DESIGN OF A COMMUNICATION TOOL TO SUPPORT INCLUSIVE SPORTS PARTICIPATION OF CHILDREN WITH CONGENITAL HEART DEFECTS

A communication system for creating and sharing personalized sports advice

Image source: iStock

Frédérique Pel
Master Thesis
Industrial Design Engineering
Delft University of Technology

16 January 2026

Design of a Communication Tool to Support Inclusive Sports Participation of Children with Congenital Heart Defects

Graduation date - 16-01-2026

Master Thesis
MSc Integrated Product Design
Faculty of Industrial Design Engineering
Delft University of Technology

Author
F.C.M. (Frédérique) Pel
Student number - 5012880

TU Delft Supervisory Team
Dr. ir. J.W. Hoftijzer - chair
Ir. K.R. Boltjes - mentor

Erasmus MC Sophia - external client
R.S.C. Meuldijk, MSc - researcher and psychologist

Preface

This master's thesis, "Design of a Communication Tool to Support Inclusive Sports Participation of Children with Congenital Heart Defects," is the result of my graduation project within the Master's program Integrated Product Design at Delft University of Technology. In this project, I developed a communication tool intended to support children with congenital heart defects in participating safely and inclusively in organized sports activities.

My interest in this topic developed during an elective course in my master's program, where I worked with children for the first time in an academic context. Their openness, enthusiasm and the feedback they shared during testing sessions made me realize how much I value designing solutions that support children and the people around them. From that moment on, I knew that I wanted my graduation project to focus on a context in which children play a central role.

I want to use my role as a designer in a way that feels relevant in practice, and the healthcare domain offered a context in which this felt appropriate and meaningful. The topic of congenital heart defects also has personal relevance to me, as heart-related conditions occur within my own family. This project therefore allowed me to combine my interest in design, healthcare, and social impact within a subject that is close to my heart.

Throughout this project, I worked within the context of healthcare and organized sports and collaborated with a diverse group of stakeholders, including healthcare professionals, parents, children, sports coaches, and other involved parties. Through literature research, interviews, and co-creation sessions, I gained insight into the experiences, needs, and challenges of children with congenital heart defects and the people around them in relation to sports participation, as well as the difficulties involved in sharing and interpreting information across different stakeholder groups. While the process was sometimes complex, it helped me better understand my role as a designer working at the intersection of healthcare, communication, and sports practice involving children and their families.

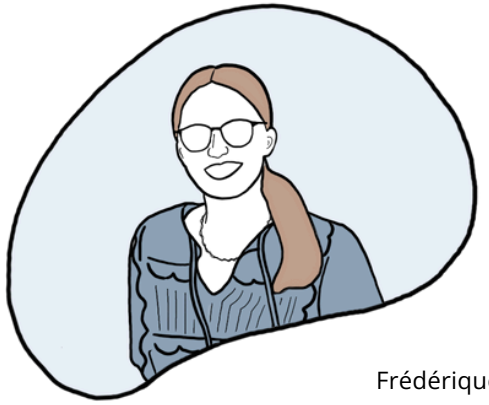
I would like to thank my supervisors at TU Delft, JanWillem Hoftijzer and Kim Boltjes, for their guidance throughout my graduation project. I would like to thank JanWillem for his support during the process, his input during discussions and brainstorming sessions, and his practical guidance in his role as chair. I am grateful to Kim for introducing this graduation project to me. Her constructive and detailed feedback helped me to strengthen the content of the project and sharpen my design decisions, from which I have learned a lot as a designer.

I would also like to thank Rebecca Meuldijk, my supervisor from Erasmus MC, for her valuable feedback and the perspectives she shared from her expertise. Her open and enthusiastic approach made the collaboration very pleasant and motivating.

Furthermore, I would like to thank all participants who participated in the interviews and co-creation sessions for sharing their experiences and insights, which were essential to the development of the final design. I am also grateful to everyone who helped put me in contact with these participants.

Finally, I would like to thank my parents, brother, grandfather and friends for their support throughout this project. Whether through practical help, brainstorm sessions, emotional support, or simply offering moments of distraction, their involvement was invaluable to me throughout this project.

I hope you enjoy reading my thesis.



Frédérique Pel
Delft, January 2026

Summary

Physical activity and sports participation are important for children's physical and social development, including children with congenital heart disease (CHD). Although many children with CHD are medically able to participate, participation in practice is often hindered by uncertainty about what is safe and appropriate. This uncertainty is partly related to how information on sports participation is communicated between healthcare professionals, parents, sports coaches, and children. This graduation project, therefore, investigated the needs of stakeholders and designed a tool to improve communication and understanding around sports participation, to support accessible and inclusive participation in organized sports activities for children with CHD.

The project followed a human-centered and iterative design approach. Literature research and qualitative interviews were conducted and synthesized into journey maps, from which key intervention moments were identified. These insights informed the development of design requirements and initial concept directions, which were further explored and refined through two co-creation sessions with stakeholders. Two key components were subsequently evaluated with users to gather feedback.

The findings show that communication about sports participation is fragmented, unclear, and inconsistent across healthcare and sports contexts. In consultations, sports participation is frequently addressed briefly and superficially due to time constraints, variation in counselling practices, and assumptions about the child's preferences and needs, which may result in possible underlying uncertainties or concerns of the child not always being discussed.

Parents are generally expected to pass on information to the sports environments and want control over what is shared with whom. However, this transfer of information often occurs without a standardized structure and carries a risk that medical guidance is interpreted differently once it reaches the sports environment. As a result, sports coaches may receive information that lacks clarity. Sports coaches are responsible for providing a safe, inclusive environment, but often lack CHD-specific knowledge and practical guidance.

Taken together, these findings suggest that improving communication and understanding requires a shared and structured approach that connects healthcare and sports contexts, supports consistent information transfer, and fits within stakeholders' existing roles and working practices. Such an approach should make needs and uncertainties explicit, and support shared understanding of what is safe and appropriate to enable more inclusive sports participation for children with CHD.

To achieve this, a concept communication tool was developed to demonstrate how this approach can be supported in practice. The final design consists of a pre-consultation questionnaire and a sports advice form, supported by a digital parent-child sports advice platform. Prior to the consultation, children complete the questionnaire via their patient-portal, which enables the cardiologist to prepare in advance and tailor discussion during the consultation. Afterwards, the cardiologist completes a sports advice form, which families will receive.

They can use the platform to add context-specific information and filter which information from the sports advice they want to share with sports coaches and distribute it through their existing communication channels.

In this way, the tool brings together relevant information from various stakeholders and supports clearer and more consistent communication between the healthcare and the sports context, while fitting within existing workflows.

Table of contents

Glossary

Congenital heart defects/disease (CHD) - problems in the structure of the heart that are present from birth (i.e. congenital).
A congenital heart defect refers to a more specific abnormality that occur during development, whereas congenital heart disease is a broader term used for any heart-related condition that exists at birth.
In this report, both terms are used interchangeably.

Double diamond model - a representation of a design process consisting of two diamonds, each with diverging and converging phases: discover, define, develop, and deliver.

Physical Activity (PA) - In this report, PA refers to everyday physical movement and sport participation in the context of children with a congenital heart defect.

Self-efficacy - The belief in one's own ability to successfully perform a specific task or activity, such as engaging in physical activity or sports.

Sports coaches - In this report, the term sports coaches is used as an umbrella term to refer to people responsible for guiding or supervising physical activity in children. This includes professional sports coaches, physical education (PE) teachers and other sport-related professionals, unless otherwise specified.

Stakeholders - All individuals or groups with an interest in or influence on a particular issue. In this project, stakeholders include children with CHD, parents, healthcare professionals and sports coaches.

Image source: Vecteezy

1 Introduction

This chapter introduces the context of this graduation project. It describes the project background, stakeholders and involved parties, and outlines the problem and design goal. In addition, this chapter presents the research questions and provides an overview of the approach of the design process and structure of the report.

1.1 Project context

Sport and exercise are essential for children's physical and social development. Research shows that regular physical activity during childhood has immediate benefits for psychological well-being, overweight, skeletal and cardiorespiratory health and also supports motor skill development that has long-term health benefits (Loprinzi et al., 2012). To achieve these benefits, the World Health Organization recommends that children and adolescents should engage in moderate to vigorous exercise for at least 60 minutes a day, including muscle- and bone strengthening activities at least three times a week (World Health Organization, 2020).

In the Netherlands, about 1300-1400 babies are diagnosed with a congenital heart defect (CHD) each year (Amsterdam UMC, 2023). Due to medical advances, more than 90% of these children reach adulthood and many of them are able to lead relatively normal lives (Amsterdam UMC, 2023). For children with a congenital heart defect, exercise is especially important, as reduced physical fitness can increase the risk of co-morbidities, i.e. type 2 diabetes, obesity, depression and anxiety (West et al., 2019). Even modest amounts of physical activity can already provide significant health benefits (Janssen & LeBlanc, 2010).

However, it appears that despite having minimal medical restrictions in many cases, these children are often less active than their healthy peers (Voss et al., 2017). The hesitation in sports participation is not only related to medical factors, but also to psychosocial factors, such as social barriers, parental overprotection and uncertainty about physical limits (Chong et al., 2018). Research shows that uncertainty and lack of information can create fear and apprehension about physical activity, not only in children with CHD but also in their families, teachers and physicians supporting them in sports (Buchanan et al., 2023).

Clear and individualized physical activity advice can reduce this uncertainty and support more confident participation (Buchanan et al., 2023). This highlights the importance of better knowledge sharing and clearer communication between the stakeholders involved in sports participation of these children (Saxena et al., 2021).

This forms the basis of my graduation project, which focuses on organized sport activities, such as training at sports clubs and physical education classes at school, for children with congenital heart defects.

1.1.1 Stakeholders

The main stakeholders involved within the scope of this graduation project, who play a role in communication and decision-making around sports participation are:

- **Children with a congenital heart defect (CHD)** in the age of 6-16 years old. This age group was chosen because it includes important stages at which choices around sports participation are often made and is representative of relevant developmental stages in physical activity. For example, many children begin participating in organized team sports around the age of six, after obtaining their swimming certificates. The transition from elementary school to high school is also an important moment in children's physical and social development.
- **Parents** of children with a congenital heart defect.
- **Healthcare professionals** who provide medical advice about sports participation of children with a congenital heart defect.
- **Sports coaches and PE teachers** who teach sports classes and work in environments that support physical activity (e.g. sports clubs and schools).

Children with CHD

Parents

Healthcare professionals

Sports coaches/ PE teachers

1.1.2 Involved parties

This graduation project is conducted in collaboration with Erasmus MC and is part of a broader research context within the Convergence initiative Healthy Start.

Erasmus MC is the largest university medical center in the Netherlands. Pediatric care is provided by the Erasmus MC Sophia Children's Hospital, which offers specialized treatment for children with congenital heart defects. The pediatric cardiology department at Sophia is part of the largest academic center for CHD in the Netherlands (Erasmus MC, n.d.).

Healthy Start is an initiative of Erasmus MC, Erasmus University Rotterdam and TU Delft, which focuses on the health and well-being of children and young adults. Through research and collaboration between medical, social and technological sciences, as well as societal partners, Healthy Start strives for equal developmental opportunities for all children and young adults, regardless of their background (Convergence, n.d.).

(Erasmus MC, n.d.)

(Convergence, n.d.)

1.2 Problem and design goal

Each child with CHD has a unique medical history and specific limitations or abilities. Pediatric cardiologists provide advice on sports participation, but in practice, parents often face many challenges when they try to apply these guidelines in daily life (Longmuir et al., 2021). Although they indicate understanding the doctors' advice, uncertainty remains in translating it into concrete situations (Longmuir et al., 2021).

Research shows that only 39% of clinicians give exercise advice at every consultation (Williams et al., 2017). Lack of time, lack of training and uncertainty about appropriate recommendations are cited as major barriers. As a result, giving clear and specific guidance is often lacking (Williams et al., 2017).
Parents subsequently struggle to communicate this advice clearly and effectively to sports coaches or teachers. Sports coaches or teachers, in turn, often do not know how to safely and appropriately support these children (Saxena et al., 2021). This may lead to uncertainty, misunderstanding and overprotectiveness, resulting in children participating in sports activities less frequently or in a less inclusive manner than medically necessary (Longmuir et al., 2021).

Moreover, children with CHD themselves may also experience uncertainty or anxiety about their physical abilities, which can negatively affect their motivation to participate in sports activities (Longmuir et al., 2021).

There is a need for clear, tailored and effective communication and knowledge sharing about the abilities and limitations of children with CHD, between the stakeholders involved.

Therefore the goal of this graduation project is:

__Investigate needs__ and __design a tool__ to __improve__ the __communication__ between parents, sports coaches, healthcare professionals and __children with a congenital heart defect__, so that these children can __participate__ in organized sports activities in an __accessible and inclusive__ way.

1.3 Research questions

Based on initial exploration of the topic, the following main research question was defined.

1.3.1 Main research question

How can **communication and understanding** between parents, sports coaches, healthcare professionals and children with a congenital heart disease be **improved,** in order to enable **accessible and inclusive participation** in organized sports activities?

1.3.2 Sub questions

To answer the main research question, the following sub-questions are formulated:

1. What are the **experiences and needs** of parents, children with CHD, healthcare professionals and sports coaches regarding current communication about sports participation?
2. What **tools** are **currently being used** to share information within the fields of sports and healthcare?
3. How do the different stakeholders perceive their own **roles and responsibilities** within the communication process?
4. In what ways can a communication tool contribute to **improving communication and accurate understanding** between the involved parties?

The full project brief is shown in Appendix A.

1.4 Approach and structure of the report

The design process followed throughout this project is based on the **Double Diamond model** (Figure 1). This model consists of two diamonds, each with a divergent and convergent phase. The first diamond focuses on researching and defining the problem and the second on developing and testing a solution (Design Council, n.d.). The Double Diamond was chosen because it supports a human-centered and iterative approach, which is suitable for this project as it involves multiple stakeholders and requires exploration of needs and iterative development of a communication tool.

The structure of this report reflects the four phases of the Double Diamond model:

- **Discover:** understanding the problem by doing literature research and conducting interviews with stakeholders.
- **Define:** analyzing the obtained data and refining the problem.
- **Develop:** creating multiple solution directions based on the defined needs.
- **Deliver:** further developing a concept and testing it with users to gather feedback.

The report is structured accordingly. Chapter 2 presents the literature review, providing background and context of the project. Chapter 3 describes the qualitative interviews conducted with key stakeholders, offering insight into their experiences, needs, and challenges. In Chapter 4, insights from the literature and interviews are synthesized into journey maps, through which potential intervention moments are identified and the insights are translated into design requirements.

Chapter 5 explores existing tools and initiatives related to healthcare and sports participation, which are analyzed to identify opportunities and inspiration for the design. Based on the combined insights gathered throughout the project, Chapter 6 develops and refines a concept direction,. Chapter 7 presents the final concept, which is evaluated with users in Chapter 8. Finally, Chapter 9 reflects on the findings and outcomes of the project through a discussion and conclusion.

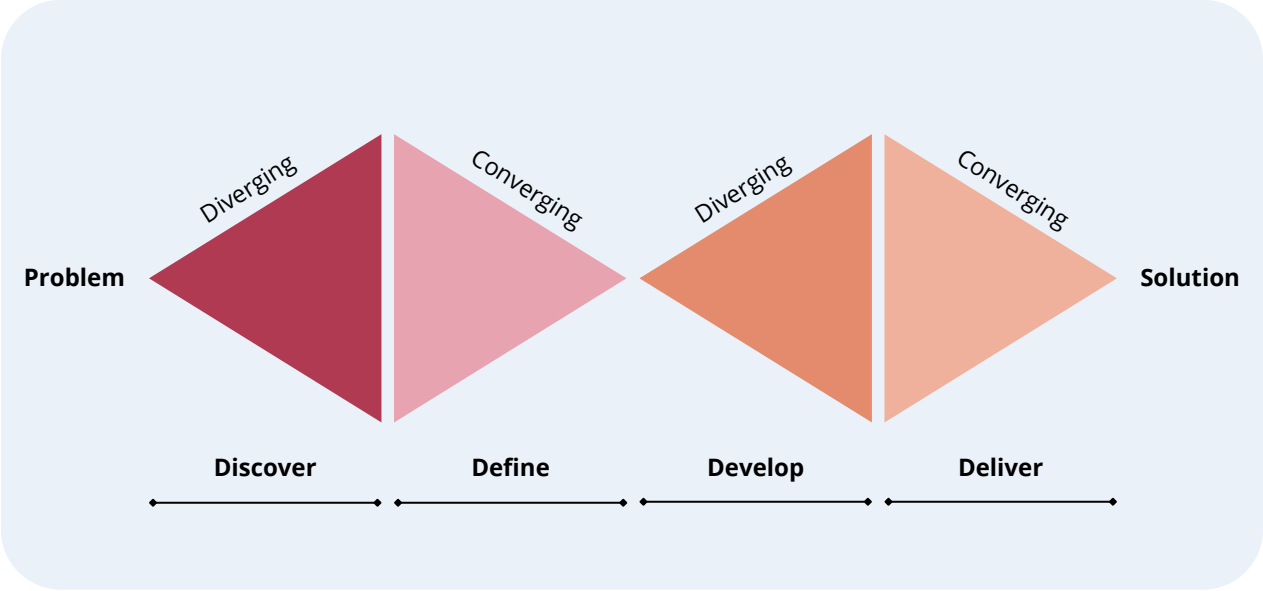


Figure 1: The Double Diamond model

Image source: Pixabay

2 Literature research

This chapter presents the findings of the literature research conducted to understand sports participation in children with CHD. It provides background information on children with CHD, physical activity guidelines, actual physical activity behavior, and internal and external factors that influence sports participation. The chapter concludes by summarizing key insights and outlining how these informed the subsequent interview study.

2.1 Children with a congenital heart defect

Congenital heart defects (CHD) include structural problems of the heart that occur before birth. They are the most common congenital condition in children (Sun et al., 2015).
CHDs can vary widely in type and severity. They often involve holes in the heart wall or narrowed heart valves. Some children may also develop heart rhythm disorders (arrhythmias), caused by the heart defect itself or, for example, as a result of their treatment.
There are several ways to classify CHDs, including by anatomical location, clinical presentation or most common types (Patiëntenvereniging Aangeboren Hartafwijkingen, n.d.). In this report, heart defects are classified according to their complexity, into mild, moderate or severe defects. See Table 1 for a broad overview.

Some children have minor conditions that require little to no medical intervention, while others have complex defects that involve multiple surgeries or lifelong care.

The severity and nature of the defect determine the treatment pathway, which may include medication, repair via cardiac catheterization, one or more surgical interventions, or the implantation of a pacemaker or ICD (Wong, 2021). Long-term follow-up care is often required after these interventions. Most CHDs are diagnosed before birth or within the first week of life, although milder forms may only be detected later (Pavlicek et al., 2021).
Figure 2 shows a visual timeline of a general care trajectory for a child with CHD.

As previously mentioned, due to advances in medical care, most children with CHD now reach adulthood and can lead relatively normal lives (West et al., 2019). Consequently, the focus of care is shifting from survival to promoting quality of life (Roston et al., 2013). Participation in sports plays an important role in this, due to its positive effects on both physical and mental health.

Nevertheless, many children with CHD, as well as their parents and other people involved, experience barriers and uncertainties when it comes to participating in sports.

The following sections will explore the current guidelines, physical activity behaviors and psychosocial factors that influence sports participation in children with CHD.

Mild	Multiple interventions and/or implants (such as a pacemaker or ICD), prolonged medical trajectory with lifelong follow-up.
Moderate	More complex defect, one or more interventions (such as surgery or catheterization), annual follow-up.
Severe	Multiple interventions and/or implants (such as a pacemaker or ICD), prolonged medical trajectory with lifelong follow-up.

Table 1: General overview of congenital heart defect severity levels

Prenatal

A CHD is often detected during the 20-week ultrasound.

If an underlying syndrome is suspected, additional genetic testing may be offered.

Parents are prepared for specialized care around delivery.

A multidisciplinary team is involved:

- gynecologist
- pediatric cardiologist
- pediatric neurologist
- neonatologist
- pediatric thoracic surgeon
- radiologist

0-1 years

In approximately 30–50% of children with a CHD, no intervention is necessary.

The remaining children undergo one or more procedures during their first year of life, such as a catheter-based intervention or open-heart surgery. The exact treatment depends on the type of defect and the individual situation.

A large proportion of these children can lead a reasonably normal life after the intervention.

Lifelong cardiologic monitoring

However, about one-third of the children experience lasting limitations and/or undergo multiple surgeries in the subsequent years.

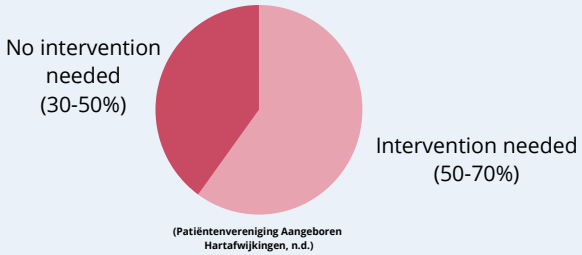
Complex CHDs (involving heart failure or arrhythmias) often also require medication, sometimes long-term or lifelong.

Possible complications	Treatment
Arrhythmias	Medication
Heart failure	Pacemakers
Endocarditis	ICDs
Valve insufficiencies	Additional surgeries
Stenosis of implanted valves or other surgical materials	Catheter interventions
	Medication
Pulmonary hypertension	

14-18 years

From age 14 to 18, children attend a transition clinic (transitiespreekuur), where they learn to manage their own heart condition and transfer from a pediatric cardiologist to an adult congenital cardiologist.

Proportion of children with CHD requiring an intervention in the first year of life



Long-term outcomes after initial CHD intervention

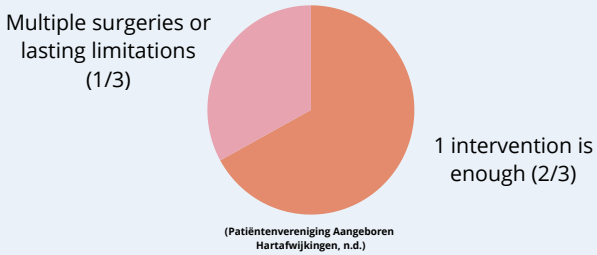


Figure 2: Visual timeline of a general care trajectory for a child with CHD. Based on information retrieved from Patientenvereniging Aangeboren Hartafwijkingen (n.d.)

2.1.1 Guidelines & medical recommendations for physical activity in children with CHD

International guidelines, such as those from the World Health Organization (WHO), recommend that children should engage in at least 60 minutes of moderate to vigorous physical activity daily, including muscle- and bone strengthening activities at least three times a week (World Health Organization, 2020). For children with CHD, physical activity is also recommended in most cases, provided it is tailored to their individual medical condition. According to the American Heart Association, the benefits of physical activity, such as improved cardiovascular health, muscle development, weight management and psychosocial well-being, often outweigh the potential risks (Longmuir et al., 2013).

However, specific exercise recommendations for children with CHD are lacking. Existing guidelines often focus on adolescents or adults training for competitive sports, or on individuals of all ages with genetic heart conditions or arrhythmias. These recommendations are frequently and incorrectly applied to younger children or to situations for which they were not intended, such as physical education, free play, or recreational sports (Longmuir et al., 2013).

Moreover, many current recommendations are based on expert consensus and risk estimation rather than solid scientific evidence. Fear of sudden cardiac death (SCD) during physical exertion plays a major role in this cautious approach. For example, research from the province of British Columbia estimates the prevalence of SCD in individuals in the population under 35 to be only 5,26 per 100.000 (Roston et al., 2013).

Importantly, Roston et al. (2013) also note that the incidence of SCD in patients with repaired or palliated congenital heart disease is very low, as demonstrated in several CHD-specific studies. Furthermore, Silka and Bar-Cohen (2012) show that mortality and SCD rates in individuals with CHD have decreased substantially over recent decades, and that risk profiles have shifted due to improved survival and long-term care.

Despite these developments, commonly cited guidelines do not consistently incorporate this more recent evidence, which may contribute to more conservative counselling practices and, as a result, unnecessarily limit physical activity participation among children with CHD.

2.1.2 Actual physical activity behavior

Children with CHD are often less active than recommended and also less active than their healthy peers (Chong et al., 2018; Longmuir et al., 2022), even when their exercise capacity is medically considered comparable to their healthy age group. Inactive lifestyles are associated with sedentary morbidities, such as depression and atherosclerosis (Longmuir et al., 2022).

One contributing factor is the misjudgment of a child's physical activity level by parents. Research shows that parents tend to overestimate how active their child is. While many believe their child leads an active lifestyle, objective measurements indicate that only 28% of children actually meet the recommended 60 minutes of daily activity (Longmuir et al., 2021).

Nevertheless, both parents and children acknowledge the importance of physical activity for heart health. Presenting objective activity data to parents may help provide a more realistic view of their child's lifestyle (Longmuir et al., 2021).

Other factors influencing physical activity behavior, such as psychosocial and environmental influences, are explored in the following chapters.

2.1.3 Internal factors: psychosocial influences on sports participation

Psychological factors also play a significant role in the physical activity behavior of children with CHD. These factors strongly influence how children perceive their own bodies, limitations and capabilities.
One of the key underlying psychological processes involved is self-efficacy.
Bandura (1994) describes self-efficacy as an individual's belief in their capability to execute actions required to achieve desired outcomes. These beliefs shape how people feel, think, motivate themselves and behave (Bandura, 1994). In the context of physical activity, self-efficacy refers to an individual's confidence in his or her ability to engage in physical activity (Buchanan et al., 2023). This confidence is a strong predictor of sports participation throughout life (Buchanan et al., 2023). Studies have shown that children with CHD often score lower on self-efficacy compared to their healthy peers, due in part to negative experiences, physical symptoms, social exclusion and overprotection (Buchanan et al., 2023; Saxena et al., 2021).

Low self-efficacy is associated with avoidance of sports, while positive experiences and support from the environment, such as encouragement from family, healthcare providers, or role models, may help strengthen this confidence (Buchanan et al., 2023).

The study by Chong et al. (2018) identified six overarching themes that provide insight into the experiences of children and adolescents with CHD. Three of these themes are directly relevant to physical activity: warring with the body, hampering potential and goals and establishing one's own pace. These are explained below.

Warring with the body

Some children with CHD experience physical symptoms such as shortness of breath, fatigue, dizziness and chest pain. These complaints are often mentioned as barriers to physical activity, due to fear of discomfort or overexertion (Saxena et al., 2021). However, such complaints may not always be directly caused by the heart condition itself, but may also result from anxiety or reduced physical fitness. This shows that psychological barriers can sometimes be more impactful than actual physical limitations (Buchanan et al., 2023).

As a result, some children become discouraged and start avoiding physical activity. This avoidance behavior can reduce their self-efficacy and create a negative cycle of inactivity and declining confidence. Many children also feel sadness or frustration when they are unable to participate in sports activities that seem natural or easy for their peers (Chong et al., 2018). Not being able to join in sports can result in social exclusion and reinforcing feelings of being different (Sprong et al., 2024).

Some adolescents attempt to compensate for their physical limitations by engaging in risk-taking behaviors such as motorcycling, fighting, or using alcohol and drugs, to prove that their condition does not define or restrict them (Chong et al., 2018). This suggests that supporting adolescents in finding safe, meaningful forms of participation may reduce the likelihood that they turn to alternative ways of expressing their autonomy or capability.

The way children cope with challenging situations often follows one of two behavioral patterns, as described by Longmuir et al. (2021). A mastery pattern, in which the child continues to try and improve despite setbacks, and a helpless pattern, in which the child withdraws due to fear of failure. Many children with CHD tend to show the helpless pattern in sports settings, often because they expect limited success or are worried about injuries (Longmuir et al., 2021).

The way parents or others respond to these situations also influences how the child reacts (Longmuir et al., 2021). If adults are themselves uncertain about the child's physical capacity, they may unintentionally discourage participation and autonomy. In contrast, a positive, task-oriented approach, such as encouraging effort, perseverance and small successes can help foster a mastery pattern and build the child's confidence (Longmuir et al., 2021). These behavioral patterns are elaborated on in Figure 3.

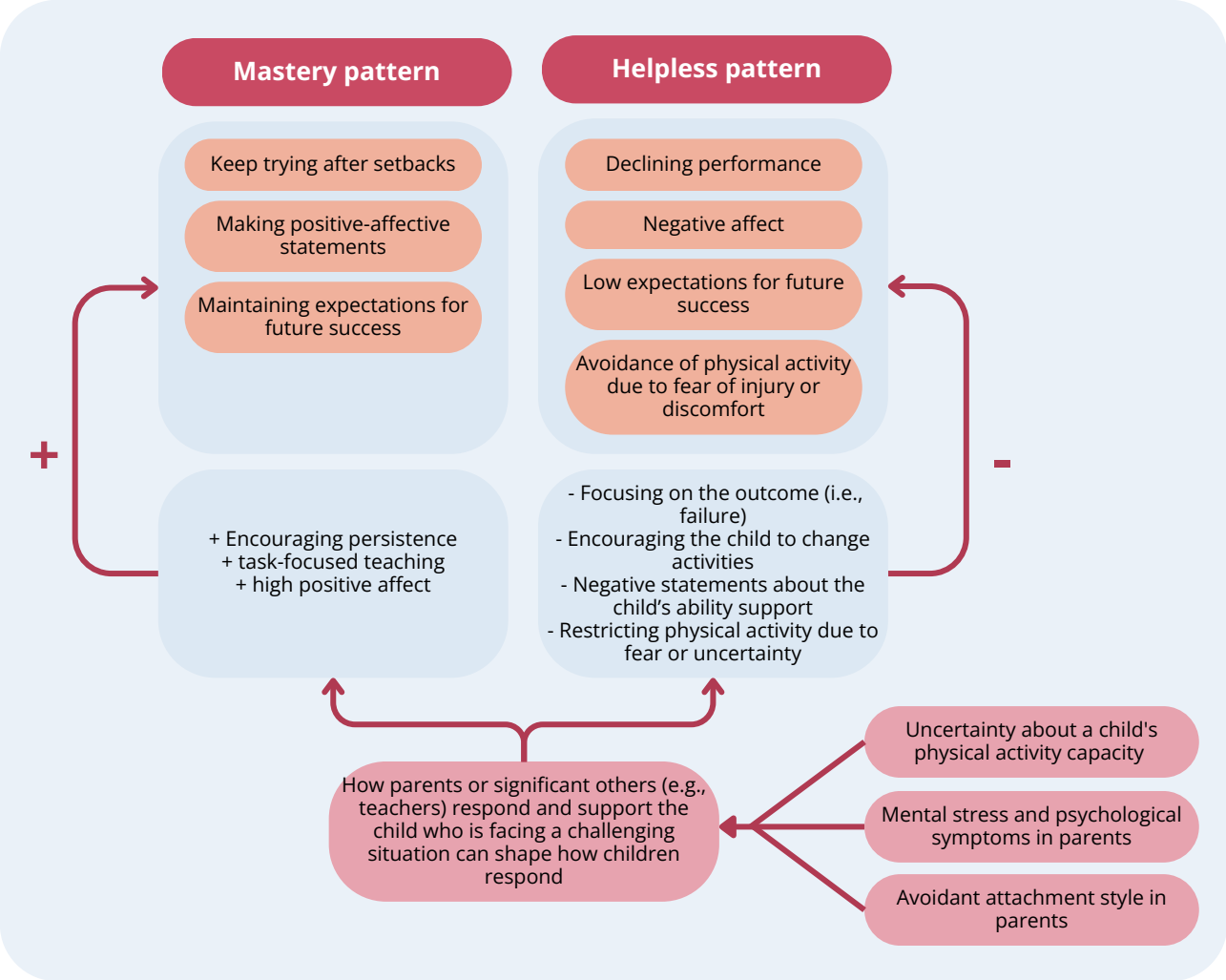


Figure 3: Patterns influencing sports participation (Longmuir et al., 2021)

Hampering potential and goals

Some children with CHD perceive themselves as "disabled" and feel socially or physically inferior compared to their peers (Chong et al., 2018). At the same time, they struggle with a desire to be seen as "normal" (Sprong et al., 2024).

Reactions from the environment, such as overprotection, low expectations, or exclusion, can reinforce this sense of being different (Chong et al., 2018). Some children believe they are labelled by others as fragile, weak or incapable of enjoying activities. Some report being bullied by peers who are aware they cannot fight back due to physical weakness or medical devices. Others experience discrimination from adults, such as parents discouraging their children from playing with someone who has CHD, because of fear of responsibility (Chong et al., 2018). Research shows that overprotection by parents or teachers is associated with lower self-efficacy and reduced sports participation (Buchanan et al., 2023). These experiences collectively undermine children's self-efficacy (Buchanan et al., 2023).

In contrast, positive experiences, moments of success and encouragement from the environment can help build self-confidence and strengthen motivation to stay active (Saxena et al., 2021). The feeling of competence, the belief that one can keep up with peers, has been shown to influence children's engagement in physical activity (Longmuir et al., 2021).

Some children with CHD feel that their condition limits them from achieving broader personal goals, such as school performance, social participation or future plans (Chong et al., 2018). Although these goals fall outside the direct context of sports, they reflect the same underlying theme of feeling hampered. This can negatively impact motivation, self-esteem and long-term commitment to physical activity (Chong et al., 2018).

Establishing one's own pace

To navigate the previously mentioned challenges, some children with CHD develop their own ways of coping with their condition in daily life. Rather than focusing solely on their limitations, they learn to recognize their physical boundaries and adapt accordingly. This may include selecting suitable forms of physical activity, participating at an adapted level or taking on coaching roles (Chong et al., 2018). Others regain a sense of control by strictly following lifestyle recommendations and medication regimens (Chong et al., 2018).

Support from the environment also plays a key role in facilitating this self-regulatory process. Clear explanations from healthcare professionals about what is safe and why certain limitations apply, help children gain a better understanding of their own capacity. This type of tailored communication not only reduces uncertainty but also fosters autonomy and trust (Buchanan et al., 2023).

In addition, many children find strength in adopting a positive outlook. Focusing on what remains possible, rather than on restrictions, helps shift their mindset. Some consciously invest in their strengths, while others reframe their limitations in a strategic way, for example by using their condition as a reason to avoid activities they don't like (Chong et al., 2018).

Support from family, peers with CHD and religion also contributes significantly to emotional strength. Children appreciate friends who actively engage them, such as by waiting during physical activities so they can stay together. In addition, advice and hopeful stories from older people with cardiovascular disease offer support and practical coping strategies (Chong et al., 2018).

This combination of resilience and support enhances children's self-efficacy and influences the likelihood of long-term engagement in physical activity (Longmuir et al., 2021; Buchanan et al., 2023).

In summary, psychosocial factors play an important role in how children with CHD engage in physical activity. Fear of symptoms, feelings of difference, low self-efficacy and negative social reactions can create barriers in participation. At the same time, positive experiences, supportive environments, feelings of competence and positive role models can foster self-efficacy and engagement in physical activity.

Because these internal experiences are closely shaped by the people and environments surrounding the child, the following chapter examines external influences, such as home, school and healthcare environments and how these contexts may facilitate or hinder participation in sport.

2.2 External factors: environmental influences on sports participation

Besides the previously discussed internal factors, children with CHD are also influenced by external factors that shape how they engage in physical activity and sports.

According to Longmuir et al. (2021), three environmental contexts play a crucial role:

- The social environment at home
- The health environment
- The peer-related social and physical environments such as school and daycare

In this report, the latter is referred to as the sports environment, as the focus of this project lies specifically on participation in physical activity in organized sports, which typically take place in settings such as sports clubs and schools.

The following sections will explain how each of these environments can both promote or hinder sports participation.

2.2.1 Home environment

The home environment can both support and hinder physical activity in children with CHD. Siblings often play a positive role, because their presence encourages children to be more active (Longmuir et al., 2021). On the other hand, many children reported that their parents restricted their physical activity, for example by telling them to calm down or sit still (Longmuir et al., 2021).

Parents themselves acknowledge being hesitant to encourage physical activity, especially when they are unsure about their child's physical capacity, even when doctors indicate that few limitations are necessary (Buchanan et al., 2023; Longmuir et al., 2021). This hesitancy is partly caused by concerns about the child's long-term health and a different perception of the child's capabilities than the child has themselves (Buchanan et al., 2023).

In a study by Sprong et al. (2024), parents reported that the heart defect greatly impacts them, in a higher degree than children themselves. Many parents express doubts about how to interpret physical responses, such as sweating and increased heart rate, and struggle to distinguish the normal effects of physical activity from symptoms of heart problems and warning signs (Longmuir et al., 2021).

Several studies suggest that part of this uncertainty results from limited knowledge. Cheuk et al. (2004) found that although many parents knew the name of their child's heart defect and why surgery was performed, they often lacked understanding of medication, side effects, and the implications for physical activity. Only 59% could correctly assess their child's exercise capacity. Similarly, Chessa et al. (2005) demonstrated that only 40% of parents knew whether their child could safely participate in competitive sports, and many were unable to answer the question at all. The authors conclude that existing educational programs are insufficient and should be improved to strengthen parents' understanding and they can better guide their children.

Quantitative studies indicate that 80% of parents underestimate their child's physical abilities and 20% impose restrictions that are not medically necessary (Longmuir et al., 2021).

Interestingly, inactivity among these children is barely related to the severity or type of the heart defect. The mere presence of a chronic condition seems to trigger protective behavior from parents, regardless of the child's age, sex, or the complexity of their diagnosis (Ong et al., 2011).

Consequently, children with both mild and severe forms of CHD are often less active than their healthy peers (Ong et al., 2011). This highlights that parental overprotection, rather than medical severity, is a key barrier to physical activity in children with CHD. Children who did want to be active often found this overprotection frustrating. Nevertheless, they tended to adopt their parents' advice and became more hesitant to participate in sports themselves (Longmuir et al., 2021). Perceived overprotection during childhood is associated with increased heart-focused anxiety in adulthood (Ong et al., 2011). Such anxiety may reduce confidence in one's own body and become a long-term obstacle to leading an active lifestyle.

However, Sprong et al. (2023) found that physical activity was not associated with parental overprotection, but with parental perceptions of vulnerability. Children whose parents believed they were vulnerable participated less in sports activities and showed lower levels of moderate-to-vigorous physical activity (MVPA), even when their cardio respiratory fitness and motor performance were within normal ranges. This suggests that reduced participation is driven less by objective physical limitations and more by parental influences. Sprong et al. (2023) therefore recommend that clinicians explicitly communicate when no physical activity restrictions apply, in order to prevent parents from unnecessarily assuming that their child is vulnerable.

Therefore, targeted communication from healthcare professionals to parents (and children) about the benefits and safety of physical activity is essential, both to improve current activity levels and to prevent misconceptions from influencing behavior later in life (Saxena et al., 2021; Sprong et al., 2024).

2.2.2 Sports environment

Studies suggest that many children with CHD experience the school and sports environment as encouraging. For many children, enjoyment and social interaction play a key role in motivating participation in physical activity (Longmuir et al., 2021). However, some children report taking on a more passive or hesitant role themselves in these contexts, often due to uncertainty or a feeling of not being able to keep up with their peers. This can hinder participation, even when the environment is supportive (Longmuir et al., 2021).

The social context at school or in sports clubs not only affects the moment itself but also influences the development of self-efficacy regarding physical activity (Sprong et al., 2024). Positive experiences at a young age, such as during physical education or after-school sports, help children build confidence in their abilities and lay the foundation for an active lifestyle later in life (Sprong et al., 2024). Social and inclusive settings, such as physical education lessons and sports clubs, provide opportunities to engage children with CHD in physical activity in an accessible way through positive role models, peer interaction and varied activities. In addition, Saxena et al. (2021) emphasize that teachers, coaches and recreation professionals are important sources of verbal persuasion, which can increase children's self-efficacy towards physical activity. This means that informing and supporting coaches may contribute directly to children's motivation and long-term engagement in sport.

Despite these positive factors, research shows that teachers and sports coaches often feel insufficiently informed or confident in how to support children with CHD (Buchanan et al., 2023; Longmuir et al., 2021). Many of them are hesitant to actively involve these students in physical activities unless they have received explicit written medical clearance from a physician (Buchanan et al., 2023; Longmuir et al., 2021). As a result, environments that have the potential to be stimulating may, in practice, become limiting.

To prevent potentially supportive environments from becoming limiting in practice, collaboration between healthcare professionals, parents, (children) and sports coaches is essential. Sports coaches need clear, personalized guidance on what types of physical activity are safe and appropriate for each child (Longmuir et al., 2021; Buchanan et al., 2023). Such communication can reduce uncertainty, build confidence among coaches and ensure that children with CHD are offered meaningful and inclusive opportunities to participate in sports (Buchanan et al., 2023).

2.2.3 Health environment

The healthcare environment plays a crucial role in how parents and children with CHD approach physical activity. However, interactions between healthcare professionals, parents and children often contribute more to uncertainty and confusion than to the encouragement of sports participation (Roston et al., 2013).

Research shows that most children with CHD do not recall their doctor ever explicitly discussing physical activity with them (Longmuir et al., 2021). What they do remember is often interpreted as restrictions (Longmuir et al., 2021). Furthermore, studies have found that young adults with CHD report feelings of uncertainty and being different, partly because they were often excluded from conversations between parents and healthcare providers about their own condition during childhood (Longmuir et al., 2021). This exclusion contributed to a lack of knowledge about their physical abilities and may negatively impact their confidence in sports settings (Longmuir et al., 2021).

Parents, too, often struggle with unclear and inconsistent guidance. Over the years, they often receive various and sometimes conflicting recommendations about what their child is allowed or not allowed to do and they struggle to translate these medical guidelines into concrete, everyday situations (Longmuir et al., 2021). Additionally, research shows that parents tend to hold on to and accumulate earlier advice, even when it is outdated. This contributes to the ongoing uncertainty and confusion about what their child can safely do (Longmuir et al., 2021).

In addition, parents express a need for care tailored to their child's condition and family context. They prefer receiving follow-up from experienced professionals who are familiar with the specific heart defect, rather than general practitioners, and value clear, personalized advice that is given at important developmental milestones, such as going to school or choosing a sport. Parents also appreciate being able to reach out to healthcare providers between scheduled appointments for clarification or support (Sprong et al., 2024).

There are also challenges on the side of healthcare professionals. Although they generally consider physical activity important, only 39% of healthcare professionals provide physical activity advice at every consultation. Barriers include time constraints, lack of training and uncertainty about appropriate recommendations. Legal liability concerns also play a role (Williams et al., 2017). Clinicians report that their main concerns when prescribing activity include the risk of sudden cardiac death (96%), limited exercise capacity (61%) and time since the last cardiac event or procedure (39%). These concerns explain why healthcare professionals may adopt a cautious approach, even though, as discussed earlier, the actual risk of sudden cardiac death in children with CHD is extremely low in most cases (Roston et al., 2013).

In addition, the criteria healthcare professionals use to guide their recommendations vary. The most frequently considered factors are the intensity, duration and frequency of the activity. Despite this, many healthcare professionals still experience uncertainty about how to make appropriate recommendations. 71% reports regularly consulting published literature and 96% expresses the need for more comprehensive and consensus-based guidelines. This illustrates the widespread uncertainty and desire for clearer frameworks in clinical practice (Roston et al., 2013).

Restrictions also vary significantly between providers. 49% of respondents place no restrictions on children with structural CHD. The most common restrictions are competitive sports (30%), weight training (30%), contact sports (29%), endurance activities (15%) and even recreational sports (3%) (Roston et al., 2013). However, the study does not specify what these restrictions actually entail.

For example, it remains unclear whether activities such as competitive or contact sports are discouraged entirely, or only permitted under specific conditions, such as with modifications or under supervision.

In summary, the healthcare environment holds great potential to support children with CHD in participating in sports environments. However, in practice, it often contributes to confusion, uncertainty and unnecessary restrictions. This highlights the need for clear, consistent and accessible communication tools that help healthcare professionals engage in structured, tailored and practical conversations about physical activity.

2.3 Conclusion literature research

2.3.1 Summary and key insights

Medical guidelines emphasize the importance of physical activity for children with CHD and state that most children, even those with moderate to severe heart defects, can participate safely in sports activities with appropriate guidance. Despite these recommendations, actual physical activity levels remain lower than recommended and often lag behind those of healthy peers.

Several factors contribute to this, including vague medical guidelines, psychological barriers, and environmental influences at home, in sports settings and in healthcare settings.

- Parents frequently overestimate their child's actual activity level, while objective measurements show that only a minority of children with CHD meet the physical activity guidelines.
- Psychosocial barriers, in both child and stakeholders, such as low self-esteem, overprotection, fear and social exclusion contribute to avoidance of sports participation. Positive reinforcement and an environment that supports autonomy can influence this behavior and promote engagement.
- Parents play an important role, but often limit activity due to uncertainty, fear or misconceptions, regardless of the actual severity of the condition. This overprotection can lead to long-term anxiety and reduced confidence in the child's own physical abilities. However, recent findings suggest that it is not overprotection alone, but parental perceptions of vulnerability of their child that are associated with reduced sports participation and lower levels of physical activity.
- Research also shows gaps in parental knowledge. Many parents lack essential information about their child's condition, medication and exercise capacity.
- Although the school and sports environment can be potentially stimulating, sports coaches often lack specific knowledge or guidance to safely involve children with CHD in sports activities. Without clear instructions from healthcare professionals, they may unnecessarily exclude or restrict these children.
- Physical activity is not sufficiently or effectively discussed explicitly in healthcare settings. Parents and children often perceive advice as restrictive, even when few or no limitations apply, or find it difficult to implement in daily life. Healthcare professionals mention time pressure, lack of training, the absence of clear guidelines and sometimes legal concerns as barriers to provide sports recommendations.

Taken together, the reviewed literature shows that many barriers to physical activity participation among children with CHD are not solely related to medical limitations, but to how sports-related advice is communicated, interpreted and applied in everyday contexts. Research shows that parents, children, sports coaches and healthcare professionals often receive or provide unclear, inconsistent or incomplete information, and struggle to translate medical advice into daily life. As a result, uncertainty increases, and physical activity is often guided by caution or fear rather than by accurate knowledge, even when no medical restrictions apply.

Based on these synthesized literature insights, improving the quality and clarity of communication, rather than simply increasing the amount of communication, appears essential.

Effective communication would therefore involve:

- Translating medical guidelines into practical, child-specific advice
- Providing concrete, sport-specific guidance that is easy to apply in practice
- Addressing and clarifying misconceptions and outdated or unclear recommendations
- Reassuring stakeholders about safety and warning signs
- Involving children in conversations about their abilities, experiences and goals in PA
- Giving healthcare professionals a structured way to discuss physical activity within limited consultation time

A brief elaboration on these elements is provided in Appendix B.

A communication tool can support this by providing a structured, consistent and accessible way to share personalized sports advice between stakeholders. Such tools can support stakeholders in applying medical recommendations in practice and in creating safe and inclusive opportunities for physical activity for children with CHD.

2.3.2 From literature to interviews

The literature research provides a strong foundation for understanding the main barriers to sports participation in children with CHD. It identifies communication problems between parents, healthcare professionals and sports coaches and demonstrates the roles that different stakeholders play in encouraging or restricting sports participation.

However, the examined literature provides limited insight into the practical experiences of the involved stakeholders. In particular, it remains unclear how communication between certain stakeholders actually takes place, why stakeholders may hesitate to initiate conversations, what their specific needs are regarding a communication tool, which communication channels they prefer and how a tool could fit into their daily routines and contexts.

To answer these questions, the next phase of this project will involve qualitative interviews with children, parents, healthcare professionals and sports coaches. These interviews aim to gain deeper insight into the stakeholders' personal experiences and needs, to validate assumptions derived from the literature and to gather input for the design of a communication tool that is applicable within the daily lives and context of all involved stakeholders.

Image source: Vecteezy, edited by author

3 Interviews

This chapter presents insights from interviews conducted to gain deeper insight into practical experiences, needs, and communication challenges related to sports participation of children with CHD. It describes the interview method, analysis approach, and resulting themes across different stakeholder groups. The chapter provides input for the design requirements and design decisions described in the following chapters.

3.1 Method

Semi-structured interviews were conducted with the main stakeholder groups identified in this project: children with CHD, parents, sports coaches and healthcare professionals. In total, 12 interviews were conducted. Figure 4 provides an overview of the interviewed participants per group.

Recruitment

Children and parents were recruited through professional networks of one of the supervisors of this project. Most healthcare professionals were recruited the same way, except from one physical therapist who was recruited through a personal network. Sports coaches were recruited through personal networks. All participants volunteered to participate in the interviews.

Participant characteristics

Two interviews with children were conducted together with a parent, one interview was conducted with a parent only.

Among the sports coaches, only the sports club coach had experience with children with CHD, both PE teachers had no experience with working with children with CHD.

For the children interviewed, none had received exercise restrictions from a cardiologist. This means their experiences may not be fully representative for the wider group of children with CHD, especially those with stricter limitations.

Due to time constraints within the project, the number of participants per stakeholder group is relatively small.

Interview content

For each stakeholder group, a tailored interview guide was created. Although the specific questions differed per role, all interview guides addressed similar overarching themes, such as sharing information with other stakeholders and communication needs regarding support for children with CHD. Children and parents were additionally asked about their experiences and concerns related to sports participation, sports coaches were asked about working with children with CHD during sports lessons or, if they had no prior experience, how they would hypothetically approach such situations. Healthcare professionals were asked about their views on sports participation and their experiences with providing sport-related advice to children with CHD. The full interview guides are included in Appendix C.

Children

Child + parent (2x)

Parents

Child + parent (2x)
Parent (1x)

Healthcare professionals

Pediatric cardiologist (3x)
Physical therapist (2x)
Sports physician (1x)

Sports coaches

Sports club coach (1x)
PE teacher (primary school, also hockey coach) (1x)
PE teacher (secondary school) (1x)

Figure 4: Overview of the interview participants

Procedure

Interviews were conducted either online or in person, depending on the availability of the participant. All participants signed informed consent prior to the interview. Consent procedures for parents and children followed the ethical protocol approved by the METC of Erasmus MC. Consent procedures for healthcare professionals and sports coaches followed the HREC approval from TU Delft (Appendix D contains the blank consent form).

All interviews were audio-recorded and transcribed for analysis. Each participant has a pseudonymized code based on stakeholder type and interview order. These codes are used throughout the results section when referred to quotes.

Figure 5 shows participants with their pseudonymized coding and roles.

Healthcare professionals

Participant	Role
R-H1	Physical therapist
R-H2	Pediatric cardiologist
R-H3	Physical therapist
R-H4	Pediatric cardiologist
R-H5	Sports physician
R-H6	Pediatric cardiologist

Sports coaches

Participant	Role
R-S1	Sports club coach
R-S2	PE teacher primary school (also hockey coach)
R-S2	PE teacher secondary school

Children and parents

Participant	Role
R-F1-C	Family 1, child with CHD
R-F1-P	Family 1, parent
R-F2-P	Family 2, parent
R-F3-C	Family 3, child with CHD
R-F3-P	Family 3, parent

Figure 5: Overview of interview participants with pseudonymized coding

3.2 Analysis

All interview transcripts were analyzed and converted into individual statement cards, with each statement card containing a valuable statement or insight. This approach was inspired by Stappers in Convivial Toolbox: Generative research for the front end of design (Sanders & Stappers, 2012).

Figure 6 shows the format that was used for all statement cards. These statement cards were clustered multiple times in Miro. The clustering process was iterative. In each round, clusters were refined, merged, or rearranged to create a more logical structure and to identify patterns across the different stakeholder groups.

The final clusters consisted of a mix of thematic clusters and context clusters. While thematic clusters focus on what stakeholders need, experience, think, or find difficult, context clusters help to understand the background and circumstances in which these insights emerge.

The complete set of statement cards and cluster groupings used as supporting material for Chapter 3 are collected on a Miro board. Access is limited to the supervisory team and can be requested by contacting the researcher.

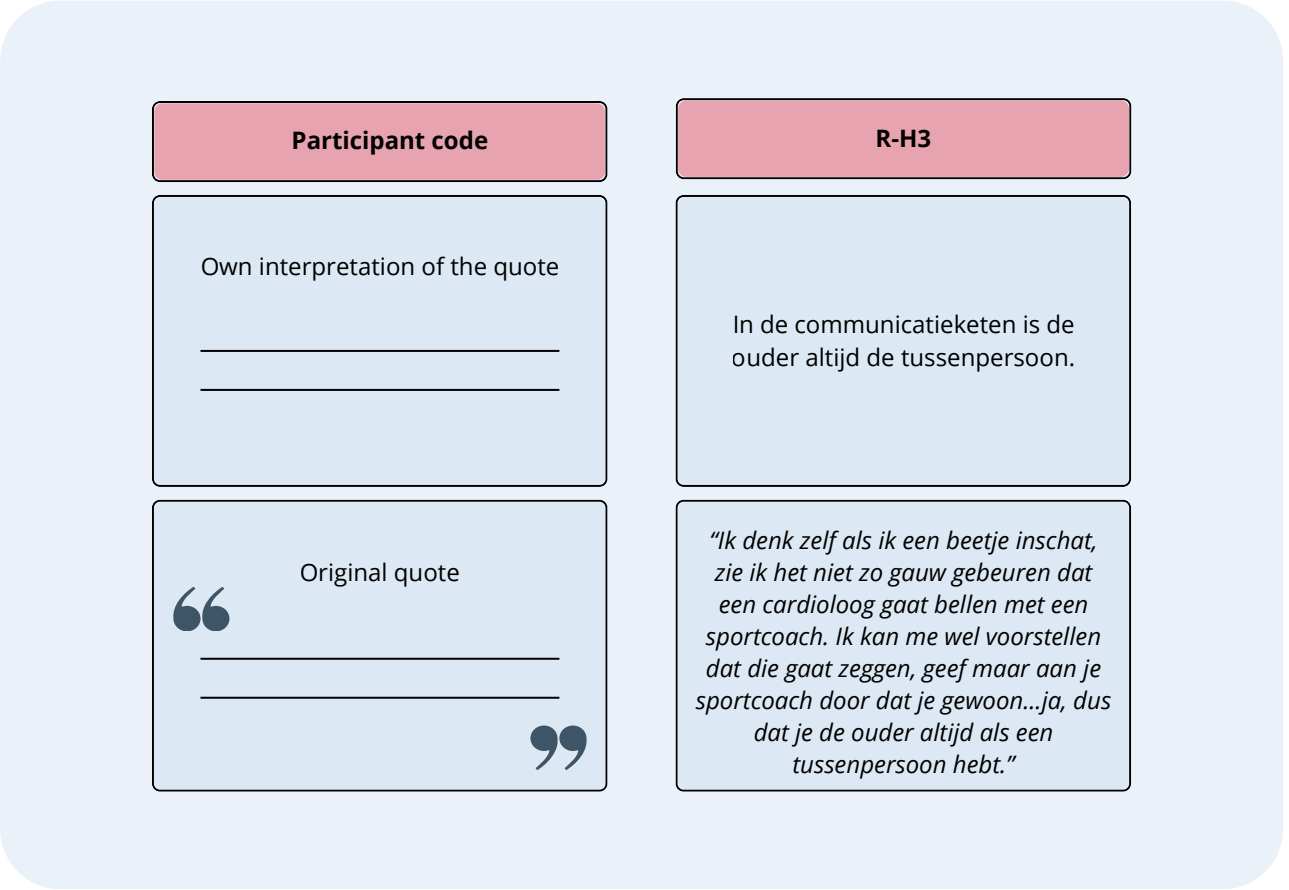


Figure 6: Format of a statement card, consisting of the participant code, an interpretation of the quote and the original quote from the interview

3.3 Results

This chapter presents the main insights from the interview analysis, organized per stakeholder group. The results focus on recurring patterns in communication, role expectations, experienced barriers, needs for support, and current practices related to sports participation and information exchange for children with CHD.

Not all insights from the interviews are included in this chapter. Some of the insights mainly served as input for later stages of the design process, such as for the development of journey maps or for idea generation. These insights are therefore discussed in the corresponding chapters.

The following sections describe the interview insights that are most relevant for understanding the current situation and the interactions between the involved stakeholders.

3.3.1 Overview of communication routes and stakeholder roles

3.3.1.1 Communication routes between stakeholders

To properly understand the interview findings, it is important to first provide an overview of the stakeholders involved and how they communicate with each other in practice. Figure 7 therefore visualizes the main communication routes between children with CHD, their parents, healthcare professionals, and sports coaches. This overview is based on the interviews conducted with these stakeholder groups.

The interviews show that the pediatric cardiologist is the only structural medical contact for all children with CHD. Only when a child is referred to additional professionals, such as a physical therapist or sports physician, does further contact occur between these professionals, the parents, and the child. However, this applies only to a small number of children. For most children, the cardiologist is the sole medical point of contact. This is highlighted in Figure 8.

Information transfer to the sports environment almost always takes place via parents or the child themselves. Direct contact between medical professionals and sports coaches at sports clubs or schools rarely occurs. Only in specific cases when needed may a physical therapist contact a sports coach, but always with explicit parental consent.

In practice, parents and children do not necessarily communicate directly with all sports-related stakeholders shown in the overview. Depending on the communication practices within a specific school or sports club, information may be passed on indirectly. For example, information may be shared with a class mentor or school management, who then relay it to the PE teacher, without direct contact between parents and the teacher. Similarly, within sports clubs, information may be communicated via the sports club committee before reaching the sports coach, meaning that parents do not always have direct contact with the coach. In addition, the responsibility for sharing information may shift between parents and children themselves, depending on the child's age, the context, and the perceived need for support or adaptations.

The visual highlights that there is no fixed or standardized route or communication channel for information exchange between healthcare, school, and sports clubs. Organizations and individuals use their own preferred communication channels such as email, phone calls, face-to-face conversations, or organization-specific platforms such as Magister in many secondary schools. This leads to variation in how and whether relevant information about a child with CHD reaches the appropriate person. As a result, the sports environment often depends on how parents and children interpret medical advice, what they choose to share, and the way in which they communicate this information.

Legend

——— Standard communication routes

– – – – Indirect or context-dependent communication routes

····· Occasional or non-standard communication routes (only when needed)

Type of communication channel mentioned in the interviews

- Organisation specific communication platforms
- Email
- Phone calls
- Conversations

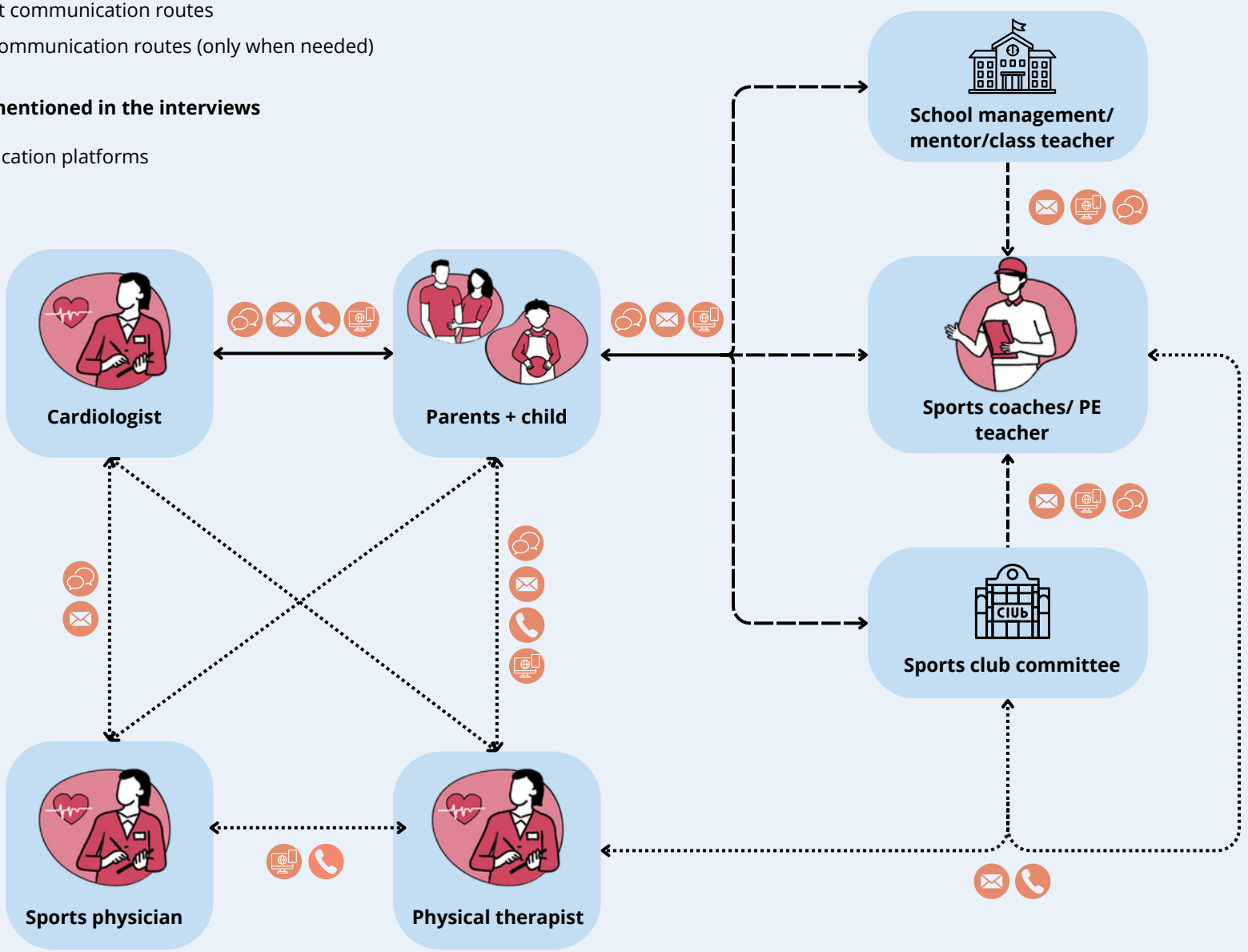
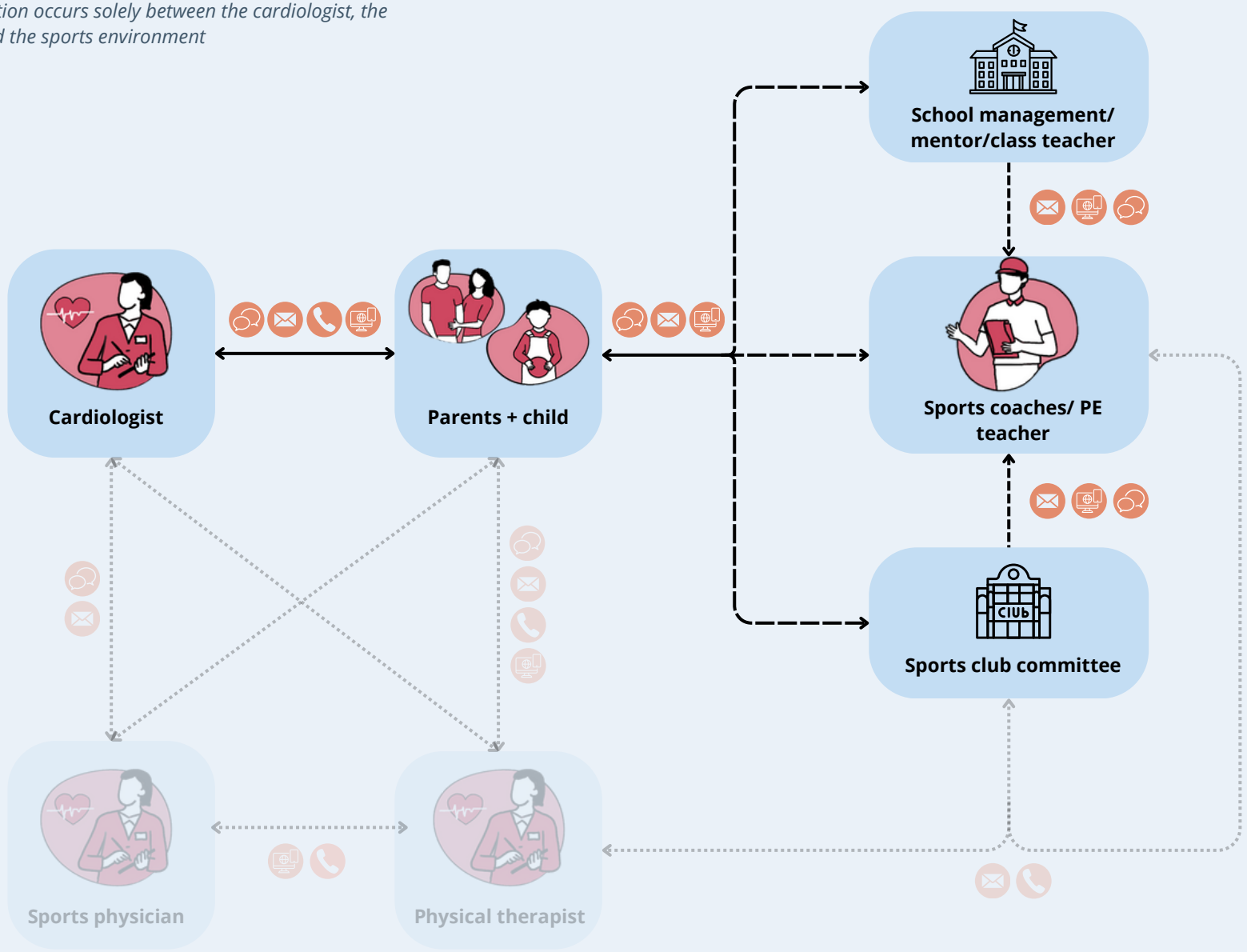


Figure 7: Overview of current communication routes between stakeholders involved in supporting a child with CHD

Figure 8: Simplified visualization of the most common communication routes. Most communication occurs solely between the cardiologist, the parents/child, and the sports environment



3.3.1.2 Roles and responsibilities of involved stakeholders

Figure 9 shows an overview of how the various stakeholders interviewed view each other's roles and their own roles in supporting a child with CHD.

- **Cardiologists** are the primary medical authority. They assess risks, can determine whether restrictions apply and can provide sports advice. Because they see every child with CHD and possess the relevant medical information, they are the most reliable and consistent source of sport-related advice.
- **Parents** are expected to inform schools and sports coaches, but their knowledge levels vary and they do not always know what information to communicate or how to explain it. This may lead to a risk of miscommunication or incomplete information transfer.
- **Children** are often expected to indicate physical limits themselves, even though they may not always recognize symptoms or feel confident to communicate them.
- **Sports coaches** are responsible for creating a safe and inclusive environment and support and comfort the child, but often lack medical guidance to fulfil their role confidently.
- **Sports physicians** and **physical therapists** support a small group of children with specific problems or questions and are therefore not consistently involved in every child's care trajectory. Therefore they cannot function as a consistent communication link in the care trajectory for all children with CHD.

Together, these visuals provide an overview of how information related to sports participation is shared and what expectations stakeholders have in supporting a child with CHD. The following chapters describe, for each stakeholder group, the experiences, challenges, and needs that emerged from the interviews.

Cardiologist

- Identifying potential problems in the child
- Referring the child to other medical professionals when necessary
- Determining whether there are any medical restrictions
- Providing sports advice in relation to the child's condition

Parents

- Sharing relevant information from healthcare professionals with the sports coach or school
- Informing the sports coach or school about their child's heart condition
- Observing signals in their child and discussing them with healthcare professionals

Child

- Learning to recognize physical signals
- Indicating when limits are reached

Sports coach/ PE teacher

- Creating a safe and positive atmosphere during sports activities
- Supporting the child when necessary and considering potential limitations
- Maintaining an open and approachable attitude so children feel comfortable to express themselves
- Sharing information with parents or professionals when explicitly asked or when someone else takes the initiative
- Having limited medical background information and therefore relying on information provided by parents or children

Physical therapist

- Supporting children with questions or difficulties related to physical activity
- Enabling children to exercise with more confidence

Sports physician

- Providing sport-specific advice within his/her area of expertise

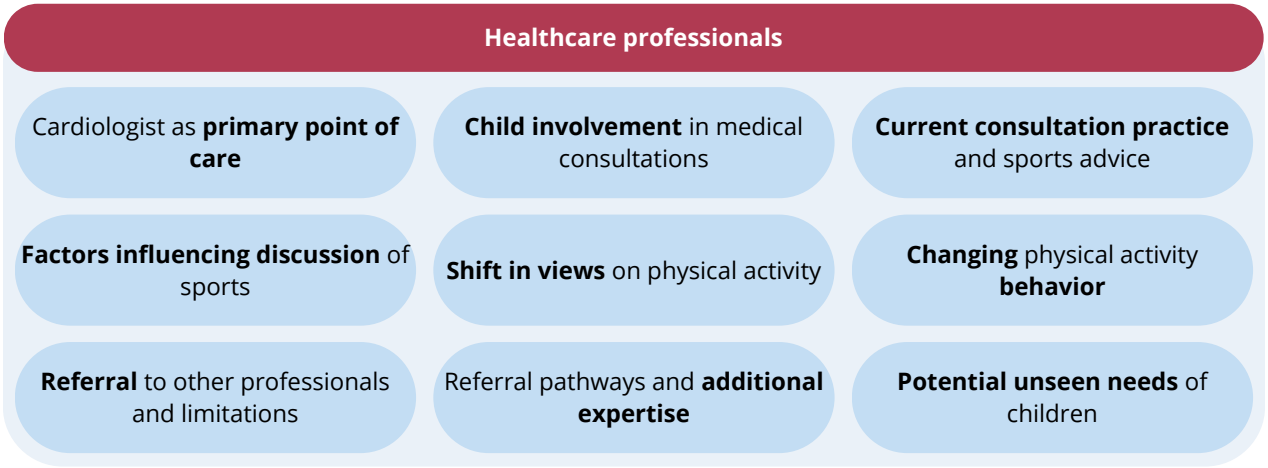
Figure 9: Roles and responsibilities of involved stakeholders

3.3.2 Role-specific insights from interviews

3.3.2.1 Healthcare professionals

This section presents the main insights about healthcare professionals as described in the interviews, including perspectives from different stakeholders.

The visual to the right presents the main themes discussed in this chapter. These themes are based on the qualitative analysis of the interviews and link to the cluster labels in Miro. More specific subthemes are described in the subsections below, with the underlying interview data supporting these insights available in Miro.



A. Positioning of the cardiologist within the care trajectory

The interviews show that pediatric cardiologists play a central role in the guidance of children with CHD. Cardiologists are the primary and often the only consistent medical point of contact for most children. The frequency of follow-up appointments varies considerably per child and per medical complexity. Most children who are doing relatively well and have no additional comorbidities visit the cardiologist once every two to three years. Children with more complex heart defects are seen more frequently, often once or twice a year.

During these periodic consultations, cardiologists typically follow a structured approach: they ask how the child is functioning, conduct a physical examination, and discuss the results of any additional diagnostic tests. This is more elaborately shown in the journey map in Figure 11 on page 56. Based on this information, they determine the follow-up plan.

Within this consultation, they also assess whether there are any indications of risks during physical activity and whether sports or exercise restrictions are necessary.

Other healthcare professionals, such as physical therapists or sports physicians, are only involved occasionally and are not a standard part of the care trajectory for all children with CHD. As a result, the cardiologist is the only source of medically informed sports advice for most children and their parents.

Design implication:
A tool should support cardiologists in providing information about sports participation, as they represent the primary and often only moment of receiving sports-related medical advice for most children.

B. The consultation and current sports advice

B1. Child as the primary conversation partner

Interviews with healthcare professionals and parents show that the child is generally the central focus during the consultation. Cardiologists, sports physicians, and physical therapists typically direct their questions and explanations to the child first, with parents adding information when needed. A parent indicated that he appreciated this approach and experienced that the child was actively included in the conversation.

However, one child (R-F1-C) mentioned remembering very little concrete sports advice from the hospital:

"Nou, ik heb het nog niet zo vaak gehoord, maar ik denk wel dat het een keer is gezegd."

In this case, the child was also given nearly no restrictions, which may explain why the sports advice was not strongly remembered.

Interestingly, this practice differs from what is described in the literature, which often highlights that children with CHD were previously insufficiently involved in discussions about their health, which could lead to uncertainty and fear around physical exercise. Although children are actively involved in conversations, the extent to which sports is discussed remains limited.

B2. Discussion of sports during the consultation

Interviews with three cardiologists show that sports participation is mentioned in almost every consultation, but the topic is usually addressed briefly and often superficially. For most children, cardiologists state that no restrictions apply.

Cardiologist R-H6 mentioned:

"Maar dan is het wel vrij algemeen... en zeg ik van nou weet je, meestal is het geen beperkingen, je mag gewoon alles doen dus ga lekker zo door."

The core of the sports advice is mainly focused on reassurance and encouraging an active lifestyle, rather than providing restrictions. This aligns with cardiologists' view that most heart defects do not require specific limitations on physical exercise, and that restrictions are only recommended when clear physical limitations are present. According to the cardiologists, the emphasis should be placed on possibilities rather than limitations.

Because most children engage in recreational sports at relatively low intensity levels, cardiologists often consider precise intensity limits unnecessary. In cases of higher levels of sports participation, interviews indicate that sports advice is sometimes discussed in more detail and follow-up may occur more frequently, depending on the intensity of the sport and the perceived urgency from parents, children, or sports organizations.

Design implication:
A tool should emphasize what children can do without creating unnecessary restrictions.

The interviews revealed several factors that influence the extent to which sports is discussed during the consultation. These factors are elaborated in the following paragraphs.

B2a. Assumptions made by cardiologists

The interviews show that cardiologists make intuitive assessments during consultations about the child and their family: how active the child seems to be, how important sports seem to be for them, the extent to which parents encourage or protect, and whether there is reason to discuss sports in more depth. These impressions could influence how much attention talking about sports during consultation receives, whether the cardiologist actively encourages the child, and whether the advice remains general or becomes more concrete.

Cardiologists acknowledge that this may lead to mismatches. For example, a child may need more guidance than the cardiologist assumes based on a first impression, or parents may have concerns that remain unspoken if it is assumed that sports is going well.

At the same time, the consultation strongly depends on what the child brings up themselves. As one cardiologist (R-H2) explains:

"Want elke kindercardioloog gaat de vragen beantwoorden die vanuit het kind komen. Dus op het moment dat het kind zegt ik wil het over sport hebben, dan dwing je de kindercardioloog ook om het over sport te hebben."

The cardiologist also noted that questions from parents and children about sports often remain superficial, and that much could be gained by exploring these questions more deeply.

This presents an opportunity to support children beforehand in expressing their questions or wishes related to sports, so that the consultation does not depend solely on spontaneous input.

Design implication:
The tool should systematically capture the needs, concerns, and sport-related behavior of children and parents, ensuring that the content of the consultation does not only rely on the cardiologist's assumptions.

B2b. Time pressure

A recurring theme in the interviews is the limited time available to discuss physical activity. Consultations typically last around twenty minutes, during which many different topics should be addressed: medication, school, symptoms, test results, diagnostic procedures that may need to be scheduled and possible questions from parents. As a result, topics compete for attention and physical exercise often receives only limited time.

Consequences for the quality and depth of sports advice.

Due to the limited time, sports advice often remains brief and general. Underlying uncertainties among parents or children are therefore not always expressed, which may cause worries or doubts to persist, potentially affecting the child's participation in sports. Cardiologists note that time pressure determines the extent to which they can probe further or address underlying fears or uncertainties.

One cardiologist explained (R-H2):

"Omdat ik weet, op het moment als ze zeggen, ik ben best wel bang om te sporten, dan is het lastig. Dan wil je daar ook op ingaan. Een beetje zo van ah oke, goed dat je het zegt, maar ik kan er niks mee, want de tijd is op."

Another cardiologist (R-H6) indicated that time pressure may also influence how accessible the conversation feels to parents and children:

"Maar ik denk zelf dat ik wel vrij toegankelijk ben in de spreekkamer. Ik denk dat ze tegen mij wel zouden zeggen, maar ik denk ook dat als ik inderdaad heel druk ben, dat je misschien ook minder voor openstaat, dat kan best. Dat ze het dan misschien toch niet zeggen."

Time pressure can additionally affect how specific the physical exercise advice can be. Often, the information available during the consultation about the child's sports behavior, context, motivation, or potential barriers is limited. As a result, the advice cannot be fully tailored to the individual situation.

Design implication:
A tool should deliver relevant information efficiently and without taking up too much consultation time, helping cardiologists provide accurate and personalized sports advice.

B2c. Variation between cardiologists

In addition to assumptions and time pressure, interviews indicate that variation between cardiologists also plays an important role in how physical exercise is discussed during the consultation. This variation was described by cardiologists themselves. Some cardiologists reported being more inclined than others to make sports an important topic of discussion during consultation.

One cardiologist described proactively exploring underlying reasons why some children do not participate in sports, while others may not do so to the same extent.

The interviews further reveal variation in cardiologists' perceived expertise regarding physical exercise guidance. Not every cardiologist feels equally confident in answering questions about limits, intensity, or suitable sports activities. Advice may often depend on the personal experience and background of the cardiologist.

These differences in the perceived importance of discussing sports, the level of proactiveness in asking follow-up questions, and expertise may lead to inconsistencies in the amount and quality of physical activity advice that families receive.

Design implication:
The tool should create a consistent foundation for discussing sports, ensuring that families are not dependent on individual differences between cardiologists.

C. Changes in PA advice over time
Several cardiologists indicated that sports advice in the past was primarily focused on caution and restriction. Children were often advised to slow down or not to participate in sports, based on the assumption that this would be safer. One cardiologist (R-H2) explained:

"Nu weten we steeds beter dat sport veilig is, maar ook steeds beter hoe slecht het is om niet te sporten."

As a result, most cardiologists now actively encourage sports participation during consultations.

According to the cardiologists, these older, now outdated recommendations may have led some patients to become hesitant or fearful of engaging in sports. When children or parents have been told for years that exercising is risky, this perception may tend to persist. One cardiologist mentioned occasionally seeing patients who were previously given different advice by another cardiologist and are then surprised to hear that they are allowed to participate in sports.

The attitude of the treating physician from the start appears to shape how children and parents view sports, and outdated advice from earlier clinicians may be difficult to reverse. Changing these deeply ingrained beliefs may take time for both parents and children, as well as for cardiologists themselves.

Design implication:
The tool should offer clear, up-to-date, and consistently presented information about sports participation, helping reduce the chance that outdated advice continues to influence the attitudes of children, parents, or healthcare professionals.

D. Changing physical activity behavior
Interviews show that actually changing children's sports behavior is challenging. Healthcare professionals noted that some children, even when they are medically cleared to be physically active, simply cannot be motivated to participate in sports. In such cases, sports participation often remains low, regardless of the advice or encouragement provided.

One cardiologist (R-H6) described that sports suggestions proposed by healthcare professionals may sometimes be perceived by children as imposed. When a sport or activity does not originate from the child themselves, the cardiologist indicated that the likelihood of children following the advice or maintaining the behavior is limited. For this reason, the cardiologist often encourages children to first think about which sport suits them and which activities they enjoy, and then assess whether this is medically appropriate. This increases the likelihood that the advice aligns with the child's interests and that the behavior will be sustained over time.

Healthcare professionals also mentioned that some children find it difficult to identify a suitable sport, and that organizations such as the Esther Vergeer Foundation can play a supportive role in these cases. As one healthcare professional explained (R-H3):

"Die [Esther Vergeer Foundation] denken dan heel erg mee bij deze kinderen en die gaan ook echt met de kinderen mee bij sportverenigingen kijken in de buurt. Nou, past dit bij je, zou je dit leuk vinden? Heb je hier een klik?"

Design implication:
Aligning sports advice with the child's own preferences increases the likelihood that the advice is followed and that physical activity behavior is maintained.

E. Referral to other professionals for more in-depth support
As noted earlier, the interviews show that the involvement of other healthcare professionals in supporting sports participation varies widely among children with CHD. For most children without additional health issues, the pediatric cardiologist is the only consistent point of contact within the hospital.

Although children who may need extra physical or psychosocial support are sometimes referred, cardiologists indicated that no standardized referral policy exists. The decision to refer mainly depends on the cardiologist's own assessment, based on the medical history, physical examination, and any additional diagnostic tests.

Several professionals mentioned that parents themselves often need to take the initiative when they have concerns or uncertainties. While cardiologists do offer support programs, it is largely up to the family to request such help and how proactively cardiologists encourage this varies. As a result, some families, for example those less inclined to express concerns may access support more slowly.

The interviews show that cardiologists mostly refer when a child explicitly expresses a wish or when parents actively ask for support. Cardiologist R-H6:

"Ze moeten het écht zelf willen."

Design implication:
The tool should help identify early on when a child may need additional support and assist parents in expressing these needs more explicitly, so that referrals no longer depend on incidental clinician judgments or fully on the family's own initiative when not proposed.

F. Physical therapists and sports physicians: additional expertise
When children need more in-depth support, for example due to anxiety, uncertainty, or symptoms during physical activity, referral to a physical therapist or sports physician can be valuable. Unlike cardiologists, physical therapists and sports physicians can observe children during exercise, provide practical guidance, and spend more time on explanation and coaching. They can therefore offer support that is not feasible within a standard cardiology consultation.

Healthcare professionals view physiotherapy as a place where children learn to recognize and interpret physical signals and develop confidence in their own physical abilities. In addition, the physical therapist sometimes acts as an intermediary between parents and the cardiologist, translating medical advice into the practical reality of sports and physical exercise. One parent (R-F2-P) mentioned that this guidance helped reduce uncertainty about what was and was not safe for their child. The parent indicated that physiotherapy support had been very beneficial for her child and felt that cardiologists should routinely recommend it to all parents.

Despite its potential value, this additional expertise, such as support from physical therapists, seems to be used relatively little in current practice.
As one cardiologist (R-H6) stated:

"Ik denk dat echt bijna niemand naar fysiotherapie gaat of naar een... Ik denk dat we die echt volledig... dat we die niet goed bedruipen [gebruik van maken] wat dat betreft."

As a result, the involvement of physical therapists or sports physicians is often limited to situations in which symptoms or specific questions are explicitly raised, something that does not always happen during a short cardiology consultation.

Design implication:
The tool should increase the visibility and accessibility of additional expertise by providing concrete information about physical therapists and sports physicians, enabling more frequent and consistent referrals when appropriate.

G. Possible invisible needs among relatively healthy children
One cardiologist explained that the large group of children with mild heart defects is particularly at risk of having their need for support go unnoticed. Because these children have few symptoms and sometimes only visit the clinic once every few years, there are very few moments in which concerns about sports behavior or uncertainty can be discussed. The cardiologist suggested that for some families, this long interval without appointments may feel reassuring, whereas for others it may leave underlying uncertainty.

This perspective is also reflected in the interviews with parents. One parent described that his child is doing well, which reassured the cardiologist and resulted in no specific restrictions being imposed.

The cardiologist advised the family to explore what is possible and to get in touch if symptoms occur. the parent appeared to be relaxed about this approach, based on how he described the situation, and the absence of restrictions was interpreted as a positive sign. At the same time, another parent described that, despite the child functioning well, uncertainty about physical exertion may remain in the background. In this case, medical check-ups were described as providing reassurance and confidence. This parent indicated that although doubts sometimes arise about whether certain signals might be heart-related, these doubts tend to fade again when the child continues to do well overall.

From the perspective of healthcare professionals, infrequent contact can make it difficult to detect whether questions or insecurities exist at all. When children are seen only sporadically, concerns about sports participation or feelings of uncertainty may remain unnoticed, particularly when families do not explicitly raise these issues during consultations.

One cardiologist also mentioned that in cases of mild CHD, it may be assumed that children can participate in sports without additional guidance, which means that physical exercise sometimes receives little attention during follow-up visits. As the cardiologist (R-H6) described:

"En als we dan één keer in die vijf jaar zien, dan denk ik ook van ja, jij moet gewoon kunnen sporten. Jij bent gewoon als de gewone kinderen. Je hebt een soort van gezond hart. Dus dan heb ik het idee dat ik daar minder aandacht aan hoef te geven."

However, this group may also benefit from additional support, as their concerns are less likely to be expressed and therefore less likely to be noticed.

Design implication:
The tool should help identify early on when a child may need additional support and assist parents in expressing these needs more explicitly, so that referrals no longer depend on incidental clinician judgments or fully on the family's own initiative when not proposed.

H. Potential role of the nurse specialist
The interviews show that nurse specialists serve as an accessible and approachable point of contact for parents during the early years of a child's life. However, once children with CHD grow older and no direct medical issues remain, this contact almost completely disappears. As a result, there is no structural form of follow-up between consultations, meaning that signs of uncertainty, questions about physical exercise, or needs for additional support may go unnoticed.

A cardiologist (R-H6) noted that families sometimes stall after a referral due to long waiting times and a lack of follow-up. According to cardiologists, a nurse specialist could play a role in this by acting as an intermediate link and monitoring children's well-being between consultations.

Design implication:
Within the communication tool, the nurse specialist can be positioned as a low-threshold and continuous point of contact who supports cardiologists with interim follow-up, helping ensure that families do not fall out of sight.

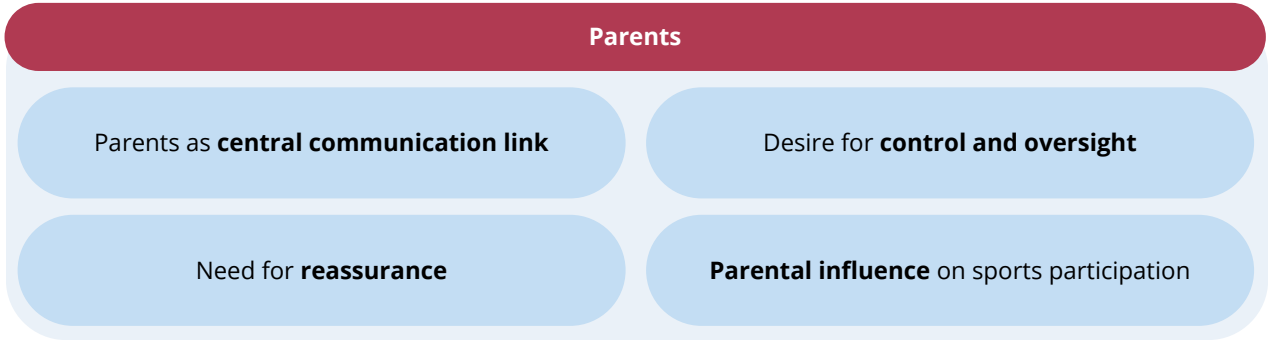
I. Limited referral to external information platforms
In addition to the limited and inconsistent referrals to other medical professionals, the interviews show that referrals to information platforms outside the hospital consultation room also rarely occur. Cardiologists, physical therapists, and sports physicians almost never refer parents or children to websites, brochures, or digital platforms with additional information. Reasons mentioned include insufficient awareness of reliable sources, making professionals unsure where to refer parents. Others doubt whether parents would actually read extra information and therefore limit themselves to giving a verbal summary during the consultation. It was also noted that parents do not always explicitly ask for additional information, resulting in limited further discussion of the topic.

Design implication:
The tool should provide a single, easy-to-share source that brings together reliable, curated, and accessible information for healthcare professionals to share with others.

3.3.2.2 Parents

This section presents the main insights about parents as described in the interviews, including perspectives from different stakeholders.

The visual to the right presents the main themes discussed in this chapter. These themes are based on the qualitative analysis of the interviews and link to the cluster labels in Miro. More specific subthemes are described in the subsections below, with the underlying interview data supporting these insights available in Miro.



A. Core role and responsibilities
The interviews show that parents hold a central position in the communication chain surrounding their child's heart condition and sports participation. Parents reported feeling primarily responsible for passing on medical information about their child to sports clubs and schools. They explained that they know their child best and therefore understand who needs to be informed.

This is confirmed by sports coaches. They expect parents to report medical conditions on their own initiative and do not contact healthcare professionals themselves unless parents explicitly request it.
Healthcare professionals also assign parents a central role in the communication chain. They direct their explanations and advice towards parents and expect them to share relevant information with the sports environment when necessary. Only when parents struggle with this, some professionals offer active support.

While parents are positioned as the central link in the communication chain, the interviews also reveal several challenges and concerns related to this role as perceived by different stakeholders.

A1. Challenges and vulnerabilities of parents as key communicators
Professionals indicated that they have limited insight into how their advice ultimately reaches sports coaches. As a result, it remains unclear whether coaches receive all relevant information and whether nuances are preserved in the transfer.

Professionals also observed that indirect communication through parents or children more easily leads to confusion or uncertainty. One professional (R-H5) explained that coaches ideally need to address their questions to the right person:

"En er zijn natuurlijk best wel dingen die ze wel aan ouders kunnen vragen. Maar het moet in ieder geval de juiste informatie zijn. En als ouders dat doorgeven, weet je ook niet altijd of daar de juiste informatie achter zit."

Because the sports environment is entirely dependent on what parents communicate, the information chain becomes vulnerable.

When parents do not share information, share it incompletely, misinterpret advice, or pass it on selectively, important information may not reach the sports environment, or may arrive altered, leading coaches to receive advice that differs from what healthcare professionals intended and possibly restricting children more than needed.

Design implication:
- The tool should support parents in transferring relevant information.
- The tool should help prevent information loss within the communication chain.
- The tool should provide clear, complete, and easily transferable advice so that coaches are less dependent on parental interpretation.

B. Parents' desire for control over information flows

In addition to their role as a central link in the communication chain, parents also expressed a desire to maintain control over how and with whom information is shared. They do not consider it relevant for everyone to know about their child's heart condition and want to prevent their child from being treated differently when this is not necessary, for example when there are no symptoms or when the condition is mild. They usually share information only when there is a reason to do so, for instance when someone asks or when they believe sharing the information is important for safety.

A parent (R-F3-P) explained:

"Nou, het is niet dat je het in het eerste gesprek zegmaar gelijk deelt. Er moet wel iets van een aanleiding zijn ofzo dat iemand zegt van joh ik zie een litteken bij hem, van joh wat is er gebeurd? Nou ja, dan ga je gewoon het gesprek aan. Maar niet dat je zegt hoi, dit is [naam van het kind] en hij heeft een hartafwijking. Dat hoeft van ons nou ook weer niet. Ook omdat je niks aan hem ziet doen of dat hij niet anders behandeld moet worden dan anderen."

A sports coach (R-S1) noted that parents differ widely in how open they are about sharing information. According to the coach, some parents find it difficult to talk about their child's condition, while others are more open. Fear of something going wrong can also motivate parents to share information sooner.

Another parent (R-F3-P) described having little difficulty sharing information when others ask about it. This illustrates that parents vary significantly in their comfort levels and motivations when it comes to sharing information.

The interviews also revealed that parents are not always aware of which sports coaches are informed about their child's heart condition. One parent (R-F3-P) explained that they had not explicitly informed the sports coach because they did not see it as necessary and simply had not thought about it. In another family, a child described that certain coaches may know while others probably do not. The child (R-F1-C) said:

"Nou mijn [hockey]coach weet het nog niet, maar ik weet niet of juf [dansjuf] het al wel weet. Ik denk het niet."

The parent clarified that they had previously informed the dance teacher, but that the hockey coach would likely be informed personally at an upcoming team event.

These examples show that information transfer does not follow a structured process, but instead depends on timing, context and parental judgment. As a result, it is not always clear to parents or children which coaches have the correct medical information.

Parents also indicated that they prefer sports coaches not to contact the cardiologist directly, but instead want to manage that communication themselves.

Two parents expressed that they want sports coaches to approach them first with questions or concerns, rather than contacting the cardiologist directly. Another parent (R-F2-P) was open to direct contact, as long as they were informed and received feedback about what had been discussed.

Design implication:

- The tool should give parents control within the communication process and allow them to choose which information is shared with whom.
- The tool should help parents keep track of which sports coaches have been informed.

C. Parental influence on sports participation

The home environment plays an important role in shaping the sports behavior of children with CHD. Interviews with healthcare professionals indicated that the family environment in which a child grows up has a strong influence on sports participation. They mention that in physically active families, parents may actively look for creative solutions to ensure that the child with a heart defect can also participate. Several healthcare professionals described that when parents introduce sports early on, children tend to discover more quickly that it is enjoyable and are more likely to participate in sports later. In families that are less engaged in sports, avoiding physical activity may occur more easily. In two interviews, parents themselves mentioned that they were active in sports, and their children were also highly active.

The parents interviewed in this study all had children who participated in multiple sports and were very active. However, they acknowledged that other parents of children with CHD tend to be more anxious or cautious. They themselves also described experiencing a tension between encouraging and protecting their child when it comes to sports participation. Healthcare professionals similarly noted that uncertainty among parents about the safety of physical exercise is often seen.

Design implication:
The tool should support both highly active and less active families.

D. Need for reassurance
The interviews showed that some parents may frequently seek reassurance from healthcare professionals to be certain that physical exercise is safe for their child. For example, a parent may want medical confirmation before allowing their child to engage in more intense physical activity. The parent (R-F3-P) explained:

"En wilde hij eigenlijk de 10 km gaan rennen. Ik zei nou, schrijf je maar gewoon in voor de 5 en dan kijken we wel even wat het ziekenhuis zegt en die zei gisteren van nou, maak je geen zorgen, hij mag gewoon de 10 gaan lopen. Dus dat is dan wel weer fijn om te horen."

Consultations, echocardiograms, ECGs, and exercise tests were mentioned as important moments that reduce parental uncertainty. Even when children function well, some doubt may persist about "what is happening on the inside" during physical exertion. One parent (R-F3-P) described that despite the child being one of the fastest on the team during running exercises, uncertainty remained about how the heart functions internally. Hospital check-ups were therefore experienced as reassuring, as they provide confirmation and reduce doubts about the child's internal condition during physical activity.

In addition to medical reassurance from the hospital, one parent described using technology as a form of supplementary support. The parent explained that a smartwatch was used to monitor the child's heart rate during sports activities. Initially, this was mainly used to track physical responses and, when necessary, to perform ECG recordings. As the child continued to do well, this helped the parent to gradually let go of constant monitoring. At the same time, the parent emphasized that it is important for the child to eventually learn to recognize bodily signals themselves and to develop confidence in doing so, rather than being constantly monitored.

Differences in parental need for reassurance may also be influenced by background knowledge. One parent with a background in nursing (R-F2-P) described experiencing less uncertainty about recognizing physical signals, but mentioned that parents without a medical background may feel more unsure and have a stronger need for reassurance when interpreting their child's signals during physical activity.

Experience also plays an important role in reducing uncertainty. Parents explained that their confidence grows as their child participates in sports repeatedly without problems. A parent (R-F1-P) noted that the first times can be stressful, but confidence builds as things continue to go well:

"Natuurlijk is het aan het begin best wel spannend en de eerste paar keer dat ze dan bijvoorbeeld een uur aan het sporten is geweest, dan ben je toch wel heel benieuwd hoe gaat het met je, hoe voel je je? Je krijgt op een gegeven moment ook wel een beetje vertrouwen."

Being physically present during sports activities can also provide reassurance. A parent (R-F1-P) mentioned joining the first training to observe how their child responded and whether the child indicated when rest was needed. In addition, a primary school gym teacher (R-S3) noted that allowing parents to observe a lesson can help them experience the sports setting as safe, which may contribute to increased parental confidence and allow their child to participate independently over time.

Design implication:
The tool should support parents in developing confidence in their child's sports participation over time by accommodating different forms of reassurance, such as medical confirmation, experience, observation, and a shift toward trusting the child's own bodily awareness, for example with appropriate guidance from professionals when needed.

E. Variation in processing and understanding medical information

Parents differ significantly in how much medical information they remember during consultations. One parent (R-F1-P) described that the amount and speed of information in the early phase felt overwhelming, which made it necessary to write everything down and read it again later in order to maintain an overview.

Another parent (R-F2-P) explained that she had been involved in medical care trajectories since her child's birth and therefore "grew along" with the information, making it feel less overwhelming. Her nursing background also played a role, as it helped her better understand what to pay attention to and possibly made her more confident in assessing situations compared to parents without such a background.

Healthcare professionals confirmed that there is considerable variation in what parents remember. They noted that a large amount of information is discussed in a short period of time, and it is not always clear which information parents ultimately retain.

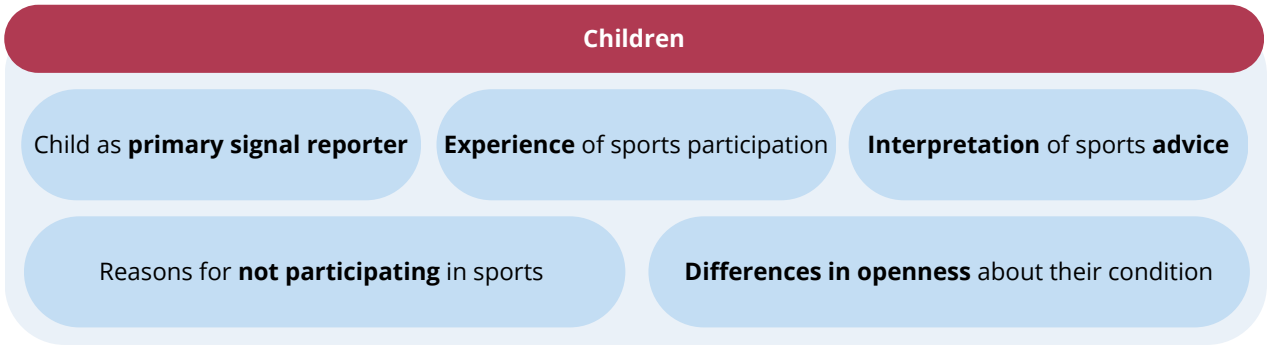
These differences in how parents process medical information may also influence how advice is conveyed to sports coaches.

Design implication:
The tool should provide consistent information that can be revisited later and should be designed to be understandable for parents both with and without a medical background.

3.3.2.3 Children with CHD

This section presents the main insights about children with CHD as described in the interviews, including perspectives from different stakeholders.

The visual to the right presents the main themes discussed in this chapter. These themes are based on the qualitative analysis of the interviews and link to the cluster labels in Miro. More specific subthemes are described in the subsections below, with the underlying interview data supporting these insights available in Miro.



A. Child as the primary signaler of symptoms
The interviews show that children are considered the main signalers of their own physical limits during physical exercise. Parents, sports coaches, and healthcare professionals rely on what the child feels and reports. At the same time, children vary in how well they can recognize or interpret these signals themselves.

A parent can play a supportive role in helping the child learn to recognize these signals and in building confidence that being active is possible. One parent (R-F1-P) described how he regularly reassured the child when the heart rate increased during play, explaining that this is a normal response to physical activity as long as it returns to baseline afterward. Through this repeated reassurance and explanation, the child was reported to gain confidence and feel more at ease during physical activity. However, the same parent also emphasized his own uncertainty, after all he "cannot look inside her body" and must rely on what his child experiences.

This illustrates that parental reactions play a significant role in how children learn to interpret physical signals.

While this parent provides reassurance, more anxious parents may unintentionally reinforce doubt or caution in their child.

Uncertainty can also appear in PE classes, both for the child and the sports coach. The same parent (R-F1-P) described:

"Ik weet wel dat ze me een keer heeft verteld dat ze inderdaad beetje aan het begin van die tijd, met gym, dat dat ze wel vaak even weer aan de kant werd gezet door de gymleraar van ga maar even rustig zitten. Komt ook een beetje omdat ze zelf ook denk ik niet helemaal goed wist van wat mag ik nu, wat is goed en dat ze dan haar hartje voelt en denkt oké, ik moet zitten, ik moet stoppen. Dus dat was voor haar ook een beetje het zoeken van wat kan ik, wat is goed, wat voelt niet goed."

A cardiologist mentioned that, in practice, sports advice often comes down to teaching children to "listen to their bodies," noting that coaches have difficulty determining when a child should stop and that children sense this quite well themselves.

Sports coaches also indicated that they depend on children to report signals. During practice, they cannot always monitor each child individually and do not always know what specific signs to look out for. This means the responsibility for regulating effort often lies with the children themselves. At the same time, a PE teacher (R-S3) expressed uncertainty about whether it is appropriate or safe to place this responsibility on children. This uncertainty creates tension for PE teachers, who may feel unsure about their role as decision-makers in determining when a child should continue or stop participating in physical activity.

In summary, because all stakeholders rely on what the child feels and reports, it is essential that children understand their bodily signals well, and that those who find this difficult receive appropriate support.

Design implication:
The tool should support children in developing the ability to recognize and interpret physical signals, especially those who are still unsure about what is normal during physical exertion.

B. Experience of sports participation
The interviews show that children deal with their condition in different ways during sports activities and when comparing themselves to peers. A physical therapist (R-H1) noted that some children may also experience feelings of grief or acceptance because they feel different from others. While this was not always explicitly linked to sports participation in the interview, it may influence how children perceive themselves and how they experience physical activity.

A parent (R-F2-P) explained that her child sometimes experiences performance anxiety when he notices that other children can perform certain activities more easily. The same parent described that sports can be both enjoyable and exciting for him, illustrated by an example in which he enjoyed horse riding but also showed visible tension:

"Hij was supertrots als het goed ging, maar ik kon echt gewoon zien hoe spannend hij het vond. En dat ik denk van ja, je hart gaat nou wel mega tekeer… is dit wel wijs?"

Meanwhile, another child (R-F3-C) indicated that he is able to keep up well during PE class and that his heart condition does not stand out. He assumes participation is safe as long as it continues to feel good. His parent (R-F3-P) added that he sometimes even sets the bar higher for himself. Another child (R-F1-C) shared that sports generally go well for her and that she consciously uses physical signals, such as a fast heartbeat, to monitor her limits and sit out when necessary, while still wanting to remain involved in the activity and her team.

This variation shows that experiences and behaviors related to sports participation differ widely between children and across types of heart defects, and that each child copes in their own way with uncertainty, physical boundaries, and the desire to participate alongside peers.

C. Interpretation of sports advice by children and parents
The interviews show that children do not always interpret sports advice in the way healthcare professionals intend. A physical therapist (R-H3) noted that advice about what is allowed often sticks less than advice about what is not allowed. This may lead to misunderstanding, for example when children believe they are not allowed to participate in certain activities, even though the cardiologist actually encourages physical exercise. The physical therapist explained that the cardiologist's words are sometimes "translated into their own truth," causing children and parents to develop a more cautious understanding than medically necessary. By explicitly asking children and parents what they believe the children are or are not allowed to do, these misinterpretations become visible more quickly, according to the physical therapist.

This insight highlights the importance of discussing children's and parents' own understanding of advice so that misinterpretations do not become an unnecessary barrier to sports participation.

Design implication:
The tool should provide insight into how children and parents understand physical activity advice, so that any misinterpretations become visible early and explanations can be clarified when needed.

D. Reasons why some children do not participate in sports
Although the children interviewed in this study all actively participate in sports, healthcare professionals described several reasons they often hear in consultations from children who do not engage in sports. These insights provide important context about the barriers that may affect other children with CHD.

Although limited consultation time does not always allow for extensive exploration, several recurring reasons why some children do not participate in sports were mentioned.

A cardiologist (R-H6) explained that common reasons children give for not participating in sports include *"geen zin"*, *"niet leuk"* and *"te druk"*. Overprotective parental behavior was also mentioned by the cardiologist. Some parents protect their child too much, which, according to the cardiologist, may lead to reduced sports participation later in life.

Healthcare professionals suggested practical barriers to play a role as well, such as parents being unable to bring their child to sports activities or sports not fitting well within family routines. Professionals (R-H3 and R-H6) further noted that cultural and language barriers can influence participation. In some cultural backgrounds, sports are less self-evident, and, for example, girls may be less likely to participate due to certain norms or beliefs.

According to several professionals, it is essential to determine the underlying reason why a child is not participating in sports. Without understanding the root cause, referrals or advice have little effect, as the support would not match the child's actual needs.

Design implication:
The tool should help identify why a child is not participating in sports , enabling healthcare professionals to provide more tailored advice or referrals.

Meanwhile, another child (R-F3-C) indicated that he is able to keep up well during PE class and that his heart condition does not stand out. He assumes participation is safe as long as it continues to feel good. His parent (R-F3-P) added that he sometimes even sets the bar higher for himself. Another child (R-F1-C) shared that sports generally go well for her and that she consciously uses physical signals, such as a fast heartbeat, to monitor her limits and sit out when necessary, while still wanting to remain involved in the activity and her team.

E. Differences in children's openness to report symptoms during sports lessons

The interviews show that not all children find it equally easy to talk about their condition or to report symptoms to a sports coach, and their openness varies greatly from child to child. A secondary school PE teacher without direct experience teaching children with CHD, who therefore based his observations on other medical conditions, explained that some children report issues very easily, while others find it stressful or prefer not to stand out.

Feelings of uncertainty, embarrassment, or not wanting to deviate from the group may create barriers. The teacher noted that older children and girls tend to be more hesitant, and that children are more likely to approach a teacher with whom they feel safe and comfortable. At the same time, he emphasized that when there is really something wrong or when symptoms clearly interfere with participation, children ultimately do come forward.

A primary school PE teacher said that he has not experienced children feeling uncomfortable talking about a medical condition. A sports coach with experience working with children with CHD stated that some children prefer not to share everything with others, R-S1:

"Waar het vaak om gaat van... Ik ben geopereerd, maar niet zeggen wat. (...). Eigenlijk willen ze er vaak niet aan herinnerd worden, ik ben nou eenmaal zo."

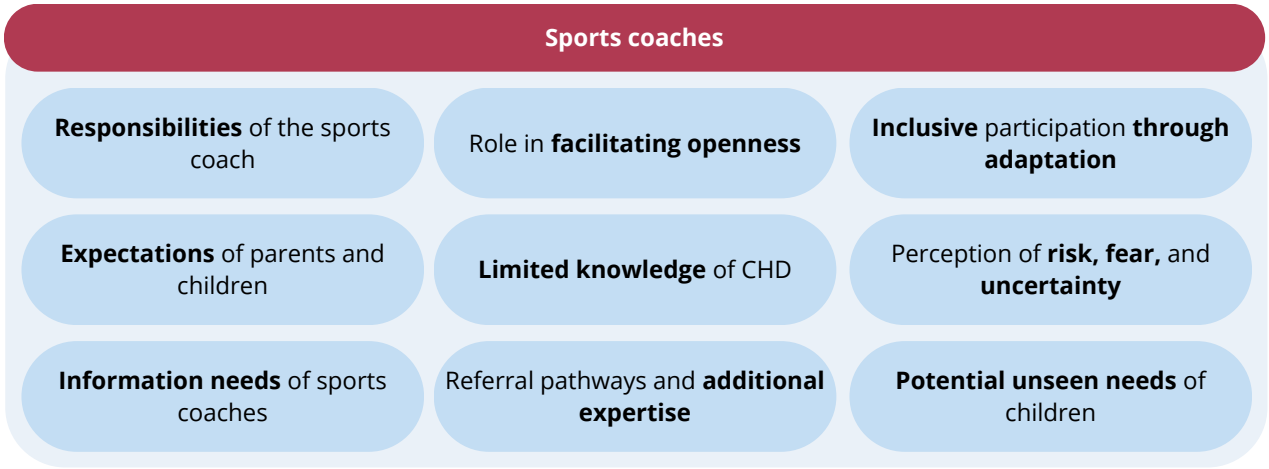
The two children interviewed in this study (R-F1-C and R-F3-C) indicated that they generally do not struggle with talking about their condition, as they have had to explain it several times before. One parent (R-F1-P) confirmed this and mentioned that sharing information can even be reassuring, because others then understand what is going on. Additionally, both a parent and a child noted that it is helpful when sports coaches are informed, so they can respond appropriately to symptoms and contact the parents if needed.

Design implication:
Because openness to report symptoms varies greatly, the tool should help children make clear agreements in advance about how and when they can report concerns, so that expectations are communicated and social barriers may be reduced.

3.3.2.4 Sports coaches

This section presents the main insights about sports coaches as described in the interviews, including perspectives from different stakeholders.

The visual to the right presents the main themes discussed in this chapter. These themes are based on the qualitative analysis of the interviews and link to the cluster labels in Miro. More specific subthemes are described in the subsections below, with the underlying interview data supporting these insights available in Miro.



A. Core role and responsibilities

A1. Providing a safe and inclusive sports environment

Interviews revealed that sports coaches see their primary task as organizing a safe, structured sports lesson in which all children can participate. They consider it important to adopt an open, approachable attitude in which children feel free to indicate when something does not feel right, and they try to keep the threshold low so that children dare to do so.

Coaches also attach great importance to social inclusion: belonging, playing together, and collaborating (R-S3). This approach helps create an environment in which children with medical conditions can participate without being singled out, as long as the activity is organized safely.

The sports coaches mentioned that every child can participate, provided that the coach can be flexible in structuring the lesson. Small adjustments, such as offering choices between multiple activities, assigning a certain position on the field, adapting rules, or varying tempo, can make participation safe for all children.

As R-S2 explained:

"Er is altijd wel een rol in het veld waarbij het kind niet te intensief hoeft te bewegen."

The sports coach emphasized the importance of knowing such information beforehand so that it can be considered in lesson preparation.

A PE teacher (R-S3) acknowledged that pupils with limitations may at times be left out during certain sports activities, but saw it as his responsibility to address this and work with the group to find a solution.

A2. Communication about CHD

Regarding communication about children with CHD, as already mentioned in an earlier chapter, sports coaches do not see this as part of their own role. They expect parents to inform them proactively and will not seek out this information themselves.

They are willing to share observations about the child's participation with healthcare professionals, but only when explicitly asked by others.

A3. Recognizing limits & expectations towards the child

Sports coaches vary in how they approach the recognition of children's physical limits and symptoms, depending on the specific sports activity and their own experience. One coach explained that he relies on his personal experience and observation of non-verbal cues to monitor children during physical activity. According to the coach, subtle changes are often noticed before a child explicitly reports them, particularly because children may be highly motivated to continue participating.

Other school sports coaches prefer to place this responsibility largely on the children themselves, as it is not always feasible to monitor individual pupils during the busy dynamics of a PE lesson. As a result, part of the responsibility shifts to the child.

One sports coach (R-S2) indicated that when clear signs are visible, he would intervene immediate, but that in many situations such signs are not easily observable. Continuously asking the child how they feel was described as impractical, which means that the responsibility to report concerns often lies with the child.

And another sports coach (R-S3):

"Want ik vind het heel moeilijk om tijdens een les zo'n individueel puntje eruit te pikken, eruit te lichten. Er gebeuren natuurlijk zoveel verschillende dingen, je bent daar bezig, je bent daar bezig, je bent daar bezig. En als je dan zo'n specifiek geval extra in de gaten moet houden, dan vind ik dat moeilijk. Daarom maak ik altijd de afspraak, omdat ik dat wel waardevol vind om die verantwoordelijkheid weer terug bij leerlingen te leggen."

At the same time, coaches acknowledge that some children find it difficult to indicate when something does not feel right. They therefore emphasize that clear agreements between parents, the child, and the coach are important. This shows that responsibility is shared, but coaches differ in how they interpret and enact that responsibility.

Design implication of section A1-3:

- The tool should make it possible to clearly define and document agreements about limits and responsibilities during sports class.
- The tool should support sports coaches in creating a safe sports environment in which children feel comfortable indicating when something does not feel right.
- The tool should support sports coaches in translating information from healthcare professionals, parents and children into practical adaptations that fit within their own training context.
- The tool should ensure that relevant sport-related information is available before the sports class, so that coaches can take this into account during the lesson.

B. Limited knowledge about CHD

The interviews show that PE teachers have little to no knowledge about CHD.

The first aid (EHBO) training that qualified sports coaches and PE teachers are required to complete focuses mainly on general emergency situations such as epilepsy, diabetes, or resuscitation. Guidance on how to act in cases of CHD is not included. As a result, one PE teacher (R-S2) stated that he does not really know how CHD may present itself during physical activity:

"Ik ben er zelf niet zo heel erg in thuis hoe dat in de lessen zich vormgeeft."

Another sports coach with experience teaching children with CHD bases his understanding on what parents tell him and gauges children's limits through his general life experience. He noted that some parents share more information than others. Often, the advice he receives remains very general and does not relate to a specific sport.

A parent (R-F2-P) also mentioned in an interview that it is uncertain whether all parents are able to accurately indicate what their child can or cannot do.

This lack of knowledge may lead to situations in which coaches rely too heavily on the child to report symptoms, which may not be appropriate or safe if the child is unsure, and potential risks may be underestimated. Conversely, it may also lead to unnecessary caution or restrictions.

Design implication:
The tool should provide sports coaches with practical basic knowledge about CHD.

C. Perception of risks, fear, and uncertainty

Despite their limited knowledge of CHD, several sports coaches indicated that they are not afraid that something might go wrong during a sports lesson. They rely on their experience and on the safety structures embedded in PE classes. A sports coach (R-S1) described remaining alert, but emphasized that fear should not guide his actions. Another sports coach (R-S3) said he relies on his on the existing safety structures and routines embedded in PE classes to create a safe environment. Constantly focusing on potential risks was described as undesirable.

However, conversations with parents and healthcare professionals show that fear or uncertainty can have an influence, especially when coaches are unsure about what a child is allowed to do. A parent (R-F1-P) described a situation in which the child was repeatedly asked to stop or sit out by the PE teacher during PE, not necessarily due to observable physical limitations, but rather because of uncertainty about what was safe or appropriate.

A physical therapist (R-H3) explained:

"Ik had pas ook een jongen die zat op voetbal en die mocht maar een halve helft spelen van zijn coach. Want die was bang dat het mis zou gaan."

Another physical therapist (R-H1) noted that sports coaches may feel uncertain about how to respond to medical signals or emergencies during physical activity. According to the physical therapist, this uncertainty can be a reason for involving healthcare professionals directly, even if only to clarify that, in many cases, a child is allowed to participate fully in sports activities.

D. Information and communication needs

The interviews show that sports coaches require several types of information to guide children with CHD safely.

Figure 10 provides an overview of the needs mentioned by coaches. These information needs show that sports coaches mainly look for clarity and actionable guidance. Their focus lies in being able to assess risks and knowing what to do at critical moments.

An important insight shared by a sports coach is that he does not expect precise instructions for particular sports or exercises in order to work effectively. As the sports coach (R-S2) stated:

"Ja, ik denk dat het zo specifiek niet echt mogelijk is. Ik denk dat dat veel tijd kost. Wat algemener kan. Ik denk alleen wel dat het goed is om aan te geven dat bijvoorbeeld bij wedstrijdsporten ofzo of ze dat wel of niet mogen. Ik denk dat daar namelijk de grootste... Ja, de meeste problemen bij kunnen ontstaan in ieder geval."

Sports coaches are often able to estimate the intensity of exercises themselves and to recognize when extra caution may be needed. For physicians, this is more difficult because they have limited visibility into the specific movements and demands of a sports lesson. This makes a combination of medical basic information and practical guidance particularly useful for coaches.

Sports coaches also indicated that having written documentation helps create clarity. This may involve agreements about what a pupil can or cannot do, but also about dividing responsibility when activities involve higher risks. One coach (R-S3) mentioned that formally signing off responsibilities can sometimes be reassuring, as it provides security in case of incidents.

Several sports coaches also expressed that they appreciate an in-person conversation, as it helps them better understand how the child and parent themselves handle the situation.

Design implication:

- The tool should help clearly define and document agreements, including who holds which responsibilities.
- Information should align with the expertise of coaches: not overly medical, yet sufficiently complete to be used during sports lessons.
- The tool should provide coaches with the information presented in Figure 10.
- The tool should ensure that information is documented in written form.
- The tool should offer the option to facilitate an in-person conversation if needed.
- The tool should address specifically competitive elements and intensity, as these are moments when children may push themselves fully.

Information needs mentioned by sports coaches

- **Background information** about the heart condition and the severity of the situation
- **Frequency of symptoms**, to help assess the child's risk profile
- **Triggers** that may provoke symptoms
- **Physical signals** coaches should pay attention to, including when to take action
- **Agreements on how responsibilities** are divided between the child, coach, parent, and healthcare professional
- **Instructions:** what to do in case of symptoms or incidents
- **Contact persons** in case of an emergency
- **Clear guidelines** on what is and is not possible during sports activities
- Specific to **high-intensity activities:** whether a child may participate in competitive elements
- Specific to **school settings**: who the trusted **contact persons** are within the school

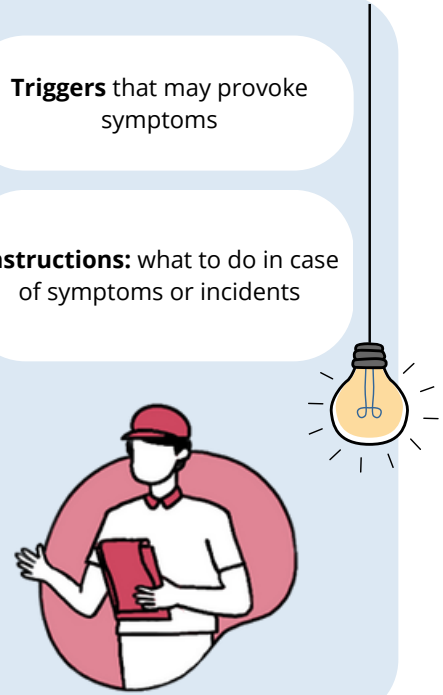


Figure 10: Information needs for a communication tool mentioned by sports coaches

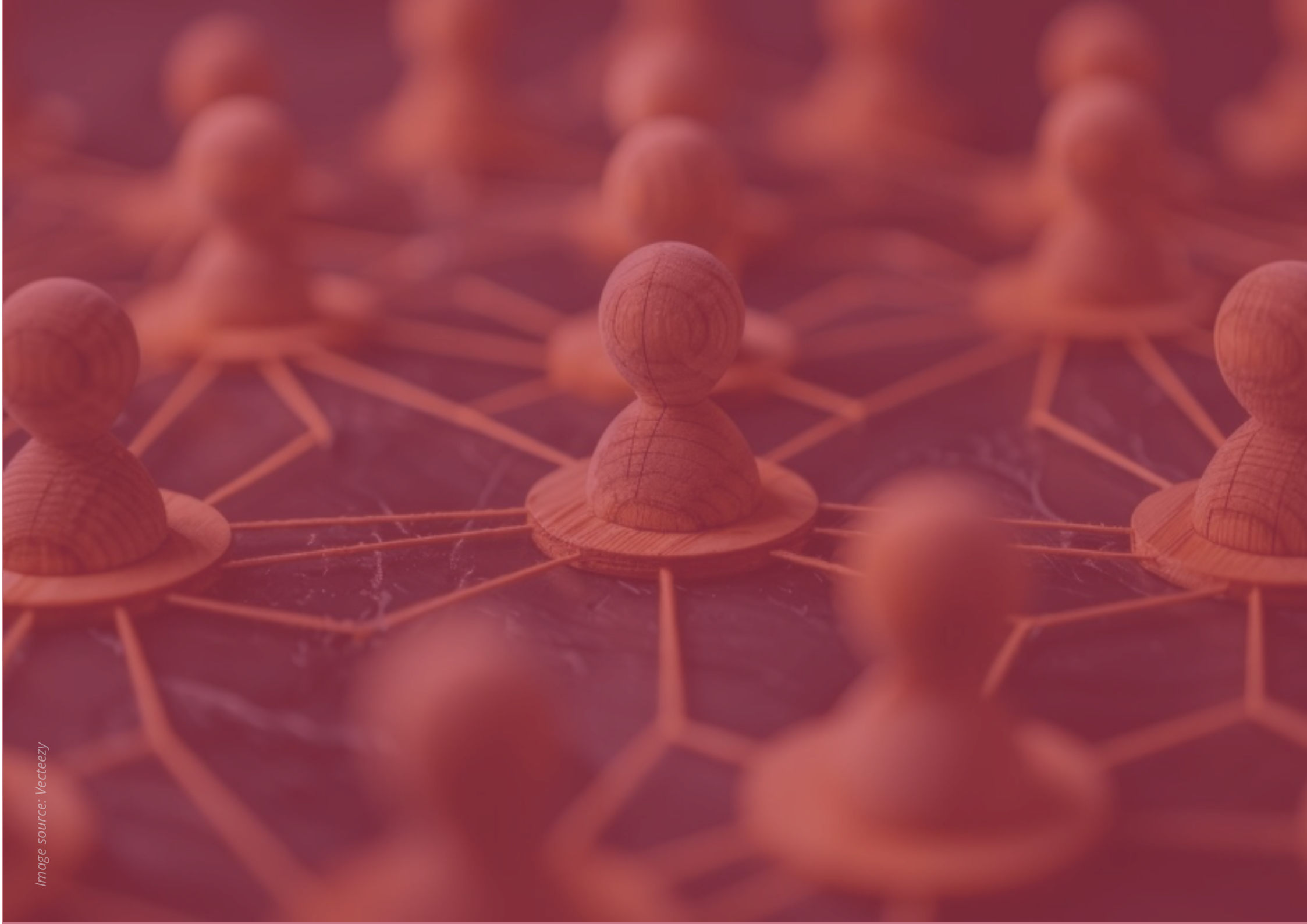


Image source: Vecteezy

4 Synthesis

In this chapter, insights from the literature research and interviews are combined into an integrated overview of the experiences of children with CHD and the involved stakeholders in different contexts. These insights are visualized through journey maps, which illustrate how stakeholders navigate the care and sports environment and where challenges and opportunities emerge. Based on these journeys, key intervention moments were identified: specific points at which a tool could support stakeholders. Together, insights from the literature, interviews, and journey maps, form the basis for a list of requirements that guide the design exploration and concept development in the following chapters.

4.1 Journey maps of the current experience

To better understand the dynamics surrounding communication and sports participation in children with CHD, journey maps were created, based on literature findings and later validated and supplemented with insights from interviews to create a more complete and reliable overview.
These journeys illustrate what different stakeholders experience during key moments in the child's care and sports participation.

Based on the literature and interview findings, two stages were selected as most relevant for understanding communication patterns and identifying opportunities for a communication tool for the sports environment:

- The consult with a pediatric cardiologist (Figure 11)
- The sports class (Figure 12)

For each stage, the relevant stakeholders were identified. Although peers play an important contextual role in sports settings, and siblings can often play a role in the child's broader home and activity environment, they are not core stakeholders for the scope of this communication tool and were therefore not included in the journey maps.

Within each stage in the journey, an overview was made of the stakeholder activities, emotions, challenges and possible opportunities.

The purpose of these journey maps is to:

- Gain insight into communication and sport-related challenges and opportunities between stakeholders
- Synthesize insights from both literature and interviews into a stage-based overview of current experiences
- Support the refinement of design requirements for the communication tool
- Identify potential intervention moments at which a communication tool could support stakeholders

The literature sources used for the journey maps are: Longmuir (2021, 2022), Williams (2017), Ong et al. (2011), Buchanan et al. (2023), Saxena et al. (2013), Roston et al. (2013), Chong et al. (2018), Etnel et al. (2017).

Appendix E describes in more detail which specific literature sources and interview insights form the basis for which statements in the sections 'Possible emotions' and 'Challenges/obstacles/pain points'.

Legend

Source of insight

- Interviews
- Literature
- Both interviews and literature

Stage	Consult with pedriatic cardiologist		
People involved	**Children with CHD** 	**Parents** 	**Pediatric cardiologist** 

Activities	**These activities are based on interviews with healthcare professionals, children, parents and assumptions.*
	
	Getting ready for the appointment
	• Thinking about questions or concerns they might want to ask
	• Going to the hospital
	• Waiting in the waiting room
	
	Before the consultation with the cardiologist
	Station 1: ECG station → measuring weight, height, blood pressure, and performing an ECG
	Station 2: Heart ultrasound
	
	During the consultation with the cardiologist
	Station 3: Consultation room
	• Sitting with the cardiologist and parent
	• Answering questions about how they have been (symptoms, school, sports)
	• Undergoing a physical examination
	• Listening to the explanation of ECG and echo results
	• Receiving information about what the findings mean for them
	• Hearing the plan and next steps, including whether additional tests or follow-up actions are needed
	• Asking questions if they have any
	• Saying goodbye and leaving the room
		**These activities are based on interviews with healthcare professionals, children, parents and assumptions.*
		
		Getting ready for the appointment
		• Thinking about questions or concerns they might want to ask
		• Going to the hospital
		• Waiting in the waiting room
		
		Before the consultation with the cardiologist
		Station 1: ECG station
		Station 2: Heart ultrasound
		
		For both stations:
		• Accompanying the child to the room, supporting the child during measurements, waiting while the ECG/echo is performed
		
		During the consultation with the cardiologist
		Station 3: Consultation room
		• Sitting with the cardiologist and their child
		• Listening to anamnesis questions and adding relevant information
		• Observing the physical examination
		• Listening to the explanation of ECG and echo results
		• Receiving information about what the findings mean for their child
		• Hearing the plan and next steps, including whether additional tests or follow-up actions are needed
		• Asking their own questions or clarifying concerns
		• Saying goodbye and leaving the room
			**These activities are based on interviews with healthcare professionals.*
			
			Before the consultation
			• Preparing the outpatient clinic schedule
			**Some cardiologists review and prepare several days to a week in advance, depending on personal workflow and available time.*
			
			During the consultation (± 20 min)
			• Conducting anamnesis, often briefly:
			  ◦ Asking how the child has been,
			  ◦ Whether any cardiac symptoms occurred since the last visit
			  ◦ How things are going at school/sport
			• Performing a physical examination
			• Reviewing and explaining the ECG and echocardiogram results
			• Discussing the need for additional tests (e.g., exercise test, MRI) and explaining their purpose
			• Outlining the plan and next steps, including possible referrals
			• Answering questions from parents and the child
			• Summarising and closing the consultation
			
			Administrative tasks (vary by cardiologist)
			• Updating the patient record
			• Documenting the plan and next steps
			• Submitting orders for additional tests
			• Finalising prescriptions if needed
			**Timing and workflow vary between cardiologists (during the consult, after the consult, or later)*

Possible emotions **These emotions are possible and based on insights from both literature and interviews. Experiences vary between individuals, not every stakeholder will feel all of these emotions.*	■ Uncertainty ■ Feeling of being different ■ Lack of knowledge about the impact of their condition **partly because they were not included in conversations between their parents and healthcare providers.*	▲ Reassurance after the hospital check ▲ Increased trust when professionals confirm that physical activity is safe ▲ Possible hesitation to ask questions if the consultation feels time-pressured ▲ Nervous feeling before a hospital visit	
Challenges/obstacles/ pain points *What barriers or difficulties are they experiencing? What isn't working well?*	● Children may not recall having conversations with their doctor about PA ● PA conversations often perceived as restrictive rather than empowering ■ Feeling uncertain about their condition and what it means for daily life ● Difficulty interpreting bodily signals and understanding personal limits	● Difficulty translating general advice into practical, daily-life decisions ● Advice often perceived as too general or vague ■ Accumulating old advice over time → confusion about what still applies ■ Assumptions from clinicians about low activity levels may increase parental doubt ▲ Need reassurance that physical activity is safe	● Time pressure during consultations ▲ Little time to ask follow-up questions or discuss PA in depth ▲ Variation between cardiologists and available time determines how extensively PA is discussed ▲ Children who visit only once every few years may fall out of view ▲ Difficult to give specific PA advice without sufficient contextual information, such as the current PA level of the child ● Information provided based on assumptions by the cardiologist may not match priorities of the child ■ Limited awareness of the relatively low risk of physical activity for most children with CHD ■ Limited knowledge of available PA resources or programmes for children ▲ Few referrals to physiotherapists or other professionals, although helpful. No guidelines for referral ▲ Minimal referral to external information platforms for parents and children
Opportunities *Where are there opportunities for improvement or support?*	• Involve children directly in the consultation conversation • Use age-appropriate language and explanations. • Emphasize what children can do, not only what they should avoid. • Check whether the child understands what they are allowed to do to identify misinterpretations. • Support the child in asking questions or sharing concerns. • Support the child in understanding bodily signals and personal limits, with additional professional guidance when helpful.	• Provide activity-specific advice based on the child's actual sports and preferences, recognising that fun and positive experiences are key drivers for long-term participation. • Avoid general statements unless supported with clear, concrete examples. • Check what parents have understood and where uncertainty remains. • Reassure parents by aligning advice with the child's real activity level and abilities. • Clarify how current advice may differ from earlier recommendations.	• Provide cardiologists with a clear structure so PA is consistently covered in consultation. • Collect information from parents and children before the consult to use consultation time efficiently and enable more specific PA advice. • Ask parents and children what they want to discuss to avoid decisions based on assumptions. • Reduce mismatches by asking more about the child's actual activities and priorities to discuss during consultation. • Identify help-needs in a concrete way to determine whether referral to other professionals (e.g., physical therapists) would be beneficial. • For children who experience anxiety or uncertainty about physical activity, the nurse consultant can provide additional time and tailored explanation. • Provide cardiologists with reliable information platforms they can refer families to when appropriate.

Figure 11: Journey map of the consultation stage

Stage	Sports class		
People involved	**Children with CHD** 	**Parents** 	**Sports coach/ PE teacher** 
Activities	**These activities are based on interviews with children, parents, sports coaches and assumptions.* **Before the sports class** • Going to the gym or sports class location • Changing in the locker room • Interacting with peers • Walking to the sports field or sports hall • Receiving a general introduction from the coach/PE teacher • (Possibly) Communicating limitations or symptoms to the coach or peers **During the sports class** • Warming up • Participating in activities • Choosing or being assigned an activity, group, or role (depending on the type of sport and coach) • (Possibly) Adjusting intensity or stopping when experiencing symptoms • (Possibly) Comparing own performance to peers • Tidying up equipment together • Walking back to the locker room • Changing clothes / showering	**These activities are based on interviews with healthcare professionals, children, parents and assumptions.* **Getting ready for the appointment** • Thinking about questions or concerns they might want to ask • Going to the hospital • Waiting in the waiting room **Before the consultation with the cardiologist** *Station 1:* ECG station *Station 2:* Heart ultrasound For both stations: • Accompanying the child to the room, supporting the child during measurements, waiting while the ECG/echo is performed **During the consultation with the cardiologist** *Station 3:* Consultation room • Sitting with the cardiologist and their child • Listening to anamnesis questions and adding relevant information • Observing the physical examination • Listening to the explanation of ECG and echo results • Receiving information about what the findings mean for their child • Hearing the plan and next steps, including whether additional tests or follow-up actions are needed • Asking their own questions or clarifying concerns • Saying goodbye and leaving the room	**These activities illustrate one detailed PE lesson example based on an interview with a secondary school PE teacher of an outside sports class. Practices may vary across teachers, sports and age groups.* **Before the sports class (preparation – outside lesson hours)** • Prepares weekly PE activities based on a mandatory programme. Determines specific game forms and exercises for the upcoming lesson. • Checks email for injuries or medical updates of children and may adjust the lesson plan accordingly. **During the sports class** • Children change clothes • Short general introduction: Explains what the children will do that lesson and mentions any important notes. (kept as short as possible because children want to start moving immediately) • Walk to the outdoor sports fields • Warm-up game • Mandatory curriculum component (e.g., endurance run) • Choice-based activity block with several stations (e.g., softball throwing, hockey, football, frisbee). Group division depends on the activity, the age group, and the coach's teaching style. This can vary from assigned groups to free choice. • Rotating between activities • Tidying up equipment together • Walking back to the sports hall • Children change clothes again
Possible emotions **These emotions are possible and based on insights from both literature and interviews. Experiences vary between individuals, not every stakeholder will feel all of these emotions.*	• Feeling limited by symptoms or needing to pause when noticing bodily signals (breathlessness, fatigue) • Worry or uncertainty about bodily signals • Feeling different or weaker than peers • Feeling good when joining peers and not standing out • Children who want to be active can be frustrated by parents limiting their physical activity	• Feels fear and overprotection about the child's ability to participate in sports • Uncertainty about how to inform other people about their child's condition • Doubts in making decisions, such as whether or not to allow certain activities	• Uncertainty and lack of information lead to anxiety and fear of exercise for people with CHD when making decisions about PA and sports participation • Uncertainty about how to respond to symptoms
Challenges/obstacles/ pain points *What barriers or difficulties are they experiencing? What isn't working well?*	• Physical symptoms may reduce full participation • Symptoms not always CHD-related (deconditioning / cardiac anxiety) • Early exhaustion lowering self-efficacy • Lack of clear safety guidance → overexertion or avoidance • Comparing performance with peers may lower perceived competence (keeping up), which can affect participation • Fun with peers is a facilitator, not keeping up is a barrier • Negative social experiences (exclusion, judgement, feeling "less capable") reducing enjoyment & motivation	• Lack of clarity about what is safe in sports environments • Fear and overprotection leading to unnecessary restriction of activities • Uncertainty about bodily signals → fear of overexertion or stopping unnecessarily • Parental overprotection lowering their child's PA self-efficacy • Tension between encouraging enjoyment, trusting their child's bodily signals, and ensuring safety during sports	• Limited understanding of CHDs and what they mean for sports participation • Lack of training or tools to confidently guide children with CHD • Relying heavily on information from parents, which may be incomplete, inconsistent or unclear • Lack of effective communication, between school/sportsclub, parents, children and healthcare professionals • Lack of clear, written PA guidelines makes coaches uncomfortable to include children with CHD in sports • Uncertainty about responsibility and monitoring on symptoms • Focus on performance can unintentionally exclude or discourage children with CHD • Difficulty managing a full group of children while also monitoring and supporting individual medical needs
Opportunities *Where are there opportunities for improvement or support?*	• Encourage children to listen to their bodies and adjust intensity when needed. • Clarify that symptoms can stem from deconditioning or anxiety rather than disease severity. • Support self-efficacy through positive encouragement and small mastery experiences. • Provide clear, personalized safety guidance to prevent overexertion or unnecessary avoidance. • Emphasize what is possible, focusing on inclusion, adaptation, and capability. • Emphasize participation and enjoyment rather than performance or comparison. • Offer choice-based and adjustable activities to match different abilities. • Promote an inclusive and supportive sports class environment that reduces negative social experiences.	• Provide parents with clear, consistent guidance and support, involving additional healthcare professionals when needed, so that uncertainty about their child's abilities decreases. • Increase parental confidence by explaining what is possible and safe in sports. • Educate parents about typical versus concerning bodily signals and when to encourage activity versus rest. • Help parents support their child's self-efficacy through positive encouragement and small success experiences. • Provide parents with clear, easy-to-share information to communicate with sports coaches/school/sports club. • Acknowledge the emotional tension between safety and independence in encouraging sports and provide strategies to manage it.	• Improve understanding, awareness and implications of CHDs • Provide tools to help coaches confidently guide children with CHD • Strengthen communication channels between coaches, families, schools and healthcare professionals. • Collaborate with parents and healthcare professionals to build a shared understanding of safe participation. • Provide clear, written PA/safety guidelines so coaches feel confident including children with CHD. • Clarify who is responsible for monitoring physical limits and ensure that this person can recognize signs of overexertion and act if needed. • Focus on participation and enjoyment rather than performance, and design activities that are fun and accessible for all children. Offer alternative roles and modified tasks that emphasise inclusion. • Use encouragement, positive feedback, and small success experiences to strengthen children's PA self-efficacy.

Figure 12: Journey map of the sports class stage

4.2 Identified intervention moments for communication and support

To identify where a communication tool could provide value, the journey maps were analyzed for moments in which stakeholders experience uncertainty, information gaps or a need for additional support.

These intervention moments represent opportunities where a communication tool could be implemented. Below, the key intervention moments are described for each stage, together with how a tool could support stakeholders at that specific moment.

4.2.1 Consult-related intervention moments

The consultation is an essential but time-limited touchpoint. For most children with CHD, it is the only structured moment where their sports participation and physical activity is discussed. Interviews show that while physical activity often is addressed, the depth and specificity of conversation about sports vary between cardiologists and situations. Relevant issues may remain underexposed when parents or children do not explicitly raise them, and the opportunities for follow-up questions may be limited due to time constraints.

In addition, research indicates that parents and children may struggle to translate medical advice into daily sports practice after the consultation. There may also be uncertainty about how sports advice is communicated to others, such as schools or sports clubs, and whether its meaning remains consistent and reliable when it is passed on through interpretation or incomplete transfer. Also, research shows that parents and children may struggle to translate advice into daily sports practice afterwards.

The following intervention moments illustrate where a communication tool could support appropriate, personalized guidance and the exchange and transfer of information before, during, and after the consultation:

Before the consultation

A tool could help by:

- Helping parents and children prepare questions or concerns in advance
- Providing a structured way to reflect on symptoms and sports experiences beforehand
- Ensuring that relevant updates (symptoms, activity level, worries) are not forgotten
- Making it easier to bring up important topics during the short consultation time
- Providing pre-structured information for cardiologists, reducing time spent on the anamnesis
- Helping avoid assumptions or mismatches by giving the cardiologist a clearer starting point from the perspective of child and parent

During anamnesis

A tool could help by:

- Allowing the cardiologist to quickly review key updates, making the consultation more efficient
- Helping ensure important information is not overlooked
- Supporting more personalized and specific advice

When discussing PA and sports participation

A tool could help by:

- Providing tailored, sport-specific guidance on safe participation
- Reducing confusion or misinterpretation about advice and what is allowed
- Helping cardiologists provide clear and consistent advice without increasing consultation time
- Clarifying which signals are normal exertion versus when to stop
- Supporting children in learning to recognize and interpret their own bodily signals

After the consultation

A tool could help by:

- Providing a clear, accessible, written summary that families can revisit
- Offering a take-home component with ready-to-share formats for schools or sports clubs about PA recommendations

4.2.2 Sports class-related intervention moments

In the sports setting, coaches must balance group management with individual needs, including those of children with CHD. Although interviews indicate that coaches aim to be inclusive and supportive, they often lack condition-specific information and may feel uncertain when interpreting bodily signals. As a result, some coaches may rely on caution rather than confidence when supporting children with CHD.

The following intervention moments highlight where a communication tool could provide clarity and guidance within the sports context.

Before the sports class (sports coach preparation)

A tool could help by:

- Providing concise, reliable information about the child's condition and participation needs
- Supporting sports coaches in preparing activities with appropriate adaptations when needed
- Reducing reliance on inconsistent or last-minute information from parents

Arrival at the sports class

A tool could help by:

- Allowing parents or children to share relevant updates and information in a consistent way

During warm-up and main sports activities

A tool could help by:

- Clarifying which signals are normal exertion vs. when to stop
- Supporting coaches in deciding when to adjust intensity or offer a different role and providing clarity about responsibility in these decisions
- Providing guidance on how to respond appropriately when a child needs to pause or rest

After the sports class

A tool could help by:

- Providing clear channels for follow-up questions or concerns and indicating who to contact

4.3 Requirements

This chapter presents the requirements for the communication tool designed to support children with CHD, their parents, sports coaches and healthcare professionals in enabling safe and inclusive sports participation. The requirements are derived from a synthesis of two main sources within the research phase: a literature review and an interview analysis.

The literature review established the broader understanding of main barriers to sports participation, roles that different stakeholders play in encouraging or restricting sports participation, and common communication problems.
The interview analysis confirmed most of these insights in practice and provided additional, context-rich insights into stakeholder behaviors, needs and expectations. These interview findings were translated into statement cards, iteratively clustered and synthesized into themes, which informed the design implications presented throughout the Results chapter.

The journey maps, developed using insights from both literature and interviews, further clarified when and where stakeholders experience challenges across key moments in the child's sports context and care trajectory. These maps highlighted opportunities for the tool to support the stakeholders.

Additionally, the intervention moments identified helped determine at which specific points in the communication chain the tool could provide support. These moments clarified when stakeholders need guidance and also helped translate stakeholder needs into requirements.

Together, the literature review, interview findings, design implications, journey maps and intervention moments form the foundation for the requirements presented in this chapter.

The requirements are structured by stakeholder group (children, parents, sports coaches/PE teachers and healthcare professionals), followed by cross-stakeholder requirements that apply to the broader communication network.

Children

- The tool should **actively involve children** in conversation about sports with their healthcare professionals.
- The tool should **create space** for children to **ask questions, share experiences** and express their **goals, concerns and interests** related to sports participation.
- The tool should help **uncover potential support needs** of the child related to sport participation and make these visible to healthcare professionals so they can **offer appropriate guidance or refer** if needed.
- The tool should support communication that **focusses on abilities and possibilities,** rather than restrictions, to support self-efficacy and participation.
- The tool should help shift the focus towards what the child **can do, rather than** on **limitations.**
- The tool should support children in **learning to recognize and interpret bodily signals** during physical activity.
- The tool should support children in making clear **agreements about when and how to report** symptoms or concerns during sports lessons.

Parents

- The tool should provide insight into **how current advice** from healthcare professionals **relates to earlier advice.**
- The tool should help parents **understand and assess what PA levels are safe** for their child.
- The tool should provide relevant **guidance** on physical activity and sports participation, **tailored to families' needs**, **regardless** of whether the child is **currently participating in sports or not.**
- The tool should give parents **control over which stakeholders receive what information** about their child's condition and sports participation.
- The tool should help children and parents to **communicate their wishes and needs** regarding sports participation to sports coaches.
- The tool should **support** parents in **communicating advice** about sports participation **accurately and consistently** to sports coaches.

Sports coaches/ PE teachers

- The tool should **provide** sports coaches with **background knowledge** about CHD and its **implications** for a child's **participation in sports activities.**
- The tool should provide sports coaches with **clear, concise and practical information** about what a child can do safely during sports.
- The tool should provide sports coaches with clear **insight into the wishes and needs** of the child (and parents) regarding sports participation, **supporting safe, inclusive and enjoyable participation.**
- The tool should ensure that the sport-related **information** described above is **available before the sports class,** enabling sports coaches to prepare their training accordingly.
- The tool should **support sports coaches in identifying suitable activities and adaptations,** based on the sport-related information provided, while allowing coaches to apply this within their own training context.
- The tool should provide clarity about what **symptoms or signals** to pay attention to and what **actions to take** if these occur.
- The tool should clarify who coaches can **contact** in case of **questions, concerns or uncertainty.**

Healthcare professionals

- The tool should ensure that relevant **information and insights** from parents and children are available **before the consultation,** so that healthcare professionals can **prepare.**
- The tool should give healthcare professionals **insight** into the child's sports experiences, concerns or limitations and home situation to **offer appropriate guidance or refer** if needed.
- The tool should provide healthcare professionals with **insight** into how children and parents **interpret sports advice,** enabling early **identification of misunderstandings** and supporting clarification of outdated, unclear or incorrect assumptions.
- The tool should support healthcare professionals in **giving personalized sports advice** that reflects the unique situation of each child with CHD and their specific sports or activities.
- The tool should help **tailor sports advice to the child's personal interests and preferences,** thereby increasing motivation and long-term participation in sports.
- The tool should **support** healthcare professionals in providing **clear, understandable and consistent information** about sports participation.
- The tool should make it possible for healthcare professionals to **discuss sports participation within the limited time** available during consultations.
- The tool should provide a **standardized structure** that helps cardiologists **consistently discuss sports participation** during consultations and reduces variability between them.
- **(Medical) information** provided within or referenced by the tool should be **trustworthy** and originate from **reliable, evidence-based sources** that healthcare professionals can **confidently use or refer to.**

Cross-stakeholder

- The tool should support a **shared understanding of safe participation** among all stakeholders.
- The tool should **encourage collaboration** between cardiologists, parents, children and sports coaches (and other stakeholders).
- The tool should **clearly indicate the roles and responsibilities** of children, parents, sports coaches and healthcare professionals in supporting safe sports participation, so that each stakeholder knows what actions are expected from them.
- The tool should **support efficient transfer** of sport-related information between stakeholders.
- Information should be **transferable to multiple stakeholders,** such as different sports clubs and schools.
- The tool should help **prevent information loss** by ensuring that all stakeholders have access to **consistent, complete and up-to-date** sports-related **information.**
- The tool should be **updateable** when changes occur in the child's medical status or sports advice.
- The tool should make **provided advice accessible for later reference,** to ensure families and sports coaches can revisit information when needed.
- The tool should be **easy to use** for all stakeholders.
- The tool should **protect the privacy of the child** by ensuring that personal information is only accessible to authorized stakeholders.

Image source: Vecteezy

5

Design exploration

This chapter explores the design space by analyzing existing tools, platforms, and initiatives related to communication and support around CHD and sports participation. Through desk research, interviews, and co-creation sessions, relevant existing tools and solutions are identified and analyzed. The insights are used as inspiration and inform the direction of the concept development in the next chapter.

5.1 Analysis of tools identified during early desk research

To explore possible directions for the design of a communication tool, existing tools used in healthcare and sports contexts were reviewed. This analysis focused on their content, target users, what works well, or not, and specific strengths or elements that could serve as inspiration for a tool tailored to the context of this project.

Based on their primary focus, the identified tools were grouped into three categories:

- Information and educational materials
- Conversation tools
- Communication platforms in healthcare

Figures 13, 14, and 15 show the analysis of these tools.

What this analysis contributed to the design process

The tools reviewed in this early phase of the design process were identified before the full problem space had been mapped out. Therefore, they served as broad inspiration during the initial ideation stage as a way to understand what types of solutions already exist in a broader context, which challenges they attempt to address, and which elements might be relevant for a communication tool in this project.

Although the tools varied widely in format and purpose, they supported the early conceptualization by highlighting several recurring needs, such as the need for clear, structured information, visualizations, role-specific guidance and practical communication support.

One tool that was particularly valuable was the “Physical Activity & Congenital Heart Disease” guide by Heart Research UK, which later helped shape the content of the concept. This influence is discussed in more detail in Chapter 6.5.2.

Information/educational materials

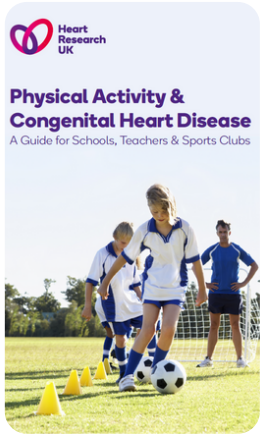
	Description	Context/ target audience	What works well	What is missing	Inspiration for design
 (Belt & Engelen, 2020)	This **informational brochure** provides an overview of the possible effects of a (congenital) heart defect on a child's functioning at school. It offers both background information and practical advice.	Teachers in primary and secondary education.	• Emphasizes the importance of communication and coordination between the teacher, parents, and - if applicable - the child. • Highlights relevant topics that should be discussed (such as symptoms, how to respond to them, physical exertion, and necessary adjustments). • Provides concrete examples of possible adjustments (e.g., adapted physical education, extra rest periods).	• The brochure is mainly focused on children with severe heart defects and is less suitable for children with mild or moderate CHD, who may require different focus points, limiting its ability to provide child-specific guidance. • It is unclear whether the teacher, parent, or child should initiate the conversation. This lack of role clarity conflicts with the need for clearly defined responsibilities across stakeholders and may result in the conversation not taking place or occurring too late. • The brochure does not provide concrete guidance, tools, or conversation starters to help facilitate effective communication. • Examples of possible adjustments are mentioned, but there is no explanation of when these are necessary, for whom they are appropriate, or who is responsible for making such decisions, which may hinder practical application. • The brochure implicitly assumes that parents and children themselves have sufficient insight into what is safe and can inform the teacher accordingly. However, research shows that they often experience uncertainty and lack clear information. As a result, sports coaches and teachers may receive incomplete or inconsistent information, and the brochure does not adequately support shared understanding or confidence in decision-making about safe sports participation.	• Conversation cards or structured questionnaires to guide discussions. • Clarify roles and implementation moments: who initiates the conversation, at what point, and how to prepare for it. • Ability to concretely tailor the content to the individual situation of each child.
 (Todd et al., n.d.)	This **communication document** is designed to inform and support school staff, in particular teachers and club leaders, in supervising children with congenital heart disease (CHD) during physical activity.	A guide for schools, teachers and sports clubs.	• Includes a detailed Physical Activity Recommendations Form that outlines what types of activity should be suitable or not for a specific child. • Addresses multiple relevant topics: symptoms to monitor, medication and very specific ones like outdoor pursuits and fairground/theme-park rides. • Includes a template for a personalized PE lesson plan, which enables tailored physical education based on the child's capabilities. • Ends with a verification section to confirm which school staff have read the information. This makes it clear who has received and reviewed the information.	• The document structure may be unclear, as section titles are not always intuitive, and important information may be difficult to locate, limiting sports coaches' ability to quickly access clear and practical information needed during sports lessons. • The content seems sometimes written for teachers in general rather than specifically for PE teachers, limiting the provision of clear, role-specific guidance aligned with the responsibilities of sports coaches. • Some information may be interpreted as confusing or contradictory. General warnings about avoiding breath holding activities (such as swimming or weightlifting) may contradict previous personalized recommendations allowing these activities. This lack of clarity may lead to confusion and increase uncertainty among PE teachers about what is safe for the specific child. • Instructions on who to consult and when may be interpreted as unclear. The tool advises to monitor symptoms and consult medical specialists, but does not specify who is responsible for taking action (the parent, teacher or coach), which conflicts with the need for clearly defined roles and responsibilities. • Language and terminology may be too complex. Because medical terms and drug names are not explained, the content may limit accessibilty and practical usability for readers without a medical background. • There may be an inconsistent level of personalisation. Some sections are tailored to the specific child (such as activity recommendations), while others (medication section) show long, general lists of drugs that may not apply to the specific child. This might make it harder for users to focus on relevant information. • No visual support, the tool is almost entirely text based. This may reduce clarity and ease of use for PE teachers who need to quickly interpret and apply information in practice. • Altough the document includes a template for creating a personalized PE lesson plan, it does not specify who is responsible for completing it, which may lead to confusion among teachers, parents and healthcare professionals. • In the section where readers are asked to tick off who has read the document, only staff roles are listed (e.g., "PE/Games Teacher 1"), not actual names, which may make follow-up unclear.	• Use of visuals to improve readability and accessibility. • Nice to tailor information specifically to the role of the reader (such as sport coach vs. general teacher). • Make the tool adaptable or modular, so only the most relevant information is visible to each stakeholder. • Simplify language and avoid overwhelming medical terms. • Ensure consistency across different sections like uniform headings, structure and terminology. • Clarify who is responsible for filling in forms or contacting specialists. • Avoid contradictions, make sure that individual recommendations don't conflict with general safety guidelines or explain it. • Include a sign-off section with names (not just roles), to make clear who has read the document, even if staff roles change over time.

Figure 13: Information/ education materials

Conversation tools 1/2

	Description	Context/ target audience	What works well	What is missing	Inspiration for design
 (Kenniscentrum Sport & Bewegen, n.d.–b)	The Beweegcirkel is a **step-by-step conversation tool** designed to help professionals having conversations with patients or clients (both individuals and groups) to achieve behavior change regarding exercise.	Professionals such as lifestyle coaches, practice nurses, or physiotherapists) in a conversation with patients/clients.	• It may be an accessible conversation starter, as it might make it easier to talk about physical activity. • It may provide a clear, step-by-step structure for discussing exercise behaviour with people. ◦ *"Wat doe jij al op een dag? Welke activiteit lijkt jou leuk en waarom? Welke activiteit past in jouw dag? Omgaan met moeilijke momenten en jezelf belonen!"* • It may encourage personal reflection and setting goals, tailored to the daily routine of the individual. • Included worksheets (physical as well as digital) may make the tool more interactive and practical.	• Not specifically designed for children with CHD or sports participation in organized settings. • Medical safety considerations or child-specific guidelines relevant to children with health conditions are not included, limiting support for informed decision-making about safe sports participation. As a result, additional professional input or advice is required when applying the tool to specific target groups, such as children with CHD.	• Nice use of a step-by-step structure to guide conversations and set personal goals. • Fillable materials that children can take home or use during sessions. • Interactive and inclusive tool, suitable for both consults and sports settings. • Invites the child to reflect on their own preferences and activities. • It makes the conversation more action-oriented. • This tool bridges the gap between professional advice and personal motivation.
  (Kenniscentrum Sport & Bewegen, n.d.–a)	The Argumentenkaartjes are a **conversation tool** that professionals (such as physical therapists) can **use in the consultation room,** to discuss their child's physical activity with parents, from the parents' perspective. Parents choose a card with an argument they consider important, for example: "I think it's important that my child...can manage stress." Each argument explains how exercise contributes to this. The scientific evidence base ensures that parents are convinced of the value of exercise for their child.	Professionals in education, sports and healthcare who have conversations with parents about the importance of exercise of their child.	• Accessible and playful format that may lower the threshold for starting conversations about the importance of physical activity of children. • Focuses on what the parent values for their child, not just medical advice. • Use of illustrations on the cards may make the tool visually appealing and engaging. • Although the format of the cards may appear as playful, it is scientifically grounded. • Suitable for individual and group settings, and applicable for various types of professionals.	• Not specifically designed for parents of children with medical conditions, such as CHD. • The existing cards may be difficult to adapt to highly individualized situations, such as those involving specific limitations or safety considerations for children with CHD. • The cards focus primarily on what parents find important and do not sufficiently incorporate the child's own views, experiences and preferences, which conflicts with the requirement to actively involve children in conversations about sports participation.	• Use visual-based tools to initiate conversations. • Start the conversation from the perspective of the parent or child, not from the professional. • Adapt the tool to involve children more actively, encouraging them to share their own perspectives and priorities. • Make the conversation personal and values-driven to discover underlying motivations or barriers. • Combine personally meaningful themes with practical, evidence-based advice to strengthen the impact.

Figure 14: Conversation tools

Conversation tools 2/2

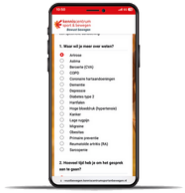
	Description	Context/ target audience	What works well	What is missing	Inspiration for design
Digizorg Assistent (Erasmus MC, 2024)	The Digizorg Assistent is a **digital tool** developed to **reduce the administrative burden** on healthcare professionals **using AI.** During a consultation, the Digizorg Assistent records the conversation and converts it into text in real time.	Healthcare professionals during the administration of patient consultations.	• Real-time transcription of consultations. • Saves healthcare professionals time in reporting. • Future updates will focus on consultation preparation (by doctors) and sharing summaries with patients via the Digizorg app. • Using AI to translate medical language into patient-friendly communication in summaries.	• Currently, the app does not support sharing information with other stakeholders such as sports coaches or schools, limiting cross-stakeholder communication and the transfer of sport-related advice beyond the healthcare setting. • Not specifically aimed at children, but it may have potential. • Focused only on medical consultations and not integrated within the sports context. It does not translate medical information into practical guidance for sports participation. • Patients currently receive information in a passive way.	• Potential to use AI to generate personalized output, specific for the other stakeholders, such as tailored language and content for parents, children, and sports coaches. • Opportunity to design a platform that makes medical information accessible and understandable across different contexts (such as home, school and sports) and not just within healthcare. • Opportunity to shift from passive information delivery for the patient, to more active involvement of patients and other stakeholders in the medical situation and lifestyle (/sport) decisions.
 (Kenniscentrum Sport & Bewegen, n.d.–c)	Bewust Bewegen is a **tool** designed **to support healthcare professionals in having conversations about physical activity** with patients who have **chronic conditions.** It offers practical conversation strategies, background knowledge of the impact of exercise on the condition and tips for tailoring advice to help patients incorporate more movement into their daily routines.	A healthcare professional, such as a doctor, practice assistant, physiotherapist, or lifestyle coach, who has conversations with people with a chronic condition.	• Provides flexible conversation formats depending on available time (1 minute, 5 minutes, or extended versions).	• The tool is not designed to support the transfer of sport-related information or facilitate communication and collaboration between key stakeholders, such as healthcare professionals, parents, PE teachers and sports coaches.	• A flexible conversation structure based on available time

Figure 14 (continued): Conversation tools

Communication platforms in healthcare

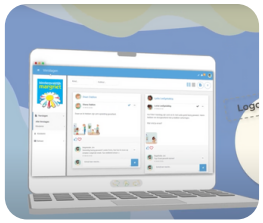
	Description	Context/ target audience	What works well	What is missing	Inspiration for design
 (Quli, n.d.)	Quli is a **personal health environment** where people can share information, documents and messages care providers and caregivers.	Patients & healthcare providers in a medical context.	• Healthcare providers can upload medical information and patients have access to that data at one central location. • Patients don't have to explain anything over and over again, new healthcare providers can be informed via Quli. • Patients can set their own health goals on the platform. • There's a diary where patients can provide updates on how they're doing with video, photos or text. • The patient has control over who can see which information.	• Not specifically designed for children or adolescents, it does not support age-appropriate involvement of children in their health trajectory. • Not accessible or understandable for sports coaches or people outside of healthcare, limiting cross-stakeholder communication. • The platform does not actively support or encourage discussion about physical activity or sports participation. • Medical information is not translated into clear, practical guidance for daily contexts, such as sports lessons, which limits its applicability for supporting sports participation.	• Make information available in one central location for multiple stakeholders. • Allow children to set their own goals. • A personal diary for receiving feedback. • Give children/parents control over who can see which data.
 (Schriftje, n.d.)	Schriftje is a **healthcare communication platform**, a kind of digital notebook where healthcare professionals can exchange messages with parents, daycare centers and schools.	Healthcare professionals in contact with parents, caregivers, teachers, schools.	• Easily accessible. • Collaboration across multiple domains. • All healthcare communication in one place.	• The platform is not specifically applicable to sports contexts and does not support translation of healthcare information into practical guidance for sports participation. • Control over which stakeholders are involved appears to lie primarily with the healthcare professional. This does not align with the requirement that parents and children want control over information sharing across different stakeholder environments. • The platform does not appear to be directly accessible to children, limiting their active involvement in conversations/communication about their own health and conflicting with the requirement to include the child's perspective, experiences and preferences.	• Accessible and user-friendly platform for different stakeholders • Option to share stories, newsletters, photos and plans.

Figure 15: Communication platforms in healthcare

5.2 Additional tools, platforms and initiatives

In addition to the tools identified during the early phase of the design process, interviews, co-creation sessions, and discussions with stakeholders revealed several additional tools, platforms, and initiatives. These solutions are not specifically aimed at communication between families, cardiologists, and sports coaches, but reflect a broader range of support, education, and digital healthcare infrastructure surrounding children with CHD and other chronic conditions.

Figure 16 provides an overview of these tools, categorized by their primary purpose. Some tools appear in more than one category, as they support multiple functions across different contexts. For example both background information provision and information transfer.

A more extensive explanation of these tools is provided in Appendix F.

Timing and influence on the design process
Because the design process followed an iterative approach, some tools were discovered earlier and had a more direct influence on the development of ideas and elements of the concept.

Other tools, such as the Hartpaspoort, Digizorg app and several digital communication systems used in hospitals, were discovered only at later stages of the project. As a result, they did not shape the early ideas or concepts presented in the following chapters. Instead, these later tools mainly helped me refine or confirm design decisions afterwards.

What these additional tools contributed to the design process
From these tools, platforms and initiatives several design relevant insights emerged:

- *Hartpaspoort & Waaier het samen op maat:* These tools inspired elements in my design concept related to how practical, role-specific information can be summarised clearly for schools or sports contexts. This influence is further explained in Chapter 6.5.2.
- *BeterDichtbij & Cyberpoli:* These platforms show how families may deal with questions or concerns between hospital visits. They helped me think about how communication could continue across different settings, for example through follow-up options in the tool.
- *Patiëntenvereniging Aangeboren Hartafwijkingen & Cyberpoli (as information sources):* These websites represent that CHD information is already widely available online. This implies that the communication tool does not need to recreate such information but can instead link to trustworthy existing sources or use information from these platforms for stakeholders via the tool.
- *Digizorg app (Erasmus MC):* Since the Digizorg app is already familiar to a lot of children and parents, integrating certain features of the communication tool into this existing system, or ensuring compatibility, may support adoption and ease of use.

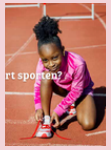
Support encouraging PA

Beweegredenentest

An online questionnaire that gives children insight into what motivates them to be active by generating a personal movement profile.

So Fit & Fun

An initiative that enables children with chronic heart, lung or airway conditions to exercise safely and enjoyably by playfully assessing their abilities and providing a personalised exercise and lifestyle program.



Esther Vergeer Foundation

Supports children with disabilities or chronic illnesses in finding a suitable sport and local sports club.

esther vergeer foundation

Background information CHD

Patiëntenvereniging Aangeboren Hartafwijkingen

Provides accessible background information on CHD and practical guidance for daily life, school and sports.

Patiëntenvereniging Aangeboren Hartafwijkingen

Cyberpoli Hartenkinderen

An online platform with animations, explanations and the option for children with CHD to ask questions to specialists.

Waaier het samen op maat

A brochure for children with chronic conditions, helping schools, parents and the child make clear agreements and understand support needs.

Helpline / contact for questions or concerns

Cyberpoli Hartenkinderen

An online platform with animations, explanations and the option for children with CHD to ask questions to specialists.

Beter Dichtbij app

A secure messaging app that allows patients to contact their healthcare providers with questions at any time.

Communication/ transfer of information to school

Hartpaspoort

A booklet with essential CHD information about a child and practical points for teachers in primary education.

Waaier het samen op maat

A brochure for children with chronic conditions, helping schools, parents and the child make clear agreements and understand support needs.

(Healthcare) communication systems (digital infrastructure)

Digizorg app

The Erasmus MC patient app for viewing appointments, letters, test results and notifications in one place.

Siilo

A secure messaging app used by BIG-registered healthcare professionals to exchange medical questions and patient cases.

Siilo

VIPLive

A secure communication platform where patients and healthcare providers can exchange messages, forms and medical information.

viplive

Zivver

A secure system for sending privacy-sensitive emails and documents.

zivver
A Kiteworks Company

Figure 16: Overview of tools, platforms and initiatives across healthcare and sports. Some tools appear in multiple categories, as they serve more than one primary function

5.3 Conclusion

The overview of additional tools, platforms and initiatives shows that a wide range of resources and tools already exist that may support children with CHD and their families, such as motivational programs, educational platforms, helplines, school guidance tools and digital infrastructures. However, none of these solutions address all core issues identified in the reviewed literature and interviews.

These tools reflect the broader ecosystem surrounding children with CHD or other conditions, sports participation and healthcare environments, rather than tools specifically designed to support clear, consistent and child-specific communication about sports participation between children, parents, healthcare professionals and sports coaches. While several tools offer valuable elements, they were not developed with this specific cross-context communication challenge as their primary focus.

Nevertheless, these resources demonstrate that both families and healthcare professionals may already have access to various existing systems. Therefore, these solutions can serve as:

- a source of inspiration, by identifying elements that work well (or do not work well) in other contexts.
- a supplement to the design, where existing tools can complement or enrich the concept.
- an opportunity for integration, by exploring how the new concept could connect to or function within the current healthcare and sports environment.

Image source: Vecteezy

6

Concept development

This chapter presents the iterative development of the concept throughout the project, from early exploratory sketches to the final concept. It describes how insights from research, feedback moments with stakeholders, and co-creation sessions informed the refinement of the concept over time.

Introduction

The visual below shows the most important phases and decisive moments that shaped the final concept. These phases include various forms of research, iterative design rounds, feedback moments with stakeholders, and co-creation sessions. Each of these elements is explained in more detail in the following paragraphs, in the same order as in the diagram.

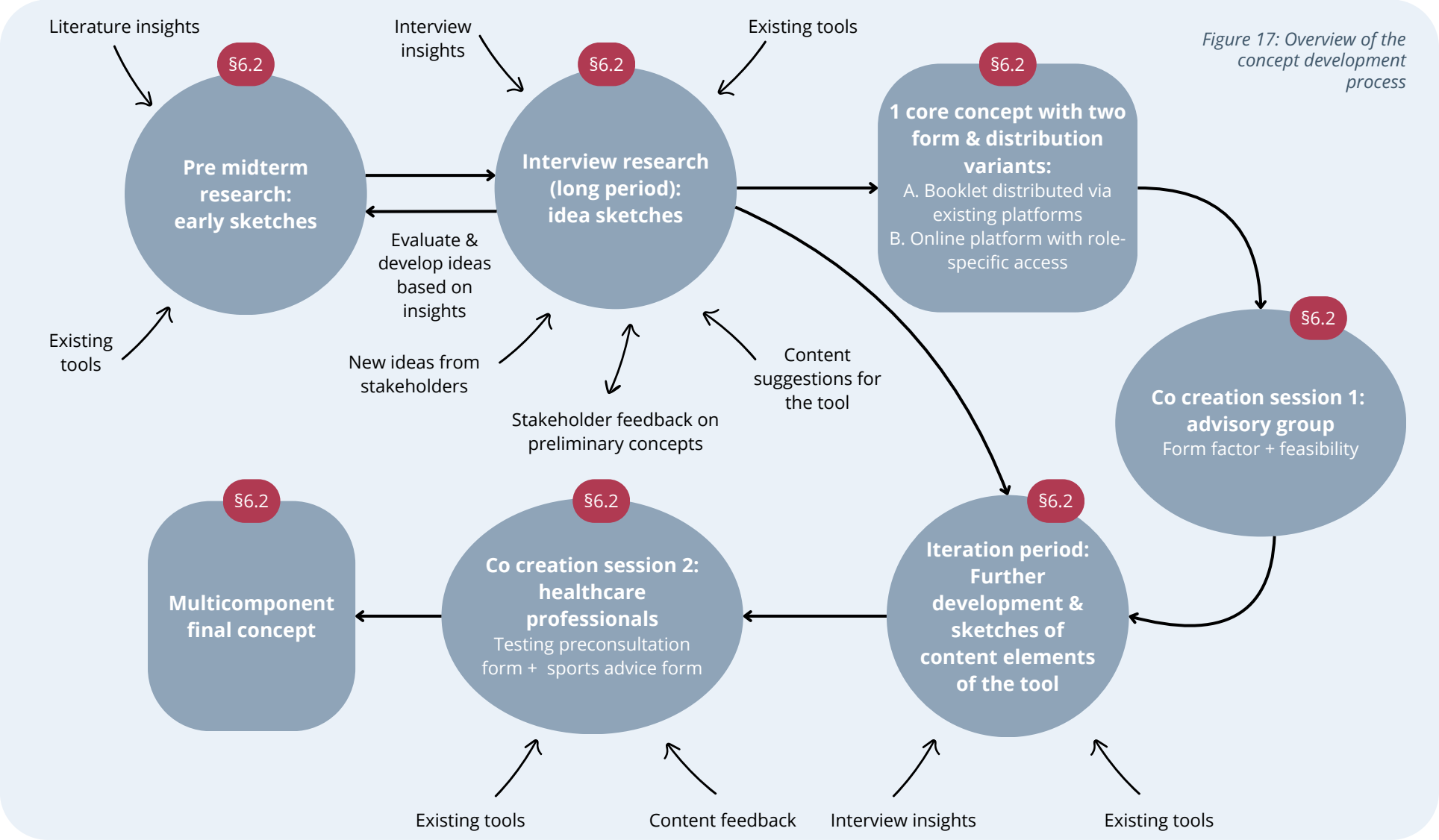
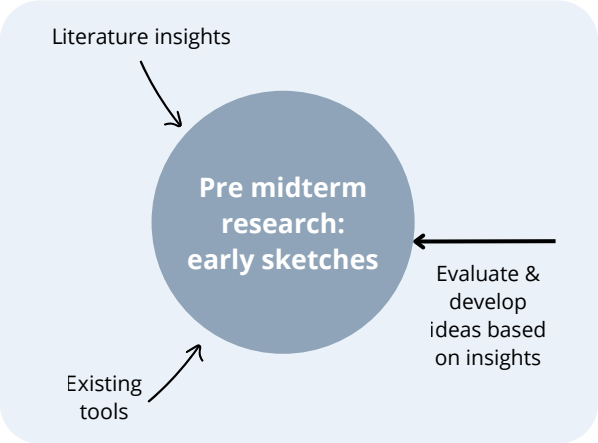


Figure 17: Overview of the concept development process

6.1 Pre-midterm research: early sketches



During the first ten weeks of the project, several early ideas emerged in parallel with, and as a result of, the literature review and the analysis of existing communication tools. The sketches below, in Figure 18, show this initial exploration of possible solution directions.

These exploratory sketches focused on different aspects of the communication problem identified in the early research phase.

For example, several sketches focused on making sports advice and conversations about physical activity more concrete and understandable for both parents and children. This reflects insights from the literature showing that sports advice is often experienced as vague or difficult to translate into daily life and sports contexts. These sketches showed, for example, the use of cards depicting sports-related situations that parents and children would recognize, which could be discussed during the consultation in order to ask for advice.

Other sketches explored how children could be more actively involved in conversations about sports during the consultation, in response to literature indicating that children with CHD are insufficiently included in discussions between their parents and healthcare providers. One idea involved a child-focused workbook, allowing children to reflect on their experiences and preferences in sports participation, which could be discussed together with the healthcare professional during the consultation.

Another idea focused on the use of a RASCI framework to clarify roles and responsibilities between stakeholders, addressing insights from existing tools that highlight unclear role division across healthcare, home, and sports environments. The RASCI method is often used in organizations to support role division and stands for Responsible, Accountable, Supporting, Consulted and Informed (RASCI Methode, n.d.).

In addition, several sketches examined how medical advice could be translated into practical, sport-specific guidance for sports coaches, responding gaps identified in literature between clinical recommendations and their application in the sports context. These explorations included ideas such as using AI within a tool to translate medical advice into accessible, audience-specific language, or developing a comic-style scenario guide for sports coaches that illustrates common situations during sports lessons and appropriate ways to respond.

Finally, some sketches explored how information could be shared or transferred across different environments, inspired by literature describing fragmented communication and the lack of structured information transfer between these environments. One sketch, for example, focused on a shared platform in which each stakeholder can log in and access role-specific information, tailored to their responsibilities and needs.

Most of these sketches only addressed a small subset of the identified requirements. They mainly helped to explore the problem and make possible solution directions more concrete.
At a later stage, the early ideas were revisited using insights that emerged from the interviews. This led to additional notes and reflections on the original sketches. This is shown on the orange and green post-its.

In addition to the exploratory sketches, early brainstorm mind maps were created to explore different ways of educating stakeholders (How can you educate?) and communicating information (How can you communicate?). These mind maps helped to systematically explore communication strategies and formats for different target groups. Additional inspiration for the tool was drawn from the website Pharos, particularly regarding key considerations for tool development, such as identifying end users and considerations for distribution (Pharos, n.d.).

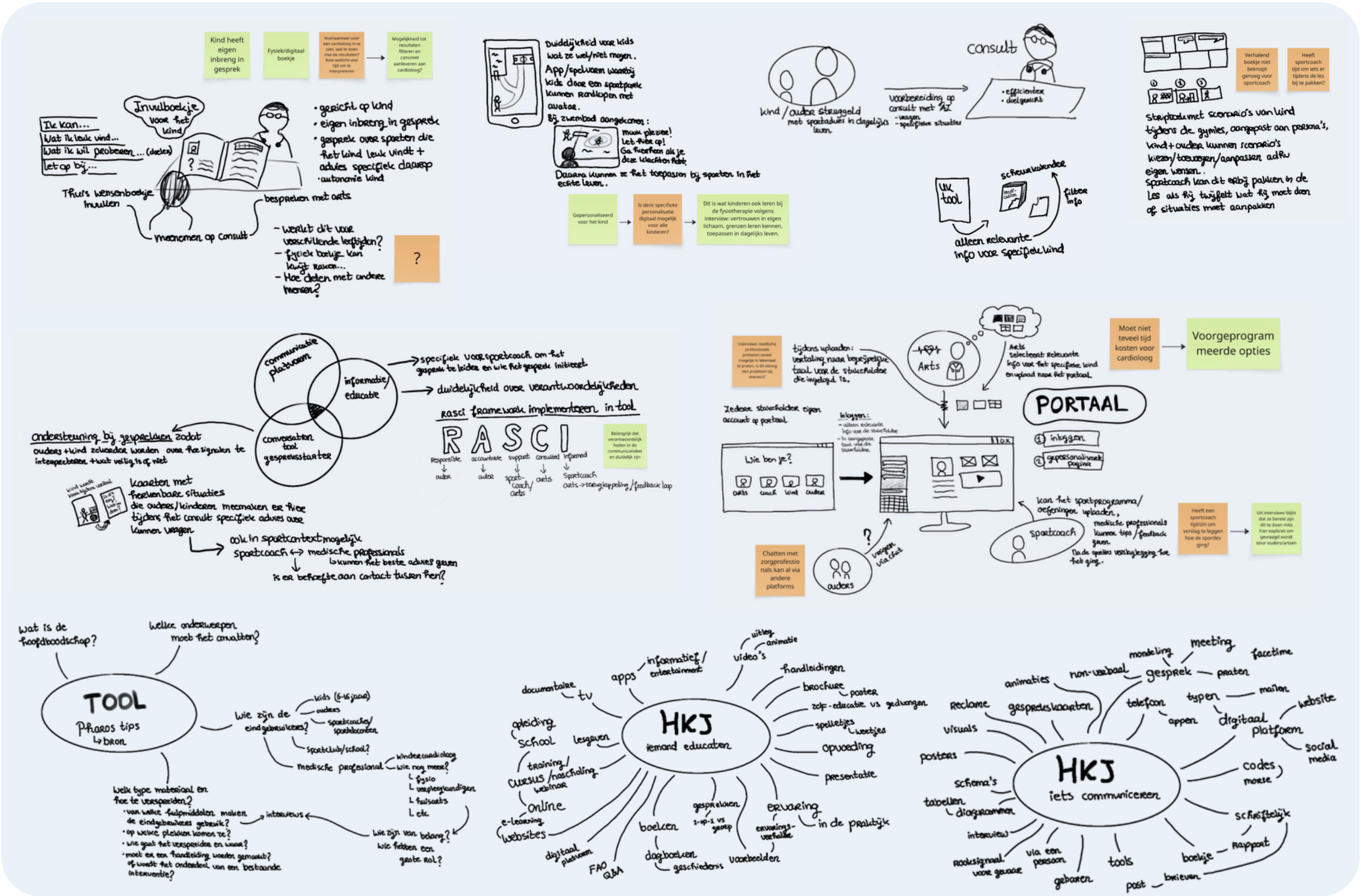
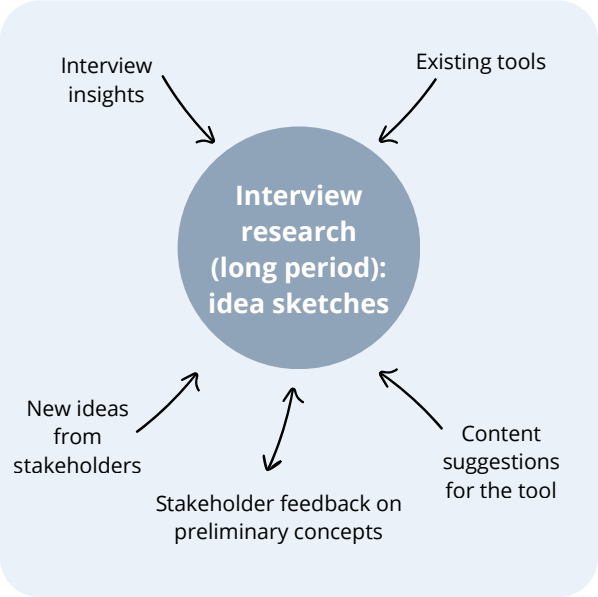


Figure 18: Early ideation sketches and brainstorm during the first 10 weeks of the project

6.2 Interview research: idea sketches



The interview period lasted over 2 months and ran in parallel with the design process. During this time, interviews were conducted and analyzed, new sketches were continuously created and existing ideas refined. The interviews provided concrete content-related suggestions for the future tool, participants provided feedback on emerging design ideas and generated new ideas themselves. The ideation sketches and brainstorm ideas are shown in Figure 19.

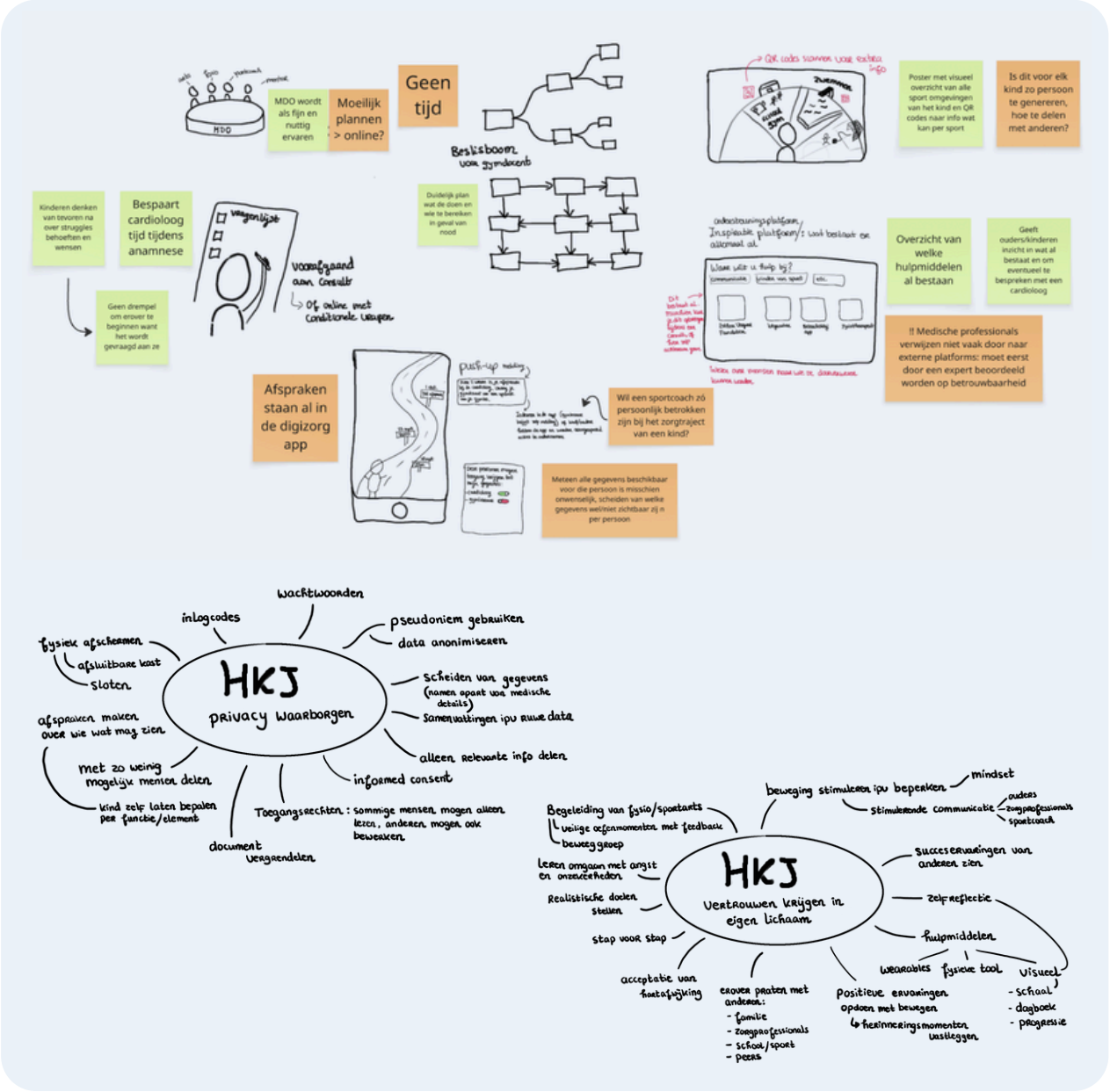


Figure 19: Ideation sketches and brainstorm during the interview phase

During the interviews, two emerging design ideas were discussed with participants:

- The concept of a **shared platform** for all stakeholders
- The idea of a **pre-filled questionnaire** that child/ parents complete before the consultation

These ideas emerged at different moments in the project, but were both explored and validated further during the interview phase.

A shared platform

The idea of a shared platform emerged during the early research phase of the project, in which literature was reviewed and existing tools were analyzed. This phase showed that existing solutions do not support communication between children with CHD, parents, healthcare professionals and sports coaches within one shared environment, but are fragmented across healthcare, home and sports settings. In addition, sports coaches often lack specific knowledge or guidance to safely involve children with CHD in sports activities.

The shared platform concept responds to these issues by proposing one central digital environment in which all relevant stakeholders can access and exchange information related to sports participation and health. Within this platform, information can be tailored to each stakeholder's role and level of understanding, using clear, non-medical language where appropriate. The potential use of AI for adapting and translating information was explored, inspired by applications such as the Digi Assistant app. This platform aims to support better mutual understanding and more consistent information transfer across contexts.

The idea was presented to several stakeholders during the interviews. Their responses showed that almost all stakeholders see potential in having one shared place where information about the child's sports participation and health comes together and where stakeholders are connected over time. At the same time, participants emphasized several important conditions for such a platform. These included clear agreements about roles and responsibilities, privacy protection, and practical feasibility within existing workflows. In particular, healthcare professionals noted that the platform should not increase their workload, for example by requiring extensive time to read or respond to reports from sports coaches about experiences in sports lessons. Sports coaches, in turn, indicated that they are in principle willing to share feedback about sports sessions, but only when this is explicitly requested by parents or healthcare professionals.

Although the concept was seen as ideal in theory, its practical feasibility was questioned due to the potential time burden for stakeholders.

A pre-consultation questionnaire

In contrast to the platform concept, which existed before the interviews, the idea of a pre-consultation questionnaire emerged during the interview period itself. Several healthcare professionals mentioned that consultation time is often limited, and that important follow-up questions related to sports participation are not always asked. As a result, concerns, uncertainties, or relevant experiences may remain unnoticed during the consultation.

The pre-consultation questionnaire concept addresses this issue by enabling children and parents to reflect on sports participation, concerns and wishes before the consultation. The completed questionnaire can be reviewed by the cardiologist in advance, allowing consultation time to be used more efficiently and enabling sports-related issues to be identified and discussed proactively rather than remaining unaddressed.

Later in the interview period, this idea was presented to new participants. Stakeholders recognized several benefits of a pre-consultation questionnaire. It could help children and parents reflect on sport, concerns and wishes beforehand, make potential issues related to physical activity visible at an earlier stage, and reduce the need to gather basic information during the consultation itself, provided that healthcare professionals have access to the responses in advance. In addition, the questionnaire can highlight situations that might require multidisciplinary coordination, such as referral to or consultation with other healthcare professionals (e.g., within an MDO).

Overall, stakeholders with whom this concept was discussed responded positively to the pre-consultation questionnaire.

Content suggestions and new ideas from stakeholders

In addition to feedback on these two concepts, the interviews generated a large number of concrete content-related suggestions relevant for both the questionnaire and the sports advice shared with sports coaches. A full overview is shown in Figure 20.

Healthcare professionals emphasized the importance of gaining insight into the home situation and the type of child, in order to provide more tailored sports advice. They also indicated which types of information sports coaches should ideally receive from a medical perspective. This included, among other things, background information about the heart condition, physical load and capacity, potential risks, points of attention during sports, precautionary measures, and a clear contact person in case of questions or concerns.

From the perspective of sports coaches, participants highlighted the importance of practical and actionable information, for example clear agreements about what to do in case of emergencies, and accessible contact details, clarity about responsibilities, insight into the child's possibilities and limitations, and guidance on how to recognize and respond to relevant bodily signals during sports activities.

In addition to content suggestions, participants also proposed several new ideas for formats or tools that could support communication. These included, for example, an app in which the child or parent could enter information and generate a document to share with the sports coach, a small card or pass that the child could carry with key information, or a flyer or concise reference document for coaches to provide guidance in practice.

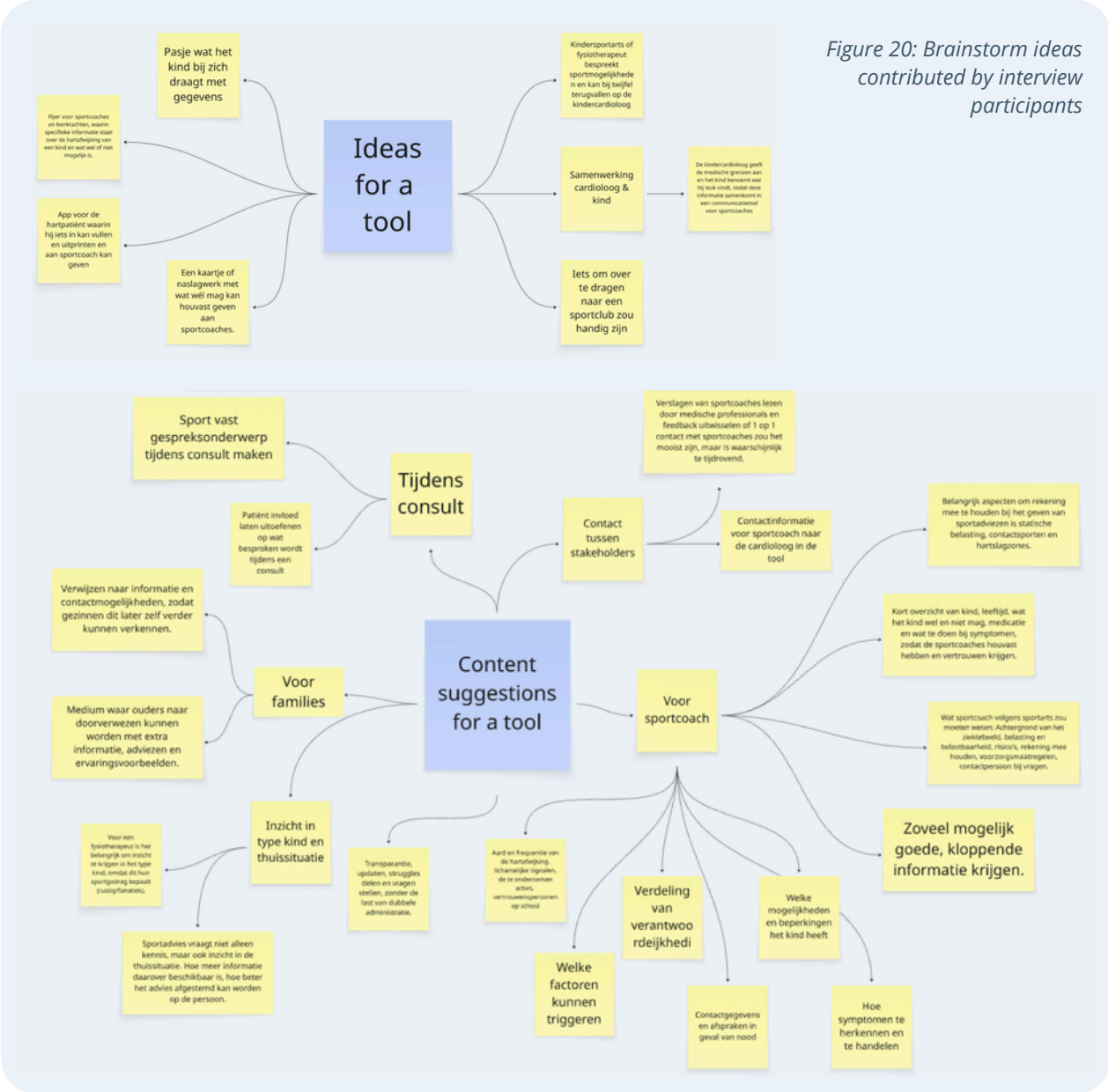


Figure 20: Brainstorm ideas contributed by interview participants

These information needs, suggestions, and new ideas served as input for the further design and refinement of the communication tool.

Conclusion

The interview phase was essential for broadening and refining the design directions. Stakeholders confirmed the potential of both a shared platform and a pre-consultation questionnaire, while also highlighting important conditions. In addition, the interviews generated concrete content suggestions and new ideas that directly influenced the further development of the final concept.

All statement cards related to the shared platform, pre-consultation questionnaire, tool ideas and content suggestions can be found in Appendix G.

6.3 Formation of one core concept with two form & distribution variants

1 core concept with two form & distribution variants:
A. Booklet distributed via existing platforms
B. Online platform with role-specific access

The interview study, literature review, analysis of existing communication tools and the identified intervention moments in the journey maps showed that communication challenges related to sports participation in children with CHD do not arise at a single point, but occur throughout the entire care and sports trajectory.

During the analysis, however, two moments emerged as particularly decisive for improving the flow of information:
(1) before the consultation
(2) an advice moment in or around the consultation

Although multiple intervention moments were identified as potentially valuable, these two moments appeared to be the key leverage points where support could have the greatest impact. Interventions at these points can influence several other steps in the communication and information flow.

Intervention moment 1: before the consultation

Before the consultation is a suitable moment to collect information from parents and the child. This could support earlier identification of sports-related signals (such as symptoms, concerns, wishes or practical obstacles). As a result, consultation time related to physical activity and sports participation can be used more efficiently, allowing for a more meaningful conversation and a better tailored sports recommendation.

Intervention moment 2: advice moment around the consultation

The advice moment around the consultation is primarily a moment to understand, discuss and document sports-related advice, which can subsequently be shared with the sports environment. During this moment, medical recommendations are clarified and contextualised to the child's daily sports practice, and aligned with the questions and concerns of parents and children. The agreed advice is then documented in a clear and transferable format for sports coaches. At present, parents and children often pass on this information verbally or through unstructured messages, which can lead to noise, misunderstandings and different interpretations.

A clear, reliable and role-specific sports recommendation that can easily be shared with sports coaches can be created at different moments: partly before the consultation (as preparation for the cardiologist), during the consultation (together), or directly afterwards (as a concluding step). The exact moment may differ per cardiologist, but the underlying function remains the same.

6.3.1 From multiple ideas to one core concept

Across the different research activities conducted during the project, it became increasingly clear which functions and information elements were necessary to improve communication about sports between children with CHD, their parents, sports coaches and healthcare professionals. These insights ultimately led to one overarching core concept consisting of two functional components:

1. A **pre-consultation questionnaire**, designed to support parents and children in reflecting on sports, symptoms and concerns, and to help the cardiologist prepare for the consultation more effectively.
2. A **sports advice form**, completed by the cardiologist before, during or after the consultation and intended for the sports coach or school. This form provides coaches with clear, role-relevant and reliable information about what the child can and cannot safely do.

These two components form the content basis of the concept and align directly with the two key intervention moments identified in the journey maps. However, questions remained regarding the best form and distribution method. This led to the development of two form- and distribution variants of the core concept. This includes the shared platform idea introduced during the interviews, which led to a possible distribution format of the concept.

6.3.2 Two form & distribution variants of the core concept

The core components of the concept had already been defined, namely the pre-consultation questionnaire and the sports advice form. Based on the interviews, it was also clear which specific information needed to be included. This included, among other things, the information healthcare professionals want to receive from parents and children prior to the consultation, the information sports coaches need to support safe sports participation, and the information parents and children find relevant to share.

At the same time, the interviews showed that stakeholders use a variety of communication systems, have different preferences, and work within diverse digital infrastructures. As a result, uncertainty remained about how this information should be distributed and integrated into daily practice.

Therefore, the core concept was developed in two alternative form and distribution variants that provide the same content but differ in their method of distribution and use.

The idea was presented to several stakeholders during the interviews. Their responses showed that almost all stakeholders see potential in having one shared place where information about the child's sports participation and health comes together and where stakeholders are connected over time. At the same time, participants emphasized several important conditions for such a platform. These included clear agreements about roles and responsibilities, privacy protection, and practical feasibility within existing workflows. In particular, healthcare professionals noted that the platform should not increase their workload, for example by requiring extensive time to read or respond to reports from sports coaches about experiences in sports lessons. Sports coaches, in turn, indicated that they are in principle willing to share feedback about sports sessions, but only when this is explicitly requested by parents or healthcare professionals.

Although the concept was seen as ideal in theory, its practical feasibility was questioned due to the potential time burden for stakeholders.

A pre-consultation questionnaire

In contrast to the platform concept, which existed before the interviews, the idea of a pre-consultation questionnaire emerged during the interview period itself. Several healthcare professionals mentioned that consultation time is often limited, and that important follow-up questions related to sports participation are not always asked. As a result, concerns, uncertainties, or relevant experiences may remain unnoticed during the consultation.

Variant A: Booklet distributed via existing platforms

A fillable booklet that can be used both digitally and physically and shared through existing communication channels, such as Somtoday, Social Schools, email or physical distribution. In this variant, parents and children complete the short pre-consultation questionnaire and send it to the cardiologist through a familiar platform. Before, during or after the consultation, the cardiologist completes the sports advice section, which parents can then easily share with sports coaches using the same existing channels. Variant A is visualized in Figure 21.

Advantages: aligns with existing routines and systems used by parents, schools and sports coaches, requires no new accounts or login systems, low-threshold and flexible, suitable in contexts with limited digital infrastructure.

Challenges: risk of fragmentation across different communication channels, limited possibilities for automatic updates or version control.

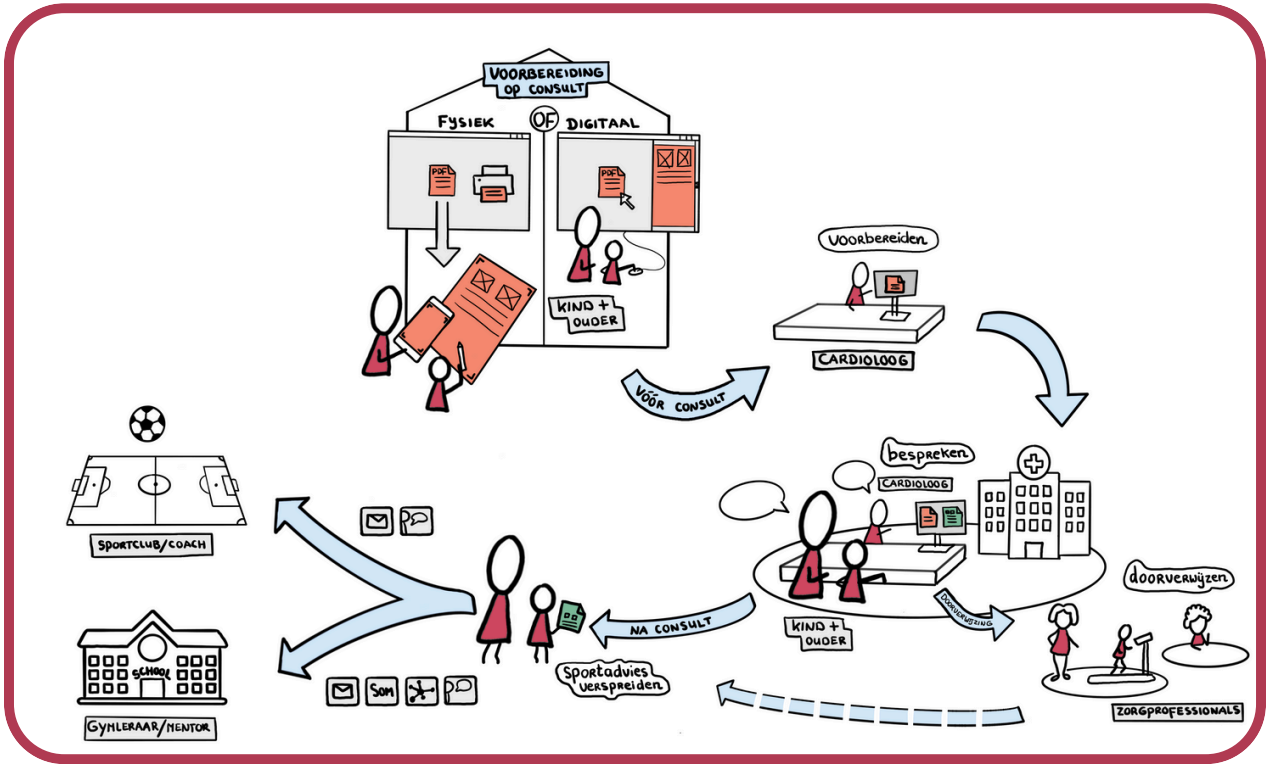


Figure 21: Variant A, booklet distributed via existing platforms

Variant B: Online platform with role-specific access

A new shared digital environment where all involved stakeholders can log in and access an interface tailored to their specific role, such as parent/child, cardiologist or sports coach. Parents have full control over who can access which information. The platform can send notifications, for example to remind families to complete the pre-consultation questionnaire. The sports advice can be updated and shared easily within a single central environment. Variant B is visualized in Figure 22.

Advantages: centralizes information, reduces fragmentation and supports smooth transfer between contexts.

Challenges: privacy and data security, reliance on stakeholder willingness to use a (another) login-based system, and greater technical complexity.

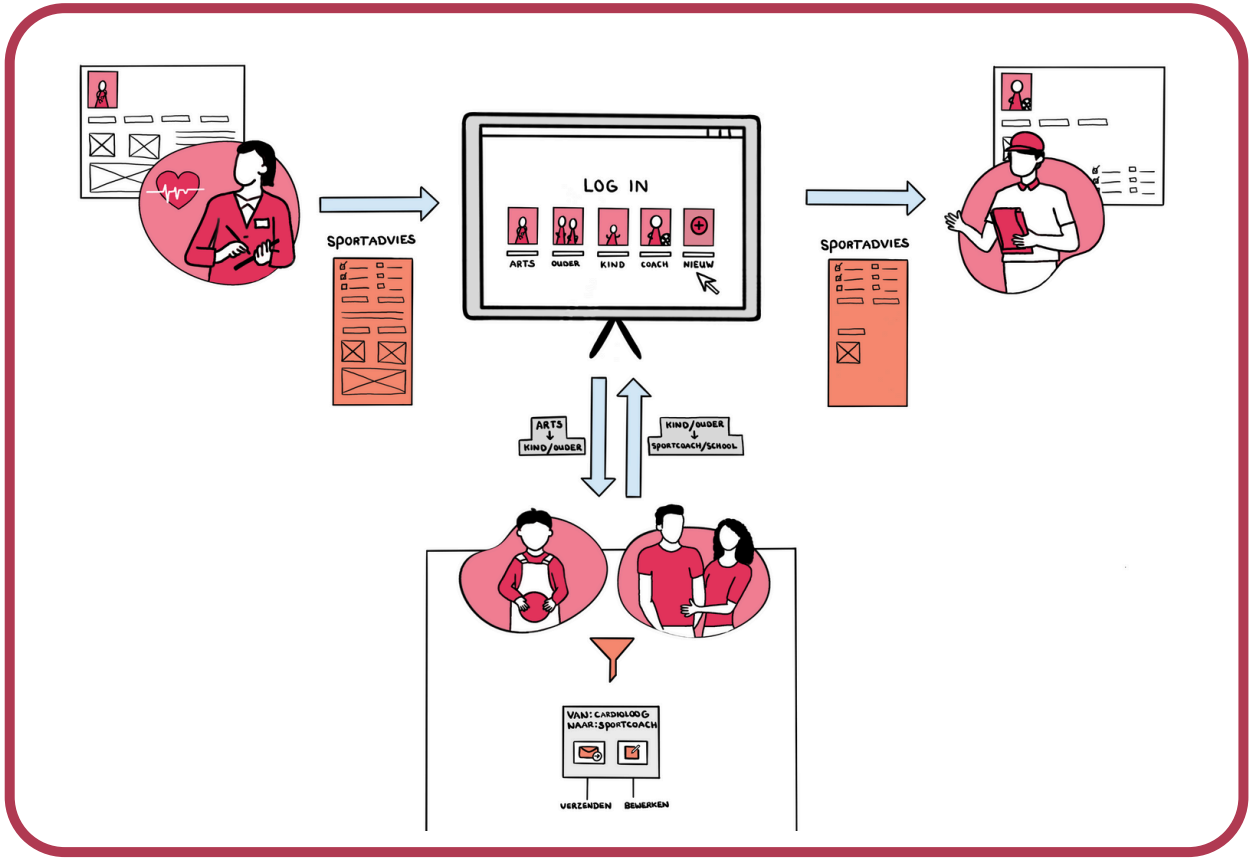


Figure 22: Variant B, online platform with role-specific access

These two variants formed the basis for the first co-creation session, in which stakeholders provided feedback on feasibility, preferred formats and practical considerations. This session is described in Chapter 6.4

6.4 Co-creation session 1: advisory group

6.4.1 Goal of the session

To assess the practical feasibility of the two form and distribution formats introduced in Chapter 6.3, a co-creation session was organized with an advisory group representing key stakeholders in the CHD and sports context. The group included representatives from the Patiëntenvereniging Aangeboren Hartafwijkingen, Sportbedrijf Rotterdam, Kenniscentrum Sport & Bewegen, and additional experts from both healthcare and sports domains.

The goal of the session was not to choose a preferred format, but to explore how both variants performed in relation to several form-related requirements and to identify practical strengths and weaknesses.
Because the content of the tool (the questionnaire and the sports advice form) was still under development, the session focused specifically on form-related requirements rather than on the content itself.

6.4.2 Method

The two distribution formats developed in Chapter 6.3 were briefly introduced:

- Variant A: Booklet via existing platforms
- Variant B: Online platform with role-specific access

Participants were shown only the structural outline of each variant, without detailed content examples, to prevent discussions from shifting towards content considerations.

Evaluation criteria
The evaluation was based on nine form-related requirements shown in Figure 23. These requirements were derived from a combination of literature insights, interview findings and design reasoning. While several criteria directly reflect needs expressed by stakeholders during the interviews or described in the literature, others emerged from logical considerations based on the context of use. For example, the requirement concerning transferability was formulated to ensure that sports-related advice can be shared with multiple stakeholders, such as when a child participates in multiple sports clubs. Each requirement was used as a separate evaluation criterion.

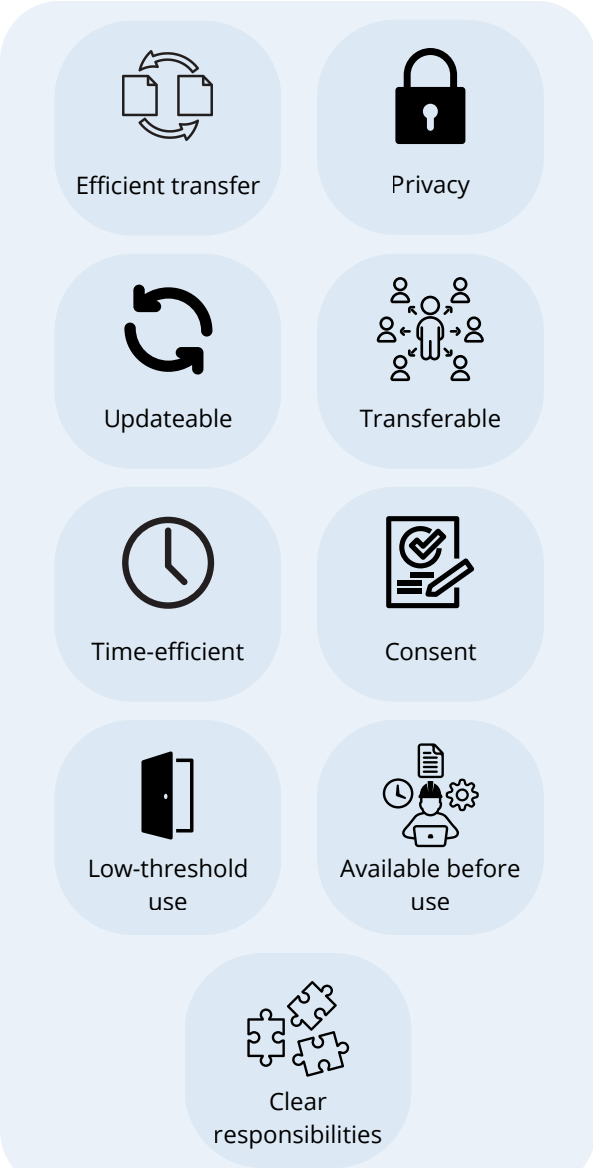


Figure 23: Form-related requirements used as evaluation criteria

Session procedure
After a short introduction, participants were divided into two subgroups, each working with one of the variants. Each group used an evaluation worksheet containing four steps per requirement:

- Identify strong points
- Identify weak points
- Rate the requirement on a 10-point scale
- Suggest potential improvements

The worksheet is shown in Figure 24.

The goal of the exercise was to strengthen both directions, not to converge on a single preferred option.

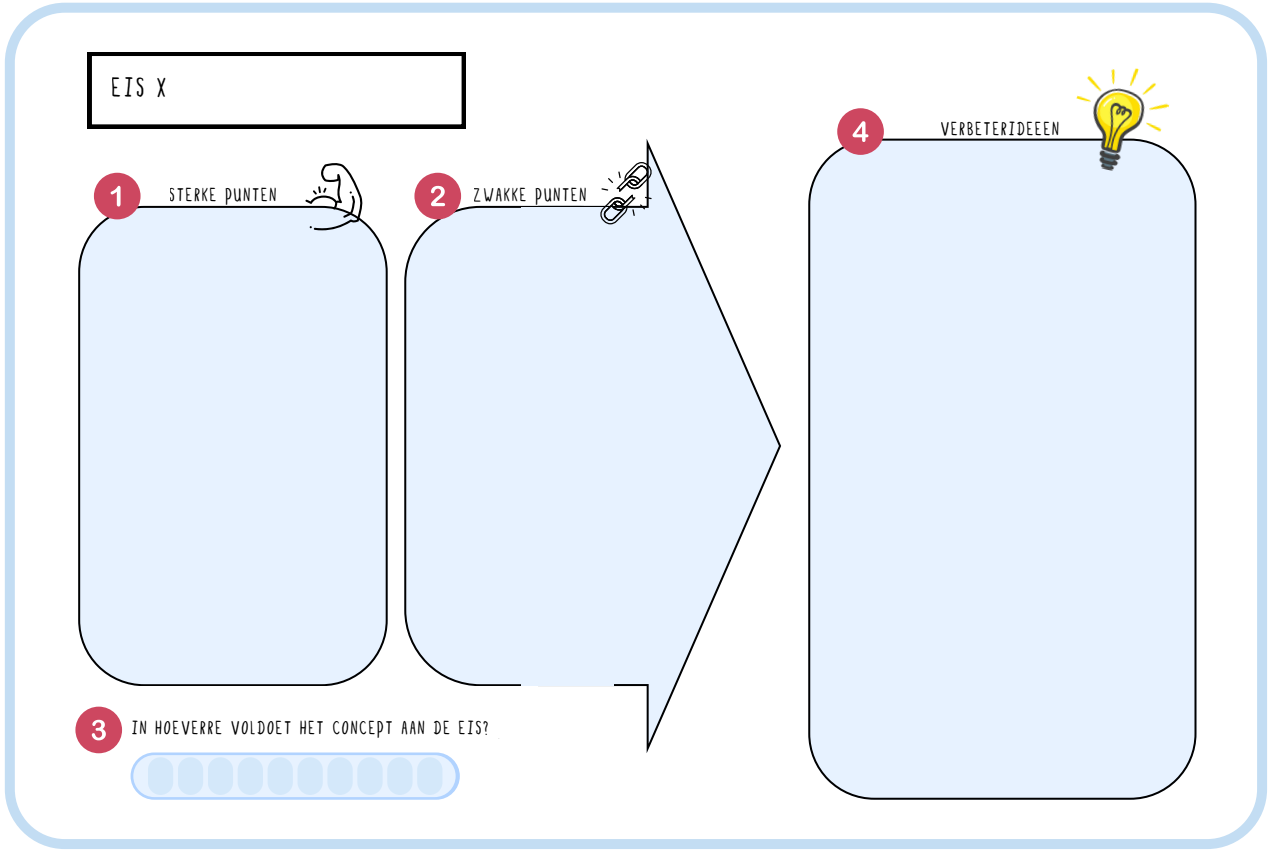


Figure 24: Worksheet used by participants to evaluate each concept per requirement

6.4.3 Results & conclusion

Due to time limitations during the session, not all nine requirements could be discussed in detail. For concept 1, participants evaluated low-threshold use and clear responsibilities, and concept 2 was mainly discussed in relation to transferability, with additional reflections on low-threshold use, updateability and privacy.
The raw data from the co-creation session can be found in Appendix H.

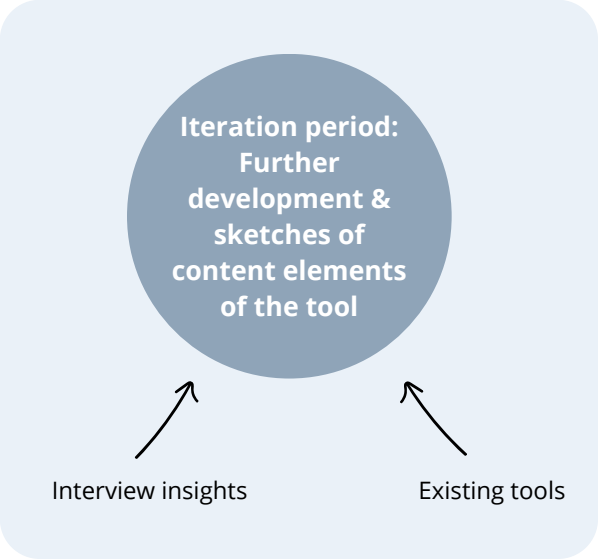
Both concepts demonstrated a mix of strong and weak points on specific requirements, indicating that each concept had valuable aspects but also areas for improvement. Variant A was appreciated for its accessibility, flexibility across different settings, and independence from devices or internet connection. However, logistical limitations such as physical distribution and the risk of the booklet being lost were noted. Variant B was valued for the transparency and sense of control it offers parents within the communication chain, its accessibility for multiple professionals, the reduced risk of information loss, and the ease of which information could be updated. Weak points included privacy considerations and a higher threshold for adoption, because stakeholders would need to invest in using a new platform.

The insights from this co-creation session will be taken into account during the further concept development. During the session, a participant referred to the Hartpaspoort as an example of a practical and concise way to communicate essential information to schools. Later, the Hartpaspoort served as inspiration for the further refinement of the concept, as discussed in Chapter 6.5.2.

During the same session, one participant mentioned that it was difficult to rate the form-related requirements, because the actual content of the tool was not yet shown. Without concrete examples of what the questionnaire or the sports advice would contain, participants found it challenging to assess how well each variant would work in practice. So this limited understanding of the content of the tool may have influenced how participants judged the form-related requirements and the perceived feasibility of each concept.

Conclusion
Altogether, the insights of the session suggest that when presenting concepts in co-creation sessions, future sessions would benefit from using more concrete and tangible examples of the content. Moreover, a hybrid approach, combining beneficial elements of both concepts may best accommodate the diverse contexts and preferences of different stakeholders.

6.5 Iteration period: development of content elements



After the first co-creation session, the focus shifted from exploring different form variants to developing the content and presentation of the components of the concept. As described earlier, two key components were identified:

1. A pre-consultation questionnaire
2. A sports advice form to be shared with the sports environment

While the pre-consultation questionnaire was further refined by formulating specific questions, most brainstorm sketches focused on exploring how the sports advice could be structured, visualized and practically applied for different stakeholders.

During this iteration period, a brainstorm session was conducted (Figure 25) to explore how information could be translated into clear, role-specific and actionable guidance for different stakeholders. For sports coaches, this focused on practical applicability during sports lessons, for children and parents on control over information and privacy, and for healthcare professionals on efficiency and alignment with existing workflows, in line with the design requirements identified earlier. The sketches primarily addressed how information is presented and interacted with and what information is included.

Several sketches explored ways to make sports-related advice more visual and concrete for sports coaches, for example through short instructional videos or visual tutorials explaining how to recognize bodily signals and how to respond to them in practice. This aligns with requirement indicating that sports coaches value clear and practical support.

Other sketches focused on visually distinguishing which parts of the sports advice are completed by the cardiologist and which are supplemented by parents or the child, for instance through the use of color coding or clear visual separation. This exploration responds to interview insights about the risk of incorrect or incomplete information transfer by filling in information by the appropriate stakeholders. It also supports design requirements related to clarifying roles and responsibilities within the communication process.

To account for the limited time available to healthcare professionals, several sketches explored ways to make the creation of sports advice more efficient, for example by using predefined options or selectable elements for common heart conditions or sport-related considerations. This allows relevant information to be compiled quickly without adding administrative burden, aligning with requirements related to time pressure in clinical practice. In addition, sketches explored how reliable existing information sources, such as patient association websites, could be integrated or referenced. This could reduce duplication of work while ensuring medical accuracy, which was a concern raised by healthcare professionals.

Another sketch explored including an overview of the specific sports the child participates in, enabling healthcare professionals to provide more tailored and personalized advice, which was also identified as an important requirement.

Finally, another idea focused on privacy and control over information sharing, for example through modular or selectively shareable parts of the sports advice that parents and children can choose to make available to sports coaches. This directly reflects interview insights about parents' desire to retain control over information flows and aligns with design requirements related to privacy protection.

Together, these sketches illustrate how the iteration period was used to translate insights from the literature and interviews into more concrete design ideas.

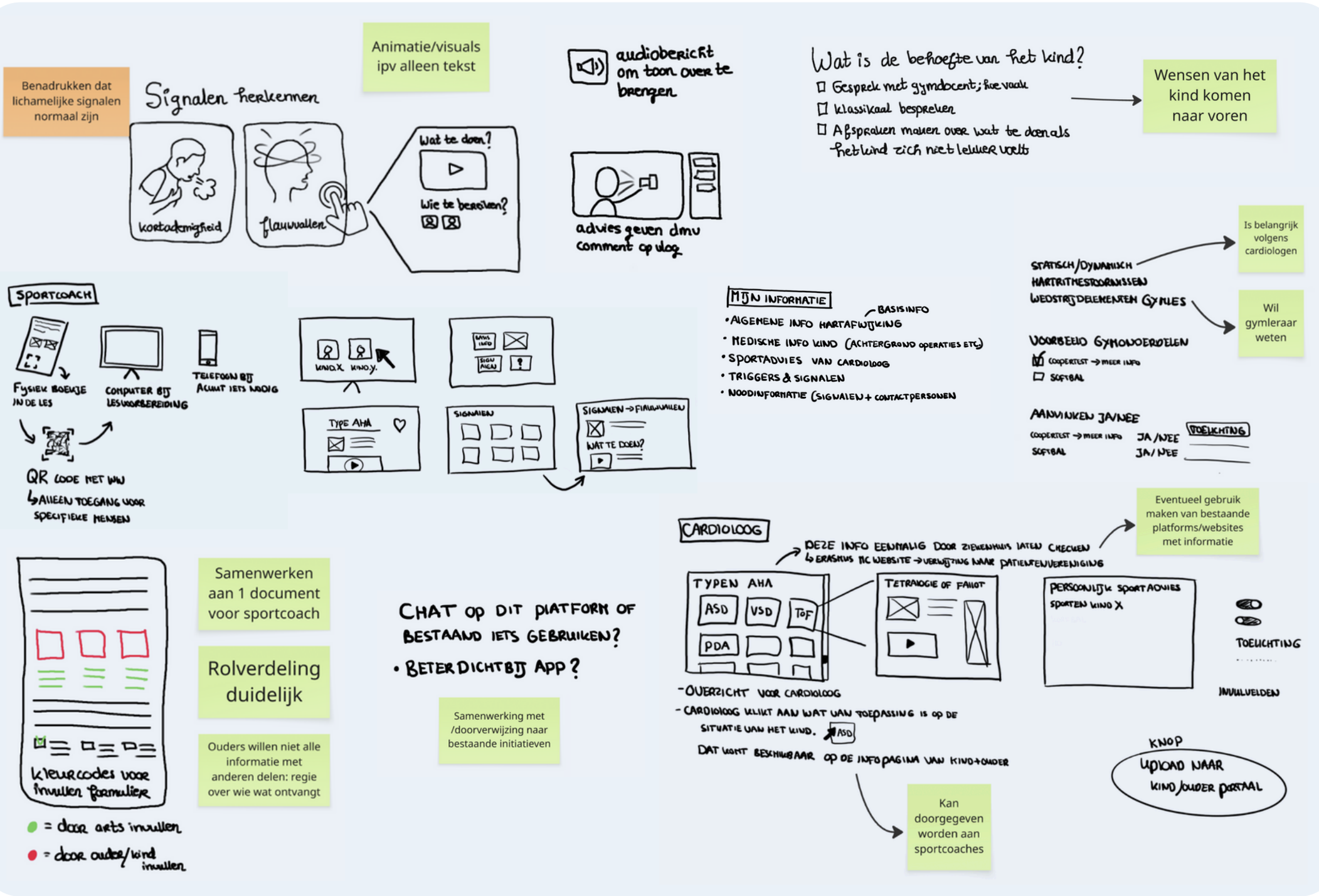


Figure 25: Brainstorm to explore the content of the sports advice form

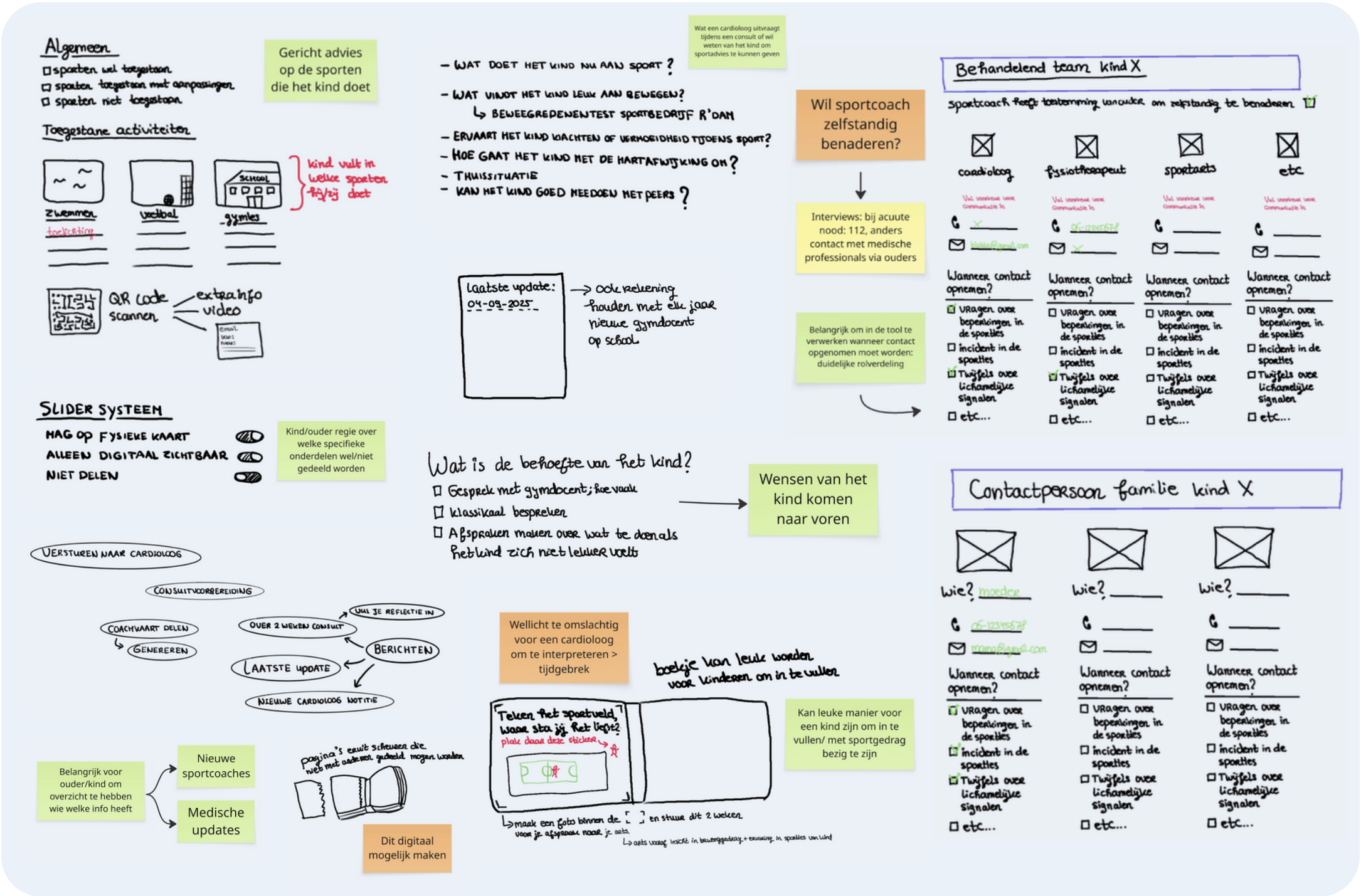


Figure 25 (continued): Brainstorm to explore the content of the sports advice form

6.5.1 Pre-consultation questionnaire

Purpose of the questionnaire
The pre-consultation questionnaire was developed to better prepare and enrich the consultation with the pediatric cardiologist. The questionnaire serves three purposes that emerged from the research:

Gaining insight into the child
The responses in the questionnaire provide insight into what sports a child currently engages in, whether and which barriers they experience, and what kind of support they may need. This gives the cardiologist a more complete picture of the child, their sport experiences, home situation and preferences, elements that may not always be discussed during a short consultation, but are important for offering more personalized sports advice or potential efficient referrals.
The questionnaire also gives children (and parents) the opportunity to reflect at home on their experiences, which may help ensure that children do not feel overwhelmed or put on the spot once they are in the consultation room.

Improving quality and efficiency of the consultation
Because certain information is submitted beforehand, the cardiologist needs to spend less time on standard anamnestic questions. The available time during the consultation can therefore be used more effectively for explanation, tailored advice or more in-depth discussions. This means that part of the time investment moves to the preparation phase, a point that was also recognized by healthcare professionals and is addressed later in the design and co-creation session with cardiologists.

The questionnaire also includes a section where children (or parents) can indicate which topics they would like to discuss. This helps align the consultation with their information needs and preferences and allows space to be made for topics that might otherwise remain unspoken, for example due to time pressure.

Reducing misinterpretations caused by assumptions
Interviews revealed that healthcare professionals sometimes rely on assumptions about the child, which may influence both the depth and direction of their questioning, and ultimately the advice they provide. By explicitly asking children about certain topics, the questionnaire reduces the risk of a mismatch between what the child needs and what the clinician assumes to be wanted.

Basis for the content
The content of the pre-consultation questionnaire is based on:

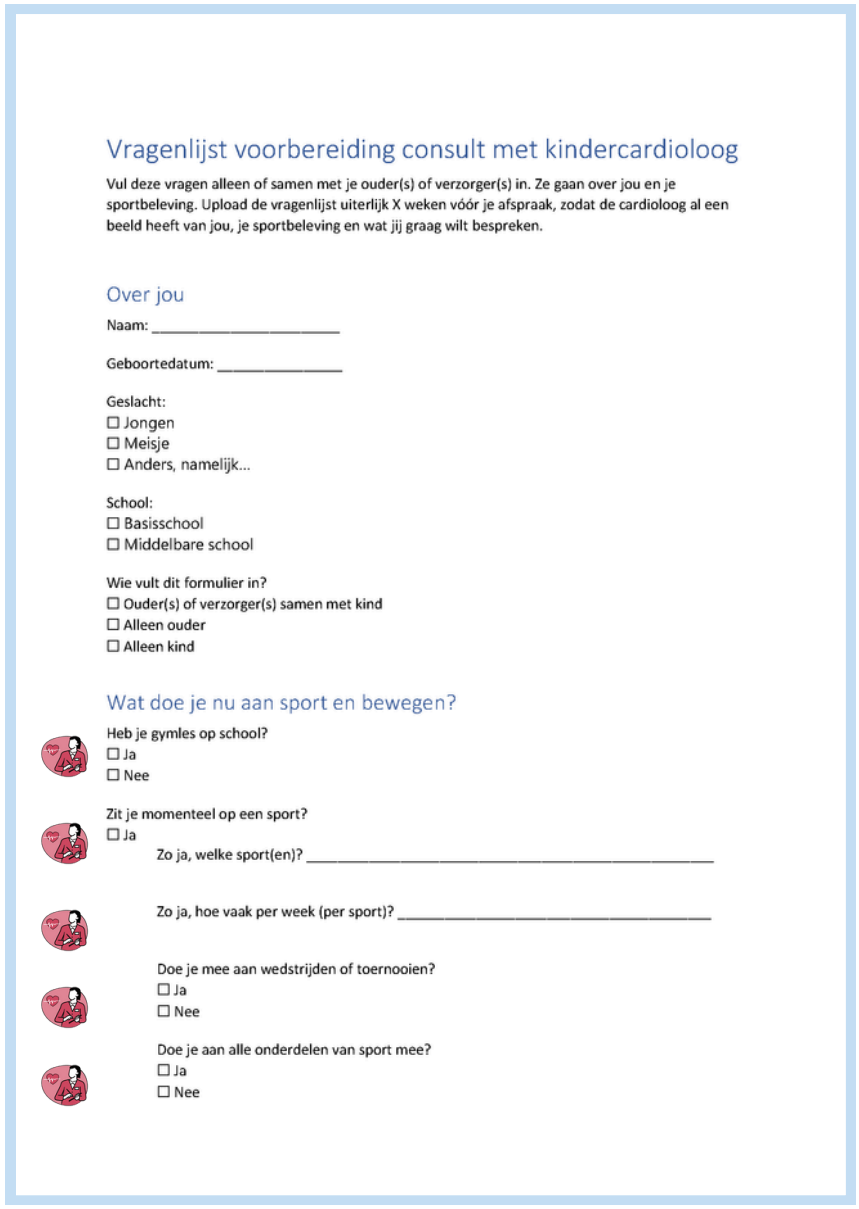
- Physical activity related topics that cardiologists often routinely ask during the anamneses
- Insights from interviews (such as fears, insecurities and motivation)
- Topics that often remain underexposed in current consultation practice, but are relevant for improving sport-related advice.

Structure
The questionnaire is organized into five components:

1. About the child: basic information and who completed the form (child, parent or together)
2. Current sports and physical activity behavior: participation, frequency and context
3. Sport experience and confidence: enjoyment, insecurities, complaints and fears
4. Support needs: what the child may need to engage (more) in sport
5. Topics for the consultation: what the child (or parent) wishes to discuss

The questionnaire is shown in Figure 26. Icons in the figure indicate which parts of the questionnaire are based on insights from interviews with healthcare professionals (such as cardiologists, physical therapists and sports physician) or with parents.

Figure 26: Pre-consultation questionnaire



Vragenlijst voorbereiding consult met kindercardioloog

Vul deze vragen alleen of samen met je ouder(s) of verzorger(s) in. Ze gaan over jou en je sportbeleving. Upload de vragenlijst uiterlijk X weken vóór je afspraak, zodat de cardioloog al een beeld heeft van jou, je sportbeleving en wat jij graag wilt bespreken.

Over jou

Naam: _____

Geboortedatum: _____

Geslacht:
☐ Jongen
☐ Meisje
☐ Anders, namelijk...

School:
☐ Basisschool
☐ Middelbare school

Wie vult dit formulier in?
☐ Ouder(s) of verzorger(s) samen met kind
☐ Alleen ouder
☐ Alleen kind

Wat doe je nu aan sport en bewegen?

Heb je gymles op school?
☐ Ja
☐ Nee

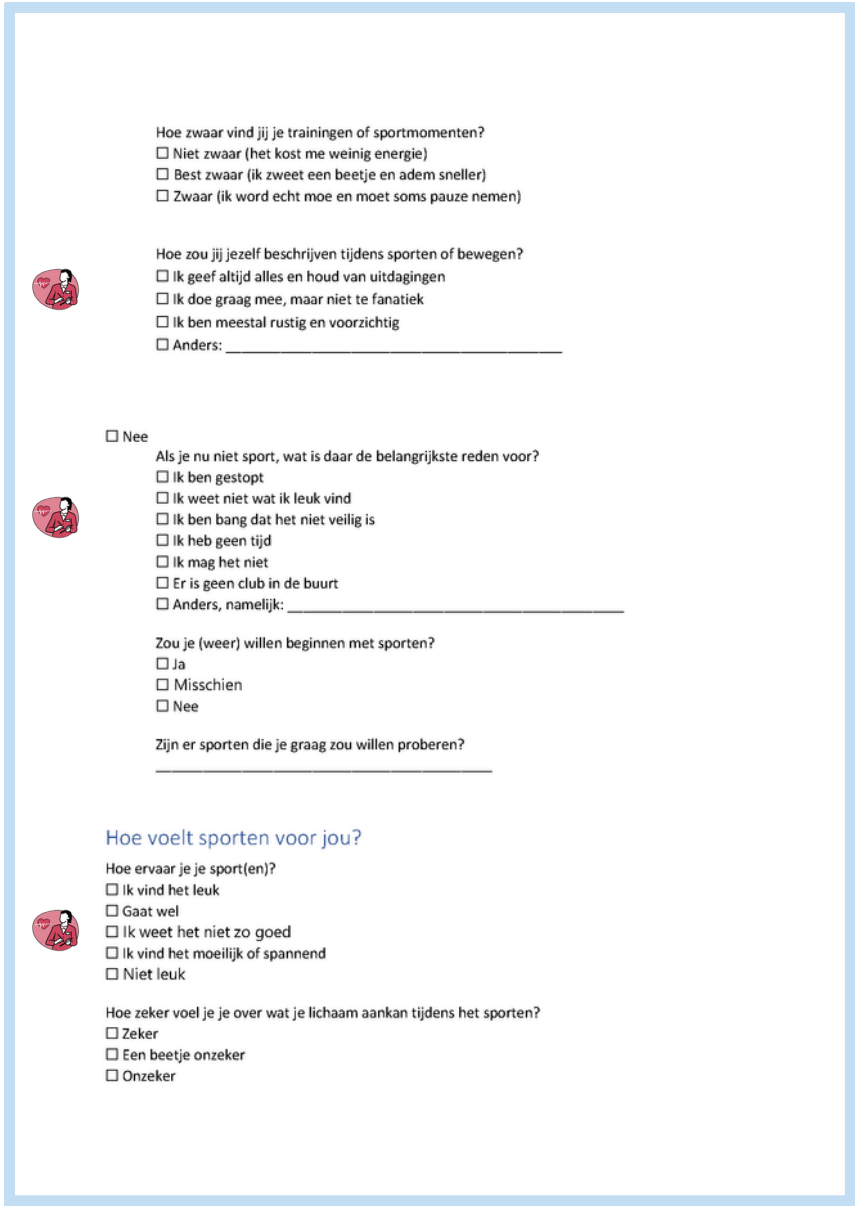
Zit je momenteel op een sport?
☐ Ja

Zo ja, welke sport(en)? _____

Zo ja, hoe vaak per week (per sport)? _____

Doe je mee aan wedstrijden of toernooien?
☐ Ja
☐ Nee

Doe je aan alle onderdelen van sport mee?
☐ Ja
☐ Nee



Hoe zwaar vind jij je trainingen of sportmomenten?
☐ Niet zwaar (het kost me weinig energie)
☐ Best zwaar (ik zweet een beetje en adem sneller)
☐ Zwaar (ik word echt moe en moet soms pauze nemen)

Hoe zou jij jezelf beschrijven tijdens sporten of bewegen?
☐ Ik geef altijd alles en houd van uitdagingen
☐ Ik doe graag mee, maar niet te fanatiek
☐ Ik ben meestal rustig en voorzichtig
☐ Anders: _____

☐ Nee

Als je nu niet sport, wat is daar de belangrijkste reden voor?
☐ Ik ben gestopt
☐ Ik weet niet wat ik leuk vind
☐ Ik ben bang dat het niet veilig is
☐ Ik heb geen tijd
☐ Ik mag het niet
☐ Er is geen club in de buurt
☐ Anders, namelijk: _____

Zou je (weer) willen beginnen met sporten?
☐ Ja
☐ Misschien
☐ Nee

Zijn er sporten die je graag zou willen proberen?
_____

Hoe voelt sporten voor jou?

Hoe ervaar je je sport(en)?
☐ Ik vind het leuk
☐ Gaat wel
☐ Ik weet het niet zo goed
☐ Ik vind het moeilijk of spannend
☐ Niet leuk

Hoe zeker voel je je over wat je lichaam aankan tijdens het sporten?
☐ Zeker
☐ Een beetje onzeker
☐ Onzeker

Are there any uncertainties for the child or parent?

Is there a support need that may not come up during the consultation?

Heb je weleens klachten tijdens het sporten?
- ☐ Mijn borst doet pijn
- ☐ Ik word duizelig of val flauw
- ☐ Ik ben kortademig
- ☐ Mijn hart gaat heel snel kloppen
- ☐ Ik word bleek of voel me klam
- ☐ Ik word erg moe
- ☐ Ik heb geen klachten tijdens het sporten

Wat weet je op dit moment over wat je wél en niet mag doen qua bewegen?
- ☐ Goed beeld
- ☐ Onzeker
- ☐ Geen idee

Waar zou je graag meer duidelijkheid over willen?

_____

_____

Ben je weleens bang dat sporten slecht is voor je hart?
- ☐ Vaak
- ☐ Soms
- ☐ Nooit

Hoe moe voel je je na sport of gym?
- ☐ Niet moe
- ☐ Beetje moe
- ☐ Erg moe

Wat maakt sporten soms moeilijk of spannend voor jou?
- ☐ Ik vind het niet moeilijk of spannend
- ☐ Ik weet niet goed wat ik mag
- ☐ Ik ben bang dat ik klachten krijg
- ☐ Ik vind het moeilijk om bij te blijven met leeftijdsgenoten
- ☐ Ik vind het niet leuk
- ☐ Anders, namelijk: _____

Wie moedigt jou aan om te bewegen?
- ☐ Ouders
- ☐ Vrienden
- ☐ Leraar
- ☐ Sportcoach
- ☐ Niemand
- ☐ Anders, namelijk: _____

Hoe voelen je ouder(s) of verzorger(s) zich als jij sport?
- ☐ Ze voelen zich gerust als ik sport
- ☐ Soms maken ze zich zorgen
- ☐ Ze maken zich vaak zorgen

Toelichting door ouder(s) of verzorger(s): _____

Wat zou jou helpen om (meer) te sporten?

Wat zou jou helpen om goed mee te kunnen doen met sporten?
- ☐ Iemand die met me meekijkt wat voor sport bij me past
- ☐ Meer vertrouwen krijgen in wat mijn lichaam kan
- ☐ Weten wat ik wél en niet mag doen
- ☐ Betere uitleg van een arts of fysiotherapeut
- ☐ Dat mijn sportcoach of gymleraar beter weet wat ik kan en mag
- ☐ Meer begrip van klasgenoten of teamgenoten
- ☐ Anders, namelijk: _____

Wat wil je bespreken tijdens het consult?

Waar wil je het graag over hebben tijdens je afspraak met de kindercardioloog? (meerdere antwoorden mogelijk)
- ☐ Sportadvies (wat mag ik wel of niet doen)
- ☐ Een nieuwe sport kiezen
- ☐ Angst of onzekerheid bij sporten
- ☐ Vermoeidheid of klachten tijdens sporten
- ☐ Sport of gymles op school
- ☐ Informatie voor mijn sportcoach
- ☐ Doorverwijzing naar fysiotherapeut of sportarts
- ☐ Anders: _____

Is er nog iets anders dat je wilt vertellen voor het gesprek?

_____

_____

By indicating which topics they wish to discuss, the child can help guide the conversation, which reduces the risk of misalignment caused by cardiologist's assumptions.

6.5.2 Sports advice form

Purpose of the sports advice form
The sports advice form was developed to support a clear, and consistent transfer of sport-related recommendations between the healthcare and sports environment. It provides healthcare professionals with a structured way to translate medical knowledge into actionable guidance, offers parents and children a reliable, structured document to share with sports coaches instead of relying on verbal and informal communication, which may lead to misunderstandings inconsistencies, or incomplete information. And it equips sports coaches with relevant information, practical and child-specific guidance they can take into account during training.
Together, these functions reduce ambiguity, support consistent communication across environments, and enable safe and tailored participation in physical activity.

Basis for the content
The content and structure of the sports advice form were shaped by three sources:

Interview analysis (see also Figure 20 in Chapter 6.2).

- What sports coaches reported they need to know in order to supervise children with CHD safely.
- What healthcare professionals (cardiologists, physical therapists, sports physician) find essential for safe physical activity in children with CHD.
- What parents and children want their sports coaches to know.

Figure 27 provides an overview of the information needs mentioned by sports coaches, as well as the information that healthcare professionals and parents/children consider essential to share with the sports environment.

Together, these insights highlight the need for a combination of medical background information, practical sport-related guidance, clear agreements on responsibilities, and contact information.

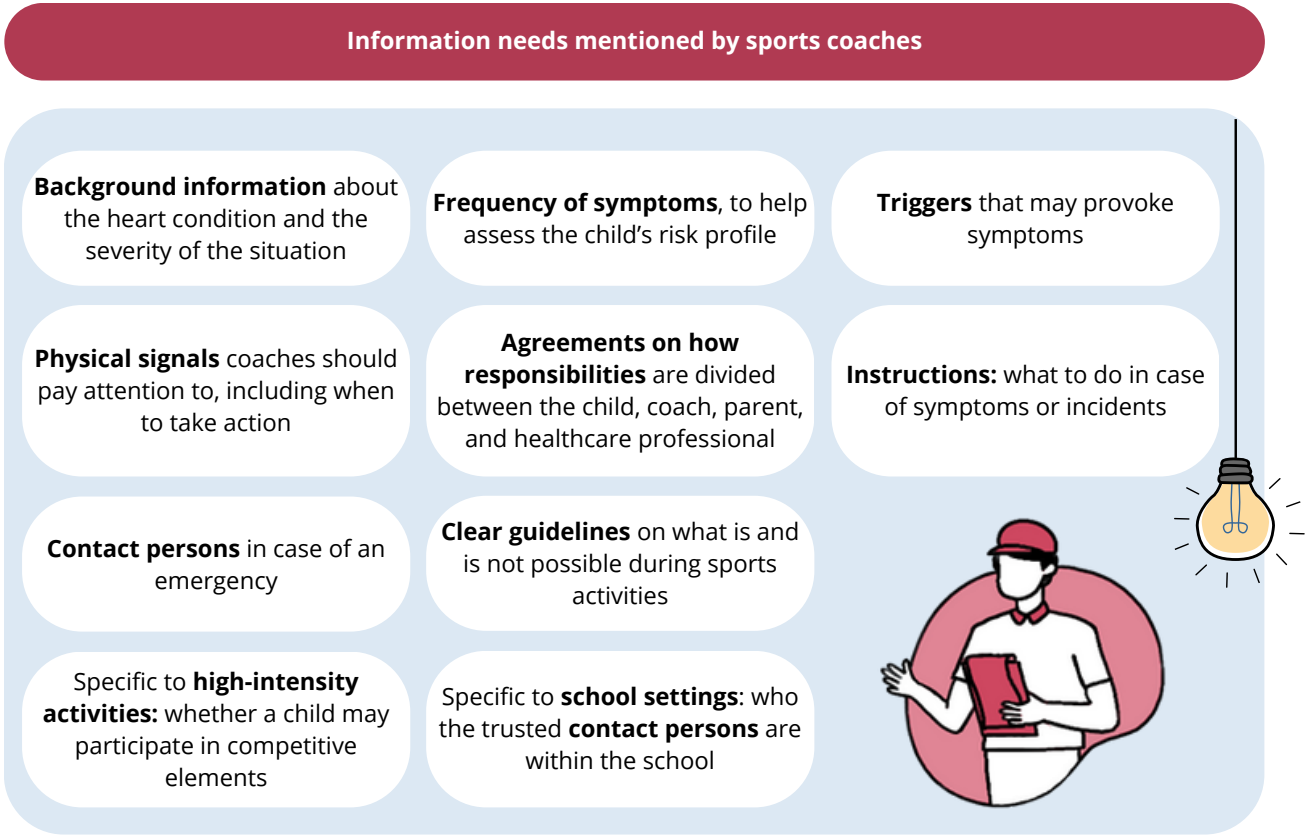


Figure 27: Overview of sport-related information needs, derived from the interviews, and used as input for defining the content of the sports advice form

What coaches need to know (according to healthcare professionals)

- Background of the condition
- Static load
- Contact sports
- Heart-rate zones
- Accurate and trustworthy information
- Potential risks, key considerations, precautions
- Contact person

What coaches need to know (according to parents/children)

- What the child can and cannot do
- Medication
- What to do in case of symptoms
- Contact person

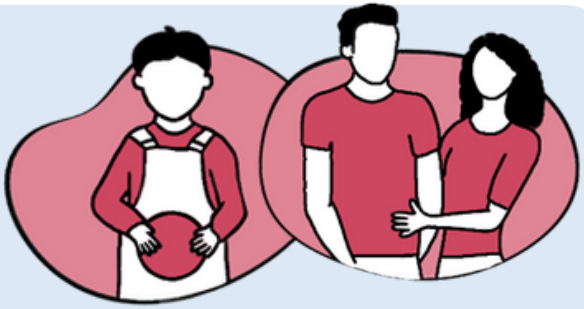


Figure 27 (continued): Overview of sport-related information needs, derived from the interviews, and used as input for defining the content of the sports advice

Existing tools

Several as considered relevant fields in the form are (directly) adapted from the Hartpaspoort and the "Physical Activity & Congenital Heart Disease" guide.

- The Hartpaspoort, used by parents to inform teachers about their child's cardiac condition. More information about the Hartpaspoort in Figure 16, in Chapter 5.2. (a more elaborate analysis of the Hartpaspoort is shown in Appendix I). Elements adapted from the Hartpaspoort include the medical diagnosis, medication use, effects of temperature changes, and motor functioning, as these were considered relevant for understanding a child's participation in physical activity within the sports environment.
- The "Physical Activity & Congenital Heart Disease" guide by Heart Research UK, which is elaborated on in Figure 13, in Chapter 5.1. This guide informed several medically oriented and sports-related components of the sports advice form. Adapted elements include medical diagnosis, presence of implanted devices, medication use, recommended exercise intensity and duration, distinction between dynamic and static exercise, guidance on competitive sports participation, activities that should be avoided, and symptoms to monitor during physical activity.

Design requirements emerging from the research

The content of the sports advice form was directly informed by a selection of design requirements derived from the literature and interviews. These requirements specifically relate to the type of information that should be included in the form and the way this information should support different stakeholders in practice.

Based on the research, the sports advice form was designed to ensure that it:

- Focuses on what the child can do safely, rather than only mentioning limitations.
- Provides sports coaches with clear, concise and practical guidance, including attention points, recognizable bodily signals, instructions on what actions to take if concerns arise and contact information, so sports coaches know whom to contact in case of questions or uncertainty.
- Helps parents communicate wishes, concerns and safety-related agreements consistently to the sports environment.
- Supports healthcare professionals in giving personalized sports advice, tailored to the child's specific condition, interests and current sports activities.
- Clarifies roles and responsibilities by distinguishing between medical input from healthcare professionals and contextual input from parents and children.

Structure
The form consists of two main sections:

1. Medical information completed by the cardiologist

This section contains concise medical background and safety-critical details relevant for sports coaches.
Elements include:

- Basic information about the child
- Medical background: diagnosis, possible implanted devices or medication.
- General sports advice (no restrictions/ some restrictions)
- ·Recommended intensity and duration of sports
- Type of exertion: dynamic and static exercise
- Key notes or attention points for the sport environment
- Application to the child's current sports activities
- Action plan in case of symptoms or emergencies

2. Additional context completed by parents and child

Although not yet fully shown in this sports advice form, a complementary section will allow parents to share contextual information. For example, the frequency of symptoms, potential triggers, what helps or reassures the child during exercise, and who to contact in case of questions or emergencies.

This complementary input approach ensures that each stakeholder contributes information from their own area of expertise: the cardiologist provides the medical assessment, while parents and children add practical insights and preferences. It also clarifies the division of responsibilities in the communication chain, making it explicit who provides which type of information.

The sports advice form is shown in Figure 28.

Legend

Based on interviews

- Insights from healthcare professionals
- Insights from sports coaches
- Insights from parents
- Insights from children

Source

- Derived from the UK tool
- Derived from the Hartpaspoort

Figure 28: Sports advice form, perspective from cardiologist

Sportadvies medische professional

De kindercardioloog vult dit formulier in. Onderaan wordt het later aangevuld door kind en ouder met aanvullende informatie voor de sportcoach.

Basisinformatie

Naam kind: _____
Geboortedatum: _____
Medisch behandelaar: _____
Datum: _____

Medische achtergrond

Medische diagnose:
**Wanneer aangeklikt op scherm, verschijnt achtergrondinformatie over de specifieke hartafwijking en symptomen.*

Eventueel korte uitleg voor sportcoach (aandachtspunten):

Toelichting:

Device geïmplanteerd?
☐ ICD
☐ Pacemaker
☐ Geen

Medicatie
Naam: _____
Dosis: _____
Tijdstip van toediening: _____

Toelichting:

Algemeen sportadvies

☐ Geen beperkingen (zie toelichting)
☐ Enkele beperkingen (zie toelichting)

Toelichting:

Aanbevolen intensiteit en duur

Aanbevolen intensiteit van inspanning
☐ Laag: actief, bewegen, maar geen duidelijke verandering in ademhaling of hartslag
☐ Gemiddeld: wordt warmer, ademt zwaarder, hart klopt sneller, maar kan nog steeds een gesprek voeren
☐ Intensief: ademt veel zwaarder, hart klopt veel sneller, moeilijk om een gesprek te voeren

Toelichting:

Aanbevolen duur van fysieke activiteit per dag:
☐ ≥ 60 min/dag
☐ 30-60 min/dag
☐ Tot 30 min/dag

Toelichting:

Type inspanning

Dynamische inspanning (spieren werken om beweging te produceren, bijv. hardlopen, zwemmen)
☐ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☐ Vermijden

Voorwaarden/ toelichting:

Statische inspanning (krachtig aanspannen van spieren zonder veel beweging, bijv. gewichtheffen):
☐ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☐ Vermijden

Voorwaarden/ toelichting:

Overige belangrijke aandachtspunten bij sportdeelname

Belangrijke medische bevindingen (echo, MRI, inspanningstest, holter)

Toelichting:

Contactsporten
☐ Toegestaan
☐ Alleen onder voorwaarden
☐ Vermijden

Voorwaarden/ toelichting:

Competitieve sporten (of wedstrijd elementen in de gymles):
☐ Volledige deelname aan alle competitieve sporten toegestaan.
☐ Deelname aan sommige competitieve sporten toegestaan, maar rust wanneer nodig.
☐ Vermijd alle competitieve sporten.

Toelichting:

Activiteiten om te vermijden
☐ Activiteiten met hoog impactrisico (bijv. vechtsporten, hockey)
☐ Activiteiten met risico op snij- of schaafwonden
☐ Anders: _____

Toelichting:

Hartslagzones
☐ Vrij binnen eigen kunnen
☐ Aanhouden tussen ..... en ..... bpm

Toelichting:

Temperatuurwisselingen
Moeite met temperatuurwisselingen:
☐ Ja
☐ Nee

Gevolgen:

Toelichting:

Motorisch functioneren
☐ Fijne motoriek beperkt
☐ Grove motoriek beperkt

Toelichting:

Toepassing op huidige sporten

Gerelateerd aan de sporten die het kind doet, ingevuld door cardioloog op basis van gesprek met kind/ouder of vragenlijst.

Sport (Voorbeeld ingevuld)	**Aanbevolen deelnamevorm**	**Eventuele aanpassingen of aandachtspunten** (bijv. vermijden van harde tackles, extra rustmomenten, geen competitie-element)
Gymles op school	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
Zwemmen	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
Voetbal	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
...		

Actieplan bij klachten of noodsituatie

Let op bij:

- Duizeligheid of flauwvallen
- Kortademigheid waardoor praten moeilijk wordt
- Hartkloppingen
- Bleek of klam worden
- Extreme vermoeidheid of uitputting
- Blauwe tint van de huid.

Actie: (In te vullen door medische professional)

1. ...
2. ...
3. ...

Aan te vullen door kind en ouder *(wordt later toegevoegd)*

- Frequentie van klachten bij het kind
- Mogelijke triggers
- Wat helpt of stelt het kind gerust
- Houding kind/ouder tegenover sportdeelname
- Wie te bereiken in geval van nood/vragen

6.5.3 Conceptual workflow for cardiologist

During the iteration period, an initial prototype was developed to explore how cardiologists might interact with both content elements: the pre-consultation questionnaire and the sports advice form. In this concept, the cardiologist logs into a digital platform to prepare the consultation, review the child's and parent's responses, and compose the sports advice (shown in Figure 29). A larger, detailed view of these interface screens is provided in Appendix J.

The idea is that the cardiologist only completes a limited set of medically relevant fields, to reduce time and to align with their workflow. Based on the selected options and inputs provided by the cardiologist, the system automatically composes an expanded, coach-facing version. This version includes predefined explanations of medical terms, standardized contextual information and optional visual support, tailored to the selected medical inputs and translated into role-appropriate language for the sports environment.

For the pre-consultation questionnaire, only the relevant output is shown to the cardiologist. The full list of questions and answer options is not displayed, but the cardiologist receives a concise summary of the child's responses. This keeps the information brief and manageable.

Although the visual examples presented here focus on the cardiologist's perspective, the same platform concept also includes role-specific views for parents, children, and sports coaches, each showing only the functions and information relevant to their role. The parents'/children's specific view is elaborated on in Chapter 6.5.4.

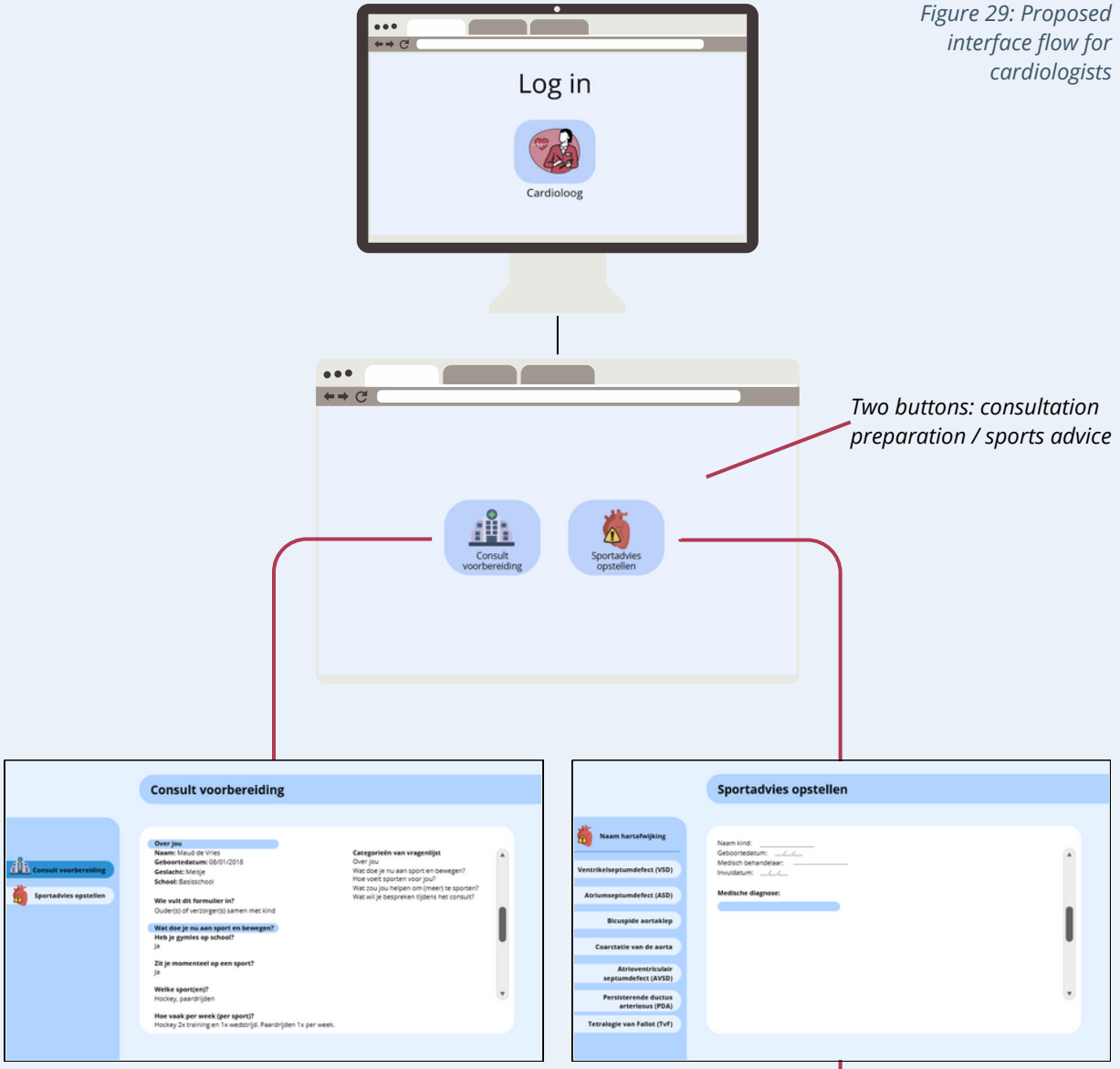


Figure 29: Proposed interface flow for cardiologists

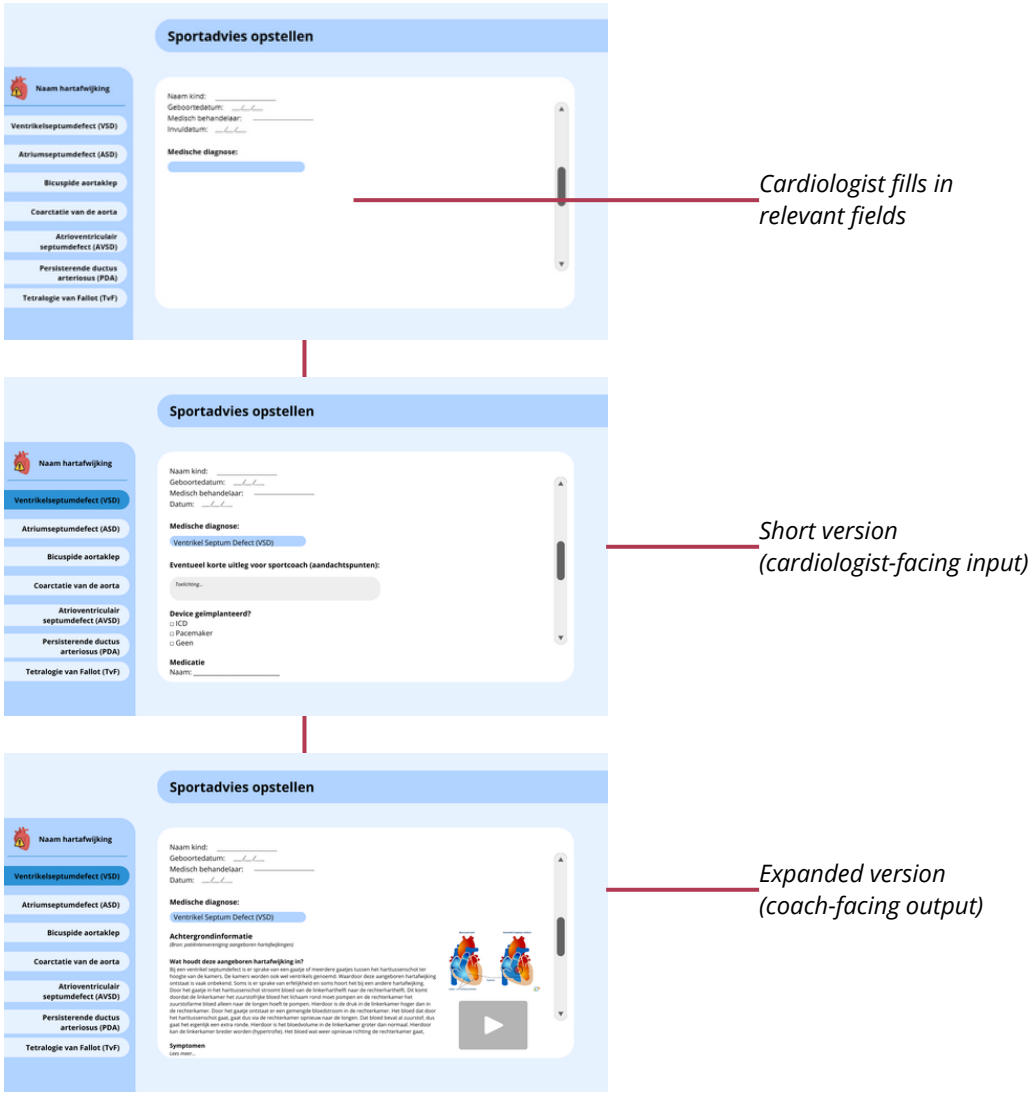


Figure 29 (continued): Proposed interface flow for cardiologists

6.5.4 Role specific view for parents/children

During the concept development phase, a prototype was created to explore how parents and children might use and share the pre consultation questionnaire with their cardiologist and the sport-related and medical information with sports coaches. This concept built on the earlier platform idea but focused specifically on the family perspective.

It consists of:

- A digital portal (with login for child and parent)
- A physical coach card generated from that portal

This is showed in Figure 30.

Functionalities

In this concept, parents and children could:

- Log into their own role-specific interface
- Complete and send the pre-consultation questionnaire to the cardiologist
- Select which information layers different sports coaches are allowed to access (such as basic information, emergency instructions, medical background, personal sports advice)
- Generate:
  - a physical coach card (PDF) for handover in sports settings
  - digital access via a QR code, where additional sensitive information would only be visible after log in
- Send messages to healthcare professionals and sports coaches via the portal

The layering of information and the use of QR-based access were initially explored as a precautionary design choice, based on the assumption that a physical coach card could be lost or shared unintentionally, potentially leaving sensitive information about the child insufficiently protected.

This approach ensures that basic, non-sensitive information is visible on paper, while more detailed medical information remains protected behind a login.

The parent/child-facing platform interfaces are shown in Figure 31. A larger view of these interface screens is provided in Appendix K.

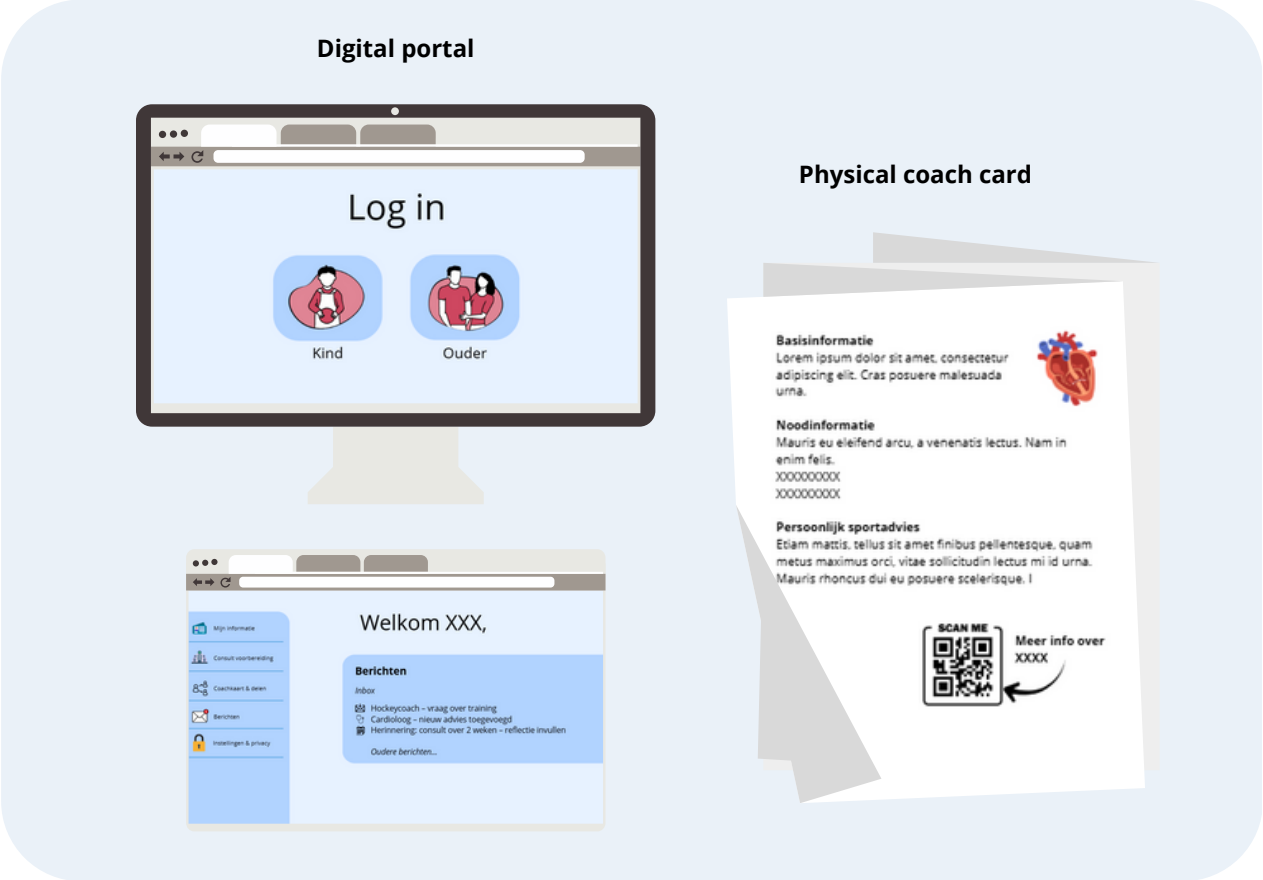


Figure 30: Platform for parents/child

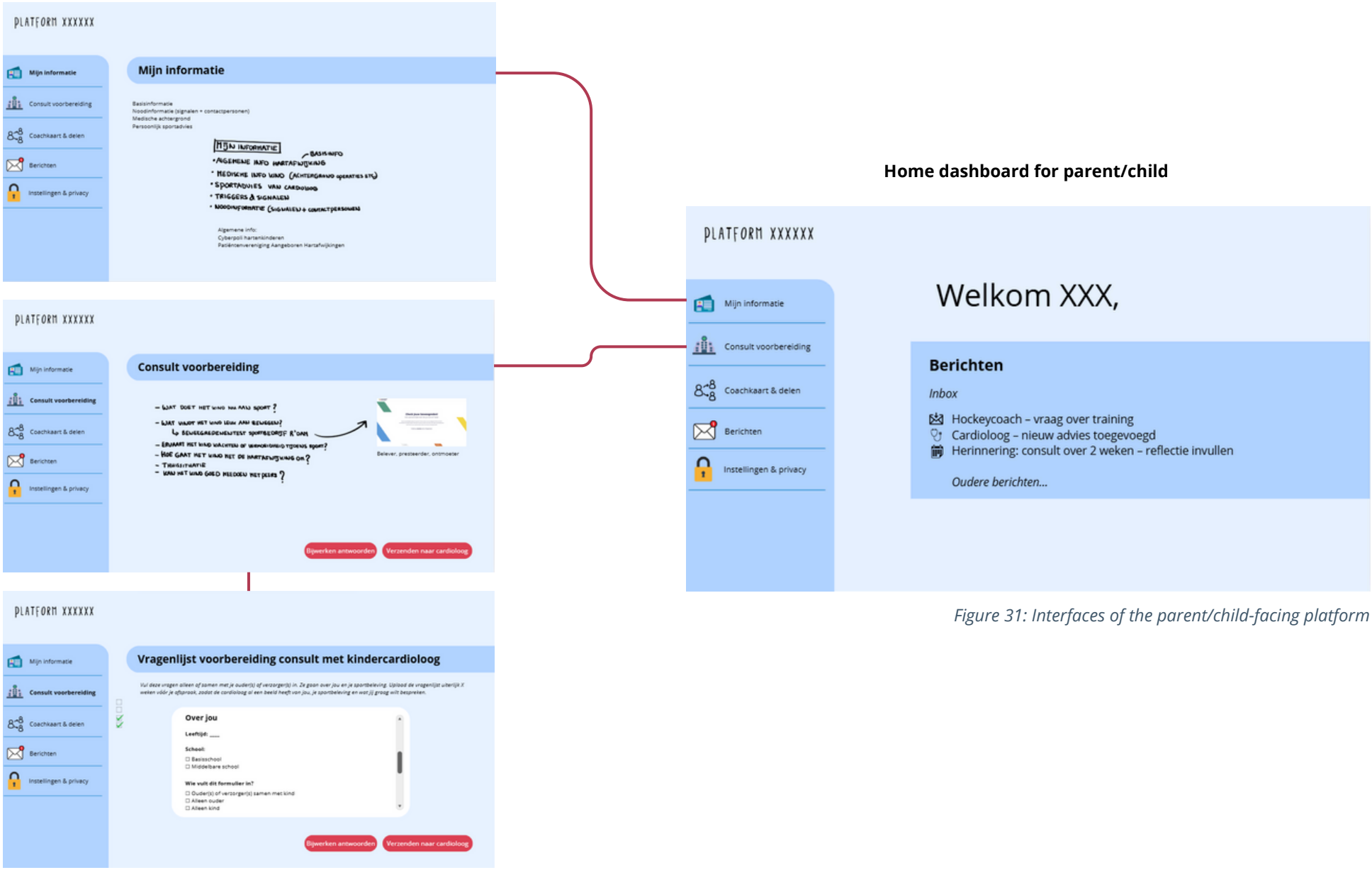
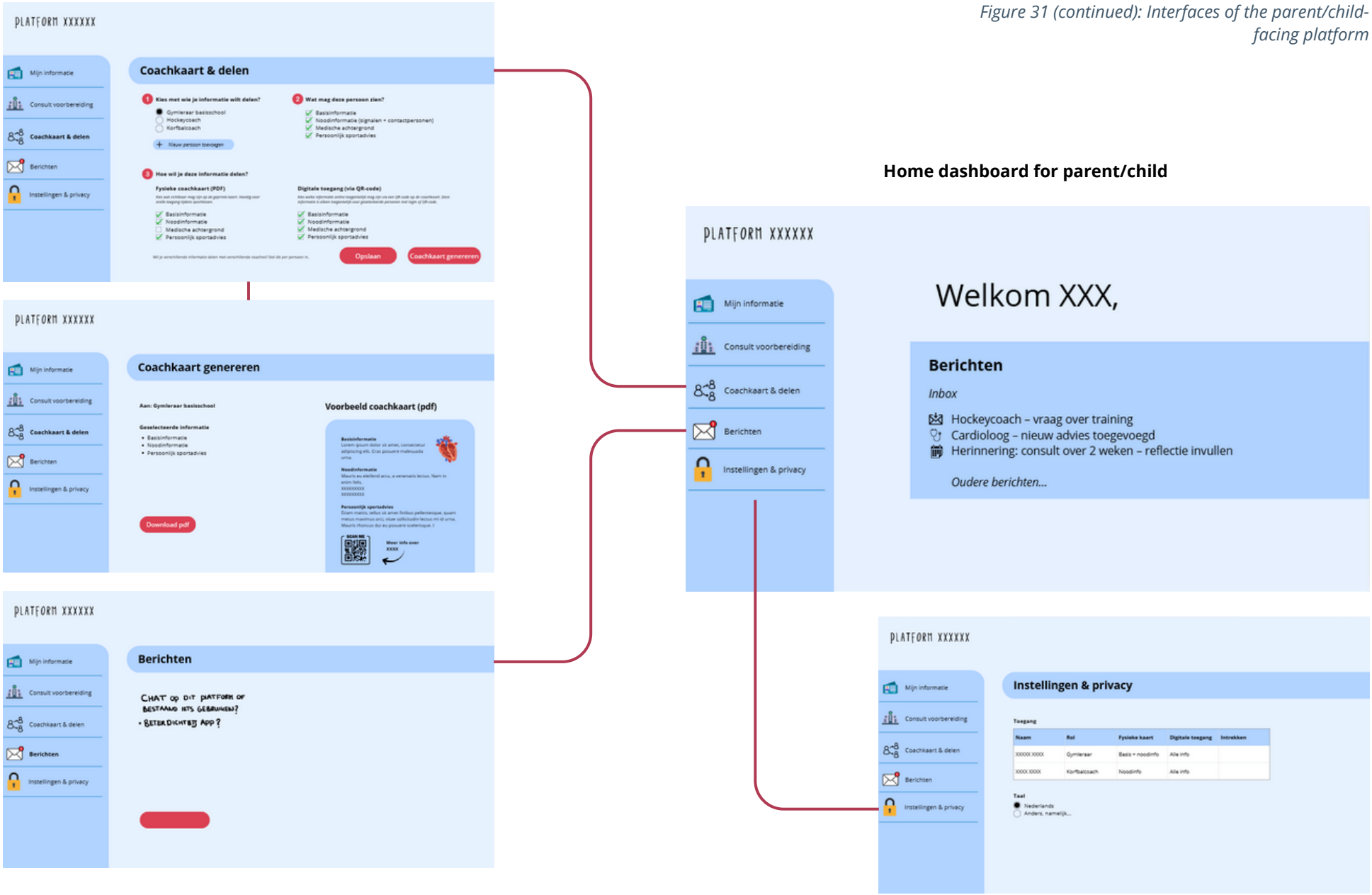


Figure 31: Interfaces of the parent/child-facing platform

Figure 31 (continued): Interfaces of the parent/child-facing platform



Insights gained from this exploration
This prototype did provide several concrete insights relevant to the design.

Although the layering of information primarily served as a security measure in case the physical coach card would be lost, with only basic data without sensitive information being printed and additional medical information remaining secure behind a login, this level of access control proved to be less relevant in light of the broader research insights. While privacy protection was mentioned by healthcare professionals and control over information sharing was clearly important to parents, the interviews with stakeholders did not explicitly indicate a strong need to restrict access per individual sports coach or to introduce additional login steps for them. Therefore, it raised the question of whether the benefit of restricting access to certain information outweighs the effort required from sports coaches to retrieve it via separate login or QR-based access. The interviews confirmed that families consider it important to maintain control over what is shared, and therefore the part of the platform where they can update, delete, or add information before it is distributed will be retained.

Second, the analysis of existing tools throughout the design process showed that adding a new messaging function within the platform is not necessary. Interviews indicated that parents generally prefer to take responsibility for transferring information from the hospital to the school or sport setting and appreciate maintaining control over that process.

In addition, several existing channels already support medical questions or communication with healthcare professionals (such as the BeterDichtbij app and the Cyberpoli chat function), which means that an additional messaging feature within this platform would not provide a functional addition.

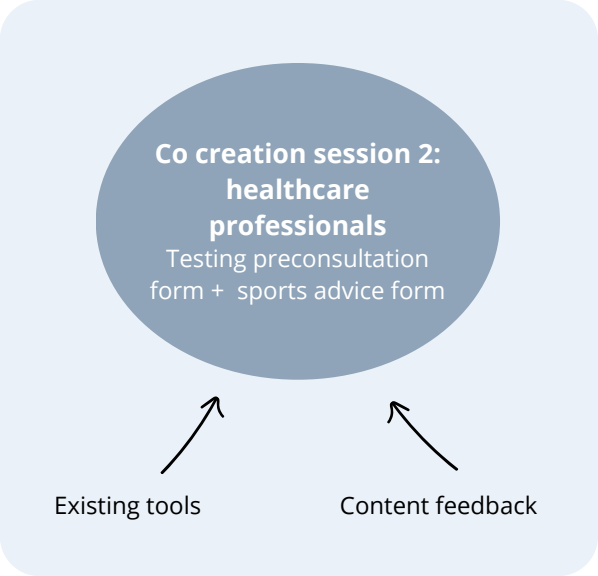
Third, although the visual prototype only presented the parent/child view, it became evident that a separate login environment for sports coaches would likely be impractical. For coaches, it is questionable whether it is desirable to log into an external platform for one specific child in their class or team, in addition to managing all other children and the existing systems in which they already operate. This insight contributed to the decision not to continue developing a coach-specific platform and instead to distribute sports advice through communication channels already used by schools and sport clubs, even if this may result in information being fragmented across multiple channels.

Finally, the exploration with this prototype did reveal a potential added value of the ability to keep track of which coaches have been informed and which version of the sports advice they received. This could help families maintain oversight of their own information sharing, as interviews indicated that some parents and children occasionally struggled to recall who had been informed.

Similarly, the platform could serve as a practical tool to help families supplement the sports advice form with contextual details (e.g., symptom triggers, emergency contacts, etc.) without relying on external editing software such as PDF modification tools, which not all users may be familiar or comfortable with.

In summary, this exploration helped distinguish which functionalities are necessary to keep within the final design and which functions may add unnecessary complexity or layers. These insights directly led to the refinements described in Chapter 7.

6.6 Co-creation / feedback session Erasmus MC



6.6.1 Goal of the session

A second co-creation and feedback session was held during a research meeting at the Erasmus MC. The session involved several cardiologists, supported by PhD candidates are involved in the care trajectory of children with CHD.

Because cardiologists were present, this session focused specifically on the medical view on elements of the concept.

The goal of the session was to test the usability, clinical relevance, and feasibility of the two components of the tool.

6.6.2 Method

The two core components of the tool were presented for evaluation:

- The pre-consultation questionnaire for children and parents to fill out
- The sports advice form intended for the cardiologist to complete for sports coaches

Session procedure
Participants were divided into three groups. One group completed and reviewed the pre-consultation questionnaire (from the perspective of a parent and child), while the others worked on completing and discussing the sports advice form. Later, the group working on the advice form also reviewed the questionnaire.

Each group was asked to complete specific tasks from the perspective of relevant stakeholders. The group working on the pre-consultation questionnaire first filled it in themselves, adopting the role of a parent and child. They then discussed whether the questionnaire would provide the cardiologists with the right type and amount of information for preparation of their consult. The groups working on the sports advice form completed the form as if before/ during a real consultation, and assessed whether its content was relevant, clear, and feasible to complete within the limited consultation time.

Although the tool is intended to be filled in digitally in future use, for this session the materials were provided as printed forms to allow for annotations and discussion.

Evaluation materials

Feedback was gathered through annotations on both forms, worksheets completed during the session (see Figures 32 and 33) and some verbal reflections captured during group discussion.

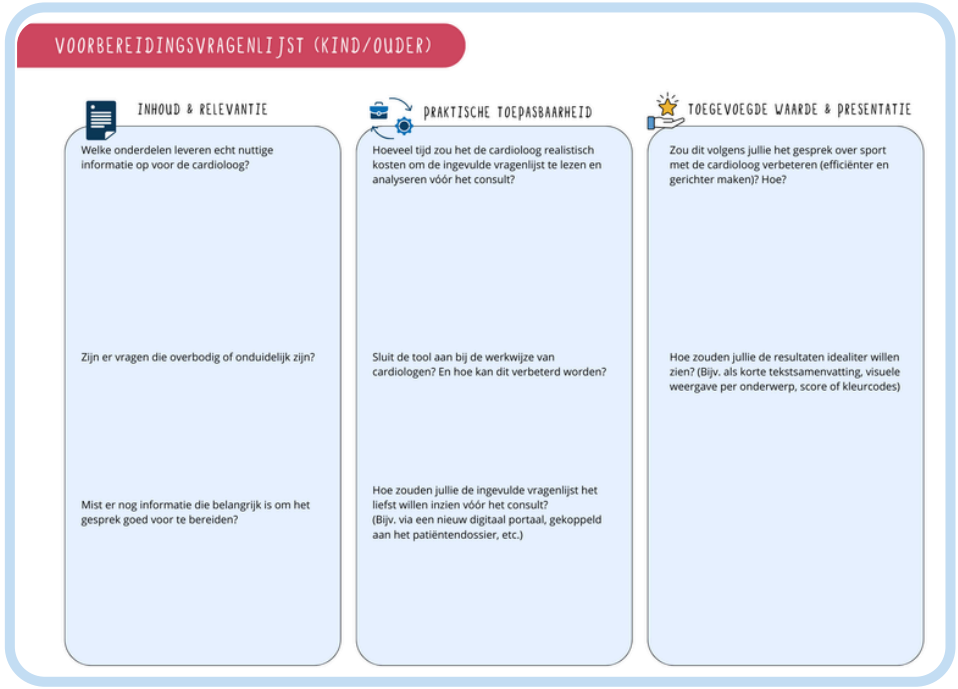


Figure 32: Worksheet used by the participants to evaluate the questionnaire

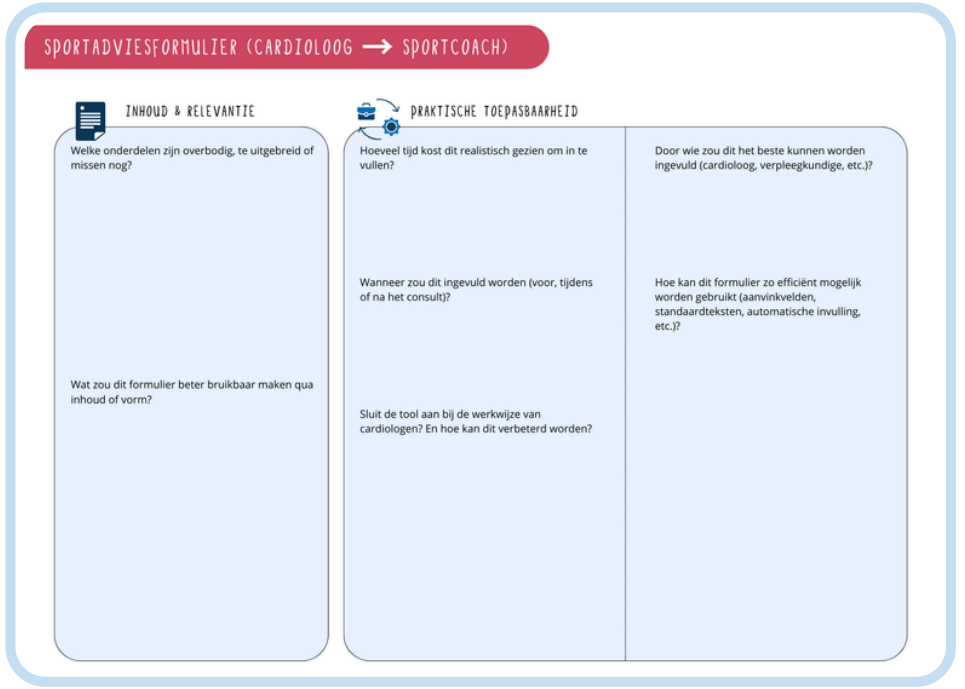


Figure 33: Worksheet used by the participants to evaluate the sports advice form

6.6.3 Results & conclusion

The co-creation session with pediatric cardiologists provided concrete feedback on both tool components. The conclusions of the feedback are listed below, details and raw data are provided in Appendix L and M. Additionally, implications for the next design phase are proposed, which are incorporated in Chapter 7.

Pre-consultation questionnaire (parent/child)

Key feedback and insights

- Several questions provided limited added value for cardiologists to know. For example, a question about how tired a child feels after sports was considered difficult to interpret, as fatigue strongly depends on the type of the activity. A cardiologist indicated that questions focusing on recovery after exercise are more clinically relevant. Another question addressing the child's confidence in what their body can handle during sports was considered difficult to interpret. Cardiologists suggested replacing this with a more concrete and comparative question focusing on whether the child feels able to participate or keep up with peers during sports activities.
- Some questions in the questionnaire should be simplified to be understandable for children, according to the participants. Cardiologists immediately proposed concrete ways to achieve this, for example by rephrasing questions or adding visual scales.
- In addition, some answer options were considered to provide limited clinical value. During the session, cardiologists directly adjusted these sections on the forms. For example, a question assessing whether the child had a clear understanding of what they are allowed to do during physical activity was reformulated from abstract response options (clear understanding / uncertain / no idea) to a more concrete format (yes / no / don't know). In some cases, the response options were expanded to better reflect the experiences of children that cardiologists encounter in practice. For example, when asking about reasons for not currently participating in sports, cardiologists suggested adding options such as uncertainty about physical abilities or lack of enjoyment.
- A cardiologist emphasized that the core value of the questionnaire lies in revealing whether the child currently participates in sport, why or why not, what would help them, and what they wish to discuss.
- A cardiologist mentioned that there are already existing questionnaires in use, however, they do not cover several of the aspects addressed in this questionnaire.
- The current format of the questionnaire requires too much time for cardiologists to process prior to the consultation, as the information is not integrated into their existing HiX workflow, but could be made more efficient if integrated directly within HiX.

HiX is the electronic health record system used in Dutch hospitals.

Implications for further design

- Remove or rephrase questions that did not provide clinical value. For example, a question that focused on fatigue after exercise should be rephrased to assess recovery rather than just fatigue.
- Reformulate some questions to be more understandable for children while still clinically informative.
- Although the information deemed most relevant by cardiologists includes whether the child currently participates in sport, why or why not, what would help them, and which topics they wish to discuss, some additional items were included based on the needs of other professionals (such as physical therapists). It should therefore be reviewed whether these additional items remain necessary in the final version or whether they can be reduced to prevent unnecessary clinical load.
- Because some questionnaires are already in circulation within Erasmus MC, there is a risk that this questionnaire becomes an additional form rather than replacing or merging with existing ones. Some overlapping items were identified when comparing the tools (comparison is not shown due to confidentiality).
- Although this report presents the questionnaire as a standalone component, future implementation should consider integration of some questions into existing questionnaires to avoid duplication and reduce burden for both families and healthcare professionals.
- The existing patient app Digizorg is currently used to distribute and complete questionnaires. This allows the tool to make use of systems that families already access, and removes the need for a separate platform
- Integration into HiX is recommended rather than implementation in a new platform, because cardiologists already work there, automated distribution of existing questionnaires already exists and responses can be compared over time.

Sports advice form (cardiologist → sports coach)

Key feedback and insights

- Some sections are not relevant for specifically a cardiologist to fill in or are unnecessary for CHD-related sports guidance. For instance, the section addressing difficulties with temperature regulation prompted surprise. Cardiologists indicated that although reduced heat tolerance is sometimes mentioned in clinical practice, it is not directly related to the congenital heart defect itself. Regarding the section on motor functioning, one cardiologist acknowledged that information on motor functioning can be valuable for sports coaches and useful for certain children, but another cardiologist considered its assessment outside the cardiologist's scope and more appropriate for a physiotherapist.
- The advice should place more emphasis on what the child can do and clarify that experiencing mild physical signals during sports is often a normal part of physical activity for children in general and is not necessarily a sign of medical concern, even for children with CHD.
- Cardiologists differed in when they would fill in the form (before/ after consultation or before/during), this indicates variation in workflow preferences. One cardiologist indicated that they would fill out the form in advance and discuss it during the consultation, while another indicated that they wanted to fill out parts of it before and parts of it after the consultation.
- Regarding the tool within their current workflow, cardiologists indicated that implementation would only be feasible when integrated into HiX. While one cardiologist noted that the tool would be useful and feasible but would require additional time, another emphasized that the topics addressed are already routinely discussed during consultations and therefore fall within the existing scope of practice.
- Some cardiologists suggested that a nurse specialist could play a role in completing parts of the form, after which the cardiologist would finalize it and discuss with the child and parent.
- A set of pre-selected options would reduce the time needed to fill in the form.

Implications for further design

- Some sections could be removed or reformulated based on clinical relevance. The section on temperature regulation could be removed, whereas the section on motor functioning could be retained but supplemented with a "not applicable" option and a "requires additional assessment" option. This allows cardiologists to indicate whether motor functioning is relevant for the individual child and, if needed, to signal that further assessment by another healthcare professional may be required.
- The section previously titled Action plan in case of symptoms or emergency could be reframed in a more positive tone such as Dealing with signals during sports, to emphasize that many physical responses during exercise are normal, rather than immediately framing them as warning signs.
- Because cardiologists vary in when they prefer to complete the sports advice form, the tool should not prescribe a fixed completion moment. Instead, it must remain flexible and support different workflow preferences
- Integration within HiX was considered crucial for adoption, as it could save time and automatically link the sports advice to the medical record, relevant fields can be pre-filled automatically and it suits the current workflow of the cardiologists.
- Consider the possibility of dividing tasks, where the nurse specialist prepares the form and the cardiologist validates and communicates to families.

Conclusion

The session confirmed the value of both tool components but highlighted several necessary adjustments. Content should be refined, integration into HiX is a prerequisite for adoption,
workflow flexibility is required, and some responsibilities may be shared, for example between a nurse specialist and cardiologist.

These outcomes directly informed the refinements implemented in the next design iteration, presented in the following chapter.

Image source: Pexels

7

Final design

This chapter presents the final design of the communication tool developed in this project. It explains the system overview and describes how the design is used in practice across different phases, supported by scenarios and interface examples.

7.1 Introduction

The final design addresses the core problem identified throughout the research phase, which is fragmented, unclear and inconsistent communication about sports participation of children with CHD across healthcare, home and sports environments.

The literature review, interviews and combined insights from journey maps revealed that parents, children, healthcare professionals and sports coaches often lack a shared understanding of what is safe and appropriate in relation to sports participation of children with CHD. This may result in uncertainty, overprotection, inconsistent advice and missed opportunities for those children to participate confidently and inclusively in sports.

These insights highlighted the need for a solution that brings sport-related information and needs together and supports clearer and more consistent communication between children, parents, healthcare professionals and sports coaches.

The final communication tool presented in this chapter addresses this by structuring information and communication throughout the consultation process. By combining a pre-consultation questionnaire with a sports advice form, the system brings relevant information from different stakeholders together, supports communication during the consultation, and enables clear and consistent information transfer to different stakeholder environments, while fitting within existing workflows of stakeholders.

7.1.1 System summary

Support for communication about sports participation for children with CHD begins before the consultation with the cardiologist. The child (and parent) complete a questionnaire prior to their appointment with the cardiologist and send it to the hospital through their patient portal. The cardiologist or nurse specialist reviews the results in HiX to prepare for the consultation.

Before, during or after the consultation, the cardiologist or nurse specialist completes a sports advice form. This form is then made available in a platform for the child and parent. In this platform, the child and parent can adjust, remove information or add additional context-specific information for the sports environment.

After this, the sports advice form (including any additions or changes) can be sent to the sports coach through the existing communication channel used by the sports club or school. It can be provided to the sports coach either digitally or in printed form.

The figure on the next page shows the overview of the system.

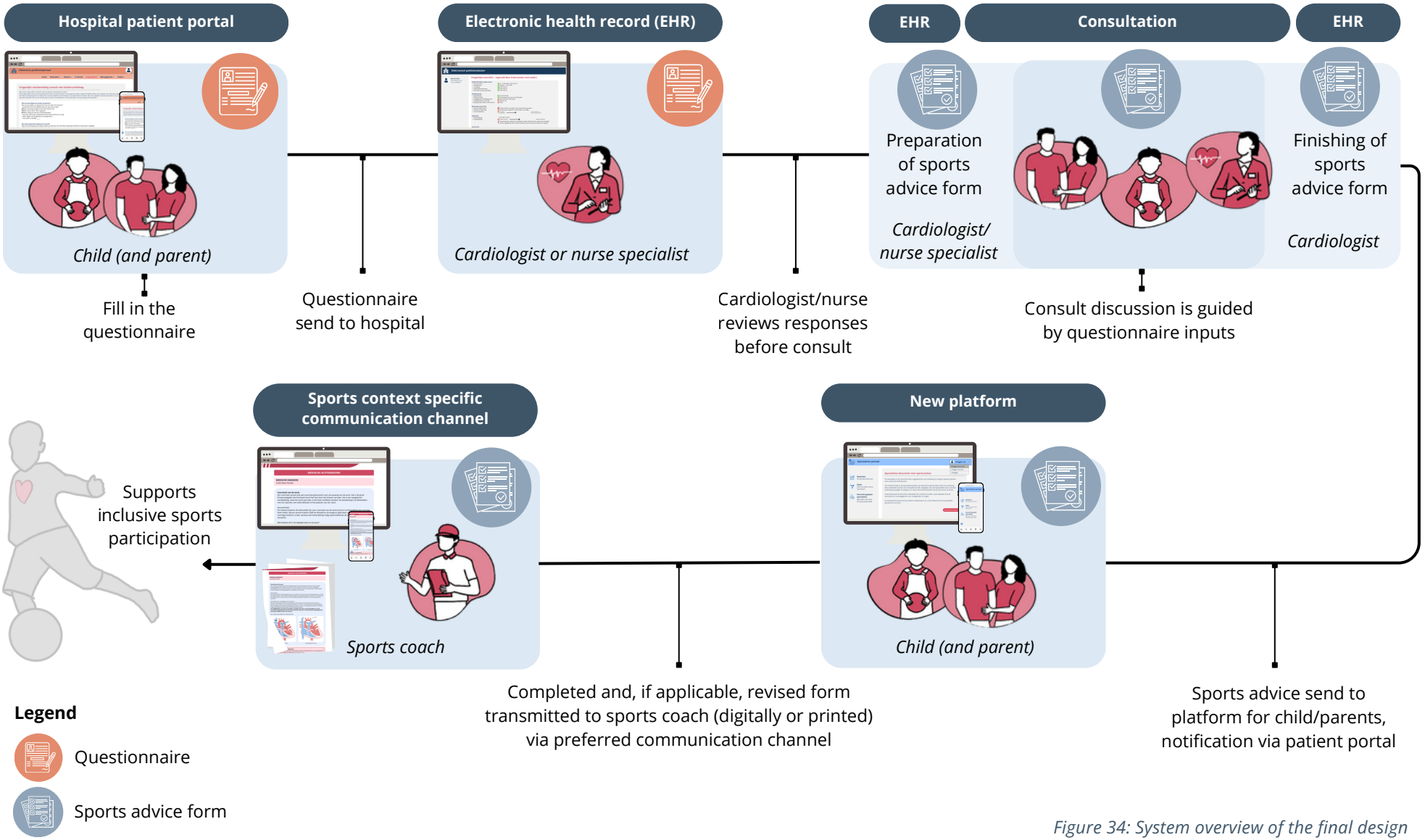


Figure 34: System overview of the final design

7.2 Use and details of the final design across different phases

The questionnaire and the sports advice form are used at different moments within the communication process, by multiple stakeholders and across different contexts, such as the hospital, home and sports environment. To create a clear overview, these moments are structured into eight phases. The questionnaire is the main subject in phases 1 to 3 and the sports advice form in phases 4 to 8.

Sections 7.3 and 7.4 describe the questionnaire and the sports advice form respectively in more detail. Each subsection starts with an overview of the corresponding phase, the context in which it takes place, and the stakeholders involved.

This is followed by a usage scenario, and subsequently by a description of the key interactions, design choices, and considerations.

An overview of the different phases within this communication chain is provided below.

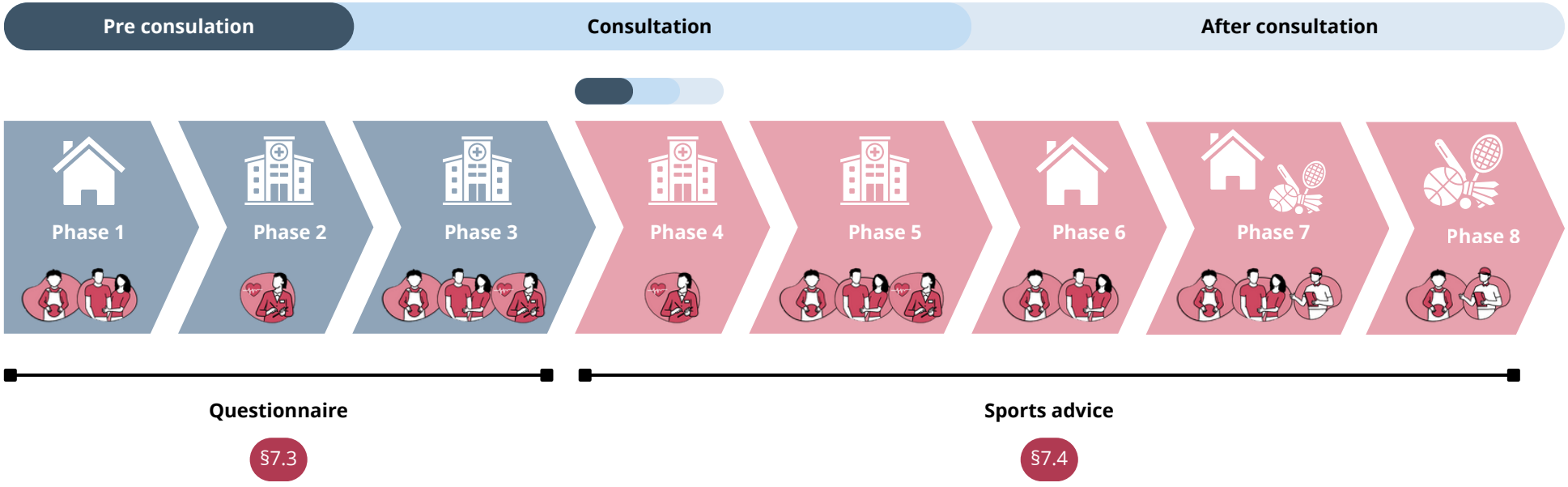
The scenario images are obtained from Vecteezy (unless stated otherwise) and have been adapted and edited by the author to support the visualization of the scenario.

Legend

Context

- Hospital environment
- Home environment
- Sports environment

Involved stakeholders



7.3 Questionnaire

Purpose of the questionnaire
The pre-consultation questionnaire has the primary function of giving healthcare professionals insight into the child's sports experiences, concerns or limitations, and home situation prior to the consultation. This helps create space for topics that might otherwise remain unspoken during the consultation, reduces the risk of mismatches in expectations or concerns between the child, parents, and healthcare professionals, and supports offering the child appropriate guidance or referral when needed. The questionnaire therefore functions as a preparatory tool, allowing consultation time to be used more efficiently and focused on the child's needs.

Distribution and digital integration
Feedback from cardiologists emphasized that adoption is only feasible if the questionnaire is embedded within existing hospital systems rather than introduced via an additional platform. Therefore, the questionnaire is distributed to patients via the hospital patient portal (e.g. Digizorg at Erasmus MC) and integrated directly into the electronic health record (HiX), where responses are available for clinical review by a healthcare professional.

This approach aligns with current practices for existing pre-consultation questionnaires, supports workflow compatibility and minimizes administrative burden for healthcare professionals.

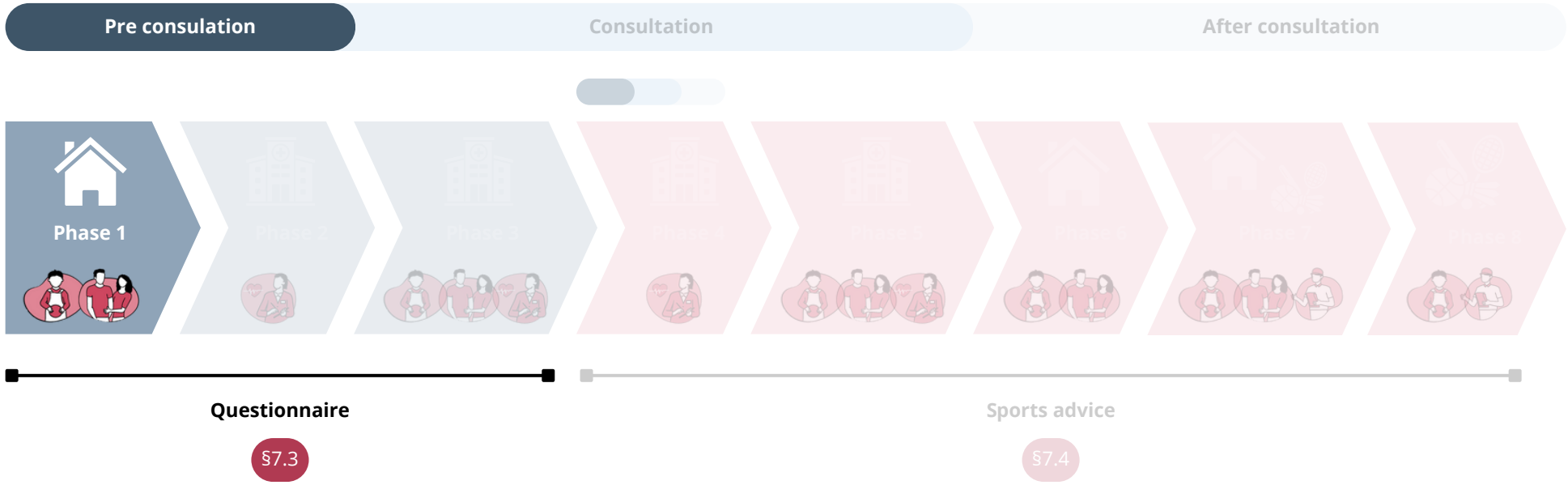
Automation
The questionnaire builds on existing digital workflows within the hospital and is distributed directly through the electronic health record system. Integration of the questionnaire within the electronic health record system is handled by dedicated technical staff, similar to the implementation of other pre-consultation questionnaires currently in use.

Once the questionnaire is completed by the child and parent, the responses are automatically processed and stored within the patient's electronic record. Healthcare professionals can access the results directly in HiX, where they can review an overview of the outcomes.

The timing and frequency of the distribution of the questionnaire can be configured within the electronic health record, in line with existing practices for other questionnaires. For example, questionnaires could be sent in advance of a scheduled outpatient appointment and limited to a defined frequency per patient.

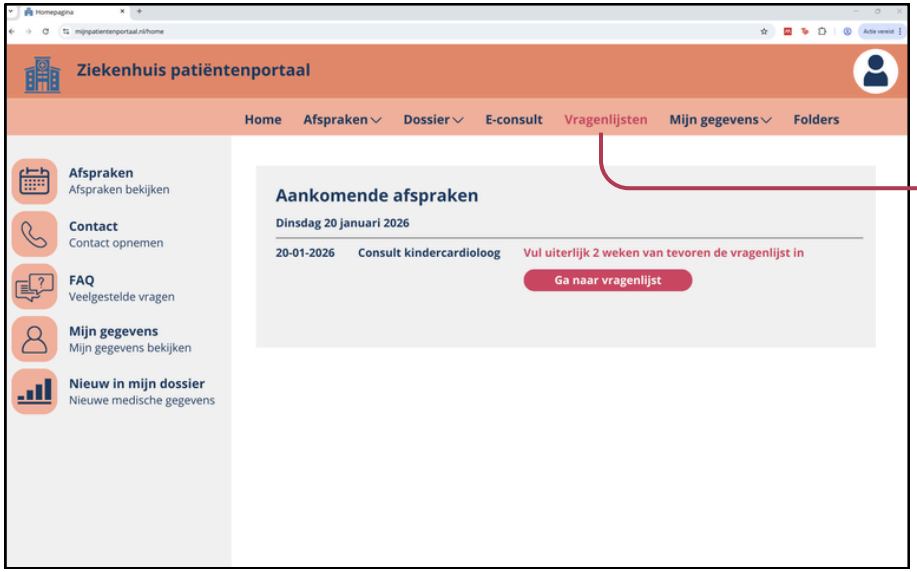
7.3.1 Phase 1: completing the questionnaire (by child & parent)

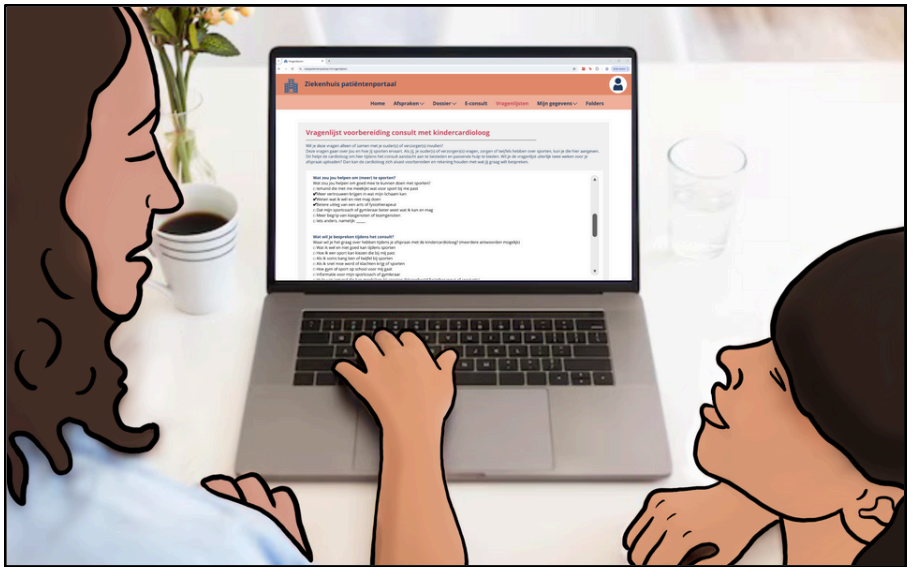
The first phase of the final design starts at home, where the child and parent complete a pre-consultation questionnaire prior to the hospital appointment.



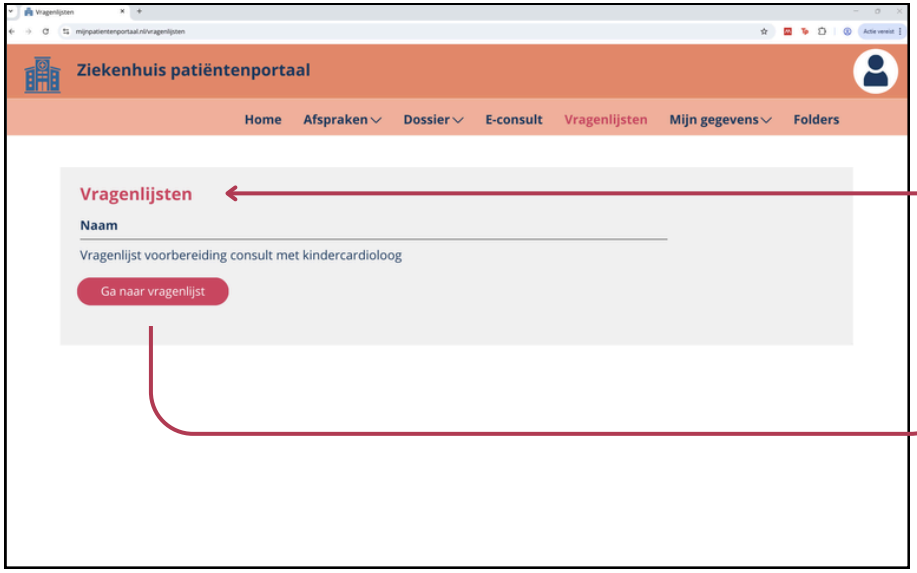
Scenario and interface illustration

1 Approximately two weeks prior to the scheduled appointment, the child and parent receive an automated notification via the hospital patient portal.





2 At home, they complete the questionnaire together, reflecting on the child's sports participation, experiences, concerns and topics they would like to discuss during the consultation.



Who completes the questionnaire?
The questions are designed in such a way that children should be able to answer them independently, as earlier findings showed that children should be actively involved in conversations about their health. No distinction is made within the ages of the target group of this project, children aged 6 to 16. Younger children may complete the questionnaire together with a parent or caregiver, while older children may fill it in independently if preferred.

Level of abstraction on hospital patient portal interface
The hospital patient portal interfaces illustrate a possible representation of how the questionnaire might be accessed and completed within commonly used portals. This is shown in Figure 35. In practice, the exact visual appearance and interaction design will depend on the specific patient portal used by a hospital, such as Digizorg at Erasmus MC or comparable systems used in other hospitals.

Final questionnaire questions
Figure 36 presents screenshots of the final version of the pre-consultation questionnaire.

The purpose, underlying reasoning and components of the pre-consultation questionnaire have already been elaborately discussed in Chapter 6.5.1 and are therefore not further elaborated here. After feedback from cardiologists on the content and relevance of the questionnaire, as described in Chapter 6.6.3, the refined version showed below was created.

Highlighted design decisions
To support children and parents in sharing their experiences, concerns, and possible help needs, a short introductory text was added to the questionnaire explaining its purpose. By clearly stating that questions, worries, or doubts about sports can be indicated, children and parents are encouraged to think about these topics before the consultation. This lowers the threshold for expressing a help need and explains why this input is valuable for the cardiologist.

The questionnaire mainly focuses on the child's experiences, as the child is the focus of the consultation.

However, one question is included that asks how parents feel when their child participates in sports. This helps highlight that parents and children may experience sports participation differently. For example, a parent may feel worried while the child does not experience problems, or parental concerns may influence the child's sports behavior. By also including the parent's perspective, the cardiologist can recognize possible differences in experiences and address them during the consultation. This supports a better understanding of the situation of the child and family and may help to provide appropriate support together.

Figure 35: Interface of the questionnaire in the patient portal

Figure 36: Pre-consultation questionnaire

Vragenlijst voorbereiding consult met kindercardioloog

Wil je deze vragen alleen of samen met je ouder(s) of verzorger(s) invullen?
Deze vragen gaan over jou en hoe jij sporten ervaart. Als jij, je ouder(s) of verzorgers(s) vragen, zorgen of twijfels hebben over sporten, kun je die hier aangeven. Dit helpt de cardioloog om hier tijdens het consult aandacht aan te besteden en passende hulp te bieden.

Wil je de vragenlijst uiterlijk twee weken voor je afspraak uploaden? Dan kan de cardioloog zich alvast voorbereiden en rekening houden met wat jij graag wilt bespreken.

Over jou

Naam: _____ (wordt automatisch ingevuld via het ziekenhuisdossier)

Geboortedatum: _____(wordt automatisch ingevuld via het ziekenhuisdossier)

Ik identificeer me als:
☐ Jongen
☐ Meisje
☐ Non-binair
☐ Anders

School:
☐ Basisschool
☐ Middelbare school

Wie vult dit formulier in?
☐ Ouder(s) of verzorger(s) samen met kind
☐ Alleen ouder
☐ Alleen kind

Wat doe je nu aan sport en bewegen?

Heb je gymles op school?
☐ Ja
☐ Nee

(Vervolgvragen - verschijnen alleen wanneer "ja" is aangevinkt)

Hoe vaak per week heb je gymles? ____

Doe je mee met gymles?
☐ Ja
☐ Nee

Zit je momenteel op een sport?
☐ Ja

(Vervolgvragen - verschijnen alleen wanneer "ja" is aangevinkt)

Welke sport(en)? ____

Hoe vaak per week (per sport)? ____

Doe je mee aan trainingen?
☐ Ja
☐ Nee

Doe je mee aan wedstrijden of toernooien?
☐ Ja
☐ Nee

Doe je aan alle onderdelen van sport mee?
☐ Ja
☐ Nee

☐ Nee

(Vervolgvragen - verschijnen alleen wanneer "nee" is aangevinkt)

Als je nu niet sport, wat zijn daar redenen voor?
☐ Ik ben gestopt
☐ Ik weet niet wat voor sport ik leuk vind
☐ Ik vind sporten niet zo leuk
☐ Ik heb andere hobby's
☐ Ik ben bang dat het niet veilig is
☐ Ik weet niet of ik het kan
☐ Ik heb geen tijd
☐ Ik mag het niet
☐ Er is geen club in de buurt
☐ Andere beperkingen (geld, tijd, taal, etc.), namelijk: _____

Zou je (weer) willen beginnen met sporten?
☐ Ja
☐ Misschien
☐ Nee

Zijn er sporten die je graag zou willen proberen? _____

Hoe goed voelt sporten voor jou?

(Vervolgvragen - verschijnen alleen wanneer "ja" is aangevinkt op "Zit je momenteel op een sport?" of "Heb je gymles op school?")

Hoe zwaar vind jij je trainingen of sportmomenten?

Ik houd het makkelijk vol — Ik word echt moe en moet soms pauze nemen

Hoe zou jij jezelf beschrijven tijdens sporten of bewegen?
- ☐ Ik geef altijd alles en houd van uitdagingen
- ☐ Ik doe graag mee, maar niet te fanatiek
- ☐ Ik ben meestal rustig en voorzichtig
- ☐ Anders: _____

Wat vind je van sporten?
- ☐ Ik vind het leuk
- ☐ Gaat wel
- ☐ Ik weet het niet zo goed
- ☐ Ik vind het moeilijk of spannend
- ☐ Niet leuk

Kun je even goed sporten als je vriendjes?
- ☐ Net zo goed als de anderen
- ☐ Soms lukt het minder goed
- ☐ Ik vind het moeilijk om mee te komen

Heb je weleens klachten tijdens het sporten?
- ☐ Ik heb geen klachten tijdens het sporten
- ☐ Mijn borst doet pijn
- ☐ Ik word duizelig of val flauw
- ☐ Andere klachten, namelijk _____

Hoe snel kun je bijkomen na sporten of gym?
- ☐ Snel (binnen 5-10 minuten ben ik weer fit)
- ☐ Na een pauze (ongeveer 15-30 minuten rust nodig)
- ☐ Pas veel later (bijvoorbeeld pas aan het eind van de dag)

Is het voor jou duidelijk wat je wél en niet mag doen tijdens sporten/bewegen?
- ☐ Ja
- ☐ Nee
- ☐ Weet ik niet

Waar zou je graag meer duidelijkheid over willen?

_____
_____

Ben je weleens bang dat sporten slecht is voor je hart?
- ☐ Vaak
- ☐ Soms
- ☐ Nooit

Wie moedigt jou aan om te bewegen?
- ☐ Ouders
- ☐ Vrienden
- ☐ Ikzelf
- ☐ Leraar
- ☐ Sportcoach
- ☐ Cardioloog
- ☐ Fysiotherapeut
- ☐ Niemand
- ☐ Iemand anders, namelijk: _____

Hoe voelen je ouder(s) of verzorger(s) zich als jij sport?

Meestal heel gerust — Meestal best bezorgd

Toelichting door ouder(s) of verzorger(s):
Hoe voelt het voor u wanneer uw kind sport?

_____
_____

Wat zou jou helpen om (meer) te sporten?

Wat zou jou helpen om goed mee te kunnen doen met sporten?

☐ Iemand die met me meekijkt wat voor sport bij me past
☐ Meer vertrouwen krijgen in wat mijn lichaam kan
☐ Weten wat ik wél en niet mag doen
☐ Betere uitleg van een arts of fysiotherapeut
☐ Dat mijn sportcoach of gymleraar beter weet wat ik kan en mag
☐ Meer begrip van klasgenoten of teamgenoten
☐ Iets anders, namelijk: _____

Wat wil je bespreken tijdens het consult?

Waar wil je het graag over hebben tijdens je afspraak met de kindercardioloog? (meerdere antwoorden mogelijk)

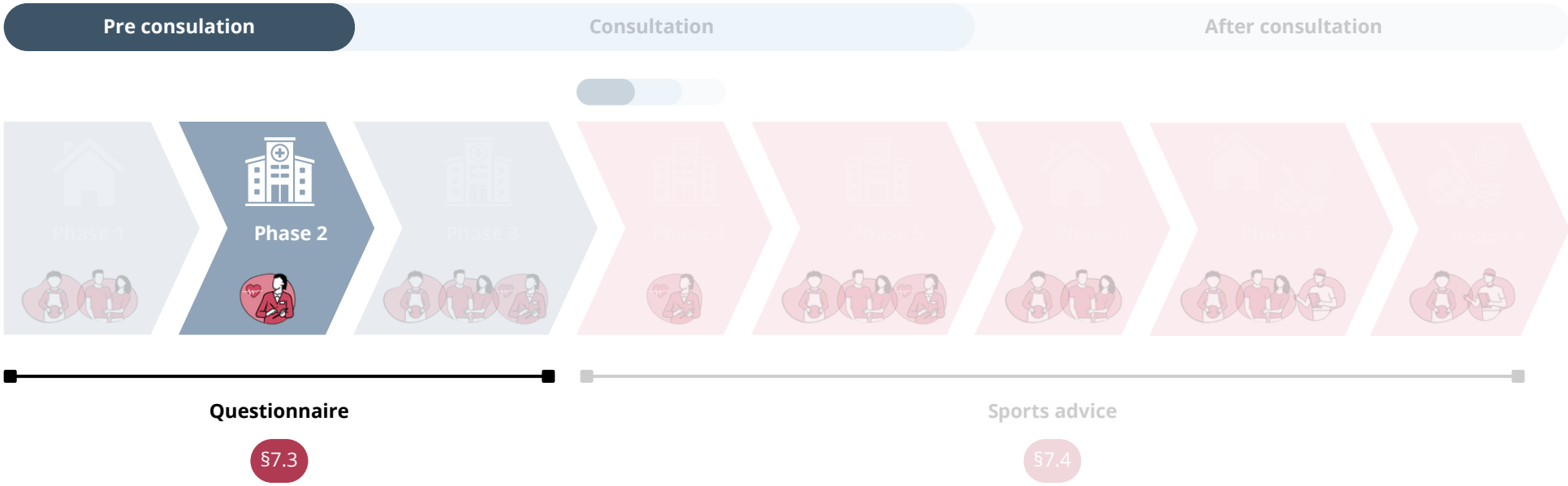
☐ Wat ik wel en niet goed kan tijdens sporten
☐ Hoe ik een sport kan kiezen die bij mij past
☐ Als ik soms bang ben of twijfel bij sporten
☐ Als ik snel moe word of klachten krijg tijdens sporten
☐ Hoe gym of sport op school voor mij gaat
☐ Informatie voor mijn sportcoach of gymleraar
☐ Hulp van iemand die kan meekijken bij sporten (bijvoorbeeld fysiotherapeut of sportarts)
☐ Iets anders, namelijk: _____

Is er nog iets anders dat je wilt vertellen voor het gesprek?

_____
_____

7.3.2 Phase 2: consultation preparation by cardiologist and/or nurse specialist

The second phase of the final design takes place in the hospital, during the preparation of the consultation by the cardiologist and/or nurse specialist.

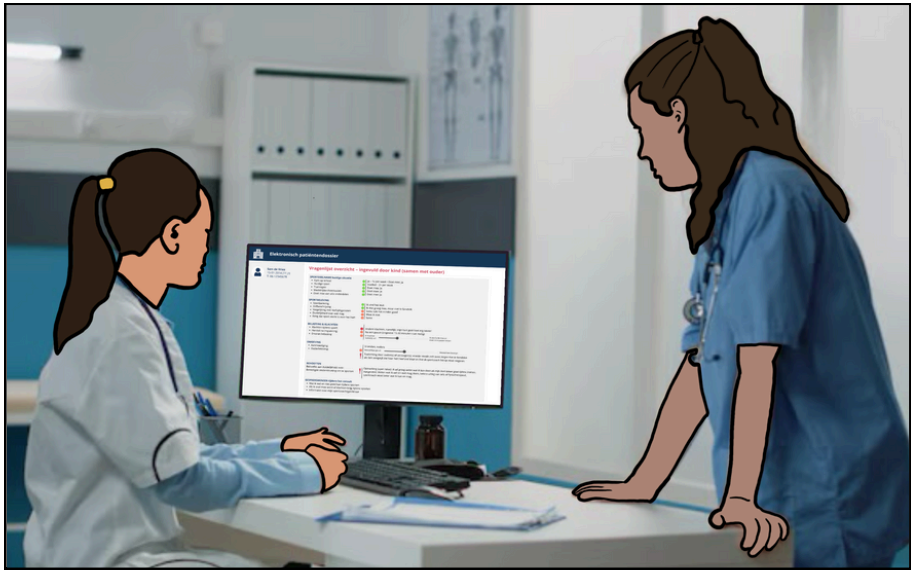


Scenario and interface illustration

1 After the questionnaire is completed, responses are automatically processed and made available within the electronic health record. The thematic structure and visual indicators support a quick identification of key points of attention.

Illustrative example of questionnaire results based on a fictitious child.

2 Prior to the consultation, the questionnaire overview is reviewed by a healthcare professional involved in the child's care, such as the cardiologist or a nurse specialist. By reviewing the overview in advance, healthcare professionals can prioritize topics and tailor their guidance to the child's experiences and needs during the consultation.



Who analyses the questionnaire?
As part of the consultation preparation, the cardiologist reviews the results of the completed questionnaire. The way in which the questionnaire results are structured is intended to support quick interpretation and to limit the additional time required for preparation. However, it remains unclear how much time this would take in practice and whether a nurse specialist could play a supportive role in reviewing the results and preparing the consultation together with the cardiologist.

Level of abstraction of questionnaire results in the electronic health record
The electronic health record interface and the summary overview for healthcare professionals represent a design vision of how questionnaire results could be presented within systems such as HiX. Access to HiX is limited to healthcare professionals and the exact interface and level of detail may therefore differ in practice. The design focuses on defining which information is essential to be visible to support consultation preparation, rather than prescribing a fixed interface layout.

In practice, the exact layout and technical implementation of this summary overview would depend on the configuration options of the electronic health record system.

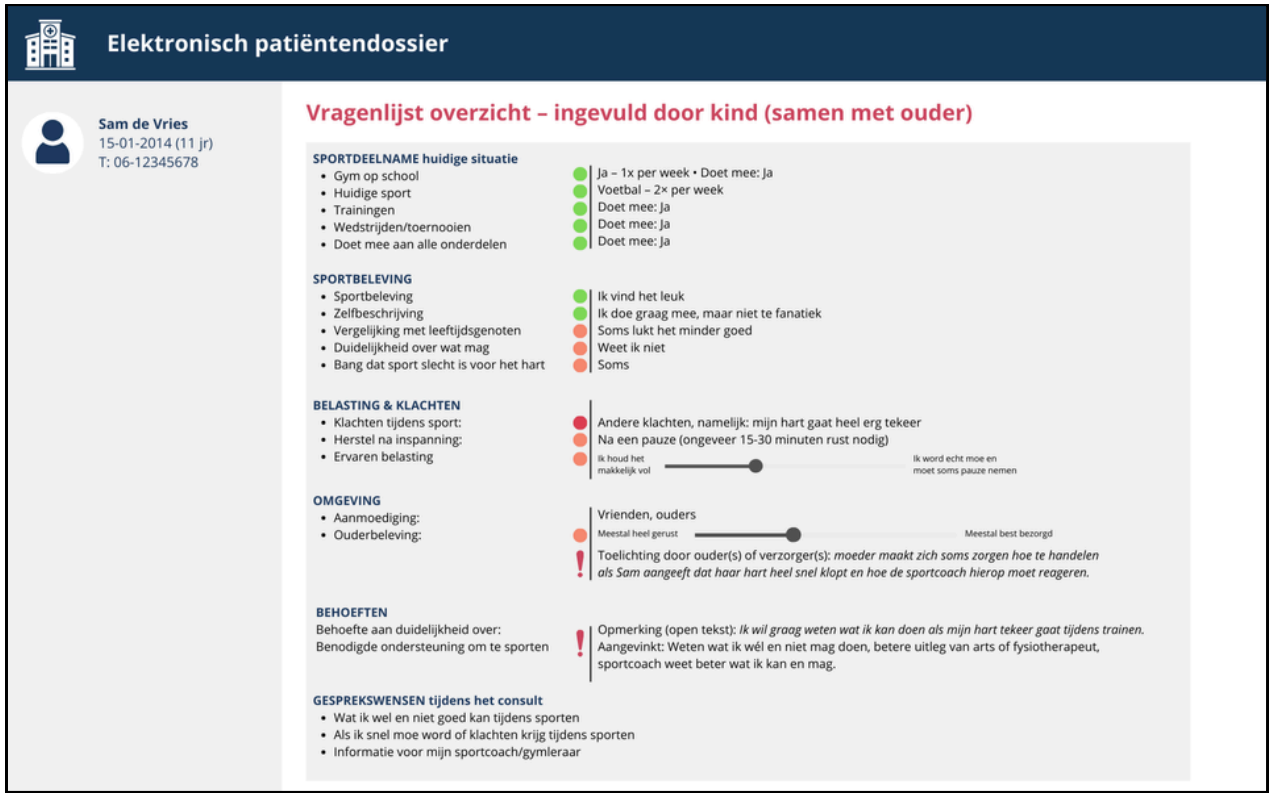
Results shown to cardiologist
Instead of showing the full questionnaire with all answer options, the summary overview presents only selected responses to support efficient consultation preparation. They are grouped into six themes: current sports participation, sports experience, physical load and symptoms, environment, needs, and consultation wishes. These themes are based on the structure of the questionnaire, but have been adapted to support quick interpretation by the cardiologist.

For reference, the original questionnaire sections completed by the child and parent are: About you, Current sports and physical activity, How does sports participation feel?, What would help you to (continue or increase) sports participation?, and What would you like to discuss during the consultation?

Visual elements such as icons and color indicators are used to highlight potential points of attention. Each answer option is assigned a color label in advance, based on its relevance or potential level of concern.

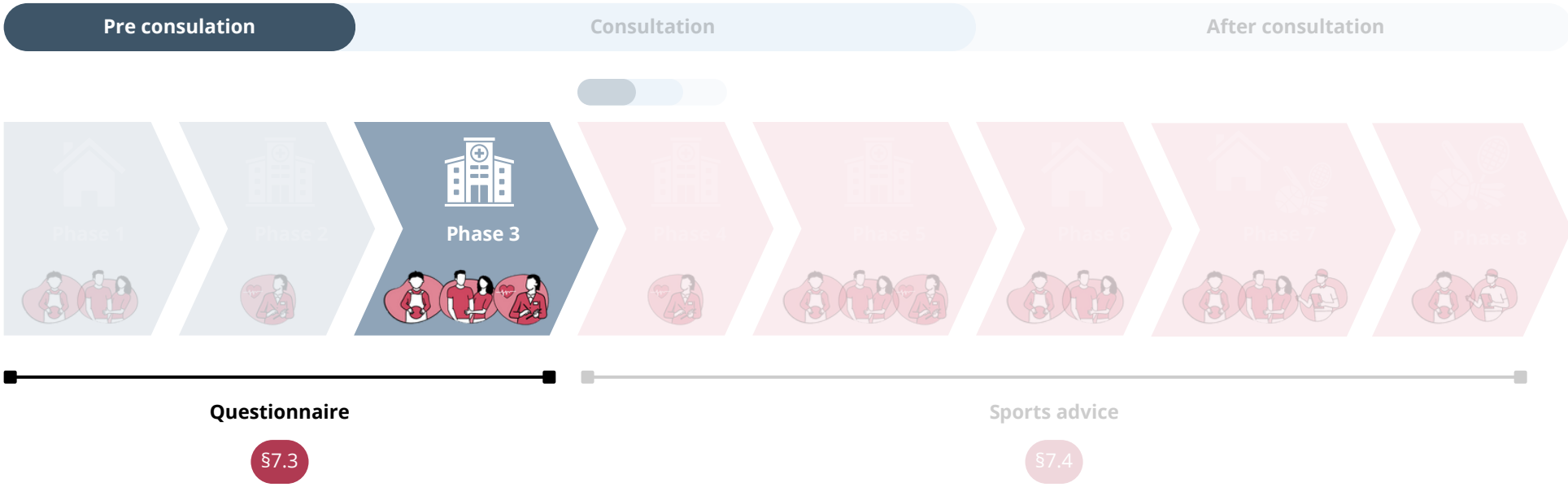
When an option is selected, the corresponding indicator is shown automatically. Green indicates no particular concerns, orange highlights topics that may be useful to discuss, and red indicates answers that require attention. A red exclamation mark is used for specific points that should be addressed during the consultation. These visual cues support prioritization and help guide the conversation.

Figure 37: Interface of the questionnaire in the patient portal



7.3.3 Phase 3: Discussing sports participation during the consultation

The third phase of the final design takes place in the hospital during the consultation between the cardiologist, the child, and the parent.



Scenario

1 Discussing sports participation during the consultation using the pre-consultation questionnaire as a PA related conversation guidance.

Based on the preparation using the pre-consultation questionnaire, the cardiologist can discuss sports participation with the child and address identified points of attention, questions or needs.

Although reviewing the questionnaire requires additional preparation time, many of the questions cover topics that would otherwise be discussed during the anamnesis.

Having this information available in advance allows the limited consultation time to be used more efficiently and shifts the focus from general questions to more specific sports-related concerns and needs.

If specific needs are identified that require additional attention, the cardiologist can also decide to refer the child to appropriate support.

7.4 Sports advice form

Purpose of the sports advice form
The sports advice form supports a clear, consistent and transferable communication of sport-related recommendations between the healthcare, home and sports environment. It provides parents and children with a reliable document to share with sports coaches, and equips coaches with relevant knowledge and information and child-specific points of attention to enable safe and inclusive sports participation for children with CHD.

Positioning within earlier chapters
The underlying basis for the content and structure of the sports advice form have already been discussed in Chapter 6.5.2 1 and are therefore not further elaborated here. After feedback from cardiologists on the content and relevance of the sports advice form, as described in Chapter 6.6.3., a refined version was created, which is shown in this chapter.

Who completes the sports advice form?
The sports advice form is completed by the cardiologist, possibly in collaboration with a nurse specialist. Depending on the cardiologist's workload and workflow preferences, parts of the form may be prepared or supported by another healthcare professional, such as a nurse specialist, after which the cardiologist reviews and confirms the content.

Parents and children can add or adjust for example context-specific information, relevant contact details and preferences for sports guidance. They cannot modify the medical recommendations given by the healthcare professional. However, they can choose which parts of the form they want to share with sports coaches. This division of responsibilities ensures clarity about who contributes what, while allowing each stakeholder to add information from their own expertise and perspective.

This aligns with the design requirements regarding clear roles and responsibilities identified in the earlier research phase.

This division of responsibilities is illustrated in Figure 38, which shows how clinical input, contextual information by parents or children, and automatically generated explanations are combined within the sports advice form. This is further elaborated in the following sections.

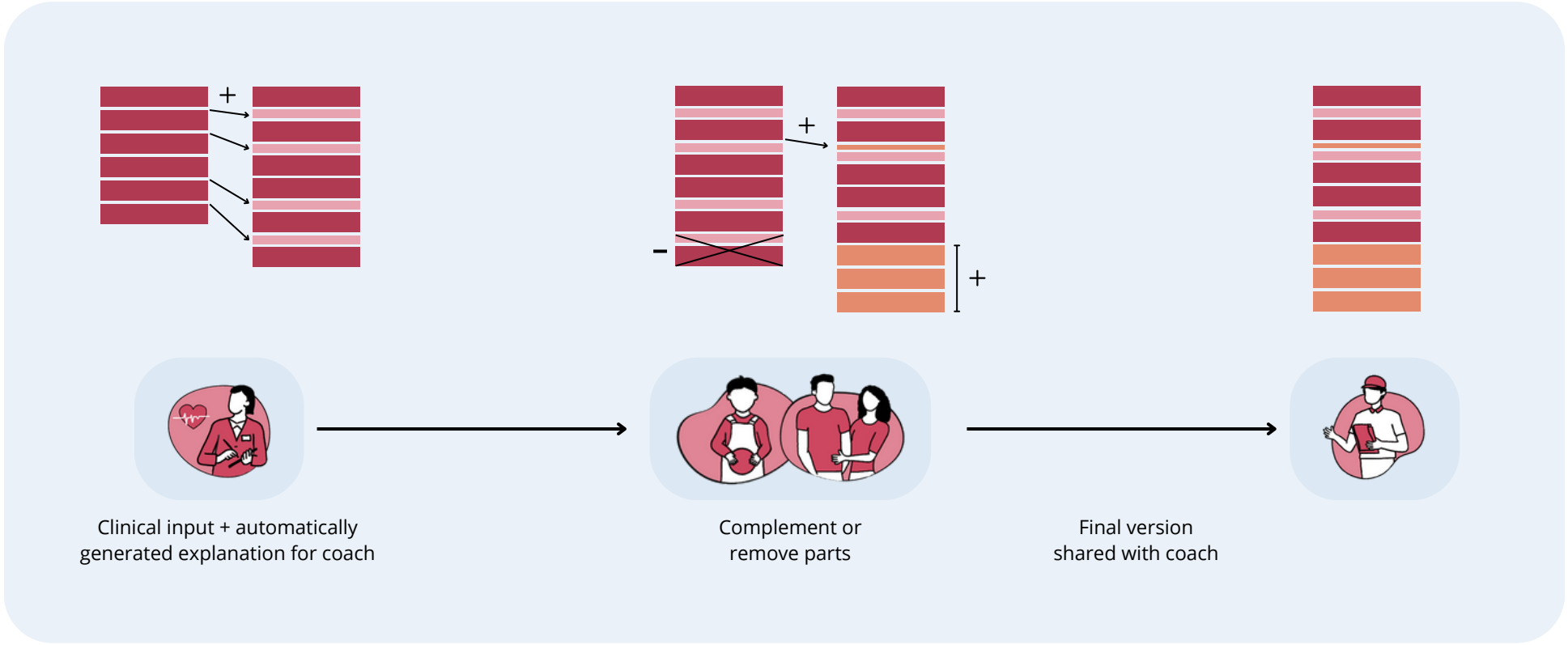
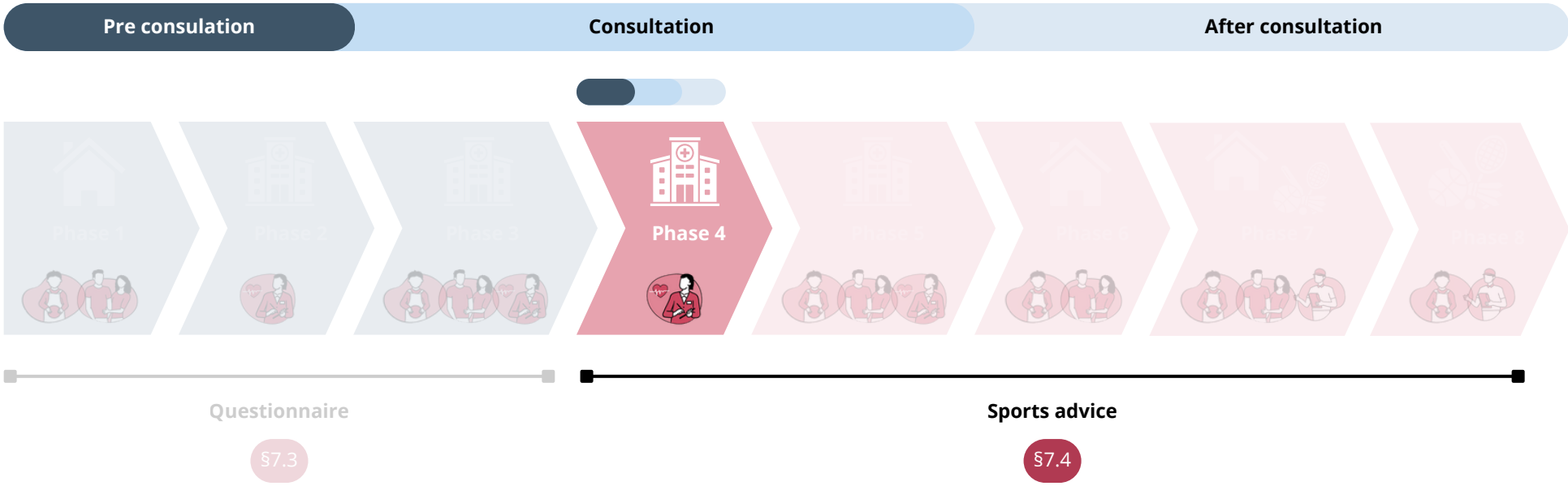


Figure 38: Process of completing and sharing the sports advice form

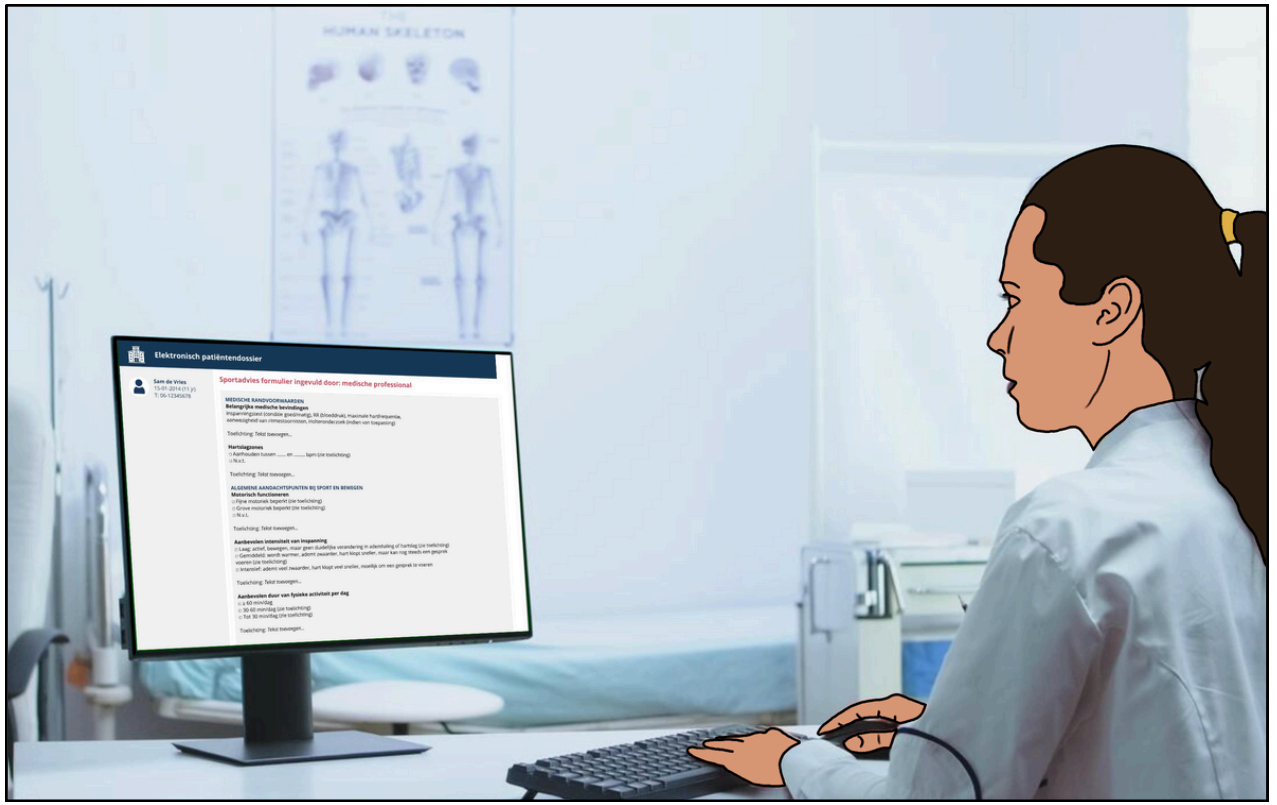
7.4.1 Phase 4: Setting up the sports advice

The fourth phase of the final design takes place in the hospital, where the sports advice is prepared by a healthcare professional.



Scenario and interface illustration

1 Depending on individual workflow preferences, the sports advice form can be partially prepared before the consultation, supplemented and discussed during it, or finalized afterwards. Core medical inputs are either entered by the healthcare professional or automatically pre-filled from the electronic health record system, after which the system generates additional explanatory information for non-medical stakeholders, such as sports coaches or PE teachers. This ensures that the medical advice is supported by accessible explanations, without increasing the documentation burden for healthcare professionals



The figures on the following pages are illustrative example of the sports advice template within the electronic health record. Annotated fields indicate whether information is filled in automatically or entered manually. Some fields are completed as examples, while others are left empty. The examples are shown to illustrate the concept, rather than a medically accurate case. In this visualization, explanations are shown only for static and dynamic exercise as examples, but the final document for sports coaches includes additional explanatory terms.

Elektronisch patiëntendossier

Sam de Vries
15-01-2014 (11 jr)
T: 06-12345678

Sportadvies formulier ingevuld door: medische professional

Pre-filled from the hospital record

BASISINFORMATIE

Naam kind: Sam de Vries
Geboortedatum: 15-01-2014
Medisch behandelaar: Dr. J. Bakker, kindercardioloog
Datum: 16-01-2026

MEDISCHE ACHTERGROND

Medische diagnose: Coarctatio Aortae (CoA)

Optional explanation by the cardiologist (blue text shows an example)

Eventueel korte uitleg voor sportcoach (aandachtspunten, medische geschiedenis):
Deze vernauwing is behandeld (via een operatie), waardoor de bloedstroom nu weer goed kan doorstromen en Sam veilig kan deelnemen aan sport en gym.

Pre-filled from the hospital record

Device geïmplanteerd?
☐ ICD
☐ Pacemaker
☒ Geen

Medicatie
Naam: Enalapril
Dosis: 2 × 5 mg
Tijdstip van toediening: 10:00 en 18:00 uur
Toelichting: *Tekst toevoegen…*

Optional explanation by the cardiologist

Manually selected by the cardiologist

OVERKOEPELEND SPORTADVIES

☐ Geen beperkingen (zie toelichting)
☒ Enkele beperkingen (zie toelichting)

Optional explanation by the cardiologist (blue text shows an example)

Toelichting:
Hoog statische kracht vermijden vanwege mogelijke hypertensie (hoge bloeddruk).

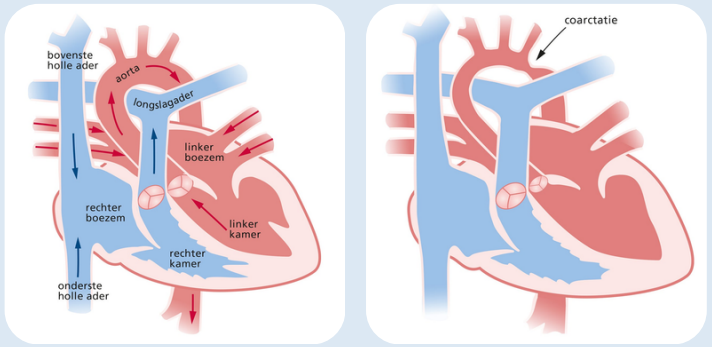
Coarctatie van de aorta

Een coarctatio aortae (ook wel coarctatie genoemd) is een vernauwing van de aorta. Dat is de grote lichaamsslagader die het bloed vanuit het hart door het lichaam vervoert. Het is een aangeboren hartafwijking, maar kan soms pas later in het leven zichtbaar worden. De aandoening is te behandelen met een operatie, een ballondilatatie of het plaatsen van een stent.

Vooruitzichten
De meeste kinderen die behandeld zijn voor coarctatie van de aorta kunnen na behandeling een normaal leven leiden. Bij een aantal kinderen blijft de bloeddruk verhoogd en gebruiken zij hiervoor medicatie. Bij sommige kinderen is later opnieuw een behandeling nodig, bijvoorbeeld als de vernauwing opnieuw toeneemt.

Wat betekent dit in het dagelijks leven en bij sport?
Door de vernauwing van de aorta moet het hart harder werken om het bloed door het lichaam te pompen. Dit kan leiden tot een verhoogde bloeddruk, met name in het bovenlichaam. Na behandeling kan de bloeddoorstroming meestal weer goed verlopen, maar in sommige gevallen blijft extra aandacht nodig, bijvoorbeeld bij inspanning of intensieve sportactiviteiten.
De mogelijkheden voor sport en bewegen verschillen per kind en zijn afhankelijk van hoe de coarctatie is behandeld en hoe het hart functioneert. Daarom is het sportadvies altijd afgestemd op de persoonlijke situatie van het kind.

Bron: UMC Utrecht Wilhelmina Kinderziekenhuis



Een normaal hart | Coarctatie bij een kind

Belangrijk om te weten over **enalapril:**
Enalapril verlaagt de bloeddruk en zorgt dat het hart het bloed beter rondpompt.

Sam de Vries
15-01-2014 (11 jr)
T: 06-12345678

Manually selected + optional explanation by the cardiologist

Sportadvies formulier ingevuld door: medische professional

MEDISCHE RANDVOORWAARDEN

Belangrijke medische bevindingen
Inspanningstest (conditie goed/matig), RR (bloeddruk), maximale hartfrequentie, aanwezigheid van ritmestoornissen, Holteronderzoek (indien van toepassing)

Toelichting: *Tekst toevoegen...*

Hartslagzones
□ Aanhouden tussen ..... en ..... bpm (zie toelichting)
□ N.v.t.

Toelichting: *Tekst toevoegen...*

ALGEMENE AANDACHTSPUNTEN BIJ SPORT EN BEWEGEN

Motorisch functioneren
□ Fijne motoriek beperkt (zie toelichting)
□ Grove motoriek beperkt (zie toelichting)
□ N.v.t.

Toelichting: *Tekst toevoegen...*

Aanbevolen intensiteit van inspanning
□ Laag: actief, bewegen, maar geen duidelijke verandering in ademhaling of hartslag (zie toelichting)
□ Gemiddeld: wordt warmer, ademt zwaarder, hart klopt sneller, maar kan nog steeds een gesprek voeren (zie toelichting)
□ Intensief: ademt veel zwaarder, hart klopt veel sneller, moeilijk om een gesprek te voeren

Toelichting: *Tekst toevoegen...*

Aanbevolen duur van fysieke activiteit per dag
□ ≥ 60 min/dag
□ 30-60 min/dag (zie toelichting)
□ Tot 30 min/dag (zie toelichting)

Toelichting: *Tekst toevoegen...*

Elektronisch patiëntendossier

Sam de Vries
15-01-2014 (11 jr)
T: 06-12345678

Manually selected + optional explanation by the cardiologist

Sportadvies formulier ingevuld door: medische professional

TYPE INSPANNING

Dynamische inspanning
□ Toegestaan
□ Alleen onder voorwaarden (toezicht, begeleiding, etc) (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting: *Tekst toevoegen...*

Dynamische inspanning is beweging waarbij spieren afwisselend aanspannen en ontspannen om beweging te produceren, bijvoorbeeld bij hardlopen, fietsen, zwemmen.

Statische inspanning
□ Toegestaan
□ Alleen onder voorwaarden (toezicht, begeleiding, etc) (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting: *Tekst toevoegen...*

Statische inspanning is het krachtig aanspannen van spieren zonder dat er veel beweging plaatsvindt. De spieren blijven daarbij gedurende een bepaalde tijd aangespannen, bijvoorbeeld bij dragen, duwen of vasthouden. Bij sporten is dit bijvoorbeeld bij gewichtheffen.

Bij sommige hartaandoeningen kan dit type inspanning een andere belasting voor het lichaam geven dan inspanning met beweging. Daarom wordt statische inspanning apart benoemd in medische adviezen.

SPORTCONTEXT

Contact sporten
□ Toegestaan
□ Alleen onder voorwaarden (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting: *Tekst toevoegen...*

Competitieve sporten/ wedstrijd elementen
□ Volledige deelname aan alle competitieve sporten toegestaan.
□ Deelname aan sommige competitieve sporten toegestaan, maar rust wanneer nodig (zie toelichting)
□ Vermijd alle competitieve sporten (zie toelichting)

Toelichting: *Tekst toevoegen...*

Sam de Vries
15-01-2014 (11 jr)
T: 06-12345678

Sportadvies formulier ingevuld door: medische professional

Specific sports are automatically generated from the questionnaire. Recommendations are manually entered by the cardiologist

TOEPASSING OP HUIDIGE SPORTEN (SPORT-SPECIFIEK ADVIES)

Sport	**Aanbevolen deelnamevorm**	**Eventuele aanpassingen of aandachtspunten** (bijv. vermijden van harde tackles, extra rustmomenten, geen competitie elementen)
Gymles op school	□ Volledig □ Met aanpassingen □ Afgeraden	
Zwemmen	□ Volledig □ Met aanpassingen □ Afgeraden	
Voetbal	□ Volledig □ Met aanpassingen □ Afgeraden	

PDF genereren

Who completes the sports advice?
The cardiologist is responsible for completing the medical sections of the sports advice form. These sections focus on medically defined boundaries and recommendations related to sports participation.

Depending on the cardiologist's workflow and time constraints, parts of the form may be prepared or supported by a nurse specialist. For example, by pre-filling fields based on the patient record and integrating responses from the pre-consultation questionnaire to tailor the sports advice to the child's specific sports activities, symptoms, and support needs.

However, final review and confirmation of the medical advice always remain the responsibility of the cardiologist.

Level of abstraction of sports advice in the electronic health record
Similar to the visualization of the pre-consultation questionnaire results, the interface of the electronic health record represents an illustrative example of how the sports advice could be presented within systems such as HiX. Access to HiX is limited to healthcare professionals and the exact interface and level of detail may therefore differ in practice.

The interface focuses on which information is added by the healthcare professional to the sports advice, rather than prescribing how this information would be visually or technically implemented in an electronic health record.

In practice, the exact layout and technical implementation of the sports advice within the electronic health record would depend on the configuration options of the system in use.

Automatically generated explanations for non-medical stakeholders
Based on the information available in the patient record, or selected by the healthcare professional, additional explanation blocks are automatically generated. These information blocks are intended to support non-medical stakeholders, such as parents, children and sports coaches, in understanding the medical context and the practical implications for sports participation and physical activity.

These explanation blocks are generated when the sports advice is compiled into a PDF, instead of during data entry in the electronic health record. In this way, the explanations are linked to the selected medical information, while the clinical workflow for healthcare professionals remains focused on entering medical input.

For example, when a pacemaker or ICD is selected under "Implanted device?", a corresponding explanation will be included in the generated sports advice document. This block provides accessible information about the specific device, complemented with points of attention related to sports and physical activity. The healthcare professional does not need to write this explanation themselves, but the content is automatically linked to the selected medical data. This is illustrated in Figure 39. The same mechanism is also visualized in the scenario.

This approach ensures that the medical input required from healthcare professionals remains limited, while relevant explanations are still provided at the right moment and in the appropriate context.

The same principle is applied to other medical information, such as the diagnosed heart condition and the use of medication. In addition, more explanations are provided for commonly used exercise-related terms, for example static and dynamic exercise, which may be less familiar to non-medical stakeholders.

"See explanation"
For selected options in the sports advice form that indicate (potential) restrictions, the text "see explanation" is added. This is intended to encourage healthcare professionals to provide additional context and clarification regarding the restrictive measure, so the advice would be more meaningful and actionable for sports coaches.

Device geïmplanteerd?

□ ICD

□ Pacemaker

□ Geen

ICD

Een ICD (Implanteerbare Cardioverter Defibrillator) is een klein elektronisch apparaat dat onder de huid wordt geplaatst en verbonden is met het hart via één of meerdere draden. Het apparaat bewaakt continu het hartritme en grijpt in wanneer er een gevaarlijke hartritmestoornis optreedt om een hartstilstand te voorkomen.

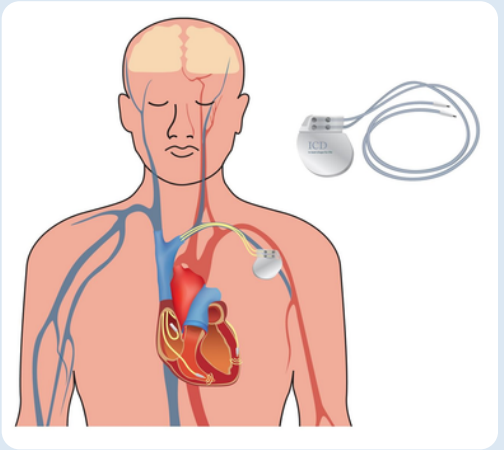
Een ICD heeft meerdere functies:

- Waarnemen: de ICD houdt het hartritme voortdurend in de gaten.
- Corrigeren: bij een gevaarlijk snel of chaotisch hartritme kan de ICD het ritme proberen te herstellen. Dit gebeurt meestal eerst met kleine, snelle prikkels die vaak niet worden gevoeld.
- Schokken: als het hartritme niet herstelt, kan de ICD een elektrische schok geven om het ritme weer normaal te maken.
- Pacemakerfunctie: bij een te trage hartslag kan de ICD ook functioneren als een pacemaker.

Sport en lichamelijk contact

Met een ICD is sporten vaak mogelijk, maar niet alle sporten zijn even geschikt. Sporten met veel lichamelijk contact of zware krachtinspanning kunnen extra risico's geven, bijvoorbeeld door een harde klap op de plek van de ICD of de draden. Daarom is het belangrijk om sportkeuzes altijd af te stemmen met de cardioloog.
Bij sommige sporten kan extra bescherming rond de ICD worden gebruikt om de kans op pijn of beschadiging te verkleinen.

Bron: Hartstichting



Pacemaker

Een pacemaker is een klein elektronisch apparaatje dat onder de huid wordt geplaatst. Het bestaat uit een batterij, een chip en elektrodedraden die contact maken met het hart. Het apparaatje helpt het hart om in een stabiel en voldoende snel ritme te kloppen.

Een pacemaker kan twee dingen:

- Waarnemen: de pacemaker kijkt of er eigen elektrische activiteit van het hart is.
- Stimuleren: als het hartritme te langzaam is, geeft de pacemaker een klein elektrisch seintje waardoor het hart weer samentrekt.

Wanneer het hartritme vanzelf goed loopt, doet de pacemaker niets. Wanneer het hartritme te traag wordt, valt de pacemaker in en zorgt hij dat het hartritme voldoende blijft om goed bloed rond te pompen.

Pacemakerkaartje

Het is belangrijk dat het kind altijd een pacemakerregistratiekaartje bij zich heeft. Op dit kaartje staat welk type pacemaker is geïmplanteerd en wie gecontacteerd kan worden bij vragen of problemen. Dit is vooral handig in onverwachte situaties, bijvoorbeeld bij sportactiviteiten of medische controles.

Sport en lichamelijk contact

Sporten met veel lichamelijk contact kunnen soms worden afgeraden. Bij een harde botsing of klap op de borst kunnen de draadjes die verbonden zijn met het hart beschadigd raken. Bij andere sporten is deelname vaak mogelijk, mits hier rekening mee wordt gehouden.

Bron: Patiëntenvereniging Aangeboren Hartafwijkingen

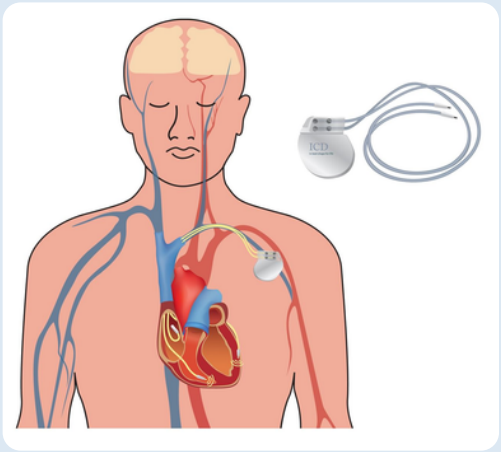


Figure 39: Example of implanted device as automatically generated explanation for non-medical stakeholders

Sources of the automatically generated explanations
The automatically generated explanation blocks are based on predefined content that is linked to selectable fields within the sports advice form. This content is intended to be developed once, reviewed for medical accuracy and subsequently reused.

As mentioned in Chapter 5.2, reliable information about CHDs and physical activity is already widely available online, for example through platforms such as patient associations, hospital websites, and other specialized educational websites. The medical information therefore does not need to be recreated, but the explanations can be derived from or aligned with existing, trustworthy sources.

Medical validation of the explanation blocks remains essential and is positioned within the healthcare organization, ensuring that all information linked to the sports advice form is validated for accuracy and appropriateness.

Integrated in a PDF format
After the sports advice has been completed and confirmed by the cardiologist within the electronic health record, the cardiologist can generate a PDF version of the sports advice. This PDF contains the completed section of the sports advice template by the cardiologist, including the automatically generated explanation fields and extra pages with contextual information fields that can be filled in by parents and children at home. Figure 40 shows the pages of the sports advice form that are generated. The medical background pages are partially filled in for illustrative purposes, while the remaining pages are shown as an empty template intended to be completed by parents and children in the home context.

Figure 40 shows an example of the generated sports advice PDF. The medical background pages are partially filled in for illustrative purposes, while the remaining pages are shown as an empty template intended to be completed by parents and children in the home context.

Preferably, this step takes place within the electronic health record environment. By doing so, the medical content of the sports advice remains under the responsibility and supervision of the cardiologist. This ensures that all medical information and explanatory texts linked to the sports advice can be reviewed, validated, and, where necessary, adjusted by a healthcare professional before sending it to the parent-child platform.

The PDF can subsequently be uploaded to the parent-child platform. This is elaborated on in phase 6.

Figure 40: example of the generated sports advice PDF

SPORTADVIES [NAAM KIND X]

Praktische ondersteuning voor sport en gymlessen

Sport en bewegen zijn belangrijk voor de gezondheid, ontwikkeling en het plezier van kinderen. Dat geldt ook voor kinderen met een aangeboren hartafwijking. Met de passende begeleiding kunnen zij in de meeste gevallen gewoon deelnemen aan sport- en gymlessen.

Dit sportadvies ondersteunt u als sportcoach of gymleraar bij het veilig en inclusief laten deelnemen van [naam kind X] aan sport- en gymlessen. Het biedt houvast bij uw lesvoorbereiding en tijdens sportlessen.

Het sportadvies is opgesteld door de kindercardioloog en aangevuld met informatie van ouders en kind, met als doel om relevante medische en sportgerelateerde informatie op een duidelijke en bruikbare manier over te dragen naar sportcoaches en gymleraren.

In dit document vindt u informatie over de hartafwijking en sportgerelateerde aandachtspunten van [naam kind X]. Het geeft inzicht in wat [naam kind X] kan tijdens sport en waar soms extra aandacht nodig is zodat u weet waar u tijdens trainingen en lessen rekening mee kunt houden.

Hoe gebruikt u dit sportadvies?

- Gebruik dit sportadvies als hulpmiddel bij uw lesvoorbereiding en begeleiding tijdens de training of sportles.
- Het advies is afgestemd op dit specifieke kind en kan per kind verschillen.
- Bij twijfel of vragen: overleg altijd met de ouders of de contactpersoon onderaan dit document.

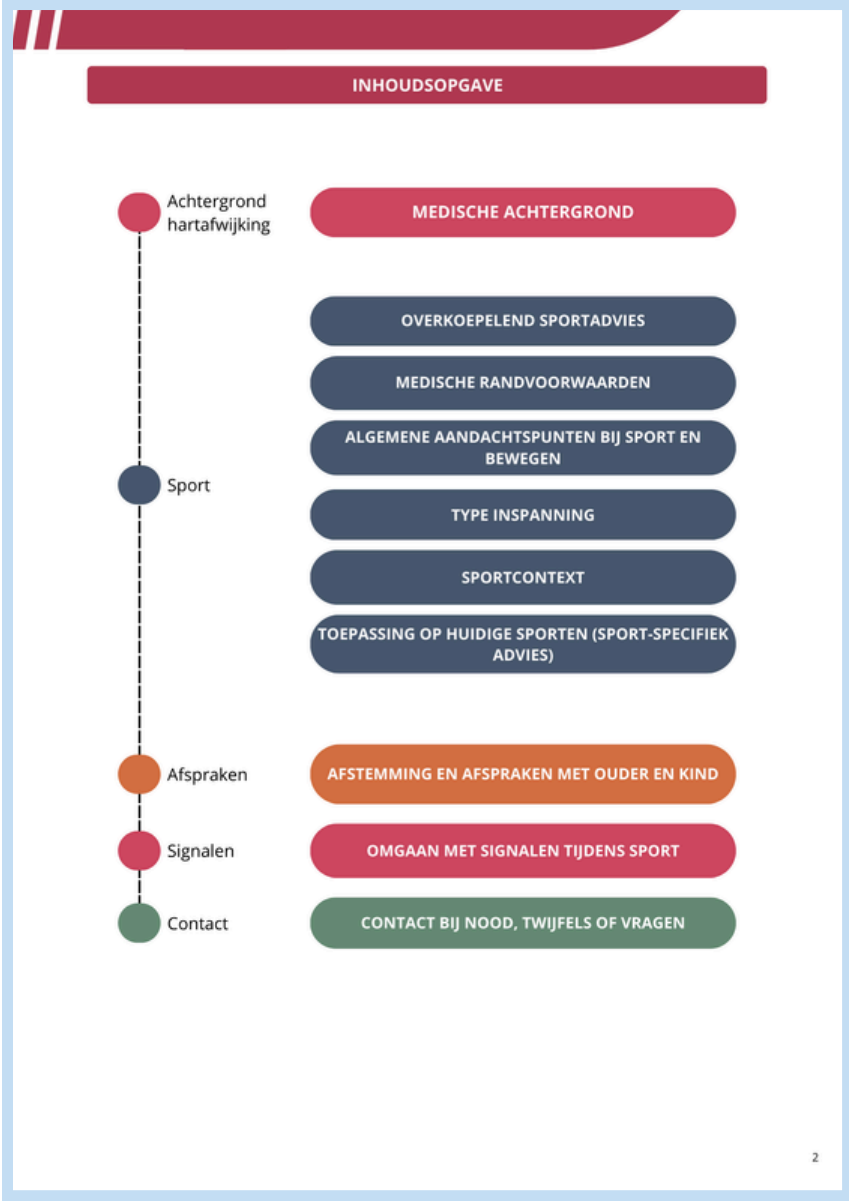
Goed om te weten: dit sportadvies kan in de loop van de tijd worden aangepast. Ouders en/of kind brengen u hiervan op de hoogte.

INFORMATIE OVER [NAAM KIND X]

Naam kind

School/sportclub

Datum laatste update sportadvies



INHOUDSOPGAVE

Example medical background
(illustrative purposes only)

MEDISCHE ACHTERGROND

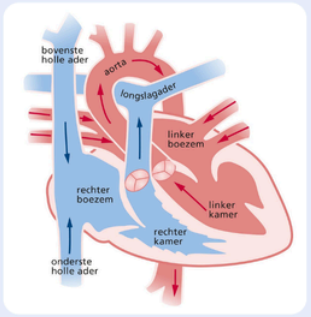
MEDISCHE DIAGNOSE
Coarctatio Aortae

Coarctatie van de aorta
Een coarctatio aortae (ook wel coarctatie genoemd) is een vernauwing van de aorta. Dat is de grote lichaamsslagader die het bloed vanuit het hart door het lichaam vervoert. Het is een aangeboren hartafwijking, maar kan soms pas later in het leven zichtbaar worden. De aandoening is te behandelen met een operatie, een ballondilatatie of het plaatsen van een stent.

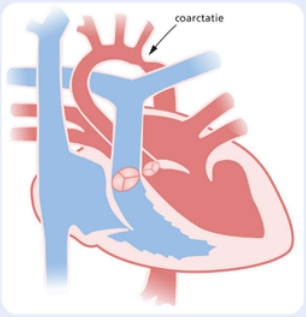
Vooruitzichten
De meeste kinderen die behandeld zijn voor coarctatie van de aorta kunnen na behandeling een normaal leven leiden. Bij een aantal kinderen blijft de bloeddruk verhoogd en gebruiken zij hiervoor medicatie. Bij sommige kinderen is later opnieuw een behandeling nodig, bijvoorbeeld als de vernauwing opnieuw toeneemt.

Wat betekent dit in het dagelijks leven en bij sport?
Door de vernauwing van de aorta moet het hart harder werken om het bloed door het lichaam te pompen. Dit kan leiden tot een verhoogde bloeddruk, met name in het bovenlichaam. Na behandeling kan de bloeddoorstroming meestal weer goed verlopen, maar in sommige gevallen blijft extra aandacht nodig, bijvoorbeeld bij inspanning of intensieve sportactiviteiten.
De mogelijkheden voor sport en bewegen verschillen per kind en zijn afhankelijk van hoe de coarctatie is behandeld en hoe het hart functioneert. Daarom is het sportadvies altijd afgestemd op de persoonlijke situatie van het kind.

Bron: UMC Utrecht Wilhelmina Kinderziekenhuis



Een normaal hart



Coarctatie bij een kind

Toelichting van medische professional:
Deze vernauwing is behandeld (via een operatie), waardoor de bloedstroom nu weer goed kan doorstromen en Sam veilig kan deelnemen aan sport en gym.

Toelichting van ouder:
Tekst toevoegen...

DEVICE GEÏMPLANTEERD?
☐ ICD
☐ Pacemaker
☒ Geen

MEDICATIE
Naam: Enalapril
Dosis: 2 × 5 mg
Tijdstip van toediening: 10:00 en 18:00 uur

Belangrijk om te weten over **enalapril:**
Enalapril verlaagt de bloeddruk en zorgt dat het hart het bloed beter rondpompt.

Toelichting van ouder:
Sam neemt haar medicatie normaal gesproken om 10.00 uur. Wanneer gym op hetzelfde tijdstip valt, is het voor haar prettig als ze hier even kort aan herinnerd kan worden. Ze neemt de medicatie zelf in, een korte reminder is voldoende.

Toelichting van medische professional:

Template of the sports advice form
(not filled in)

Sommige onderdelen bevatten aanvullende uitleg bij gebruikte termen. De betekenis en toepassing verschillen per kind en worden vastgelegd en waar relevant toegelicht door medische professionals.

OVERKOEPELEND SPORTADVIES

ALGEMEEN SPORTADVIES
□ Geen beperkingen (zie toelichting)
□ Enkele beperkingen (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

MEDISCHE RANDVOORWAARDEN

BELANGRIJKE MEDISCHE BEVINDINGEN
Inspanningstest (conditie goed/matig), RR (bloeddruk), maximale hartfrequentie, aanwezigheid van ritmestoornissen, Holteronderzoek (indien van toepassing)

Toelichting van medische professional:

Tekst toevoegen...

HARTSLAGZONES
□ Aanhouden tussen ..... en ..... bpm (zie toelichting)
□ N.v.t.

Toelichting van medische professional:

Tekst toevoegen...

5

ALGEMENE AANDACHTSPUNTEN BIJ SPORT EN BEWEGEN

MOTORIEK, INSPANNINGSNIVEAU EN BELASTBAARHEID

MOTORISCH FUNCTIONEREN

Motorisch functioneren gaat over hoe een kind beweegt en heeft te maken met coördinatie, kracht, balans en uithoudingsvermogen. Bij kinderen met een hartaandoening kan dit per kind verschillen. Sommige kinderen doen motorisch gewoon mee met hun leeftijdsgenoten, terwijl andere kinderen bij bepaalde activiteiten meer moeite hebben.
Deze verschillen kunnen van invloed zijn op hoe een kind meedoet tijdens sport- en gymlessen, bijvoorbeeld in tempo, uitvoering van oefeningen of bij de beoordeling tijdens sportlessen.

□ Fijne motoriek beperkt (zie toelichting)
□ Grove motoriek beperkt (zie toelichting)
□ N.v.t.

Toelichting van medische professional:

Tekst toevoegen...

AANBEVOLEN INTENSITEIT VAN INSPANNING
□ Laag: actief, bewegen, maar geen duidelijke verandering in ademhaling of hartslag (zie toelichting)
□ Gemiddeld: wordt warmer, ademt zwaarder, hart klopt sneller, maar kan nog steeds een gesprek voeren (zie toelichting)
□ Intensief: ademt veel zwaarder, hart klopt veel sneller, moeilijk om een gesprek te voeren

Toelichting van medische professional:

Tekst toevoegen...

AANBEVOLEN DUUR VAN FYSIEKE ACTIVITEIT PER DAG
□ ≥ 60 min/dag
□ 30-60 min/dag (zie toelichting)
□ Tot 30 min/dag (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

6

Template of the sports advice form
(not filled in)

TYPE INSPANNING

DYNAMISCHE INSPANNING
Dynamische inspanning is beweging waarbij spieren afwisselend aanspannen en ontspannen om beweging te produceren, bijvoorbeeld bij hardlopen, fietsen, zwemmen.

□ Toegestaan
□ Alleen onder voorwaarden (toezicht, begeleiding, etc) (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

STATISCHE INSPANNING
Statische inspanning is het krachtig aanspannen van spieren zonder dat er veel beweging plaatsvindt. De spieren blijven daarbij gedurende een bepaalde tijd aangespannen, bijvoorbeeld bij dragen, duwen of vasthouden. Bij sporten is dit bijvoorbeeld bij gewichtheffen.

Bij sommige hartaandoeningen kan dit type inspanning een andere belasting voor het lichaam geven dan inspanning met beweging. Daarom wordt statische inspanning apart benoemd in medische adviezen.

□ Toegestaan
□ Alleen onder voorwaarden (toezicht, begeleiding, etc) (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

7

SPORTCONTEXT

CONTACTSPORTEN
Contactsporten zijn sporten waarbij lichamelijk contact of botsingen kunnen voorkomen, zoals teamsporten of vechtsporten. De hoeveelheid contact kan verschillen per sport en per situatie. Bij sommige hartaandoeningen of bij kinderen met een geïmplanteerd device, zoals een pacemaker of ICD, kan lichamelijk contact relevant zijn om mee te nemen in het sportadvies. Daarom wordt contactsport apart benoemd, zodat kan worden afgestemd of en hoe hiermee rekening kan worden gehouden tijdens sportlessen.

□ Toegestaan
□ Alleen onder voorwaarden (zie toelichting)
□ Vermijden (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

COMPETITIEVE SPORTEN/ WEDSTRIJD ELEMENTEN
Competitieve sporten zijn sportactiviteiten waarbij prestatie of winnen een belangrijke rol speelt. In deze context kan de intensiteit van inspanning hoger liggen en is er vaak minder ruimte voor pauzes of aanpassingen.
Dit wordt meegenomen in het sportadvies om te bepalen of en hoe competitieve elementen passend zijn voor het specifieke kind tijdens sportactiviteiten.

□ Volledige deelname aan alle competitieve sporten toegestaan
□ Deelname aan sommige competitieve sporten toegestaan, maar rust wanneer nodig (zie toelichting)
□ Vermijd alle competitieve sporten (zie toelichting)

Toelichting van medische professional:

Tekst toevoegen...

8

Template of the sports advice form
(not filled in)

TOEPASSING OP HUIDIGE SPORTEN (SPORT-SPECIFIEK ADVIES)

Hieronder een lijst met de sporten waaraan het kind deelneemt en de specifiek daarbij horende aandachtspunten.

Sport (Voorbeeld ingevuld)	**Aanbevolen deelnamevorm**	**Eventuele aanpassingen of aandachtspunten** (bijv. vermijden van harde tackles, extra rustmomenten, geen competitie element)
Gymles op school	□ Volledig □ Met aanpassingen □ Afgeraden	
Zwemles	□ Volledig □ Met aanpassingen □ Afgeraden	
Voetbal	□ Volledig □ Met aanpassingen □ Afgeraden	
...	□ Volledig □ Met aanpassingen □ Afgeraden	

9

AFSTEMMING EN AFSPRAKEN MET OUDER EN KIND

ERVARINGEN VAN KIND EN OUDER

HOE VAAK ERVAART HET KIND KLACHTEN TIJDENS SPORT OF INSPANNING?
□ Zelden
□ Soms
□ Regelmatig

Toelichting ouder/kind

Tekst toevoegen...

ZIJN ER BEPAALDE FACTOREN DIE KLACHTEN KUNNEN INITIEREN?

Toelichting ouder/kind

Tekst toevoegen... Eventuele factoren of voorbeelden

WAT HELPT OF STELT HET KIND GERUST TIJDENS SPORT?
(bijv. eigen tempo bepalen, pauzeafspraak, vriend(in) in het team, teamgenoten op de hoogte brengen)

Toelichting ouder/kind

Tekst toevoegen...

COMMUNICATIE EN AFSPRAKEN

HOE SPREEKT HET KIND HET LIEFST MET DE COACH AF OVER GRENZEN EN PAUZES?
□ Het kind geeft dit volledig zelf aan
□ Het kind geeft dit meestal zelf aan, waarbij de coach ondersteunt
□ De coach let actief mee op signalen en tempo

Toelichting ouder/kind

Tekst toevoegen... Eventuele afspraken of voorbeelden

WILLEN OUDER/KIND GRAAG EEN AFSTEMMOMENT MET DE COACH OM AFSPRAKEN DOOR TE NEMEN OF EEN SPORTLES BIJ TE WONEN?
□ Ja graag (ouder/kind neemt contact op)
□ Niet nodig
□ Misschien later (ouder/kind neemt eventueel op een later moment contact op)

Toelichting ouder/kind

Tekst toevoegen... Eventuele afspraken of voorstellen

10

Template of the sports advice form
(not filled in)

OMGAAN MET SIGNALEN TIJDENS SPORT

Tip!
Het kan handig zijn om deze pagina's te printen of apart op te slaan, zodat u ze tijdens sportlessen snel bij de hand hebt.

Normale reacties tijdens sport

Tijdens inspanning is het normaal dat:

- je hart sneller gaat kloppen
- je buiten adem raakt
- je warm of bezweet wordt
- je moe wordt van het bewegen

Deze reacties horen bij sporten en betekenen niet dat er direct gestopt moet worden.

Hartslag omhoog | Buiten adem | Zweten | Vermoeidheid

Wanneer even rusten of stoppen

Neem een korte pauze wanneer je:

- duizelig wordt of je licht in je hoofd voelt
- bleek of klam wordt
- een blauwe tint van de huid hebt

Na een korte rust kan meestal rustig weer verder worden gesport.

Duizelig | Bleek/klam | Blauwe huid

Noodsituatie (alleen bij bewustzijnsverlies)

In het geval dat het kind flauwvalt of het bewustzijn verliest:

- bel 112
- start (indien bekend) basisreanimatie
- gebruik een AED als deze aanwezig is

Dit noodplan is alleen bedoeld voor situaties waarin iemand niet meer aanspreekbaar is.

Flauwvallen/ bewustzijnsverlies

CONTACT BIJ NOOD, TWIJFELS OF VRAGEN

Tip!
Het kan handig zijn om deze pagina's te printen of apart op te slaan, zodat u ze tijdens sportlessen snel bij de hand hebt.

CONTACTPERSOON 1

Naam	*Tekst toevoegen...*
Relatie tot het kind	*Tekst toevoegen...*
Telefoon	*Telefoonnummer toevoegen...*
E-mail	*Emailadres toevoegen...*

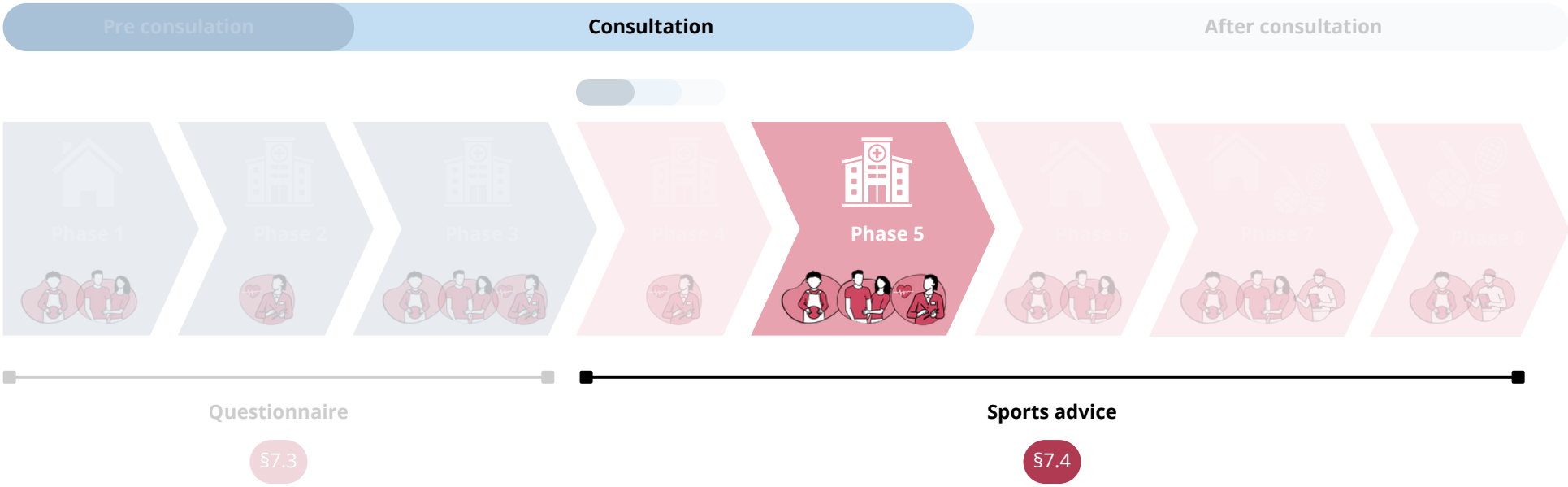
CONTACTPERSOON 2

Naam	*Tekst toevoegen...*
Relatie tot het kind	*Tekst toevoegen...*
Telefoon	*Telefoonnummer toevoegen...*
E-mail	*Emailadres toevoegen...*

IN NOODGEVALLEN: BEL 112

7.4.2 Phase 5: Reviewing and aligning the sports advice (optional)

The fifth phase of the final design takes place during the consultation and focuses on briefly reviewing and aligning the sports advice with the child and parent.



Scenario

1 The healthcare professional may briefly review key elements of the sports advice together with the child and parent during the consultation. This allows for clarification and alignment, to ensure that the advice is understood and agreed upon.
This step is optional and may be skipped or shortened depending on consultation time, preferences and needs of the healthcare professional, child and parent.

In this phase, key elements of the sports advice are discussed to ensure that the recommendations are understood and agreed upon.

This phase is optional. Insights from the co-creation/feedback session with cardiologists showed variation in clinical practice. While one cardiologist preferred to complete the sports advice before or after the consultation, another cardiologist preferred to prepare it in advance and discuss it during the consultation.

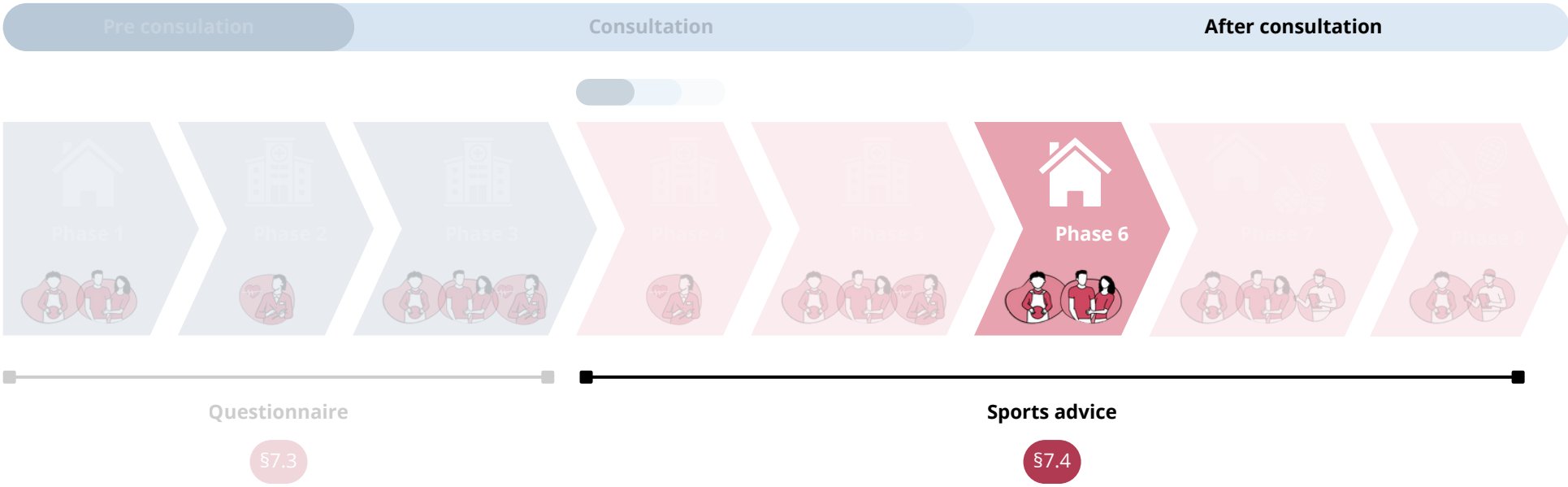
Depending on available consultation time, workflow of the cardiologist, and the needs of the child and parents to discuss it, this step may be shortened or skipped.

In cases where the sports advice is already clear, further explanation may not be necessary. When additional explanation is needed, families may be referred to a nurse specialist for further clarification or to a sports physician or physiotherapist if additional guidance or supervision is required.

After the consultation, the sports advice is made available for further review by the child and parent at home. At the consultation, they are informed that they will receive a notification via their patient portal when the sports advice is available, and that they can review and complement the advice within the parent-child platform. This transition to the home context is further explained in the next phase.

7.4.3 Phase 6: Reviewing and complementing the sports advice at home

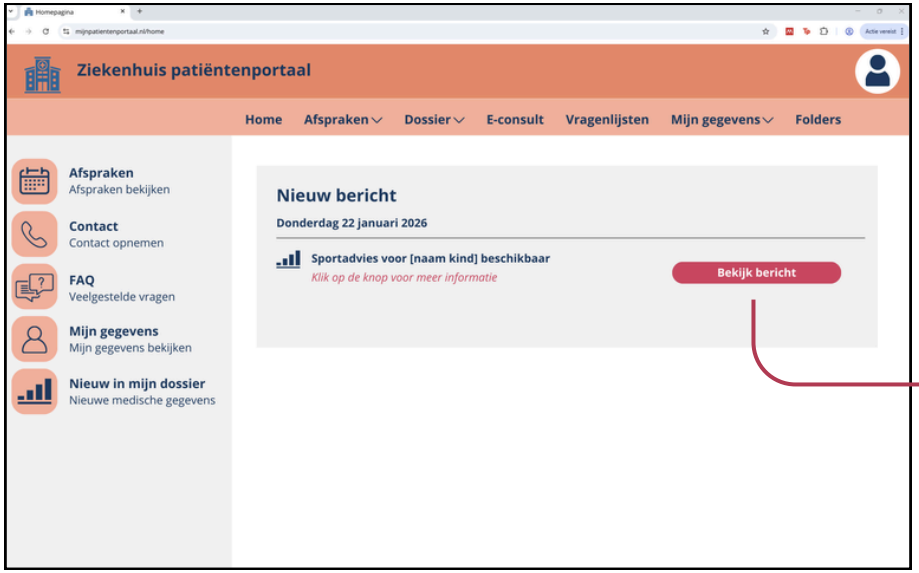
The sixth phase of the final design takes place in the home context, where parents and children review and complement the sports advice after the consultation.

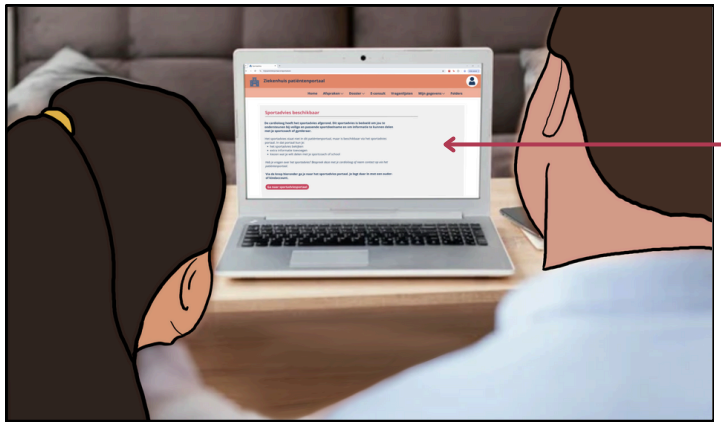


Scenario and interface illustration

1 After the sports advice form has been finalized by the cardiologist and sent to the child parent platform, parents and children receive a notification in the patient portal informing them that the sports advice is available.

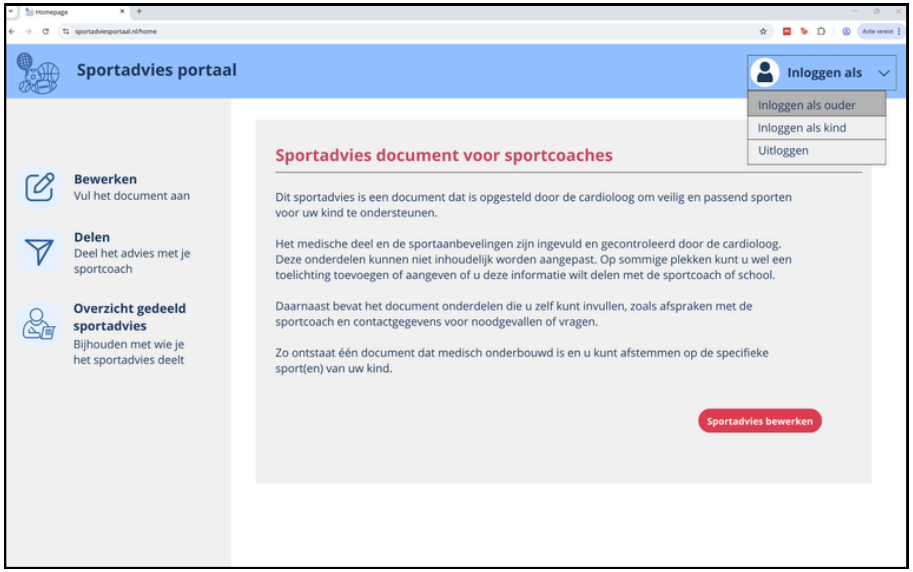
2 Through this notification, they are directed to a message page explaining that the sports advice can be accessed and complemented via the parent-child platform, including a button that guides them to the platform.





Source: Mockup Hunt, edited by author

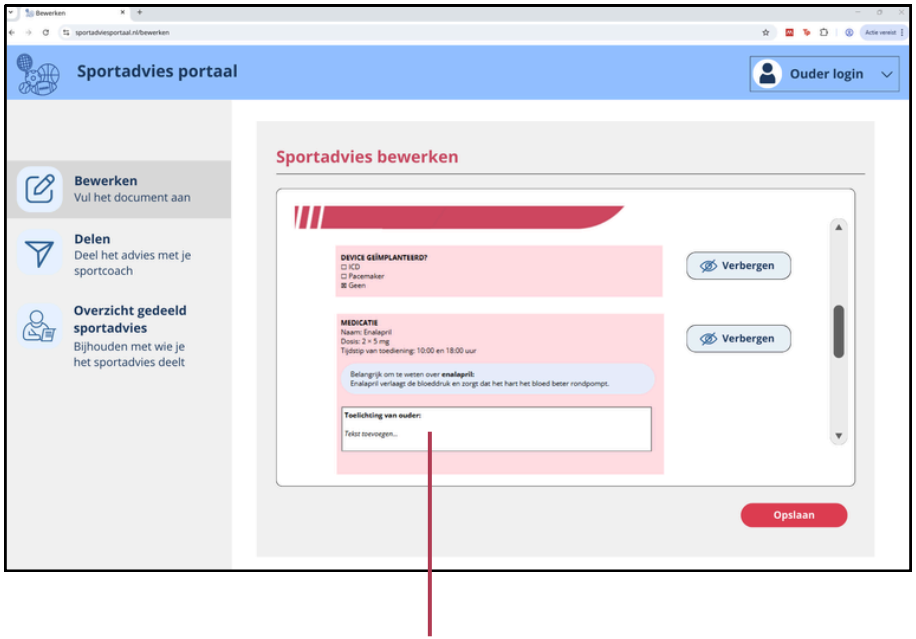
3 Within the parent-child platform, parents and children can review the sports advice.



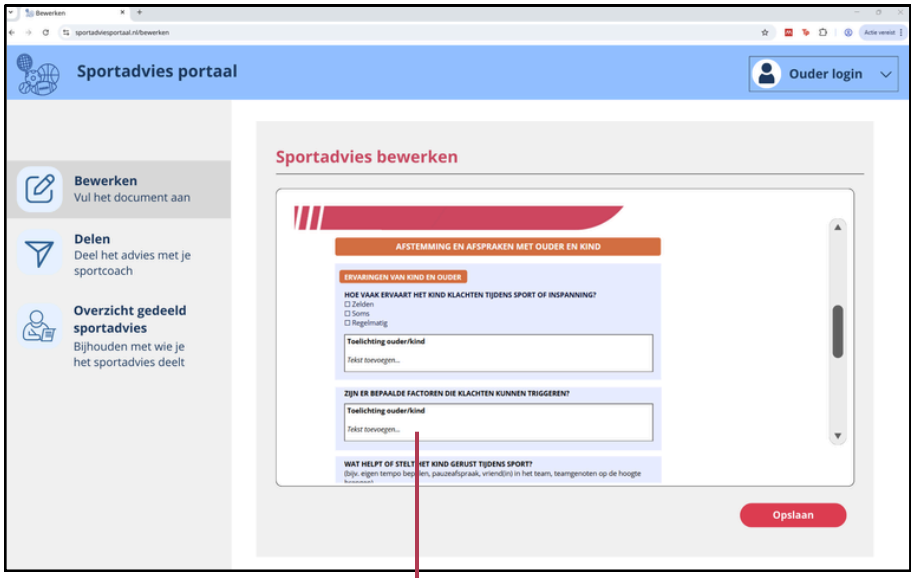
Although both parents and children can access the platform, the following scenario and interface illustration are shown from the parent's perspective.

Source: Mockup Hunt, edited by author

4 Parents and children can add contextual information intended for the sports environment, such as clarifications, practical agreements, or contact details. They can also decide which information they want to be be visible in the version intended for the sports environment.



For example explanation of medication use



Contextual information, for example factors that may trigger symptoms

Who can review and complement the sports advice?
Parents and children each have individual logins for the platform. They can decide whether the sports advice is reviewed and complemented by the parent, the child, or together. This flexibility accommodates differences in the child's age, level of autonomy, and personal preferences.

Editing and complementing the sports advice
The parent child platform allows parents and children to view the sports advice form and add or adjust information intended for the sports environment.
Parents and children can add context-specific information to the sports advice that has been completed by the healthcare professional. This allows them to clarify how the medical recommendations apply in their daily sports practice. An example of this integration of information is shown in Figure 41, where medical input, contextual clarification by child or parent, and automatically generated explanations are combined within one section of the sports advice form.

The platform also includes dedicated sections that are specifically intended for input from parents and children, such as Alignment and agreements for the sports practice and Contact in case of emergencies, doubts, or questions. Within these sections, parents and children can add practical agreements, preferences for sports guidance, and relevant contact details.

While the medical and sport-specific recommendations themselves cannot be modified, parents and children can decide which parts of the sports advice are visible in the version shared with sports coaches.

This selective visibility supports privacy, gives parents and children control over what information is shared and with whom, and allows families to tailor the information transfer to the needs of the specific sports context.

This directly addresses the design requirement that parents remain central actors in the communication chain, with control over which stakeholders receive which information about their child's condition and sports participation.

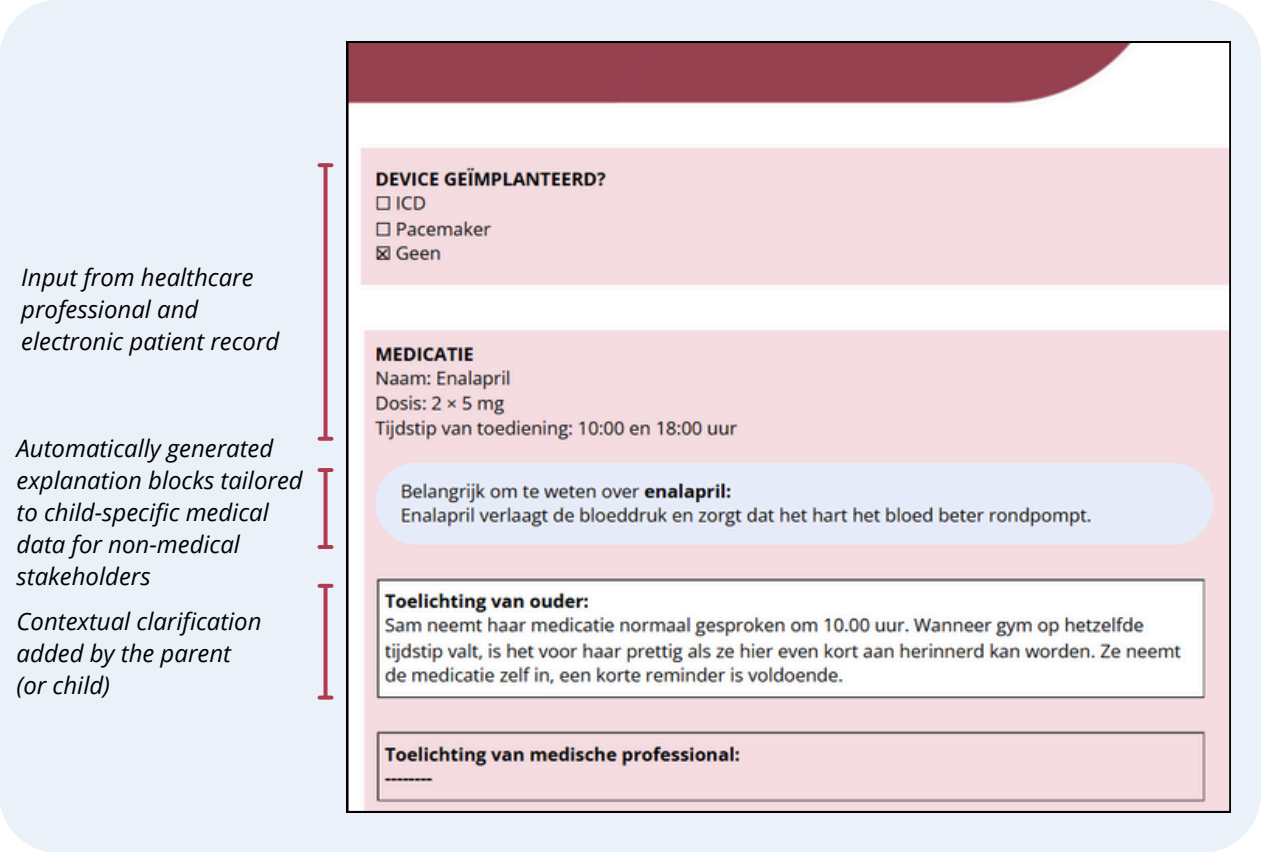


Figure 41: Example of a sports advice form section showing the combination of clinical input, contextual information by parents or children, and automatically generated explanation blocks tailored to child-specific medical data for non-medical stakeholders

Limiting parental input in sport-specific recommendations

Parents and children are intentionally not able to add or modify content in the sport-specific recommendation sections of the document. These sections are completed exclusively by the cardiologist and supplemented with accessible explanations for the sports environment.

This design decision is based on insights from interviews and literature, which showed that parents sometimes tend to be extra cautious when it comes to sports participation of their child. When a cardiologist indicates that a child can safely participate in sports, possible additional cautious comments from parents could unintentionally create mixed messages for sports coaches and lead to unnecessary restrictions in practice.

By ensuring that sport-specific recommendations originate solely from the cardiologist, the design provides clear, consistent, and medically grounded guidance towards the sports environment. However, parental input is intentionally used in other parts of the document, such as providing contextual information, practical agreements, and contact details, where this input adds value without affecting the clarity of the medical advice.

Ownership and management of the parent-child platform

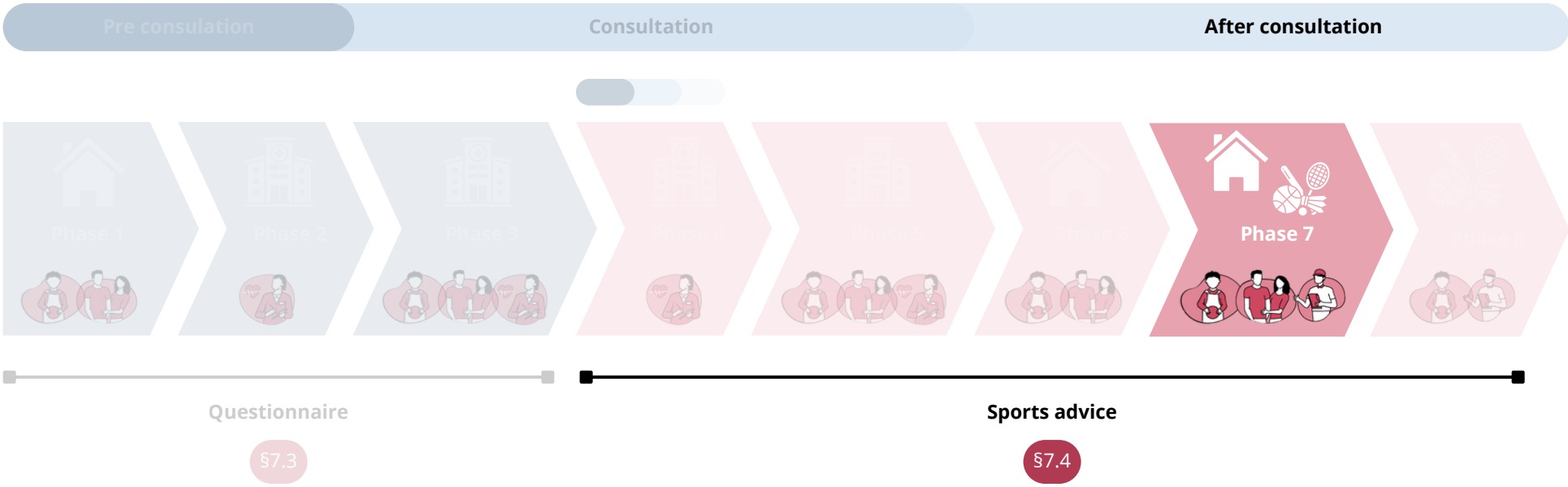
The parent-child platform is designed as a standalone system. Parents and children do not have access to HiX, which is used by healthcare professionals to complete the medical part of the sports advice. Although it would be possible in theory to add a function for parents and children to edit the sports advice within existing patient apps, this would require significant modifications to those apps. In addition, hospitals use different patient apps, which means that a new function would need to be developed and maintained separately for each app.

For this reason, a standalone platform was chosen that can be used independently of hospital-specific patient apps. The platform provides a simple and accessible way to supplement the sports advice without requiring parents and children to edit PDF files themselves, use software they may not be familiar with, or exchange separate documents.
Ownership and operational management of this platform is not defined within this graduation project, but could be assigned to an external organization.

The medical content of the sports advice is created and validated within the hospital and exported from HiX as a completed document. Within the parent-child platform, this medical content is read-only and cannot be modified. The platform is used only to facilitate parents and children in reviewing the sports advice, adding contextual information, and preparing the document for sharing with the sports environment.
Due to the sensitive nature of the information available on the platform, it is assumed that strict requirements for data security and privacy are met.

7.4.4 Phase 7: Sharing the sports advice with the sports environment

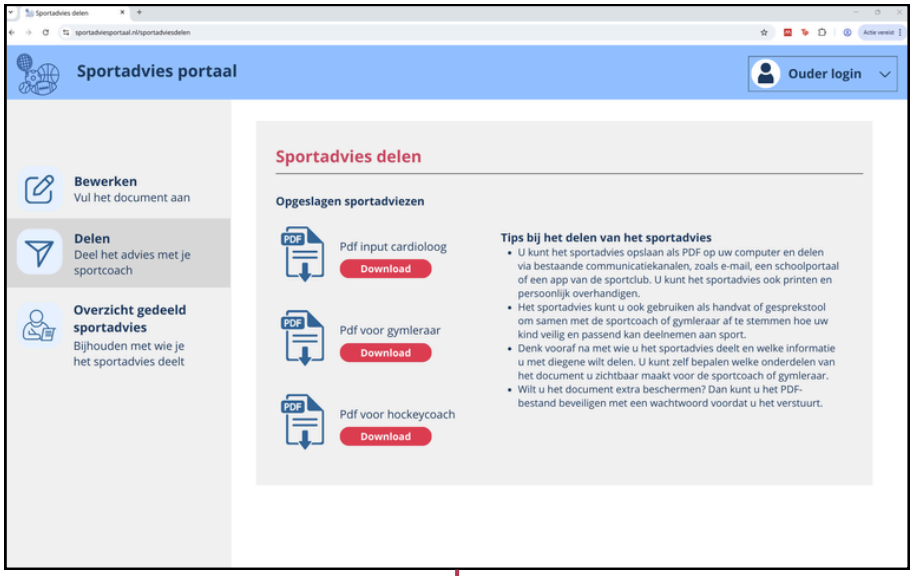
The seventh phase takes place at home or at the sports club between the child, parent, and sports coach.

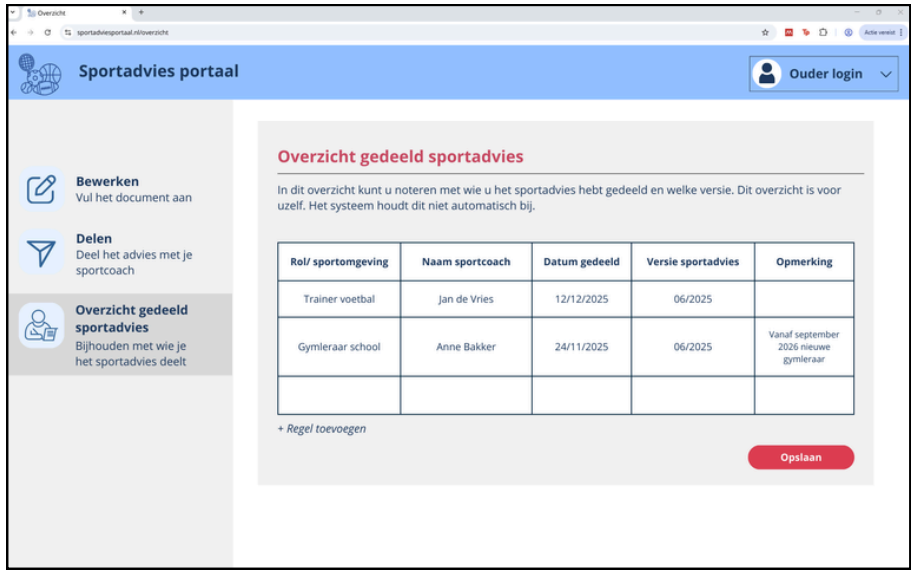


Scenario and interface illustration

1 Parents and children can store multiple versions of the sports advice and share these with sports coaches via existing communication channels.

2 Within the parent-child platform, parents and children can manually keep track of which version of the sports advice has been shared with which sports coach.





Source: Mockup Hunt, edited by author

Multiple stored versions of sports advice
The platform allows parents and children to store multiple versions of the sports advice. This enables them to maintain control over which information is shared with which sports coach, particularly when a child participates in multiple sports. Parents and children can choose to hide certain information for one coach, while retaining it for another, depending on the context and relevance.

Tips before sharing the sports advice
The platform provides parents with guidance on sharing the sports advice. These tips address how the advice could be shared, digitally or in printed form, how it should be used in practice, and raises awareness among parents about what information they share and with whom. It also includes a suggestion for privacy-supporting measures, such as adding a password to the document.

Overview of shared sports advice
The platform also includes an overview of which version of the sports advice has been shared with which sports coach at what moment. Parents and children can manually maintain this overview within the platform to support oversight across different sports contexts. This design decision was informed by interview findings indicating that parents and children are not always aware of what information has been shared and with whom.

Timing and frequency of sharing
The platform does not automatically track when a child starts a new sport or enters a new school year. Responsibility for deciding when and how often the sports advice is shared therefore remains with parents and children. After each medical consultation, an updated sports advice document is sent by the cardiologist, which may or may not differ from the previous version. Parents and children can then decide whether this updated advice needs to be shared again.

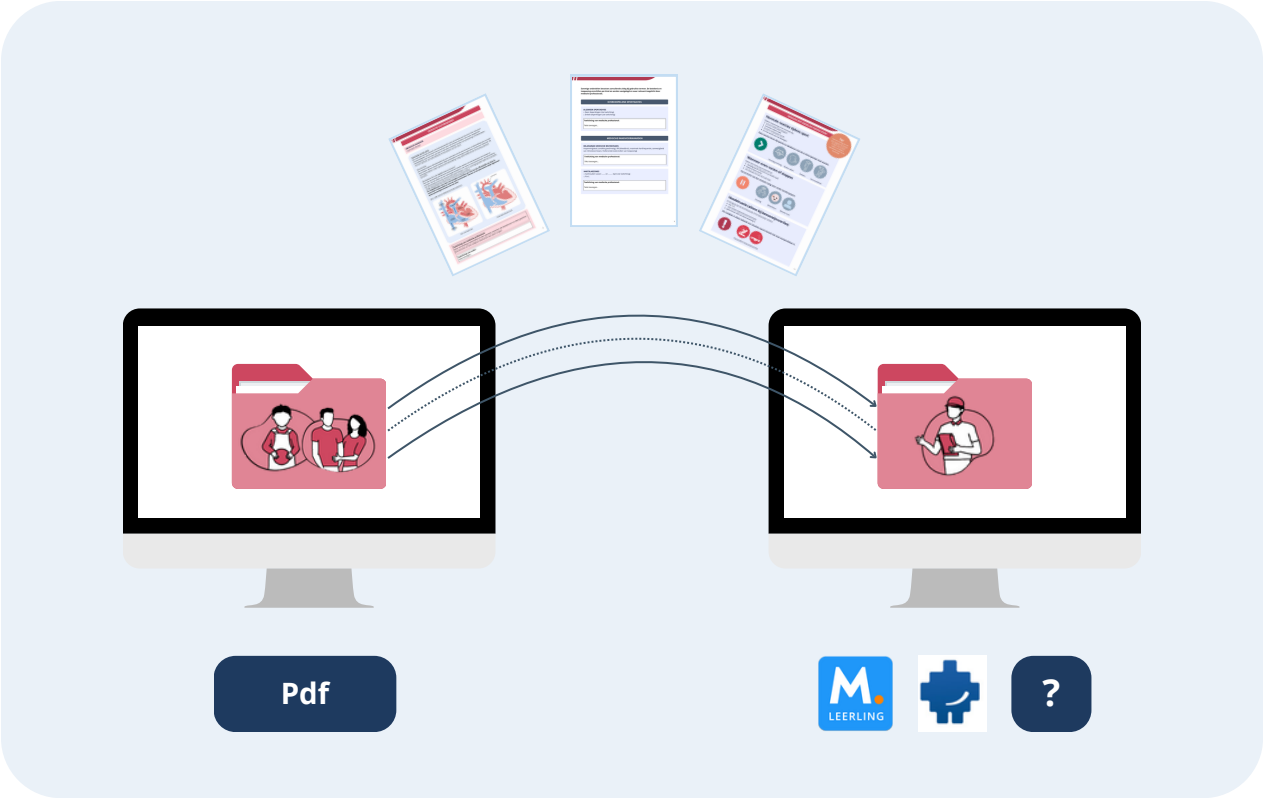
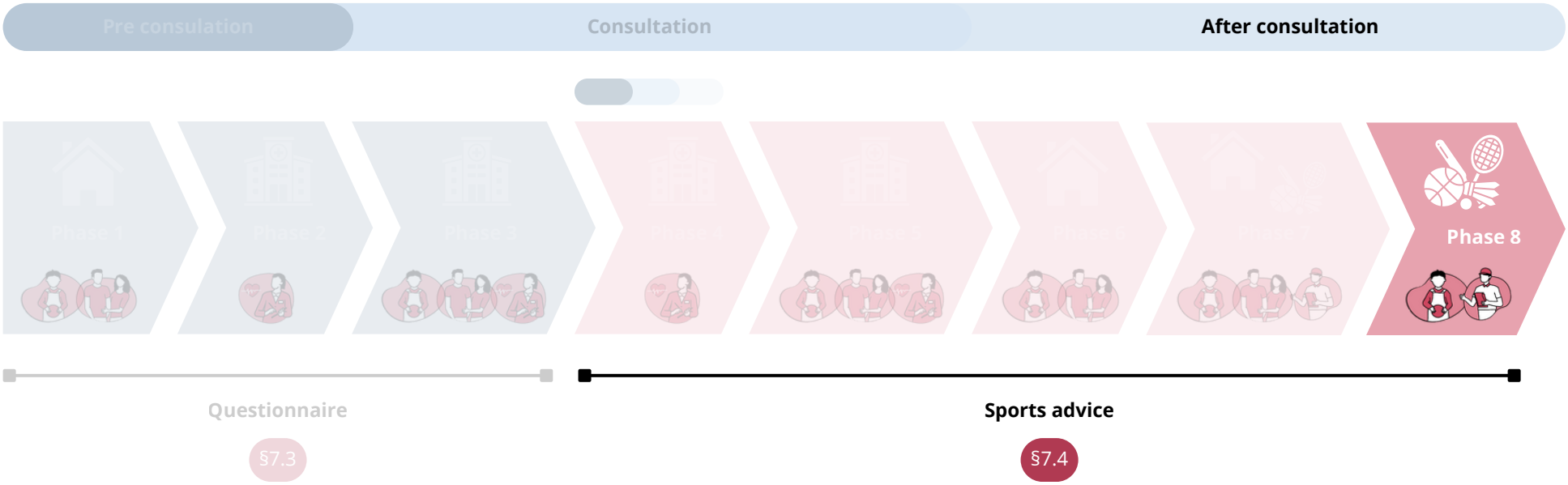


Figure 42: Sharing the sports advice with the sports environment via existing communication channels (when shared digitally)

7.4.5 Phase 8: Applying the sports advice in practice

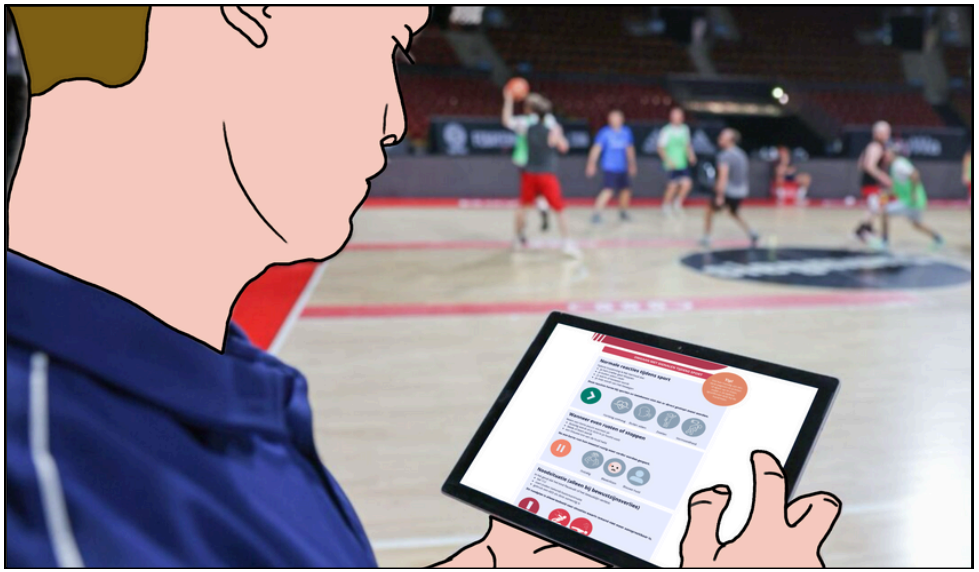
The final phase of the concept is the practical application of the sports advice by the sports coach.



Scenario

1 The sports coach could use the sports advice to prepare activities and make informed decisions in practice.

Preparation of the sports lesson using the sports advice.



Referring to the sports advice during the lesson when uncertainties arise, for example about what is allowed or how to recognize warning signs.

Full presentation of the sports advice
In contrast to the summary of the questionnaire results for the cardiologist, which is presented as concisely as possible, the sports advice for sports coaches shows all sections fully. This is shown in Figure 43. This includes both the selected and non-selected answer options, including situations in which activities are allowed or when a child has no restrictions at all.
This design choice was made deliberately to prevent sports coaches from having to interpret or infer what is or is not recommended based on missing information. By explicitly stating what a child is allowed to do, as well as which alternative recommendations a cardiologist could have given but did not select, the design helps prevent sports coaches from acting based on assumptions or on experiences with other children with CHD who do have restrictions.

Explanation of terms
Bridging the gap between the medical and sports domains in terms of information and understanding was an important element in this design project. Interviews showed that sports coaches do not expect detailed instructions, but do need general, understandable information that helps them assess situations. For this reason, additional explanations were provided for specific terms used in the sports advice, as illustrated in Figure 43.
By providing context and clarification for certain terms, they can become meaningful for sports coaches and clarify why certain activities are or are not appropriate for the child. Based on this information, combined with their own expertise and experience, sports coaches can make informed decisions. This allows them to retain their professional autonomy to adapt activities within their own lesson preparation, while being able to make choices with more confidence.

Figure 43: Pages of the sports advice PDF, including selected and non-selected options, and contextual explanations of medical and sports-related terms.

Image source: photograph taken during a test session

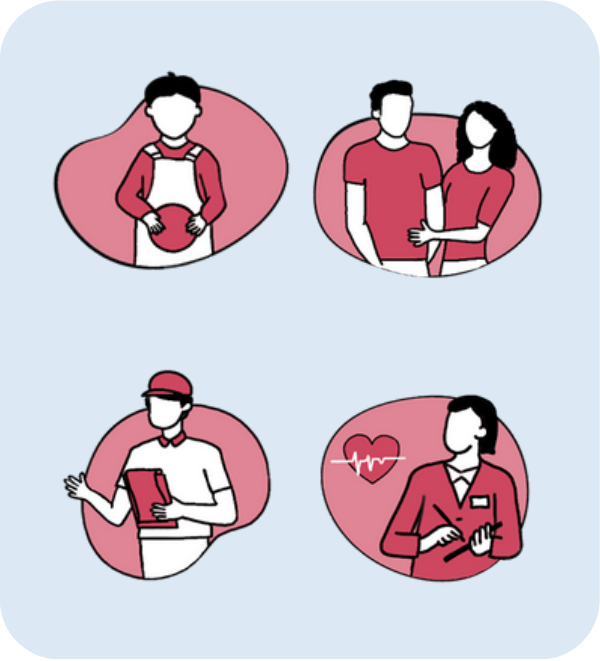
8

Validation & evaluation

This chapter describes the validation and evaluation of two components of the final concept. The sports advice and the parent-child portal were tested with users to assess their comprehensibility and applicability in practice.

8.1 Evaluation scope

This chapter describes the evaluation of two selected components of the final design. The evaluation focuses on assessing the comprehensibility and practical applicability of the concept. Given the limited duration of this graduation project and the dependence on external stakeholders, a deliberate scope was defined for what parts of the final design were and were not included in tests with stakeholders.



Within the scope of the evaluation

The evaluation focuses on two components of the concept that could realistically be tested with representative users within the available time and resources:

The sports advice in practice (sports coach test)
This component is evaluated to examine whether sports coaches understand the sports advice document, whether they perceive the information as relevant and useful, and whether it provides sufficient guidance to support children with CHD in an appropriate manner during sports activities.

Usability of the parent-child sports advice portal
The usability of the parent-child portal is tested to assess whether users understand how the portal works, which actions they can perform, and how they can supplement, adjust, and share the sports advice with the sports coach.

Outside the scope of the evaluation

Not all components of the concept could be tested within this graduation project. The following components fall outside the scope of this evaluation:

Comprehensibility of the questionnaire for children
Testing the questionnaire with children themselves was ultimately not feasible within the project period. However, during an earlier co-creation/feedback session, expert feedback from cardiologists was used to make the wording of the questions as child-friendly as possible. However, the questionnaire was not tested with the final user group.

Integration and interaction within the electronic patient record (HiX)
The presentation of the questionnaire results, the completion of the sports advice by the healthcare professional and the associated ease of use and required time, depend in practice on the configuration options within HiX. However, access to HiX and the technical implementation are outside the scope of this graduation project, so this part has not been evaluated as an usability test. However, the content of the sports advice has been tested on a paper version in a co-creation/feedback session with cardiologists, looking at usability, clinical relevance, and feasibility. Based on this session, the sports advice has already undergone an iteration.

8.2 Sports advice in practice

8.2.1 Goal

The goal of this test is to investigate whether the sports advice document for sports coaches is understandable, relevant, and applicable in the sports practice. The test focuses on how sports coaches interpret the information in the sports advice, whether the explanations of terms are clear, and whether the document provides sufficient guidance to appropriately guide children with CHD during sports activities.

8.2.2 Method

Participants
The test was conducted with two sports coaches who have experience in supervising children in a sports context, but no experience with children with CHD. These participants could be future representative end users of the sports advice document.

Materials
During the test, the participants were shown a sports advice form that had been partially filled in as an example. Some fields had been filled in based on a fictional case, for example the medical part, while the actual sports advice had been left blank. The sports advice did not contain any detailed medical sport-related recommendations. This choice was made deliberately to prevent the evaluation from focusing too much on the medical content rather than on comprehensibility and interpretation by sports coaches.

Session procedure
The participants were given a brief explanation of the purpose of the test and it was explicitly stated that the sports advice form did not represent a real medical case, but was intended to examine how they would interpret and apply the information in practice.

The sports coaches were shown the sports advice document and were free to browse through it. They were asked to share their first impressions, including what they thought the purpose of the document was and how they would approach the document when reading it.

Then there was zoomed in on specific parts of the sports advice, such as certain terms that were explained and the possible response options given by the cardiologist, such as allowed, only under certain conditions, and avoid. Participants were asked how they would interpret these terms and how they would influence their actions during sports activities.

Using a short example situation focused on one specific part of the sports advice, it was discussed how the sports coaches would apply the advice during a training session. They were asked whether they felt sufficiently supported by the document to make comfortable choices about appropriate sports activities.

Finally, participants were asked whether they felt any information was missing, whether they found any parts unclear, if they knew what to do in case of doubt or emergency, and to what extent the sports advice gave them confidence and guidance in coaching children with CHD.

8.2.3 Analysis

The results of the test with the sports coaches were analyzed qualitatively based on observations and verbal responses from participants during the test sessions. During the sessions, the participants were asked to think aloud in order to gain insight into their interpretations and motivations. These were noted down on paper.

The insights were used to create recommendations for the sports advice form.

Figure 44: Testing the sports advice form with a sports coach

8.2.4 Results

Comprehensibility and purpose of the sports advice
Both sports coaches indicated that the purpose of the sports advice was clear. After reading the document, they understood what to take into account during sports classes when a child with CHD participates. In addition, it was clear to both participants who they could contact in case of questions or doubt.

The division of roles and responsibilities was also experienced as clear. One sports coach indicated that she appreciated that the information was provided in a “ready-to-use” manner and that it was explicitly stated when parents and/or the child would contact the sports coach themselves. The other sports coach confirmed this and indicated that this clarity was helpful and prevented uncertainty about who should take the initiative.

Interpretation of medical information and explained terms
In the sports advice form used during the test, an example explanation from a medical professional was included. This example illustrated the type of information that could be shared with sports coaches and was based on guidance in the explanation field for cardiologists when filling in the sports advice in HiX: “Optional explanation for sports coach (points of attention and medical background)”. During the think-aloud process, both participants indicated that they appreciated knowing whether the heart defect had been treated or not, as was described in this specific example.

One sports coach specifically mentioned the explanation of the medication example about enalapril as helpful, but also indicated that she would prefer a more explicit explanation of what the use of this medication means for sports participation.

The explanations of the sport related terms were also experienced as valuable. Both participants indicated that they were not familiar with all of the terms used, but found the explanations clear and understandable. As one participant stated:

“De wat en waarom zijn duidelijk.”

Practical applicability and guidance
The checkbox options “allowed", ”only under conditions”, and “avoid” were interpreted as sufficiently clear by both participants. One participant indicated that he would interpret “only under conditions” as being extra alert during the activity and monitoring the child more closely, but not necessarily restricting the activity.

Both sports coaches indicated that the sports advice provided them with guidance in supporting children with CHD. One sports coach described the added value as follows:

“Als je alleen weet dat een kind een aangeboren hartafwijking heeft, ben je al snel extra voorzichtig. Met dit document wordt duidelijker wat wel en niet kan.”

Alignment with parent and child, additional information and points for improvement
After reviewing the document, one sports coach could not identify any missing elements. However, he indicated that it could be a valuable addition to include a section about how open the sports coach may be towards peers of the child, taking into account the child’s preferences.

The other sports coach indicated that it would be important for her to know whether a child is anxious or not, as this would determine how intensively she monitors the child during and after sports activities and allows her to take this into account.

One sports coach noted that it could be confusing if a checkbox option with an accompanying explanation is selected in the sports advice, but the explanation itself is not filled in.

Regarding the section on heart rate zones, the other sports coach indicated that it was not yet fully clear how this should be monitored in practice. She needed more concrete guidance, for example on how she can monitor the heart rate and how to determine whether it is too high.

Layout and presentation
Both sports coaches indicated that the table of contents helped them understand the structure of the document. The use of color coding per chapter was also mentioned as supportive.

When asked whether more visual support would be desirable, both participants indicated that they did not feel a need for this. One sports coach stated that additional visuals could be distracting and that the current document was experienced as clear and concise.

Finally, one sports coach indicated that she would probably print the last two pages of the document with signals and contact details, and keep them close at hand. She suggested adding a brief summary of key information about the child on this page, such as the specific heart defect, so that this information would be immediately available in case of an acute emergency.

8.2.5 Recommendations

Impact of medication on sports participation
When medication is used, it would be helpful for sports coaches when the impact of the specific medication on sports is explained. This could be incorporated into the development of standardized explanatory texts for medication that is commonly prescribed to children with CHD, so that these can be automatically generated within the sports advice form.

Mandatory explanation for specific response options
To prevent confusion among sports coaches when an explanatory text field remains empty while an explanation is expected, it is recommended, if technically feasible, to link a mandatory field within HiX to specific response options. This ensures that relevant explanations are provided by the cardiologist.

Practical monitoring of heart rate zones
For the section on heart rate zones, it is recommended to more explicitly describe how sports coaches can monitor this in practice. This can be supported by a guiding prompt for cardiologists in HiX, specifying the practical information sports coaches require. An example is shown in Figure 45.

Figure 45: Current and proposed sports advice section in HiX showing added guidance for cardiologists on heart rate zones

Alignment and agreements with parent and child
As an addition to the section Alignment and agreements with parents and child, it is recommended to record how open the sports coach may be towards peers and whether the child experiences anxiety during sports activities. This information can help sports coaches better tailor their guidance to the child's needs.

Example questions that could be added could be:

- Zijn klasgenoten of teamgenoten momenteel op de hoogte van de hartafwijking van het kind?
- Vind het kind het prettig als klasgenoten of teamgenoten hiervan op de hoogte zijn?
- Wat is voor het kind prettig dat de sportcoach eventueel richting de groep kan zeggen als het tijdens sport even moet stoppen of aangepast meedoet?
- Ervaart het kind weleens spanning of angst tijdens sport- of gymlessen?

Emergency information summary on printed pages
It is recommended to add a summary or extra information block that includes essential information such as the specific CHD of the child, to ensure that critical information is immediately available in case of an emergency. For example on the emergency and contact pages, as these pages are likely to be printed and kept close at hand by sports coaches. A proposal is illustrated in Figure 46.

GEGEVENS VOOR NOODSITUATIES

Naam kind	*Sam de Vries*
Diagnose	*Coarctatio aortae*
Behandeld?	*Ja, operatie*
Medicatie	*Enalapril*

Figure 46: Recommendation for an additional section with key child information on the final page of the sports advice

8.3 Parent-child sports advice portal

8.3.1 Goal

As described in the evaluation scope in Chapter 8.1, the usability of the parent-child portal was tested to assess whether users understand how the portal works, which actions they can perform, and how they can supplement, adjust, and share the sports advice with the sports coach. The focus was on the clarity of the interface, the provided information, and the ease of completing the pages. It also included a short evaluation of the completion of the additional pages related to alignment and agreements in the sports practice and contact information for situations involving emergencies, doubts, or questions.

8.3.2 Method

Participants
The test was conducted with two participants who were not parents of children with CHD and were therefore not fully representative of the platform's final target group (in addition to the children themselves). Nevertheless, their input was considered valuable for this usability test, as the evaluation primarily focused on the comprehensibility of the interface, the logic of the interaction steps, and the ease of completing the pages, rather than on CHD-specific content or experiences.

Materials
Participants were shown the parent-child portal on a computer. The portal was not an interactive or functional prototype, but consisted of a series of interface slides. During the test, participants indicated where they would click or which action they expected to be able to perform.

Based on these indications, the researcher manually navigated to the corresponding follow-up interface screens to simulate the interaction.

Session procedure
Before the test, participants were given a brief explanation of the purpose of the session. They were then given the task of navigating from the notification about the available sports advice in the patient portal to the sports advice itself, and to modify and share it with a sports coach. They were also asked to review the additional pages related to alignment and agreements in the sports practice and contact information, and asked to indicate whether they understood these sections.

The test examined whether participants understood:

- where they could find the sports advice
- how they could complete, save, and share the sports advice
- where they encountered difficulties and why
- whether they understood that selective sharing of information was possible, and the reason for this
- why and how multiple versions of the sports advice could be created and shared with different sports coaches
- the content of the additional pages related to alignment and agreements in the sports practice

8.3.3 Analysis

The results were analyzed qualitatively based on observations and verbal responses from participants during the test sessions. As with the evaluation of the sports advice form, participants were asked to think aloud during this test in order to gain insight into their interpretations and motivations. These insights were documented on paper.

The insights were used to create recommendations for the parent-child portal.

8.3.4 Results

Core functionalities are clear and easy to use
Both participants were able to complete, save, and share the sports advice without any problems. The core functionalities of the platform were clear.

Unclear editability of checkboxes
Itt was not immediately clear to one participant that the checkboxes within the section "Alignment and agreements with parent and child" could still be completed. These boxes were left unchecked because this section is not completed by the cardiologist but by the parent and child. But for the participant, it was insufficiently clear that these fields were still editable.

Understanding of selective sharing and multiple versions
Although the participants were not parents of children with CHD and therefore not fully representative of the end-user group, they did understand the purpose and added value of selectively sharing information. They also recognized the usefulness of being able to create multiple versions of the sports advice to share with different sports coaches.

Need for an editable base document
Both participants indicated that it would be desirable that after completing an initial sports advice, a pre-filled base document would remain available. This would allow only specific information to be adjusted or hidden when creating a new version for another sports coach, rather than having to complete the entire document again.

Read-only view when logging in
One participant indicated that it would be preferable to first see a read-only version of the sports advice after logging in, before switching to edit mode.

Shared sports advice overview not standing out
The function “Overview of shared sports advice” was not immediately noticed by either participant. This page was only viewed after it was pointed out by the researcher. While the function was considered useful, it did not stand out sufficiently within the platform.

Unclarity about active and previous versions
Finally, one participant indicated that it was unclear which version of the sports advice is displayed in the sharing interface, and whether previously shared or older versions of the sports advice can still be viewed.

The additional pages related to alignment and agreements in the sports practice and contact information for situations involving emergencies, doubts, or questions were reviewed by the participants and were generally understood.

8.3.5 Recommendations

Based on the feedback gathered during the test, the following design recommendations are formulated, some of which are supported by visualizations.

Clarify the editability of input fields
To reduce uncertainty about the editability of the checkboxes, it is recommended to make them visually identical to other editable input fields, for example by making them white. This would make it clearer that these fields can still be filled in. This is shown in Figure 47.

Support reuse with a base version
Another recommendation is to allow a base document to be saved after the first sports advice has been edited by the parent and child. Multiple versions can then be generated from this basic document, with specific information hidden or modified for each sports coach. This reduces repetitive data entry and is more user-friendly.

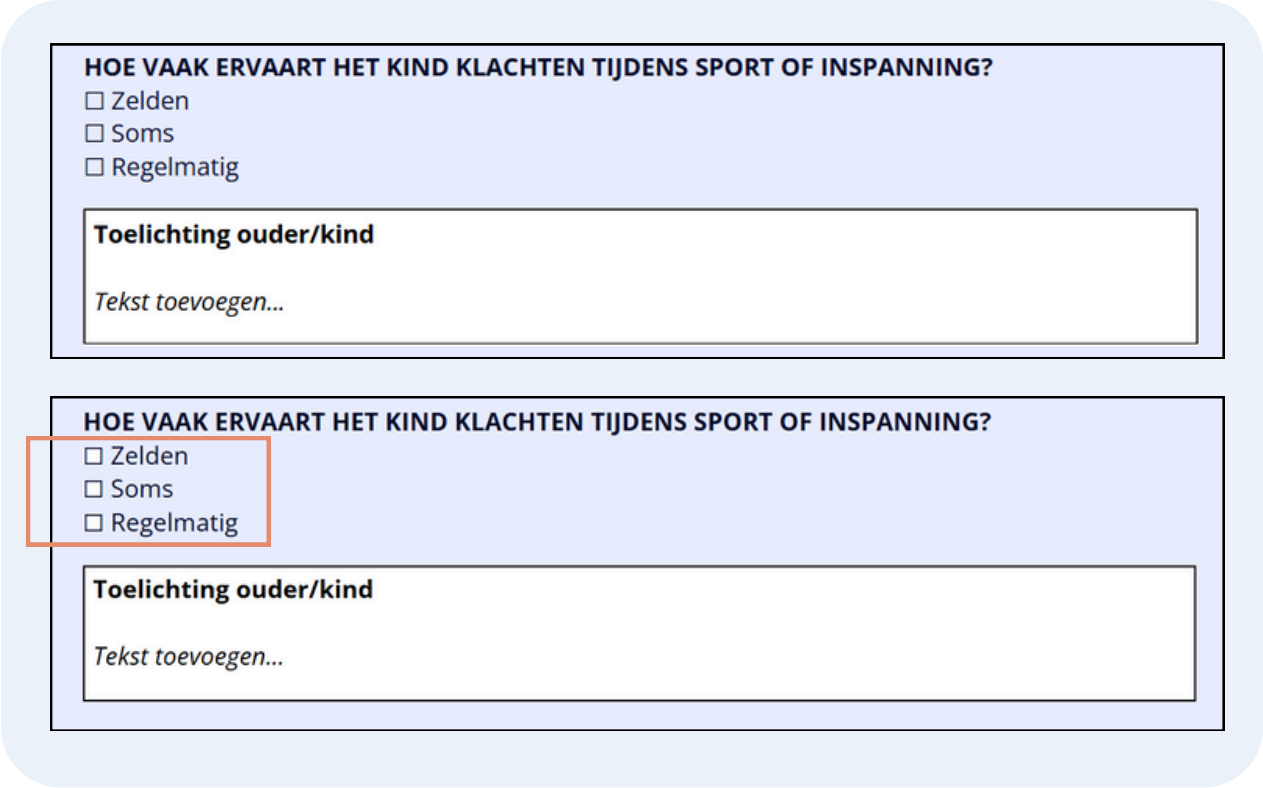


Figure 47: The top question shows the original, the answer options below include the recommended changes

Read-only view after login
Another recommendation is to first show a non-editable read-only mode of the sports advice after logging in, after which users can go to the edit mode themselves via the navigation menu on the left.

Improve visibility of the shared sports advice overview
To make the function "Overview of shared sports advice" more visible, it is recommended to explicitly refer to this option on the page where the sports advice is shared. This is illustrated in Figure 48.

Version history
As an additional recommendation, an archive function could be added in which previously created and shared sports advice documents are stored and can be easily retrieved. This is illustrated in Figure 49.

Figure 48: Link to the "Overview of shared sports advice" on the sports advice sharing page.

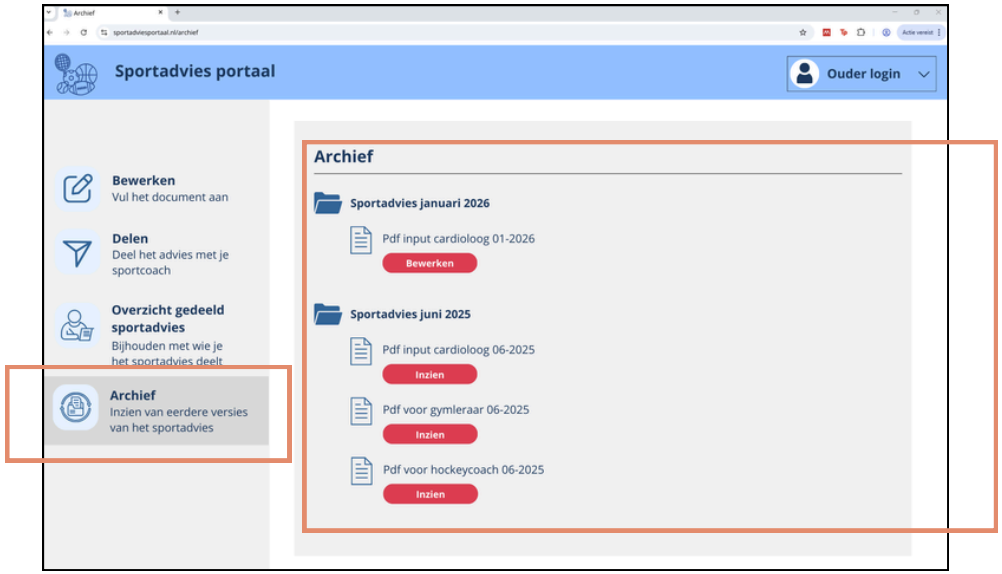


Figure 49: Addition of an archive to the platform, to allow viewing previously created sports advice documents.

Image source: Pexels

9

Discussion & conclusion

This chapter reflects on the previously defined requirements and evaluates how they are addressed in the final design. It discusses research limitations and the feasibility, viability and desirability of the concept and concludes with recommendations for future research and development, followed by a final conclusion.

9.1 Requirement evaluation

This section provides an overview of the defined requirements as described in Chapter 4.3 and shows how well the final design meets each requirement using color coding. This is visualized in Tables 2-6.

The evaluation shows that most requirements from the different stakeholder groups have been addressed within the final design. Some requirements are directly translated into concrete design elements, such as implementation in the questionnaire, the parent-child platform, or the sports advice form. Other requirements are supported more indirectly through the interaction and coherence between different components of the concept, or through the overall design approach, instead of through one specific component. This distinction is indicated by icons in the tables.

A number of requirements are only partially met or fall outside the scope of this graduation project. These requirements are discussed further in the Recommendations section.

Legend

Status of the requirement

- Addressed within the design
- Partially addressed

Icons


Implemented in or supported by the questionnaire


Implemented in or supported by the sports advice form


Implemented in or supported by the parent-child platform


Supported through the overall design approach and communication flow, instead of through a single specific component

Children	
Requirement	**Evaluation**
The tool should **actively involve children** in conversation about sports with their healthcare professionals.	
The tool should **create space** for children to **ask questions, share experiences** and express their **goals, concerns and interests** related to sports participation.	
The tool should help **uncover potential support needs** of the child related to sport participation and make these visible to healthcare professionals so they can **offer appropriate guidance or refer** if needed.	
The tool should support communication that **focusses on abilities and possibilities,** rather than restrictions, to support self-efficacy and participation.	
The tool should help shift the focus towards what the child **can do, rather than** on **limitations.**	
The tool should support children in **learning to recognize and interpret bodily signals** during physical activity.	
The tool should support children in making clear **agreements about when and how to report** symptoms or concerns during sports lessons.	

Table 2: Evaluation of requirements related to children

Parents	
Requirement	**Evaluation**
The tool should provide insight into **how current advice** from healthcare professionals **relates to earlier advice.**	
The tool should help parents **understand and assess what PA levels are safe** for their child.	
The tool should provide relevant **guidance** on physical activity and sports participation, **tailored to families' needs**, **regardless** of whether the child is **currently participating in sports or not.**	
The tool should give parents **control over which stakeholders receive what information** about their child's condition and sports participation.	
The tool should help children and parents to **communicate their wishes and needs** regarding sports participation to sports coaches.	
The tool should **support** parents in **communicating advice** about sports participation **accurately and consistently** to sports coaches.	

Table 3: Evaluation of requirements related to parents

Sports coaches	
Requirement	**Evaluation**
The tool should **provide** sports coaches with **background knowledge** about CHD and its **implications** for a child's **participation in sports activities.**	
The tool should provide sports coaches with **clear, concise and practical information** about what a child can do safely during sports.	
The tool should provide sports coaches with clear **insight into the wishes and needs** of the child (and parents) regarding sports participation, **supporting safe, inclusive and enjoyable participation.**	
The tool should ensure that the sport-related **information** described above is **available before the sports class,** enabling sports coaches to prepare their training accordingly.	

Sports coaches	
Requirement	**Evaluation**
The tool should **support sports coaches in identifying suitable activities and adaptations,** based on the sport-related information provided, while allowing coaches to apply this within their own training context.	
The tool should provide clarity about what **symptoms or signals** to pay attention to and what **actions to take** if these occur.	
The tool should clarify who coaches can **contact** in case of **questions, concerns or uncertainty.**	

Table 4: Evaluation of requirements related to sports coaches

Healthcare professionals	
Requirement	**Evaluation**
The tool should ensure that relevant **information and insights** from parents and children are available **before the consultation,** so that healthcare professionals can **prepare.**	
The tool should give healthcare professionals **insight** into the child's sports experiences, concerns or limitations and home situation to **offer appropriate guidance or refer** if needed.	
The tool should provide healthcare professionals with **insight** into how children and parents **interpret sports advice,** enabling early **identification of misunderstandings** and supporting clarification of outdated, unclear or incorrect assumptions.	
The tool should support healthcare professionals in **giving personalized sports advice** that reflects the unique situation of each child with CHD and their specific sports or activities.	
The tool should help **tailor sports advice to the child's personal interests and preferences,** thereby increasing motivation and long-term participation in sports.	

Healthcare professionals	
Requirement	**Evaluation**
The tool should **support** healthcare professionals in providing **clear, understandable and consistent information** about sports participation.	
The tool should make it possible for healthcare professionals to **discuss sports participation within the limited time** available during consultations.	
The tool should provide a **standardized structure** that helps cardiologists **consistently discuss sports participation** during consultations and reduces variability between them.	
(Medical) information provided within or referenced by the tool should be **trustworthy** and originate from **reliable, evidence-based sources** that healthcare professionals can **confidently use or refer to.**	

Table 5: Evaluation of requirements related to healthcare professionals

Cross-stakeholder		
Requirement	**Evaluation**	
The tool should support a **shared understanding of safe participation** among all stakeholders.		
The tool should **encourage collaboration** between cardiologists, parents, children and sports coaches (and other stakeholders).		
The tool should **clearly indicate the roles and responsibilities** of children, parents, sports coaches and healthcare professionals in supporting safe sports participation, so that each stakeholder knows what actions are expected from them.		
The tool should **support efficient transfer** of sport-related information between stakeholders.		
Information should be **transferable to multiple stakeholders,** such as different sports clubs and schools.		

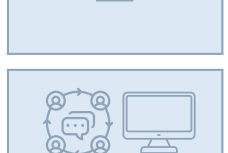
Cross-stakeholder		
Requirement	**Evaluation**	
The tool should help **prevent information loss** by ensuring that all stakeholders have access to **consistent, complete and up-to-date** sports-related **information.**		
The tool should be **updateable** when changes occur in the child's medical status or sports advice.		
The tool should make **provided advice accessible for later reference,** to ensure families and sports coaches can revisit information when needed.		
The tool should be **easy to use** for all stakeholders.		
The tool should **protect the privacy of the child** by ensuring that personal information is only accessible to authorized stakeholders.		

Table 6: Evaluation of cross-stakeholder requirements

9.2 Limitations

This graduation project had a number of limitations that may have influenced the outcomes of the final design. Time constraints and available resources played an important role in determining the scope of the research and evaluation.

Limited sample size and representativeness in interviews
The interview phase included interviews with healthcare professionals, sports coaches, parents, and children. Although these interviews provided valuable qualitative insights, the sample size was relatively limited, which may have affected the generalizability of the findings.

Only three sports coaches were interviewed, representing different subgroups (sports clubs, primary school, and secondary school), but each subgroup was represented by only one person. As a result, several design decisions and input for the sports advice form were based on individual perspectives. This became clear during the evaluation of the sports advice form, when two additional sports coaches suggested further additions.

Similarly, three parents and two children were interviewed. Although their experiences provided meaningful input, this group was too small to be representative of the broader population of children with different types of CHDs and their families.

Limited diversity within the participant group
All children interviewed participated in multiple sports activities or were members of sports clubs. As a result, the perspectives of children with CHD who do not participate in sports, or experience significant anxiety, or face other barriers were underrepresented. Although these perspectives were considered during the design process based on insights from the literature, they were less prominently reflected in the interview data.

Also, in interviews, healthcare professionals mentioned language barriers and cultural differences as factors that may influence how sports advice is interpreted and discussed. These aspects were not explored within this project, and their impact on the usability and effectiveness of the tool for families with diverse language or cultural backgrounds remains unclear.

Scope and testing limitations of the design
Due to limited time and resources, not all components of the final design could be evaluated. Integration and interaction within the electronic patient record and patient portal, including completing the questionnaire and generating sports advice by cardiologists in HiX, was beyond the scope of this project.

Furthermore, the comprehensibility of the questionnaire was not tested with children themselves. The questionnaire was designed to be broadly applicable within the target group of 6 to 16 year olds and assumed support from parents for younger children. But there was no age-specific evaluation conducted to assess whether the wording, structure, or length of the questionnaire is equally suitable for younger and older children.

Limited in context and long-term validation
The sports advice was tested with two sports coaches using scenarios and discussions, rather than in a real sports environment. Although the participants indicated that the document was clear and useful, it remains unknown how the sports advice would be used during actual training sessions or PE classes. The long-term effects and the extent to which the sports advice contributes to a more inclusive sports environment for children with CHD in practice were not evaluated.

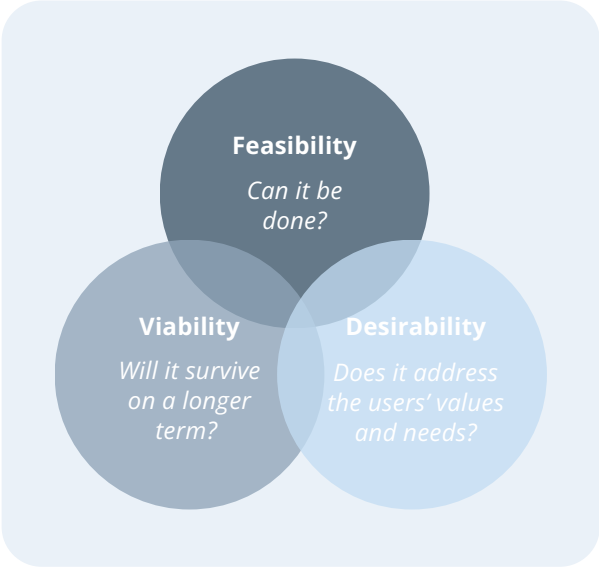
Furthermore, the sports advice was tested in paper form. Although digital use is also a realistic scenario, its usability in a digital context was not evaluated.

In addition, the final design primarily focuses on children who already participate in sports. Reasons for no participation of sports are explored in the questionnaire, but it is not examined how the sports advice should be applied when a child does not engage in sports or which follow-up steps should be taken. These decisions are left to the current practice of the cardiologist.

Also, the assumed role of a nurse specialist in supporting the cardiologist with the analysis of questionnaire results and preparation of the sports advice was not explored in detail. The feasibility of embedding this role within existing clinical workflows and time constraints remains unclear.

9.3 Feasibility, viability & desirability

This section evaluates the concept in terms of feasibility, viability, and desirability,



9.3.1 Feasibility

Based on a co-creation and feedback session with cardiologists it became clear that for the tool to be feasible in practice, it needs to align with existing workflows. Therefore, the decision was made to integrate core components of the concept, the questionnaire and the sports advice, within HiX instead developing a separate platform for healthcare professionals. This decision supports adoption of the concept within the clinical context.

From a technical point of view, integrating certain aspects within HiX seems feasible, based on existing functionalities. Existing questionnaires are already distributed via HiX and completed via linked patient portals, which suggests that the questionnaire part of this tool can be integrated in a similar way. In addition, HiX supports the automatic completion of templates with patient data, such as medical history and medication, as well as the generation of PDF documents, for example for letters to general practitioners. This indicates that it is technically feasible to link relevant patient data to a template for sports advice and generate a PDF within HiX.

The concept is designed to fit within existing systems and workflows, yet its full feasibility depends on a number of conditions. These include the ability to automatically add explanatory texts to the sports advice form based on selected answer options provided by the cardiologist and the secure transfer of the generated sports advice to the parent-child platform. Due to limitations in time, resources and the scope of the project, these aspects were not technically explored and therefore remain assumptions and need further validation.

For future research, it is recommended to test these assumptions in collaboration with technical HiX specialists, particularly with regard to content generation based on completed fields and document exchange with external systems.

9.3.2 Viability

In order for the concept to be viable in the long term, several conditions must be met. An important condition is the availability of a parent-child platform that allows parents and children to view and supplement the sports advice and selectively share information. For the long-term use of this platform, an organization is needed that is responsible for the management, further development, and secure storage of personal data and medical information. This organizational responsibility has not been determined within this graduation project, but the concept has been designed on the assumption that this responsibility can be assigned to a suitable (healthcare) organization or other external party.

Another essential condition for viability is alignment with existing clinical workflows. The preparation and discussion of the questionnaire and sports advice should fit within the limited time available during consultations, without leading to an increased workload for cardiologists. The concept has been deliberately designed with this in mind, for example by structuring and summarizing questionnaire results and providing a fixed and clear structure for completing the sports advice. However, the actual efficiency of this workflow depends on integration within HiX and can only be fully assessed when this integration has been realized.

Long-term viability of the concept also depends on the distribution of the workload in practice. The assumed role of a nurse specialist in supporting the analysis of questionnaire results and preparing sports advice could contribute to a more sustainable distribution of work.

However, this role has not been further investigated within this graduation project, so its practical applicability within existing clinical workflows is still uncertain. Further development and validation of this role is therefore an important condition for the sustainable application of the concept in clinical practice.

The concept supports an explicit division of roles between healthcare professionals, parents, children, and sports coaches. In contrast to many existing tools and initiatives, in which responsibilities between stakeholders are often unclear or which function as standalone information solutions, this concept is designed as a connecting element between multiple stakeholders within healthcare, home, and sports contexts. This clarity in roles and responsibilities supports the use of the concept within existing tasks and workflows.

Through this combination of system integration and role-specific use with clearly defined responsibilities, this concept explores a new route to make this type of communication tool viable within existing healthcare and sports contexts. It suggests that long-term use of the concept in practice is possible, provided that the identified conditions are addressed in future research.

9.3.3 Desirability

For healthcare professionals, the concept addresses the lack of structure and guidance when discussing sports participation during consultations. In interviews, healthcare professionals indicated that they are open to using a supportive tool for providing sports advice, provided that it fits within existing workflows and does not add an additional administrative burden.

The concept adds value by supporting more consistent and in-depth discussions of sports participation during consultations. While healthcare professionals indicated that sports participation is usually addressed in every consultation, the depth of these discussions often varies, depending on factors such as time constraints. By providing structured, pre-collected contextual information, the concept enables healthcare professionals to focus the discussion when relevant.

For sports coaches, desirability mainly lies in clear and accessible transfer of information. Interviews showed that sports coaches need clear, concise, and practical information about what a child can safely do during sports, with the information being delivered to them proactively. The sports advice is therefore deliberately designed as a passive supporting document that facilitates understanding, while maintaining the professional freedom of the coach to organize and adapt their lessons. This approach was positively received during the evaluation with sports coaches. By providing relevant context in this way, coaches are better prepared to plan their activities and make decisions with greater confidence, thereby supporting inclusive sports participation for children with CHD.

For parents and children, the desirability of the tool is more situational. In cases where children participate in sports without difficulties and parents do not feel the need to actively inform sports coaches, the necessity of using the tool is limited. In other situations, such as when a child requires additional support, parents and children feel uncertain about sports participation or assistance is needed in communicating with sports coaches, the tool offers clear added value.

The design accommodates this variation by giving parents and children control over whether, what, how, and with whom information is shared. This aligns with parents' need to retain control over communication. It supports parents' need to manage information sharing in a way that fits the specific context, without feeling pressured to disclose information they consider personal or unnecessary.

Several design choices were deliberately made to increase acceptance of the concept. The sports advice is designed as a structured, form-based document that aligns with existing medical documentation practices. In addition, a clear distinction is made between information provided by healthcare professionals and information added by parents and children. This prevents uncertainty about responsibilities and contributes to a clear and accessible user experience for all stakeholders. By allowing the sports advice to be shared through existing communication channels with sports coaches, this further supports adoption by sports coaches.

In summary, the concept is likely desirable for the involved stakeholders because it responds to their need for clarity, structure, and control in communication about sports participation. The design supports this by collecting sports-related information and translating it into concrete, context-specific sports advice that is subsequently distributed to the relevant stakeholders. By making roles and responsibilities explicit and tailoring information to the context in which healthcare professionals, sports coaches, parents, and children interact, the concept aligns with existing roles and expectations. As a result, it provides greater consistency and guidance in supporting sports participation for children with CHD.

9.4 Recommendations

he following recommendations are proposed to support future development, validation, and implementation of the concept.

9.4.1 Recommendations based on limitations

To increase the reliability and generalizability of the findings, future research could involve a larger and more diverse group of stakeholders, including a broader range of sports coaches and families.

Future research could include families with diverse language or cultural backgrounds, to explore how the tool can better support these people and to identify potential adaptations in communication or content of the tool.

In addition, future development could explore how the tool should be used when children do not participate in sports or have specific help needs, including referral pathways to the Esther Vergeer Foundation, physical therapists or sports physicians and how feedback could be communicated back to the cardiologist. Or what role they can play in for example the sports advice form.

Further evaluation could focus on testing the use of the sports advice in real sports settings and over a longer period of time to provide insights into its practical impact on sports participation and inclusivity for children with CHD.

Further evaluation could focus on testing the sports advice in a digital format and using a fully completed sports advice prepared by a cardiologist, based on either a fictitious or real case.

This would allow sports coaches to interact with the document more realistically and may reveal additional usability issues or information needs.

Another recommendation is to evaluate additional components of the design that were outside the scope of this project, such as the completion of the sports advice by cardiologists within HiX and the technical integration and document generation process of the questionnaire and sports advice. In addition, testing the comprehensibility of the questionnaire with children is recommended.

Finally, further research could explore the role of nurse specialists in supporting the use of the tool in practice and assess how this role could be integrated within existing clinical workflows.

9.4.2 Recommendations based on requirements

A number of requirements identified in the requirement evaluation were only partially addressed within the scope of this graduation project. The following recommendations provide an overview of possible directions for further development to better meet these requirements.

The tool should support children in learning to recognize and interpret bodily signals during physical activity.
While the tool supports the identification of uncertainties or concerns through the questionnaire, it does not actively support children in learning to interpret bodily signals during sports.

A recommendation is to involve additional healthcare professionals, such as physical therapists or sports physicians, in the process to provide more targeted guidance and follow-up when needed.

The tool should provide insight into how current advice from healthcare professionals relates to earlier advice.
The tool does not explicitly support reflection on changes in advice over time, parents and children are only able to see differences when the sports advice is updated. Future development could explore how healthcare professionals can more explicitly address changes in sports advice during consultations or provide guidance on how to communicate these changes to parents and children.

The tool should help parents understand and assess what PA levels are safe for their child.
While parental concerns can be identified through the questionnaire, the tool currently focuses primarily on communication towards sports coaches. Future iterations could explore how the tool might also better support parents' understanding of safe physical activity levels, for example through additional explanations for parents or to explore ways in which they can get tailored feedback or advice from healthcare professionals.

The tool should provide sports coaches with clear insight into the wishes and needs of the child (and parents) regarding sports participation, supporting safe, inclusive and enjoyable participation.
Although sports coaches indicated that the wishes and needs of the child and parents were clear when reviewing the sports advice, further evaluation in real sports settings involving both children and sports coaches is recommended to assess whether this actually leads to safe, inclusive, and enjoyable participation in practice.

The tool should support healthcare professionals in giving personalized sports advice that reflects the unique situation of each child with CHD and their specific sports or activities.
The tool provides cardiologists with a structured format for personalized sports advice, but it does not take into account differences in experience or confidence among healthcare professional to provide recommendations for physical exercise. Future research could explore which aspects of sports advice healthcare professionals may find challenging and how additional guidance or support could be provided.

The tool should make it possible for healthcare professionals to discuss sports participation within the limited time available during consultations.
The integration within HiX was outside the scope of this project, so the impact on consultation time could not be evaluated. Future testing after integration in HiX could assess whether the questionnaire and sports advice support efficient discussions about sports during consultations.

(Medical) information provided within or referenced by the tool should be trustworthy and originate from reliable, evidence-based sources that healthcare professionals can confidently use or refer to.
A recommendation is to develop a validated knowledge base containing information on CHDs, medication and sport-related terms to ensure consistency and reliability of information generated in the sports advice form.

The tool should support a shared understanding of safe participation among all stakeholders.
The extent to which the tool contributes to a shared understanding among stakeholders was not evaluated within this project. It is recommended that to test this with multiple stakeholders involved in different contexts.

The tool should be easy to use for all stakeholders.
Usability testing was not conducted with all stakeholder groups, particularly children and healthcare professionals within HiX. Future evaluations could include usability testing with all stakeholders, preferably after full system integration has been realized to ensure a realistic assessment of use in practice.

9.5 Conclusion

This graduation project explored how communication and understanding between parents, sports coaches, healthcare professionals, and children with CHD can be improved to enable accessible and inclusive participation in organized sports activities. The findings show that communication about sports participation is often fragmented, unclear, and inconsistent across healthcare and sports contexts, which may lead to uncertainty in how guidance about sports participation is discussed, understood, and applied in practice.

Improving communication and understanding requires more than clearer information exchange alone. This highlights the need for a shared and structured approach that connects healthcare and sports contexts, aligns with stakeholders' roles and responsibilities, and this way supports shared understanding between the involved parties. When communication is better structured and mutual understanding is strengthened, stakeholders are better supported in making decisions that encourage sports participation for children with CHD.

Based on the insights gathered during the project, a communication concept was developed to illustrate how such an approach could be supported in practice, centered around a pre-consultation questionnaire and a structured sports advice form. Initial evaluation indicates that the concept addresses the majority of identified stakeholder requirements, but further evaluation is required to assess its feasibility and viability within existing healthcare and sports contexts.

Overall, this project provides a foundation for future work towards supporting more inclusive sports environments for children with CHD.

References

Amsterdam UMC. (2023). *Aangeboren hartafwijkingen (in het algemeen).* https://www.amsterdamumc.nl/nl/patienteninformatie/aangeboren-hartafwijkingen-in-het-algemeen.htm

Bandura, A. & Stanford University. (1994b). Self-Efficacy. In V. S. Ramachaudran & H. Friedman (Reds.), *Encyclopedia Of Human Behavior* (Vols. 4–4, pp. 71–81). Academic Press. https://happyheartfamilies.citymax.com/f/Self_Efficacy.pdf

Belt, J., & Engelen, A. (2020). *Een leerling met een hartafwijking: Informatie en advies voor leraren* [Brochure]. Netwerk Ziezon. https://ziezon.nl/wp-content/uploads/sites/19/2020/06/Ziezonbrochure-Hartafwijking_WEB_Mei2020-2.pdf

Buchanan, M., Spence, C., Keir, M., & Khoury, M. (2023). Physical Activity Promotion Among Individuals With Tetralogy of Fallot. *CJC pediatric and congenital heart disease, 2*(6Part A), 322–334. https://doi.org/10.1016/j.cjcpc.2023.08.002

Chessa, M., De Rosa, G., Pardeo, M., Negura, D. G., Butera, G., Giamberti, A., Bossone, E., & Carminati, M. (2005). What do parents know about the malformations afflicting the hearts of their children? *Cardiology in The Young,* 15(2), 125–129. https://doi.org/10.1017/s1047951105000284

Cheuk, D. K. L., Wong, S. M. Y., Choi, Y. P., Chau, A. K. T., & Cheung, Y. F. (2004). Parents' understanding of their child's congenital heart disease. *Heart,* 90(4), 435–439. https://doi.org/10.1136/hrt.2003.014092

Chong, L.S.H., Fitzgerald, D.A., Craig, J.C. et al. Children's experiences of congenital heart disease: a systematic review of qualitative studies. *Eur J Pediatr* 177, 319–336 (2018). https://doi.org/10.1007/s00431-017-3081-y

Convergence. (n.d.). *Our approach- Healthy Start.* https://convergence.nl/healthy-start/healthy-start-our-approach/

Design Council. (n.d.). *Framework for Innovation - Design Council.* https://www.designcouncil.org.uk/our-resources/framework-for-innovation/

Erasmus MC. (2024). *Digizorg: meer zorg, minder typen* [Webpage]. https://www.erasmusmc.nl/nl-nl/artikelen/digizorg-meer-zorg-minder-typen/

Erasmus MC. (2025). *Digizorg app voor patiënten.* https://www.erasmusmc.nl/nl-nl/digizorg-app

Erasmus MC. (n.d.). *Over het Erasmus MC Sophia.* https://www.erasmusmc.nl/nl-nl/sophia/pages/over-erasmusmc-sophia#a1346724-5d4e-4597-8c02-4545f1d209cf

Etnel JRG, van Dijk APJ, Kluin J, Bertels RA, Utens EMWJ, van Galen E, Bogers AJJC and Takkenberg JJM (2017) Development of an Online, Evidence-Based Patient Information Portal for Congenital Heart Disease: A Pilot Study. Front. Cardiovasc. Med. 4:25. doi: 10.3389/fcvm.2017.00025

Hartenkinderen | Cyberpoli. (n.d.). https://www.cyberpoli.nl/aha/
Hartpaspoort - Patiëntenvereniging aangeboren hartafwijkingen. (2022).

Patiëntenvereniging Aangeboren Hartafwijkingen. https://aangeborenhartafwijking.nl/belangenbehartiging/hartpaspoort/

Home – BeterDichtbij. (2025). BeterDichtbij. https://www.beterdichtbij.nl/
Janssen, I.; LeBlanc, A.G. Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *Int. J. Behav. Nutr. Phys. Act.* 2010, 7, 40.

Kenniscentrum Sport & Bewegen. (n.d.-a). *Argumentenkaartjes* [Webpage]. https://www.kenniscentrumsportenbewegen.nl/producten/argumentenkaartjes-2/

Kenniscentrum Sport & Bewegen. (n.d.-b). *Beweegcirkel* [Webpage]. https://www.kenniscentrumsportenbewegen.nl/producten/beweegcirkel/

Kenniscentrum Sport & Bewegen. (n.d.-c). *Bewust Bewegen* [Webpage]. https://www.kenniscentrumsportenbewegen.nl/producten/bewust-bewegen/

Longmuir, P. E., Brothers, J. A., de Ferranti, S. D., Hayman, L. L., Van Hare, G. F., Matherne, G. P., Davis, C. K., Joy, E. A., & McCrindle, B. W. (2013). Promotion of physical activity for children and adults with congenital heart disease: A scientific statement from the American Heart Association. Circulation, 127(21), 2147–2159. https://doi.org/10.1161/CIR.0b013e318293688f

Longmuir, P. E., Corey, M., & McCrindle, B. W. (2021). Interactions with Home and Health Environments Discourage Physical Activity: Reports from Children with Complex Congenital Heart Disease and Their Parents. *International Journal of Environmental Research and Public Health,* 18(9), 4903. https://doi.org/10.3390/ijerph18094903

Longmuir, P. E., Wang, S., Timmons, B. W., Mondal, T., Cinanni, N. L., Di Cristofaro, N. A., Dillenburg, R., Adamo, K., Tremblay, M. S., & Lee, S. (2022). Inactive Lifestyles Among Young Children With Innocent Murmurs or Congenital Heart Disease, Regardless of Disease Severity or Treatment. *The Canadian journal of cardiology,* 38(1), 59–67.

Loprinzi, P.D.; Cardinal, B.J.; Loprinzi, K.L.; Lee, H. Benefits and Environmental Determinants of Physical Activity in Children and Adolescents. *Obes.* Facts 2012, 5, 597–610.

Ong, L., Nolan, R.P., Irvine, J. et al. Parental Overprotection and Heart-Focused Anxiety in Adults with Congenital Heart Disease. *Int.J. Behav. Med.* 18, 260–267 (2011). https://doi.org/10.1007/s12529-010-9112-y

Patiëntenvereniging Aangeboren hartafwijkingen. (2025). Home - Patiëntenvereniging Aangeboren Hartafwijkingen. https://aangeborenhartafwijking.nl/

Patiëntenvereniging Aangeboren Hartafwijkingen. (n.d.). [Informatie voor de huisarts over Aangeboren hartafwijkingen]. In *Informatie voor de huisarts over Aangeboren hartafwijkingen.* https://www.nhg.org/wp-content/uploads/2023/01/aangeboren_hartafwijkingen_okt21.pdf

Pavlicek, J., Klaskova, E., Kapralova, S. et al. Major heart defects: the diagnostic evaluations of first-year-olds. *BMC Pediatr* 21, 528 (2021). https://doi.org/10.1186/s12887-021-02997-2

Pharos. (2017). Samenwerken aan beeldverhalen in de zorg voor de jeugd [PDF]. Pharos. https://www.pharos.nl/kennisbank/samenwerken-aan-beeldverhalen-in-de-zorg-voor-de-jeugd/

Quli. (n.d.). *Over Quli* [Webpage]. https://quli.nl/over-quli/

RASCI Methode. (n.d.). *RASCI-methode* | Wat is RASCI? https://www.rascimethode.nl/nl/rasci

Roston, T.M., De Souza, A.M., Sandor, G.G.S., et al. (2013). *Physical Activity Recommendations for Patients With Electrophysiologic and Structural Congenital Heart Disease: A Survey of Canadian Health Care Providers.* Pediatric Cardiology, 34, 1374–1381. https://doi.org/10.1007/s00246-013-0654-z

Sanders, EBN., & Stappers, PJ. (2012). *Convivial toolbox: Generative research for the front end of design.* Bis.

Saxena S., Millage J., Wong D., et al. (2021). Perceptions of healthy lifestyles among children with complex heart disease and their caregivers. CJC Open. 2021;3:854–863. doi: 10.1*016/j.cjco.2021.01.013.*

Schriftje. (n.d.). Over Schriftje [Webpage]. https://schriftje.nl/over-schriftje/

Silka, M. J., & Bar-Cohen, Y. (2012). A Contemporary Assessment of the Risk for Sudden Cardiac Death in Patients With Congenital Heart Disease. Pediatric Cardiology, 33(3), 452–460. https://doi.org/10.1007/s00246-012-0165-3

Sportbedrijf Rotterdam. (n.d.). *Check jouw beweegreden!.* https://www.sportbedrijfrotterdam.nl/beweegredenen

Sprong, M.C.A., Zwagerman, I.R., Soeters, L. et al. Prioritizing family-centered developmental care: insights from parents of children with critical congenital heart disease: a qualitative study. *Eur J Pediatr* 183, 3863–3876 (2024). https://doi.org/10.1007/s00431-024-05600-9

Sun, R., Liu, M., Lu, L. et al. Congenital Heart Disease: Causes, Diagnosis, Symptoms, and Treatments. Cell Biochem Biophys 72, 857–860 (2015). https://doi.org/10.1007/s12013-015-0551-6

Todd, L. T. B., Horn, R. H., Heart Research UK, Stuart, G. S., & Williams, C. W. (n.d.). *Physical Activity & Congenital Heart Disease: A Guide for Schools, Teachers & Sports Clubs.*

Verwey Jonker Instituut. (2019). *Waaier het samen op maat!* [Guide]. https://www.zorgeloosnaarschool.nl/application/files/8815/7340/1416/WAAIER.pdf

VIPLive. (n.d.). VIPLive | *Zorgplatform voor Slimme Samenwerking.* VIPLive | Zorgplatform Voor Slimme Samenwerking. https://viplive.nl/

Voss, C., Duncombe, S. L., Dean, P. H., De Souza, A. M., & Harris, K. C. (2017). Physical Activity and Sedentary Behavior in Children With Congenital Heart Disease. *Journal Of The American Heart Association,* 6(3). https://doi.org/10.1161/jaha.116.004665

Vrienden van het Sophia Kinderziekenhuis. (2023). *So Fit & Fun Centrum - Sophia Kinderthoraxcentrum – Vrienden van het Sophia.* Vrienden van het Sophia. https://vriendensophia.nl/sofitenfun/?gad_source=1&gad_campaignid=18209706892&gbraid=0AAAADBi8z41cT2i-2SQLf77UMZNI5BAs&gclid=EAIaIQobChMI2bex2L-ikQMVaZmDBx2cvh3IEAAYASAAEgJQ3fD_BwE

West, S. L., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., & Wells, G. D. (2019). Physical activity for children with chronic disease; a narrative review and practical applications. *BMC pediatrics,* 19(1), 12. https://doi.org/10.1186/s12887-018-1377-3

Williams, C. A., Gowing, L., Horn, R., & Stuart, A. G. (2017). A survey of exercise advice and recommendations in United Kingdom paediatric cardiac clinics. *Cardiology in the Young,* 27(5), 951–956. doi:10.1017/S1047951116002729

Wong C (2021) Congenital Heart Disease - A Review of the Treatment Methods. Int J Clin Cardiol 8:228. doi.org/10.23937/2378-2951/1410228

World Health Organization. (2020). *WHO guidelines on physical activity and sedentary behaviour.* https://iris.who.int/bitstream/handle/10665/336656/9789240015128-eng.pdf?sequence=1

Zivver Ltd. (n.d.). *Veilig zakelijk mailen* | Zivver. https://www.zivver.com/nl/

Use of AI

ChatGPT was used during this graduation project to support the writing process, including improving clarity and structure, checking grammar and spelling, providing feedback on style, and translations. All substantive content and conclusions remain the responsibility of the author.

Image source: Vecteezy

Appendix

The Appendix includes supporting materials referenced throughout this report.

Appendix A: Project brief

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Name student Frédérique Pel **Student number** 5,012,880

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title Design of a communication tool for inclusive sports participation of children with congenital heart defects.

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

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

My graduation project is carried out for Healthy Start and Erasmus MC Sophia Children's Hospital. Healthy Start is an initiative of Erasmus MC, Erasmus University Rotterdam and TU Delft, which focuses on the health and well-being of children and young adults. Through research and collaboration between medical, social and technological sciences, as well as societal partners, Healthy Start strives for equal developmental opportunities for all children and young adults, regardless of their background. (Convergence, n.d.). Erasmus MC Sophia, the pediatric hospital within Erasmus MC, is involved in this. My research focuses specifically on organized sport activities (i.e. regular sports clubs and school gym classes) for children with congenital heart defects.
Sport and exercise are essential for children's physical and social development. Research shows that regular physical activity during childhood has immediate benefits for psychological well-being, overweight, skeletal and cardiorespiratory health, and also supports motor skill development that has long-term health benefits. (Loprinzi et al., 2012). However, for children with a congenital heart defect, sport participation is not always taken for granted.
In the Netherlands, about 1300-1400 babies are diagnosed with a congenital heart defect each year. Due to medical advances, more than 90% of these children reach adulthood and many of them are able to lead relatively normal lives. (Amsterdam UMC, 2023). (West et al., 2019).
Research shows that children with CHD often do not get enough physical activity, despite minimal medical restrictions (Voss et al., 2019). Exercise is especially important for them, as reduced physical fitness can increase the risk of co-morbidities, i.e. type 2 diabetes, obesity, depression and anxiety (West et al., 2019). However, uncertainty among parents and children leads to hesistation in sports participation (Longmuir et al., 2021). This shows that there is a mismatch between what is medically considered safe and what parents or children actually feel confident doing, which makes effective communication between different stakeholders - parents, children, sports coaches and healthcare professionals - important.
My graduation project identifies the needs of different stakeholders and looks for ways to improve information transfer in the context of organized sport activities, such as through a communication tool, so that children with heart defects can participate in sports activities in an accessible and more inclusive way.

→ *space available for images / figures on next page*

introduction (continued): space for images

References

Amsterdam UMC. (2023, November 1). *Aangeboren hartafwijkingen (in het algemeen).* https://www.amsterdamumc.nl/nl/patienteninformatie/aangeboren-hartafwijkingen-in-het-algemeen.htm

Convergence. (n.d.). *Our approach- Healthy Start.* https://convergence.nl/healthy-start/our-approach/

Longmuir, P. E., Corey, M., & McCrindle, B. W. (2021). Interactions with Home and Health Environments Discourage Physical Activity: Reports from Children with Complex Congenital Heart Disease and Their Parents. *International Journal of Environmental Research and Public Health, 18*(9), 4903. https://doi.org/10.3390/ijerph18094903

Loprinzi, Paul & Cardinal, Bradley & Loprinzi, Kristina & Lee, Hyo. (2012). Benefits and Environmental Determinants of Physical Activity in Children and Adolescents. Obesity facts. 5. 597-610. 10.1159/000342684.

Voss, C.; Duncombe, S.L.; Dean, P.H.; De Souza, A.M.; Harris, K.C. Physical activity and sedentary behavior in children with congenital heart disease. *J. Am. Heart Assoc.* **2017**, *6*, 1–10.

West, S. L., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., & Wells, G. D. (2019). Physical activity for children with chronic disease; a narrative review and practical applications. *BMC Pediatrics, 19*(1). https://doi.org/10.1186/s12887-018-1377-3

image / figure 1 References

image / figure 2

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

The problem I want to solve is the lack of clear communication and knowledge about the abilities and limitations of children with congenital heart defects, between parents, sports coaches, children and healthcare professionals. Each child has a unique medical background and specific limitations or abilities. Despite pediatric cardiologists providing advice for childrens' sports participation, conversations within Healthy Start reveal that many parents struggle to communicate this advice to sports coaches. The current advices are often too general and parents find it difficult to make the advice discussable and concrete to sportcoaches and teachers. Sports coaches or teacher, in turn, often do not know how to appropriately support these children. This leads to uncertainty and misunderstanding, which results in overprotectiveness and some children participating in sports activities less frequently or in a less inclusive manner than medically necessary. Nor it is clear what insecurities and fears are involved among the children themselves.

The opportunity for this project lies in developing a tool that supports parents, sports coaches and children to exchange information. By breaking down assumptions and identifying the needs of different stakeholders, a safe, more accessible and inclusive sports environment can be created for children, enabling them to participate in those organized sports activities (such as school gym classes and regular sports clubs) more frequently and responsibly.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Investigate needs and design a tool to improve the communication between parents, sports coaches, healthcare professionals and children with a congenital heart defect, so that these children can participate in organized sports activities in an accessible and inclusive way.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

For my graduation project I will start with a research phase, in which I will conduct literature research on congenital heart defects of children, their sports participation and its social/mental aspects, current inclusivity within sports associations and explore existing tools for communication and knowledge transfer between different stakeholders within sports and healthcare. In addition, I want to conducts interviews with the stakeholders involved (parents, children, sports coaches and healthcare professionals) to gain insight into their experiences and current bottlenecks in communication and knowledge sharing.
Based on these insights, I want to redefine the problem and develop multiple solution directions in co-creation sessions with stakeholders. Then, I want to develop one concept further and, if possible, test it again with the stakeholders to gather feedback and refine it.
The final result depends very much on the insights from the research phase and a possible redefinition of the problem. It will be a solution that improves communication between parents, children and sports coaches, so that children with heart defects can participate in sports activities in an accessible and inclusive way. I hope to deliver a desgin that is worked out on the level of a detailed concept with visualisations and guidelines for implementation.

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting**, **mid-term evaluation meeting**, **green light meeting** and **graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	7 mei 2025
Mid-term evaluation	25 juli 2025
Green light meeting	6 nov 2025
Graduation ceremony	5 dec 2025

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	✓
For how many project weeks	25
Number of project days per week	4,0

Comments:

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

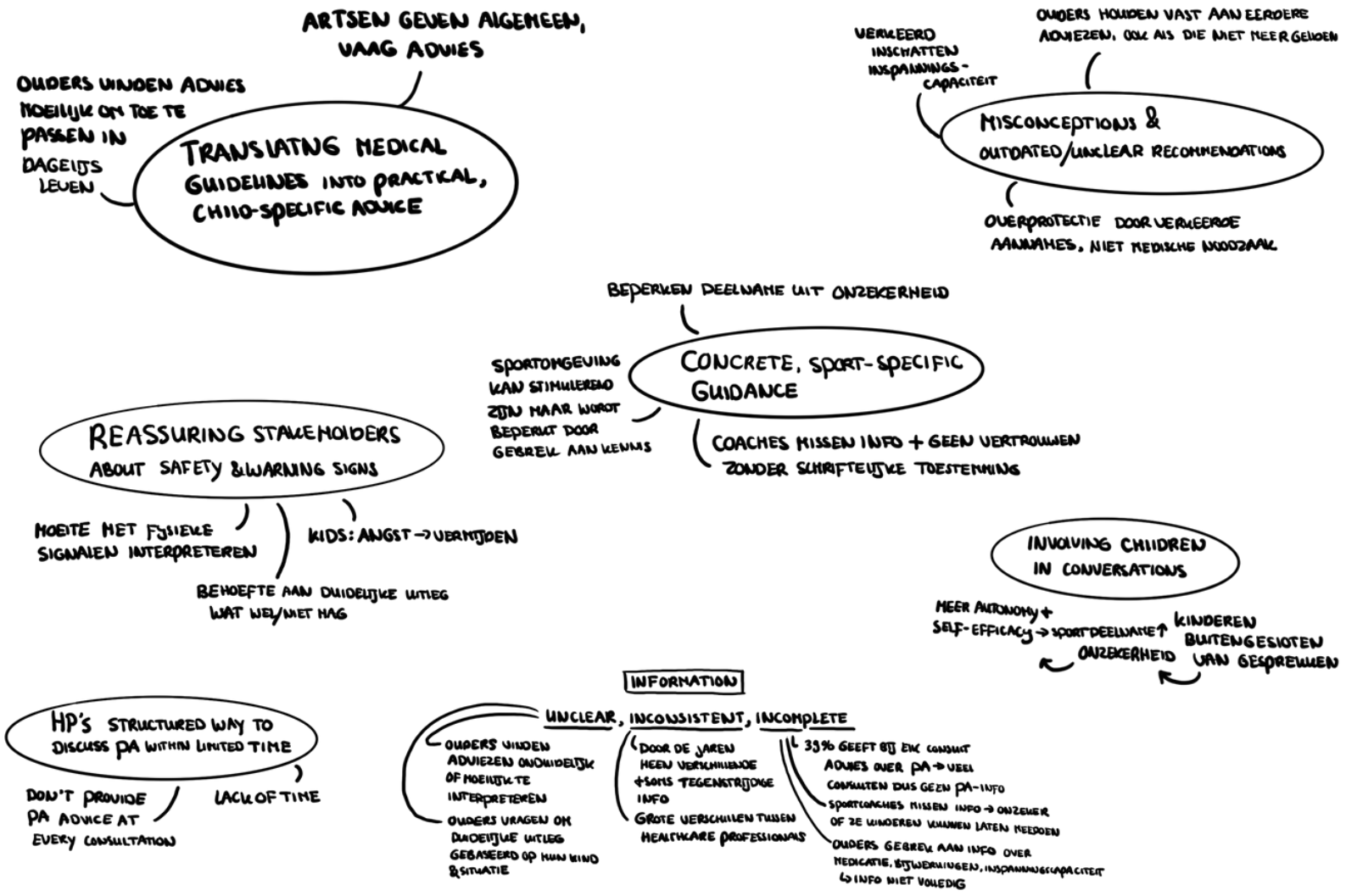
Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

During the elective Design for Children's Play, I worked with children for the first time during my studies. This made me realize how fun, valuable and inspiring I found designing for children, especially during the test phases, because of their enthousiasm and open-mindedness from which I got a lot of feedback. Because of this, I knew that for my graduation project I was looking for a topic related to children.

I find it very important for myself to focus on design that can really make an impact on people. Therefore, I think that designing something within the healthcare industry is a good fit for this. In addition, the topic of heart defects appeals to me personally, partly because heart problems also occur in my family. This project combines my interest in designing for children and impact with a subject that is close to my heart. What I am really looking forward to is the opportunity to work with the target audience, hear their personal stories and develop a solution that makes a real difference.

My personal learning ambitions:
To gain experience in designing for healthcare.
Collaborate with an interdisciplinary team and multiple stakeholders.
Gain knowledge about what barriers children with congenital heart defects, parents and sports teachers experience in sports participation of the children.
Investigating how best to convey information between different audiences.

Appendix B: Elaboration of effective communication elements



Appendix C: Interview guides

Introduction scripts

Introductie script

Bedankt dat u mee wilt doen aan dit interview en hier tijd voor heeft vrij gemaakt. Ik zal mezelf even kort voorstellen. Ik ben Frédérique, ik studeer aan de TU Delft en ben op dit moment bezig met mijn afstudeeropdracht voor de studie Industrieel Ontwerpen.

In mijn onderzoek kijk ik naar hoe de communicatie verloopt over sportdeelname van kinderen met een aangeboren hartafwijking tussen ouders, medische professionals, sportdocenten en de kinderen zelf.

Het doel is om ervaringen, wensen en suggesties van verschillende betrokkenen te verzamelen. Op basis daarvan wil ik iets ontwerpen dat de communicatie makkelijker en duidelijker maakt. Bijvoorbeeld bij het krijgen en delen van informatie of het afstemmen van verwachtingen, zodat deze kinderen met een hartafwijking op een veilige en inclusieve manier kunnen meedoen aan sportactiviteiten. Het gaat daarbij om zowel sportactiviteiten op school als daarbuiten. Vandaar dat ik u graag wil spreken. Dit onderzoek is dus gericht op een interventie in de toekomst, die communicatie kan vergemakkelijken of verbeteren.

Ik ben geen medisch professional, ik geef dus geen advies. Ik ben vooral benieuwd naar uw ervaring, wat u prettig of juist lastig vindt en wat u zou helpen in de communicatie over de gezondheid van uw/het kind in relatie tot sportactiviteiten.

Het gesprek duurt ongeveer *XX* minuten. Het gaat dus puur om het delen van uw ervaringen, er zijn geen goede of foute antwoorden. Als u een vraag liever niet beantwoordt, is dat helemaal prima. U kunt op elk moment pauzeren of stoppen.

Alles wat u vertelt wordt vertrouwelijk behandeld. In de verslaglegging gebruik ik geen namen of gegevens die naar u (of uw kind) te herleiden zijn.

☐ Heeft u het toestemmingsformulier ondertekend?

Is het goed als ik dit gesprek opneem, zodat ik het later kan terugluisteren en analyseren?
(Wachten op toestemming)

Dan start ik nu de opname.

☐ Start opname

Zou u voor de zekerheid op de opname nog even kunnen zeggen dat u akkoord gaat met deelname en met de opname?

Heeft u nog vragen voordat we beginnen?

Introductie script voor jongere kinderen

Hoi, fijn dat jullie mee willen doen met dit interview en tijd hebben vrijgemaakt. Ik zal mezelf eerst even kort voorstellen. Ik ben Frédérique, ik ben 24 jaar en ik woon in Delft. Ik ben bezig met een opdracht voor mijn school. Voor mijn school ontwerp ik nieuwe dingen, dus ik zoek oplossingen voor bepaalde problemen en bedenk ideeën en dan maak ik het. Maar om die nieuwe ideeën te bedenken heb ik wel hulp nodig van mensen die er echt iets van weten.

Voor deze opdracht van mijn school wil ik graag weten hoe kinderen, ouders, artsen en sportleraren met elkaar praten over sporten bij kinderen die iets aan hun hart hebben. Dus daarom praat ik hier vandaag over met jullie.

Ik ben heel benieuwd hoe het bij jou gaat met sporten: wat je leuk vindt, wat goed gaat, wat lastig is, en wat jou zou helpen in de sportles. En ook hoe en met wie je daarover praat.

Met alle verhalen van de kinderen en andere mensen die ik spreek, wil ik straks iets maken dat helpt om makkelijker te praten over sporten bij kinderen die iets aan hun hart hebben, tussen jullie en bijvoorbeeld een sportleraar of iemand in het ziekenhuis. Dan weet iedereen goed wat bij jou past en wordt het hopelijk nog leuker en fijner om mee te doen aan sport en gymlessen.

Het gesprek duurt ongeveer XX minuten. Ik heb eerst een paar vragen aan jou. Je ouder mag daarbij helpen als je dat fijn vindt. Daarna praat ik ook nog even alleen met je ouder.

Ik ben zelf geen dokter, dus kan je niet vertellen wat je wel of niet moet doen voor je gezondheid. Dat weet ik zelf ook niet. Ik ben gewoon benieuwd hoe dat bij jou gaat, naar jullie ervaringen en ideeën.

Er zijn geen goede of foute antwoorden. Je mag altijd zeggen als je er geen zin meer in hebt, als je liever niet antwoordt op een vraag of als je even hulp nodig hebt van je ouder. Wat jullie vertellen gebruik ik voor in mijn schoolverslag. Maar ik schrijf geen namen op, dus mensen kunnen later niet zien dat het van jou of van jullie komt.

Vinden jullie het goed als ik dit gesprek opneem, zodat ik het later kan terugluisteren en niks vergeet?

(wachten op toestemming)

☐ Start opname

Zouden jullie nog voor de zekerheid even willen zeggen dat jullie het goedvinden dat jullie meedoen aan dit interview en dat het opgenomen wordt?

Hebben jullie nog vragen voordat we beginnen?

Interview children

Kinderen

Introductievragen

- Ik heb net iets over mezelf verteld, maar ik ben ook heel benieuwd naar jullie. Zouden jullie misschien iets over jezelf kunnen vertellen? Bijvoorbeeld je naam, hoe oud je bent, in welke klas je zit? + aan de ouder vragen zich voor te stellen.
- Kun je mij iets laten zien dat met jou te maken heeft? Bijvoorbeeld een hobby, een sport die je doet, of iets waar je plezier uit haalt.
- Bijvoorbeeld een knuffel, een tekening of iets dat je leuk vindt om te doen.
    - *Het kind kan thuis iets pakken wat hij/zij leuk vindt om te doen en dat voor de camera laten zien. Ik zelf een voorbeeld erbij pakken om te laten zien.*

Sport en bewegen

- Wat vind jij leuk om te doen als het gaat om sport en bewegen? (Bijvoorbeeld de gymles op school of een sportclub, maar ook bijvoorbeeld buiten spelen, fietsen ofzo…).
- Kun je vertellen welke sporten je doet of hebt gedaan?
    - *Slide laten zien met sportplaatjes en vragen of ze hun sport kunnen aanwijzen.*
    - *Eventueel (ligt aan hoeveelheid tijd): Het kind in huis iets laten pakken wat te maken heeft met zijn/haar (favoriete) sport en dat voor de camera laten zien.*
- Is er een sport die je nog heel graag zou willen doen (maar nu (nog) niet doet)? En waarom?

Ervaringen met sportdeelname

- Hoe vind je de gymles op school? + ingaan op specifieke sport van het kind.
    - *Emoji's laten zien op slide en vragen of het kind kan aanwijzen hoe leuk hij/zij dat vindt.*
    - Wat vind je leuk aan gym of sport?
- Kun je goed meedoen in de sportles? Zijn er dingen die je spannend of moeilijk vindt tijdens het sporten? Eventueel: wat helpt jou om toch mee te doen als je het spannend vindt?
- Zijn er soms dingen die je anders moet doen dan de rest van de klas/het team? (bv. eerder stoppen, een andere oefening). Eventueel: hoe gaat dat dan?

Hartafwijking

- Wil je daar kort iets over vertellen?
- Merk je daar weleens iets van als je aan het sporten bent?

Delen van informatie + communicatie

- Weet je of er ook dingen zijn die je wel of niet mag doen bij het sporten? Wie legt dat dan aan jou uit? Begrijp je dat dan goed?
- Weet je gymleraar of trainer wat er met je hart aan de hand is? Hoe heeft hij/zij dat gehoord?
    - Wil je dat liever zelf vertellen of laat je dat liever aan iemand anders over (bijvoorbeeld je ouder/de school/sportclub/medisch professional)?
    - Of: wie weet er allemaal van je hartafwijking af? Plaatjes laten zien op een slide.
    - Wat vind je ervan dat anderen dat van jou weten? Wie vind je dat daarover mag besluiten?

Behoeften/wensen ten aanzien van (ondersteuning in) informatie-uitwisseling en communicatie

- Wat zou je willen dat je sportcoach/ gymleraar / trainer weet over jouw hart?
- Stel je voor dat je iets kon maken voor gymdocenten om je beter te begrijpen, wat zou dat zijn?

Afrondende vragen

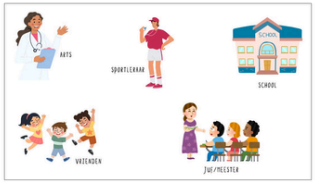
- Dat waren mijn vragen, is er nog iets dat je zelf wil vertellen of vragen?

Dankjewel dat je dit met mij wilde delen, dat helpt mij heel erg!

Ik heb nu nog een paar vragen aan je ouder. Als je wil mag je erbij blijven, maar je hoeft niet meer mee te doen.

[Hierna start het interview met de ouders]

Bijlage: eventueel gebruiken tijdens interview als hulpmiddel bij jonge kinderen:



Interview parents

Ouders

Introductievragen

- Ik heb net met uw kind gepraat over wat hij/zij leuk vindt om te doen. (noem de sporten).
- Kunt u kort iets vertellen over uw kind? Is hij/zij graag actief?
- Uw kind heeft een hartafwijking. Zonder in te veel medische details te gaan, weet u of dit in zijn/haar geval beperkingen met zich mee brengt bij sport of bewegen? Zijn er dingen waar hij/zij rekening mee moet houden bij bewegen of sporten, bijvoorbeeld vanwege zijn/haar hartafwijking?

Ervaringen met en zorgen over sportdeelname

- Ziet u verschillen tussen hoe uw kind sport en bewegen ervaart en hoe u dat zelf ervaart?
- Zijn er momenten dat u zich zorgen maakt als uw kind gaat sporten/aan het sporten is? Kunt u een voorbeeld noemen?
- Zijn er momenten geweest waarop u het lastig vond om te bepalen wat wel of niet veilig was qua sport?
- Wat gaat u om met signalen bij uw kind zoals bijvoorbeeld vermoeidheid, flauwte of benauwdheid? Hoe bepaalt u dan of hij/zij door kan gaan of moet stoppen?
- Bent u zelf weleens onzeker geweest over wat uw kind wel of niet aankan bij bewegen?
- In hoeverre beïnvloeden uw eigen twijfels of zorgen de mate waarin u uw kind stimuleert of afremt om te sporten?
- Gaat uw kind ook naar een fysio, sportarts, ect? Of is het contact alleen met een kindercardioloog?

Delen van informatie

- Met wie deelt u informatie over de gezondheid van uw kind als het gaat om sport (bijvoorbeeld met school of een sportclub)?
- Welke informatie vind u belangrijk om met hen te delen? Zijn er dingen die u liever voor uzelf houdt?
- Hoe ervaart u het delen van die informatie? Gaat dat makkelijk of soms lastig?
- Deelt u deze informatie zelf of is uw kind hierbij ook betrokken? Overlegt u ook met uw kind welke informatie er wordt gedeeld?

Communicatie met anderen

Medische professionals

- Krijgt u van artsen informatie/adviezen over beweging/sportdeelname van uw kind? Wat voor informatie ontvangt u hierover? In welke vorm?
- Wordt uw kind actief bij zo'n gesprek betrokken?
- Hoe/ op welke manier (of überhaupt) bespreekt u gegeven adviezen thuis met uw kind?
-
- Met welke medische professionals heeft u/uw kind contact? Kindercardioloog, fysiotherapeuten, sportarts, etc.?
- Hoe ervaart u de communicatie met medische professionals over sportdeelname? Ervaart u dit contact als laagdrempelig? Heeft u tussen consulten door ook nog contact met medische professionals?
- Hoe goed voelt u zich geïnformeerd over wat uw kind fysiek aankan? Is het advies duidelijk genoeg? Voelt u zich weleens overweldigd door de hoeveelheid informatie ('blijft het hangen')? Hoe gaat u daar dan mee om? Of vind u het weleens verwarrend?
- In hoeverre volgt u dit advies in het dagelijks leven op? Heeft u weleens moeite gehad om het advies van artsen geven toe te passen in het dagelijks leven? Tegen welke obstakels loopt u aan?
- Hoe vaak krijgt u deze (of: nieuwe) informatie en wat doet u daarna met eerder gegeven adviezen?

Sportcoaches

- Hoe verloopt de communicatie met de sportcoaches/ gymdocenten / trainers van uw kind? (-> Misschien specifiek even ingaan op eerder genoemde sporten van het kind en per sport afgaan hoe de communicatie verloopt).
- Zijn er situaties geweest waarin u moeite had om dingen te bespreken met een sportcoach?
- Heeft u weleens meegemaakt dat sportcoaches moeite hadden met verantwoordelijkheid nemen over uw kind (bij het sporten) omdat ze bijvoorbeeld bang waren dat er iets zou gebeuren? Hoe voelt u zich hierover?

Verbeteringen in communicatie en ondersteuning

- Heeft u het gevoel dat u op dit moment goed ondersteund wordt als het gaat om sportdeelname van uw kind?
- Wat denkt u dat u zou helpen om uw kind met meer vertrouwen te laten sporten?
- Wat denkt u dat u zou kunnen helpen om informatie over uw kind makkelijker te kunnen delen?
- Bij wie vindt u dat de verantwoordelijkheid ligt voor het delen van gezondheidsinformatie van uw kind met sportcoaches? Wie zou volgens u het initiatief moeten nemen of de leiding moeten hebben? Bijvoorbeeld bij u zelf, medische professionals, de school/sportclub?
- Zou een communicatietool u hierbij kunnen helpen? Waarom wel/niet? Wat zou een effectieve communicatietool in uw ogen moeten kunnen?
- Wat maakt voor u een advies over sport duidelijk? Is een ja/nee voldoende, of juist met toelichting/uitzonderingen/voorbeelden?
- In welke vorm zou u die informatie het liefst zien (bijvoorbeeld tekst, visual, app, spel, enz.)?
- Denkt u dat het u zou helpen als u iets heeft om mee te kunnen nemen naar/geven aan bijvoorbeeld een sportcoach waarop informatie gedeeld wordt over waar hij/zij rekening mee kan houden?
- Hoe vaak zou u nieuwe of geupdate informatie willen ontvangen over de medische situatie van uw kind?

- Heeft u nog vragen of zijn er nog dingen niet besproken waar u nog iets over kwijt wilt?

Interview sports coaches/ PE teachers

Sportcoaches/ gymleraren

Introductievragen

- Kunt u iets vertellen over uw werk als sportcoach/sportleraar? (Wat voor type sportles, de doelgroep, op een school/sportclub).
- Heeft u hiervoor een specifieke opleiding gedaan? Welke?
- Is een bhv cursus verplicht?
- Heeft u ervaring met het begeleiden van kinderen met medische aandoeningen, zoals aangeboren hartafwijkingen?
    - *Als u geen ervaring heeft met kinderen met een aangeboren hartafwijking, zou ik graag willen weten hoe u denkt dat u hiermee zou omgaan.*
- Hoe ziet een sport- of gymles bij u er doorgaans uit? Kunt u stapsgewijs uitleggen hoe u zo'n les voorbereidt en uitvoert?
- Worden rollen in de sportactiviteit door u toegewezen (zoals keeper, aanvaller, scheidsrechter), of kiezen kinderen dat zelf? Hoe bepaalt u wie wat doet?

Omgaan met kinderen met een aangeboren hartafwijking tijdens sportlessen

**in het geval dat de deelnemer geen ervaring heeft met kinderen met een aangeboren hartafwijking vraag ik hoe diegene denkt dat hij/zij ermee zou omgaan*

- Hoe kijkt u aan tegen sportdeelname van kinderen met een aangeboren hartafwijking (voor zover u daar iets over weet)?
- Heeft u weleens informatie gekregen over hoe om te gaan met kinderen met een medische aandoening zoals een hartafwijking in sportlessen? Is dit onderwerp weleens aan bod gekomen tijdens bijvoorbeeld uw opleiding of een training?
- Hoe merkt u tijdens de les of een kind fysieke beperkingen heeft? Of een kind bijvoorbeeld signalen geeft zoals vermoeidheid, flauwte of benauwdheid? Geven zij dit dan zelf aan?
- Stel dat je het advies krijgt dat een kind "matig intensief kan sporten", weet je hier dan mee om te gaan? En statische en dynamische inspanning?
- Hoe gaat u (in het algemeen) om (of denkt u om te gaan) met beperkingen of medische bijzonderheden van kinderen tijdens uw lessen?
- Hoe gaat u om (of denkt u om te gaan) met signalen bij een kind zoals bijvoorbeeld vermoeidheid, flauwte of benauwdheid? Hoe bepaalt u dan of het kind door kan gaan of moet stoppen?
- Stel dat u een kind met een aangeboren hartafwijking in de sport/gymles heeft, in hoeverre voelt u zich zeker over wat een kind met een aangeboren hartafwijking wel of niet aankan?
- Delen ouders (of kinderen), collega's of andere kinderen weleens zorgen met u over sportdeelname van een kind? Wat voor zorgen zijn dit vooral?
- Hoe gaat u om met signalen van vermoeidheid, zweten of pijn bij een kind?
- In hoeverre bent u weleens bang of onzeker dat er iets mis kan gaan tijdens een sport/gymles (bijvoorbeeld bij een kind met een hartafwijking)? Kunt u een voorbeeld geven?
- Hoe beïnvloedt uw eigen angst/onzekerheid/terughoudendheid de mate waarin u het kind stimuleert of juist afremt om te sporten?
- Hoe probeert u kinderen zelfvertrouwen te geven in hun eigen kunnen tijdens de sport/gymles?
- In hoeverre ervaart u het als een uitdaging om meerdere kinderen tegelijk te begeleiden, inclusief kinderen met medische behoeften? Hoe balanceert u aandacht en veiligheid?

Delen van informatie/communicatie met anderen

- Hoe wordt u meestal geïnformeerd over de medische achtergrond van kinderen? En door wie? (Bijvoorbeeld door de ouders, het kind zelf, de school/sportclub, medische professionals).
- Welke informatie ontvangt u vaak wel of juist niet?
- Hoe vaak ontvangt u dit soort informatie? Is dat bij elk schooljaar, bij het eerste contact met een kind, of bijvoorbeeld alleen als er een medisch consult is geweest?
- Hoe goed voelt u zich geïnformeerd over wat het kind fysiek aankan? Is het advies duidelijk genoeg en goed toepasbaar in de lessen? Eventueel: tegen welke obstakels loopt u aan?
- Heeft u de mogelijkheid of behoefte om na afloop van een les iets terug te koppelen aan ouders of medische professionals over hoe het is gegaan? Zo ja, hoe zou dat het beste kunnen?

Verbeteringen in communicatie en ondersteuning

- Vind u dat u genoeg ondersteund wordt in het begeleiden van kinderen met een aangeboren hartafwijking in de sportles?
- Wat denkt u dat u zou kunnen helpen om het kind op een meer inclusieve manier te laten meedoen in de sportles?
- Zijn er dingen die u op dit moment mist in de communicatie rond sport en hartafwijkingen?
- Bij wie vindt u dat de verantwoordelijkheid ligt voor het delen van gezondheidsinformatie van het kind met u? Wie zou volgens u het initiatief moeten nemen of de leiding moeten hebben? Bijvoorbeeld de ouder, medische professionals, de school/sportclub, of u zelf?
- Met wie zou u het liefst hierover communiceren? (vergeleken met wie de sportdocent nu communiceert -> eerdere vraag)
- Zou het voor u toegevoegde waarde hebben om in direct contact te staan met een medische professional als u vragen heeft? Wat zou dat eventueel kunnen verbeteren?
- Welke informatie zou u nodig hebben om een kind goed te begeleiden?
- Zou u meer behoefte hebben aan algemene achtergrondinformatie of praktische tips en handvaten?
- Wat maakt voor u een advies over sport duidelijk? Is een ja/nee voldoende, of juist met toelichting/uitzonderingen/voorbeelden?
- Zou een communicatietool u hierbij kunnen helpen? Waarom wel/niet? Wat zou een effectieve communicatietool in uw ogen moeten kunnen?
- In welke vorm zou u die informatie het liefst zien (bijvoorbeeld tekst, visual, app, spel, enz.)?
- Welke vormen van informatie vindt u het meest bruikbaar in de context van uw sportlessen? (Bijv. pictogrammen, kleuren, korte beschrijvingen, risiconiveaus, voorbeeldactiviteiten)
- Welke informatie zou u daarin willen/kunnen toevoegen?
- Zou u een tool ook willen gebruiken tijdens de les (bijvoorbeeld als naslag of signaalmiddel), of liever vooraf/thuis?
- Hoe vaak zou u nieuwe of geupdate informatie willen ontvangen over de medische situatie van een kind?
- Hoeveel tijd heeft u (realistisch gezien) om informatie voorafgaand aan een les te bekijken of voor te bereiden?

- Heeft u nog vragen of zijn er nog dingen niet besproken waar u nog iets over kwijt wilt?

*The questions highlighted in purple were added after feedback from supervisors and insights from the interviews that had already been conducted.

Interview healthcare professionals

Medische professionals

Introductievragen: rol en visie op sportdeelname

- Kunt u iets vertellen over uw rol in de begeleiding of behandeling van kinderen met een aangeboren hartafwijking?
- Hoe belangrijk vindt u sport en beweging voor deze groep kinderen?
- Waar liggen volgens u de grootste risico's en kansen bij sportdeelname voor deze kinderen?

Adviezen over sportdeelname

- Wat is uw ervaring met het geven van sportadvies aan kinderen met een aangeboren hartafwijking? / Geeft u ouders/kinderen adviezen over hoe om te gaan met sportdeelname en de hartafwijking?
    - *op basis waarvan geven ze nu advies, wat zijn belangrijke elemente/variabelen die ze moeten weten om persoonlijk en specifiek advies te kunnen geven, hoe specifiek zit hun advies nu in elkaar, hoe vaak updaten ze dat advies?*
- Wordt de fysieke activiteit van kinderen met een aangeboren hartafwijking weleens gemeten? Hoe?
    - Voert u inspanningstesten uit bij kinderen met een aangeboren hartafwijking? Zo ja, hoe interpreteert u de resultaten in relatie tot sportadvies?
    - Op basis waarvan bepaalt u of een kind veilig kan deelnemen aan een bepaalde sport? (Bijv. hartfunctie, fysieke fitheid, risicoprofiel sport)
- Hoe ziet dit advies er meestal uit? Zijn er protocollen of hulpmiddelen? Hoe bespreekt u dat met ze?
    - Welke informatie vindt u essentieel om een goed sportadvies te kunnen geven? Wordt deze informatie altijd beschikbaar gesteld tijdens het consult?
    - Neemt u bij het advies ook psychosociale aspecten mee, zoals motivatie van het kind of angst van de ouders?
    - Hoe actueel blijft uw advies? Wordt het periodiek aangepast, en zo ja, wanneer of op basis waarvan?
    - Zijn deze adviezen/aanbevelingen afgestemd op de interesses van het kind en het type activiteit (schoolplein/gymles/ georganiseerde sport buiten school, individuele/team sport) of puur op het type hartafwijking? Worden ook de intensiteit, duur en frequentie van de meegenomen?
- Hoe ziet het verschil in begeleiding of follow-up eruit tussen kinderen met complexe en minder complexe hartaandoeningen?
- Ook bij kinderen zonder medische beperkingen: merkt u dat er toch vragen of onzekerheid over sport zijn?
- Zijn er situaties waarin u sportdeelname zou afraden of juist extra stimuleren?
- Zijn er momenten geweest/ Kunt u een situatie beschrijven waarop u het moeilijk vond om te bepalen welke sport/activiteit wel of niet veilig is?
- Bespreekt u het advies vooral met ouders, kinderen, of beiden? Waarom?
- Hoe vaak geeft u deze adviezen?
- Heeft u zicht op het daadwerkelijke beweeggedrag van het kind? Wordt dat besproken of gemeten?

Ervaringen en zorgen van ouders/kinderen

- Krijgt u weleens terugkoppeling van ouders over hoe het advies uitpakt in het dagelijks leven?
- Delen ouders (of kinderen) weleens zorgen met u over sportdeelname van het kind? Wat voor zorgen zijn dit vooral? Hoe gaat u hiermee om?
    - Heeft u het idee dat ouders soms voorzichtiger zijn dan nodig is? Hoe gaat u daarmee om?

Delen van informatie/communicatie met anderen

- Hoe verloopt de afstemming met andere zorgprofessionals (bijv. cardioloog, fysiotherapeut, huisarts) bij het opstellen van beweegadviezen?

Ouders/kinderen

- Hoe zorgt u ervoor dat de informatie/adviezen duidelijk toe te passen zijn in de praktijk?
- Verwijst u ouders/kinderen weleens door naar bijvoorbeeld websites met extra informatie over sporten en hartafwijkingen?
- Worden ouders/kinderen doorverwezen naar specialisten voor begeleiding, zoals bewegingswetenschappers of fysiotherapeuten?

Sportcoaches

- Hoe verloopt de communicatie tussen ouders, kinderen, sportcoaches/ gymdocenten / trainers en u? Loopt u tegen obstakels aan?
- Krijgt u weleens vragen van sportcoaches of scholen over wat kinderen met CHD wel of niet mogen doen?
- Welke informatie over sportdeelname van kinderen met een hartafwijking vindt u essentieel om door te geven aan sportcoaches?
    - Welke concrete informatie vindt u belangrijk dat sportcoaches ontvangen? (bijv. max hartslag, vermoeidheidssignalen, duur/intensiteit)
    - Wordt deze informatie structureel gedeeld of ligt dat bij ouders?
    - In uw ervaring, wie neemt meestal het initiatief in het informeren van sportcoaches, de ouders of uzelf?

Verbeteringen in communicatie en ondersteuning

- Zijn er dingen die u op dit moment mist in de communicatie rond sport en hartafwijkingen?
- Wat zou u helpen om ouders, kinderen (en/of sportdocenten/-coaches) beter te informeren of adviseren? (bijv. tijd, training, richtlijnen, tools).
- Bij wie vindt u dat de verantwoordelijkheid ligt voor het delen van gezondheidsinformatie van een kind met sportcoaches? Wie zou volgens u het initiatief moeten nemen of de leiding moeten hebben? Bijvoorbeeld de ouders, de school/sportclub, u zelf?
- Zou een communicatietool u hierbij kunnen helpen? Waarom wel/niet? Wat zou een effectieve communicatietool in uw ogen moeten kunnen?
- Hoe ziet u een duidelijk en bruikbaar advies over sportdeelname voor zich? ? Is een ja/nee voldoende, of juist met toelichting/uitzonderingen/voorbeelden?
- In welke vorm zou u die informatie het liefst zien (bijvoorbeeld tekst, visual, app, spel, enz.)?
- Welke informatie zou u daarin willen/kunnen toevoegen?
- Hoe vaak denkt u dat het nuttig is om informatie over de medische situatie van het kind te updaten?

- Heeft u nog vragen of zijn er nog dingen niet besproken waar u nog iets over kwijt wilt?

*The questions highlighted in purple were added after feedback from supervisors and insights from the interviews that had already been conducted.

Appendix D: Blank consent form

**In het geval dat de deelnemer internationaal is, wordt dit document vertaald naar het Engels.*

Informatie en toestemming

Doelgroep – medische professionals en sportcoaches

Ontwerp van een communicatietool voor sportdeelname van kinderen met een aangeboren hartafwijking

U wordt uitgenodigd deel te nemen aan een onderzoek genaamd "Ontwerp van een communicatietool voor sportdeelname van kinderen met een aangeboren hartafwijking". Dit onderzoek wordt uitgevoerd door Frédérique Pel, als onderdeel van een afstudeerproject van de Master Integrated Product Design aan de TU Delft, in opdracht van het Erasmus MC.

Doel van het onderzoek

Het doel van het onderzoek is om de communicatie tussen zorgprofessionals, ouders, kinderen en sportdocenten te verbeteren rondom sportdeelname van kinderen met een aangeboren hartafwijking. Met behulp van uw ervaringen, wensen en/of suggesties wordt een communicatietool ontwikkeld die deze groepen ondersteunt bij het delen van informatie en verwachtingen, zodat kinderen op een veilige en inclusieve manier kunnen meedoen aan sport.

U kunt gevraagd worden om deel te nemen aan één of meer van de volgende onderdelen:

☐ Een interview

In een interview wordt u gevraagd naar uw ervaring met het begeleiden of behandelen van kinderen met een aangeboren hartafwijking in relatie tot sport.
Vragen kunnen gaan over:

- Communicatie tussen ouders, kinderen, zorgprofessionals en sportdocenten
- Uw ervaringen, wensen en/of suggesties rondom het delen/krijgen van informatie over de gezondheid van het kind in relatie tot sportactiviteiten.
- Zorgen, obstakels of behoeften die u ziet bij sportdeelname van de kinderen

☐ Een co-creatie sessie

In een kleine groepssessie werkt u samen met andere betrokkenen aan ideeën of oplossingen die de communicatie kunnen verbeteren.
U wordt gevraagd om:

- Mee te denken over mogelijke functies of vormen van een communicatietool
- Te reageren op voorbeelden of scenario's
- Uw ervaringen, wensen en/of suggesties te delen in de brainstormsessie als input voor oplossingsrichtingen

☐ Een testsessie voor het evalueren van een prototype

U krijgt een (fysiek of digitaal) prototype te zien.
U wordt gevraagd om:

- Het product te bekijken of te testen
- Feedback te geven over begrijpelijkheid, toepasbaarheid en effectiviteit
- Mogelijke verbeterpunten te noemen

Gegevensverzameling en privacy

Tijdens het onderzoek kunnen de volgende gegevens verzameld worden:

- Uw functie/rol, professionele of persoonlijke ervaringen en mening
- Uw antwoorden gedeeld in een interview, tijdens gesprekken of in de sessies.
- Uw naam en handtekening op het toestemmingsformulier. Dit formulier wordt apart en veilig opgeslagen en niet gekoppeld aan de onderzoeksgegevens (zoals gedeelde ervaringen of materialen).
- Mogelijk: naam of e-mailadres (alleen voor administratieve doeleinden, wordt niet gepubliceerd)

Audio-opnames

Als u akkoord gaat, worden interviews opgenomen (audio). Deze opnames worden getranscribeerd (uitgeschreven). In de analyse en verslaglegging worden geen namen of herleidbare informatie gebruikt. Citaten kunnen worden gebruikt in de rapportage, zonder dat deze herleidbaar zijn naar u persoonlijk.

Foto's/video's

Mogelijk worden er tijdens sessies foto's/video's gemaakt. Deze worden enkel gebruikt voor analyse en verslaglegging en u zult niet herkenbaar in beeld worden gebracht. Als u herkenbaar in beeld bent (bijvoorbeeld uw gezicht), dan worden deze beelden direct na de opname geblurred. Alleen de geblurde versies worden bewaard. De originele, onbewerkte beelden worden direct verwijderd zodra de bewerkte versie is gemaakt.

Beveiliging van data

Persoonsgegevens (zoals naam, e-mailadres of handtekening) en onderzoeksgegevens (zoals gedeelde ervaringen of meningen) worden apart van elkaar bewaard. Alleen de onderzoeksgegevens worden gedeeld met het Erasmus MC voor eventueel aanvullend onderzoek en analyse. De persoonsgegevens worden apart opgeslagen en niet gedeeld. De bewaartermijn is 10 jaar.

Voor aanvullende vragen over dataopslag of -verwerking kunt u contact opnemen met het onderzoeksteam via f.c.m.pel@student.tudelft.nl. Na 5 december 2025 kunt u contact opnemen via j.w.hoftijzer@tudelft.nl.

Vrijwillige deelname

Uw deelname aan dit onderzoek is volledig vrijwillig, en u kunt zich elk moment terugtrekken zonder reden op te geven. U bent vrij om vragen niet te beantwoorden.

Mogelijke risico's

Gesprekken kunnen mogelijk persoonlijke of gevoelige onderwerpen aanraken. U bent altijd vrij om vragen over te slaan of te stoppen wanneer u dat wilt, zonder consequenties.

Contact information researcher

Bij vragen, opmerkingen of klachten kunt u contact opnemen met:

Frédérique Pel
Master student Integrated Product Design
F.C.M.Pel@student.tudelft.nl

TU Delft

Healthy Start
improving the future for new generations

Erasmus MC
Sophia Kinderziekenhuis

Toestemmingsverklaring

Wilt u per onderdeel aangeven of u akkoord gaat?

A. ALGEMENE TOESTEMMING VOOR DEELNAME

Ik geef toestemming om deel te nemen aan de volgende onderdelen van het onderzoek (kruis aan wat van toepassing is):

☐ Een interview
☐ Een co-creatie sessie
☐ Een testsessie voor het evalueren van een prototype

Ik heb de informatie over het onderzoek, gedateerd [../../....], gelezen of deze is aan mij voorgelezen. Ik heb de gelegenheid gehad om vragen te stellen. Mijn vragen zijn voldoende beantwoord.
☐ JA ☐ NEE

Ik doe vrijwillig mee aan dit onderzoek en weet dat ik op elk moment mag stoppen of vragen mag overslaan zonder hiervoor een reden te geven.
☐ JA ☐ NEE

Ik geef toestemming voor het maken van een audio-opname van mijn gesprek (bv. tijdens het interview of de sessies).
☐ JA ☐ NEE

Ik geef toestemming voor het maken van een foto/video-opname tijdens een groepssessie of testsessie. Als ik herkenbaar in beeld ben, worden deze beelden direct na de opname onherkenbaar gemaakt (geblurred). Alleen de geblurde versies worden opgeslagen en gebruikt, de originele beelden worden direct verwijderd.
☐ JA ☐ NEE

B. MOGELIJKE RISICO'S EN GEGEVENSBESCHERMING

Ik begrijp dat mijn deelname weinig tot geen risico's met zich meebrengt, en dat ik altijd vragen mag overslaan of mag stoppen als ik mij ongemakkelijk voel.
☐ JA ☐ NEE

Ik begrijp dat mijn identiteit wordt beschermd via pseudonimisering in transcripten en op foto's/in video's en dat er beperkte toegang is tot deze gegevens, zoals eerder beschreven.
☐ JA ☐ NEE

Ik begrijp dat identificerende informatie zoals naam, e-mailadres en handtekening alleen gebruikt wordt voor administratieve doeleinden binnen het onderzoeksteam en niet wordt gedeeld met derden.
☐ JA ☐ NEE

C. PUBLICATIE EN TOEPASSING VAN RESULTATEN

Ik geef toestemming voor het gebruik van gepseudonimiseerde resultaten (zoals niet-herleidbare citaten, beeldmateriaal) in een masterscriptie, presentatie of projectvideo.
☐ JA ☐ NEE

D. OPSLAG EN TOEKOMSTIG HERGEBRUIK VAN DATA

Ik geef toestemming om de gepseudonimiseerde data (zoals transcripten of notities) die over mij verzameld worden gearchiveerd worden in de TU Delft repository zodat deze gebruikt kunnen worden voor toekomstig onderzoek en onderwijs.

☐ JA ☐ NEE

Ik geef toestemming om de gepseudonimiseerde data (zoals transcripten of notities) die over mij verzameld worden te delen met het Erasmus MC voor verdere analyse, onderzoek, (wetenschappelijke) publicatie en presentatie.

☐ JA ☐ NEE

Naam deelnemer	Naam onderzoeker
----------	----------
Handtekening deelnemer	Handtekening onderzoeker
----------	----------
Datum	Datum
----------/----------/----------	----------/----------/----------

Appendix E: sources related to journey maps

The following overview shows the specific sources related to the journey statements in Chapter 4.1. These include both literature sources and references to evidence that is explained in more detail in specific subsections of section 3.3 of the interview results.

Stage | **Consult with pedriatic cardiologist**

People involved

Children with CHD	Parents	Pediatric cardiologist
		

Possible emotions

*These emotions are possible and based on insights from both literature and interviews. Experiences vary between individuals, not every stakeholder will feel all of these emotions.

Children with CHD	Parents	Pediatric cardiologist
■ Uncertainty ***(Longmuir, 2021)*** ■ Feeling of being different ***(Longmuir, 2021)*** ■ Lack of knowledge about the impact of their condition ***(Longmuir, 2021)*** **partly because they were not included in conversations between their parents and healthcare providers.*	▲ Reassurance after the hospital check ***(§3.3.2.2.D)*** ▲ Increased trust when professionals confirm that physical activity is safe ***(§3.3.2.2.D)*** ▲ Possible hesitation to ask questions if the consultation feels time-pressured ***(§3.3.2.1.B2b)*** ▲ Nervous feeling before a hospital visit ***(R-F3-P)***	

Challenges/obstacles/ pain points

What barriers or difficulties are they experiencing? What isn't working well?

Children with CHD	Parents	Pediatric cardiologist
● Children may not recall having conversations with their doctor about PA ***(Longmuir, 2021) (§3.3.2.1.B1)*** ● PA conversations often perceived as restrictive rather than empowering ***(Longmuir, 2021) (§3.3.2.3. C)*** ■ Feeling uncertain about their condition and what it means for daily life ***(Longmuir, 2021)*** ● Difficulty interpreting bodily signals and understanding personal limits ***(§3.3.2.3.A) (Buchanan et al., 2023)***	● Difficulty translating general advice into practical, daily-life decisions ***(Longmuir, 2021) (§3.3.2.3. C)*** ● Advice often perceived as too general or vague ***(§3.3.2.1.B2) (Longmuir, 2021)*** ■ Accumulating old advice over time → confusion about what still applies ***(Longmuir, 2021)*** ■ Assumptions from clinicians about low activity levels may increase parental doubt ***(Longmuir, 2021)*** ▲ Need reassurance that physical activity is safe ***(§3.3.2.2.D)***	● Time pressure during consultations ***(Williams, 2017; Longmuir, 2022) (§3.3.2.1.B2b)*** ▲ Little time to ask follow-up questions or discuss PA in depth ***(§3.3.2.1.B2b)*** ▲ Variation between cardiologists and available time determines how extensively PA is discussed ***(§3.3.2.1.B2c)*** ▲ Children who visit only once every few years may fall out of view ***(§3.3.2.1.G)*** ▲ Difficult to give specific PA advice without sufficient contextual information, such as the current PA level of the child ***(§3.3.2.1.B2b)*** ● Information provided based on assumptions by the cardiologist may not match priorities of the child ***(Etnel et al., 2017) (§3.3.2.1.B2a)*** ■ Limited awareness of the relatively low risk of physical activity for most children with CHD ***(Roston et al., 2013)*** ■ Limited knowledge of available PA resources or programmes for children ***(Saxena et al., 2021)*** ▲ Few referrals to physical therapists or other professionals, although helpful. No guidelines for referral ***(§3.3.2.1.F)*** ▲ Minimal referral to external information platforms for parents and children ***(§3.3.2.1.I)***

Stage | **Sports class**

People involved

Children with CHD	Parents	Sports coach/ PE teacher
		

Possible emotions

*These emotions are possible and based on insights from both literature and interviews. Experiences vary between individuals, not every stakeholder will feel all of these emotions.

Children with CHD	Parents	Sports coach/ PE teacher
● Feeling limited by symptoms or needing to pause when noticing bodily signals (breathlessness, fatigue) ***(Chong et al, 2018) (§3.3.2.3.A)*** Worry or uncertainty about bodily signals ***(Buchanan et al., 2023) (§3.3.2.3.A)*** Feeling different or weaker than peers ***(Buchanan et al., 2023) (§3.3.2.3.B)*** Feeling good when joining peers and not standing out ***(Longmuir, 2021) (§3.3.2.3.B)*** ■ Children who want to be active can be frustrated by parents limiting their physical activity ***(Longmuir, 2021)***	● Feels fear and overprotection about the child's ability to participate in sports ***(Longmuir, 2021; Saxena et al., 2023; Ong et al., 2011) (§3.3.2.2.D)*** Uncertainty about how to inform other people about their child's condition ***(§3.3.2.4.B)*** Doubts in making decisions, such as whether or not to allow certain activities ***(Longmuir, 2021) (§3.3.2.2.D)***	● Uncertainty and lack of information lead to anxiety and fear of exercise for people with CHD when making decisions about PA and sports participation ***(Longmuir, 2021; Saxena et al., 2023) (§3.3.2.4.B&C)*** Uncertainty about how to respond to symptoms ***(§3.3.2.4.A3&C)***

Challenges/obstacles/ pain points

What barriers or difficulties are they experiencing? What isn't working well?

Children with CHD	Parents	Sports coach/ PE teacher
● Physical symptoms may reduce full participation ***(Chong et al., 2018) (§3.3.2.3.A)*** ■ Symptoms not always CHD-related (deconditioning / cardiac anxiety) ***(Buchanan et al., 2023)*** ■ Early exhaustion lowering self-efficacy ***(Buchanan et al., 2023)*** ● Lack of clear safety guidance → overexertion or avoidance ***(§3.3.2.3.A)*** ■ Comparing performance with peers may lower perceived competence (keeping up), which can affect participation ***(Buchanan et al., 2023; Chong et al., 2023)*** ■ Fun with peers is a facilitator, not keeping up is a barrier ***(Longmuir, 2021)*** ■ Negative social experiences (exclusion, judgement, feeling "less capable") reducing enjoyment & motivation ***(Buchanan et al., 2023; Chong et al., 2023)***	● Lack of clarity about what is safe in sports environments ***(Saxena et al., 2023) (§3.3.2.3.C)*** ■ Fear and overprotection leading to unnecessary restriction of activities ***(Longmuir, 2021)*** ■ Uncertainty about bodily signals → fear of overexertion or stopping unnecessarily ***(Buchanan et al., 2023) (§3.3.2.3.A)*** Parental overprotection lowering their child's PA self-efficacy ***(Buchanan et al., 2023)*** ▲ Tension between encouraging enjoyment, trusting their child's bodily signals, and ensuring safety during sports ***(§3.3.2.2.C)***	● Limited understanding of CHDs and what they mean for sports participation ***(Longmuir, 2021; Saxena et al. 2023) (§3.3.2.4.B)*** ● Lack of training or tools to confidently guide children with CHD ***(Longmuir, 2021; Saxena et al. 2023) (§3.3.2.4.B)*** ▲ Relying heavily on information from parents, which may be incomplete, inconsistent or unclear ***(§3.3.2.2.A1)*** ● Lack of effective communication, between school/sportsclub, parents, children and healthcare professionals ***(Saxena et al., 2023) (§3.3.2.2.A)*** ● Lack of clear, written PA guidelines makes coaches uncomfortable to include children with CHD in sports ***(Longmuir, 2021) (§3.3.2.4.D)*** ▲ Uncertainty about responsibility and monitoring on symptoms ***(§3.3.2.4.A3)*** ■ Focus on performance can unintentionally exclude or discourage children with CHD ***(Longmuir, 2021)*** ▲ Difficulty managing a full group of children while also monitoring and supporting individual medical needs ***(§3.3.2.4.A3)***

Appendix F: Inspiring tools, platforms and initiatives

Beweegredenentest
The Beweegredenentest from Sportbedrijf Rotterdam is an online questionnaire that gives users insight into their personal motivation for physical activity. Rather than focusing on physical skills, the test explores why someone enjoys being active. Based on the answers, an exercise profile is generated, such as Presteerder (Performer), Ontmoeter (Socializer) or Belever (Experiencer). The underlying principle is that children remain motivated longer when their sport or activity matches what they enjoy doing.
(Sportbedrijf Rotterdam, n.d.).

So Fit & Fun
So Fit & Fun is an initiative of the Sophia Children's Hospital to enable children with chronic heart, lung, or airway conditions to exercise in a safe and enjoyable way. In a playful environment, children are tested to determine what they are capable of and are given a personalized exercise and lifestyle program. The goal of the center is to improve children's exercise capacity and increase children's confidence and enjoyment in being active.
(Vrienden van het Sophia Kinderziekenhuis, 2023).

Esther Vergeer Foundation
The Esther Vergeer Foundation supports children with physical disabilities or chronic illnesses in finding a suitable sport and a sports club in their neighborhood.
(Esther Vergeer Foundation, n.d.).

Patiëntenvereniging voor Aangeboren Hartafwijkingen
The website of the Patiëntenvereniging voor Aangeboren Hartafwijkingen provides extensive background information on different types of congenital heart defects and what they mean for daily life. It also offers practical advice on topics such as school, sports, nutrition and psychological wellbeing, and organises peer-support events and information sessions for families.
(Patiëntenvereniging Aangeboren Hartafwijkingen, 2025).

Cyberpoli Hartenkinderen
Cyberpoli Hartenkinderen is an online platform for children and adolescents with congenital or chronic heart conditions. It provides accessible medical information through animations and videos, as well as interviews and personal stories from other young people with CHD. The platform also offers the option to ask questions directly to doctors and other experts.
(Hartenkinderen | Cyberpoli, n.d.).

Waaier het samen op maat
The "Waaier het samen op maat" brochure from Stichting Zorgeloos naar School is intended for all children with a chronic physical condition in mainstream education to inform and establish agreements between the child, parent and school. The brochure provides information about chronic conditions in general, a checklist of discussion points, tips and a list of additional resources.

Beter Dichtbij app
With the BeterDichtbij app, patients can securely send messages to their healthcare providers, ask questions, and read back information about their treatment at any time.
(BeterDichtbij, 2025).

Hartpaspoort
The Hartpaspoort is developed for children with CHD who attend primary school and contains medical information and practical points of attention, so that teachers and school staff know how to properly support the child.
(Hartpaspoort - Patiëntenvereniging Aangeboren Hartafwijkingen, 2022).

Digizorg app
Digizorg is the patient app of Erasmus MC, where patients can view appointments, medical letters, test results and questionnaires. Patients receive notifications when new information becomes available and can store documents in one central location.
(Erasmus MC, 2025).

Siilo
Siilo is a secure platform that allows healthcare providers with a BIG-registration to consult with each other quickly and securely, even with colleagues whose contact details they do not yet have. The app is used to exchange medical questions and patient cases.

VIPLive
A secure communication platform where patients and healthcare providers can exchange messages, forms and medical information.
(VIPLive, n.d.)

Zivver
A secure system for sending privacy-sensitive emails and documents.
(Zivver Ltd., n.d.).

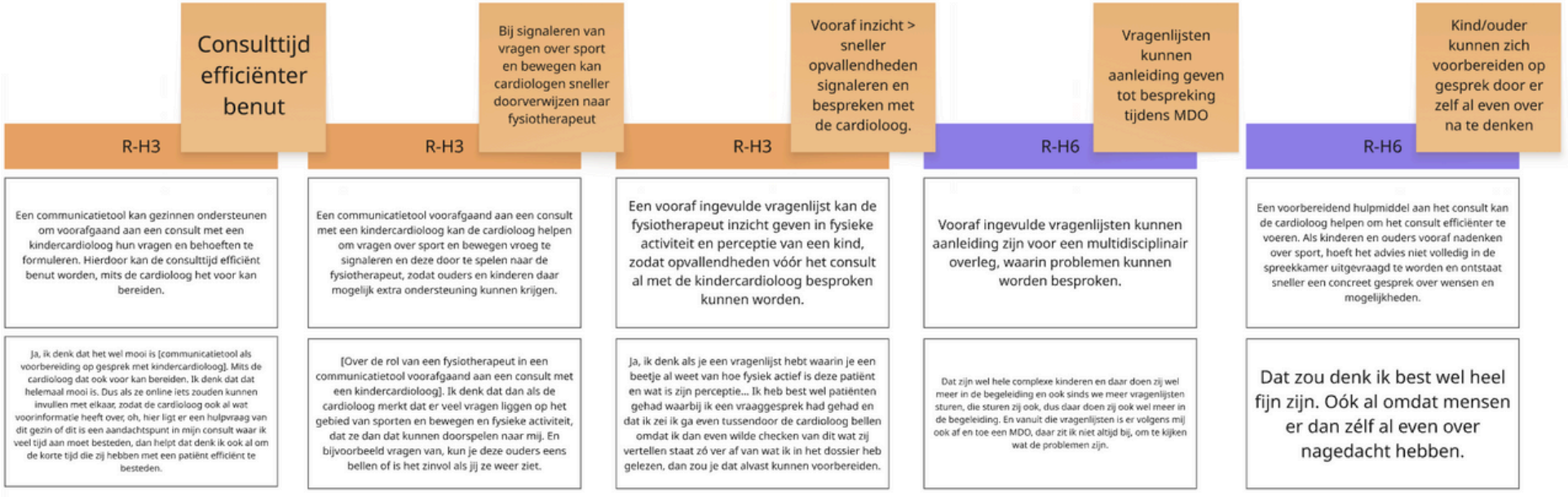
Appendix G: Statement cards

Statement cards on the shared platform concept, pre-consultation questionnaire and tool ideas and content suggestions

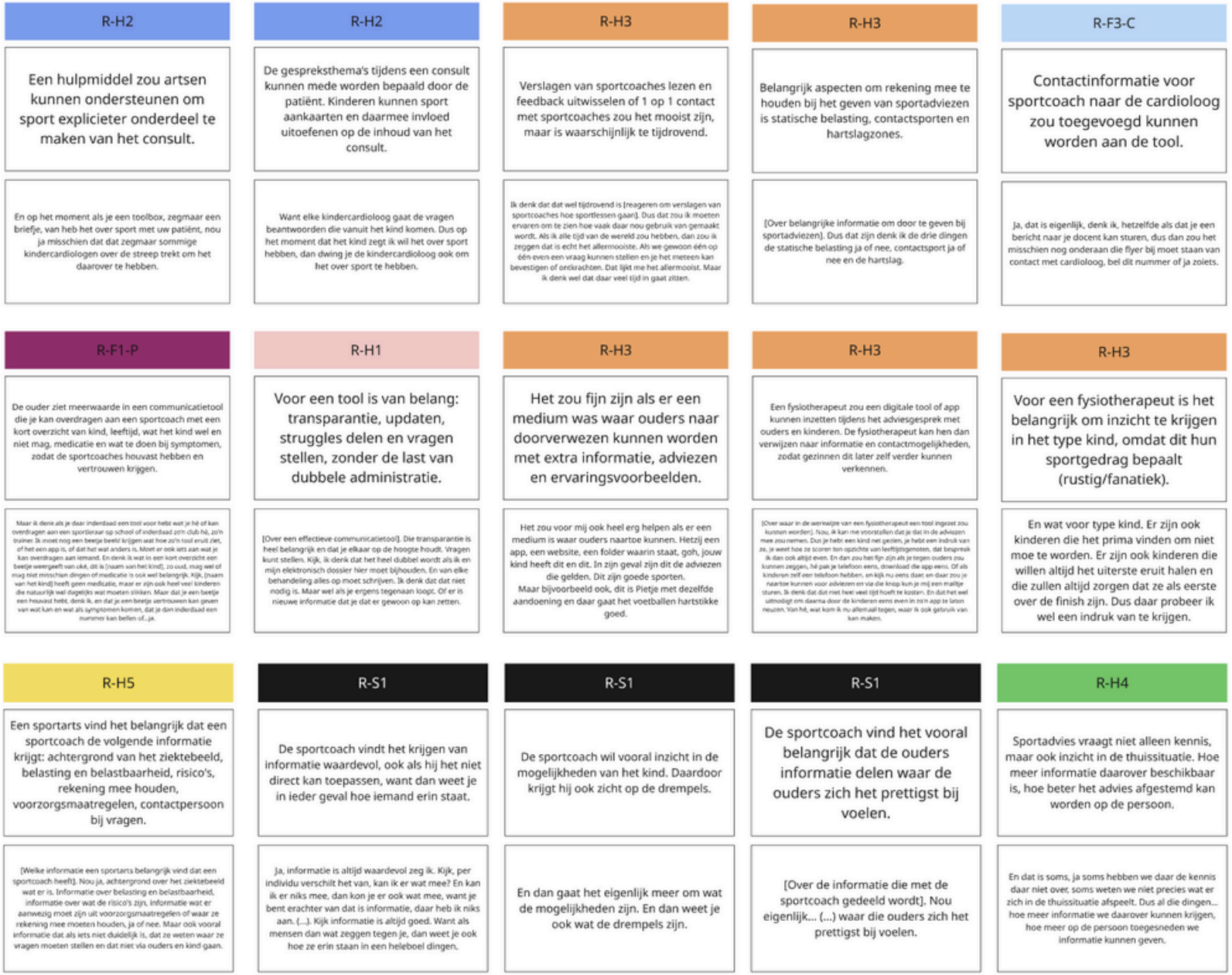
Shared platform

Tool ideas from stakeholders

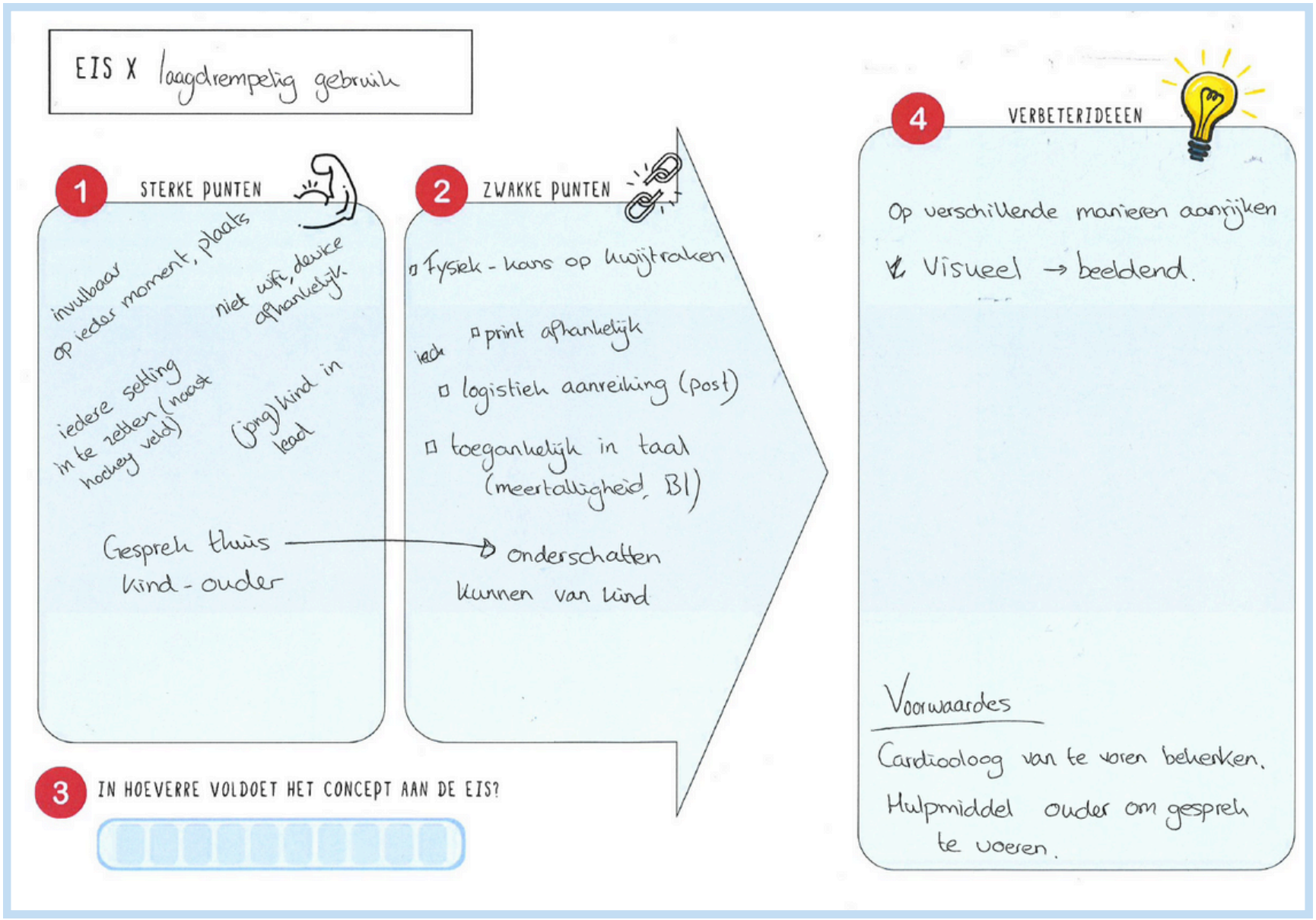
Pre-consultation questionnaire

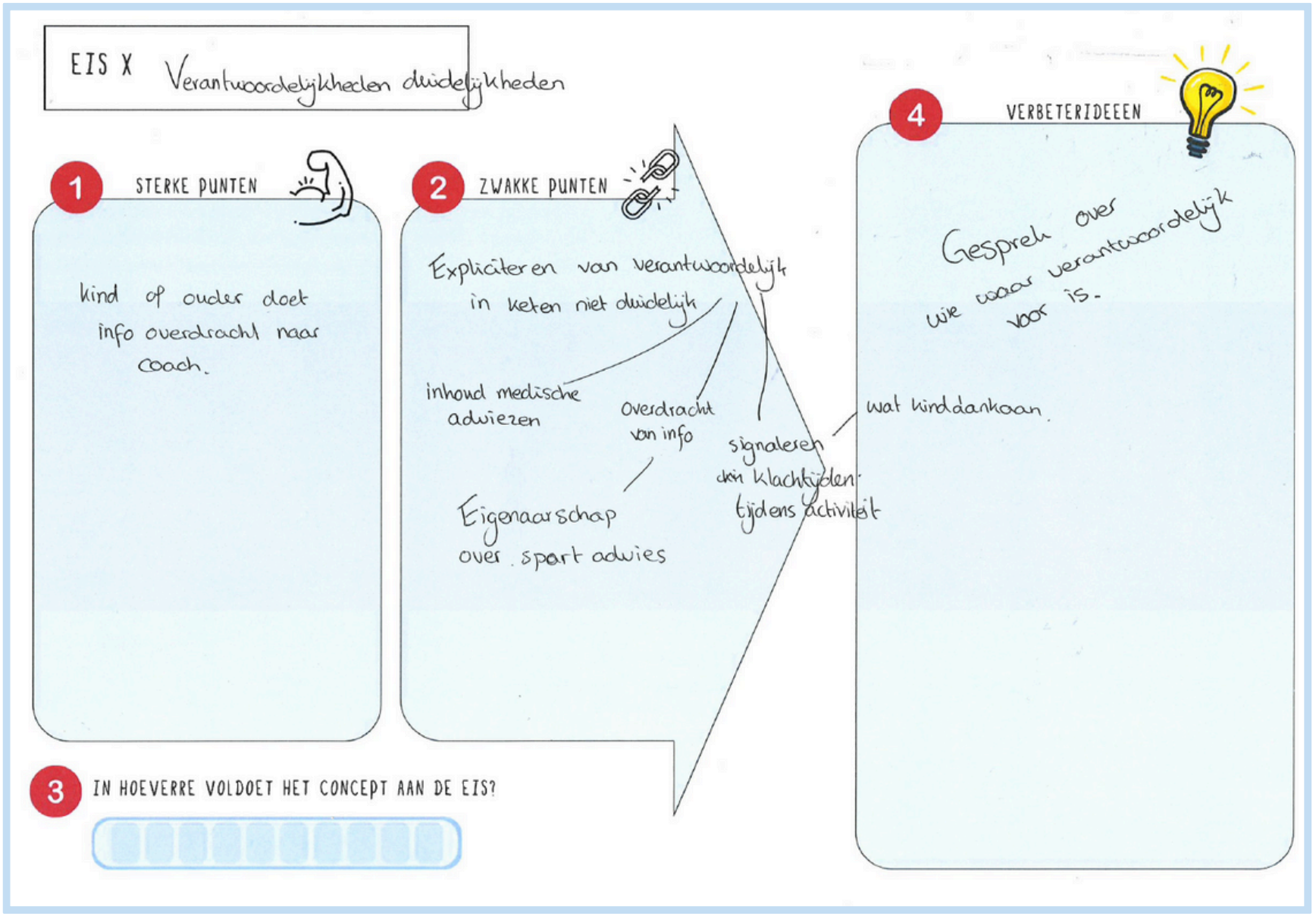


Content suggestions for the tool



Appendix H: Raw data co-creation Adviesraad




EIS X Verantwoordelijkheden duidelijkheden
1 STERKE PUNTEN
kind of ouder doet info overdracht naar coach.
2 ZWAKKE PUNTEN
Expliciteren van verantwoordelijk in keten niet duidelijk
inhoud medische adviezen
Overdracht van info
Eigenaarschap over sport advies
signaleren drin klachtijden tijdens activiteit
4 VERBETERIDEEEN
Gesprek over wie waar verantwoordelijk voor is.
wat kind dankaan
3 IN HOEVERRE VOLDOET HET CONCEPT AAN DE EIS?

EIS X Overdraagbaar

1 STERKE PUNTEN

- Ouders hebben inzicht en controle
- toegankelijkheid voor veel professionals
- minder kwetsbaar voor "verlies" van info
- nieuwe inzichten kunnen worden toegevoegd. (update baar)
- gestandardiseerde vragen toevoegen

2 ZWAKKE PUNTEN

- Infostroom via ouders → ook wat betreft de specifieke sport deelname
- privacy,
- ook toevoegen van interactie van prof → naar ouder / kind

~~Bijstatus~~

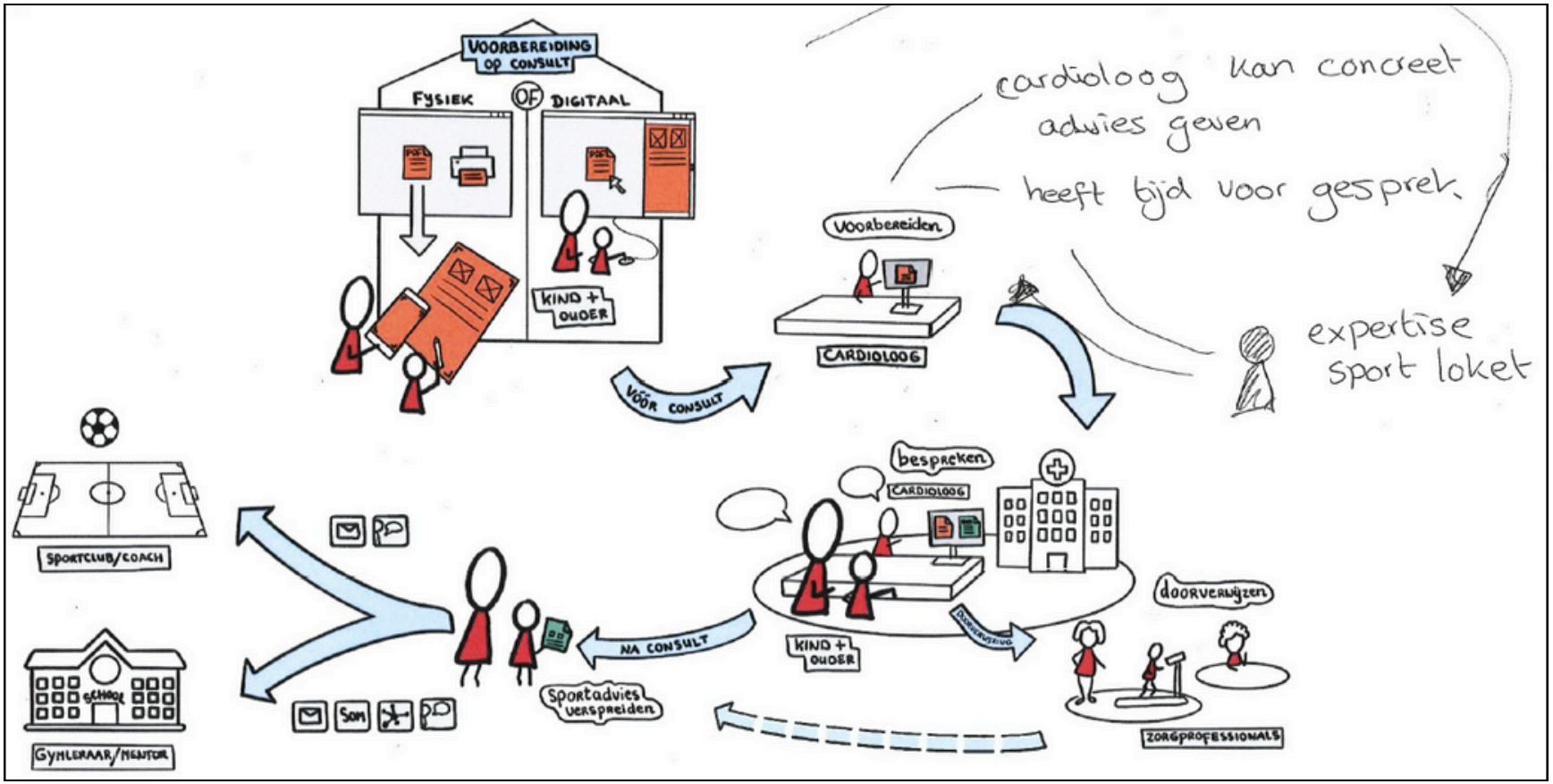
- laag drempelig gebruik = mogelijk een risico
- Zou goed kunnen werken, maar redden moet hierin investeren (alle gebruikers)

3 IN HOEVERRE VOLDOET HET CONCEPT AAN DE EIS?

X X X X X X X X

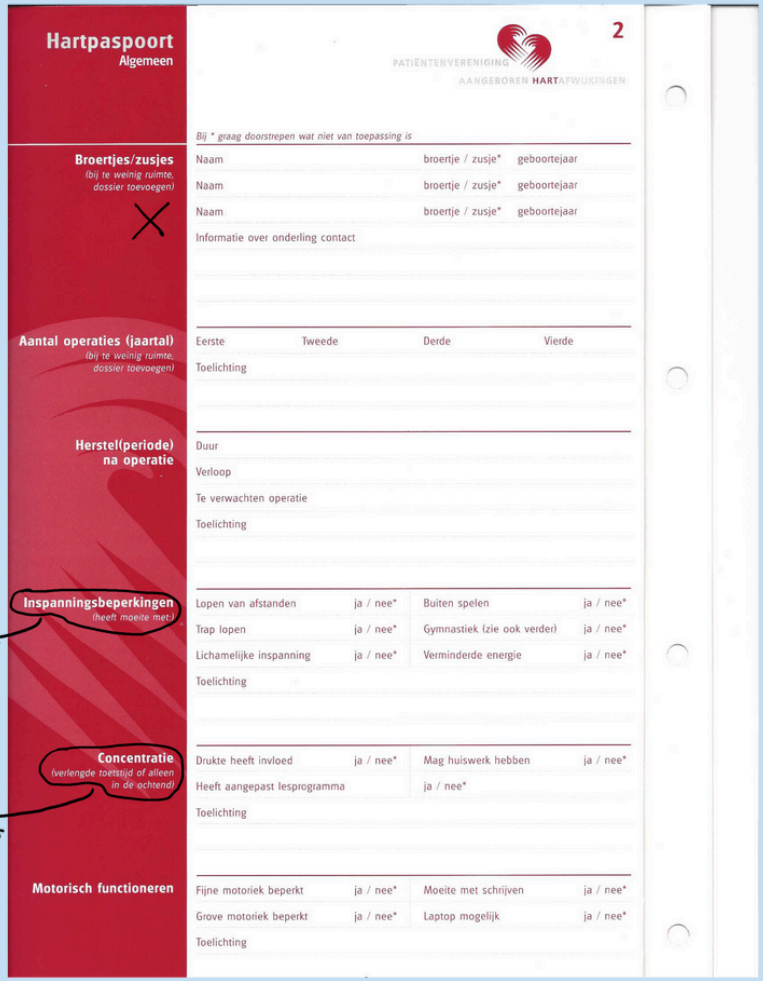
4 VERBETERIDEEEN

- In een ideale wereld is er een koppeling met elkaar, bv. Fysio + Cardio loog. (bv over bellen)
- Is er in enstige gevallen wel rechtstreeks contact tussen Fysio en cardio?


VOORBEREIDING OP CONSULT
FYSIEK
OF
DIGITAAL
KIND + OUDER
VÓÓR CONSULT
cardioloog kan concreet advies geven
heeft tijd voor gesprek
Voorbereiden
CARDIOLOOG
expertise sport loket
besproken
CARDIOLOOG
KIND + OUDER
doorverwijzen
ZORGPROFESSIONALS
SPORTCLUB/COACH
NA CONSULT
Sportadvies verspreiden
GYMLERAAR/MENTOR

Appendix I: Hartpaspoort analysis

Source: Patiëntenvereniging Aangeboren Hartafwijkingen



Hartpaspoort
Algemeen

PATIËNTENVERENIGING AANGEBOREN HARTAFWIJKINGEN

2

*Bij * graag doorstrepen wat niet van toepassing is*

Broertjes/zusjes
(bij te weinig ruimte, dossier toevoegen)

Naam — broertje / zusje* — geboortejaar
Naam — broertje / zusje* — geboortejaar
Naam — broertje / zusje* — geboortejaar
Informatie over onderling contact

Aantal operaties (jaartal)
(bij te weinig ruimte, dossier toevoegen)

Eerste — Tweede — Derde — Vierde
Toelichting

Herstel(periode) na operatie

Duur
Verloop
Te verwachten operatie
Toelichting

Inspanningsbeperkingen
(heeft moeite met:)

Lopen van afstanden	ja / nee*	Buiten spelen	ja / nee*
Trap lopen	ja / nee*	Gymnastiek (zie ook verder)	ja / nee*
Lichamelijke inspanning	ja / nee*	Verminderde energie	ja / nee*

Toelichting

Concentratie
(verlengde toetstijd of alleen in de ochtend)

Drukte heeft invloed	ja / nee*	Mag huiswerk hebben	ja / nee*
Heeft aangepast lesprogramma		ja / nee*	

Toelichting

Motorisch functioneren

Fijne motoriek beperkt	ja / nee*	Moeite met schrijven	ja / nee*
Grove motoriek beperkt	ja / nee*	Laptop mogelijk	ja / nee*

Toelichting

ARE THE PARENTS ABLE TO FILL THIS OUT THEMSELVES OR NEED HELP FROM HEALTHCARE PROFESSIONAL?

NOT RELEVANT FOR SPORTSCONTEXT

Hartpaspoort
Algemeen

PATIËNTENVERENIGING AANGEBOREN HARTAFWIJKINGEN

3

*Bij * graag doorstrepen wat niet van toepassing is*

Gymnastiek

Mag meedoen aan sportdag	ja / nee*	Beperking bepaalde sporten	ja / nee*
Mag meedoen aan Coopertest	ja / nee*	Heeft een litteken	ja / nee*

Hoe beleeft het kind deze beperkingen?
Toelichting

Schoolreisje/schoolkamp

EHBO aanwezig? ja / nee*

Vervoer tijdens uitje

O Buggy	ja / nee*	O Rolstoel	ja / nee*
O Extra rust nodig	ja / nee*	O Anders nl.	

Begeleiding

O Ouder(s) mee	ja / nee*	O Extra leerkracht	ja / nee*

Beperkingen

O Mag op achtbaan	ja / nee*	O Mag op glijbaan	ja / nee*
O Mag op draaitoestellen	ja / nee*	O Mag op simulator	ja / nee*

Toelichting

Temperatuurswisselingen

Moeite met grote temperatuurswisselingen ja / nee*

(bijvoorbeeld vermoeidheid of verminderde energie)

Moeite met extreme warmte	ja / nee*	Moeite met extreme kou	ja / nee*

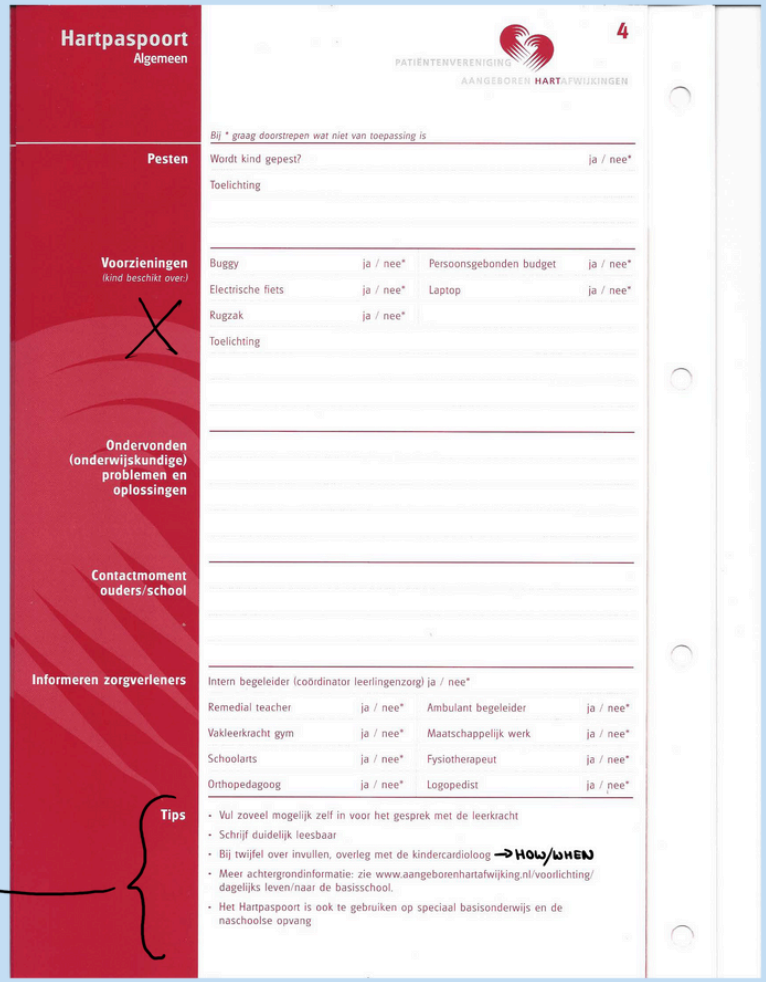
Gevolgen
Toelichting

Sociaal/emotioneel

Heeft faalangst	ja / nee*	Uit zich boos of huilt snel	ja / nee*
Overcompenseren of perfectionistisch			ja / nee*
Vraagt veel aandacht	ja / nee*	Problemen met litteken	ja / nee*
Trekt zich terug	ja / nee*		

Hoe gaat het kind met hartafwijking om / toelichting

INTERVIEW INSIGHT: THE SPORTSCOACH WANTS TO KNOW HOW THE CHILD (/PARENT) IS COPING WITH THE SITUATION



Hartpaspoort
Algemeen

4

PATIENTENVERENIGING AANGEBOREN HARTAFWIJKINGEN

*Bij * graag doorstrepen wat niet van toepassing is*

Pesten

Wordt kind gepest? ja / nee*

Toelichting

Voorzieningen
(kind beschikt over:)

Buggy	ja / nee*	Persoonsgebonden budget	ja / nee*
Electrische fiets	ja / nee*	Laptop	ja / nee*
Rugzak	ja / nee*		

Toelichting

Ondervonden (onderwijskundige) problemen en oplossingen

Contactmoment ouders/school

Informeren zorgverleners

Intern begeleider (coördinator leerlingenzorg) ja / nee*

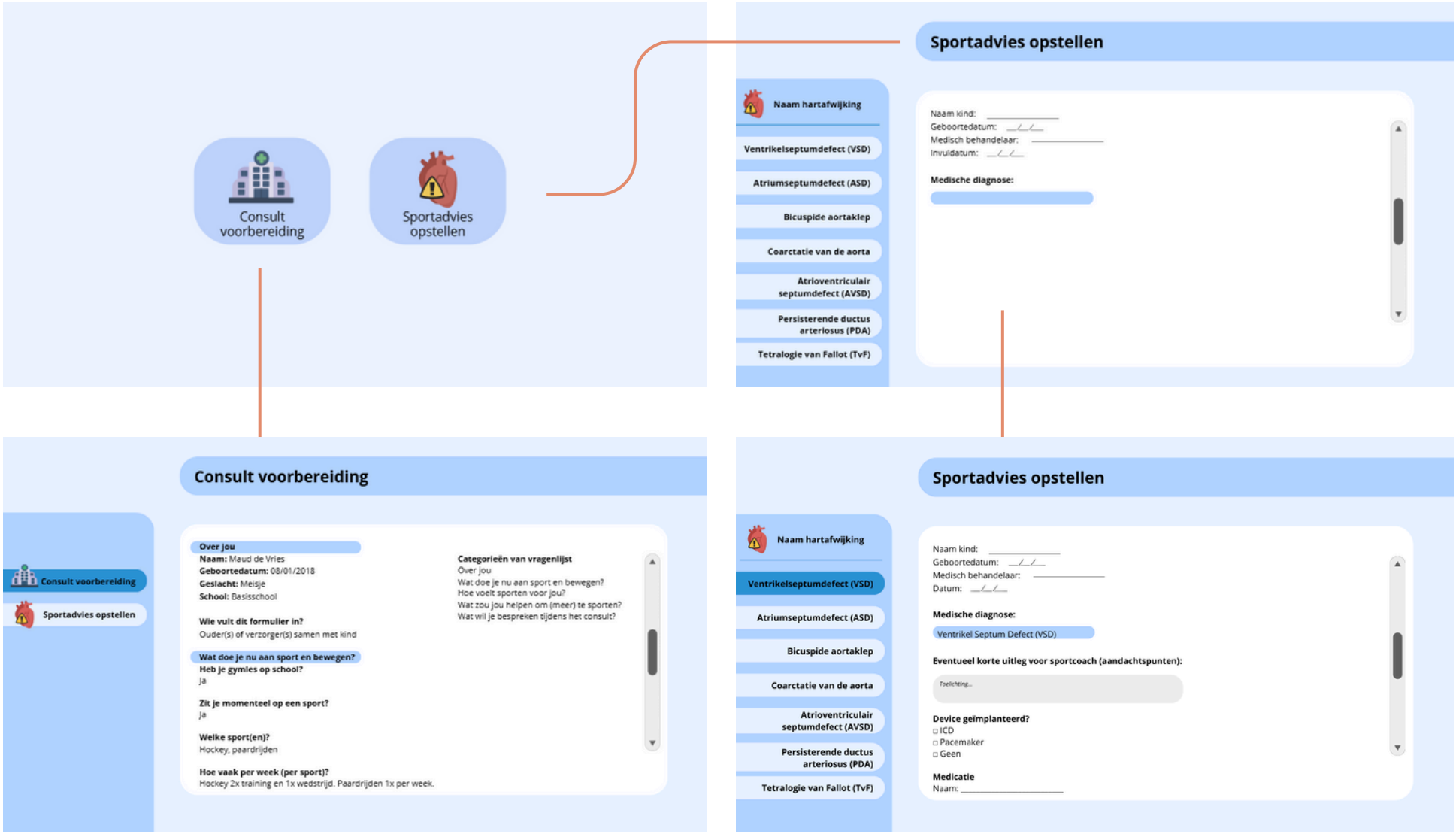
Remedial teacher	ja / nee*	Ambulant begeleider	ja / nee*
Vakleerkracht gym	ja / nee*	Maatschappelijk werk	ja / nee*
Schoolarts	ja / nee*	Fysiotherapeut	ja / nee*
Orthopedagoog	ja / nee*	Logopedist	ja / nee*

Tips

- Vul zoveel mogelijk zelf in voor het gesprek met de leerkracht
- Schrijf duidelijk leesbaar
- Bij twijfel over invullen, overleg met de kindercardioloog → HOW/WHEN
- Meer achtergrondinformatie: zie www.aangeborenhartafwijking.nl/voorlichting/dagelijks leven/naar de basisschool.
- Het Hartpaspoort is ook te gebruiken op speciaal basisonderwijs en de naschoolse opvang

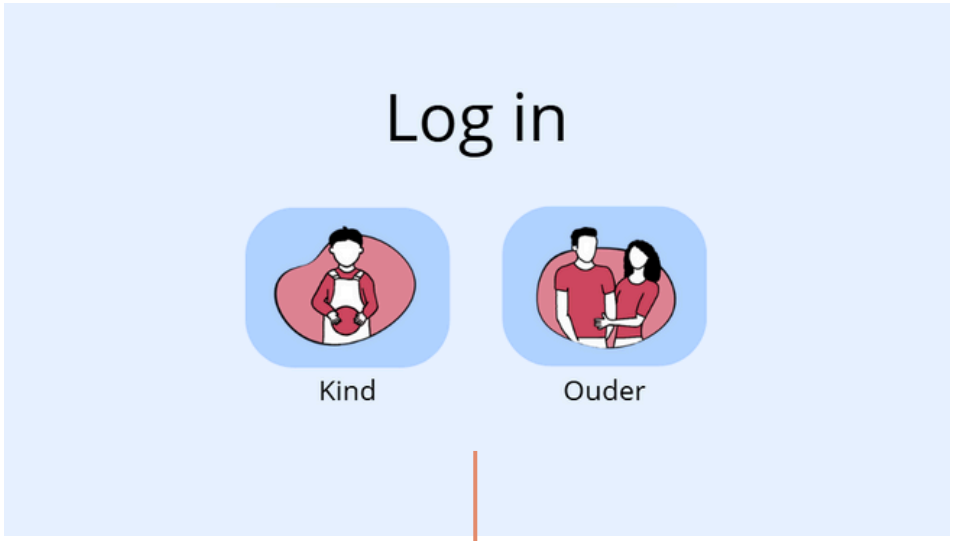
EXPLANATION/ MANUAL FOR USERS OF THE BOOKLET

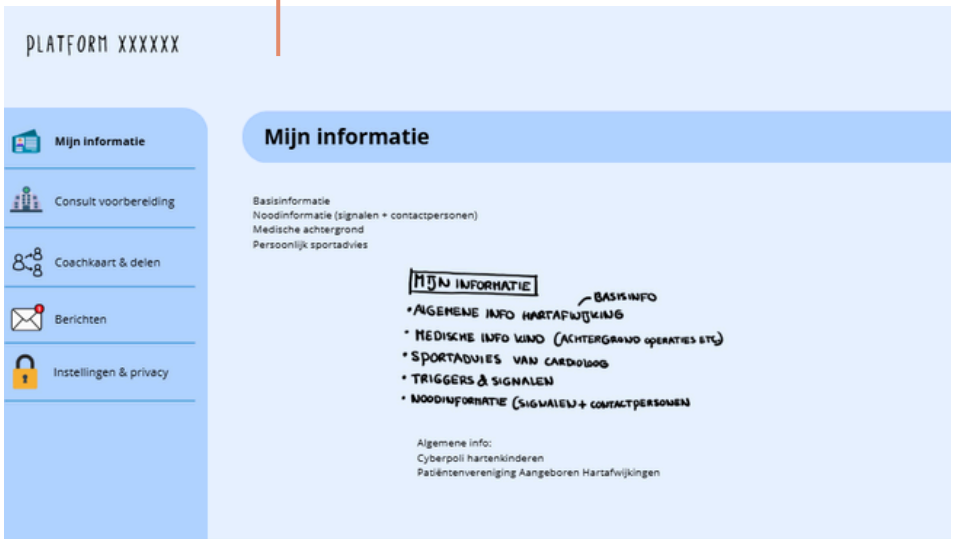
Appendix J: Proposed interface flow for cardiologists




Sportadvies opstellen
Naam hartafwijking
Ventrikelseptumdefect (VSD)
Atriumseptumdefect (ASD)
Bicuspide aortaklep
Coarctatie van de aorta
Atrioventriculair septumdefect (AVSD)
Persisterende ductus arteriosus (PDA)
Tetralogie van Fallot (TvF)
Naam kind:
Geboortedatum: __/__/__
Medisch behandelaar:
Datum: __/__/__
Medische diagnose:
Ventrikel Septum Defect (VSD)
Achtergrondinformatie
(Bron: patiëntenvereniging aangeboren hartafwijkingen)
Wat houdt deze aangeboren hartafwijking in?
Bij een ventrikel septumdefect is er sprake van een gaatje of meerdere gaatjes tussen het harttussenschot ter hoogte van de kamers. De kamers worden ook wel ventrikels genoemd. Waardoor deze aangeboren hartafwijking ontstaat is vaak onbekend. Soms is er sprake van erfelijkheid en soms hoort het bij een andere hartafwijking.
Door het gaatje in het harttussenschot stroomt bloed van de linkerharthelft naar de rechterharthelft. Dit komt doordat de linkerkamer het zuurstofrijke bloed het lichaam rond moet pompen en de rechterkamer het zuurstofarme bloed alleen naar de longen hoeft te pompen. Hierdoor is de druk in de linkerkamer hoger dan in de rechterkamer. Door het gaatje ontstaat er een gemengde bloedstroom in de rechterkamer. Het bloed dat door het harttussenschot gaat, gaat dus via de rechterkamer opnieuw naar de longen. Dat bloed bevat al zuurstof, dus gaat het eigenlijk een extra ronde. Hierdoor is het bloedvolume in de linkerkamer groter dan normaal. Hierdoor kan de linkerkamer breder worden (hypertrofie). Het bloed wat weer opnieuw richting de rechterkamer gaat,
Symptomen
Lees meer...

Appendix K: Interface screens parents/child platform





PLATFORM XXXXXX

- Mijn informatie
- Consult voorbereiding
- Coachkaart & delen
- Berichten
- Instellingen & privacy

Consult voorbereiding

- WAT DOET HET KIND NU AAN SPORT ?
- WAT VINDT HET KIND LEUK AAN BEWEGEN?
  - ↳ BEWEEGREDENENTEST SPORTBEDRIJF R'DAM
- ERVAART HET KIND KLACHTEN OF VERMOEIDHEID TIJDENS SPORT?
- HOE GAAT HET KIND MET DE HARTAFWIJKING OP?
- THUISSITUATIE
- KAN HET KIND GOED MEEDOEN MET PEERS ?

Belever, presteerder, ontmoeter

Bijwerken antwoorden | Verzenden naar cardioloog

PLATFORM XXXXXX

- Mijn informatie
- Consult voorbereiding
- Coachkaart & delen
- Berichten
- Instellingen & privacy

Vragenlijst voorbereiding consult met kindercardioloog

Vul deze vragen alleen of samen met je ouder(s) of verzorger(s) in. Ze gaan over jou en je sportbeleving. Upload de vragenlijst uiterlijk X weken vóór je afspraak, zodat de cardioloog al een beeld heeft van jou, je sportbeleving en wat jij graag wilt bespreken.

Over jou

Leeftijd: ____

School:

☐ Basisschool
☐ Middelbare school

Wie vult dit formulier in?

☐ Ouder(s) of verzorger(s) samen met kind
☐ Alleen ouder
☐ Alleen kind

Bijwerken antwoorden | Verzenden naar cardioloog

PLATFORM XXXXXX

- Mijn informatie
- Consult voorbereiding
- Coachkaart & delen
- Berichten
- Instellingen & privacy

Coachkaart & delen

1 Kies met wie je informatie wilt delen?

- (●) Gymleraar basisschool
- ( ) Hockeycoach
- ( ) Korfbalcoach

+ *Nieuw persoon toevoegen*

2 Wat mag deze persoon zien?

- ☑ Basisinformatie
- ☑ Noodinformatie (signalen + contactpersonen)
- ☑ Medische achtergrond
- ☑ Persoonlijk sportadvies

3 Hoe wil je deze informatie delen?

Fysieke coachkaart (PDF)

Kies wat zichtbaar mag zijn op de geprinte kaart. Handig voor snelle toegang tijdens sportlessen.

- ☑ Basisinformatie
- ☑ Noodinformatie
- ☐ Medische achtergrond
- ☑ Persoonlijk sportadvies

Digitale toegang (via QR-code)

Kies welke informatie online toegankelijk mag zijn via een QR-code op de coachkaart. Deze informatie is alleen toegankelijk voor geselecteerde personen met login of QR-code.

- ☑ Basisinformatie
- ☑ Noodinformatie
- ☑ Medische achtergrond
- ☑ Persoonlijk sportadvies

Wil je verschillende informatie delen met verschillende coaches? Stel dit per persoon in.

Opslaan | Coachkaart genereren

PLATFORM XXXXXX

- Mijn informatie
- Consult voorbereiding
- Coachkaart & delen
- Berichten
- Instellingen & privacy

Coachkaart genereren

Aan: Gymleraar basisschool

Geselecteerde informatie

- Basisinformatie
- Noodinformatie
- Persoonlijk sportadvies

Download pdf

Voorbeeld coachkaart (pdf)

Basisinformatie
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Cras posuere malesuada urna.

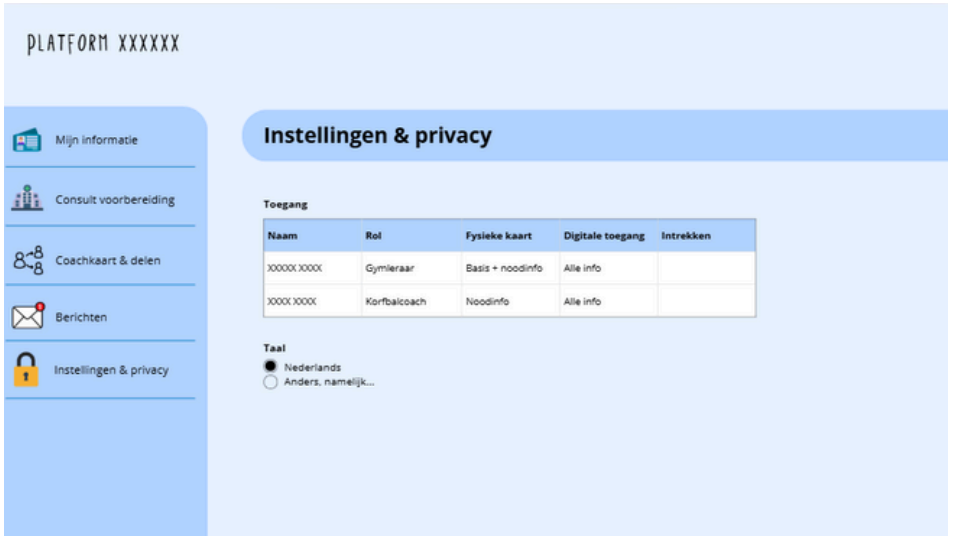
Noodinformatie
Mauris eu eleifend arcu, a venenatis lectus. Nam in enim felis.
XXXXXXXXX
XXXXXXXXX

Persoonlijk sportadvies
Etiam mattis, tellus sit amet finibus pellentesque, quam metus maximus orci, vitae sollicitudin lectus mi id urna. Mauris rhoncus dui eu posuere scelerisque. I

SCAN ME

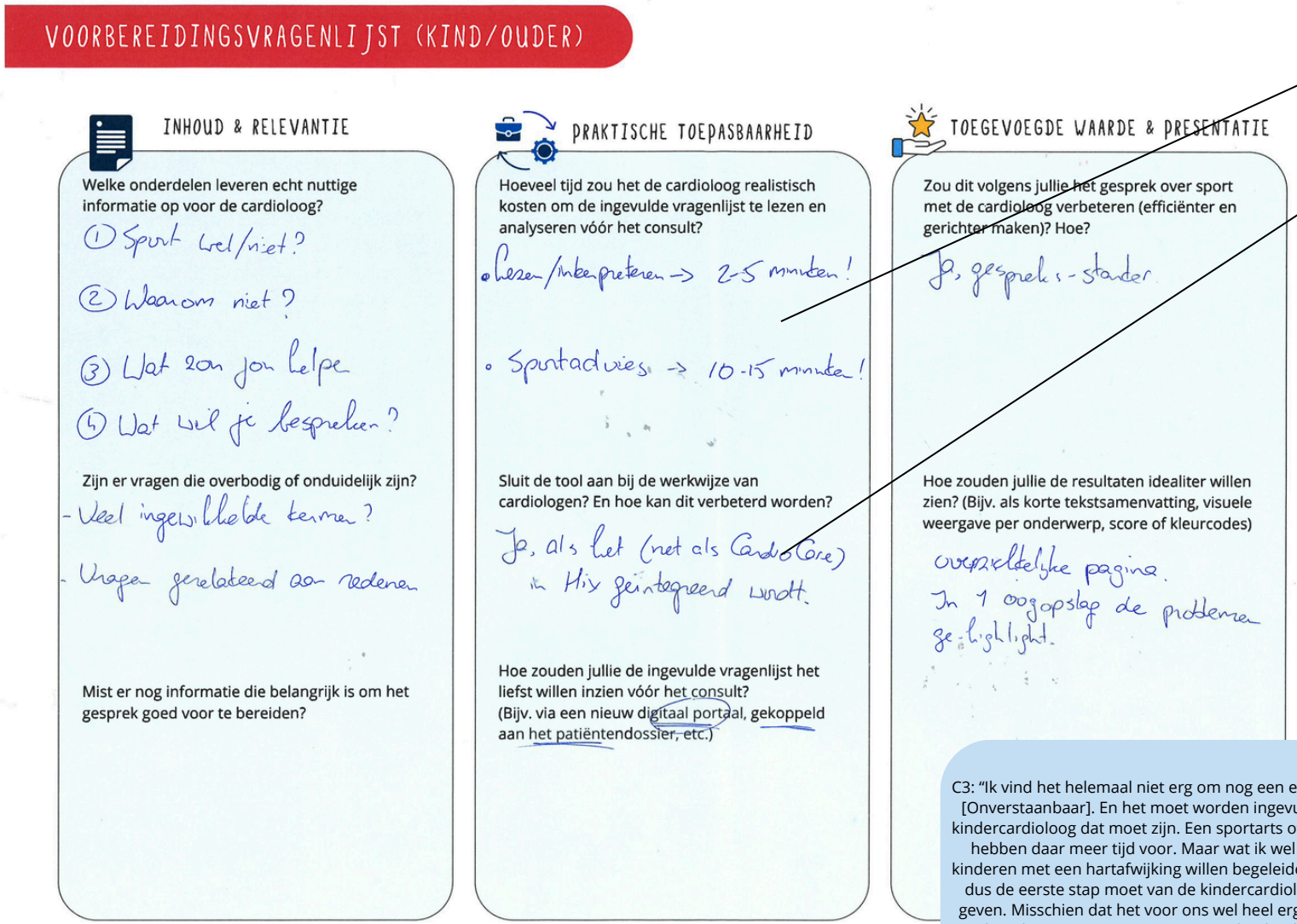
Meer info over XXXX


PLATFORM XXXXXX
Mijn informatie
Consult voorbereiding
Coachkaart & delen
Berichten
Instellingen & privacy
Berichten
CHAT op DIT PLATFORM OF BESTAAND IETS GEBRUIKEN?
• BETER DICHTBIJ APP?


PLATFORM XXXXXX
Mijn informatie
Consult voorbereiding
Coachkaart & delen
Berichten
Instellingen & privacy
Instellingen & privacy
Toegang
Naam
Rol
Fysieke kaart
Digitale toegang
Intrekken
XXXXX XXXX
Gymleraar
Basis + noodinfo
Alle info
XXXX XXXX
Korfbalcoach
Noodinfo
Alle info
Taal
Nederlands
Anders, namelijk...

Appendix L: Raw data co-creation session 2, questionnaire

Worksheet group 3



VOORBEREIDINGSVRAGENLIJST (KIND/OUDER)

INHOUD & RELEVANTIE

Welke onderdelen leveren echt nuttige informatie op voor de cardioloog?

① Sport wel/niet?

② Waarom niet?

③ Wat zou jou helpen

④ Wat wil je bespreken?

Zijn er vragen die overbodig of onduidelijk zijn?

- Veel ingewikkelde termen?
- Vragen gerelateerd aan redenen

Mist er nog informatie die belangrijk is om het gesprek goed voor te bereiden?

PRAKTISCHE TOEPASBAARHEID

Hoeveel tijd zou het de cardioloog realistisch kosten om de ingevulde vragenlijst te lezen en analyseren vóór het consult?

- lezen/interpreteren → 2-5 minuten!
- Sportadvies → 10-15 minuten!

Sluit de tool aan bij de werkwijze van cardiologen? En hoe kan dit verbeterd worden?

Ja, als het (net als CardioCore) in Hix geïntegreerd wordt.

Hoe zouden jullie de ingevulde vragenlijst het liefst willen inzien vóór het consult? (Bijv. via een nieuw digitaal portaal, gekoppeld aan het patiëntendossier, etc.)

TOEGEVOEGDE WAARDE & PRESENTATIE

Zou dit volgens jullie het gesprek over sport met de cardioloog verbeteren (efficiënter en gerichter maken)? Hoe?

Ja, gesprek-starter

Hoe zouden jullie de resultaten idealiter willen zien? (Bijv. als korte tekstsamenvatting, visuele weergave per onderwerp, score of kleurcodes)

overzichtelijke pagina. In 1 oogopslag de problemen gehighlight.

C3: "Als je dit voor alle patienten moet doen op een polidag, dan ben je wel even bezig."

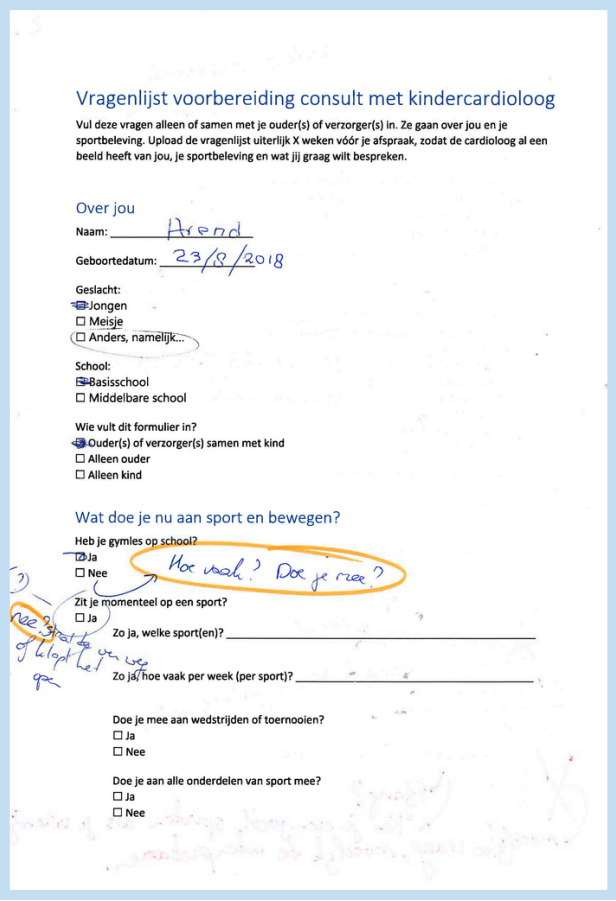
C3: "Sommige cardiologen bereiden hun poli een week van tevoren voor."

C3: "Dit zou een screening kunnen zijn. Als kinderen antwoorden ja ik sport, nee ik maak me niet zorgen en ik hoef eigenlijk geen hulp. En uit een sport en bewegen vragenlijst komt inderdaad dat zij voldoende bewegen en kinderen zeggen ja ik sport en dan ga je meten... (...). Maar je moet geen problemen maken die er niet zijn, als kinderen gewoon sporten, geen angsten hebben, zich gestimuleerd voelen en zich gesteund voelen...

C3: "kinesiofobie vragenlijst is in ontwikkeling, sport en bewegen vragenlijst is er al wel"

C3: "Ik vind het helemaal niet erg om nog een extra vragenlijst te hebben, als het de kinderen helpt. [Onverstaanbaar]. En het moet worden ingevuld in een persoonlijk advies consult. Ik twijfel of de kindercardioloog dat moet zijn. Een sportarts of kinderfysiotherapeut kunnen dat denk ik beter, die hebben daar meer tijd voor. Maar wat ik wel vaak hoor is dat kinderfysiotherapeuten wel vaak kinderen met een hartafwijking willen begeleiden maar die weten helemaal niet wat er kan en mag, dus de eerste stap moet van de kindercardioloog komen. En dan kunnen wij het ook uit handen geven. Misschien dat het voor ons wel heel erg gaat over formele restricties, deze sporten passen wel en deze sporten passen niet. En dat dat dan verder helemaal gepersonaliseerd gaat worden door het kind zelf in combinatie met een fysiotherapeut."

Annotations group 3



Vragenlijst voorbereiding consult met kindercardioloog

Vul deze vragen alleen of samen met je ouder(s) of verzorger(s) in. Ze gaan over jou en je sportbeleving. Upload de vragenlijst uiterlijk X weken vóór je afspraak, zodat de cardioloog al een beeld heeft van jou, je sportbeleving en wat jij graag wilt bespreken.

Over jou

Naam: Arend

Geboortedatum: 23/8/2018

Geslacht:
- ☒ Jongen
- ☐ Meisje
- ☐ Anders, namelijk...

School:
- ☒ Basisschool
- ☐ Middelbare school

Wie vult dit formulier in?
- ☒ Ouder(s) of verzorger(s) samen met kind
- ☐ Alleen ouder
- ☐ Alleen kind

Wat doe je nu aan sport en bewegen?

Heb je gymles op school?
- ☒ Ja
- ☐ Nee

Hoe vaak? Doe je mee?

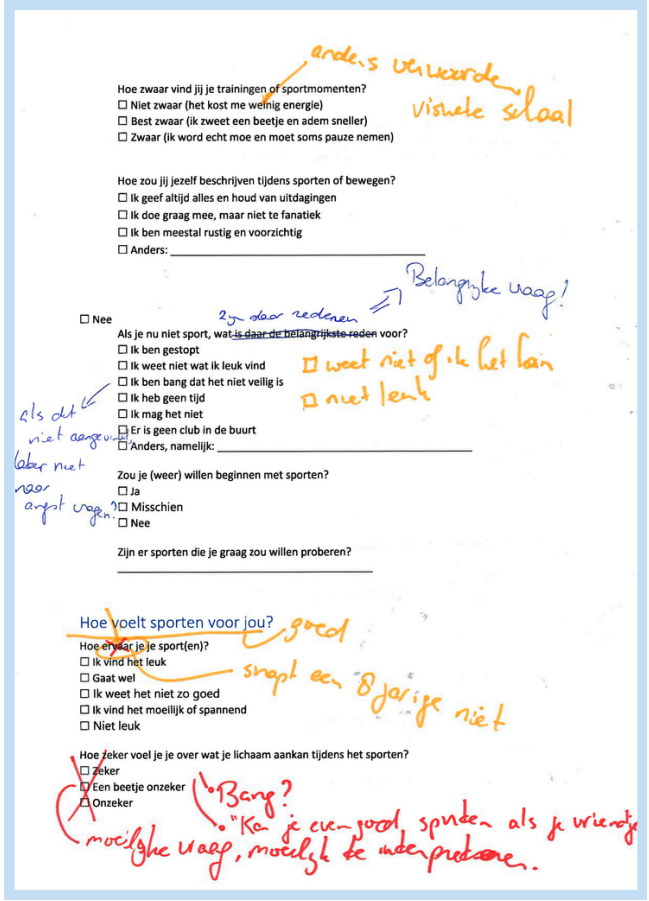
Zit je momenteel op een sport?
- ☐ Ja

Zo ja, welke sport(en)? _____

Zo ja, hoe vaak per week (per sport)? _____

Doe je mee aan wedstrijden of toernooien?
- ☐ Ja
- ☐ Nee

Doe je aan alle onderdelen van sport mee?
- ☐ Ja
- ☐ Nee



anders uitwerken visuele schaal

Hoe zwaar vind jij je trainingen of sportmomenten?
- ☐ Niet zwaar (het kost me weinig energie)
- ☐ Best zwaar (ik zweet een beetje en adem sneller)
- ☐ Zwaar (ik word echt moe en moet soms pauze nemen)

Hoe zou jij jezelf beschrijven tijdens sporten of bewegen?
- ☐ Ik geef altijd alles en houd van uitdagingen
- ☐ Ik doe graag mee, maar niet te fanatiek
- ☐ Ik ben meestal rustig en voorzichtig
- ☐ Anders: _____

Belangrijke vraag!

☐ Nee

2e daar redenen

Als je nu niet sport, wat ~~is daar de belangrijkste reden~~ voor?
- ☐ Ik ben gestopt
- ☐ Ik weet niet wat ik leuk vind
- ☐ Ik ben bang dat het niet veilig is
- ☐ Ik heb geen tijd
- ☐ Ik mag het niet
- ☐ Er is geen club in de buurt
- ☐ Anders, namelijk: _____

☐ weet niet of ik het kan
☐ niet leuk

als dit niet aangevinkt laten niet naar angst vragen.

Zou je (weer) willen beginnen met sporten?
- ☐ Ja
- ☐ Misschien
- ☐ Nee

Zijn er sporten die je graag zou willen proberen?
_____

Hoe voelt sporten voor jou?

goed

Hoe ervaar je je sport(en)?
- ☐ Ik vind het leuk
- ☐ Gaat wel
- ☐ Ik weet het niet zo goed
- ☐ Ik vind het moeilijk of spannend
- ☐ Niet leuk

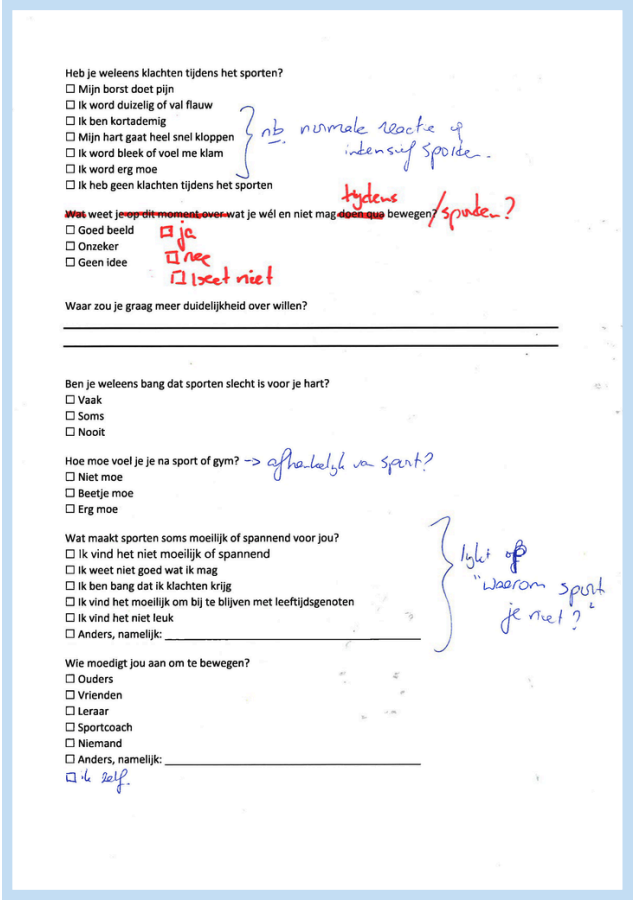
stopt een 8jarige niet

Hoe zeker voel je je over wat je lichaam aankan tijdens het sporten?
- ☐ Zeker
- ☐ Een beetje onzeker
- ☐ Onzeker

Bang?

"Kan je even goed sporten als je vriendje"

moeilijke vraag, moeilijk te interpreteren.



Heb je weleens klachten tijdens het sporten?
- ☐ Mijn borst doet pijn
- ☐ Ik word duizelig of val flauw
- ☐ Ik ben kortademig
- ☐ Mijn hart gaat heel snel kloppen
- ☐ Ik word bleek of voel me klam
- ☐ Ik word erg moe
- ☐ Ik heb geen klachten tijdens het sporten

nb. normale reactie op intensief sporten.

tijdens

~~Wat~~ weet je ~~op dit moment over~~ wat je wél en niet mag ~~doen qua~~ bewegen? / sporten?
- ☐ Goed beeld
- ☐ Onzeker
- ☐ Geen idee

☐ ja
☐ nee
☐ weet niet

Waar zou je graag meer duidelijkheid over willen?
_____
_____

Ben je weleens bang dat sporten slecht is voor je hart?
- ☐ Vaak
- ☐ Soms
- ☐ Nooit

Hoe moe voel je je na sport of gym? -> afhankelijk van sport?
- ☐ Niet moe
- ☐ Beetje moe
- ☐ Erg moe

Wat maakt sporten soms moeilijk of spannend voor jou?
- ☐ Ik vind het niet moeilijk of spannend
- ☐ Ik weet niet goed wat ik mag
- ☐ Ik ben bang dat ik klachten krijg
- ☐ Ik vind het moeilijk om bij te blijven met leeftijdsgenoten
- ☐ Ik vind het niet leuk
- ☐ Anders, namelijk: _____

lijkt op "waarom sport je niet?"

Wie moedigt jou aan om te bewegen?
- ☐ Ouders
- ☐ Vrienden
- ☐ Leraar
- ☐ Sportcoach
- ☐ Niemand
- ☐ Anders, namelijk: _____

☐ ik zelf.

Hoe voelen je ouder(s) of verzorger(s) zich als jij sport? } visuele schaal?
☐ Ze voelen zich gerust als ik sport
☐ Soms maken ze zich zorgen
☐ Ze maken zich vaak zorgen

Toelichting door ouder(s) of verzorger(s): _____

Wat zou jou helpen om (meer) te sporten?

Wat zou jou helpen om goed mee te kunnen doen met sporten?
☐ Iemand die met me meekijkt wat voor sport bij me past
☐ Meer vertrouwen krijgen in wat mijn lichaam kan
☐ Weten wat ik wél en niet mag doen
☐ Betere uitleg van een arts of fysiotherapeut
☐ Dat mijn sportcoach of gymleraar beter weet wat ik kan en mag
☐ Meer begrip van klasgenoten of teamgenoten
☐ Anders, namelijk: _____

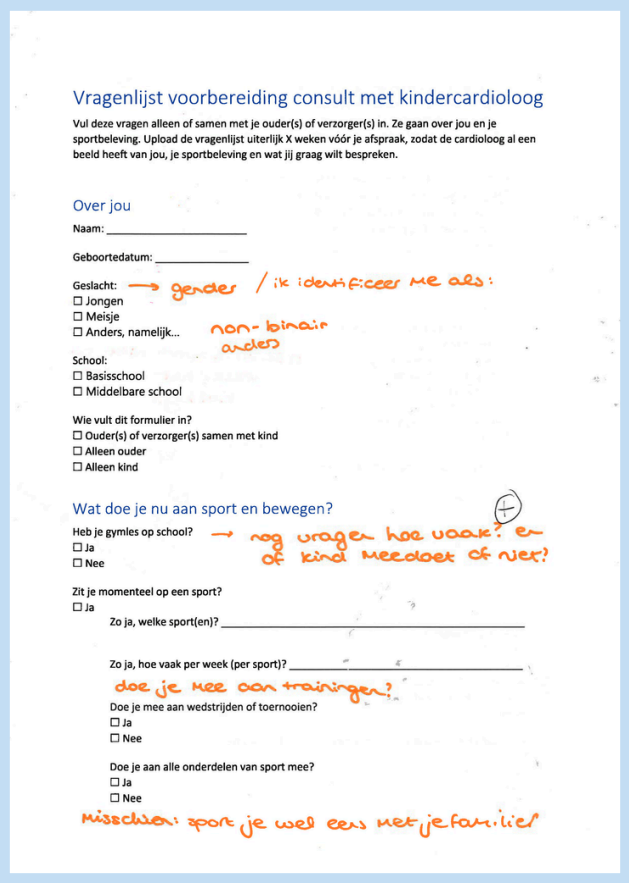
Wat wil je bespreken tijdens het consult?

Waar wil je het graag over hebben tijdens je afspraak met de kindercardioloog? (meerdere antwoorden mogelijk)
☐ Sportadvies (wat mag ik wel of niet doen)
☐ Een nieuwe sport kiezen
☐ Angst of onzekerheid bij sporten
☐ Vermoeidheid of klachten tijdens sporten
☐ Sport of gymles op school
☐ Informatie voor mijn sportcoach
☐ Doorverwijzing naar fysiotherapeut of sportarts
☐ Anders: _____

Belangrijk! Veel mogelijke termen.

Is er nog iets anders dat je wilt vertellen voor het gesprek?
_____
_____

Annotations group 2



Vragenlijst voorbereiding consult met kindercardioloog

Vul deze vragen alleen of samen met je ouder(s) of verzorger(s) in. Ze gaan over jou en je sportbeleving. Upload de vragenlijst uiterlijk X weken vóór je afspraak, zodat de cardioloog al een beeld heeft van jou, je sportbeleving en wat jij graag wilt bespreken.

Over jou

Naam: _____

Geboortedatum: _____

Geslacht: → gender / ik identificeer me als:
☐ Jongen
☐ Meisje
☐ Anders, namelijk... non-binair anders

School:
☐ Basisschool
☐ Middelbare school

Wie vult dit formulier in?
☐ Ouder(s) of verzorger(s) samen met kind
☐ Alleen ouder
☐ Alleen kind

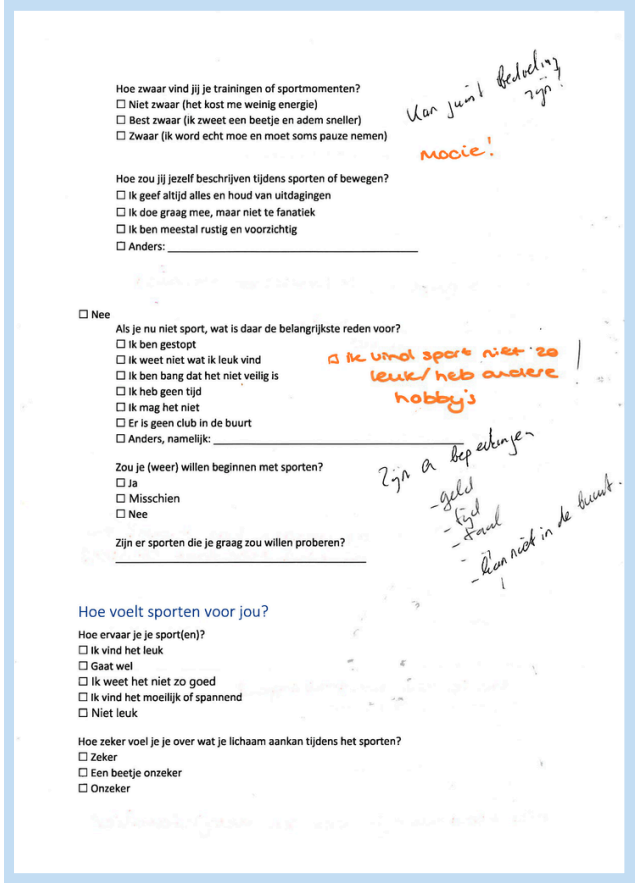
Wat doe je nu aan sport en bewegen?

Heb je gymles op school? → nog vragen hoe vaak? en of kind meedoet of niet?
☐ Ja
☐ Nee

Zit je momenteel op een sport?
☐ Ja
Zo ja, welke sport(en)? _____

Zo ja, hoe vaak per week (per sport)? _____
doe je mee aan trainingen?
Doe je mee aan wedstrijden of toernooien?
☐ Ja
☐ Nee

Doe je aan alle onderdelen van sport mee?
☐ Ja
☐ Nee
Misschien: sport je wel eens met je familie?



Hoe zwaar vind jij je trainingen of sportmomenten?
☐ Niet zwaar (het kost me weinig energie)
☐ Best zwaar (ik zweet een beetje en adem sneller)
☐ Zwaar (ik word echt moe en moet soms pauze nemen)
kan jun't bedoeling zijn?
mooie!

Hoe zou jij jezelf beschrijven tijdens sporten of bewegen?
☐ Ik geef altijd alles en houd van uitdagingen
☐ Ik doe graag mee, maar niet te fanatiek
☐ Ik ben meestal rustig en voorzichtig
☐ Anders: _____

☐ Nee

Als je nu niet sport, wat is daar de belangrijkste reden voor?
☐ Ik ben gestopt
☐ Ik weet niet wat ik leuk vind
☐ Ik ben bang dat het niet veilig is
☐ Ik heb geen tijd
☐ Ik mag het niet
☐ Er is geen club in de buurt
☐ Anders, namelijk: _____
☐ Ik vind sport niet zo leuk/ heb andere hobby's

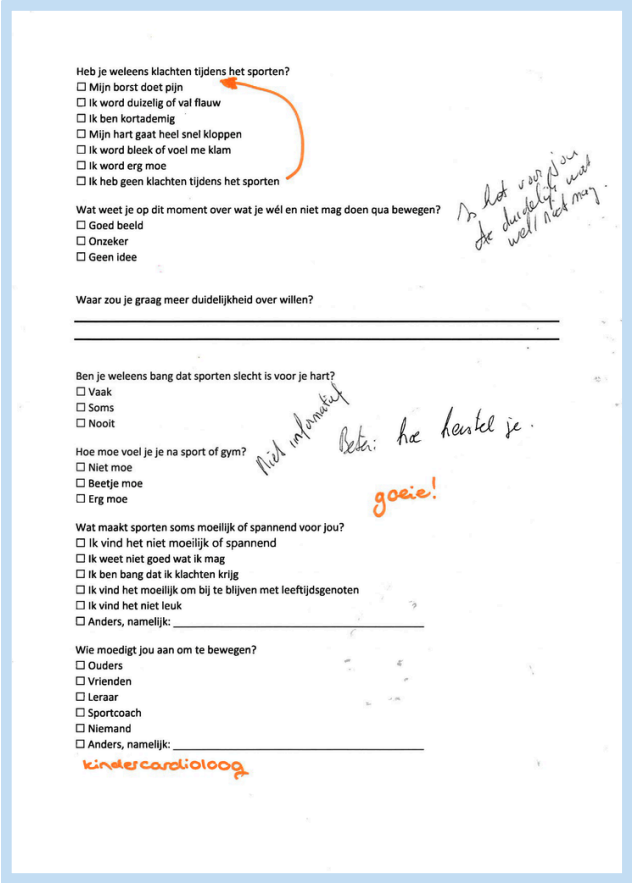
Zou je (weer) willen beginnen met sporten?
☐ Ja
☐ Misschien
☐ Nee
Zijn er bepalingen
- geld
- tijd
- vervoer
- kan niet in de buurt

Zijn sporten die je graag zou willen proberen?
_____

Hoe voelt sporten voor jou?

Hoe ervaar je je sport(en)?
☐ Ik vind het leuk
☐ Gaat wel
☐ Ik weet het niet zo goed
☐ Ik vind het moeilijk of spannend
☐ Niet leuk

Hoe zeker voel je je over wat je lichaam aankan tijdens het sporten?
☐ Zeker
☐ Een beetje onzeker
☐ Onzeker



Heb je weleens klachten tijdens het sporten?
☐ Mijn borst doet pijn
☐ Ik word duizelig of val flauw
☐ Ik ben kortademig
☐ Mijn hart gaat heel snel kloppen
☐ Ik word bleek of voel me klam
☐ Ik word erg moe
☐ Ik heb geen klachten tijdens het sporten

Wat weet je op dit moment over wat je wél en niet mag doen qua bewegen?
☐ Goed beeld
☐ Onzeker
☐ Geen idee
Is het voor jou de duidelijkheid wat wel/niet mag.

Waar zou je graag meer duidelijkheid over willen?
_____
_____

Ben je weleens bang dat sporten slecht is voor je hart?
☐ Vaak
☐ Soms
☐ Nooit
Niet informatief
Bedr: hoe herstel je.

Hoe moe voel je je na sport of gym?
☐ Niet moe
☐ Beetje moe
☐ Erg moe
goeie!

Wat maakt sporten soms moeilijk of spannend voor jou?
☐ Ik vind het niet moeilijk of spannend
☐ Ik weet niet goed wat ik mag
☐ Ik ben bang dat ik klachten krijg
☐ Ik vind het moeilijk om bij te blijven met leeftijdsgenoten
☐ Ik vind het niet leuk
☐ Anders, namelijk: _____

Wie moedigt jou aan om te bewegen?
☐ Ouders
☐ Vrienden
☐ Leraar
☐ Sportcoach
☐ Niemand
☐ Anders, namelijk: _____
kindercardioloog

Hoe voelen je ouder(s) of verzorger(s) zich als jij sport?
☐ Ze voelen zich gerust als ik sport
☐ Soms maken ze zich zorgen
☐ Ze maken zich vaak zorgen

Toelichting door ouder(s) of verzorger(s): _____

Wat zou jou helpen om (meer) te sporten?

Wat zou jou helpen om goed mee te kunnen doen met sporten?
☐ Iemand die met me meekijkt wat voor sport bij me past
☐ Meer vertrouwen krijgen in wat mijn lichaam kan
☐ Weten wat ik wél en niet mag doen
☐ Betere uitleg van een arts of fysiotherapeut
☐ Dat mijn sportcoach of gymleraar beter weet wat ik kan en mag
☐ Meer begrip van klasgenoten of teamgenoten
☐ Anders, namelijk: _____

Wat wil je bespreken tijdens het consult?

Waar wil je het graag over hebben tijdens je afspraak met de kindercardioloog? (meerdere antwoorden mogelijk)
☐ Sportadvies (wat mag ik wel of niet doen)
☐ Een nieuwe sport kiezen
☐ Angst of onzekerheid bij sporten
☐ Vermoeidheid of klachten tijdens sporten
☐ Sport of gymles op school
☐ Informatie voor mijn sportcoach
☐ Doorverwijzing naar fysiotherapeut of sportarts
☐ Anders: _____

Is er nog iets anders dat je wilt vertellen voor het gesprek?
_____
_____

Appendix M: Raw data co-creation session 2, sports advice form

Worksheet group 1

SPORTADVIESFORMULIER (CARDIOLOOG → SPORTCOACH)

INHOUD & RELEVANTIE

Welke onderdelen zijn overbodig, te uitgebreid of missen nog?

- Belangrijke medische bevindingen
  → alleen specifieke dingen belangrijk voor de sport in de formulier
- Temperatuurwisselingen
  → niet cardiologisch
- Motorisch functioneren
  → advies via andere hulpverleners niet via cardioloog

Wat zou dit formulier beter bruikbaar maken qua inhoud of vorm?

- Actieplan:
  - o Bespreek wat normaal is ook: door HF ↑ en buiten adem ↑
  - o Tools bij elk kind, ook zonder hartafwijking ⇒ Stoppen / Rust bij: duizelig / flauwvallen, bleek / blauw, Blauwe tint huid
  - o Noodplan = alleen bij hartafwijking → • 112 bellen + start BLS • haal AED

PRAKTISCHE TOEPASBAARHEID

Hoeveel tijd kost dit realistisch gezien om in te vullen?

Als gericht 5 min → pre-set per hartafw maken, gericht aanpassen ze mogelijk

Wanneer zou dit ingevuld worden (voor, tijdens of na het consult)?

Vooraf invullen en tijdens bespreken

Sluit de tool aan bij de werkwijze van cardiologen? En hoe kan dit verbeterd worden?

Het zou heel goed moeten passen en is heel nuttig. Maar qua tijd binnen het consult duurt het wel lang.

Door wie zou dit het beste kunnen worden ingevuld (cardioloog, verpleegkundige, etc.)?

Vooraf invullen door een verpl. of cardioloog, ism pre-set, tijdens consult bespreken door cardioloog met pt./ouders

Hoe kan dit formulier zo efficiënt mogelijk worden gebruikt (aanvinkvelden, standaardteksten, automatische invulling, etc.)?

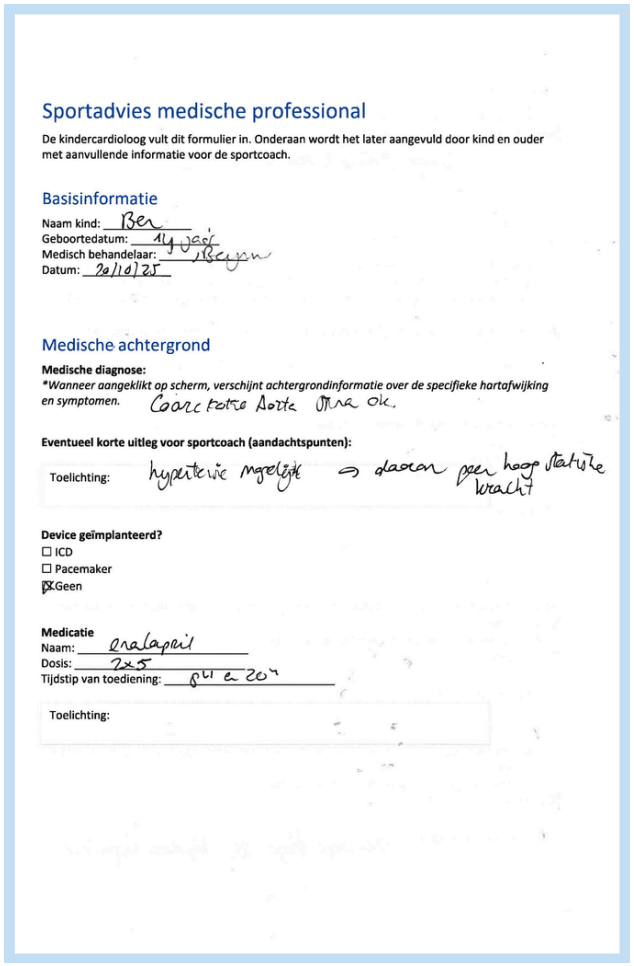
- pre-set = automatische invulling + standaard tekst per hartafwijking
- Aanpassen via aanvinkvelden
- Beschikbaarheid mogelijkheid tot aanpassen van standaardtekst per hartafwijking

C1: "Eigenlijk moet je jouw ingevulde ding met ze bespreken"

C1: "Je wilt het wel bespreken. Het is natuurlijk digitaal, maar je wilt niet dat het kind thuis komt, en dat er dan adviezen staat dat het kind denkt huh waarom zegt die cardioloog dat. Dus ik denk dat het fijn zou zijn om het vooraf in te vullen, tijdens het consult te zeggen: ik heb dit en dit ingevuld. Je kan het inzien, je kan het gebruiken om aan je sportcoach te geven"

C2: "Over die onderwerpen heb je het toch ook vaak al. Het is niet zo dat het helemaal buiten de scope staat"

Annotations group 1



Sportadvies medische professional

De kindercardioloog vult dit formulier in. Onderaan wordt het later aangevuld door kind en ouder met aanvullende informatie voor de sportcoach.

Basisinformatie

Naam kind: Ben
Geboortedatum: 14 jaar
Medisch behandelaar: [illegible]
Datum: 20/10/25

Medische achtergrond

Medische diagnose:
**Wanneer aangeklikt op scherm, verschijnt achtergrondinformatie over de specifieke hartafwijking en symptomen.* Coarctatio Aorta ORA ok.

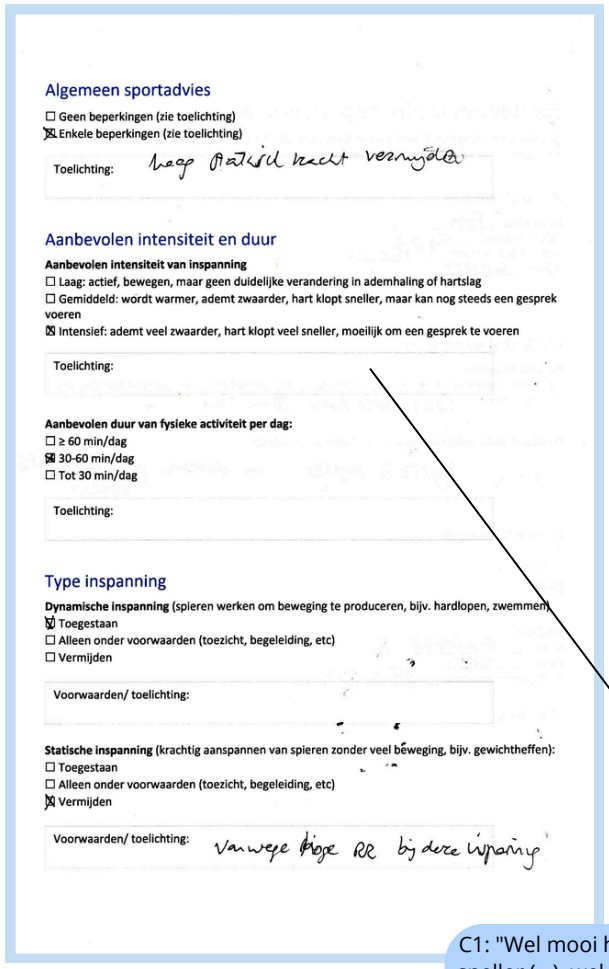
Eventueel korte uitleg voor sportcoach (aandachtspunten):

Toelichting: hypertensie mogelijk ⇒ staven per hoog statische kracht

Device geïmplanteerd?
☐ ICD
☐ Pacemaker
☒ Geen

Medicatie
Naam: enalapril
Dosis: 2x5
Tijdstip van toediening: 8u en 20u

Toelichting:



Algemeen sportadvies

☐ Geen beperkingen (zie toelichting)
☒ Enkele beperkingen (zie toelichting)

Toelichting: hoog statisch kracht vermijden

Aanbevolen intensiteit en duur

Aanbevolen intensiteit van inspanning
☐ Laag: actief, bewegen, maar geen duidelijke verandering in ademhaling of hartslag
☐ Gemiddeld: wordt warmer, ademt zwaarder, hart klopt sneller, maar kan nog steeds een gesprek voeren
☒ Intensief: ademt veel zwaarder, hart klopt veel sneller, moeilijk om een gesprek te voeren

Toelichting:

Aanbevolen duur van fysieke activiteit per dag:
☐ ≥ 60 min/dag
☒ 30-60 min/dag
☐ Tot 30 min/dag

Toelichting:

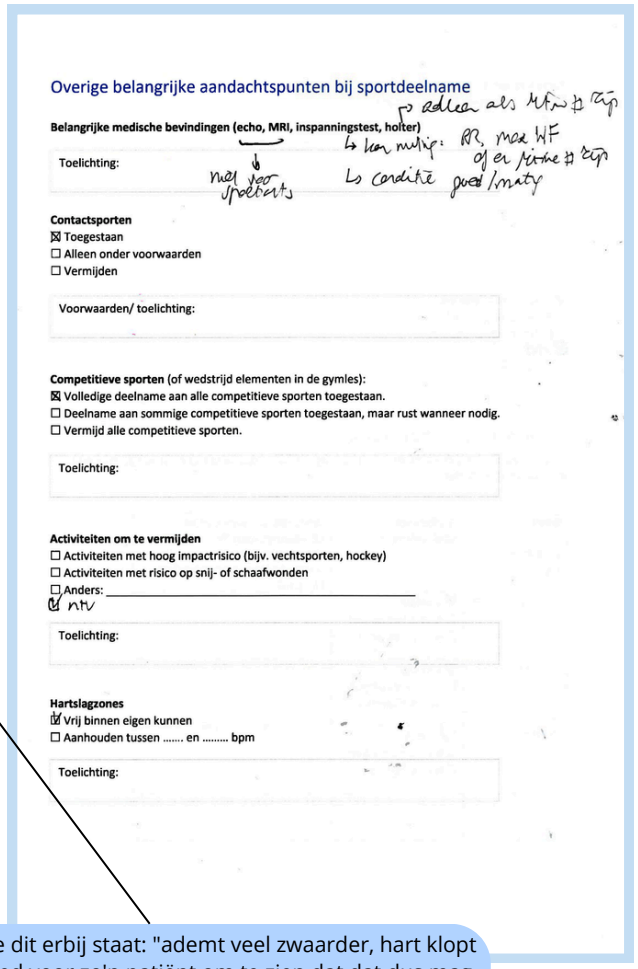
Type inspanning

Dynamische inspanning (spieren werken om beweging te produceren, bijv. hardlopen, zwemmen)
☒ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☐ Vermijden

Voorwaarden/ toelichting:

Statische inspanning (krachtig aanspannen van spieren zonder veel beweging, bijv. gewichtheffen):
☐ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☒ Vermijden

Voorwaarden/ toelichting: vanwege hoge RR bij deze inspanning



Overige belangrijke aandachtspunten bij sportdeelname

Belangrijke medische bevindingen (echo, MRI, inspanningstest, holter)

Toelichting: mag voor sporten

Contactsporten
☒ Toegestaan
☐ Alleen onder voorwaarden
☐ Vermijden

Voorwaarden/ toelichting:

Competitieve sporten (of wedstrijd elementen in de gymles):
☒ Volledige deelname aan alle competitieve sporten toegestaan.
☐ Deelname aan sommige competitieve sporten toegestaan, maar rust wanneer nodig.
☐ Vermijd alle competitieve sporten.

Toelichting:

Activiteiten om te vermijden
☐ Activiteiten met hoog impactrisico (bijv. vechtsporten, hockey)
☐ Activiteiten met risico op snij- of schaafwonden
☐ Anders: _____
☑ MTV

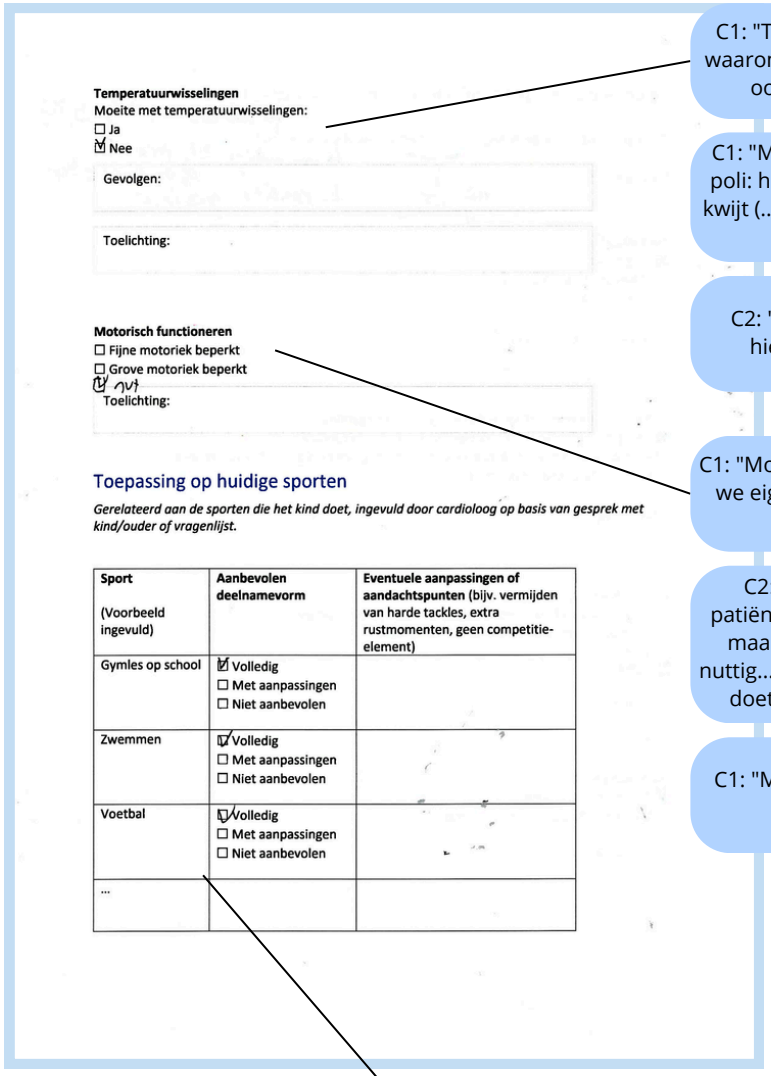
Toelichting:

Hartslagzones
☑ Vrij binnen eigen kunnen
☐ Aanhouden tussen ..... en ..... bpm

Toelichting:

C1: "Wel mooi hoe dit erbij staat: "ademt veel zwaarder, hart klopt sneller (...). wel goed voor zo'n patiënt om te zien dat dat dus mag. Ik vind dat een goede toevoeging."

C2: "Om het heel concreet te maken, dat vind ik een goeie. Het maakt de intensiteit van de sport concreet"



Temperatuurwisselingen
Moeite met temperatuurwisselingen:
☐ Ja
☑ Nee

Gevolgen:

Toelichting:

Motorisch functioneren
☐ Fijne motoriek beperkt
☐ Grove motoriek beperkt
☑ nvt
Toelichting:

Toepassing op huidige sporten

Gerelateerd aan de sporten die het kind doet, ingevuld door cardioloog op basis van gesprek met kind/ouder of vragenlijst.

Sport (Voorbeeld ingevuld)	**Aanbevolen deelnamevorm**	**Eventuele aanpassingen of aandachtspunten** (bijv. vermijden van harde tackles, extra rustmomenten, geen competitie-element)
Gymles op school	☑ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
Zwemmen	☑ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
Voetbal	☑ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
...		

C1: "Temperatuurwisselingen, grappig, waarom zit dit erin. Ik vind het misschien ook wel een beetje overdreven"

C1: "Mensen zeggen het wel vaak op de poli: hij kan echt heel slecht zijn warmte kwijt (...). Maar dat is niet gerelateerd aan de hartafwijking"

C2: "Ik vraag me af wat de gedachte hierachter is wil ik graag weten"

C1: "Motorisch functioneren, daar hebben we eigenlijk geen verstand van dus dat zou ik ook..."

C1: "Ik vind dat dat een beetje buiten onze scope gaat"

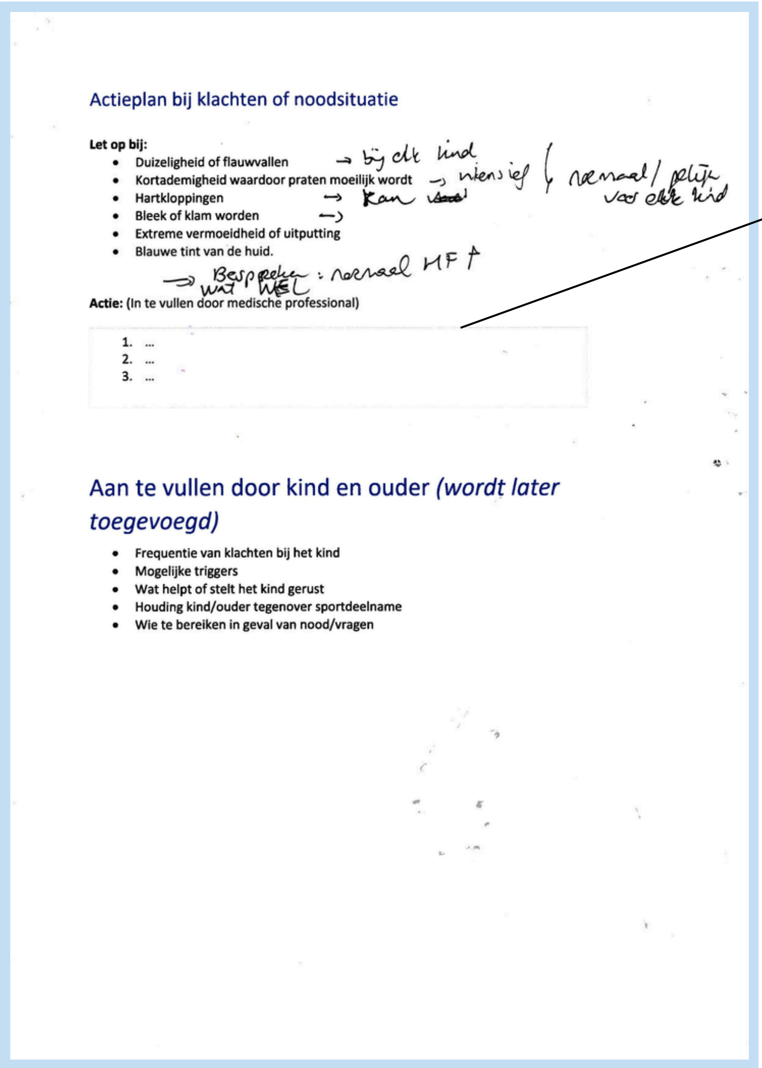
C2: "Je hebt voor een deel van de patiënten, ik zou een hokje n.v.t. maken maar voor sommigen is het echt wel nuttig... Voor iemand die sportbegeleiding doet is het wel handig om te weten"

C1: "Ik vind het wel lastig of wij dit nou moeten doen. Je komt wel van de cardioloog, je krijgt een inspanningsadvies op basis van je hart. Vind ik wel lastig of ik nou ook dan nog die grove motoriek van het kind mee moet nemen. Daarnaast gaan we er denk ik ook voor heel veel dingen niet over geïnformeerd zijn."

C1: "Maar het is natuurlijk iets wat heel kind specifiek is"

C2: "Is dit niet het advies van of via ouders of via andere hulpverleners. Het is de vraag of dat ligt in onze handen. Ook al zouden we het weten, is het misschien niet iets dat wij moeten beoordelen. (...). De fysio kan daar wat meer over zeggen"

C2: "Het is wel fijn dat je het hierin kwijt kan"



Actieplan bij klachten of noodsituatie

Let op bij:

- Duizeligheid of flauwvallen → bij elk kind
- Kortademigheid waardoor praten moeilijk wordt → intensief { normaal / gelijk voor elk kind
- Hartkloppingen → kan
- Bleek of klam worden →
- Extreme vermoeidheid of uitputting
- Blauwe tint van de huid.

→ Bespreken wat WEL : normaal HF ↑

Actie: (In te vullen door medische professional)

1. ...
2. ...
3. ...

Aan te vullen door kind en ouder *(wordt later toegevoegd)*

- Frequentie van klachten bij het kind
- Mogelijke triggers
- Wat helpt of stelt het kind gerust
- Houding kind/ouder tegenover sportdeelname
- Wie te bereiken in geval van nood/vragen

C1: “Misschien moet je hier meer bespreken dat het normaal is dat je buiten adem raakt.”

C1: “Als je het als een soort noodplan schrijft kan het ze misschien wel heel angstig maken en dan denken ze, ik raak nu buiten adem en dan durven ze misschien niet meer verder te gaan. Dus misschien moet je juist in het actieplan bespreken dat dit eigenlijk normaal is. En dan zijn er dingen als wegrakingen en duizeligheid, dan moet elk kind eigenlijk stoppen. En misschien moeten we dat niet zo specifiek voor dat ene kind houden met ASD of een afwijkende aortaklep. Want dan denken ze ik heb extra kans om weg te raken, terwijl dat is denk ik niet zo. Maar het is natuurlijk wel zo dat als ze duizelig worden, dan moet jij ook stoppen en ik ook. Dus ik denk dat dat meer een algemeen advies moet zijn voor kinderen, en we niet zo moeten benadrukken dat dit alleen is omdat het bij hun hartafwijking afwijkt.”

C1: “Ik denk wel dat mensen het heel fijn vinden om een noodplan te hebben, maar dat geldt eigenlijk alleen als een kind echt wegraakt. En dan moet je gewoon 112 bellen.”

C1: “Rust bij als je duizelig bent of dreigt flauw te vallen of dat je bleek of klam wordt of dat je een blauwe tint van de huid krijgt. Dan moet je even rustig doen en stoppen. En als je echt wegraakt, dan moet er een noodplan zijn dat de sportcoach weet dat hij dit moet doen.”

Worksheet group 2

SPORTADVIESFORMULIER (CARDIOLOOG → SPORTCOACH)

INHOUD & RELEVANTIE

Welke onderdelen zijn overbodig, te uitgebreid of missen nog?

Geen, maar moet praktischer
- uit Hix halen
- categorien v.h. programmeren

Wat zou dit formulier beter bruikbaar maken qua inhoud of vorm?

Zoveel mogelijk info (b.v. diagnose, medicijngebruik) automatisch koppelen via Hix

Sportadvies

PRAKTISCHE TOEPASBAARHEID

Hoeveel tijd kost dit realistisch gezien om in te vullen?

Veel

Wanneer zou dit ingevuld worden (voor, tijdens of na het consult)?

Deels voor, deels na.

Sluit de tool aan bij de werkwijze van cardiologen? En hoe kan dit verbeterd worden?

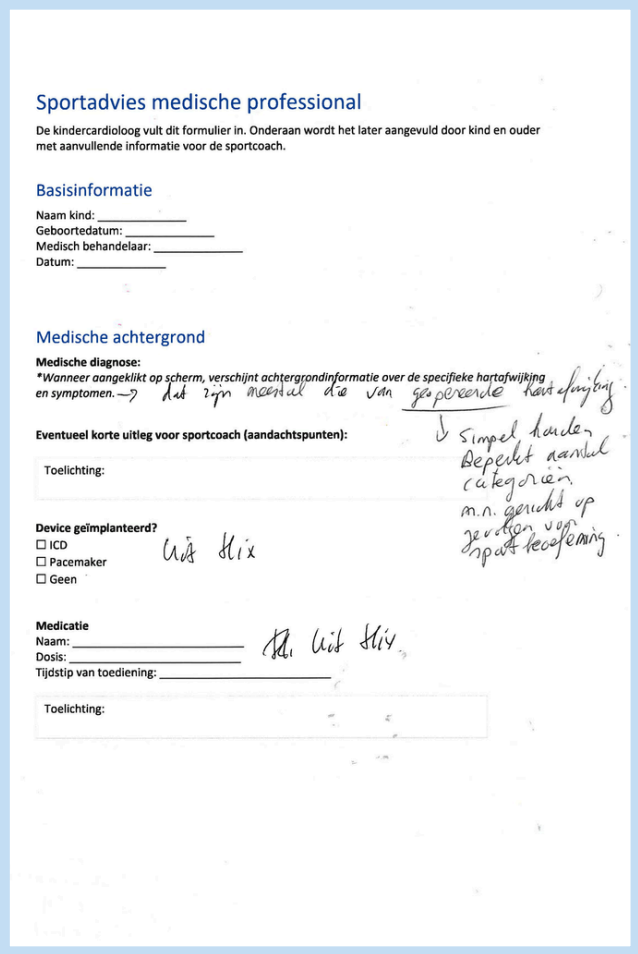
Nu te weinig tijd op spreekuur.

Door wie zou dit het beste kunnen worden ingevuld (cardioloog, verpleegkundige, etc.)?

- Kinder cardioloog
- Verpleegkundig consulent.

Hoe kan dit formulier zo efficiënt mogelijk worden gebruikt (aanvinkvelden, standaardteksten, automatische invulling, etc.)?

Annotations group 2



Sportadvies medische professional

De kindercardioloog vult dit formulier in. Onderaan wordt het later aangevuld door kind en ouder met aanvullende informatie voor de sportcoach.

Basisinformatie

Naam kind: _____
Geboortedatum: _____
Medisch behandelaar: _____
Datum: _____

Medische achtergrond

Medische diagnose:
**Wanneer aangeklikt op scherm, verschijnt achtergrondinformatie over de specifieke hartafwijking en symptomen.* —>

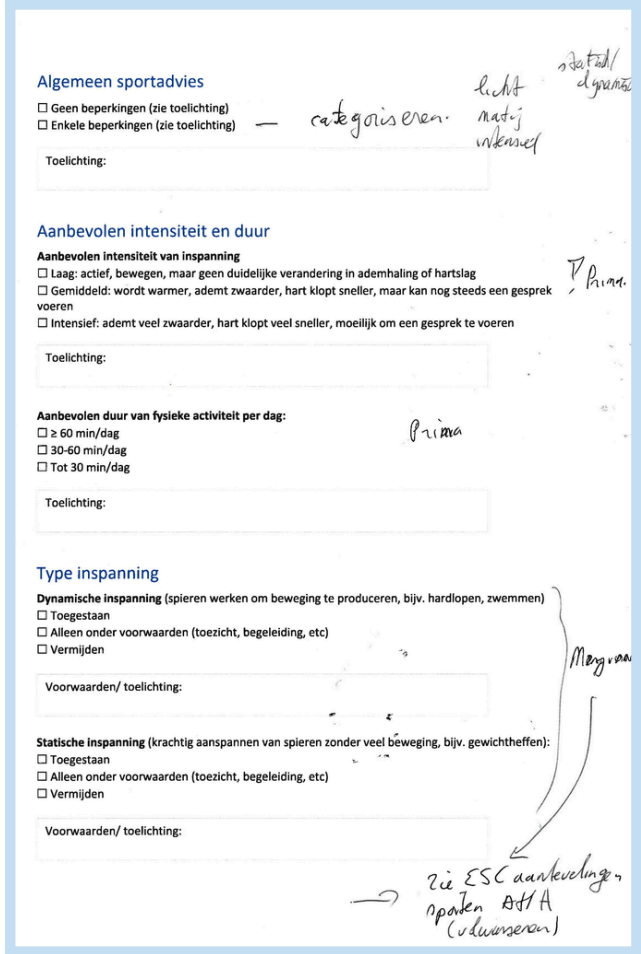
Eventueel korte uitleg voor sportcoach (aandachtspunten):

Toelichting:

Device geïmplanteerd?
☐ ICD
☐ Pacemaker
☐ Geen

Medicatie
Naam: _____
Dosis: _____
Tijdstip van toediening: _____

Toelichting:



Algemeen sportadvies

☐ Geen beperkingen (zie toelichting)
☐ Enkele beperkingen (zie toelichting)

Toelichting:

Aanbevolen intensiteit en duur

Aanbevolen intensiteit van inspanning
☐ Laag: actief, bewegen, maar geen duidelijke verandering in ademhaling of hartslag
☐ Gemiddeld: wordt warmer, ademt zwaarder, hart klopt sneller, maar kan nog steeds een gesprek voeren
☐ Intensief: ademt veel zwaarder, hart klopt veel sneller, moeilijk om een gesprek te voeren

Toelichting:

Aanbevolen duur van fysieke activiteit per dag:
☐ ≥ 60 min/dag
☐ 30-60 min/dag
☐ Tot 30 min/dag

Toelichting:

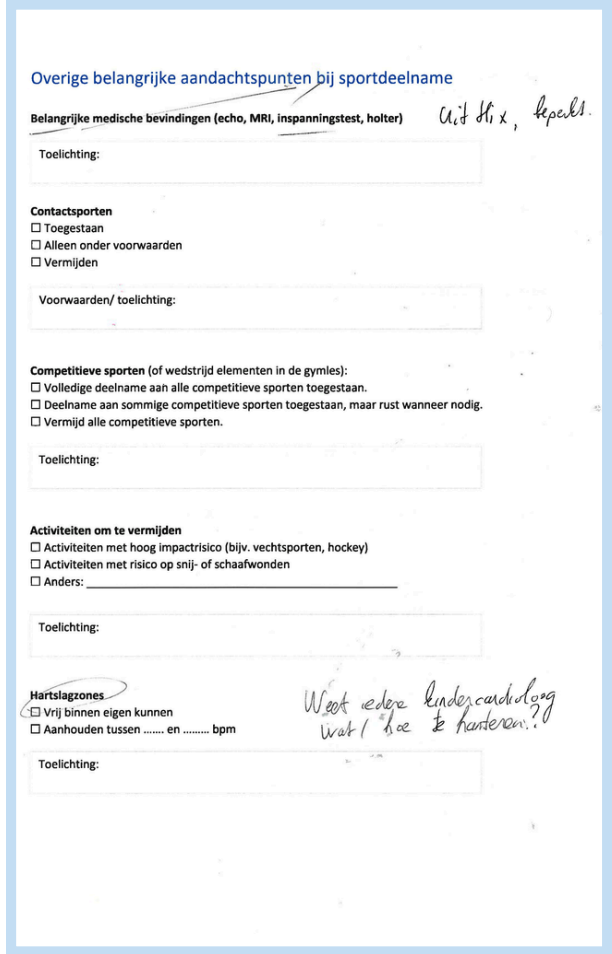
Type inspanning

Dynamische inspanning (spieren werken om beweging te produceren, bijv. hardlopen, zwemmen)
☐ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☐ Vermijden

Voorwaarden/ toelichting:

Statische inspanning (krachtig aanspannen van spieren zonder veel beweging, bijv. gewichtheffen):
☐ Toegestaan
☐ Alleen onder voorwaarden (toezicht, begeleiding, etc)
☐ Vermijden

Voorwaarden/ toelichting:



Overige belangrijke aandachtspunten bij sportdeelname

Belangrijke medische bevindingen (echo, MRI, inspanningstest, holter)

Toelichting:

Contactsporten
☐ Toegestaan
☐ Alleen onder voorwaarden
☐ Vermijden

Voorwaarden/ toelichting:

Competitieve sporten (of wedstrijd elementen in de gymles):
☐ Volledige deelname aan alle competitieve sporten toegestaan.
☐ Deelname aan sommige competitieve sporten toegestaan, maar rust wanneer nodig.
☐ Vermijd alle competitieve sporten.

Toelichting:

Activiteiten om te vermijden
☐ Activiteiten met hoog impactrisico (bijv. vechtsporten, hockey)
☐ Activiteiten met risico op snij- of schaafwonden
☐ Anders: _____

Toelichting:

Hartslagzones
☐ Vrij binnen eigen kunnen
☐ Aanhouden tussen ..... en ..... bpm

Toelichting:

Temperatuurwisselingen
Moeite met temperatuurwisselingen:
☐ Ja
☐ Nee

Gevolgen:

Toelichting:

Motorisch functioneren
☐ Fijne motoriek beperkt
☐ Grove motoriek beperkt

Toelichting:

Toepassing op huidige sporten

Gerelateerd aan de sporten die het kind doet, ingevuld door cardioloog op basis van gesprek met kind/ouder of vragenlijst.

Sport (Voorbeeld ingevuld)	**Aanbevolen deelnamevorm**	**Eventuele aanpassingen of aandachtspunten** (bijv. vermijden van harde tackles, extra rustmomenten, geen competitie-element)
Gymles op school	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen → 1 dag.	afgeraden ?
Zwemmen	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
Voetbal	☐ Volledig ☐ Met aanpassingen ☐ Niet aanbevolen	
...		

Actieplan bij klachten of noodsituatie

Let op bij:
- Duizeligheid of flauwvallen
- Kortademigheid waardoor praten moeilijk wordt
- Hartkloppingen → hartfrequentie > .. /min. (220 - leeftijd) Onregelmatige hartslag
- Bleek of klam worden
- Extreme vermoeidheid of uitputting
- Blauwe tint van de huid.

Actie: (In te vullen door medische professional)

1. ...
2. ...
3. ...

Aan te vullen door kind en ouder *(wordt later toegevoegd)*

- Frequentie van klachten bij het kind
- Mogelijke triggers
- Wat helpt of stelt het kind gerust
- Houding kind/ouder tegenover sportdeelname
- Wie te bereiken in geval van nood/vragen