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Chapter 1 - Childhood Cancer

550 children get diagnosed with cancer in the Netherlands each year. Their treatment takes place in one of the 7 academic hospitals. There is a special child oncology department in these hospitals. The NKOC is going to combine all these child oncology departments into one hospital. This new hospital will open in 2015.

Chapter 2 - Eating with Cancer

The cancer treatment has a big impact on the food-intake of children. They get a lot of side effects from the medication that discourages them to eat. Many of them get nasogastric tube feeding (NGT) at one point or Nutrini drinks to keep them from getting malnutrition.

At Dutch hospitals it is now a custom to order dinner early in the morning. There are no special menu's for children. The order gets served by a nutritionist.

Besides the nutritionist there is a dietician at the department. She makes sure children do not get mal fed.

Teaching assistants have educational materials to get children to eat but they mainly focus on stopping parents and children stressing about food.

Teenagers were interviewed about eating with cancer. They explained that they would do anything to not get an NGT. Their motivation to eat is very high, still hardly any manage without any NGT.

Four problem fields were indicated from this research and they were made into four design directions.

Chapter 3 - Vision and ideas

With the help of five criteria a final design direction was chosen: My taste profile. A metaphor was made to illustrate what kind of future interactions the design should have.

Go treasure hunting.

Combined with the five criteria the future vision became:

The product should enable children and their family to rediscover the fun in eating, that the sick child lost due to cancer treatment. It should be a challenging activity that is even something to look forward to on a boring hospital day. And in the end, it should have a fulfilling outcome.

Two ideas were chosen to paper prototype and shown to parents. There opinions were used to come to a final concept, a merge of the Taste Toolkit and the Hero on Socks game.

Chapter 4 - Final Concept

The final concept is called “Proefmonster”. It is a hospital food application that incorporates a personally adapted menu, a personal eating profile and a game.

For this game the patient can order a free Proefmonster every day. This Proefmonster is a possible new inhabitant to a personal city that is protected by themselves, or at least their hero alias. The monster gets served together with their dinner. They taste the sample, open the game and indicate whether they liked the flavour or not. If they liked it they receive a new monster villager, if they do not like it they receive a “monster in sheep clothes”.

These monster villagers can be played with. Their houses can be visited or the user can play with the corresponding augmented reality card that came with the Proefmonster.

A monster in sheep clothes can be traded in for cool gadgets to improve your own hero character or they can be saved to be tasted again later.

The sheep can also be played with in AR. Putting two cards together gives surprising interactions between characters.

Chapter 5 - Prototyping

A prototype was made of the concept and a user test was performed with the target group. The children were very enthusiastic about the idea. Their interest however were different. One child liked the idea of getting a city and visiting houses and the other child wanted to play with his monsters.

The game was not yet social enough. It is recommended that children have to visit each other to play with their monsters, they will get unique rewards.
Preface

This product falls within the Medesign research portfolio of the TU Delft, faculty of industrial design engineering. It is a graduation assignment of the Master Design for Interaction.

This graduation is part of a research project for the Nationaal Kinderoncologisch Centrum (NKOC) and more graduation assignments and courses within the TUDelft contribute to this project.

Aknowledgements

There are many people I would like to thank for helping me in this graduation project.

First of all my supervisory team. My chair Walter Aprile. Walter thank you for your many good advices and your attempts of pulling me out of my shell every now and then and your inspiring stories.

Thank you Priscilla for your being critical, helpful and enthusiastic. Thank you also for helping me "chop some knots" every now and then.

Mum thank you for listening to me on the phone every day walking back to the train. Thank you also for your endless patience and your ability to listen.

Dad thanks for all the support, for not giving up on me ;-) and for being proud of me.

Many thanks also for the staff at the hospital.

Huib Caron thank you for helping me get started, for your criticism and enthusiasm.

Thea Spierings, thank you for the very inspirational talk and the lovely evening.

Prof E. Kampman, thank you for seeing me. It was really great to hear your side of the story food and cancer. It was really different from anything anybody told me before. It was quite an eye-opener.

Tijmen, thanks for showing what great things can be done to food and the ideas about how this could be interesting for children.

Helma van Rijn, thank you for your advice on doing research with difficult target groups.

Furthermore I would like to thank the parents and children (T, G, S, A, L, W, L, D, B, J, P, E.) that talked to me at the hospital. You were great and you honesty has been valued greatly. Especially A, thank you so much for your enthusiasm during the interview and filling in my booklet with such precision. I wish you all of you the very best.

Last but not least I would like to thank my friends.

Sophie I could not have done this without you. You really are the best. Teaching me to talk about my ideas and not be embarrassed.

Moniek v thank you for being the voice-over in the movie.

Marieke Bakker, thank you for understanding. We started off together and together we finish. And you know, as long as there is doubt, you cannot find the way.

Thanks to Carmen and Gwan for overcoming my doubt about this graduation assignment. You were right.

Rinze thank you for reading some of my chapters and for letting me get fries.

Fellow graduates thank you for our discussions and your valuable tips and tricks: Lieke, Maarten, Linus, Frank, Laura, Piet, Tim, Hilde, Lot, Frank, Sandra and Aurora.

Suzanne thank you for also seeing me at AMC when Monique was on holiday. I know you were very busy and still you made time.

Nutritionis thank you for letting me follow you around all day long and explaining everything that went on in the department kitchen. I really got a good inside look!

There were also a lot of experts that helped me that had nothing to do with the hospital.

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Introduction

Each year, about 550 children aged 0 to 18 years old in the Netherlands are diagnosed with cancer, making it the most common cause of death for children. Child oncology in the Netherlands is about to take the next step towards specialized care in the National Child Oncology Centre (NKOC), in order to make the chances of survival grow drastically. This centre will accommodate about 90 children and their caregivers every day.

Problem definition

Most children suffering from cancer will experience problems with eating and drinking at some stage. This can be due to the disease itself, its treatment or medication. Sometimes the taste of food seems strange and food can be difficult to swallow or digest. Often the children just do not feel hungry or prefer meals the parents bring. These problems can be short term or may last all throughout treatment.

It is important that a child eats well, because a well-nourished child is better able to cope with their treatment and fight potential infections. It will also help a child to feel better and keep up their strength. Many parents worry about the diet of their child before, during and after treatment. For some families, food and diet therefore becomes a great source of stress and anxiety.

Assignment

Creating new eating experiences for children with cancer during hospitalization. The experience should aim at making food fun as well as accommodate to specific health problems that affect appetite. Continuation of normal daily routines within the hospital environment is an important aspect of the experience, as meal times are important moments for families.

This report

This report will illustrate how this problem definition and assignment led to a solution that fits the needs and requirements.

The first chapter is the exploratory research, it is general information about childhood cancer. It explains the context in which the product will be used, the child oncology department in the hospital, the educational materials available here to explain the disease and treatment to children and some information about the company, the NKOC.

The second chapter is the analysis phase. It explains the specific eating problem and several experts were consulted to gather information. This chapter ends with four design directions that came from the analysis.

The third chapter explains the journey from design directions to concept. This is done mainly by thinking about the future context, what is the ideal situation here? What metaphor can be used to explain this situation and what product vision follows from this? Two ideas were chosen to present to parents and with their feedback a final concept was created.

The fourth chapter explains the final concept. Why were certain decisions made and how does the product work. Furthermore thought has been given to the NKOC, what will the product mean for them.

In the fifth chapter the concept was tested by presenting the target group with a prototype of the design. This user research again resulted in recommendations.

Finally I evaluated on this graduation assignment. How do I look back, what went good and what can I work on in the future.

Appendices can be found on the accompanying CD-rom.

The basic structure used for this design process is the “basic design cycle” described in Roozenburg en Eekels, Productontwerpen, structuur en methoden (Product design, structure and methods, 1998).
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In this first chapter the broad context of this graduation project will be illustrated. How many children are diagnosed with childhood cancer in the Netherlands each year, what does the treatment involve, where are they treated, what are the physical effects for the child and what materials are there to help them understand everything that is going on? In the second paragraph the client, and the contribution that industrial design engineering can provide, will be further explained.

§ 1.1 CHILDHOOD CANCER

- Statistics
- Treatment
- Hospital
- Physical effects
- Educational materials

§ 1.2 NKOC

- In general
- Opportunities
Creating New Eating Experiences for Children with Cancer

To get a better understanding of the project a concise explanation of childhood cancer is given in this paragraph. The main focus is on the time spent in the hospital during treatment because this is the context that has the main focus of this graduation project.

1.1 Childhood Cancer

Statistics from the Netherlands

Around 550 children in the age of 0-18 are diagnosed with cancer in the Netherlands each year. These cancers can be clustered and divided into 9 groups. Over half of these children have either leukaemia or a brain tumour. (See figure 1)

The childhood cancer age deviation is as follows:

0-2 years old: 26%
3-5 years old: 21%
6-11 years old: 26%
12-18 years old: 27%

Over 70% of these children get cured, meaning the cancer never comes back.
For more specific statistics on Childhood cancer, see Appendix A.

Reasons for hospitalization are:

- Chemotherapy
- Radiation (normally this is day-care)
- Surgery
- For observation due to complications, for instance infections that could be potentially very dangerous.

The length of stay varies from mostly a day, to a week or even months.

On average, the treatment for childhood cancer takes 1 to 2 years. A lot of this time is spent in the hospital by the child as well as the caretaker (in most cases, a parent). This time in the hospital is either for day-care, where no overnight stay is needed, or hospitalization, where at least one night is spent in the hospital.

In general most child oncology departments in the Netherlands currently have space for 10-20 children at a time. The arrangement of these departments is more or less the same. There is a hallway with several rooms in it (see figure 2), a ward, a kitchen (not to be used by parents or children), a parent room, a play room, treatment room and a staff room.

The hallways are used by the children to drive toy cars or ride bicycles as a playing activity. Usually followed closely by a parent, carrying the IV pole.

To make the hospital room where the child is staying feel as safely as possible, most painful and bothersome procedures like: injections, inserting the nasogastric tube, removing of bandages, or puncturing the Port-a-cath are taken care of in the treatment room (see figure 3). There are things in the room to distract the child. Sometimes a DVD can be played above the bench, or there are stuffed animals for the children to cling on to.

Figure: 1. Deviation of types of child cancer in the Netherlands

Figure: 2. Hallway of child oncology department at Emma childrens hospital AMC

Figure: 3. Treatment room of the child oncology department at Emma Childrens Hospital AMC
Creating New Eating Experiences for Children with Cancer

Patient room

Children with cancer have their own department in the hospital, child oncology. No other children will be admitted here. These departments have two different types of rooms, a ward (see figure 4) or a single patient room (SPR) (see figure 5). In most hospitals, SPRs are only used for children that are in isolation due to their low resistance to infections. Every room has one bed for the patient, a stretcher or chair-bed for the caretaker, a chair to sit on for the caretaker, a television and an IV pole for the patient. There is a toilet and shower per ward/SPR but this is not supposed to be used by parents. There is a table that can be placed over the bed for whatever purpose (see figure 4).

Play room

The fun room of the department is the play room (figure 6). This is a room filled with toys that entertain children on long and boring hospital days. Naturally this room is mostly used by small children that are, at that point, feeling fit. Being in isolation however means no use of this room can be made unless a reservation is made. This because these children have to kept away from other children.

Parent room:

In most cases there is a room for the parents on the department, sometimes financed by the Ronald McDonald fund. This is a place where they can withdraw if they would like to, get some coffee, put personal food in the refrigerator, watch television, talk to other parents privately or heat up their own dinner in a microwave. (Figure 7)

Physical changes for the child

Due to the treatment, children with cancer do not only feel very sick, they start looking really sick too. They turn pale, skinny or bloated, get hollow eyes and they lose all their hair. Many of them also have a tube in their nose and a sticker on their cheek, due to nasogastric tube feeding and their inability to eat.

Because they start looking different they get stares from people. Girls will be mistaken for boys because they are bold, and other children might bully them or ask a lot of questions.
Creating New Eating Experiences for Children with Cancer

For children with cancer it is quite important that they understand what is going on with them. To help them to understand everything that is happening to them, as well as being able to explain it to their friends. But how do you explain this complex disease and the even more complex treatments to children? To help with that there are specialized teaching assistants and several educational materials.

**Paultje en de Draak**

To explain a solid tumour, there is a silent movie called: “Paultje en de Draak”. Paul gets hospitalized for a Wilms tumour (dragon in his kidney, figure 8) and is fighting this, with all its setbacks. Illustrated from the fantasy of a child. (Stichting Il Lustre Films 2008)

**Chemo Kasper and Radio Robbie**

To explain chemotherapy and its side effects there is a storybook called “Chemo-Kasper en zijn jacht op de slechte kankercellen” (Chemo-Kasper and his hunt for evil cancer cells) and in the same series there is Radio Robbie to explain radiation therapy (figure 9). (Motzfeldt 2001)

**Kanjerketting**

Focussing on how to explain all the things you have to go through to your friends, classmates and family, there is the Kanjerketting (hero chain, figure 10). For every procedure done, and other special occasions there is a special bead. In the end, resulting in a meters long chain of everything a child went through. Every single child from 4-18 likes this and knows the meaning and history of (almost) every bead on their chain.

---

**Educational Materials**

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In this graduation project an advice is given to the board of the NKOC. In this paragraph concise explanation of the plans of the NKOC and their objectives will be given.

### In general

The National Centre for Child Oncology (NKOC) will be a specialized hospital that is going to centralize all child oncology treatment and knowledge in the Netherlands.

The NKOC has clear objectives:
- A cure rate of over 90% in 2025, by developing new treatments and reducing deaths from treatment side effects.
- Reducing Late effects of treatment by improving the treatments, so that in 2025 less than 50% of survivors has to deal with health problems.
- Give children who can not be cured and their families the best possible support.
- In 2020: having the best children’s cancer research in Europe and being amongst the five best children’s cancer research institutes in the world.
- By 2020: have an internationally recognized advanced training in paediatric oncology, and an advanced training for children’s oncology expertise for other specialities for the Netherlands and abroad.

The NKOC is designed to contribute to the best possible comprehensive care for children with cancer. Children are developing into maturity, a development that continues even if a child is sick. The building is in service of the children’s development and the needs of the family.

In addition, the building will be designed for multidisciplinary teams to take care of children and families in the most effective working environment.

### Departments

In the NKOC the care is placed into three specialist units. Each unit is organized around the nature of the child cancer:
- **Unit HO** hemato-oncology (including leukaemia and lymphoma)
- **Unit ST**: solid tumours (including tumours of kidney, liver, bone and muscle)
- **Unit NO**: neuro-oncology (inter alia brain tumours)

Each unit consists of three components of care: clinic, day treatment (DBH) and polyclinic.

According to child cancer statistics the distribution of patients amongst the departments will be:
- **Unit HO**: 42%
- **Unit ST**: 35%
- **Unit NO**: 23%

The NKOC will not have wards like the current children’s hospitals, because research commissioned by the centre showed that parents and children much prefer a private room. In these new and improved SPRs there will be room for the parent and patient to live and sleep comfortably.

### Opportunities

The big advantage of building a new hospital from scratch is that it can be arranged completely by modern standards. On top if this it can be furnished and organized in revolutionary ways. In cooperating with the faculty of Industrial Design Engineering (IDE) ideas will be proposed from an other than medical perspective. Especially in the field of “being in service of the children’s development and the needs of the family” big leaps can be made.
This chapter gives an overview of the analysis done about the combination of children, eating, and cancer. As shown, there are many different aspects that play a part in this subject and there are many different stakeholders.

§ 2.1 EATING AND CANCER
- Physical effects
- Psychological effects

§ 2.2 EATING IN DUTCH HOSPITALS
- Food staff
- Nasogastric tube feeding
- Nutrinidrink

§ 2.3 DIFFERENT PERSPECTIVES
- Dietician
- Child oncologist
- Professor Food and Cancer
- Teaching assistant
- Parents
- Teens

§ 2.4 INPUT FROM TEENS
- Internet research
- Interviews

§ 2.5 PROBLEM FIELDS
- Overview
2.1 Eating and Cancer

To determine the challenges children might encounter with eating during their cancer treatment, a literature research and expert interviews were performed. In this paragraph, first the physical complaints caused by medicine side effects are explained followed by the psychological factors that influence the experience of eating while being hospitalized.

**Physical effects**

When treated with cancer patients are exposed to many different types of medication and treatments. Different types of chemotherapy, radiation, hormones, you name it. These medicine all have their own corresponding side effects, so one can imagine the side effect roller coaster these patients are on. The most important side effects that influence a patients food intake are listed below:

**Loss of appetite**

“There was also a chip shop where we could get some tasty food. Me, I didn’t eat anything because I did not have any appetite. Today I will survive on one pink cake, cola, some candy and a few slices of grilled sausage. My mum says this is not enough but I really do not feel like eating and nothing tastes good…. Sometimes I just get tired by everybody offering me food/drinks. I know they mean well but I just don’t feel like it.” (Akker 2008-2011)

Many patients suffer from a loss of appetite, sometimes with a very specific reason but a lot of the times because there is just no appetite.

**Oral mucositis**

Mucositis is a painful ulcerative condition of the oral cavity and gastrointestinal tract, occurring in association with chemotherapy and radiotherapy regimes. (Berry, Corfield et al. 2011) Depending on type of cancer and its treatment, the percentages of children suffering from oral mucositis vary between 30-100%. R0(Davies and Epstein 2010) It generally means having a sore mouth and throat, with all its consequences. (Figure 11)

“In the evening, when we are sitting downstairs, we can hear her moaning and crying. She really has a terrible pain in her throat, even a sip of water is unbearable. Guys, this is only chemo 1”!! (Marlies 2011)

**Dysgeusia**

Dysgeusia is a common oral side effect of cancer therapy (radiotherapy, chemotherapy, or combined modality therapy) and often impacts negatively on quality of life. Dysgeusia is variably defined as an abnormal or impaired sense of taste, an unpleasant alteration of taste sensation, or a distortion or perversion of the sense of taste.

“As soon as she puts the bun in her mouth her face falls and the bun gets put back on the plate. This also happens with pancakes with extra butter and powdered sugar, bags of crisps, fries, sausages and everything we try to let her eat. The same thing happens with drinks. Every time the same sad little face.”(Marlies 2011)

From the current literature, there does not appear to be a predictable way of preventing or treating dysgeusia. (Hovan, Williams et al. 2016)

**olfactory changes**

In a Swedish study (Bernhardson, Tishelman et al. 2009) executed with 518 patients, 49% reported smell changes. They provide examples of how patients receiving chemotherapy could describe smell changes as unpleasant or as an increased awareness or sensitivity, with no patients reporting decreased sensitivity to smell. The consequence is often that “the wrong smell” can make a person feel sick.

“Her sisters have to wash their hands if they’ve eaten cheese and onion crisps... [and] the smell of marmite woke her up and made her feel and be sick.” (Gibson, Shipway et al. 2011)

**Germ Diets**

After certain chemotherapies the body has decreased resistance because the white blood cell count plummets. On top of this, because the intestinal lining can get damaged (mucositis) bacteria to enter in the bloodstream more easily. At this time the child receives a “germ diet” prescription. This means avoiding as much sickening bacteria, yeasts and fungi as possible. In addition, some storage and preparation recommendations are observed. B1(AMC/Dietiek/Kinderoncologie 2011) executed with 518 patients, 49% reported smell changes. They provide examples of how patients receiving chemotherapy could describe smell changes as unpleasant or as an increased awareness or sensitivity, with no patients reporting decreased sensitivity to smell. The consequence is often that “the wrong smell” can make a person feel sick.

“Because now I am on a germ diet, no beschuit met musjes [dutch delicacy celebrating birth], but vanilla slices from the freezer. Yum!!” R1.5(Brussel 2010)

**Craving**

Associated with the use of prednisone (steroids) is a craving for food. Especially children suffering of leukaemia get high doses of these drugs during long periods of time.

“On our way home we give M. a phone call to ask her to preheat the sandwich maker. H. is very hungry and wants 10 grilled cheese sandwiches. In the end he ate 5 easily and a slice of rice cake with spam. Our next challenge will be to eat less and more healthy...” (Remkes 2011)

**Nausea**

Nausea as a side effect of medication or as a cancer symptom.

“The amount of food/drink he can keep inside is little. Yesterday he was really looking forward to the lasagne he was going to have. When he finished it last night (great, it’s in!) the next thing he did was throw up again…… To had, an empty stomach again.” (Akker 2008-2011)

**Psychological effects**

**Learned food aversions**

Learned food aversions can be allocated to psychological causes. They are said to develop towards food or snacks that had become distasteful or had been consumed in close relation to chemotherapy that was followed by nausea.

“Once I ate ice cream after I got my chemotherapy. After that I had the medicine, I felt nauseous and vomited, so I can’t eat ice cream any longer.” (Skolin, Wahlin et al. 2006)

Eating after cancer treatment

Because a child that suffered from cancer experienced an abnormal eating pattern for at least a year (generally 2 years), their eating behaviour might be changed for good. Background Childhood cancer survivors (CCS) are at increased risk of complications such as obesity, diabetes, and osteoporosis. R5(Cohen, Wakefield et al. 2011)
2.2 Currently in Dutch Hospitals

In this paragraph an explanation is given about how food services are generally arranged in Dutch child oncology departments. This information is gathered by visiting three of these departments and asking different people how things are organized.

Food staff

At all three hospitals visited, regular nutritionists are assigned to the child oncology department. This means the children and their family get to know and recognize this person. At AMC and Radboud these nutritionists are present on this department during the whole day. They have their own “kitchen” where you can get drinks or cold snacks all day long. At Erasmus a fixed nutritionist visits the department a couple of times a day to check if the children want anything.

At AMC there is a kitchen with a table and chairs for children to sit down and eat. There is also a nutritional assistant that makes sure there is coffee and tea for the parents. She hands out the menus, takes the order and prepares the steam meals in the kitchen (figure 12). There is an unlimited amount of fruit and packaged snacks.

Children that have problems with eating will also talk to a dietician. She makes sure there are solutions for problems they might encounter. In some cases she guides parents to deal with strict diets or makes appointments with children about their weight. If they have a sore mouth she might prescribe Nutridrink (or as some children call it, astronaut food).

Meals

Breakfast

At all hospitals the nutritionist will pick up a filled in form early in the morning that states what the child wants to eat for breakfast. Normally they can choose between white or whole grain bread, how many slices, gingerbread, crackers, spreads, etc. She will prepare the plates and ask them what they want to drink with it. At UMCN Radboud you can also order croissants a day before and here, the present caretaker is offered breakfast too.

Lunch

Lunch is done almost the same way as breakfast. There is no caterer involved but the nutritionist makes sure the kitchen is supplied with all sorts of products. Bread, crackers and spreads but also microwave products like sate, omelette or hotdog sausages.

Dinner

At Erasmus, dinner is delivered to the hospital by a caterer. At dinner time a nutritionist visits the children with food they scoop up at the bed side. This personal approach is the way to get the child to eat according to educational staff member N. van Wageningen:

“Because the nutritional assistant visits them personally, asks them what they want and scoops up small portions, the children don’t get a plate full they cannot finish in front of them. They also tell them “Don’t you want to try a little bite of this?” in a positive way you know?”

At AMC there are five different menus interspersed over a period of two months (see figure 13). There is a choice between:

- three types of meat, two fish, one poultry, two vegetarian or one halal meal.
- two salads (figure X) or sandwiches, they are the same every day.

These meals are heated in the microwave at the department by the nutritionist and brought to the bed of the child.

At UMCN Radboud it works the same only the offer is a bit more extensive. Children can choose between menu’s or pick their vegetables, meat and, for instance, potatoes separately.

Snacks

At Erasmus they have a system called “wensdiët” (diet wishes) where the children can choose what they want to snack from a menu. They can also order any snack they would like (grilled cheese sandwich, fries, hamburger, et cetera), since they are prepared at the central hospital kitchen. They do have to order in the morning what they would like to have in the evening.

At UMCN Radboud they have a similar system called “top-30” where snacks can be ordered in the morning and served at dinner time. This is offered every other day. At AMC this is possible on Sundays.
Parents

The caretakes stays at the oncology department all day but they can not order food. There is a small room for parents where parents have access to a coffee machine, a sink and a microwave. They are able to bring food from home for themselves or their children, but the latter is not recommended:

“It does happen, but generally they prefer the children to eat the hospital food. Because you never know with the hygiene and everything. You transport it and you have to heat it up again, well there are some risks involved.”
(N. van Wageningen)

At most hospitals there are no arrangements for the parents. At Radboud one parent is offered breakfast but at the other hospitals this is not intended. Some parents order a lot or bread for their child to eat it themselves but this is considered very inappropriate by the nutritionists. It is not allowed.

Parents

Even though there are initiatives like “diet wishes” and children are given the opportunity to order any snack they fancy in advance, nasogastric tube feeding is introduced quickly in all the hospitals. As N. van Wageningen puts it:

““You cannot force a child to eat, and malnutrition is very undesirable. So it is done in precaution. We want to make sure they take their medicine and food and because we cannot battle for it every time, this is the least stressful way.” (N. van Wageningen)

She does admit the children do not really like it. Inserting the tube is very uncomfortable and children do not like the way it looks:

“There are children that hate having nasogastric tube feeding. They don’t want to go to school because they are embarrassed.” (N. van Wageningen)

At Emma Childrens Hospital they also introduce nasogastric tube feeding quite easily. Asking Prof. dr. H. Caron, child oncologist about this he responds:

“Yes, I am not sure it is a good thing we do that. There is even more stress and more fixation and stigmatization because you get those patches on your cheek.”(H. Caron)

Having an NGT does not mean you are unable to eat. It is still possible and many children still enjoy an ice-cream or hamburger every now and then. But, for many parents the NGT means they do not have to worry about their child’s eating pattern.

Nasogastric tube feeding

Nutrinidrink

Due to the intensive treatment the children are exposed to, their bodies need extra nutrients. If they are not on NGT feeding but they have trouble eating, another source of protein is often provided “Nutrinidrink” (1-12 years old) or “Nutridrinks” (>12) are often prescribed. There are different types for different needs (figure 16).

Nutritional information Nutrinidrink per bottle (200ml):

Energy 1260 kJ / 300 kcal
Proteins 6.8 g / 9%
Carbohydrates 37.6 g / 50% of which lactose <0.04 g
Fats 13.6 g / 41%
Dietary Fiber - g

As can be seen, these drinks contain mainly protein and energy.

Sometimes these drinks are used as a total replacement for a normal diet.

Conclusions

When hospitalized for cancer treatment a child generally eats dinner alone at 5 o’clock. This dinner has been ordered in the morning or it is scooped up at the bedside. It is prepared by a caterer, reheated in the hospital and distributed amongst the patients by a nutritionist. The children eat in bed. A little table can be placed over the bed and the dinner tray is placed on there. While eating most children watch television. None of the hospitals visited had dinner arrangements for the parents. Meaning they have to bring their own food or buy something from a store or restaurant near the hospital. There is no kitchen on either of the departments where food can be prepared, only a microwave for reheating. Because children with cancer have so much trouble eating a lot of them get NGT feeding or supplement drinks at some point of their treatment.
2.3 Different Perspectives

Different stakeholders have different perspectives on why a child does not eat and what could be done to help them and their families. These different perspectives on what is best for them mainly originate from their different knowledge and experience. In this paragraph these different perspectives are illustrated using the words of the different parties involved. (Figure 18)

Dietician

The two main activities a dietician in the child oncology department gets to do on a regular basis are:

1. Explaining and answering questions about (germ) diets to parents and patients.
2. Finding suitable solutions for health issues concerning nutrition. For instance, protein rich food, supplement shakes or nasogastric tube feeding.

As long as a child is capable of eating and is actually eating, no advice needs to be given but in many cases problems start arising at one point or another. Solutions to these problems differ for two different groups of children: under the age of 10 (from now on I will call them children) and teens.

Children

For children the most important reasons not to eat, indicated by the AMC dietician, are:

1. Nausea.
2. Use food as a means of power

In the first case there is not much that can be done. Medication can be given to reduce nausea but everybody can imagine why a child would not eat when they feel nauseous. The dietician stated that efforts are done to convince children it is not the food that makes them vomit but the chemotherapy. But of course food is the thing coming out of their stomach and food aversions start to arise.

In the second case there is more that can be done. For some children rewards are given if they actually eat, indicated by the AMC dietician, are:

• If there would be space to eat together
• If the food looked more like childrens food
• If there would be space to eat together

Child oncologist

There is a big fixation on nutrition. As well from the medics point of view, as from the family of the child. The medics want them to eat healthy so they stay strong, and on their turn parents think “Ohh, this kid needs to eat, and eat more, and healthy!” You can try to change the ways of the family for them to cope better, but you can also relief them from causes of stress. Now at AMC, we use NGT feeding, but this might not be the best way. NGT feeding also causes stress and stigmatization due to the stickers on your cheek. Another way would be to make a hole directly in the stomach because it is hidden underneath you clothes. But making this hole and the risks would also cause stress.

Professor Food & Cancer

The fact that children get a “weight ultimatum” does not make any sense according to Ellen Kampman, Professor Food&Cancer. In this way you are making children eat as many calories as possible to make sure they do not lose weight. Maybe it prevents them from loosing fat, but what about muscle? That is way more important. It should be measured if they do not lose too much muscle or bone structure and that is what should be addressed. Also a varied diet is very important. Your body might have reserves, but you never know what happened before somebody got treated for cancer, did they eat healthy then? It really should not be stimulated that children eat pasta with cream sauce everyday so they keep their weight.

Teaching assistant

There is not much discussion with children about eating. The change of taste perception due to chemotherapy might be mentioned but there are just not a lot of children that eat. Almost every child has an NGT because, according to the teaching assistant, they cannot do without. It also helps the children with taking medication. An NGT also does not prevent you from eating yourself and everything that goes in is a bonus, but parents are relieved from the continuous eating battle. A battle that you cannot win from a child that does not want to eat.

Not all children like the NGT. Inserting the tube is very uncomfortable and they are embarrassed because it is really in your face. They do not want to go to school anymore. Some older children refuse the NGT but they seldom manage on their own. The resistance to food is just too big, just by the smell alone. The sense of smell increases as their taste decreases, it just hits them.
For parents, the eating behaviour of their child is a measure of how well they are doing. They blog and Twitter about it (figure 17) to illustrate to others how their child is feeling. Family B. (T1 2011) for instance wrote:

Really just got back from the recovery room 3 minutes ago!! She finished the pancakes, now a sausage roll! (T1 2011)

At almost any blog or Twitter account from worried parents, reports about food are placed. Especially in the beginning of the treatment, because in a later stadium the child often has an NGT, meaning there is less talk of food. Still, if a child eats well, the followers will be notified.

The nutritionist at AMC does not talk much with the children. For a big part she is ignored and not always given a warm welcome when she enters the room. People are not interested in her name. Bringing the food in, people do not look at her and she is told to put the food somewhere in the far corner. During the day parents drop by her kitchen to get coffee or tea or to get something to eat for their child. Bread, prepackaged snacks, fruit and drinks are available all day long. Sometimes the children themselves come asking for something. The nutritionist noticed that children are more prone to accept and eat a snack or drink from here if the parents are not present in the room at that time. The nutritionist has a lot of knowledge about the menu that cannot be found anywhere else. For instance she knows which meals are tasty and which are not. She also knows what meals and products fit into what diet and she probably could mean a lot more to the families if they would consult her every now and then.

The different points of view shine different lights on the situation. There are different opinions about what a child should eat. Anything (dietician) or balanced (professor food&cancer). The NGT is to make sure a child does not get malnourished, but is this the best way? And what happens if a child refuses? Medically this seems to be where the biggest problem lies. Teenagers especially, refuse an NGT and start eating only calories to keep their weight up, but these foods do not always contain necessary nutrients and besides that they still lose weight, NGTs are still refused and the treatment gets delayed. Therefore, at this point the decision was made to focus on teenagers only.
2.4 Input from teenagers

Input from teenagers was gathered in three ways. First an internet research was performed. Blogs were read, and information was gathered via Twitter. Followed by three interviews held with teenagers at Radboud Childrens Hospital in Nijmegen. Here, these teenagers were given a seven day diary and were asked to fill this in. One booklet was received back. For the research set-up see appendix C.

Internet research

Many teenagers with cancer write blogs or keep friends, family and others that are interested posted on Twitter. One of the biggest battles to fight, seems to be eating. Some of them post pictures of what they had for breakfast, lunch and dinner that day and how they feel about it. They also inform other teens with tips and tricks and experiments considering food. (See figure 19) The conversation between J (T5 2011) and x (T2 2011) is as follows:

J: Trying a half frozen Nutricia [Nutridrink]... Does not actually look tasty. pic.twitter.com/...
x: no indeed that does not look tasty! Or was it okay?
J: Still working on it, it’s not easy to finish! Those gross Nutricias..
x: I also really didn’t like them! Did you try an NGT, or do you really don’t want to?
J: No I really don’t want to :(
x: Yes I get that! It did help me! But I see your point!

An update about dinner can be read in figure 20, by S (T6 2011) and w (T3 2011):

S: Just finished eating: chicory salad, oven fries and a beef hamburger. Thought it was quite contradictory beef-hamburger.
w: Are some gross gossk food #yuck what to do tonight? #dtv (dare to ask)
S: Many will get insatiable hunger on dexa but I get thirsty. Do more of you have that #dtv (dare to ask)
S: Just made dinner wearing my chef hat #gotitfromsanta

Another way their Tweets are used is to express their worries and fears (figure 21). t (T4 2011) says:

t: Aahh gatverdamme neee, bedenken me net weer dat de komende 9 dagen prednisone zit. Krijg ik weer zo’n opgebloezen kop & mega honger :( 

These are just a few tweets given as an example to illustrate what social networks and blogs are used for even in the field of food. Even though these teenagers vary between the age of 12-17, are all in different situations, their cancers are different, their disease progression differs and they only know each other due to their disease, these teenagers with cancer find comfort and benefit in sharing experiences with each other.
Creating New Eating Experiences for Children with Cancer

Three teenagers were interviewed at Radboud children's hospital in Nijmegen (figure 22).

<table>
<thead>
<tr>
<th></th>
<th>01</th>
<th>02</th>
<th>03</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
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<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td><strong>Alias</strong></td>
<td>F01</td>
<td>M01</td>
<td>F02</td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<td>17</td>
<td>13</td>
</tr>
<tr>
<td><strong>Type of cancer</strong></td>
<td>Bone cancer</td>
<td>Rhabdomyosarcoma in the neck</td>
<td>Leukaemia</td>
</tr>
<tr>
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<td>5 weeks</td>
<td>2 months</td>
<td>5 months</td>
</tr>
<tr>
<td><strong>Eating</strong></td>
<td>No problems</td>
<td>Only nutridrinks</td>
<td>Okay.</td>
</tr>
<tr>
<td><strong>Diet</strong></td>
<td>No</td>
<td>7-8 nutridrinks a day</td>
<td>2 year germ diet</td>
</tr>
<tr>
<td><strong>Dysgeusia</strong></td>
<td>Yes</td>
<td>Lost all taste</td>
<td>Yes</td>
</tr>
</tbody>
</table>

All three teenagers interviewed had the same thing in common. Without asking them about it, they all mentioned how they did not want an NGT and therefore struggled to maintain their body weight. Even F01, that had no trouble eating so far, mentioned how she would do anything to prevent it. Another thing they all experienced was a change in taste perception. F01 described how normal bread had lost its taste and she now preferred grilled cheese sandwiches or croissants. M01 lost all his taste due to radiation and therefore eating became impossible:

"Try eating 7 packages of butter; that is how I feel with anything I put in my mouth." (M01)

F02 did not like sweet tastes like chocolate milk or candy anymore, but suddenly red cabbage tasted good. She did not know why, it was just the way it was. From any research performed in the past, there is no consistency found in what flavours are liked and which are not after taste alteration due to chemotherapy. (Sources.) Only asking two teenagers with cancer, that eat, about what they preferred F01 did nothing but drinking chocolate milk and F02 explained how she once loved chocolate milk and now thought it was disgusting. Again they were not asked about specific foods or drinks, they came up with chocolate milk as an example themselves. Both F01 and F02 did say you should never order potatoes in the hospital. Because internet research showed teenagers find support in talking to peers they were asked about this. All teenagers interviewed were very motivated to eat because they want to avoid getting an NGT and based on a hospital that would accommodate about 90 children a day, of which less then 1/3 would be teenager of which 1/3 would experience trouble with eating the target group might get a bit small. Therefore the decision is made to broaden the target group to include all children from the age of 7.

Conclusions

Based on these three interviews one can already deduce that no individual case is the same. In this small sample, one in three was not able to eat at all, one in three had no trouble with eating at all and one had experienced some issues in the past but was currently eating well. As for their need of contact with other teenagers in the same situation the opinions differ as well. One participant said she would like that because it is quite boring sitting in your room alone all day. The others said they would not be interested in that.

"Some of dinner room. Where you could eat with other patients, this way you will get into contact with other children and it is just more fun than being alone in your room. It would also be nice if there would be activities with food: for example, cooking dinner together (and eating it...)."

To the question what she would wish considering eating in the hospital, F01 answers in her booklet (see figure 23):

"Some sort of dining room. Where you could eat with other patients, this way you will get into contact with other children and it is just more fun than being alone in your room. It would also be nice if there would be activities with food: for example, cooking dinner together (and eating it...)."

"I never really, eh... Felt that. But no, some people, they don’t understand it, they don’t know what it is like... They don’t understand exactly what it is like, but they do understand how hard it is for me.”

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"I never really, eh... Felt that. But no, some people, they don’t understand it, they don’t know what it is like... They don’t understand exactly what it is like, but they do understand how hard it is for me.”

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"Some sort of dining room. Where you could eat with other patients, this way you will get into contact with other children and it is just more fun than being alone in your room. It would also be nice if there would be activities with food: for example, cooking dinner together (and eating it...)."
2.5 Problem Fields

To make the previous information more clear, in this paragraph a schematic overview is given. In this overview, four problem fields are indicated.

Schematic overview

From the scheme there are four “problem fields” that are indicated as design directions.

1. The first one responds to the physical differences children experience considering eating, with all its consequences.

2. The second design direction is about hospital food. How can you make this less horrible to children?

3. The third design direction is more about the context of eating. Eating in alone in a bed when nobody else is eating around you. A room that did not smell of food before but where you for instance just took a nap.

4. And finally the fourth design direction where the nasogastric tube feeding is redesigned so it is less stigmatizing for people around you.

For a more detailed description on these design directions, see appendix D.
Creating New Eating Experiences for Children with Cancer

2.6 Before designing

From the research it was quite evident that patients and their parents were sceptical about any improvements for eating experiences in the hospital due to their lack of trust in the hospital food. Literally it was said “you can think of anything but I will never like hospital food” by participant F02 (§2.4). Before making a design it needs to be assumed that the points described in this paragraph are well arranged in the NKOC hospital.

1. Eating alone versus eating together

In the hospital children eat alone. Especially in rooms meant for only one patient, but even in larger wards. Many (especially younger) children have nasogastric tube feeding, which stops them from eating normal meals. The meals are served in bed and naturally the smell, look and taste of the food is different than at home. The hospital is unable to make everybody’s food taste like it does at home. Allowing parents to cook in the hospital is the only way to solve this obstacle. Another way to have children accept and eat more hospital food is to have the parents eating the same thing with them, so serve dinner to parents too. A lot of research has been done about how effective this is and it is surely proven that eating together increases the food-intake of children, even of a novel food (Addessi, et.al, 2005). It creates trust about the food and distraction while eating. That is, if the parents eat enthusiastically. Children will not complain about eating in bed though. It is easy for them and they can meanwhile watch television.

2. Serving proper portions

Most hospitals currently serve adult portions to children. Having a big amount of food in front of you when you do not feel like eating already is not motivating. Many children are taught that they should finish their plate, making an adult portion seem like a very big obstacle that is not stimulating to begin with. Have children or parents decide their own portions or serve portions to children according to their age will give the children a more realistic task.

3. More variation in menu’s

Children with cancer spent many months hospitalized during their treatment. In this time, the menu varies a bit but the complaint is that it is still more or less the same thing over and over again. In research it has been proven that over intervals of weeks, minimal variety (e.g. rotation of four different meals) leads to a drop in hedonic (like/dislike) rating of the foods (bron). In another studies it is shown that monotonous eating leads to a decreased intake. (bronnen) This however does not mean having more items on the menu.

5. The menu itself

Offering Dutch children “poached salmon with hollandaise-sauce” or “pork medallion with stroganoff-sauce, chicory and homemade rösti” will probably not make them jump up and down with joy. It is not necessary to serve hamburgers and pizza on a daily basis but a menu that is understandable for children at least gives them more options. They will at least have options to choose from.

4. Visually oriented

Having a strange food presented to you, the first thing you do is judge it by the way it looks. For instance, many children do not like the looks of green vegetables because it is associated with a bitter taste (bron) and love the idea of blue ice-cream or princess-shaped pasta. Colors, smells and textures of the food itself and the context in which it is presented will also determine if it will be eaten and how much it will be accepted.
This chapter shows the process of moving from the four design directions in §2.5, to a final concept.

<table>
<thead>
<tr>
<th>$3.2$ DESIGN DIRECTION</th>
<th>$3.3$ IDEAS</th>
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<tbody>
<tr>
<td>Criteria</td>
<td>Ideas</td>
</tr>
<tr>
<td>Decision</td>
<td>Testing</td>
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<td>Design direction</td>
<td>Conclusion</td>
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<th>$3.4$ CONCEPT</th>
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<td>Metaphor</td>
<td>Merge</td>
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<tr>
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</table>
3.1 Design direction

The four different design directions were tested upon the five criteria by means of a Harris Profile (Roozenburg en Eekels 1998). One design direction was chosen and used as the basis to generate ideas. First the criteria will be explained, then the Harris Profile and in the end the description of the chosen design direction.

Criteria

<table>
<thead>
<tr>
<th>Suitable for all children from seven years old and up, in all phases of their cancer treatment of any type of cancer.</th>
<th>Suitable as a project for the NKOC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aiming the product from the age of seven makes sure we are dealing with an age-group that has a decent understanding of the world around them. They can read and write and will not need guidance to understand.</td>
<td>Taking into account that the NKOC is a hospital and medical research centre, there are certain limitations to what kind of product would be suitable from them to introduce. Taking into account the costs and complexity of the product. Also taking into account the different stakeholders involved in the childs dinner.</td>
</tr>
</tbody>
</table>

Making eating more fun

Due to all the physical, contextual and psychological changes, eating becomes less fun for the child. Taking these factors and use them in a positive way will uplift the experience.

Stimulating a healthy, varied diet

Many children with cancer have phases in their treatment where they do not have a healthy and varied diet. Sometimes because eating is impossible, but other times because they do not know how. If possible, it is worth the while to mind the food intake, for just that bit more energy.

Social activity

Because eating alone is not motivating, it is best if the family is involved too. Just like it was suppose to be if there was no question of the childs sickness.

Decision

In the Harris Table a comparison is made between the four different design directions and the criteria established for the product. The most important criteria are on top. (see table on the next page)

From this profile can be concluded that directions one and three meet the requirements most. Because direction one does not only meet the requirements most, but also because the solution is less straight forward, this is the chosen direction.

<table>
<thead>
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<th>Criteria</th>
<th>Decision</th>
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<tbody>
<tr>
<td>1. Taste toolkit</td>
<td>Suitable for all children above 7 years old</td>
</tr>
<tr>
<td>2. Hospital food presentation</td>
<td>Making eating more fun</td>
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<tr>
<td>3. Bringing back routines</td>
<td>Social activity</td>
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<tr>
<td>4. Changing the NGT</td>
<td>Suitable as a project for NKOC</td>
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<td>Challenging/ original design challenge</td>
</tr>
<tr>
<td></td>
<td>Stimulating a healthy varied diet</td>
</tr>
</tbody>
</table>

Figure: 25. Harris Profile with four design directions and criteria

Design direction

Make solution/toolkit for changes in eating experience due to the cancer treatment: Dysgeusia, olfactory changes, mucositis and diets.

A taste toolkit could help the child, parents and the dietician anticipating with the difference in taste perception the child is experiencing. For a child it might seem that nothing is tasty anymore, food that was once favourite is now disgusting and food that was once disgusting is now edible, or even nice.

Not just the change in taste is different when eating, but also the sense of smell might have changed, a patients mouth might hurt while eating due to mucositis or are on a special diet.

All these different factors could be placed in a “taste profile” that maps the differences you are experienced, helps you rediscover you taste buds and helps your parents in making sure you keep a healthy and varied diet.

In the hospital advice could be given on dinner choice. To make children interested there could be some sort of feeling of accomplishment or challenge.

For whom?


Solving what problem?

- Eating is no fun anymore  
- Food does not taste “right”  
- Eating hurts

Interaction

Child <-> Food  
Family <-> Child  
Dietician <-> Child  
Dietician <-> Family

Solve the problem where?

- At home  
- At the hospital

Figure: 26. My taste profile
3.2 Vision

To get a clear picture of what to accomplish with the design, a vision is made. This is done formulating a metaphor for the desired interaction first. Transforming this metaphor into product qualities gives the design vision.

Metaphor

Making eating fun again for all ages from 7-18 in an innovative social activity evokes the feeling of playing an exciting game together. A game that has a clear goal, eating something you like. Therefore the following metaphor was chosen:

Go treasure hunting

Characteristics of this metaphor are:
> Anticipatory pleasure
> Discover
> Together
> Fulfilling
> Fun (for children)

Vision

The product should enable children and their family to rediscover the fun in eating, that the sick child lost due to cancer treatment. It should be a challenging activity that is even something to look forward to on a boring hospital day. And in the end, it should have a fulfilling outcome.
3.3 Ideas

The chosen design direction was “My Taste Profile”. This means helping children and parents with the different side effects and complaints due to the cancer treatment. Combine this with the metaphor of “Treasure hunting” and ideas were made. Here the two most promising of those ideas are explained. For more ideas and the vision-qualities they were given, see Appendix E.

3.3.1 Ideas

There are different ways of coping with a disease. It can be preferred to not think about it and dream away (blunting) or it can be preferred to control everything and try to understand everything (monitoring). (Karen et al, 2002) Different ideas might address different users.

Blunting

This concept will address children who do not like to think about their disease and escape in distraction prefer to avoid confronting information. It is also described as “wishful thinking and escape coping” (Karen et al, 2002)

As a patient you have your own eating-profile, this contains data about stuff you like and things you do not like. In this profile you are portrait as a superhero, starting of as a “hero on socks” (a Dutch saying meaning, you act tough but you are a coward). As a hero you protect your own city (like Gotham and Batman). To evolve your superhero and your city you need to earn credits. Once a day, with your meal you receive a surprise side-dish with a code that corresponds with a character, this character might be a new inhabitant to your city. Taste the dish, if you like it this inhabitant becomes a new member of your city and if you do not like it becomes your enemy and by beating it you evolve yourself.

(Figure 27)

To see the story behind the super hero, see Appendix F:

Monitoring

For children who find comfort in understanding everything that is going on with them it would also be interesting to know what is going on with their taste. Doing experiments and games to get to know more and more about flavour, taste and finding solutions is a nice way for them to cope with the changes in their bodies by gaining some control.

If the daily meal is incorporated in the food-application it makes you come back at least once a day. The only food-items shown on the menu are the items you are allowed to have with your allergies and diets. There might also be some input about your physical complaints. For instance, if you have a sore mouth you might be advised to eat something cold, soft and not acid.

This personal profile also incorporates a game to help coping with one of the most common side-effect, dygeusia. With taste samples the patients sensitivity to the five basic flavours: sweet, sour, salt, bitter and umami can be measured. With this knowledge about the patients sensitivity an advice can be given on what could taste good to them. (Figure 28) Say, with a decreased sensitivity to sour taste, fruit or Coke will taste “wrong”, but this might not influence the taste of bread, rice or cream or something you never ate before.

(Figure 28)
To get a first response upon the ideas they were shown to two parents at AMC Emma Kinderziekenhuis. Two paper prototypes and two flowcharts and the super hero comic were shown to the parents.

The two prototypes that were shown:
Prototype 1: overview of complaints, game to understand taste difference. Practical output of data
Prototype 2: superhero game. “Collect” different flavours by tasting them and improve your character/world.

For the entire research set-up, see appendix F.

**Parent 1: Mother of B.**
Childs age: 7  
Sex: Female  
Type of cancer: Neuroblastoma  
Time of treatment up to now: 9 months  
Did the child ever have problems with eating during treatment: yes. She has nasogastric tube feeding.  
How was eating before treatment: It was good. Never any problems and mother never forced her children to eat anything.

**Prototype 1: Taste toolkit**
B. Always wants to know everything. She understands it all and would find it interesting to know about her taste. Even general things like “how does taste work”. She might be 7 years old but she already is very mature due to everything she has been through. Not only is she treated for 9 months already, her younger brother recently died of neuroblastoma.

A possible game for taste could for instance be “Guess Who?”.

**Prototype 2: Hero on socks**
Will probably not be effective for her daughter. She has been in the AMC for 9 months now and she knows the food, you cannot fool her. If she does not want to eat red cabbage, she won’t.

The mother being a teaching assistant she does think something like this might work for some or younger children that are new to the hospital and do not have a strong opinion about the food yet.

**Parent 2: Father of D.**
Childs age: 9  
Sex: Male  
Type of cancer: Leukaemia  
Time of treatment up to now: since December 5th 2011  
Did the child ever have problems with eating during treatment: Yes. He almost immediately got nasogastric tube feeding because eating got very difficult.  
How was eating before treatment: It was good. He ate everything, never any problems.

**Prototype 1: Taste toolkit**
It might be fun for once, but dad has the idea that his taste changes with the day so it is not useful. Another thing is that dad does not believe that adjusting your eating-pattern as a family should change especially for the sick child. If everybody likes macaroni except him, it is still macaroni that is served.

**Prototype 2: Hero on socks**
It seems more appropriate for girls. D. might like it a couple of times but he would get bored. Thinking of his daughter playing this game she would like it but the idea of “tasting the princess” and if you don’t like it “we send the princess away” would not make her happy. First you give her something and then you take it away again, that means trouble.

**Testing**

Both ideas have their strengths and weaknesses. One idea helps the user coping in their disease and the other idea helps the child to have fun at dinner time. They are both very important and address different types of children.

Looking back at the metaphor and its qualities of:
• Anticipatory pleasure  
• Discover  
• Together  
• Fulfilling  
• Fun for children

The decision is made to finalize prototype 1, Hero on Socks. It provides mainly anticipatory pleasure, fulfilment and fun for children that strongly lacks in the other ideas and is not easy to add to those. It is essential to improve the eating experience daily.

Discover and together however seems easier to add since it requires more depth into taste, side effects, tips and tricks and involve others into the game.

The comments of the parents are going to be taken into account in the next step.

**Conclusions**
3.4 Concept

The concept that will be finalized will be “Hero on Socks”. It is a fun game that aims to make patients look forward to dinner time every day.

Merge

As described in paragraph 3.3 the fun and easy blunting game “Hero on Socks” (figure 29) is going to get the informative aspect of the “Taste Toolkit” to give it more depth to those children who are interested. Less focus will be placed upon creating a hero and more focus will be on what is tasted. Getting information about it and getting practical output to even take home.

On the right (Figure 30) show first possible examples of how this informative aspect could be integrated in the game. A meaty type of food could resemble a cat. A cat character is added to the city and can tell you all about this meaty dish.

Figure: 29. The very first paper prototype of the concept

Figure: 30. One of the first concept sketches
In this chapter the final concept is explained. Starting off in a general explanation and moving on to explaining in more detail.

$\S$ 4.1 INTRODUCTION

- Why an app?
- Methodology

$\S$ 4.2 HOSPITAL FOOD APPLICATION

- The name of the game
- Menu of the day
- My eating profile
- Game
- Design with intent

$\S$ 4.3 PROEFMONSTERS

- Components
- The game - scenario’s
- Blueprint

$\S$ 4.4 IPAD CASING

- Using the iPad in bed
- Casing ideas

$\S$ 4.5 LOGISTICS

- Before starting off
- The kitchen
- The nutritionist
- Other staffmembers
Creating New Eating Experiences for Children with Cancer

“My personal eating profile” as a design direction resulted in a software application (app) that helps parents and children coping with different physical side effects, diets and makes eating more fun. Because there are many different types of children hospitalized with cancer, from different backgrounds and cultures this app aims to assist them all taking there specific needs into consideration.

Why an app?

Why choose for a tablet application instead of a programme for the personal computer? There are several reasons for that:

Hygiene

A tablet is a lot more hygienic than a laptop, because there is no keyboard involved. The screen is covered with glass that properly can be disinfected.

Simplicity

A tablet is a lot simpler than a personal computer. It only shows programs the user wants/has to have. For the hospital one can imagine programs like: Safari, Skype, Msn, custom made hospital applications, radio, uitzending gemist, rtl xl, and some applications, books and movies especially for children of all ages.

Methodology

During the design process, three different methodologies were combined: vision in product design (VIP) (Hekkert 2011), design with intent (Lockton 2010) and the basic design cycle (Roozenburg 1998).

In this phase of the design process the “design with intent” toolkit (Lockton 2010) provided guidance.

It also helped improving the design at certain points with simple tricks.

Comfort

Since the device will be used mostly in bed a laptop is not the most comfortable option. It is heavy and it gets really warm. A tablet does not have all these discomforts, although for the safety of the device it will need to be attached somewhere near the bed, it will also need a casing to protect it against water and accidental hits.

iPad

For now it has been decided to use an iPad as the desired platform. The interface and use are very simplistic. It is less prone to viruses and illegal downloading is less likely on this device.

Figure: 31. A hero at the hospital. (T7 2012)
4.2 Hospital food application

From the research and first ideas a final concept was put together. This final concept has three aspects that are all necessary for it to work. The menu to lure the user in every day, the personal profile to give accurate personal information and a game to make it fun.

This chapter will give a general overview of the application. Since the game is the most complex feature of the design, additional and more specific in depth information will be given in chapter 4.3.

The name of the game

In this chapter a Dutch word will pop-up on a regular basis. This word is the name of the game that binds the three aspects of the hospital food application together: Proefmonster.

According to http://www.mijnwoordenboek.nl/vertaal/NL/EN/Proefmonster (doe hier iets mee), the English translation for Proefmonster is either “test sample” or “taste sample”. But in Dutch it also has a literal meaning, namely “Taste Monster”.

The logo reflects this literal meaning. The separate meanings of Proef and Monster are emphasised by given them different colours, the “o” in monster is given the shape of a monster so the association with something fun and different will be made by the user. The chosen font resembles greatly to the font of the NKOC logo. It is round and friendly which will appeal to children.

There are three aspects to this application. The first one to open is the menu of the day. Even if the user wants nothing to do with the Proefmonster game, he/she needs to order food here.

Understandable language

The menu needs to be understandable for children. There may still be many things a child has never heard of before but it needs to be explained what is in it, in simple language.

During research one ten year old child (chapter X) complained about the menu item “chicken sandwich”. The English word sandwich was used, for adults it sounds so simple, but this kid had no idea what they were talking about.

Portion size

Because some children have to deal with great appetite due to their medication, and other with very little appetite due to their medication there needs to be a choice in portion size. It is very discouraging for a child to try and eat if there is way to much on food their plate.

When a small or large circle is tapped, food will appear on the plate on the right, this long and wide “piece of paper” is their receipt and will show all they ordered. Tapping another dish on the menu will replace the previous shown dish on the plate (Figure 34)

Parents

Because one caretaker is always present at the child’s bedside, and it is very stimulating for a child to eat together with someone, the caretaker should also be able to order a meal. Whether or not this meal needs to be paid for needs further investigation.

This meal can be ordered by pressing the plate containing “+1” (next to the Proefmonster). An extra plate turns up on the receipt (right). Now the dish can be chosen. The +1 now turns into a -1, so the plate can be removed again. (See Figure 35 and 36)

Proefmonster

Next to the extra plate on the menu is a Proefmonster. (Figure 33) This also can be pressed after which it shows up on the top plate. Only one Proefmonster a day is available.
Creating New Eating Experiences for Children with Cancer

Hints

The hints and arrows on the menu are only shown the first day to explain the options once. After seeing it three or more times for one day it is assumed that the meaning of the two pictures will be known to the users.

My eating profile

Parents of children admitted currently to the AMC fill in a nutrition-letter (Appendix K). This information is important to the hospital. In the central computer allergy and diet information is also kept so no wrong order can be made in the child's name by the nutritionist. The only problem is that the menu does not show what dish is and what dish is not appropriate for the different diets and/or allergies. It is only when the meal order is processed by the nutritionist she finds out the meal is not suitable for the child. Meaning she needs to go back to the child to tell them they can not order that specific dish.

Integrating the nutrition letter into the application means it can make a menu selection for the patient, meaning they will not be disappointed when their order gets rejected. Other complaints considering food-intake can also be incorporated here, for instance “little appetite”, “sore mouth” or “dysgeusia”. The menu can show tips with ordering food. A sore mouth might mean you would benefit from ordering something that is not sour or has a sharp texture and a menu can help you with that. For a list of tips like these, see Appendix P.

General information

The first information asked in this nutrition-letter (or My Eating Profile as it is called in the application) is general information. Name of the patient, nickname, age and gender. (Figure 37) This information is used to generate their superhero. The nickname (or alias) becomes the name of the hero, the age will be the age of the hero and the gender will be the gender. This hero will then be the main character in the game “Proefmonster”.

Food

The second part is the more detailed part that will need to be filled in by parents for younger children. If necessary it can also very easily be adjusted by the nutritionist, dietician, doctor or nurse. This, however, is not expected. Parents are very aware of the diets and allergies their child is following because they need to provide food themselves at home.

The blue (+) symbols are there to add more. A child can be allergic to more than one thing for instance.

Any time of day

When the menu is opened it will show the most logical menu. Meaning, breakfast in the morning, lunch from 11.30 am and dinner from 16.30 o’clock. Once “send to kitchen” is pressed a pop-up will show saying “your meal will be served in an hour” followed by the option to adjust this, for instance schedule for serving in two or three hours. With the tabs on the left of the shown menu an other meal can be selected, meaning dinner can be ordered up front if necessary.

Game

When dinner is served and the patient ordered a Proefmonster, on the tray will be a small, desert like, fun looking, plastic container with an unknown taste sample inside. On top lies a little square card with a pixalyzed monster portrait on it. The patient opens the Proefmonster to taste before or after eating dinner. He/she opens the application and the game. If it is dinnertime the scan menu will open automatically. A message pops up asking: “Did you taste your Proefmonster already?”. When answered with “Yes” the iPad camera is aimed at the augmented reality code by the patient, and a message shows asking: “Did your like the taste of this Proefmonster or not?”. The patients makes their pick and if the taste sample is liked he gets a new monster-inhabitant and 3D monster to play with and if the sample is not liked he gets a monster in sheep clothing. Based on the saying “a wolf in sheep clothing”. Meaning that although it might have looked promising at first, this monster is not tasty and disliked by the patient. This monster in sheep clothing will also become an augmented reality movie, but then the sheep eats something and burps in a sheep-like way.

Design with intent

From the beginning on, the design had a goal to change the eating behaviour of hospitalized children with cancer. To help designers influence behaviour with a design “The Design with Intent Toolkit” was created (Lockton 2010). This toolkit contains a set of cards that all relate very clearly how a “value” of a product can be added with a certain product feature. In designing the application, these cards gave a practical insight in the cause and effect of different aspect of the design. Next an overview of these values in relation to the Proefmonsters will be given. It starts with a question given by the design with intent cards. (Figure 39)
Role-playing

What happens if your system gives users particular roles to play, or makes them feel like they’re playing a role?

The user plays the role of the superhero. From the beginning on they see this superhero in “My Personal Profile”. They are the superhero that can taste the difference between a friend or an enemy.

Emotional engagement

Can you design your system to engage people’s emotions, or make them emotionally connected to their behaviour?

Because the user has the superpower of taste, that digital hero’s do not have, the user needs to make up the difference between tasty or not tasty. The hero needs to ask the user for “help”, for their engagement.

Collections

What happens if you encourage users to collect a set of things through using your system?

Every day of hospitalization the user has the opportunity to collect either a new monster or improve his/her hero. The square card with the augmented reality code should also be kept (and collected) in order to be able to see the augmented reality monsters again. Every card must look different and show an indication of the rest of the possible collection.

Rewards

Can you encourage users to take up or continue a behaviour by rewarding it, through the design of the system?

In the application itself the user also collects the houses of the monsters that can virtually be visited. They contain information about the type of food the monster represents. So, liking the food gives the user two rewards:

- an augmented reality monster and his house of wonder. Disliking the food however, gives one reward, a monster in sheep clothing. It is shown in augmented reality and it can be traded for cool gadgets.
- The big reward however is the fact that, if the game is played honestly, you create an overview of the foods the user likes and dislikes. In the end, if a child is done with its treatment this data can be presented in a nice overview to take home.

Bundling

Can you include something you want users to do with something they want to do, so both get done?

Because patients need to order food anyway it is decided that the Proefmonster can be ordered at the same spot.

4.3 Proefmonsters

This chapter will go into more detail about the Proefmonster game and all its aspects. The order of explanation will be in the order of using the application. The system has three different physical components. The Proefmonster taste sample, the augmented reality (AR) code card on top and the iPad application. These components will be explained first before the game is illustrated with various scenarios.

Components

Proefmonster taste sample

The Proefmonster will be served in a plastic container that looks like it is hiding something tasty or friendly, like a desert because it will be about the size of a Danoontje. (Appendix I) It is only possible to see what is inside if the lid is taken off. On the lid (see figure 41) is a little paper placemat (Figure 40) with the picture of a little plate, this plate will literally serve the AR card.

The food inside the taste sample should be hypo-allergenic and germ free so there are no limitations for children to play the game.

To keep it exciting, the taste sample must meet the following requirements:
- Use different textures of food
- Frozen - warm
- No boiling hot foods like soup. Because the user does not know, this can cause serious burns.
- The container should be made of an isolating material so it keeps the frozen things frozen and warm things warm.
- The lid should not open by itself, but opening should also not require a lot of strength.
- The containers should be stackable as a convenience to the nutritionist.

Augmented reality monster cards

On top of the plastic container containing the taste sample, lies a separate square card. This card has two sides: on one side the Proefmonster logo (figure 42) and the number of the monster you received that day and on the other side the monster portrait in big pixels. You can see the general shape of the monster and its colour (Figure 43-44). It has been decided to do it this way because to play with the monsters on another day the cards need to be kept. They become a
Creating New Eating Experiences for Children with Cancer

collectable themselves (figure 45). Meaning, they should be fun to look at, even without using the application. They can be put together or the child can look at what numbers they are still missing, put them in order, etcetera.

Basically an augmented reality code can be in any shape or form, but to keep it fast the reference points need to be kept simple. In the case of the green monster it is set up like a quick response (QR) code, with squares in three corners. Because this is generally known by many people owning a smart phone you can tell it is “scannable” with a camera. The three squares are not really necessary for an AR code though because it is not “universal” like QR. To read an AR code a special application is needed to read that specific code. AR can even recognize photographs for instance because it just needs certain reference points. That is why for every code these squares will defer (see Figure 43-44).

An AR code is associated with an image. This image can be 2D or 3D animated or static. It can be controlled like an interactive game or it can behave like a movie (so not interactive). In this case it will behave like a movie. A monster pops-up from the code and it will do something silly (figure 46).

**Application**

The final component is the iPad application itself. It is what binds the physical world of food and taste with something even more exciting for children, and something to brighten up the hospital stay.

To see all screens and a flowchart of the game, see Appendix J.

**The game - Scenarios**

The following scenarios will give a general overview of the usage of the Proefmonster game.

1. **Ordering dinner and a Proefmonster**

   Figure 47. Explaining: standard dinner order + Proefmonster.

   The order will be delivered in one hour tops:
   - Okay
   - Delay
   - Cancel
2. Tasting a Proefmonster and liking it

Explaining: Delivery of a Proefmonster, tasting a Proefmonster and liking the Proefmonster.

In this scenario (figure 48) the nutritionist delivers the Proefmonster to the patient. He tastes the proefmonster, opens the game within the application, scans the AR code and presses the button saying he likes the taste. Next the friendly Proefmonster appears and moves into his city.

If dinner is served along side the Proefmonster and the family wants to eat at the table, the Proefmonster should be kept until after dinner because scanning needs to take place with the iPad attached to the bed. Of course it can also be tasted before dinner but it might backfire, since the child would probably want to play with his new monster and not eat dinner. It would probably be best if the nutritionist would “pretend” it is not allowed before dinner.

Figure: 48. Scenario for liking the Proefmonster
3. Tasting a Proefmonster and disliking it

Explaining: Delivery of a Proefmonster, tasting a Proefmonster and disliking the Proefmonster.

In this scenario (figure 49) it is explained what happens if the child does not like the taste of the Proefmonster.
4. Playing with the app

Explaining:
• Visiting a house
• Playing with AR

This scenario explains two things you could do when you just want to play with the application. Monster-houses can be visited or previous AR codes can be scanned. Another option would be to chat with other children at the hospital or check out the vegetables in the patch (Appendix Q).

Figure: 50. Scenario for playing with Proefmonster
Welcome Nick!

The belt shows how many sheep you can trade.

Click on a house to visit the monster and learn more about that food.

Monsterdorp

The monster sheep ate your disliked food for you, click on the sheep to retry this dish or trade it to pump up your hero.

Vegetables are growing in your vegetable patch, click on them to get information.

<< The ground can be moved left and right, until you reach your village border >>
This blueprint (figure 52) gives an overview of what happens with the Proefmonster on different levels. What does the user have to do, what happens on the interface, what happens inside the game, what does the kitchen get to see and do and finally the nutritionist.
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It is most convenient to have the iPad next to the bed. Children often feel bound to stay there due to their attachment to the IV-pole. In fact they can walk around with the IV pole but it is easiest to stay put. Because the iPad is a very mobile device it is necessary to attach it somewhere so it does not get lost, stepped on or damaged in any other way. This attachment might also help with using the iPad comfortably when lying in a bed and avoiding unwanted behaviour and have a power cable integrated. In this paragraph I will give an idea of how to solve this issue.

4.4 iPad casing

What are ways the iPad should be able to used when being in bed?

It needs to be kept in mind that to control an iPad, force needs to be applied upon the screen. It is most comfortable to do this if the iPad rests on the legs of the user. Meaning that the iPad needs to be “free” and not held up by a system (like for instance a television would). On the other hand a patient might want to lie down and watch a movie, with the iPad above or next to the face (depending if you want to watch lying on your back or side). The camera also needs to be uncovered to be able to scan a Proefmonster. (Figure 53)

What are ways the iPad should not be used in bed?

The main usage that would be very undesirable is that the iPad is used as a table. Therefore it should not be able to lie on the bed or float in the air in a horizontal position. (Figure 54)

Make use of gravity

If the back of the iPad casing is sloped, gravity will make sure it hangs under an angle. Creating an angle will also help prevent it being used as a table. Because the iPad screen can rotate it can also be put down the other way around if you want to put in your lap sitting with your knees up. See sketch (Figure 55) for further explanation. There has been no look at the attachment system yet, here it is illustrated as a wire but obviously this is a hazard for children, a safer option will need to be considered.

Making the iPad casing of a soft, foamy material will make sure it is comfortable in bed and nobody can bump their head. The foam will need to be coated to make it water-resistant.

Casing idea

To lie in bed and watch a movie on the iPad it would be nice if the user does not have to hold the iPad up above their head. It should hang by itself.
Creating New Eating Experiences for Children with Cancer

4.5 Logistics

The NKOC hospital plans to have its own kitchen. A kitchen that is possibly set up like La Place (a Dutch caterer/restaurant chain). (see Appendix B) Meaning they use fresh vegetables from local farmers with seasonal products. Using products that are in season means that a lot of money can be saved. Furthermore they have very simple recipes that everybody can make without any special culinary education, meaning a lot of money can be saved on staff. In the end you get simple and fresh dishes that are a lot tastier than the standard hospital meal.

Having a hospital kitchen will mean that making the Proefmonsters will be a hospital responsibility. So what will it mean for them? What stakeholder are there? That is what will be explained in this paragraph.

Before starting off

The biggest task for the hospital will be to decide what the Proefmonsters will actually be. 100 different small dishes made with seasonal ingredients that are suitable for all children in the hospital, meaning it will not make them ill in any way. Come up with a 100 different dishes with different themes (Appendix O).

But this will only be a one-time thing. It could even be done by different chefs, a cookbook could be made out of it and after the treatment is done, the children that played the game can take it home.

After this the application needs to be developed. This will need to be outsourced.

The kitchen

A Proefmonster needs to be prepared daily (or in the case of ice-cream the day before). It requires planning but no more than preparing the menu for the day. Very little is served per child (around three bites) so not many ingredients are needed.

In figure 56 it is illustrated what happens in the kitchen. The white line illustrates a normal food delivery and the blue line illustrates a Proefmonster. Ordering a Proefmonster besides a normal meal will result in:

1. See dinner order and Proefmonster order
2. Prepare dinner and Proefmonster
3. Add the placemat and AR
4. Send dinner and Proefmonster to the nutritionist of the department

Meaning the real additional actions are scooping the Proefmonsters up and putting the little placemat on the lid and the AR code.

The nutritionist

For the nutritionist it does not really mean extra work. A few more items for the dishwasher and the paper placemats to throw away. Even though it would be even better if she would stimulate the children a bit, ask how they liked it.

Other staffmembers

In principle there are no other staffmembers involved in operating this system. The “personal eating profile” might be hard for some children to fill in and parents should check this and keep it up to date. It is very well possible for them since they also take care of the food at home and should know what is going on with their child.

More ideally however, would be to have it filled in and adjusted automatically after the parents fill in check-in forms for the hospitalization of their child. The one considering food is shown in Appendix K.

Figure: 56. Fragment of the blueprint that shows what staffmembers have to do.
A prototype was made of the final concept to be able to get responses from the target group. This chapter will be explaining how that went.

§ 5.1 USER TESTING

- Aim of the research
- Prototype
- Research set-up
- Responses
- How does the product meet the vision?

§ 5.2 RECOMMENDATIONS

- Proefmonsters
- One step further
5.1 User testing

To see whether or not the design fits the vision a user research had to be performed. In this paragraph it will be described, why, how and what came out of the research. This information will be used to make recommendations for possible further development.

Aim of the research

The aim of the research is to find out if the concept meets the vision. It needs to be observed if the product provides a feeling of: anticipatory pleasure, discovery, togetherness, fulfillment and enjoyment (fun), as described in chapter 3.2.

Prototype

To test the concept, three prototypes were made, one digital one on the iPad and one of the Proefmonster.

iPad prototype

To make the experience as real as possible it was decided to present the prototype on an actual iPad. The prototype is operable and shows all the options and possibilities the concept has. It explains the game by means of a movie that is especially made for children (Appendix M).

The interaction with a tablet is different from the interaction with a laptop because it is a touchscreen and it is (also for children) very manageable. Not all children are familiar with tablets but the prototype was designed in a intuitive way and in general it can be said that children handle electronic gadgets very well.

The prototype consists of six screens (see Figure 58, for a big version see Appendix L). When a plate is tapped the underlaying option slides up. When “Sluit” (close) is tapped the screen slides back up to the plate. The three plates are next to each other. With several hints the user could be seduced to slide between them.

There were many buttons there that were inoperable, participants pressing them will however show that they stand out. They are also an opportunity to ask “what do you think would happen if that button works?”

Proefmonster prototype

The Proefmonster (taste sample) was made with prepackaged apple puree. The apple puree label was covered-up with a Proefmonster placemat (see Figure 59). A fictional AR code was taped loosely on top to show that the child can take them off and collect them.

AR prototype

Another prototype that looked and felt just like the Proefmonster prototype was made, the Proefmonster label was now replaced with an AR label that belongs to the game AR Defender. This functioned as an illustration for what would happen if the Proefmonster was scanned. It is still quite a new and unknown technology and therefore it could not be assumed that the participants would understand what was meant by just explaining the AR technology.

Research set-up

To begin with it will be explained to the participant that he/she is going to be testing an iPad application that is designed to make eating in the hospital a nicer experience. They are told the app is not yet finished and that their opinion is needed.

The participants were handed the iPad at whatever location they were in the hospital. Meaning if they were enjoying themselves playing the playroom the research would be performed there.
Not because this is a realistic setting for the product to be used but because it is great to see children as ill as this enjoying themselves, putting them back in bed does not feel right. It was assumed however that this location will turn out to be the hospital bed since the hospitalized children spent most of their time there.

The participant receives a Proefmonster and it is explained that it could be ordered besides their usual dinner and they did not know what was in it. Next they received the Proefmonster with the augmented reality (AR) code that works with an already existing app called AR Defender, to show the 3D technology that is explained in the movie. They were allowed to play with this before the Proefmonster app was opened, so that it would be understood at the time the movie was watched.

So, the participants were first shown how augmented reality works, then they were asked to work with the application. Parents were present and were allowed to participate.

After they watched the movie the children were asked four questions:

1. Would you like to receive a monster at the hospital? Why?
2. Would you be curious about what the monster tastes like? Would you dare to taste?
3. Would you like to chat to with other children about the app? What would you talk about?
4. If you keep the codes you can see all the monsters at once and they will interact. Would you like that? Would you collect them?

The research will be performed at AMC Emma Childrens Hospital and recorded on video. The number of participants will be dependent upon how many children are available that day.

For the entire research set-up see appendix N.

The girl E turned out to be too shy (and probably too young) to participate in this research.

The first thing that happened

The first thing the children noticed was the word Proefmonster. They started laughing and were curious what it was. (see Figure 62)

J: “Haha! Do you also want a Proefmonster! Hahaha!”

It was at that point the only thing the children wanted to know about the menu. They went out by pressing “close” automatically, and started looking for the Proefmonster. They both skipped the “My Personal Profile” and found the plate saying Proefmonster. It was opened and the movie was watched.

Would they taste?

To both boys it seemed very logical to taste the Proefmonster before “liking it” in the application. They would never say they like something if they don’t. Maybe they would not taste if it was something they knew they did not like beforehand. For instance J does not like apple puree, knowing it was in the Proefmonster made him not want to taste. He would just say “I don’t like it”.

P. was also not afraid to taste something he did not know for the game. He was eager to get a city of all the monsters he had liked and visiting their houses.

J. was more excited about playing with the AR monsters. He started brainstorming for literally an hour about what kind of monsters certain foods could give you. Eating potato chips for instance would give a bag-of-crisps-monsiter with little potato chip monsters inside.

Monster-mania

J. also said he would like monsters in more places in his room besides with his food.

J: “For instance an IV-monster, or a heart monster that keeps fainting because he has high blood pressure. Or for instance a monster that jumps out of the window. Or a clock-monster that keeps telling you what time it is. Tring! Or one on the door, a picture on the doors. Yes… For instance the pee-bottle could have a monster. It will make everything in the hospital more fun.”
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How does the product meet the vision?

To know whether or not the design meets the desired interaction the responses of the children and parents are compared with the interactions of the metaphor.

Social

Asking the children, they were not planning to use the chat function, they did however want to be able to have interaction between their monsters. Fight, make babies, whatever.

The parents were happy about the idea of ordering food together with their children. They acknowledge that this would be stimulating for them. As the caretaker of P. said:

“We often bring leftovers for ourselves, and then he eats alone. But what happens is that he wants what we are having. But with diseases and stuff. It’s not clever. It would best to eat the same meal.”

Anticipatory pleasure

The children were curious about what kind of Proefmonster would show up. If you order a Proefmonster you know it is coming and either you like it or not, you will get something out of it and you can play with something new. It will make dinner more exciting.

Discovery

There are two things to discover, what is in the Proefmonster and what will I get out of it. In the end it is also a discovery of your own taste. It is up to the user what appeals most to them to discover. It will really depend on the character and interests of the child. Either you play with monsters without concerning yourself too much about the food, or you want to know all about the food you ate.

Togetherness

The game is played alone. The children were not planning to use the chat function to interact with other children. Asking them about it they would approach other children to play with their monsters if it were possible.

The togetherness so far is in the opportunity for parents to order a plate of food too, so they can eat the same thing together.

Fulfilment

Something needs to be tasted and for children it is interesting to then say “I do not like this”, then be able to do something to that food. In the application the sheep could eat it if it were an apple for instance. As long as they get feedback on what it was they did not like and it is shown that, that food is not going to live with them.

Enjoyment (fun)

One child found it particularly interesting and fun to play with the AR-monsters. The other child would find it fun to create a city of foods he liked and visit the houses. Apparently the children found the idea “Proefmonster” very humorous because they kept laughing at the idea and the word every time it popped up.

Thus it can be concluded that the game is fun for children, it looks like they would not be afraid to try the Proefmonster and it even looks like they will not lie about liking or either disliking it. However the game itself is not yet a real social event and here is still room for improvement.
5.2 Recommendations

To see whether or not the design fits the vision a user research had to be performed. In this paragraph it will be described, why, how and what came out of the research. This information will be used to make recommendations for possible further development.

Proefmonsters

The daily anticipatory pleasure, the fun and the educational value of this Proefmonster seem to be good. However there are some recommendations to be made.

Make the game more social

The application in a whole has the big social advantage of the caretaker being able to eat together with the child. They can order the same food at the same time and the same place in the hospital, which means that even mealtime can be shared, even if a child is in isolation in an SPR

The game however, in this form is not yet very social. There is a chat function but the two participants did not think they would chat here to other children in the hospital. They were however interested in playing with other monsters. Placing special rewards and features doing this will stimulate them to play together. If you are a boy and a girl for instance, your monsters could fall in love, you both get a baby monster. If you are two boys the monsters could get in a fight or behave like clowns.

A simpler option however could be to give children a notice after or before they get their Proefmonster, saying “Hey, Pete in room 4 also ordered today’s Proefmonster! Do you want to know what he thought?”

More accessible and less scary might be to make it social with your present caretaker. Give him/her a Proefmonster too so you share the experience of tasting something unknown.

Simplify

The application as it is designed now is an optimal solution. Creating a city of your liked tastes and flavours and having a physical collectable as well that you can play with.

However taking budgets and development into consideration, making a big improvement on hospital meals for children can start off smaller. Simplifying it to a menu where a Proefmonster can be ordered besides dinner, having a personal eating profile and a game where “Proefmonsters” can be collected is already great. These monster would not have to be physical or augmented reality but could just be tokens that you get if you have tasted the Proefmonster. This way it is more like collecting soccer-cards, “get them all”, but then on a digital platform. Showing what you tasted and some information about this main ingredient. It is probably a lot more “boring” and will not keep you entertained as long but it is a reward for tasting something new daily and could very well be considered interesting to many children.

Younger children

A big percentage of children suffering from cancer is younger than 5 years old. The application as it is now might not be totally suitable for them. How could it be made more accessible to them? Here are some ideas:

• Make the monsters look cute
• Explain a lot with audio instead of written words.
• Use more pictures instead of written words. Especially the “do you like the Proefmonster?” functionality should be accessible to them. Use facial expressions to say whether it was “yum” or “yuk”.
• It should be able to turn the audio function on or off, because for older children this could be considered very childish and put them off.

One step further

As patient J of 10 years old already said, it would be great if the monsters would be everywhere in the hospital. But this accounts for the application as a whole. Now it is just about food and dinner, but it could be integrated with a lot more for children to find out. What is the name of that doctor for instance, what does he do? He could carry a AR code on his name tag, it is a childrens hospital isn’t it? How does an x-ray work and why are IV poles boring like that? There is a reason for everything and everything could be explained nicely using augmented reality codes, you just need to go and find them in the hospital.
In this short chapter I will look back on the product and on the process followed during this graduation assignment. It is important to reflect back on the experience to be able to take it with you on projects yet to come.
6.1 Product Evaluation

Looking back on the product it was sometimes difficult to temper the many ideas I had going on. Looking at the final concept you can see quite well that it was sometimes hard to decide. Even though it is quite “a lot” I put into one application, I believe it is not too much. Reading it in a text or trying to explain it to people might set that illusion but it is a game and explaining a game can be hard without playing it. Try explaining somebody the rules to “Puerto Rico” (a board game), it is nearly impossible but the amount of options and rules make it a great game. When playing it, Proefmonster will be intuitive, it does not matter if you press all the buttons and you cannot do anything wrong. It has many layers and they are waiting to be discovered. If you don’t figure it all out on the first day, the next day you might.

I believe this product has the potential to have children at the hospital look forward to dinner time. If it will increase their food-intake I cannot say, but I have a suspicion it might. Many children now do not even want their food near them in the hospital, this might trigger their curiosity.

There is no product like this at any hospital, and I am quite sure it would make a big improvement.

6.2 Process Evaluation

All in all this graduation project has been an amazing experience for me. It was not the easiest choice, but I am sure it was the best one.

The thing that made it especially difficult for me sometimes was the fact that from the part of the parents and children I was dealing with quite some scepticism. It is understandable. The hospital food is not great and as long as it is as untasty as it is, nothing will work. Many parents and children could not even imagine good food in the hospital, it was unthinkable and therefore everything was received quite cynical.

It was also tricky that, going to the hospital for research, I never knew what I was going to get. Were there going to be any children available? What was the atmosphere going to be like? Sometimes the atmosphere was very tense and unsettling, another time it was quite good. This atmosphere however made great impact on how children and parents are going to react to my presence.

Doing research you get interrupted a lot by beeping IV poles and nurses that start asking a lot of questions to the child. Again, very understandable because they need to take care of the child, but again it did not make the research any easier.

It took quite a while for me to finish the analysis but I truly believe I could not have done it a lot faster. Beforehand I knew nothing about children with cancer, nothing about cancer for that matter and also not that much about hospital food. There was hardly any previous research about the subject at the time of my analysis phase, no research at all had been done about increasing food-intake of children with cancer, only about the effectiveness of the nasogastric tube feeding.

Making design decisions however are not my strongest asset. Not because I cannot make decisions but because of perfectionism. Accepting things are the way they are and moving on proved to be quite hard sometimes and this will definitely be something I need to work on to become a good designer. Taking the interaction vision as a lead point helped me through this and that is why I like vision in product design (VIP). If I keep it in mind it is the only thing that really helps me justify choices. Demands and wishes are there to be broken, but a future interaction vision helps to make a design feel “right or wrong” and for me it is the best basis.
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Known medically as a malignant neoplasm, is a large group of different diseases, all involving unregulated cell growth. In cancer, cells divide an grow uncontrollably, forming malignant tumours, and invade nearby parts of the body. The cancer may also spread to more distant parts of the body through the lymphatic system or bloodstream. Not all tumours are cancerous. Benign tumours do not grow uncontrollably, do not invade neighbouring tissues, and do not spread throughout the body.

Chemotherapy: the treatment of cancer with an antineoplastic drug or with a combination of such drugs into a standardized treatment regimen. Most commonly, chemotherapy acts by killing cells that divide rapidly, one of the main properties of most cancer cells. This means that it also harms cells that divide rapidly under normal circumstances: cells in the bone marrow, digestive tract and hair follicles.

Cytoxic drugs: any drug that has a toxic effect on cells; commonly used in chemotherapy to inhibit the proliferation of cancerous cells.

Dysgeusia: the distortion of the sense of taste.

Germ cell tumour (GCT): a neoplasm derived from germ cells. Germ cell tumours can be cancerous or noncancerous tumours. Germ cells normally occur inside the gonads (ovary and testis). Germ cell tumours that originate outside the gonad may be birth defects resulting from errors during development of the embryo.

Hedonics: branch of psychology. The study of pleasant and unpleasant sensations.

Hypergeusia: a taste disorder where the sense is abnormally heightened.

Hyperosmia: a type of cancer of the blood or bone marrow characterized by an abnormal increase of immature white blood cells called “blasts”. Leukaemia is a broad term covering a spectrum of diseases. In turn, it is part of the even broader group of diseases affecting the blood, bone marrow and lymphoid system, which are all known as haematologic neoplasms.

Lymphoma: a cancer in the lymphatic cells of the immune system. Typically, lymphomas present as a solid tumour of lymphoid cells.

Mucositis: the painful inflammation and ulceration of the mucous membranes lining the digestive tract, usually as an adverse effect of chemotherapy and radiotherapy treatment for cancer.

Nasogastric intubation: a medical process involving the insertion of a plastic tube (nasogastric tube, NGT) through the nose, past the throat, and down into the stomach.

Neuroblastoma (NB): the most common extracranial solid cancer in childhood and the most common cancer in infancy. Close to 50 percent of neuroblastoma cases occur in children younger than two years old. It is a neuroendocrine tumour, arising from any neural crest element of the sympathetic nervous system or SNS. It most frequently originates in one of the adrenal glands, but can also develop in nerve tissues in the neck, chest, abdomen, or pelvis.

Neocception: the neural processes of encoding and processing noxious stimuli. It is the afferent activity produced in the peripheral and central nervous system by stimuli that have the potential to damage tissue. Neocception triggers a variety of autonomic responses and may also result in the experience of pain in sentient beings.

Nutridrink: liquid food/ nutritional drink from Nutricia.

Prednisone: a synthetic corticosteroid drug that is particularly effective as an immunosuppressant drug. It is used to treat certain inflammatory diseases (such as moderate allergic reactions) and (at higher doses) some types of cancer, but has significant adverse effects. Because it suppresses the immune system, it leaves patients more susceptible to infections.

Proefmonster: taste sample, test sample, sample, taste monster.

Radiotherapy: sometimes abbreviated to XRT or DXT, is the medical use of ionizing radiation, generally as part of cancer treatment to control or kill malignant cells. Radiation therapy may be curative in a number of types of cancer if they are localized to one area of the body. It may also be used as part of curative therapy, to prevent tumour recurrence after surgery to remove a primary malignant tumour (for example, early stages of breast cancer). Radiation therapy is synergistic with chemotherapy, and has been used before, during, and after chemotherapy in susceptible cancers.

Retinoblastoma (Rb): a rapidly developing cancer that develops in the cells of retina, the light detecting tissue of the eye. In the developed world, Rb has one of the best cure rates of all childhood cancers (95-96%), with more than nine out of every ten sufferers surviving into adulthood.

Single patient room (SPR): A room in the hospital only meant for one patient.

Tumour: A tumour or tumour is commonly used as a synonym for a neoplasm (a solid or fluid-filled (cystic) lesion that may or may not be formed by an abnormal growth of neoplastic cells) that appears enlarged in size.
References


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T2: http://twitter.com/#/xenahuizinga
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T7: http://twitter.com/#/lolaar


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