

# Bo

*An intelligent network agent to promote physical activity in children with Congenital Heart Defects*

Master thesis · Hosana Morales

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**Delft, January 2020**

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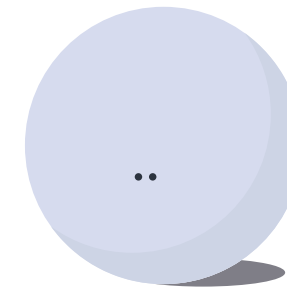
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# Abstract

There are various organisations such as the European Society of Cardiology (2012) and American Heart Association (2013), which describe why physical activity is essential for the development in youth. Unfortunately, children who have a Congenital Heart Defect (CHD), may suffer from a lack of opportunity to perform physical activity, decreasing cognitive maturation, motor development and autonomy during childhood (Krol, 2003). This impediment arises due to a misunderstanding from parents, who do not know to what extent their child can exercise safely, and therefore adopt overprotective behaviours (Schwerzmann, Thomet, & Moons, 2016). In order to understand better overprotection during childhood, 305 online parental stories from various patient-association websites were analysed using Natural-Language-Processing techniques. The results exhibited the lifetime journey of these families, where an uncertain future evoked a constant search for symptoms. The findings of this phase were employed during generative interviews with seven families with a CHD paediatric patient to understand the continuous search for symptoms during exercise. The combination of the insights gathered from interviews and the lifetime journey was presented to five medical team members to inspire a co-creation session. The outcome of the meeting helped to define the problem and create

a design vision which helped to ideate a potential Product-Service-System (PSS) solution to support parents to let their children safely perform physical activities. To encourage families to have a safe, ordinary sports-life, BO is introduced, a smart PSS aiming to support parents and their children with a CHD to understand better the safety boundaries of exercise during free-living conditions. With an activity tracker and his nine system modules, Bo aims to guide the child through different heart rate zones defined by doctors. Furthermore, Bo has a conversational agent function where parents can send concerns to the medical team and find relief when seeing their child's heart rate zone.

A functional prototype of the conversational agent was developed and implemented in the real context of four families to understand how could it influence overprotection. The implementation experience and overall concept of Bo were evaluated through in-depth interviews with paediatric CHD patients and their parents and three different specialities from the medical team. The results showed that Bo provides a supportive exploratory environment for the family, where the child can self-discover the safety boundaries and parents, instead of limiting the child, adopt an encouraging attitude towards physical activity.

Hi! My name is Bo :)



# Reading guide

## Highlights in the report

The reading guide presented in this section aims to support the reader by guiding him towards the desired content.

At the beginning of each chapter, a brief introduction of the chapter's content is presented. At the end of the chapters, a pink rectangle (Figure 1) provides the main takeaways from the chapter. Reading this rectangle can provide an understanding of the overall project insights in case there is no time for further reading.

Main insights are highlighted in this way throughout the text.

*And quotes from users are formatted in this way.*

Figure 1. Example of a figure containing takeaways from a chapter.

### Takeaways from this chapter

- Takeaway number one
- Takeaway number two
- Takeaway number three
- Takeaway number four
- Takeaway number five

## Report structure

The report is divided into eleven chapters; each of them is built with the same structure. First, a brief introduction and background are provided, then, research and design activities are described in detail, subsequent results are shown, and to conclude, the chapters provide a summary with key takeaways. The chapters content is as follows:

### Chapter 1 - General introduction

This chapter provides the information related to the project description, such as background, main stakeholders, problem definition, design assignment and scope.

### Chapter 2 - Text analysis

This chapter presents the manual and computational analysis process performed with a total of 305 online stories from parents to understand overprotection during childhood.

### Chapter 3 - Family interviews

This chapter contains the process followed to interview seven families with a CHD patient about their worries and symptom perception when their child participates in physical activity.

### Chapter 4 - Medical team co-creation

The current chapter describes the process followed during a co-creation session with five different specialities from the medical team and designers from Philips Healthcare and TU Delft.

### Chapter 5 - Problem definition

This chapter gathers all the insights from the research phase (chapters 2, 3 & 4), defines the problem, provides a design vision and validates both activities with parents and the medical team.

### Chapter 6 - PSS Ideation

This chapter narrates the ideation process followed to ideate the final Product-Service-System inspired by the co-creations results and design vision and describes the technology chosen for the concept.

### Chapter 7 - PSS Final concept

This chapter presents the final PSS concept. It describes the overall structure, the service phases and the details of each function. A storyboard to understand the experience is presented at the end.

### Chapter 8 - PSS Prototype

Chapter 8 elaborates on the scope for the PSS prototype, the process followed to build the conversational agent and the prototype structure.

### Chapter 9 - Implementation

This chapter describes the implementation study done with four families. It shares the iteration cycle of the prototype and its findings.

### Chapter 10 - PSS Evaluation

This chapter contains the evaluation results from the implementation and evaluation phase. It describes the interview structure and the main findings from the family and medical team perspective.

### Chapter 11 - General discussion

To finalise, this chapter presents a general conclusion of the project. It discusses the main research questions, future opportunities and limitations.

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# Abbreviations

<b>CHD</b>	Congenital Heart Defect
<b>PA</b>	Physical Activity
<b>PSS</b>	Product-Service-System
<b>HREC</b>	Human Research Ethics Committee
<b>NLP</b>	Natural Language Processing
<b>ML</b>	Machine Learning
<b>GTM</b>	Grounded Theory Method
<b>BoW</b>	Bag-of-Words
<b>LR</b>	Logistic Regression
<b>RF</b>	Random Forest
<b>NN</b>	Neural Network
<b>AUC</b>	Area Under the Curve
<b>ROC</b>	Receiver-Operating Curve
<b>CCS</b>	Co-creation Session
<b>HZ</b>	Healthy Zone
<b>SZ</b>	Symptom Zone
<b>DZ</b>	Danger Zone
<b>ST</b>	Safety Threshold
<b>HR</b>	Heart Rate
<b>IoT</b>	Internet of Things
<b>DT</b>	Discussion Topic
<b>HG</b>	Human Goal
<b>API</b>	Application Programming Interface

## Chapter 1

# General introduction

This chapter aims to provide an overview of the project context and primary stakeholders. First, it presents background information on physical activity, congenital heart defects, and physical activity in children with congenital heart defects to understand the overall problem. Then the problem statement introduces the scope and the three main research questions. To conclude, the chapter presents the assignment and the design approach followed throughout the project.

# General Introduction

Every child has the intrinsic need to play and interact with their surrounding. While they get older, their social abilities begin to go beyond family bonds when children attend school. During this scholar period, children immerse themselves in the social world, and this requires children to play with others and participate in social and recreational events. Hence, it is undeniable that physical activity is embedded in the social development of the child as it is in the physical milestones of childhood (European Society of Cardiology, 2012).

There are various organizations such as the European World Health Organization (2015), European Society of Cardiology (2012), and American Heart Association (2013), which describe why physical activity is essential for the development in youth. Unfortunately, children who have a Congenital Heart Defect (CHD), might suffer from a lack of opportunity to perform physical activity during childhood (van der Mheen, 2018), decreasing cognitive maturation, motor development and autonomy in the child (Krol, 2003).

Congenital heart defects are the most common congenital malformation presented in approximate 1 out of 100 live births worldwide (Voss & Harris, 2017). In the Netherlands, congenital heart defects affect around 1500 children per year (KinCor, 2015), and currently, 25.000 children suffer from a CHD (Hartekind, 2019). Nonetheless, as a result of the technological advances in healthcare over the past years, 90% of children born with a CHD survive into adulthood (Utens et al., 2018). Therefore, levels of Physical Activity (PA) in youth have been recently receiving more attention due to the higher predisposition to obesity and cardiovascular risk factors that CHD patients face in maturity (American Heart Association, 2013). However, a majority of paediatric CHD patients, are deprived of physical activity due to a misunderstanding from parents who do not know to what extent their child can exercise safely (Moola, Fusco & Kirsh, 2011), thus leading to overprotective attitudes towards the child (European Society of Cardiology, 2012).

Therefore, in a conjoint effort, TU Delft CardioLab, the Erasmus MC, in close collaboration with the

patient's association Stichting Hartekind, decided to pursue a project aiming to support parents and their children with a CHD to understand better the safety boundaries of exercise during free-living conditions provided by the medical team.

## 1.1 Background

### 1.1.1 Physical activity

According to the American Heart Association (2013), every physical activity (PA) can be defined by six dimensions. These are mobility, object manipulation, cognitive function, behaviour and social skills, communication and perception, and fitness (Figure 2). Current processes at the hospital such as the Cardiopulmonary Exercise Test (CPET) are used to assess exercise capacity in CHD patients, and determine if a patient can exercise safely (European Society of Cardiology, 2012). However, the accurate measurement in a hospital environment comes at expenses of actionable knowledge, and it is of interest for the physicians the ability to know real-time activity levels related to daily life. Due to the potential of this knowledge to provide new insights into patterns and behaviours and therefore enable the physicians to deliver tailored advice and promotion of physical exercise (Voss & Harris, 2017). Only a few medical studies use other methods such as accelerometers, pedometers, and questionnaires to quantify activity levels during free-living conditions (American Heart Association, 2013). Nonetheless, most of the time, all these procedures focus on the fitness component of PA and leave behind the other five aspects, which together provide a holistic perspective of physical activity.

### 1.1.2 Congenital heart defects

Congenital Heart Disease is a terminology employed to describe heart malformations conceived before birth, that affect the normal behaviour of the heart (NHS, 2018). This health condition can be presented as an abnormal growth of the heart's or major blood vessels' formations (American Heart Association, 2017), and be detected before birth during routine scans or once the child is born. Table 1 provides a summarized overview of the different defects that

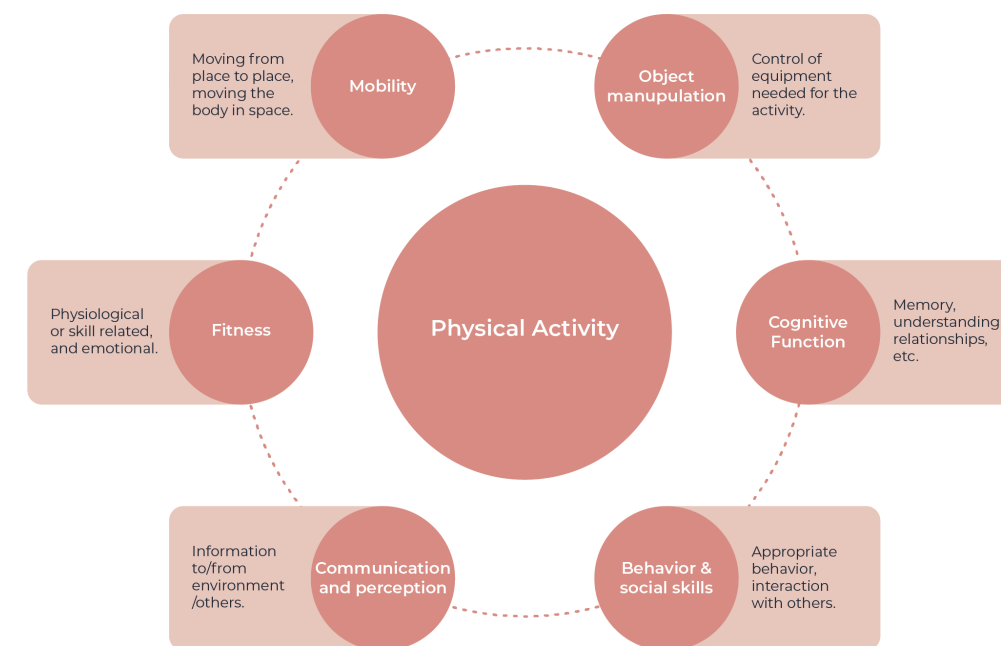


Figure 2. Six dimensions of physical activity from American Heart Association (2013).

can be presented in the heart. However, among the CHD types, there are different levels of CHD severity. These levels represent various complications after treatment that later are essential when deciding adequate levels of physical activity recommended (Noroz, et al., 2005). Appendix B shows the different degrees of CHD complexity based on the findings of Warnes et al. (2001).

### 1.1.3 Physical activity in children with Congenital Heart Defects

Physical activity and exercise can bring many benefits to a child's life. According to the American Heart Association (2013), exercising during childhood can prevent cardiovascular diseases, obesity, improve skeletal-muscle capacity, vascular health, and benefit cognitive and social function. Furthermore, increased physical activity is associated with better developed gross motor skills and positive emotional development (European Society of Cardiology, 2012). Moreover, in most children with a CHD, being physically active can improve their endurance, just like a healthy child, and it can also help to prevent further complications in adulthood. However, physical activity can also be a sensitive topic when referring to children who have a cardiac defect due to the reduced activity levels noted (Arvidsson et al., 2009). Usually, the correlation between exercise capacity and physical activity levels is low in CHD patients, and this sensitive attitude concerning physical activity comes from caretakers who have a misperception regarding the relative risk versus benefits of participation (European Society of Cardiology, 2012). Thus, the level of caregiver's anxiety increase with child's PA participation, and they end presenting an overprotective attitude

towards the child which restricts participation in physical exercise (Dulfer et al., 2015).

Among literature, parental overprotective attitudes towards PA are attributed to different factors such as being unaware of the extent their child can exercise safely, and knowing which sports alternatives and physical activities are the most appropriate for their child (American Heart Association, 2013, European Society of Cardiology, 2012). In addition to this misinformation, other psychological factors such as negative past experiences, uncertainty in long-term prognosis, and loss of control were found as overprotection triggers (Moola, Fusco & Kirsh, 2011).

This overprotective parental behaviour, in contrast to autonomy promotion for PA, might give the CHD paediatric patient a sense that PA is dangerous, strengthen avoidance, and limit the child's possibilities to acquire skills and confidence in managing possible challenges (Clarke, Cooper & Creswell, 2013). To prevent these complications, children with a CHD should pursue an active lifestyle and have the support of their parents to accomplish it (Dulfer et al., 2015). These healthy lifestyle practices are commonly developed in early adolescence and usually persist into adulthood (De Cocker et al., 2011).



Type	Description
Holes in the heart	Holes can form in the walls between heart chambers or between major blood vessels leaving the heart. In certain situations, these holes allow oxygen-poor blood to mix with oxygen-rich blood, resulting in less oxygen being carried to the child's body. Depending on the size of the hole, this lack of sufficient oxygen can cause the child's skin or fingernails to appear blue or possibly lead to congestive heart failure. Some examples of this condition are ventricular septal defect (VSD), atrial septal defect (ASD), Patent ductus arteriosus, and atrioventricular canal defect.
Obstructed blood flow	When blood vessels or heart valves are narrow because of a heart defect, the heart must work harder to pump blood through them. Eventually, this leads to enlarging of the heart and thickening of the heart muscle. Examples of this type of defect are pulmonary stenosis or aortic stenosis.
Abnormal blood vessels	Several congenital heart defects happen when blood vessels going to and from the heart don't form correctly, or they're not positioned the way they're supposed to be. Some examples of this condition are transposition of the great arteries, coarctation of the aorta, and anomalous pulmonary venous connection.
Heart valve abnormalities	If the heart valves can't open and close correctly, blood can't flow smoothly. Examples of this type of defect are Ebstein's anomaly and pulmonary atresia.
Underdeveloped heart	A major portion of the heart fails to develop properly. An example of this defect is hypoplastic left heart syndrome.
Combination of defects	Some infants are born with several heart defects. The most common example of this condition is the Tetralogy of Fallot.

Table 1. Types of congenital heart defects from Mayo Clinic (2018).

## 1.2 Problem statement

### 1.2.1 Scope

As previously mentioned, the first step towards increased physical activity participation in CHD paediatric patients is to create a shared understanding among the physicians, parents and the child regarding what is possible, desired, and allowed considering the safety boundaries of PA during free-living conditions. Therefore, the scope of this project is on the conflict between what is permitted (parent's beliefs) and what is possible (physical activity), with a primary focus on the parental factors that interfere in physical activity participation, such as overprotection and anxiety.

Since overprotection manifests itself when CHD patients participate (or try to) in physical activities and sports (European Society of Cardiology, 2012, Schwerzmann, Thomet & Moons, 2016, Dulfer et al., 2015), it will be necessary to understand parental perception of child's safety to reduce overprotective behaviour and thus increase the support to pursue an active lifestyle. Moreover, psychological factors among parents, such as perceived anxiety

during past experiences could provide a better understanding of overprotection throughout the years and uncover potential links between the six dimension of PA to implement them as part of the design solution on a later phase.

### 1.2.2 Solution space

The design solution envisioned as a Product-Service-System (PSS) will consider the context of patients aged 6 to 12 years old since researching and proposing a solution for parents during this period could directly provide a positive influence on the adolescent years of the patient regarding PA healthy habits. Furthermore, the ideation around the PSS will consider physical activity tracking sensors already on the market (e.g. Fitbit, Garmin) to increase the feasibility of the outcome and the potential of the data generated to enable physicians to deliver tailored advice and promotion of physical exercise.

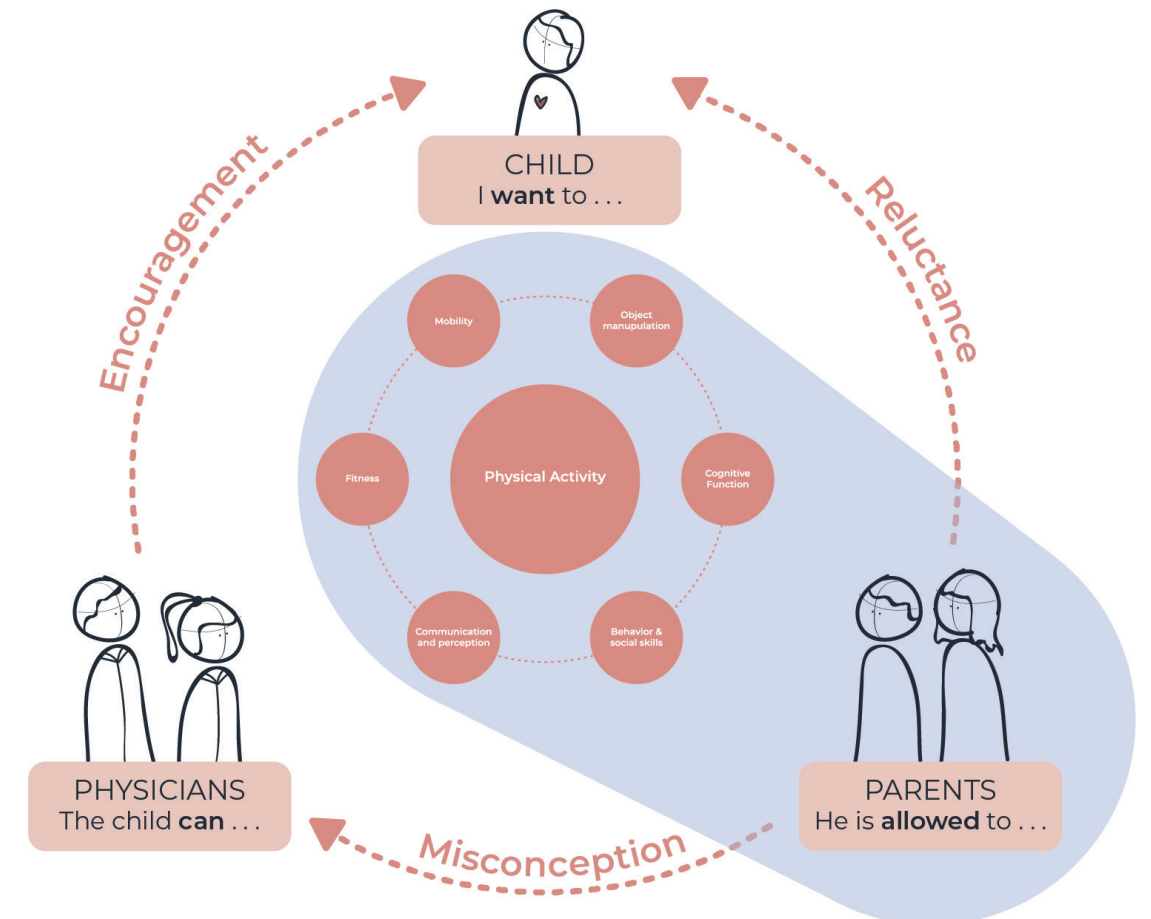


Figure 3. Context (overall figure) and scope of the project (blue area). Source, own visualisation.

## 1.3 Assignment and approach

### 1.3.1 Assignment

In order to answer the research questions in the previous section, the following design assignment was created considering the solution-space requirements and the opportunities that a PSS could offer to relieve perceived anxiety and overprotective behaviours.

*“To develop a proof of concept for a Product-Service-System that increases the support from parents towards the CHD patient to pursue an active lifestyle by providing data-based awareness to decrease perceived levels of overprotection and anxiety in parents.”*

Figure 4. Assignment.

### 1.2.3 Research questions

With the purpose of making the research process more specific and generate a better understanding of the factors surrounding physical activity and overprotection throughout childhood, three research questions were created.

1. Which are the triggers for overprotection according to past experiences?
2. Which are the dimensions of the physical activity model that relate to the triggers identified?
3. Which data-based features should the PSS have to decrease perceived levels of overprotection and anxiety in parents?

### 1.3.2 Project approach

As a first step to address the overprotective attitude that parents of children with CHD have towards physical activity, the process to achieve the completion of the assignment divides into the four phases of the double diamond design approach, (1) Discover, (2) Define, (3) Develop, (4) Deliver (Design Council, 2019). The following paragraphs will explain the purpose of each phase and briefly describe the methodologies employed.

#### - Discover

During the Discover phase, the aim is to understand in a broad perspective how parents perceive their babies, their behaviours with their child, and therefore how does overprotection develop throughout childhood. Chapter 2 presents the procedure followed by means of the Grounded Theory Methodology (Glaser & Strauss, 1968) and computational text analysis with Natural Language Processing techniques to dive deep into parental stories found online.

#### - Define

For the Define phase, two goals are set to conclude in a problem definition for further development. These are first, understand when, during PA participation, the concerns from family members arise, and which are the causes. Second, gather the perspective of different medical team members who

treat CHD paediatric patient, to better comprehend the overall medical situation, and ideate together possible design alternatives. To do so, Chapter 3 presents in-depth interviews with parent and child together, conducted employing generative material (Sanders & Stappers, 2012). Furthermore, Chapter 4 describes the process followed in a co-creation session (Sanders & Stappers, 2008) with the medical team, in which the findings of Chapter 2 and 3 in combination with their expertise inspired them to ideate the envisioned PSS. Finally, the insights of Chapter 2, 3 and 4 are consolidated in Chapter 5, where the integration of the three perspectives from the main stakeholders, child, parents, and physician, provide the problem definition and design vision.

#### - Develop

Two objectives compose the Develop phase. The first one intends to ideate the potential modules composing the envisioned PSS by integrating the ideas gathered in previous phases. The second one aims to detail the PSS based on the modules defined with the previous objective. Therefore, to accomplish both objectives, Chapter 6 exhibits the iteration process followed to define the PSS modules and exploration of technology to power the system, and Chapter 7 present the resultant PSS conceptualization.

#### - Deliver

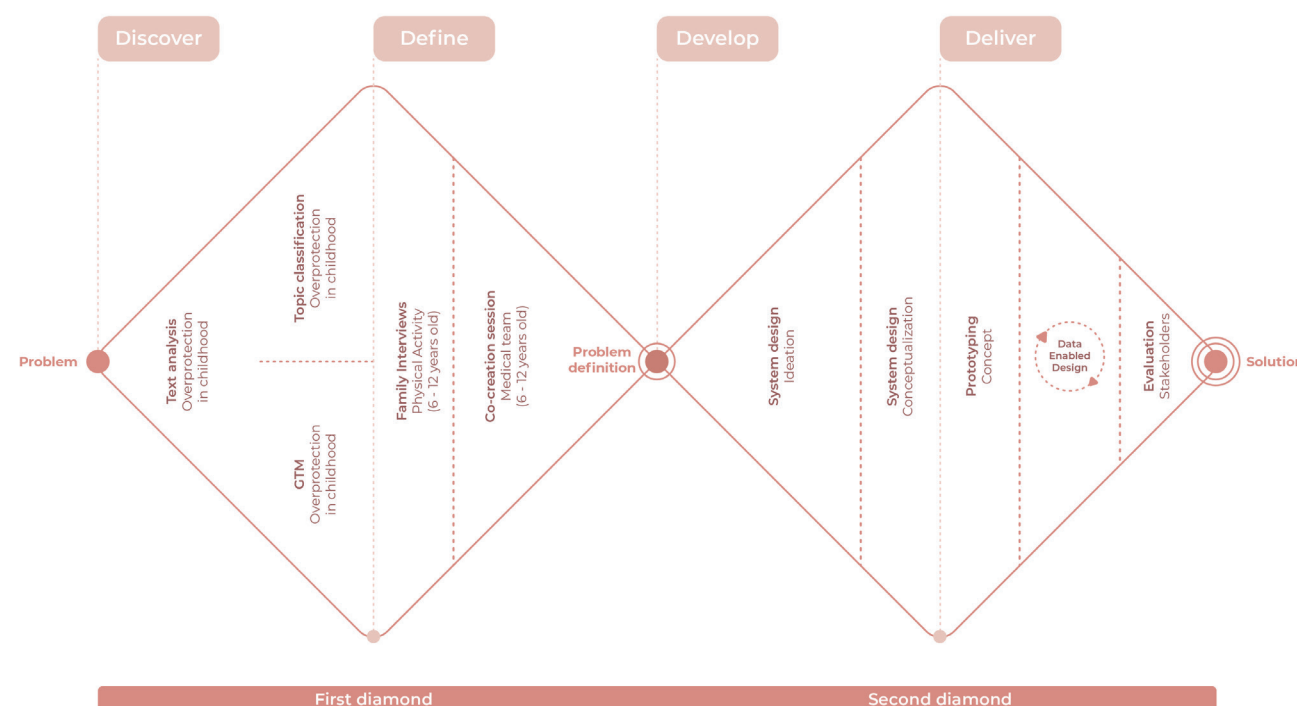
Finally, during the Deliver phase, three goals are defined to conclude with the envisioned proof of concept for anxiety and overprotective attitudes in parents with CHD cardiac patients. The first goal intends to develop a prototype of a selected PSS sub-module, which can serve as a proof of concept to test with the parents and their child with CHD. The second goal aims to implement the selected system module with the families, observe their behaviour and improve the prototype in real-time. To conclude, the third goal intends to evaluate the PSS with the main stakeholders. In order to accomplish the goals, Chapter 8 presents the development process to prototype a module of the PSS. Chapter 9 introduces the testing phase with the Data-Enabled Design approach (Bogers et al. 2016), and Chapter 10 exhibits the final interviews with the families and physicians involved and further recommendations. As a final result, Chapter 11 provides a conclusion for the overall design process and provides an answer to the three research questions previously defined.

Figure 5 presents the overall design process for this project.

### Summing-up

The present chapter introduced diverse aspects of the design challenge and the design process intended to follow to accomplish the assignment formulated. The next chapters will describe in detail how each goal stated for the four design phases was achieved along the project span.

Figure 5. Double Diamond model. From Design Council, 2019.



### Takeaways from this chapter

- Congenital Heart Defect severity levels represent various complications after treatment that later are essential when deciding adequate levels of physical activity.
- Parental overprotective attitudes towards PA are often attributed to being unaware of the extent their child can exercise safely, and knowing which sports alternatives and physical activities are the most appropriate for their child.
- The scope of this project is on the conflict between what is permitted (parent's beliefs) and what is possible (physical activity), with a primary focus on the parental factors that interfere in physical activity participation.
- The envisioned solution aims to create a Product-Service-System (PSS) for patients aged 6 to 12 years considering physical activity tracking sensors already on the market.



## Chapter 2

# Text analysis

This chapter aims to generate a broad perspective of how parents perceive their baby, their behaviours towards their child, and thus understand how does overprotection develops throughout childhood. The chapter begins by providing background information on online parental stories as the subject to analyse the main research questions. Afterwards, the methodology and procedure followed to analyse the online stories by Natural Language Processing techniques is described. Finally, the results from the analysis are shown, and the discussion section addresses the main findings answering the research questions.

# Text analysis

## 2.1 Background

Foundations from all over the world dedicated to supporting families with a CHD patient often provide stories written by parents in which they explain how it has been to raise a child with a CHD for other parents to be aware of possible future scenarios. These online parental stories (Figure 6) aim to describe how the life of these families have been since learning about the Congenital Heart Defect and present different aspects that range from past medical procedures to current everyday life details.

### 2.1.1 The relation of past experiences and overprotection

According to a qualitative study done with caregivers (Moola, Fusco & Kirsh, 2011), three primary triggers for overprotective behaviours towards physical activity participation were found, (1) negative past experiences, (2) loss of control and (3) uncertainty in long-term prognosis. Therefore, due to a lack of information to understand current overprotection, and the connection that past experiences might

represent towards overprotective behaviours in the present, it was decided to start the analysis with online parental stories. These stories had a detailed description of past parental experiences that could be used to understand how does overprotection and anxiety manifest during childhood. However, due to the duration of the project, and the number of stories found, Natural Language Processing (NLP) computational techniques were employed. These techniques allowed to analyse a more significant number of stories (n=305) and consequently add a quantitative approach to the analysis.

The three main research questions for the present study were the following:

1. What behaviours do parents have towards the CHD patient according to past experiences?
2. Which aspects trigger overprotection during childhood?
3. Which aspects trigger anxiety during childhood?

Figure 6 - Screenshot of a foundation website with an online parental story (Hartekind, 2019).

The screenshot shows the website for Stichting Hartekind. The main content is a parental story titled "Born with a large VSD and DORV". The text describes the family's experience with their child's heart condition, including the diagnosis, surgery, and the challenges of caring for a child with a complex heart defect. The story is written in a personal, narrative style. A search bar is visible at the top right, and a navigation menu is at the top left.

## 2.2 Method

### 2.2.1 Data collection

A total of 350 online stories from five countries were manually copied (title, body text and representative image) into an excel file for further analysis (Table 2). A Script code to collect the stories was not an option to extract the text due to the different format of each website (n=16) and the extra labour that represented to adapt the code to each website.

The criteria for selecting a story as eligible for the analysis was the following:

Writer: father or mother  
 Patient age: 0 to 12 years old  
 Patient health condition: Congenital Heart Defect or Heart Rhythm Disorder

### 2.2.2 Ethical considerations

The Human Research Ethical Committee (HREC) from TU Delft and the Data Steward of the IDE faculty provided the approval to conduct the text analysis and suggested to contact each website to get a written consent statement. Therefore, after extracting the stories, a total of 16 websites were contacted through e-mail to explain the analysis and ask for permission to analyse their stories. Two websites decided to retire from the study and a total of 305 stories from 14 websites was used to conduct the analysis.

Table 2 - Distribution of Country and number of online parental stories  
 CHD - Congenital Heart Defect, HRD - Heart Rhythm Disorder.

Country	Website	Number of online stories	
		CHD	HRD
Australia	Heart kids	4	0
	Heart centre for children	16	0
	Hearts of hope	20	0
Canada	Cardiac kids	24	0
The Netherlands	Stichting Hartekind	45	0
	Stichting Hartedroom	0	33
United Kingdom	Cardiomyopathy	2	0
	Children's Heart Federation	34	0
	Lagan's Foundation	8	0
	Little hearts matter	30	0
	Children's heart association	5	0
United States of America	Tiny tickers	78	0
	Centers for disease, control and prevention	3	0
	Little hearts	2	0
	The children's heart foundation	9	0
Total number of stories per health condition		317	33
	<b>Total number of online stories</b>	<b>350</b>	

### 2.2.3 De-identification procedure

Each of the 305 online stories was carefully read. Later, all the data classified as Direct Identifier (e.g. name, address, zip code, telephone number, voice, picture) and Indirect Identifier (e.g. institutional affiliations, occupation and geographic region) was removed or replaced to increase the confidentiality of the stories provided (Qualitative data repository, 2019). In the case of images, all the faces were distorted. A complete overview of the de-identification procedure can be found in Appendix C.

## 2.3 Procedure

Natural Language Processing (NLP) is a sub-discipline of Artificial Intelligence that employs different computational techniques to analyse natural occurring texts and achieve human-like processing (Liddy, 2001). This sub-discipline enables a range of applications such as chatbots to have 'real' conversations or text classification to index large amounts of data. Therefore, due to the number of online stories gathered (n=305), it was decided to analyse the data with an NLP technique. Different NLP methods were enlisted to understand their benefits and disadvantages (see Appendix D). The process chosen was Topic Analysis, defined as "a technique to indicate what topics are included in a text and how topics change within the text" (Li & Yamanishi, 2000), due to possibility to create later an overall story composed with the topics encountered. Topic Analysis works as a supervised classification Machine Learning (ML) method in which an algorithm is told the categories to be found and the algorithm "learns" the similarities and differences between each category. Therefore, it was necessary to create a reference for the algorithm to learn how to classify the text topics. Hence, the analysis was divided into two phases, phase one - manual analysis and phase two - computational analysis.

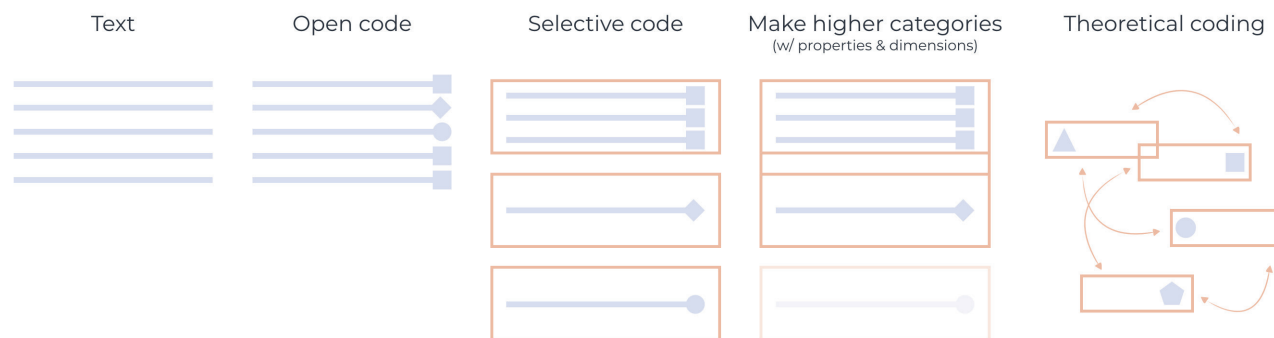
### 2.3.1 Phase one - Manual analysis

Phase one was conducted on a manual setting by means of the Grounded Theory Method (Glaser & Strauss, 1968) to get familiar with the data, generate an initial understanding of the families, and create the first topic classification from the stories for later use. This method aims to generate analytic categories with their own set of dimensions, to later identify the relationships between them (Ritchie, Lewis, Nicholls, & Ormston, 2013). The following figure provides an overview of the different steps followed during the Grounded Theory Method (GTM).

#### Procedure

A total of 70 out of 305 online parental stories were selected using a Proportionate Stratified Random Sampling method (see Appendix E) and separated into sentences. Due to the limited time and the language barrier (Dutch), two student assistants were hired having as a selection criterion their familiarity on working with the GTM. Each student was given a total of 23 stories and 24 to the leading researcher to categorize based on a random assignation to diversify the different country stories among the different coders.

Figure 7. A general overview of Grounded Theory process adapted from Birks & Mills (2015).



#### 1. Open code

The first phase of the GTM consisted on individually reading five stories to obtain the initial codes (categories). The focus of the coding process was on the behaviours of parents towards the child, how they felt, and why they felt that way. The overall meaning of each sentence was extracted, and later the three coders gathered all the sentences with their respective meaning, compared the dimensions of each possible category, and created an agreement to strengthen the validity (Ravitch & Mittenfeller, 2015). In order to avoid losing the meaning of each categories, the use of In-vivo codes and the preservation of gerunds was applied during the cluster creation. Besides a process of Memo writing (Birks & Mills, 2015) was used to write the coder's emerging thoughts and doubts to later discuss with the team. As a result, a provisional codebook (Figure 9) was created containing the first set of codes.



Figure 8. An impression of meeting to create the first set of codes.

#	Code name	Total quotes supporting	Description	Example quote	Add ons Regina		Add ons Frans		Add ons Hosana	
					10S	8S	10S	8S	10S	9S
1	<b>Finding something is wrong</b>	97	Usually in the beginning of the story where parents share how they found the CHD.	'The sonogram technician kept circling around his heart and said "there's a problem with his heart anatomy.'	41	8	10	6	10	7
2	<b>Not going home</b>	8	Medical staff explaining and/or saying that child couldn't go home.	'The doctors weren't going to be able to reassure us and they weren't going to be sending us home.'	2	2	0	0	1	0
3	<b>Before discovery of CHD</b>	66	Thoughts before knowing their child had a CHD.	'We'd decided we didn't want to find out the gender of our baby.'	19	14	9	5	6	4

Figure 9. Provisional 'codebook'. Screenshot from Microsoft Excel.

#### 2. Selective code

The second step consisted on individually classifying ten stories into the agreed codes, keep updating the count of sentences supporting each category, and if necessary, create a new code to categorize new information. A total of 68 codes were discovered until this step.

by applying the same instructions as the previous step. However, since the number of sentences supporting each code had grown, clear patterns of properties started to appear. These patterns inside each code were called 'sub-codes' (Figure 10) and were an additional source of classification to increase the understanding of the stories. Moreover, all the text from the Dutch stories was translated to English using Google translate to increase the understanding of the classification among the three coders.

#### 3 Make higher categories

The last round of classification took place with the remaining stories (n=25); these were categorized

STORY	LINE	QUOTE	CODE	SUB-CODE
S1 - 15	106	The excitement was building, but we didn't want to get too excited as there were still tests to be done, and his weight was being closely monitored.	"hoping for the best but planning for the worst"	Describing dilemma
S1 - 15	108	Even nine weeks on, the emotions are still quite raw.	"Re-playing what happened"	Deepness of recap
S1 - 15	109	I still find myself replaying what happened through my mind, particularly in the early hours after feeding the little man.	"Re-playing what happened"	Moment of recap
S1 - 15	12	I just kept saying "that's ok, whatever we need to do, better to know in advance", my husband was quiet.	"whatever we need to do"	Describing willingness
S1 - 15	80	Nothing could have prepared us for that moment.	Being unprepared	Anticipation not possible
S1 - 15	69	None of this prepared us for the extent of what we saw and felt.	Being unprepared	Anticipation not possible
S1 - 15	70	Our little boy, 8 days old, had tubes coming from everywhere.	Body-machine connections	Describing appearance
S1 - 15	71	Every limb had something attached, he had tubes coming out of his nose, neck and chest cavity.	Body-machine connections	Describing appearance
S1 - 15	99	This felt like a setback because despite having another cannula removed, he had a feeding tube added.	Body-machine connections	Unit of measure -
S1 - 15	103	He had his final major tube removed, the one in his neck, with just the feeding tube remaining! This was such a milestone for mummy and daddy as we could finally see our beautiful little boy, unhampered by the tubes! By midday, it was confirmed and our discharge papers were being drawn up! We were elated! On the Thursday we saw lots of progress. He had tubes removed every few hours, starting with his feet cannulas and then his ventilator tubes.	Body-machine connections	Unit of measure +
S1 - 15	94	The next day our baby was discharged and we were given an appointment to return so that surgery dates could be determined.	Child being discharged	Activities after

Figure 10. Table with subcodes. Screenshot from Microsoft Excel. The complete table can be found in Appendix F.



#### 4. Theoretical coding

Once all the stories were classified according to the codebook, the 61 final codes were transcribed in post-it to proceed with finding the relationship between them. During this step, the Memo writing notes from the three coders were used as the first ground to start finding the connections.

The following list shows the 61 codes in alphabetical order. See Appendix F for a complete table with sentence-count and sub-codes.

- |  |   |
|--|---|
| 01. "Having a son with CHD changed us"               | 32. Getting information                             |
| 02. "hoping for the best but planning for the worst" | 33. Giving birth                                    |
| 03. "Re-playing what happened"                       | 34. Having a new chance                             |
| 04. "Tending to think he is cured"                   | 35. Interaction with medical staff                  |
| 05. "whatever we need to do"                         | 36. Looking forward to the future                   |
| 06. Admitted into the hospital                       | 37. Medical decisions                               |
| 07. Baby thriving after treatment                    | 38. Not going home                                  |
| 08. Before discovery of CHD                          | 39. Not knowing diagnosis                           |
| 09. Being a normal baby                              | 40. Parents showing relief                          |
| 10. Being afraid of the future                       | 41. Parents Worrying                                |
| 11. Being proud of your kids                         | 42. Patient's development                           |
| 12. Being unprepared                                 | 43. Physical contact                                |
| 13. Body-machine connections                         | 44. Procedures                                      |
| 14. Challenges after hospitalization                 | 45. Protect child                                   |
| 15. Cherishing the moment                            | 46. Realise seriousness                             |
| 16. Child battling for its life                      | 47. Realise strength of child                       |
| 17. Child being discharged                           | 48. Recovery  |
| 18. Child coping with CHD                            | 49. Religion procedures                             |
| 19. Child having ups & downs                         | 50. Saying goodbye to undergo medical procedure     |
| 20. Child's physical activity                        | 51. Seeing baby                                     |
| 21. Connecting with other CHD families               | 52. Support from family and friends                 |
| 22. Dealing with set-backs                           | 53. Supporting child                                |
| 23. Doctor Fearing your child might not live         | 54. Surgery   |
| 24. Early detection                                  | 55. Symptoms  |
| 25. Emergency happening                              | 56. Taking news from staff                          |
| 26. Facing reality                                   | 57. Telling each other everything will be all right |
| 27. Family life changed                              | 58. Time perception                                 |
| 28. Feelings after hospitalization                   | 59. Understanding diagnosis                         |
| 29. Feelings towards medical staff                   | 60. Waiting   |
| 30. Finding something is wrong                       | 61. Waiting for surgery date                        |
| 31. Follow-up checking and treatment                 |   |

Figure 11. An impression of meeting to perform Theoretical coding.







Figure 12. Grounded Theory timeline.

**GTM Results**

The theoretical coding outcome resulted in a timeline (Figure 12) with eight big moments present in almost every story. These were (1) Finding something is wrong, (2) Admitted to the hospital, (3) Being born, (4) Surgery, (5) Recovery, (6) Being discharged, (7) Follow up appointments and (8) Patient's development. Inside each moment, the different codes were placed with their corresponding sub-codes, emotions and relationships. The post-its were placed according to the positive (up) or negative (down) associated feeling along the timeline. This overview provided an understanding of past parental experiences and their relationship with their child over the years.

The eight moments clustered are explained below:

**1. Finding something is wrong**

Most parents find about the CHD during the 20-week scan. This event generates significant confusion due to the unclear nature of the CHD and the possible implications in the future. The doctors usually explain the possible treatment options, chances of survival, and possible downsides to later ask parents to decide which path to follow. The main objective during the decision-making process is to maximise the chances of the child having a comfortable life. Therefore, parents try to balance the chances of survival against the future procedures to take a decision. Based on this dilemma, most parents decide to give their baby a chance to fight the CHD. However, there are a few parents that due to the complexity of the CHD decide to terminate the pregnancy.

**2. Admitted to the hospital**

There are a few families that do not know about the CHD until the baby starts to present evident symptoms such as looking blue while breastfeeding or not having the energy for breastfeeding at all. This progressive deterioration in health is described as scary due to the uncertainty of not knowing what is wrong, and it is the first event to raise an alarm that the baby is not healthy. Therefore, parents usually take their babies to the medical team asking for specialised advice to later find that the CHD of their child was not detected until that moment.

**3. Being born**

When babies with a CHD born, there is usually a group of medical specialist waiting to stabilise them and prepare them for the upcoming surgery. Therefore, most babies are being taken away from their parents just after birth to treat the CHD. Mothers describe this experience as being difficult due to the lack of bonding time between the baby and parents. Moreover, some parents adopt a mindset of “not getting too excited” and “hoping for the best but planning for the worst” as a result of the survival chances of their child.

**4. Surgery**

For parents, surgery starts when the medical team takes their baby away. Some families will have time to say goodbye, but others will not due to the urgency of the operation. After this moment, parents enter a constant state of worry in which feelings of shock and anxiety are related to the fear of losing their baby. While waiting, parents describe the perception of time as being slower and agonising.

**5. Recovery**

After surgery, parents are allowed to see their baby, which causes a big sentiment of relief. However, these babies are usually connected to different machines and tubes come in and out from different parts of the baby's body. For most of stories, this is a remarkable moment. Parents describe seeing their baby for the first time as a shocking experience. Moreover, during recovery, it is often the case that complications appear resulting in life-threatening situations which make parents feel helpless. However, these critical moments also make parents realise all the strength that their baby has.

**6. Being discharged**

Once the baby's recovery goes as expected, parents are able to take their baby home. During this time, parents describe being overwhelmed by all the symptoms they should be aware of and sometimes terrified that their baby's health gets worse. Nonetheless, the positive feeling of being with their baby at home and have a sense of stability increases and makes them realise that their baby is a fighter.

**7. Follow-up appointments**

During the following years, parents have to attend follow-up appointments with their child. These events make parents sometimes feel scared due to past experiences. When the complexity of the CHD is higher, certain surgeries will take place in the upcoming years. Therefore, doctors look for symptoms that indicate the surgery is getting closer with each appointment. On the other hand, for parents, this “permanent waiting” means seeing a gradual deterioration of their child's health which

brings feelings of anxiety, uncertainty and fear towards the future.

Moreover, during this waiting years, parents describe their experiences as a two-way path. On the one hand, the trauma caused by the first surgery is something they will always remember and do not want to go over again. On the other hand, seeing their child full of life makes them truly appreciate life and reflect on the lessons learned and how far they are now from the moment they knew about the CHD.

**8. Patient's development**

With the pass of the years, parents see their babies becoming growing, gaining strength day by day, and hitting the expected childhood milestones. These moments make parents feel pleased about having their child alive. Moreover, seeing their child being able to do what they want to do (e.g. play soccer) provides immense satisfaction to parents. All these positive moments make parents feel proud of their child and admiration towards the child's journey.



### 2.3.2 Phase two - Computational analysis

Besides providing a first understanding of the families, the Grounded Theory Method established 61 codes (Appendix F) to use as a reference for the Topic Analysis algorithm and classify the remaining 235 stories. Since the unit of analysis in phase one was a sentence, the 235 stories were separated into sentence-by-sentence to have the same unit for the envisioned classification.

#### Procedure

The software chosen to make the computational analysis was Orange 3. This software, running with Python code, provided an add-on for text mining and tools for preprocessing and transforming the text into vectors. This last step being necessary for the machine to “understand” each sentence and classify later.

#### 1. Preprocess text

The main functionality of this step was to split the sentences into smaller unities called “tokens” (Orange 3, 2019a). However, without proper cleaning of the text from common words such as ‘the’, ‘a’, ‘an’, called “Stop words”, the results of the classification could be affected for this specific case of topic classification (Schütze, Manning & Raghavan, 2008). Therefore, before the tokenization process, the cleaning of the sentences was required. Although the software provided a tool to remove punctuation symbols and stop words, from the text, it was necessary to create a separate file with words-to-ignore to ensure the confidentiality of the training data. This file contained the names of all the cities of the five countries and the 100 most common names and surnames for each country.

#### 2. Bag-of-Words (BoW)

The following step for the training data to be ready was to transform each sentence into a set of numbers that the computer could recognize.

Therefore, the ‘Bag-of-words’ model was used to transform the text (Figure 13). This function represented each sentence as the “bag” of its words without considering the order or grammar of the text. However, the frequency of each word (token) was considered for each ‘bag’ (Goldberg, 2017).

#### 3. Finding the correct algorithm for classification

In order to discover which algorithm was the most appropriate for classifying the stories three different algorithms, (1) Logistic Regression, (2) Random Forest and (3) Neural Network (See Appendix G for definitions) were tested using a cross-validation technique (Figure 14). This validation method divided the data into ten groups and tested the model iteratively on each chunk of data until completing all of the groups (Orange 3, 2019b).

After training each algorithm with the GTM codes, the results were the following:

- Logistic Regression - AUC = 0.784
- Random Forest - AUC = 0.711
- Neural Network - AUC = 0.754

According to the above results, the method that presented the best results was Logistic Regression with an Area Under Receiver-Operating Curve (AUC) of 0.784. This number indicated how much the model was capable of distinguishing between the different categories; therefore, the higher the number, the better the model performance (Google developers, 2019).

#### 4. Logistic Regression optimization

- Classified bias problem

One problem present in ML classification models related to the size of the training data is the model bias. The nature of this problem relied on the

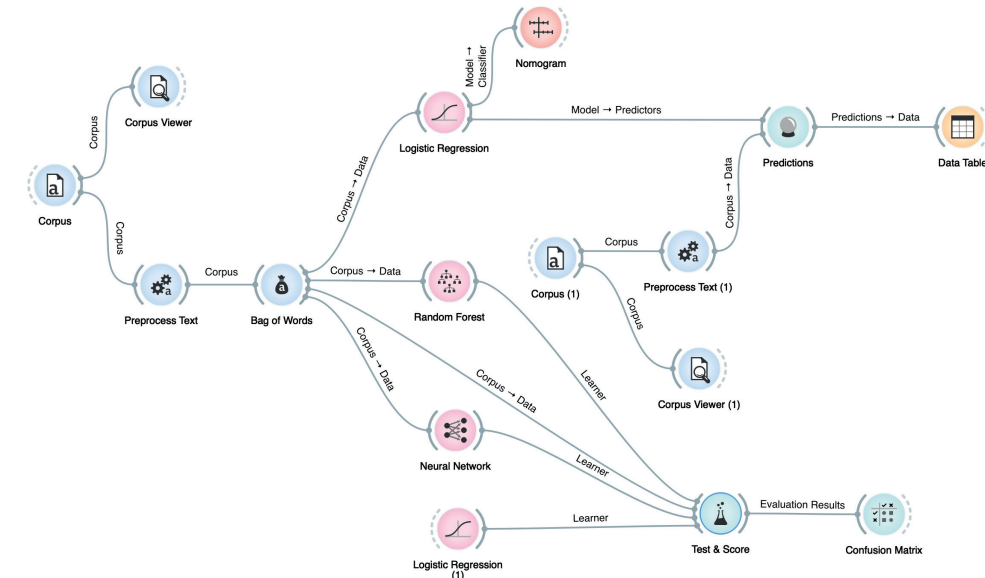


Figure 14. Orange 3 screenshot of try-out to find the adequate classification method.

classification model having a higher tendency to classify the new data to the categories that had more examples in the training data (Mac Namee et al., 2002). Since the first set of training data coming from the GTM had different quantities of sentences per code, it was decided to create a selection of 15 example sentences from each code to provide the algorithm with an equal number of examples and avoid a classified bias problem. After using the 15-example dataset as training material, the result was the following:

- Logistic Regression - AUC = 0.757

Therefore it was decided to leave the initial GTM dataset for the classification of the 305 stories.

- N-grams

Since the BoW does not respect grammar or the order of the words, it was decided to transform the Token from word-to-word to N-grams of different

sizes to extract more meaning of the sentences as changing a BoW to Bag-of-Bigrams has proven to be a powerful representation of text (Goldberg, 2017). An N-gram is a sequence of N words; therefore, a bigrams a two-word sequence of words (Figure 15), and trigram a three-word sequence (Jurafsky & Martin, 2000). After trying to modify the Token to bigrams and trigrams, the results were the following:

- N-gram and bigram - LR-AUC = 0.798
- N-gram to trigram - LR-AUC = 0.774

The model improved from an AUC of 0.784 to 0.798 by using bigrams. Therefore the classification of the 305 stories proceeded with a Logistic Regression model configured for a range of N-grams to bigrams (Figure 16).

Figure 13. Preprocess and Bag-of-Words. Source: own visualization.

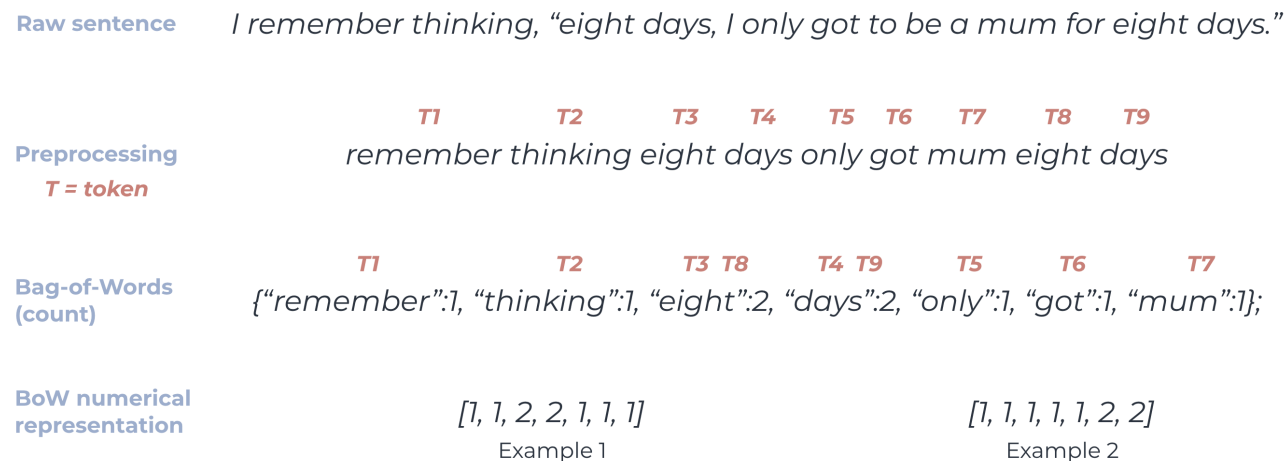
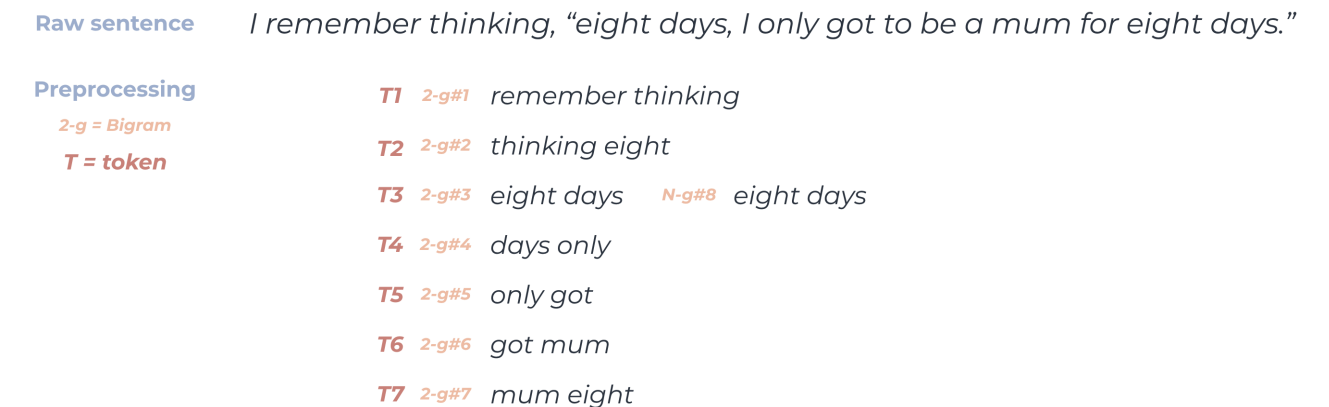


Figure 15. Bigram example. Source: own visualization.



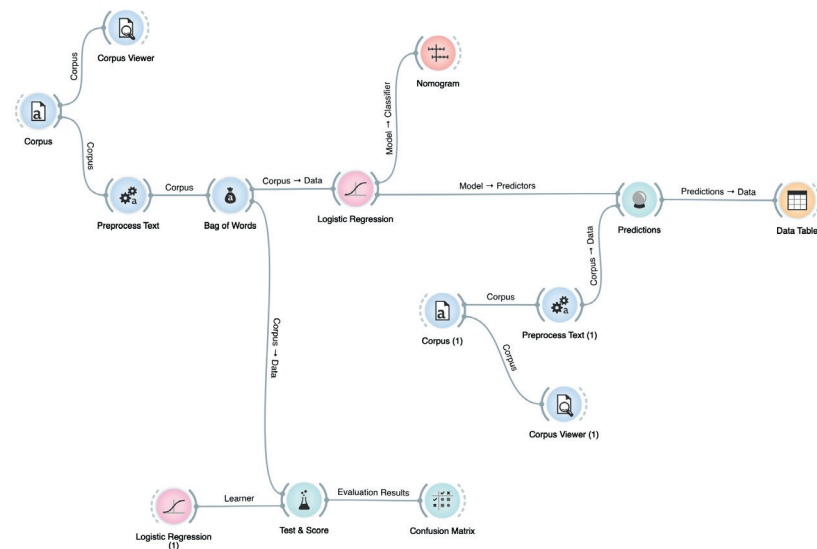


Figure 16. Orange 3 screenshot of classification set-up for the 305 stories

Once the LR model was trained according to the previous configuration, the Nomogram function was used to understand how the algorithm classified new data into the different categories. This step provided a list of relevant token combinations for each code.

Once each sentence from the 305 stories had an assigned code, the number of families talking about each code was obtained (Table 3). This procedure was achieved by having each sentence linked to the story source, therefore to each family. The process consisted of selecting all the sentences from each code, removing the duplicated story sources and counting the total. All this procedure was done in Microsoft Excel.

## 2.4 Results

The results from the Logistic Regression model showed the predicted code for each sentence and the numerical score of the sentence compared with all the other categories (Figure 17).

Quote	Logistic regression prediction	"Having a son with CHD changed us"	"Re-playing what happened"	"Tending to think he is cured"	"Hoping for the best but planning for the worst"	"Whatever we need to do"	Admitted into the hospital	Baby thriving after treatment
My son, Elliott, was born with hypoplastic left heart syndrome, a type of congenital heart defect (CHD). After two previous normal pregnancies, I was shocked to receive this diagnosis during my 20th week of pregnancy with Elliott. I have to admit, receiving the diagnosis during pregnancy was both a blessing and a curse. It robbed me of any sort of normal pregnancy. After the diagnosis, we grieved a lot.	Finding something is wrong	0.00736263	0.00286006	0.00734301	0.00149925	0.00634887	0.00371235	0.00111625
Everything we had in our minds about this pregnancy went away. We had to prepare for a whole new pregnancy.	Before discovery of CHD	0.00832571	0.00553026	0.00464628	0.00463185	0.00559933	0.0107289	0.00911823
	Before discovery of CHD	0.0138762	0.012328	0.00788179	0.00714535	0.0114196	0.0114486	0.0123808
	Before discovery of CHD	0.00954096	0.010483	0.00679786	0.00632871	0.0096983	0.00981278	0.0126934
	Symptoms	0.0178037	0.0132039	0.0200421	0.00748994	0.0123818	0.0122456	0.0128986
	Before discovery of CHD	0.0100565	0.00528544	0.00427795	0.00819392	0.00915421	0.00957864	0.0111387
	Before discovery of CHD	0.0105115	0.0122436	0.00735294	0.00680531	0.0105275	0.0107475	0.0114048

Figure 17. Overview of a few sentences classified.

Table 3. Number of families talking about each code

Color code	Codes	No. families	%
75 to 100 %	Finding something is wrong	284	93.1%
	Symptoms	271	88.9%
	Child being discharged	241	79.0%
	Recovery	241	79.0%
	Surgery	232	76.1%
	Before discovery of CHD	230	75.4%
	Feelings towards medical staff	200	65.6%
	Admitted into the hospital	198	64.9%

Table continues on next page

50 to 75 %

25 to 50 %

0 to 25 %

Feelings after hospitalization	194	63.6%
Follow-up checking and treatment	192	63.0%
Interaction with medical staff	188	61.6%
Procedures	178	58.4%
Parents Worrying	157	51.5%
Understanding diagnosis	155	50.8%
Realise seriousness	155	50.8%
Taking news from staff	154	50.5%
Patient's development	144	47.2%
Emergency happening	144	47.2%
Giving birth	140	45.9%
Support from family and friends	131	43.0%
Medical decisions	120	39.3%
Body-machine connections	109	35.7%
Waiting	94	30.8%
"Re-playing what happened"	92	30.2%
Time perception	88	28.9%
Physical contact	85	27.9%
Baby thriving after treatment	80	26.2%
Realise strength of child	72	23.6%
Seeing baby	71	23.3%
Connecting with other CHD families	61	20.0%
Facing reality	60	19.7%
Not knowing diagnosis	58	19.0%
Waiting for surgery date	50	16.4%
"whatever we need to do"	49	16.1%
Parents showing relief	46	15.1%
Looking forward to the future	43	14.1%
Child's physical activity	39	12.8%
"Having a son with CHD changed us"	37	12.1%
Child having ups & downs	36	11.8%
Family life changed	34	11.1%
Child coping with CHD	32	10.5%
Being a normal baby	27	8.9%
Cherishing the moment	27	8.9%
Challenges after hospitalization	23	7.5%
Early detection	23	7.5%
"Tending to think he is cured"	19	6.2%
Protect child	17	5.6%
Getting information	16	5.2%
Saying goodbye to undergo medical procedure	16	5.2%
Doctor Fearing your child might not live	15	4.9%
Having a new chance	15	4.9%
Being afraid of the future	14	4.6%
Being unprepared	14	4.6%
Religion procedures	14	4.6%
Supporting child	14	4.6%
Telling each other everything will be alright	13	4.3%
Being proud of your kids	12	3.9%
Dealing with set-backs	9	3.0%
Child battling for its life	7	2.3%
Not going home	7	2.3%
OTHER	5	1.6%
"hoping for the best but planning for the worst"	4	1.3%

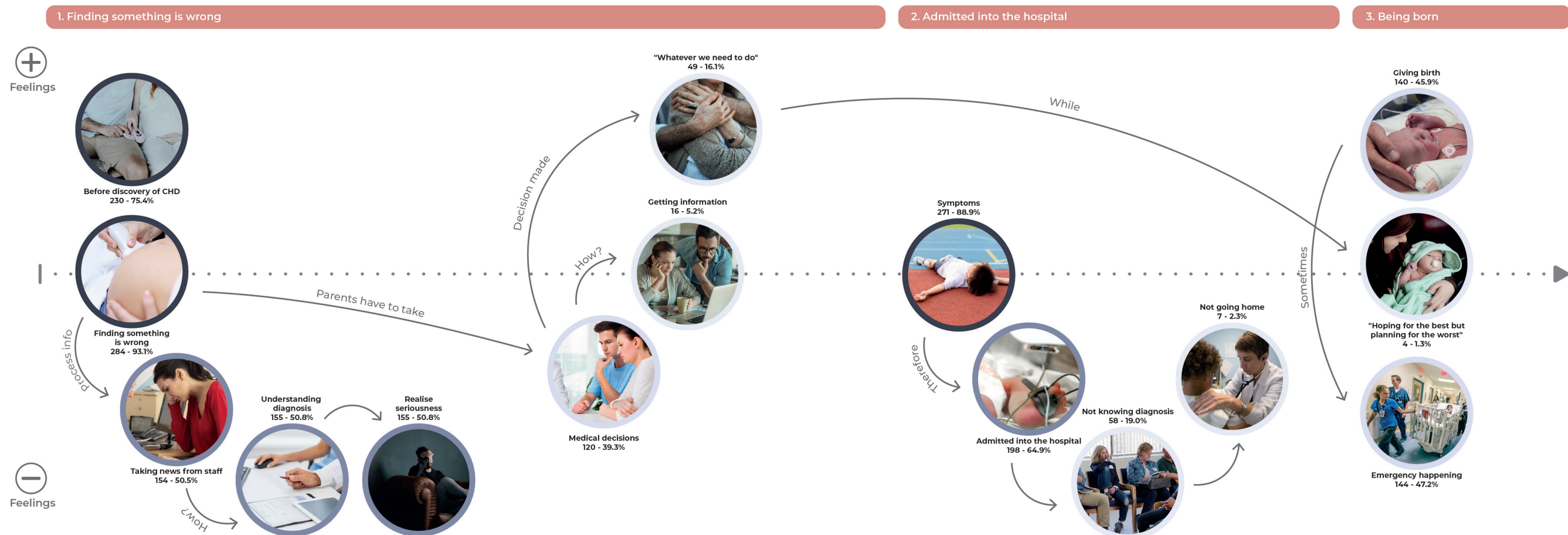
Based on the table, 'moment cards' were created per code. This cards contained a brief description of the each code, an image and one or two representative sentences chosen to help others empathize with the category. Moreover, the cards also contained the number of families talking about the topic and the percentage they represented. A color code (Table 3) was additionally included to improve the visibility of codes that were mentioned more than others by dividing the 100% in multiples of 25%.



Figure 18. Overview of moment cards. See appendix H for all the cards. The colour-code in this picture belongs to the first version of the cards.

The moment cards were used to create the final version of the life-time journey these families experience with their child (Figure 18). The arrangement of the moments relates to how the family describes their journey. Moments experienced as negative are below the dotted line, and moments experienced with a positive feeling are above. The arrows highlight the connections between these moments, and the intensity of the 'blue' colour surrounding each moment indicates how many families mentioned the moment (darker refers to more families, lighter to fewer families). All these arrangements were based on the previous timeline (Figure 12).

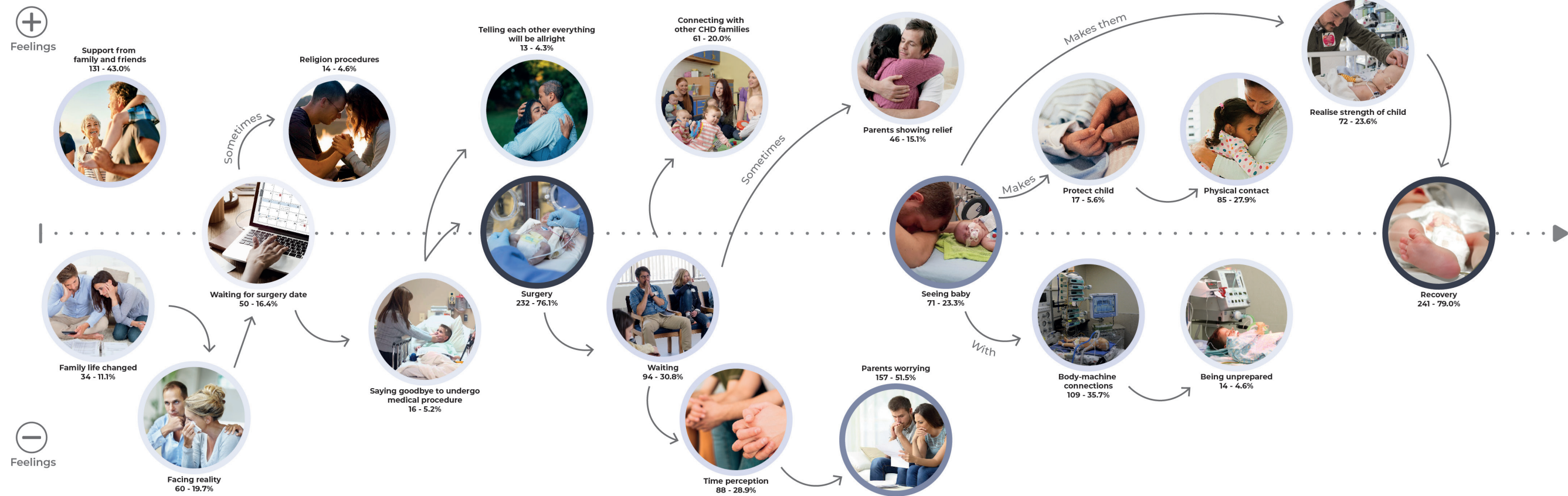
Figure 19. Final timeline. The color code is related to Table 3.





4. Surgery

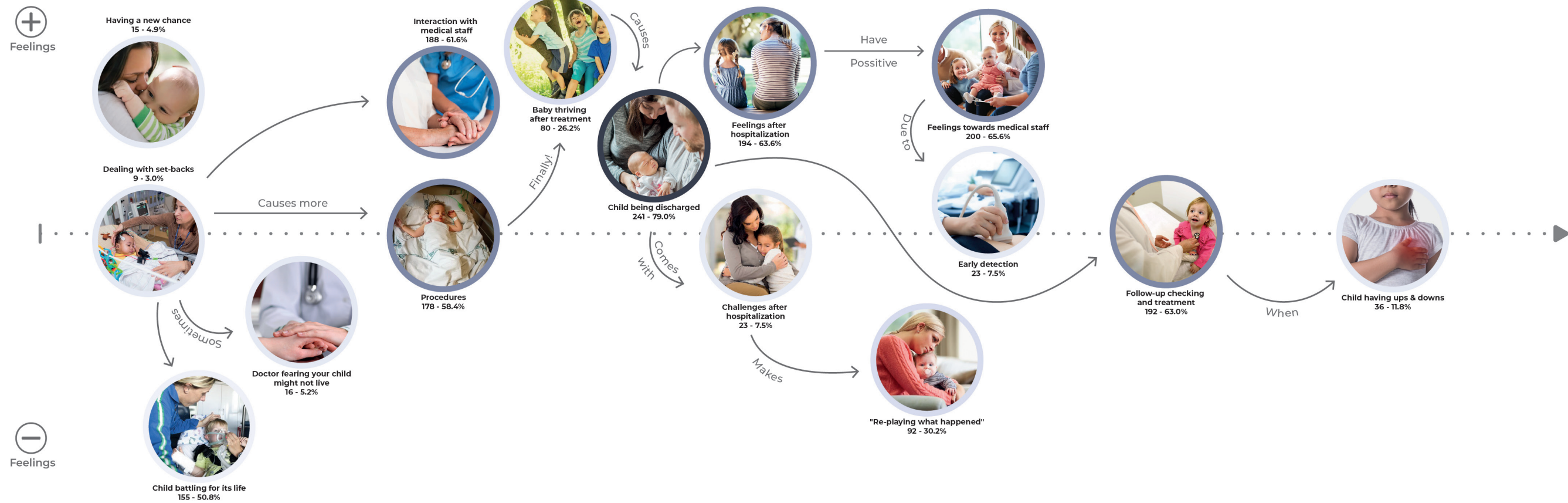
5. Recovery

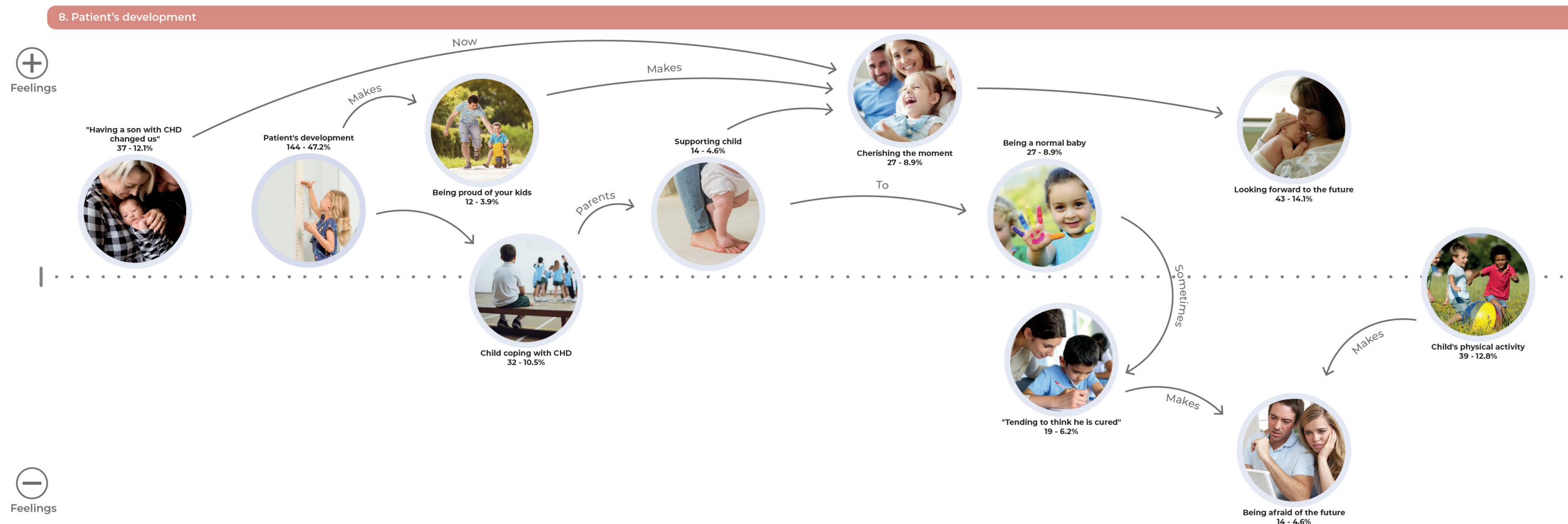


5. Recovery

6. Being discharged

7. Follow-up appointments





## 2.5 Discussion

In general, the results from the text analysis of the online parental stories indicate that parents of children with a CHD experience more negative experiences during their journey (Figure 19) due to the different medical procedures performed and the relation it represents with losing their child.

### 2.5.1 Research questions

#### 1. Which aspects trigger anxiety during childhood?

The lowest negative event found in the stories was related to the first surgery the child experienced. During this event, parents expressed high levels of anxiety and fear related to losing their child. Followed by surgery, the uncertainty of not knowing when would be the next surgery, and therefore being predisposed to look for symptoms and see a health deterioration proved to be relevant events leading to parental anxiety. Moreover, in Table 3, it can be seen that 'symptoms' are the second most mentioned topic with a total of 271 families describing them.

This uncertainty in health correlates with the findings of Moola et al. (2011) concerning uncertainty in long-term prognosis. However, by analysing the

stories, it was possible to get a better understanding of what "uncertainty in long-term prognosis" meant for parents.

#### 2. Which aspects trigger overprotection during childhood?

According to the analysis, seeing their child under extreme health circumstances such as being connected to different machines was one trigger directly related to wanting to hold and protect their child. Moreover, when symptoms are detected, most of the time they serve as triggers for remembering painful past experiences such as surgery.

The findings of negative past experiences provided by Moola et al. (2011) were observed among the stories. Nonetheless, the detail of when exactly negative past experiences were triggered was something found during this study.

#### 3. What behaviours do parents have towards the CHD patient according to past experiences?

Parents seem to be more careful with the activities their child performs. However, their primary goal is to let the child have a life as normal as possible, considering the health limitations. Although there are painful memories of the first years of life, being in this situation of uncertainty proved to make

parents truly appreciate seeing their child full of life gathering all kinds of achievements. The combination of this extremely positive and negative experiences made parents realise and admire the strength their child has.

#### 4. How do overprotection and anxiety manifest during childhood?

Anxiety begins when parents are confronted for the first time with the heart defect since they are unaware of its nature and how the future will be for their child (see Table 3 - "finding something is wrong"). Later, depending on the CHD complexity, follow-up surgery will be necessary. Parents will relate this event to an expected health deterioration on their child, and therefore generate anxiety and overprotective behaviours when parents perceive a symptom (see Table 3 - "symptoms").

### 2.5.2 Limitations

One of the limitations of the study was the accuracy of the algorithm to classify the sentences. Regardless of the intent to optimise the LR model, the improvement achieved was not as significant as expected. Therefore the classification of the stories has a 0.2 classification error. Furthermore, another limitation was the translation of the Dutch stories to English. Although a Dutch-speaking

coder interpreted the first set of Dutch codes, the remaining stories classified by the machine were translated so the algorithm could classify them.

### Summing-up

The end of this chapter provided an overview of the life of parents who have a child with a Congenital Heart Defect, their behaviours towards their child and reasons behind overprotective attitudes. However, more information about the physical activity context was needed to understand the problem better. Therefore, a set of interviews with families was arranged at the hospital to dive in-depth into the feelings and opinions related to physical activity. Chapter 3 describes the process.

### Takeaways from this chapter

- The complexity of the CHD plays a role in the parental tendency to see health deterioration over time.
- An uncertain future generates a constant search for symptoms.
- Seeing the child full of life is a powerful moment due to complicated past experiences.



## Chapter 3

# Family interviews

Chapter 3 aims to understand when, during the child's physical activity participation, the concerns from family members arise. In order to gather the necessary knowledge, seven semi-structured interviews with mother and child were conducted employing generative material (Sanders & Stappers, 2012). Topics such as 'Seeing health deterioration over time', 'Feeling uncertainty about the future', 'Replaying past experiences', 'Realizing the child's strength', and 'Seeing the child's development' were found in the previous chapter and adopted to compose questions. Moreover, the general overview of the daily context aid to create context-material for the interview. The structure of the chapter is as follows; first background information and research questions are provided, and afterwards, the method and procedure are described. To conclude, the data-analysis phase is explained, and the outcomes of it are summarized in an infographic and five personas.

# Family interviews

## 3.1 Background

Based on previous research (Chapter 2), a general understanding of the life of these families was illustrated. However, a more in-depth understanding of the attitudes towards physical activity from a child and parent perspective was necessary to understand their worries while physical activity was taking place. Therefore seven interviews were conducted with families to understand how does parental overprotection and anxiety manifest during the patient's participation in physical activity.

The two main research questions for the present study were the following:

Which aspects of physical activity prompt anxiety in parents and the patient?

Which aspects of physical activity trigger overprotective behaviours towards the patient?

## 3.2 Method

Seven in-depth interviews were conducted with groups consisting of a mother and the CHD patient. As the main interest was to understand their concerns while PA was taking place, it was decided to collect self-reported data using semi-structured interviews to have the freedom of exploring emerging topics of interest during the process (Patton, 2002).

### 3.2.1 Participant selection

The recruitment process was done by placing posters in the outpatient clinic of the paediatric chest centre, and by recruiting families during the outpatient clinic waiting time. The only criteria for selecting participants was the age of the patient being between 6 to 14 years old. Since the child ability to speak English could be compromised due to the age range, the interviews were conducted by an external Dutch-speaker student assistant.

In the table below are shown the demographics of the families interviewed. The family number was used for further quote reference in the findings section.

Table 4. Details of families interviewed.

Family number	Adult present	Child	
		Gender	Age
1	Mother	Boy	10
2	Mother	Girl	14
3	Mother	Boy	11
4	Mother	Boy	9
5	Mother	Girl	9
6	Mother	Boy	11
7	Mother and Grandmother	Girl	10

### 3.2.2 Ethical considerations

All the study was previously supervised and approved by the HREC of the Tu Delft. Besides, a paediatric cardiologist reviewed the interview material before the interviews began to ensure that sensitive information from the families was not deliberately asked. Moreover, families were asked to read a description of the study and the parent to sign a consent form before starting the interview.

## 3.3 Procedure

The interviews took place at the end of the outpatient clinic appointment, in an unoccupied room of the clinic. The procedure was divided into three main activities (see Appendix J for a detailed description). Moreover, the session made use of inquiry via verbal questions and generative tools used as sensitizers and thinking tools (see Data collection) to support the reflection in both participants (Casteleijn-Osorno, 2018).

### First activity

Parent and child were asked to think about their weekly routine. The interviewer provided image cards of children doing different activities (e.g. soccer, video-games, riding a bike) to be used for inspiration. Later, the participants were asked to place these images into a timeline to describe how does an active day in their life was.

### Second activity

Based on their timeline, participants were asked to indicate their level of worry regarding the activities they placed in the timeline with the help of a circle diagram. Then, the interviewer tried to understand better the situation by asking questions such as:

- When does the worry happen? (before/after the event)
- What do you think is the cause of your worry? (e.g. past experiences, the future uncertainty)
- Are there moments in which you identify the strength of your child? (e.g. by seeing him with good health).

### Third activity

During the last exercise, the child and parent were asked to think about how they could feel safer while the child participated in physical activity. The interviewer took note of their ideas on a post-it and place them on the top of their worries.

### Reward

In the end, the family was rewarded with a 10 EURO gift card from Hema.

### 3.3.1 Data collection

During the interviews, information about worry levels of the patient's physical activity was collected from both participants, child and parent. A set of generative tools were designed to help and stimulate participants during the process (Sanders & Stappers, 2012; Visser et al., 2005). The design of the tools was partly based on the previous research (Chapter 2) and the aim of understanding worries related to PA. While the tools were used, questions were asked to reveal the different points of view

of the two participants regarding worry levels. Furthermore, an audio recording was used during each session to transcribe and later analyse the shared information.

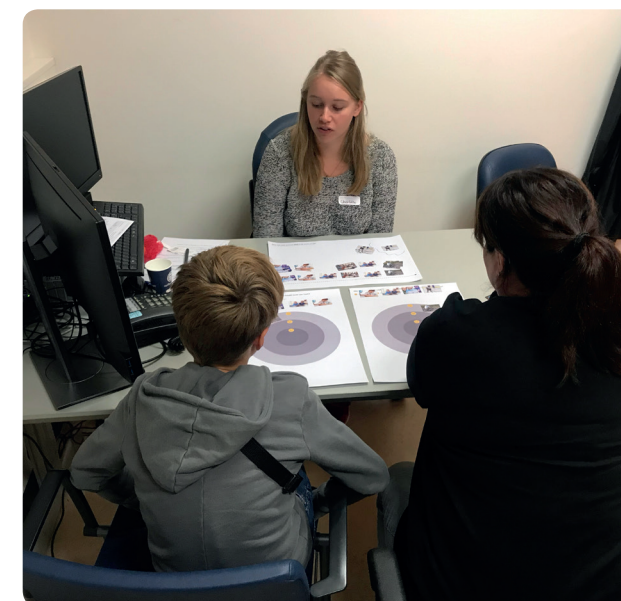
### Generative tools

Two thinking materials were created to be used during the interview, a timeline and a circle diagram (Appendix K).

- **Timeline:** The timeline was composed of a line at the bottom to represent the time of one day. The second element of the timeline were image cards of children doing different activities, from sports to art class, to help the child and parent to recall the activities done by the child on an active day. The ideation of this images was inspired by the different activity contexts found in Chapter 2.

- **Circle diagram:** A visualisation with three concentric circles of different sizes was used to classify the level of worry perceived from the mother and child regarding chosen activities from the timeline. The closer the activity was to the centre, the higher the level of worry. This canvas aimed to help participants to reflect on their feelings towards each activity placed on the timeline.

Figure 20. Interview set-up (left) and data collection (right).



### 3.3.2 Data analysis

The first step to analyse the data was to translate and transcribe the Dutch audio. All the seven audios were transcribed directly to English by a student assistant. Afterwards, a selection of quotes from child and mother related to the two research questions was made using the statement card format to facilitate interpretation of data and pattern finding during the clustering exercise (Sanders & Stappers, 2012). A total of 109 statement cards (See Appendix L for the complete list of cards) were gathered out of the seven transcript documents to proceed with clustering (Figure 21) and discover patterns and connections in the data.

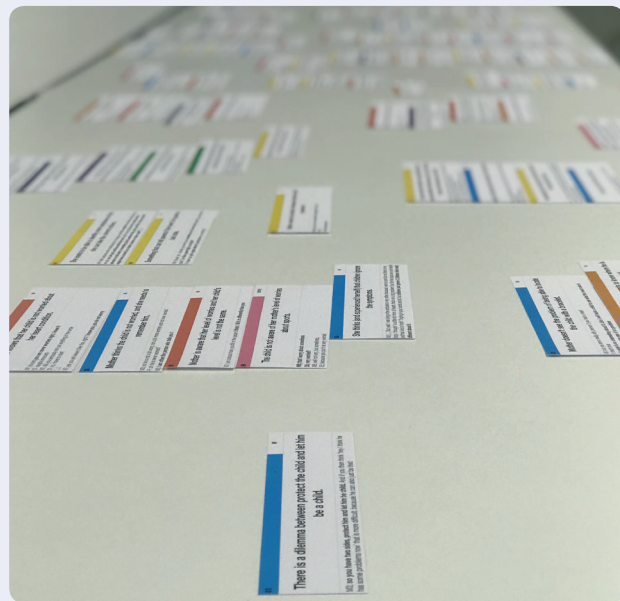
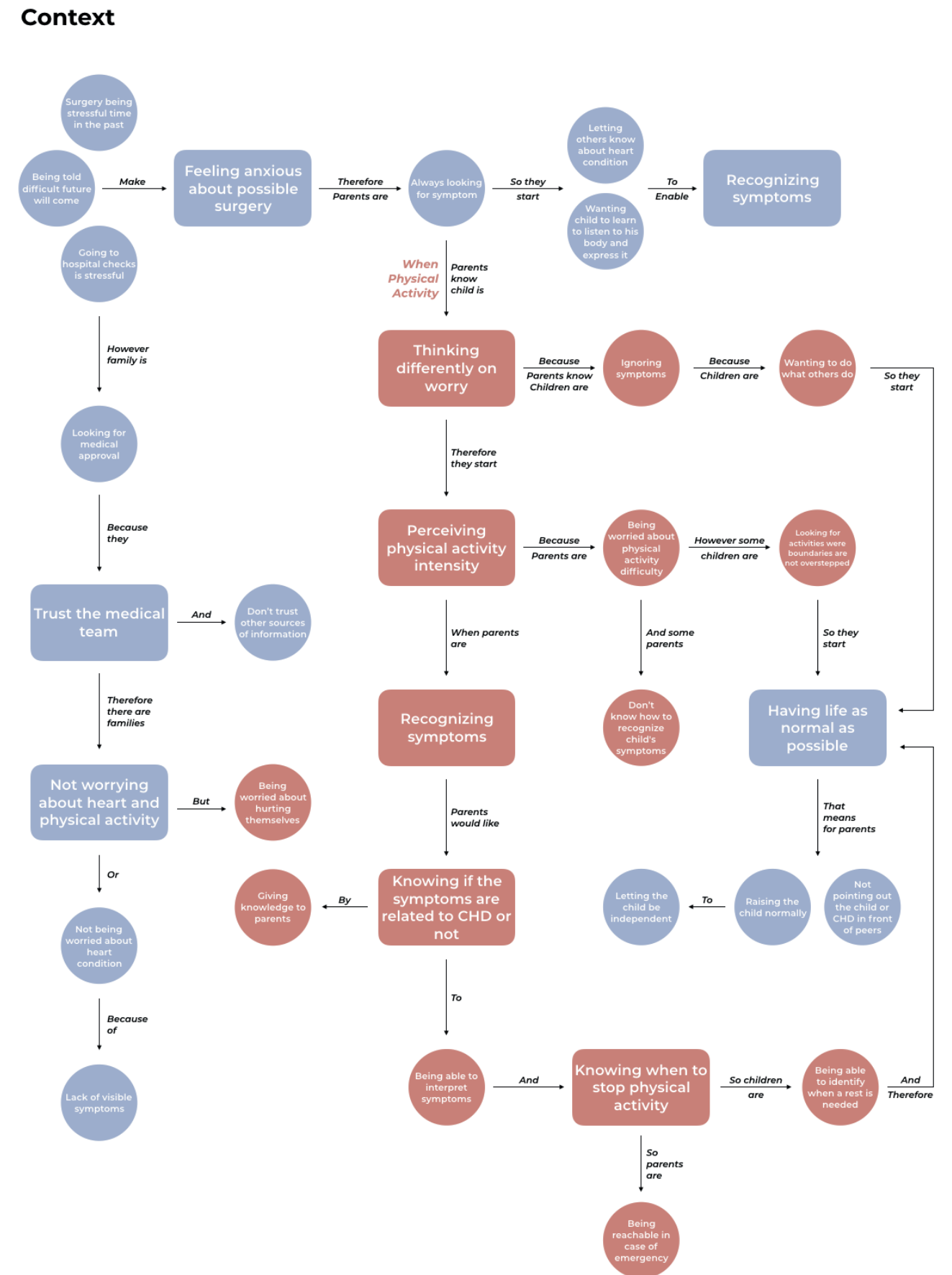


Figure 21. Overview of the clustering process.

### 3.4 Findings

The analysis of the statement cards provided 24 small clusters grouped into nine bigger clusters; this arrangement gave a detailed overview of the family context around physical activity. In Figure 22, the circles represent the smaller clusters, the rectangles the bigger clusters, and the arrows the relationship between them. Moreover, the blue colour refers to physical activity as an overall, and red colour to the moment when physical activity is happening.

Figure 22. Overview of clusters found with their respective relationships. Source, own visualization.





The nine big clusters are described below.

### 1. Feeling anxious about possible surgery

Since birth, some parents were told the future of their baby could be at risk due to the CHD complexity. This thought, in combination with the different surgeries over the years, have been generating anxiety concerning what the future will bring for their family. Moreover, when parents attend follow-up appointments, they know the goal of those meetings is to check if the CHD has gotten worse. Therefore, this event functions as a reminder of the uncertainty about future prognosis since they know, and have in the back of their minds, their child could still be a candidate for another surgery.

*“In the beginning we were quite anxious, they told us it would be a difficult time, it would be hard for us... so I thought, will it be a normal child?” - Mom, family 5*

*“So probably we won’t even notice. We come here and they say, okay, let’s go back a little. So we have to increase the frequency of controls, and then the deal is so bad. We have to get a new operation. But so properly, it won’t change anything. But still, it’s for your mindset, you’re always conscious about it” - Mom, family 4*

### 2. Recognizing symptoms

With a thought of possible surgery during the upcoming years, parents develop a mindset to always look for symptoms since they know health deterioration is a possibility and in some cases, an expected reality. Therefore, when their child starts asking for more independence, parents try to tell other persons who are responsible for the child (e.g. school teacher, coach) to look for possible symptoms when the child participates in PA, and get him out if necessary. On the contrary, other parents described the need for teaching the child to be aware of the symptoms so they could identify them correctly and be able to express them to the responsible adult. However, if parents are present when the child participates in PA, and they see a symptom, they will directly stop the activity.

*“But yeah you know, I do inform the sport organization that he has it. But he does not show symptoms to make me worry currently. But when we will see symptoms, I will directly blow the whistle” - Mom, family 1*

*“And training the child itself, you are diagnosed but the child is not trained” - Mom, family 3*

### 3. Thinking differently on worry

The awareness of parents regarding the level of worry their child has towards physical activity symptoms causes a distinction in how careful are they at the moment their child participates in PA. If parents see their child knows when it is necessary to stop the activity, they are more “relaxed” with their child doing PA. However, if parents see their child ignores the possible symptoms, they prefer to be present while the child is doing PA to avoid danger and stop the child when necessary.

*“He is not a bit worry, not a bit more worried and not over worried, I am often the person who tells you about it” - Mom, family 3*

### 4. Perceiving physical activity intensity

Feelings of anxiety towards physical activity raise the moment parents see that the level of resistance and difficulty of the exercise increases (e.g. swimming under the water for a long time). As a result, thoughts of the capabilities of their child start to be challenged due to the CHD. Regarding the child’s perspective, some children prefer not to perform very demanding PA and focus on other activities that do not require high levels of resistance so they can fully immerse on the activity and not feel limited by their health condition.

*“From not able to do anything, a surgery is of course quite an attack on your body, she had zero condition. That is why I am a bit worried, not a lot, so that is why it is in the outer ring” - Mom, family 7*

*“But he never did so much running. but its okay, He is smiling and laughing, and then a week after, he didn’t want to go. And I really, I couldn’t get a grip on why he didn’t want to go and at the end, like a lot of questions. We noticed that he had also noticed his physical capacity. And he didn’t run that much before. So he was confronted with really” - Mom, family 4*

### 5. Knowing if the symptom is related to CHD or not

Parents do not feel secure about how to distinguish between a symptom and a healthy manifestation of physical activity exhaustion. They would like to be able to distinguish between the two to make better decisions on when to intervene during PA. However, parents that feel confident on how to distinguishing between the two cases considered that knowledge about symptoms is essential to be able to comprehend them and therefore act when needed.

*“In summer we did a hike in the mountains. And there you see that he is much slower than his brothers. He has three brothers. And that’s not a problem. But then you, with him, you start asking, okay, is this just a child? Is this just this condition? Or is this related to his heart?” - Mom, family 4*

### 6. Knowing when to stop physical activity

Parents ask to stop PA after they have detected a symptom. Still, they would prefer their child to learn to identify when it is necessary to stop physical activity. In case of not being possible, being accessible or immediately informed if an emergency occurs would be a possible solution for them. However, if parents know that their child is not capable of stopping when needed, this situation will increase anxiety, leading to stopping the child themselves.

*“He does not understand the rule of going home after school, rest a bit and then go outside. He goes by bike to school and they do a lot of activities on school” - Mom, family 3*

*“Often I feel it in my legs, but yeah that is logical. Often I think I will just go on for a while, sometimes I then feel my heart beat in my throat and then I stop for a while. Then I know that when I go on I will not make it” - Child, family 6*

### 7. Having life as normal as possible

Mothers want to provide a typical childhood experience for their children. This experience includes encouraging them to try new activities, letting the child exercise his independence according to his age and health, and looking for places where others do not point out the child’s capabilities in front of their peers. The practice of respecting independence is achieved by focusing on the joy that children express when they can experience it. Moreover, children’s desires were related to doing what others do in order to belong to a group of friends or a sports team.

*“We try to give him a normal life and upbringing” - Mom, family 6*

*“Of course, you will stay worried. But when I see how good things go and how happy she is, I let her go” - Mom, family 5*

*“I want ABC, because I am the only one of my classmates who does not have all the diplomas already” - Child, family 5*

### 8. Trusting the medical team

Mothers and children express that talking with their doctor is a trustworthy source of information when they are worried about health-related concerns. The personal attention they receive from the medical team gives them confidence in the recommendations they receive. Looking for information on the internet does not provide the personalization aspect that they can receive while talking with their doctor.

*“I do not worry, only with swimming sometimes he has to swim a whole track below water and I also just asked the doctor if that is a problem” - Mom, family 1*

*“They watch her so closely and do not quickly send her home” - Mom, family 7*

### 9. Not worrying about heart and physical activity

Most children do not feel worried about their heart when they do physical activity. On the other hand, parents who do not feel worried, associated their absence of worry to the pass of time, absence of medication and trust in the medical team.

*“[Mom] You are never worried right? I knew it [Child] -Laughs innocent- [Mom] Did you seriously not put anything in the circle? [Child] No, I have to start [...] [Mom] Yes you will leave it like this, right? I know you, you do not worry” - Family 7*

*“But since November 2006 she is already medicine-free, so we thought, well we will find out what she can do and not. And when it goes fine it goes fine” - Mom, family 2*

**Personas**

Substantial differences in attitudes towards physical activity and levels of worry emerged from the interviews done. Based on the data gathered, five personas (Figure 23 & 24); three personas related to mothers and two personas related to children were created (Van Boeijen et al., 2013). Each mom-persona describes a different posture related to who should be responsible for looking symptoms,

anxiety level, anxiety triggers, and an overall opinion of physical activity in relation to the CHD. On the other hand, the two children-personas describe their level of awareness towards symptoms, worry level and pains related to physical activity.

Figure 23. Personas (children).

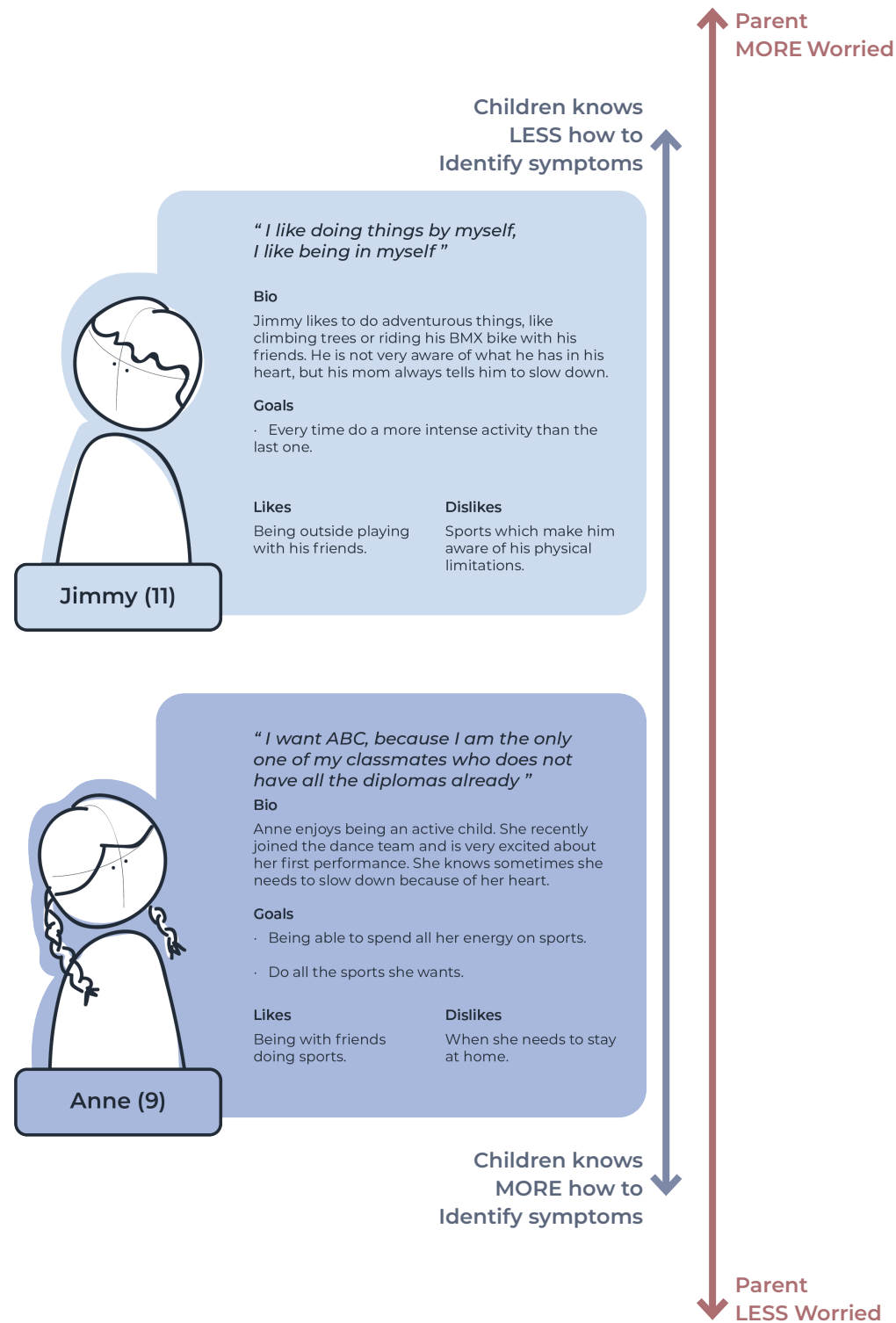
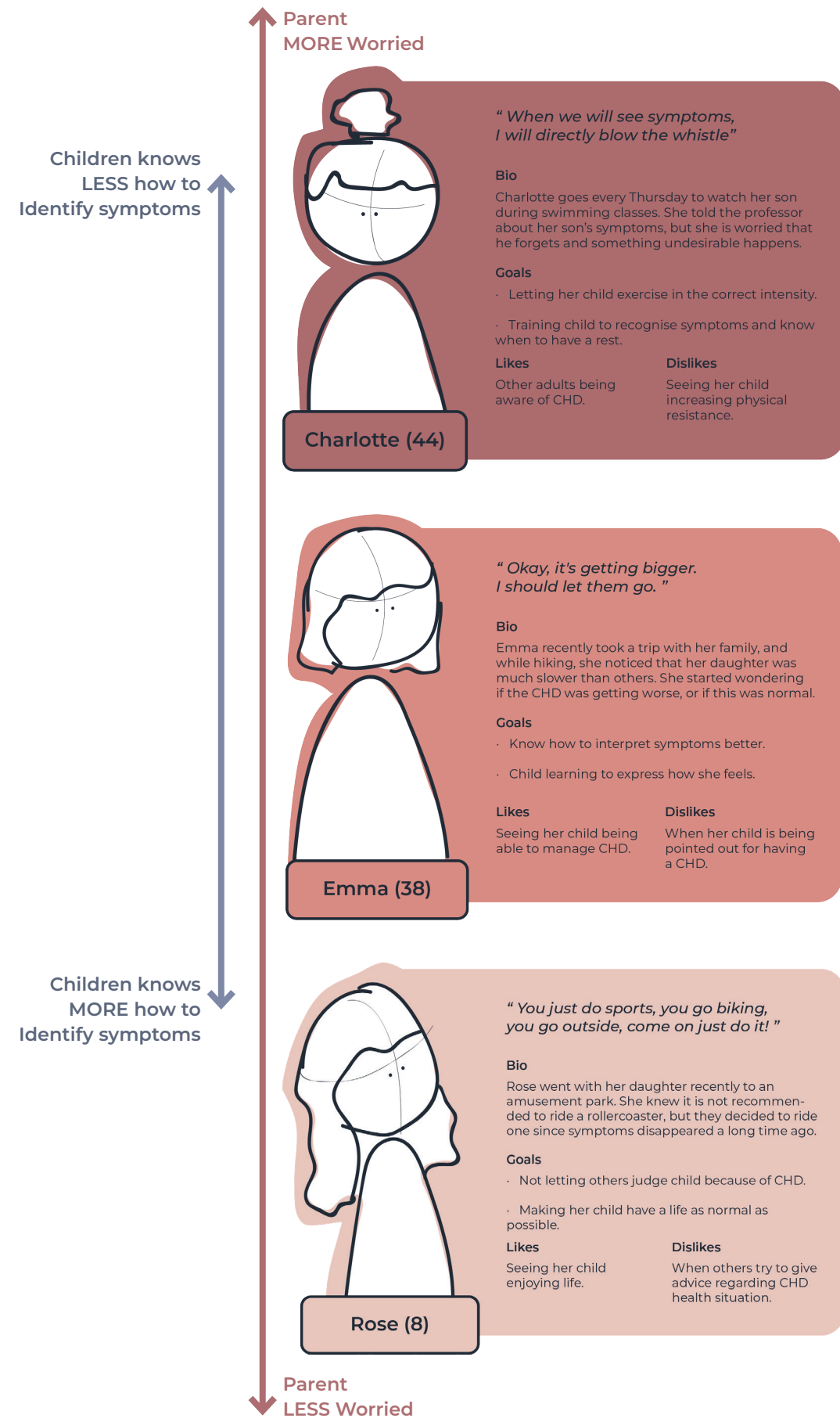


Figure 24. Personas (Mothers).



## 3.5 Discussion

Interviews with families demonstrated a significant difference between the level of worry between mothers and their child. When looking through the child's lenses, they gave more importance to being with their peers, do what other children do than caring about the appropriate levels of PA. However, children who knew how to identify a symptom acted accordingly and stopped the activity.

On the other hand, mothers did not express a very high level of worry concerning physical activity. However, they shared different views towards the responsibility to identify symptoms and know when a symptom was genuinely related to the CHD. Highly concerned mothers often asked others to become "vigilantes" whenever the child was involved in PA. Other mothers stressed the impotence of educating the child to be able to recognize symptoms and act when necessary.

### 3.5.1 Research questions

#### 1. Which aspects of physical activity prompt anxiety in parents and the patient?

The level of anxiety in parents and children was different and varied on causes. On the parent's side, they stressed the importance not only of perceiving the symptom, but knowing if the symptom was related to the heart condition or not. Being aware of the difference between a healthy manifestation of physical exhaustion and a symptom was considered a difficult decision to make among parents.

On the child's side, the anxiety level was low. However, the few events related to this feeling were when children started to feel that their body was starting to struggle to keep up the PA resistance demand.

#### 2. Which aspects of physical activity trigger overprotective behaviours towards the patient?

Two different triggers for overprotection emerged from the interview analysis. The first trigger for an overprotective behaviour is activated when parents detect that the difficulty of a sport in terms of resistance increases since they do not know if the heart of their child will be able to handle it. This difficulty can be by "having experienced" how does it feel to do what a coach asks the child to do, or by seeing your child having difficulties that their peers do not present.

The second trigger is related to knowing how much their child is aware of the symptoms that can

appear. parents who presented an overprotective behaviour claimed that their child did not know how to identify a symptom. Therefore, they felt the need to remaining what to do and when. Related to this trigger, was also the security parents feel to know if their child would stop the activity if he or she identified a symptom.

### 3.5.2 Limitations

The main limitation of the study was the language. Although the interviews were conducted by an external student for the analysis phase, the audio had to be translated, and between translation, some details might have been lost. Furthermore, another limitation deliberately chosen was to have the interviews with the child and parent present to see their interaction concerning worries. However, this resulted in the child being quiet unless a specific question was directed to him or her.

### Summing-up

Now that an in-depth understanding of worries from the child perspective and mother perspective is gathered, a view on the issue from the third most relevant stakeholder is needed to complete the overall vision of the PSS. Therefore, a co-creation session with the medical team of the Erasmus MC was conducted. Chapter 4 presents the process and results.

### Takeaways from this chapter

- Parents keep in the back of their minds that their child could still be a candidate for another surgery.
- Parental awareness of their children knowing how to identify and act towards CHD symptoms moderates overprotective behaviours.
- Anxiety raises when an increase in physical activity intensity and difficulty is detected.
- Distinguishing between healthy physical activity exhaustion and CHD symptoms is complicated.
- Seeing the child full of joy full is a powerful link to overcome worries.
- Interpretation of worries needs to be personalized to each unique case of CHD.
- Communication with the medical team is essential to ease parental concerns.



## Chapter 4

# Medical team co-creation session

This chapter intends to gather the perspective of different medical team members who treat CHD paediatric patient, to better comprehend the overall medical situation, and ideate together possible design alternatives. Therefore, this chapter describes the process followed in a co-creation session (Sanders & Stappers, 2008) with the medical team held to understand the medical view. Findings and outcomes such as stakeholders awareness, lifetime journey, personas, and worry circles from previous chapters were used to create the ideation materials and inspire participants. Chapter 4 begins by providing background information about the current medical situation. Afterwards, it describes the methodology employed, and the procedure followed in conducting the session. To finalise, it presents the data analysis process and the findings composed of 18 underlying problems identified and six PSS concepts.

# Medical team co-creation

## 4.1 Background

Along the journey of a paediatric CHD patient, the medical team has an essential role in their lives. Depending on the complexity of the CHD, families will have to come to the outpatient clinic more or less often. They will support families to overcome the challenges that the CHD represents in everyday life and solve the concerns from the child and parents until the child has reached adolescence and starts treatment with the cardiologist for adults.

Based on the understanding gathered in previous chapters, the only perspective missing to have an overall view of physical activity and overprotection is the medical team. Since medical staff are the ones supporting the family along the CHD journey, they have relevant knowledge regarding concerns and behaviours child and parents showed over the years. Therefore, a Co-creation session (Sanders & Stappers, 2008) with different specialists of the Erasmus MC, Philips Healthcare and TU Delft members was conducted.

The goal of the co-creation session was the following: Understand the pre-processed data and based on it, ideate potential parental supporting systems to reduce anxiety and overprotective behaviour in parents of paediatric CHD patients.

## 4.2 Method

The objective of this session was to inspire participants with the results of the data gathered in previous chapters and bring together the different views of diverse specialists that work closely with Paediatric CHD patients and their families. During this event, the method chosen to conduct the session was Co-creation (Sanders & Stappers, 2008). This method allows the researcher to introduce the information collected through interviews and text analysis, and later create a set of exercises to explore the different perspectives on the envisioned Product-Service-System mentioned in Chapter one.

### 4.2.1 Participant selection

The recruitment process of the multidisciplinary team was done through Convenience Sampling

(Miles, Huberman, & Saldaña, 2014) and e-mail contact to invite participants for the session. Convenience Sampling was chosen as the researcher had limited access to a large cohort of healthcare professionals. The participants were professional medical employees from the Erasmus MC working in diverse job functions. The diversity in specialities was seen as an essential element for the session since previous research on multidisciplinary care for CHD patients showed that a multidisciplinary collaboration was necessary to provide holistic treatment of patient and family (Utens et al., 2018).

There were no boundaries besides diverse job functions to select participants as the study had an exploratory nature. However, a conscious decision was to exclude CHD patients and their families since they had already given ideas on how to feel less worried in the last step of the interview, and the session's objective was to incorporate a medical point of view. Moreover, it was decided to invite professional designers from TU Delft and Philips Healthcare to the session. This decision, to enhance a creative environment for the medical team to be inspired and share all kinds of ideas.

A total of nine participants, each with a different background, accepted to be part of the co-creation session (CCS). The specialities can be seen in the following table:

Table 5. Participants of the co-creation session.

Organization	Speciality
Erasmus MC, Sophia Children's Hospital	Paediatric Cardiologist
	Pedagogical Assistant
	Sports Doctor
	Psychologist
	Specialist Nurse
TU Delft, Industrial Design Engineering Faculty	Assistant professor, Product Innovation Management
	Graduate Industrial Designer (IPD)
	Interaction Design
Philips Design	Consultant for Healthcare Philips Intern

### 4.2.2 Ethical considerations

Before the session started, participants were asked for approval of voice and video recording for later analysis. Furthermore, the co-creation session proposal was reviewed and approved by TU Delft's HREC.

## 4.3 Procedure

The co-creation session was held in a meeting room of the Erasmus MC, facilitated by the researcher. The activity was divided into four main exercises (see Appendix M for a detailed description). Moreover, results from text analysis and interviews as well as a customized generative tool canvas were used as sensitizer and thinking tools (see Data collection) to help participants frame the envisioned system.

First activity - Get inspired by the pre-processed data (15 minutes)

All participants were asked to stand up and explore the timeline on-the-wall prepared for sharing the data gathered in the text analysis and the interviews. The timeline (see Figure 28) had two copies of the same moment card (Figure 26), and participants were asked to take three moments they thought were interesting, to help them create a system that reduced anxiety and overprotection in parents.

Second activity - Individual ideation (10 minutes)

Based on the moment cards chosen and knowledge

Figure 25. Explanation of the complete timeline to inspire participants.

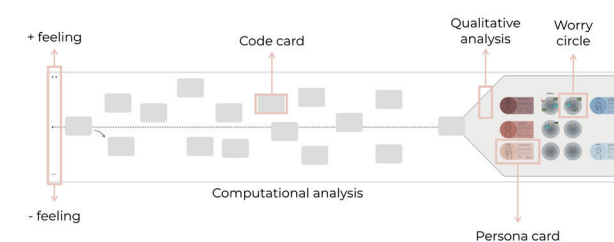
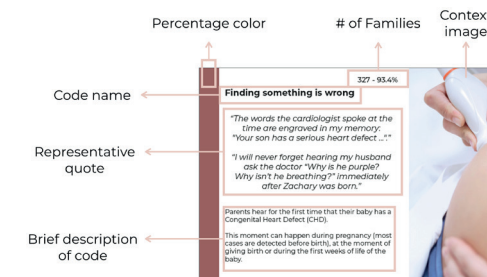


Figure 26. Moment card. See appendix H to see all the cards.



gathered in the previous step, participants were told to individually ideate potential supporting systems directions. The ideation took place in a customized canvas (see figure 29), where they were asked to draw the system connections, involve as many stakeholders as possible, make use of smart devices and be inspired by the PA dimensions given in the template.

Third activity - Group ideation 1 (35 minutes)

The next step involved the integration and ideation of the supporting system as a whole by sharing ideas and opinions as the system evolved. Participants were asked to share an initial idea and from there build-up the system. For this exercise, a big white paper was given to allocate the stakeholders where needed and draw the envisioned connections. Additionally, participants were requested to include all PA dimensions and stakeholders in the group's ideas.

Fourth activity - Group ideation 2 (10 minutes)

The last activity consisted of generating an improved version of the system as a complete overview based on the previously discussed ideas. During this exercise, participants were told to ideate and draw the ultimate system in a larger piece of white paper and place the stakeholders where needed.

Figure 27. Participants during individual exercise.



Figure 28. Participants during group exercise.



### 4.3.1 Data collection

During the session, ideas regarding the envisioned PSS were collected from the medical and design team. A generative canvas tool was created to help and stimulate participants during the activities (Sanders & Stappers, 2012). The design of this tool was based on the results from the previously conducted research (Chapter 1, 2 & 3), and the goal of creating possible directions for the PSS. While the tool was used, the facilitator tried to remember the participants, the goal and the requirements. Moreover, the audio was recorded during the whole session to analyse later the ideas shared.

#### Generative tool - The system canvas

The system canvas construction was based on the different stakeholders found during the text analysis and the interviews. It was decided to use a circular structure to facilitate the connections between the stakeholders. Furthermore, the six dimensions of Physical Activity, discussed in Chapter 1, were added to remind participants of the diversity of perspectives they could use to see physical activity. Besides, since each participant had a different background, a 'producer name' section was added to observe later how each speciality had a different vision on the system.

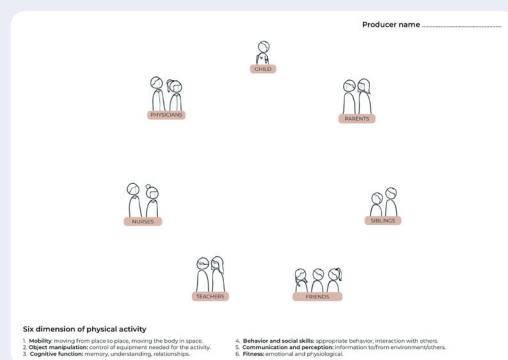


Figure 29. System canvas.

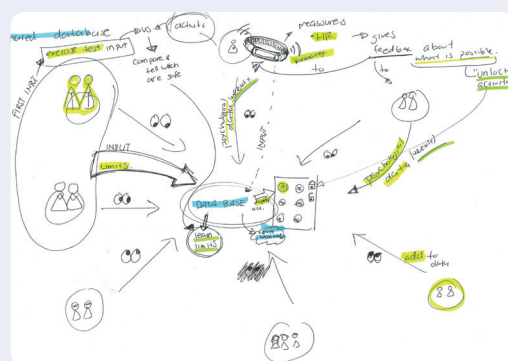


Figure 30. Rapid sketch based on co-creation audio. All sketches can be seen in Appendix N.

### 4.3.2 Data analysis

The data analysis started by first understanding the group ideas and later, the results from the individual exercise. The analysis did not start chronologically to preserve the value and richness of the discussions and ideas that the CCS provided within the multidisciplinary team. Therefore, when the review of the individual ideas took place, the personal ideas were categorised accordingly to the information provided by the group discussion to strengthen the results.

#### Analysing group exercise

Based on the audio and the drawings from the group exercises (Figure 31), rapid sketches were drawn based on the discussion (Figure 30). This drawings later helped to visualize the emerging topics from each conversation. In the end, thirteen discussion topics were identified based on the audio and sketches. The table below shows the topics found.

Topic	Frequency
Entering data	13
Stimulate PA	11
Empowerment	8
Show data (all)	7
Supervision	4
Tell why & what	4
Collecting data	3
Dialogue	3
Dr sets limits	3
Patterns	2
Show data (Dr)	2
Subtle feedback	2
Appearance	1

Table 6. Initial topics discussed during the co-creation session.

Once the initial topics were identified, these were clustered into solution-oriented themes to create a first overview of the envisioned PSS and the stakeholders involved in each phase. Figure 32 shows the distribution of stakeholders and their involvement in the envisioned PSS.

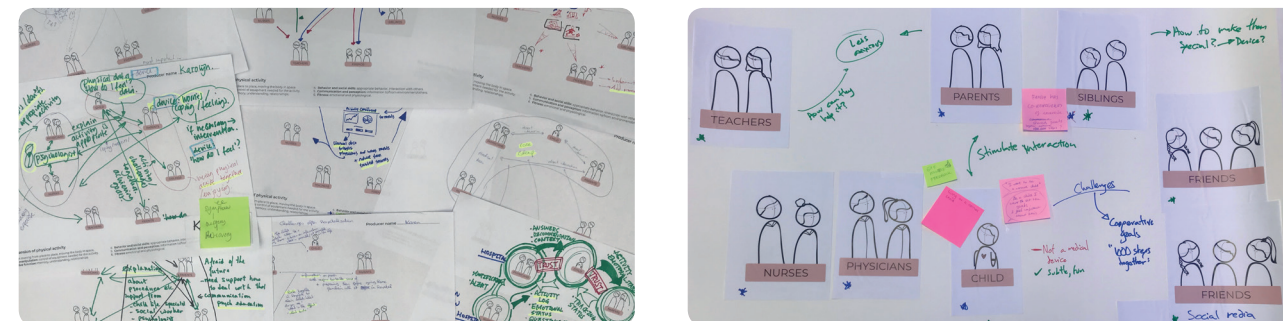


Figure 31. Individual (left) and group (right) co-creation drawings. All drawings are available in Appendix O.

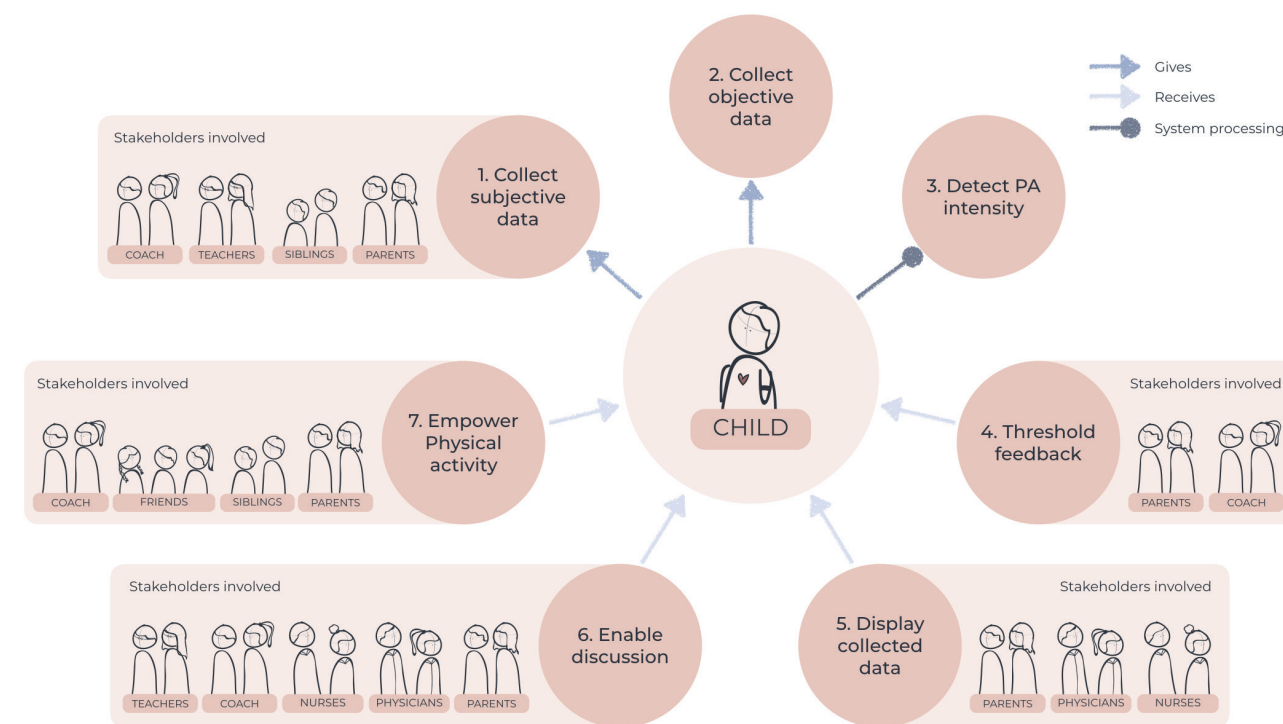


Figure 32. Overview of first envisioned PSS



## 4.4 Findings

### 4.4.1 Problems identified

Afterwards, the results from the individual exercise (Figure 33) were examined in combination with the previous work. As a result, they provided an

overview of 18 underlying problems identified by the participants. Each of the problems was presented as a 'Problem card'. The following figure display the first 5 problems found.

Figure 33. Problem cards. See Appendix P for all cards.

#### Underlying problem #1

*Lack of psychological data from family members*

Times mentioned: 10



#### Underlying problem #2

*Inexistent hierarchy in information management*

Times mentioned: 9



#### Underlying problem #3

*Misunderstanding of physical activity safety limits*

Times mentioned: 9



#### Underlying problem #4

*Child doesn't have ownership of health condition*

Times mentioned: 5



#### Underlying problem #5

*Lack of HR measurement outside hospital context*

Times mentioned: 5



### 4.4.2 System concepts

Six concepts were identified after reviewing the audio and drawings from the session. These concepts were translated into concept cards (Figure 34) which contained features classified into the topics found in the group exercise. Moreover, by gathering all the features per concept, it was easier to generate a brief description of the solution and the envisioned problem each concept tried to tackle.

Figure 34. Concept card 5. See all cards in Appendix Q.

**Concept 5** **'THE COACH CLIPBOARD' A platform to facilitate discussions.**  
**Description:** *The child moderates discussion between different stakeholders and Drs place the discussion in the right context to avoid shared misinformation and increase of anxiety.*  
**Problem:** *Different stakeholders interacting without the correct supervision could increase misinformation and negative perception of physical activity.*

Features	Topic
Child is in control of the discussion (moderator)	Empowerment
Child accepts who can see the information	Empowerment
Child looks at the adult's interactions	Empowerment
Medical team provides information	Dr sets limits
Sports teacher can see in APP	Show data (all)
Generate a dialogue between the persons in charge of the child	Dialogue
Medical team sets the context of worries	Supervision
The platform gathers psychological information about participants	Entering data
Child knows why they are discussing topics	Tell why & what

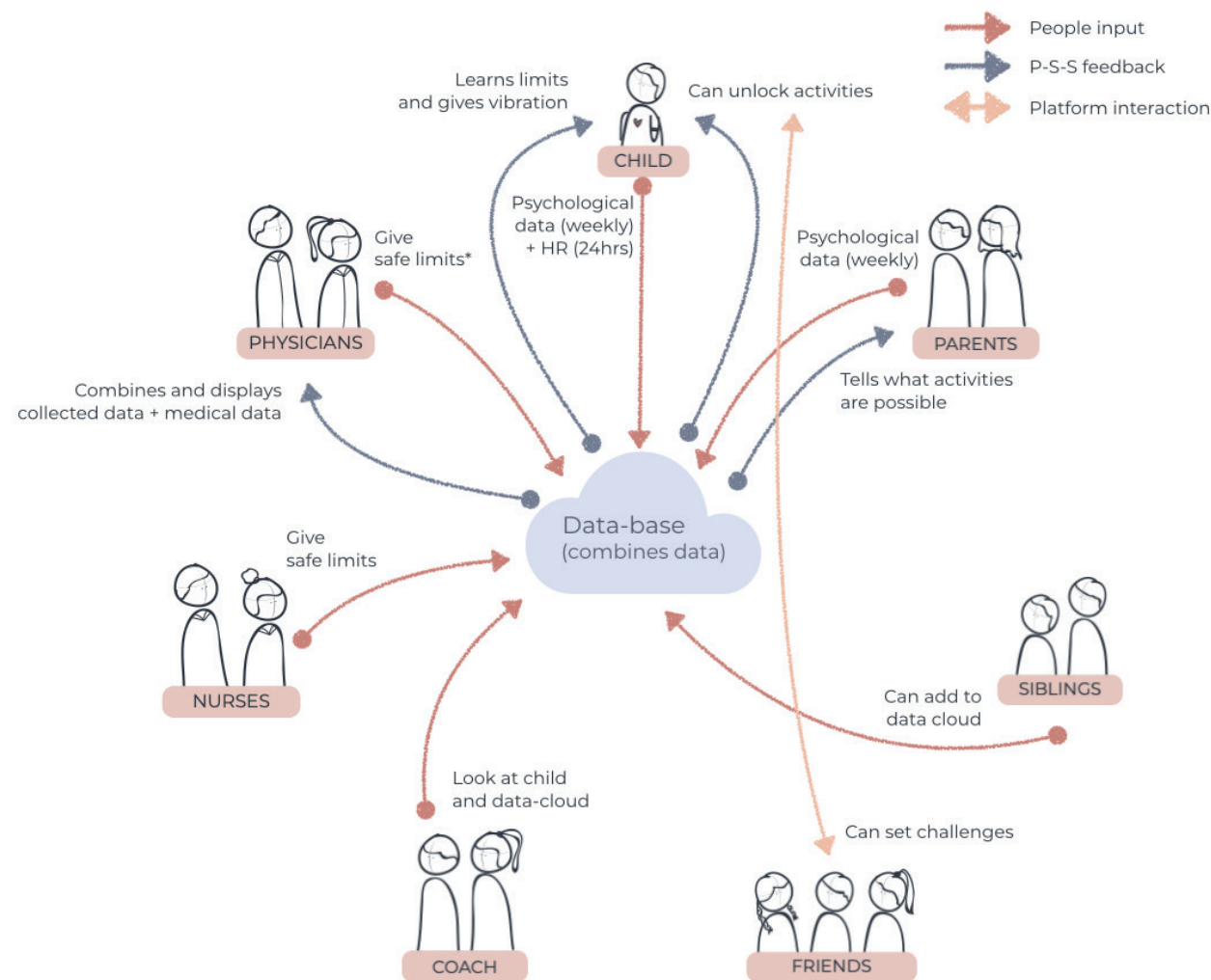
Afterwards, an illustration based on the drawings was created for each card to detail the proposal concerning which stakeholder was involved in each feature. The design concepts are shown in the next pages.

**Concept 1 'The observer cloud' - Sharing data between stakeholders**

**Description**  
The aim is to know what is possible for the child and make the limits more clear for him and the family. Everyone can add information to the platform and see the status.

**Overall problem identified**  
It is difficult to notice the physical activity limit in a daily life setting. Besides, gathering and sharing information about the child's health between all stakeholders is challenging.

Figure 35. The observer cloud.



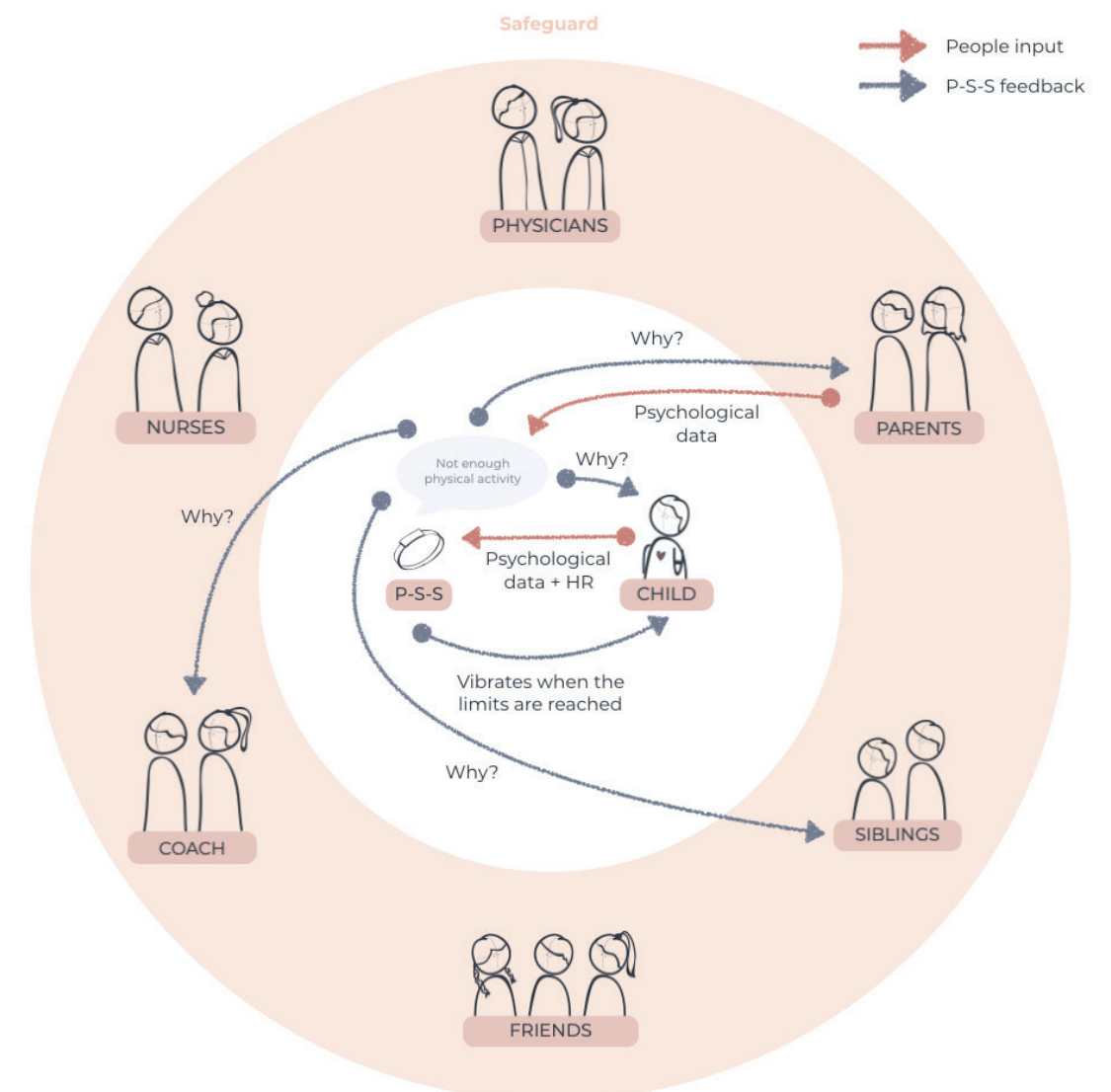
\*Limits from exercise test

**Concept 2 'The lifesaver' - Creating a safeguard for children**

**Description**  
Other stakeholders should create a safe space for the child to play without worrying much about the limits he has. The system can recognize patterns and ask others why the activity is low or spread activities during the week (when overprotection is less of an issue).

**Overall problem identified**  
The child has to be aware of his limitations and assume the responsibility to take care of the limits settle by the medical team.

Figure 36. The lifesaver.



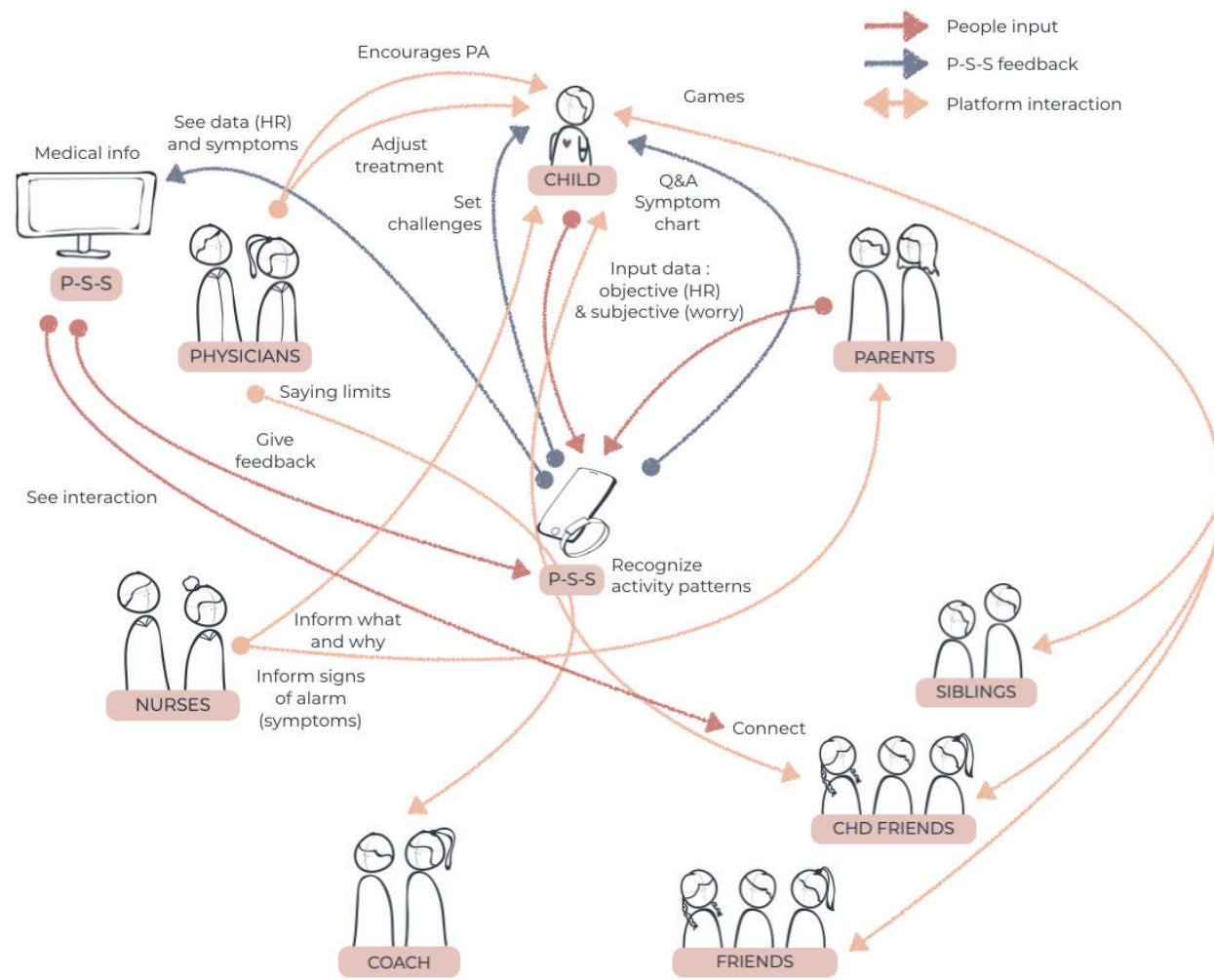


**Concept 3 'The coach' - Encouraging positive aspects of physical activity**

**Description**  
The child should be encouraged to pursue an active life instead of always showing what he can't do. The family members can express their physical activity concerns; the doctor thinks of why are symptoms happening and adjust medicine or treatment.

**Overall problem identified**  
Constantly exposing all the limitation makes others think that physical activity is dangerous.

Figure 37. The coach

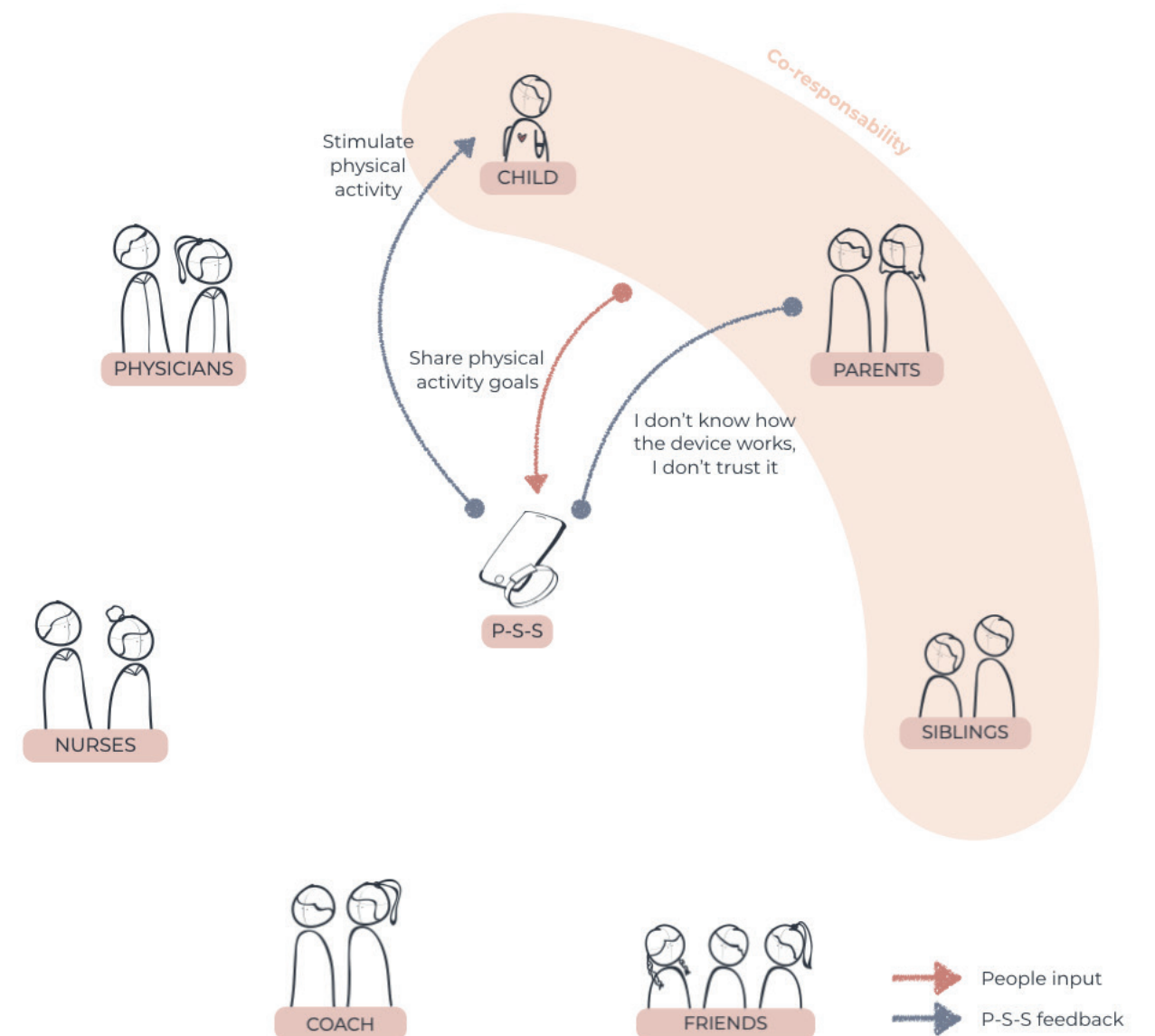


**Concept 4 'The physical activity team' - Increasing co-responsibility of physical activity**

**Description**  
Working on increasing physical activity is a goal that should be set for all family members, not just one person.

**Overall problem identified**  
What is the family attitude towards physical activity? If the family doesn't have a very active lifestyle, the child will hardly be encouraged to pursue an active lifestyle as well.

Figure 38. The physical activity team

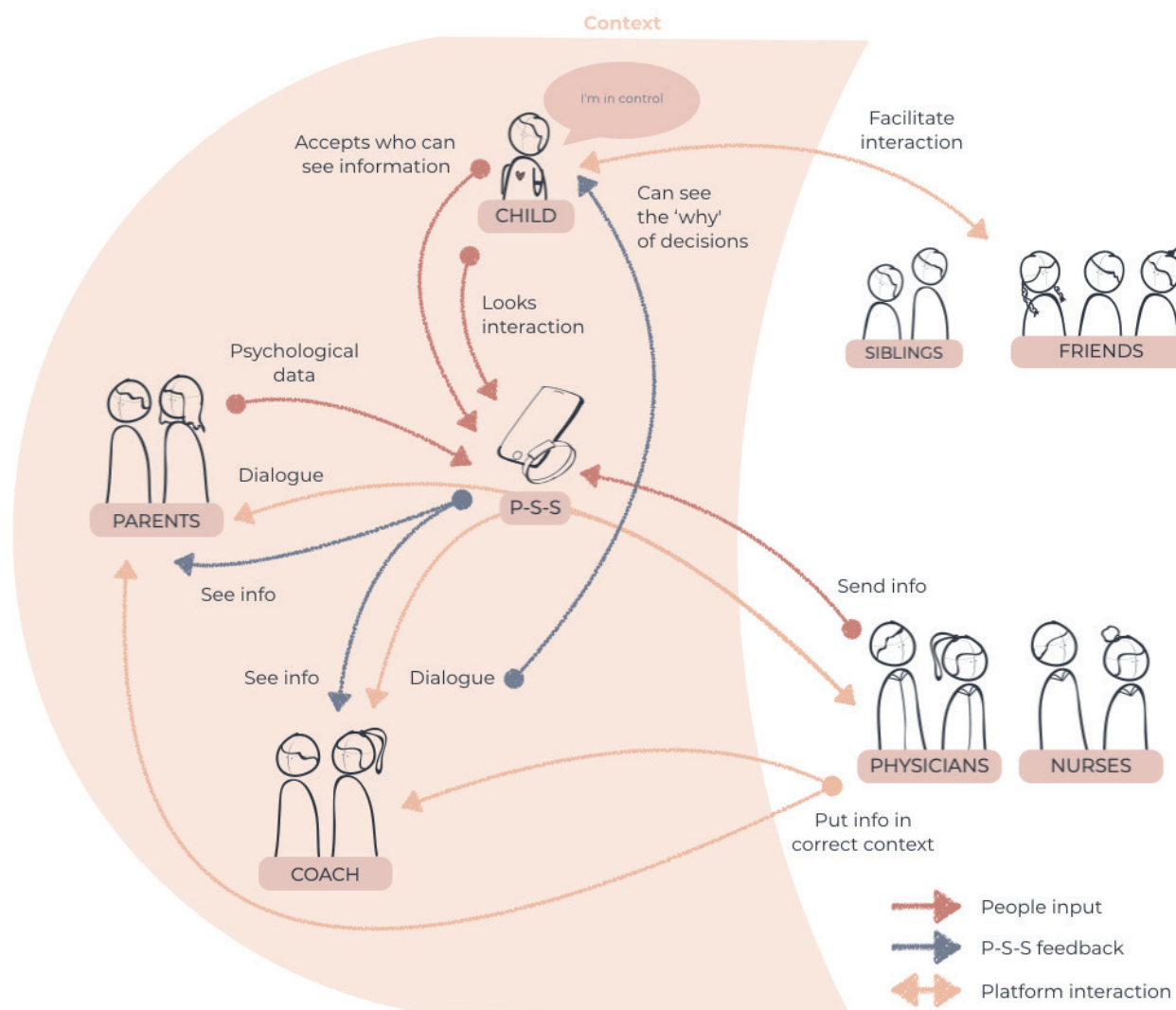


**Concept 5 'The coach clipboard' - A platform to facilitate discussions.**

**Description**  
The child moderates discussion between different stakeholders and the doctors place the discussion in the right context to avoid shared misinformation and increase of anxiety on the family.

**Overall problem identified**  
Different stakeholders interacting without the correct supervision could increase misinformation and negative perception of physical activity.

Figure 39. The coach clipboard

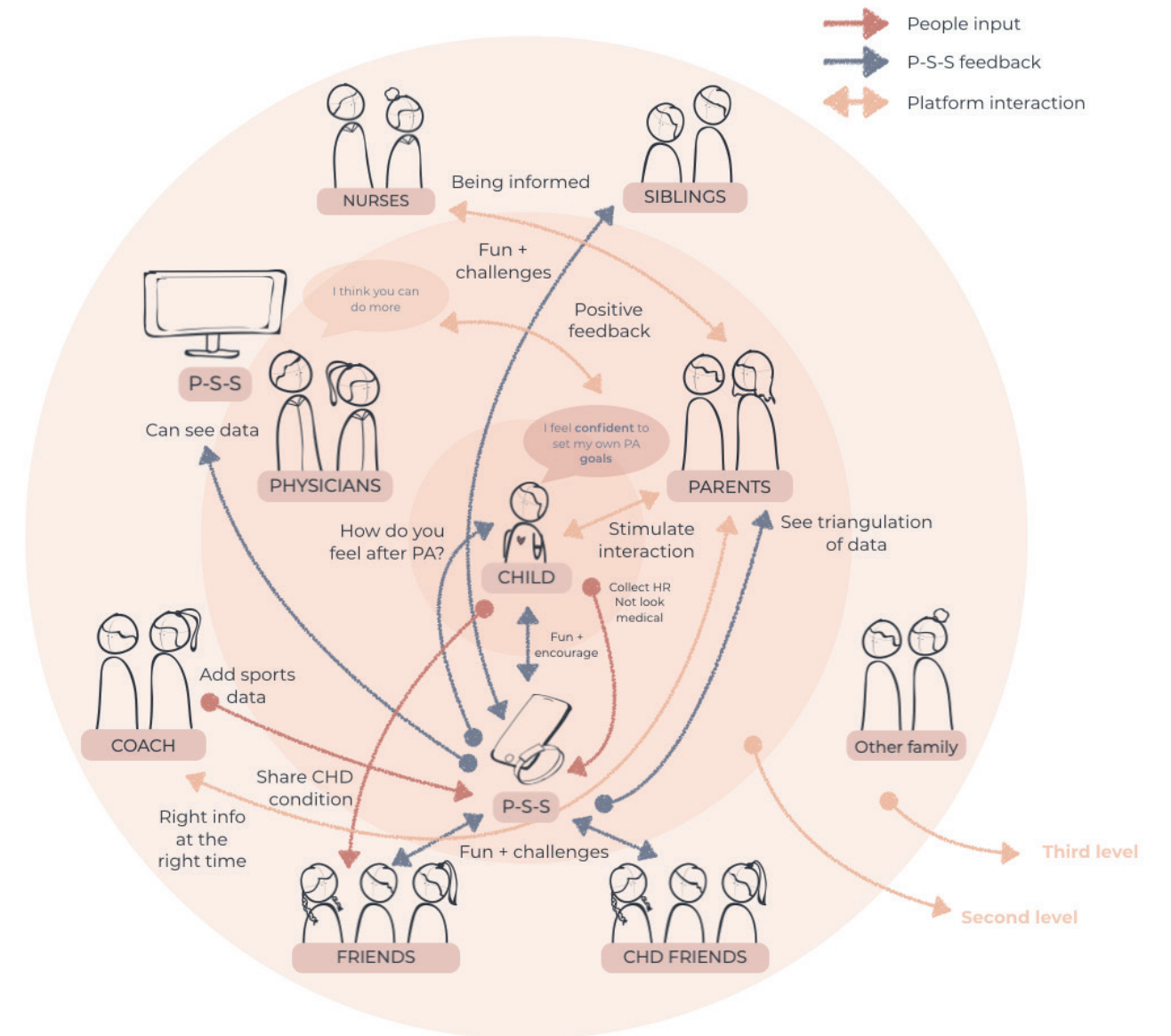


**Concept 6 'Team captain' - The child as captain of the stakeholder's team**

**Description**  
The child sets what he wants to achieve, and other stakeholders contribute to making it happen by providing information at the right time and stimulating interaction between stakeholders. The second level (Parents and doctors) supervise the third level of information.

**Overall problem identified**  
The child doesn't have any power concerning the CHD, and due to his physical activity limitations, others can notice that he is not a healthy 'normal' child.

Figure 40. Team captain.



## 4.5 Discussion

A crucial moment in the CCS took place when the first group ideas were surrounding the topic of how to make the limits clearer for the family in everyday life. However, one of the participants changed the ideation by giving the following remark:

*“ We have to move away from the idea that physical activity is dangerous, for most children what is dangerous is the lack of physical activity” - Paediatric cardiologist*

The above statement changed the direction of ideation from trying to restrict children to enhancing physical activity and helped other participants to see the problem with a different perspective. This view on overprotection later highlighted an apparent misconception of possible symptoms related to the ‘communication and perception’ dimension from physical activity. Physicians recognised that there are certain symptoms and aspects of the heart condition that are being interpreted in a certain way by parents and children. Hence, as a medical team, a re-interpretation of those symptoms and concerns could be done to indicate when further action is needed, or when the child is out of risk. This re-interpretation process, with the objective of help families to understand their symptoms better, make them feel less anxious about possible symptoms and therefore enhance physical activity.

### 4.5.1 Limitations

One downside pointed out during the session was the inefficient distinction between the four-colour codes of the moment cards to distinguish between the number of families talking about each code. Moreover, a combination of the above limitation with limited time to conduct the session resulted in a very tight schedule for participants get acquainted with all the data presented.

### Summing-up

All the ideas gathered during the co-creation session provided an overview of the medical team point of view on how the PSS should be developed. With the conclusion of this chapter, the three points of view from the main stakeholders presented in Chapter 1 were finally examined. Therefore, the following step in the design process relates to the definition of the problem after analysing the different perspectives. Chapter 5 provides an exploration of the problem definition process and the definition of a future design vision.

### Takeaways from this chapter

- An interdisciplinary collaboration requires an individual information flow per medical speciality for the envisioned PSS.
- The PSS should be an entity to encourage physical activity instead of restricting children.
- ‘Communication and perception’ highlighted as the most relevant PA dimension for decreasing anxiety.
- Re-interpretation of symptoms and concerns from a medical point of view can help parents to decrease anxiety.
- A hierarchical information structure for the PSS is recommended to avoid misinformation.



## Chapter 5

# Problem definition

This chapter aims to consolidate the findings from chapter 2, 3 and 4 into a problem definition. The chapter starts by providing background information about the research done. Afterwards, it describes the 'Activity path', as an outcome of the research phase, and integrates the three perspectives from the main stakeholders, child, parents, and medical team into three moments to illustrate the problem definition employing different underlying problems found in the previous chapter. To finalise, it provides a design vision for the PSS and shares the validation outcome done with a parent and a member of the medical team concerning problem definition and design vision.

# Problem definition

## 5.1 Background

Along the Discover and Define phases of the design process, several insights have pointed out to a lack of understanding in physical symptoms. Chapter 2, gave a perspective on how the uncertainty about the future caused a tendency in parents to see a health deterioration over time and look for symptoms (n= 271, Table 3) since these children were babies. However, it also provided a great positive view when seeing the child full of life. Chapter 3 described physical activity through the eyes of these families and highlighted anxiety starting when a change in intensity was perceived, and the challenge that represented knowing if a symptom was definitely a symptom. Surprisingly, this chapter connected the moment of 'seeing the child full of life' to helping in overcoming concerns showed by parents. Finally, Chapter 4 gave the last perspective to the problem by involving the medical team suggesting that a re-interpretation of the family symptom-concerns, from a medical perspective, could help patients to overcome anxiety and overprotective behaviours.

This chapter will synthesize the insights gathered and provide a problem definition that will be translated into a design vision for the envisioned Product-Service-System.

## 5.2 The physical activity path

The research highlighted three relevant stages during physical activity to understand anxiety and overprotection, (1) healthy zone, (2) symptom zone, (3) danger zone, and a safety threshold variable (Figure 41 a).

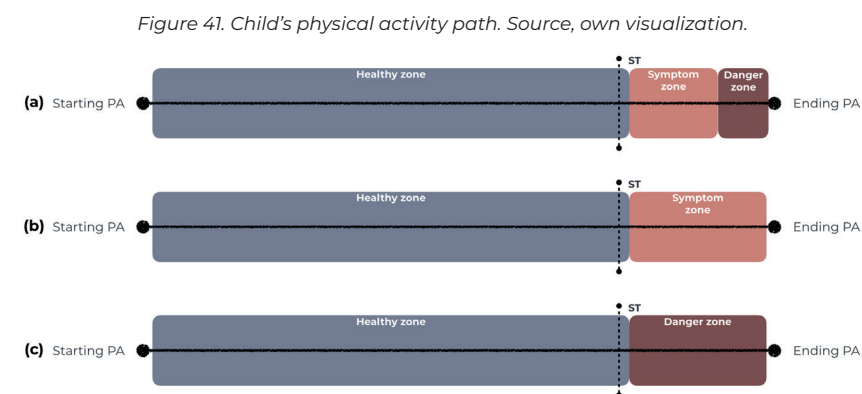
**Healthy Zone (HZ):** resembles the exercise done by the child where there are no visible symptoms, but exercise intensity can be perceived (e.g. sweating, breathing heavily, palpitations, tiredness). However, these manifestations of exhaustion occur in healthy children when doing PA and are not considered symptoms.

**Symptom Zone (SZ):** this zone is first explored by the cardiologist in hospitals by using an exercise test (see Appendix R) where they have a safe environment to examine the endurance levels of the child. When a child enters the symptom zone, any manifestation of tiredness, shortness of breath or palpitations are related to the CHD, and therefore child and parents should be careful with going further.

**Danger Zone (DZ):** a danger zone occurs when the exercise activity asks for more effort than the one the heart can handle. This zone is life-threatening.

However, there might be the case that a patient does not have a SZ or DZ (Figure 41 b & c).

**Safety Threshold (ST):** during the exercise test, doctors observe the heart rate (HR), blood pressure and oxygen level of the child while doing exercise. These parameters help physicians to understand what are the symptoms, what is the symptom zone, and when do symptoms become dangerous to recommend the family later. However, these parameters are not communicated to the family as the values obtained; they are interpreted and translated to sport possibilities for the child.



## 5.3 Three relevant moments to understand overprotection

The research highlighted three relevant stages during physical activity to understand anxiety and overprotection, (1) healthy zone, (2) symptom zone, (3) danger zone, and a safety threshold variable (Figure 41 a).

According to the above table, and the findings of previous chapters, three moments emerged to understand overprotection and anxiety in families. Each of these moments will be explained according to the views of the family members and physicians involved.

### 1. The follow-up appointment

- Physicians: during a follow-up appointment conducted every one to three years depending on the CHD complexity, the paediatric cardiologist interprets results from blood pressure, oxygen level, ECG readings, ultrasound images and if available, results of an exercise test. Moreover, the physician asks the family to recall possible symptoms since their last encounter. All this information helps the doctor indicate if a CHD patient should be extra careful while doing physical activity or not.

In case the family needs to be cautious with PA, the doctor will try to suggest sports according to the child's capabilities and tell which kind of symptoms they should be aware of when participating in physical activity (Symptom Zone). The main reason for suggesting to look for symptoms relies on the lack of other visible ways to monitor the child while being physically active during free-living conditions.

*"We only have the symptoms. So that's why we try to teach parents and children to perceive the symptoms and to react on those symptoms"*

- Paediatric cardiologist

- Parents: when parents attend a follow-up appointment, they know the objective is to evaluate their child's health and detect if the CHD has gotten worse. Therefore, parents (n=192, Table 3) feel anxious about this meeting because it reminds them their child could still be a candidate for surgery. Furthermore, after the cardiologist's diagnosis, just as when their baby left for the first time the hospital, they are suggested to look for symptoms while the child participates in physical activity.

*"Every time I come here I have some anxiety, you hope it is the same" - Mom, family 1*

- Child: depending on the interest and personality of the child, a child like Anne (Persona - Chapter 3) will be concentrated on the diagnosis because the child later can argue the doctor agreed on the child's preferences. However, a child like Jimmy (Persona - Chapter 3) will not give attention to it due to a lack of understanding or interest, and demonstrate a lack of ownership of the health condition.

*"[Mom] When I heard it from the doctor, I wondered myself if we should go on with soccer because it is quite intensive. But the doctor said, no worries.*

*[Child] He said I could do what I want."*

- Family 5

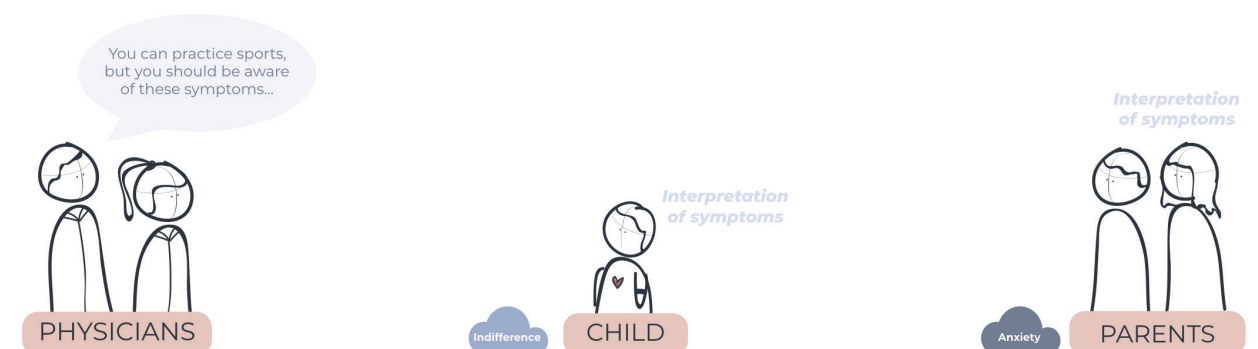
*"[Mom] Do you even have any idea what you have?*

*[Child] Uhm no*

*[Mom] He goes to the doctor but does not listen"*

- Family 3

Figure 42. The follow up appointment



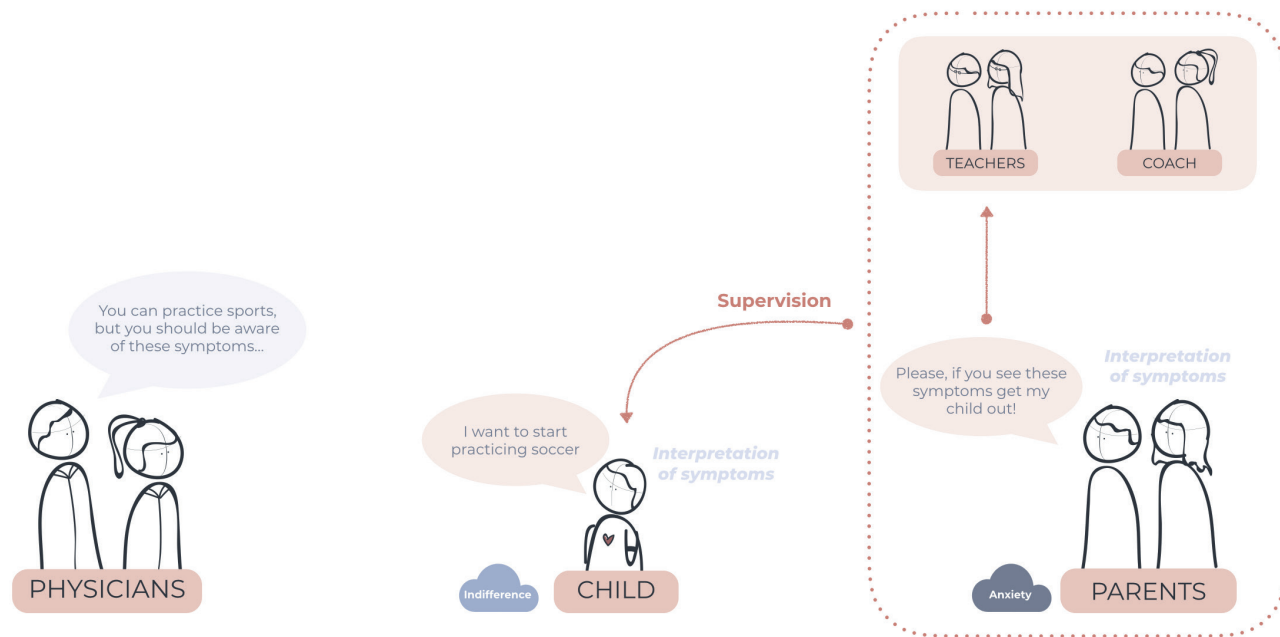


Figure 43. Before starting physical activity

## 2. Before starting physical activity

- Parents: once the child decides to participate in a sport or physical activity, parents try to tell the adults in charge (e.g. coach, teacher) that their child has heart disease. They explain that the CHD might compromise his or her physical performance. Therefore, they ask others to look for symptoms when the child is under their responsibility and understand when the child asks for a rest. As requested, parents and other adults will be looking for the safety of the child when he or she begins the exercise activity (Figure 43).

*"And from the start I had told every time she went to a higher level I had told the teacher: she has a heart disease, she does not really have problems with it, but when she goes blank, gets red circles around her eyes or goes below the water, then you have to get here out"*

- Mom, family 2

*"At every sport or club, they know, just in case that they also understand when he says he has to listen to his body that they respect it and act like it"* - Mom, family 4

## 3. During physical activity

- Parents: While the child is doing physical activity and an increase of intensity or difficulty is detected, parents will be confronted with the dilemma of having to distinguish between a genuine symptom and a healthy symptom. As previously mentioned, a symptom it is not always considered a symptom.

However, the only task suggested by doctors while doing PA is to look for the Symptom Zone since it is the only visible manner to know the state of the child's heart outside the hospital.

*"So you have two sides, protect him and let him be child. And if you then think 'hey I think he has some problems now' that is more difficult, because he can also just be tired"* - Mom, family 3

Furthermore, one aspect that helps parents to be more or less anxious about physical activity is to acknowledge if their child knows how to identify symptoms and stop when needed. On the contrary, parents who know their child is not capable of identifying symptoms or stop PA, feel more anxious when their child is active, and feel the need to intervene during PA.

- Child: during physical activity participation, the child could know how to interpret symptoms and therefore know when it is necessary to stop the activity. On the other hand, children who misunderstand their PA symptoms will keep playing until someone asks them to stop or when they start feeling very exhausted.

*"Often I think I will just go on for a while, sometimes I then feel my heartbeat in my throat and then I stop for a while. Then I know that when I go on I will not make it"* - Child, family 6

To better illustrate the third moment 'During physical activity', two cases with different personas

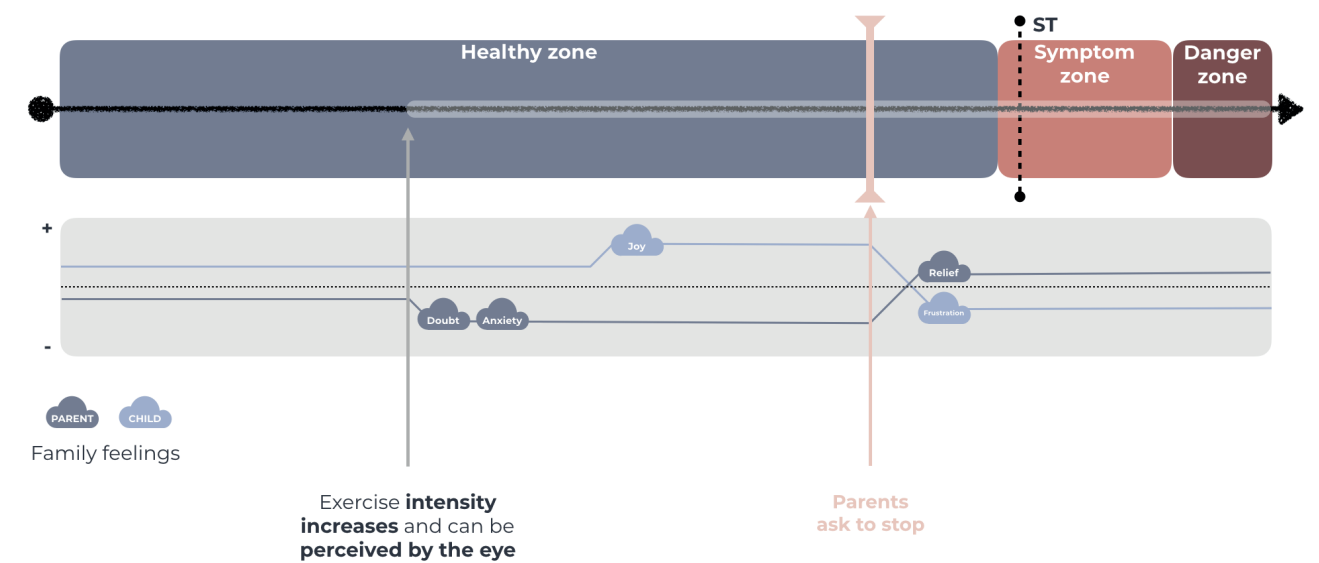


Figure 44. Parent stopping activity before Symptom Zone

created in Chapter 3 are shown in figure 44 and 45.

### — Case one - Charlotte and Jimmy

Charlotte knows her son Jimmy only cares about playing and does not know when physical activity is enough. This incomprehension makes her feel that she continually needs to supervise him and remind her son to take a break. Therefore, she decided to tell the coach of Jimmy to help her keep an eye on her child.

When she watches Jimmy practice with his BMX bike, she worries every time Jimmy needs to bike from one place to the other because she sees that the intensity goes from 0 to 100 in a very short time with some exercises. These sprints make her start doubting if Jimmy will be able to finish the BMX track. She feels anxious when seeing Jimmy more and more tired with each phase of the game.

Meanwhile, Jimmy feels great while biking! He does exactly what his other peers do in the BMX class, and so far he feels a bit tired, but nothing to worry.

*"I have a long track and the first part goes easy and the second part as well, but the third part, then I am already tired. But it is better when you can pump it up at the end to make some speed. So the last part I really have to keep up, persist"* - Child, family 6

At some point, Charlotte cannot distinguish if she is looking at an ordinary tiredness level or if Jimmy is actually presenting a symptom. Therefore, she

prefers not to risk the health of her child and asks the coach to get him out.

*"You go from 0 to 100 in one time and then I sometimes had to yell to the coach get him out"* - Mom, family 3

When Jimmy is asked by the coach to retire from the activity, he feels frustrated because he did not reach the performance he wanted and does not feel sick. However, his mother feels relief now that the class is over.

### — Case two - Emma and Anne

Emma always sees her daughter Anne play soccer. She is aware that soccer is a quite intense sport, but she knows her daughter knows when she is feeling sick and needs to take a break.

*"I know that I have to take it easy because I get tired more easily. With soccer as well or with sports at school I tell the teacher when I have pain, muscle pain for example, because at Tuesdays we also have sports and then I tell the teacher I have muscle pain and will take it easy or when I do not feel very well"* - Child, family 5

When Emma sees Anne in her soccer class, she worries seeing her daughter running for an extended period and observes that Anne looks more tired than the other players. These thoughts make her feel anxious and doubtful, wondering if Anne will be able to finish the training.

At some point, Emma is not sure if Anne is

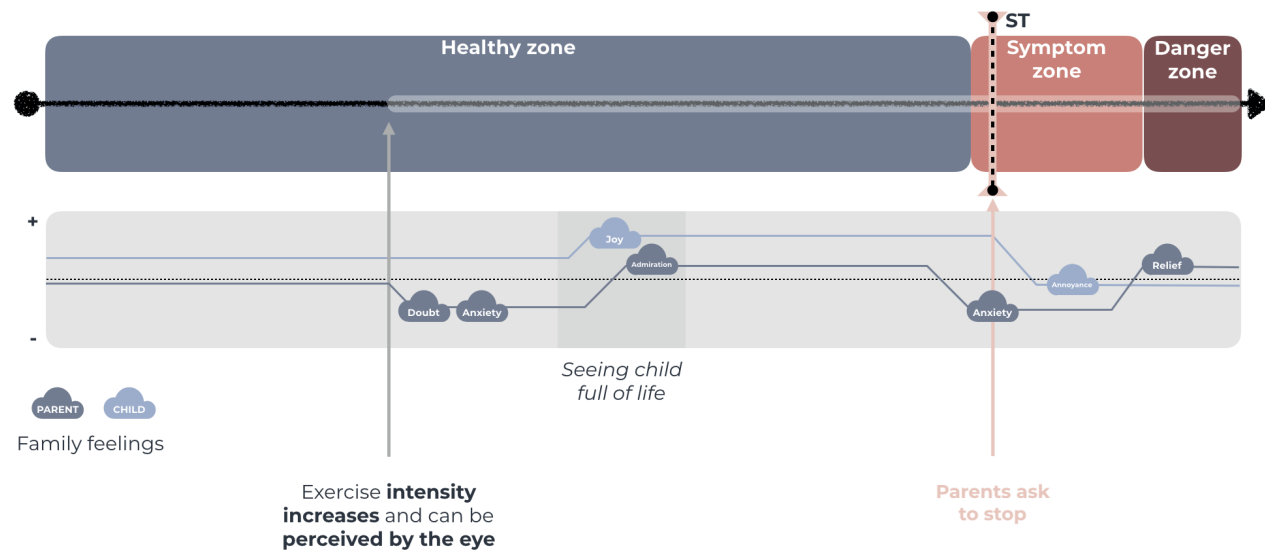


Figure 45. Parent stopping activity in Symptom zone.

exhausted, or she is just taking it easy for a little while in the soccer field. However, Emma sees her daughter having a great time playing soccer with the team, and therefore she reconsiders to ask the coach to stop the activity. Ultimately, she prefers to give her daughter more time to enjoy the activity, and when seeing her daughter stopping to take a breath, she starts to get worried and asks the coach to give her child a break.

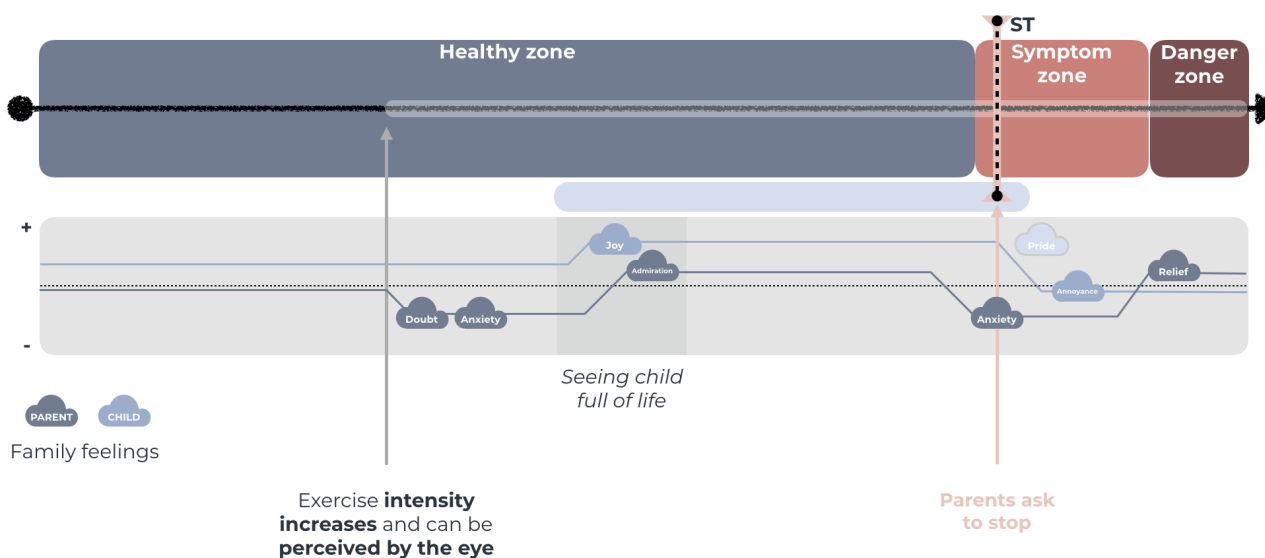
a bit annoyed that she had to stop the game but is aware that it was getting more challenging to keep running. Furthermore, Emma feels relief because Anne is OK, and she had the opportunity to play something that she enjoys.

*“Of course, you will stay worried. But when I see how good things go and how happy she is, I let her go” - Mom, family 5*

When Anne goes out of the soccer field, she feels

Figure 46. Problem definition.

### How to uncover and train child and parents on *THIS PHASE* by using smart systems in a way that offers relief towards perceived worries during physical activity participation?



## 5.4 Problem definition

Both cases demonstrated how the distinction between a genuine and healthy symptom, and the trust in the child’s capabilities to identify and act while feeling symptoms can have an impact in when parents decide to stop physical activity. By delaying the stop moment, children can enjoy the activity longer, and enable the opportunity to explore the symptom zone inside the Safe Threshold, which is invisible to the human eye during free-living conditions. Therefore, the re-defined design challenge is described in Figure 46.

## 5.5 PSS Design vision

Based on the above statement, and findings from Chapter 3 and 4 describing the influence physicians have in clarifying perceived concerns from family members, and the focus on encouraging PA instead of restricting children, the following design vision (Figure 47) was created to inspire the next phases of the creative process.

*“Create a supportive exploratory environment during the child’s physical activity participation where parents and physicians contribute as a team to the child’s self-discovery of safe boundaries.”*

Figure 47. Assignment.

### Overall meaning of the PSS

The PSS should provide a supportive real-time channel between the child, parents and physicians, that offers relief towards perceived worries during physical activity participation, and where each of the members contributes to creating an understandable relationship between the child and his heart condition.

### Reason of existence

When the child participates in physical activity, and there is an increase in intensity or difficulty, his parents start to feel worried about until what extent their child can engage safely. It is very challenging for family members to identify the difference between healthy signs of physical exhaustion and symptoms that the CHD could cause during exercise participation. Therefore, sometimes parents ask the child to stop before he reaches the safety threshold zone indicated by physicians, where the child can

explore his physical activity limitations. If the child is not able to explore his boundaries, he will never be able to identify them and act on them by his own in the future.

### Identity of the PSS

The PSS should be perceived as a trustworthy channel between the physicians and the family. Where the members can express their concerns without feeling judged, and all of the adults involved build a supportive atmosphere for the child to explore his boundaries.

For detailed information regarding the design vision, please refer to Appendix S.

## 5.6 Validation of problem definition and design vision

In order to confirm that the problem definition and design vision were relevant for tackling the problem, two meetings, one with a father of a CHD patient and one with a paediatric cardiologist were arranged.

### From a parent perspective

An informal meeting with the chairman of Stichting Hartekind was done to present the findings of the research phase, possible directions found in the co-creation session and the problem definition. After concluding the presentation, he showed enthusiasm with the results and acknowledged that a direction to go was to train and support children to recognize symptoms while participating in physical activity.

### From a paediatric cardiologist perspective

An informal meeting with a paediatric cardiologist of the Erasmus MC took place to share the findings of the research done, problem definition and the possible design directions encountered in the co-creation session.

When showing the different directions found he pointed out that Concept 5, a platform to facilitate discussion and share information was essential to help families in interpreting symptoms.

*“I really like this last concept because for me, it’s not about, interpreting biological data and setting limits. It is also coaching the parent and the child to perceive the symptoms maybe in a more realistic way”*

*“Well as a co-creation session, what really opened my eyes was that it’s more about*



*sharing information, but also information about perceived symptoms, about the perceived boundaries and about what the coach think is good for them”*

He also corroborated that the interpretation is a challenge for parents when the child is doing physical activity and that the medical team could play a role in helping families to solve their doubts.

*“There are certain symptoms or certain aspects of the heart disease that are being interpreted in a certain way by the parents and their children. And that as a doctor or as a medical team, you can you can try and reinterpret it in good way”*

Moreover, he recognized that meetings with patients to solve their concerns are done within a broad timespan, and sometimes families do not reach to the hospital when they should.

*“[Physician] “Did anything happen in the last couple of months?”*

*[Child] “Yeah, well, like two months ago, I really had this horrible heart rate, or I fainted or collapse”*

*And sometimes I think, well, you should have called me then. So now we’re a little bit too late”*

Therefore, he saw great potential in using smart system technology to connect families and the medical team to interpret the concerns of families, but also to react better when the health situation gets worse.

*“You can decrease anxiety by looking at the symptoms and measuring some simple biological things like heart rate or oxygen level, and then say, well, all is fine. You shouldn’t worry. I think that can be really, really helpful. But on the other hand, you can also help children and even intervene in a better way, when you think that the things are going the wrong way.”*

## Summing-up

The present chapter synthesized and reframed the different information gathered through the research phase into inspiration for the ideation phase and confirmed with the main stakeholders the proposed vision for the future PSS. Chapter 6 demonstrates the iteration process of building the envisioned PSS based on the new vision and design direction.

### Takeaways from this chapter

- Children’s physical activity participation can be divided into three heart rate areas, (1) healthy zone, (2) symptom zone, (3) danger zone, and one limit stated by the doctor.
- Three moments emerged to understand overprotection and anxiety in families, (1) the follow-up appointment, (2) before physical activity, and (3) during physical activity. In each of them, different triggers for overprotection cross the mind of the parent.
- Before starting PA, parents build a supervision network to be able to identify symptoms.
- The envisioned PSS should create a supportive exploratory environment and enhance the child’s self-discovery of safe exercise boundaries.
- From a parent perspective, as stated in the validation, training the child to listen to his body is essential.
- From a medical perspective, as stated in the validation, facilitate discussion between the medical team and parents about perceived symptoms seems to be a great perspective to ideate on for further design phases.

## Chapter 6

# Product-Service-System Ideation

This chapter aims to narrate the ideation process of the potential modules composing the envisioned PSS by integrating ideas gathered in the co-creation session, such as a new PSS structure including additional relevant stakeholders. The chapter first introduces background information on technology and healthcare. Then, it exhibits the iteration process followed to define the Product-Service-System modules, and afterwards, presents the exploration of technology to power the system.



# Product-Service-System Ideation

## 6.1 Background

Digital health ecosystems offer the possibility to move healthcare beyond hospital walls, by applying technologies such as the Internet of Things (IoT), Virtual Health, and Artificial intelligence (AI). The objective - bring closer patient, caregivers and physicians to enable efficient patient monitoring by collecting and analysing health data in real-time, but most importantly tailor treatment and offer patient support in complex situations (Deloitte, 2019; McKinsey, 2017).

This chapter will present the PSS ideation, and iteration process followed to integrate the stated design vision, smart health systems and previous ideas from the co-creation session to build an optimal structure for the system considering the stakeholders found throughout the research phase.

## 6.2 System versions

The ideation of the PSS began reviewing the ideas generated in the CCS as an inspiration. A total of five iterations were done. The following paragraphs will explain which variables were considered for each iteration and how they contribute to the system as a whole.

### 6.2.1 First version - Defining the discussion topics

The first step to create the PSS was defining what information was necessary to be discussed and between whom. Therefore it was decided to review the ideas gathered related to 'discussion' in the co-creation session and see which topics the medical team thought were important to discuss with the family.

#### Including relevant stakeholders

At this moment, the system canvas employed during the CCS was the basis to start developing the concept. However, while reviewing the discussion ideas, it was noticed that the psychologist profession was marked as relevant, but was not illustrated in the current canvas. Therefore, the inclusion of the speciality was done since the first underlying problem identified was the lack of psychological

data from family members (Chapter 4). At the end of the first system version, six discussion topics were identified among the co-creation ideas. The following figure shows how the topics were associated with different stakeholders according to the CCS.

### 6.2.2 Second version - Defining the discussion topics with idea-features

To further explore the scope of the discussion, it was decided to look at the final concepts with a different perspective. Therefore, based on the concept cards (Figure 34 - Chapter 4) a total of 59 idea-features were extracted and labelled according to the discussion topic (DT) they were addressing with the family (see Appendix T). To conclude, all the labelled idea-features were clustered into 13 family-physician discussion topics. Figure 48 shows an overview of the clustering exercise.

#### Including relevant stakeholders

Furthermore, based on the illustrations of each concept card, the connection-chains were plotted in an improved canvas that included CHD friends, and Coach instead of Teacher due to changes that the illustrations suggested.

Figure 50 displays the 13 family-physician discussion topics. Additionally, it includes a new one called "Emergency Line" which was inspired in the comments of the paediatric cardiologist during the validation meeting. The dotted lines on some DT were used to differentiate inclusion ideas from the researcher. To illustrate the upcoming steps of the PSS ideation the example of the first cluster "Real-time worry line" (Figure 51) will be shown in each iteration.

Figure 48. An overview of the procedure done to get discussion topics from idea features

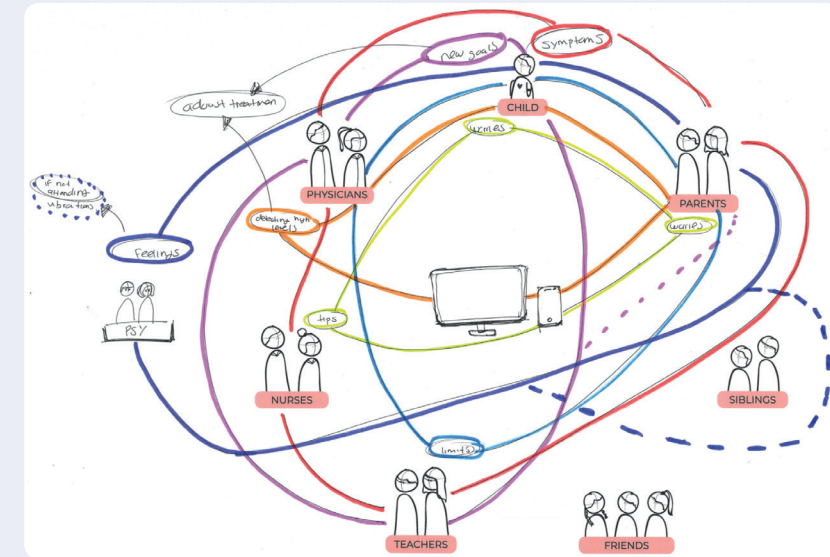


Figure 49. First discussion topics.

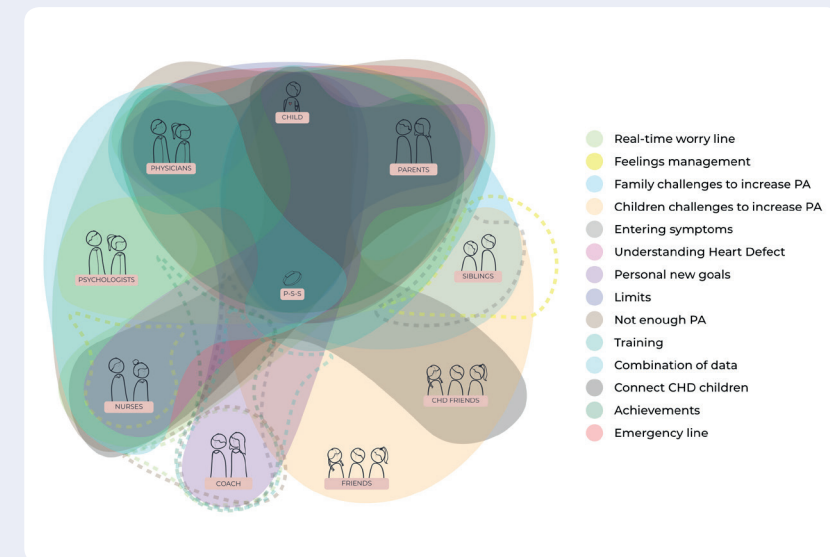


Figure 50. The Second version of discussion topics extracted from idea-features.

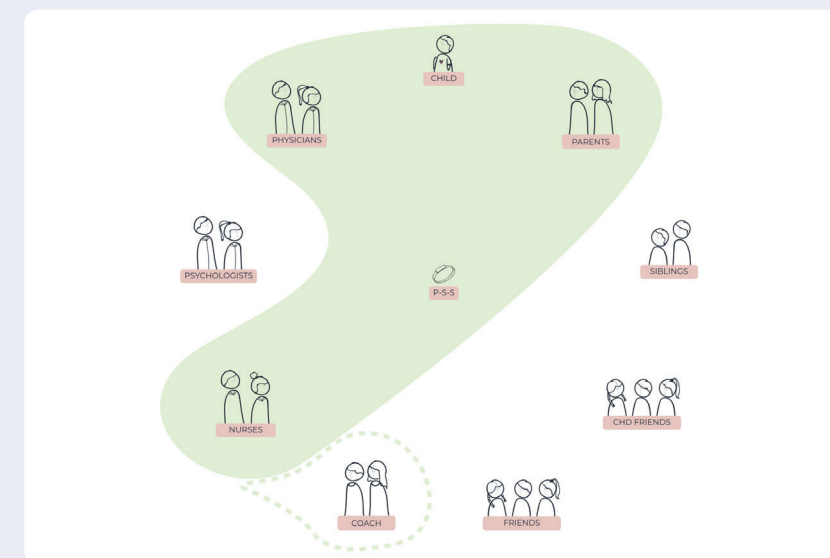


Figure 51. Real-time worry line, version 2. All individual clusters in Appendix U.

### 6.2.3 Third version - Defining communication actors

Once the family-physician discussion topics were settled, the detailing of the PSS began. Since the discussion topics came from solution-oriented ideas, it was known that inside each DT, an exchange of information would occur to prompt the discussion. Hence, the following step consisted of identifying which actors were senders and which ones receivers inside each cluster.

#### A new structure

However, before start with the communication actors, it was noticed that the current circular structure did not follow the hierarchical information-flow suggested by the medical team. Therefore, three levels representing the level of involvement in relevant health decisions were built to rearrange the stakeholders.

#### Including relevant stakeholders

Furthermore, since interdisciplinary collaboration required individual information-flows per speciality, it was decided to review the individual ideation of the CCS to discover the different roles envisioned by each specialist and how they saw themselves acting inside the PSS. As a result, the character for a sports doctor, social worker and child life specialist were included in the structure. In addition, the stakeholder 'CHD families' was incorporated since the text analysis had shown that there was a supportive relation between CHD families.

With the structure on placed, two circles on the top of each stakeholder were added to indicate 'sending information' (bottom/dark grey) and 'receiving information' (top/light grey). Lastly, by observing individual and group CCS concepts, the communication arrows were identified and drawn, and a brief description of the interactions on each discussion topic was written to preserve the overall meaning of the arrows.

### 6.2.4 Fourth version - Defining the characteristics of each PSS interaction

The next phase in developing the system consisted of defining the characteristics of each arrow and how will the PSS interact with the stakeholders on each discussion topic. Hence, the WWWWWH (Who, What, Where, When, Why, and How) checklist (Van Boeijen et al., 2013) was used to define the context surrounding each action (arrow).

Based on the brief description from the previous version, the following questions were answered on an Excel document (see Appendix V) and referred to each arrow with a unique number.

1. Who, To/ From
2. What is happening?
3. What device is used?
4. When does the interaction take place?
5. Why the action takes place? (triggers)
6. What is expected from the interaction?
7. How will the interaction happen?

Table 7 shows the primary information sources for answering each question.

Question	Source
1	Co-creation individual and group ideas, computation analysis, interviews
2	Co-creation individual ideas, researcher's creativity
3	Co-creation group ideas Interviews, researcher's creativity
4	Researcher's creativity
5	Co-creation individual and group ideas, problem validation meetings
6	Co-creation individual and group ideas, researcher's creativity
7	Researcher's creativity

Table 7. Primary information sources for answering each question.

This method defined the actions performed by the system and stakeholders and defined an interaction order. Therefore to give the PSS an active role, each level ground symbolized the PSS as an active entity that could send (right side) and receive (left side) information.

In Figure 53, the little numbers represent how the interaction should happen. However, at this point, the excel document was still necessary to pair the

name of the interactions with the arrows. Moreover, different line types were created to indicate if some interactions were thought to happen in person, and if some of those actions had a conditional agreement between stakeholders.

#### Building meaningful interactions for the PSS

Once the fundamental actions were defined, it was observed that some interactions could be improved by adding an emotive purpose to them. Therefore, an evaluation of the overall design dilemmas for the child and parent was done using the interview material to define which emotions and human goals were appropriate to strengthen (Ozkaramanli, Desmet & Özcan, 2017). The resulting emotions and human goals were the following:

Child: the child's dilemma was associated with the desire to keep playing what other friends played and the desire to feel physically good while playing. The underlying Human Goal (HG) identified for the first statement was belonging and in case of keep playing the emotion evoked joy. For the second statement, the HG was physical wellbeing, and in case of accomplishment, it could arouse pride.

Parents: on the other hand, the parental dilemma was related to the desire of stopping physical activity when seeing a possible symptom and the desire to let their child enjoy physical activity. The underlying HG for the first desire was safety, and in case of stopping PA, it could bring relief.

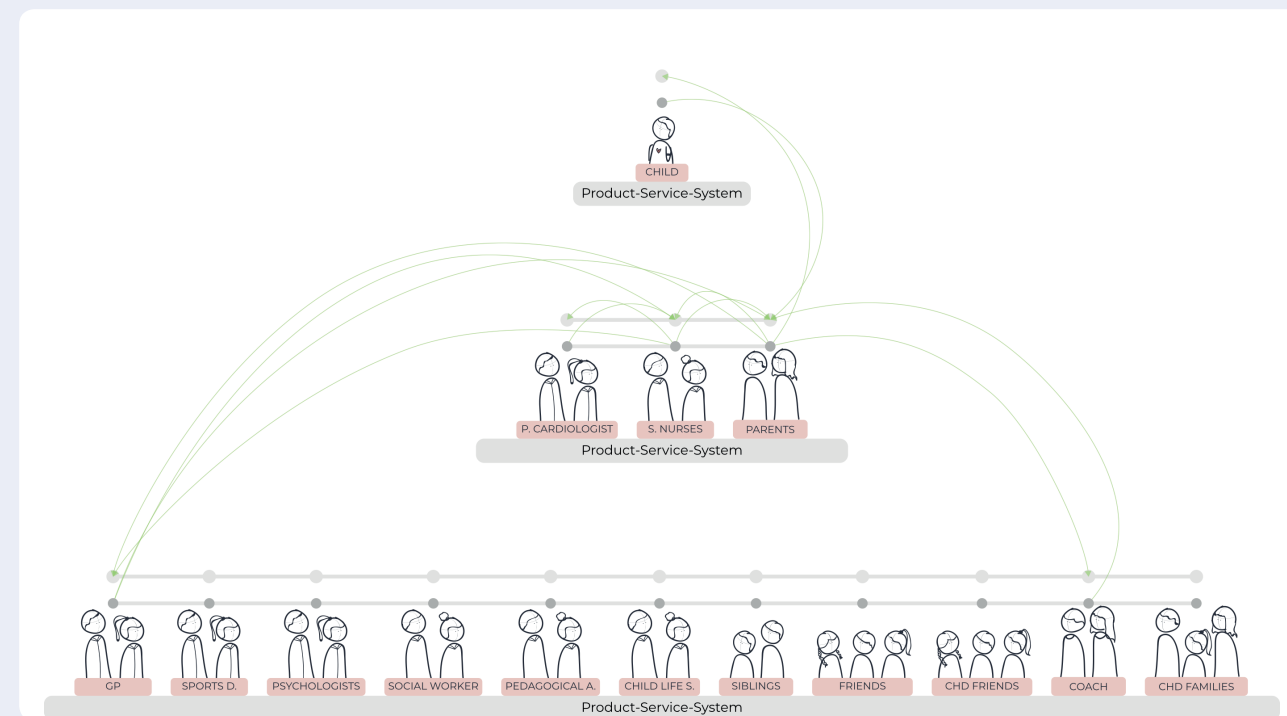


Figure 52. Real-time worry line, version 3.

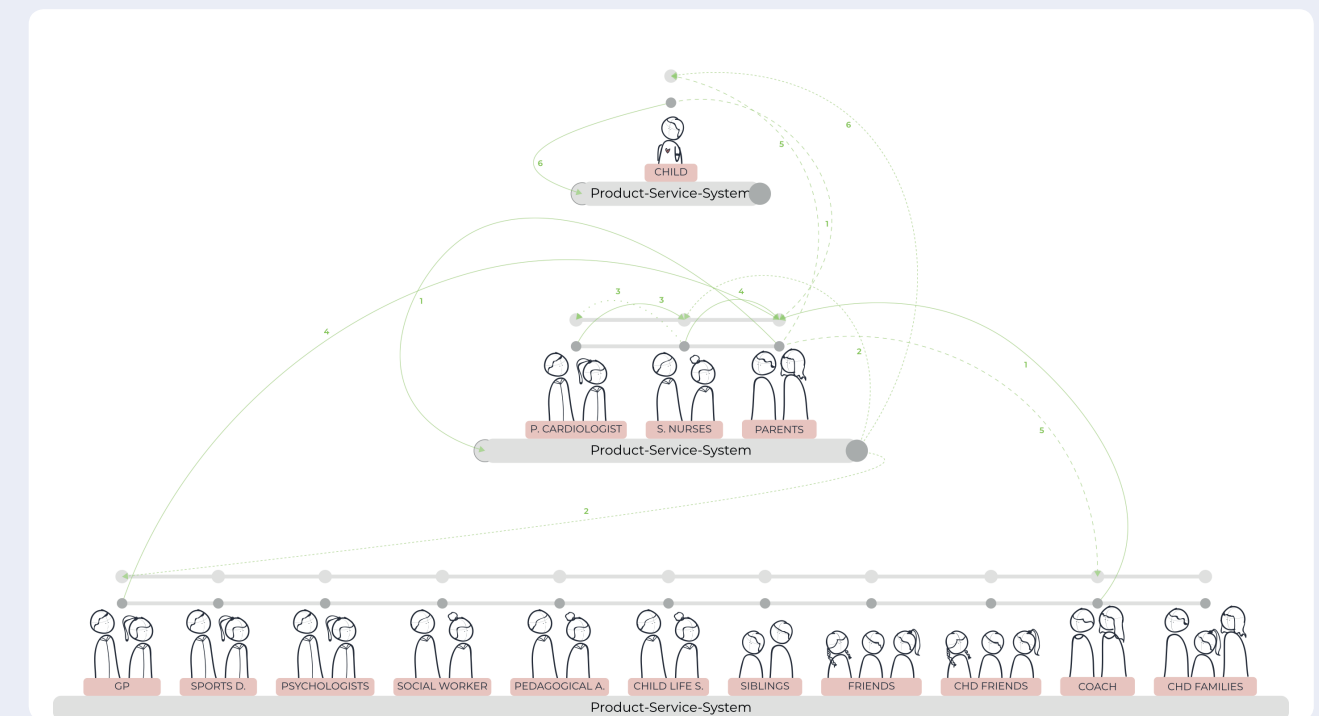


Figure 53. Real-time worry line, version 4.

However, for the second statement, the HG was resource provision, and in case of letting the child enjoy PA, it could evoke admiration for the achievements accomplished.

Based on the aforementioned human goals and emotions, the lenses for designing the PSS interaction changed, and some actions were improved using the Design for Happiness deck (Delft Institute of Positive Design, 2017) to try evoking meaningful interactions.

### 6.2.5 Fifth version - Creating the final system structure

Along with the five iterations of the system, the discussion topics of (1) Entering symptoms, (2) Not enough PA, (3) Achievements, (4) Connect CHD children, and (5) Combination of data were merged with other DT since they represented actions better than the discussion itself. As a result, the remaining nine discussion topics were renamed to sub-modules. Lastly, the actions (arrows) of each sub-module were clustered to create the system functions.

#### Stakeholder rearrangement

Currently, the Sports Doctor is not involved in the routine assessment of physical activity in children with CHD, only if other specialists request it. However, during the CCS, it was mentioned the need for creating multidisciplinary collaborations to provide better care for patients. Therefore, the

sports doctor was rearranged to the second level of the structure, to involve him/her more in physical activity boundaries and goals, which were mainly discussed between the higher PSS levels.

#### PSS final canvas

Furthermore, the final canvas illustrating the PSS was modified to provide detailed information about each sub-module and system functions. The following changes were made:

- Each system function cluster was illustrated by using low-transparency figures of the same colour resembling the sub-module (see Figure 55).
- The device usage per stakeholder was included in the visualisation to provide a better idea of how each function was performed. Moreover, low-transparency circles were added surrounding each device every time the device was used to enable seeing which devices were used the most on each sub-module.

The final symbology can be seen in the following figure.

## 6.3 Defining the technology integration

The proposed system engaged different stakeholders to provide better care for CHD patients and enabled the possibility to enhance physical activity by taking care of the parent's concerns. However, some functions seemed dense in terms of workload for the medical team. Therefore, it was decided to do a Technology map with emerging trends to look for inspiration on how to decrease the medical team's workload. Figure 56 (on next page) provides an overview of the technological trends found during the exploration.

Based on the emerging technologies found, the conversational agents (chatbots) powered by NLP in combination with Agentive AI Technology provided an attractive alternative for further exploration considering that interpretation of worries needed to be personalised to each unique case of CHD.

#### Agentive Technology

According to Chris Noessel (2017), the AI knew today (Narrow AI) could be classified into 'Assistive' and 'Agentive'. Assistive AI, relates to technology that helps the user to complete a task in real-time, while in Agentive AI, the user gives a task and technology acts on behalf of the user, enabling the user to disengage once the setting-up is ready. The essential difference relies on transitioning from using AI tools to manage them. Moreover, one of

the aims of Agentive AI is to remove the initiative from people and work on the background to ensure that the tasks given run smoothly.

Four phases can be distinguished to apply Agentive AI in the user experience domain, (1) setting up, (2) tune and handoff when trust, (3) monitor and (4) stop agent.

#### Conversational agents

With the recent wave of interest in AI and NLP, text-based conversational agents or 'chatbots' have gotten more awareness in the business world due to the capacity of managing multiple customers queries in real-time (Gartner, 2019). Chatbots enable people to interact with a conversational partner and mimic human-like conversations in a natural text language and, in sophisticated cases, with voice. A chatbot is an intelligent conversation platform that interacts with users via a chatting interface (Chung & Park, 2019). It employs AI-enabled language capabilities such as NLP to adapt to user responses. Some conversational agent benefits are mentioned below.

- Can adapt to unseen flows of information based on their NLP nature, and training data.
- Can assist users in simple tasks regardless of time and space, and therefore reduce the workload of the human worker.

(more benefits on next page)

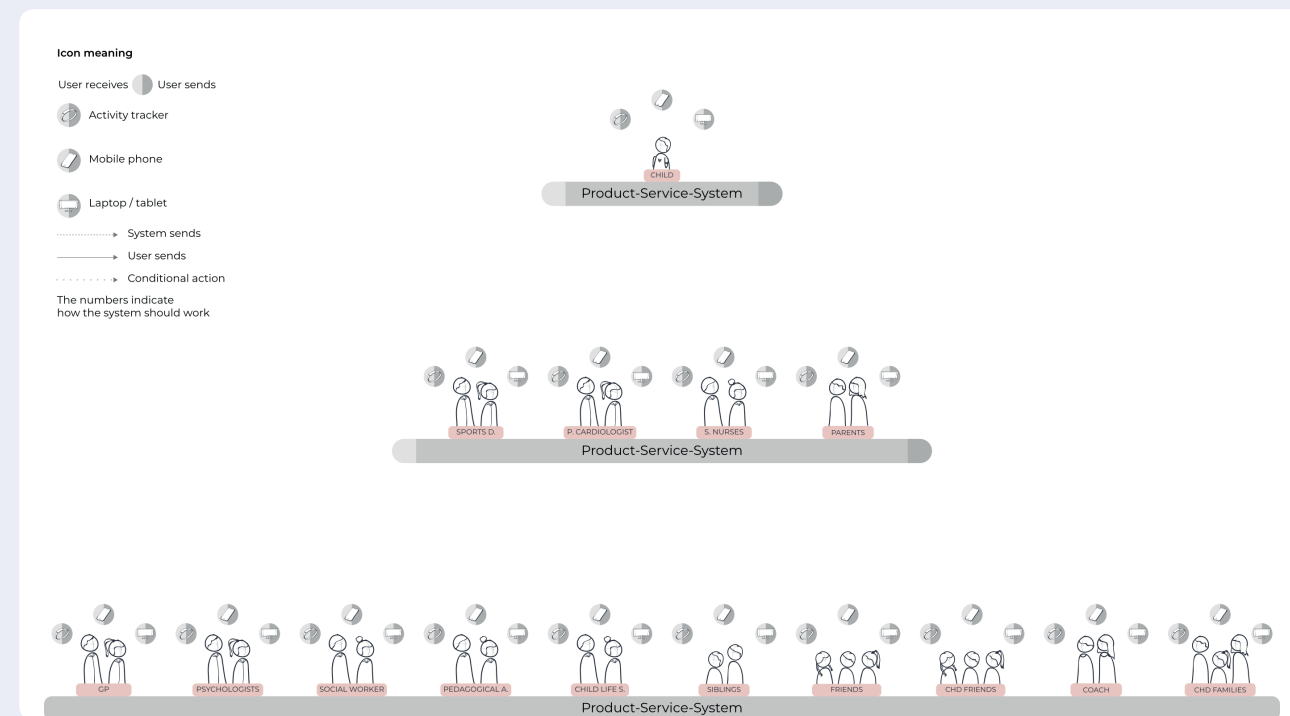


Figure 54. PSS Symbology and final canvas.

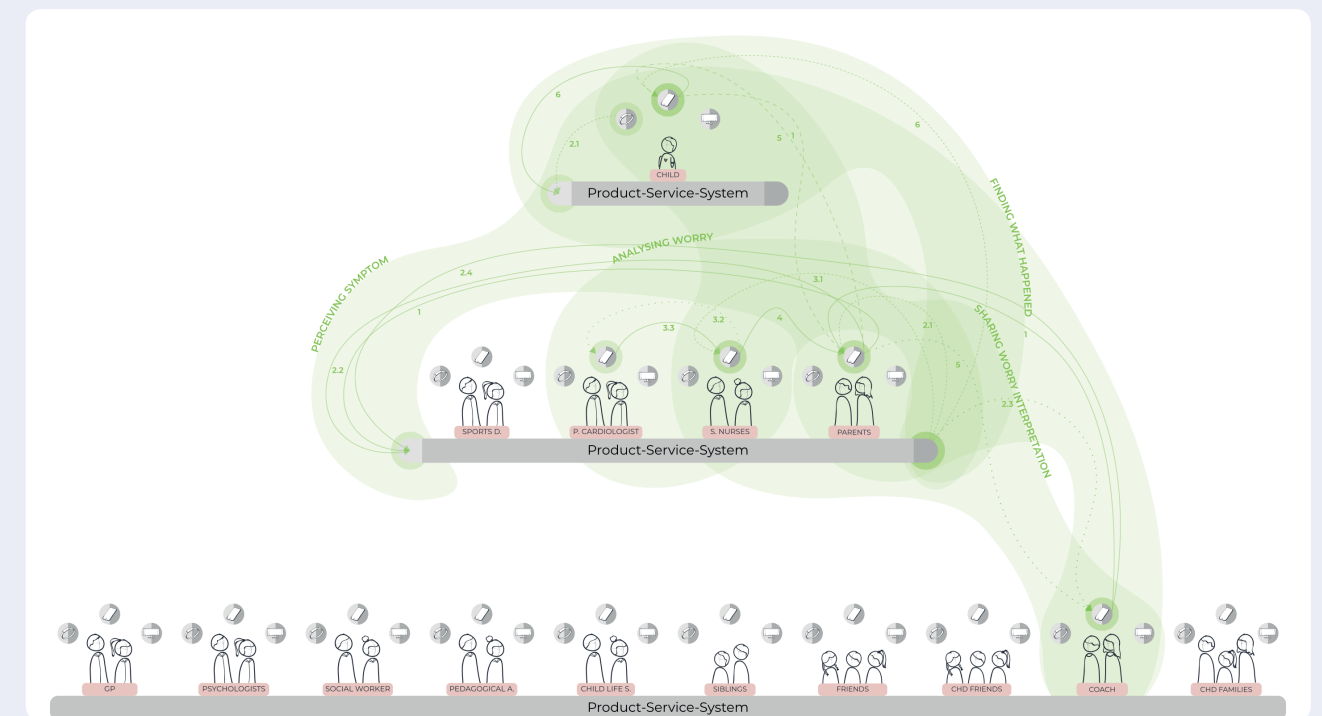
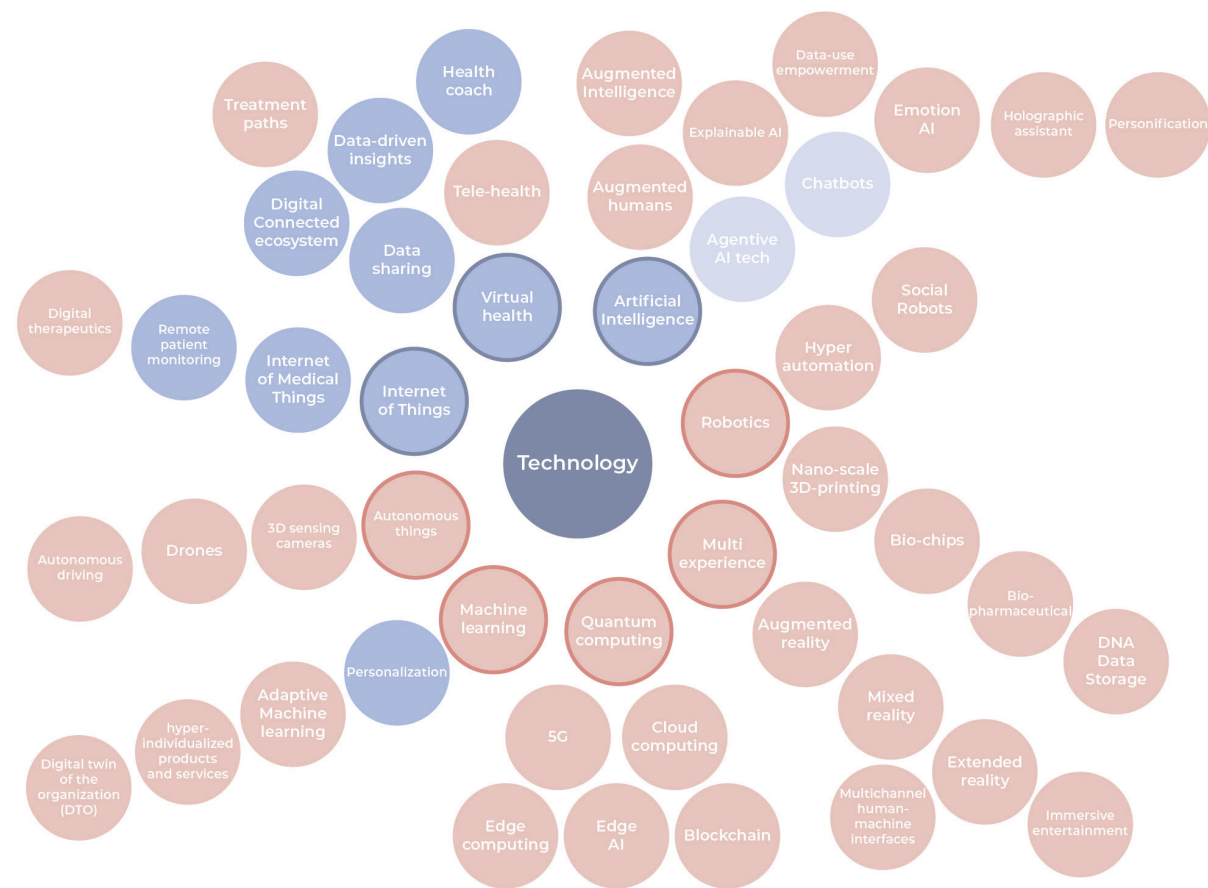


Figure 55. Real-time worry line, version 5.



Figure 56. Technology map. The blue color represents the concepts related to the envisioned PSS. See the sources in Appendix X.



- Its implementation can be adapted to any platform with the use of API, including various social network messenger services such as WhatsApp or Telegram.
- In case of emergency, a human can quickly be notified and take over the conversation.

Since AI was the engine behind both themes, literature in Human-AI interaction by Amershi, et al. (2019) was explored to get a better understanding of the opportunities and limitations while designing AI-powered systems. The following table exposes the AI design guidelines found.

### 6.4 Agentic ideation

Due to the initial aim of reducing the workload of the medical team, and the possible benefits perceived by the Agentic AI and conversational agents towards the aimed goal, it was decided to proceed with individual sketching-ideation considering both topics and the PSS structure previously designed.

Hence, 'Bo' an AI conversational agent, was created to represent the system in direct interaction with

Number	AI guideline
1	Make clear what the system can do
2	Make clear how well the system can do what it can do
3	Time services based on context
4	Show contextually relevant information
5	Match relevant social norms
6	Mitigate social biases
7	Support efficient invocation
8	Support efficient dismissal
9	Support efficient correction
10	Scope services when in doubt
11	Make clear why the system did what it did
12	Remember recent interactions
13	Learn from user behaviour
14	Update and adapt cautiously
15	Encourage granular feedback
16	Conver the consequences of user actions
17	Provide global controls
18	Notify users about changes

Table 8. AI Design Guidelines from Amershi et al. (2019).

the families. Bo mimics the shape and behaviour of a playful ball (Figure 57); it was created to let family members associate the ball shape with physical activity as a game or as a sport due to the varied meanings of the term physical activity.

The 'agentic' ideation was done considering each sub-module and functions defined. Figure 58 provides an example for the submodule 'Training'. The complete ideation can be found in Appendix W.

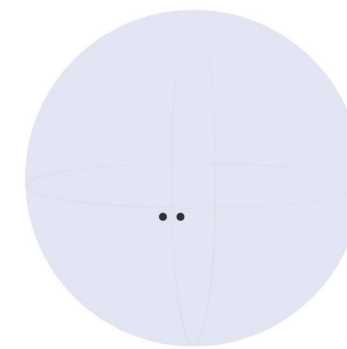


Figure 57. Bo - The envisioned agent to interact with the family.

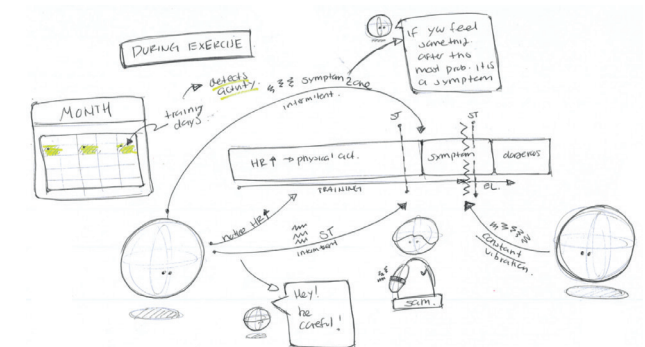


Figure 58. Ideation of Training considering the Agentic tech.

### Summing-up

Chapter 6 merged the co-creation ideas, design vision, AI technology and the researcher's creativity to bring to life the first PSS concept to promote physical activity in children with Congenital Heart Defects. The ideation process involved several rounds of iteration to build upon the stakeholder's ideas, and concluded with a robust PSS network conformed of submodules and functions. Chapter 7 present the concept in detail.

#### Takeaways from this chapter

- Discussion topics for the envisioned PSS were based on the co-creation session concepts and the idea-features inside each of them.
- The following steps of the ideation process defined which actors should be present on each discussion topic and the characteristics of the interaction.
- The envisioned PSS structure resulted in three information levels based on the involvement of each stakeholder when making health-related decisions.
- Conversational agents (chatbots) powered by NLP in combination with Agentic AI Technology provided an attractive alternative for reducing the physician's workload and provide a personalised interpretation of concerns shared.
- Results of ideation with AI agentic technology and chatbots created 'Bo', an AI conversational agent, created to represent the system in close interaction with the family.

## Chapter 7

# Product-Service- System Final proposal

Chapter 7 aims to introduce the final PSS proposal - Bo, an intelligent network agent to promote physical activity in children with CHD. The chapter first provides a general overview of the design process followed up to this point. Afterwards, it describes the aim, approach, devices involved, overall structure and service phases. Based on the service envisioned, the following sections provide a detailed description of each PSS function and a storyboard that integrates them to understand the primary interaction with Bo when parents have concerns during physical activity participation.

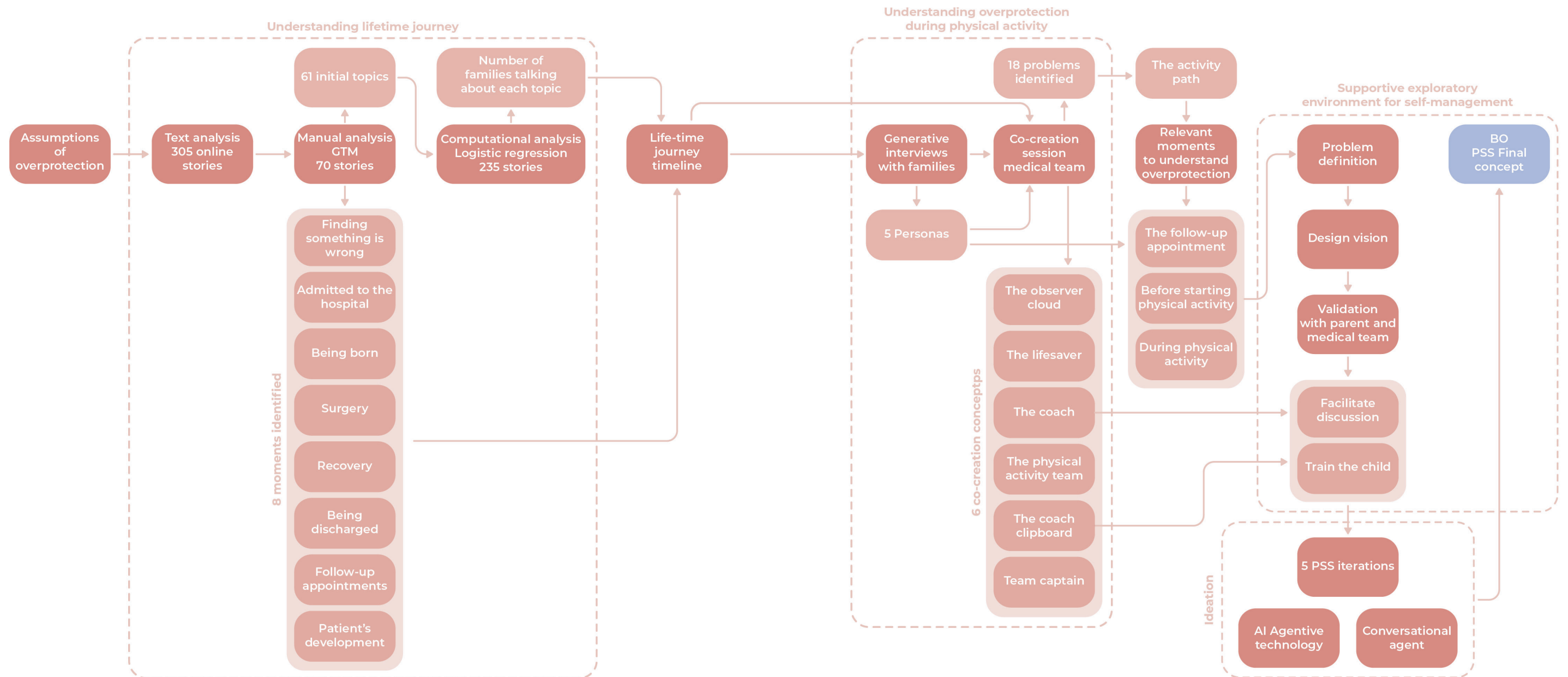
# Product-Service-System Final proposal

## 7.1 Background

The concept proposed in the following section is the result of the integration of insights from the various activities performed throughout the master thesis explained in past chapters.

The following figure provides a simplified overview of the design process followed until the final PSS proposal.

Figure 59. Simplified overview of the design process.





## 7.2 PSS overview

The envisioned Product-Service-System was built around the idea of a smart communication network that brings data from different contexts (inside and outside the hospital, objective and subjective) and stakeholders together at the right time to provide a better overview of the child's health to the family members and medical team (Figure 60).

The present PSS is composed by an application hosting a conversational agent called 'Bo' to interact with the family members, an activity tracker to measure the child's Heart Rate and a desktop version of the application for communicating with the medical team (Figure 61).

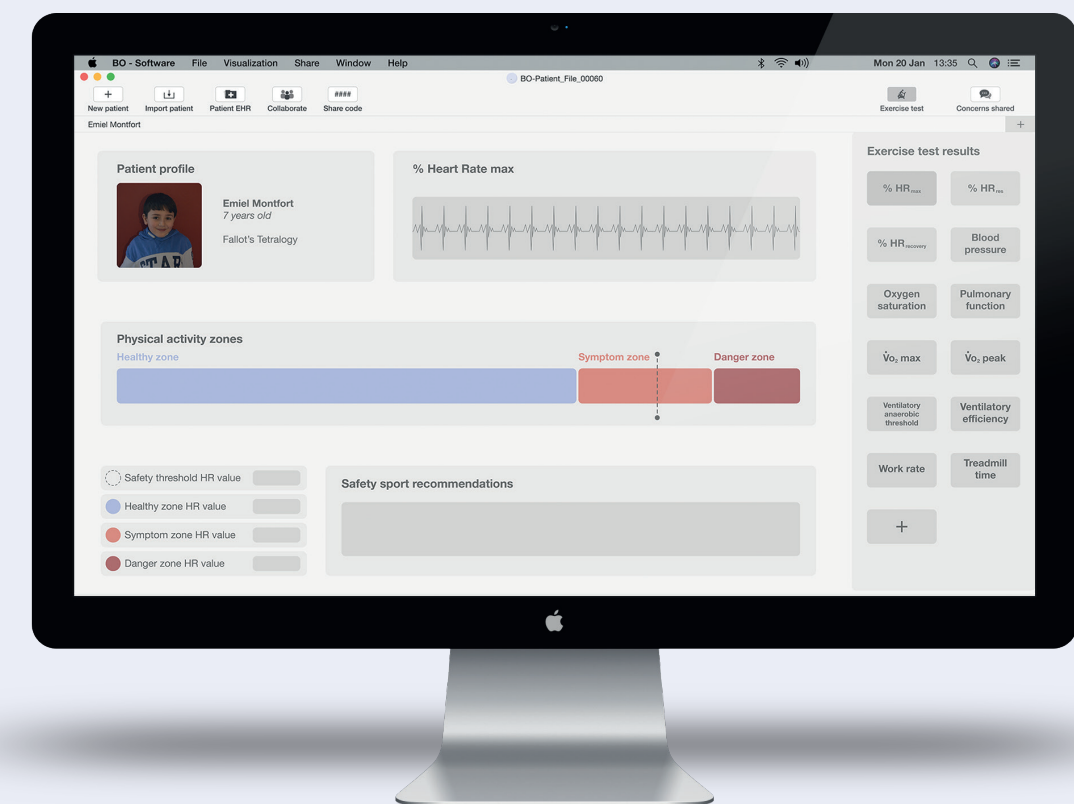
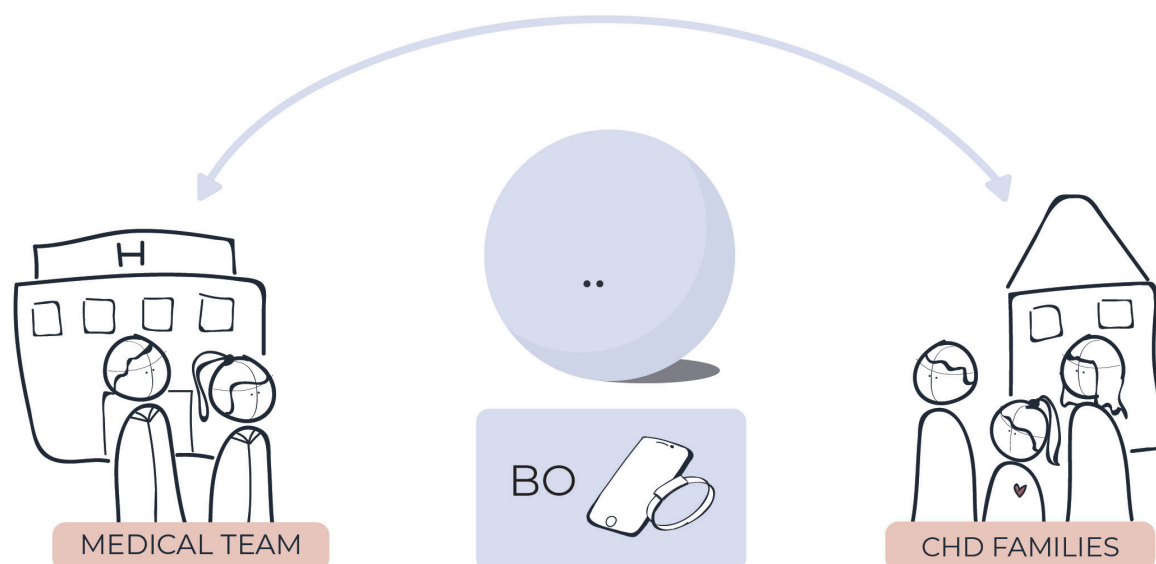
The data shared inside the system is gathered from medical tests (e.g. exercise tests) and the daily life setting of the family with the use of sensors and APP. This overall patient-data is shared between different medical specialities and specialities external to the medical field (e.g. coach) who are in contact with the patient outside the hospital environment.

The chapter will introduce the main sub-modules and the functions of the PSS with their corresponding purpose and structure.

Figure 61. Overview of the devices used in the PSS.



Figure 60. Product-Service-System overview.



### 7.3 PSS structure

The final structure of the PSS consists of four modules representing the main pillars of the design vision and its core meaning. The modules break down into nine sub-modules, and each submodule is composed of a variety of functions. The following image presents the overall structure.

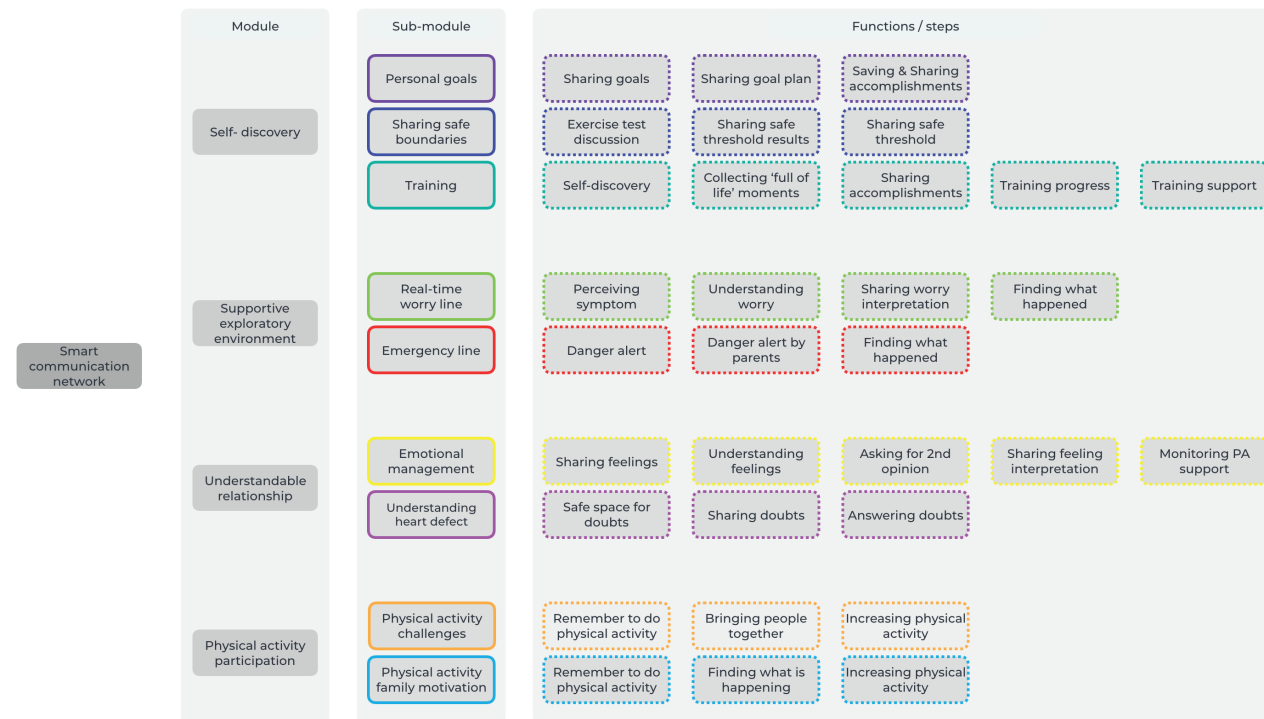


Figure 62. Complete overview structure of the PSS.

### 7.4 PSS service phases

#### 1. Entry point

The service starts when the child begins to be interested in joining sports, different physical

activities or ask for more independence while playing. In order to assess how safe it is for the child to practice sports, usually a meeting to do a Cardiopulmonary Exercise Test (CPET) is scheduled. When the results of the CPET are ready, the system starts.

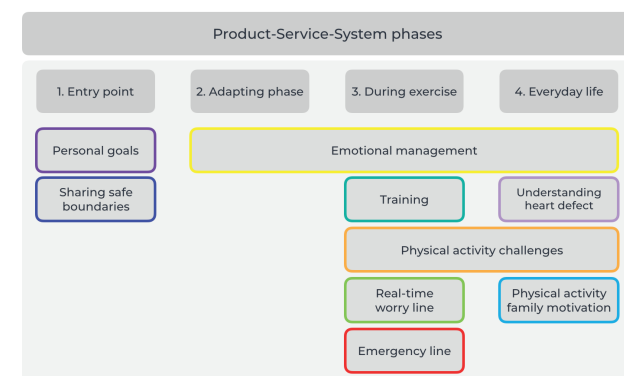


Figure 63. Envisioned usage of the sub-modules as a service.

prepare for medical appointments), it also requires access to the parent's calendar.

#### 2. Adapting phase

Since seeing the child going to the symptom zone produces anxiety in parents, it was decided to provide a focused adaptation phase for emotional management for the family members. This phase will decrease in the frequency of interactions according to the feedback from the psychologist.

#### 3. During exercise

The most significant support that the PSS can provide is during physical activity. During this phase, the child can enjoy the training benefits to explore the safety threshold, and the parent can alleviate the concerns evoked by not having a clear understanding of when a symptom is a dangerous symptom. Moreover, it provides a fast connection to people around the child in case physical activity triggers a life-threatening situation.

#### 4. Everyday life

The system provides a space for sharing doubts related to not only physical activity but the Congenital Heart Defect to support the child and parents in their everyday life concerns. Moreover, it encourages physical activity from the two closest human relationships during childhood, family and friends. Some of the encouragement interaction will happen while the parents and child are active.

### 7.5 Sub-modules of the PSS

The following section of the document provides an explanation of the sub-module structure and the stakeholders involved. In Appendix Y, the individual visualization of each function can be found in combination with the envisioned interactions (arrows) for each function. The transparency of the colours aims to indicate how often each stakeholder and device interact in the overall sub-module.

Moreover, the drawings shown will describe how the interaction is envisioned.

### Personal goals (PG)

#### Goal

Enhance the positive side of physical activity by providing an adaptable connection line between the child's physical activity goals and a plan according to his health condition to reach them.

#### Description

When the child wants to achieve something related to PA, and the follow-up appointment is not soon, the child will be able to contact the medical team. This connection will enable him to let them know his/her ambitions, so the specialist can review the idea, ask for more details if needed and give suggestions if applicable. Once relevant events or achievements related to the goal are detected, the family will be able to save and share them with the medical team or other family members.

#### Functions

- Sharing goals

In case the CHD patient wants to do a sport that was not mentioned during one of the previous appointments, the child types or sends by a voice note message his or her ideas to practise a sport. The system will share the wish with parents as a notification and will share it with the sports doctor in the desktop version of Bo's interface. In case the sports doctor sees an objection to the envisioned sport, the details can be forwarded with the sports

doctor's comments to the Paediatric cardiologist for further evaluation and schedule an appointment.

- Sharing goal plan

Once the sports doctor decides on further recommendation or only approving the new ambition, the doctor will reply to the request. The request then will be sent to the child and the parents so everyone knows that it is secure to pursue the envisioned sport. Moreover, every time a new relationship between CHD type and sports is made, Bo's NLP brain will be trained continuously to give suggestions in the future.

- Saving and sharing accomplishments

Bo is continuously monitoring the child's activity levels, and looking for keywords related to significant PA events for the child in the parent's calendar such as "soccer game". When Bo detects a relevant PA event in the child's life, either by the EM sub-module or parent's calendar, it will send a notification asking how the event went, and if the child would like to save and share his accomplishment. If the child decides to share it, Bo will send the achievement to parents. These accomplishments would be little trophies saved in the goal's profile of the child, and if needed, the parent will be able to add accomplishments as well.

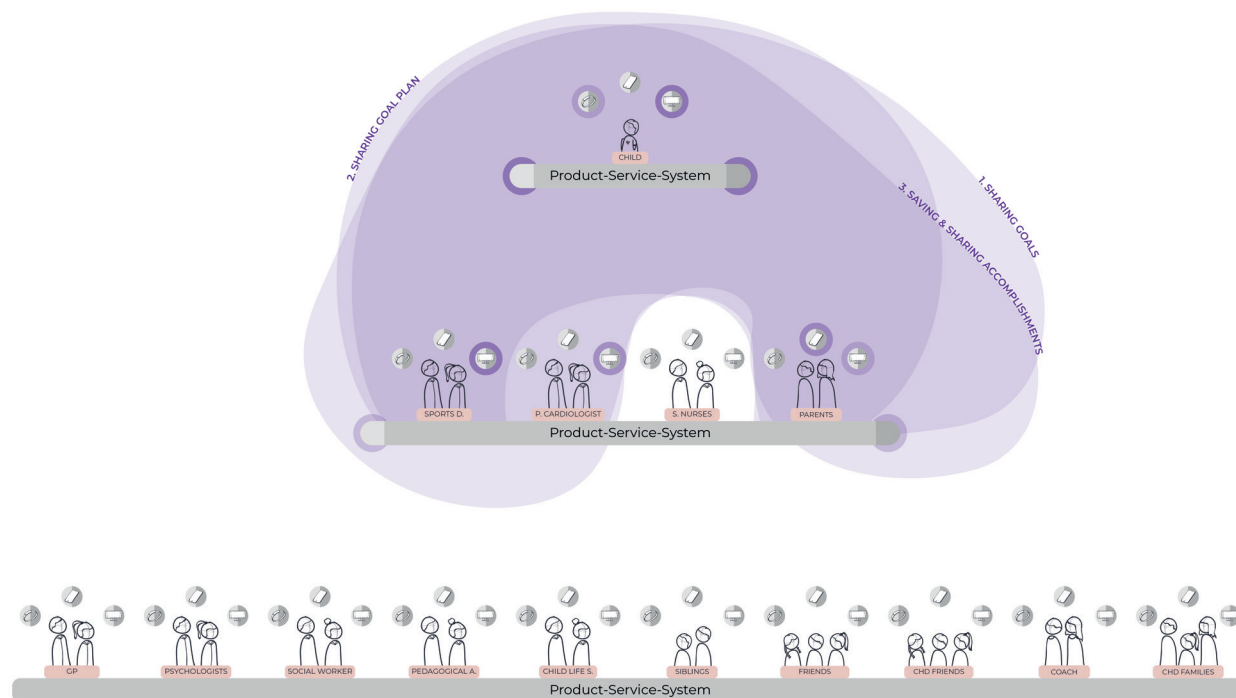
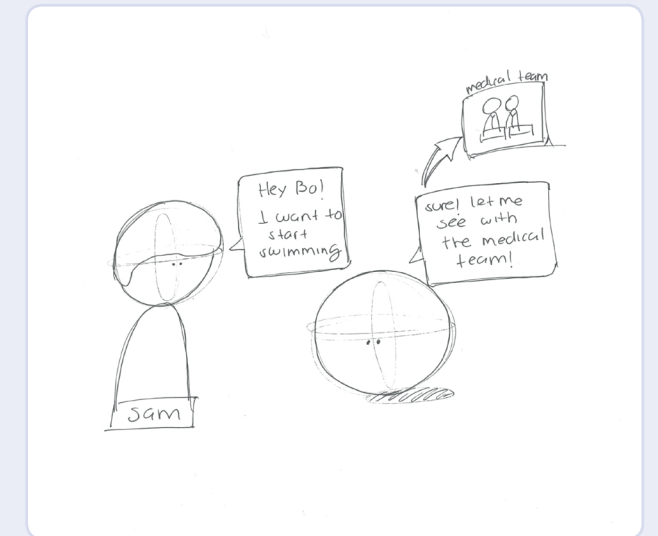


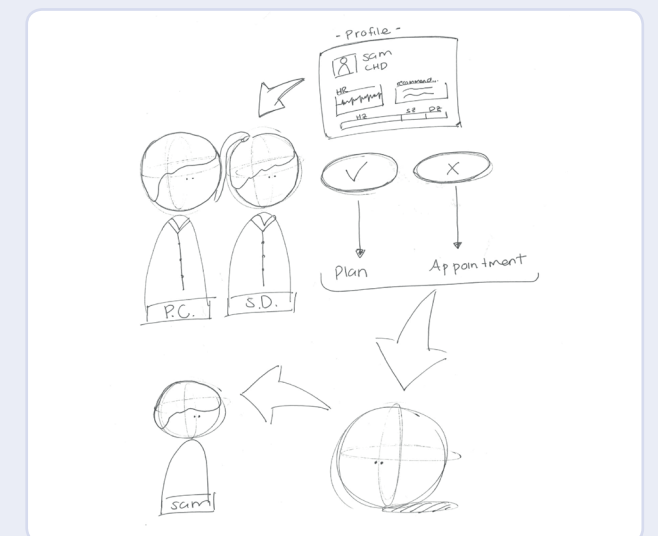
Figure 64. Sub-module personal goals.

Figure 65. Personal goals storyboard.

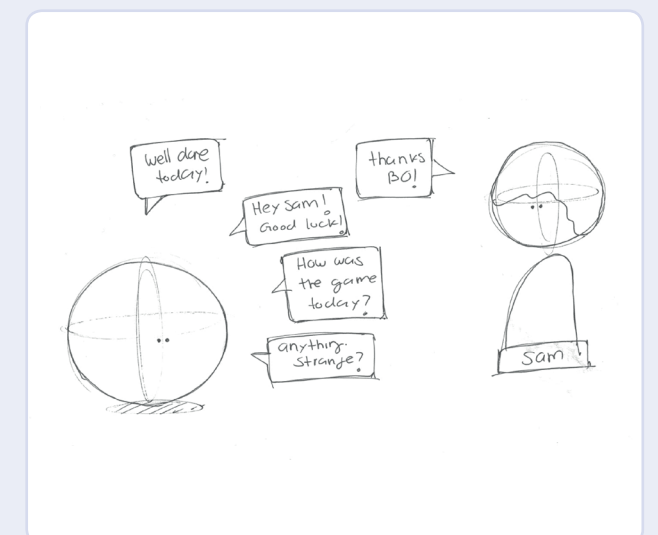
### 1. Sharing goals



### 2. Sharing goal plan



### 3. Saving and sharing accomplishments





### Sharing Safe Boundaries (SB)

#### Goal

Enable an objective interpretation of healthy boundaries and recommendations to family and other stakeholders.

#### Description

When an objective interpretation of the healthy boundaries is required by the family or other stakeholders, the safe threshold of Heart Rate provided by exercise test can be shared if child and parents agree.

#### Functions

- Exercise test discussion with HIX program  
The pediatric cardiologist assesses the CPET results considering the child's age, weight and height in comparison to a standard threshold for healthy children and consults with Sports doctor if necessary. Once the assessment is done, an appointment by telephone or in person is scheduled with the family to share the Safety Threshold results.
- Sharing Safe Threshold results  
Sharing results can be done through phone or an appointment, depending on the outcomes of the test. In case the results are shared in person, the following paragraph will illustrate the envisioned interaction.

Before appointment: since Bo has access to the parent's calendar, he can see if there is an outpatient clinic appointment. Therefore, Bo asks two days before the meeting to parents if they have doubts that they want to share and save to as later. Later, one day before the appointment, Bo send the same question to the CHD patient in case the child also wants to ask something.

Almost at the appointment: ten minutes before the meeting Bo will ask parents if the microphone can be turned on to "hear" the meeting and record the meaning of relevant topics such as identification of concerns, sports recommendations, safe recommendations and child wishes. Lastly, the physician sends a summary of possible symptoms and safe threshold (HR) to the family and shares a patient code that could be used to access the information later in Bo's APP.

- Sharing boundaries  
When the child starts practising a new sport, the system will ask parents and child if they want to share the given summary with the coach. Parent and child need to agree in order to send the information.

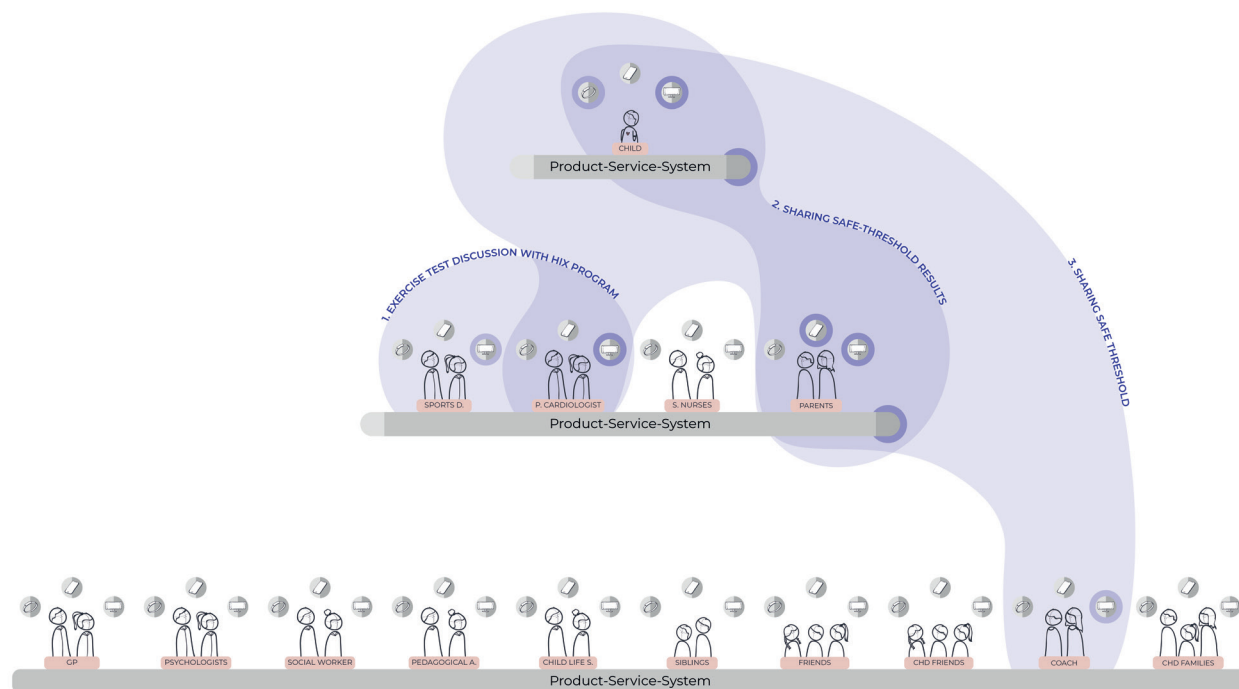
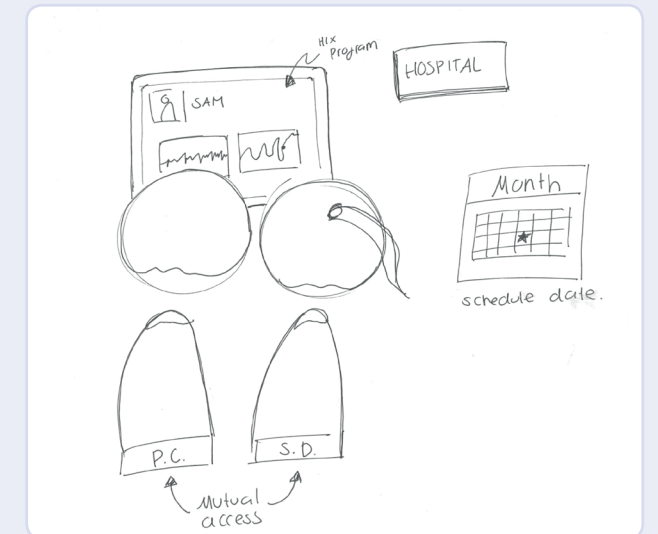


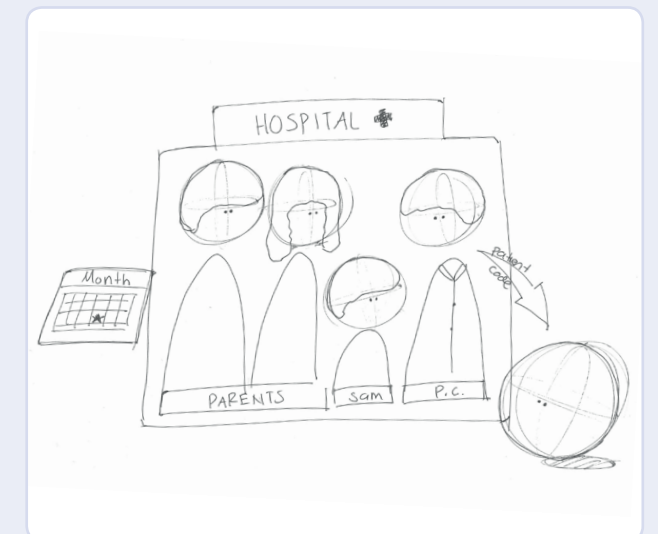
Figure 66. Sub-module sharing safe boundaries.

Figure 67. Sharing boundaries storyboard.

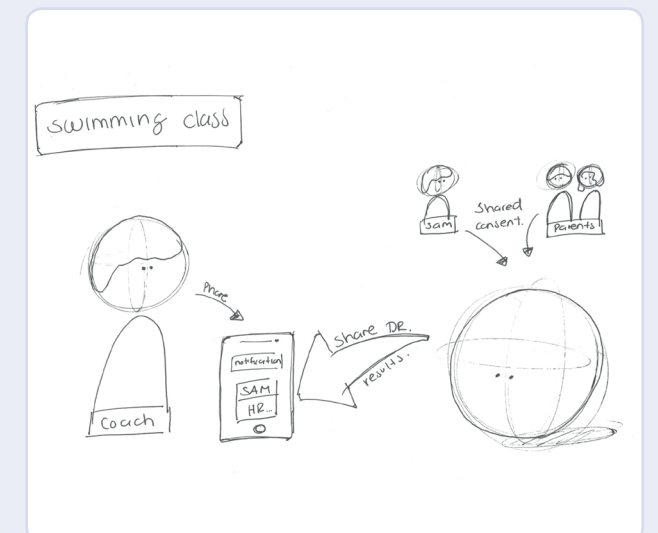
### 1. Exercise test discussion with HIX program



### 2. Sharing Safe Threshold results



### 3. Sharing boundaries



### Emotional management (EM)

#### Goal

Support the child and parents to cope with their feelings during the process of self-discovery of safe boundaries.

#### Description

During the discovery of the child's safe boundaries, children and parents can express their feelings towards the process and receive support from a psychologist or social worker through Bo, the communication platform. Moreover, the system will be monitoring the feel of both family members weekly. If there are signs of alarm (e.g. not filling the evaluation, sadness), a psychologist or social worker will be notified to intervene.

#### Functions

##### • Sharing feelings

Each week Bo will summarize physical activity levels, compare it with the sentiment of the messages sent to the medical team, and use the information to ask parents and child if they have 'PA stories' to share through audio or text. Bo will conduct an NLP sentiment analysis to know the sentiment of the information shared.

##### • Understanding feelings

Based on the sentiment analysis, if the negative sentiment level found is above a specific limit

(imposed by the psychologist), the psychologist and social worker will be reached to analyse the stories shared among the family members.

##### • Asking for 2nd opinion

In case of doubts regarding biological data related to emotional factors, the psychologist will be able to exchange information with other specialities such as the nurse specialist, to solve doubts and deliver a holistic perspective on families concerns.

##### • Sharing feeling interpretation

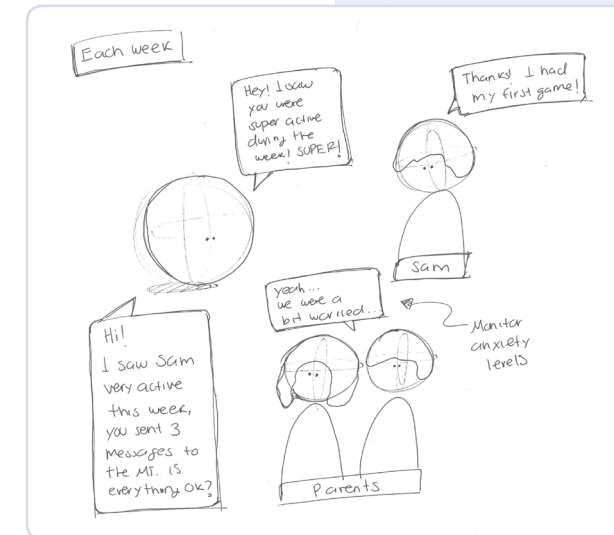
Once the psychologist or social worker know what will be the next steps after analysing the concerns and feelings of the family members, they will contact the child or parent to offer online support with exercises or schedule an appointment.

##### • Monitoring physical activity support

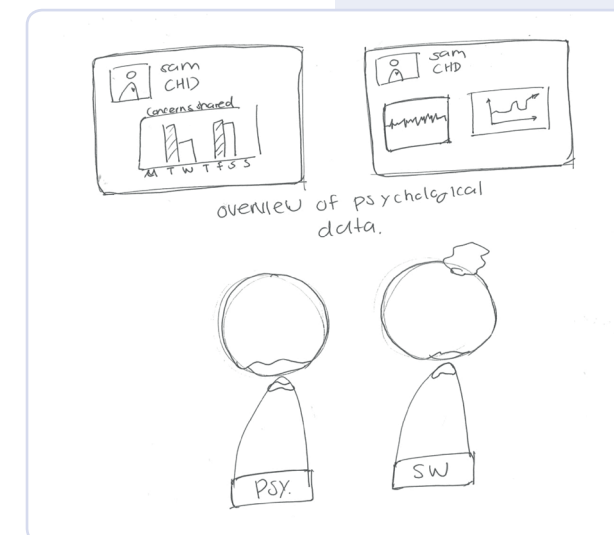
Since the format of the PA stories rely on what the child and parent want to share, some aspects of physical activity support might not be evaluated within the weekly tasks. Therefore, the questionnaire 'Social Support for exercise behaviours' from Sallis et al. (1987) will be sent monthly to CHD patient to monitor the support perceived from family and friends regarding physical activity. The results will be sent monthly to the psychologist, and if Bo detects low levels on the metrics, it will provide an alert to the psychologist so they can address the problem.

Figure 69. Emotional management storyboard.

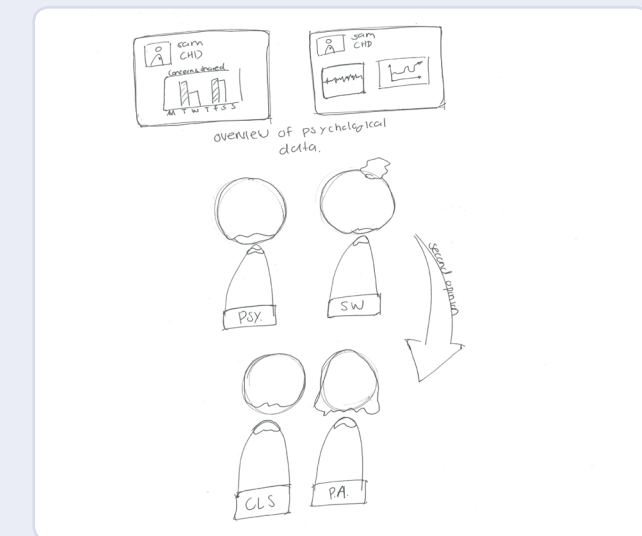
#### 1. Sharing feelings



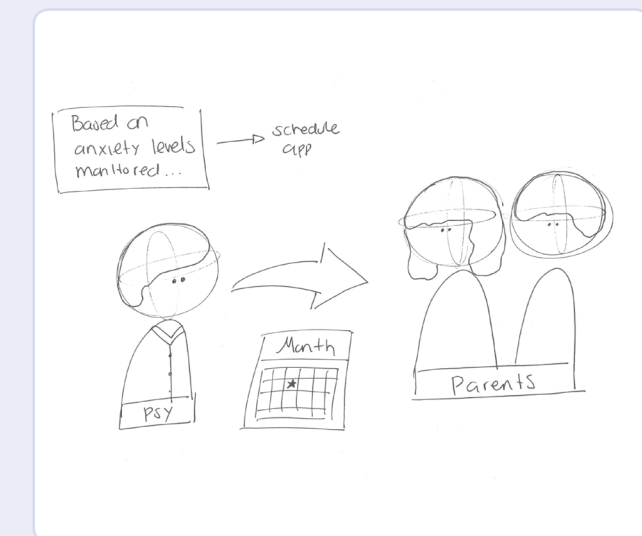
#### 2. Understanding feelings



#### 3. Asking for 2nd opinion



#### 4. Sharing feeling interpretation



#### 5. Monitoring physical activity support

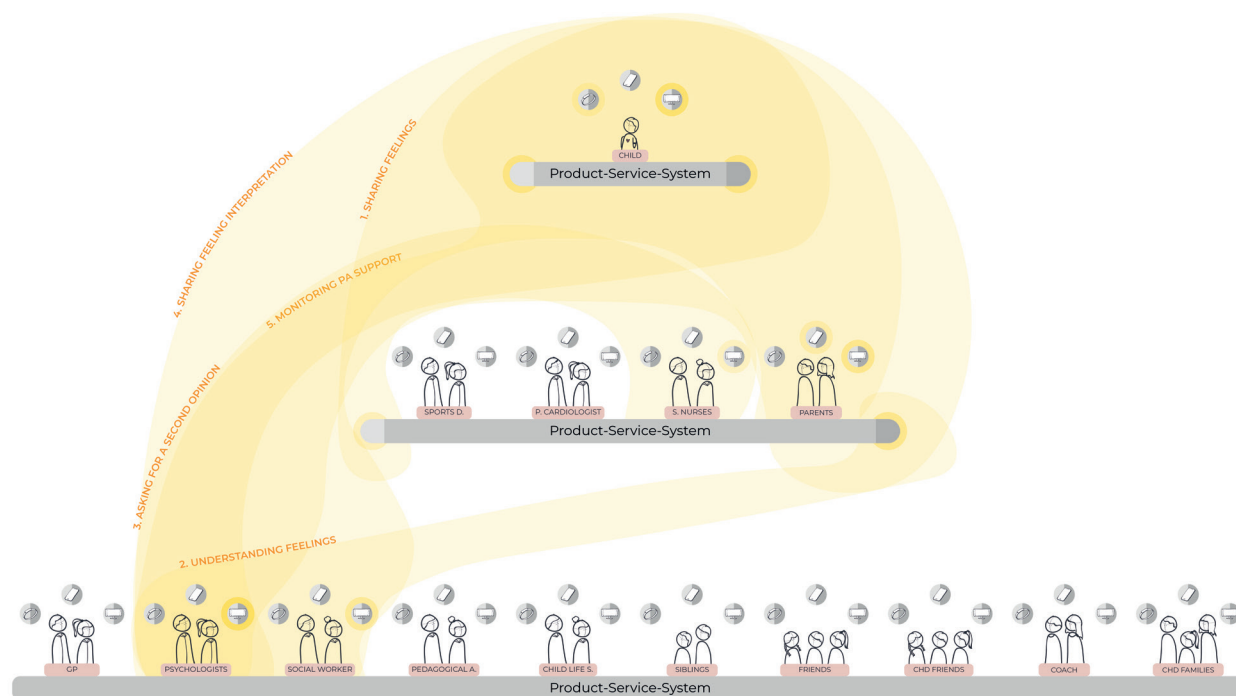


Figure 68. Sub-module emotional management.



## Training (T)

### Goal

Support the child in the self-discovery of healthy boundaries while doing physical activity.

### Description

When the child enters the Self-training zone (safety threshold-symptom zone), the activity tracker provides cues to inform different zones. After each training milestone reached, they can be shared with family and specialists team through an online communication interface. If the system detects that support is needed during training, the specialist team can provide guidance using the communication interface.

### Functions

#### • Self-discovery

The activity tracker is always sending HR data to the system. When the child reaches the Safety Threshold, the activity tracker vibrates to notify the child. Once the child enters a different zone, the device vibrates for a longer period and displays in the screen the symbol of the zone, so the child is aware that if he feels sick, it is a symptom. Moreover, after one hour of being finished with PA, the child will be asked to share briefly if a symptom was perceived during PA participation. Furthermore, the PA path could be reviewed during outpatient clinic appointments and adjusted by the physician, depending on the patient's health condition.

#### • Collecting 'full of life' moments

During the Self-discovery step, parents might feel anxious. Therefore, the task for them is to take pictures or video of the moments they value the most while their child is participating in PA.

#### • Sharing accomplishments

After five consecutive PA stops inside the ST, the system will congratulate the child and also will let the parents know how the child's training is going. These accomplishments would be little trophies saved in the goal's profile of the child, and if needed, the parent will be able to add accomplishments as well.

#### • Training progress

During the weekly training progress, Bo will provide an overview of the activity levels of the child according to the PA path to the child, parents and if necessary, the coach to see if some aspects of PA could be improved. Besides, it will display the symptoms gathered by parent and child and possible trends related to the HR concerning symptoms.

#### • Training support

If support is needed concerning the insights visualized in the training progress, or if the training is not going well, a copy of the information from that week including the recent HR reading will be shared with the pediatric cardiologist for further exploration.

Figure 71. Training storyboard.

1. Self-discovery



2. Collecting 'full of life' moments



3. Sharing accomplishments



4. Training progress



5. Training support

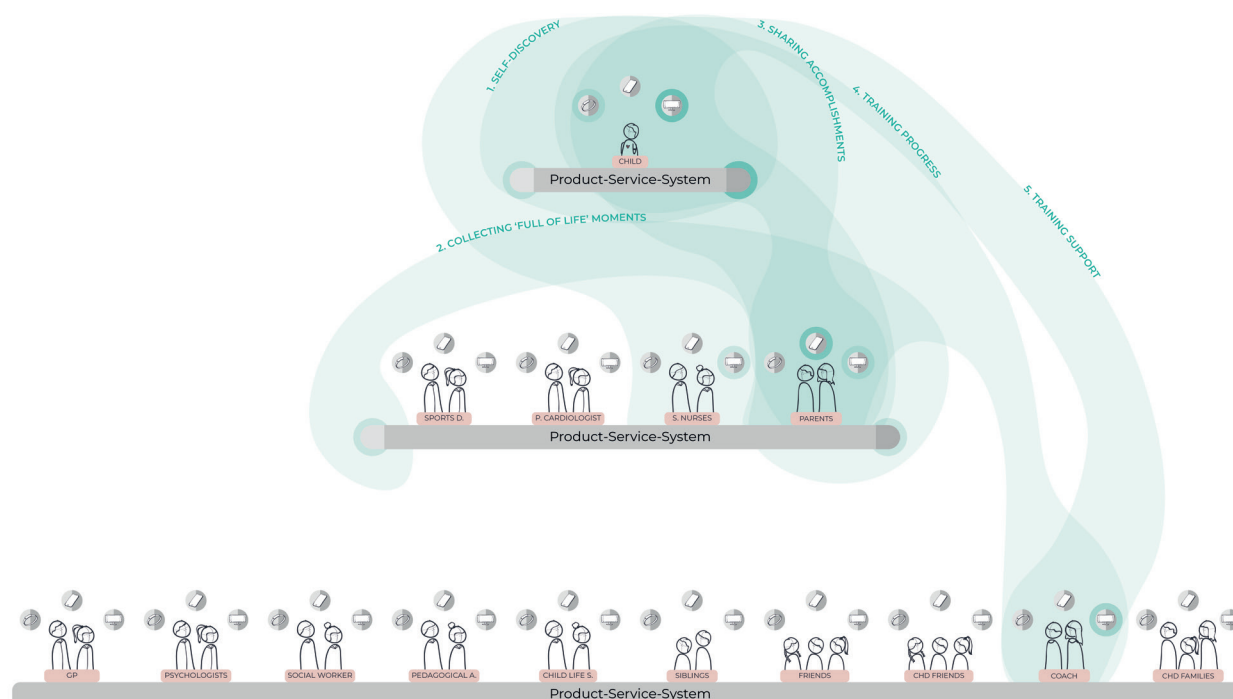


Figure 70. Sub-module training.



### Real-time worry line (RTWL)

#### Goal

Support the parents in the self-management of worries related to symptom perception while the child participates in physical activity.

#### Description

When the child is participating in physical activity, parents have the option to have a real-time connection with the medical team to ask their concerns and interpretation about the perceived symptoms through the communication interface.

#### Functions

- Perceiving symptom

Parents could be informed about perceived symptoms by the CHD patient, coach or themselves. When the parent sends a worry to the system, Bo will reply with the activity path showing in which zone is the child based on data collected with the activity tracker. Therefore, the system will indicate that the “possible” symptoms registered most probably are not dangerous. If the parent still decides to send the worry, or if the child is close to the danger zone, Bo will ask more details such as activity type, indoors/ outdoors and to specify symptom to send the concern.

- Finding what happened

Each time the parent sends a concern to the medical

team, the child will be required to fill in a brief survey about perceived symptoms to contextualize the worry and triangulate the information. The symptom keywords extracted from the concern sent will be used on the survey as possible answers to corroborate information.

- Understanding worry

The system will provide the nurse specialist with a range of the HR measurement at the moment of the perceived symptom and the information mentioned above. If the nurse is not sure of the answer, the system will offer to contact a paediatric cardiologist to solve the doubt. Moreover, Bo’s NLP brain will associate the symptom keywords (e.g. blue lips) of the worry described to specific HR measurements to try to find patterns on symptoms.

- Sharing worry interpretation

The medical team will have three working days to provide an answer to the concern. The nurse will answer directly to the parent, and the parent will be in charge of distributing the knowledge to third parties (e.g. coach, child) in the case is needed.

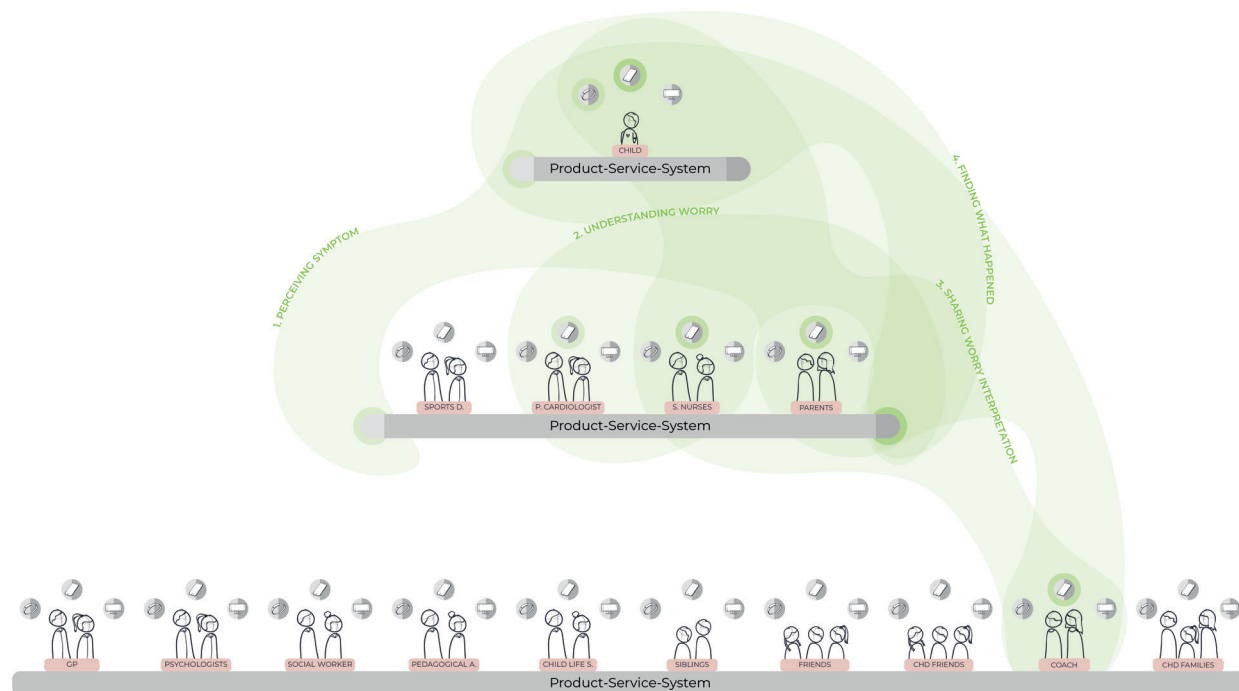


Figure 72. Sub-module real-time worry line.

Figure 73. Real-time worry line storyboard.

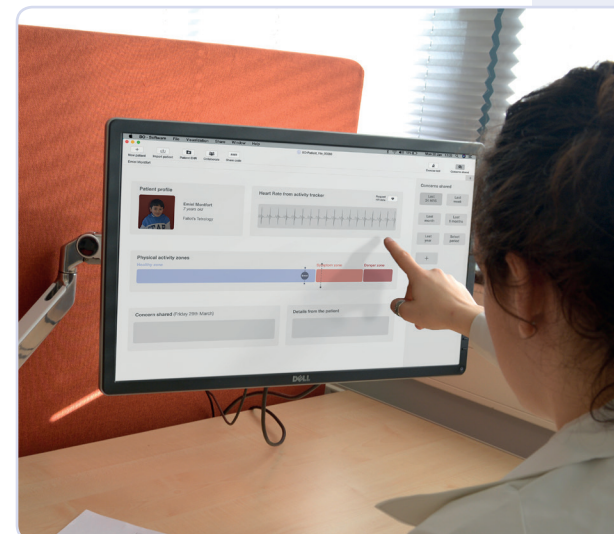
1. Perceiving symptom



2. Finding what happened



3. Understanding worry



4. Sharing worry interpretation



### Emergency line (EL)

**Goal**

Provide an alarm to the child and others around before the child reaches the danger zone to provide assistance.

**Description**

When the child goes beyond the safety threshold, the system alerts emergency contacts and child to stop the activity through a communication interface and vibrations by the activity tracker. When the emergency finishes, the system tries to gather information about the occurrence by asking parents to provide information so the system can identify patterns later.

**Functions**

• Danger alert

When the child is participating in physical activity, and the safety threshold is surpassed, the activity tracker will start vibrating until the child stops the activity. Moreover, Bo will send an alert message to the parents, coach, and other friends and family that are enlisted in the 'emergency list'.

• Danger alert by parents

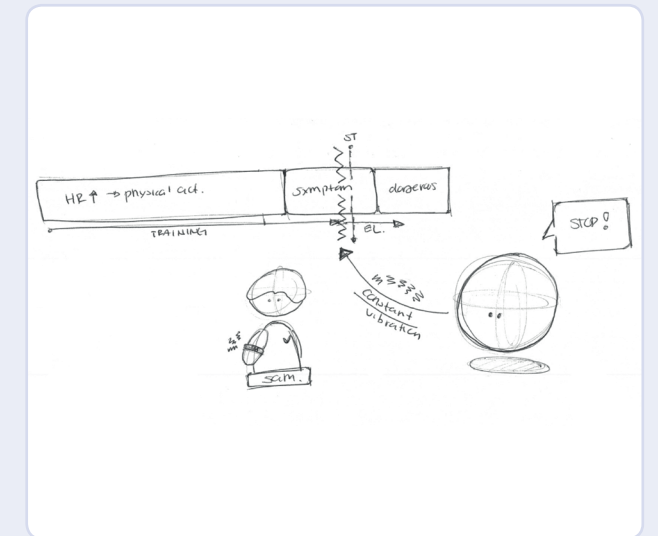
Once the alert arrives at the parent's phone, they have the option to send another alert to the emergency list, call the coach or call directly to the hospital.

• Finding what happened

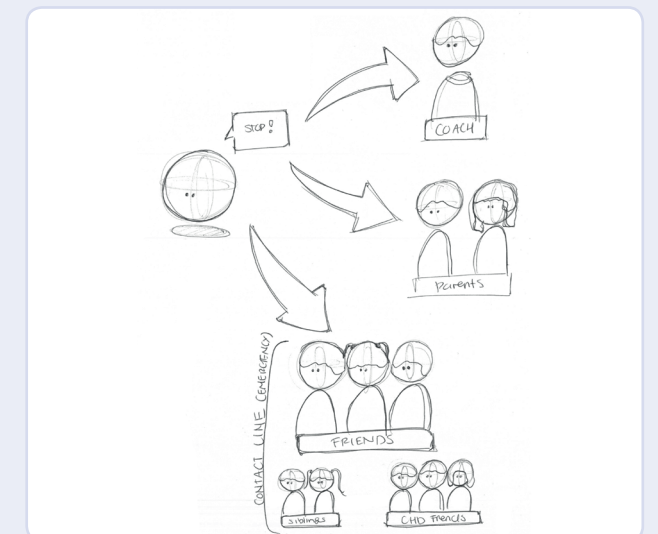
One hour after the incident, the system will send a notification to parent and child asking to describe the activity, and the symptoms briefly. The information provided by the child will be sent to the parent for reviewing it, and then the parent will be able to send the overview to the medical team.

Figure 75. Emergency line storyboard.

1. Danger alert



2. Danger alert by parents



3. Finding what happened

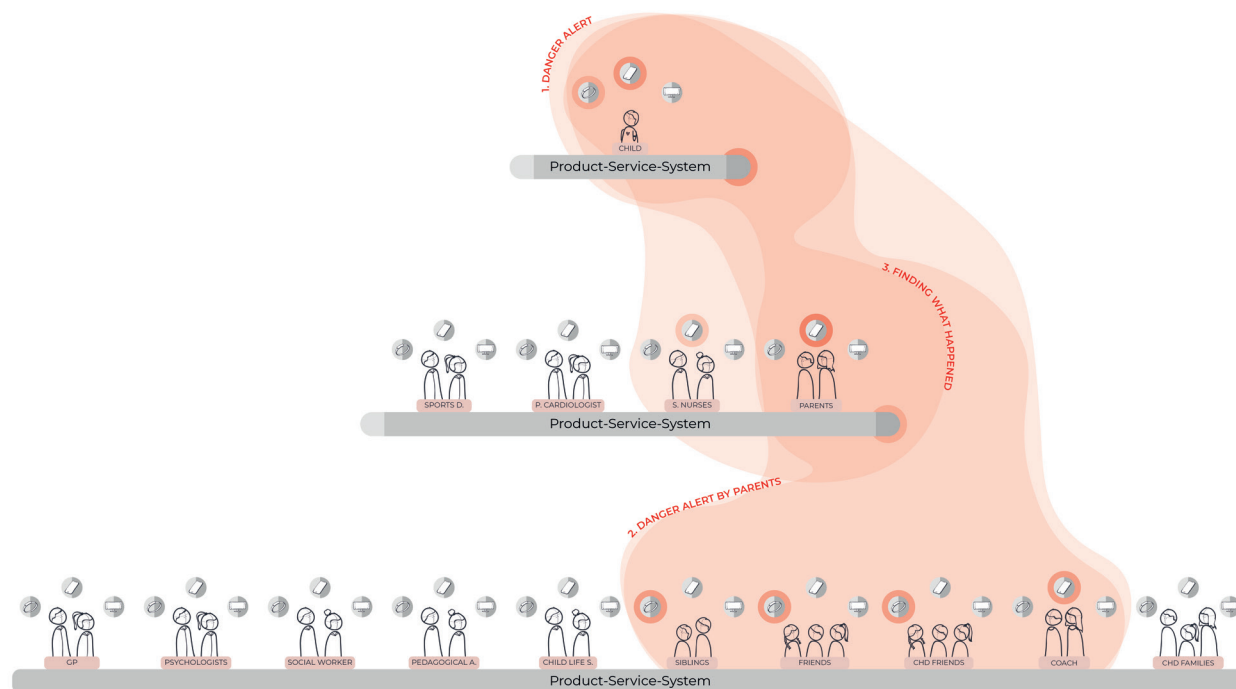
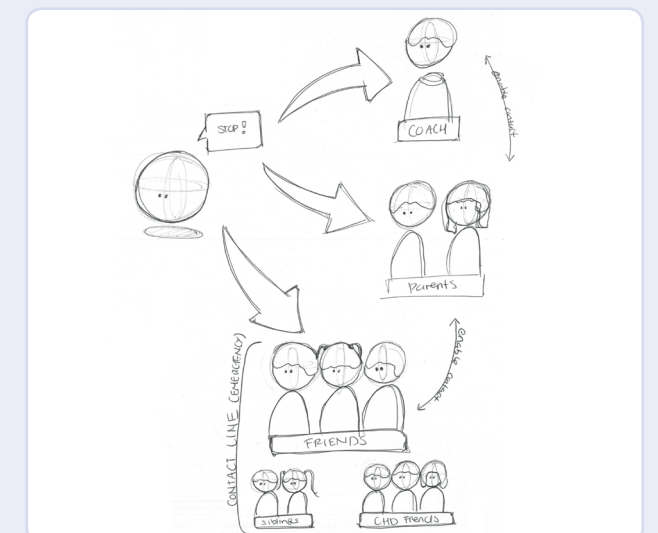


Figure 74. Sub-module emergency line.



### Understanding heart defect - (UHD)

#### Goal

Provide a flexible connection space between the medical team and family members where they can understand the health condition better in an everyday life setting.

#### Description

When parents or children have doubts that are not urgent (life-threatening), they can write their concerns in the conversation with Bo, and find answers in questions that previous families already asked as a first instance. If there is a match between a new question and existing answer, both families will have the possibility to connect in a safe space where they could further discuss the concern. However, if the answer is not found, the system will enable an option to ask for support from experts to solve their doubts through the same communication interface.

#### Functions

- Safe space for doubts

Every time a parent or the CHD patient have a doubt, family members can share it by typing it or sending a voice message directly to the conversational agent. The keywords of the questions, in combination with the CHD profile of the patient, will lead the search for a possible answer around questions asked by other families with the same CHD profile. If the

system finds a match, it will display the answer previously given (provided by the medical team), and if wanted, give the possibility to reach the other family to talk more about their doubt.

- Sharing doubts

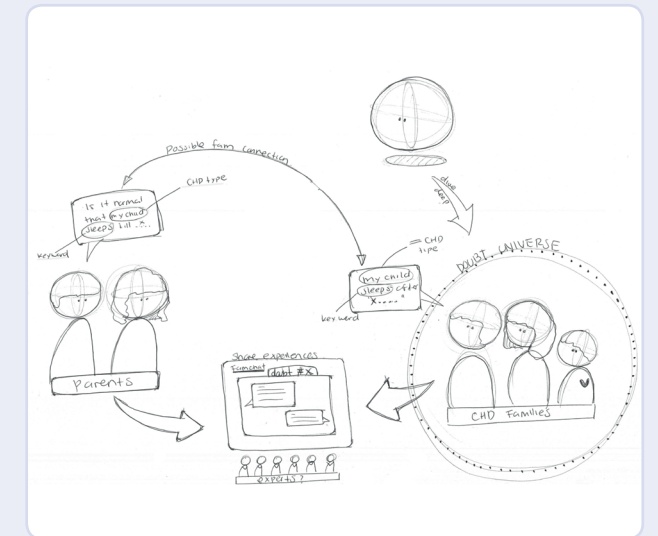
In case the answer to the question is not in the "pool" of questions answered before, Bo will use the same keywords to index the question and send it to the correct medical team member.

- Answering doubts

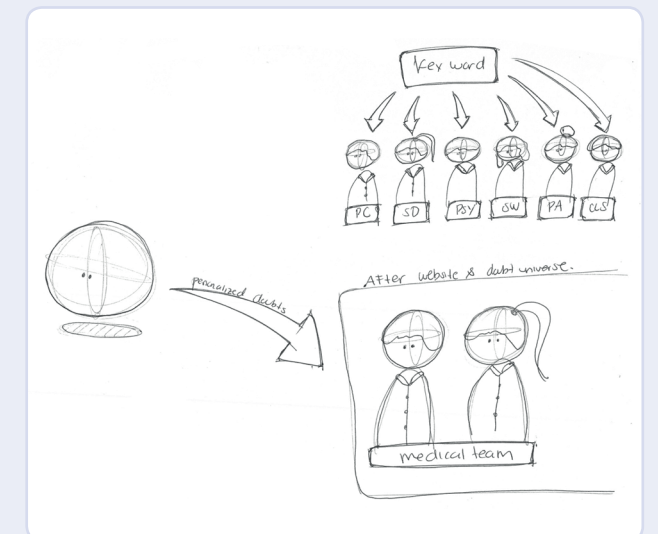
Once the appropriate specialist has the question, they will be able to see the child's profile (CHD characteristics), analyse the question and send the answer through the conversational agent.

Figure 77. Understanding heart defect storyboard.

#### 1. Safe space for doubts



#### 2. Sharing doubts



#### 3. Answering doubts

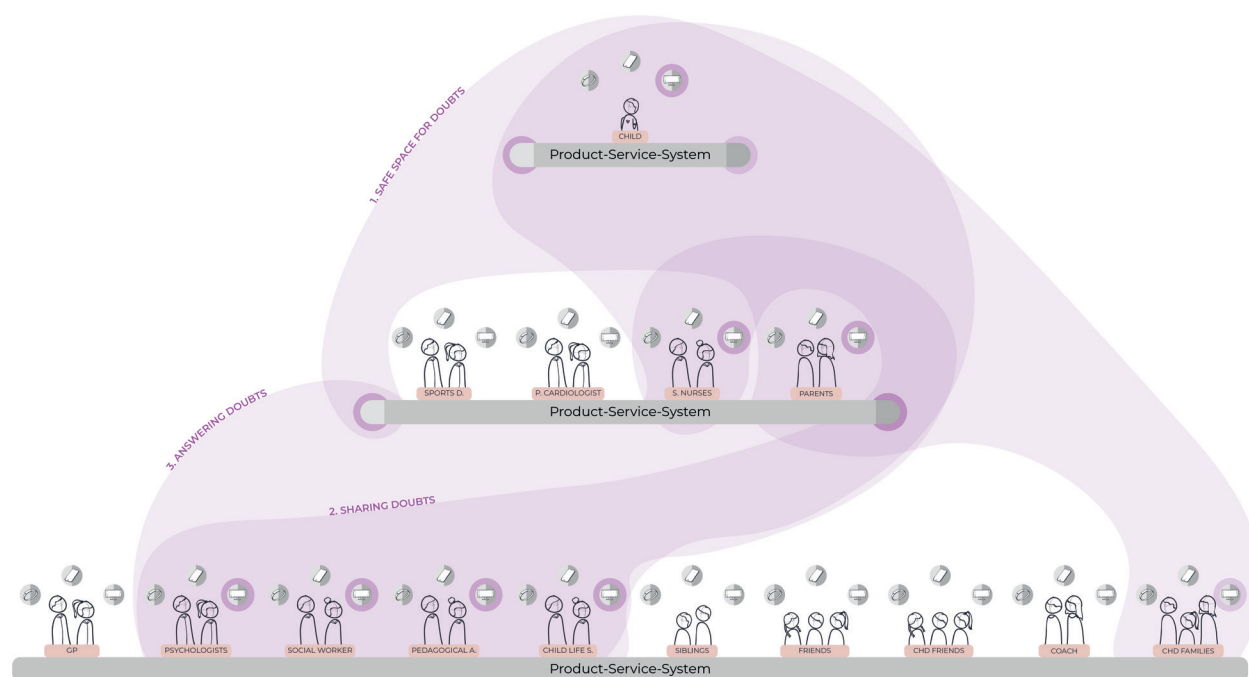
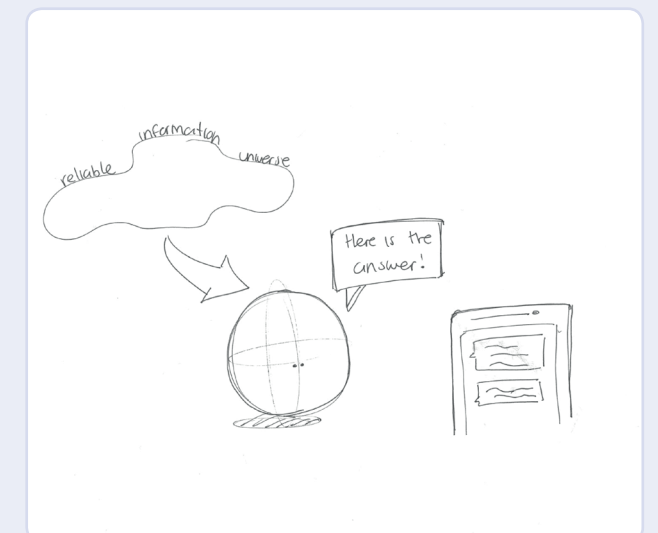


Figure 76. Sub-module understanding heart defect.



### Physical activity challenges (PAC)

#### Goal

Bring together children and other families through fun activities to increase physical activity participation in an everyday life setting.

#### Description

When levels of the child's physical activity are low, the system can detect them based on the active minutes from the activity tracker and suggest to start a group activity with friends and other families through the communication interface.

#### Functions

- Remember to do physical activity

The first reminder will happen when the child does not have the normal activity levels for three consecutive days. Bo will invite parents and siblings to start a group challenge with the child. The only condition to start challenge is to be in groups of two or more since the child might be in a disadvantage being alone against healthy individuals.

- Bringing people together

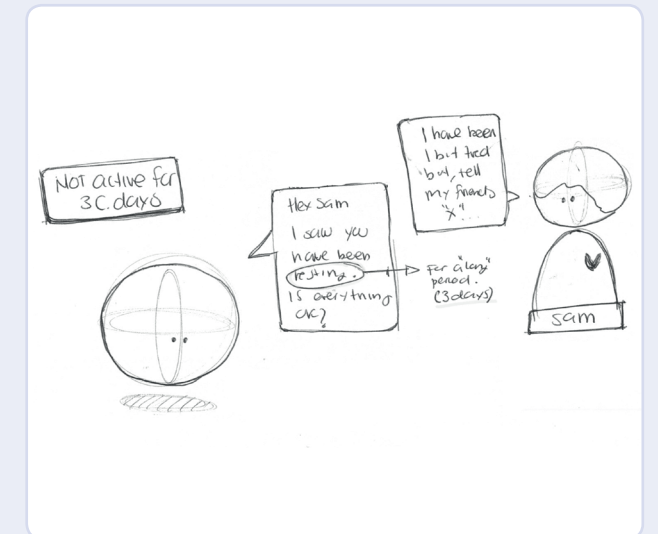
Bo will try to arrange a group game with friends or family by contacting them and adding the participants to a challenge chat. For example, one family against another one to try to gather as much activity as possible.

- Increasing physical activity

Once the connection is settled, members can invite each other to complete new challenges.

Figure 79. Physical activity challenges storyboard.

#### 1. Remember to do physical activity



#### 2. Bringing people together



#### 3. Increasing physical activity

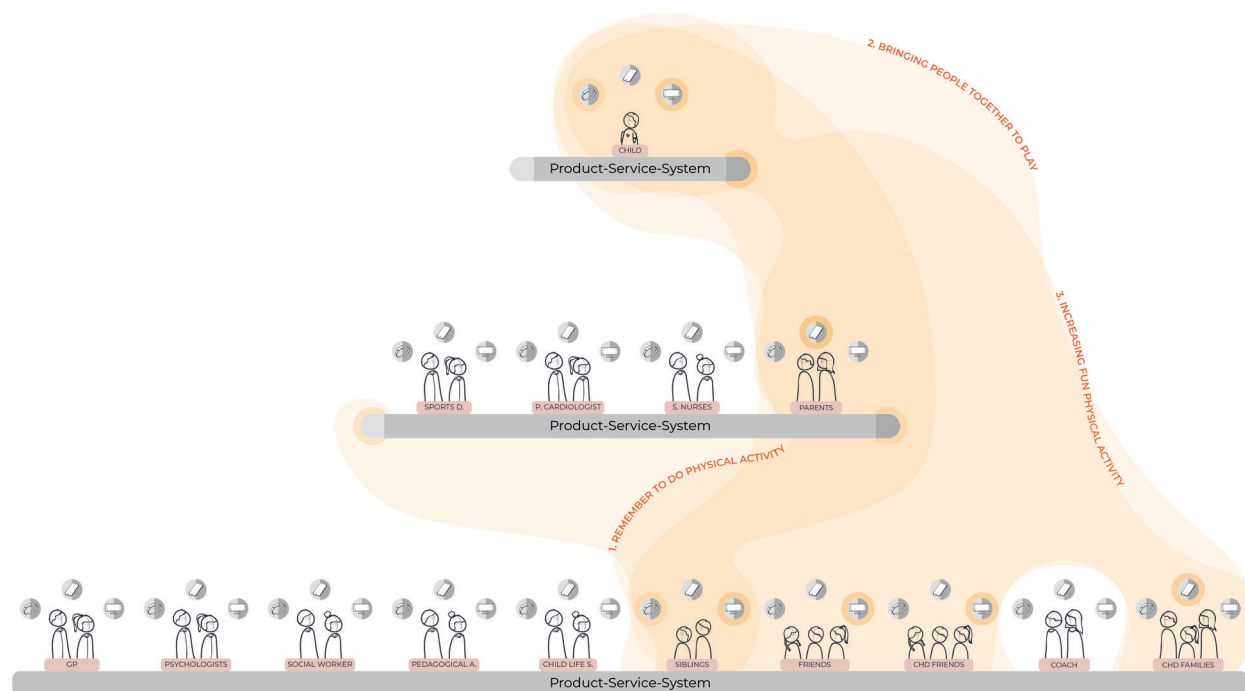
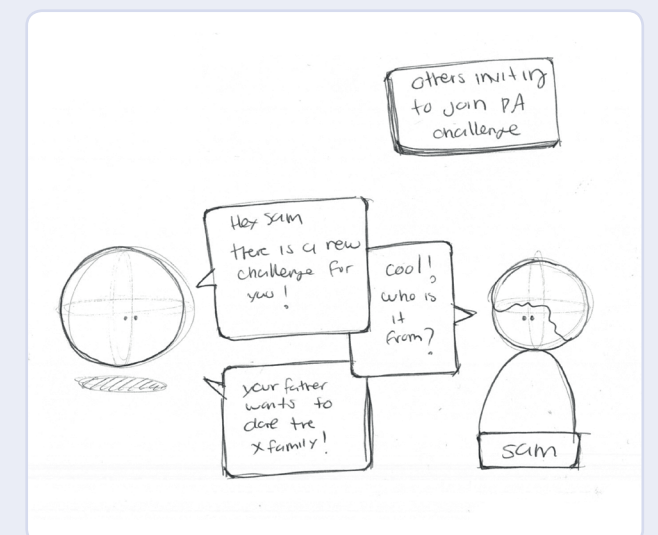


Figure 78. Sub-module physical activity challenges.

### Physical activity family motivation (PAFM)

#### Goal

Support family members to help each other to pursue healthy levels of physical activity in an everyday life setting.

#### Description

When levels of the child's physical activity are low, the system can detect them based on the active minutes from the activity tracker and bring together the family to find out if help is needed, or give a hint to the child, and parents to make something about it. In case of support needed, the system can contact professionals with the use of an online communication interface.

#### Functions

- Remember to do physical activity  
If the above module does not motivate the child to do physical activity, Bo will share the next reminder after one week of detecting inactivity.
- Finding what is happening  
After 1.5 weeks of inactivity, Bo will contact parents to know if the child is doing well and to motivate them to encourage physical activity. After two consecutive weeks of not being active, Bo will recommend parents to contact the social worker or psychologist to look for advice on what to do.

- Encouraging physical activity  
The medical team will analyse the past weeks' emotional management interventions to provide advice on what to do or directly try to address the child only if parents request it. The negative events found by analysing the sentiment of the sentences in the past month will be shared with the team to help them discover what might be the problem.

Figure 81. Physical activity family motivation storyboard.

#### 1. Remember to do physical activity



#### 2. Finding what is happening



#### 3. Encouraging physical activity

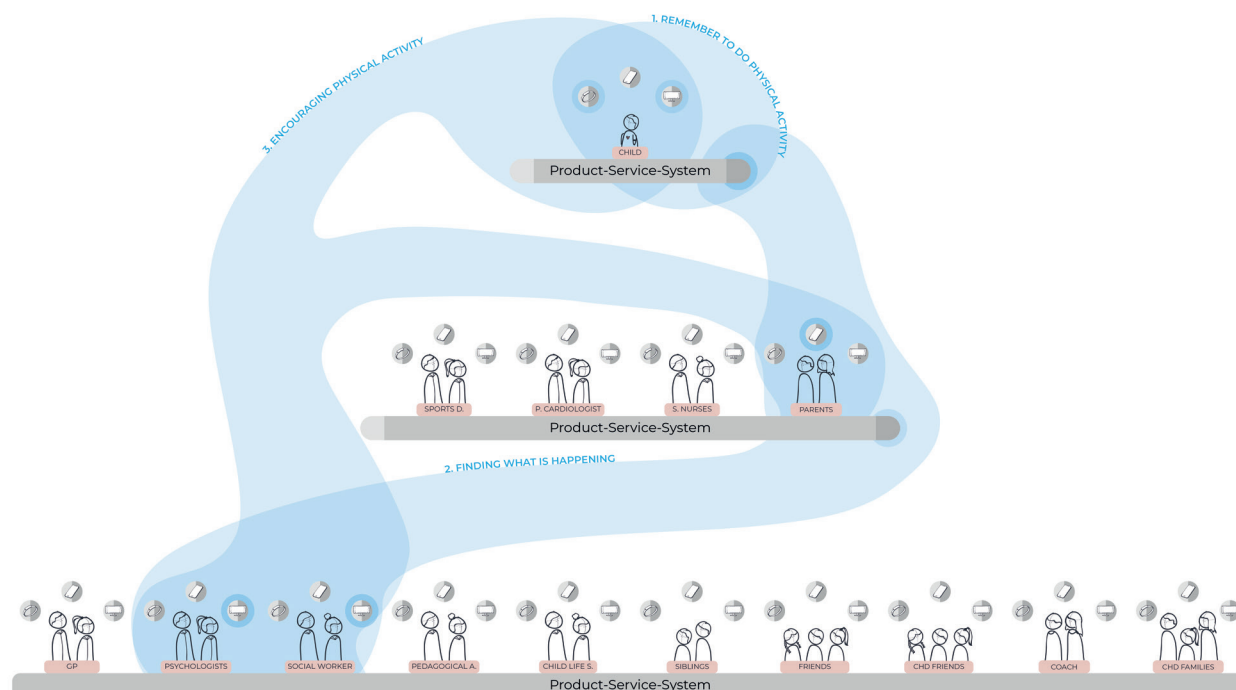
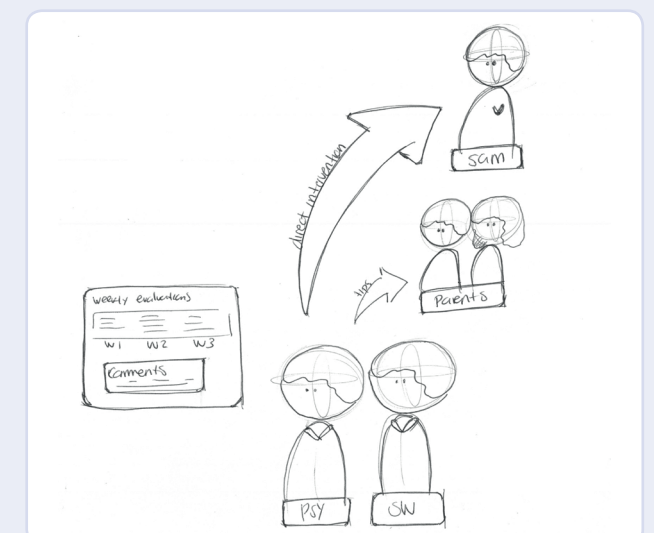


Figure 80. Sub-module physical activity family motivation.



## 7.6 Scenario of PSS use

The following images (Figure 82) provide an overview of how Bo interacts with the families as a service. The storyboard integrates all the functions from the sub-modules “Training” and “Real-Time Worry line” in its structure since those modules are highly related to the overprotective behaviours and how to manage them. However, since the system works as a whole, some of the functions from other sub-modules such as sharing boundaries and emotional management were included.

Figure 82. Bo's storyboard (continues on next pages).

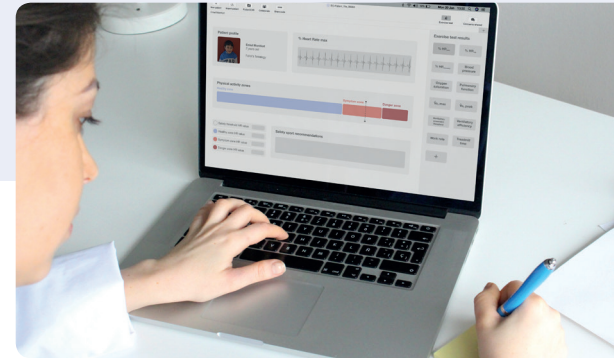
Meet Emiel, He was born with a CHD, and now he is 7 years old. He LOVES soccer and collects stamps. Currently, he told his mom that he wants to join the soccer team at school.



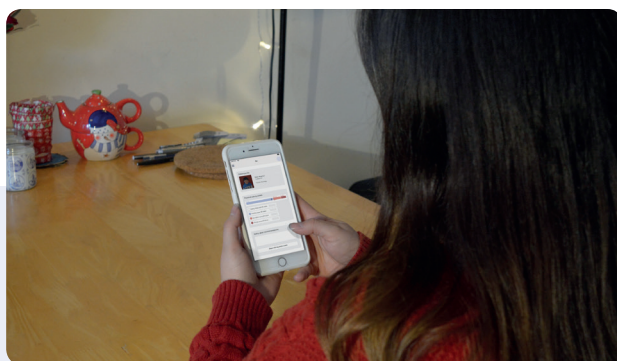
His mom, Danielle, feels insecure, so she decides to call the hospital, and they tell her that she needs to bring Emiel for an exercise test to check how he is doing.



After the exercise test, the paediatric cardiologist interprets the results. She sets the physical activity zones and writes recommendations for Emiel's family.



She contacts Danielle and tells her that it is secure to play soccer. However, if she still has doubts, she could download BO the APP to see the recommendations and PA zones.



Danielle, feeling anxious about Emiel playing soccer, decides to download Bo. She writes the patient's code provided by the physician and checks the physical activity zones.



She buys the activity tracker, pairs it with Bluetooth and explains Emiel that Bo will vibrate to let him know when he needs to rest or slow down while playing soccer.



When Emiel is playing, and his HR is close to the symptom zone (SZ), Bo vibrates to let him know that if he feels something strange, probably it is a symptom.



When Emiel's HR is close to the safety threshold (ST), Bo's vibrations intensify to let him know that he needs to slow down.



When Bo detects that Danielle is nearby (with Bluetooth), and Emiel's HR is close to the SZ, Bo asks Danielle to take a picture of Emiel having fun to enhance positive PA memories.



If Danielle thinks Emiel is presenting symptoms, she can share her concerns with the medical team using Bo's chatbot function.



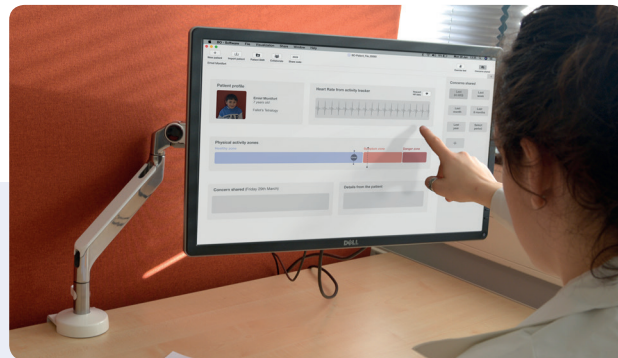
Bo shares the PA zones with Danielle based on how is Emiel's HR at the moment. Emiel is close to the SZ, but Danielle still wants to share her worry with the medical team.



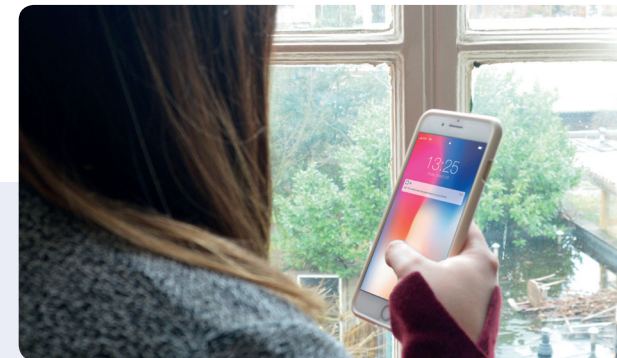
Therefore, Bo calls Emiel to go with his mom to register how he feels before sending the worry to the medical team.



Bo asks Emiel (based on Danielle's inquiry) if he feels his heart is going fast, or if he feels pressure in his chest. Danielle types what Emiel shares and sends it to the physicians.



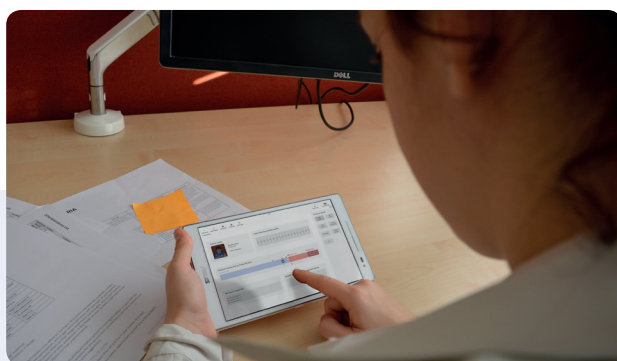
The nurse specialist will have three days to answer to Danielle's worry. When she does, Bo will also show the Emiel's HR measurements registered at that time.



Bo notifies Danielle that the nurse reviewed the concern, and Emiel's heart is fine. Also, Bo tells her that Emiel is doing great with stopping PA to rest when Bo indicates him to do it.



At the end of the week, Bo shares an overview of how Emiel is doing, which symptoms were registered, and he asks some questions to monitors Emiel's and Danielle's, feelings.



If Danielle thinks or Bo suggests some symptoms could be a possible pattern, she has the option to send them to the medical team for further exploration.



With this system, Danielle will feel more relief when Emiel is doing PA, and in case she has concerns, she will always be able to contact the medical team.

### Summing-up

Chapter 7 presented the concept of an intelligent network agent to encourage physical activity in children with congenital heart defects. However, the concept needed to be implemented with families of CHD patients to get a better understanding of future challenges for development. Therefore, a chatbot prototype was built to enable the implementation phase. Chapter 8 presents the process and results.

#### Takeaways from this chapter

- The PSS is composed of an application hosting a conversational agent called 'Bo', an activity tracker to measure the child's Heart Rate and a desktop version for the medical team.
- The final structure of the PSS consists of four modules representing the main pillars of the design vision. The modules break down into nine sub-modules which are arranged into four service phases, (1) entry point, (2) adapting phase, (3) during exercise, and (4) everyday life.
- The sub-modules "Training" and "Real-Time Worry line" are highly related to overprotective behaviours management.

## Chapter 8

# Product-Service-System Prototype

Chapter 8 attempts to describe the process of developing a prototype of a selected PSS sub-module, which can be used as a proof of concept to test with parents and their child with CHD. The chapter starts by introducing the scope of the prototyping phase. Later, it narrates the prototyping process of Bo as a conversational agent. To conclude, the chapter provides an overview of the different interactions prototyped and how they relate to the functions from the PSS.



# Product-Service-System Prototype

## 8.1 PSS prototype scope

Through the first diamond of the design process, it was found that providing a supportive exploratory environment during the child's PA participation could have a positive impact on overprotective parental behaviours. In order to act as a determinant to decreasing overprotection and anxiety, this environment should aid parents to distinguish between genuine and healthy symptoms, and at the same time, make them acknowledge their child knows when to stop PA.

Therefore, since the requirements relate to (1) the physician's knowledge to distinguish symptoms and (2) communicate the child's awareness of SB, this supportive exploratory environment transformed into the underlying value proposition that a dialogue between the family and physicians is meaningful for both parties and creates value around the content of what people exchange. On the one hand, the family would have the opportunity to obtain relief towards perceived concerns during PA participation through the physician's knowledge. On the other hand, physicians would have the possibility to understand better what is the situation of the patient in a real-time context and enable them to deliver tailored advice.

As a result, the two sub-modules of the PSS directly related to this value exchange were Training (T) and Real-Time Worry Line (RTWL). Hence, the focus on the prototyping phase turned around both sub-modules. However, due to concerns mentioned by the HREC about placing activity trackers in children with CHD, it was not possible to further continue the Training sub-module prototyping due to timing limitations to follow medical-ethical approval procedures. However, the prototyping of the RTWL sub-module was possible to some extent according to the HREC.

## 8.2 RTWL sub-module prototyping

As previously shown, RTWL consist of four functions, (1) perceiving symptom, (2) understanding worry, (3) sharing worry interpretation, and (4) finding what happened. For the prototyping phase, it was possible to build all the functions. Nevertheless, showing the

family worries and closing the communication loop by giving the doctor's feedback were not possible due to the lack of medical ethical approval to involve doctors in giving an interpretation of the shared concerns to the families. Therefore, function 2 and 3 did not take part in the prototyping process.

### Chatbot prototyping

Based on the conversational agent product-experience envisioned for Bo's system, the software chosen to build the chatbot prototype was Flow AI. This software, provided an intuitive process to construct interactions with the users and contained an NLP algorithm for Dutch and English language that could continuously learn from the user's conversation context and give appropriate answers.

In order to start the training of the chatbot's NLP algorithm, the worries shared during the interviews previously conducted were used as a starting point. Immediately, it was noticed that a different style of communication was needed for the child and adult to share their concerns. Therefore, two chatbot prototypes were created to interact with the families. The building process began with an English language prototype. Afterwards, a Dutch native-speaker translated and adjust the language of both prototypes to the adequate age of the users. Moreover, since there was not sufficient content in the interviews to foresee all the scenarios of families sharing worries, it was decided to create a half automated prototype that could be quickly taken over by a human if the context was complex. Therefore the prototype transformed into a combination of an automated chatbot with a Wizard of Oz technique (Höysniemi, Hämäläinen & Turkki, 2004).

Furthermore, an HTTP-API was used to connecting both chatbots to Telegram and thus share them with families. This APP program was chosen due to the encryption security measures provided, the flexibility to install it in different devices (e.g. mobile phone, tablets, desktop computers), and the compatibility to implement different functionalities of the chatbot in their interface. Figures 83 and 84 show the implementation of two interaction flows.

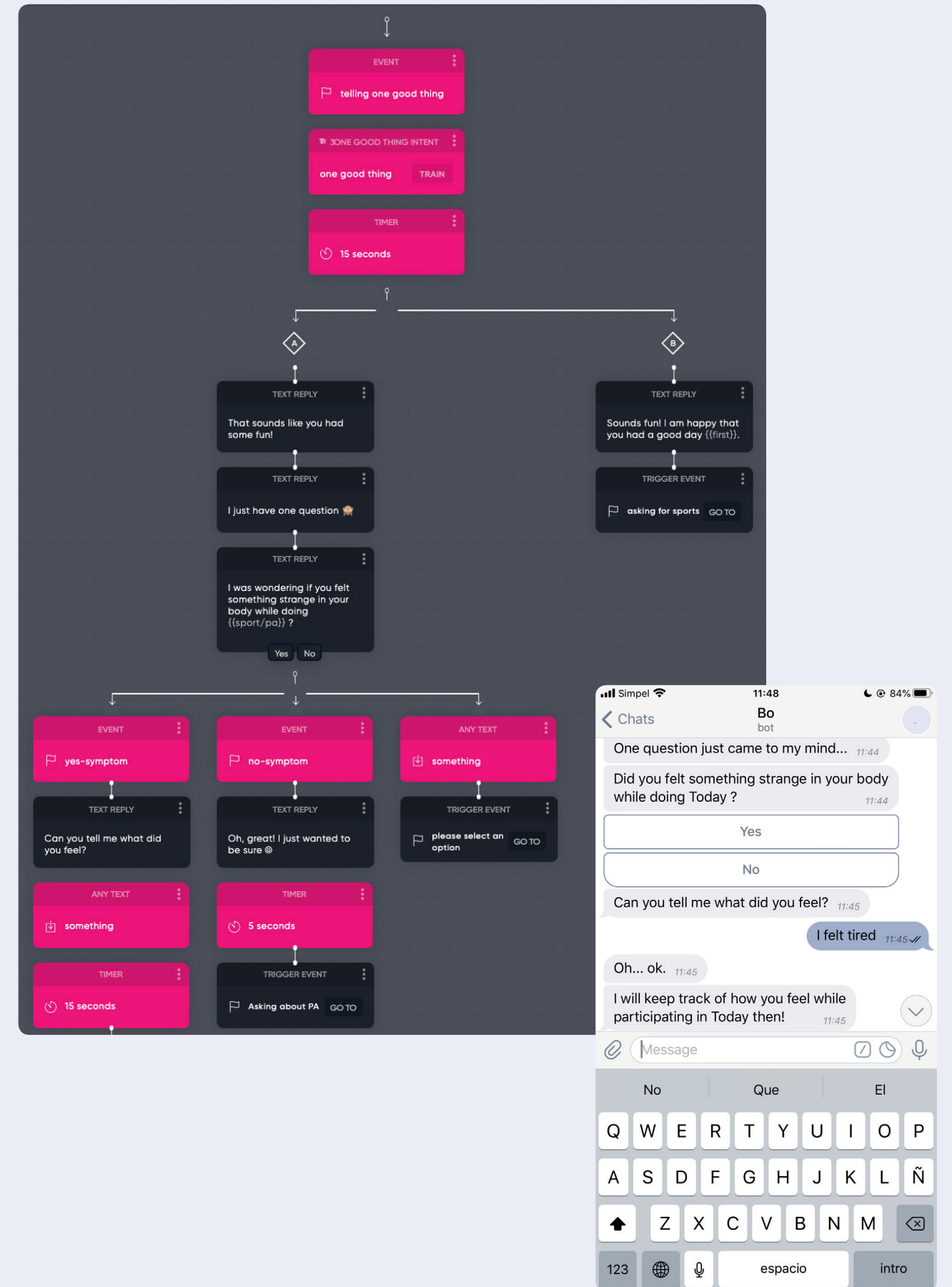


Figure 83. Part of interaction for 'telling one good thing' for child. Screenshot from Flow AI (left) and Telegram APP (right).



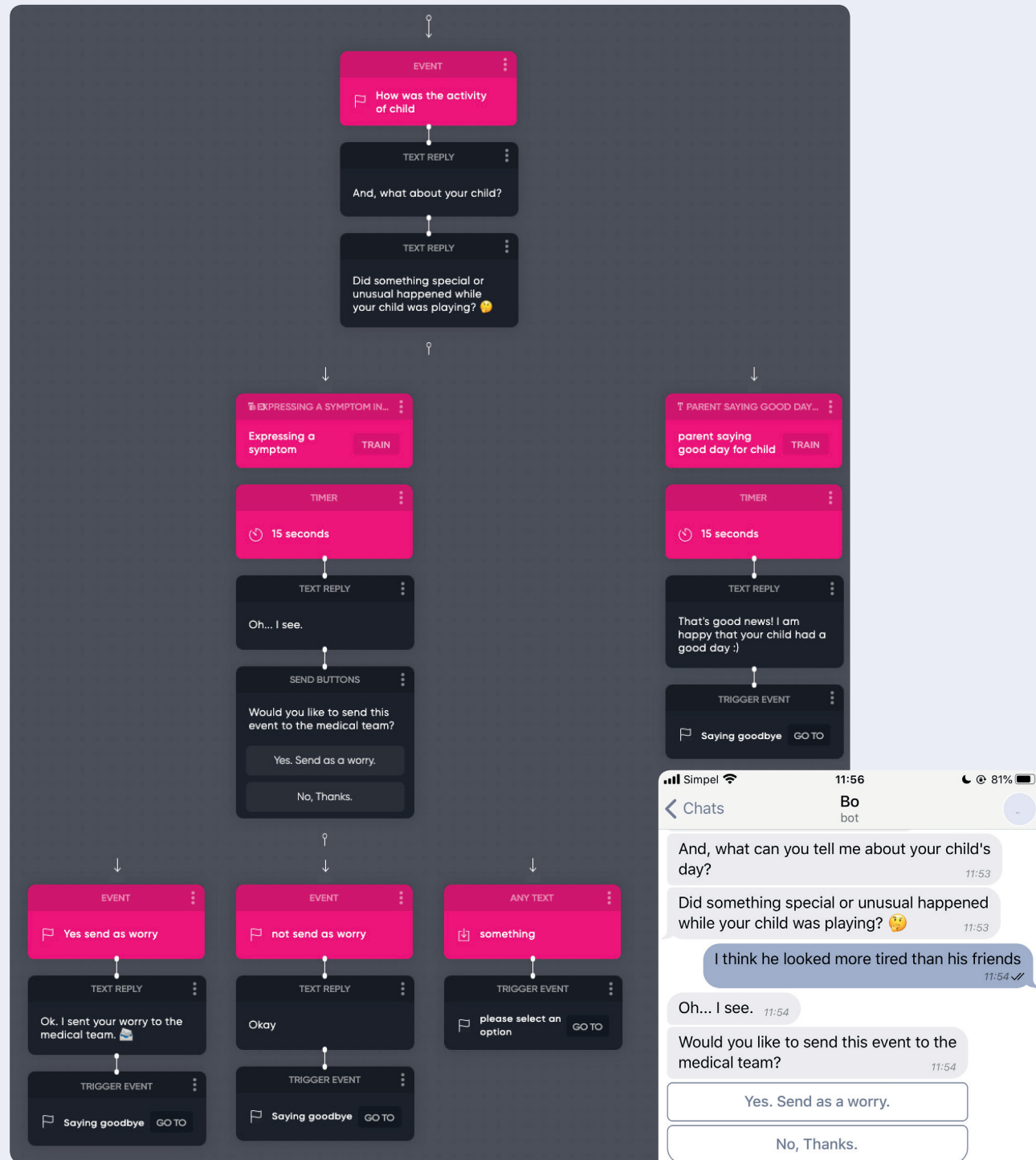


Figure 84. Part of interaction for 'how was the activity of your child' for parents. Screenshot from Flow AI (left) and Telegram APP (right).

### 8.3 Prototyped functions

While building the prototype of RTWL, it was noticed that including some functions of other PSS sub-modules was necessary due to the interconnectedness the PSS shares. Therefore, the following functions (Figure 85) were prototyped:

- Training - Collecting full of life moments
- Emotional Management - Sharing feelings
- Understanding Heart Defect - Sharing doubts

Findings in Chapter 5 showed that parents seeing their child full of life had a positive impact (delay in asking when to stop PA) when detecting PA intensity increasing. Since this function did not require an activity tracker to function, and parents will share concerns during PA, it was decided to build an interaction for it to decrease the negative feeling on seeing their child doing PA. Moreover, sharing feelings concerning their experience with PA was something that parents did naturally throughout the interviews (in chapter 3) when asked about physical activity. Therefore, an interaction flow was created to provide support in case family members wanted to share their feelings on the concerns shared. In addition, it was observed during interviews, that parents had doubts towards other aspects of physical activity not related to possible symptoms (e.g. is it safe to practice Karate?). Hence, the interaction support for this function was built to give users the possibility of asking health-related concerns. The three functions were incorporated

with the RTWL prototype. Nonetheless, the main focus of the prototype iterations and analysis remained on the RTWL and the functions above were treated as secondary analysis.

The first part of the interaction with the family intended to introduce Bo to them. The following experiences tried to enhance small talk about their day, how child and parent they felt, and see if they wanted to share something with Bo. If the system detected keywords concerning physical activity (e.g. soccer), these words acted as triggers to unleash a detective behaviour from Bo in which details about the activity were asked to gather information about their health condition.

The prototype had also support for occasional interaction. These actions were sensing doubts, worries and registering symptoms.

Figure 86 shows a simplified overview of the prototype modules composing the PSS experience.

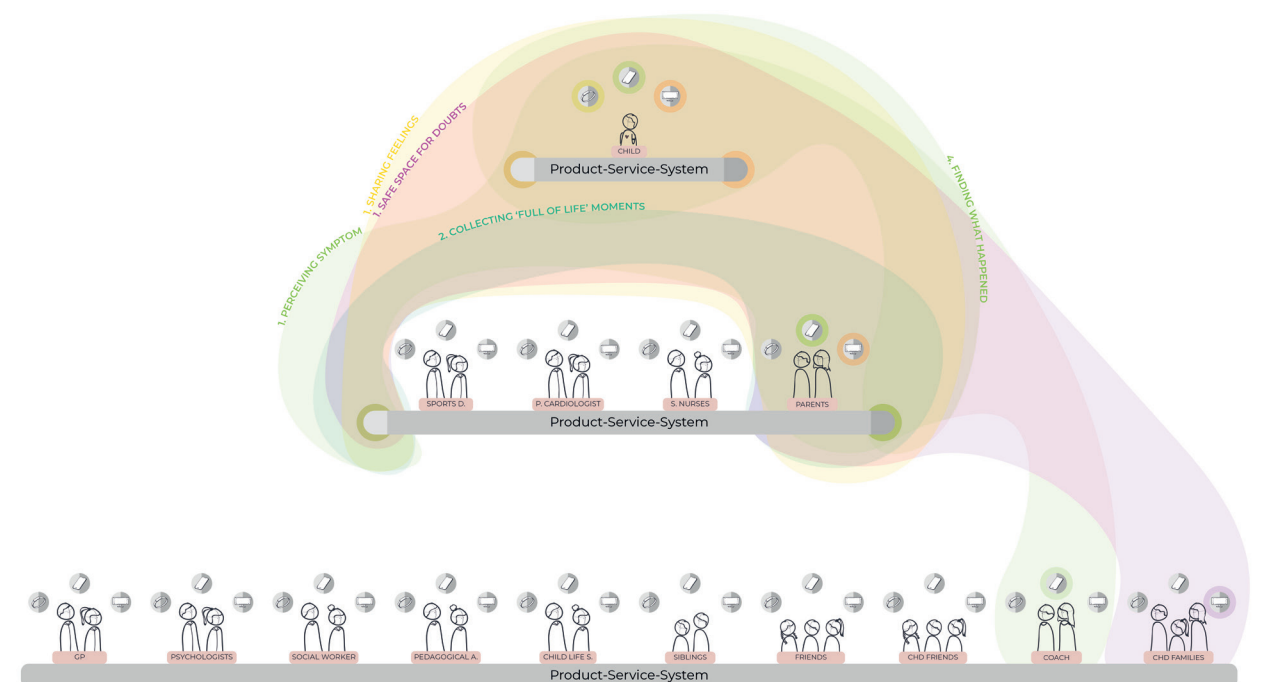
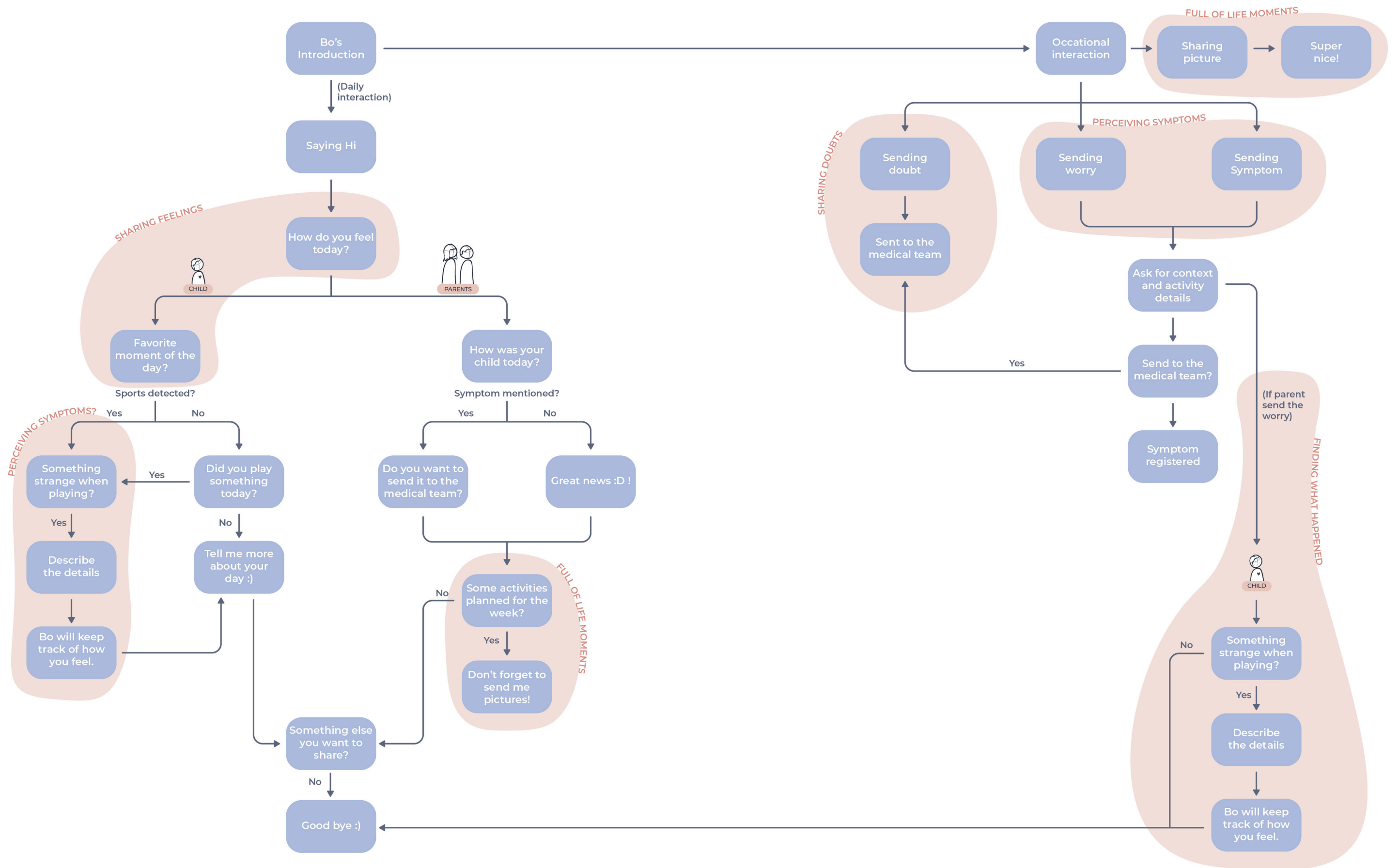
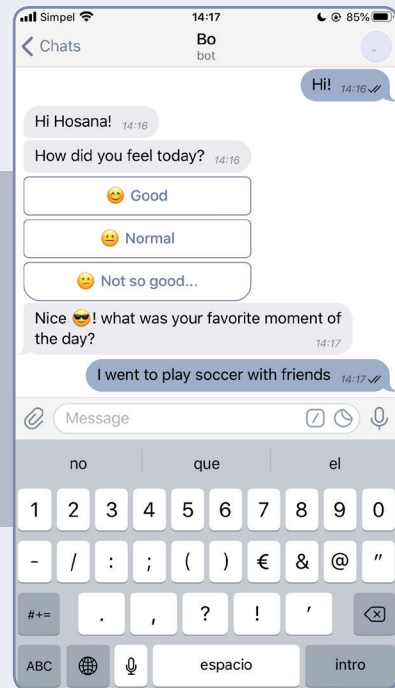


Figure 85. Overview of the prototyped functions.

Figure 86. Simplified overview of the interactions build. (continues on next page with iPhone screenshots)

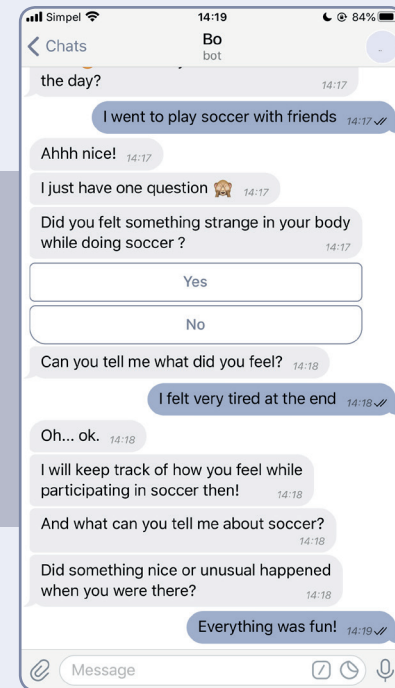


### Sharing feelings - Both



Emotional management is something humans do not share spontaneously. Therefore, Bo was programmed to try to establish a relationship with the user to let them know he cared about them.

### Perceiving symptoms - Child



In case the child shared some thoughts related to PA, Bo's program would try to detect if the user experienced something unusual while doing the activity.

### Perceiving symptoms - Parent



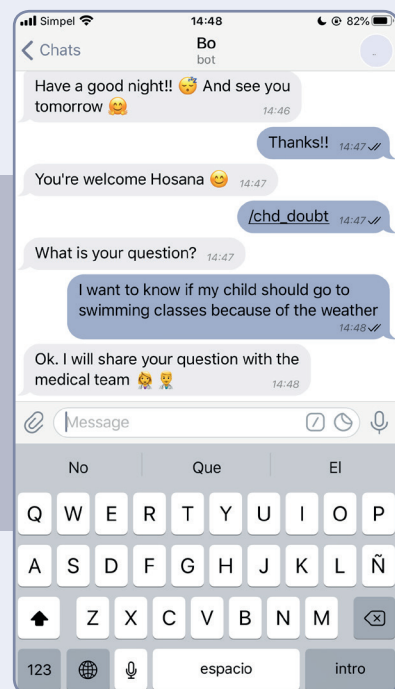
In case parents shared occasional worries with Bo, he could follow the conversation and tell them he would send their worry. However, answering the worry would not possible due to HREC restrictions.

### Collecting full of life moments - Parent



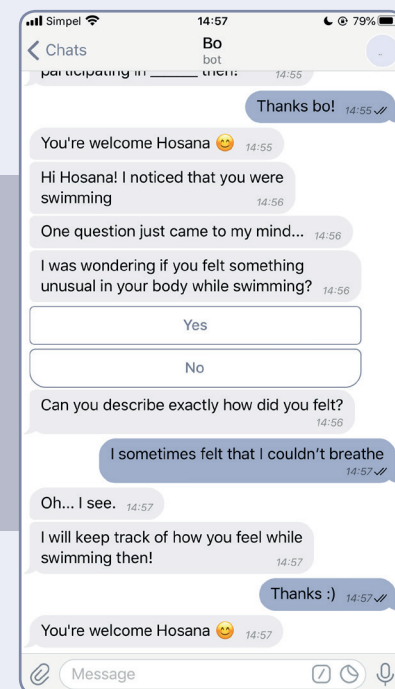
Since Bo did not have an AT to detect PA, he asked about the activities planned for the week and reminded parents to send him pictures of fun moments while their child was doing PA.

### Sharing doubts - Both



Bo also supported parent and child asking medical doubts not related to physical activity in case they had. However, answering them would not be possible due to HREC restrictions.

### Finding what happened - Child



In case parents shared a worry or registered a symptom, Bo will automatically ask the child if he felt something, based on the activity and information the parent shared to corroborate information.

## Summing-up

Chapter 8 described the scope of the prototyping phase, where the underlying value proposition of Bo determined which PSS sub-modules were necessary to tests in order to create a proof of concept. Based on the scope, Real-Time Worry Line and Training were selected for prototyping. However, due to ethical concerns from the HREC, the Training sub-module and part of the RTWL functions could not be prototyped. Hence, some functions from RTWL and other modules were prototyped and implemented in Telegram as a chatbot program to interact with families.

Having the prototype ready allowed to introduce it to a real user context with families of CHD patients. Chapter 8 presents the process of a one-week implementation study using the Data-Enabled design methodology (Bogers et al. 2016).

### Takeaways from this chapter

- The envisioned supportive exploratory environment provided the underlying value proposition that a dialogue between the family and physicians is meaningful for both parties and creates value around the content of what people exchange. Therefore enabling a communication channel when family members feel worried worked as the first proof of concept to know what could be the impact in overprotective behaviours.
- It was not possible to foresee all the scenarios of families sharing worries. Therefore, a half automated prototype was created.
- Besides the two functions prototyped for RTWL, one function of each of the following submodules was prototyped, 'Training', 'Emotional management', and 'understanding heart defect'. However, the main focus of the prototype iterations and analysis remained on the RTWL functions.
- Bo's chatbot was designed to support daily interactions and unexpected interactions with the family members.



## Chapter 9

# Implementation

This chapter introduces the implementation study of the RTWL sub-module with four families in their everyday life context. The chapter starts by describing the implementation vision of this sub-module and the research question. Afterwards, it presents the methodology employed and the procedure done. To finalise, it shares the situated design exploration results and discusses the main findings.

# Implementation

## 9.1 Background

Previously conducted interviews with families with a CHD paediatric patient showed that these families are experts on the current dilemma of overprotection. However, the intention of conducting this study was to share with them a future vision (Figure 87) of the problem with the implementation of Bo, let them experience the possibility to share their concerns and find out new barriers for further development.

Based on the potential value exchange between family members and medical team explained in the previous chapter, the present study aimed to create a better understanding of how real-time communication provided with Bo's chatbot could help families to decrease overprotective behaviours during PA.

The research question for the study was the following:

'How can real-time communication about physical activity concerns help parents and children with Congenital Heart Defects to decrease perceived overprotection and anxiety when the child is physically active?'

The primary assumption of the research was that parents would be more at ease during their child's PA participation by knowing that they could share their concerns (related to possible symptoms) to the medical team.

## 9.2 Method

The methodology employed for this study was Data-Enabled Design (Bogers et al. 2016). By using data collected in real-time, this methodology enabled an iterative loop between the physical activity context of the family and the researcher. This loop provided insights into the behaviour and feelings of the family concerning physical activity. These insights were translated into design interventions continuously shared with the family during the study time.

### 9.2.1 Participants recruitment

The recruitment process was done through the database of previews interviews, and Facebook posts published by the two leading CHD associations in The Netherlands. Eleven families showed interested in joining; most of them answered the research call through email; however, others decided to call to know more about the project and requirements. The necessary criteria for joining the study was to have a child with a CHD between 8 to 12 years old. Due to the child's possibility to know how to read, and hence communicate with Bo. Moreover, a willingness from the child to participate, and availability during the implementation week were asked to each interested family. In the end, nine families were suitable candidates for the study. However, since the gift for participating, and primary communication channel during the study, was a tablet for children, only four places were available.

Figure 87. Implementation vision

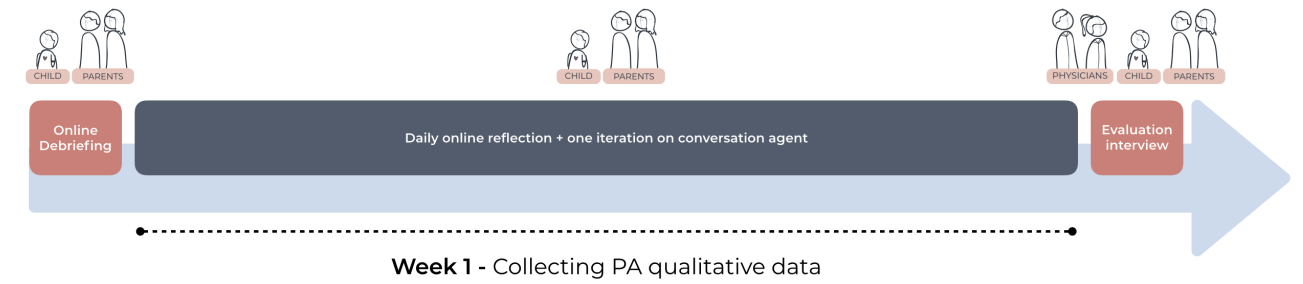
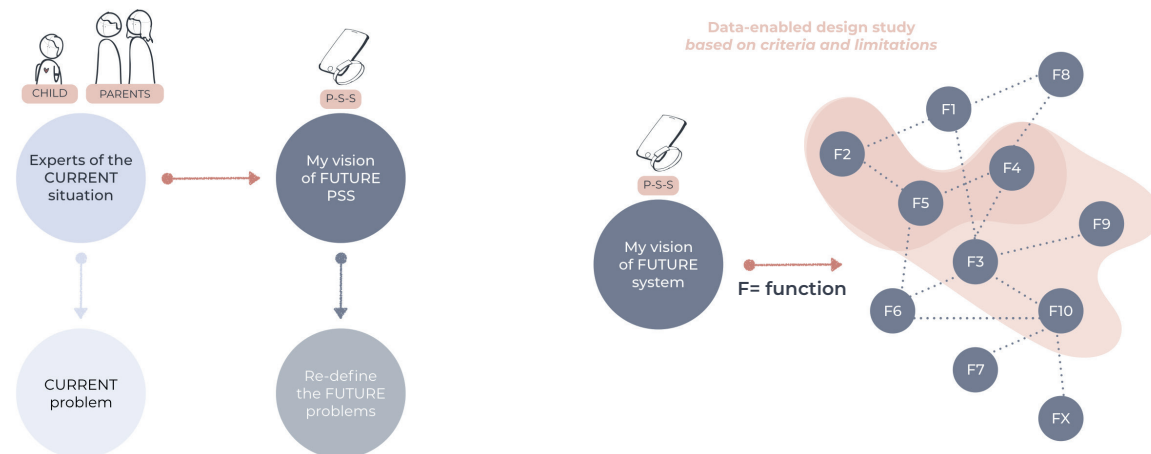


Figure 88. DED study overview

Therefore, the new criteria consisted of recruiting two kids from the same gender, all with different CHD and age. The demographics of the selected participants can be seen in the following table.

Table 9. Details of families who joined the implementation study.

Family number	Adult present	Child Gender	Age
1	Mother	Girl	9
2	Mother	Girl	11
3	Mother	Boy	10
4	Mother	Boy	12

took approximately 7 minutes, depending on how much information was shared, and how much time they needed to answer.

### Iteration based on data insights

The data and personal stories collected during the interaction of the first four days inspired and triggered new possibilities that informed the next design decisions. However, the data collected from each family was widely different between families and between the family members along the days, as PA was something that regularly changed during the week. Through the iteration process, Bo's chatbot moved from general interactions with the family to a more personalized approach. In the results section, the iterations performed are described.

## 9.3 Procedure

The duration of the situated exploration was seven days, and the process divided into an online debriefing, a daily online reflection, one iteration based on the insights gathered, and a final interview for evaluation. The phases of the procedure can be seen in Figure 88 and will be explained in the following paragraphs.

### Online debriefing

An initiation package (Figure 89) was sent to the family's home two days in advance to start the study. Inside this package, the family members could find a tablet to communicate with Bo, its accessories, a consent form, and an introductory booklet that explained the tablet had Telegram installed. However, they needed to make the configuration with their number in both devices, tablet and mobile phone. Two chatbots were introduced to the families, one for children and one for parents to enable them to interact with Bo at different times.

### Daily interaction

Participants were told that they could interact with Bo during the day to share their concerns, worries and symptoms. In addition, extended interaction with Bo was planned during the evenings to chat about their day and reflect on PA. These interactions

### Final interview for evaluation

After seven days of implementation with the four families. Three semi-structured interviews were done with the family members together. However, family 4 could not participate in the final interview due to sudden health-related problems with their child's heart.

Figure 89. Bo's introduction kit



### 9.3.1 Data collection

The chatbot prototype, described in Chapter 8, was employed as the main channel of communication with the families, as well as the main device to collect data. The study and chatbot prototype were in Dutch to allow a more natural communication for the child and parents.

As previously stated, the chatbot was implemented in Telegram. Each of the tablet provided had Telegram installed, but further requirements such as their phone number were requested before starting the study. Moreover, it was required for the families to install Telegram in their mobile phones, as this setting was necessary to interact while the child was doing physical activity.

The chatbot collected feelings and thoughts on physical activity from the child and mother perspective and sometimes, used the information provided from one family member to ask a question to the other family member.

Concerning the safe boundaries of interaction with the prototype, Bo's interaction with families could not provide advice on how much activity level the child should do or not do. Moreover, under any circumstances, the chatbot should provide medical advice to the parent or child.

Based on the analysis of the physical activity qualitative data shared, the insights were translated into design interventions. Examples of such interventions can be seen in Table 10.

Table 10. Iterations with DED

Observation	Change	Change applied?
1. Children asked Bo general questions as if it was google.	Classification of different types of doubts shared, (1) medical advice, (2) medical clarification and (3) general.	Yes
2. All the children mentioned tiredness during the day.	Creation of a 'scale for tiredness' to detect variation in-between days and times of the day.	Yes
3. Mother and child did not share the same symptoms.	Use symptoms/concerns expressed by the other participant to complete the information.	Yes
	Classification of different types of symptoms shared.	Yes
4. Concern expressed before, not expressed again.	Provide a follow up of the symptom shared, be careful not to increase anxiety or create symptom ideas.	No
5. A parent shares a not visible symptom.	Clarify and corroborate the symptom with the child.	Yes

## 9.4 Situated design exploration results

### Technical complications

The first two days, diverse technical complications were presented with the chatbot answers. While looking at the possible causes, it was found that implementing both chatbots in one telegram account confused the program and sometimes mixed the keywords (e.g. name of the child/parent) between both chats. This issue was the most relevant. Other issues were related to the chatbot's NLP algorithm and the learning time to recognize different ways to say the same and answer according to the user's comment.

### Usability

Concerning the different options that Bo explained in his menu, some families prefer to have a fluid conversation with Bo and do not use the menu options to share doubts, worries or symptoms.

Moreover, the implementation of buttons inside the chat sometimes was not the optimal interaction for parents. This situation, due to the tendency they showed when answering questions typing instead of clicking one of the provided options. However, children did not show the same behaviour; they always used the buttons when presented.

### Iteration insights

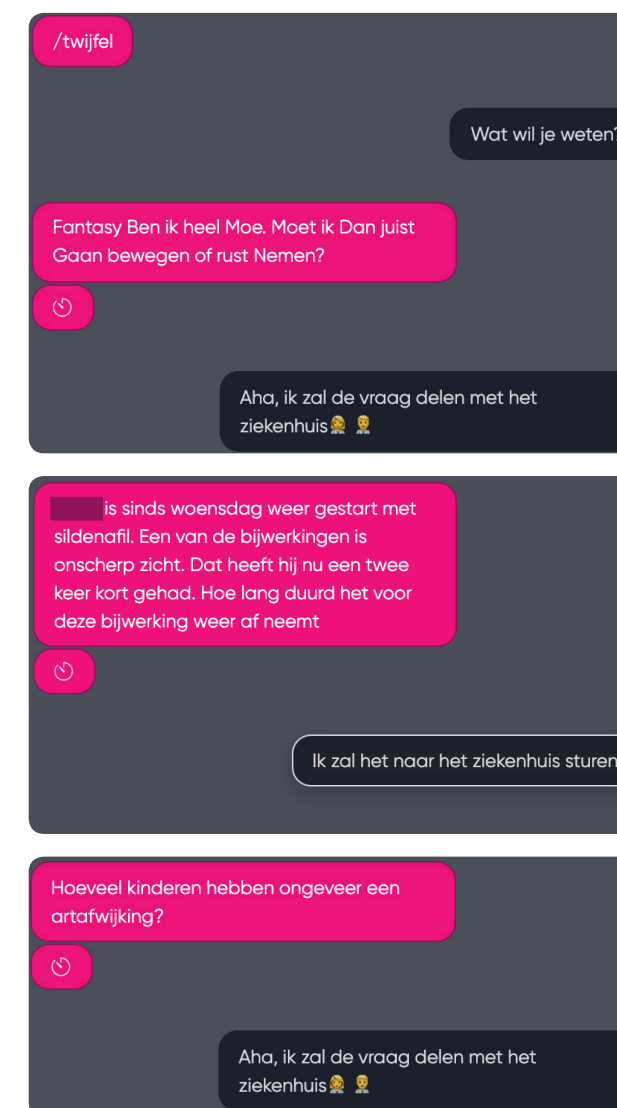
Table 10 presents the observations which led to the first iteration of the chatbot. The following

paragraphs will describe each of them and provide images related to the observation.

#### 1. Children asked Bo general questions as if it was google

When parents and children used the option 'doubt' they asked different types of doubts (Figure 90). Although the categorization idea began when one child asked a question as if it was google, afterwards, other families started asking different doubts which could be categorized in different topics for further processing. The overall topics found where, (1) medical advice, (2) medical clarification, and (3) general.

Figure 90. Examples of doubts. Screenshot from Flow AI.



#### 2. All the children mentioned tiredness during the day

Feeling tired is one of the most common symptoms among CHD paediatric patients. Among the participants of the study, this symptom shared by all of them. Therefore it was decided to implement

a 'tiredness scale' when they expressed being tired to try, in the future, to detect variation in-between days, but also at different times of the day since children expressed different levels also in the same day.

Figure 91. Example of tiredness scale. Screenshot from Flow AI.



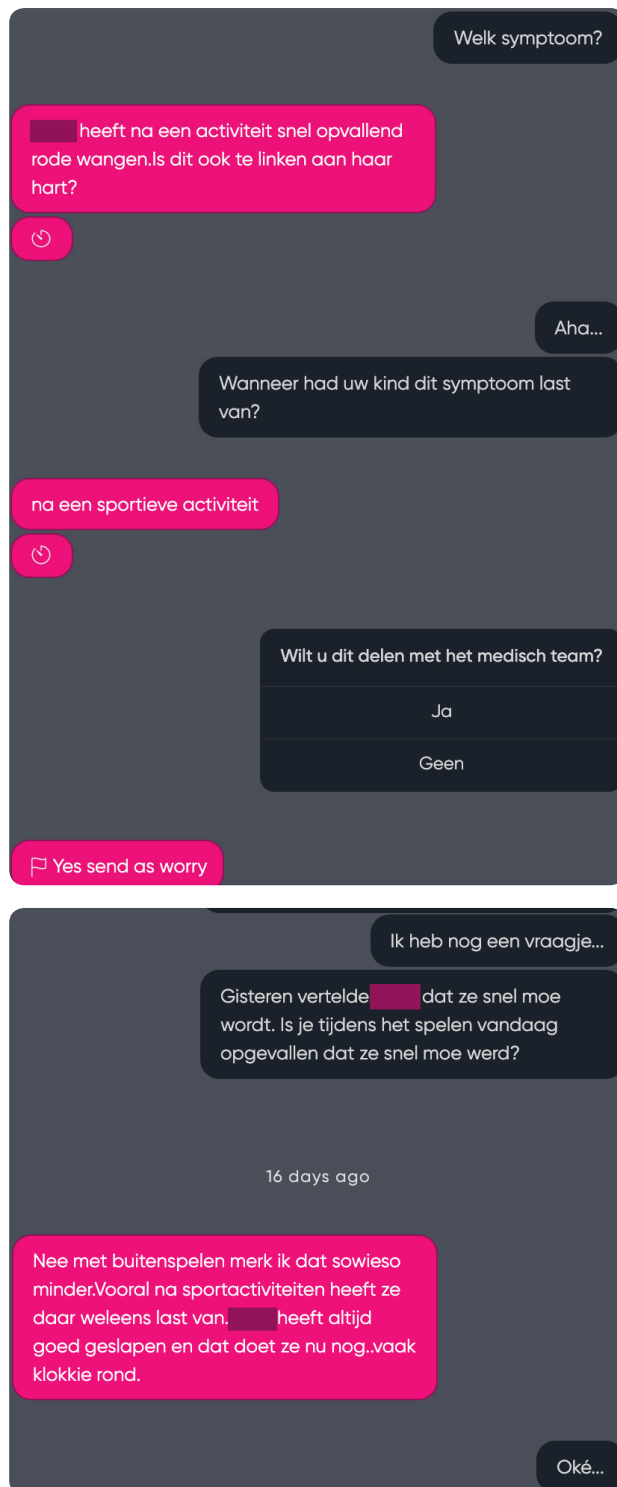
#### 3. Mother and child did not share the same symptoms.

During the daily interaction with the family members, it was noticed that sometimes, the mother shared one symptom. When asking the same questions, the child did not share something related to what the mother mentioned. Therefore, it was decided to use the possible symptom shared as a base to ask how the day went in an attempt to complete the symptom information.

Moreover, along with the study, it was noticed that the symptoms shared by the four families could be categorized into two main groups. These are directly visible (e.g. red cheeks), and not visible, only with interpretation beforehand or by being told about it (e.g. tiredness, blurred vision). Hence, a possible organization of the symptom-keywords in this way could help the machine to ask follow up questions.



Figure 92. Example of symptom shared and symptom usage in other conversation. Screenshot from Flow AI.



#### 4. Concern expressed before, not expressed again

When family members shared symptoms or concerns, there was no medical follow-up. However, asking a follow-up question was possible to see the symptom evolution. When doing it, it was noticed that some parents started doubting about common situations and reflect if the concerns could be a symptom. Therefore it was decided no to keep this change.

Figure 93. Examples of follow-up. Screenshot from Flow AI.



#### 5. A parent shares a not visible symptom.

From observation number 3, the category of non-visible symptoms is something that often requires interpretation from the parent. However, the level of ability to know if a symptom is a genuine symptom could vary per parent. Therefore, it was decided to clarify with parents every time they shared a not visible symptom, if their child mentioned it or if they saw it. Since this information can also be helpful for the doctor to know the patient perspective.

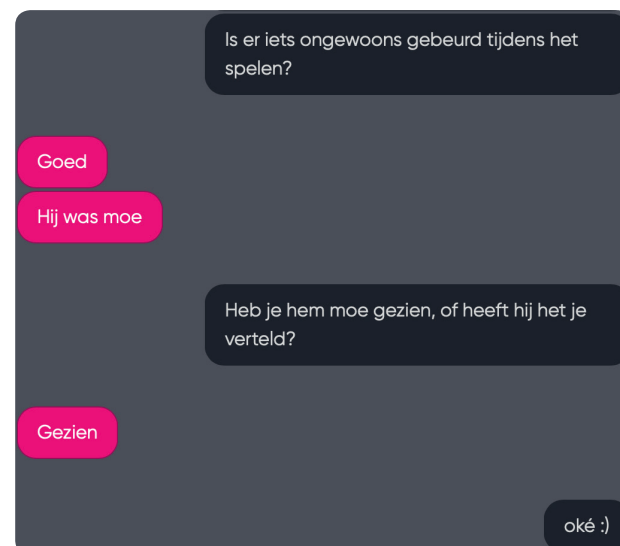


Figure 94. Examples of symptom corroboration. Screenshot from Flow AI.

## 9.5 Discussion

One of the outlined pain points of Bo was that it could represent an increase in the workload of the medical team. An assumption suggested that by enabling parents to have a direct channel with the medical team would make them send a large number of concerns. However, that was not the case. Only five concerns were requested to be shared with the medical team for one week among all the participants. Still, this situation influenced the development of the RTWL sub-module, considering there was not too much material to work with.

However, the interaction with families presented an interesting insight for the RTWL sub-module, the distinction in visible and no visible symptoms and how reflective questions can influence them at the moment of perception.

Training the NLP algorithm to make the distinction among these symptoms could enable different reflective questions for parents besides asking the envisioned questions about detailing the symptom and context. Changing the perception of this 'possible symptoms' could influence overprotective behaviours and be a buffer before deciding to send a worry.

### 9.5.1 Research question

The last step in the implementation study consisted of conducting in-depth interviews with the families to understand if having this channel with the medical team could influence overprotection. However, the interview purpose broader, and also an overall view of Bo's service was provided. Therefore, the answer to the research question is discussed in Chapter 10 - Evaluation.

### 9.5.2 Limitations

One significant limitation was the time of the implementation. The short duration of the study could have influenced the low amount of concerns shared, as well as the winter weather by not encouraging physical activity behaviours and families who were not very concerned about the CHD.

Furthermore, the technical difficulties at the beginning of the study could have influenced the usage of Bo, and a few monotonous conversations presented when interacting with the families.

## Summing-up

The present chapter described the implementation process of Bo's chatbot with four families. The results and observations were discussed in the final section. However, the final evaluation interview was combined with the evaluation of Bo as a system. Chapter 10 presents these results and also provides three medical perspective evaluations on the PSS concept.

### Takeaways from this chapter

- The primary assumption of the study was that parents would be more at ease during their child's PA participation by knowing they could share their concerns with the medical team.
- The purposed research study shared Bo's chatbot prototype with four families during one week to see which type of concerns would be shared with the medical team.
- Five main insights were found during the study, which resulted in a new classification of doubts and symptoms, and a new approach to asking specific symptoms. These findings represented the primer iteration for the chatbot prototype.
- No visible symptoms could represent an opportunity to create a buffer before sending a concern to the medical team.

## Chapter 10

# Product-Service-System Evaluation

This chapter gathers the impressions and recommendations from children, parents, and members of the medical team regarding Bo's implementation study and the envisioned future experience for Bo. First, it provides an overview of the interview process followed. Then it presents a summary of the impressions and thoughts of children, mothers, sports doctor, psychologist and paediatric cardiologist. To conclude, the chapter provides recommendations based on the points of view from various interviewees.



# Product-Service-System Evaluation

## 10.1 Background

With the implementation of Bo in the everyday life setting of the families, behaviour and usability system-level aspects were explored to improve Bo throughout the iteration cycle followed with the prototype. However, an evaluation of the overall system was needed to understand if the value exchange that Bo enabled between the medical team and family members could be meaningful for both sides.

Therefore, members from the medical team and families were invited to share their experience and thoughts on the overall view of the final PSS concept.

## 10.2 Method

Six in-depth interviews were conducted to evaluate Bo. Three of them were conducted with groups consisted of a mother and a CHD patient. The last three were done with three different specialities from the medical team. Since the aim was evaluating the PSS from different views, it was decided to use a Semi-structured interview to enable the researcher to explore emerging topics (Patton, 2002). Therefore, two different structures for the interviews were created. The first one was employed with family members and covered the experience of using the prototype and the future vision of Bo. The second version was created for the medical team, and only covered the envisioned functions of Bo due to the lack of ethical approval to show raw concerns shared by the family members during the implementation phase.

### 10.2.1 Participant selection

All the selected families to participate in the implementation phase were invited to share their experience with an interview at the end of the study. However, one family could not take part in the interview process due to an urgent visit to the hospital regarding their child's health, presented the day of the interview.

Moreover, the previous medical multidisciplinary team participants of the co-creation session were invited by e-mail to join the interviews and provide

a follow-up of the proposals generated during the session. Out of the five specialities, three of them were available to participate in the interviews.

In the following table, the demographics of the families interviewed are shown.

Family number	Adult present	Child	
		Gender	Age
1	Mother	Girl	9
2	Mother	Girl	11
3	Mother	Boy	10

Medical speciality
Sports doctor
Psychologist
Paediatric cardiologist

Table 11. Details of families and physicians interviewed.

## 10.3 Procedure

The interviews took place at the end of the implementation study, during the weekend at home for families, and during working days at the Erasmus MC for the medical team. The duration of the interview for both users was one hour. As previously mentioned, two structures were created; these will be explained below.

### For families

The interview procedure was divided into two main phases. The first phase was related to their experience during the implementation study and the possible value it represented to enable a connection with the medical team with Bo's chatbot function. However, the prototype did not show the overview of Bo as a service. Therefore, the second part of the interview consisted of showing a storyboard (Figure 95) made with pictures (Figure 82 - Chapter 7) to explain how Bo could help them with the implementation of an activity tracker (Figure 96), and how a family could start with the

service that Bo offers to them. In order to provide a better understanding, the storyboard covered all the functions from (1) Training and (2) Real-Time Worry line, and some of the functions from (3) Sharing boundaries and (4) Emotional Management.

Since most of the children could not speak English fluently, a Dutch native speaker assistant was hired to take over the interview and ask about the prototype experience, explain the storyboard, and ask about the storyboard to the child.

### For the medical team

The interview for the medical team was also divided into two parts. However, the first part aimed to give a brief recapitulation of what happened after the co-creation. The second part employed the storyboard previously explained, and during each step, they were asked to say their thoughts and suggestions out loud for further improvement. In the end, an overall opinion of the concept was given.

All interviews were audio-recorded for further analysis.



Figure 95. Researcher explaining storyboard to parent during interview



Figure 96. Researcher facilitating storyboard interaction to child during interview



## 10.4 Insights from a child perspective

### Interacting with Bo is fun

Children expressed that interacting with Bo through the Chatbot application was a fun activity to do. When diving depth into the reasons, they expressed that Bo cared about their preferences, and how did they feel during the day.

*[Mom] Bo is the small iPad?  
[Researcher] Yes  
[Child] Fun!"  
- Family 3*

*"He is fun [...] because he asks questions like if I had a good day or not and I like that [...] And he asks what you like the least and to tell about some things. And he asks about my heart. If something is wrong with it. I can tell about it and that is nice."  
- Child, family 1*

*"[Child] It was fun that he asked what sports I like and then we talked about it  
[Researcher] So that he gets to know you?  
[Child] Yeah. I like that."  
- Child, family 1*

However, children expressed that sometimes it was a little strange to interact because they didn't know who was behind Bo. And also, that categorizing their feelings into scales was something that they found a little difficult to do.

*"[Child] Uhm  
[Mom] You always wondered who it was right?  
With whom am I talking?  
[Child] Yes."  
- Family 2*

*"[Mom] Did you find it difficult?  
[Child] Yes  
[Mom] A little bit difficult sometimes  
[Researcher] Oké and why was it difficult for you  
[Child] Uhm... I don't know  
[Mom] Why was it difficult to say how tired you were?  
[Child] I just feel it sometimes."  
- Family 3*

### A moment for reflection about body and feelings

Furthermore, when discussing their conversation with Bo, they expressed that they do not talk much

about their heart condition during their daily life, and having a reflective moment to acknowledge how they feel was a good thing to have.

*"[Child] Sometimes, when he contacted me in the evening, I would focus more on how and what I feel during the day. So that was quite nice.  
[Researcher] All-right, so it was nice that you became aware of yourself?  
[Child] Yes."  
- Child, family 2*

*"[Researcher] Why do you like to he asks how was your day?  
[Child] Because we do not often talk about that  
[Mom] Well...  
[Child] Yeah sometimes, but it is nice to talk a bit about it."  
- Family 1*

When Bo did a follow-up of their concerns (e.g. feeling tired the day before), one child expressed that Bo enhanced a reflection by taking a moment to think thoroughly about their body based on what Bo asked. Also, they suggested that setting how often Bo interacts with them about how they feel could be a nice feature for Bo.

*"Uhhh, I think that you are more aware of it. Because sometimes you think 'I did not feel anything' and then Bo asks things and then you think 'oh yeah right, that is actually what I felt today.'  
- Child, family 2*

*"[Child] Maybe, when you are in the beginning [of the problems with your heart]. You sometimes feel things during the night. So it would be nice when Bo asks how everything is in the morning. Then you could write everything down from the night  
[Researcher] Aha, okay. So that you could set yourself when or how often Bo asks how you feel?  
[Child] Yes."  
- Child, family 2*

### A helpful connection with the medical team

Children expressed that Bo can help to make the connection between their family and the medical team, and therefore, the medical team will be able



CHILD

*"I think that would be really nice. Then you know yourself when to stop when you do a lot of exercising for example. That would be useful."*

- Child, family 2

Figure 97. Quote from child.

to know beforehand how is the situation and act according to it if necessary.

*"[Child] Yes, for example when I ... am sick or something and I tell that to Bo. Then he can send it directly to the doctors and then they know it as well  
[Researcher] Yes, and why do you like that?  
[Child] Then they can help us directly. And when we go to the hospital they directly know what we are talking about. Then they can help directly."  
- Child, family 1*

*"[Researcher] And would you use this to contact the doctors in real?  
[Child] Yes, I think so. It has to be developed further, but I think when it is done it would be nice, yes."  
- Child, family 2*

However, one child expressed that he would prefer his mom to interact with the doctors instead of him through Bo.

*"[Mom] Do you want to ask questions to the doctors or should I do that?  
[Child] You  
[Mom] Yeah right"  
- Family 3*

### Bo enabling the possibility to know when it is necessary to take a rest

Children found useful having a bracelet that could show them when a break was necessary. They expressed that sometimes they are playing and they forget about resting, but with Bo, they could be more aware of it.

*"[Researcher] And what would you think of an activity tracker which vibrates to show you need to rest?  
[Child] That would be nice, because then you know, okay pause. Because I am always a bit..  
[Mom] Enthusiastic [laughs]  
[Child] yeah [...] and then I run a lot sometimes,*

*but then I would know to take it a bit slowly. Before my heartbeat gets to high."  
- Family 1*

*"[Researcher] Okay, and what would you think of a activity tracker that vibrates when your heartbeat gets too high?  
[Child] I think that would be really nice. Then you know yourself when to stop when you do a lot of exercising for example. That would be useful."  
- Child, family 2*

*"[Mom] When your wristband says: no you are done Sam, no you have to stop for a while. When it vibrates... what do you think about that?  
[Child] Very good  
[Mom] Yeah. Good right?  
[Researcher] Yeah? Would you like to know that?  
[Child] Yes."  
- Family 3*

Concerning the perceived worries during exercise, children express that with the bracelet BO could be helpful when going out of surgery because then they could know if their heart is OK, and if it is necessary to come back to the hospital for a check. Also, Bo could help to talk with other adults (e.g. teacher or coach) to explain how they feel and have something as a backup.

*"[Researcher] And, how helpful would you say that Bo will be for your physical activity worries?  
[Child] Well, uhm... I think really well, when you still have a lot of troubles from it [= Your heart]. Then it would be really helpful to know if it is okay, or if you should go back to the hospital.  
[Mom] Or take some rest  
[Child] Or take some rest or can I go on. So I think it would be really nice."  
- Family 2*

*"[Mom] Yes, that when it does not vibrate it is all-right, but that when it vibrates you say*

to teacher: hey teacher, I have to stop. Would that be good for you sam?

[Child] Yes."

- Family 3

And thought that having guidance on which activity might be good to try for exercise could also be something that Bo could help with.

"[Researcher] Okay. And during sporting activities, would you like some help from Bo. For example, that he says: this activity is better for you and this one not?

[Child] That would be useful, yeah."

- Child, family 1

"[Researcher] And since the app is special for Emiel now, it also contains recommendations about what activities he could better do and which not...

[Mom] That would be great for Sam

[Researcher] Yeah?!

[Child] Yes

[Mom] Yes, we want that. Because now we have to figure everything out ourselves. How long you can bike, how long you can swim..."

- Family 3

## 10.5 Insights from a parent perspective

### Interacting with Bo is easy

The chatbot function of Bo was described as easy and "nice" to use, and the character itself was perceived as funny due to the use of emojis and phrases employed when he made a mistake such as "I'm sorry. I am learning".

"It is nice to do."

- Mother, family 3

"He was funny sometimes with the emojis."

- Mother, family 1

"It's easy to use [...] it was easy to connect, and I really liked it."

- Mom, family 2

However, one mother mentioned that since it is not a human, sometimes she did not know until what extend Bo could understand her and how she needed to explain something to him, or if he could be able to understand the explanation.

"[...] He said, sometimes, I don't understand. I'm learning. So I did laugh about it. But, it's okay. Sometimes you don't know how to explain something to something, you know, it's not a person."

- Mother, family 1

Furthermore, Bo helped family 2 to have a "reality check" to evaluate how was the day concerning the child's heart. The reflection moments with bo were perceived as eye-opening for parent and child since both interacted with Bo at the same time and discussed what Bo was asking.

"I thought maybe it costs a lot of time but it doesn't. It is just a few minutes and it's what she was saying also just the reality check. How did you feel today? Because we're always running and flying and sometimes you forget to listen to your body."

- Mom, family 2

"But it's an eye-opener sometimes. Because this morning also she went to bed late yesterday night, about 11 o'clock, but I have to wake her at quarter past 12 this morning. I said, please. And then sometimes I think it has to do with her heart? or is she just the sleepyhead? [...] And then I think Bo it's really nice to have to ask your questions."

- Mom, family 2

"I really enjoyed it because she was thinking also about herself. Because I do not know how she's feeling during gym at school or when she went to school. Now after doing evening she was thinking, what did I do and was I very sporty today or was I more tired than before, so that, I think it was really good also for me to see oh... This is how she feels today."

- Mom, family 2

### A valuable connection with the medical team

Mothers described that having a connection with the medical team is very important, and that provides comfort to know that Bo is backed up from specialist. Also, they mention that the fact of knowing the worry is on it's way also provides relief.

"You can put your worries and then he contacts the medical doctor. I think that's the most important thing."

- Mom, family 2

"But when she was not okay, I would like to have something like this, to get with my problems and ask, How can I help her? Is it



PARENTS

"Also the stimulation because when we see he's very quiet, maybe we can try. For example. 15 minutes was good. Maybe 20 minutes now it's good [...] try to stretch some activities, not only the limit, but try one minute over and see what happens."

- Mom, family 3

Figure 98. Quote from parent.

okay when she gets this kind of problems to ask somebody anytime. It's really getting you comfort. It's always 24 hours. But they can't answer 24 hours. But you can get your question to something. Bo gets the question to the medical team. So is the way to answer. We can wait, it's not a problem but gets you a good feeling that something like this it's possible."

- Mom, family 1

"It's a feeling there is somebody or some group of persons next to Bo of course. They can help you if you have any questions or any problems that's the function I like about it. And there is a listening ear for you. So I like that."

- Mom, family 1

Moreover, Family 3 mentioned that sometimes doctors give general advises, so Bo has the opportunity to have a more personalized approach. It was also perceived that Bo asked the right questions to the parent but also to the child, which is very important.

"Most of the time, doctors are useful but not all the times. [...] Because they gave some general advice and not typical for his heart problem."

- Mom, family 3

"Somebody [Bo] asked me the right questions. Questions that doctors don't say to me. [...] They say, How is he doing? Not how he feels."

- Mom, family 3

### Implementing Bo when arriving home after an operation

Furthermore, Parents also mentioned that the implementation of Bo could start when children go home after surgery. He could help with complications after surgery, or to know if the child is it really okay to start playing sports, since the time of inactivity is long and suddenly doing sports causes anxiety in parents.

"We live no really nearby the doctors, and Bo can help me to ask and look for answers"

- Mother of family 3

"Like, what kind of complications you can get. I'm a little bit tired, scared? Because last operation, you have complications you can get. So if you know it, and they can say, well, don't worry."

- Mother of family 1

"It will be useful, because after her operation I was afraid because she started with soccer. So I asked her doctor, is it okay she is playing soccer? she wants to do it. He said, it's okay she can do it. Well if I had this [Bo] I will be very comforted."

- Mother of family 1

"So, I was thinking maybe it was nice to have some exercise also in the hospital before, you know, from doing nothing, and in normal life, yeah, normal life, you know, it's a big difference there. Yeah. So that's a little bit insecure for me."

- Mother of family 2

### HR function as a meaningful element to decrease anxiety

Mothers expressed that an activity tracker with a heart rate function could help them when they are not sure if a symptom is a symptom because currently, they do not have something to know. Moreover, one mother expressed that the HR function could help to decrease the anxiety when thinking if indeed it is okay to do exercise regardless of what the doctor said.

"In the Christmas holiday she was standing next to me just to hug me. And then I felt also a heart beating just because she was leaning on me. But I was saying, whoa, your heart is beating really fast. So I was like, Whoa, it's way too fast. Because I can feel it. I can almost see it. Then I would like something like that [Bo] just to recognize if it's way too much, or is it



*just me being? again..."*  
- Mother of family 2

*"The tracker, I think it's a good idea. Because we have to find all the edges by ourselves, and sometimes he goes too fast. Sometimes we take, uhm... you are lazy, but there is no medium or balance. We don't know anything!"*  
- Mother of family 3

*I think it's very helpful [the HR]. Because we get some information. And we can look after it. [...] We need some analytics.*  
- Mother of family 3

*"It will be handy. But after operation it will be I think. Because you're afraid, Is it okay? She can do this? Because the doctor said okay, she's okay, but back in your head. You think is it okay. He says so. But is it REALLY okay?"*  
- Mother of family 1

*"When I know that Bo, he is getting control of her heartbeats. That gives me a lots of comfort. [...] I trust him. So I know she's with him and checking out her heartbeats and everything. So it gives me a comfort. So it will be okay. I like the idea there is something or someone with her when there's something going wrong. So that's gives me comfort."*  
- Mother of family 1

### **Bo enabling the possibility to know when it is necessary to take a rest**

For parents of children who are doing well, sometimes seeing the child doing various activities during the day makes them doubt if their child should be doing all of them. Therefore, Bo represents the possibility of feeling relief because they could see how their child is doing and how to manage energy levels better.

*"I like her energy, she got lots of energy, so it will be nice. If I know now it's enough now you have to rest."*  
- Mother of family 1

*"[Researcher] Well and would you say that having a heart rate tracker will be useful for your physical activity worries?  
[Mom] Yeah, yeah, I really think so. And also for her self, just that she knows well I have to stop running now, or I have to sit for a few minutes now and then I can come back."*  
- Mother of family 2

However, one mother mentioned that Bo is not only to manage energy levels but also to see abnormalities. For example, if the child is doing okay, but he is in a symptom zone, what could be happening there, or the other way around, when he is feeling very tired, but he is not in a symptom zone.

*"Bo is connected to an activity tracker, so I can see when Sam has two or three times, by example, some very heavy interactions, and his heart has to work very hard and he is not tired. I think huh? And sometimes then I would like to ask, why? What's wrong? or what is not wrong?"*  
- Mother of family 3

### **Bo as an opportunity to encourage my child to do more physical activity**

Besides describing how Bo could help to balance the activity of children, mothers mentioned that Bo could also enhance physical activity. Bo could help them to know when their child can do more activity, and thus take action and encourage their child to do it.

*"Because now, when you don't know anything you do like you feel, but if you know there are some risks or challenges you can act like it."*  
- Mother of family 3

*"Bo it's doing also very nice, so what will be better, I think maybe he can say you're doing fine. You can do more, you have it in you, you can do it."*  
- Mother of family 1

*"Also the stimulation because when we see He's very quiet, maybe we can try. For example. 15 minutes was good. Maybe 20 minutes now it's good [...] try to stretch some activities, not only the limit, but try one minute over and see what happens. [...] Now we are very careful, because we say no! don't do it"*  
- Mother of family 3

## **10.6 Insights from a medical perspective**

### **10.4.1 Medical Sports Doctor**

#### **Bo's physical activity path as the convergence point between cardiology and sports**

After reviewing the physical activity path, the sports

doctor noted that the path was disease-related and mentioned that it could be improved by adding a "sports zone" since the goal of Bo it is also to motivate healthy exercise levels. The physician advised to add five zones, (1) Recovery, (2) Endurance, (3) Intensity Endurance, (4) Interval, and (5) anaerobic into the current healthy zone. This zones could also help the medical team and the family members to know if the perceived symptoms are related to the heart or if they are related to the exercise level. Moreover, these zones could help Bo's system to automate messages to encourage physical activity when a child is doing physical activity in the lower HR zones.

*"What we also want to do is motivate normal exercise. Without symptoms. Or without thinking about their congenital heart disease."*

*"So I think you miss one zone [...] When you start someone training on basis of this, zone, this point and this point, you can make training zones and you have recovery. So it's at the very low heart rate that the first part of your test. And then you have endurance and that's heart rates in between you can exercise for two-three hours and then you have intensity endurance. So you can do this for like, one hour or something and then you get more interval. And then you get anaerobic."*

The doctor also mentioned that there should be an agreement between the cardiologist and sports doctor about where the Safety Threshold should be in the graph because if it is closer to the healthy zone (inside the symptom zone), it could confuse the family members.

*"I think the symptom zone is your buffer. And then you won't need this line [ST]. But that's discussion I should take with the pediatric cardiologist. [...] Because this line will make doubt with parents. Because this is the danger zone but here's a line and he should stay out of this line. What happens is if I go between this line oh, that's danger..."*

*"I think the training zones because when someone is continuously in one of the lower he's getting, he won't train his exercise endurance. Then you can motivate him to go a little bit further if it's possible."*

#### **Bo has the responsibility to also notify of HR abnormalities when he detects them**

Since Bo promotes safe-physical exercise, the physician mentioned that it is essential that one of Bo's functionalities relates to detect and share with

the medical team when the HR shows arrhythmias even when the parent or child do not share symptoms.

*"When there are alarm things you should know them right now. [...] I think it's very important because you are going to track daily life. And you will say, okay, we managed a system which supports your exercise activity and make sure it's safe. But when someone hasn't any symptoms, but it isn't safe, but you're tricking them. So you have to do something with this kind of information."*

### **Bo enhancing a multidisciplinary collaboration**

While asking what would be the role of a sports doctor inside Bo's PSS, the physician mention that she would collaborate closely with the cardiologist to make a distinction between symptoms and non-symptoms. Moreover, she thinks that she can design the exercise program for children and have meetings in person with other specialities to discuss exceptional patient cases.

*"I think as a sports doctor, you make the exercise test and you make those zones and relate them together with the cardiology, together to say, training mode. So the sports medicine doctor for their activity zones and cardio more for the danger and disease zones. And I think you have to be in the background of a nurse practitioner or something to discuss symptoms and all that kind of stuff. Together with the cardiology. And related to this kind of thing. So is it a symptom, symptom like or is it exercise? Or is both of them and also what we told earlier... When somebody is continuously in the lower zone, encourage your patient, to go a little bit higher. So I think it's a role together with the cardiologist and nurse a practitioner. And you should discuss patients every two months or every three months."*

### **Bo's system is perceived as a beneficial tool to manage physical activity concerns.**

Finally, the doctor expressed that Bo is a tool that integrates different aspects of the problem, such as parental concerns and physical activity, to offer relief when it is needed and exercise enhancement when it is possible.

*"I think Bo is very cool. [...] Apart of the things we discussed. I think it's very cool. And I think that are things that we have to think about and discuss. What we want and what we have to do with it."*





SPORTS DR.

*“Bo is very helpful! Because you can manage not only the symptoms but also the type of exercising and you can incorporate the child, but also relief the mother to getting into safe worry-less zone for both of them.”*

*- Sports Medical Doctor, Erasmus MC*

Figure 99. Quote from sports medicine doctor.

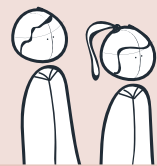


PSYCHOLOGISTS

*“I think Bo it's a pretty good idea! Especially when you can connect the physical part. The medical reflections. And, especially because you will link the experience of physical activity and the child with the feelings, and you motivate the parents to look at the child under activity and how happy they will be.”*

*- Psychologist & ICU researcher, Erasmus MC*

Figure 100. Quote from psychologist.



P. CARDIOLOGIST

*I really liked your idea. And I really think that is the first steps we can take on this issue. When they ask for certain information that Bo can give it to them. What can be automated is that Bo can be like this channel for the doctor and the parent to communicate. And I think that's also a really nice potential of Bo.*

*- Paediatric Cardiologist, Erasmus MC*

Figure 101. Quote from paediatric cardiologist.

*“Bo is very helpful! Because you can manage not only the symptoms but also the type of exercising and you can incorporate the child, but also relief the mother to getting into safe worry-less zone for both of them.”*

#### 10.4.2 Psychologist

***Bo helps to integrate hospital measurements and daily life activity and concerns in a holistic manner***

While discussing the advantages of using Bo, the psychologist mentioned that the fact that Bo supported “normal” ranges from the hospital and that he related them to the daily activity where parents could check anytime provided parents with control over the situation. By giving control to parents, this could help to manage their emotions towards physical activity. Moreover, she mentioned that the reflection moments from family members were powerful moments to realise if it was necessary to worry or if the child was doing fine.

*“I think that both can be helpful for a lot of things, not only for the physical activity. But I think it is very important. Especially with the assessments in the hospital, that you've got the ranges. So you know, what's normal? And then, Bo will reflect on the activity that child does, like, Is it okay, should it be more or should it be less? And it gives insights to the child but also to the parents, I think for physical activity. Yeah, you could connect the tracker is very important.”*

*“I think the availability of Bo. [...] I think it's, you can reach it old all day. And then it will reply to you like okay, I don't know the answer right now, but I will check with whoever. I will check with the position and he or she will return within one or two days. And then you have control, because you know somebody is listening, that you send it. You've got your worries. You shared your worries and Bo will take it seriously. He or she will come back to you. And I also like the idea of reflections of your emotions. Like not everyday perhaps? Because that was the feedback from your parents. But, okay, just take a moment and reflect how is the child doing? And what could be improved? Or? I think that's a very strength of Bo.”*

***Bo as a buffer to decrease the burden of doctors***

When asking about the increased workload due

to the concerns shared to the medical team, the psychologist saw Bo as a contingency system before parents reached to the hospital. She expressed that Bo could filter common doubts concerning the heart defect but also about the “normality” of the child's behaviour with the use of questionnaires. Moreover, while Bo monitors emotions from the family members, he could gather data from various families, know what is “normal” emotion-wise and contact the psychologist to share which could need more support than others.

*“I think as a buffer. It's between you and the parents. And it filters the problems like, Is it a normal normality? Then when a parent has a question to Bo and Bo reflects like, okay, it's normal because I checked the physical activity of the child because I check the emotions of a child are normal. And then the parent decides, will I contact the specialist or is it okay? So I think it's a filter between you and the parents because you said care specialists are very over questions like they're always busy. I think it gives me an opportunity to monitor emotions. And then you can also see, okay, this parent has a lot of anxiety, anxiousness or anxiety. Perhaps I should invite the parents like if he or she needs help.”*

*“There are validated questionnaires and you could let Bo ask this question. This can be four or three questions actually. And then because you screen and monitor very frequently, you can see okay, this is normal because you collect all the data of all the other parents and eventually you've got your own real-time database, so Okay, it's normal that you're anxious when your child is one week out of the hospital. Yeah, but it's also important to tell the parent what could you expect, like for within in three weeks we see normally anxious over our symptoms will decrease when Yours are high at that moment, then we will have an appointment or we will have an intervention or so. I think it's for to parent also a feeling of Okay, I'm normal and what can I expect? When it's not within the expectation then I know that there will be action from the hospital or I can ask. The psychologist or I think the the feeling of control is very important. [...] I think Bo is really helping with that [managing worries]. [...] I am very enthusiastic!”*

***A new opportunity - implementing Bo after the Intensive Care Unit***

While asking about the role of a psychologist inside Bo's system, the psychologist mentioned that

a system like Bo could be beneficial to manage all the concerns and traumatic experiences that parents have when they go to the ICU. The value of having a connection with the hospital during those uncertain times could support parents to manage their doubts and anxiety by connecting them with the correct specialist.

*“Well, in the emotional management part. Well, it's more like I'm a researcher at the Intensive Care Unit and when parents leave the intensive care [...] So I think that was my first reaction. To your plan. Like, for my research, I'm thinking about an intervention for parents when they leave the hospital, especially the Intensive Care Unit. It's very traumatic. A lot of it's like, living or dead. And so, I think it would be, that was my reaction to not only physical activity, but it's a connection between you and the hospital, actually. And like, is my child's doing normal? Yeah. Is it normal, that he's anxious? This is normal that he doesn't want to go to school? Is it normal that he doesn't want to be physical active? Yes, it's normal. But you want to, You want to support you want parents to know that they can always question Bo. And that Bo will find the right medical assistant. [...] Perhaps is a psychologist, perhaps it's official therapist, perhaps it's a pediatric? Yeah. So I think it could be you just started with physical activity, but I think it could be more actually.”*

#### **Bo's emotional management during physical activity can help to enhance a positive perception in the child and parents**

To conclude, the psychologist expressed that Bo's implementation was an excellent merge between the physical aspects and the emotional ones. She expressed that asking the parents to reflect on how happy their child can be while being physically active was a powerful moment to enhance positive feelings towards physical activity, instead of the negative connotation that it has.

*“I think Bo it's a pretty good idea especially when you can connect the physical part. The medical reflections. And, especially because you will link the experience of physical activity and the child with the feelings, and you motivate the parents to look at the child under activity and how happy they will be and then you can see, okay, he's very active and normally I wouldn't allow it or because I'm too scared or I think something will happen. But now I see my child is doing well. And the physician says it's okay. So you link these, like,*

*take a picture and you can look back. It was the moment that he was very active. And look how is he's playing and feeling well. Especially the emotional management I think it is very important.”*

#### **10.4.3 Paediatric Cardiologist**

##### **Bo must be a reliable system to provide safety advice**

During the interview, the pediatric cardiologist mentioned that in case Bo used more AI to advise on how much more the child can do, this should be tested several times. Because on the contrary of other APPs like Fitbit, if Bo makes a mistake by advising to do more activity than the one, it is possible, the consequences could be life-threatening. Bo was created with the aim to promote safe physical advise and that is what he should achieve.

*“And to go one step further like this artificial intelligence device. I think it would be like perfect, and it will be really nice to envision in like four years or maybe five or six or seven or maybe 10 years. Yeah, of course, because it's really, it has to be fault proof. So, of course there are a lot of apps like exercise APP they show you live feedback on your heart rate for training or for like training for marathons. But, as you said for yourself this is for safety reasons so you really have to be sure that the information you are giving the parents you are giving the child is absolutely medically sound. So, really, really safe. Because, you can do it like 1000 times right, if you do one time wrong, and the child, cross that and it goes wrong. That's unacceptable.”*

##### **Bo can help to make the information management more dynamic between the family and the medical team**

To conclude, the physician expressed that Bo could be the communication channel that provides the right information at the right time when parents feel concerned. Moreover, he mentioned that Bo is a great start to help these families to manage their concerns.

*“I think it's a good interactive way to answer like general questions. I think it would probably be like a more interactive way of what we do now with, like, patient information because we have a lot of brochures and we have a lot of websites and the physician assistant pediatric cardiology, he also made them. [...] But what you are trying to make is something more*

*dynamic, like they can get the information when they need it. And that's what I think is the future of Bo.”*

*“I really liked your idea. And I really think that is the first steps we can take on this issue. When they ask for certain information that Bo can give it to them. What can be automated is that they can be like this channel for the doctor and the parent to communicate. And I think that's also a really nice potential of Bo.”*

## **10.7 Recommendations**

When comparing the different perspectives on Bo, it was noticed that one topic emerged from the evaluation as a possible future step, implementing Bo after an operation. Parents, children and doctors mentioned this implementation. All of them expressed that the anxiety levels when leaving the hospital are high and trying to see what the child can and cannot do is a stressful experience which intensifies when the paediatric patient wants to practice physical activity. This topic was also seen during the implementation phase, where parents mentioned to Bo that when they left the hospital after an operation, they had more worries. However, now since they had seen a gradual improvement in their child's health, the worries were less.

Further Recommendations from the different stakeholders are shown below

#### **Recommendations from family members**

Children and mothers mentioned some suggestion for improving the interaction with Bo. They are summarized in table 12.

Table 12. Recommendations from family members. (Continues on next column).

#### **Recommendations from children**

- Have the possibility to communicate and interact with other children who use Bo.
- Have positive feedback from Bo when they have done something right.
- Keep the interaction in the tablet.
- Children shared that being able to send videos could help to show Bo more how they feel.

#### **Recommendations from mothers**

- Bo could help with other kinds of questions about the health of their child, not only just physical activity.
- Having the possibility to share information or show information to the coach could be an idea because they are also concerned about how the child is doing and if the child can keep exercising specially after surgery.

#### **Recommendations from the medical team**

The recommendations from the three medical specialities are shown below.

##### **- Improving the feedback for the medical team when sending concerns**

The sports physician recommended using the Borg scale to have a better reference for the level of perceived exertion of the child when doing physical activity. This scale could be implemented when doing the exercise test first, to have data related to the perceived exertion, and later if the parents share a concern, ask the child to use the scale when sending a concern. This implementation could help the medical team to see if the perceived worry or symptom is indeed related to the heart or exercise intensity.

*“But you can ask at what point of exhaustion he is. You have the Borg scale. [...] And you will ask this at the exercise test in the hospital. And when you, so he has to give points between zero and 20, I think. You can ask him at that point. What is your level of perceived exertion? and then you can relate it to the maximal exercise test. But also see okay... eight out of 20. That's not very exerted. So when he's getting symptoms at that point maybe it's more related to the heart than to the exercise intensity.”*

Moreover, it was mentioned that knowing which type of palpitation the child feels is very relevant for the doctor when making a diagnosis of the concerns shared. Therefore, the doctor suggested that Bo could share different types of sounds related to (1) regular heartbeat, (2) fast heartbeat and (3) irregular heartbeat. She mentioned that making sounds has worked for her before with families that can't distinguish between the different heartbeats.



*“Maybe you can make sounds of a heartbeat. So just a normal heartbeat and then fast but regular heartbeat or an irregular heartbeat. [...] But when you make sounds, then they can connect. So when you when I do it with my hands, then they recognize what’s regular or irregular. [...] It’s important for the doctor.”*

Another topic that was discussed with the physician was the frequency of concerns sent from the family members, and how could they impact the workload of doctors. However, the sports doctor mentioned that there should not be a limit to send worries, but Bo, should detect when a family member is sending worries while the child is in a healthy zone and keep track of those false-positive cases, so in the future, Bo maybe can automate if a limit is needed or not.

*“I think that you can’t take in account because it’s, I think, it’s a combination of how much and how real the worries are. Because when you have a mother who’s sending 10 worries who are all symptom related then 10 worries is okay. But when you have 10 worries from a mother of which none of them is symptom related, then is too much. So I don’t think you can say okay, you shouldn’t take more than five worries a day. [...] But maybe, when you track them for three months or something, you can give parents their own limits.”*

Finally, she advised that when sending the HR measurements to the medical team, it would be useful to have a complete overview of the HR from all day.

*“I think you want to see the whole day. I think you want to know how we are the whole day and in rest or at all the time.”*

#### **- Improving the feedback for the medical team from an emotional perspective**

The psychologists expressed that having the possibility to monitor emotions of the daily members could be very helpful to provide better support to them. Moreover, she mentioned that Bo could have an autonomous function to share reliable information with parents; they have concerns instead of contacting the hospital when they have their doubts. This suggestion, based on the fact that the internet has many sources which are not reliable, and some parents believe the information they should not.

*“The possibility to screen and monitor the emotion of the child and the parents. in*

*combination with physical activity. Like, are they more happy when they do more physical activity during the week? Because they always say at the evening, I’m so tired. I’m so tired. But the next day in the morning do they feel better or? Because when I do sports a lot and in the evening I’m also tired but when I wake up. I’m like, okay, I am feeling fit. [...] and perhaps giving feedback on that also. [...] I feel anxious, is it normal?, what can I expect expect? In combination with medical information.”*

*“Where can I find reliable information? Like the internet is full of information but I think 75% it’s not okay. So, I think it could be automated to give, when a parent has a question, you can give a link of trusted information like the hospital decided that this is trusted information you’ve got a website.”*

Furthermore, the psychologist mentioned that the frequency of contact with the family highly depends on the stage they are. Bo, could learn when parents need more support based on all the families in the system and adapt depending on how the family behaves by offering more or less emotional support. Besides, she mentioned that one characteristic of Bo is that families could perceive that interacting with Bo is personalised when in reality Bo learns from a significant cohort of families and makes them feel better when interacting when him. Therefore,, the contacts with them should not be standardised.

*“I think it depends on the moment. I think in the first week or the child has come to the hospital for physical activity tests. Exercise capacity tests. And I think, Bo perhaps should be a learning system. I think in the first week, you want to have three moments, for example, and then when you go further in time, it could be less, but it could also be a learning system like okay, these parents or this child needs a lot of help. So I make it more frequent actually. It shouldn’t be standardised. It should be reacting on depending on the situation.”*

*“That’s the nice thing of Bo. It feels like personalised. Well, it’s actually isn’t but it feels like and it’s learning. Yeah. So that’s the power I think is learning from the other children, the other parents... and so I think it’s personalised.”*

#### **- Improving the feedback for the medical team from a cardiac perspective**

When discussing the possible burden for doctors that Bo could represent, the doctor mentioned

that he did not know if Bo will reduce or increase it. However, what Bo could do to decrease it could be to make use of questionnaires to monitor the patients, and only address the doctor when irregularities were found. In this way, doctors could focus on the possible problem and not search for it first.

*“I’m curious about what happened here [...] will it increase the burden or to decrease the burden of the medical team?”*

*“You actually ask the things that you find important because there are quite a few examples of, well, it’s old fashioned, but questionnaires. [...] When children fill in the questionnaire and they say, well, it’s cool, everything is fine at home, everything is fine. But sports club are not doing so well. Then you can directly focus on that. So you don’t have to ask How’s it going? in school? We know is going well. Then you can only focus on the problem because you already filter out. What’s the problem areas are.”*

*“So that’s also something. I think that’s a nice potential of the interaction with Bo, you can ask a lot of standardized questions. And then Bo and check. Okay, everything is going well, this and this area and this area it’s not going so well and then alert the doctor to focus on that.”*

## Summing-up

The present chapter provided an overview of the results from the evaluation with children and their parents, as well as with diverse medical team members. Overall, Bo was received with enthusiasm by all the interviewees. However, physicians provided relevant feedback to improve Bo in the future and remarked the importance of making sure that Bo offers a safe alternative for these families. Moreover, the chapter summarized essential recommendations from the implementation and evaluation phase.

The next and final chapter will recapitulate the initial research questions and provide the conclusion of the overall project.

### Takeaways from this chapter

- Families were not used to talking with a system. However, it did not represent an obstacle to share their concerns.
- Reflection moments at the end of the day were highly appreciated among family members.
- Bo’s chatbot function was perceived as valuable due to the back-up from the medical team to provide personalized feedback.
- Knowing when to stop physical activity with the activity tracker was perceived by child and mothers as a beneficial feedback system to self manage the child’s energy.
- Bo could be implemented when the child goes out of the hospital after surgery since that experience is the most traumatic among family members.
- HR measurement was perceived as a great way to know if a symptom is a genuine symptom.
- Having HR will enable parents to monitor better the child and try to enhance PA incrementally. Doctors suggested adding training zones to offer better advice to families.
- Doctors remarked that for future development, Bo should be a reliable and secure device to promote PA, since Bo is promoting safety exercise. In case of malfunctioning, it can result in severe consequences.
- Bo’s system can be a buffer to decrease the burden of the physicians by using standardized questionnaires and scales to measure variables before contacting the hospital.
- The frequency of concerns shared should not be limited. The system should supervise false-positive cases of concerns and learn based on them to create a family profile.



## Chapter 11

# General discussion

Chapter 11 aims to provide a conclusion for the overall design process and answer to the three research questions previously defined. Moreover, the chapter will reflect on the design assignment and the limitations faced during the realisation of a proof of concept for anxiety and overprotective attitudes in parents with CHD paediatric patients.

# General discussion

The presented design process in this master thesis culminates with the recapitulation of the three main research questions defined in Chapter 1 and their corresponding answers. Moreover, it reflects on the assignment previously established and describes the limitations of the project.

## 11.1 Answers to research questions

### 1. Which are the triggers for overprotection according to past experiences?

According to the text analysis of 305 online parental stories from five different countries described in Chapter 2, the uncertainty of not knowing when would be the follow-up surgery had a high impact in overprotective behaviours during childhood. Depending on the CHD complexity, children will have to undergo open-heart surgery in the future years. Therefore this uncertainty predisposes parents to constantly look for symptoms and health deterioration over time which generates anxiety and overprotective behaviours when they believe they perceive a symptom. These symptoms, when detected, acted as triggers for remembering past painful experiences.

Furthermore, uncertainty in follow-up surgery in combination with looking for symptoms was found repeatedly in the in-depth interviews conducted with seven families (Chapter 3) and during the evaluation phase interviews in Chapter 10.

### 2. Which are the dimensions of the physical activity model that relate to the triggers identified?

Based on the findings from Chapter 3 and 4, the physical activity dimensions that were related to a constant search of symptoms and health deterioration were 'Communication and perception' and 'Fitness'. The first dimension 'Communication and perception' was highly related to the perception of possible symptoms presented during physical activity participation. When perceiving a symptom or health deterioration, the correct differentiation between healthy physical activity exhaustion and CHD symptoms was found to be complicated and

confusing. Therefore, parents preferred not to take a risk with their child's health.

Moreover, the 'Fitness' dimension was found to be associated with the anxiety that arises when an increase in physical activity intensity and difficulty is detected when their child participates in physical activity.

### 3. Which data-based features should the PSS have to decrease perceived levels of overprotection and anxiety in parents?

Incorporating Heart rate (HR) measurement as 'Physical activity zones' in the envisioned PSS solution resulted in an excellent function for parents to feel relief and comfort when their child is doing physical activity. In chapter 10, parents and children described that HR in an activity tracker could benefit the child by providing feedback to self manage their safety boundaries and learn from it.

Furthermore, parents mentioned that HR measurements could help them to know if a symptom is a genuine symptom, and hence, encourage their child to do more physical activity when is possible based on the pre-defined physical activity zones.

## 11.2 Reflection on the design assignment

This project aimed to develop a proof-of-concept for a PSS that increased support from parents towards the CHD patient to pursue an active lifestyle. It aimed to accomplish it by providing data-based awareness to decrease perceived anxiety and overprotection in parents.

By carrying out different activities such as text analysis, in-depth interviews and a co-creation session, the project achieved an optimal integration of the most relevant stakeholders. The outcome of the design process resulted in a proof-of-concept implemented in a real-life scenario and that according to the families, provided a feeling of comfort and the opportunity to stimulate their child to do more physical activity.

Moreover, Bo provided a supportive exploratory environment, in which physician and parents shared a tangible connection to alleviate concerns in a reduced time and, at the same time, enabled the child to self-discover his safe boundaries during exercise participation.

The value proposition for the main stakeholders, according to Bo's vision, and their evaluation is the following:



CHILD

Know the recommended time to stop physical activity for a moment, to learn how to self-manage safety boundaries and energy levels



PARENTS

A reliable and personalized source of relief for their concerns. Where they can see by themselves, how is their child's HR at any given time.



MEDICAL TEAM

A buffer to filter concerns before they arrive at the hospital, where only problem-defined cases arrive with their corresponding HR data.

To conclude, Bo delivers a Product-Service-System alternative to family, and medical team were the primary focus is to offer a safe and ordinary sports-life where children enjoy all the benefits that physical activity has to offer.

## 11.3 Limitations

A significant limitation encountered when planning the implementation phase was the time remaining in comparison to all the procedures required to bring the prototype to the everyday life of families. Administrative and ethical procedures at the TU Delft took more time than the one available and

therefore, the implementation phase had to be reduced to one week instead of the two weeks as previously defined.

Moreover, due to the duration of the Master thesis project, and the time required to gather Medical-Ethical approval to place activity trackers on children, only some parts of different sub-modules were implemented. Future testing phases of the envisioned sub-modules should be considered in the further development of Bo, and the implementation of activity trackers should be the next study to be implemented in order to validate the insights shared concerning HR measurements and its impact in overprotection.

Furthermore, each of the stakeholders plotted into the system canvas should be interviewed to know how they see themselves in the PSS network. Due to time limitations, it was possible to discuss with five out of the 15 envisioned stakeholders.

To finalize, it is important to remark that as the doctors mentioned, what Bo offers to families is a safe device to promote physical activity. Therefore exhausting testing should be done to see the accuracy of the HR monitors (in the activity tracker) to see the accuracy of the measurement and determine which brand of activity trackers offers the best option for Bo to be as secure as possible.

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