whenever music is employed as an aid to the rehabilitation therapy [12]. An additional suggestion by Paul & Ramsay [28] consists in having a pre-warm-up and post-cool-down phases, where music either raises in tempo or winds down at the end of the session. In conclusion, music therapy is a valid aid to a classic rehabilitation program when designed by a professional music therapist, to ensure an appropriate interaction between patient and music.

3.3 Gamification

One of the factors that can be embedded in a rehabilitation program is gamification. In this chapter, the advantages that it brings in aiding the therapy sessions will be highlighted, and the potential inclusion in breathing training programs will be suggested. Gamification consists in the insertion of game mechanics and game design techniques into non-game contexts, such as therapy [10] [4]. However, this definition can be broadened and abstracted by stating that it consists in increasing the user experience and the engagement of a user with a system [5]. Indeed, what video games manage to accomplish is the creation of a fictional environment enriched by narrative, visuals and audio elements, which can promote the interest in something not strictly related to games, such as history [40]. Salen & Zimmerman [31] also support the importance of creating such an immersive context, to allow the players to feel engaged as much as in real life: an

example of a technological development that excels in this approach is Virtual Reality (VR), which allows the users to play within a virtual environment with an additional dimension, which they can explore by wearing a special headset that track their head movements. On top of this setup, additional controllers can be employed to further control the game mechanics (see an example in figure 3.1).



Figure 3.1: gameplay of a VR game.

Over the last two decades, an increasing interest towards the inclusion of video games in therapy setting has developed. Various researchers have assessed the potential gain yielded by the inclusion of gaming elements in different fields, such as education. Amongst these advantages there are immediate feedback, availability of information on-demand, productive learning, motivating cycles of expertise, self-regulated learning or team collaboration [10]. The video games efficiency in motivating and engaging the players is given by the way they impact their cognitive, emotional and social areas [19]. For instance, the aforementioned cycles of expertise are strictly connected to the cognitive area: a game is usually designed with a set of rules that regulate the virtual environment, and tasks are provided to the user in order to learn and master these rules through trial and error [5] [10]. Regarding the emotional aspect, there are two main outcomes: success or failure. On the one hand, upon successfully completing a quest the player usually receives either points, trophies or items to reinforce the positive emotions he/she experienced.

Wang & Sun [39] identified eight different forms of reward that can be used to celebrate success in a game: score systems, experience points, items, resources, achievements, instant feedback messages, plot animations, and game content. On the other hand, failing to complete a goal should lead to a state of anxiety (frustration should be avoided to ensure that the user keeps playing) that should be well calibrated, potentially including low penalties that encourage experimentation and task repetition [5]. It is interesting to note that the combination of repetitive skills training (cognitive area) and rewards (emotional area) have the effect to facilitate the release of dopamine, which in turn facilitates learning and neuroplasticity [33]. It has been proved that video games have this effect as well, thanks to the adoption of repetition and rewards as inner mechanics [16]. Therefore, the inclusion of game mechanics in a therapy program could help to change the behavior and focus of the patient, leading to an improve attendance of the exercises [14]. This assumption has been tested by Villozzi et al. [38] in an experiment utilizing video games for therapy purposes, and success was achieved since all the patients completed the assigned exercises. Lastly, the social area is affected when interaction between different players is involved. The outcomes of this interaction could be either of a cooperative or competitive nature, and it can yield a sense of recognition from peers [20]. Concerning the aforementioned cycles of expertise and their connection to the cognitive area, it is interesting to further define the kind of tasks that are required within a video game. Indeed, a difference stands between little and big games: the former consist in the set of sub-skills which are fundamental for the game mechanics (e.g. learning how to jump or hit an enemy in Super Mario), while the latter are focused on the end goal of the game (e.g. defeating the final boss) [14]. The reason why this division is important stands in the fact that the little games are designed sequentially to allow the player to increasingly train and master the available skills, with the big game being the final goal that can be reached once all these abilities have been properly acquired. Following this structure, it becomes possible to add gamification elements in therapy by using video games which require the patients to train skills for example inhaling deeply and coughing in the case of DMD that are needed to proceed in the levels of the game [34]. Following the discussion above on the cognitive, emotional and social aspects to enhance motivation and

engagement, it can be derived that the main goal of game design is to change a players behavior [31]. For instance, it has been observed that gamification mechanics can be used to motivate students and trigger a certain behavior [23]. To design a game with such desired outcome in the case of children affected by DMD , it is useful to refer to the 6 dimensions of game design discussed by Garriss et al. [9].

- *Fantasy*: create a compelling narrative that stimulates the childs imagination;
- *Rules/Aims*: the child has to follow the rules put in place by the therapist;
- *Sensory stimuli*: based on these, the child has to carry out actions and react to novel situations;
- *Challenge*: there are constraints that make the game challenging, for example a time limit or a certain threshold to reach;
- *Mystery*: there should be some unknown parts that motivate the child to further explore the game;
- *Control*: the goal of the game must be clear to the child, and he/she must be confident in using the controller (e.g. Groovtube) to achieve the goal.

It can be stated that there are several advantages in including game mechanics in therapy settings, with the end goal of enhancing motivation and engagement of the patients which potentially lead to an increased intensity of the exercises that the patient is willing to take. The design of interactive, gamified rehabilitation tools can bring novelty and attraction to the user, therefore facilitating the cognitive/motor rehabilitation process [14]. To achieve this end goal, the therapist and game designer should collaborate to create a game setting that includes challenges that have a therapeutic effect, although the child should not be aware of these as they are hidden as skills that need to be developed in order to proceed through the levels [14]. Another important consideration regarding the end user is the current stage of the disease: indeed, Villozzi et al. [38] suggest that video games should be designed for breathing exercises that aim at improving/maintaining the respiratory performance especially for children affected by DMD who were recently immobilized and still have moderate lung functionality.

To conclude the gamification section, it can be said that by including some of the aforementioned gamification elements, such as rankings and special elements, it is possible to trigger the release of dopamine which in turn gives a positive feeling towards the game and allows an easier inclusion of the respiratory exercises in a daily routine.

3.4 Related work

In this section, an overview of the available technologies currently used in therapy is given. Thanks to this analysis, it will be possible to get an understanding of which devices are used to sense the breathing pattern of the patient and which applications have been designed to embed either music and/or gamification elements into therapy.

3.4.1 Hardware solutions

Groovtube

The Groovtube is a device that can sense both inhaling and exhaling and the intensity of the airflow. It uses the Bluetooth Smart technology to seamlessly communicate with the device that is running the related apps, such as a tablet.



Figure 3.2: The Groovtube device.

Depending on the arms functionality of the patient, it can be either held with the hands or fixated on a stand. One downside of the Groovtube is the cost: indeed, one family needs to spend approximately 1500 euro (as reported by the interviewed therapist) in order to purchase one for home use.

MagicFlute

The MagicFlute comes from the same producer of the Groovtube. However, it has a different interaction mechanism which makes it possible for patients to change the pitch of the instrument they play through the device. Indeed, a subject can move the head upwards while blowing into the device to reach a higher pitch, while he/she can lower it to obtain the reverse effect. This additional interaction makes it possible for subjects to express their creativity with music, without the need to know how to play a particular instrument. Moreover, the use of speakers that amplify the volume of the music compensates for the usually lower lung functionality of the patients, potentially making them feel powerful and in control of the music they produce. As the previous product, it is not affordable by every family since the cost of the device is around 2500 euro.

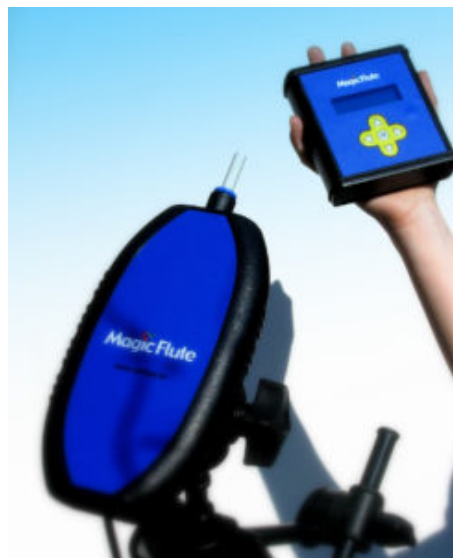


Figure 3.3: The MagicFlute device.

Wind Synthesizers

Wind synthesizers do not produce sounds directly; instead, they have a built-in MIDI controller that sends information to a device capable to interpret those messages (e.g. a personal computer). They allow much more control than the Groovtube and the MagicFlute, since they simulate a normal flute holes with areas that can be pressed to generate a different note (figure 3.4). It is therefore good to observe that they provide much more creative freedom, although some knowledge of music theory might be needed to avoid frustration in being unable to generate pleasant, coherent melodies. Moreover, they might not be usable for most of the patients affected by DMD since the disease renders the upper limbs not functional in a quite early stage already.

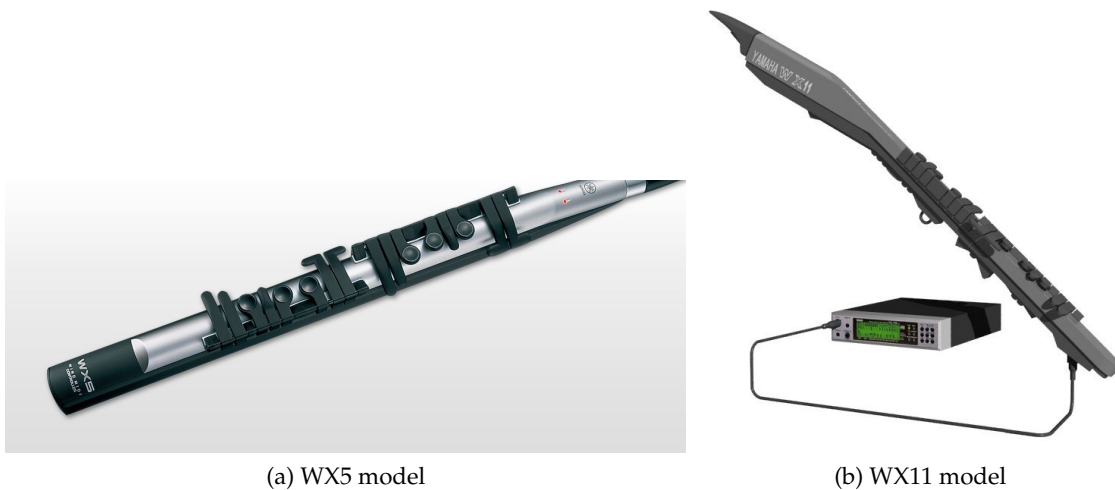


Figure 3.4: Two wind synthesizers by Yamaha

SoundBeam

Although not strictly related to breathing, the SoundBeam is a device that is worth mentioning since it has been used in several projects concerning rehabilitation through music. The SoundBeam, as depicted in figure 3.5, works through a combination of ultrasound (sonar) sensors and tangible controllers. By moving the hands in front of the red torch-shaped devices, it is possible to control the pitch of the currently selected effect, while pressing the tangible controllers allows to quickly change or add more sounds to the



Figure 3.5: The SoundBeam system.

composition, therefore adding a more complex dimension to the composition. For the specific case of DMD patients, this device could be used in the very early stage of the disease to further train the upper limbs, combined with a singing-along practice that would help them to train the diaphragm muscle.

3.4.2 Software implementations

In the previous section, a collection of hardware devices currently employed in rehabilitation through music has been described. However, all of them need a software component to work being it an application that assigns sound samples to input MIDI files or an app that can use the breathing patterns as a controller for a game. Especially regarding games, the increase of game-based applications over the last decades also in the education and health sectors make this approach valuable in rehabilitation since children are growing up in a technologically advanced world [15][41]. In this section, the focus will be on the available software solutions, especially focusing on the Groovtube app suite since it uses breathing patterns for musical and/or gamification purposes. In the following sections, a thorough analysis of how they work, their advantages and issues will be carried out.

Groovtube app

The first application that was released with the homonym device was the Groovtube app. As depicted in figure 3.6, the user can select an available image in the gallery and an effect to apply. Moreover, either exhaling or inhaling can be chosen to control the effect. The game consists indeed in either exhaling or inhaling to control the amount of effect applied to the picture: when the user breaths at his/her maximal, the effect will distort the image the most, while when the breathing effort ceases the image goes back to normal.

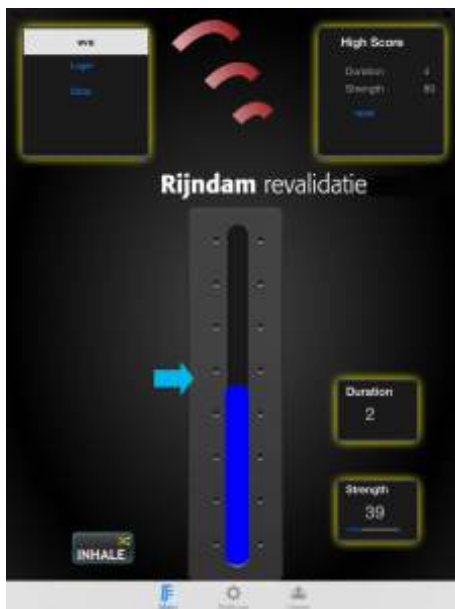


Figure 3.6: the Groovtube app, showing an increased effect when the patient exhales.

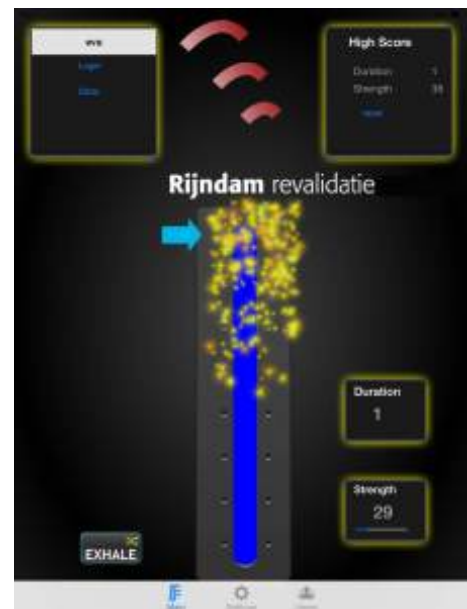
Carrying out observations on children using the app, there are two main considerations that need to be reported. First, they seemed to find the game quite funny and enjoyable, since they could pick new pictures and effects to play with. However, the second consideration would be that the long-term engagement achievable with such application could potentially be very low, since once all the effects have been explored there is no mechanism, such as badges and rewards, that could motivate the children to return and use the application again. However, this potential issue needs to be further investigated with further interviews both to the therapists and children.

Fairhammer

Fairhammer simulates a typical Dutch game called De Kop van Jut, which is fairly famous also in other countries. The goal of the original game is to hit a surface with a hammer, which pushes an object upwards in a tube depending on the amount of force applied to the surface. This mechanism has been re-used in Fairhammer, since the blue bar that can be seen in figure 3.7a grows in height depending on the exhalation/inhalation force received through the Groovtube device. On one hand, this game has the perk of using already existing familiar knowledge of a classic game, therefore making it easier to approach at first instance. Moreover, an interesting gamification element consists in the general ranking visible on the upper-right corner, which could potentially give more motivation to perform better given the competition factor.



(a) Raising bar



(b) Goal reached, showing celebratory animation

Figure 3.7: Screenshots of the Fairhammer app

BilliardBreath

Another game in the Groovtube suite is BilliardBreath. The goal of the game consists in raising the black balls depicted in figure 3.8a to the uppermost boundary of the container through breathing. The game was designed to support different difficulty levels (low, mid and high) and three different modes: duration, sequence and power. In duration mode the children will practice the endurance of their breathing: indeed, they will need to inhale/exhale for a specific amount of time to raise all the balls. In sequence mode the balls need to be controlled one at the time: this favors the training of rhythmic breathing, with quick and powerful inhalation/exhalation efforts. The last available mode is power, and it consists in training the breathing strength by having to raise all the balls to the ceiling by putting as much power as possible in the exhalation/inhalation process.



(a) Billiard balls moving up

(b) Final celebratory effect

Figure 3.8: Screenshots of the BilliardBreath app.

As shown in the rightmost picture of figure 3.8b, when the patient reaches the goal of the current exercise the game shows a celebratory animation and also plays a corresponding sound. The praise of the performance appears to be an interesting addition to the game, but it could be made more interesting by the addition of badges or rewards, which are common gaming elements embedded in several games that aim for the long-term commitment of the player nowadays.

Breath Music

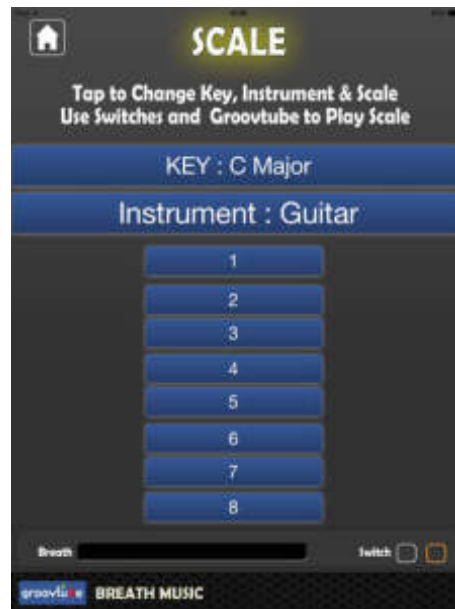


Figure 3.9: Screenshot of the BilliardBreath app in Scale mode.

The Breath Music app is one of the two apps in the Groovtube suite that embeds music in the breathing exercises. It does so by offering three different modes:

- *Scale*: this mode offers the user to select a scale and an instrument. When the game starts, he/she can create pleasant melodies by inhaling/exhaling in the Groovtube device.
- *Tap*: the patients can select between the available songs and, once the game starts, they can increase the playing speed of the music by exhaling and decrease it by breathing in.
- *Song*: this mode allows the patient to choose a song to perform, with the goal of breathing in the device to rhythmically follow the song.

The interesting aspect of this app is the investigation on how music can be altered by people with disabilities. Indeed, the breathing is used as controlling element to change different property of music as tempo, or to allow one to create pleasant melodies without the need of music theory knowledge or the use of the limbs.

Breath Trainer

The goal of the game is to cycle as fast as possible through breathing. Figure 3.10 shows the three different modes available to the user: endurance & strength, endurance and strength. As depicted below, the difference between them consists in the slope that the character cycles on: the steeper it is, the more strength is required to proceed. Moreover, there are four difficulty levels that can be chosen to make the game more challenging low, medium, high and very high.

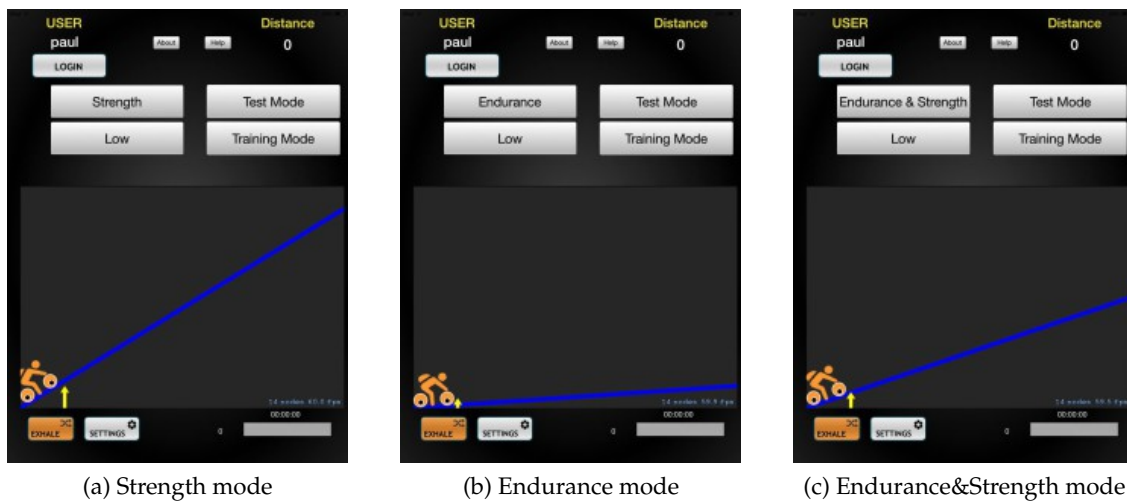


Figure 3.10: Screenshots of the Breath Trainer app in the three available modes.

An interesting addition compared to the other apps are the test and training modes. The former is used as a calibration tool to assess the maximal inhalation/exhalation levels of the patient, while the latter gives the opportunity to set the repetitions for a set of exercises. A calibration might be needed also in the other application discussed in this chapter, since the breathing maximal level differs between patients based on the stage of the disease.

BreathScore

BreathScore is the second and last app in the Groovtube suite that incorporates music in the proposed exercises. The game consists in selecting one of the available songs and listen to it in its entirety as a first step. Subsequently, as depicted in figure 3.11, the child

plays it note by note by either inhaling or exhaling in the Groovtube device. Once the breathing has been sensed, the next note is highlighted and it proceeds this way until the end of the song. Without hands-on experience on the app, the guess is the duration of the breath should match the duration of the current note as reported on the score sheet.

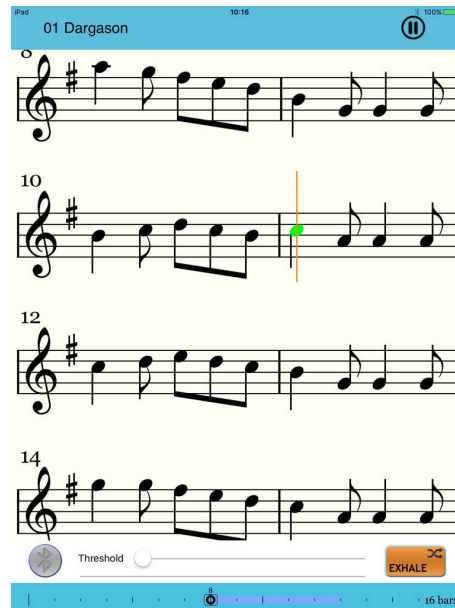


Figure 3.11: Screenshot of the BreathScore app.

Groovy the Dragon

Compared to the previously analyzed apps, Groovy the Dragon seems the one where the gamification aspect has been thoroughly developed. Indeed, Groovy the Dragon takes the same game mechanics of more commercial, mainstream video games such as Flappy Bird and allows to control the character through breathing. As shown in figure 3.12, the player controls a dragon that has to proceed from left to right on a screen, avoiding the obstacles on the track. To achieve this there are two ways, since different modes are available. In the gravity mode, the dragon will keep its position after the player stops blowing or inhaling into the Groovtube. In the most difficult setting, the dragon will start to fall down to the bottom of the screen when the inhaling/exhaling process is over: the consequence is that the child needs to keep breathing more often into the device in order

to maintain the dragon position. Compared to the previous attempts by Groovtube, this app seems to potentially provide a longer engagement for the children, and it could be further improved by adding further gamification elements such as rankings, badges and rewards.

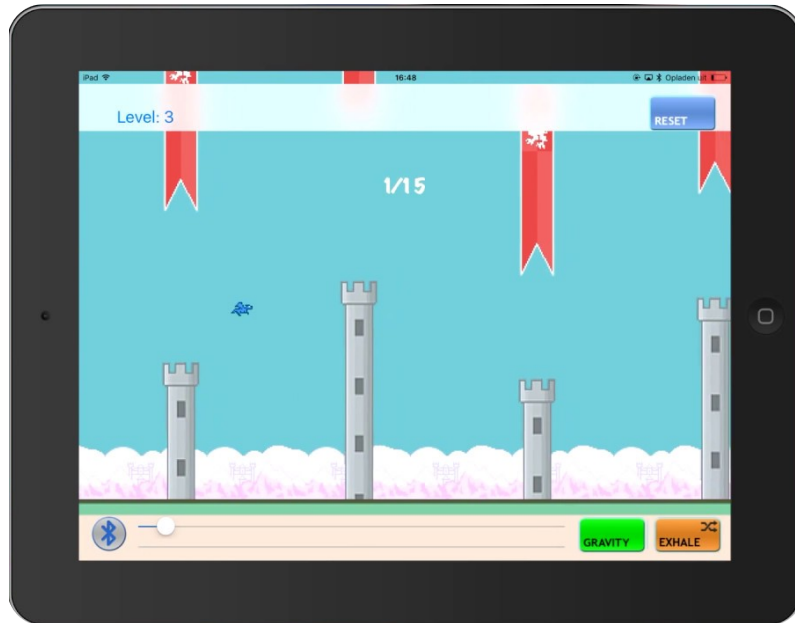


Figure 3.12: screenshot of the gameplay in the Groovy the Dragon game.

General comments on the Groovtube suite

Overall, Groovtube created several interesting applications that explore different ways of training the breathing muscles. A general remark goes to the lack of consistency in the different apps: indeed, some of them have useful game mechanics embedded, such as rankings that could enhance the motivation in sticking to the games in the long-term therefore leading to an improved therapy attendance and celebratory animations when the end goal is reached. However, these useful elements are not used in every game despite the potential they could bring. I suggest that by making the apps more consistent in their content and visual design, it could also improve their familiarity and ease of use when switching between the. An additional remark goes to the interface of most of the apps: as it can be observed, there is a striking difference in the visual appeal of the screens

of figure 3.8 and 3.12 in terms of richness of color and attention to details. I consider this an important factor, since the apps are targeting mainly young children that might be more attracted to a cheerful and colorful interface rather than a mostly black screen filled with gray buttons.

3.5 User research

In order to shape the product according to the final users' needs and limitations, different stakeholders have been involved in the design process. There are two main figures that can give insights on the children's lives and attitudes towards DMD and the therapy they follow: the therapists, which assist them during the rehabilitation process, and the parents. Semi-structured interviews have been used to gather relevant data for the project, since they allow the researcher to explore topics of interest while being open to break from the strict structure and follow the conversation to potentially discover topics and gather additional qualitative insights.

3.5.1 Observations of a music therapy session

The music therapy sessions organized in the Roessingh Centre take place always in the same room, which is equipped with a big table around which all the children sit. A keyboard (figure 3.13), which can be played by exhaling in a tube connected to it, is placed in front of every child. The session is led by the music teacher, who is also playing a guitar, singing along and giving instructions on which note has to be played at a specific time. As it can be already noted from figure 3.13, the keys have been equipped with coloured labels with the name of the note printed on them.

The following discussion with the music therapists revealed that nowadays music education is not taught anymore in many schools, including the Roessingh Centrum, therefore children grow up without the basic knowledge about musical notes, hence the coloured labels. This is an interesting finding, since it suggests that any system incorporating music and directed to children as main user should not take music education for granted, therefore offering a way to successfully play and transform music in a more straightforward

ward and simple way. Another important aspect that has been incorporated in therapy was a **narrative**: instead of presenting the breathing exercises as a must-do task for rehabilitation, the therapist and music teacher invented a story where the children were acting as archers who needed to shoot an arrow and kill a monster. The imaginary bow was loaded by deeply inhaling, and fast exhalations were used to shoot the arrows. This setup confirms a need for coupling the breathing efforts with meaningful controls that results in game actions in the current project.



Figure 3.13: Keyboard used in the music therapy sessions.

Another important finding came from further observing the music therapy session. Indeed, when a child was playing out of tempo he performance was not stopped and the teacher kept repeating patiently at the right time which note needed to be played next. The fact of carrying on with the musical act avoids to put a child under stress because he/she is not getting the right notes at the right time. This is potentially an important factor to keep into consideration for the final design of the system: a child affected by DMD already goes through physical and psychological stress, the game should not pun-

ish for a bad performance. Conversely, as it happens during the music therapy sessions, the performance should be complimented anyway at the end to encourage retention.

The need for a complete system which allows the training of both exhalation and inhalation revealed itself during the therapy session. Since the centre was not equipped with a device to train inhalation, the therapists use an hookah, which is a device traditionally used in many countries to smoke some flavoured tobacco. Clearly no smoking was involved in the therapy, however the device was used to train inhalation. The exercise consisted in inhaling at the same intensity level for approximately 5 to 8 seconds. It is important to notice that the feedback for a bad performance is still positive, encouraging the kid to try again if possible to reach an higher performance without putting stress on him. In later interviews, a therapist affirmed that the device is liked by the children, since it gives a nice bubbly feedback that is perceived as playful and funny. Moreover, he also stated that giving the children the power to transform something through breathing gives them a sense of control and power, aspects which are progressively taken away by the disorder that affects them. Therefore, this partly suggests that controlling a digital system through breathing could be an engaging and powering experience or them.

3.5.2 Interviews

A limited number of interviews were carried out to inform the design of the system. This is due to several reasons: regarding the parents, only few children with DMD that are following the therapy sessions at the Roessingh Centre fully developed the cognitive skills necessary to understand and play a game effectively. Therefore, few cases were eligible to gather insights for the current project. Concerning the therapists, after two interviews the data yielded was very similar, since they shared the same professional opinions on the therapies and their efficacy. Consequently, no additional professional was interviewed. However, given the qualitative nature of the study, enough insights were gathered to get a sufficient overview, although more participants would have potentially brought more insights. The questions, the information and consent forms used for the interview process can be found in appendix A.

Thematic analysis of user research

All the interviews were recorded, in order to give the researcher the ability to focus on the conversation and follow potential interesting divergences from the main questions, while being able to further analyse the conversation afterwards. As previously discussed in chapter 2, the method used to gather insights from these interviews is called thematic analysis. The results presented below (see appendix A) will inform the personas describing the stakeholders involved in this project, which can be found in section 3.6.

Focusing on the analysis of the physiotherapists interviews, the following themes were found to be relevant for the current project.

- **Ideal home training:** both physiotherapists agreed on an important point, namely the non-hazardous nature of training at home without a professional figure following the session. On the contrary, they both stated that it is more dangerous for the children to not train, therefore reducing their lung functionality levels. Moreover, there was an agreement on the fact that a gamified solution could help in delaying the dependence upon mechanical assisted breathing devices. It is fundamental to stress the importance of the gamification component, since in their professional experience traditional methods are considered boring by children and are rarely employed in a home setting on a long-term basis. On top of these considerations, the game should be easy to play and short, allowing for gaming sessions between 10 and 20 minutes per day.
- **Issues to stick to the therapy at home:** children affected by DMD have more tasks to carry out during the day, since that on top of school duties they also need to participate to therapy sessions. The main consequence of this aspect consists in less motivation to spend part of their free time in the evening to exercise, according to the physiotherapists.
- **Features needed by therapists:** there are three main features the interviewees mentioned. First, the ability to schedule a training plan for the week and have the game adapt to it. Secondly, the possibility to tweak the settings to keep the children exercise at their maximum capacity. Lastly, the system should be able to save the

previous calibrations and settings for the children, so the physiotherapists are not forced to input them every time they access the game.

- **General and individual therapy:** the general therapy includes all the different respiration patterns, which include inhaling and exhaling with difference force and depth. This routine should generally be practised by all patients, although a specific therapy is needed when particular respiratory issues are present.
- **Advantages of embedding gamification elements:** the physiotherapists reported that games, compared to traditional exercises employing medical equipment, seem to increase the motivation and consequently the attendance to the therapy. Another insight on the reasons behind this preference resides in the ability to change elements of the virtual world with their breath offered by this kind of videogames, which potentially make them temporarily unaware on their disability by shifting the focus to a different environment, where they are in control.
- **System / game design considerations:** both professionals mentioned that a social aspect embedded in the game would be more engaging for children ("like in sports, if there's a group is usually more fun to do, right?"). Regarding a potential ranking system to motivate them in competing with each other, an important insight consisted in avoiding the comparison of respiratory performances, since it could be demotivating. The scoring system should be based solely on the gaming skills. Additionally, some minor insights on respiration levels and equipment design were discussed.
- **Issues or missing features in current solutions:** the current gamified therapy carried out through the Groovtube suite does not allow to save calibration data. The therapists reported that for some time they wrote down the data on paper and tried to keep track of children's performances. Moreover, sometimes the apps freeze and the therapist is forced to close them and open them again, therefore losing precious time that should be dedicated to train the children's lung functionality.

In the following paragraphs, the thematic analysis of the parent's interview will be discussed. Some insights that emerged were not related to a particular theme, although

they offer a deeper understanding of the ways in which the DMD disorder affects these children. Indeed, the parent interviewed for this study has two children affected by DMD, but they are profoundly different in cognitive functions. Indeed, one of them is as intelligent as peers of the same age group, while the other has not fully developed and cannot communicate neither verbally nor in a written form. This aspect is important to consider, since it shows that although they are affected by the same disorder there might be a considerable gap in mental and motor skills. Regarding the motor ability, the insights previously gathered through observation during the music therapy session also showed that there is a wide spectrum of differences in how precisely they can use fingers to interact with physical objects. Thus, the future addition of controllers requiring this kind of interaction needs to be thoroughly tested and potentially target a sub-group of children affected by DMD.

From the thematic analysis, the following insights were gathered:

- **Motivation:** this theme highlights the difficulty that children affected by DMD have to keep a high level of motivation regarding the therapy they should carry out individually in the home setting. As the interview revealed, the main cause seems to be an intense schedule throughout the day, as the physiotherapists also reported. To make sure that the children do a sufficient amount of therapy, the Roessingh centre allows them to participate to the therapy sessions throughout the day, so when they return home they do not have to perform necessarily any.
- **Autonomy:** the way DMD changes children's lives concerns especially autonomy. Indeed, they rely on their parents almost totally, from moving around on long distances to personal care. However, videogames seem to offer an escape from this reality, where they are in power to change the virtual environment without assistance. Moreover, the possibility to play with friends online contributes to keep a contact with them, despite the physical distance.
- **Preferences regarding therapies:** there are a few therapies that the children undergo. For instance, in music therapy sessions they train the respiratory muscles by playing a keyboard which produces sounds by breathing through a tube. For

general muscle training, they participate in activities such as swimming and cycling. An interesting insight coming from this aspect is that the children mainly like the group activities: indeed, the worst experience reported concerns the individual tests for lung functionality carried out in the hospital setting, whereas group therapy sessions such as playing music and swimming are the most liked ones. Although the hospital introduced some gamified solutions to motivate the children to complete the tests, such as blowing off candles or playing bowling with breath as control system, the setting and lack of a group creates a sort of hostility towards them. Conversely, the games played in the cozy rooms of the Roessingh centre in a group setting received positive feedbacks.

- **Social gaming:** the importance of the social aspect in gaming was mentioned several times during the interview. Videogames have a special significance for the child with normal cognitive abilities, since he plays both online when he cannot physically reach friends and also on-site when they are visiting him.
- **Game design:** lastly, the interviewee gave some insights on game design aspects. The game should be used as a visual system where children can focus on, embedding it with music elements that can improve the engagement with the product. Moreover, the possibility to play either in a competitive or collaborative manner with others, both school friends and other children affected by DMD, has been confirmed as a very desirable feature. All the aforementioned elements would concur in giving to the product a game-like feeling, leaving the therapy aspect in the background.

3.6 Personas

The method concerning the creation and use of personas is described in chapter 2. In this section, three different personas will be portrayed to represent the main stakeholders of the project: physiotherapists, children affected by DMD and their parents. These fictional descriptions are based on the data collected through interviews and observations; however, the number of samples has no statistical significance and more participants would

be needed to generalize these descriptions and potentially create new ones that describe different facets of the same persona's group. Nonetheless, personas are an useful design tool that can summarize well the data gathered and be used as a reality check when design decisions are taken.

Thomas, physiotherapist

"Planning exercises in sets and repetitions is highly desirable. After all, we are training muscles like in the gym".

Thomas is a 35 years old professional physiotherapist who has worked several years in different rehabilitation centres. At this point of his career, he is focusing on muscular disorders that affect children. Since he is constantly in contact with the children for whom he plans sessions and exercises, he knows well what they like and dislike regarding the different therapies they have to follow. He strongly believes that the group ones are the most effective in terms of engagement for them. Moreover, he is curious and always looking into new innovative system to incorporate into the sessions he organizes, such as have the children creating music together with special instruments or playing videogames through accessible controllers.

He is also aware of the power that technology brings and the possibilities that it could open in terms of therapy. Lately, he is been searching for a gamified system that allows to plan the individual therapy for children in terms of repetitions and sets, subsequently having the game adapt to these settings. Moreover, he believes that collecting data about the children's performances could give a better understanding of the their lung function in the long term and offer a better therapeutic overview on their current situation.

Part of the therapy he prepares is intended to be carried out by the children individually in their home, however he believes it is really difficult to reach a good result in this scenario for many different factors. However, he believes that an engaging game could be helpful since therapeutic exercises could be hidden in it, therefore avoiding to give the feeling of training.

Ines, parent

"Playing video games is basically the only activity that our child can do without our assistance".

Ines is a 52 years old mother and full-time worker as a doctor's assistant in a clinic. She has been married with her husband Jos for 16 years, and they are the parents of a 14 years old teenager named Lucas, who is affected by DMD.

A normal day for her is really busy: she starts preparing Lucas for school early in the morning, around 06:30 AM. When he catches the bus, she heads to work for the rest of the day. When Lucas comes back after school, they spend some time together and do some activities, such as listening to music, walking out the dog or playing some games together. After that, she helps him with his personal care and get him to bed around 21:30.

The family does not live in the city where Lucas attends school or the rehabilitation sessions. This is an issue, since for him seeing his friends becomes difficult and he always has to rely on the availability of the parents. However, friends frequently come to his place to visit him and spend some time playing videogames together. On top of this, online gaming is an opportunity for Lucas to stay in touch with friends, since during the week his parents cannot drive him around due to their working schedule.

Ines know whether Lucas finds a therapeutic exercise enjoyable or not. For instance, she knows that he prefers activities that are done in a group setting, such as swimming or music therapy. Moreover, the hospital setting is very disliked by Lucas, while he does not complain about the setting at the rehabilitation centre.

She is open to new ideas on how to help her son practice more and be healthier. She would be interested in trying out new systems, although the cost is really important since the current expenses the parents undergo for special equipment and therapy are becoming quite consistent.

Lucas, child

Lucas is a 14 years old boy affected by DMD. He lives with his parents outside the

city where he goes to school and does rehabilitation. Compared to friends of his own age, he has a normal level of intelligence and cognitive functions are developed, despite being affected by the DMD disorder. This aspect has equally positive and negative sides, since unlike other children with low cognitive abilities he is aware of his situation, and he struggles with the fact that his health is going to deteriorate over time. Despite this fact, he talks with the parents about his future plans such as getting married and having children. His mood swings frequently, mostly on a daily basis, depending also on other factors, such as the quality of sleep and whether or not he experienced pain on that day.

In order to move around independently, he uses an electric wheelchair since he cannot walk and stand up straight on his own anymore, whereas he still has some ability in controlling the muscles of the arms and almost full control of his fingers. Although the wheelchair is an useful aid for his autonomy, he cannot travel back to the city on his own to visit his friends: in this case, the assistance of his parents is needed. However, he is able to roam around the neighbourhood and visit some relatives with whom he likes to spend some time. Regarding the autonomy aspect, he is dependent on the help of a third person for virtually every task. However, playing videogames is one of the rare activities he can carry out independently, since he still has full control of his fingers.

His schedule in a normal day of the week is quite tight compared to an average teenager not affected by DMD, since on top of school he needs also to participate to different therapy sessions. Due to this busy itinerary, when he comes home in the evening he is tired and lacks of motivation to carry out additional exercises given by the physiotherapist: it is seldom the case that he forgets to complete them. If he could choose, he would play videogames online with his friends.

Lucas follows different therapies, such as swimming, cycling and music therapy. His preference goes for the ones that are done in group, since they are less boring. The task he likes the least is doing the respiratory tests at the hospital, because the setting is not nice and the mask he needs to wear make his jaws hurt.

Daan, child with cognitive deficiencies

Although the interview with the parent gave some insights on this type of child in the

Duchenne realm, it is very difficult to portray them in the form of a persona like the previous cases. The main issue is that they generally have some degree of difficulty in communicating with whom is around them, thus making it difficult for the researcher to give a detailed description of this kind of user. Generally speaking, some insights gathered through interviews and observations during the evaluation phase gave the impression that children like Daan are introvert and have a hard time focusing on the tasks at hand.

Chapter 4

Conceptual Design

THANKS to both the literature and the user research analysed in the previous chapter, the design of the overall system and the requirements to be complied with have been made clear. In the following sections, the conceptual model of the system will be discussed. The next chapter will focus on its technical implementation, delving into the details regarding every component of the system.

Overall, the system as a whole consists of both hardware and software components (see figure 4.1). On the hardware side it is instrumental to retrieve data about the patient's breathing pattern and be able to forward this information through an Internet connection to the gaming system, which will be further processed and transformed in controls that allow to proceed throughout the levels. Regarding the software aspect, the game itself is played on a tablet/computer: the pre-game calibration is saved online and retrieved for analysis purposes, with the leaderboard being saved on an online database as well.

4.1 Generalized input mapping

Although the current project focuses on using respiration as controls, the architecture of the system allows to integrate other sensors which can address different motor issues that need rehabilitation. For instance, to train the arm movement it would be possible to send the proximity data coming from an infra-red sensor to the gaming component, mapping the yielded distances to an in-game action. This flexible approach allows to have separate hardware components, which can be programmed to send data to the game; the latter will contain the logic that accepts a given input source and maps the data received

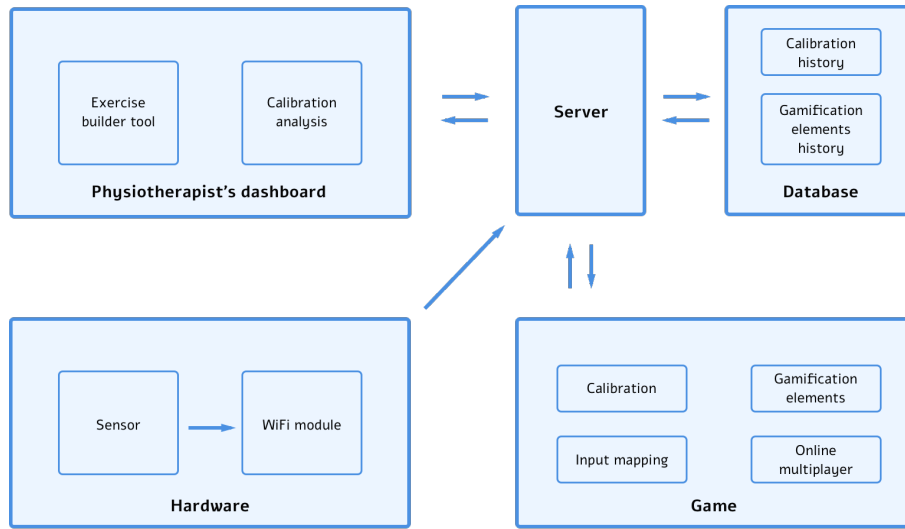


Figure 4.1: Conceptual design architecture of the system.

to specific actions. Therefore, it is possible to envision a single game which can be played with different controllers and make it accessible to a wider audience of people affected by disorders which limit their mobility and dexterity. Microsoft recently announced that it will release an adaptive controller for Xbox ¹, which will allow the definition of customized controls. This system is specifically targeting customers with limited mobility, hence proving that the topic of accessible gaming is gaining traction even at the industry level.

4.2 Inclusion of therapeutic aspects

However, there is one important facet that this project aims to address unlike the Microsoft controller: the inclusion of therapeutic elements in the game design. Whereas the latter focuses on the onboarding of a different audience in their platform, the current project tries to address a need that has emerged in the interviews with professionals physiotherapist and music therapists, namely the inclusion and scheduling of therapeutic exercises into the game design. Indeed, the levels architecture could change depending on which training patterns the physiotherapist decides to include. For instance, as reported in the interviews analysed in chapter 3.5, there are different breathing patterns

¹<https://www.microsoft.com/en-us/p/xbox-adaptive-controller/8nsdbhz1n3d8>

that should be scheduled and worked out, potentially for the whole week. Through a web interface, the physiotherapist could access the data of the children using the system, checking whether their breathing performance is steady or has worsened over time and consequently plan the following week, focusing for example more on fast exhalations rather than deep inhalation. As for the music therapists, their contribution would consist in developing more music and subsequently cooperate on the level design, in order to offer a wider range of songs. This, in turn, has the effect of keeping an high engagement with the platform. Once the exercises have been set, whenever a child plays the game the interface would inform him on the currently active controls.

4.3 Game concepts and music as hinting system

As previously discussed in chapter 3.2, music is an additional element that has been proven by several studies to be effective in therapy settings. There are many potential implementations of music as an effective dimension in gaming setting of the current project: for example, it would be possible to create music with the breath, perhaps choosing sounds of different instruments. Extending this particular idea, there could be different modalities such as following along a song or playing freely and improvise without constraints. Aside from the inclusion of breathing patterns as controller, there are many existing games that have explored this paradigm: some notable examples comprise Guitar Hero, Frets on Fire and DJ Hero. The common design pattern they follow is to have a path in which the controls, which are paired with the music beat, flow into the direction of the user (see figure 4.2). Once they come to a specific point in this track, the beat of the music will happen and the player should press them at the right time. Depending on the precision of the user, they usually give different feedback messages such as "Perfect", "Great", "Good" or "Missed" and assign a different score based on the timing.

Additionally, a common feature these kind of games have is to require a specific controller designed by the producer, which is intended to better fit the metaphor of the game. For instance, Guitar Hero comes with a controller shaped like an electric guitar, in which the frets are represented by 5 buttons, which colours match the ones used in the user



Figure 4.2: Screenshot of the Guitar Hero 2 gameplay.

interface. Moreover, another knob placed where strings are usually struck in a normal guitar needs to be activated at the same time as the beat to effectively play the note. The DJ Hero custom controller (figure 4.3) exemplifies this concept, giving the user the possibility to effectively mimic how a DJ turntable would be used in a real-world setting.



Figure 4.3: The custom DJ Hero controller.

While exploring potential candidate ideas for the game design, an interesting concept

has been found. Indeed, a peculiar category of videogames exists in which the music shapes the level design and the movement of the elements within. A few representative instances of such group include Sound Shapes ², a platformer where elements in the level react to a specific song's beat and details. For instance, part of the floor where the player can walk on appears and vanishes based on the presence or not of a chorus in the background song, or the missiles move or stop in the air according to the bass guitar rhythm. A similar game concept can be found in Lost in Harmony ³, a musical runner where the music gives hints on the exact moment when to perform an action, such as move on another side of the screen to avoid incoming obstacles. The same concept is offered in several levels of Rayman Legends ⁴. An additional runner game utilizing a similar approach is Melody's Escape ⁵ (figure 4.4), where on top of the hinting system the speed of the player varies based on the increasing/decreasing beat of the song.

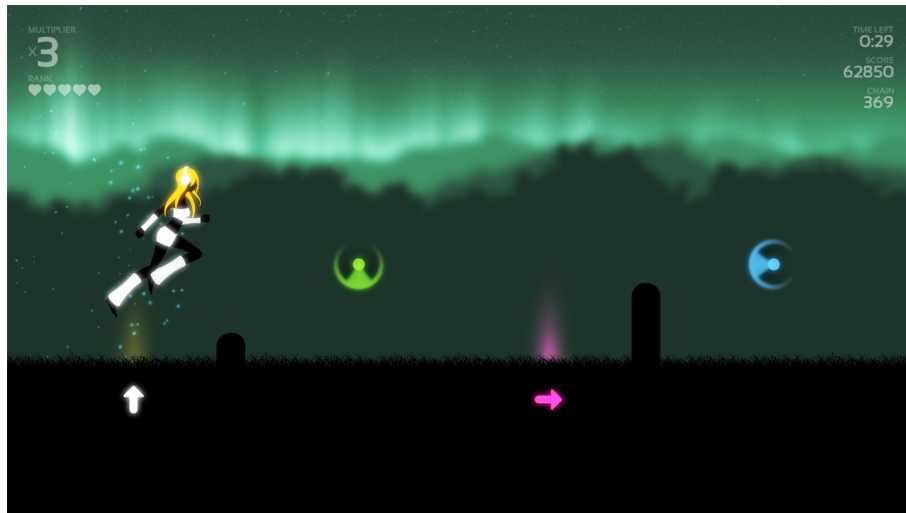


Figure 4.4: Melody's Escape level design.

Many other similar games were found, however they were not reported here as they share the same traits and characteristics as the aforementioned ones. A special mention, however, goes to BeatSaber ⁶, which is notably one of the first games porting this concept

²<https://www.soundshapesgame.com/home/public.html>

³<http://lostinharmony.com/en/home/>

⁴<https://www.ubisoft.com/en-us/game/rayman-legends>

⁵<https://www.melodysescape.com/>

⁶<http://www.beatsaber.com/>

to Virtual Reality (VR) and aims at offering the player an even more immersive experience.

Eventually, the decision reverted to the latter form of gameplay: during an interview with the physiotherapists, it was mentioned the preference of a platform game since children are already familiar to the concept, since they are used to games such as Super Mario. Moreover, the former kind of game design would potentially have required a more complex design of the hardware to mimic a breath musical instrument, which was out of the scope for the current research.

4.4 Online multiplayer for social gaming

It is worth mentioning that during the interviews with physiotherapists and the parent a clear desire for a social dimension of the game was expressed. Nowadays, online multiplayer games are very popular amongst several age groups and especially for children affected by DMD they represent an opportunity to stay in touch with friends, given that they are not able to autonomously move around in most situations. Therefore, the game could allow them to play together to reach the end of the levels: as suggested by the interviewees, the game format could either be of a competitive or collaborative nature.

4.5 Gamification components

Another aspect the game includes are the gamification elements, since previous research efforts discussed in chapter 3.3 have proven that these factors contribute to positive outcomes in terms of engagement and motivation. The game should include a leaderboard, which promotes the competitiveness between the players; special elements, to make the game more unpredictable and therefore contributing to user retention; and achievements or trophies, which are given as a reward when the player meets special conditions during the game.

4.6 Internet connection as fundamental requisite

For most of the aforementioned features, a prerequisite is the connection to Internet. The Groovtube, described in chapter 3.4.1, operates through a Bluetooth connection to send the data from the sensor to the game. After a brief interview with the creator of the device, he confirmed that this design choice was made to avoid the issues that a weak or unstable Internet connection would have caused. It is definitely a source of concern, since its quality differs in terms of service providers and location. However, this choice greatly limits the implementation of the elements discussed in this chapter. For instance, the use of an Internet connection on the hardware prototype level allows for the synchronization of different players' moves and the broadcasting of this data between all the connected players, therefore enabling a real-time multiplayer setup. This solution could potentially be implemented with a combination of the aforementioned communication technologies: the Bluetooth connection could be used to send data to the gaming device, and the latter would communicate the information on the player's movement to the server. However, this technique would require the setup of a double connection, namely Bluetooth and Internet, potentially introducing more issues in case of failure of one of the two. Moreover, the gamification component depends on this connection as well since the information must be stored in a central source accessible to all the game instances connected to it. Most importantly, the possibility to save the calibration history and set the training routines, an important aspect emerged during the interviews with the physiotherapists, is easily solved thanks to a typical client/server architecture. Indeed, such set-up would allow to save this information in a central source and access it through other interfaces, for instance a web page exclusively accessible to professionals.

4.7 Determination of focus areas for implementation

Many interesting concepts were raised from the research in literature and the analysis of the interviews carried out with the stakeholders of the project. However, a number of issues arose throughout the project's life that did not favour the inclusion of the requirements in their entirety.

The inclusion of therapeutic exercises into game design has been partially included in the final system. Indeed, the current level design is focused on just one typology of exercise, namely the fast exhalation and inhalation training. Many approaches can be taken to fulfil this requirement in its entirety: as previously discussed, the manual level design would have the advantage of yielding carefully crafted environments, which can adapt both to the song beat and therapeutic needs after an accurate analysis. A more advanced scenario would consist of an algorithm developed in collaboration with the music therapists that automatically analyses any song the player chooses, subsequently integrating the therapeutic exercises selected by the physiotherapist and eventually shapes the level design. However, for the current project this option has revealed to be practically impossible to implement in the short amount of time dedicated to develop the overall system.

Another important aspect discussed in the conceptual design chapter regards the availability of a multiplayer option. During the initial development stages, a side game has been created to test the implementation of this feature. Although managing to successfully have a working prototype, where multiple people could access the test application from different devices and play the game together, there have been many issues regarding latency. Indeed, there are many communication channels where the information needs to flow through before displaying a feedback on the computer's screen: the breathing data has to reach the server, which then forwards that particular player's movements to all the others. This feedback loop has to work for each player towards all the users that joined the game, and since the entire communication has to go through a central server located in Ireland (the only one offered in Europe by the hosting platform used for this project), some delay in the reception of the packages is unavoidable. Given the limited time granted to this project, this specific feature was therefore not implemented.

Lastly, only a part of the gamification elements discussed in the conceptual design made it to the final version of the game, namely the leaderboard and the some special game elements. The main reason resides in the limited time available, considering the efforts required also for the other parts of the system. However, the current structure of the project allows for an easy integration regarding the achievements logic. Indeed, every user's detail is saved already in an online database, and additional data can be added to

the user profile in order to fulfil the gamification elements requirement as well.

Chapter 5

Technical design and implementation

IN the previous section, the conceptualization of the project has been outlined by presenting the requirements emerged from project goals, literature and user research. The following sections will report the implementation efforts of the whole system, firstly presenting a general, abstract overview of the system and subsequently delving into the development details regarding both hardware and software. Since not all the elements discussed in chapter 4 were included, it is essential to discuss the ones that were not included in this version and the rationale behind the decision. Subsequently, the technical details about the architecture of the system and the single components that constitute the prototype will be presented.

The game can be reached on the space offered by the hosting company¹, while the code has been hosted on Github².

5.1 General overview

The high-level working pattern of the system is quite straightforward. The user either exhales or inhales in a tube connected to the physical prototype; the data is captured by the differential pressure sensor, which sends it to the microprocessor/WiFi module. Afterwards, this information is sent through the internet connection to a custom server, which is programmed to send the newly received data to the clients (i.e. device such as laptop or tablet where the game is played) so that the main character will move accordingly. Figure 5.1 portrays visually how the information flows through the entire system.

¹<https://duckieduck.herokuapp.com/>

²<https://github.com/alessandrocapra/master-thesis>

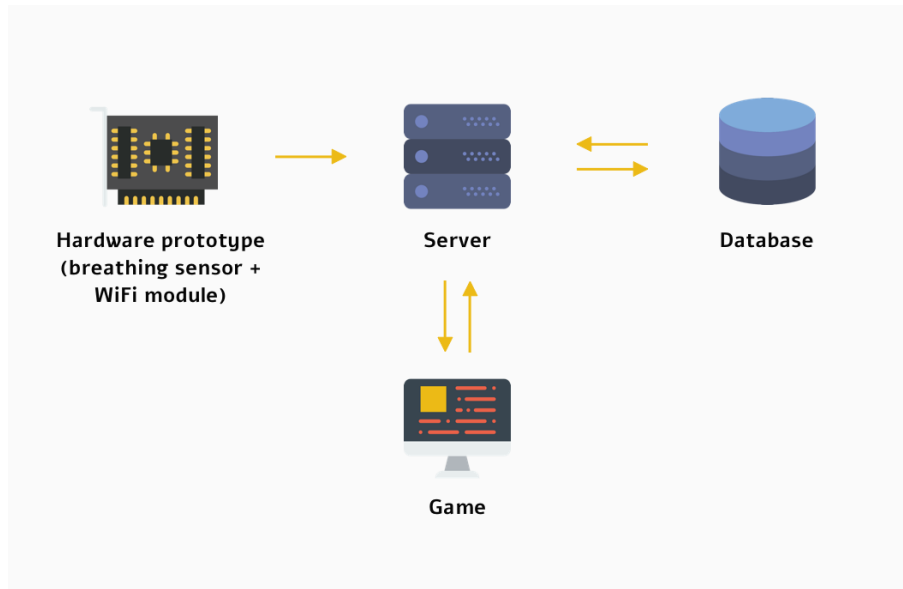


Figure 5.1: Overview of the final system implemented.

Before the examination of the single component's implementation, it is worth to mention some motivations behind the exclusion of some features in the system that have been previously discussed in chapter 4.

5.2 Hardware

Several options concerning the hardware setup were evaluated. Indeed, one of the most important features of the current project is the ability to sense breathing patterns, and many alternative methods exist to determine the needed breathing dimensions further discussed in section 5.2.1. Table 5.1 briefly analyses every potential solution's advantages and disadvantages, followed by an explanation on the choices taken for the final prototype.

5.2.1 Desired measurements of breathing patterns

In order to make a sound decision regarding the best sensor for this project, it is instrumental to take into consideration the kind of data that needs to be measured. Thanks to the information gathered through the literature review (chapter 3.1) and the interviews

with the physiotherapists (chapter 3.5), it has been possible to define the following measurement that the sensors must be able to provide:

- *direction*: the children need to train both inspiration and expiration. Therefore, the sensor must be able to provide data for both actions, such as the previously discussed Groovtube device does.
- *strength*: the game design (discussed in chapter 5.4) potentially needs continuous data, for instance a range of values that will allow the player to keep the character floating mid-air at different levels to avoid obstacles. Therefore, a sensor that yields analog data is required.
- *duration*: being able to differentiate, for instance, a long, slow exhaling effort and a fast exhalation is important since different muscles are employed in respiration and they all need to be trained.

With this preamble, the following sections will focus on the suitability of specific breath sensing solutions for the current project.

5.2.2 Final hardware prototype

The options analysed in table 5.1 led to the inclusion of the Adafruit Feather HUZZAH microprocessor to cover the processing and Internet connectivity requirements, while the MPXV7002DP differential pressure sensor has been chosen to fulfil the breath sensing prerequisite. Amongst the aforementioned advantages regarding these two solutions, some additional details regarding the implementation are worth to be further discussed. Regarding the Adafruit Feather Huzzah, in the last stages of hardware design the potential use of a lithium battery to power the board was rejected: the main reason for this choice stands in the insufficient voltage of 3.7V that the battery could yield to power the sensor, which needs 5V according to its datasheet. However, as showed in figure 5.2, a pin labelled USB has been used to draw the power from the USB port, which has also been used to upload the code on the microprocessor. To allow a truly wireless setup, an external powerbank has been incorporated in the prototype casing which can be seen in

WiFi connectivity	
ESP8266	
advantages	disadvantages
• microprocessor + WiFi (usable as standalone module) • cheap (around \$5) • programmable through Arduino Software Development Kit (SDK)	• imprecise documentation • difficult switch between bootloading and operational modes • external voltage divider needed • lack of analog pins • same setup behaving differently in different times
Adafruit Feather HUZZAH	
advantages	disadvantages
• works with the Arduino SDK • automatic switch between bootloading and operational modes • slot for additional lithium battery • embedded voltage divider • one analog pin available	• none to mention in the context of this project

Table 5.1: Comparison of different hardware solutions for the WiFi connection.

Breath sensors	
XeThru X4M200	
advantages	disadvantages
• Infrared technology (no cumbersome equipment) • high precision in recording chest movements • differentiates between inhalation and exhalation	• high cost (\$249) • no measure of airflow speed
Wind Sensor Rev. C	
advantages	disadvantages
• easy integration with Arduino • cheap (\$17) • it is able to measure the airflow speed	• cannot differentiate between inhalation and exhalation
Oxygen sensor	
advantages	disadvantages
• can discern between inhalation (high oxygen level) and exhalation (low oxygen level) • easy to integrate with Arduino • cheap (below \$30)	• unable to measure the strength of breath
Anemometer through fan	
advantages	disadvantages
• can measure strength, direction and duration of breath • easy to integrate with Arduino • cheap (under \$10)	• mechanical parts would introduce delay at airflow direction change (not suitable for a game which is essentially based on timing of actions)
MPXV7002DP differential pressure	
advantages	disadvantages
• can measure strength, direction and duration of breath • ideal supported pressure range (between -2Kpa/2Kpa) • cheap (around \$10) • easy to use with Arduino	• lower precision than advertised due to the use of Arduino and its limited processing power

Table 5.2: Comparison of different sensors for breath.

chapter 5.2.3. Another advantage of the Adafruit Feather HUZZAH over the ESP8266 option was the native presence of an analog pin, which was instrumental to read the data yielded by the differential pressure sensor. However, the specifications of the microprocessor highlighted that this pin accepts a maximal voltage of 1V, which means that the 5V output yielded by the MPXV7002DP could have damaged the board if not properly addressed. To solve this issue, a simple voltage divider has been included in the final design: two resistors, respectively with a resistance of 820Ω and 180Ω , have been used to reduce the voltage intake in the analog pin from 5V to 0.86V (figure 5.2), therefore below the maximal recommended threshold.

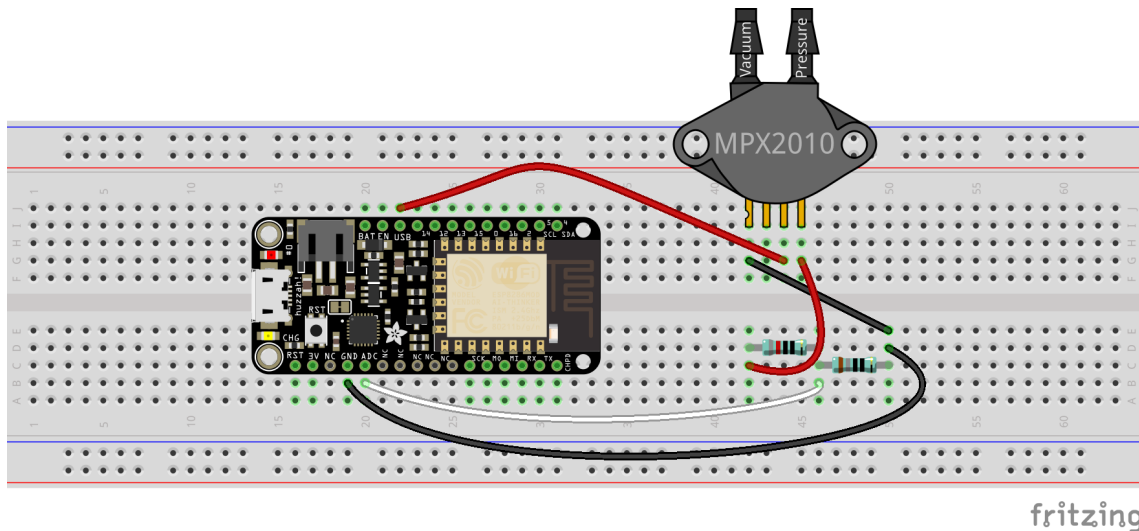


Figure 5.2: schematics for the final prototype setup with the Adafruit Feather Huzzah and the MPXV7002DP differential pressure sensor (the component for the sensor in the figure has a different label, but the functionalities are equal).

To briefly summarize the inner working of the hardware setup, the Adafruit Feather HUZZAH is powered by a powerbank with 5V. Next, the 5V power supply is also transferred to the MPXV7002DP differential pressure sensor, which linearly maps the sensed pressure in the following way: 0V when the pressure reaches -2Kpa (inhaling maximal threshold), 2.5V when the pressure measured is close to 0Kpa and 5V when the pressure is 2Kpa (maximal exhaling level). This information is then passed through the voltage divider, since the voltage intake of the analog pin has to be reduced to maximum 1V as previously discussed. This mapped value (from 0V-5V to 0V-1V) is then returned to

the Adafruit Feather HUZZAH, which will execute some calculations software-wise and send the data through the previously established Internet connection. The final soldered board of the setup hereby discussed is depicted in figure 5.3.

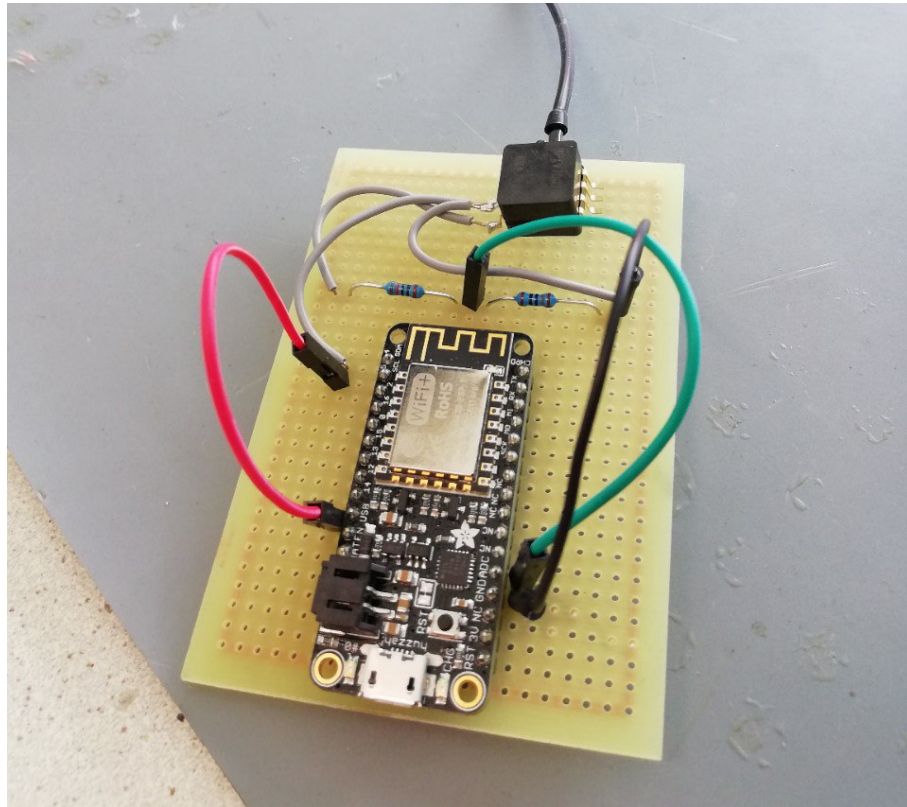


Figure 5.3: Final hardware setup.

5.2.3 Physical casing for the hardware prototype

A casing for the hardware components has been designed, both for functional and aesthetic reasons. Indeed, the box depicted in figure 5.4 has a better appeal than the mere soldered board, especially with a regard on the evaluation phase with users. Regarding the functional aspect, the single components will be discussed in the following sections.

The casing itself has been created with the use of plywood surfaces, which have been laser-cut to take the desired shape. The whole setup can be closed thanks to 4 screws placed on the upper side.

3D printed custom parts were also needed: one is used to hold down the powerbank

— used to power the whole setup — in a safe position, so it does not move inside the box with the risk of damaging the electronic components. However, the most important part is the adaptor (which can be seen partially on the upper side of the case) which needs to converge the air coming from the tube where the user breaths in or out inside a much smaller tube (12mm versus 1mm of diameter). The requirement behind these different diameters is due to the dimension of the measuring ports on the MPXV7002DP sensor, which are quite narrow and a tube precisely fitting them was needed to make sure that the entire airflow would be converged in such apertures.

The last components to mention in this setup are the flexible outer tube, which perfectly fits the mouthpiece that is currently used for other devices in the Roessing Revalidatie Centrum. The inclusion of the latter in the design was a fundamental requirements, since it incorporates some parts that prevent the spreading of bacteria between children who have to share these devices.

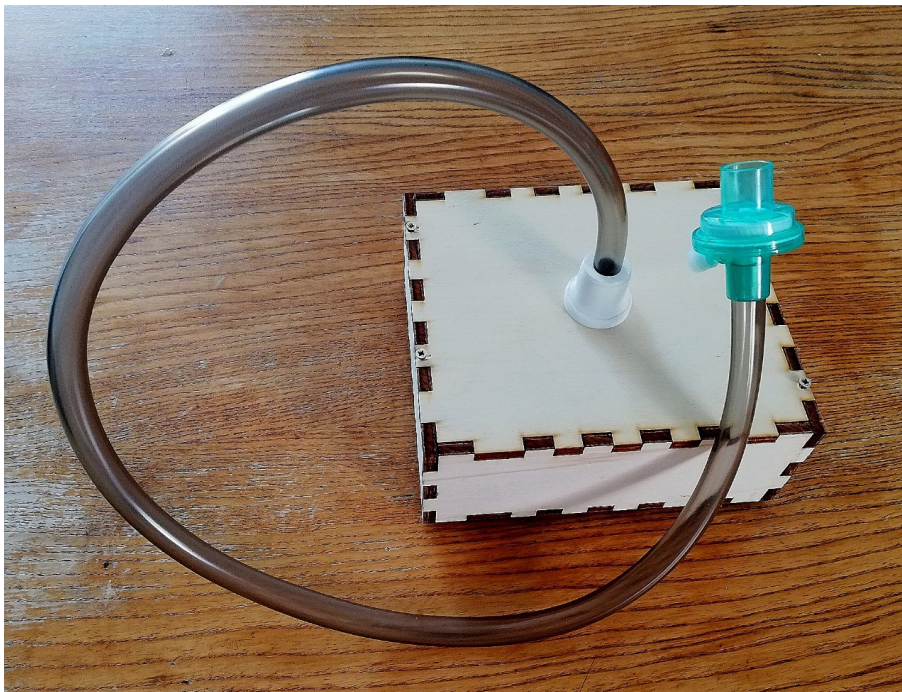


Figure 5.4: Casing of the prototype.

5.3 Software

This section will focus on the software implementation of all the components included in the system: the microcontroller/WiFi module, which reads the data from the sensor and sends it via Internet; the server, which handles the communication with the clients and database; the client, which displays the game interface to the user.

5.3.1 General architecture

The system is set up following the state-of-the art implementation of a client-server architecture, previously depicted in figure 5.1. The server is the central source that handles and forwards information between clients, either the Adafruit Feather HUZZAH or the game itself. Moreover, it offers a simplified interface to retrieve, update, create or delete entries from the database thanks to a set of Application Programming Interfaces (APIs). These are used to offer a way to access data without directly querying the database, therefore allowing to impose a limit on the data that an external entity can access.

A brief example on how the system works is the following: when the user exhales or inhales in/from the tube, this data is processed by the sensor and yielded to the microcontroller. This information is then mapped from the voltage that the sensor yields to a specific pressure value in Kpa, which is subsequently sent to the central server (the microprocessor tries to establish a connection with the WiFi network at the booting up stage). On the server, another client (in this case some a browser who visited the official game webpage³) has established a connection. With this configuration, a channel of real-time communication has been established between the hardware collecting the raw data, the server that forwards it to the game and the game which interprets and maps the values as actions.

5.3.2 Javascript as the main programming language of the project

It is important to mention that a specific design choice went into the main programming language utilized throughout the whole project, namely Javascript. Indeed, excluding

³<https://duckieduck.herokuapp.com>

the C++ code needed to write a new firmware on the Adafruit Feather Huzzah through the Arduino interface, both the server and the game client have been written entirely in Javascript. There are mainly two reasons behind this choice: first, the author has a personal and professional interest in further developing skills in such programming language, as over the past 10 years the expansion of its adoption has grown both on the server and client side thus making it a reliable and flexible technology thanks to the introduction of different frameworks (as an example, React ⁴ has been created by Facebook and has since become the industry standard on the creation of user interfaces in progressive web-app development).

Additionally, the advantage of employing Javascript on the client side resides in the fact that every modern browser can interpret it natively; this also means that every device able to run a web browser, such as tablets and smartphones, can be used to play the game, therefore making it truly multi-platform. This is a huge advantage over existing solutions, such as Groovtube, which require specifically to own an iPad, a quite expensive device that not all the families can afford on top of the equipment their children need because of the DMD disorder. However, if in future scenarios a native application is preferred, existing tools can be leveraged to easily create a mobile version from the same codebase both for Android and iOS devices.

5.3.3 Server

To allow the access to the database resources, the server architecture follows a common approach called Representational State Transfer (REST)⁵, which relies on the methods offered by the HTTP protocol. This means that through different methods in this standard it is possible to retrieve, modify and delete resources stored on the database without having the client directly querying it. In this context, Application Program Interfaces (APIs) are used in web development to yield the retrieved data in an accessible, easy to process format, such as JSON or XML.

The implementation of the server in the current project offers several endpoints, aimed

⁴<https://reactjs.org/>

⁵<https://restfulapi.net/>

Endpoint	HTTP Method	Resulting output
/api/users	GET	gets a list of all the users of the system
/api/users	POST	creates a new user in the database with the data passed
/api/users/:id	GET	gets information on the specific user
/api/users/:id	PUT	updates the specific user in the database
/api/users/:id	DELETE	deletes the specific user from the database
/api/calibrations	POST	adds calibration record for a specific user, whose id is passed in the request

Table 5.3: Endpoints for the APIs of the system.

at offering a quick access to the database. Table 5.3 offers an overview of all the available calls and the result yielded. It can be noticed that there is no endpoint defined to retrieve the calibrations; the reason for this design choice is that all the calibrations related to a specific user are yielded when retrieving information specifically about him/her, so all the information is collected in a more relevant, structured way.

5.3.4 Database

The database is employed to store all the user details. The current implementation has two tables: one where the user data such as name, password and high score are saved; the second one stores the calibrations carried out by every user, saving the maximal inhalation and exhalation measurements and the timestamp when they have been recorded (for a more detailed depiction, see figure 5.5). A Structured Query Language (SQL) database has been chosen, since it is a reliable technology that has been used and improved over the course of many decades. In particular, a specific implementation called PostgreSQL was chosen from the researcher, mainly for the convenience of being offered for free by the same company that offers the hosting of the whole application, namely Heroku (further discussed in the following sections).

5.3.5 Clients

The clients are intended as entities that communicate and exchange through a central source, which is the server. In the current setup two client types are existing: the micro-

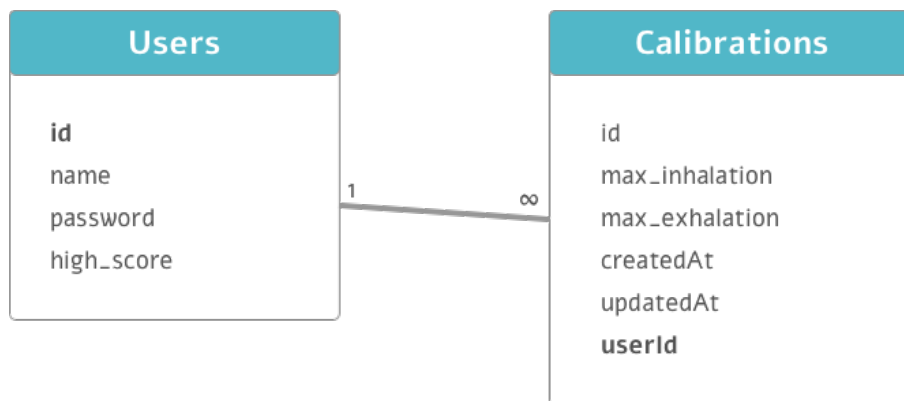


Figure 5.5: Architecture of the database used for the project. The bolder fields indicate a relationship between them.

controller/WiFi module and the game clients.

Microcontroller + WiFi module

As previously reported in table 5.1, the Adafruit Feather Huzzah microprocessor supports the Arduino Software Development Kit (SDK), therefore allowing to write a new firmware in the microprocessor memory using default libraries for Arduino. This has been a design choice, given the previous experience with the Arduino platform and the vast amount of information available on the Internet.

On top of the default libraries, it is worth to mention that the availability of a specific one named `ESP8266WiFi.h` allowed for a straightforward connection to a WiFi network, which is usually not easy to achieve with the Arduino platform. The first tentative of communication of the data pressure between this client and the game one was achieved by sending a single POST request for every reading coming from the differential pressure sensor: this kind of request is included in the standard Hypertext Transfer Protocol (HTTP) definition, and is usually employed to send data to a server, such as form contents. However, this setup has a critical flaw: when a POST request is sent, a connection to the server is opened and once the data is sent the connection is closed immediately. The main consequence of this issue is given by the impossibility of sending real-time data, since the creation and elimination of a connection requires too much time.

After additional research on this issue, a solution was found in WebSockets ⁶. This technology allows a server and multiple clients to maintain an open channel of communication, where messages gets exchanged between parties without the need for the clients to send additional requests to the server. An interesting feature of this architecture resides in the server's ability to send messages to clients, indeed changing the nature of the classic HTTP protocol where the server is seen as the party that merely receives requests and responds to them. This functionality is fundamental to the project, since the pressure data that the Adafruit Feather Huzzah sends to the server needs to be broadcasted to other clients, where the game is played, that are connected via the same WebSocket instance. There are several implementations of the WebSocket technology for different frameworks, but since the server, as explained in section 5.3.3, is based on the NodeJS framework, the choice of service that perfectly supports this architecture fell on Socket.io ⁷. The service is straightforward to implement, thanks to a custom library ⁸ kindly provided by the user washo4evr on Github, which allows to connect to the server and forward messages pertaining the pressure sensed by the differential pressure sensor.

The implementation of this part of the project can be accessed on Github ⁹.

Game

This section focuses on giving an overview on the available libraries and frameworks that could have been used to implement the final game. After a brief discussion regarding their advantages and disadvantages, a more detailed description regarding the chosen framework will be offered. Generally, two main options were feasible: a combination of different libraries that take care of specific aspects, such as rendering, audio and input handling; frameworks, which embed already all these aspects in one package. In the case of the former, an exemplary setup could include:

- PixiJS ¹⁰ (2D rendering) or ThreeJS ¹¹ (3D rendering)

⁶https://developer.mozilla.org/en-US/docs/Web/API/WebSockets_API

⁷<https://socket.io/>

⁸<https://github.com/washo4evr/Socket.io-v1.x-Library>

⁹<https://github.com/alessandrocapra/arduino-thesis>

¹⁰<http://www.pixijs.com/>

¹¹<https://threejs.org/>

- HowlerJS ¹²(audio)
- HammerJS ¹³(user input)

This kind of setup leaves freedom of implementation, but requires additional work to carry out more heavy tasks, such as physics calculations. On the other hand, frameworks are a collection of functionalities that aims to offer a complete solution to the developer. Given the limited amount of time for the development of the final solution, the framework setup seems more a more suitable choice. However, several frameworks are available online, each with perks and disadvantages. Some notable examples are examples are:

- MelonJS ¹⁴
- Impact ¹⁵
- CreateJS ¹⁶
- Phaser ¹⁷

The comparison took in account features such as functionalities offered, pricing and support from the online community. After a careful evaluation, Phaser has been chosen as the framework in which the game will be developed: it can be used for free, there is a great support from the community online on different channels and hundreds of code examples that shows how to achieve the desired functionalities.

5.3.6 Hosting platform

In order to access the game from any location, the server and databases need to be stored online. In order to achieve this, Heroku ¹⁸ has been chosen as deployment service. It

¹²<https://howlerjs.com/>

¹³<https://hammerjs.github.io/>

¹⁴<http://melonjs.org/>

¹⁵<http://impactjs.com/>

¹⁶<https://createjs.com/>

¹⁷<https://phaser.io/>

¹⁸<https://www.heroku.com>

allows to host a low traffic application for free on their servers, which perfectly suits the prototypical nature of the project. If needed, the subscription plan can always be upgraded to sustain higher traffic. In addition, Heroku offers also an online database that can always be accessed, which has been previously presented.

5.3.7 Music

Initially, an important effort was put in trying to achieve the ideal solution, namely having a software that could examine any song and automatically build a level based on this analysis. However, mainly due to time issues, this options was abandoned afterwards. It is worth mentioning though that achieving this goal might be possible thanks to external libraries or services, such as SonicAPI ¹⁹. This product focuses on offering API access to their algorithms, which can analyse many aspects of music such as tempo, keys, loudness and melody. As an example, being able to get the beats information for a chosen song could allow an automatic, dynamic creation of game levels. A similar service is made available from Spotify as well especially for developers ²⁰. In another scenario of a game that allows to choose an instrument and play it (e.g. via the breathing device developed in this project), the MIDI.js library ²¹ seems the perfect candidate to achieve such result. Indeed, it offers functionalities that enables the developer, as an example, to map the incoming pressure data ranges to notes that will be generated thanks to many soundfonts already included in the software.

However, as already discussed due to time restraints the research group opted for focusing on a single musical piece, around which the level design would be structured. Thanks to the support and professional help of the experts in music therapy at the ArtEZ University of the Arts, some parts of the Ode to Joy from Beethoven have been selected as the perfect candidates for the evaluation. The rationale behind this decision concerns the structure of the song: indeed, its arrangement of modi, variations and contrast shape how predictable the song is, making it more suitable for therapeutic goals. Moreover, familiarity is an aspect that derives from the fact that this is a musical piece frequently

¹⁹<http://www.sonicapi.com/>

²⁰<https://developer.spotify.com/console/tracks/>

²¹<https://github.com/mudcube/MIDI.js/>

used in music therapy sessions and therefore well known from the children. Together with the music therapists, it has been chosen to divide the exercise in 3 parts: introduction, workout and outro. The central part was the one representing the forte dynamics, the climax of the composition, where the children were required to put more effort with the breathing since the obstacles to overcome were higher.

5.4 Level design

This section will focus particularly on the game level. Additionally, the screens that allow the navigation and contain the other functionalities of the project are reported in appendix A.7.

The reasons for which the game has eventually been designed as a runner game are contained in chapter 4.3. The current implementation partially includes the gamification and musical elements previously discussed in the thesis (see chapter 4.7 for a detailed description). Unfortunately, many of the gamification elements that were discussed in the conceptual design part could not be implemented in the final prototype, mainly for time constraints. Indeed, the inclusion of special boxes with specific functions and additional trophies and badges to collect are feasible to incorporate given the architecture of the system. As for the music, more tracks should be included to offer more variety and encourage to play on a regular basis.

During the gameplay, several elements are depicted on the interfaces as depicted in figure 5.6. In the following paragraphs, a concise description will be given for each one of them, excluding the self-explanatory ones like score and the pause button. Another element which is not visible in the aforementioned figure are the instructions that are briefly visualized at the beginning of the level, which instruct the player about the consequences of the breathing action (blowing out equals jumping and flying, while inhaling corresponds to swimming underwater).

- The main character is located on the left side of the screen, and its position remains fixed while the camera scrolls left to right, displaying new elements of the level as the player proceeds.

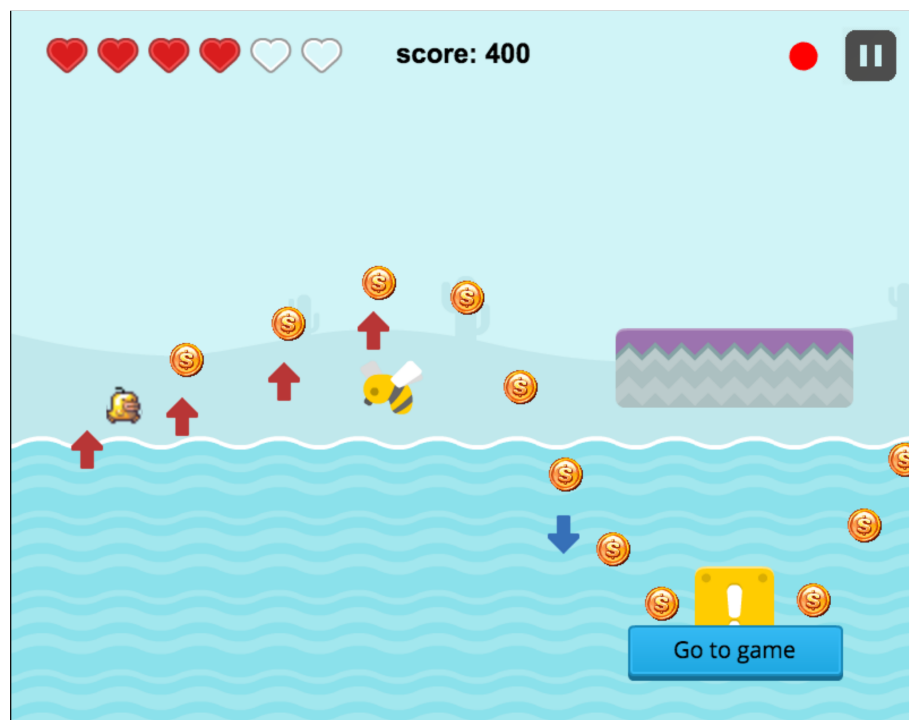


Figure 5.6: Training level of the game.

- enemies that need to be avoided are displayed in the form of bees, which also pulse according to the beat of the song.
- the training and actual game levels have exactly the same structure, although there are some differences in the interface. As an aid, in the training level arrows are positioned where the player should apply the breathing action to help him/her understand how the game is supposed to be played.
- in the upper left corner the player can see the remaining lives, which are detracted whenever the main character bumps into enemies or walls.
- the red dot in the upper right corner indicates whether the breathing device is connected / used for the session. It is represented in the same way in the calibration screen.
- some special boxes are placed throughout the whole level. To balance the difficulty level and make it possible to reach an higher score, they have been designed to

randomly provide either an additional heart or make the coins double they value for a limited amount of time.

- the fundamental element of the game certainly resides in the coins. Indeed, on top of being the only way to accumulate score points, they embed both the gamification and music therapy elements: given the physics of the game, the player needs to perform a specific type of breathing (fast exhalation and inhalation) to retrieve the most of them, which also overlaps with the beats of the music piece. Moreover, their placement is not random but carefully crafted with the help of the music therapists to represent the dynamics of the music and mimic the way the notes sound (higher or lower.)

5.5 Limitations

The main issue with the current implementation concerns the suitability of mobile devices to run the game. More specifically, the game perfectly adapts to a different screen size but due to the framework inner mechanisms the mobile version needs a more accurate design. As an example, the main problem consists of several elements such as level tiles, enemies, coins and special boxes being loaded all at once when the game loads. Since every single element has a function that checks whether the main character collides with it, there is a lot of computational power needed and the browser on mobile devices could not offer it during different tests. However, it is possible to solve the issue in future versions as described in chapter 9.

Chapter 6

Evaluation

To assess whether the implemented system is well suited for the intended final users, an evaluation activity has been carried out. Both physiotherapists and children were included in such study: the therapist had to help the children to go through the interface of the game, since they have a limited hand/finger dexterity. Once the necessary tasks were carried out by the physiotherapist, he would start the game and the control would switch to the children. In the following sections a thorough description of the study will be given, while the results will be presented in the following chapter.

6.1 Approach

Since the beginning, the research group has been aware of the difficulty of finding potential candidates to test the game with, especially regarding children. Indeed, between 3 and 5 children were expected to take part to the final test of the system, a prediction that correctly matches reality. For this reason, a qualitative study seems more appropriate, since the number of participants would not be significant for a quantitative, generalizable study. Moreover, a qualitative inquiry supports a more thorough and open exploration, which gives a strong understanding on the particular context and stakeholders group.

The methods used for the evaluation were the following:

- observations, both during the set-up and gaming phases.
- video recordings from two different angles to focus both on the gameplay and on the facial reaction of the children. Moreover, the set-up phase carried out by the physiotherapist was also recorded.

- semi-structured interviews following the end of the gameplay. As an additional tool to stimulate the conversation, the smiley-o-meter method has been used to ask an initial opinion about a topic [29]. Afterwards, more in-depth questions were asked.
- unstructured interviews with the physiotherapists after the children would leave to room, to wrap up the session and get additional feedback on topics such as usability of the interface, their perspective on the children's experience and the potential therapeutic benefits of the game.

6.2 Background & Goals

The project focused on building a more engaging breathing exercise system for children affected by Duchenne Muscular Dystrophy. There are existing solutions, but initial interviews with physiotherapists following these children suggested that they would not use such systems in the setting of their home, without the assistance of the therapist. By including elements of gamification and music therapy, this project aims to increase the motivation and foster the independent gaming in a home environment. This, in turn, could lead to an increased lifespan expectancy thanks to a continuous daily training.

The goal of this particular evaluation sessions is to find an answer to the research questions presented in the introductory chapter, which are reported below for convenience:

- what is the added value of adding gamification and musical elements to the classic breathing therapy exercises?
 - do they stimulate different breathing behaviour patterns during exercises?
 - do they provide more motivation and engagement towards the therapy?
- do users understand the game mechanics and perform actions correctly?
- can the therapist have control over the settings of the game in a way that contributes to the therapy?

6.3 Context

The test took place in the Roessingh Revalidatie Centrum, which is the same structure where the children go to school and carry out their therapy routines. The decision to do it in this setting has to do with mainly with logistic issues in moving the participants in another location, such as the university premises, and the interference that this will bring to their schedule.

The evaluation was carried out in a private room to avoid external interruptions. The children were sitting on their electric wheelchair, which they use to move around the facility in autonomy. The hardware prototype was placed on the table-like surface which comes with these special wheelchairs, directly in front of the child. They needed to be placed exactly in front of the computer screen where the game was running, both for comfort and recording purposes.

Regarding the video recordings, as just mentioned one source was the computer camera. An additional reflex camera mounted on a tripod was placed behind the child on their side, in order to capture both the gameplay and the interaction with the physiotherapist assisting him/her.

6.4 Participants

Eventually, 4 children were allowed by their parents to participate and be filmed for research purposes while playing the game. They were all male participants, aged between 10 and 15 years of age. It is important to mention that the physiotherapists reported that 2 of the kids were cognitively challenged / less developed than the others, a condition that is quite common and believed to be related to the lack of the dystrophin protein [2]. This specific type of user profile is also described and generalized in chapter 3.6.

Also 3 physiotherapists participated to the evaluation. Their role consisted in assisting the children, for instance by helping them with the placement of the tube and mouthpiece, and interact with the interface to set-up the game.

6.5 Risk analysis

Before running the evaluation, the most dangerous outcomes could have been the potential light-headed feelings and minor breathing issues, as a result from the frequency of action required by the game. However, the therapist was there to assist them while playing the game, therefore these issues could be foreseen and quickly addressed in the case of their manifestation. Eventually, no such episodes were reported.

The approval to conduct this evaluation session has been granted by the Ethical Committee of the University of Twente under the reference number RP 2018-11.

6.6 Schedule

The duration of the test phase will be approximately 30 minutes long for each child and include the following phases:

- 5 minutes introduction about the test and the game itself.
- 5 minutes set-up phase, where the physiotherapist goes through some tasks to prepare the game for the child.
- 10 minutes testing, in which the children goes through the training level to eventually play the game and try to get the highest score possible
- 5 minutes interview with the child, where opinions about specific topics will be asked.
- 5 minutes post-evaluation interview with physiotherapists.

6.7 Script

Preparation

- Set-up the camera and tripod for video recording (if parents allowed it).
- Power up the hardware prototype and make sure it is connected to the Internet.

- Place the computer in front of the children, and open the main screen of the game in the browser.
- Prepare the hardware device on the table, in front of the user.
- Notepad + pen to take notes while observing
- Set-up the smartphone for post-evaluation interview recording (if parents allowed it)

Introduction to the test

- Explain what the test will consist of, namely trying out a game and getting some feedback on how to improve it.
- Make sure to stress that the child is not the one being tested, but his/her opinion is precious to improve the game.
- Tell the goal of the game: to get the higher score, by collecting as many coins as possible. Mention also the special boxes and their meaning.
- Say that there is a training level before the actual game starts, so they can practice a bit and get a better idea on how the game works.
- Explain to the physiotherapist that they will participate by setting up the game for the child.
- Let the physiotherapist take over and prepare the game.

Set-up of the game

In this phase, the therapist needs to sign-up the child by inputting name and password. Secondly, the calibration for the child's breathing levels has to be taken. Once these phases are over, the physiotherapist will start the training level.

Playing the game

The child will play the training level, asking the physiotherapist whenever he wants to restart the level or proceed to the next phase. Once the real game is started, the final score will be recorded and saved on the database.

Interview

Ask the following questions to the children. Given the choice of a semi-structured interview, if an interesting topic emerges from an insight diverge from these momentarily.

- What did you think about the game? How did you play it? (*checking what they understood about the game*)
- Do you want to play once more right now?
- What do you think about the music in the game? Did it help you to play or did it create confusion? (*music therapy aspect*)
- If a friend beats your high score, would you try to beat him again? (*social aspects + gamification*)
- Would play these games sometimes also in your free time? (*check if the system is engaging and they are motivated to play*)
- What would you add in the game that you like? What would you remove?

Chapter 7

Results

This chapter will outline the outcomes of the evaluation session described in the previous one. Overall, the system had a good first impression on the children, proven by the fact that they asked to play it again several times. An interesting fact worth mentioning is that although none of them managed to complete the level in its entirety, they were not discouraged to play and actually wanted to achieve a better result by trying to improve their score. Additionally, although the level design seemed to be too difficult for quickly switching between breathing efforts, the overall impression was that every child improved over time and understood better the controls. The kind of therapeutic breathing that was meant to be exercised in this game regarded the fast inhalation and exhalation efforts. Initially, the children tried to breathe long and hard to move the character around, resulting in the main character to fly instead of jumping in a more controlled manner. However, since the coins were carefully placed to stimulate the intended kind of breathing and the goal is to collect as many as possible, the participants changed the way they played once they got a good understanding of the commands. This resulted in an improvement on the final score, which is related to a more controlled gameplay and an improved attendance to the desired breathing pattern.

For recommendations on potential solutions and improvements of the current prototype, as well as ideas for the future development of the system, refer to chapter 9

7.1 Approach

The approach used for the analysis of the data gathered (observations, video and audio recordings) consisted in the phases described hereafter.

- separation of the whole process the participants had to go through in phases, which corresponds approximately to the game screens. Additional insights which were not confined to the current screen were reported in different categories, such as Persona for details concerning the kind of user taking part to the test.
- examination of the recordings and observation: whenever an interesting insight or pain point was mentioned or noticed by the researched, it was noted down on a post-it, as well as in which phase it happened and by which user (using a different coloured paper).
- once all the materials have been investigated, the phase of finding patterns and grouping them together started. For instance, a common theme that resulted in the game itself was its difficulty.

The analysis in its entirety can be found in appendix A.6, but the general insights will be discussed details in the following sections.

7.2 Differences in children's cognitive abilities and consequences on the gameplay

It became clear at the end of all the 4 testing sessions that significant individual differences exist in children with DMD. Apart from diverse motor abilities, the cognitive ones also emerged during the evaluation. As an example, one of the participants was constantly blowing air in the opposite direction as the arrows displayed in the training level. The physiotherapist noticed it as well, therefore asking the child if that aspect was clear. Despite receiving a positive answer, the child kept on performing the direction wrong throughout the different times he tried the demo level.

Another instance of the low cognitive abilities was made clear in the post-evaluation interview, when one of the children was asking first what the faces on the smiley-o-meter represented (inability to differentiate between happy and sad emotions), and then proceeded to answer to questions previously asked, not being able to focus on the current topic.

This is an interesting finding, since it shows the many facets within the user group targeted and might inform the design of future products targeting it. However, it is important to stress the fact that despite not achieving good results in terms of ranking and game understanding, the children with cognitive problems during the game were focusing on it and practising a specific type of respiration, which eventually reaches the therapeutic goals the physiotherapist is interested in for rehabilitation purposes.

7.3 Interface usability issues

As mentioned in the previous chapter, during the evaluation also the interface was tested to highlight usability issues and inform a potential future redesign of the game. The participant carrying out these tasks was the physiotherapist (in this particular section the term always refers to the professional figure), and thanks to the feedback received many problems have been noticed. First, the use of a native browser tooltip / pop-up has been a design mistake, because all the participants skipped it by clicking the OK button without even reading the content. When asked why, they reported that they are normally seen as annoying or not important. Therefore, the calibration part, which is essential to adjust the controls of the game to the specific child's breathing levels, was skipped and the researcher needed to intervene and make them notice that it was an important step to take.

Furthermore, an issue was highlighted in the settings page. Here the professional figure can select which input device to use, currently allowing either keyboard/touch or the breathing device. In two cases, when asked to switch to the other device the physiotherapists were puzzled, since the non-selected option has 50% opacity to show its state. However, what they understood was that the option was not available.

The observations of this phase led the researcher to the impression that it was not clear to the carer that the default option for the input device was the keyboard/touch one.

Lastly, a lack of information caused a misuse of the calibration feature. Indeed, the game works with both inhalation and exhalation as controls, and both are measured for the single child in order to calibrate the effort needed to carry out an action. Despite this preamble, two physiotherapist asked if also the inhalation was needed, potentially because no instructions were included in the actual calibration page, only in the previous one.

7.4 Level design, proximity of breathing actions and prototype structure

A general feedback that has been gathered thanks to both observations and interviews with the physiotherapists has been the difficulty mainly deriving from the level design. Indeed, the distance between the obstacles is not sufficient to allow the children to properly finish one action and initiate the following one. This problem initially caused a bit of frustration in the children, but the game mechanics were better assimilated in the subsequent tries. In this regard, the physiotherapist suggested that having more time between actions would be easier for them; moreover, higher obstacles would be appreciated since the therapeutic effect would be even more effective, requiring the children to operate a more explosive exhalation and a deeper inhalation.

Another potential cause of difficulties concerns the mouthpiece and tube design. In this prototypical version, the latter was flexible and needed to be hold either by the child or the physiotherapist. The consequence of this flexibility is that sometimes the kid has to keep the mouthpiece secured to his/her mouth with the lips muscles, without having the chance to breathe without it in the way. This, in turn, activates the controls for moving the game character down, inducing actions that the child did not intend to carry out and therefore causing frustration.

Although these issues were found, the children wanted to keep playing and over time

their performance regarding the level completion and the understanding of the mechanics improved.

7.5 Gamification elements as a necessary tool for motivation and engagement

Amongst the most interesting results of the study, the inclusion of the leaderboard system was a successful component for motivation. Indeed, all the participants agreed that they would try to beat a friend's high score if he/she gets an higher score than them. Moreover, in some instances the children asked to see the ranking and check their position compared to the other players, also enjoying a little competition with one of their parents to see who could perform better. Therefore, it could be stated that the gamification component is an important part of the system, and other elements could be included to stimulate the engagement and the motivation even more, such as special elements, achievements and trophies. Overall, thanks also to inclusion of gamification aspects, the game was appreciated and all the participants wanted to try multiple times despite a little frustrated for the difficulty of completing the level (especially in one case, a child played for a total of 10-12 times, asking for additional 3 games at the end). All of them agreed on the fact that they would play again.

7.6 Music therapy component's issues

In some cases the role of music was recognized at least partially helpful in the game, for instance by realizing that the coin placement was following it by going up and down. However, in most cases the function of music was perceived as a background element, not really giving clues on how to proceed in the level. One aspect that came out of the testing is the visual predominance over the sound, since they needed to collect the coins as main goal.

Regarding the role of music in the project, especially after conducting the observations, the researcher is positive that the negative outcomes were due to the level design

and the lack of possibilities to improve the skills required to play the game level. As previously discussed in chapter 3.3, the design of a game should take into account the presence of little and big games. A more thorough discussion regarding this matter can be found in chapter 9.

In conclusion, with a more detailed and gradually built skill-set and a focus on pairing the actions with increasingly difficult musical clues should allow for an easier integration of the music therapy elements within the context of the current project.

7.7 Game design issues and feature requests

Many suggestions were given around the game design and some issues that were encountered. For instance, many participants were jumping on top of the enemies in the level expecting to kill them, being instead penalized because they were supposed to avoid them. The physiotherapist actually commented "why does the duck get hurt when it jumps on top of enemies? Shouldn't it be like in Super Mario?". This shows that familiarity with games of the same kind is also potentially known by these kids, and for reasons of consistency should be also integrate into the current implementation.

A visual clue integrated into the game consisted of a vertical bar expanding in height, either growing upwards or downwards, to simulate the breathing patterns exercised by the children. Moreover, the bar would change the colour in the case the strength of the breath passed the necessary threshold to carry out an action in the game. However, this visual depiction was not understood neither by the carers nor the children: a physiotherapist asked: "about the green bar on the left of the duck, what is that again?". This feedback shows that this functionality might either not be needed or some redesign should be carried out.

The final point regards the feature requests. Two participants mentioned that the possibility of playing online with other friends would be a worthy addition. It is interesting to notice that this aspect has been mentioned also during the interviews with physiotherapists and parents, therefore making this topic a candidate feature for a future version of the game.

Chapter 8

Conclusions

In this thesis a gaming ecosystem for respiratory rehabilitation purposes in the context of the Duchenne Muscular Dystrophy disorder has been introduced, discussed and evaluated. The broader goal that this project focused on addressing is to create a more engaging experience by hiding therapeutic exercises in a gaming context, in order to increase the rate of training carried out autonomously by the children at home.

The project tackled many different areas, ranging from hardware to software implementations. First, a custom hardware device was designed and assembled to sense breathing patterns and send this data over the Internet. Second, a videogame embedding gamification and music therapy elements was developed, moreover adding the possibility to control it through different input sources, such as keyboard/touch or the breath sensing device just mentioned. Lastly, the back-end technology was developed and hosted online to direct the data from the custom device to the game itself, also allowing the communication with a database to store and retrieve the children calibration data for gaming and therapy purposes.

In the following section, an answer to the research questions outlined in the introduction of this document will be given.

8.1 Research goals

Each research question will be reported in the following paragraphs and given an evaluation based on the work carried out in this thesis.

1. *What is the added value of adding gamification and musical elements to the classic breath-*

ing therapy exercises?

Following the insights presented in the results of the evaluation session, it can be stated that both gamification and music therapy elements seemed to be useful, to different degrees, to enhance the motivation and engagement to the game solution developed. The gamification component of the leaderboard seemed to be particularly effective in stimulating the competitiveness side of the participants, therefore potentially leading to an improved adherence to the therapy. Regarding the music component, the results were less impressive due to a non-optimal implementation of the level design and pairing of action to musical clues as discussed in the results chapter. However, the feedback collected was very valuable and a more thoughtful implementation which builds on the observations collected could massively improve the effect of the influence of music in combination with the aforementioned gamification elements.

2. *Do they (gamification and music components) stimulate different breathing behaviour patterns during exercises? Do they provide more motivation and engagement towards the therapy?*

It has been noted that especially in some of the participants these elements proved to enhance motivation and lead to a high level of engagement. These factors had the effect on yielding an increased effort that the children put into completing the level, both in terms of breathing strength and repetition of the exercises, consequently favouring the requirements outlined during the interviews with the physiotherapists.

3. *Do users understand the game mechanics and perform actions correctly?*

The game proved to be quite challenging to master in the initial phases, requiring some tries in the training level to get a hold of the controls and to understand the physics correctly. However, after some repetitions the participants showed an overall improvement in the gameplay and the feeling of being able to control the main character properly in such a short time (10 minutes on average) stimulated a general re-play effect.

4. *Can the therapist have control over the settings of the game in a way that contributes to the therapy?*

In the current version of the videogame, the physiotherapist has the ability to tweak the level at which the children have to perform according to their level, which was established in the calibration phase. This option allows him to adjust the expected performance for every session, which is a desirable feature since the children could have bad days in which they cannot and shouldn't perform at high levels. Therefore, this aspect has been covered and it shows that it is possible to allow the control of the therapeutic concerns through the game interface.

Overall, the project has proven the validity of the research inquiries just discussed, paving the way for further work in this area.

Chapter 9

Discussion and future work

The work presented in the previous chapters revealed the potential of gamification and music therapy assets to increase the engagement of the children affected by DMD. However, many shortcomings were assessed during the evaluation phase with users, and many solutions can be implemented to further improve the whole setup. Over the next chapters, suggestions on how to develop them will be discussed, eventually setting a broader vision towards which the project could evolve.

9.1 Performance improvement

As reported in chapter 5.5, there are issues in running the current version on mobile device due to performance issues. However, many solutions exist to fix them: for instance, instead of loading the whole level at once the tilesets (which are maps describing the level structure and graphic elements) could be split and loaded in chunks, avoiding to have functions that listen for collisions on every part of the level at the same time. Moreover, by removing all the elements that pass over the left side of the screen from memory, the colliders of these objects will also become inactive.

9.2 Level design and music therapy

Regarding the level design, a needed tweak would consist in representing the little games as minor levels that can be leveraged to teach the basic skills that are needed to proceed through the level. An important aspect that should be addressed through these levels that

gradually increase in complexity is the relationship between game actions and music: for instance, the first level could consist of a simple drum beat which requires to do a simple action as jumping (exhalation), while the next level could focus only on the inhalation part. Afterwards, the ability of combining those should be tackled, and gradually build up other skills such as double jumps. Once these techniques have been mastered, the player should be able to successfully deal with any level design the game offers. With the collaboration of the music therapists, it is possible to perfectly match the musical clues to the desired therapeutic actions and effects.

The topic of music therapy is strictly related to the level design. Indeed, the latter is totally dependent on the tracks prepared in collaboration with the music therapists. Currently, two scenarios seem to be the most likely to happen: the ideal one would be to develop an algorithm that can analyse the tracks and map the features of music to the level objects, as previously discussed in this thesis. However, this requires a considerable effort and resources and it is likely to be carried out by a larger research group that involves different professional figures. The second scenario consists of manually hard-coded levels that fit a specific musical piece, where the placement and height of the obstacles would be analysed in collaboration with the music therapists. In both cases, the option to adapt the level for a specific breathing training should be included: as an example, the second scenario would then offer three different versions of the same level/song, focusing on either fast exhalations and inhalations, controlled and deep ones or a mix of both. This setup depends on the input given by the physiotherapist.

Another chance for improvement stands in the motion design of the on-screen elements. For instance, in the current version the bees are pulsing at the same rhythm of the beat of the song, but it is very subtle and the attention is drawn more on the coins, since they contribute to increase the score. By increasing the motion of elements that move with the music, like previously discussed games such as SoundScapes do, it is arguable that a better understanding of the role of the music might derive from this improvement.

Lastly, the inclusion of additional gamification elements would potentially increase the re-play factor. For instance, in-game elements such as special boxes give either extra lives or temporarily double the coins value in the current implementation. However,

more behaviours are available, such as invincibility for a limited amount of time. Thanks to the inclusion of these elements, which all intend to help the player to reach an higher score, it is possible to assume that more diversity would allow for an increased interest in the game and a higher engagement over time. Moreover, the advantage brought by these special elements could promote their collection, and by carefully designing the levels they could be placed in locations that require an increasing breathing effort to be reached, thus fostering the respiration patterns with therapeutic benefits.

9.3 Interface improvements

During the evaluation phase, many issues were observed regarding the user interface, both while the therapist was setting up the game and when the children were playing through the levels. However, many solutions are available to solve these problems.

One of the most critical concerns relates to the skipping of the calibration phase, caused by the pop-up which was perceived as not important. To fix this matter, two ideas come to mind: for instance, when no calibration has ever been recorded for a new user the first step before starting the game the calibration step could be enforced, subsequently allowing to play the game. Another method consists in blocking the welcome screen and creating an in-game tooltip menu that directly takes the user to the calibration page without giving the chance to incur into mistakes by selecting the start button. Another unclear aspect regarding the calibration was the need to do it both for inspiration and exhalation: a more contextual explanation should help in carrying out this operation correctly, for example by displaying first the instructions to breathe in and afterwards switching to the ones asking to breathe out.

Concerning the device selection in the settings page, this issue can be solved by changing the paradigm used for the visualization of buttons states. The current implementation mistakenly associated the selected state with what traditionally is meant to communicate a disabled state: by changing the former with a different visual style that follows general guidelines, it would be possible to inform the user about what is active or not in a more efficient manner. Moreover, from the welcome page the carers were not

able to instantly understand which device was selected by default. To improve this aspect, an addition of the currently selected device as additional information in this page would be helpful.

Regarding the reversed breathing pattern showed during the gameplay with one child, a button to quickly invert the mapped action should suffice and add flexibility for the setup even during the game. Moreover, this setting could be added to the preferences related to the user's account and saved on the online database. Another visual element related to the breathing which brought some doubts to the users is the bar visualized on the left part of the screen, which failed to communicate clearly its function: a possible solution to improve it consists in utilizing the same circles that are proposed as a measuring unit in the calibration phase, since the children would be already familiar with their meaning.

9.4 Physical prototype

The hardware and casing were suitable for the initial testing purposes, although some issue were observed. For instance, the mouthpiece and tube design should be improved in such a way that once their position is set, no further assistance from a parent or carer is needed. A solution would consist of a flexible arm, which can be adjusted according to the required height and vicinity to the child and can also maintain that position.

9.5 Desirable features

As previously discussed in the results chapter, the multiplayer online feature was mentioned or requested from every stakeholder that took part in the project. Although it was not implemented in the current version, the existing codebase already supports this functionality thanks to the SocketIO library. While experimenting the potential of this service, a quick multiplayer game was developed for testing purposes, therefore confirming that it is pragmatically possible to add it to the project. The abstract idea on how it would work consists in having the clients communicating their own character's position to the

server, which then broadcasts this information to all the other connected clients to update the position of the character as well. On top of this information, additional data such as collected elements needs to be forwarded to all the connected players in order to have an up-to-date situation in real-time.

9.6 The vision and meaning of the project

The current project solely focused on DMD children as a starting point to design this system. In the previous chapters, the chance to offer the same game to people with other kind of disabilities thanks to the use of different sensors has been mentioned. However, what this project revealed through the interviews with the stakeholders is that these children also have important connections in their life with friends with no disabilities. Therefore, allowing to control the game through diverse inputs, such as a normal touch interface or computer keyboard, allows the development and preservation of the connections with friends and family members, offering an entertaining platform that apart from serving a therapeutic goal also helps to close the gap between people with disabilities and the world from which they are frequently excluded.

Appendix A

Appendix

A.1 Forms

A.1.1 Information brochure

Duchenne Muscular Dystrophy (DMD) is een degeneratieve ziekte dat leidt tot progressieve spier functionaliteit beschadiging. Gedurende de beginfase van de ziekte zullen alle ledematen het meest aangetast zijn. Gedurende het laatste stadium worden belangrijke spieren zoals in de luchtwegen en het hart aangetast. Vooral tijdens het laatste stadium van DMD, hebben vele onderzoekers onderzoek gedaan of dagelijks oefening routines kunnen bijdragen aan het vertragen van het afbreken van de genoemde spieren, met als effect voor beter leef kwaliteit en het verlengen van de levensduur. Het huidige project focust op alleen ademhalingsoefeningen, met als doel om de betrekking en motivatie te verbeteren tijdens therapie. Om dit resultaat te behalen, wordt de ademhalingsoefeningen getransformeerd in spelletjes waarbij de patint ademhaling gebruikt om het spel te spelen. Elementen van "gamification", zoals het uitreiken van trofee en een scorebord. Ook wordt muziek in het uiteindelijke systeem gentegreerd, omdat een aantal onderzoekers hebben bewezen dat het een verhoogde opkomst oplevert voor therapie dankzij betere motivatie en betrokkenheid. Het onderzoek richt zich niet op medische aspecten, maar om kinderen het systeem te laten uitproberen en om terugkoppeling te ontvangen over mogelijke verbeteringspunten volgens hun behoefte en voorkeuren. Het onderzoek focust om erachter te komen of traditionele ademhalingsoefeningen, gemengd met spel en muziek elementen de betrokkenheid verhoogd van het kind.

Lees de brochure voordat je beslist of je mee wilt doen aan het onderzoek; als je vragen hebt over het project, kun je contact opnemen met de universiteit.

Contactgegevens

Je bent gevraagd of uw kind kan participeren in een testsessie van dit project. Je kunt er meer over lezen in de brochure. De informatie zal je helpen om een beslissing te nemen of je denkt dat uw kind kan participeren in dit onderzoek. Er zijn twee onderzoekers wie het onderzoek leidt: Dennis Reidsma en Alessandro Capra. Als er iets niet duidelijk is, kan je het altijd vragen aan de onderzoekers voor extra uitleg. De contactgegevens zijn hieronder te vinden.

Research group: Human Media Interaction

Alessandro Capra, Masters student: a.capra@student.utwente.nl

Dennis Reidsma, Assistant Professor: d.reidsma@utwente.nl

Onderzoek tijdens de testdag: Hoe het werkt

Wat gebeurt er tijdens het testen?

De kinderen zullen verschillende prototypes van het spel / de spellen op verschillende dagen, van een initieel basisversie van het uiteindelijke prototype. Ze zullen spelen door te exhaleren/inhaleren door een zelf gemaakte systeem dat ademhaling detecteert. Hierdoor hebben de kinderen de controle over de spelmechanieken. Tijdens de activiteit zullen de onderzoekers observaties uitvoeren, door bijvoorbeeld notities te maken over wanneer het spel moeilijk te begrijpen is of wanneer onderdelen van het spel te moeilijk zijn om af te ronden. Ook wordt er een kort interview gehouden aan het eind van de test om vragen te stellen aan het kind of ze het spel leuk vonden of bepaalde specifieke wensen wat voor hen het spel zal verbeteren. Deze benadering zal de verdere ontwikkeling van het prototype helpen in de volgende fasen.

Wie begeleidt en vindt de activiteiten uit?

De spelletjes zijn gemaakt door de onderzoekers bij de universiteit, met terugkoppeling van de therapist wie de kinderen zal volgen om zeker te zijn om potentiële schade niet op te roepen. De onderzoekers zijn verantwoordelijk voor de directe begeleiding van de activiteiten, met de aanwezigheid van de therapist om de veiligheid van de kinderen te bewaken.

Wat voor soort informatie wordt er verzameld?

Gedurende de activiteiten worden de kinderen geobserveerd en eventueel gefilmd bij toestemming van de ouders/voogden van de kinderen. Kinderen worden kort geïnterviewd wanneer ze klaar zijn met het testen van het systeem. De filmpjes en interview antwoorden worden verwerkt en opgeslagen waardoor de identiteit van het kind niet meer te achterhalen is. Elke (interview) vragen worden van tevoren beoordeeld en goedgekeurd door de opzichter van het project en de therapist.

Wie kunnen de beelden en interviews bekijken?

Het beeldmateriaal en interviews zijn alleen toegankelijk voor mensen die betrokken zijn met dit onderzoeksprogramma. Een lijst van namen wie toegang heeft op het materiaal is beschikbaar en kan worden aangevraagd by Dennis Reidsma. Deze materialen worden absoluut niet toegankelijk voor derden of voor reclame doeleinden.

Kunt u uw toestemming wijzigen?

Als je al toestemming hebt gegeven, en je wilt het beeldmateriaal van het kind verwijderen, kunt u dit aangeven bij Dennis Reidsma.

Krijgen de ouders ook informatie toegestuurd over het resultaat?

De geanonimiseerde resultaten worden deel van een Master's thesis onderzoek. Ook is het mogelijk om contact op te nemen met de onderzoekers voor de resultaten.

Meer informatie en onafhankelijk advies.

Wilt u graag onafhankelijk advies ontvangen over participatie in dit onderzoek of over een klacht? Dan kunt u contact opnemen met Anja Strootman-Baas, de secretaris van de ethiek commissie (ethics-comm-ewi@utwente.nl). De commissie bestaat uit onafhankelijke experts van de universiteit en zijn beschikbaar voor vragen en klachten over het onderzoek.

Voor andere vragen kunt u contact opnemen met de docenten en beheerder van de school of de onderzoekers van de universiteit.

A.1.2 Consent for interview with parents

The document, both in English and Dutch, can be found at the following link: <https://goo.gl/UeBonv>.

A.1.3 Consent for testing with children

The document, both in English and Dutch, can be found at the following link: <https://goo.gl/PrNdNu>.

A.2 Interview questions / therapist

1. Can you state your name and age?
2. What is your profession about?
3. How many years did you work as therapist for children?
4. How is the therapy session organized? How many exercises and how long do they last?
5. Which exercises are usually employed? Can you describe them?
6. Which kind of measurement on the lung capacity are made on a recurring basis?
 - (a) Is it needed to calibrate the exercises every day based on the lung performance of the kid?
7. Do kids have the same tolerance regarding the length of the exercise? How long is it safe for them to exercise before getting exhausted?
8. Are there some exercises that are more dangerous and could potentially harm the patient if not followed directly by the therapist?
9. How do you see kids reacting to the exercises? (Bothered, sad...)
10. Do you see any issue in the way exercises are currently done? (in terms of engagement of the children) Any idea on what/how to improve?
11. How do you interact with the kids during the exercises? Any advice on how to approach them?

12. Are these children used to technology, especially tablets and mobile devices (they cannot use it directly, but do they know them and interact with them?)
13. There are some video games solutions to train the respiratory muscles, usually consisting in a game on iPad controlled with a specific device (Groovtube) that measures breathing. Have you ever tried them out?
14. If yes, what are your thoughts about them?
 - (a) Are some more effective than others in your opinion? Which elements do you think are making them better?
 - (b) What are the elements that you find truly problematic in these games?
 - (c) How would you improve them? Any idea is welcome
15. Both regarding musical therapy and the games, what is your view on what children really like about these approaches?
16. On the other hand, when do you see that they are not properly engaged or motivated? What are the elements that causes this reaction in your opinion?
17. One possible implementation of this project would see the children playing independently (helped by parents to use a tablet) at home.
 - (a) Do you think the attendance to traditional exercises would still be high as when followed by the therapist?
 - (b) How do you see this scenario? (need to have therapist always close?)
18. The solution that is going to be developed incorporates elements of music and gamification (e.g. rankings, trophies). Do you think, compared to the available games, that this approach could enhance the interest of the kids? Any idea?
19. Final question: any thought or idea you would like to share after this discussion?

A.3 Thematic analysis / physiotherapists

Ideal training at home

- No, I don't think that [exercising at home without therapist] is dangerous, I don't see problems with it
- The biggest harm that can be done is that they don't train at their current threshold, therefore undertraining and losing some functionality
- a gamified solution where they train every day could help delaying the assisted breathing therapy
- 10-20 minutes a day would be ideal for individual therapy better to have some exercise per day and not for a long time they are busy with other tasks so if they had to do training, it should be easy to do
- but it's not only [important] the exercise, we try to make it more fun since it has to be done for years and they get bored.

Issues in following therapy at home

- these kids have quite a lot of activities on a daily basis
- Problem is that they have to do these exercises on top of the other tasks
- "I don't have the time", "I forgot about it". The issue is that when people do not have immediate results on their training, then as human beings are not very likely to keep on doing it in the long term.
- very few do their exercises [individually at home]

Features needed by therapists

- It would be nice to build [exercises] in this sets and repetitions

- interesting to make a plan after the child lung functionality has been tested, and put these plans in the game itself
- set [exercise] up and connect them with the agenda saying "we train these days with these sets of exercises".
- programs with blowing 10-15 times, and then we repeat it 3 times [with EMT device] we test during the process to increasingly adjust the resistance to train lung function.
- for us it's important to be able to modify the environment to make them blow even harder during the exercise
- You could measure and store data, using the threshold for the next time
- it would be nice to keep those values [calibration of previous session] for the next time, being able to test it also the next time at the same level

General and individual therapy

- general things are deep inhaling, deep exhaling and alternate it with an explosive sucking and explosive blowouts.
- (General): keep your breath for a long time and breathe out all the way.
- (General): if you train the exhalation muscles those are the ones used for coughing most of the times they should do all the exercises [excluding special cases]
- (Personalized): [number and length of breathing exercises] depends on their problem
- (Personalized): Duration of breathing is very personal, it can vary a lot. Some max exhale have 3-4 seconds, while others have 15 seconds.
- (Personalized): Games like Groovtube uses a threshold that can be moved to control the difficulty.

Advantages of embedding gamification elements

- When they do (exercises) with a game or music, I see that they are happier. It's more functional, and if they do only the exercises they feel just like a patient.
- all of these trainings and exercises add up to the daily routine, but a game could be more of a motivation for them
- these games have an effect of increasing motivation, and especially with children with low cognitive functionality. They are more able to reach their threshold.
- In the past, children had masks to wear when doing respiration exercises, but it's very difficult to keep that going over time, because it's a boring exercise.
- I believe the interaction between their breathing and the game elements take the attention away from their current situation and they are focused on something else
- ability to change something (e.g. change photo effect) with their breath

System / Game design considerations

- "a really important aspect is the social one. I was thinking, is it also maybe possible to play music and make a game that they can play together with others? Like in sports, if there's a group it's usually more fun to do right?"
- the idea of connecting with each other and train together is really nice
- not forced to keep on blowing repeatedly, so they won't inhale and get lightheaded
- if you can measure the maximal exhalation and maximal inspiration before the game starts, you will have individual data you can control The levels required to perform have to be submaximal, because research tells that it's best not to aim for the maximal level.
- have air going out (of the tube, to lower resistance).
- if [children] have a decrease in functionality and you become aware of it, keeping track of it could become demotivating. It's something to keep in mind.

- Comparing their performance is a no-go.

Issues or missing features in current solutions

- (calibration on max inhalation and exhalation) is what I miss in Groovtube
- The system doesn't keep track of the data you input the last time [when exercising] we took some notes by hand on the kids performances
- only thing I miss from serious gaming is that they never reach the level of the famous videogames, FIFA or GTA.
- every time [in GroovTube] you can set the bar and number of repetitions, but after the exercise is over everything is gone and you have to setup a new test.
- sometimes the [Groovtube] apps freeze and they need to be restarted, making it frustrating both for the child that has to wait and the therapist

A.4 Interview questions / parents

1. Name and age
2. Profession
3. About childrens daily life
 - What is a common day for them (what do they do from morning to evening)?
 - What do they like to do? Do they give you any feedback about something they like/dislike?
 - How do they spend their free time, once they are done with their tasks for the day?
 - How does Duchenne affects the kids life in your perspective? Their mood? Social life? How do you see their mental wellbeing over time?
4. About childrens life in social contexts (e.g. school)

- How much time of the day do they spend with other kids? Do they have difficulties in making friends, for instance at school, because of their condition?
- Do they get into good friendship with other kids affected by Duchenne?
- Do they wish / ask you to meet them occasionally? Do you think they feel good when they can meet up with them and do activities together?

5. Perspective on the therapies they follow

- Which kinds of therapy do they follow (breathing exercises with a machine, music therapy etc.)?
- Are you informed on the research about Duchenne, especially regarding the advantages of frequent exercises on a daily basis?
- What do you think is your kid perspective on the classic breathing exercises therapy? How do they feel about it?
- What do you think about the music therapy sessions (given the feedback from the kids)?
- Comparing the two different approaches we just talked about, which one do you think will work better in a home setting without the therapist assisting the kid?
- What is something you think could be improved in the current therapy, especially regarding the enhancement of continuous participation?
- Do you play often with your kids? Which kind of activities do you do?
- Do you have time / are able to support your children for training at home? Do you already do that?
- Do your children like playing games on iPad or similar devices (also with your participation)?
- Which kind of games do they like to play? Any example that comes to your mind?

6. Do you know the Groovtube? Would you be interested in a cheaper solution than Groovtube (if its known) to allow them to play home and exercise? Would you have time to assist them in setting up the game?
7. Any suggestion for the game? (playing with others? Kind of game?)
8. Finally, any idea or suggestion about features that you think should be included in the system?

A.5 Thematic analysis parent's interview

As a reminder, this parent has two children with Duchenne. In the following analysis, two abbreviations (B. and T.) are used to refer to the two different kids while maintaining their anonymity.

Differences of disease in children

- (T.) low cognitive function and doesn't speak
- (B.) he is as intelligent as other peers of his age. Plays online games on the Playstation
- B. is still struggling with the fact that he is aware that it's going to get worse with time.
- When he has no pain, T. is a very happy boy. He smiles and takes life as it is.

Game design

- It should be something visual that they could focus on
- It should have some musical elements inside
- they can also play with others
- nice if also other people (not only Duchenne kids) could play with him.

- Format could be either competitive (see who is the best at it) or collaborative
- it should be done in a way that is not felt like doing a therapy.
- games should be something that they can do together
- thanks to these (games at hospital, like blowing candles), now B. has something he can focus on

Social gaming

online he can play with school friends

- B. plays on the Playstation online, and he likes that a lot!
- (since the family lives outside Enschede, away from B. friends) during the week playing the game online is so nice for him!
- play videogames together (when friends are visiting B.)
- B. likes to visit school friends here in Enschede or they come over to our place.

Preferences regarding therapies

- music therapy (play the keyboard with their breath.), B. likes it a lot
- physiotherapy (swimming is liked, cycling not so much)
- at hospital (use some games like blowing off candles or play bowling with breath), not liked mainly because of setting
- (he does not like games in hospital because of setting) but also because of being or not in a group
- what B. doesn't like (hospital tests) especially is that you have to wear this mask on your nose, and some tube he has to put the mouth around. It costs him a lot of pain in the muscles here (jaws).
- what B. likes is when he can do these things with others, it makes it easier.

Motivation

- B. says that he does enough at school, and he has the right to play videogames in his spare time!
- (if they didn't do therapies throughout the day), they would have to do therapies after their school time, and they would be even busier and have less free time for themselves.

Autonomy

- since he (the uncle) lives in the same town he can go there by himself.
- With other friends, unfortunately they live far away and he cannot go there on his own
- (parents were trying to limit how much B. could play) but then we saw that it's the only thing (videogames) he can do without us, by himself.

A.6 Thematic analysis of evaluation session

Abbreviations used: PT (PhysioTherapist), INT (Interview), OBS (Observations).

A more visual depiction of this analysis, showcasing the different users that took part in it with different colors, can be found here: <https://goo.gl/Wqs6jS>

A.6.1 General

- PT: Idea of recording some instruments on your own, and then collaborate online on different tracks

A.6.2 Persona

- **Theme: Low cognitive abilities**

- INT: he asked what the smileys on the scale used in the interview meant, since he couldn't understand it.
- OBS: Not sure he understood that he has to avoid bees and walls.
- During the interview, he was answering wrong questions asked before the current one.

A.6.3 Signup

No insights or pain points in this phase

A.6.4 Welcome

- **Theme: Calibration pop-up ignored**
 - PT skipped the calibration.
 - PT: "Usually I dismiss pop-us automatically, it's an habit"
 - PT would have clicked OK in the popup without reading the contents.
 - PT did not understand she had to access a menu to do calibration, she was just preparing the kid to blow after pressing start.
 - PT clicked OK in the popup without reading the contents. "I though it was not important".
- PT couldn't find the ranking icon.

A.6.5 Settings

- PT: "the breath button was half visible, I thought I couldn't press it"

A.6.6 Calibration

- **Theme: Uncertainty about how the interface works**
 - Calibration of inhaling not well done, basically skipped.

- PT: "Does he also have to inhale?"
- OBS: Tried to reach maximal calibration several times.
- To change threshold, PT would have calibrated again and "then I think I can change it there".

A.6.7 Training / Game

- **Theme: Game difficulty**
 - OBS: First time frustration, "It is difficult!"
 - OBS: 80% calibration is hard to use in a game with quick sequence of actions.
 - "It is difficult!"
 - OBS: to breath normally, child inadvertently activates controls of the game
 - OBS: Difficult to complete the level.
 - When playing without mouthpiece's valve: "It is very difficult"
 - PT: "The gameplay should be easy"
 - INT: he says it's difficult, but not too much and he became better at it
 - OBS: breathing in and out fast is quite difficult
 - Child wants to practice more, 3 training levels to get comfortable with controls
 - Child did not like the game, because it was too difficult (saddest smiley)
 - Would not play the game again, because it was too difficult (saddest smiley)
 - If the game would be less difficult, he would play it again (happiest smiley)
 - PT: "reaching the highest and deepest point was too fast, slowing it down is good"
 - OBS: difficult to understand how to breathe to properly control the character
 - OBS: the kid showed significant improvements after some trials.
 - PT: "By the end, he was only breathing out".
 - INT: "At the beginning it was difficult, but then it became easier".

- **Theme: Music**

- INT: the music helped the gameplay (happy smiley).
- PT: "The music is a bit low in the beginning, you cannot get the clue in time"
- Kid: "The first time I was following the coins, not the music"
- Child did not initially understand to follow music as hint on when to do an action
- Child used the music to go up and down in the game, he said it helped him.
- INT: child did not understand the music was meant to be followed.
- INT: child realized the music was going together with the coins (smiling)
- Child said he played by following the music
- INT: child perceived music more as background, not very helpful (neutral smile)
- INT: child used coins and arrows to get an idea on what to do, not music.
- INT: child did not follow the music to play the game.

- **Theme: Prototype comfort**

- It is more comfortable to play with additional mouthpiece given by father
- OBS: having to keep the mouthpiece in mouth is difficult
- OBS: problems in fitting the mouthpiece in mouth, cannot control well muscles.

- **Theme: Gamification**

- Smiling after having reached the first place in ranking
- INT: he would try to beat a friend's high-score (happiest smiley). Smiling when saying this.
- After making it to first place, he wants to play again.
- Laughing at the father making mistakes in the game.

- He asks the PT to check the position in the rankings.
- He wants to play again after checking his position in ranking, he was 4th.
- INT: if he sees a friend going over his score, he would play to try to beat him.
- INT: he would play again to beat a friend's high score if he receives a notification (happiest smiley).
- After playing for the score and seeing the ranking, he says that he wants to play again and that he likes the game.
- INT: he definitely would play to beat a friend's high score (happiest smiley)

- **Theme: Engagement & Motivation**

- INT: he says he wants to play again (happiest smiley).
- INT: he wouldn't add or remove anything, he says it's good.
- INT: he liked the game (happy smiley), would play again (same smiley)
- End of interview: "Next time I'll come again!"
- Saying "Yeah" out loud after a successful series of actions
- When asked if he is done with playing, he says the he wants to play more.
- OBS: he played for a total of 10-12 times between training and game.
- Almost towards the end, he asks if he can play 3 more times.
- INT: he enjoyed the game (happy smiley).
- INT: he would like to play again (happy smiley).
- He asks interested "Will this game be also in the Netherlands?"

- **Theme: Game design**

- PT: "Why does the duck get hurt when he jumps over enemies? Shouldn't it be like Super Mario?"
- Father: "Can this be played also on a big screen, like a TV?"
- PT: "Playing together, for instance create music, would be nice"
- PT: "About the green bar on the left of the duck, what is that again?"

- INT: he would like to have such a game, but racing with cars
- INT: he would like a multiplayer option
- INT: he would really like to play online with friends
- OBS: the visual clues are dominant over the music

- **Theme: Home training**

- INT: he would play at home (happiest smiley)
- He says he would play at home in the evening sometimes
- INT: he would probably not play at home, since he has other games on the Playstation (neutral smiley).
- PT: "I think the game is good, we should be able to make them play here and at home"
- INT: he definitely would play at home (he says "if I can play against others").

A.7 Game screens

These can be found at the following url: <https://goo.gl/5NoFwm>.

Bibliography

- [1] John R Bach, Ravindram Rajaraman, Frederic Ballanger, Alice C Tzeng, Yuka Ishikawa, Renata Kulesa, and Tina Bansal. Neuromuscular ventilatory insufficiency: effect of home mechanical ventilator use v oxygen therapy on pneumonia and hospitalization rates. *American journal of physical medicine & rehabilitation*, 77(1): 8–19, 1998.
- [2] Rudaina Banihani, Sharon Smile, Grace Yoon, Annie Dupuis, Maureen Mosleh, Andrea Snider, and Laura McAdam. Cognitive and neurobehavioral profile in boys with duchenne muscular dystrophy. *Journal of child neurology*, 30(11):1472–1482, 2015.
- [3] Virginia Braun and Victoria Clarke. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2):77–101, 2006.
- [4] Sebastian Deterding, Dan Dixon, Rilla Khaled, and Lennart Nacke. From game design elements to gamefulness: defining gamification. In *Proceedings of the 15th international academic MindTrek conference: Envisioning future media environments*, pages 9–15. ACM, 2011.
- [5] Adrián Domínguez, Joseba Saenz-De-Navarrete, Luis De-Marcos, Luis Fernández-Sanz, Carmen Pagés, and José-Javier Martínez-Herráiz. Gamifying learning experiences: Practical implications and outcomes. *Computers & Education*, 63:380–392, 2013.
- [6] G.-B. Duchenne. *De la paralysie musculaire pseudo-hypertrophique ou paralysie myosclerosique*. 1868.
- [7] A. E. H. Emery, Muntoni F., and Quinlivan R. C. M. *Duchenne muscular dystrophy*. 2015.
- [8] Jesse James Garrett. *The elements of user experience: user-centered design for the web and beyond*. Pearson Education, 2010.
- [9] Rosemary Garris, Robert Ahlers, and James E Driskell. Games, motivation, and learning: A research and practice model. *Simulation & gaming*, 33(4):441–467, 2002.
- [10] James Paul Gee. What video games have to teach us about learning and literacy. *Computers in Entertainment (CIE)*, 1(1):20–20, 2003.

- [11] Elia Gomez-Merino and John R Bach. Duchenne muscular dystrophy: prolongation of life by noninvasive ventilation and mechanically assisted coughing. *American journal of physical medicine & rehabilitation*, 81(6):411–415, 2002.
- [12] Cathie E Guzzetta. Effects of relaxation and music therapy on patients in a coronary care unit with presumptive acute myocardial infarction. *Heart & lung: the journal of critical care*, 18(6):609–616, 1989.
- [13] Carolyn R Houser and Donna M Johnson. Breathing exercises for children with pseudohypertrophic muscular dystrophy. *Physical therapy*, 51(7):751–759, 1971.
- [14] Joep Janssen, Olaf Verschuren, Willem Jan Renger, Jose Ermers, Marjolijn Ketelaar, and Raymond van Ee. Gamification in physical therapy: More than using games. *Pediatric Physical Therapy*, 29(1):95–99, 2017.
- [15] Kristian Kiili. Digital game-based learning: Towards an experiential gaming model. *The Internet and higher education*, 8(1):13–24, 2005.
- [16] Matthias J Koepp, Roger N Gunn, Andrew D Lawrence, Vincent J Cunningham, Alain Dagher, Tasmin Jones, David J Brooks, CJ Bench, and PM Grasby. Evidence for striatal dopamine release during a video game. *Nature*, 393(6682):266, 1998.
- [17] Carol L Krumhansl. An exploratory study of musical emotions and psychophysiology. *Canadian Journal of Experimental Psychology/Revue canadienne de psychologie expérimentale*, 51(4):336, 1997.
- [18] A Blythe LaGasse and Michael H Thaut. Music and rehabilitation: Neurological approaches. *Music Health, and Wellbeing*, R. MacDonald, G. Kreutz and L. Mitchell, Eds.(Oxford University Press, Oxford, 2012), pages 153–163, 2012.
- [19] Joey J Lee and Jessica Hammer. Gamification in education: What, how, why bother? *Academic exchange quarterly*, 15(2):146, 2011.
- [20] Joey J Lee and Christopher M Hoadley. Leveraging identity to make learning fun: Possible selves and experiential learning in massively multiplayer online games (mmogs). *Innovate: Journal of Online Education*, 3(6):5, 2007.
- [21] Wendy L Magee. Case studies in huntingtons disease: music therapy assessment and treatment in the early to advanced stages. In *Arts therapies and progressive illness*, pages 72–83. Routledge, 2003.
- [22] C Maranto. Applications of music in medicine. *Music therapy in health and education*, pages 153–174, 1993.
- [23] Cristina Ioana Muntean. Raising engagement in e-learning through gamification. In *Proc. 6th International Conference on Virtual Learning ICVL*, volume 1. sn, 2011.
- [24] Jakob Nielsen. *Usability engineering*. Elsevier, 1994.
- [25] Jakob Nielsen. Usability inspection methods. In *Conference companion on Human factors in computing systems*, pages 413–414. ACM, 1994.

- [26] National Institute of Neurological Disorders and Stroke (NINDS). Muscular dystrophy: Hope through research. <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Muscular-Dystrophy-Hope-Through-Research>, 2013. Accessed: 2018-09-03.
- [27] Michael Quinn Patton. *Qualitative evaluation and research methods*. SAGE Publications, inc, 1990.
- [28] Stanley Paul and David Ramsey. Music therapy in physical medicine and rehabilitation. *Australian Occupational Therapy Journal*, 47(3):111–118, 2000.
- [29] Janet C Read, SJ MacFarlane, and Chris Casey. Endurability, engagement and expectations: Measuring childrens fun. In *Interaction design and children*, volume 2, pages 1–23. Shaker Publishing Eindhoven, 2002.
- [30] Paul A Romitti, Yong Zhu, Soman Puzhankara, Katherine A James, Sarah K Nabukera, Gideon KD Zamba, Emma Cialfoni, Christopher Cuniff, Charlotte M Druschel, Katherine D Mathews, et al. Prevalence of duchenne and becker muscular dystrophies in the united states. *Pediatrics*, 135(3):513–521, 2015.
- [31] Katie Salen and Eric Zimmerman. *Rules of play: Game design fundamentals*. MIT press, 2004.
- [32] Marilyn I Sandness. The role of music therapy in physical rehabilitation programs. *Music Therapy Perspectives*, 13(2):76–81, 1995.
- [33] Aaron R Seitz, Dongho Kim, and Takeo Watanabe. Rewards evoke learning of unconsciously processed visual stimuli in adult humans. *Neuron*, 61(5):700–707, 2009.
- [34] David Williamson Shaffer, Kurt R Squire, Richard Halverson, and James P Gee. Video games and the future of learning. *Phi delta kappan*, 87(2):105–111, 2005.
- [35] Michael H Thaut, Gerald C McIntosh, Ruth R Rice, Robert A Miller, J Rathbun, and JM Brault. Rhythmic auditory stimulation in gait training for parkinson’s disease patients. *Movement disorders*, 11(2):193–200, 1996.
- [36] Raymond van Ee, Jeroen JA van Boxtel, Amanda L Parker, and David Alais. Multisensory congruency as a mechanism for attentional control over perceptual selection. *Journal of Neuroscience*, 29(37):11641–11649, 2009.
- [37] Lex Van Velsen, Jobke Wentzel, and Julia EWC Van Gemert-Pijnen. Designing ehealth that matters via a multidisciplinary requirements development approach. *JMIR research protocols*, 2(1), 2013.
- [38] Daphna Vilozni, Ephraim Bar-Yishay, Ilan Gur, Yehuda Shapira, Shirley Meyer, and Simon Godfrey. Computerized respiratory muscle training in children with duchenne muscular dystrophy. *Neuromuscular Disorders*, 4(3):249–255, 1994.
- [39] Hao Wang and Chuen-Tsai Sun. Game reward systems: Gaming experiences and social meanings. In *DiGRA Conference*, 2011.

- [40] William R Watson, Christopher J Mong, and Constance A Harris. A case study of the in-class use of a video game for teaching high school history. *Computers & Education*, 56(2):466–474, 2011.
- [41] Nicola Yelland. The future is now: A review of the literature on the use of computers in early childhood education (1994-2004). *AACE Journal*, 13(3):201–232, 2005.