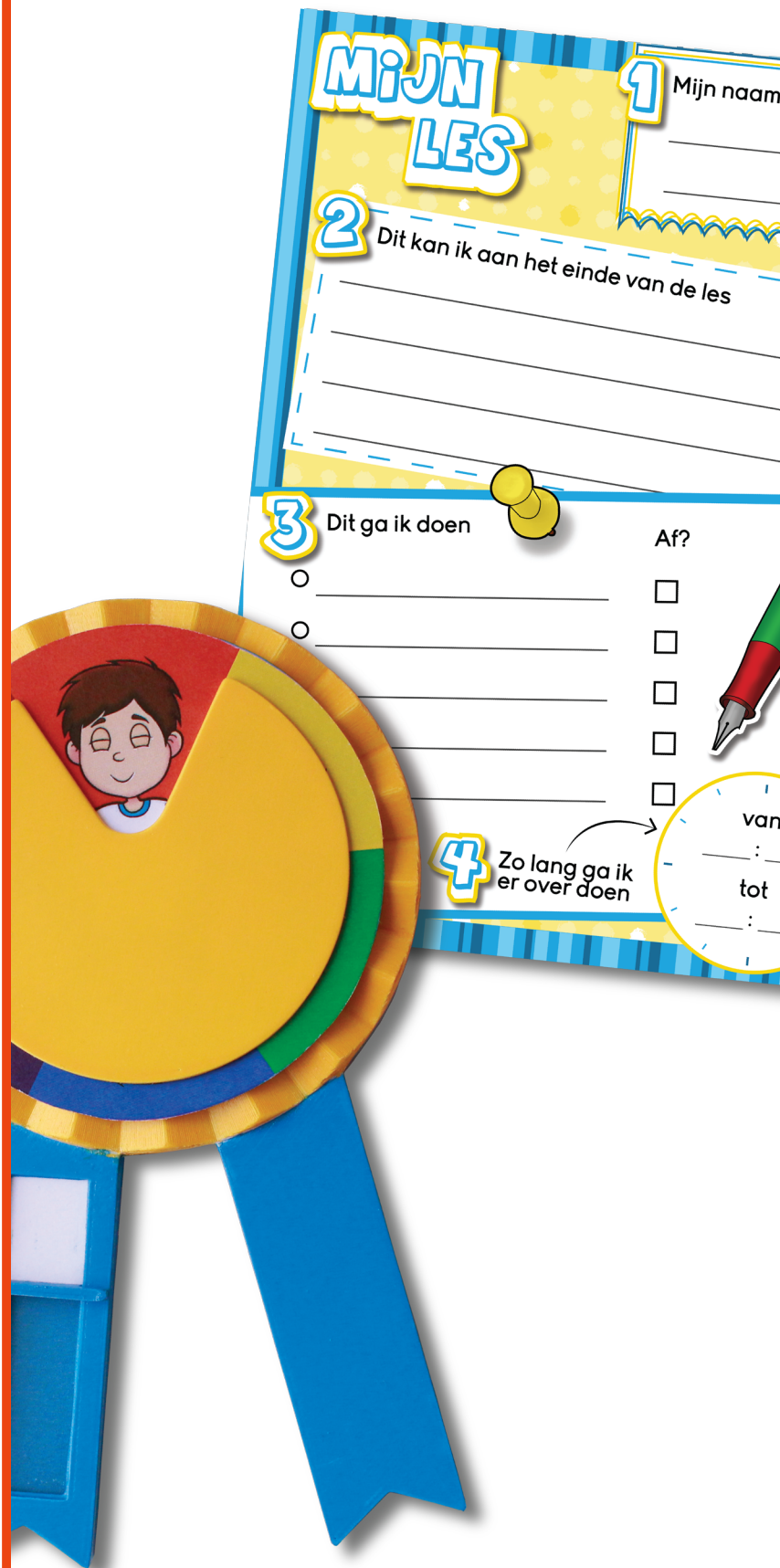


Master thesis

**Improving the
school experience of
children with cancer**

Inge Bartels



Colofon

Master thesis
Improving the school experience of children with cancer

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Preface

This report introduces the graduation project 'Improving the school experience for children with cancer'. This graduation project is the final project of the master Design for Interaction which is one of the masters at the faculty of Industrial Design Engineering of the Delft University of Technology. The graduation project is developed under the project 'Meedoen = Groeien!' in which research on interactive products is conducted to support the physical and psychosocial development of children with cancer and their family (Meedoen is Groeien, n.d.). During this graduation project a concept proposal has been developed to improve the school experience of children with cancer.

Since the project is executed within the master Design for Interaction with the Specialisation Medesign (designing for medical applications), the research was focussed on the users, context, and the interaction between the users, context, and product/service in the medical context. Therefore lot of field research was conducted with professionals and experts with experience. Without those people it would not have been possible to develop this product/service. I would like to express my gratitude to all the people for their stories, participation, honest opinions, and enthusiasm.

Furthermore, I would like to thank my family and friends for their mental support and giving their opinions. Special thanks goes to my chair and mentor: Gert Pasman and my mentor Patrizia D'Olivo. Their suggestions, feedback, and support to make choices, helped me a lot throughout this project.

Inge Bartels

Executive Summary

The aim of the project was to design a product and/or service that improves the psychosocial school experience of children with cancer (aged between 8-10 years old) and the people around them during the treatment phase.

Research

A literature and field research led to the following insights:

- The impact cancer and its treatment have differ a lot per situation (e.g. social support), child (e.g. coping strategies), and treatment phase (symptoms and side effects). This results in changing needs.
- The development is affected by the sickness. The social and personality development is affected by becoming more dependend instead of independed and becoming faster mature
- School is the place where the child doesnot feel sick. School keeps normalcy, challenges the child, and gives hope for recovery.
- Mood and energy level influence the behaviour and school performance. For a sick child it can differ a lot throughout the day and is difficult to understand based on only observations for a teacher.
- In order to stimulate the cognitive development of the sick child, the tasks and time should be differentiated.

Design goal

The product/service should support the child with cancer to express his emotional and physical state and support the teacher to create together with the child an individual planning suitable for his current well-being throughout the day.

In the current situation teachers tend to underestimate sick children and sick children tend to overestimate themselves, this has a negative effect on the self-image, self-confidence, and development of the child. This should be prevented by creating an understanding of the well-being of the child.

Next to this, the product/service must

- Gives the sick child the feeling he is treated as a "normal" child.
- Gives the sick child the feeling of control.
- Addresses the different needs of children.
- Stimulates to keep or create a new normalcy.

'Humeur adviseur'- Concept proposal



'Mijn les'

The cards are used by all children. Before each lesson the teacher decides which children will use the cards which they fill out themselves. The cards

- make **learning visible**.
- give the teacher **insight into the reflection process** of the children.

The cards are differently used for the sick child. Before the lesson the teacher checks the 'Gevoelens medaille' and fills out the tasks the child could do. Based on these tasks the child chooses which ones he is going to do. The cards

- **communicate** what the teacher expects the child could do.
- stimulate **creating an individual planning together** by differentiating the tasks.
- give **feedback** to the teacher about how the sick child perceived the lesson.

'Gevoelens medaille'

The 'Gevoelens medaille is used only by the sick child. The child can place it on his table and use it throughout the day. The 'Gevoelens medaille;

- stimulates the sick child to **think and talk about** his mood and energy level.
- supports the sick child in **expressing** himself easily and quickly. The wheel shows the mood and the slide at the bottom the energy level.
- **reminds** the teacher and classmates of the impact of cancer on the sick child, which results in understanding and empathy.

Different needs



The introduction booklet supports the sick child and teacher to communicate about their preferences and needs with regards to the use of the 'Humeur adviseur'. This does give the child a sense of control.

Safe environment



The sick child is involved in the gradual implementation process and can personalise the 'Gevoelens medaille' to create a safe environment to support the child in expressing himself honestly.

Belonging



The cards are used by the whole class to give the children the feeling that the sick child is treated similar as his classmates. The 'Gevoelens medaille' is only used by the sick child to reduce the workload of the teacher.

Create new normalcy



The 'Humeur adviseur' is envisioned as a contemporary tool to support the teacher and child in understanding each other and the new situation. This is explained in the folder for the teacher.

Control



Based on the tasks the teacher proposes, the sick child can choose which tasks he is going to do. However it appeared that this did not gave the child a feeling of control.

Abbreviations & Terminology

ALL	Acute lymphoid leukaemia
EAO	Education Advice Office
EF	Educational Facility
IC	Internal Counsellor
LUMC	Leids Universitair Medisch Centrum
MC-Sophia	Erasmuc MC-Sophia Kinderziekenhuis
PMC	Prinses M \grave{a} xima Centrum
SKION	Stichting Kinderderoncologie Nederland
TU Delft	Delft University of Technology
VOKK	Vereniging Ouders, Kinderen & Kanker
WKZ	Wilhelmina Kinderziekenhuis
Home school	The regular primary school in which the child is registered
Home teacher	The teacher who educates the child at home
Individual planning	Set of tasks specially composed for the sick child
Product/service	Refers to the concept proposal, before it was decided what the concept proposal was going to be
Teacher	The teacher who educates the child at the home school
Target group	Children with cancer in group 5/6 (aged 8-10 years old) and their teacher(s) and classmates

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1 Introduction

This chapter provides a brief introduction into the project and the topic childhood cancer. Here the design brief can be found, which was the starting point of the project. Afterwards the followed approach is visualised and explained. Furthermore, this chapter gives insights into childhood cancer and an overview of people and parties involved in the sick child's care.

1.1 Design Brief

This graduation project is part of the project 'Meedoen = Groeien!', which is a collaboration between the Revalidatiefonds, the Prinses Máxima Centrum (PMC) for childhood cancer and the Delft University of Technology (TU Delft). Within this collaboration interactive products are developed and researched to support the physical and psychosocial development of children with cancer and their family (Meedoen is Groeien, n.d.). By supporting the development during the sickness, it is aimed to reduce the consequences of late effects (Meedoen = Groeien, n.d.).

1.1.1 Princes Máxima Centrum

The PMC is a **specialised centre for child oncology** where research is conducted on the development of children and child oncology and where the complex care (e.g. diagnostic, setting up the treatment) for child oncology is centred (Prinses Máxima Centrum, n.d.a). Less complex care (e.g. taking blood samples) is provided by shared care centers, which are hospitals located all over the Netherlands, led by the PMC (Prinses Máxima Centrum, n.d.a). By bringing the care for the children together at one place combined with research, the best care can be developed and provided to the children.

The mission of the PMC (Prinses Máxima Centrum, n.d.b) is:

'Healing all children from cancer, with optimal quality of life.'

To realise this mission the PMC introduced the innovative **Development-Oriented Care approach**. Which means that the focus of the treatment will not only be related to the sickness itself, but also on fostering the development of the children and the wellbeing of the whole family.

1.1.2 Graduation assignment

In line with the mission of the PMC, this graduation project focuses on **fostering the psychosocial development of children with leukaemia, aged between 8 and 10 years old, while following education at a regular school** during or after the treatment of cancer. It was chosen to focus on the age 8-10 (group 5 and 6), since at this age children start to become independent from their parents and start to form their own identity (CJG, 2016) in which school is a relevant factor.

The aim of the project is:

'Research how design can contribute positively to the school experience of children with cancer during the treatment phase at primary schools.'

The design goal is:

'Design a product and/or service that improves the psychosocial school experience of children with cancer and the people around them during the treatment phase.'

1.1.3 Background

In the Netherlands, every year 550 children (aged between 0-18 years) are diagnosed with childhood cancer (VOKK, 2016a). Currently over 75% of the children survive cancer (VOKK, 2016a). In the recent decades this percentage has greatly increased (Lähteenmäki, Huostila, Hinkka & Salmi, 2002), due to the improvements in treatment (Charlton, Pearson & Morris-Jones, 1986). The aim is to increase this number to 90-95% in 2025 (KiKa 8118, 2013). This means that **more children will continue or re-enter school** after a diagnosis of cancer. It is important that a child continues or re-enters school as soon as possible for several reasons, such as improving academic skills (Vance & Eiser, 2002); structure, security, self-confidence and hope for the child; and social contacts (VOKK, 2016b).

1.1.4 Opportunity

In the current situation there are a lot of **challenges** which could arise when the child re-enters/continues school during treatment. For example the child may fear teasing or rejection; teachers feel unsure about their knowledge about cancer or have the feeling there is a lack of information; or parents are

overprotective and feel reluctant to send their child back to school (Worchel-Prevatt, et al., 1998).

An effective school re-entry/continuance implies a **multistakeholders structure** where the needs of child, family, teacher/school, and classmates are taken into account (figure 1).

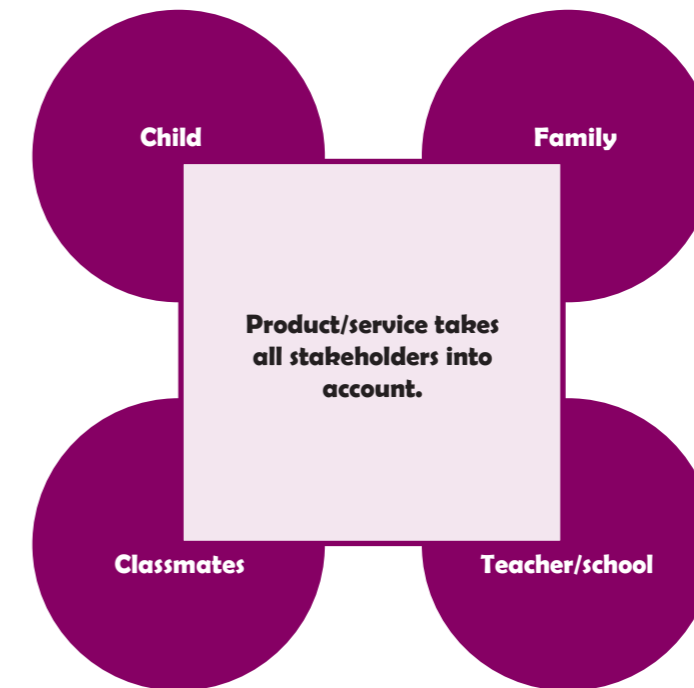


Figure 1: A multistakeholder structure with the child, family, teacher, and classmates

1.2 Approach

The approach used within this project is based on **human-centred design**. Human-centred design focuses at first on the users and their physical and psychological needs, and results in a design suitable for the users and their needs (Design Kit, n.d.) (Greenhouse, 2010). Throughout the project the users stay at the centre of the project. In line with this approach during the start up, orientation, and goal definition phases an understanding of the users (and context) was created to serve as inspiration and create guidelines for the product/service. During the ideation and evaluation this knowledge was used to create ideas, and the users were involved in giving feedback to evaluate the ideas. By going back to the users the design can be adjusted to the needs of the users.

This report shows the results from the project in a logical order and is, therefore, not chronological. To give insight into the process of this project a timeline was made (figure 2). In the timeline the different phases of the project are visualised with the activities performed. The colours correspond with the chapter in which the results are described. As can be seen in (figure 2) the ideation phase already started during the analysis phase, due to which it was possible to use the insights from the analysis directly into the ideation and to answer questions which arose during the ideation within the analysis.

Below for each phase the reasons to perform the activities are explained, more information can be found in appendix A.

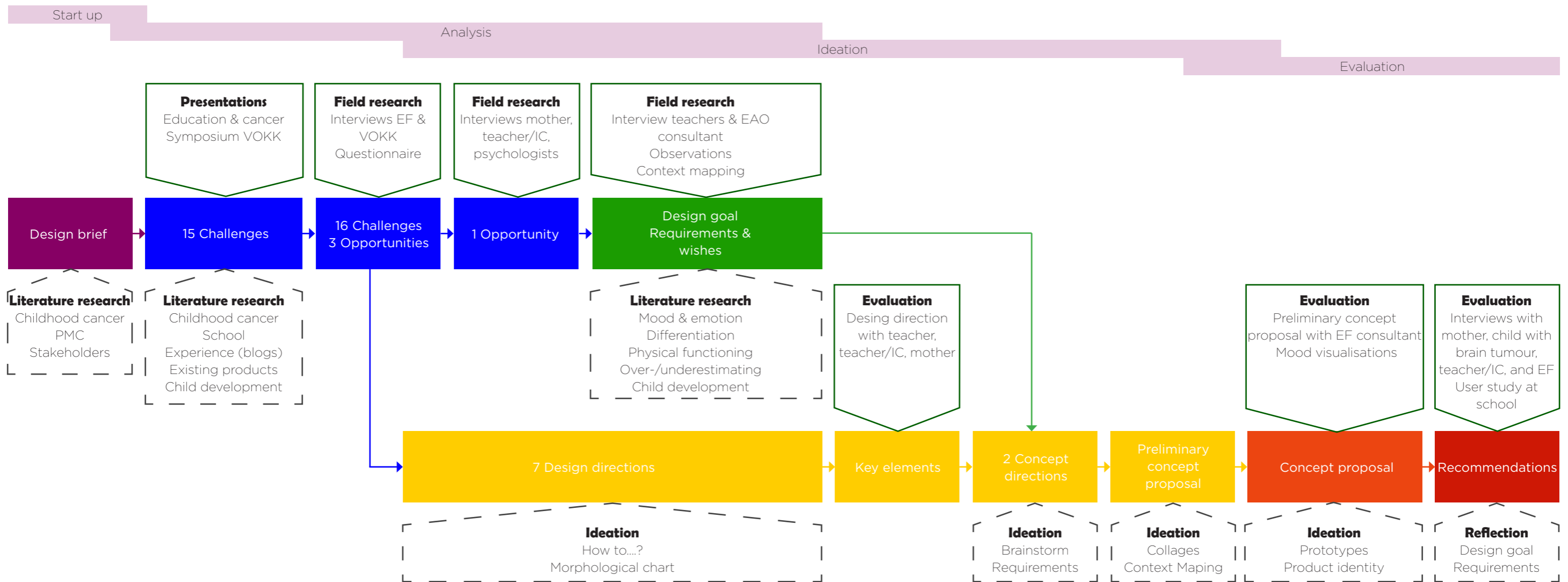


Figure 2: A timeline of the phases of the project with the activities performed

1.2.1 Start up

A small desk research was conducted to gain the first knowledge about childhood cancer and the PMC. This knowledge was used to **formulate the design brief** and define a focus point for the project. The results of this phase can be found in the introduction (Chapter 1).

1.2.2 Analysis

The goal of the analysis was to **find a design opportunity** and gain enough knowledge to be able

to make a suitable product/service. The analysis consisted of three parts: 1) Exploratory literature analysis, 2) field research, and 3) in dept analysis.

Part 1) Exploratory literature analysis

An exploratory literature analysis was done to gain **background information** about childhood cancer and school. This information was used to create an overview of challenges experienced related to the school experience of a child with cancer, and to prepare the field research. The results of this part can be found in analysis part 1 (Chapter 2.1. till 2.4.).

1.3 Childhood Cancer

Part 2) Field research

The literature analysis was partly based on information from foreign countries and a larger age range than targeted. Therefore a field research was conducted to **validate** the information retrieved during the literature analyses and to **find answers to questions that were not possible to answer** with a literature analysis.

Several methods are used with participants with different backgrounds to fully understand the situation and their needs with taking **different perspectives** into account. The field research activities are explained in appendix B.

The information gained was used to formulate and choose a design direction. The results of the field research are presented in the analysis part 1 and 2 (Chapter 2.1 till 2.7).

Part 3) In depth literature analysis

Due to the focus of the design opportunity and the ideation some **specific questions** about emotion and mood, physical functioning, and differentiation arose. These were answered by a literature study and a last field research activity. The results of this part can be found in the 3th part of the analysis (Chapter 2.8 till 2.10).

1.2.3 Goal defining

Based on all the gained information a **goal of the product/service** was formulated as starting point

for the ideation. An interaction vision was formulated which served as inspiration and guidance for the product/service (Chapter 3).

1.2.4 Ideation

During the field research the ideation started. Several creative techniques were used to **stimulate the ideation** and come up with the first ideas for design directions. These were evaluated with experts from the field to gain **insight into the needs** and wishes of the users.

Based on this information key insights were identified which formed the input for a brainstorm session. The brainstorm session was organised to come up with **new ideas**.

The last part of the ideation was **combining all insights** into concept directions and come up with a detailed concept proposal. By involving the user in the last part of the process as well, it was possible to include all needs of the users within the concept proposal. The results of the ideation can be found in chapter 4 Ideation.

1.2.5 Evaluation

During the last phase the concept proposal was evaluated with different users. The evaluation was done by interviews and a user test to gain information from different perspectives. The results helped to **optimise the concept proposal** and formulate recommendations.

The scientific community refers with childhood cancer to: "a collective name for several malignant diseases which occur at childhood age (0-18 year)" (Stichting Signaal, 2015). Childhood cancer **differs a lot from cancer which occurs in adults**, due to diverse body conditions and way of reaction (KiKa 8118, 2013). Therefore the type of cancer, the causes, the treatment, and the survival rates are different (Kanker.nl, 2016a).

Figure 3 presents a visualisation of a few relevant aspects of childhood cancer and a brief introduction of the treatment, side effects, and late effects. This will be further explained in chapter 2.1.

Statistics

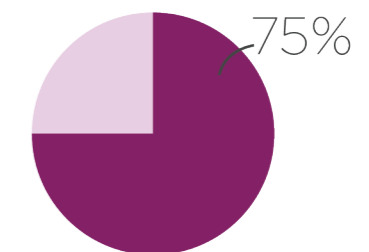
Every year **500 - 550** children are diagnosed with a type of cancer.

Currently around **800** children undergo an active treatment for a type of cancer.

More than **7000** people are successfully treated for a type of childhood cancer.

Yearly around **69** children die due to cancer.

The average survival rate of childhood cancer is:



The percentage of cancer mortality of the total mortality of children is:

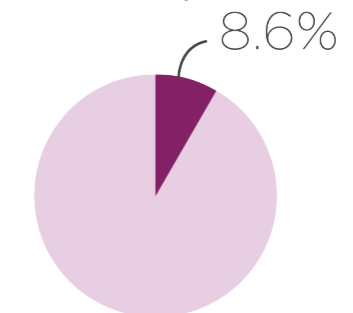


Figure 3: Overview of relevant aspects of childhood cancer (1/2)

1.4 Stakeholders

Treatment

Childhood cancer is treated with radiation, chemotherapy, and/or surgery depending on the type of cancer.



Radiation

A local treatment to kill the cancer cells with radiation. It is also possible to give radiation from the inside of the body. Mostly combined with another type of treatment.



Chemotherapy

Medication to kill the cancer cells. Mostly a combination which includes mainly medication which slows down the mitoses, and medication with protein kinase inhibitors or monoclonal antibodies.

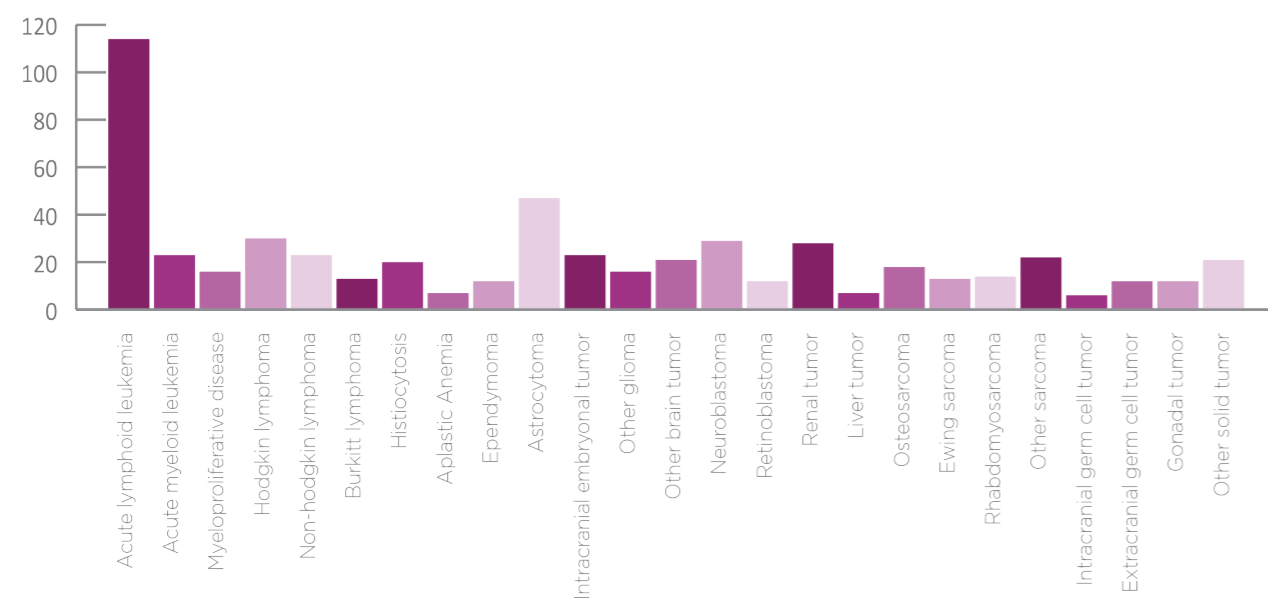


Surgery

To remove the tumor with cancer cells. A surgery is mostly combined with another type of treatment.

Types of cancer

The most common types of childhood cancer are shown below with the amount of children who have this type of cancer.



Figur 3: Overview of relevant aspects of childhood cancer (2/2)

When a child gets cancer, a lot of people and parties will be involved in the child's care. An overview of these people and parties is shown in figure 4. As can be seen multiple people are involved in the education of the child, however the home school of the child will always be responsible for the child's education. The home school is the regular primary school in which the child is registered. More information about these stakeholders can be found in appendix C.

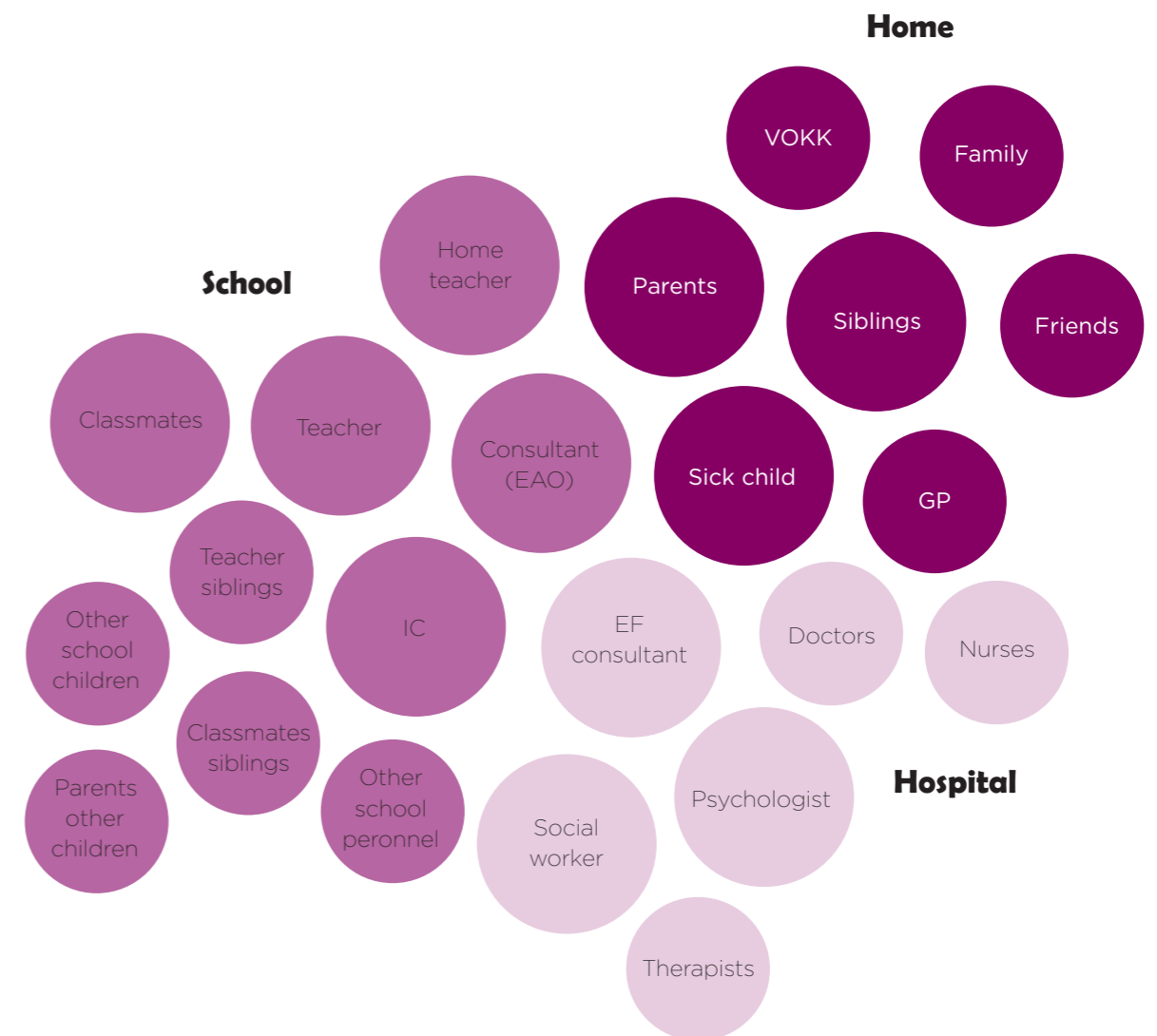


Figure 4: Overview of the people and parties involved in the care of the child

2 Analysis

An analysis has been conducted to get insight into the user and context; to identify challenges to formulate a design opportunity which is analysed in depth. The analysis is divided into three parts: 1) *orientation*, 2) *design opportunity*, and 3) *deepening*.

The first part, *orientation*, presents the first insights into the user and context to answer the research question: 'What challenges are experienced by children with cancer, their family, teachers, and/or classmates related to the school experience?'. A literature analysis is combined with several field research activities about living with cancer, child development, primary schools, and taking care of a child with cancer at school. Based on this analysis challenges are formulated.

In the second part, *design opportunity*, the identified challenges are evaluated with professionals from the field to answer the research question: 'To which challenge can design contribute most positively to the school experience and how?'. Based on the results from the literature analysis and the field research three design opportunities were formulated of which one was chosen to continue this project.

The third part of the analysis, *deepening*, is an in depth analysis focused on the design opportunity chosen in the second part to answer the research question: 'How can a suitable individual planning be created by the teacher and child?'. This in dept analysis is based on literature and a field research activities about mood and emotion, physical functioning, and differentiation.

The analysis is concluded with guidelines for designing for children with cancer and primary schools.

Part 1 Orientation

What challenges are experienced by children with cancer, their family, teachers, and/or classmates related to the school experience?

2.1 Living With Cancer

As mentioned in the introduction of this report, childhood cancer is a collective name for several malignant diseases. The types of cancer differ a lot from each other and also the impact of the life of the child and family can assure different connotations. I decided to focus on children with acute lymphoid leukaemia (ALL), since almost 25% of the children with cancer are diagnosed with this type of cancer.

This subchapter describes how the life of a child with leukaemia and his family is affected by the cancer.

What is the impact of cancer and its treatment on the life of the child and his family?



Literature



Questionnaire



Presentations



Interviews

2.1.1 Acute lymphoid leukaemia

Leukaemia is another word for **blood cancer** (kanker.nl, 2016b). Acute leukaemia arises when white blood cells start to divide before they are completely developed. Due to this incorrect mitoses the DNA of these cells gets damaged. The cause for the incorrect mitoses is unclear.

When the white blood cells do **not fully develop** and start to multiply, more and more incorrect

cells appear. The normal white blood cells stop multiplying, since the body assumes there are already enough white blood cells. The incorrect cells do not stop multiplying and start to suppress the normal blood cells; not only the normal white blood cells, but also the red blood cells and the platelets. (kanker.nl, 2016b)

Due to the **suppression of the normal blood cells**, these cells are not able to fulfil their functions properly. The effects of this suppression are shown in figure 5.

Type	Functions	Effect
White blood cells	Part of the immune system: they repel infections, and help to heal wounds (Ziezon, n.d.)	<ul style="list-style-type: none"> • Infections • Fever (UMC Utrecht, 2017).
Red blood cells	Responsible for transporting the oxygen through the body (Ziezon, n.d.).	<ul style="list-style-type: none"> • Fatigue • Looking pale, due to the resulting anemia (UMC Utrecht, 2017).
Platelets	Partly responsible for blood clotting are lacking (Ziezon, n.d.)	<ul style="list-style-type: none"> • Spontaneous bleedings • Bruises could appear.

Figure 5: Effects of the suppression of the normal blood cells

2.1.2 Diagnosis

The first symptoms of ALL are caused by the lack of normal blood cells, such as small infections, fatigue, and irregular bleedings. Based on these vague symptoms, which could be experienced already for several weeks, children go to the doctor (Alderfer & Kazak, 2006). To diagnose ALL the **bone marrow and blood** of the child must be **examined** (Hematologie Groningen, 2014). The amount of blood cells in the blood and the percentage of lymph blasts give an indication to diagnose ALL (Bloedkanker, n.d.). After the indication of ALL children are in generally referred to a **specialised centre** in which the child is again examined to diagnose the type of ALL (Hematologie Groningen, 2014). After the diagnosis the treatment should be started as soon as possible (Bloedkanker, n.d.).

Impact

When a child is diagnosed, **not only the child is affected, but his whole family** (Alderfer & Kazak, 2006). The individual members of the family are affected, but also the family system (Van Schoor, Goubert & Verhofstadt, n.d.).

Diagnosing a child with ALL is a process of days or weeks during which parents will feel **powerless and insecure**, but still have hope of their child not having cancer. During this process parents, and depending on the parents the child as well, are already informed about the possibility their child could have cancer. Nevertheless when the child is diagnosed the family will feel **shocked, overwhelmed, and powerless**. Immediately after the diagnosis the treatment will be started, due to which parents are overwhelmed by information and decisions they have to make. During the diagnosis process the child has to deal with a lot of new procedures and situations which is **confusing and overwhelming**.

2.1.3 Level of risk

All hospitals in the Netherlands follow the protocols of the Stichting Kinderoncologie Nederland (SKION) to treat children with ALL (Ziezon, n.d.). The children will be treated with chemotherapy and medication (Ziezon, n.d.). Within the protocol, ALL-I1, there are three main treatments related to the level of risk. Based on the response on the chemotherapy children are categorised into one of the three groups: **Standard risk (SR)**: These children will follow a treatment of 2 years with a lower dose of medication (SKION, n.d.). **Medium risk (MR)**: Depending on the genes of the child a treatment of 2 or 3 years needs to be followed (SKION, n.d.). **High risk (HR)**: These children have to undergo a highly intense treatment for 2 years (SKION, 2016). More information about the level of risk can be found in appendix D.

Impact

The higher the level of risk the lower the survival rate and the more intense the treatment will be for the child and the family. Therefore the moments when the response of the treatment is examined and communicated are **extra stressful** for the family.

2.1.4 Treatment

The length of the treatment and the medication given differs between the groups of level of risk. The phases into which the treatment is divided, are the same: 1) *induction*, 2) *consolidation*, and 3) *maintenance* (American Cancer Society, 2016) (figure 6).

On the next pages the phases are explained with common symptoms and side effects, and the impact on the child and his family.

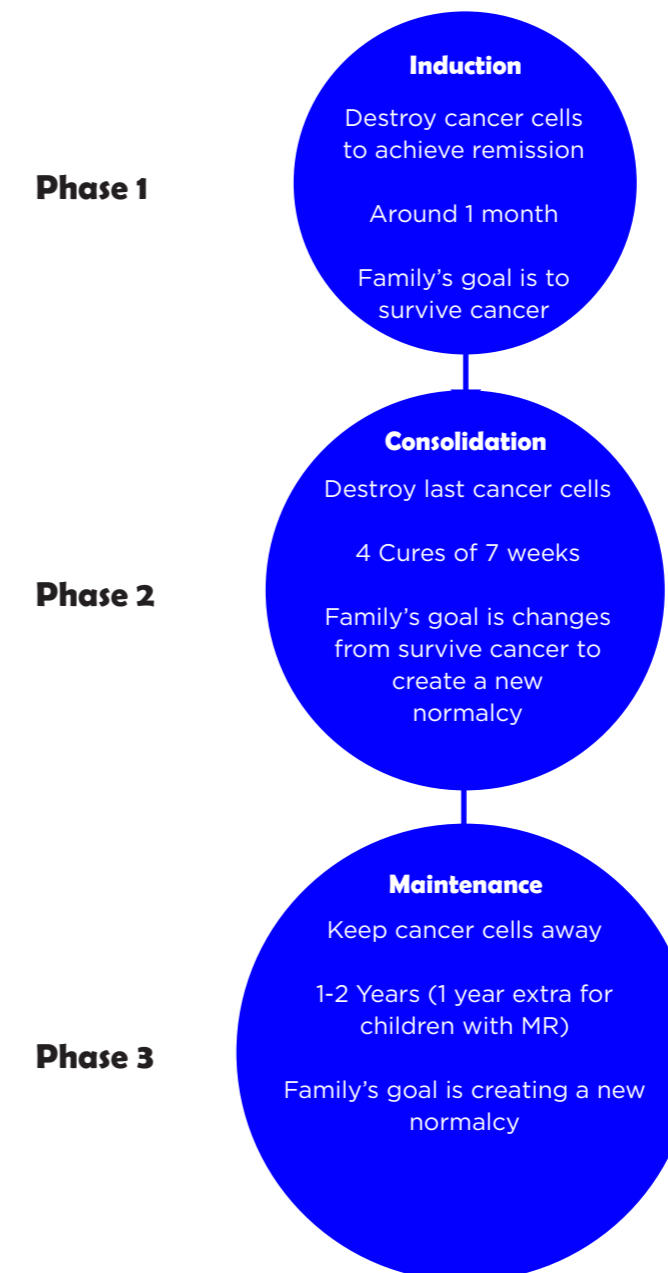


Figure 6: The phases of the cancer treatment for all three levels of risk

Induction

Induction is the first phase in which the **cancer cells are destroyed to achieve a remission**. Not all cancer cells will be destroyed. Around 99.9% of the cancer cells will be destroyed (American Cancer Society, 2016), which means there are no cancer cells visible anymore in the bone marrow and the normal blood cells are recovered fully (Nederlandse Vereniging voor Hematologie, 2016). During this phase children get medication and several types of chemotherapy to destroy the cancer cells (Nederlandse Vereniging voor Hematologie, 2016). For 95% of the children remission is achieved after **1 month** (American Cancer Society, 2016). The induction phase is an **intense phase** during which a lot of children are hospitalised to prevent infection and complications (American Cancer Society, 2016).

Symptoms

Next to the symptoms mentioned above common symptoms are (based on kanker.nl (2016c) and UMC Utrecht (2017)):

- Fever
- Dizziness
- Black spots

Side effects

Common side effects are (Kanker.nl, 2016d) (Smith & Philips, 2012):

- Hair loss
- Nausea
- Diarrhea
- Fatigue
- Problems with the fine motor skills
- Mood swings

Next to these physical effects children will experience cognitive and psychological effects (Van Schoors, Goubert & Verhofstadt, n.d.).

Impact

After the diagnosis families feel shocked, overwhelmed, uncertainty, and powerless. They have to change their lives around the cancer treatment and their **goal is to survive cancer**.

The child has questions about if he/she will die and why he/she has cancer. The child has to **learn to coop** with the painful and uncomfortable procedures and the physical symptoms. Next to this the child should adapt to his new life in the hospital and being different from his peers (Kupst & Bingen, 2006). The child is not able to attend school as much as before the diagnosis and afterschool activities are not possible anymore. The child has to learn to **live with the restrictions of his freedom** (Last & Grootenhuis, 1998)

Parents will feel shocked after the diagnosis. They will feel **disbelief, anxiety, sadness, confusion, and fear**. After the diagnosis a lot of information should be processed, new people become involved, and decisions should be made which is overwhelming for the parents. During the first week to a month, parents tend to believe their child will die, even though the survival rate has been improved (Alderfer & Kazak, 2006). The parents should **gain information** about childhood cancer and its treatment, **take care** of their child (e.g. go to the hospital for clinic visits and hospitalisation), **coop with their own emotions** (such as feeling powerless, lack of control, insecure, sadness, anger, hope) (Alderfer & Kazak, 2006), **arrange practical issues** (e.g. transportation, a babysitter for the sibling, communication) and financial considerations should be made (Kupst & Bingen, 2006). The relationship between the parents and the child with cancer is also influenced by the diagnosis, some parents become overprotective and other parents have difficulties in being consistent in the discipline (Alderfer & Kazak, 2006).

Siblings are not always informed about the diagnosis cancer, however they will notice there is something wrong with their brother or sister. This will give the siblings a **feeling of confusion and fear**. During the diagnosis and the induction, their sibling will become the centre of attention and parents spend a lot of time with their child with cancer. This could make the sibling jealous and give him/her a **feeling of being overlooked**. The siblings should also coop with their emotions and challenges such as less concentration (Alderfer & Kazak, 2006).

Consolidation

The consolidation phase starts when **remission is established**. This phase exists of **four chemotherapy cures of seven weeks** to prevent the cancer cells to multiply and to destroy the last cancer cells. (Nederlandse Vereniging voor Hematologie, 2016). The drugs and chemotherapy given differ per group and child. During the consolidation phase the child receives the cures, if possible, during day visits at the hospital (Bloedkanker, n.d.). After the second cure it is also decided if the child will receive a bone marrow transplantation (Nederlandse Vereniging voor Hematologie, 2016).

Symptoms

The common symptoms during the consolidation are similar to the symptoms during the induction (based on kanker.nl (2016c) and UMC Utrecht (2017)).

Side effects

Next to above mentioned side effects, the following side effects are common (Kanker.nl, 2016d) (Smith & Philips, 2012):

- Painful mouth
- Hunger or loss of appetite

Impact

During the consolidation phase the impact on the family is **similar to the impact during the induction phase**, as described on the previous page, **or similar to the impact during the maintenance**, as described on the next page. It depends on the family how fast they are able to move from the goal of surviving cancer to creating a new normalcy.

Maintenance

The last phase is maintenance which is only received by children who did not receive a bone marrow transplantation (Bloedkanker, n.d.). The maintenance phase exists of daily and weekly drugs and reinduction cures to **prevent the cancer cells to come back**. The duration of this maintenance phase is around **14 months** with monthly check ups (Nederlandse Vereniging voor Hematologie, 2016).

Symptoms

Next to the symptoms mentioned above common symptoms are (based on kanker.nl (2016c) and UMC Utrecht (2017)):

- Bone pain
- Enlarged lymph nodes
- Pain in the belly caused by an enlarged liver or spleen

Side effects

The side effects during maintenance are similar to the side effects during consolidation (Kanker.nl, 2016d) (Smith & Philips, 2012).

Impact

During the first period, the goal was to survive cancer, however as the treatment continues the goal elaborates to live with cancer. During the first period the families are overwhelmed and they have to adapt their lives to the cancer and its treatment. During the maintenance the families understand the treatment and know what to expect. **They adapt their lives to a new normalcy** (Kupst & Bingen, 2006).

Many children with cancer **grief about the loss of their normal life**, the life before the diagnosis. The child has to deal with the physical, cognitive, social, and psychological limitations and should find out what he/she is able to do, related to friends, school, and his future. Feelings of **anger and sadness** are common (Kupst & Bingen, 2006).

The parents also adapt to their new life and **get partly the feeling of control back**, even though it is still an insecure time. Due to progression which is made, parents start to believe in the possibility their child will heal from the cancer next to their feelings of **doubts and fears** (Alderfer & Kazak, 2006).

Siblings still get less attention and care from their parents than the sick sibling which could result in feelings of **jealousy and envy**. But next to these feelings the siblings see the impact of the cancer on their brother/sister. They want to help their brother/sister, help their parents around the house and **be good** to not add extra stress. But this is also the period where siblings are starting to **have problems** for example with their behaviour or at school (Alderfer & Kazak, 2006).

2.1.5 End of treatment

After the treatment, children still need to go to the hospital for **regular checkups**. First children are checked every month, which will be reduced over time (Alderfer & Kazak, 2006).

Late effects

The physical consequences of the treatment after the treatment. These effects could arise years after the end of the treatment. Common late effects are (kanker.nl, 2016d):

- Numbness in the hands and feet
- Decreased muscle strength
- Decreased memory and concentration
- Growth disorder

Next to these physical effects children will experience cognitive and psychological effects as explained above (Van Schoors, Goubert & Verhofstadt, n.d.).

Impact

At the end of the treatment and after the treatment the goal for the families is to **rebuild their lives**. It is not possible to go back to their lives as before the diagnosis, since they have been changed.

Even after the treatment the children are not yet completely healed, they still have to **deal with emotional and physical effects** of the cancer and its treatment. Most children underestimate the time it will take to recover emotionally and physically (Kupst & Bingen, 2006). Some children also have to learn to deal with the **late effects** of the treatment. Also after the treatment children should be aware of their medical history when making choices (Kupst & Bingen, 2006). Next to this, during the treatment the child **was the centre of attention**. After the treatment this will change which should be accepted by the child as well (Interview psychologists, appendix B.5.).

The parents will have mixed feelings. They have **positive feelings**, because the treatment healed their child, but they have feelings of **fear and insecurity** as well. There is still the possibility for a relapse and they do not have as much support from the medical professionals anymore (Alderfer & Kazak, 2006). Next to this, most parents did not allow themselves to **deal with their emotions** during the treatment, due to which they have to do this after the treatment.

2.1.6 Coping strategies

Last and Grootenhuis (1997) defined coping as "how a person deals with a stressful situation". A coping strategy is a specific way of coping with a difficult or stressful situation. People can switch between coping strategies and it is assumed that learning can influence the coping strategy. There is evidence that heredity has an influence on the coping strategy as well (Rigter, 2008). So the coping strategy used depends on the person, situation, and environment (Kupst & Bingen, 2006). Within the literature several classifications of the coping strategies are made (Kupst & Bingen, 2006; Last & Grootenhuis, 1997; Rigter, 2008). The classification that is made is not based on the outcome of the coping strategy, but on the process of the coping strategy (Krohne, 2002). Within this project the classification is used with the categories: 1) *Problem-focussed*, 2) *Emotion-focussed*, and 3) *Avoidance* (Rigter, 2008).

Problem-focussed

Problem-focussed is an active, outer-directed coping style in which the **person tries to change the environment** (Krohne, 2002) and manage the problem causing the distress (Last & Grootenhuis, 1998).

Research suggests that problem-focussed coping strategies only result in a **positive effect if the person is able to change the environment**. If this is not possible and the person tries to change the environment, this could become frustrating and stressful after a longer period of time (Rigter, 2008). Examples of problem-focused coping strategies are removing yourself from the stressful situation, seeking information, or social support (Carroll, 2013).

According to Kupst and Bingen (2006) younger children (under 9 years old) tend to use mainly problem-focussed strategies, while older children (9-14 years old) tend to make more use of both problem-focussed and emotional-focussed strategies. Teens and adolescents reported to make mainly use of emotional-focussed strategies. The older children and the adolescents tend to have a more positive outcome.

This combined with the fact that the families cannot change the situation, **emotional-focussed strategies should be supported**.

An important emotional-focussed coping strategy for families dealing with cancer is **control**, since, as explained above, families will feel uncertainty and uncontrollability (Last & Grootenhuis, 1998) More information about control as coping strategy can be found in appendix D.

Emotional-focussed

The second category is emotional-focussed coping. This is an active, inner-directed style in which the **person tries to change his mind set** (Rigter, 2008) and regulate the distress (Last & Grootenhuis, 1998).

As problem-focussed strategies are mainly suitable for situations which can be changed, are emotional-focussed strategies mainly **suitable for situations which cannot be changed**. In these situations the person should define the positive elements of the situation and accept the situation (Rigter, 2008). Examples of emotional-focussed coping strategies are expressing emotions, writing in a diary, or seeking distraction (McLeod, 2009).

Avoidance

Avoidance is a passive coping style in which the **person acts hesitant and ignores the problems** (Rigter, 2008). Avoidance strategies tend to have the **least positive effects** especially over a longer period of time. Examples of avoidance coping strategies are suppressing negative thoughts and emotions (McLeod, 2009) double protection (appendix D).

2.1.7 Misconceptions about childhood cancer

There are a lot of misconceptions about childhood cancer by children and adults. The reason for these misconceptions could be the associations people have with the word cancer, limited or wrong education, or the tendency to consciously or unconsciously compare childhood cancer with cancer in adults. As already mentioned before, childhood cancer is very different from cancer in adults.

Based on a small questionnaire and the conducted interviews an overview of these misconceptions is made (figure 7). More information about the misconceptions can be found in appendix E.

Projecting own experiences on the situation
Healthy after treatment
Situation is not that severe
Child is not able to do anything
Much lower survival rate Contagious

Figure 7: Misconceptions about childhood cancer

The treatment of ALL and its **impact differs** per child and family and the phase of the treatment, due to which children and families have different needs over time. The product/service should be able to address these different needs.

Cancer and its treatment result in **various symptoms and side effects**, such as fine motor skill problems and mood swings. These should be taken into account when designing the product/service.

Coping strategies are a specific way of coping with difficult or stressful situations. Problem-focussed strategies are mainly suitable for situations that can be changed by the person, while emotional-focussed strategies are suitable for situations which cannot be changed. The product/service should **support the children and families in using coping strategies**, especially emotional-focussed coping strategies. Control is a suitable coping strategy, since families feel uncertainty and uncontrollability.

2.2 Child Development

The development of a child is affected by the cancer and its treatment, therefore the child development is analysed.

In the first part the factors that influence the development are explained. In the second part the role of the school within the development is described. In the last part presents the regular child development and how this could be affected by cancer and its treatment.

How could the development of a child be affected by cancer?

Literature Context mapping Interviews

2.2.1 Factors

Child development is influenced by multiple factors which can be categorised into three categories: 1) *within the child*, 2) *within the family*, and 3) *within the environment of the child* (Meij & Ince, 2013) (figure 8).

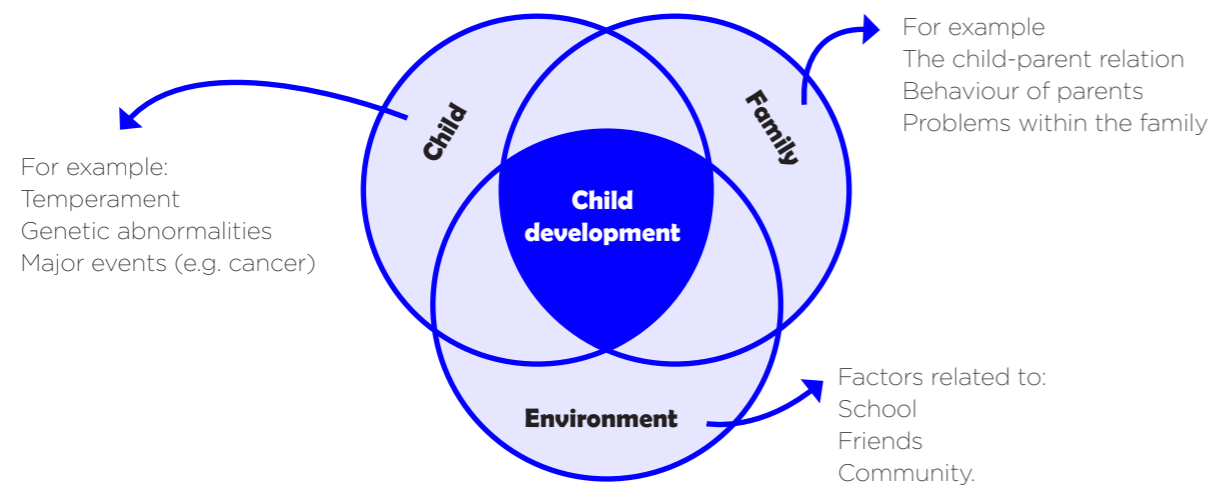


Figure 8: The three factors that influence the child development (Meij & Ince, 2013)

All factors from the three categories together define the development of the child. During school time the factors within the environment, especially related to school and peers, will have a large influence on the development. For a child with cancer a lot of these factors are affected, due to which the development will be influenced.

2.2.2 Role of school

School plays an important role in the development of children, since they spend a lot of time at school (Van der Ploeg, 2011). The development can be divided into three aspects: 1) *physical*, 2) *cognitive*, and 3) *social & personality*.

School has the **largest influence on the cognitive development**, however it also influences the other two aspects. The physical development is stimulated during the physical education lessons, playing, and writing. The social & personality development is also influenced by school in which especially the teacher and peers play an important role (Zeelenberg, 2012). Children learn to interact with other children, organise, gain self-confidence, dealing with peer pressure, sharing, emotion regulation, and so on (Van der Ploeg, 2011).

A child with cancer is not able to go to school every day the full time, due to which the development of the child will be affected. The **cognitive development will be continued** as much as possible by education at home and in the hospital with a focus on calculations and language. The physical development will be stimulated during therapy. But there are **hardly possibilities to continue the social & personality development**.

2.2.3 Regular development

Figure 9 till 11 (based on Feldman (2010), Thuisonderwijs (2017a-f), Gommans (2005), Saarni (2011), CJG (2016), and Acuff and Reiher (1997)) gives an overview of the regular physical, cognitive, and social & personality development of children aged between 6 and 12 years old. Appendix F gives an overview of the complete child development from the prenatal period till adolescence (20 years old).

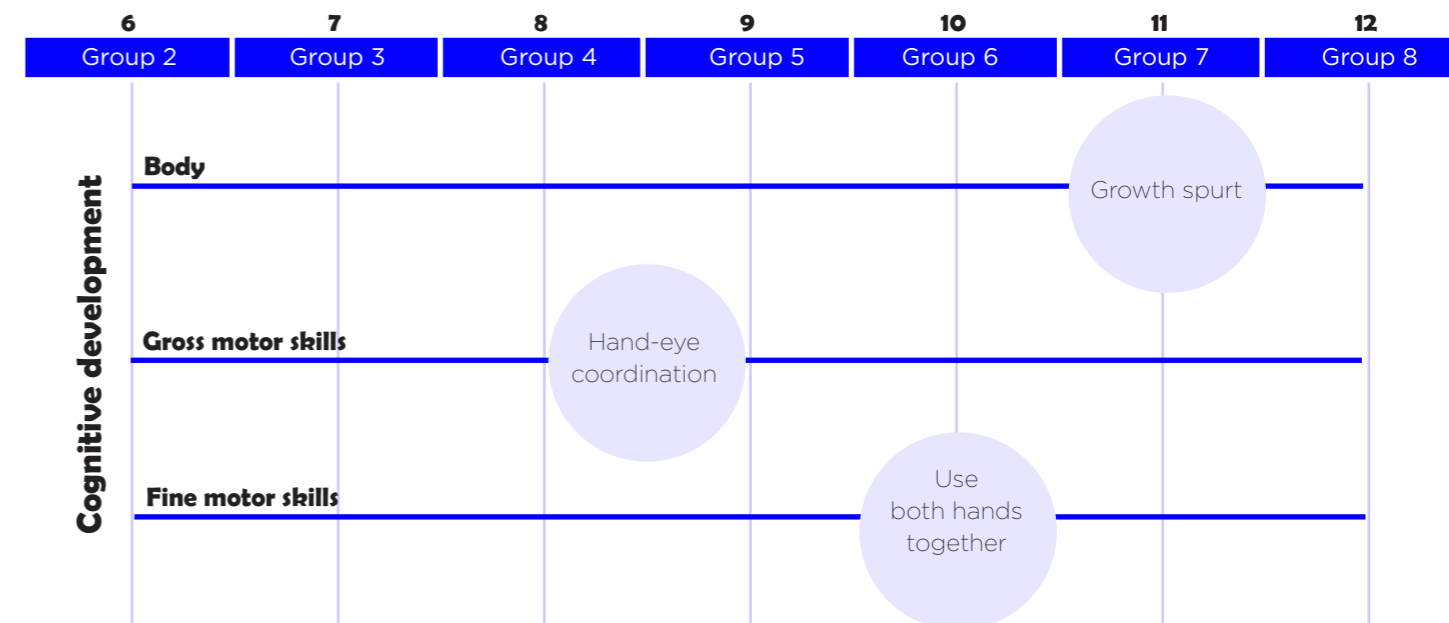


Figure 9: Regular cognitive development

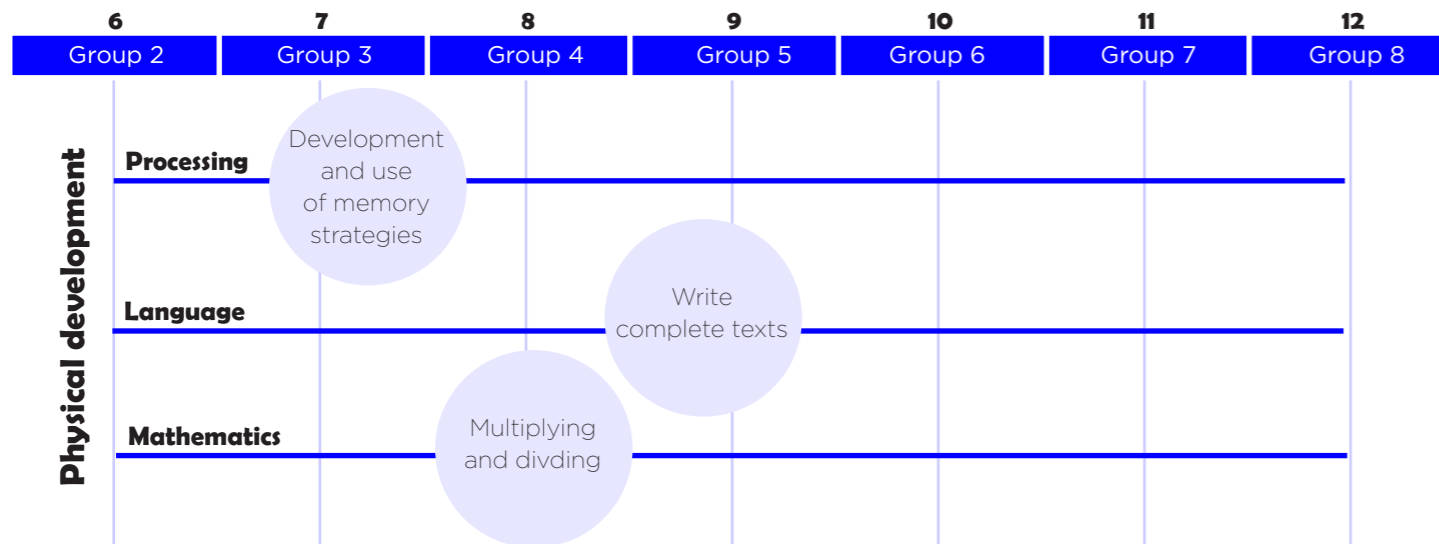


Figure 10: Regular physical development

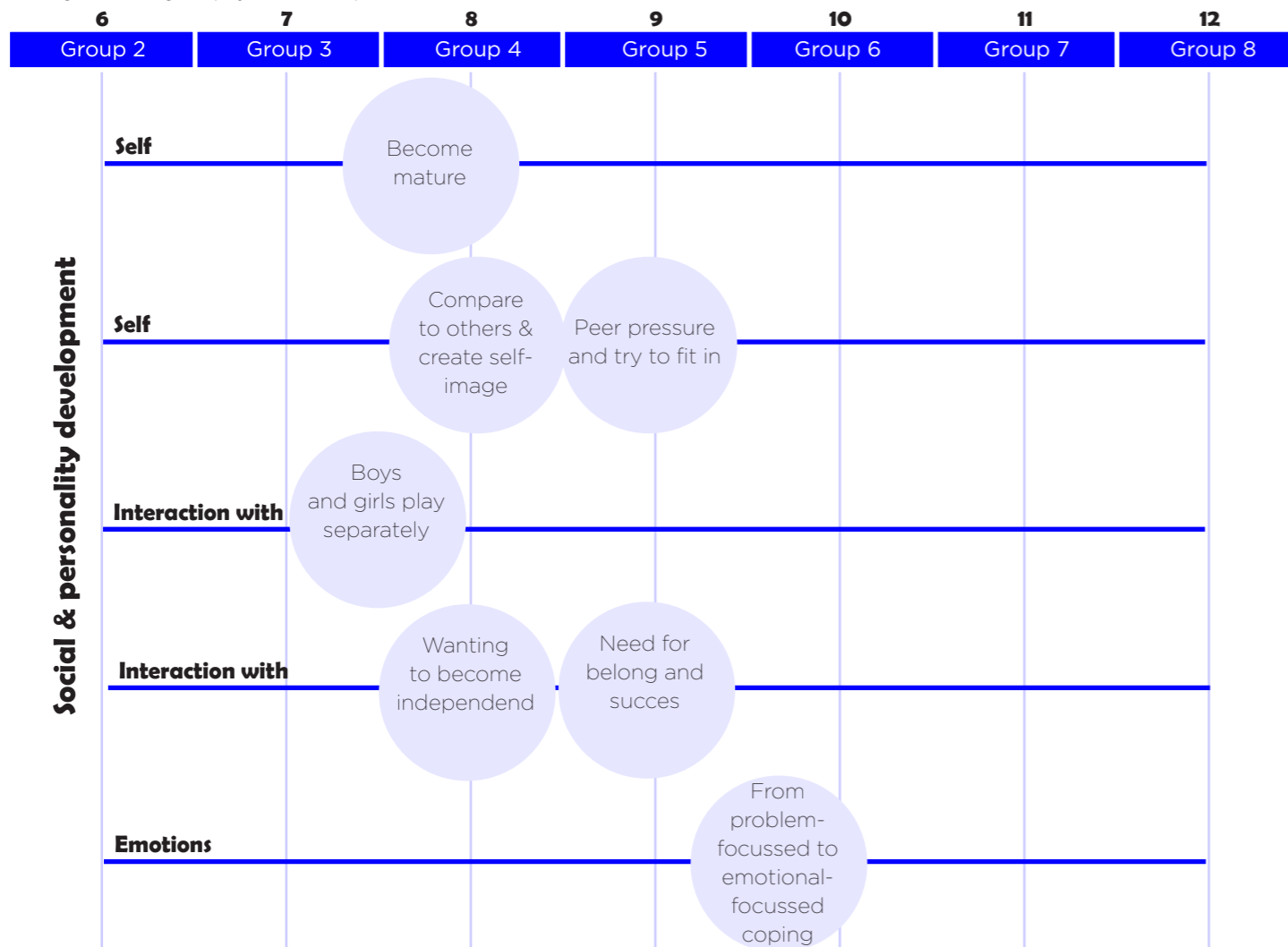


Figure 11: Regular social & personality development

2.2.4 Affected development

Due to cancer and its treatment almost all elements of the development of a child are affected. Below a few of these elements are discussed. An explanation of the effects of cancer and its treatments on all elements of the three aspects and how these effects are aimed to be minimised can be found in appendix G.

Cognitive – Memory

Due to the side effects of the treatment children have more **difficulties with memorising and concentrating** (Van Riel, 2013). This influences the linguistic and arithmetic development negatively as well.

Social & Personality – Mature

Cancer is a life disruptive event due to which children have to become **mature faster** than regular children (Kupst & Bingen, 2006). This can have a negative influence on their relationships with peers.

Social & Personality - Independent

Children start to want to become independent from their parents by for example going to school or doing groceries by themselves. Cancer and its treatment make children **become more dependent** on their parents even though they would like to be independent.

Social & Personality – Need for belonging and success

Sick children spend less time and have less similarities with their peers, due to which **belonging becomes more difficult and a feeling of loneliness** can be felt. Success will also be different for a sick child due to the physical and cognitive restrictions, however the child should accept this first.

Social & Personality – Self-image

All mentioned above elements can have a **negative influence** of the self-image of the child. The self-image created at this age has a large influence on the self-image of the rest of the child's life.

Social & Personality – Problem- and emotional-focussed coping strategies

Around 9 years old children start to use both problem- and emotional-focussed coping strategies. The cancer could have a **positive or negative effect** on the development of the emotional-focussed strategies depending on the abilities of the child and his support.

2.2.5 Interests

The interests of children develop as well. To gain insights into the interests of children aged between 8 and 10 years old a context mapping session was done (source 1), children were observed (appendix B.13), and a desk research was conducted about the playing materials of children. The results of these researches (figure 12) served as inspiration to make the product/service suitable for children.



Playing together by co-operating or competing



Mental or physical challenges



Humor & Cartoons



Variety



More complex creativity



Rewarding and collecting

Figure 12: Collage of the interests of children

As can be concluded children have to let go their childish products and toys and start to **become more mature**. They like to be **challenged mentally or physically** and **looks and status** become more important.

Context Mapping Sessions

Three context mapping sessions were conducted in which a total of 5 children (4 boys, 1 girl) aged between 7 and 10 years old participated. The goal of these session was to gain insight into their interests and preference to be able to make the product/service appealing to them (appendix B.14). During the sessions the sensitising booklet was discussed and the children were asked to come up with solutions to make an unpleasant moment of school more pleasant. The results were used to create figure 12.



Physical or mental challenges, Supporting creativity and fantasy , Humor , Visuals and colour

Source 1: Description of the context mapping sessions

School is an environmental factor which plays an important role in the physical, cognitive, and social & personality development of children. Especially **the role of school in the social & personality development is difficult to continue** during treatment.

Three elements of the development which could be negatively affected by cancer and its treatment are: **memory, becoming independent, and need for belonging and success**. This together with becoming mature faster, could have an **negative influence on the self-image** of the child. Therefore the product/service should stimulate the regular development of these aspects.

8-10 Years old children let go their childish toys and start to become mature. The product/service should fit in the **children's vision of maturity**.

2.3 School

In the Netherlands, there are around 7000 primary schools (Onderwijs in Cijfers, 2016). The type of school differs based on the denomination and the used education method (Scholenkeuze, 2013). For this project, I decided to focus on the **public and confessional schools** which apply traditional, whole- instructions, since most schools apply this education method. Whole-class instruction means that there are on average 23 children per class (PO Raad, n.d.), who are educated together by an allocated teacher, and all children follow a similar program.

This chapter gives insight into how primary schools look like and work nowadays and which changes can be expected based on the trends and developments.

How do primary school look and how are they organised?

Literature Observations Interviews

Michelle
26 years old
Teacher group 5
PABO
Single
Likes to read

Goal
"I want to get the best out of my children."

Apathetic
Caring
Creative
Structured
Social

2.3.1 Teachers

At primary school children are educated by an allocated teacher or 2 allocated teachers who alternate on fixed days of the week. To become a teacher a teacher degree should be obtained at the (University) PABO. Figure 13 shows a persona of a teacher.

In general, teachers have a great apathetic ability and stimulate all children to get the best out of themselves. A challenge for teachers is the **too high workload** (Nu, 2016).

Coach individual children Monitor development of children Write education plans Assemble with school personnel Maintain contact with parents and IC's

Figure 13: Persona of a teacher

2.3.2 Context

At primary schools in the Netherlands children are educated in their **'own' classroom**. Each group is allocated to one room. I went to a primary school to observe one day how a primary school and a classroom looks like and which products and tools are used. Figure 14 gives an impression of several interesting elements within the classroom and figure 15 presents a selection of tools/products which are used within class. These visuals served as inspiration for the product/service and supported in creating requirements to make the product/service fit in the school context. More pictures of the classroom and used tools/products can be found in appendix B.13.



Desk teacher
The desk of the teacher is placed on the front of the classroom, so the teacher has an overview on the classroom. At the side of the desk there is space for the teacher to help one or two children.

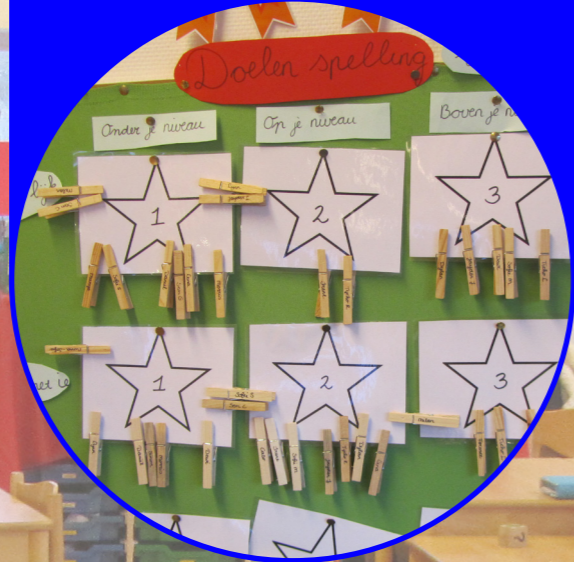
Table layout
The tables of the children are placed in groups which contributes to the collaboration between the children. The children have their own table. However for some courses the children switch places, so the children who need more help are sitting in the front of the classroom.

Figure 14: Impression of the context - classroom primary school



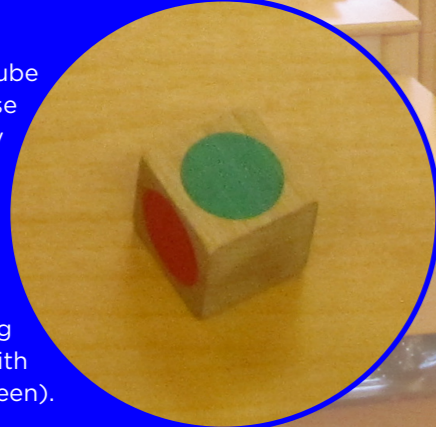
Make learning visible

A lot of materials in the classroom are related to make learning visible. These stars for example indicate the level for the goals of language.

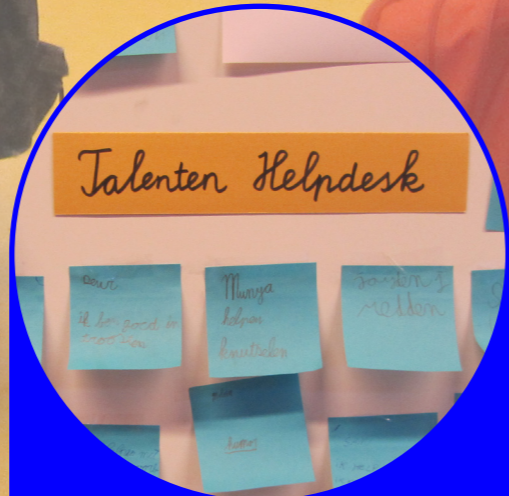


Work mode

All children have a cube which they can use to indicate if they have a question (question mark), if they do not want to be disturbed by classmates (red), or they are willing to work together with other classmates (green).



Talenten Helpdesk



Simulate social & personality development

Several materials within the classroom stimulate the social & personality development. At this school the children had to formulate a personal goal on which they want to work and the children made a 'help desk' in which the children indicated their strengths.

Figure 15: Impression of the products/tools used within the classroom

2.3.3 Schedule

In the Netherlands, primary schools/teachers are flexible in composing their own daily schedule and structure within a lesson.

Day planning

In general, schools start at 08.30 and end at 15.15 with a lunch break in the middle of the day during which children can go home or stay at school for lunch (NOG, 2016). Most schools have a free Wednesday afternoon, which can be used by teachers for training or meetings.

Most teachers use every day the same daily schedule with exceptions, for example for gymnastics or excursions. An example of a daily schedule can be seen in figure 16, which is based on Basisschool de Bron (n.d.), observations (appendix B.13), and interviews (source 2) (appendix B.7 and B.15). The dark blue dots mark the busy moments of a day for a teacher.

As can be seen most teachers **start the day with the more difficult lessons**, language and mathematics, since at the beginning of the day children are **better able to concentrate**. At the end of the day the less intensive lessons are scheduled, such as presentations, history, geography, and arts.

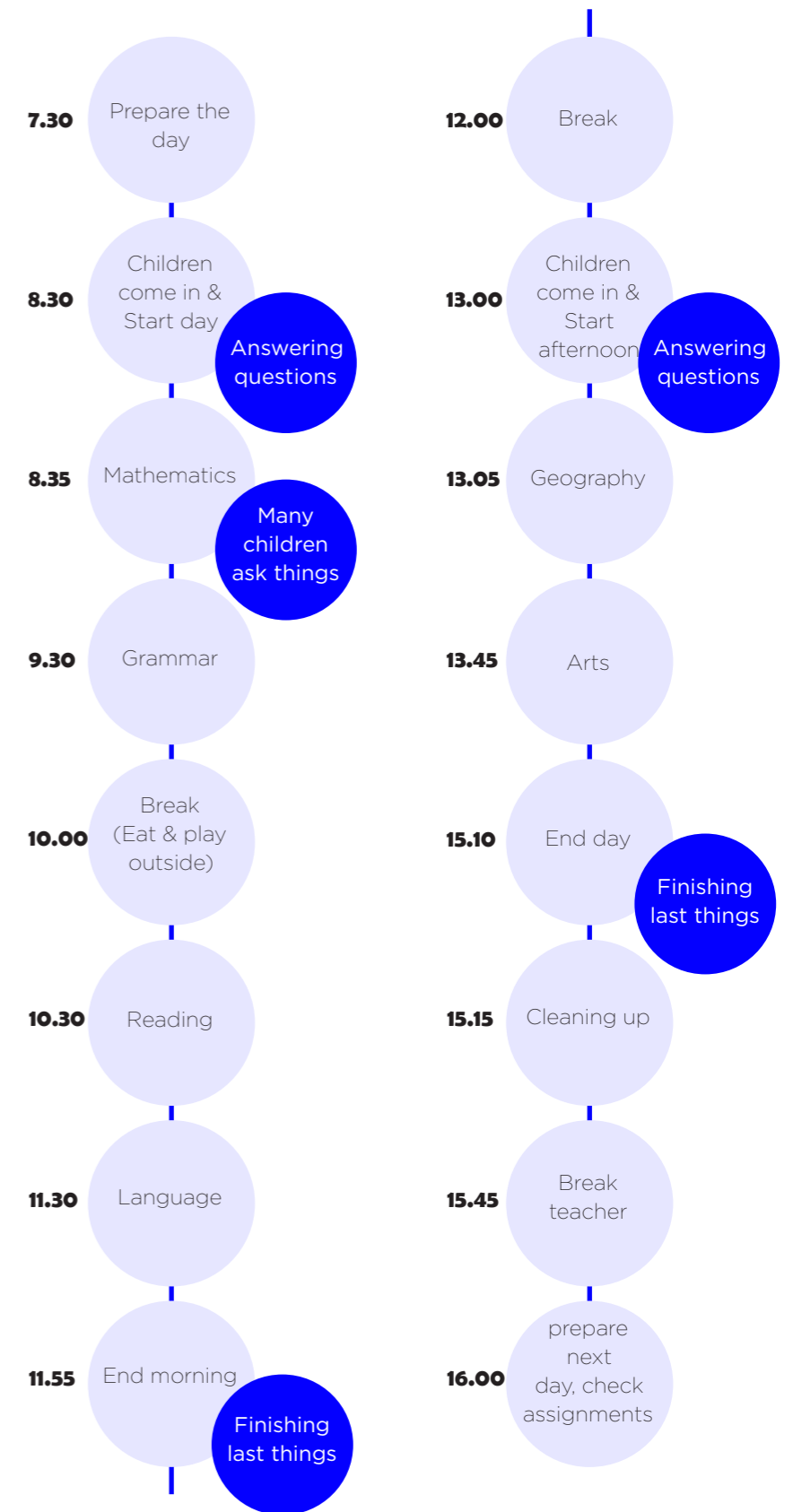


Figure 16: Schedule of a regular school day

Interview Teacher

To gain a complete understanding of how primary schools work, the school experience, and responsibilities of a teacher, an interview was conducted with a primary school teacher (appendix B.7). During the interview the participant was asked to make a timeline on which the follow up questions were based. The insights about the schedule of the day are used to create figure 16 and 17.

The social & personality development is supported by dedicated lessons and throughout the day, for example after an incident between two children.

The goal of a lesson is in general set by the used education method and mostly communicated to the children via the book or during the instructions.

Lesson structure

Teachers are able to create their own structure for the lessons. Based on the observations and interviews two structures which are used often for several lessons are identified. These structures are presented in figure 17. The first structure, in which children **work individually**, are mostly used during the **language and mathematics lessons**, while the second structure, **working in groups**, is often used for the **less intensive lessons**. Variations and combinations of the presented structures are used as well.

Based on the figures 16 and 17 it can be concluded that at the **beginning and end of the day and lesson teachers have minimal or even no time** to help an individual child. During the moments the children work themselves or in groups, teachers have most time to help children individually. However teachers should always be available to help the other children when it is really needed.

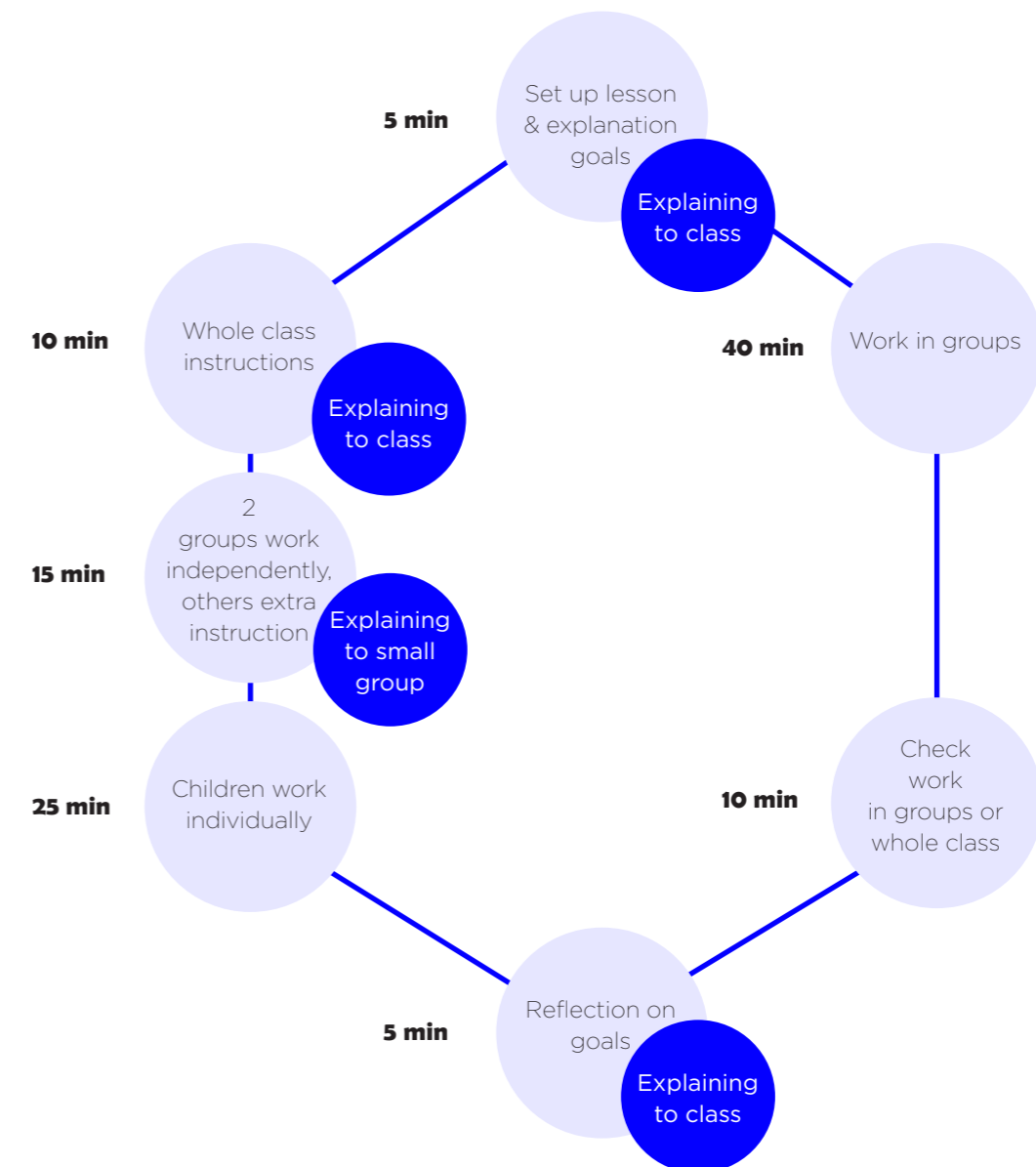


Figure 17: Two options to structure the lesson

2.3.4 Trends & developments

A DEPEST analysis is done to gain insights into the external influences on primary schools. The trends and developments serve as inspiration for the product/service and resulted in requirements and wishes (chapter 3) to make the product/service suitable for now and the future. A selection has been made based on the relevance of the trend/development presented in figure 18. A complete overview of all found trends and developments with explanation can be found in appendix I.



Heterogeneous school population

Due to the increase in differences between children, the child with cancer will be less outstanding. Next to this, children are getting used to tools/products individually used by a child with special needs, this will help in the acceptance of the product/service.



Focus on personal development

The current methods which are used to apply the individual development within education serve as inspiration for the product/service.



Personal learning environment

The personal learning environments could serve as inspiration for the product/service.



Attention for social and emotional skills

This development shows the importance of school for the social and emotional development. The lessons/activities serve as inspiration.



Increase workload for teacher

The product/service may not increase the workload (too much).

Figure 18: Overview of existing products

Teachers indicated that their **workload is (too) high**. Therefore the product/service should not or minimally increase the workload of the teacher. The best moment for a teacher to spend individual time on a child is during the individual or group work throughout the day.

There is an **increase** in children with **special needs**. Due to this children with cancer and the product/service will stand out less within class.

Schools pay more **attention on the development of social and emotional skills**. An example of doing this is making learning visible. This is an interesting development which can be used in the product/service.

2.4 Cancer At School

Every year 550 children get cancer of which around 140 children go to primary school (Integraal Kankercentrum Nederland, 2017). This means that the chance of having a child with cancer at school or in class is small. Due to this most schools and teachers are not prepared for taking care of a child with cancer. But schools are responsible for continuous education for the sick child.

This chapter describes the importance of school for children with cancer, how schools currently take care of children with cancer, and which products and services are available to support schools and the children.



2.4.1 Importance of school

People tend to assume school is not that important for children with cancer, since they suppose that the child should focus on getting better first. However, school is very important for those children, therefore children and their parents are advised to continue school as soon and much as possible if the physical and mental condition permits it (Georgiadi & Kourkoutas, 2010). There are several reasons why school is important for children with cancer:

Keep updated and stimulated

75% Of the children survive cancer (VOKK, 2016b) and these children will stay part of the community. To be able to be part of the community, the child needs to be kept updated and stimulated.

Keep normalcy

The diagnosis cancer has a large influence on the life of the complete family, however it has a positive effect on the child to keep normalcy. School is one of the most important elements which could help in keeping this normalcy (Prevatt, Heffer, & Lowe, 2000). Children want to be normal and school is

one of the few places in which they have the feeling they are accepted as a normal child (Lähteenmäki, Huostila, Hinkka, & Salmi, 2002).

Hope

Children associate school with hope for the future (source 3). Especially for children who were hospitalised for a longer period of time, school can give the child the feeling it is becoming better and give faith for the future (Worchel-Prevatt, et al., 1998).

Friends

School is seen by most children as more than just a place for education. School is also the place where they have friends and can have fun (American Cancer Society, 2015). School could help the children to stay in contact with their friends and give them the feeling they belong to the group (VOKK, 2016b).

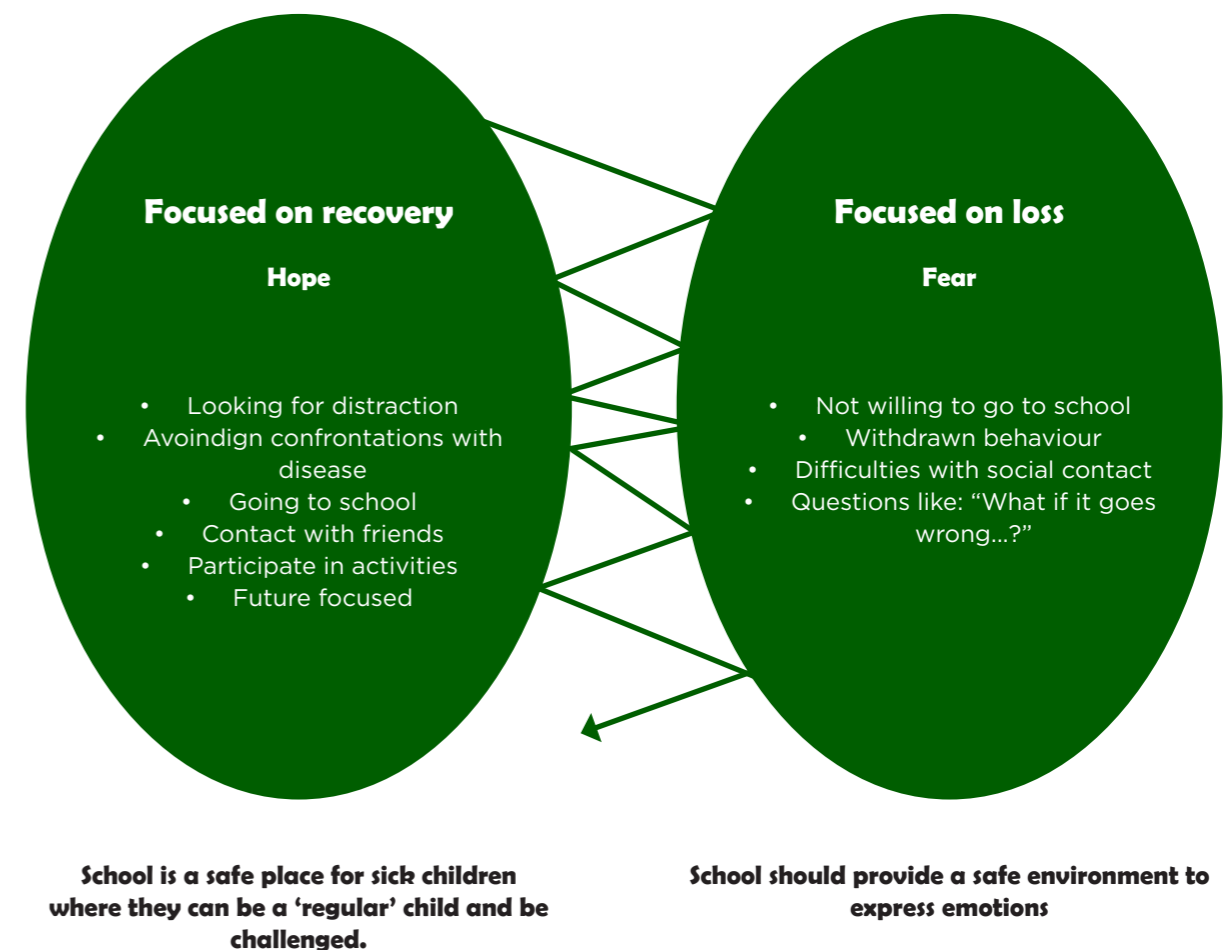
Structure and challenges

School provides the children with structure and challenges the child, which has a positive effect on the self-confidence and self-esteem of the child (VOKK, 2016b).

Interview Tanja van Roosmalen

Tanja van Roosmalen worked as EAO consultant and is mourning therapist. Based on her presentation given during the meeting about education and cancer (appendix B.1), she was interviewed about the two sided process model (appendix B.6).

The goal of the interview was to create an understanding of how the two sided process model can be applied on children with cancer and how this can be used within class.



Source 3: Description of the interview in which the two sided process model was discussed

2.4.2 Taking care for a child with cancer

Due to the small amount of children with cancer, most schools have **no protocols** to follow or experience which can be consulted (van Roosmalen, 2012). Each school has to create an own way to take care of a child with cancer together with the parents.

Figure 19 presents some important steps schools and the family take in the process of taking care of a child with cancer and the challenges which could arise. However this **process differs for each situation, depending on the school, teacher, parents, and child**. An explanation of these steps can be found in appendix J.

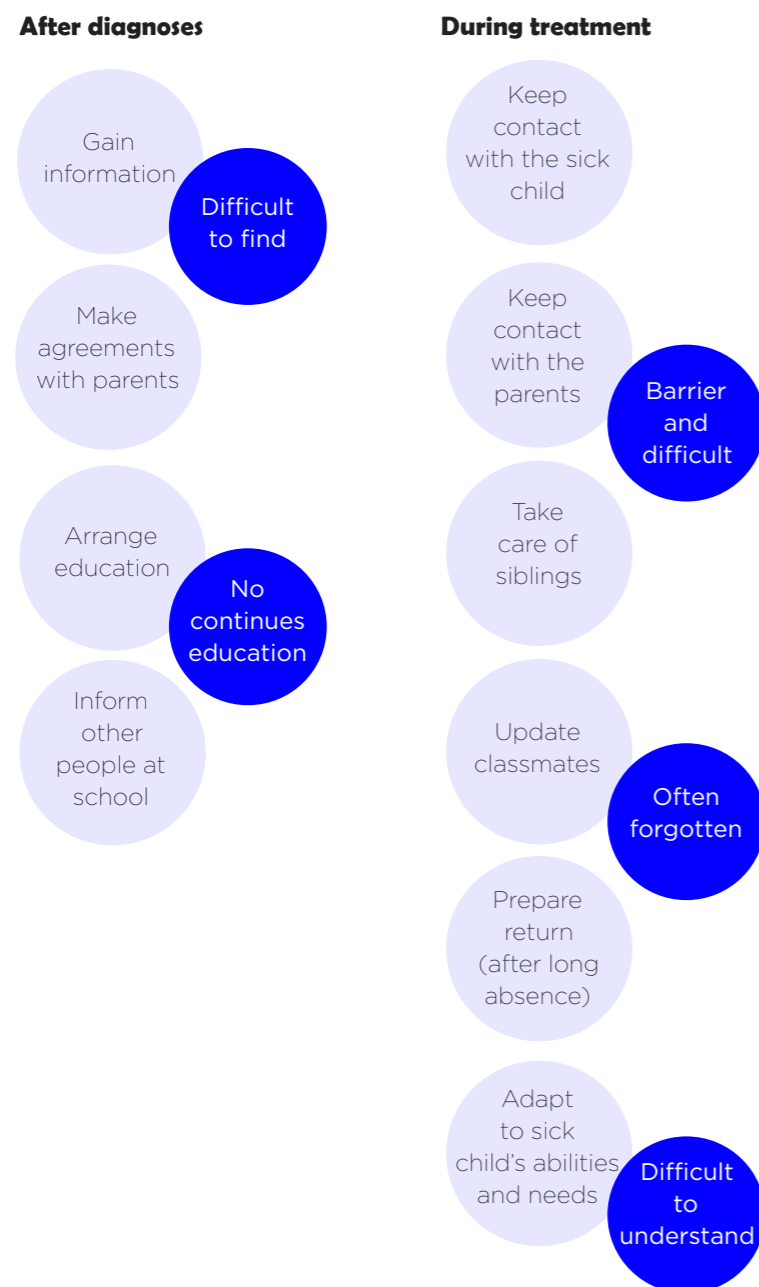


Figure 19: Process of how schools can take care of a child with cancer

2.4.3 Existing products

A desk research is conducted to make an overview of products/services which are currently available to support children with cancer and their teacher (figure 20). This overview is made to find a gap within the market. All found products/services are presented and explained in appendix K combined with an overview of products for children with autism, which served as inspiration for the product/service.



Connect children with classmates

The 'KPN klasgenoot' makes it possible for the sick child to be digitally in class. The child can follow education, but more important communicate with classmates (KlasseContact, n.d).



Materials to educate children about cancer

The 'Leskoffer' of the VOKK provides teachers with tools to inform and educate the classmates about cancer (VOKK, 2016e).



Materials to support teachers and schools

With the Ziezon Onderwijsmap schools can keep track of a chronically sick child and find information about the sickness of the child (Onderwijs Databank, 2016).

Figure 20: Overview of existing products

It can be concluded that the existing products/services are very limited. The products/services which are available are focussed on solving two challenges: 1) *preventing isolation when the child is not able to go to school* and 2) *education for teachers or classmates*. There are a lot of challenges the children with cancer experience for which no products/services are available. Therefore, the product/service will focus on a **challenge which is not addressed** in the existing products/services

It is important that children with cancer go to school for their **cognitive and social & personality development**, but more important to **keep normalcy** for the child.

Taking care for a child with cancer could result in challenges for the child, family, teacher, and classmates. An overview is given in the next chapter (2.5.).

The existing products/services focus on **preventing isolation and education for teachers and classmates**. Therefore the product/service should address a different challenge.

2.5 Challenges

Based on the literature study and field research presented in the previous subchapters, challenges were identified which could be experienced by children with cancer, their family, teachers, and/or classmates related to the school experience. To conclude the orientation part of the analysis an overview of these challenges is presented. These challenges are used to formulate a design opportunity as presented in the next part of the analysis.

An explanation of the challenges can be found in appendix L.

1. The child feels afraid or insecure to go back to school	2. The child feels lonely and isolated	3. Due to physical and cognitive differences the child is not able to participate in the school activities which results in problems or worries	4. The child does not feel or is afraid of being not accepted by their classmates
5. The child has difficulties in coping with the behaviour difference which he experiences in comparison with before the diagnoses or in comparison with classmates	6. There is less empathy of classmates and school at the end of the treatment (and after the treatment)	7. The child is not receiving education continuously	8. There are large differences in the capabilities of teachers and schools, due to which large differences between children arise
9. Teachers have difficulties to cope with their own feelings and emotions	10. Teachers have difficulties with discussing the subject cancer (or related subjects) in class	11. Teachers miss information and guidance , which results in insecurities and a lack of clarity	12. The communication is seen as difficult and a barrier by teachers and parents
13. The expectations of the surrounding (school, home, and hospital) about the child do not match with each other and are not realistic, they over- or underestimate the child	14. Children, teachers, and classmates have difficulties in expressing themselves	15. The parents are afraid to let their child go back to school	16. School does not take good enough care for siblings

Part 2 Design opportunity

To which challenge can design contribute most positively to the school experience and why?

2.6 Evaluation Challenges

The previous chapter presented a list of challenges. These challenges are evaluated during interviews with EF consultants from different hospitals. Based on the results of this evaluation and the literature analyses the challenges are ranked on relevance and impact. These ranking is used to formulate design opportunities.

This subchapter presents the ranking of the challenge and the design opportunities.

How relevant are the identified challenges and how large is their impact?



Literature



Interviews

Interviews EF consultants

Interviews were conducted with EF consultants from different hospitals (appendix B.3). The goal of these interviews was to create an understanding of the role of the EF and gain insights from the field on the identified challenges.

4 Most relevant and impactful challenges: 2, 6, 13, and 15.

3 New challenges:
8. There are large differences in the capabilities of teachers and schools, due to which large differences between children arise
7. The child is not receiving education continuously
16. School does not take good enough care for siblings



Source 4: Description of the interviews with the EF consultants

2.6.1 Ranked challenges

The challenges are ranked on relevance and impact.

The relevance of a challenge is classified as high, if:

- the challenge is **often experienced** by sick children, their family, teachers, and/or classmates
- **little or no solutions are available** or are expected to become available to prevent or solve the challenge
- the **need to solve** the challenge is large

The impact of a challenge is classified as high, if:

- the **magnitude of effect** of the challenge is large on sick children, their family, teachers, or classmates
- **multiple groups of people** (children with cancer, their family, teachers, or classmates) experience the challenge

Figure 21 shows how the challenges are ranked based on the conducted interviews (source 4) and the literature analysis. An explanation of the ranking of each challenge can be found in appendix L.

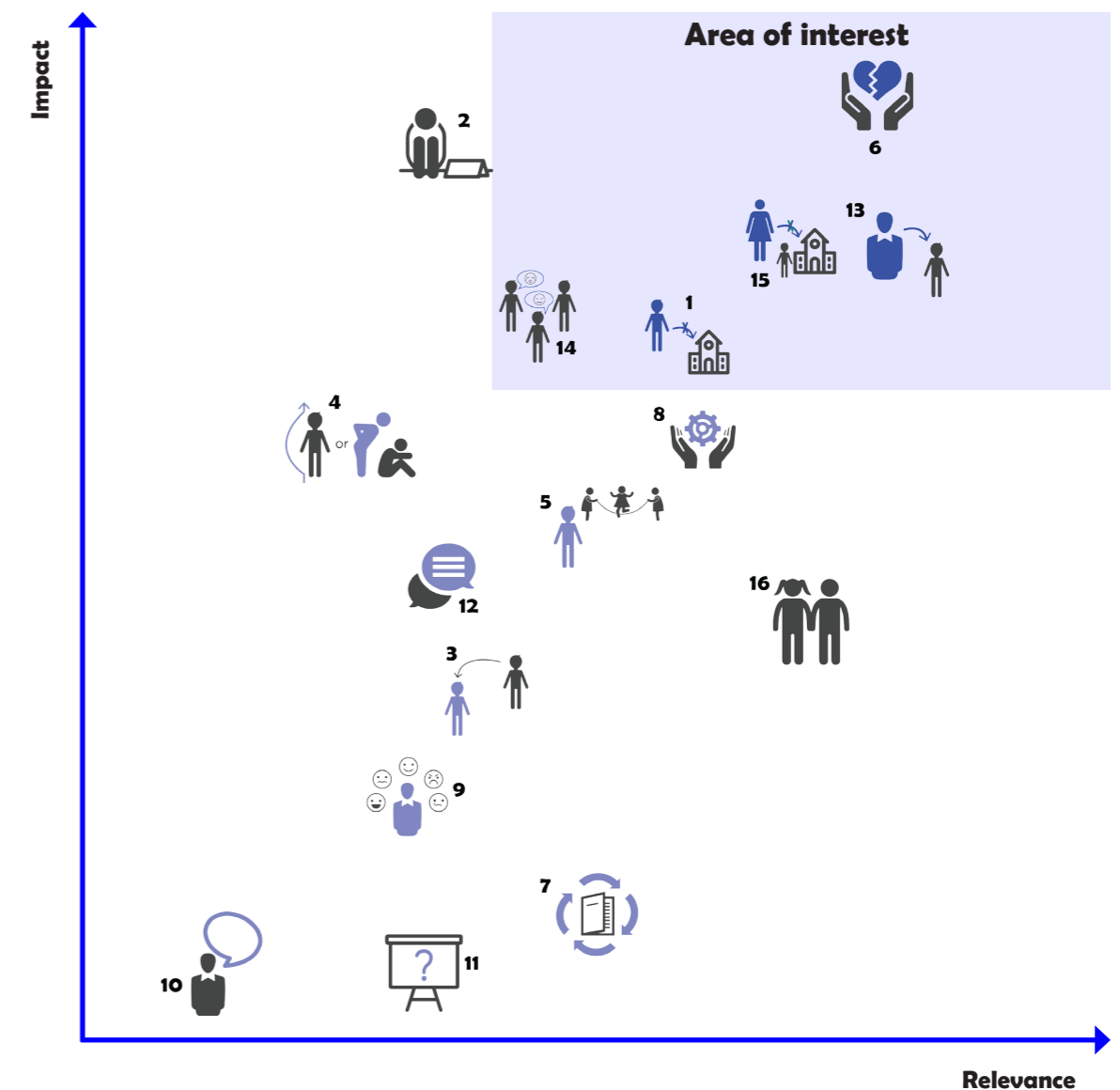


Figure 21: Overview of the challenges ranked on relevance and impact

2.7 Evaluation Design Opportunities

2.6.2 Design opportunities

It can be concluded from the graph (figure 21) that there are five interesting challenges for a design opportunity, since they have a high relevance and high impact. These challenges are combined into three design opportunities: 1) *Empathy of classmates*, 2) *Understanding what to expect*, and 3) *Fear to go to school*.

1) Empathy of classmates

Based on: challenge 6 “Less empathy of classmates and school at the end of (and after) the treatment”

It was indicated that classmates have less empathy for the child if cancer or late effects are less visible, because the classmates forget the child has/had cancer or they are not aware of it (anymore). Therefore, the opportunity is focussed on the end of the treatment, the first months after the treatment, and children dealing with late effects.

Goal

Support classmates to **have empathy** for their classmate with cancer (or dealing with late effects).

Effect

By creating empathy by the classmates, they will have a better understanding and more guidance in how to interact with the child. This will result for the child with cancer in a feeling of being understood and one belonging to the class.

2) Understanding what to expect

Based on: challenge 13 “The expectations of the surrounding about the child do not match are not realistic” and challenge 14 “Difficulties in expressing themselves”.

Teachers have difficulties in deciding what they can expect from a child with cancer, which makes the teacher insecure. If a teacher over- or underestimates the child with cancer, the child could feel bored, frustrated, or insecure. This has a negative influence on the self-image and confidence of the child. What can be expected from the child depends on the physical and emotional state of the child. This can differ each day, which makes it even more difficult for the teacher to understand what to expect, especially if the child does not share his feelings and emotions.

Goal

Support teachers to **understand what to expect** from a child with cancer.

Effect

A well informed and prepared teacher should not over- or underestimate the child. Due to this the child can work and develop on its own level, create a more positive self-image, and feel self-confident.

3) Fear to go to school (of the parents and the child)

Based on: challenge 1 “The child feels afraid or insecure for going back to school” and challenge 15 “The parents are afraid to let their child go back to school”.

Parents are sometimes afraid their child will be infected by contagious diseases at school or they are afraid that their child will be bullied by classmates. The fear of being bullied is also felt by some children themselves, especially when they have undergone physical changes. In reality almost none of the children is bullied at school.

Goal

Give children and parents the **confidence that school is a pleasant and safe environment**.

Effect

By giving the parents the confidence that their child can go to school pleasantly and safely, they will let their child go back to school earlier and the parents will be less worried and stressed. By giving the child the feeling it will not be bullied at school, he will go back to school with a more relaxed feeling.

As shown in the previous subchapter, three design opportunities are formulated. These are evaluated during interviews with a mother, teacher/IC, and two child psychologists (source 5) (appendix B.5.) to gain information from different perspectives. Based on these interviews, literature analysis, and interviews with the EF consultants I ranked the design opportunities and chose a design opportunity to continue the project.

This subchapter describes the choice for the design opportunity.

How can design contribute positively to the challenges identified as most relevant and with the highest impact?



Literature



Interviews

Interview: Mother, Teacher/IC, & Child Psychologists

A mother of a survivor, the teacher/IC of this survivor, and two child psychologists were interviewed about their experience with cancer and school, and the design opportunities. The goal of these interviews was to gain in depth information about the design opportunities to rank these opportunities (appendix B.5). The set up of the interviews was similar, but the questions were adjusted to the background of the participants.

1) Empathy of classmates

Mother: “At school it went very well, but after school it was more difficult.”

EF: “There was less empathy when it was less visible.”

Psychologist: “Unpleasant comments are mainly made at high schools.”

2) Understanding what to expect

IC: “The student was often under- or overestimated which gave the student an unpleasant feeling.”

EF: “Some teachers have a totally different expectation. Most teachers underestimate the students.”

Psychologist: “A wrong expectation is bad for the self-confidence.”

3) Fear to go to school (of the parents and the child)

Psychologist: “It is the job of the doctor to say the child is able to go to school again.”

EF: “Most children are very enthusiastic to go back to school.”

EF: “The fear is especially noticeable if the child has changed physically, for example becoming bald.”

Source 5: Description of the interviews about the design opportunities

2.7.1 Ranked design opportunities

The design opportunities were, like the challenges, ranked based on relevance and impact, however in more detail in the top of the graph. Figure 22 presents how the design opportunities are ranked, which is based on the results of the interviews combined with the literature analysis. An more in dept explanation of the ranking can be found in appendix M.

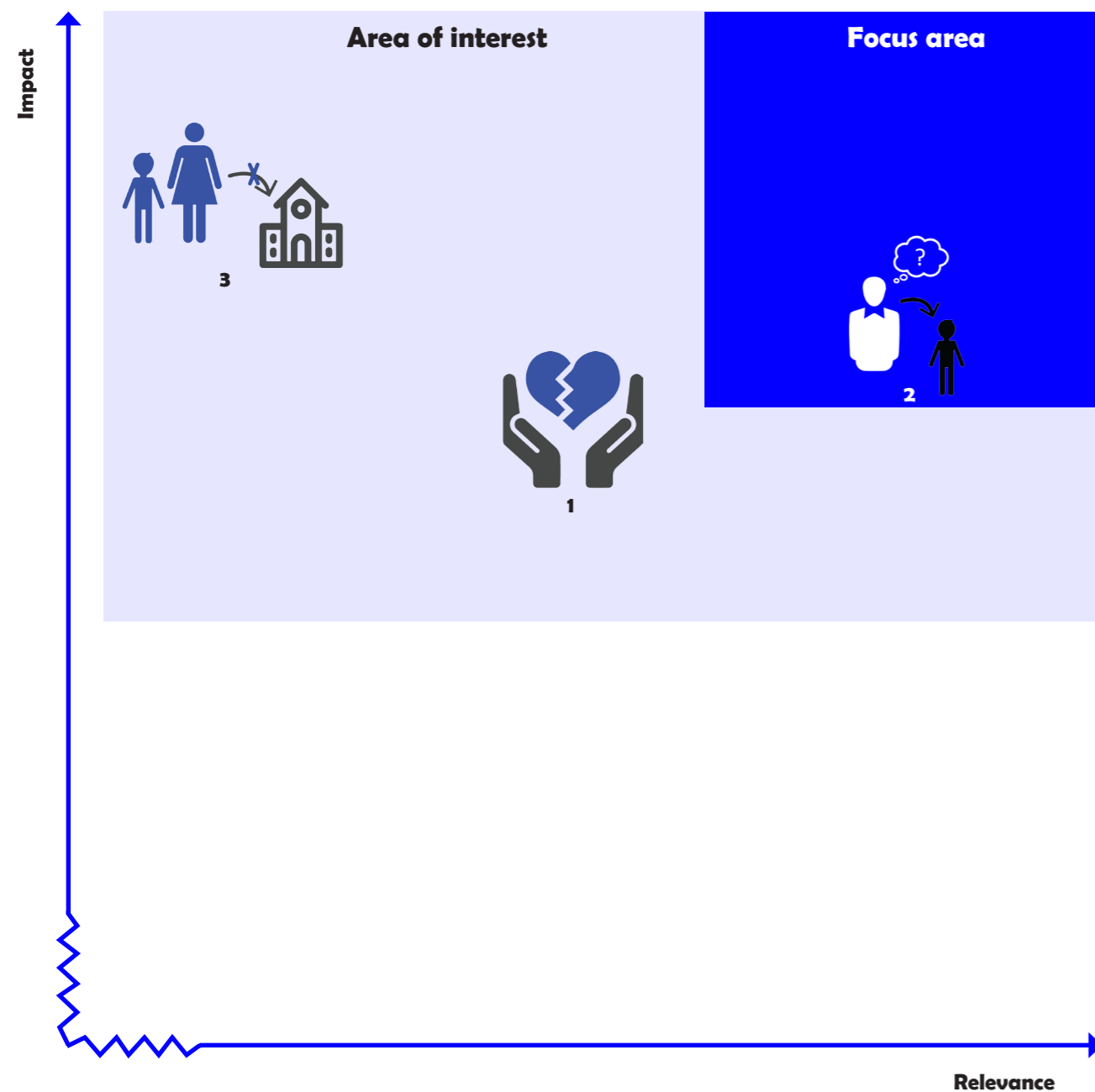


Figure 22: Overview of the ranked design opportunities

2.7.2 Support teachers to understand what to expect from a child with cancer

I have decided to continue with the design opportunity 2) 'Support teachers to know what to expect from a child with cancer'.

As can be seen in figure 22 this opportunity has a **high relevance and a high impact** confirmed by all interviewed participants for the target group and context. Furthermore a **product/service would be a suitable** to support the children and/or teacher in overcoming the addressed challenge(s). Due to the involvement of different people, sick child and teacher, who experience the addressed challenge(s) with a different effect makes the opportunity **interesting for the project**. At last, it is expected that a product/service that supports the teacher in what to expect from a child, also support can be giving in **other challenges** which are experienced.

To be able to formulate a design goal more in depth information about the design opportunity was needed. This can be found in the next section, deepening.

Part 3 Deepening

How can a suitable individual education plan be created by the teacher and child?

2.8 Mood & Emotion

I choose the design opportunity 'Support teachers to understand what to expect from a child with cancer'. To support teacher in creating this understanding, it is needed that the teachers gets a understanding of how the child is feeling, mentally and physically.

To get an understanding of mental feeling a literature analysis is done about mood and emotion. The physical capacity is explored in the next chapter.

How is learning influenced by mood and emotion?



Literature



Interviews

2.8.1 Mood vs. Emotion

Mood and emotion have a different meaning, even though they are related and often used interchangeably (Beedie, Terry & Lane, 2005). Within this report there is made a distinction between mood and emotion.

Many definitions exist for the word emotion and mood, to make the distinction the definitions of Desmet, Vastenburger, Van Bel, and Herrera (2012) are used. They state that **emotions** are intentional, involve a relation between the person experiencing them and a particular object, and are acute and have a duration of limited seconds or minutes. Desmet, Vastenburger, Van Bel, and Herrera (2012) define **moods** as "low-intensity, diffuse feeling states that usually do not have clear antecedents, are not directed at particular object, and can last for hours or days but are limited in time".

So emotions have a short duration and have a clear stimulus from the environment or memories (one cause: feeling anxious for a medical procedure), while moods have a long duration and are based on the surrounding in general (combined causes: feeling anxious, because insecure what is going to happen, unclear feature, coming medical procedures).

Based on this distinction, I decided to focus within the product/service on **expressing mood**, since mood will have a **larger influence** on the child and is **more difficult to estimate** based on observations.

2.8.2 Influence of mood

Several researches are conducted which investigated the influence on mood. Based on these researchers the aspects which are influenced are identified.

Influence on behaviour

Gendolla (2000) has done research on the influence of mood on behaviour. Based on his research he states that **mood has an informational and directive impact** on behaviour, which means judgements and preferences are affected. A positive mood will make people make more optimistic judgements than a negative mood. When a person has a negative mood, he/she will try to do something pleasant to enhance his mood, while a person with a positive mood will try to maintain this mood (Gendolla, 2000).

Influence on school performance

Next to this, school performance is affected by mood. Gumora and Arsenio (2002) have researched the

impact of a negative mood on school performance. According to them children with a **negative mood perceive themselves as less academically competent** and they score lower achievement scores.

Influence on pain experience

At last, a research is conducted about the influence of daily stress and a negative mood on the pain experience and school activity for adolescents with sickle cell disease (Swain, Mitchell & Powers, 2006). According to Swain, Mitchell, and Powers (2006) daily stress and a **negative mood increases the same-day pain and reduces the school and social activities.**

For these reasons, it is assumed it helps a teacher to understand the mood of a child to create an individual planning.

2.8.3 Measuring mood

Mood must be measured by asking people about their mood, which is called self-report.

The traditional ways to measure mood (for example Positive and Negative Affect schedule and Profile of Mood States) was with questionnaires with verbal items which had to be ranked to define the mood. Later methods (for example Self-Assessment Manikin and Gaston Lagaffe scale) made use of non-verbal pictograms to prevent misinterpretation, which were further developed with non-verbal dynamic cartoon animations (for example Layered Emotion Measurement tool and Product Emotion Measurement instrument) (Desmet, Vastenburg, van Bel & Herrera, 2012). Based on these methods Desmet, Vastenburg, van Bel, and Herrera (2012) concluded that "pictorial instruments are well suited for situations in which respondents have limited time or motivation to express their affective state." Based on that reason, they decided to develop a tool to measure mood states in a **quick and intuitive way**, Pick-A-Mood (PAM). PAM is used as inspiration for the product/service which is designed.

2.8.4 Mood states

Researchers did not made a general selection of basic or principal mood states. Therefore I created an **own set of mood states**. Different sets of mood states are identified within different researches (Desmet, Vastenburg, van Bel & Herrera, 2012; DeLancy, 2006; Ortony & Turner, 1990; Al-Shawaf, Conroy-Beam, Asao & Buss, 2015; and Ekman, 1992). These are used to create an own set (appendix N).

The mood states (figure 23) are chosen based on moods which are experienced by children, useful to know for the teacher, and the ability of the child to make a distinction between the states. The set is composed out of moods which **covers a diverse range** of mood with **limited options** to be able to indicate the mood intuitively. Next to this, an **equal amount of pleasant and unpleasant** states are chosen to prevent biases. How these mood states are visualised in the product is shown in chapter 5.2.

Pleasant

Happy Hopeful, Optimistic, Having fun, Joyful, Having pleasure, Excited, Interested, Enthusiastic, Cheerful, Lively

Relaxed Calm, Dreamy, Serene, Fine, Carefree

Satisfied Proud, Loved, Sympathy, Belonging

Unpleasant

Angry Frustrated, Irritated, Annoyed, Confused, Furious, Grumpy

Sad Gloomy, Bored, Weary, Lonely, Depressed, Rejected, Grief, Disappointed, Guilty, Ashamed

Afraid Tense, Nervous, Worried, Anguish, Timidity, Apprehension

Figure 23: Chosen mood states

2.8.5 Mood and cancer

Cancer and its treatment can have an effect on the mood of the child. The diagnosis and the treatment are shocking and overwhelming which already affects the mood of a child. Next to this, the mood is influenced by the drugs used within the treatment. Especially the corticosteroid drugs, such as Prednison and Dexamethasone, have a large impact on the mood and can result in **mood swings** (Mrakotsky et al., 2011).

Mood swings are defined by Grohol (n.d.) as "noticeable changes in one's mood or emotional state". Small mood swings are experienced by most people (Grohol, n.d), but the mood swings caused by the corticosteroid drugs are extreme, unexpected, and rapid. More information about the impact of these medication can be found in appendix N.

Therefore it becomes even more difficult for teachers to understand the mood of a child with cancer.

The product/service should **support teachers to understand the mood of a child**. Mood has a larger influence on a child and is more difficult to estimate based on observations. Next to this, the side effects of the cancer treatment influence the mood of a child.

Mood has an influence on **behaviour, the school performance, and the pain experience**.

A set of mood must contain **limited and a balance between pleasant and unpleasant** mood states to be able to indicate a mood state individually.

2.9 Physical Functioning

As explained in the previous chapter, a teacher should understand how the child is mentally and physically feeling. The previous chapter elaborated on mood. This chapter focuses on the physical functioning of the child, which is divided into capacity and energy (figure 24).

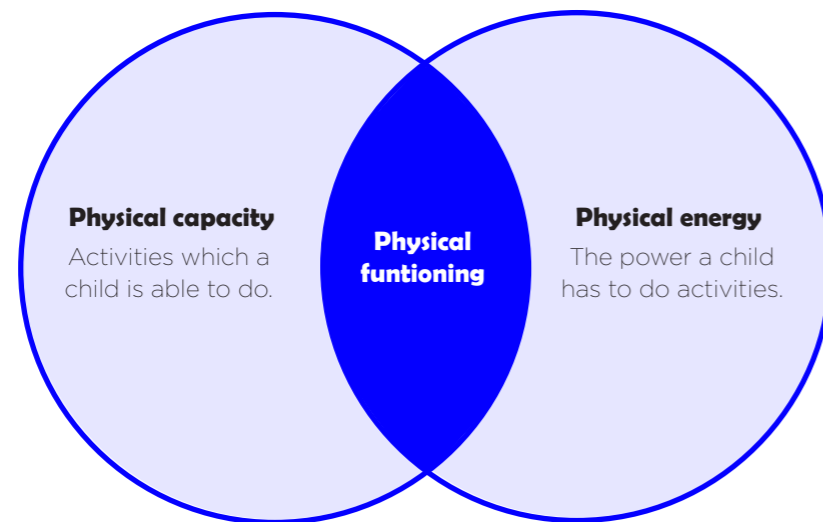


Figure 24: Physical functioning is the physical capacity combined with physical energy

2.9.1 Physical capacity

Physical capacity is defined as the **activities which a child is able to do**. Children with cancer are limited in their physical capacity due to the symptoms and side effects of the cancer and its treatment. One of the symptoms of cancer is for example bone pain, due this bone pain some children are not able to walk. The drug Vincristine has the side effect of problems with the fine motor skills, due to which some children are not able to write. Teachers need

to understand the physical capacity of the child and the limitations to be able to create an individual planning for the child and provide the child, if needed, with supporting devices. The school can for example provide the child with a tablet, when writing is not possible anymore.

Measuring

There is done research to measure physical capacity mainly focussed on elderly (Van Lummel, In 't Veen

& Van 't Hul, 2015; Kasper, Chan & Freedman, 2016; Daltroy et al, 1995). There are two methods to measure physical capacity: self-report and performance-based (Kasper, Chan & Freedman, 2016).

The oldest and commonly used methods are the self-report methods (for example Health Assessment Questionnaire and Modifiable Activity Questionnaire (Sylvia, Bernstein, Hubbard, Keating & Anderson, 2013)). Within these methods the people are asked to report what they are able to do. The methods differ in what is asked, how data is reported and obtained, and the quality of the data (Sylvia et al, 2013).

Performance-based methods (for example Short Physical Performance Battery and Hand Function Test) measure and/observe different aspects of the physical capacity, such as balance and walking speed (Van Lummel, In 't Veen & Van 't Hul, 2015).

The self-report methods and performance-based methods are compared with each other. According to Kasper, Chan, and Freedman (2016) self-report assessments have the advantage of cost effective and suitable for large groups, while performance-based assessments have the advantage of direct observation and objective results.

Therefore it is chosen to **measure the physical capacity of the children with observations** (performance-based) done by the teacher which can be combined with the information, such as the type of medication, from the parents and child (self-report).

2.9.2 Physical energy

Physical energy is defined as the **power a child has to do activities**. As explained in the chapter 2.1.

'Living with cancer' one of the side effects of the cancer treatment is feeling fatigue. In combination with difficulties with sleeping, an affected appetite, and energy consuming activities related to the cancer and its treatment, the physical energy of a child with cancer is reduced.

The physical energy depends on several factors due to which the physical energy differs a lot per day and over time. The physical energy should be taken into account by creating the individual planning for the child, to give the child the opportunity to participate in all activities without exhausting himself. Therefore it is difficult for teachers to define the amount of energy the child has and makes it necessary the child communicates his energy level to the teacher.

Measuring

Not much research is conducted in measuring the physical energy of a human. In 2015 an application is developed to measure physical energy (Dutch Cowboys, n.d.). This application uses the heart rate to define the energy level. However the accuracy and the reliability is not validated.

Next to this, several tools are developed to measure the physical energy by self-report, such as the PedsQL (PedsQL, 2017). Within this tool children are asked several questions about their physical functioning by a researcher. The child has to answer the questions by pointing at a happy, neutral, or unhappy smiley. This tool is evaluated and their conclusion was that children are able to report their physical functioning adequately. (PedsQL, 2017)

Therefore it is chosen to measure the physical energy by **self-report**.

Physical functioning exists of **capacity and energy**. Both are affected by the cancer and its treatment.

Physical capacity is defined as the activities which a child is able to do and can be measured with **performance-based observations**.

Physical energy is the power a child has to do activities and will be measured by **self-report** within the product/service.

2.10 Differentiation

Currently working differentiated at primary schools becomes more and more important, since there is an increase in special needs children and there is more attention for individual development. Differentiation means adapting education to the level differences of the pupils to support to work on different levels.

This chapter explains the types of differentiation and how it is applied by teachers.



2.10.1 Types of differentiation

Within differentiation there is made a distinction between convergent versus divergent and internal versus external (Kerpel, 2014) (figure 25).

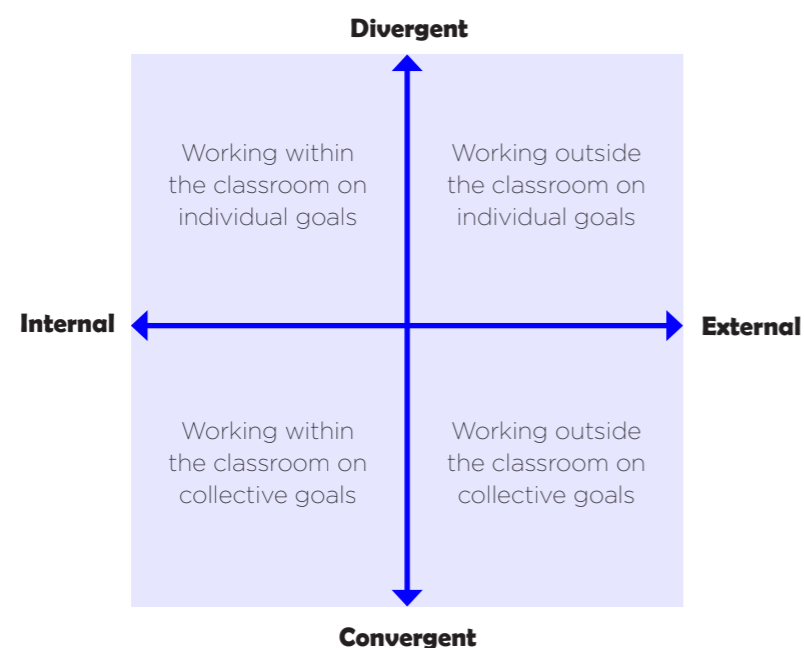


Figure 25: Types of differentiation

Convergent vs. Divergent

Within convergent differentiation teachers determine **a minimum goal for the whole class** and work within three groups towards this goal. The children receive a group instruction in which the basics about a topic are explained (Kerpel, 2014). Afterwards the children are divided into three groups. The strong children work individually on the assignments and receive extra assignments to challenge them. The children within the regular group work individually on the assignments. The weaker children receive extra instructions or the assignments are made together with the teacher. Due to this type of differentiation the children still work as a class and the same goals are reached (Kerpel, 2014).

The opposite of convergent differentiation is divergent differentiation. Within **divergent differentiation children work on their own level** (Broesder, 2013). Children work on their own goal in their own pace, due to which the individual differences are taken into account (Kerpel, 2014).

Convergent differentiation is more common in the Netherlands, since divergent differentiation results in larger differences between the pupils with negative effects for the weaker children (Wikiwijs, n.d.).

Internal vs. External

Internal differentiation means that there are **within one class** children with different levels within one class. Within the class groups are made to differentiate.

External differentiation means that the children within a **class are grouped by level**, for example special schools for intellectual gifted children (Kerpel, 2014).

In the Netherlands **internal differentiation is most common** at primary schools. Sometimes it is combined with external differentiation, for example special mornings for the strong children as observed (appendix B.13).

Convergent and internal differentiation methods will serve as inspiration for the product/service.

2.10.2 Applying differentiation

Differentiation is in general applied during the language and mathematics lessons. Within these lessons the knowledge gained during previous lessons is needed to understand the next lessons.

There are different options to apply convergent differentiation (Kerpel, 2014) (Wikiwijs, n.d.):

Instruction: Extra instruction can be given to a selection of the children.

Curriculum: The teacher composes different sets of tasks which are made by different (groups of) children.

Pace: Children get more or less time to make the assignments.

Goal: The minimum goal for children is set by the government, but children can work on extra goals or reach higher levels of goals

Examine: The exams are different for the children, for example with less assignments or easier assignments.

Rating: The rating of exams is adapted to the level of the children, the norm to rate the exams is flexible.

Extra care: Children receive extra care when needed for example from the IC.

Within the observation and during the interview (source 6) it became clear that multiple options are used at the same time. All interviewed teachers made use of differentiation in instruction and curriculum. One of the teachers combined this with differentiation in pace and goal.

Interview Differentiation

An teacher was interviewed to gain insight into how differentiation is applied in class and how this can be used for the product/service (appendix B.15). A 1 hour interview was conducted by phone. The topics discussed were how she applies differentiation and about the goal for a lesson.

The 'veilig leren lezen' method provides teachers with workbooks to differentiate. The children are divided into three groups, 1) moon, 2) star, and 3) sun based on their level. Each group has their own workbook.

If books do not provide teachers with materials to differentiate, they try to find their own materials to differentiate.

Teachers always have a goal for a lesson, provided by the book. They tend to forget to communicate this to the children, however they would like to do this.



Source 6: Description interview teacher differentiation

Convergent differentiation is preferred, so all children will reach the same minimum goal and minimise the differences between pupils.

Internal differentiation means differentiation within the class, which is preferred for a child with cancer to support the normal school experience.

The most interesting type of differentiation for a child with cancer which can be used within the product/service is **personalising the curriculum**. This type influences the school experience the least and supports the child in reaching the same goals.

2.11 Design Guidelines

Based on the analysis design guidelines are formulated for products/services targeted at children with cancer and products/services which will be used at primary schools. These guidelines are used throughout the design process and were the starting point for the requirements and wishes for the concept proposal. The guidelines are amplified in appendix O.

1. Design the product/service with taking the **different and changing needs** of different users into account.

2. Design to keep or create **normalcy**.

3. Stimulate **copng strategies**.

4. Provide a sense of **control**.

5. Design **benefits**.

6. Take all **involved stakeholders** into account.

7. Stimulate **regular development**.

8. Take **common symptoms and side effects** into account.

9. Design from the **perspective of the child**.

10. Design a **ready to use and time efficient** product/service.

3 Design Goal

The first chapter of this report presented the design brief in which the design goal of the project is stated. Based on the literature analysis and the field research, a design opportunity within this design goal was chosen. Within this chapter a specified design goal for the chosen design opportunity is presented. For this design goal an interaction vision and a list of requirements and wishes is formulated which set the boundaries for the concept proposal.

3.1 Design Goal

As presented in the second part of the previous chapter the chosen design opportunity is 'Support teachers to understand what to expect from a child with cancer'. This chapter explains the design goal within the opportunity based on the current and desired situation.

3.1.1 Current situation

The current situation is described from the perspective of the teacher and child and the effects on the child.

Teacher

In the current situation children with cancer are often **underestimated** and **sometimes overestimated** by their teacher. For teachers it is difficult understand what to expect from a child with cancer, since:

- the child's mood and physical functioning is affected by the cancer
- the mood and physical functioning changes over time, even during the day
- the teacher has to let go the picture of the child before it became sick and create a new picture
- it is a new situation in which the teacher has no or limited knowledge or experience

Due to this teacher often feel **uninformed and insecure**.

Child

Children with cancer tend to **overestimate themselves**. They are in general very pleased they are able to go to school and they would like to do the same things as they did before they became sick and their classmates. Due to this enthusiasm and willingness most children overestimate themselves.

Effects

The effects of over- and underestimating a child are similar. It has a **negative effect on the self-confidence** of a child; it makes the child insecure.

When a child is doing too easy tasks, he will get the feeling he is not smart enough to do more difficult tasks. On the other hand if the child is doing too difficult tasks he is not able to fulfil the task properly which makes the child insecure about his capacities as well.

Next to this, the child will **not be able to use all his capacities** and develop as much as possible.

Therefore it is important that teachers understand what a child is able to do bases on the child's moods and physical functioning, so the teacher can create a suitable individual planning for the child.

3.1.2 Desired situation

The design should **prevent the child being over- or underestimated** by the teacher and himself. Therefore the product/service should support the teacher and child in making an individual planning for the child which suits the current abilities of the child. This is possible if the teacher **understands the emotional and physical well-being** of the child. So the design should support the child to express his emotional and physical state; the child should teach the teacher how he is feeling for which the child should **feel secure**. Due to this the teacher will feel informed and the child will feel understood.

Furthermore, the product/service should support the teacher and child to use this understanding in **creating a suitable individual planning**. Due to this the teacher will feel **confident** about the tasks he gives to the child. The child will be able to always work on its own level which empowers the child's development and self-confidence like normal. By creating the planning together the child will get **control**.

3.1.3 Target group

The target group is children with cancer in group 5 or 6 and their teacher(s). The child's parents and classmates are taken into account as well, however they have a much smaller role within the design. Figure 26 shows some important qualities of the people within the target group.



Child with cancer

- Aged between **8 and 10 years** old (group 5 or 6)
- Wants to **become independent and have control**, but this is not possible due to the cancer
- Wants to be **normal and belong to the group**, due to which the child can overestimate himself
- **Happy** to go to school
- Mood and physical functioning are **affected by cancer and its treatment**



Classmates

- **Concerned** about their sick classmate
- **Curious** about their sick classmate
- **Focussed on themselves**



Teacher

- Background **PABO**
- Teacher group 5 or 6
- **Minimal knowledge** about childhood cancer
- **Over- and/or underestimating** the child
- **Lack of time**
- Willing to take care of the child
- **Afraid** to take care of the child in a wrong way



Parents

- **Concerned** about their child
- Want to know when there are problems or difficulties

Figure 26: Qualities of the people within the target group

To summarise, the design goal is:
The product/service should **support the child with cancer to express his emotional and physical state** and support the **teacher to create together with the child an individual planning** suitable for his current well-being throughout the day.

3.2 Interaction Vision

An interaction vision is formulated to describe the intended qualities of the interaction with the design. To define these qualities a metaphor is chosen (figure 27).

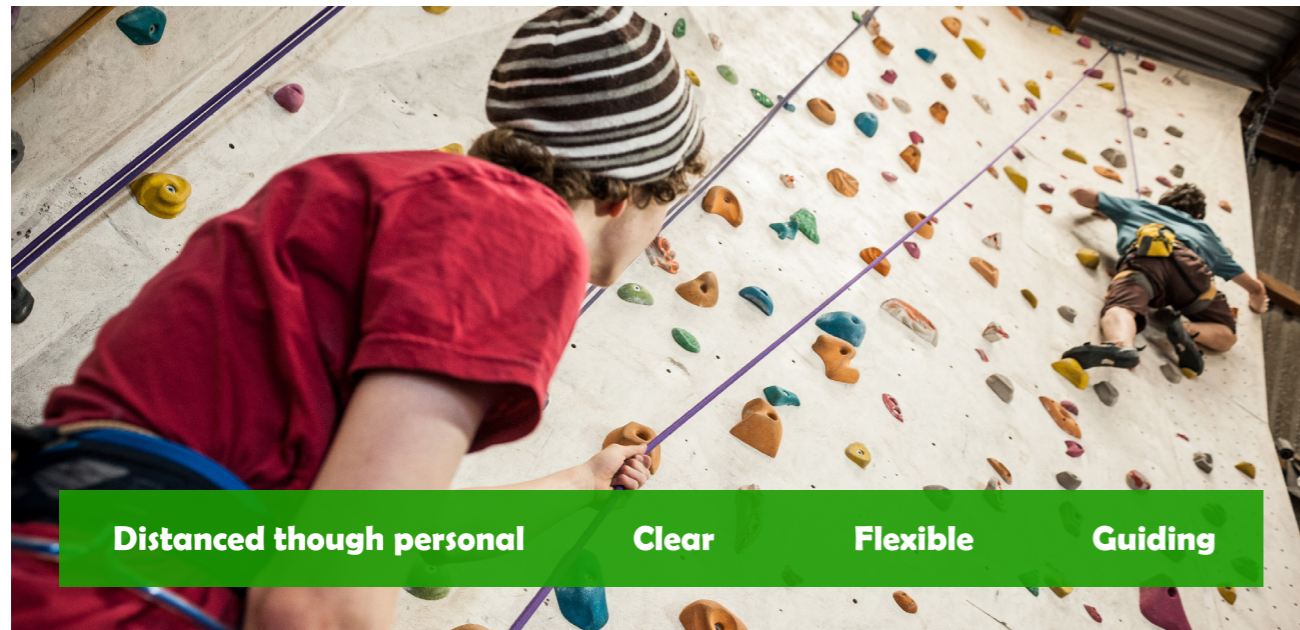


Figure 27: Climbing a rock as metaphor for the interaction vision

The metaphor which is chosen is climbing on a wall in which the climber represents the child and the belayer represents the teacher. In these metaphor there are three interesting elements: 1) Coloured climbing rocks, 2) Rope, and 3) Way of communication.

3.2.1 Coloured climbing rocks

The climbing rocks give the climber guidance on how to go up, but also gives the climber a choice in level of difficulty. In general the climber chooses at the start a level of difficulty and discusses this with the belayer. However throughout the climbing the climber can easily decide together with the belayer to make it more easy or difficult if needed.

The product/service should give the child and teacher this **guidance and flexibility**.

3.2.2 Rope for safety

Via the rope the belayer can insure the safety of the climber from a distance. The rope is only used when needed, which does not limit the movements or freedom of the climber.

The products/service should give the child **mental safety** without stranglehold the child.

3.2.3 Way of communication

The climber and belayer communicate via the rope, but also by talking. The first information is given via the rope, when more information is needed they talk. The rope is used as a tool to communicate the first information.

The product/service should fulfil a similar role as the rope, **start and enhance communication**.

3.3 Requirements & Wishes

A list of requirements and wishes is made to set boundaries for the product/service. These are used to evaluate generated ideas and directions. The complete list can be found in appendix P. Below an overview is given of the most important requirements and wishes.

3.3.1 Requirements

The product/ service

1. should support the child in **expressing his mood and energy level** throughout the day.

2. should facilitate the teacher in **understanding the moods and energy level** when walking through the classroom.

3. should be able to adapt to or **address the different needs** of children.

4. should support the teacher and child to **communicate** with each other about mood, energy level, and the individual planning.

5. should give the child the **feeling of control** by involving the child in creating the individual planning.

6. should be **easy to use** by children dealing with symptoms of cancer or side effects of the treatment.

7. may **not disturb the regular school experience** of the child with cancer.

8. should **fit the school context**.

3.3.2 Wishes

The product/ service

1. should be used in the **shortest time** as possible by the sick child, teacher, and classmates and only be used during individual or group work.

2. should give the child the ability to **only communicate** his mood and energy level **with his teacher** and not his classmates.

3. stimulates the child to **create a new normalcy**.

4. is able to **monitor** the mood and energy level of the child over time.

4 Synthesis

Based on the design goal and set boundaries as presented in the previous chapter ideas were generated. This chapter shows a brief overview of the synthesis from first ideas till the concept proposal.

During the first phase, *ideation*, ideas were generated to create diverse design directions which could be evaluated with users. Based on this evaluation key elements for the concept proposal are identified.

This is presented in the first part of this chapter. Based on these key elements a brainstorm session was conducted to create concept directions. By combining these concept directions a preliminary concept proposal was created. This is shown in the second part, *conceptualisation*.

In the last part, *detailing*, the explorations are presented to optimise the preliminary concept proposal.

4.1 Ideation

The goal of the ideation was to generate diverse ideas which could be translated into design directions to be evaluated to identify key elements for the design. An overview of the performed activities are presented in figure 28 with the main insights of the ideation.



Figure 28: Ideation which led to the key elements for the concept proposal

4.2 Conceptualisation

The goal of the conceptualisation was applying the key elements in a preliminary concept proposal. During this phase the key elements were used to create a preliminary concept proposal. The activities performed during this phase are presented in figure 29 with the main insights which were used for detailing the concept proposal.

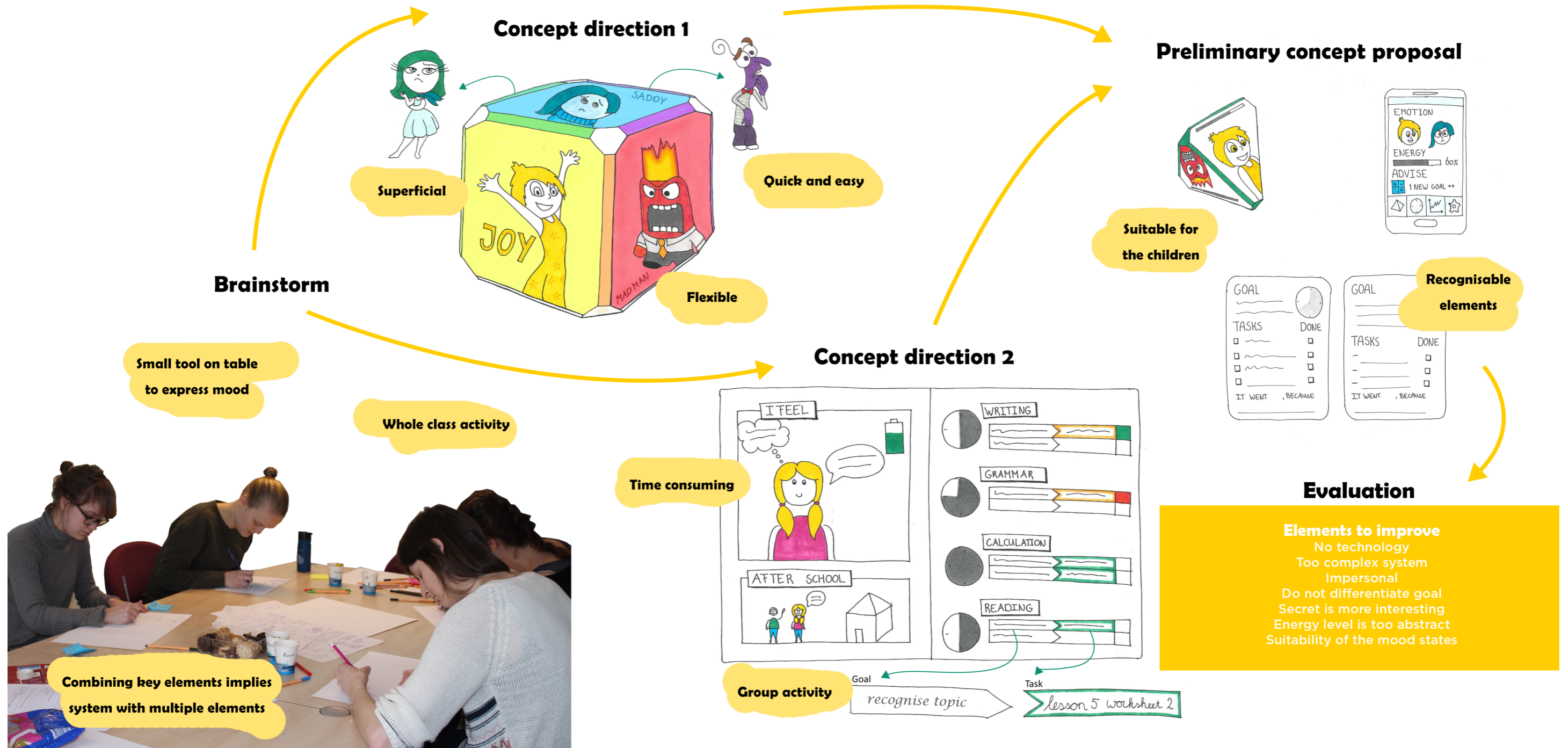
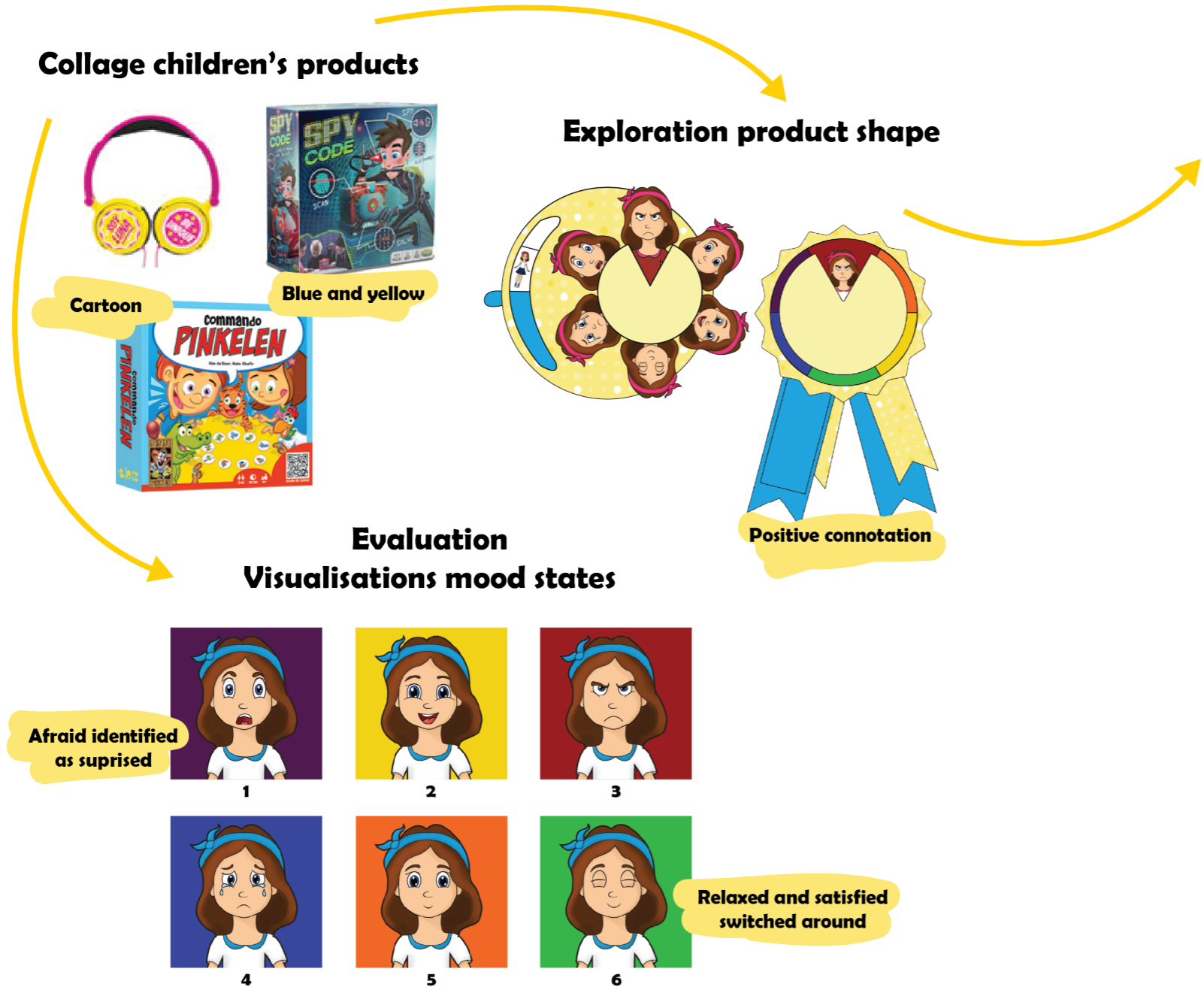


Figure 29: Conceptualisation in which the key elements are translated into a preliminary concept proposal

4.3 Detailing

The last phase of the synthesis was exploring how to detail the preliminary concept proposal into a concept proposal. This process with the main insight is visualised in figure 30.



Product identity

PRODUCT IDENTITY

HEADING
Playful headings
Body in a large font size,
so it is easy to read
for children.

Visuals
White shape around the
visuals to give the
suggestion it are stickers.
English words since those
are more attractive for
children.

LIKE!

Unisex and bright colours to make it look appealing

Lay out
Playful to make it
attractive for
children and
inviting to use.
A combination
of different
shapes and
dynamic lines
are used.

Tone of voice
Simple words and short sentences.
Questions/assignments are formulated as sentences
the children can finish.

FUN

Figure 30: The last steps taken to create optimise the preliminary concept proposal to a concept proposal

5 Concept Proposal

Based on the synthesis a concept proposal was developed. The concept proposal is called 'Humeur adviseur', Dutch for 'mood consultant'. The name refers to the core function of the concept proposal: support the child with cancer to express his emotional and physical state towards the teacher and support the teacher to create together with the child an individual planning. The 'Humeur adviseur' exists of two main elements: 1) the '*Gevoelens medaille*'- product, 2) the '*Mijn les*'- cards.

This chapter starts with an overview of the functions and usage of the different elements of the system. The second part elaborates on the '*Gevoelens medaille*' with regard to interaction, experience, appearance, and working principle. These same aspects are discussed for the '*Mijn les*'-cards in the third part. At last the envisioned implementation is discussed.

5.1 System

The 'Humeur adviseur' exists of two main elements: 1) the 'Gevoelens medaille'-product, and 2) the 'Mijn les'-cards (figure 31). This chapter explains the functions of these two elements and the interaction with and between the elements.



1) 'Mijn humeur' - product

2) 'Mijn les' - card

Figure 31: The 'Gevoelens medaille' and the 'Mijn les' are the main elements of the 'Humeur adviseur'

5.1.1 Functions

Each element has its own function within the system. Figure 32 shows a list of the main functions for the elements.



'Gevoelens medaille'

'Gevoelens medaille' is a personal product of the sick child. The child keeps the product throughout the school day close to himself, so it can be used at any moment the child wants to. The functions of this product are:

- to stimulate the sick child to **think and talk** about his mood and energy level
- to give the sick child the possibility to **express** his mood and energy level towards the teacher and his classmates
- to **remind** the teacher and classmates about the impact of cancer on the mood and energy level of the sick child

'Mijn les'

'Mijn les' are cards which are provided by the teacher to all children in class. Before a lesson the children receive a card which they hand in again after the lesson. The teacher decides which children are going to use the cards, and the sick child will use the cards for each language and mathematics lesson. The cards are similar for the sick child and the classmates, however the cards are used slightly different and have extra functions.

The functions of the cards are:

- to make **learning visible**
- to give the teacher **insight into the reflection** process of the children

The extra functions of the cards for the sick child are:

- to **communicate** what the teacher expects the child to be able to do during the lesson
- to **create an individual planning together** with the sick child by differentiating the tasks (or time)
- to give **feedback** to the teacher about how the sick child perceived the lesson

Figure 32: The main functions of the 'Gevoelens medaille' and 'Mijn les'

5.1.2 Scenario of use

Figure 33 shows how the 'Humeur adviseur' is envisioned to be used by the sick child, the classmates, and the teacher.



1. Sick child enters the class and takes her 'Gevoelens medaille'



2. Sick child chooses a mood state



3. Sick child chooses an energy level



4. Teacher starts lesson and decides which children will receive a card



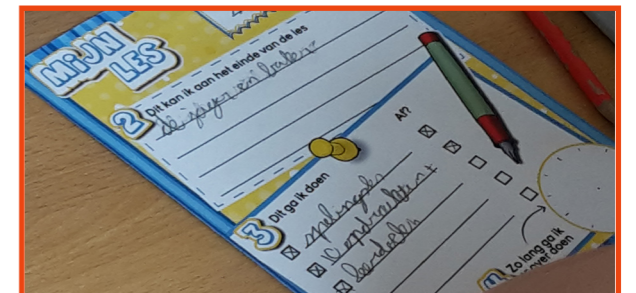
5. After the instructions, the cards are handed out



6. Teacher checks how the sick child is feeling & writes down the tasks the child could do (Teacher or sick child can have a conversation)



7. Sick child completes the front side of the card and can choose to add extra tasks or make a selection of the tasks proposed by the teacher



8. Children work on the tasks and check off the tasks they have finished



9. If the sick child wants, she can adapt her mood and energy level



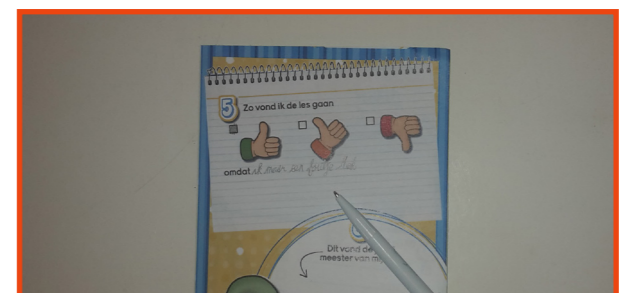
10. Teacher can check how the sick child is feeling and react on that if necessary with a conversation or by adapting the tasks

And so on



11. At the end of the lesson, the children reflect on the lesson and hand in the cards

When the teacher has time



12. Teacher checks the cards and gives feedback and hands back the card to the children or writes down notes for herself

Figure 33: Scenario of the envisioned use of the 'Humeur adviseur'

5.2 'Gevoelens medaille' - Product

The 'Gevoelens medaille' (figure 34) is a product used by the sick child to express his mood and energy level. As explained in chapter 2.8, mood and energy are two different elements to show how you are feeling. Therefore the 'Gevoelens medaille' makes it possible to set these separately.

Only the sick child uses the product to keep it exclusive and keep the focus of the teacher on using the product to support the sick child.

On the next pages several aspects of the 'Gevoelens medaille' are explained.



Figure 34: The male version of the 'Gevoelens medaille' showing a sad mood state and an average energy level

5.2.1 Mood

The mood states that can be chosen are: 1) *angry*, 2) *afraid*, 3) *sad*, 4) *relaxed*, 5) *happy*, and 6) *satisfied*. Chapter 2.8. elaborates on the choice for these mood states.

Setting mood state

The mood can be changed easily by **turning the wheel** (figure 35). To support the child to do so and find the right mood state, the colours of all mood states are always visible and the interaction is simple and fast. Small ribs are added on the side of the turning wheel as use cue for the sick child (figure 36).

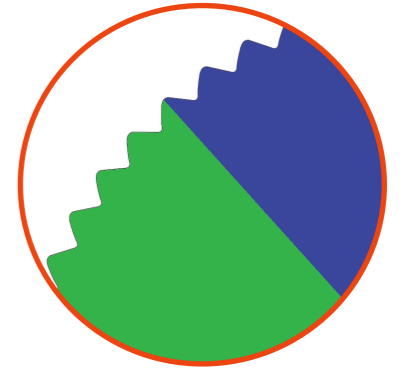


Figure 36: Small ribs on the turning wheel as use cue



Figure 35: Changing the mood state by turning the wheel

Recognising mood state

The moods are visualised with a facial expression and colour (figure 37). The **facial expression** supports the child in choosing a mood which suits him best, since the child can relate to the facial expression. The **colours** make it possible for the teacher to easily see the chosen mood from a distance.

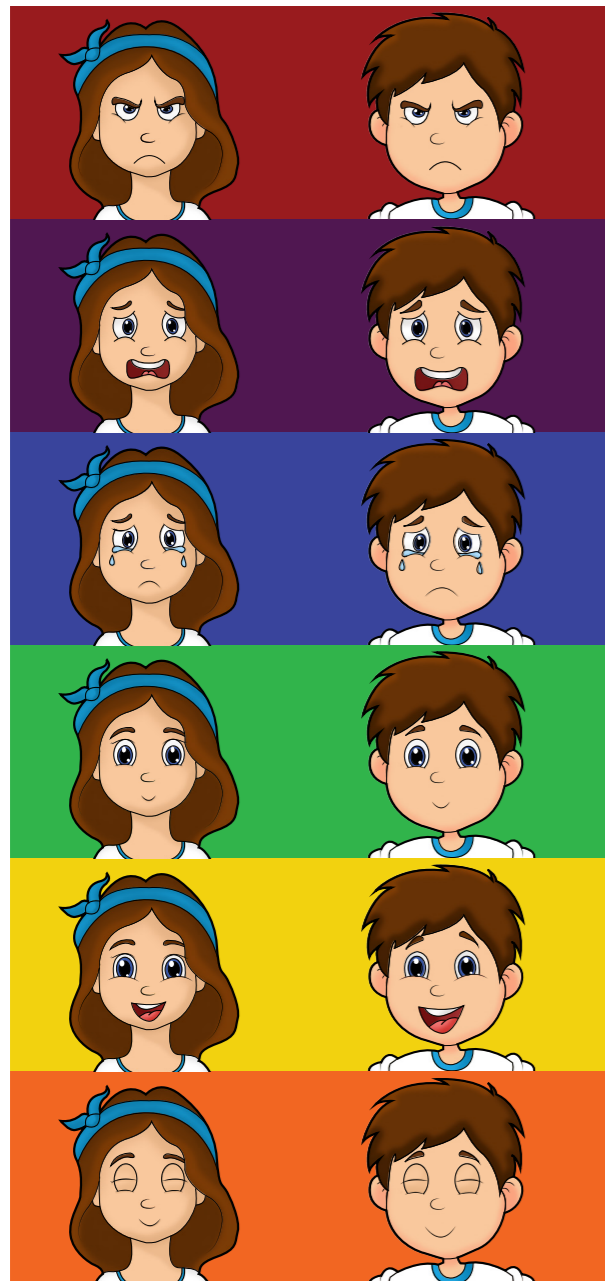


Figure 37: Overview of the visualisations of the 6 mood states (inspired by Tigatelu (2017) and Kavalenkava (2017))

Boy and girl version

To **enhance the recognition** with the facial expressions, there is made a boy and girl version (figure 37). At this age, the children start to see gender difference and react on that. Girls tends to play mainly with girls and boys with boys.

Angry - Boos

Frustrated, Irritated, Annoyed, Confused, Furious, Grumpy

Afraid - Bang

Tense, Nervous, Worried, Anguish, Timidity, Apprehension

Sad - Verdrietig

Gloomy, Bored, Weary, Lonely, Depressed, Rejected, Grief, Disappointed, Guilty, Ashamed

Relaxed - Ontspannen

Calm, Dreamy, Serene, Fine, Carefree

Happy - Blij

Hopeful, Optimistic, Having fun, Joyful, Having pleasure, Excited, Interested, Enthusiastic, Cheerful, Lively

Satisfied - Tevreden

Proud, Loved, Sympathy, Belonging

5.2.2 Energy

The energy level can be set with the bar (figure 38), due to this the sick child has a lot of options.

Setting energy level

The energy level can be set by **moving the slide up or down**. This is, like the turning wheel, a simple, small, and fast interaction to stimulate the sick child to adapt it throughout the day. The interaction is

different from setting the mood, which supports the understanding that mood and energy are not (necessarily) connected.

There are **no levels indicated** on the bar to stimulate the child to choose the energy level based on gut feeling and not in comparison to other days. It should be prevented that the sick child will compare his energy level to days he was not able to go to school due to the sickness or its treatment, since that will lead to always a feeling of high energy.

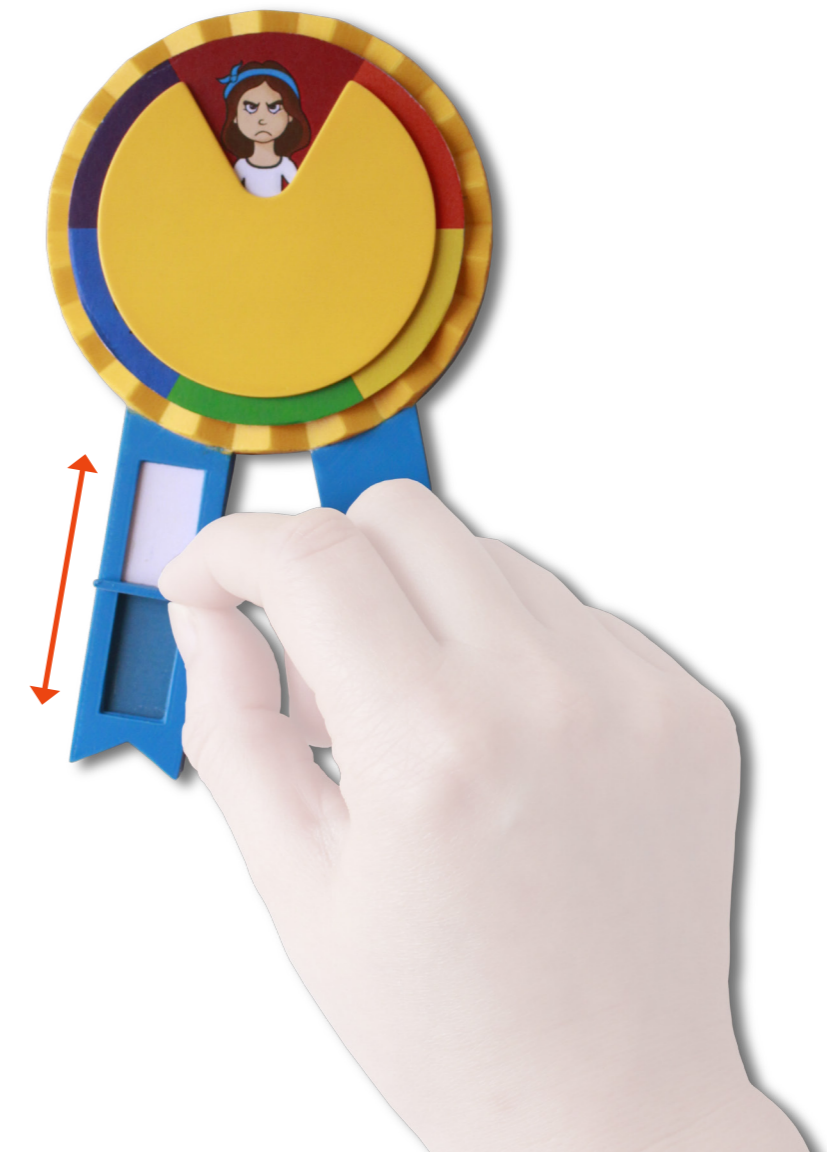


Figure 38: Setting the energy level by moving the slide up or down

Recognising energy level

The energy level is shown with a dark blue bar with a minimum and maximum. These boundaries give the child a reference to the meaning of the energy. The amount of blue represents the energy of the child. The movement sliding upwards, supports the child in understanding more blue represents more energy (figure 39).

The bar is coloured with two **highly contrasting colours**, dark blue and white, to make it possible for the teacher to recognise the energy level from a distance.

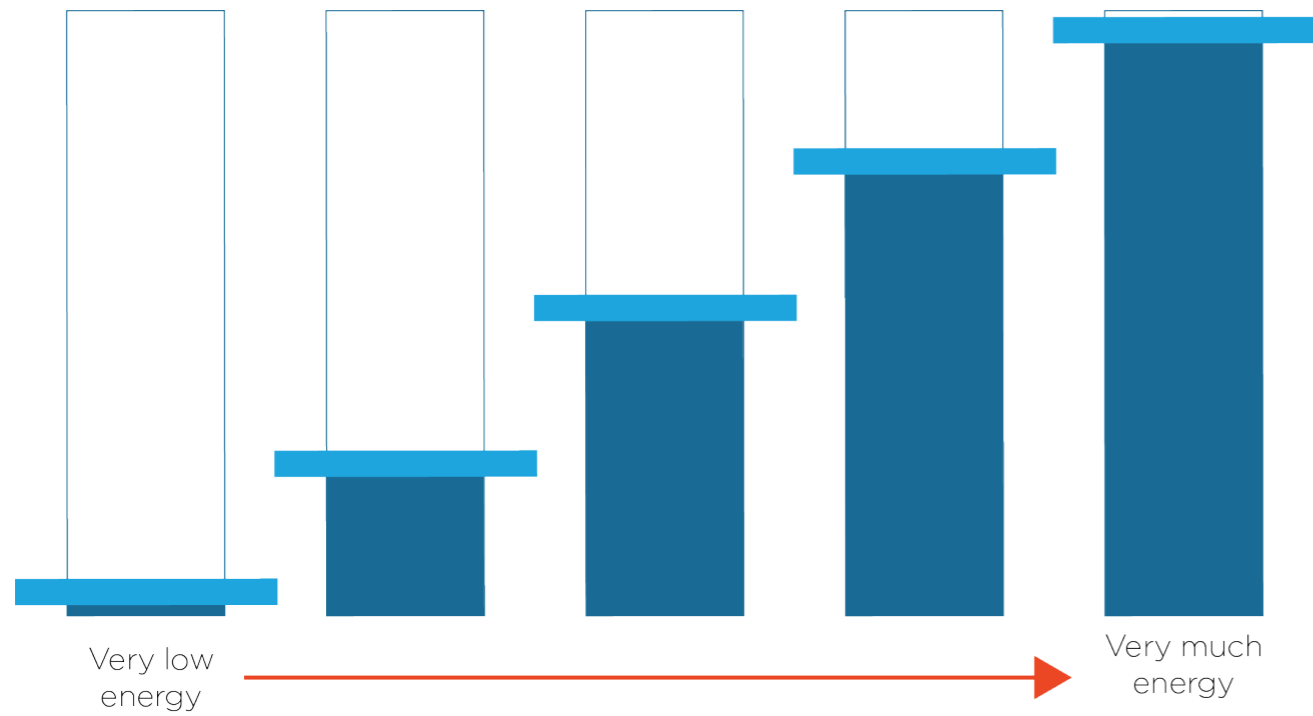


Figure 39: Interpreting the energy level, more blue means represents more energy

5.2.3 Appearance

Only the sick child will use the product, therefore the product needs to feel personal for the child. Furthermore, it has to fit the child's vision on maternity, be inviting to use, and fit in the school context. This is established by personalisation, an add on, colour, and shape based on the product identity as showed in chapter 4.3.

Personalisation

The child receives diverse **stickers** to personalise the product in a way they prefer to give the product a personal feeling (figure 40).

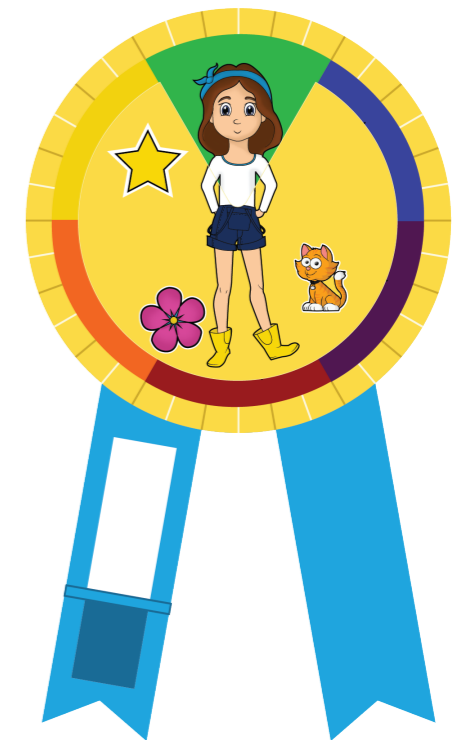
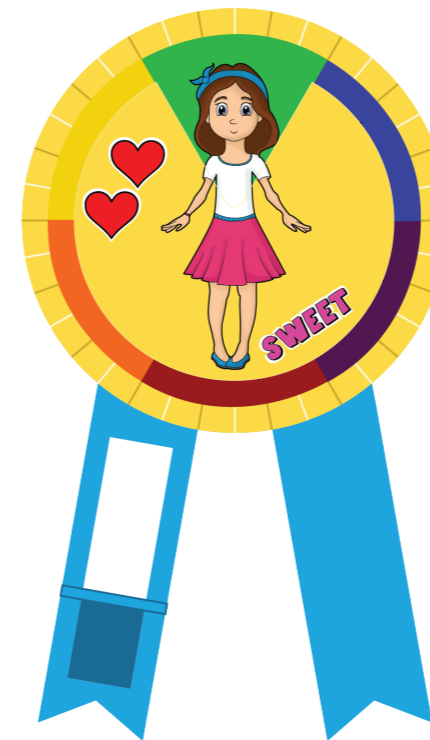


Figure 40: Example of how the 'Gevoelens medaille' can be personalised with the stickers

Add on

At the back of the 'Gevoelens medaille' a **clip** is attached. Also, there is a **hole** to attach a rope (figure 41), with which the sick child can attach the 'Gevoelens medaille' to a familiar object (figure 42).

By attaching it to a familiar object the 'Gevoelens medaille' will **feel less special/different** for the sick child. Next to this, it makes it possible to take the 'Gevoelens medaille' along easily, for example to the IC.



Figure 41: Clip and hole for rope to attach the 'Gevoelens medaille' to a familiar object



Figure 42: Examples of the 'Gevoelens medaille' attached to familiar objects of the child

Colour

The colours are **gender neutral** to make the product attractive for both boys and girls. The colours are **bright and outstanding** to make the product visible, attractive, and inviting.

A light colour is chosen for the parts around the turning wheel, to make the colours on the turning wheel outstanding and quick to recognise.

Shape

The shape of the product refers to a medal/rosette to have a **positive connotation**. This supports the sick child to create a positive attitude towards the product and be proud of it. By this, the child is stimulated to use the 'Gevoelens medaille'.

Within the product, setting the **mood and energy level are visually clearly separated**. Combined with the different interaction it supports the sick child (and teacher) in reminding that mood and energy level are two separate elements.

5.2.4 Detailing

An advice is given about the general dimensions and material of the 'Gevoelens medaille'.

Size

The child should be able to attach the 'Gevoelens medaille' on its own product, therefore the product may **not be too large**. However the product must be large enough to have an easy interaction and it must be **visible** for the teacher when he walks by. Figure 43 presents the general dimensions of the 'Gevoelens medaille'.

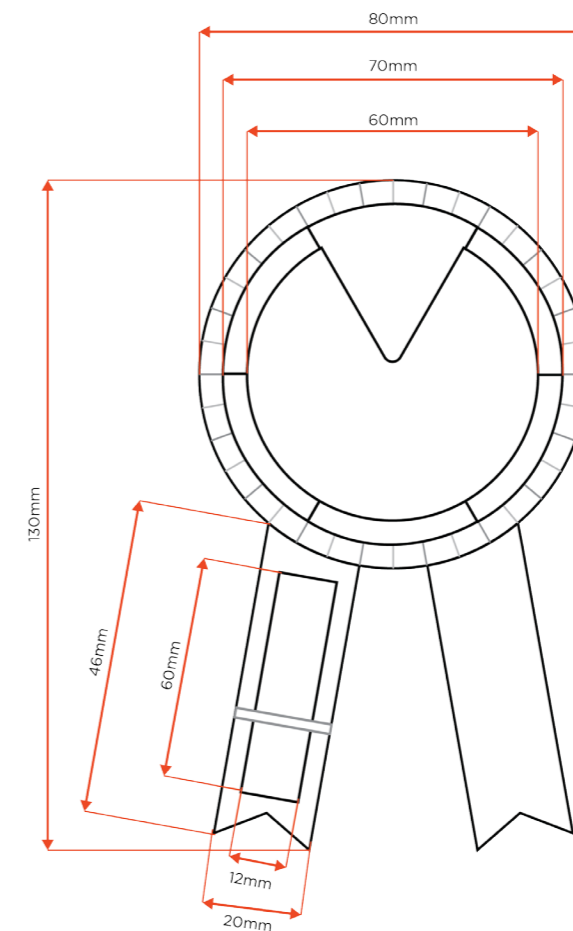


Figure 43: General dimensions of the 'Gevoelens medaille'

5.3 'Mijn les' - Cards

Slide energy level

Figure 44 shows the working principle of the slide to express the energy level.

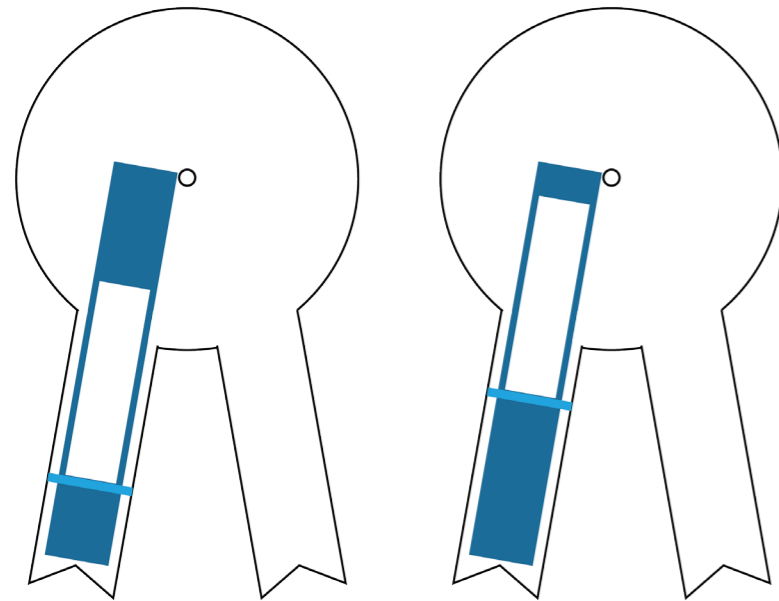


Figure 44: Working principle of the slide

Material

The product must be hygienic, safe, robust, and light weighted. A material which could be used is **PLA**. This is a bio based plastic with a low density, high strength, and is easy to clean. PLA can be **injection moulded**, if the product will be produced in a large badge, or **3D printed**, if the product will be product in a small badge.

The 'Mijn les'-cards are used by the sick child and by the classmates. The appearance of the cards is similar. However the goal of the cards and the use is slightly different. The cards are used by all children in class to give the sick child a feeling of belonging and to not imply the sick child is treated differently.

An example of a filled out card by a teacher and sick child is presented in figure 45. On the next pages (figure 46 and 47) the different aspects of the cards are explained for the sick child and the classmates.



Figure 45: Example of a filled out card by a sick child and his teacher

The product stimulates the sick child to **think** about his mental and physical state, since the product is visible throughout the day and is used by the teacher to create the individual planning.

The product supports the sick child to **express** his feelings throughout the day, since the product is flexible and makes expressing simple and non-committal. Expressing becomes simple, due to the ease of use of the product, always around, and indirect (distanced).

The product stimulates children and teachers to **talk** about mood and energy. The product works as a reminder and a conversation starter. The conversation makes the communication about mood and energy personal.

The product also creates **awareness and empathy** by the teacher and classmates. The product reminds them the child has cancer and supports them in what to expect from the child.

The product empowers the sick child to use **emotional-focussed coping strategies and get control**.

5.3.1 Content cards

Before the lesson (and during the lesson) the front of the card is filled out, namely 1) *name and lesson*, 2) *goal*, 3) *tasks*, and 4) *time*. The back of the cards, 5) *reflection* and 6) *notes teacher*, are filled out after the lesson.

Goal

The goal is filled out to **make learning visible** and help the children to reflect on the lesson.

Tasks

This part is used by the teacher and sick child to create together an individual planning, and is therefore used differently in comparison with how the classmates use it.

Sick child

The **teacher fills out the tasks** he expects the child is able to do. The teacher can base the tasks on the how the child is feeling, mood and energy, and the agreement made on how the teacher should interpret this information.

When the child receives the card from the teacher, the **child can choose which tasks he wants to do**. This can be indicated in the round check boxes before the tasks. Afterwards the child can decide to add extra tasks if the child expects to be able to do more tasks.

During the first times the cards are used, the teacher can discuss with the sick child which tasks he will do so the teacher can create an understanding what to expect in which situation.

Classmates

The classmates will fill out the tasks themselves based on the whole-class instructions of the teacher.

When a task is finished the child can indicate this in the squared check boxes behind the tasks.

The image shows the front of a colorful 'Mijn les'-card. At the top left, the title 'MIJN LES' is written in large, bubbly letters. The card is divided into four numbered sections:

- 1** Mijn naam: A box for writing the name and the lesson type (e.g., '_____ les').
- 2** Dit kan ik aan het einde van de les: A section with four horizontal lines for writing goals.
- 3** Dit ga ik doen: A section with five horizontal lines for tasks. To the right of each line is a small square checkbox. A green pen is illustrated on the right side of this section.
- 4** Zo lang ga ik er over doen: A section for time management. It includes a clock face with 'van' at the top and 'tot' at the bottom, and two sets of blank lines for writing start and end times.

Name & course

The name of the children is needed for the teacher to **process or store the cards**. The type of lesson can be filled out to be able to sort out the cards per lesson. In this way, the teacher can get an overview of the performance of the children per child or per lesson.

Time

The children can fill out the **time they think they have** to fulfil the tasks by adding the start and end time. This can be used for time management during the lesson and in the reflection.

If it is not possible to create the individual planning for the sick child based on differentiating the tasks, the time can be differentiated.

Figure 46: Front 'Mijn les'-card

Reflection

The reflection exists of **thumbs** with a coloured accent, so the children can **easily and quickly** indicate how the lesson went. This standardised system makes it possible for the teacher to interpret the reflections quickly.

There is **space for notes**, so the children can give an **explanation** if they want to. This explanation can be used by both the teacher and child to learn. Furthermore it gives insight into the self-image and self-confidence of the children.

This section is especially important for the teacher to read from the sick child to be able to support the sick child better during next lessons.

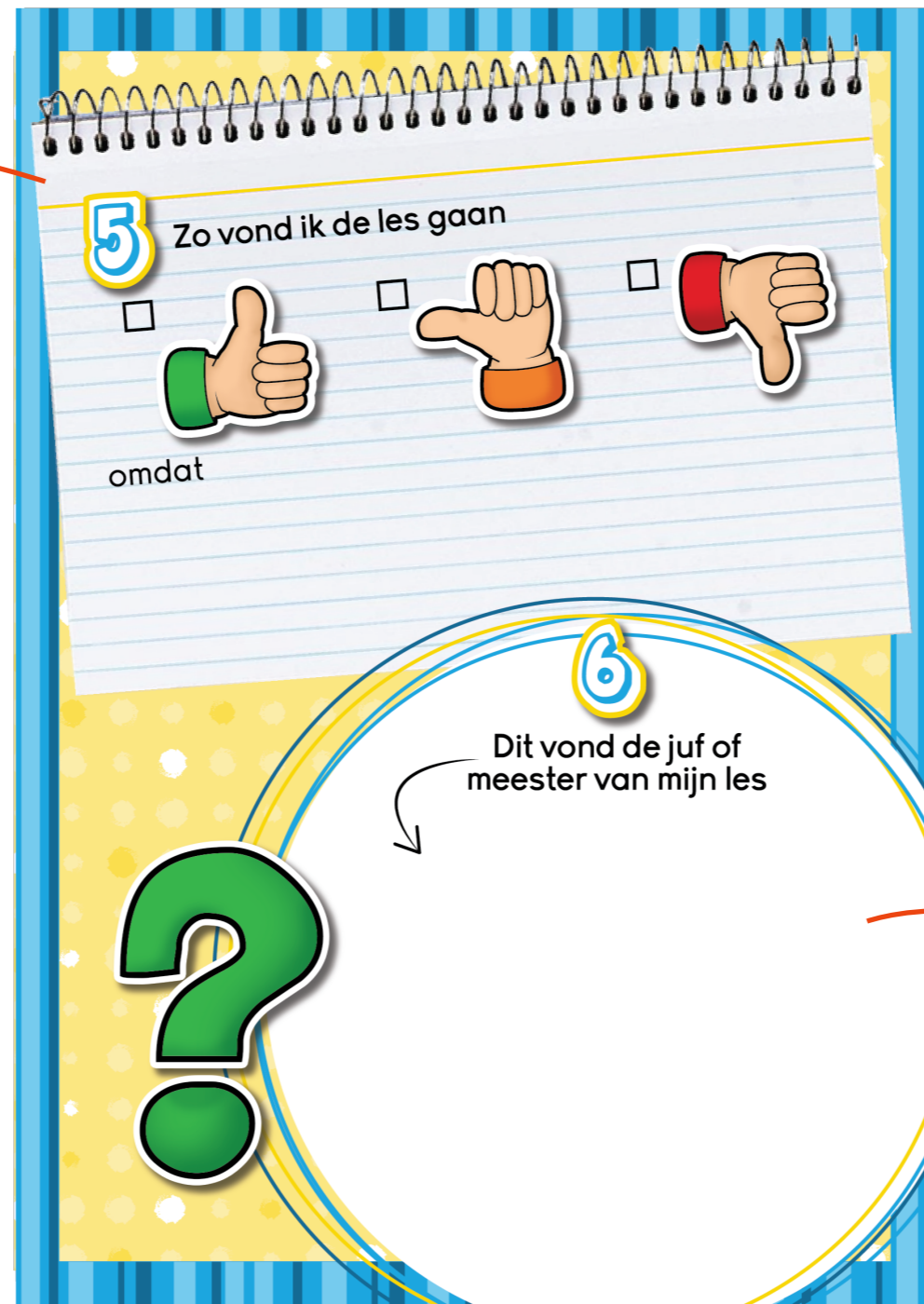


Figure 47: Back 'Mijn les'-card

Notes teacher

At last teachers can add notes after the children handed in their cards. These notes could be used for **feedback** for the children, for example you worked well, or **tips for the teacher himself**, for example 'this was a suitable individual planning when the child feels sad and tired.

5.4 Implementation

5.3.2 Appearance

The cards should look inviting, fit in the school context, and match with the 'Gevoelens medaille'. The cards are designed based on the product identity.

Structure

The content of the card is structured in a way that the **front side is filled out before** (and during) the lesson and the **back side is filled out after** the lesson. On each side the elements are ordered to be filled out from bottom to top. The different elements are numbered to guide the children through the advised order to fill out the cards and can be used by the teacher to refer to a certain element. The space to write is large, so children dealing with fine motor skills problems have enough space to write as well.

Colour

The used colours **match with the colours of the 'Gevoelens medaille'**. The areas to write are white, so the content can be written with any writing materials the children prefer.

Shape and size

The size of the paper cards is **A5**. This size offers enough space for the children to write down the requested information. However, it is not too large to fit on the children's tables. Furthermore this size can be easily copied by the teacher.

The implementation of the 'Humeur adviseur' should enhance the willingness of the sick child and the teacher to use the product and cards. This subchapter explains the envisioned implementation.

Figure 48 gives an overview of the materials needed for the implementation.



Since the cards are also used by classmates, a **feeling of belonging** is created for the sick child.

The cards make **learning visible** by letting children write down the goal for the lesson, how this goal will be achieved, and by reflecting on the lesson.

The reflections give teachers **insight into the reflection process, the self-image, and self-confidence** of the children. This supports the teacher in offer children the help they need and focus on more than just the results of their work.

For the sick child the cards are used to **communicate** with the teacher about the individual planning a way integrated in the normal school flow. As a result the sick child will not get the feeling treated differently nor the classmates.

The sick child **creates the individual planning together** with the guidance of the teacher, since the teacher proposes tasks and the sick child makes the final decision. By involving the child in this process, the child will get a **feeling of control**.

The appearance of the cards is in line with the appearance of the 'Gevoelens medaille'. The cards are **playful**, but not childish, clear, and **inviting**. The appearance should be appealing for the children to **stimulate them to keep filling out the cards**.

Figure 48: Overview of the implementation materials

5.4.1 Implementation scenario

Within the implementation the 'Humeur adviseur' should be introduced to the 1) *sick child*, 2) *teacher*, and 3) *classmates*. When introducing the product to the classmates, a **safe environment** for the sick child should be created, to support the sick child in expressing himself honestly. Figure 49 shows the envisioned implementation scenario.



1. EF introduces the 'Humeur adviseur' to the sick child after having contact with the school of the child and they explore the functions together.



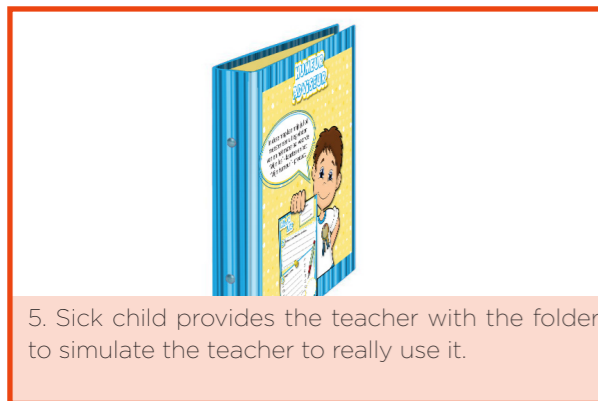
2. Sick child personalises the 'Gevoelens medaille'.



3. Sick child fills out the booklet with help of the EF.



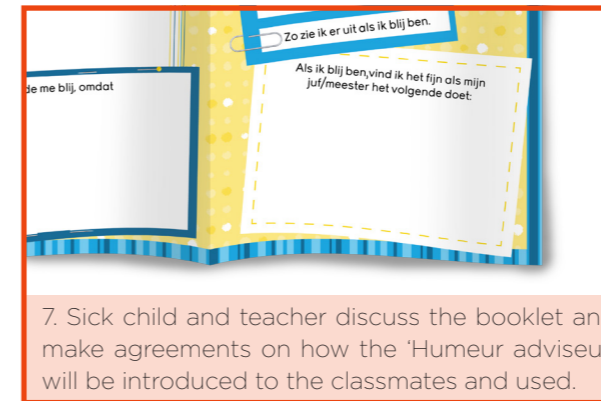
4. Sick child tries out the 'Humeur adviseur' with the EF, to get familiar with using it.



5. Sick child provides the teacher with the folder, to simulate the teacher to really use it.



6. Teachers reads the explanation of the 'Humeur adviseur'. If the teacher has questions he can contact the EF or website.



7. Sick child and teacher discuss the booklet and make agreements on how the 'Humeur adviseur' will be introduced to the classmates and used.



8. Teacher gives a lesson about mood.



9. Teacher gives a lesson about energy and introduces the 'Gevoelens medaille'.



10. Sick child starts to use the 'Gevoelens medaille'.



11. Teacher gives a lesson about reflecting.



12. Children start to use the cards in class.

Figure 49: Scenario of the envisioned implementation of the 'Humeur adviseur'

5.4.2 Implementation materials

Within the implementation scenario several materials are mentioned to support the implementation. All materials are available in a boy and girl version. Below these materials are presented and explained.

Packaging

The packaging (figure 50) is a box which includes all elements of the 'Humeur adviseur'. The sick child receives the box of the EF. The child will give the folder to his teacher, due to this the child will get the feeling of control and being in charge of the product and its use.

Nevertheless, before the child receives the box, it is communicated with school. The advice to use a product from a health/education professional is needed for some teachers to be willing to use the 'Humeur adviseur'.

The box is in line with the style of the 'Gevoelens medaille' and 'Mijn les'. It looks **inviting, positive, and unisex**.



Figure 50: Packaging of how the child receives the 'Humeur adviseur' of the EF

Booklet child

The booklet contains an explanation of and stickers to personalise the 'Gevoelens medaille', and a sensitising part. Below the elements of the booklet are presented and explained.

Explanation

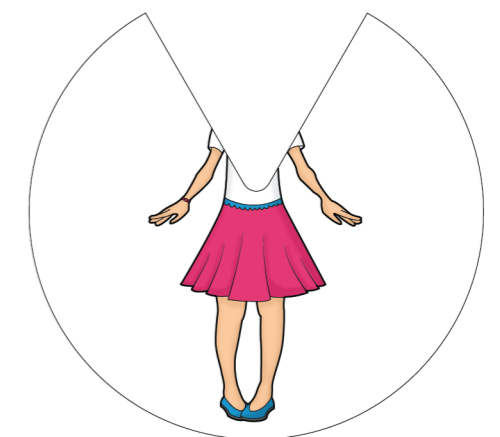
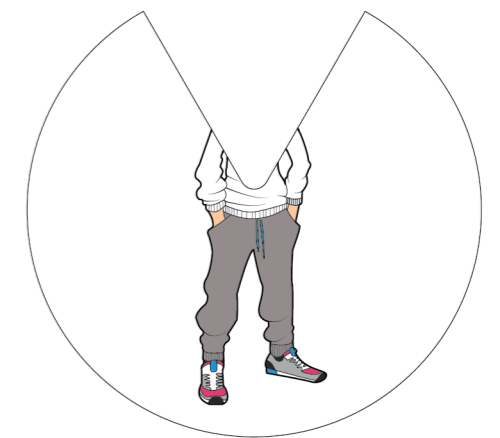
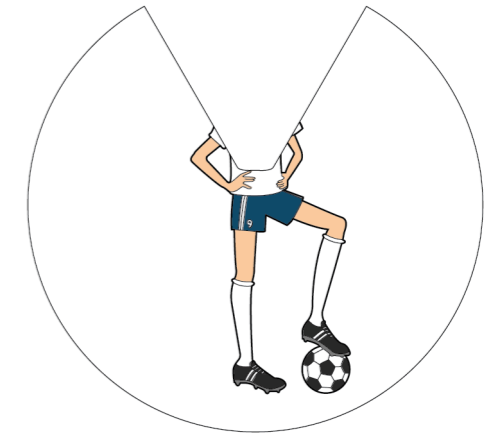
After the introduction, the booklet describes briefly how the 'Humeur adviseur' can be used and describes the advantages of its use by making use of small scenarios.

Stickers

The second part contains stickers to personalise the 'Gevoelens medaille' (figure 51). Examples to personalise are given to inspire the children (figure 40, page 93). The stickers are divers and empty stickers are added, in order to ensure all children are able to personalise it in a way they prefer. An overview of all stickers for both the boys and girls can be found in appendix U.



Figure 51: Stickers to personalise the 'Gevoelens medaille' and example for inspiration



Sensitising

The last part of the booklet is used as a sensitising booklet as **guidance during the conversation** between the teacher and child. The child can fill out the booklet, if needed together with the EF consultant, to prepare the conversation with the teacher. During this conversation the child can discuss the booklet with the teacher, so they can make agreements on how the 'Humeur adviseur' will be used and introduced in class. By letting the child think about this before the conversation, the child can think at its own pace and decides what would suits him. An example page of the booklet is presented in figure 52.

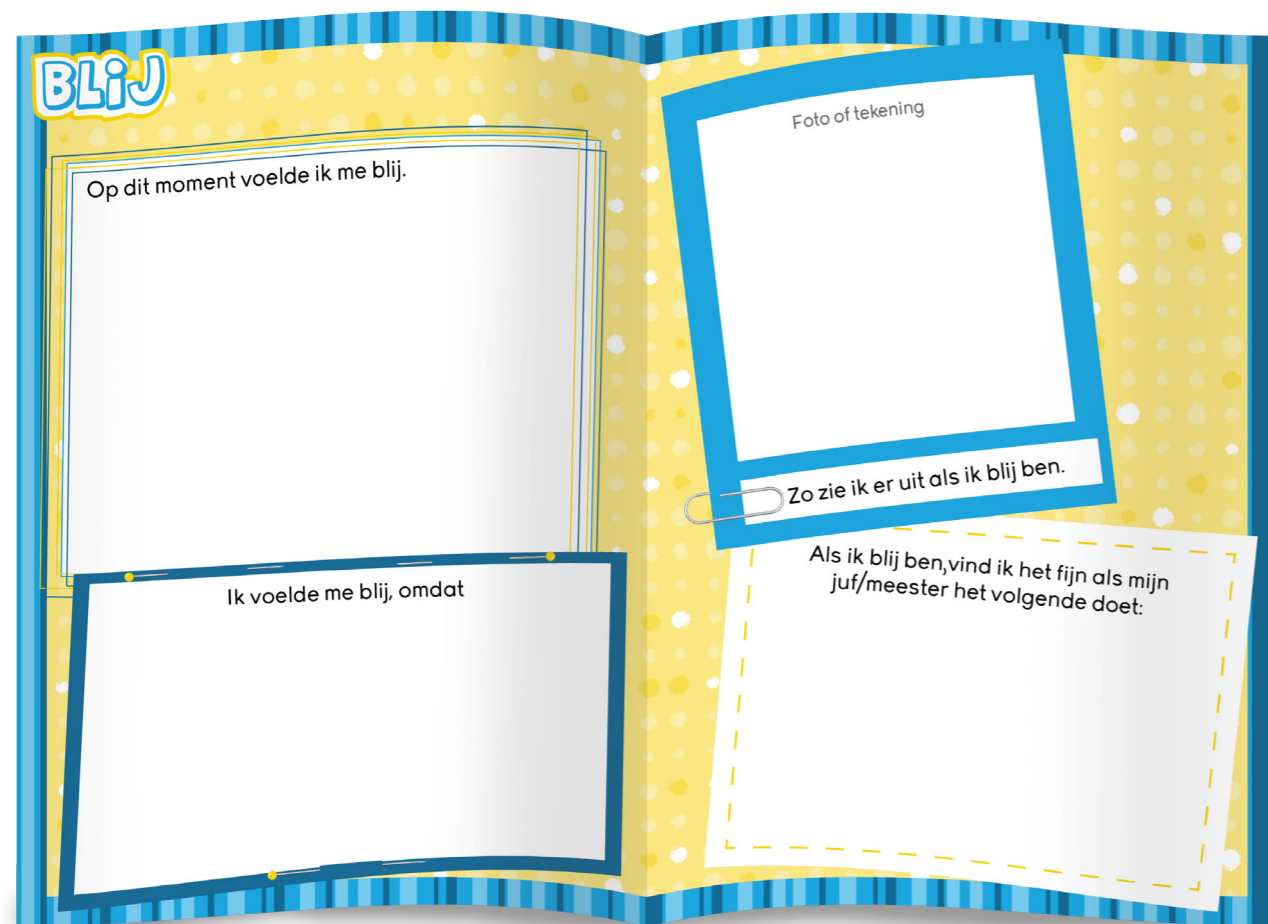


Figure 52: Example page of the sensitising part of the booklet - mood state happy

Folder teacher

The folder (figure 53) for the teacher contains the explanation of and materials for the 'Humeur adviseur'.

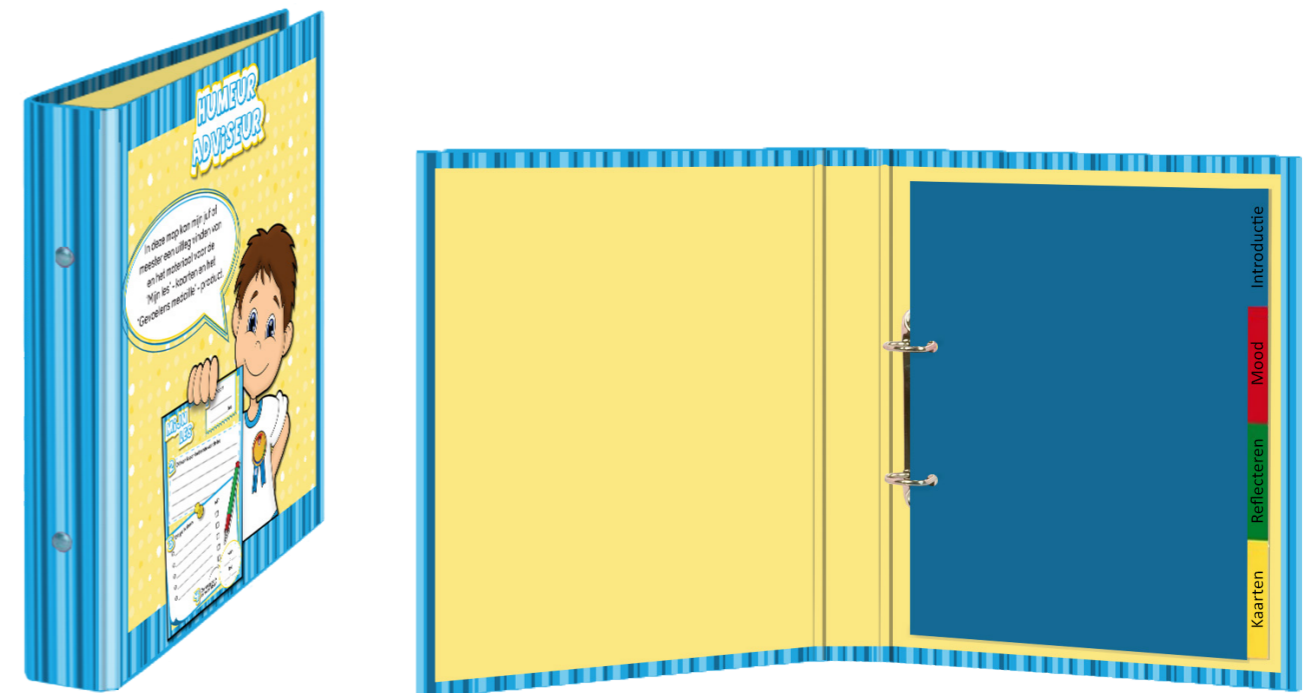


Figure 53: Folder for the teacher for information and store cards of the sick child

Explanation 'Humeur adviseur'

The first part of the folder exists of an explanation of the 'Humeur adviseur'. Within this **explanation the goal and use** of the 'Humeur adviseur' is explained with guidelines how to interpret the information of the product. These **guidelines** should support the teacher, together with the agreements made with the child, in how to interact with the child and create the individual planning.

The explanation should be short and highlight the advantages of use for the teacher, sick child, and classmates to convince teachers to use the 'Humeur adviseur'.

Next to this, a 'Mijn les'-card is attached which can be copied by teachers themselves.

At last **background information** can be found about taking care of a child with cancer at school and the

impact of mood and energy level on the school experience.

Educational materials for the lesson about mood

After the explanation the folder contains educational materials ('lesbrieven') for the lessons about mood, energy, and reflection. The lessons are presented as ready to use, stimulate teacher to use these lessons for introducing. The teacher can download the presentations for the lessons from the website of the 'Humeur adviseur'.

Store information about the sick child

At last the folder can be used to store information about the sick child. For example filled out cards or information from the parents, so the teacher can learn from previous lessons. Next to this, the overview of the cards can be used to communicate with the parents.

Website

The 'Humeur adviseur' is accompanied with a website. Within the website a page is created for children, teachers, and parents.

Children

Sick children and classmates can use the website to gain information about the 'Humeur adviseur', exchanges experiences, and play games about mood and energy.

Teachers

The main reason for the website is to provide teachers with the **educational materials**. On the

websites teachers can download the presentations and 'lesbrieven' for the lesson (figure 54).

Furthermore the website provides the teachers with an **explanation and example of the use** of the 'Humeur adviseur' and extra background information.

Finally, the website provides a **forum** in which they can exchange experiences with the product.

Parents

The page for the parents presents information about how they can support their child in using the 'Humeur adviseur' and a forum to exchange experiences.

Lessons

To introduce the 'Humeur adviseur' to the classmates, a set of three lessons is created. These lessons are a complete set of lessons ready to use by the teacher. The lessons can replace a social development activity, since the lessons not only introduce the 'Humeur adviseur', but are also educational.

The lessons explain, in a fun way and without putting the child with cancer in the center of attention, the reasons why the sick child will use the 'Gevoelens medaille'. By creating an open atmosphere, being clear why it is used, introducing it gradually, and involving the child, the child will feel **safe to use** the product.

The goals of, the method for, and an example of slides for the three lessons can be found in appendix U.

Mood

The lesson about mood is an interactive lesson in which children explore different mood states. By sharing experience, acting out, and naming mood states children learn what mood is, recognise the 6 principle mood states, and understand the impact mood can have.

Energy

The lesson about energy has a similar set up as the lesson about mood. The goals of this lesson are to understand what energy is, how to get energy, and understand the influence of energy on the school performance.

The lessons about mood and energy can be elaborated with the effects of cancer on mood and energy. This will be done in consultation with the child.

Figure 55 presents an example slide of the presentation about energy.

After the lesson about energy the 'Gevoelens medaille' will be introduced. To prevent questions or prying eyes of classmates, the teacher is advised to let the classmates test the product and explain clearly why only the sick child will use the 'Gevoelens medaille'.



Figure 54: Example of the website - page where the teachers can download the presentations and 'lesbrieven'



Figure 55: Example slide of the presentation about energy

Reflecting

The last lesson is about reflecting, during which children will perform small tasks on which they reflect. In an interactive way the children learn stepwise what reflecting means, why it is done, and how it can be done. At the end of the lesson the 'Mijn les'-card is introduced and the children can practise with the cards.

5.4.3 Lifecycle

The 'Humeur adviseur' supports the sick child to express his emotional and physical states and empowers the teacher in creating, together with the sick child, a suitable individual planning. This is mainly needed when the child and teacher are not yet familiar with each other or the situation, for example after the diagnosis or when the child gets a new teacher.

It is envisioned that the 'Humeur adviseur' can be used in these situations. In these situations both the child and teacher (and the classmates) will be empowered and stimulated learn to recognise the mood state and energy level without the product.

When the child and teacher are able to understand each other without the 'Humeur adviseur', they can reduce the use of it. The time span for this process will differ per child, teacher, and situation.

5.4.4 Costs

The costs for the 'Humeur adviseur' are roughly estimated for a badge size of 100 pieces. The cost price per 'Humeur adviseur' is based on the price for materials and production, other costs, such as transportation costs, are not taken into account.

'Gevoelens medaille'-product

Raw materials	€0.32
Production and assembly	€1.50
Total	€1.82

'Mijn les'-card

Copy sheet 'Mijn les'-card	€0.26
Total	€0.26

Packaging

Box (including print)	€4.11
Total	€4.11

Booklet child

Booklet	€0.90
Stickers	€1.50
Total	€2.40

Folder teacher

Folder (including print)	€5.87
Tabs	€0.47
Papers (with instructions)	€2.15
Total	€8.49

Total

€17.08

This overview is based on DiscountOffice.nl (2017); Druk.zo (n.d.); Easymappen (2017); Flyeralarm (2017); Internetshop.nl (n.d.a.); Internetshop.nl, (n.d.b.); Laserbeest (2017); SchoolspullenXL (n.d.) and Papierenkarton.nl (n.d.)

The cost price is roughly estimated on €17.08 per piece, but must be further explored. The estimated cost price is a lot of money for a product which will be distributed for free to the users, due to which it will become difficult to find a financier.

The cost price can be reduced by **cheaper options for the folder for the teacher and the packaging**, since these costs are relatively high and these elements are used less intensive as the 'Gevoelens medaille'- product and 'Mijn les'- cards. An cheaper option for the folder would be a fast closer, however these option will be less sturdy and attractive in appearance and use.

Another option to **reduce costs it to make all paperwork digital** and let teachers and schools print the papers themselves. However, this will have a negative effect on the ease of use for the teachers and therefore probably their willingness to use.

It is also possible to change the business model, for example by **selling the 'Humeur adviseur' to cover its own costs** or part of it or to lend the product to the user to minimise the amount of products which should be made.

5.4.5 Opportunities

The 'Humeur adviseur' is designed for children with cancer within the school context. Due to the combination of the mental and physical state and the possibility to change this over time, the product is especially for children with cancer. The product can be easily understood by the teacher and the 'Mijn les'-cards make it possible to translate the information to education.

Despite there are contexts in which the 'Humeur adviseur' could be supportive as well.

Different context

The 'Gevoelens medaille' - product is an add on and can be easily taken by the child to another context. The child can, for example, use it in the **hospital** to show the hospital personnel how he is feeling.

Tool to communicate

The 'Mijn les' - cards can be used to **communicate with the other parties involved in the education**

of the child. If the teacher knows the child will be absent, the teacher can prepare cards and give them to the home teacher or EF. The home teacher and EF can use the cards to communicate towards the teacher how it went. If the child is missing school, the teacher can use the cards to keep track of the missed education.

Different target group

The product can be used by all **children with special needs**, for example by siblings of a child with cancer or by children with autism.

Educational material

The 'Humeur adviseur' can be used as educational material. The 'Gevoelens medaille' can be used to **teach children about mood** and the 'Mijn les' - cards can be used for reflection, which is one of the things which is often forgotten by teachers. These elements are important for all children to learn.

The implementation should **enhance the willingness** of the sick child and teacher to use the 'Humeur adviseur'.

The willingness of the sick child is enhanced with the implementation by supporting in **creating a safe environment** for the sick child to use the 'Gevoelens medaille'. This is established by giving the child the option to **personalise** the product, provide tools to **communicate** with his teacher about his preference, tools to introduce it **gradually** to his classmates, and involving the child in the implementation process.

To enhance the willingness of the teacher to use the 'Humeur adviseur' the implementation exists of **ready to use** materials and the **advantages** for the child and teacher are highlighted.

6 Evaluation

The concept proposal is evaluated with teachers, mothers, and children to define to what extent the concept proposal meets the set design goal, requirements, and wishes; and formulate recommendations. For this evaluation a previous version of the concept proposal, as presented in the previous chapter, was used. Based on the results of the evaluation small changes are made to optimise the concept proposal. The evaluated concept proposal and the reasons to make the changes are explained in appendix V and W.

Within the first part of this chapter the evaluation is summarised by explaining the goal, used methods, results, conclusion, and discussion. Based on the evaluation recommendations were formulated which can be found in the second part of this chapter.

6.1 Evaluation Concept Proposal

The goal of the evaluation was to define to what extent teachers and children experience the set design goal, requirements, and wishes by using the 'Humeur adviseur'. The results of this evaluation were used to optimise the concept proposal and formulate recommendation for further research and optimisation.

To be able to reach this goal the following research questions were formulated:

1. How do children and teachers experience the support for the children to **express their emotional and physical state**?
2. How do the children and teachers experience the support of **creating a suitable individual planning together**?
3. How do children and teachers experience the **implementation** of the 'Humeur adviseur'?
4. How does the 'Humeur adviseur' and its implementation **fit into the school system**?

To answer the research questions two different methods were used, since it was not possible to evaluate the concept proposal within the targeted context with the targeted users. Therefore **two methods** were combined in this evaluation. The first method was interviewing people with experience with cancer and the second method was a user test with follow up interview with a class. The used methods and a summary of the results are shown in sources 7 and 8, a detailed overview of the evaluation can be found in appendix V.

Figure 56 presents an overview of the used research materials. Based on the results the research questions are answered as conclusion which is described in this section.



Figure 56: The use research materials are high fidelity prototypes supported with examples and overviews on paper

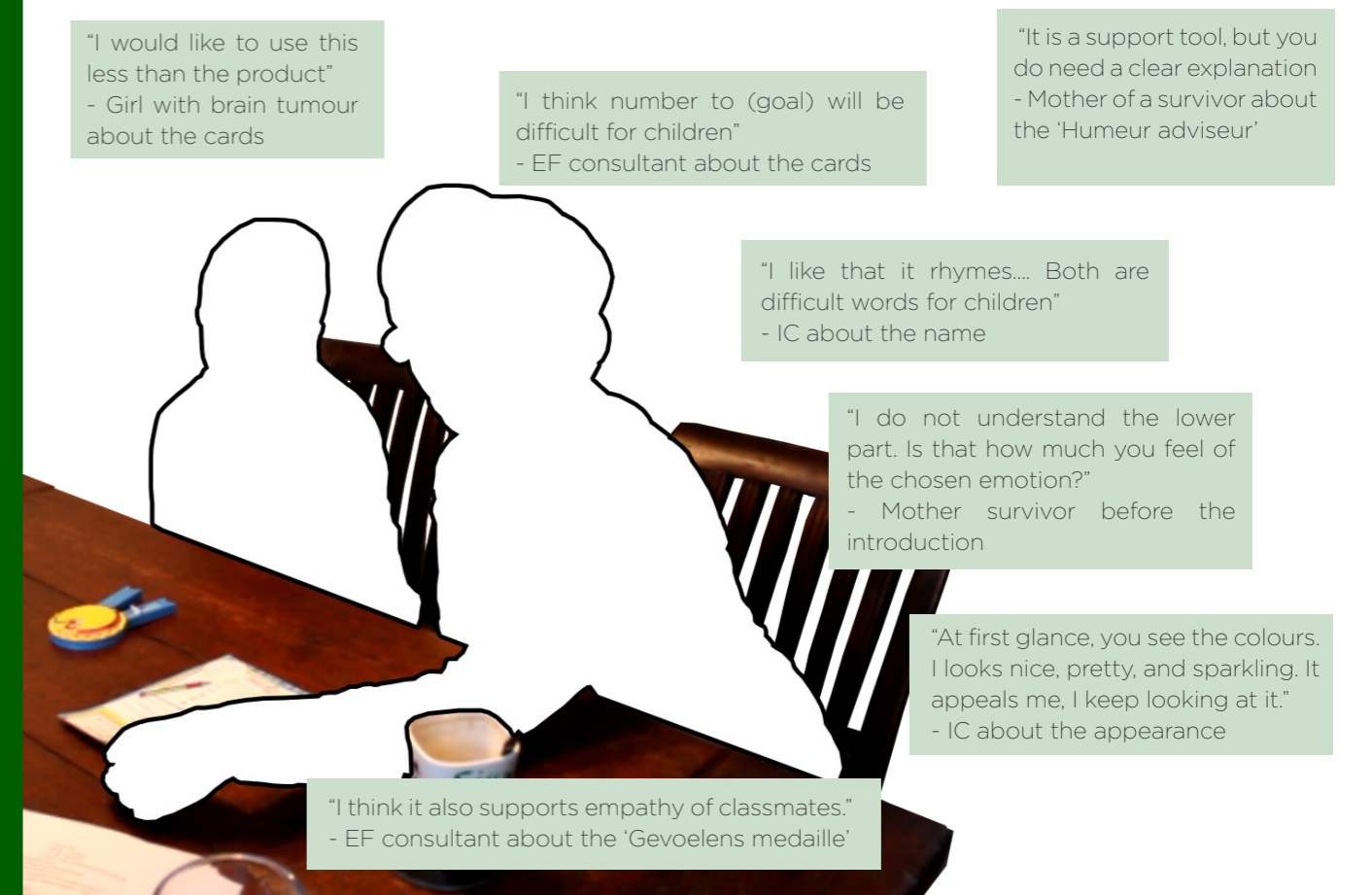
Interviews

Four interviews were conducted to answer research question 1, 2, and 3. The participants were a girl (12 years old) with a brain tumour and her mother, a mother of a survivor, EF consultant of the WKZ, and a teacher/IC. The last 3 participants have participated in previous research as well.

Set up

- 1. Introduction:** An explanation of the project, consent form, and getting to know each other
- 2. Cancer and school:** Questions about how they have experienced cancer at school
- 3. Scenario:** Describing a familiar situation in which the concept proposal could have been used on which the explanation of the concept proposal was based
- 4. Appearance:** Questions related to the appearance of both the product and the cards

- 5. Product:** Questions about the functions and interaction
 - 6. Cards:** Questions about the functions and interaction
 - 7. Implementation:** Explanation of the implementation scenario with questions
 - 8. Close off:** Last remarks
- Due to limited time part 7 was left out during the first interview. Part 1, 2, and 3 were shortened and used as a recap within the other three interviews, since this information was known due to previous participation.



Source 7: Description of as summary the method and results of the interviews conducted with experts with experience

User Test School

The goal of this user test was to gain insight into how the concept proposal is experienced by children and their teacher within the classroom to answer research question 1, 2, and 4. The concept proposal was evaluated by one class with 8/9 year old children (group 5). This was the same class as observed. Two of the children (1 girl and 1 boy, sitting on the other side of the classroom) have used the product and cards as how the concept proposal is envisioned to be used by a sick child. The other children have used the cards as how it is envisioned the classmates of a sick child would use it.

Set up

- 1. Presentation:** At the beginning of the day I gave a presentation in which I explained the goal of today and a short version of the 3 lessons for the implementation.
- 2. Using the product:** The children who were chosen to use the product received the product and got an extra instruction.
- 3. Using the cards:** During 4 lessons the cards were used as envisioned
- 4. Interview personalisation:** During the day, 3 children were asked to personalise the product and answer several questions about this.
- 5. Interview appearance:** 3 Other children were asked to answer questions about the appearance of

the product and cards. They first had to rank words on which the later questions were based.

- 6. Interview functionalities and interaction cards:** After using the cards, 3 children were asked to answer questions about the functionalities of and interaction with the cards.
- 7. Interview functionalities and interaction product:** At the end of the day the 2 children who used the product were asked to answer questions how they have experienced using the product and cards.
- 8. Follow up interview teacher:** After using the cards and product for a day the teacher was asked several questions about how she had experienced the use of the cards and product.

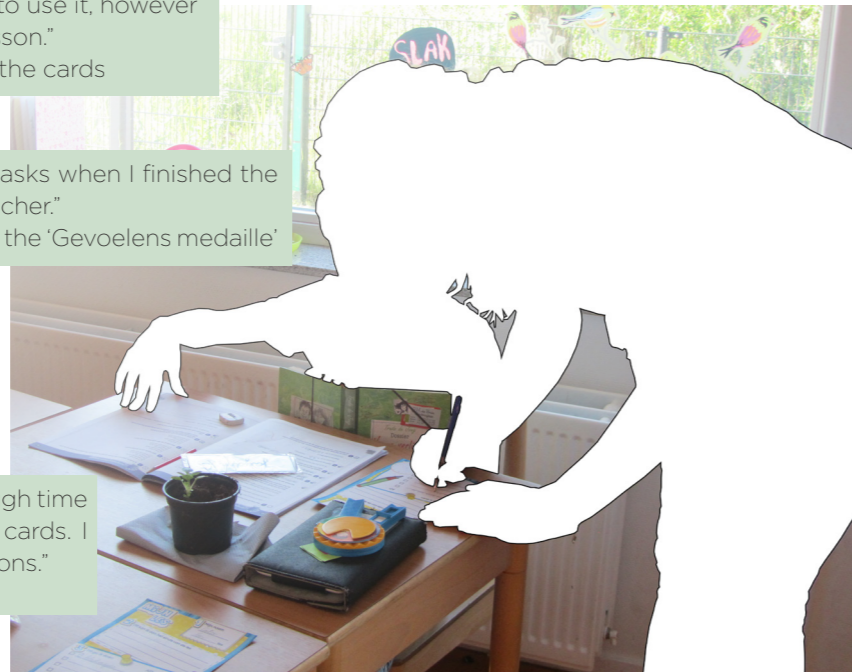
"It is for both and girls since everybody can choose what they like"
- Boy after personalising

"I would like to use it, however not for all lesson."
- Boy about the cards

"I added extra tasks when I finished the tasks of the teacher."
- Boy who used the 'Gevoelens medaille'

"I would have like to use this, when my mother had cancer"
- Girl about 'Gevoelens medaille'

"I have definitely not enough time to write feedback on all cards. I would look at the reflections."
- Teacher



6.1.1 How do children and teachers experience the support for the children to express their emotional and physical state?

All participants were enthusiastic about the product. The mother of the girl with a brain tumour said: "This would be perfect for her, since she is always very quiet and only says yes or no.". One of the teachers said: "This helps me to offer the child what he needs".

Below the three main insights are explained.

Stimulating

The 'Gevoelens medaille' stimulates the sick child to think about his mood and energy level, to express himself, and talk with classmates. The teacher is stimulated to consider the mood and energy level of the child and communicate about it. The participants indicated that this was achieved, since the product:

- makes it **easy to express yourself**, showing is easier than talking, and it is anonymous
- serves as a **reminder** for both the child and the teacher
- serves as a **starting point** for an 'in depth' conversation

Honest

Teachers are doubting if children would also honestly show their mood and energy level. They suggest that a good introduction would help in creating a safe environment.

Children indicated that they want to do it honestly, however they do **not always want to show their mood to their classmates** and are **not always sure how to fill it out 'correctly'**.

Different needs

Children have different ways to coop with their mood, sometimes a child does not want to talk. Therefore the teachers indicated that it is needed to **discuss with the child how they want the teacher to react**.

6.1.2 How do the children and teachers experience the support of creating a suitable planning together?

The teachers were positive about using the cards to create together an individual planning, however the children did not experience it as doing this together. The boy who the used the product said: "I have the feeling my teacher decides what I had to do."

Below the main insights about creating the individual planning with the card are presented:

Together

Children **did not had the feeling they created the individual planning with their teacher**. The teacher filled out the tasks and the children only added tasks after they finished the tasks of the teacher. Due to this the feeling of self-control of the child is limited.

Translating the information of the product

As mentioned above children have different needs, as well in how they **prefer that their teacher uses the information** from the product to create the individual planning. Mother: "It can also go wrong. Maybe the child just wants to work to forget it".

Communication

The communication of the tasks was **similar to what they are used to**. The communication of the reflection via the cards would be a first step, but a **conversation can be needed**.

6.1.3 How do children and teachers experience the implementation of the 'Humeur adviseur'?

The implementation was seen as crucial for the concept proposal. Teacher: "It depends on the way of introducing if children would fill it out honestly." The envisioned way of intruding was perceived as positive if the child would be involved during the complete introduction.

Child must be involved

The child must be **involved during the complete implementation**, to take the needs and preferences of the child into account and create a safe environment. The booklet helps to involve them during this process.

Introduction into classroom

The teachers preferred **open and honest communication**. The lessons were expected to be a good way to introduce the 'Humeur adviseur' to the class, which could result in interesting conversations.

Lifecycle

It would **depend on the child and teacher**, if the teacher would learn to understand the child without the product. The mother of the girl with the brain tumour said: "By [name daughter] you see it only a little, so I do not know if a teacher will be able to learn it at a certain moment."

6.1.4 How does the 'Humeur adviseur' and its implementation fit into the school system?

As observed the 'Humeur adviseur' was easy to integrate in a regular school day, only giving feedback by the teacher would be too time consuming.

Appearance

All participants liked the appearance. The colours were outstanding and catchy, which made the 'Humeur adviseur' **inviting**. The shape of the product is **positive** and something to be **proud** of. The size is perfect for at the table and in the drawer. The sturdiness of the product was doubtful.

Time

It was expected that the 'Humeur adviseur' would be too time consuming. It appeared that during the lessons both the teacher and children had enough time to use it. Giving feedback on the cards by the teacher would probably be **too time consuming**, however looking at the reflections it would be possible to do after school.

Moment of use

The envisioned use of the product **fits within the school context** and how children used it. It did not work to use the cards for all language and mathematics lessons. It became **boring** for the children and it was not felt as helpful for all lessons.

6.1.5 Discussion

Below an overview of the most important points of discussion can be found. These points could have influenced the reliability and credibility of the conclusion of the evaluation. An explanation of these points and their effect on the conclusion can be found in appendix V.

Participants

- It was **not possible to find participants within the target**. Participants as close to the target group and from multiple perspectives participated.
- The amount of participants was **low**.
- At last most of the participants participated before, due to which they were **biased**. On the other hand, since I was familiar to the participants they felt more **at ease**.

Context

- Parts of the evaluation existed of only interviews, due to which the **context of use was missing**.
- The user study was conducted with a class **without sick child**, due to which this context differed as well.
- The concept proposal is used for only a day within the class, however **long term use** is envisioned.

Research materials

- The prototypes of the product and the cards were **high fidelity**, due to which the interaction with the product could be evaluated with reliable results.

Questions

- The questions for the children appeared to be **too difficult** to answer for the children.
- A few of the questions were **biased**. For example: Would you or the child feel stimulated to think/talk about the child's feelings?

6.2 Recommendations

Based on the conclusion of the evaluation and the set requirements and wishes, recommendations are formulated. Below a list of the most profound recommendations is presented. Appendix W shows the complete list of recommendations with explanation.

6.2.1 'Gevoelens medaille'-product

Turning wheel: It should be indicated that the coloured circle must be turned instead of the yellow part on top.

Personalisation: Extra personalisation options should be added to help the children relate to the puppet shown on the product.

6.2.2 'Mijn les'-cards

Scenario of use: The use of the cards was too much during the evaluation. It should be evaluated if the new scenario of use fits the school context better, but still supports the sick child and teacher.

Involving the sick child: The cards do not support the child and teacher to create the planning together. The cards stimulate the child to be involved within creating the planning.

6.2.3 Implementation

Detail implementation materials: The implementation materials should be detailed to ready to use materials for a teacher. The materials should be clear and support creating a safe environment for the sick child to express himself.

Business aspects: The business aspects should be elaborated, such as an owner, financier, costs, distribution, and a business model.

6.2.4 Technical detailing

Material: The product can be made of PLA, which is a bio based plastic. It has a low density, high strength, and is easy to clean which makes it suitable for the product.

Production: Depending on the badge size the production technique can be chosen. For large amounts it is advised to use injection moulding. For smaller size, which is more likely, 3D printing is advised.

6.2.5 Future research

The concept proposal is evaluated, however with a lot of limitations. Extra and **more reliable research** should be conducted within the **targeted context** and with the **target group** to validate the concept proposal and investigate the effects of the 'Humeur adviseur'.

At least the following topics should be researched:

- Long term use
- Feeling safe
- Long term effects
- Experience in different situations
- Fits children with cancer the way of expressing

6.3 Reflection Concept Proposal

Throughout the project goals and requirements were set for the concept proposal. This subchapter presents the reflection of the concept proposal with regard to these set goals and requirements.

6.3.1 Design goal

The product/service should support the child with cancer to **express his emotional and physical state** and support the **teacher to create together with the child an individual planning** suitable for his current well-being throughout the day.

Express his emotional and physical state

The first part of the goal, support the child to express his emotional and physical state, is achieved by the **'Gevoelens medaille'**. The product **reminds** the child to express himself and **provides an easy and prose way** to this throughout the day. A safe environment is needed for the child to dare to express himself honestly. The implementation supports teachers in creating this **safe environment**, however this is highly dependent on the atmosphere at the school and in the class, and the capabilities of the teacher.

Create a individual planning together

The second part of the goal is partly achieved. The teacher is supported in creating the individual planning. The information from the **'Gevoelens medaille'**, together with the conversation about the booklet to discuss the preferences of the child, will give the teacher **guidance** in how to create a suitable planning. The **cards**, related to a lesson, support the teacher to look throughout the day how the child is feeling and adjust the planning for the next lesson. This makes it possible to create a suitable planning throughout the day.

The concept proposal **does not stimulate enough to create the planning together**. Teachers were positive about the possibility for children to add extra tasks, however it appeared that children did not do that until they were finished with the tasks of the teacher. This does not give the sick child the

feeling he is involved in creating the planning. To give the child the feeling the planning is created together, it would be possible to create the planning together during a short conversation or let the child fill out the tasks on the cards. This can be checked by the teacher.

6.3.2 Interaction vision

To describe the interaction vision the metaphor of **climbing a wall** was chosen. In this metaphor the climber represents the child, and the belayer represented the teacher. The interaction qualities were distance though personal, clear, guiding, and flexible.

Distance though personal

The interaction between the child and teacher had to feel distanced though personal. The distanced interaction gives the child the feeling he is independent and in control, and supports the child in taking the first step in expressing himself. However a personal interaction is needed for the teacher to create a complete understanding of how the child is feeling and create a relationship with trust. The distanced interaction is established by the **'Gevoelens medaille'**. The child is able to express his mood and energy level **indirectly** with the **'Gevoelens medaille'** instead of directly towards the teacher. As one of the participants of the evaluation said: "It feels anonymous." This makes it easier for the child to express himself.

The personal interaction is stimulated by the product and the cards by only providing superficial information, however is depending on how the teacher and child will use the **'Humeur adviseur'**. The product provides a **starting point for a conversation** about mood and energy level, the cards stimulate a conversation about the individual planning.

Clear

The interactions with and the purpose of the different parts of the design are tried to be designed self-explanatory. However since the system is rather **complex** and the use **open ended**, this was not entirely successful. This could be improved, however the open ended use may not be limited.

Guiding & Flexible

The 'Humeur adviseur' had to give guidance, however be flexible. The sick child needs guidance in expressing himself and the teacher needs guidance in creating an individual planning. Flexibility was needed to be able to address the different needs of sick children in different situations. The 'Gevoelens medaille' gives children **limited options**, however can be **interpreted in the way a child wants** to.

The teacher is guided by the **'Gevoelens medaille'** in which the child express how he is feeling. The booklet stimulates the child and teacher to **discuss how the child would like to be treated** by the teacher, and thus how the 'Humeur adviseur' will be used. This gives the product an open ended use, and thus flexible. Since the guidance is mainly **depending on the abilities of the child** to express himself and communicate the teacher could feel not guided enough by the concept proposal. However all teacher indicated during the evaluation that the 'Gevoelens medaille' on its own would already guide them.

6.3.3 Requirements and wishes

A list of requirements and wishes was created throughout the project. The most interesting requirements and wishes are used to reflect on the concept proposal.

The product/service should be able to adapt to or address the different needs of children.

As explained above, the 'Humeur adviseur' does not force one specific way of use. An envisioned way of use is communicated during the implementation, however within this envisioned use, the teacher and child are **stimulated it to adjust it** to their needs and preferences.

The way of **expressing is not possible to adjust**. It is expected that not all children will prefer this way of expressing themselves.

The product/service should give the child the feeling of control by involving the child in creating the individual planning.

As explained above the sick **children do not feel involved** in creating the individual planning, and thus do not have a feeling of control when creating the individual planning.

Other parts of the concept proposal do give children a feeling of control. **The child for example gives the teacher the 'Humeur adviseur'** which gives the child the feeling he has chosen to use the product. Within the implementation the child is **involved in discussing** how the product will be used and introduced. During the used, the child can express himself whenever he wants.

The product/service may not disturb the regular school experience of the child with cancer.

The 'Humeur adviseur' fits in school context, responds to the trend and developments, and gives the child the feeling treated equally.

The appearance of the 'Humeur adviseur' is **in line with other products** used within the classroom and looks appealing due to the bright colours. The content of the cards contain **similar elements** as already used, such as the defining the goal of a lesson.

The cards **make learning visible and stimulate differentiation**, which are two main trends.

Since all children use the cards, the sick child will not feel treated differently. The sick child works on the **same goal** as his classmates, however by performing less of different tasks.

The 'Gevoelens medaille' is only used by the sick child. This could give the sick child the feeling he is treated differently and thus disturb the regular school experience. However the product is presented as positive **object to help the teacher** understand the child, it is expected it will have a positive influence on the school experience.

The product/service stimulates the child to create a new normalcy.

Cancer is life disruptive. Therefore a child (and his family) should create a new normalcy. The school context is one of the contexts which changes the least. Nevertheless a wish was to stimulate children in creating a new normalcy. Within the school context the 'Humeur adviseur' is a **contemporary tool** to help creating the child and teacher together an individual planning, which must become the new normalcy for the sick child and teacher.

Furthermore the sick child is **stimulated to use emotional-focussed coping strategies**, such as talking about mood and energy level and taking control. The positive influence on these strategies can be used in creating a new normalcy in a different context as well.

6.3.4 Desirability, feasibility, and viability

The 'Humeur adviseur' was perceived as a **useful tool** for both the sick child and the teacher. The advantages clearly outweighed the possible disadvantages.

Especially the 'Gevoelens medaille' could be immediately be used, the cards have to be optimised to **make the practical use more efficient**. The participants of the evaluation were all willing to use the 'Gevoelens medaille' and the 'Mijn les'-cards.

Before the product can be put on the market the implementation should be detailed. The introduction of the 'Humeur adviseur' exists of many steps, which makes it **complex**. Next to this, it is envisioned that children will receive the 'Humeur adviseur' for free. The roughly estimated **costs are too high** to find a financier. The business part should be further explored and optimised

6.4 Reflection Project

Before the project started the aim and goal of the project were formulated as presented in chapter 1.1. This subchapter reflects on this aim and goal.

6.4.1 Aim of the project

The aim of the project was to research how design can contribute positively to the school experience of children with cancer during the treatment phase at primary schools.

Opportunities

During the literature and field research challenges related to the school experience which could occur were identified. Based on these challenges I choose the focus of this project, however many more opportunities could be formulated to contribute to the school experience. Three of the most interesting opportunities are discussed below.

Enhance the empathy of classmates and teacher

As discussed in the analysis (chapter 2) sick children do not always get empathy for their situation. Especially when the cancer is less visible, since people forget the impact it still has on the sick child. This could result in feeling lonely, misunderstood, and insecurity.

Design could contribute in **creating awareness and understanding** to enhance the empathy.

Support acceptance

The symptoms and side effect of the cancer and its treatment negatively influence the physical and cognitive abilities of a child. Especially within the school context the child will be aware of his limitations, since the child is not able to participate in all activities and he will compare himself with his classmates. Some children have difficulties in accepting these physical and cognitive limitation, which result in a frustration, a negative self-image, and stress.

Design could **empower the child in accepting** his physical and cognitive limitations and embrace his abilities and the new possibilities.

Guide teachers in supporting the sick child (and siblings)

This project focused on supporting the teacher in creating an individual planning for the sick child. However teachers indicated to miss guidance and support in taking care of a sick child and siblings. Siblings are affected by the cancer and its treatment as well, however is often forgotten by schools. Due to the guidance teachers miss, some sick children or siblings, are minimally supported by their teacher.

By **giving teachers tools to support the child**, the overall school experience of the child will be positively affected.

Guidelines

To create a positive contribution by design, guidelines were formulated. The following paragraphs discuss the two most important guidelines

Design to keep or create normalcy

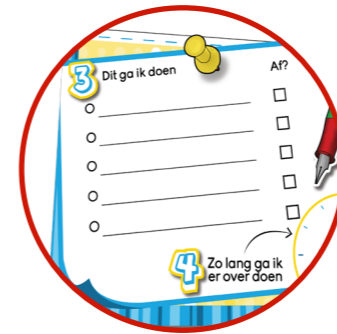
A product/service for a sick child should empower the child to keep normalcy or create a new normalcy. Since cancer is life disruptive, sick children and their family have a need for normalcy.

Design from the perspective of the child

The impact of cancer and its treatment is impossible to understand. Next to this, children cope differently with the situation than adults. Therefore a designer should design from the perspective of the child. Within the project it was not possible to involve sick children or survivor, which made it difficult to design from their perspective.

6.4.2 Goal of the project

The goal of the project was to design a product and/or service that improves the psychosocial school experience of children with cancer and the people around them during the treatment phase. In figure 57 four improvements on the psychosocial school experience established by the 'Humeur adviseur' are explained.



Working on own level

Due to the 'Humeur adviseur' the teacher creates for each lesson an individual planning, which can be adapted by the child. This helps in not under-, nor underestimating the sick child which results in **self-confidence and a more positive self-image**.



Stimulating emotional-focussed coping strategies

The 'Humeur adviseur' stimulates the child to use emotional-focussed coping strategies by offering an easy way to express himself. This helps the child to **accept the situation** and be able to participate at school.



Empathy of classmates

The sick child shows his mood and energy level to his classmates as well. By expressing this, the classmates could create empathy towards the sick child, due to which the child feels **understood and supported**.



Guidance teacher

The 'Humeur adviseur' provides guidance for the teacher in taking care of the sick child. This helps the teacher in understanding the needs and offering the needed support to the child. The teacher will feel more **confident** in take care of the child.

Figure 57: Improvements of the psychosocial school experience established by the 'Humeur adviseur'

7 References

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